







Survivorship Conference

The inaugural national conference bringing together clinicians, researchers and survivors to focus on understanding and addressing the issues facing cancer survivors and the priorities for survivorship care and research.

February 1-3, 2013 Stamford Grand Hotel Glenelg, South Australia



On behalf of the Flinders Centre for Innovation in Cancer Survivorship Conference committee we would like to thank the following sponsors for their support.

Principal and Host









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Convenor's Welcome



I am delighted to welcome you to the inaugural Flinders Centre for Innovation in Cancer Survivorship Conference 2013.

This Conference is unique in its scope as we have worked hard to ensure the content is accessible to all who are interested in this important topic.

Today you might find yourself sitting next to a cancer clinician, a researcher, a policy advisor, a cancer survivor or a relative of someone touched by this disease.

This diversity has attracted speakers and experts from around Australia and the world to share their insights into the most exciting developments in the field of cancer survivorship. In its comprehensive and inclusive scope, this conference promises to be a truly one of a kind premier global event.

We have put together a wide array of topics ranging from research presentations to models of care delivery to policy consideration. The theme of the conference "Cancer Survivorship - Partnerships for the Future" highlights the overarching aspect of survivorship care and research and its connection with patients and survivors.

The conference will also highlight the unique perspective that survivors and other consumers can bring to this field, as well as the importance of collaboration amongst those involved in care, research and policy seeking to deliver optimal outcomes.

The scientific programme features guest lectures, plenary symposia, posters and selected oral presentations from delegate submissions and is sure to appeal to the varied interests of participants.

A trade exhibition will also be held throughout the meeting by the many sponsors who have supported this event – who we thank for their generosity.

With one of South Australia's best beaches on our doorstep, a vibrant art scene and exciting sightseeing opportunities, I am certain that you will enjoy your time here in Adelaide.

With warm regards,

Professor Bogda Koczwara Conference Convenor



FCIC Cancer Survivorship

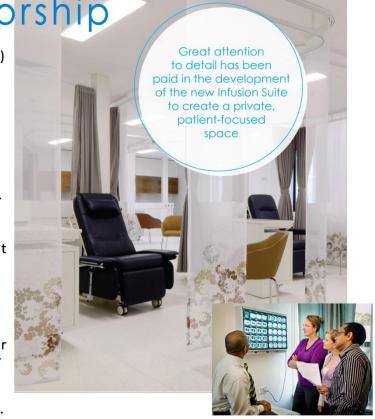
The Flinders Centre for Innovation in Cancer (FCIC) is a leading cancer centre in Australia, housing world-class care and survivorship services alongside innovative cancer prevention and early intervention research.

At the FCIC the Cancer Survivorship Program focuses on developing a plan with each individual that encompasses all of their physical, emotional, practical and spiritual needs to help them on their journey through and beyond cancer.

The Program provides a comprehensive assessment to identify and address patient concerns, thereby ensuring that cancer survivors maintain their health and wellness and minimise any adverse effects of their cancer and treatment.

Excellence in survivorship care is a driving goal for all involved in creating better outcomes for cancer patients at the FCIC.

For more information please visit www.fcic.org.au.



Flinders Medical Centre Foundation

The FCIC is a joint venture between the Flinders University, Flinders Medical Centre (FMC) and FMC Foundation.

The FMC Foundation has been the driving force behind the campaign to build the FCIC and to help facilitate programs such as the FCIC Survivorship Conference.

100% of every donation, bequest or in memoriam gift made to the FMC Foundation is dedicated to the nominated cause.



For more information please visit www.fmcfoundation.com.au or call 08 8204 5216.

Committees

Thank you to all the individuals who have made this conference possible, including:

Conference Convenor

Prof Bogda Koczwara Head of Medical Oncology, Flinders Medical Centre

Scientific Program Advisory Committee

Prof Jeff Dunn CEO, Cancer Council Queensland

Prof Afaf Girgis Executive Director, Translational Cancer Research Unit, University of

NSW

Dr David GoldsteinConjoint Clinical Professor, Medical Oncologist,

Prince of Wales Hospital NSW

Assoc Prof Michael Jefford Clinical Director, Australian Cancer Survivorship Centre, Peter

MacCallum Cancer Centre (Peter Mac)

Prof Bogda Koczwara Head of Medical Oncology, Flinders Medical Centre

Prof Ian Olver CEO, Cancer Council Australia

Organising Committee

Ms Deborah Heithersay CEO, Flinders Medical Centre Foundation

Dr Rebecca Keough Research Development Officer,

Flinders Centre for Innovation in Cancer

Prof Bogda Koczwara Head of Medical Oncology, Flinders Medical Centre

Prof Ross McKinnon Director, Flinders Centre for Innovation in Cancer

Ms Maxine Pollard FCIC Communication Manager,

Flinders Medical Centre Foundation

Consumer Advisory Group

Cancer Voices SA members: Julie Marker, Ashleigh Moore, Agnes Vitry, Con Nakos, Cathy Carter, Don Piro, Arthur Seager, Kevin Turner - Cancer Care Centre

Keynote Speakers



Prof Patricia Ganz

Professor of Medicine at David Geffen School of Medicine; Professor of Health Services, Jonathan and Karin Fielding School of Public Health at UCLA; Director, Cancer Prevention & Control Research, Jonsson Comprehensive Cancer Center, Los Angeles, CA, USA

Professor Patricia A. Ganz, M.D., a medical oncologist, has been a member of the faculty of the UCLA School of Medicine since 1978 and the UCLA School of Public Health since 1992. Since 1993 she has been the Director of Cancer Prevention and Control Research at the Jonsson Comprehensive Cancer Center. In 1999 she was awarded an American Cancer Society Clinical Research Professorship for "Enhancing Patient Outcomes across the Cancer Control Continuum," and in 1999 and 2000 received the Susan G. Komen Foundation Professor of Survivorship Award. Prof Ganz was elected to the Institute of Medicine, U.S. National Academy of Sciences, in 2007 and she served on the National Cancer Institute Board of Scientific Advisors from 2002-2007 and the American Society of Clinical Oncology (ASCO) Board of Directors from 2003-2006. She served on the Institute of Medicine (IOM) Committee responsible for the 2005 report "From Cancer Patient to Survivor: Lost in Transition," and on the 2008 IOM Committee for the report "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs."

A pioneer in the assessment of quality of life in cancer patients and survivors, Prof Ganz is active in clinical trials research with the National Surgical Adjuvant Breast and Bowel Project (NSABP). She has focused much of her clinical and research efforts in the areas of breast cancer and its prevention, and was a member of the NCI Progress Review Group on Breast Cancer.

At the Jonsson Comprehensive Cancer Center, she leads the scientific program focused on Patients and Survivors. In 1997 she established the UCLA Family Cancer Registry and Genetic Evaluation Program, which serves patients and survivors, as well as those at high risk for familial/hereditary cancers. Her other major areas of research include cancer survivorship and late effects of cancer treatment, cancer in the elderly, and quality of care for cancer patients.

Prof Ganz is an Associate Editor for the *Journal of the National Cancer Institute*, and *CA-A Journal for Clinician*, and is on the Editorial Board *of the Journal of Cancer Survivorship*. She was a founding member of the National Coalition for Cancer Survivorship (NCCS) in 1986, and has directed the UCLA-LIVE**STRONG** Survivorship Center of Excellence at the Jonsson Comprehensive Cancer Center since 2006.



Dr Lee Jones

Assistant Research Professor Department of Surgery Preston Robert Tisch Brain Tumor Center at Duke University Medical Center, USA

Dr Lee W. Jones is an Associate Professor in the Department of Radiation Oncology and the Scientific Director of Cancer Survivorship at Duke Cancer Institute. Dr Jones completed his Bachelor's of Science (Hons) in Sport and Exercise Science at the University of Brighton (Eastbourne, East Sussex,

England). In 1996, Dr Jones moved to Canada where he completed his Masters of Science in Kinesiology at Lakehead University (Thunder Bay, Ontario, Canada) and his PhD in Physical Education (Exercise Oncology) at the University of Alberta (Edmonton, Alberta, Canada). He completed his Postdoctoral Fellowship in Exercise Oncology also at the University of Alberta. Dr Jones was recruited to Duke Medicine in January 2005. His research program focuses on a translational approach to: (1) evaluate the cardiovascular/functional impact of cancer therapy, and efficacy of defined exercise training to prevent and/or treat dysfunction, and (2) elucidate the effects, and underlying systemic and molecular mechanisms, of defined aerobic training on tumor progression and metastatic dissemination.

He has published numerous scientific articles and book chapters and is also a member of the International Editorial Board for Lancet Oncology. His research program is supported by the National Institutes of Health, American Cancer Society, and U.S. Department of Defense Breast Cancer Research Program.

Invited Speakers



Dr Sarah Arvey

Manager of the Research and Evaluation Team at the LIVESTRONG Foundation

Sarah R. Arvey joined the LIVE**STRONG** Foundation as Manager on the Research and Evaluation Team in February 2011. She manages and conducts collaborative research activities with partners such as the LIVE**STRONG** Survivorship Center of Excellence Network, as well as evaluates programs intended to improve the lives of cancer survivors. Trained in medical anthropology with a focus on Latino culture and health-seeking practices, Dr Arvey received her doctoral degree from the University of Michigan in 2007. After graduate training, she sought further training and experience in cancer control and health disparities as a Postdoctoral Fellow in the National Cancer Institute Cancer Education and Career Development Program at the University of Texas, School of Public Health.

Sarah's publications have been in: American Journal of Public Health, Journal of Oncology Practice, Ethnicity & Health, Health Education & Behavior, Hispanic Health International, and the Hispanic American Historical Review.



Cancer Conversations

Cancer Conversations is a method for sharing Survivorship issues and perspectives. This interactive session will present the Canadian "Cancer Conversations" methodology along with results from survivor-led "Cancer Conversations" in Australian Aboriginal communities.



Assoc Prof Andrew Cole

Chief Medical Officer of HammondCare, Hammond Village, Sydney

Andrew Cole grew up in SE Asia and graduated MBBS (Sydney) with first class honours in 1978. After completing his Fellowship in Rehabilitation Medicine, he was the founding Director of the St George Community Rehabilitation and Geriatric Services between 1985 and 1991, with a conjoint academic appointment at UNSW continuing since 1985. He was then appointed Development Consultant in Extended and Aged Care at the Changhua Christian Hospital in central Taiwan, where he established models for community-based Rehabilitation and Palliative Care services, and clinic-based services for frail disabled aged persons.

Since 1996, Andrew has been working with Hope Healthcare and then HammondCare as a Senior Specialist in Rehabilitation Medicine, initially at Braeside Hospital, and was promoted to conjoint Associate Professor with UNSW in 2004. Since 2008 he has been the Chief Medical Officer of HammondCare, and is now based at the Hammond Village in NSW Sydney. His interests are in neurological, cancer and community-based rehabilitation, and clinical education at both undergraduate and postgraduate levels. He has driven the recent funding and establishment of multidisciplinary Clinical Training Centres at Hammondville and Greenwich, with appointments respectively of a Hammond Chair in Positive Ageing and Care with UNSW, and Chairs in Palliative Care and Pain Medicine with the University of Sydney.



Sondra Davoren

McCabe Centre for Law and Cancer; Senior Legal Policy Advisor at Cancer Council Victoria

Sondra is a Senior Legal Policy Advisor at Cancer Council Victoria, working in alcohol law and policy, and the role of law in cancer treatment and supportive care. She is a member of Australia's National Preventive Health Agency's Expert Committee on Alcohol, the National Alliance for Action on Alcohol and the Victorian Alcohol Policy Coalition. She has published papers on alcohol advertising regulation, and legal and regulatory interventions to reduce alcohol-related cancers. Prior to joining Cancer Council Victoria, Sondra worked as a legal advisor to the Victorian Legal Services Board and in multi-party litigation for Irwin Mitchell Solicitors (UK), specialising in product liability claims. Sondra studied law at the University of Canterbury, New Zealand and University of Sheffield, United Kingdom.



Prof Jon Emery

Winthrop Professor of General Practice at the University of Western Australia and Senior Clinical Research Associate at the University of Cambridge

Prof Jon Emery is Winthrop Professor of General Practice at the University of Western Australia. Prof Emery is a Senior Clinical Research Associate at the University of Cambridge, a practising GP and Director of the Cancer Australia Primary Care Collaborative Cancer Clinical Trials Group (PC4). He has also recently been appointed to the Chair of Primary Care Cancer Research at the University of Melbourne as part of the Victorian Comprehensive Cancer Centre.

Prof Emery studied medicine at Cambridge and Oxford and obtained his DPhil at Oxford on computer decision support to assess cancer risk in general practice. His specific research interests are in the role of primary care in cancer diagnosis and management, complex interventions, genetic medicine and primary care trials. Much of his research entails parallel programs of work on cancer screening, diagnosis and follow-up care in Australia and Cambridge. He has published over 100 peer-reviewed papers in the last 12 years and has been a Chief Investigator on research grants and awards totalling GBP11m and an additional \$AUD16m, including more than \$AUD13m in competitive NHMRC and Australian government grants since he arrived in Australia in 2004.



Prof Afaf Girgis

Executive Director, Translational Cancer Research Unit, Ingham Institute for Applied Medical Research, University of NSW

Professor Afaf Girgis is Executive Director of the Translational Cancer Research Unit, Ingham Institute for Applied Medical Research at the University of NSW. For the past 23+ years, her research program in cancer control and psycho-oncology has focused on the development and psychometric testing of measures to assess cancer patients', caregivers' and health care professionals' unmet needs; development and evaluation of strategies for improving psycho-social outcomes in clinical practice using rigorous research designs; and research and teaching in health professional communication skills. Her work is increasingly focusing on health service research and translation of evidence into policy and practice.

In 2008, Prof Girgis Chaired the National Breast Cancer Centre Survivorship Advisory Group and in 2010, she co-convened the inaugural Clinical Oncological Society of Australia (COSA) Cancer Survivorship Workshop.



Dr Craig Hassed

General Practitioner and Senior Lecturer at Monash University Department of General Practice

Dr Craig Hassed is a General Practitioner and Senior Lecturer at the Monash University Department of General Practice. His teaching, research and clinical interests include mindfulness-based stress management, mind-body medicine, meditation, holistic healthcare, health promotion, integrative medicine and medical ethics. Craig is the founding president of the Australian Teachers of Meditation Association and is regularly invited to speak and run courses in Australia and overseas.

He is a regular media commentator, writes regularly for medical journals and has published five books; "New Frontiers in Medicine" (Volumes 1 and 2), a third book on mindfulness-based stress management entitled "Know Thyself", a fourth on an holistic lifestyle approach to healthcare, "The Essence of Health" and most recently a textbook co authored with Kerryn Phelps, "General Practice: the integrative approach". Craig's sixth book, written with Stephen McKenzie, "Mindfulness for Life", was released in mid-2012.



Assoc Prof Michael Jefford

Deputy Head of the Department of Medical Oncology at Peter MacCallum Cancer Centre; Senior Clinical Consultant at Cancer Council Victoria; Principal Fellow, University of Melbourne; Director, Australian Cancer Survivorship Centre

Associate Professor Michael Jefford is Deputy Head of the Department of Medical Oncology at Peter MacCallum Cancer Centre (Peter Mac). He is a Senior Clinical Consultant at Cancer Council Victoria, a Principal Fellow with the University of Melbourne and is Director of the Australian Cancer Survivorship Centre, a Richard Pratt legacy.

Michael completed a laboratory-based PhD and holds Masters Degrees in Health Services Management and in Public Health. His clinical practice, and part of his clinical research, focuses on the management of people with gastrointestinal cancers. He has extensive experience designing interventions to improve the psychological wellbeing and supportive care outcomes of people affected by cancer.

Michael has published 85 peer-reviewed manuscripts and book chapters and has presented work at several international meetings covering cancer control, clinical oncology and psycho-oncology.



Phil Kerslake

Lifepaths, New Zealand

Phil Kerslake is a New Zealand based, seven-time lymphoma survivor (Hodgkin and non-Hodgkin) whose education in the art, science and practice of coping with cancer and survivorship began 33 years ago when he was diagnosed with an incurable disease as a teenager.

Phil shares what his personal experience and enquiry over the decades has led him to believe with patients, health care and cancer support professionals. His mission is to help reduce patient suffering by empowering them with knowledge and hope. He also encourages empathetic, patient-centric service delivery from all those professionals who interface with the patients.

Described by the Cancer Council Australia as 'A book that can make a real difference in the lives of cancer patients from all walks of life...,' Phil's patient support book 'Life, Happiness... & Cancer' (NZ 2006 -) is also published in Australia, Africa and Poland.



Prof Bogda Koczwara

Head of Department, Medical Oncology, Flinders Medical Centre; ; Past President of the Clinical Oncology Society of Australia (COSA); Chair of the Education Program in Cancer Care (EPICC); a Director of Cancer Council of Australia and Cancer Council SA

Professor Bogda Koczwara is a medical oncologist and of the Head of the Department of Medical Oncology at Flinders Medical Centre. Her clinical interests revolve around management of breast cancer, in particular in young women, survivorship care, psycho-oncology and supportive care and she has a particular interest in strengthening the interface between specialist and primary care for cancer patients, especially in rural Australia.

Professor Koczwara is the immediate past President of the Clinical Oncology

Society of Australia (COSA), the peak cancer professional organisation in Australia and the past president of the Medical Oncology Group of Australia (MOGA), the national professional organisation of medical oncologists. She is the initiator and the immediate past Chair of the Australia Asia Pacific Clinical Oncology Research Development, a collaborative of international cancer organisations aimed at improving cancer research capacity in Australia and Asia Pacific and is the Chair of the Education Program in Cancer Care (EPICC), an online program of Cancer Australia aimed at improving skills of cancer management for non-cancer specialists.

Bogda serves as a Director of the Cancer Council of Australia and South Australia.



Assoc Prof Sharon Lawn

Lead Writer and Researcher on Chronic Condition Management and Self-Management at Flinders University, Adelaide, South Australia

Sharon's PhD on 'Systemic Factors that Perpetuate Smoking for Mental Health Populations' was completed in 2001, and her subsequent efforts in this field have led to significant policy and practice changes throughout Australia and overseas.

Sharon commenced working at Flinders University in 2004 as lead writer of the self-management brief for the National Chronic Disease Strategy. She leads research in Chronic Condition Management and Self-Management and coordinates a multi-disciplinary post-graduate course in this field.

Prior to her current role at Flinders University, Sharon was a clinician for 23 years, working in aged care and mental health services. She maintains a strong consumer perspective, and is an active advocate in the mental health field for consumers and carers. In 2007, she won the 'Australasian Award for Exceptional Contribution by an Individual to Mental Health across Australia and New Zealand' and in 2012 won the SA Pride of Australia Community Spirit award.



Devon McGoldrick

Director of the Community Programs and Engagement team at the LIVESTRONG Foundation

Devon McGoldrick is the Director of the Community Programs and Engagement team at the LIVE**STRONG** Foundation. In this role, Devon oversees national and community partnerships, and designs programs and services to support people affected by cancer around the world.

Devon has twelve years experience in the healthcare field. She holds a Bachelor of Science degree from Rochester Institute of Technology and received her Master of Public Health from the Mailman School of Public Health at Columbia University. Her expertise includes adolescent/young adult oncology, the development, implementation and oversight of innovative projects and partnership building.

Before joining the LIVE**STRONG** Foundation in 2006, Devon held positions at the U.S. National Cancer Institute and Memorial Sloan-Kettering Cancer Center in New York.



Dr Michael Rice

Consultant Paediatrician at the Women's and Childrens Hospital, South Australia

I graduated in Medicine from the University of Adelaide in 1959. I undertook postgraduate training in paediatric medicine and paediatric oncology in Adelaide, Melbourne and New York (at The Sloan- Kettering Cancer Centre) from 1960-67. I then returned to Adelaide where I established a paediatric oncology service at the Adelaide Children's Hospital and I have worked as a consultant paediatrician in private and public hospital practice ever since.

I was a founding member of the paediatric section of The Clinical Oncology Society of Australia (1975) and of The Australian and New Zealand Childhood Cancer Study Group (1987). I have had a long-standing involvement with clinical trials in paediatric oncology at a national and international level and a specific interest in late adverse effects of treatment among survivors of cancer in childhood.



Sue Sinclair

General Manager, Service Delivery and Clinical Practice at Cancer Australia

Sue Sinclair is the General Manager of Service Delivery and Clinical Practice at Cancer Australia, which is funded by the Commonwealth Government of Australia to reduce mortality and improve the wellbeing of people affected by cancer.

Sue has a background in clinical nursing, education, clinical research and executive management in both the public and private health care sectors. Whilst working in cancer control in Australia for the last six years, she has been responsible for leading core programs at a state and national level, to improve evidence based cancer care, approaches to services delivery and education programs to support cancer health professionals and the uptake of best evidence based care.



Danielle Tindle

PhD Candidate at the Institute of Health and Biomedical Innovation, Queensland University of Technology (QUT)

Danielle is currently undertaking PhD research into the survivorship experiences of Adolescent and Young Adults (AYA) diagnosed with cancer in Australia, England and the United States of America. This cross-cultural study will enhance an understanding of how meaning and identity develop in relation to AYA cancer, and what this may mean for quality of life in adult- hood. Her research is supported by a three year PhD scholarship awarded by Leukaemia Foundation Australia.

As a survivor of AYA cancer herself, Danielle has extensive experience working in this field and advocating for young patients. In both professional and consumer advocacy roles, she is involved with a number of national and international organisations such as CanSpeak (AU), Teenage Cancer Trust (UK) and LIVE**STRONG** (US).

