Background

There are an estimated 716,000 Australian people who have had a cancer diagnosis (3.2% of the population overall, and 14% of people aged 65 years and older). While cancer still remains the leading cause of death in Australia, improvements in early detection and treatment mean about 60% of people diagnosed with cancer will be alive at least five years later. These improvements, and the ageing of our population, mean there is a growing number of ‘cancer survivors’ in Australia.

There is increasing national and international awareness of the particular physical, psychosocial and practical issues facing cancer survivors as a consequence of their cancer and cancer treatment. In many countries, including Australia, there is a growing focus on conducting research and providing services to meet the unique, and to date largely unmet, needs of people with cancer after acute treatment ends.

Workshop objectives and format

Given increasing interest and research related to cancer survivorship, the Clinical Oncological Society of Australia (COSA), as the peak national body representing multidisciplinary health professionals whose main work is cancer control, hosted a workshop to bring together people identified as the key players in survivorship practice and research across Australia to:

- foster and encourage collaboration
- identify opportunities for convergence and difference to best exploit our competitive position internationally
- consider the value and roles of a national coordinating body.

The workshop was co-convened by Professor Afaf Girgis, Centre for Health Research & Psycho-oncology (Cancer Council NSW, University of Newcastle & Hunter Medical Research Institute) and Professor David Goldstein, Prince of Wales Hospital and University of NSW.
The workshop featured:

- brief overviews of international survivorship research and service development, and current and planned survivorship research and programs in Australia

- small group discussion about three key questions:
  - What are the key research priorities, and how should we develop a national research agenda?
  - Is there a need for a central coordinating body and, if so, what role should it play?
  - Is there a need for survivorship service provision? What form should a service take?

- reports from the small groups and discussion about next steps.

The workshop program, which includes a list of presenters, is at Appendix A. A full list of workshop attendees and invited participants is at Appendix B.

This report of the workshop was written for COSA by Lisa-Maree Herron.

**Overview of international survivorship activities**

Professor Girgis presented a brief overview of approaches to providing survivorship care and/or coordinating research in several different countries, garnered from her participation in a pre-MASCC Symposium in June 2010. The symposium, hosted by the MASCC Rehabilitation-Survivorship Study Group, brought together people from various countries, focused on survivorship research and clinical priorities, with the aim of creating international collaborations to study the supportive care needs of cancer survivors.

In advance of the June symposium, Professor Girgis did a straw poll of Australian consumers, researchers and clinicians, who identified key survivorship research and clinical priorities as:

- Relevant and meaningful survivorship measures
- Survivorship issues in indigenous, under-studied, minority populations, older survivors
- Survivorship trajectories (longitudinal) – survivors, caregivers
- Follow-up care practices and preferences study
- Role of family practitioners in follow up care, management of long-term toxicities – patterns of care study
- Studies of impact of longer-term toxicities and treatment side effects on quality of life and survivorship
- Evaluation of patient-held treatment/care plans
- Models of follow up care – comparison of outcomes between countries.
Professor Girgis described existing models and survivorship programs in development in several countries:

- Denmark – establishing a multidisciplinary survivorship team through the National Centre of Cancer Rehabilitation Research; in the early stages of development.

- Netherlands – web-based self-help programs for post-cancer treatment and a patient-created personal health record and supportive care plan (OncoCompass).

- United States – LIVESTRONG Network of Survivorship Centres of Excellence, linked to community-based centres, with the Lance Armstrong Foundation providing leadership and facilitation.

- Canada – BC Cancer Agency’s Cancer Transitions program, a supportive care program to help survivors transition from active treatment to post-treatment care. Available to others who wish to adopt the program.

- United Kingdom – Cancer Survivorship and Supportive Care Consortia, funded to increase research and build capacity at a national level.

The MASCC Rehabilitation-Survivorship Study Group is now pursuing three priority initiatives to facilitate international collaboration:

- survey of survivors, looking at acceptability of different models of survivorship care (coordinated by Afaf Girgis)
- survey of survivorship programs – to understand models of care currently being implemented across the world
- catalogue of current guidelines for cancer survivorship.

**Australian Cancer Survivorship Centre (ACSC)**

Associate Professor Jefford described the Australian Cancer Survivorship Centre (ACSC), based at Peter MacCallum Cancer Centre in Melbourne. The Centre is not a clinical service, but its major emphasis is on supporting clinical care through resource development and capacity building. It has no funding for research.

The ACSC’s strategic directions are to:

1. Build a state-wide then national role as an authoritative source of knowledge and expertise in cancer survivorship.
2. Become a focal point for the exchange of information and resources and links to support relevant to survivor experience.
3. Build capacity in professional communities.
4. Build capacity in individuals and consumer communities to improve individual post-treatment health outcomes.
5. Influence key ‘agents of change’ to trial new ways of providing effective and appropriate care for cancer survivors and their carers.

The ACSC is a resource for the Victorian Cancer Survivorship Program, focused on piloting models of care. As such, it will provide education and training for the Victorian healthcare community, and develop resources to support enhancement of survivorship care across Victoria. The ACSC also is a resource for PeterMac, aiming to incorporate post-treatment considerations into the PeterMac model of care and to integrate with and expand the existing survivorship research program.

**Current and planned survivorship programs and research**

Workshop participants were invited to present a very brief overview of their current and/or planned survivorship programs and research. The aim of this section was to identify the range of issues being addressed by individuals and groups around Australia, rather than to provide any detail about the initiatives.

The information provided is collated in the table below, and copies of the presenters’ Powerpoint presentations are attached at Appendix C.
Table 1: Current and planned survivorship programs and research described by workshop participants

<table>
<thead>
<tr>
<th>Survivorship services/programs</th>
<th>Centre/Lead agency</th>
<th>Presenter</th>
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</thead>
</table>
| **NSW Cancer Survivors Centre** – will assess and refer survivors to services and conduct research. The Centre is being developed by a UNSW/Randwick hospitals collaboration, building on partnerships with the UNSW Lifestyle Clinic and the Childhood Cancer Long-term Follow-up Clinic. Research underway or planned in:  
  - post-cancer fatigue  
  - fertility and sexual dysfunction  
  - bone health  
  - cancer genetics  
  - lymphoedema management  
  - lifestyle interventions to improve quality of life, such as increasing physical activity  
  - distress in survivors and unmet needs – both psychological and practical. | UNSW/Randwick hospitals | David Goldstein |
| **Flinders Medical Centre Survivorship Program** – a nurse-led clinic, developing a treatment summary and care plan for patients after treatment ends. A hormonal clinic is planned and the program is setting up a statewide database. Research underway or planned in:  
  - psycho-oncology and self care (web-based support) | Flinders Medical Centre | Bogda Koczwara |
A survivorship conference was convened in September 2010 for survivors and care providers.

**Cancer Council NSW programs and services for survivors:**
- ENRICH program (exercise and nutrition advice for survivors and partners), in collaboration with CHeRP
- Helpline & Information Centres
- Living Well After Cancer program
- Cancer Connections (survivors support group)
- Working Beyond Cancer program
- Counselling and financial planning

Planned:
- Cancer Connections online forums for young adults with cancer
- National scoping for survivorship needs of young adults (18 – 45) leading to pilot programs in 2011.

**Long-term follow-up clinics for childhood cancer survivors**

<table>
<thead>
<tr>
<th>Centre/Lead agency</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>Cancer Council NSW</td>
<td>Annie Miller</td>
</tr>
<tr>
<td>ANZCHOG</td>
<td>Richard Cohn</td>
</tr>
</tbody>
</table>
Seven of the eight Australian paediatric cancer centres have a dedicated clinic, but only two have the facility for life-long follow up.

Research underway or planned:
- More collaborative research, particularly psychosocial
- Models of care for paediatric patients (transition to more robust follow up once patients reach 18 years)

