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# Chronic Disease and the Australian Health Care System

## Introduction

2.1 This chapter provides background information on what chronic disease means in the Australian context and what chronic disease prevention and management entails in the current primary healthcare system in Australia.

2.2 Chronic disease prevention and management in primary health care in Australia is an evolving and transitionary field of medicine. The burden of chronic disease in Australia is increasing, as it is internationally, and the Australian system of General Practitioner-led primary health care is coming under challenge as the best means to prevent and treat chronic disease.

2.3 The Committee received consistent submissions and evidence that the system of chronic disease management needs to change, and that the breadth of care and coordination needs to be better managed and take multiple life stages and contributory factors into account, when formulating policy, as well as supporting the primary care system.

## What is Chronic Disease?

2.4 Chronic Disease is described by the Australian Institute of Health and Welfare (AIHW) as 'Australia's biggest health challenge'.[1] Rapid medical advances throughout the last century have successfully limited infant mortality and reduced mortality due to infectious diseases, significantly increasing life expectancy. Lifestyles have also changed dramatically, with

1 Australian Institute of Health and Welfare (AIHW), *Australia's Health 2014*, 2014, p. 94.

automated transport, a mostly sedentary workforce, and dietary changes. These factors combined have shifted the burden of disease heavily towards chronic conditions.

2.5 The Australian Government has accepted definitions of chronic disease, as expressed by the AIHW:

> …a diverse group of diseases, such as heart disease, cancer and arthritis, which tend to be long-lasting and persistent in their symptoms or development. Although these features also apply to some communicable diseases (infectious diseases), the term is usually confined to non-communicable diseases.[2]

2.6 The emphasis on a chronic disease being long-lasting and persistent is an important point of focus when considering prevention and management, as will be discussed later in this chapter. However, the relatively fluid nature of a definition that only requires a disease to be persistent in symptomatology and effect can lead to some inconsistency in identification of a condition as 'chronic'. Chronic conditions can be mild, such as short- or long-sightedness, or can be debilitating and even fatal.

2.7 In its report *Australia's Health 2014* the AIHW identified that chronic disease in Australia is the biggest health challenge facing the nation and that according to 2007-2008 health survey data, over one third of Australia's population report living with at least one chronic disease.[3] Additionally, many people have more than one chronic disease.

2.8 The high incidence of chronic disease within the Australian population is indicative of the multiple factors leading to chronic disease, plus the fluidity of the nature of 'chronic disease' as a concept.

2.9 According to the Rural Doctors Association of Australia, as many as two-thirds of Australian adults have three or more risk factors concurrently, while 10 per cent have five or six risk factors.[4] In a joint submission, the Public Health Association Australia and the Foundation for Alcohol Research & Education stated that 'the majority of chronic disease' can be traced to just four 'modifiable behavioural risk factors': smoking, alcohol use, physical inactivity, and poor nutrition.[5]

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2 AIHW, *Glossary*, http://www.aihw.gov.au/australias-health/2014/glossary/, viewed 15 January 2016.

3 AIHW, *Australia's Health 2014*, 2014, p. 95.

4 Rural Doctors Association of Australia, *Submission 17*, p. 3; different estimates are given by Professor Mark Nelson, *Submission 3*, p. 5.

5 Public Health Association Australia and Foundation for Alcohol Research & Education, *Submission 114*, p. 4.

2.10 Chronic disease is disproportionately distributed throughout the population. Chronic disease is higher among Aboriginal and Torres Strait Islanders than non-Indigenous Australians,[6] with chronic disease reportedly accounting for 70 per cent of the health gap between these two groups.[7] More socioeconomically disadvantaged people also face higher rates of chronic disease,[8] as do older Australians,[9] asylum seekers and refugees, 'certain immigrant groups', and the LGBTI community.[10] Cohealth reported that groups in the lowest 20 per cent of socioeconomic status have a 32 per cent higher burden of chronic disease than those in the top quintile.[11]

2.11 Part of the disproportionate incidence of chronic disease is due to the corresponding incidence of risk factors.[12] For example, people in 'outer regional and remote' areas are more likely to smoke, be overweight, be insufficiently active, drink harmful levels of alcohol, and have high blood cholesterol than those in urban areas.[13] Aboriginal and Torres Strait Islanders also have higher incidence of risk factors, which contributes to the higher rates in rural areas.[14] Socially and economically disadvantaged communities likewise have higher risk factors.[15]

2.12 The federal Department of Health identifies five conditions that account for around 80 per cent of the total burden of chronic disease in Australia:

- Arthritis and Musculoskeletal conditions;
- Asthma and other chronic respiratory conditions;
- Cardiovascular Disease;
- Chronic Kidney disease; and
- Diabetes.[16]

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6 Australian Association of Social Workers, *Submission 46*, p. 5; The Royal Australasian College of Physicians, *Submission 81*, p. 6.

7 Dr Paul Burgess, *Submission 92*, p. 5.

8 Graduate School of Medicine, *Submission 16*, pp 2-3; Australian Association of Social Workers, *Submission 46*, p. 5; Australian Health Promotion Association, *Submission 49*, p. 8; Dr Paul Burgess, *Submission 92*, p. 8; Public Health Association Australia and Foundation for Alcohol Research & Education, *Submission 114*, pp 11-12; Victorian Council of Social Service, *Submission 120*, pp 5-8.

9 Australian Medical Association, *Submission 107*, p. 5.

10 Cohealth, *Submission 88*, p. 8.

11 Cohealth, *Submission 88*, p. 8.

12 Centre for Primary Health Care and Equity, *Submission 6*, pp 1-2.

13 Rural Doctors Association of Australia, *Submission 17*, p. 4; see also National Rural Health Alliance, *Submission 67*, p. 2.

14 National Rural Health Alliance, *Submission 67*, p. 3.

15 WentWest Limited, *Submission 53*, p. 1; Public Health Association Australia and Foundation for Alcohol Research & Education, *Submission 114*, pp 11-12.

16 Department of Health, *Submission 143*, p. 5.

## Arthritis and Musculoskeletal Conditions

2.13 Chronic musculoskeletal conditions include arthritis, osteoarthritis and rheumatoid arthritis, osteoporosis, back and neck pain, and other conditions affecting the bones, muscles and joints.[17]

2.14 These conditions impose a very large burden on the Australian health system. Arthritis and Osteoporosis Victoria states that the national cost exceeded $55 billion in 2012.[18]

2.15 Musculoskeletal conditions affect a large proportion of Australians, with 6.1 million people, or 28 per cent of the population, having at least one condition. Of these, 3.3 million are affected by arthritis, 2.8 million by back problems and disc disorders, and 725 500 by osteoporosis or osteopenia (low bone density). Furthermore, over 64 000 children 14 years of age or younger are estimated to be affected by a musculoskeletal condition.[19]

2.16 These conditions are increasing in prevalence, with conservative estimates forecasting a rise of 43 per cent over the next few decades, driven mostly by osteoarthritis.[20]

2.17 Arthritis and Osteoporosis Victoria states that arthritis and musculoskeletal conditions account for the greatest burden of disability in Australia, and the second greatest burden of disease after cancer when considering mortality and morbidity.[21]

## Asthma and Chronic Respiratory Conditions

2.18 Chronic respiratory conditions include asthma, chronic obstructive pulmonary disease (COPD), allergic rhinitis or hay fever, chronic sinusitis, cystic fibrosis, bronchiectasis, occupational lung diseases and sleep apnoea.[22] According to Lung Foundation Australia (LFA), these diseases are:

> …major contributors to disability, premature mortality and health care utilisation in Australia. Patients with chronic lung disease experience significant disability as a result of their symptoms, particularly breathlessness.[23]

2.19 Asthma is defined by the Department of Health as:

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17 AIHW, *Australia's Health 2014*, 2014, p. 122.

