Inaugural COSA Cancer Survivorship Workshop

Thursday 11 November 2010
Melbourne

Clinical Oncological Society of Australia

Co-convenors: Professor Afaf Girgis and Professor David Goldstein

---

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 – LIVE**STRONG** 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

	Centre/Lead agency	Presenter
Survivorship services/programs		
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

	Centre/Lead agency	Presenter
- rehabilitation and employment - nutrition - fertility - complementary care - oncologists' role in survivorship (survey). 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.	Cancer Council NSW	Annie Miller
Long-term follow-up clinics for childhood cancer survivors	ANZCHOG	Richard Cohn

	Centre/Lead agency	Presenter
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)		
Research		
Quality of life, psychosocial outcomes and/or unmet needs		
Survey of needs, QoL, distress, coping and social support of **testicular** cancer survivors (with ANZUP) and qualitative study of high and low distressed	PoCoG and CeMPED	Phyllis Butow
Studies of **Arabic, Greek and Chinese speaking immigrants** – QoL, distress, anxiety and depression patterns of care	PoCoG and CeMPED	Phyllis Butow
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

	Centre/Lead agency	Presenter
- Clinician survey of attitudes / Rx strategies - Intervention study: Clustered RCT		
QoL and unmet needs of **pancreatic** cancer patients and their caregivers	Queensland Institute of Medical Research	Vanessa Beesley
Validating a supportive care needs instrument in **Indigenous** 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?	Queensland Institute of Medical Research	Vanessa Beesley
QoL, unmet needs and lifestyle of longer-term **endometrial** cancer survivors	Queensland Institute of Medical Research	Vanessa Beesley
Colorectal cancer – issues with returning to work and participation in work after cancer, and how that affects QoL	Queensland Institute of Medical Research	Vanessa Beesley
Unmet needs and QoL of **melanoma** survivors	Queensland Institute of Medical Research	Vanessa Beesley
QoL and unmet needs of women with **ovarian** cancer (+ piloted physical activity program during chemotherapy; submitted grant for full scale trial)	Queensland Institute of Medical Research	Vanessa Beesley
Predictors of psychological distress in post-treatment adult cancer survivors (of **breast**, **prostate**, **colorectal** cancers, **Hodgkins lymphoma** and **DLBCL**)	Peter MacCallum Cancer Centre	Michael Jefford
Cancer Survival Study – longitudinal study of survivors' (top eight incident cancers) needs, anxiety, depression, QoL, distress, coping, social support for first five years post diagnosis	Centre for Health Research & Psycho-oncology (CHeRP)	Afaf Girgis

	Centre/Lead agency	Presenter
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		
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
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
Planned evaluation of CCNSW Living Well After Cancer program	Centre for Health Research & Psycho-oncology (CHeRP)	Afaf Girgis
Nurse and peer interventions (three arm RCT) for couples where man has been treated for **prostate** cancer with surgery.	Cancer Council Queensland	Suzanne Chambers

	Centre/Lead agency	Presenter
Physical sequalae of cancer/treatment		
Addressing co-morbidities in women diagnosed with **endometrial** cancer	University of Sydney Nursing School	Kate White
Early menopause	Peter MacCallum Cancer Centre	Kelly-Anne Phillips
Intervention studies – physical activity		
Treatment of Post-Cancer Fatigue Study (TOPS) trial – evaluating the effectiveness of CBT and graded exercise interventions for **breast** and **colon** cancer survivors	UNSW	David Goldstein
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	CeMPED Survivorship Research Group	Haryana Dhillon
PAL – impact of physical activity on fatigue and QoL of patients with incurable **lung** cancer	CeMPED Survivorship Research Group	Haryana Dhillon
Role of exercise in reducing potential cardiovascular and metabolic risk factors for cancer patients – two RCTs in WA, Qld and NZ	School of Exercise, Biomedical and Health Sciences, Edith Cowan University (WA)	Daniel Galvao
CCNSW ENRICH (Exercise and Nutrition Routine Improving Cancer Health) program: Efficacy and feasibility of an exercise and nutrition program for cancer survivors and carers	Centre for Health Research & Psycho-oncology (CHeRP)	Afaf Girgis
Lifestyle interventions in breast cancer survivors, particularly physical activity,	Cancer Prevention Research	Afaf Girgis on behalf of

	Centre/Lead agency	Presenter
weight loss, telephone delivery (reaching survivors living outside major cities)	Centre, Qld	Elizabeth Eakin
Survival outcomes for women with **breast cancer** following long-term physical activity intervention (with ANZBCTG)	Cancer Prevention Research Centre, Qld	Afaf Girgis on behalf of Elizabeth Eakin
Lifestyle interventions for menopause symptoms.	QUT	Patsy Yates
Web-based intervention for **young women with breast cancer** (>50 years) providing information and links to other sources of information about treatment and diagnosis, dealing with emotional states and menopause symptoms.	Centre for Behavioural Research in Cancer (CBRC), Cancer Council Victoria	Vicki White
Cognitive function		
Cognitive function in adult survivors of **colorectal** cancer	CeMPED Survivorship Research Group	Haryana Dhillon
BrainTrain – web-based cognitive rehabilitation program	CeMPED Survivorship Research Group	Haryana Dhillon
Cognitive Rehab Study in planning stages – **breast** cancer survivors	CeMPED Survivorship Research Group	Haryana Dhillon
Efficacy and safety of *Ginkgo biloba* for cognitive function and fatigue in **breast** cancer patients undergoing adjuvant treatment	CeMPED Survivorship Research Group	Haryana Dhillon
Cognitive function of **germ cell** cancer patients treated with chemotherapy	ANZUP	Ian Olver

	Centre/Lead agency	Presenter
(compared to those who did not receive CT)		
International cognitive function studies	Peter MacCallum Cancer Centre	Kelly-Anne Phillips
Models of care		
Web-based case management model – central record completed by patient, automated follow up, exception management	Sir Charles Gairdner Hospital, WA	Nigel Spry
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	PC4	Jon Emery
Survivorship care plans (development and piloting of plan with **breast** cancer survivors through BCNA)	PoCoG and CeMPED	Phyllis Butow
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.	Peter MacCallum Cancer Centre	Michael Jefford
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.	Centre for Health Research & Psycho-oncology (CHeRP)	Afaf Girgis

	Centre/Lead agency	**Presenter**
Planned studies: Use of SMS to promote maintenance Integration with Survivorship Care Plans	Cancer Prevention Research Centre, Qld	Afaf Girgis on behalf of Elizabeth Eakin
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.	QUT Centre for Palliative Care Research and Education	Patsy Yates
Review of nurse-led follow up for women with **gynaecological** cancer.	University of Sydney Nursing School	Kate White
Distress of follow up – does follow up ease or create distress?	Liverpool/Campbelltown Hospitals	Geoff Delaney
Web-based support tool for **breast** and **prostate** cancer patients; with ultimate aim to support follow-up (exception-based case management model).	Liverpool/Campbelltown Hospitals	Geoff Delaney
Potential trial of model of shared care model for survivors of Hodgkin's disease	Liverpool/Campbelltown Hospitals	Geoff Delaney

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

Clinical Oncological Society of Australia (COSA) Cancer Survivorship Workshop
Thursday 11th November 2010, 4.00-6.30pm
Melbourne Convention and Exhibition Centre – Room 212

Time	Agenda item	Presenter	
4.00 – 4.05 pm	Welcome; workshop objectives	Afaf Girgis	
4.05 – 4.15 pm	Overview of international activities	Afaf Girgis	
4.15 – 4.20 pm	Overview of the Australian Cancer Survivorship Centre (ACSC)	Michael Jefford	
4.20 – 5.05 pm	Brief overviews:	David Goldstein	NSW Cancer Survivors Centre (NSWCSC), NSW
	Current and planned survivorship programs and research from around Australia	Phyllis Butow	Centre for Medical Psychology & Evidence Based Decision Making (CEMPED), NSW
		Haryana Dhillon	Sydney Cancer Centre, NSW
		Nigel Spry	Sir Charles Gairdner Hospital, WA
	NB: strictly 3 minutes per presenter; maximum 3 slides each	Jon Emery	PC^{4} Primary Care Collaborative Cancer Clinical Trials Group, WA
		Rob Newton	School of Exercise, Biomedical and Health Sciences, WA
		Vanessa Beasley	Queensland Institute of Medical Research, QLD
		Annie Miller	Cancer Council NSW
		Bogda Koczwara	Flinders Medical Centre, SA
		Michael Jefford	Peter Mac Cancer Centre, VIC
		Afaf Girgis	Centre for Health Research & Psycho-oncology (CHeRP), NSW
		Others (12 mins)	Others
5.05 – 5.10 pm	Overview of aims and process of small groups discussions	David Goldstein	
5:10 – 5.50 pm	Small group discussion:	Facilitators:	
	1. What are the key research priorities currently and how should we develop a national research agenda?	G1: Afaf Girgis	
	2. Is there a need for a central coordinating body (eg COSA)? What role should it play?	G2: Bogda Koczwara	
	3. Is there are a need for survivorship service provision? What form should a service take?	G3: David Goldstein	
5.50 – 6.20 pm	Each group reports backs & general comments	Group reps	
6:20 - 6:30 pm	Next steps	David, Afaf	