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<thead>
<tr>
<th>Research</th>
<th>Centre/Lead agency</th>
<th>Presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quality of life, psychosocial outcomes and/or unmet needs</strong></td>
<td></td>
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</tr>
<tr>
<td>Survey of needs, QoL, distress, coping and social support of <em>testicular</em> cancer survivors (with ANZUP) and qualitative study of high and low distressed</td>
<td>PoCoG and CeMPED</td>
<td>Phyllis Butow</td>
</tr>
<tr>
<td>Studies of <em>Arabic, Greek and Chinese speaking immigrants</em> – QoL, distress, anxiety and depression patterns of care</td>
<td>PoCoG and CeMPED</td>
<td>Phyllis Butow</td>
</tr>
</tbody>
</table>
| Fear of cancer recurrence (FCR):  
  - Systematic reviews of FCR instruments and FCR  
  - FCR in young women with *early breast cancer* – quantitative and qualitative studies  
  - Prevalence and predictors of FCR over first 5 years in CHeRP Cancer Survival Study  
  - Information processing biases and FCR (*breast, prostate and colorectal* cancer survivors) | PoCoG and CeMPED | Phyllis Butow |
<table>
<thead>
<tr>
<th>Topic</th>
<th>Centre/Lead agency</th>
<th>Presenter</th>
</tr>
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<tbody>
<tr>
<td>• Clinician survey of attitudes / Rx strategies</td>
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<tr>
<td>• Intervention study: Clustered RCT</td>
<td></td>
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<tr>
<td>QoL and unmet needs of <strong>pancreatic</strong> cancer patients and their caregivers</td>
<td>Queensland Institute of Medical Research</td>
<td>Vanessa Beesley</td>
</tr>
<tr>
<td>Validating a supportive care needs instrument in <strong>Indigenous</strong> population + implementing that validated tool to look at the needs of this group + sub-study: Does an Indigenous patient navigator help meet some of these needs?</td>
<td>Queensland Institute of Medical Research</td>
<td>Vanessa Beesley</td>
</tr>
<tr>
<td>QoL, unmet needs and lifestyle of longer-term <strong>endometrial</strong> cancer survivors</td>
<td>Queensland Institute of Medical Research</td>
<td>Vanessa Beesley</td>
</tr>
<tr>
<td><strong>Colorectal</strong> cancer – issues with returning to work and participation in work after cancer, and how that affects QoL</td>
<td>Queensland Institute of Medical Research</td>
<td>Vanessa Beesley</td>
</tr>
<tr>
<td>Unmet needs and QoL of <strong>melanoma</strong> survivors</td>
<td>Queensland Institute of Medical Research</td>
<td>Vanessa Beesley</td>
</tr>
<tr>
<td>QoL and unmet needs of women with <strong>ovarian</strong> cancer (+ piloted physical activity program during chemotherapy; submitted grant for full scale trial)</td>
<td>Queensland Institute of Medical Research</td>
<td>Vanessa Beesley</td>
</tr>
<tr>
<td>Predictors of psychological distress in post-treatment adult cancer survivors (of <strong>breast, prostate, colorectal</strong> cancers, <strong>Hodgkins lymphoma</strong> and DLBCL)</td>
<td>Peter MacCallum Cancer Centre</td>
<td>Michael Jefford</td>
</tr>
<tr>
<td><strong>Cancer Survival Study</strong> – longitudinal study of survivors’ (top eight incident cancers) needs, anxiety, depression, QoL, distress, coping, social support for first five years post diagnosis</td>
<td>Centre for Health Research &amp; Psycho-oncology (CHeRP)</td>
<td>Afaf Girgis</td>
</tr>
</tbody>
</table>
## Partners and Caregivers Study – longitudinal study of needs, anxiety, depression, QoL, distress, coping, social support, cost and impact of caring

- Centre for Health Research & Psycho-oncology (CHeRP)  
  Afaf Girgis

## Unmet needs, QoL and care experiences of people with **kidney** cancer, **multiple myeloma** and Hodgkins and non-Hodgkins lymphoma in first 12 months post diagnosis.

- Centre for Behavioural Research in Cancer (CBRC), Cancer Council Victoria  
  Vicki White

### Intervention studies

1. **Beating the Blues After Cancer (BBAC):** RCT of a tele-based psychological intervention for high distress patients and carers calling the Cancer Council Helpline (Anxiety, depression, cancer specific distress, unmet supportive care needs, positive adjustment, QoL)

   - Cancer Council Queensland and Centre for Health Research & Psycho-oncology (CHeRP)  
     Afaf Girgis

2. **Coping-Together:** Multi-media, self-directed coping skills intervention for patients with cancer and their partners (cancer specific distress and depression, and increasing positive illness appraisal or care giving appraisal, self-efficacy, quality of life, relationship satisfaction and positive individual and dyadic coping)

   - Centre for Health Research & Psycho-oncology (CHeRP)  
     Afaf Girgis

3. **Planned evaluation of CCNSW Living Well After Cancer program**  
   - Centre for Health Research & Psycho-oncology (CHeRP)  
   Afaf Girgis

4. **Nurse and peer interventions (three arm RCT) for couples where man has been treated for **prostate** cancer with surgery.**

   - Cancer Council Queensland  
   Suzanne Chambers
### Physical sequelae of cancer/treatment

<table>
<thead>
<tr>
<th>Topic</th>
<th>Centre/Lead agency</th>
<th>Presenter</th>
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</thead>
<tbody>
<tr>
<td>Addressing co-morbidities in women diagnosed with <strong>endometrial</strong> cancer</td>
<td>University of Sydney Nursing School</td>
<td>Kate White</td>
</tr>
<tr>
<td>Early menopause</td>
<td>Peter MacCallum Cancer Centre</td>
<td>Kelly-Anne Phillips</td>
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</tbody>
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### Intervention studies – physical activity

<table>
<thead>
<tr>
<th>Topic</th>
<th>Centre/Lead agency</th>
<th>Presenter</th>
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<tbody>
<tr>
<td>Treatment of Post-Cancer Fatigue Study (TOPS) trial – evaluating the effectiveness of CBT and graded exercise interventions for <strong>breast</strong> and <strong>colon</strong> cancer survivors</td>
<td>UNSW</td>
<td>David Goldstein</td>
</tr>
<tr>
<td>CHALLENGE: phase III study of the impact of a physical activity program on disease-free survival in patients with high risk stage II or III <strong>colon</strong> cancer</td>
<td>CeMPED Survivorship Research Group</td>
<td>Haryana Dhillon</td>
</tr>
<tr>
<td>PAL – impact of physical activity on fatigue and QoL of patients with incurable <strong>lung</strong> cancer</td>
<td>CeMPED Survivorship Research Group</td>
<td>Haryana Dhillon</td>
</tr>
<tr>
<td>Role of exercise in reducing potential cardiovascular and metabolic risk factors for cancer patients – two RCTs in WA, Qld and NZ</td>
<td>School of Exercise, Biomedical and Health Sciences, Edith Cowan University (WA)</td>
<td>Daniel Galvao</td>
</tr>
<tr>
<td>CCNSW ENRICH (Exercise and Nutrition Routine Improving Cancer Health) program: Efficacy and feasibility of an exercise and nutrition program for cancer survivors and carers</td>
<td>Centre for Health Research &amp; Psycho-oncology (CHeRP)</td>
<td>Afaf Girgis</td>
</tr>
<tr>
<td>Lifestyle interventions in breast cancer survivors, particularly physical activity,</td>
<td>Cancer Prevention Research</td>
<td>Afaf Girgis on behalf of</td>
</tr>
<tr>
<td>Weight loss, telephone delivery (reaching survivors living outside major cities)</td>
<td>Centre, Qld</td>
<td>Elizabeth Eakin</td>
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<tr>
<td>Survival outcomes for women with <strong>breast cancer</strong> following long-term physical activity intervention (with ANZBCTG)</td>
<td>Cancer Prevention Research Centre, Qld</td>
<td>Afaf Girgis on behalf of Elizabeth Eakin</td>
</tr>
<tr>
<td>Lifestyle interventions for menopause symptoms.</td>
<td>QUT</td>
<td>Patsy Yates</td>
</tr>
<tr>
<td>Web-based intervention for <strong>young women with breast cancer</strong> (&gt;50 years) providing information and links to other sources of information about treatment and diagnosis, dealing with emotional states and menopause symptoms.</td>
<td>Centre for Behavioural Research in Cancer (CBRC), Cancer Council Victoria</td>
<td>Vicki White</td>
</tr>
</tbody>
</table>

**Cognitive function**

<table>
<thead>
<tr>
<th>Cognitive function in adult survivors of <strong>colorectal</strong> cancer</th>
<th>CeMPED Survivorship Research Group</th>
<th>Haryana Dhillon</th>
</tr>
</thead>
<tbody>
<tr>
<td>BrainTrain – web-based cognitive rehabilitation program</td>
<td>CeMPED Survivorship Research Group</td>
<td>Haryana Dhillon</td>
</tr>
<tr>
<td>Cognitive Rehab Study in planning stages – <strong>breast</strong> cancer survivors</td>
<td>CeMPED Survivorship Research Group</td>
<td>Haryana Dhillon</td>
</tr>
<tr>
<td>Efficacy and safety of <strong>Ginkgo biloba</strong> for cognitive function and fatigue in <strong>breast</strong> cancer patients undergoing adjuvant treatment</td>
<td>CeMPED Survivorship Research Group</td>
<td>Haryana Dhillon</td>
</tr>
<tr>
<td>Cognitive function of <strong>germ cell</strong> cancer patients treated with chemotherapy</td>
<td>ANZUP</td>
<td>Ian Olver</td>
</tr>
<tr>
<td>Models of care</td>
<td>Centre/Lead agency</td>
<td>Presenter</td>
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</tr>
<tr>
<td>Web-based case management model – central record completed by patient, automated follow up, exception management</td>
<td>Sir Charles Gairdner Hospital, WA</td>
<td>Nigel Spry</td>
</tr>
<tr>
<td>ProCare Trial (in collaboration with ACSC) – model of shared care for follow-up in prostate cancer including tailored care plan and use of distress thermometer and specific prompt list</td>
<td>PC4</td>
<td>Jon Emery</td>
</tr>
<tr>
<td>Survivorship care plans (development and piloting of plan with breast cancer survivors through BCNA)</td>
<td>PoCoG and CeMPED</td>
<td>Phyllis Butow</td>
</tr>
<tr>
<td>A randomised controlled trial evaluating a nurse-led survivorship care package (SurvivorCare) for bowel cancer survivors – multi-site, multi-state trial investigating distress, QoL and unmet needs.</td>
<td>Peter MacCallum Cancer Centre</td>
<td>Michael Jefford</td>
</tr>
<tr>
<td>Cancer Survivors Follow-up Care Study – to better understand what people think to be the most important aspects of follow-up care; what they get at the moment; perceived gaps; acceptability of a range of models of survivorship care.</td>
<td>Centre for Health Research &amp; Psycho-oncology (CHeRP)</td>
<td>Afaf Girgis</td>
</tr>
<tr>
<td>Planned studies: Use of SMS to promote maintenance integration with survivorship care plans</td>
<td>Centre/Lead agency</td>
<td>Presenter</td>
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<tr>
<td>Cancer Prevention Research Centre, Qld</td>
<td>Afaf Girgis on behalf of Elizabeth Eakin</td>
<td></td>
</tr>
<tr>
<td>Training program for health professionals to assist people with chronic disease to self-manage. Pilot study data expected by the end of 2010/early 2011.</td>
<td>QUT Centre for Palliative Care Research and Education</td>
<td>Patsy Yates</td>
</tr>
<tr>
<td>Review of nurse-led follow up for women with gynaecological cancer.</td>
<td>University of Sydney Nursing School</td>
<td>Kate White</td>
</tr>
<tr>
<td>Distress of follow up – does follow up ease or create distress?</td>
<td>Liverpool/Campbelltown Hospitals</td>
<td>Geoff Delaney</td>
</tr>
<tr>
<td>Web-based support tool for breast and prostate cancer patients; with ultimate aim to support follow-up (exception-based case management model).</td>
<td>Liverpool/Campbelltown Hospitals</td>
<td>Geoff Delaney</td>
</tr>
<tr>
<td>Potential trial of model of shared care model for survivors of Hodgkin’s disease</td>
<td>Liverpool/Campbelltown Hospitals</td>
<td>Geoff Delaney</td>
</tr>
</tbody>
</table>
Reports of small group discussions

