About the Garvan Institute of Medical Research

The Garvan Institute of Medical Research (Garvan) was founded in 1963 and is a world leader in gene-based medical research, pioneering study into some of the most widespread diseases affecting our community today.

Garvan is a multi-disciplinary research institute with more than 400 scientists and PhD students working across six major research areas:

- Cancer – breast, colorectal (bowel), lung, ovarian, pancreatic and prostate;
- Diabetes and Metabolism – Type 2 diabetes, obesity and metabolic disorders;
- Immunology – Asthma, Rheumatoid arthritis, MS and Type 1 diabetes;
- Neuroscience – Alzheimer’s and Parkinson’s disease, anorexia, hearing loss;
- Osteoporosis and bone disorders;
- Genomics and epigenetics.

Each Division investigates the origins, diagnostic markers and most effective treatments of disease with the ultimate aim of prevention and cure.

One of Garvan’s greatest strengths is the extent of active cross-collaboration between the research areas and the consequent innovation this drives.

About the Garvan Research Foundation

The Garvan Research Foundation was established in 1981 to provide fundraising and marketing support to the Garvan Institute’s medical research programs.

The Foundation has successfully grown from a fundraising base of $110,000 in its first year to around $20 million a year. In addition to its fundraising activities, the Foundation’s activities have since expanded to support Garvan with a public engagement program. This initiative aims to increase understanding of the need for and importance of Garvan’s medical research across the broader community, including rural and regional Australia through the Healthy Families, Health Communities Education and Awareness program.

The information in this report was derived from the most recent data published by the Australian Institute of Health and Welfare, the Australian Bureau of Statistics and the peer reviewed research literature available at the time of preparation.

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Any enquiries about or comments on this publication should be directed to the Garvan Research Foundation: foundation@garvan.org.au.
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In 2015, the Garvan Research Foundation published *Medical Research and Rural Health – Garvan Report*, which examined the federal government’s National Health Priority Areas in relation to rural Australia. These areas are arthritis, asthma, cancer control, cardiovascular health, dementia, diabetes mellitus, mental health, musculoskeletal conditions, and overweight and obesity. This new adjunct report places the spotlight on just one of these health priority areas – cancer.

One in two Australian men, and one in three Australian women will develop cancer before the age of 85. While this statistic is alarming, it never really hits home until it becomes personal and it is inevitable that we will all feel the impact of cancer, either personally or by association. Nowhere is this more apparent than in rural Australia.

In my experience within the consumer health advocacy sector, I have been acutely aware that incidence and mortality rates for cancer in rural Australia are dire. We work hard to improve these outcomes through raising awareness, increasing support and funding medical research.

When it comes to cancer incidence and mortality rates in rural Australia, we are generally not seeing the improvements experienced in major cities. If we don’t act now, the gap will only continue to grow.

Medical research has an important role to play in addressing the issue of poor cancer outcomes in rural Australia. This report highlights how breakthroughs in the way we diagnose, treat and prevent cancer, through approaches including genomics, personalised medicine and cancer immunotherapy, are changing the way we think about the disease and improving outcomes for all Australians.

However, my hope is that this report also highlights the urgency for greater focus, and spurs policy makers into action to provide a coordinated, nationwide approach on addressing this area of significant need. Innovation in medicine must also be equalled by innovative policies so that all Australians can claim their share of the benefit.
Australian Standard Geographical Classification Remoteness Areas

ARIA+ 2011
(Scores rounded for demonstration purposes)
- Major Cities (0.0-0.20)
- Inner Regional (> 0.20-2.40)
- Outer Regional (> 2.40-5.92)
- Remote (> 5.92-10.53)
- Very Remote (>10.53-15.00)

Data Sources:
GISCA, The University of Adelaide
Australian Government Geoscience Australia
Australian Bureau of Statistics

Defining Remoteness
This paper adopts the definitions of remoteness employed by the Australian Bureau of Statistics Australian Standard Geographic Classification Remoteness Areas (RAs), as recommended by the Australian Institute of Health and Welfare. RAs are calculated according to the road distance to the nearest urban centres, using the ARIA+ and ARIA++ indices.

