MEDICAL RESEARCH AND RURAL HEALTH GARVAN REPORT 2015

A REPORT BY THE GARVAN RESEARCH FOUNDATION

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ABOUT US

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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"We are currently in the midst of the genomic revolution – using the information contained in an individual's DNA to understand the basis of human development, help evaluate the genetic risk of disease, predict outcomes, and determine the most effective treatments for that individual.

I am proud to say that Garvan is one of the leading institutes internationally in the development and application of new genomic technologies to understand human disease and its prevention and treatment."

Professor John Mattick AO FAA
Executive Director
Garvan Institute of Medical Research

Garvan Institute of Medical Research's Clinical Genomics collaborators and customers.

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FOREWORD

For more than 50-years, researchers at the Garvan Institute of Medical Research have been responsible for significant breakthroughs that have improved our understanding of some of the most common, yet complex diseases.

This work has also improved the lives of people, not only those in rural and regional Australia, but across all of society today. Since it was founded in 1963, the Garvan Institute has focused on understanding the role of molecular and cellular processes in health and disease, as the basis of developing future preventions, treatments and cures. In recent years, Garvan has invested in new genomic technologies to enable its research across key areas, including cancer, diabetes, immunology, osteoporosis and neuroscience.

This unique report brings together, for the first time, the most pertinent evidence-based data aligned to the Federal Government's National Health Priorities (NHPs), and to the Garvan Institute's research areas. The aim is to better understand the health issues facing rural and regional populations across Australia today. This report highlights the state of rural health and gaps in health information, and how this might be improved by expanding our knowledge through medical research and the development of personalised medicine.

We are currently in the midst of the genomic revolution – using the information contained in an individual's DNA to understand the basis of human development, help evaluate the genetic risk of disease, predict outcomes, and determine the most effective treatments for each individual. This has the potential over time to improve the health of those Australians living in regional, rural and remote areas.

I am proud to say that Garvan is one of the leading institutes internationally in the development and application of new genomic technologies to understand human disease, its prevention and treatment. The acquisition of the most advanced sequencing technology in the world has positioned Garvan as a human genomics hub for Australia and the region. It allows massive increases in genome sequencing capacity, accelerating medical research across the spectrum to include cancer, cardiovascular disease, mental health, osteoporosis, autoimmune diseases, diabetes and neurological diseases – those diseases highlighted under the National Health Priority Areas for Rural and Regional Australia.

Given Garvan's exceptional research talent, combined with its innovative use of leading-edge technology, I am excited by the potential of our work to deliver real benefits to this generation and those to come.

Andrew Giles
Chief Executive Officer
Garvan Research Foundation

EXECUTIVE SUMMARY

Australia's National Health Priority Areas (NHPA) are diseases and conditions given focused attention in this report because of their significant contribution to the burden of illness and the resulting high social and financial costs imposed on regional, rural and remote communities.

The priority areas are asthma, arthritis and musculoskeletal conditions, cancer control, cardiovascular health, diabetes mellitus, mental health and obesity. The diseases and conditions targeted under the NHPA initiative were chosen because through appropriate and focused attention on them, significant gains in the health of the rural population can be achieved.

It is widely accepted that remote and very remote communities experience particular issues and challenges associated with their geographic isolation. The health of Australians in rural and remote areas is generally poorer than that of people who live in major cities and towns.

They experience:

• higher mortality rates and lower life expectancy
• higher reported rates of high blood pressure, diabetes, and obesity
• higher death rates from chronic disease
• higher prevalence of mental health problems including dementia
• higher rates of alcohol abuse and smoking.

A variety of factors can influence the health of individuals and communities. These include environmental and socioeconomic factors, community capacity and individual behaviours. The differences between the metropolitan and rural and remote populations in relation to the social determinants of health include:

• lower levels of income, employment and education
• higher occupational risks, particularly associated with farming and mining
• geography and the need for more long distance travel
• access to fresh foods
• access to health services.

"THERE IS A 40% HIGHER DEATH RATE IN REMOTE AREAS THAN IN MAJOR CITIES."

Poorer health outcomes for rural and remote Australians include:

• there is a 40% higher death rate in remote areas than in major cities
• life expectancy is 2.5 years lower for males and 1.3 years lower for females for outer regional, remote and very remote areas compared with major cities and inner regional areas
• five-year relative survival for cancer decreases with increasing remoteness
• diabetes ranks higher as a cause of death among people living in remote and very remote areas compared with regional and major city areas
• the prevalence of asthma is significantly higher in people living in inner regional areas compared with those living in major cities or outer regional and remote areas
• adults living in outer regional and remote areas of Australia are more likely to be overweight or obese (69.5%) compared with adults living in major cities (60.2%)

EXECUTIVE SUMMARY

- an estimated 20% of adults, including about 960,000 people living in regional, rural and remote areas, have experienced a mental disorder in the previous 12 months
- the rate of suicide is 66% higher in the country than in major cities
- the rate of suicide among young Indigenous people (aged 15-24) is five times higher than that for non-Indigenous people
- the leading causes of death for Indigenous Australians are cardiovascular diseases, cancer, injury, diabetes and respiratory diseases
- higher death rates and poorer health outcomes outside major cities, especially in remote areas, also reflects the higher proportions of Aboriginal or Torres Strait Islander Australian living in those areas.

Although largely preventable, chronic diseases, once they develop, can often be effectively controlled through behavioural change, medication and other health-care interventions. While Australia has had some successes in preventing and treating these diseases, their prevalence continues to grow as the population increases and better treatment allows people to live longer. If left unchecked, adverse and increasing trends in some risk factors, such as being overweight or obese, physical inactivity and insufficient fruit and vegetable consumption, combined with an ageing population, suggest that the burden of chronic disease including cardiovascular disease, diabetes, arthritis and associated morbidities will continue to grow.

The risk of developing these diseases is closely associated with smoking, physical inactivity, poor nutrition and the harmful use of alcohol. Some of which, in turn, contribute to being overweight or obese, high blood pressure and high blood cholesterol levels. Each of these risk factors, however, is modifiable.

"THE RATE OF SUICIDE IS 66% HIGHER IN THE COUNTRY THAN IN MAJOR CITIES."

While deaths due to asthma have declined substantially since the 1980's, there has been less success in preventing and managing dementia.

Populations living in rural and remote areas make up 30% of the population, but do not receive anywhere near 30% of health funding and services for mental health.

Rural and remote health services are more dependent on primary health care services, particularly those provided by General Practitioners (GPs). Facilities are generally smaller, provide a broad range of services (including community and aged care), have less infrastructure and locally available specialist services, and provide services to a more dispersed population.

The limited supply of specialist professionals and services means that it is harder for people in more remote areas to know about and access professional services, even if they want to.

This lack of access to services can mean that rural and remote patients are forced to travel to metropolitan areas for treatment, often at considerable cost. For example, the travel costs attributed to osteoarthritis and rheumatoid arthritis alone were estimated as $78.6 million in 2012[1].

