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About Cancer Council Queensland

Reducing the burden of cancer.
Cancer Council Queensland (CCQ) raises funds that are dedicated to improving quality of life for people living with cancer, through research, patient care, prevention and early detection.

Our purpose
CCQ is dedicated to supporting the community in cancer control. CCQ is dynamic, outcome focused, responsive to community needs, committed to voluntarism and the pursuit of excellence in all its activities. All employees and volunteers of CCQ, through their work, are actively involved in cancer control.

Our values
With integrity, agility and a deep sense of belonging – we are committed to supporting the cancer community.

We work across every aspect of cancer to:
• Support Queenslanders affected by cancer.
• Work with the community to change laws and policies to reduce cancer risks and improve cancer-care.
• Conduct and fund world-class research to reduce the impact of cancer.
Cancer Council Queensland’s strategic priorities

**SUPPORT AND EMPOWER THE COMMUNITY**
- Improve access to cancer information, programs and services.
- Mobilise resources to build community capacity and strengthen cancer care systems.
- Lead local, national, and global dialogue to make cancer a priority in health and development planning.

**PREVENT CANCER AND ENCOURAGE HEALTHY LIFESTYLES**
- Reduce cancer risks by delivering and advocating for evidence-based population-wide programs and interventions that promote healthy lifestyles and uptake of screening.
- Encourage healthy communities through engagement across regions, sectors and industries, targeting at-risk groups.
- Deter high-risk behaviours by informing and advocating for public health policy and program development.

**SUPPORT PEOPLE AFFECTED BY CANCER**
- Advocate to ensure the assessment and care of people affected by cancer is timely, safe, comprehensive, and of consistently high quality.
- Provide evidence-based high-quality programs and services in line with best practice, establishing need, access and efficiency for each.
- Disseminate the latest news, information, and evidence on cancer.

**DRIVE AND FUND WORLD-CLASS RESEARCH**
- Conduct collaborative investigations into cancer control, with a focus on reducing the burden of cancer and the rapid translation of research into practice.
- Invest in Queensland-led cancer research, with demonstrable potential to improve the survival and wellbeing of Queensland patients.
- Inform worldwide understanding of cancer control, through the publication and presentation of new evidence.

**IMPROVE SURVIVAL OUTCOMES AND ADDRESS INEQUITIES**
- Invest in studies and programs to overcome the barriers to equity in cancer survival.
- Promote integrated and multi-disciplinary service approaches, centred on patient and community need.
- Monitor and report on trends and emerging developments in cancer incidence, mortality, survival, and prevalence.

**DRIVE CAPABILITY, AGILITY AND EFFECTIVE USE OF RESOURCES**
- Build and leverage the necessary capability, underpinned by agile systems and processes to enable positive customer experiences.
- Develop workforce capability and drive cultural shifts with a focus on core values, greater simplicity, performance and accountability.
- Actively pursue opportunities to reshape the asset portfolio to align with the mission.

**FUNDRAISE AND BUILD EFFECTIVE PARTNERSHIPS**
- Inspire community and volunteer involvement in fundraising.
- Create diverse, innovative and inspiring fundraising experiences that encourage community and corporate supporters to our mission.
- Engage networks of influence in cancer control through collaboration.
From the CEO

Thanks to generous support from the Sylvia and Charles Viertel Charitable Foundation and the community, Cancer Council Queensland’s Viertel Cancer Research Centre has delivered cutting-edge research to solve complex challenges in cancer control.

In this report you will read about how from 2015-2018, the Viertel Cancer Research Centre has built on strong foundations in the professional fields of descriptive epidemiology and applied psycho-oncology, with an aim to improve outcomes for cancer patients and reduce the burden of cancer on our community.

We continued our strategic focus on geographical inequalities and in September 2018 launched Australia’s first online interactive national atlas of cancer. Since its release, the Australian Cancer Atlas has brought new insights about cancer patterns across Australia and been accessed 41,000 times.

The Viertel Cancer Research Centre also worked collaboratively with research groups in the US, China and New Zealand to strengthen insights into global variations in cancer survival.

In the area of childhood cancer, our researchers continued to manage the Australian Childhood Cancer Registry and released the world’s first comprehensive manual for collection of childhood cancer state by population cancer registries based on new international staging guidelines. Of significance, statistics from the registry were formally included in the Commonwealth Government’s National Cancer Control Indicators.

Our research was also translated into support settings, with an evidence-based framework for psychological care now being used by Cancer Council Queensland health professionals. Our recommendation for integration of distress management into routine clinical practice was also formally adopted by Queensland Health.

The significant of the results arising from our work is further highlighted through acceptance of original research articles in 240 scientific publications with our publications being cited over five times more than the world average for their field, age and type.

These and the other achievements outlined in this report would not have been possible without the generous support of the Sylvia and Charles Viertel Charitable Foundation and the Foundation Trustees.

I also acknowledge Cancer Council Queensland’s Board of Directors and Chairman, Mr Andrew Arkell, our employees, our network of distinguished research collaborators, and the thousands of community members who support and participate in our work so we can deliver on our vision to one day create a cancer free future.

Our achievements over the five years from 2015-2018 will underpin our continued efforts to eliminate cancer as a life-threatening and distressing disease for future generations.

I commend this report to you as evidence of our impact.
Cancer in Queensland – the facts

Based on current trends and predicted population changes, **36,000 Queenslanders** are expected to be diagnosed with cancer in the year 2025.

Approximately **234,000 Queenslanders** are alive today after a cancer diagnosis in the past 25 years (1992 – 2016).

Overall, five-year relative survival from cancer in Queensland has **increased from 53 per cent in the 1980s to 71 per cent** during 2012-2016.

**1 in 2** Queenslanders expected to develop cancer before age 80 years

**9207** Number of Queenslanders who died of cancer in 2016

**1 in 8** Queenslanders expected to die from cancer before age 80 years

**28,823** Number of Queenslanders who were diagnosed with cancer in 2016

Data source: Queensland Cancer Register, CCQ Data extract, 1982-2016
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 the Foundation Trustees.

Our research focuses on increasing survival and enhancing quality of life after cancer.
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 social and behavioural science.

Our findings have worldwide impact, demonstrating the importance of community-based cancer control in preventing and reducing the burden of cancer at population 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 that the Centre’s work is future-focused, innovative, and responsive to emerging trends.

Over the past 15 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 broader community.

We are committed to eliminating cancer as a life-threatening and distressing disease for future generations.
Leading the progress towards a cancer free future (2014 – 2018)

The aim of Cancer Council Queensland is to contribute to the worldwide effort to improve cancer control.

Every step brings us closer to that goal.

Our publications on average are being cited\(^1\) **5.35 times more**\(^*\) than world average\(^2\)

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1. A ‘citation’ occurs when a scientific publication refers explicitly to, and gives credit to, an earlier publication from the VierTEL Cancer Research Centre. A ‘citation count’ is a measure of how important or influential a publication has been.

2. The metric used in the infographic graph is called “Field-Weighted Citation Impact”. A Field-Weighted Citation Impact of greater than 1.00 indicates that the publications have been cited more than would be expected based on the world average for similar publications.
56 publications (23% of our total) in the top 10% most cited publications worldwide (field-weighted)

The Lancet
The Lancet Oncology
The Lancet Child and Adolescent Health
The Lancet Global Health
The Lancet Public Health
Nature Genetics
Journal of Clinical Oncology
British Journal of Dermatology
Journal of the American Medical Association (Dermatology)
International Journal of Cancer
Journal of Investigative Dermatology
Psycho-oncology
CA: A Cancer Journal for Clinicians

240 scientific publications with a total citation count over 9,000
10 publications in the top 1% most cited publications worldwide (field-weighted)

Awarded/collaborated on 29 grants and consultancies
99.2% of publications involve collaboration national and international

214 presentations at national and international conferences
Over 1000 mentions in national and international news/blogs
Impact on health policy and practice

Publications authored or co-authored by members of our team have been cited in policy documents from:

- World Health Organization (Switzerland)
- Centers for Disease Control and Prevention (USA)
- National Institute for Health and Care Excellence (UK)
- UK Government (UK)
- UK Parliament Briefing notes (UK)
- Chatham House, the Royal Institute of International Affairs (UK)
- The King’s Fund (UK)
- Analysis & Policy Observatory (Australia)

(Altmetric, July 2019)

Australian Cancer Atlas

- Australia’s first online interactive national atlas of cancer
- Accessed to date by over 40,000 users from almost every country
- Used by NZ Ministry of Health to develop a NZ Cancer Atlas
- Used in National Viral Hepatitis Mapping Report by Doherty Institute for Infection and Immunity
- Included in University cancer epidemiology training courses

Australian Childhood Cancer Registry

- Released world’s first comprehensive manual for collection of childhood cancer stage by population cancer registries based on new international staging guidelines
- Endorsed by the Union for International Cancer Control (IUCC), the European Network of Cancer Registries, and the Australasian Association of Cancer Registries
- Translated into Italian, French, Portuguese, Spanish, Japanese
- Implementation trials underway in four continents
- Statistics from the Australian Childhood Cancer Registry formally included in in the Commonwealth Government’s National Cancer Control Indicators.

