

Paving the way to a brighter future

ANNUAL REPORT 2020



VIERTEL
Cancer Research Centre



**Cancer
Council**
Queensland

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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:

- Continue to undertake and invest in research aligned with strategy
- 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
- 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.



Message from the CEO

Ms Chris McMillan

Cancer research is an integral part of everything that we do. It provides hope for improved, less invasive treatments, enhanced care for cancer survivors and eventually, a future free from the disease altogether.

I am proud to say that despite the widespread effects of COVID-19, which impacted the way Cancer Council Queensland and the Viertel Cancer Research Centre operated in 2020, we continued to conduct and fund critical cancer research. In a year filled with challenges and uncertainty, we recognised that these difficulties are faced by Queenslanders living with cancer every single day. Our researchers embodied what soon became our 2020 motto: cancer never rests, so neither do we.

I am pleased to share with you the vital progress we have made on our long-term research projects and to uncover a few new promising studies. Our researchers continue to be a trusted voice of authority in the fields of descriptive epidemiology and psycho-oncology worldwide.

In 2020, we have seen an increased focus on research which analyses and evaluates how we can better support rural Queenslanders diagnosed with cancer, including Aboriginal and Torres Strait Islander communities living remotely across the state. As our support services continue to expand throughout Queensland, this research informs where cancer support is needed most. It also identifies any logistical or attitudinal barriers that we need to overcome to ensure those living in rural areas feel comfortable accessing our support services. This important research is helping us to live out our pledge to be here for all Queenslanders, and all cancers.

Our important work on the Australian Cancer Atlas continues. In 2020, we began work to help us advance the Atlas to include geographical information for new topics of cancer concern, including cancer risk factors, cancer screening behaviour and treatment patterns. This will help inform policy makers when deciding where

cancer support and resources are needed most and reveal where interventions must be focused to improve screening rates.

The Australian Childhood Cancer Registry remains a strong focus for our researchers. In 2020, increased emphasis was placed on the study of childhood cancer survivors and how their experiences can help improve treatment and quality of life for those diagnosed today and in the future. Our researchers are collecting data that will improve our understanding of how treatment of childhood cancer affects a person's health later in life. This knowledge is so critical to improving how we treat childhood cancer; helping us find less toxic approaches while maintaining the improved survival rates we have seen for children diagnosed with cancer over the past few decades.

I would like to wholeheartedly thank the Sylvia and Charles Viertel Charitable Foundation and the Foundation Trustees for their dedicated support. The vital research detailed in this report would not be possible without their generosity.

I also 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 paving the way to a brighter future for all Queenslanders.

Chris McMillan
Chief Executive Officer



Based on current trends and predicted population changes, **42,000 Queenslanders** are expected to be diagnosed with cancer in the year 2028



31,327

Queenslanders were diagnosed with cancer in 2018

9401

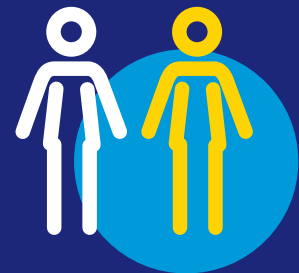
Queenslanders died of cancer in 2018



Cancer in Queensland

THE FACTS

Approximately **265,036** Queenslanders are alive today after a cancer diagnosis in the past 30 years (1989-2018)



Overall, 5-year relative survival from cancer in Queensland has increased from **53 per cent** in the 1980s to **72 per cent** during 2014-2018

1 in 2

Queenslanders expected to develop cancer before age 85 years



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 – 2020)

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 and our vision for a cancer free future.



2004 - 2020 Publication metrics



Our publications on average are being cited¹
three times more
than the world average²

114 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

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.

97% of publications involve national
and/or international collaboration

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

Over **2000**
MENTIONS
in national and
international
news/blogs

674
scientific
publications with
a total citation
count of over
33,000

8 PRESENTATIONS
at national and international conferences
(via video-link) **in 2020**

Awarded/collaborated on
12 GRANTS
in 2020

Impact on health policy

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

- World Health Organization (Switzerland)
- Centers for Disease Control and Prevention (USA)
- National 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

- Abidjan Cancer Registry, Ivory Coast
- African Cancer Registry Network
- Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Boston
- European Joint Action on Rare Cancers
- Felix Houphouet Boigny University, Ivory Coast
- Global Initiative for Cancer Registry Development
- International Agency for Research on Cancer, Lyon
- Integral Cancer Center Netherlands (IKNL)
- International Association of Cancer Registries
- Karolinska Institute, Sweden
- Makerere University, Uganda
- National Child Cancer Network NZ, Christchurch
- New Zealand Children's Cancer Registry
- New Zealand Ministry of Health
- 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 of Toronto
- University of Zimbabwe
- Zimbabwe National Cancer Registry

Queensland

- Griffith University
- Jack and Madeleine Little Foundation
- Mater Hospital & Mater Medical Centre
- 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
- Cancer Council Victoria
- Curtin University
- Flinders University
- FrontierSI (formerly Cooperative Research Centre for Spatial Information)
- Menzies School of Health Research, Charles Darwin University
- Perth Children's Hospital
- Prostate Cancer Foundation of Australia
- South Australian Health and Medical Research Institute
- Sydney Children's Hospital
- The Children's Hospital, Westmead
- The University of Adelaide
- The University of Melbourne
- The University of New South Wales
- The University of South Australia
- The University of Sydney
- The University of Western Australia
- Victorian Cancer Registry
- Women's and Children's Hospital, Adelaide

Impact on health practice

The Cancer Research Centre's manual for assigning childhood cancer stage at diagnosis in population registries has been internationally endorsed, translated into multiple languages, and is being used in over 30 countries.

ESTADIAMENTO DOS TUMORES MALIGNOS DA INFÂNCIA PARA OS REGISTROS DE CÂNCER

de acordo com o
Toronto Childhood Cancer Stage Guidelines*



* Soares S, Adami J, Barak O, Barlow J, Bhatia M, Hachimi P, Karamanolis G, Serrão DP, Soria G, Gouveia-Ferreira M, Gross T, Henschel C, Kishimoto T, Maruya R, Padoja S, Pichard-Geslin A, Serrano O, Piss JCG, Rodriguez-Garcia C, SFRH M, Takahashi-Facher E, Wang L, Yoshida E, Yonemura H, Zavadil J, Zucchi M. Evidences for Pediatric cancer stage in population-based cancer registries: the Toronto consensus, principles and guidelines. Lancet Oncol. 2018; 19(1): 85-93. doi:10.1016/S1473-3099(17)33333-3


Cancer Council Queensland

トロント小児がん病期分類ガイドラインに基づく
住民ベースのがん登録のための
小児がん病期分類



AFCRN
Alliance for Cancer Control
Answers for Cancer Control

Règles de stadification du cancer pédiatrique pour les registres basés sur la population



basées sur
Les directives de Toronto pour la stadification du Cancer Pédiatrique¹