Danielle was previously employed as the Senior Project Officer for AYA Cancer Services based at the Royal Children's Hospital, Brisbane. Her work focused on the research and development of a state-wide model of specialised AYA cancer care. Danielle also holds a Masters of International Studies (University of Sydney), a Bachelor of Arts majoring in Philosophy (University of Queensland) and postgraduate qualifications in Teenage and Young Adult Cancer Care (Coventry University, UK).



Assoc Prof Jane Turner

Associate Professor in the Discipline of Psychiatry at the University of Queensland

Jane Turner is Associate Professor in the Discipline of Psychiatry at the University of Queensland where she is course coordinator for the teaching of Psychiatry to students in the medical programme. She has worked clinically in oncology for 20 years, and has had extensive involvement in the development of evidence-based clinical practice guidelines, and health professional education and skills development.

Jane's research interests are promotion of wellness after completion of cancer treatment, the impact of advanced cancer on patients and families, and development of sustainable models of psycho-social care. She is investigator on a current study evaluating a structured intervention to assist people with high fear of cancer recurrence.



Dr Agnes Vitry

Senior Research Fellow at the University of South Australia

Agnes is a drug information pharmacist who has been working as a Senior Research Fellow at the University of South Australia for the last 10 years. She has a strong research interest in the quality use of medicines, quality of medicine information for health professionals and consumers, medicines policy and regulation.

In 2003, Agnes was diagnosed with breast cancer. It was the start of a survivorship journey where her professional interests and her health activist involvement helped her to understand the new challenges of living with cancer.

In 2009, she began to collaborate with Cancer Voices SA to encourage and support the recognition of the experiences and views of cancer patients, their carers and supporters and to promote their participation in all aspects of cancer health care and research.



Prof Patsy Yates

Professor of Nursing with the Institute of Health and Biomedical Innovation at Queensland University of Technology and Director for Queensland Health's Centre for Palliative Care Research and Education

Patsy is jointly appointed as Professor of Nursing with the Institute of Health and Biomedical Innovation at Queensland University of Technology, and Director for Queensland Health's Centre for Palliative Care Research and Education. She leads a range of research and service improvement programs focused on developing workforce capacity in cancer and palliative care, advancing the management of cancer related symptoms and treatment side effects, and strengthening the nexus between research, policy and practice in cancer care.

Patsy served as inaugural National Chairperson for the Cancer Nurses Society of Australia, and as a member of the Executive Committee and Council of the Clinical Oncological Society of Australia. She is currently chairperson for the Cancer Care Coordinator Interest Group of the Clinical Oncological Society of Australia.

Session Convenors

Each of the conference sessions is hosted by session convenors who bring to the topic a survivor and clinical or research perspective. We thank each individual for volunteering their time to take part in this important meeting.



Prof Jeff Dunn

Chief Executive Officer, Cancer Council Queensland

Professor Jeffrey Dunn is the Chief Executive Officer of The Cancer Council Queensland. He currently holds Professorial appointments with the Griffith University School of Public Health where he is also a member of the Behavioural Basis for Health Program; University of Queensland's Faculty of Social and Behavioural Science and James Cook University's Faculty of Public Health, Tropical Medicine and Rehabilitation Sciences. He has a central focus on the development and delivery of supportive care for cancer patients and is actively involved in research in this field.

Professor Dunn continues to serve on numerous advisory and planning committees to Cancer Australia and the International Union Against Cancer (UICC) and is on the Board of the International Psycho-oncology Society (IPOS). He currently serves, among other things, as the Chair of the Reach to Recovery International Breast Cancer Support Service and Chair of the Asia Pacific Cancer Society Training Grants Programme (APCASOT) as well as Chair of the Global Capacity Building Fund.

Professor Dunn has extensive experience in the development of supportive care programs for people with cancer both in Australia and internationally.



Prof Afaf Girgis

Executive Director, Translational Cancer Research Unit, Ingham Institute for Applied Medical Research, University of NSW

Please refer to the Invited Speakers section for a full biography.



Prof David Goldstein

NSW Cancer Survivors Centre, University of NSW

Conjoint Clinical Professor David Goldstein is a senior staff specialist in the Department of Medical Oncology at Prince of Wales Hospital in Sydney. He works in a clinical capacity seeing a wide range of malignancies but particularly specialises in Gastrointestinal malignancies.

He is immediate past President of the Clinical Oncologic Society of Australia. He is on the board of the Australasian Gastrointestinal Trials Group.

Prof Goldstein has been involved as a senior investigator in numerous therapeutic clinical trials. He has over 180 peer reviewed publications as well as book chapters and invited papers.

A major research interest has been psychosocial aspects of cancer care including the incidence and natural history of fatigue after adjuvant treatment, participating in studies of enhancing communication and studies in cross cultural aspects of cancer.

He is the adult program director of the NSW Cancer Survivors Centre at UNSW and supervises the program of care and research there.



Assoc Prof Michael Jefford

Deputy Head, Department of Medical Oncology, Peter MacCallum Cancer Centre; Senior Clinical Consultant at Cancer Council Victoria; Principal Fellow, University of Melbourne; Director, Australian Cancer Survivorship Centre

Please refer to the Invited Speakers section for a full biography.



Prof Bogda Koczwara

Head of Department, Medical Oncology, Flinders Medical Centre; ; Past President of the Clinical Oncology Society of Australia (COSA); Chair of the Education Program in Cancer Care (EPICC); a Director of Cancer Council of Australia and Cancer Council SA

Please refer to the Invited Speakers section for a full biography.



Julie Marker

Cancer Voices SA

Cancer Survivorship wasn't a term being used when I was first diagnosed with colon cancer in 2001, or after liver secondaries were found in 2005 and 2006.

After joining Cancer Voices SA in 2007, I now try to 'give back', using this experience to advocate, share information and help others.

Through all my treatment I searched for information to help me understand, make decisions and cope better with what we were going through. I discovered meditation helped me with the emotional roller-coaster of relapses, fear and uncertainty. Cycling helped too with physical and mental toughness, proving we're a lot stronger than we might think we are!



Prof Ross McKinnon

Director, Flinders Centre for Innovation in Cancer; Professor in Cancer Research, Flinders University

Professor Ross McKinnon is the Foundation Director of the Flinders Centre for Innovation in Cancer and Professor in Cancer Research at Flinders University.

He also holds Professorial appointments in the Faculty of Pharmacy and Pharmaceutical Sciences at Monash University and the School of Pharmacy and Medical Sciences at the University of South Australia. Professor McKinnon was previously the National Facilitator for the Translating Health Discovery into Clinical Applications Super Science Project and the Inaugural Director of the Sansom Institute at the University of South Australia.

A pharmacist by training, Professor McKinnon has a broad research agenda relating to the discovery, development and optimal use of medicines in cancer and related conditions and is an author of more than 350 published outputs. His research interests include a strong focus on the increased clinical uptake of pharmacogenomics and personalised medicine. He holds a number of patents with collaborators at UniSA related to chemoprevention for skin cancer and the identification of novel anti-inflammatory plant extracts and purified compounds based on indigenous knowledge.

Professor McKinnon holds a number of prominent positions nationally and internationally including Vice-President of the International Pharmaceutical Federation and Chair of the 2014 Pharmaceutical Sciences World Congress to be held in Melbourne. He was named as a member of the National Health and Medical Research Council Academy in 2010 and was awarded the Australasian Pharmaceutical Science Association's highest honour, the APSA Medal in 2011.



Ashleigh Moore

Cancer Voices SA

Ashleigh Moore is a 3-times cancer survivor and passionate volunteer advocate, having been diagnosed with advanced Stage 4 head and neck cancer in 2005 and advanced Stage 3 lung cancer in 2010 and again in 2012. Ashleigh has a young family and in 2012 was awarded an Order of Australia Medal for services to the community through Cancer Voices - acknowledgement of their critical work, as "the voice of the people for the people affected by cancer" at the highest level.

In 2006 Ashleigh became the founding chair of Cancer Voices SA, the statewide independent, 100% voluntary "grassroots" consumer advocacy group "raising a voice for those affected by cancer". He holds advisory positions on peak bodies that include the SA Health Minister's Complaints Advisory Council, Cancer Voices Australia, Cancer Australia and the SA Cancer Clinical Network. It is in these positions that Ashleigh has been able to make a 'real' difference to cancer treatment and care services for other Australians. Ashleigh was a speaker representing Australian cancer survivors at international events including the inaugural LIVE**STRONG** Global Cancer Summit, Ireland and the Go Public Global Cancer Leadership Forum, Canada in 2009.



Don Piro

Consumer Representative, SA Health Cancer Clinical Network

My name is Don Piro and I am a Consumer Representative on the SA Health - Cancer Clinical Network. I am Colorectal/metastatic cancer survivor and have enjoyed the last 4 years being cancer free.

I am an Accredited Mental Health Social Worker with a Private Clinical Practice in the Barossa Valley and I have had a long term interest in working with Men's Health and co-ordinating the local Prostate Cancer Support Group.



Meg Rynderman

Volunteer, Australian Cancer Survivorship Centre; Volunteer, Cancer Council Victoria's Cancer Connect program

Meg Rynderman is a survivor of recurrent Hodgkin disease & hormone positive Breast Cancer. Treatment for her disease has included radiotherapy, high dose chemotherapy, stem cell transplant, bi-lateral mastectomy & reconstruction. Meg volunteers her time at the Australian Cancer Survivorship Centre and also volunteers for Cancer Council Victoria's Cancer Connect program. Meg's 20-year cancer journey has instilled in her a passion that other cancer survivors should be offered more appropriate support and follow-up care than she experienced in her early years and that cancer should no longer be seen as a one-off incident, but rather a whole-of-life health issue. Meg is a Governor of Bialik College in Hawthorn and has a background in family business.



Danielle Tindle

PhD Candidate at the Institute of Health and Biomedical Innovation, Queensland University of Technology (QUT)

Please refer to the Invited Speakers section for a full biography.



Dr Agnes Vitry

Cancer Voices SA; Senior Research Fellow at the University of South Australia

Please refer to the Invited Speakers section for a full biography.

Program

Friday 1st February 2013

6.00 – 7.00pm Welcome Presentation Flinders Centre for Innovation in Cancer

Cancer Survivors – We can no longer ignore you

Prof Patti Ganz, UCLA, USA

Session sponsored by COSA

7.00 – 8.00pm **Networking Function**



Saturday 2nd February 2013

7.00am	Registration desk open	Function Lobby
8.00 - 8.15am	Official Welcome Prof Bogda Koczwara, Conference Convenor, Flinders Medical Convenor Ross McKinnon, Flinders Centre for Innovation in Cancer His Excellency Rear Admiral Kevin Scarce AC CSC RANR, Governo South Australia	
8.15 -10.15am	Session 1 - Survivorship: The Unanswered Questions Session Convenors: Prof Bogda Kocwara, Flinders Medical Centre and Julie Marker, Cancer Voices SA	Ballroom 1-2
	Developing a Cancer Survivorship Research Agenda: Where to sta Prof Patti Ganz, UCLA, USA	rt?
	Cancer Survivorship - A clinical perspective Prof Michael Jefford, Peter Mac Callum Cancer Centre	
	What matters to a survivor? Dr Agnes Vitry, Cancer Voices SA Clinical Oncological Society of Australia	
10.15 - 10.45am	Morning Tea	Function Lobby
	Sponsored by Roche	
10.45 - 12.30pm	Session 2 - Survivorship: The Challenges Session Convenors: Prof David Goldstein, NSW Cancer Survivors Centre, UNSW and Danielle Tindle, QUT	Ballroom 1-2
	Fear of Recurrence Assoc Prof Jane Turner, University of QLD	

Suffering in silence: The impact of cancer on caregivers

Prof Afaf Girgis, UNSW

Creating meaning: the experiences of young adult cancer survivors

Danielle Tindle, QUT

Late effects of cancer treatments

Dr Michael Rice AM, Women's & Children's Hospital

Morbidity and mortality in a hospital-based cohort of adult survivors of childhood cancer

Assoc Prof Richard Cohn, Sydney Children's Hospital

(Discussant: Prof David Goldstein)

12.30 - 1.15pm Lunch and Poster Presentation

Function Lobby and Ballroom 3

1.15 - 3.15pm

Session 3 - Survivorship: What Can Be Done

Ballroom 1-2

Session Convenors: Assoc Prof Michael Jefford, Peter MacCallum Cancer Survivorship Centre and Meg Rynderman, Volunteer at Peter MacCallum Cancer Centre

Examining the Effects of Exercise as a Treatment for Cancer: A Translational Approach

Dr Lee Jones, Duke University Medical Centre, USA

The Essence of Cancer Survival

Dr Craig Hassed, Monash University

Rehabiliatation after cancer

Assoc Prof Andrew Cole, HammondCare

Chronic disease management

Assoc Prof Sharon Lawn, Flinders University

Chronic conditions and lifestyle behaviour after cancer: the differences between 2,103 cancer cases and 4,185 age and gender matched controls

Prof Bogda Koczwara, Flinders Medical Centre

(Discussant: Assoc Prof Michael Jefford)

3.15 - 3.35pm

Afternoon Tea

Function Lobby

3.35 - 5.00pm

Session 4 - Bringing it all together to deliver care that works

Ballroom 1-2

Session Convenors: Prof Jeff Dunn, Cancer Council QLD and

Don Piro, Cancer Voices SA

Integrating Survivorship Care with Primary Care

Prof Jon Emery, University of WA

Cancer Survivorship Care Coordination

Prof Patsy Yates, QUT

 $How \ can \ e Health \ support \ self-directed \ and \ shared \ survivorship \ care?$

Prof Afaf Girgis, UNSW

The roles of Survivors in shaping care that works

Phil Kerslake, Lifepaths NZ

Session sponsored by Varian



5.00 - 6.00pm Social Networking Function

Horizon Cocktail Lounge

Sunday 3rd February 2013

7.00am	Registration desk open	Function Lobby
7.30am	Breakfast Function Lobby, N	Moseley, Colley Rooms
7.30 - 8.30am	Breakfast Session 1 Breast Cancer Survivorship: Bio-psychosocial Mechanisms of Fatigue & Cognitive complaints Prof Patti Ganz, UCLA, USA	Ballroom 1-2
	Breakfast Session 2 Exercise as treatment for cardiovascular impairments in cancer patients Dr Lee Jones, Duke University Medical Centre, USA	Moseley Rooms 1-3
	Breakfast Session 3 Cancer Conversations: a method for sharing Survivorship issues and perspectives Cancer Voices SA	Colley Rooms 1-2
8.30 - 10.30am	Session 5 - Survivorship research: oral presentations Session Convenors: Prof Patti Ganz, UCLA, USA and Prof Afaf Girgis, UNSW	Ballroom 1-2
	Sleep disturbance is associated with post cancer fatigue - find from a prospective cohort study Dr Barbara Bennett, UNSW	lings
	Development of an optimised, multi-disciplinary intervention for chronic fatigue states Carolina Sandler, UNSW	
	(Discussant: Prof Patti Ganz for abstracts 3 and 4)	
	When the 'all clear' is not so clear: Families' coping with fear childhood cancer recurrence Jordana McLoone, UNSW	of

Unmet needs in CALD (Chinese, Greek and Arabic speaking) first generation immigrant cancer survivors

Prof Phyllis Butow, PoCoG, Sydney

The needs of cancer survivors and their comfort levels for discussing them with GPs and oncologists – results from a cross-sectional survey **Dr Kate Webber, UNSW**

(Discussant: Prof Afaf Girgis for abstracts 5-7)

Investigating patient preferences for breast cancer follow-up - a discrete choice experiment

Dr Jackie Street, University of Adelaide

(Discussants: Prof Patricia Ganz and Prof Afaf Girgis for abstract 8)

9.00- 9.45am Session 6 - Survivors Informing Survivorship

rvivors Informing Survivorship Moseley Rooms 1-3
rming Survivorship

VAR**İ**AN

Survivors Informing Survivorship **Devon McGoldrick, LIVESTRONG**

10.30 - 11.00am Morning Tea Function Lobby

Sponsored by Varian

Ballroom 1-2

11.00 - 1.00pm Session 7 - Where To From Here?

Session Convenors: Professor Ross McKinnon, Flinders Centre for Innovation in Cancer and Ashleigh Moore, Cancer Voices SA

Essential Elements of Survivorship Care

Dr Sarah Arvey, LIVESTRONG

Survivorship now and into the future Ms Sue Sinclair, Cancer Australia

 ${\it Insurance, Discrimination \ and \ the \ Law-Protecting \ rights \ of}$

Cancer Survivors

Sondra Davoren, McCabe Centre, Cancer Council VIC

Survivorship: Where to from here?

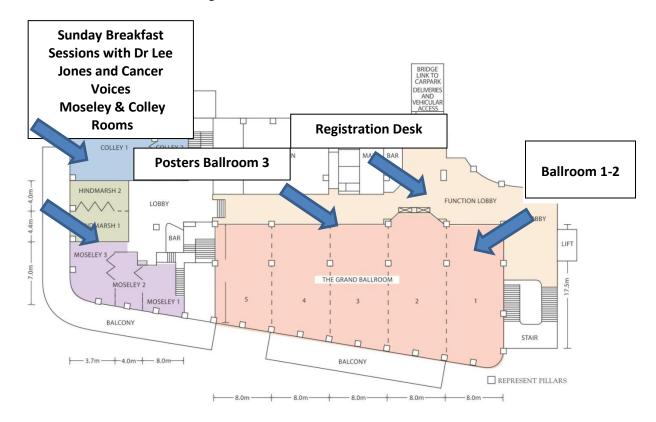
Prof Bogda Koczwara, Flinders Medical Centre

1.00pm Conference Close Ballroom 1-2

Delegate Information

Venue: Stamford Grand Adelaide, First Floor

The Stamford Grand Adelaide Hotel at Glenelg, one of Adelaide's premier luxury resorts is a 10 minute drive from the airport and a 20 minute drive from Adelaide's CBD, and is located right on the beach in the popular seaside suburb of Glenelg. Stamford Grand luxury resort is accessed via Jetty Road's vibrant retail 7-day trading strip. If you have any questions during your stay, don't hesitate to ask at reception or see ASN Events staff at the Conference registration desk.



Registration Desk

The registration desk will be located in the Function Lobby on the first level and will be open from Saturday 7.00am to 5.00pm and Sunday 7.00am to 1.00pm.

Session Rooms

All Saturday sessions will be held in Ballroom 1 and 2. Breaks will be held in the Function Lobby and posters will be held in the Ballroom 3. The Sunday Breakfast Session with Prof Patti Ganz will be held in Ballroom 1 and 2 and the Sunday Breakfast Sessions with Dr Lee Jones and Cancer Voices will be held in the Moseley and Colley rooms. Please refer to above map for reference.

What is included in your full registration

- Access to all sessions
- Conference satchel with delegate handbook
- Friday public lecture
- Sunday breakfast session (cont. next page)
- Sunday Breakfast, Morning teas, afternoon tea and lunches
- The networking function and welcome function

Name Tags

Delegates are required to wear their name tags to all sessions.

Friday Public Lecture

The Friday public lecture is being held on Friday 1st February at Flinders Centre for Innovation in Cancer on Level 1 in the Function Centre from 6.00pm to 7.00pm. Prof Patricia Ganz will be presenting on the topic of "*Cancer Survivors: We Can No Longer Ignore You*". Car parking is free from 6pm and is highlighted on the map in yellow. Please refer to below map for reference.

Level 1 Function Centre Flinders Centre for Innovation in Cancer Flinders Drive, Bedford Park SA 5042



Social Functions

Networking Function is being held on Friday 1st February at Flinders Centre for Innovation in Cancer from 7.00pm to 8.00pm after the Friday public lecture with Prof Patricia Ganz. Drinks and finger food will be served.

Welcome Function is being held on Saturday 2nd February at the Stamford Grand Adelaide in the Horizons Cocktail Lounge, from 5.00pm to 6.00pm. The Welcome Function is included for all FULL delegates (not including General public Sunday only registrations). Drinks and canapés will be served.

Internet access at the Conference

Wireless internet is available free of charge for delegates in the conference area. To connect to the wireless

internet please use these login details:

Username: ASNEvents Password: 1nternet

Instructions for Oral Presenters

Please upload your presentation onto the computer in the ballroom either on the morning of the day you are presenting, or in the break prior to your session commencing. The standard AV set up for all presentations will be data projection using MS PowerPoint. As per instructions already supplied, you will need to have your talk supplied on a USB thumb drive. If you wish to use your Macintosh please ensure you bring the appropriate projector converter cables. A technian will be there to assist you.

Instructions for Poster Presenters

The poster session is being held on Saturday 2nd February with formal viewing time across lunchtime in Ballroom 3 from **12.50-1.15pm**. You are required to stand by your poster during this time and can mount your poster on Saturday from morning tea time. The maximum size provided is 1m wide by 1m high. The approved way of attaching your abstract is with Velcro – which is available at the registration desk. Please remove posters by **5.00pm** Saturday evening.

Mobile Phones

Please ensure your mobile is turned off or to silent during the sessions.

Hotel Check Outs

You are required to check out of your room before 11am. The hotel reception has facilities to store your luggage. Late departures up to 6.00pm are available subject to availability at an applicable hourly fee. Beyond 6.00pm the full daily rate will be applicable.

Insurance

The hosts and organisers are not responsible for personal accidents, any travel costs, or the loss of private property and will not be liable for any claims. Delegates requiring insurance should make their own arrangements.

Disclaimer

The hosts and organisers are not responsible for, or represented by, the opinions expressed by the participants in either the sessions or their written abstracts.

Smoking

Smoking is not permitted in the venue.

Local Information

Glenelg Attractions

Located only 10km from the heart of Adelaide City, Glenelg is a charming seaside resort set on the long sandy white shores of Holdfast Bay. Glenelg has some fantastic activities and sites to see, some places to visit include;

Jetty Road: Jetty Road is the shopping and dining hub for beachside Glenelg, one of Adelaide's most popular beaches. The kilometre-long strip offers al fresco dining. There are fabulous restaurants, including the award-winning Goodlife Organic Pizza, and plenty of good coffee and delicious ice cream. You'll find fashion houses here, gifts, music, books and more. Most stores and services are open seven days a week. On weekends, the area becomes even more vibrant, with the addition of street markets, adventure activities and entertainers.

