

Supporting Queenslanders through research

ANNUAL REPORT 2021



VIERTEL
Cancer Research Centre



**Cancer
Council**
Queensland

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We're here for all Queenslanders affected by all cancers

Our vision
is a cancer free future.

Our mision
is to lead Queenslanders in a
partnership against cancer.

Our values
Collaborative. Responsible.
Inclusive. Equitable.





Message from the CEO

Andrew Donne

The Viertel Cancer Research Centre is an integral part of Cancer Council Queensland's strategy to improve cancer prevention, reduce cancer deaths and improve wellbeing of those affected by cancer. Our researchers are a trusted voice of authority in the fields of cancer epidemiology and behavioural research, and our programs and services are informed by the results of our research.

I am pleased to share with you the progress made in 2021 towards our long-term research goals, as well as our contribution to improving cancer outcomes for First Nations peoples.

Our findings on the disparity in cancer survival outcomes for Aboriginal and Torres Strait Islanders received extensive media coverage during NAIDOC Week, and is informing the development of the Queensland Government's draft *Queensland Cancer Strategy for Aboriginal and Torres Strait Islander peoples*.

Work started this year on the Australian Cancer Atlas 2.0, which will provide the first national picture of geographic variation in cancer risk factors, screening, and treatment, in addition to cancer incidence and survival. Methods developed for the original Australian Cancer Atlas have informed the development of similar national cancer atlases in the Netherlands and New Zealand. In 2021, the Atlas was accessed by 55,000 users from over 100 countries. The next version of the Australian Cancer Atlas will take this technology even further, using advances in visualisation techniques and online story telling methods to show the patterns of cancer, and factors that influence cancer outcomes, throughout Australia.

On pages 12 and 13 of this report, you'll find examples of the national and international impact of our work. We are proud that our research is contributing to the development of the new US National Childhood Cancer registry, as well as

a review of the National Bowel Cancer Screening Program in Australia. Our data on the needs and experiences of regional cancer patients is supporting our campaign to improve the Queensland Government's Patient Travel Subsidy Scheme.

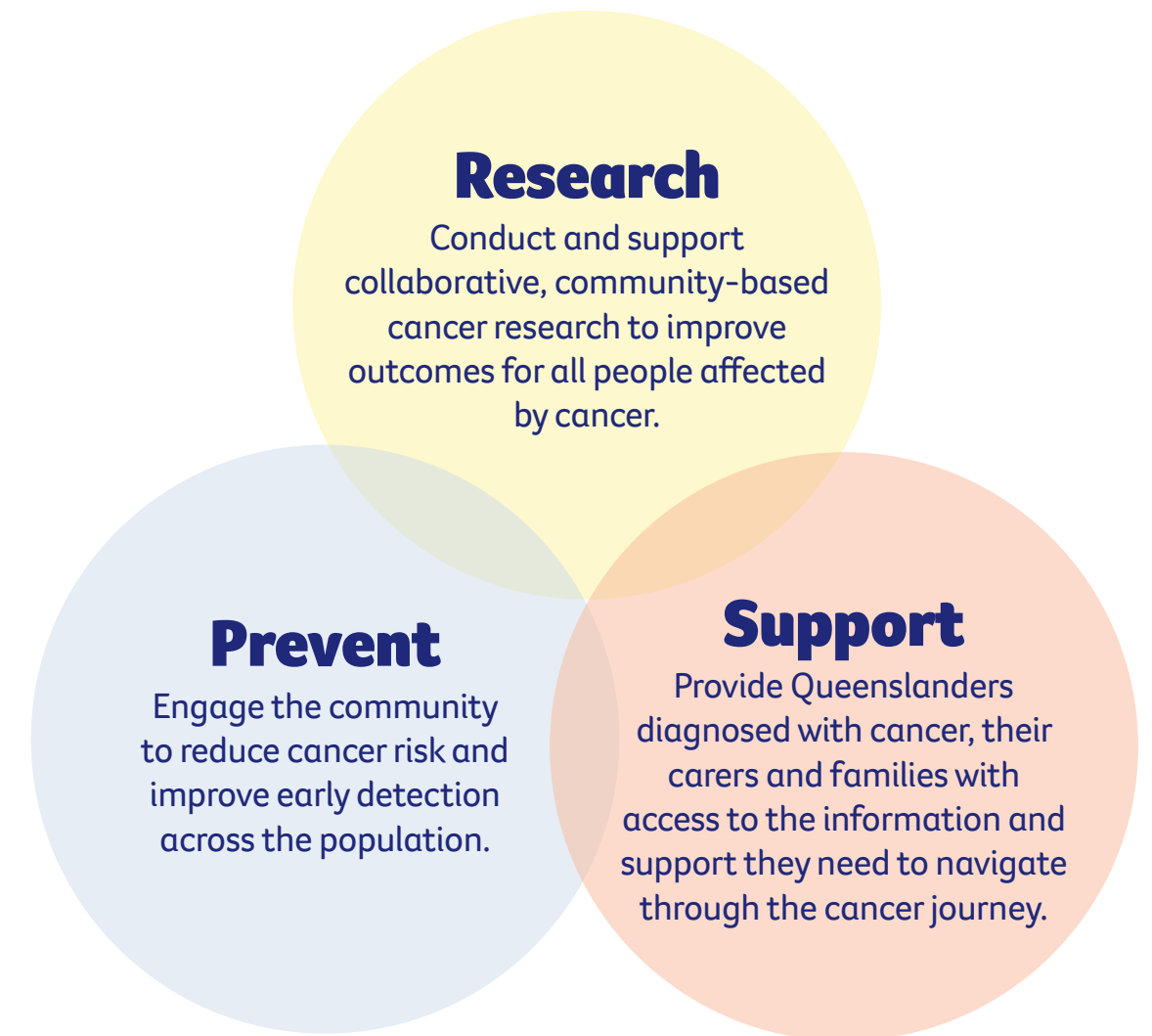
These are just some examples of the impressive scope and quality of the research initiatives and collaborations underway in the Viertel Cancer Research Centre. I hope you will enjoy reading about these and other achievements highlighted within the report.

I acknowledge Cancer Council Queensland's Board of Directors and Chair, Dr Anita Green, our employees, our network of distinguished research collaborators, and the thousands of community members who support and participate in our work. Together, we are helping to improve the quality of life of Queenslanders affected by cancer.

I thank the Sylvia and Charles Viertel Charitable Foundation and the Foundation Trustees for their ongoing support without which the vital research detailed in this report would not have been possible.

Andrew Donne
Chief Executive Officer

Cancer Council Queensland's **Strategic priorities**



Our work is enabled by: high-performing people, positive partnerships, trusted brand, financial sustainability, quality systems and sound governance.

Informed by data, driven by research.

Cancer in Queensland **the facts**



32,307

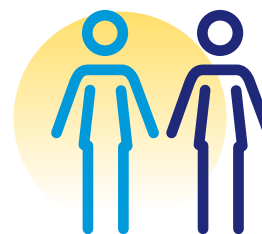
Queenslanders were diagnosed with cancer in 2019



Based on current trends and predicted population changes, **41,000 Queenslanders** are expected to be diagnosed with cancer in the year 2027



9703 Queenslanders died of cancer in 2019



Approximately **1 in 2** Queenslanders will develop cancer before age 85 years



Overall, 5-year survival from cancer in Queensland has increased from **53%** in the 1980s to **72%** during 2015-2019



Approximately **276,497 Queenslanders** are alive today after a cancer diagnosis in the past 30 years (1990-2019)

Data source: Queensland Cancer Register, Cancer Council Queensland Data extract, 1982-2019

Charles Viertel 1902 -1992

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

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

Cancer Council Queensland gratefully acknowledges the generous support of the Sylvia and Charles Viertel Charitable Foundation and the Foundation Trustees.

Contributing to the global cancer research effort (2004-2021)

Our aim is to improve outcomes for all people affected by cancer.