18 Arthritis and Osteoporosis Victoria, *Submission 82*, p. 1.

19 AIHW, *Australia's Health 2014*, 2014, p. 122.

20 Arthritis and Osteoporosis Victoria, *Submission 82*, p. 1.

21 Arthritis and Osteoporosis Victoria, *Submission 82*, p. 1.

22 AIHW, *Australia's Health 2014*, 2014, p. 138.

23 Lung Foundation Australia, *Submission 66*, p. 2.

> …a chronic inflammatory condition of the airways associated with episodes of wheezing, breathlessness and chest tightness.[24]

2.20 The Department of Health defines COPD as:

> …a serious long-term lung disease that mainly affects older people. It is characterised by airflow limitation that is not fully reversible with bronchodilator medications. Some people with COPD also have a frequent cough with sputum due to excessive mucus production in the airways. This condition is often referred to as chronic bronchitis. People with COPD may also have evidence of destruction of lung tissue with consequent enlargement of the air sacs and further impairment of lung function. This condition is known as emphysema. The terms COPD, emphysema and chronic bronchitis are often used interchangeably.[25]

2.21 The Department of Health adds that COPD is commonly associated with comorbidities (concurrent conditions) such as cardiovascular disease and diabetes. COPD is also progressive and largely irreversible.[26]

2.22 Smoking is considered the 'predominant cause of COPD'[27] and a major risk factor for chronic respiratory conditions in general.[28] Environmental and genetic factors are also contributors to chronic respiratory conditions.

2.23 An estimated 6.3 million Australians are affected by one or more chronic respiratory conditions. The most common condition is hay fever, with over 3.7 million sufferers. It is estimated that COPD affects over half a million people.[29] The LFA notes the prevalence of COPD in people over the age of 40 (7.5 per cent).[30] The LFA also states that COPD is the second leading cause of avoidable hospital admissions, and a leading cause of mortality and disease burden after heart disease, stroke, and cancer.[31] Asthma Australia estimates stated that asthma affects nearly 2.4 million people.[32]

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24 Department of Health, *Submission 143*, p. 32.

25 Department of Health, *Submission 143*, p. 32.

26 Department of Health, *Submission 143*, p. 32.

27 Department of Health, *Submission 143*, p. 32.

28 AIHW, *Australia's Health 2014*, 2014, p. 138.

29 AIHW, *Australia's Health 2014*, 2014, p. 138.

30 Lung Foundation Australia, 'COPD: The statistics', http://lungfoundation.com.au/health-professionals/clinical-resources/copd/copd-the-statistics/, viewed 16 February 2016.

31 Lung Foundation Australia, 'COPD: The statistics', <http://lungfoundation.com.au/health-professionals/clinical-resources/copd/copd-the-statistics/>, viewed 16 February 2016.

32 Mr Mark Brooke, Asthma Australia, *Official Committee Hansard,* Brisbane, 17 February 2016, p. 11; see also AIHW, *Australia's Health 2014*, 2014, p. 138.

2.24 Asthma is also one of the leading chronic health conditions for children, with an estimated 393 000 children aged 14 or younger affected. Asthma and COPD are both more common in lower socioeconomic areas.[33]

## Cardiovascular Disease

2.25 Cardiovascular disease is defined by the Department of Health:

> Cardiovascular disease (CVD) generally refers to diseases of the heart and blood vessels and includes such diseases as coronary heart disease (CHD), acute myocardial infarction and stroke. CVD is primarily associated with the consumption of foods high in fats such as those obtained from domestic animals (fatty meats), milk, cheese and food that has been fried in fats (Lawson, 1998). Risk factors for CVD such as smoking, lack of exercise, being overweight, excessive alcohol use and a poor diet, areas where change can greatly reduce the impact of CVD.[34]

2.26 According to the Heart Foundation, cardiovascular disease affects 3.7 million Australians, imposing a direct healthcare cost of $7.7 billion per year.[35] Cardiovascular disease causes nearly a third (30 per cent) of all mortality, and altogether contributes to over half (55 per cent).[36]

2.27 Within the broader category of cardiovascular disease, coronary heart disease (CHD) is the leading cause of mortality for both men and women in Australia. 15 per cent of all mortalities are caused primarily by CHD.[37] Cerebrovascular disease, which includes stroke, is the second leading cause of mortality, accounting for 8 per cent of all mortalities.[38]

2.28 Cardiovascular disease disproportionately affects Aboriginal and Torres Strait Islanders, people with low socio-economic status, and those living in rural and remote regions.[39]

## Chronic Kidney Disease

2.29 Chronic kidney disease (CKD) is defined by the Department of Health as referring to:

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33 AIHW, *Australia's Health 2014*, 2014, p. 138.
34 Department of Health, *Submission 143*, p. 25.
35 Heart Foundation, *Submission 131*, p. 4.
36 Heart Foundation, *Submission 131*, p. 4.
37 AIHW, *Australia's Health 2014*, 2014, p. 18.
38 AIHW, *Australia's Health 2014*, 2014, p. 19.
39 Heart Foundation, *Submission 131*, pp 4-5.

> …all kidney conditions where a person has evidence of kidney damage and/or reduced kidney function, lasting at least 3 months.[40]

2.30 There are a number of risk factors for CKD, many of which are also risk factors for other chronic diseases such as cardiovascular disease and diabetes. Many risk factors are modifiable, including high blood pressure, smoking, and obesity. At its most severe level, end-stage kidney disease requires kidney replacement therapy, either through a kidney transplant or through dialysis.[41]

2.31 Kidney Health Australia states that about 1.7 million Australian adults have 'at least one clinical sign of CKD',[42] affecting lower socio-economic groups and Aboriginal and Torres Strait Islanders disproportionately:

> …prevalence is about eight per cent in the highest socioeconomic group, increasing to 14 per cent in the lowest socioeconomic group.[43]

2.32 One of the biggest challenges regarding the impact of CKD is that many people can have advanced CKD before it is diagnosed, as up to 90 per cent of kidney function can be lost before symptoms become evident.[44]

## Diabetes

2.33 Diabetes mellitus, commonly referred to simply as diabetes, is defined by the Department of Health as:

> …a chronic condition marked by high levels of glucose in the blood and is caused either by the inability to produce insulin, or by the body not being able to use insulin effectively, or both. There are two main types of diabetes, type 1 and type 2. Type 1 diabetes is a lifelong autoimmune disease that is generally diagnosed in childhood. Type 2 diabetes is usually associated with lifestyle and behavioural factors and is considered to be largely preventable. Gestational diabetes occurs when higher-than-normal blood glucose is diagnosed in pregnancy.[45]

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40 Department of Health, *Submission 143*, p. 36.

41 AIHW, *Australia's Health 2014*, 2014, p. 144.

42 Kidney Health Australia, *Submission 126*, p. 4.

43 Professor Timothy Usherwood, Member, Kidney Check Australia Taskforce, Kidney Health Australia, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 6.