REGISTRO ESPAÑOL DE TUMORES INFANTILES RETI-SEHOP

SEHOP

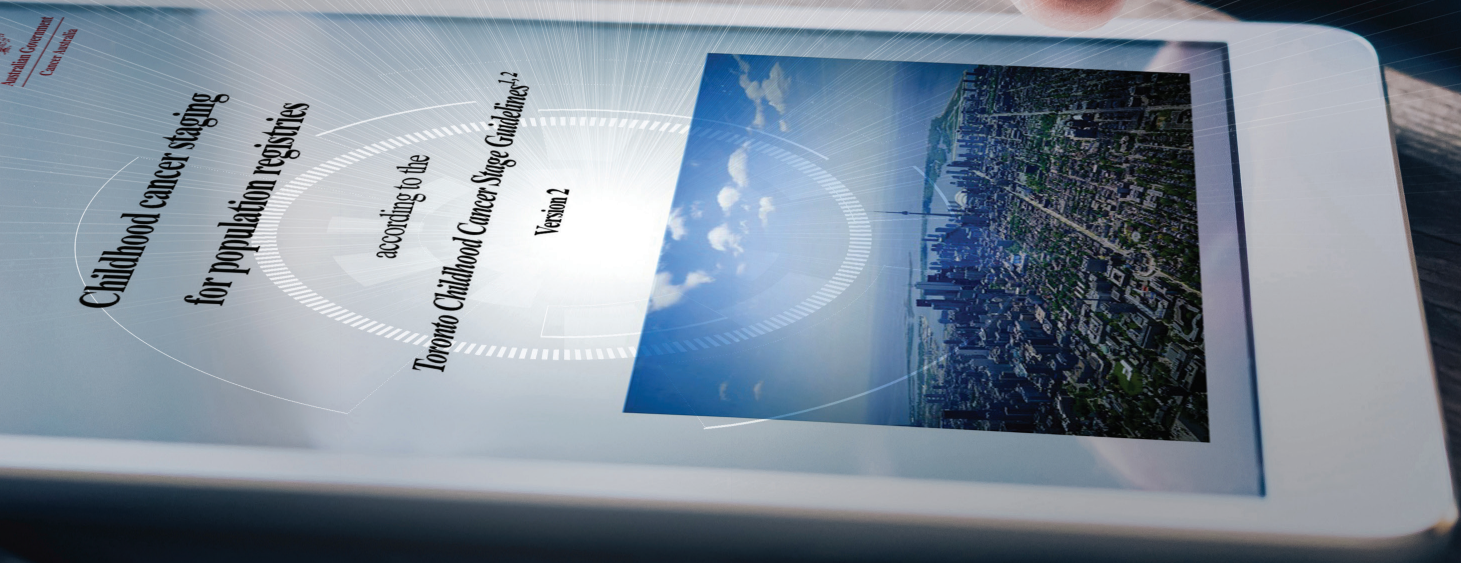
Estadificación del cáncer infantil para registros de base poblacional

Traducción realizada por el Grupo de trabajo del RETI en la SEHOP de "Childhood cancer staging for population registries. Toronto Childhood Cancer Stage Guidelines"

Childhood cancer staging for population registries according to the Toronto Childhood Cancer Stage Guidelines¹

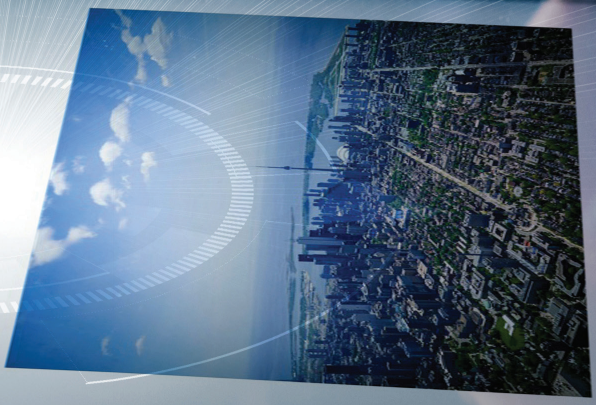


Febrero, 2020



*Childhood cancer staging
for population registries*

*according to the
Toronto Childhood Cancer Stage Guidelines,^{1,2}
Version 2*



Cancer Council Queensland's **Research goals**



Projects underway in 2020

Cervical cancer screening in Indigenous women	●	●	●			●
Experiences of Queensland women diagnosed with breast cancer*	●		●			
Survival among Aboriginal and Torres Strait Islander Australians with cancer*	●		●			
New methods for spatial analysis of cancer	●		●			
Measuring cancer survival	●	●	●			
Queensland Cancer Statistics Online	●	●			●	
Improving quality and utilisation of national cancer datasets	●					
Geographical patterns in cancer-related indicators*	●	●	●			
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	●	●		●	●	
National Cancer Control Indicators for childhood cancer	●	●		●	●	
Late effects of treatment for childhood cancer*	●	●		●	●	
Improving childhood cancer data for Australia*	●	●		●	●	
Incidence trends and projections for childhood cancer*	●	●		●	●	●
Patterns of presentation for childhood leukaemia		●	●	●		
Geographic variation in childhood cancer incidence and survival	●	●	●	●		
Stage at diagnosis and survival for children with cancer in Australia	●		●	●		
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*			●			●
Attitudes and help-seeking in rural cancer patients			●			
Quality of life and unmet supportive care needs in rural cancer caregivers			●	●		
Assessing diagnosis and treatment pathways in rural head and neck cancer patients			●			
Barriers to bowel cancer screening*	●	●	●		●	
Home bowel cancer screening kit modification design and testing	●	●	●		●	
Assessing modifiable cancer risk in Australia*		●				

*See following pages for details

Experiences of Queensland women diagnosed with breast cancer



What is the project?

The Breast Cancer Outcomes Study is a large cohort study designed to describe the impact that a diagnosis of breast cancer has on women in Queensland. Since it started in 2010, more than 3000 Queensland women diagnosed with breast cancer have provided detailed information about their diagnosis, the type of treatment they received, and their experiences throughout this process.

What is the need?

While cancer registries provide important statistics on the burden of cancer in Queensland, they are limited in the type of information they collect for each cancer patient. Cohort studies such as the Breast Cancer Outcomes Study allow us to look behind those statistics and investigate the factors (including clinical features of the tumour and characteristics of the patients themselves) that are associated with better or worse outcomes.

What has been achieved in 2020?

The results have highlighted the clear benefits of regular screening for breast cancer. Women whose breast cancer was detected through routine mammography screening, or who had regular mammograms, were less likely to be diagnosed with advanced breast cancer. Women with a higher risk of breast cancer overall (older women, those who smoked, had longer duration of menstruation, used hormone replacement therapy, and had a family history of breast or ovarian cancer) were also less likely to be diagnosed with advanced disease, possibly due to earlier detection in this high-risk group.

This study demonstrated that women diagnosed with breast cancer who live in remote areas of Queensland are not provided with adequate information about the travel required to access treatment, accommodation and financial concerns. Overall, about one third of women in the study reported a relatively high quality of life, low psychological distress and low unmet needs; these women tended to be younger with less advanced

breast cancer. In contrast, about one in eight women had much lower quality of life and higher distress. These women were more likely to be overweight with low levels of physical activity or were currently receiving chemotherapy. Importantly, women in this group also recognised their need for support, as they were the group most likely to intend to seek help.

What is the importance of this research?