As remoteness increases, communities are increasingly affected by environmental extremes (such as flood, fire or drought) and economic variability. For most rural and remote communities, equitable access is restricted by: the frequent need to travel great distance to access basic hospital services; the difficulties involved in accessing more specialised services in regional and metropolitan centres including travel, accommodation; and financial, family and employment related impacts.


The cost of providing health services also increases with remoteness, while the availability of existing infrastructure and workforce become more limited. In addition to changes in the geography, population demographics change with increasing remoteness.

On the positive side, Australians living in rural areas generally have higher levels of social cohesiveness – for example, higher rates of participation in volunteer work and feelings of safety in their community.

Medical research has the potential to help change the future health of rural and remote Australians because it is evolving at a dizzying rate. For example, researchers are producing genome wide data sets on ever-expanding study populations. Broad access to this data, stored samples, and electronic medical records are accelerating our understanding of the role of genes, the environment, and human behaviour in health and disease. Translational research is converting new scientific knowledge into improved diagnostics, targets for drug development, and new insights about how to prevent and treat disease. The challenge is to ensure that innovation in research and medicine is equalled by innovative policies that increase access to discovery for all Australians.

"AUSTRALIANS LIVING IN RURAL AREAS GENERALLY HAVE HIGHER LEVELS OF SOCIAL COHESIVENESS."

[1] National Rural Health Alliance http://ruralhealth.org.au/sites/default/files/publications/nrha-factsheet-arthritis.pdf. Accessed 10 June
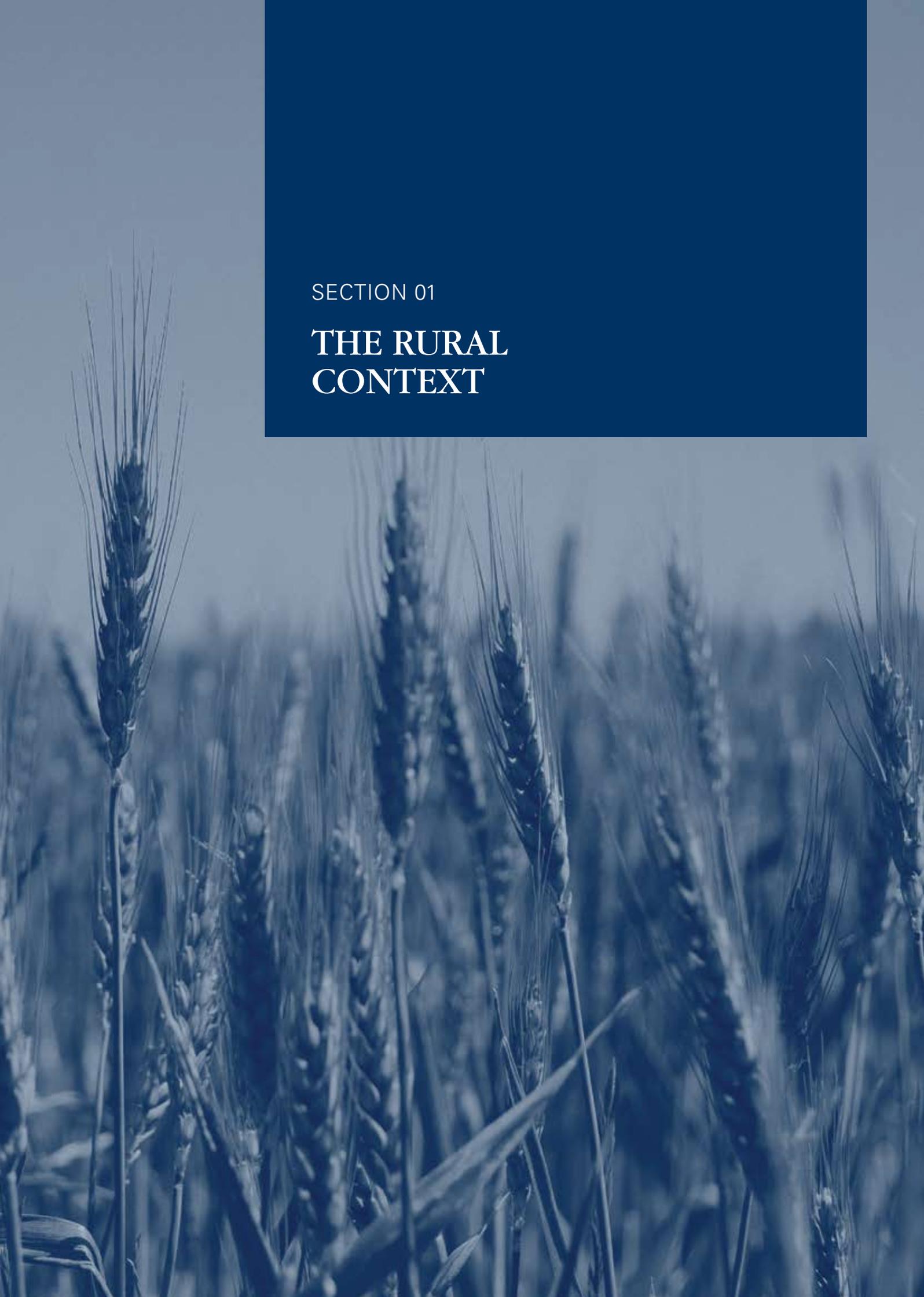
SECTION 01

THE RURAL CONTEXT

SECTION 01

THE RURAL CONTEXT

Classifying 'remoteness'[2]

For the purpose of this paper, the term 'rural and remote' is used to encompass all areas outside Australia's major cities.

Remoteness areas:

Refers to categories within the Australian Standard Geographical Classification, which is based on an index that measures the remoteness of a point according to the physical road distance to the nearest urban centre.

Examples of localities in different remoteness categories are:

Major cities, covers 0.3% of Australia, which include most capital cities, as well as major urban areas such as Newcastle, Geelong and the Gold Coast.

Inner regional, covers 3.2% of Australia, includes cities such as Hobart, Launceston, Mackay and Tamworth.

Outer regional, covers 10.8% of Australia, includes cities and towns such as Darwin, Whyalla, Cairns and Gunnedah.

Remote, covers 13.2% of Australia, includes cities and towns such as Alice Springs, Mount Isa and Esperance.

Very remote, covers 72.5% of Australia, includes towns such as Tennant Creek, Longreach and Coober Pedy.

Population

The estimated resident population (ERP) of Australia in June 2014 was 23,490,700 people[3]. This reflects an increase of 364,900 people since 30 June 2013 and 68,400 people since March 2014. As at June 2013, almost 71% of the population resided in Australia's major cities. Of the total population, a little over 27% resided in regional areas and just 2.3% lived in remote or very remote Australia[4].

