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100% VIRTUAL

ONLINE AND  
ON DEMAND

# CANCER SURVIVOR- SHIP

PROGRAM

18-19  
March  
2021



LIFE AFTER CANCER  
REDEFINED, REIMAGINED  
AND REBUILT

21



Clinical  
Oncology  
Society of  
Australia



Flinders  
UNIVERSITY

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# Convenor's Welcome

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Dear Friends,

I am delighted to welcome you to the fifth national cancer survivorship conference. While this time we are meeting online and not in person, I am confident that this novel form of delivery will not hinder our usual collegiality and inclusivity supporting open inquiry and innovation.

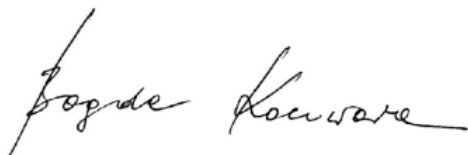
The partnership between the Flinders University and COSA ensures this national conference reflects the latest developments in research and care of relating to life after cancer. We pride ourselves on creating a conference that engages clinicians, researchers, policy-makers and consumers in one collaborative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

As always, we want to push the envelope and in 2021 we hope to be more thought provoking and provocative than ever before! With the theme “LIFE AFTER CANCER – REDEFINED, REIMAGINED AND REBUILT” the program will tackle some challenging concepts in survivorship including living with life limited disease, when cancer cannot be cured.

Past delegates have told us they want more hands-on practical sessions, so we are dividing the 2021 program into a mix of plenaries and workshops. Virtual delegates have access to all content including the plenaries and workshops. With the permission of presenters, all recorded content will be available via the online portal for 12 months after the conference. Workshop breakout rooms are not being recorded.

We look forward to you joining us to connect, recharge, and be inspired by being part of this growing, like-minded community.

With best wishes,



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

# Committee

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

## Conference Convenor

Bogda Koczwara                                      Flinders Medical Centre

## Program Committee

Ray Chan    Queensland University of Technology

Haryana Dhillon                                      University of Sydney

Eng-Siew Koh                                        Liverpool Hospital

Annie Miller                                         Cancer Council NSW

Sally Sara     Prostate Cancer Foundation Australia

Agnes Vitry                                         Cancer Voices SA

Fran Doughton                                      Clinical Oncology Society of Australia

Marie Malica                                        Clinical Oncology Society of Australia

# Host Organisations

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## Flinders University

Flinders University is a proud leader in life-changing medical innovations over the past 50 years. The Flinders Health and Medical Research Institute (FHMRI), an initiative of Flinders University, brings together research experts to improve health, prevent disease and combat health inequalities.

<https://www.flinders.edu.au>



## Clinical Oncology Society of Australia (COSA)

The Clinical Oncology Society of Australia (COSA) is the peak national body representing multidisciplinary health professionals whose work encompasses cancer control and care. COSA has over 1000 members who are doctors, nurses, scientists and allied health professionals involved in the clinical care of cancer patients.

<https://www.cosa.org.au>

# Delegate Information

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## The Organisers – ASN Events

ASN Events Pty Ltd  
9/397 Smith St, Fitzroy 3065  
P: +61 3 8658 9530  
Web: [www.asnevents.com.au](http://www.asnevents.com.au)

## Conference Managers

Alycia Manuel  
ASN Events  
Email: [alycia.m@asnevents.net.au](mailto:alycia.m@asnevents.net.au)

Gemma-ann Taylor  
ASN Events  
Email: [gemma-ann.t@asnevents.net.au](mailto:gemma-ann.t@asnevents.net.au)

## What Your Registration Includes:

All virtual registrations include:

- Access to the sessions of your choice\*\*
- Access to presentations and conference content for 12 months post conference
- Live chat function enabling interaction with speakers, delegates and exhibitors

\*\*Participation in workshops is available for pre-registered delegates only. All delegates had the option to register for the workshops via the registration portal.

## Virtual Platform

Log in information for the Virtual Platform, Pheedloop, will be sent to the email address registered with. If it is not in your inbox, please check the junk box.

The Virtual Platform provides the opportunity to view all sessions live, connect with exhibitors, view e-Posters and network with other delegates, speakers and sponsors.

## Displaying Your e-Poster

e-Posters are accessible via the 'e-Posters' tab on the left hand menu.

You will be able to converse with delegates and answer any questions through the chat functions within the virtual platform. Delegates will post questions in the Public Chat on the right-hand side of your e-Poster Presentation page on the virtual platform. They also have the option to start a private chat with you during the conference.

Please make sure that you refer back to your e-Poster page to answer any questions that are asked.

All presentations (unless permission is withheld) for the conference will displayed on the online platform for up to 12 months post meeting.

# Ashleigh Moore Oration 2021

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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 **Cancer Voices South Australia (CVSA)** as the recipient of the 2021 Award. On behalf of CVSA, Julie Marker who will be presenting the 2021 Ashleigh Moore Oration on Thursday 18 March, which will include a special tribute to Chris Christensen, past CVSA Chair who sadly passed away on 31 October 2020 aged 65.



## **Ms Julie Marker**

Julie is a colon cancer survivor, diagnosed initially in 2001 at 45 years of age, then again with liver secondaries in 2005 and 2006.

Julie is the Deputy Chair of Cancer Voices South Australia (CVSA) - an independent, 100% volunteer survivor and carer led organisation. Cancer Voices focus is on system level advocacy ...'good systems not just good luck!', and on wellness not just illness. We use our collective lived experiences to inform better cancer related policy, practice, services, research and education.

Julie is an active consumer representative on a number of state and national projects and advisory groups including the Psycho-Oncology Trials Group (PoCoG), Australasian GastroIntestinal Trials Group (AGITG) and PC4 Primary Care Collaborative Cancer Clinical Trials Group.

Julie works hard to represent, respect and respond to the diversity of views of 'people affected by cancer', as well as assisting others to participate and use their own cancer experiences in a variety of ways. Amongst other things, Julie coordinates Cancer Voices 'survivors as teachers' series of 15 tutorials/year with medical students (ongoing since 2012), and helps lead Cancer Voices weekly survivor-led cycling group, walking group and 'Walk/n/Talk with cancer researchers' group.

In recognition of the Award, Julie will deliver her Oration "Survivors and leadership reimagined" at the Conference.

## International Speakers

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**Dr Doris Howell**

**Princess Margaret Cancer Research Institute, Toronto, Canada**

Dr. Doris Howell completed a PhD as a health services outcomes researcher at the Institute of Health Policy, Management and Evaluation (IHPME) in the Outcomes and Evaluation Stream, University of Toronto. She is an Emeritus Senior Scientist in the Division of Supportive Care, Princess Margaret Cancer Centre Research Institute, University Health Network and Adjunct Professor, Lawrence S. Bloomberg Faculty of Nursing with a cross-appointment in IHPME & Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada. She is also an Affiliate Scientist with the ELLICSR Health, Wellness & Cancer Survivorship Centre. Dr. Howell led an applied research unit testing accuracy of a range of generic and disease specific Patient Reported Outcomes and led implementation in multi-site disease groups in two provinces for personalized symptom management in cancer care. Currently, she has been conducting trials testing the effectiveness of remote monitoring for real time symptom monitoring and management of systematic chemotherapy and immunotherapy toxicities using smart phones. Additionally, she leads an implementation trial of a proactive model of care intervention to activate patients in self-management through a web-based program (icanmanage.ca) a cancer self-management support program) combined with cancer coaching by trained nurses. She has developed and delivered the first international health care professional training program for Cancer Coaching across the cancer continuum in preparation for licensing of the first Cancer Coaches in Canada under the auspices of York University. She has led multiple awards for practice transformation through development of national guidelines in symptoms and cancer survivorship and for her contributions to the advancement of psychosocial and supportive care research.



**Dr Thomas Smith**

**Johns Hopkins and Sidney Kimmel Comprehensive Cancer Center, Baltimore, USA**

Dr Smith is an oncologist and palliative care specialist with a lifelong interest in better symptom management and improving access to high quality affordable care. As an oncologist he specialized in comprehensive multi-disciplinary breast cancer for 25 years. With the late Dr Chris Desch he helped start the Rural Cancer Outreach Program (RCOP) of Virginia Commonwealth University's Massey Cancer Center. This brought state of the art cancer care including clinical trials and palliative care to five rural hospitals in Virginia. The RCOP improved care dramatically, saved patients millions of travel miles, and ensured that indigent patients could receive care near their home. As an oncologist, he worked to remove the financial incentives for giving chemotherapy, and to standardize guidelines for care.

With Patrick Coyne and others, he helped start the Thomas Palliative Care Unit and Program at VCU-MCV in the late 1990s, one of the first academic palliative care programs in the country. He and colleagues showed that palliative care improved symptoms, allowed patients and families to choose the care they wanted, did not cost more than usual care, and even improved survival.

Currently, he is the Director of Palliative Medicine for Johns Hopkins Medicine, charged with integrating palliative care into all the Johns Hopkins venues. The PC consult service sees over 1500 new patients a year, and a research agenda with “Scrambler Therapy” for chemotherapy induced neuropathy, neuromyelitis optica spectrum disorder pain, and central pain; palliative care for patients on Phase I drug trials; palliative care for patients undergoing Whipple procedures; and auricular point acupuncture for cancer pain, among others.

Dr Smith has been recognized in “Best Doctors in America” for many years and is a Fellow in the American College of Physician, the American Society of Clinical Oncology and the American Academy of Hospice and Palliative Medicine. He received the ACS Trish Greene Award for “outstanding research that benefits cancer patients and their families”, and in 2018 was recognized as a “Visionary in Palliative Care” by AAHPM. In 2019 he received the Project on Death in America (PDIA) Palliative Medicine National Leadership Award, and the Walther Foundation- ASCO award for excellence in supportive oncology. In 2020 he received the Ellen Stovall Award from the National Coalition of Cancer Survivors that recognizes individuals, organizations, or other entities who demonstrate innovation in improving cancer care for patients in America. He has published over 400 articles, editorials and reviews, and helped write the test questions for the ABIM hospice and palliative medicine exam.

Dr Smith is also a metastatic prostate cancer survivor, experiencing firsthand surgery, recurrence, “salvage” radiation therapy and androgen deprivation therapy with many significant side effects, and recurrence. He knows all too well the experience of living and working while waiting for the other shoe to drop. He and his late colleague Terry Langbaum pointed out the trials of “metastatic cancer survivorship” in an opinion piece published in the New England Journal of Medicine, hopefully stimulating research into this area.



## National Speakers

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**Prof David Currow**  
**Cancer Institute NSW**

David is Chief Cancer Officer, New South Wales and the Chief Executive Officer of the Cancer Institute, NSW, the state's cancer control agency.

The agency is responsible for prevention, screening, improved cancer services, and funding of research infrastructure. David is also Professor of Palliative Medicine at University of Technology Sydney, the Matthew Flinders Distinguished Professor, Flinders University and Associate Director (Research) at the Wolfson Palliative Care Research Centre, University of Hull, England. Research includes clinical trials and use of large datasets to understand better the impact of life-limiting illnesses on patients and caregivers. Research into chronic breathlessness is a particular area of focus. He is the principal investigator for the Australian national Palliative Care Clinical Studies Collaborative (PaCCSC) which has randomised more than 2000 people to phase III symptom control studies. He initiated an active international phase IV collaborative with data on more than 1200 people from 18 countries. These studies have been shown to influence clinical practice. He is a foundation partner in the Australian national Palliative Care Outcomes Collaborative (PCOC), an initiative to improve palliative care clinical outcomes through point-of-care data collection. David has published more than 640 peer-reviewed articles, editorials and books. He is senior associate editor of Journal of Palliative Medicine and Editor of the 5th and 6th editions of the Oxford Textbook of Palliative Medicine. David is a former president of Palliative Care Australia and the Clinical Oncological Society of Australia.



**Ms Abbey Diaz**  
**Menzies School of Health Research**

Dr Abbey Diaz is an early career researcher with the cancer research team in the Wellbeing and Preventable Chronic Diseases Division at

Menzies School of Health Research, based in Brisbane, Queensland. She is an emerging expert in cancer and cardiovascular epidemiology and heads up a new cardio-oncology research program under the auspice of the Centre of Research Excellence in Targeted Approaches to Improve Cancer Services for Aboriginal and Torres Strait Islander People (TACTICS CRE). Abbey has a Bachelor of Health Science, Masters of Applied Science, and a Doctor of Philosophy (Epidemiology). She has worked in Aboriginal and Torres Strait Islander health research for over a decade and is committed to working through partnership and respect to privilege the lived experiences of Aboriginal and Torres Strait Islander people living with and beyond cancer. Her PhD, completed in 2018, focused on understanding the impact of Aboriginal and Torres Strait Islander women's higher comorbidity burden on gynaecological cancer treatment, survival and supportive care needs. Her current research program aims to better understand the prevalence and impacts of adverse cardiovascular events after cancer and identify gaps in care for at risk patients to inform the development of an Australian cardio-oncological model of care that is both optimal and equitable. Abbey is the Vice President of the Australasian Epidemiology Association (AEA), the Convener of the Queensland chapter of the AEA, and a member of the Psycho-Oncology Co-operative Research Group, Early Career Researcher Special Interest Group.



**A/Prof Louisa Gordon**  
**QIMR Berghofer Medical**  
**Research Institute**

Associate Professor Louisa Gordon is a Health Economist, Senior Research Fellow and Group Leader of Health

Economics at QIMR Berghofer Medical Research Institute. A/Prof Gordon holds a Bachelor of Economics and a Masters' degree and PhD in Public Health. Her program of research is devoted to evaluating the cost-effectiveness of health interventions for cancer populations and the financial burdens of cancer survivors. A/Prof Gordon was recently appointed as the Australian Scientific Committee Member for the International Agency for Research in Cancer.



**Mr Paul Grogan**  
**Cancer Council NSW**

Paul Grogan is Senior Strategic Adviser at the Cancer Research Division of Cancer Council NSW, where he advises on research strategy, horizon

scanning, program evaluation and opportunities for collaboration. From 2004 to 2019, Paul was Director of Public Policy at Cancer Council Australia, where he oversaw the development, publication and promotion of Cancer Council Australia's public policy resources and clinical practice guidelines, and managed government relations. He co-developed proposals that translated into the \$640 million regional cancer centres initiative, the first ever allocation of Commonwealth funds for cancer clinical trials and a doubling of the asset threshold for cancer patients' eligibility for sickness benefits. In the 1990s Paul was a government media and policy adviser, including seven years as head of media and parliamentary liaison at the NSW office of the Australian Department of Health. He lectures at the School of Public Health at the University of Sydney on health policy, communications and the relationship

between research, advocacy, government relations and evidence-based policy reform.



**Prof Michael Jefford**  
**Australian Cancer**  
**Survivorship Centre**

Professor Michael Jefford is both a Consultant Medical Oncologist and Director of the Australian Cancer Survivorship

Centre at Peter Mac, and is a Professorial Fellow with the University of Melbourne. His major clinical focus is on the management of people with gastrointestinal cancers. Michael has made significant contributions around service delivery, research, policy and program development, and to the international literature regarding cancer survivorship. He is the current Chair of the Clinical Oncology Society of Australia's Cancer Survivorship Committee and (2020/2021) is Chair Elect of the American Society of Clinical Oncology's Cancer Survivorship Committee. He chairs the Survivorship Special Interest Group with the International Psycho-Oncology Society. Most of his research has a cancer survivorship focus, aiming to better understand issues affecting survivors; to develop and implement strategies to minimise post-treatment consequences; to develop improved models of care, and to better understand and minimise disparities in cancer survivorship outcomes. He is widely published and has presented work at numerous international meetings covering clinical oncology, survivorship, psycho-oncology and cancer control broadly.



**Dr Yada Kanjanapan**  
**The Canberra Hospital**

Dr Yada Kanjanapan is a Medical Oncologist at The Canberra Hospital, and Clinical Lecturer at the Australian National University. Her areas of interest include breast and

gynaecological cancers, melanoma and cancer immunotherapy. She has also developed an interest in the impact of the COVID-19 pandemic in oncological care. She has previously written a perspective piece on Considerations for cancer immunotherapy during the COVID-19 pandemic, published in the Medical Journal of Australia. Currently, she is leading a collaboration to produce a position statement on COVID-19 Vaccination in People with Cancer within the Medical Oncology Group of Australia.



**Prof Bogda Koczwara**  
**Flinders University**

Professor Bogda Koczwara is a senior staff specialist in medical oncology at the Flinders Medical Centre in Adelaide, Australia and she leads the Survivorship

Research Program at the Flinders University Health and Medical Research Institute. She chairs the Psychosocial Group of the Multinational Association of Supportive Care in Cancer and leads the Global Partnership on Self-management in Cancer.

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.



**Mr Dan Kent**  
**Cancer Voices NSW**

Dan Kent lost a 33-year-old daughter to metastatic breast cancer in 2002 then experienced his own rectal cancer journey in 2006 and has recently assisted his

wife on her breast cancer journey in late 2020. In 2008 Dan joined the inaugural Consumer Advisory Panel (CAP) of the Australian Gastro Intestinal Trials Group (AGITG) and from 2010-2016 he chaired the CAP before becoming a Director of the AGITG in 2017. In 2015 he was awarded the inaugural AGITG John Zalberg OAM Award for Excellence in AGITG Research – citation “In recognition of outstanding leadership contribution to AGITG clinical trials research over a sustained period”. Dan’s current cancer involvement includes being the Australian Cancer Consumers Network (ACCN) member of the Cancer Australia Inter Collegiate Advisory Group, Consumer member on the National Cancer Screening Program Quality Committee, member of Cancer Voices NSW Executive Committee and a Hospital based Volunteer with the Council Cancer NSW. This is the fourth Survivorship Conference which he has attended and he very much looks forward to his involvement in the Closing Plenary of this Conference.



**Dr Kelvin Kong**  
**HUNTER ENT**

Kelvin graduated from the University of NSW in 1999. He embarked on his internship at St. Vincent's Hospital in Darlinghurst and pursued

a surgical career, completing resident medical officer and registrar positions at various attachments. Along the way, his has been privileged in serving the urban, rural and remote communities.

He was awarded his fellowship with the Royal Australasian College of Surgeons in 2007. Once completed he pursued further training in Paediatric ENT surgery, being grateful and honored by his fellowship at The Royal Children’s Hospital, Melbourne in 2007-8.

He is now practising in Newcastle (Awabakal Country) as a board certified Surgeon specializing in Paediatric & Adult Otolaryngology, Head & Neck Surgery (Ear, Nose & Throat Surgery). He has joined an outstanding group of surgeons at Hunter ENT and together they provide a varied comprehensive practice. He has a very broad adult and paediatric Otolaryngology, Rhinology and Laryngology practice, whilst having special interests in Paediatric Airway, Adult and Paediatric Cochlear Implantation, Voice and Swallow disorders and Head & Neck Cancer management.

He is an active member of RACS and ASOHNS, serving on the Indigenous Health and Fellowship Services Committee’s. He is a board member of the National Centre of Indigenous Excellence (NCIE). He has published articles and presented on a variety of ear, nose and throat conditions as well as Indigenous health issues both nationally and internationally. He is active in reviewing articles for publication, lecturing and teaching allied health professional, medical students at several universities and both unaccredited and advanced medical and surgical trainees.

Kelvin hails from the Worimi people of Port Stephens, north of Newcastle, NSW, Australia. Being surrounded by health, he has always championed for the improvement of health and education. Complementing his practice as a surgeon, he is kept grounded by his family, who are the strength and inspiration to him, remaining involved in numerous projects and committees to help give back to the community.



**Ms Lillian Leigh  
Consumer Advocate**

Following a rare lung cancer diagnosis, Sydney lawyer Lillian Leigh found her passion in patient advocacy. Lillian was appointed as an Advisory

Council member of Cancer Australia where she also serves on its Research and Data Advisory Group. She is an inaugural Board member of the Thoracic Oncology Group of Australasia, which is a collaborative organisation dedicated to clinical trials and translational research in thoracic cancers. As a research advocate, she is also on the Advisory Board of Woolcock Institute’s Lung Cancer Research Network and had served for five years on committees of the Australasian Lung cancer Trials Group. Lillian is an Executive Committee member of Cancer Voices, as well as a Patient Advisory Committee member of Rare Cancers Australia. For a second year, Lillian has been selected as a research advocate Mentor for the International Association for the Study of Lung Cancer’s Supportive Training & Advocacy in Research and Science (STARS) Program. She was a recipient of the international Patient Advocacy Award at the World Conference for Lung Cancer in Vienna in 2016.