The workshop participants divided into three small groups, each of which considered one of the following questions:

- What are the key research priorities, and how should we develop a national research agenda?
- Is there a need for a central coordinating body and, if so, what role should it play?
- Is there a need for survivorship service provision? What form should a service take?

Group 1: Research priorities and recommendations for developing a national research agenda

The group acknowledged the significant and increasing amount of survivorship research underway across Australia. It identified a number of priorities to improve collaboration, translation of outcomes into practice and policy and address gaps.

Priorities for survivorship research

The group recommended:

- Developing a set of outcome measures appropriate for survivorship research, including a recommended core set of measures, to enable comparison of research findings.

- More collaborative research — formation of a national collaboration to develop studies that can’t be done on a state level or where greater numbers of survivors are needed, for example:
  - cluster randomised trials of different models of survivorship care
  - cluster randomised trials of supportive care models
  - research into issues facing survivors of rare and under-studied cancers.

- Intervention research needs to be translational and include health economics measures.
  The group suggested intervention research needs to have a strong translational element i.e. interventions need to be able to ‘survive’ outside of a research study.
  Research also needs to incorporate health economic measures, to demonstrate the cost-benefit ratio of interventions to health service funders.

- More longitudinal studies — using existing cohorts (such as the 45 and Up Study in NSW and others across Australia) to save expense.

- Studies of applications of IT in survivorship care — for example the use of patient-held records or e-Health records.
  The group noted that different levels of government across Australia are
exploring e-Health, so it would be beneficial for a national body to scope current activity, advocate for oncology to be a demonstration project and coordinate research (including engaging IT experts).

**Group 2: Is there a need for a central coordinating body (e.g. COSA)? What role should it play?**

The group agreed there is a need for central coordination of both survivorship research and clinical services, and identified several potential roles of a coordinating body:

- Establishing a clearinghouse or repository of information, resources, expertise and services (who does what), to prevent unnecessary duplication e.g. moderating production of information for survivors.

- Facilitating access to all cooperative trials groups – via one coordinating body, rather than contacting each individually – to encourage incorporation of survivorship end points into existing clinical trials, and to assist survivorship researchers who require cohorts of patients across different tumour types.

- Facilitating access to groups of clinicians and health professionals — for example if a researcher wants to study patients with a particular symptom or at a particular stage they may need to contact clinicians treating patients with a specific profile.

- Providing education — developing and providing access to educational resources and training clinicians to appreciate the need and evidence for survivorship care. This may also lead to the development of clinical practice guidelines.

- Advocating for greater awareness of the importance of, and resources for, survivorship research and services, including clinical positions.

The group decided there were two organisations that could potentially fulfil these roles: COSA and the Australian Cancer Survivorship Centre (ACSC). It considered whether it was necessary to nominate one organisation as the coordinating body, and decided there were benefits of the two organisations having delineation of specific aspects of the role:

- ACSC has a very clear focus on and expertise in survivorship care, has resources to develop educational materials, and has the capacity to serve as a repository of information.

- COSA has strong access to clinician groups and is an ‘umbrella body’ for the cooperative clinical trials groups. As such, COSA can play a significant role as an enabler and facilitator of research. COSA also has significant credibility as an advocacy body.
The group felt it was appropriate for two organisations to continue to develop their respective roles, collaborating closely to ensure there a consistency in messages.

COSA’s demonstrated track record and capacity to coordinate groups was highlighted, including facilitating a network of cooperative clinical trials groups and representing and enabling access to all groups of health professionals involved in clinical and supportive care. Through its partnership with Cancer Council Australia, COSA also has an ability to coordinate development of guidelines.

**Group 3: Is there a need for survivorship service provision? What form should a service take?**

This group considered existing models of survivorship care and identified some of the key issues and challenges in delivering services and some options for addressing them.

- **Sustainability/triaging**

In follow up of survivors of childhood cancers, the problem of sustainability has been met through triage of patients into high, medium and low need groups in order to:

- rapidly transition low need people out of the intensive follow up model
- recognise which of the medium needs patients can be transitioned to GP follow up (with a ‘road map’ they can take with them)
- retain patients with high needs, such as those who had a bone marrow transplant or are known to be at high risk of late toxicities, within the centralised model of care.

The challenge of integrating general practice has been met by embedding GPs in the centralised follow up program.

The group suggested the same type of triage model might be applied for care of adult survivors, where the number of survivors is much larger and a model focused predominantly on adult hospitals providing services will be unsustainable. This would require consideration about how to define high, medium and low needs to ensure appropriate triaging.

- **Case management (exception-based follow up)**

The group considered the idea of entirely using a distance, patient-centered model of follow up, with an automated intervention system that alerts a case manager, who is monitoring the data and knows who to refer to, when there is an exception.

One of the advantages is that this model upskills survivors, and puts them in charge of their care and using the services provided. This also is more sustainable.

However, this model of care requires clear consensus on what follow up should entail (what types of monitoring/assessment and for whom) and care plans that are standardised and agreed to. The group noted that for some cancers, such as lymphoma, this would be complex as there is no agreed approach to follow up.
It was noted that a key problem with exporting all the follow up care is the inability to document long-term issues. However if patients see the benefits of entering data, then they may be motivated to sustain their own data entry and therefore a very long-term database will be created that can be interrogated when there is new knowledge about a late side-effect of a particular cancer or treatment.

The group also acknowledged survivorship as a ‘teachable moment’, and queried whether the opportunity to encourage lifestyle change and behaviour modification is lost if care is totally exported.

- Models of survivorship care

The group highlighted the need to define ‘survivors’ and ‘survivorship’ and noted that survivorship care needs to be more than just monitoring for recurrence, including issues from employment to long-term toxicities, distress and other unmet needs. It recommended the first priority is to establish survivorship as an issue, which therefore has a right to seek funding to establish whatever model is considered best for all cancer survivors.

The group did not propose a single solution, but highlighted possible advantages and disadvantages of different models of care for further investigation and consideration.

Is there any role for specialist survivorship centres or indeed any individuals who specialise in survivorship care?

Is it such a broad field with so many different cancers and so many things you need to know that that’s not a realistic idea at all?

Or is there something about the survivorship experience that is unrelated to the individual cancer and more related to treatment and its consequences that justifies a survivorship research model and certain people who identify themselves as experts?

The group suggested that a comprehensive model of survivorship care requires tools that can elicit patient needs and measure outcomes. The group considered the Flinders Medical Centre Survivorship Program, which requires initial agreement between a patient and a provider about what the most likely issues are and what they think follow up should entail, asking the patient to commit to that, and following up to see if needs change.

In order to avoid ‘over-medicalising’ survivorship, the group recognised the potential of community-based follow up e.g. having nurse practitioners in community health centres do the triaging, effectively acting as community-based cancer (survivorship) care coordinators.

It was noted that a lot of time in follow up is spent ‘saying the same thing to multiple people and multiple time points’, prompting a discussion of whether mass education could be part of a survivorship care model, e.g. educational forums such as webcasts or face-to-face meetings, that also incorporate patient support or written resources.
Peer support was also noted as a very important part of survivorship care, with indications that peers provide a significant proportion of education and help meet survivors’ unmet needs.

Participants cautioned that the notion of survivorship needs to be very carefully considered so that it doesn’t become an imposition, a construction of health professionals, that creates the identify of individuals quite contrary to where they themselves might be travelling. In constructing models of service, we need to be particularly sensitive to the potential to create or maintain identities rather than to enable person to move towards their own sense of health and wellbeing quite independent of health professionals.

**Next steps**

Professors Goldstein and Girgis thanked attendees for their participation in the workshop.

Following the observations and recommendations of the groups, some immediate actions would be:

- Seek COSA Council approval (via Professor Bogda Koczwara) to form a Survivorship Interest Group. This network will enable interested individuals to share information and outcomes and, after considering this report, determine research, education, advocacy and other priorities.