Our publications on average are cited **2.9 times more** than the world average²

123 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 Cancer Journal for Clinicians

702
scientific publications
with a total citation
count of over
38,000

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

Over **7000**
mentions in national
and international
news/blogs/social
media³

97%
of publications
involve national
and international
collaboration



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-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.
3. Source: Altmetric Explorer



Our partners and collaborators

International

- African Cancer Registry Network
- Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Boston
- Global Initiative for Cancer Registry Development
- Istituto Nazionale dei Tumori, Milan
- International Agency for Research on Cancer, Lyon
- Integral Cancer Center Netherlands (IKNL)
- International Association of Cancer Registries
- Karolinska Institute, Sweden
- Northern Ireland Cancer Registry
- Paediatric Oncology Group of Ontario
- St Jude Children's Research Hospital, Memphis
- The Hospital for Sick Children, Toronto
- Union for International Cancer Control, Geneva
- University College London (UCL)
- University of Oxford

Queensland

- Cancer Alliance Queensland
- Centre for Children's Health Research
- Griffith University
- Metro South (Brisbane) Hospital and Health Service
- Princess Alexandra Hospital
- QIMR Berghofer Medical Research Institute
- Queensland Children's Hospital
- Queensland Health
- Queensland University of Technology
- The University of Queensland
- University of Southern Queensland

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 Institute of Health and Welfare
- Australian Skin and Skin Cancer Research Centre
- Cancer Australia
- Cancer Council New South Wales (including The Daffodil Centre)
- Cancer Council Victoria
- Cancer Institute New South Wales
- Curtin University
- Department of Health, Western Australia
- Flinders University
- John Hunter Children's Hospital
- Menzies School of Health Research, Charles Darwin University
- Monash Children's Hospital
- Perth Children's Hospital
- Prostate Cancer Foundation of Australia
- Royal Children's Hospital, Melbourne
- Sydney Children's Hospital
- The Children's Hospital, Westmead
- The University of Adelaide
- The University of Melbourne
- The University of Sydney
- The University of Tasmania
- The University of Western Australia
- Wellbeing SA
- Women's and Children's Hospital, Adelaide

Our impact on health policy and practice

Our evidence of survival disparities among Indigenous Australians is informing the Queensland Government's draft *Queensland Cancer Strategy for Aboriginal and Torres Strait Islander Peoples*.

Our evidence of supportive care needs of rural cancer patients and their carers has supported the development of Cancer Council Queensland programs and services for rural cancer survivors and advocacy for an increase in the Queensland Government's Patient Travel Subsidy Scheme.

Our report of lower life expectancy after cancer diagnosis in Aboriginal and Torres Strait Islander peoples reached 3 million people during NAIDOC week and has improved community awareness of this issue.

Our co-leadership of the Scientific Advisory Boards of two international childhood cancer research initiatives is contributing to improved outcomes for children with cancer in over 26 countries.

Our evidence of national variation in myeloproliferative neoplasms (MPN) has enabled advocacy by the MPN Alliance Australia to improve national reporting for this malignancy.

Our statistical and visualisation methods developed for the Australian Cancer Atlas have informed the development of national cancer atlases in the Netherlands and New Zealand.

Our contributions to the development of new cancer staging protocols for Australia's Youth Cancer Service is helping to improve national data on cancer in adolescents and young adults.

Our protocols for assigning stage at diagnosis for childhood cancer have been adopted by the US National Cancer Institute's SEER registry program and US National Childhood Cancer Registry.

Our membership of the national Primary Care Collaborative Clinical Cancer Trials Group is assisting strategic planning for cancer research within primary care in Australia.

Data from the Australian Childhood Cancer Registry has assisted service modelling for the new Australian Bragg Centre for Proton Therapy and Research, Adelaide.

Our leadership of the Board of Directors of the International Association of Cancer Registries is contributing to improved global cancer registration practice.

Our evidence of barriers to bowel cancer screening has informed a review of the National Bowel Cancer Screening Program commissioned by the Australian Government, and the development of a national bowel cancer screening media campaign.

Our reports of National Cancer Control Indicators for childhood cancer by stage at diagnosis is assisting the Australian Government to track progress in childhood cancer outcomes.

Our report to the Queensland Government on the prevalence of coal mine dust lung disease is informing future action on the disease.

Our mentorship as part of the International Agency for Research on Cancer's 'Global Initiative for Cancer Registry Development' has contributed to improved knowledge and quality of childhood cancer registration and data in low and middle-income countries.



Projects underway in 2021

						Page
Survival among Aboriginal and Torres Strait Islanders diagnosed with cancer*						16
Cervical cancer screening in Indigenous women	●	●	●			
Inequities in breast cancer management and survival*						18
Development of new methods for spatial analyses of cancer outcomes			●			
Application of new methods for reporting cancer survival	●		●			
Communicating cancer statistics – Queensland Cancer Statistics Online	●		●		●	
The Australian Cancer Atlas 2.0*	●		●		●	20
Estimating the future burden of cancer in Australia using Bayesian models			●		●	
Understanding international variation in cancer outcomes			●		●	
Report to government on prevalence of coal mine dust disease in Queensland	●				●	
Quantifying national geographical patterns of mesothelioma incidence and survival	●				●	
Quantifying national geographical variation in rates of prostate cancer screening and surgery	●		●		●	
The Australian Childhood Cancer Registry*			●	●	●	22
Communicating childhood cancer statistics – Australian Childhood Cancer Statistics Online	●			●	●	
Updating the Australian Government’s National Cancer Control Indicators for childhood cancer				●	●	
Cancer in Aboriginal and Torres Strait Islander children*			●	●	●	24
Improving national data on childhood cancer stage, prognostic factors, and treatment				●	●	
Identifying disparities in outcomes for children with cancer in Australia*		●	●	●		26
Patterns of presentation for childhood leukaemia	●		●	●		
Incidence and survival trends for childhood tumours of the central nervous system*				●		28
Travelling for Treatment longitudinal cohort study	●	●	●		●	
Attitudes and help-seeking among rural cancer patients		●	●			
Identifying information needs of rural cancer patients and their families		●	●		●	
Improving the quality of cancer survivorship for rural and regional patients*		●	●		●	30
Assessing diagnosis and treatment pathways in rural head and neck cancer patients			●			
Evaluation of the Queensland Government’s Patient Travel Subsidy Scheme for rural cancer patients		●	●		●	
Supporting the health and wellbeing of those caring for a cancer patient in rural Australia		●	●		●	
Designing interventions to increase bowel cancer screening*	●		●	●		32
Identifying barriers to bowel cancer screening	●		●		●	
Facilitating bowel cancer screening promotion of bowel cancer screening through general practice	●		●			
The effects of psychological distress on bowel cancer screening participation	●		●			
Mental health and cancer risk behaviours*	●		●			34

*View following pages for details

Survival among Aboriginal and Torres Strait Islander peoples diagnosed with cancer

What is the project?

Using data obtained through population-based cancer registries in Queensland and other Australian states and territories, we have applied new statistical methods to understand the disparity in survival among Aboriginal and Torres Strait Islander peoples diagnosed with cancer compared to other Australians.

What has been achieved in 2021?

Our previous research showed that, in Queensland, cancer survival has increased over the last two decades among both Aboriginal and Torres Strait Islander peoples and other Queenslanders diagnosed with cancer. However, the extent of the survival gap between Aboriginal and Torres Strait Islander and other patients had not changed over this time.

We have extended this work using a semi-national population-based cohort of over 700,000 cancer patients from Queensland, Western Australia,

the Northern Territory and New South Wales. We found that Aboriginal and Torres Strait Islander cancer patients live on average for 12 years after their cancer diagnosis compared with 20 years for other Australians. This disparity in life expectancy was due to higher rates of death from both cancer and non-cancer causes among Aboriginal and Torres Strait Islander peoples. On average, 51 of every 100 Aboriginal and Torres Strait Islander cancer patients die within five years of their diagnosis (44 dying from cancer and 7 from other causes), compared to 40 per 100 for other Australians (37 dying from cancer and 3 from other causes).