**Mr Craig McGowen  
WealthPartners**

Craig commenced his career in Financial Planning in 2015, joining WealthPartners in 2019. Craig previously worked at BT Financial Advice from

2015-2019 where he was awarded Adviser of the Year in 2019. Craig’s specialties are in Financial Planning, Superannuation Advice, Budgeting and Cash Flow Planning, Retirement Planning, Investment Strategies, Risk Planning and Tax Planning. WealthPartners has been involved with the Cancer Council since 2012 as it is “a wonderful way for the individuals within our business to

use their skills and expertise to give back to the community.” Since that time, WealthPartners have provided free financial planning and assistance to over 35 families affected by cancer.



**Dr Vivienne Milch**  
**Cancer Australia**

Dr Vivienne Milch is Medical Director, at Cancer Australia. In this role, she provides strategic clinical policy input to Cancer Australia’s work to minimise the impact of cancer, address disparities, and improve the health outcomes of people affected by cancer in Australia.

Dr Milch is also medical advisor to the Commonwealth Department of Health on cancer screening policy.

Prior to joining Cancer Australia, Dr Milch was a General Practitioner and clinical researcher at the Garvan Institute of Medical Research, Sydney, and she holds a Masters in Health Policy from the University of Sydney.



**A/Prof Susanna Park**  
**University of Sydney**

Associate Professor Susanna Park PhD is a NHMRC RD Wright Biomedical Research Career Development Fellow and Associate

Professor in Physiology at the Brain and Mind Centre, University of Sydney. A/Prof Park is a leader in chemotherapy-induced peripheral neurotoxicity research, awarded >\$7.5 million in competitive research funding in the past 5 years. She obtained her PhD from UNSW and subsequently undertook postdoctoral training at the Institute of Neurology, University College London. She was awarded the Australasian Neuroscience Society AW Campbell award (2018) for the best contribution to neuroscience in the first five postdoctoral years. Dr Park has led a number of studies examining clinical translation,

assessment strategies, treatment and risk factors for chemotherapy-induced peripheral neuropathy, leading to >95 peer-reviewed publications.



**Ms Danielle Spence**  
**Cancer Council Victoria**

Danielle has extensive experience working in the health care industry across a range of organisations including public, private and not-for-profit agencies. She has a background in oncology nursing with a Masters in Breast Care Nursing. She has served on numerous cancer care advisory groups and worked in senior policy and advocacy positions in leading cancer organisations.

Danielle is passionate about ensuring patients have equitable access to quality cancer care and has worked on national and international campaigns to improve and extend the lives of people living with advanced disease.



**Prof Paul Ward**  
**Flinders University**

Professor Paul Ward is Head, Discipline of Public Health in the College of Medicine and Public Health at Flinders University, Australia. Paul is a social scientist with a background in medical sociology and qualitative research. Paul’s main research interests are around lay and professional perceptions, knowledge and understandings of health, healthcare, medicines, risk and trust.



**Ms Lucy Wilson**  
**WPPAUNZ**

Lucy Wilson is the Director of People & Culture for WPP AUNZ (QLD Campus) and both her professional and personal mantra is always do it with Purpose,

on Purpose! Having spent over 8 years partnering closely with the Cancer Council, her exposure and experience diverse and spans across a significant number of client cases, all varying in their challenges at the time.

Lucy has spent over 15 years professionally within People & Culture (Human Resources) Teams, leading organisations through creating one of a kind People & Culture Strategies and implementing those into best practices, that enable people to do their best work and encourage an inclusive workplace. Specialist areas include, Strategy, Generalist HR, Talent Development, Employment Relations, Scale up/Start up Cultures, and Leading teams.



**A/Prof Lisa Whop**  
**Australian National University**

Associate Professor Lisa Whop is from the Wagadagam tribe of the Goemulgal people of Mabuiag Island in the Torres Strait. She is Senior Research Fellow at

the National Centre for Epidemiology and Population Health at The Australian National University. She is Australia's leading authority on cervical cancer control in Aboriginal and Torres Strait Islander women.

Lisa has a Bachelor of Medical Science, Master of Applied Epidemiology and a Doctor of Philosophy (Epidemiology). She brings years of research experience working with Aboriginal and Torres Strait Islander people and the health sector, is skilled in community engagement and frequently speaks at state, national and international meetings and conferences on the topic of Aboriginal and Torres Strait Islander health.

As an advocate for Aboriginal and Torres Strait Islander people and improved health outcomes Lisa skilfully translates research into policy and health practice which centres on the voices and experience of Aboriginal and Torres Strait Islander peoples.

Lisa is a committee member of the Cancer Australia Leadership Group on Aboriginal and Torres Strait Islander Cancer Control and the Quality Committee of the National Cancer Screening Register Telstra Health, and a member of the Australian Epidemiological Association and Clinical Oncology Society of Australia. She is a recipient of a National Health and Medical Research Council Early Career Fellowship.

# Program - Thursday 18 March 2021

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## Official Opening

9:00AM - 9:15AM

Chair: Bogda Koczwara

Welcome to Country by David Copely  
Official Opening by Prof Dorothy Keefe

## Plenary: When cancer cure is not the goal

9:15AM - 10:45AM

Chair: Bogda Koczwara

Discussant: David Copley

This conference acknowledges the sponsorship of



### Tom Smith

Lessons Learned from Brushes with Death Serious Illness: or, what I wished my team had done.... *abs# 1*

### Lisa Whop and Abbey Diaz

What matters to Aboriginal and Torres Strait Islander people living with and beyond cancer  
*abs# 2*

### David Currow

What is the role of palliative care in survivorship care *abs# 3*

**Panel discussion** - When cancer cure is not the goal

## Morning Tea

10:45AM - 11:05AM

## Best of the Best Survivorship Abstracts – e-Poster discussion

11:05AM - 11:20AM

Discussant: Janette Vardy

### Kate Anderson

Fear of cancer recurrence in Indigenous and minority peoples globally: a systematic review  
*abs# 102*

**Bethany Crowe**

The Use of Domain Experts in Addressing Frequently Asked Questions relevant to Implementing a Shared-Care Model between Cancer Specialists and Primary Care Providers *abs# 114*

**Jennifer Fox**

Perceived roles of general practice team members in the delivery of cancer survivorship care: An interpretive qualitative study *abs# 121*

**Bogda Koczwara**

Impact of comorbidities on survival and physical functioning of middle-aged (50 – 64 years) cancer patients *abs# 132*

**Vicki White**

Disparities in quality of life, social distress and employment outcomes in cancer survivors *abs# 162*

**Plenary: Neurotoxicity and neuropathy**

11:20AM - 12:50PM

Chair: Lee Hunt

Discussant: Fran Boyle

**Tom Smith**

Chemo induced neuropathy (CIN) -- and what can be done about it *abs# 4*

**Susanna Park**

Chemotherapy-induced Neurotoxicity in Cancer Survivors in Australia *abs# 5*

**Julie Marker**

Finding my feet *abs# 6*

**Panel discussion** - Neurotoxicity and neuropathy

**Ashleigh Moore Award Oration**

12:50PM - 1:10PM

Chair: Bogda Koczwara

Recipient: **Cancer Voices SA**

**Julie Marker**

Survivors and leadership reimagined *abs# 7*

**Lunch**

1:10PM - 1:40PM



## **Workshop: Cognition and Cancer Survivors**

1:40PM - 3:10PM

Co-Ordinator: Eng-Siew Koh

## **Afternoon Tea**

3:10PM - 3:30PM

## **Workshop: Mental Health**

3:30PM - 5:30PM

Co-Ordinators: Haryana Dhillon & PoCoG

# Program - Friday 19 March 2021

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## Workshop: Self-Management of Cancer and Health

9:00AM - 10:30AM

Co-Ordinators: Bogda Koczwara & Anes Vitry

Speakers: **Sharon Lawn & Doris Howell**

This conference acknowledges the sponsorship of



## Morning Tea

10:30AM - 10:50AM

## Workshop: Practical issues – Financial, Insurance and Employment

10:50AM - 12:20PM

Co-Ordinators: Annie Miller & CCNSW

Facilitators: Michelle Bass & Laura Muir, CCNSW

Speakers: **Craig McGowen & Lucy Wilson**

## COVID-19 Learnings

12:20PM - 1:05PM

Chair: Agnes Vitry

Discussant: Fran Boyle

### **Yada Kanjanapan**

COVID-19 and Cancer: Clinical Considerations *abs# 8*

### **Vivienne Milch**

COVID-19: Implications for cancer care *abs# 9*

### **Danielle Spence**

COVID-19 and cancer: The patient experience *abs# 10*

**Panel discussion** - COVID-19 learnings

## Lunch

1:05PM - 1:35PM

## **Best of the Best Survivorship Abstracts – Oral presentation discussion**

1:35PM - 1:55PM

Chair: Afaf Girgis

### **Louisa Gordon**

Out-of-pocket medical expenses for the common cancers are rising and public patients are faring worse *abs# 11*

### **Daniel Lindsay**

The development of a tool assessing the supportive care needs for caregiver's of Aboriginal and Torres Strait Islander cancer survivors *abs# 12*

## **Plenary: Achieving Equity for all survivors: How we can rebuild the system?**

1:55PM - 3:25PM

Chair: Haryana Dhillon

Discussant: Don Piro

This conference acknowledges the sponsorship of



### **Paul Ward**

Stigma + discrimination = poorer access to healthcare to minority groups. How do we change the formula? *abs# 13*

### **Lillian Leigh**

The patient perspective *abs# 14*

### **Kelvin Kong**

Systemic and institutional racism that is a barrier to the First Nations peoples of Australia engaging in healthcare *abs# 15*

**Panel discussion** – Achieving Equity for all survivors

## **Afternoon Tea**

3:25PM - 3:45PM

## **Plenary: Value-based survivorship care – Would the Health Minister “buy” your idea?**

3:45PM - 4:55PM

Chair: Sally Sara

Discussant: Raymond Chan

### **Sally Sara & Ray Chan**

Introduction

**Dan Kent**

Consumer proposal

**Paul Grogan**

Health Minister's Advisor

**Michael Jefford**

Health Professional proposal *abs#17*

**Louisa Gordon**

Health Economist proposal *abs#18*

**Minister Bogda Koczwara**

Verdict on whether to fund the service

**Closing remarks, conference reflections, next steps**

4:55PM - 5:00PM

Bogda Koczwara

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Our scientists are exploring new frontiers in the future of personalised medicine, and through new digital platforms, we are converting decades of research and data into insights that sharpen the focus of our work.

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Beyond our treatments, we know that cancer can have a relentless grasp on many parts of a patient's life, and we are taking clear actions to address all aspects of care, from diagnosis to survivorship.

That means supporting patients and caregivers beyond our medicines with the resources and education they need about their disease, help with navigating the healthcare system, and ensuring our life-changing therapies are accessible to patients who need them.

Because as a leader in cancer care, Bristol Myers Squibb is working to empower people with cancer and help them to have a better future.



# Poster Listing

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A Systematic Scoping Review of Cancer Survivorship Education Programs for Primary Care Providers *abs# 100*

## **Andi Agbejule**

Implementation of Cancer-Related Fatigue Management Interventions: A Systematic Scoping Review *abs# 101*

## **Kate Anderson**

Fear of cancer recurrence in Indigenous and minority peoples globally: a systematic review *abs# 102*

## **Annabel Askin**

Rapid response to pandemic restrictions to maintain survivorship programs access for vulnerable rural patients in North-west Victoria *abs# 103*

## **Monique Bareham**

Minding the Gap - Revisited: Consumer advocacy leads to the development of much needed cancer related lymphedema services and subsidy in South Australia *abs# 104*

## **Lisa Beatty**

Developing and piloting a self-guided web-based psychosocial care program for women living with incurable breast cancer: Finding My Way-Advanced. *abs# 105*

## **Victoria Bedford**

What tools measure Quality of Life in paediatric cancer patients? A scoping review *abs# 106*

## **Nicolas BOUGAS**

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**Catherine Devereux**

Empowering older adults with cancer to be partners in treatment decisions. The Older and Wiser project. *abs# 115*

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**Abbey Diaz**

Adverse cardiovascular events after cancer for Indigenous, ethnic and minority populations: a systematic review *abs# 117*

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Return to work after breast cancer: the role of working conditions *abs# 118*

**Jasmine Foley**

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## Australian Cancer Survivorship Centre

The Australian Cancer Survivorship Centre (ACSC) is a unique service based at Peter Mac, Melbourne, with a vision to optimise the health and wellbeing of cancer survivors and their carers. ACSC works with a broad range of providers to enable improved care, and connect survivors and those close to them with information and support.

Visit: [petermac.org/cancersurvivorship](http://petermac.org/cancersurvivorship)

# myCarePlan.org.au

This free, online cancer survivorship care plan generator is currently available for survivors of **early stage breast, bowel or prostate cancer**. Additional cancer types are coming soon, including non-Hodgkin's lymphoma and early stage melanoma. Survivors and health professionals can create a personalised health and wellbeing plan for the future.

Visit: [mycareplan.org.au](http://mycareplan.org.au)

## Common Survivorship Issues Directory

[petermac.org/survdirect](http://petermac.org/survdirect)



Cancer survivors experience a common range of issues following cancer and its treatment. This free directory provides survivors, their carers, and health professionals evidence-based information and tools to support quality survivorship care.

Visit: [petermac.org/survdirect](http://petermac.org/survdirect)

# Abstracts

## 1

### **Lessons Learned from Brushes with Death Serious Illness: or, what I wished my team had done....**

**Thomas Smith**<sup>1</sup>

*1. Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, Baltimore, MD, United States*

In this presentation, I will draw on my experience as a medical oncologist and someone dealing with metastatic prostate cancer myself. I have undergone surgery, chemotherapy/androgen deprivation therapy (to lower the testosterone to zero), and “salvage” radiation. Despite this, my prostate cancer has returned and I am co-existing with it until some treatment is absolutely necessary. Complications have included a transient ischemic attack, respiratory failure only somewhat recovered, incessant hot flashes, severe fatigue (for an ultramarathoner), depression and suicidality. While I received very good technical care, I wished that my team had done the following: 1. Anticipated the depression and mood swings, and warned me about it, since I had a long-ago history of depression; 2. Had an algorithm for managing my hot flashes and insomnia; 3. Anticipated osteopenia to prevent bone loss; 4. Paid more attention to my breathing rather than ascribe it to muscle loss from zero testosterone; 5. Inquired about sexual satisfaction and side effects rather than concentrate on the ability to get erections; 6. Asked at every visit, “How are you coping?” and “How is your family coping?”; 7. Before treatment, given me a written list of the top 10 most common side effects, their incidence, and what could be done about them. In my own practice, I have learned to ask “How are you coping?” of the patient at every visit, and then address the family with “How are you coping?” I have learned to use a formal multi-symptom assessment tool like the Edmonton Symptom Assessment System, and to always ask “Are there symptoms that we have not covered?” As a treating oncologist, I recognize that every advanced cancer patient (metastatic disease or symptoms) should be referred to a multidisciplinary palliative care team within eight weeks of diagnosis, per the American Society of Clinical Oncology.

## 2

### **What matters to Aboriginal and Torres Strait Islander people living with and beyond cancer**

**Abbey Diaz**<sup>1</sup>, **Lisa Whop**<sup>2</sup>

*1. Menzies School of Health Research, Charles Darwin University, Brisbane, QLD, Australia*

*2. Australian National University, Canberra, ACT, Australia*

Until recently there was very little known about the epidemiology of cancer for Aboriginal and Torres Strait Islander people. Over the past two decades there has been a critical increase in evidence regarding differences in cancer prevention, screening, diagnosis and treatment, which underpin the persistent gap in five-year cancer survival between Aboriginal and Torres Strait Islander people and other Australians with cancer. This foundational evidence has begun to shift from descriptive work to interventional, implementation, and community outreach work.

Now, as more and more Aboriginal and Torres Strait Islander people are living beyond their cancer treatment and the five-year survival mark, attention is turning towards understanding other health and wellbeing outcomes for Aboriginal and Torres Strait Islander people who have been diagnosed with cancer. Research into cancer survivorship beyond cancer treatment and access to culturally safe and optimal cancer survivorship care for Aboriginal and Torres Strait Islander people is a relatively new field of enquiry. This presentation will provide a snap shot of some of the work that has been done, highlight key prevailing evidence gaps, and draw out some of key findings about what it means to live well with, and beyond, cancer for Aboriginal and Torres Strait Islander people.

## Chemo induced neuropathy (CIN) -- and what can be done about it

### Thomas Smith<sup>1</sup>

1. *Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, Baltimore, MD, United States*

Chemotherapy induced neuropathy has become the dose-limiting factor for a lot of diseases, reducing curability. Up to 40-70% of people will experience it depending on the chemo regimen, and at least 10-20% will have a severe case. About 20% of people will develop CIN *after* the chemo has stopped. CIN always affects the terminal ends of the longest nerves first – usually the soles and toes, and the palms and fingers. Once chemo has stopped, the CIN should reach a plateau and most often slowly improves. It is important to rule out other causes such as diabetes or a low vitamin B12.

There are no proven preventive strategies or drugs yet, although several are in development. Cooling the hands and feet to prevent the drug from getting to the hands and feet has produced very mixed results, and the largest trial showed no difference between cooled and control extremities. Exercise by walking before, during and after chemo therapy may slow its development.

Treatment is more successful for pain than for numbness and tingling (different nerves are involved in each sensation). Duloxetine (Cymbalta) is the only drug with proven efficacy in reducing CIN pain. Gabapentin, pregabalin, nortriptyline and other neuro-active drugs can occasionally be helpful, alone or in combination with low doses of opioids such as oxycodone or morphine. It is essential to trial drugs or combinations for 3 weeks (or maximum tolerance) and if not successful, change strategies. Palliative care professionals can assist in this. Topical 1-2% menthol, cannabidiol (CBD), and baclofen-amitriptyline-ketamine (BAK) gel can all be helpful sometimes.

Other promising forms of treatment include neuromodulation include auricular (ear) acupressure, Scrambler Therapy, and in severe cases, spinal cord stimulation.

## Chemotherapy-induced Neurotoxicity in Cancer Survivors in Australia

### Susanna Park<sup>1</sup>

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

Chemotherapy-induced peripheral neuropathy (CIPN) is a serious consequence of cancer treatment, often resulting in deficits in sensation, function and balance, producing long-lasting disability. However, there remain many gaps in our understanding of CIPN, which limit the ability for prevention, treatment and optimal management. This presentation will address our understanding of the impact of long-term neurotoxicity on cancer survivors. The development of optimal CIPN assessment tools and a neurotoxicity risk profile to guide prevention will be discussed. Strategies to improve assessment, rehabilitation and treatment in clinical practice will be considered in order to redefine how best we can support cancer survivors with CIPN to improve quality of life.

## Finding my feet

### Julie Marker<sup>1</sup>

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

Julie has been 'finding her feet' since peripheral neuropathy (initially debilitating) set in **after** oxaliplatin chemotherapy ceased in 2007. Coupled with 'climbing the mountain of recovery' from a liver resection, frozen shoulder and 'fear of another recurrence'... it's been quite a journey, that's for sure! My quest continues to manage and understand ongoing peripheral neuropathy from a survivors perspective.

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## Survivors and leadership reimagined

### Julie Marker<sup>1</sup>

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

Cancer Voices SA has been nominated as an organisation which makes an outstanding contribution to the care of cancer survivors through diverse and innovative contributions to clinical practice improvement, research, policy and by advocating for cancer survivors perspectives to be incorporated in an ongoing co-design manner. Not bad for a 100% volunteer organisation led by cancer survivors and carers!

