

SUPPORTING CANCER COUNCIL QUEENSLAND

# Committed to the community

ANNUAL REPORT 2016

# Cancer Council Queensland strate



## SERVE AND EMPOWER THE COMMUNITY

- Improve access to cancer-related services and programs
- Mobilise resources to build community capacity and resilience
- Lead local, national, and global dialogue to make cancer control a priority



## DRIVE AND FUND WORLD-CLASS RESEARCH

- Conduct collaborative multi-centre investigations in cancer control
- Invest in Queensland-led cancer research, with demonstrable impact
- Inform worldwide understanding of cancer control, through research and innovation



## PREVENT CANCER AND ENCOURAGE HEALTHY LIFESTYLES

- Reduce cancer risks by advocating for evidence-based lifestyle changes and screening
- Encourage healthy communities through engagement and education
- Deter high-risk behaviours by informing public health and policy



## SUPPORT ALL PEOPLE AFFECTED BY ALL CANCERS

- Advocate to ensure the assessment and care of all people affected by cancer
- Deliver innovative outreach and supportive care programs
- Disseminate the latest news, information, and evidence to the public



## IMPROVE SURVIVAL OUTCOMES AND ADDRESS INEQUITIES

- Invest in studies and programs to overcome the barriers to cancer control
- Promote integrated and multi-disciplinary service approaches
- Monitor and report on trends and emerging developments in cancer control



## FUNDRAISE AND FOSTER EFFECTIVE PARTNERSHIPS TO PROGRESS OUR VISION

- Inspire community involvement in fundraising for cancer control
- Innovate to create cutting-edge approaches for cancer control
- Engage networks of influence in cancer control by collaborating with community organisations, and other public benefit organisations



# Strategic priorities

Programs for all Queenslanders.

and strengthen cancer care systems.

Cancer a priority in health and development planning.

Focus on cancer control, with a focus on reducing the burden of cancer in Queensland.

Unconstrained potential to improve the survival and wellbeing of Queensland patients.

Through the publication and presentation of new evidence.

Integrated population-wide programs and interventions that promote healthy lifestyles and uptake

Consistent across regions, sectors, and industries, targeting at-risk groups.

Supports policy and program development.

Information for people affected by cancer is timely, safe, comprehensive, and of consistently high quality.

Programs with a focus on patient-centred care and optimum quality of life.

Focus on cancer, dispelling stigma and misconceptions.

Barriers to equity in cancer survival, enabling the rapid translation of research into practice.

Approaches, centred on patient and community need.

Reductions in cancer incidence, mortality, survival, and prevalence.

Focus on cancer control, engaging volunteers, staff, and the community.

Connecting with Queenslanders online and in person.

Collaborating with businesses, governments, health agencies, educational institutions, and associations.




# About Cancer Council Queensland

## Our Mission

Medical research has successfully beaten most disease – it will beat cancer. Cancer Council Queensland raises funds which are dedicated to eliminating cancer and diminishing suffering from cancer through research, treatment, patient care, prevention and early detection.

## Our Strengths

Cancer Council Queensland is dedicated to serving the community in cancer control. Cancer Council Queensland is dynamic, outcome-focused, responsive to community needs, committed to voluntarism and the pursuit of excellence in all its activities. All staff and volunteers from Cancer Council Queensland, through their work, are actively involved in cancer control.



# Our role



Cancer Council Queensland's Viertel Cancer Research Centre is a multi-disciplinary research centre dedicated to collaborative work to advance global cancer control, strengthening the knowledge base that informs specialist expertise in the fields of cancer epidemiology, childhood cancer, psycho-oncology and community engagement.

Our findings have worldwide impact, demonstrating the importance of community-based cancer control in preventing and reducing the burden of cancer at a population-wide level.

From 2004, the Centre's work has been underpinned by a major long-term philanthropic commitment from the Sylvia and Charles Viertel Charitable Foundation. The Foundation's commitment ensures the Centre's work is future-focused, innovative, and responsive to emerging trends.



Over the past 13 years the Centre has gained recognition as a world-class research institute, helping to guide local, national and international understanding of the issues that impact quality of life and survivorship outcomes for those affected by cancer, including family members and the broader community.

**We are committed to eliminating cancer as a life-threatening and distressing disease for future generations.**







## Charles Viertel

### 1902 -1992

The Sylvia and Charles Viertel Charitable Foundation was established in 1992, following the passing of Mr Charles Viertel, prominent Queensland investor and philanthropist.

In 2004, the Foundation made a significant and ongoing commitment to Cancer Council Queensland in support of the Viertel Cancer Research Centre.

Cancer Council Queensland gratefully acknowledges the generous support of the Sylvia and Charles Viertel Charitable Foundation and its Chairman, Mr George Curphey OAM.





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**Our research  
focuses on  
*increasing  
survival and  
enhancing  
quality of life  
after cancer.***

# From the CEO



Since joining Cancer Council Queensland earlier this year as the Chief Executive Officer, it has been a great pleasure to meet and work alongside a team of talented researchers and partner organisations dedicated to advancing cancer control in Queensland.

In 2016 we delivered world-leading research to improve the lives of Queenslanders affected by cancer, benefiting from community support and the ongoing generosity of the Sylvia and Charles Viertel Charitable Foundation.

Our work culminated in the publication, or acceptance for publication, of 72 peer-reviewed manuscripts in national and international scientific journals, with citations of the Centre's published research now at over 17,000.

We also partnered with leading research institutes including Griffith University, the University of Southern Queensland, QIMR-Berghofer Medical Research Institute and Menzies School of Health Research, and together continue to achieve important milestones.

Highlights included the launch of the national Centre of Research Excellence in Prostate Cancer Survivorship, led by Griffith University and CCQ, to investigate the psychosocial and psychosexual health of prostate cancer survivors, the economic costs of prostate cancer and geographic inequalities in prostate cancer outcomes.

Of particular significance, CCQ continued to manage the Australian Childhood Cancer Registry and released findings showing that survival for many childhood cancers has improved and deaths from childhood have decreased by 40 per cent over the last 15 years – a tremendous improvement.

CCQ also secured funding in collaboration with the University of Queensland to investigate whether peer support, a strong focus of our support programs, can improve maintenance of exercise in people who have been treated for cancer.

These and the other achievements outlined in this report would not have been possible without the continuing support of the Sylvia and Charles Viertel Charitable Foundation and its Chairman, Mr George Curphey OAM, to whom I extend my deepest appreciation.

Equally, I acknowledge with appreciation Cancer Council Queensland's Board of Directors, our Chairman from 2012 until 2017 Mr Graham Gibson QC, current Chairman Mr Andrew Arkell, our staff, and our network of distinguished research collaborators for their contributions to our vision for a cancer-free Queensland.

Finally, I acknowledge with deepest appreciation the thousands of community members who enable our research to reach all Queenslanders, affected by all cancers.

**Chris McMillan**  
Chief Executive Officer



# From the head of research



Once again, this has been a productive year for the Viertel Cancer Research Centre. From the Centre's establishment in 2004, our research programs have focused on providing tangible benefits for the community with a strong emphasis on research to improve the lives of cancer patients, their families and all Queenslanders.

With this in mind, the Centre's program of work is focused on research in four key areas – cancer epidemiology, psycho-oncology, community engagement and childhood cancer.

The Centre's epidemiology research program has revealed that cancer risk and cancer survival vary according to where people live and in particular that regional and rural cancer patients are significantly more likely to die of their disease within five years of diagnosis. To help understand the reasons for this, we are building Australia's first digital cancer atlas based on small geographical areas. The Atlas will use cutting-edge visual methods that will form an evidence base for advocacy and targeted service delivery to address the survival gap.

We are also investigating key questions in breast cancer, bowel cancer, prostate cancer and melanoma – the most common cancers in Queensland. For example, we are examining the roles of vitamin D and sunlight in health, the survival of patients with multiple melanomas, quality of life for patients with advanced disease, treatment pathways for breast cancer, and colorectal cancer screening. Within our psycho-oncology research program, we are testing web-based and other programs offering support for cancer patients who experience distress after their diagnosis, helping to improve the quality of life of patients and their families.

The Viertel Centre's focus on childhood cancer research has continued through our management of the Australian Childhood Cancer Registry, one of the few national digital databanks for childhood cancer in the world. The Registry

has improved understanding of childhood cancer in Australia and helped to inform our clinical collaborations and partnerships going forward. This year we were excited to have completed the world's first feasibility trial of new international guidelines for the collection of childhood cancer stage in population registries, supported by Cancer Australia. This project, and the full range of our research programs, are outlined in the following pages.

I acknowledge with appreciation the members of the Viertel Cancer Research Centre, our research collaborators and partners, our volunteers for their able assistance in the Centre's work, and our research participants for their willingness to become involved.

Our sincere thanks go to the Sylvia and Charles Viertel Charitable Foundation and its Chairman, Mr George Curphey OAM, for the Foundation's generous support and ongoing commitment that has made all of this possible.

I commend this report to you as a record of the Centre's achievements during 2016.

Professor Joanne Aitken

Head of Research and Director of Cancer Registries

# Cancer in Queensland - the numbers

# 214,376

Queenslanders are alive today after a cancer diagnosis in the past 25 years.

# 36,582

Queenslanders are estimated to be diagnosed with cancer each year by 2024.

# 1 in 2

Queenslanders will develop cancer before age 80.

# 8,732

Queenslanders died of cancer in 2014.

# 27,022

Queenslanders were diagnosed with cancer in 2014.

# 70%

Overall cancer survival in Queensland has improved from 53 per cent to 70 per cent over the past 25 years.

# 1 in 7

Queenslanders will die from cancer before age 80.



# Our research at a glance

## 2004 - 2016



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# 41

Research grants awarded

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# 10

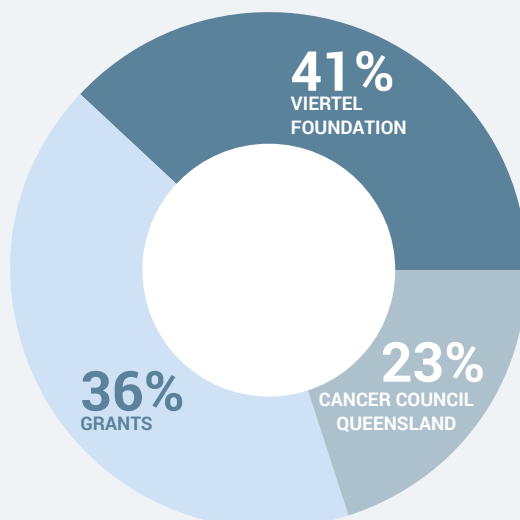
Reports on cancer in  
Queensland

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# 70

Contributions  
to national and  
international expert  
scientific advisory  
groups and clinical  
practice guidelines

Funding 2004-2016







# 100,000+

Queenslanders took part in our research

# 17,000+

Citations of our research

# 10

Books and book chapters

# \$11.5M

Research grant income

# 8

National awards  
and fellowships

# 617

Research conference  
presentations

# 522

Peer-reviewed  
publications

# Partnerships and collaborations

## INTERNATIONAL

1. American Cancer Society
2. Cancer Foundation PNG, Port Moresby
3. Cancer Patients Aid Association, Mumbai
4. Cancer Research Malaysia, Kuala Lumpur
5. Dana-Farber Cancer Institute, Boston
6. Global Initiative for Cancer Registry Development
7. Hong Kong Polytechnic University, Hong Kong
8. International Agency for Research on Cancer
9. International Association of Cancer Registries
10. Irish Cancer Society, Dublin
11. Memorial Sloane Kettering Cancer Center, New York
12. National Child Cancer Network NZ, Christchurch
13. Nepal Cancer Relief Society, Kathmandu
14. New Zealand Children's Cancer Registry
15. Royal Marsden Hospital, London
16. Tallaght Hospital and St James's Hospital, Dublin
17. The Hospital for Sick Children, Toronto
18. Union for International Cancer Control, Geneva
19. US Department of Defense, Washington
20. University of British Columbia, BC
21. University of Virginia, Charlottesville

## NATIONAL

1. ARC Centre of Excellence for Math and Stats Frontiers
2. Australian Institute of Health and Welfare
3. Australian National University
4. Australian and New Zealand Children's Haematology/ Oncology Group
5. Australian and New Zealand Urogenital and Prostate (ANZUP) Cancer Trials Group
6. Australasian Association of Cancer Registries
7. Cancer Australia
8. Cancer Council New South Wales
9. Cancer Council Victoria
10. Clinical Oncology Society of Australia (COSA)
11. Cooperative Research Centre for Spatial Information
12. Edith Cowan University
13. Major paediatric hospitals in Sydney, Perth, Brisbane, Melbourne, Adelaide
14. McCabe Centre for Law and Cancer
15. Menzies School of Health Research, Charles Darwin University
16. Monash University
17. Prostate Cancer Foundation of Australia
18. University of Adelaide
19. University of Melbourne
20. University of South Australia
21. Victorian Cancer Registry
22. Victorian Cytology Service



# Our journey so far

In 2004, the Sylvia and Charles Viertel Charitable Foundation made a generous ongoing commitment to Cancer Council Queensland (CCQ) in support of cancer research. This support has made possible significant and sustained improvements in evidence-based cancer control for Queensland, some of which are outlined in the timeline below.