Tiered model of psychological care

- Developed an evidence-based framework for psychological care of cancer patients including distress screening at first point of contact, now used by CCQ
- Recommendation for integration of distress management into routine clinical practice formally adopted by Queensland Health
Partnerships and collaborations

**International**
- African Cancer Registry Network
- American Cancer Society, Atlanta
- Cancer Patients Aid Association, Mumbai
- Cancer Research Malaysia, Kuala Lumpur
- Childhood Cancer Registry of Piedmont, Torino
- China Centre for Disease Control, Beijing
- Dana-Farber/Boston Children’s Cancer and Blood Disorders Center, Boston
- European Joint Action on Rare Cancers
- Global Initiative for Cancer Registry Development
- Hong Kong Polytechnic University, Hong Kong
- International Agency for Research on Cancer, Lyon
- International Association of Cancer Registries
- International Childhood Cancer Cohort Consortium (14C)
- Irish Cancer Society, Dublin
- Karolinska Institute, Sweden
- Memorial Sloan Kettering Cancer Center, New York
- National Cancer Institute, Washington DC
- National Child Cancer Network NZ, Christchurch
- National Office for Cancer Prevention and Control & National Central Cancer Registry (China)
- Nepal Cancer Relief Society, Kathmandu
- New Zealand Children’s Cancer Registry
- New Zealand Ministry of Health
- Oxford University, Oxford
- Paediatric Oncology Group of Ontario
- Prostate Cancer Foundation of New Zealand
- Royal Marsden Hospital, London
- Shandong Center for Disease Control and Prevention
- South African Medical Research Council
- St Jude Children’s Research Hospital, Memphis
- The Hospital for Sick Children, Toronto
- Union for International Cancer Control, Geneva
- University of Auckland
- University of British Columbia, BC
- University of Georgia, Athens
- University of New Mexico, Albuquerque
- University of Virginia, Charlottesville
- US Centre for Disease Control, Atlanta
- US Department of Defence, Washington

**National**
- ARC Centre of Excellence for Mathematical and Statistical Frontiers
- Australasian Association of Cancer Registries
- Australian and New Zealand Children’s Haematology/Oncology Group
- Australian and New Zealand Urogenital and Prostate (ANZUP) Cancer Trials Group
- Australian Institute of Health and Welfare
- Australian National University
- Australian Skin and Skin Cancer Research Centre
- Cancer Australia
- Cancer Council New South Wales
- Cancer Council Victoria
- Clinical Oncology Society of Australia
- Edith Cowan University
- Flinders University
- FrontierSI (formerly Cooperative Research Centre for Spatial Information)
- McCabe Centre for Law and Cancer
- Menzies School of Health Research, Charles Darwin University
- Monash University
- Prostate Cancer Foundation of Australia
- South Australian Prostate Cancer Clinical Outcomes Collaborative
- The University of Adelaide
- The University of Melbourne
- The University of South Australia
- The University of Sydney
- Victorian Cancer Registry
- Victorian Cytology Service

**Queensland**
- Children’s Health Queensland
- Griffith University
- Jack and Madeleine Little Foundation
- Mater Hospital & Mater Medical Centre
- QIMR Berghofer Medical Research Institute
- Queensland Children’s Hospital
- Queensland Health
- Queensland University of Technology
- The University of Queensland
- University of Southern Queensland
- University of the Sunshine Coast
- Volunteering Queensland
- West Moreton Hospital and Health Service
Cancer Council Queensland’s research goals

- Strengthen national capacity in cancer control
- Understand cancer risk and prevention
- Reduce inequities in cancer outcomes
- Improve outcomes for children with cancer
- Empower and engage the community
- Support people affected by cancer
# Flagship projects

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<th>Flagship Project</th>
<th>2014</th>
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<td>The Australian Cancer Atlas</td>
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<td>Understanding international variation in cancer outcomes</td>
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<td>New methods for spatial analysis of cancer</td>
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<td>Cancer in Indigenous Australians</td>
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<td>Improving cancer outcomes in regional communities</td>
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<td>Inequities in breast cancer management and survival</td>
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<td>The Australian Childhood Cancer Registry</td>
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<td>Australian Childhood Cancer Statistics Online</td>
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<td>Increasing population screening for colorectal cancer</td>
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<td>Preventing melanoma</td>
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<td>Patients at risk of multiple melanomas</td>
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<td>Vitamin D and melanoma progression</td>
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<td>Clinical trials of supportive care for men with prostate cancer</td>
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<td>Clinical trial of online supportive care for distressed cancer patients</td>
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<td>Improving outcomes for men with prostate cancer</td>
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The Australian Cancer Atlas

The Australian Cancer Atlas is Australia’s first online interactive national atlas of cancer.

It is a world-first innovation that uses cutting edge digital technology to map patterns in cancer diagnosis and survival across the 2,148 small geographic areas that cover the Australian continent. Designed to be informative and easy to use, the Atlas is visually appealing, interactive and freely available to all. It features explanatory graphics and narratives and was developed with mobile technology in mind. It is the most comprehensive examination of cancer patterns that has ever been achieved.

The Australian Cancer Atlas is a collaborative project with the Queensland University of Technology, FrontierSI (formerly the Cooperative Research Centre in Spatial Information), and the Australian Institute of Health and Welfare. It was developed with the support of Australia’s State and Territory population cancer registries.

The project has been a long-term commitment for CCQ that has only been possible with the sustained support of the Sylvia and Charles Viertel Charitable Foundation. It has required years of foundation work in statistical spatial modelling and the development of innovative visualization techniques to suit a variety of audiences including researchers, clinicians, and the general community. The Atlas is truly an Atlas ‘for the people’.

Since its release in September 2018, the Australian Cancer Atlas has brought new insights about cancer patterns across Australia. It has helped people to learn about the cancer burden where they live and has been a tool to raise awareness of how cancer risk can be reduced through healthy lifestyle choices.

To date, the Atlas has been accessed 41,000 times by users from almost every country in the world and has received 450 mentions in local and national press. Spatial information on liver cancer has been used in the National Viral Hepatitis Mapping Report published by the Doherty Institute for Infection and Immunity; our Atlas research team is collaborating with the NZ Ministry of Health to develop a New Zealand Cancer Atlas; and the Australian Cancer Atlas is now included in Australian university course content.
Understanding international variation in cancer outcomes

We are collaborating with international research groups in the US, China and New Zealand to investigate international patterns of cancer outcomes, providing insights into cancer causes and global variation in cancer survival.

In collaboration with China’s National Office for Cancer Prevention and Control, the American Cancer Society, the International Agency for Research on Cancer, and Cancer Council New South Wales, we have produced updated statistics for cancer incidence and mortality in China, illustrating the very high cancer burden in that country. Findings were published in the highest-ranking cancer journal CA: Cancer Journal for Clinicians. A second study considered the changing cancer survival experiences of Chinese cancer patients over a 13-year period.

With collaborators at the Shandong Center for Disease Control and Prevention and the Queensland University of Technology, we have examined the high burden of oesophageal cancer in Shandong, China, with a focus on the geographical and socioeconomic disparities within that province. This work resulted in the awarding of a PhD to a new member of our team.

We have critically reviewed published literature and data on international trends, inequalities and tumour characteristics for lung cancer; published a critical review of international geographical disparities in prostate cancer diagnosis, survival, mortality and other outcomes; and in collaboration with colleagues from Malaysia, reported incidence and mortality patterns for female breast cancer in the Asia-Pacific region.

In collaboration with the University of Auckland, New Zealand, we compared oropharyngeal and oral cavity squamous cell cancer incidence and trends in New Zealand with those in Queensland. While separated by 2000km of ocean, given that both environments have universal public health care systems, generally similar social patterns, and well-established cancer registries, the different risks observed in this study suggests different causes of the diseases.
New methods for spatial analysis of cancer

Investigating geographical and other patterns in very large datasets depends on the appropriate application of statistical methods. Recent developments in statistical theory and their applications in the latest statistical software have provided exciting opportunities to push this field forward.

CCQ has a strong focus and expertise in the development and application of complex statistical models and enjoys a long-term collaboration in this research area with the School of Mathematical Sciences at the Queensland University of Technology.

Statistical methods used previously to estimate geographical variation in cancer survival have suffered from many limitations that have restricted their real-world potential. We developed an alternative statistical model, known as the spatial flexible parametric relative survival model, that overcame many of these limitations, and demonstrated its application using breast, colorectal, and lung cancer data from the Queensland Cancer Register across nearly 500 geographical areas. We expanded this model to include a temporal, or time trend parameter, and used this to investigate geographical changes in cancer incidence and relative survival over time for the five leading cancers between 1997–2004 and 2005–2012 across Queensland.

Using data from a cohort of over 20,000 colorectal cancer patients, we examined the relative merits of the two major classes of statistical models (multilevel models and spatial models), and generated decision rules to guide the use of one method over the other.

The expertise and methodology that we have developed through this ongoing statistical research program have laid the analytic foundation for the Australian Cancer Atlas, the most comprehensive examination of geographical cancer patterns that has ever been achieved in this country.
Queensland Cancer Statistics Online

The Queensland Cancer Statistics Online (QCSOL) website provides free, open access to comprehensive data about the burden of cancer in Queensland including the most current information on cancer diagnosis, survival, deaths and prevalence for 27 of the most common cancers and cancer groups in Queensland.

This information underpins all cancer control activities and as such, making it available for the community is a CCQ priority. The QCSOL website utilises the latest digital technology and includes easy-to-understand navigation tools, graphs and tables. It is available on mobile devices and provides a modular framework to enable easy expansion with additional statistics in the future.