Attended	Title	First Name	Surname	Title	Department	Institution
Attended	Ms	Gill	Batt	Director	Cancer Information and Support Services	Cancer Council of NSW
Attended	Dr	Vanessa	Beesley	NHMRC Public Health Research Fellow	Genetics & Population Health Division, Queensland Institute of Medical Research	Royal Brisbane Hospital
Attended	Ms	Allison	Boyes	Research Academic		Centre for Health Research & Psycho-oncology (CHeRP)
Attended	Prof	Phyllis	Butow	Director	School of Psychology, Centre for Medical Psychology & Evidence Based Decision Making (CEMPED)	The University of Sydney
Attended	Prof	Suzanne	Chambers	Director of Research and General Manager Services		Cancer Council Queensland
Attended	A/Prof	Richard	Cohn	Head - Clinical Oncology	Centre for Children's Cancer & Blood Disorders	Sydney Children's Hospital
Attended	Prof	Geoff	Delaney	Director	Radiation and Oncology	Liverpool Hospital
Attended	Ms	Haryana	Dhillon	Research Co-ordinator	Medicine, Central Clinical School	D02-QEII Research List for Mothers & Infants
Attended	Dr	Peter	Downie	Consultant Oncologist, Head of Unit	Children's Cancer Centre	The Royal Children's Hospital, Melbourne
Attended	W/Prof	Jon	Emery		Department of General Practice	The University of Western Australia
Attended		Daniel	Galvao			
Attended	Prof	Afaf	Girgis	Director		Centre for Health Research & Psycho-oncology (CHeRP)
Attended	Prof	David	Goldstein	Senior Staff Specialist	Department of Medical Oncology	Prince of Wales Hospital
Attended	A/Prof	Michael	Jefford	Medical Oncologist		Peter MacCallum Cancer Centre
Attended	A/Prof	Bogda	Kocszwara	Director	Cancer Services	Southern Adelaide Health Service
Attended	Dr	Eng-Siew	Koh	Radiation Oncologist		Liverpool Hospital
Attended	Dr	Sylvie	Lambert	HMRI Post-Doctoral Research Fellow		Centre for Health Research & Psycho-oncology (CHeRP)
Attended	Prof	Andrew	Lloyd		Department of Pathology, School of Medical	The University of NSW
Attended	Ms	Annie	Miller	Project Co-ordinator	Community Education Programs	Cancer Council of NSW
Attended		Fiona	Newman		UNSW Lifestyle Clinic	
Attended	Prof	Ian	Olver	Chief Executive Officer		Cancer Council Australia
Attended	A/Prof	Kelly-Anne	Phillips	Colebatch Clinical Research Fellow		Peter MacCallum Cancer Centre
Attended	Clin/Prof	Nigel	Spry	Clinical Professor	Clinical & Adjunct Staff (Medicine & Pharmacology, SCGH)	The University of Western Australia (M503)
Attended	Mr	John	Stubbs	Executive Officer		Cancer Voices Australia
Attended	Dr	Claire	Wakefield	Program Leader	Behavioural Sciences Unitd, Centre for Children's Cancer & Blood Disorders	Sydney Children's Hospital
Attended	Ms	Vicki	White	Deputy Director		Centre for Behavioural Research in Cancer (CBRC)
Attended	Prof	Kate	White	Chair Cancer Nursing	Sydney Nursing School	M02 Sydney Nursing School
Attended	Prof	Patsy	Yates	Director	Centre for Palliative Care Research & Educatio	Qld University of Technology
Accepted		Julie	Hassard	Independent Consultant		
Accepted	Prof	Bruce	Mann	President	COSA	
Accepted		Margaret	McJannett	Executive Officer	COSA	
Accepted	Prof	Robert	Newton	Director	Vario Health Institute	Edith Cowan University
Accepted	A/Prof	Violet	Platt	Director of Nursing	WA Cancer & Palliative Care Network	
Accepted	W/Prof	Christobel	Saunders	Deputy Head of School	School of Surgery	The University of Western Australia (M507)
Accepted	Ms	Emma	Sayers	Manager		Australian Cancer Survivorship Centre
Attended	A/Prof	Eva	Segelov	Director		St Vincent's Clinical School
Accepted	Prof	Brad	Zebrack	University of Michigan	UNITED STATES	
Apology	Dr	Diana	Adams	Medical Oncologist	Macarthur Cancer Therapy Centre	Campbelltown Hospital
Apology	Dr	Meagan	Brennan	Clinical Senior Lecture	School of Public Health	NSW Breast Cancer Institute
Accepted	A/Prof	Elizabeth	Eakin	Principal Research Fellow	School of Population Health, Cancer Prevention Research Centre	The University of Queensland
Apology	Dr	Sandi	Hayes	Snr Research Fellow	School of Public Health	Queensland University of Technology
Apology		Kathy	Chapman	Director, Health Strategies	The Cancer Council	PO Box 572
Apology	Dr	Kate	Stern	Head of Clinical Research	Melbourne IVF	Suite 3, 320 Victoria Pde
Accepted	A/Prof	Janette	Vardy	Staff Specialist	Medical Oncology	Sydney Cancer Centre
Invited	Prof	Sanchia	Aranda	Director of Nursing Research		Peter MacCallum Cancer Centre
Invited	A/Prof	Fran	Boyle	Associate Professor of Medical Oncology & Director of Patricia Ritchie Centre for Cancer Care and Research	School of Medicine	The University of NSW
Invited	Ms	Angela	Cotroneo		Sydney Cancer Centre	RPA
Invited	Prof	Michael	Friedlander	Director, Department of Medical Oncology	Department of Medical Oncology	Prince of Wales Hospital
Invited	Ms	Karen	Johnston	Clinical Nurse Consultant	Centre for Children's Cancer & Blood Disorders	Sydney Children's Hospital
Invited	Dr	Bettina	Meiser	Head of Psycho-social Research	Department of Medical Oncology	Prince of Wales Hospital
Invited		Steve	Pratt	Nutrition & Physical Activity Manager	Cancer Council WA	46 Ventnor Avenue
Invited	Laureate P	Rob	Sanson-Fisher		Health Behaviour Research Group	Faculty of Health/The University of Newcastle
Invited	Mrs	Lyn	Swinburne AM	Chief Executive Officer		Breast Cancer Network, Australia
Invited	Ms	Kate	Thompson		Peter MacCallum Cancer Centre	Locked Bag 1
Invited	A/Prof	Jane	Turner		School of Psychiatry, Mental Health Centre	Royal Brisbane Hospital
Invited	Mr	Chris	Tzar	Director	Lifestyle Clinic	UNSW Lifestyle Clinic

UNSW

Clinical Oncological Society of Australia

Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

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

UNSW

Clinical Oncological Society of Australia

Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

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

Clinical
Oncological
Society of
Australia

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

November 2009

Vol 33 Issue No 3

Survivorship

Forum

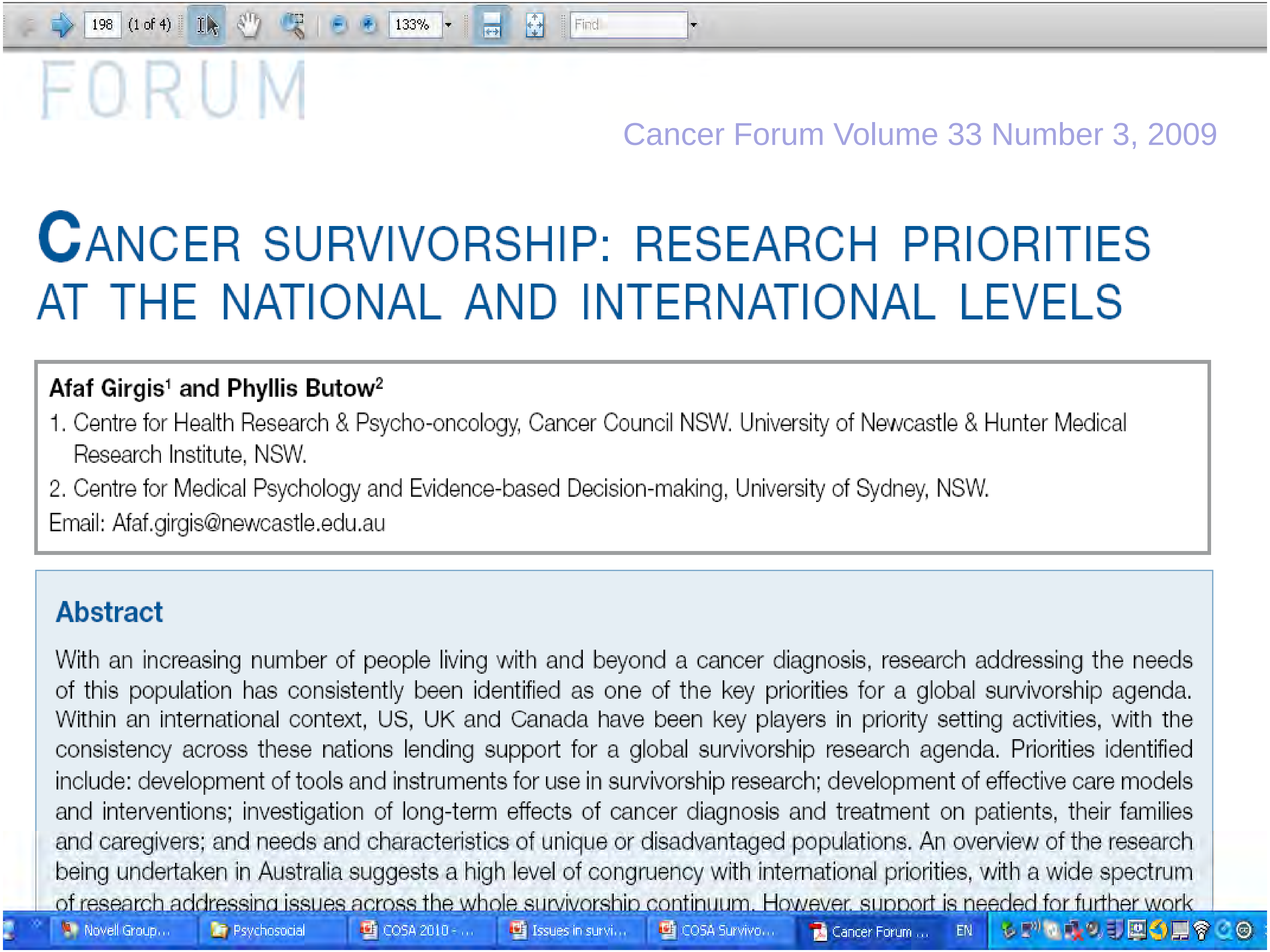
- Overview: Improving outcomes for cancer survivors in Australia
- Issues for cancer survivors in Australia
- Caregivers of cancer survivors: the state of the field
- What constitutes ideal survivorship care?
- Nurse-led survivorship care
- General practitioner-based models of post-treatment follow up
- Health behaviour interventions for cancer survivors: An overview of the evidence and contemporary Australian trials
- Challenges facing survivors of childhood and adolescent cancer
- Cancer survivorship: research priorities at the national and international levels
- Measuring the unmet needs of those with cancer: a critical overview

Articles

- Fuel, beds, meals and meds: out-of-pocket expenses for patients with cancer in rural Queensland
- Cancer Council Australia's Student Essay Competition - Multidisciplinary teams in cancer care: pros and cons

Reports

- Australian behavioural research in cancer



FORUM

Cancer Forum Volume 33 Number 3, 2009

CANCER SURVIVORSHIP: RESEARCH PRIORITIES AT THE NATIONAL AND INTERNATIONAL LEVELS

Afaf Girgis[1] and Phyllis Butow[2]

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

Leading supportive care in the 21st century

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

Time	Wednesday June 23rd, 2010	Presenter
8:30-8:45 a.m.	Workshop Objectives – purpose and desired outcomes	*Moderators: Paul Jacobsen* *Richard Doll*

http://www.mascc.org/mc/page.do?sitePageId=86981&orgId=mascc

10:35-11:15 a.m.	Cancer Survivorship Consortia: International research & clinical priorities	*Lance Armstrong Foundation, USA:* *Caroline Huffman(Moderator)* *Linda Jacobs* *K. Scott Baker* *Karen Syrjala*
11:15-11:30 a.m.	Cancer Survivorship Consortia: International research & clinical priorities *cont.*	*Afaf Girgis, Australia*
11:35-11:50 a.m.	Cancer Survivorship Consortia: International research & clinical priorities	*Margaret Fitch, Canada*
11:55-12:10 p.m.	Cancer Survivorship Consortia: International research & clinical priorities *cont.*	*Alex Molassiotis, United Kingdom*
12:15-12:30 p.m.	Cancer Survivorship Consortia: International research & clinical priorities *cont.*	*Ulla Hjortebjerg, Denmark*
12:35-12:50 p.m.	Cancer Survivorship Consortia: International research & clinical priorities *cont.*	*Irma Verdonck-de Leeuw, Netherlands*

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?