- **2004** With support from the Sylvia and Charles Viertel Charitable Foundation, the **Viertel Centre for Research in Cancer Control** opens at CCQ with the remit to conduct research, develop evidence, and take direct action on the key issues for cancer control in Queensland.
- **2005** Accreditation by the Australian Government's National Health and Medical Research Council. Evaluated the diagnostic accuracy of skin clinics versus general practitioners, leading to the release of revised public guidelines for skin cancer checks. Publication of Queensland's largest statewide study of cancer risk behaviours, leading to CCQ's QUEST program for cancer prevention.
- **2006** Hosted Australia's 8th Biennial Conference on Behavioural Research in Cancer Control. Developed an evidence-based framework for a tiered model of psychological care including distress screening at first point of contact that now forms the basis for CCQ's program of supportive care for cancer patients. Contributed to the development of national clinical guidelines for psychosocial care of advanced prostate cancer.
- **2007** Major report on lung cancer in Queensland published and disseminated to clinicians, researchers and the community, contributing to changes in public policy to reduce smoking prevalence in Queensland from 22 per cent (2004) to 15 per cent (2016). Release of a free online system allowing community access to the latest information on cancer in Queensland (Queensland Cancer Statistics Online).
- **2008** Developed the world's first scientific evidence of the effectiveness of clinical whole-body screening for early detection of melanoma. Membership of Working Party that developed and published revised Clinical Practice Guidelines for the Management of Melanoma in Australia and New Zealand, incorporating guidelines for population skin screening. Media interest and coverage of our research reaches estimated value of \$1,000,000 per annum.
- **2009** Released results of Australia's largest study of the quality of life of colorectal cancer patients up to five years after treatment, leading to a successful randomised clinical trial of a behavioural intervention to improve patients' health and wellbeing. **Opening of Townsville Hospice and Palliative Care Centre with generous support from the Sylvia and Charles Viertel Charitable Foundation.**





- **2010** Published first national report of childhood cancer survival showing that outcomes for Australian children diagnosed with cancer are in line with the best results reported internationally. Demand from clinicians leads to start of development of CCQ website providing free access to latest childhood cancer incidence and survival data from the Australian Childhood Cancer Registry (managed by the **Viertel Centre**).
- **2011** **Sylvia and Charles Viertel Charitable Foundation** awarded **Research Australia's prestigious Great Australian Philanthropy Award for outstanding contribution and support of medical research**. Announcement of landmark "Atlas of Cancer in Queensland" by the then Governor of Queensland, Her Excellency Ms Penelope Wensley AC and then CCQ Chairman the Hon. Richard Chesterman AO, leading to significant changes to public policy and services for regional patients.
- **2012** Medical Journal of Australia publishes our finding that almost 43,000 cancers in 2005 in Australia could be prevented by improvements in diet and physical activity. Developed randomised trial evidence of the most effective methods for delivery of psychosocial support for cancer patients and families, leading to improvements in CCQ's provision of face-to-face and telephone counselling services.
- **2013** The number of Queenslanders who have participated directly in our research reaches 100,000. CCQ's evidence-based recommendation for integration of distress management into routine clinical practice formally adopted by the Queensland Department of Health. **The Sylvia and Charles Viertel Charitable Foundation generously renews funding for CCQ's research program for 2014-2018.**
- **2014** Contributed evidence leading to a full ban on commercial solarium in Queensland and to a reduction in the risk of melanoma in young people due to tanning beds. Membership of an international expert panel that developed and published the first consensus-based classification system for childhood cancer staging for population registries globally, since endorsed by the Union for International Cancer Control.
- **2015** Developed national recommendations and strategies to reduce rural and Indigenous disparities in breast cancer outcomes, since endorsed by Cancer Australia - the lead cancer control agency to the Government of Australia. Partnering in a national Centre of Research Excellence to develop and test world-first computer imaging methods to improve early detection of skin cancer in high-risk patients.
- **2016** **Highlights over page...**

# 2016 research highlights

1. Published 72 research reports in national and international peer-reviewed scientific journals, with total citations of the Centre's published research now over 17,000.
2. Secured National Health and Medical Research Council funding for a national Centre of Research Excellence, led by Griffith University and CCQ, to investigate the psychosocial and psychosexual health of prostate cancer survivors, the economic costs of prostate cancer and geographic inequalities in prostate cancer outcomes.
3. Secured funding to investigate how statistical estimates and measures of risk and uncertainty are perceived by the public, as part of the background work for the Atlas of Cancer for Australia.
4. Released findings from the Australian Childhood Cancer Registry showing that survival for many childhood cancers has improved and that deaths from childhood cancer have decreased by 40% over the last 15 years.
5. Signed a two-year research partnership with the Menzies School of Health Research to conduct a joint program of research focusing on cancer in Indigenous Australians.
6. Found that people with multiple invasive melanomas have lower survival than those with a single invasive melanoma, contradicting earlier published research. Work was conducted in partnership with the University of Queensland and QIMR-Berghofer Medical Research Institute. Results have been confirmed in a similar study from the Netherlands.
7. Published findings that cancer patients without a partner at diagnosis are more likely to die within 10 years than those with a partner regardless of their cancer type, receiving strong community and media interest.
8. Completed a clinical trial of a telephone-delivered group therapy intervention for men with advanced prostate cancer, published in the Journal of Clinical Oncology.
9. Undertook the first successful feasibility trial of new international guidelines for the collection of childhood cancer stage in population registries, funded by Cancer Australia.
10. Completed an implementation project with Griffith University to introduce routine distress screening for cancer patients treated at the Gold Coast University Hospital, resulting in a 40% increase in screening for distress with referral to psychosocial care services.
11. Secured funding in collaboration with the University of Queensland to investigate whether peer support (a strong focus of CCQ's support programs) can improve maintenance of exercise in people who have been treated for cancer.

# Key program areas

Our research is directed at preventing cancer, ensuring early detection, helping patients achieve the best possible quality of life after a diagnosis, and supporting cancer patients and their families.

## **EPIDEMIOLOGY RESEARCH PROGRAM**

Objectives are to understand patterns and trends in cancer incidence, prevalence, mortality and survival with a view to identifying areas of improvement or need, and to investigate factors that impact on diagnosis, clinical management, health service delivery and cancer outcomes.

## **PSYCHO-ONCOLOGY RESEARCH PROGRAM**

Objectives are to identify and understand impacts on psychosocial and survivorship outcomes for people with cancer, to undertake applied research to understand how to improve these outcomes, and to translate the results into improved services and supportive care.

## **COMMUNITY ENGAGEMENT RESEARCH PROGRAM**

Objectives are to develop CCQ's capacity to realise its cancer control goals through community engagement and action. This program informs activities relating to public health, fundraising and volunteering, providing a better understanding of the community's aspirations and expectations of non-government organisations in cancer control.

## **CHILDHOOD CANCER RESEARCH PROGRAM**

Objectives are to conduct and facilitate national and international research into the epidemiology, causes and outcomes of childhood cancer. Underpinning this work is CCQ's management and support of the Australian Childhood Cancer Registry, a national clinical database of all cases of childhood cancer diagnosed in Australia, housed in the Viertel Cancer Research Centre.

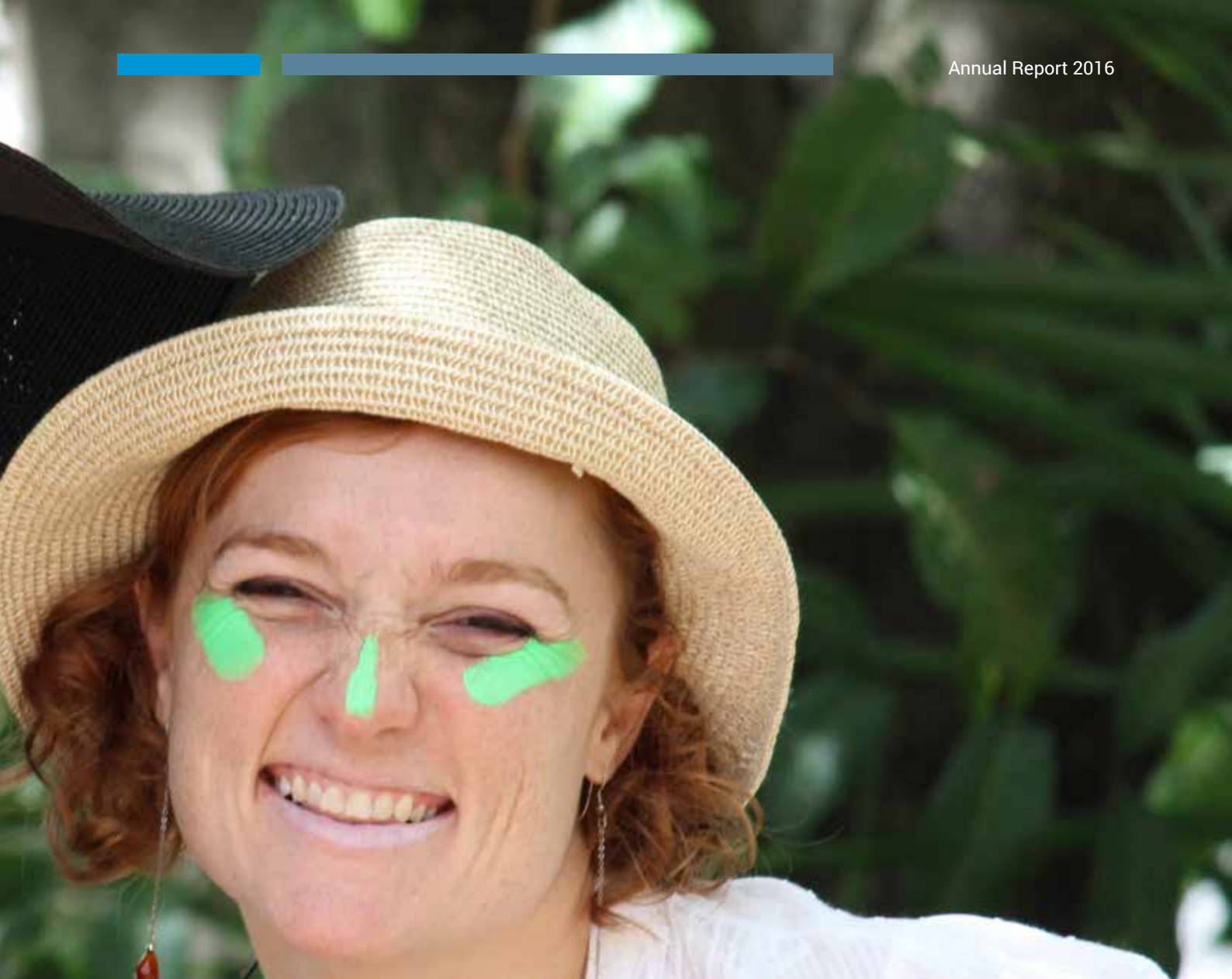




## **Cancer control** initiatives

The Viertel Cancer Research Centre is at the forefront of population-based research, with over 100,000 Queenslanders having taken part in our research to date.