Chris Christensen led Cancer Voices SA from 2017 until her death in Oct 2020, and we pay tribute to her contributions which built on the foundations established by Ashleigh Moore from 2007 - 2013. Organisations are more than individual leaders. The sustainability and capacity for maximising consumer involvement across the spectrum of treatment & care, in all aspects of research, policy and practice is still a 'work in progress'. More than 10 years of advocacy and action will be illustrated by our roles as change agents, policy influencers, community mobiliser, co-designers, research collaborators, educators and experts by experience.

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## COVID 19 - and cancer: Clinical considerations

### Yada Kanjanapan<sup>1</sup>

1. *Department of Medical Oncology, Canberra Hospital, Canberra, ACT*

The COVID-19 pandemic has caused significant impact across all disciplines in medicine, including oncology. People with cancer can be vulnerable to serious complications from SARS-CoV-2 infection, due to immunosuppression from their underlying malignancy and/or treatment. The current literature around incidence and severity of COVID-19 in people with cancer, and the impact from cancer therapy is examined. COVID-19 vaccination is an important measure to minimise harm from COVID-19, including in the oncology population.

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## COVID-19: Implications for cancer care

### Vivienne Milch<sup>1</sup>

1. *Cancer Australia, Strawberry Hills, NSW, Australia*

The COVID-19 pandemic has presented many challenges to cancer care in Australia. Cancer Australia has undertaken a number of initiatives to inform and support the cancer community during the pandemic and understand the impact of COVID-19 on cancer care. This presentation will focus on three key initiatives .

- **Understanding the impact of the COVID-19 pandemic on cancer-related services:** Australian oncologists have reported reductions in cancer investigations and treatment procedures during the pandemic. As real time data were difficult to acquire, Cancer Australia used surrogate measures to infer where reductions in medical services occurred. We analysed data available through the Medicare Benefits Schedule (MBS) for 2020 for the five highest incidence cancers: breast, colorectal, lung, prostate, and skin cancers.
- **Embedding high-value changes to cancer care prompted by the pandemic:** The COVID-19 pandemic has prompted unprecedented changes to cancer care across the care pathway. Social distancing and quarantine measures employed in response to the pandemic have challenged the delivery of cancer care and have led to potential delays in cancer diagnosis and treatment, which are likely to impact cancer outcomes. However, the pandemic has also provided opportunities for improvement in quality cancer care. High-value changes in care should be identified and retained to improve resilience of cancer care.

- **Information and communication initiatives on the COVID-19 vaccines and people affected by cancer:** People affected by cancer are more vulnerable to COVID-19 and are at increased risk of severe infection. Cancer Australia has compiled a suite of information on the COVID-19 vaccines for people affected by cancer, including Frequently Asked Questions, health professional guidance, and research articles. This information is being communicated to the cancer community via a multi-faceted information and communications strategy (including dedicated messaging for culturally and linguistically diverse populations) and is being updated regularly as new evidence emerges.

Cancer Australia continues to provide national leadership to address the ongoing and emerging information and support needs of people with cancer, health professionals, researchers, and policymakers in relation to the COVID-19 pandemic and COVID-19 vaccination.

## 10

### COVID-19 and cancer- the patient experience

#### Danielle Spence<sup>1</sup>

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

During the pandemic response in Victoria Cancer Council supported more than 5000 patients and carers who called our 13 11 20 information and support line for assistance with cancer and COVID related inquiries. Many of these inquiries related to complex issues including end of life challenges, financial hardship, loneliness and emotional concerns. As we enter the roadmap to recovery, it is important that we reflect on these experiences to ensure we integrate the consumer voice into new service model designs, such as telehealth and chemotherapy at home, and addresses the variations in care and support identified during the pandemic.

## 11

### Out-of-pocket medical expenses for the common cancers are rising and public patients are faring worse

#### Louisa Gordon<sup>1</sup>, Raymond Chan<sup>3, 2</sup>

1. *Population Health, QIMR Berghofer Medical Research Institute, Herston, Brisbane, Queensland, Australia*

2. *Division of Cancer Services, Princess Alexandra Hospital, Brisbane, Queensland, Australia*

3. *School of Nursing, Queensland University of Technology, Brisbane, Qld, Australia*

**Background:** Patient medical out-of-pocket expenses are thought to be rising in Australia yet data describing trends over time is scant. We evaluated trends of out-of-pocket expenses reported by Medicare for Australians with one of five major cancers in the first-year after diagnosis.

**Methods:** Participants from the QSKIN Sun and Health Study with a histologically confirmed breast, colorectal, lung, melanoma, or prostate cancer diagnosed between 2011 and 2015 were included (n=2,165). Medicare claims data on out-of-pocket expenses were analysed using a two-part model adjusted for year of diagnosis, health insurance status, age and education level. Fisher price and quantity indexes were also calculated to assess prices and volumes separately.

**Results:** On average, patients with cancer diagnosed in 2015 spent 70% more out-of-pocket on direct medical expenses than those diagnosed in 2011. Out-of-pocket expenses increased significantly for patients with breast cancer (mean AU\$2,513 in 2011 to AU\$6,802 in 2015). Out-of-pocket expenses were higher overall for individuals with private health insurance. For prostate cancer, expenses increased for those without private health insurance over time (mean AU\$1,586 in 2011 to AU\$4,748 in 2014) and remained stable for those with private health insurance (AU\$4,397 in 2011 to AU\$5,623 in 2015). There were progressive increases in prices and quantities of medical services for patients with melanoma, breast and lung cancer. For all cancers, prices increased for medicines and doctor attendances but fluctuated for other medical services.

**Conclusion:** Out-of-pocket expenses for patients with cancer have increased substantially over time. Such increases were more pronounced for women with breast cancer and those without private health insurance. Increased out-of-pocket expenses arose from both higher prices and higher volumes of

health services but differ by cancer type. Further efforts to monitor patient out-of-pocket costs and actions to prevent health inequities are required.

## 12

### **The development of a tool assessing the supportive care needs for caregiver's of Aboriginal and Torres Strait Islander cancer survivors**

**Daniel Lindsay<sup>1</sup>, Lorraine Bell<sup>1</sup>, Kate Anderson<sup>1</sup>, Joan Cunningham<sup>1</sup>, Afaf Girgis<sup>2</sup>, Claire Wakefield<sup>2</sup>, Abbey Diaz<sup>1</sup>, Ben Smith<sup>2</sup>, Samar Aoun<sup>3</sup>, Shaouli Shahid<sup>4</sup>, Gail Garvey<sup>1</sup>**

1. Menzies School of Health Research, Brisbane City, QUEENSLAND, Australia

2. University of New South Wales, Sydney

3. La Trobe University, Melbourne

4. Curtin University, Perth

**Background and aim:** A cancer diagnosis has significant impact not only on the survivor themselves, but also their caregiver. Although caregivers commonly assist with illness management and provide other important forms of support for the patient, they are rarely given information, training, or support for this role. This can lead to significant amounts of distress and burden for the caregiver. Understanding the supportive care needs of caregivers of Indigenous cancer survivors is particularly important given Indigenous peoples' poorer cancer outcomes compared to non-Indigenous people. Despite the invaluable roles that caregivers perform, there remains a limited understanding of the supportive care needs of caregivers of Indigenous cancer survivors. Therefore, this study outlines the development of a culturally appropriate tool for assessing the supportive care needs of caregivers for Indigenous cancer survivors.

**Methods:** This tool was developed through focus groups with Indigenous cancer survivors and their caregivers, and brief interviews with experts in Indigenous cancer care. Key themes generated from the focus groups lead to initial item creation. Upon discussion with experts in the area, the items and format of the tool were refined. Final item inclusion and format was again discussed with carers of Indigenous cancer survivors in separate detailed interviews, leading to a tool ready for validation.

**Results:** Through this process, a 29-item tool was developed aiming to measure the supportive care needs for caregivers of Indigenous cancer survivors. Key themes in the tool include accessing support for the caregiver, accessing support for the patient, understanding the healthcare system, and accessing services.

**Conclusions:** Understanding the needs of caregivers for Indigenous cancer survivors is essential in developing focused interventions and allocating resources to support them and in turn support the cancer survivor. The tool must be further validated in order to ensure it is appropriate and useful for practice.

## 13

### **Stigma + discrimination = poorer access to healthcare to minority groups. How do we change the formula?**

**Paul Ward<sup>1</sup>**

1. Flinders University, Adelaide, SA, Australia

Stigma and discrimination are two key reasons why some people/groups feel unable to access appropriate healthcare services. This is inherently unfair. This presentation will explore stigma in the context of cancer and highlight some of the stigmatising processes at play for people with and post cancer. Finally, the presentation will outline the central importance of developing/maintaining healthcare provider-patient trust in order to reduce stigma and improve the equity of access to healthcare services.

## 14

### **The patient perspective**

**Lillian Leigh<sup>1</sup>**

1. Consumer advocate, Artarmon, New South Wales, Australia



For many cancer survivors, clinical trial is not just research, it is access to optimal care. Although the number of clinical trials registered globally have increased over the past 20 years, the number of eligibility criteria has also increased over time. This suggests that trials are becoming less diverse. Barriers such as restrictive eligibility criteria prevent certain categories of people from enrolling in trials. In this presentation, the impact of this lack of diversity will be explored from the consumer's perspective, along with possible solutions to shift the paradigm.

## 17

### **The persuasive case for a new multidisciplinary model of survivorship care for the state of COSAtopia**

**Michael Jefford<sup>1</sup>**

*1. Australian Cancer Survivorship Centre, Peter MacCallum Cancer Centre, Melbourne, VIC, Australia*

The ageing population, increased cancer detection, and improved cancer treatments are all contributing to a growing number of cancer survivors. Australia has excellent cancer survival rates, though the standard of post-treatment survivorship care is suboptimal. Despite regular follow up, survivors frequently report persistent, bothersome symptoms and unmet needs. They often have adverse health behaviours such as poor diet, inactivity, excess alcohol and tobacco use, overweight and obesity. Many survivors of working age struggle to remain in, or return to the workforce, with a major impact on Australia's gross domestic product. The majority of survivors have comorbid illness, which may not be adequately managed. A substantial number of survivors are at risk of serious long-term effects. There are calls, both nationally and internationally, to reform the current model of care. New models of care should be responsive to the needs and concerns of survivors, and also the anticipated risks from treatments. New models need to be more effective, affordable, scalable and sustainable. Interventions have been developed that can effectively manage many common survivorship issues. Lifestyle interventions (for example, to support increased physical activity and healthy diet) can be delivered at scale. These interventions are highly cost-effective. Different models of care (e.g. care that is shared between cancer specialists and general practitioners (GPs), GP-led care, nurse-led care and supported self-management) can be as effective as oncology-led care, are often cheaper, and may afford other benefits. Given the suboptimal outcomes of current care, and the availability of proven, cost-effective interventions, we must work to implement these improved survivorship care models. This will almost certainly lead to reduced symptom burden, reduced unmet needs, improved quality of life, better management of chronic disease, improved work participation, lower costs to individuals, lower health care costs, more efficient use of health resources, and reduction in health disparities.

## 18

### **Health economics of a new multidisciplinary survivorship model of care**

**Louisa Gordon<sup>1</sup>**

*1. QIMR Berghofer Medical Research Institute, Herston, QUEENSLAND, Australia*

Health system costs of cancer are rising fast and in 2019 were estimated at \$8.4 billion in Australia. The number of Australians diagnosed with cancer is rising as the population ages. Nowadays, there are more services, more expensive diagnostics and therapies per person than in previous times. The financial burden on families of having to take time off work and productivity losses to society are also huge as mid-aged Australians are unable to work or return to work quickly after cancer. There is a strong economic case for a new multidisciplinary survivorship care model that integrates GP-care, exercise programs, psychological care and nurse-led initiatives to collectively provide a holistic patient-centred model of coordinated care and best-possible outcomes. A growing body of evidence on the economics of these survivorship programs shows these services are generally low-cost, cost-saving or cost-effective. The evidence consistently shows they provide high-value cancer care. Although a new multidisciplinary survivorship model of care is likely to be a major investment in healthcare resources, funds to pay for the upfront costs can feasibly be sourced from reducing other very low-value services we continue to fund in Australia. This presentation will provide the economic evidence for cancer

survivorship as high-value for cancer survivors and illustrate low-value services where funding can be re-directed from.

## A Systematic Scoping Review of Cancer Survivorship Education Programs for Primary Care Providers

**Andi Agbejule<sup>1</sup>, Raymond Chan<sup>1,2</sup>, Patsy Yates<sup>1</sup>, Jon Emery<sup>3</sup>, Michael Jefford<sup>4,5</sup>, Bogda Koczwara<sup>6</sup>, Nicolas Hart<sup>1,7</sup>, Larissa Nekhlyudov<sup>8</sup>**

1. Queensland University of Technology (QUT), Kelvin Grove, QUEENSLAND, Australia
2. Princess Alexandra Hospital, Metro South Hospital and Health Services, Woolloongabba, Queensland, Australia
3. Centre for Cancer Research and Department of General Practice, University of Melbourne, Melbourne, Victoria, Australia
4. Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia
5. University of Melbourne, Carlton, Victoria, Australia
6. Flinders Medical Centre, Flinders University, Bedford Park, South Australia, Australia
7. Exercise Medicine Research Institute, Edith Cowan University, Perth, Western Australia, Australia
8. Department of Medicine, Brigham and Women's Hospital, Harvard Medical School, Boston, Massachusetts, USA

**Background.** Primary care providers (PCPs) have an important role in addressing the diverse healthcare needs of cancer survivors. This review sought to identify published literature regarding cancer survivorship education programs for PCPs and assess their outcomes.

**Methods.** PubMed, EMBASE and CINAHL databases were searched for entries between January 2005 and July 2020. Included studies had to describe an education program for PCPs, have cancer survivorship as the main topic, and evaluate program outcomes. The Quality of Cancer Survivorship Care Framework and Kirkpatrick's Framework for Training Evaluation were used to summarise program content and outcomes, respectively. Data extraction and critical appraisal were conducted by two authors.

**Results.** Twenty studies were included, describing self-directed online courses (n=4); live webinars (n=1); in-person presentations (n=2); workshops and training sessions (n=6); placement programs (n=2); a fellowship program (n=1); a referral program (n=1); a survivorship conference (n=1); a dual in-person workshop and webinar (n=1); and an in-person seminar and online webinar series (n=1). Most studies had high risk of bias. Eight studies described the use of a learner framework/theory to guide program development (e.g., Adult Learning Theory, Social Cognitive Theory). The most common content covered included communication and decision making (n=18); surveillance and management of physical effects (n=17), and psychosocial effects (n=15). Surveillance and management of chronic conditions was the least common component covered (n=8). All 20 programs were reported to be beneficial to PCP learners (e.g., increased confidence, knowledge, skill, behaviour change). Three studies reported positive outcomes at the patient (i.e., satisfaction with PCP care received) and system-level (i.e., increased screening referrals, changes to institution practice standards).

**Conclusions.** A range of cancer survivorship educational programs for PCPs exist. Evidence for clinical effectiveness (i.e., patient- and system-level outcomes) was rarely reported. Future educational programs should include broader content and examine the patient- and system-level outcomes.

## Implementation of Cancer-Related Fatigue Management Interventions: A Systematic Scoping Review

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**Background.** Cancer-related fatigue (CRF) is one of the most common and distressing symptoms in people with cancer. Whilst efficacy of CRF interventions have been extensively investigated, less has been done to ensure successful translation into routine practice. The objectives of this review were to synthesise knowledge surrounding the implementation of CRF interventions, summarise processes and outcomes of implementation strategies used, and identify opportunities for further research.

**Methods.** PubMed, Cochrane CENTRAL, EMBASE and CINAHL databases were searched. The EPOC Group taxonomy and the RE-AIM Framework were used to guide evaluation of implementation strategies and outcomes, respectively.

**Results.** Six studies were included. Three studies utilised an implementation framework (PARIHS, KTA, Cullens & Adams' Implementation Guide). Implementation strategies used across all studies were reported to have resulted in immediate changes at the clinician level (e.g., increased clinician behaviours, self-efficacy, CRF management knowledge). No relationship was found between the use of implementation models and the number or type of implementation strategies used. For outcomes, Effectiveness and Implementation were the most highly reported RE-AIM measures followed by Reach then Maintenance. Adoption was the least reported.

**Conclusions.** Despite the high prevalence of CRF and evidence-based interventions for managing CRF, there is limited evidence informing intervention implementation. There was an absence of external indicator reporting (e.g., start-up and ongoing intervention costs) in included studies, limiting transability of study findings. Factors such as lack of clinician time, insufficient program funding, and unsustainable maintenance costs, were highlighted as key implementation barriers of CRF programs. This review emphasises the lack of quality CRF implementation studies available in literature, leading to a disconnect between effective CRF interventions, routine clinical care, and cancer survivors at present. Further, this review highlights the need for robust study designs guided by established frameworks to design and evaluate the implementation of CRF interventions in the future.

## Fear of cancer recurrence in Indigenous and minority peoples globally: a systematic review

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**Background:** Between 40-70% of cancer survivors experience an enduring and debilitating fear that their cancer will return. While there has been significant progress made in screening, assessing, and reducing fear of cancer recurrence (FCR), little is known about FCR among Indigenous, ethnic and racial minority cancer populations.

**Objective:** We reviewed the literature (1997-2019) to synthesis the available and relevant published evidence to inform the development and delivery of strategies to improve psychosocial care for Indigenous, ethnic and racial minority groups.

**Methods:** Peer-reviewed, English, original research articles related to FCR in adult cancer survivors from Indigenous, ethnic and racial minority populations were identified from CINAHL, EMBASE, PsychINFO and PubMed. Articles were independently screened for inclusion by two reviewers; a third adjudicated disagreements. Data was extracted and synthesised.

**Results:** Of 304 records retrieved, 19 records were deemed eligible for inclusion. Included articles were heterogeneous in the study population, setting, and measures and methods. Overall, there were 16 studies from the United States, and 1 each from Australia, Canada, and the United Kingdom. Only one study reported on an Indigenous population. FCR prevalence ranged from 14% to 67 and generally Hispanic cancer survivors had higher FCR prevalence and severity than other groups. Meta-synthesis of qualitative study findings revealed six themes related to the lived experience of FCR for Indigenous, ethnic and racial minority populations: (i) variations in the lived experience; (ii) triggers of FCR; (iii) spirituality and worldview impacting on FCR' (iv) the importance of staying positive; (v) complexities around family and community support; (vi) increasing cancer knowledge.

**Conclusion:** This review reveals a lack of FCR for many Indigenous, ethnic and racial minority populations around the world. It also highlights the need for a culturally-specific lens to be used in consideration and measurement of FCR in these groups.

## Rapid response to pandemic restrictions to maintain survivorship programs access for vulnerable rural patients in North-west Victoria

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### **Aims:**

The SARS-CoV-2 pandemic presented an opportunity for Wimmera Health Care Group (WHCG) in Horsham Victoria to expand access options for vulnerable patients to the successful Telehealth Wellness and Cancer Exercise (TWCE). We report on the process and results.

The 8-week Telehealth Wellness and Exercise Program was a funded project by the Victorian Cancer Survivorship Program from 2016-18 with collaboration from Cancer Council Victoria, five regional cancer services and two Integrated Cancer Services. Lifestyle improvements were demonstrated in its evaluation.

The program's previous standard of care included participants completing 1-hour of exercise therapy in 3 Wimmera rural communities combined with a 1-hour telehealth education component shared across all sites. This model caters well for those when cure is not the goal or are on maintenance therapies.

All face-to-face programs were halted due to the pandemic.

### **Method:**

A rapid adaptation to a virtual home-based program using supplied electronic devices with real-time support from the cancer team including an exercise physiologist was trialed using qualitative improvement methodology.

Key implementation barriers were identified and addressed. Most notable were participants' lack of access to or appropriate knowledge of electronic devices. An electronic device loan scheme and documented telehealth support processes have improved patient confidence. Ongoing individual problems require real-time resolution by the cancer team including administration support.

Exercise assessment and prescription preparation was adapted by combining in-home assessment, telephone connection for personal details, and assessment venue relocation in collaboration with medical oncologists and the WHCG COVID risk management committee advice.