Introduction
Among Australia’s population of 24 million, the cities compress two-thirds into 0.7 per cent of the landmass. The remaining 7 million people are unevenly distributed across more than 7.5 million square kilometres, with 27 per cent residing in regional areas and 2.3 per cent in remote or very remote Australia. This computes as one of the lowest population densities in the world at three people per square kilometre of land, and brings unique health challenges. Such challenges can be broadly divided into delivery of health care through reduced access and quality, and patterns of patient behaviour as impacted by socioeconomic status, Indigenous status, and environment and lifestyle.

Though Australia’s regional and remote areas include a broad mix of geographic and social factors, and with them differing health implications, evidence points to a generally lower standard of health. When compared to their city equivalents, 20 per cent more remote Australians live with disease. Life expectancy drops with distance from the city, with people in remote Australia dying around three years younger than their urban counterparts.
Challenges to health in rural Australia

Access
For most rural communities, equitable access is restricted by the frequent need to travel a great distance to reach basic hospital services. Specialised services may require accommodation in regional or metropolitan centres, which brings additional financial, family, emotional and employment impacts. The cost of providing health services also increases with remoteness, while the availability of existing infrastructure and workforce become more limited. Rural areas have lower numbers of the health care professionals, with 42 per cent fewer pharmacists, 65 per cent fewer psychologists, 68 per cent fewer podiatrists, 68 per cent fewer optometrists and 65 per cent fewer occupational therapists per 100,000 people compared to major cities.9 Furthermore there are 86 per cent fewer specialists in remote Australia compared to major cities and only 27 medical oncologists, representing 6 per cent of the national total.9 For cancer, the shortage of clinicians translates to longer waiting times and risks a more advanced stage of disease at diagnosis. Such figures additionally demonstrate the resource challenges among a cancer patient’s broader health care team, beyond the oncologist.

Standards of care
The standard of rural health services have been documented to be of poorer quality than in the metropolitan areas, directly influencing survival rates.10 Facilities are generally smaller, provide a broad range of services, have less infrastructure and locally available specialist services, and cater to a more dispersed population.11 Furthermore, a higher proportion of cancer patients in rural areas (39 per cent) had no treatment at all, compared to metropolitan areas (29 per cent).12

Socioeconomic disadvantage
The proportion of socioeconomic disadvantage runs in parallel with both remoteness and poorer health, including cancer mortality. Disadvantage may include less access to education, lower incomes, dependency on government benefits, less fluency in English, low-skilled employment/unemployment and poorer access to goods and services. The relationship with cancer mortality is presumed to align with socially determined differences in how people seek, access, understand and act on health information, particularly regarding prevention and early detection, as well as a relative lack of healthcare affordability and less access to private health insurance and services.13

Indigenous populations
The health disadvantage of Indigenous Australians is well documented, with evidence indicating a life expectancy gap of 10.6 years for males (69.1 years) and 9.5 years for females (79.9),14 and a standardised mortality ratio more than triple that of the non-Indigenous population.15 As Indigenous populations increase with remoteness, the statistical profile of a region is accordingly impacted. The complexity of this problem thus includes cultural and language barriers.16

Environmental and lifestyle risk factors
A high incidence of melanoma among rural populations,17 including a 60 per cent higher death rate among farmers,18 correlates with higher risk of exposure to ultraviolet radiation among outdoor and agricultural workers. Additionally, rural areas of Australia witness a higher prevalence of cancer risk factors such as smoking, alcohol consumption and obesity.19 More people in major cities report a smaller number of risk factors (up to three) compared with rural areas: 66 per cent, compared with 58 per cent for inner regional and 54 per cent for the remainder. Similarly, major cities also have a fewer proportion of people with four or more risk factors: 33 per cent, compared with 40 per cent of those living in inner regional areas and 45 per cent living in other areas.20 Having multiple risk factors increases the likelihood of developing a chronic condition.21

Health care workforce disparities: Rural health care workforce, compared to major cities per 100,000 people

![Health care workforce disparities](image-url)

**“ONE IN TWO MALES AND ONE IN THREE FEMALES IN AUSTRALIA WILL DEVELOP CANCER.”**
Cancer is a diverse group of several hundred diseases in which some of the body’s cells become abnormal and begin to multiply out of control. The abnormal cells can invade and damage the tissue around them, spreading to other parts of the body where they cause further damage. As a painful, distressing and often life-ending illness, cancer has a significant impact on individuals, families and the healthcare system, and has had a prominent policy focus for decades. Despite this, the unique challenge of cancer in the rural setting is a relative newcomer to the public agenda.

