A brighter future through research

ANNUAL REPORT 2019
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### Every minute, every hour, every day, we’re working towards our vision of a cancer free future.

**Our mission**

To reduce the burden of cancer.

**Our commitment**

To improve the quality of life of Queenslanders living with cancer.

**Our values**

We support the cancer community with integrity, agility and a deep sense of belonging.
Cancer Council Queensland’s Strategic priorities

1. Inform Queenslanders with trusted knowledge and advice.

Position Cancer Council Queensland as the trusted ‘go-to’ source of truth.
How we will do it:
• Inform the community of our impact and activities
• Develop a bespoke brand integration plan
• Partner with other trusted organisations
• Develop an integrated marketing, digital and engagement strategy to target key stakeholders
• Continue to undertake and invest in research aligned with strategy
• Provide up-to-date cancer resources and information
• Develop and leverage video content
• Create emotive storytelling to engage the community to influence change

2. Support and connect Queenslanders living with cancer to the right services and people.

Optimise services and support to be the premier navigator of cancer information and services.
How we will do it:
• Map existing services and support to identify gaps
• Increase feedback from service and program users
• Identify technologies that could enhance support and extend reach e.g. e-support groups
• Improve Helpline by making it a more comprehensive navigation aid
• Improve website information and navigation options
• Implement customer relationship management to underpin service delivery

Develop model for living with cancer to support local community.
How we will do it:
• Pilot new models of community cancer care and support
• Continually review and repurpose existing facilities

Build strong service and support partnerships.
How we will do it:
• Develop a presence throughout the public, private and community agencies to increase referrals
• Use information from these relationships to improve evidence informed advocacy
• Identify best-practice partners

3. Grow sustainability to ensure our future.

Improve systems to underpin growth and efficiency.
How we will do it:
• Implement an improved CRM and communications platform
• Improve website functionality and navigation
• Develop fit for purpose IT Systems, including data and document management
• Investigate efficiencies with other Cancer Councils and health sector Not For Profits

Invest in people.
How we will do it:
• Attract and retain skilled volunteers with a focus on young volunteers
• Optimise volunteer management by funding and implementing a volunteer management system
• Attract and retain skilled employees
• Improve change management, implementation and communication
• Conduct an annual employee engagement and volunteer survey

Grow financial base.
How we will do it:
• Explore new sustainable avenues of revenue
• Attract, acquire and retain donors and supporters
• Identify considered philanthropic opportunities
• Ensure that the investment approach has the correct balance of risk and reward and is in line with mission and values
• Increase profitable revenue sources from government, corporates, mid-value and major gifts

Optimise governance.
How we will do it:
• Increased diversity of input into Cancer Council Queensland governance
• Measure the organisation’s governance against best practice
• Implement rolling internal audit program to minimise risk
Cancer in Queensland

THE FACTS

Based on current trends and predicted population changes, 40,000 Queenslanders are expected to be diagnosed with cancer in the year 2027.

30,121 Number of Queenslanders who were diagnosed with cancer in 2017

9442 Number of Queenslanders who died of cancer in 2017

Overall, five-year relative survival from cancer in Queensland has increased from 53 per cent in the 1980s to 72 per cent during 2013–2017

Approximately 244,090 Queenslanders are alive today after a cancer diagnosis in the past 25 years (1993–2017)

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

Message from the CEO

Ms Chris McMillan

Research is the gateway to Cancer Council Queensland’s vision of a cancer free future. In 2019, the Viertel Cancer Research Centre has scaled new heights to bring us another step closer to that vision.

It is with pleasure and a deep sense of pride that I introduce this report to you. Throughout, you will discover how Cancer Council Queensland has risen as a global leader in cancer research, taking part in several high-profile international collaborations in 2019. Our publications are cited three times more than the world average, proving that we are a voice of authority on respected, world-class research.

In the report, you will find updates on our progress in the fields of descriptive epidemiology and psycho-oncology. The Australian Cancer Atlas continues to expand and is gaining recognition from other countries wishing to use our model to develop their own. We have not lost sight of issues at home, however, as we strive to improve cancer control for Indigenous women in Australia through our cervical cancer screening program.

A key milestone in 2019 was the launch of our bowel cancer screening project, which aims to improve screening uptake through consultation with regional and rural people. The purpose of this project is to increase bowel cancer diagnosis to an early stage, to improve survival.

I would also like to highlight the completion of the Prostate Cancer Supportive Care and Patient Outcomes project conducted at Cancer Council Queensland. We remain committed to improving the survivorship experience of Australian men who have had a prostate cancer diagnosis.

We continue to manage the Australian Childhood Cancer Registry to provide one of the most comprehensive databases for childhood cancer in the world. In 2019, a comprehensive report titled ‘Childhood Cancer in Australia, 1983–2015’ was released, using the latest available Australian data. This report was distributed to paediatric oncologists and hospitals throughout Australia and has been welcomed by families of children with cancer and those who care for them.

The achievements published in this report simply would not have been possible without the generous support of the Sylvia and Charles Viertel Charitable Foundation and the Foundation Trustees. Their commitment to our joint mission is invaluable.