QCSOL has been developed in collaboration with CCQ’s Information Technology team, and all data reported in QCSOL is obtained through the Queensland Cancer Register. The website improves understanding and awareness of the latest trends in the burden of cancer for researchers, media, clinicians, cancer patients and carers, and members of the public.
Improving information on cancer stage for adult patients

The Commonwealth Government’s national cancer agency Cancer Australia has stated that the absence of population-wide data on cancer stage is a fundamental gap that seriously limits capacity to interpret survival and other cancer outcomes in Australia.

In 2017 CCQ completed the Queensland component of a national pilot study designed to test the feasibility of collecting national data on cancer stage for adult patients using the information in pathology reports.

Over 15,000 cases of bowel cancer, lung cancer, prostate cancer, female breast cancer and melanoma were examined, using medical records held by the Queensland Cancer Register. These five cancer types comprise over half of all cancers diagnosed nationally. The study results combined from all states showed that over three quarters of female breast cancers were diagnosed at an early stage, and even higher proportions of prostate cancer and melanomas.

In contrast, less than half of colorectal cancers were diagnosed at an early stage, along with one fifth of lung cancers. The proportion of cases able to be staged was similar by Indigenous status and across socioeconomic areas, but lower for remote and very remote areas.

As a result of this project, population-wide information on stage at diagnosis is available for the first time for the top five adult cancers in Australia. This information will help identify and inform the most appropriate targets for future public health initiatives, early detection and awareness campaigns to improve early detection of cancer, and will assist in interpreting cancer survival, recurrence and treatment patterns at a population level.
Cancer Council Queensland is committed to working in partnership with Indigenous research organisations, health professionals, and communities to prevent cancer and improve cancer-related outcomes for Indigenous Australians. Our research aims to 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.

Indigenous Australians report lower participation in screening programs, have higher incidence of poor-prognosis cancers, higher mortality rates and poorer survival. The reasons for these inequalities are multi-faceted, and likely to include later stage diagnosis and reduced uptake of, or access to, treatment and supportive care. To date, work in this area has been limited, particularly nationally.

CCQ signed a formal partnership agreement with the Menzies School of Health Research to carry out a program of research that aims to describe and understand patterns and inequities in cancer outcomes among Indigenous people. Our partnership has enhanced and strengthened CCQ’s research activity among Australian Indigenous people and supported our researchers to apply their statistical, methodological and epidemiological expertise to this important area of research.

With support of Cancer Australia and the Menzies School of Health Research, a systematic review summarised the information on published literature describing Australian women with breast cancer, and assessed survival outcomes, patient and tumour characteristics, diagnosis and treatment patterns by Indigenous status. A second review considered the inequalities in psychosocial outcomes for Australian women with breast cancer according to Indigenous status and residential location.

In collaboration with the Menzies School of Health Research and the QIMR Berghofer Medical Research Institute, we have investigated treatment of Indigenous Australians for non-small cell lung cancer and cervical cancer, the link between comorbidities and survival for Indigenous and non-Indigenous women with cervical cancer and health-related quality of life among Indigenous Australians diagnosed with cancer.
Cervical cancer screening in Indigenous Australians

Indigenous women experience a significantly higher burden of cervical cancer than non-Indigenous women.

Information on Indigenous status is lacking from state-based Pap Smear Registers and this gap hinders research to improve cervical cancer screening in Indigenous communities. In 2017, we collaborated in the National Indigenous Cervical Screening Project, managed by the Menzies School of Health Research, to identify Indigenous women on the Pap Smear Registers through probabilistic record linkage. Analyses of the resulting data highlighted high levels of geographical variation across Queensland in key measures including five-year participation rates of cervical screening, the prevalence of high-grade cytologic abnormalities, and timely follow-up of abnormal Pap smears. This geographic variation was particularly marked among Indigenous women and our analyses found that the much poorer cervical screening participation by Indigenous women in Queensland compared to non-Indigenous women was evident across the state. Further work is planned in collaboration with the Menzies School of Health Research to investigate the key drivers of this variation and to understand barriers to cervical cancer screening in Indigenous communities.

This work was conducted with support from the Jack and Madeleine Little Foundation.

Improving cancer outcomes in regional Queensland

One of the most important issues for cancer control in Queensland is the significantly lower cancer survival in regional and rural areas compared to major cities.

In 2016, in partnership with the University of Southern Queensland, Cancer Council Queensland commenced the Building Regional Resilience in Cancer Control initiative. This is 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.

Patients moving back to regional areas following treatment are among those most at-risk of experiencing poorer survival and outcomes. A flagship longitudinal cohort study of regional cancer patients and their carers is underway at CCQ’s six state-wide lodges. Patients and carers are accommodated at the lodges during their cancer treatment. Participants who consent to join the project are interviewed by our research staff and volunteers during their stay and complete follow up surveys at multiple time-points after returning home (3 months, 12 months, then annually), providing detailed information on the journey of a regional cancer patient from diagnosis through 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 unique study is highlighting factors that underlie the existing geographic variations in cancer outcomes and will provide the foundation to develop and trial empirically driven interventions and solutions.
Inequities in breast cancer management and survival

Breast cancer is one of the most common cancers affecting Australian women with over 16,800 Australian women diagnosed with breast cancer and over 2,800 dying from it in 2015. Survival from breast cancer has improved markedly over the last 20 years but improvements have not been consistent across all groups.

Systematic review
Our systematic review of all published literature on this topic found that non-metropolitan and Indigenous women had consistently lower participation in breast cancer screening, were more likely to be diagnosed with advanced cancer and had less optimal clinical management than other groups. Non-metropolitan women with breast cancer were more likely to experience poorer quality of life and more likely to report unmet psychosocial needs.

Treatment pathways
Using data linkage between the Queensland Cancer Register and the Queensland Hospital Admitted Patient Data Collection, we investigated clinical characteristics and surgical treatment patterns for women diagnosed with breast cancer according to residential location. Consistent with our review, we found that women living in regional, remote or disadvantaged areas were more likely to be diagnosed with advanced cancer and experienced less optimal clinical management (including lower rates of breast reconstruction following mastectomy for localised cancer, and lower rates of sentinel node biopsy (the recommended standard of care)).

Cohort study
Lastly, in the largest Australian study of this topic ever conducted, we assessed over 3,300 women with breast cancer from urban, regional and rural areas of Queensland to identify in more detail why women from non-metropolitan areas have poorer breast cancer survival than women living in cities. Detailed data on diagnostic and treatment pathways, clinical characteristics and psychosocial outcomes were collected from all women. We obtained blood samples and established a DNA and RNA biobank to allow future studies of genetic susceptibility.

Results showed that despite availability of free biennial mammographic screening, about 40 per cent of breast cancers are discovered because of symptoms rather than at screening. The time from presentation to definitive diagnosis was longer for symptom-detected cancers and such tumours were likely to be more advanced at diagnosis. Time to diagnosis was also longer for Indigenous women and those living in rural or socioeconomically disadvantaged areas.

Our findings, released through publications in high-profile journals including The Breast, BMJ Open, ANZ J Surgery and Psycho-oncology, recommended priority actions to reduce variations in breast cancer outcomes. These included strategies to increase participation in routine breast cancer screening, improve timely access to primary and specialist care, and promotion of routine assessment of all patients by a multidisciplinary team.
Dr Andy Moore’s story

Dr Andy Moore is a paediatric oncologist who has worked closely with Cancer Council Queensland’s Research Team to improve care, treatment and outcomes for children diagnosed with acute myeloid leukemia, using data obtained from the Australian Childhood Cancer Registry.

“Acute Myeloid Leukemia, while relatively rare, is responsible for a disproportionate number of childhood deaths”, said Doctor Moore.

Over the years, Dr Moore and the CCQ team have utilised Registry data to delve deeper into the impact of acute myeloid leukemia and release several papers which have not only highlighted the severity of the disease but also demonstrated improved survival rates over time.

“It’s worthwhile being able to show improved patient outcomes”, continues Dr Moore. “We’ve published papers that have helped put patient prognosis into perspective: children who go into remission and receive a bone marrow transplant have a very reasonable survival rate – more than half of patients who respond well to treatment will be long-term survivors”.

In addition to the Registry being vitally important in providing accurate and local data on childhood cancer, Dr Moore believes the Registry is also an indispensable resource of data for further research.

“One of the most positive experiences I’ve had with the Registry is seeing new researchers and Junior Doctors so willing to analyse the data and use it to formulate new ideas and ask the meaningful questions we need to ask to improve patient outcomes”.

The Registry is also useful to document patient outcomes – especially good outcomes.

“One of the things I do on a day-to-day basis is to chat with parents whose child has been newly diagnosed. It’s nice being able to tell them – with some clarity and clear evidence gained from the Registry – that it will be ok. It’s certainly hard work and there’s a long road ahead but the data tells us that we can cure 90% of children with leukemia”.

Dr Moore says collaborating so closely with Joanne and the rest of the CCQ research team is another positive aspect of being part of the Australian Childhood Cancer Registry. “The whole team is friendly and welcoming and always interested to hear about projects I’d like to work on. This certainly makes it easier to keep working together for a cancer free future”.

“The data plays an important role in the whole puzzle of improving outcomes for children diagnosed with leukemia”.

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Australian Childhood Cancer Registry (ACCR)

Cancer is the leading cause of disease-related death among Australian children aged 1 to 14 years. The Australian Childhood Cancer Registry contains complete, population-wide information on childhood cancer in Australia including details of diagnosis, treatment and outcomes for every patient under 15 years of age diagnosed since 1983.