One in two males and one in three females in Australia will develop cancer and three in ten Australians will die from it by the age of 85. Cancer is Australia’s second-biggest killer after coronary heart disease, with 44,108 deaths in 2013. In 2016, an estimated 130,466 new cancers will be diagnosed in Australia, and there will be 46,880 cancer deaths, representing about 30 per cent of Australia’s total deaths. Though an aging population means more people die from cancer each year, the age-standardised mortality rate per 100,000 people has fallen by more than 20 per cent between 1982 and 2014 due to medical research into the causes, detection, prevention and treatment of cancer, along with supportive policy and implementation. This decrease is not seen in some sub-populations such as Indigenous Australians, however, and differs across types of cancer.

The most commonly diagnosed cancers in Australia are prostate (among men), bowel, breast (among women), melanoma of the skin, and lung. Grouped together, they account for more than 60 per cent of all cancers in 2012. Lung cancer is Australia’s most deadly cancer, accounting for 9.4 per cent of all cancer deaths and 5.4 per cent of total deaths, followed by prostate (among males), breast (among females), colorectal, pancreas and unknown primary site.
Cancer in the rural setting

Whether or not someone survives cancer depends, in part, on where they live. Rural Australia has demonstrably poorer survival outcomes when compared to major cities, with five-year relative survival for cancer decreasing with remoteness.32 When compared with metropolitan public hospitals, teaching hospitals and private hospitals (whether rural or metropolitan), rural public hospitals witness a chemotherapy drop-out rate of more than 50 per cent, approximately double that of private hospitals,33 and a decreased likelihood for patients to undergo radiotherapy in remote and very remote areas.34 Participation in cervical cancer screening is lowest in very remote areas.35 The 10 years to 2010 saw no improvement in the difference in cancer outcomes between rural and urban patients, with 7 per cent higher mortality equating to almost 9000 additional rural deaths.36 The contrast between incidence and mortality in very remote Australia adds further emphasis. The further a cancer patient lives from a major city, the more likely they are to die within five years of diagnosis.37 People in very remote areas are most likely to die from cancer (191.9 deaths per 100,000, all cancers combined) despite being the least likely to be diagnosed (398.3 cases per 100,000).38

Data indicates two ‘hot spots’ for cancer incidence and impact: incidence is highest in inner regional areas (lowest in very remote), while mortality is highest in very remote areas (lowest in major cities). People living in inner regional areas of Australia had the highest incidence rate in six of the selected cancers: prostate cancer (206 per 100,000), breast cancer in females (120 per 100,000), colorectal cancer (70 per 100,000), melanoma of the skin (62 per 100,000), non-Hodgkin lymphoma (19 per 100,000) and kidney cancer (13 per 100,000).39 People living in very remote areas had the highest age-standardised mortality rate for cervical cancer (4.6 per 100,000), cancer of unknown primary site (13.6 per 100,000), lung cancer (43.2 per 100,000), bladder cancer (5.2 per 100,000) and prostate cancer (35.0 per 100,000), while people living in major cities had the lowest rate for the same cancers.40

“THE FURTHER A CANCER PATIENT LIVES FROM A MAJOR CITY, THE MORE LIKELY THEY ARE TO DIE WITHIN FIVE YEARS OF DIAGNOSIS.”
Indigenous Australians and cancer

As noted above, Indigenous populations increase with remoteness, constituting nearly half the people (45 per cent) in very remote areas. Research indicates that Indigenous cancer survival decreases with remoteness, which may be underpinned by longer times to diagnosis and thus stage at diagnosis.\(^{43}\) In 2008-12, cancer was the second-biggest cause of Indigenous death after circulatory disease, accounting for 20 per cent of deaths. This is a smaller proportion than non-Indigenous deaths (30 per cent), while diabetes and external causes were more common than in non-Indigenous Australians. Though Indigenous mortality rates are declining across all causes of death, cancer represents an exception. Between 2001 and 2012, the improvement in cancer mortality for the non-Indigenous population did not occur in the Indigenous population – indeed among females it increased by 17 per cent – further widening the gap for this cause of death.\(^{44}\)