I also acknowledge Cancer Council Queensland’s Board of Directors and Chair, Mr Andrew Arkell (2017–2019), our employees, our network of distinguished research collaborators, and the thousands of community members who support and participate in our work. Together, we are creating a brighter future, not only for Queenslanders with cancer, but for people impacted by cancer worldwide.

Chris McMillan – Chief Executive Officer
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.
Contributing to the global cancer research effort (2004 – 2019)

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.

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 is called "Field-Weighted Citation Impact". A Field-Weight 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.

2004 - 2019 PUBLICATION METRICS

Our publications on average are being cited more than world average.

120 PUBLICATIONS 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
- Nature Communications
- Nature Genetics
- Journal of Clinical Oncology
- British Journal of Dermatology
- International Journal of Cancer
- Journal of Investigative Dermatology
- Psycho-Oncology
- CA: A Cancer Journal for Clinicians

96% of publications involve national and/or international collaboration

18 PRESENTATIONS at national and international conferences in 2019

Over 2000 MENTIONS in national and international news/blogs

Awarded/collaborated on 15 GRANTS in 2019

629 scientific publications with a total citation count of over 27,000

13 publications in the TOP 1% most cited publications worldwide (field-weighted)

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2. The metric used is called "Field-Weighted Citation Impact". A Field-Weight 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.
Impact on health policy and practice

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

- Centers for Disease Control and Prevention (USA)
- National Academies Press (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)
- The Association of the Scientific Medical Societies in Germany
- Analysis and Policy Observatory (Australia)
Our partners and collaborators

**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, Hong Kong
- International Agency for Research on Cancer, Lyon
- International Association of Cancer Registries
- International Childhood Cancer Cohort Consortium (ICCC)
- 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 Childhood 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
- Shanghai Chinese 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 (ANZCHOG)
- Australian and New Zealand Urogential 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 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

Projects underway in 2019

Cervical cancer screening in Indigenous women*
Cancer outcomes in Indigenous Australians
Inequities in breast cancer diagnosis, management and survival
New methods for spatial analysis of cancer
Measuring cancer survival*
Queensland Cancer Statistics Online
Improving quality and utilisation of national cancer datasets
Patterns of treatment for upper-gastrointestinal cancer in Queensland
Deaths from early invasive melanomas*
Understanding drivers and impact of multiple melanomas
Improving sun protection behaviour in young Australian adults using text messaging
Australian Childhood Cancer Registry*
Australian Childhood Cancer Statistics Online
Improving childhood cancer information for Australia*
Area-based variation in childhood cancer incidence and survival
Improving prognostic information for childhood cancers
Improving Australian data on childhood cancer treatment
Stage at diagnosis and survival for children with cancer*
Systematic review of geographical patterns in prostate cancer outcomes
Prostate cancer survivorship*
Understanding international variation in cancer outcomes
Systematic reviews of international liver cancer incidence trends among adults and children
Travelling for Treatment project*
Improving participation in bowel cancer screening*
General practitioner attitudes to care of rural cancer survivors
Volunteering for cancer control

*See following pages for details
Cervical cancer screening in Indigenous women

Improving cancer control for Indigenous Australians is a key strategic priority for Cancer Council Queensland. Cancer survival rates are lower among Indigenous Australians than non-Indigenous Australians for all malignancy types. Indigenous Australians are also less likely to participate in cancer screening programs and, if diagnosed with cancer, are more likely to be diagnosed with advanced disease.

Until recently, there has been no information about cervical screening participation rates among Indigenous Australian women. This was due to the lack of an Indigenous identifier on the cervical screening registers.

This started to change in 2013, when Cancer Council Queensland was part of a national data linkage study designed to quantify cervical screening participation among Indigenous women. Even though Pap smear registries do not include Indigenous status, by linking these registries with the Hospital Admitted Data Collections (which do record Indigenous status), the Indigenous status of screened women could be ascertained. Funded by the National Health and Medical Research Council and led by Menzies School of Health Research, this study quantified for the first time the lower screening rates among Indigenous Australian women, and how they varied by geographical location.

While this study provided new and important information, it was important to update these results with more contemporary information up to the introduction of the new cervical screening program (Renewal) in 2018. To facilitate this, additional data linkages between the hospital data collection and the Pap smear registry were carried out. This process included records for over one million women and over two million cervical screening episodes. Analyses of these and other data will continue over the next few years, and will aim to answer questions about how the most recent screening rates vary by geographic area, whether these screening rates, and the geographical patterns are changing over time, and what are the driving factors behind the lower screening rates among Indigenous women. Disturbingly, initial results have shown that participation rates have recently decreased among both Indigenous and non-Indigenous women, and that this decrease is consistent across all geographical areas of Queensland.