Indigenous Australians

Aboriginal and Torres Strait Islander people are respectfully referred to as Indigenous Australians in this paper. Indigenous Australians comprise approximately 3% of the total Australian population, but they make up a much higher proportion of the population in remote and very remote areas, comprising almost half of the very remote population.

Determinants of health

Australians in regional and remote areas, including Indigenous people, tend to have shorter lives and higher rates of disease and injury than people in major cities[5]. Poorer health outcomes in these areas may reflect a range of social and other factors that are detrimental to health.

The social determinants of health are social and economic factors that can have a positive or negative effect on health of individuals and communities by affecting the environment and conditions in which they live. Australians living in rural and remote areas, including Indigenous Australians and Australians from low socioeconomic groups are more likely to have poor health than those living in urban areas. People living in more remote areas are often disadvantaged with regard to educational and employment opportunities, income, and access to goods and services.

Around 39 per cent of those living in remote areas have low socioeconomic status compared to 24 per cent of those living in regional areas and 17 per cent of those in major cities. Lower socioeconomic status also increases barriers to accessing health promotion services. Overall Australians living in regional, rural and remote areas are subject to a difference in the social determinants of health to those living in major cities. These include:

- lower levels of income, employment and education
- higher occupational risks, particularly associated with farming and mining
- geography and the need for more long distance travel
- access to fresh foods
- access to health services.

Household income tends to be lower in regional and remote areas than in capital cities. Research indicates that there is a socioeconomic gradient of health, with people of higher socio-economic status having proportionately better health, while poverty, inadequate housing and lower education and employment opportunities are major health risk factors[6].

The relationship between lifestyle risk factors and specific chronic diseases and conditions

Health risk factors are behaviours or characteristics that increase the likelihood of a person developing a disease. People with multiple risk factors have markedly increased risks. Risk factors also influence disease severity and reduce the ability to optimise care for people who already have, for example, cardiovascular disease or diabetes. Healthy lifestyle choices can both reduce disease occurrence and improve disease management[7]. There is increasing emphasis on encouraging healthy behaviours and disease prevention as the major means to reduce chronic disease burden and health care costs.

Regional and remote Australians, particularly men, (excluding very remote areas and discrete Indigenous communities), are more likely than their urban counterparts to engage in risky health behaviours, although their diet is likely to include more vegetables.

These risky behaviours include:

- being a daily smoker (outer regional and remote 22% and inner regional 18% compared with 15% in major cities)
- being overweight or obese (70% and 69% compared with 60%)
- being insufficiently active (60% and 63% compared with 54%)
- drinking alcohol at levels that place them at risk of harm over their lifetime (24% and 21% compared with 19%) or at risk of an alcohol-related injury from a single occasion (52% and 47% compared with 43%)
- having high blood cholesterol (37% and 38% compared with 31%)[8].

Risk factors, by remoteness area, 2011–2012[9]

RISK FACTORS	OUTER REGIONAL AND REMOTE	INNER REGIONAL AND REMOTE	MAJOR CITIES
Daily smoker	22%	18%	15%
Overweight or obese	70%	69%	60%
Insufficiently active	60%	63%	54%
Risky alcohol drinking (lifetime)	24%	21%	19%
High blood cholesterol	37%	38%	31%

Life expectancy

Australians have one of the highest life expectancies in the world; we can expect to live about 25 years longer, on average, than a century ago. In Australia, life expectancy at birth is 79.7 years for men and 84.2 years for women[10].

Life expectancy is 2.5 years lower for males and 1.3 years lower for females for outer regional, remote and very remote areas compared with major cities and inner regional areas[11].

Indigenous Australians

Indigenous Australians compared to other Australians have poorer health outcomes overall. Over the period 2010 to 2012, Indigenous life expectancy at birth was 69.1 years for males and 73.7 years for females. This was lower than for non-Indigenous Australians by 10.6 years for males and 9.5 years for females.

Leading underlying causes of death

There were 147,678 deaths in Australia in 2013[12].

- Cardiovascular disease remained the leading cause of death in Australia in 2013, accounting for almost 20,000 deaths in all areas, from major cities to very remote areas.

- Dementia and Cerebrovascular diseases ranked higher among diseases causing death in major cities and inner regional and outer regional areas compared with the more remote areas.
- There were 11,000 deaths from Dementia (including Alzheimer's) in 2013, an increase of more than five per cent in the past year, and more than 30 per cent in the past five years[13]. Twice as many women as men died from dementia[14].
- Diabetes ranked higher as a cause of death among people living in remote and very remote areas compared with regional and major city areas[15].
- The leading causes of death for Indigenous Australians were cardiovascular diseases, cancer, injury, diabetes and respiratory diseases.
- Cancer deaths also outnumbered deaths from circulatory diseases for the first time in 2013: more than 8,000 Australians died from lung cancer in 2013, a 13 per cent increase since 2004. Colon cancer, blood cancers, prostate, breast, pancreatic and skin cancers were all among Australia's 20 leading causes of death.
- There were 4,995 male deaths from lung cancer, making this the second leading cause of death for men.
- Lung cancer caused 3,222 deaths among females making it the fifth leading cause of death.
- Prostate cancer was the underlying cause of 3,112 male deaths, while breast cancer caused 2,862 female deaths, with both ranked as the sixth leading cause of death respectively.

Indigenous Australians

- Cancer was the underlying cause of one in five deaths (541 or 20.5%) of Indigenous people, with a rate ratio of 1:3 deaths of Indigenous Australians for every death of a non-Indigenous person.
- Trachea, bronchus and lung cancers were the fourth leading cause of death of Indigenous Australians in 2013 and occurred at a rate of 1.8 times than the rate for non-Indigenous Australians.
- Diabetes was the second leading underlying cause of death of Aboriginal and Torres Strait Islander Australians accounting 202 deaths or 7.6% of all deaths of Indigenous Australians. The age standardised death rate[16] for diabetes was six times higher for Indigenous Australians compared to non-Indigenous Australians.

Overall, death rates rise with increasing remoteness. In 2012, the death rate in very remote areas was 8.4 per 1,000 population compared with 5.5 in major cities; the age-standardised rate was highest in very remote areas (8.4 per 1,000 population), followed by remote (6.7), outer regional (6.4), inner regional (6.1) and major cities (5.5). Five-year relative survival decreased with increasing remoteness. It was highest for people living in major cities of Australia (67%) and lowest for people living in remote and very remote areas (63%)[17].