It is one of the few, and most comprehensive, national population registries of childhood cancer in the world. It is funded and managed entirely by Cancer Council Queensland.

The Registry is a unique tool for research about cancer in children and an essential source of accurate information for researchers, clinicians and families. It facilitates national and international collaborative research to improve outcomes of childhood cancer in Australia and around the world.

Key facts*

1983 year that the Australian Childhood Cancer Registry began, one of only a few national databanks of childhood cancer anywhere in the world

One in four children with cancer are diagnosed with acute lymphoblastic leukaemia

38% decrease in childhood cancer mortality rates between 1998 and 2015, mainly due to fewer children dying from leukaemia

Increase in the incidence rate of childhood cancer between 1983 and 2015

34%

Increase in the incidence rate of childhood cancer between 1983 and 2015

39% of childhood cancer deaths are caused by brain cancers

100 children aged under 15 die from cancer each year

85% Current five year survival rate for all childhood cancers combined, up from 73% during the 1980s

5-fold increased risk of a childhood cancer survivor being diagnosed with a second cancer within 30 years of first diagnosis compared to the incidence of cancer in the general population

*BASED ON LATEST DATA AS AT 31 DECEMBER 2015
International guidelines for staging childhood cancer

Research conducted through CCQ’s Australian Childhood Cancer Registry is changing the way that vital information on childhood cancer is collected by population cancer registries around the world.

This research is having a direct impact on understanding and addressing inequities in cancer survival amongst our youngest patients. Cancer “stage” is a measure of how far cancer has spread in the body by the time of diagnosis. Stage is one of the main factors that predicts the patient’s outcome and it is essential information for understanding variations in survival within and between populations. Assigning “stage” for a child with cancer is complex and until now this information has rarely, if ever, been collected in population cancer registries.

In 2014, CCQ was an invited member of an international working group that developed the first consensus guidelines, known as the “Toronto Paediatric Cancer Stage Guidelines”, for the collection of childhood cancer stage by population cancer registries. Our team then tested the Guidelines in a study that included 4,200 children aged under 15 who had been diagnosed with cancer in Australia between 2006 and 2014. We showed that, using the Toronto Guidelines, cancer stage could be assigned quickly, consistently and cost-effectively by registry staff for more than 90% of childhood cancer patients.

In an important development, the detailed staging manual developed by CCQ as part of this project was formally endorsed by the Union for International Cancer Control and the International Association of Cancer Registries (IACR) and has been made freely available through the IACR website.

Translation of the manual by teams around the world into Portuguese, Spanish, French, Italian and Japanese is underway. Pilot studies using our methods are completed, underway or planned in Europe, Africa, New Zealand, Brazil, Japan and Turkey. In Australia, childhood cancer incidence and survival by stage at diagnosis using the Toronto Guidelines is now part of Cancer Australia’s National Cancer Control Indicators.

This work was supported by Cancer Australia to improve national data for childhood cancers as part of the Investing in Medical Research – Fighting Childhood Cancer initiative. Between 2015 and 2018 a total of $334,000 in funding was received from Cancer Australia.
Therapy-related acute myeloid leukaemia following childhood cancer

In an important clinical collaboration, our research has provided new understanding of a rare but devastating “late effect” following treatment for childhood cancer.

Therapy-related acute myeloid leukaemia (t-AML) is a disease in which acute myeloid leukaemia develops in a patient who has received chemotherapy and/or radiotherapy in the past. Although t-AML is rare, it is one of the most common second malignancies to develop following treatment for a first primary cancer during childhood. t-AML accounts for approximately one in six of all second primary cancers diagnosed among survivors of childhood cancer in Australia. Little information has been available about this condition until now.

Using data in the Australian Childhood Cancer Registry, we discovered that patients who were treated with chemotherapy and/or radiotherapy for a childhood cancer had an almost 50-fold increased risk of being diagnosed with AML in the following years compared to people in the general population, matched by sex, age group and calendar year. Males recorded double the number of cases of t-AML compared to females.

We confirmed that t-AML is associated with very poor survival with only one in three patients remaining alive five years after their t-AML diagnosis. We showed a significant survival advantage, however, for t-AML patients who received a stem cell transplantation, indicating that patients should be prepared for stem cell transplantation as soon as possible after a diagnosis of t-AML.

Australian Childhood Cancer Statistics Online

A new website for patients, families, researchers and clinicians, Australian Childhood Cancer Statistics Online, was launched on 15 February 2018 to coincide with International Childhood Cancer Day.

The website provides rapid, free and easy access to the latest statistics on childhood cancer in Australia, in one location, using data from CCQ’s Australian Childhood Cancer Registry. This is the first time that this information has been available online.

Information on childhood cancer incidence, survival and mortality by sex, age group and time period is presented in an interactive, easy-to-understand format for 17 of the most common types of childhood malignancies. The website, created in a collaboration between CCQ’s Childhood Cancer Research team and Information Technology teams, uses contemporary digital software and is updated annually. Content and design were developed in consultation with the Australian and New Zealand Children’s Haematology/Oncology Group (ANZCHOG), the peak body representing the interests of children and adolescents with blood diseases and cancer.

The website is increasing awareness and understanding of childhood cancer amongst government and the community and supports research into the causes, prevention and cure of these diseases. Australian Childhood Cancer Statistics Online can be found at https://cancerqld.org.au/research/queensland-cancer-statistics/accr/.
Increasing population screening for colorectal cancer

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 survival rates are significantly lower in regional and rural areas.

With proven effective screening methods, the colorectal cancer mortality rate could be significantly reduced yet screening rates for colorectal cancer are the lowest of any population cancer screening program in Australia, particularly in non-urban areas.

Our colorectal cancer screening research is focused on investigating ways to improve early detection of colorectal cancer in Australia through increasing participation in the National Bowel Cancer Screening Program, particularly in regional and remote Australia. Our work links with consumers and health professionals to identify and develop evidence-based solutions to overcome practical barriers to colorectal cancer screening, focusing on changing behaviour through new screening strategies and updated kit design.

Work to date has involved several systematic reviews to identify the most successful interventions for increasing participation in population mail-out colorectal cancer screening programs, the demographic groups for which they are most effective, and the behavioural mechanisms underlying their success. In addition, several cross-sectional surveys and semi-structured interviews with National Bowel Cancer Screening Program recipients have been conducted to better understand the experience of consumers and the barriers and facilitators associated with colorectal cancer screening kit use.

Findings to date point to the need for interventions to be developed that reduce practical and physical barriers to kit use which the team are currently in the process of designing in collaboration with consumers, health professionals and health promotion specialists.
Preventing melanoma

Queensland has the highest incidence and mortality from melanoma in the world. In 2016, more than 3,900 people were diagnosed with melanoma and over 300 died from this disease.

Preventing melanoma

Improved sun protection and reduced sun exposure, particularly among young people, is the key to preventing melanoma, and Australia leads the world in skin cancer prevention efforts.

A Sunscreen Summit was convened by the Australian Skin and Skin Cancer Research Centre in collaboration with Cancer Council Queensland on 19 – 20 March, 2018 in Brisbane to review evidence for the use and effectiveness of sunscreen and to adopt a consensus approach to sunscreen policy. The Summit brought together over 100 representatives from cancer control agencies, government, research institutions, specialist medical colleges and consumer organisations. The Summit produced a consensus statement on the use of sunscreen for the populations of Australia and New Zealand, published in 2019 in the Australian and New Zealand Journal of Public Health and endorsed by Cancer Council Australia and other national peak bodies.

Improving communication about melanoma prognosis

The ability of medical practitioners to communicate risk estimates to patients diagnosed with melanoma relies on accurate information about prognostic factors and their impact on survival. In collaboration with experts from the UK and USA, we led the development of a melanoma prognostic model using data from the Queensland Cancer Register. Beyond the immediate clinical use, this model has the potential for public health and research applications in evaluating public health interventions aimed at reducing deaths from melanoma.

Evidence that melanoma incidence is falling in young people

Public campaigns encouraging sun protection began in Queensland in the early 1980s. We investigated the impact of these campaigns on melanoma incidence by examining changes in incidence in Queensland over the 20-year period 1995 – 2014. We found that, for the first time, rates of melanoma have stopped rising among people aged 40 – 59 years and are falling for those under 40 years old. These promising trends were most apparent among people born since the 1980s who were brought up with the sun protection message from early childhood.

In related research, we found that while melanoma incidence rates among young people under 25 years of age were much higher in Australia compared to England, there was a decreasing trend in Australia from the mid-1990s onwards compared to ongoing increases in England. Again, this difference is likely to reflect the success of long-standing primary prevention strategies targeted at curbing exposure to sunlight in Australia whereas similar programs have only been implemented in England more recently.
Patients at risk of multiple melanomas

People who have been diagnosed with a melanoma are known to have an increased risk of developing a second and even a third melanoma.

We have conducted one of the largest studies in the world to discover the true risk of developing a second melanoma in the Queensland population, and where on the body this second melanoma was likely to develop.

We found that people who had been diagnosed with an invasive melanoma (a melanoma that has invaded into the deeper layers of the skin) had a five-fold increased risk of developing a second invasive melanoma. Surprisingly, we also found that this risk was almost as high for people diagnosed with an in situ melanoma (a very early melanoma that has not invaded into the deeper layers of the skin). Such patients had more than a four-fold increased risk of developing a subsequent invasive melanoma. The risk of developing a second invasive melanoma was particularly high around the body site of the first melanoma.