Through our findings and achievements, the Centre has built a respected scientific profile, reflected in the publication of over 522 peer-reviewed articles in medical and scientific journals since the Centre's establishment, over 17,000 citations of our research, accreditation by the Commonwealth Government's National Health and Medical Research Council and continuing success in securing nationally competitive research grant awards.

The work of the Centre has had a major impact on cancer control in Queensland through the translation of research findings into changes in cancer control policy and practice. The community has been the ultimate beneficiary of this important work.

The key research initiatives underway during 2016 are profiled in the following pages.

# Centre of Research Excellence in Prostate Cancer Survivorship



The Centre for Research Excellence in Prostate Cancer Survivorship supports CCQ's mission by delivering new knowledge and tested interventions to support CCQ programs and services. It will provide a unique and crucial pathway to focus individual and community efforts to help men with prostate cancer.

## Key facts

- Prostate cancer is the most common male cancer in Queensland today.
- Treatment leaves many with serious ongoing physical effects and psychological distress.
- Few studies consider the long-term impact of living with prostate cancer.

### Project partners

Griffith University

Edith Cowan University

Cancer Council New South Wales

The University of Adelaide

Monash University

The University of Queensland

Prostate Cancer Foundation of Australia

Prostate cancer survivorship is a major challenge both for CCQ and for our national health system and its workforce. In 2016, the National Health and Medical Research Council awarded funding for a Centre for Research Excellence in Prostate Cancer Survivorship, led by Griffith University and Cancer Council Queensland. The multidisciplinary research team includes national health experts from the two leading organisations and from Edith Cowan University, Monash University, The University of Adelaide and The University of Queensland. The broad goal of this program of research is to improve knowledge and translate this into action across four main themes: psychosocial and psychosexual health, exercise medicine, the economic costs of prostate cancer and geographic inequalities in prostate cancer outcomes. Initial work has involved a systematic review of randomised controlled trial evidence regarding the benefit

of psychosocial and psychosexual interventions for quality of life and psychological wellbeing of prostate cancer survivors and their partners. The review, published recently in the world-leading journal *Psycho-Oncology*, will serve as a key resource for clinicians and researchers and provides practice and research recommendations. Linked to this work, a longitudinal study of 575 newly diagnosed men examined health-related and disease-specific quality of life, life satisfaction, cancer-specific distress and anxiety about PSA levels over a 6-year period. Results, also published in *Psycho-Oncology*, show distinct patterns of quality of life and psychological wellbeing throughout survivorship for these men and highlights the importance of considering men's life-course and treatment side-effects when planning prostate cancer survivorship care. Work is underway for the next phases of the research.

## Case Study.

# Garth Stephens



When Garth Stephens was diagnosed with prostate cancer at age 60 – support played a key role in helping him transition through the journey.

Eight years on, Garth continues to dedicate his time to supporting men affected by the disease through peer support programs, and is a valued volunteer at Cancer Council Queensland.

“I’ve found just how important it is to give men diagnosed with prostate cancer a supportive environment that they can open up in and talk about the challenges they face.

**“MEN ARE OFTEN RELUCTANT TO TALK ABOUT THEIR JOURNEY AND RELATIONSHIPS WITH THEIR WIVES OR PARTNERS, BUT ONCE YOU GET TALKING TO THEM AND THEY REALISE THEY WEREN’T ALONE, AND THAT OTHERS HAD THE SAME SORTS OF PROBLEMS AND CHALLENGES, THEY OVERCAME THEM QUITE WELL.”**

With a key interest in supportive services and investment into prostate cancer research, Garth is passionate about the work of the Vietel Cancer Research Centre which is focused on delivering new knowledge and tested interventions to support Cancer Council Queensland’s programs and services in this area.

Prostate cancer is the most common cancer diagnosed among men in Queensland, yet there are few studies that consider the long-term impact of living with the disease.

Together with the support of people like Garth, Cancer Council Queensland will continue leading the way in research to provide unique programs that will help men diagnosed with prostate cancer at each stage of their cancer journey.



# A National Atlas of Cancer for Australia



Based on the success of CCQ's Atlas of Cancer in Queensland, released in 2011, the digital National Atlas of Cancer will provide Queenslanders, and all Australians, with the first, detailed picture of how cancer risk and survival vary by small geographical areas across Australia. The National Cancer Atlas will support CCQ's goal of improving cancer outcomes for all in the community regardless of geographic location.

## Key facts

- Cancer risk and survival vary according to where people live.
- The first national digital cancer map based on small geographical areas.
- Will use innovative visual methods to communicate complex information.
- An evidence base for research, advocacy and targeted service delivery.

### Project partners

Queensland University of Technology  
Cooperative Research Centre in Spatial Information  
Australian Institute of Health and Welfare  
Australasian Association of Cancer Registries

In 2016, CCQ commenced a collaboration with the Queensland University of Technology (QUT) and the Cooperative Research Centre in Spatial Information to produce the first National Cancer Atlas based on small geographical areas. This project builds on many years of work by CCQ to understand the cancer divide between metropolitan and rural areas, and the link with socio-economic status and other factors.

The Atlas will be an online, interactive system that will use digital technology to illustrate geographical differences in cancer risk and survival throughout Australia in greater detail than has been possible before. We are developing novel visualisation methods to communicate the information to different audiences including researchers, clinicians, and the general community. Underpinned by state-of-the-art statistical methods, the Atlas will bring new insights about

cancer patterns across Australia and will also allow people to learn about the cancer burden where they live. Initial work has included formal reviews of other disease atlases published internationally, the statistical methods used for these atlases, and the visualisation methods currently used to communicate spatial estimates and uncertainty. We are also conducting research to understand how people interpret risk information presented in maps and graphs, and how they use that information in their decision-making processes.

This work will provide an extraordinary resource to build on our knowledge of cancer in Australia, to accelerate the pace of research translation, and to advance CCQ's vision for a cancer free future. It is due for completion in June 2018.



## Building Regional Resilience in Cancer Control



Cancer patients diagnosed in regional and rural Queensland have a higher risk of dying from their disease than urban patients do. In 2016, CCQ commenced a joint research program with the University of Southern Queensland to examine the cultural, social and behavioural factors underlying this, and to develop the knowledge and strategies required to address this issue.

### Key facts

- Regional and rural cancer patients are significantly more likely to die of their disease.
- Cultural, social and behavioural factors likely to be an important part of the problem.
- Developing interventions to address this is a priority for Cancer Council Queensland.

#### Project partners

Institute for Resilient Regions,  
University of Southern Queensland

Public Health Network

West Moreton Hospital and Health  
Service

The reasons for lower cancer survival rates in regional and rural areas are complex. Distance and access to services play a role, but are not the whole explanation. In 2016, in partnership with the University of Southern Queensland, CCQ began a long-term program of applied research with three objectives: to identify the social, behavioural and cultural factors that shape health behaviours and access to cancer services for people in regional areas; to deliver innovative tools and strategies to motivate people and communities to change behaviours; and ultimately to improve cancer control and cancer outcomes in regional communities.

A flagship project will be a longitudinal cohort study of 3,500 regional cancer patients and their carers accommodated at CCQ's six state-wide lodges during cancer treatment. It is known that patients moving back to regional areas

following treatment are among those most at-risk of experiencing poorer survival and outcomes. Patients and carers will be assessed at multiple time-points (baseline, 6- & 12-months post-baseline, and annually) over a multi-year follow-up period, to provide an insight into the journey of a regional cancer patient from diagnosis through to treatment, follow-up and recovery/recurrence. We will examine patients' health profiles and comorbidities, screening and early detection, treatment and clinical management, patient support and care, and identify specific socio-behavioural factors that may impact on poor treatment outcomes.

This is a unique study which to highlight factors that underlie the existing geographic variations in cancer outcomes and then to trial empirically-driven interventions and solutions.

# Cancer outcomes among Indigenous Australians



Cancer Council Queensland is committed to working in partnership with Indigenous research organisations, health professionals, and communities to prevent cancer and improve cancer survival outcomes for Indigenous Australians. This research will provide a better understanding at the population level of what is driving the poorer outcomes experienced by Indigenous people and guide future efforts to intervene.

## Key facts

- Indigenous Australians diagnosed with cancer face poorer survival outcomes.
- Indigenous women are much less likely to participate in cervical cancer screening.
- Formal research partnership signed with Menzies School of Health Research to address this.

### Project partners

Menzies School of Health Research,  
Charles Darwin University

Cancer Australia

University of South Australia

QIMR Berghofer Medical Research  
Institute

Victorian Cytology Service

Australian National University

In 2016, CCQ entered a formal partnership with the Menzies School of Health Research to conduct a program of research aimed at better describing and understanding patterns and inequalities in cancer-related outcomes among Indigenous people. This partnership will greatly strengthen Cancer Council Queensland's research activity among Indigenous Australians and inform interventions to reduce inequities.

Within this partnership, the Viertel Centre is collaborating in a population-based data linkage project to quantify participation in the National Cervical Screening Program by Indigenous women. This project combines data from the Pap test registries, hospitals and cancer registries to overcome the lack of an Indigenous identifier in the Pap test registry. Queensland results show that only about a third

of Indigenous women participate in cervical screening compared to 56% of other Queensland women, with no improvement since 1999. Of those who did participate in screening, Indigenous women were more likely to have low- and high-grade abnormalities compared to non-Indigenous women, and have longer time from initial pap smear to the clinical investigation.

Using data from the Queensland Cancer Registry, we have also found that Indigenous people diagnosed with cancer in Queensland still face a poorer survival outlook than their non-Indigenous counterparts, particularly in the first year after diagnosis. Although there has been a significant improvement in cancer survival for Indigenous people over the past 10 years, inequity between Indigenous and non-Indigenous cancer patients remains.

# Improving survival following melanoma



Updated evidence on the risk of death associated with multiple melanomas has important implications for how this group of patients should be clinically managed and monitored. Our work has highlighted the growing need for supportive care services to assist patients following treatment for advanced melanoma. These projects contribute to CCQ's mission by providing important new information and directions for control of melanoma.

## Key facts

- Queensland has the highest rate of melanoma in the world.
- Ten percent of patients with invasive melanoma develop a second melanoma.
- Treatment for advanced melanoma has serious long-term effects.

### Project partners

The University of Queensland  
QIMR Berghofer Medical Research Institute  
The University of the Sunshine Coast  
Griffith University  
Royal Marsden Hospital, UK

### Survival following multiple melanomas

We have recently published new information to show that the approximately one in ten patients who develop multiple melanomas have significantly worse survival than those with a single melanoma, even after accounting for the stage at diagnosis. This result is contrary to several previous studies that, because of flawed methodology, had incorrectly reported that patients with multiple invasive melanomas had improved survival. We have recommended that the lower stage-specific survival rates of patients with multiple primary melanomas be accounted for in current management guidelines.