Holdfast Shores Marina: Holdfast Shores Marina provides stylish dining and shopping at the water's edge. It offers beautiful seaside and marina views and sunset vistas of great beauty. This is also the home of Temptation Sailing's dolphin cruises, based at the marina. You can also enjoy a stroll around the Holdfast Shores Marina Promenade, where you will find contemporary cuisine many featuring South Australia's finest seafood including King George Whiting, world renowned Coffin Bay Oysters and Spencer Gulf Prawns.

Museums and History: Learn about the early days of Glenelg at the Bay Discovery Centre which tracks the history of Holdfast Bay – its early settlement, federation days and evolving seaside lifestyle.

Arts and Culture: There are many galleries to visit while in Glenelg, including the Glenelg Art Gallery, The Little Shop & Gallery, and Glenelg Fine Art Gallery.

Local Attractions

Glenelg Night Life

Dublin Hotel: Moseley Square **The Holdfast Hotel:** 83 Brighton Road **The Pier Bar:** 18 Holdfast Promenade **Chalkers 8 Ball Centre:** 112 Jetty Road

Glenelg Restaurants

The Holdfast Hotel: 83 Brighton Road
The Grand Bar: At The Stamford Grand
Glenelg Pier Hotel: 18 Holdfast Promenade
Sammys on the Marina: 12 Holdfast Promenade
Glenelg Surf Life Saving Club: 20 Holdfast Promenade
The Oyster Bar: Shop 10/12 Holdfast Promenade

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Surrounding Attractions

Adelaide City

A short 25 minute tram trip departing from the centre of Glenelg - Moseley Square, takes you into Victoria Square in the heart of Adelaide. A major feature of Adelaide's unique city design is the Park Lands which surrounds the city and are home to a range of historical and heritage-listed locations. For those who wish to shop, Rundle Mall has more than 600 retail stores, three major department stores and 15 arcades. Paved and pedestrian friendly, there are also outdoor cafes and bars to rest your tired but happy shopping feet.

Barossa Valley

Just over an hour drive from Glenelg is the Barrossa Valley Wine Region. The Barossa has cool summers and rainy winters which make it perfectly suited for red wine production, particularly Shiraz and richly flavoured Cabernet. The fertile soil of the Barossa is home to some of the world's most lauded vineyards. For more information on the region, visit: www.barossa.com

Kangaroo Island

Minutes from the mainland, but a million miles away, Kangaroo Island is a sanctuary for wildlife and natural, rugged beauty. It is the perfect place to disconnect from the world and reconnect with what and who is truly important to you. Escape to an island you will never want to leave.

For more information on kangaroo Island, visit: www.southaustralia.com/regions/kangaroo-island.aspx

Port Adelaide

At Port Adelaide, find evocative seafaring history, a waterside heritage precinct, a colourful pub scene and the world's only inner-city dolphins – only a half an hour drive from Glenelg. Take a walk along the docks and through the 'old Port' to experience the ambience and observe some of the finest colonial and Victorian buildings in Australia.

Poster Listings

Gabrielle Asprey

Recruitment of cancer survivors and carers to a face-to-face lifestyle intervention: balancing methodological considerations and logistical challenges *abs# 35*

Lisa Beatty

Developing and Evaluating an Online Self-Help Program for Cancer Distress: A Randomised Pilot Trial abs# 36

Barbara Bennett

What do patients really mean when they complain of fatigue after treatment? – development of a semi-structured clinical interview to reliably identify post cancer fatigue *abs# 37*

Colleen Berryman

Melanoma shared care, a tripartite approach for survival. The patient, their GP and their specialist - A survivorship project. *abs# 38*

Amanda Bobridge

An exploration of the support care needs of men who have undergone prostate cancer treatment and their partner *abs# 39*

Kim Brauer

Living Well: Delivering Survivorship Hospital Programmes abs# 40

Jo Anne Canaria

A systematic review of factors which breast cancer patients associate with their diagnosis abs# 41

Adrienne Cavini

A Supportive Care Service for Oncology Patients and their Carers at Northern Health. A. Cavini. The Northern Hospital, Epping, Melbourne, Victoria. Australia *abs# 42*

Tina Cheng

Physical activity levels and barriers and facilitators towards exercise for Haematopoietic Stem Cell Transplant (HSCT) survivors *abs# 43*

Linda Denehy

Lower levels of depression, anxiety, distress, fatigue and symptoms are associated with higher levels of physical activity in non-small cell lung cancer *abs# 44*

Jaklin Eliott

Surviving cancer: the psycho-social impact on the family abs# 45

Marie Ennis

Analysing the blog narratives of a cohort of breast cancer survivors provides a new framework for a richer understanding of the lived experience of cancer survivorship *abs# 46*

Priscilla Gates

The development and implementation of survivorship care plans across the Peter MacCallum Cancer Centre. *abs# 47*

Priscilla Gates

Development of a nurse-led survivorship intervention for long term survivors of Hodgkin lymphoma. abs# 48

Stacey George

Return to driving after a diagnosis of brain tumour abs# 49

Lucy Holland

Primary care in survivorship: an exploration of the relationship between young people diagnosed with cancer and general practitioners *abs# 50*

Paula Howell

Implementing a self-management oriented survivorship intervention abs# 51

Justin Keogh

Perceptions on the role of physical activity in maintaining quality of life in men with prostate cancer: influence of androgen deprivation therapy. *abs# 52*

Nicole Kinnane

Two models of group based education for cancer survivors abs# 53

Kelvin Leung

Resilience: What Influences Treatment Outcomes for Patients Treated with Early Stage Cancer? abs# 54

Donna Lever

The challenges of developing a nurse led survivorship model of care – Initiating a service within a regional and a rural domain. abs# 55

Catherine Mackenzie

Promoting physical activity to breast cancer survivors - what may work? abs# 56

Michelle McKimmie

Engaging with Survivors – A Regional Participation Strategy abs# 57

Michelle McKimmie

Addressing the needs of survivors with lymphoedema - a transferrable model for providing lymphoedema services in a regional context *abs# 58*

Helen McLauchlan

Development of a Survivorship Project – 'Positive Change for Life' abs# 59

Annie Miller

Utilising life changing experiences of cancer survivors and care-givers to deliver community based psychosocial program *abs# 60*

Annie Miller

When treatment finishes – Opportunities for a multidisciplinary approach to service and support delivery for cancer survivors *abs# 61*

Annie Miller

Cancer Survivorship: Employment and Return to Work – An Australian report abs# 62

Janine Mitchell

The patient experience of melanoma follow-up: An online survey abs# 63

David Mizrahi

An exercise physiologist derived exercise intervention for women with recurrent ovarian cancer abs# 64

Rebecca Nund

Patients' perspective of dysphagia in the survivorship phase of head and neck cancer abs# 65

Clare Oakes

"Building yourself to better cope": a qualitative case study of a cycling team led by cancer survivors abs# 66

Alicia Olsen

Fatigue, Physical Activity, and Autonomic Nervous System Function in Breast Cancer Survivors: A Pilot Study abs# 67

Michael Osborn

Improving survivorship outcomes in adolescents and young adults with cancer: the development of a national survivorship care process abs# 68

Anna Petterson

Living with, through and beyond cancer: Giving survivors the skills, support and confidence to take control of their lives *abs# 69*

Gillian Prue

Development of a self-management psychosocial intervention for men with prostate cancer and their partners: lessons learnt from the 'real world' abs# 70

Carolina Sandler

A randomised controlled trial of an optimized multidisciplinary intervention for post-cancer fatigue – TOPS Trial. *abs# 71*

Karen Saxty

Influencing diet and lifestyle changes in a high risk cohort diagnosed with benign colorectal neoplasia *abs#* 72

Emily Schneider

Moving on from Allogeneic Stem Cell Transplants? abs# 73

Kate Schofield

Implementing a survivorship service for patients with head and neck cancers. Are some cancer survivors more forgotten than others? *abs# 74*

Maryanne Skarparis

Returning to work after treatment: An important survivorship issue. abs# 75

Maryanne Skarparis

Survivorship research in Haematology: Findings from Queensland. abs# 76

Jackie Street

How good is the guidance for cutaneous melanoma follow- up? A systematic review of clinical practice guidelines *abs# 77*

Kate Thompson

Survivorship connections: the development of a model of survivorship care for young people diagnosed with cancer *abs# 78*

Samantha Van Staalduinen

Through their eyes: understanding the survivorship needs and experience of young people with cancer abs# 79

Kate Webber

Early experience of implementation of a triage model for survivorship care at the NSW Cancer Survivors Centre abs# 80

Fiona Young

The ovary and cancer treatment -- the future of fertility preservation abs#81

Abstracts

Printed abstracts reflect the views of the authors

Orals

1 - Developing a Cancer Survivorship Research Agenda: Where to Start?

Patricia A. Ganz¹

1. UCLA Jonsson Comprehensve Cancer Center, Los Angeles, CA, United States

The dramatic gains in survival for cancer patients has challenged the medical and scientific community to think about the long-term and late effects of cancer treatments and how they might be mitigated. During that latter half of the 20th century, much effort was focused on increasing survival, through earlier diagnosis and improvements in treatment. Little thought was given to the post-treatment sequelae of cancer treatments and their impacts on the lives of survivors. Studies in long-term survivors of childhood cancer have led the way in helping us to conceptualize how to frame the research agenda. In adult survivors of childhood cancer we see accelerated aging, premature failing of organ systems, functional declines, and second malignancies. Will this be the fate of long-term adult cancer survivors?

The challenge today is to construct a survivorship research agenda for adult cancer survivors, who span young adulthood to the oldest old, and to determine what are the most pressing medical, functional, and psychosocial issues that need our attention. We have limited understanding of the late effects of specific cancer treatments in adults, with some exceptions, and how they interact with normal age related organ changes e.g., anthracycline toxicity and atherosclerotic heart disease; cognitive effects of cancer treatment and age-related cognitive decline. Preventing the late effects of treatments, particularly for younger adults who can expect extended survival after cancer treatments, may be increasingly important. Management of persistent symptoms (e.g., fatigue, insomnia, neuropathy, depression, pain, cognitive changes) can best be addressed through development of treatment strategies based on an understanding their biological mechanisms. No single institution can take on this challenge; global effort is required. This will include basic and clinical research, as well as implementation and evaluation of new models of care.

2 - Cancer Survivorshipo - A Clinical Perspective

Michael Jefford¹

1. Peter MacCallum Cancer Centre, East Melbourne, Vic, Australia

Increasing cancer incidence together with improved survival rates are contributing to the growing number of cancer survivors. Survivors may encounter a range of potential effects as a result of the cancer and its treatment. Traditionally, follow up has been undertaken by oncology specialists, generally medical staff. The major focus has been on detection of cancer recurrence; however the efficacy of such strategies is questionable. Current follow up frequently fails to identify or adequately address many survivors' concerns. After care needs to be planned to enable better outcomes for survivors, whilst using scarce health care resources efficiently.

A number of principles have been established to facilitate improved care for those living with and beyond cancer. These include the use of risk stratified pathways of care, treatment summaries and care plans, information and education to enable self management, rapid re-access to specialist care, remote monitoring and effective care coordination. This presentation will consider the above issues and discuss a number of examples of redesigned models of care.

3 - What matters to survivors? From awareness to advocacy

Agnes Vitry¹, Julie Marker¹

1. Cancer Voices SA, Adelaide, Australia

Cancer survivorship may have a myriad of meanings for different individuals and appear as a reductionist approach with an unwanted focus on the disease to some. However, it is a useful concept for consumer advocates, heath care providers and researchers to examine the ongoing and long-term needs of people who had cancer, and to develop the best services for a patient-centered, evidence-based, integrated health care system (as well as society in general).

Dramatic improvements in cancer treatments have led to greater chances of survival and an ever increasing number of cancer survivors. Despite this, a diagnosis of cancer still focuses individuals to think about death and then fear of recurrence. This diagnosis as well as the consequences of cancer treatments, whether they are physical or psychological, may have strong influences on the ways that people live after the cancer diagnosis in terms of their relationships with family and friends or work opportunities. This may also lead to fundamental changes in the individuals' own sense of identity because of the multiples losses (including the loss of power), grief and the reappraisal of their own values and priorities.

The diversity of cancer survivor needs, depending on the type and the stage of cancer and the socio-economic conditions, requires an holistic approach that integrates individualised and coordinated medical and psychosocial care with special attention to certain groups: medical care (with appropriate follow-up to identify and manage possible recurrences and adverse effects of therapies), psycho-social care that involves all stakeholders (e.g. to facilitate return to work, to offer a diversity of support options for individuals and their families), and to respond to the specific needs of groups most at risk of poorer survivorship such as the Aboriginal and Torres Strait Islanders population, children, rural inhabitants, and the cultural and linguistically diverse populations.

4 - Fear of Recurrence

Jane Turner¹

1. University of Queensland, Herston, QLD, Australia

Completion of treatment for cancer intuitively promises relief and hope. However between 40% and 70% of people struggle with concerns that the cancer could recur, leading to reduced quality of life for patients and their families, and increased attendance for health checks and requests for investigations. In addition to the obvious cost for health services, it is apparent that repeated investigations incur potential risks and potentially compound anxiety and fear for the individual. Unfortunately, this disabling problem (which is known as Fear of Cancer Recurrence) has received little research attention until recently, and there is limited evidence regarding appropriate interventions. This presentation will provide an overview of a novel conceptualisation of Fear of Cancer Recurrence, describing the pathway to the development of the problem and describe a study evaluating the impact of a structured manual-based therapy delivered over 5 sessions by a trained psychologist or psychiatrist. Pilot data demonstrating the acceptability of the intervention and preliminary evidence of benefit will also be presented.

5 - Suffering in silence: The impact of cancer on caregivers

Afaf Girgis¹, Sylvie Lambert¹

1. Ingham Institute for Applied Medical Research, UNSW, Liverpool, NSW, Australia

Cancer is one of the most common health conditions in receipt of informal caregiving, with the majority of caregivers reporting taking on the role of caring because of the family responsibility and there being little choice or no one else to provide the care. For some, caregiving can extend for several years and become equivalent to a full time job, with significant consequent health, psychosocial and financial burdens. Having a better understanding of the critical and broad roles that caregivers play in the oncology setting and the impact of these on their health and wellbeing may assist health care professionals in supporting caregivers with these tasks and targeting services and interventions towards those most in need. This is particularly important in light of the predicted shortfall in the number in caregivers and especially as caregivers are increasingly replacing skilled health workers in the delivery of unfamiliar complex cancer care at home. This presentation will include Australian research examining the psychosocial and financial impact of caring for someone with cancer over the first five years post-diagnosis.

6 - Creating meaning: the experiences of young adult cancer survivors

Danielle Tindle¹

1. Institute of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, QLD, Australia

Cancer in the adolescent and young adult (AYA) population is uncommon; however a diagnosis at this age may significantly impact a young person's life experiences during and after treatment. Over the past few decades, improvements have been made in the diagnosis and treatment of common AYA cancers resulting in an increase in the number of young people surviving their diseases. However, little is known about the ongoing effects of cancer and treatment on a young person's life beyond the initial treatment phase. To address some critical gaps in knowledge about this growing population, this qualitative study aims to understand the phenomenon of cancer survivorship as experienced in the everyday life worlds of young adults who were diagnosed between the ages of 15 and 29 years, and are at least two years post treatment. It does so by hermeneutically exploring the cultural, temporal and social contexts that frame young survivors' experiences.

The research focuses on three countries: Australia, England and America, in order to capture a wide variety of perspectives from different healthcare and cultural settings. A sample of 45 participants will be interviewed (15 from each country). This presentation will discuss some of the preliminary findings from data collected in Australia and England. Specifically, it explores the temporal perspectives of young cancer survivors in a state of uncertainty about the future. When cancer threatens the horizon of the possible, time orientation is revised and this significantly influences how young people create meaning in life.

7 - Late effects of cancer treatment in childhood

Michael Rice1

1. Womens and Childrens Hospital, North Adelaide, SA, Australia

Cure rates for cancer in childhood have improved substantially in the past 50 years. Today, 80% of children with acute lymphoblastic leukaemia (ALL) survive, similar results occur in non-Hodgkin lymphoma, 90% of children with Wilms'tumor are cured and improvement has occurred in various sarcomas.

But for some survivors, cure comes at a price, best illustrated by the evolution of treatment for ALL where cure did not occur until measures were taken to prevent leukaemic involvement of the central nervous system (CNS). It was subsequently recognised that many survivors exhibited neuro-cognitive problems which required remedial education support. Further studies were then undertaken to determine whether effective CNS prophylaxis could be achieved without long-term toxicity. Another example of serious late adverse effects occurred in South Australia where more patients treated for Hodgkin lymphoma have died from treatment complications than from progressive disease.

All modalities of cancer treatment can cause late adverse effects despite careful monitoring during the acute treatment phase. Thus some surgical procedures can produce long-term functional problems which have resulted in a re-appraisal of certain surgical interventions. Radiation therapy causes abnormalities in soft tissue and bone development, various endocrinopathies, and increases the risk of occurrence second tumors. In the past 20 years, chemotherapy has been progressively intensified and while this has clearly improved survival, it can also cause late organ dysfunction, infertility and secondary leukaemia. The new concept of "risk-adapted therapy" promotes less intensive treatment for those with "low-risk disease" with the aim of minimising late effects without compromising the chance of cure. Finally, long-term follow-up of childhood cancer survivors is generally considered to be necessary, but how is it best conducted – in primary care settings or in hospital-based late-effects clinics, and should such follow-up be physician or nurse led? Discussion of this topic continues.

8 - Morbidity and mortality in a hospital based cohort of adult survivors of childhood cancer

Richard J Cohn¹ ² ³ ⁴,Lesley Ashton¹ ⁴, Carmon E Wilson¹ ⁴, Karen Johnston² ³, Kristin Neville¹ ², Claire E Wakefield¹ ²

- 1. School of Women's and Children's Health, University of New South Wales, Kensington, New South Wales, Australia
- 2. Centre for Children's Cancer and Blood Disorders (CCCBD), Sydney Children's Hospital, Randwick, New South Wales, Australia
- 3. New South Wales Cancer Survivor Centre, University of New South Wales, Kensington, New South Wales, Australia
- 4. Children's Cancer Institute Australia, Lowy Cancer Research Centre, Kensington, New South Wales, Australia

Backgound: Establishing representative cohorts of individuals treated for childhood cancer is vital to enable characterisation of the long-term effects of cancer therapies, which often only become evident many years after treatment, with growth, and the normal aging process.

Method: Of 1198 patients resident in NSW who were treated at Sydney Children's Hospital between 1972 and 1999, and followed for at least 5 years, 1156 were shown to be alive by cross-match with the National Death Index. 70.1% were successfully traced by linkage to public data-bases or their attendance at a Long-term Follow-up Clinic. Further data was obtained from medical records, the NSW Cancer Registry, patient self-report and prospective studies.

Results: Standardised mortality and incidence ratios were 7.46 and 4.98 times higher among survivors relative to the NSW population. Causes of death included primary cancer recurrence (55%), second cancers (12%), and treatment-related complications (17%). Sixty-two percent of survivors reported at least 1 chronic late effect and 27% reported.

Studies on the survivors have guided follow-up and have prompted changes to care of new patients. Avoidance of mantle irradiation for Hodgkin's Lymphoma has translated into significantly fewer second malignancies. Long-term morbidities in stage 4 neuroblastoma patients conditioned for autograft with TBI have resulted in protocols without TBI. Knowing that 10/12 females treated with 24Gy cranial radiation failed to lactate after delivery, assists in counselling new mothers. 11% pubertal and 11% adult survivors studied had Impaired Glucose Tolerance /Diabetes Mellitus (vs 0 and 4.9% controls, p<0.001), highlighting the importance of follow-up and lifestyle education. Documentation of persisting psychological distress in survivors, parents and siblings many years after treatment, supports intervention in all family members to prevent ongoing psychological morbidity.

Conclusions: Adult survivors of childhood cancer experience life-threatening and life-altering late effects. Knowledge of late-effects informs risk-based follow-up and modification of new treatment protocols.

9- Examining the Effects of Exercise as a Treatment for Cardiovascular and Oncologic Outcomes in Cancer Patients

Lee Jones¹

1. Duke Cancer Institute, Durham, NC, United States

In this presentation, Dr. Jones will provide a comprehensive overview of his research program focusing on the cardiovascular / functional impact of cancer therapy, and efficacy of structured exercise training to prevent and/or treat dysfunction. In the second part of his presentation, he will discuss the evidence supporting the association between exercise behaviour and prognosis following a cancer diagnosis. A major focus of the presentation will be on the role of exercise to alter the host-tumor interaction. Specifically, he will discuss the potential biologic and molecular mechanisms underlying the effects of exercise on prognosis drawing on evidence from clinical and preclinical studies. The talk will conclude with future directions of the field as well as an overview of ongoing trials in this rapidly emerging field of research.

10 – The Essence of Surviving Cancer

Craig Hassed¹

1. Monash University, Notting Hill, VIC, Australia

Oftentimes people living with cancer feel that they are very passive participants in their own healthcare and believe there is little they can do to improve their wellbeing and outcome in the face of dealing with a cancer diagnosis and related treatments. Essence is an acronym that stands for Education, Stress management (mindfulness-based), Spirituality, Exercise, Nutrition, Connectedness and Environment. This presentation will explore the Essence model and how it can enable people living with cancer to foster better wellbeing, coping and cancer outcomes.