We also explored how having multiple invasive melanomas affects the patient’s survival. Our results challenged the prevailing, although counter-intuitive, belief that patients with multiple invasive melanomas had higher survival compared to patients with a single melanoma. Most previous studies had used a flawed approach that failed to take ‘survival bias’ into account. Using a more appropriate methodology, our findings showed instead that survival was significantly worse for patients diagnosed with multiple invasive melanomas. After adjusting for key prognostic factors, we found that the risk of dying within 10 years from the first melanoma was twice as high for patients with two melanomas and nearly three times as high for those with three melanomas, compared to patients with a single melanoma. Subsequent studies from other countries have confirmed our results.

Our research has led to a call for changes in clinical practice guidelines to highlight the need for a careful history of earlier melanomas and consideration of the occurrence of a second primary invasive melanoma within 10 years of first diagnosis as a criterion of poorer prognosis.

Kylee’s story

Kylee Sanson was just 21, a young Mum and pregnant with her second child when she heard the words ‘you’ve got cancer’.

Following the diagnosis of malignant melanoma on her back, Kylee soon realised what it meant not only for her own life but that of her family.

“It was important for me to protect my family, my children particularly, and we made changes in our lifestyle to ensure a skin cancer diagnosis didn’t happen again.”

Kylee and her family understood the importance of prevention and early detection and are thankful for our ongoing investment to protect Queenslanders from skin cancer.

“Without the Slip, Slop, Slap campaign, and the ongoing research into melanoma and other skin cancers, we would be far less effective in getting this vital message out to all Queenslanders,” Kylee said. “CCQ’s landmark studies into melanoma are crucial in saving lives and helping more of us avoid this devastating disease.”
Vitamin D and melanoma progression

Queensland has the highest incidence of melanoma in the world.

The main risk factor for melanoma is sun exposure however there is still much that we do not understand about melanoma development. Vitamin D is produced by the action of ultraviolet radiation on exposed skin, the same radiation that causes melanoma, and there is evidence that vitamin D may play a role in melanoma progression.

In a collaborative project between CCQ and the University of the Sunshine Coast, we are investigating the relationship between a patient’s serum vitamin D status at the time of melanoma diagnosis and the characteristics of the tumour to assess whether patients with low serum Vitamin D present with more advanced tumours.

The study includes patients treated for skin cancer in private and public medical clinics including general practice, dermatology, and plastic surgery clinics. Blood samples are being collected in addition to detailed information on patients’ sun exposure and sun protection, dietary intake, health indicators, melanoma history, and diagnostic pathways. Information about the melanoma tumour is being obtained patient pathology records held at the Queensland Cancer Register.

The project is funded through a grant from the US Department of Defence who have an interest in how the findings may benefit military personnel deployed in regions of high sun exposure. Results will also have direct relevance to Queensland and the broader Australian population.
Clinical trials of supportive care for men with prostate cancer

Clinical trial of a couples-based support program after surgery for prostate cancer
Couples experiencing prostate cancer can be challenged by the impact of treatment side effects on their relationship. The ProsCan for Couples Study trialled different support programs to help couples adjust to changes they may experience after surgery for prostate cancer, particularly sexual changes. This trial was the largest in the world targeting the concerns of couples experiencing prostate cancer (with 189 couples taking part) and the first internationally to apply peer support in this approach and compare it to nurse-delivered support and self-management.

Overall, couples viewed the research program as highly positive, with peer support and nurse-delivered support offering different expertise which was equally acceptable to couples. Couples were also followed up in the longer term over 5 years, to see how they adjusted over time and what extra support they might need down the track. We can now work on tailoring the support programs and possibly combining support delivered by peers and nurses, as both appear to be helpful in different ways to couples experiencing prostate cancer. The valuable findings from this study have also been used to help further work in peer support for men with prostate cancer.

Clinical trial of a supportive care program for localised prostate cancer
Many Queensland men report a lack of support and information after diagnosis and treatment of prostate cancer. A general wellness approach can help meet the supportive care needs of men affected, incorporating information and support on a range of issues including physical activity, which has been shown to reduce the impact of side effects associated with prostate cancer treatment. The Living with Prostate Cancer Study trialled a support program (including a group peer support and exercise component) for 463 men recently diagnosed with prostate cancer.

The program was found to help men engage in more resistance exercise and meet recommended guidelines for exercise in the short to medium term. These important findings will help to improve support services for men in the future. Trial participants were followed up for a further 12 months to look at help-seeking in the first year after a diagnosis of prostate cancer. The majority of men reported unmet supportive care needs, with reported barriers to help-seeking including older age, lower education and higher depression. Support programs that link across medicine, nursing and community-based peer support may be an accessible approach to meeting these needs.
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 to ensure that CCQ can offer the best possible programs for people with cancer.

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 described 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.
Clinical trial of an online support program for distressed cancer patients

Feelings of distress are common after a diagnosis of cancer. Psychosocial care services throughout a patient’s cancer journey are essential to quality cancer care; however, geographic and sociodemographic barriers mean that support services are not readily accessible by all cancer patients.

Self-managed support programs that are available online can be delivered at home, reducing the need for cancer patients to travel great distances to receive support, and allow patients to access these services at their own convenience, whilst also being a cost-effective method of providing support on a population level.

To assess the potential of such services, we conducted a randomised trial of an innovative online supportive care program for distressed cancer patients called CancerCope.

CancerCope was a six-week interactive program providing information on stress management, relaxation exercises, managing unhelpful thoughts, problem-solving, decision-making and self-care (including exercise, sleep, fatigue and nutrition). Its aim is to reduce cancer-related distress and improve quality of life. A total of 163 distressed cancer patients were recruited and randomly assigned to the intervention and control arms of the trial.

The results of the trial showed that this online support program was associated with greater decreases in distress for those patients who most closely adhered to the program, but overall did not demonstrate a significant change in distress in the intervention arm.
Trial of peer-support to improve physical activity after cancer

Regular exercise can improve the health of cancer survivors, although few are sufficiently active. Peer support (connecting volunteers who are cancer survivors with cancer patients) is an unexplored means of helping cancer patients maintain physical activity in the long-term.

Improvements in cancer diagnosis and treatment mean more people are now surviving cancer; however, many cancer survivors have reduced functional capacity and poorer quality of life. High-intensity interval training is a time-efficient, highly effective means of rapidly improving health, with research showing it can improve cardiovascular fitness, body composition and quality of life in cancer survivors. Peer support may help adherence to these exercise programs.

In 2017, The University of Queensland and CCQ were awarded an NHMRC Partnership Grant to conduct a randomised trial of the effectiveness of a structured peer-support program in maintaining physical activity among cancer survivors following a 4-week supervised exercise program. The study combines two interventions – high-intensity interval training and peer-support – that collectively have the potential to address a critical area in exercise oncology: maintenance of exercise in a growing clinical population characterised by high risk of disease recurrence, low functional capacity, poor quality of life and comorbidities.

The trial is underway. If results show that high-intensity interval training combined with peer-support can help cancer survivors maintain the levels of exercise necessary to improve their physical and psychosocial health, the next phase of our work will involve expansion throughout Queensland and Australia.

Bill’s story

After being diagnosed with prostate cancer in 2011, Rochedale local, Bill Koch, discovered how vital exercise was in keeping both his mind and body healthy.

“Getting fit after a diagnosis is beneficial for your health and keeps your body sharp”.

His passion to ensure other cancer patients and survivors also had support to keep active is what drove Bill to register as a peer support volunteer and partake in a world-first research project - Maintaining physical activity of cancer survivors: A randomised controlled trial of volunteer peer-support. Cancer Council Queensland is conducting the research project in partnership with The University of Queensland to investigate whether peer support can assist with exercise maintenance and health after a cancer diagnosis. The study assessed men and women who have been diagnosed with either breast, bowel or prostate cancer as they undertake a supportive exercise program over 12 months.

Bill said he has been delighted to be involved in the study as research played a key role in improving the lives of Queenslanders affected by cancer. “This is an important study. Getting fit not only improves your physical state but also greatly improves your state of mind.”

This project will play a vital role in determining future peer support programs. Research is key to advancing cancer care in Queensland and aims to reduce the burden of the disease on those affected. Current evidence demonstrates that regular physical activity reduces the risk of a cancer recurrence, so this research project aims to vastly improve the health outcomes of cancer survivors.
The 1000 Survivor Study

In Australia, the five-year survival rate for cancer has steadily increased over the past three decades. This is largely due to earlier diagnosis and improved treatment.

Increasing numbers of people are surviving cancer longer and experiencing ongoing effects of the disease and treatment. These effects include impacts on pain, fatigue and sexual function; psychological function including anxiety, depression, and fear of cancer recurrence; quality of life; disruption to social or working life; and economic effects including loss of income and costs of treatment. Many of these issues are often under-reported or not addressed in follow-up care. There is an urgent need for more information about how cancer survivors cope, in order to better support those affected by the disease, inform clinicians and primary health care professionals about the challenges faced, and direct advocacy and policy.

The 1000 Survivor Study used an online survey of people aged over 18, living in Queensland, who had completed treatment for cancer. The survey specifically addressed the physical, emotional and practical challenges that Queensland cancer survivors may face. Over 1,000 Queenslanders completed the online survey.