Ultimately, the goal of this program of research is to understand the screening and treatment pathways among Indigenous cancer patients and the role that this plays in their reduced survival rate. This information can then be used to guide the development of effective and culturally sensitive interventions to reduce the existing gap in cancer outcomes.
When clinicians and researchers talk about cancer survival, often they are referring to a term called ‘net survival’, or the mortality that is associated specifically with a cancer diagnosis. This ‘net survival’ refers to the very hypothetical (and non-realistic) situation where cancer is the only cause of death. This is difficult to interpret in the real world. However, there are a range of other statistical measures that can be used in describing cancer survival. These alternative measures of survival assist in communicating and understanding the impact that a cancer diagnosis has on a person’s life.

We have used data from each of the eight state and territory-based population cancer registries across Australia to calculate these different measures and so provide new insights into the survival experience of Australians diagnosed with cancer between 1982 and 2014.

Results to date have consistently highlighted the improving survival outcomes for Australian cancer patients over time. This is great news. However, it implies that the number of Australians who are living with a cancer diagnosis is increasing, and this increasing number of cancer survivors poses a challenge to the health system in ensuring equitable access to appropriate evidence-based care for all patients during the many years after their cancer diagnosis.

These specific measures include:

- **Loss of life expectancy**, which reflects the difference between the life expectancy of people diagnosed with cancer and the life expectancy of similar individuals from the general population. A fifty-year-old male diagnosed with cancer during the 1980s could, on average, anticipate losing 14 years of life expectancy as a result of his cancer diagnosis. The corresponding estimate for a fifty-year-old male diagnosed after 2000 was nine years of life expectancy.

- **Probability of population cure** is when the mortality rate associated with a cancer diagnosis returns to the same level as that expected within the general population. This method can also be used to calculate the survival expectation for the group of cancer patients who eventually die from their cancer. For example, on a population level, 90% of Australians diagnosed with cancer can eventually be considered ‘cured’, compared to about 5% of those diagnosed with pancreatic cancer.

- **Crude probability of death** estimates the probability of dying from cancer within a certain time period, while also accounting for the probability of dying from another cause. For example, within a group of 100 fifty-year-old women diagnosed with breast cancer in Australia in 2013, on average, nine would be expected to die from the cancer within 10 years, two would die from other causes, and 89 would be alive after 10 years. These values vary substantially by cancer type; for 100 fifty-year-old women diagnosed with lung cancer in 2013, 74 women would be expected to die from lung cancer within 10 years, one die from other causes and 25 would be alive.
Deaths from early invasive melanomas

Why do some people die from melanoma even when it is detected early?

Queensland has the unwanted reputation of being the melanoma capital of the world. In 2017 alone there were over 4,000 Queenslanders who were diagnosed with an invasive melanoma, and over 350 Queenslanders died from the disease.

The prognosis for melanoma is much better when it is diagnosed early, when the tumour is thin. Despite this, there are still a high number of Queenslanders who die each year from thin melanoma. We need to understand what distinguishes “fatal” thin melanomas from others so that we can improve early detection and treatment.

With collaborators from QIMR Berghofer Medical Research Institute, the University of Queensland and other institutes, we have been investigating why some thin melanomas are more aggressive than others.

Through this work we have demonstrated that death from thinner melanomas tends to happen more than five years and often up to ten years after diagnosis. We have also highlighted that even in the thinnest category of melanomas, that is, those under 1mm at diagnosis, thickness is still an important predictor of survival. Melanomas between 0.8mm and 1.0mm are six times more likely to cause death than those that are thinner than 0.3mm at diagnosis. In addition, people diagnosed with a thin melanoma on the scalp were six times more likely to die of melanoma than those whose thin melanoma was located on their back.

This ongoing research will help us understand what it is about the patient and/or their melanoma that increases the risk of dying from this cancer. With this information, we can more accurately communicate the risk to patients, guide clinical management and surveillance, and ultimately develop non-invasive, cost-effective technologies that can reliably detect high-risk tumours.
Australian Cancer Atlas

The Australian Cancer Atlas is Australia’s first interactive, digital atlas of cancer that shows the patterns of cancer incidence and survival rates for the top 20 cancer types across all 2,148 small geographical areas that cover Australia. The Atlas highlights the dramatic geographical variation in the cancer burden across Australia, and the marked contrast in these geographical patterns for the different types of cancer.

The Atlas incorporates innovative visualization technology to convey complex messages in a clear way to a wide audience. It is freely and easily accessible online to anyone interested in understanding more about patterns of the burden of cancer across Australia. This, combined with its interactive nature, has made it an ideal resource for teaching purposes, already being utilised in University Masters-level courses. It has also been used by government, scientists and health professionals to identify priority areas for cancer research and action.

Up to December 2019 it had been used by over 40,000 distinct users from over 100 countries.

In a collaboration with the New Zealand Ministry of Health, the methods and technology underpinning the Australian Cancer Atlas are being used to develop a New Zealand Cancer Atlas, with a planned launch at the end of 2020. Other international collaborations are being developed that will allow direct comparisons of geographical patterns of cancer in different countries.

The Atlas needed a large team, and over 40 people contributed to its development, across multiple organisations and a range of disciplines, including statistics, epidemiology, visualisation, information technology, web development, policy and media.