Ulla Hjortebjerg, RN
Danish Cancer Society
hjo@dallund.dk

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

VU medisch centrum

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

VU medisch centrum

Research:
Guided self help targeting anxiety and depression

VU medisch centrum

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

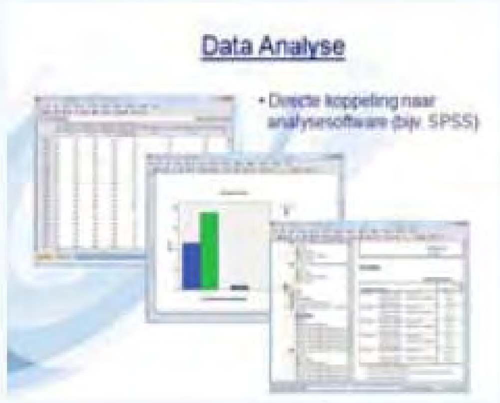
OncoCompass

VU medisch centrum

Personal Health Record and Supportive Care Plan

Webportal for care provider

Aggregated (group) Health record and care plan

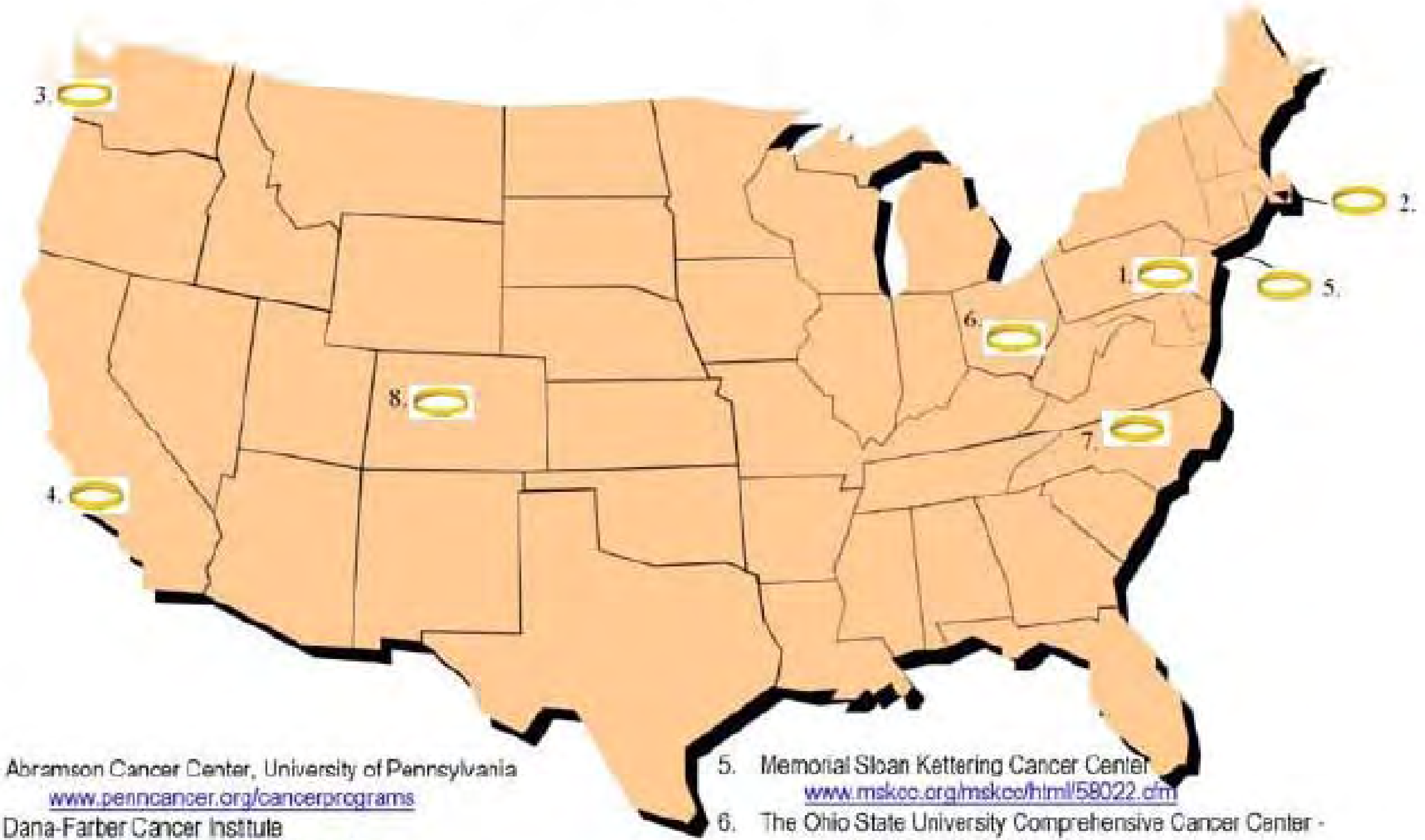


Data Analyse

- Directe koppeling naar analysesoftware (bijv. SPSS)

Caroline Huffman, LAF

LIVESTRONG
SURVIVORSHIP CENTER OF EXCELLENCE NETWORK



1. Abramson Cancer Center, University of Pennsylvania
   www.penncancer.org/cancerprograms
2. Dana-Farber Cancer Institute
   www.dana-farber.org/pat/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/patientandvisitors/survivors
7. University of North Carolina, Lineberger Comprehensive Cancer Center,
   N.C. Cancer Hospital
   www./cancer.unc.edu/patient
8. University of Colorado Cancer Center, AMC Cancer Research Center
   www.uccc.info/for-healthcare-professional/cancer-center/prevention/
   survivorship/uccc-livestrung.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

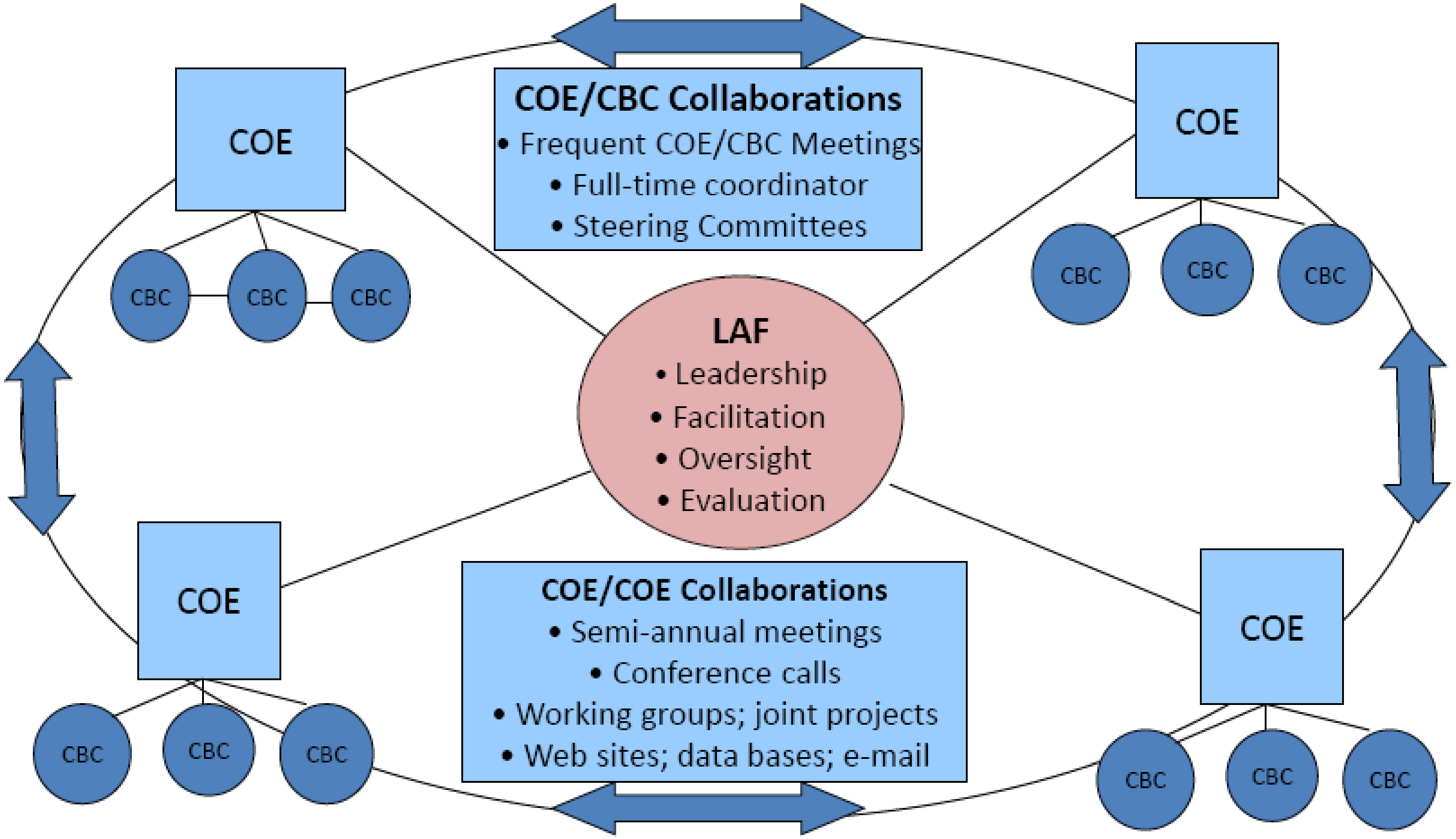
- Training -- Next generation of healthcare professionals, social service providers, researchers committed to survivorship

LIVESTRONG
SURVIVORSHIP CENTER
OF EXCELLENCE NETWORK

LIVE**STRONG** SURVIVORSHIP CENTER OF EXCELLENCE NETWORK

◆

COLLABORATIONS



COE/CBC Collaborations

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

LAF

- Leadership
- Facilitation
- Oversight
- Evaluation

COE/COE Collaborations

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

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

BC Cancer Agency
CARE + RESEARCH
An agency of the Provincial Health Services Authority

Cancer Survivorship: creating uniform and comprehensive supportive care programming in Canada

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 LIVE**STRONG** (Lance Armstrong Foundation) to help cancer survivors make the transition from active treatment to post treatment care. It is 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
Session3: 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
    accounte
    research
  - In respor
    strategic
    recomme
    undertak

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)

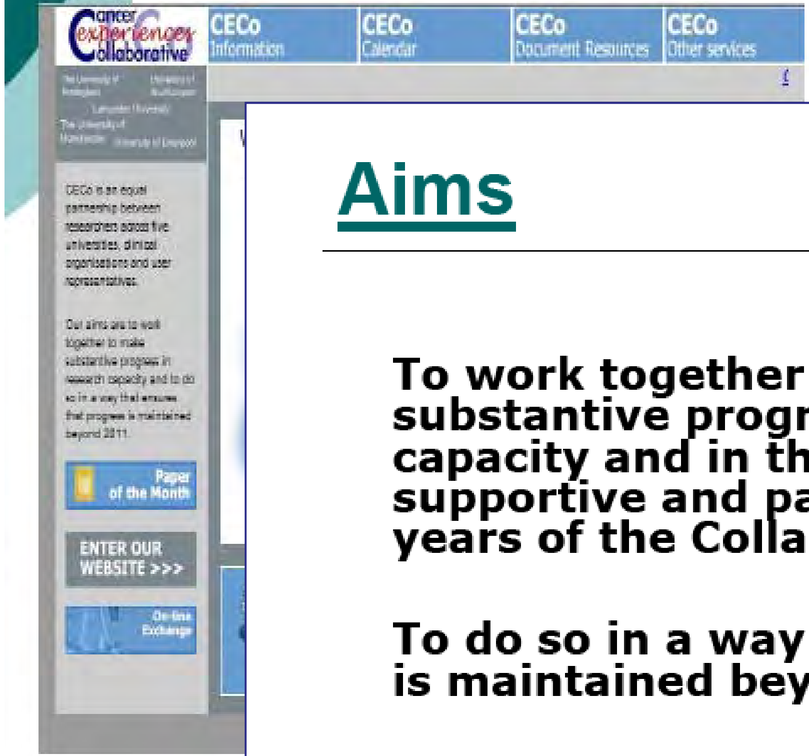
www.ceco.org.uk & www.compasscollaborative.com

CECo is an equal partnership between researchers across five universities, clinical organisations and user representatives.