[2]AIHW 2015 http://www.aihw.gov.au/rural-health-remoteness-classifications/
[3]ABS 2014
[4]ABS 2015.
[5]National Mental Health Commission 2014
[6]Michael Marmot et al. 1997.
[7]AIHW Cardiovascular, diabetes and chronic kidney disease series no. 4. 2015
[8]ABS. Australian Health Survey (AHS), 2012
[9]Ibid
[10]AIHW Australia's Health 2014
[11]Ibid
[12]ABS. Causes of Death, Australia 2015
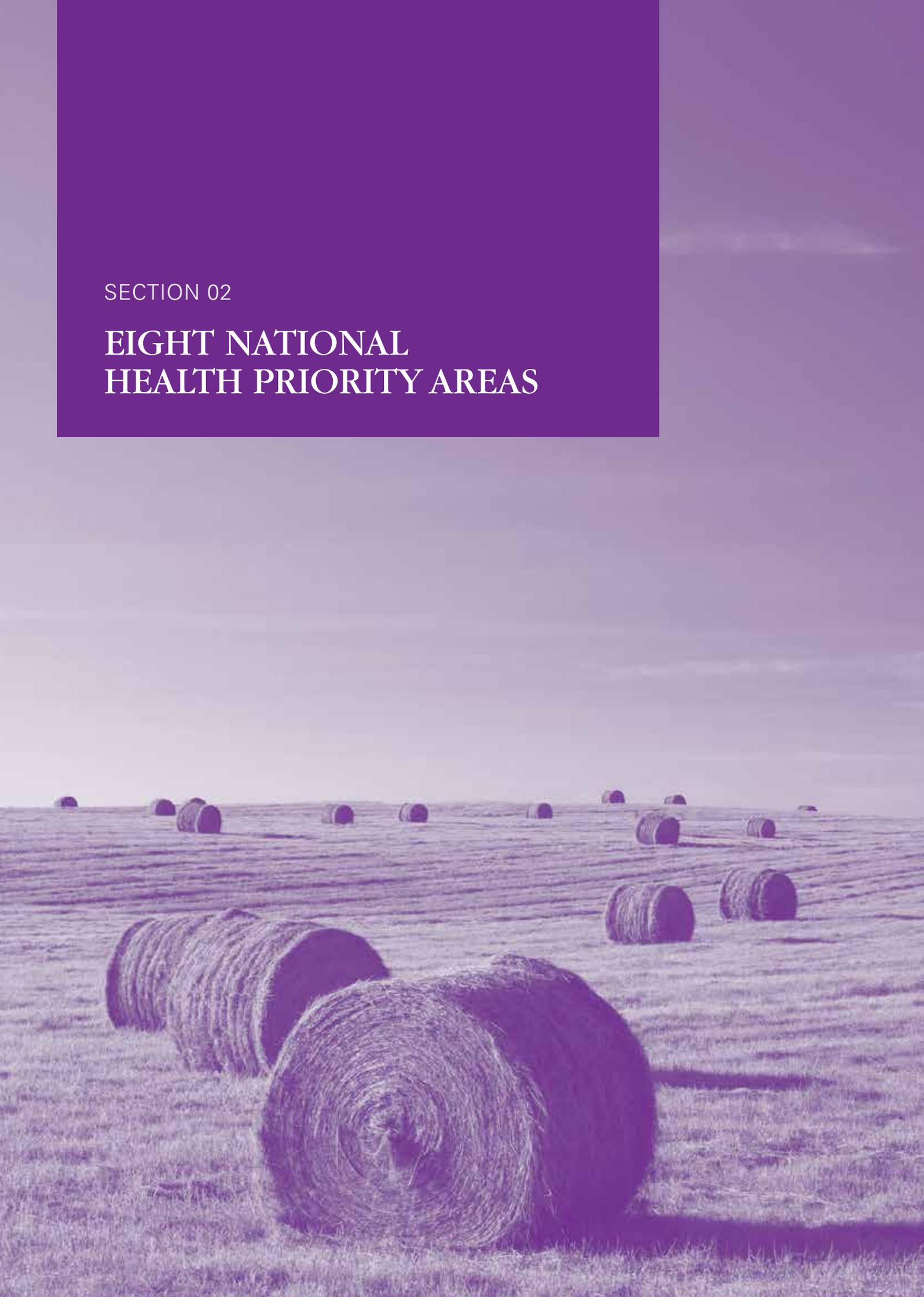[13]Ibid
[14]Ibid
[15]AIHW Australia's Health 2014
[16]Age standardisation is a way of allowing comparisons between two or more populations with different age structures, in order to remove age as a factor when examining relationships between variables. ABS 2015
[17]AIHW Australia's Health 2014

EIGHT NATIONAL HEALTH PRIORITY AREAS

Asthma[18]

1 in 10 children and adults (2.3 million people) suffer from asthma. This is equivalent to more than 2 million Australians.

Deaths from asthma are higher in:

• people residing in remote areas of Australia compared to major cities

• Indigenous Australians compared to non-Indigenous Australians

• people residing in areas of greatest socioeconomic disadvantage.

In 2011–12, asthma interfered with daily living of a sizable proportion (34%) of people with the condition.

$655 million was spent on asthma in 2008–09. That's 0.9% of all direct health expenditure on diseases.

Asthma is a chronic lung disease affecting people of all ages. It can be controlled, but not cured. The prevalence of asthma is significantly higher in people living in inner regional areas compared with those living in major cities or outer regional and remote areas. Women aged 75 years and over are almost three times more likely to die from asthma compared to their male counterparts.

Asthma death rates in Australia are high compared with many other countries. Many deaths due to asthma are potentially preventable and can usually be managed through effective treatment[19].

Arthritis and Musculoskeletal Disease

Arthritis and Musculoskeletal Disease are conditions in which there is inflammation of the joints that can cause pain, stiffness, disability and deformity. It also includes other joint problems and disorders of the bones, muscles and their attachments. The symptoms often have a significant impact on everyday life.

Arthritis[20]

Arthritis, often referred to as a single disease, is an umbrella term for more than 100 medical conditions that affect the musculoskeletal system, specifically joints where two or more bones meet. It is possible to have more than one type of arthritis.

In 2011–12, 15% of Australians – around 3.3 million people had arthritis. More than half of people with arthritis had osteoarthritis, 13.6% had rheumatoid arthritis, and 37.3% had an unspecified type of arthritis.

Arthritis is the second leading cause of disability and the most common cause of chronic pain in Australia; it is the most prevalent long-term health condition[21].

$5.7 billion was spent on Arthritis and other musculoskeletal conditions in 2008–09. Of this, $1,637 million was spent on osteoarthritis, $1,177 million on back problems, $355 million on rheumatoid arthritis and $305 million on osteoporosis[22].

Other lifestyle-related risk factors for developing arthritis are also more common among rural residents including being overweight and/or physically inactive, having joint injuries and, for rheumatoid arthritis, smoking. It is likely to increase at a faster rate in rural and remote areas where the ageing of the population is more pronounced than in major cities.

Osteoarthritis[23]

1 in 13 Australians (approximately 1.8 million) had osteoarthritis in 2011–12.

The prevalence of osteoarthritis is the same in major cities, inner and outer regional and remote areas although farming is particularly associated with a higher risk of developing osteoarthritis.

Aboriginal and Torres Strait Islander people are 1.1 times more likely than non-Indigenous people to report having osteoarthritis.