11 - Cancer Rehabilitation - much can be done to help cancer survivors with physical disability

Andrew M Cole¹

1. HammondCare, Sydney, NSW, Australia

Survivors of cancers involving neurological and musculoskeletal systems may be left with very significant physical and functional daily living problems at the conclusion of their cancer treatment.

Individual professionals working in rehabilitation teams can bring their skills to bear, to improve these cancer survivors' ability to return to living as independently as possible in ordinary daily life. The outcomes of rehabilitation can be measured with standard assessment tools, including Barthel and Functional Independence Measures (FIMTM), which are being built into standard subacute casemix funding algorithms in Australia.

There are no randomised control studies of rehabilitation and restorative care provided to survivors of neurological and musculoskeletal cancers. Observational studies however provide level III evidence for the efficacy of rehabilitation programs in improving residual functional disability left in people after acute treatment of brain, spinal and bony tumours. Indeed, survivors with disability arising from these tumours can expect a response to multidisciplinary rehabilitation therapy that is entirely comparable with that seen in individuals with "benign" lesions in similar anatomical locations, as in strokes, fractures or brain or spinal trauma, for example.

One problem requiring particular attention is in restoring social mobility and participation, for return to safe driving of a motor vehicle after treatment of a brain tumour. As we all know, learning independent and safe driving is an important social rite of passage into adult life for most people, especially here in Australia, and restoration of this ability is a central concern for most brain tumour survivors. The multi-disciplinary program usually involves medical, visual and psychological review as well as occupational therapy assessment of the survivor's skills and abilities in offroad and on-road settings.

In summary, there is absolutely no place for therapeutic nihilism in the presence of physical disability in survivors of neurological and bony tumours, any more than there is in the presence of similar disability due to "benign" illnesses.

12 – What can cancer care learn from the chronic condition management field?

Sharon Lawn¹

1. Flinders University, Adelaide, SA, Australia

The concepts of chronic condition self-management by people with long-term health conditions, and chronic condition self-management support from formal health care providers and the person's informal support networks, are well established for long-term diseases. With growing rates of cancer survivorship, it is timely to consider how adverse yet unavoidable impacts of cancer treatments and the experience of cancer can be managed to minimise long-term adverse impacts on the person's health and wellbeing, and the development of other chronic conditions. Therefore, it is timely to consider what cancer care can learn from these concepts given that, for many oncologists and other cancer care professionals, looking at cancer as a chronic illness is a novel concept. This is also important for those working in the chronic condition management area, as more cancer survivors are likely to approach these services for ongoing support. This presentation will explore a range of chronic condition self-management support principles and approaches, applied to cancer survivors' care and self-care. Lifestyle interventions (diet and exercise), complementary therapies, and rehabilitation, focused on person-centred, motivational and goal-focused support may prevent and alleviate the development of further comorbid chronic health problems and disability for cancer survivors. The feasibility and acceptability of these approaches, applied to cancer survivors, will be discussed, drawing examples from recent collaborations at Flinders University between chronic condition and cancer care researchers.

13 – Chronic conditions and lifestyle behaviour after cancer: the differences between 2,103 cancer cases and 4,185 age and gender matched controls

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Background: There is growing evidence suggesting that weight gain and inactivity after cancer are associated with poorer cancer outcomes and may predispose individuals to chronic conditions but the prevalence of these among cancer survivors is not well defined. Objectives: To determine whether those diagnosed with cancer have a greater prevalence of chronic conditions and whether their lifestyle behaviours differ from cancer free controls.

Methods: Cross-sectional self-reported data were obtained from adults aged >18 years conducted as part of the South Australian Monitoring and Surveillance System between January 2010 and March 2012. For each cancer case, approximately two age and gender matched individuals who did not report a cancer diagnosis were randomly selected from the same data source to represent a control population.

Outcome measures: Chronic conditions including cardiovascular disease, hypertension, hyperlipidaemia, diabetes, and osteoporosis, lifestyle behaviours (diet, physical activity and smoking), obesity, psychological distress and self-reported health. Between-group differences were assessed using McNemar's test.

Results: 6,288 respondents (2,103 cases, 4,185 controls) were included in the analyses. Cancer cases had a higher prevalence than controls for all chronic conditions: cardiovascular disease 22.1% vs 18.4%, p=0.001; hypertension 53.3% vs 50%, p=0.015; hyperlipidaemia 47.8% vs 41.8%, p<0.001; diabetes 16% vs 13%, p=0.006; osteoporosis 13% vs 11%, p=0.013. There were no differences in lifestyle behaviours or obesity. Cancer cases were more likely to score "very high" psychological distress (2.9% vs 1.7%, p=0.005) and "poor-fair" self-rated health (33.5% vs 22.9%, p<0.001).

Conclusion: Despite similar lifestyle habits and levels of obesity the prevalence of chronic conditions was significantly higher amongst those with history of cancer compared to controls. Further research is warranted to explain this increased predisposition to chronic conditions and to determine the feasibility and the role of lifestyle interventions in their management for cancer patients and survivors.

14 – Integrating Survivorship Care with Primary Care

Jon Emery

1. University of Western Australia, Crawley, WA, Australia

Improvements in early detection and treatment have led to substantial improvements in cancer survival rates in Australia. Long term cancer survivors have unique health needs as a result of living through cancer and its treatment. The late-effects of chemotherapy and radiotherapy are increasingly well documented, including fatigue, chronic pain,

infertility, anxiety and depression. Many survivors also face the risk of recurrence and secondary neoplasms. The growing number of cancer survivors makes long term hospital-based follow-up increasingly unsustainable for publically funded healthcare systems. Consequently, alternative models of follow-up that recognise an important role for primary care have been examined. The key elements of generalist practice include accessibility, holistic patient-centred, team-based care, care coordination, continuity and management of complex multiple problems. Primary care is therefore potentially better suited than current models of hospital follow-up to meet the complex needs of cancer survivors.

This presentation will discuss the existing evidence identified through a Rapid Review conducted by PC4 about the role of primary care in cancer survivorship and follow-up. It will also discuss the ProCare Trial which is currently testing a model of shared care for prostate cancer. Novel elements of the ProCare Trial intervention include a prostate cancer survivorship care plan, and applying the Distress Thermometer and screening for unmet need in primary care. The issue of risk-stratification will also be discussed as a future approach to developing appropriate and cost-effective survivorship care in Australia.

15 – Cancer Survivorship Care Coordination: Opportunities and Challenges

Patsy Yates¹

1. Queensland University of Technology, Kelvin Grove, QLD, Australia

Effective coordination of cancer services continues to present many challenges. In Australia, a range of system, team and health professional led strategies have been implemented to improve cancer care coordination. Much of the focus of these interventions has been on improving treatment related experiences of people affected by cancer, with less attention being given to how best to coordinate care for cancer survivors. Emerging evidence regarding effective care coordination for cancer survivors reflects that strategies and approaches will need to take a more population and systems based approach to cancer care coordination, and incorporate a substantial focus on supported self-management. Identifying and evaluating outcomes from care coordination interventions continues to be a priority across the entire cancer experience.

16 – How can eHealth support self-directed and shared survivorship care?

Afaf Girgis¹

1. Ingham Institute for Applied Medical Research, UNSW, Liverpool, NSW, Australia

Colorectal cancer (CRC) is the second most common cancer in Australia; third in terms of highest number of years lost due to disease, disability or injury. People diagnosed with CRC report physical, psychosocial and financial needs, which if unmet, adversely impact on quality of life and well-being. There is currently no systematic assessment promoting timely response to these needs. Furthermore, hospital-based follow-up care for cancer survivors has resulted in fragmented, sub-optimal care and under-recognition of increasingly complex survivorship issues, is unsustainable and unlikely to continue except for the most high-risk patients. In the South Western Sydney Local Health District, we are developing and testing the acceptability, feasibility and costs of "Healthy Life", an innovative and potentially sustainable cancer care model. Translating evidence into practice, Healthy Life aims to minimise variation in cancer care and facilitate individually tailored holistic care from the time of diagnosis, during treatment and into survivorship or palliative care. Healthy Life will be built using the UNSW Healthy.me eHealth system, which has been trialled with university students and in fertility clinics, with a pilot study recently completed with breast cancer survivors. This innovative eHealth system will include a) routine, perpetual screening of physical and psychosocial needs, from diagnosis, to trigger prompt identification of burden and efficient channelling of health services towards those most pressing needs; b) a personal illness/health management system to inform tailored self-directed and shared care; and c) enhanced continuity of care, through automated feedback and information exchange between patients' treating team and GPs. The model will be embedded into the current local area health cancer care model, initially for CRC patients, with future extension to other tumour groups; and has potential for utilisation with other chronic illnesses in the future.

17 – The roles of Survivors in shaping care that works

Phil Kerslake¹

1. Cancer Survivor, Upper Hutt, , New Zealand

Cancer survivors, as the consumers of survivorship care have crucial roles to play in creating successful care programs. This presentation will discuss the potential nature of their roles and how they may be integrated into the overall care. It will look at how survivors may be identified and engaged, and introduce the kinds of cultural and structural barriers

to optimal survivor contributions. Finally the importance of the feedback loop will be discussed in avoiding survivor enrolment becoming a tokenistic activity.

18 – Cancer Conversations: a method for sharing Survivorship issues and perspectives

Julie Marker¹, Ashleigh Moore¹

1. Cancer Voices South Australia, Kensington Park, SA, Australia

This interactive session will present the Canadian "GoPublic Cancer Conversations" methodology along with findings from our survivor-led conversations, including those in Australian Aboriginal communities. 'Cancer Conversations' are a method we used and have adapted for discussing survivorship issues and perspectives.

In 2009 the Canadian GoPublic Campaign to Control Cancer launched a global initiative with a toolkit of resources to help volunteers around the world conduct community conversations. Online forms collected feedback from 201 conversations held around the world, and culminated in 'The Real World of Cancer' report and Global Leadership Forum in Ottawa in 2009. These conversations proved to be an effective way to engage people in developed as well as developing countries eg Africa, India, America, UK and Canada.

Cancer Voices SA held 13 conversations in 2009, and in 2010-11, piloted an adaptation in 3 Australian Aboriginal communities. By talking with people affected by cancer in Aboriginal communities, we aimed to raise awareness about cancer, reduce the stigma of cancer and encourage Aboriginal people to attend health clinics for cancer checkups so cancer can be prevented or detected earlier.

Our experience agreed with the Canadian GoPublic report that: cancer conversations were an effective way to engage people , the conversations seemed to be an important delivery channel for awareness, education and action, participants were encouraged to talk to others about their experience.

Some survivorship issues and perspectives from 'people affected by cancer' will be presented, along with our insights on the positives and challenges using this methodology.

19 – Sleep disturbance is associated with post cancer fatigue – findings from a prospective cohort study

<u>Barbara K Bennett</u>^{1 2}, David Goldstein^{1 2 3}, Michael Friedlander³, Kate Webber^{1 2 3}, Andrew Lloyd^{1 2}, FolCan Study Group

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- 3. Medical Oncology, Prince of Wales Hospital, Sydney, NSW, Australia

Introduction: Daytime fatigue and poor quality sleep are more common in patients treated for cancer than healthy populations. Self-reported sleep disturbance is significantly associated with fatigue severity in post-cancer fatigue (PCF) [1]. Indeed a recent review suggested that sleep disturbance may be underreported by patients. In women treated for breast cancer early menopause-associated vasomotor symptoms may trigger sleep disturbance. A "domino theory" of sleep disruption leading to insomnia followed by fatigue and depression has been suggested, whereby, despite alleviation of the vasomotor symptoms insomnia may persist, driving ongoing fatigue. An alternative hypothesis is that PCF and cancer-related sleep disorders may share a common underlying aetiology.

Methods: Women treated for early-stage breast cancer participated in a prospective cohort study exploring the aetiology of PCF. Clinical assessment and blood sampling were performed post-surgery (baseline) and repeated at end-adjuvant treatment and 1, 3, and 6 months later. Physical and psychological health was monitored using interviews and self-report questionnaires.

Results: Data from 218 women (median age 52) were evaluated. The case-rate for PCF was 24% post-surgery, 42% at end-treatment, and 19% at 6-months. "Poor sleep" was reported by 71% of cases with cancer related fatigue at end-treatment and 70% at six months, compared to 33% and 25% of subjects without fatigue. Women who were premenopausal at baseline (n=104) were not more likely to be fatigue cases at 6 months post-treatment (X^2 .01; p=.92). The only significant predictor of PCF was 'sleep disturbance' at 1-month post-treatment (odds ratio, 1.2; 95% confidence interval, 1.0-1.4; p=.047).

Conclusions: Sleep disturbance was prevalent in patients with fatigue. However, menopausal status was unrelated to sleep disturbance. Sleep disturbance at one-month post-treatment predicted PCF. Sleep disturbance is a likely contributor to the genesis of PCF suggesting that targeted, early intervention for sleep disturbance may be warranted in patients treated for cancer.

Roscoe, J A et al. Cancer-related fatigue and sleep disorders The Oncologist 2007;12(suppl 1):35-42

20 – Development of an optimised, multi-disciplinary intervention for chronic fatigue states

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- 4. Inflammation and Infection Research Centre, , School of Medical Sciences, University of New South Wales, Sydney, NSW , Australia

Medically-unexplained chronic fatigue states inlcude Post-Cancer Fatigue (PCF)¹ and Chronic Fatigue Syndrome (CFS)². Both have similar natural history and clinical characteristics including complaints of fatigue, neurocognitive difficulties, disturbances in sleep and mood. Evidence suggests multi-disciplinary interventions incorporating cognitive-behaviour therapy, activity pacing, and graded exercise improves symptoms and functional status³⁻⁶.

An outpatient program was established with research components aimed at optimizing the intervention. The 12-week program includes independent treatment modules delivered by exercise physiologists and clinical psychologists to form an integrated approach, including four core modules: Activity pacing and Graded exercise therapy; Psychoeducation; Interventions for sleep-wake cycle disturbance; and Interventions for neurocognitive disturbance. Additionally three optional modules targeting: Depression, Anxiety, and Coping. Regular case discussions are conducted between clinicans and expert medical practitioners.

Outcomes at 12 and 24-weeks for the first 155 patients (CFS=146; PCF=9) have been analysed. Subjects included 106 women (68%), with mean age of 36 years, a mean duration of illness of 5.2 years. By both intention-to-treat and complete dataset analyses significant improvements were recorded at 12 and 24-weeks in self-reported fatigue (12-week:Mdiff =1.5, CI:0.97-2.10, (p<0.001); 24-weeks:Mdiff=1.1, CI:0.54-1.66 (p<0.001)) and mood disturbance (12-week:Mdiff = 1.2, CI: 0.55 - 1.84 (p<0.001); 24wk:Mdiff=1.1, CI: 0.53 - 1.68 (p<0.001)). Increases in physical functioning was also seen after treatment between baseline and follow up (Mdiff=3.8, CI: 0.83 -6.76 (p<0.01)) and end treatment and follow-up (Mdiff=2.8, CI: 0.13 - 5.52 (p<0.05). Younger age and lower pain levels revealed to be predictors for treatment response. Similar but non-statistically significant trends were observed in the PCF sample.

A modularized, multi-disciplinary intervention for patients with chronic fatigue states has been developed. Subsequently, a randomized control trial dedicated to applying this approached specifically to Post-Cancer Fatigue has been developed. Additionally, an operations manuals, DVD and web-based training package for clinicians are in progress.

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21 – When the 'all clear' is not so clear: Families' coping with fear of childhood cancer recurrence

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Objective: Childhood cancer survivors remain at increased risk of experiencing recurrence, relapse, and second malignancies for decades after treatment completion. However, whether or not such negative outcomes will ever eventuate for any individual remains unknown. This study investigated participants' concerns regarding the potential for children's cancer to return after treatment completion and the associated coping strategies used by survivors and their families.

Methods: One hundred and twelve semi-structured telephone interviews were administered to survivors of childhood cancer recently off-treatment and their families (19 survivors, 44 mothers, 34 fathers, 15 siblings). Interviews were analyzed using the framework of Miles and Huberman and emergent themes were organized using *QSR NVivo8*.

Results: Almost all participants (110/112) reported experiencing uncertainty regarding the survivor's future due to the risk of cancer recurrence. Overwhelmingly, these concerns led to feelings of anxiety, though only a small proportion of participants sought professional support and only some reported personal coping strategies adequate to manage their fear. For the majority of participants, less useful coping strategies such as avoidance, distraction and the internalization of emotions were used.

Conclusions: Study findings highlight the importance of specifically addressing fear of recurrence in interventions developed for pediatric cancer survivors and their families. Additionally, mental health promotion within the oncology setting is needed to ensure that interventions are utilized by families who may not believe help seeking is appropriate years after a child has been 'cured'.

22 – Unmet needs in CALD (Chinese, Greek and Arabic speaking) first generation immigrant cancer survivors

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- 5. Ingham Institute for Applied Medical Research, South Western Sydney Clinical School, , University of NSW, Sydney, NSW, Australia
- 6. Dept of Medical Oncology, Prince of Wales Hospital, Sydney, NSW, Australia

Background: Social suffering, language difficulties and cultural factors may all make the cancer experience more difficult for immigrants. This study aimed to document unmet needs, and variables associated with these, in a population-based sample of first generation immigrants and Anglo-Australians who had survived cancer.

Methods: Participants were recruited via Cancer Registries in New South Wales, Queensland, and Victoria, Australia. Eligible cancer survivors had a new diagnosis of one of 12 most incident cancers (all stages) 1–6 years earlier, were aged between 18 and 80 years at the time of diagnosis and had a treating doctor assigned to their registry record who approved approach. Eligible immigrant participants and both parents were born in a country where Arabic, Chinese (Mandarin, Cantonese, and other dialects), or Greek is spoken and they spoke one of these languages. A random sample of English-speaking Anglo-Australian-born controls, frequency matched for cancer diagnosis, was recruited.

Results: 596 patients of whom 277 were immigrants were recruited to the study (response rate of 26%). Due to 20% missing data on cancer stage and small numbers with known metastatic disease, stage was excluded from analyses, but estimates for impact of immigration status were unaffected when stage was included in sensitivity analyses. In multiple logistic regression models which adjusted for age, sex, education, socio-economic status, time since diagnosis and type of cancer, Arabic immigrants were 3.9 and 2.7 times more likely and Chinese immigrants were 5.1 and 2.2 times more likely than Anglo-Australians to have at least one unmet information and physical need, respectively. Greek patients did not appear to have more unmet needs than Anglo-Australians. Written information and having a specialist, support services and other health professionals who spoke their language were in the top 10 unmet needs amongst immigrants.

Discussion: Immigrants who are survivors of cancer, several years after initial diagnosis, are significantly more likely to have an unmet need for information or for help with a physical problem than Anglo-Australian controls. They strongly desire information and support in their own language.

23 – The needs of cancer survivors and their comfort levels for discussing them with GPs and oncologists – results from a cross-sectional survey

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- 7. Royal Hospital for Women, Randwick, NSW, Australia
- 8. St Vincent's Clinical School, University of New South Wales, Sydney, NSW, Australia

Aims: We have previously reported on the components of survivorship care ranked as most important by adult cancer survivors, and their unmet needs in each of these areas. This report describes predictors of multiple unmet needs, and levels of comfort in addressing these issues with general practitioners (GPs) and cancer specialists.

Methods: A cross-sectional survey was mailed to adult cancer survivors from 5 NSW oncology units. Self-report data were obtained regarding current care (provider and frequency of visits); ranking of physical, psychological and practical areas of importance to survivors; how well their needs were met in each of these areas; and whom among a range of care providers they would be happy to see regarding each issue. Univariate and multivariate logistic regression analyses were undertaken to assess for demographic and clinical variables associated with 4 or more unmet care needs.

Results: 228 surveys were returned (ongoing, response rate 50.5% to date). Respondents had a mean age of 59.3 years (range 32-87), 71.5% were female, with most common primary cancers being breast (71.5%), colorectal (13.9%), prostate (4.5%) and ovarian (2.2%). The most commonly reported unmet needs were information about late effects (50.3%), managing fatigue (41.7 %), genetic risk to family (34.7%), reassurance (32.0 %) and diet (31.4 %). The median number of unmet needs was 4 (range 0-23). On univariate analysis, female gender, younger age and tertiary education were associated with higher levels of unmet needs (p<0.001, p=0.11 and p=0.013). Marital status, tumour type and treatment modalities were not associated with needs, although we acknowledge limitations due to breast cancer predominance in this cohort. On multivariate analysis higher education (p=0.042) remained independently associated with higher unmet needs. Survivors were more likely to discuss the following issues with their oncologist than their GP: cancer treatment (89.9% vs 40.1%), follow-up care (80.8% vs 42.4%), frequency of check-ups (87.8% vs 28.5%) and late side-effects (77.8% vs 35.1%). They were more likely to discuss general health check-ups (94.9% vs 6.4%), lifestyle behaviours (62.5% vs 26.1%) and fatigue (61.2% vs 35%) with their GP. The majority of respondents with needs in the following areas would not discuss them with either oncologist or GP: finances (85.5%), education (84.4%), employment (68.7%), psychological support (54.8%), exercise (52.5%) and diet (51.1%)

Conclusions: Cancer survivors currently report significant unmet survivorship care needs, and their comfort levels for discussing aspects of their care varies between providers, with some key issues not entrusted to either oncologists or GPs. Models of care for cancer survivors must address these potential deficits in care.