Our aims are to work together to make substantive progress in research capacity and to do so in a way that ensures that progress is maintained beyond 2011.

2 Supportive & Palliative Care Research Collaboratives (2006-2011) £3.8M ($US 5.6M)

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



CECo is an equal partnership between researchers across five universities, clinical organisations and user representatives.

Our aims are to work together to make substantive progress in research capacity and to do so in a way that ensures that progress is maintained beyond 2011.

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)

November 2007	Cancer Reform strategy
May 2008	NCSI was launched *(Led by DoH & Macmillan Cancer Support)*
October 2008	7 work streams established
October 2009	Collaboratives led on evidence synthesis

National Cancer Survivorship Initiative (NCSI)

November 2007 Cancer Reform strategy

May 2008

October 2008

October 2009

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

SUMMARY OF PRE-CONFERENCE WORKSHOP ON SURVIVORSHIP
June 23, 2010 – MASCC Symposium – Vancouver, Canada

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: Afaf Girgis afaf.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 MHlthServMt GAICD 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

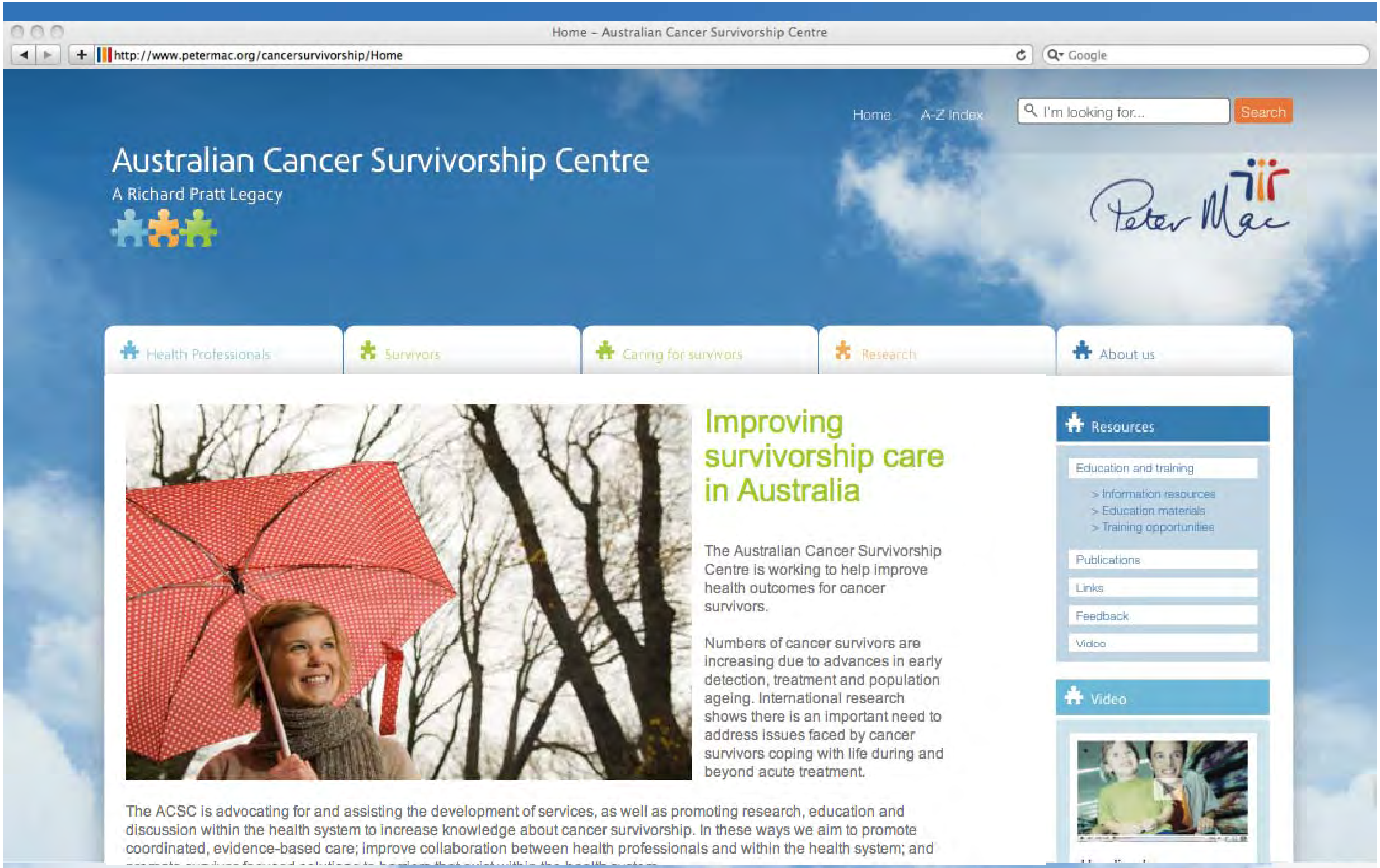
A Richard Pratt Legacy

- 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

Australian Cancer Survivorship Centre

A Richard Pratt Legacy

- 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



Australian Cancer Survivorship Centre

A Richard Pratt Legacy

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

www.petermac.org/cancersurvivorship

Clinical
Oncological
Society of
Australia

Brief Overviews
(3 mins each)

Current and Planned survivorship programs and research from around Australia

Clinical Oncological Society of 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.

The University of Sydney

School of Psychology

PoCoG and CeMPED work in Survivorship

Phyllis Butow

Chair, PoCoG and

Co-Director, CeMPED

University of Sydney

CeMPED
Centre for Medical Psychology &
Evidence-based Decision-making

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
Centre for Medical Psychology &
Evidence-based Decision-making

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)

Cognitive Function in Adult Cancer Survivors

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

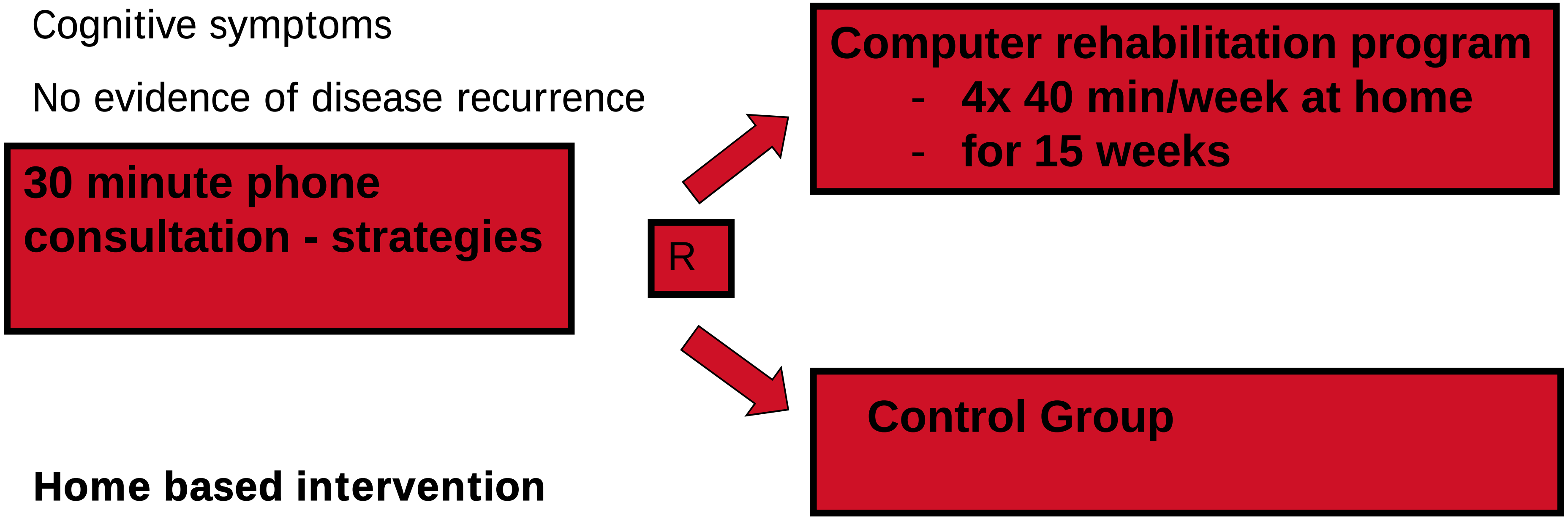
Brain Train: Evaluation of a web-based cognitive rehabilitation programme in cancer survivors with self reported cognitive impairment