$1.6 billion was spent on osteoarthritis in 2008–09. That's 29% of the $5.7 billion spent on arthritis and other musculoskeletal conditions.

Osteoarthritis (OA) is a degenerative condition that mostly affects the hands, spine and joints such as hips, knees and ankles, and usually gets worse over time. It is the predominant condition leading to knee and hip replacement surgery in Australia.

"1 IN 13 AUSTRALIANS (APPROXIMATELY 1.8 MILLION) HAD OSTEOARTHRITIS IN 2011–12."

[18]AIHW Asthma Series 2011.
[19]AIHW 2014. Mortality from asthma and COPD in Australia.
[20]Ibid
[21]Bates et al 2014
[22]AIHW 2014 http://www.aihw.gov.au/arthritis-and-musculoskeletal-conditions/
[23]AIHW Australia's Health 2014

Overall, OA is poorly managed in Australia. Two thirds of people with OA report that they are faring badly with their condition and 57% do not receive appropriate care according to current guidelines. Most General Practitioners report dissatisfaction with the care they are able to provide to people with OA due to the limited effectiveness of current OA treatment options. Management is compromised by the fact that little is known about the causes of OA and there is no confirmed cure or intervention to slow its progression.

"OSTEOARTHRITIS IS THE PREDOMINANT CONDITION LEADING TO KNEE AND HIP REPLACEMENT SURGERY IN AUSTRALIA."

Rheumatoid arthritis[24]

2% of Australians (approximately 445,000) reported having rheumatoid arthritis in 2011–12.

5 out of 8 people with rheumatoid arthritis are women (2.4% of women compared to 1.5% of men).

$355 million was attributed to rheumatoid arthritis in 2008–09 - 6.0% of the total direct expenditure allocated to arthritis and other musculoskeletal diseases.

Rheumatoid arthritis is an autoimmune disease where the body's immune system attacks its own tissues. Rheumatoid arthritis can affect anyone at any age, and may cause significant pain and disability. Among more than 100 types of arthritis, rheumatoid arthritis is the most severe, and the second most common after osteoarthritis.

There has been little change in the prevalence over the past 10 years.

It is difficult to evaluate the full impact of this condition on affected individuals due to the limited national statistics available.

Osteoporosis and Osteopenia[25]

Nearly 1 in 10 Australians (Approximately 652,500) aged 50 and over (9.4%) have osteoporosis or osteopenia.

5 times more women compared with men aged 50 or over have osteoporosis or osteopenia — 15.1% of women and 3.3% of men.

$306 million of the total direct expenditure allocated to arthritis and other musculoskeletal diseases was attributed to osteoporosis in 2008–09.

Osteoporosis is a condition of the musculoskeletal system in which a person's bones become fragile and brittle, leading to an increased risk of fractures. Fractures can lead to chronic pain, disability and loss of independence.

Osteopenia is a condition when bone mineral density is lower than normal but not low enough to be classified as osteoporosis. Older people and post-menopausal women are at greater risk of having these conditions.

Risk factors associated with the development of osteoporosis include increasing age, female sex, and family history of the condition, low vitamin D levels, low intake of calcium, low body weight, smoking, excess alcohol consumption, physical inactivity, long-term corticosteroid use and a reduced oestrogen level.

Back pain and problems

1 in 7 Australians (14%) reported back problems in 2011–12 - that's 3 million people.

In 2011–12 the prevalence of back problems was higher in inner regional (15.7%) and outer regional and remote (15.2%) areas compared to major cities (12.3%).

In 2008–09, $1.2 billion, or 1.8% of selected disease allocated health-care expenditure, was attributed to back problems.

Back problems are a range of conditions related to the bones, joints, connective tissue, muscles and nerves of the back. These conditions are a significant cause of disability and lost productivity. The chronic and widespread nature of back problems often leads to poorer quality of life, psychological distress, bodily pain and disability. For example overall, people aged 18 and over with back problems are 2.6 times as likely to report very high levels of psychological distress (6.9%) than those without the condition (2.7%)[26].

Cancer[27]

Cancer is a major cause of illness in Australia and has a significant impact on individuals, families and the health-care system.

There were 42,844 deaths due to cancer in 2010. Of these deaths, 24,328 were male and 18,516 female.

The 5 most common causes of death from cancer in 2010 were lung (8,099), bowel (3,982), prostate (3,235), breast (2,864) and pancreas (2,434).

In 2004–08, cancer was significantly higher in inner regional areas (504 per 100,000 population) than in major cities (480), outer regional (495) and remote and very remote (474) areas.

Despite a decline in cancer mortality and an increase in survival over time, 1 in 2 Australians will develop cancer and 1 in 5 will die from it before the age of 85.

The most commonly reported cancers for 2012 were:

- prostate cancer
- bowel cancer
- breast cancer
- melanoma of the skin
- lung cancer.

Grouped together, these five cancers are estimated to account for more than 60% of all cancers in 2012[28].

Estimated 10 most commonly diagnosed cancers, Australia, 2012[29]

Cancer	Number of Cases
Prostate	18,560
Bowel	15,840
Breast	14,680
Melanoma of the Skin	12,510
Lung	11,280
Non-Hodgkin lymphomas	4,680
Kidney	3,000
Unknown primary site	2,850
Pancreas	2,740
Thyroid	2,420

Number of Cases

Cardiovascular Health[30]

In 2011–12, an estimated 585,900 Australians had cardiovascular disease (CVD), with the condition being more common in men than women and among those aged 70 and over.

1 in 4 four people living in regional and rural areas are suffering from cardiovascular disease compared with 1 in 5 in five in metropolitan areas.

CVD has a 40% higher death rate in remote areas than in major cities.

Rates of heart attack events in Indigenous adults aged 25 and over were 2.6 times higher than in other Australians in 2011.
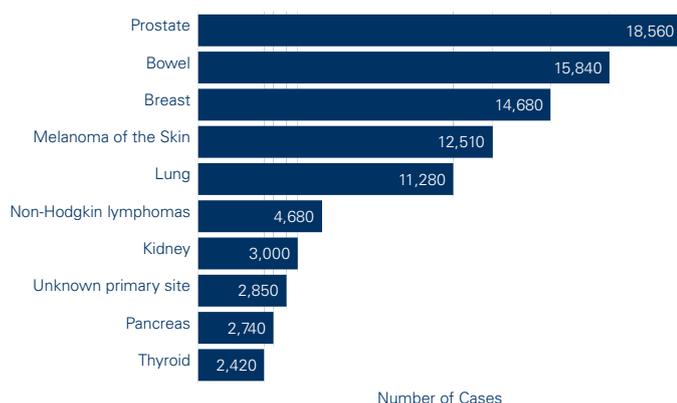
If Australians living in rural and remote areas had the same death rates as urban Australians, there would have been 3,632 fewer deaths due to cardiovascular disease (16.5 per cent fewer) in rural areas in 2009–2011[31].

