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The Parliament of the Commonwealth of Australia

# Inquiry into Chronic Disease Prevention and Management in Primary Health Care

House of Representatives Standing Committee on Health

May 2016  
Canberra

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## Chair's Foreword

Chronic disease is not a unique problem to Australia; it is a global health concern. Chronic disease is placing a heavy burden on Australia's health care system and more broadly on Australian society. Recent societal and lifestyle changes have had profound effects on the illnesses that beset the population. While medical advances have served to increase life expectancy and decrease mortality rates, the increase in sedentary workplaces and lifestyle factors such as diet, exercise and habitual behaviour such as smoking and excess alcohol consumption has seen the incidence of chronic disease skyrocket, both domestically and internationally.

According to the World Health Organization non-communicable chronic diseases are responsible for 70 per cent of mortality rates worldwide and 90 per cent of mortality rates in Australia. The vast majority of these diseases, such as type 2 diabetes and most chronic respiratory conditions, are primarily caused by lifestyle. The primary health care system is ideally the mechanism for addressing this rise in chronic disease, however the fragmented nature of the current care model challenges the system's ability to deliver the best patient outcomes.

The fluid and open definition of chronic disease can also complicate prevention and management programs, as any condition with persistent symptoms and duration can be classified as a chronic disease. Many specific conditions were highlighted during this inquiry, however many illnesses and conditions not mentioned in this report are just as relevant for consideration as those that are mentioned.

Prevention is a crucial approach required to combat the rising incidence and impact of chronic disease in Australia. There are a number of local and national programs that aim to educate and support people to adopt healthier lifestyles and avoid risk factors that can contribute to the onset or worsening of chronic disease. The federal, state and territory governments, as well as private health insurers and individual providers and peak bodies all have a role in preventing chronic disease, although more could be done to coordinate the programs that exist, as well as widening the scope of screening activities that can identify the earliest signs of chronic disease. Chronic disease prevention should be ongoing. This can be evidenced from the gains from tobacco programs in Australia, many of which stem from initial programs commenced forty years ago.

The coordinated care and multidisciplinary approach to improved chronic disease management is evident in the examples that show best practice in Australia and internationally. The Wagner Chronic Care Model, Patient Centred Medical Homes and supported self-management of chronic disease are evident in health care systems from the United Kingdom, the USA, Canada, across Europe, to here in Australia and New Zealand. These models can help inform the development of chronic disease care into the future, the first steps of which will be made with the 'Healthier Medicare' introduction of Health Care Home trials in 2017. These improvements are welcomed by all Australians, though the positive impact they can have on care outcomes for low socioeconomic status, rural and regional and Aboriginal and Torres Strait Islander populations may be profound.

The submissions and evidence received during this inquiry have indicated that the groundwork to improve the primary health care system to better prevent and manage chronic disease already exists, across all providers and interested parties. It is clear, however, that this cannot occur without cooperation, coordination, evaluation and adequate data and records to support Primary Health Networks in fulfilling their important role as coordinators of care.

Performance measurements, expansion of chronic disease items, improved referral and rebate claiming processes and encouraging private health insurers to manage their members in cooperation with the primary health care system is a clear goal.

The current regulatory and legislative framework that governs private health insurance in Australia is complex, but there are small areas of improvement that could be made to the *Private Health Insurance (Health Insurance Business) Rules 2015* regarding expanding the providers that can be used in a chronic disease management plan.

Preventive health promotion as well as expanded health checks will help to provide the awareness and early detection required to help combat these diseases. The Health Care Home trials which are expected to commence in 2017 will help to improve this outcome, and with appropriate funding, privacy considerations, capture and consolidation of data, and a focus on research and improvement, the cooperative care goals required to improve chronic disease primary care can become a reality.

The Committee appreciates the efforts and honesty of the large number of organisations and individuals that provided submissions and evidence to this inquiry. The breadth of chronic disease prevention, management and research in the Australian community is clearly evident and the desire to improve the system was the overwhelming message received. The recommendations made in this report, as well as the implementation of the current 'Healthier Medicare', reforms will help to achieve the first steps required in that improvement journey.

I thank all those who contributed to this inquiry. I also thank the Committee Members for their participation and contribution to this important and wide-ranging inquiry.

Steve Irons MP  
Chair





## Committee Membership

Chair Mr Steve Irons MP

Deputy Chair Mr Tony Zappia MP (From 19.10.2015)

Mr Tim Watts MP (Until 19.10.2015)

Members Ms Lisa Chesters MP

Mr Andrew Laming MP

Dr David Gillespie MP (From 9.09.2015)

Mrs Karen McNamara MP (From 19.10.2015)

Ms Jill Hall MP

Dr Andrew Southcott MP

Ms Sarah Henderson MP (Until 9.09.2015)

Mrs Ann Sudmalis MP (Until 13.02.2016)

Mr Stephen Jones MP

Mr Ken Wyatt AM, MP (Until 12.10.2015)

## Committee Secretariat

Secretary Ms Stephanie Mikac

Inquiry Secretary Mr Jeff Norris (from 25. 11. 2015)

Mr Shane Armstrong (until 6. 10. 2015)

Research Officer Mr Daniel Simon

Administrative Officer Ms Carissa Skinner





## Terms of Reference

The Standing Committee on Health will inquire into and report on best practice in chronic disease prevention and management in primary health care, specifically:

1. Examples of best practice in chronic disease prevention and management, both in Australia and internationally;
2. Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management;
3. Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care;
4. The role of private health insurers in chronic disease prevention and management;
5. The role of State and Territory Governments in chronic disease prevention and management;
6. Innovative models which incentivise access, quality and efficiency in chronic disease prevention and management.
7. Best practice of Multidisciplinary teams chronic disease management in primary health care and Hospitals; and
8. Models of chronic disease prevention and management in primary health care which improve outcomes for high end frequent users of medical and health services.





## Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ACCHS	Aboriginal Controlled Community Health Services
ACMHN	Australian College of Mental Health Nurses
ACN	Australian College of Nursing
ADA	Australian Dental Association
AHP	Allied Health Professions Australia
AHPA	Australian Health Promotion Association
AHSA	Australian Health Service Alliance
AIDS	Acquired Immune Deficiency Syndrome
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
AMS	Aboriginal Medical Services
AMSANT	Aboriginal Medical Services Alliance NT
ANMF	Australian Nursing and Midwifery Federation
ANPHA	Australian National Preventive Health Agency
APCC	Australian Primary Care Collectives
APMA	Australian Pain Management Association

APNA	Australian Primary Health Care Nurses Association
ASID	Australasian Society for Infectious Diseases
ATSI	Aboriginal and Torres Strait Islander
BHC	Broader Health Cover
CACLD	Clinical Advisory Committee on Lyme Disease
CATSINaM	Congress of Aboriginal and Torres Strait Islander Nurses and Midwives
CCSVI	Chronic Cerebrospinal Venous Insufficiency
CDC	Centers for Disease Control and Prevention (US)
CDM	Chronic Disease Management
CDMP	Chronic Disease Management Plan
CEO	Chief Executive Officer
CFS	Chronic Fatigue Syndrome
CHD	Coronary Heart Disease
CHN	Community Health Nurse
CKD	Chronic Kidney Disease
COAG	Council of Australian Governments
COPD	Chronic Obstructive Pulmonary Disease
COSA	Clinical Oncology Society of Australia
CVC	Coordinated Veterans' Care
CVD	Cardiovascular Disease
CWA	Country Women's Association
DALY	Disability-Adjusted Life Year
DHAA	Dental Hygienists Association of Australia

DHHS	Department of Health and Human Services Victoria
DNA	Deoxyribonucleic Acid
ED	Emergency Department
ELISA	Enzyme-linked Immunosorbent Assay
GDP	Gross Domestic Product
GP	General Practitioner
HARP	Hospital Admission Risks Program
IDSA	Infectious Disease Society of America
ILADS	International Lyme and Associated Diseases Society
HIV	Human Immunodeficiency Virus
KMF	Mark McManus Foundation
LDAA	Lyme Disease Association of Australia
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
LFA	Lung Foundation of Australia
LWwPP	Living Well with Persistent Pain
MBS	Medicare Benefits Schedule
MCaFHNA	Maternal, Child and Family Health Nurses Australia
ME	Myalgic Encephalomyelitis
MS	Multiple Sclerosis
NeHTA	National Electronic Health Transition Authority
NHMRC	National Health and Medical Research Council
NHS	National Health Service
NSW	New South Wales
NT	Northern Territory

NVDPA	National Vascular Disease Prevention Alliance
OECD	Organisation for Economic Co-operation and Development
OPAL	Obesity Prevention and Lifestyle
PBS	Pharmaceutical Benefits Scheme
PCEHR	Personally Controlled Electronic Health Record
PCMH	Patient-Centred Medical Home
PCR	Polymerase Chain Reaction
PHA	Private Healthcare Australia
PHC	Primary Health Care
PHCAG	Primary Health Care Advisory Group
PHI	Private Health Insurer
PHN	Primary Health Network
Qld	Queensland
RACGP	Royal Australian College of General Practitioners
RD	Rare Disease
RFDS	Royal Flying Doctor Service
RPBS	Repatriation Pharmaceutical Benefits Scheme
RVA	Rare Voices Australia
SA	South Australia
SARRAH	Services for Rural & Remote Allied Health
SES	Socioeconomic Status
Tas	Tasmania
TROG	Trans-Tasman Radiation Oncology Group
UK	United Kingdom

UoW	University of Wollongong
USA	United States of America
VCOSS	Victorian Council of Social Services
Vic	Victoria
WA	Western Australia
WHO	World Health Organization





# Recommendations

## 3 Provision of Primary Health Care for Chronic Disease

### Recommendation 1

The Committee recommends that the Australian Government undertake an independent review of the privacy restrictions governing medical practitioner access to patient records.

### Recommendation 2

The Committee recommends that the Highlight Performance Indicators for Primary Health Networks be expanded in future cycles to include the specific data capture of the:

- incidence of chronic disease in Primary Health Network catchments and the number of people with comorbid or multi-morbid conditions;
- range of services that these people access and how often they utilise different forms of treatment (general practice, allied health, hospital); and
- that this data be prioritised for research to inform targeted service provision to chronic disease populations and the expansion of Health Care Home trials and programs.

### Recommendation 3

The Committee recommends that the Australian Government investigate expanding the number of allied health treatments that can attract a Medicare Benefits Schedule rebate (MBS items 10950 to 10970) within a year, on the proviso that the patient has the relevant General Practitioner Management Plan and Team Care Arrangements in place.

**Recommendation 4**

The Committee recommends that the Australian Government examine the process for a chronic disease patient to be referred for initial specialist assessment by a Medicare Benefits Schedule registered allied health professional without the need to get a referral from their general practitioner, only when:

- the patient was originally referred to the allied health professional by their general practitioner; and
- the original referral indicates that specialist assessment may be warranted if the allied health professional agrees it is warranted.

**Recommendation 5**

The Committee recommends the Australian Government explore ways to expand and better utilise the role of nurses in the provision and coordination of care for chronic disease management within a general practitioner-led care system.

**4 Best Practice, Multidisciplinary Teams and Education****Recommendation 6**

The Committee recommends that the Australian Government examine the inclusion of an integrated health assessment check for cardiovascular, kidney disease risk and diabetes as per that developed by the National Vascular Disease Prevention Alliance, where a patient does not already qualify for an existing assessment and the treating practitioner suspects they are at risk of these chronic diseases.

**Recommendation 7**

The Committee recommends a review of the self-identification process for accessing health checks and the like.

**Recommendation 8**

The Committee recommends that the development and implementation of the Health Care Home trials, as part of Healthier Medicare, be prioritised and continue to be developed in consultation with relevant expert panels; and

That the outcomes of the trials be evaluated as they occur to inform further coordinated care developments for chronic disease patients and the wider Australian community.

**Recommendation 9**

The Committee recommends that the Australian Government examine reforms to the Medicare Benefit Schedule to allow for a practitioner to

claim a rebate for a chronic disease management consultation and a general consultation benefit, for the same person on the same day.

#### Recommendation 10

The Committee recommends that the Australian Government examine the feasibility of linking relevant Medicare Benefits Schedule, Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data, with applicable hospital patient data, to create a unified patient dataset, or to consider this link when developing the National Minimum Data Set for Healthier Medicare purposes.

## 5 Funding Models

#### Recommendation 11

The Committee recommends that the Australian Government commit to providing consistent support and funding for the establishment of Primary Health Networks or similar into the future, to enable consistent development and support for chronic disease prevention and management.

#### Recommendation 12

The Committee recommends that the Australian Government examine the current Practice Incentives Program with the aim that it be expanded to include programs for breast, bowel and skin cancer screening, as well as the Integrated Health Check developed by the National Vascular Disease Prevention Alliance; and

That these programs, as well as the existing Practice Incentive Programs, be evaluated and measured to identify improvements to management of chronic disease.

#### Recommendation 13

The Committee recommends that the Australian Government continue to prioritise funding of the evolution and expansion of the My Health Record to support improvements in the prevention and management of chronic disease, as well as the wellness of all Australians.

## Appendix A - Case Study

#### Recommendation 14

The Committee recommends that the Australian Government consider:

- developing a case definition for tick-borne and Lyme-like illnesses for addition to the national notifiable disease register;

- developing protocols of diagnosis and treatment for tick-borne and Lyme-like diseases; and
- continuing to prioritise the research areas identified by the Clinical Advisory Committee on Lyme Disease.

## Introduction

- 1.1 Chronic diseases are the leading cause of illness, disability, and mortality in Australia, accounting for 90 per cent of all mortalities in 2011.<sup>1</sup> According to the Australian Institute of Health and Welfare, in 2014 seven million people, or 35 per cent of the population, have at least one of nine major chronic conditions: asthma, type 2 diabetes, coronary heart disease, cerebrovascular disease, arthritis, osteoporosis, chronic obstructive pulmonary disease, depression, or high blood pressure.<sup>2</sup>
- 1.2 This large percentage of the Australian population suffering from chronic disease is indicative of the changing nature of how Australians suffer from disease, and how the current primary health care system in Australia, whilst world class, is predicated on a system of health care that is largely based on a notion of episodic and disjointed care, that is costly and does not cater to the needs of chronic disease patients.
- 1.3 This cost imposed by chronic disease on Australian society is very large. The direct health care cost of the four most expensive chronic diseases alone – cardiovascular diseases, oral health, mental disorders and musculoskeletal conditions – was estimated at about \$27 billion, or 36 per cent of total allocated health expenditure, in 2008-09.<sup>3</sup>
- 1.4 This does not account for the broader social costs, such as lost productivity and residential care, outside of the health care system. For example, musculoskeletal conditions including osteoarthritis, osteoporosis and back and neck pain are estimated to cost the Australian community

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1 Department of Health, 'Chronic disease', <http://www.health.gov.au/internet/main/publishing.nsf/Content/chronic-disease>, viewed 14 January 2016.

2 Australian Institute of Health and Welfare, *Australia's Health 2014*, 2014, Chapter 4.2: 'Chronic disease – Australia's biggest health challenge', p. 95.

3 Australian Institute of Health and Welfare, *Australia's Health 2014*, 2014, Chapter 4.2: 'Chronic disease – Australia's biggest health challenge', p. 98.

\$55 billion per year;<sup>4</sup> chronic pain is estimated to cost \$34 billion per year;<sup>5</sup> and diabetes costs are estimated at about \$14.6 billion per year.<sup>6</sup>

- 1.5 These significant costs indicate the requirement to consider alternative funding models and the potential for a shift in the Medicare system from episodic care support, where a patient's care needs are supported related to each discrete visit to a healthcare provider, to a more holistic care cycle system, where a patient's support is calculated and paid based on wellness and their overall care needs and outcomes, from all appropriate health care providers.
- 1.6 Often chronic diseases impact on the hospital and emergency health care systems, through the escalation of often preventable complications of chronic disease. These costly episodes could potentially be avoided in some cases by providing appropriate holistic and patient-centred care in the primary health care setting, resulting in a better use of resources and better outcomes for the patients involved.
- 1.7 Improved health education, promotion and screening have also been shown to significantly impact on the burden of chronic disease, by helping patients, or potential patients, to understand the contributory lifestyle and other factors that often lead to chronic diseases such as diabetes, cardiovascular disease and chronic kidney disease.
- 1.8 The combination of improved chronic disease education, coordinated care, and revised funding models, as experienced in some international jurisdictions, could ultimately reform chronic disease management in primary health care in Australia.

## About the Inquiry

### Objectives and Scope

- 1.9 On 26 May 2015, the Minister for Health, the Hon. Sussan Ley MP, referred the Inquiry into Chronic Disease Prevention and Management in Australia (the inquiry) to the House of Representatives Standing Committee on Health (the Committee).

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

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

6 Diabetes NSW, *Submission 60*, p. 1.

- 1.10 The terms of reference required the Committee to inquire into and report on best practice in chronic disease prevention and management in primary health care, specifically:
- Examples of best practice in chronic disease prevention and management, both in Australia and internationally;
  - Opportunities for the Medicare payment system to reward and encourage best practice and quality improvement in chronic disease prevention and management;
  - Opportunities for the Primary Health Networks to coordinate and support chronic disease prevention and management in primary health care;
  - The role of private health insurers in chronic disease prevention and management;
  - The role of state and territory Governments in chronic disease prevention and management;
  - Innovative models which incentivise access, quality and efficiency in chronic disease prevention and management;
  - Best practice of Multidisciplinary teams chronic disease management in primary health care and Hospitals; and
  - Models of chronic disease prevention and management in primary health care which improve outcomes for high end frequent users of medical and health services.

## Inquiry Conduct

- 1.11 The inquiry was announced on 26 May 2015 via media release, with submissions sought by 31 July 2015. In an effort to capture as much evidence as possible for the duration of the inquiry, the Committee accepted submissions after this date.
- 1.12 In total, the Committee received 210 submissions and 30 exhibits from a wide range of individuals and organisations. Submissions and exhibits received during the inquiry are listed at Appendices A and B respectively.
- 1.13 The Committee held 13 public hearings as shown below.

<b>Date</b>	<b>Place</b>
18 August 2015	Canberra, ACT
21 August 2015	Canberra, ACT
18 September 2015	Sydney, NSW

1 October 2015	Melbourne, Vic
23 October 2015	Sydney, NSW
18 November 2015	Bendigo, Vic
12 February 2016	Bomaderry, NSW
18 February 2016	Brisbane, Qld
19 February 2016	Tumbi Umbi, NSW
23 February 2016	Canberra, ACT
4 March 2016	Adelaide, SA
11 March 2016	Perth, WA
31 March 2016	Newcastle, NSW

- 1.14 The witnesses who gave evidence at these hearings are listed at Appendix C. Submissions received and transcripts of public hearings are available on the Committee's webpage at: <[www.aph.gov.au/health](http://www.aph.gov.au/health)>.

## Senate Inquiry into Tick-Borne Diseases

- 1.15 On 12 November 2015, the Senate referred the matter of 'The growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients' to the Senate Community Affairs References Committee.<sup>7</sup>
- 1.16 As part of this Committee's chronic disease inquiry, there were a number of submissions received highlighting concerns about the categorisation, identification and treatment of a Lyme-like tick-borne disease in Australia.<sup>8</sup> As a result, the Committee held a roundtable public hearing in Sydney on 18 November 2015 to hear about the growing evidence and concern about how this illness is managed in Australia.

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7 See the Inquiry homepage at <[http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Lyme-like\\_Illness](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Lyme-like_Illness)>

8 Lyme Disease Association of Australia, *Submission 85*; Ms Emily O'Sullivan, *Submission 156*; Karl McManus Foundation, *Submission 158*; Dr Richard Schloeffel, *Submission 162*; Sarcoidosis Lyme Australia, *Submission 166*; Name withheld, *Submission 171*; Ms Sharon King, *Submission 176*; Mrs Joanne O'Donoghue, *Submission 186*.

- 1.17 However, the relevant condition covered by this hearing is one of only a number of conditions that can be classified as chronic diseases within Australia.
- 1.18 The Senate Inquiry is welcomed by the Committee, as this important emerging condition can be given special focus by that inquiry, and accordingly the Committee has referred the Senate Committee to the evidence received to date.
- 1.19 Due to the specific focus of the Senate inquiry, this report focuses on the evidence received regarding tick-borne and Lyme-like illnesses as a case study.<sup>9</sup>

## **‘Healthier Medicare’ Chronic Disease Announcement**

- 1.20 On 31 March 2016, the Prime Minister, the Hon. Malcolm Turnbull MP, and the Minister for Health, the Hon. Sussan Ley MP, made a joint announcement introducing a package of reforms as part of ‘Healthier Medicare’ aimed at modernising and uniting the chronic disease management process in Australia.<sup>10</sup>
- 1.21 The reforms outlined in this package align substantively with the models and best practice reforms suggested to the Committee during the conduct of this inquiry. The two year trial of Health Care Homes, to be undertaken from 1 July 2017, will introduce many elements of the suggested reforms discussed in this report.
- 1.22 The Committee welcomes this announcement, and will acknowledge the reforms, as relevant, throughout the evidence and consideration ahead.

## **Report Structure**

- 1.23 The report is comprised of 5 chapters and outlines the Committee’s findings, comments and recommendations in relation to its Inquiry into Chronic Disease Prevention and Management in Primary Health Care in Australia. More specifically:
- Chapter 2 defines what chronic disease means in Australia; the major conditions constituting the burden chronic disease has on Australian

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<sup>9</sup> Please see Appendix A.

<sup>10</sup> The Hon. Malcolm Turnbull MP, Prime Minister and The Hon. Sussan Ley MP, Minister for Health, Minister for Aged Care, Minister for Sport ‘A Healthier Medicare for chronically-ill patients’, *Media Release*, 31 March 2016.

health care; the role of prevention in chronic disease health care and what the role of primary health care is within the current system. This chapter also discusses a number of other conditions that were raised with the Committee during the conduct of the inquiry that may not normally be considered widely in the discussion of chronic disease in Australia.

- Chapter 3 discusses the current provision of chronic disease primary health care in Australia and how state and territory Governments, Primary Health Networks, allied health providers and private health insurers contribute to this system. This chapter also discusses what the identified gaps in current care provision may be and how they can be better catered for. Relevant international examples are also outlined.
- Chapter 4 outlines the extensive evidence that the Committee received on best practice in chronic disease management, multidisciplinary teams and education for both prevention and management of chronic disease. The chapter also discusses whether best practice can, or should, be a 'one size fits all' concept, as well as the benefits and risks of the expansion of electronic health technology and the associated patient and health data.
- Chapter 5 concludes the report by discussing the issue of funding for chronic disease prevention and management, practice incentive payments, how the current model can potentially be informed by recent and current changes in international jurisdictions, as well as the recently announced reform trials in Australia.