Breast cancer is the most common cancer diagnosed among women in Queensland and is responsible for almost 600 deaths in the state annually. This research is significant because it provides greater insights into the challenges faced by breast cancer patients than can be achieved using the routine data collected from cancer registries. The research will help to improve support for women with breast cancer, with the insights gained from the participants' collated experiences informing decisions about how to positively alter support services and programs to ensure their effectiveness.

This project has provided a vehicle to train six postgraduate research students in biostatistics, epidemiology and psycho-oncology during 2020, giving them the opportunity to be part of a research group under the supervision of experienced researchers and developing future cancer research capacity for Queensland.

Additional funding from the National Health and Medical Research Council and Cancer Council Queensland.



Bernardette's story

Bernardette was diagnosed with breast cancer in July 2020, during COVID-19 restrictions. She found this period of her life extremely challenging and isolating, as a young, single mother who wasn't even able to connect with other patients during her sessions of chemotherapy.

'My whole life changed in one second. I went from being an active and social woman, to not being able to exercise and having to stay at home. My depression became so much worse, and I felt so lonely,' said Bernardette.

Bernardette was thankfully able to seek support from her sisters and mother, who helped her immensely during this time. One of her sisters had undergone treatment for breast cancer previously, and her grandmother had died from the disease at 42, though Bernardette did not test positive for the hereditary gene.

Because Bernardette was not in the age bracket for regular mammograms when she was diagnosed, she is very passionate about ensuring younger women know their bodies.

'Cancer can happen to anyone; it doesn't discriminate. I often encourage the younger women in my life to check their breasts, be aware of changes in their body and speak with their GP if they notice anything different.'

Bernardette believes that breast cancer screening is the best way to improve the lives of women diagnosed, advocating strongly for early detection, before the disease becomes too advanced.

'I don't want anyone to have to go through what I went through. I'd like chemotherapy to never exist. I'd like screening to be able to detect cancer at the very earliest of stages so that invasive treatments such as these are not necessary.'

Bernardette's story is one of thousands of personal stories behind the statistics collected by cancer registries. It is only through the generosity of patients like Bernardette, who are willing to talk about the personal impact of breast cancer in their lives, that research studies such as the Breast Cancer Outcomes Study, are possible. The information collected can help us understand what changes need to be made to enhance the support available to women with breast cancer, to improve early diagnosis and screening, and breast cancer outcomes.

Survival among Aboriginal and Torres Strait Islander Australians diagnosed with cancer



What is the project?

This project investigates the survival following a diagnosis of cancer among Aboriginal and Torres Strait Islander peoples and considers how that is different to the cancer survival for other Australians.

What is the need?

It has been reported that Aboriginal and Torres Strait Islander people in Australia who are diagnosed with cancer, generally experience lower survival rates than other Australians diagnosed with the same cancer type. Over recent years, cancer registries across Australia have developed new methods that significantly improve the quality of information they collect on Indigenous self-identification. There is a need to use these improved data to revise the previous survival estimates and assess whether the survival gap between Aboriginal and Torres Strait Islander peoples and other Australians has changed over time.

What has been achieved in 2020?

These analyses have shown that while cancer survival rates for Aboriginal and Torres Strait Islander peoples have improved over the last 20 years, they remain lower than cancer survival rates for other Australians. The poorer cancer survival among Aboriginal and Torres Strait Islander peoples is due not only to deaths from cancer, but also to a higher risk of death from non-cancer causes.

What is the importance of this research?

This research has shown that although significant resources and research effort has been devoted to reducing the cancer burden among Australian Aboriginal and Torres Strait Islander people, the survival gap with other Australians has not improved. These findings highlight the urgent need to better understand the multiple factors that underlie disparities in survival rates, and to communicate this information in a manner that motivates change. We aim to partner with Aboriginal and Torres Strait Islander organisations to develop more effective methods to address this.

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



Spotlight on our collaborators



Professor Gail Garvey

Professor Gail Garvey is an Aboriginal woman who hails from the Kamilaroi nation in New South Wales. She has more than 25 years' experience working in Aboriginal and Torres Strait Islander health research, education, and capacity building, and currently works as the Senior Principal Research Fellow and Deputy Division Leader at the Menzies School of Health Research.

In 2010, Professor Garvey established the first Roundtable in Australia to identify research priorities in cancer care for Indigenous Australians, and six years later convened the inaugural World Indigenous Cancer Conference. Professor Garvey's work in health services research and psychosocial aspects of cancer care has resulted in major contributions to key policy and practice initiatives to improve cancer outcomes for Aboriginal and Torres Strait Islander peoples.

Cancer survival rates are lower among Aboriginal and Torres Strait Islander peoples than among other Australians for all malignancy types. Aboriginal and Torres Strait Islander peoples are 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, due to the lack of an Indigenous identifier on the cervical screening registers. However, this changed seven years ago, when Cancer Council Queensland was invited to collaborate as part of a national data linkage study led by Professor Garvey.

This study, entitled Cervical screening participation and outcomes for Indigenous Australian women, quantified, for the first time, the lower levels of cervical screening participation among Aboriginal and Torres Strait Islander women throughout Australia, and the poorer outcomes for those who were screened. Detailed analyses showed significant geographical variation in cervical cancer participation among Aboriginal and Torres Strait Islander women in Queensland. This partnership led to better understanding of those factors that may have contributed to higher rates in some regions.

This collaboration has highlighted the relatively low rates of cervical cancer screening participation among Aboriginal and Torres Strait Islander women across Australia. It has been the catalyst for research into identifying the factors that influence screening uptake or are barriers to cervical screening and subsequent follow up among Aboriginal and Torres Strait Islander women.

Cancer Council Queensland continues to play a leading role in the highlighting the greater impact of cancer in some subgroups of the population, and how the burden varies according to where people live. The spatial analyses of cervical screening participation conducted for this study will be used to guide similar national analyses of screening activities for all Australians that will be included in subsequent versions of the Australian Cancer Atlas.

Geographical patterns in cancer-related indicators – building on the Australian Cancer Atlas



What is the project?

Since its launch in 2018, the Australian Cancer Atlas has provided unique insights into the striking geographic variation in cancer incidence and survival across Australia. This program of research has been expanded to investigate variation in other key cancer indicators, including years of life lost to cancer, and cancer screening behaviour. The work builds on data collected through the Queensland Cancer Register, and a large dataset of over two million Queensland women involving linkage between the Queensland Hospital Admitted Patient Data Collection and the Queensland Pap Smear Register.

What is the need?

An accurate picture of how the cancer burden varies by geographical location is needed to support resource planning and allocation, to guide research into the reasons for the variation, and to inform the development of effective interventions.

What has been achieved in 2020?

On average, Queenslanders diagnosed with cancer lose about four years of life expectancy due to their cancer diagnosis. Queensland cancer patients diagnosed in 2016 can be expected to lose a combined total of over 100,000 years of life. However, this impact varies depending on where people live. For example, Queenslanders living in the most disadvantaged areas lost about 10% more life expectancy due to a cancer diagnosis than those living in the most affluent areas. The total number of years of life lost would be reduced by about one fifth if all cancer patients experienced the same survival as those living in the most affluent and accessible parts of the state.