Early stage Cancer Survivors

6-60 mths post CTh

Cognitive symptoms

No evidence of disease recurrence



30 minute phone consultation - strategies

R

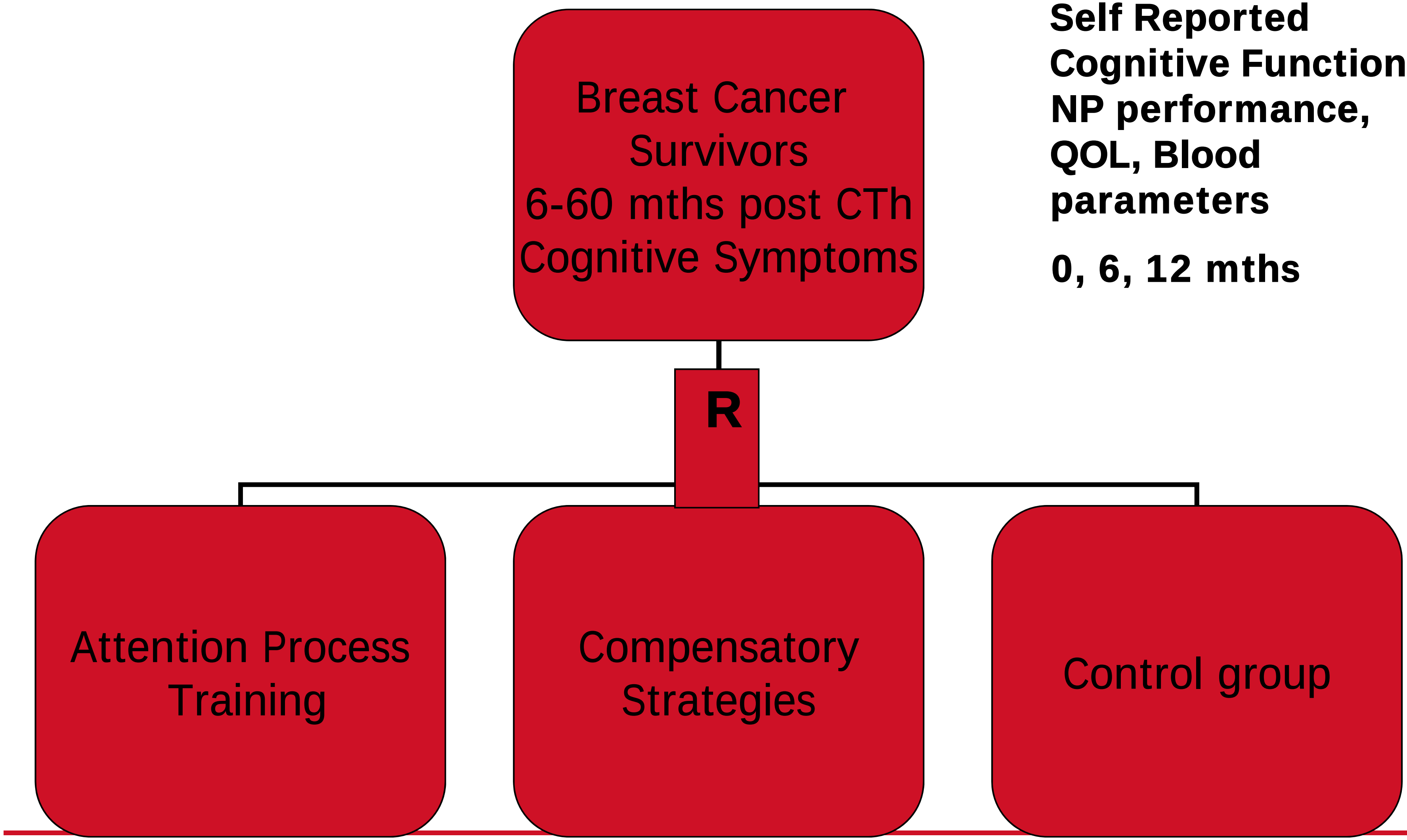
Computer rehabilitation program
- **4x 40 min/week at home**
- **for 15 weeks**

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

R

Attention Process Training

Compensatory Strategies

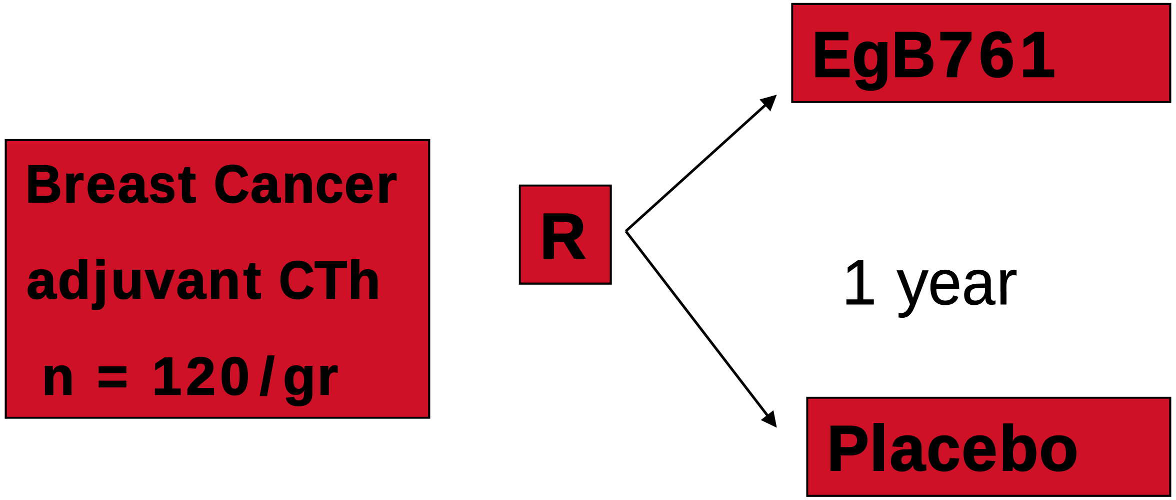
Control group

Self Reported Cognitive Function, NP performance, QOL, Blood parameters

0, 6, 12 mths

THE UNIVERSITY OF SYDNEY

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

R

EgB761

1 year

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

THE UNIVERSITY OF SYDNEY

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

• Genera
material

• PA prog
change -36 months

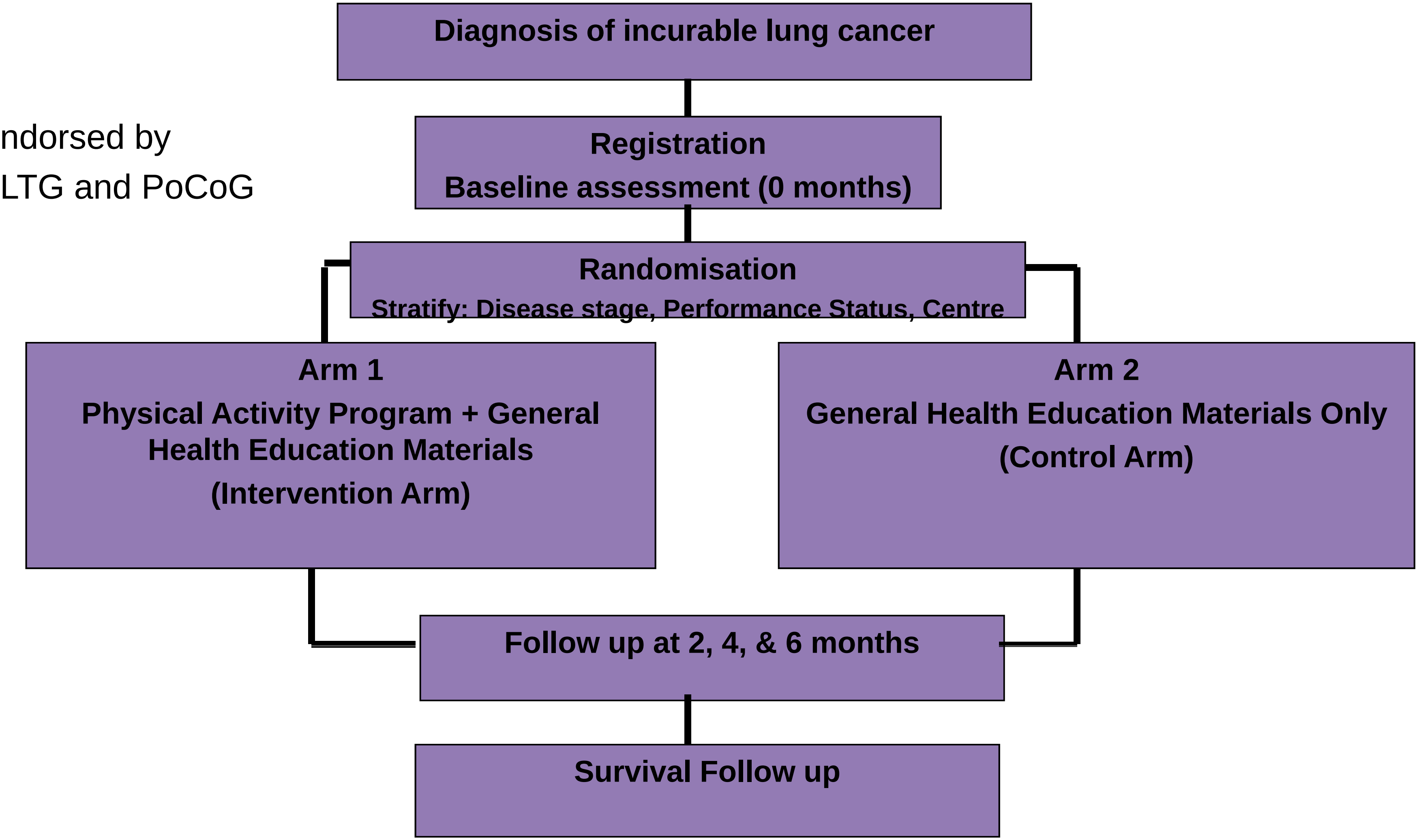
Control Arm

tion

3 year DFS

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

Endorsed by
ALTG and PoCoG



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

THE UNIVERSITY OF SYDNEY

Survivorship Research Group

Haryana Dhillon
Janette Vardy
Victoria Bray
Joanna Fardell
Corrine Renton

Emma Goddard
Anne Warby
Rhonda Devine
Felicity Lesley
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