# 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 transitional 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'.<sup>1</sup> 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

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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.<sup>2</sup>

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.<sup>3</sup> 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.<sup>4</sup> 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.<sup>5</sup>

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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,<sup>6</sup> with chronic disease reportedly accounting for 70 per cent of the health gap between these two groups.<sup>7</sup> More socioeconomically disadvantaged people also face higher rates of chronic disease,<sup>8</sup> as do older Australians,<sup>9</sup> asylum seekers and refugees, ‘certain immigrant groups’, and the LGBTI community.<sup>10</sup> 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.<sup>11</sup>
- 2.11 Part of the disproportionate incidence of chronic disease is due to the corresponding incidence of risk factors.<sup>12</sup> 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.<sup>13</sup> Aboriginal and Torres Strait Islanders also have higher incidence of risk factors, which contributes to the higher rates in rural areas.<sup>14</sup> Socially and economically disadvantaged communities likewise have higher risk factors.<sup>15</sup>
- 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.<sup>16</sup>

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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.<sup>17</sup>
- 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.<sup>18</sup>
- 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.<sup>19</sup>
- 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.<sup>20</sup>
- 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.<sup>21</sup>

## 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.<sup>22</sup> 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.<sup>23</sup>
- 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.<sup>24</sup>

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.<sup>25</sup>

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.<sup>26</sup>

2.22 Smoking is considered the 'predominant cause of COPD'<sup>27</sup> and a major risk factor for chronic respiratory conditions in general.<sup>28</sup> 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.<sup>29</sup> The LFA notes the prevalence of COPD in people over the age of 40 (7.5 per cent).<sup>30</sup> 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.<sup>31</sup> Asthma Australia estimates stated that asthma affects nearly 2.4 million people.<sup>32</sup>

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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.<sup>33</sup>

## 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.<sup>34</sup>

- 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.<sup>35</sup> Cardiovascular disease causes nearly a third (30 per cent) of all mortality, and altogether contributes to over half (55 per cent).<sup>36</sup>
- 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.<sup>37</sup> Cerebrovascular disease, which includes stroke, is the second leading cause of mortality, accounting for 8 per cent of all mortalities.<sup>38</sup>
- 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.<sup>39</sup>

## 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.<sup>40</sup>

- 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.<sup>41</sup>
- 2.31 Kidney Health Australia states that about 1.7 million Australian adults have 'at least one clinical sign of CKD',<sup>42</sup> 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.<sup>43</sup>
- 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.<sup>44</sup>

## 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.<sup>45</sup>

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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.<sup>46</sup>
- 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,<sup>47</sup> 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.<sup>48</sup>
- 2.36 According to Diabetes Australia, diabetes will become the leading burden of disease in Australia by 2017.<sup>49</sup> 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.<sup>50</sup> 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.<sup>51</sup>
- 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.<sup>52</sup>
- 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.<sup>53</sup> Diabetes was the sixth leading cause of mortality in Australia in 2011, contributing to 10 per cent of all mortalities.<sup>54</sup>

## 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
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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.<sup>55</sup>

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%.<sup>56</sup>

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).<sup>57</sup>

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.<sup>58</sup>

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.<sup>59</sup>

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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’<sup>60</sup> and notes the application of chronic disease management to people living with HIV.<sup>61</sup>
- 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’.<sup>62</sup> The AIHW also notes that HIV/AIDS is one of the causes of dementia, especially among those with younger onset dementia.<sup>63</sup>
- 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.<sup>64</sup>
- 2.55 The Victorian AIDS Council called HIV a ‘preventable’ disease, commenting that the use of HIV pre-exposure prophylaxis, which has been approved in the USA, is still to be approved in Australia.<sup>65</sup>
- 2.56 The Committee made limited reference to HIV in its previous report this Parliament, *The Silent Disease: Inquiry into Hepatitis C in Australia*.<sup>66</sup>

## Cancer

- 2.57 Cancer is considered one of the four major disease groups within chronic disease by the AIHW,<sup>67</sup> 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](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.<sup>68</sup>

- 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'.<sup>69</sup> 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.<sup>70</sup>
- 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.<sup>71</sup>
- 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'.<sup>72</sup> In its submission, TROG stated the effectiveness of radiation oncology, with 90 radiation oncology centres throughout Australia.<sup>73</sup>
- 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.<sup>74</sup>

## Chronic Pain

- 2.62 The Committee also received submissions addressing chronic pain.<sup>75</sup> 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...<sup>76</sup>

- 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.<sup>77</sup> Painaustralia reports that five per cent of those with chronic pain also report severe disability.<sup>78</sup>
- 2.64 APMA and Painaustralia cite evidence that the condition costs \$34 billion a year, including healthcare costs and lost productivity.<sup>79</sup> Painaustralia also notes that chronic pain affects one in three people over 65.<sup>80</sup>
- 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'.<sup>81</sup>

## 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.<sup>82</sup>
- 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.<sup>83</sup>

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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'.<sup>84</sup>
- 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'.<sup>85</sup> This point was reinforced by the Garvan Institute of Medical Research.<sup>86</sup>

## Lymphoedema

- 2.70 The Committee received a submission from the Lymphoedema Action Alliance and from one individual suffering from lymphoedema.<sup>87</sup> 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.<sup>88</sup>
- 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.<sup>89</sup> 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.<sup>90</sup>

## 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.<sup>91</sup>

- 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.<sup>92</sup> 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.<sup>93</sup>
- 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.<sup>94</sup>
- 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’.<sup>95</sup>
- 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’.<sup>96</sup>
- 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.<sup>97</sup>

- 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’.<sup>98</sup>
- 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’.<sup>99</sup>

## 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.<sup>100</sup>
- 2.84 The submission notes that up to 24 000 Australians are currently diagnosed with MS.<sup>101</sup>
- 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’.<sup>102</sup> The Australian Physiotherapy Association identified that MS is also a chronic condition which can benefit from targeted physiotherapy interventions.<sup>103</sup>
- 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

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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.<sup>104</sup>

## Myalgic Encephalomyelitis (Chronic Fatigue Syndrome)

2.87 The Committee heard from several individuals about myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS).<sup>105</sup> It is contended in several submissions that up to 100 000 Australians suffer from ME,<sup>106</sup> with about a quarter of those confined to their houses or beds as a result of their illness.<sup>107</sup> The Victorian Government, on its Better Health Channel website, states that 'at least 35 000 Victorians have ME/CFS'.<sup>108</sup> 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.'<sup>109</sup> 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.<sup>110</sup>

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.<sup>111</sup>

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

105 Mrs Kim Crowe, *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](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.<sup>112</sup>
- 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.<sup>113</sup> The Dental Hygienists Association of Australia (DHAA) also states that people with chronic diseases have higher rates of dental disease.<sup>114</sup> AIHW notes that oral health accounts for the second highest amount of spending nationally, over \$7 billion in 2008-09.<sup>115</sup>
- 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.<sup>116</sup> This connection was also identified by the Australian Dental Association,<sup>117</sup> and the DHAA also stated that people with chronic disease have an increased risk of dental disease.<sup>118</sup>
- 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.<sup>119</sup>

## 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.<sup>120</sup>

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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’.<sup>121</sup>
- 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’.<sup>122</sup>
- 2.98 Swallowing difficulties can lead to malnutrition, respiratory problems, and sometimes can be fatal.<sup>123</sup>

## Tick-Borne and Lyme-Like Diseases

- 2.99 The Committee received several written submissions from individuals suffering from tick-borne or Lyme-like diseases,<sup>124</sup> as well as organisations and doctors advocating on their behalf.<sup>125</sup> 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’.<sup>126</sup>
- 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.<sup>127</sup> Vision conditions affect an estimated 575 000 Australians,<sup>128</sup> with a total cost to the economy of as much as \$16.6 billion.<sup>129</sup> 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’.<sup>130</sup>
- 2.104 Poor vision is associated with co-occurring chronic diseases, particularly with diabetes.<sup>131</sup> 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.<sup>132</sup>
- 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.<sup>133</sup>

## 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 Ophthalmologists, *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'.<sup>134</sup> 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.<sup>135</sup>

- 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'.<sup>136</sup>
- 2.108 Despite this, RVA states that 'collectively the RD community is larger than the AIDS and Cancer communities combined'.<sup>137</sup>
- 2.109 E-health and telemedicine were identified as having potential to improve the delivery of health care for people living with a RD,<sup>138</sup> while RVA also emphasised the need for best practice guidelines specific to RDs.<sup>139</sup> 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.<sup>140</sup>

## 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

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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.<sup>141</sup>

## 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.<sup>142</sup> 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.<sup>143</sup>

## 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.<sup>144</sup> 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;<sup>145</sup>
  - 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;<sup>146</sup>
  - 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;<sup>147</sup>
  - beyondblue's Man Therapy campaign – promotion campaign and online tools to allow men to assess and understand mental health factors about depression and anxiety;<sup>148</sup> 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.<sup>149</sup>
- 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;<sup>150</sup> and
  - HCF's My Health Guardian – telephone based support to HCF members to promote healthy behaviours and adherence with medications and GP action plans.<sup>151</sup>
- 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.<sup>152</sup>
- 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.<sup>153</sup>

- 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.<sup>154</sup>

## 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.<sup>155</sup> 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.<sup>156</sup> Over a third of this expenditure is

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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.<sup>157</sup>

- 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.<sup>158</sup> 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.<sup>159</sup>
- 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,<sup>160</sup> while beyondblue estimates a 10 to 32 year discrepancy in life expectancy.<sup>161</sup>
- 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.<sup>162</sup>
- 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.<sup>163</sup>
- 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.<sup>164</sup> Chronic diseases also occur more frequently among lower socioeconomic people,<sup>165</sup> and the incidence of chronic disease increases with age.<sup>166</sup>

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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.<sup>167</sup>

- 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.*<sup>168</sup>

- 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.<sup>169</sup>

- 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.<sup>170</sup>

- 2.140 Socioeconomic status (SES) of communities and their targeted provision of health care or health promotion programs was raised with the Committee:
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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.<sup>171</sup>

- 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.<sup>172</sup>

- 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.



## Provision of Primary Health Care for Chronic Disease

### Introduction

- 3.1 Health care for chronic disease in Australia would ideally be a cohesive and coordinated care cycle; however it is often a result of competing priorities or interactions between the patient, their primary care provider (GP or specialist), allied health providers and hospital or emergency care.
- 3.2 The disconnected nature of many care pathways for chronic disease sufferers is often the result of poor planning, education and awareness, lack of coordination between acute and primary care, or due to the complications that arise from having comorbid or multi-morbid conditions. For example, an elderly patient with diabetes may often have over 100 encounters with the health care system per year, seeing anywhere up to eight or nine different providers.<sup>1</sup>
- 3.3 The requirement for a patient-centred holistic care model has been a central message received by the Committee during the conduct of this Inquiry, with best practice models, programs and coordinated care frameworks provided as the solution to improving chronic disease management and prevention in Australia. These suggested models and reforms are discussed in more detail in Chapter 4.
- 3.4 Currently in Australia the overarching system of health care is moving towards an adaptive model of health care and an understanding of that current system is crucial to understanding the elements that can improve.
- 3.5 The 31 March 2016 announcement of the 'Healthier Medicare' chronic disease management reforms, to introduce trials of Health Care Homes, is a step in the right direction to providing coordinated, multidisciplinary

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1 Professor Libby Roughead, *Submission 41*, p. 2.

care for chronic disease sufferers. However, trials are not scheduled to start until July 2017, so analysing the current primary health care system is relevant to chronic disease prevention and management in the shorter term.

- 3.6 This Chapter will outline how the current system caters for chronic disease management and will identify some of the pilot programs, reviews and changes that are currently occurring in primary health care.

## **Responsibilities – Role of Commonwealth and States**

- 3.7 The dichotomy of health care in Australia is related to the Commonwealth's responsibility for primary health care and the state and territory responsibility for acute hospital care. Policy responsibilities for the two are separated, though the funding mechanisms are not as clearly separated.

- 3.8 According to the Australian Institute of Health and Welfare (AIHW), in 2011-12:

The second largest component of health spending was for primary health care services (\$50.6 billion, or 36.1% of total health expenditure). Primary health care includes a range of front-line health services delivered in the community, such as GP services, dental services, other health practitioner services (for example, physiotherapists, optometrists), and all community and public health initiatives. It also includes the cost of medications not provided through hospital funding.<sup>2</sup>

- 3.9 Hospital services are the largest component of health care, totalling \$53.5 billion, with \$42 billion of that expenditure through public hospitals.<sup>3</sup>

- 3.10 These large components of the health care system, and their associated expenditures, reflect the essential components of the health care system that interact with patients suffering from chronic disease, however the separation of responsibilities between the Commonwealth and state and territory governments for these components of health care is complex.

- 3.11 Additionally, state and territory governments have some responsibility over the social determinants of health, as outlined by the Royal Australian College of General Practitioners (RACGP):

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2 Australian Institute of Health and Welfare, *Australia's Health 2014*, 2014, Chapter 4.2: 'Chronic disease – Australia's biggest health challenge', p. 49.

3 Australian Institute of Health and Welfare, *Australia's Health 2014*, 2014, Chapter 4.2: 'Chronic disease – Australia's biggest health challenge', p. 48.

States and territories have a major role in population chronic disease prevention by influencing the social determinants of health (eg food supply and marketing, urban design, public transport, community safety, education). States and territories are motivated to reduce potentially preventable hospital admissions and offer services with the same aim as CDM in general practice – keeping people well and out of hospital.

State and territory primary healthcare services provide a safety net for patients who cannot afford to access private allied health or nursing services, or when the patient requires more support from allied health professionals and have exhausted their allowed Medicare rebates.<sup>4</sup>

3.12 These social determinants can impact on a person's overall wellbeing and the policy directions set for primary health care can affect their overall influence on a patient as well.

3.13 The complexities of the interactions patients face was outlined in the Reform of the Federation White Paper *Issues paper 3: Roles and Responsibilities in Health*:

...there is currently no single overarching 'health system' in Australia. Rather, health care is a complex web of services, providers and structures. All levels of government – the Commonwealth, the States and Territories, and local government – share responsibility for health. They have different roles (funders, policy developers, regulators and service deliverers) and in many cases those roles are shared.

The Commonwealth is predominantly responsible for primary care, which includes general practitioners and some medical specialists. Since the successful referendum on social services in 1946, the Commonwealth has become increasingly involved in almost all aspects of health care. The States and Territories are predominantly responsible for public hospitals, ambulances, community and mental health services, and health infrastructure. Both levels of government have a role in community health, mental health, public health programmes, and the health workforce. The not-for-profit and private sectors have significant roles in health care, particularly in service delivery...<sup>5</sup>

3.14 The evolution of Commonwealth involvement in primary health care has been a constant process since after World War I. Prior to that and at the point of Federation, health care was considered to be a local issue and was the responsibility of state governments.

3.15 The landmark introduction of the Pharmaceutical Benefits Scheme (PBS) in 1944 and the successful referendum of 1946 established the social

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4 RACGP, *Submission 135*, p. 13.

5 Commonwealth of Australia, *Reform of the Federation White Paper: Roles and Responsibilities in Health: Issues Paper 3*, December 2014, pp 1-2.

security foundation for Commonwealth provision of primary health care. The creation of Medibank in 1975 and Medicare in 1984 have guided the policy and primary health care system development into the general practitioner-led system that Australia has today.<sup>6</sup> More detail on Medicare and the Medicare Benefits Schedule (MBS) are outlined in Chapter 5.

3.16 This constitutional separation of health care responsibility has led to robust developments in primary health care nationwide, with associated state and territory driven hospital and tertiary care services. However, the coordination required for the multidisciplinary care of chronic disease patients is often complicated or threatened by transition between the two systems.

3.17 While the coordination of care in transition is a challenge to chronic disease care, the cooperation between the sectors is increasing, as commented on by the Centre for Research Excellence:

I think the discussion around the new approach to federalism and looking at much better cooperation between the state and the Commonwealth has – just over the last six months – really lifted that out of contention. Now we are seeing many hospitals looking at these very complex patients who are not well-served by the episodic visit, and thinking, 'How can we keep these people healthy in the community?' and being true consultants to a chronic disease process, which... lasts for years. The hospital is just a snapshot.<sup>7</sup>

3.18 Additionally, the intent of the Health Care Home reform trials announced to commence in 2017 will presumably allow for closer coordination between state hospitals and multidisciplinary care teams in primary care, to allow for better discharge care coordination.

3.19 Also, the Council of Australian Governments (COAG) Health Council communique of 8 April 2016 reflects a common agreement that the challenges of coordinating care for chronic disease patients can only be addressed across systems and 'that major pressures on the health system can only be fully addressed if governments act collaboratively'.<sup>8</sup>

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6 More detailed information on the history of this development can be found in Chapter 2 of *Reform of the Federation White Paper: Roles and Responsibilities in Health: Issues Paper 3*, December 2014.

7 Professor Claire Jackson, Director, Centre of Research Excellence in Quality and Safety in Integrated Primary-Secondary Care, University of Queensland, *Official Committee Hansard*, Brisbane, 18 February 2016, p. 25.

8 Council of Australian Governments Health Council, 'Communique', 8 April 2016, <<http://www.coaghealthcouncil.gov.au/Publications/Communiques/ArtMID/522/ArticleID/92/CHC-Communique-8-April-2016>>, viewed 12 April 2016.

## Patient Transition – Tertiary to Primary Care

3.20 The nature of the impact of many chronic diseases results in patients receiving acute care in the hospital system, either for their chronic condition directly, or complications related to comorbid or concurrent conditions. After this care is complete, the patient will transition back into the primary care system to allow for their ongoing usual care to proceed.

3.21 The importance of a clear and concise discharge and care plan between a patient's tertiary acute care and their ongoing primary care is paramount, as outlined by Dr Jodi Graham:

I think it is all about communication, however you communicate with the GPs. At the moment in my hospital in WA we do not have electronic health records. If we had an electronic health record that you could share with the GPs it would be a very easy way to put the discharge summary out there so that they could see it immediately. It is really the immediacy of getting the information to the GPs so that they can take over management... It is a matter of improving that communication and of the hospitals making sure that they actually get good information available to the GPs immediately so that there is no gap for the patients.<sup>9</sup>

3.22 Additionally, Dr Graham highlighted the variable timeliness and quality of discharge summaries and that progressing to a system of timely treatment information is essential:

It varies between two hours and four weeks, and the quality is highly variable. It depends on who does the discharge summary. In hospitals we have a lot of junior doctors. If the junior doctor does the discharge summary and they do not know what the specialist was thinking, you get a different answer coming out of them. So sometimes I see people walking out with a discharge summary, and I would look at it and go, 'Wow, that looks nothing like what I thought the patient actually had – nothing like it'.

...

Real-time information is the key to treating people. It really is.<sup>10</sup>

3.23 This requirement for patient treatment information and coordination is especially relevant given the identification of instances where patients were not able to be treated in hospitals or primary care due to privacy concerns around identifying the patient or their care history.

3.24 Dr Peter Dobson identified the issue of privacy restrictions hampering the timely and appropriate care of a patient:

I can sit in my office with a lady who has had a CT of her brain – she might have had a stroke; she might not have – and I am not

<sup>9</sup> Dr Jodi Graham, *Official Committee Hansard*, Perth, 11 March 2016, p. 7.

<sup>10</sup> Dr Jodi Graham, *Official Committee Hansard*, Perth, 11 March 2016, p. 7.

able to get the result out of the local hospital. Of course, the receptionist says, 'No. You have to get a signed declaration from the lady, and send it in to our medical records. We'll have a look at it and we'll send you the result.' This lady is dribbling in the chair next to me. I need the result now. It is ridiculous.<sup>11</sup>

- 3.25 This aspect of care coordination, provision of care information, or the provision of channels to provide it, and the direct management of a patient's care into a multidisciplinary care setting is one that the Primary Health Networks (PHNs) are ideally established to manage.
- 3.26 The RACGP stated:
- States and territories need to have the will and ability to work with PHNs to create an integrated system. It is in the interest of all parties to facilitate patient transition from hospitals to primary care when the patient has a long-term condition, but does not require specialist care.<sup>12</sup>
- 3.27 Lung Foundation Australia also commented on PHN coordination with peak bodies:
- The new Primary Health Networks, as commissioning bodies, should look to engage these peak bodies as partners to deliver evidence-based and nationally consistent training and to provide direct support to patients as they transition from hospital to the community. Ideally, this should be done in partnership with the hospital networks.<sup>13</sup>
- 3.28 Partnering with hospitals, either by the PHNs or directly by other primary care providers (general practices or community health providers) is essential to managing a patient's ongoing care needs and coordination. The enhanced role of electronic patient records is also a contributing factor to this coordination required.
- 3.29 The evolving role of the PHNs is discussed below and the models and electronic records that can be used to inform better practice for managing transition and care are discussed in Chapter 4.

## **Role of Primary Health Networks**

- 3.30 In May 2014, the then Health Minister, the Hon. Peter Dutton MP, announced the establishment of Primary Health Networks (PHNs), centred around general practice, and aligned to state and territory health

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11 Dr Peter Dobson, Chair, Central Queensland, Wide Bay, Sunshine Coast Primary Health Network, *Official Committee Hansard*, Brisbane, 18 February 2016, p. 9.

12 RACGP, *Submission 135*, p. 13.

13 Mrs Heather Allan, Chief Executive Officer, Lung Foundation Australia, *Official Committee Hansard*, Brisbane, 18 February 2016, p. 11.

network arrangements to ensure efficiency and effective working relationships.<sup>14</sup>

- 3.31 The then Health Minister acknowledged primary health care as the sector best positioned to manage chronic disease, and committed PHNs to working with both public and private providers to develop innovative health solutions.<sup>15</sup> PHNs started operating from 1 July 2015, and replaced existing Medicare Locals.
- 3.32 To date, 31 PHNs have been established and interact with general practitioners via GP-led Clinical Councils in each PHN. Allied health professionals are also be represented in Clinical Councils. Further, Community Advisory Committees will be established to allow members of the community to interact with PHNs.<sup>16</sup>
- 3.33 As commissioners of health care services (from 1 July 2016), the PHNs are limited in delivering services; however, they can do so if required:
- Where the PHN needs assessments identify that there is a lack of, or inequitable access to medical and healthcare services, PHNs must exhaust all possibilities for local service provision by an external provider prior to seeking the department's approval to directly provide services either as an interim or longer term arrangement. In these instances, the PHN must demonstrate to the department that the region is lacking appropriate services and the PHN has investigated alternative avenues for service delivery.<sup>17</sup>
- 3.34 Against this background, there was much evidence presented during the inquiry addressing the role of PHNs in chronic disease management and prevention. A number of common themes arose, including the role of each PHN as a commissioner of services, as coordinator of partnerships within their regions, and the various programs developed and piloted by PHNs, often in conjunction with state and territory governments.
- 3.35 The Brisbane South Primary Health Network commented on the central role of coordination and integration that PHNs are aiming for:
- With the commissioning process there is the opportunity for primary health networks to provide a better coordinating and integrating role and I suppose, through a contract with the service provider, provide more detail about what sorts of services are

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14 The Hon. Peter Dutton MP, Minister for Health, Minister for Sport, 'Rebuilding Primary Care', *Media Release*, 13 May 2014.

15 The Hon. Peter Dutton MP, Minister for Health, Minister for Sport, 'Rebuilding Primary Care', *Media Release*, 13 May 2014.

16 Department of Health, *Frequently Asked Questions on the Establishment of Primary Health Networks*, pp. 4- 5, <<http://www.wapha.org.au/wp-content/uploads/2016/01/Primary-Health-Networks-FAQ.pdf>>, viewed 19 April 2016.