44 Department of Health, *Submission 143*, p. 36.

45 Department of Health, *Submission 143*, p. 28.

2.34 Diabetes can progress to other health complications, including heart and kidney disease, blindness, and lower limb amputation.[46]

2.35 Type 1 diabetes is believed to be due partly to genetic disposition and partly due to environmental factors. Type 2 diabetes, which accounts for around 85 per cent of cases,[47] is largely preventable and is caused by a variety of factors including physical inactivity, unhealthy diet, obesity, tobacco smoking, and high blood pressure and blood lipids.[48]

2.36 According to Diabetes Australia, diabetes will become the leading burden of disease in Australia by 2017.[49] The AIHW estimates that there are a million Australians with diagnosed diabetes, adding that up to a quarter of a million Australians have undiagnosed diabetes.[50] Cases of all types of diabetes are increasing: Diabetes Australia estimates nearly 100 000 new cases of diabetes developed in 2014, with over 65 000 Australians developing type 2 diabetes and 30 000 women developing gestational diabetes.[51]

2.37 To put this in a global context, in the recently released *Global Report on Diabetes*, the World Health Organization (WHO) stated that 422 million people worldwide had diabetes in 2014, a prevalence of 8.5 per cent among adults. Altogether the disease caused 1.5 million mortalities in 2012, with 43 per cent of mortality occurring before the age of 70.[52]

2.38 Diabetes affects population groups differently. Aboriginal and Torres Strait Islander peoples are over three times as likely to have diabetes as non-Indigenous Australians, and people in lower socioeconomic groups and those living outside of major cities are also more likely to have diabetes.[53] Diabetes was the sixth leading cause of mortality in Australia in 2011, contributing to 10 per cent of all mortalities.[54]

## Multi-Morbidity and Concurrent Conditions (Comorbidity)

2.39 The Royal Australian College of General Practitioners (RACGP) states:

> Multimorbidity, the presence of multiple chronic conditions in a single individual, is common and increasingly the norm in general

46 AIHW, *Australia's Health 2014*, 2014, p. 141.
47 Department of Health, *Submission 143*, p. 28.
48 AIHW, *Australia's Health 2014*, 2014, p. 141.
49 Diabetes Australia, *Submission 102*, p. 1.
50 AIHW, *Australia's Health 2014*, 2014, p. 141.
51 Diabetes Australia, *Submission 102*, p. 1.
52 World Health Organization, *Global Report on Diabetes*, 2016, p. 21.
53 AIHW, *Australia's Health 2014*, 2014, p. 142.
54 AIHW, *Australia's Health 2014*, 2014, p. 142.

> practice patients. The prevalence of multimorbidity increases with age, and as Australia's population this figure to grow. Multimorbidity is associated with reduced quality of life, polypharmacy issues and increased risk of hospitalisation.[55]

2.40 The RACGP adds that multi-morbidity requires greater planning and coordination by GPs and their teams.

2.41 A number of chronic conditions are associated with comorbidities, often due to common risk factors and behaviours. For example, the Department of Health notes that COPD is:

> …commonly associated with comorbidities such as cardiovascular disease and diabetes mellitus, due to common causes such as smoking and/or systemic effects of COPD. In addition, the prevalence of bronchiectasis among people with COPD was estimated at 29 – 50%.[56]

2.42 The AIHW notes that comorbidity is common among people with mental health conditions:

> Comorbidity is common among people with a mental disorder, and people with multiple disorders are more disabled and consume more health resources than those with only 1 disorder (ABS 2008). Data from the 2007 survey of the Australian adult population indicate that 12% of Australians aged 16-85 had a mental disorder and a physical condition concurrently, and that these people were more likely to be female, and aged in their early forties (ABS 2008). The most common comorbidity (9%) was an anxiety disorder combined with a physical condition, affecting about 1.4 million Australian adults (ABS 2008).[57]

2.43 The AIHW also stated that comorbidity increases with increasing disadvantage, with people in the most disadvantaged areas 65 per cent more likely to be comorbid than those in the least disadvantaged areas.[58]

2.44 The AIHW, commenting that better statistical information on chronic disease generally is required, notes that additional data on comorbidity would be helpful in determining the effect of chronic diseases on Australians.[59]

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55 Royal Australian College of General Practitioners, *Submission 135*, p. 2.

56 Department of Health, *Submission 143*, p. 32.

57 AIHW, *Australia's Health 2014*, 2014, p. 135.

58 AIHW, *Australia's Health 2014*, 2014, Figure 2.6, p. 135.

59 AIHW, *Australia's Health 2014*, 2014, Figure 2.6, p. 103.

## Wider Burden of Diseases

2.45 Submissions and evidence received by the Committee corroborate the conditions above as a focus for chronic disease prevention and management, however there are many other diseases and conditions that can be classified as chronic diseases, as well as the fact that most people who suffer from one chronic condition often have another associated condition (comorbid) or many other conditions (multi-morbid).

2.46 Submitters to the inquiry also argued that many conditions that are not even classified as diseases in Australia are some of the most debilitating chronic diseases that need the most prevention and management. Paired with the fluid nature of the definition of chronic disease (relating to the simple requirement to be long-lasting and persistent), there are many conditions that could be classified as chronic diseases that the Committee did not receive any evidence regarding.

2.47 Also, the status of mental health conditions as chronic diseases is inconsistently referenced or supported across chronic disease literature, but the Committee strongly feels that mental health conditions, or comorbid mental health conditions that result from other diseases, are just as important to educate about, prevent and manage within primary health care within Australia.

## Other Chronic Diseases

2.48 Other than the emphasised five major areas of chronic disease that make up 80 per cent of the chronic disease burden outlined above, the Committee heard evidence through submissions and public hearings about a wide range of other chronic health conditions. Chronic diseases raised with the Committee include, but are not limited to, AIDS, cancer, chronic fatigue syndrome, chronic pain, haemochromatosis, tick-borne and Lyme-like illnesses, lymphoedema, mental health conditions, multiple sclerosis, oral health, speech impediments and vision conditions.

2.49 Some of these conditions, such as cancer, AIDS, and mental health conditions are well known, although are sometimes discussed separately from chronic disease, despite their ongoing nature. Others are relatively minor in terms of incidence, societal awareness, and government investment, but are significant in terms of the challenges they present to the health care system and in terms of the hardship they can inflict on those who live with these conditions.

2.50 The Committee acknowledges the people living with all these conditions, including those not directly outlined, as well as their carers and families. The importance of these conditions are evident in the several submissions

and testimonies from those who appeared at public hearings throughout the inquiry.

## AIDS

2.51 While the primary definition of chronic disease accepted for this report does not generally include communicable diseases, the impact of Acquired Immune Deficiency Syndrome (AIDS) and Human Immunodeficiency Virus (HIV) is high, both on sufferers as well as the community and the health care system.