### **Results**

This rapid response has improved access for those affected by cancer on maintenance therapies, are older, are geographically or socially isolated, have low digital literacy and/or socio-economic constraints to receive exercise and education via a telehealth platform.

These processes are adaptable for the increasing number of Victorian health services that deliver this program.

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## **Minding the Gap - Revisited: Consumer advocacy leads to the development of much needed cancer related lymphedema services and subsidy in South Australia**

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Cancer Related Lymphoedema is a major concern for many cancer survivors. The Lymphoedema Support Group South Australia Inc. (LSGSA) is the peak consumer led body committed to the promotion of positive health outcomes for the South Australian lymphoedema community through peer support, empowerment and advocacy.

In 2017 cancer related lymphoedema patients in South Australia often fell through the gaps and found themselves in the 'lymphoedema maze'. There was an absence of referral pathways, limited assessment and treatment clinics and no financial support for compression garments. Confusion within the medical fraternity regarding appropriate lymphoedema management procedures meant many consumers were given misinformation and inadequate treatment. Consumers shared this confusion often becoming overly fearful of developing the condition. Many living with it reported feelings of anxiety and depression relating directly to their diagnosis and the lack of treatment options available to them. Over time, their symptoms worsened and associated conditions developed further diminishing their ability to thrive after cancer.

In response to this, the LSGSA endeavoured to plug the gaps and advocate for improved health outcomes for the SA lymphoedema community.

Fast forward four years and South Australian cancer survivors identified as high risk or who develop cancer related lymphoedema are faring better. SA Health launched the first ever SA Compression Garment Subsidy Scheme in July 2020 leading to the expansion and improvements in public lymphoedema services state-wide.

In this presentation we outline the strategies LSGSA took to develop and implement our awareness and advocacy campaign and how it led to change. We show how our consumer group continue to collaborate with key stakeholders. This good news story demonstrates how when consumers harness their unique lived experiences and partner with clinicians, key stakeholders and policy makers, great things can be achieved which can redefine, reimagine and rebuild the lives of cancer survivors.

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## **Developing and piloting a self-guided web-based psychosocial care program for women living with incurable breast cancer: Finding My Way-Advanced.**

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**Introduction:** Women with metastatic breast cancer (MBC) face significant distress and unmet needs, yet few resources have been developed. The current study aimed to develop and evaluate the usability of *Finding My Way-Advanced (FMW-A)*, a web-based self-guided psychosocial program for women with MBC, and to report preliminary findings of feasibility testing.

**Methods:** FMW-A was co-designed through (a) adapting an efficacious online program for people with curatively treated cancer, and (b) receiving iterative rounds of input and feedback from a

multidisciplinary co-design team including consumers, clinicians and academics. A think-aloud protocol was then implemented to test usability of the resulting 6-module prototype, with women living with MBC accessing 1-3 modules with an interviewer sitting along-side. Participants were recruited until saturation of themes occurred. Data were analysed thematically, and identified pragmatic issues addressed prior to feasibility testing via pilot RCT.

**Results:** Usability participants (n=8) were, on average, 65.3 years old, mostly partnered (n=5), retired (n=6), post-secondary school educated (n=6), with non-dependent children (n=7). Feedback fell into 6 themes. *Positive feedback* summarised the supportive and informative nature of the programme, supplemented by comments about broadly *relatable content*. However, one size clearly did not fit all: within themes, diverging experiences emerged regarding *navigability*, *worksheets* and *layout*. Participants noted that *having/making time* would be important to program engagement. Preliminary feasibility data indicates 65% uptake among approached women (N=15 participants). Despite positive feedback, challenges in approach, uptake and adherence have occurred, including health issues (progression, side-effects), low computer/internet confidence, and other life stressors arising.

**Conclusions:** This process highlights the importance of co-design and usability testing, as many pragmatic issues were corrected. The development of FMW-A represents an important step in providing acceptable resources for women with MBC. Preliminary feasibility data highlight the promises and challenges of delivering interventions for MBC, and justifies a phase III RCT.

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### What tools measure Quality of Life in paediatric cancer patients? A scoping review

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**Aims:** The intention of this scoping review was to examine the health-related quality of life (QOL) tools that are being used to capture patient reported outcomes (PRO) in paediatric cancer, during or directly after radiation therapy. The aim was to be able to use this work for future research in the field of patient reported QOL for those undergoing proton radiation therapy in Australia at the soon to be built Australian Bragg Centre for Proton Therapy and Research, in Adelaide South Australia.

**Methods:** A search of six databases was conducted in July and September 2020 to span all published and grey literature. Search terms were formed using the population, intervention and outcome model and correlated with MESH terms. The review method was based on the Joanna Briggs Institute framework using the PRISMA-ScR checklist. Title, abstract and full-text screening was performed by three reviewers and was managed in Covidence software. Following data extraction, main findings were presented in tables.

**Results:** A total of 407 articles were found. After a thorough screening process researchers ended with 27 articles, revealing 37 QOL tools being used in the paediatric oncology setting, some available in digital format. One tool, the PedsQL Core Questionnaire version 4.0 was cited with highest frequency, a total of 18 times. All tools found were used to capture baseline QOL plus at least one other data point for comparison. The most comprehensive tools continued data capture annually at follow up appointments.

**Conclusions:** The use of 37 different tools in both digital and paper format gave insight to the most used. Results showed collaboration between international institutions to be best practice and allowed for a high number of participants in data collection. Future research is needed to evaluate the tools based on their validity and reliability.

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## Medical follow-up after childhood cancer: Are survivors with an increased risk for cardiomyopathy regularly followed-up?

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**Background.** Childhood cancer survivors (CCS) may face various late effects because of cancer treatment. These late effects, especially cardiovascular diseases, can be reduced by prevention or early detection. Thus, evaluating prevention strategies for individuals at high risk of cardiovascular outcome is crucial. The aim of this study was to analyze the medical follow-up of childhood cancer survivors at increased risk for developing a cardiomyopathy.

**Methods.** This study involved 3,599 5-year childhood cancer survivors from the French childhood cancer survivor study (FCCSS) cohort who were treated for solid malignant tumours or lymphoma between 1948 and 2000. Survivors who received  $\geq 250$  mg/m<sup>2</sup> of an anthracycline dose and/or  $\geq 30$  Gy on  $\geq 10\%$  of the volume of the left ventricular were defined as subjects at high risk for developing a cardiomyopathy. Medical follow-up was assessed through completion of an echocardiogram within the five previous years, using administrative database of the French health system. Determinants of medical follow-up included the following factors: long-term follow-up clinic attendance, gender, current age, age at diagnosis, tumour type, treatment characteristics and educational level. Associations of medical follow-up and determinants among survivors at risk of cardiomyopathy were investigated using multivariable logistic regressions.

**Results.** Only 18% of the survivors at risk of cardiomyopathy had an echocardiogram within the five previous years. Survivors at risk who were younger than 40 years and those who did not have a follow-up consultation within the five previous years were more likely to not have an echocardiogram within the five previous years (OR 2.20, 95%CI 1.42 to 3.43 and OR 2.28, 95%CI 1.41 to 3.70), respectively).

**Conclusion.** Only few childhood cancer survivors at risk of cardiomyopathy completed medical follow-up within the previous five years, despite the risk of treatment-related cardiovascular outcome. Long-term follow-up care is needed to inform and prevent at-risk survivors.

## Living with MPN Fatigue

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**Background:** Myeloproliferative neoplasms (MPNs) are rare, chronic haematological cancers. Several studies report fatigue as the most common MPN symptom which leads to a reduction in quality of life. There is limited research into how fatigue affects the lives of people with MPN.

**Aims:** This study aimed to gain insight into the lived experience of fatigue in MPN.

**Methods:** People diagnosed with MPN were invited to complete an online survey and if eligible, express interest in further participation. Online semi-structured interviews and focus groups explored participant's experience of fatigue. Thematic analysis was conducted by two researchers and themes describing the lived experience of fatigue were developed.

**Results:** Twenty-three people with an MPN (Polycythemia Vera =14, Essential Thrombocythemia =3, Myelofibrosis =6) aged 31-76, participated in seven interviews and four focus groups. Results show how fatigue dramatically affected the functional, social/family and emotional wellbeing of participants to the ultimate detriment of their quality of life. Four qualitative themes describing the experience of fatigue in MPN were developed. (1) Life with an MPN explains the lived experience surrounding the diagnosis of an MPN. (2) “It’s not being tired, it’s completely different. It’s fatigue” relates the feeling of fatigue. (3) “It changes your life completely” describes the impact of fatigue on daily lives. (4) Strategies to manage MPN fatigue involves professional advice and self-help approaches tried by participants. These findings highlight the multifactorial nature of fatigue and the absence of information surrounding the experience of it.

**Conclusions:** Fatigue in MPN can affect all aspects of health, wellbeing and general life, yet is seldom addressed by health professionals. This raises issues of awareness and capacity to respond. A greater understanding of fatigue as a symptom of MPN, and its management is urgently needed to help improve patient quality of life.

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### Access to loans after breast cancer

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**PURPOSE:** Cancer treatment can have potentially profound effects on survivors’ quality of life and well-being because of its socioeconomic repercussions. While many studies have investigated impact on employment and income, very few research has investigated access to loans after cancer. This study aimed to describe difficulties that breast cancer survivors encountered when attempting to obtain loans after cancer and to analyze both clinical and social determinants related to a breast cancer (BC) survivor’s access to loans in France.

**METHODS:** We used a French prospective clinical cohort of patients with stage I-III breast cancer including 9,730 women recruited from 26 medical centers. Our outcome was reporting difficulties in accessing loan-related insurance 2 years post diagnosis, which is a required step to access loans in France. A difficulty was if a participant reported a premium related to their health status or an outright refusal of loan-related insurance.

Independent variables included treatment characteristics as well as toxicities (Common Toxicity Criteria Adverse Events [CTCAE] v4) and pre-diagnosed comorbid medical conditions (Charlson comorbidity index). Socioeconomic covariates included working status, socio-professional category, professional situation, and monthly household income.

Logistic regression models assessed correlates of loan access, adjusting for age, stage, pre-diagnosis comorbidities, and socioeconomic covariates.

**RESULTS:** Two years after diagnosis, 32% of women reported difficulties obtaining loan-related insurance. Half reported higher premiums (52%) while the other half were outright refused due to their medical history of having had BC (48%). After adjusting on socioeconomic covariates and pre-diagnosis comorbidities, women reporting any grade >3 toxicity related to treatment were more likely to report difficulties in accessing loans 2 years after diagnosis (OR= 1.80, CI=1.02-3.13).

**CONCLUSION:** The impact of cancer treatment and its physical toxicities can have adverse effects that impair survivors’ well-being in various ways.

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## **Perturbation in the Renin Angiotensin Pathway is Associated with Cancer-Related Cognitive Impairment**

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### **Background:**

Cancer-related cognitive impairment (CRCI) occurs in 30% patients prior to and 75% patients during chemotherapy. For approximately 35% of patients, CRCI can persist for months or years after treatment. It is postulated that a complex network of pathogenic mechanisms work synergistically to promote neuronal apoptosis and the subsequent clinical manifestations of CRCI. Findings from pre-clinical and clinical studies suggest associations between cognitive impairment in patients with Alzheimer's Disease and changes in renin angiotensin system (RAS). In this study, we hypothesized that CRCI may be associated with RAS-related mechanisms and evaluated for differentially expressed genes and perturbation in the RAS pathway in patients with and without CRCI.

### **Methods:**

This longitudinal study included patients with breast, gastrointestinal, gynaecological, and lung cancer receiving chemotherapy. Patients completed assessment of CRCI in the week prior to their second or third cycle of chemotherapy. Severity of CRCI was evaluated using the Attentional Function Index (i.e., no CRCI = score >7.5, CRCI = score <5.0). Univariate and multiple logistic regression analyses were used to determine significant covariates for inclusion in the differential expression (DE) analysis. DE analyses were performed in two independent samples using RNA-sequencing (Sample 1, n=185) and microarray (Sample 2, n=158) methodologies. Fisher's combined probability test was used to determine significant differentially expressed genes and perturbed pathways between the two CRCI groups across both samples.

### **Results:**

CRCI was reported by 49.2% of the patients in S1 and 49.4% in S2. Across the two samples, the RAS pathway was found to be perturbed ( $FWER=0.0067$ ) between patients with and without CRCI.

### **Conclusions:**

This study is the first to suggest that perturbations in the RAS pathway is associated with CRCI in patients undergoing chemotherapy. Centrally-acting angiotensin-converting enzyme inhibitors or angiotensin receptor blockers may be promising low-cost therapeutic options for preventing CRCI that warrant future investigations.

## **The Importance of Hope and Healing in Rehabilitation of Cancer Survivors.**

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### **Objective:**

An in-depth exploration of the lived experiences of cancer survivors during specialist inpatient rehabilitation programs, in preparation for return to life at home.

### **Methods:**

Using semi-structured interviews, 22 cancer survivors aged between 51-87 years were interviewed on admission to and discharge from inpatient rehabilitation programs. Analysis of their lived experiences of cancer and survival used an Interpretative Phenomenological Analysis framework.

### **Results:**

Within the overall scope of the individual's cancer narrative, major parts of the sub-theme of them 'Looking forward' to their future life included 'Healing self' and 'Rising hope' as well their positive expectations of the rehabilitation program itself.

It is now well recognized that exercise and the physical aspects of rehabilitation are very powerful factors in enhancing cancer survivorship. Our sample of cancer survivors found just as much value in

the psychosocial and emotional support provided by other members of the multi-disciplinary rehabilitation team, as survivors came to grips with the immense challenges that cancer-related helplessness posed to their self-identity.

#### **Conclusion:**

Understanding concurrent psychological distress and growth in cancer survivors is an essential component that underlines the importance of holistic rehabilitation that supports healing of body, mind and spirit, as individuals seek to resume life in community after cancer treatments.

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## **Defining research priorities for cancer survivorship in Australia**

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**Background:** Cancer survivorship research seeks to improve the health and wellbeing of cancer survivors and those providing care to survivors. It also seeks to ensure efficient and sustainable models of survivorship care. Advances in cancer survivorship care require the identification and prioritisation of research needs. Australia has major strengths in cancer survivorship research, and we must leverage these to foster cutting-edge research that translates into widespread policy and practice changes in the future.

**Aim:** To establish expert consensus on the key priorities for cancer survivorship research in Australia.

**Methods:** A two-round modified online Delphi consensus process will be utilised with 82 experts in cancer survivorship that included leaders in research and clinical care, together with representatives from community, advocacy and consumer groups. An initial 77 research priority items were generated based on international literature. These were categorised into five research domains according to the NCI Office of Cancer Survivorship Research Framework: physiological outcomes, psychosocial outcomes, population groups, health services, and infrastructure. Expert consensus for the top priorities

within each category will be achieved iteratively through two online survey rounds: item consolidation and then selection of the final most important research priorities.

*Results:* Data collection for the first round of the Delphi is currently underway. Data analysis of the round 1 survey is expected to be completed in December 2020, with data collection and analysis of the round 2 survey completed in January 2021. Final results will be presented at the scientific meeting.

*Conclusions:* Results from this study will define cancer survivorship research priorities, to support coordinated action among researchers, funding bodies, and other key stakeholders, ultimately optimising the excellence, relevance, and impact of cancer survivorship research in Australia.

## The Use of Domain Experts in Addressing Frequently Asked Questions relevant to Implementing a Shared-Care Model between Cancer Specialists and Primary Care Providers

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### Background:

The barriers to implementing shared-care models for post-treatment cancer follow-up are well documented. These may include the lack of clearly defined roles for each care provider, lack of awareness about the benefits of a shared-care model, and preconceptions about if and how follow-up care should be arranged or conducted. Here we describe the development of short videos of domain experts addressing frequently asked questions (FAQs) relevant to the implementation of shared-care in cancer.

### Methods:

A list of 45 health professional concerns about shared-care model implementation were documented by the QUT Cancer Survivorship Research Team during the consultation with the multi-disciplinary teams at sites enrolled to participate in the IBIS Breast Cancer Survivorship Study - an NHMRC-funded implementation study (APP1170519). The concerns were grouped by professional disciplines (breast surgeons, medical oncologists, radiation oncologists, general practitioners, and specialist nurses) and ordered by frequency. Through consensus among the QUT Cancer Survivorship Research Team and consultation with the domain experts, the top 10 most relevant FAQs were determined.

Six domain experts in the fields of breast surgery, medical oncology, general practice, and cancer nursing were invited to record their responses to the FAQs. They were provided with brief suggested responses to the FAQs but were also encouraged to incorporate their own knowledge and experience of cancer survivorship shared-care into their responses. The video responses were recorded in person or via videoconference to accommodate COVID-19 restrictions, where necessary. Post-production video-editing was supported by Primary Care Collaborative Cancer Clinical Trials Group (PC4).

### Results and Conclusion

Video responses to 10 FAQs regarding cancer survivorship shared-care have been developed and are hosted on the IBIS Breast Cancer Survivorship Study website. These videos have the potential to have a positive influence towards uptake of the shared-care model in breast cancer survivorship.

## **Empowering older adults with cancer to be partners in treatment decisions. The Older and Wiser project.**

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### **Introduction**

In Australia, the risk of having a diagnosis of cancer increases with age. For some older adults a cancer diagnosis can complicate existing health issues.

Information resources specifically for older adults affected by cancer are limited, impacting awareness of what functional, psycho-social or clinical co-morbidities people should share with their treating team to inform person centred treatment decision-making.

The Older and Wiser project will deliver novel co-designed resources for older adults to promote wellbeing and survivorship outcomes.

### **Methodology**

Utilising co-design methodology the project has worked closely with older patients and carers.

Six focus groups with older people, advocacy groups and expert stakeholders have been undertaken to understand the experiences and health information needs of older adults, and a suite of prioritised co-designed resources developed.

### **Results**

Focus group data has provided rich insight into the experience of being an older Australian diagnosed with and having treatment for cancer.

Consumer facing resources that empower older adults have been co-produced. During this presentation two of the key resources will be discussed:

- The *This is me* resource facilitates older people to share information about their co-morbidities, functional ability, emotional wellbeing and personal preferences with their treating team, to prompt geriatric assessment.
- The *Asking questions and making decisions* resource offers advice and strategies for open conversations with the cancer team about treatment decisions, so that personal goals and values can be shared and together good decisions for each individual can be made.

The Older and Wiser resources will be housed in the *WeCan* ([www.wecan.org.au](http://www.wecan.org.au)) supportive care website.

### **Conclusion**

Co-design methodology has enabled production of health information resources informed by the experiences of older people with cancer. These resources address a current gap in informational support for older people affected by cancer.

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## **The utility of screening tools for the initial screening for chemotherapy induced peripheral neuropathy**

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**Aims:** Chemotherapy induced peripheral neuropathy (CIPN) is a disabling condition associated with a poor quality of life. Given that assessment is lengthy and not routinely done for all patients, screening tools could provide an efficient and cost-effective method for early detection of CIPN. The aim of this review was to examine the utility of screening tools for CIPN and to assess their psychometric properties.

**Methods:** A search was conducted on Medline, ProQuest, Scopus and Cochrane for papers written in the last 15 years, examining screening tools for CIPN in adult patients undergoing neurotoxic chemotherapy. Psychometric properties (discrimination, sensitivity, specificity and reliability) were the outcomes of interest. Randomized controlled trials, case-series and cross-sectional studies written in

the English language were included. Two reviewers screened studies based on title and abstract before full text screening and data extraction. Any discrepancies were resolved by consensus.

**Results:** After removing duplicates, 2649 studies were identified with 6 cross sectional studies meeting the eligibility criteria. Adult patients undergoing neurotoxic chemotherapies with colorectal cancer, testicular cancer, multiple myeloma and others were included. Screening tools included: sEMG, mTNS, DN 4, SCIN, ICPNQ, peripheral sensory neuropathy item from NCI-CTCAE v4.03, symptom severity item from numbness and tingling section of PRO-CTCAE and a pilot screening tool. Good discrimination was reported with SCIN, PSRI-NCI-CTCAE, SSINT-PRO-CTCAE, mTNS and ICPNQ. SCIN was also found to have good reliability. Studies found high sensitivity in DN4, mTNS and sEMG with DN4 showing high specificity as well. Moderate to high correlation between screening tools (PSRI - NCI-CTCAE, SSINT-PRO-CTCAE, PST) and assessment tools (TNSr, FACT-GOG/Ntx) was reported.