17 Department of Health, *Frequently Asked Questions on the Establishment of Primary Health Networks*, p. 5.

offered and what level of integration there is with other care providers. So I suppose that commission does provide some opportunities there.<sup>18</sup>

3.36 Similar comments were made by the Murray PHN:

I think a big change will be the introduction of the commissioning role that Primary Health Networks will play from 1 July 2016, based upon identification of needs and then commissioning health services to specifically ensure that services are available and, in addition, ensure greater coordination and engagement of those services that are available for those specific health needs.<sup>19</sup>

3.37 Primary Health Tasmania reaffirmed this approach,<sup>20</sup> adding that it has an established reputation demonstrated through its role as facilitator which:

...has been evidenced in work with the mental health services sector in preparation for Partners in Recovery funding and with the health and aged care sector in preparation for Better Access to Palliative Care (THAP) funding. In both instances the PHN role was valued as a neutral leader who, in not competing for funding, could assist the sector to most appropriately plan for and develop collaborative approaches to applications.<sup>21</sup>

3.38 On the commissioning role, Adelaide PHN stated:

As a commission agency, the Adelaide PHN will ensure existing and new services meet criteria around best practice in chronic disease prevention and management. The assessment processes will look at the services from a number of viewpoints - ensuring they meet population health outcomes, evidence-based indicator guidelines, best practice chronic care, and value for money.<sup>22</sup>

3.39 Adelaide PHN also provides GP support through a variety of methods, and encourages local primary healthcare research in collaboration with research organisations and universities.<sup>23</sup> The Adelaide PHN also aims to foster community engagement and clinical input into governance of the PHN, developing the connections between health providers and the community across the region.<sup>24</sup>

3.40 South Eastern Melbourne PHN (SEMPHN) stated that PHNs are:

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18 Dr Peter Adkins, Brisbane South Primary Health Network, *Official Committee Hansard*, Brisbane, 18 February 2016, p. 5.

19 Mr Matthew Jones, Murray Primary Health Network, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 56.

20 Primary Health Tasmania, *Submission 142*, pp 13-14.

21 Primary Health Tasmania, *Submission 142*, p. 13.

22 Adelaide Primary Health Network, *Submission 119*, p. 32.

23 Adelaide Primary Health Network, *Submission 119*, p. 32.

24 Adelaide Primary Health Network, *Submission 119*, p. 34.

- ...ideally placed to bring health leaders together to encourage the partnerships needed for fully integrated out-of-hospital care.<sup>25</sup>
- 3.41 Ways in which PHNs can fulfil the role of bringing together various service providers were enumerated in SEMPHN's submission.<sup>26</sup>
- 3.42 This theme was repeated throughout the various submissions received from PHNs.<sup>27</sup> As Murrumbidgee PHN outlined, PHNs:
- ...have the ability to be the 'glue' between providers and services to effectively improve coordination of care for the benefit of the consumer, without the goal of organisational commercial gain.<sup>28</sup>
- 3.43 Country South Australia PHN stated:
- The ideal sought by our Primary Health Network is to create real, local networks of the patient-centred care model with the patient at the centre of care, supported by local general practice with wraparound of wider allied health and other services.<sup>29</sup>
- 3.44 Health Network Northern Territory (HNNT) highlighted the potential for PHNs to provide health literacy support:
- Primary Health Networks are well positioned to provide coordinated health literacy support and resources for health professionals, clinic managers and reception staff. To ensure sustainability, allocation of funding for culturally appropriate resource development and updating is recommended.<sup>30</sup>
- 3.45 This view was shared by SEMPHN.<sup>31</sup>
- 3.46 The HNNT also stated that chronic disease prevention and management networks and forums could 'link academic, research, policy and practice professionals', enabling a coordinated approach.<sup>32</sup>
- 3.47 Initially, to help inform government on performance and data relevant to PHN areas, the PHNs are required to report on four national performance headline indicators:
- Potentially preventable hospitalisations;
  - Childhood immunisation rates;
  - Cancer screening rates; and
  - Mental health treatment rates.<sup>33</sup>

25 South Eastern Melbourne PHN, *Submission 123*, p. 6.

26 South Eastern Melbourne PHN, *Submission 123*, p. 7.

27 See e.g. WA Primary Health Alliance, *Submission 180*, pp 6-7; Brisbane North PHN, *Submission 182*, p. 2;

28 Murrumbidgee Primary Health Network, *Submission 168*, p. 1.

29 Mr Kim Hosking, *Proof Committee Hansard*, Adelaide, 4 March 2016, p. 13.

30 Health Network Northern Territory, *Submission 27*, p. 2.

31 South Eastern Melbourne PHN, *Submission 123*, p. 3.

32 Health Network Northern Territory, *Submission 27*, p. 2.

- 3.48 These indicators and the relevant data that is collected will allow for the initial stage collection of consistent data for these critical chronic disease indicators and their relevant datasets. The role of datasets is discussed in Chapter 4.

## Primary Health Network Programs

- 3.49 The PHNs gave evidence of a number of programs they are involved in supporting or coordinating. Some examples of these are listed below.
- 3.50 The Western Victoria PHN cited several activities it has been undertaking in the chronic disease area: the Rural Allied Health Project, a pilot model which includes a diabetes education telehealth service, and multidisciplinary face-to-face services; HealthPathways, an online central source of information for GPs and healthcare providers; and encouraging Nurse Led Best Practice, Prevention and Support in Chronic Disease Management.<sup>34</sup>
- 3.51 WentWest, the PHN covering Western Sydney, has been a project partner in the Western Sydney Integrated Care Demonstrator Project, funded by the NSW Government. WentWest's role has been 'to expand the impact of Patient Centred Medical Home principles'.<sup>35</sup>
- 3.52 The HNNT identified an opportunity for PHNs to coordinate and support child health, development and well-being programs, 'supporting the prevention of chronic disease from an early age in high risk and disadvantaged populations'.<sup>36</sup>
- 3.53 The role that PHNs have in the current primary health care system is still evolving, especially in the chronic disease space, however as identified above, many PHNs are already experimenting with alternative models of care for chronic disease patients. The 'Healthier Medicare' reform trials from July 2017 will also potentially expand their coordination and measurement roles into the future.

## Role of Other Health Care Providers

### Allied Health

- 3.54 Allied health is an umbrella term generally encompassing all primary health providers excluding doctors and nurses. In general terms, allied

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33 Mr Richard Nankervis, Chief Executive Officer, Hunter New England and Central Coast Primary Health Network, *Official Committee Hansard*, Tumbi Umbi, 19 February 2016, p. 17.

34 Western Victoria PHN, *Submission 54*, pp 3-8.

35 WentWest, *Submission 53*, p. 2.

36 Health Network Northern Territory, *Submission 27*, p. 2.

health providers can include, but are not limited to, providers such as: osteopathy, optometry, physiotherapy, pharmacy, podiatry, and occupational therapists. The term can apply in a wider sense to practitioners such as: counsellors, speech therapists, social workers and nutritionists.<sup>37</sup> The Department of Health explains:

In very broad terms, allied health professionals provide services to enhance and maintain function of their patients (clients) within a range of settings including hospitals, private practice, community health and in-home care.<sup>38</sup>

- 3.55 Allied health providers play an essential role in chronic disease health care provision. Services for Australian Rural & Remote Allied Health (SARRAH) states that allied health services are ‘basic and fundamental to Australians’ health care and wellbeing’.<sup>39</sup> Allied Health Professions Australia (AHP Australia) called the role of allied health in prevention, management, and treatment of chronic disease ‘essential’, adding:

Best practice guidelines for the management of chronic conditions encompass access to a range of services across the health and social services spectrum. As many allied health disciplines span this continuum, allied health professionals are able to provide seamless care for those needing a range of services.<sup>40</sup>

- 3.56 According to AHP Australia, there are an estimated 120 000 allied health practitioners in Australia.<sup>41</sup>
- 3.57 One of the main issues for allied health providers and consumers identified throughout the inquiry is the lack of access to these services. There were two main reasons for this raised in evidence: the challenges of adequate resourcing in remote areas, and the limited cover of Medicare for allied services.
- 3.58 Regarding the challenge of the allied health workforce in rural areas, SARRAH identified three areas which require action:

Comprehensive data on the allied health workforce that can be used to map supply and demand for allied health services...

Support and incentives for AHPs to relocate or remain in rural and remote settings...

37 Department of Health, ‘Allied Health Workforce’, <<http://www.health.gov.au/internet/publications/publishing.nsf/Content/work-review-australian-government-health-workforce-programs-toc~chapter-8-developing-dental-allied-health-workforce~chapter-8-allied-health-workforce>>, viewed 28 April 2016.

38 Department of Health, ‘Allied Health Workforce’, <<http://www.health.gov.au/internet/publications/publishing.nsf/Content/work-review-australian-government-health-workforce-programs-toc~chapter-8-developing-dental-allied-health-workforce~chapter-8-allied-health-workforce>>, viewed 28 April 2016.

39 Services for Australian Rural & Remote Allied Health, *Submission 115*, p. 2.

40 Allied Health Professions Australia, *Submission 77*, p. 2.

41 Allied Health Professions Australia, *Submission 77*, p. 1.

Funding models for health services that enable AHPs to establish financially viable practices...<sup>42</sup>

- 3.59 This issue was raised by Primary Health Networks as well. For example, Western Victoria PHN said that:

Workforce issues and the greater need for health services have meant that the current allied health service delivery models in rural communities have become difficult to maintain and therefore further investigation into alternative ways in which health services can be delivered in rural areas is required.<sup>43</sup>

- 3.60 Allied health provision in rural areas is a challenge to providing multidisciplinary care, however the challenge of maintaining an adequate GP workforce, as well as allied health professionals to support the population is an issue that is addressed further in Chapter 4.

- 3.61 A number of submissions contended that, as it currently stands, the allied health MBS item numbers provide up to five treatment sessions for allied professions, and that this may not be sufficient for people with ongoing chronic conditions.<sup>44</sup>

- 3.62 The current restriction of session numbers may not adequately allow for the treatment of the person's condition adequately, while also restricting a lot of treatments from certain allied health providers (such as social workers or genetic counsellors), as well as excluding care providers such as nurse practitioners.<sup>45</sup>

- 3.63 It was contended by a number of witnesses and submissions that the current funding model does not allow for efficient coordination of health services, and results in 'professional silos'.<sup>46</sup> AHP Australia stated:

42 Services for Australian Rural & Remote Allied Health, *Submission 115*, p. 3.

43 Western Victoria PHN, *Submission 54*, p. 3.

44 Australian Pain Society, *Submission 35*, pp 6-7; Victorian Healthcare Association, *Submission 78*, p. 6; cohealth, *Submission 88*, pp 25-27; Emma Bird, *Submission 103*, p. 2; Australian Diabetes Educators Association, *Submission 109*, p. 8; Services for Australian Rural & Remote Allied Health, *Submission 115*, pp 7-9; Speech Pathology Australia, *Submission 118*, p. 2; Occupational Therapy Australia, *Submission 137*, pp 5-6; Australian Physiotherapy Association, *Submission 145*, p. 2; the George Institute for Global Health, *Submission 169*, pp 4-5.

45 Victorian Healthcare Association, *Submission 78*, p. 6.

46 Australian Association of Social Workers, *Submission 46*, p. 2; Allied Health Professions Australia, *Submission 77*, p. 3; Diabetes Australia, *Submission 102*, pp 6-7; Australian Podiatry Council, *Submission 125*, p. 1; Dr Thomas Wenkart, *Submission 146*, pp 1-2; Mr Jason Trethowan, Chief Executive Officer, Western Victoria Primary Health Network, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 57; Professor Sophie Zoungas, President Elect, Australian Diabetes Society, *Official Committee Hansard*, Sydney, 23 October 2015, p. 19; Mr David Quilty, Executive Director, Pharmacy Guild of Australia, *Official Committee Hansard*, Canberra, 23 February 2016, p. 2; Associate Professor Alistair Vickery, Associate Professor, Primary Health Care, School of Primary Aboriginal and Rural Health, University of Western Australia, *Official Committee Hansard*, Perth, 11 March 2016, p. 22;

The current model of funding, rather than promoting service integration and supporting team-based care, has created “professional silos”, which results in medical and allied health professionals working independently of each other, leading to poor overall services and outcomes.<sup>47</sup>

- 3.64 One other problem identified is the ‘circular referral process’. In order to access the MBS rebate, a patient has to consult a GP for a referral to an allied health provider. In addition, a patient must consult the GP again for a referral to a specialist, as a referral from the allied health provider does not attract a rebate.<sup>48</sup> Allowing access to MBS rebates for direct referrals from allied health professionals to specialists was raised as an important way to increase efficiency and remove a significant financial and time burden from the patient.<sup>49</sup>

## Nursing

- 3.65 A number of organisations and individuals submitted that nurses have an integral role in primary health care. Their broad skills can transcend disciplines and cover a wide range of conditions, and they are well placed to coordinate multidisciplinary care.
- 3.66 For example, Sydney Nursing School highlighted the role of community health nurses (CHNs), their advanced skills and extended scope of practice, and their capacity to work ‘across disciplinary boundaries in consultation with other health professionals’.<sup>50</sup>
- 3.67 Sydney Nursing School also stated the role of practice nurses:
- Nurses working in general practice are now recognised as integral members of the PHC [primary healthcare] multidisciplinary team. This is associated with increasing evidence about the effectiveness of their involvement in chronic illness prevention and management of population groups with high behavioural health risk. Also related to the increasing importance of practice nurses is the role they continue to play in maintaining the capacity of PHC services, both in metropolitan and in rural areas.<sup>51</sup>
- 3.68 The Australian Nursing and Midwifery Federation (ANMF) added that general practice nurses work in collaboration with GPs and provide a

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47 Allied Health Professions Australia, *Submission 77*, p. 3.

48 Queensland Government, *Submission 167*, pp 9-10.

49 Exercise and Sports Science Australia, *Submission 24*, p. 2; Australian Dental Association, *Submission 55*, p. 5; Allied Health Professions Australia, *Submission 77*, p. 4; Australian Medical Association, *Submission 107*, p. 7; Australian Diabetes Educators Association, *Submission 109*, p. 11; Services for Australian Rural & Remote Allied Health, *Submission 115*, p. 8; Australian Physiotherapy Association, *Submission 145*, p. 10; Queensland Government, *Submission 167*, p. 10.

50 Sydney Nursing School, *Submission 91*, p. 4.

51 Sydney Nursing School, *Submission 91*, p. 5.

range of services including chronic disease management.<sup>52</sup> The ANMF highlighted several other areas in which nurses have a leading role, with occupational health nurses, school nurses, maternal and child health nurses, rural nurses, remote area nurses, and mental health nurses all playing a crucial part of primary health care in those areas.<sup>53</sup>

- 3.69 The joint submission by ACN, CATSINaM, APNA, MCAFHNA, and ACMHN commented on some of the other roles nurses can fulfil:

Other significant roles involve nurses working in the aged care, cancer, mental health, and Aboriginal and Torres Strait health areas where chronic disease rates are highest, or in maternal, child and family health nursing where the opportunity for primary prevention is greatest. Moreover, nurses in general practice and other primary health care settings work across the full spectrum of chronic disease areas playing pivotal roles in the creation of a 'no wrong door' system that works to treat people efficiently and seamlessly.<sup>54</sup>

## Role of Private Health Insurers

- 3.70 Private health insurers (PHIs) have an essential role in Australia's health system. While Australia has a strong public health care system, about half of all Australians are insured with a private insurer.<sup>55</sup> Hirmaa, a peak body representing 19 community-based not-for-profit private health insurers,<sup>56</sup> states that private health insurers have a commercial relationship with over 55 per cent of the population.<sup>57</sup>
- 3.71 Defining factors in the role that PHIs have in chronic disease management in Australia are the impact of community rating and risk equalisation:
- Community rating – PHIs are not permitted to exclude anyone from joining or alter the price of cover based on pre-existing conditions, health status or risk factors such as age, gender or race; and
  - Risk equalisation – introduced in 1976, risk equalisation allows PHIs to share the risk of higher cost members in the premiums of younger and

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52 Australian Nursing and Midwifery Federation, *Submission 110*, pp 28-29.

53 Australian Nursing and Midwifery Federation, *Submission 110*, pp 23-33.

54 ACN, CATSINaM, APNA, MCAFHNA, and ACMHN, *Submission 106*, pp 13-14.

55 Mr Robert Bransby, *Official Committee Hansard*, Perth, 11 March 2016, p. 13.

56 Hirmaa, 'What is hirmaa?', <<http://www.hirmaa.com.au/what-we-are/>>, viewed 22 March 2016.

57 Hirmaa, *Submission 25*, p. 3.

healthier members. This risk pool of premiums is then shared across members, even between different PHIs.<sup>58</sup>

- 3.72 These factors help support the universal health care system within Australia and equitable access to health insurance, but the risk equalisation burden would appear to be potentially untenable into the future, as the proportion of older or complex chronic disease patients increases. NIB highlighted that currently at the age of 55, 20 per cent of hospital claims enter the risk equalisation pool, with approximately 80 per cent at the age of 85.<sup>59</sup>
- 3.73 PHIs also have an important role in chronic disease prevention and management. As well as paying billions of dollars in healthcare costs for members with chronic conditions, PHIs are also heavily invested in developing programs for management and prevention of chronic disease, often in partnership with state governments.
- 3.74 There are strong financial incentives for PHIs to invest in these programs. According to Private Healthcare Australia (PHA), PHIs paid a total of \$7.4 billion during 2013-14 for hospital services treating patients with at least one chronic disease.<sup>60</sup> The Australian Health Service Alliance (AHSa), which represents 23 'small to medium-sized' PHIs,<sup>61</sup> states that its member funds estimate that 'outlays almost doubled for chronic disease related claims' over the last decade.<sup>62</sup>
- 3.75 Medibank Private stated in its submission that, as a funder of 'predominantly hospital based care' it is 'exposed to the cost of hospital admissions resulting from chronic disease', and thus motivated to invest in effective clinical care.<sup>63</sup>
- 3.76 As two examples of high cost ongoing chronic conditions, Medibank Private stated that congestive heart failure and chronic obstructive pulmonary disease cost over \$8 000 per year per patient on average, and type II diabetes and coronary artery disease average over \$4 000 per year per patient. Given these high costs, the affordability of private health insurance depends largely on improving prevention and management of

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58 Commonwealth of Australia, Department of Health, *Better Outcomes for People with Chronic and Complex Health Conditions: Report of the Primary Health Care Advisory Group*, December 2015, pp 30-31.

59 Dr Justin Vaughan, Group Executive, Benefits and Provider Relations, NIB Health Funds, *Proof Committee Hansard*, Newcastle, 31 March 2016, p. 40.

60 Private Healthcare Australia, *Submission 108*, p. 2.

61 Australian Health Service Alliance, *Submission 26*, p. 1.

62 Australian Health Service Alliance, *Submission 26*, p. 5.

63 Medibank Private, *Submission 43*, p. 4.

chronic disease.<sup>64</sup> This principle was reinforced by Geelong-based PHI GMHBA.<sup>65</sup>

3.77 Australian Unity, a 'national healthcare, financial services and retirement living organisation',<sup>66</sup> stated that 'effective chronic disease prevention and management is a critical component [of] a PHI provider's business model'.

3.78 Bupa also advocated for a core role for PHIs in the chronic disease healthcare space:

The ability of health insurers to be more than just passive players will be essential to foster innovation and quality improvements in the chronic disease prevention and management space... As such, no matter what form the next iteration of Australia's chronic disease prevention and management approach takes, health insurers must be included and their expertise leveraged.<sup>67</sup>

3.79 The contribution of PHIs to chronic disease prevention and management is generally acknowledged through the sector, including by government departments. In most states, PHIs have an important role and often partner with state governments.

3.80 For example, the Commonwealth Department of Health identified the role Chronic Disease Management Plans (CDMPs) have in increasing allocative efficiency, stating:

Private health insurance helps with the cost of a range of non-Medicare funded services, such as dentistry, allied health and private hospital treatment and assists patients in avoiding long waiting lists in the public system.<sup>68</sup>

3.81 The Department of Health and Human Services in Victoria (DHHS) commented that the limits applied to reimbursements for primary health services mean that PHI models 'may not adequately cover the cost of care', resulting in extra costs for patients or the decision to access publically funded care.<sup>69</sup> The DHHS stated:

Governance of a larger role for private insurers could be supported by strengthening the performance monitoring role of the Primary Health Networks, across all service providers in the primary care sector (including private insurers).<sup>70</sup>

3.82 The DHHS highlighted the CarePoint integrated care trial, a joint initiative between the Department and Medibank Private.<sup>71</sup> NSW Health also

64 Medibank Private, *Submission 43*, pp 8-9.

65 GMHBA, *Submission 157*, p. 6.

66 Australian Unity, *Submission 75*, p. 2.

67 Bupa, *Submission 144*, p. 7.

68 Department of Health, *Submission 143*, p. 11.

69 Department of Health and Human Services Victoria, *Submission 173*, p. 13.

70 Department of Health and Human Services Victoria, *Submission 173*, p. 13.

71 Department of Health and Human Services Victoria, *Submission 173*, p. 13.

identified the innovative role in chronic disease prevention and management PHIs have and their partnerships with government, such as through the CarePoint trial program.<sup>72</sup>

- 3.83 The CarePoint program is discussed further below.
- 3.84 NSW Health identified the 'major role' PHIs have in the health system, commenting:
- By collaborating with the public sector on service integration, chronic disease prevention and management programs, and sharing information to avoid service duplication (e.g. test results), the private sector can play a significant role in helping to improve efficiencies and health outcomes.<sup>73</sup>
- 3.85 Many of the Primary Health Networks also commented on the role of PHIs. For instance, South Eastern Melbourne PHN stated that PHIs 'shared the same sustainability concerns as the public sector', highlighting the 'disproportionately high cost of long hospital stays'.<sup>74</sup> Brisbane North PHN similarly identified the 'alignment between the motives of private health insurers and PHNs when it comes to chronic disease management and prevention'.<sup>75</sup> The Brisbane South and Darling Downs and West Moreton PHNs also highlighted the current collaboration and the potential for more collaboration with PHIs.<sup>76</sup>
- 3.86 Several PHNs also discussed the joint collaborations between governments and private insurers, discussed above.<sup>77</sup>
- 3.87 Several other organisations commented on the role of private health insurers in chronic disease prevention and management. For example, the joint submission from the nursing organisations ACMHN, MCAFHNA, APNA, CATSINaM, and ACN made note of PHI activity in prevention and health promotion, and suggested that PHIs should be encouraged to ensure smooth transitions from hospital to community settings and to ensure appropriate follow-up care.<sup>78</sup>
- 3.88 The submission added that PHIs should be obligated to coordinate with other sections of the health system. This could be done by providing 'de-identified population health data from their members for input into PHN comprehensive needs assessments', providing evaluation results from

72 NSW Health, *Submission 152*, p. 15.

73 NSW Health, *Submission 152*, p. 14.

74 South Eastern Melbourne PHN, *Submission 123*, p. 8.

75 Brisbane North PHN, *Submission 182*, p. 2.

76 Dr Peter Adkins, Senior Clinical Adviser, Brisbane South Primary Health Network, *Official Committee Hansard*, Brisbane, 18 February 2016, p. 7; Dr Roland Owen, Director, Darling Downs and West Moreton Primary Health Network, *Official Committee Hansard*, Brisbane, 18 February 2016, p. 7.