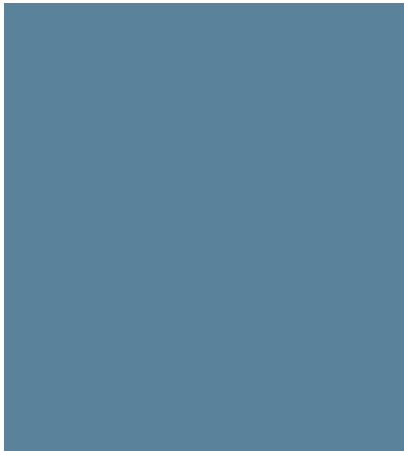
### Quality of life for patients with advanced melanoma

Although results are promising, new drug treatments that prolong survival for a subset of melanoma patients with advanced disease have serious side-effects that reduce

quality of life and may not be easily managed. We have conducted a systematic review of the evidence for the psychological and social wellbeing of patients with advanced melanoma contrasting quality of life before the new treatments became available, with that after the introduction of these treatments. The review revealed that survivorship research for this group of patients lags behind medical advances. Compared to people with localised disease, survivors of advanced melanoma have worse emotional and social wellbeing, and greater levels of distress than other melanoma patients. There is an urgent need to address the psychosocial concerns and supportive care needs of these patients who may live for many years after their treatment.



# The Australian Childhood Cancer Registry



Improving outcomes for childhood cancer is a key priority area for CCQ. For the past three decades, the Australian Childhood Cancer Registry has been the only source of complete, population-wide information on childhood cancer in Australia for researchers, clinicians and affected families.

## Key facts

- Over 700 children diagnosed with cancer in Australia each year.
- The Australian Childhood Cancer Registry is one of a few national data repositories for childhood cancer globally.
- Strong ongoing links with clinical research collaborators are vital.

### Project partners

The Australasian Association of Cancer Registries

All major paediatric oncology treating hospitals in Australia

The Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG)

QIMR Berghofer Medical Research Institute

Children's Health Queensland

Because the number of cases of childhood cancer is low compared to cancer in adults, childhood cancers tend to be either omitted or grouped up with adult cancers in routine state and national cancer statistics. Access to basic data such as incidence, mortality and survival for children with cancer is therefore often limited when reported through Australia's national cancer framework. The Registry fills this gap by providing a high-quality database of diagnostic, clinical and treatment information on every case of childhood cancer diagnosed in Australia and uses this information to report national incidence, mortality, survival and trends over time. In doing so, the Registry continues to provide the foundation for epidemiologic, biomedical and clinical research into this rare but significant disease; it enables national dissemination of information about childhood cancer; and it facilitates national and international collaborative research

to improve outcomes of childhood cancer in Australia.

As the reputation of the Registry continues to grow, we are increasingly being approached by local and overseas clinicians who have an interest in using our data to answer research questions of national and international interest. For example, a collaboration which commenced during 2016 will investigate the characteristics of survivors of childhood cancer who then go on to develop "therapy-related" acute myeloid leukaemia. Little is known about this disease, particularly in children, and the prognosis is poor. It is believed to be primarily brought about by chemotherapy and/or radiation therapy received for the initial cancer. Data from the Registry will help to give a better understanding of the epidemiology of therapy-related AML in childhood, which in turn may lead to improved outcomes.



## Case Study.

# Missy Clarkson

At 10 years old, Missy Clarkson has gone through more than any child should have to in a lifetime. At nine she was diagnosed with acute lymphoblastic leukaemia, a common childhood cancer.



Declared a high-risk case, Missy immediately began ten months of intensive chemotherapy, travelling back and forth from her home in Malanda to Cairns and Brisbane.

While most children are enjoying school and playing with friends, Missy has spent months in and out of hospital, fighting infections and undergoing gruelling treatment.

It has not been an easy journey, and it is one she will continue for many years as she undergoes maintenance treatment. Sadly, Missy is one of around 700 children aged 0-14 diagnosed with cancer annually in Australia. Approximately 100 will die from the disease each year, before their 15th birthday. While cancer has taken so much from Missy, hope for a cancer free future is strengthening so that more children can be spared.

Through its Childhood Cancer Research Program, the Viertel Cancer Research Centre plays a key role in conducting and facilitating national and international research into the epidemiology, causes and outcomes of childhood cancer.

Part of this is managing, and funding, the Australian Childhood Cancer Registry, a national databank that provides statistical information on childhood cancers across Australia.

Our work in this area will have lasting impact on the way childhood cancer survival is analysed and assessed, not only in Australia, but around the world, and also paves the way for more targeted research projects and relevant support services for those affected.

The Viertel Cancer Research Centre is proud to be a part of this research, working to help children like Missy.

# Treatment pathways for breast cancer in Queensland



Survival for breast cancer has improved consistently over time in Queensland, driven largely by improvements in breast cancer treatment and management. However, these benefits have not been shared by all groups in the community. The findings from these studies provide crucial evidence needed to inform the next steps.

## Key facts

- Breast cancer is the most common cancer in Queensland women.
- Rural women have longer time to diagnosis and less optimal treatment.
- Non-urban women less likely to survive advanced breast cancer.
- Detailed investigation of diagnostic and treatment pathways of 3,200 women.

### Project partners

Queensland University of Technology

ARC Centre of Excellence for Mathematical and Statistical Frontiers

Griffith University

Mater Private Breast Cancer Centre

### Breast cancer outcomes study

The Viertel Centre is following more than 3,200 Queensland women diagnosed with breast cancer and living in urban, regional and rural areas of Queensland, the largest such Australian study to date. Despite availability of free biennial mammographic screening, about 40 per cent of breast cancers are still symptom-detected, with these cancers more likely to be advanced. The time between first noticing symptoms to final diagnosis was longer for Indigenous women and those living in rural or socioeconomically disadvantaged areas, and the median time to histological diagnosis was significantly longer for women who self-detected their breast cancer compared to those detected through mammography.

### Survival inequities

We have developed and applied flexible parametric relative survival

models to highlight the poorer survival for women diagnosed with cancer in rural and remote areas of Queensland compared to women living in urban centres. However, the extent of these differences was substantially greater for women diagnosed with advanced breast cancer, with only small geographical differences in survival being observed among women diagnosed with localised breast cancer.

### Treatment inequities

Through data linkage between the Queensland Cancer Registry and the Queensland Hospital Data Collection, we have found Queensland women diagnosed with localised breast cancer and living in non-urban or disadvantaged areas of the state are significantly less likely to undergo breast conserving surgery and experience less optimal clinical management.

## Improving colorectal cancer screening and outcomes



Colorectal cancer is one of the most common cancers in Queensland, second only to prostate cancer in men and to breast cancer in women. It causes over 1,000 deaths per year and has significantly lower survival rates in regional and rural areas. Yet with the availability of proven effective screening methods, the colorectal cancer mortality rate could be significantly reduced.

### Key facts

- Over 1,000 Queenslanders per year die from colorectal cancer.
- Deaths are preventable with screening and early treatment.
- Colorectal cancer screening participation is very low particularly in non-urban areas.

#### Project partners

University of Southern Queensland  
Griffith University

Survival from colorectal cancer has improved over in recent decades, largely as the result of more effective diagnosis and treatment. However, as for breast cancer, these benefits have not been shared equally by all groups in the community. Using flexible parametric relative survival modelling, and data from the Queensland Cancer Registry, we have found that both localised and advanced colorectal cancer survival is worse for patients living outside urban areas. Regular screening with the faecal occult blood test (FOBT) has been proven to be effective in detecting colorectal cancer early and reducing mortality, yet screening rates for colorectal cancer are the lowest of any population cancer screening program in Australia particularly in non-urban areas. There is strong potential to improve colorectal cancer survival rates in regional and rural areas through improved screening participation and access to treatment, but a better understanding of differences in clinical

characteristics and current treatment and screening practices is needed.

In 2016, the Viertel Centre in collaboration with the University of Southern Queensland, began a program of research to address this gap. We have completed and published a systematic literature reviews of geographical disparities in colorectal cancer stage at diagnosis, clinical management and survival; and are analysing the health profiles, comorbidities and survival of a sample of 1,500 Queensland colorectal cancer patients from different geographic regions. We have published an analysis of Australian Institute of Health and Welfare (AIHW) data assessing the extent of geographical and socio-demographic disparities in colorectal cancer screening participation. New knowledge will feed into the next stage of the work, to design and test interventions to improve screening participation and other outcomes.

# Centre for Research Excellence in Sun and Health



The relationship between sun exposure and health is complex – on the one hand, too much sun exposure increases the risk of skin cancers, while on the other hand, too little sun exposure can lead to vitamin D deficiency. The Centre for Research Excellence in Sun and Health was established to generate new knowledge about the adverse and beneficial effects of sunlight and to translate this into improved policy and practice guidelines for sun exposure.

## Key facts

- Sunlight increases the risk of skin cancer but is essential for vitamin D production.
- Amount of sun exposure required for health varies by latitude and climate.
- Clear guidelines for sun exposure for the Australian population are urgently needed.

### Project partners

University of the Sunshine Coast  
Cancer Council Queensland  
QIMR-Berghofer Medical Research Institute  
Cancer Council Victoria  
Australian National University  
The University of Melbourne

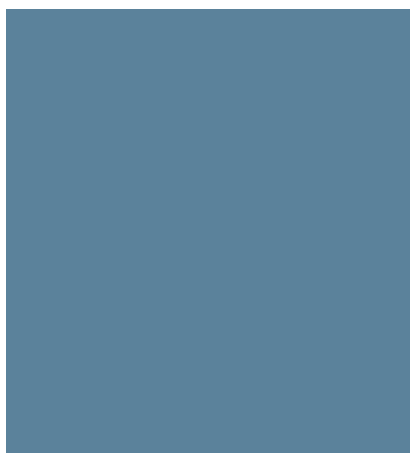
The Centre for Research Excellence in Sun and Health is a National Health and Medical Research Council funded five-year program led by the University of the Sunshine Coast with the collaboration of Cancer Council Queensland. Its research objective is to investigate the mechanisms through which sunlight causes but may also help to prevent cancer in humans. The “health duality” of sunlight is poorly understood and better information is urgently needed for appropriate public health messaging in Queensland and throughout Australia.

To date, this project has investigated the relationship between vitamin D, sun exposure and cancer; sun protection behaviours; better ways to identify skin cancers and target treatments; and new technologies for

estimating skin cancer risk. Many of the findings have fed directly into CCQ’s population health messaging for skin cancer prevention. A key translational outcome of this project has been its contribution to Cancer Council Australia’s revised position statement on the risks and benefits of sun exposure, as part of the National Cancer Control Policy. The statement describes guidelines for the general Australian population, as well as specific risk groups, about how much sun they need to avoid vitamin D deficiency and stay healthy without increasing the risk of skin cancer.



## Role of vitamin D in melanoma progression



While it is well known that the main risk factor for melanoma is sun exposure, there is evidence that vitamin D may play a role in melanoma progression. Melanoma diagnoses are increasing in Queensland and other predominantly fair-skinned populations around the world, and better understanding of melanoma development is essential for melanoma control programs.

### Key facts

- Vitamin D is formed in the skin through exposure to sunlight.
- Vitamin D may have an important role in melanoma progression and survival.
- Investigation of vitamin D in 600 Queensland melanoma patients.