Ninety percent of participants reported experiencing at least one physical or emotional concern after treatment. Although help was received for at least one of their concerns, over 80 per cent reported that they did not receive help or care for remaining physical or emotional concerns and that they had tried to learn to live with their concern. One-third reported that cancer had a negative impact on their job or finances. Encouragingly, 70 percent reported attempting to take better care of their health after treatment through regular screening and physical activity. Around 53 per cent found it helpful to connect with others who had also experienced a diagnosis of cancer.

This research has highlighted the high unmet need for care of patients in emotional distress, has supported advocacy efforts and provided an evidence base for CCQ’s strategy for improving cancer survivorship.
Improving outcomes for men with prostate cancer

Prostate cancer is the most commonly diagnosed cancer in Australian men and treatment can result in serious long-term physical side-effects and psychological distress. We have conducted a long-term program of research to address the issues that impact quality of life and survivorship for men affected by prostate cancer, their partners and family members.

A landmark study, Patterns of care and health-related outcomes for men newly diagnosed with prostate cancer in Queensland (ProsCan) was the first large-scale study in Australia to track outcomes for men with prostate cancer from the point of diagnosis. We followed over 1000 men with prostate cancer for 10 years and documented their patterns of care and the impact on their health and quality of life. Findings published from the ProsCan project include the following:

Decision support: A total 740 men participated in a trial of decision support and psycho-education delivered by nurse counsellors, aiming to reduce distress associated with treatment decisions. Younger men with higher education and higher income benefited from the program, while men with lower educational and income levels are likely to need alternative support programs.

Patterns of care: The study has helped to identify geographic disparities in diagnosis and treatment for men in urban versus non-urban residential locations, contributing to planning and development of health delivery and supportive care services in Queensland.

Distress screening: We developed a distress screening tool specific to prostate cancer patients that has allowed health care teams including prostate cancer nurses from the Prostate Cancer Foundation of Australia to better support men after prostate cancer by providing a level of matched to their needs.

Financial impact: Information collected from our participants combined with Medicare data was used to produce a report in collaboration with Griffith University that outlined the significant financial impact of being diagnosed with prostate cancer in Australia. This information will help men and their health care team to make more informed decisions about treatments and costs.

Partners’ experiences: A proportion of partners of men with prostate cancer experience ongoing anxiety and distress. We developed a distress screening tool to identify those partners in most need of in-depth care that has led to new support programs and services for partners.

Masculinity and sexual health: Our research highlighted the important role that masculinity plays in the way that men respond to a prostate cancer diagnosis and their attitudes towards help-seeking. Our finding that a man’s response to diagnosis and treatment is influenced by his life stage (i.e. work status, family responsibilities and sexual relationships) led to the development of a self-report tool, the Masculinity in Chronic Disease Inventory (MCD-I) to measure men’s masculinity in the context of chronic disease. The development of this tool is helping to personalise support services that talk directly to men about strategies for adjusting to identity changes after prostate cancer. The Men and Sexual Health (Prostate Cancer) Study involved over 700 men from Australia, Ireland, New Zealand and Canada in an investigation of masculinity and how it affects decisions to seek help in the long term. Information provided through this project will inform the development of services for prostate cancer patients.
Our program of work in prostate cancer culminated in funding from the National Health and Medical Research Council for a Centre of Research Excellence in Prostate Cancer Survivorship, led by Griffith University in collaboration with CCQ. This collaborative program of research aims to deliver new knowledge and interventions to improve policy and practice for men with prostate cancer.

The wellbeing of people surviving cancer is one of the most important issues facing cancer control initiatives now and in the future. Prostate cancer survivorship is a major challenge for our health system because prostate cancer is the most common cancer in Australian men and treatment can result in serious long-term physical side-effects and psychological distress. Research into ways to improve the quality of life for prostate cancer survivors has been limited. The Centre of Research Excellence in Prostate Cancer Survivorship (CRE-PCS), launched in 2016, aims to deliver knowledge and improvements in health services and research to help Australian men living with prostate cancer.

Research is focussed on four key themes:

- Effective delivery of psychosocial and sexual care in prostate cancer
- Integration of tailored exercise medicine into supportive care to improve quality of life and extend survival
- Optimisation of clinical pathways for diagnosis and treatment
- Reducing inequity in outcomes across geographic and socio-demographic boundaries.

CCQ is leading efforts to engage with consumers and prostate cancer specialist nurses to identify essential components of survivorship care and develop supportive care interventions for men with prostate cancer and their partners.

A key component now underway is the development of an Australian Prostate Cancer Atlas. This will map prostate cancer incidence, survival, PSA testing, prostate cancer treatment and prostate cancer mortality on a small area basis, as part of the Australian Cancer Atlas project.
Volunteering for cancer control

Volunteers play a key role in non-profit cancer control organisations by increasing cancer awareness and prevention, and providing support and services to cancer patients, families, and the broader community. Increased time constraints, personal pressures and changing forms of participation (e.g. short-term, flexible, or episodic volunteering) are impacting the availability of volunteer resources.

Non-profit organisations such as CCQ rely on sustained and episodic volunteers to assist with the delivery of vital community services and fundraising events. Episodic volunteering and the impact of volunteering patterns on cancer control is poorly understood.

Awarded in 2015, an Australian Research Council Linkage Grant has supported CCQ and our research partners to investigate changing patterns in volunteering for cancer control.

In the first component of this project, a longitudinal study of episodic volunteers at CCQ’s Relay For Life events throughout Queensland is collecting information about the number of years a person volunteers, the amount of time they give, how often they volunteer, and volunteers’ unique qualities and contributions. Participants are followed up every six months to determine the factors that encourage episodic volunteering and the transition to long-term volunteering.

In the second component, CCQ has partnered with Griffith University, the Union for International Cancer Control, American Cancer Society and Volunteering Queensland to conduct an international survey about the experience of people who manage and coordinate episodic volunteers. The results will inform the practice of non-profit organisations wanting to improve their recruitment and management of episodic volunteers and to address knowledge gaps including maximising the retention of volunteers, and the economic and social impact of episodic volunteering.
Communicating progress in cancer control

The number of cases of cancer and the cost of cancer treatments are increasing each year. Governments require accurate measures of the success of current cancer control strategies to prioritise health resources effectively and efficiently.

‘Cancer survival’, that is, the average time that a patient survives after a cancer diagnosis, has traditionally been used to assess the success of cancer strategies on a population level. This single measure does not communicate the full extent of the burden of cancer in our communities. CCQ is utilising novel measures of cancer survival, each providing a different perspective for communicating the full impact of cancer to government, clinicians and patients.

These measures include ‘loss of life expectancy’, that is, how much does average life expectancy change after a diagnosis of cancer. We have collaborated with the Karolinska Institute in Sweden to generate national estimates of the loss of life expectancy for the most common types of cancer and how these estimates have changed over time.

A second method (‘competing risks analysis’) estimates cancer survival following a specific cancer while also taking into account the risks of dying from other cancers and from non-cancer causes. With the Menzies School of Health Research, we have used this method to compare long term survival among Indigenous and non-Indigenous cancer patients, two groups for whom the competing risks of death are very different.

A final measure, used to assess survival inequities in disadvantaged subgroups, calculates the number of lives that could be saved in a subgroup if their survival experience was equal to the average for the population. Easy to interpret and understand, this measure has been used to illustrate the survival disadvantage suffered by regional communities and Indigenous people diagnosed with cancer.
Understanding law at the end of life

Led by the Australian Centre for Health Law Research at the Queensland University of Technology and in collaboration with CCQ, this study was the first attempt to investigate 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.

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 four-year project explored 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.

The project employed qualitative and quantitative methodologies to consider law and practice in three jurisdictions: Queensland, Victoria and New South Wales. It comprised three stages: first, critical analysis of current resources and information available to the community about legal duties and rights; second, a telephone survey of community knowledge and experience of end of life decision-making; and third, in-depth interviews with people who had experienced or were undergoing end-of-life decisions, including adult patients with a diagnosis of terminal cancer.

Evidence and findings gathered from this project were synthesised and summarised in recommendations for law reform and community education to address the gaps and needs that were identified. A resource outlining the key findings in relation to community resources about law at the end of life was produced and made available to stakeholders including government.
Meet our researchers and research partners

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Danny Youlden
Leisa O’Neill
Chloe Henshaw

Health Systems & Psycho-Oncology
Nicholas Ralph
Belinda Goodwin
Fiona Crawford
Leah Zajdlewicz
David Porter
Pamo Lozang

Professor Joanne Aitken
General Manager, Research

Professor Joanne Aitken is Head of the Viertel Cancer Research Centre at Cancer Council Queensland, Director of the Australian Childhood Cancer Registry, a member of Cancer Australia’s Advisory Council and President of the International Association of Cancer Registries.

She received her BSc (Honours) from Griffith University, her Science Masters from the Harvard School of Public Health and her PhD from the University of Queensland. She has Honorary Professorial appointments in the School of Public Health, The University of Queensland and in the Menzies Health Institute Queensland, Griffith University, and Adjunct Professorial appointments at Queensland University of Technology and the University of Southern Queensland. Professor Aitken has over 250 publications in journals including Nature, Nature Genetics, The Lancet and the Journal of Clinical Oncology.

Her work has been cited over 13,000 times in the scientific literature. She is a cancer epidemiologist who is internationally recognized for her work in the epidemiology of skin cancer and cancer in children.

She lives with her family in Brisbane’s western suburbs where they enjoy conserving and replanting native forest and wildlife habitat.