77 See e.g. South Eastern Melbourne PHN, *Submission 123*, p. 8; WAPHA, *Submission 180*, p. 3.

78 ACN, CATSINaM, APNA, MCAFHNA, and ACMHN, *Submission 106*, p. 34.

their interventions, and communicating generally with other elements of the system such as general practices to avoid duplication, inefficiency, and waste.<sup>79</sup>

- 3.89 The potential role of PHI data is discussed further in Chapter 4.
- 3.90 Some organisations were wary of PHI involvement. While most government departments viewed the role of PHIs positively, the Northern Territory Department of Health stated that there is ‘limited role for private providers in chronic disease prevention and management’ due to the greater burden of chronic disease in remote areas with low PHI coverage.<sup>80</sup>
- 3.91 While also noting the ‘very strong’ role PHIs have in ‘working with the rest of the system in a coordinated way’, WestWent Limited, the Western Sydney PHN, was concerned that chronic disease management be well coordinated and not ‘siloed’, commenting:
- It is a very important part of that analysis to make sure that integrated care is integrated care for everybody, not just for people with private health insurance. I think we are very conscious of that in Western Sydney.<sup>81</sup>
- 3.92 The Australian Medical Association (AMA) identified the range of programs PHIs have introduced but commented that PHIs ‘generally work in isolation to the usual GP who understands their patient’s care needs’, calling this a ‘significant problem [that] fragments patient care’.<sup>82</sup> The AMA was also wary of the PHIs’ ‘more interventionist approach’ to funding.<sup>83</sup>
- 3.93 Similarly, the Royal Australian College of General Practitioners (RACGP) was concerned with PHI involvement in general practice, stating as their main concern the ‘likelihood of private health insurers prioritising profit and cost savings over continuity of care’.<sup>84</sup>
- 3.94 The RACGP offered three principles for PHI involvement in general practice: preventing the duplication and fragmentation of care; limiting the impact on clinical judgement; and ensuring access based on need rather than on insurance status.<sup>85</sup>

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79 ACN, CATSINaM, APNA, McaFHNA, and ACMHN, *Submission 106*, p. 34.

80 Northern Territory Department of Health, *Submission 133*, p. 1.

81 Adjunct Associate Professor Walter Kmet, Chief Executive Officer, WentWest Limited (Western Sydney Primary Health Network), *Official Committee Hansard*, Sydney, 23 October 2015, pp 52-53.

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

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

84 Royal Australian College of General Practitioners, *Submission 135*, p. 11.

85 Royal Australian College of General Practitioners, *Submission 135*, pp 11-12.

- 3.95 However, Mr Rob Bransby, Managing Director of HBF, highlighted that often due to the disconnect between PHIs and GPs, services may often be duplicated, when PHIs provide chronic disease plans:
- So there is a very high likelihood that we are providing a chronic disease management service to our membership at our cost, and it is very likely that they are on a GP's own program, which is just a massive piece of duplication. The very fact that we do not talk to each other and integrate it is a massive concern. All that is doing is putting a greater impost back onto the community, in terms of health premiums, and/or on the health system in general.<sup>86</sup>
- 3.96 The Australian Health Promotion Association (AHPA) acknowledged the role PHIs have in supporting their members but was wary of 'the risk of developing a two-tiered health system'.<sup>87</sup> Such concerns were shared by the Public Health Association of Australia<sup>88</sup> and the Aboriginal Medical Services Alliance NT (AMSANT). AMSANT said PHI involvement in primary health care would be 'inflationary' and 'produce a two tier PHC system'. The AMSANT also questioned whether PHIs improve outcomes in primary health care.<sup>89</sup>
- 3.97 The WA Primary Health Alliance, while also noting the CarePoint trial, cautioned that any increased role for PHIs must not result in 'barriers to access', increased costs for non-insured consumers, or a 'negative impact on clinical independence or a shift towards managed care models'.<sup>90</sup> Managed care models are where clinicians 'ration care to reduce costs' rather than adopting 'a holistic, patient-centred approach'.<sup>91</sup>
- 3.98 Similar comments were made by the Health Care Consumers' Association of the ACT<sup>92</sup> and by Vision 2020 Australia, who said those with private health insurance benefit from a 'two-tier health system' and enjoy 'privileged and disproportionate access' to tailored disease management and prevention programs.<sup>93</sup>
- 3.99 Other submissions similarly stated the importance of maintaining a strong universal health care system, and that private health insurance should not threaten this principle.<sup>94</sup>

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86 Mr Rob Bransby, Managing Director, HBF Health Ltd, *Official Committee Hansard*, Perth, 11 March 2016, p. 10.

87 Australian Health Promotion Association, *Submission 49*, p. 7.

88 Public Health Association of Australia, *Submission 111*, p. 7.

89 Aboriginal Medical Services Alliance NT, *Submission 153*, p. 5.

90 WA Primary Health Alliance, *Submission 180*, p. 7.

91 Royal Australian College of General Practitioners, *Submission 135*, p. 11.

92 Health Care Consumers' Association of the ACT Inc, *Submission 116*, p. 7.

93 Vision 2020 Australia, *Submission 89*, p. 13.

94 Rural Doctors Association of Australia, *Submission 17*, p. 9; Primary Care Collaborative Cancer Clinical Trials Group, Clinical Oncology Society of Australia, and Cancer Council Australia,

- 3.100 Some submissions and witnesses raised international examples of the integrated roles PHIs can have in a country's health system. One such example is the hybrid model introduced in the Netherlands.

### Case Study – Private Health Insurance in the Netherlands

In the Netherlands, the health care system is provided in partnership with private health insurers (PHIs).

Since 2006, under the Dutch Health Insurance Act, all residents of the Netherlands have been required to purchase basic statutory health insurance, via their employer, at a contribution rate of 7.75 per cent of up to €50 853 of annual taxable income (as at 2013).<sup>95</sup>

There are four types of statutory insurance:

- *Zorgverzekeringswet (Zvw)*, often called 'basic insurance', covers common medical care.
- *Wet langdurige zorg (Wlz)* covers long-term nursing and care.
- *Wet maatschappelijke ondersteuning (Wmo)* covers every day support services provided by the municipality.
- *Jeugdwet* covers short and long-term medical care for youth.

The basic insurance is what is mentioned above, whereas the Dutch government automatically cover residents for long-term nursing care.<sup>96</sup>

The basic insurance generally covers:

- GP consultations;
- Treatments from specialists and hospital care;
- Certain mental health care;
- Medication;
- Dental care up to 18 years;
- Care from certain therapists, such as speech therapists;
- Dieticians; and
- Maternity care.<sup>97</sup>

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*Submission 63*, p. 9; Aboriginal Medical Services Alliance NT, *Submission 153*, Attachment A, p. 13; Consumers Health Forum of Australia, *Submission 159*, p. 9.

95 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, p. 9.

96 Expatica, 'Healthcare in the Netherlands', <[http://www.expatica.com/nl/healthcare/Healthcare-in-the-Netherlands\\_100057.html](http://www.expatica.com/nl/healthcare/Healthcare-in-the-Netherlands_100057.html)>, viewed 14 April 2016.

97 Expatica, 'Healthcare in the Netherlands', <[http://www.expatica.com/nl/healthcare/Healthcare-in-the-Netherlands\\_100057.html](http://www.expatica.com/nl/healthcare/Healthcare-in-the-Netherlands_100057.html)>, viewed 14 April 2016.

The services covered above are more expansive than that provided under the Medicare system in Australia, however the percentage of income contribution is a lot higher than the current 2 per cent Medicare levy. Low-income earners in the Netherlands still need to purchase insurance, however they can apply for a 'care allowance, to help with the cost of premiums if they earn under a certain amount.<sup>98</sup>

Much like Australia, the premiums are community-rated, so each member with each insurer pays the same premium regardless of age, gender, nationality and health status.<sup>99</sup>

- 3.101 The TROG cited the Dutch care model of hospitals funded by insurers rather than the government, calling it a 'public-private partnership by definition'. Hospitals are funded 'on the basis of delivering the best quality care', as well as for research and innovation.<sup>100</sup>
- 3.102 The Graduate School of Medicine, University of Wollongong (UoW) also cited the Dutch 'bundled payment scheme', with PHIs involved in primary care funding. At the public hearing in Bomaderry, Professor Bonney described the Netherlands' system of universal health care via private health insurers.<sup>101</sup> The UoW stated that 'exploration of private insurer involvement in a similar capacity is warranted'.<sup>102</sup>
- 3.103 The role of alternate funding schemes and relevant international examples are covered in Chapter 5.

## Regulation of Private Health Insurers in Chronic Disease Management

- 3.104 The role of PHIs in chronic disease prevention and management was expanded in 2007 with the Broader Health Cover (BHC) initiative. The initiative was designed to encourage insurers to cover 'clinically appropriate alternatives to hospital treatment',<sup>103</sup> and include Chronic Disease Management Programs (CDMPs) employing dieticians,

98 Expatica, 'Healthcare in the Netherlands', <[http://www.expatica.com/nl/healthcare/Healthcare-in-the-Netherlands\\_100057.html](http://www.expatica.com/nl/healthcare/Healthcare-in-the-Netherlands_100057.html)>, viewed 14 April 2016.

99 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, p. 9.

100 Dr Fiona Hegi-Johnson, Member, Trans Tasman Radiation Oncology Group Cancer Research, *Proof Committee Hansard*, Newcastle, 31 March 2016, pp 34-35. See also TROG Cancer Research, *Submission 190*, p. 10.

101 Professor Andrew Bonney, Roberta Williams Chair of General Practice, Graduate School of Medicine, University of Wollongong, *Official Committee Hansard*, Bomaderry, p. 6.

102 Graduate School of Medicine, University of Wollongong, *Submission 16*, p. 3.

103 Medibank Private, *Submission 43*, p. 6.

physiotherapists, exercise physiologists and other practitioners.<sup>104</sup>

According to Hirmaa, there has been significant growth in BHC services in that time, with 10 000 services and about \$2 million in benefits paid in 2007 rising to more than 450 000 services and \$47 million in benefits paid across the PHI sector in 2014.<sup>105</sup>

- 3.105 Medibank Private submits that the vision of this BHC initiative has been ‘stymied’ in subsequent years, in particular by Rule 12 of the *Private Health Insurance (Health Insurance Business) Rules 2015*.<sup>106</sup> Despite the policy goal underpinning the rule being ‘sound’, Medibank Private states that it is ‘one of the reasons the vision [of the BHC] has never been fully realised.’<sup>107</sup> Many of the PHIs shared similar concerns about this Rule.
- 3.106 Among other things, Rule 12, which is titled ‘Chronic disease management programs’, requires management programs to involve one of a list of 14 allied health service modalities.<sup>108</sup> Private Healthcare Australia calls this list ‘too restrictive’, stating:
- The rule states that the treatment must involve one of a list of provider modalities all within the allied health practitioner field. This list is too restrictive and should be removed to allow health funds to pay for the most appropriate care for any given chronic disease or illness. These may or may not involve allied health professionals, medical doctors etc. Positioning health insurers to access funding of primary health care is critical to the management of chronic diseases.<sup>109</sup>
- 3.107 Medibank Private similarly calls the rule ‘unnecessarily restrictive’, commenting that the rule prevents insurers from doing all they can to address chronic disease.<sup>110</sup>
- 3.108 Medibank Private contends that the rule contains three ‘key impediments’: one, that the program must involve an allied health service; two, that the allied health practitioner must be eligible to claim a Medicare rebate for the service provided; and three, that although insurers can provide programs which are not compliant with Rule 12 to members, they are not subject to risk equalisation processes, meaning that insurers are less willing to invest in such programs.<sup>111</sup>

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104 Hirmaa, *Submission 25*, p. 2.

105 Hirmaa, *Submission 25*, p. 2.

106 Medibank Private, *Submission 43*, pp 5-6.

107 Medibank Private, *Submission 43*, pp 5-6.

108 Rule 12, *Private Health Insurance (Health Insurance Business) Rules 2015* (Cth),

109 Private Healthcare Australia, *Submission 108*, p. 3.

110 Medibank Private, *Submission 43*, p. 6.

111 Medibank Private, *Submission 43*, p. 6.

- 3.109 Medibank Private adds that relaxing Rule 12 would ‘enable further innovation in chronic disease management program delivery’,<sup>112</sup> adding that doing so would not result in additional costs for the Commonwealth but would benefit all health system funders, including the Commonwealth.<sup>113</sup>
- 3.110 Similar comments were made by Bupa,<sup>114</sup> Hirmaa,<sup>115</sup> and Australian Unity.<sup>116</sup>
- 3.111 Bupa agreed that Rule 12 should be relaxed. In its submission, Bupa stated that the rule is:
- ...drafted in a manner which unfortunately prevents health insurers from doing all they can to assist their members in preventing and managing chronic conditions. It is also our experience that Rule 12 does not promote best practice evidence, which supports a wider variety of providers in the provision of chronic condition prevention and management than mandated by Rule 12.<sup>117</sup>
- 3.112 Bupa supported a review of the regulations, specifically the removal of the requirement of an allied health service from a prescriptive list be included on a chronic disease management program.
- 3.113 Some comments on the regulations came from allied health and other peak bodies. The Australian Orthotic Prosthetic Association commented on the restrictive effects of ‘red tape’,<sup>118</sup> stating:
- The exclusion of orthotics and prosthetics as a listed health service in the *Health Insurance Regulations 1975* determination restricts access to orthotists under Medicare and clinical rebates for orthotist services within the private health insurance system.<sup>119</sup>
- 3.114 While PHIs broadly agreed that the regulations were too restrictive, other submitters warned against relaxing the regulations too quickly. For example, the Queensland Government stated that tight regulations were due to Australia’s commitment to universal health care and stated that ‘consideration of any changes would need to be carefully explored to avoid unintended consequences’.<sup>120</sup>

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112 Medibank Private, *Submission 43*, p. 7.

113 Medibank Private, *Submission 43*, p. 7.

114 Dr Robert Grenfell, Bupa, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 62. See also Bupa, *Submission 144*, p. 8.

115 Hirmaa, *Submission 25*, p. 3.

116 Australian Unity, *Submission 75*, p. 7.

117 Bupa, *Submission 144*, p. 8.

118 Australian Orthotic and Prosthetic Association, *Submission 140*, p. 5.

119 Australian Orthotic and Prosthetic Association, *Submission 140*, p. 1.

120 Queensland Government, *Submission 167*, p. 16.

- 3.115 The RACGP said in its submission it does not support amending the *Private Health Insurance Act 2007* to allow PHIs to fund services currently funded by Medicare.<sup>121</sup>

## Pilot Programs

- 3.116 Partly as a response to the rising costs of chronic disease, PHIs are heavily invested in developing chronic disease management programs (CDMPs). Insurers have developed a number of these programs, and are frequently involved in piloting programs in conjunction with state and territory Governments.
- 3.117 After launching a number of ‘small scale pilot projects’ in 2005 in conjunction with suppliers of CDMPs, HCF began to implement larger initiatives in 2007.<sup>122</sup> My Health Guardian was launched in 2009 as ‘a long-term strategy to improve the health and well-being of members with chronic health conditions’.<sup>123</sup> The program is delivered by registered nurses, promoting healthy behaviours and adherence with medications and GP action plans, and encouraging active engagement by members in their own health.<sup>124</sup>
- 3.118 Managing Director of HCF, Dr Shaun Larkin, stated that My Health Guardian is a \$100 million investment and has provided phone-based support to about 40 000 members suffering from chronic conditions. Dr Larkin added that the program has been effective:
- Peer reviewed studies of My Health Guardian published in 2013 in *Population Health Management* and earlier this year in *Health Services Research* found that the program significantly reduced the rate of hospital admissions for participants with cardiovascular disease and diabetes, which together, as the committee would know, make up the bulk of chronic illness in Australia today.<sup>125</sup>
- 3.119 In its submission, Bupa outlines several CDMPs it has developed.<sup>126</sup> These include the COACH Program for members who have experienced cardiac or stroke-related illness; Genesis Heart Care; the Integrated Osteoarthritis Management Program; Young At Heart; GP Clinic; and Bupa Model of Care, which aims to provide an improved level of care and access to services with a multidisciplinary and person-centred approach.<sup>127</sup> Considered to be ‘front and centre’ of these programs is the Bupa Medical

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121 Royal Australian College of General Practitioners, *Submission 135*, p. 11.

122 HCF, *Submission 122*, p. 5.

123 HCF, *Submission 122*, p. 7.

124 HCF, *Submission 122*, p. 7.

125 Dr Shaun Larkin, *Official Committee Hansard*, Sydney, 23 October 2015, p. 22.

126 Bupa, *Submission 144*, Appendix C.

127 Bupa, *Submission 144*, Appendix C.

TeleHealth business, a telephonic coaching program provided to Bupa members identified through its hospital claims database.<sup>128</sup>

- 3.120 At the time of its submission, Geelong-based insurer GMHBA was conducting a Health and Wellbeing Pilot involving ten GP practices in the region. Members of GMHBA with chronic disease are identified who have a GP management plan and require more than five subsidised allied health visits. According to GMHBA, the Pilot program has been successful and has begun to foster 'some sound relationships with health providers that traditionally would not have a relationship purely due to funding arrangements'.<sup>129</sup>
- 3.121 In Western Australia, HBF acquired a chain of pharmacies to provide services in an 'out of hospital' setting:
- Things we provide are flu vaccinations – which are incredibly important for the elderly – health checks; healthy weight programs; hearing checks; and diabetes programs, funded by the fund.<sup>130</sup>
- 3.122 Medibank Private runs a suite of programs called the 'Care Suite',<sup>131</sup> which includes CareFirst, CarePoint, and CareTransition. CareFirst is a 16-week program with a specifically designed care plan for members. CarePoint is 'an integrated care model which focusses on intensive support and behavioural improvement'. CareTransition focusses on members with complex needs, such as older members with comorbidities. This suite of programs is being funded in partnership with the two state Health Departments (Victoria and Western Australia) and Perth-based private insurer HBF.<sup>132</sup>
- 3.123 The CarePoint trial was discussed in some detail at the public hearing in Melbourne by representatives of the Victorian DHHS.<sup>133</sup> The trial program is designed 'to keep people out of hospital'. People involved in the trial have had 'multiple admissions to hospital – a total of four in the previous two years – with a significant chronic illness'. The role of GPs in the program was emphasised. The patients are identified through general

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128 Ms Natalie Dubrowin, Bupa, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 63.

129 GMHBA, *Submission 157*, pp 7-8.

130 Mr Robert Bransby, Managing Director, HBF Health Ltd, *Official Committee Hansard*, Perth, 11 March 2016, p. 9.

131 Mr James Connors, Medibank Private, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 61.

132 These programs are outlined in Medibank Private, *Submission 43*, pp 8-10.

133 Professor Robert Thomas, Chief Advisor Cancer, Principal Investigation CarePoint, and Ms Josephine Beer, Relationship Manager, CarePoint Trial, Department of Health and Human Services, Victoria, *Official Committee Hansard*, Melbourne, 1 October 2015, pp 1-5.

practice, and a 'program of support' developed for each patient, constructed with the patient's GP.<sup>134</sup>

- 3.124 Also appearing at the public hearing in Melbourne were representatives of Medibank Private. Mr James Connors identified other Care Suite programs including the GP-led chronic disease management program CareFirst, which encourages 'self-treatment and behaviour modification that is supported by health coaching, health system navigation and online education segments', and the CareTransition program, a collaboration between Medibank Private and hospitals to enhance the discharge process for people with a higher risk of readmission.<sup>135</sup>
- 3.125 In Western Australia, the CarePoint trial is a collaboration between Medibank Private and the Western Australian Government, with the University of Western Australian to review the trial.<sup>136</sup>
- 3.126 It was stated at both hearings that there are, as yet, no evaluation reports.<sup>137</sup> The Western Australia Primary Health Alliance identified that the first evaluation report in Western Australia is due in May of 2016.<sup>138</sup>
- 3.127 Increasingly, PHIs are offering programs promoting healthy lifestyles as a preventative strategy against chronic disease. This will be discussed further in Chapter 4.

## Care Coordination

- 3.128 Bringing together the contributions that all of the above health care providers can bring to a patient's care ideally leads to a coordinated care plan and provision for chronic disease patients.
- 3.129 The AMA listed five key points for effective care coordination:
- Care that is led by the patient's usual GP and based on clinical need.
  - Actively involving the patient in goal setting and decision-making.

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134 Professor Robert Thomas, Chief Advisor Cancer, Principal Investigation CarePoint, Department of Health and Human Services, Victoria, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 1.

135 Mr James Connors, Head of Government and Regulatory Affairs, Medibank Private, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 61.

136 Mr Robert Bransby, Managing Director, HBF Health Ltd, *Official Committee Hansard*, Perth, 11 March 2016, p. 9.

137 Ms Lucinda Bilney, Senior Strategy Manager, Medibank Private, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 63; Professor Learne Durrington, Chief Executive Officer, Western Australia Primary Health Alliance, *Official Committee Hansard*, Perth, 11 March 2016, p. 16.

138 Professor Learne Durrington, Chief Executive Officer, Western Australia Primary Health Alliance, *Official Committee Hansard*, Perth, 11 March 2016, p. 16.

- Enabling patients to better understand and manage their condition.
  - Funding that follows the patient, i.e. through the existing Medicare Benefits System (MBS), and supports the provision by GPs of initial and ongoing care.
  - Funding that supports the coordination and transition of patient care between health care providers and across health care and community sectors.<sup>139</sup>
- 3.130 Opinion on the GP-led nature of care coordination was divided.
- 3.131 As discussed above, many organisations and individuals view the role of nurses as central to effective management of chronic conditions, including the potential for nurse-led care coordination for chronic disease management. For example, the joint submission by ACN, CATSINaM, APNA, MCaFHNA, and ACMHN stated:
- ...nurses act as care coordinators for people with chronic heart failure, diabetes and chronic obstructive pulmonary disease (COPD), applying prevention and management strategies that work to keep people well and out of hospital.<sup>140</sup>
- 3.132 This view is shared by the Sydney Nursing School.<sup>141</sup>
- 3.133 The Adelaide Primary Health Network supported nurse-led care management:
- Studies have shown that nurse-led management of chronic disease has a positive effect on many aspects of the patient journey, including patient satisfaction, hospital admissions and mortality. There is also evidence to suggest that medical practitioners recognise the skills of practice nurses in screening and risk assessment roles and that they support the concept of nurse-led care.<sup>142</sup>
- 3.134 Another PHN, Western Victoria PHN, emphasised the role nurses have in chronic disease management and prevention:<sup>143</sup>
- The Western Victoria PHN supports practice nurses to promote examples of best practice in chronic disease prevention and management locally through continued professional development activities, nurse leadership forums and health expos. We also support practice nurses to promote best practice models nationally through presentations at conferences.
- Western Victoria PHN supports practice nurses to share skills and best practice models in chronic disease management through a

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139 Australian Medical Association, *Submission 107*, p. 3.