2.52 The Committee received a submission from the Victorian AIDS Council, which defines HIV as 'a chronic manageable illness'[60] and notes the application of chronic disease management to people living with HIV.[61]

2.53 The AIHW notes the association between illicit drug use and HIV/AIDS, stating that users, particularly young people who are more likely to experiment with 'psychotropic drugs', 'expose themselves to increased risks of HIV'.[62] The AIHW also notes that HIV/AIDS is one of the causes of dementia, especially among those with younger onset dementia.[63]

2.54 According to the AIHW, the rate of HIV notifications for 15-24 year olds had increased from 3 per 100 000 in 2001 to 5 per 100 000 in 2012.[64]

2.55 The Victorian AIDS Council called HIV a 'preventable' disease, commenting that the use of HIV pre-exposure prohylaxis, which has been approved in the USA, is still to be approved in Australia.[65]

2.56 The Committee made limited reference to HIV in its previous report this Parliament, *The Silent Disease: Inquiry into Hepatitis C in Australia.*[66]

## Cancer

2.57 Cancer is considered one of the four major disease groups within chronic disease by the AIHW,[67] which defines cancer as:

> …a diverse group of several hundred diseases in which some of the body's cells become abnormal and begin to multiply out of

60 Victorian AIDS Council, *Submission 47*, introductory letter.

61 Victorian AIDS Council, *Submission 47*, pp 12-16.

62 AIHW, *Australia's Health 2014*, 2014, p. 230.

63 AIHW, *Australia's Health 2014*, 2014, p. 274.

64 AIHW, *Australia's Health 2014*, 2014, p. 230.

65 Victorian AIDS Council, *Submission 47*, introductory letter.

66 See the report at the Committee's website - <http://www.aph.gov.au/Parliamentary_Business/Committees/House/Health/Hepatitis_C_in_Australia/Report>

67 AIHW, *Australia's Health 2014*, 2014, Figure 2.6, p. 94.

> control. The abnormal cells can invade and damage the tissue around them, and spread to other parts of the body, causing further damage and eventually death.[68]

2.58 In their joint submission, the Primary Care Collaborative Cancer Clinical Trials Group (PC4), Clinical Oncology Society of Australia (COSA), and Cancer Council state that cancer is the 'leading cause of disease burden in Australia accounting for 19.4 per cent of the total disease burden'.[69] Cancer accounted for over 40 000 mortalities in 2011, or 3 in 10 mortalities overall, with the most common forms being lung cancer, bowel cancer, prostate cancer, breast cancer, and pancreatic cancer. There were over 115 000 new diagnoses of cancer in 2010, but despite the increase in new cases of cancer, mortality rates from cancer have fallen 17 per cent in the last twenty years.[70]

2.59 Commenting on this trend, Cancer Australia identified that advances in screening, early detection and treatment has increased survival rates from 46 per cent in the mid-1980s to 67 per cent in the period 2007-2011. These improving rates will result in more people living longer with cancer, with the consequent increase in treatment, support, and long-term care required.[71]

2.60 Contributing to these advances is medical research undertaken by groups such as the Trans-Tasman Radiation Oncology Group (TROG), the peak body for radiation oncology research in Australia and New Zealand, 'recognised internationally for both the volume and quality of its scientific research'.[72] In its submission, TROG stated the effectiveness of radiation oncology, with 90 radiation oncology centres throughout Australia.[73]

2.61 Cancer Australia notes that cancer and other chronic diseases share common risk factors, including smoking, physical inactivity, poor diet, and harmful alcohol use.[74]

## Chronic Pain

2.62 The Committee also received submissions addressing chronic pain.[75] The Australian Pain Society argued that while traditionally considered to be a

68 AIHW, *Australia's Health 2014*, 2014, Figure 2.6, p. 94.

69 PC4, COSA, Cancer Council, *Submission 63*, p. 2.

70 AIHW, *Australia's Health 2014*, 2014, Figure 2.6, p. 105.

71 Cancer Australia, *Submission 65*, p. 1.

72 TROG Cancer Research, *Submission 190*, p. 4.

73 TROG Cancer Research, *Submission 190*, p. 4.

74 Cancer Australia, *Submission 65*, p. 1.

75 The Australian Pain Society, *Submission 35*; Australian Pain Management Association, *Submission 52*; Painaustralia, *Submission 96*.

manifestation of disease, chronic pain is increasingly regarded as 'a disease in its own right':

> …research has demonstrated genetic susceptibility to developing chronic pain, and pathophysiological processes specific to chronic pain…[76]

2.63 The Australian Pain Management Association (APMA) estimates that 3.2 million Australians are suffering from chronic pain, and that one in five Australians will suffer persistent pain at some point in their lifetime.[77] Painaustralia reports that five per cent of those with chronic pain also report severe disability.[78]

2.64 APMA and Painaustralia cite evidence that the condition costs $34 billion a year, including healthcare costs and lost productivity.[79] Painaustralia also notes that chronic pain affects one in three people over 65.[80]

2.65 While chronic pain can manifest as a chronic disease alone, it often leads to associated comorbid mental health conditions, where 'over 1.5 million people (10 per cent of Australians aged 16-85 years) had at least one musculoskeletal condition and one mental disorder in the preceding 12 months'.[81]

## Haemochromatosis

2.66 Haemochromatosis is an inherited iron overload disorder, causing the body to absorb and store too much iron. It affects over 100 000 Australians, and a significant proportion of people with this condition will develop cardiac arrhythmia, diabetes, chronic fatigue, arthritis, or suffer liver damage, hormonal changes, or joint pain.[82]

2.67 According to Haemochromatosis Australia, 'between 50 per cent and 100 per cent' of cases of haemochromatosis (in certain populations) are undetected, often until one of its associated symptoms develops. These additional symptoms could be prevented with early detection of the underlying haemochromatosis.[83]

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76 Australian Pain Society, *Submission 35*, p. 3.

77 Australian Pain Management Association, *Submission 52*, p. 2.

78 Painaustralia, *Submission 96*, p. 4.

79 Australian Pain Management Association, *Submission 52*, p. 2; Painaustralia, *Submission 96*, p. 4.

80 Painaustralia, *Submission 96*, p. 4.

81 Painaustralia, *Submission 96*, p. 7.

82 Haemochromatosis Australia, *Submission 19*, p. 2.

83 Haemochromatosis Australia, *Submission 19*, p. 2.

2.68 The National Health and Medical Research Council (NHMRC) outlines that 'in the majority of patients with overt Hereditary Haemochromatosis, the first symptoms develop between the ages of 30 and 60 years'.[84]

2.69 Haemochromatosis and its associated symptoms can be prevented if the genetic predisposition is detected early. Iron levels can be monitored and venesection (surgical bloodletting) is the 'accepted and uncontroversial means of avoiding or reducing iron overload'.[85] This point was reinforced by the Garvan Institute of Medical Research.[86]

## Lymphoedema

2.70 The Committee received a submission from the Lymphoedema Action Alliance and from one individual suffering from lymphoedema.[87] The Lymphoedema Action Alliance defines lymphoedema as:

> …a chronic and debilitating condition caused by the collection of lymph fluid, leading to persistent swelling in the affected body part. It most often affects arms or legs, but the trunk, head, or genital area can also be affected. It is caused by poor development or damage to the lymphatics of the body. Lymphoedema is progressive and incurable, so early diagnosis and commencement of best practice treatment methods are critical to improving patient outcomes.[88]

2.71 The Lymphoedema Action Alliance estimates, based on international rates, that there are about 32 000 people with lymphoedema in Australia, including 19 000 over the age of 65.[89] Both submissions highlight the high cost of treating lymphoedema as a significant difficulty for lymphoedema patients.

2.72 The Australian Physiotherapy Association advocated the role physiotherapists have in managing chronic diseases, including lymphoedema.[90]

## Mental Health and Dementia (including Alzheimer's Disease)

2.73 According to beyondblue, mental health conditions are:

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84 National Health and Medical Research Council, 'Genetics in Family Medicine: The Australian Handbook for General Practitioners: Hereditary Haemochromatosis', 2007, p. 3.