This work was underpinned by an ongoing partnership between Cancer Council Queensland, Queensland University of Technology, and FrontierSI.

The Australian Cancer Atlas has received top industry awards from the Surveying & Spatial Sciences Institute (SSSI), the national peak body of the spatial information industry:

- 2019 Asia Pacific Spatial Excellence Awards (APSEA) Award for Spatial Enablement
- JK Barrie Award for Overall Excellence – “the highest pinnacle of spatial achievement that the judging panel can confer.”

Spotlight on our collaborators

The Australian Cancer Atlas needed a large team, and over 40 people contributed to its development, across multiple organisations and a range of disciplines, including statistics, epidemiology, visualisation, information technology, web development, policy and media.

This work was underpinned by an ongoing partnership between Cancer Council Queensland, Queensland University of Technology, and FrontierSI.

Distinguished Professor Kerrie Mengersen, Professor of Statistics in the School of Mathematics, Queensland University of Technology.

‘The collaboration with Cancer Council Queensland and FrontierSI has been one of the highlights of my research career,’ said Professor Mengersen.

‘It has provided a golden opportunity to work with a dedicated interdisciplinary team to translate knowledge and develop new quantitative tools to extract insights and patterns from data, with a focus on making a real difference to understanding the spatial patterns and determinants of cancer.’

Professor Mengersen’s work focuses on using and developing new statistical and computational methods that can help to solve complex problems in the real world, in the fields of environment, genetics, health and medicine, and industry.

“We created important new knowledge, long-lasting collaborations, and an amazing Australian Cancer Atlas (underpinned by rigorous state-of-the-art statistical modelling) that can be used by the public, managers, and government to learn about and better manage cancer. The Atlas has won multiple prestigious awards and is being replicated in other countries and for other health outcomes, which are strong indicators of its impact.’

The project has had a long-lasting impact on Professor Mengersen’s work. ‘The collaboration has considerably deepened my understanding of cancer and motivated other research in this field as well as generating new contributions in statistical and data science, computational methods and visualisation.’

Working with the team at Cancer Council Queensland has been inspiring for Professor Mengersen. ‘My colleagues from the Viertel Cancer Research Centre are the best collaborators! They are willing to share their considerable expertise and are interested in the expertise and perspectives of their collaborators. They respect research, and endeavour to translate statistical ideas to meaningful results for the Viertel Cancer Research Centre and for cancer research.’

‘However, the greatest outcome for me is when someone uses our Atlas and says, “Look at that – I didn’t know that before.” That’s a real indicator of how this collaboration can create change.’

The Australian Cancer Atlas has been used by over 40,000 distinct users from over 100 countries.

In a collaboration with the New Zealand Ministry of Health, the methods and technology underpinning the Australian Cancer Atlas are being used to develop a New Zealand Cancer Atlas, with a planned launch at the end of 2020. Other international collaborations are being developed that will allow direct comparisons of geographical patterns of cancer in different countries.
The Registry is a national resource and operates in collaboration with the Australasian Association of Cancer Registries, all Australian State and Territory population cancer registries, the Australian Institute of Health and Welfare, and each of the major paediatric oncology treating hospitals throughout the country. Information held by the Registry includes details of all children diagnosed with cancer in Australia aged under 15 years.

Using data from the Registry, a comprehensive report titled ‘Childhood Cancer in Australia, 1983-2015’ was released in February 2019 to coincide with International Childhood Cancer Day. The report detailed the latest available information on childhood cancer incidence, survival, mortality, prevalence, second primary cancers and key population groups of interest. Copies of the report were sent to paediatric oncology clinicians and other major stakeholders throughout Australia and internationally, and an electronic version was also made freely available online (see https://cancerqld.org.au/research/viertel-cancer-research-centre/childhood-cancer/australian-childhood-cancer-registry/).

Some of the main findings included in the report were as follows:

• On average, approximately 770 children aged 0-14 years old were diagnosed with cancer each year in Australia between 2011 and 2015.

• Leukaemias, tumours of the central nervous system and lymphomas were collectively responsible for two out of every three cases (66%) of childhood cancer.

• Almost half (47%) of all childhood cancers were diagnosed among children aged 0-4 years.

• After adjusting for changes in the population, the modelled incidence rate of all childhood cancers combined in Australia increased by a total of 34% between 1983 and 2015.

• As at the end of 2015, five-year relative survival for all children diagnosed with cancer combined in Australia between 2004 and 2013 was 85%.

• Five-year relative survival for all childhood cancers combined has improved significantly in Australia over the last three decades, from 73% for children diagnosed between 1983-1993 to 85% for those diagnosed between 2004-2013.

• There were just under 100 deaths per year due to cancer for children under the age of 15 in Australia each year on average between 2011 and 2015.

• Childhood cancer mortality rates have decreased significantly over the last two decades and were 38% lower in 2015 compared to 1998.

• It was estimated that a total of 14,760 childhood cancer survivors were living in Australia as at 31 December 2015.

• Compared to expected rates of cancer in the general population matched by age, sex and calendar period, people with a history of childhood cancer were around five times more likely to be diagnosed with a second primary cancer.