140 ACN, CATSINaM, APNA, MCaFHNA, and ACMHN, *Submission 106*, p. 13.

141 Sydney Nursing School, *Submission 91*, p. 5.

142 Adelaide Primary Health Network, *Submission 119*, p. 27.

143 Western Victoria PHN, *Submission 54*, pp 6-8.

Nurse Leadership Peer Network (NLPN) which meets at regular intervals. This provides local practice nurses with opportunities to share innovative ways to tackle chronic disease within the primary care setting.<sup>144</sup>

- 3.135 The CarePoint model discussed above is an example of a ‘system-wide coordinated care approach to high utilisers’. CarePoint focuses on:

patient engagement, patient experience, patient activation and general practitioner led care, along with close collaboration between providers to enhance patient outcomes and reduce hospital admissions/readmissions.

...

The model integrates and coordinates care across the entire spectrum of health and social services via a unique blend of physical and virtual touch points, underpinned by integrated data and a proactive care integration workflow.<sup>145</sup>

- 3.136 The Coordinated Veterans’ Care (CVC) Program was raised in several submissions as an Australian example of best practice coordinated care.<sup>146</sup> The program was initiated in 2011 by the Department of Veterans’ Affairs. More detail on the CVC program is provided in Chapter 4.
- 3.137 The Patient-Centred Medical Home (PCMH) is an example of a coordinated care model, developed in the United States for ageing populations with chronic conditions.<sup>147</sup> The PCMH was raised repeatedly in submissions and will be discussed further in Chapter 4.

## Filling Treatment Gaps

- 3.138 Effective care coordination as outlined above has been identified as the key to filling treatment gaps experienced by consumers. The South Eastern Melbourne Primary Health Network stated that care coordination is ‘one of the big challenges’ to filling treatment gaps, and better facilitation of team based approaches is needed.<sup>148</sup>

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144 Western Victoria PHN, *Submission 54*, p. 6.

145 Department of Health and Human Services Victoria, *Submission 173*, p. 9.

146 Flinders University, Human Behaviour & Health Research Unit, *Submission 4*, pp 2-3; Centre for Primary Health Care and Equity, University of NSW, *Submission 6*, p. 2; Australian Healthcare and Hospitals Association, *Submission 40*, p. 7; Pain Australia, *Submission 96*, p. 10; Australian Medical Association, *Submission 107*, pp 7-8; Royal Australian College of General Practitioners, *Submission 135*, p. 4.

147 Cohealth, *Submission 88*, p. 12.

148 Ms Anne Lyon, General Manager and Acting CEO, Primary Health Services, South Eastern Melbourne Primary Health Network, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 55.

- 3.139 Primary Health Networks were identified in several submissions as having a key role in providing this facilitation and coordination. For example, La Trobe University stated:
- ...the Primary Health Networks... must be planners and commissioners of healthcare, and not service providers. In cases where there are service gaps, the PHNs should not duplicate or replicate services that are available in other locations, but must commission and coordinate service providers to fill these gaps.<sup>149</sup>
- 3.140 The Centre for Primary Health Care and Equity at the University of New South Wales stated that one of the objectives of PHNs as defined in their foundation documents is to understand the health care needs of their communities, and that this should include:
- ...identifying those groups who have trouble accessing services, including specialist services, and the social, economic and physical environments that may be contributing to the emergence of chronic disease. They will know what services are available and help to identify and address service gaps where needed, including in rural and remote areas, while getting value for money.<sup>150</sup>
- 3.141 This crucial aspect to the role of PHNs was supported by a number of submissions, including from PHNs themselves.<sup>151</sup> Adelaide Primary Health Network also identified the role of Clinical Councils within the PHNs, stating:
- Clinical Council members have the appropriate knowledge and specific skill sets to address inter-sectoral care, service gap[s] and integrated care pathways.<sup>152</sup>
- 3.142 The Rural Doctors Association of Australia highlighted the 'critical' role of PHNs in addressing market failure and filling service gaps in rural areas.<sup>153</sup> This view was supported by Services for Australian Rural & Remote Allied Health (SARRAH).<sup>154</sup>
- 3.143 The Victorian Council of Social Service (VCSS) highlighted the 'Peninsula Model for Primary Health Planning', based in Frankston and the Mornington Peninsula. The model is based on a population health approach and 'wraps the collective effort of providers around agreed health priorities to address service gaps for the catchment'.<sup>155</sup> The VCSS identified the opportunity provided by the PHNs to continue building upon examples such as the Peninsula Model.

149 La Trobe University Rural Health School, *Submission 164*, p. 7.

150 Centre for Primary Health Care and Equity, UNSW, *Submission 6*, p. 3.

151 Primary Health Tasmania, *Submission 142*, p. 1; NSW Health, *Submission 152*, p. 14; see also Royal Australian and New Zealand College of Ophthalmologists, *Submission 58*, p. 7.

152 Adelaide Primary Health Network, *Submission 119*, p. 34.

153 Rural Doctors Association of Australia, *Submission 17*, p. 11.

154 Services for Australian Rural & Remote Allied Health, *Submission 115*, pp 9-10.

155 Victorian Council of Social Service, *Submission 120*, p. 16.

- 3.144 The Dietitians Association of Australia (DAA) commented on the ‘long standing’ gaps in service delivery in rural and remote areas, and agreed that PHNs have a ‘vital role’ in filling these service gaps,<sup>156</sup> but added that state and territory governments should take the lead in responding to such gaps and ensuring that ‘the spectrum of health care is comprehensive’.<sup>157</sup> As an example of a state government doing this, the Australian Pain Society and Painaustralia identified the Chronic Pain Service Plan being developed by the South Australian Government, modelled on a similar NSW plan and tailored to address ‘massive service gaps especially in rural and regional SA’.<sup>158</sup>
- 3.145 Technology also has an important role in filling treatment gaps. In its submission, GMHBA supported telehealth and video conferencing as a way to address service gaps, noting that allied health providers, nurses, and care coordinators in addition to GPs should have access to MBS item numbers for these consultations.<sup>159</sup> Later on, GMHBA notes that a central data system such as My Health Record requires support by all sectors ‘to enable the health care team to create a holistic view of the patient’.<sup>160</sup>
- 3.146 The complex nature of coordinated care for chronic disease patients, and the requisite identification and filling of treatment gaps, is a challenge for primary and secondary health care providers. However, systems and frameworks exist that would suggest that models can be adapted to ensure the best coordinated care for patients can be achieved. These are discussed in Chapter 4.

## Concluding Comment

- 3.147 The Committee acknowledges the breadth of dedicated and professional health care providers, both in the primary and secondary systems, currently providing world-class care to Australian patients.
- 3.148 The health care provided to the majority of Australians by their GP is suitable and well-supported by the current Medicare system, as well as by private health insurance for any ancillary or allied health treatment required. However, once the complexities of chronic disease or diseases enter into a patient’s treatment framework, the interconnected web of primary health care becomes somewhat tangled.
- 3.149 The Committee understands that a lot of the concerns outlined in this chapter will be addressed by the introduction of Health Care Homes
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156 Dietitians Association of Australia, *Submission 148*, pp 4, 9-10.

157 Dietitians Association of Australia, *Submission 148*, p. 11.

158 Australian Pain Society, *Submission 35*, pp. 9-10; Painaustralia, *Submission 96*, p. 20.

159 GMHBA, *Submission 157*, p. 8.

160 GMHBA, *Submission 157*, p. 8.

under the 'Healthier Medicare' reform trials, however the need for the following issues to be considered by the Australian Government is still valid, given that the reforms are only entering trials as of July 2017.

### Primary Health Networks

- 3.150 The evolution of Medicare Locals into PHNs is still at its early stages, but with the potential impact of Health Care Homes under the 'Healthier Medicare' reforms, the role that PHNs can have in coordinating and commissioning multidisciplinary services for chronic disease patients can only grow.
- 3.151 The PHNs coordination role is also important for care during transition periods for patients. The situation where a primary care provider cannot identify a condition or treat a patient, due to privacy concerns or restricted access to patient records is a circumstance that requires reform. The PHNs must have a central role in creating channels for this coordination and developing ways to easily access relevant records.
- 3.152 The data that both PHNs and PHIs collect about their patients, especially chronic disease patients, can be used in furthering the analysis of chronic disease treatment efficacy and coordination efforts. The Committee believes that the data targeted by headline performance indicators should be prioritised for research and analysis and expanded as the PHNs enter into key future phases of their development.
- 3.153 Additionally, as PHN data increases, this can help feed further information into the burgeoning eHealth space, as discussed in Chapter 4.

### Allied Health, Nursing and Other Care Providers

- 3.154 The Committee also recognises the wider elements of primary health care provision to chronic disease patients, often provided by allied health professionals and other qualified care providers, including nurses. The requirements of care for chronic disease patients are wide and often that care may not fall directly to their GP or key allied health professionals for short periods of time.
- 3.155 The Committee recognises the important assistive role of nursing care in chronic disease management and treatment. The Committee believes that the role of nurses in relation to chronic disease prevention and management should be considered for possible expansion and better utilisation in this care space.
- 3.156 The current requirement for a referral from a GP for a restrictive number of allied health treatments may not always be the best mechanism for ongoing care for a chronic disease patient and a change to referral processes and numbers of treatments may be warranted.

## Private Health Insurers

- 3.157 The Committee was grateful to the PHIs that both submitted to the inquiry, as well as appeared before the Committee to provide frank advice about the work that they have been doing in a restrictive environment, to both educate their members on the lifestyle factors that can contribute to their wellness, as well as the potential room for improvement in providing chronic disease management programs (CDMP) to their members with chronic disease.
- 3.158 The Committee recognised that the regulatory and legislative framework that governs private health insurance in Australia is complex, but believes that there are small areas of improvement that could be made to the *Private Health Insurance (Health Insurance Business) Rules 2015* regarding expanding the providers that can be used in a CDMP.

## Recommendations

### Recommendation 1

- 3.159 **The Committee recommends that the Australian Government undertake an independent review of the privacy restrictions governing medical practitioner access to patient records.**

### Recommendation 2

- 3.160 **The Committee recommends that the Highlight Performance Indicators for Primary Health Networks be expanded in future cycles to include the specific data capture of the:**
- **incidence of chronic disease in Primary Health Network catchments and the number of people with comorbid or multi-morbid conditions;**
  - **range of services that these people access and how often they utilise different forms of treatment (general practice, allied health, hospital); and**
  - **that this data be prioritised for research to inform targeted service provision to chronic disease populations and the expansion of Health Care Home trials and programs.**

**Recommendation 3**

- 3.161        **The Committee recommends that the Australian Government investigate expanding the number of allied health treatments that can attract a Medicare Benefits Schedule rebate (MBS items 10950 to 10970) within a year, on the proviso that the patient has the relevant General Practitioner Management Plan and Team Care Arrangements in place.**

**Recommendation 4**

- 3.162        **The Committee recommends that the Australian Government examine the process for a chronic disease patient to be referred for initial specialist assessment by a Medicare Benefits Schedule registered allied health professional without the need to get a referral from their general practitioner, only when:**
- **the patient was originally referred to the allied health professional by their general practitioner; and**
  - **the original referral indicates that specialist assessment may be warranted if the allied health professional agrees it is warranted.**

**Recommendation 5**

- 3.163        **The Committee recommends the Australian Government explore ways to expand and better utilise the role of nurses in the provision and coordination of care for chronic disease management within a general practitioner-led care system.**



## Best Practice, Multidisciplinary Teams and Education

### Introduction

- 4.1 Throughout the course of the inquiry the requirement for unified best practice programs and models for chronic disease prevention and management was the strongest theme presented to the Committee. The system of health care in Australia is world-class, but there is always room for improvement and the foundations of care for chronic disease patients is one such element of the system that is experiencing change and could improve to ensure the sustainability of care.
- 4.2 As discussed in earlier chapters, the sometimes disconnected nature of primary and secondary health care in Australia challenges the ability of the system to deliver consistent care between acute and ongoing treatment episodes for chronic disease.
- 4.3 Equally there is inconsistent application across the board of prevention programs that educate current or potential chronic disease patients on the best ways to manage or prevent their disease or diseases.
- 4.4 This chapter presents a summary of the best practice models identified as part of the inquiry and discusses whether the idea of standardised care is appropriate and how the information technology and communication systems need to develop to support any robust developments in care.

### Best Practice in Prevention – National and International

- 4.5 The prevention of chronic disease is not an outcome that can be easily quantified. Many chronic diseases can manifest based on infection, genetic

factors or through trauma, however many of the biggest chronic diseases in Australia have contributory factors that are related primarily to lifestyle, as discussed in Chapters 2 and 3.

- 4.6 The impact of these lifestyle factors on both the person's wellbeing and the impost they place on the health system can be ameliorated or removed completely, as in the example of a patient with type 2 diabetes, by modifications in behaviour, including diet, exercise, smoking and controlling obesity.<sup>1</sup>
- 4.7 The ability to effectively prevent these lifestyle factors from causing or further contributing to chronic disease relies on education, intervention and willingness for the patient to modify lifestyle elements that are deleterious to their health.
- 4.8 Many programs that aid patients in these modifications of lifestyle or awareness of early signs of disease are either already present in Australia or can be highlighted in the international context.
- 4.9 Preventive health is a key factor in managing the burden of chronic disease. The Public Health Association of Australia identifies the World Health Organization's (WHO) definition of preventive health:
- The WHO describes preventive health as: approaches and activities aimed at reducing the likelihood that a disease or disorder will affect an individual, interrupting or slowing the progress of the disorder or reducing disability. Primary prevention reduces the likelihood of the development of a disease or disorder.<sup>2</sup>
- 4.10 Funding for preventive health programs is relatively low in Australia, when compared to other OECD countries. The Heart Foundation identified this funding gap:
- In 2011-12, just 1.7% of total government health expenditure went to public health activities, including prevention, protection and promotion. This was well behind New Zealand (7%), Canada (6.5%) and Slovakia (5%).<sup>3</sup>
- 4.11 While funding may be low comparatively, the requirement for a longer-term time investment in preventive health strategies is a more important goal. Professor Vickery of the University of Western Australia commented:

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1 Diabetes Australia, *Submission 102*, pp 2-3.

2 Public Health Association of Australia, *Submission 111*, p. 5.

3 Heart Foundation, *Submission 131*, p. 12.

The 40-year program is a preventative program, like the antismoking program: people should exercise more, eat less and not take drugs. They are the three messages that we want to get out. Those messages need to be good public policy – much as we introduce smoking – hiking taxes on low-quality foods and high-energy foods – reducing the access.<sup>4</sup>

- 4.12 This time investment is a lengthy policy commitment required to reduce the effect of chronic disease, but many programs have had marked effects on chronic disease factors in Australia.

## National Prevention and Screening Programs

### Tobacco control

- 4.13 Australia has had one of the most successful tobacco control and smoking reduction strategies in the world. As outlined by the Australian Health Promotion Association (AHPA):

Australia is a world leader in reducing smoking rates because of the comprehensive, multi-strategy approach implemented in recent years to preventing the uptake of smoking and assisting people to quit. This includes policy and legislative reforms including pricing, supply, smoke free regulations, sponsorship etc.; concerted and continuous social marketing; support services to assist people to quit; upskilling health providers on the importance of the issue and how to assist people to quit and many other strategies.<sup>5</sup>

- 4.14 The Prevention 1<sup>st</sup> campaign outlined more critical success factors:

Starting from as early as 1971 to now, tobacco control has incorporated a suite of strategies such as sustained public education, graphic warning labels and plain packaging laws. In that time there has been an associated decrease in smoking, from 35 per cent of adults in 1980 to 20 per cent in 2010, and male deaths from lung cancer and obstructive lung disease have dropped from peak 1970s and 1980s levels.<sup>6</sup>

- 4.15 The impact that tobacco tax and policies affecting smoker behaviour could influence policy in other lifestyle areas, as supported by the AHPA:

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4 Professor Alistair Vickery, University of Western Australia, *Official Committee Hansard*, Perth, 11 March 2016, p. 21.

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

6 Foundation for Alcohol Research and Education and Public Health Association of Australia, *Submission 114*, p. 9.

It would be the same if we were to think about obesity; at the national level, we would be in favour of more policies such as the soft drink tax. I think that the severity of obesity is such that we need to learn from tobacco and start to implement some of these things.<sup>7</sup>

- 4.16 The effects of plain-packaging and taxation have been marked on tobacco consumption within Australia, but as outlined earlier, the time investment has been lengthy, with over 40 years of concerted education and policy control only now having an effect on smoking population totals. However, more could be done, with 13.3 per cent of Australians over the age of 18 reported as being daily smokers in 2013.<sup>8</sup>

### Alcohol Consumption Management

- 4.17 Programs for the management of alcohol consumption in Australia are not as advanced as for tobacco consumption. The taxing of alcohol and national advertising campaigns have had some impact, but more could be done on a national level.<sup>9</sup>

- 4.18 The entrenched societal aspects of alcohol consumption in Australia make it difficult to counter risky drinking behaviour in Australia, with the regular advertising of alcohol still permitted and sports sponsorship still prevalent.<sup>10</sup>

- 4.19 Alcohol consumption in Australia is often highlighted in light of risky drinking behaviours, with the Victorian Health Promotion Foundation outlining:

In 2010, 20 per cent of Australians aged 14 or over had consumed alcohol at a level that put them at risk of alcohol-related disease or injury over their lifetime. Nearly 40 per cent drank at levels that put them at risk of alcohol-related injury from a single drinking occasion over the past 12 months.<sup>11</sup>

- 4.20 The federal Department of Health outlined the risky alcohol consumption policy work underway and the role that primary care providers can play:

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7 Ms Michelle Herriot, Vice-President, Australian Health Promotion Association, *Proof Committee Hansard*, Adelaide, 4 March 2016, p. 27.

8 Department of Health, 'Tobacco key facts and figures', <<http://www.health.gov.au/internet/main/publishing.nsf/content/tobacco-kff>>, viewed 18 April 2016.

9 Foundation for Alcohol Research and Education and Public Health Association of Australia, *Submission 114*, pp 13-14.

10 Foundation for Alcohol Research and Education and Public Health Association of Australia, *Submission 114*, p. 15.

11 Victorian Health Promotion Foundation, *Submission 117*, p. 2.

With alcohol, there is ongoing work around labelling and also information campaigns and the guidelines on alcohol consumption. So there are a number of measures. Of course, we work closely with the NGOs that are very active in this space and also with our states and territories.

There is absolutely no doubt that prevention is the first point of attention in this space, and also recognising, as is evident in the terms of reference for your inquiry, that primary care plays a great role in this. GPs and other primary care practitioners are the first point of contact for Australians in their healthcare system, and they are a great source of authoritative and respected information for consumers about measures that can be taken in the prevention space.<sup>12</sup>

## Exercise and Healthy Lifestyle Promotion

4.21 Generalised wellness and healthy lifestyle promotion is one key area to managing the impact of lifestyle-related risk factors.

4.22 As mentioned in Chapter 2, the LiveLighter program is an example of a national awareness campaign, aimed at promoting better lifestyle, diet and exercise choices. The AHPA identified:

LiveLighter is an initiative developed by the Heart Foundation (WA Division) in partnership with Cancer Council WA. NHF and CCWA were contracted in 2011 by the Department of Health WA to conduct a new public health education program in WA to encourage people to eat well, be physically active and maintain a healthy weight. The LiveLighter campaign aims to encourage healthier changes in behaviour through targeted mass media, effective stakeholder relations, sponsorship and branding opportunities, and planned advocacy. The campaign is currently in the third year of implementation.<sup>13</sup>

4.23 At a state level, programs such as Healthy Together Victoria promote similar healthy lifestyle benefits. The Victorian Council of Social Service outlined the program and its implementation:

Healthy Together Victoria is a comprehensive preventive health initiative, funded through the National Partnership Agreement on Preventative Health, and designed to improve people's health and wellbeing. Under the initiative a number of "healthy together

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12 Dr Lisa Studdert, First Assistant Secretary, Population, Health and Sport Division, Department of Health, *Official Committee Hansard*, Canberra, 21 August 2015, p. 3.

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

communities” have been established across Victoria, including in Wyndham, west of Melbourne.

Only five per cent of adults living in Wyndham eat enough vegetables and about 53 per cent are overweight or obese. 25 per cent of women in Wyndham smoke, well above the national average. In the two-and-a-half years that Healthy Together Wyndham has operated, the program has reached about 54,500 residents. Two-thirds of Wyndham schools, kindergartens and childcare centres are involved in the program, along with 39 businesses.<sup>14</sup>

- 4.24 Healthy lifestyle programs are not only the responsibility of government; many private health insurers are offering programs to their members to enable them to take better control of their health and limit or at least understand the contribution of lifestyle factors on health.
- 4.25 Medibank Private<sup>15</sup>, HCF<sup>16</sup>, Bupa<sup>17</sup>, and HBF<sup>18</sup> all outlined either healthy lifestyle promotion programs for their members, or associated programs for their members with chronic disease that emphasises the benefits of healthy lifestyle factors on overall health and the impacts of their particular disease or diseases.
- 4.26 As outlined in Chapter 3, the role of private health insurers in relation to chronic disease management has potential to expand, but the initial foundation for their involvement in chronic disease prevention is already being undertaken.
- 4.27 Given the increasing number of Australians that are privately insured, the access to tailored lifestyle and health programs aiding in chronic disease prevention would appear to be an expanding role that could be explored.
- 4.28 Indeed, the collaboration between Medibank Private, Victoria Department of Health, HBF and the WA Department of Health in the CarePoint trials is evidence that partnerships and collaborations in this space already exist and are achieving results.<sup>19</sup>

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14 Victorian Council of Social Service, *Submission 120*, p. 11.

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

16 HCF, *Submission 122*, pp 7-13.

17 Bupa, *Submission 144*, pp [18-22].

18 Mr Robert Bransby, Managing Director, HBF Health Ltd, *Official Committee Hansard*, Perth, 11 March 2016, pp 9-12.

19 Medibank Private, *Submission 43*, p. 10.

## Mental Health Awareness and Promotion

- 4.29 Mental health promotion and support programs are an essential part of preventing the worsening of chronic mental health conditions or lessening the impact of comorbid mental health conditions.
- 4.30 Beyondblue outlined the importance of mental health promotion, prevention and management programs in helping battle the increasing incidence of mental health issues in Australia:

Online programs can also be used to facilitate better self-management, and improve physical and mental health outcomes for people with chronic disease. An example of an effective online self-management program is the 'Stepping Up' program ... This six to eight week online program is for people with arthritis, back pain or other musculoskeletal conditions. It supports people to deal with some of the physical and emotional challenges of living with a musculoskeletal condition, such as stress, pain, fatigue, depression, low mood, anxiety, worry, sleep problems and making lifestyle changes. The program has been demonstrated to achieve significant reductions in distress, with participants reporting a 17 per cent improvement in their mental health assessment after completing the program. Initiatives such as Stepping Up have the potential to be expanded to other health conditions, and be integrated as a core component of chronic disease management practices within primary care.<sup>20</sup>

- 4.31 The increased incidence of mental health conditions in Aboriginal and Torres Strait Islander populations<sup>21</sup> and lesbian, gay, bisexual, transsexual and intersex people<sup>22</sup> increases the need for diversified promotion and prevention strategies.
- 4.32 Coordinated funding and control of mental health programs is an important factor to ensuring success and consistency in delivery, especially in relation to Aboriginal mental health programs.<sup>23</sup>
- 4.33 Increased awareness of the impacts of mental health conditions and their potential to lead to risky lifestyle behaviours is essential, as beyondblue outlined:

We also can see that some mental health conditions may be potentially contributing to some of the risk behaviours that we know lead to physical ill health. So the recent child and adolescent

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20 Beyondblue, *Submission 37*, p. 6.

