Clinical Oncology Society of Australia

Flinders Centre for Innovation in Cancer

2019

# CANCER SURVIVORSHIP

## FUTURE OF CANCER SURVIVORSHIP
## EVOLUTION OR REVOLUTION?

# PROGRAM & PROCEEDINGS

**28-29 MARCH 2019**

Rydges World Square | Pitt St Sydney | NSW 2000

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# Contents

# Convenor's Welcome

Dear Friends,

I am delighted to welcome you to the fourth national cancer survivorship conference.

Following three successful events in Adelaide, we listened to your feedback and have decided to host the 2019 conference in Sydney, on 28-29 March 2019 at the Rydges World Square. The move gives us an opportunity for a change of perspective and a chance to bring the meeting closer to some of you!

The fruitful partnership between the Flinders Centre for Innovation in Cancer and COSA ensures this national conference reflects the latest developments in research and care of relating to cancer survivorship. We pride ourselves on creating a conference that engages clinicians, researchers, policy-makers and consumers in one collegial and collaborative forum.

In 2019 we hope to be thought provoking and a bit provocative as well! And that's why we are focussing on the theme of "Future of cancer survivorship: Evolution or revolution?" The last 20 years have witnessed a significant evolution of the field of survivorship. But is it enough? Are there aspects where a revolution is in the making? We recognise of course that revolutions are not usually designed – they are often spontaneous, arising in response to pressing, challenges that cannot be solved in a traditional way – but aren't these just the challenges that cancer survivors grapple with?

The committee has developed a program that we hope will engage our broad audience and perhaps revolutionise a thing or two.

I hope that you will learn and be inspired, that you will connect with old friends and make many new ones and that you will find some time to enjoy the delights of Sydney.

With best wishes,

Bogda Koczwara

Professor Bogda Koczwara AM, BM BS FRACP MBioethics FAICD
Conference Convenor

# Committee

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

**Conference Convenor**

| | |
|---|---|
| Bogda Koczwara | Flinders Centre for Innovation in Cancer |

**Program Committee**

| | |
|---|---|
| Shirley Baxter | Cancer Voices NSW |
| Ray Chan | Queensland University of Technology |
| Chris Christensen | Cancer Voices SA |
| Prue Cormie | Australian Catholic University |
| Haryana Dhillon | University of Sydney |
| Eng-Siew Koh | Liverpool Hospital |
| Annie Miller | Cancer Council NSW |
| Janette Vardy | University of Sydney & Concord Hospital |
| Fran Doughton | Clinical Oncology Society of Australia |
| Marie Malica | Clinical Oncology Society of Australia |

# Host Organisations

Flinders Centre
for Innovation
in Cancer

**The Flinders Centre for Innovation in Cancer (FCIC)**
The FCIC is a leading cancer centre in Australia, housing world-class care and survivorship services alongside innovative cancer prevention and early intervention research. Building on the Flinders Medical Centre's reputation as a leader in compassionate cancer care and the Flinders University's world-class medical research, the FCIC provides an integrated approach to tackling cancer. It is a place where survivorship is not just an ideal but an everyday achievable goal, a place of support and care for all from the point of diagnosis, through treatment and as they continue in life.
http://www.fcic.org.au

Clinical
Oncology
Society of
Australia

**Clinical Oncology Society of Australia (COSA)**
COSA is the peak national body representing health professionals from all disciplines whose work involves the care of cancer patients. COSA's vision is that all Australians receive quality multidisciplinary cancer care from supported and informed health professionals who work in a multidisciplinary manner.
https://www.cosa.org.au

# Ashleigh Moore Oration 2019

The Oration was established to recognise the significant contribution of Ashleigh Moore to the field of cancer survivorship in South Australia and beyond. To commemorate Ashleigh's lasting contribution to the care of those affected by cancer, the Flinders Centre for Innovation in Cancer established the annual Ashleigh Moore Oration to recognise an individual or organisation in Australia who has made an outstanding contribution to the care of cancer survivors through contribution to clinical practice, research, policy, and/or advocacy affecting cancer survivors.

Congratulations to Richard Cohn who will be presenting the 2019 Ashleigh Moore Oration on Friday 29 March.

**Professor Richard Cohn**

Richard is the Head of Clinical Oncology and Director of the Survivorship Program at the Kids Cancer Centre and Clinical Program Director (Medical and Diagnostics) at Sydney Children's Hospital, Randwick and a Conjoint Professor at UNSW Sydney. He has been a leader in paediatric and adolescent cancer survivorship for over 30 years publishing his first paper in this area in 1984 detailing complications in lymphoma patients. He has made outstanding national and international contributions to care of cancer survivors through preclinical and clinical research and the translation into clinical practice, as well as to the education of health care professionals and patients in this area.

In recognition of the Award Richard will deliver his Oration "Cancer Survivorship: Cure is not enough" at the Conference.

# International Speaker

**Dr Yousuf Zafar**
**Duke Cancer Institute, North Carolina, USA**

Dr. Zafar is a gastrointestinal medical oncologist and healthcare delivery researcher. He is an Associate Professor of Medicine and Public Policy at the Duke Cancer Institute and Sanford School of Public Policy. He serves as Director of the Center for Applied Cancer Health Policy at the Duke Cancer Institute. Dr. Zafar's research explores ways to improve cancer care delivery with a primary focus on improving the affordability of cancer treatment. He approaches this issue from both patient-focused and policy perspectives. He has over 80 publications in top peer-reviewed journals including the New England Journal of Medicine, the Journal of Clinical Oncology, and JAMA Oncology. Dr. Zafar also serves as Clinical Associate Director of Duke Forge (Health Data Science Center), and Co-Leader for Duke Cancer Institute's Healthcare Delivery Research Focus Area. His research has been funded by the National Institutes of Health and the American Cancer Society, among others. His work has been covered by national media outlets including Forbes, New York Times, Wall Street Journal, NPR, and Washington Post.

# National Speakers

**Prof Sanchia Aranda**
**Cancer Council Australia**

Professor Sanchia Aranda AM is CEO of Cancer Council Australia, the immediate Past President for Union for International Cancer Control. Sanchia is inaugural Board Chair, of the Cancer City Challenge Foundation. With 40 years' experience in cancer control as a clinician, researcher, educator and health-system administrator, Professor Aranda is a former Deputy CEO at the Cancer Institute NSW and a past-President of the International Society of Nurses in Cancer Care. As CEO of Australia's peak non-government cancer control organisation, Professor Aranda is a strong independent voice on evidence-based cancer control. She is engaged in all fields of cancer from prevention through to survivorship and has a particular professional interest in improved ways to care for and support people with cancer. Her passion is to ensure that all Australian's achieve best possible outcomes from cancer.

**Prof Emily Banks**
**Australian National University**

Professor Emily Banks is a public health physician and epidemiologist with interest and expertise in chronic disease, large scale cohort studies, pharmacoepidemiology, Aboriginal Health and healthy ageing. She has over 250 publications in peer-reviewed journals. She currently leads the Epidemiology for Policy and Practice Group at the National Centre for Epidemiology and Population Health, Australian National University, is Scientific Director of the 45 and Up Study at the Sax Institute, a Fellow of the Australian Academy of Health and Medical Sciences and a Visiting Professor at the University of Oxford. She has previously served as Chair of the Advisory Committee on the Safety of Medicines and an advisor to the World Health Organization. The main emphasis of her work has been in using large-scale data to identify potentially modifiable factors affecting individual and population health in different settings and to quantify their effects, to inform improvements in health and health care.

**Dr Ben Bravery**

Dr Ben Bravery is a junior doctor in Sydney. He was diagnosed with stage three colorectal cancer at the age of 28, an experience that inspired him to change careers from zoology and science communication, to medicine. During treatment, Ben started blogging about the science of cancer and his journey. As a patient-turned-doctor, he now writes and speaks about patient advocacy and the cancer experience for outlets including the ABC, The Huffington Post and Medical Observer. Ben has also advised multiple cancer organisations, researchers and a primary health network. Recent research includes an assessment of radiation oncology teaching at medical schools across Australia and New Zealand, a review into research on depressed people with cancer and exploration of how general practitioners diagnose psychiatric conditions in people with cancer.

**Dr Ben Britton**

Dr Ben Britton is a Senior Clinical and Health Psychologist who has worked with patients with cancer and their families for 15 years and currently works in the John Hunter Hospital Liaison Psychiatry Service in Newcastle.

**Prof Alex Broom**
**University of New South Wales**

Alex Broom is Professor of Sociology and Co-Director of the Practical Justice Initiative at The University of New South Wales (UNSW), Sydney. He is recognised as an international leader in the sociology of health and illness. He has worked extensively in cancer and palliative care across contexts and cultures. He has published over 240 publications including 14 books, and his recent books include Dying: A Social Perspective on the End of Life (Routledge, 2015), Bodies and Suffering: Emotions and Relations of Care (Routledge 2017, with Ana Dragojlovic), and, Survivorship: A Sociology of Cancer in Everyday Life (Routledge, forthcoming). The substantive focus of his recent critical sociological work has been on empirically mapping and theorising the lived experience of cancer and the end of life from patient, family and clinician perspectives, and has featured in journals such as The Sociological Review, Social Science & Medicine, Subjectivity and Critical Public Health. These studies have largely focused on mapping lay experiences of illness, healing and survivorship, and the complexity of cancer care in everyday life (whether curative, supportive or palliative). Working collaboratively with clinical partners he has consistently translated his research into practice-relevant formats, with some recent examples including: guidance for nurses on how to manage conversations about futility, enablers of more timely referral for palliative care by doctors, better models for managing bereavement for families, and strategies for fostering workforce sustainability in oncology in Australia. He an investigator on over AU$8.5 million in competitive research grants, and currently holds Honorary/Visiting Professorial positions at King's College London, The University of Vienna and The University of Queensland.

**Victoria Cullen**
**RMIT, and "A Touchy Subject"**

Victoria is the founder of 'A Touchy Subject', a website for sexuality products and conversation about life after sexual function changes. She loves hosting free webinars on the latest research in this space. She is conducting her PhD research at RMIT University applying a 'design thinking' perspective to sexuality challenges faced after prostate cancer surgery. In 2015, Victoria co-founded the world's first 'sexuality and design' course in an academic setting at RMIT University, featured in The Age and on The BBC. She is passionate about creating more options for people who want to understand and solve their sexuality challenges.

**Rodney Ecclestone**
**Australian Digital Health Agency**

Influenced through frontline clinical practice experiences in the acute setting, Rodney has a career long interest in consumer safety and quality in healthcare, holding senior appointments in clinical governance, clinical and biomedical research administration, commercialisation and safety leadership. He has led consultation on national reform initiatives aimed at achieving improved efficiencies in the Australian national system of 'human research ethics and scientific review' of multi-centre oncology clinical trials and epidemiological research.

Rodney has been at the forefront of national efforts to focus on the application of systems safety methods in digital services and product delivery, particularly relating to healthcare identifier services and consumer controlled electronic health records.

Rodney holds post graduate qualifications in applied philosophy, bioethics, and public health.

**Dr Katharine Hodgkinson**
**HeadwayHealth**

Dr Katharine Hodgkinson is a Clinical Psychologist with over 20 years' oncology experience in client care, research and education. Katharine worked specifically in gynaecological oncology for 8 years where she developed her interest in addressing intimacy concerns and conducted her research on the assessment of cancer survivors and partners unmet supportive care. Katharine's interested in practical advice for health professionals led to a collaborative practical text the psychosocial care of cancer patients and Katharine currently leads a group of clinical and consulting psychologists at HeadwayHealth providing clinics across Northern Sydney.

**Lee Hunt**
**Cancer Voices NSW and Cancer Voices Australia**

Lee is an Executive Member of Cancer Voices NSW (CVNSW) and Cancer Voices Australia (CVA). She is the leader and coordinator of the Consumers in Research program for CVNSW and CV Australia. In 2000, Sally Crossing founded Cancer Voices to advocate on behalf of all people with cancer. CVNSW, in conjunction with the Cancer Council NSW, runs advocacy and research training for cancer consumers and supports consumer representation on a range of committees. It has been influential in improving cancer diagnosis, treatment, care, information and the direction of cancer research in Australia. Lee was diagnosed with an aggressive Grade 3 cancer at age 53. Following surgery to remove the tumour, she undertook an 18-month treatment program to reduce the risk of a reoccurrence. Unfortunately, she suffered significant side effects from all three treatments. Realising that the cancer journey doesn't stop when treatment finishes led Lee to look for ways she could connect and advocate with others who shared the same experience. After a 40-year career in education she joined CVNSW and has since taken on various consumer roles on research projects and committees. She is presently a member of the Faculty of Radiation Oncology Council (RANZCR), the Radiation Therapy Advisory Group and the Centre for Research Excellence DISCOVER TT, at Menzies School of Health Research.

**A/Prof Ilona Juraskova**
**University of Sydney**

Associate Professor Ilona Juraskova is a teaching academic and psychosocial researcher at the School of Psychology, the University of Sydney. She is also Deputy Director at the Centre for Medical Psychology and Evidence-based Decision-making (CeMPED) at the University of Sydney. Trained as a clinical psychologist, Ilona has over 20 years' experience conducting psycho-oncology research, and has taught health psychology to students and clinicians from a range of disciplines over the last 10 years. Her current research program focuses on the development and evaluation of evidence-based interventions to improve clinician-patient-family communication and psychosexual adjustment following chronic illness. Ilona has authored over 80 publications and has been a Chief Investigator on 16 peer-reviewed grants valued over $6.8 million. With her research team, she has developed/evaluated over 20 educational and decision-making resources for patients and their family, as well as communication skills training modules for clinicians.

**Dr Deme Karikios**
**Nepean Cancer Care Centre**

Dr Deme Karikios graduated from the University of Sydney Medical Program in 2005 and obtained his FRACP in Medical Oncology in 2012. He is a medical oncologist at Nepean Cancer Care Centre in Sydney with a clinical interest in gastrointestinal, thoracic and genitourinary malignancies.
Deme is currently writing up his PhD entitled "The costs and effects of anticancer drugs" at the NHMRC Clinical Trials Centre, University of Sydney, under the primary supervision of Professor Martin Stockler.
Deme's research interests include costs and cost-effectiveness of anticancer drugs, decision making and preferences for expensive unfunded anticancer drugs. Deme has an interest in cancer care policy, is an executive member of the Medical Oncology Group of Australia and chairs the Oncology Drugs Working Group.

**Prof Bogda Koczwara**
**Flinders Centre for Innovation in Cancer**

Professor Bogda Koczwara is a senior staff specialist in medical oncology at the Flinders Centre for Innovation in Cancer in Adelaide, Australia and the National Breast Cancer Foundation Fellow. Her clinical interests revolve around management of breast cancer, survivorship care, psychooncology and supportive care and she has a particular interest in strengthening of the interface between specialist and primary care for cancer patients especially in rural Australia.

Professor Koczwara leads the Survivorship Program at the Flinders Centre for Innovation in Cancer. She is the Lead in Survivorship for the South Australian Health and Medical Research Institute Comprehensive Cancer Consortium and she leads the development and implementation of the survivorship framework for cancer patients in South Australia. She is the Chair of the Survivorship Group of the Clinical Oncology Society of Australia and the Vice chair of the Psychosocial Group of the Multinational Association of Supportive Care in Cancer. She is a member of the international Survivorship Taskforce for the Breast Cancer International Group.

Professor Koczwara is the 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 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.

Professor Koczwara has been recognized as a Member of the Order of Australia in January 2015 for her services to oncology through clinical practice, education and research and through a range of professional organisations. In 2018 she was nominated for a prestigious Women who Conquer Cancer Mentorship Award sponsored by the American Society of Clinical Oncology Foundation.

**Dr Eng-Siew Koh**
**University of Sydney**

Dr Eng-Siew Koh is a Senior Staff Specialist in Radiation Oncology, based at Liverpool Hospital, NSW and Conjoint Senior Lecturer at the University of New South Wales. Her interest in the field of cancer survivorship was fostered during a three year Fellowship at Princess Margaret Hospital, Toronto Canada, developing sub-specialty interests in neuro-oncology, haematological, breast and lung cancer, with a particular research focus on late effects after cancer treatment in paediatric and adult survivors. Her current research interests include addressing the impact of cancer treatments including radiotherapy and other systemic therapies on the manifestation and chronology of cardiovascular disease in oncology populations. Dr Koh is also co-lead for a prospective cardiac MRI and echo study addressing the detection of cardiac sequelae in patients undergoing radiation for breast and other intra-thoracic cancers. She is part of an imaging research group in South Western Sydney Local Health District (SWSLHD) which is developing a multi-atlas cardiac segmentation technique that aims to automatically generate heart and valvular structures from a radiation planning CT scan, so that radiation dosage to these structures and therefore cardiovascular risk can be more accurately estimated in larger scale cohorts. Together with Cardiology collaborators, a cardio-oncology service has been established in 2017 for SWSLHD accepting referrals of oncology and haematology patients requiring assessment and management of acute and chronic cardiovascular conditions. Dr Koh is a chief investigator on the successfully-funded ACRF Oncology Alliance for the Science of Integrative Survivorship ("OASIS") Centre, of which cardio-oncology research will be a central pillar.

**Lillian Leigh**

A Sydney lawyer turned patient advocate, Lillian Leigh hopes to use her personal experiences and those of whom she meets to create positive change and improve health outcomes. Lillian is a member of Cancer Australia's Advisory Council, the Research and Data Advisory Group, and the PdCCRS Grants Review Committee. She is also a consumer representative on the Australasian Lung cancer Trials Group (ALTG) Management Advisory Committee, and the Woolcock Institute's Lung Cancer Research Network Advisory Committee. As a lung cancer and a rare cancer patient, she has also represented patients as a volunteer advocate for Lung Foundation Australia, Rare Cancers Australia and Cancer

Council NSW. In December 2016, Lillian received a Patient Advocacy Award at the 17th World Conference on Lung Cancer Conference in Vienna.

**Prof Thomas Marwick**
**Baker Heart and Diabetes Institute**

Prof Thomas Marwick, MBBS, PhD, MPH, completed training in medicine and cardiology in Australia, before undertaking an Imaging Fellowship at Cleveland Clinic, a PhD at the University of Louvain, Belgium and a Masters in Public Health at Harvard. He is Director of Baker Heart and Diabetes Institute, and has divided his career mostly between Australia (formerly at the Menzies Institute for Medical Research and Professor of Medicine and Head of Cardiovascular Imaging Research Centre, UQ) and the USA (former Head of Cardiovascular Imaging at Cleveland Clinic). His main contribution has been in clinical research and research training, and has supervised about 30 research higher degree students – mainly clinical – including 22 completed PhDs. He was one of the initiators of stress echocardiography, and has made contributions to the prognostic evidence underlying cardiovascular imaging. His main current research interests relate to the detection of early cardiovascular disease and cost-effective application of cardiac imaging techniques for treatment selection and monitoring. He has published over 650 papers, reviews, chapters and editorials, and is an Associate Editor at JACC and Deputy Editor at JACC-Cardiovascular Imaging. Professor Marwick has been the recipient of more than fifty significant research grants and several awards, including the Simon Dack Award from the American College of Cardiology, 2009 and the RT Hall Prize (2006) and Kempson Maddox Lecture (2011) of the Cardiac Society of Australia and New Zealand.

**Julie McCrossin**

Julie McCrossin gets people talking. After 20 years as a broadcaster with ABC Radio National, ABC TV and Network Ten, she is now a freelance journalist and broadcaster. Julie writes for the NSW Law Society Journal and facilitates conferences and seminars. Julie has qualifications in the arts, education and law. After treatment for stage 4 throat cancer in 2013, Julie is now an Ambassador for Beyond Five, Targeting Cancer and TROG Cancer Research. In 2017, she hosted the podcast series, The Thing About Cancer for Cancer Council NSW. www.juliemccrossin.com

**Jessica Medd**
**HeadywayHealth**

Jessica Medd is a Senior Clinical Psychologist with has over 20 years' experience providing services to both men, women and couples dealing with a wide range of emotional and health concerns. Jessica's extensive experience working within a specialist hospital-based Urological Department, provides her with unique clinical skills in cancer, urological conditions and sexual difficulties. She also offers a clinic at HeadwayHealth where she provides the latest psychological and physical techniques to maximise sexual functioning, emotional wellbeing and quality of life. Jessica's research and teaching interests have included managing emotions, sexual functioning and prostate cancer (removed survival).

**Prof Bettina Meiser**
**University of NSW**

Professor Bettina Meiser is a Professor and Head of the Psychosocial Research Group, Prince of Wales Clinical School, University of New South Wales, Sydney, Australia. She is a an internationally recognised expert in the area of psychosocial aspects of cancer genetics. She has published over 170 peer-reviewed articles. Her research program focuses on the psychological impact of cancer genetic counselling and testing, and the design and evaluation of interventions in this setting. She has undertaken research on the psychological impact of genetic testing a range of conditions including, amongst others, hereditary breast and/or ovarian cancer (HBOC), Lynch Syndrome, Familial Adenomatous Polyposis (FAP), and hereditary melanoma. She has also conducted innovative research on the psychosocial implications of new gene testing technologies, including the impact of treatment-focused genetic testing following a diagnosis of breast and/or ovarian cancer and the impact of testing for low-risk gene variants related to breast cancer. Bettina Meiser has been involved in the development and evaluation of a range of psycho-educational materials, including decision aids, for use in different settings in the cancer genetic counselling setting and oncology. All of the decision aids she has developed for people at increased genetic risk for hereditary disorders are being widely disseminated to familial cancer services around Australia. She is also undertaken extensive research on cultural aspects of cancer genetics.

**Prof Janette Perz**
**Western Sydney University**

Janette Perz is the Professor of Health Psychology and Director of the Translational Health Research Institute, Western Sydney University. She researches in the field of reproductive and sexual health with a particular focus on gendered experiences, subjectivity and identity. She has undertaken a significant research program in psycho-oncology including the evaluation of gendered experiences and interventions for cancer carers; research on sexual experiences and interventions for people facing cancer; an examination of changes to fertility across a range of cancer types; and the cancer experience of LGBTI cancer survivors and their partners.

**Sam Patterson**

Sam was diagnosed with Stage IIIb Hodgkin's Lymphoma seven years ago at the age of 21. When most people's lives are just getting started his was put on hold. With a lengthy diagnosis and the subsequent treatment he received, which lasted for approximately two years. Throughout and after his treatment Sam's life played host to range of different experiences brought about directly due to his diagnosis. The most prominent being the loss of a close friend to a rare form of cancer whilst going through his own treatment. His journey was featured on Channel Nine's RPA and he has been an ambassador for Cancer Council NSW since finishing chemotherapy in February 2012. Sam has featured on numerous advertisements for the Cancer Council and was heavily involved with the Rekindle Project, which focuses on strengthening sexual health after a cancer diagnosis. Sam is currently working for the Federal Opposition of the Australian Labor Party.

**Dr Micah Peters**
**University of South Australia**

Based in the Rosemary Bryant AO Research Centre at the University of South Australia, Dr Micah Peters is the inaugural National Policy Research Adviser (Federal Office) of the Australian Nursing and Midwifery Federation. Micah has over ten years of experience working in research, having held positions at the University of Adelaide, Cancer Council SA, and the Joanna Briggs Institute. Micah's primary foci are evidence-based healthcare and policy, research synthesis methodology, and consumer and stakeholder engagement in research. Micah has led high-profile research projects funded by the Stillbirth Foundation Australia and the United Kingdom Department for International Development as well as rapid reviews for the New South Wales and Victorian Health Departments and as the JBI Academic Lead for the Cancer Care Speciality, has authored over 200 evidence-based recommended clinical practice resources in cancer care. Micah has published over 50 peer reviewed papers since 2013 and has also taught courses in the conduct of systematic reviews as well as the implementation of evidence-based practice in clinical settings around Australia and internationally. Micah is an Associate Editor for BMC Medical Research Methodology and the JBI Database of Systematic Reviews and Implementation Reports and has been a member of the Multinational Association of Supportive Care in Cancer (MASCC) since 2016, is involved in the Rehabilitation, Survivorship, and Quality of Life and Palliative Care study groups, and sits on the MASCC Membership Committee. Micah has a research interest in the healthcare experiences of gender and sexually diverse people and enhancing the reporting of scoping reviews. Micah's two most recent co-authored publications, in Psycho-oncology and Annals of Internal Medicine, focus on these respective topics. Micah currently supervises higher degree students and is involved in several research projects in the Rosemary Bryant AO Research Centre.

**Ms Sana Qadar**

Sana Qadar is a journalist and podcaster who has worked with a number of international broadcasters including the ABC, SBS, BBC and Al Jazeera. In 2011, her partner was diagnosed with stage three colorectal cancer. She then took on her toughest job to date: becoming his carer.

**Dr Ursula Sansom-Daly**
**University of NSW**

Dr Ursula Sansom-Daly is a clinician-researcher and a Post-Doctoral Fellow at the School of Women's and Children's Health, UNSW Medicine, University of NSW. She leads the mental health research team within the Behavioural Sciences Unit, Sydney Children's Hospital. Ursula is also the lead Clinical Psychologist for Sydney Youth Cancer Service, the leading clinical team for the treatment and care of adolescents and young adults aged 15-25 years with cancer in Sydney. Reflecting her dual clinical-research roles, Ursula focuses on applying evidence-based psychology to both understand, and address, mental health issues among adolescents and young adults with cancer from diagnosis through to survivorship and end-of-life. For the past 5 years, she has led two large national randomised-controlled trials, 'Recapture Life' and 'Cascade', evaluating the feasibility and efficacy of online videoconferencing interventions for adolescent/young adult cancer survivors, and parents, in adjusting to life after cancer. Ursula also has a growing research focus on improving end-of-life communication with young people with life-limiting illnesses. Ursula holds prestigious Early Career Fellowships from both the National Health and Medical Research Council (NHMRC) and the Cancer Institute NSW, and has been a chief investigator on grants >$4.9M. She was also one of the ABC's 'Top 5 Under 40' scientists in residence in 2017.

**Lesley Shears**

Lesley Shears is an advocate, a carer and a survivor. Her life changed in 2013 when her husband was diagnosed with mesothelioma. The long-anticipated retirement dream of travelling around Australia evaporated – instead there was the reality of facing a terminal illness together. She is passionate about raising awareness of the dangers of asbestos through advocacy and education. She now puts the skills learned in her working life with The Law Society of SA and the Mediator Standards Board to good use by volunteering with the Asbestos Victims Association (SA) Inc. Lesley is a breast cancer survivor and volunteers for the Survivors as Teachers programme initiated by Cancer Voices SA and the University of Adelaide.

**Carla Thamm**
**Princess Alexandra Hospital**

Carla has worked as a Registered Nurse for 18 years in many clinical areas in Melbourne and throughout Queensland and the UK. Carla has been consistently working with cancer patients since 2004 and in advanced practice roles since 2009. Along with her clinical experiences she gained an Honours degree, through a written dissertation about survivorship and resilience in cancer care. She also has a Post Graduate Certificate in Advanced Nursing (Cancer) and a Masters of Nursing (Practice). She is currently in the final stages of completing her PhD investigating how discourse effects the head and neck cancer experience. She has previously been awarded the Pam Renouf Career Development Study Award. Carla presents at both national and international conferences regularly and has recently published a systematic review in the Collegian. She is a committee member on the Cancer Nurses Society of Australia, Queensland regional group, and the Knowledge and Development committee for International Society for Nurses in Cancer Care. Carla is passionate improving the care of cancer patients, increasing the profile of specialist cancer nurses and developing the role of nurse researchers in the clinical space.

**Mrs Nyan Thit Tieu**

Mrs Nyan Thit Tieu migrated from Burma in 1977. Her career spanned over 30 years working in education and training and management within the Department of Education as Operations Manager of NSW Adult Migrant English Service. In 2013 Thit was diagnosed with breast cancer, a life changing experience that ushered in a new phase in her life. She founded and facilitates “Sisters’ Cancer Support Group Inc.”(SCSG), the Illawarra based not-for-profit charity organisation. SCSG provides support to those women in CALD communities who are affected by cancer. Thit is a member of the Cancer Institute NSW “Community and Consumer Advisor Panel”. She works in collaboration and partnership with health professionals, Cancer Council NSW, Multicultural Community Council of Illawarra and Illawarra and Shoalhaven Local Health District (ISLHD). SCSG aims to work as a catalyst between the Multicultural Communities and the Cancer Care Service providers in NSW. Her vision and mission is to enhance cancer survivorship, awareness, healthy living and access to cancer services for all women affected by cancer from Multicultural communities by sharing, caring and supporting each other in our cancer journey.

**Dr Elysia Thornton-Benko**
**Specialist General Practitioner and Driector of Wellac Lifestyle**

Dr Elysia is a General Practitioner/Family Physician who cares for all age groups, genders and medical conditions including preventative health and wellness. Dr Elysia has a special interest in Oncology and Cancer Survivorship and has both personal and professional oncology experience. She has worked for various hospital oncology units, including 2 years in Radiation Oncology Specialty Training, in addition to 6 months as a community palliative care registrar. Dr Elysia has several research publications and was awarded a PhD for her Thesis which focused on enhancing edge detection in Breast Mammograms. Elysia currently works in a consulting and advisory capacity on a variety of Cancer Survivorship projects. She is a Member of Scientific Advisory Committee for the Harry McPaul Cancer Council NSW Program Grant ; A Cancer and Palliative Care and Breast Medicine Network Member, RACGP National Faculty of Specific Interests; A member of PC4 (The Primary Care Collaborative Cancer Clinical Trials Group); Multidisciplinary GP Review Board Member for the Re-Engage Study for childhood cancer survivors run out of the Behavioural Sciences Unit of the Kid’s Cancer Centre, Sydney Children’s Hospital Randwick, NSW; A Content Advisor for the Cancer Institute NSW EVIQ information sheets for GP Education regarding cancer patients during active treatment. Dr Elysia is passionate about Cancer Survivorship and believes there is a growing need for GP and community health professional involvement to support those that have been affected by a cancer diagnosis. This will ultimately lead to delivering optimal care to cancer survivors and their families while working cohesively alongside hospital oncology treatment teams. In this way, survivors and their families can thrive in the community with great support linkages and improved quality of life.

**Jane Turner**
**University of Sydney**

Jane Turner is an accredited exercise physiologist at the Sydney Survivorship Centre, Concord Cancer Centre and Researcher with the Survivorship Research Group (SuRG) at the University of Sydney. Her clinical and research interests focus on improving outcomes for people diagnosed with cancer through prescribing targeted exercise across the cancer continuum from pre-habilitation through to survivorship. Jane is an active member of the Clinical Oncology Society of Australia Exercise Cancer Group and Exercise and Sports Science Australia Cancer Special Interest Group. She also is engaged in undergraduate and master of exercise physiology teaching for cancer sciences courses and chair of the Sydney Local Health District Exercise Physiology Clinical Network.

# Program

## Thursday 28 March 2019

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### Registration Open

7:30AM - 5:30PM Ballroom Foyer

### Official Opening

8:45AM - 9:00AM Grand Ballroom
Chair: Bogda Koczwara

Welcome to Country
Official Opening by Helen Zorbas

### A pacifist's guide to starting a survivorship revolution

9:00AM - 10:30AM Grand Ballroom
Chairs: Bogda Koczwara & Murray McLachlan

9:00 AM **Yousuf Zafar**
First do no (financial) harm *abs# 1*

9:20 AM **Julie McCrossin**
What do consumers want from a survivorship revolution? *abs# 2*

9:35 AM **Ben Bravery**
Cancer survivorship through the lenses of a doctor and consumer – respect, teamwork and connection *abs# 3*

9:50 AM **Panel discussion** - A pacifist's guide to starting a revolution

10:20 AM **Release of the COSA PRO Think Tank report**

### Morning Tea & Poster Viewing (Poster Session 1 - see page 19 for listing)

10:30AM - 11:00AM Exhibition Area

### Financial toxicity

11:00AM - 12:00PM Grand Ballroom
Chairs: Christine Paul & Lee Hunt

11:00 AM **Sanchia Aranda**
The Australian and international perspectives on financial toxicity *abs# 4*

11:15 AM **Yousuf Zafar**
The path to affordable cancer care *abs# 5*

11:35 AM **Deme Karikios**
Cost of anticancer drugs *abs# 6*

11:50 AM **Louisa G Gordon**
Patient out-of-pocket medical expenses over two years among Queenslanders with and without a major cancer *abs# 7*

*The conference acknowledges the sponsorship of* Cancer Council NSW

## The Best of the Best Survivorship Abstracts: Session 1

12:00PM - 12:30PM Grand Ballroom
Chair: David Joske

12:00 PM **Leisa Leon**
The Clinical Placement Program in Cancer Survivorship: improving provider knowledge and confidence to deliver survivorship care *abs# 8*

12:10 PM **Carolyn G Mazariego**
Prostate cancer survivorship: examining long-term self-reported quality of life and unmet supportive care needs in the second post-treatment decade *abs# 9*

12:20 PM **Janette Vardy**
Health Concerns of cancer survivors after primary anti-cancer treatment *abs# 10*

## Lunch & Poster Viewing (Poster Session 1 - see page 19 for listing)

12:30PM - 1:30PM Exhibition Area

## What's app doc? Life in the digital world

1:30PM - 2:30PM Grand Ballroom
Chairs: Ben Bravery & Phyllis Butow

1:30 PM **Ben Bravery**
Introduction to the digital world from a cancer patient perspective *abs# 11*

1:40 PM **Rodney Ecclestone**
My Health Record *abs# 12*

2:00 PM **Bogda Koczwara**
Development of a Strategic Framework for Digital Health in Cancer Care *abs# 13*

2:20 PM **Jennifer R Job**
Healthy Living after Cancer+Text: A text message-delivered, extended contact intervention targeting healthy weight, diet and physical activity behaviour *abs# 14*

## Carers and families: perspectives from the front line

2:30PM - 3:30PM Grand Ballroom
Chairs: Chris Christensen & Shirley Baxter

2:30 PM Shirley Baxter - Introduction

2:35 PM **Ben Britton**
What research tells us about carers and families of people diagnosed with cancer *abs# 15*

2:45 PM **Panel discussion** chaired by Chris Christensen
**Panel**: Ben Britton, Sana Qadar, Gail O'Brien, Tania Rice-Brady and Lesley Shears

## **Afternoon Tea & Poster Viewing** (Poster Session 1 - see page 19 for listing)

3:30PM - 4:00PM Exhibition Area

## The Best of the Best Survivorship Abstracts: Session 2

4:00PM - 4:30PM Grand Ballroom
Chair: David Joske

4:00 PM **Rebekah Laidsaar-Powell**
A qualitative meta-review of psychosocial cancer survivorship research: Areas of density and paucity *abs# 18*

4:10 PM **Chloe Yi Shing Lim**
Cancer-related cognitive impairment: a comprehensive evaluation of a standard patient factsheet *abs# 19*

4:20 PM **Sim Yee (Cindy) Tan**
Using Patient Reported Outcome Measures (PROMs) as routine in the Survivorship Clinic *abs# 20*

## Moving + Making – integrating physical activity and creative interests that can benefit an individual's lifestyle before, during + after treatment

4:30PM - 5:30PM Grand Ballroom
Chair: Judith Lacey

4:30 PM **Jane Turner**
Something for the body – Beyond the gym: Tailoring the exercise prescription to people who don't wear lycra *abs# 16*

4:40 PM Arterie – An arts + health hospital based program using the creative, visual and performing arts to engage, educate and enhance the clinical experience + environment

## Welcome Reception & Dinner

5:30PM - 7:30PM Exhibition Area

# Program
Friday 29 March 2019

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## Registration Open

8:30AM - 4:00PM Ballroom Foyer

## Ashleigh Moore Award Oration

9:00AM - 9:30AM Grand Ballroom
Chair: Bogda Koczwara

Recipient oration by **Richard Cohn**

## The 3Cs of Life: how Cancer, Cardiovascular Disease and Co-morbidity collide

9:30AM - 11:00AM Grand Ballroom
Chairs: Geoff Delaney & Elysia Thornton-Benko

9:30 AM **Eng-Siew Koh**
What about my heart health Doctor?? Understanding the broad aetiology and spectrum of cardiovascular disease in cancer survivors *abs# 17*

9:45 AM **Tom Marwick**
Cardio-oncology – an emerging field *abs# 21*

10:05 AM **Emily Banks**
Big Data approaches to cancer and cardiovascular health *abs# 22*

10:25 AM **Lauren Ha**
Cardiovascular fitness and physical activity in childhood survivors of cancer, potential role for exercise physiology services *abs# 23*