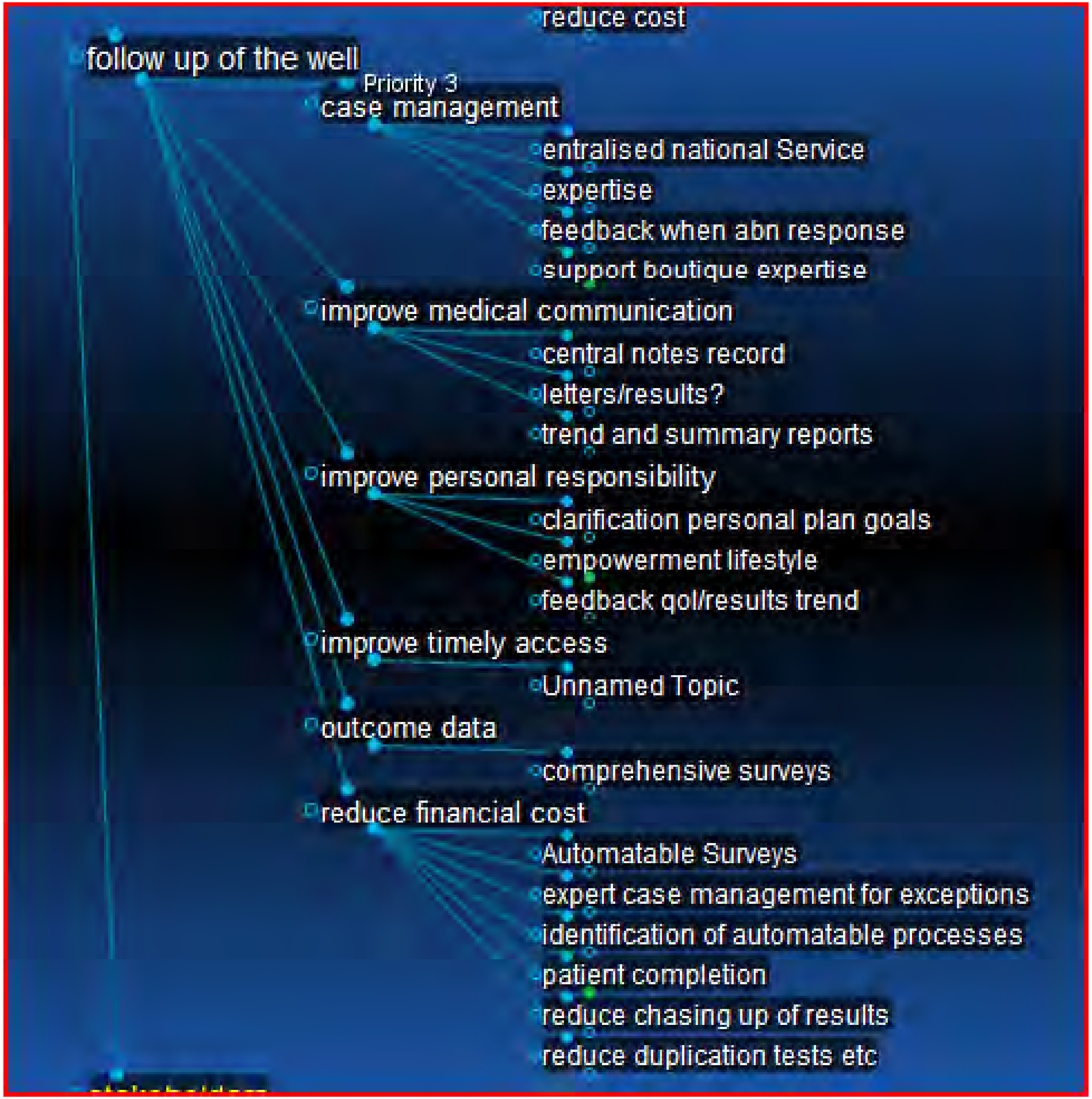
Nigel Spry WA

- 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


Unnamed Topic
patient perspective
access
GP waiting
reduce country city disparity
advice
contradictory advice
none
up to date
wrong
communication
doctors don't talk
get lost in system
empowerment
personal responsibility
plan
contradictory advice
none
wrong
progress reports
health screen
illness management
pt delay
who is boss

W
H
Y



- reduce cost
- follow up of the well
  - Priority 3
  - case management
    - entralised 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

W

H

A

T

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

THE UNIVERSITY OF WESTERN AUSTRALIA

THE UNIVERSITY OF MELBOURNE

Peter Mac
EXCELLENCE INNOVATION COMPASSION

THE UNIVERSITY OF SYDNEY

PC4
CANCER RESEARCH IN PRIMARY CARE
PRIMARY CARE COLLABORATIVE CANCER CLINICAL TRIALS GROUP

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

	End Rx	2 w	6 w	3 m	6 m	9 m	12 m
‘Usual care’		---------	Hosp	Hosp	Hosp	Hosp	Hosp
Trial shared care		GP	Hosp	Hosp	GP	GP	Hosp
Pt Recruitment	√						
PSA testing and examination				√	√		√
Outcome measures	√			√	√		√

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

Edith Cowan University
Health and Wellness Institute
vario
wellness
clinic
AUSTRALIA
ECU
EDITH COWAN
UNIVERSITY

Associate Professor Daniel Galvão
Director, ECU Health and Wellness Institute

JOURNAL OF CLINICAL ONCOLOGY

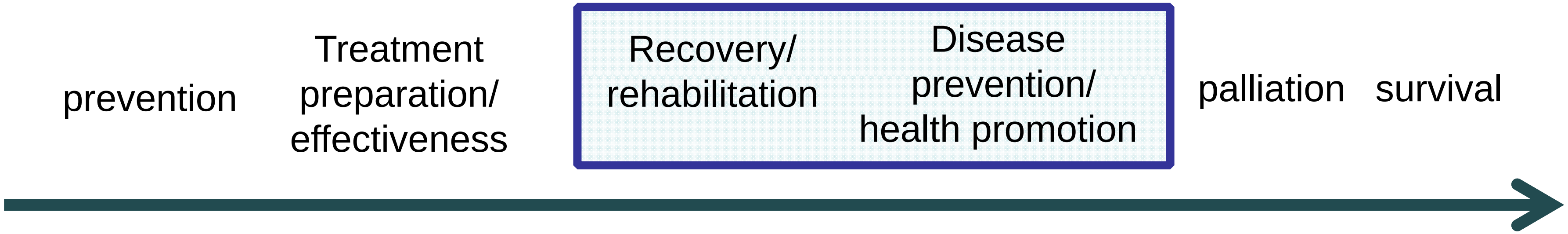
REVIEW ARTICLE

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/ effectiveness

Recovery/ rehabilitation

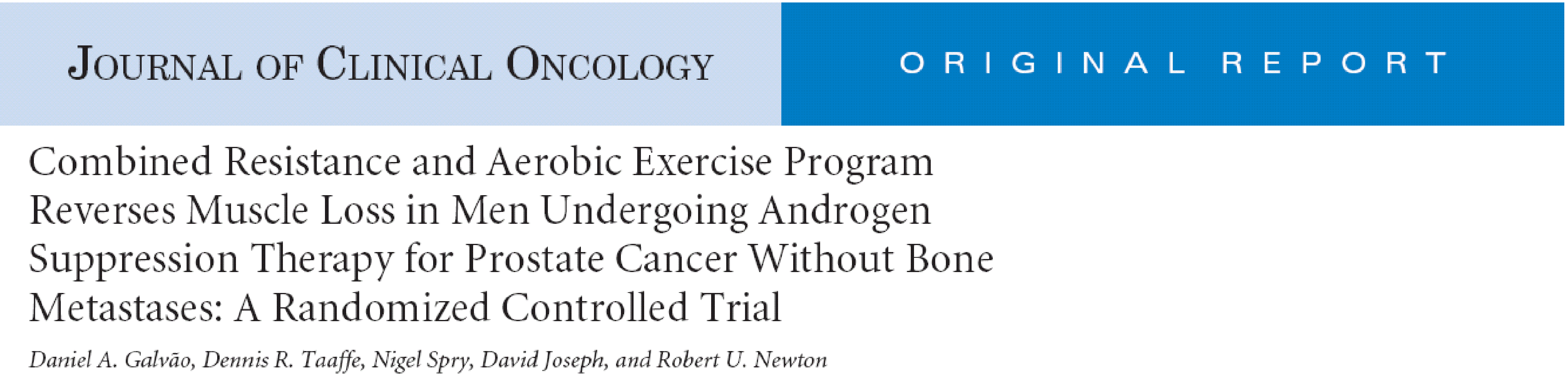
Disease prevention/ health promotion

palliation

survival

Courneya and Friedenreich *Sem Onco Nurs* 2007;23:24

Galvão & Newton. *J Clinical Oncology*



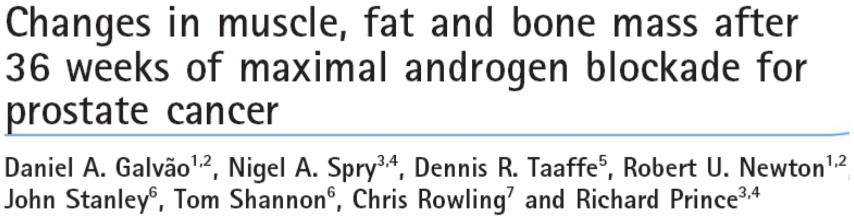
JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

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

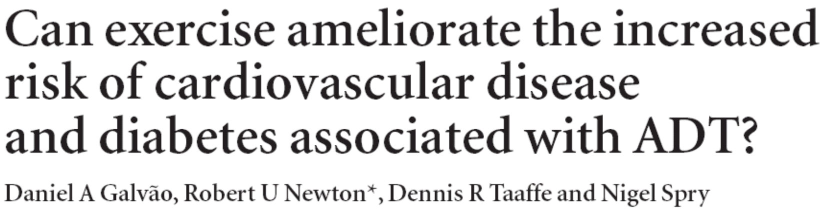
Daniel A. Galvão, Dennis R. Taaffe, Nigel Spry, David Joseph, and Robert U. Newton

Lean Mass	~1kg	EX>CO
Muscle Strength	5-31kg	EX>CO
Aerobic Capacity	-7sec	EX>CO
Dynamic Balance	-4sec	EX>CO
General Health	+12	EX>CO
Fatigue	-11	EX>CO



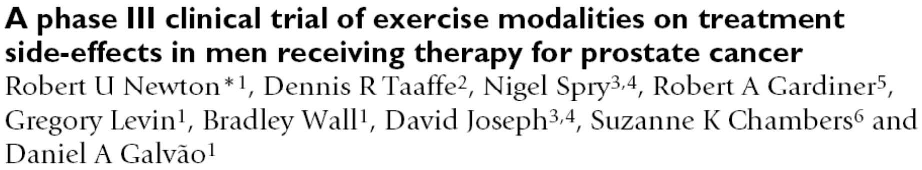
Changes in muscle, fat and bone mass after 36 weeks of maximal androgen blockade for prostate cancer

Daniel A. Galvão[1,2], Nigel A. Spry[3,4], Dennis R. Taaffe[5], Robert U. Newton[1,2], John Stanley[6], Tom Shannon[6], Chris Rowling[7] and Richard Prince[3,4]



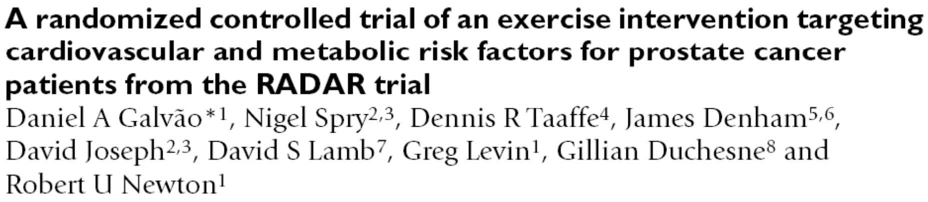
Can exercise ameliorate the increased risk of cardiovascular disease and diabetes associated with ADT?