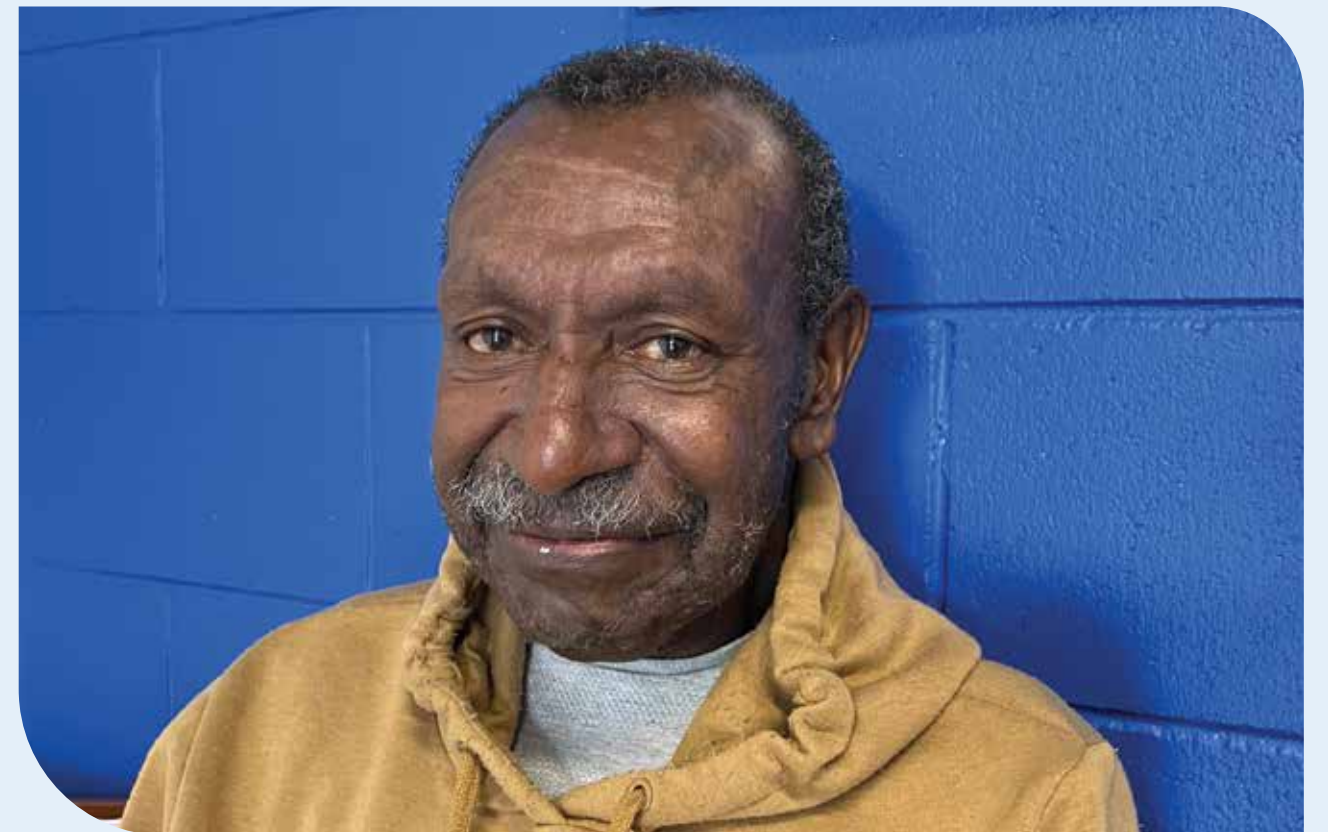
Of approximately 1300 Aboriginal and Torres Strait Islander people in the study cohort diagnosed with cancer every year, about 650 died within five years of diagnosis. If survival had been comparable to other Australian cancer patients, there would have been 133 fewer deaths among Aboriginal and Torres Strait Islander cancer patients each year.

Why is this research important?

This research shows the real-world impact that a cancer diagnosis has among Aboriginal and Torres Strait Islander peoples, exacerbating an already lower life expectancy. Interventions must address the multiple factors contributing to the gap in cancer survival experienced by Aboriginal and Torres Strait Islanders with cancer and must consider both cancer-related factors and those contributing to non-cancer mortality. Our analyses received extensive media and other publicity during NAIDOC Week and have informed the development of the Queensland Government's draft *Queensland Cancer Strategy for Aboriginal and Torres Strait Islander Peoples*.

Cancer Council Queensland and Benny are working together to encourage Aboriginal and Torres Strait Islander people who are impacted by a cancer diagnosis to access Cancer Council Queensland's support services.

Aboriginal and Torres Strait Islander people are advised that this page may contain images of deceased people.



Benny's story

B Mabo uAkoko (Bua/Benny Mabo Jr), who is third-generation Mabo, was diagnosed with oesophageal and tonsil cancer in November 2021.

Living in a remote area, Benny needed to travel to Townsville to receive lifesaving chemotherapy and radiation treatment. He was able to stay at Cancer Council Queensland's Gluyas Rotary Lodge in Townsville during this time and used the Transport to Treatment service.

Cancer Council Queensland's accommodation support lodges are invaluable for people like Benny who need to travel from regional and remote areas to access vital cancer treatment that they wouldn't otherwise receive.

'The lodge and transport services are extremely valuable. I always feel so welcome and supported; I feel like part of the furniture,' Benny said.

Cancer Council Queensland and Benny are working together to encourage Aboriginal and Torres Strait Islander people who are impacted by a cancer diagnosis to access Cancer Council Queensland's various support services.

Benny is an excellent advocate for raising cancer awareness in his region and is planning to raise funds to establish cancer awareness programs to create more community engagement, support and education around cancer prevention, screening, and self-health responsibility.

Research conducted by Cancer Council Queensland has revealed improvements in the percentage of Aboriginal and Torres Strait Islander people who survive at least five years after being diagnosed with cancer, however their survival rates are still lower than other Queenslanders.

Life expectancy among Aboriginal and Torres Strait Islander people who have been diagnosed with cancer is unfortunately also lower than other Australians. Cancer screening can help improve outcomes and Cancer Council Queensland has found that the rate of participation in screening for cervical cancer was higher where women had access to culturally appropriate primary health care, particularly via Aboriginal Community-Controlled health Organisations.

This research is helping to show the real-world impact that a cancer diagnosis has among Aboriginal and Torres Strait Islander peoples, as well as identify areas of improvement to close the gap and improve outcomes for Aboriginal and Torres Strait Islander people.

Inequities in breast cancer management and survival

What is the project?

Cancer Council Queensland's Breast Cancer Outcomes Study is one of the largest population-based cohort studies of breast cancer patients in the world. Over 3300 Queensland women diagnosed with breast cancer have been followed for up to eight years and have provided new understanding of the experiences of women diagnosed with breast cancer, and of the individual and clinical features associated with better or worse outcomes.

What is the need?

This year the project has focussed on three key questions:

1. What are the predictors of delays between diagnosis of breast cancer and first treatment?
2. What factors are associated with unmet supportive care needs for women diagnosed with breast cancer?
3. What factors influence the survival of women diagnosed with breast cancer?

What has been achieved in 2021?

We found that, on average, women waited 15 days between diagnosis and treatment, with the majority receiving treatment within the recommended

maximum period of 30 days. However, about one in six women diagnosed with breast cancer experienced treatment waiting times greater than 30 days, and these women were more likely to have no private health insurance, have lower income and live outside major cities. This highlights the unique challenges of women with breast cancer living in outer regional and remote areas, and the importance of having access to quality care tailored to their situation.

Women living in outer regional areas were more likely to report unmet needs compared to those living in major cities, such as the need for emotional and physical support while in hospital, wider choice of hospital, and the need for written information about their care. We found that physically active women with localised breast cancer who had completed treatment were least likely to report unmet care needs.

In addition to recognised clinical factors including more advanced stage at diagnosis, higher tumour grade, and 'triple negative' hormone-receptor status, women who were diagnosed because they noticed symptoms had lower survival than women whose breast cancer was detected at a screening examination, highlighting once again the survival benefits of screening for breast cancer.

Why is this research important?

Breast cancer is the most common cancer diagnosed among women in Australia and is responsible for over 3100 deaths nationally each year. Understanding the experiences of women diagnosed with breast cancer and knowing which subgroups of women tend to have poorer outcomes and/or unmet needs will directly inform supportive care services and other strategies to address these issues.

Anita's story

Anita was diagnosed with breast cancer in early 2020, and her cancer treatment journey was complicated. After an initial lumpectomy was unsuccessful, she had 25 courses of radiation followed by a mastectomy. After a long hospital stay, thankfully the pathology results showed no evidence of cancer detected.

However, not long afterwards she suffered heart failure, chemotherapy-induced cardiomyopathy and had blood clots on her lungs and heart. Anita slowly recovered, and life has finally returned to 'some normality'.

Anita found Cancer Council Queensland's support services to be invaluable, especially the free wig and turban service when she experienced hair loss while going through chemotherapy. 'The wig and turban service gave me so much confidence. It was a positive experience and made something as terrible as losing your hair so much easier to deal with,' said Anita.