- COSA and ACSC to discuss opportunities for collaboration in relation to supporting and promoting survivorship research and services.

- Establish a database or matrix of research underway or planned, to reduce duplication and enable researchers to form new collaborations.

- Form a small working group to start development of a core set of outcome measures.

The aim is to progress these actions early in 2011 to maintain the momentum.
Appendixes

A: Workshop program

B: List of workshop attendees and invited participants

C: Presenters’ Powerpoint slides
<table>
<thead>
<tr>
<th>Time</th>
<th>Agenda item</th>
<th>Presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.00 – 4.05 pm</td>
<td>Welcome; workshop objectives</td>
<td>Afaf Girgis</td>
</tr>
<tr>
<td>4.05 – 4.15 pm</td>
<td>Overview of international activities</td>
<td>Afaf Girgis</td>
</tr>
<tr>
<td>4.15 – 4.20 pm</td>
<td>Overview of the Australian Cancer Survivorship Centre (ACSC)</td>
<td>Michael Jefford</td>
</tr>
<tr>
<td>4.20 – 5.05 pm</td>
<td>Brief overviews: Current and planned survivorship programs and research from around Australia</td>
<td>David Goldstein, Phyllis Butow, Haryana Dhillon, Nigel Spry, Jon Emery, Rob Newton, Vanessa Beasley, Annie Miller, Bogda Koczwara, Michael Jefford, Afaf Girgis, Others (12 mins)</td>
</tr>
<tr>
<td></td>
<td>NB: strictly 3 minutes per presenter; maximum 3 slides each</td>
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<tr>
<td>5.05 – 5.10 pm</td>
<td>Overview of aims and process of small groups discussions</td>
<td>David Goldstein</td>
</tr>
<tr>
<td>5:10 – 5.50 pm</td>
<td>Small group discussion:</td>
<td>Facilitators: G1: Afaf Girgis, G2: Bogda Koczwara, G3: David Goldstein</td>
</tr>
<tr>
<td></td>
<td>1. What are the key research priorities currently and how should we develop a national research agenda?</td>
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<td></td>
<td>2. Is there a need for a central coordinating body (eg COSA)? What role should it play?</td>
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<td></td>
<td>3. Is there a need for survivorship service provision? What form should a service take?</td>
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<tr>
<td>5.50 – 6.20 pm</td>
<td>Each group reports backs &amp; general comments</td>
<td>Group reps</td>
</tr>
<tr>
<td>6:20 - 6:30 pm</td>
<td>Next steps</td>
<td>David, Afaf</td>
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<tr>
<td>Attended</td>
<td>Title</td>
<td>First Name</td>
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<tr>
<td>Ms Gill</td>
<td>Ms</td>
<td>Vanessa</td>
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<tr>
<td>Ms Alison</td>
<td>Ms</td>
<td>Geoff</td>
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<tr>
<td>Ms Haryana</td>
<td>Ms</td>
<td>Bede</td>
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<tr>
<td>Dr Peter</td>
<td>Dr</td>
<td>Jon</td>
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<tr>
<td>Ms Allison</td>
<td>Ms</td>
<td>Daniel</td>
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<tr>
<td>Dr Vanessa</td>
<td>Dr</td>
<td>Jefford</td>
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<tr>
<td>Dr Vanessa</td>
<td>Dr</td>
<td>Kocszwara</td>
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<tr>
<td>Dr Andrew</td>
<td>Dr</td>
<td>Lloyd</td>
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<td>Dr Annie</td>
<td>Dr</td>
<td>Miller</td>
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<td>Dr Fiona</td>
<td>Dr</td>
<td>Newman</td>
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<tr>
<td>Dr Claire</td>
<td>Dr</td>
<td>Wakefield</td>
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<tr>
<td>Ms Miss</td>
<td>Ms</td>
<td>White</td>
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<tr>
<td>Dr Accepted</td>
<td>Dr</td>
<td>Patry</td>
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<tr>
<td>Prof Julie</td>
<td>Prof</td>
<td>Hassard</td>
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<td>Prof Bruce</td>
<td>Prof</td>
<td>Mann</td>
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<td>Accepted</td>
<td>A/Prof Robert</td>
<td>Newton</td>
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<td>Accepted</td>
<td>A/Prof Violet</td>
<td>Platt</td>
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<td>A/Prof Christobel</td>
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<td>Accepted</td>
<td>A/Prof Emma</td>
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<td>A/Prof Eva</td>
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<td>Accepted</td>
<td>A/Prof Brad</td>
<td>Zabrack</td>
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<td>Accepted</td>
<td>A/Prof Elizabeth</td>
<td>Eakin</td>
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<td>Accepted</td>
<td>A/Prof Sandi</td>
<td>Hayes</td>
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<td>Accepted</td>
<td>A/Prof Kathy</td>
<td>Chapman</td>
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<td>Accepted</td>
<td>A/Prof Kate</td>
<td>Stern</td>
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<tr>
<td>Accepted</td>
<td>A/Prof Janette</td>
<td>Vardy</td>
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<tr>
<td>Invited</td>
<td>A/Prof Sandra</td>
<td>Aranda</td>
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<tr>
<td>Invited</td>
<td>A/Prof Fran</td>
<td>Boyle</td>
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<tr>
<td>Invited</td>
<td>Ms Angela</td>
<td>Cotroneo</td>
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<td>Invited</td>
<td>Prof Michael</td>
<td>Friedlander</td>
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<tr>
<td>Invited</td>
<td>Ms Karen</td>
<td>Johnston</td>
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<td>Invited</td>
<td>Dr Bettina</td>
<td>Meiser</td>
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<td>Invited</td>
<td>Steve Pratt</td>
<td>Pratt</td>
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<td>Invited</td>
<td>Dr Launae</td>
<td>Sanson-Fisher</td>
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<td>Invited</td>
<td>Dr Lyn</td>
<td>Swinburne</td>
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<td>Invited</td>
<td>Dr Jane</td>
<td>Turner</td>
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<tr>
<td>Invited</td>
<td>Mr Chris</td>
<td>Tzar</td>
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COSA
Cancer Survivorship Workshop

Afaf Girgis
Centre for Health Research & Psycho-oncology (CHeRP)
Cancer Council NSW, University of Newcastle
& Hunter Medical Research Institute

David Goldstein
Price of Wales Hospital & UNSW

COSA 2010
Workshop Goal

To bring to the table key players in survivorship research and practice from across Australia to:

• Foster and encourage collaboration
• Identify opportunities for convergence and difference to best exploit our competitive position internationally
• Consider value of and role for a coordinating body
Workshop Format

• Very brief overviews – international and national activities
• Small group discussion
• Feedback and plan for next steps
Overview of international activities
(10 mins)

Afaf Girgis
Director, Centre for Health Research
& Psycho-oncology (CHeRP)
At a national level, survivorship issues are a priority
Cancer Survivorship: Research Priorities at the National and International Levels

Afaf Girgis¹ and Phyllis Butow²
1. Centre for Health Research & Psycho-oncology, Cancer Council NSW. University of Newcastle & Hunter Medical Research Institute, NSW.
2. Centre for Medical Psychology and Evidence-based Decision-making, University of Sydney, NSW.
Email: Afaf.girgis@newcastle.edu.au

Abstract

With an increasing number of people living with and beyond a cancer diagnosis, research addressing the needs of this population has consistently been identified as one of the key priorities for a global survivorship agenda. Within an international context, US, UK and Canada have been key players in priority setting activities, with the consistency across these nations lending support for a global survivorship research agenda. Priorities identified include: development of tools and instruments for use in survivorship research; development of effective care models and interventions; investigation of long-term effects of cancer diagnosis and treatment on patients, their families and caregivers; and needs and characteristics of unique or disadvantaged populations. An overview of the research being undertaken in Australia suggests a high level of congruency with international priorities, with a wide spectrum of research addressing issues across the whole survivorship continuum. However, support is needed for further work.
Pre-MASCC Symposium Study Group Workshop

Cancer Survivorship: Creating International Collaborations to Study the Supportive Care Needs of Cancer Survivors

Wednesday, June 23rd, 2010
John Jambor Room, BC Cancer Agency, 600 West 10th Avenue, Vancouver, B.C. V5Z 4E6

<table>
<thead>
<tr>
<th>Time</th>
<th>Wednesday June 23rd, 2010</th>
<th>Presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30-8:45 a.m.</td>
<td>Workshop Objectives – purpose and desired outcomes</td>
<td>Moderators: Paul Jacobsen, Richard Doll</td>
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http://www.mascc.org/mc/page.do?sitePageId=86981&orgId=mascc
<table>
<thead>
<tr>
<th>Time</th>
<th>Event Description</th>
<th>Speakers</th>
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<tbody>
<tr>
<td>11:15-11:30 a.m.</td>
<td>Cancer Survivorship Consortia: International research &amp; clinical priorities cont.</td>
<td>Afaf Girgis, Australia</td>
</tr>
<tr>
<td>11:35-11:50 a.m.</td>
<td>Cancer Survivorship Consortia: International research &amp; clinical priorities</td>
<td>Margaret Fitch, Canada</td>
</tr>
<tr>
<td>11:55-12:10 p.m.</td>
<td>Cancer Survivorship Consortia: International research &amp; clinical priorities cont.</td>
<td>Alex Molassiotis, United Kingdom</td>
</tr>
<tr>
<td>12:15-12:30 p.m.</td>
<td>Cancer Survivorship Consortia: International research &amp; clinical priorities cont.</td>
<td>Ulla Hjortebjerg, Denmark</td>
</tr>
<tr>
<td>12:35-12:50 p.m.</td>
<td>Cancer Survivorship Consortia: International research &amp; clinical priorities cont.</td>
<td>Irma Verdonck-de Leeuw, Netherlands</td>
</tr>
</tbody>
</table>
Australia: A straw poll of consumers, researchers, clinicians