• Only minor differences in childhood cancer incidence and mortality were observed by Indigenous status, remoteness of residence and area-based socio-economic status.
### Improving childhood cancer information for Australia

During 2019, Cancer Council Queensland was engaged by Cancer Australia to conduct a project titled ‘Improving childhood cancer data for Australia: Enhancing the collection of population data on childhood cancer treatment and non-stage prognostic indicators’. This project consisted of three main components:

- Investigate area-based variation in childhood cancer;
- Contribute to the development of consensus guidelines for collection of non-stage prognostic data for childhood cancers; and,
- Improve population data on childhood cancer treatment.

#### Area-based variation in childhood cancer

Previous analyses of all childhood cancer patients diagnosed in Australia between 1996 and 2006 reported some associations between residential location and childhood cancer incidence and survival. Due to the efforts of the Australian Childhood Cancer Registry, Australia was the first country in the world to have national data on childhood cancer stage. Using this information, we were able to look at area-based variation in the distribution of stage and stage-adjusted survival for childhood cancer on a population basis.

Data from the Australian Childhood Cancer Registry generally did not support the idea that childhood cancer is diagnosed at a more advanced stage outside major cities or in more disadvantaged areas. However, the analysis suggested that for the period 2006 to 2015, two of the most common childhood cancer types - acute lymphoblastic leukaemia and acute myeloid leukaemia - had poorer survival in more disadvantaged areas, after adjustment for sex, age group and stage at diagnosis. There was also possible evidence that children with acute myeloid leukaemia, osteosarcoma or hepatoblastoma had lower five-year adjusted survival outside major cities. The fact that variation in cancer survival persists for these types of childhood cancer after factoring in any variation in stage at diagnosis raises the question of what other issues may contribute to the apparent survival patterns.

#### Improving prognostic information for childhood cancers

Although stage at diagnosis is recognised as a key prognostic indicator for most childhood malignancies, other non-stage prognostic factors including genetic markers and tumour cytology are also important in assessing prognosis and are used to classify patients into prognostic risk groups for planning management. As a result, it is important to include non-stage prognostic indicators in population-based analyses of outcome, leading to the need to create consensus guidelines for registries to collect this information.

A panel of international experts and stakeholders was assembled in Lyon during October 2019, representing diverse content expertise (clinicians, epidemiologists and cancer registry representatives) from a range of countries, including low, middle and high-income countries, to ensure the most generalizable and feasible recommendations. Prof Joanne Attkan, General Manager of Research at Cancer Council Queensland, was one of the three co-leads for this work. The expert panel identified a number of key principles that should underly guidelines for the collection of non-stage prognostic indicators and also developed recommendations as to which indicators should be collected for the various types of childhood cancer. The next step of this work will involve assessing the feasibility of collecting these additional data items within the Australian Childhood Cancer Registry.

#### Improving Australian data on childhood cancer treatment

The Australian Childhood Cancer Registry collects information from hospital medical records as to whether a child has received surgery, radiotherapy and/or chemotherapy. Until now, the names of the chemotherapy protocols used for each patient were collected, but not the specific chemotherapy agents included in these protocols. The focus of this component of the project was to improve the quality and completeness of these chemotherapy data, and in particular, to collect information on the specific chemotherapy agents that were administered.

The method for ascertaining the specific chemotherapy agents for patients varied by hospital, and involved either obtaining patient pharmacy records, review of medical records (on-site or electronically) or approximation based on the agents listed in the chemotherapy protocol documentation if the data were not directly available. Details of the specific chemotherapy agents were ascertained for all childhood cancer patients who were diagnosed with cancer between 2010 and 2015 and who were known to be treated with chemotherapy at one of the major paediatric oncology hospitals in Australia. Following on from the success of this project, Cancer Council Queensland is committed to prospectively enhance treatment data in the Australian Childhood Cancer Registry through the ongoing collection of information on standardised chemotherapy protocols and chemotherapy-related drugs. This information will be important in the future when assessing the effects of childhood cancer treatment on morbidity and mortality.
Stage at diagnosis and survival for children with cancer

Stage at diagnosis of cancer is one of the most important predictors of cancer survival. Information on stage at diagnosis is therefore vital for interpreting treatment outcomes and for identifying differences between jurisdictions. This year, an analysis of data from the Australian Childhood Cancer Registry, focusing on the most common childhood blood cancers and solid cancers, showed that survival rates in Australia are among the best in the world. For childhood blood cancers, our results typified the much-improved survival rates that are now achieved even for patients presenting with higher stages, with five-year survival of at least 85-90%. Some of the findings indicated possible areas for further investigation, including superior survival in acute myeloid leukaemia among children in Australia and higher presenting stage in Hodgkin lymphoma than reported elsewhere in the world. Regarding childhood solid cancers, we found that around three out of every four children with a solid cancer were diagnosed at a lower stage and that most of these cancers exhibited highly significant differences in stage-specific survival.