85 Haemochromatosis Australia, *Submission 19*, p. 2.

86 Garvan Institute of Medical Research, *Submission 149*, Attachment A, p. 5.

87 Lymphoedema Action Alliance, *Submission 33*; Mrs Yvonne Hughes, *Submission 10*.

88 Lymphoedema Action Alliance, *Submission 33*, p. 4.

89 Lymphoedema Action Alliance, *Submission 33*, p. 6.

90 Australian Physiotherapy Association, *Submission 145*, p. 4.

> …extremely common, with one in seven Australians experiencing depression in their lifetime and one quarter of Australians experiencing an anxiety condition.[91]

2.74 Chronic mental health conditions commonly contribute to or co-occur with chronic physical conditions, with one survey finding that a third of people with a long-term mental illness also had a chronic physical condition.[92] There is also a significant 'health gap' for people living with severe mental illness, who die an average of 25 years earlier than the general population.[93]

2.75 A number of submissions discussed mental health as an area needing more attention in the health care system, and that it should be considered as a chronic disease. For example, the La Trobe University Rural Health School stated that:

> …people with serious and enduring mental health and intellectual disability (and other lifelong developmental disabilities) must be included in health policy and planning related to chronic conditions.[94]

2.76 Inversely, the Australian Psychological Society stated that 'around 80 to 90 per cent of people with mental illness have high prevalence disorders such as depression and anxiety and can be effectively treated directly through psychological services in the community', while only '…10 to 20 per cent of people with mental illness have complex and/or chronic conditions that require coordinated team-based care'.[95]

2.77 This differing opinion on the impact of mental illness in the community and the best treatment and management protocols highlights the complexity of addressing mental health as a standalone or comorbid chronic condition.

2.78 The burden of dementia in Australia is also a growing concern, especially in relation to the care for aging chronic disease sufferers.

2.79 Dementia is not actually a discrete disease, rather referring to 'an umbrella term that describes a syndrome associated with more than 100 different conditions. Dementia is characterised by the impairment of brain functions'.[96]

2.80 Alzheimer's Australia highlighted the grim statistics regarding dementia:

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91 Beyondblue, *Submission 37*, p. 3.

92 Beyondblue, *Submission 37*, p. 3.

93 SANE Australia, *Submission 79*, p. 2.

94 La Trobe University Rural Health School, *Submission 164*, p. 3.

95 Australian Psychological Society, *Submission 130*, p. 4.

96 Department of Health, *Submission 143*, p. 41.

> It is estimated that there are now more than 340,000 Australians living with dementia and over a million people involved in their care. By 2050 there will be nearly 900,000 people with dementia. Each week there are 1,800 new cases of dementia in Australia, and this is expected to increase to 7,400 new cases each week by 2050.[97]

2.81 Dr John Ward identified the fear attached to dementia, especially for older people in the population, as dementia 'carries with it the belief that the 'self' is being destroyed'.[98]

2.82 Additionally, the care needs for people with dementia are varied as '70 per cent of the population with dementia live in their own home. The remaining 30 per cent live in residential aged care'.[99]

## Multiple Sclerosis

2.83 The MS Network and CCSVI Australia, in a joint submission, defined multiple sclerosis (MS) as:

> …a progressive condition the cause of which is not known and for which there is no cure or long term effective containment. Its presence frequently becomes apparent during early to middle adulthood from which point, and over an extended time spans (up to 20 years) wide ranging disabilities can progressively develop.[100]

2.84 The submission notes that up to 24 000 Australians are currently diagnosed with MS.[101]

2.85 MS is one of a number of autoimmune diseases. Professor John Mattick of the Garvan Institute called autoimmune diseases 'one of the great challenges of our time'.[102] The Australian Physiotherapy Association identified that MS is also a chronic condition which can benefit from targeted physiotherapy interventions.[103]

2.86 The MS Network and CCSVI Australia reported that most people with MS also have 'vascular irregularities that slow the flow of deoxygenated blood

97 Alzheimer's Australia, *Submission 98*, p. 2.

98 Dr John Ward, *Submission 195*, p. [1].

99 Mr Brendan Moore, General Manager, Policy, Research and Information, Alzheimer's Australia NSW, *Proof Committee Hansard*, Newcastle, 31 March 2016, p. 11.

100 MS Network and CCVSI Aust, *Submission 15*, p. 2.

101 MS Network and CCVSI Aust, *Submission 15*, p. 2.

102 Professor John Mattick, Executive Director, Garvan Institute of Medical Research, *Official Committee Hansard*, Sydney, 23 September 2015, p. 32.

103 Australian Physiotherapy Association, *Submission 145*, p. 11.

back to the heart', something for which treatment, most commonly angioplasty, can provide relief.[104]

## Myalgic Encephalomyelitis (Chronic Fatigue Syndrome)

2.87 The Committee heard from several individuals about myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS).[105] It is contended in several submissions that up to 100 000 Australians suffer from ME,[106] with about a quarter of those confined to their houses or beds as a result of their illness.[107] The Victorian Government, on its Better Health Channel website, states that 'at least 35 000 Victorians have ME/CFS'.[108] Advocacy group Emerge Australia states 'between 94 000 and 242 000 Australians are estimated to be affected by ME/CFS at any one time', with 'around 25 per cent so profoundly affected by the condition they don't recover.'[109] One of the issues raised in submissions is the difficulty for patients with ME to access medical services. The potential of eHealth and home doctor visits were raised as a way of addressing this difficulty.[110]

2.88 The condition manifests in symptoms including: 'post-exertional malaise', dysfunctional sleep, pain, neurological and cognitive symptoms including confusion, lack of concentration, disorientation and weight change; and autonomic, neuroendocrine, and immune manifestations.

2.89 Mrs Kim Crowe outlined the complications and pain caused by her condition:

> I cannot stand for more than around ½ hour, I cannot sit for more than about an hour. This depends on where my pain is and its hourly level. There are some days I cannot sit, stand or lay down pain free.[111]

104 MS Network and CCVSI Aust, *Submission 15*, p. 2.

105 Mrs Kim Crow, *Submission 7*; name withheld, *Submission 8*; Ms Kitty Lobert, *Submission 11*; name withheld, *Submission 14*; name withheld, *Submission 48*; Ms Elizabeth Bartlett, *Submission 50*; Ms Margaret Fleuren, *Submission 86*; Ahmo Garden, *Submission 104*; name withheld, *Submission 128*; name withheld, *Submission 174*.

106 Name withheld *Submission 11*, p. 1; name withheld, *Submission 8*, p. 1; name withheld, *Submission 14*, p. 1; Ms Elizabeth Bartlett, *Submission 50*, p. 2; name withheld, *Submission 128*, p. 1.

107 Name withheld, *Submission 128*, p. 1.

108 BetterHealth Channel, 'Myalgic encephalomyelitis (ME)/Chronic fatigue syndrome (CFS)', <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/chronic-fatigue-syndrome-cfs>, viewed 10 March 2016.

109 Emerge Australia, 'Mission and Vision', <http://emerge.org.au/mission-vision/#.VuD0p_l95aQ>, viewed 10 March 2016.

110 Name withheld, *Submission 128*, p. 1.

111 Mrs Kim Crowe, *Submission 7*, p. [1].

## Oral Health

2.90 The AIHW stated that oral health has improved in Australia in recent decades, largely as a result of fluoride in water supplies, but has recently trended downwards, probably as a result of diet.[112]

2.91 The Australian Dental Association (ADA) stated that oral diseases have been recognised as chronic disease. The ADA emphasised the connection between oral health and other chronic diseases including cardiovascular disease, diabetes, respiratory disease and stroke, noting also that oral health shares common risk factors with other chronic conditions.[113] The Dental Hygienists Association of Australia (DHAA) also states that people with chronic diseases have higher rates of dental disease.[114] AIHW notes that oral health accounts for the second highest amount of spending nationally, over $7 billion in 2008-09.[115]

2.92 Mr Tan Nguyen, an oral health therapist, stated that evidence suggests there are common risk factors for oral diseases and chronic health diseases including diabetes, heart disease, chronic obstructive pulmonary disease, as well as perinatal health.[116]This connection was also identified by the Australian Dental Association,[117] and the DHAA also stated that people with chronic disease have an increased risk of dental disease.[118]

2.93 Mr Nguyen stated that oral diseases are 'largely chronic and dietary-related', and observed that projects such as the Victorian 'Healthy Together Victoria' project, which targets childhood obesity, are likely to improve oral health as a result of better nutritional behaviours.[119]

## Speech Conditions

2.94 The Committee received a submission from Speech Pathology Australia, as well as from an individual, Ms Emma Bird, whose son suffers from a stutter.