1. Relevant & meaningful s/ship measures
2. S/ship issues in indigenous, under-studied, minority populations, older survivors
3. S/ship trajectories (longitudinal) – survivors, caregivers
4. Follow-up care practices & preferences study
5. Role of family practitioners in f/up care, management of long-term toxicities - patterns of care study
6. Studies of impact of longer-term toxicities & treatment side effects on QoL and s/ship
7. Evaluation of pt-held treatment/care plans
8. Models of f/up care – comparison of outcomes between countries
Other priority questions:
A consumer perspective

1. Assessment of workforce and other investments needed – *can we afford best practice* *s/ship care?*

2. Role of definitions in service design & planning? Disease-free survivors vs survivors living with disease

3. Care of pt vs survivor – who’s responsible? Embedding self-management principles

4. What are the issues influencing translation of policy into practice?
Denmark!
National Centre of Cancer Rehabilitation Research (NCCRR)

Multidisciplinary team

- Nurses
- Physiotherapists
- Social worker
- Scientific assistant
- Dietician, sexologist, medical doctor, psychologist, art therapist, clergyman and masseurs
- Cleaning staff, cooking staff and administrative staff
Cancer survivorship: research and clinical practice in the Netherlands

Prof dr Irma Verdonck-de Leeuw

VU University Medical Center / Cancer Center Amsterdam
Dept of Otolaryngology Head & Neck Surgery

VU University
Dept of Clinical Psychology

Amsterdam, The Netherlands
Research:
Guided self help targeting anxiety and depression

Research:
Guided self help targeting speech, swallowing and shoulder dysfunction
OncoCompass

Personal Health Record and Supportive Care Plan

Webportal for care provider

Aggregated (group) Health record and care plan
Caroline Huffman, LAF

LIVESTRONG®
SURVIVORSHIP CENTER
OF EXCELLENCE NETWORK

1. Abramson Cancer Center, University of Pennsylvania
   www.pennmedicine.org/services/cancer
2. Dana-Farber Cancer Institute
   www.dana-farber.org/patients/surviving
3. Fred Hutchinson Cancer Research Center
   www.fhcrc.org/patient/support/survivorship
4. Jonsson Comprehensive Cancer Center at UCLA
   www.cancer.ucla.edu
5. Memorial Sloan Kettering Cancer Center
   www.mskcc.org/mskcc/html/58022.cfm
6. The Ohio State University Comprehensive Cancer Center - James Cancer Hospital
   www.jamesline.com/patients/visitors/survivors
7. University of North Carolina, Lineberger Comprehensive Cancer Center, N.C. Cancer Hospital
   www.canncancer.org/patient/survivorship
8. University of Colorado Cancer Center, AMC Cancer Research Center
   www.uccs.edu/cancer-center/prevention/survivorship/uccs-livestrong.aspx
CORE ELEMENTS OF LIVESTRONG NETWORK

- **Collaborative Research** -- Clinical, biomedical, psychosocial, health services

- **Care and Services** -- Improving accessibility, quality, relevance, & integration of care; develop and test new medical, psychosocial, behavioral modalities

- **Training** -- Next generation of healthcare professionals, social service providers, researchers committed to survivorship
LIVESTRONG SURVIVORSHIP CENTER OF EXCELLENCE NETWORK

COLLABORATIONS

COE/CBC Collaborations
- Frequent COE/CBC Meetings
  - Full-time coordinator
  - Steering Committees

COE/COE Collaborations
- Semi-annual meetings
  - Conference calls
- Working groups; joint projects
- Web sites; data bases; e-mail

LAF
- Leadership
- Facilitation
- Oversight
- Evaluation

Centers of Excellence: Regional, NCI-designated comprehensive centers or equivalent stature

Community-Based Centers: Local centers providing direct services to survivors, especially traditionally underserved populations
In 2009 CJAG funded implementation and evaluation of a supportive care program in Canada called *Cancer Transitions*. *Cancer Transitions* is a program developed by the Cancer Support Community (CSC—formally The Wellness Community) and LIVESTRONG (Lance Armstrong Foundation) to help cancer survivors make the transition from active treatment to post treatment care. It is a six-week psycho-educational program for survivors of all cancer types. It was successfully piloted at 15 locations in the United States in 2008. In partnership with the BC Cancer Agency (BCCA) and CJAG, four Canadian pilot sites delivered and evaluated the program and measured its impact on participants.
The Program – Cancer Transitions: Moving Beyond Treatment

The Cancer Transitions program is a six session intervention targeted towards those 0 to 24 months post treatment. The program covers significant aspects of cancer survivorship including exercise, emotional well-being, nutrition, medical management, and survivorship care planning. It provides the opportunity to practice skills that can help cancer survivors manage their life after treatment. Also, the program is not specific to one type of cancer diagnosis, and is thus applicable and adaptable to survivors of a variety of tumour sites.

Session 1: Get Back to Wellness: Take Control of Your Survivorship
Session 2: Exercise for Wellness: Customized Exercise
Session 3: Emotional Health and Well-Being: From Patient to Survivor
Session 4: Nutrition Beyond Cancer
Session 5: Medical Management Beyond Cancer
Session 6: Life Beyond Cancer
Booster Session: Follow up and check in session
Cancer Survivorship & Supportive Care Consortia: the UK experience

Prof. Alex Molassiotis, RN, PhD
Professor & Chair of Cancer & Supportive Care
University of Manchester, UK
Analysis of research activity and capacity:

- Strategic analysis published in 2002 by NCRI
- Research into supportive and palliative care accounted for only about 4% of direct cancer research expenditure by NCRI partners
- In response to this the NCRI established a strategic planning group to make recommendations on actions that could be undertaken to enhance research in this field
Analysis of research activity and capacity:

- Strategic analysis published in 2002 by NCRI
- Research capacity accounted for
- In response to the strategic recommendations, undertaken

Call for research collaborative proposals - November 2004

- **Critical mass** - a number of academic organisations working together as a single partnership
- **Span of expertise** - individuals and groups from a wide range of different research disciplines and clinical professions
- **Methodological approaches** to tackle challenges in this area
- **Increase capacity** of the UK to conduct high quality research in this area
- **Maximum positive impact** on policy and practice
- To nurture high quality *researchers of the future*
2 Supportive & Palliative Care Research Collaboratives (2006-2011) £3.8M ($US 5.6M)

www.ceco.org.uk & www.compasscollaborative.com
2 Supportive & Palliative Care Research Collaboratives (2006-2011) £3.8M ($US 5.6M)

www.ceco.org.uk & www.compasscollaborative.com

Aims

To work together to make significant and substantive progress in both research capacity and in the quality of research in supportive and palliative care over the 5 years of the Collaboratives

To do so in a way that ensures that progress is maintained beyond this period

Our research themes are platforms on which to build our research capacity – building activities
# National Cancer Survivorship Initiative (NCSI)

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>November 2007</td>
<td>Cancer Reform strategy</td>
</tr>
<tr>
<td>May 2008</td>
<td>NCSI was launched (Led by DoH &amp; Macmillan Cancer Support)</td>
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<tr>
<td>October 2008</td>
<td>7 work streams established</td>
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<tr>
<td>October 2009</td>
<td>Collaboratives led on evidence synthesis</td>
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# National Cancer Survivorship Initiative (NCSI)

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<th>Date</th>
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## NCSI work streams

**Focus on the survivorship pathway:**
- Assessment and Care Planning
- Active and advanced Disease
- Consequences of cancer treatment

**Cross cutting themes covering the whole survivorship pathway:**
- Supported Self Management
- Work and Finance
- Research

**Particular group:**
- Children and young people
The pre-conference workshop on Survivorship was attended by 55 people. The purpose of the workshop was to develop international collaborations. The morning was dedicated to information giving via presentations with break out groups taking place in the afternoon. Three collaborative short-term projects were identified. Project leads were identified for each of the projects and MASCC members are now encouraged to contact the project lead if they are interested in being involved in the projects. In brief, the projects are as follows:

- **Survey of Survivors**: Initially a survey instrument would need to be identified then applied in several countries. The purpose of the work is to identify the acceptability of different models of survivorship care to inform service delivery. Project Lead: Araf Girgis aaf.girgis@newcastle.edu.au

- **Survey of Survivorship Programmes**: The purpose of this work is to identify international established models of Survivorship care. Project Leads: Winson Cheung wcheung@bccancer.bc.ca; Martin Chasen martinchasen@rogers.com

- **NB Those present were reminded that all surveys must be approved by the MASCC executive committee prior to distribution.**

- **Catalogue of Current Guidelines for Cancer Survivorship**: This purpose of this project is to identify current guidelines through a web based and non-web based review. No language restrictions will be applied. Lead: Paul Jacobsen paul.jacobsen@moffitt.org
Australian Cancer Survivorship Centre
A Richard Pratt Legacy