21 Royal Australian and New Zealand College of Psychiatrists, *Submission 31*, p. 3.

22 Victorian Council of Social Service, *Submission 120*, p. 22.

23 AMSANT, *Submission 153, Attachment A*, p. 18.

mental health survey showed that amongst the teenagers that were self-diagnosed or diagnosed with depression they had substantially higher rates of smoking, misuse of alcohol or risky use of alcohol, misuse of cannabis and high levels of obesity. So mental health can drive some of the risk conditions and may drive some of the risk factors that lead to physical health problems down the track.<sup>24</sup>

## International Prevention and Screening Programs

- 4.34 The small number of examples of chronic disease prevention programs with international success identified to the Committee were mainly due to their influence on the establishment or improvement of Australian programs or their potential to be informative models for similar programs within Australia.
- 4.35 The Obesity Prevention and Lifestyle (OPAL) program identified in Chapter 2 was successfully modelled on a French program called Epode. Epode International Network now provides support to any international organisation or community based program that models their obesity prevention program on the Epode methodology, aimed at reducing childhood and overall obesity in communities.<sup>25</sup>
- 4.36 Collaborative screening programs, such as the Scottish Diabetic Retinopathy Screening Collaborative, provide concerted awareness and screening programs to identify and counter early signs of chronic disease, such as diabetes-related blindness.<sup>26</sup> Collaborative efforts such as these, where representatives from all National Health Service Boards in Scotland to coordinate screening efforts, could help inform the coordination of similar programs across Primary Health Networks in Australia.
- 4.37 The WHO identifies a number of international programs in its 2014 report *Global Status Report on Noncommunicable Diseases*:
- Mongolia – Due to a nationwide harmful consumption of alcohol, the Mongolian government set up a network of 80 governmental and non-governmental organisations to increase public awareness, formulate policies and establish a legal environment to reduce the consequences of alcohol use and strengthen implementation of stricter legal

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24 Dr Stephen Carbone, Policy Research and Evaluation Leader, beyondblue, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 14.

25 Epode International Network, 'Epode International Network', <<http://epode-international-network.com/about/context/2014/09/15/epode-international-network>>, viewed 29 March 2016.

26 NHS Scotland, 'Welcome to the Scottish DRS Collaborative', <<http://www.ndrs-wp.scot.nhs.uk/>>, viewed 29 March 2016.

requirements on such elements as alcohol advertising bans and licensed vendor requirements;<sup>27</sup>

- Tonga - Recognising the seriousness of women's sedentary behaviour, the Tongan ministry of health and Ministry of Internal Affairs, with the support of the Australian Sports Outreach Program, joined with the Tonga Netball Association in a campaign commenced in 2011 that brought together a broad range of technical skills and networks to deliver a highly targeted intervention. The campaign, branded Kau Mai Tonga: Netipol (Come on Tonga, let's play netball!), was launched in June 2012 and has delivered physical activity outcomes to more than 20 netball clubs;<sup>28</sup> and
- Pacific Islands and Kiribati - As a means of reducing the availability of products that are high in salt and fat, the Ministry of Health and Medical Services has decided to include maximum levels of sodium and fat in selected processed food items in the draft Food Regulations and Standards. The maximum levels of salt and fat are derived from the "Salt targets in Pacific Foods" that were agreed and mandated by the meeting of Pacific Ministers of Health in 2013 and supported by the WHO, to help address the Non-Communicable Disease crisis in the Pacific. The draft Food Regulations and Standards also include restrictions on marketing of food and non-alcoholic beverages to children, as well as restrictions on the promotion of breast-milk substitutes and baby-feeding accessories.<sup>29</sup>

4.38 Programs such as those outlined above outline the varied ways that international jurisdictions address lifestyle and dietary factors in chronic disease prevention. Considering the catalysts for such programs can help inform the Australian response to promoting and preventing the increase of chronic disease and their associated lifestyle factors within the community.

## The 5As – Framework for Chronic Disease Prevention

4.39 As a general guide for policy and program development within chronic disease prevention systems, the 5As is a framework presented for

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27 World Health Organization, *2014 Global Status Report on Noncommunicable Diseases*, 2014, p. 29, <[http://apps.who.int/iris/bitstream/10665/148114/1/9789241564854\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/148114/1/9789241564854_eng.pdf?ua=1)>, viewed 29 March 2016.

28 World Health Organization, *2014 Global Status Report on Noncommunicable Diseases*, 2014, p. 40, <[http://apps.who.int/iris/bitstream/10665/148114/1/9789241564854\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/148114/1/9789241564854_eng.pdf?ua=1)>, viewed 29 March 2016.

29 World Health Organization, *2014 Global Status Report on Noncommunicable Diseases*, 2014, p. 47, <[http://apps.who.int/iris/bitstream/10665/148114/1/9789241564854\\_eng.pdf?ua=1](http://apps.who.int/iris/bitstream/10665/148114/1/9789241564854_eng.pdf?ua=1)>, viewed 29 March 2016.

organising screening and interventions across modifiable lifestyle risk factors.<sup>30</sup>

- 4.40 The Royal Australian College of General Practitioners (RACGP), in its *Guideline for preventive activities in general practice: 8<sup>th</sup> edition* outlines the 5As as ‘...an internationally accepted framework for organising the assessment and management of all the behavioural risk factors in primary healthcare’.<sup>31</sup>
- 4.41 More specifically, the 5As entail:
- Ask – a systematic approach to all patients regarding their smoking, nutrition, alcohol or physical activity, which may occur opportunistically as they present for other conditions and/or by recall for health checks;
  - Assess – assess readiness to change, and dependence (for smoking and alcohol);
  - Advise – provide brief, non-judgemental advice with patient education materials and work with the patient to set agreed goals;
  - Assist – provide motivational interviewing; refer to telephone support services, group lifestyle programs or individual providers (e.g. dietitian or exercise physiologist); and consider pharmacotherapy; and
  - Arrange – regular follow-up visits to monitor maintenance and prevent relapse.<sup>32</sup>
- 4.42 This framework can be applied to both the prevention and management of chronic disease, as well as informing research into the effectiveness of such interventions.<sup>33</sup>
- 4.43 The RACGP has modified the 5As framework to create their own smoking, nutrition, alcohol, physical activity (SNAP) guide. The application of the framework is presented as below.

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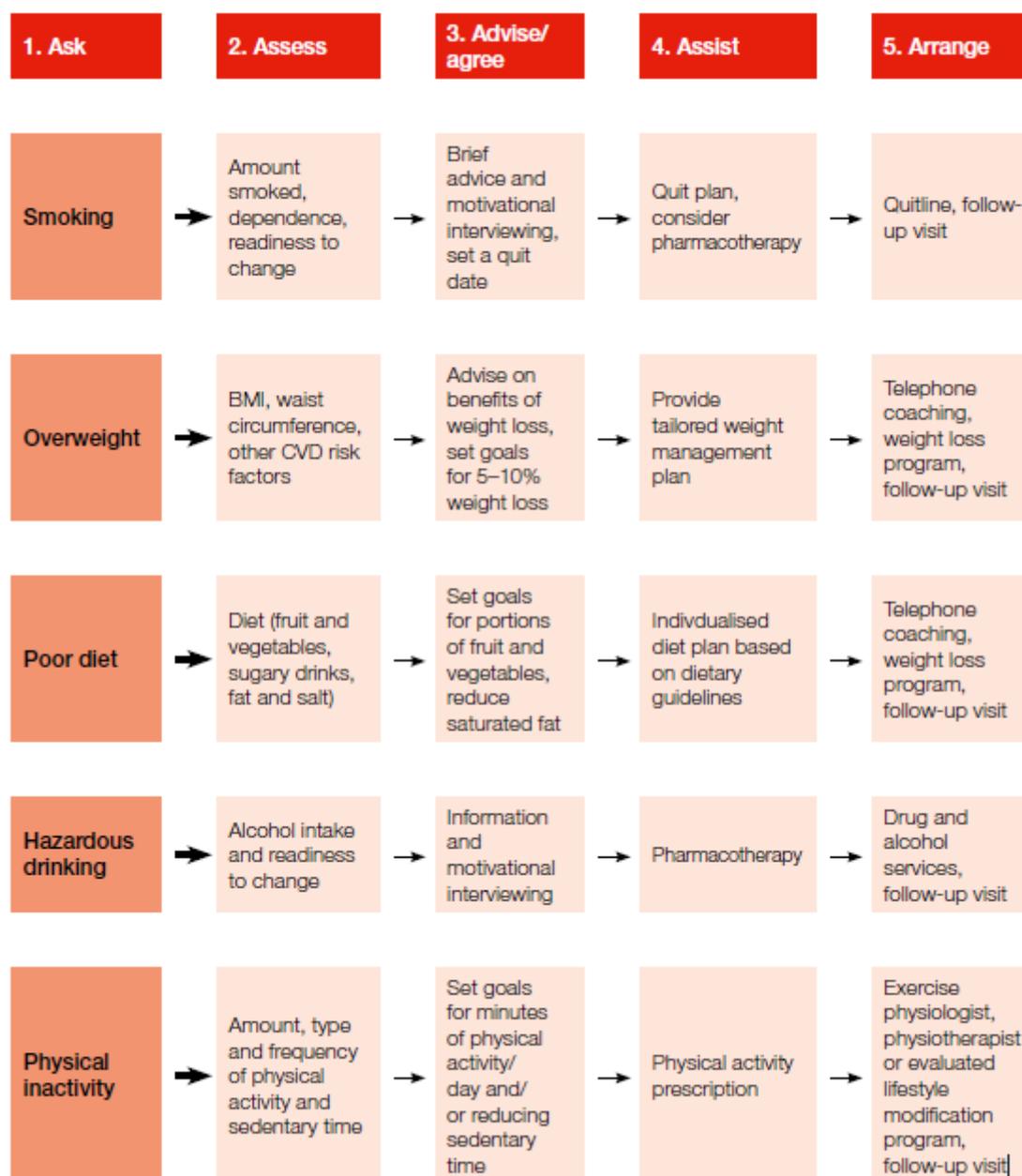
30 PC4, COSA and Cancer Council Australia, *Submission 63*, p. 7.

31 Royal Australian College of General Practitioners, *Guideline for preventive activities in general practice: 8<sup>th</sup> edition*, 2012, p. 40, <<http://www.racgp.org.au/download/Documents/Guidelines/Redbook8/redbook8.pdf>>, viewed 29 March 2016.

32 Royal Australian College of General Practitioners, *Guideline for preventive activities in general practice: 8<sup>th</sup> edition*, 2012, p. 40, <<http://www.racgp.org.au/download/Documents/Guidelines/Redbook8/redbook8.pdf>>, viewed 29 March 2016.

33 Centre for Primary Health Care and Equity, University of New South Wales, *Submission 6*, p. 1.

Figure 4.1 RACGP use of the 5As for the SNAP guide



Source Royal Australian College of General Practitioners, *Smoking, nutrition, alcohol, physical activity (SNAP): A population health guide to behavioural risk factors in general practice, 2nd edn.* Melbourne: The Royal Australian College of General Practitioners 2015, p. 7.

4.44 The 'Ask' categories outlined above align with the key lifestyle factors identified in Chapter 2 and earlier in this chapter as being the key factors contributing to the incidence or worsening of chronic disease within Australia. Accordingly, it is pertinent to consider these factors, and the 5As framework, as a guidance tool for prevention policy and programs.

## Integrated Health Checks

- 4.45 As an expression of the preventative and management aspects of models such as the 5As above, the concept of an integrated health check is a key element to achieving the detection and treatment protocols required for chronic disease best practice.
- 4.46 The National Stroke Foundation advocates for an integrated health check, as developed by the National Vascular Disease Prevention Alliance (NVDPA):
- ...to promote the early detection and management of those at high risk of developing chronic kidney disease, type 2 diabetes, heart disease or stroke. An integrated health check, includes the following:
- Establishment of kidney function
  - Establishment of diabetes status including use of the AUSDRISK tool and blood tests to determine risk of developing type 2 diabetes or having undiagnosed existing diabetes.
  - Calculation of an absolute cardiovascular risk score for cardiovascular disease
  - Timely referral to diabetes prevention programs (high risk) or coordinated care service (existing diabetes)
  - Timely referral to cardiovascular disease prevention programs.<sup>34</sup>
- 4.47 Diabetes Australia also supports the development of the NVDPA's health check approach.<sup>35</sup>
- 4.48 Health checks do currently exist under the Medicare Benefits Schedule (MBS) for a number of categories:
- There are four time-based MBS health assessment items: **701 (brief)**, **703 (standard)**, **705 (long)** and **707 (prolonged)**. The following categories of health assessments may be undertaken by a medical practitioner (other than a specialist or consultant physician) under these items:
- a health assessment for people aged 45-49 years who are at risk of developing chronic disease
  - a type 2 diabetes risk evaluation for people aged 40-49 years with a high risk of developing type 2 diabetes as determined by the Australian Type 2 Diabetes Risk Assessment Tool
  - a health assessment for people aged 75 years and older
  - a comprehensive medical assessment for permanent residents of residential aged care facilities

34 National Stroke Foundation, *Submission 113*, p. 4.

35 Diabetes Australia, *Submission 102*, pp 3-4.

- a health assessment for people with an intellectual disability
  - a health assessment for refugees and other humanitarian entrants<sup>36</sup>
- 4.49 The first three categories listed above are especially relevant to the population affected by or at risk of chronic disease, however their use is still relatively low in the general population.<sup>37</sup>
- 4.50 The current stratification of health assessments based on age was questioned by Dr Tracy Brown, who as a geriatrician, questioned whether the trigger point of age 45 and at risk of chronic disease was early enough:
- Then we are going to look at other pivotal points; you can use decades if you want to; I would even like to see it every five years. Let us make it at 25, 30, 35, 40, 45 and 50, and it needs to be a half-hour visit.<sup>38</sup>
- 4.51 There is also a specific Aboriginal and Torres Strait Islander health assessment (MBS item 715), which is used extensively by health providers such as South Coast Medical Service Aboriginal Corporation:
- For clients with chronic disease in our section we have GP services, so they do health checks, GP management plans, team care arrangements, referrals and ongoing monitoring.<sup>39</sup>
- 4.52 One issue of concern also raised by the South Coast Medical Service Aboriginal Corporation was the confirmation of a person's Aboriginal heritage when accessing the MBS item 715 health checks:
- One of my concerns overall, I suppose, with regard to chronic disease is that in the health check assessments there is no verification of Aboriginality. We have had, in our clinic, a number of people going down to the chemist writing 'CTG', and they are not Aboriginal people. It is a real concern that we have and it is something that I think really needs to be addressed. Our organisation has – I am looking at Jo's registered clients here – 7,115 clients. However, when I last counted Aboriginal people,

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36 Department of Health, 'MBS Health Assessments Items 701, 703, 705, 707 and 715', <[http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare\\_mbsitem\\_general\\_factsheet](http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare_mbsitem_general_factsheet)>, viewed 4 April 2016.

37 Dr Erin Lalor, Chief Executive Officer, National Stroke Foundation, *Official Committee Hansard*, Sydney, 23 October 2015, p. 9.

38 Dr Tracy Brown, *Proof Committee Hansard*, Newcastle, 31 March 2016, p. 30.

39 Ms Josephine Naughton, Senior Manager, Primary Health Care, South Coast Medical Service Aboriginal Corporation, *Official Committee Hansard*, Bomaderry, 12 February 2016, p. 12.

there were some 5,700 Aboriginal people, and that was a couple of years back. The ABS statistics say there were 4,316 in 2011.<sup>40</sup>

4.53 This issue was also raised in Tumbi Umbi by Ms Sue Maher, who stated:

I have a practice manager at Morisset. She got a phone call the other day and the lady said to her, 'What proof does a person have to show to be put on the Aboriginal register to get free scripts,' and Sharon said, 'Well, no, there's no proof. They're encouraged to self-identify, and we're not actually allowed to ask for proof. They don't have to sign.' There are supposed to be three identifying markers for Aboriginal people, which is that they are of Aboriginal descent, that they self-identify and that they are recognised in their community. They are the three identifiers for an Aboriginal person. In general practice we cannot do any of that; they just self-identify. If you were going for a loan or going for Centrelink, you would have to fill those criteria and you would have to sign a stat dec [statutory declaration]. This lady said to our practice manager, 'Well, I just want to report a fraud.' It was a relative of hers who was showing off and bragging about how she has got free scripts because she just went in and told the doctor she was Aboriginal, and she said, 'And I can tell you she's not. So what are you going to do about it.'

That money should really be spent on the Aboriginal people, not on other people, and it is getting out. We have got quite clever people in our area that know how to rort the system – and try to rort the system. My suggestion for it would be that most people that are of Aboriginal or Torres Strait Islander descent would be registered with Centrelink for the healthcare card that they get to take to the chemist and show the chemist to get their scripts, so why can't there be a card which the person has to go and sign a stat dec for at Centrelink or at the Aboriginal clinics? [...] What if they went there and they had to actually sign a stat dec before an elder or they had to do it through Centrelink and then they got a card that they show at the chemist every time they go, instead of just having this ticked on their file that they are registered for the gaps program and they go and get free scripts? To me, it is an area where it has just opened up, and it will get worse.<sup>41</sup>

4.54 Dr Wolf du Plessis added:

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40 Mr Craig Ardler, Chief Executive Officer, South Coast Medical Service Aboriginal Corporation, *Official Committee Hansard*, Bomaderry, 12 February 2016, p. 11.

41 Ms Sue Maher, private capacity, *Official Committee Hansard*, Tumbi Umbi, 19 February 2016, pp 10-11.

It is not only about the scripts. They have got access to more allied health services and so forth. So, literally, people are abusing it who we believe are not entitled to it. The only thing they have to do is sit in front of you and say, 'I'm Aboriginal.' There is no means test for that. There are no questions asked further.<sup>42</sup>

- 4.55 The importance of health checks is high, especially when attempting to capture the early stages of chronic disease, or the lifestyle risk factors that contribute to disease, so the robust access and control of these assessments is important to future management of chronic disease growth.

## **Best Practice in Treatment – Practical and Theoretical**

- 4.56 Chronic disease management and treatment is a role undertaken within the primary care setting for the majority of patients. Episodes of acute care will often occur within the hospital system, but for most patients the foundation of their care and the best benefit to be gained in their disease management is through the primary care system.
- 4.57 The inquiry's first term of reference seeks best practice examples in chronic disease management and there have been three main themes of best practice emerge:
- Self-management of chronic disease;
  - The Wagner Chronic Care Model; and
  - The Patient-Centred Medical Home.

## **Self-Management of Chronic Disease**

- 4.58 Underpinning many of the best practice models and theories for chronic disease care and management is the active participation of the patient in their ongoing wellness.
- 4.59 Patient-centred outcomes require the patient themselves to have the knowledge and support to manage their condition, as outlined by the Australian Diabetes Educators Association:

It has now been well recognised that medical intervention alone is insufficient to improve diabetes outcomes. There is an increasing focus on patient-centred outcomes. The critical role of empowering the person with diabetes in their own self-management to improve quality of life, the factors that influence their capacity to self-manage, and the need for self-management support and education provided by a range of health care providers, are widely

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42 Dr Wolf du Plessis, private capacity, *Official Committee Hansard*, Tumbi Umbi, 19 February 2016, p. 11.

acknowledged. Self-management education and support are key strategies identified in both the *National Chronic Disease Strategy* and the *National Service Improvement Framework for Diabetes*.<sup>43</sup>

4.60 More explicitly, the Western Australian Department of Health defines self-management and self-management support:

Self-management is a shared responsibility between the individual and service provider.

Self-management is defined in the National Chronic Disease Strategy as “the active participation by people in their own health care”. Self-management involves consumers adopting attitudes and learning skills that facilitate a partnership with carers, general practitioners, and health professionals in treating monitoring and managing their condition.

Self-management support describes the techniques and strategies that health providers, carers, organisations and systems do to assist those living with chronic conditions to practice self-management. Also known as ‘collaborative care strategies’, these techniques are based on self-management principles.<sup>44</sup>

4.61 These principles of self-management and self-care must underpin the successful planning and ongoing provision of health care to patients. The tie-in with chronic disease prevention, and how that has evolved with trends in patient-centred care, was raised by the Australian Primary Health Care Research Institute:

We have gone from a situation a few decades ago where patient education, because that is what it was called then, was something you did on the side of medical care. What we now know is that self-management, supporting self-management and a number of related concepts such as health literacy, empowerment and patient partnerships are central to good care. That does mean that we are not all the same. We do not have all the same needs in terms of support for self-care, so some tailoring is required.<sup>45</sup>

4.62 The Flinders Program of Chronic Condition Management and Self-Management Support (Flinders Program), created by the Human Behaviour and Health Research Unit at Flinders University has been successfully used to demonstrate the impact of self-management support

43 Australian Diabetes Educators Association, *Submission 109*, p. 2.

44 Department of Health, Western Australia, *WA Chronic Conditions Self-Management Strategic Framework*, Perth: Health Networks Branch, 2011, p. 3.

45 Associate Professor Terence Findlay, Head of Programs, Australian Primary Health Care Research Institute, Australian National University, *Official Committee Hansard*, Canberra, 21 August 2015, p. 49.

in chronic disease management, through both the Coordinated Veterans' Care Program (CVC) and the Flinders Closing the Gap Program.<sup>46</sup>

- 4.63 The flexibility of the Flinders Program was highlighted by the Dietitians Association of Australia:

The program has been applied in Australia, New Zealand, USA, Canada, Hong Kong, Scotland and Sweden and to population groups such as Aboriginal and Torres Strait Islanders, children, mental health, disability and rural and remote.<sup>47</sup>

- 4.64 Another example of a self-management program is the Living Well with Persistent Pain Program operated in South Australia.<sup>48</sup>

### Case Study – Flinders Program in New Zealand

As a result of surveys and studies in New Zealand in the mid-2000s, identifying the increasing incidence of complex chronic disease in the New Zealand population, a trial introduction of the Flinders Program to train health care providers to enable self-management of chronic disease by patients was commenced.

#### Trial Goals

The program was implemented in primary health care settings including general practice, community Hauora services and independent nursing practice by a Primary Health Organisation, with one goal being to achieve critical mass by having a certified Flinders Program practitioner in every area or practice capable of supporting patients in self-managing their chronic disease. A team of 10 registered nurses were trained in November 2010 as accredited trainers and this group ran workshops to train providers during 2011.

The majority of those trained were registered nurses including clinical nurse specialists, nurse practitioners, district nurses and practice nurses. However, other health providers, such as those in aged care, prison services, teams providing support needs assessment, community pharmacists, general practitioners, physiotherapists and dietitians also received training.

#### Outcomes

From February to December 2011, 150 health care providers were trained in the program across thirty practices and the District Health Board in the Hawkes Bay

46 Flinders Human Behaviour and Health Research Unit, *Submission 4*, p. 1.

47 Dietitians Association of Australia, *Submission 148*, p. 18.

48 Adelaide Primary Health Network, *Submission 119*, p. 46.

region, with the majority having at least one certified provider and some practices having all nurses trained in the program.