Professor Peter Baade
Senior Manager, Descriptive Epidemiology

Peter is Senior Manager of Descriptive Epidemiology in the Viertel Cancer Research Centre, 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 230 peer reviewed manuscripts and monographs with 17,000 citations and received more than $12million in total grant funding.
**Associate Professor Danny Youlden**  
*Senior Manager, Childhood Cancer Research*

Danny is a biostatistician with 30 years of experience, mostly working in health-related fields, and has been with the Viertel Cancer Research Centre since 2005. He is Senior Manager of Childhood Cancer Research and holds an adjunct appointment at the Menzies Health Institute Queensland, Griffith University. Danny has a pivotal role in national and international projects to place the Australian Childhood Cancer Registry at the forefront of population-based epidemiological research into childhood cancer, including his involvement in world-leading research to successfully implement data collection protocols used to determine stage at diagnosis and leading the development of the “Australian Childhood Cancer Statistics Online” website. He has co-authored more than 60 peer-reviewed papers since joining CCQ and has been the lead author on several major reports.

**Associate Professor Nicholas Ralph**  
*USQ/CCQ Senior Manager, Health Systems & Psycho-Oncology*

Nick is joint Senior Manager for Health Systems & Psycho-Oncology between Cancer Council Queensland and the University of Southern Queensland. He leads a cross-organisational team investigating ways to address key challenges facing health systems across the areas of health systems, cancer survivorship and cancer prevention. He also holds a substantive position as Research Program Director (Cancer Control and Survivorship) at the University of Southern Queensland and an Adjunct Associate Professorship at the University of Technology Sydney. He has authored over 40 peer-reviewed publications, three textbooks, and attracted over $2 million in research and project funding to date. He is a previous Australian Nurse of the Year (2012) for innovation and a Registered Nurse with the Nursing and Midwifery Board of Australia.

**Professor Michael Kimlin**  
*Professor of Cancer Prevention Research, University of the Sunshine Coast (2014–2018)*

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 195 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.
Strategic advisors

**Professor Jeff Dunn, AO**  
*Strategic Research Advisor in Social and Behavioural Sciences*

Jeff is an adviser on Social and Behavioural Sciences at Cancer Council Queensland. He is currently Chief Executive Officer, Prostate Cancer Foundation of Australia (PCFA) and is the Professor and Chair of Social and Behavioural Science at the University of Southern Queensland. He also serves on the West Moreton Hospital and Health Services Board and is on the Board of the Union for International Cancer Control (UICC). He has a central focus on the social and behavioural aspects of cancer control, spanning across the continuum of research, prevention, early detection, supportive care and quality of life.

Jeff 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. Jeff was appointed an Officer in the Order of Australia in June 2014 for distinguished service to medical administration through leadership roles with cancer control organisations, and to the promotion of innovative and integrated cancer care programs.

**Professor Suzanne Chambers, AO**  
*Strategic Research Leader in Psycho-Oncology (2014 –2018)*

Suzanne held the position of Strategic Research Leader in Psycho-oncology within the Viertel Cancer Research Centre until 2018 and was Director of the Menzies Health Institute of Queensland at Griffith University. She is currently Dean of the Faculty of Health at University of Technology Sydney (UTS). 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. She has published extensively on the psychosocial effects of cancer and effective ways to enhance quality of life and psychological outcomes after diagnosis and treatment. In particular she has focussed her research effort on the supportive care needs of men with prostate cancer and their families and currently leads an NHMRC Centre of Research Excellence in Prostate Cancer Survivorship. She has received research grants from esteemed agencies such as the National Health and Medical Research Council and Australian Research Council. She has over 230 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 is an Associate Editor for the European Journal of Cancer Care and is on the Editorial Board of Psycho-Oncology.
Appendix A: Publications

2014


2015


2016


**2017**


2018


Appendix B: Books, Book Chapters and Monographs


Appendix C: Grants and Fellowships

2014

2015

2016
2018
Chambers SK, Hofman M, Dhillon H, Davis I, Dunn J, Ralph N. QualTheraP: A nested, multi-perspective longitudinal qualitative study of participants in the TheraP trial. ANZUP 2018 Below the Belt Research Fund. 2018. $50,000.
Cramb S. CRE-PC Mentorship Award. Centre for Research Excellence in Prostate Cancer Survivorship. 2018. $4,000.
Appendix D: Presentations

2014

1. Aitken J. The Australian Paediatric Cancer Registry. 7th General Assembly of the Asia Pacific Organisation for Cancer Prevention, March 2014, Taipei, Taiwan.


6. Aitken J. The Australian Paediatric Cancer Registry. 46th Congress of the International Society of Paediatric Oncology, October 2014, Toronto, Canada.

7. Chambers S. A program of Australian survivorship research in prostate cancer. Faculty of Medicine in Psychiatry Grand Rounds, University of Ferrara, February 2014, Ferrara, Italy.

8. Chambers S. A program of Australian survivorship research in prostate cancer. Psychiatry Grand Rounds, Memorial Sloan Kettering Cancer Center, February 2014, New York, USA.


15. Cramb S. As time goes by: exploring cancer survival differences across small areas and time periods. UICC World Cancer Congress, December 2014, Melbourne.


17. Dunn J. Translating Research in Cancer Control to the Community. Memorial Sloan-Kettering Cancer Center, February 2014, New York, USA.

18. Dunn J. Cancer burden in the Asia Pacific Region – Trends and Future Challenges. 9th International Conference of Anticancer Research, October 2014, Sithonia, Greece.

19. Dunn J. Integrating Psychosocial Oncology into Mainstream Cancer Care: From Research to Action. 16th World Congress of Psycho-Oncology and Psychosocial Academy, October 2014, Lisbon, Portugal.

20. Dunn J. Role of Civil Society Organisations in Cancer Control. 9th International Conference of Anticancer Research, October 2014, Sithonia, Greece.

21. Hyde M. Relay For Life... or a few years? Episodic volunteer retention in the cancer control context. UICC World Cancer Congress, December 2014, Melbourne.

22. Hyde, M. Translating distress screening into cancer care: Phase 1 of an implementation case study at Gold Coast University Hospital. Gold Coast Health & Medical Research Conference, December 2014, Gold Coast.


2015


33. Chambers SK. Australian survivorship research in prostate cancer: key targets and challenges. Invited Speaker. American Cancer Society, 2 March 2015, Atlanta, USA.

34. Chambers SK. Prostate cancer support. Invited Speaker. Mt Tamborine RSL, 16 May 2015, Mt Tamborine.


37. Chambers SK. Australian survivorship research in a community setting. Invited Speaker. Tumorbiology Centre University of Freiburg, 5 June 2015, Freiburg, Germany.


43. Chambers SK. Coping with aging and cancer: psychosocial factors and geriatric-specific interventions. Invited Panel Member. World Psycho-Oncology Congress, 1 August 2015, Washington DC, USA.

44. Chambers SK. Patient Advocacy: consumers & advocates – adding the “rock & roll” to the practice of contemporary psycho-oncology. Invited Plenary Speaker. World Psycho-Oncology Congress, 1 August 2015, Washington DC, USA.


51. Dunn J. The role of peer support in survivorship care. Session Chair. World Congress of Psycho-oncology, 30 July 2015, Washington DC, USA.

52. Dunn J. Consumers and advocates adding the “rock and roll” to the practice of contemporary psycho-oncology! Plenary Chair. World Congress of Psycho-oncology, 31 July 2015, Washington DC, USA.


56. Hyde MK. Developing a commitment to cancer control organisations in Relay for Life volunteers from Queensland, Australia. Poster. World Psycho-Oncology Congress, 30 July 2015, Washington DC, USA.

57. Hyde MK. Translating distress screening into cancer care: an implementation case study at Gold Coast University Hospital, Australia. World Psycho-Oncology Congress, 31 July 2015, Washington DC, USA.


59. Hyde MK. Sexuality and body image. Session Chair. 18th Reach to Recovery International Breast Cancer Support Conference, 7 September 2015, Beijing, China.

60. Hyde MK. Motivations in volunteering. Invited Plenary. 18th Reach to Recovery International Breast Cancer Support Conference, 8 September 2015, Beijing, China.


64. Youl PH. Research in the not-for-profit sector, invited lecture. University of Queensland Research Higher Degrees, 4 February 2015, UQ St Lucia Campus.

65. Youl PH. The cancer burden, invited lecture. University of Queensland Health Sciences Course, 23 March 2015, UQ Ipswich Campus.


67. Youl PH. The cancer burden, invited lecture. University of Queensland Health Sciences Course, 23 March 2015, UQ Ipswich Campus.


70. Zajdlewicz L. The 1000 survivor study. Poster. 18th Reach to Recovery International Breast Cancer Support Conference, 7 September 2015, Beijing, China.

71. Zajdlewicz L. Psychological distress and locally advanced prostate cancer. Gold Coast Health and Medical Research Conference, 3–4 December 2015, Gold Coast.


73. Zajdlewicz L. Psychological distress and locally advanced prostate cancer. World Congress of Psycho-Oncology, 28 July–1 August, Washington DC, USA.

74. Zajdlewicz L. The 1000 survivor study. World Congress of Psycho-Oncology, 28 July–1 August, Washington DC, USA.

2016


74. Aitken JF. Background to cancer clusters. Invited Speaker. Griffith University, 21 March 2016, Brisbane.


81. 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.


86. 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.


106. 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.
125. Hyde MK. Understanding volunteers’ commitment to cancer control events. Asia-Pacific Cancer Leaders’ Summit 8th General Assembly (APOCP8), 13–14 April 2016, Brisbane.
127. 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.
128. 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.
130. 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.
133. 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.