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

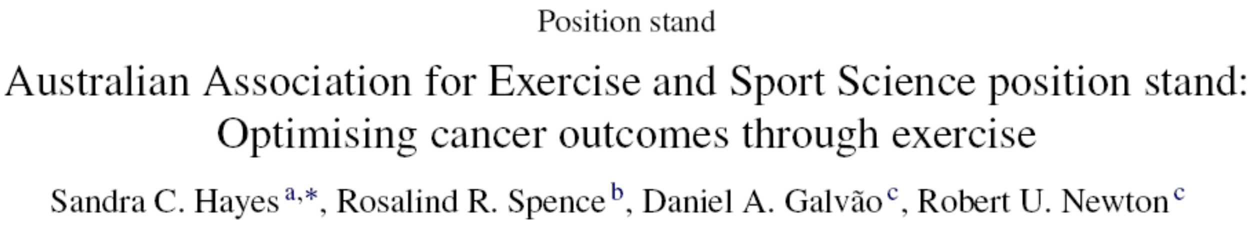
Robert U Newton*[1], Dennis R Taaffe[2], Nigel Spry[3,4], Robert A Gardiner[5], Gregory Levin[1], Bradley Wall[1], David Joseph[3,4], Suzanne K Chambers[6] and Daniel A Galvão[1]



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

Daniel A Galvão*[1], Nigel Spry[2,3], Dennis R Taaffe[4], James Denham[5,6], David Joseph[2,3], David S Lamb[7], Greg Levin[1], Gillian Duchesne[8] and Robert U Newton[1]

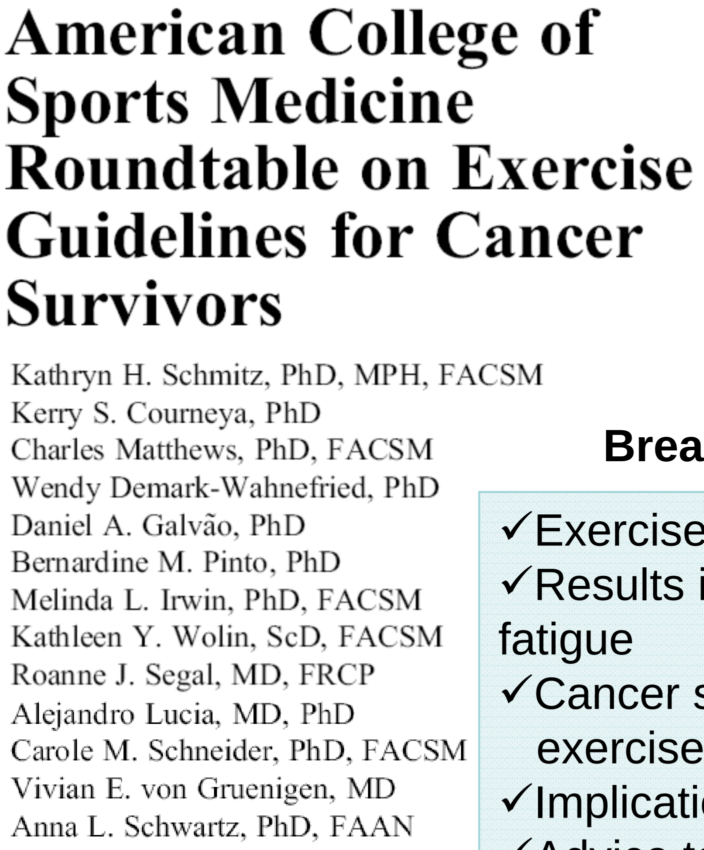
Galvão et al. *J Clinical Oncology*



Position stand

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

Sandra C. Hayes [a,*], Rosalind R. Spence [b], Daniel A. Galvão [c], Robert U. Newton [c]



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

SPECIAL COMMUNICATIONS

Roundtable Consensus Statement

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

American College of Sports Medicine. *Med Sci Sports Exerc.*

Cancer Survivorship

Research at QIMR:

Vanessa Beesley: Current and planned projects

Queensland Institute of
Medical Research

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

Endometrial Cancer

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

Colorectal Cancer

- 2010-2012: Work life after cancer, Louisa Gordon, $240,000, ARC

Melanoma

- 2010-2013: QoL & unmet needs in primary invasive melanoma patients, Adèle Green, $200,000 NHMRC

Ovarian Cancer

- 2003-2004: QoL & chemotherapy end-points in ovarian cancer, Adèle Green, $141,832, CCQ.
- 2005-2007: QoL, unmet needs & lifestyle of ovarian cancer survivors, P Webb *in collab with* P Butow & M Price at USyd, $533,574, CCNSW
- 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 Biankin, 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. CI's: Prof Adèle Green, Prof B. Mark Smithers, A/Prof Kiarash Khosrotehrani, Dr Vanessa Beesley, Dr Alexander Molassiotis, Dr Paul Lorigan, Dr Jackie Hodgetts. AI's Dr Louisa Gordon.
6. Ovarian Cancer Walking Intervention. CI's: Dr Vanessa Beesley, Dr Sandi Hayes, Ms Melissa Newton, Dr Penelope Webb, Prof Andreas Obermair, Dr David Wyld, Dr Alessandra Francesconi. AI's: 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 in to 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

Flinders University and Flinders Medical Centre, with the proud support of the FMC Foundation, present

THE FLINDERS CENTRE FOR INNOVATION IN CANCER

2010 CANCER SURVIVORSHIP CONFERENCE

Marking the commencement of the construction of the new Flinders Centre for Innovation in Cancer incorporating the LIVESTRONG Cancer Research Centre. The 2010 Survivorship Conference will bring together cancer professionals and cancer survivors to discuss latest strategies in survivorship care and supportive care in cancer.

- What is survivorship?
- How best to meet the needs of survivors
- Complementary care in cancer
- Nutrition in cancer
- Interactive workshops in yoga, massage and nutrition

ONLY 50 PLACES AVAILABLE

"I look forward to hearing all of the good stories that come out of this Centre. This is the birth of hope and the birth of inspiration for so many people".

SEPTEMBER 11TH 2010
FLINDERS UNIVERSITY HEALTH SCIENCES LECTURE COMPLEX
corner of University Drive & Ring Road
9AM - 4.30PM
Full registration: $20; Survivor, student, unemployed: $10
For Bookings call the FMC Foundation on 08 8204 5216
or foundation@health.sa.gov.au or www.fmcfoundation.com.au

Clinical
Oncological
Society of
Australia

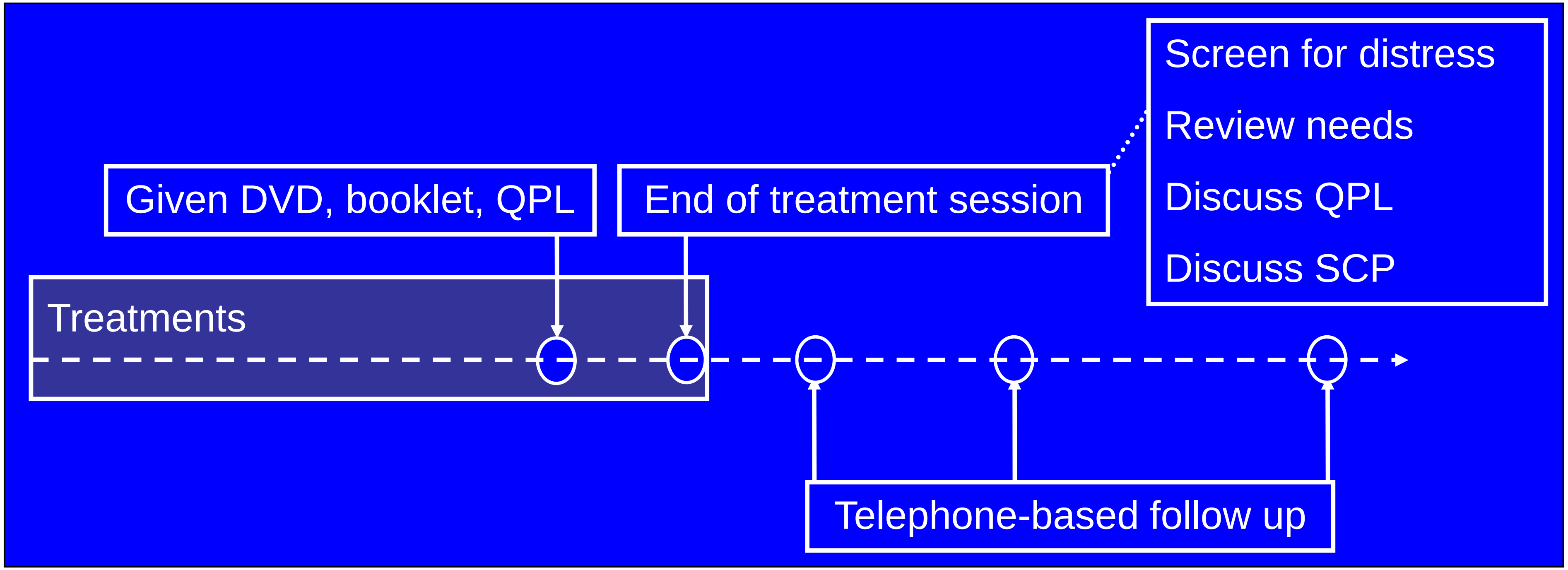
Michael Jefford

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



Screen for distress

Review needs

Discuss QPL

Discuss SCP

Given DVD, booklet, QPL

End of treatment session

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 ($r=-0.431$, $p<0.000$).

HMRI
Hunter Medical Research Institute

THE UNIVERSITY OF
NEWCASTLE
AUSTRALIA

Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

Afaf Girgis

Centre for Health Research & Psycho-oncology (CHeRP) NSW

CHeRP Program Managers:
Afaf Girgis, Allison Boyes, Sylvie Lambert

Longitudinal survivorship studies

Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

- 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

Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

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, 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, depression, cancer specific distress, unmet supportive care needs, positive adjustment, QoL]
  CIs: Chambers, Girgis, Occhipinti, Turner, Carter, Dunn

CURRENT trials

Cancer Council New South Wales
Centre for Health Research & Psycho-oncology (CHeRP)

- **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)

UNSW

Clinical Oncological Society of Australia

Cancer Council
New South Wales
Centre for Health Research
& Psycho-oncology (CHeRP)

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)

UNSW

Clinical Oncological Society of Australia

Cancer Council New South Wales
Centre for Health Research & Psycho-oncology (CHeRP)

Other programs around Australia (finish by 5.20pm)