Cervical screening prevents deaths from cervical cancer and is provided free to all Australian women in the target age group. Our results indicate that, concerning, cervical screening rates have generally decreased across all areas of Queensland, between 2008-2012 and 2013-2017.

Participation in cervical screening by Queensland women varies depending on where they live, their ethnicity and socioeconomic status. Screening rates are generally higher in affluent areas.

Participation rates among Aboriginal and Torres Strait Islander women are substantially lower than for other Queensland women, except in Far North Queensland, possibly due to Indigenous community-run health clinics in that region.

Future directions

Cancer Council Queensland, in collaboration with our national and international research partners, has committed to further develop and expand the award-winning Australian Cancer Atlas to incorporate online mapping of key cancer indicators such as those outlined above: cancer risk factors, cancer screening behaviour and treatment patterns. A key component of the Australian Cancer Atlas Phase 2 will be the development of new visualisation techniques to effectively communicate the key messages to the wide range of people who use the Atlas.

Additional funding from Jack and Madeline Little Foundation and Cancer Council Queensland.

Spotlight on our collaborators



Dr Jaike Praagman

Dr Jaike Praagman is an epidemiologist with vast experience in nutrition and cancer epidemiology. Her research is focused on identifying trends and patterns in cancer burden and measuring the extent of inequalities within this burden. Currently, she is working at the Netherlands Comprehensive Cancer Organisation (IKNL), as part of a team that is responsible for the development of a Dutch Cancer Atlas – an idea that came about following the release of the Australian Cancer Atlas in 2018.

After some initial email discussions and various video teleconferences, IKNL is now formally collaborating with both Cancer Council Queensland and the Queensland University of Technology to develop a Dutch Cancer Atlas.

'The opportunity to collaborate with the Australian Cancer Atlas team has substantially reduced the development time we would have needed to generate a Cancer Atlas for the Netherlands,' said Dr Praagman.

'Having access to the syntax files to run the statistical models, as well as having the opportunity to ask questions of the investigators through conference calls and emails has been immensely helpful. It makes a project like this feasible for us in the short term.'

The development of the Dutch Cancer Atlas has been a major project for IKNL in 2021 and has already received positive feedback from several stakeholders, including those working in policy and behaviour change. Despite still being in its infancy stages, the methodology of the Dutch Cancer Atlas has already been used successfully to provide policymakers with insightful information on the regional variation of certain cancer types in specific parts of the Netherlands.

'We know that variation in cancer burden exists, and it is important to know the extent of this variation. That is the starting point of any effort to reduce this variation and why the Atlas is so important.'

The collaboration has also proven to be beneficial for Cancer Council Queensland. Over the past few years, Dr Praagman's team have been developing their expertise in a new analysis method called Federated Learning, which involves statistical analyses being carried out using data from multiple organisations, without that data having to leave the respective organisation. One of its many benefits includes the freedom it grants to future collaborative projects by safeguarding the important privacy and confidentiality constraints of each data custodian.

In the future, the team at IKNL is looking to expand the Atlas into other European countries and use it as the catalyst for more long-term collaborations where the work of both the Atlas and Federated Learning can be expanded. She and her team are adamant that international collaborations such as this one, in which knowledge, expertise and data are all shared, are vital to reducing the burden of cancer.

'I hope that this collaboration is a prime example of the fact that the work at Cancer Council Queensland is of value not only within Australia, but also beyond its borders.'

'Being able to work with the Australian team and having the opportunity to tap into their methodology, knowledge and expertise has really lifted this research project to a higher level.'

Late effects of treatment: Second primary cancers and non-cancer mortality following childhood cancer



What is the project?

As many as one in three people who survive childhood cancer are known to face an increased risk of severe health complications later in life, relating to either the original cancer or its treatment. Two of the more serious of these 'late effects' are second primary cancers and death from causes other than cancer. Using data from the Australian Childhood Cancer Registry, we investigated these outcomes for the first time on a national level in Australia.

What is the need?

Cancer Council Queensland is committed to improving outcomes for children with cancer. 'Late effects' of childhood cancer and its treatment is one of the least understood areas of childhood cancer research. Addressing this knowledge gap is becoming progressively more urgent as increases in the incidence of childhood cancer, combined with improvements in survival rates has led to an ever-growing population of cancer survivors in Australia.

What has been achieved in 2020?

Our findings uncovered that the risk of a second cancer is five times higher among people who experienced cancer as a child compared to cancer rates in the general population. Patients were found to have the highest relative risk within the first few years following their original cancer. In addition, we found that the risk of death due to causes other than cancer is more than four times as high among childhood cancer

survivors than in the general population, and that this risk continues at around that same level for at least 30 years after the original cancer diagnosis. A key finding was that the risk of death from causes other than cancer was significantly higher among patients who received more intensive treatment compared to those on less intensive treatment regimens.

What is the importance of this research?

Information on late complications and deaths are vital for the development of guidelines for the long-term surveillance of childhood cancer survivors. These studies highlight the continuing need to refine existing treatments for childhood cancer by reducing toxicity, while simultaneously maintaining the huge improvements in childhood cancer survival that have been achieved over recent decades.



Natalie and Kane's story

Kane was diagnosed with a rare form of lymphoma when he was just 12 years old. From this point forward, he spent much of his time in hospital, rather than running around in the playground, going on family holidays and hanging out with his mates, like other boys his age.

'Seeing your child hooked up to chemo the first time is very daunting, but we soon learnt that we just needed to be strong for Kane,' said his mum, Natalie.

Despite the hard work and dedication of countless health professionals, and the endless love and devotion of his parents, Kane passed away just weeks after his 13th birthday. One of the doctors told Natalie that Kane had one of the most aggressive cancers she had ever seen.

Five years on, Natalie is passionate about ensuring that Kane is remembered, by sharing his story to encourage others to support critical research into childhood cancers.

Kane's cancer records have been added to the Australian Childhood Cancer Registry, to help researchers gain a clearer view of childhood cancer, and hopefully save more young lives in the future.

'I was, and am still, so proud of my boy. He was such a good person, and so many people loved him and miss him every day.'

'If we can help other parents not have to go through this agony, then that will be a legacy worthy of Kane's memory.'



Improving childhood cancer data for Australia: Enhancing the collection of population data on childhood cancer treatment



What is the project?

Detailed information on the treatments received by children with cancer is important in understanding long-term outcomes of those treatments. Our aim in this project was to improve the quality, consistency and completeness of national information on chemotherapy agents administered to children diagnosed with cancer in Australia over recent years. This information supplements the detailed data already housed in the Australian Childhood Cancer Registry, one of the longest running and most comprehensive databanks on childhood cancer in the world.

What is the need?

It is common for people who are treated for cancer as a child to experience severe health effects later in life that are linked to the earlier treatments they received. Documenting and reporting the therapies received by childhood cancer patients in Australia on a whole-of-population basis, and tracking changes in therapies over time, provides an essential foundation for understanding the burden of late effects on patients and the health system.

What has been achieved in 2020?

We have acquired accurate information for most children who were treated with chemotherapy at a major paediatric oncology hospital in Australia between 2010–2015. Specifically, we have acquired data on:

- the chemotherapy agents received by each patient
- whether the chemotherapy administered differed from the prescribed protocol (i.e. lower or higher dose than is generally recommended); and
- whether the child completed the prescribed chemotherapy protocol.