*The conference acknowledges the sponsorship of*

PoCoG
Psycho-oncology Co-operative Research Group

**Panel Discussion –** Eng-Siew Koh, Thomas Marwick, Emily Banks, Lee Hunt and Elysia Thornton-Benko

## Morning Tea & Poster Viewing (Poster Session 2 - see page 23 for listing)

11:00AM - 11:30AM Exhibition Area

## Oh Lord, please don't let me be misunderstood! Language and cultural considerations in survivorship

11:30AM - 12:30PM Grand Ballroom
Chairs: Afaf Girgis & Thit Tieu

11:30 AM **Alex Broom**
The significance of culture and language within the pursuit of person-centred care in oncology *abs# 24*

11:45 AM **Thit Tieu**
How we navigate the health system: A personal perspective (of a patient or caregiver) *abs# 25*

12:00 PM **Bettina Meiser**
Training our health care professionals to communicate more effectively with migrants *abs# 26*

**Panel discussion –** Alex Broom, Thit Tieu and Bettina Meiser

## **Lunch & Poster Viewing** (Poster Session 2 - see page 23 for listing)

12:30PM - 1:30PM Exhibition Area

## Love and other things: Managing sexpectations after cancer

1:30PM - 3:00PM Grand Ballroom
Chairs: Haryana Dhillon & Sam Patterson

1:30 PM **Victoria Cullen**
Kinky stuff: where to get useful information & resources *abs# 27*

1:45 PM **Ilona Juraskova**
Rekindling sexual communication: what we learnt from the Rekindle project *abs# 28*

2:00 PM **Janette Perz**
Inclusion in cancer survivorship care: addressing the sexual concerns of LGBTIQ cancer survivors *abs# 29*

2:15 PM **Katharine Hodgkinson and Jessica Medd**
Sex talk: facilitating communication about desire in couples and singles after cancer *abs# 30*

**Panel discussion –** Victoria Cullen, Ilona Juraskova, Janette Perz, Katherine Hodgkinson, Jessica Medd and Sam Patterson

## **Afternoon Tea & Poster Viewing** (Poster Session 2 - see page 23 for listing)

3:00PM - 3:30PM Exhibition Area

## Communication matters: conquering stigma, marginalisation and fear

3:30PM - 4:45PM Grand Ballroom
Chairs: Ray Chan & Lillian Leigh

3:30 PM **Carla Thamm**
Overcoming stigma can enhance communication with head and neck cancer survivors? *abs# 31*

3:45 PM **Micah Peters**
Principles for good communications with LGBT patients with cancer *abs# 32*

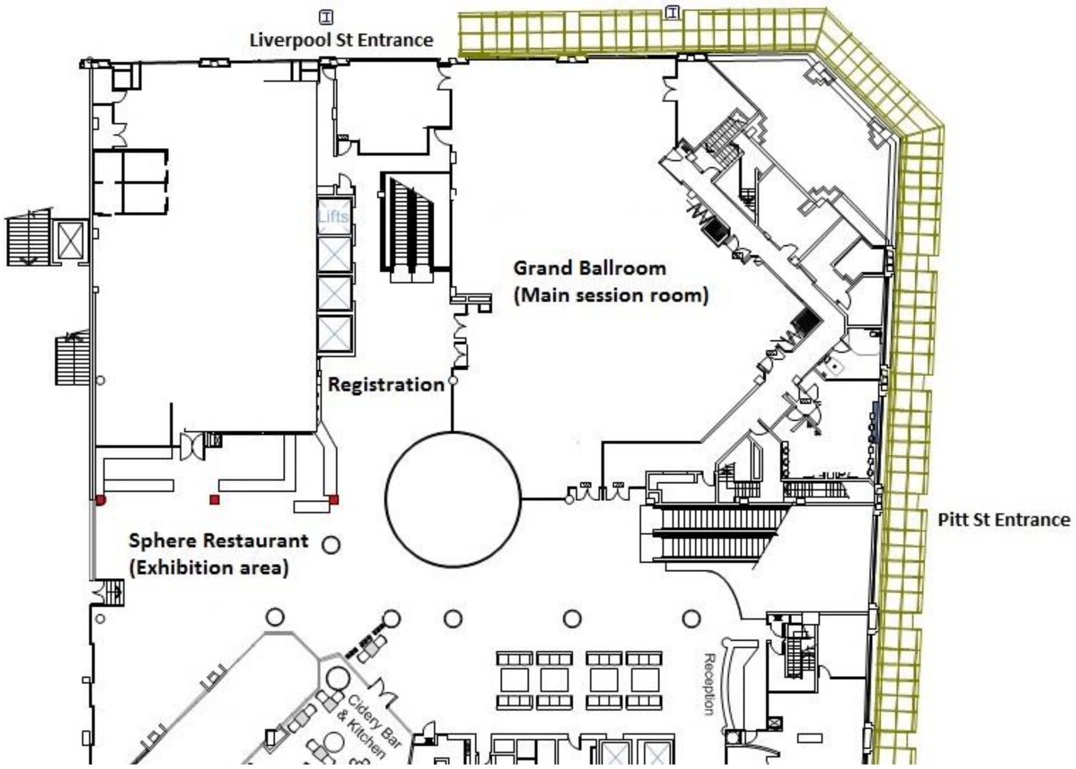
4:00 PM **Ursula Sansom-Daly**
Strategies for effective communication in caring for children with cancer *abs# 33*

**Panel discussion –** Carla Thamm, Micah Peters, Ursula Sanson-Daly, Lillian Leigh

## Closing remarks, conference reflections, next steps

4:45PM - 5:00PM Grand Ballroom
Chair: Bogda Koczwara

# Delegate Information



*Venue: Rydges World Square, Pitt St, Sydney*

### *Registration desk*

The registration desk will be located in the Foyer outside the Grand Ballroom and will be open from 7.30am to 5.30pm Thursday and 8.30am to 4.00pm Friday.

### *Session rooms*

All sessions will be held in the Grand Ballroom. Breaks and posters will be held in the Sphere Restaurant (Exhibition area). The welcome reception on Thursday evening will also be held in this space. Please refer to above map for reference.

### *What is included in your full registration*

- Access to all sessions
- Conference book
- Welcome reception
- Morning teas, afternoon teas and lunches
- Access to the conference app

### *Name tags*

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

### *Social function*

**The welcome reception** is being held on Thursday 28th March in the Sphere Restaurant from 5.30pm to 7.30pm.

### *Internet access at the conference*

1. Select “Rydges Conference” from the list of available networks
2. Key in password/passphrase: conference
3. You will then be prompted to key in the activation code for the respective event: *code provided on the day

### *Conference App*

The official Survivorship web based ‘App’ will keep you organised during the meeting. The output is displayed in a simple and easy to read format on your phone, iPad, or even your computer. To get the ‘App’, please open the following link in your internet browser. You can save the page to your home screen; the conference logo will then appear as an icon on your home screen for you to open as an ‘App’. You must *log in* each day to utilise all of the functions. Simply enter the same email & password you used to register. The web based ‘App’ will allow you to:

- View the full conference program
- View all abstracts for the conference
- View speaker bios and photos
- Save your favourite sessions and plan your day

http://survivorship-2019.m.asnevents.com.au/

### *Instructions for oral presenters*

Please upload your presentation onto the computer in the Lecture Room, either on the morning of the day you are presenting, or in the break prior to your session commencing, an ASN staff member will be on hand to assist. 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.

*Instructions for poster presenters*

Poster viewings will be held over two days as below:

**Poster Session 1 - Thursday 28 March**
**Morning tea:** 10:30am – 11am
**Lunch:** 12:30pm – 1:30pm
**Afternoon tea:** 3:30pm – 4:00pm

**Poster Session 2 - Friday 29 March**
**Morning tea:** 11:00am – 11:30am
**Lunch:** 12:30pm – 1:30pm
**Afternoon tea:** 3:00pm – 3:30pm

It is requested that you stand by your poster on your allocated day. Those presenting in Poster Session 1 can mount their poster when arriving at the conference on Thursday morning, and must remover their poster at the end of afternoon tea. Those presenting in Poster Session 2 can put up their poster on Friday morning and they must be removed by the end of afternoon tea on Friday. There will be Velcro available on the poster boards provided.

# Local Information

Discover one of the most visited destinations in all of Australia. Home to the UNESCO World heritage Sydney Opera House, located on the iconic Sydney Harbour, idyllic beaches famous the world over, national parks, a thriving entertainment & restaurant scene and a fascinating heritage. Take a break and enjoy whats on offer in this famous Australian city.

**Beaches & pools:** When mercury rises head to one of Sydney's soft white sand beaches. Known for its cosmopolitan beach lifestyle, there are fantastic beachside experiences on offer. From the world- famous Bondi and Manly beach, surf beaches Cronulla and Maroubra to countless secluded beaches in Sydney's south. With activities including surfing, swimming, boating and fishing, you will never want to leave. Take a break at one of the many enticing eateries along popular beaches and enjoy the true Sydney beach lifestyle first hand. Along with the wonderful coastline of beaches Sydney also has a wonderful array of ocean pools and swimming baths. At the southern end of Bondi Beach is the world-famous saltwater pool *Bondi Icebergs*. Other Sydney pools include: Wylies Baths at Coogee, Bondi baths at Bondi Beach, Fairy Bower Pool in Manly and Palm Beach rock pool at Palm beach, just to name a few!

**Explore historical laneways:** Discover cobbled laneways, marvel in the iconic Sydney Opera House and the Sydney Harbour bridge or enjoy a drink in some of Australia's oldest colonial pubs. Regarded as a famous strip of land where European settlers stepped ashore in 1788, essentially being the birthplace of modern Sydney. With markets, galleries, museums, delicious food and wine experiences, these cobbled laneways are best explored on foot. There are ample walking tours which operate throughout The Rocks and you can also hire a bicycle and pedal around the harbour foreshore.

**The flavour capital:** Savor in the delicious authentic cuisines from around the world, thanks to Sydney's multicultural heritage, Sydney is a food lover's dream! From waterside dining and countless street eats; including Dixon Street in Chinatown & Kensington Street in Chippendale to soaring sky bars overlooking the city and fresh produce markets, including *Sydney Fish Market* one of the biggest seafood markets in the world. Explore Angel Place nestled in the city centre, this intricate series of lane ways are filled with charming restaurants and bars, marvel in the artwork canopy of birdcages with recorded bird songs *Forgotten Songs*. Enjoy fine dining in the acclaimed restaurants Bennelong and Sixpenny or the culinary experience of 360 Bar and Dining, offering fresh seasonal dishes matched with award winning wines, located high above the city in iconic Sydney Tower offers revolving views of Sydney's skyline. For outdoor dining Sydney has an array of options including heritage listed Finger Wharf in Woolloomooloo and lively Darling Harbour (where you can also visit a zoo and an aquarium) Milsons Point, Lavender Bay, Rose Bay and Watsons bay. Or for something different why not take a scenic Rose Bay seaplane flight to Sydney's waterside restaurants.

**Sport and adventure:** Sydney is packed full with countless sports and activities making this city one big adventure. Climbing the *Sydney Harbour Bridge* has remained one of Sydney's 'must dos'. The panoramic views from the top of the largest steel arch bridge in the world are breathtaking and guaranteed to be an unforgettable experience! If heights aren't your thing, why not try kayaking, stand-up paddle boarding or sailing on Sydney Harbour, or wander through one of the magnificent walking trails around the harbour. For the horse lovers out there saddle up for some wonderful adventures with horse-riding through the Centennial Parklands in the heart of Sydney. With lessons for beginners all the way to experienced riders, this is an activity for everyone to enjoy. For more adrenaline; Western Sydney is where you will experience it all! Countless sports including white-water rafting at Penrith White water stadium, jetpack adventures and wake boarding at Cables Wake Park. The options are truly endless.

# Poster Listing

## Poster Session 1 – Thursday 28 March

**Anupriya Agarwal**
Effects of cancer treatment on household income and employment status – A prospective single centre study *abs# 100*

**Georgina Akers**
The impact of a state-wide Survivorship Program: Outcomes of the first two years of the Phase II Victorian Cancer Survivorship Program. *abs# 101*

**Michael Back**
Reflecting on survivorship outcomes to aid initial decision-making in patients managed for IDH-mutated anaplastic glioma *abs# 103*

**Julia Baenziger**
"I grew the confidence": The doctor-patient communication experience for parents of children with cancer *abs# 104*

**Sue Baker**
CanCare - Using volunteers to build a support network for a person with cancer from diagnosis to survivorship *abs# 105*

**Vanessa Beesley**
The hidden burden of anxiety and depression in ovarian cancer: a prospective study from diagnosis *abs# 106*

**Vanessa Beesley**
When Will I Feel Normal Again? Exploring the Trajectories and Predictors of Delayed Recovery of Symptoms and Wellbeing after Completion of Primary Therapy for Ovarian Cancer. *abs# 107*

**Tammy Boatman**
Engaging sedentary women with cancer to participate in a group exercise program – what helped? *abs# 108*

**Jenni Bruce**
Do podcasts work for cancer information and support? Evaluating the impact of *The Thing About Cancer* podcast series *abs# 112*

**Raymond Chan**
RESPONSE: Adaption and validation of a Patient Reported Outcome Measure for Australian Children and Adolescents with Cancer *abs# 110*

**Julie Campbell**
Embedding survivorship care into a regional cancer service. Getting from pilot to standard practice *abs# 113*

**Bena Cartmill**
*Do cancer clinicians identify the health service needs of patients and their families? abs# 114*

**Bena Cartmill**
*What factors contribute to distress in carers of patients undergoing radiotherapy for head and neck cancer? abs# 115*

**Sarah Wing-yu Chan**
What do cancer survivors need and want? The voices of cancer survivors in Hong Kong *abs# 116*

**Dongqing Chen**
FSTL3 release occurs synchronously with onset of doxorubicin-induced cardiotoxicity in an isolated myocardial cell model *abs# 117*

**Chris Christensen**
Evolution and Revolution: 10 Years of Cancer Advocacy and Counting *abs# 118*

**Nadia Corsini**
Testing the feasibility to routinely collect Patient Reported Outcomes post breast cancer surgery via BreastSurgANZ Quality Audit *abs# 119*

**Belle H de Rooij**
Patients' information coping style influences the benefit of a survivorship care plan in the ROGY Care Trial: new insights for tailored delivery *abs# 120*

**Ali Dulfikar**
Can an individualised exercise program assist in maintenance of HRQOL in low and high grade glioma patients undergoing post-operative chemo-radiotherapy? *abs# 121*

**Kate Falconer**
Why Wait for Wellness - The evolution of a multidisciplinary approach to cancer prehabilitation *abs# 145*

**Kurt Fittler**
Surviving and Thriving:  The Active Survivor Exercise Program at Macarthur Cancer Therapy Centre *abs# 124*

**Kathy Flitcroft**
*The impact of lack of choice of breast reconstruction options following mastectomy for breast cancer on Australian women's quality of life. abs# 125*

**Paul Glare**
Cancer survivors with pain have similar unhelpful thoughts and beliefs to other chronic pain patients. *abs# 126*

**Helen Gooden**
Survivors Teaching Students: Saving Women's Lives® (STS)- an ovarian cancer survivors learning initiative for health professional students. *abs# 127*

**Sharon He**
Cancer Clinicians' understanding of cancer-related cognitive impairment and whether a fact sheet can drive practice change: a qualitative exploration *abs# 130*

**Roslyn Henney**
Have your say with ARCHWAY! Recruitment strategies in adolescent and young adult cancer survivors *abs# 109*

**Karen Hennings**
Cancer Survivorship - Introducing key concepts and access to resource availability. A review of education provided to community generalist nurses. *abs# 131*

**Beth Ivimey**
Centralised specialist cancer survivorship assessment clinic (cisco) for patients with early breast cancer or dcis *abs# 132*

**Ilona Juraskova**
The Type and Timing of Breast Reconstruction after Mastectomy: Qualitative Insights into Women's Decision-Making *abs# 128*

**Ilona Juraskova**
Psychosocial and Decisional outcomes Following Breast Reconstruction after Mastectomy: the Role of Body Image Attitudes *abs# 129*

**Emma Kemp**
Digital Health and Disparities in Cancer Care: Opportunities for digital inclusion *abs# 135*

**Emma Kemp**
Development of a Strategic Framework for Digital Health in Cancer Care: Stakeholder-identified barriers, enablers and needs for implementation. *abs# 136*

**Christina Kozul**
Identification of breast cancer survivors' side effects and supportive care needs *abs# 137*

**Rebekah Laidsaar-Powell**
A review of interventions and online resources to improve carer involvement in medical consultations and decision-making *abs# 133*

**Rebekah Laidsaar-Powell**
Strategies to promote effective clinician engagement with cancer carers: The TRIO Guidelines *abs# 138*

**Dianne Legge**
Building the bridge to brain cancer survivorship: a work in progress. *abs# 139*

**Janelle Levesque**
Cancer-related challenges, unmet needs and emotional distress in men caring or women with breast cancer: The influence of self-efficacy *abs# 140*

**Karolina Lisy**
Evaluation of a survivorship care plan database *abs# 141*

**Karolina Lisy**
Recommendations for implementing and delivering shared survivorship care: a systematic review *abs# 142*

**Rachael Morton**
Cost-effectiveness of a psycho-educational intervention targeting fear of cancer recurrence in melanoma survivors *abs# 143*

**Rachael Morton**
Radiation risk from computed tomography surveillance imaging in Stage III melanoma survivors: a simulation modelling study *abs# 144*

**Amanda Piper**
Connecting to wellness: Telehealth as an enabler for regional cancer survivorship supportive care *abs# 102*

**Kyleigh Smith**
Upskilling the primary care workforce in cancer survivorship *abs# 122*

**Christina Signorelli**
E-health tools for childhood cancer survivorship care management: A qualitative analysis of interviews with survivors, parents and General Practitioners. *abs# 111*

**Christina Signorelli**
Parent and child quality of life in long term survivorship *abs# 123*

**Christina Signorelli**
Pain, fatigue, information needs, and fear of cancer recurrence among adult survivors of childhood cancer *abs# 134*

**Julie Symons**
Pathways for older people in a rural hospital's cancer rehabilitation and survivorship service *abs# 146*

# Poster Session 2 – Friday 29 March

**Eva Battaglini**
Exercise as medicine for cancer survivors with chemotherapy-induced peripheral neuropathy (CIPN): A pilot study *abs# 209*

**Bena Cartmill**
*Using an experience-based co-design process to co-create cancer wellness services for patients and their families abs# 244*

**Bena Cartmill**
*ScreenIT: Development, validation, implementation, and expansion of a web-based patient-reported outcome screening tool abs# 245*

**Laura Gilmour**
ENRICHing Survivorship – Wellness and wellbeing for the mind, body and soul *abs# 208*

**Lorna Huang**
The impact of breast reconstruction surgery decision-making on body image outcomes in women with breast cancer: a qualitative study *abs# 246*

**Bora Kim**
The role of generalist community nurses in survivorship cancer care *abs# 251*

**Janelle V Levesque**
Content and delivery preferences for an online intervention to support men caring for women with breast cancer *abs# 200*

**Yunhui Liang**
Investigating follow up of women with early stage breast cancer *abs# 202*

**Karolina Lisy**
Return to work in survivors of human papillomavirus-associated oropharyngeal cancer: An Australian experience *abs# 203*

**Karolina Lisy**
What matters most to breast cancer survivors? Development of a patient-reported outcome measure for clinical assessment *abs# 204*

**Fiona Lynch**
Fear of cancer recurrence and progression in melanoma survivors on novel therapies *abs# 206*

**Lynette Mackenzie**
Cognitive Difficulties for Women after Breast Cancer: Compounding Problems When Trying to Return to Work *abs# 201*

**Lynette Mackenzie**
*The impact of cancer-related fatigue non-pharmacological interventions on occupational performance and participation in adult cancer survivors: A systematic review. abs# 207*

**Megan McIntosh**
A systematic review of the unmet supportive care needs of men on active surveillance for prostate cancer *abs# 247*

**Sue McKelvie**
Canopy TV - An education resource *abs# 210*

**Fiona McRae**
Counterpart Peer Support Volunteers - themes of their conversations *abs# 211*

**Greg Millan**
Shining a Light on Support for Gay Bi Men with Cancer *abs# 212*

**Jillian Mills**
Chinese Cancer Survivors living in Australia: Findings from a Systematic Review and Focus Groups *abs# 213*

**Laura Muir**
Free workplace and recruitment advice for people affected by cancer *abs# 214*

**Alexandra Muirhead**
Breast Cancer Survivorship: exploring the issues faced by culturally and linguistically diverse (CALD) patients in the survivorship period *abs# 215*

**Sharon Nahm**
Fear of Cancer Recurrence in Breast and Colorectal Cancer Survivors *abs# 216*

**Jennifer Nicol**
Quality of life in people with blood cancer after participation in a specialised exercise intervention *abs# 217*

**Sophie Nightingale**
Walking the boundaries – is the 6-minute walk test achievable in a outpatient breast clinic? *abs# 250*

**Jodie Nixon**
Surviving the distress of head and neck cancer: a qualitative study of the experience of distress in the long-term and re-engagement in daily life following treatment *abs# 218*

**Melissa Opozda**
Sexual help-seeking by prostate cancer survivors: A longitudinal study of intentions, behaviours, and needs. *abs# 219*

**James Otton**
Establishment of a dedicated cardio-oncology service for rapid assessment and management of acute and late cardiovascular conditions *abs# 220*

**Punyavathi Paturi**
Setting up a Cardio-oncology clinic at MQ Health- no time to miss a beat *abs# 221*

**Imogen Ramsey**
The impact of attrition on longitudinal, patient-reported health-related quality of life among colorectal cancer survivors participating in the PROFILES registry *abs# 222*

**Eli Ristevski**
Cultural understandings of care giving in Australian Aboriginal families can help to improve cancer survivorship services and outcomes *abs# 223*

**Chloe Salisbury**
Peer support for the 12-month maintenance of exercise and health following a brief exercise training intervention in cancer survivors: Study protocol *abs# 224*

**Saira Sanjida**
How many endometrial cancer patients diagnosed with clinical level of anxiety and depression, and how many received psychological treatment during survivorship? *abs# 225*

**Dianne Sheppard**
Supporting breast cancer survivors to transition back to sustainable work *abs# 226*

**Gemma Skaczkowski**
Supportive care for cancer survivors: Predictors of opinion in the general population *abs# 227*

**Aaron L Sverdlov**
Ibrutinib Related Atrial Fibrillation – A Single Centre Australian Experience *abs# 229*

**Simon Tang**
Using Serial cardiac MRI to detect myocardial changes in patients treated with left sided tangential breast radiation *abs# 230*

**Karen Taylor**
Qualitative results of a phase II pilot randomised controlled trial of a lymphoma nurse-led survivorship model of care. *abs# 231*

**Karen Taylor**
Results of a phase II pilot randomised controlled trial of a lymphoma nurse-led survivorship model of care. *abs# 232*

**Christina Teng**
Patient reported peripheral neuropathy in breast cancer survivors following adjuvant therapy *abs# 233*

**Caroline Terranova**
Effects of a weight loss intervention on metabolic syndrome in overweight or obese women following treatment for breast cancer: a randomized controlled trial *abs# 234*

**Marianne Tome**
Development of a unique digital information delivery tool to empower patient-centred health care *abs# 228*

**Marc Trudeau**
Incidence of diagnosis of relapsing cancer, secondary cancers and other serious diseases in a Survivorship Clinic *abs# 235*

**Jane Turner**
Evaluation of a hospital-based weight management program for overweight and obese cancer survivors. *abs# 236*

**Ida Twist**
Bone Marrow Transplant follow up and transition – who should care? *abs# 248*

**Ida Twist**
NQOL-ALL Study – Evaluating the long-term Neurocognitive outcomes and Quality of Life of children with childhood leukaemia undergoing a Bone Marrow Transplant (BMT). *abs# 249*

**Janette Vardy**
Evaluation of Survivorship Care Plans from survivors attending the Sydney Survivorship clinic *abs# 237*

**Janette Vardy**
Longitudinal follow up of medical oncology survivors attending the Sydney Survivorship Centre Clinic *abs# 238*

**Ngan Vo**
Promoting sustainable healthy eating, exercise and weight maintenance strategies through a community integrated model of health promotion and self-management in a regional area *abs# 239*

**Adam Walker**
Tales from shift working mice: The impact of circadian disruption on cancer progression and CNS toxicities *abs# 240*

**Deborah Kirk Walker**
Developing a Community Based Nurse Practitioner (NP) led Chronic Disease Survivorship Clinic (CDSC) *abs# 241*

**Thomas Walwyn**
Cardiovascular health in asymptomatic, anthracycline-treated survivors of childhood leukaemia: a pilot study. *abs# 205*

**Gregory Webb**
Identification of sexuality and sexual health as an unmet need for cancer survivors in South Western Sydney Local Health District (SWSLHD) *abs# 242*

**Verena Wu**
"Through wind and rain": Chinese cancer patient and caregiver feedback on WeCope, a self-management resource. *abs# 243*

# Abstracts

1

## First do no (financial) harm

**Yousuf Zafar**[1]

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

Not available at time of print

2

## What do consumers want from a survivorship revolution?

**Julie McCrossin**[1]

*1. Public Speaker, Sydney*

Julie McCrossin will share the five key lessons she has learnt about surviving cancer since her experience of stage four oropharyngeal cancer which was diagnosed in 2013. Julie will offer practical suggestions about the steps we can take before, during & after treatment, in partnership with our multidisciplinary team, to improve the quality of our life after cancer. www.juliemccrossin.com

3

## Cancer survivorship through the lenses of a doctor and consumer – respect, teamwork and connection

**Ben Bravery**[1]

*1. Public Speaker, Sydney*

The relationship between patient and doctor is as old as medicine itself. Despite advances in drugs, surgery and scans, the process of getting better always starts with a conversation. Yet, this fundamental aspect of the doctor's craft is often neglected in their training. I know this because I've just finished medical school. My journey to medicine started with a bowel cancer diagnosis at age 28. After receiving the 'all clear', I decided to become a doctor. But, as my knowledge of medicine grows, so does my frustration about the things doctors don't talk enough about and yet can't afford to get wrong. Doctors should reflect on and develop their interpersonal skills like they do any other part of their work. Just like mastering a new procedure or understanding new drug dosing, doctors should be encouraged to evaluate and practise their teaching, leadership and mentoring skills. One problem is that we aren't taught how to be good workers and team members. Doctors are thrust into positions full of status and power, but where are the courses at medical school on leadership, team management, mentorship and peer support?

4

## The Australian and international perspectives on financial toxicity

**Sanchia Aranda**[1]

*1. Cancer Council Australia, Sydney, NSW, Australia*

Financial toxicity is defined by NCI as the "problems a patient has related to the cost of medical care". While out-of-pocket costs for medical care are a substantial driver of financial toxicity or distress, they are far from the only source of costs for the patient and family. Inability to work, costs associated with accessing treatment such as transport and accommodation, and additional requirements such as dressings, over-the-counter medicines and special equipment all add to the problem. There is growing evidence that financial toxicity is relevant to patient outcomes, including survival and that the problem exists across settings of care and across countries of vastly different developmental index. This presentation will explore the range of factors contributing to financial toxicity in Australia and Internationally and consider some of the policy imperatives Cancer Council has identified in seeking to address this problem in Australia. These imperatives include redefining informed consent to include matters related to treatment costs, adoption of a new standard of informed financial consent, changes to Centrelink and other government services to provide improved financial navigation and counselling and raising awareness of the significant gap in cancer outcomes between the poorest and wealthiest Australians.

5

## The path to affordable cancer care

**Yousuf Zafar**[1]

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

Not available at time of print

### 6

## Cost of anticancer drugs

**Deme Karikios**[1]

*1. NHMRC Clinical Trials Centre, Camperdown, NSW, Australia*

The number of anticancer drugs available to treat individuals with cancer has grown exponentially in recent years. This growth in the number of anticancer drugs has been accompanied by a rapid growth in expenditure on anticancer drugs, driven largely by their high price. The high cost of anticancer drugs places strain on publicly funded health systems, and individuals with cancer and their oncologists making decisions about treatment. Accurately determining their value, that is whether the potential benefits are worth the high cost, is important so that individuals with cancer and health systems do not invest their time and resources in treatments of low value.

### 7

## Patient out-of-pocket medical expenses over two years among Queenslanders with and without a major cancer

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**Background:** Patients with certain diseases such as cancer may be more vulnerable to high medical costs owing to the complexity of diagnosis and treatment. We determined the extent of and factors associated with out-of-pocket medical expenses among Australians newly diagnosed with one of five common cancers. Further, we explored if individuals with cancer had higher or lower expenses than individuals without cancer.

**Methods:** During 2010-11, 419 participants from the QSkin Study (n=43,794) had a confirmed diagnosis of either melanoma, prostate, breast, colorectal or lung cancer. These were matched to a general population group (n=421) and a group of high users of general practitioner (GP) services (n=419). Medical fees charged and out-of-pocket medical expenses for Medicare services were analysed. As cost data are typically right skewed, we tested differences in unadjusted mean costs using non-parametric bootstrapping and used generalised linear modelling to identify determinants of high costs.

**Results:** Over two years, median provider fees were $9,821 for the cancer group (75th percentile $20,551), $6,332 for the high GP user group (75th percentile $10,995) and $2,933 (75th percentile $6,394). Out-of-pocket expenses were significantly higher for those with cancer (mean $3,514) compared with the high GP user group (mean $1,837) and general population group ($1,245). Highest expenses for individuals with cancer were for therapeutic procedures (mean $2,062). We found breast and prostate cancer to have the highest out-of-pocket expenses of the five major cancers studied. Older individuals, those with poor perceived health or private health insurance had the highest costs.

**Conclusion:** Individuals with one of the main five cancers pay significantly higher out-of-pocket costs for health care compared with those without cancer even after adjustment for socio-demographic factors and irrespective of private health insurance status.

### 8

## The Clinical Placement Program in Cancer Survivorship: improving provider knowledge and confidence to deliver survivorship care

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**Aims**

The Clinical Placement Program in Cancer Survivorship (CPPiCS) aims to improve access to quality survivorship care by enhancing the capacity of primary care to deliver appropriate care. Specific aims of the program are to increase provider knowledge and confidence to deliver survivorship care, and to enhance links between primary care and hospital-based professionals.

**Methods**

Placement participation is open to primary care professionals including general practitioners (GPs), practice nurses and allied health professionals. Hospital placements are determined by practice location and applicants' area of interest. The program involves attendance at 2-3 specialist clinics and one multidisciplinary meeting (up to 10 hours). Participants complete pre- and post-placement surveys to set and reflect on learning goals, assess perceptions of the program and measure knowledge and confidence.

**Results**

Eight tertiary hospitals are involved, offering 144 specialist clinics across 16 different cancer services. To date total of 98 participants (51 GPs, 22 practice nurses and 25 allied health professionals) have enrolled in the program, and 40 have completed (at October 24 2018). Response rates were 85% (83/98) and 83% (33/40) to pre- and post-placement surveys, respectively. The main learning goals identified were to improve confidence to deliver survivorship care, increase knowledge about cancer treatments, increase knowledge regarding management of long-term and late effects, establish relationships with specialists, and better understand the patient experience; 64% reported these goals had been entirely met. Comparison of pre- and post- responses showed mean scores for all knowledge items increased. Following the program, 91% (30/33) reported increased confidence, 85% (28/33) agreed they had opportunities to enhance clinical relationships, and 91% (30/33) agreed the program was relevant to practice.

**Conclusion**

The CPPiCS is highly regarded by primary care participants, led to increased knowledge and confidence regarding survivorship care, and provided opportunities to strengthen relationships between primary care and cancer specialists.

## 9

### Prostate cancer survivorship: examining long-term self-reported quality of life and unmet supportive care needs in the second post-treatment decade

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**Aim:** To describe self-reported, health-related quality of life (HRQoL) outcomes and unmet supportive care needs in a cohort of men with previously diagnosed prostate cancer, and their partners.

**Methods:** Participants were drawn from the NSW Prostate Cancer Care and Outcomes Study, a longitudinal prospective cohort study. Eligible men were aged less than 70 years, diagnosed with prostate cancer in 2000 to 2002 and resident in NSW. Partners were recruited through participating men. 15-year follow up was undertaken with consenting men using the Expanded Prostate Cancer Index measure for HRQoL and the Cancer Survivors' Unmet Needs (CaSUN) Survey for unmet supportive care needs. Participating partners completed the Cancer Survivors' Partners Unmet needs (CaSPUN) survey.

**Results:** Of the 1398 eligible men, 701 completed 15-year follow-up. 350 men went on to compete the CaSUN survey and 138 partners completed CaSPUN. Patient mean age and follow-up time were 75.8 and 15.6 years respectively. ANCOVA Quality of Life analysis revealed that men who initially had external-beam radiation continue to report significant issues with bowel function (AMD -9.5, 95% CI [-17.44, -1.49]) with radical prostatectomy as the referent. Additionally, 37.4% of men, and 30.1% of partners, reported at least one unmet need at 15-year follow up. Logistic regression revealed clinical factors of disease, specifically a higher PSA score at diagnosis (OR 5.74 CI 1.61-20.5), to be the only significant predictor of future unmet needs.

**Conclusions:** 15 years post-diagnosis men are still experiencing quality of life issues in the domains of sexual function, urinary incontinence and bowel function. Men and their partners are also expressing the need to ensure clinicians are working together to coordinate care. This research suggests that follow-up care in the second post-treatment decade is still needed, and a proportion of prostate cancer survivors may benefit from a multidisciplinary approach to long-term cancer care.

## 10

### Health Concerns of cancer survivors after primary anti-cancer treatment

**Sim Y Tan**[1, 2, 3], **Jane Turner**[1, 4], **Kim Kerin-Ayres** [1, 5], **Sue Butler**[1, 6], **Cole Deguchi**[1, 5], **Sonia Khatri**[1, 5], **Christopher Mo**[4], **Anne Warby**[4], **Ilona Cunningham** [1, 7], **Ashanya Malalasekera**[1], **Haryana Dhillon**[4, 3], **Janette Vardy**[1, 4, 3]

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**Background:**

Cancer survivors experience significant health concerns compared to the general population. Sydney Survivorship Clinic (SSC) is a multi-disciplinary clinic that aims to help survivors treated with curative intent manage side-effects, and establish a healthy lifestyle. Here we determine the health concerns of survivors post-primary treatment.

**Methods:**

Survivors complete questionnaires assessing: symptoms, quality of life (QOL), distress, diet, and exercise before attending SSC; and a satisfaction survey after. Body mass index (BMI), clinical findings, and recommendations were reviewed. Descriptive statistical methods were used.

**Results:**

Overall, 410 new patients attended SSC between September 2013-April 2018, with 385 survivors included in analysis: median age 57 years (range 18-86); 69% female; 43% breast, 31% colorectal and 19% haematological cancers. Median time from diagnosis: 12 months. Common symptoms of at least moderate severity: fatigue (45%), insomnia (37%), pain (34%), anxiety (31%); with 56% having >5 moderate-severe symptoms. Overall, 45% scored distress ≥4/10 (cut-off requiring further investigation) and 62% were rated by our clinical psychologist as having 'fear of cancer recurrence'. Compared to a population mean of 50, the mean global QOL T-score was 47.2, with physical and emotional well-being domains most affected. Mean BMI was 28.2kg/m2 (range 17.0 – 59.1); 61% of survivors were overweight/obese. Only 31% met aerobic exercise guidelines, and 3% met guidelines for aerobic and resistance exercise. In total, 38/113 (34%) had more than two lifestyle risk factors (overweight, not meeting exercise guidelines), in addition to psychological issues (distress thermometer 4+/10, and/or rated as having fear of cancer recurrence), and five or more symptoms of at least moderate severity. Overall, 98% "agreed"/"completely agreed" attending the SSC was worthwhile, and 99% would recommend it to others.

**Conclusion:**

Distress, fear of cancer recurrence, fatigue, obesity and sedentary lifestyle are common in cancer survivors attending SSC and may best be addressed in a multi-disciplinary Survivorship clinic to minimise longer-term effects. This model was highly rated by survivors.

### 11

## Introduction to the digital world from a cancer patient perspective

**Ben Bravery**[1]

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The most digital thing as a cancer patient is the hospital kiosk that scans my appointment barcode. This is in deep contrast to my digital experience of cancer outside the hospital – via messaging platforms, blogs, Instagram, Twitter and (some) support services. In the rush to merge these two worlds when first diagnosed I friend-requested my surgeon on Facebook. After some months I embarrassingly, and quietly, withdrew the request. The gulf between the world of service delivery outside the hospital and service delivery coordinated by a hospital is enormous. I can watch an Uber Eats bicycle pedal from my local Italian restaurant to my front door, but I can't seem to track my cancer surveillance. On the oncology ward I work on now (as a doctor) patients are constantly left to dwell in information vacuums, and that just isn't good enough in a so-called 2.0 world.