[24]AIHW 2013
[25]AIHW 2015. Musculoskeletal fact sheet: osteoporosis. Arthritis series no 23. Cat. no. PHE 187. Canberra: AIHW.
[26]ABS 2012
[27]AIHW 2015
[28]AIHW Australian Cancer Database 2009
[29]Ibid
[30]AIHW Australia's Health 2014
[31]Ibid

EIGHT NATIONAL HEALTH PRIORITY AREAS

Referred to under the broader term of 'heart disease' (or 'cardiovascular disease') this group of conditions encompass a range of circulatory conditions including ischaemic heart diseases, cerebrovascular diseases, oedema, heart failure, and diseases of the arteries, arterioles and capillaries. Heart disease remains one of the leading causes of death worldwide, and therefore an emphasis has been placed around preventing its onset through modifying risk factors such as healthy eating, exercise and avoidance of smoking.

Cardiovascular disease, primarily heart attack, stroke and vascular disease, is a major cause of premature death and disability and is the reason for thousands of avoidable hospital admissions in Australia each year. Moreover it is the most expensive disease in Australia, costing about 12% of total healthcare costs, or $7.6 billion a year[32].

It is largely preventable, as many of its risk factors are modifiable, including: tobacco smoking, high blood pressure, high blood cholesterol, physical inactivity, poor nutrition and obesity. Australians living in rural and remote Australia experience more CVD risk factors, higher rates of CVD-related hospitalisation and are more likely to die of CVD than those in metropolitan areas. The further a person lives from a metropolitan centre, the greater their risk of hospitalisation and death from cardiovascular disease[33].

There is no reliable national and jurisdictional data on the number of new cases of CVD each year.

Dementia[34]

On average, 27 Australians die from dementia every day.

In 2014, it is estimated that there were 332,000 people with dementia, of whom 62% are women.

Among Australians aged 65 and over, almost 1 in 10 (9%), have dementia and among those aged 85 and over, 3 in 10 (30%) have dementia.

The number of Australians with dementia is projected to reach almost 400,000 by 2020, and around 900,000 by 2050.

There is no data available on whether or not the prevalence of dementia varies geographically across Australia.

Dementia, most commonly associated with older age, is not a single specific disease. It is an umbrella term describing a syndrome associated with more than 100 different diseases that are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. The most common types of dementia are Alzheimer disease, vascular dementia, dementia with Lewy bodies, and fronto-temporal dementia (which include Pick disease)[34].

Emerging evidence suggests that a number of lifestyle and health factors may influence the risk of developing dementia. Relatively few of these factors however have yet to be definitively established, with most considered either probable determinants or inconclusive.

Studies also indicate that a number of other factors, many of which are modifiable, may increase the risk of dementia including:

- diabetes
- mid-life hypertension
- excessive alcohol consumption
- smoking
- head injury
- depression
- obesity.

> "IN 2011-12, ALMOST 1 MILLION PEOPLE AGED 2 YEARS AND OVER HAD SOME TYPE OF DIABETES[35]."

Diabetes[38]

In 2011–12, almost 1 million people aged 2 years and over had some type of diabetes[35]:

- around 119,000 people (or 11.9% of those with diabetes) had Type 1 diabetes, and
- around 848,000 people (or 84.9% of those with diabetes) had Type 2 diabetes.

Diabetes in pregnancy is common, affecting around about 1 in 20 pregnancies.

Diabetes was the sixth leading cause of death in Australia in 2011, contributing to 10% of all deaths. In around 4,200 deaths, diabetes was the underlying cause and in a further 10,900 it was an associated cause of death[36].

3 in 5 of people with diabetes also have cardiovascular disease[37].

Diabetes is a chronic condition marked by high levels of glucose in the blood. It is caused either by the inability to produce insulin (a hormone produced by the pancreas to control blood glucose levels), by the body not being able to use insulin effectively, or both.

The main types of diabetes are[38]:

- **Type 1 diabetes** – an autoimmune disease that usually has an onset in childhood or early adulthood but can be diagnosed at any age
- **Type 2 diabetes** – largely preventable, usually associated with lifestyle factors and with a later onset
- **Gestational diabetes** – when higher than normal blood glucose is diagnosed in pregnancy.

If left undiagnosed or poorly managed, diabetes can lead to cardiovascular disease, stroke, kidney failure, limb amputations or blindness.

Among people with diabetes, CVD has an earlier onset, and is more resistant to treatment and therapies, compared to those without diabetes. Individuals have a higher rate of mortality as a result of their

first cardiovascular event and poorer outcomes in the months and years following such an event[39]. It significantly affects the health of many Australians and can result in a range of complications, including serious damage to the nerves and blood vessels.

Currently, there is no national data collection on new cases of diagnosed Type 2 diabetes each year. Symptoms are often absent in the early stages of diabetes, so people can go undiagnosed for a long time. In addition, there can be problems with misdiagnosis and misreporting of diabetes type. There is a lack of good information on diabetes in Indigenous people and Australians from different ethnic backgrounds[40]. In 2004–05, after adjusting for differences in age structure, approximately 12% of Indigenous Australians reported diabetes/high sugar levels compared with 4% of non-Indigenous Australians[41].

Mental Health[42]

An estimated 20% of adults, including about 960,000 people living in regional, rural and remote areas, have experienced a mental disorder in the previous 12 months.

About 45% of Australian adults, or 7.3 million people, will experience a mental disorder sometime in their lifetime. This includes more than 2 million regional, rural and remote Australians.

The rate of suicide is 66% higher in the country than in major cities.

Mental illness is a clinically diagnosable disorder that significantly interferes with an individual's cognitive, emotional or social abilities. 'Mental illness' and 'mental disorder' are both used to describe a wide spectrum of mental health and behavioural disorders, which can vary in both severity and duration. The most prevalent mental illnesses are depression, anxiety and substance use disorders. Less prevalent, and often more severe, illnesses include schizophrenia, schizoaffective disorder and bipolar disorder. Depression, anxiety and sleep disturbance were the three mental health-related problems most frequently managed by GPs in 2012–13; these three problems accounted for 60% of all mental health-related problems managed[43].

Rates of mental illness do not vary much across the country. People in regional, rural and remote Australia face unique circumstances that shape mental health and wellbeing. For example, Medicare expenditure per person is much lower in rural and remote areas. As remoteness increases, communities are increasingly affected by environmental extremes (such as flood, fire or drought) and economic variability. Tragically, suicide rates are also higher in rural and remote areas than they are in major cities:

- the rate of suicide among men aged 15-29 who live outside major cities is twice as high

- farmers are twice as likely to die by suicide as the general employed public

- the rate of suicide among men aged 15-29 who live outside major cities is twice as high as the general population

- the rate of suicide among young Aboriginal and Torres Strait Islander people (aged 15-24) is five times higher than that for non-Indigenous people[44].