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24 – Investigating patient preferences for breast cancer follow up – a discrete choice experiement

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Publish consent withheld

25 - Survivors informing survivorship care

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There are nearly 12 million cancer survivors in the United States, making late effects caused by cancer and its treatment a public health priority. In 2010, the LIVESTRONG Foundation fielded its second LIVE**STRONG** Survey. The 2010 survey instrument included items from existing scales and asked about physical, emotional, and practical concerns encountered by cancer survivors after the end of cancer treatment. More than 15,000 individuals affected by cancer responded to the survey. The results presented here include findings for 3,129 post-treatment cancer survivors (PTCS) who completed a minimum of 75% of the items reflecting post-treatment concerns. Overall, the vast majority of PTCS experienced physical, emotional and/or practical concerns as a result of having cancer. However, in many cases, they did not receive care for those needs. When asked why respondents had not received care, the majority reported that it was because they learned to live with the concern. Opportunities to address the results found here include connecting people to the resources they need and using these experience-driven results to inform the identification and dissemination of the essential elements of survivorship care delivery. Data from this large-scale survey enables the voice of people affected by cancer to play a role in guiding programs and policies to meet the needs of this large and growing population.

26 – The LIVESTRONG Essential Elements of Survivorship Care: Advancing the Implementation of Quality Care

Sarah R Arvey¹, Ruth Rechis¹

1. LIVESTRONG Foundation, Austin, TX, United States

Despite the rapid increase of the cancer survivors in the U.S. over the past decades, there is no strong evidence base on best practices, nor guidance on how to implement quality survivorship care services. In September 2011, the LIVESTRONG Foundation and the LIVESTRONG Survivorship Center of Excellence Network convened researchers, providers, advocates, and cancer survivors to identify and prioritize a list of 20 Essential Elements of survivorship care. LIVESTRONG continues to work on the Essential Elements Project to disseminate a framework for care delivery and tools to facilitate implementation of the Essential Elements in clinical practice for administrators, program directors, and providers; and advance a research agenda around these elements so that recommendations can be supported by a robust evidence base. These efforts should provide the cancer care community with a common platform for the development of clinical and research programs. This presentation will describe the consensus-building process, the outcomes, and future directions of the project. By the end of the session attendees will be able to:

- 1. Explain the need to identify the Essential Elements of Survivorship Care and how the LIVE**STRONG** Foundation addressed the need via a stakeholder consensus-building process
- 2. Describe the consensus-building process by which Essential Elements of Survivorship Care were established
- 3. Identify the 20 Elements of Survivorship Care; explain the rationale behind their ranked order and categorization; and describe recommendations for basic and enriched levels of care for each Essential Element
- 4. Describe next steps in the LIVESTRONG Essential Elements of Survivorship Care Project

27 – Survivorship now and into the future

Sue Sinclair¹

1. Cancer Australia, Surry Hills, NSW, Australia

This presentation will focus on Cancer Australia's survivorship initiatives to date and future priorities.

Cancer Australia as the national cancer control agency recognises the importance of people affected by cancer being at the centre of our cancer control efforts. Collaboration across the health and cancer sectors is required to reduce the impact of cancer on those diagnosed and to improve outcomes for all Australians affected by cancer. Ensuring an all of systems approach to cancer control is key to supporting the wellbeing of those living with cancer before, during and after treatment and for survivors of cancer.

Cancer is estimated to be the leading cause of burden of disease in Australia, accounting for approximately 19% of the total disease burden in 2012. The number of people diagnosed with cancer in Australia is increasing and cancer death rates have fallen. Over the past 20 years and across all cancers, the five year survival rate of people diagnosed with cancer has continued to increase, with potential late effects of treatment, other co-morbidities and psychosocial impacts (including fear of recurrence). With this is mind, there is a need for a collaborative and strategic approach to support the increasing number of people affected by cancer now and in the future.

Initiatives relating to survivorship are integrated within Cancer Australia's program of work, including: evidence based information and resources for consumers and health professionals in best practice cancer care, including updating the Clinical practice guidelines for the psychosocial care of adults with cancer; consumer involvement in all cancer control initiatives; on-line learning through *Cancer Learning*; in developing new models of care resulting in the acceptability and feasibility of shared follow-up care for early breast cancer between specialists and GPs; and funding of priority research initiatives in survivorship and supportive care.

Ensuring cancer sector collaboration with people affected by cancer is central in shaping survivorship strategies and building the evidence base to inform survivorship care in the Australian context.

28 – Insurance, discrimination and the law – protecting rights of cancer survivors

Sondra Davoren¹²

- 1. McCabe Centre for Law and Cancer, Carlton, VIC, Australia
- 2. Strategy and Support Division, Cancer Council Victoria, Carlton, VIC, Australia

Outcomes for cancer patients, their experiences of cancer and those of their families and health professionals, are impacted by the law in multiple ways.

Access to insurance (particularly life and travel insurance) is a significant issue for people who have finished active treatment for cancer. For some cancer survivors, accessing insurance coverage can be problematic, due to their medical history or pre-existing conditions, and the denial of insurance can severely hamper cancer survivors' ability to participate in areas such as employment, travel and home ownership.

Cancer survivors are protected from discrimination—including in relation to the provision of insurance—under the *Disability Discrimination Act 1992*, (the Act) which prohibits discrimination on the basis of disability. Cancer is included in the definition of disability in the Act.

Protection under the Act includes protection from discrimination based on past, imputed or future disabilities; thus a cancer survivor who is discriminated against because they previously had cancer, or because they are wrongly thought to still have cancer, or because they may develop cancer symptoms again in future, can avail themselves of the protection offered under the Act.

In a 2004 case, *Bassanelli v QBE Insurance*, the Federal Court upheld the protection from discrimination in the Act, when it held that a person cannot be discriminated against for having a pre-existing condition—in this case, cancer—when the insurance sought did not relate to the condition.

Although *Bassanelli* concerned protection under Commonwealth anti-discrimination law, the states and territories have their own anti-discrimination laws to protect cancer survivors from discrimination.

Using access to insurance as a focal point, this paper outlines the protections for cancer survivors in Australian federal, state and territory anti-discrimination laws. It briefly compares the development of anti-discrimination protection for cancer patients and survivors in Australia with similar developments in the US and UK, highlighting the ways in which laws can be formulated to improve outcomes for cancer patients and their experiences of cancer.

Posters

35 – Recruitment of cancer survivors and carers to a face-to-face lifestyle intervention: balancing methodological considerations and logistical challenges

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Introduction: Healthy lifestyle behaviours can reduce survivors' co-morbidities, protect against recurrence and cancer-specific mortality, and improve quality of life. Face-to-face programs have been identified by survivors as a preferred delivery mode. The ENRICH (Exercise and Nutrition Routine Improving Cancer Health) program aims to improve the lifestyle behaviours of survivors and carers, via 6 face-to-face education and skill development sessions. ENRICH is being evaluated via a wait-list randomised controlled trial (RCT). Wait-list RCTs are recommended as a means to ensure scientific rigor whilst maintaining ethical standards. This presentation will outline the specific logistical challenges faced when conducting a wait-list RCT with this target group.

Methods: Participants included 169 survivors and carers (mean age= 55 years) recruited through support groups, health professionals, medical centres, and media advertising. Participants completed study measures at baseline, 8-and 20-weeks and provided program acceptability information. Recruitment and retention rates were assessed.

Results: Preliminary results indicate challenges with recruiting and retaining participants with 15% attrition post randomisation but prior to attending any sessions. Commonly reported reasons for withdrawal included scheduled holidays, and injury or illness (unrelated to the program). Those who did attend ENRICH reported high acceptability: relevant (97%); enjoyable (99%); useful (98%); participation was "worth their time and effort" (100%), and "would recommend the program to other cancer survivors" (99%). Trial outcomes demonstrate improvements in self-reported physical activity (PA) and diet outcomes.

Conclusions and future directions: ENRICH is an acceptable and efficacious behaviour change program for survivors and carers. However, due to the age and health status of potential participants, and possibly due to competing priorities following cancer treatment, there were challenges in recruiting and retaining survivors. It may be necessary to reconsider what is an acceptable retention rate for trials with this target group and consider the use of attention-control rather than wait-list RCTs.

36 – Developing and Evaluating an Online Self Help Program for Cancer Distress: A Randomised Pilot Trial

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Objectives: Despite the demonstrable psychosocial impact of cancer diagnoses, less than 25% of distressed individuals elect to attend face-to-face therapy. Therefore this study developed and evaluated the efficacy of an internet cognitive behaviour therapy self-help program for cancer-distress.

Methods: Participants were 60 individuals in the acute survivorship phase (recently diagnosed), treated with curative intent, recruited from March 2011-November 2012. An interim analysis of the first 53 participants enrolled is the focus of the current report. Participants were randomised to receive a password protected 6 week program; either (a) the intervention, or (b) an internet attention-control. Measures of distress (negative affect, traumatic stress), coping and health-related quality of life were administered at baseline, post-treatment, and 3 month follow-up. Changes over time between groups were analysed using Linear Mixed Models, and qualitative feedback was obtained both during the program (end of module feedback), and at follow-up assessments.

Preliminary results/progress: From pre- to post-treatment, a significant interaction was found, with intervention participants experiencing reductions in traumatic stress (Mpre=12.09, SE=0.53; Mpost=9.84, SE=0.49) compared to small increases occurring in controls (Mpre=12.09, SE=0.53; Mpost=13.39, SE=0.44; p=.04). A similar trend approaching significance was also obtained for anxious preoccupation. However, these statistically significant effects were not sustained at follow-up. Qualitative feedback was largely positive. Future research could usefully explore ways of maintaining improvements over time, such as via the inclusion of a booster module.

Discussion: Given the access barriers to obtaining psychosocial support in Australia, innovative methods of providing psychosocial care are required. This research program represents one method of partially addressing this gap in resources. In addition, early intervention during the acute survivorship phase has the potential to prevent distress from escalating over the survivorship period. The findings of this study will be extended in a three year NHMRC-funded national multi-site RCT commencing in 2013.

37 – What do patients really mean when they complain of fatigue after treatment? Development of a semi-structured clinical interview to reliably identify post-cancer fatigue

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Introduction: Fatigue is a ubiquitous symptom. Fatigue following cancer diagnosis and treatment continues to be reported with a wide range of prevalence, potentially due to the lack of consensus on the diagnostic criteria for the syndrome and the diversity of tools (predominantly self-reported) used to measure it. While questionnaire scales are useful for screening they provide only sparse information on the nature of the symptom. We report on the development of a semi-structured clinical interview schedule to reliably identify cancer related fatigue syndrome and differentiate co-morbid symptoms such as insomnia or mood disturbance.

Methods: Analogous to clinical interview schedules used in sleep medicine or psychiatry, a semi-structured clinical interview to identify post cancer fatigue (PCF) has been developed. It incorporates published diagnostic criteria for the syndromes of cancer related fatigue; chronic fatigue and major depression. Importantly, clinically significant fatigue can be identified.

Results: An algorithm for classification of the symptom complexes is incorporated together with the assessment of symptom severity. For validation, the interview is currently being trialled in a series of patients with clinician identified fatigue syndromes such as multiple sclerosis, post infectious and chronic fatigue and post cancer fatigue. An interviewer training manual and supplementary instructional DVD are also currently in development.

Conclusion: The interview schedule will facilitate the diagnosis of cancer related fatigue syndrome. It has the potential to facilitate both aetiopathological studies by identifying homogenous cases of the syndrome, and clinical management by monitoring patients participating in clinical intervention trials for cancer related fatigue.

38 – Melanoma shared care, a tripartite approach for survival. The patient, their GP and their specialist - a survivorship project

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This project is a collaboration between Victorian Melanoma Service (Alfred Health), Melanoma Patients Australia and SMICS funded by the Victorian Department of Health.

Aim: To develop a model for long-term care of survivors of malignant melanoma including patient self-management, GPs/specialist shared care, supportive care screening, patient and family centred care planning.

Method:

- a) Map current service models and consumer perception of these models.
- b) Undertake a literature search to determine best practice models of care.
- c) Development of a risk stratified follow-up protocols and care pathways including:
- patient self-examination
- GP examination
- specialist examination
- dermoscopy and digital total body photography and digital serial monitoring
- d) GP and primary care engagement into model delivery with education modules and seminars and fast track access to specialist care ensured.
- e) Development of continuous supportive care through a patient owned supportive care screening tool and pathways for addressing revealed supportive care needs.
- f) Development of an electronic means for the implementation of a patient reminder system to prompt follow-up care, whether to perform a self-assessment, attend GP assessment or specialist appointment.
- g) Recruitment of patients to participate in the shared care model of care.
- h) Evaluation including patient, GP's/primary care and specialist care providers surveys, interviews and assessment of identified health outcome measures. Operational outcomes such as follow-up compliance will also be measured.

Results: Chaired by a Melanoma Patients Australia consumer representative, a multidisciplinary Survivorship Steering Group has been established to provide leadership and direction. The literature review and identification of models of care have been completed and are currently being considered by the Group. The risk stratification tool, patient information and consent, patient self assessed support screening and patient held treatment record and data collection tools have been drafted and will be reviewed continuously as users trial them in practice.

Conclusion: There is strong consumer, specialist and GP commitment to collaborate to improve the long term care and management of melanoma survivors using innovative approaches.

39 – An exploration of the support care needs of men who have undergone prostate cancer treatment and their partner

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Objective: To explore through questionnaire the support care needs of men who have undergone prostate cancer treatment and their partners.

Subjects/Patients: Men who had undergone prostate cancer treatment within the last 6 years and their partner.

Methods: Men and partners individually answered a semi-structured questionnaire that used the 5-point Likert Scale and which explored support care issues as identified in the literature and from focus groups. Data were analysed using sample

Results: Thirty one men and partners (n=62) participated and were similar in age, educational level and employment status. The mean time since prostate cancer diagnosis was 32mths (\pm 19.2). Men and partners were moderately satisfied with information given regarding diagnosis, treatment and side effects, but partners were more satisfied with information relating to the particular chosen treatment (p=0.014). Men's understanding of their chosen treatment's potential side effects was significantly different from their understanding of diagnosis (p = 0.001), cancer outcome (p = 0.031), treatment options (p = 0.000) and selected treatment (p = 0.000). Timing of information delivery was preferred by men at diagnosis, whilst partners preferred after the diagnosis (p=0.009). Men wanted more time to think about the diagnosis and treatment (p=0.039), whilst partners wanted an opportunity to discuss the diagnosis (p=0.039). The management of common side effects such as emotional changes, incontinence and erectile dysfunction was rated as 'somewhat' satisfactory. The majority of participants indicated that having the same health professional, such as nurse, throughout diagnosis and treatment would be beneficial.

Conclusions: Given the identified differences in the response from, and the gaps in the care provided to men and partners, it is proposed that a specialised prostate cancer nurse provide tailored care to both men and their partner throughout the prostate cancer journey.

40 – Living Well: Delivering Survivorship Hospital Programmes

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Background: 'As more people are surviving cancer treatments and living longer, quality of life becomes as important as length of life' (Landier 2009). The focus of cancer treatment is now shifting to include helping people deal with the 'aftermath of treatment' or survivorship (Wolfson 2010). Our Living Well After Cancer Treatment Programmes (LWACTP) are modelled on Hettler's Wellness Wheel. This model focuses on the 6 dimensions of wellness including the physical, social, environmental, emotional, intellectual and spiritual well being of the patient (National Wellness Institute 2010).

Aim: To develop programmes that address survivorship issues in a wellness context.

Method: Breast Cancer and Lymphoma were the tumour sites selected for the LWACTP. The programmes are delivered by specialist Cancer Care Coordinators and Social Workers. The delivery method was based on tumour group size and staffing resources. The Breast Cancer programme is a group based education session, whilst the Lymphoma programme are individual clinic sessions. These programmes address both the medical and psychosocial aspects of patient care following cancer treatment.

Evaluation: By December 2012, 65 number of cancer survivors have participated (Breast Cancer 35 and Lymphoma 30) in LWACTP. Initial feedback results will be presented. It has also facilitated additional referrals for psychosocial support and awareness of wellness and survivorship issues.

Future plans: Ethics approval has been submitted. A validated evaluation tool is under development in collaboration with Ingham Research Institute. Comparative assessment of programme methodology and the wellness concept will be incorporated into the evaluation. Due to the unique nature of the LWACTP, there has been significant interest in the adoption of this programme into the standard practice of other Cancer Therapy Centres and tumour streams.

41 – A systematic review of factors which breast cancer patients associate with their diagnosis

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Introduction: Cancer continues to be a major cause of morbidity and mortality. Risk factors for cancer can be categorized into non-modifiable factors such as age, gender, and genetics and modifiable factors which pertain to behavioural or lifestyle choices. Approximately 30-40% of cancers can be attributed to alcohol consumption, lack of physical activity, unhealthy diet, and/or tobacco smoking. For women with breast cancer, exposure to oestrogen related factors such as the decision to delay or not to have children also increased their risk.

Health behaviour theories suggest that patients' beliefs about the cause of their illness are associated with their psychological adjustment and way of coping.

Objective: To synthesize evidence on causal attributions or beliefs about the causes of breast cancer among women who have been previously diagnosed with the said condition.

Method: Studies were identified via CINAHL, Pubmed, PsycINFO, and Web of Knowledge databases from October 1982- present and were evaluated according to predetermined criteria. A total of 3284 articles were identified, with

3253 articles excluded after title and abstract screening and removal of duplicates. A total of 31 articles were fully reviewed to assess eligibility.

Results: A total of 19 studies met the inclusion criteria. Findings of this review suggest that breast cancer patients tend over-estimate the influence of non-modifiable factors such as family history and stress. There were also participants in the reviewed studies who said, that they "don't know" what caused their breast cancer or declined to answer the said question. Among patients from ethnic minority groups, fatalistic attributions and "cancer myths" were prevalent.

Conclusions: A deeper understanding of factors believed by breast cancer patients to be the causes of cancer would provide insights on how to further promote positive health behaviours among this cohort.

42 – A Supportive Care Service for Oncology Patients and their Carers at Northern Health

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The literature confirms that many oncology patients report high levels of anxiety and stress. Furthermore, clinical experience has identified that cancer patients have difficulty in accessing affordable quality stress reduction therapies.

A Quality Project was completed by The Northern Hospital (TNH), Social Work Department, titled "Evaluation of Social Work Services in Oncology Breast Clinic" (2008). The study reported that 69% (11/16) of patients participating answered "yes" to a question in regard to attending relaxation sessions if offered.

In addition, patients attending a "Living with Cancer" Education session in 2009 identified limited access to quality complimentary therapies in the North Western metropolitan area, as well as issues of affordability.

In August 2009, a BreaCan workshop was conducted at another Northern Health site - Craigieburn Health Service (CHS). A number of participants attending the workshop articulated their interest in meditation or relaxation sessions and also identified a need for a cancer support group.

In response to:

• Patient interest

treatment and survivorship.

- Northern Health's strategic goals of quality patient care, appropriate access and consumer participation.
- The Department of Human Services' Supportive Care initiative.

Social Work offered a meditation program for cancer patients and their significant others, with the aim of:

• Reducing identified levels of distress or anxiety, particularly in relation to adjustment to a cancer diagnosis,

• Improving the quality of life for the participants.

In 2009, an evaluation of an eight-week pilot program clearly showed that a high percentage of participants' stress levels were significantly reduced after each of the 1-hour sessions.

As a result of the successful pilot program, it was agreed that TNH would continue to offer a weekly 1-hour open support and meditation group, facilitated by Oncology Social Work. To date the program continues to be well attended and supported by patients, survivors and significant others.

43 – Physical activity levels and barriers and facilitators towards exercise for Haematopoietic Stem Cell Transplant (HSCT) survivors

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Background: With increasing survival rates for childhood cancer, there is increased interest in the health and well-being of survivors. Children who have undergone HSCT are at risk of deleterious late effects affecting the cardiovascular, endocrine and musculoskeletal systems¹. Late complications may include avascular necrosis in bone, osteoporosis, cardiopulmonary disease, neurological complications and more². Being sedentary can exacerbate these conditions. Studies indicate that childhood cancer survivors are not meeting the WHO physical activity guidelines and

are less active than healthy peers³. However, despite the increased risk of health concerns for HSCT survivors, no studies have specifically investigated the physical and sedentary activity levels of this population.

Method: This study was a cross-sectional survey of children (aged 6-18 years) who were more than 1-year post-HSCT. Children were recruited from the Sydney Children's Hospital Network. Parents and children completed a physical activity questionnaire which included questions relating to sedentary behaviour and barriers and facilitators to physical activity.

Results: 35 children were recruited (56% boys). Less than half (48.3%) were sufficiently active in summer and only 51.7% were sufficiently active in winter school terms compared with 63% (summer) and 51% (winter) of healthy NSW school children. Fifty nine percent exceeded recommended daily screen time (ST). Fifty percent of children were less active than pre-transplant, whilst 50% were similarly or more active. The most common barriers cited were fatigue, physical limitations and poor motivation. Facilitators towards exercise included children being more health conscious and having higher energy levels.

Discussion: Early results indicate that physical activity participation is low among childhood HSCT survivors. As survival rates increase, interventions that encourage increased physical activity and decreased ST may be beneficial to maximize long-term health and well-being. Common barriers to physical activity were treatment-related indicating that HSCT survivors may require individualized exercise programs that consider their needs.

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- 2. Kelly, A. K. (2011). Physical activity prescription for childhood cancer survivors. Curr Sports Med Rep, 10(6), 352-359.
- 3. Juan, A. F. S., Wolin, K., & Lucía, A. (2011) Physical activity and pediatric cancer survivorship. Vol. 186, pp. 319-347.

44 – Lower levels of depression, anxiety, distress, fatigue and symptoms are associated with higher levels of physical activity in non-small cell lung cancer

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Aims: 1) Compare association between physical activity (PA) and health-related quality of life (HRQoL), mood and symptoms in surgically and non-surgically treated individuals with non-small cell lung cancer (NSCLC). 2) Measure change in PA, HRQoL, mood and symptoms over time.

Methods: 50 participants from three tertiary hospitals with stage I-III NSCLC (32male), mean±SD age 68±9years, forced expiratory volume (FEV₁) 74±21%predicted, BMI 27±6kg/m² were assessed at diagnosis, 10weeks and six months. 24% were undergoing chemotherapy/radiotherapy at time of 10week assessment. Measures included Physical Activity Scale for the Elderly (PASE), European Organisation for the Research and Treatment of Cancer (EORTC-QLQ-C30), Hospital Anxiety and Depression Scale (HADS), Distress Thermometer and Memorial Symptom Assessment Scale (MSAS).