The data used in these studies represent an important step towards consistent and reliable information on stage for childhood cancers within Australia. These world-first results were published in international peer-reviewed journals and will provide a baseline for future comparisons. It is also anticipated that more widespread implementation of the Toronto Childhood Cancer Staging Guidelines will allow an international picture of stage-specific incidence and outcome that ultimately may inform better targeted control of childhood cancer.

International engagement

Given the rarity of childhood cancers, internationally consistent data standards and definitions are crucial for pooled data analyses and population comparisons. Over recent years, a detailed manual for deriving childhood cancer stage has been developed, tested and implemented in national work led by Cancer Council Queensland. In an important development, the staging manual was formally endorsed by the Union for International Cancer Control (UICC) and the International Association of Cancer Registries (IACR) in early 2019 and was made freely available through the IACR website. The staging manual has been implemented in Europe, parts of Asia, Africa and South America. To facilitate its use in non-English speaking countries, the staging manual has been translated by registries in those countries into Portuguese, Japanese, Italian, Spanish and French. Cancer Council Queensland has proactively established a working group including representatives of GREL (the Group for Epidemiology and Cancer Registry in Latin Language Countries (Spanish translation), the Italian Institutes for Cancer Patient Care and Research (Italian translation), the Brazilian National Cancer Institute (Portuguese translation) and the African Cancer Registry Network (French translation) to resolve any inconsistencies in the translated versions, and to recommend a suitable central online repository for all translations.

As a direct result of our collaboration, it will be possible for the first time to compare survival outcomes for children with cancer between whole populations in a meaningful way, not just between individual hospitals or clinical trials. This is opening our eyes to the extreme disparities between low- and high-income countries and gives us some of the key information we need to start to push for improvements.

The clinical stage of childhood cancers, or the extent of cancer spread at the time of diagnosis, is not available in most populations throughout the world. Even though stage is one of the most fruitful as well as most delightful experiences of my career.

Professionally, without the Cancer Council Queensland team, our work might have been another one of those great ideas that never get put into practice. Only due to the Cancer Council Queensland team’s remarkable ability to translate concepts into day-to-day work has this seemingly simple but in practice extraordinarily complex, concept been transformed into the real world. Not only did they spell out exactly which data were needed, and how to find that data, but they went further and developed an app to make it even simpler—with built-in accuracy checks.

The guidelines developed by the Cancer Council Queensland team have been literally translated into multiple languages and adopted around the world. Cancer Council’s advocacy for childhood cancer, and registration of childhood cancer cases, means that we will finally begin to understand the true gap in diagnoses and outcomes of children with cancer worldwide. This collaboration, and I speak for both Dr. Gupta and myself, has been one of the most fruitful as well as most delightful experiences of my career.

Professor Lindsay Frazier is a paediatric physician at Dana-Farber/Boston’s Children’s Cancer and Blood Disorders Center; Associate Professor of Epidemiology, Harvard School of Public Health; and Professor of Paediatrics, Harvard Medical School.

‘Honestly, without the Cancer Council Queensland team, our work might have been another one of those great ideas that never get put into practice. Only due to the Cancer Council Queensland team’s remarkable ability to translate concepts into day-to-day work has this seemingly simple but in practice extraordinarily complex, concept been transformed into the real world. Not only did they spell out exactly which data were needed, and how to find that data, but they went further and developed an app to make it even simpler—with built-in accuracy checks.

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Dr Sumit Gupta is a Paediatric Oncologist in the Division of Haematology/Oncology at The Hospital for Sick Children (SickKids) in Toronto, Canada. He is also Associate Professor at the University of Toronto in the Department of Paediatrics; the Institute for Health Policy, Management and Evaluation; and Institute of Medical Sciences.

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Prostate cancer survivorship

Survival rates for prostate cancer are greater than 95%, however, many men encounter significant and ongoing treatment related symptoms and distress. To improve the survivorship experience of men and their families, Cancer Council Queensland works in partnership with the NHMRC Centre of Research Excellence in Prostate Cancer Survivorship (CRE-PCS), the Prostate Cancer Foundation of Australia (PCFA) and the University of Southern Queensland (USQ).

A key milestone in 2019 was the completion of the Prostate Cancer Supportive Care and Patient Outcomes project conducted at Cancer Council Queensland. This project followed men for 10 years after a diagnosis of prostate cancer and found that about one third of men still experience poor physical and mental quality of life outcomes 10 years down the track, highlighting the importance of long-term follow-up. Other work identified aspects of masculinity that may prevent men from accepting the need for help and acknowledged that gender-sensitised health interventions may be required to target men effectively and lead to optimal outcomes. A culmination of this work was a set of recommendations for screening for distress and psychosocial care for men within a proposed model for delivery for healthcare providers. Researchers also sought to address the distinctive needs of advanced prostate cancer patients by designing a nurse-delivered tele-based supportive care intervention which has been strongly endorsed by prostate cancer specialist nurses across Australia.