**Conclusion:** All screening tools have shown good psychometric properties. Further research regarding their acceptability in the clinical context is required. Comparison studies to choose the ideal screening tool and discussion regarding severity cut-off scores for further evaluation are also needed.

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### **Adverse cardiovascular events after cancer for Indigenous, ethnic and minority populations: a systematic review**

**Abbey Diaz<sup>1</sup>, Rachael Jaenke<sup>1</sup>, Gail Garvey<sup>1</sup>, Alana Gall<sup>1</sup>, Joanne Shaw<sup>2</sup>, Doan Ngo<sup>3</sup>, Joan Cunningham<sup>1</sup>, Lisa Whop<sup>4</sup>, Brian Kelly<sup>3</sup>, Aaron Sverdllov<sup>3</sup>**

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Publish consent withheld

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### **Return to work after breast cancer: the role of working conditions**

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**Background:** One-third of breast cancer patients is younger than 55 years old at time of diagnosis. Employment issues among BC survivors are therefore a major challenge. The aim of this study was to understand the impact of work environment on return-to-work (RTW) after breast cancer diagnosis.

**Methods:** CANTO is a French multicenter prospective cohort study including patients with stage I-III breast cancer treated in 26 centers. We used data from 3,004 patients enrolled in 26 centers who were professionally active and under age 57 at diagnosis. Detailed working conditions were collected at diagnosis and RTW was collected 2 years post-diagnosis. Working conditions included information on type of contract, size of the firm, working hours, strenuous work conditions, employer's accommodation, supportive environment (measured by perceived support from colleagues and/or supervisor), control over the work situation, and perception of work. Logistic regression models evaluated the impact of pre-diagnosis working conditions on return to work (RTW). Models were adjusted for stage and treatment, socioeconomic characteristics, pre-diagnosis health status and health status at the end of treatment,

using the common toxicity criteria adverse events (CTCAE) scale and patient reported outcomes (PROs): EORTC QLQ-BR23 and QLQ-FA12, and the Hospital Anxiety and Depression Scale.

**Results:** Overall, 21% of survivors had not returned to work 2 years post-diagnosis. In the multivariate models, odds of RTW were reduced among women who had more invasive local treatments, combination of systemic treatments, who reported severe physical toxicities, arm morbidity or depression and those who had a manual work. Working conditions significantly related to RTW after taking into account those factors included shifting working hours, working in a non-supportive environment and perceiving one's job as boring.

**Conclusion:** This study brings a comprehensive overview of factors related to RTW and highlights the need to develop intervention targeting colleagues and supervisors of survivors.

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### Mapping the service needs and access for people with head and neck cancer across the recovery phase of care: utilising journey mapping to understand healthcare needs in order to address service barriers

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**BACKGROUND.** People with head and neck cancer (HNC) have significant healthcare needs following treatment and require access to multidisciplinary services well into the recovery phases of care. The pathways and models of care that patients may traverse are often complex and circuitous, with additional barriers in rural areas. The study aim was to map the healthcare service needs of people with HNC from metropolitan and regional/rural areas in order to understand service access and needs.

**METHODS.** Longitudinal cohort study (using a mixed-methodology) tracking people with HNC across the initial 6-months of post-acute care. Data collected included appointment records from state-wide public hospital electronic health service booking systems, patient appointment diaries and monthly phone-calls to patients discussing service needs. Results are presented as individual journey maps.

**RESULTS.** 11 patients had their recovery services mapped which highlighted the complexity of care for this patient cohort. A total of 22 different medical and allied health services were needed during the recovery phase. Metropolitan participants had an average of 21.6 health service appointments (range of 9-35) whereas regional/remote participants had an average of 57.3 appointments (range of 35-108). Metropolitan participants saw an average of 7 health professionals each (range of 5-9) whereas regional/remote participants saw an average of 15 (range of 10-18) with greater fragmentation of care.

**CONCLUSIONS.** This is the first known reported study to track and map the service needs of people with HNC across a 6-month recovery trajectory with a focus on differences by rurality. Considerable differences in total services accessed existed between the metropolitan and regional/rural patients, with regional/remote patients requiring more appointments, travelling greater distances for treatment, seeing multiple service providers and reporting greater burden in accessing services.

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### Factors beyond diagnosis and treatment that are associated with return to work in Australian cancer survivors - a systematic review

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### **Aims**

There is known variability in outcomes for cancer survivors. Return to work (RTW) is a marker of functional recovery for working-age cancer survivors. Little is known about factors that facilitate or hinder RTW following cancer diagnosis within the Australian context.

The aim of this systematic review was to identify non-treatment, non-cancer related variables impacting RTW in Australia.

### **Methods**

A systematic search was conducted in EMBASE, PsycINFO, CINAHL, PubMed and Google Scholar in September 2020. Keywords describing 'cancer survivor' were combined with keywords describing 'return to work'. Studies were eligible if they (1) included adults living post diagnosis of malignancy; (2) included quantitative data related to non-treatment, non-cancer related variables impacting on RTW; (3) included only Australian participants; (4) were written in English.

### **Results**

Six studies were eligible. Studies were of variable quality and mixed methodology. All were published within the last 12 years. One study included malignancies of any type with the remainder focussing on survivors of colorectal cancer, oropharyngeal cancer and glioblastoma multiforme. Three studies were single institution studies from Victoria and New South Wales, the remainder were state-wide studies from Queensland. The number of included participants ranged from 19 to 975.

Factors found to be statistically significant predictors of work cessation included older age, fewer work hours pre-morbidly, lower BMI, excessive sleep at 6 months post diagnosis and not having private health insurance. There was limited consistency in findings between studies. Multiple other variables were examined including: number of comorbidities, personal income insurance, occupation type, household income, healthy lifestyle behaviours, flexibility and duration of employment with workplace, however no statistically significant associations with RTW were reported.

### **Conclusions**

Further study is required to establish factors that influence RTW in cancer survivors in Australia.

## **Perceived roles of general practice team members in the delivery of cancer survivorship care: An interpretive qualitative study**

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### **Background**

The importance of cancer survivorship care in primary care is well recognised. Primary care providers are well positioned to integrate cancer survivorship care into ongoing health management in the community. However, understanding of the actual role of the general practice team in providing cancer survivorship care is limited.

### **Aim**

The aim of this study was to explore general practice team members' perspectives of their roles in the delivery of survivorship care, to understand whether there is agreement regarding roles, and determine

whether work is needed to establish a level of agreement regarding the optimal roles of general practice team members.

### Methods

An interpretive qualitative study using a social constructivist framework was utilised. Data were collected via semi-structured, in-depth telephone interviews guided by study aims and previous research. General practice team members were recruited through professional networks, including the Primary Care Collaborative Cancer Clinical Trials Group. Data were recorded, transcribed and analysed using grounded theory methods.

### Results

General practitioners (n=10), practice nurses (n=9) and practice managers (n=5) from 20 metropolitan and regional general practices across Queensland, New South Wales and Victoria were interviewed. Variation was evident in individual general practice team members' perceptions of the needs of cancer survivors; in perceptions of individual scopes of practice; and in perceptions of the professional knowledge and skills of individual team members. A lack of clarity in the roles and responsibilities of general practice team members within and between practices was thought to contribute to a lack of consistency in survivorship care.

### Conclusions

Findings from this study highlight key areas of variation. Future work might seek to clarify roles and responsibilities, and training requirements to establish a level of agreement regarding the optimal roles of general practice team members, as well as promote effective teamwork, aiming to support improved cancer survivorship care.

## Fear of cancer recurrence among Aboriginal and Torres Strait Islander women diagnosed with breast cancer

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**Background:** Little is known about fear of cancer recurrence (FCR) among Aboriginal and Torres Strait Islander cancer survivors and it is unclear whether existing programs and interventions aimed at reducing FCR are appropriate and effective for Aboriginal and Torres Strait Islander people. This project aimed to quantify levels of FCR among Aboriginal and Torres Strait Islander women diagnosed with breast cancer, and gain an understanding of their experiences and coping strategies.

**Methods:** To assess levels of FCR, Aboriginal and Torres Strait Islander breast cancer survivors were invited to complete the Fear of Cancer Recurrence Inventory, which includes subscales of triggers, severity, psychological distress, coping strategies, functioning impairments, insight, and reassurance. Total FCR score and sub-scale scores will be calculated. Logistic regression will be used to identify sociodemographic and clinical factors associated with FCR. Women completing the survey were invited to participate in an interview about their experiences of FCR, and its impact on their daily life and as well as their coping strategies. Qualitative data will be analysed thematically.

**Anticipated results and outcomes:** The results of the FCR survey will provide vital information about FCR levels among Aboriginal and Torres Strait Islander women. Qualitative interviews will reveal critical information about how women with low FCR scores cope. It is anticipated that themes such as trusting relationships with health care providers, the importance of family and kinship networks, and coping strategies emphasizing expression of cultural identity will emerge as important coping strategies for FCR among Aboriginal and Torres Strait Islander women diagnosed with breast cancer. Both the survey outcomes and qualitative data will provide priority areas for the development of culturally-appropriate programs and interventions for women experiencing high FCR.

**Conclusions:** This project is the first to assess FCR among Aboriginal and Torres Strait Islander breast cancer survivors. By obtaining a greater understanding of FCR, this study will identify important barriers



and enablers in providing better care for this population. Results can inform the development of effective and appropriate supportive care interventions for Aboriginal and Torres Strait Islander women diagnosed with breast cancer.

### **Measurement burden in a study of cancer related cognitive impairment. Views of patients with newly diagnosed aggressive lymphoma.**

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**Aims:** Cancer-related cognitive impairment (CRCI) is a recognised adverse consequence of cancer and its treatment that can occur in up to 75% of patients. For some patients their cognitive impairment may be transient, but for a subgroup these symptoms can be long-standing and have a major impact on quality of life and ability to function. One aim of this prospective longitudinal study of cognition in patients with newly diagnosed aggressive lymphoma, is to explore acceptability of a comprehensive, multi-faceted cognition assessment during treatment and recovery.

**Methods:** Thirty participants recruited to the longitudinal study will complete repeated measures of cognition including self-report, neuropsychological assessment, blood cell-based inflammatory markers, and brain imaging including PET/CT and MRI. To explore acceptability of the neuropsychological assessment and self-report measures in a population for whom there is no reported data, the first five participants enrolled have completed a face-to-face burden interview one week after completion of the baseline assessments.

**Results:** Recruitment is complete and data collection is ongoing. Of the five participants who have completed the burden interview, one thought components of the self-report measures were repetitive, one found the assessment tiring, one felt that completion time took longer than expected and three found specific neuropsychological tests difficult. No participants suggested changes to the measures.

**Conclusions:** These findings indicate the requirement to complete a comprehensive and challenging suite of cognition assessments are acceptable to people with newly diagnosed aggressive lymphoma within the context of a clinical study. These data will determine the feasibility of collecting assessments for cognitive function in patients during treatment and recovery and will add to an underexplored area of cancer survivorship research.

### **Cost-effectiveness analysis from a randomized controlled trial of tailored exercise prescription for women with breast cancer with 8-year follow up**

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**Background:** Physical activity is advocated by cancer organizations to reduce the impacts of symptoms and side-effects from cancer and its treatment. Evidence is emerging that physical activity also reduces breast cancer mortality and events, and all-cause mortality. However, less information is available on whether exercise interventions for women with breast cancer are cost-effective and this study filled this gap.

**Methods:** We undertook a Markov cohort model and modelled women with early stage breast cancer over their remaining lifetime. The measure of benefit used was quality-adjusted life years (QALYs), a generic metric that combines survival with quality of life, commonly used for economic evaluations. Costs and QALYs were aggregated in yearly cycles and compared across the exercise intervention and usual care groups. Data inputs were obtained from the 8-year *Exercise for Health* randomized controlled trial, supplemented with epidemiological, quality of life and healthcare cost studies. Outcomes were calculated from 5000 Monte Carlo simulations, and one-way and probabilistic sensitivity analyses.

**Results:** Over the cohort's remaining life, the incremental cost for the exercise versus usual care groups was \$7,409 and quality-adjusted life years (QALYs) gained were 0.35 resulting in an incremental cost per QALY ratio of AU\$21,247 (95% Uncertainty Interval (UI): Dominant, AU\$31,398). The likelihood that the exercise intervention was cost-effective at acceptable levels was 93.0%. The incremental cost per life year gained was AU\$8,894 (95% UI Dominant, AU\$11,769) with a 99.4% probability of being cost effective. Findings were most sensitive to the probability of recurrence in the exercise and usual care groups, followed by out-of-pocket expenses and the model starting age.

**Conclusion:** This exercise intervention for women after early-stage breast cancer is cost-effective and would be a sound investment of healthcare resources. Investing in prevention through prescribed regular exercise in this population should be a priority for cancer service providers.

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**Targeted and modular multimodal exercise is safe for advanced prostate and breast cancer patients with stable sclerotic and osteolytic bone metastases.**

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**Background:** Bone is the most common location for metastatic prostate and breast carcinomas, with skeletal lesions identified in >80% of patients in the advanced stages, dysregulating bone metabolism in favour of excess mineralisation (sclerotic) or porosity (osteolytic). Preclinical studies demonstrate mechanical load may suppress tumour growth and promote skeletal preservation at metastatic bone sites [1]. The safety of a mechanical loading program in human patients with bone metastases has yet to be established [2,3].

**Methods:** 40 men with prostate cancer and sclerotic bone metastases, and 40 women with breast cancer and osteolytic bone metastases were recruited. All patients had structurally stable bone disease as per Taneichi [4] and Mirels [5]. Supervised exercise was provided three days per week (for 12 weeks) at an exercise clinic with accredited exercise physiologists, consisting of resistance and high-intensity

aerobic training that avoided bone lesion sites, additional to targeted isometric exercise focusing on spinal lesion sites [2,3]. A further two home-based isometric sessions were provided after two weeks. Safety was assessed using CTCAE criteria.

**Results:** 36 prostate cancer (90%) and 32 breast cancer patients (80%) completed the full exercise program. Withdrawn patients were due to changes in cancer treatment (9/12), or significant treatment toxicities (3/12) while on-study. Median 5.5 skeletal lesions per patient (range: 1 to 16), with a high overall bone metastatic burden (552 lesions in 80 patients). There were no skeletal adverse events (vertebral compressions, increases in bone pain, or fragility fractures), and no serious adverse events attributable to exercise. 9 minor adverse events (Grade  $\leq 2$ ; shoulder bursitis and knee pain) were reported but were aggravations of pre-existing conditions only.

**Conclusion:** Supervised and targeted mechanical loading of sclerotic and osteolytic spinal metastases within a modular multi-modal exercise program (otherwise avoiding lesion sites) is safe and feasible for advanced prostate and breast cancer patients.

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### ***A novel online intervention to promote childhood cancer survivors' health-related self-efficacy***

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#### **Aim:**

Childhood cancer survivors develop on average, 17 chronic health conditions by age 50, with 5 graded as "severe-life threatening". Survivors face challenges managing their complex healthcare needs and seeking support when needed. There is an urgent need for interventions that engage childhood cancer survivors, provide clinical care, and increase health-related self-efficacy. We aimed to evaluate 'Engage': a patient-centric, distance-delivered intervention to improve survivors' confidence managing their care.

#### **Method:**

We invited long-term survivors of childhood cancer to participate in Engage, which includes a: i) clinical nurse consultant-led teleconsult guided by a digital triage tool to establish survivors' medical history and health needs, ii) review of survivors' care needs by a multidisciplinary team, and iii) a second nurse-led teleconsult to provide education and health behaviour counselling, and to provide a written letter to the survivor and their general practitioner containing personalised risk-based care recommendations based on the Children's Oncology Group survivorship guidelines. We measured survivors' self-efficacy (confidence managing their survivorship care), health-related quality of life (HRQoL), and satisfaction with care at baseline, 1- and 6-months post-intervention.

#### **Results:**

To date, we have recruited 39 survivors (56% male, mean age=30 years). Survivors had most commonly been diagnosed with Leukaemia (48.7%) or Lymphoma (25.6%). At 6-months post-intervention, survivors reported improvements in health-related self-efficacy (77%) and HRQoL (50%), compared to baseline. Survivors' composite self-efficacy scores significantly increased 6-months post-

intervention ( $t_{12}=-3.959, p=.002$ ). Survivors' HRQoL was significantly higher 6-months post-intervention ( $t_{13}=-2.584, p=.023$ ). Survivors reported an increase in satisfaction with cancer-related care after participating in the intervention (59% vs 100%).

**Conclusions:**

Early data suggest that the intervention may improve survivors' self-efficacy, HRQoL and satisfaction with cancer survivorship care. This distance-delivered program may provide childhood cancer survivors with the critical education and empowerment needed to advocate for, and manage, their complex healthcare needs throughout their long-term cancer survivorship journey.

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## Co-design of a nurse-led clinical intervention to reduce cardiovascular disease in cancer patients and survivors

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**Aims:** Many cancers share risk factors with cardiovascular disease (CVD), and treatments for common cancers, including breast, prostate, and haematological cancers, can substantially increase CVD risk. However, little is known regarding preferred models of care to address these risks. This study reports on an umbrella review and co-design process to develop a nurse-led clinical intervention to manage CVD risks in people with cancer.

**Methods:** A systematic umbrella review of interventions to manage CVD in cancer was combined with stakeholder consultation (focus groups and individual interviews) with consumers, health professionals, and non-government organisation representatives, to inform a nurse-led clinical pathway for management of CVD.

**Results:** The most consistent evidence found in included reviews/meta-analyses ( $n=14$ ) was for pharmaceutical and exercise interventions; however, little information was provided on the 'who and how' of implementation to inform a model of care. Our stakeholder consultation included consumers, and health professionals across oncology, haematology, cardiology, general practice, and non-government services ( $n=47$  participants). Most consumers experienced a lack of awareness/discussion of CVD risks associated with cancer and treatment, while health professionals identified the need for effective clinical pathways to address these risks. Stakeholder views on the roles of treating oncologists/haematologists and GPs varied; some saw CVD management for people with cancer as core business for these professionals, while others considered it outside of scope of practice/ expertise, or impractical due to time limitations. Most preferred a specialist cardiologist to manage existing CVD, but preferred other professionals for early education, assessment, and risk management. General support was found for a specialist nurse to perform these roles using a three-tiered assessment and management model.

**Conclusions:** We found limited review-level evidence for effective models of care for the management of CVD risk in cancer; although stakeholders favoured nurse-led models. Further research is needed to investigate implementation and effectiveness of interventions to evaluate and monitor the risk of cardiotoxicity from cancer treatment.

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## Identifying predictors of digital engagement for people with cancer living with socioeconomic disadvantage: an interim analysis

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**Background:** Digital health approaches have potential to improve cancer survivor outcomes. However, people living with socioeconomic disadvantage are impacted by disparities in digital access/inclusion and digital health literacy. Therefore, disparities in care experienced by these groups may persist despite digital health implementation, or may be exacerbated by them. This paper reports an interim analysis of a mixed methods study aiming to use the eHealth Literacy Framework (Kayser et al. 2018) to determine ways in which health care engagement via digital health applications can be better supported for people with cancer living in socioeconomically disadvantaged circumstances.

**Methods:** Surveys assessing demographic characteristics, eHealth literacy, and self-report measures of user engagement and satisfaction with digital health technologies were distributed to people with cancer of any type via clinicians at a tertiary cancer centre. Associations between demographic characteristics, digital literacy and digital engagement were examined using analysis of correlations and differences between groups. Follow-up qualitative telephone interviews investigating the interaction of these factors in depth were analysed using thematic analysis.