Results: Linear mixed models demonstrated significant change from baseline to six months for the whole cohort (n=50) in PASE (p=0.010) and symptoms (p=0.001) but not in HRQoL. For non-surgical individuals there was deterioration in PA, physical function, global quality of life, fatigue and total symptoms over 10weeks from baseline (p<0.05). At 10weeks 17.4% met PA guidelines and PA was moderately correlated with depression (r=-0.527), anxiety (r=-0.554), physical function (r=0.662), global quality of life (r=0.651) and fatigue (r=-0.503); but correlations with distress (r=-0.352), symptom score (r=-0.399) and dyspnoea (r=-0.287) were fair. In comparison, individuals undergoing surgery did not experience deterioration in HRQoL or fatigue. At 10weeks 25.4% met PA guidelines. Correlations between level of PA with depression (r=-0.451), distress (r=-0.251) and global quality of life (r=0.277) were fair.

Conclusion: Lower levels of PA are associated with worse depression, anxiety, distress, fatigue, symptoms and HRQoL in individuals with NSCLC undergoing chemotherapy/radiotherapy. A weaker relationship is found in surgically treated individuals. There is deterioration in PA at 10weeks regardless of treatment type.

Funding: Victorian Cancer Agency, Eirene Lucas Foundation.

45 - Surviving cancer: the psycho-social impact on the family

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A cancer diagnosis has a profound effect on the affected family, and some experience increased distress. As cancer incidence and survival rates rise, the number of people living with cancer will increase significantly, but little is known about the psycho-social impact upon the family of surviving cancer. 23 self-defined families (total number participants = 23) of cancer survivors (12 more than 3-years post-diagnosis) were recruited through Australian media and participated in a family interview covering long-term outcomes. Interviews were recorded, transcribed verbatim, then thematically-analysed. Participants noted various long-term outcomes of a cancer diagnosis within their families. Many reported challenges in managing changes in their working life and their geographical location. Some noted that the physical effects of cancer and treatment had changed what they could do as a family. For some, relationships with external family members were problematic due to disagreements regarding familial choices. Families spoke of difficulties in managing their own or others' emotions, or in adjusting to changes of personality or priorities exhibited by the cancer patient. Finally, several families raised management of risk factors as problematic: views about the importance and consequences of behavioural change to manage risk varied, and could cause on-going tension. These (relatively high-functioning) families faced ongoing psycho-social challenges long after diagnosis. Cancer changed the present circumstances and the future possibilities resulting in changed behaviour, and related to issues around identity. This required, but did not always result in, adjustment within and without the family. Some families may benefit by psycho-therapeutic family-centred interventions to address these issues.

46 – Analysing the blog narratives of a cohort of breast cancer survivors provides a new framework for a richer understanding of the lived experience of cancer survivorship

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Background: Personal narratives shared through social media are an area of rapid development in communication among breast cancer survivors. ¹ Many are turning to blogs (internet weblogs) to tell their stories. These blog narratives provide a framework for a richer understanding of the lived experience of cancer survivorship.

Purpose: The purpose of this study is to propose a new framework for understanding the issues faced by breast cancer survivors after treatment and to explore how they integrate the cancer experience into their lives over the long term.

Methods: (1) a qualitative analysis of the overarching themes of 25 blogs written by breast cancer survivors at various stages of the survivorship trajectory and (2) a literature review were undertaken.

Results: While an analysis of blog narratives convey common themes related to physical, psychosocial and emotional issues, the uniqueness of each blog demonstrated that the survival trajectory is a dynamic concept, the challenges of which can vary at different life stages and times. This study extends previous findings that cancer is not just a single event with a defined end, but an evolutionary journey with short and long-term challenges. A cancer diagnosis initiates a survival trajectory that extends over the remainder of life, regardless of life expectancy.

Conclusions: If healthcare professionals are to adequately prepare patients for the transition to survivorship, they must have a deeper understanding of the survivorship experience. Cancer survivors' own narratives open up the lived experience of survivorship, providing a rich framework for examining the effects of cancer at various life stages throughout the remainder of a person's life. Furthermore, the narratives have the potential to inform interventions for psycho-social support to aid survivors in their adjustment to life after cancer. Future research with a larger and more diverse sample of cancer survivors is recommended.

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- 3. Zebrack BJ. Cancer survivor identity and quality of life. Cancer Pract. 2000;8(5):238-42.

47 – The development and implementation of survivorship care plans across the Peter MacCallum Cancer Centre

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Background: Sixty-six percent of cancer patients in Australia survive more than five years. A pivotal report by the US Institute of Medicine recommends that every cancer survivor be given a survivorship care plan (SCP) at the end of initial cancer treatment to enable smooth transition into the post-treatment phase. However there is little evidence to inform SCP implementation models in acute cancer centres. To support the introduction of SCPs at the Peter MacCallum Cancer Centre, a project is underway to develop a SCP implementation framework.

Method: Since February 2011 group discussions and one-on-one interviews with key clinicians involved in post treatment care have been undertaken to:

- ascertain current perceptions of survivorship issues and use of SCPs, and models of providing post-treatment care;
- identify ways to assist translation of best-practice guidelines regarding SCPs into clinical practice across 11 clinical services, and
- evaluate implementation.

Results: SCPs have been developed and implemented in five clinical streams and implementation is underway in two clinical streams. A total of 101 SCPs have been developed and distributed by nurse coordinators. Although each SCP contains specific disease and treatment information there is common content for SCPs across clinical streams. The need to provide primary care providers with a copy of the SCP has been universally recognized. Ongoing challenges include engagement of clinical services, time to complete SCP and embedding SCPs into routine practice.

Conclusion This project is in its infancy, establishing critical links with multidisciplinary team members to support implementation of SCPs. Ongoing work will determine how to deliver SCPs to greater numbers of survivors as well as determine the impact of SCPs.

48 – Development of a nurse-led survivorship intervention for long term survivors of Hodgkin lymphoma

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Publish consent withheld

49 – Return to driving after a diagnosis of brain tumour

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Return to driving after recovery from neurological damage improves independence and quality of life. But, there is a general apprehension about the driving ability of brain tumour (BT) survivors. Identifying individuals who are safe to return to driving following the diagnosis and treatment of BT requires validated assessment tools. Medical guidelines regarding return to driving following BT's are general in nature, and as a consequence the decisions made related to driving are largely determined by the clinical judgment of individual medical practitioners. A lack of consensus exists regarding the responsibilities of medical practitioners in managing return to driving when treating people with BT [1], resulting in patients often being given conflicting advice [2].

The design of this pilot study is a prospective correlational study on a cohort of drivers treated for BT. The research objective in this study is examine the validity of pre-driving tools in BT survivors through comparison to a standardised on-road assessment at point of referral. This information will inform clinical practice by evaluating objective measures for practitioners to guide decision-making related to driving following cancer.

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50 – Primary care in survivorship: an exploration of the relationship between young people diagnosed with cancer and general practitioners

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Background: Recognition of the unique medical and psychosocial impacts of cancer on the long term health of adolescents and young adults (AYAs) is increasing. Services are developing in response and in alignment with acknowledgement of the importance of survivorship care. International guidelines have identified acute/primary partnerships and shared care as essential to the health and well being of survivors and ensure the most efficient allocation of healthcare resources [1-2]. However, for AYAs, a diagnosis of cancer is often the first presentation into the health sector. A lack of community healthcare engagement may place young people at risk and a significant burden on acute facilities to address a broad range of health concerns, both oncology related and not. Relationships between acute/community healthcare facilities are therefore essential to the wellbeing of AYA patients. However there is a dearth of research into AYA/GP engagement in Australia to date.

Aim: The aim of this project was to describe the extent to which AYAs (15-25y.o.) engage with GPs by the nature of the relationship and barriers to engagement.

Method: AYA patients in Victoria were asked about their experiences in a retrospective online survey. Outcomes include a description of how young people engage with GPs, areas of health discussed and barriers to engagement.

Discussion: The majority of AYAs surveyed had a relationship with a family GP and felt comfortable discussing general health. Sexual/mental health and relationship issues were not frequently addressed. Barriers to engagement included a lack of time, cost and inconsistency in care. These outcomes highlight the importance of acute/community partnerships to ensure that AYAs can address a broad range of health concerns during treatment and beyond. This has informed the development of Survivorship Connections, a project aiming to build such partnerships in Victoria by engaging youth friendly, local GPs in AYA survivorship care.

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- 2. Institute of Medicine and National Research Council, From Cancer Patient to Survivor: Lost in Transition. 2006, Institute of Medicine and National Research Council of the National Academies: Washington.

51 – Implementing a self-management oriented survivorship intervention

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Introduction: Numbers of cancer survivors are increasing in Australia. Cancer survivors report physical, psycho-social and practical concerns that are not routinely addressed by health services. Specifically, reduced self-efficacy in recognising new symptoms and fully engaging in life after cancer are commonly reported. Evidence supports trialling goal-focussed self-management approaches that target self-efficacy with cancer survivors. The 'Moving forward with confidence' project is piloting a self-management directed intervention following transition from hospital-based cancer treatment.

Aims:

- 1. To provide cancer survivors with adequate knowledge and support to: more independently and competently manage their post-treatment health, and optimise their sense of wellbeing in the context of their disease history.
- 2. Build health professional awareness of common issues facing cancer survivors
- 3. Educate cancer professionals to support self-management abilities in their patients

Method: 100 participants are being recruited across three health services located within north-eastern Melbourne. Participants develop an individualised 'Health and Wellbeing Plan' with support from an oncology nurse. Copies of the plan are shared with the participant, their GP and a Nurse HELPLINE service. The HELPLINE nurses provide telephone support at 4 weeks, 4 months and 8 months following initial plan development. A staff mentoring program supports the development of self-management facilitation skills.

Discussion: Implementation of this project has identified a number of enablers and challenges that have impacted on the progress of the project. Implementation issues will be discussed in relation to health service organisational and workforce factors; identification and recruitment of participants; and acute verses community-based service provision.

Results: Recruitment commenced in May 2012 and to date 28 participants have been recruited. Preminary results will be presented. Evaluation will include pre and post project implementation surveys of participants and staff, and the final report will be available in September 2013.

52 – Perceptions on the role of physical activity in maintaining quality of life in men with prostate cancer: influence of androgen deprivation therapy

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The aim of this study was to examine how androgen deprivation therapy (ADT) may influence the perceptions of 14 men with prostate cancer regarding their quality of life and physical activity post-diagnosis and to the potential benefits and risks associated with increasing physical activity levels. To address these questions, two focus groups were conducted, with these separated into ADT (n = 6) and non-ADT (n = 8) groups. The probe questions used assessed the link between quality of life and physical activity as well as the benefits and risks associated with increasing levels of physical activity. Data was transcribed verbatim and themes identified using a general inductive thematic approach. The primary themes identified were sexual health, "plumbing" and non-urogenital side-effects, return to and increased levels of physical activity post-diagnosis, physical health and psychological benefits of physical activity as well as over-doing it and age-related risks of excessive physical activity. However, not all themes were present in both the ADT and non-ADT groups. These results further highlight the link between physical activity and quality of life in prostate cancer survivors and how each group may use physical activity as a part of their survivorship process. Of particular interest was how several men on ADT used resistance training to counteract some of the ADT-related side-effects affecting their perceived maleness and potency. As the benefits of physical activity for men with prostate cancer are becoming better understood, cancer clinicians and service providers may need to focus more of their counseling on these issues, especially for those men on ADT.

53 – Two models of group based education for cancer survivors

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Background: Patients experience significant challenges and mixed emotions after finishing cancer treatment. To address this, ACSC has supported 2 programs of group based survivorship education at Peter Mac.

Method: 'What happens now? Life after Cancer treatment' was developed by Cancer Council Victoria to assist survivors cope with the transition from treatment completion through to emotional and physical recovery. It was piloted within the gynaecological cancer service at Peter Mac and available for women who had completed treatment within the preceding 18 months.

'Getting on with Life' was developed by the Haematology service at Peter Mac for people within the first three months post treatment. It aims to assist people gain maximum physical, social, psychological and work-related functioning after treatment.

Both are free, multidisciplinary-led, presented as a single one-day session (5 hours) and open to survivors, carers, partners and family members. Both forums include information about: (i) what to expect after finishing treatment; (ii) healthy living, including nutrition and exercise; (iii) emotions and cancer and (iv) hospital and community based support services.

Results: To date, 54 people have participated in sessions, with further sessions planned. The one day program was considered acceptable. Participants indicated the content was very helpful and the opportunity to meet others in a similar situation was supportive. Several participants indicated they would take steps as a result of their attendance, including making lifestyle changes and contacting support services.

Conclusion: These programs demonstrate the acceptability of group based survivorship care which emphasises a rehabilitative approach and the promotion of healthy living.

54 - Resilience: What Influences Treatment Outcomes for Patients Treated with Early Stage Cancer?

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Resilience is the subject of increasing research over the past decade due to its potential to impact on health outcomes. A diagnosis of cancer is often regarded as a potentially traumatic event with adverse consequences. Research frequently focuses on negative aspects of cancer diagnosis and treatment (e.g. mood disorder). It has been suggested however, that a psycho-pathological approach discounts the human capacity for resilience [1]. Defining the concept of resilience is complex, with no current 'gold standard' for its measurement. This study explored the concept of 'attributional style' (the habitual way in which individuals explain their positive and negative life events) as a potential mediator for resilience in patients treated for cancer. Patients (n=40; 60% female; mean age 63.6 years) attending a metropolitan medical oncology department for a follow-up visit, completed self-report questionnaires measuring attributional style (Attributional Style Questionnaire - ASQGU); resilience (Brief Resilience Scale - BRS); fatigue, mood; functional health status and social support. Participants had completed treatment for breast, colon, or prostate cancer with curative intent, a mean of 28.2 months previously. Results demonstrated a modest correlation between attributional style and resilience rho=-.388, p<.005, with a more optimistic attributional style associated with higher resilience . Trajectories of health outcomes - defined by fatigue and psychological distress caseness were assessed and used to categorise those individuals with a resilient versus non-resilient clinical outcome. No significant associations were observed between resilience and other self-reported variables. Though the small sample size limited conclusions that can be drawn from the study, it served as a pilot to provide support for the feasibility of conducting such investigations into the factors which may influence outcomes from a cancer diagnosis and treatment and be amenable to intervention.

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55 – The challenges of developing a nurse led survivorship model of care – Initiating a service within a regional and a rural domain

Donna Lever, Kate Schofield

Aims: With consideration for growing clinic numbers and acknowledgement of the urgent need to address the increasing number of patients diagnosed and living through the cancer experience, the Barwon Health cancer service aimed to address survivorship needs of the cancer population by initiating a nurse led clinic. This decision was supported by the growing evidence of the benefits of nurse led clinics to improve outcomes for cancer survivors with complex needs.

Methods: An 18 month project was funded by the Victorian Department of Health in July 2012. To date the project has initiated and commenced evaluating a nurse led survivorship services within two tumour streams - Head & Neck Cancer and non Hodgkins' Lymphoma survivors. The project and clinic commenced first at the regional cancer facility to test and refine the process. Subsequently a rural cancer service introduced an adapted model of this nurse led survivorship model of care.

The study participants were recruited following completion of curative intent chemotherapy &/or radiotherapy treatment within the regional cancer service. The suitable candidates were invited to attend two nurse led interviews. The first allowed for assessment and discussion of their survivorship needs. The second appointment includes the provision of a survivorship care plan and empowerment of the cancer survivor to provide a way to move forward in their life after a cancer experience.

Results: The project will evaluate the effectiveness of the survivorship intervention with specific consideration of quality of life, health literacy and useability of the intervention. The participants were surveyed before and after the nurse led intervention and three months later. The project's preliminary results will be discussed.

56 – Promoting physical activity to breast cancer survivors – what may work?

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Background: Australian women are increasingly likely to survive breast cancer at least five years from diagnosis. Consequently, the health of breast cancer survivors is an important field of cancer survivorship research. Regular physical activity participation improves several health outcomes for breast cancer survivors. Yet, little is known

regarding how women who have/had breast cancer respond to information about health benefits of regular participation in physical activity.

Methods: This paper explores the perspectives of women diagnosed with breast cancer while mothers of dependent children, in terms of their responses to information about, and participation in, physical activity. The paper reports on in-depth qualitative interviews with 36 rural and metropolitan Australian women diagnosed with breast cancer while mothers of dependent children.

Results: The women responded to health promotion messages that use population risk factors to promote individual behaviour change over a continuum of resistance, acceptance, cynicism and/or blaming themselves for their breast cancer diagnosis. The results suggest that this approach to health promotion was unhelpful for most of these women and did not have the desired effect of changing their behaviour toward participating in health promoting practices. In relation to physical activity participation, the women reported social/structural and individual enablers and constraints to their participation; level of intimate partner support was the strongest factor.

Conclusion: This paper will suggest ways to reframe physical activity and other health promotion messages by taking into account women's everyday lives and changing the ways population risk/protective factors are translated into promoting individual behaviour change, while nevertheless encouraging the uptake of physical activity participation.

57 – Engaging with Survivors – A Regional Participation Strategy

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Aim: To develop and implement a consumer engagement strategy that supports and enables those affected by cancer to partner with GRICS to influence service delivery change.

Background: Cancer care professionals believe they know and understand the service access issues confronting the cancer patient. However it is the cancer patient who, having navigated the complexities of their own cancer path, has the knowledge and experience to raise awareness and inform cancer service improvement priorities. Recognising this, GRICS developed a comprehensive consumer engagement strategy to facilitate robust, sustainable survivor participation.

Method: To achieve our aim GRICS developed;

- A Participation Plan that articulated the role of the consumer within the GRICS Governance structure and the strategies that would facilitate participation regardless of the health needs, lifestyle priorities or geographic location of members
- Recruitment material
- A Consumer Participation Kit
- A consumer education framework
- Key performance indicators, review and evaluation methodology.

Achievements:

- 1. A comprehensive consumer engagement strategy that could inform other regional and metropolitan service providers.
- 2. A robust Consumer Reference Group that;
- Meets monthly and is progressing into a third year
- Has a diverse membership from across Gippsland
- Had an 81% attendance rate in 2012
- Combines videoconferencing and venue rotation to facilitate participation
- Offered education at 100% of meetings
- Produced the Handy Essential for Local Patients (HELP) Kit for Gippsland cancer patients
- 3. Linkages with 16 regional cancer support groups
- 4. Hosting regionally based, consumer centred, health forums
- 5. Productive partnerships with cancer information and support providers e.g. Breacan, Cancer Council.

Future Directions: In 2013 GRICS will work towards;

- Investigating collaboration opportunities with health service Community Advisory Committees
- Independently peer reviewing our consumer engagement performance against current national and Victorian standards, best practice and benchmarks in health services.

58 – Addressing the needs of survivors with lympoedema – a transferrable model for providing lymphoedema services in a regional context

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Context: Lymphoedema is a chronic condition, which can be debilitating for cancer survivors, but manageable with early detection and appropriate intervention. It is predicted that 20% of patients with melanoma, breast, genitourinary or gynaecological cancer will develop lymphoedema throughout their lifetime (NBOCC 2008). This equates to more than 8000 new cases per year in Australia, of which 155 new cases could be predicted in Gippsland.

In 2010 GRICS identified a shortage of lymphoedema practitioners in the Gippsland region. Surveyed Gippsland lymphoedema practitioners reported many patients were either not receiving lymphoedema services; receiving service from staff without appropriate training or travelling long distances to access services. Additional consultation with key stakeholders was undertaken to define and clarify regional requirements. The 'Lymphoedema Framework An International Perspective' was identified as current best practice for lymphoedema service provision. An accredited training program for Level 1 Lymphoedema Practitioners was funded by GRICS with local Level 2 practitioners assisting in delivering the program. Health services nominating staff for training provided a commitment to deliver a lymphoedema service and support newly trained practitioners.

The objectives were to:

- obtain commitment from health services to provide lymphoedema services utilising best practice principles
- support local provision of accredited Level 1 lymphoedema training
- implement a structure to support ongoing service provision.

Conclusion: GRICS identified a service provision and workforce shortfall and strategically partnered with health services to remedy these. There are now 20 qualified lymphoedema practitioners employed in nine Gippsland health services compared to ten practitioners in five health services. This outcome was achieved through provision of free local training which assisted in building sustainable professional relationships with regional peers and training facilitators. Support from GRICS includes Community of Practice meetings, mentoring, educational opportunities and consideration of succession planning. Cancer survivors can expect to benefit significantly and this model could be transferrable to other regions.

59 – Development of a Survivorship Project – Positive Change for Life

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Introduction: Lifestyle modification is an increasingly important component of cancer survivorship to ameliorate the effects of treatment, minimise co-morbidities and promote long-term wellness. Although curative for many people with blood cancer, stem cell transplant (SCT) survivors often carry a burden of associated morbidity. Within an established Late Effects Clinic, a high prevalence of obesity (60%), hypertension (51%), elevated triglycerides (55%) and smoking (14%) has been identified. Survivors are also at risk of osteoporosis with 59% having low bone mineral density and increased fracture risk. Lifestyle modification focusing on nutrition and physical activity has the potential to impact substantially on these cardiovascular and bone health risk factors.

Aim: To provide a range of community-based physical activities, support and education opportunities to enable survivors, at any fitness level, to develop lifelong healthy eating and physical activity patterns to benefit health, wellbeing and quality of life.

Method: Autologous or allogeneic SCT survivors (≥2 years in ongoing remission) attending the Late Effects Clinic are offered the opportunity to participate in the 'Positive Change for Life' project. Each participant enters a 12 month program integrating the key components of dietary advice, tailored individual and group physical activity, motivational strategies and GP support.