ANZ CHOG
AUSTRALIAN & NEW ZEALAND
Childrens Haematology/Oncology Group

Long-Term Follow-up of Adult Survivors of Childhood Cancer

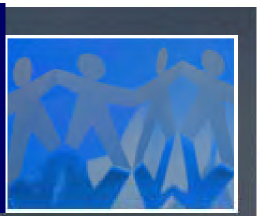
Richard Cohn

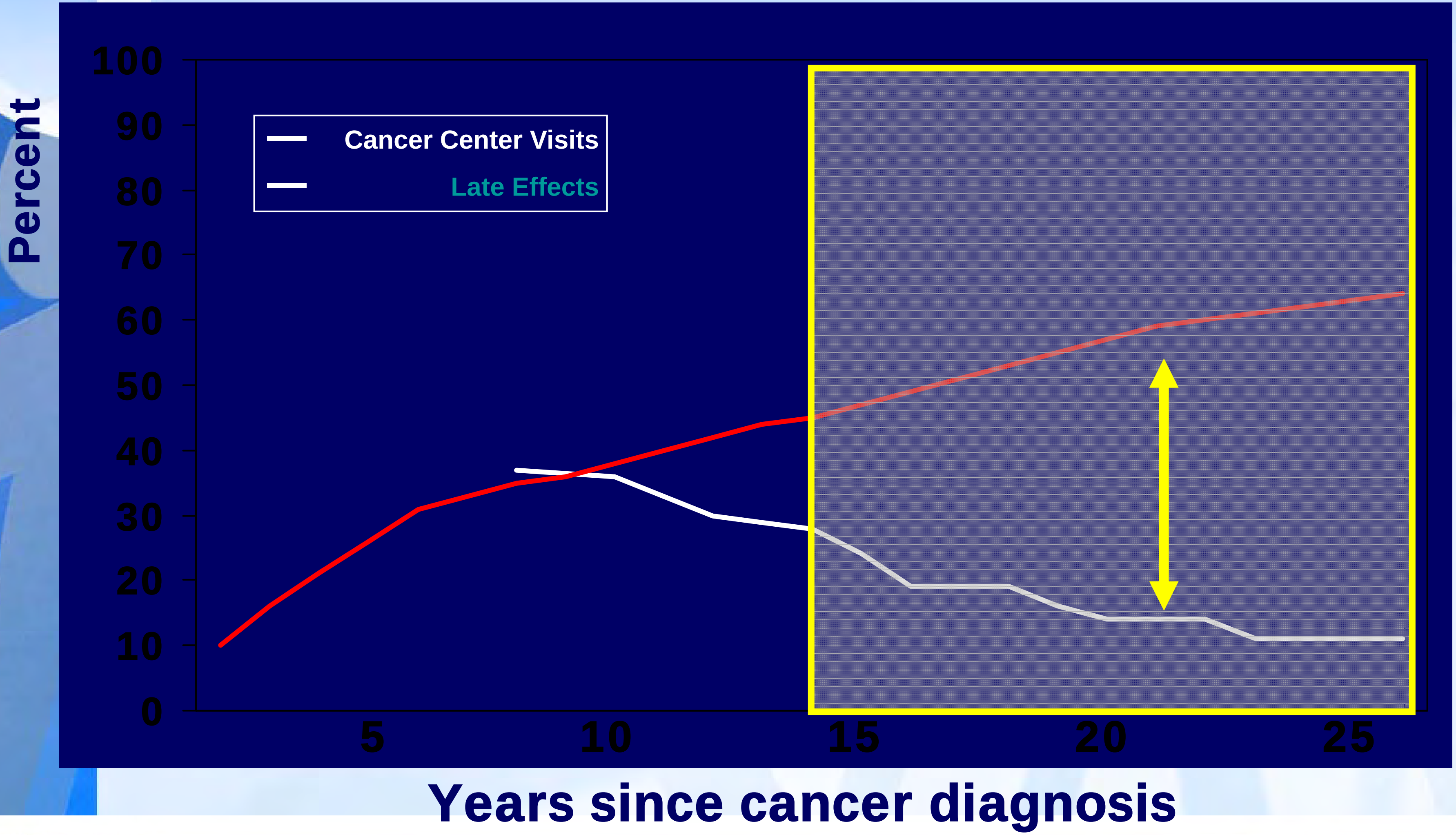
Sydney Children's Hospital

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 18-24years



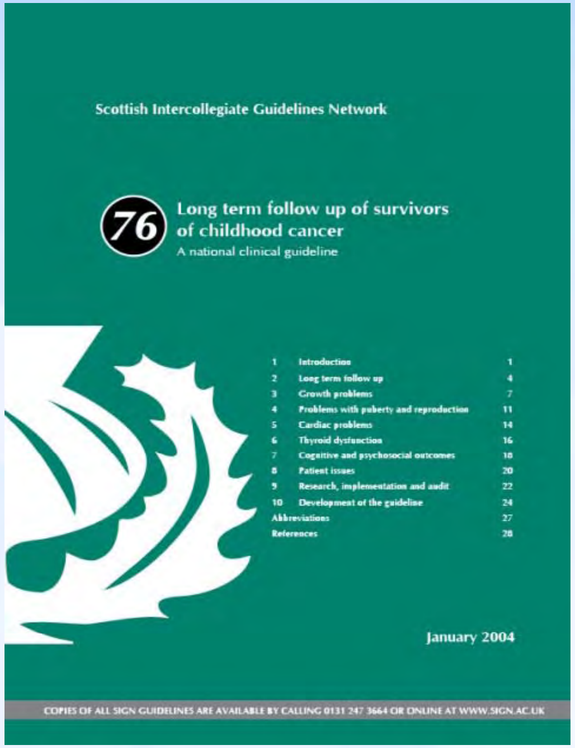


CCSS
CHILDHOOD CANCER SURVIVOR STUDY

An NCI-Funded Resource

Aiming for harmonisation of Co-operative Group Guidelines

Practice Statement



Scottish Intercollegiate Guidelines Network

76 Long term follow up of survivors of childhood cancer

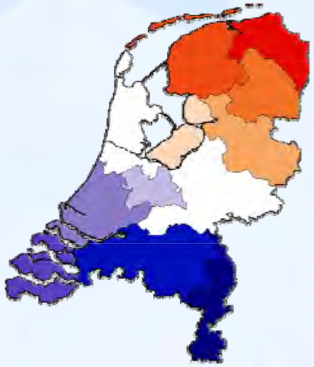
A national clinical guideline

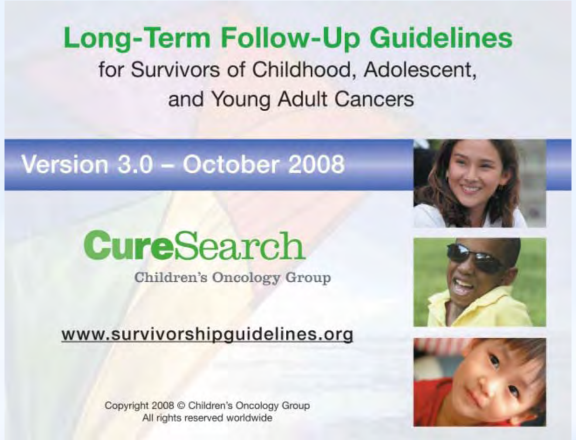
January 2004

COPIES OF ALL SIGN GUIDELINES ARE AVAILABLE BY CALLING 0131 247 3664 OR ONLINE AT WWW.SIGN.AC.UK

SKION Later

Langetermijneffecten na kinderkanker





Long-Term Follow-Up Guidelines
for Survivors of Childhood, Adolescent, and Young Adult Cancers

Version 3.0 – October 2008

CureSearch
Children's Oncology Group

www.survivorshipguidelines.org

CCLG

ANZCHOG
AUSTRALIAN & NEW ZEALAND
Childrens Haematology/Oncology Group

Breast Cancer Surveillance in Women Treated with Radiation for Childhood Cancer

Breast Cancer Surveillance in Women Treated with Radiation for Childhood Cancer

Cooperative Group		CCLG	COG	DCOG
Risk by Radiation Dose and Field	At risk	Chest wall and breast radiation	Any radiation impacting breast	Thorax radiation
	High risk	Not specified	Not specified	≥ 7-20 Gy thorax (excluding TBI) -Or- ≥ 14-40 Gy abdomen including diaphragm
	Very high risk/ highest risk	Not specified	≥ 20 Gy radiation impacting breast -Or- Genetic predisposition	≥ 20 Gy thorax -Or- 40 Gy abdomen including diaphragm -Or- Total body radiation -Or- Genetic predisposition
Breast Cancer Surveillance Parameters	Age at initiation	25 years	25 years (or 8 years from radiation, whichever occurs last)	25 years
	Frequency	Yearly from age 25-50 years Every 3 years from > 50 years	Yearly without specification of maximum age	Yearly from 25-60 years Every 2 years from > 60-75 years
	Clinician exam	At risk: 10 years from cancer treatment and > age 25 years	Highest risk: Yearly from puberty Every 6 months from 25 years	Very high risk: Yearly from 25-60 years High risk: Yearly from 35-60 years
	Age 25-30	MRI (ultrasound if MRI contraindicated)	Mammography + MRI	MRI
	Age 30-50 years	Mammography if fatty breast Mammography + MRI if dense breast (ultrasound if MRI contraindicated)	Mammography + MRI	Mammography + MRI
	Age > 50 years	Mammography	Mammography + MRI	Mammography until age 75 years MRI until age 60 years

Opportunities for collaborative research

- Carmen L Wilson, **Richard J Cohn**, Karen A Johnson, Lesley J Ashton. **Second cancers and late mortality among a cohort of childhood cancer survivors.** Med J Aust. 2010 Sep 6;193(5):258-61.
- Wilson CE, **Cohn RJ** & Ashton LJ. **Survivors of Childhood Cancer: Issues and Challenges. In: When cancer crosses disciplines**, eds. Robotin M, Olver I, Girgis Afaf. Imperial College Press (London, UK), 2009.(book chapter) pages 1047 -1076.
- Wilson CW**, Cohn RJ**, Johnson K, Ashton LJ (2009). **Tracing survivors of childhood cancer in Australia**. Pediatric Blood and Cancer. Apr 52(4): 510-5.
- Goodenough B, Johnston K, Suneson Casey J, Foreman T, **Cohn RJ. The priority of risk-based health care for Australian survivors of childhood cancer: Patient self-reports of concerns and the "Health Passport" initiative.** *Austral-Asian Journal of Cancer 2008 January: 7(1):29-39*
- K Johnston, M Vowels, S Carroll , **RJ Cohn**. **Failure to Lactate: A possible Late Effect of Cranial Radiation.** Pediatric Blood and Cancer. 2008 March:50(3):721 -722.
- Trahair TN, Vowels MR, Johnston K, Cohn RJ, Russell SJ, Neville KA, Carroll S, Marshall GM (2007). **Long-term outcomes in children with high-risk neuroblastoma treated with autologous stem cell transplantation.** Bone Marrow Transplantation, 40(8): 741-746.
- Kristen A Neville, **Richard J Cohn**, Katharine Steinbeck, Karen Johnston, Jan L Walker. **Hyperinsulinemia, IGT and DM in survivors of childhood cancer: prevalence and risk factors.** J Clin Endocrinol Metab. 2006 : 91(11):4401–4407.
- 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
- Suneson Casey J, Goodenough B, Johnston K, **Cohn RJ** (2008) **The Applicability of a Cognitive Model of Trauma to the Assessment and Treatment of Childhood Cancer Survivors (CCS), Their Parents and Siblings**. 10th International Conference Long-Term Complications of Treatment of Children and Adolescents for Cancer, Niagara on the Lake, Ontario Canada. 6-7 June 2008.

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)

UNSW

Clinical Oncological Society of Australia

Cancer Council New South Wales
Centre for Health Research & Psycho-oncology (CHeRP)

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 (eg 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)