Overweight and Obesity[45]

63% of adults are now overweight or obese, with 28% classified as obese.

People living in inner regional, outer regional and remote areas of Australia are more likely to be overweight or obese compared with people living in major cities.

Australia's rate of obesity (28% of the population aged 15 and over) is the fourth highest among 34 OECD countries, behind the United States (37%), Mexico (30%) and Hungary (29%).

It is estimated that by 2025, the number of Australians considered overweight or obese will increase to more than 70%, with approximately one third of the adult Australian population classified as obese.

Over half (55.7%) of Australians are trying to lose weight. Only 30% of Australians who are obese (based on their BMI) described their weight status as obese. Furthermore, only one in three obese people are concerned about their weight[46].

Being overweight or obese increases a person's risk of developing cardiovascular disease, high blood pressure and/or Type 2 diabetes. Being Australian born, having English as the main language spoken at home and being employed also significantly increases the likelihood of being overweight/obese[47].

"63% OF ADULTS ARE NOW OVERWEIGHT OR OBESE, WITH 28% CLASSIFIED AS OBESE."

[32]National Heart Foundation 2014
[33]AIHW 2011
[34]AIHW Dementia in Australia 2012.
[35]Excluding diabetes in pregnancy AIHW 2015. http://www.aihw.gov.au/diabetes-in-pregnancy/
[36]AIHW Australia's Health 2014
[37]Ibid
[38]AIHW 2015
[39]Buse et al 2007
[40]AIHW 2015
[41]AIHW 2013
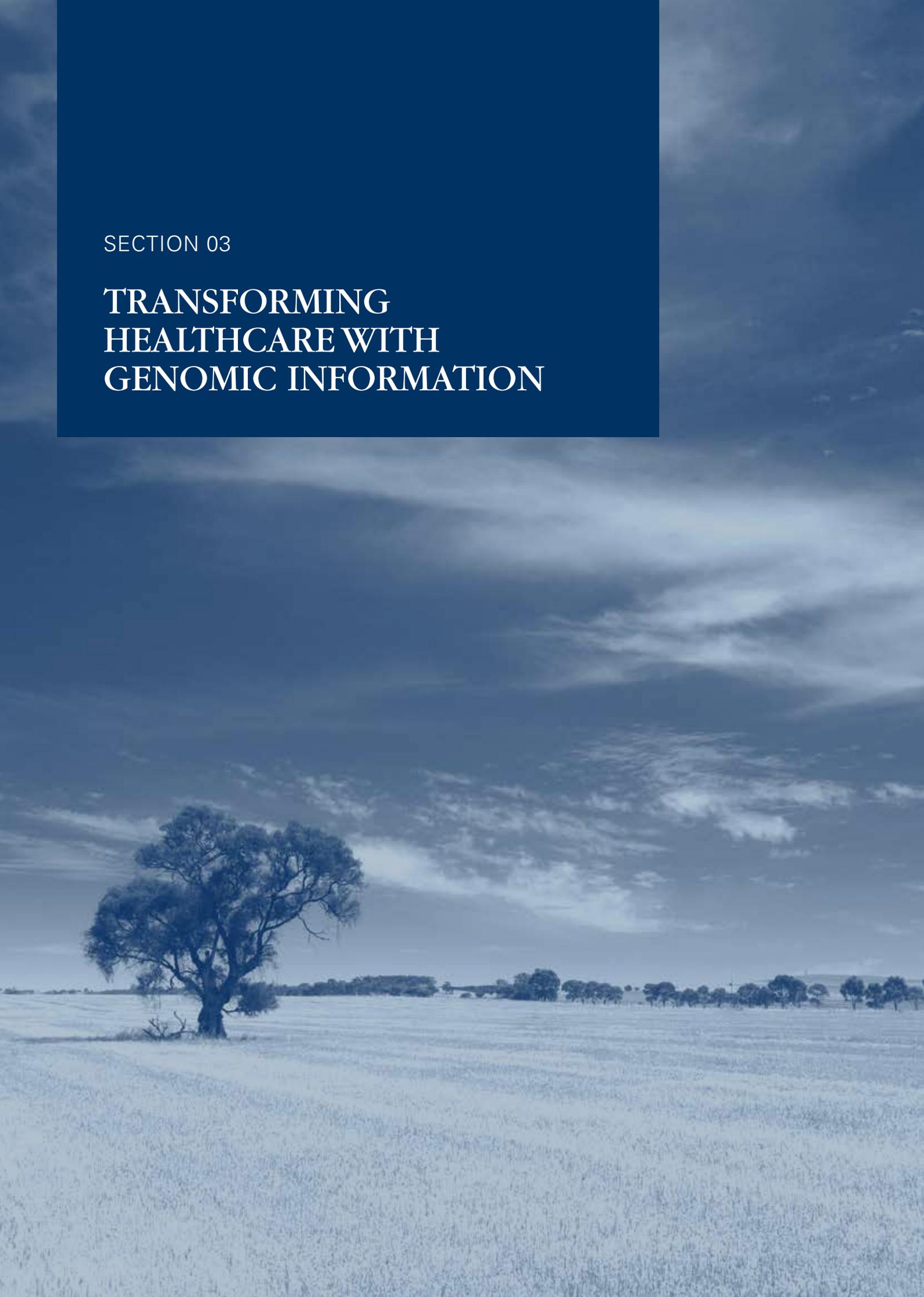[42]National Mental Health Commission 2014
[43]Ibid
[44]Ibid
[45]AIHW 2015
[46]AIHW 2014
[47]Ibid

TRANSFORMING HEALTHCARE WITH GENOMIC INFORMATION

Genomic medicine uses the information encoded in our DNA to guide diagnosis and treatment. Genetic information underpins every aspect of our development – from embryo into adulthood and old age – and almost every human disease.

The Garvan Institute of Medical Research anticipates that genomic medicine will radically impact and improve disease diagnosis, characterise cancer risk, and guide treatment. This will be potentially important in helping to address the health disadvantage experienced by many Australians. For example, future improvements in risk assessment of an individual's likelihood of developing a disease may change medical–decision making in ways that improve patient outcomes. This includes the potential to adopt healthier life styles known to minimise or prevent the risk of developing diseases highlighted in this report much sooner than before.

> "GLOBALLY THE MOST EXTRAORDINARY EXPLORATION OF HUMAN GENETIC INFORMATION IN HISTORY IS UNDERWAY."

Although our understanding of the human genome is far from complete, our current knowledge is already powerful in the clinic. Timely genetic diagnoses and better characterisation of disease provide critical information to doctors and families. Similarly, information that predicts an individual's risk of developing a disease, or their response to treatment, can optimise medical practice and reduce costs.

Globally the most extraordinary exploration of human genetic information in history is underway. The cost of genome sequencing has fallen exponentially to the point where population-scale genome sequencing is accessible to a broad community of medical researchers and clinicians. It is rapidly becoming more cost effective to sequence a whole genome rather than selected sections, one at a time.