Results: Recruitment commenced July 2012. Baseline data collection is ongoing and changes over time for dimensions of interest relating to anthropometric measurements, laboratory parameters and questionnaire items examining quality of life, barriers to physical activity, leisure time exercise habits, dietary intake and fatigue will be assessed.

Conclusion: The completion of cancer treatment can represent an opportunity to make changes to improve health & wellbeing. A critical need for SCT survivors to address lifestyle has been identified. Regular exercise, good nutrition & maintaining a healthy weight are all strategies that may improve health, wellbeing and quality of life for long-term survivors of curative SCT.

60 – Utilising life changing experiences of cancer survivors and care-givers to deliver community based psychosocial programs

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There is a dynamic opportunity within community and not-for-profit organisations to engage volunteers to facilitate programs that will assist others.

For many people that have lived through a diagnosis and treatment of cancer or who have had a hands-on caring role, it is a life altering experience. A great deal of focus is placed on active treatment and prevention of recurrence. It is often not until the acute phase of treatment has finished, that patients and care-givers start to learn and cope with a "new normal" and process what has actually happened.

Could there be a better way to name and normalise the different experiences of people affected by cancer other than bringing together a team of people who have experienced the disease first hand? Surviving cancer for many instils a great sense of wanting to "give back" to the community. The passion and commitment to assist others becomes a priority where they can provide insights, support, strategies and understanding that no others can provide unless it has been experienced personally.

Cancer Council NSW is committed to providing quality evidence-based programs to the NSW cancer community. Since 2008, trained volunteer facilitators who are cancer survivors and/or former care-givers have delivered the "Living Well After Cancer" program throughout NSW supported by trained volunteer administration staff. In addition to their personal experience with cancer, they have the necessary professional skills that are required to become a program leader.

This is an initiative that honours how life-changing experiences can empower an individual to utilise their existing professional skills to support and deliver a sustainable community education program.

61 – When treatment finishes – opportunities for a multidisciplinary approach to service and support delivery for cancer survivors

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Aim: To provide accessible, sustainable supportive care and practical support pathways for cancer survivors in NSW and beyond.

Method: Research shows that post-treatment interventions for cancer survivors should be available in several modalities. In response, Cancer Council NSW created a Cancer Survivorship Unit (CSU) to develop and deliver evidence-based support services for cancer survivors.

The CSU was created by utilising Cancer Council's existing support infrastructure and network. The unit works collaboratively with internal and external stakeholders to create referral pathway linking services for cancer survivors and caregivers. Services are facilitated not only within the organisation but also on an external basis.

Results and Future Direction: Since April 2012, the CSU has addressed unmet survivor and caregiver needs by developing face-to-face programs and complementary downloadable or printed resources. Programs include Living Well After Cancer (psychosocial), ENRICH (exercise and nutrition routine improving cancer health), and Working Beyond Cancer (employee and workplace support). Other support services that the unit is cross referring with, include legal, financial and workplace (HR) advice through our pro bono team; peer support, and in development a return-to-work resource, and vocational counselling.

In addition, pilots are underway to develop support services for young adults aged 18-45. These include tailored Living Well after Cancer and ENRICH programs, art therapy and a young adults online group. Focus group outcomes from these pilot programs will guide support delivery from 2013.

Cancer Council NSW has an opportunity to further extend post-treatment support services by working in collaboration with allied health professionals, treatment or survivor centres and other cancer charities.

62 - Cancer Survivorship: Employement and Return to Work - An Australian Report

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In Australia, in 2007, 775,000 (3.6%) of people had a history of cancer and the five year survival rate for all cancers has increased to 66% for the 2006 to 2010 period. Young cancer survivors often experience chronic health conditions into adulthood, requiring specific attention and adult onset cancer survivors often experience co-morbid health conditions. Cancer survivors are often overwhelmed at the prospect of maintaining their current job or returning to work and the risk of becoming unemployed rises by 37%. A review of the literature was conducted, peer reviewed journal articles and reliable websites were accessed examining the issues of cancer survivorship, employment and return to work. Articles were sourced from MEDLINE (Ovid: January 2005 to September 2012), Psychinfo (Ovid: January 2005 to September 2012), and Google Scholar (September 2012). Many cancer survivors experience persistent physical and psychological issues, with new issues related to employment occurring. Returning to work is an important milestone in recovery, restoring a sense of self, normalcy and control. Improving occupational motivation and reducing skepticism regarding returning to work have been identified as important factors to consider when providing interventions, with education and self efficacy facilitating increased rates of return to work. Maximising opportunities for return to work is important, however major limitations have been identified in the research literature and much work is still required to inform service delivery and health policy. Cancer Council NSW is preparing literature addressing the return to work issues of legal rights, communication with employers and colleagues and an interactive return to work resource for job seekers. The provision of specific work related counselling and an online forum are also being scoped.

63 – The patient experience of melanoma follow-up: An online survey

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Using an online survey, this project investigated, from the patients' perspective, the experience of melanoma follow-up care in Australia,

Methods: Patients treated for primary melanoma after 1 January 2007 and who were diagnosed at least 12 months prior to survey date, were recruited across Australia through health professionals, cancer advocacy and research organisations and patient support groups. Data collection was June-September 2012.

In the context of follow-up, the survey explored provision of melanoma specific information to patients, intervals between visits to health professionals, and imaging tests received. Findings were compared with ACN/NHMRC guidelines for melanoma follow-up.

Results: Of 150 individuals accessing the survey, 64 participants were eligible and completed. Participants reported considerable variation in visits to health professionals from less than the recommended intervals through to duplication of care. Some participants reported test provision and test frequency outside ACN/NHMRC guidelines. One-third described the internet as their main source of information about melanoma and nearly two-thirds would have liked more information. Follow-up care was primarily provided by surgeons and dermatologists but nearly one-quarter saw 3 or more care providers. Nearly half reported inadequate psychosocial support. Having a care-coordinator, was selected as valuable, by 40 participants.

Conclusion: This study provides indications as to the nature of follow-up care for melanoma in Australia. Considerable variability and gaps in follow-up care were identified. The findings suggest that many patients feel that follow-up care provided does not meet their needs. Redirection of funding from expensive radiological tests (CT, PET) that are outside recommended guidelines, or duplicated specialist visits, into patient education, psychosocial support, and care coordinators may be useful measures to help meet the needs of melanoma survivors post-treatment.

Limitations: The study is small, only e-literate individuals could participate and, as a retrospective study, there is potential for recall bias.

64 – An exercise physiologist derived exercise intervention for women with recurrent ovarian cancer

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There is increasing recognition for the need to assist advanced and recurrent cancer patients during treatment. Recent literature into advanced breast cancer/primary ovarian cancer suggests exercise may be beneficial in reducing physiological and psychological deterioration, whilst maintaining Quality of Life (QoL).

This study aims to assess the feasibility of a 12 week exercise intervention for women with recurrent ovarian cancer. The primary outcome was adherence to a 90 minute weekly exercise target and QoL. Secondary outcomes included physiological and psychological side-effects of treatment.

Women undergoing chemotherapy for recurrent ovarian cancer were recruited from the Royal Hospital for Women and the UNSW Lifestyle Clinic. Baseline assessments of n=11 subjects (73% recruitment rate) included mean age of 55±10 years, FIGO stage 3.1±0.7 at first diagnosis and 3.1±2.8 months since most recent recurrence. Subjects demonstrated a BMI = 23.1±3.7, QoL = 93.3±23.8 (FACT-O), fatigue = 2.8±3.1 (SPHERE-SOMA), sleep quality = 8.3±4.2 (global PSQI) and 83.9±8.5% efficiency (Actigraph), aerobic capacity = 26.8±6.3 mL/kg/min (submaximal VO₂), mental health = 36.2±11.7 (SF-36), upper and lower body strength = 23.1±3.4kg and 33.3±9.1kg respectively (10RM) - with re-assessments at 12 and 24 weeks. Whilst we expect to see maintained scores at reassessment, the majority of these baseline measurements scored poor compared to similar aged healthy women. An individualised exercise program prescribed by accredited exercise physiologists including aerobic, resistance, balance and core exercises at 90+ minutes/week. Intensity, type and duration of exercise were recorded in a weekly diary – consisting of clinic and home-based activity. Adherence is high with participants meeting exercise targets 90% of the time, with mean duration of 185±83 minutes/week. Compliance to returning the weekly exercise diaries is 67%.

There have been no reported adverse affects from women undergoing chemotherapy treatment being physically active. Preliminary stages of the trial demonstrates positive signs of feasibility.

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65 – Patients' perspective of dysphagia in the survivorship phase of head and neck cancer

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Purpose: The impact of dysphagia on the patient in the survivorship phase of head and neck (H&N) cancer is not well understood. The current study adopted a patient centred, qualitative approach to examine the lived experience of dysphagia from the patients' perspective in the months and years following treatment. It forms part of a larger project which will map issues to the World Health Organization's International Classification of Functioning, Disability, and Health (ICF), to inform optimal dysphagia assessment and establish future care models for dysphagic patients during the survivorship phase.

Methodology: A demographically diverse group of 24 participants who had undergone curative non-surgical treatment for a mucosal H&N cancer in the past five years were recruited using maximum variation sampling. All participants took part in a semi-structured in-depth interview where they were encouraged to speak about the full

impact of dysphagia. Thematic analysis was utilised to identify key phrases and themes that emerged from the transcripts.

Results: Thematic analysis revealed information rich descriptions of the profound impact associated with food as a result of treatment for H&N cancer. The main themes identified were: 1) the physical impacts of treatment on swallowing; 2) highly emotive responses to chronic dysphagia; 3) altered perceptions and changed appreciation of food; and 4) enforced personal and lifestyle changes. Preliminary mapping across ICF domains confirms both activity and participation level deficits, in addition to body functions and structures with strong influences of personal and environmental factors.

Conclusion: These data confirms the clinical belief that dysphagia has a negative and multi-faceted impact on the patient in the survivorship phase. New assessment methods are required for long-term monitoring of patients with dysphagia which encapsulate environmental and personal factors. Data also highlights the need for new models of long term support to help individuals adjust to changing physical states and to enhance psycho-social adjustment.

66 – "Building yourself to better cope": a qualitative case study of a cycling team led by cancer survivors

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Given the importance of physical activity for cancer survivors, this research aimed to understand the experiences of members of a cycling team led by cancer survivors. Thematic content analysis was employed to resolve major themes across three data sources: semi-structured interviews (N = 7), participant observation of two CVSA group rides (N = 15) and naturally-occurring data from team social media sites (123 posts).

Themes describing the data suggested that valued aspects of the group included a shared understanding of the cancer experience, the positive and health-focused setting, forming friendships based on shared experience, the informal nature of support, and the ability to improve and monitor their health by cycling. Other themes covered the choice of cycling, motivation, the group's ongoing nature, support interactions, and cycling team identity. Further analysis of descriptive themes led to the development of two interpretive themes. 'A unique combination of sport and support' described the multi-layered benefits of the cycling team, which combines some benefits of a support group with the identity of a cycling group, and is potentially more appealing to cancer survivors (males in particular). 'Survivorship on survivors' terms' encapsulated the various ways in which the cycling team enables cancer survivors to regain control over their lives in terms of their physical health, psychological health, support needs and identity.

Recommendations made for exercise groups for cancer survivors included: to consider cycling, an adaptable form of PA which could engage males; to maximise accessibility by catering for differing ability levels; to engage with members using social media; to frame exercise as potentially beneficial for cancer outcomes; to have the group led by cancer survivors; and to ensure ongoing participation with inclusive membership.

67 – Fatigue, Physical Activity, and Autonomic Nervous System Function in Breast Cancer Survivors: A Pilot Study

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Background: Recently, a relationship between autonomic nervous system dysfunction and fatigue was established. In Breast Cancer Survivors (BCS) it was demonstrated that heart rate variability (HRV) was lower in those who experienced high levels of fatigue compared to those who did not experience high levels of fatigue. It has been established that physical activity can normalize autonomic nervous system function in other populations.

Hypothesis: High levels of physical activity and/or exercise tolerance will be associated with greater autonomic nervous system function and lower levels of fatigue.

Methods: Nine women were recruited from the San Francisco Bay Area. Each participant completed the Aerobic Center longitudinal Physical Activity Questionnaire, a 6-minute walk test, and a body composition evaluation via BodPod. An electrocardiogram was collected during rest and during the cold pressor test (COLD) for HRV analysis. Five breast cancer survivors completed the Piper Fatigue Index. Pearson correlation coefficients were computed to examine the relationships between variables. All tests were considered significant at the 0.05 level.

Results: BCS and controls did not differ in age, weight, height, total kcals/week of energy expenditure or blood pressure. During COLD InLF and SDNN were greater in the control group (p < .05). Greater total energy expenditure and InTPcold were negatively correlated (p < .05).

Conclusion: This pilot study provides evidence for possible autonomic nervous system dysfunction in breast cancer survivors.

68 – Improving survivorship outcomes in adolescents and young adults with cancer: the development of a national survivorship care process

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Supporting healthy psychosocial survivorship for AYA patients entails more than monitoring and responding to the physical late-effects of treatment. It involves educating, informing and supporting patients to move beyond their treatment phase and adjust to life after cancer.

To help facilitate this, we developed an Adolescent and Young Adult (AYA) Psychosocial Survivorship Care Process, which includes an age-specific Survivorship Screening Tool and Survivorship Care Plan. The aim of this package is to improve the care provided to survivors of AYA cancer by the early identification of the potential difficulties associated with psychosocial recovery and post-treatment functioning, and to provide a structure for addressing these

The Survivorship Screening Tool is a detailed, check-box style questionnaire, exploring the psychosocial domains which AYA cancer patients frequently identify as being problematic when they transition to the post-treatment phase. These include distress secondary to physical changes, friendships, existential processing, intimate relationships, independence, family, fertility, concentration and memory, education, finances, and others. The screening tool also incorporates an overall measure of distress, and an opportunity for patients to identify their goals, as well as topics that they would like more information about. The Survivorship Care Plan assists the clinician to collate the psychosocial issues identified in the screening tool by their patient as being important, and to collaboratively develop an individualised plan to address these issues. The AYA Psychosocial Survivorship Care Process was developed in collaboration with AYA cancer survivors, who participated in an initial focus group and formed a working party to provide ongoing guidance, and Australian AYA cancer clinicians, from the fields of nursing, social work, psychology, haematology / oncology and late-effects. Piloting of the package has begun in South Australia and Victoria.

It is hoped that by incorporating this newly developed AYA Psychosocial Survivorship Care Process into routine AYA patient management throughout Australia, all young survivors of cancer will receive a minimum standard of psychosocial survivorship care – regardless of their treatment location.

69 – Living with, through and beyond cancer: Giving survivors the skills, support and confidence to take control of their lives

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Background: Cancer patients disclose that when their medical treatment ends, they feel abandoned. the structure of their lives gone. Although the number of cancer survivors has been increasing over the past decades there are knowledge gaps regarding the needs of cancer survivors. The purpose of this study was to identify specific concerns of patients in the key domains of physical functioning, psychological wellbeing and social relationships.

Methods: Patients who had completed their primary cancer treatment within the previous six months self-selected to develop a self-management care plan by attending a structured program, two-hours each week for five-weeks. Patients were asked to describe the ways in which their diagnosis and treatment impacted their lives, to outline deficiencies in survivorship care and to suggest ways of addressing any unmet needs. Discussions were noted and a content analysis was subsequently conducted by the group to identify major themes. Patients set agreed goals addressing, physical functioning, psychological wellbeing and social relationships.

Results: Although the sample was too small for formal statistical testing, overall, the ten women's' psychological experiences of the difficulties of early survivorship indicated persistence of negative intrusive thoughts (90%), grief reaction (80%), shock (20%), distress (70%) and for some, a dysfunctional fear of recurrence (80%). Inequalities in the economic and social determinants impacting on access to cancer survivorship care were recorded.

Conclusion: This program assisted with the transition from treatment to survivorship, and significantly increased the capacity to address this gap. It improved understanding of the specific survivorship care needs of patients related to

type of cancer, or cancer treatments, age and risk profiles. The creation of a sustainable course designed on evidence-based techniques and built around a theoretical framework of positive health psychology to help enhance wellbeing and developing a self-managed survivorship care plan to assist patients in coping with the after effects of treatment and identifying needs along the survivorship trajectory is a beneficial resource, which could be implemented by other cancer centres.

70 – Development of a self-management psychosocial intervention for men with prostate cancer and their partners: lessons learnt from the 'real world'

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The purpose of this feasibility study was to investigate the acceptability of a psychosocial intervention to men with prostate cancer and their partners, and to gain feedback from facilitators, participants and non-participants to make changes to and enhance the intervention. The intervention was assessed in terms of structure, process and outcome. Recruitment strategies, randomisation procedures and acceptability of questionnaires were also tested. The nine week group and telephone intervention commenced following treatment. The intervention focused on symptoms, sexual dysfunction, uncertainty, positive thinking and couple communication. Couples were assigned to the intervention or control group using a randomised block design. Participants were assessed at baseline, immediately post-intervention and at one and six months post-intervention. Outcome measures included self-efficacy, quality of life, symptom distress, uncertainty, benefits of illness, health behaviour, couple communication and support. Process evaluation was conducted through a feedback questionnaire and qualitative interviews. Over the course of 12 months, 18 couples agreed to participate. There was no significant difference between the age of intervention group (Mean = 64.2, SD 7.6) and the control group (Mean = 62.3, SD = 5.9; t = 0.585, p = 0.564). One of the main reasons for declining participation was the group format. Participants were satisfied with the information provided, the structure of the programme and the level of support received. They stated it provided a focus and time for reflection, helped them prioritise issues as couples and made them more aware of their behaviour, needs and wants within their relationship. They valued the group format and peer encouragement attained through this. The partners appeared to have particularly gained from the intervention. The small numbers prevented the determination of the effect of the programme on patient reported outcomes. Further research is needed to enhance recruitment and target 'hard to reach' men.

71 – A randomised controlled trial of an optimised multidisciplinary intervention for post-cancer fatigue – TOPS Trial

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Cancer-related fatigue is a distressing and disabling symptom. When cancer-related fatigue persists beyond the treatment period and is unexplained by alternative medical or psychiatric conditions, it is termed post-cancer-fatigue (PCF)¹.

Since currently no clear understanding of the aetiological basis of PCF exists and no effective prevention or treatment strategy has been defined, a pragmatic approach to intervention is required based on existing evidence for management of patients with chronic fatigue syndromes. It's likely that cognitive-behavioural therapy (CBT)², coupled with graded exercise therapy (GET)³ will improve functional outcomes. A randomised control trial - Treatment of Post-cancer fatigue Study has been developed assigning patients to receiving either an education intervention (n=50), or a 12-week supervised (by exercise physiologist and clinical psychologist), GET and CBT intervention (n=50). The

intervention arm is based on the successful Fatigue Clinic program developed by the Lifestyle Clinic. Potential subjects are screened for clinically-significant fatigue at 3 months post successful-treatment for breast or bowel cancer.

Protocols and ethics applications have been established. Recruitment began recently with 83 potential participants approached. Current recruitment sites include Prince of Wales public (n=33) and private hospitals (n=23), St George public and private hospitals (n=5), Register4 website (n=9) and various private consulting rooms (n=13). 43 patients have been screen with 16 (37%) eligible and 8 enrolled most of whom are female (n=15) with breast cancer (n=15). Of the 27 (63%) ineligible patients mostly with breast cancer (n=20) and female (n=22), major reason for exclusion was reporting not clinically significant fatigue (44%). 36 patients remain to be screened and 4 have been lost to follow-up. The limitations with recruitment numbers to date reflect recent findings that the rate of post-cancer fatigue is not as high as previously thought. Focusing on identification of patients who are at higher risk of sustained fatigue may be beneficial.⁴

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72 – Influencing diet and lifestyle changes in a high risk cohort diagnosed with benign colorectal neoplasia

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Individuals diagnosed with benign colorectal neoplasia (BCN) are at higher than normal risk of developing further polyps or colorectal cancer (CRC)¹. Multiple modifiable diet and lifestyle (D&L) behaviours are associated with CRC risk reduction². Health promotion interventions can influence these behaviours³. A paucity of evidence exists addressing successful Australian health promotion D&L studies among cohorts diagnosed with BCN. This study investigated the efficacy of two D&L interventions. Ninety six participants were randomly allocated to three groups; Information only (IO), Information only + single Motivational Interview with tailored feedback (MI), and Control (usual care) (C). Sixty two participants completed the 6-month study with attrition evenly distributed across the 3 groups. An action research mixed-methods design was used to determine D&L changes pre- and post-intervention. A validated questionnaire determining key predictors of behaviour change was administered to participants at baseline and 6month endpoint. In addition dietary intakes were measured at the same time points using 4-day self-reported food intake diaries. While qualitative self-reports suggest improvement in dietary behaviours improvement, p<0.05) for the MI group (p=0.026) after 6-months compared to the IO and C groups, quantitative statistical analysis did not produce similar findings. Total fat and saturated fat intakes were significantly lower (p<0.05) at endpoint for IO (total fat: baseline 78.0 ± 44.9 ; endpoint $60.9 \pm 28.7 \text{g/d}^{-1}$, p<0.001; saturated fat 30.0 ± 18.8 ; 23.4 ± 11.9 , p=0.001) and MI (total fat: baseline 82.4 ± 40.0 ; endpoint 64.8 ± 29.3 ,p<0.001; saturated fat 31.1 ± 18.2 ; 27.1 ± 15.9, p=0.042) compared with C. Although within group improvements for self-reported smoking behaviour and alcohol frequency were statistically significant (p<0.05) over the study duration for all groups, inter-group comparisons showed no significant differences. These results suggest there were no differences in the efficacy of IO and a single MI health promotion tool among a cohort diagnosed with BCN.