#### Project partners

University of the Sunshine Coast

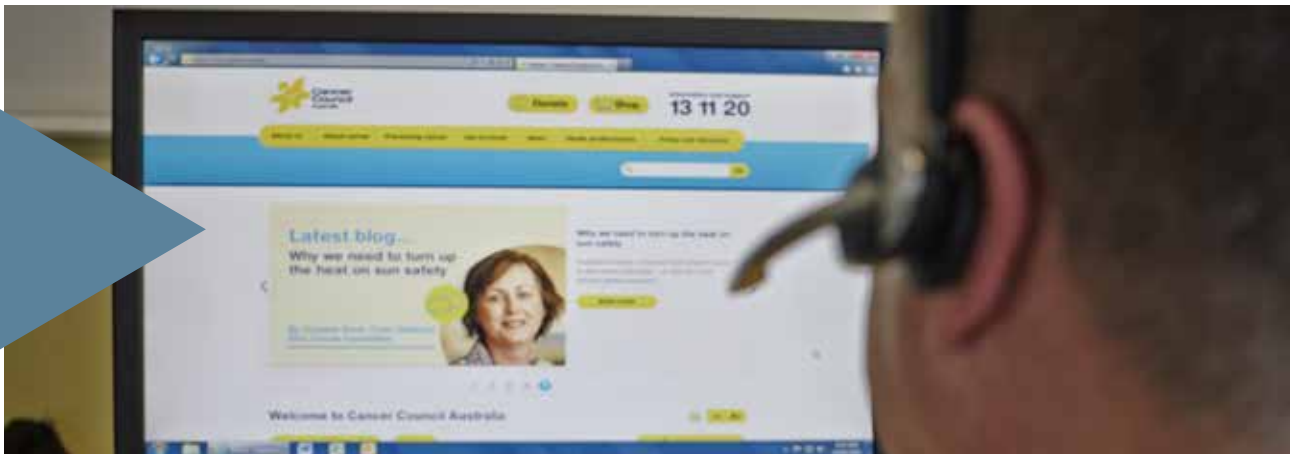
US Department of Defence

Vitamin D is produced by the action of ultraviolet radiation on exposed skin, the same radiation that causes melanoma. There is a growing body of evidence suggesting vitamin D may play an important role in melanoma progression. Further, some studies have suggested that higher lifetime sun exposure is associated with lower risk of mortality during the five years following melanoma. While excessive sun exposure is a major risk factor, this hypothesis suggests that increased vitamin D from sun exposure may also increase survival.

This project, involving 600 Queensland melanoma patients, and funded through a grant from by the US Department of Defence will investigate the possibility that

vitamin D could be used as a potential biomarker of melanoma progression, with an additional role in melanoma treatment and prevention. The project will generate new knowledge in melanoma and have direct relevance to Queensland and the broader Australian population. Results will be rolled out to study partners, including the US Department of Defence who have a specific interest in how the findings may benefit active military personnel. The findings will also be used as a foundation for future melanoma research projects. With melanoma incidence continuing to rise globally, identifying those factors that may impact diagnosis and prognosis is critical to reduce the burden of this cancer.

## CancerCope: a clinical trial of an online support program for distressed cancer patients



Developing and trialling supportive care programs such as CancerCope ensures CCQ can provide the best evidence-based and effective support to cancer patients who need it, in a way that is accessible to everyone in the community.

### Key facts

- Distress after cancer diagnosis is common and can persist long-term.
- Web-based programs increase accessibility to support.
- Potential benefit for patients in regional and rural areas.

#### Project partners

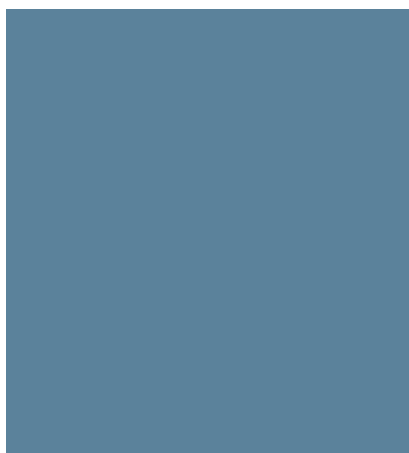
Griffith University

University of Virginia, USA

Psychosocial care is now well acknowledged as an essential part of quality cancer care, but there are limitations on how to deliver this on a population-level. Self-managed support programs available online may provide the answer, as they can help to overcome geographic and socio-demographic barriers associated with access to psychosocial care. To address this, we are conducting a clinical trial of an innovative online supportive care program (CancerCope) for distressed cancer patients, compared to a static website containing patient education materials, to reduce cancer-related distress and improve quality of life. CancerCope is a six-week interactive program with six core areas covering stress management, relaxation exercises, managing unhelpful thoughts,

problem-solving, decision-making and self-care (including exercise, sleep, fatigue and nutrition). In 2016, we completed recruitment for this trial with 163 participants completing baseline assessment. Fifty percent of patients had clinically significant distress. The area of greatest need was in the psychological domain, and in particular fears about cancer recurrence. Needs around feeling depressed or anxious, tiredness, loss of control and concerns about family were also highly prevalent. These results were published in BMJ Open. Follow-up of participants will end in 2017. Once completed, this trial will provide important information about the effectiveness of an online psychological intervention to improve the mental health of people with cancer, at minimal cost and high community accessibility.

# Clinical trial of mindfulness for advanced prostate cancer



Patients with advanced prostate cancer often suffer distress and poor quality of life. While there are some indications that mindfulness-based cognitive therapy may be effective, CCQ requires strong scientific evidence before implementing these programs. Clinical trials are the best means of providing such evidence, and will ensure that CCQ can offer the best possible programs for people with cancer.

## Key facts

- Men with advanced prostate cancer face significant psychological challenges.
- Mindfulness-based therapy may help reduce psychological distress.
- A clinical trial is the best way to test if this approach is effective.

### Project partners

Griffith University

ANZUP Cancer Trials Group

Prostate Cancer Foundation of Australia

Men with advanced prostate cancer report higher levels of psychological distress and poorer quality of life compared to men with localised disease. Mindfulness-based cognitive therapy can help patients to be less reactive to difficult experiences and become more accepting of their illness and situation, leading to less distress. In 2016, we completed a world-first effectiveness clinical trial of mindfulness-based approaches for men with advanced prostate cancer. The 8-week mindfulness-based cognitive group therapy intervention, Living Well with Prostate Cancer, was delivered to men by telephone (in addition to usual medical care) to assess whether they improved over time compared to men who received self-help booklets. A total of

189 men took part in the trial, which showed that mindfulness-based cognitive therapy did not improve the men's wellbeing in comparison to their usual medical management. Men reported no reduction in psychological distress, anxiety about testing for prostate specific antigen, or distress related to their cancer, and no improvement in quality of life or post-traumatic growth. Although wellbeing did not change, many men did describe the program as helpful in terms of not feeling alone, learning meditation and breathing exercises, understanding the meaning of well-being and perceived control of thoughts and health. Results of this trial were published in the Journal of Clinical Oncology.



## Case Study.

# Yasha Watkins

If survival rates were the same for people in the country as in the city, there would be 350 fewer cancer deaths in Queensland each year.



When Ellesmere local Yasha Watkins was diagnosed with breast cancer this year, she felt alone, knowing that she faced a difficult time ahead.

With no treatment available in her hometown, Yasha had to travel 140km to Toowoomba for six weeks to access lifesaving treatment.

With that came stress, fear of the unknown, loneliness and financial strain.

Sadly, many other regional Queenslanders face the same reality.

**“AFTER I WAS DIAGNOSED MY STORY ONLY GOT WORSE. IT’S HARD WHEN YOU HAVE TO GO SO FAR AWAY FOR TREATMENT, WHERE YOU DON’T HAVE FRIENDS OR NEIGHBOURS TO SUPPORT AND ENCOURAGE YOU.**

“You’re alone and you go through emotions of not knowing whether you are going to get through it, not knowing whether you will have to say goodbye to family, or whether life will begin again.”

Closing the gap in regional survival is core to Cancer Council Queensland’s mission and key to cancer control in the future.

There is an urgent need to understand why cancer outcomes are worse for regional patients and what should be done to address this.

Part of our research strategy is to engage with local communities, talk to them about the problems, and involve them in designing solutions.

It’s crucial that all Queenslanders, no matter where they live, have the best possible chance of surviving a cancer diagnosis.

# Understanding volunteering



Our focus on the experience and contributions of volunteers supports CCQ's mission to serve and empower the community. The Viertel Centre's research gives valuable insight into how cancer control and other non-profit organisations can best support volunteers who give their time in different ways, and will provide recommendations for non-profit sector policy and practice involving volunteers.

## Key facts

- Volunteers are essential for cancer control organisations globally.
- Increasing demand for flexible volunteering opportunities.
- CCQ needs to respond to this trend while also supporting long-term volunteers.

### Project partners

Griffith University

Union for International Cancer Control

American Cancer Society

Volunteering Queensland

Prostate Cancer Foundation of Australia (PCFA)

### Volunteering patterns in cancer control

In 2016, we commenced a new program of research funded by an Australian Research Council Linkage grant to gain a better understanding of changing volunteering patterns in cancer control. We interviewed volunteers and managers from cancer control organisations across the globe and surveyed volunteers at Queensland Relay For Life events. More activities are planned for 2017 and these include attending more events and surveying volunteers and non-profits about the economic and social costs and benefits of different types of volunteering. Findings will feed into strategies to improve recruitment and retention of volunteers who support cancer control initiatives.

### Peer support

Peer support connects cancer survivors (volunteers) with cancer patients soon after their diagnosis or treatment, either in-person, by telephone, or as a group. In Australia, community peer support groups

for men with prostate cancer have emerged however there is little understanding of why these groups formed. We interviewed 21 prostate cancer support group leaders nationally and conducted focus groups to chronicle the history and basis of the support group movement. Results showed that men felt isolated and neglected in the health system and that support groups enabled them to give mutual help to each other. Negotiating the health system was challenging and men found that together, and by affiliating with the national prostate cancer organisation, they could use their collective voice to bring about change. Men described the challenges of making support groups sustainable and inclusive of men from different backgrounds. Findings were published in the European Journal of Cancer Care and a monograph documenting the history of the movement, *Mates Helping Mates – A History of Prostate Cancer Support Groups in Australia* has been released.

# Law at the end of life



Led by the Health Law Research Centre at the Queensland University of Technology in collaboration with CCQ, this study is the first attempt to understand whether members of the community understand and act upon their legal right to participate in decisions about medical treatment for themselves or family members at the end of life. The project will provide evidence-based recommendations to assist CCQ and other Cancer Councils to support and educate the community and encourage broader discussion of these sensitive issues.

## Key facts

- Australian law requires informed consent prior to medical treatment.
- Many barriers exist to genuine participation in treatment decisions.
- Need for evidence-based community education and information strategy.

### Project partners

Health Law Research Centre,  
Queensland University of Technology

Cancer Council Victoria

Cancer Council NSW

McCabe Centre for Law and Cancer

Although Australian law requires that informed consent about medical treatment be given prior to treatment, and that patients participate in decisions about their healthcare, there are major barriers to such participation, particularly for patients who are terminally ill and at the end of life. Genuine participation in decisions such as continuing aggressive treatment or taking a palliative approach requires knowledge and understanding from the patient about their legal rights. This project is exploring the community's knowledge of law at the end of life, and how that affects the ability of patients and their families to make decisions about treatment. This four-year project employs qualitative and quantitative methodologies to consider law and practice in three jurisdictions: Queensland, Victoria and New South

Wales. Stage 1 (critical analysis of current resources and information available to the community about legal duties and rights) and Stage 2 (telephone survey of community knowledge and experience of end of life decision-making) are completed. Stage 3, involving in-depth interviews with people who have had or are undergoing end-of-life decisions, including adult patients with a diagnosis of terminal cancer, is underway. In the final Stage 4, we will synthesise the evidence and findings to make recommendations about law reform, health service system changes and community education. This will include the design and pilot of a community education and information strategy to address identified knowledge gaps.