### 12

## My Health Record

**Rodney Ecclestone**[1]

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Not available at time of print

### 13

## Development of a Strategic Framework for Digital Health in Cancer Care

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**Aims**

Digital health approaches, including electronic medical records, decision support, wearables and electronic education platforms, promise to improve access and personalisation in cancer care but little is known about consumer preferences regarding digital health applications in cancer and their implementation. This study therefore sought to develop the Australian Digital Health in Cancer Roadmap, a consumer-driven strategic framework for implementation of digital health applications in cancer care.

**Methods**

A systematic literature meta-review (Jan 2013-June 2018) was combined with stakeholder consultations (consumers, health care providers, researchers, policy representatives, and technology developers) to identify barriers, enablers, needs and opportunities for implementation of digital health in cancer care in Australia. Thematic analysis by two independent researchers was then undertaken with resulting themes assessed by an expert reference group to identify corresponding needs and actions for a preliminary framework. Finally, stakeholders rated action items via a Delphi consensus process, to determine inclusion and level of importance/priority in the Roadmap.

**Results**

Ninety-three published reviews and focus groups/interviews with 51 stakeholders were analysed. Barriers, enablers, needs and opportunities for implementation were identified in a total of 23 themes, impacting from initial design and development through to implementation in clinical practice. Priorities included higher quality evidence and more translational research, increasing user access and engagement (including tailoring to individual characteristics/circumstances), ensuring validity, safety, and data security, and developing a coordinated approach with infrastructure and investment for effective integration within and across health services.

**Conclusions**

This study identified priorities for broader inclusion of digital health in cancer care. The Roadmap resulting from this work will enable effective implementation to maximise benefit to health systems and consumers.

Not available at time of print

### 14

## Healthy Living after Cancer+Text: A text message-delivered, extended contact intervention targeting healthy weight, diet and physical activity behaviour

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**Title:** Healthy Living after Cancer+Text: A text message-delivered, extended contact intervention targeting healthy weight, diet and physical activity behaviour

**Authors:** Jennifer R Job, Elizabeth G Eakin, Marina M Reeves, Brianna S Fjeldsoe

**Keywords: mHealth, health behaviour, cancer**

**Background:** Text message-delivered interventions have shown potential as a broad-reach method to extend contact with participants following lifestyle interventions and provide support to prevent weight regain and maintain behaviours.

**Aims:** To evaluate (in a historical controlled trial) the acceptability, implementation and effectiveness of a 6-month text message-delivered, extended contact intervention for participants completing Healthy Living after Cancer (HLaC). HLaC is a 6-month, telephone-delivered intervention for adult cancer survivors, offered by Cancer Councils in Australia.

**Methods:** HLaC completers received either: no further intervention (control n=144) or; extended contact (HLaC+Txt n=78; accrual target = 103) via 1–11 personalised text messages/fortnight for 6-months. Participants (88.2% female, 63.5% breast-, 7.9% colorectal-/bowel-, 28.6% other cancers) had mean age 58.1 years (SD=17.9), BMI=28.7 kg/m$^2$ (SD=6.3) and mean time since diagnosis of 1.9 years (SD=2.8). Acceptability was assessed using qualitative interviews. Implementation was quantified as text message dose. Linear regression, adjusting for baseline, quantified the effectiveness of extended contact relative to historic controls concerning changes in self-report: weight, moderate-vigorous physical activity (MVPA), fruit and vegetable intake between HLaC completion (baseline) and 6-month follow-up. Data collection will be complete in January 2019.

**Results:** To date, HLaC+Txt participants (n=78) found texting acceptable, although had suggestions for program improvement, and requested an average of 6.6 text messages/fortnight. No large or significant (two-tailed $p<0.05$) difference in outcomes were seen in HLaC+Txt relative to controls. Between group effects were small: -0.1 kg weight (95%CI -1.0, 0.8); 2 min/week MVPA (95%CI -53, 57); 0.1 fruit serves (95%CI -0.1, 0.3); and, -0.0 vegetable serves (95%CI -0.45, 0.41).

**Conclusion:** The program was feasible to deliver and broadly acceptable. However, interim results did not support its effectiveness concerning the maintenance of weight, MVPA, fruit and vegetable intake, and the qualitative findings suggested reasons for this. Final results will inform future delivery of the program.

## 15

## What research tells us about carers and families of people diagnosed with cancer

**Ben Britton**[1]

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Cancer survivorship does not occur in a vacuum. Family and carers around the survivor are also affected. This presentation will examine the evidence around various aspects of survivorship for families and carers, providing context for the panel discussion.

## 16

## Something for the body – Beyond the gym: Tailoring the exercise prescription to people who don’t wear lycra

**Jane Turner**[1]

*1. Concord Cancer Centre, Concord*

Exercise for people with cancer is no longer a foreign and alternative concept. Recent research developments have resulted in the release of a position statement outlining the role of exercise as an adjunct therapy for the management of cancer which have been endorsed by the peak oncology and exercise bodies in Australia. Yet many cancer survivors are still not adequately meeting the recommended amounts of weekly exercise.

This presentation will explore the common questions such as “Are these activities and amounts of exercise realistic for most?”; “Do you have to go to the gym?”; and “Are there other types of activities in addition to walking, cycling, swimming and lifting weights that can be done yet still receive the same health benefits?” As well as providing a series of alternative and creative ways that cancer survivors have increased their exercise to combat persisting side effects without attending a formalised gym setting.

## 17

## What about my heart health Doctor?? Understanding the broad aetiology and spectrum of cardiovascular disease in cancer survivors

**Eng-Siew Koh**[1]

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The field of cardio-oncology is an expanding area of medical practice that identifies, prevents and treats the cardiovascular complications related to cancer therapy. It is gaining increasing importance due to the growing spectrum and incidence of cancer therapies in use that have the potential to cause a broad range of acute and late cardiac side-effects. Cancer survivors may be at risk of adverse effects due to radiotherapy, systemic chemotherapy, immunotherapy and targeted agents, either alone or in combination.

Despite the existence of a number of clinical practice guidelines in this area, there is the need to better understand how to optimally select appropriate cancer treatments, identify at-risk patient groups, effectively manage concurrent cardiovascular co-morbidity and also initiate successful interventions.

Internationally and across Australia, we are observing the growth of dedicated cardio-oncology services which seek to facilitate more rapid assessment and management for relevant patients. Aspects of how to deliver a successful cardio-oncology service will be addressed.

There is great opportunity for education and collaborative cardio-oncology research in cancer survivors at both an individual and population-based level.

A greater awareness on the part of the health professional community spanning specialist and primary care providers, as well as consumers regarding their heart health is needed.

## 18

### A qualitative meta-review of psychosocial cancer survivorship research: Areas of density and paucity

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**Aims:** The number of qualitative studies examining psychosocial aspects of cancer survivorship have significantly increased in recent years, with a large number of systematic reviews published. This meta-review (systematic review of systematic reviews) aimed to assess the evidence base, summarising existing qualitative findings and identifying gaps for further research.

**Methods:** Systematic reviews published from 1980-2018 were identified via database searches (Medline, Embase, CINAHL, PsycINFO). Both qualitative and mixed methods reviews were included, however only results pertaining to the qualitative experiences of cancer survivors (post-treatment) were included. Two authors assessed eligibility and extracted data. The quality of the included articles was assessed using the JBI Critical Appraisal Checklist for Systematic Reviews.

**Results:** 1001 titles were retrieved, and 64 reviews were included in the final review. 20 reviews included only qualitative studies and 44 reviews included quantitative and qualitative studies. Whilst many reviews included mixed cancer types (24), the majority of reviews included only one cancer type (breast (20), gynaecological (10), prostate (5), haematological (2) colorectal (1), bladder (1), and melanoma (1)). A high proportion of original qualitative studies were conducted in the USA, Canada, the UK, and Australia. Reviews focused on several specific survivorship areas including psychological experiences of survivors (QoL, fear of cancer recurrence, psychological needs, distress/anxiety/depression), follow-up healthcare, sexuality, return to work, (in)fertility, and cognitive impairment among survivors. A small number of reviews examined diverse experiences of survivors according to demographic differences such as ethnicity, age, and rurality.

**Conclusions:** This meta-review provides insight into areas of research density and paucity. Breast and gynaecological cancer survivors are strongly represented, with few or no reviews for other common cancers (e.g. lung, colorectal, melanoma). Insights from each of the specific survivorship topic areas (e.g. psychological experiences, follow-up healthcare, sexuality) will be discussed, as well as identification of topic areas lacking qualitative insights.

## 19

### Cancer-related cognitive impairment: a comprehensive evaluation of a standard patient factsheet

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**Background:** Cancer patients commonly self-report subtle cognitive impairment. While most common during chemotherapy, impairment can occur before and persist after cancer treatment. The term cancer-related cognitive impairment (CRCI) has emerged to replace '*chemo-brain'*. Despite its prevalence, patients receive little information about CRCI. To address this, Cancer Council Australia released a CRCI factsheet. This study **aimed** to explore the impact of accessing this CRCI information on patients.

**Methods**: The factsheet was reviewed against a linguistic framework for evaluating healthcare text and readability tests. Cancer survivors were recruited, via social media or referral by health professionals, to explore patient perspectives of the factsheet. Participants completed a questionnaire assessing pre- and post-factsheet CRCI knowledge. Semi-structured interviews were conducted and analysed via thematic analysis using a framework approach.

**Results:** The factsheet demonstrated coverage of most elements in the linguistic framework. Readability assessment indicated factsheet is written at a higher level (11.26 years of schooling) than required for the general Australian community.

Interviews with 17 participants generated five themes: perceptions of the factsheet; experience of CRCI; strategies used to manage CRCI; interactions with healthcare system; and impact of the factsheet. Overall, the factsheet's presentation and wording were acceptable to participants. Its ability to normalise and raise awareness for CRCI helped validate patients' perceptions of their symptoms. The factsheet's potential as first intervention in a stepped-care approach was identified. Access to the factsheet may encourage patients to self-report CRCI to healthcare professionals. Barriers to self-reporting include negative perceptions of the healthcare system, lack of perceived need, and limited knowledge of CRCI.

**Conclusion:** The factsheet presentation and content were robust, and while participant perspectives reflected different preferences and experiences, it was well-received overall. We recommend the factsheet be provided to all cancer patients during treatment planning discussions. Policy changes are recommended to ensure ongoing monitoring of symptoms.

## 20

### Using Patient Reported Outcome Measures (PROMs) as routine in the Survivorship Clinic

**Sim Yee (Cindy) Tan[1, 2], Jane Turner[3, 2], Kim Kerin-Ayers[2], Sue Butler[2], Cole Deguchi[4], Sonia Khatri[2], Ilona Cunningham[2], Haryana Dhillon[3], Ashanya Malalasekera[1, 2], Janette L Vardy[1, 3, 2]**

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Background:

The multidisciplinary Sydney Survivorship Clinic (SSC) aims to help survivors manage their disease and lasting treatment effects. Patient Reported Outcome Measures (PROMs) are integrated into the clinical consultation. Here we report patient adherence to PROMs attending their first clinic.

Method:

SSC attendees are mailed PROMs questionnaires and asked to bring completed forms to clinic. PROMs include symptoms, quality of life (QOL), distress, exercise questionnaire, 3-day food diary, food questionnaire, and self-rated performance status. After clinic, patients are asked to complete a satisfaction questionnaire. Descriptive statistics were used to report proportions of completed PROMs as a surrogate of patient acceptability.

*Results:*

Between September 2013-September 2018, 469 patients attended their first SSC visit. Demographics: 68% (n=318) female; main tumour types: breast cancer 41%, colorectal 33%, haematology 17.5% and others (9%). Median age 57years (IQR 17.5years). Average completion rate for PROMs ranged from 83-89%. The food questionnaire was completed by 90% but the 3-day food diary by 53%. Reasons for not completing the food diary included language barriers and attendees not receiving the package.

Overall, 98% (347/354) "agreed" or "completely agreed" attending SSC was worthwhile, and 99% (257/260) would recommend it to others.

Conclusion:

Comprehensive PROMS can be incorporated into clinical practice with excellent adherence, despite some language difficulties. Ensuring streamlined administrative processes helps to reduce avoidable missing data. The need to complete PROMs prior to attending the clinic did not appear to affect patient's satisfaction rating of the clinic.

## 21

## Cardiotoxicity from cancer chemotherapy

**Tom Marwick**[1]

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In addition to myocardial injury, mechanisms of CV toxicity include arterial damage, valve dysfunction, and involvement of the pericardium and conduction tissue. Apart from dealing with the event outcome of HF, cardiologists have primarily been involved in detection of LV dysfunction. HF may develop acutely due to anthracycline cardiotoxicity, myocarditis and takotsubo mechanisms. However, the usual course is chronic, and attributable to multiple injuries with worsening LV impairment. CV imaging plays a vital role in risk stratification and detection of cardiotoxicity (3). However, guidelines range from using modern imaging as a cornerstone (4), to others with a more conservative approach (5). Guidelines are largely opinion based, which is understandable because much evidence is observational and there are few RCTs (6).

Detection of subclinical LV dysfunction has proven difficult and complicated, as standard tools (eg. EF) are not up to the task of sensitive discrimination over sequential assessment. Strain imaging has been a particularly useful tool in cardio oncology but its use is constrained by unfamiliarity in Oncology circles. The fact that this dysfunction is subclinical has led to concerns that we are not detecting a disease entity, with real risks of over-zealous screening - anxiety and unnecessary interference with cancer therapy. Important work has been done over the last decade in standardization of measurements (7), serial follow up (8) and population-based studies (9).

The use of CV imaging in cardio-oncology is part of a larger effort in cardiology to detect early disease and intervene to prevent it from progressing – especially in HF (10,11).

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## 22

### Big Data approaches to cancer and cardiovascular health

**Emily Banks**[1]

*1. ANU, Canberra*

Cancer survival has improved substantively over time such that the majority of people diagnosed with cancer now survive long term. This necessitates holistic consideration of prevention and management of cardiovascular disease and other comorbidities in cancer survivors, alongside optimal management of cancer, to support lives that are as long and fulfilling as possible for those affected. Large-scale data have transformed cancer prevention, diagnosis and treatment and are likely to transform our understanding and optimisation of cancer survivorship. Cancer diagnosis and its treatment predispose to cardiovascular disease. Cardiovascular risk factors and disease are very common in the general population and may be neglected in the setting of cancer diagnosis. This presentation will outline a world-first large-scale general-population linked data platform for survivorship research, comprising >70,000 cancer survivors (including >20,000 developing cancer during follow up) and >190,000 people without cancer, participating in the Sax Institute's 45 and Up Study. It will present preliminary data on cardiovascular risk and outcomes in participants with and without cancer, including according to cancer type, to inform prevention and management.

## 23

### Cardiovascular fitness and physical activity in childhood survivors of cancer, potential role for exercise physiology services

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**Background:** Childhood cancer survivors (CCS) are at increased risk of cardiovascular diseases. This risk is likely exacerbated by low physical activity levels and low cardiovascular fitness. This study aimed to explore cardiovascular fitness and physical activity in CCS and to determine the acceptability of an exercise physiology consultation.

**Methods:** We measured physical activity levels and cardiovascular fitness in survivors aged 8-18 years and ≥1-year post-treatment completion. We assessed fitness using the 6-Minute Walk Test (6MWT) and predicted their maximal cardiovascular fitness using an algorithm based on their age, waist-to-height ratio, gender and 6MWT performance. Survivors received an exercise physiology consultation and a feedback report, additionally provided to treating physicians. Acceptability of the consultation was surveyed one month later.

**Results:** One-hundred and two survivors (mean age=12.9±3.3 years, mean=6.0±4.0 years post-treatment) reported median physical activity levels of 235min/week (0-1470min/week), with only 37.6% meeting the recommended levels. Survivors completed 665±83.5m on 6MWT and had low fitness levels (mean=38.5th±23.4 percentile) based on the algorithm. Forty-five survivors and 59 parents (65 unique families) completed follow-up surveys. Most parents (86%) found the consultation helpful particularly the information and education received, and 91% reported it was not burdensome. The majority of parents (96%) and survivors (95%) recommended other survivors to participate in the study. Most survivors (93%) reported they would be happy to repeat the fitness assessments at their next follow-up visit.

**Conclusion:** Survivors have low fitness, with only one-third meeting the recommended physical activity levels. Considering the risk of cardiovascular late-effects in survivors, there is a need for early intervention to reduce cardiovascular morbidity. Parents and survivors confirmed the acceptability of fitness testing and exercise physiology services, which are not standard of care in this cohort. Assessing fitness in CCS is vital as it allows clinicians to monitor patients at risk and promote behavioural changes.

## 24

### The significance of culture and language within the pursuit of person-centred care in oncology

**Alex Broom**[1]

*1. UNSW, Sydney, NSW, Australia*

Oncology has been interested in the idea and practice of person-centred care for some time, much like medicine more broadly. Alongside this pursuit has been recognition of the importance of integrating cultural and linguistic diversities (e.g. the importance of cultural awareness), in providing quality care and supporting cancer survivorship. Both these professional projects emphasise the qualities of the person as important for delivering quality cancer care, decision-making and supporting survivorship. But how do these values and practices interplay in everyday oncological practice, if at all? In this talk I draw on the results of a qualitative study, funded by the Australian Research Council, focused on migrants living with cancer in Australia and the health professionals who care for them. I focus here on the idea of complex personhood, to bridge concern for engaging the person with a desire to acknowledge their cultural, ethnic and linguistic biographies. This, I will argue, to be successful, necessarily includes recognition of the complex personhood of clinicians themselves, and how this shapes treatment and care.

## 25

### How we navigate the health system: A personal perspective (of a patient or caregiver)

**Thit Tieu**[1]

*1. Sisters Cancer Support Group, NSW, Australia*

The words **"You've Got Cancer"** is like a dagger that pierce a person's heart and immediately turns one's life upside down. As a cancer survivor, Mrs Thit Tieu will be sharing her personal experiences in dealing with her cancer diagnosis, treatment and her survivorship. She touches on her encounters with health professionals covering both the positive and negative aspects during her diagnosis and treatment.

Thit will also talk about the observations she made with regards to the gap that exists for the multicultural cancer patients in their survivorship journey after treatment, leading on to the actions she took to minimise this gap in her own way by setting up the Illawarra based not-for profit organisation "Sister's Cancer Support Group Inc.".

The talk emphasizes the importance of clear understanding and consideration of **Culture**, **Language** and **Faith traditions** in the provision of Survivorship Services. It concludes with some pointers on the strategies that have been most helpful in getting the message across with some suggestions on the best way to provide the cancer survivorship support services to the multicultural communities.

## 26

## Training our health care professionals to communicate more effectively with migrants

**Bettina Meiser[2, 1], Elvira Zilliacus[2], Tim Wong[2], Lisa Woodland[3], Kaaren Watts[2], Sarah Tomkins[4], David Kissane[5], Afaf Girgis[6], Phyllis Butow[7], Sandra Hale[2], Astrid Perry[8], Sanchia K Aranda[9], Tim Shaw[10], Helen Tebble[11], Christie Norris[3], David Goldstein[3]**

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*7. School of Psychology, University of Sydney, Sydney, NSW, Australia*

*8. Settlement Services International, Ashfield, NSW, Australia*

*9. Cancer Council, Sydney, NSW, Australia*

*10. Charles Perkins Centre, Faculty of Health Sciences, University of Sydney, Sydney, NSW, Australia*

*11. School of Languages, Literatures, Cultures & Linguistics, , Monash University, Clayton, Victoria, Australia*

*Objective:* This study aimed to develop and assess the feasibility of an online communication skills training intervention to increase cultural competence amongst oncology healthcare professionals working with individuals from minority backgrounds**.**

*Methods*: The intervention provided examples of communication strategies using vignette-based, professionally produced videos, developed through an iterative process with input from a large multidisciplinary team. Fifty-three oncology nurses completed all three questionnaires at baseline, and within two weeks and then three months after accessing the programme.

*Results:* The online intervention was well received by the majority of participants, and was endorsed as clearly presented, informative, relevant and useful by more than 90% of participants. Eighty seven percent of participants reported increased confidence in communicating with patients via an interpreter, and 93% agreed that skills they gained would be useful in providing better patient care. Participants reported significant improvements in practice while interacting with people with limited English proficiency two weeks and three months after accessing the website ($X^2$=13.66, P<0.001).

*Conclusion*: This online communication training programme can now be tested for its utility in improving patient care for health professionals working with patients from minority backgrounds.

## 27

## Kinky stuff: where to get useful information & resources

**Victoria Cullen[1]**

*1. RMIT and "A Touchy Subject", CBD, VIC, Australia*

*But where do I send them next? What should I suggest? I don't want to raise something I can't then help with!*' One of the main barriers I hear around addressing sexual concerns with patients is the need for further information. It makes perfect sense. No one wants to leave a conversation feeling like they bought up something that led to more questions than answers. We all want to be able to help. However, sexuality is complex, and it can be uniquely challenging to find the right answer or pathway for every scenario. This talk aims to go 'beyond the pamphlet' and equip with you with a toolbox of trusted and easy to access sexual health resources. You will leave feeling confident and capable in navigating the next sex-related conversation you have.

## 28

## Rekindling sexual communication: what we learnt from the Rekindle project

**Ilona Juraskova[1]**

*1. University of Sydney, Sydney, NSW, Australia*

Deteriorating sexual wellbeing can impact long-term quality of life for cancer patients. *Rekindle* is an online intervention aimed to provide accessible and tailored psychosexual support to cancer survivors/partners with unmet sexual concerns. We have previously reported the feasibility results of this study demonstrating a need for psychosexual support amongst cancer survivors; feasibility of online recruitment and delivery of intervention for sexual concerns; although no changes in the outcomes measured were seen. This talk will discuss qualitative findings exploring participants' experiences of the online intervention and its perceived impact on sexual function.

**Methods:** Participants in the phase II study were all Australian adult cancer survivors who had completed primary therapy > 6 months earlier and/or partners. Participants were randomized to either: i) wait-list control (WC); ii) Rekindle (10-week online intervention addressing psychoeducational sexual communication and function) (Int); iii) Rekindle Plus (Rekindle plus three support calls) (Int+). At T2

(10 week) timepoint participants were invited to take part in a semi-structured telephone interview discussing the user experience of the *Rekindle* intervention, the trial, and ongoing sexual concerns. All interviews were completed by telephone, audio-recorded, and transcribed verbatim. Thematic analysis using a Framework approach was undertaken.

**Results:** We interviewed 54 participants (WC = 12, Int = 32, Int+ = 10); the majority were in a relationship (n=41), heterosexual (n=50), and male (n=32). Identified themes were grouped into three overarching categories: the intervention, the trial, and the cancer experience/sexual concerns. Themes related to *the intervention* included: usability, patterns of use, user experience, and evaluation of the content. Themes related to *the trial* included: recruitment and evaluation of content. The themes related to *the cancer experience /sexual concerns*, included: unmet needs, impact of intervention, interaction with the healthcare system, and cancer as a journey.

**Conclusions:** The *Rekindle* intervention was largely acceptable to participants, but additional tailoring of content is required. Timing of the intervention is critical, as many participants would have preferred access to the information conveyed earlier in their cancer trajectory. Work is ongoing to make the *Rekindle* resources more widely available as an information resource for those affected by cancer.

**29**

## Inclusion in cancer survivorship care: addressing the sexual concerns of LGBTIQ cancer survivors

**Janette Perz**[1]

*1. Western Sydney University, Penrith, NSW, Australia*

Research has increasingly recognised the profound impact that cancer can have upon embodied subjectivity and gender identity. However, there has been little acknowledgment of the centrality of sexuality to subjectivity, and marginalisation of the experiences of lesbian, gay, bisexual and transgender (LGTBT) cancer survivors. This paper will present the results of a program of Australian mixed method research examining sexual embodiment and subjectivity after cancer across a range of cancer types and stages in LGBTI cancer survivors. This includes a study of 147 gay and bisexual (GB) men with prostate cancer, and accounts of 23 LGBT cancer survivors who took part in a study of sexuality across tumour types. Across gender and sexual identities, participants took up the following post-cancer subject positions: 'Dys-embodied sexual subjectivity' - characterised by bodily betrayal, sexual loss, lack of acceptance, challenges to gender identity; 'Re-embodied sexual subjectivity' – characterised by greater sexual confidence, acceptance, the exploration of non-coital sexual practices, and increased relational closeness; and 'Oscillating sexual subjectivity' – involving a shift between states of sexual dys-embodiment and sexual re-embodiment. Gay and bisexual men were more likely than lesbian and bisexual women to report disembodied sexual subjectivity, associated with reports of psychological distress and disruption to intimate relationships. The findings point to the importance of an intersectional framework in understanding sexual subjectivity after cancer.

**30**

## Sex talk: facilitating communication about desire in couples and singles after cancer

**Katharine Hodgkinson**[1], **Jessica Medd**[1]

*1. HeadwayHealth, Sydney*

Despite acknowledgement of the importance of intimacy on well-being and extensive research in the cancer setting over the past decade or more, we know that most health professionals and patients struggle to communicate about intimacy. This session aims to give participants practical skills and strategies to address intimacy and sexual functioning in clinical practice. Topics covered will include:

- the importance of communication between the health professional and patient;
- strategies for enhancing skills, improving comfort levels and reducing barriers to care;
- finding opportunities for the discussion of intimacy: when and how to raise the topic for those with and without partners;
- a model for assessment and intervention/referral;
- suggestions of phrases to assess functioning across the continuum of care;
- key "top tips" for addressing common concerns with desire and functioning (eg. navigating changes to one's body including psychological, hormonal and menopausal changes, erectile, anatomical and functional changes, managing intimacy in the context of fatigue and pain); and
- developing referral skills and networks as part of good practice.

Health professionals do not need to offer "sexual counselling" to all patients, but we do need to offer a basic assessment of needs to triage to appropriate care services. The presentation aims to offer validation and confidence in the application of communication skills refined in other areas of clinical practice to this important area of care. We hope to encourage a positive awareness of interventions to improve care delivery and help this become a rewarding area of clinical practice**.**

**31**

## Overcoming stigma can enhance communication with head and neck cancer survivors?

**Carla Thamm**[1]

*1. Princess Alexandra Hospital, Woolloongabba, QLD, Australia*

Head and neck cancer accounts for approximately 2% of all cancers reported in Australia, with over 4000 new cases diagnosed each year. The diagnostic group of 'head and neck cancer' encompasses tumours inside the sinuses, nose, mouth, salivary glands and the throat. It is often categorised into three main types, according to site of origin: tongue, lip and laryngeal cancer. This talk will focus on head and neck cancers of the oral cavity and oropharynx region. Approximately 75% of these head and neck cancers are attributed to substance abuse, with an increasing incidence attributed to the human papilloma virus (HPV), which is a sexually transmitted disease.

Cancer of the head and neck is a confronting condition, as the disease and its multimodality treatments alter the appearance and function of organs of the body associated with a person's physical appearance, their identity, and their ability to obtain nutrition. They can also adversely affect a person's ability to engage with the important social rituals associated with eating and drinking. Head and neck cancer patients can therefore have significant physical and psychosocial needs especially related to the effects of stigma. The particular stressors associated with both their principal diagnosis and the side effects of treatment include body image concerns, loss of speech, and respiratory and nutritional alterations, which can challenge self-esteem and percolate into many aspects of everyday life. In addition, head and neck cancers caused by smoking, drinking alcohol and HPV can have negative social and moral permutations. These relationships to what are perceived as physical and behavioural deviances mean that head and neck cancer patients can be at risk of both enacted and felt stigma. As a cancer community this is something we need to address.

## 32

## Principles for good communications with LGBT patients with cancer

**Micah Peters**[1]

*1. UniSA, Adelaide*

Gender and sexually diverse people (GSD) experience disproportionate cancer burden in comparison to mainstream populations. Risk factors, social determinants of health, engagement with healthcare services, real and anticipated discrimination, maltreatment, assumptions and poorer health and wellbeing outcomes mean that while inclusion of GSD people is growing in some parts of the world, true equity is far from achieved.

Every health professional has or will treat someone who is lesbian, gay, bisexual, transgender, intersex, queer, asexual, questioning, or has sex or other intimate relationships with a person or people of the same sex. There is growing awareness of the importance of sexual issues for people affected by cancer, but how cancer impacts GSD people and how sexuality and gender relates to experiences of cancer and healthcare are less understood.

Every person should receive the best possible care and treatment delivered in a way that meets their personal, individual needs. It is the health professional's responsibility to ensure that each person is informed and able to participate and make decisions that are right for them in relation to that care. Underpinning effective, safe, appropriate, and meaningful healthcare is communication between staff within healthcare contexts and the people who they engage with including patients and their significant others. Communication does not occur in a vacuum however; society and history shapes beliefs and the way that people behave and think, so communicating with GSD people in the context of cancer care and survivorship must be based upon an understanding and appreciation of these factors as well as of each person as an individual.

GSD people are themselves a diverse group with special, unique needs in relation to healthcare. Understanding some key principles for communicating with GSD people is vital for all health staff to ensure that every person experiences equitable care and health outcomes.

## 33

## Strategies for effective communication in caring for children with cancer

**Ursula Sansom-Daly**[1, 3, 2]

*1. Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital, Randwick, NSW Australia*

*2. School of Women's and Children's Health, UNSW Medicine, University of New South Wales (UNSW), Sydney, NSW*

*3. Sydney Youth Cancer Service, Prince of Wales Hospital, Randwick, NSW Australia*

Cancer-related communication is inherently challenging. Healthcare professionals need to convey complex medical information to patients frequently in the context of considerable uncertainty. Several important social factors and processes can further complicate these discussions. Firstly, patients and families understandably enter into cancer-related conversations with considerable fear and anxiety. Secondly, in the healthcare-system context, the power dynamics at play in the patient-clinician relationship remain inherently imbalanced. Societal taboos around talking about mortality and death can further interfere with effectively addressing these topics on the part of both patients/families and clinicians. For children and adolescents, their young age and minor status adds an additional layer of vulnerability to their involvement in cancer-related communication. This can lead many families to shield children from distressing cancer-related conversations, a situation in which clinicians may unwittingly (or knowingly) collude. However, even when families attempt to avoid difficult discussions, young people often understand and perceive more than their families realise. Further, young people can experience considerable anxiety and emotional isolation when they perceive either that information is being withheld from them, or that they are not able to talk openly with their families about cancer. By contrast, when provided with age-appropriate opportunities to engage in cancer-related communication, research indicates that young people are capable of understanding and coping with complex medical information, including topics related to treatment options and decision-making, prognosis, and end-of-life. In this context, it is critical that clinicians are able to work with, and around, the unique barriers involved in cancer-related communication with young people and their families. This talk will highlight what is currently known about best-practice communication with young people, in particular when it comes to addressing some of the most challenging conversations of the cancer trajectory - those surrounding prognosis, likelihood of cure, and other palliative and end-of-life topics. Strategies relevant to the entire multidisciplinary healthcare team will be highlighted.

## 100

## Effects of cancer treatment on household income and employment status – A prospective single centre study

**Anupriya Agarwal**[1, 2], **Deme J Karikios**[3, 1], **Martin R Stockler**[4, 1, 2], **Philip J Beale**[4, 1], **Prunella L Blinman**[4], **Annabel Goodwin**[4], **Rachael L Morton**[1, 2]

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*4. Concord Repatriation General Hospital, Drummoyne, NSW, Australia*

Background: Improvements in cancer treatment have resulted in substantial growth in the costs of care, and patients can bear significant out-of-pocket costs for their treatment. In addition, studies have shown that up to one third of patients do not return to work following cancer treatment. These factors can culminate in financial toxicity for cancer survivors, which has a debilitating effect on quality of life and optimal cancer care."

Aim: To describe changes in employment and household income due to advanced cancer treatment in the Australian setting.

Methods: We conducted a prospective cross-sectional observational pilot study examining adults treated with anticancer therapy in both adjuvant and palliative settings in the outpatient department of a tertiary cancer hospital in Sydney, Australia. Patients had to be currently receiving anti-cancer therapy, with the aim for treatment to continue for at least 3 months. At the time of pariticipant recruitment, data was collected using a questionnaire comprising socio-demographic characteristics, employment/income history, health insurance and treatment information; and analysed using descriptive statistics.

Results: Of 31 participants, the median age was 59 years (range 37 - 80 years), 52% females. 7 patients (23%) were receiving adjuvant therapy for their cancer.

At time of data collection, 12 patients (39%) were in paid employment. 7 patients were not in any paid employment prior to the diagnosis of cancer (4 retired, 2 unemployed, 1 volunteer). The majority of patients were in full-time jobs (21/31) with others being self-employed (2/31) or in part-time employment (1/31). 30% of patients (9/31) described a reduction in their hours and duties as a result of their cancer treatment. A further 38% (12/31) patients had retired or ceased working during the course of their cancer treatment. Over half (16/31, [52%]) of the patients reported a reduction in their household income level during the course of their treatment. One patient reported an increase in income level due to an inheritance.

Conclusions: This study highlights the substantial changes in patients' financial status as a result of cancer, and a significant issue with a growing population of cancer survivors. There are considerable effects on patients' ability to return to workand income which can have long-term consequences despite completion of therapy. Patient-physician discussions about potential loss of income due to cancer and its treatment are recommended.

## 101

## The impact of a state-wide Survivorship Program: Outcomes of the first two years of the Phase II Victorian Cancer Survivorship Program.

**Georgina Akers[1], Barry Curran[1], Kathryn Whitfield[1]**

*1. Department of Health & Human Services, Melbourne, VIC, Australia*

The Victorian Cancer Survivorship program (VCSP) Phase II Grants Scheme was established in 2016 to further support development of innovative programs and models of care across acute, primary and community care sectors over a three year period.

A total of 24 grants have been awarded to services in metropolitan, rural and regional areas through this scheme. This includes Type 1 Grants aiming to build capacity (15), Type 2 Grants to support innovative approaches to survivorship care (2) and Type 3 Grants to test models of shared care and to facilitate greater collaboration between the acute, primary and community care sectors (7).

An evaluation framework and a further package of evaluation training and mentoring was developed for the VCSP with the aim to build evaluation capability of project teams and enable consistency, quality and efficiency in data capture and analysis. Consistency in the formative and summative evaluation design and execution will enable assessment of the state-wide reach and impact of VCSP.

Eleven projects, comprising 10 Type 1 projects and one Type 3 project have been completed to date. The outcomes of the projects have included the development of resources for specific patient groups, individual and group programs to support cancer survivors, and programs for the education of clinicians in survivorship care. This poster presentation will detail outcomes of the 11 already completed projects and preliminary results of the 13 projects still in implementation.

Evaluation of the impact of VCSP Phase II is already in progress to inform future directions and focus for the next Victorian Cancer Plan in 2020.

## 102

## Connecting to wellness: Telehealth as an enabler for regional cancer survivorship supportive care.

**Jane F Auchettl[1], Megan Chiswell[1], Lea Marshall[2], Carmel OKane[3], Tracey Daffy[3], Amanda Piper[1]**

*1. Cancer Council Victoria, Melbourne, VIC, Australia*

*2. Grampians Integrated Cancer Services, Ballarat, Victoria, Australia*

*3. Wimmera Health Care Group, Horsham, Victoria, Australia*

**Aim**

Additional cancer survivorship challenges are often faced by rural and regional Victorians. Teleoncology enables innovative alternatives to support patients; however, few examples feature group education and allied health interventions.

'Telehealth for Supportive Survivorship Care' project innovates delivery of Cancer Council Victoria's Wellness and Life after Cancer program, aiming to develop, pilot and assess a regional telehealth model for sustainable delivery.

**Method**

Eight programs were delivered during the project across five rural and regional health services in the Grampians and Hume regions in Victoria. The 16-hour program included weekly group exercise sessions delivered by local Exercise Physiologists, followed by education delivered via telehealth, over a period of eight weeks.

Program evaluation includes collection of participant, facilitator and health service data through program surveys and focus groups. The use of action research methodology enables refinement of program delivery throughout the project to best suit the region and participants.

**Results**

Eight programs were completed during the project phase.

Focus groups from the first programs in each region highlighted positive social and emotional outcomes which had improved patients' lives.

Embedded action research methodology has informed amendments to content inclusions and delivery, improving delivery of subsequent programs. The use of telehealth has enabled access to a comprehensive survivorship assessment, education, exercise and wellness program for regional cancer survivors, allowing participants to remain close to home. Workforce development and linking health services has increased the capacity of regional health services to provide supportive cancer survivorship care.

**Conclusion**

Results identify that this model can be successfully embedded into existing workforce structures, increasing capacity and enhancing professional relationships and program delivery otherwise hindered by distance. For those regionally who are affected by cancer, the program is proving to be viable, acceptable, accessible and beneficial in improving outcomes.