'I also utilised the nurse counselling and psychologist service, and I've accessed a huge amount of information and support from the wonderful caring team at Cancer Council Queensland,' said Anita.

'They provide so many resources and totally support you and your family and friends during the entire cancer journey and I am eternally grateful.'

'It also made me feel far less alone knowing how much support I had, not just from family and friends, but from services offered by Cancer Council Queensland.'

Anita's story is one of many personal stories behind the statistics collected by cancer registries. It is only through the generosity of patients like Anita, who are willing to speak about their experience with breast cancer, that research studies such as the Breast Cancer Outcomes Study are possible.

The information collected can help us understand the experiences of women diagnosed with breast cancer and help us identify which subgroups of women tend to have poorer outcomes and unmet needs, so that we can provide supportive care services and other strategies to address these issues.



'I also utilised the nurse counselling and psychologist service, and I've accessed a huge amount of information and support from the wonderful caring team at Cancer Council Queensland.'

The Australian Cancer Atlas 2.0

What is the project?

The award-winning Australian Cancer Atlas (atlas.cancer.org.au) is a cutting-edge, digital tool that maps patterns of cancer across Australia. It was the first attempt to quantify and visualise small-area spatial patterns in cancer incidence and survival for 20 cancer types. The Atlas provides high resolution, interactive maps showing localities that are above or below the national cancer average.

The Australian Cancer Atlas was the winner of the industry Asia-Pacific Spatial Excellence Awards in two categories: Overall Excellence and Spatial Enablement. It has been accessed by over 55,000 users from over 100 countries with China, Indonesia, Hong Kong and Singapore among the highest international users.

A new and expanded version of the Australian Cancer Atlas is now under development using the latest advances in digital technology, visualisation techniques and online storytelling methods to show the impact of cancer.

What is the need?

Research has shown that cancer diagnosis and survival are influenced by both treatment and lifestyle factors (including smoking, obesity, and cancer screening

behaviour). It is not known how these factors vary geographically, how this has changed over time, nor the contribution of these factors to the impact of cancer among Australians. A critical part of this work is to ensure that the Atlas is easy to use and provides users with a clear understanding of the key messages that are revealed by the statistical patterns.

What has been achieved in 2021?

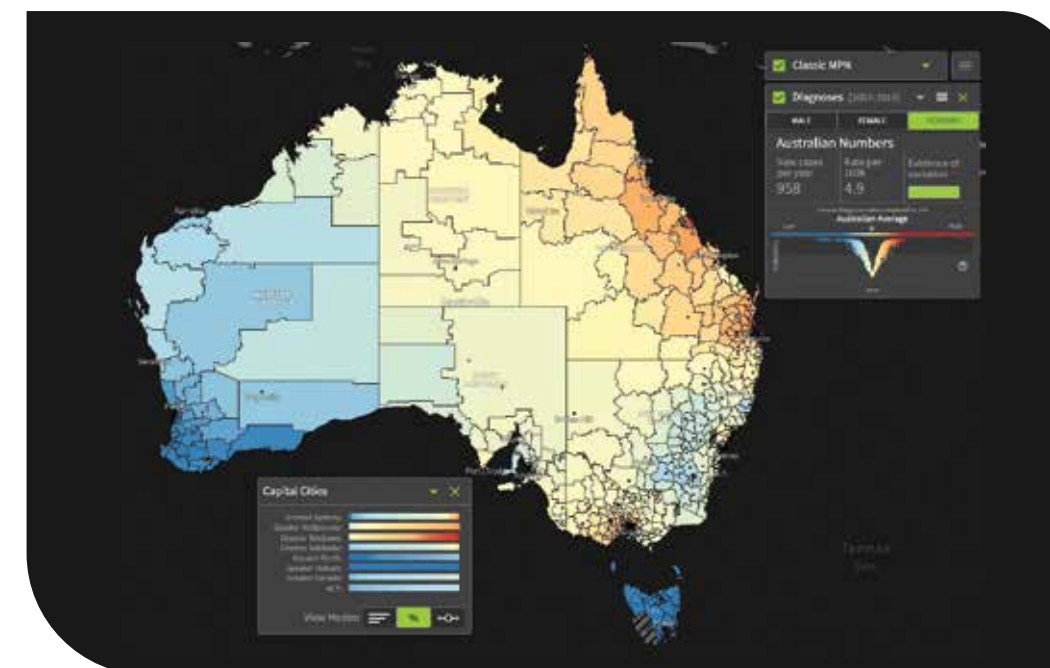
Work started this year on the Australian Cancer Atlas 2.0, with a release planned for 2023. Continuing our successful collaboration with the Centre for Data Science at QUT, our first step has been to develop and apply the complex statistical models required. Multiple post-graduate students have joined our team and are making innovative contributions, and international collaborations are underway with research groups in the Netherlands, New Zealand, Canada, and the United Kingdom.

We added myeloproliferative neoplasms (MPNs) to the cancers included in the Atlas. This is relatively uncommon group of cancers that start in the bone marrow. Supported by MPN Alliance Australia, this work has directed advocacy efforts by the Alliance to improve the quality and national consistency of diagnosis and reporting of this malignancy.

Why is this research important?

The Australian Cancer Atlas 2.0 will provide the first national, visual picture of geographic variation in cancer risk factors, screening, and treatment, in addition to cancer incidence and survival. The Atlas will be freely available online to assist health agencies, policymakers, researchers, and community members to understand national variation in the burden of cancer, and the reasons for this variation. It will provide the evidence essential for policy improvements and resource allocation and will support research and teaching to address geographic and socioeconomic inequity in cancer outcomes.

Additional funding was provided by the Australian Research Council to develop statistical methods to estimate how the geographical variation in cancer outcomes vary over time.



Spotlight on our collaborators

MPN Alliance Australia

Myeloproliferative neoplasms (or MPNs) are a rare and chronic form of blood cancers. Given that MPNs were only recognised as a distinct cancer type in the last two decades and that its diagnosis requires a combination of medical evidence, the awareness of MPN among the general community, including the medical profession, is limited.

A key goal of the patient support group, MPN Alliance Australia, is to raise awareness of MPNs and shine a light on a rare disease which can have a big impact on a person's life, and thus lead to more informed medical services and greater motivation to conduct and fund further research.

Following an earlier collaborative study led by Cancer Council Queensland that described the diagnostic patterns of MPNs across Australia, MPN Australia approached the Cancer Council Queensland team to include MPNs as a cancer type within the Australian Cancer Atlas.

As part of an update of the Australian Cancer Atlas In 2021, MPNs are now on the map!

The amount of geographic variation of MPN diagnoses across Australia has raised intriguing

questions about how MPN cases are diagnosed by medical professionals and then notified to the different cancer registries across Australia.

It is likely that variability in MPN diagnosis methods leads to inconsistent reporting of these relatively 'new' cancer types. In particular while reporting processes are consistent when a diagnosis is confirmed with a bone marrow biopsy, the reporting processes are less consistent when diagnoses are based on blood tests, molecular tests and clinical presentation alone.

This issue has been reported by MPN Alliance in a leading Australian medical journal, to raise awareness among the medical profession and stimulating further discussions among a broader medical audience.

'That this collaboration could motivate more accurate reporting of MPNs across Australia is incredibly exciting, and could then lead to new insights about the potential causes of MPNs.'

The Australian Childhood Cancer Registry

What is the project?

Cancer Council Queensland's Australian Childhood Cancer Registry is one of the most comprehensive national clinical databanks of childhood cancer in the world. It contains irreplaceable information on every child diagnosed with cancer in Australia since 1983. The database holds over 22,000 individual case records and new data items are continually being added in response to the rapidly evolving information requirements of childhood cancer researchers and clinicians.

What is the need?

Compared to adults, the number of cases of cancer in children is few. Epidemiologic research is only possible by pooling high-quality data from all childhood cancer oncology centres in Australia. These data underpin research and health service initiatives to improve outcomes for children with cancer.

What has been achieved in 2021?

In work completed this year, the Viertel Cancer Research Centre published the first national study showing that the risk of death from diseases other than cancer was significantly higher among childhood cancer patients who received more intensive treatment compared to those on less intensive treatment regimens.