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73 - Moving on from Allogeneic Stem Cell Transplants?

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Over recent decades there has been an increasing number of allogenic haematopoietic stem cell transplants (HSCT) performed with a growing number of survivors. Severe fatigue induced by this procedure affects 30 -75% of allogenic HSCT survivors and hinders long-term quality of life. This prospective cohort study will include 5-8 people who have had an allogenic HSCT in the last 3-9 months and who have consented to being part of the study. Prticipants will undertake an 8 week group program which will include 8 sessions with an exercise physiologist, 4 sessions with a dietition and 3 sessions with a psychologist. Topics to be addressed will include cancer treatment induced side-effects; improving lost muscle mass with through diet and exercise; healthy eating recommendations; exercising at home; returning to work; and regaining your social life. Pre-program testing will consists of the Piper Fatigue Scale questionnaire; a fitness test (6 minute walk, sit-to-stand, balance, body composition, blood pressure, spirometry and grip strength), the S-F 36 questionnaire; and the Cancer Council dietary questionnaire for epidemiological studies. Participants will be re-assessed immediately after and at 6, 9 and 12 months post program completion. This study will not commence until Janurary 30, 2013 so we do not have any results at this stage.

74 – Implementing a survivorship service for patients with head and neck cancers: Are some cancer survivors more forgotten than others?

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Selecting tumour streams for a Survivorship Pilot Project raised the question, are some cancer survivors more forgotten than others? Whilst some tumour groups such as breast and prostate patients have received an increasing profile and services, are head and neck cancer patients and survivors missing out?

Background: Barwon Health's Andrew Love Cancer Centre in Geelong Victoria, is the single radiation treatment centre for the Barwon and South Western region in Victoria. The population is demographically diverse, has a higher than average 50+ age bracket and includes city, rural and sea side communities.

During 2011, 73 curative courses of radiation therapy were delivered by Andrew Love Cancer Centre to patients with head and neck tumours. With improvements in treatment technology the number of patients living with the impact of radiation and chemotherapy is growing. In 2010 head and neck patients made up just 2% of patients diagnosed with cancers in the region, however the level of complexity of medical and psychosocial needs for survivors is high. Sometimes considered more challenging because of lower socio economic levels, substance abuse and low health literacy, the project team received varied responses from professionals after choosing this survivor group.

Aims: The project aimed to trial a Nurse Led Survivorship Clinic and patients were provided with a written Survivorship Care Plan. Guidelines to enhance co-ordinated care and communication between patients, cancer specialists and GPs were implemented and aligned to GP Management Care Plans. Assessment of patients medical and psychosocial risk enabled identification of high risk patients who were provided with more supportive follow up.

Results: Evaluation of health literacy, health education, quality of life and acceptance were conducted, and preliminary results will be discussed.

75 – Returning to work after treatment: An important survivorship issue

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Due to improved prognosis of many forms of cancer, an increasing number of cancer survivors are willing and able to return to work after treatment. This paper presents a sub-set of findings on the experience of haematology patients returning to work after treatment from a major survivorship study funded by the Leukaemia Foundation of Queensland. A qualitative methodology was used including 50 open-ended interviews and one focus group audio-recorded, transcribed verbatim, coded and thematically analysed. All participants had to meet the criteria for survivorship in that they were an adult individual with a haematological malignancy who was at least one year post-diagnosis. 50 participants (n = 26 male; n = 24 female) participated representative of a range of ages, geographical locations and the major haematological diagnostic groups including Multiple Myeloma (n = 15), Lymphoma (n = 14), Leukaemia (n = 17) and other (n = 4). Of the overall cohort, 11 participants had a Bone Marrow Transplant and 15 had a Stem Cell Transplant (allogeneic and autologous transplants). There were three groups identified in relation to employment: (1) those who were retired and work was not an issue; (2) those who had successfully re-entered the

workforce; and, (3) those who wanted to work but were finding the process of return-to-work difficult. It is the third group that is the major focus for this presentation. The clear indications are that Group 3 requires assistance with return-to-work and were vulnerable to a range of psychosocial distress caused by inability to return to employment. The presentation outlines an innovative 'return to work' program presently being developed by the Leukaemia Foundation of Queensland in response to this research.

76 – Survivorship research in Haematology: Findings from Queensland

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- P. McGrath,1 M. Skarparis,2 B Hartigan.2

The Leukaemia Foundation of Queensland recently funded a major study examining the issues associated with survivorship for haematology patients. The research project has provided a wealth of insights to inform the development of supportive care services. A qualitative methodology was used including 50 open-ended interviews and one focus group audio-recorded, transcribed verbatim, coded and thematically analysed. All participants had to meet the criteria for survivorship in that they were an adult individual with a haematological malignancy who was at least one year post-diagnosis. 50 participants (n = 26 male; n= 24 female) participated representative of a range of ages, geographical locations and the major haematological diagnostic groups including Multiple Myeloma (n = 15), Lymphoma (n = 14), Leukaemia (n = 17) and other (n = 4). Of the overall cohort, 11 participants had a Bone Marrow Transplant and 15 had a Stem Cell Transplant (allogeneic and autologous transplants). The findings challenge established ideas of survivorship through an enriched understanding of the meaning of the term survivorship, the importance to patients and their families of keeping the focus on life, and the development of an innovative concept of 'receptivity'. This presentation will provide an overview of the findings with a particular focus on the innovative strategies documented as important in developing supportive care for these individuals.

77 – How good is the guidance for cutaneous melanoma follow-up? A systematic review of clinical practice guidelines

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Background: Clinical practice guidelines are produced to assist clinicians in making evidence-based choices for patient care. We were interested in determining the extent of evidence-based support for recommended patterns of follow-up for melanoma survivors with a history of melanoma and whether this differs according to guideline quality.

Materials and Methods: Guidelines that provide recommendations regarding patient follow-up or surveillance were identified through electronic database searches and appraised using the AGREE II instrument. Evidence relating to melanoma follow-up recommendations in each of the guidelines was reviewed. Guidelines from the USA, Canada, UK, Europe and Australia/New Zealand were included in the study.

Results: Most guidelines performed well in 'clarity of presentation' and poorly in terms of 'applicability'. 'Rigour of development' scores were highly variable. Despite the availability of clear frameworks for guideline development, methodological quality of recently published guidelines is similar to older guidelines. Most guideline recommendations concerning the follow-up of melanoma patients were based on low-level evidence or consensus expert opinion. There was considerable variability between guidelines as to what constituted 'best care' in melanoma follow-up.

Conclusions: The variable methodological quality of guidelines for melanoma follow-up could be improved by attention to the criteria ascribed in AGREE II. Clinicians should be aware of how scant the evidence base is for many of the recommended courses of action and that this can lead to considerable variability in the guidance that is provided and potentially in the quality of care provided to melanoma survivors.

78 – Survivorship connections: the development of a model of survivorship care for young people diagnosed with cancer

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Background: Developing models of survivorship care are considered essential to promote ongoing health and wellbeing for patients, reduce the burden of late effects and ensure the most efficient division of resources. While this applies to all patients, adolescents and young adults (AYA) who experience a diagnosis of cancer are different as they

negotiate a life-stage characterised by rapid development and have the potential of a long life ahead facing many ongoing medical and psychosocial ramifications of cancer and its treatment. In alignment, the NHS has recently defined principles of developmentally appropriate AYA SC. These include: best care, in the best place, delivered by the most appropriate person; care coordination and planning; collaborative healthcare partnerships; supporting primary care; risk stratification; a focus on transition[1]. Recognition of the importance of SC for young people led to the development of the Victorian Department of Health funded Survivorship Connections project by ONTrac at Peter Mac Victorian AYA Cancer Service in 2010 to meet the gap in services for young people and their families.

Aim: The aim of this project is to implement a phase 1 model of survivorship care for young people with cancer in Victoria and evaluate its appropriateness, impact on patient's quality of life and the sustainability of this model.

Method: The project involves: nurse-led intervention; care-coordination; building acute/primary partnerships; care-planning; review and exploring need. Evaluation will be undertaken with formative and summative data focussing on patient reported outcome measures and sustainability. A total of 75 patients will be recruited over 3 sites during a 12 month period.

Discussion: This paper will explore the development of the Survivorship Connections protocol and its key components. The rationale behind this work will be delineated and the anticipated outcomes described.

With Acknowledgement to Dr L. Sanci 2 & Dr K. Drummond 3

- 2 The University of Melbourne
- 3 The Royal Melbourne Hospital

79 – Through their eyes: understanding the survivorship needs and experience of young people with cancer

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- 2. ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service, East Melbourne, VIC, Australia

Background: The period of adolescence and young adulthood (AYA) is characterised by rapid physiological and psychological change and the accomplishment of key tasks required for a successful transition into adulthood. A cancer diagnosis during these years can markedly disrupt all aspects of development. These young people additionally often face significant long term physical and psychosocial morbidity associated with their diagnosis and treatment. In recognition of the unique impacts of cancer on this patient cohort, AYA oncology services are developing which predominantly address the needs of patients undergoing treatment. To date within Australia there are no formal models of survivorship care (SC) which support young people post-treatment and beyond.

Aim: The aim of this project was to better understand the needs and experiences of AYAs with cancer throughout the cancer journey from diagnosis in the transition to post-treatment SC to inform service development.

Method: A comprehensive literature review examining reported survivorship experiences and needs for AYA patients was initially undertaken and used to inform the structure for focus groups. Four groups were held with patients who had experienced a diagnosis of cancer between the ages of 15-25 years. Themes explored during these groups included: the definition of survivorship; experience in transition to post-treatment follow-up care; needs and concerns; what was helpful; what may be improved in relation to service provision and care. Groups were transcribed for analysis.

Discussion: This paper presents the preliminary findings from the groups and the themes which arose in response to the exploration of patient need and experience. The outcomes of these groups have informed the development of a national Victorian survivorship initiative funded in 2011 by the Victorian Department of Health and run by ONTrac at Peter Mac Victorian Adolescent & Young Adult Cancer Service which aims to improve SC for young people diagnosed with cancer.

80 – Early experience of implementation of a triage model for survivorship care at the NSW Cancer Survivors Centre

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Background: Cancer survivors are a large and growing population, whose needs are not well met by traditional models of care.

Aim: to implement a triage model of care within the context of an academic cancer survivorship clinic.

Methods: Cancer survivors attended the NSW Cancer Survivors Centre (NSW CSC) for a single visit with a medical oncologist. Patients underwent comprehensive assessment of physical, psychological and practical sequelae of their cancer and its treatment and individualised Cancer Survivorship Care Plans were developed with recommendations for cancer follow-up care, general health, lifestyle, psychosocial and practical issues. All visits were Medicare funded with no out-of-pocket cost to patients.

Results: 23 survivors have attended the NSW CSC to date, with 22 giving consent for data to be used for research purposes. Survivors had a mean age of 59 (range 29 - 78), were a median of 2 years since their primary diagnosis (range 3 months - 37 years) and 60% were female. The majority of attendees had a primary cancer diagnosis of colorectal (46%) or breast cancer (23%), with smaller numbers of other primary sites represented (lymphoma, leukaemia, head and neck cancer, testicular cancer). Two attendees had experienced a second cancer. A median of 5 survivorship issues were identified (range 3 - 9). The most commonly identified survivorship care issues were physical inactivity (14), fatigue (11), metabolic syndrome (10), care co-ordination (9), mood disturbance (8), neuropathy (7), and cancer screening (5). Equal numbers were referred by their oncologist (10) or self-referred (10) to the service, with the remainder referred by exercise physiologists affiliated with the NSW CSC.

Conclusions: A triage model of care for cancer survivors is feasible within existing funding mechanisms and identifies a range of oncological, general health and psychosocial issues which may subsequently be addressed. These survivors will form the beginning of a cohort whose outcomes will be prospectively reported.

81 – The ovary and cancer treatment – the future of fertility preservation

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Follicular granulosa cells are essential for oocyte growth and maturation. It is postulated that local radiation or systemic chemotherapy is toxic to these cells, causing premature ovarian failure with consequent infertility and premature menopause.

Strategies to avoid these undesirable consequences of cancer treatment include identifying treatment regimes that minimise impact on the ovary, and the cryopreservation of oocytes or ovarian tissue. Each strategy poses specific challenges. Few studies have identified combination regimes that minimise gonadotoxicity (1) or unique targets for minimising follicle depletion. Controlled ovarian hyperstimulation (COH) produces mature, fertilisable oocytes, and subsequent IVF rates of those that survive vitrification (~90%) are similar to fresh oocytes, but an average COH procedure requires 12 days which may be incompatible with treatment, and potentially undesirable in hormone-sensitive cancers. The collection of immature oocytes can occur immediately, but in vitro maturation (IVM) rates are presently too low for clinical application. The IVM, vitrification and IVF of larger metaphase II oocytes has limited clinical success. Autologous transplantation of ovarian tissue has resulted in ~12 births in cancer survivors since 2004 (2) and resumption of menstrual cycles in others. Despite concerns about the lifespan of transplanted tissue and the risk of contamination with haematological malignancies, this emerging technology, as well as advances in IVM, holds promise for the preservation of survivors' fertility.

We are developing novel methods to improve post-cancer fertility; new vitrification protocols, an innovative modification to ovarian transplantation procedures, and the quantification of patients serum anti-mullerian hormone to test the gonadotoxic potential of specific treatments. A close collaboration between fertility experts and oncologists is required to realise the promise of these novel technologies. This will facilitate the translation of innovative advances in the laboratory into sufficiently powered clinical trials.

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Neuhaus, S	63	Segelov, E	23,71	Woodman, R	13
Neville, K	8	Seymour, J	48	Yates, P	15,51
Nund, R.L	65	Shand, M	51	Young, F	81
Nutt, S	25	Shaw, P	43	Young, G	72
O'Brien, I	43	Simons, K	51		
Oakes, C	66	Sinclair, S	27		
Olsen, A.B	67	Skarparis, M	75,76		
Olver, I.N	45	South	66		
Orme, L	78,79	Australia, C	00		
Osborn, M	68	Stacey, F	35		
Palmer, S	68	Street , J	24,63,77		
		Study Group, F	19		

Sponsors & Exhibitors

Aspen Pharma Pty Ltd Table 6

Aspen Pharma Pty Ltd is a dynamic company with an established reputation in Australia since 2001. In February 2011, Aspen acquired Sigma Pharmaceuticals including Orphan Australia. Aspen has assembled a diverse product range including branded and generic pharmaceuticals, healthcare, nutritional, specialty pharmaceutical and advanced technology wound care products. Aspen products are some of the most prescribed brands in Australia, touching the lives of many Australians.

www.aspenpharma.com.au

Breast Cancer Network Australia

Table 4

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer. We have more than 75,000 members, united by a shared experience of breast cancer. We work to ensure that women diagnosed with breast cancer, and their families, receive the very best information, treatment, care and support possible. Through information, support and advocacy we help to inform, empower, represent and link together people affected by breast cancer. More than 90 per cent of BCNA's members have had a breast cancer diagnosis; the remaining members have had a personal experience with breast cancer through a family member or friend.

www.bcna.org.au

Cancer Care Centre Table 3

Cancer Care Centre Inc is a community based, not for profit organisation offering a wide range of complementary care to support cancer patients and their families. Complementary care refers to a variety of holistic health services which enhance wellbeing on physical, emotional, mental and spiritual levels. Areas specific to cancer care include interpersonal support such as counselling and support groups, stress management approaches such as meditation and massage and nutritional approaches such as diet and nutrients. Cancer Care Centre staff consist of a variety of dedicated health care professionals and trained volunteers – many of whom have been affected by cancer.

www.cancercarecentre.org.au

Cancer Council NSW Table 7

The Cancer Council is the leading cancer charity in NSW. The organisation has been the focus of public action, public giving, and public communication about cancer for more than 50 years. Whether as donors, supporters, volunteers or collaborators, the community places great trust in the capacity of The Cancer Council NSW to fulfi I its mission to defeat cancer. Our commitment is to effectively deliver on this trust.

www.cancercouncil.com.au

Cancer Voices SA Table 1

Cancer Voices South Australia is 'raising a voice for those affected by cancer' through advocacy, involvement, awareness and information. Our focus is on wellness and not just illness. Having cancer is not a pre-requisite for joining up. Membership is free and open to all South Australians because 'Cancer doesn't affect one person, it affects the entire community around them'. Our members are cancer patients, their partner, carers, family, friends, neighbours, colleagues and supporters. We are an independent, not-for-profit, 100% volunteer organisation, formed in 2007. We cover all types & stage of cancers across all ages, social circumstances, gender and locality.

www.cancervoicessa.org.au

COSA

The Clinical Oncological Society of Australia (COSA) is Australia's peak multidisciplinary society for health professionals working in cancer research, treatment, rehabilitation and palliative care. COSA currently has over 1600 members who are doctors, nurses, scientists and allied health professionals involved in the clinical care of cancer patients. COSA conducts an Annual Scientific Meeting each November, as well as seminars

and educational activities related to current cancer issues. COSA is recognised as an activist organisation whose views are valued in all aspects of cancer care. COSA is allied with, and provides high-level clinical advice to Cancer Council Australia.

www.cosa.org.au

Fleurieu Cancer Network Table 2

A non funded community based initiative run by dedicated volunteers all touched by cancer, the Fleurieu Cancer Network has:

- 1. Established multi-sectorial partnerships within community, business, government and non government agencies using a top down, bottom up approach for advocacy and support.
- 2. Influenced the design of the Flinders Centre for Innovation in Cancer
- 3. Produced 'My Diary' practical resource for patients
- 4. Produced DVD 'My Cancer Journey- from despair to inspiration' and developing written stories 2013
- 5. Established a generic cancer support group
- 6. Convened three stakeholder 'Working Together' Forums
- 7. Developed and maintains Website, E-newsletter and Facebook pages

www.fcn.org.au

Mundipharma

Mundipharma is a leader in the development and provision of treatments for moderate to severe pain. We provide a broad range of long-acting analysis medicines to accommodate the wide-ranging needs of patients. Mundipharma also has particular expertise in the development of drug delivery systems, including controlled release technology, that have been successfully applied to a range of analysis to benefit patients around the world.

www.mundipharma.com.au

PC4 – The Primary Care Collaborative Cancer Clinical Trials Group

Table 5

PC4 is the Primary Care Collaborative Cancer Clinical Trials Group funded by Cancer Australia to support the development of high quality research and build research capacity in cancer in primary care. We foster collaboration between researchers, health care practitioners and consumers to improve health outcomes and care for cancer patients by filling the evidence gaps in oncology in primary care. Find out more about us by visiting our website www.pc4tg.com.au

www.pc4tg.com.au

Roche Products Table 8

Headquartered in Basel, Switzerland, Roche is a leader in research-focused healthcare with combined strengths in pharmaceuticals and diagnostics. As the world's largest biotech company and leading provider of cancer care products, Roche has a personalised healthcare strategy which aims to provide medicines and diagnostic tools that enable tangible improvements in the health, quality of life and survival of patients. Investing heavily in local research (approx. \$36 million in pharmaceutical salone in Australia in 2008), Roche is looking at a bright future with its strong development pipeline. Roche's innovative anti-cancer medicines include five products approved for use in different cancer types in Australia: Avastin (bevacizumab), Herceptin (trastuzumab), Xeloda (capetcitabine) MabThera (rituximab), and Tarceva (erlotinib).

www.roche-australia.com

Sirtex Table 10

Sirtex Medical Limited (Sirtex) is an Australian publically listed company operating globally with offices in the US, Europe and Asia Pacific. The Sirtex primary objective is to research and develop effective treatments for liver cancer using novel small particle technology. The lead product of Sirtex, SIR-Spheres microspheres, is a form of targeted internal radiotherapy which enables high doses of absorbed radiation to treat extensive unresectable liver tumours whilst conserving normal liver parenchyma. Sirtex is supporting an extensive and ongoing programme of both prospective and randomised clinical studies with SIR-Spheres

microspheres in liver cancer including collaborative group and investigator-initiated studies as well as those run directly by the company.

www.sirtex.com.au

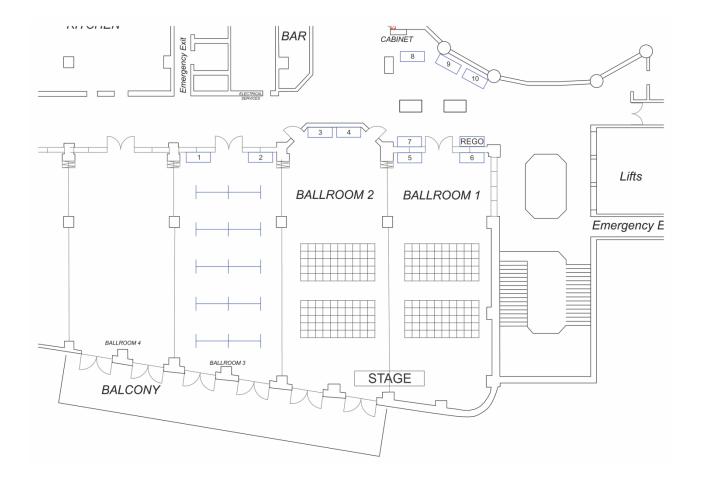
Varian Medical Systems

Table 9

Varian Medical Systems is the world's leading supplier of fully integrated systems for treating cancer and other conditions with radiotherapy, radiosurgery, proton therapy, and brachytherapy. We partner with physicians, scientists, researchers, and others around the world to offer patients the most advanced radiotherapy and radiosurgery treatments. The company supplies informatics software for managing comprehensive cancer clinics, radiotherapy centres and medical oncology practices. For more information, visit http://www.varian.com or contact the Australasian office on +61 2 9485 0111.

www.varian.com

Trade Floor Plan



Notes			
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Flinders Centre for Innovation in Cancer Survivorship Conference 2013 Notes