## 103

### Reflecting on survivorship outcomes to aid initial decision-making in patients managed for IDH-mutated anaplastic glioma

**Michael Back**[1, 2, 3, 5, 4], **Dasantha Jayamanne**[1], **Marina Kastelan**[1, 4], **Nicola Cove**[2], **Helen Wheeler**[1, 5, 4]

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Background

Patients with anaplastic glioma (AG) harbouring the isocitrate dehydrogenase (IDH) mutation have the potential for long survival duration following intensity modulated radiation therapy (IMRT) and chemotherapy. Thus, to guide future decision-making, there is an importance of understanding the level of long term functioning following management, and the factors that may impact on later adverse effects.

Methods:

Consecutive AG patients managed with IMRT from January 2008 to December 2017 were reviewed regarding features associated with impact of IMRT on Six Survivorship Domains. These included Performance Status; Treatment Late Toxicity; Neurological Status, Medical Co-morbidity Events; Functional Status with Employment and Driving; and Psychosocial Events. Overall survival was calculated from date of IMRT, and assessments were performed at baseline pre-RT, month+6, Year +1, Yr+3 and Yr+5. Analysis was performed in relation to the patient, tumour and treatment factors potentially associated with the two primary endpoints, ECOG performance status and Employment at year +3.

Results:

146 patients with median age 43 years were included with a median follow-up for survivors of 5.1 years. The 6-year overall survival from start of RT was 78.7% (95% CI: 71.1-87.0). Baseline ECOG Performance status, was 0 or 1 in 82.2% of patients but improved at Y+1 and Yr+3 of 95.7% and 97.2% of patients respectively. In the 51 patients evaluable at Yr+5, the ECOG was 0,1 in 96.1% of patients. For Employment Status at Yr+3 and Yr+5 the proportion of potential employable patients fully or partially employed was 70.1% and 76.5% respectively. This compared with baseline preIMRT of 61.6% being at a point of working or being able to return to work. The proportion of patients who were retired prior to IMRT remained consistent across the three time points with 8.2%, 8.9% and 9.8% at baseline, Yr+3 and Yr+5 respectively. The factors associated with worse ECOG Score at Yr+3 included WHO Path of AAmut ($p=0.001$), delayed timing of RT ($p=0.081$), multiple craniotomies prior to RT ($p=0.002$), worse ECOG preRT ($p<0.001$), worse MRC Score preRT ($p<0.001$), seizures at Yr+1 ($p=0.038$), neurocognitive disturbance at Yr+1($p<0.001$) and presence of relapse ($p=0.004$). The factors associated with absent or impaired Employment at this timepoint included: older age ($p=0.007$), delayed timing of RT ($p=0.023$), multiple craniotomies prior to RT ($p=0.005$), worse ECOG preRT ($p<0.001$), worse MRC Score preRT ($p<0.001$), and neurocognitive disturbance at Yr+1($p<0.001$).

Conclusion:

AG with IDH mutation have prolonged survival. Functional status at Year+3 post treatment is good with > 95% of patients having high performance status and greater than 75% in employment. Deficits relate more to the initial tumour and surgery, especially when IMRT is delayed to second or later relapse with multiiple surgical procedures being performed.

## 104

### "I grew the confidence": The doctor-patient communication experience for parents of children with cancer

**Julia Baenziger**[1, 2, 3], **Claire E Wakefield**[2, 3], **Lauren Carlson**[2, 3], **Kate Hetherington**[2, 3], **Brittany McGill**[2, 3], **Richard Cohn**[2, 3], **Ursula Sansom-Daly**[2, 3]

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**Aims**

Following their child's cancer diagnosis, parents have to rapidly familiarize themselves with cancer-specific information and the health-care setting. Previous studies have stated a need for theory to help address parents' difficulties when navigating the health care system. We examined parents' experiences with health care professionals (HCP) to better understand the communication during and after their child's cancer treatment.

**Methods**

We recruited parents of children (aged <18 years) who recently completed cancer treatment with curative intent from nine Australian hospitals. We conducted in-depth interviews using the *Psychosocial Adjustment to Illness Scale* as part of the baseline assessment of the 'Cascade' survivorship intervention. We used grounded theory to explore parents' health care experiences.

**Results**

Parents of 49 survivors participated, including 46 mothers and six fathers (mean age 41 years [range 21-56]). The average age of the child at diagnosis was 5.6 years (0-15); time since treatment, 2.6 years (0.3-10.7). Parents' experiences with HCP were characterized by four themes: 1) positive and negative interactions, 2) attitudes towards doctors and treatment, 3) trust and mistrust in the doctor-parent relationship and 4) active engagement in past and future care. Parents valued the skills and support (informational, practical, emotional) of HCP. When parents experienced adverse interactions, they rationalized those by the limiting circumstances of the medical environment. A majority of parents felt detached from the health care system and professionals after treatment ended. We propose a framework describing potential mechanisms in parents' communication-experience.

**Conclusion**

Identifying characteristics impacting parents' experiences disclosed new points for targeted intervention: HCP who were approachable and personable seemed to gain parents' trust more easily. Transparency through continuous communication was important to mitigate treatment uncertainty. Explicit and well-explained guidance, e.g. in form of tailored survivorship care plans might benefit parents' engagement in long-term follow-up care, including care outside of oncology.

## 105

## CanCare - Using volunteers to build a support network for a person with cancer from diagnosis to survivorship

**Sue Baker**[1]

*1. Prostate and Breast Cancer Foundation, Surry Hills, NSW, Australia*

The CanCare Navigation Program is a free peer based, non-medical service that focuses on support, education and advocacy for people with any type of cancer who live in southern Sydney. As part of this program we recruit and train volunteers to become CanCare Navigators.

Navigators then provide one-on-one support to people, who do not have the support they need as they face the many challenges a cancer diagnosis brings. The logistic and practical help a navigator can provide allows a person to take time to process information, improve their personal well-being, receive patient centred care and build a support network.

The Program complements the provision of existing healthcare services by bridging a gap between the hospital and the home. People with cancer spend most of their time outside of the healthcare setting, where many people have little support. People identified as vulnerable, elderly, or isolated by health care staff at Sutherland Hospital, St George Public Hospitals and St George and Waratah Private Hospitals and the NSW Cancer Council are referred to the program. People can also self-refer.

Once referred the person is matched with a navigator, who then becomes part of their support network. There is a regular feedback mechanism where the navigator or Program Manager updates hospital staff and alerts them to any concerns. The program commenced in October 2016. Since then we have trained over 30 volunteers who have supported more than 50 people with cancer. Our volunteers have provided over 600 hours of free support to people who are vulnerable, socially isolated or economically disadvantaged and have performed over 250 tasks.

Evaluations with users and stakeholders have been extremely positive. Those using the service cite knowing there is always someone there is the best part of having a navigator and being involved in the program.

## 106

## The hidden burden of anxiety and depression in ovarian cancer: a prospective study from diagnosis

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**Background:** Most studies of anxiety (A) and depression (D) among women with ovarian cancer (OC) have used a cross-sectional design and/or not considered prior history or medication. Our aims were to quantify A/D among women with OC; the proportions who experienced symptoms only after their OC diagnosis and those with persistent symptoms; and determine use of medication/services by those affected.

**Methods:** The OPAL (Ovarian cancer Prognosis And Lifestyle) Study is a prospective study of Australian women diagnosed with OC from 2012-15. At baseline, women were asked if they had ever been diagnosed with A or D in the year before their OC diagnosis. At follow-up (3, 6, 9, 12, 24, 36 & 48 months after diagnosis) women completed the Hospital Anxiety and Depression Scale and were asked about current medication use.

**Results:** Of 893 women, almost half (42%) reported clinical anxiety (18%) and/or depression (15%) and/or use of anxiolytic or antidepressant medications (A/D meds) (18%) on ≥1 occasion during the first 3 years after diagnosis. An additional 166 women (19%) reported subclinical A or D. Of those with clinical A/D or taking A/D meds, 159 (42%) reported this at ≥3 time-points and 218 (58%) reported no prior history of A or D. When women reported clinical A or D, only 45% reported taking medication (37%) and/or seeing a psychiatrist or psychologist (19%). A prior history of A/D and low levels of optimism were the strongest predictors of A/D onset.

**Conclusions:** More than 40% of women with OC experienced clinical A or D during the first 3 years of follow-up. For 42% of those affected this was their first experience of A/D and >50% did not receive treatment. The hidden burden of A/D in this population is much greater than previously reported but is amenable to effective intervention if recognised.

## 107

## When Will I Feel Normal Again? Exploring the Trajectories and Predictors of Delayed Recovery of Symptoms and Wellbeing after Completion of Primary Therapy for Ovarian Cancer.

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*Background:* After primary treatment for ovarian cancer, women often ask when they will feel "normal" again. We aimed to document the proportions of women who report high levels of physical and emotional symptoms at the end of treatment, determine if/when they return to normal and identify groups at risk of persistent symptoms/delayed recovery.

*Methods:* Women in the OPAL (Ovarian cancer Prognosis And Lifestyle) study who received ≥3 cycles of first-line chemotherapy and completed questionnaires on or <6 weeks after completing chemotherapy (baseline) were included in this analysis (n=605). Questionnaires measured symptoms (anxiety, depression, insomnia fatigue) and wellbeing (quality-of-life) at baseline, 3, 6, 9 and 18 months post-baseline. Group-based trajectory models identified clusters of individuals who followed similar trajectories. Logistic and Cox regression identified factors associated with persistent symptoms and delayed recovery, respectively.

*Results:* At baseline, 57% of women reported clinically significant fatigue, 21% sub/clinical anxiety or depression and 13% clinical insomnia; 46% had quality-of-life scores significantly lower than the general population. For 50-70% of women, individual symptoms and wellbeing normalised within six months, with the exception of emotional wellbeing where recovery rates for were lower (39% at 6 months). Overall, 35% of women still had at least one persistently poor symptom or wellbeing domain at 18 months. Women with more severe symptoms at baseline, who were younger, had multiple comorbidities or a history of anxiety/depression were more likely to have persistently poor or delayed symptoms/wellbeing recovery.

*Conclusions:* Although most women report resolution of symptoms and normalisation of wellbeing within six months of completing primary treatment for ovarian cancer, one-in-three never fully return to normal. Those at risk of delayed or no recovery should be triaged for early intervention with supportive measures.

## 108

## Engaging sedentary women with cancer to participate in a group exercise program – what helped?

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### Aims

The 2018 COSA physical activity guidelines are clear; people who have been diagnosed with cancer should work towards and then maintain 150 minutes of exercise per week to promote health and wellbeing, mitigate the impact of cancer treatment and potentially reduce the risk of cancer recurrence (Cormie et al., 2018). Yet many women who have been diagnosed with breast or gynaecological cancer are not reaching these targets and the challenge remains how to engage those who are sedentary. This Masters project explored women's experiences of Counterpart's six-week introductory community-based exercise program, with a focus on women's decision-making to attend.

### Methods

A purposive sampling strategy was utilised to recruit women who had attended a group exercise program to one of three focus groups. Thirteen women diagnosed with breast or gynaecological cancer participated, and most were previously sedentary. Focus group transcripts were analysed thematically, each elicited similar themes.

### Results

Women felt vulnerable and lacked the confidence to exercise following their cancer diagnosis. Practical issues including cost, location, being aware of the program and receiving an external prompt were highly influential in decision-making to participate. Undertaking exercise with others who had similar experiences was perceived to provide physical and emotional safety, and trust in the instructor was also important. Some women sought exercise in a group for support and camaraderie, others attended despite the group format but found the support beneficial. Women were attracted to the short duration of the program as a manageable introductory level of commitment and to the advertised variety of exercises. Feelings of guilt and stigma at being sedentary were a motivator and a source of distress.

### Conclusions

This small-scale study highlights factors which encouraged exercise participation by previously sedentary women with cancer. Suggestions for the development of group exercise programs and for future research are offered.

1. Cormie, P., Atkinson, M., Bucci, L., Cust, A., Eakin, E., Hayes, S., . . . Adams, D. (2018). Clinical Oncology Society of Australia position statement on exercise in cancer care. The Medical journal of Australia, 209(4), 184-187.

## 109

## Have your say with ARCHWAY! Recruitment strategies in adolescent and young adult cancer survivors

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Approximately 2000 young people (15-29 years) are diagnosed with cancer each year in Australia and most (88%) will survive. Late effects are commonly experienced and include risk of second cancers, endocrine, cardiopulmonary, cardiovascular, renal, fertility and neurosensory dysfunctions, as well as psychosocial, financial and educational complications. Identifying perceived unmet needs in survivorship is a crucial step in developing new services to promote wellness and reduce consequences of late effects.

We aimed to recruit 50 survivors to our ARCHWAY project, a study that aims to identify unmet needs of young people and their perceptions of optimal components for a wellness program. Participants were to complete an online survey with a subset of 30 completing an interview. As well as targeted recruitment through Queensland Youth Cancer Services, we set out to optimise recruitment using social media. Targeted recruitment involved face-to-face discussion in clinic and telephone and email communication. The Queensland Youth Advisory Group helped design promotional material for advertisements containing a QR code and links to the survey; these were pushed out through social networks using Facebook, Twitter and Instagram.

Two months into a planned three month recruitment timeframe, 29 surveys were completed and 16 interviews. Social media promotions resulted in few (8) participants while targeted recruitment was more successful. Still, only 50% of those who provided an email address to complete the survey actually did so. A number of young people gave specific reasons for not participating. Those who were closer to end of treatment were more reluctant to participate with statements such as ‘I’m too busy’ and ‘I just want to forget about it all’. Those who had completed treatment six or more months previously were more willing to participate. The use of an iPad to facilitate immediate completion of surveys during clinic was a useful strategy. Multiple strategies were needed to engage young people and reach our target sample size.

## 110

## RESPONSE: Adaption and validation of a Patient Reported Outcome Measure for Australian Children and Adolescents with Cancer

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In Australia, there are no standard tools used to routinely assess symptoms associated with cancer and cancer treatment in children 0-18 years, yet young people experience a significant number of symptoms. The associated distress can lead to poor treatment adherence, increased hospitalisation and compromised quality-of-life. Moreover, high symptom burden is associated with poor psychological outcomes including risk of Post-Traumatic Stress Disorder that may not emerge for years following treatment for childhood cancer.

This project is using a co-design process to develop a web-based app for remote symptom monitoring and delivery of tailored and personalised self-management advice for children and adolescents (8-18 years) with cancer. As part of this project, we validated an Australian translation of a 15 item Symptom Screening Tool in Paediatrics (SSPedi). This tool, developed in Canada, measures patient reported experience of distress from symptoms experienced during cancer treatment. Input was obtained from an Australian expert clinical group to modify SSPedi wording. Cognitive interviewing was completed with 10 children (9-16 years) using ‘think aloud’ techniques. Probing was used to evaluate understanding of individual items and of the response scale. We used a five point Likert scale (1=very hard to 5= very easy) to rate child’s ease with completing the SSPedi and a four point Likert scale (1= completely incorrect to 4=completely correct) to rate the child’s understanding of the scale.

Despite the tool being developed in English, there were a number of changes required for translation to Australian English. The mean difficulty for completing all items on the modified SSPedi was 3.9 (mean of individual item range 3.5 to 4.2). The items most difficult for children to complete were having problems thinking or remembering things (3.5), feeling disappointed or sad (3.6), and having tingly or numb hands and feet (3.6). Despite children reporting some difficulty with completing items, they were able to correctly understand items and the response scale (mean all items 3.8, mean of individual item range 3.2-4.3). Further validation work is underway to assess psychometric properties of the adapted tool for the Australian population. These are our first steps towards improving symptom control for children with cancer.

## 111

## E-health tools for childhood cancer survivorship care management: A qualitative analysis of interviews with survivors, parents and General Practitioners.

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**Background:** Childhood cancer survivors require long-term care and assistance navigating the healthcare system. E-tools designed for care coordination have been widely developed. E-tools can be expensive and require regular upkeep of technology and stored information. However, healthcare consumers' and providers' perceived acceptability of, and desire to use, these tools is understudied.

**Aim:** We aimed to assess the acceptability of e-tools among adult survivors of childhood cancer, parents of childhood cancer survivors and General Practitioners (GPs).

**Method:** We invited adult survivors of childhood cancer (16 years and older), parents of survivors (whose child was aged 25 years or younger), and GPs with at least one childhood cancer survivor patient to complete semi-structured interviews. We asked participants about perceived use of an e-tool to manage care, benefits of and barriers to use, concerns about using e-tools and desired features in an e-tool to manage survivorship care.

**Results:** We interviewed 36 survivors, 24 parents and 51 GPs. Among parents and survivors, e-tools were widely endorsed with high perceived uptake (83%). Commonly reported benefits included increased access to evidence-based information, personalised information on patients' cancer history, easier information sharing with health professionals, and increased confidence in managing their survivorship care. E-tools were less acceptable among GPs and perceived uptake was lower (51%). GPs named more diverse barriers to using an e-tool and less benefits to its use, including demands on time, patient confidentiality concerns and possible technical errors. They acknowledged that e-tools catered to relocating patients and allowing information sharing.

**Conclusions:** E-tools are a welcome resource for healthcare consumers and may be valuable in encouraging self-managed care and aiding patient-practitioner communication. Consideration must be given to the feasibility of implementing e-tools in General Practice given the barriers which may impact on uptake. E-tools may be most effective as a patient-held, managed and shared resource.

## 112

## Do podcasts work for cancer information and support? Evaluating the impact of *The Thing About Cancer* podcast series

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**Background:** Digital technologies offer innovative ways to meet the information needs of people affected by cancer. In 2017 Cancer Council NSW launched a new information resource: *The Thing About Cancer* podcast. Episodes feature interviews with cancer experts and survivors, and cover topics such as coping with fatigue, managing fear, sex after cancer, and the impact on carers and families. An evaluation of the podcast was conducted in 2018.

**Aim:** To evaluate the effectiveness of the podcast in providing information and support to people as they navigate the experience of cancer.

**Method:** A self-report online survey was available on the Cancer Council NSW website for 15 weeks. SoundCloud analytics measured overall listens.

**Results:** During the study period, the podcast had 5482 listens, with 81% accessed through third-party apps on smartphones and other devices, and the remaining 19% via the podcast webpages. A total of 29 surveys were completed, with 31% from people diagnosed with cancer, 24% from carers and a further 24% from family or friends. The evaluation found that the podcasts:

- increased knowledge about cancer (85%) and where to find help (95%)
- provided strategies for managing side effects and lifestyle changes (90%)
- helped listeners feel supported knowing others had been through similar experiences (100%).

**Conclusion:** *The Thing About Cancer* podcast helps to fulfil unmet information needs by increasing knowledge about cancer, the management of side effects and lifestyle changes and where to find further support and information. Because listeners can hear the voices of experts and survivors, podcasts are also an effective way to normalise the experience of cancer and reduce feelings of isolation. The high proportion of carers, family and friends among the participants indicates that podcasts appeal to hard-to-reach groups and thus have particular potential in connecting with people who have entered the survivorship phase.

## 113

## Embedding survivorship care into a regional cancer service. Getting from pilot to standard practice

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*3. Flinders University and Flinders Centre for Innovation in Cancer, Adelaide, SA, Australia*

Aim: The South Australian (SA) Cancer Survivorship Framework facilitates equitable access to survivorship care across the state. This study aims to review the implementation of the Framework in a regional cancer service.

Method: Mt Gambier District Health Service (MGDHS) regional cancer service was identified as a champion site for pre-implementation pilot of the Framework in early 2016. This required service reorientation to provide individualised treatment summary, needs assessment and care planning to cancer patients completing adjuvant therapy. The local team engaged with metropolitan counterparts to learn from and further refine process and templates with the view to continuation and expansion of practice beyond the pilot.

Results: Since commencement, 34 patients completed adjuvant chemotherapy in MGDHS. Of these 28 (82%) attended a Survivorship Clinic appointment with similar projections for 2018. Implementation of the survivorship framework was delivered with no additional resources. Its success was dependent on a committed oncology team who re-prioritised workload to include survivorship care. Smaller numbers of clinicians and patients involved made for a simpler process and more manageable workload demands, as well as integration to a larger statewide process. Challenges included the streamlining of workflow and timely access to clinical information. Patient feedback during the pre-implementation pilot showed value in the treatment summary and care plan and further evaluation of both the patient and GP experience is planned.

Conclusion: Embedding survivorship care into a regional cancer service has been possible through a stepwise approach to implementation of the statewide Framework. This phased approach can be utilised to support planning and implementing in other regional cancer services.

## 114

## Do cancer clinicians identify the health service needs of patients and their families?

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Aims: Delivering best-practice cancer care requires partnership between patients, carers, and their multidisciplinary team (MDT). Increasing patient numbers and continued resource constraints necessitates review of current service/prioritisation models, to ensure that patients and families receive personalised, holistic multidisciplinary care.

This project compared consumer-reported (patients/family members) healthcare needs with services provided by members of the cancer MDT, in a quaternary hospital in Brisbane, Australia.

Methods: Using a cross-sectional design, patients diagnosed with head/neck (HNC), lung, oesophageal, brain or haematological cancers, and their family member/carer, were interviewed regarding perceived supportive care needs prior to a scheduled outpatient review (medical/MDT), at any time from diagnosis. Blinded clinician data, including identified care needs and intervention +/- referrals actioned were retrieved from electronic medical records. Data sources were triangulated and analysed descriptively.

Results: Patients (n=309; 202 male, age range 19-94) reported a variety of supportive care needs related to physical, practical and psychosocial concerns. Of those, 205 patients (total 66.3%; HNC 80%, haematology 75%, brain 59%, lung/oesophagus 53%) reported one or more concerns requiring MDT intervention. These issues were not actively identified or managed by clinicians up to 80% of the time. Family member/carer distress was also highly prevalent (40%, 69/173) which was rarely identified or managed by health professionals.

Conclusions: Patients and their families, report multiple unmet healthcare needs throughout the treatment continuum, which are poorly identified by clinicians. Collaborative teams need to explore novel ways to identify and prioritise patients for supportive care intervention, to minimise the burden of cancer for patients/families, as well as cost to health systems.

## 115

## What factors contribute to distress in carers of patients undergoing radiotherapy for head and neck cancer?

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Aims: It is well-known that up to 40% of carers of patients with head and neck cancer experience significant distress during treatment. This study aimed to examine the incidence and causes of distress over the course of treatment using an electronic, web-based screening tool for carers.

Methods: A longitudinal cohort design was used to investigate the incidence and factors contributing to distress among carers of patients undergoing radiotherapy treatment for head and neck cancer. Carers of patients with head and neck cancer undergoing radiotherapy were enrolled at radiotherapy planning, and completed an electronic, carer reported screening tool, “ScreenIT” weekly during treatment. Cohort data was analysed descriptively.

Results: From June 2015 – September 2018, 141 carers completed ScreenIT during their family members radiotherapy treatment for head and neck cancer. Across the 141 carers, 393 entries were recorded (m = 2.8, range 1-10). The majority of carers identified as spouses (n= 283, 72%) or son/daughter (n= 78%, 18%). More than half the carers reported distress at at least one timepoint during treatment (55% with score >4 on Distress Thermometer). The factors contributing to distress included emotional (worry 32%, fears 12%, sadness 12%), patient’s physical symptoms (eating/drinking 27%, fatigue 28%, sleep 13%, pain 12%, mouth sores 11%), and practical (knowing what food/drinks will be suitable 20%, planning meals 14%, and mealtime preparation/cooking 10%). Only 4% of carers wished to discuss their concerns with a health professional.

Conclusions: During radiotherapy treatment, carers of patients of head and neck cancer commonly report distress related to emotional, physical and practical concerns, however very few wished to discuss their concerns with a health professional.

## 116

## What do cancer survivors need and want? The voices of cancer survivors in Hong Kong

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**Background**

Cancer patients who have completed treatment often face different challenges in adjusting their life. Considering the increasing number of cancer survivors, Maggie's Cancer Caring Centre in Hong Kong (Maggie's HK) would develop multi-disciplinary, holistic support service for these patients. To help designing these survivorship programmes, cancer survivors had been invited to identify their needs and expectations for the preliminary service development.

**Method**

A qualitative study design was adopted. Five semi-structured focus group interviews regarding the survivorship issues, each with 6-8 cancer survivors recruited from Maggie's HK or website, were held between March and April 2018. Each interview lasted about 2 hours and were audio recorded and transcribed verbatim. Different themes were generated through repeated readings and content analysis with structured comparison.

**Results**

Different needs under four main themes regarding survivorship were emerged from the focus groups. ***1. Physical needs:*** Participants reported the needs of accurate information about cancer and maintaining physical health, and suggested to have nurse consultation and practical programmes including nutrition, Chinese medicine and exercise. ***2. Psychological needs:*** Participants reported concerns about fear of recurrence, self-image, marital and family relationships. They wanted to learn about better emotional regulation and have psychological support programmes. ***3. Practical needs:*** Participants mentioned financial and work stress after completing treatment and the needs of seeking work-life balance and subsidies for various medical/healthcare expenses. ***4. Social needs:*** Needs of peer support among cancer survivors, concerns about "normal" social life and communication with doctors were found from participants.

**Conclusion**

As there is not many, if not none, significant studies about cancer survivorship in Hong Kong, this study could reveal in details the cancer survivors' local needs and the importance of multi-disciplinary and holistic care for the survivorship service development.

## 117

## FSTL3 release occurs synchronously with onset of doxorubicin-induced cardiotoxicity in an isolated myocardial cell model

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Chemotherapies such as doxorubicin are associated with cardiotoxicity. Follistatin-like 3 (FSTL3) has been shown to contribute to cardiac remodelling, and hypertrophy via activation of the TGF-β1-Smad 2/3 pathway. In this study, we evaluated the potential role of FSTL3 as an early biomarker and mediator of early onset chemotherapy-induced cardiomyopathy (CIC). The study is to elucidate the role of FSTL3 in doxorubicin induced cardiomyocyte injury.

The dose-response relationships for doxorubicin treatment (15.6 nM to 500μM) for 24 and 48 hours were evaluated in primary human cardiac myocytes. Extracellular and intracellular concentrations of FSTL3 were measured in cell supernatants and cell lysates, assayed by ELISA. Cell lysates were obtained for measurements of Smad2/3, and TGF-β1 via Western blot. Cardiomyocyte cytotoxicities were measured using Alamar Blue and lactate dehydrogenase (LDH) release. Doxorubicin dose-dependently induced cell mortality was significantly correlated with FSTL3 release ($R=0.7$, $p=0.02$) after 48 hours but not after 24 hours. There was also a significant relationship between extracellular and intracellular FSTL3 concentrations. There was a trend towards significant between increased intracellular FSTL3 and TGF-β1 expression but not with total Smad 2/3 ratio.

In this model, FSTL3 and TGF-β1 expressions appear synchronously with onset of doxorubicin- induced cardiotoxicity, suggesting that FSTL3 could play a role in doxorubicin-induced cardiotoxicity. Future studies manipulating FSTL3-mediated pathways are required to fully elucidate this mechanism.

## 118

## Evolution and Revolution: 10 Years of Cancer Advocacy and Counting

**Chris Christensen[1], Julie Marker[1]**

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**Title: Evolution and Revolution – 10 years of cancer advocacy and counting**

**Aims**

This presentation highlights 10 years of cancer advocacy by Cancer Voices South Australia (CVSA). It analyses the evolutionary and revolutionary approaches utilised by CVSA that have influenced change for people affected by cancer. With an increasing number of people surviving a cancer diagnosis there is an increasing number of people seeking to become involved in advocacy, wellness and systems improvement.

**Methods**

Using qualitative phenomenological research, we analyse the meaning of the lived experience of Cancer Voices SA members over the past 10 years identifying knowledge gained about cancer advocacy and the role of the independent voice in influencing the achievement of better outcomes for people affected by cancer.

**Results**

Analysis of the work of CVSA since its inception identifies a number of key outcomes:

- a greater focus on quality, safety, access and equity in treatment and care
- the relationships built within and across health organisations, policy makers, researchers and people affected by cancer
- increased education and training using cancer survivors lived experience
- increased involvement of cancer survivors in research

- increased focus on wellness not just illness
- collaborations formed that support the improvement of the effectiveness and efficiency of systems.

**Conclusions**

The independent nature of CVSA and its collaborations with health, government and research organisations has been both evolutionary and revolutionary and will need to continue in this vein if it is to survive and thrive. By reflecting the diversity, knowledge and experience of those affected by cancer, CVSA has been able to forefront the views of cancer survivors, their partners, family, friends, colleagues and supporters across all cancer types and stages to influence and improve a broad range of issues across the cancer continuum.

1. http://www.cancervoicessa.org.au/

## 119

## Testing the feasibility to routinely collect Patient Reported Outcomes post breast cancer surgery via BreastSurgANZ Quality Audit

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Approximately 18,000 Australians will be diagnosed with breast cancer this year and 90% will survive at least 5 years. Whilst there is universal understanding that cancer affects the health and quality of life of individuals there is limited long term evidence reported to demonstrate the impact this diagnosis has on a persons life. There is an opportunity to expand the roles of registries to inform clinical care, health service planning, policy and evaluation by establishing mechanisms for routine monitoring of patient reported outcomes. This will increase awareness by health services of the late effects and chronic side effects of cancer and its treatment, allow timely evaluation of outcomes, and increase the likelihood of an informed health service response.

Aim: To establish the viability of collecting Patient Reported Outcomes (PRO's) routinely via BreastSurgANZ Quality Audit

Methods: A proof-of-principle study will be undertaken using the South Australian cohort of the BreastSurgsANZ Quality Audit (BQA) to establish the viability of collecting patient reported outcomes routinely. A software platform developed by Envido will be used and integrated with current workflow to enable identification and periodic surveying of patients. Governance, ethical/privacy, consenting, data security and linkage process will be established. Prospective and retrospective data collection will be tested. Outcome dashboards will be developed to meet the needs of clinicians and patients. Outcome measures will include patient response rate and experience and clinician satisfaction and perceived benefits. The project will be undertaken by a multidisciplinary team including clinicians, behavioural scientists, cancer epidemiologists, consumer advocates, data specialists, and software developers.

Results: The project will demonstrate the viability of collecting patient-reported data via the BQA and will establish dashboard reporting and feedback systems that are meaningful to patients and clinicians. Opportunities for national scalability and further funding will be explored.

Conclusion: Currently there is a critical gap in the establishment of routine patient-reported surveillance which is paramount in an environment of increasing fiscal demands, health system reform and consumer driven engagement. If implemented broadly, the inclusion of patient-reported data to clinical registries will address a key gap in national cancer outcome data and provide stronger intelligence to inform multiple layers of care delivery including quality and safety reporting, auditing, direct clinical care, health economic analysis and research.

## 120

## Patients' information coping style influences the benefit of a survivorship care plan in the ROGY Care Trial: new insights for tailored delivery

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**Aims:** Previous trials failed to identify beneficial effects of survivorship care plans (SCPs) in unselected survivor populations. However, SCPs may be beneficial for subgroups of survivors. Considering that individuals may respond differently to SCPs according to their information coping style, we aim to assess whether the impact of SCPs on patient reported outcomes is different in survivors with an information seeking coping style ('monitoring') versus survivors with an information avoiding coping style ('blunting').

**Methods:** In the ROGY Care Trial, twelve hospitals in the Netherlands were randomized to 'SCP care' or 'usual care'. All newly diagnosed endometrial and ovarian cancer patients in the 'SCP care' arm received an SCP that was automatically generated by the oncology provider through the web-based Registrationsystem Oncological GYnaecology (ROGY). Outcomes (satisfaction with information provision and care, illness perceptions and health care use) were measured directly after initial treatment and after 6, 12 and 24 months. Information coping style was measured at 12 months after initial treatment.

**Results:** Among patients with a 'monitoring' coping style (N=123), those in the 'SCP care' arm reported higher satisfaction with information provision (73.9 vs. 63.9, p=0.04) and care (74.5 vs. 69.2, p=0.03) compared to those in the 'usual care' arm. Among patients with a 'blunting' coping style (N=102), those in the 'SCP care' arm reported a higher impact of the disease on life (5.0 vs 4.5, p=0.02) and a higher emotional impact of the disease (5.4 vs. 4.2, p=0.01) compared to those in the 'usual care' arm.

**Conclusions:** Information coping style moderates the impact of SCPs in gynaecological cancer patients. SCPs may be beneficial for patients who desire information about their disease, while they may be less beneficial and perhaps even harmful for patients who avoid medical information, suggesting a need for tailored SCP provision to efficiently and effectively improve survivorship care.

## 121

## Can an individualised exercise program assist in maintenance of HRQOL in low and high grade glioma patients undergoing post-operative chemo-radiotherapy?

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**Aims**

Optimal glioma treatment includes maximal safe surgical resection followed by radiation and/or chemotherapy - however treatment toxicities are common that adversely affect HRQOL. This study aimed to assess the effect of an individualised exercise prescription during chemo-radiation and its effects on HRQOL.

**Methods**

Since 2015, 21 patients with grade II-IV glioma at Liverpool and Princess Alexandra Hospitals were prospectively recruited as part of an ongoing exercise feasibility study. Patients were prescribed a thrice-weekly individualised exercise program during radiation, and completed the EORTC-QLQ-C30 questionnaire pre radiation and then 7 weeks later. Change scores were calculated using the computed function of SPSS25 and used to describe the direction of change within EORTC-QLQ-C30 domains across time-points. Linear transformations convert scores into percentages with a higher score representing higher functioning and QOL.

**Results**

On average, comparing baseline to week 7 assessments, all functional scales showed positive increases except for cognitive functioning which decreased slightly. Mean increases for Physical Functioning was (M=8, SD=23), Role functioning was M= 16, SD = 31; and Emotional Functioning was M=19, SD= 28 respectively. Global Health and Quality of life increased by (M=6, SD= 27).A mean decrease was noted with respect to Cognitive Functioning - M= -0.05, SD= 34).

**Discussion**

Despite the expected acute side-effects (including fatigue) anticipated with post-operative chemo-radiation in glioma patients, these preliminary results suggest that a tailored physical activity program could mitigate against treatment side-effects and thus help to maintain quality of life. Further recruitment is ongoing with QOL measures to be analysed at later time-points to assess if these early effects can be maintained.

## 122

## Upskilling the primary care workforce in cancer survivorship

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**Aim**

There is a growing number of people living with and beyond cancer. Primary care practitioners (PCP) will play an important role in the care of cancer survivors however there is seemingly a lack of knowledge in this area. The Cancer Survivorship for Primary Care Practitioners program aims to enhance the knowledge and skills of PCPs in the transition of survivors from oncology treatment into shared care.

**Methods**

The program was developed in consultation with a multidisciplinary steering group and educational experts in curriculum development, design and evaluation. A flexible online platform was identified as the most appropriate modality to engage the target audience with optional face to face workshops. Aimed at primary healthcare practitioners including General Practitioners, nurses and allied health professionals; the program was developed to adhere to best practice survivorship care in the areas of: Survivorship Fundamentals; Communication and Coordination of Care; Surveillance, Late and Long-Term Effects; Palliative Care and New Cancer Therapies.

An online evaluation was distributed to all participants after their completion of the program, measuring the effect of participation in the online and workshop on confidence, knowledge and intention to change practice.

**Results**

The program delivered a four-week Massive Open Online Course (MOOC) to a registration of over 1000 participants from around the globe and a local representation of over 50 attended the face to face workshops. Participation in either the MOOC, workshop or both programs together envisage a positive impact on the confidence, awareness, knowledge and intention to change practice for all participating craft groups. These results / outcomes will be reported.

**Conclusion**

Best practice survivorship care promotes the formation and consolidation of a collaborative, interdisciplinary care team who are sensitive and responsive to each individual and their needs. The program delivers an innovative, interactive, flexible and free professional development opportunity for PCPs in response to the evolving population health landscape.

*The development and delivery of this program has been proudly supported by the Victorian Cancer Survivorship Program.*

## 123

### Parent and child quality of life in long term survivorship

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**Aims**: Quality of life (QoL) of long-term survivors of childhood cancer and their parents is rarely investigated. This study aimed to describe the QoL of childhood cancer survivors (<16) and their parents compared to population norms.

**Methods**: We surveyed Australian and New Zealand parents of a survivor of childhood cancer (<16 years) who were >5 years from diagnosis. We measured parents' QoL using the EQ-5D-5L index score, which evaluates mobility, self-care, participation in 'usual activities, pain/discomfort, and anxiety/depression. Parents completed a proxy measure of their child's QoL, using the KIDSCREEN10 which assesses loneliness, activity levels, and school performance. We compared parents self-report QoL and proxy reported child QoL to population norms.