These providers then helped coach relevant patients in the self-management principles of the program, to help them achieve better outcomes for their chronic condition.

As a result of the trial, the Flinders Program has been widely implemented across District Health Boards in New Zealand, with over 500 practitioners having been trained since 2005.<sup>49</sup>

### Coordinated Veterans' Care Program

4.65 The Australian Medical Association recognises the CVC Program as being one of the most innovative coordinated self-management programs in Australia:

It is a pro-active approach to care that targets support to those veterans with chronic and complex conditions that put them at risk of unplanned hospitalisation. CVC supports improved quality of life for eligible veterans and, in the long term, has the potential to reduce hospitals costs by focusing on improving their care in the community.<sup>50</sup>

4.66 The CVC Program actively involves the patient as part of the coordination of their care:

The CVC Program aims to improve the health of participants by:

- providing ongoing planned and coordinated care from a GP and a nurse
- educating and empowering participants to self-manage their conditions
- encouraging the most socially isolated to participate in community activities.<sup>51</sup>

4.67 While the key deliverable from a program like the CVC is better health outcomes for the patient, the equally as important outcome is that the veteran is 'more educated and empowered to self-manage their conditions'.<sup>52</sup>

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49 New Zealand Ministry of Health, 'Effective behaviour change in long-term conditions: Case Study 5', <<http://www.health.govt.nz/publication/effective-behaviour-change-long-term-conditions>>, viewed 12 April 2016.

50 Australian Medical Association, *Submission 107*, p. 7.

51 Flinders Human Behaviour and Health Research Unit, *Submission 4*, p. 3.

52 Department of Veterans' Affairs, 'CVC Guide for General Practice', <<http://www.dva.gov.au/about-dva/publications/health-publications/provider-publications/guide-general-practice>>, viewed 4 April 2016.

- 4.68 Key to the success of building capability in the patient to self-manage their conditions is training and educating the care-givers and clinicians in the best ways to support their self-management. This is achieved through the use of accredited learning modules and resources for the care team.<sup>53</sup>
- 4.69 An especially important component of the CVC program is in trying to engage patients in community activities, as the effect of chronic disease can often lead to patients feeling cut off from the community and suffering 'social isolation, mental health issues, family breakdowns and poor health literacy'.<sup>54</sup>

### Flinders Closing the Gap Program

- 4.70 The Flinders Closing the Gap Program was also developed by the Human Behaviour and Health Research Unit at Flinders University and has:

...provided training and implementation support to primary health care services providing care to Indigenous populations across Australia in the national initiative known as the Flinders Closing the Gap Program (FCTGP). Its focus has been on training health practitioners and health workers in self-management support.

This training program has aimed to improve the self-management capabilities of Aboriginal and Torres Strait Islander people with chronic diseases and conditions across Australia so that they, together with their health workers and health practitioners, could improve their health outcomes and ultimately close the gap in life expectancy between Aboriginal and Torres Strait Islander people and the general Australian population.<sup>55</sup>

- 4.71 The work undertaken and results achieved from the program have resulted in '...genuine change in the way clients think about their health as well as the way practitioners work with their clients to achieve better health outcomes'.<sup>56</sup>

### Living Well with Persistent Pain Program

- 4.72 The Adelaide Primary Health Network outlined a successful self-management program run in the norther region of Adelaide – the Living Well with Persistent Pain (LWwPP) Program.
- 4.73 The program has self-management support at its core:

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53 Flinders Human Behaviour and Health Research Unit, *Submission 4*, p. 3.

54 Australian Association of Social Workers, *Submission 46*, p. 3.

55 Flinders Human Behaviour and Health Research Unit, *Submission 4*, p. 3.

56 Flinders Human Behaviour and Health Research Unit, *Submission 4*, p. 4.

Combining a group program and individual pain service assessments, this evidence-based program supports individuals to better understand their pain condition, equips them with the necessary tools to improve their quality of life and thereby minimises the burden of pain on them, their families and the wider community...

It provides a holistic self-management course, case coordination and extended allied health services. A GP with a particular interest in managing persistent pain is available to access. A care coordinator undertakes an initial assessment and supports the patient and GP through the process of both group sessions and one-on-one allied health services...

Self-management support is at the heart of the LWwPP program. Both the group education sessions and the individual care plan are centred on the concept that the patient is best placed to determine their own management pathway. The individual assessment is structured in a way that assists the patient to identify their own life-experienced based goals. This is in comparison to indication-focused goals decided on and led by health providers.<sup>57</sup>

- 4.74 The example of the LWwPP Program shows that self-management is an integral part to achieving better outcomes in chronic disease management, where the patient is involved in their care and support, rather than being at arm's length to the process. Being involved in their own care and management enables a patient to avoid being isolated by their condition, ultimately withdrawing from appropriate care practices or from the people that can support them the most in the community.

## Wagner Chronic Care Model

- 4.75 One of the most resounding and recurring examples of best practice in chronic disease management and care highlighted throughout the inquiry was the Wagner Chronic Care Model, identified by many as the ideal model for creating high quality coordinated care, or as being the basis for existing care models, either in Australia or internationally.<sup>58</sup>

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57 Adelaide Primary Health Network, *Submission 119*, p. 46.

58 Dr Jodi Graham, *Submission 1*, p. 7; Flinders Human Behaviour and Health Research Unit, *Submission 4*, p. 3; Centre for Primary Health Care and Equity, UNSW, *Submission 6*, p. 1; Metro North Hospital and Health Service, *Submission 9*, p. [2]; Graduate School of Medicine, University of Wollongong, *Submission 16*, p. [1]; Lymphoedema Action Alliance, *Submission 33*, p. 26; Victorian Primary Care Partnerships, *Submission 36 – Attachment 1*, p. 16; beyondblue, *Submission 37*, p. 5; Medibank Private, *Submission 43*, p. 4; Australian Association of Social Workers, *Submission 46*, p. 4; The Peninsula Model, *Submission 64*, pp 2-3; Carrington Health, *Submission 72*, p. [1]; Australian College of Rural and Remote Medicine, *Submission 76*, pp 4-5;

- 4.76 Developed at the MacColl Center for Health Care Innovation in the mid-1990s, and further refined into the 21<sup>st</sup> century, the Wagner Chronic Care Model (named for one of the original researchers – Dr Edward Wagner) is a widely recognised best practice system for coordinating care. The Centre for Primary Health Care and Equity described the foundations of the model:
- ...identifies system supports required for effective patient centred care of patients with chronic conditions - self management support, delivery system redesign for team care, decision support, information systems and electronic health records, health care organisation (including non-fee for service funding and incentives) and community resources (including engagement of non-government and religious organisations).<sup>59</sup>
- 4.77 The World Health Organization has endorsed the Chronic Care Model in its report *Innovative care for chronic conditions: building blocks for action: global report* as the preferred model and framework for building innovation in coordinated chronic disease care models in chronic disease health care systems.<sup>60</sup>
- 4.78 The theoretical basis for application of this model is visualised below.

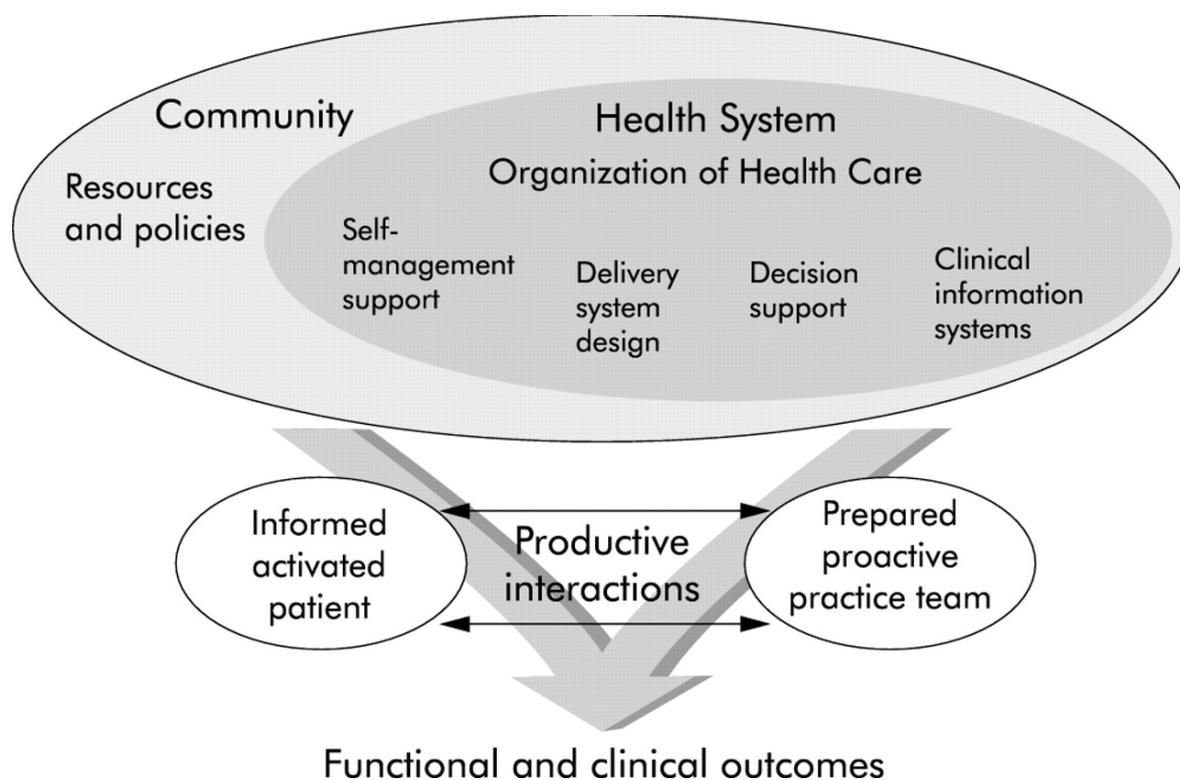
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Dr Chris Bollen, *Submission 87*, p. 5; cohealth, *Submission 88*, p. 11; Sydney Nursing School, University of Sydney, *Submission 91*, pp 2-3; Dr Paul Burgess, *Submission 92*, p. 5; ACN, CATSINaM, APNA, MCAFHNA & ACMHN, *Submission 106*, p. 46; Australian Medical Association, *Submission 107*, p. 6; Private Healthcare Australia, *Submission 108*, p. [2], Adelaide Primary Health Network, *Submission 119*, p. 11; Australian Psychological Society, *Submission 130*, pp 8-9; Northern Territory Department of Health, *Submission 133*, p. 4; Royal Australian College of General Practitioners, *Submission 135*, p. 4; Health Issues Centre, *Submission 139*, p. 4; Dietitians Association of Australia, *Submission 148*, pp 16-17; Mostyn Street Clinic, *Submission 163*, pp 3-4; WA Primary Health Alliance, *Submission 180*, p. 10; Grattan Institute, *Submission 188 – Attachment 1*, p. 18.

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

60 World Health Organization, *Innovative care for chronic conditions: building blocks for action: global report*, 2002, pp 41-65.

Figure 4.2 Wagner Chronic Care Model



Source National Public Health Service for Wales, 'Chronic Disease Management Models', December 2005, p. 36.

4.79 The theoretical basis of the Wagner model has practical examples within Australia where programs have been developed to apply the principles of the model to health care planning and/or delivery:

- Peninsula Model - The Peninsula Model is a Primary Health Planning Framework developed through a partnership of agencies with a role in primary health care planning at a catchment-wide level in the Frankston and Mornington Peninsula local government areas in Victoria;<sup>61</sup>
- Hospital Admission Risks Program (HARP) - A Victorian program with a focus on care coordination, self-management support, and specialist care. It aims to reduce avoidable hospital presentations and admissions by targeting those who are current or are at risk of becoming, frequent hospital service users;<sup>62</sup>
- Improving the Diabetes Journey Project - an agreed model for identifying gaps in services to patients with type 2 diabetes in the Eastern Metropolitan Region (EMR) of Victoria. By using elements of the Wagner model to realign service delivery based on a more informed

61 The Peninsula Model, *Submission 64*, pp 2-3.

62 CAN, CATSINaM, APNA, MCAFHNA & ACMHN, *Submission 106*, p. 46.

understanding of the types of education programs that would best suit communities across the EMR;<sup>63</sup> and

- Medibank Private – an example of a private health insurer, recognising and adapting the Wagner model to better inform their member program design through recognising ‘positive outcomes for people with long-term health conditions are achievable when they and their families, community partners and health professionals are informed, motivated and working together’.<sup>64</sup>

### Case Study – England’s House of Care Model

Due to a recognition of the need to reform medical treatment models for chronic diseases (known as long term conditions in the UK), the National Health Service (NHS) in England has introduced a model of care, informed by the Chronic Care Model, known as the House of Care.

The NHS identifies the increasing chronic disease problem in England:

The 15 million people in England with long term conditions have the greatest healthcare needs of the population (50% of all GP appointments and 70% of all bed days) and their treatment and care absorbs 70% of acute and primary care budgets in England.<sup>65</sup>

As a result of this increasing burden and the identification of the need for patient-centred care, the House of Care Model was developed with the following four key elements:

- *Commissioning* – which is not simply procurement but a system improvement process, the outcomes of each cycle informing the next one.
- *Engaged, informed individuals and carers* – enabling individuals to self-manage and know how to access the services they need when and where they need them.
- *Organisational and clinical processes* – structured around the needs of patients and carers using the best evidence available, co-designed with

63 Victorian Primary Care Partnerships, *Submission 36 – Attachment 5*.

64 Medibank Private, *Submission 43*, p. 4.

65 National Health Service England, ‘House of Care Model - Background’, <<https://www.england.nhs.uk/resources/resources-for-cgcs/out-frwrk/dom-2/house-of-care/house-care-mod/>>, viewed 12 April 2016.

service users where possible.

- *Health and care professionals working in partnership* – listening, supporting, and collaborating for continuity of care.<sup>66</sup>

By engaging patients and their carers and health care providers in care planning, health literacy and service provision, the House of Care employs a number of the principles of the Chronic Care model, to create the framework envisaged below.



Source National Health Service England, 'Enhancing the quality of life for people living with long term conditions – The House of Care', <<https://www.england.nhs.uk/house-of-care/>>

Whilst mainly a conceptual care framework, the House of Care model enables NHS providers to plan the care required by long term condition patients, by involving the patient's family, carers and numerous providers in their care planning and provisioning, to ensure the best coordinated care outcomes. This model shares a number of similarities to the 'Health Care Homes' reforms announced recently in Australia, with similar coordinated care goals and patient-centred outcomes at the heart of delivery targets.

4.80 The concept of the Chronic Care Model informs other models of coordinated care, such as the patient-centred medical home (PCMH) as discussed below. It also helps inform the 'Healthier Medicare' chronic disease reforms announced by the Australian Government on 31 March

66 National Health Service England, 'House of Care Model - Background', <<https://www.england.nhs.uk/resources/resources-for-cgcs/out-frwrk/dom-2/house-of-care/house-care-mod/>>, viewed 12 April 2016.

2016, which focuses on providing better coordinated care to chronic disease patients, utilising elements of the PCMH.

## Patient-Centred Medical Home

- 4.81 The PCMH is the manifestation of the service delivery coordination and organisation from care models, such as the Wagner Chronic Care Model. The PCMH as a mechanism for delivering the coordinated care for chronic disease patients was the prime example raised with the Committee.<sup>67</sup>
- 4.82 The PCMH is a coordinated care delivery system developed in the United States since its inception in the early 21<sup>st</sup> century that has grown to be adapted by many countries and health care systems.<sup>68</sup>
- 4.83 This model has five key attributes that align with coordinated care, normally led by the patient's general practitioner or primary care provider:
- Comprehensive care that meets the majority of a patient's needs.
  - Patient-centred care that prioritises the development of relationships between patients and providers.
  - Coordinated care where care is planned and coordinated across healthcare settings to maximise positive outcomes.
  - Accessible care, available to patients easily, when it is needed and in responsive settings.

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67 Dr Jodi Graham, *Submission 1*, p. 7; Centre for Primary Health Care and Equity, UNSW, *Submission 6*, p. 4; Pharmaceutical Society of Australia, *Submission 32*, pp 3-4; WentWest Limited, *Submission 53*, p. [2]; Orimary Health Care Ltd, *Submission 71*, pp 2-3; Australian College of Rural and Remote Medicine, *Submission 76*, p.15; cohealth, *Submission 88*, p. 12; Dr Paul Burgess, *Submission 92*, p. 10; Country SA Primary Health Network, *Submission 94*, p. [2]; Painaustralia, *Submission 96*, p.10; Western Health, *Submission 100*, p. 13; ACN, CATSINaM, APNA, MCAFHNA & ACMHN, *Submission 106*, pp 49-50; Australian Medical Association, *Submission 107*, p. 13; Adelaide Primary Health Network, *Submission 119*, pp 37-38; South Eastern Melbourne PHN, *Submission 123*, p. 4; Australian Primary Health Care Research Institute, *Submission 124*, p. 24; Royal Australian College of General Practitioners, *Submission 135*, pp 3-4; Bupa, *Submission 144*, p. 16; NSW Health, *Submission 152*, p. 18; Aboriginal Medical Services Alliance Northern Territory, *Submission 153*, p. 4; Sydney North PNH, *Submission 155*, p. 2; Dr Rosemary Panelli, *Submission 161*, p. 2; Mostyn Street Clinic, *Submission 163*, p. [1]; Department of Health and Human Services Victoria, *Submission 173*, p. 6; WA Primary Health Alliance, *Submission 180*, pp 2-3; Brisbane North PHN, *Submission 182*, p. [3]; Australian General Practice Network and Australian Association of General Practitioners, *Submission 184*, p. 7; Grattan Institute, *Submission 188 – Attachment 1*, p. 18; Professor Timothy Usherwood, Member, Kidney Check Australia Taskforce, Kidney Health Australia, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 8.

68 Improving Chronic Illness Care, 'Patient Centred Medical Home', <[http://www.improvingchroniccare.org/index.php?p=Patient-Centered\\_Medical\\_Home&s=224](http://www.improvingchroniccare.org/index.php?p=Patient-Centered_Medical_Home&s=224)>, viewed 6 April 2016.

- Safe and quality care, where practitioners and practice systems aim for continuous quality improvement.<sup>69</sup>
- 4.84 These principles have guided the development of the 'Health Care Home' presented in the Primary Health Care Advisory Group's (PHCAG) report *Better Outcomes for People with Chronic and Complex Health Conditions: December 2015*,<sup>70</sup> which has been adopted in the Australian Government's 31 March 2016 announcement of the 'Healthier Medicare' chronic disease reforms.
- 4.85 The Health Care Home will have seven key features (as recommended by the PHCAG):
- **Voluntary patient enrolment** with a practice or health care provider to provide a clinical 'home-base' for the coordination, management and ongoing support of patient care. This includes the development of an individualised care plan for patients tailored to their specific conditions and health care needs.
  - **Patients, families and their carers as partners in their care** where patients are motivated to maximise their knowledge, skills and confidence to manage their health, aided by technology and with the support of a health care team.
  - **Patients have enhanced access** to care provided by their Health Care Home in-hours, which may include support by telephone, email or videoconferencing, and effective access to after-hours advice or care.
  - **Patients nominate a preferred clinician** who is aware of their problems, priorities and wishes, and is responsible for their care coordination.
  - **Flexible service delivery and team based care** that supports integrated patient care across the continuum of the health system through shared information and care planning.
  - **A commitment to care which is of high quality and is safe.** Care planning and clinical decisions are guided by evidence-based patient health care pathways, appropriate to the patient's needs.
  - **Data collection and sharing** by patients and their health care teams to measure patient health outcomes and improve performance.<sup>71</sup>

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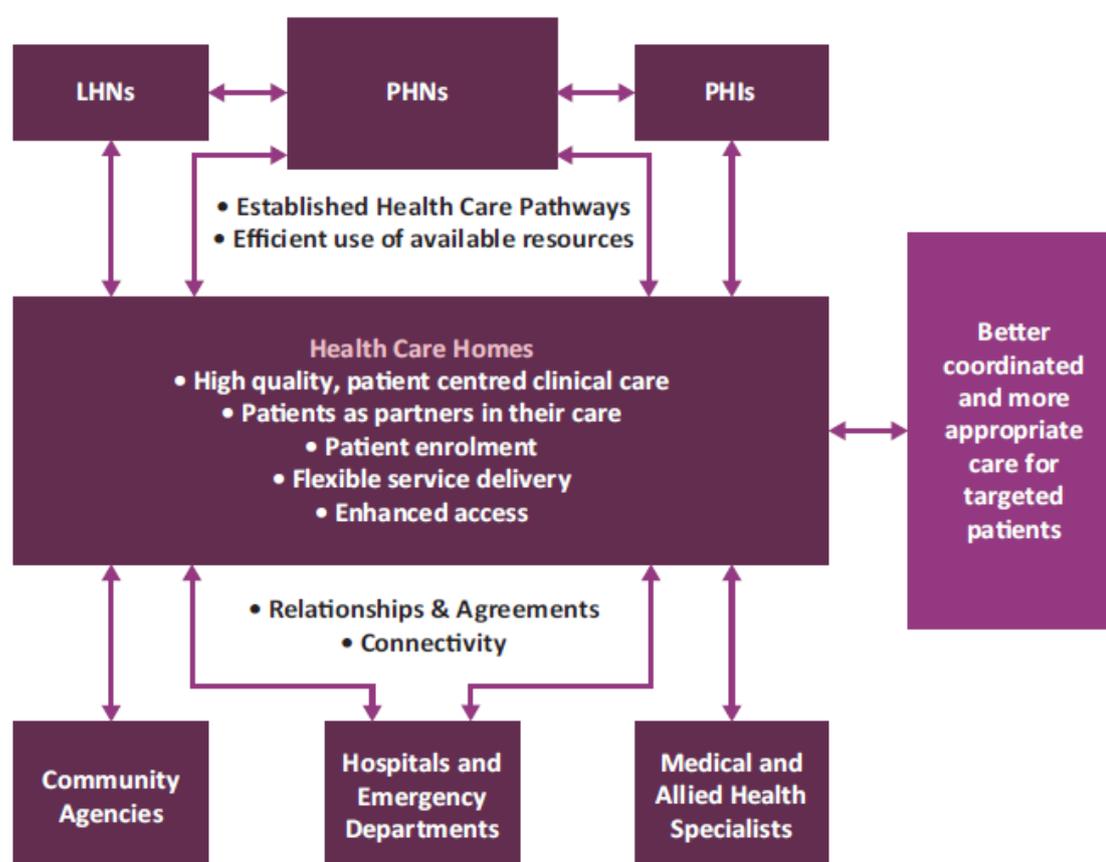
69 Royal Australian College of General Practitioners, *Submission 135*, p. 3.

70 Commonwealth of Australia, Department of Health, *Better Outcomes for People with Chronic and Complex Health Conditions: Report of the Primary Health Care Advisory Group*, December 2015, pp 18-21.

71 The Hon. Sussan Ley MP, Minister for Health, Minister for Aged Care, Minister for Sport, 'Health Care Homes to keep chronically-ill out-of-hospital', *Media Release*, 31 March 2016.