# Improving cancer staging for all patients



Differences in cancer stage at diagnosis amongst Queenslanders are likely to contribute to differences in survival between regions and population groups. Access to this vital information will inform the development of appropriate interventions to reduce these disparities. Further, our world-leading research in staging of childhood cancers will allow, for the first time, accurate international comparisons of childhood cancer outcomes and inequalities.

## Key facts

- Stage at diagnosis is one of the strongest predictors of cancer survival.
- National data on cancer stage at diagnosis are not available.

### Project partners

Cancer Australia

Hospital for Sick Children, Toronto, Canada

Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Boston, USA

The Australasian Association of Cancer Registries (AACR)

All major paediatric oncology treating hospitals in Australia

The Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG)

QIMR Berghofer Medical Research Institute

Queensland Health

The Victorian Cancer Registry

### Staging for adult cancers

The Viertel Centre is conducting the Queensland component of a national study designed to test the feasibility of extracting stage information from pathology reports. Over 15,000 cases of colorectal cancer, lung cancer, prostate cancer, breast cancer and melanoma are being examined, using medical records held by the Queensland Cancer Registry. The national project will provide the first data on cancer stage at diagnosis for these cancers, for the whole Australian population. This will allow stage at diagnosis to be assessed according to socioeconomic and geographic groups, enabling appropriate interpretation of national cancer survival outcomes.

### Staging for childhood cancers

Unlike adult cancers, many types of childhood cancer lack universally-accepted staging systems. New guidelines, published recently by the Union for International Cancer Control, offer the potential for population registries to collect comparable and consistent information on stage at diagnosis for children with cancer, using data

components available in medical records. In 2015, the Viertel Centre was asked to lead the development and testing of detailed staging rules based on these new international guidelines. Preliminary results show that stage can be assigned for over 90% of eligible childhood cancers within a population registry setting. Of the children included in the study, approximately three-quarters were found to have localised or regional disease while one-quarter had metastatic or advanced disease at diagnosis.

CCQ's achievements in national staging of childhood cancers will help lead to the consistent collection of data not only throughout Australia, but internationally. Staging rules developed by the Viertel Cancer Research Centre were published in the international staging manual, "The TNM Classification of Malignant Tumours", 8th Edition (released December 2016). This marks the first time that staging rules specific to childhood cancer have been included in this international standard.

# Digital technology

The Viertel Centre's Queensland Cancer Statistics Online (QCSOL) provides open access for everyone to comprehensive data about the burden of cancer in Queensland. Provision of this information for the community is a CCQ priority as this information underpins all cancer control activities. An online staging application being developed for childhood cancer will contribute to CCQ's aim to inform global understanding of cancer control by facilitating the collection of internationally consistent childhood cancer staging data.

## Key facts

- Innovative technology is required to meet the information needs of the community.
- Developing a world first online application to electronically collect stage information for childhood cancers.

### Project partners

New Zealand Children's Cancer Registry (NZCCR)

Hospital for Sick Children, Toronto, Canada

Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Boston, USA

### Queensland Cancer Statistics Online

Queensland Cancer Statistics Online (QCSOL) is an online data tool that provides free access to the most recent incidence, survival, mortality and prevalence statistics for Queensland. The website presents selected results by sex, age group and calendar year for 27 of the most common cancers and cancer groups in Queensland. QCSOL was re-developed in 2016 to utilise the latest digital technology, enable greater interactivity, enhance its performance on mobile devices and provide a modular framework to readily enable additional statistics to be added in the future. It not only informs Cancer Council Queensland staff, but also enables prompt responses to requests for information from the media, cancer patients and the general community.

### Childhood cancer staging application

In conjunction with Information Technology experts from CCQ, staff of the Viertel Centre are guiding the development of a world-first custom-made online application for collecting the data required to assign stage for childhood cancer patients. Separate modules are required for each of the 16 different types of eligible cancer. The purpose of the application is to reduce human errors and maximise consistency by automatically assigning stage from the input data, in accordance with the staging rules we developed from the Toronto Paediatric Cancer Stage Guidelines.

Initial testing of the staging application was successfully conducted in both Australia and New Zealand during 2016 and further testing is planned in Europe and North America. Once completed, the application will be made freely available to cancer registries worldwide.





# Meet our researchers and research partners



## PROFESSOR JOANNE AITKEN

Head of Research, Cancer Council Queensland

Joanne is Head of Research and the Director of the Australian Childhood Cancer Registry at Cancer Council Queensland. She has worked as a cancer epidemiologist for the past 25 years, with over 200 scientific publications and 9,000 career citations. She was co-winner of the Queensland Government's inaugural Smart Women Smart State award in the research scientist category for cancer control research. Joanne sits on advisory boards for cancer registration, cancer in young adults, and cancer service quality and safety and she is the elected regional representative for Oceania on the Executive Board of the International Association of Cancer Registries. Her research interests include the epidemiology of childhood cancer, improved methods for population-based cancer surveillance, and development of novel approaches to reduce inequity in cancer outcomes.



## PROFESSOR JEFF DUNN, AO

Chair, Social and Behavioural Sciences, Institute for Resilient Regions, University of Southern Queensland

Jeff held the position of Chief Executive Officer, Cancer Council Queensland from January 2002 until March 2016, when he was appointed to the prestigious position of Professor and Chair of Social and Behavioural Sciences within the University of Southern Queensland's Institute for Resilient Regions. Jeff is Strategic Research Leader of Social and Behavioural Science within the Viertel Cancer Research Centre. Jeff also holds Professorial appointments with the Griffith University School of Medicine and the University of Queensland School of Social Science. He has a central focus on the social and behavioural aspects of cancer control, spanning the continuum of research, prevention, early detection, supportive care and quality of life. He is actively involved in research in this field and has dedicated his career to the development of novel supportive care strategies that underpin cancer prevention and improve community awareness of the disease.



## PROFESSOR SUZANNE CHAMBERS

Director and Menzies Foundation Professor of Allied Health Research, Menzies Health Institute Queensland.

Suzanne is the Director of the Menzies Health Institute Queensland at Griffith University and Strategic Research Leader in Psycho-oncology within the Viertel Cancer Research Centre. She is a registered nurse and psychologist who has worked as a practitioner and researcher in psychological support for people with cancer for over 25 years. Suzanne has published extensively on the psychosocial effects of cancer and effective ways to enhance quality of life and psychological outcomes after diagnosis and treatment. She has received research grants from esteemed agencies such as the National Health and Medical Research Council and Australian Research Council. She has over 200 peer reviewed publications, chapters and reports. Her research is published in internationally leading journals including the Journal of Clinical Oncology, The Lancet and Lancet Oncology, and Psycho-Oncology. She currently chairs the Quality of Life and Supportive Care Subcommittee of the Australia and New Zealand Urogenital and Prostate Cancer trials group (ANZUP).





### PROFESSOR MICHAEL KIMLIN

Professor of Cancer Prevention Research, University of Sunshine Coast

Michael is USC/CCQ Professor of Cancer Prevention Research. He has developed a world-first research program to understand the health duality of human exposure to ultraviolet radiation. His career spans both the USA and Australia culminating with leadership of the NHMRC Centre of Research Excellence in Sun and Health. He has published over 180 articles on skin cancer prevention, vitamin D and sun exposure assessment. His vitamin D and UV radiation research provided key evidence for the "Risks and Benefits Statement for UV Exposure" – a joint position statement by Cancer Australia, Osteoporosis Australia, Australasian College of Dermatologists and the Australian Bone and Mineral Society.



### PROFESSOR PETER BAADE

Senior Research Fellow (Biostatistics)

Peter Baade is a Senior Research Fellow (Biostatistics), with several adjunct university appointments. He is an Accredited Statistician with the Statistical Society of Australia. His primary research interests are to describe the patterns of cancer-related outcomes both nationally and internationally, and to better understand why these outcomes depend on where people live, including the role of remoteness, area disadvantage and ethnicity. He has published over 200 peer reviewed manuscripts and monographs and received more than \$12 million in total grant funding.



### MR DANNY YOULDEN

Research Fellow (Biostatistics)

Danny Youlden is a biostatistician with over 25 years of experience, mostly working in health-related fields. He is Research Fellow (Biostatistics) and Team Leader for the Australian Childhood Cancer Registry and holds an adjunct appointment as Senior Lecturer at the Menzies Health Institute Queensland. Danny has been with the Viertel Cancer Research Centre since 2005. His main contributions during that time have been as the lead author on several comprehensive reports examining the descriptive epidemiology of major cancers in Queensland as well as heading national studies on the incidence and survival of childhood cancer.



### DR MEL HYDE

Senior Research Fellow, Menzies Health Institute Queensland.

Mel holds a conjoint position with Cancer Council Queensland and Griffith University as a Senior Research Fellow. She contributes to the Psycho-Oncology Research Program which aims to improve psychosocial and quality of life outcomes for cancer patients and their families, with a particular focus on prostate cancer survivorship. She also contributes to research aiming to understand and engage the community in prosocial behaviours (e.g., donation, volunteering) to support cancer control. She is a Chief Investigator on an Australian Research Council Linkage grant examining episodic volunteering in non-profit organisations. Since 2007 Mel has co-authored over 90 scientific publications and has received local and international recognition for her work in health psychology and cancer survivorship.

# Appendix

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65. Yaxley JW, Coughlin GD, Chambers SK, Occhipinti S, Samaratunga H, Zajdlewicz L, Dunglison N, Carter R, Williams S, Payton DJ, Perry-Keene J, Lavin MF, Gardiner RA. Robot-assisted laparoscopic prostatectomy versus open radical retropubic prostatectomy: early outcomes from a randomised controlled phase 3 study. *The Lancet*. 2016; 388(10049):1057-1066.
66. Youl PH, Aitken JF, Turrell G, Chambers SK, Dunn J, Pyke C, Baade PD. The impact of rurality and disadvantage on the diagnostic interval for breast cancer in a large population-based study of 3202 women in Queensland, Australia. *International Journal of Environmental Research and Public Health*. 2016; 13(11):1156.
67. Youl PH, Dasgupta P, Youlden D, Aitken JF, Garvey G, Zorbas H, Chynoweth J, Wallington I, Baade PD. A systematic review of inequalities in psychosocial outcomes for women with breast cancer according to residential location and Indigenous status in Australia. *Psycho-Oncology*. 2016; 25(10):1157-1167.
68. Youlden DR, Baade PD, Soyer HP, Youl PH, Kimlin MG, Aitken JF, Green AC, Khosrotehrani K. Ten-year survival after multiple invasive melanomas is worse than after a single melanoma: a population-based study. *Journal of Investigative Dermatology*. 2016; 136(11):2270-2276.
69. Youlden DR, Baade PD, Soyer HP, Youl PH, Kimlin MG, Aitken JF, Green AC, Khosrotehrani K. Response to Commentary "Utility and Limitations of Large Population-Based Data for Skin Cancer Outcomes". *Journal of Investigative Dermatology*. 2016. DOI: 10.1016/j.jid.2016.12.003.
70. Youlden DR, Khosrotehrani K, Green AC, Soyer HP, Kimlin MG, Youl PH, Aitken JF, Baade PD. Diagnosis of an additional in situ melanoma does not influence survival for patients with a single invasive melanoma: A registry-based follow-up study. *Australasian Journal of Dermatology*. 2016; 57(1):57-60.
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72. Zopf EM, Newton RU, Taaffe DR, Spry N, Cormie P, Joseph D, Chambers SK, Baumann FT, Bloch W, Galvao DA. Associations between aerobic exercise levels and physical and mental health outcomes in men with bone metastatic prostate cancer: a cross-sectional investigation. *European Journal of Cancer Care*. 2016. DOI: 10.1111/ecc.12575.