**Results**: In total, 182 survivors' parents participated (14.4% were fathers). Parents reported on their child who was on average 12.4 years old and 8.4 years since treatment completion. Survivors' parents overall QoL was no different to population norms (mean(SD); 0.90(0.13) and 0.91(0.14) respectively, p>.05). Anxiety and depression problems were almost twice as common among survivors' parents when compared to population norms (43.4% and 24.7% p<.0001). Survivors' parents reported worse overall QoL for their child than population norms (48.0(10.8) and 50.56(9.9), p=.001).

Higher parent QoL was significantly associated with higher overall self-rated health (*p<0.001*), and lower perceived risk of their child developing a subsequent cancer (p=0.006). Higher survivor QoL was significantly associated with higher parent QoL (p=0.002). Lower survivor QoL was associated with a brain cancer diagnosis (*p=0.021*). No other parent (e.g. sex, ethnicity) or child factors (e.g. treatment, time since diagnosis) were significant.

**Conclusions**: Although overall parent QoL was no different to population norms, a significant proportion of parents continue to report problems with their emotional functioning long after their child's treatment is completed.

## 124

### Surviving and Thriving: The Active Survivor Exercise Program at Macarthur Cancer Therapy Centre

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**Background:** At the Macarthur Cancer Therapy Centre (MCTC), patients at any stage of their cancer diagnosis can be referred by their oncologist to 'Active Survivor', a best practice exercise program delivered at MCTC and/or an external exercise physiology provider (Health Solutions).

**Methods**: All participants complete a comprehensive review and assessment and then receive a 16-week individualized exercise program consisting of two supervised group-based sessions per week led by an exercise physiologist and two prescribed home-based sessions per week performed without supervision. The exercise program includes resistance/plyometric, aerobic and flexibility exercises. Assessments measured before and after the 16-week program include dual-energy X-ray absorptiometry, 6 Minute Walk (6MW), 60s Sit-to-Stand (STS), Brief Fatigue Inventory (BFI) and the Quality of Life Scale (QOLS).

**Results:** Forty-five patients aged 29 to 77 years have been recruited to date. Most are women (84%) with a diagnosis of breast cancer (62%), while the remainder have been diagnosed with prostate, gynecological or lower gastrointestinal cancers. Primary treatments have included surgery (91%), radiation (77%), chemotherapy (68%) and endocrine therapy (62%). To date, 18 patients (age: 58±11y; 88% women, 61% breast cancer; BMI: 30.5±5.08 kg/m$^2$) have completed baseline and follow-up assessments. These participants attended 92±6% of supervised exercise sessions. Paired Student's t-test (one-tailed) demonstrate a trend toward improved waist circumference (104.8±11.6cm to 102.5±12.1cm; p=0.06) while significant improvements were noted in body fat percentage (46.5 ± 7.1% to 45.4±7.7%; p=0.03), appendicular muscle mass (17.2±3.3 to 18.1±4.0 (kg; p=0.03), lean body mass (41.0±6.29kg to 42.9±7.8kg; p=0.02), 6MW (491±61m to 548±89; p=0.001), STS (29±6 to 41±12; p<0.001), BFI (5.0±2.2 to 2.8±2.4; p=0.002) and QOLS (85±14 to 91±16; p=0.03).

**Conclusions:** Our findings demonstrate that cancer patients can significantly improve body composition, physical functioning, fatigue and quality of life through a 16-week exercise program embedded as best practice at the MCTC.

## 125

### The impact of lack of choice of breast reconstruction options following mastectomy for breast cancer on Australian women's quality of life.

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**Aims:** Many studies have demonstrated the positive impact of breast reconstruction (BR) on women's quality of life following mastectomy for breast cancer. However, women's preferences for BR are not always fully considered by surgeons prior to mastectomy. The aim of this research is three-fold: to document the negative impact lack of choice has had on some Australian women; to explore potential reasons for the absence of informed discussion; and to develop a checklist of discussion topics to aid informed decision-making.

**Methods:** As part of a broader study, semi-structured interviews with 22 women with breast cancer, 31 oncoplastic and plastic reconstructive breast surgeons and 37 health professionals (mainly breast care nurses – BCNs) were conducted by either by telephone or face-to-face, between May 2015-May 2017. This presentation focuses on responses from the 22 women who were purposively selected for participation based on their self-identified negative experiences with accessing information about BR options following mastectomy.

**Results:** Interviews revealed cases where BR was not offered prior to mastectomy, even though it was available locally; where BR was not available locally, but patients were not informed about BR options available in other locations; where only delayed BR options were discussed; and where the type of BR being offered did not align with patient preferences. Breast surgeons are the gate-keepers to facilitating the range of choices but too often appeared to limit access to reconstructive surgery.

**Conclusion:** A lack of BR information or choice at the time of mastectomy led to severe and enduring emotional distress in this select cohort of women. We have suggested essential BR referral pathways and discussion points to be raised with all clinically eligible women interested in considering BR. The challenge is how to translate these principles of informed decision making into policy and clinical practice. We discuss some possible methods.

## 126

## Cancer survivors with pain have similar unhelpful thoughts and beliefs to other chronic pain patients.

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Background: Cancer pain is not usually managed in pain clinics. Due to advances in screening and treatment, there are more cancer survivor. Managing treatment –related pain and comorbid pain is a growing survivorship issue. Since 2014, Patient Reported Outcomes for chronic pain have been standardized in Australia, under the Australasian Electronic Persistent Pain Outcomes Collaboration (ePPOC).[1] The aim of this study was to characterize the pain experience of cancer survivors seen at the pain clinic (PC) at Sydney's Royal North Shore Hospital (RNSH) in the ePPOC era.

Method: All patients with a history of cancer who had an initial assessment in RNSH PC between 2013 and 2017 were identified from the EMR and their data were collected and entered into a database, including demographics, clinical details, and ePPOC questionnaire scores. Data analysis included descriptive and comparative statistics.

Results: Of some 2800 patients seen in the 5 year period, 281 (10%) had a history of cancer. 42 were excluded from analysis (cancer pain, not seen, refused). Of the remaining 239, initial questionnaires were available in 212 (89%), of whom pain was attributed to cancer treatment in 82 (31%). The commonest cancers were breast 22, colorectal 7, heme 12, and melanoma 9, with prostate and lung uncommon. 52 (62%) of the cancer treatment-related pain syndromes were post-surgical. The mean scores on the ePPOC questionnaires (see table) indicate survivors have the same levels of unhelpful thoughts and beliefs about pain (catastrophising, sense of injustice, fear of moving and lack of confidence to cope).

Discussion: Cancer survivors were common in this pain clinic, though most were seen for comorbid chronic non-malignant pain. Survivors with treatment-related pain may benefit from learning cognitive behavioral strategies to help them cope better with their pain, without needing to take analgesics.

Table. Mean scores for cancer survivors, compared to clinic norms

| | Cancer treatment-related pain, n= 82 | Cancer survivors with comorbid pain, N=129 | Pain clinic, normative values |
|---|---|---|---|
| Age (years) | 59 | 66 | |
| Males (%) | 48 | 44 | |
| Time since diagnosis (years) | 5 | 10 | |
| Average pain intensity | 5.2 | 6.0 | 7.0 |
| Pain interference | 5.8 | 6.7 | 7.5 |
| Depression | 13 | 18 | 14 |
| Anxiety | 8 | 11 | 9 |
| Pain self-efficacy | 27 | 24 | 26 |
| Pain catastrophising | 23 | 27 | 22 |
| Fear of moving | 37 | 38 | 41 |
| Sense of Injustice | 19 | 23 | Work injury 17; MVA:25 |

1. Tardif, H. et al. Establishment of the Australasian Electronic Persistent Pain Outcomes Collaboration. Pain Med 2017; 18 (6):1007-18.

## 127

## Survivors Teaching Students: Saving Women's Lives® (STS)- an ovarian cancer survivors learning initiative for health professional students.

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**Introduction** Ovarian cancer has the poorest survival rate of all gynaecological cancers at 43%. The rising incidence (predicted1640 per year by 2020) represents a growing burden for women in Australia[1].

The *National Framework for Gynaecological Cancer Control* (2016)[2] identifies as a priority, *"greater awareness of symptoms of gynaecological cancer, timely investigation and referral of a woman who may have symptoms… [to] improve earlier detection, enabling more timely treatment and improving the chances of long-term survival."* McRae (2016)[3] emphasised in a recent review article "improving outcomes for patients affected by cancer starts with undergraduate medical education curricula" and that despite "the impact of cancer in Australia being immense", this is not "reflected in the time devoted to its teaching and learning." Survivors are powerful advocates for change in outcomes for ovarian cancer.

**Aim** To empower survivors to use their own lived experience to advocate for better outcomes and awareness of ovarian cancer into the future.

**Method** *Survivors Teaching Students® is* an experiential learning program for medical and nursing students. This program targets the identified priority areas: *raise awareness of ovarian cancer signs and symptoms; and enhance learning opportunities in medical curricula.* This consumer led program, developed in 2002 in the US (also now in Canada and UK) takes a pedagogical approach that focuses on broadening the student experience through engaging them with survivors, women and caregivers telling their "real-life experience".

**Conclusion** STS demonstrates benefits for both students and survivors. The international data (2017) shows an increase in students' knowledge and awareness of ovarian cancer (medical - 22%; nursing - 40% improvement). Our (2018) data supports these findings. Survivors feel empowered to tell their stories. Qualitative data indicates high levels of satisfaction, with significant benefits reported as: *regaining control of one's life*, *sense of purpose, hope and feelings of empowerment.*

1. 1. Australian Institute of Health and Welfare 2014. Cancer in Australia: an overview 2014. Cancer series No 90. Cat. no. CAN 88. Canberra: AIHW. 2. Cancer Australia, 2016. National Framework for Gynaecological Cancer Control, Cancer Australia, Surry Hills, NSW. 3. McRae, R. (2016) How best to teach and learn about cancer in medical schools: moving towards a patient-centred approach that reflects the needs of Australia. Cancer Forum. Vol 40, Issue 3.

## 128

## The Type and Timing of Breast Reconstruction after Mastectomy: Qualitative Insights into Women's Decision-Making

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**Background:** Women who choose to have a breast reconstruction (BR) following mastectomy for breast cancer need to make decisions concerning the type and timing of their reconstruction. They may opt for the increasingly common delayed-immediate (expander-based) reconstruction, however, little is known about women's motivations for choosing this option. BR decisions are further complicated when post-mastectomy radiation therapy (PMRT) is indicated, as radiation to the reconstructed breast may lead to complications and poorer aesthetic outcomes.

**Aims:** To qualitatively explore Australian women's experiences of BR decision-making and factors that influence their BR decision.

**Methods:** Semi-structured telephone interviews were conducted with women treated with mastectomy and prosthetic or autologous reconstructions that were immediate, delayed or delayed-immediate. Purposive sampling continued until data saturation was reached. Interviews asked women about: information received from their medical team; reasons for reconstructive choices; and their feelings about their decision. Interviews were audiotaped, transcribed verbatim and analysed thematically using the Framework method.

**Results:** From interviews with 29 women, mean age 54 years (SD 6.78), seven main themes were identified: i) information provision and needs; ii) values and preferences; iii) decisional pressure; iv) feasibility; v) social influence and support; vi) interprofessional team and organisational structures; and vii) decision implementation and outcomes. Women commonly chose delayed-immediate expander-based BR due to practical factors and to lessen their feelings of (perceived/actual) decisional pressure. Women reported receiving little information about possible PMRT impact on reconstructed breast(s). Collaboration and communication within multidisciplinary teams were found to support the BR decision-making process.

**Conclusion:** These themes offer a comprehensive explanation of how Australian women make BR decisions. The findings explain women's reasons for choosing delayed-immediate (expander-based) reconstructions, and highlight the often limited information-sharing regarding adjuvant PMRT. Strategies for patients, clinicians and organisations to enhance patient-centred interprofessional care are proposed, including development of in-consultation decision support tools.

## 129

## Psychosocial and Decisional outcomes Following Breast Reconstruction after Mastectomy: the Role of Body Image Attitudes

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**Background:** Implant-based and immediate breast reconstructions (BR) are increasingly popular following mastectomy for breast cancer. These BR procedures are associated with additional risks such as implant loss and poorer cosmetic outcomes, compared to alternative procedures. Women's body image attitudes (investment and evaluation) and decision-making contexts are under-explored in this context.

**Aims:** to investigate whether: i) women's body image investment predicts body image evaluation and psychological morbidity; ii) body image attitudes differ according to BR type and timing; and iii) BR type and timing predict variance in decisional outcomes, in this population.

**Methods:** This cross-sectional survey was completed online by women recruited through the Breast Cancer Network of Australia, social media, and participating hospitals. They completed standardised questionnaires assessing: body image attitudes (investment and evaluation), psychological status (depression and anxiety), and decisional outcomes (extent of informed-decision making, decisional satisfaction and regret). Multiple linear regression was performed.

**Results:** Respondents were 184 Australian women treated with breast cancer, mean age 55 (*SD*=10.19) years. Higher body image investment predicted higher body image dissatisfaction (*p*<.001, CI 2.213-4.880), levels of anxiety (*p*<.001, CI 1.490-3.698), decisional regret (*p*=0.010, CI 2.791-20.887) and lower decisional satisfaction (*p*=0.027, CI-0.899—0.056). Body image investment was not associated with a single type of BR.  Decision-making factors did not differ as a result of BR type.

**Conclusions.** the importance of fostering of realistic expectations prior to BR, as well as enhancements of current decision aids to include aspects of body image schemas.

## 130

## Cancer Clinicians' understanding of cancer-related cognitive impairment and whether a fact sheet can drive practice change: a qualitative exploration

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**Background:** Cancer-related cognitive impairment (CRCI) can have debilitating effects on cancer survivors. Despite this, patients often report a lack of information from their treating team to assist with understanding and management of cognitive changes. This study aimed to qualitatively explore cancer clinicians' understanding of and clinical practice related to CRCI including acceptability of a Cancer Council Australia Fact Sheet – Understanding changes in memory and thinking.

**Methods**: Semi-structured telephone interviews were conducted with 26 cancer clinicians; medical oncologists (n=7), cancer nurses (n=12) and clinical psychologists (n=7). Framework analysis was conducted to identify key themes. A quantitative survey was also conducted to assess pre-interview CRCI knowledge.

**Results:** Four themes emerged from the data: (1) CRCI - real or over-rated? (2) Does knowledge drive patient communication? (3) Fact Sheet Acceptability; (4) Barriers to Fact Sheet uptake into routine clinical care. Based on the survey, although recognition of CRCI causation and symptom management was high, very few clinicians utilised more than one strategy. Overall the fact sheet was perceived as useful for patients and the content comprehensive. However, a need for further CRCI education for clinicians was highlighted as necessary prior to wider implementation of the fact sheet.

**Conclusion:** This study's in-depth multi-disciplinary exploration of Australian cancer clinicians' perceptions of CRCI highlighted that clinicians' attitudes drive CRCI discussions with patients. Although the Cancer Council Fact Sheet was viewed as an important patient resource, further education to support clinicians in providing management strategies to patients is required for successful integration into routine care.

## 131

## Cancer Survivorship - Introducing key concepts and access to resource availability. A review of education provided to community generalist nurses.

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With an ever growing population of cancer survivors in Australia, the education of community nurses in recognising the challenges and potential health care concerns is paramount. Community nurses are an integral part of the team likely to be involved in the provision of health care in the years following treatment for cancer.

Aims: To develop, deliver and evaluate an education program on cancer survivorship for nurses working in the community setting.

Methods: The program was designed as a Microsoft Office PowerPoint presentation. The presentation included audio visual content, oral presentation and a case study to consolidate understanding of the information provided. It was delivered at a community nurse education forum.

Results: 22 out of the 29 attendees completed a pre-education questionnaire. Results clearly indicate that knowledge of survivorship issues post treatment for cancer are not well known amongst generalist community nurses. Most nurses described themselves as having a fair to reasonable awareness of the physical and psychological side effects of treatment for cancer (72.27%, N = 17). However, their awareness of the aims of survivorship care and what should be included in a survivorship care plan (SCP) is much lower, just 4 nurses identified a reasonable or very good awareness of this (18.84%). Awareness of available resources for consumers and health care practitioners (HCP) was also very low, with only 2 nurses knowing where to access HCP resources.

19 out of 29 attendees returned a post education questionnaire. Both awareness and confidence were higher on every individual question. In all questions relating to awareness of cancer survivorship, more than 94% (N = 18) of attendees stated they had a reasonable, very good or excellent awareness of key survivorship concepts. Over 84%, (N = 16), now rated their confidence levels in supporting a cancer survivor as reasonable, very good or excellent.

Conclusion: The aim of the study was to evaluate the effectiveness of an education program on cancer survivorship to nurses working in the community. It is the first step in developing patient centred and evidence based SCPs for survivors in our local health district. Continued education with links to the latest evidence as it emerges, will guide focus groups of key stakeholders in the development of a SCP that is relevant and useful to all involved.

## 132

## Centralised specialist cancer survivorship assessment clinic (cisco) for patients with early breast cancer or dcis

**Beth Ivimey**[1], **Sandra Avery**[1], **Geoff Delaney**[1], **Afaf Girgis**[2], **Ivana Durcinoska**[2], **Peter Smith**[1], **Gui Xiong**[1], **Andrew Knight**[3],

**Eugene Moylan**[1], **Gregory Webb**[1], **Kylie Smith**[1], **Danielle Peterman**[1], **Ashanya Malalasekera**[1], **Eng-Siew Koh**[1]

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**A Centralised Specialist Cancer Survivorship (CISCO) clinic for patients with Early Breast Cancer and DCIS: preliminary results of an implementation study**

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### Aims

The Patient-Reported Outcome Measures for Personalized Treatment and Care (PROMPT-Care) project aimed to capture PROs, including validated screening tools for distress, symptoms, and unmet needs, supporting clinical decisions and patient self-management. The CISCO assessment clinic utilises this model by developing and implementing a systematic, centralised model of shared survivorship care. We aim to assess the feasibility of a fully integrated electronic treatment summary and survivorship care plan (SCP), including PROMPT-Care assessments, within oncology Electronic Medical Records (EMR).

### Methods

Patients with EBC and/or DCIS having completed adjuvant chemotherapy and/or radiotherapy (RT) were eligible for a baseline and follow-up CISCO consultations 6-9 months later. Patients were asked to complete their baseline assessments prior to the initial CISCO assessment and then monthly. A treatment summary was generated from the oncology EMR.

The CISCO clinic is co-staffed by a Haemato-oncologist and nurse coordinator who undertake comprehensive consultations incorporating post-treatment physical and supportive care needs, actioned allied health/community referrals and confirmed follow-up investigations. Assessments were incorporated live during the consult into an electronic SCP, which was provided to the patient and their GP. Feedback will be sought from patients, referring specialists and GPs regarding SCP content / process.

### Results

To date, of n=**26** patients referred, **14** subsequently declined participation . Of **n=10** assessed at baseline, median age **61** years, n=**7** underwent RT**, n=2** chemo-radiation, and **n=5** were receiving endocrine therapy. One NESB patient attended the initial CISCO consultation and completed PROMPT-Care[1] assessments. The most common symptoms described were fatigue, scan anxiety, fear of cancer recurrence and weight issues. Monthly PROMPT-Care completion compliance was variable .

**Conclusions**

embed electronic PROs within the oncology EMR, and generate 'live', dynamic survivorship care plans within the context of a comprehensive survivorship consultation. If successful, outcomes from the CISCO model will aid scalability and implementation to other survivor cohorts.

## 133

## A review of interventions and online resources to improve carer involvement in medical consultations and decision-making

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**Aims:** Family carers often attend medical consultations and can be valuable members of the cancer care team, however some family carers report feeling overwhelmed and unsure of their role. We aimed to understand what help and guidance exists for family carers on how to be effectively involved in medical consultations and decisions, by reviewing the academic evidence-base as well as the web-resources directly available to carers.

**Methods:** Relevant studies of carer-directed interventions or tools published from 1950-2018 were identified via database searches (Medline, Scopus, CINAHL, PsycINFO). Searches were also performed using lay search strings on Google, to identify websites directed at carers that provided information or advice on being involved in medical consultations, communicating with health professionals, advocacy, or decision-making.

**Results:** Academic database searches retrieved 12 eligible studies with the majority targeting carers of cancer patients. The interventions and tools reported were question-prompt lists, communication skills workshops and coaching, and checklists and written guides. Positive carer outcomes included increased self-efficacy, greater involvement in consultations and reduced distress. However, only two interventions had been rigorously tested in randomised controlled trials. The Google searches yielded 24 relevant websites, including 9 directed specifically at carers of people with cancer. Websites provided tips on preparing for medical consultations (e.g. self-educating, writing question lists and negotiating roles) and participating in consultations (e.g. how to communicate assertively with HPs, ensure understanding, and record information).

**Conclusions:** Together, these reviews provide insight into carer-directed interventions and resources. The findings will be used to inform the development of an online education module (eTRIO-pc) for cancer carers. By educating and empowering family members on how to be effectively involved in consultations and communicate with health professionals, it is hoped that both patient and carer outcomes will be improved across the cancer care trajectory, including into survivorship.

## 134

## Pain, fatigue, information needs, and fear of cancer recurrence among adult survivors of childhood cancer

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Pain and fatigue are two under-researched late effects of childhood cancer and its treatment, both of which have profound impacts on survivors. This study investigated the prevalence of self-reported pain and fatigue since treatment completion and anticipated future pain and fatigue. We explored how these factors related to demographic and medical characteristics, information needs, and fear of cancer recurrence. We surveyed 404 adult survivors of any form of childhood cancer ($M$=16.82 years since treatment completion). Many survivors reported experiencing pain (28.7%) and fatigue (40.3%) since treatment completion, and anticipated future pain (19.3%) and fatigue (26.2%), which were all significantly associated with one another (all $p$'s <.001). Bone or soft tissue sarcoma diagnoses were associated with reporting pain since treatment completion (compared with leukaemia; OR=4.27, 95%CI=1.21-15.02). Having received radiotherapy was associated with future anticipated fatigue (OR=3.68, 95%CI=1.56-7.34). Bone marrow transplants were associated with experiencing fatigue (OR=2.83, 95%CI=1.13-7.08) and anticipated future fatigue (OR=2.54, 95%CI=1.01-6.36). Survivors who reported pain, fatigue, anticipated future pain, and anticipated future fatigue had greater needs for information about managing these late effects. Additionally, 8.7% of participants reported 'a lot' or 'a great deal' of fear of cancer recurrence. Survivors with unmet needs for information about managing pain and fatigue reported higher fear of cancer recurrence than survivors with no reported need for information (B=0.48, 95%CI=0.19-0.76, $p$ <.001). Long-term follow-up clinics should assess pain and fatigue, especially among survivors of bone and soft tissue sarcomas and recipients of bone marrow transplant. Information provision about pain and fatigue may be an important tool to help manage fear of cancer recurrence.

### 135

## Digital Health and Disparities in Cancer Care: Opportunities for digital inclusion

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Aims: Digital health applications, such as information and support websites, mobile apps, telehealth, and wearables can support care for people with cancer. However, research indicates disparities occur in digital health benefit realisation for some population groups due to "digital exclusion", which refers to access, affordability, usage, skills, and relevance of digital technologies. This study is a sub-analysis of a systematic meta-review of literature on digital health in cancer care, which aimed to explore disparity issues identified in the review papers.

Methods: A systematic literature review of review papers, guidelines and recommendations pertaining to digital health applications and cancer care, published from January to July 2018, was undertaken to identify barriers, enablers, and high priority needs in the implementation of digital health applications in cancer care. The themes related to barriers to, and enablers for, implementation relevant to disparity in digital health in cancer care were identified.

Results: The literature search identified 93 review papers focusing on digital health applications in cancer care. Of these, 57 (61%) identified issues for implementation within the theme of disparity and inclusivity, across all digital health modalities reviewed Forty-five papers (79%) identified barriers and 36 (63%) identified enablers. Whilst digital health was seen as increasing access to services for underserved areas and populations, including in remote areas and developing countries, disparities were also evident due to barriers including age, technological/digital literacy, health literacy, language, ethnicity, and socioeconomic disadvantage. Personalisation/tailoring offered potential to reduce these disparities.

Conclusion: This research identified the potential for digital health to reduce disparity and increase inclusivity in cancer care; however, the potential for digital exclusion to increase disparities in cancer outcomes in underserved groups was observed. Digital health applications need to be strategically implemented in such a way that they reduce, rather than increase, existing disparities in access to cancer care.

### 136

## Development of a Strategic Framework for Digital Health in Cancer Care: Stakeholder-identified barriers, enablers and needs for implementation.

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Aims

The potential of digital health to increase access, integration, and personalisation of care is particularly relevant to cancer care, given growing numbers of cancer survivors, their complex, often long-term health care needs, and the importance of self-management, health behaviour modification, and longitudinal data monitoring. Despite this, we have not been able to identify a strategic framework for development and implementation of digital health specific to cancer care. Existing digital health frameworks focus on health system over consumer priorities, despite the potential for digital health to assist cancer consumers to navigate the plethora of information available electronically and meet their needs for decision support. This study aimed to engage multiple stakeholders on digital health in cancer care, to identify barriers, enablers, gaps and priority needs and subsequently inform the development of a strategic framework for digital health in cancer care in Australia.

Methods

Stakeholders with expertise or interest in digital health and/or cancer care were recruited through consumer organisations, professional organisations, and individual invitation of NGO and policy body leadership. Stakeholders participated in focus groups or individual interviews, exploring their perspectives on advantages and disadvantages, barriers and enablers, opportunities and priority needs for digital health in cancer care in Australia. Prevalent themes were identified using thematic analysis.

Results

Participants (N = 36) included consumers, health care providers, academics, developers, and NGOs and policy representatives. Issues in implementing electronic health records were emphasised. Themes related to barriers, enablers and needs included privacy and security, disparity and inclusivity, convenience and ease of use (including interoperability), and the need for a coordinated approach to avoid redundancy and enable effective scaling and implementation of digital health approaches.

Conclusions

Barriers, enablers and needs identified by stakeholders will enable a coordinated approach to digital health in cancer care in Australia, to the benefit of users.

## 137

### Identification of breast cancer survivors’ side effects and supportive care needs

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Identification and management of side effects and supportive care needs arising from treatment is essential for treatment adherence and quality of life of breast cancer patients.

A retrospective audit of 160 women with early breast cancer who received treatment at a single breast service in Melbourne was performed. Information was retrieved from medical and nursing survivorship planning consultations. Data extracted included all symptoms/issues recorded and referrals/services offered. Symptoms were categorised into six domains. McNemar's test was performed to analyse the differences.

Mean±SD age at diagnosis was 60±11 years. The majority of patients were postmenopausal (76%), had breast-conserving surgery (83%), and received radiotherapy (72%) and endocrine therapy (92%). A substantial incidence of issues/symptoms was recorded: 76% menopause/hormonal therapy-related, 58% psychosocial-related, 67% lifestyle-related, 22% bone health-related, 37% sexuality-related and 2% fertility-related. Nurses were more likely to record symptoms than doctors: menopausal/hormonal therapy 74% vs 52% (p<.001); psychosocial/mental health 56% vs 11% (p<.001); lifestyle 62% vs 19% (p<.001); bone health 21% vs 11% (p<.001); sexuality 37% vs 4% (p<.001); and fertility 8% vs 4% (cells too small to analyse), respectively. Nurses were significantly more likely than doctors to refer patients for follow-up for psychosocial/mental health (p<.001), lifestyle (p<.001) and sexuality (p<.001) issues, respectively.

Side effects and other issues are common after breast cancer treatment. Overall, nurses are significantly more likely to identify/report symptoms and make referrals. The findings highlight the need to identify and address unmet needs and the value of a multidisciplinary approach to the long-term management of women with early breast cancer.

## 138

### Strategies to promote effective clinician engagement with cancer carers: The TRIO Guidelines

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#### Aims

Family carer involvement in cancer care is often beneficial, but can at times be challenging and complex. Effective carer engagement by oncology clinicians can result in improved patient/survivor care and outcomes, and can also provide an ideal opportunity for carers to have their own informational and emotional needs met. However, if not well managed, some family carers can derail consultations and impede effective clinical care. Few strategies or interventions have been developed to enhance positive carer engagement in cancer consultations. The aim of this presentation is to describe the development and evaluation of evidence-based guidelines (the TRIO Guidelines) for oncology health professionals to manage and enhance carer involvement in cancer consultations.

#### Methods

Development of the TRIO Guidelines was based on a comprehensive review of the evidence-base and feedback from an advisory group of 10 academic and clinical experts. Draft guidelines underwent two rounds of evaluation via an online Delphi consensus process involving 35 international experts in medical communication, cancer carers, and oncology care. A multidisciplinary expert advisory group assisted in the development of 8 professionally produced short films which demonstrate the guidelines in practice.

#### Results

Thirteen key guidelines for managing and enhancing carer involvement in consultations will be presented. These guidelines cover topics such as building rapport with carers, managing sensitive patient information, meeting the emotional needs of carers, and managing challenging and complex situations such as family dominance, conflict, and anger. Purpose developed short films, which demonstrate use of the TRIO Guidelines in common clinical scenarios, will be featured.

#### Conclusions

These educational resources, designed to enhance carer engagement, have the potential to improve patient’s and family carer’s experiences in cancer consultations as well as improving clinicians confidence when interacting with family carers.

## 139

### Building the bridge to brain cancer survivorship: a work in progress.

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**Background:**

Information and supportive care resources for people with brain cancer are currently targeted to those with aggressive disease profiles. However, improved survival duration has raised awareness of the impacts and challenges for people living with grade 2 and 3 brain cancers. These survivors can experience significant and long-term physical, cognitive and behavioural impacts from the tumour and its treatment.[1] *Building the bridge* is a Victorian cancer survivorship grant project aimed at developing tailored and accessible resources for brain cancer survivors, supporting self-management and providing tools for health professionals to use in survivorship conversations.

**Process:**

An experience-based co-design approach has placed survivor experiences central to the project. Stage one has seen initial focus groups define high prevalence issues faced by survivors in returning to life after a brain cancer diagnosis. Consultation with health professionals across neuro-oncology and key project partners have refined themes and explored accessibility. Further consumer focus groups will prioritise and direct the format of the resource. Stage two will continue the co-design process with analysis of the collected data and development of the survivorship resource. Review and feedback from survivors and health professionals will be incorporated prior to resource production. The final stage will entail dissemination, resource testing and evaluation of the survivorship resource by brain cancer survivors not previously engaged in the co-design. Emerging themes are centered on mental health, fatigue, family resources, and neuro-cognitive rehabilitation.

**Expected Outcome:**

This project will create a survivorship resource tailored to the needs and priorities of Victorian brain cancer survivors, carers and health professionals. The project partners will ensure these resources are sustainable and widely available, providing accessible support for survivorship transition. The *Building the Bridge* project is aimed at improving the capacity of brain cancer survivors and families to access appropriate post-treatment support and re-engage in community life.

1. 1. Sloane, K., et al., Late effects in survivors of central nervous system tumors: reports by patients and proxies. Journal of Cancer Survivorship, 2016. 10(2): p. 234-240

## 140

## Cancer-related challenges, unmet needs and emotional distress in men caring or women with breast cancer: The influence of self-efficacy

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Aims: As cancer care is being increasingly delivered in outpatient clinics, demands on family caregivers are intensifying. While some caregivers will rise to the demands, others will report numerous challenges and unmet needs, which have a detrimental impact on caregiver well-being. The current study aimed to examine whether self-efficacy, the belief in one's ability to succeed and accomplish tasks, influences the relationship between challenges and unmet needs with emotional distress.

Methods: An online survey of 89 men who were caring/had cared for a woman with breast cancer was conducted. Participants completed measures of cancer-related challenges, caregivers unmet needs, self-efficacy and emotional distress.

Results: Overall, participants reported low levels of emotional distress (M = 6.92, SD = 8.90, range = 0-37) and high levels of self-efficacy (M = 39.37, SD = 6.76, range = 16-48). Self-efficacy was significantly correlated with cancer-related challenges ($r = -.54$, $p<.001$), unmet needs ($r = -.49$, $p< .001$), and emotional distress ($r = -.36$, $p < .01$). Mediation analysis revealed that cancer-related challenges significantly predicted emotional distress, however this relationship was not mediated by self-efficacy ($b = -.002$, 95% CI -.25 - .25). In contrast, the relationship between unmet needs and emotional distress was mediated by self-efficacy ($b = .05$, 95% CI .01 - .10).

Conclusions: Self-efficacy is related to emotional well-being in men caring for women with breast cancer and mediates the association between unmet needs and emotional distress. Caregiver support interventions designed to enhance self-efficacy may help to reduce distress in male caregivers.

## 141

## Evaluation of a survivorship care plan database

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**Aims**

The Australian Optimal Care Pathways recommend that survivors and general practitioners be provided with a survivorship care plan (SCP) after treatment completion, however implementation has been limited. We developed a database of key SCP components for survivors of early-stage breast, colorectal or prostate cancer. Development was guided by a steering committee comprising survivor, medical and nursing representatives (oncology and community-based), and three similarly constituted reference groups, one for each cancer type. This evaluation aimed to assess use of the database and areas for refinement/further development.

**Methods**

The SCP database was advertised from May 2018. Dissemination is ongoing; data presented are current to October 23 2018. Interested users applied for database access via an online form that also collected institutional information and data regarding intended use of the database. User feedback was collected via an online survey sent at two months.

**Results**

A total of 99 individuals requested database copies; majority were from Victoria (72%) and New South Wales (12%). Most requested all cancer types (37%) or the breast database only (31%), and 72% indicated intent to use the SCP database clinically. Of 81 users sent the follow-up survey, 19 responded (response rate 23%). At two months, 79% (15/19) were not using the SCP database, although 100% indicated that the user guide was helpful. User feedback revealed praise for database content, intention to use or share with colleagues, and limitations of the format (Microsoft Excel), particularly limited functionality. Reasons for not using the SCP database included the need for a more 'user-friendly' design, limited time, and need for further education and support. Most respondents (67%; 12/18) indicated interest in a web-based SCP generator.

**Conclusions**

Development of a web-based interface for the SCP database is expected to maximise use of the content. This is due to be completed in March 2019.

## 142

### Recommendations for implementing and delivering shared survivorship care: a systematic review

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**Aim**

To care for the growing number of cancer survivors in Australia, health services must reconsider appropriate models of care. Sharing care between specialists and primary care providers may allow for more effective and efficient care for cancer survivors, and this approach has been endorsed by Cancer Australia. However, many unknowns remain regarding practical evidence-based recommendations to guide implementation. The aim of this systematic review was to explore facilitators and barriers to shared care between primary and specialist providers for people with cancer.

**Methods**

A literature search was constructed by a library scientist and conducted in July 2018 across MEDLINE, Embase and Emcare databases, without date restrictions. Two reviewers selected eligible studies and assessed their quality using study-specific appraisal tools. Data relevant to the review question were extracted and synthesised following a mixed methods approach.

**Results**

Twelve studies were included; eight qualitative, two cross sectional, one program evaluation and one case report. Studies were from Australia (n=5), US (n=4), and one each from the Netherlands, UK and Canada. Seven major themes were developed: 1) the importance of communication between different providers, and also between providers and patients; 2) potential roles of electronic medical records and survivorship care plans to enhance communication; 3) the need for clarity between GPs and specialists regarding roles and responsibilities; 4) further training for GPs to increase their knowledge and confidence in providing survivorship care, and increase patient trust; 5) the need for established shared care guidelines; 6) the importance of care coordination and clear referral pathways; 7) and the need for a supportive policy framework encompassing information sharing, privacy and funding issues.

**Conclusion**

Based on review findings, a set of recommendations for support future implementation of shared survivorship care are proposed.

## 143

### Cost-effectiveness of a psycho-educational intervention targeting fear of cancer recurrence in melanoma survivors

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Background: Fear of cancer recurrence is a major psychological challenge related to cancer survivorship. This study aimed to evaluate the cost-effectiveness of a newly-developed psycho-educational intervention compared with usual care to reduce fear of cancer recurrence among melanoma survivors managed in a high-risk melanoma clinic.

Methods: A within-trial cost-effectiveness and cost-utility analysis was conducted from the Australian health system perspective using data from linked Medicare records. Outcomes included fear of cancer recurrence (FCR), measured with the severity subscale of the FCR Inventory; quality-adjusted life years (QALYs) measured using the preference-based instrument, Assessment of Quality of Life-8 Dimensions (AQoL-8D) and 12-month survival. An incremental cost-effectiveness ratio (ICER) was calculated for two economic outcomes: (i) cost per additional case of 'high' FCR avoided and (ii) cost per QALY gained. Means and 95% confidence intervals around the ICER were generated from non-parametric bootstrapping with 1,000 replications.