The cost of cancer

In health care infrastructure, absence from work and premature mortality, cancer has a significant social and economic impact on individuals, families and the community. Cancer costs more than $4.526 billion in direct health system costs, which represents 7 per cent of the total health system expenditure on chronic diseases.\(^{46}\) By contrast, cancer accounts for the greatest burden of disease in Australia, at 19 per cent,\(^{46}\) and thus it is the leading cause of 'lost health' through death or disability. The age-standardised burden increases with remoteness, with very remote areas experiencing 70 per cent more than major cities.\(^ {47}\)

For any disease, not least cancer, prevention is the most effective strategy for minimising its impact in any arena: personal, social and economic. For instance, tobacco smoking is the largest single cause of cancer and accounts for 90 per cent of lung cancers in men and 65 per cent in women in Australia.\(^ {48}\) Total expenditure on lung cancer was calculated as $166 million in the 2004-05 financial year.\(^ {49}\) The tobacco tax has been identified as the most effective disincentive for smoking,\(^ {50}\) saving 270,000 disability-affected life years and $700 million.\(^ {51}\) Lifestyle change could prevent as many as 37,000 cancers each year – a third of cancers diagnosed – with 90 per cent of preventable cancers caused by six risk factors: smoking, UV radiation, poor diet, overweight, physical inactivity and alcohol intake.\(^ {52}\) Many of these risk factors overlap with a higher incidence in rural areas.

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**Notes**

52. Cancer Council Australia. ‘Numbers are in: 37,000 Australians can avoid a cancer diagnosis each year’, Media Release, 7 October 2015. Sydney: Cancer Council Australia.
In answering the challenges of rural health, many studies and policies address the immediate issues of access, socioeconomic disadvantage and increased risk factors. Recommendations include decentralising services, enabling community and self-management, technology initiatives such as telehealth and clinical data systems, targeted awareness campaigns, subsidised travel and accommodation schemes, and improving care through surgical oncology networks, fly-in-fly-out services and psychosocial support. The 2009-10 federal budget announced the establishment of Regional Cancer Centres, with a commitment of $560 million over five years. This initiative reduces travel to metropolitan areas for chemotherapy and radiotherapy, though exceptions remain for state-of-the-art treatments and some specialised surgery.53

While such measures play an important role in improving cancer outcomes in rural Australia, medical research provides the potential for lasting transformation. Until we better understand how cancer operates on a molecular and cellular level, prevention and treatment for these diseases will remain unchanged. Public health and medical research exist in a symbiotic relationship and both require ongoing investment and support in order to translate research innovations swiftly into clinics.

The benefit of medical research in cancer is self-evident, and existing therapies have saved and extended many lives (see ‘Cancer mortality rate in Australia’ graph, below). Despite this they remain imperfect with toxic side effects and sometimes long-term complications. For rural patients, difficulties with access are compounded when treatments require a schedule of weeks or months. Thus ongoing cancer research is critical in order to address the shortfalls in our knowledge and improve outcomes.

Cancer mortality rate in Australia (all cancers combined, 1982-2014)

The rates were age-standardised to the Australian population as at 30 June 2001 and are expressed per 100,000 population.

Source: Australian Institute of Health and Welfare

New technologies

Propelled by ever-evolving genome sequencing technology there has been an extraordinary leap in knowledge of the human genome and its role in health and disease. We now understand cancer to be a disease of the genes, where mutations lead to uncontrolled cell growth. Studies in epigenetics additionally reveal how the environment and other non-genetic factors influence gene expression in cancer. Sequencing human cancer genomes and epigenomes provides researchers with a catalogue of mutations that can be compared to a patient’s tumour, highlighting molecular markers that particular treatments will (or will not) address. Armed with such insights, clinicians can provide a more nuanced and informed treatment schedule.

Whole genome sequencing is now available to Australian researchers through Garvan’s Kinghorn Centre for Clinical Genomics, which is sequencing more than 1000 genomes each month. Such initiatives open up researchers’ potential to better understand the drivers of cancer and to identify an individual’s cancer risk in advance of the onset of disease, enabling a shift in emphasis towards prevention. Prevention is not only the most cost-effective strategy for managing disease; it is also the most effective for saving lives.