2.95 Speech Pathology Australia estimates that 1.1 million Australians have a communication disorder, and one million suffer from swallowing difficulties.[120]

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112 AIHW, *Australia's Health 2014*, 2014, p. 151.

113 Australian Dental Association, *Submission 55*, p. 1.

114 Dental Hygienists Association of Australia, *Submission 38*, p. 3.

115 AIHW, *Australia's Health 2014*, 2014, Figure 2.6, p. 51.

116 Mr Tan Nguyen, *Submission 68*, p. 3.

117 Australian Dental Association, *Submission 55*, p. 1.

118 Dental Hygienists Association of Australia, *Submission 38*, p. 3.

119 Mr Tan Nguyen, *Submission 68*, pp 3-4.

120 Speech Pathology Australia, *Submission 118*, p. 2.

2.96 Ms Bird identified that although stuttering 'seems like an insignificant sort of diagnosis and we assume that it affects only speech', it nevertheless not only can 'affect one's ability to communicate fluently, but it also has big psychological effects'.[121]

2.97 Speech Pathology Australia notes that the impacts of communication disorders are 'far reaching and debilitating', as they result in 'poor educational outcomes, reduced employment opportunities and an increased likelihood of social, emotional and mental health issues'.[122]

2.98 Swallowing difficulties can lead to malnutrition, respiratory problems, and sometimes can be fatal.[123]

## Tick-Borne and Lyme-Like Diseases

2.99 The Committee received several written submissions from individuals suffering from tick-borne or Lyme-like diseases,[124] as well as organisations and doctors advocating on their behalf.[125] As a result of the issues raised in these submissions a separate roundtable hearing was held in Sydney on 18 September 2015. Ten individual experts and organisations were represented in the first two sessions, and six individual Australians – five living with tick-borne or Lyme-like disease, and one who has two daughters living with Lyme-like disease – gave evidence in the final session.

2.100 The evidence received demonstrated tick-borne or Lyme-like disease to be an example of a chronic illness which has significant, life-changing effects on its sufferers but which is commonly misunderstood in the medical community and relatively unknown in the broader community. People living with this condition express their frustration at the lack of medical understanding, which can result in misdiagnosis and delayed treatment. Evidence also reveals frustration people have at the controversy that surrounds the definition of tick-borne or Lyme-like disease, and whether true Lyme borreliosis is native to Australia.

2.101 The example of tick-borne or Lyme-like diseases helps to identify the frustrations that can sometimes occur for chronic disease patients in Australia. As such, the case study at Appendix A identifies the situations outlined by patients, clinicians and associated support groups.

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121 Emma Bird, *Submission 103*, p. 1.

122 Speech Pathology Australia, *Submission 118*, p. 1.

123 Speech Pathology Australia, *Submission 118*, p. 1.

124 Emily O'Sullivan, *Submission 156*; Jolinda Evans, *Submission 171*; Sharon King, *Submission 176*.

125 Lyme Disease Association of Australia, *Submission 85*; Karl McManus Foundation, *Submission 158*; Sarcoidosis Lyme Australia, *Submission 166*; Dr Richard Schloeffel, *Submission 162*.

## Vision Conditions

2.102 Vision conditions were identified by the AIHW as one of the 'most common chronic diseases among older Australians'.[126]

2.103 Vision 2020 Australia states that 'many eye conditions are chronic by nature' and fit the National Chronic Disease Strategy's definition of chronic disease.[127] Vision conditions affect an estimated 575 000 Australians,[128] with a total cost to the economy of as much as $16.6 billion.[129] The University of Melbourne's Indigenous Eye Health notes that vision loss 'accounts for 11 per cent of the health gap', and that Aboriginal and Torres Strait Islanders 'experience a high burden of diabetes and related eye disease'.[130]

2.104 Poor vision is associated with co-occurring chronic diseases, particularly with diabetes.[131] Vision 2020 Australia states:

> Many chronic conditions also exhibit early signs and symptoms that can only be detected upon comprehensive ocular investigation. Primary eye care readily facilitates the early detection of chronic disease that may otherwise go undetected until the later stages of disease progression and primary eye care professionals such as optometrists are therefore essential and willing participants in the multi-disciplinary approach to chronic disease prevention and management.[132]

2.105 The Royal Society for the Blind notes that there is:

> …a strong correlation between vision loss and other health issues and chronic diseases including cardiovascular (hypertension, high cholesterol and [stroke]), smoking, poor diet and nutrition, depression and diabetes.[133]

## Rare Diseases

2.106 The Committee received a submission from Rare Voices Australia (RVA), an advocacy group which 'provides a unified voice for the estimated 1.2 to

126 AIHW, *Australia's Health 2014*, 2014, p. 101.

127 Vision 2020 Australia, *Submission 89*, p. 5.

128 Royal Society for the Blind, *Submission 69*, p. 1.

129 Optometry Australia, *Submission 59*, p. 3.

130 Indigenous Eye Health, University of Melbourne, *Submission 45*, p. 1.

131 Indigenous Eye Health, University of Melbourne, *Submission 45*, p. 1; Royal Australian and New Zealand College of Opthalmologists, *Submission 58*, pp 4-5; Vision 2020 Australia, *Submission 89*,p. 6.

132 Vision 2020 Australia, *Submission 89*, p. 5.

133 Royal Society for the Blind, *Submission 69*, p. 1.

2 million Australians living with a Rare Disease'.[134] A Rare Disease (RD) is described by RVA as 'a disease that occurs infrequently in the general population', with the proposed definition:

> A life-threatening or chronically debilitating disease which is statistically rare (with an estimated prevalence of less than 5 in 10,000), but with a high level of complexity requiring special combined efforts to address the needs of people with the disorder or condition.[135]

2.107 The rarity of these individual diseases means that most RDs lack awareness and information, as well as funding for research, with only 15 per cent currently having 'organizations or foundations providing specific support or driving research'.[136]

2.108 Despite this, RVA states that 'collectively the RD community is larger than the AIDS and Cancer communities combined'.[137]

2.109 E-health and telemedicine were identified as having potential to improve the delivery of health care for people living with a RD,[138] while RVA also emphasised the need for best practice guidelines specific to RDs.[139] The WA Rare Disease Strategic Framework 2015-2018 was highlighted by RVA, who also suggested that it be adopted as a National Initiative and in every state and territory. The Framework recommends key initiatives for the Primary Health Networks to gather information and data, collaborate with relevant organisations, and develop policy.[140]

## Chronic Disease Prevention

2.110 The inquiry combines prevention and management in its title and in many of the terms of reference, but the Committee would like to make the strong distinction that prevention and management of chronic disease requires different policies and approaches.