Results: A total of 151 trial participants were included in the economic evaluation. At 12 months, participants in the intervention group reported significantly lower FCR severity; the between-group mean difference was −1.41 (95% CI −2.6 to −0.2; $p$=0.02). The mean cost of the psycho-educational intervention was AU$1,614 per participant, including psycho-educational intervention (booklet) development costs. The ICER per case of high FCR avoided was AU$12,903. The cost-effectiveness acceptability curve demonstrated a 78% probability of the intervention being cost-effective relative to the control at a threshold of AU$50,000 per extra person avoiding FCR. The

ICER per QALY gained was AU$116,126 and the probability of the intervention being cost-effective for this outcome was 36% at a willingness to pay of AU$50,000 per QALY.

Conclusion: Although it is not known how much the government would be willing to pay to reduce one case of high FCR, this psycho-educational intervention is effective and may represent good value for money.

## 144

## Radiation risk from computed tomography surveillance imaging in Stage III melanoma survivors: a simulation modelling study

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**Background:** The use of computed tomography (CT) surveillance imaging as a part of post-cancer treatment follow-up schedules is increasing rapidly. However quantification of radiation-attributable cancer risk associated with long-term CT surveillance imaging, is lacking.

**Methods:** A simulation model was built to calculate life-long radiation exposure in asymptomatic adults treated for AJCC stage IIIA-D melanoma aged 20, 40, or 60-years at diagnosis. Imaging protocols included CT chest-abdomen-pelvis and CT brain imaging at intervals of three, six or 12-months, over a three, five or 10-year surveillance duration. Organ doses were estimated using Monte-Carlo-simulation-based dosimetry software (CT Expo) with parameters from national delivered CT dose data (2015), calculated using methods from the Biological Effects of Ionizing Radiation (BEIR VII) report, and the National Cancer Institute's Radiation Risk Assessment Tool (RadRAT); with adjustment for stage III melanoma life-expectancy. New cancers attributable to CT radiation were presented as cases per 100,000 population.

**Findings:** Mean estimated lifetime attributable risk of new cancers from cumulative CT imaging for males was 250 (90%CI 107 to 443) to 6,310 (90%CI 2550 to 11,230) cases per 100,000 population depending on age, frequency of imaging and surveillance duration. For females, this risk was 252 (90%CI 135 to 406) to 7,710 (90%CI 2,550 to 11,230) cases per 100,000 population. Risk was highest for both genders at 20-years-old undergoing three-monthly imaging for 10-years (n=40 scans), and for those with Stage IIIA compared to IIIB/C/D melanoma. Cancer risk from radiation exposure decreased markedly as a function of age and fewer total CTs.

**Interpretation:** In cancer survivors, frequent and prolonged CT surveillance may increase the absolute risk of new cancers, particularly among young people. This harm needs to be considered alongside potential benefits including earlier detection of treatable disease.

## 145

## Why Wait for Wellness - The evolution of a multidisciplinary approach to cancer prehabilitation

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### Introduction

Early access to Allied Health after cancer diagnosis and prior to or at the beginning of treatment positively influences patient experiences and outcomes. Intervention at an early stage in the cancer journey enables timely management of complex physical and emotional issues and can decrease the likelihood of crisis for patients and families at a later stage of their journey (1, 2).

### Method

This study describes the outcomes of a review of an existing multidisciplinary service to inform a multidisciplinary prehabilitation service at the Ballarat Regional Integrated Cancer Centre (BRICC) for people with newly diagnosed cancer. BRICC, part of Ballarat Health Services, participated in a multicentre study looking at an early multidisciplinary Allied Health intervention using a prehabilitation model (2). Feedback from consumers/patients on current practice was sought and this information informed the development of the new prehabilition service.

### Major Finding

The existing multidisciplinary program delivered by a Dietitian, Physiotherapist and Exercise Physiologist focused on weight management by targeting diet, behaviour modification and physical activity.. The positive feedback received from the patients who participated in the multicentre study soon after diagnosis, and from the existing group weight management participants who identified group education and social support as positive aspects of the existing multidisciplinary program, provided incentive to advocate and continue with this prehabilitation style of education.

The multidisciplinary program now focuses on optimising wellness through supporting people with nutrition, emotional wellbeing and physical exercise and promoting strategies to manage symptoms, treatment side effects, self-advocacy, and timely access to services as early as possible from the time of diagnosis in a supportive environment. No changes were made to which Allied Health disciplines were involved in program delivery.

### Concluding Statement

The multidisciplinary prehabilitation service continues to evolve in response to people's experiences with allied health service provision and what the patients and their families value post cancer diagnosis.

1. Cancer Prehabilitation: An Opportunity to Decrease Treatment-Related Morbidity, Increase Cancer Treatment Options, and Improve Physical and Psychological Health Outcomes

Silver, Julie K. MD; Baima, Jennifer MD American Journal of Physical Medicine & Rehabilitation: August 2013 - Volume 92 - Issue 8 - p 715–727

2. Optimising the Capability of the Allied Health Workforce within Cancer Prehabilitation: A Feasibility Study Final Report.Professor Lynette Joubert, Melbourne School of Health Sciences, University of Melbourne. Dr Lucio Naccarella, PhD, Centre for Health Policy. Melbourne School of Population and Global Health, University of Melbourne. December 2017

## 146

### Pathways for older people in a rural hospital's cancer rehabilitation and survivorship service

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In 2017 Castlemaine Health established a Cancer Rehabilitation and Survivorship Program by re-orienting existing allied health and nursing resources into a cancer-specific stream within the Outpatients service.

During the first year 48% of clients in the service were over 70 years of age. Baseline FACT-G results demonstrated that these clients presented with lower T-scores for "Social/Family Wellbeing" (t= 41.7) and "Functional Wellbeing" (t=32.9) compared to their younger counterparts (t= 48 and t= 36.1 respectively).

In response to the proportion of older clients in the program and the complex nature of their needs, in 2018 we further developed our existing service to include pathways for providing targeted assessment and intervention for older people in our community and their carers.

The first pathway incorporates the specialised nursing skills of an Older Persons Nurse Practitioner (OPNP) as part of the multidisciplinary team. Clients ≥ 70 years are routinely screened using the Edmonton Frail Scale, and those identified as vulnerable or frail are offered the OPNP service in addition to their usual care.

Another pathway focuses on improving processes for recognising and supporting carers through integrating the Carer Support Needs Assessment Tool (CSNAT) and intervention guidelines into existing practice.

The final pathway explores the experience and needs of older cancer survivors in residential aged care facilities, and their families, through interviews. As part of the exploration into residents' experience, 39 residential aged care staff were surveyed to determine their knowledge and confidence in providing cancer survivorship care. This survey showed that 80% had not received any cancer-specific education, and only 10% felt highly confident in accessing credible information in order to provide best practice interventions.

Findings from the project will be presented. This project is supported by a grant from a Victorian Cancer Survivorship Program: Phase II Grants Scheme - Capacity Building Grant 2018.

## 200

### Content and delivery preferences for an online intervention to support men caring for women with breast cancer

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Aims: The diversity in caregiver responsibilities when caring for someone with cancer often means that caregivers feel ill-prepared for the caring role. This study aimed to examine male caregivers' views on intervention mode, timing, and content preferences.

Methods: A mixed methods study where 89 men with a history of caring for a woman with breast cancer completed an online survey which included questions regarding preferences for caregiver training and cancer-related challenges. Thirteen men also participated in a qualitative interview to further explore their views on the development of a caregiver training intervention.

Results: Over one-third of participants (36.8%) expressed a moderate to strong desire for a caregiver training intervention. Most participants expressed a desire for an online intervention/app (71.5%) with all content always available (i.e. not released over time, 54%) so that they could access the intervention around specific milestones (38%) or on demand (31%). The survey results indicated that the most common challenges experienced included fear of recurrence, changes to sexual relationships, worry, knowing what to expect and the impact on everyday life, which was echoed in the interview data. The semi-structured interviews revealed that most caregivers found the emotional elements of caring more challenging than managing physical matters. The interviewees highlighted that intervention content needs to help caregivers know what to expect and address psychological challenges for themselves and the person they care for.

Conclusions: It is evident that male caregivers experience numerous challenges that are primarily psychosocial in nature and impact on both their relationship with the loved one they care for, and their everyday functioning in other areas of their lives. There is encouraging support for an online caregiver training intervention that covers numerous topics and is available for men to tailor how they use the content based on their individual needs.

## 201

### Cognitive Difficulties for Women after Breast Cancer: Compounding Problems When Trying to Return to Work

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**Introduction:** Women with breast cancer report cognitive difficulties during and after treatment. The cause of cognitive changes continues to be debated. It is estimated that 70% of women report cognitive changes and for some, the symptoms lasting up to 20 years. With the survival rates for breast cancer increasing, women have to manage these cognitive changes, whilst trying to return work.

**Objectives:** Firstly, to identify how a combination of problems related to cognitive changes after breast cancer impact on a woman's ability to perform her work tasks and participate in employment. Secondly, explore the potential role of occupational therapy in addressing cognitive changes at various points in the recovery process.

**Method:** A scoping review was conducted to explore what is known about the issues contributing to difficulties performing work tasks and participating in employment for women with cognitive changes due to breast cancer.

**Results:** In early stages of breast cancer recovery, cognitive symptom recognition may be overlooked as medical professionals may be unaware intervention options. Formal cognitive assessments may not validate self-reported symptoms, or accurately identify task specific problems experienced. At work, women may hide their cognitive difficulties. Employers may feel ill - equipped to deal with such problems. Regardless of when cognitive changes are identified, there is little recognition of the role occupational therapy can play in providing ecologically valid assessments and interventions.

**Conclusion:** There are substantial opportunities for occupational therapists to provide workplace based cognitive assessments and interventions for women with breast cancer experiencing cognitive difficulties.

## 202

## Investigating follow up of women with early stage breast cancer

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**Introduction**: Cancer Australia recommends a standard follow-up schedule for women with early stage breast cancer (ESBC). A number of guidance documents describe essential elements of survivorship care. This study aimed to describe the frequency and content of follow up visits for survivors of ESBC. Study 1 assessed number of visits to hospital-based specialists; study 2 assessed documentation relating to survivorship visits.

**Method**: Women with ESBC diagnosed between Jan 2010 and Dec 2015 were identified through hospital databases. Eligible patients had treatment with curative intent (stages I to III) and were disease-free during the examined years of follow up. Follow up appointments were counted during years of follow up, with year 1 of survivorship beginning 12 months from diagnosis. Study 2 assessed the documentation of 20 follow up appointments against a study specific tool developed based on key survivorship dimensions (including assessment for recurrence, persisting side effects, health behaviours, practical issues).

**Results**: 391 cases were identified for study 1. In survivorship years 1 and 2, 229 cases (70%) were compliant with recommended number of follow up visits (11% greater, 19% fewer). Range of visits were 0-27. Whilst 89 cases (48%) were within the recommended range in years 2 to 5, only 36 cases (27%) were followed at recommended intervals beyond 5 years.

For study part 2, nearly all follow up visits resulted in correspondence with the patient's GP. New symptoms, physical examination and recent mammogram results were well documented. However, health behaviours and practical needs such as return to work were often missing in documentation.

**Conclusions:** Many patients have fewer, or a greater number of follow up visits than guideline recommendations. This may result in suboptimal outcomes and / or create additional costs to the patient and healthcare system. In a pilot evaluation, documentation review suggests that some recommended elements of cancer survivorship are not covered consistently in follow up visits.

## 203

## Return to work in survivors of human papillomavirus-associated oropharyngeal cancer: An Australian experience

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### Aim

The incidence of human papillomavirus (HPV)-associated oropharyngeal cancer (OPC) is increasing. It commonly affects people of working age. This study aimed to understand the return to work (RTW) experience of survivors, examining RTW rates following treatment completion, and the clinical, treatment and social factors associated with RTW.

### Methods

This was a cross sectional, single institution study. Eligible patients were aged 18-65 years at diagnosis, employed at or within three months of diagnosis, and had completed treatment with curative intent ≥ four months prior to study enrolment. Clinical data was collected from medical records. Patients completed a questionnaire assessing RTW status and quality of life (QoL; FACT-HN). Open-ended questions explored the impact of treatment toxicity, workplace factors, financial issues and supportive care on RTW. Associations between RTW and baseline factors, as well as correlation with QoL, were examined. Responses to open-ended questions were analysed using thematic analysis.

### Results

The survey response rate was 79% (68/86). Mean age of participants was 54.1 years and 89.7% were male. Most participants received chemoradiation (85.3%), and mean time since treatment completion was 2.6 years. Overall, 58 participants had RTW (85.3%), 45 (77.6%) returned to the same role and 35 (60.3%) to identical hours. Ten were not working; of these, three were retired and seven unemployed, of whom five cited ongoing treatment toxicity preventing RTW. In those who did RTW, the mean time off work was 7.8 months. Survivors who RTW reported higher QoL ($p=0.002$, 95% CI=8.06-33.73) compared with those who had not RTW. A supportive work environment, access to leave and support from treating doctors were facilitators of RTW, and fatigue was frequently reported as a major barrier.

### Conclusions

The majority of patients with HPV-associated OPC RTW following treatment. Attention to symptom management and workplace support may enable more successful RTW.

## 204

## What matters most to breast cancer survivors? Development of a patient-reported outcome measure for clinical assessment

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### Aims

Assessment of patient-reported outcomes (PROs) in clinical settings confers many benefits for cancer survivors. Currently, there is no patient-reported outcome measure (PROM) intended specifically to assess the issues experienced by breast cancer survivors (BCS). The overall aims of this study were to: 1) investigate the most prevalent issues experienced by BCS; 2) explore survivors' preferences about PRO assessment and receiving additional care; and 3) develop a PROM that may be suitable for clinical use in BCS.

### Methods

A cross sectional study using online and paper-based questionnaires. Participants were adults with a prior diagnosis of stage I, IIA, IIb or IIIa breast cancer, had completed treatment with curative intent (ongoing adjuvant hormonal/antibody therapy was allowed), and were disease-free. Participants were recruited through outpatient clinics at Peter Mac and the Breast Cancer Network Australia (BCNA) Review and Survey Group.

### Results

Response rates were 93% (122/131) for Peter Mac participants and 11% (159/1474) for BCNA. Overall, 280 women and one man were included, mean age at diagnosis 51.6 years, and mean time since treatment 6.1 years. Treatments included surgery (n=254), radiotherapy (n=209), hormonal therapy (n=187) and chemotherapy (n=176), either alone or in combination. The most prevalent issues reported were fear of recurrence (67.3%), trouble sleeping (63.4%), fatigue (63.3%), anxiety (62.1%) and menopausal symptoms (59.1%). Participants supported enquiry about survivorship issues at follow-up appointments, most commonly endorsing questions about sleep (86.8%), pain (85.0%), fatigue (84.3%), depression (84.2%), anxiety (82.8%), menopausal symptoms (82.5%) and fear of recurrence (80.7%). Fewer participants however reported wanting help for these issues (range 26.8-39.4%). Overall, participants preferred help from community rather than hospital-based providers for all issues except fertility.

### Conclusions

Research findings informed development of a 14-item PROM suitable for assessment of issues experienced by BCS. Future research should include pilot testing and implementation in clinical settings.

## 205

## Cardiovascular health in asymptomatic, anthracycline-treated survivors of childhood leukaemia: a pilot study.

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Childhood leukaemia survivors are at a heightened risk of cardiac mortality due to the late consequences of anthracycline chemotherapy. Timely detection of parameters that may represent early clinical deterioration is crucial for providing a window to treat and prevent complications. Current screening protocols may not be sensitive enough to do this. The present study utilised a battery of alternative tests to characterise cardiovascular health in survivors of childhood leukaemia. Eleven (4 male) long-term (age, 20±3y) survivors were recruited. All were asymptomatic and had normal cardiac health based on resting echocardiogram findings. No survivors had received radiotherapy. Cardiac health was assessed using exercise echocardiography and cardiac magnetic resonance imaging (cMRI), while vascular health was measured using blood pressure and flow mediated dilation (FMD). Anthropometry, body composition (dual x-ray absorptiometry), blood profile and fitness ($VO_{2peak}$) were also assessed. Eleven similarly aged (22±2y) controls were recruited for comparison. As controls did not undergo blood assessment or cMRI, normative data was used for comparison of these measures. Echocardiography revealed reduced mid-circumferential strain in the survivor hearts at exercise (p=0.003) and recovery (p=0.029). On cMRI, two survivors had clinically abnormal left ventricular ejection fractions <50%. Resting heart rate was higher in the survivors than the controls (p=0.016), while FMD was lower (p=0.026). The survivors had an increased body-mass (p=0.031), body-mass index (p=0.021), waist (p=0.049) and hip circumference (p=0.020) compared to the controls. They also experienced higher amounts of total (mass, p=0.016), central (percentage, p=0.050; mass, p=0.023), and peripheral (mass, p=0.014) fat. Compared to normative data, three survivors had high total cholesterol, five had high LDL cholesterol, two had low HDL cholesterol and one had high triglycerides. Minute ventilation (p=0.001) and relative $VO_{2peak}$ (p=0.002) were reduced in the survivor group. Childhood leukaemia survivors have an adverse cardiovascular profile that is undetectable using current follow-up screening protocols.

## 206

## Fear of cancer recurrence and progression in melanoma survivors on novel therapies

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**Aims:** Fear of Cancer Recurrence (FCR) and Fear of Progression (FoP) are recognised as one of the most significant unmet needs of cancer survivors, including melanoma survivors. Emerging research suggests that survivors who receive immunotherapies and targeted therapies may be at increased risk of FCR/FoP. There is scarce research assessing FCR/FoP using validated measures in survivors with advanced disease on novel therapies. The severity of FCR and need to differentiate between FCR and FoP in this population remains unknown. This project aims to 1) screen and assess severity of FCR/FoP in survivors with stage 4 melanoma treated with novel therapies; 2) determine if screening for FCR/FoP is acceptable and relevant to survivors; 3) assess feasibility of screening for FCR/FoP.

**Methods:** Approximately sixty adults with stage 4 melanoma who are receiving or have previously received immunotherapy and/or targeted therapy and have evidence of a disease response will be screened for FCR and FoP using the Fear of Cancer Recurrence Inventory – Short Form (FCRI-SF) and the Fear of Progression Questionnaire – Short Form (FoP-Q-SF). Survivors will complete a patient experiences survey to assess acceptability. Clinician time to deliver screening will measure feasibility.

**Results:** Results of the severity of FCR and FoP in survivors with stage 4 melanoma treated with novel therapies will be presented. Acceptability of screening to survivors and clinician feasibility will be presented. It is anticipated that patient surveys will demonstrate that screening for FCR and FoP is acceptable to survivors and feasible.

**Conclusions:** It is anticipated that the descriptions of severity of FCR and FoP in survivors with stage 4 melanoma on novel therapies will inform the importance of differentiating between FCR and FoP in this population. The results of this project will direct future research to screen for FCR and/or FoP in survivors with advanced disease on novel therapies.

## 207

## The impact of cancer-related fatigue non-pharmacological interventions on occupational performance and participation in adult cancer survivors: A systematic review.

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**Background**: Increased cancer survivorship means more people are living with cancer-related fatigue (CRF). CRF is reported as the most distressing symptom survivors experience and is associated with occupational performance limitations, restricted participation in meaningful life roles and reduced quality of life (QOL).

**Objectives:** This systematic review aims to identify and evaluate randomised control trials (RCTs) for non-pharmacological CRF interventions that measure outcomes related to occupational performance and participation.

**Methods:** This study is currently in progress. Eight databases were searched (Medline, CINAHL, PsychINFO, EMBASE, Scopus, OT Seeker, CENTRAL, Cochrane SR database), including years 1998-2018 and limited to studies published in English. Eligibility criteria include: RCTs of non-pharmacological CRF interventions in adult cancer survivors (all cancer types and treatment stages) with fatigue measured as a primary outcome and occupational performance, participation or related measured as a primary or secondary outcome.

**Emerging results:** The search strategy identified 5762 records (excluding duplicates), of which 54 studies (1%) met the eligibility criteria. A total of 32 studies (59%) identified QOL, participation or related functional activity as a primary outcome and 22 studies (41%) included these as a secondary outcome. Self-report QOL instruments were used in 47 studies (87%), however, results were inconsistently reported.

**Discussion:** Data extraction will reveal the characteristics of the selected studies and will provide guidance for practitioners on the impact of interventions on occupational performance, participation and quality of life, and will allow a critique of the choice of outcomes for intervention studies and how these are assessed. Evaluation of the quality of selected studies will also identify best practice in researching interventions for fatigue that can improve occupational performance and participation for cancer survivors. Consideration of the sensitivity and precision of QOL instruments to measure occupational performance and participation should be incorporated into future CRF research designs.

## 208

## ENRICHing Survivorship – Wellness and wellbeing for the mind, body and soul

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The ENRICH Program was developed as an educational program and assessed the impact of health behaviour change amongst cancer survivors, their family and carers. The initial randomised controlled trial results reported improvements in health behaviours, however the study did not assess the psychosocial benefits. Cancer Council NSW implemented a revised program, ENRICHing Survivorship, introducing 2 new sessions, peer support and yoga. Qualitative analysis reports improved psychosocial benefits and holistic wellbeing.

- 90% of participants agreed it was helpful to be around others who were in a similar situation to themselves.
- Participants indicated the value in hearing others' stories. They understood that whilst everyone's story was unique, there were similar concerns that they all shared. This helped to normalise the cancer experience, to give them ideas and strategies of how to cope with the 'new normal'.
- People made new friends and felt less alone in their experience.
- Self-rated improvements in psychological health were reported by most participants; 78% felt less worried and anxious, 82% felt less sad and depressed.

**Qualitative responses;**

"Cancer is a personal journey, [but] the connection with others about it, is useful. It is nice to share experiences."

"It was the first real opportunity to start processing cancer as part of my life. Up until now it was all doing surgery and radiotherapy. This was the beginning of the processing of emotions."

"I have genuinely looked forward to coming each week. Emotionally I feel stronger and better equipped for the coming years. I have formed friendships that I know will continue."

A participant will share their personal reflections of their cancer experience and how the ENRICHing Survivorship program helped to improve their psychosocial wellbeing. For example, establishment of friendships, acknowledgment of emotions, improved self-esteem and confidence.

## 209

## Exercise as medicine for cancer survivors with chemotherapy-induced peripheral neuropathy (CIPN): A pilot study

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**Aims:** Chemotherapy-induced peripheral neuropathy (CIPN) is a prominent side effect of cancer treatment affecting up to 40% of cancer survivors and associated with balance and mobility deficits and an increased falls incidence. There are presently no recommended treatment strategies for CIPN, although exercise has demonstrated promise in limited studies. The aim of this study is to investigate the impact of exercise rehabilitation for cancer survivors with persistent CIPN using comprehensive assessments of patient function and CIPN symptoms, including neurophysiologic endpoints.

**Methods:** Cancer survivors ≥3-months post-treatment with known neurotoxic chemotherapies and reporting CIPN symptoms affecting function completed an 8-week exercise intervention consist of three weekly one-hour sessions including balance, resistance, and cardiovascular exercises conducted at a rating of perceived exertion of 13-15 out of 20. Patients attended for a baseline assessment, followed by an 8-week control period, pre-exercise assessment, 8-week exercise program, and post-exercise assessment. Assessments included evaluation of objectively assessed and patient-reported neuropathy, standing balance (four conditions), dynamic balance, mobility, quality of life, and sensory and motor nerve excitability and conduction studies.

**Results:** 29 cancer survivors (8 male; 61.6 ± 11.8 years; target sample N=26) completed all assessments. Objectively-assessed and patient-reported CIPN, dynamic balance, mobility, quality of life, and standing balance in eyes open conditions were significantly improved from pre- post-exercise ($4.0<F<10.2$; $p<.05$), with no significant baseline to pre-exercise changes ($p>.21$). No pre- to post-exercise changes were observed in standing balance in eyes closed conditions or any sensory or motor neurophysiologic parameters ($p>.10$).

**Conclusions:** This study provides promising evidence using comprehensive assessments of the rehabilitative potential of exercise for cancer survivors with persisting CIPN. Given the implications for quality of life in cancer survivorship, large randomised controlled trials are justified and needed to confirm observed benefits and determine the mechanisms and clinical significance of exercise effects in CIPN.

## 210

## Canopy TV - An education resource

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Providing patient education is one of the most challenging but important aspects of nursing care.

Canopy Cancer Care is a medical oncology/haematology centre based in Auckland, New Zealand, providing world class patient care, delivered locally. Canopy continuously looks for ways to improve the quality of the care we provide. Our latest patient focused quality improvement project is Canopy TV - an online education resource made up of a number of short videos covering some confronting topics that patients and their families might be faced with during their treatment journey.

After a distressing diagnosis, patients identified that they need time to review and reflect on the information given, ideally in the privacy of their own homes. The aim of Canopy TV is to provide interesting and topical information to cancer patients and their families in a format that they prefer. Video was identified as a useful and necessary tool to support the existing traditional methods of providing patients with information. Topics address areas and subjects that patients are uncomfortable discussing in a face-to-face consultation or are too overwhelmed to absorb. We hope the information provided will increase people's understanding of cancer and showcase interesting clinical developments in cancer treatment.

Canopy TV is developed and presented by a team of Specialist Oncologists, Nurse Specialists and multidisciplinary experts such as Psychologists, Dietitians, and Exercise Physiologists as well as patients and supporters. Content is not just for Canopy patients, but is available to the broader cancer community. Canopy TV is accessible via Canopy Cancer Care website, Canopy Facebook page or via YouTube.

As we move more and more into the digital age, a digital solution to information sharing is imperative. We know that patients absorb information in different ways and so it is necessary to accommodate that need. By using the patient voice, we have been able to engineer a solution that is slick, useful and relevant.

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## 211

## Counterpart Peer Support Volunteers - themes of their conversations

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Background

Counterpart, a community-based organisation, has been connecting, supporting and informing women with breast or a gynaecological cancer since 2003.Peer support forms the core of Counterpart's services; provided by highly trained and skilled volunteers who have their own experience of cancer. Peer Support Volunteers provide practical and emotional support and a listening ear. They do not provide medical, legal or financial advice or counselling.

The conversations

Counterpart has contact with women from diagnosis, through treatment and beyond. Contact may be one conversation, but many women engage in on-going conversations over months and sometimes longer, depending on their needs. In 2017, Counterpart introduced a system to record the themes of peer support conversations. The choice of themes and topics is based on the experiences of volunteers and staff engaging in over 30,000 interactions with women over 15 years.

For the period July 2017 to June 2018, over 1500 peer support conversations with women with cancer have been recorded. The themes of these conversations range across thirty topics including: living with metastatic cancer, after surgery, isolation, financial or legal difficulties, life after cancer, waiting for results, managing side effects and fear of recurrence. Initial analysis of these conversations suggests that regardless of cancer type, the most frequently occurring themes include: general check-in, coping with treatment and side effects, both short and long term, emotional support and family relationships.

The outcomes

Counterpart is now able to capture and analyse this data to gain a better understanding of the issues and needs of women following a cancer diagnosis and how they use peer support. This provides valuable evidence to support further development of Counterpart, including peer support training and to identify gaps in support and resources for women with cancer more generally.

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## 213

## Chinese Cancer Survivors living in Australia: Findings from a Systematic Review and Focus Groups

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**Aim**

Conduct a systematic review and focus groups exploring the challenges and unmet needs experienced by the Australian Chinese community affected by cancer. Produce in-language webinars and resources addressing the identified unmet needs.

**Methods**

Systematic review - Database, reference list, and author searches were conducted to identify studies reporting information needs of the Chinese community affected by cancer. Data synthesis was undertaken to define categories of information needs.

Focus groups - Mandarin and Cantonese speaking adult cancer survivors and carers, were recruited through community cancer support organisations. Focus groups were conducted, audio-recorded, transcribed, translated into English and thematically analysed using qualitative methods.

**Results**

Chinese migrant cancer survivors and carers face multiple barriers to accessing quality cancer information and support and exhibit worse cancer and psycho-social outcomes than Australian-born cancer patients. Barriers include sub-optimal health literacy, difficulties navigating the healthcare system, linguistic and cultural barriers. Information and support unmet needs include the themes of trust, wellness and rights. In-language webinars & resources have been produced and are available online and on DVD.

**Conclusions**

This study provides new insights into the impact of language, culture and health literacy barriers on the unmet information and support needs of the Chinese community affected by cancer living in Australia. This community will benefit from accurate information about cancer and personal stories of cancer survivors in their native language. These findings underscore the importance that the voices of migrants are heard to ensure that health care systems provide best practice, culturally appropriate care. It also highlights the need to collaborate with the Chinese community to develop and implement culturally appropriate interventions and improve access to coordinated and quality cancer support for Chinese migrants' affected by cancer.

***Funding***

The Chinese webinar project is a Cancer Australia *Supporting people with cancer* Grant initiative, funded by the Australian Government.

### 214

## Free workplace and recruitment advice for people affected by cancer

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### Background

Cancer patients, survivors and carers can face significant challenges in the workplace. Since its inception in 2010, the Cancer Council Pro Bono Program has received referrals for 1174 people experiencing difficulties in the workplace or seeking to return to work. A program evaluation and our experience providing support services to people affected by cancer demonstrates that professional assistance is often required to effectively address workplace issues. The program connects clients with free professional support, so clients can understand their rights and negotiate with their employer, enabling them to enter or return to a suitable workplace.

### Design

Starting as a Legal Referral Service, the program expanded in 2012 to provide clients free access to human resources (HR) professionals. The service has connected 797 patients, carers and survivors with lawyers (n=387), HR professionals (n=272) and recruitment specialists (n=138). The service recognised these people needed support to negotiate flexible working arrangements and manage employer expectations. The service also assists people who haven't been working due to a diagnosis and who need support returning to work. Clients may have difficulty drafting a CV, explaining gaps in employment, or disclosing details of past cancer.

### Outcomes

Within the first year, the program received a 50% increase in referrals for workplace and recruitment advice and figures have remained steady. In a 2015 evaluation, 9 in 10 professionals indicated they were able to clarify issues for clients most or all the time with 25% of HR professionals noting they resolved client issues frequently. Qualitative evidence has shown the program's positive impact. One cancer survivor who was referred to a recruitment specialist for assistance returning to work: "*Thanks to her I got a job ... I was at my wits end and she pulled me back from the mire and gave me hope and strength*."

1. Pearce, A., Penman, S., Valks, S., Chapman, K., Miller, A., Bartley, N. (2015): Pro Bono Program: Research Report 2015. Cancer Council NSW: Woolloomooloo

### 215

## Breast Cancer Survivorship: exploring the issues faced by culturally and linguistically diverse (CALD) patients in the survivorship period

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Australia has one of the most culturally and linguistically diverse (CALD) populations in the world, with over 6.1 million people living in Australia who were born overseas. The Australian healthcare system faces unique challenges in attempting to provide culturally competent care to CALD communities which often underutilise health and preventative services secondary to language and cultural barriers. This is particularly evident in breast cancer survivors, who now constitute the greatest population of cancer survivors. The Western Health Breast Care Nurse (BCN) Survivorship Clinic is conducted across both Sunshine and Footscray campuses. During the client consultation, which occurs 12 months post initial diagnosis, the BCN is able to assess a patient’s needs and refer patients to existing supportive programs and services at Western Health as well as to local community programs and primary care. At the conclusion of the consultation a survivorship care plan is generated for the patient’s medical record, with copies to the patient and their nominated GP.

The aim of this study is to identify and evaluate if there is any difference in the supportive care needs between CALD and non-CALD breast cancer survivors 12 months after initial diagnosis.

This is a retrospective cohort study. The survivorship care plans for 396 patients (63 CALD) who attended the Western Health BCN Survivorship Clinic between 2014-2018 have been collected and analysed for types and number of referrals made.

The study is ongoing and results will be discussed.

We expect to find a significant difference in the number and types of referrals in the CALD population when compared with the non-CALD population.

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## Fear of Cancer Recurrence in Breast and Colorectal Cancer Survivors

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### Aims

Fear of cancer recurrence (FCR) is a major concern for patients who have received curative treatment for cancer. We aimed to: (a) define the incidence and severity of FCR; and (b) identify factors associated with FCR in breast cancer (BC) and colorectal cancer (CRC) survivors who attended the Sydney Survivorship Clinic at Concord Hospital.

### Methods

Data from a prospectively collected RedCap database were used to perform a cross-sectional study. Survivors completed questionnaires on quality of life (QOL) and symptoms prior to attending the clinic. QOL and symptoms were measured by the Distress Screening Tool, Patient's Disease and Treatment Assessment Form (PDTA) and Functional Assessment of Cancer Therapy-General (FACT-G). All patients were formally assessed by a clinical psychologist for the presence of FCR. Clinical and QOL variables were evaluated for associations with FCR. Factors independently associated with FCR were identified using logistic regression.

### Results

Overall, 254 survivors (146 BC, 108 CRC) were included. 160 survivors (63%) had FCR diagnosed by psychology assessment and 44/78 (56%) had moderate-severe FCR. On univariable analysis, factors associated with FCR included younger age ($p<0.001$), BC compared with CRC ($p=0.001$), higher distress score ($p=0.004$), insomnia ($p=0.006$), anxiety ($p<0.001$), poorer emotional wellbeing ($p=0.003$), and poorer overall wellbeing ($p=0.002$). FCR was significantly associated with less support from friends ($p=0.028$), less satisfaction with family communication about the illness ($p=0.038$) and poorer emotional wellbeing subscale ($p<0.001$) on the FACT-G. On multivariable analysis, younger age ($p=0.021$), being more bothered by side effects of treatment ($p=0.021$) and more worry about dying ($p=0.045$) were independently associated with FCR.

### Conclusion

FCR is an important problem for cancer survivors. There were high rates of FCR amongst BC and CRC survivors, and the majority was moderate-severe. FCR was independently associated with younger age, being more bothered by side effects of treatment and more worry about dying.

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## Quality of life in people with blood cancer after participation in a specialised exercise intervention

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**Aims:** 'Fit to Thrive' (FTT) is an individualised, focussed exercise program available to people with blood cancer who are clinically able to carry out exercise. This study aimed to assess the effect of the FTT program on health-related quality of life (HRQoL) in people with blood cancer.

**Methods:** The 12-week FTT program utilises progressive aerobic and resistance training, supervised by an Accredited Exercise Physiologist, in group sessions (n=6), twice per week from weeks 4 to 12, with associated psychosocial and peer support. HRQoL was measured using the 36-item Short Form Survey Instrument (SF-36) and the Functional Assessment of Cancer Therapy General (FACT-G) at baseline, immediately post-intervention and, for a subset of participants, at 3 months post-intervention. Minimally important differences (MID) involved a change of 2 points for the SF-36 and 3 points for the FACT-G.

**Results:** Participants (n=106) who attended the FTT program between 2014 and 2016 were included in this analysis, with 36 participants followed up 3 months post-intervention. The SF-36 physical component summary (PCS) significantly increased (+4.99 [95% CI 3.29-6.68] $p<0.001$) immediately following the intervention, with 68% (n=72) of participants achieving the MID. Whilst all mental health domains significantly increased, the improvement in the SF-36 mental component summary did not achieve statistical significance (+2.36 [95% CI -0.06-4.78] $p=0.06$), with 51% (n=54) achieving the MID. FACT-G scores improved significantly from pre- to post-intervention (+5.90 [95%CI 2.52-8.47], $p<0.001$) with 58% (n=62) of participants meeting the MID. MID improvements in PCS and FACT-G were maintained in 77% (n=20/26) and 95% (n=19/20) of participants 3 months following completion of the program.

**Conclusions:** The FTT program is effective in improving and maintaining HRQoL. An individually-prescribed exercise program, supervised by an Accredited Exercise Physiologis,t should be considered as part of standard care to improve HRQoL in patients with stable blood cancer.

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### Surviving the distress of head and neck cancer: a qualitative study of the experience of distress in the long-term and re-engagement in daily life following treatment

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Aims: This study aimed to explore the experiences of distress from the perspective of people who were treated for head and neck cancer (HNC) 7-15 years prior.

Methods: A qualitative, interpretative descriptive design was utilized to interview people following HNC treatment to explore their experiences of distress. Participants were recruited from a quaternary hospital in Brisbane, Australia, and underwent semi-structured, qualitative one-off interviews. Interview data was recorded, and transcribed verbatim, prior to two of the research team coding and developing themes. Four researchers reviewed the coded interviews until consensus was reached.

Results: Twenty-one people (19 male, 2 females, age range 48-79) were recruited. Six initial themes emerged related to their experiences of distress: challenges of treatment; attitudinal coping to changes; looking back what would have helped; strategies used to cope; factors affecting adjustment; mortality; and financial toxicity. Sub analysis revealed the emergence of two distinct participant groups – those <10 years and those >10 years post treatment. Those >10 years reported a temporal weighting to their experience and were less likely to discuss mortality.