In 2019, we gained new insights into the priorities for prostate cancer survivorship from the perspective of patients and key healthcare providers through important qualitative studies. Researchers from Cancer Council Queensland and USQ presented nationally and internationally on survivorship issues for men with prostate cancer and we also supported the CRE-PCS, in partnership with the PCFA and the Australian and New Zealand Urogenital and Prostate Cancer Trials Group, to deliver the ‘Changing the Face of Prostate Cancer Survivorship in Australia: Implementation Forum’ in Brisbane.

Colin’s story

Colin’s first experience with cancer was in 2005 after a cancer was found on his kidney.

‘I was a fit and healthy man and was shocked with the diagnosis.’

‘I lost my kidney due to the cancer and thought it was all over, but then a few years later I was diagnosed with prostate cancer.’

‘I went through radiation treatment in Rockhampton where I utilised Cancer Council Queensland’s accommodation lodge, and I am very grateful to now be a survivor and be in a position to raise awareness of the disease.’

‘Prostate cancer is such a tricky topic to navigate, as I know lots of men who wouldn’t recognise the symptoms or might ignore them if they noticed them.’

Colin understands the importance of our research into survivorship and is thankful for our ongoing investment into helping other men affected.

‘Knowing about the support available and having someone to talk to was key to my recovery. I take every opportunity now to start those conversations in the community.’
Spotlight on our collaborators

Dr John Oliffe Professor and Canada Research Chair (Tier 1)
Men’s Health Promotion at the School of Nursing, University of British Columbia, Canada.

‘I am honoured to be part of this unique international collaboration and to work with professional and productive colleagues. Our shared goal of improving the experiences of prostate cancer for men and their families has driven this collaboration forward.’

Dr Oliffe is the founder and lead investigator of UBC’s Men’s Health Research program. His work focuses on masculinities as it influences men’s health behaviours and illness management, and its impact on partners, families and overall life quality.

“Our international research collaboration brings together leading experts in the field of the psychosocial prostate cancer care from the Vierdel Cancer Research Centre at Cancer Council Queensland, the University of Southern Queensland, the Prostate Cancer Foundation of Australia and the University of British Columbia,” said Dr Oliffe.

“The work we are undertaking together is a crucial part of understanding and improving men’s health. I believe it has helped us demonstrate the complexities of communication and medical care for men and will ultimately help us to change the conversation to connect more effectively with men around their health.”

“Our findings from this collaboration have highlighted the role of masculinities on behaviour, showing that men who appear to approach challenges in an optimistic action-oriented manner may in fact be less likely to seek psychological help when needed.”

Working with the research team at Cancer Council Queensland and specialists in the psychosocial aspect of prostate cancer has not only significantly informed John’s work at UBC’s Men’s Health Research program but the partnership will have a lasting impact for men with prostate cancer internationally.

‘Through this collaboration, we have been able to disseminate the findings of our research to an international audience in highly regarded scientific journals, and design evidence-based solutions that can be applied in national and international settings to improve outcomes for prostate survivors and their partners.’
The project investigates the experiences of regional cancer patients who are required to travel long distances in order to receive their healthcare. Patients who stay at Cancer Council Queensland’s accommodation lodges during their treatment are invited to participate in the project. This invitation also extends to carers (family or friends) of cancer patients to help us understand the unique experience of those who provide patient care outside the formal healthcare setting. We are privileged to capture the individual stories of study participants over time, from the point of their stay at the lodge to when they return home and beyond. Recruitment for this project reached 618 patients and 188 support people in 2019. The team will continue to follow up these participants and to track their experiences and outcomes over time while analysing the data to inform the development of interventions to improve these outcomes. Cancer Council Queensland is grateful for the support that we have received for this research from our participants – support that will help to improve services tailored to the unique needs of the people who live outside urban Queensland.

The Travelling for Treatment Project is a flagship project of the Building Regional Resilience in Cancer Control (BRRICC) program, a collaboration between Cancer Council Queensland and the University of Southern Queensland to investigate the healthcare challenges faced by rural and remote Queenslanders who are diagnosed with cancer.

Robyn and Rod Mackenzie’s lives changed forever when Rod was diagnosed with melanoma and prostate cancer in late 2017.

The Stanthorpe couple began travelling back and forth to Brisbane for treatment from January 2018 following Rod’s diagnosis. Robyn knows that people diagnosed with cancer in regional areas face a unique set of challenges, often facing long bouts of treatment far from home.

“He (Rod) had four procedures in Brisbane for his cancers so we were staying in Brisbane for a lengthy period,” Robyn said.

“Rod’s cancer became inoperable and he now has monthly treatments at the PA hospital.”

Robyn came across Cancer Council Queensland’s accommodation lodge facilities after doing some research online.

“I didn’t know much about Cancer Council Queensland until our family was affected by cancer. I did research and found the lodge online.”

The Travelling for Treatment project aims to better understand the healthcare challenges faced by rural and remote Queenslanders who are diagnosed with cancer. Robyn and Rod are happy to share their experience to help others in the same position.

“The lodge has done so much to help us, and I have made sure people in Stanthorpe know about Cancer Council Queensland’s lodges.”
Improving participation in bowel cancer screening

One in 13 Australians will be diagnosed with colorectal cancer (CRC) in their lifetime. If diagnosed at an early stage, usually before symptoms appear, CRC is treatable and five-year relative survival rates are higher than 90%.