2.111 Prevention of chronic disease, especially those diseases that have strong lifestyle contributory factors, requires very different policies, programs and approaches to management of those conditions. While they share a

134 Rare Voices Australia, *Submission 51*, p. 1.
135 Rare Voices Australia, *Submission 51*, p. 2.
136 Rare Voices Australia, *Submission 51*, p. 2.
137 Rare Voices Australia, *Submission 51*, p. 2.
138 Rare Voices Australia, *Submission 51*, p. 6.
139 Rare Voices Australia, *Submission 51*, p. 4.
140 Rare Voices Australia, *Submission 51*, p. 5.

common care and treatment goal, the funding, providers and resources required have very different focuses and requirements.

2.112 Prevention of chronic disease requires education, monitoring and engagement with the community to ensure that contributory lifestyle/risk factors are avoided, or at least monitored and controlled before conditions can manifest or have irreversible contributions.

2.113 Prevention of chronic disease and the wide approach required to manage prevention effectively is outlined by the Australian Health Promotion Association:

> Chronic disease 'prevention' operates from an overall population health promotion perspective. The most cost-effective health promotion interventions utilise broad behaviour-change levers that reach the whole population, such as legislation, public policy, education and comprehensive social marketing and improvements to the social and physical environment.[141]

## Risk Factors

2.114 The key element of chronic disease prevention is in identifying and managing key risk factors, mostly related to lifestyle, which can contribute to chronic disease.

2.115 The Victorian Health Promotion Foundation identifies the four key factors contributing to non-communicable chronic disease as smoking, physical inactivity, unhealthy diet, and harmful use of alcohol.[142] These risk factors contribute greatly to the prevalence and severity of cardiovascular disease, cancer, respiratory disease, and diabetes in the Australian population.

2.116 The impact of resultant or associated obesity on these risk factors is significant as well, with the effects on a patient's risk of chronic disease increasing with each risk factor present in their life. Reduction in these risk factors, sometimes referred to as lifestyle interventions, will often help in controlling or sometimes reversing their adverse impact.[143]

## Health Literacy

2.117 Identification of the above risk factors in a person's lifestyle is a critical element of the prevention of avoidable chronic disease. However, the general health literacy of patients, or potential patients, is an element of chronic disease prevention that requires consistent focus and promotion.

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141 Australian Health Promotion Association, *Submission 49*, p. 1.

142 Victorian Health Promotion Foundation, *Submission 117*, p. 1.

143 Dietitians Association of Australia, *Submission 148*, p. 7.

2.118 The establishment of the former Australian National Preventive Health Agency (ANPHA) in 2011 emphasised the role that health promotion and prevention needs to play in chronic disease management in Australia.[144] As of July 2014, the ANPHA's functions were absorbed into the federal Department of Health, but the important work of preventive policy and program development continues.

2.119 The Committee had examples of many chronic disease prevention and promotion programs brought to its attention. Some examples include:

- The Newcastle Alcohol Management Strategy – a local government led initiative to educate and control abusive alcohol use;[145]
- OPAL (Obesity Prevention and Lifestyle) - an initiative that supports children, through their families and communities, to be healthy now, and stay healthy for life. Established in South Australia in 2009 by SA Health, OPAL is coordinated through local government and works with communities to create opportunities to eat well and be active;[146]
- Northern Respiratory Partnership – an Adelaide-based program identifying a comprehensive set of strategies designed to achieve the goal of reducing the number of avoidable emergency department (ED) attendances and potentially preventable admissions for asthma and COPD in the Northern Adelaide Medicare Local region. The program also emphasised risk factors such as smoking and lack of exercise;[147]
- beyondblue's Man Therapy campaign – promotion campaign and online tools to allow men to assess and understand mental health factors about depression and anxiety;[148] and
- Live Lighter Program - a program developed in Western Australia, now delivered in multiple states, which aims to encourage Australian adults to lead healthier lifestyles - to make changes to what they eat and drink, and to be more active.[149]

2.120 Additionally, many private health insurers are now providing healthy lifestyle and risk factor reduction programs to their members, such as:

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144 Department of Health, 'ANPHA – About Us', <http://health.gov.au/internet/anpha/publishing.nsf/Content/about-us>, viewed 8 March 2016.

145 Australian Health Promotion Association, *Submission 49*, p. 3.

146 SA Health, 'OPAL : SA Health', <http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/healthy+living/healthy+places/where+we+live+and+play/opal/opal>, viewed 8 March 2016.

147 Adelaide Primary Health Network, *Submission 119*, pp 12-13.

148 Beyondblue, *Submission 37*, p. 9.

149 Live Lighter, 'About', <https://livelighter.com.au/About/>, viewed 8 March 2016.

- Medibank Private's 'Care' suite of programs – education and assistance programs for members aimed at reducing avoidable hospital admissions and readmissions;[150] and
- HCF's My Health Guardian – telephone based support to HCF members to promote healthy behaviours and adherence with medications and GP action plans.[151]

2.121 The role of private health insurers in wider chronic disease prevention, management and direct service provision will be discussed further in Chapter 3.

## Chronic Disease Management

2.122 Management of chronic disease, as with prevention, requires a concerted and discrete policy, funding and coordination approach. If prevention attempts are not successful, then coordinated and patient-centred care is a must to maximise outcomes for patients affected by chronic disease.

2.123 The weight of chronic disease management is split between the primary and hospital health care sectors. Primary health care generally manages the ongoing care of patients, or attending to their care needs in the initial stages of diagnosis. The hospital system then manages either the acute episodes of care, surgery, tertiary care or the ultimate palliative stage of some chronic diseases.

2.124 This inquiry is focused on the primary health care role in chronic disease management, however, this does not take away from the critical role that the hospital system plays in chronic disease management. The interplay between the two sectors of health care is crucial, but the responsibilities and funding for the separate sectors is an increasing pressure for state and federal governments.

2.125 The Reform of the Federation White Paper *Issues paper 3: Roles and Responsibilities in Health* highlights these exact issues.[152]

2.126 The Department of Health summarised the policy and funding separation issues:

> While Australia has an excellent health system and Australians enjoy one of the longest life-expectancies in the world, our health care arrangements face a number of pressures that are leading to

150 Medibank Private, *Submission 43*, pp 9-10.

151 HCF, *Submission 122*, pp 7-8.

152 Australian Government, 'Issues Paper 3: Roles and Responsibilities in Health', <https://federation.dpmc.gov.au/issues-paper-3>

> increased demand and expenditure. The growing burden of chronic conditions, together with the ageing population, increased consumer expectations and more expensive technologies, are all contributing to ever increasing demand for services and growing cost pressures.
>
> Although there are strong incentives for all governments to improve people's health, the complex split of government roles means no single level of government has all the policy levers needed to ensure a cohesive health system. This particularly affects patients with chronic and complex conditions, such as diabetes, cancer and mental illness, who regularly move from one health service to another and can suffer if their care is not provided in a coordinated manner.[153]

2.127 This commentary is especially pertinent to consider for the purposes of this inquiry, as the best practice models of care outlined to the Committee generally require a coordinated care model between the patient's primary care providers, allied health providers and hospital care.

2.128 The ability of the primary health care system to provide this coordinated care, and what that care could entail, is covered in more detail in Chapters 3 and 4.