Future directions: The results of this study will be mapped to the Clinical Oncological Society of Australia (COSA) model of survivorship to identify the long-term service needs of the HNC population.

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### Sexual help-seeking by prostate cancer survivors: A longitudinal study of intentions, behaviours, and needs.

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Aims: Though unmet sexual care needs are common to men with prostate cancer (PCa), little is known about sexual help-seeking in this population. The theory of planned behaviour (TPB) is one of the most widely examined models of health-related behaviours and may assist in understanding this issue. Utilising the TPB framework, this study examines the sexual help-seeking intentions, behaviours, and care needs of PCa survivors.

Methods: Men diagnosed with PCa completed online questionnaires at baseline (n=599) and six months later (n=414). Assessments included measures of help-seeking intentions and behaviours, TPB variables (attitudes, norms, and perceived behavioural control), erectile function, sexual desire, and care needs.

Results: Participants were M=64 years old, 3.9 years post-diagnosis, and 87% had undergone radical prostatectomy. Half (53%) reported severe erectile dysfunction, 78% had mild-moderately reduced sexual desire, and 53% had unmet sexual care needs. Greater needs were predicted by poorer sexual quality of life ($p<.001$), placing greater value on sex ($p<.001$), and more severe depression ($p=.002$). Greater intention to seek sexual help was predicted by younger age ($p=.03$), less time since diagnosis ($p=.03$), having recently sought sexual help ($p<.001$), greater perceived control ($p<.001$), and a more positive attitude ($p<.001$). At follow-up, 53% had accessed help in the past six months, most often from a doctor (65%) or another PCa survivor (58%). Men who had intended at baseline to seek sexual help were 1.8x more likely to have sought help at follow-up ($p<.001$), and those had recently sought help at baseline were 4.3x more likely to have also done so at follow-up ($p<.001$).

Conclusions: Men with PCa experience significant sexual difficulties and frequently have unmet sexual care needs. Potentially modifiable TPB variables (norms, attitudes, and perceived control) predicted men's intentions to seek sexual help, but did not directly influence their help-seeking behaviours.

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### Establishment of a dedicated cardio-oncology service for rapid assessment and management of acute and late cardiovascular conditions

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**Aims**

The field of cardio-oncology is gaining importance due to the rise and range of cancer therapies causing acute and late cardiac toxicity, as well as the need to optimally manage concurrent cardiovascular co-morbidity. We aim to describe the caseload and benefits of a dedicated cardio-oncology clinic (COC) over the first 12 months of operation.

**Methods**

In October 2017, a cardio-oncology clinic was established and co-located at Liverpool Cancer Therapy Centre staffed by a cardiologist accepting referrals from Oncology and Haematology services in Sydney Southwest Local Health District. The oncology EMR was used as a common data platform. Reason for referral as well as new and follow-up caseload was recorded. Clinico-demographic and oncology treatment for all patients was extracted.

**Results**

Over a 12 month period, total of 123 (n=86 new and n=37 follow-up) consultations took place. The majority of patients were treated for breast cancer (n=48) followed by colorectal (n=19), lung (n=16), lymphoma (n=14), prostate (n=9), renal and multiple myeloma (n=6). Median time from cancer or haematological diagnosis to COC referral was on average 18 months (range 1-124 months). Therapies with potential cardiotoxic effects included trastuzumab (n=19), 5FU and capecitabine (11), sunitinib (6). Almost half (44%) received radiotherapy. The vast majority of patients were seen within 2 weeks of referral. The most common indications for referral included cardiomyopathy ; LV dysfunction, chest pain / acute coronary syndrome and palpitations/arrhythmia. Notably, only 5% of referrals pertained to management of late effects post treatment, cardiovascular surveillance or long-term preventative therapies.

**Conclusions**

A dedicated cardio-oncology service can facilitate more rapid assessment and management of patients with both acute and late cardiovascular toxicities. Future directions include expansion of the service especially to primary care, and incorporation of more comprehensive screening and clinical pathways for at-risk survivor cohorts.

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## 221

## Setting up a Cardio-oncology clinic at MQ Health- no time to miss a beat

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MQ Health is Australia's first fully integrated university led- health sciences center, combining excellence in clinical care with teaching and research. MQ Health's care services plan2018-2020 has identified having a cardio-oncology clinic will make the existing cancer services holistic. A literature review has been completed with an aim to review different clinic models across the world and their effectiveness. Therefore, we will set up our best practice clinic based on the findings of the literature review.

***Findings of the Literature review***

A Literature review was undertaken through Medscape, PubMed and Mayo Clinic proceedings with keyword search used for as setting up cardio-oncology clinic .25 articles were reviewed cardio-oncology clinic models existing in the United States of America, Europe. These clinics suggested that multidisciplinary team approach consisting of oncologist, hematologist, pharmacist, nurse and cardiologists with additional expertise in prevention, heart failure, vascular disease, and cardiovascular imaging has seen positive outcomes. Because of the complex needs of the multisystem patients, this model of care is gaining acceptance. An electronic referral system, which communicates with all stakeholders for the cardio-oncology clinic, should be established with emphasis on protocols, inpatient cover, data collection, research and audit.

***Conclusion***

Literature review has shown that Cardio-oncology clinic provides one- stop service for patients from cancer diagnosis to survivorship, facilitates monitoring and therapy of cancer treatment related cardiovascular complications, evaluates baseline cardiovascular risks prior to cancer treatment and implements strategies for risk reduction of developing cardiovascular complications, assist patients with cardiovascular care through long-term follow-up. However, this type of clinic is not widely available in Australia hence at MQ Health we will set up a cardio-oncology clinic to benefit the patients by influencing the journey from diagnosis at the right time with right treatment.

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## 222

## The impact of attrition on longitudinal, patient-reported health-related quality of life among colorectal cancer survivors participating in the PROFILES registry

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**Aims**

A ubiquitous challenge in longitudinal oncology research is attrition and subsequent missing data. This study aimed to determine the rate of and factors associated with attrition in the PROFILES registry among a cohort of colorectal cancer survivors, and to assess the impact of attrition on observed health-related quality of life (HRQOL) estimates.

**Methods**

Sociodemographic, clinical and patient-reported outcome (PRO) data was collected annually from a cohort of 2625 colorectal cancer survivors participating in PROFILES between 2010 and 2015. Sociodemographic and clinical characteristics according to time of dropout were compared using analysis of variance and chi-square tests. Predictors of attrition were examined in logistic regression analysis comparing full response and dropout. Multilevel linear mixed models were constructed to investigate associations between attrition and HRQOL over time.

**Results**

Colorectal cancer survivors who were women, elderly, had low or medium socioeconomic status, had low education, and reported depressive symptoms were more likely to drop out. Full responders reported better and more stable HRQOL than participants who dropped out after the first or second wave. Over time, participants who dropped out after the second, third or fourth wave showed a steeper decline in global HRQOL and physical functioning and a steeper increase in depression than full responders. Participants who dropped out after the third or fourth wave also showed a steeper decline in social functioning, emotional functioning and the summary score. Sensitivity analyses suggested this trend was driven by mortality.

**Conclusions**

Although attrition is not fully preventable, additional strategies to retain participants at risk of attrition due to illness could improve the representativeness of future studies. Using appropriate methodological and statistical techniques to account for attrition and missing data will facilitate the interpretation of findings in longitudinal PRO research.

## 223

## Cultural understandings of care giving in Australian Aboriginal families can help to improve cancer survivorship services and outcomes

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**Background:** For Aboriginal people, family is defined by a complex system of cultural values, keeping of knowledge, kinship responsibilities, connection to country and responsibilities to community. The role and meaning of family is not readily understood by mainstream health services, often resulting in poorer treatment experiences and survivorship outcomes for Aboriginal people.

**Methodology:** This research examined the cancer treatment and survivorship experiences of Aboriginal people in regional south-eastern Australia, and the meaning and context of 'family' in their cancer treatment and recovery. Yarning Circles, an ancient Aboriginal approach to sharing knowledge and culture, were used to support Aboriginal people diagnosed with cancer and their families share their stories.

**Findings**: Family was central to people's identity and roles and responsibilities in community. Family connected people to country, and provided strength and spiritual support for healing. It was recognized as important to raise family awareness of a history of cancer. The constancy of deaths 'cancer is taking our mob', the removal of children from family and lost family ties, meant people did not know their family's medical history. Putting the needs of the family first, and caring for sick family members, was more important than an individual's own health; there was 'no time to grieve' for your own cancer diagnosis and look after yourself. There were negatives attitudes in hospitals when family come to visit, seeing family as too large and overstaying visiting times. Health professionals did not seek family assistance with communication of information with family with low literacy levels, or include family in treatment decision making. Access to services was dependent on family support with transport, finances and family responsibilities, often resulting in lapses in treatment and follow-up services.

**Conclusion**: Understanding Aboriginal kinship structures, and responding with culturally safe practices, can help to improve cancer survivorship outcomes for Aboriginal people.

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## Peer support for the 12-month maintenance of exercise and health following a brief exercise training intervention in cancer survivors: Study protocol

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Available evidence shows that brief, supervised high intensity interval training programs improve a range of outcomes with cancer survivors. However, maintenance of exercise beyond a supervised exercise phase remains poor. This randomised controlled trial will evaluate the influence of a structured peer support program on exercise adherence and the maintenance of cardiorespiratory fitness and quality of life for 12 months in cancer survivors, following a four week supervised high intensity interval training (HIIT) intervention. Breast, colorectal or prostate cancer survivors (n=244) will complete a four week supervised HIIT intervention before being randomly assigned to either a 'peer support group' or 'no peer support' group for 12 months. All participants will have free access to a gym, and be encouraged to accumulate either 150 minutes of moderate exercise or 75 minutes of vigorous exercise each week (i.e., to meet the current exercise oncology guidelines). Peer supporters (cancer survivors who have also completed the four week HIIT and undergone training to provide them with the skills to help motivate and assist their partners) will help maintain exercise in those assigned to them. $VO_{2peak}$, quality of life and exercise levels will be assessed for all participants before and immediately after the four week intervention and again at three, six and twelve months. Results from this study will inform clinical practice and provide a framework for implementing peer support programs into the community to improve health outcomes for cancer survivors.

## 225

## How many endometrial cancer patients diagnosed with clinical level of anxiety and depression, and how many received psychological treatment during survivorship?

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Aims: Patients face psychological distresses after cancer diagnosis as well as throughout the survivorship. It is unknown the prevalence of anxiety and depression or treatment received for them. The aims were to determine the prevalence of anxiety and depression in patients with endometrial cancer underwent for surgical treatment and, psychological treatment received for clinically diagnosed anxiety and depression

Methods: A secondary analysis was undertaken on an international multi-centre study commenced between 2005 to 2010. Patients aged >18 years, histologically confirmed stage I endometrial cancer, and underwent for surgery were included in this study. Data used for these analyses were collected in detail during the perioperative period and then one-week, four-week, three-month and six-month postoperatively. Hospital anxiety and depression scale (0-21) screening tool was used to determine clinical level of anxiety and depression (≥11).

Results: 334 sample data were included in this analyses. The overall prevalence of clinical level of anxiety and depression was 22.7% (n= 76/334) and 9.0% (n= 30/334), respectively during perioperative to 6-month post-surgery. Among them, 7.2% (n= 24/334) patients were diagnosed with both anxiety and depression. Only 14 patients diagnosed with anxiety depression were visited mental health care professionals. 33 patients (9.9%) received antidepressants and anxiolytics for the treatment of anxiety and depression, however, no patients did not receive any treatment for clinically diagnosed depression only.

Conclusions: One in four patients were diagnosed with anxiety and/or depression, however only half of them received psychological or pharmacological treatment during early stage cancer survivorship. It is also possible that treatment was focused of the many physical conditions presented by the patients rather than their psychological well-being and secondary data did not allow the aforementioned potential explanation regarding not receiving treatment. Qualitative analysis could be used in future research to explore the psychological treatment received during cancer survivorship.

## 226

## Supporting breast cancer survivors to transition back to sustainable work

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**Background & Aim:** The health benefits of work for individuals, employers and society are well established [1]. Transitioning back to sustainable work for cancer survivors is a marker of social recovery, a move towards improved quality of life and financial security, and is a research priority. Researchers, occupational rehabilitation (OR) and insurance sectors and Cancer Support services have collaborated to implement and evaluate a tailored, multimodal rehabilitation innovation in breast cancer survivor (BCS) care that aims to optimise recovery and return to sustainable work through improving beliefs and perceptions about breast cancer and work.

**Methods:** Participants are BCSs of working age who have been unable to work in their pre-diagnosis capacity for >3 months due to cancer, and their employers. The multimodal intervention consists of an evidence-based biopsychosocial assessment and health coaching program (weekly face-to-face sessions), and other services (e.g. exercise physiology) tailored to breast cancer. Health coaching identifies current barriers and empowers to facilitate recovery and return to social function, including work. Employer education and support facilitates (early) communication and improved support when transitioning back to work.

**Pilot results:** Life insurance sector pilot results from 65 cancer survivors (>50% BCSs, working age) showed improvements in work capacity, physical and cognitive fatigue, concerns about recurrence, and pain. Consultant surveys found considerable barriers to participation in and engagement with the program, including referral delays, cancer recurrence and health concerns.

**Conclusions:** Pilot results have informed the refinement of the next stage longitudinal study that will compare baseline and 6 month follow-up data on work and capacity outcomes, and a range of biopsychosocial factors known to affect return to work for BCSs. The service stands to benefit survivors, families and workplaces in Australia and moves toward improved work and health outcomes and competency improvements within the life insurance, OR and large employer sectors.

1. [1] The Royal Australasian College of Physicians, Australasian Faculty of Occupational and Environmental Medicine Position Statement on Realising the Health Benefits of Work. 2011, The Royal Australasian College of Physicians: Sydney, Australia. p. 1-30

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## Development of a unique digital information delivery tool to empower patient-centred health care

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### Introduction

Breast cancer is a disease where treatment and survivorship care is individualised. Consumers report difficulty navigating available information to find treatment and survivorship options most appropriate for them. Consumers who feel empowered by the information they receive, rather than overwhelmed, are better able to participate in decision making throughout their breast cancer journey - from initial diagnosis through to follow-up and survivorship care.

**Objectives**

To develop a digital, interactive tool that provides people with access to tailored information at the time they need it. To provide information in various formats and for user groups with specific needs, including young women, Aboriginal and Torres Strait Islander women, women from CALD backgrounds, men and people living in rural areas.

**Methodology**

Guided by a reference group of clinicians and consumers, BCNA reviewed and updated existing resources to better meet online user needs and to deliver a user friendly, interactive digital experience to people affected by breast cancer. New information was developed to meet the specific needs of people diagnosed with DCIS.

**Outcomes**

Each user's experience of the *My Journey Online Tool* is unique as information delivery is prioritised according to a set of criteria selected by the user. This has resulted in a 'one stop' tool that meets user needs at all points from diagnosis to follow-up and survivorship care.

**Conclusions**

The *My Journey Online Tool* was launched in October 2018. Using an agile methodology, the tool is managed through a process of continuous monitoring and review, with findings informing updates and future developments. Ongoing development will ensure the tool continues to meet changing needs, in particular, the provision of information that empowers people to make decisions appropriate to them at various points in their breast cancer experience.

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## Ibrutinib Related Atrial Fibrillation – A Single Centre Australian Experience

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**Background:** Ibrutinib increases the risk of atrial fibrillation (AF) and is associated with bleeding tendencies. Reported rates of arrhythmia are variable in different studies. The aim of the current analysis was to evaluate the incidence of AF in a single center cohort of patients.

**Methods:** This analysis was conducted at Hunter New England Local Health District, Australia between 1 April 2015 and 30 June 2017. We included all consecutive patients commenced on ibrutinib for haematological malignancies. Patients with a history of paroxysmal AF were excluded. The primary end point was incidence of AF. Time to diagnosis and management were secondary outcomes of interest.

**Results:** A total of 24 patients (age 73±9 years, males n=16 (67%)) were commenced on ibrutinib treatment during the study period with chronic lymphocytic leukemia (n=21, 88%) as the main indication. During a median follow up of 12 months, 4 (17%) patients were diagnosed with AF with increasing age, duration of ibrutinib treatment as associations. The median time to AF diagnosis was 9 (IQR: 7 – 18) months. All patients were managed with a rate control strategy with beta blockers as the preferred agents. 3 (75%) patients were commenced on anticoagulation for stroke prevention. During a follow up of 18 (IQR: 17 – 23) months following AF onset, 1 patient required hospitalization for AF. There were no bleeding complications reported.

**Conclusions:** In conclusion, this series noted a higher incidence of AF than previously reported. Oncologists and cardiologists need to be aware of the increased risk of AF in patients receiving ibrutinib.

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## Using Serial cardiac MRI to detect myocardial changes in patients treated with left sided tangential breast radiation

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Purpose

Acute cardiac changes following tangential breast radiation(RT) have been demonstrated using cardiac scintigraphic studies[1, 2] and advanced echocardiographic techniques[3, 4]. This study evaluates the prospective use of serial novel cardiac MRI (CMR) sequences in detecting myocardial changes using serial cardiac mapping techniques over a 12 month period.

Methods

Twenty-one left-sided female breast cancer patients receiving tangential RT were prospectively recruited between October 2015 to October 2016. Three CMR scans were obtained; a baseline scan 2-3 days before adjuvant RT, 6 – 8 weeks and 12 months following RT. No patients received chemotherapy. CMR was performed at 3 tesla using a modified look-locker inversion sequences(T1/T2 mapping) to detect myocardial oedema and inflammation. Extracellular volume (ECV), which may be elevated in oedema, was calculated from pre and post contrast T1 maps[5]. Two independent T1/T2map segmentations of the left ventricle(LV) were performed in cvi42, and averaged for analysis. LV ejection fraction (LVEF) was acquired from single breath-hold SSFP cine acquisitions of the cardiac short axis. Paired t-tests were used to compare the baseline scan with the 6-8 week and 12 month post treatment scans. A p value of ≤0.05 was considered significant. Median mean heart dose(MHD), the average radiation delivered to the heart, was documented.

Results

Median MHD was 2.6Gy(1.5-3.9). There was no change in LVEF at either 6-8 weeks or 12 months post RT. T1 and T2 values were not significantly elevated at 6-8 weeks, but were significantly elevated at 12 months (T1(ms) – 1213 vs 1246ms p=0.02 95% CI 4.4-47.5, T2(ms) – 43.2 vs 45.7ms p<0.01 95% CI 0.8-3.0). There was no change in ECV values.

Conclusions

Preliminary results suggest T1 and T2 values, whilst not significantly different at 6-8 weeks post RT, were elevated 12 months following radiotherapy. These results may be suggestive of post RT myocardial inflammation detected utilising CMR.

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## 231

## Qualitative results of a phase II pilot randomised controlled trial of a lymphoma nurse-led survivorship model of care.

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Aims: Lymphoma is the sixth most common cancer diagnosed worldwide and can require treatment regimens that impact long-term quality of life. The aim of this study was to explore and describe lymphoma survivors' thoughts, perceptions and personal experience of the components of a nurse-led survivorship model of care intervention that provided support to lymphoma patients who had completed treatment. This substudy provided qualitative semi-structured interview data which added depth to the quantitative findings from the randomised controlled trial.

Methods: An exploratory, qualitative descriptive study was undertaken using interviews from 10 participants who had transitioned post-treatment into the survivorship phase via a nurse-led lymphoma survivorship model of care intervention. The intervention included validated assessment measures, the delivery of a unique an individualised survivorship care plan and treatment summary and a tailored resource pack. It comprised three face-to-face appointments at 3, 6 and 9 months post-treatment completion.

Results: Thematic analysis revealed three major themes: reassurance and individualised care; information and support; and Individual sense of empowerment. Participants described the reassurance they gained from having contact with a health professional post-treatment who individualised information and support. The survivorship care plan and treatment summary, developed for this study, was perceived by participants as very patient-centred and helpful. This enabled participants to take back control of their health and well-being and to rebuild self-confidence.

Conclusions: In this study, participants were appreciative of patient-centred follow-up care that addressed their concerns and supported them in the survivorship phase to get their life back on track. Nurse-led follow-up may offer a viable model of post-treatment survivorship care to lymphoma cancer survivors.

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## Results of a phase II pilot randomised controlled trial of a lymphoma nurse-led survivorship model of care.

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Aims: New models of lymphoma survivorship care are limited in the published literature. Therefore a nurse-led lymphoma survivorship model of care was developed and tested in a phase II pilot pragmatic randomised controlled trial (RCT). The main aim was to deliver individualised care to meet the informational, practical and emotional needs of lymphoma patients who had completed treatment, to help them return to normal functioning sooner.

Methods: Three months' post-treatment completion, consenting lymphoma patients were randomised 1:1 to usual care (control) or usual care plus intervention. Survivorship unmet needs, distress, adjustment to cancer and self-empowerment were assessed in both groups at baseline, three and six months. The intervention comprised three face-to-face appointments, delivery of tailored resources and an individualised survivorship care plan and treatment summary (SCPTS), shared with the general practitioner (GP). A sample size of sixty patients was planned and recruitment completed when this target was reached. Univariate and multivariate analyses examined changes within and between groups at the three time points. A GP evaluation survey sought information on the perceived utility of the SCPTS.

Results: Statistical significance was set at 0.05 (2-tailed). By study completion, although not statistically significant, the data revealed a trend toward intervention participants (n=30) reporting less unmet informational, practical and emotional needs ($M$=21.41 vs $M$=25.72; 95% CI= -8.59, 17.21; $p$=.506), less distress ($M$=13.03 vs $M$=15.14; 95% CI= -5.04, 9.25; $p$=.558) and an increase in empowerment ($M$=50.21 vs $M$=47.21; 95% CI= -6.08, 0.08; $p$=.056) compared with control participants (n=30). The SCPTS was rated good to very good by a majority of GPs (n=13, 81%).

Conclusions: Survivors require individualised support and resources. This trial indicates the nurse-led lymphoma survivorship model of care may be a helpful intervention for lymphoma patients who have completed treatment. A tailored SCPTS may promote survivor self-management and increase GP engagement.

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## Patient reported peripheral neuropathy in breast cancer survivors following adjuvant therapy

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Background: Taxanes used to treat breast cancer can cause chemotherapy-induced peripheral neuropathy (CIPN). In phase III trials, ≥ grade 2 neuropathy affected 16% and 27% of patients receiving 3-weekly docetaxel vs weekly paclitaxel respectively[1].

Aim: To assess patient-reported sustained CIPN in breast cancer survivors.

Methods: Review of prospectively collected data from patients' initial appointment at the Sydney Survivorship Centre clinic (SSC). Patients scored the severity of numbness and tingling affecting their hands and feet from 0 (none) to 10 (worst). Analysis was descriptive with comparisons by independent samples t-test.

Results: Overall, 191 women with breast cancer attended SSC between December 2013 - June 2018. Median age at visit was 52 years (range 29-74). Patients were evaluated a median of 11 months (range 2-149) from their diagnosis of breast cancer. Of the 168/191 (88%) women who received chemotherapy, 22/168 (18%) had neoadjuvant treatment and 136/168 (91%) had any adjuvant treatment including chemotherapy, endocrine therapy and/or antibody therapy. Chemotherapy was anthracycline and taxane in 135/168 (70.7%), anthracycline without taxanes in 20/168 (11.9%), and taxane-based treatment in 13/168 (6.8%). At a median 5 months after finishing chemotherapy, numbness or tingling was reported in 79/168 (53%) patients who received taxane chemotherapy, and 17/168 (40%) of patients who did not receive taxanes. Moderate to severe numbness or tingling (score ≥4/10) occurred in 34% of patients who received taxanes and 26% of patients who did not receive taxanes. Mean score for numbness or tingling was 3.0 in patients receiving taxanes vs 2.4 in patients who did not receive taxanes (95% CI -0.57 to 1.76, p=0.32).

Conclusion: Patient-reported CIPN is more common in "real-world" breast cancer survivors than in clinical trials, with over half of patients experiencing any grade CIPN and a third with moderate to severe symptoms of CIPN five months after finishing taxane chemotherapy.

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## 234

## Effects of a weight loss intervention on metabolic syndrome in overweight or obese women following treatment for breast cancer: a randomized controlled trial

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**Aims** Almost half of deaths among women diagnosed with breast cancer are attributable to non-breast cancer causes, most commonly cardiovascular disease. Metabolic syndrome (MetS) is a cluster of risk factors that increases risk of cardiovascular disease, but is also independently associated with poor outcomes (disease recurrence and death) in breast cancer survivors. We aimed to evaluate the effects of a telephone-delivered weight loss intervention (diet and exercise) on MetS in breast cancer survivors.

**Methods** Eligible women (18-75 years, BMI 25-45kg/m$^2$, stage I-III breast cancer, <2-years post-treatment completion) were allocated to intervention (n=79) or usual care (n=80). The intervention group received 22 counseling calls, with optional text messages, over 12 months. MetS components (waist circumference, triglycerides, HDL-cholesterol, glucose and blood pressure) were measured at baseline, 6- , 12- and 18 months; and were used to compute a MetS risk score (average of z-scores [(value – population mean) / sample SD] for MetS components). Intervention effects, assessed by linear mixed models, accounted for repeated measures and baseline values.

**Results** At baseline, participants were (mean±SD) aged 55±9 years, with a BMI of 31.4±5.0 kg/m$^2$, 10.7±5.0 months post-diagnosis, and 47% had MetS. At 12 months, significant intervention effects were observed in MetS risk score, waist circumference and fasting glucose, which were sustained at 18 months for MetS risk score and waist circumference. Significant intervention effects were observed for blood pressure at 6 months only, and no significant intervention effects were observed for lipids.

**Conclusions** Sustained improvements in MetS risk score and waist circumference were achieved following a pragmatic weight loss intervention; but limited improvements were observed for other MetS components. Further research is needed to understand how to improve MetS components more comprehensively using interventions that may be translatable into real-world practice, in order to improve breast cancer outcomes and reduce chronic disease risk.

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## Incidence of diagnosis of relapsing cancer, secondary cancers and other serious diseases in a Survivorship Clinic

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Despite guidelines including early detection of recurrence or secondary cancers, the rate of this condition remains relatively unknown on a day to day practice in a cancer Survivorship Clinic. In a community Survivorship Clinic, the incidence of such situation has been retrospectively reviewed for the last 12 months. Since early 2018, 12 % of patients have been diagnosed with recurrent, locally or metastatic or second breast cancer, relapsing NHL or melanoma and serious hematological conditions such as hemolytic anemia and second cancers such as thyroid and CML. In summary, it remains important to be vigilant in such an environment to the symptoms patients may present with.

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## Evaluation of a hospital-based weight management program for overweight and obese cancer survivors.

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**Background:** Obesity, high amounts of adipose tissue and lack of physical activity are linked with cancer incidence. For cancer survivors, these factors contribute to poorer disease and health-related outcomes. We aimed to determine the feasibility of implementing an outpatient weight management program for overweight/obese cancer survivors.

**Method:** Overweight/obese (BMI $\geq$25kg/m$^2$) adults who had completed treatment for localised cancer and ENRICH (6-week lifestyle program) were eligible. Intervention: i) three clinic consultations; ii) supervised exercise sessions (2x/week); and, iii) 12 dietary sessions over 6 months. Assessments: baseline, 3, 6 (post-intervention) months. Primary outcome was adherence. Secondary outcomes: body composition, exercise levels, food intake, Patient Reported Outcomes (PROs), biomarkers(fasting glucose, IGF-1, cholesterol, C-reactive protein) and qualitative interview.

**Results:** Seventeen of twenty-four (80%) eligible women were recruited, median age 53 (42-74) years. Tumour groups: breast 76%, colorectal 18%, Non-Hodgkin's Lymphoma (6%). At baseline: 4 participants were overweight (BMI ≥ 25-29.9kg/m2), 13 obese (≥30kg/m2); 14 had 1+ comorbidity. Participants attended 97% of clinics, 71% of exercise and 81% of dietary sessions. Post-intervention, mean weight loss was 3.7kg (range +0.1 to -19.6kg) and 3.6% reduction of initial body weight. Waist circumference reduced by 3.4cm (-13.2 to 4.8cm) and total body fat mass reduced by 2%, with lean body mass 2% increase. Improvements in 6-minute walk test (mean +71m) and 1-repetition maximal leg press (mean +33kg) were seen. Post-intervention diet quality, PROs and biomarkers will be available at time of reporting. Participant's identified support from program staff and co-participants, and program tailored to their needs as facilitators of adherence.

**Conclusion:** This study confirms overweight and obese cancer survivors are able to attend an intensive weight management program. The program enabled positive changes in weight, body composition, fitness and diet quality. Structured programs to support weight management in survivors are important in improving overall health.

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## Evaluation of Survivorship Care Plans from survivors attending the Sydney Survivorship clinic

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**Background**

Survivorship Care Plans (SCP) contain individualised information about a person's cancer diagnosis and treatment, recommendations for managing treatment-related side effects and reducing lifestyle risk factors for cancer recurrence and chronic disease. At the initial Sydney Survivorship clinic, a SCP is developed by the Survivorship multidisciplinary team (medical oncologist, dietitian, exercise physiologist, consultant nurse and clinical psychologist), in conjunction with the survivor, and then posted to the survivor, their GP and cancer specialists.

**Methods**

Cancer survivors were invited to participate in an interview via phone or in person, 6-14 months after their initial clinic visit. Structured questions were used to investigate whether the survivor received the SCP, and how it was used and shared. Open ended questions evaluated adherence to SCP recommendations and survivors' feedback on usefulness of the SCP.

**Results:**

From October 2017 to September 2018, 62 survivors participated (52% response rate from 119 eligible patients). Mean time between initial clinic visit and interview was 11months (SD2.7) (range 6.4-18.4months). Most participants were female (n=42, 68%); median age was 59years (IQR15yrs) (range 33-81yrs). In total, 43/62 (69%) participants acknowledged receiving the SCP, 11 (18%) stated they did not receive one, and 8 (13%) were not sure. Overall, 35 (81%) found it helpful, 4 (9.3%) did not. Four survivors showed the SCP to other health care professionals; 21/43 (50%) showed it to family or friends. In total, 39/43 (91%) survivors who received the SCP reported carrying out >1 of the recommendations, in particular increasing exercise and improving diet.

**Conclusion**

Most survivors received their SCP and found it useful, but 31% of survivors either did not receive it or did not remember receiving it, highlighting the need to improve SCP delivery. As recruitment continues, this study will provide a better understanding of efficacy and how to improve SCP uptake.

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## Longitudinal follow up of medical oncology survivors attending the Sydney Survivorship Centre Clinic

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Background:

Sydney Survivorship Centre clinic (SSC) offers multidisciplinary care after primary adjuvant treatment, with ~40% receiving their ongoing follow-up at SSC. Here we evaluate change between initial visit (T1) and first follow-up (T2).

Methods:

Survivors attending SSC for follow-up care were evaluated for changes in symptom and lifestyle factors from T1 to T2 using paired t-tests.

Results:

Data from 111 survivors attending follow-up from December 2013 to September 2018 were included: 47% female, median age 64 (32-86 years), tumour types included colorectal 73%, upper gastrointestinal 13.5%; lung 7%; breast 6%. Mean time between visits was 3.7months (SD1.1). Proportion reporting fatigue and anxiety increased, while reductions in moderate severity of other symptoms were noted.

Proportion with symptoms of at least moderate severity:

| Symptom | N with paired data | T1 n(%) | T2 n(%) |
|---|---|---|---|
| Fatigue | 77 | 21(27.3%) | 27(35.1%) |
| Anxiety | 75 | 10(13.3%) | 20(26.7%) |
| Pain | 70 | 20(28.6%) | 19(27.1%) |
| Sleep | 77 | 22(28.6%) | 20(26.0%) |
| Depression | 75 | 11(14.7%) | 14(18.7%) |
| Irritability | 76 | 14(18.4%) | 16(21.1%) |
| Trouble concentrating | 76 | 13(17.1%) | 11 (14.5%) |
| Sore hands/feet | 72 | 17(23.6%) | 12(16.7%) |
| Numbness | 72 | 25(34.7%) | 20(27.8%) |
| Problems with sex | 60 | 12(20.0%) | 11(18.3%) |

There was no difference in mean weight (77.5kg vs 77.7kg) but change ranged from 14kg weight loss to 5kg weight gain, with 35/111 (31.5%) losing >0.5kg, and 49(44%) gaining >0.5kg. Mean moderate intensity exercise increased from 79 to 137mins/week (n=44) and vigorous from 26 to 77mins/week (n=43). Proportion doing 2+ resistance sessions/week increased from 4.5% to 10.8%: from 9mins/week to 55mins/week in 29 respondents with paired data (p<0.005).

Conclusions:

Attendees increased aerobic and resistance exercise between visits. Although mean weight remained stable, a third lost weight. Fatigue, pain, insomnia, numbness and anxiety remain major problems for survivors, with increasing anxiety and fatigue but some improvement in numbness from T1 to T2. Promotion of healthy lifestyle can assist cancer survivors to change lifestyle behaviours.

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## Promoting sustainable healthy eating, exercise and weight maintenance strategies through a community integrated model of health promotion and self-management in a regional area

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**Background:** For people diagnosed with cancer, changes in the body occur throughout treatment and survivorship. Knowing how to respond to, and address these changes early, can decrease unmet needs, distress and worry. Addressing weight management through tailored dietetic and physical activity interventions and health coaching has been associated with reduced cancer treatment toxicities and late affects, reduced risk of obesity and onset of chronic disease, and increased health related quality of life. The I.CAN program was established to implement a tailored nutrition and exercise program to promote sustainable healthy eating, exercise and weight maintenance strategies for people diagnosed with cancer through a community integrated model of health promotion and self-management.

**Methods:** Patients from all tumour streams were invited to attended individual and/or group nutrition and exercise sessions The Australian Guide to Healthy Eating and evidenced-based practice guidelines for nutritional management of cancer were used for nutrition education and encouraging nutritional adequacy. Exercise prescriptions based on individual needs were completed by an exercise physiologist. Data collection at baseline, three and six months included body mass index (BMI), Food Frequency Questionnaire (FFQ), Godin Leisure Time Physical Activity Questionnaire (GLTPAQ), the NCCN Distress Thermometer and Problem Checklist and the FACT-G7.

**Results:** 56 participants were recruited into the program, eight declined. Although, participants' BMI did not significantly change, improved food choices in meeting daily requirements on the FFQ were seen between baseline, three and six months. Participants in group sessions also showed improved nutrition knowledge. A significant increase of 40% ($p= 0.0008$) in the GLTEQ scores between baseline and 3 months was seen in all participants and maintained at six months. FACT-G7 showed positive quality of life outcomes at follow-up.

**Conclusion:** Implementing strategies which promote and support positive eating patterns and ability to be physically active during and post cancer treatment are feasible.

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## Tales from shift working mice: The impact of circadian disruption on cancer progression and CNS toxicities

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Disruption of sleep and circadian rhythms has been implicated in cancer progression and cancer-related side-effects, such as cognitive impairment and depression. Sleep disruption is commonly reported in cancer patients and survivors. This study examined the role of circadian disruption on cancer progression, cognition and depression-like symptoms in a mouse model of metastatic breast cancer. 80 female mice were placed on either a stable 12 h light:dark schedule or a rotating light cycle that advanced by 8 h every two days to induce chronic jet-lag, comparable to the impact of shift work. Mice were injected with 4T1.2 mammary adenocarcinoma cells or given a sham injection of PBS into the 4th left mammary fat pad. Tumour cells were tagged with luciferase so that bioluminescence imaging could be used to track tumour growth and metastasis. Running wheel activity was used as a marker of circadian disruption, as well as overall activity levels. Circadian disruption profoundly impacted cancer progression by increasing both primary tumour growth and metastasis ($p < 0.05$). Behavioural assessments of depression (using the forced swim and sucrose preference tests) and memory (using the novel object recognition test) were assessed as circadian disruption and cancer progressed. Circadian disruption and tumours each independently impaired memory ($p < 0.05$). Circadian disruption alone induced depression-like behaviour on the sucrose preference test that was not exacerbated by cancer ($p < 0.05$), confirming our preclinical findings and clinical studies indicating that depressive symptoms are not correlated with cognition symptoms driven by the cancer. These findings demonstrate that circadian disruption seen in cancer patients and vulnerable populations such as shift workers can drive cancer progression and impact cancer-associated side-effects. The results of this preclinical model of circadian disruption and metastatic breast cancer, in the absence of psychosocial factors and cancer treatments, identify the need for clinical studies to dissociate poor sleep from circadian rhythms when assessing these factors in cancer-related outcomes.