In addition, we:

- led international collaborative research showing that five-year survival for children with liver cancer is comparable at around 80% in Australia, the United States and Canada
- provided data needed for modelling service user requirements for Australia's second Centre for Proton Therapy and Research
- collaborated with the International Agency for Research on Cancer in a three-year project to assess the international prevalence of childhood cancer and risk of second primary cancers in childhood cancer survivors in over 26 countries, including Australia
- mentored staff from childhood cancer registries in lower- and middle-income countries as part of the WHO's Global Initiative for Cancer Registry Development
- tracked cancer incidence and survival among Aboriginal and Torres Strait Islander children over the last 20 years (see project over page).

The database has been completely re-developed to include improved analytics and the highest possible level of security for automated data import, export, and storage. Feasibility testing has begun for collection of information on additional clinical factors that are now recognised as having an important influence on childhood cancer survival including tumour cytogenetics and molecular classification. If shown to be feasible, the Australian Childhood Cancer Registry will be the first in the world to collect this information on a population basis.

Why is this research important?

Childhood cancer accounts for more deaths in Australia between the ages of one and 14 than any other form of illness. Methods developed by the Viertel Cancer Research Centre have been influential in improving the quality of childhood cancer data both in Australia and worldwide. The Australian Childhood Cancer Registry is used by policy makers to track and benchmark national trends in childhood cancer incidence, stage at diagnosis and survival.

Spotlight on our collaborators



Professor Kathy Pritchard-Jones

Professor Kathy Pritchard-Jones is a Professor of Paediatric Oncology at University College London, Great Ormond Street Institute of Child Health, London, England, and honorary consultant oncologist at Great Ormond Street NHS Foundation Trust. She is one of the United Kingdom's leading experts in childhood cancer, working as a specialist consultant in the field for 20 years, and is President of the International Society of Paediatric Oncology.

Professor Pritchard-Jones is a Principal Investigator on a groundbreaking research initiative called the International Benchmarking of Childhood Cancer Survival by Stage project (also known as BENCHISTA). The project aims to understand why childhood cancer survival rates vary between countries, to highlight areas that could be improved, and ultimately to contribute to better cancer care for all children.

An important aspect of the project is to encourage the application of the international Toronto Guidelines for staging childhood cancer by a large number of European and non-European cancer registries for the most common solid paediatric cancers, building on feasibility work undertaken by Cancer Council Queensland.

Cancer Council Queensland developed and published a standard set of rules for assigning childhood cancer

stage using the Toronto Guidelines and demonstrated the feasibility of using these rules in a population registry setting.

This work has been recognised as having the potential to provide "a unified platform for global monitoring of childhood cancer incidence and outcomes" (Lancet Child and Adolescent Health [https://doi.org/10.1016/S2352-4642\(18\)30023-3](https://doi.org/10.1016/S2352-4642(18)30023-3)).

Cancer Council Queensland is delighted to be collaborating with Professor Pritchard-Jones and other investigators on the BENCHISTA project, and proud that our work is contributing to knowledge that will improve childhood cancer survival around the world.

'The importance of the work done by our Australian colleagues at Cancer Council Queensland is that they have developed a practical means to allow cancer registries in over 26 countries to collect and compare data on childhood cancer stage, a key indicator of outcome.'

Cancer in Aboriginal and Torres Strait Islander children

What is the project?

This study used data from the Australian Childhood Cancer Registry for the 20-year period 1997 to 2016 to understand changes in cancer incidence and survival for Aboriginal and Torres Strait Islander children.

What is the need?

Ten years ago, our research showed that Aboriginal and Torres Strait Islander children had lower rates of cancer incidence, but also poorer survival rates, compared to other Australian children. The accuracy with which Aboriginal and Torres Strait Islander peoples are identified in routine health records, including cancer registry data, has improved dramatically since that time. This provided the opportunity to obtain a clearer picture of childhood cancers within this population group than had previously been possible.

What has been achieved in 2021?

Using data from the Australian Childhood Cancer Registry, we studied more than 13,800 cases of cancer diagnosed in children aged under 15 over a 20-year

period, including 506 Aboriginal and Torres Strait Islander children. We found that although incidence rates had increased rapidly among Aboriginal and Torres Strait Islander children over the study period, they were still lower than among other Australian children.

Survival rates for Aboriginal and Torres Strait Islander children were similar to those for other Australian children for blood cancers (leukaemia and lymphoma) and brain tumours but were significantly worse for other cancers.

The apparent rapid increase in cancer incidence among Aboriginal and Torres Strait Islander children is likely to be due to improvements in Aboriginal and Torres Strait Islander identification in health records, rather than a real increase in cancer rates. While the parity in survival for children with blood or brain cancers was a positive finding, further investigation is needed to determine why Aboriginal and Torres Strait Islander children fare worse following other cancer diagnoses.

Why is this research important?

Understanding the patterns of cancer in Aboriginal and Torres Strait Islander children and how these have changed over time allows us to track progress and to see where future resources should be focused. These data are essential for the development of culturally appropriate solutions to improve cancer outcomes, particularly for Aboriginal and Torres Strait Islander children with solid tumours.

This work was supported through the Australian Government's 'Investing in Medical Research - Fighting Childhood Cancer' measure.



Identifying disparities in outcomes for children with cancer in Australia

What is the project?

Among adults, it is known that the type of treatment received for cancer may vary according to where the patient lives – whether in an urban or rural location, or in a disadvantaged area. Our goal was to investigate whether treatment for childhood cancer varies by remoteness of residence or by area-based socio-economic status and, secondly, whether differences in treatment result in differences in survival, after adjusting for other important factors including age, sex, stage at diagnosis and Indigenous status.

What is the need?

All of Australia's paediatric oncology hospitals are in major cities, meaning that children from regional or remote areas must be away from home for an extended time to complete their treatment. This places an added burden on children and families, and our goal was to understand what impact this may have on treatment or outcomes for children with cancer.

Why is this research important?

Our research shows that for some cancers, treatment and survival vary according to the area where the child lives. These results raise important questions that will guide future research to ensure that all children with cancer have the best possible chance of surviving the disease regardless of where they live.

'The Australian Childhood Cancer Registry enables critical research that will help families like ours understand the impact of treatment on developing bodies. It enables us to track over time whether we are improving cancer outcomes.'

- Dr Hazel Harden

This work was supported through the Australian Government's Investing in Medical Research - Fighting Childhood Cancer measure, and Cancer Australia's national initiative to improve national cancer data on stage, treatment, and recurrence.

What has been achieved in 2021?

Using data from the Australian Childhood Cancer Registry, we found variation in the types of treatment received (e.g., curative surgery, chemotherapy and/or radiotherapy) according to remoteness of residence for several types of cancer (acute lymphoblastic leukaemia, Hodgkin lymphoma, osteosarcoma, Ewing sarcoma and retinoblastoma). For some cancers, there was also some variation in the types of treatment received according to the socioeconomic status of the area, although these differences appeared to have no impact on survival.

However, we found five-year average survival rates for two of the most common types of childhood leukaemia – acute lymphoblastic leukaemia and acute myeloid leukaemia – were lower among children from the most disadvantaged areas, and average survival for acute myeloid leukaemia and hepatoblastoma was lower for children from outer areas. These differences in survival could not be explained by differences in treatment, stage at diagnosis or Indigenous status.

Spotlight on our collaborators



Dr Hazel Harden

Co-Founder Australian Families 4 Genomics (AF4G) and childhood cancer research collaborator

Hazel's son was 13 years old when he was diagnosed with leukaemia in 2018.

'To be told that your child has cancer is every parent's worst nightmare and nothing can ever prepare you for what will come next. You soon realise that it's not just your family that are dealing with this awful disease but every day there are wards and waiting rooms full of children, teenagers, siblings, parents and loved ones all living this nightmare,' said Hazel.

'The treatment for children considered very high risk is intense and long – two and a half years of chemotherapy and you're always on guard that an everyday bug could be life-threatening. For my son and our family, the first 12 months was the worst. He experienced ongoing nausea, sickness, extreme weight loss, hair loss and walking difficulties. On top of this there was regular blood and platelet transfusions and hospital admissions – it all meant that school and online learning was impossible.'

'The treatments are harsh on growing bodies and the high dose steroids left my teen with avascular necrosis. A teenage boy with extreme knee pain and difficulty walking meant that life was far from normal. These effects from chemotherapy was definitely not what we had expected – you believe that this could never happen to your child. The avascular necrosis meant reconstructive knee surgery on both knees – life was on hold again for another 12 months! It took three and a half years until he could finally rebuild his life.'