Shifting diagnosis to an early stage is key to improving survival, reducing CRC-related morbidity and mortality, and reducing healthcare cost. The National Bowel Cancer Program (NBCSP) distributes self-administered immunochemical faecal occult blood test (FOBT) kits every two years by mail to all adults aged 50–74 years. Participation is strongly linked to five-year relative survival from CRC in the Australian population; however, only four in 10 people complete and return their FOBT kits.

In late 2019, a project was launched to address the barriers to CRC screening kit use. The project involves a specific focus on practical challenges associated with kit use and includes consultations with consumers to review the physical features of a range of CRC screening kits (i.e. packaging, collection tools and containers, and instructions).

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Our researchers and research partners

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 recognised 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 adjunct university appointments at Queensland University of Technology and Griffith University. An experienced Biostatistician, 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 was the co-lead investigator on the industry-award winning Australian Cancer Atlas. He has published over 250 peer reviewed manuscripts in national and international journals including Lancet Public Health, Journal of Clinical Oncology and CA: Cancer Journal for Clinicians, along with numerous monographs, and has been an investigator on research projects receiving over $12million in funding. His work has been cited over 22,500 times in the scientific literature.

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Associate Professor Danny Youlden
Senior Manager, Childhood Cancer Research

Danny is a biostatistician with more than 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. His other major area of research interest is in the epidemiology of skin cancer. He has co-authored more than 75 peer-reviewed papers since joining Cancer Council Queensland and has been the lead author on several major reports.

Associate Professor Nick Ralph
Senior Manager, Health Systems and Psycho-Oncology (2019)

Nick held the position of joint Senior Manager for Health Systems & Psycho-Oncology between Cancer Council Queensland and the University of Southern Queensland in 2019. He led 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 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 $2million 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.

Dr Belinda Goodwin
Senior Research Fellow, Health Systems and Psycho-Oncology

Belinda was appointed as a Senior Research Fellow at Cancer Council Queensland in July 2019 and is currently coordinating the Health Systems and Psycho-Oncology team. She was awarded her PhD in 2017 and has a strong research background in psychology and health behaviour. Over the past three years Belinda has been a member of the University of Southern Queensland/Cancer Council Queensland collaborative research program ‘Building Regional Resilience in Cancer Control’ where she has led several investigations into the barriers and facilitators of colorectal cancer screening and played a key role in projects aimed to improve cancer outcomes in regional and rural Australia. As an early career researcher, she has authored more than 30 peer-reviewed publications yielding 430 citations.

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.

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Scientific presentations 2019

5. Baade P. Frontier St Partner Forum, 28 August 2019, Brisbane.

Grants and awards 2019

Grants awarded 2019


Grants ongoing 2019


Awards 2019

Australian Cancer Atlas. Surveying and Spatial Sciences Institute (SSSI) 2019 Asia-Pacific Spatial Data Harnessing Awards (APSDA) Award for Spatial Enablement and the iGeoRISE Award for Overall Excellence.

Professional and community activities

EXPERT ADVISORY COMMITTEES, SCIENTIFIC PANELS AND WORKING GROUP MEMBERSHIPS

National

• Australian Institute of Health and Welfare Cancer Monitoring Advisory Group
• Australian Association of Cancer Registers, Executive Board
• Cancer Council Australia Research Executive Committee, Chair
• National Adolescent and Young Adult Cancer Stage Working Group, Co-Chair
• QMHR Bergofsky Medical Research Institute, Appointments and Promotions Committee
• Queensland Cooperative Oncology Group, Management Committee
• Queensland Cancer, Queensland Cancer Control Safety and Quality Partnership
• Queensland University of Technology, Faculty of Health Advisory Committee
• The Kids’ Cancer Project, Childhood Cancer Research Steering Group
• University of Southern Queensland, Research Committee, USQ/CCQ Joint Research Program
• Youth Cancer Service, National Adolescents and Young Adult Cancer Dataset Advisory Group, Deputy Chair

International

• Global Burden of Disease Collaborator Network, University of Washington
• International Association of Cancer Regions, President and Chair of Board
• International Consensus Panel, Paediatric Cancer Stage for Population Registries
• Lancot Oncology Commission on Sustainable Paediatric Cancer Care, Advisor

CONFERENCE ORGANISING COMMITTEES

• National Melanoma Screening Summit, Brisbane, 2019

PROFESSIONAL MEMBERSHIPS

• Australian and New Zealand Urological and Prostate (ANZUP) Cancer Trials Group
• Australasian Epidemiology Association
• Australian Statistical Society
• International Society for Bayesian Analysis
• Psycho-oncology Cooperative Research Group (PoCoG)
• Queensland Epidemiology Group
• Statistical Society of Australia

REVIEWS AND EDITORIAL ACTIVITIES

Reviews for journals

• Acta Oncologica
• Asia-Pacific Journal of Clinical Oncology
• Australian Health Review
• Australian and New Zealand Journal of Public Health