What is the importance of this research?

This new and unique dataset will have a central role in projects now underway to assess the effects of treatment on subsequent morbidity, mortality and other outcomes among survivors of childhood cancer.

Incidence trends and projections for childhood cancer



What is the project?

Although relatively rare, childhood cancer remains the leading cause of disease-related death among Australian children aged one to 14 years old. In this project, we examined data for children diagnosed up to 2015 to determine the trend in incidence rates over recent years. For the first time in Australia, we also estimated how the incidence of childhood cancer is likely to change into the foreseeable future.

What is the need?

Cancer in children differs from cancer in adults in its aetiology, biology and classification. Despite this, statistics for childhood cancer are usually not included in routine cancer reporting or are aggregated with data for adult cancers (which are far more numerous), making it difficult to ascertain findings specific to younger cancer patients. Examining differences in childhood cancer incidence over time in Australia, or in comparison with other countries, can provide insights into the possible causes of cancer by suggesting links with genetic or environmental factors.

What has been achieved in 2020?

Analysis of data from the Australian Childhood Cancer Registry revealed that the incidence rate of childhood cancer increased by around 1% per annum on average in Australia between 2005-2015. Using conservative estimates, we predicted that the number of children diagnosed annually was likely to increase by almost 40%, from 770 cases per year in 2015 to 1060 cases per year by 2035, or by a total of 7% over and above population growth.

What is the importance of this research?

This new information provides greater certainty around the future burden of cancer among Australian children. Our findings will inform health care planning to address the needs of children who will be diagnosed with cancer in the years ahead, including the number of beds required in paediatric oncology hospitals, costs of medicines and workforce requirements.





Spotlight on our collaborators

Professor D Maxwell Parkin and the African Cancer Registry Network

Professor Maxwell Parkin MD is one of the world's leading epidemiologists with a myriad of achievements to his name. He is an Honorary Senior Research Fellow in the Nuffield Department of Population Health at the University of Oxford, a Senior Visiting Scientist at the International Agency for Research on Cancer in Lyon, and the Coordinator of the African Cancer Registry Network.

He is also Foreign Adjunct Professor at the Karolinska Institute in Stockholm and an Honorary Professor at both the Universities of Peking (Beijing) and Tianjin in China. He has been granted Honorary Doctorates by the University of Tampere in Finland and the Queen Mary University of London. This is all in addition to the 400-plus papers and reviews he has published on topics such as cancer epidemiology, international cancer patterns and trends, cancer surveillance and registration, and cancer prevention and control.

After an early career in clinical medicine, he moved to Public Health, working in Edinburgh, Leeds, and the USA before moving to Lyon, France, to join the International Agency for Research on Cancer (IARC) where he was head of the department of Descriptive Epidemiology for over 20 years. He continues his association with the IARC as Senior Visiting Scientist in order to coordinate the activities of cancer registries in Africa through the African Network of Cancer Registries. Researchers from Cancer Council Queensland's Viertel Cancer Research Centre were invited to collaborate with Professor Parkin and his team in an examination of stage (extent of disease) at diagnosis and stage-specific survival for children with cancer in sub-Saharan Africa. This collaboration was a world first attempt to collect and compare population-wide information on childhood cancer stage in two vastly different world regions – Africa and Australia – using the consensus-based international staging protocols, the Toronto Childhood Cancer Stage Guidelines. Data was collected by cancer registries in Abidjan (Côte d'Ivoire), Harare (Zimbabwe)

and Kampala (Uganda) for the following four cancer types: non-Hodgkin lymphoma, Burkitt lymphoma, retinoblastoma, and Wilms tumour. These results were then compared with childhood cancer outcomes in the Australian population and published in the International Journal of Cancer. Final results revealed aggregated three-year survival rates across the three African registries of between 25% for children with Burkitt lymphoma to 46% for children with retinoblastoma. This compares to a target of 60% five-year survival by 2030 set by the Global Initiative for Childhood Cancer, and an overall five-year survival rate in Australia of 86% for all childhood cancers combined.

This collaboration helped increase international awareness of the burden of childhood cancer in sub-Saharan Africa and the stark contrast between childhood cancer survival rates between low- and high-income countries. According to Professor Parkin and his team, stage at diagnosis is one of the most important predictors of survival for children with cancer, with reliable data on stage, on a population basis, being vital to implement effective and targeted strategies to improve cancer survival.

Cancer Council Queensland continues to play a leading role in the development and testing of standard protocols regarding the collection of childhood cancer stage by cancer by international cancer registries and feels honoured to be working alongside Professor Parkin's team in Africa, as well as other leading cancer groups in Europe, Canada, and America, with the aim of implementing said protocols as globally as possible.

This collaboration has demonstrated the feasibility of collecting information about childhood cancer stages in low-income nations where it is most needed.



Travelling for treatment



What is the project?

The Travelling for Treatment project examines the experiences of cancer survivors and their caregivers who must travel to major cities for treatment. The project aims to understand the needs and challenges experienced by rural patients and caregivers from cancer diagnosis and treatment, to follow up and beyond.

What is the need?

People living with cancer in rural Australia experience poorer outcomes than those living in metropolitan areas, including lower survival rates for some cancers and poorer physical and emotional wellbeing. Regional and remote cancer patients face unique challenges, often travelling long distances to receive treatment and spending long periods away from their homes and family support. A focused effort is required to identify the challenges of this vulnerable group and to improve outcomes.

What has been achieved in 2020?

More than 1000 cancer survivors and their caregivers consented to take part in this research. Data are collected during in-depth interviews at baseline, and at three, 12 and 24-month intervals.

Key findings published in 2020 show that good communication with health professionals, and the patient's involvement in their own care, promote wellbeing; however, individual experiences vary according to the cancer site, educational level and age of the patient. Current cancer care guidelines recommend that patients receive Survivorship Care Plans at the end of their treatment to provide self-management information and to assist patients to maintain their health after treatment. We found that a large proportion of rural and regional patients do not receive Survivorship Care Plans when they leave treatment facilities in major cities to return home. Our future work will address this gap.

What is the importance of this research?

Rural cancer patients experience disadvantage, isolation, and poorer outcomes. This research provides strong support for targeted service-based interventions for rural cancer patients that facilitate better coordination of care, improved communication with health professionals, and appropriate practical and emotional support.

Barriers to bowel cancer screening



What is the project?

This project seeks to understand and address barriers to bowel cancer screening through consultation with recipients of the National Bowel Cancer Screening Program (NBCSP). We have collected detailed information about consumers' opinions, behaviours and experiences to inform intervention design.

What is the need?

The NBCSP provides a simple and convenient way to detect bowel cancer early by sending home test kits to Australians aged between 50 and 74. The NBCSP saves lives by detecting bowel cancer at an early stage, however, almost six in 10 people do not complete and return their test kit. If participation rates could be increased to 60% of the target population over the next 20 years, approximately 84,000 lives and \$2.1 billion in health care costs could be saved.

What has been achieved in 2020?