A/Prof Michael Jefford
MBBS MPH MAICD FRACP

Deputy Head, Department of Medical Oncology, Peter MacCallum Cancer Centre
Director, Australian Cancer Survivorship Centre
Australian Cancer Survivorship Centre
A Richard Pratt Legacy

- Based at Peter Mac in East Melbourne
- Funded by The Pratt Foundation, Victorian Department of Health and Peter MacCallum Cancer Centre
- Funding primarily supports staffing, resource development, capacity building
- Not a clinical service, though major emphasis is on clinical care
Australian Cancer Survivorship Centre
A Richard Pratt Legacy

Vision / goal

“To optimise the health and well being of cancer survivors and their carers”
Australian Cancer Survivorship Centre
A Richard Pratt Legacy

• Strategic directions

1. Build a state-wide then national role as an authoritative source of knowledge and expertise in cancer survivorship
2. Become a focal point for the exchange of information and resources and links to support relevant to survivor experience
3. Build capacity in professional communities
Australian Cancer Survivorship Centre
A Richard Pratt Legacy

- Strategic directions

4. Build capacity in individuals and consumer communities to improve individual post treatment health outcomes
5. Influence key ‘agents of change’ to trial new ways of providing effective and appropriate care for cancer survivors and their carers
Australian Cancer Survivorship Centre
A Richard Pratt Legacy

Features

• Collaborative
• Sharing
• Capacity building
• Facilitating
Australian Cancer Survivorship Centre
A Richard Pratt Legacy

• Acts as a dedicated resource to the Victorian Cancer Survivorship Program (VCSP)
  – VCSP will pilot models of post-treatment survivorship care
  – Centre will scope needs and deliver education and training for health professionals
  – Centre will develop resources to support improved survivorship care throughout Victoria
Similarly a resource for Peter Mac

Goal is to incorporate post-treatment considerations into the Peter Mac model of care

Aim to integrate with and expand upon Peter Mac’s existing survivorship research program
Improving survivorship care in Australia

The Australian Cancer Survivorship Centre is working to help improve health outcomes for cancer survivors.

Numbers of cancer survivors are increasing due to advances in early detection, treatment and population ageing. International research shows there is an important need to address issues faced by cancer survivors coping with life during and beyond acute treatment.

The ACSC is advocating for and assisting the development of services, as well as promoting research, education and discussion within the health system to increase knowledge about cancer survivorship. In these ways we aim to promote coordinated, evidence-based care; improve collaboration between health professionals and within the health system; and advocate for policies and resources to support the health and wellbeing of survivors.
Brief Overviews
(3 mins each)

Current and Planned survivorship programs and research from around Australia
David Goldstein
NSW Cancer Survivors Centre (NSWCSC), NSW
A UNSW collaboration between –
Randwick Health Campus Staff - POWH/RHW/Sydney Childrens, UNSW Lifestyle Clinic
UNSW Hospitals - St Vincents/ Liverpool ..........
UNSW School of Community Health
Collaborating Partners – CHeRP/ Cancer Council NSW
Initial Goals

• Establish a physical space to which cancer survivors can be referred for assessment
• Initiate early research programs.
• Determine cancer survivors’ needs and preferences.
• Provide a clinical and teaching facility for students.
Research through service

- post-cancer fatigue
- fertility and sexual dysfunction
- bone health
- cancer genetics
- lymphoedema management
- lifestyle interventions to improve quality of life, such as increasing physical activity
- distress in survivors and unmet needs – both psychological and practical.
Partnerships

• The Centre will develop in collaboration with two well-established programs:

• The UNSW Lifestyle Clinic provides clinical services and research in exercise and lifestyle therapies for people with chronic disease.

• The Childhood Cancer Long-term Follow-up Clinic is the longest running survivorship program for adult survivors of childhood cancer in Australia.
PoCoG and CeMPED work in Survivorship

Phyllis Butow

Chair, PoCoG and Co-Director, CeMPED

University of Sydney
PoCoG: Testicular Cancer Survivors

- **CIs:** Olver, Butow, Luckett, Grimison, Toner, King, Stubbs, Stockler, Hovey
- Collaboration with ANZ Germ Cell Trials Group
- Cross-sectional survey of men 6 months to 5 years post treatment
  - needs, QOL, distress, coping, social support
- Qualitative study of high and low distressed
PoCoG: CALD studies

CIs: Butow, Girgis, Goldstein, Eisenbruch, Schofield, Jefford, King

- Cross sectional survey of Arabic, Greek, Chinese speaking immigrants and Anglo-Australian controls
  - Diagnosed with cancer 6 months to 2 years previously
  - QOL, Distress, Anxiety and Depression, Patterns of care

- Recruited through cancer registries in NSW, Victoria, Queensland

- N=500
PoCOG / CeMPED: Fear of Cancer Recurrence studies

CIS: Thewes, Butow, Beith - Girgis, Turner, Bell

1. Systematic reviews of FCR instruments and FCR
2. FCR in young women with early breast cancer (n=200)
   - Quantitative and qualitative studies
3. Prevalence and predictors of FCR over first 5 years in CHeRP Cancer Survival Study (n=1,453)
4. Information processing biases and FCR (n=100 breast, prostate and colorectal cancer survivors)
5. Clinician survey of attitudes / Rx strategies
6. Intervention Study: Clustered RCT
CeMPED: Survivorship care plans

- CIs: Brennan, Boyle, Butow, Spillane
- Systematic review of literature
- Surveys and interviews with clinicians and consumers re survivorship care
- Development of Survivorship Care Plan (with BCNA)
- Piloting of SCP
Survivorship Research Group (SuRG)
Centre for Medical Psychology & Evidence-based Decision-making

Haryana Dhillon PhD
Janette Vardy B.Med (Hons), PhD, FRACP
Sydney Cancer Centre
University of Sydney
Cancer Institute NSW
Overview

› Cognitive Function:
  - Incidence
  - Duration
  - Risk Factors
  - Mechanisms
  - Treatment
  - Animal model

› Physical Activity:
  - Impact on disease free survival in colon cancer
  - Impact on fatigue in people with lung cancer

› Symptom Control:
  - Fatigue
  - Pain
  - Sleep
  - Patient perceptions of side effects of chemotherapy (on the receiving end in the 21st century)
Colorectal Cancer – Cognitive study:

- prospective longitudinal study comparing cognitive function and fatigue in patients who do and do not receive chemo for localised CRC
- Evaluating putative mechanisms of cognitive impairment and fatigue
- N = 365 patients

- No high level evidence to recommend any intervention to prevent or treat cognitive impairment in cancer survivors
Early stage Cancer Survivors
6-60 mths post CTh
Cognitive symptoms
No evidence of disease recurrence

30 minute phone consultation - strategies

Computer rehabilitation program
- 4x 40 min/week at home
- for 15 weeks

Control Group

Home based intervention and assessments:
NP and self report

Recruitment is open to cancer survivors around Australia
Cognitive Rehabilitation

Breast Cancer Survivors 6-60 mths post CTh Cognitive Symptoms

Self Reported Cognitive Function, NP performance, QOL, Blood parameters 0, 6, 12 mths

R

Attention Process Training
Compensatory Strategies
Control group
Efficacy and safety of *Ginkgo biloba* for cognitive function and fatigue in breast cancer patients undergoing adjuvant chemotherapy.

**Breast Cancer adjuvant CTh**  
*n = 120/ gr*

**EgB761**

**Placebo**

**Assessments:** 0 (preCTh), 3, 6, 12, 24 months: NP tests,

**Self-report:** cognitive, QOL, fatigue, anxiety/depression

**Blood tests:** mechanisms

fMRI substudy, interactions of Ginkgo - CTh/hormones
CHALLENGE: Phase III study of the impact of a physical activity program on disease-free survival in patients with high risk stage II or III colon cancer

Investigators: Janette Vardy, Haryana Dhillon, Hidde van der Ploeg, John Zalcberg, Kerry Courneya, Ralph Meyers

Collaboration: National Cancer Institute of Canada Clinical Trials Group

Endorsed: Australasian Gastro-Intestinal Trials Group Psycho-Oncology Cooperative Research Group
CHALLENGE: phase III study of the impact of a physical activity program on disease-free survival in patients with high risk stage II or III colon cancer

Stage 2-3 Colon Cancer
- Disease resected
- Adjuvant CTh completed (2-6 mo)

Stratified: stage (II vs III), BMI (>,<27.5), ECOG PS (0 vs 1), centre

RANDOMISE

Intervention Arm
- General health education material
- PA program & behaviour change – 36 months

Control Arm

3 year DFS
PAL: The impact of physical activity on fatigue and quality of life in lung cancer patients

Diagnosis of incurable lung cancer

Registration
Baseline assessment (0 months)

Randomisation
Stratify: Disease stage, Performance Status, Centre

Arm 1
Physical Activity Program + General Health Education Materials (Intervention Arm)

Arm 2
General Health Education Materials Only (Control Arm)

Follow up at 2, 4, & 6 months

Survival Follow up

Endorsed by ALTG and PoCoG
Survivorship Research Group

Haryana Dhillon    Emma Goddard
Janette Vardy      Anne Warby
Victoria Bray      Rhonda Devine
Joanna Fardell     Felicity Lesley
Corrine Renton     Anna Jones
                   Jane Turner