**Results:** Quantitative analysis (N=47) indicated moderate digital health engagement (45% once per week or more), but no significant association between demographic characteristics and frequency, duration or perceived helpfulness of engagement. While some eHealth Literacy domains were associated with digital health engagement indices, eHealth Literacy was not associated with demographic factors pertaining to socioeconomic disadvantage. Initial qualitative interviews (N= 7) indicated education/experience facilitated digital health engagement. Financial disadvantage in a limited number of participants impacted negatively on access to updated technologies.

**Conclusions:** Interim analysis suggests socioeconomic disadvantage can impact digital health engagement for people with cancer, but highlights challenges of recruiting participants living with socioeconomic disparity and suggests that factors precluding digital engagement may also discourage research participation. Future research in this area requires innovative targeted recruitment to facilitate better representation of socioeconomically disadvantaged groups.

## Development and evaluation of cancer survivorship focussed webinars

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### Background

There are broad calls for discipline-specific, flexible educational programs in cancer survivorship. In 2020, the Australian Cancer Survivorship Centre (ACSC) collaborated with a number of professional organisations including the Clinical Oncology Society of Australia (COSA) to deliver survivorship webinars for i) primary care professionals (PCP): general practitioners and primary care nurses, and ii) allied health (AH) professionals.

### Methods

ACSC and partners jointly researched target groups' educational requirements; developed learning objectives; tailored content, scripts for expert panellists; developed resource lists and used targeted promotional communications. Each webinar was a facilitated panel discussion, using case studies and intra-webinar polling questions. Post-webinar evaluation assessed perceived webinar relevance and quality and asked about areas for future education.

### Results

Webinar registrations totalled 239 (PCP) and 545 (AH), attendance rates 49% (117/239) and 59% (322/545) respectively. Primarily GPs (45%, 52/117) and physiotherapists / exercise physiologists (39%, 127/322) attended the PCP and AH webinars respectively. 35% (41/117) of PCP and 28% (90/322) AH attendees completed post-webinar evaluations. 98% (PCP 40/41; AH 88/90) rated the

webinars very good or excellent; content as extremely or very relevant. 93% (38/43) PCP, 88% (79/90) AH were extremely or very likely to use webinar information in practice. 81% (32/41) indicated learning needs as entirely met (PCP). Polling revealed 100% (65/65) agreed or strongly agreed survivorship care is important in their role (PCP). Both audiences indicated the most valuable learnings focussed on understanding: the benefits of multidisciplinary care; common survivorship issues and needs and their management; evidence-based resources and shared-care models. Proposed education topics included: i) palliative care within survivorship, ii) complex survivorship issues, iii) AH discipline-specific webinars. ACSC and partnering organisations perceived careful planning and joint communications were critical to success.

#### Conclusions

The webinars were well attended. Attendees rated content and their own learning, highly. Organisational partnerships support success.

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### Intermediate-high risk and high risk endometrial cancer: exploring the existing model of follow-up

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Background Follow-up (FU) for women with intermediate-high risk and high risk endometrial cancer remains intensive, medically led, lasts five years or more, based on the assumption that early recurrence detection could lead to improved survival. We aimed to assess the current patterns of care in FU. Methods A retrospective case audit was conducted of women referred for adjuvant radiation treatment between 2004 and 2014, who subsequently recurred. Results were analysed using descriptive statistics. Results Of the 786 women referred, 19% (150/786) subsequently recurred, 123 met eligibility criteria. Prior to recurrence detection, 95% (117/123) remained in active FU. Most (63%, 74/118) had 2 or more pre-existing comorbidities, 9% (11/118) had documented lifestyle discussions addressing these pre-treatment. Radiation-specific toxicities effected bladder (6%, 8/123), bowel (7%, 9/123) and vagina (4%, 5/123). Eleven percent (14/123) developed lymphoedema. Other than pelvic insufficiency fracture (3%, 4/123), no grade 3 or 4 toxicities were experienced. Documented holistic approaches to FU were scarce: 16% (20/123) of notes contained references to emotional status; 12% (15/123) to exercise recommendations. Notes for 7 women documented nursing consultation. Most recurrence (87%, 107/123) occurred less than 3 years post-primary treatment, 59% (73/123) was multifocal. Most recurrence (70%, 86/123) was symptomatic, pain being the main symptom (56%, 68/123). More than half (59%, 73/123) were detected by the treating clinician in response to symptoms, 46% (56/123) at scheduled FU. Two years after treatment for recurrence, a third (31%, 38/123) remained alive, 15% (18/123) with no evidence of disease. Of these, 11 were alive for more than 4 years. Conclusion Benefits of traditional intense FU require re-consideration. Twenty percent experienced recurrence, more than half detected outside of scheduled FU. Customising FU and including a focus on women's post-treatment experiences is recommended. Better understanding women's experiences post-treatment is needed to inform approaches to care.

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### Clinician and cancer survivors' feedback and preferences regarding the content and implementation of a digital tool to identify and manage cardiovascular disease (CVD) risk in older cancer survivors

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**Introduction:** Guidelines recommend cancer survivorship care includes CVD risk identification, surveillance and management given shared risk factors and cardiotoxic anti-cancer treatment increases risk. However, CVD risk remains under-diagnosed and under-managed.

**Aim:** To examine the needs, gaps and preferences of cancer care clinicians (CCCs) and older cancer survivors from Flinders Medical Centre (FMC) to inform the development of a digital tool to optimise and systematise the identification and management of CVD risk in older cancer survivors.

**Methods:** Convenience sampling was used to identify and recruit nine CCCs to participate in a semi-structured online focus group. Using established networks, up to five more CCCs, and ten cancer survivors will be recruited to participate in separate focus groups or interviews to be implemented in December, 2020. Participants' perceptions, knowledge and experiences will allow for the emergence of relevant and important needs, gaps and preferences to inform tool development. Qualitative data collected from all focus groups and interviews will be analysed collectively using thematic analysis, and findings will inform the development of a wireframe of the digital tool.

**Results:** Preliminary analysis of data collected from the first focus group identified: (a) confirmation of need for a coordinated and timely approach to CVD risk identification and management; (b) barriers to tool administration, including time and competing priorities for patients and clinicians; (c) lack of consensus regarding who should administer the tool, e.g. GP, nurse, cardiologist or specialist; and (d) preferences for tool: digital, accessible to patient, and facilitates seamless transition to evidence-based, location- and health service-specific recommendations for further cardiology assessment and/or risk management including pharmacological and behaviour-change interventions.

**Conclusion:** This study represents the first part of a participatory and iterative research program to develop, refine and test the usability of the digital tool to improve patient and health system outcomes in cancer.

## Impact of comorbidities on survival and physical functioning of middle-aged (50 – 64 years) cancer patients

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**Background:** Comorbidities are common in a geriatric oncology population and they increase the risk for treatment toxicity, mortality and functional impairment. There is limited evidence on the importance of comorbidities in patients who are younger than 65 years. We investigated if comorbidity predicts mortality and functional impairment in middle-aged cancer patients (50-64 years).

**Methods:** A prospective cohort study. Data were collected at baseline and five years follow-up. Outcomes were mortality and functional impairment (Katz Index and Lawton IADL-scale, impairment on  $\geq 1$  domain). Comorbidity was defined as 0, 1-2, +3 chronic conditions (adjusted Charlson comorbidity index). We also assessed polypharmacy ( $\geq 5$  drugs) as surrogate for comorbidity. Multivariate Cox-proportional hazards and binary logit models were used to assess the risk of 5-year mortality and functional impairment respectively.

**Results:** We included 481 middle-aged (<65) and 563 older (65+) cancer patients. The majority were women (68%). The prevalence of comorbidity – in addition to cancer – was 29% for middle-aged and 45% for older patients, with polypharmacy observed in 15% and 31% of middle-aged and older patients respectively.

Presence of  $\geq 3$  comorbidities more than doubled the risk for mortality in middle-aged patients (HR 2.9, 95% CI: 1.4-6.0). In older patients the HR was 1.7 (95% CI 1.1-2.8). Polypharmacy also significantly increased the risk for mortality in middle-aged (HR 2.4, 95% CI 1.4- 4.2) but not in older patients (HR 1.2, 95% CI 0.9-1.8). Presence of  $\geq 3$  comorbidities did not significantly predict functional impairment in neither of the groups. Polypharmacy quadrupled the risk for functional impairment in middle-aged (OR 4.0, 95% CI 1.6-10.1) as well as older patients (OR 4.4, 95% CI 1.6-11.7).

**Conclusion:** Comorbidity and polypharmacy are associated with inferior outcomes in younger as well as older cancer patients. Assessment and management of comorbidity and its impact should be incorporated into routine cancer care.

## Living with and beyond metastatic non-small cell lung cancer – the survivorship experience for people treated with immunotherapy or targeted therapy

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**Introduction:** Immunotherapy (IT) and targeted therapy (TT) have improved survival for a subgroup of people with metastatic non-small cell lung cancer (mNSCLC). However, their lived experience is understudied. We conducted a single centre, qualitative study to understand concerns and supportive care needs of this novel survivor population.

**Methods:** Eligible participants had mNSCLC, aged >18, English speaking and >6 months post initiation of IT/TT without progressive disease. Semi-structured interviews were conducted focusing on physical, psychological, social and functional impacts of diagnosis, therapy and prognosis. Purposeful sampling was conducted and recruitment continued until data saturation. Interviews were recorded and transcribed. Data was analysed via qualitative thematic analysis.

**Results:** Between May-December 2019, 20 participants were interviewed; median age 62 (range 34-83), 13 (65%) female; median time since diagnosis of metastatic NSCLC 27 months (range 10-108). 12/20 (60%) participants had tumours with a targetable mutation (EGFR/ALK/BRAF); 6 were receiving IT, 11 TT, 2 IT + chemotherapy, 1 IT + TT.

The main themes were: living long-term on IT and TT with chronic toxicities (cutaneous, gastrointestinal, fatigue); psychological concerns (living with uncertainty, fear of cancer progression, scan-related anxiety) and coping strategies (living in the present, practising self-care, early discussions with their treating team regarding future treatment options, accessing psychological support); stigma around smoking; support with practical issues (financial planning and employment in the setting of prognostic uncertainty, challenges with clinical trial participation) and wanting information pertinent to their lung cancer subtype and treatment (including internet resources and support groups).

**Conclusions:** Longer-term survivors of mNSCLC report substantial physical, psychological, and functional concerns and unmet needs. They may benefit from information regarding long-term toxicities, tailored psychological supports, and information regarding return to work and financial planning. These results will inform a broader cross-sectional survey and resources to address the needs of this growing survivor group.

## A qualitative exploration of the psychosocial outcomes of cancer survivors with advanced colorectal cancer



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**Aims.** Approximately 18% of colorectal cancer (CRC) diagnoses are advanced cancer, and 30-40% of people with CRC develop recurrent disease after treatment with curative intent. Recent surgical treatments (e.g., cytoreductive surgery and hypothermic intraperitoneal chemotherapy (CRS-HIPEC), and pelvic exenteration) enable longer survival for people with advanced CRC. Yet, virtually no qualitative research has explored the experiences and perspectives of these survivors. This study therefore aims to explore the different needs and views of survivorship care of people who received these treatments for advanced CRC.

**Methods.** Adult survivors of CRC are being recruited 0.5-2 years post-surgery from a major Australian public tertiary referral hospital. N=20-40 survivors who have undergone pelvic exenteration or CRS-HIPEC will be recruited. Participant demographic and clinical data are being collected from the hospital's electronic medical records. All participants will complete the Functional Assessment of Cancer Therapy – Colorectal (FACT-C), Distress Thermometer, and Comprehensive Score for Financial Toxicity (COST) questionnaires, with scores undergoing descriptive analysis, and participate in a qualitative semi-structured telephone interview, analysed via the framework approach.

**Results.** Preliminary analysis of seventeen interviews (n=9 CRS-HIPEC, n=8 pelvic exenteration) reveals some advanced CRC survivors report post-surgical complications and chemotherapy-induced peripheral neuropathy, which can limit physical activity. Participants reportedly manage these through distraction, positive reframing, and contact with other CRC survivors. Most participants appeared satisfied with their cancer treatment teams. Some viewed their GPs as important coordinators in their health care. CRC survivors reported being more cautious about leaving the house due to COVID-19, and view the change to telehealth as less personal; however, rural/regional participants prefer telehealth's convenience.

**Conclusions.** The study findings will help guide development of interventions to improve the survivorship experience of patients with advanced CRC who receive pelvic exenteration and CRS-HIPEC treatment. This may include an information booklet, patient-reported outcome measure, clinical pathway, or targeted intervention.

## **Psychosocial and quality of life outcomes in colorectal cancer survivors: A systematic review of qualitative research**

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**Aims.** Colorectal cancer (CRC) is the third most common cancer worldwide. Five-year survival rates for CRC are approximately 70%. Synthesis of qualitative research into CRC survivorship is limited. Further, limited research has explored the differences in survivorship experiences between people with early-stage and advanced CRC. This paper aims to fill these gaps through a systematic review (PROSPERO CRD42019131576) and thematic synthesis of qualitative CRC survivorship research.

**Methods.** CINAHL, Embase, MEDLINE, PsycINFO, and PubMed were searched for qualitative CRC survivorship papers. Articles with CRC survivors of any stage were included, except patients at the end of life. Titles, abstracts, and full texts were screened. Included articles underwent data extraction, CASP qualitative bias ratings, and thematic synthesis.

**Results.** 81 articles were included in the final review. CASP quality ratings ranged 5-10 out of 10 (mean = 8.7). Most studies (n=40) included patients treated with curative intent, versus for advanced cancers (stage IV, Dukes' D, recurrent, or metastatic) (n=11), and 30 had mixed or unclear staging. Thematic synthesis revealed that bowel dysfunction caused functional limitations and negative quality of life (QoL), while stomas posed threats to body image and confidence. Physical symptoms made return to work challenging, which increased financial burdens. Survivors' unmet needs included desires for: information provision regarding symptom expectations and management, and ongoing support throughout follow-up and recovery. Advanced and early-stage survivors shared similar experiences, however advanced survivors reported struggling more with fear of cancer recurrence/progression and feelings of powerlessness. Functional limitations, financial impacts, and sexuality in advanced survivors were under-explored areas.

**Conclusions.** CRC and its treatments impact survivors' QoL in all areas. A co-ordinated supportive care response is required to address survivors' unmet needs. Future qualitative studies should explore advanced CRC subpopulations, treatment-specific impacts on QoL, and long-term (>5 years) impacts on CRC survivors.

## How do we define and measure optimal care for cancer survivors? An online modified reactive Delphi study

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### Background and Aims

There is a recognised need to improve care for the growing cancer survivor population. To achieve this, it is essential that we first define key components and outcomes of optimal survivorship care. This study aimed to develop consensus-based quality criteria for cancer survivorship care.

### Methods

This was an online modified reactive Delphi study conducted over two rounds. Participants were Australian and international, and included consumers, multidisciplinary healthcare providers, researchers, policymakers, and quality and accreditation staff. Statements describing quality criteria for the Round 1 (R1) survey were based on an international literature review, and presented in three domains: policy, process and outcomes. In R1, participants were asked to rate the importance of each of 68 criteria on a five-point scale, and could make comments and suggest additions. Demographic data was also collected. Quantitative data were analysed according to pre-determined scoring thresholds and results used to develop the Round 2 (R2) survey. In R2, participants ranked their 10 most important items within each domain.

### Results

Response rates were 79% (70/89) and 84% (76/91) for R1 and R2. Most participants were based in Australia, and most were healthcare providers, consumers or researchers. Following R1, six criteria were removed, six were added, and 18 criteria were revised based on free-text comments. Following R2, 30 quality criteria were retained. These included presence of a policy for the provision of survivorship care, having processes for the assessment of emotional, psychological and physical

effects and provision of services to manage issues, a process for stratification to different models of care, and collecting data on patient-reported outcomes, including quality of life, and survival rates.

#### Conclusions

We developed a set of quality criteria that may be used to measure the quality of cancer survivorship care and to benchmark across settings.

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## Compare the pair - experiences of two childhood leukaemia survivors in Queensland

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### Background

Each year in Australia around 1,200 children and adolescents under 18 years receive a cancer diagnosis with almost 84% surviving. Four of every five childhood cancer survivors live with at least one long-term health problem because of cancer and/or its treatment. These late effects can be physical, psychological, or social and all are a source of significant distress which may persist for the rest of their lives, preventing attainment of full life potential. Survivorship programs support young cancer patients to live their best lives, but for many, access to this care is limited with less than 20% of childhood cancer survivors enrolled in survivorship care in Queensland.

### Method:

This case study compares the cancer survivorship journey for two young girls diagnosed with leukaemia before their 3<sup>rd</sup> birthday. Both received similar multi-agent chemotherapy and cranial irradiation. Now adults, both survivors report significant late effects including neurocognitive dysfunction, endocrinopathies and gastrointestinal disturbances. One survivor was referred to the After-Cancer Therapy program at Children's Health Queensland as a child and the other was discharged from Oncology care at age 14 years and referred to the program over 20 years later as an adult.

### Results

This presentation exemplifies the vast difference in survivorship outcomes for these two cancer patients. The survivor who received early intervention reports substantially less anxiety and feeling more in control of health outcomes compared to the survivor who was referred later to the program. This highlights how early intervention with a survivorship care program is pivotal and key to guiding survivors to recognise, manage and adapt to their new normal.

### Discussion

Assess to survivorship care needs to be improved in Queensland so more young cancer survivors can live their best lives.

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## Stepping responses in cancer survivors with chemotherapy-induced peripheral neuropathy

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### Aims

Chemotherapy-induced peripheral neuropathy (CIPN) is a common and debilitating condition reported to affect 30% of cancer survivors<sup>1</sup>. Despite evidence that CIPN-related neuromuscular and sensory impairments<sup>2</sup> often translate into balance and mobility deficits as well as increased risk of falling<sup>3</sup>, the effects of CIPN on stepping, a well-documented risk factor for falls<sup>4</sup>, are unclear. This study investigated

the relationship of choice-stepping reaction time (CSRT) test performance with objective and patient-related outcomes of CIPN, in cancer survivors with CIPN.

### Methods

Forty-one participants (mean±SD age: 60.8±9.7 years; 34 women) who were ≥3months chemotherapy, with NCI-CTCAE grade 2 CIPN performed two tests of simple and inhibitory CSRT<sup>4</sup>. Peripheral neuropathy severity was confirmed with the Total Neuropathy Scale. Patient-reported outcomes were assessed with the 20-item European Organization for Research and Treatment of Cancer Quality of Life Questionnaire in CIPN Questionnaire scale (EORTC QLQ-CIPN20). Spearman bivariate correlations and Chi-Square tests were computed.

### Results

Mean (± SD) total stepping response times in the simple CSRT (1160±190ms) and the inhibitory CSRT (1191±164ms) were not associated with the Total Neuropathy Scale score (range: 3-14), patient-reported toes and feet tingling and/or numbness or total EORTC QLQ-CIPN20 scale scores (range: 9-74) (all  $p>0.05$ ) but were positively correlated with self-reported increasing difficulty feeling the ground (CSRT:  $\rho=0.41$ ,  $p=0.008$ ; iCSRT:  $\rho=0.46$ ,  $p=0.004$ ). After controlling for age, participants with lower limb vibration sensation deficit had slower and more variable CSRT movement times ( $F=4.32$ ,  $p=0.044$  and  $F=12.73$ ,  $p=0.001$ , respectively) and a larger proportion of these participants made at least one error in the inhibitory CSRT ( $X^2=5.23$ ,  $p=0.022$ ).

### Conclusions

Objective and patient-related outcomes of CIPN were positively correlated with slow stepping performances in cognitively-challenging tests predictive of falls among cancer survivors with CIPN. Effective exercise interventions are urgently needed to counter the detrimental impact of CIPN on balance and fall risk in cancer survivors.

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## Top 10 cancer survivorship research priorities in primary care

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The role of primary care in cancer survivorship is an important and growing area of research. The Primary Care Collaborative Cancer Clinical Trials Group (PC4) is funded by Cancer Australia to support the development of new cancer in primary care clinical trials. To inform our future research direction, we undertook a prioritisation study to identify the top ten primary care research priorities for cancer survivorship.