Dr Harden is a passionate advocate for young people with cancer, and in her role as a clinician and researcher, she has been collaborating with Cancer Council Queensland to understand more about the late effects of childhood cancer treatment.

'The Australian Childhood Cancer Registry enables critical research that will help families like ours understand the

impact of treatment on developing bodies. It enables us to track over time whether we are improving cancer outcomes.'

'As a parent the opportunity to be a collaborator and provide input into this research is so important, because once you have a child with cancer you see the world very differently and often what matters to us wouldn't be top at the list for researchers.'

Hazel is the co-founder of Australian Families 4 Genomics, a database of genomic and health information from children and young people impacted by cancer to help accelerate research and accelerate scientific discovery for childhood cancer.

'Despite investments in genomics and childhood cancer research by philanthropists, government and community donations, the pace of scientific discovery struggles to overtake the rate that cancer is destroying young lives. We need more and better data and support for research into cancer in young people.'

That's why Hazel has co-founded Australian Families 4 Genomics, providing upfront genome sequencing to young people with the option to donate their information to a library of research data.

'By being participants in research young people and families can help accelerate scientific discovery.'

Incidence and survival trends for childhood tumours of the central nervous system

What is the project?

Central nervous system (CNS) tumours occur in the brain and spine and are one of the most common and deadly types of cancer in children. They account for 22% of all cancers diagnosed among children under 15 years old. Importantly, they also represent the most common cause of cancer-related mortality among children in Australia. This study provided the first comprehensive picture of the epidemiology for CNS tumours in Australian children.

What is the need?

CNS tumours include a broad range of childhood cancers with greatly differing prognostic outcomes. However, they are often reported in cancer registry data as a single group. Key goals of this study were to identify any variation in incidence and survival by histological subtype and tumour grade.

What has been achieved in 2021?

Using data from the Australian Childhood Cancer Registry, we found a continuous increase in incidence rates of almost 1% per year for all CNS tumours combined, corresponding to a cumulative increase of 29% between 1983-2016. The largest increases in incidence occurred for non-malignant and low-grade tumours. Improvements in diagnostic technology leading to more precise tumour classification are likely to explain at least some of this trend, with similar patterns also reported in other high-income countries.

Overall, 72% of children with a CNS tumour survived at least five years after diagnosis, although there were variations in survival associated with the type of tumour and tumour grade. Significant improvements in grade-specific survival were found for children with ependymoma and medulloblastoma. In contrast, survival remained particularly poor (<20%) among patients with high grade astrocytoma.

Why is this research important?

This research reveals that improvements in treatment since the early 1980s have resulted in better survival for children with some types of central nervous system tumours, but that research into new, targeted therapies is urgently needed to improve the limited treatment options for other central nervous system tumour types.



Improving cancer survivorship for rural and regional patients

Research proudly supported by the Sylvia and Charles Viertel Charitable Foundation in honour of Daniel Raumer.

What is the project?

In collaboration with community organisations and health care providers, this project aims to develop evidence-based strategies to improve support for cancer survivors and their caregivers living in regional and remote Queensland.

What is the need?

Regional and remote Australians tend to experience poorer outcomes than their metropolitan counterparts including lower survival rates for some cancers and poorer quality of life.

Our previous research has shown that information regarded as essential for cancer survivors, such as how to maintain general health and wellbeing, how to promote long-term recovery and how to monitor for cancer recurrence, is not routinely provided to patients from regional and remote areas. This finding is consistent across cancer types and patient characteristics. In addition to this, our research has shown very clearly that in regional and remote areas, carers of cancer patients experience poor health and lower quality of life compared to people of the same age in the general population. Further, financial concerns

and the cost of travelling away from home for cancer treatment are common issues raised by both patients and caregivers affected by cancer in regional and remote areas.

What has been achieved in 2021?

To address this need, the Viertel Cancer Research Centre is developing guidelines for health professionals to assist them to provide comprehensive survivorship information to their rural and regional patients returning home after receiving treatment in major cities. We are engaged in consultations with caregivers in regional or remote areas, first, to understand how their caregiving role affects their own health and wellbeing and, second, to identify the best ways by which to deliver support. In collaboration with Cancer Council Queensland's Advocacy team, we have begun an evaluation of the Queensland Government's Patient Travel Subsidy Scheme to assess what improvements are needed to align the Scheme with the needs of patients. The project will survey a large sample of Queenslanders who have accessed the Patient Travel Subsidy Scheme as well as administrators and health professionals to examine the delivery of the program and how it should be improved.

Why is this research important?

Rural Queenslanders diagnosed with cancer, and those caring for a cancer patient, are a large and underserved population. It is vital that they have access to practical and emotional support and information to facilitate their ongoing health and wellbeing during and after diagnosis. Through this research, we are developing practical solutions to these very real problems.

Regional and remote Australians tend to experience poorer outcomes than those living in metropolitan areas, including lower survival rates for some cancers and poorer quality of life.



Sheva's story

Sheva Butler, from Wondai in rural Queensland, was diagnosed with breast cancer in 2017 when she was 45 years old. While going through treatment, she stayed at Cancer Council Queensland's Olive McMahon Lodge in Toowoomba and used Cancer Council Queensland's Transport to Treatment service to access the nearby hospital.

Sheva says she is glad that when she felt a lump she had it checked out immediately because it turned out to be an aggressive cancer – just one millimetre off being a stage 3 cancer. The doctors suggested surgery, then chemotherapy followed by four weeks of radiation therapy. However, her treatment was not so straightforward.

'I was on five different chemo drugs, had an allergic reaction from the pain medication, I suffered a serious infection and hospitalised for a week, I also had heart failure caused by one of the chemo drugs. I was in such poor health I could barely walk. My cancer surgery was delayed because I wasn't strong enough.'

'Despite all the challenges, Cancer Council Queensland was brilliant for me. Knowing that I had somewhere safe to stay overnight for myself and a family member was great. The advice and friendly staff were always available, so I never felt alone. They are excellent at

assisting cancer patients, their carers and families. I was able to focus on trying to get better rather than worried about accommodation and travel costs which could have been stressful.'

Regional and remote Australians tend to experience poorer outcomes than those living in metropolitan areas, including lower survival rates for some cancers and poorer quality of life.

Research conducted by Cancer Council Queensland is helping to understand the challenges faced by rural Queenslanders diagnosed with cancer, develop practical solutions to address these issues, and ensure they have access to practical and emotional support and information to facilitate their ongoing health and wellbeing during and after diagnosis. This research will ultimately improve outcomes for rural Queenslanders like Sheva, affected by cancer.

Designing interventions to increase bowel cancer screening

What is the project?

In previous work we documented the key barriers to participation in the National Bowel Cancer Screening Program (NBCSP). We are now developing interventions to address these barriers. The purpose of these interventions is to improve the design of the home bowel cancer screening test kit and to facilitate its use through planning, reminders and health professional endorsement. Selected interventions will be trialled within the National Bowel Cancer Screening Program and in primary care settings to assess their effectiveness.

What is the need?

One in 13 Australians will be diagnosed with bowel cancer in their lifetime. If it is diagnosed early, five-year relative survival rates following treatment are higher than 90%. Full participation by eligible Australians in the National Bowel Cancer Screening Program will significantly reduce deaths from bowel cancer; however, less than half of those who receive an invitation to participate in the program complete and return the home test kits.

Why is this research important?

This research marks the first effort to embed evidence-based interventions for increasing bowel screening within the National Bowel Cancer Screening Program and through primary care. If bowel cancer screening participation can be increased from the current approximately 40% to 60%, it is estimated that 25,000 lives could be saved by 2040.

In Australia, current participation rates in the National Bowel Cancer Screening Program are low at 44%. Increasing participation in the program is the best way to improve early detection, reduce bowel cancer incidence and ultimately save lives.

In 2021 Cancer Council Queensland researchers were Chief Investigators on three successful National Health and Medical Research Council Grants to continue this work over the next five years.

What has been achieved in 2021?

More than 1000 National Bowel Cancer Screening Program recipients took part in an evaluation of bowel cancer screening kit modifications. Participants were presented with graphics depicting home test kit modifications via an online survey. We measured the degree to which each kit modification could potentially reduce specific barriers to screening and increase future intentions to screen for bowel cancer. We also consulted recipients who completed and returned their kits to identify the planning techniques and actions that facilitated their kit use. Data from these projects are currently being analysed to inform intervention design.