More than 800 participants took part in two surveys about bowel cancer screening behaviour, barriers and facilitators to participation in the NBCSP, and their preferences and opinions on intervention strategies. Interviews with consumers helped us to understand those features of home bowel cancer screening kits that could be modified or enhanced to make them more user-friendly.

Our findings revealed a wide range of potentially modifiable barriers to home bowel cancer screening, including disgust and hygiene concerns, physical challenges in using kits, fear of negative outcomes, forgetfulness and failure to plan, and consumers' preferences for autonomy in health decision-making.

What is the importance of this research/future directions?

If participation in the NBCSP was improved, thousands of lives would potentially be saved. This research will inform the design of intervention strategies to achieve this. These will include modifications to the home screening kit, personalised endorsement of bowel cancer screening by the consumer's general practitioner, and prompts and reminders to promote action planning.





Abbi's story

Abbi was diagnosed with bowel cancer in 2015, when she was just 29 years old. She went to see her GP after experiencing long-term symptoms that were impacting her daily life.

'I had Googled my symptoms at various times and even though cancer was always mentioned as a possibility, I ignored it out of fear and I kept telling myself I was too young for that,' said Abbi.

The doctor told Abbi that she had stage 3 bowel cancer, and would need to undergo intensive chemotherapy, radiation treatment and surgery. Five years later, Abbi thankfully has no sign of cancer in her body, but lives with long-term effects from the disease. She has a permanent colostomy and can no longer have children.

'If I had sought medical advice much earlier, the outcome may have been very different. I don't feel negative about what happened to me, and I have accepted and even embraced the changes in my life, but I don't wish to see anyone else have to go through what I went through.'

'I know many people (myself included, at first) feel too embarrassed and fearful to talk about the symptoms associated with bowel cancer. But when I finally started talking about it, I found that I had nothing to be embarrassed or fearful about – the support I received when I opened up was immense.'

Abbi is a big advocate of bowel cancer screening and early detection, and also encourages her friends, family and community to speak openly about any changes in their health with their GP.

'The screening test is so easy to do and could save your life or make treatment much less invasive and life-altering if it did detect something. I would encourage anyone in an at-risk age bracket, with family history or any symptoms to please take part in bowel cancer screening.'

Assessing modifiable cancer risk in Australia



What is the project?

This project uses existing large datasets of self-reported health behaviour (such as alcohol intake, smoking, diet, exercise and cancer screening) to calculate, map and predict the extent of modifiable cancer risk factors in the Australian population.

What is the need?

Up to 50% of cancer deaths could be prevented by improving individual health behaviours in line with current guidelines. It is well known that the risk of cancer increases with smoking, alcohol consumption, being overweight and lack of exercise, and that cancer screening saves lives. Despite ongoing efforts to encourage healthier lifestyles, up to 5 million preventable cancer deaths are estimated to occur each year worldwide. To target and design the right interventions to for the right people in Australia, it is vital that we know who has the highest level of preventable cancer risk and what factors are associated with this.

What has been achieved in 2020?

By analysing more than 30,000 responses to Cancer Council Queensland's online Cancer Risk Calculator, the average cancer risk was calculated for each Queensland postcode. This provided a visual map of modifiable cancer risk across Queensland, highlighting the regions in the state with high cancer risk due to lifestyle and behavioural factors that are potential targets for intervention.

What is the importance of this research?

These activities comprise the pilot phase of ongoing research to investigate and reduce modifiable cancer risk in Queensland and Australia. Future work will include the calculation of individual modifiable cancer risk scores and an investigation into the role of mental health in cancer risk behaviour and cancer prevention.



Cancer Risk Calculator.

Well done, you're doing well.
Your total score is:



This score is out of 100 and calculates how much you are reducing your cancer risk through healthy lifestyle behaviours. The higher your score, the more ways you are currently reducing your cancer risk.

Aim for 100 to improve your health!

Receive your Cancer Risk Scorecard with your detailed results, recommendations and tips to reduce your cancer risk.

- Identify your areas for improvement
- Access helpful resources
- Keep track of your progress

Our leadership team



Professor Joanne Aitken

General Manager, Research

Professor Joanne Aitken is Head of the Viertel Cancer Research Centre at Cancer Council Queensland and Director of the Australian Childhood Cancer Registry. She received her BSc (Honours) from Griffith University, her Science Masters from Harvard University and her PhD from the University of Queensland. She has an Honorary Professorial appointment 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 is actively involved in national and international cancer surveillance practice and policy. She is a member of the Executive Board of the Australasian Association of Cancer Registries and a member of the Australian Institute of Health and Welfare's Cancer Monitoring Advisory Group. She is President and Chair

of the Board of the International Association of Cancer Registries and sits on the Editorial Board of the World Health Organisation's reference work "*Cancer Incidence in Five Continents (Volume XII)*". She is a Ministerial appointee to the Advisory Council of Cancer Australia.

As a cancer epidemiologist, she is internationally recognised for her work in skin cancer and cancer in children. She has led or co-authored over 280 scientific publications in journals including *The Lancet*, *The Lancet Oncology* and the *Journal of Clinical Oncology* and her work has been cited over 18,000 times in the scientific literature.

Joanne 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 more than 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 \$12 million in funding. His work has been cited over 28,000 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 and is Senior Manager of Childhood Cancer Research. 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 areas of research interest are the epidemiology of skin cancer and second cancers. He has co-authored about 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