2017


152. Chambers SK. Cancer Survivorship and Quality of Life. Invited Speaker. World Psycho-Oncology Congress (IPOS), 16 August 2017, Berlin, Germany.


159. Dunn J. Evidence-based Psychosocial Care in Cancer. CANREHAB 2017 Conference on Multi-disciplinary approach towards Cancer Rehabilitation, 7 April 2017, Tote Memorial Hospital, Mumbai, India.


163. Dunn J. Volunteerism and Mobilising Communities. 24th Asia Pacific Cancer Conference, 22 June 2017, Seoul, Korea.

164. Dunn J. Cancer survivorship and work. Session Chair. IPOS World Congress of Psycho-Oncology, 16 August 2017, Berlin, Germany.

165. Dunn J. Late and long term symptom burden and distress. Session Chair. IPOS World Congress of Psycho-Oncology, 18 August 2017, Berlin, Germany.

166. Dunn J. How goes the war against cancer and cancer survivorship. Invited Speaker. University of Southern Queensland Research Week, 26 September 2017, Toowoomba, Brisbane.

167. Dunn J. Patient Support and Survivorship. 9th World Congress of Melanoma, 21 October 2017, Brisbane Queensland.


173. Hyde MK. Advanced CaP: looking forward, looking back. Invited Speaker. 18th Asia Pacific Prostate Cancer Conference, 1 September 2017, Melbourne, Victoria.


177. Kimlin MG. Vitamin D and melanoma: An update. 20th Annual Vitamin D Workshop, 30 March 2017, Orlando, Florida, USA.

178. Kimlin MG. Vitamin D and solar ultraviolet radiation. The US Endocrine Society Annual Conference, 1 April 2017, Orlando, Florida, USA.

179. Kimlin M. Vitamin D and melanoma. US Department of Defence Medical Congress, August 2017, Orlando, Florida, USA.


187. Youlden DR. Prognosis of patients diagnosed with a second primary stage I or II melanoma. World Congress of Melanoma, 20 October 2017, Brisbane.

2018


191. Aitken J. Childhood cancer in Australia: distribution and survival by stage at diagnosis using the Toronto Guidelines. 40th International Association of Cancer Registries (IARC) Annual Scientific Meeting, 14 November 2018, Peru, South America.


212. Ralph N. Developing a Nurse-Led Intervention for Men with Advanced Prostate Cancer: A Pre-implementation Study. World Cancer Congress (UICC), 1–4 October 2018, Malaysia, KL.


Appendix E: Professional and community activities

EXPERT ADVISORY COMMITTEES, SCIENTIFIC PANELS AND WORKING GROUP MEMBERSHIPS

National

- Australasian Association of Cancer Registries, Executive Board & Committee
- Australia and New Zealand Melanoma Trials Group (ANZMTG) - Nursing, Allied Health, Public Health & Primary Care Advisory Panel
- Australian and New Zealand Urogenital and Prostate (ANZUP) Cancer Trials Group
  - Quality of Life and Supportive Care Subcommittee Chair
  - Quality of Life Committee
- Australian Research Council, Engagement and Impact Assessment Pilot Evaluation Panel
- Australian Skin and Skin Cancer Research Centre (ASSC) Grant Review Panel, Chair
- Cancer Australia
  - Communications Advisory Committee, Chair
  - Expert Reference Group, Healthy Living Interactive Group
  - Expert Reference Group, Lifestyle risk factors and the primary prevention of cancer
- Cancer Council Australia
  - Cancer Councils National Research Administration Working Group
  - CEO Forum
  - National Cancer Research Grants Steering Committee
- Centre for Prostate Cancer Survivorship Research, Lead Advisory Group member
- Co-operative Research Centre in Spatial Information (CRCSI) Health Program, Program Board
- Expert Advisory Group, Development of Palliative Care Indicators for the National Cancer Control Indicators Framework
- Medical and Scientific Committee, Cancer Council Queensland
- National Health and Medical Research Council (NHMRC)
  - Assigners Academy
  - Centres for Research Excellence Review Panel
  - Partnerships Review Panel
  - Early Career Fellowship Review Panel
  - Project Grant Review Panel
- Queensland Cooperative Oncology Group Management Committee
- Queensland Health
  - Queensland Cancer Control Safety and Quality Partnership
  - Queensland Skin Cancer Prevention Collaborative Committee Chair
- Queensland University of Technology, Faculty of Health Advisory Committee
- University of Southern Queensland, Research Committee, USQ/CCQ Joint Research Program
- Youth Cancer Service
  - National Adolescent and Young Adult Cancer Dataset Advisory Group
  - National Adolescent and Young Adult Cancer Staging Working Group

International

- Asian Pacific Organization for Cancer Prevention (APOCP)
  - Regional Chairperson Australasia
  - Executive Committee member
  - President
- British Medical Journal Open, Statistical Advisory Group
- Cancer Research Malaysia, Scientific Advisory Group
- German National Skin Cancer Screening Program Steering Committee
- International Advisory Group, Population Data for Childhood Cancer
- International Association of Cancer Registries
  - President and Board member
  - Elected Representative for Oceania
- International Childhood Cancer Staging Guidelines, Implementation Advisory Group
- International Consortium for Childhood Cancer Cohorts
- International Psycho-Oncology Society (IPOS)
  - Director and Board member
  - Secretary
- Lancet Oncology Commission on Sustainable Paediatric Cancer Care, Advisor
- Reach to Recovery International, Board of Management
- Statistical Advisory Board for BMJ Open
- Union for International Cancer Control (UICC)
  - Director and Board member
  - Asia-Pacific Cancer Society Training Grant program (APCASOT) Chair
  - Cancer Care Action Advisory Group member
  - C/Can Task Force member
  - Finance Committee Chair
  - Membership Committee member
  - NCD Task Force member
  - Reach to Recovery International Breast Cancer Support Service Chair and Special Advisor
  - Regional Activities Committee member
  - Supportive Care Network International Advisory Committee member
  - Treasurer
  - World Leaders Forum meeting
CONFERENCE ORGANISING COMMITTEES

• Asian Pacific Organization for Cancer Prevention (APOCP8): 2016
• Asia Pacific Cancer Leaders’ Summit: 2016
• Asia-Pacific Prostate Cancer Conference Nursing and Allied Health: 2016, 2017
• International Psycho-Oncology Society Congress (IPOS): 2015, 2016, 2017
• National Sunscreen Summit: 2018
• Reach to Recovery International Breast Cancer Support Conference: 2015
• Vitamin D Workshop: 2017
• World Cancer Congress (UICC): 2014, 2018
• World Cancer Leaders’ Summit: 2018
• World Congress on Cancer Control in Developing Countries: 2018
• World Congress on Melanoma: 2017

PROFESSIONAL MEMBERSHIPS

• Andrology Australia
• Australian and New Zealand Urogenital and Prostate (ANZUP) Cancer Trials Group
• Australian–Canadian Prostate Cancer Research Alliance
• Australasian Epidemiological Association
• Australian Institute of Company Directors
• Australian Psychological Society (APS) College of Health Psychologists
• Australian Society for Medical Research (ASMR)
• Australasian Society of Behavioural Medicine
• Clinical Oncological Society of Australia (COSA)
• 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 Behavioural Medicine

Reviews for journals

• American Journal of Clinical Dermatology
• American Journal of Clinical Nutrition
• American Journal of Epidemiology
• American Journal of Men’s Health
• 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 Control
• Cancer Epidemiology
• Cancer Epidemiology Biomarkers and Prevention
• Cancer Medicine
• Clinical Breast Cancer
• Clinical and Experimental Dermatology
• Current Cancer Therapy Reviews
• Current Medical Research and Opinion
• 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 Dermatology
• 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 the 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 Paediatrics and Child Health
• Journal of Psychosomatic Research
• Journal of Surgery
• Journal of Urology
• Lancet
• Leukemia and Lymphoma
• Medical Journal of Australia
• Melanoma Management
• Melanoma Research
• Men and Masculinities
• Molecular Nutrition and Food Research
• Nature Scientific Reports
• Netherlands Organisation for Scientific research
• Paediatrics
• Patient Education and Counselling
• Plastic Surgery International
• PLOS ONE
• Preventive Medicine
• Protein
• Psychology and Health
• Psychology, Health and Medicine
• Psychos – Oncology
• Quality of Life Research
• Scientific Reports
• Social Behavior and Personality
• Social Science & Medicine
• Supportive Care in Cancer
• Thorax
• Tumour Biology
• World Cancer Research Fund International

**Reviews for funding bodies**
• ANZUP Clinical Trials Group
• Australian Research Council
• Breast Cancer Now
• Cancer Australia
• Cancer Council Western Australia Epidemiology Initiative
• Cancer Institute NSW
• Cancer Research UK
• Cancer Research Wales
• French National Cancer Institute
• Health Research Council New Zealand
• Hong Kong Medical Research Fund
• Hong Kong SAR Government
• Icelandic Centre for Research
• International Cancer Research Education Technology Transfer Program, UICC
• Italian Association for Cancer Research
• Medical Research Council UK
• National Health and Medical Research Council
• Prostate Cancer Foundation of Australia
• Queensland Nursing Council
• The Research Fund for the Control of Infectious Diseases (RFID) / The Health and Health Services Research Fund (HHSRF), Hong Kong
• Victorian Cancer Agency