The Viertel Cancer Research Centre has developed a partnership with researchers from the University of Melbourne and several other institutions and Cancer Councils around Australia to progress this work.

Spotlight on our collaborators



Professor Mark Jenkins

Professor Mark Jenkins is the Director of the Centre for Epidemiology and Biostatistics, School of Population and Global Health at the University of Melbourne. He is a cancer epidemiologist with more than 25 years of experience in the design, conduct, and analysis of studies examining the role of genetic and environmental causes of cancer, and the prevention and early detection of colorectal cancer, particularly in screening participation.

Researchers at Cancer Council Queensland with their expertise and knowledge of the barriers and enablers of screening participation, have joined Mark in research to decrease bowel cancer mortality and morbidity by tackling Australia's low participation in the National Bowel Cancer Screening Program.

In Australia, current participation rates in the National Bowel Cancer Screening Program are low at 44%. Increasing participation in the program is the best way to improve early detection, reduce bowel cancer incidence and ultimately save lives.

A 20% increase in bowel screening participation (similar to the screening participation in northern

Europe) would prevent an additional 37,000 bowel cancers and 25,000 bowel cancer deaths, and save Australia's national health budget \$400 million over the next 20 years.

Cancer Council Queensland continues to play a leading role in developing new innovations to improve bowel cancer screening by facilitating the trials in urban, rural and remote populations in Queensland

This collaboration with Cancer Council Queensland will ensure that the methods used to improve the program are top-class.

'The collaboration will ensure that screening participation is improved across Australia's diverse geography and demography, so that all Australians benefit from the research.'

Mental health and cancer risk behaviours

What is the project?

This project is exploring links between psychological distress and health behaviours known to affect cancer risk including alcohol intake, smoking, exercise, diet and cancer screening participation.

What is the need?

Lack of physical activity, being overweight, a poor diet, smoking, and alcohol consumption are known to increase the risk of cancer. Population-based efforts to reduce cancer risk through behavioural change, and to encourage screening, have met with varying levels of success. While it is known that cancer risk behaviours are influenced by demographic, cultural and environment factors, there is limited understanding of the individual determinants underlying health choices. Better understanding of these individual factors will directly inform innovative, evidence-based, and effective interventions to reduce cancer risk across the population.

What has been achieved in 2021?

The Australian Bureau of Statistics (ABS) National Health Survey contains extensive information on health behaviours of a random population-based sample of approximately 20,000 Australians. Using these data we estimated cancer risk scores for each person, and we will now use these scores to assess the effects of mental health and socio-demographic factors on modifiable cancer risk.

In relation to mental health and cancer screening, we are collaborating with the national Psycho-oncology Co-operative Research Group to conduct a systematic review and meta-analysis of anticipatory anxiety and its effect on cancer screening. We tested this association in a sample of over 500 National Bowel Cancer Screening Program recipients and demonstrated that people with severe levels of psychological distress, including anxiety and depression are much less likely to screen for bowel cancer. Through this work, we have a new understanding of the association between mental health and participation in cancer screening that will open new approaches to improve screening rates.

Why is this research important?

It is estimated that at least one-third of cancers are potentially preventable and that 44,000 people are diagnosed each year with a potentially preventable cancer in Australia. Findings from this research will inform new methods to assist people to reduce their cancer risk, improve screening participation, and ultimately prevent more cancers in Australia.

Research conducted at Cancer Council Queensland with National Bowel Cancer Screening Program recipients shows that people with severe levels of psychological distress, including anxiety and depression, are much less likely to screen for bowel cancer.

Kate's story

Kate Michael was diagnosed with stage 3 bowel cancer in September 2020 at the age of 35.

Before her diagnosis, Kate had struggled with multiple health issues over five years amid IVF and infertility treatments. Despite seeing multiple specialists about stomach pains, diarrhea, blood in stools, cramps, chronic fatigue and exhaustion, her health issues were put down to hormones and endometriosis issues.

Kate's local doctor then asked her to have a colonoscopy, and she was prepared to do anything to find out what was wrong. Kate was immediately diagnosed with bowel cancer.

'When told I had cancer, I was in disbelief. It scares me to think what would have happened to me if I hadn't had that colonoscopy. Who knows how advanced the cancer would have become if I was put on a wait list.'

Kate had a bowel resection which involved removing 30 cms of her bowel, and she then endured 12 rounds of chemotherapy treatments over eight months.

'Having cancer affects everyone in your family. My parents said they felt helpless and just had to watch me in pain. My husband had to work full time and take care of me, and he was exhausted.'

During this time Kate also struggled managing her own mental health and said that she never felt so alone and sick in her life.

'There are so many components to the stress and anxiety that you feel going through treatment,' she said.

'During COVID I was not invited or allowed to go to a lot of things because of being immune compromised, so that was very isolating. Also just not inviting me instead of asking me what I needed really hurt.'

'Living with the stress of recurrence is too much to handle sometimes, but I am sure that it will get easier over time. I don't think anything can ever prepare you for being told that you have cancer.'

'All I want with my second chance at life is to spread as much information about cancer prevention and early detection as I can. Speak up if you know something is not right with your body. If sharing my story inspires one person to go and get a colonoscopy, then I will be happy.'

It is estimated that at least one third of cancers are potentially preventable and that 44,000 people are diagnosed each year with a potentially preventable cancer in Australia.



For cancers such as bowel cancer, understanding barriers to participation and improving participation rates in the National Bowel Cancer Screening Program can have a big impact in preventing more cancers in Australia.

Research conducted at Cancer Council Queensland with National Bowel Cancer Screening Program recipients shows that people with severe levels of psychological distress, including anxiety and depression are much less likely to screen for bowel cancer. This important finding is helping us to understand the association between mental health and participation in cancer screening that will open new approaches to improve screening rates.

'Speak up if you know something is not right with your body. If sharing my story inspires one person to go and get a colonoscopy, then I will be happy.'

Our early career researchers and higher degree students



Dr Larry Myers

Dr Larry Myers started his post-doctoral research position in the Health Systems and Behavioural Research team at Cancer Council Queensland in May 2021. Shortly after he was awarded his PhD, which investigated behaviour change interventions to promote participation in population bowel cancer screening programs. Larry has a strong background in health psychology and quantitative data analysis. He is currently applying these skills to develop ways to increase participation in the Australian National Bowel Cancer Screening Program to facilitate early detection. Larry also plays a key role in projects aimed to improve outcomes for cancer survivors living in regional and remote Australia.



Dr Laura Anderson

Dr Laura Anderson is an Early Career Research Fellow in the Health Systems and Behavioural Research Team at Cancer Council Queensland. She has a research background in health psychology and was recently awarded her PhD from the University of Queensland. Her PhD research involved understanding sexual behaviours in children and young people to promote sexual health. Laura is interested in applying these skills to promote health behaviour change and cancer risk-prevention. Currently, she is working on improving participation in the National Bowel Cancer Screening Program by identifying potential interventions to increase kit completion and kit return. Interventions will target people's planning and actions to facilitate screening kit return.



Lizzy Johnston

Lizzy is an Early Career Research Fellow in the Health Systems and Behavioural Research team at Cancer Council Queensland. In this role, Lizzy is working on several projects to support the health and wellbeing of cancer survivors and their caregivers living in regional and remote Queensland. Lizzy is an Accredited Practising Dietitian (APD) and near-completion of her PhD at the Queensland University of Technology and QIMR Berghofer Medical Research Institute. Her doctoral research investigates dietary intake, care, and communication after treatment for ovarian cancer.



Dr Kou Kou

Dr Kou Kou completed her PhD in 2019, investigating the burden of oesophageal cancer in Shandong, China. She is currently working as a Senior Research Officer in the Descriptive Epidemiology team. Her principal research interests are geographical and socioeconomic variations in cancer outcomes, survival outcomes of Australian diagnosed with cancer, and outcomes of women diagnosed with breast cancer in Queensland, Australia. She has been an author on 16 peer-reviewed published papers with more than 70 citations.



Dr Habtamu Bizuayehu

Dr Habtamu Bizuayehu is working as the project coordinator for the Australian Cancer Atlas within the Descriptive Epidemiology research team. He manages the Australian Cancer Atlas project and contributes to epidemiological research. He has been awarded a PhD in Public Health and Behavioural Sciences. He has authored and co-authored 25 peer-reviewed publications that have been cited over 4000 times. He is experienced in large longitudinal data analysis, systematic reviews, causal modelling, and survival analysis. Dr Bizuayehu has international work experience while working in Ethiopia for over seven years as a researcher and lecturer.