Research snapshot: Molecular Screening and Therapeutics Program (MoST)

The translation of genomic information into improved health outcomes has not kept pace with scientific discovery. Led by Garvan’s Professor David Thomas, the MoST Program evaluates a new approach for testing the genomic-based precision medicine treatments for patients with advanced cancer. Its two key components are a screening platform, incorporating genomics and other molecular tests, and multiple clinical substudies of new targeted treatments. The program aims to inform future models for personalised medicine and more efficient and successful evaluation of new drugs.

Research snapshot: Epigenetics and cancer

In many diseases, particularly cancer, the epigenetic control of the genome is heavily distorted. Garvan’s research, led by Professor Susan Clark, looks at one aspect of the tumour epigenome, termed the methylome, to identify patterns associated with breast cancer. This research has enabled a way to sub-divide triple-negative breast cancer into two categories, each with distinct levels of risk. Such methylation signatures may ultimately be used to guide appropriate treatments for patients.

“The role of medical research provides the potential for lasting transformation.”
New therapies

Thanks to this deepening understanding of the genomic and molecular processes underpinning cancer, along with environmental and behavioural factors, new types of treatments are coming to light. The burgeoning field of personalised medicine potentially enables the selection of optimal therapy over trial-and-error prescribing, to minimise adverse reactions, increase patient compliance with treatment and potentially decrease the time and costs associated with a traditional one-size-fits-all approach to care.

As one type of personalised medicine, immunotherapy shows promising results for metastasised lung cancer and melanoma, cancers that disproportionately affect rural Australia. Lung cancer increases with distance from major cities, with incidence\(^54\) and death rate\(^55\) both 40 per cent higher in very remote areas. Farmers have a 60 per cent higher death rate for skin cancer, including melanoma, compared to the general population.\(^56\)

Research snapshot: Cancer immunotherapy

Most traditional cancer drugs target the tumour. Cancer immunotherapy, by contrast, targets the body’s own disease-fighting mechanism – the immune system – to help it better recognise and destroy cancer cells. Professor Stuart Tangye and his team are studying patients with primary immune deficiencies, hoping to understand how errors in specific genes can increase their susceptibility to cancer. This research aims to guide strategies to enhance the body’s immunity to viruses and cancer, with the ultimate goal of helping to develop vaccines to protect people with immune deficiencies from getting cancer.

Research snapshot: Unblocking resistance to antiestrogen therapy

Drugs that target estrogen receptors (ER) have been very successful in the management of ER-positive breast cancers. Relapse, however, remains an issue. Professor Chris Ormandy and his team are examining a protein called ELF5, which in normal circumstances enables lactation. In breast cancer, however, ELF5 can ‘go rogue’ and cause metastasis and resistance to antiestrogen drugs. Garvan’s research is developing ELF5 as a prognostic biomarker for ER-positive cancer, and aims to assess the potential for new drugs to prevent ELF5-driven resistance to therapy.

The only way to transform how we understand and treat cancer is through medical research. To achieve that, we need your support.

While we welcome every cent of government funding, it alone isn’t enough to sustain the Garvan Institute’s ambitious research program. We rely on philanthropic donations to fund innovative projects, attract high calibre research leaders and to acquire state-of-the-art technology, as the government’s research budget is insufficient to fund all the high quality applications that are submitted from across the nation every year.

This is a critical moment in cancer research for the benefit of rural Australians. Our era of genome exploration is unprecedented in its potential for understanding cancer at its molecular roots. Here at Garvan we seek to use such insights to develop tests for early detection, find ways to prevent some cancers and evolve new therapies. Garvan brings such cutting-edge health innovations to rural Australia through targeted rural research, ongoing community engagement, partnerships and awareness raising, extending our reach beyond our urban premises.

For information about how you can help Garvan’s researchers improve disease diagnosis and make genomic medicine part of routine healthcare, please visit www.giving.garvan.org.au.

"PREVENTION IS NOT ONLY THE MOST COST-EFFECTIVE STRATEGY FOR MANAGING DISEASE; IT IS ALSO THE MOST EFFECTIVE FOR SAVING LIVES."

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\(^{50}\) Fox, P. and Boyce, A. 2014. ‘Cancer health inequality persists in regional and remote Australia’, Medical Journal of Australia; 201(8): 445-446.


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