We conducted a literature review to identify existing priorities, as well as a stakeholder survey including GPs, practice nurses, cancer survivors, and researchers. The combined results were reviewed by our Scientific Committee and working groups were established to further refine the top ten priorities in each area of the cancer continuum. This was achieved using a consensus approach and a weighted question scoring system to rank priorities.

In total, 96 survivorship priorities were identified. Sixty-seven priorities were identified in the literature and an additional 29 through the survey. The survey received 58 responses with most respondents located in Victoria (43.1%) and New South Wales (32.8%). Over a quarter of respondents were academic researchers, followed by state government employees (22.4%), and consumers (15.5%). Over 50% highlighted survivorship as their speciality area or area of interest, and over half indicated at least 10 years of experience within their field of interest. The final ten priorities covered models of care, transition of care, needs of populations with poorer outcomes, behaviour change, comorbidity, assessment of physical and psychosocial needs, use of routine data, symptom management, and strategies to detect recurrence or new cancers.

This study identified ten key cancer in primary care survivorship research priorities. Moving forward these priorities will be ranked in a second national survey. Overall, these results will inform the development of new trials to improve outcomes for cancer survivors in Australia.

## An audit of current survivorship research in Australia

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**Aim:** To undertake an audit of current cancer survivorship research activities within Australia and identify research gaps and challenges.

**Methods:** An online survey was completed by Australian researchers and clinicians regarding their survivorship research, perceived gaps, and barriers to conducting research. Participants were identified as: (i) presenters at national survivorship-focussed scientific meetings; (ii) chief investigator of relevant Australian grants; (iii) principal investigator of relevant trials registered on the Australian New Zealand Clinical Trials Registry; and (iv) first authors of peer-reviewed publications obtained through a focussed PubMed search.

**Results:** Of 178 respondents (25% response rate), majority were primarily researchers (54.5%), clinicians (15.2%), or both (20.2%). Disciplines were predominated by psychology / behavioural science (21.9%), epidemiology / public health / biostatistics (17.4%), and allied health (16.9%). Respondents' survivorship research focused on all types of cancers (17.9%) followed by breast (14.3%) and colorectal (8.9%). Adult populations were the most frequently researched age cohort (55.4%), followed by the elderly (14.2%). Respondents' survivorship research infrequently focused on populations who are rurally located (8.7%), of low socioeconomic status (5.4%), culturally and linguistically diverse (5.0%), Indigenous (3.5%), sexual and gender minority groups (1.9%) or those with a disability (1.7%). Survey and qualitative research designs were the most common methodologies (14.4% each), followed by observational studies (11.7%) and clinical trials (10.9%). Respondents less commonly used epidemiological (7.4%), pre-clinical (3.3%), or dissemination research designs (1.3%). The most cited barriers to conducting survivorship research were lack of funding (49.6%), networking and collaboration (11.9%), mentoring (8.5%), time (7.3%) and training (5.4%). Infrastructure-related challenges to survivorship research, reported in free text, included adequate coordination of research, adequate funding and access to population-based data.

**Conclusion:** These preliminary data can inform a strategic approach to survivorship research in Australia. Results from the study may contribute towards an online directory of survivorship research and researchers.

## **Implementation and evaluation of a nurse-allied health clinic for patients after allogeneic haematopoietic stem cell transplantation**

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### **Introduction**

Patients who undergo haematopoietic stem cell transplantation (HSCT) often have multiple health issues following discharge. In many centres, outpatient follow up is solely conducted by specialist physicians. We aimed to implement and describe the outcomes of a nurse-allied health multidisciplinary clinic.

### **Methods**

The clinic consisted of six disciplines - nursing, pharmacy, dietetics, physiotherapy, occupational therapy and social work. All allogeneic HSCT patients were reviewed at two weeks after discharge and on day 100 post allogeneic HSCT, with additional reviews as needed. Occasions of service, interventions, readmission data and physician satisfaction survey were collected prior to and after

implementation. Additionally, patient feedback and quality of life survey (FACT-BMT) were collected during the first six months.

#### Results

From July to December 2019, 57 patients were reviewed in the clinic (475 reviews, average 8.3 reviews per patient). Common interventions included; nurse education (n=22), diet prescription (n=103), counselling by social worker (n=53), exercise programs by physiotherapist (n=111), medication lists provision (n=51) and fatigue management (n=43). The clinic did not reduce patients' readmission rate, however positive feedback from patients and physicians were reported. FACT-BMT results demonstrated that there are unmet needs, particularly fatigue management, sexual education and support, body images, back to work support and quality of life improvement.

#### Conclusions

This clinic provides an innovative approach to patient-centred care. It has been well received by patients who were supported by multidisciplinary interventions.

## Revision and evaluation of a free online cancer survivorship educational resource for health professionals

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#### Aims

The Australian Cancer Survivorship Centre (ACSC) developed and launched a free online educational course for health professionals in 2014 (<https://education.eviq.org.au/courses/supportive-care/cancer-survivorship>). In 2020, ACSC sought to: 1) review, update and re-design the existing six-module course; and 2) evaluate users' perceptions of and experiences with the updated course.

#### Methods

Course content was revised based on updated published data, and reviewed by several multidisciplinary health professionals (from Australia and internationally) and consumers. Presentation was modified in consultation with design/user experts, aiming to be engaging and support flexible learning.

An evaluation survey was embedded at the end of each module using Survey Monkey. The survey evaluated usability, knowledge and confidence providing survivorship care. Results were analysed using descriptive statistics.

#### Results

Positive feedback was received from 10 content reviewers and incorporated into module content. There were no major concerns regarding missing or inaccurate content.

To date (November 2020), 59 evaluation surveys have been completed. The majority of respondents are oncology nurses (16/59) and allied health professionals (14/59). Other respondents include nurses (other), researchers and project staff.

Respondents were satisfied or very satisfied with the length of the modules, 95% (56/59), the logical flow of module topics, 98% (58/59), module content 93% (55/59) and the look and feel of the course, 97% (57/59).

On a whole of course assessment, 95% (56/59) rated the course as either 4 or 5 (on a 1 = poor through to 5 = excellent scale). 98% (58/59) of respondents would recommend the course to colleagues.

98% (58/59) reported an increase in their knowledge after completing the module content, and 97% (57/59) reported an increase in their confidence providing survivorship care.

#### Conclusions

ACSC's revised online survivorship course is highly rated by health professionals. Participants self-report improved knowledge and confidence providing survivorship care after completing the course.

Data collection is ongoing.

## A systematic review of telehealth platforms for delivering supportive care remotely to adults with primary brain tumour and family caregivers

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**Aims:** Individuals with brain tumour and their family caregivers often face geographical, transport, financial and health-related barriers to accessing clinic-based supportive care. This systematic review aimed to evaluate the feasibility, acceptability and efficacy of supportive care interventions delivered remotely via telehealth platforms to adults with primary brain tumour and family caregivers.

**Methods:** Following registration with the International Prospective Register of Systematic Reviews, six databases (PsycINFO, MEDLINE, CINAHL, Embase, Scopus & Cochrane CENTRAL) were systematically searched from 1980 to June 2020. Eligible studies reported on feasibility, acceptability, efficacy and/or implementation outcomes of supportive care interventions involving technology for remote delivery from the perspective of people with brain tumour and/or family caregivers. Methodological quality of each study was assessed by two independent raters.

**Results:** The search yielded 17 articles that reported on 16 studies evaluating telephone ( $n = 5$ ), videoconferencing ( $n = 3$ ), web-based ( $n = 7$ ), and combined videoconferencing and web-based ( $n = 1$ ) interventions to deliver supportive care remotely. Approximately one third (31%) involved caregivers. Rates of accrual ( $M = 68\%$ ) and adherence ( $M = 74\%$ ) were typically moderate, whereas acceptability for those completing the interventions was typically high ( $M = 81\%$  satisfied). Notably, levels of adherence were generally higher and clinical gains were more evident for supportive care interventions involving real-time or synchronous communication with professionals as opposed to self-guided interventions with asynchronous communication.

**Conclusions:** This review highlighted that delivery of supportive care via telehealth platforms is feasible and acceptable to a high proportion of individuals with primary brain tumour and family caregivers. Implementation studies addressing factors influencing the uptake and sustainability of telehealth platforms in practice are recommended in future research.

## Incidence of Cardiovascular Risk Factors and Cardiovascular Disease after Allogeneic Haematopoietic Stem Cell Transplantation

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### Introduction

Cardiovascular disease (CVD) is one of the leading causes of morbidity and mortality in long term survivors of Allogeneic stem cell transplant (ASCT), likely due to a combination of therapy-related and modifiable cardiovascular risk factors (CVRFs). The echocardiographic markers of future risk of CVD in this population are not well characterised.

### Objectives

To describe the incidence of CVRFs and CVDs in patients attending our ASCT long-term follow-up (LTFU) clinic. Further, to identify patients 'at-risk' of developing clinical heart failure based on echocardiographic features, and to describe the incidence of modifiable CVRF in these patients.

### Methods

This was a retrospective study of 47 LTFU patients, 10 years post ASCT, with a minimum of 4 attendances at clinic. Data was collected using our LTFU clinic database and a review of patient medical records.

### Results



Therapy-related CVRFs included previous anthracycline exposure, previous radiotherapy, and TBI conditioning, with a prevalence of 70.2%, 10.6% and 29.8% respectively. There was a high prevalence of modifiable CVRFs, including hypertension (55.3%), diabetes (6.4%), dyslipidaemia (97.9%), obesity (42.6%), smoking history (51.1%), premature menopause (55.0%), and androgen insufficiency (7.4%). The overall incidence of one or more CVDs post ASCT was 17.0%, compared to an incidence of 5.6% in the Australian population. These included coronary artery disease (4.3%), atrial fibrillation (4.3%), cardiomyopathy (6.4%), pericarditis (2.1%), pulmonary embolus (8.5%) and deep vein thrombosis (8.5%).

Echocardiographic data collected identified an additional 13 patients (27.7%) at risk of developing clinical heart failure. Among these 13 patients, there was an average of 3.8 modifiable CVRFs.

### Conclusions

These results highlight a high incidence of CVRFs among ASCT survivors, and a consequent high incidence of CVD. Our institutional strategy of surveillance echocardiography at regular intervals post-ASCT is supported through the identification of individuals with evidence of subclinical cardiac dysfunction at risk of future symptomatic heart disease.

## Conventional Supportive Cancer Care Service Mapping in Australia Study (The CIA Study)

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**Background.** Cancer and its treatment produce significant acute- and long-term adverse effects in cancer survivors, resulting in a range of supportive cancer care (SCC) needs across the disease trajectory. To enhance SCC in Australia, this study sought to understand and describe conventional SCC interventions offered nationwide, specific to their structure (ownership, setting, duration), process (participants, delivery mode, referral pathways) and outcomes (evaluation).

**Methods.** A researcher-designed, electronic survey was distributed to 265 cancer organisations across Australia between August 2019 and April 2020. Cancer organisations were invited to participate if they provided at least one cancer-directed treatment (i.e. surgery, radiation therapy or systemic therapies); or clinical cancer care to adults, adolescents or children; or conventional SCC interventions to cancer survivors.

**Results.** The response rate was 46% (n=123/265), with 72% of cancer organisations (n=88) delivering at least one SCC intervention. Most SCC interventions were provided as outpatient/inpatient services, with few delivered at home (<13%) or via telehealth (<10%). Psychological therapy (90%), self-care (82%), exercise (77%), healthy eating (69%) and lymphoedema (69%) interventions were most common. Less common were interventions for fatigue, cognition, employment interference and sleep quality. SCC interventions were mostly provided by allied health, followed by nurses and students. Conventional SCC interventions were mostly offered to cancer survivors on treatment (88-100%) with availability reducing post-treatment (25-56%). Conventional SCC interventions were often evaluated through patient surveys (29-72%) and written feedback (12-32%).

**Conclusion.** Provision of supportive care to cancer survivors continues to evolve in Australia. Future policy and service planning efforts should focus on enhancing access to conventional SCC interventions addressing fatigue, cognition, employment interference and sleep quality. Online resources and telemedicine were underrepresented modalities and should be further explored for feasibility, efficacy

and implementation. Future research should focus on the implementation strategies of SCC interventions across modes of delivery and settings.

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### ***‘It’s costing me as much to treat the side-effects as the cancer’*: Findings from focus group discussions about the costs of cancer care**

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**Background:** While the contribution supportive care services make to financial toxicity of cancer care have been documented, how survivors’ experience these costs and their impact on care decisions is less well understood. Using data from a series of focus groups assessing costs of cancer care, this study examines survivors’ experiences of costs post their acute care and examines how costs impact on care decisions.

**Method:** Seven focus groups (four metropolitan, 3 regional) and three telephone interviews with cancer survivors (n=31) and two focus groups (one metropolitan) and one interview with carers of cancer patients (n=8). Participants had a mix of cancer diagnoses and treatment pathways. Transcripts were analysed for common themes.

**Results:** A range of post treatment costs were discussed including: allied health services to assist with physical and mental rehabilitation, dietary supplements and lymphoedema management. While the benefits of different allied health services was acknowledged, the cumulative cost was a barrier: *“your health insurance only pay \$250 a year [for physiotherapy]. These people charge \$150 a time!”*

Chronic-health care plans and mental-health care plans assisted to subsidise the cost of some services, yet the remaining out-of-pockets costs still made ongoing use problematic. Wound dressings were unexpected costs with information about financial support for this area of care missing *‘dressings were going to cost me \$100 a week, which is a huge expense’*. While stoma and incontinence products were subsidised, costs could add up over time particularly if products were needed long term.

In contrast to the situation for acute care, costs influenced survivorship care decisions *‘the physio keeps texting you ‘how come you haven’t been?’, well I can’t afford it, that’s why..’*

**Conclusions:** Costs of cancer care extend into survivorship. Current funding mechanisms may be ill equipped to provide affordable and accessible survivorship care.

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### **Current knowledge on educational participation in childhood cancer survivorship: A systematic review of the literature**

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**Aims:** Long term socioeconomic and late effects of cancer during childhood are known, yet the links with educational participation are not well understood. This systematic literature review had four aims:

- Synthesise empirical findings from studies on educational participation of children diagnosed with cancer at primary school age,
- Identify implications for practice and policy at the intersection of school, home, and clinic,
- Highlight methodological challenges and propose a comprehensive theoretical framework for future research.

**Methods:** This review implemented PRISMA guidelines. International databases for psychology, education, nursing, medical and social science were searched (i.e. CINAHL, Education Database,

Embase, ERIC, PsycInfo/APA PsycNet, Science Direct, Scopus, Sociological Abstracts, Web of Science). Inclusion criteria were: published 2000-2019 in English language, focus on educational participation after childhood cancer diagnosis at age 5-12, empirical work with relevance for practice and policy.

**Results:** 74 publications were extracted. Recommendations for practice and policy focus on improving: (1) quality of teaching and learning away from school (n=24); (2) student-centeredness (n=23), (3) home, school and hospital partnership (n=38), (4) social connectedness by building teacher and peer acceptance (n=36), (5) psychosocial support upon school re-entry (n=18); (6) resources and funding (n=12); advocacy (n=12). Methodological challenges included small sample sizes, hyper-diverse (e.g. cancer diagnoses), or developmentally insensitive sample compositions (e.g. large age brackets). Empirical findings often remained descriptive in nature. Where findings were theorised, the theoretical models rarely took developmental trajectories embedded in social context into account.

**Conclusion:** Primary school-aged children diagnosed with cancer have complex needs affecting their education crossing interdisciplinary boundaries. A life course lens is uniquely appropriate to conceptualise the long-term impacts of childhood cancer on transitions from childhood to adolescence and adulthood, and educational and occupational trajectories. Longitudinal studies utilising qualitative and quantitative designs have potential for better linking observed educational outcomes to educational participation.

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### Consumer involvement in and impact on the development of a core outcome set for cancer survivorship

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#### Background

Public or consumer involvement in research refers to the active inclusion of patients, carers, service users, and/or other relevant stakeholders in the research process. This adds a depth of knowledge that can ground research in the reality of lived experience, resulting in improved outcomes for those affected by the research. Consumer involvement in cancer survivorship research is critical to ensure that interventions, health services, systems, and policy are aligned with the needs and priorities of cancer survivors.

#### Methods

We conducted a multistage consensus study to develop a core outcome set for cancer survivorship and a key feature of this study was its emphasis on consumer involvement and co-design. Applying the *NIHR Research Design Service guide for patient and public involvement in health and social care research*, we mapped specific examples of consumer input at different stages of the research process (study design, research proposal, undertaking and managing, analysis and interpretation, monitoring and evaluation) to demonstrate its impact on the quality and credibility of the study.

#### Results

Embedding consumer involvement throughout the research process led to a study co-design that prioritized the perspective of cancer survivors, improved the relevance of the research to cancer survivors, facilitated recruitment and provided access to networks, ensured that the interpretation of findings reflected the views of and implications for cancer survivors, and enhanced dissemination of findings.

#### Conclusion

Our learnings highlight the importance of consumer involvement in the development of core outcome sets and methods for authentic engagement. These findings may inform future approaches to consumer co-design in research.

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### Optimising care: Supporting women with metastatic breast cancer through exercise and diet

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**Aims:** Despite advances in treatments, survival following diagnosis of metastatic breast cancer (MBC) remains poor (~30-35% five-year survival), with patients experiencing poor quality of life (QoL), physical well-being and function. Yet evidence supporting programs that have potential to improve QoL and function are lacking. This pilot study is the first to assess the feasibility, safety and efficacy of a combined exercise and dietary intervention for women with MBC.

**Methods:** Women with MBC, recruited via hospitals, received a 16-week individually-tailored co-designed program (8 supervised Exercise Physiologist sessions and 8 Dietitian sessions). The exercise component targeted aerobic ( $\geq 150$ mins/week) and resistance exercise (2-3 sessions/week); the dietary component targeted adequate protein intake (1.0-1.5g/kg), improving nutritional quality and managing symptoms. Primary outcomes: feasibility (recruitment rate, intervention adherence, retention and satisfaction) and safety. Secondary outcomes: changes in patient outcomes e.g. lean mass (Dual-energy X-ray Absorptiometry), physical function (6-minute walk test) and QoL (FACT-B).

**Results:** 36 women consented (86% recruitment rate;  $57 \pm 9$  years; 47% <2 years post-MBC diagnosis), with 72% and 80% adherence ( $\geq 6$  exercise and dietitian sessions), respectively. Retention was 69% (n=6 disease progression; n=2 too busy; n=3 never commenced intervention). Qualitative feedback suggests high acceptability and satisfaction with the program. Serious adverse events (n=13) were all disease progressions. Patient outcomes were all largely maintained or improved over the intervention with no clinically meaningful deterioration observed – lean mass: -0.2kg (95%CI: -0.7, 0.3); 6-minute walk test: +22.2m (7.1, 37.3); FACT-B: +0.7 (-4.1, 5.6).

**Conclusions:** Findings on feasibility and safety suggest that women with MBC were interested in support through exercise and diet, with the intervention found to be acceptable and safe. The combined exercise and dietary intervention appeared to attenuate declines in lean mass, physical function and QoL typically observed in MBC. Further research comparing the intervention to usual care is needed to understand the true impact on patient outcomes.

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### ***Exploring the experience of hair loss for women with breast cancer who have received chemotherapy***

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#### **Background**

Chemotherapy-induced alopecia is a common concern among women preparing for chemotherapy. Negative feelings associated with hair loss, such as effects on quality of life and body image, have been reported to persist for several months post-chemotherapy completion, and many women report hair loss remaining as one of their most distressing problems. Despite its recognition as a common, distressing side-effect of therapy, there has been little consideration of the impact of hair loss on a woman's wellbeing following treatment completion.

#### **Aim**

To explore and describe the experiences of women who used scalp cooling (SC) as part of their chemotherapy treatment for breast cancer.

#### **Methods**

A qualitative mixed-methods approach was used. Participants included; women with early-stage breast cancer who had received or were currently receiving SC. Women completed an online survey

measuring SC and hair loss experiences and expectations. Qualitative, semi-structured interviews were undertaken with self-selecting women.