# Grants and awards 2016

## AWARDED IN 2016

Aitken J, Baade P. The collection of registry-derived stage for five adult cancers in Queensland. Cancer Australia. 2016-2017. \$96,998.

Chambers SK, Newton R, Scuffham P, Baade P, Galvao D, Dunn J, Smith D, Wittert G, Davis I, Gardiner RA. Centre of Research Excellence in Prostate Cancer Survivorship (CRE-PCS). NHMRC CRE in Health Services Research. 2016-2020. \$2,498,842. APP1116334.

Mengersen K, Baade P, Cramb S, Aitken J, White N, McGree J, Harden F, Burrage P, Roberts J. Provision of spatial incidence and survival estimates for the National Cancer Atlas. Australian Institute of Health and Welfare and Co-operative Research Centre for Spatial Information. 2016-2018. \$200,000.

Mengersen K, Baade P, Cramb S, Aitken J, White N, McGree J, Harden F, Burrage P, Roberts J. Utilisation of Spatial Cancer Models: A National Cancer Atlas. Co-operative Research Centre for Spatial Information, Cancer Council Queensland and Queensland University of Technology. 2016-2018. \$545,000.

Mengersen K, Baade P, Cramb S, White N, McGree J, Aitken J, Harden F, Burrage P, Roberts J. Review of Statistical methodological infrastructure to underpin the development of a National Atlas of Cancer. National Health Performance Authority and Co-operative Research Centre for Spatial Information. 2016. \$100,000.

Youl P. Treatment decisions of rural women diagnosed with early breast cancer. Research Services Agreement. Breast Cancer Network Australia. 2016-2017. \$20,000.

Skinner T, Jenkins D, Dunn J, Chambers SK, Aitken JF, Adlard K, Bolam K, Gomersall S. Peer support: the key to exercise maintenance in cancer survivors? A pilot study. Tom Penrose Community Service Grant, Exercise and Sports Science Australia. 2016-2018. \$16,000.

Baade P, Cramb S, Dasgupta P. Regional analysis of Indigenous cervical screening data for New South Wales. Strategic Research Partnership to improve cancer control for Indigenous Australians Menzies School of Health Research and New South Wales Cancer Council. 2016-2017 \$31,000

## ONGOING IN 2016

Chambers SK, Dunn J, Ritterband L, Aitken JF, Scuffham P, Morris B, Baade P, Youl P. Improving Access to Psychological Services for People with Cancer: A Randomised Control Trial of an Interactive Web-Based Intervention. NHMRC Partnership Grant. 2013-2017. \$587,271. APP1056756.

Chambers SK, Hyde MK, Ng SK, Scuffham P, Dunn J, Creyton M, Torode J, Stein KD. Celebrate. Remember. Fight Back. Episodic volunteering for non-profits. ARC Linkage Grant Scheme. 2015-2018. \$221,574. LP150100368.

Kimlin M, Baade P, Youl P. Is vitamin D status at time of melanoma diagnosis associated with stage of tumour? United States Department of Defence. 2015-2017. USD\$283,166.

Soyer HP, Green A, Aitken J, Menzies S, Sturm R, Duffy D, Janda M, Prow T, Schaidt H. Centre of Research Excellence for the Study of Naevi. NHMRC CRE in Clinical Research. 2015-2019. \$2,496,835. APP1099021.

White B, Willmott L, Tilse C, Wilson J, Lawson D, Dunn J, Pearce A. Enhancing community knowledge and engagement with law at the end of life. Australian Research Council Linkage Grant Scheme. 2015-2018. \$321,527. LP140100883.

Aitken J, Youlden D, Baade P, Green A, Valery P, Gupta S, Hallahan A, Thursfield V. Development and evaluation of Business Rules for the collection of paediatric cancer stage by population registries. Cancer Australia. 2015-2016. \$127,446

Youl P. The impact of geographical location and socioeconomic on outcomes from breast cancer. National Health and Medical Research Council Early Career Fellowship; \$299,564; 2013-2016.

# Scientific presentations 2016

1. Aitken JF. The Paediatric Cancer Staging Project. Cancer Australia Research and Data Advisory Group, 25 February 2016, Sydney.
2. Aitken JF. Background to cancer clusters. Invited Speaker. Griffith University, 21 March 2016, Brisbane.
3. Aitken JF. The STaR Project: Paediatric Cancer Staging in Population Registries. Cancer Australia Staging Treatment and Recurrence Advisory Group, 5 April 2016, Sydney.
4. Aitken JF. The STaR Project: Paediatric Cancer Staging. Australasian Association of Cancer Registries AGM, 12 April 2016, Brisbane.
5. Aitken JF. Cancer in the Pacific Islands. Invited Speaker. Cancer Registration Symposium, 13 April 2016, Brisbane.
6. Aitken JF. Collecting STAGE in childhood cancer registries. Invited Speaker. Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG) 2016 ASM, 24 June 2016, Cairns.
7. Aitken JF. The changing burden of childhood cancer. Invited Plenary. Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG) 2016 ASM, 24 July 2016, Cairns.
8. Aitken JF. Cancer registration in Oceania. 38th Annual International Association of Cancer Registries (IACR) Conference, 19-21 October 2016, Marrakech, Morocco.
9. Aitken JF. Childhood Cancers: Linking data to provide evidence and inform action in low- and middle-income countries. Plenary Co-Chair. 38th Annual International Association of Cancer Registries (IACR) Conference, 19 October 2016, Marrakech, Morocco.
10. Aitken JF. From theory to practice: Implementation of the Toronto Paediatric Cancer Stage Guidelines for population registries. Plenary Speaker. 38th Annual International Association of Cancer Registries (IACR) Conference, 19 October 2016, Marrakech, Morocco.
11. Baade PD. Quantifying changes in the survival inequality for Indigenous people diagnosed with cancer in Queensland, Australia. World Indigenous Cancer Conference, 12-14 April 2016, Brisbane.
12. Chambers SK. Quality of Life Workshop. Invited presentation. ANZUP Supportive Care Research, 22 April 2016, Sydney.
13. Chambers SK. Psychological distress and stigma. Invited presentation. Head and Neck Cancer Symposium Translational Research Institute, 10 June 2016, Brisbane.
14. Chambers SK. It's not just about drugs: Supportive care. ANZUP Community Engagement Forum: A little below the belt. Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP) 2016 ASM, 10 July 2016, Brisbane.
15. Chambers SK. Mindfulness-based cognitive therapy for men with advanced prostate cancer: A randomised controlled trial. Invited Plenary. 18th International Psycho-Oncology Society (IPOS) World Congress, 19 October 2016, Dublin, Ireland.
16. Chambers SK. Post-traumatic growth, distress and cancer survivorship. Invited Symposium. 18th International Psycho-Oncology Society (IPOS) World Congress, 19 October 2016, Dublin, Ireland.
17. Chambers SK. Update on Psychosocial Care. Invited Symposium with European Society of Oncology. 18th International Psycho-Oncology Society (IPOS) World Congress, 20 October 2016, Dublin, Ireland.
18. Chambers SK. What does it mean to be a cancer survivor in 2016? Invited Plenary. Irish Cancer Society National Conference for Cancer Survivorship, 22 October 2016, Dublin, Ireland.
19. Chambers SK. Living Well as a Cancer Survivor. Invited Workshop. Irish Cancer Society National Conference for Cancer Survivorship, 22 October 2016, Dublin, Ireland.
20. Chambers SK. Prostate Cancer Survivorship. Invited Speaker. Division of Primary Practice and Population Health University of Edinburgh, 27 October 2016, Edinburgh, Scotland.
21. Chambers SK. Prostate cancer support groups in Australia: case study of a grassroots health movement. Union for International Cancer Control (UICC) World Cancer Congress, 3 November 2016, Paris, France.

22. Chambers SK. Prostate cancer survivorship. Invited Presentation. Seoul National University Bundang Hospital, 8 December 2016, Seoul, Korea.
23. Chambers SK. Prostate cancer survivorship: Key targets for action. Annual Korean Society of Cancer Prevention Meeting 2016, 9 December 2016, Seoul, Korea.
24. Clift K. Harnessing the media landscape for advocacy and effective health communications. Session Co-Chair. Union for International Cancer Control (UICC) World Cancer Congress, 2 November 2016, Paris, France.
25. Clift K. How to build on strengths and harness strategy. Union for International Cancer Control (UICC) World Cancer Congress, 2 November 2016, Paris, France.
26. Clutton S. Implementation of a stepped care model: implications for clinicians. Union for International Cancer Control (UICC) World Cancer Congress, 2 November 2016, Paris, France.
27. Cramb SM. Head and neck cancers (HNC) among Indigenous Australians living in Queensland, 1997-2012. World Indigenous Cancer Conference, 12-14 April 2016, Brisbane.
28. Cramb SM. The great divide: Remoteness of residence and cancer survival differentials for Indigenous persons in Queensland. World Indigenous Cancer Conference, 12-14 April 2016, Brisbane.
29. Cramb SM. Cancer statistics and research in Queensland – the use of cancer registry data. Invited Presentation. QCR Education Seminar. Faculty of Health Queensland University of Technology, 27 April 2016, Brisbane.
30. Cramb SM. Surviving cancer: where you live in Queensland could matter. Poster. Australian Society for Medical Research Postgraduate Student Conference, 1 June 2016, Brisbane.
31. Cramb SM. Cancer statistics and research in Queensland - the use of cancer registry data. Invited Presentation. QCR Education Seminar. Faculty of Health Queensland University of Technology, 9 August 2016, Brisbane.
32. Cramb SM. The National Cancer Atlas: Purpose and Potential. Invited Speaker. Cooperative Research Centre for Spatial Information 2016 Annual Conference, 26-27 October 2016, Sydney.
33. Cramb SM. Mapping cancer: using routinely collected data for big, bold analyses. Invited Speaker. QUT BRAG-UQ ISSR collaborative workshop, 16 December 2016, QUT, Brisbane.
34. Crowe B, Sanmugarajah J, Hyde MK, Dunn J, Chambers SK. Translating distress screening into cancer care: An implementation case study at Gold Coast University Hospital, Australia. Asia-Pacific Cancer Leaders' Summit 8th General Assembly (APOCP8), 13-14 April 2016, Brisbane.
35. Dunn J. Plenary Co-Chair. Asian Pacific Organization for Cancer Prevention (APOCP) 8th General Assembly, 13 April 2016, Brisbane.
36. Dunn J. APOCP 8th General Assembly. Chair. Asian Pacific Organization for Cancer Prevention (APOCP) 8th General Assembly, 14 April 2016, Brisbane.
37. Dunn J. APOCP Future Priorities. Plenary Co-Chair. Asian Pacific Organization for Cancer Prevention (APOCP) 8th General Assembly, 14 April 2016, Brisbane.
38. Dunn J. President's Report. Asian Pacific Organization for Cancer Prevention (APOCP) 8th General Assembly, 14 April 2016, Brisbane.
39. Dunn J. Mobilising Communities for Change. Plenary Chair. Asia-Pacific Cancer Leaders' Summit, 15 April 2016, Brisbane.
40. Dunn J. Challenges in Planning for Change. Plenary Chair. Asia-Pacific Cancer Leaders' Summit, 15 April 2016, Brisbane.
41. Dunn J, Hyde MK, Chambers SK. Peer support in cancer. Invited IPOS Academy Workshop. 18th International Psycho-Oncology Society (IPOS) World Congress, 17 October 2016, Dublin, Ireland.
42. Dunn J. Psychosocial outcomes for patients with advanced melanoma: Systematic review. Invited Presentation. 18th International Psycho-Oncology Society (IPOS) World Congress, 19 October 2016, Dublin, Ireland.