Manager, Health Systems and Psycho-Oncology

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

APPENDICES

Publications 2020

- Abrahams HJG, Knoop H, Schreurs M, Aaronson NK, Jacobsen PB, Newton RU, Courneya KS, Aitken JF, Arving C, Brandberg Y, Chambers SK, Gielissen MF, Glimelius B, Goedendorp MM, Graves KD, Heiney SPH, R., Hunter MS, Johansson B, Northouse LL, Oldenburg HS, Prins JB, Savard J, van Beurden M, van den Berg SW, Verdonck-de Leeuw IM, Buffart LM. Moderators of the effect of psychosocial interventions on fatigue in women with breast cancer and men with prostate cancer: individual patient data meta-analyses. *Psycho-Oncology*. 2020; 29(11):1772-1785.
- Atun R, Bhakta N, Denburg A, Frazier AL, Friedrich P, Gupta S, Lam CG, Ward ZJ, Yeh JM, Allemani C, Coleman MP, Di Carlo V, Loucaides E, Fitchett E, Girardi F, Horton SE, Bray F, Steliarova-Foucher E, Sullivan R, Aitken JF, Banavali S, Binagwaho A, Alcasabas P, Antillon F, Arora RS, Barr RD, Bouffet E, Challinor J, Fuentes-Alabi S, Gross T, Hagander L, Hoffman RI, Herrera C, Kutluk T, Marcus KJ, Moreira C, Pritchard-Jones K, Ramirez O, Renner L, Robison LL, Shalkow J, Sung L, Yeoh A, Rodriguez-Galindo C. Sustainable care for children with cancer: a Lancet Oncology Commission. *Lancet Oncology*. 2020; 21(4):e185-e224.
- Baade PD, Whiteman DC, Janda M, Cust AE, Neale RE, Smithers BM, Green AC, Khosrotehrani K, Mar V, Soyer HP, Aitken JF. Long-term deaths from melanoma according to tumor thickness at diagnosis. *International Journal of Cancer*. 2020; 147(5):1391-1396.
- Cramb SM, Duncan EW, Aitken JF, Soyer HP, Mengersen KL, Baade PD. Geographical patterns in melanoma incidence across Australia: can thickness differentials reveal the key drivers? *Annals of Cancer Epidemiology* 2020; 4:11.
- Dasgupta P, Aitken JF, Condon JR, Garvey G, Whop LJ, DeBats C, Baade PD. Spatial and temporal variations in cervical cancer screening participation among Indigenous and non-Indigenous women, Queensland, Australia, 2008- 2017. *Cancer Epidemiology*. 2020; 69:101849.
- Dasgupta P, Cramb S, Kou K, Yu XQ, Baade PD. Quantifying the number of cancer deaths avoided due to improvements in cancer survival since the 1980s in the Australian population, 1985-2014. *Cancer Epidemiology, Biomarkers & Prevention*. 2020; 29(9):1825-1831.
- Dasgupta P, Henshaw C, Youlden D, Aitken J, Sullivan A, Irving H, Baade P. Global trends in incidence rates of childhood liver cancers: systematic review and meta-analysis. *Paediatric and Perinatal Epidemiology*. 2020; 34(5):609-617.
- Dasgupta P, Henshaw C, Youlden DR, Clark PJ, Aitken JF, Baade PD. Global trends in incidence rates of primary adult liver cancers: a systematic review and meta-analysis. *Frontiers in Oncology*. 2020; 10:171.
- Di Giuseppe G, Youlden DR, Aitken JF, Pole JD. Pediatric hepatic cancer incidence and survival: 30-year trends in Ontario, Canada; the United States; and Australia. *Cancer*. 2020. doi: 10.1002/cncr.33319.
- Dunn J, Ralph N, Green A, Frydenberg M, Chambers SK. Contemporary consumer perspectives on prostate cancer survivorship: Fifty voices. *Psycho-Oncology*. 2020; 29(3):557-563.
- Dunn J, Scuffham P, Hyde MK, Stein K, Zajdlewicz L, Savage A, Heneka N, Shu-Kay NG, Chambers, SK. Designing Organisational Management Frameworks to Empower Episodic Volunteering. *Voluntas: International Journal of Voluntary and Nonprofit Organizations*. 2020. doi: 10.1007/s11266-020-00226-5.
- Goodwin BC, Crawford-Williams F, Castro O, Rowe A, De Cocker K. Online physical activity and sedentary behaviour information for cancer survivors. *Journal of Cancer Survivorship*. 2020; 14(5):677-688.
- Goodwin BC, Rowe AK, Crawford-Williams F, Baade P, Chambers SK, Ralph N, Aitken JF. Geographical disparities in screening and cancer-related health behaviour. *International Journal of Environmental Research and Public Health*. 2020; 17(4).
- Gupta S*, Aitken J*, Bartels U, Bhakta N, Bucurenci M, Brierley J, De Camargo B, Chokunonga E, Clymer J, Coza D, Fraser C, Fuentes-Alabi S, Gatta G, Gross T, Jakab Z, Kohler B, Kutluk T, Moreno F, Nakata K, Nur S, Parkin M, Penberthy L, Pole J, Poynter JN, Pritchard-Jones K, Ramirez O, Renner L, Steliarova-Foucher E, Sullivan M, Swaminathan R, Van Eycken L, Vora T, Frazier AL, *Joint first authors. Development of paediatric non-stage prognosticator guidelines for population-based cancer registries and updates to the 2014 Toronto Paediatric Cancer Stage Guidelines. *The Lancet Oncology*. 2020; 21:e444-451.
- Jahan F, Duncan EW, Cramb SM, Baade PD, Mengersen KL. Augmenting Disease Maps: a Bayesian meta-analysis approach. *Royal Society Open Science*. 2020; 7(8):192151.
- Jahan F, Duncan EW, Cramb SM, Baade PD, Mengersen KL. Multivariate Bayesian meta-analysis: joint modelling of multiple cancer types using summary statistics. *International Journal of Health Geographics*. 2020; 19(1):42.
- Janda M, Cust AE, Neale RE, Aitken JF, Baade PD, Green AC, Khosrotehrani K, Mar V, Soyer HP, Whiteman DC. Early detection of melanoma: a consensus report from the Australian Skin and Skin Cancer Research Centre Melanoma Screening Summit. *Australian and New Zealand Journal of Public Health*. 2020; 44(2):111-115.
- Janda M, Paul C, Horsham C, PoCoG Cancer Prevention Special Interest Group*, *Oliver I, Pern A, Wilson C, Goodwin B, Lofti-Jam K-A, Bartley N, Morris J, Horsham C, Janda M, Paul C. Changes in cancer preventive behaviours, screening and diagnosis during COVID-19. *Psycho-Oncology*. 2020. doi: 10.1002/pon.5575.
- Jones BC, Youlden DR, Cundy TP, O'Callaghan ME, Karpelowsky J, Aitken JF, McBride CA. Renal tumours in Australian children: thirty years of incidence, outcome, and second primary malignancy data from the Australian Childhood Cancer Registry. *Journal of Paediatrics and Child Health*. 2020; 56(6):908-916.
- Kou K, Cameron J, Aitken JF, Youl P, Turrell G, Chambers S, Dunn J, Pyke C, Baade PD. Factors associated with being diagnosed with high severity of breast cancer: a population-based study in Queensland, Australia. *Breast Cancer Research and Treatment*. 2020; 184(3):937-950.