### Results

Forty-nine women with breast cancer consented and completed study requirements. Twenty women took part in a semi-structured interview. Most women lost more hair than they expected and described a range of emotions as a consequence of their hair loss. Profoundly, women spoke about a loss of identity and control about who was informed of their cancer diagnosis due to hair loss. They also spoke about the importance of “wanting to look normal” especially where young children were involved or if they worked in an environment where a cancer identity was confronting or challenging to others. Hair loss caused considerable post-treatment distress for many women.

### Conclusions

This study offers new insights into the experiences of hair loss and SC among women undergoing chemotherapy. Our study has generated patient co-produced resources to better prepare women for SC and hair loss, in order to mitigate distress associated with complex identity, privacy and wellbeing survivorship issues.

## Designing a specialist nurse service to meet the needs of men and their families navigating prostate cancer: A mixed methods approach

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**Aims:** To investigate unmet needs for local men with prostate cancer, reported to be highly prevalent but poorly understood, in order to inform the implementation and ongoing evaluation of a new tailored Prostate Cancer Specialist Nurse (PCSN) service using a survivorship framework.

**Methods:** This study was conducted at a major hospital in a large health service in Queensland. A mixed methods approach was used, informed by implementation science theory. A non-identifiable cross-sectional survey using the Supportive Care Needs Survey Short-Form (SCNS-SF34) and free text questions was distributed to all living men with prostate cancer who had received surgical treatment or who attended the cancer care service in the last 2 years. Stakeholder interviews were conducted with qualitative content analysis used to build process maps and to describe key gaps in care. Descriptive statistical analyses were used for quantitative data.

**Results:** 162 men responded from the 390 surveys distributed. 60 (39%) had a radical prostatectomy and 74 (49%) had radiotherapy, 41 (27%) had >3 treatment modalities. Men reported unmet needs associated with relationships, including worrying about those close to them (49.8%) and changes in sexual relationships (42.1%). Feeling down or depressed (39.1%), feelings of sadness (38.2%), fear of cancer spreading (37.2%) and feeling in control (36.7%) were also perceived unmet needs. “Waiting” and difficulties accessing appropriate services was reported across open text responses, whereas feeling cared for and strong relationships with clinicians also strongly featured. These results were supported by qualitative data with key strategies proposed by stakeholders.

**Conclusions:** Men have a range of unmet needs following prostate cancer treatment potentially due to personal and health system factors. The PCSN service hopes to address these needs by building relationships with men, their families and communities to streamline service provision. Additional experience will provide pragmatic evidence for comprehensive patient care.

## Breast cancer and perceived discrimination in the workplace: a longitudinal cohort study.

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### Background:

Perceived discrimination (PD) in the workplace by individuals diagnosed with cancer has previously been reported. Our study aimed at understanding the social, health and work-related factors related to reported PD in the workplace after return to work (RTW) of women diagnosed with early breast cancer (BC).

### Methods:

We used data from a French longitudinal cohort (CANTO; NCT01993498) including women diagnosed with stage I-III BC. Our analysis was conducted among 2130 women working and  $\geq 5$  years younger than legal retirement age at BC diagnosis (dx) who had returned to work two years afterwards. Logistic regression models were created, with PD in the workplace after RTW (i.e. being downgraded, unwillingly relocated or refused a promotion, or losing responsibilities) self-reported two years after dx as dependent variable. We examined the independent effect of household income per capita (HI), working conditions before (contract hours, size of company, family/work-life relation) and after RTW (workplace accommodations, reason for going back to work, number of months worked since RTW), physical fatigue and depression at the end of treatment. Additional adjustments for age and tumour characteristics were carried out.

### Results:

Overall, 26% of women reported PD in the workplace after RTW, ranging from 20% when HI  $>3500\text{€}$  to 29% when HI  $<1500\text{€}$ . The gradient between HI and PD attenuated in the multivariate model. Physical fatigue and feeling depressed as well as workplace accommodations on RTW and going back to work because of fear of job loss were risk factors for PD. There was a negative association between the number of months worked since RTW and PD. Working for a small company was a protective factor.

### Conclusions:

PD is frequent among BC survivors. Working conditions, and physical and mental health before and after RTW have an impact on PD among cancer survivors.

## Managing symptoms and functions post-primary treatment in colorectal cancer survivors: stakeholder opinions and current practices

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**Introduction** Colorectal cancer (CRC) is prevalent in the developed world, with unhealthy lifestyles and diet contributing to rising incidence. Advances in effective diagnosis and treatments have improved survival rates but CRC survivors experience poorer physical and psychological function than the general population and suffer from long-term gastrointestinal (GI) symptoms. Managing these important patient-reported outcomes (PROs) is key to improving survivors' quality of life. However, the current state of care provision and management options remains unclear. We aimed to identify how GI symptoms and functioning impairments are currently managed in CRC survivors and what interventions are available for relevant PROs.

**Methods:** We conducted: 1) searches in five electronic databases for studies describing/evaluating interventions to address GI symptoms and functioning in CRC; and 2) conducted an international survey plus structured interviews with CRC survivors and managing health professionals on current practices and opinions about available interventions and gaps.

**Results:** We identified 22 interventions for managing GI symptoms and functional outcomes in individuals treated for CRC (10 behavioral, 5 complementary, 4 pharmacological, 2 psychological, 2 rehabilitation). Few interventions are available for managing fatigue, bowel and sexual function. Responses from CRC survivors revealed that while survivors have ongoing debilitating problems such as neuropathy, impaired bowel and sexual function, and anxiety, few seek professional help and often self-manage their symptoms. Health professionals stressed the need for methods to monitor and detect these PROs and affordable and established clinical pathways to specialist care such as nurse-led clinics, stomal therapists or comprehensive allied health services to provide appropriate holistic care.

**Conclusion:** Few supportive care interventions or services are routinely offered. Follow-up care for CRC survivors should integrate routine monitoring of symptoms and functions, with the goal of earlier detection and amelioration of these problems to improve quality of life.

## Evolution of a Regional Survivorship Nurse- led clinic

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**Aim:** Nurse-led models of cancer survivorship care have shown high patient satisfaction, reduced patient concerns and unmet needs, and improved preparedness to manage healthcare. Yet research on the application of this model into a rural area, with limited workforce and poorer survivorship outcomes, is limited. This study reviews the evolution of a rural nurse-led cancer survivorship clinic.

**Method:** A documentary analysis of clinical practice notes and patient survivorship care plans was undertaken. Patients were eligible for the survivorship clinic if they had completed active treatment and defined as low risk by their medical oncologist. Patient's completed various patient reported outcome measures, and a survivorship care plan was developed with the nurse over two appointments.

**Results:** Over a three-year period, xx care plans and xx appointments were implemented for patients with breast, colorectal, gynaecological, lymphoma and prostate cancer. There has been a significant increase in the number of patients attending from outside of the local government area; constituting 57% of appointments. The nurse role had evolved from general patient education on survivorship issues to follow-up care and counselling on late effects, fear of cancer recurrence, and symptom management. Building relationships with the community support services, and breast, prostate and lymphoma nurses in remote locations was essential to supporting patients locally and creating workforce capacity in survivorship care. Further work to integrate general practice into the survivorship clinic was required.

**Conclusion:** Rural models of cancer survivorship will need to continue to evolve in response to growing cancer survivorship numbers.

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**Results:** Over a three-year period, 207 care plans and 414 appointments were implemented for patients with breast, colorectal, gynaecological, lymphoma and prostate cancer. There has been a significant increase in the number of patients attending from outside of the local government area; constituting 57% of appointments. The nurse role had evolved from general patient education on survivorship issues to follow-up care and counselling on late effects, fear of cancer recurrence, and symptom management. Building relationships with the community support services, and breast, prostate and lymphoma nurses in remote locations was essential to supporting patients locally and creating workforce capacity in survivorship care. Further work to integrate general practice into the survivorship clinic was required.

**Conclusion:** Rural models of cancer survivorship will need to continue to evolve in response to growing cancer survivorship numbers.

## Supporting women to live with cancer: the role of the metastatic breast care nurse in Australia

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Although metastatic breast cancer (mBC) is incurable, the changing therapeutic landscape means many people with mBC are living longer. Individuals with mBC have complicated, varied and often long-term health and supportive care needs. Providing supportive care can therefore be complex and challenging. Dedicated mBC nurses are well positioned to support women with mBC, consequently the number of mBC nurses in Australia has increased in recent years. Yet little is known about what it is like to enact this role in order to best support those with mBC. This study addresses this key research gap by examining mBC nurses' perspectives on how their role contributes to the health and well-being of those with mBC. Semi-structured interviews were conducted with 15 breast care nurses who provided supportive care to women with mBC. Thematic analysis revealed that the mBC nurse role involved a complex mix of clinically focused, psychosocial and practical supportive care provision, encompassing support for both the person with mBC and their families, often over many years. Although similarities existed with the early breast cancer nursing role, important differences were identified. The amount and type of supportive care provided by nurses varied not just in relation to illness stage but also in response to an individual patient's changing needs across what was often an unpredictable disease course. Many reported that their primary responsibility was to provide a consistent point of contact that facilitated early identification of clinical, psychosocial and practical concerns, including the possibility of disease progression, side-effect and symptom management, and identification of anxiety and emotional distress. In addition, the mBC nurse was integral to effective care coordination, connecting patients not just with members of their immediate healthcare team, but also with support services that operated beyond the public hospital or private care setting, including community and primary care, social and financial services, cancer organisations and patient support groups. Findings from this study support



Cancer Australia's 2019 statement on best practice in mBC and the international consensus guideline recommendation that patients with mBC should have access to an mBC nurse.

## Converting a face-to-face multidisciplinary team survivorship clinic model to telehealth during the COVID pandemic: Lessons learnt and patients' experience

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Sydney Cancer Survivorship Centre clinic provides multidisciplinary care to cancer survivors after primary adjuvant treatment. Normally on initial visit survivors spend 2-hours individually meeting an oncologist/haematologist, nurse specialist, dietitian, exercise physiologist and psychologist in a face-to-face setting, with their pre-completed patient-reported outcome measures (PROMs). A satisfaction survey/Patient experience measures (PREMS) is completed afterwards. Follow-up visits (in ~40%) consist of consultation with oncologist and nurse specialist. In response to the COVID pandemic the model was changed primarily to telehealth delivery. Paper PROMs/PREMS were converted to online (REDCap). Here we report lessons learnt and patients' response to telehealth.

**Methods/Results:** From 19/3/2020 to 10/11/2020 we delivered 49 initial survivorship consultations [44 (90%) via videoconference platform; 2 by phone (4%)]; an average of two initial survivorship patients per clinic compared to usual four. Overall, 264 follow-up occasions of service were delivered: 170 (64%) by telehealth, mainly telephone. e-PREMS commenced September 2020 and e-PROMs October 2020. Barriers for rapid implementation included: initial lack of facilities to support telehealth delivery; short time for clinician/staff training in digital platform use and ePROMs; additional time needed for scheduling appointments, obtaining survivors' email addresses etc; and, time/resources required to convert to e-PROMS/e-PREMS.

	Starting Date	Number of e-PROMS/PREMS sent	Completed
<b>e-PREMS Initial clinic</b>	3/9/20	15	11/15 (68.7%)
<b>Follow-up</b>	14/9/20	69	24/69 (34.7%)
<b>e-PROMS Initial clinic</b>	28/9/20	13	32 (92%)
<b>Follow-up</b>	21/9/20	43	32 (74%)

Satisfaction surveys indicated survivors "agreed/completely agreed" the telehealth MDT clinic was worthwhile attending: initial clinic 100%; follow-up 91%. 9/10 initial clinic attendees would prefer face-to-face format; least preferred was phone consultation (87%). Follow-ups: 10/16 would prefer face-to-face; second preference was phone.

**Conclusion:** To date, e-survey pre-clinic and satisfaction surveys indicate telehealth clinic is feasible and acceptable but a face-to-face format is preferred. Larger sample size is required to determine overall acceptance.

## Strategies to support General Practitioners in addressing financial toxicity in people with cancer

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#### **Background:**

The term financial toxicity (FT) is used to describe financial distress or hardship as an outcome of cancer and its treatment. Financial toxicity can negatively impact quality of life. There is potential for FT to be alleviated in the primary care setting. However, little is known about the role General Practitioners (GPs) can play, and the support and tools they may require in addressing FT in people with cancer.

#### **Aims:**

The aim of this study was to understand GPs' perspectives on addressing FT amongst cancer patients, including support that GPs may require to address financial concerns of cancer patients in the primary care setting.

#### **Methods:**

An interpretive qualitative study was utilised. Data collection involved semi-structured telephone interviews with GPs recruited through the Primary Care Collaborative Cancer Clinical *Trials Group* and other professional networks. Data were analysed using inductive thematic analysis techniques.

#### **Results:**

A total of 20 GPs from across Queensland, New South Wales and Victoria participated in the study. Responses were diverse and often dependent on practice setting, patient population and the GPs' experience in caring for people with cancer. Most GPs felt they had a role in supporting FT in cancer patients if equipped with the right information. Many identified that improved cost and service resources would assist pathway facilitation. More knowledge about the services available from cancer organisations and education on psychosocial toxicities was also recognised as a priority. Furthermore, improved collaboration and communication with the specialist and multidisciplinary teams was essential. Telehealth was identified as an innovative option to support this. Finally, policy review around Medicare support is imperative to address FT in primary care.

#### **Conclusion:**

If supported with information and collaboration from cancer providers, GPs can play an important role in helping to address FT associated with cancer.

## **Survivors as teachers, helping students to thrive despite COVID**

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The model

'Survivors as Teachers' is an effective model for providing junior medical students with a window into the patient perspective (1,2,3). Now in its ninth year, survivors of cancer (patients and carers) become teachers in the clinical skills course. A survivor leads each small group session, telling their story in their own words. It's an interactive format and students are encouraged to ask questions. Support for the speaker is provided by another survivor attending the session, including monitoring reactions of the student group during the session and debrief afterwards.

Change to online delivery

COVID-19 raised serious concerns about safety of speakers delivering face-to-face sessions. Hence, we explored whether an online Zoom<sup>®</sup> format would be possible. Both University educators and speakers were keen to continue the program and were willing to devote time and effort to adapting to a new format.

### Challenges and Opportunities

Challenges included providing practice and support for speakers, new to online delivery. Many noted that the sessions were more tiring to deliver in online format due to cognitive overload in monitoring student reactions through technology. Despite this, the planned program of fifteen 2-hour sessions, was delivered smoothly.

The online format afforded survivors the opportunity to safely contribute during a pandemic and made it easier for rural survivors to participate. The online platform also allowed for recording of sessions which are currently being used for evaluation and thematic analysis of learnings.

Speakers were pleased to be able to contribute. Student feedback continued to be overwhelmingly positive regarding knowledge gained about the impact of cancer (and its treatment) on multiple aspects of life. Transferable learning included the importance of communication skills underpinning all clinical interactions. Student engagement appeared higher, with insightful questions. We postulate this may be due to greater psychological safety afforded through online platforms 4, 5.

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## Feasibility and acceptability of the ‘real-time’ collection and use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) in an outpatient oncology setting

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**Background:** PROMs and PREMs are broadly accepted to provide valuable information to direct care at both individual and population levels. However, testing of PROMs and PREMs in Australian settings remains limited, with little data available on the feasibility and acceptability of this approach to care from stakeholder groups.

**Aims:** 1. To determine the feasibility and acceptability of the pre-COVID-19 pilot of ‘real-time’ PROMs and PREMs collection and use in an outpatient oncology setting. 2. To gauge perceived barriers and enablers to remote PROMs and PREMs collection in conjunction with telehealth.

**Methods:** Clinicians and administrative staff participated in focus-group interviews to share their experiences of the PROMs and PREMs pilot. Patients who completed the PROMs and PREMs were invited to complete an evaluation survey or participate in a telephone interview to share their experiences. An inductive qualitative content analysis of the transcribed focus group and interview data was conducted. Descriptive statistics were used to analyse patient survey data.

**Results:** Clinicians (n=10) reported that PROMs and PREMs led to proactive symptom identification; more streamlined consultations; greater involvement of patients; and no overall increase in their workload. Administrative staff (n=2) were concerned about their capacity to assist patients with PROMs and PREMs in-person or with telehealth without research officer support. Patients who completed the survey (n=27) reported the PROMs and PREMs: were easy to complete (92.6%); relevant to them (96.3%); resulted in discussion with the doctor (63%); led to referral or further information (82.4%). Interview participants (n=9) appreciated the more holistic approach to care that PROMs and PREMs offered.

**Conclusions:** ‘Real-time’ collection and use of PROMs and PREMs in an outpatient oncology clinic was found to be both feasible and acceptable to key stakeholder groups. Further research will seek their experiences of remote collection and use of PROMs and PREMs with telehealth consultations.

## Disparities in quality of life, social distress and employment outcomes in cancer survivors

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### Background and Aims

Quality cancer survivorship care should seek to reduce disparities in outcomes. This study explored associations between demographic variables and patient-reported outcomes in survivors of breast, colorectal or prostate cancer, melanoma, or non-Hodgkin lymphoma.

### Methods

Eligible survivors were identified from the Victorian Cancer Registry (VCR). Demographic data including age at diagnosis, sex and residential postcode were collected by VCR. Paper-based questionnaires assessed language spoken at home, number and type of comorbidities, quality of life (QoL; EQ-5D-5L), social distress (Social Difficulties Inventory) and employment status. Bivariate (Chi-square and t-tests) and multivariate (logistic regression) analyses were conducted.

### Results

Survey response rate was 45.3% (2115/4674). Participants were predominantly survivors of prostate (n=502) and breast (n=459) cancer; 46.9% were female and 53.1% were male, with a mean age of 62.8 years at diagnosis.

In bivariate analyses, QoL was lower and social distress greater in those who spoke a language other than English compared with those who spoke English, and those who had  $\geq 3$  comorbidities compared with those who had none. Employment post-diagnosis was lower in those with  $\geq 3$  comorbidities compared to those with none, and lower in those from disadvantaged socioeconomic (SES) areas. No differences were seen for any outcome according to rurality.

In multivariate analyses, QoL was negatively associated with having comorbidities, and this effect was greatest in those reporting  $\geq 3$  conditions. QoL was not associated with language, rurality or SES. Social distress was negatively associated with having comorbidities and positively associated with living regionally, but not language or SES. Post-diagnosis employment was related to age and sex only.

### Conclusions

Results demonstrate the key role comorbid illness plays in determining QoL and social distress. With substantial numbers of Australians having at least one comorbid condition, models of care that consider the entire health of the person are needed.

## Review of assessment tools and resources for nurse-led clinics in cardio-oncology: delivering support for providers, patients & clinicians

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**Aims:** Breast cancer and cardiovascular disease (CVD) share common risk factors, with breast cancer treatment substantially increasing risk for CVD. Despite this, there are limited evidence-based resources to support patients and clinicians. This study aimed to identify the availability of resources and tools that can support best-practice in the management of CVD in breast cancer patients and survivors via a nurse-led model of care.

**Methods:** A search of the literature for the management of CVD in breast cancer patients and survivors, to identify best available evidence of cardio-oncology interventions. Existing resources available from the Heart Foundation and Cancer Organisations (Cancer Council; Flinders Centre for Innovation in Cancer, Breast Cancer Network Australia) were examined to determine their alignment with current recommendations.

**Results:** The Heart Foundation has numerous resources available for cardiac health, risk factors and lifestyle behaviours; however, these all have a focus on cardiac conditions. Cancer specialists have extensive resources available for all cancers, including breast cancer; however, our review noted there is limited focus on heart health and cardiac risk factors. CVD assessment tools such as a cancer patient's assessment guide, heart health and risk factor information pamphlets, medical record template, referral template and letter to GP's template, have mostly been developed using best available evidence and stakeholder feedback, with continued evaluation and updating, to meet the needs of providers, patients and clinicians.

**Conclusions:** Management of CVD risk in breast cancer patients and survivors represents an important unmet need that is currently developed on an informal basis. A more rigorous process of development could improve the quality and availability of resources and assessment tools for effective education, documentation and communication to support nurse-led models of care.



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