43. Dunn J. The Q Factor: Quality of life and patient care. Track 3 - Improving patient and family experiences. Session Chair. Union for International Cancer Control (UICC) World Cancer Congress, 1 November 2016, Paris, France.
44. Dunn J. Rapid Fire - Practice, policy and advocacy reports. Session Chair. Union for International Cancer Control (UICC) World Cancer Congress, 1 November 2016, Paris, France.
45. Dunn J. Translating fundraising and campaigning expertise. Invited Presentation. Union for International Cancer Control (UICC) World Cancer Congress, 1 November 2016, Paris, France.
46. Dunn J. Integrating the psychosocial domain into cancer care. Track 3 - Improving patient and family experiences. Session Chair. Union for International Cancer Control (UICC) World Cancer Congress, 2 November 2016, Paris, France.
47. Dunn J. UICC Regional Meeting - Asia-Pacific - Capacity Building and collaborative work in the region. Session Co-Chair. Union for International Cancer Control (UICC) World Cancer Congress, 2 November 2016, Paris, France.
48. Dunn J. Global aspects of cancer survivorship - where is everybody? Picking up after cancer treatment and bridging treatment into survivorship care. Session Co-Chair. Union for International Cancer Control (UICC) World Cancer Congress, 3 November 2016, Paris, France.
49. Dunn J. Psycho-oncology and primary prevention in cancer control plans: an absent voice? Invited Presentation. Union for International Cancer Control (UICC) World Cancer Congress, 3 November 2016, Paris, France.
50. Dunn, J. Cancer control in the Asia Pacific: Attributable risks and emerging priorities. Session Chair. Annual Korean Society of Cancer Prevention Meeting 2016, 9 December 2016, Seoul, Korea.
51. Dunn J. Emerging cancer control challenges for the Asia Pacific region in psychosocial care and quality of life. Invited Presentation. Annual Korean Society of Cancer Prevention Meeting 2016, 9 December 2016, Seoul, Korea.
52. Hyde MK. Cancer Council Queensland's volunteering research. Invited Presentation. University of Queensland, 8 March 2016, Brisbane.
53. Hyde MK. Understanding volunteers' commitment to cancer control events. Asia-Pacific Cancer Leaders' Summit 8th General Assembly (APOCP8), 13-14 April 2016, Brisbane.
54. Hyde MK. Men's help seeking after cancer treatment. Invited Presentation. Younger GU & Rehabilitation Symposium. Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP) 2016 ASM, 12 July 2016, Brisbane.
55. Hyde MK. Prostate-cancer related concerns of men in the first year after localised prostate cancer diagnosis and decisions to seek help. 18th International Psycho-Oncology Society (IPOS) World Congress, 19 October 2016, Dublin, Ireland.
56. Hyde MK. Supportive care needs and services for melanoma patients. Invited Presentation. 18th International Psycho-Oncology Society (IPOS) World Congress, 19 October 2016, Dublin, Ireland.
57. Hyde MK. Men's decisions to seek help for prostate-cancer related concerns in the first year after localised prostate cancer diagnosis. Union for International Cancer Control (UICC) World Cancer Congress, 2 November 2016, Paris, France.
58. Hyde MK. Prostate-cancer related concerns and men's decisions to seek help after diagnosis. Gold Coast Health and Medical Research Conference, 1 December 2016, Gold Coast.
59. Legg M. How does social identity motivate peer support? Data from a prospective and population-based survey of women newly diagnosed with breast cancer. Society of Australasian Social Psychologists (SASP) Conference, 31 Mar - 3 April 2016, Brisbane.
60. Legg M. Needy or resilient? Prototypes accessed in decision-making about peer support for cancer. Asia-Pacific Cancer Leaders' Summit 8th General Assembly (APOCP8), 13-14 April 2016, Brisbane.
61. Legg M. Needy or resilient? Prototypes accessed in decision-making about peer support for cancer. Gold Coast Health and Medical Research Conference, 1 December 2016, Gold Coast.
62. Youl PH. The Cancer Burden. Guest Lecture. School of Public Health University of Queensland, 12 April 2016, Brisbane.
63. Youlden DR. A new perspective on survival following multiple primary melanomas. Invited speaker. Queensland Melanoma Collaborative Forum, 2 December 2016, Brisbane.



# Professional and community activities 2016

## EXPERT ADVISORY COMMITTEES, SCIENTIFIC PANELS AND WORKING GROUPS

Australian and New Zealand Urogenital and Prostate (ANZUP) Cancer Trials Group, Quality of Life Committee

Australian Research Council, Engagement and Impact Assessment Pilot Panel

Asian Pacific Organization for Cancer Prevention (APOCP)

- President
- Regional Chairperson Australasia
- Executive Committee member

Australasian Association of Cancer Registries, Executive Committee

British Medical Journal Open, Statistical Advisory Board

Cancer Council Australia, Cancer Councils National Research Administration Working Group

Cancer Council Australia, CEO Forum

Cancer Research Malaysia, Scientific Advisory Group

Centre for Prostate Cancer Survivorship Research, Lead Advisory Group member

Co-operative Research Centre for Spatial Information (CRCSI) Health Program, Program Board

International Association of Cancer Registries

- Board member
- Elected representative for Oceania

International Childhood Cancer Staging Guidelines, Implementation Advisory Group

- International Psycho-Oncology Society (IPOS)
- Director and Board member
- Secretary

Lancet Oncology Commission on Sustainable Paediatric Cancer Care

NHMRC Early Career Fellowship Review Panel

NHMRC Project Grant Review Panel

NHMRC Partnerships Review Panel

Youth Cancer Service, National Adolescent and Young Adult Cancer Dataset Advisory Group

Youth Cancer Service, National Adolescent and Young Adult Cancer Staging Working Group

Queensland Health Queensland Skin Cancer Prevention Collaborative Committee

Queensland Health Queensland Cancer Control Safety and Quality Partnership

Union for International Cancer Control (UICC)

- Board Officer and Board member
- Asia-Pacific Cancer Society Training Grant program (APCASOT) Chair
- Supportive Care Network International Advisory Committee member
- Cancer Care Action Advisory Group member
- Reach to Recovery International Breast Cancer Support Service Chair and Special Advisor
- Finance Committee Chair
- World Leaders Forum meeting
- NCD Task Force member
- C/Can Task Force member
- Membership Committee member
- Regional Activities Committee member

University of Southern Queensland, Research Committee, USQ/CCQ Joint Program

## CONFERENCE ORGANISING COMMITTEES

- Chair, Executive Organising Committee, 8th General Assembly and International Conference of the Asian Pacific Organization for Cancer Prevention (APOCP8), Brisbane, 2016
- Chair, Asia Pacific Cancer Leaders' Summit, Brisbane, 2016
- Organising Sub-Committee 17th Asia-Pacific Prostate Cancer Conference Nursing and Allied Health, Melbourne, 2016
- Scientific committee, 18th International Psycho-Oncology Society (IPOS), Ireland, 2016
- Scientific Committee, 19th International Psycho-Oncology Society Congress (IPOS), Berlin Germany 2017
- Chair International Advisory Committee, 1st World Congress on Cancer Control in Developing Countries, Nepal 2018
- Asia-Pacific Prostate Cancer Conference 2017, Nursing and Allied Health Sub-Committee
- World Congress of Melanoma 2017, Co-Chair and Australian Steering Committee member
- Vitamin D Workshop, Orlando 2017

## PROFESSIONAL MEMBERSHIPS

Andrology Australia

Australasian Epidemiological Association Australasian Society of Behavioural Medicine

Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP)

Australian Psychological Society (APS) Australian Society for Medical Research (ASMR) Clinical Oncological Society of Australia (COSA)

College of Health Psychology, Australia Psychological Society, Academic member

International Epidemiological Association (IEA)

International Psycho-Oncology Society (IPOS)

International Society for Bayesian Analysis

Multinational Association of Supportive Care in Cancer (MASCC)

Psychology Board of Australia

Psycho-Oncology Co-operative Research Group (PoCoG)

Queensland Epidemiology Group

Society for Psychological Study of Social Issues Society of Australasian Social Psychologists Statistical Society of Australia

Urological Society of Australia and New Zealand (USANZ)

## REVIEWS AND EDITORIAL ACTIVITIES

### EDITORIAL BOARDS AND PANELS

- Asian Pacific Journal of Cancer Prevention
- European Journal of Cancer Care
- Frontiers in Public Health
- Health Psychology Bulletin
- International Journal of Behavioral Medicine
- International Journal of Environmental Research and Public Health
- Psycho-Oncology
- Translational Behavioral Medicine

### REVIEW FOR JOURNALS

- American Journal of Clinical Dermatology
- American Journal of Clinical Nutrition
- American Journal of Epidemiology
- American Journal of Preventive Medicine
- Annals of Behavioural Medicine
- Annals of Epidemiology
- Annals of Oncology
- Archives of Dermatological Research
- Asian Pacific Journal of Cancer Prevention
- Australasian Journal of Dermatology
- Australian Family Physician
- Australian Health Review
- Australian Journal of Psychology
- Australian Journal of Rural Health
- Australian and New Zealand Journal of Public Health
- BioPsychoSocial Medicine
- BMC Cancer
- BMC Dermatology
- BMC Family Practice
- BMC Public Health
- BMJ Open
- BMJ Supportive & Palliative Care
- Breast Cancer Research and Treatment
- British Journal of Cancer
- British Journal of Dermatology
- British Journal of Health Psychology
- British Journal of Sports Medicine
- British Journal of Urology International
- British Medical Journal
- Cancer
- Cancer Causes and Control

- Cancer Epidemiology
- Cancer Epidemiology Biomarkers and Prevention
- Clinical and Experimental Dermatology
- Current Cancer Therapy Reviews
- Dermatology
- Environmental Health Insights
- European Journal of Cancer
- European Journal of Cancer Care
- European Journal of Dermatology
- Expert Reviews in Dermatology
- Frontiers in Psychology
- Frontiers in Public Health
- Health and Place
- Health and Quality of Life Outcomes
- Health Education Research
- Health Promotion Journal of Australia
- Health Psychology
- Integrative Cancer Therapies
- International Journal of Cancer
- International Journal of Gynecological Cancer
- JAMA Dermatology
- Journal of Applied Social Psychology
- Journal of Clinical Oncology
- Journal of the Egyptian National Cancer Institute
- Journal of European Academy of Dermatology and Venereology
- Journal of Global Oncology
- Journal of Health Psychology
- Journal of Investigative Dermatology
- Journal of Mixed Methods Research
- Journal of Psychosomatic Research
- Journal of Surgery
- Lancet
- Medical Journal of Australia
- Melanoma Management
- Melanoma Research
- Molecular Nutrition and Food Research
- Nature Scientific Reports
- Netherlands Organisation for Scientific Research
- Patient Education and Counselling
- Plastic Surgery International
- PLOS ONE
- Preventive Medicine
- Protein
- Psychology & Health

- Psychology, Health and Medicine
- Psycho-Oncology
- Quality of Life Research
- Scientific Reports
- Social Behavior and Personality
- Social Science & Medicine
- Supportive Care in Cancer
- Tumour Biology
- World Cancer Research Fund International

## REVIEWS FOR FUNDING BODIES

- Australian Research Council
- ANZUP Clinical Trials Group
- Breast Cancer Now
- Cancer Australia
- Cancer Council Western Australia Epidemiology Initiative
- Cancer Research UK
- Cancer Research Wales
- French National Cancer Institute
- Health Research Council New Zealand
- Hong Kong SAR Government
- International Cancer Research Education Technology Transfer Program, UICC
- Italian Association for Cancer Research
- National Health and Medical Research Council Assigners Academy
- Prostate Cancer Foundation of Australia
- Queensland Nursing Council
- The Research Fund for the Control of Infectious Diseases (RFCID) / The Health and Health Services Research Fund (HHSRF), Hong Kong