This remarkable technology changes the way we see and treat diseases including the conditions described in this report. It makes it possible to pinpoint the precise molecular basis of a disorder – and therefore provide treatment with the right drug for the right patient at the right time. We are all unique and, in the future, how we are treated will be unique too.

Pioneering research studies and proof-of-concept trials in applying genome information to inform healthcare have been successful both at the Garvan and worldwide. However, the translation of genomic technology into healthcare poses many challenges. The practice of genomic medicine requires management of enormous volumes of data that need to be processed, interpreted and stored. Moreover, the accurate interpretation of an individual's genome, particularly in diagnosis of rare diseases, depends on comparison with thousands or even millions of other genomes.

These highly sophisticated analyses demand an unprecedented dependency on computational expertise and high performance computing that are unfamiliar territory for the medical system. The Garvan Institute is a leader at the translational interface, helping to develop the infrastructure and processes required to drive the integration of genomic medicine into existing medical practice.

The future of genomic medicine

Genomics is the fastest-growing area of medical research and diagnosis, and health is the largest and most important sector of the economy. The genomic revolution provides a once-in-a-generation chance for Australia to leverage its investment in world-leading medical research. A powerful combination of e-health records and genomics will create new industries in health information technologies, which can be exported to the world. Breakthroughs in our understanding of the genome, and its interaction with the environment, will realise its value in improving our health and wellbeing.

Genomic information is already delivering health benefits to individuals and their families. The Garvan is collaborating nationally and internationally to engage and educate clinicians, the health workforce and communities. However, to successfully implement genomic medicine in routine healthcare, a well-resourced community of expert health professionals is necessary. The pathway from DNA sequencing to personalised medicine will rely on enabling this community with tools that allow them access to up-to-date information to make diagnoses and guide treatment.
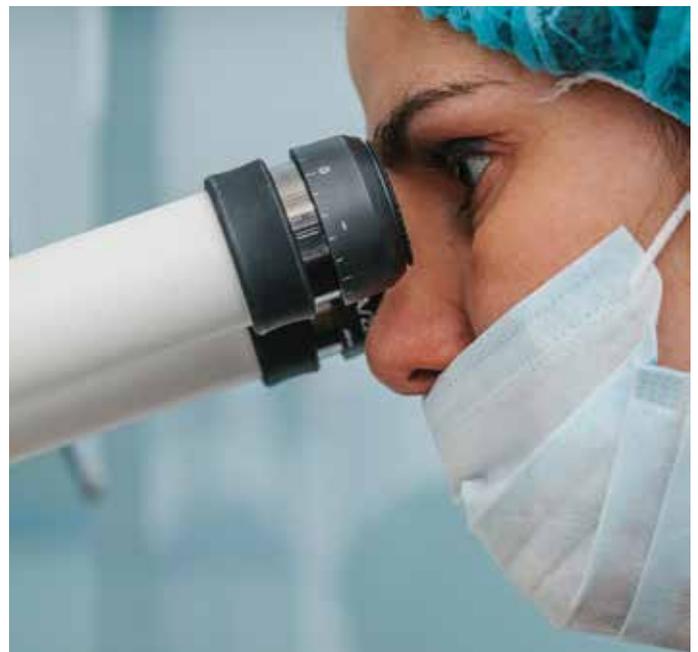
Fast facts

- Your genome is the complete set of genetic information you inherit from your parents, contained within DNA molecules that are located in every cell of your body.
- Genomic medicine has the potential to transform healthcare because all diseases have a genetic component – from inherited disorders to complex diseases such as cancer and diabetes.
- The cost of sequencing a human genome has dropped from more than $1 billion USD to less than $1,000 USD in just over a decade.

TRANSFORMING HEALTHCARE WITH GENOMIC INFORMATION

One of the key challenges of genomic medicine lies in defining the relationship between the genome and the characteristics of the individual, collectively known as the phenome. To address this challenge, the Garvan Institute has established a Phenomics team, which develops tools to capture an individual's observable traits (eg. physical, chemical or behavioural) in a consistent and structured manner.

Connecting information from genomes and phenomes will provide a means to match individuals who have the same genetic conditions. In the future, the Garvan anticipates population scale integration of genomic and phenomic data will reveal an unprecedented understanding of relationships between the human genome and disease.

Until very recently, genetic testing has been restricted to very specific sites in the genome. The advent of whole genome sequencing technology is expected to completely overturn the existing paradigm for clinical genetic testing. Rather than trying to predict the correct subset of the genome to sequence, it is possible to take a snapshot of the entire genome in a single test.

With this information, the Garvan can look for mutations in any specified part of the genome or use computer algorithms and databases to identify other sites in the genome that are damaged. Once a whole genome sequence has been captured, it can be interpreted repeatedly at a fraction of the cost for the lifetime of the individual.

Not surprisingly, the application of genome sequencing in research has shown a dramatically increased diagnostic rate for common diseases. Our current clinical collaborations include investigations into neurological and movement disorders, cardiac disease, head and neck cancers, kidney disease, diabetes and intellectual disability.

For the Garvan, The Kinghorn Cancer Centre's dual research and clinical function will provide answers for families, while accelerating the next generation of genomic research in Australia. Its research refines and improves its interpretation of the genome, as well as providing benefit to those families for whom answers are not immediately available.

Harnessing genomic information to provide families with answers

Unravelling rare disease genes

"The new technology is giving people the answers they've been seeking, sometimes for decades." Dr Tony Roscioli

About 30% of the families' disorders were diagnosed by sequencing entire exomes (the 'coded' portion of DNA containing instructions for your body's proteins). 'It's been phenomenally successful' says clinical geneticist Dr Tony Roscioli, a lead researcher for the study and the centre's Team Leader for Rare Disease Genomics. 'The new technology is giving people the answers they've been seeking, sometimes for decades,' Dr Roscioli said, pointing out that no diagnoses had been achievable in these families with previously available technologies.

Quicker answers mean patients can avoid uncomfortable diagnostic procedures and long, drawn-out testing odysseys.

In keeping with international findings, a large proportion of the disease-causing mutations diagnosed in the study were de novo (new), not inherited. Learning they did not contribute to their child's genetic disorder can lift parents' burden of fear and guilt. A specific genetic diagnosis can fundamentally improve family dynamics.

Reducing medical costs
Diagnostic shortcuts also avoid some of the medical costs of diagnostic odysseys — and may even lead to reduced treatment costs. When the study yielded a specific diagnosis for one young girl with a rare immunological disorder, doctors were able to discontinue an extremely costly drug therapy and refocus her treatment more effectively.

"The Sydney Genomic Collaborative Program is the most exciting new venture I've seen in my time as Minister for Medical Research. Sequencing of large cohorts of patients has the potential to unleash amazing improvement in health and efficiencies in health spending."

Jillian Skinner
NSW Minister for Health and Minister for Medical Research

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