**Funding:**

NHMRC
National Cancer Institute of Canada
Cancer Institute NSW
American Society of Clinical Oncology
Lance Armstrong Foundation
National Institute of Complementary Medicine & BCRF
Nigel Spry WA

• Concept: a web based resource to facilitate change to the *follow up* paradigm

1. Employ strengths of IT
   1. Central record -patient completed
   2. Automate follow up,
   3. Exception management

2. Upskill patients,
   1. not the medical nursing profession

3. Case management
   • boutique expertise
   • Geography independent
Follow up of the well

Priority 3: Case Management

- Centralised national service
- Expertise
- Feedback when abn response
- Support boutique expertise

- Improve medical communication
  - Central notes record
  - Letters/results?
  - Trend and summary reports

- Improve personal responsibility
  - Clarification personal plan goals
  - Empowerment lifestyle
  - Feedback qol/results trend

- Improve timely access
  - Unnamed topic

- Outcome data
  - Comprehensive surveys

- Reduce financial cost
  - Automatable surveys
  - Expert case management for exceptions
  - Identification of automatable processes
  - Patient completion
  - Reduce chasing up of results
  - Reduce duplication tests etc
The ProCare Trial: shared care for follow-up in prostate cancer

• Jon Emery
• Penny Schofield
• Michael Jefford
• Dickon Hayne
• Marie Pirotta
• Lyndal Trevena
• Andrew Martin
• Roger Constable
Components of model of shared care

**Communication**
- Tailored care plan
  - Disease summary
  - Adverse effects of treatment
  - Treatment team
  - Evidence-based guidance on:
    - Recurrence detection
    - Urinary and bowel symptoms
    - Psychosexual problems
  - Local services
- Faxed to practice within 1 week and given to patient
- Added to GP patient records

**Register and recall**
- Letter to patient and GP
- Prompts for areas to discuss

**Screening for distress and unmet needs**
- Distress Thermometer
- Problem prompt list

**Information resources for patient and carer**
# Follow-up schedule

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<th></th>
<th>End Rx</th>
<th>2 w</th>
<th>6 w</th>
<th>3 m</th>
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Phase I/II

- **Phase I**
  - 10 men completing treatment for prostate cancer with curative intent (surgery or radiation)
  - Test feasibility and acceptability
  - Telephone interviews with participant, GP and urologist

- **Phase II**
  - RCT shared care versus usual care
  - 188 men
    - Randomisation stratified by treatment type and hospital
    - Recruitment in WA & Victoria
  - 12 month follow-up
Physical Exercise and Cancer Survivorship

Associate Professor Daniel Galvão
Director, ECU Health and Wellness Institute
Review of Exercise Intervention Studies in Cancer Patients

Daniel A. Galvão and Robert U. Newton

Symptoms toxicities
- ↓ fatigue
- ↑ muscle function
- ↑ physical performance
- ↑ aerobic capacity
- ↔ ↑ body composition
- ↑ quality of life

specific phases along the cancer continuum
- prevention
- Treatment preparation/efficacy
- Recovery/rehabilitation
- Disease prevention/health promotion
- palliation
- survival

Courneya and Friedenreich Sem Onco Nurs 2007;23:24
Combined Resistance and Aerobic Exercise Program Reverses Muscle Loss in Men Undergoing Androgen Suppression Therapy for Prostate Cancer Without Bone Metastases: A Randomized Controlled Trial

Daniel A. Galvão, Dennis R. Taaffe, Nigel Spry, David Joseph, and Robert U. Newton

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<th>EX&gt;CO</th>
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<td>5-31kg</td>
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<td>Aerobic Capacity</td>
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<td>Dynamic Balance</td>
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<tr>
<td>General Health</td>
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<tr>
<td>Fatigue</td>
<td>-11</td>
<td>EX&gt;CO</td>
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Changes in muscle, fat and bone mass after 36 weeks of maximal androgen blockade for prostate cancer

Daniel A. Galvão, Nigel A. Spry, Dennis R. Taaffe, Robert U. Newton, John Stanley, Tom Shannon, Chris Rowling and Richard Prince

Can exercise ameliorate the increased risk of cardiovascular disease and diabetes associated with ADT?

Daniel A Galvão, Robert U Newton*, Dennis R Taaffe and Nigel Spry

A phase III clinical trial of exercise modalities on treatment side-effects in men receiving therapy for prostate cancer


A randomized controlled trial of an exercise intervention targeting cardiovascular and metabolic risk factors for prostate cancer patients from the RADAR trial

Position stand

Australian Association for Exercise and Sport Science position stand:
Optimising cancer outcomes through exercise

Sandra C. Hayes\textsuperscript{a,*}, Rosalind R. Spence\textsuperscript{b}, Daniel A. Galvão\textsuperscript{c}, Robert U. Newton\textsuperscript{c}

\section*{American College of Sports Medicine
Roundtable on Exercise Guidelines for Cancer Survivors}

Kathryn H. Schmitz, PhD, MPH, FACSM
Kerry S. Courneya, PhD
Charles Matthews, PhD, FACSM
Wendy Demark-Wahnefried, PhD
Daniel A. Galvão, PhD
Bernardine M. Pinto, PhD
Melinda L. Irwin, PhD, FACSM
Kathleen Y. Wolin, ScD, FACSM
Roanne J. Segal, MD, FRCP
Alejandro Lucia, MD, PhD
Carole M. Schneider, PhD, FACSM
Vivian E. von Gruenigen, MD
Anna L. Schwartz, PhD, FAAN

\section*{Focus on adult cancers and sites with the most evidence
Evaluation of Evidence A-D
Breast, Prostate, Colon, Hematological, Gynecological}

- Exercise is safe during and after cancer treatments
- Results in physical functioning, QoL and cancer-related fatigue
- Cancer survivors to follow PA Guidelines, with specific exercise programming adaptations
- Implications for disease outcomes/survival are still unknown
- Advice to “avoid inactivity” even during difficult treatments

Cancer Survivorship

Research at QIMR:

Vanessa Beesley: Current and planned projects
Currently funded survivorship research

**Pancreatic Cancer**
• 2009-2012: QoL & unmet needs in pancreatic cancer patients and their carers, Rachel Neale, $655,213, NHMRC

**Indigenous Cancer Patients**
• 2009-2010: A needs assessment survey for Indigenous cancer patients, Gail Garvey, $190,000, ARC
• 2009-2011: Assessing and navigating the unmet support needs of Indigenous cancer patients, Patricia Valery, $520,263, NHMRC

**Colorectal Cancer**
• 2010-2012: Work life after cancer, Louisa Gordon, $240,000, ARC

**Melanoma**
• 2010-2012: QoL & unmet needs in pancreatic cancer patients and their carers, Rachel Neale, $655,213, NHMRC

**Endometrial Cancer**
• 2009-2011: QoL, unmet needs & lifestyle of longer-term endometrial cancer survivors, Penny Webb, $596,788, Cancer Australia

**Ovarian Cancer**
• 2003-2004: QoL & chemotherapy end-points in ovarian cancer, Adèle Green, $141,832, CCQ.
• 2009-2010: A walking intervention pilot for women undergoing primary chemotherapy for ovarian cancer, Vanessa Beesley, $15,000, GCS/NHMRC
1. Pancreatic Cancer. CIs: Dr Rachel Neale, A/Pr Dianne O’Connell, Dr Monika Janda, A/Pr Neil Merrett, Prof David Goldstein, Dr Vanessa Beesley, Dr David Wyld, Ms Helen Gooden. AIs: Pr Graham Giles, A/Pr Michael Jefford, A/Pr Andrew Blankin, Dr. Louisa Gordon.

2. Indigenous Cancer Patients. CIs: Dr Patricia Valery, Dr Vanessa Beesley, A/Pr Gail Garvey, A/Pr Anna Hawkes, Dr Monika Janda, A/Pr Jacinta Elston. AIs: Mrs Catherine Jacka-Paroz, Mr Mark Wenitong, Prof Adele Green, Prof Peter O'Rourke.

3. Endometrial Cancer. CIs: A/Pr Penelope Webb, Dr Amanda Spurdle, Prof Andreas Obermair, Dr Monika Janda, Dr Christina Nagle, Prof Michael Quinn, Dr Yee Leung, Mrs Lesley McQuire. AIs: Prof Ian Hammond, Dr Vanessa Beesley.

4. Colorectal Cancer. CIs: Dr Louisa Gordon, Dr Brigid Lynch, Dr Vanessa Beesley, A/Pr Penny Webb, A/Pr Nicholas Graves, Prof Peter O'Rourke.

5. Melanoma. CIs: Prof Adele Green, Prof B. Mark Smithers, A/Prof Kiarash Khosrotehrani, Dr Vanessa Beesley, Dr Alexander Molassiotis, Dr Paul Lorigan, Dr Jackie Hodgetts. AIs: Dr Louisa Gordon.

6. Ovarian Cancer Walking Intervention. CIs: Dr Vanessa Beesley, Dr Sandi Hayes, Ms Melissa Newton, Dr Penelope Webb, Prof Andreas Obermair, Dr David Wyld, Dr Alessandra Francescon. AIs: Dr Louisa Gordon, Dr Monika Janda, A/Prof Elizabeth Eakin, Prof Peter O'Rourke.
Survivorship support

Cancer Council NSW
Annie Miller
What is CCN doing?

- Helpline & Information Centres
- Living Well After Cancer program
- Living Well After Cancer booklet
- Cancer Connections
- Working Beyond Cancer program
- ENRICH program (exercise & nutrition)
- Counselling
- Financial planning
What is CCN working on?