Doctoral students 2021

- Conor Hassan (PhD, Epidemiology)
- Jamie Hogg (PhD, Epidemiology)

Masters students 2021

- James Retell (Masters, Biostatistics)
- John Martin (Masters, Epidemiology)
- Corina Golicher-Rae (Masters, Psychology)

Honours students 2021

- Tanaya Connaughton (Honours, Psychology)
- Kristen McKenna (Honours, Psychology)
- Claire Avenell (Honours, Psychology)

Our leadership team



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 and Chair of the Board 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 Adjunct

Professorial appointments at Queensland University of Technology and the University of Southern Queensland. Professor Aitken has over 300 scientific publications and her work has been cited over 14,000 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 indicators both nationally and internationally, and to better understand why these outcomes depend on where people live, including the role of remoteness, area disadvantage and cultural identity. He is the co-lead investigator on the industry-award

winning Australian Cancer Atlas project. He has published over 275 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 \$14 million in funding. His work has been cited over 31,000 times in the scientific literature.



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. He has been with the Viertel Cancer Research Centre since 2005. He also 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 a study into producing projections for childhood cancer incidence in Australia for the first time. His other main area of research interest is the epidemiology of skin cancer and second cancers. He has co-authored more than 80 peer-reviewed papers since joining Cancer Council Queensland and has also been the lead author on several major reports during that time.



Dr Belinda Goodwin

Senior Manager, Health Systems and Behavioural Research

Belinda was appointed as a Senior Research Fellow at Cancer Council Queensland in July 2019 and is Senior Manager of Health Systems and Behavioural Research. 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 USQ/ 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 over 600 citations.

APPENDICES

Publications 2021

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1. Goodwin B, Crawford Williams F, March S, Chambers S, Dunn J, Aitken J. Evaluating cancer care pathways for rural head and neck patients: Challenges and lessons learnt. PC4 Symposium, 24 May 2021, Melbourne (virtual attendance).

2. O’Neill L. Childhood cancer data Down Under: the Australian Childhood Cancer Registry. Invited speaker. National Cancer Registrars Association (NCRA) Annual Education Conference – SEER Advanced Topics for Registry Professionals, 2 June 2021 (virtual workshop).

3. Whittaker K, Aranda S, Goodwin B, Aitken J, Baade P. Identification of cancer-related Australian dataset for measuring inequity in cancer-outcomes. Cancer Council Epidemiology Conference, 9 February 2021 (virtual meeting).

4. Youlden D. Childhood leukaemia and brain cancer statistics in Australia. Invited speaker. Transforming outcomes for child survivors of cancer, May 2021, Sydney.

5. Youlden D. Childhood cancer in Australia: understanding the full picture. Invited speaker. International Plumber’s Day Breakfast, March 2021, Brisbane.

Grants and awards 2021

Grants awarded 2021

Mengersen K, Aitken J, Cramb S, Baade P, Wraith D, Thompson H. Statistical methods for quantifying variation in spatiotemporal areal data. Australian Research Council (ARC) Linkage Project (LP200100468). 2021–2024. \$204,153.

Grants ongoing 2021

Aitken JF, Youlden D, Baade P, O’Neil L, Henshaw C, Moore A. Improving childhood cancer data to identify disparities in outcomes. Cancer Australia (contract). 2020–2021. \$261,000.

Baade P. Prevalence study of coal mine dust lung disease. Department of Natural Resources, Mines and Energy Queensland (contract). 2020–2021. \$70,025.

Baade P, Cameron J, Fritschi L. Spatial patterns of Myeloproliferative Neoplasms in Australia – adding to the Australian Cancer Atlas. MPN Alliance Australia. 2020–2021. \$10,000

Cust A, Canfell K, Aitken JF, Guitera P, Aranda S, Watts C, Rankin N, Fernandez Penas P. A national risk-stratified melanoma screening program in Australia: a modelling study of the benefits, harms, cost-effectiveness and resource implications. National Health and Medical Research Council Project Grant. 2019–2022. \$839,350. APP1165936.

Chambers SK, Newton R, Scuffham P, Baade P, Galvao D, Dunn J, Smith D, Wittert G, Davis I, Gardiner RA. Centre of Research Excellence in Prostate Cancer Survivorship (CRE-PCS). NHMRC CRE in Health Services Research. 2016–2021. \$2,498,842. APP1116334.

Nassar N, Aitken J, Cohn R, Wakefield C, Milne E, Baade P, Bell JC, Dalla-Pozza L, Signorelli C, Moore A. Life and health of childhood cancer survivors. Cancer Australia Priority-driven Collaborative Cancer Research Grant. 2020–2022. \$596,000. APP1187545.

Owensworth T, Chambers SK, Aitken JF, Foote M, Shum D, Gordon L, Pinkham M. Evaluation of a tele-health intervention for delivering psychosocial support to people with brain tumour and their families. National Health and Medical Research Council (NHMRC) Partnership Project Grant. 2018–2022. \$376,857. APP1152217.

Soyer HP, Gordon L, Gray L, Aitken JF, Whiteman D, Janda M, Eakin E, Osborne S, Finnane A, Caffery L. Implementation of an innovative tele-dermatology network for the early detection of melanoma in high risk Australians. National Health and Medical Research Council (NHMRC) Partnership Project Grant. 2018–2022. \$1,195,648. APP1153046.

Soyer HP, Green AC, Aitken JF, Menzies S, Sturm R, Duffy D, Janda M, Prow T, Schaidler H. Centre of Research Excellence for the Study of Naevi. National Health and Medical Research Council (NHMRC). 2016–2021. \$2,496,835. APP1099021.

Soyer PH, Mann G, Mar V, Janda M, Aitken JF, Fernandez-Penas P, Gray L, Menzies S, Scolyer R, Wolfe R, Cust A, Guitera P, McCormack C, Morton R, Caffery L. Australian Centre of Excellence in Melanoma Imaging and Diagnosis (ACEMID). Australian Cancer Research Fund (ACRF) Major Infrastructure Grant. 2018–2021. \$9,889,200.

Professional and community activities 2021

EXPERT ADVISORY COMMITTEES, SCIENTIFIC PANELS AND WORKING GROUP MEMBERSHIPS

International

- International Association of Cancer Registries, President and Chair of Board
- Global Burden of Disease Collaborator Network, University of Washington
- International Consensus Panel, Paediatric Cancer Staging for Population Registries

Local and national

- Australian Institute of Health and Welfare Cancer Monitoring Advisory Group
- Australasian Association of Cancer Registries, Executive Board
- Cancer Council Australia Research Executive Committee, Chair
- National Adolescent and Young Adult Cancer Staging Working Group, Co-Chair
- QIMR Berghofer Medical Research Institute, Appointments and Promotions Committee
- Queensland Cooperative Oncology Group, Management Committee
- Queensland Health, 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/ Cancer Council Queensland Joint Research Program
- Youth Cancer Service, National Adolescents and Young Adult Cancer Dataset Advisory Group, Deputy Chair

PROFESSIONAL MEMBERSHIPS

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

Editorial boards and panels

- Annals of Cancer Epidemiology

Reviews for journals

- Acta Oncologica
- Asia-Pacific Journal of Clinical Oncology
- Australian Health Review
- Australian and New Zealand Journal of Public Health
- BMJ Open
- British Journal of Dermatology
- British Medical Journal
- Cancer Biology and Medicine
- Cancer Causes and Control
- Cancer Epidemiology
- Cancer Investigation
- Cancer Medicine
- Cancer Science
- ecancermedalscience
- European Journal of Cancer Care
- International Journal of Epidemiology
- JNCI Cancer Spectrum
- Journal of Neuro-Oncology
- Journal of Pediatric Hematology and Oncology
- Journal of the European Academy of Dermatology and Venereology
- Journal of the National Cancer Institute
- Medical Journal of Australia
- Paediatric & Perinatal Epidemiology
- Spatial and Spatio-temporal Epidemiology
- The Lancet Respiratory Medicine
- Thorax

Reviews for funding bodies

- Australian Research Council
- Italian Association for Cancer Research
- JGW Patterson Foundation (UK)
- National Health and Medical Research Council
- Swiss National Science Foundation



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