2.129 Additionally, the ability to manage chronic disease not only falls on the health care system to provide the medical and support services essential for treatment, but also on the patient themselves to understand their condition and fully realise the treatment and management options open to them, making them a 'partner' in their care decisions.[154]

## Social and Economic Costs

2.130 As outlined earlier in this chapter, the financial cost of health care for chronic disease in Australia is extensive. Of the total 2015-16 Federal Budget expenditure of $434.5 billion, health expenditure totalled $69.4 billion, or just under 16 per cent of total federal expenditure.[155] Health expenditure has also grown faster than the broader economy, with the ratio of health expenditure to GDP increasing from 6.8 per cent in 1986-86 to 9.5 per cent in 2011-12.[156] Over a third of this expenditure is

153 Department of Health, *Submission 143*, p. 4.

154 Flinders University, Behaviour & Health Research Unit, *Submission 4*, p. 5.

155 Budget 2015, 'Overview – revenue and spending', <http://www.budget.gov.au/2015-16/content/overview/html/overview-29.htm>, viewed 9 March 2016.

156 AIHW, *Australia's Health 2014*, 2014, p. 47.

incurred by the four most expensive disease groups, all of which are chronic diseases: cardiovascular diseases, oral health, mental disorders, and musculoskeletal. Together these diseases accounted for over $27 billion of direct health-care costs in 2008-09.[157]

2.131 The social costs are another aspect of the overall costs of chronic disease. One obvious cost of chronic disease, other than the direct healthcare costs, is the loss of life. Chronic disease is an underlying cause in nine out of ten mortalities.[158] Chronic disease contributes 85 per cent of the total burden of disease in Australia, measured by the disability-adjusted life year (DALY, a measure of the number of years lost to ill health, disability, or mortality), and 90 per cent of the burden due to mortalities.[159]

2.132 As one example, people with severe mental health conditions have much shorter life spans than the general population. SANE Australia contends that people with severe mental health illness die an average of 25 years earlier,[160] while beyondblue estimates a 10 to 32 year discrepancy in life expectancy.[161]

2.133 Other obvious costs are lower quality of life and opportunity costs. The Rural Doctors Association of Australia states:

> Poorer quality of life and opportunities lost as a result of reduced functioning capacity is a significant issue for many individuals, families, carers and the broader community.[162]

2.134 One example of the opportunity cost of chronic disease is given by Painaustralia, which cites an Access Economics report contending that chronic pain costs $11.7 billion in lost productivity, or 36 million lost workdays per year.[163]

2.135 Chronic disease also has other social costs. Chronic disease contributes two-thirds of the gap in mortality rates between Indigenous and non-Indigenous people.[164] Chronic diseases also occur more frequently among lower socioeconomic people,[165] and the incidence of chronic disease increases with age.[166]

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157 AIHW, *Australia's Health 2014*, 2014, p. 98.
158 Department of Health, *Submission 143*, p. 4.
159 AIHW, *Australia's Health 2014*, 2014, p. 98.
160 SANE Australia, *Submission 79*, p. 1.
161 Beyondblue, *Submission 37*, p. 3.
162 Rural Doctors Association of Australia, *Submission*, p. 4.
163 Painaustralia, *Submission 96*, p. 4.
164 AIHW, *Australia's Health 2014*, 2014, p. 99.
165 AIHW, *Australia's Health 2014*, 2014, p. 99.
166 AIHW, *Australia's Health 2014*, 2014, p. 100.

2.136 A number of submissions emphasised these kinds of social costs. For example, the Centre for Primary Health Care and Equity at the University of New South Wales stated:

> There is also evidence of widening inequalities not only in mortality and disease incidence but also in the risk factors for these conditions. Thus there are widening disparities between socioeconomic groups in the prevalence of obesity, diabetes and cardiovascular mortality over the past 25 years in Australia. These health inequities are also reflected in premature mortality, increased morbidity, increased use of curative health services and less use of preventive health services and fewer disability free life years. There are not only high personal costs of this increased burden of disease but also costs to the health system an[d] society as a whole.[167]

2.137 As another example, cohealth, a not-for-profit community health service based in Melbourne, calls chronic disease an 'equity illness':

> It is increasingly acknowledged that health inequity results in a higher incidence of chronic disease and that social disadvantage is a leading modifiable risk factor for poor health outcomes. Therefore, chronic disease can be understood as an equity illness: ***the greatest burden of disease is experienced by the most socially disadvantaged group***.[168]

2.138 The Victorian Council of Social Services (VCOSS) was another group to emphasise this aspect of chronic disease:

> People on low incomes, people in rural and remote areas and Aboriginal people, on average, have poorer health, die earlier and receive less healthcare than other Australians.[169]

2.139 The social costs of this unequal distribution of chronic disease were highlighted by the VCOSS:

> Chronic conditions have significant financial impacts that extend beyond direct medical costs that can force households on low incomes into cycles of poverty and ill health. They are also a barrier to independence, participation in the workforce and in society.[170]

2.140 Socioeconomic status (SES) of communities and their targeted provision of health care or health promotion programs was raised with the Committee:

167 Centre for Primary Health Care and Equity, UNSW, *Submission 6*, p. 1.

168 Cohealth, *Submission 88*, p. 8. Emphasis added.

169 Victorian Council of Social Services, *Submission 120*, p. 5.

170 Victorian Council of Social Services, *Submission 120*, p. 6.

> The concept of including socioeconomic status in risk stratification and paying for performance; the dots have not been joined yet. The largest one that comes to mind is the Commonwealth funded Diabetes Care Project, which is run by McKinsey. It was run between 2012 and 2014 to try to inform policy around block funding for diabetes arising out of the recommendations of the National Health and Hospitals Reform Commission.[171]

2.141 The impact of SES on a person's likelihood to seek treatment was outlined by Bendigo Community Health Services:

> Chronic diseases—for example, diabetes—are not diagnosed anywhere near as early for these people. Australia does a great job of detecting and managing chronic diseases; that is part of why we live with them longer and the prevalence is higher. People in lower socioeconomic environments are not seeing their GP as often; they do not have the same relationship with a GP. We tend to connect more through community health; it seems to be a safe place. Often they will come in for a different kind of issue and then we can start to look at a health issue. But it is often diagnosed years later.[172]

2.142 In addition to the socioeconomic impact, the social impact on the family of those suffering with a chronic disease can be high, as outlined in the earlier case study on tick-borne illnesses.

## Concluding Comment

2.143 Chronic disease within the Australian context, as it is internationally, is an increasing burden on the health care system, as well as the social and community bonds around care and support for those with chronic disease.

2.144 The increasing prevalence of chronic disease within Australian society is a clear indicator that the system of prevention and management needs to adapt to the pressures and care needs of that portion of the Australian population and the support required by their families and support networks.

2.145 The number and complexity of diseases outlined in this chapter is just an indication of the complexity of chronic disease in Australia and how a

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171 Professor Andrew Bonney, Graduate School of Medicine, University of Wollongong, *Official Committee Hansard*, Bomaderry, 12 February 2016, p. 4.

172 Ms Kim Sykes, Chief Executive Officer, Bendigo Community Health Services, *Official Committee Hansard*, Bendigo, 18 November 2015, p. 2.

robust system of primary health care is required to support the initial and ongoing stages of conditions within the population.

2.146 The Committee acknowledges the members of the Australian community that are living with chronic disease and the pressure it places on them and their families. The outline of chronic diseases in the chapter serves only as an indicator of the increasing burden that the wide range of chronic diseases place, both on the patients and the health care system, to deliver meaningful outcomes for people's care and wellbeing. The Committee received submissions and evidence on only a portion of the conditions that affect Australians every day, but the coordinated care response required to maximise the care for all people suffering in the community is universal.