• Upcoming Cancer Connections online forums; YAC – chat 😊
• National scoping for survivorship needs of young adults (18 – 45) leading into pilot programs in 2011
• Collaboration with young adult specific external stakeholders
......and there is more!

• Working with CHeRP around Living Well After Cancer evaluations
• Partnership application for ARC Cancer and Fertility grant (post cancer)
Flinders Survivorship Program
Bogda Koczwara

- Since June 2009
- Based in Dept of Medical Oncology
- Modeled on UCLA – linked with Livestrong
- Good links across the state
  - late effect clinics elsewhere in SA
  - Supported by Cancer Network of SA
- Clinical, research, education
Flinders Survivorship Program

- Clinical
  - Nurse led survivorship clinic
    - Treatment Summary
    - Survivorship care plan
  - Plans for hormonal clinic
- Research
  - Psychooncology and self care
  - Rehabilitation and employment
  - Nutrition
  - Fertility
  - Complementary care
  - Providers survey re role in survivorship
- Statewide database
- Education – survivorship conference
Michael Jefford
Peter Mac Cancer Centre, VIC
A randomised controlled trial evaluating a nurse-led survivorship care package (SurvivorCare) for bowel cancer survivors

- CIs: Jefford, Schofield, Aranda, Krishnasamy, Young, Butow, King
- Multi-site, multi-state study
- Target recruitment: 334 (over 24 months)
- Funded by Cancer Australia-beyond blue / Victorian Cancer Agency (~$750k)
- Endpoints are distress, QOL, unmet needs
- Study status: Multi-site ethics approval obtained in Victoria (Peter Mac central site), with participating sites currently undergoing ethics / research governance approval
A randomised controlled trial evaluating a nurse-led survivorship care package (SurvivorCare) for bowel cancer survivors

Given DVD, booklet, QPL

End of treatment session

Screen for distress
Review needs
Discuss QPL
Discuss SCP

Treatments

Telephone-based follow up
Predictors of psychological distress in post-treatment adult cancer survivors

Aim: to map natural history of distress after completing potentially curative primary treatment.
• Identify those likely to be at risk of continuing distress
• Identify potentially modifiable predictors of distress
• Identify critical time points for intervention

Participants: Survivors of breast, prostate, colorectal or haem. cancers (Hodgkins Lymphoma, DLBCL only) completing potentially curative primary treatment

Phase 1: 120 participants complete self report questionnaire at end of treatment, 3 months and 6 months post treatment

Phase 2: A sample of 20 participants from phase 1 will be interviewed to elicit perceptions of distress and coping strategies adopted

Findings to date (baseline only):
– Overall 19% reported clinically significant distress on BSI-18, 28% on DT
– No gender differences in reported distress
– Sig. differences found in clinically significant distress reported by cancer types: Haem: 30%, Colorectal: 23%, Breast: 19%, Prostate: 11%
– Most frequently reported need – ‘Help to manage concerns about cancer coming back” (29%)
– High distress strongly correlated with unmet needs (r=0.511, p<0.000), symptom prevalence (r=0.651,p<0.000) and social support (r=-0.431, p<0.000).
Afaf Girgis
Centre for Health Research & Psycho-oncology (CHeRP)
NSW

CHeRP Program Managers:
Afaf Girgis, Allison Boyes, Sylvie Lambert
Longitudinal survivorship studies

- Longitudinal studies of survivors (NSW & VIC Registries) and their partners/caregivers over first 5 yrs, across top 8 incident cancers
  
  - *Cancer Survival Study* (n=1360) – needs, anxiety, depression, QoL, distress, coping, social support
    
    **CIs:** Allison Boyes, Afaf Girgis, Cate D’Este

  - *Partners & Caregivers Study* (n=547) – needs, anxiety, depression, QoL, distress, coping, social support, cost & impact of caring
    
    **CIs:** Afaf Girgis, Sylvie Lambert, Patrick McElduff
Cancer Survivors Follow-up Care Study

Aims

• Aspects of quality survivorship care rated as important by cancer survivors with a range of cancers
• Follow-up care received to date and perceived adequacy of this care
• Acceptability of a range of models of survivorship care

Sample

• 500 survivors, 2-6 yrs post-diagnosis (6 cancer NSW centres, Cancer Survival Study)
• 100 adult survivors of childhood cancers, 5+ yrs post-diagnosis (Sydney Children’s Hospital)

CIs: Girgis, Goldstein, Friedlander, Cohn, Segelov, Bennett, Webber, Wakefield, Eng-Siew Koh, Boyes, Boyle, Bonaventura
CURRENT trials

- **ENRICH (Exercise and Nutrition Routine Improving Cancer Health):** Efficacy and feasibility of an exercise and nutrition program for cancer survivors and carers
  
  \[PA, \text{diet}\]

  **CIs:** Stacey, James, Chapman, Lubans, Asprey, Sundquist, Boyes, Girgis

- **Beating the Blues After Cancer (BBAC):** RCT of a tele-based psychological intervention for high distress patients and carers calling Cancer Council Helpline
  
  \[Anxiety, \text{depression, cancer specific distress, unmet supportive care needs, positive adjustment, QoL}\]

  **CIs:** Chambers, Girgis, Occhipinti, Turner, Carter, Dunn
CURRENT trials

- **Coping-Together:** Multi-media, self-directed coping skills intervention for patients with cancer & their partners
  
  [cancer specific distress and depression, and increasing positive illness appraisal or care giving appraisal, self-efficacy, quality of life, relationship satisfaction and positive individual and dyadic coping]

  **CIs:** Girgis, Lambert, Turner, McElduff, Kayser, Mihalopoulos

Planned interventions

- Living Well After Cancer (CIs: Boyes et al)
- Social Support interventions (CIs: Boyes et al)
Elizabeth Eakin
Cancer Prevention Research Centre, QLD
Lifestyle Interventions in Breast Cancer Survivors
A/Prof Elizabeth Eakin

Emphasis on:
Physical activity (w/Sandi Hayes, QUT; NBCF-funded)
Weight loss (CPRC postdoc Marina Reeves)
Telephone delivery (reaching survivors living outside major cities)
Objective measurement of PA & sitting time (CPRC postdoc Gen Healy)

Planned studies:
Use of SMS to promote maintenance (CPRC postdoc Bri Fjeldsoe)
Integration with Survivorship Care Plans (CPCR postdoc Sheleigh Lawler)
Survival outcomes following long-term PA intervention (w/ANZBCTG)
Other programs around Australia (finish by 5.20pm)
Long-Term Follow-up of Adult Survivors of Childhood Cancer
Richard Cohn
Sydney Children’s Hospital
Survey of Long-term Follow-up Clinics at ANZCHOG Centres

- 7/8 paediatric oncology centres have a dedicated clinic
- bi-monthly to 4 weekly
- 50% of clinics have recurrent funding (and many soft funded positions)
- 3 centres have protected physician time
- 2 nurse led clinics (no Nurse Practitioners)
- psychosocial support variable
Cancer Center Visits and Late Effects - 2 centres follow lifelong: the rest discharge between 18-24 years

Years since cancer diagnosis

Percent

- Cancer Center Visits
- Late Effects
Aiming for harmonisation of Co-operative Group Guidelines
## Breast Cancer Surveillance in Women Treated with Radiation for Childhood Cancer

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<td><strong>At risk</strong></td>
<td>Chest wall and breast radiation</td>
<td>Any radiation impacting breast</td>
<td>Thorax radiation</td>
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<td>-Or- 40 Gy abdomen including diaphragm</td>
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<td><strong>Frequency</strong></td>
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<td>Yearly without specification of maximum age</td>
<td>Yearly from 25-60 years Every 2 years from &gt; 60-75 years</td>
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<td>Highest risk: Yearly from puberty Every 6 months from 25 years</td>
<td>Very high risk: Yearly from 25-60 years High risk: Yearly from 35-60 years</td>
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<td><strong>Age 30-50 years</strong></td>
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<td>Mammography</td>
<td>Mammography + MRI</td>
<td>Mammography until age 75 years MRI until age 60 years</td>
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Opportunities for collaborative research


- Claire E. Wakefield, Jordana K. McLoone, Phyllis Butow, Kate Lenthen, Richard J. Cohn. Parental adjustment to the completion of their child's cancer treatments. Accepted for publication by Pediatric Blood and Cancer

Aims of the LTFU clinic

○ SERVICE:
  ○ Standardised risk-based screening/ baseline/ snapshot
  ○ Early detection of remediable problems
  ○ Education of survivor
    ○ ensure that long-term survivors are well informed to make health related decisions
  ○ Education of medical profession /community/ insurers
  ○ Prevention – smoking, alcohol, diet, exercise
  ○ Advocacy

○ RESEARCH:
  ○ To document all information acquired in surveillance important in directing the design of future treatment strategies and in advising subsequent patients of future risks and possible interventions
Other programs around Australia 
(finish by 5.20pm)
Small Group discussion
(5.20-6.05pm)

• What are the key research priorities currently and how should we develop a national research agenda?

• Is there a need for a central coordinating body (e.g., COSA)? What role should it play?

• Is there a need for survivorship service provision? What form should a service take?
Report Backs – Group reps (6.05 – 6.35pm)

Next Steps – David & Afaf (6.35 – 6.40pm)