21. Kou K, Dasgupta P, Aitken J, Baade P. Impact of area-level socioeconomic status and accessibility to treatment on life expectancy after a cancer diagnosis in Queensland, Australia. *Cancer Epidemiology*. 2020; 69:101803.
22. Kou K, Dasgupta P, Cramb S, Yu XQ, Andersson T, Baade P. Temporal trends in loss of life expectancy after a cancer diagnosis among the Australian population. *Cancer Epidemiology*. 2020; 65(4):101686.
23. Kou K, Dasgupta P, Cramb SM, Yu XQ, Baade PD. Temporal trends in population-level cure of cancer: the Australian context. *Cancer Epidemiology Biomarkers and Prevention*. 2020; 29(3):625-635.
24. Laskar R, Ferreira-Iglesias A, Bishop DT, Iles MM, Kanetsky PA, Armstrong BK, Law MH, Goldstein AM, Aitken JF, Giles GG, Robbins HA, Cust AE, Australian Melanoma Family Study I, Leeds Case-Control Study I. Risk factors for melanoma by anatomical site: an evaluation of aetiological heterogeneity. *British Journal of Dermatology*. 2020. doi: 10.1111/bjd.19705.
25. Liu B, Youlden DR, Wabinga H, Namboozee S, Amulen PM, Aitken JF, Parkin DM. Survival from childhood cancer in Kampala, Uganda. *Pediatric Blood and Cancer*. 2020. doi: 10.1002/pbc.28876:e28876.
26. Merollini KMD, Gordon LG, Aitken JF, Kimlin MG. Lifetime Costs of Surviving Cancer—A Queensland Study (COS-Q): Protocol of a Large Healthcare Data Linkage Study. *International Journal of Environmental Research and Public Health*. 2020; 17(2831).
27. Myers L, Goodwin B, Ralph N, Castro O, March S. Implementation Strategies for Interventions Aiming to Increase Participation in Mail-Out Bowel Cancer Screening Programs: A Realist Review. *Frontiers in Oncology*. 2020; 10:543732.
28. Narendra A, Baade PD, Aitken JF, Fawcett J, Leggett B, Leggett C, Tian K, Sklavos T, Smithers BM. Hospital characteristics associated with better 'quality of surgery' and survival following oesophagogastric cancer surgery in Queensland: a population-level study. *ANZ Journal of Surgery*. 2020. doi: 10.1111/ans.16397.
29. Peek G, Olsen CM, Baade P, Youlden DR, Aitken JF, Green AC, Khosrotehrani K. Survival in patients with multiple primary melanomas: systematic review and meta-analysis. *Journal of the American Academy of Dermatology*. 2020; 83(5):1406-1414.
30. Rahman ST, Pandeya N, Neale RE, McLeod DSA, Bain CJ, Baade PD, Youl PH, Allison R, Leonard S, Jordan SJ. Obesity is associated with BRAF(V600E)-mutated thyroid cancer. *Thyroid*. 2020; 30(10):1518-1527.
31. Ralph N, Chambers SK, Laurie K, Oliffe J, Lazenby M, Dunn J. Nurse-led supportive care intervention for men with advanced prostate cancer: healthcare professionals' perspectives. *Oncology Nursing Forum*. 2020; 47(1):33-43.
32. Reyes-Marcelino G, Tabbakh T, Espinoza D, Sinclair C, Kang YJ, McLoughlin K, Caruana M, Fernandez-Penas P, Guitera P, Aitken JF, Canfell K, Dobbinson S, Cust AE. Prevalence of skin examination behaviours among Australians over time. *Cancer Epidemiology*. 2020. doi: 10.1016/j.canep.2020.101874.
33. Vuong K, Armstrong BK, Espinoza D, Hopper JL, Aitken JF, Giles GG, Schmid H, Mann GJ, Cust AE, McGeechan K. An independent external validation of melanoma risk prediction models using the Australian Melanoma Family Study. *British Journal of Dermatology*. 2020. doi: 10.1111/bjd.19706.
34. Youlden DR, Baade PD. Ongoing cancer burden after a diagnosis of cutaneous squamous cell carcinoma. *British Journal of Dermatology*. 2020; 183(3):414-415.
35. Youlden DR, Foresto SA, Aitken JF. Primary malignant lung tumors in children: a report from the Australian Childhood Cancer Registry, 1983-2015. *Pediatric Pulmonology*. 2020; 55(3):719-722.
36. Youlden DR, Jones BC, Cundy TP, Karpelowsky J, Aitken JF, McBride CA. Incidence and outcomes of neuroblastoma in Australian children: A population-based study (1983-2015). *Journal of Paediatrics and Child Health*. 2020; 56(7):1046-1052.
37. Youlden DR, Walwyn TS, Cohn RJ, Harden HE, Pole JD, Aitken JF. Late mortality from other diseases following childhood cancer in Australia and the impact of intensity of treatment. *Pediatric Blood and Cancer*. 2020. doi: 10.1002/pbc.28835:e28835.
38. Yu XQ, Baade P. Cancer prevention: when knowledge of cancer prevention is not enough (Invited Commentary). *Cancer*. 2020; 126(20):4451-4454.

Scientific presentations 2020

1. Aitken J. The Toronto Paediatric Cancer Stage Guidelines. Invited plenary speaker. National Cancer Centre of Japan and International Agency for Research on Cancer: 8th Seminar on International Cancer Research and Cancer Control, 13 October 2020, via video-link.
2. Aitken J, Frazier L, Gupta S. The Toronto Paediatric Cancer Stage Guidelines: an overview. European School of Oncology Webinar, 12 November 2020, online.
3. Baade P. How does the burden of Myeloproliferative neoplasms in Australia vary by where people live? MPN Awareness Day, 10 September 2020, via video-link.
4. Baade P. Australian Cancer Atlas: A critical piece of the evidence puzzle. Surveying & Spatial Sciences Institute (SSSI) / FrontierSI Webinar Series, 4 June 2020, via video-link.
5. Crawford-Williams F. Regional and remote cancer patients' experiences of health care services. Clinical Oncology Society of Australia 47th Annual Scientific Meeting, 11-13 November 2020, virtual meeting.
6. Goodwin BC. Barriers to home bowel cancer screening. Clinical Oncology Society of Australia 47th Annual Scientific Meeting, 11-13 November 2020, virtual meeting.
7. Van Eycken L, Frazier L, Gupta S, Aitken JF. The Toronto Paediatric Cancer Stage Guidelines: practical application. European School of Oncology Webinar, 19 November 2020, online.
8. Youlden D. Childhood cancer data in Australia: the Australian Childhood Cancer Registry. Invited lecture. QIMR Berghofer Medical Research Institute Population Health Series, 3 November 2020, Brisbane.

Grants and awards 2020

Grants awarded 2020

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

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.

Grants ongoing 2020

Aitken JF, Youlden D, Baade P, Moore A, Green AC, Valery P. Improving childhood cancer data for Australia: Enhancing the collection of population data on childhood cancer treatment and non-stage prognostic indicators. Cancer Australia (contract). 2019-2020. \$182,000.

Baade PD, Aitken JF. Understanding and improving cervical cancer screening participation among Indigenous and non-Indigenous women in North Queensland. Perpetual IMPACT Philanthropy, The E Robert Hayles & Alison L Hayles Charitable Trust. 2019-2020. \$70,000.

Baade P, Aitken J, Goodwin B. Identification and analysis of available data sets in Australia for cancer-related indicators. Cancer Council Australia (contract). 2019-2020. \$53,500.

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.

Ownsworth 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 2020

EXPERT ADVISORY COMMITTEES, SCIENTIFIC PANELS AND WORKING GROUP MEMBERSHIPS

National

- Australian Institute of Health and Welfare Cancer Monitoring Advisory Group
- Australasian Association of Cancer Registries, Executive Board
- Cancer Australia Advisory Committee
- 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

International

- International Association of Cancer Registries, President and Chair of Board
- Global Burden of Disease Collaborator Network, Institute for Health Metrics and Evaluation, University of Washington
- Benchmarking International Childhood Cancer Survival by Toronto Stage (BENCHISTA) Collaborative Project, Independent Advisory Board, Co-Chair
- Cancer Risk in Childhood Cancer Survivors (CRICCS), Scientific Advisory Board, Co-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 Causes and Control
- Cancer Epidemiology
- Cancer Medicine
- Croatian Medical Journal
- European Journal of Cancer Care
- International Journal of Epidemiology
- JNCI Cancer Spectrum
- 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

Postgraduate students 2020

- Renee Eggins – Master of Biostatistics, The University of Queensland
- Erika Okwuazi - Master of Epidemiology, The University of Queensland
- James Hogg – Master of Biostatistics, The University of Queensland
- Veronika Schrieber – Master of Biostatistics, The University of Queensland
- James Retell – Master of Biostatistics, The University of Queensland



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