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## Developing a Community Based Nurse Practitioner (NP) led Chronic Disease Survivorship Clinic (CDSC)

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Chronic disease (including cancer) represents a significant portion of the healthcare budget for Western Australian health system. The cost is projected to increase dramatically over the next 10 years if interventions within primary care, education, and the environment are not implemented. The growing personal, social and economic burden of chronic disease underscores the need for change and challenges us to transform the way health care is delivered, extending beyond the acute management in hospital clinics.

Historically, disease specific management has been the approach to caring for individuals; often overlooking chronic diseases can be interrelated and commonly occur together. Disease management has also focused on acute symptoms and have not been part of a multifaceted approach looking at health promotion, prevention and early intervention. Care has primarily been in hospitals and not focused on self-management and community engagement, with the main goal to support people to stay well in their community.

In the recent Sustainable Health Review Interim Report to the WA Government (2018) a strong case for healthcare transformation is made with emphasis on sustainable programs that are cost effective and patient centred. We aim to establish a NP led CDSC model that will improve health outcomes, keep people healthy, and in their communities through (1) clinical practice, (2) education opportunities for students, and (3) building an evidence base for models of innovative chronic disease management in primary health care.

The proposed clinic will be an innovative model of care, delivering coordinated services for all chronic diseases, including cancer. It will focus on management of chronic conditions taking a holistic family centred approach to assessment and management (physical, social, spiritual, lifestyle and psychological well-being) within the community setting.

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## Identification of sexuality and sexual health as an unmet need for cancer survivors in South Western Sydney Local Health District (SWSLHD)

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Sexuality is a reflection of our human character. It is unique and central to each individual's personality and is present throughout life. Sexuality is developed and altered through life experiences and perception of events. Cancer may have both psychological and physical impact on an individual's sexuality, significantly impacting on their relationships and ability to be intimate with others.

South Western Sydney Local Health District (SWSLHD) is home to a large culturally and linguistically diverse community with 36% of the population born overseas. Studies have identified that conversations about sexuality are not occurring between health professionals and patients, this being more apparent in the culturally and linguistically diverse communities.

A participant cohort of 80 patients completed the Functional Assessment of Cancer Therapy: General (FACT G- Version 4) e-tool questionnaire, within the Wellness Centres of SWSLHD Cancer Services. This preliminary data reported 38% of our patients are not satisfied with their sex life, with a further 25% reporting not feeling close to or connected with their partners. Limited access to professionals trained in sexual health was also identified as a key area of concern.

A current literature review revealed that sexual issues remain unaddressed for many cancer survivors, particularly women, highly recommending both patient and clinician interventions are required.

Addressing patient related sexuality, sexual health & intimacy issues is an unmet need in SWSLHD. Mapping of services available within SWSLHD is currently underway, including ongoing consultation with clinical psychologists, specialist nurses, doctors and an accredited clinical sexologist. Moving forward, plans are underway to develop and provide education sessions and workshops for clinicians, as well as implementing a pilot clinic. This will endeavour to address the concerns relating to sexuality and sexual health, enabling the delivery of optimal patient care across SWSLHD Cancer Services.

## 243

## "Through wind and rain": Chinese cancer patient and caregiver feedback on WeCope, a self-management resource.

**<u>Verena Wu</u>[1], Ben Smith[1], Afaf Girgis[1]**

*1. Ingham Institute for Applied Medical Research/University of New South Wales, Liverpool, NSW, Australia*

Background/Aims:

Chinese-Australian immigrant cancer patients and caregivers report worse psychological morbidity and quality of life compared to their English-speaking counterparts. Currently, there are limited self-management resources that adequately address the psychosocial needs of both Chinese patients and caregivers. This study aims to develop a culturally appropriate self-management resource (*WeCope*) to address this need.

Methods:

Six topics were proposed for *WeCope* (communicating your needs with your health care team; making your treatment decision; managing your emotions; managing your physical symptoms; managing your relationship; where to find additional support) based on a systematic review of Chinese patients' and caregivers' unmet supportive care needs. Mandarin and Cantonese-speaking patients and caregivers recruited through Chinese cancer support organisation, CanRevive, participated in three focus groups, conducted in Chinese. They provided feedback on the information content and presentation of two draft booklets - 'Communicating your needs'; 'Managing your emotions'. Transcripts were coded based on pre-defined categories regarding content relevance and presentation, and emerging themes.

Results:

Patients (n = 10, target 10) and caregivers (n = 9, target 10) found the booklets informative and comprehensive, and recommended adding illustrative anecdotes from other patients and caregivers. Cantonese-speaking caregivers felt that six booklets were too many and suggested condensing into three. Participants emphasised the need for practical information (e.g. contact details of support services) to accompany suggestions of how to communicate with doctors in 'Communicating your needs'. Information regarding treatment outcomes and emergency care were also highly preferred. For 'Managing your emotions', patients from both language groups wanted progressive muscle relaxation instructions to be accompanied by images. Most participants preferred coloured illustrations over photographs and monochrome images.

Conclusions:

*WeCope* is being refined based on participant feedback. Results from additional focus groups on the remaining four booklets will be reported.

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### Using an experience-based co-design process to co-create cancer wellness services for patients and their families

**Bena Cartmill**[3, 1, 2], **Jodie Nixon**[3, 2], **Emma McKinnell**[3], **Laurelie Wall**[3, 1, 2], **Euan Walpole**[3, 4], **Leanne Stone**[3], **Raymond Chan**[3, 5], **Mary Whitehead**[3], **Elizabeth Ward**[1, 2], **Andrew Puffett**[3], **Tracey Gardner**[6], **Brigid Hanley**[6], **Elizabeth Miller**[7]

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*5. Instutite of Health and Biomedical Innovation, Queensland University of Technology, Brisbane, Q, Australia*
*6. Cancer Council Queensland, Brisbane, Q, Australia*
*7. Consumer representative, Princess Alexandra Hospital, Brisbane, Q, Australia*

Aims:

The Queensland Collaborative for Cancer Survivorship (QCCS) and the Princess Alexandra Hospital Cancer Wellness Initiative are two dynamic schemes that bring together consumers, clinicians, researchers, and executives to optimise the access and delivery of survivorship services for people affected by cancer in Queensland. This project aimed to use an experience-based co-design method to optimise services that will ultimately promote their "wellness".

Methods:

An experience-based co-design (EBCD) method was used. First, the experiences of services that promote "wellness" for people affected by cancer (patients and their families/significant others), as well as clinicians delivering those services were explored using a range of focus group interviews. Cancer clinicians and patients/family members subsequently participated in co-design workshops to explore the barriers and facilitators to their access and engagement in "wellness" services and plan improvement initiatives.

Results:

Eighteen focus groups were conducted over a 3 month period (August-October 2018) with clinicians (n=68) and patients/family members (n= 82). Data were analysed using "Patient Journey Mapping" technique for patients/ family members. A service map was created outlining current services available on-site, and in the community. Clinicians reported limited availability and access to "wellness" programs for patients/families, and poor integration with the limited services that did exist. Patients and family members reported being unaware of programs within the hospital and in the local community that supported their wellness.

Conclusions:

Through the EBCD process, the partnership between cancer clinicians and people affected by cancer has provided rich information about service improvements, opportunities to facilitate access and engagement, and barriers to optimise cancer services promoting "wellness".

## 245

### ScreenIT: Development, validation, implementation, and expansion of a web-based patient-reported outcome screening tool

**Bena Cartmill**[1, 2, 3], **Laurelie Wall**[1, 2, 3], **Elizabeth Ward**[2, 3], **Raymond Chan**[1, 4], **Emily Packer**[2], **Adele Coleman**[2]

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Aims:

The value of implementing patient-reported outcome (PRO) in routine cancer care is increasingly recognised. This project aims to outline our five-year experience developing, validating, implementing and expanding "ScreenIT", a web-based patient-generated screening tool, into routine clinical care.

Methods:

Following a five phase methodology (consultation, needs analysis, psychometric testing, anthropometric testing/pre-implementation planning, and "go live") alongside partnering with patients and their family, ScreenIT has been developed, tested and implemented into routine clinical care with patients with head and neck cancer (HNC). ScreenIT is undergoing expansion into lung, oesophageal, brain and haematological cancers.

Results:

In the HNC population (n = 100), we found an overservicing for swallowing/nutrition by 24% and underservicing of distress. ScreenIT was more sensitive for detecting number and severity of treatment-related side effects, when compared to clinician assessment. Since June 2015, ScreenIT has been used by patients (n = 436) and their family members (n = 141) on a weekly basis during radiotherapy treatment. With a completion rate of 80%, ScreenIT achieved cancellation of up to 25% of overall appointments that were unnecessary, and a cost saving of $386,000/year. Expansion into the broader cancer population (n=309) has found a 205 (66%) reported at least one or more health concerns requiring MDT intervention, which were not identified by clinicians up to 80% of the time.

Conclusions:

ScreenIT is a web-based PRO used clinically to streamline health services for patients with head and neck cancer and their families. It is undergoing expansion across all cancer types to provide risk management algorithms and referral pathways for all members of the cancer multidisciplinary, in partnership with patients and their family.

## 246

### The impact of breast reconstruction surgery decision-making on body image outcomes in women with breast cancer: a qualitative study

**Lorna Huang[1], Sarah Guinta[1], Natasha Hatcher[1], Ilona Juraskova[2], Rebekah Laidsaar-Powell[2], Danielle Muscat[3], Susan Carroll[4, 5], Catriona McNeil[6, 4], Lucinda Burke[6], Pamela Howson[7], Belinda Chan[6, 8], Haryana Dhillon[9, 2]**

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*5. Northern Cancer Centre, Royal North Shore Hospital, St Leonards, NSW, Australia*

*6. Chris O'Brien Lifehouse, Sydney, NSW, Australia*

*7. Dept of Breast Surgery, Concord Repatriation General Hospital, Concord, NSW, Australia*

*8. Strathfield Private Hospital, Strathfield, NSW*

*9. Psycho-Oncology Cooperative Research Group, University of Sydney, NSW, Australia*

**Background:** Different types of post-mastectomy breast reconstruction (BR) have differing implications for adjuvant cancer treatment, complications, and cosmetic and disease outcomes. Body image has been a primary measure of the outcomes of treatment in previous literature, given its role in informing women's psychosocial well-being.

**Aims:** To: (1) explore women's experiences of immediate or delayed BR postmastectomy, with or without radiation therapy, and how these decisions shaped body image outcomes; (2) examine whether Cash's (2012) cognitive-behavioural model of body image could explain their experiences.

**Methods**: Semi-structured qualitative interviews were conducted via telephone July to September, 2018. Participants were recruited from social media, the Breast Cancer Network of Australia's Research and Survey Register, and Sydney hospitals. They included Australian women who had completed primary breast cancer treatment, spoke English and provided consent. Interviews were transcribed, and analysed thematically using a Framework approach.

**Results:** There were 26 participants (median age = 57 years, range = 33–76): 11 had immediate BR, eight delayed, seven no BR; and 12 had postmastectomy radiotherapy. Nine themes were identified, with few variations found between different treatment types. Themes highlighted the complex interaction of clinician communication, health system concerns, non-cancer specific life stressors, patient characteristics and integrated care shaping decision-making, outcome evaluation and body image in the context of post-mastectomy breast reconstruction. From this, a novel model was developed to understand the interactions between the themes. Cash's model of body image only partially accounts for body image adjustment, which had a bi-directional relationship with decision evaluation.

**Conclusion:** Current models of body image and decision-making in breast cancer settings are too simplistic and focused on short-term outcomes. They need to incorporate a broader range of concerns to accurately reflect women's experience and develop appropriate decision-making tools and interventions to support women through their breast cancer journey.

## 247

### A systematic review of the unmet supportive care needs of men on active surveillance for prostate cancer

**Megan McIntosh[1, 2], Holly Evans[1, 2], Amy Finlay[1, 2], Melissa J Opozda[1, 2], Daniel A Galvao[3], Camille E Short[1, 2]**

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*2. Freemasons Foundation Centre for Men's Health, Adelaide, South Australia, Australia*

*3. Edith Cowan University, Perth, Western Australia, Australia*

**Aims.** Similarly to men who receive active treatments for prostate cancer (e.g., radical prostatectomy), men on active surveillance require on-going person-centred supportive care. The aim of this study was to systematically review the currently available literature to identify the unmet supportive care needs of men on active surveillance for prostate cancer.

**Methods.** This review was conducted according to PRISMA guidelines. The following databases were searched to identify eligible studies: Pubmed, Embase, PsychInfo, CINAHL. Studies were included if they reported results specific to men on active surveillance, explored unmet supportive care needs, were available in English and were original research using a qualitative and/or quantitative design. Studies were excluded if they only reported patient outcomes (e.g., quality of life) or related to men in the treatment-decision phase.

**Results.** N= 3,613 references were identified, of which 9 studies met eligibility criteria (3 quantitative, 6 qualitative). Preliminary analysis has revealed the majority of unmet supportive care needs are informational (e.g., lack of information on active surveillance and future treatment) and emotional/psychological (e.g., lack of, active surveillance-specific support). However, the majority of studies included reported very few results specific to active surveillance, with only 2 studies including a sample of active-surveillance patients only.

**Conclusions.** Preliminary analysis suggests men on active surveillance experience a variety of unmet supportive care needs, particularly in relation to information and psychological support. This review highlights a significant research gap, as very few studies comprehensively explored the unmet needs of men on active surveillance. Further research is required in order to determine men's specific unmet needs on active surveillance in order for these to be appropriately and effectively targeted in interventions and in practice.

## 248

### Bone Marrow Transplant follow up and transition – who should care?

**Ida Twist[1]**

*1. The Children's Hospital at Westmead, Sydney, Westmead, Sydney, NSW, Australia*

The Children's Hospital at Westmead (CHW) Sydney performs 25-35 blood and marrow transplants (BMT) a year. Referrals for transplant are for both malignant (60%) and non-malignant disease (40%) for children aged between 4 weeks old to 17 years old. The paediatric BMT follow-up Nurse Practitioner (BMT FU NP) service was established to provide survivors of transplant ongoing lifelong follow-up.

The aims of this service are to assess and manage the chronic complex consequences of BMT *and* to transition patients to appropriate adult services for ongoing follow up. These consequences can manifest at any time post-transplant including well into adulthood, and these consequences cross many disciplines.

Whilst we have transitioned a handful of patents in crisis to adult services, 13% of our survivors are ready to transition due to their age with no clear process and continue to be seen in the paediatric service. Post-BMT survivors present with a mixture of issues including blending life-long surveillance with the surveillance for recurrent or new illnesses. The diversity in models of care across the continuum from paediatrics, AYA, adults and transition all highlight advantages and disadvantages to our paediatric survivors, however the pathway for transition in this population is blurred. Transitioning follow-up also remains challenging for many of our patients who were transplanted for non-malignant disorders. Until BMT FU clinics in the adult services can accommodate paediatric survivors, those beyond the age of 18yrs will remain in the care of paediatric services. The role of the paediatric BMT FU NP has extended to include advocating for transitioning paediatric survivors through networking, promoting service delivery standards, models of care scripting and continuing discussions with adult services.

This paper will discuss the **a**. rational for life long follow-up for BMT survivors and **b**. the barriers to transition.

## 249

## NQOL-ALL Study – Evaluating the long-term Neurocognitive outcomes and Quality of Life of children with childhood leukaemia undergoing a Bone Marrow Transplant (BMT).

**Ida Twist[1], Melissa Gabriel[1], Robert Battisti[1], Marie Antoinette Redoblado-Hodge[1], Peter Iiu[2], Peter Shaw[1], Karen Krakue[1]**

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Whilst preliminary research suggests an impact on neurocognitive dysfunction in survivors of leukaemia treatment there is little tangible research with a primary focus in leukaemia patients undergoing bone marrow transplant (BMT) . As survivorship numbers for children with leukaemia grows, attention shifts to quality of life and side effects of treatment. This study uses validated measures to explicitly define the short, medium and long term neurocognitive and quality of life (including sleep) outcomes associated with paediatric patients undergoing BMT leukaemia. Additionally, it remains unclear which conditioning treatment in leukaemia results in more statistically significant side effects in the short, medium or long term. Therefore, this study compares two standard pre-BMT conditioning therapies (1. Total Body Irradiation combined with chemotherapy and 2. Chemotherapy only) in a subset of patients with Acute Lymphoblastic Leukaemia (ALL) enrolled in the study. This study aims to accrue 150 participants in total. Thus far, neurocognitive and quality of life assessments have been conducted for consented participants (n=15), before BMT conditioning treatment begins. The study assesses each participant's quality of life and sleep at 6 month intervals, and assesses neurocognitive function at 1, 3 and 5 years post baseline. Currently two participants have reached their 3 year neurocognitive assessment, with the majority of participants just completing their 1 year neurocognitive assessment. The study has reported a high level of feasibility as rated by parents in a pilot study. As the study is ongoing further results are not yet available and this paper will highlight the importance of understanding the long term neurocognitive effects that survivors of childhood cancer face. The implications of the study include identifying the key impacts associated with BMT and standard conditioning regimens, and the provision of early intervention services to minimise and/or prevent long term difficulties in mental health, education and vocational functioning.

## 250

## Walking the boundaries – is the 6-minute walk test achievable in a outpatient breast clinic?

**Sophie Nightingale[1], Lei Ying[2], Melanie Fisher[2], Simon Koen[3]**

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*2. Western Health, Melbourne*

*3. University of Melbourne, Melbourne*

Aim:Healthy levels of physical activity have shown better quality of life outcomes and improved survival in women with breast cancer. This study aimed to define baseline fitness levels in a culturally and linguistically diverse outpatient breast clinic.

Methods:N=200 women aged 18-85 were surveyed on their general health status and details of treatments for those with a breast cancer diagnosis. A validated 6-minute walk test (6MWT) was then performed on a single-turn 30m walking track. Single and multiple linear regression models were performed with analysis of variance.

Results:The mean 6-minute walk distance (6MWD) was 486.6m (95%CI±12.8m), which is comparable with reference ranges. The mean age of participants was 47.5 (range 18-85). N=97(48.5%) participants had a diagnosis of breast cancer. Breast cancer diagnosis had a negative effect on 6MWD of -33.6m walked (SE=12.8m, p=0.010). Body mass index (BMI) had a negative effect on 6MWD of -4.2m walked per unit of BMI increase (SE=1.0m, p<0.001). The presence of any major medical comorbidity also had a negative effect on 6MWD of -56.9m walked (SE=14.7m, p<0.001). Smoking was not associated with a difference in 6MWD. Multiple regression analysis showed that only age, BMI and presence of comorbidities but not breast cancer had statistically significant effects on 6MWD. Self-reported exercise tolerance correlates significantly with 6MWD, but this may be clinically irrelevant because there is a high degree of variance.

Conclusion:The 6MWT was easily performed within the outpatient environment during routine clinics and a set of baseline fitness data has been established for patients attending a breast clinic. No set of variables predicts 6MWD well; the combination of age and BMI performed better than any single self-reported measure. This indicates that the 6MWT provides additional information from the general health status and self-reported measures and can be a valuable assessment tool in the outpatient setting. We now plan to incorporate the 6MWT into routine clinic use. This will allow us to identify changes in fitness during cancer treatments and make appropriate referrals for prescribed exercise interventions in our Breast Cancer population.

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# The role of generalist community nurses in survivorship cancer care

**Bora BK Kim[2, 1] , Kate KW White[2, 1], Heather HM McKenzie[1], Lillian LH Hayes[1], Judith JF Fethney[1], Janette JV Vardy[3], Jodi JM McLeod[4], Natalie NC Cook[5], Lisa LH Horvath[6], Simon SW Willcock[7], Chantale CB Boustany[2, 1], Louise LA Acret[2, 1], Gemma GC Collett[2, 1], Judy JS Simpson[8]**

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3. *Medicine, Concord Clinical School, University of Sydney, Concord, NSW, Australia*
4. *Sydney District Nursing, Sydney Local Health District , Sydney, NSW, Australia*
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6. *Chris O'Brien Lifehouse, Medical Oncology, Camperdown, NSW, Australia*
7. *Health Sciences Centre, Macquarie University, Macquarie Park, NSW, Australia*
8. *School of Public Health, Sydney University, Camperdown, NSW, Australia*

**BACKGROUND:** Equipping the health care workforce with skills to manage the needs of the growing number of cancer survivors is a challenge. Generalist/district community nursing services are an existing resource well placed to provide in-home cancer care.

**METHODS:** In collaboration with the Cancer Institute, NSW, we developed a web-based education program designed to support generalist community/district nurses providing home-based care for chemotherapy outpatients. Nurses completed a questionnaire before and after the education program, rating their confidence in managing chemotherapy-related side effects, identifying need for referral to, and liaison with the cancer centre/hospital, and knowledge of where to access reliable treatment information. Interviews were conducted with 7 nurses who had completed the education and subsequently provided targeted, supportive care to patients following treatment. Interviews were designed to gain insight into participant perceptions of (i) their confidence to provide this care, and (ii) the feasibility of community nursing services caring for chemotherapy outpatients. This is a mixed method study using a paired sample t-test and qualitative interviews.

**RESULTS:** Overall 133 community nurses were recruited and 65 nurses completed the survey. There was a significant improvement in mean confidence across all items from pre (3.24, SD 0.72) to post education (4.11, SD 0.42, $P < 0.001$). Nurses interviewed saw the benefit of providing targeted support to chemotherapy patients at home, and highly valued the education. They indicated the education equipped them to confidently care for this patient cohort, and that providing this service was within their scope of practice.

**CONCLUSION:**

The evaluation of this education program demonstrates the feasibility of extending the scope of practice of generalist nurses to provide cancer care in the primary setting. Potential exists for this model to be adapted to equip generalist community nurses with skills and confidence to provide quality survivorship cancer care.

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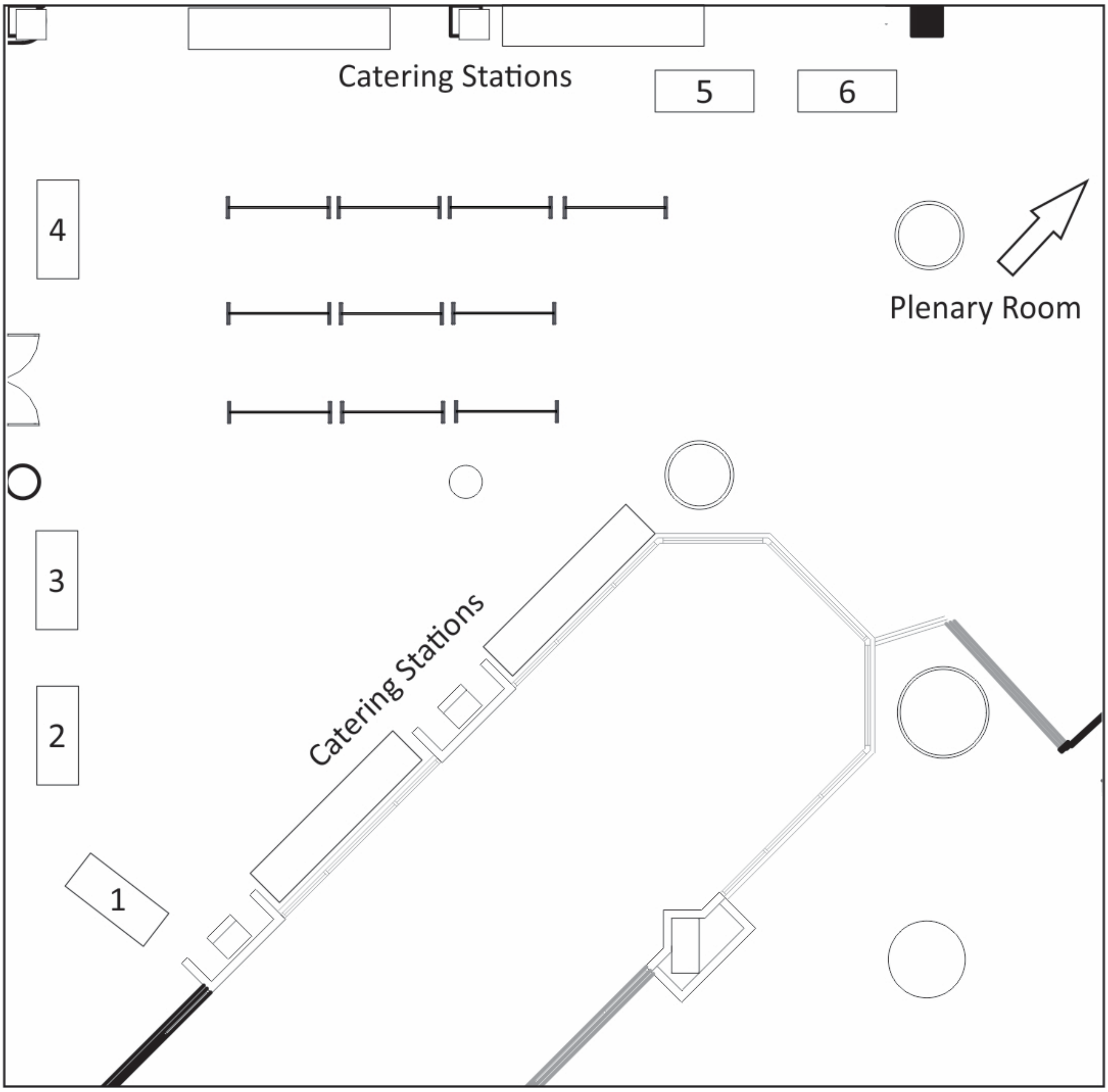

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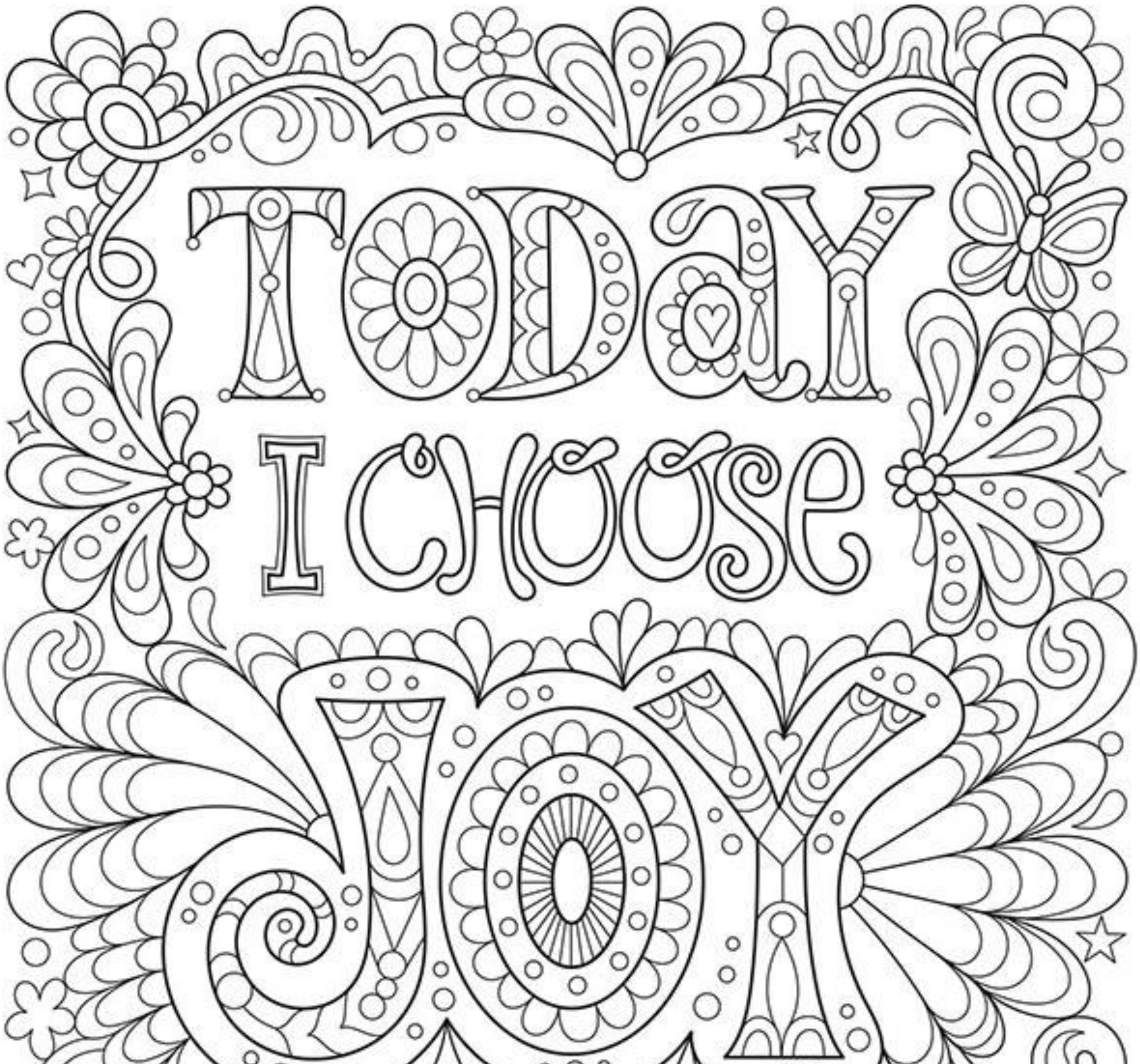
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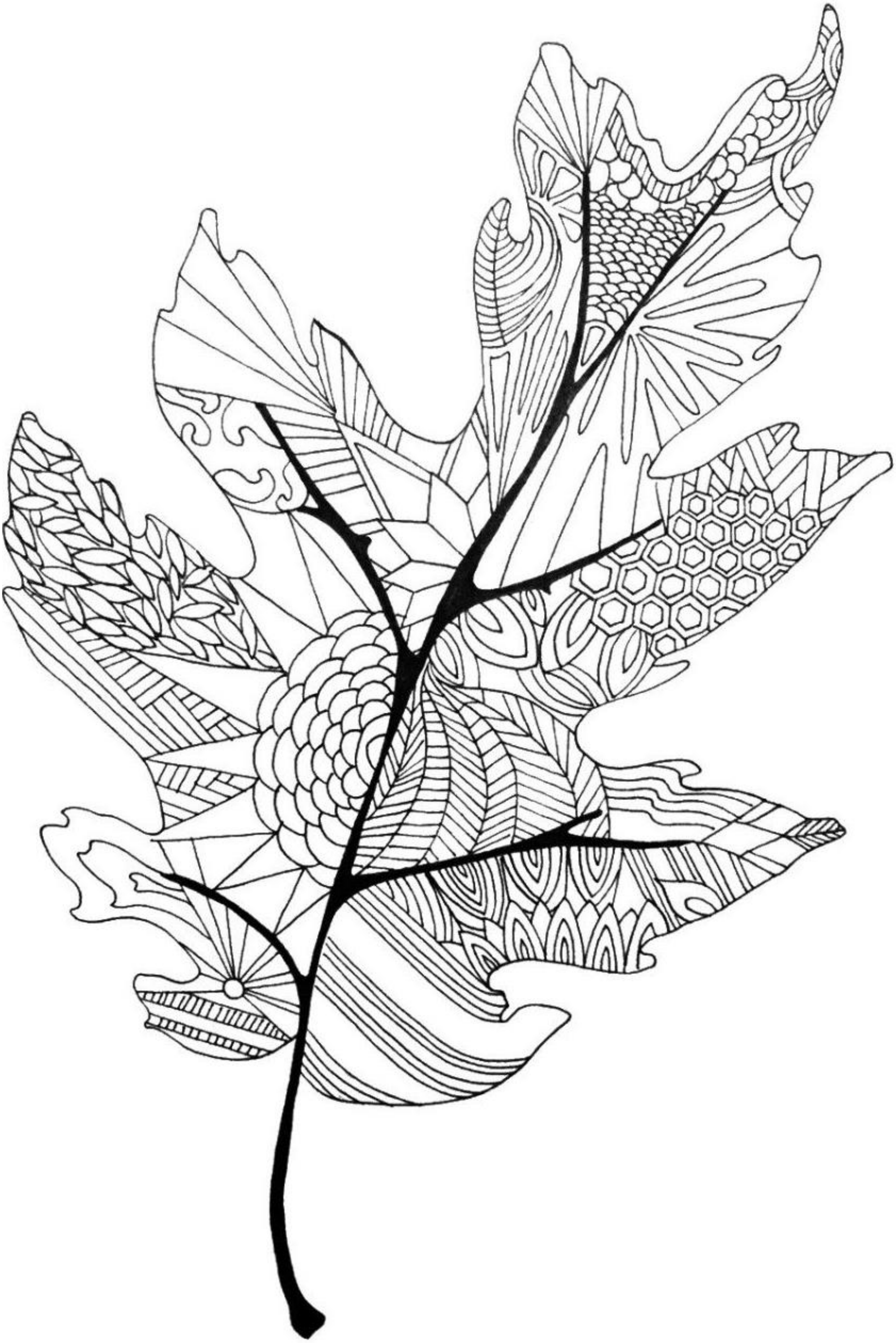

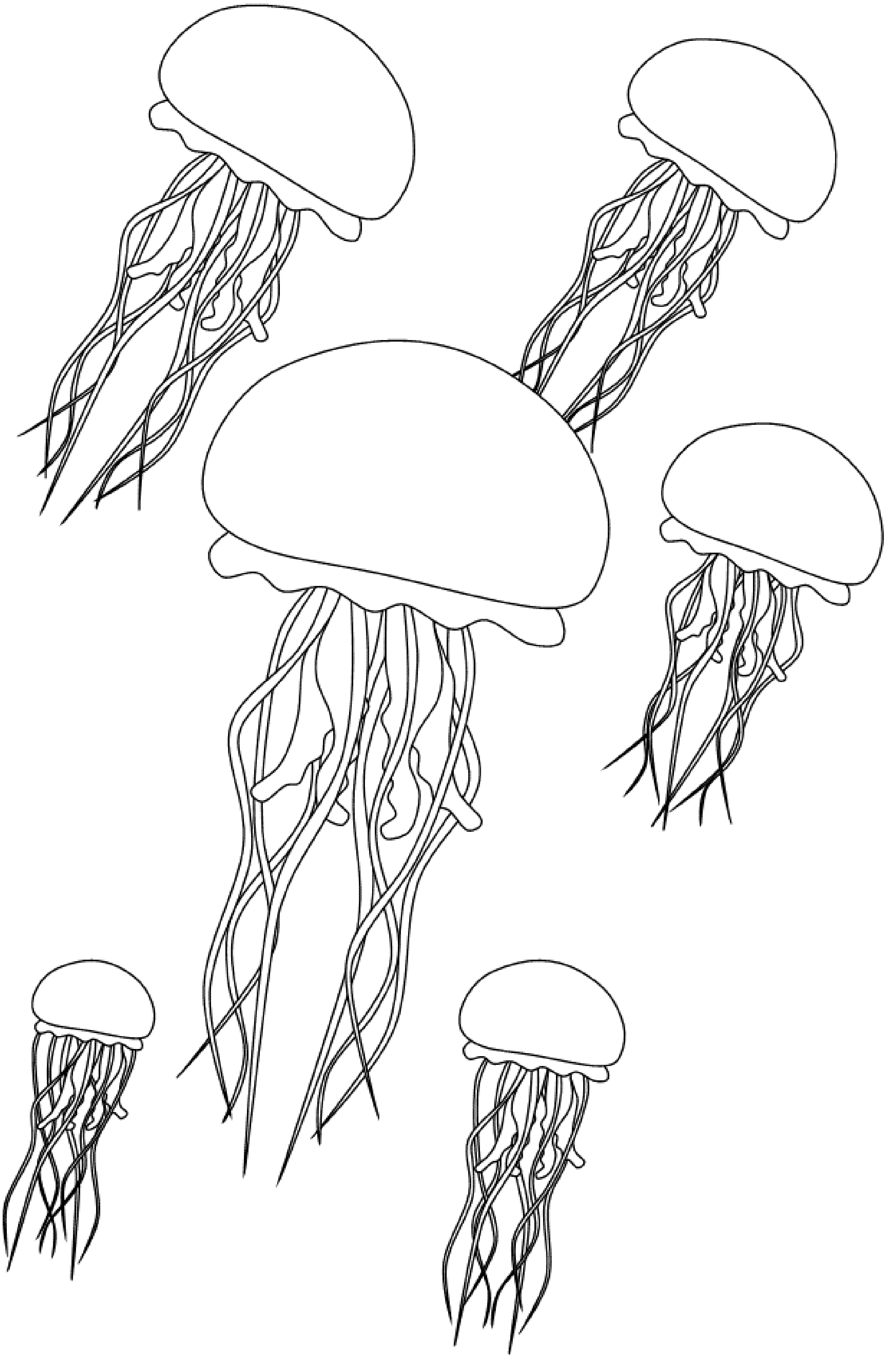


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