- 4.86 Initial two-year trials will occur in up to 200 medical practices from 1 July 2017, affecting up to 65 000 chronic disease patients across Australia.
- 4.87 The essential coordination between the patient's 'home' practice, the relevant Primary Health Network, Local Health Network and any relevant Private Health Insurer is depicted in the Health Care Home framework illustrated below.

Figure 4.3 Health Care Home Model



Source Commonwealth of Australia, Department of Health, *Better Outcomes for People with Chronic and Complex Health Conditions: Report of the Primary Health Care Advisory Group, December 2015, p. 19.*

- 4.88 This adoption of the recommendations of the PHCAG and the concepts of PCMH are a welcome addition to the Australian health care system, as highlighted on the day of the announcement by Mr Brendan Moore from Alzheimer's Australia<sup>72</sup> and Dr Justin Vaughan from NIB health funds.<sup>73</sup>

<sup>72</sup> Mr Brendan Moore, General Manager, Policy, Research and Information, Alzheimer's Australia NSW, *Proof Committee Hansard*, Newcastle, 31 March 2016, p. 13.

<sup>73</sup> Dr Justin Vaughan, Group Executive, Benefits and Provider Relations, NIB Health Funds, *Proof Committee Hansard*, Newcastle, 31 March 2016, p. 41.

## Preventing Multi-morbidity

- 4.89 The current Medical Benefits Schedule (MBS) claiming restrictions on providing care plans and chronic disease management consultations, as well as standard consultation items, for the same patient on the same day is a concern for managing chronic disease patients, especially in rural or remote settings.<sup>74</sup>
- 4.90 The presentation of a patient to a general practitioner for a chronic disease management consultation is an important service to that patient, but if the practitioner cannot claim an associated or separate normal consultation item on the same day, then this has restrictions or repercussions, as outlined by Dr Robert Menz from the Royal Australian College of General Practitioners:
- If the patient is not able to get a rebate for a service in addition to the chronic disease management service, then the option is that the doctor either treats the patient for no benefit or charges the patient, who then has to pay it out of their own pocket, or the doctor asks the patient to come back on a different day to provide that service. Most GPs will not do the latter because they have got a sick patient in front of them who needs treatment that day.<sup>75</sup>
- 4.91 For chronic disease patients trying to manage complications from their disease, that may be affecting their overall health, or that extends into comorbid or multi-morbid conditions, this restriction on claiming multiple MBS items is problematic.
- 4.92 The challenges of managing multi-morbidity are already high, as outlined by the Australian Healthcare and Hospitals Association:
- Multimorbidity negatively influences a patient's capacity to manage chronic illness in multiple ways: it creates barriers to patients acting on risk factors; it complicated the process of recognising the early symptoms of deterioration of each condition; and it complicates their capacity to manage medication.<sup>76</sup>
- 4.93 This restriction in the MBS would appear to fall under the purview of the terms of reference for the current Medicare Benefit Schedule Review Taskforce, more specifically:
- Analyse the advice from the Working Groups and, in turn provide advice to the Minister, including advice on the evidence for services,
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74 Rural Doctors Association of Australia, *Submission 17*, p. 10.

75 Dr Robert Menz, Corlis Fellow for South Australia, Royal Australian College of General Practitioners, *Proof Committee Hansard*, Adelaide, 4 March 2016, p. 2.

76 Australian Healthcare and Hospitals Association, *Submission 40*, p. 4.

appropriateness, best practice options, levels and frequency of support through Medicare.<sup>77</sup>

- 4.94 The removal of treatment and management barriers for patients with multi-morbid conditions, or who are at risk of developing multi-morbid conditions, is important to assuring the appropriate allocation and use of primary health care resources. To this end, the Health Care Home trials outlined above should help address some of these hurdles.
- 4.95 The Australian Healthcare and Hospitals Association points out that the majority of health research into chronic disease is still conducted into 'single index disease states'.<sup>78</sup> However, the increased benefit of disease and treatment data that is predicted to result from the 'Healthier Medicare' reforms will enable more robust datasets and research to occur. The importance of datasets and eHealth records is expanded later in this chapter.

## Can Best Practice be 'One Size Fits All'?

- 4.96 The concept of the medical home and a 'one-stop-shop' for chronic disease management is an attractive and admirable goal and one that was expressed by several health care providers or commissioners.<sup>79</sup>
- 4.97 However, the concept of having a universal chronic disease management model is challenged by the nature of health care delivery in Australia generally, and even more so by the provision of coordinated chronic disease care for rural, remote and Aboriginal and Torres Strait Islander health services.

## Rural, Regional and Remote Services

- 4.98 'One size will not fit all' is the direct statement of the Rural Doctors Association of Australia.<sup>80</sup> The challenges faced by metropolitan health care providers are very different from those in rural and remote areas, especially related to access to services, retention of workforce and the service requirements of general practitioners.

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77 Department of Health, 'Terms of reference - Medicare Benefits Schedule Review Taskforce', <<http://www.health.gov.au/internet/main/publishing.nsf/Content/MBSR-tor>>, viewed 6 April 2016.

78 Australian Healthcare and Hospitals Association, *Submission 40*, p. 4.

79 Queensland Government, *Submission 167*, p. 27; cohealth, *Submission 88*, p. 20; NSW Health, *Submission 152*, p. 7;

80 Rural Doctors Association of Australia, *Submission 17*, p. 7.

- 4.99 The tyranny of distance and the sparse population and separation of many rural Australians from health care providers warrants a special consideration of the models of chronic disease care required in these areas.
- 4.100 While a robust medical home model, where a physical location is identified for the ongoing care provision and coordination of a patient's chronic disease management is suitable in a metropolitan setting, the use of telehealth services is essential to providing adequate services in a rural or remote setting.<sup>81</sup>
- 4.101 The retention of rural and remote health care workers is also an ongoing issue for chronic disease management. In the twelve months from December 2011 to December 2012, from 1 707 medical practitioners operating across regional and remote areas in Queensland, 615 separations/departures were recorded.<sup>82</sup> This 36 per cent turnaround in staff is indicative of the challenges faced in retaining a stable and cohesive workforce.
- 4.102 Additionally, the requirements for a rural GP to maintain qualifications in specialisations such as obstetrics, anaesthetics and surgery can place strain on an already stretched workforce.<sup>83</sup>
- 4.103 The Australian Government has done extensive work in the rural health care workforce retention space, with the Rural Health Workforce Strategy, and more specifically the introduction of a modified General Practice Rural Incentives Programme from 1 July 2015, where incentive payments are better targeted to GPs who provide continued service in appropriately categorised rural and remote practices.<sup>84</sup>

## Aboriginal and Torres Strait Islander Health Services

- 4.104 As discussed in earlier chapters, the burden of chronic disease in Australia is greater on Aboriginal and Torres Strait Islander (ATSI) peoples. Accordingly, the requirement for catered and appropriate chronic disease care services and models is essential.
- 4.105 The current blended payment and service models provided by Aboriginal Community Controlled Health Services (ACCHSs) or Aboriginal Medical Services are helping to address the Closing the Gap targets for ATSI people, but the continued high proportion of chronic disease impacts
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81 Australian College of Rural and Remote Medicine, *Submission 76*, pp 3-4.

82 Royal Flying Doctor Service, *Submission 20 – Attachment 1*, p. 28.

83 Dr Rodney Pearce, Chairman, Australian General Practice Network Ltd, *Proof Committee Hansard*, Adelaide, 4 March 2016, p. 9.

84 Rural and Regional Health Australia, 'Rural Health Workforce Strategy Incentives', <<http://www.ruralhealthaustralia.gov.au/internet/rha/publishing.nsf/Content/changestoGPRIPfactsheet>>, viewed 7 April 2016.

- warrants a focus on chronic disease prevention and management of risk factors, such as that being coordinated by the National Aboriginal Community Controlled Health Organisation.<sup>85</sup>
- 4.106 The blended funding of Aboriginal health provision can be seen in The Glen, an Indigenous organisation which treats drug and alcohol addicted patients, both Indigenous and non-Indigenous. The Glen's CEO Mr Joe Coyte stated that there is 'quite a complicated mixture of funding', including funding from the Department of Health, Prime Minister and Cabinet (PM&C), NSW health funding and Indigenous-specific NSW health funding.<sup>86</sup> South Coast Medical Service Aboriginal Corporation also stated that they receive PM&C funding for their 'safety and wellbeing component'.<sup>87</sup>
- 4.107 The Department of Health funding to help meet Closing the Gap targets is provided through the Indigenous Australians' Health Programme, which commenced in 2014.<sup>88</sup>
- 4.108 The requirement to work with ATSI communities and people in strengthening both general primary health care principles suitable to ATSI chronic disease pressures, as well as strengthening and supporting the current ACCHSs, is crucial to ensuring that the cultural and medical needs of these communities is met in a sustainable way.
- 4.109 The ATSI focus of the 'Healthier Medicare' chronic disease reforms will potentially help the closing of the gap in mortality and burden of chronic disease in ATSI populations, but the results of the Health Care Home trials will require specific ATSI data analysis to ensure that the reforms are culturally sustainable and provision of the model can be continued through the existing strong community health care mechanisms.
- 4.110 As outlined by the Improvement Foundation, currently the Australian Primary Care Collaboratives (APCC) program only captures half of the relevant Closing the Gap health outcome data, as only ACCHs are required to provide ATSI specific data for analysis.<sup>89</sup> If an ATSI patient

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85 NACCHO, 'The state of Aboriginal health', <<http://www.naccho.org.au/aboriginal-health/aboriginal-health-state/>>, viewed 7 April 2016.

86 Mr Joe Coyte, Chief Executive Officer, The Glen, *Official Committee Hansard*, Tumby Umbi, 19 February 2016, p. 4.

87 Mr Craig Ardler, Chief Executive Officer, South Coast Medical Service Aboriginal Corporation, *Official Committee Hansard*, Bomaderry, 12 February 2016, p. 11.

88 Department of Health, 'Indigenous Australians' Health Programme', <<https://www.health.gov.au/internet/main/publishing.nsf/Content/indigenous-programme-lp>>, viewed 28 April 2016.

89 Dr Dale Ford, Principal Clinical Adviser, Improvement Foundation, *Proof Committee Hansard*, Adelaide, 4 March 2016, p. 24.

visits a community GP, then that treatment data does not flow into relevant datasets for Closing the Gap purposes.

## Telehealth and eHealth Support

- 4.111 The importance of telehealth and eHealth initiatives, especially to rural, remote and low-mobility chronic disease patients, is a focus for many health care providers and commissioners.
- 4.112 Programs such as the Royal Flying Doctor Service's 'Medical Chests' program allow patients to access the services they would not normally be able to access easily. The Medical Chests program allows for pharmaceutical dispensing for inflammation, wound care or antibiotics via caches of supplies and specialised telehealth consultations to aid in dispensing these pharmaceuticals in specific circumstances.<sup>90</sup>
- 4.113 Innovative programs and services using telehealth and eHealth support, such as linking in multidisciplinary teams to rural cancer centres<sup>91</sup> is essential to coordinating the chronic disease management of affected rural and remote populations.
- 4.114 Simplified video or telephone consultations for disease management, such as 'home monitoring, coaching, video consultation appointments and home medication management'<sup>92</sup> is a key benefit that can be realised in the delivery of health care via eHealth initiatives.
- 4.115 eHealth support in the form of websites that allow for the convenient delivery of relevant information or secure messaging between providers of relevant records or patient information are essential to diversified health care delivery.<sup>93</sup>
- 4.116 eHealth records, such as the expanding 'My Health Record' initiative are also an important component of diversified and supported health care management.

### Case Study – Diabetes Telehealth

The Royal Flying Doctor Service's Victorian Section has run its Diabetes Telehealth Service since 2013, allowing comprehensive diabetes telehealth consultations to be conducted in rural Victoria.<sup>94</sup>

The Service is based in Mildura where there is no resident diabetes specialist. Hosted by Monash School of Rural Health in Mildura, local diabetes patients are connected with endocrinologists from Baker IDI Heart and Diabetes Institute in

90 Royal Flying Doctor Service, *Submission 20 – Attachment 1*, pp 26-27.

91 NSW Health, *Submission 152*, p. 21.

92 Australian Pain Management Association, *Submission 52*. p. 11.

93 ACN, CATSINaM, APNA, MCaFHNA & ACMHN, *Submission 106*, p. 30.

94 National Rural Health Alliance, *Submission 67*, p. [15].

Melbourne. Additionally, consultations can be conducted at a number of locations across rural Victoria, hosted by local health services.<sup>95</sup>



Source Royal Flying Doctor Service, Diabetes Telehealth website gallery, [https://flyingdoctortelehealth.org.au/gallery/#IRFDS\\_Telehealth\\_1](https://flyingdoctortelehealth.org.au/gallery/#IRFDS_Telehealth_1)

Currently the partnered services are:

- Mildura Base Hospital
- Mallee District Aboriginal Services
- Sunraysia Community Health Services
- Robinvale District Health Services
- Dareton Primary Health Service
- Balranald Primary Health Service
- Northern District Community Health Service
- West Wimmera Health Service
- Robinvale District Medical Practice
- Murray Primary Health Network

The telehealth service allows support not only for patients, but also GPs and diabetes educators. The service is 100 per cent bulk billed and can allow for timely access to specialists via videoconference.

95 Royal Flying Doctor Service Victorian Section, 'Diabetes Telehealth: About the Service', <<https://flyingdoctortelehealth.org.au/index.php/about-diabetes-telehealth/about-the-service>>, viewed 7 April 2016.

## Data Registries and eHealth Records

4.117 Regardless of the expansion of the services and coordination of chronic disease care, without the appropriate data, records and patient information, both for care and evaluation and research needs, the fragmentation of chronic disease management in Australia will continue.

### eHealth Records

4.118 While primary health care, especially general practice, is a technologically advanced sector of society, the same cannot be said for allied health providers, specialists and surgeons. In 2012 only approximately 37 per cent of specialists and 22 per cent of surgeons relied on computerised patient records.<sup>96</sup>

4.119 Similarly, even though general practice do generally use electronic patient records, there are still multiple proprietary systems used and on the market. It is for this reason that the Australian Government and state and territory governments established the National Electronic Health Transition Authority (NeHTA) in 2005 to help promote eHealth initiatives and create standards for the health care sector to adopt.<sup>97</sup>

4.120 These standards and their application to patient records aid in the connectivity required for multidisciplinary and coordinated care.<sup>98</sup> The Health Network Northern Territory highlighted the importance of eHealth in a diverse community:

Given the large geographical size of the Northern Territory, increased access to eHealth technology will greatly improve the prevention and management of chronic disease. The use of eHealth has been demonstrated internationally to decrease the administration burden of health care service delivery, improve the quality of care, increase efficiencies and encourage patient self-management. Best practice includes an electronic patient record, electronic prescribing and medication administration, telehealth services and secure message services for health professionals.<sup>99</sup>

4.121 The establishment of the Personally Controlled Electronic Health Record (PCEHR) in July 2012, now the My Health Record, has enabled a universal platform for the storage and management of health information about patients in Australia and placed the control of that information with the

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96 Cancer Australia, *Submission 65*, p. 5.

97 NEHTA, 'About NEHTA', <<http://www.nehta.gov.au/about-nehta>>, viewed 7 April 2016.

98 Victorian Primary Care Partnerships, *Submission 36*, p. 16.

99 Health Network Northern Territory, *Submission 27*, p. [2].

patient themselves. The review of the PCEHR released in May 2014 establishes a firm foundation for the My Health Record to become the central repository of patient information<sup>100</sup>, for both general health and chronic disease management.

- 4.122 NeHTA will transition into the Australian Digital Health Agency as of 1 July 2016, continuing its work in the electronic health standards space, as well as taking responsibility for the continued management of the My Health Record.
- 4.123 Access to the My Health Record is currently limited to the patient and any 'nominated healthcare provider' that is granted access by the patient's consent; however access to the health information stored within can be accessed by certain parties in the case of an emergency.<sup>101</sup>
- 4.124 The patient data stored within the My Health Record, as well as in the wider electronic patient and other health record systems across Australia, can form the datasets and data registries that many identify as being crucial to coordinated chronic disease care, as well as evidence-based research and policy development.

## Datasets and Registries

- 4.125 The creation of a unified national health dataset, by combining the information from federal government data (Medicare, Pharmaceutical Benefits Scheme (PBS) and aged care) along with private and public hospital data, is an ideal outcome that could help drive health outcomes and reform.<sup>102</sup>
- 4.126 However, the reality of multiple sources, formats, quality and access to the health care data existing in Australia's systems places barriers on accessing a centrally consistent dataset or data registry for use in chronic disease prevention or management.
- 4.127 Currently there are multiple datasets of patient information within the health care sector, as well as potentially replicated data held by private health insurers related to their members. The potential to access that de-identified or secure member data, to supplement any consolidated government patient data, is a compelling reason to investigate sharing and

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100 Department of Health, 'My Health Record', <<http://health.gov.au/internet/main/publishing.nsf/Content/ehealth-record>>, viewed 7 April 2016.

101 Department of Health, 'My Health Record – Managing access, privacy and security', <<https://myhealthrecord.gov.au/internet/mhr/publishing.nsf/Content/privacy?OpenDocument&cat=Emergency%20Access>>, viewed 7 April 2016.

102 Professor Libby Roughead, *Submission 41*, p. 1.

consolidating data related to chronic disease and wider health status and outcomes.

- 4.128 The ability to plan adequate care and analyse treatment outcomes is placed at risk by these multiple sources, as expressed by the Australian Health Services Alliance:

Consolidating diverse data sets into a single, longitudinal consumer journey record will yield insights into health trends and effectiveness of interventions undertaken. This cannot be gleaned from siloed data in multiple, separate systems.<sup>103</sup>

- 4.129 The Australian Healthcare and Hospitals Association calls for Medicare Benefits Schedule (MBS) data to be made available to states and PHNs to allow for proper analysis of chronic disease impacts and multi-morbidities, as well as advocating for the increased promotion and utilisation of a complete My Health Record.<sup>104</sup>

- 4.130 Likewise, the Victorian Healthcare Association identifies the equally as important requirement to have state hospital and treatment data available 'to facilitate benchmarking, performance evaluation and population health planning. An efficient and effective health system requires continuous quality improvement, and data to inform such processes'.<sup>105</sup>

- 4.131 More realistically, the Australian Institute of Health and Welfare calls for the linking of Australian Government held data within the MBS, PBS and Repatriation Pharmaceutical Benefits Scheme (RPBS):

...linkage of MBS, PBS, RPBS and other important data sources such as hospital data, within existing strict privacy regimes, would rapidly enhance the nation's capacity to better understand the patterns of service use and health outcomes experienced by those hospitalised for chronic disease.<sup>106</sup>

- 4.132 The quality improvements expected of PHNs and to arise from the 'Healthier Medicare' reforms must be data-driven.<sup>107</sup> This data can help create 'Patient health care pathways', as identified by the Primary Health Care Advisory Group, clinical support tools to assist care planning and delivery, based on local patient and service data.<sup>108</sup>

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103 Australian Health Services Alliance, *Submission 26*, p. 1.

104 Australian Healthcare and Hospitals Association, *Submission 40*, pp 9-10.

105 Victorian Healthcare Association, *Submission 78*, p. 8.

106 Australian Institute of Health and Welfare, *Submission 127*, p. 5.

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

108 Commonwealth of Australia, Department of Health, *Better Outcomes for People with Chronic and Complex Health Conditions: Report of the Primary Health Care Advisory Group*, December 2015, p. 28.

- 4.133 These pathways are an embodiment of the practical application of datasets and data registries enabling better coordination and improvement in health care for chronic disease. One such example is the Canterbury Experience in New Zealand.

### The Canterbury Experience

- 4.134 The Canterbury Experience is an online tool for health care providers where centralised data regarding patients in the Canterbury District Health Board can be accessed by practitioners, such as referrals, diagnostic information and treatment options within the district, based on data from the area.<sup>109</sup>
- 4.135 Complementing this in an online tool called 'HealthInfo', that allows patients to access similar consumer-targeted information to allow for their self-management of their conditions and to complement the health pathways recognised by the District Health Board.<sup>110</sup>
- 4.136 The framework created for the Canterbury Experience was adopted by a number of Medicare Locals and is now being used by multiple PHNs across Australia to help establish similar practice and consumer information portals and datasets.<sup>111</sup>

### Australian Primary Care Collaboratives

- 4.137 Domestically, the APCC (delivered by the Improvement Foundation and funded until recently by the Department of Health) creates a similar health pathways framework and dataset for the Australian health care system.
- 4.138 Performance and improvement tools for general practice, based on practice data is the key to the APCC's goals, as expressed by the Improvement Foundation:

...our experience has been that people, by and large, think they are doing a good job, because they are working hard and they are concentrating on the relationship with the individual. But unless they have the data that shows where they fit against their peers, against benchmarks and, more importantly, against what the evidence says you should do, nothing happens.<sup>112</sup>

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109 Canterbury District Health Board, 'HealthPathways', <<http://www.cdhb.health.nz/Hospitals-Services/Health-Professionals/Pages/Health-Pathways.aspx>>, viewed 12 April 2016.

110 Canterbury District Health Board, 'HealthInfo', <<http://www.healthinfo.org.nz/>>, viewed 12 April 2016.

111 Grattan Institute, *Submission 188 - Attachment 1*, p. 27.

112 Dr Dale Ford, Principal Clinical Adviser, Improvement Foundation, *Proof Committee Hansard*, Adelaide, 4 March 2016, p. 19.

- 4.139 The data collected from practice systems can then be used to train practitioners on better ways to manage their patients:

The model supports general practices to improve clinical outcomes, help maintain good health for those with chronic and complex conditions, and improve access to Australian general practice by promoting a culture of quality improvement in primary health care.<sup>113</sup>

- 4.140 The key role that data plays in building an improvement framework such as the APCC, is an example of how intelligent use of data can drive better outcomes for patients, as well as create snapshots of data from individual practice level, up to national dataset levels.

### Healthier Medicare Reforms

- 4.141 As part of the 31 March 2016 announcement of the chronic disease focus of 'Healthier Medicare' reforms, the role of the My Health Record is to be prioritised in coordinating care for patients, as well as providing de-identified data to help establish a 'quality improvement framework and the foundation of a National Minimum Data Set'.<sup>114</sup>

- 4.142 The details of this dataset are still to be determined, but any move to integrate coordinated data, with the help of the PHNs, can help to support the role of quality data in chronic disease management into the future.

### Privacy Concerns

- 4.143 Underlying the use of patient data, either in eHealth records or in general datasets and data registries, is the key consideration that overarching the data integrity of any such information is that privacy requirements in Australia may potentially threaten any expansion of use of such data.

- 4.144 Queensland PHNs commented:

One real problem we have at the moment is the privacy commissioner, who has identified that, fundamentally, every general practice is in breach of the privacy rules and could be subjected to massive fines if they used the My Health Record.<sup>115</sup>

- 4.145 When asked to comment on whether they had any concerns around privacy breaches regarding the use of the My Health Record, the Royal Australian College of General Practitioners commented:
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113 Country South Australia PNH, *Submission 94*, p. 1.

114 The Hon. Sussan Ley MP, Minister for Health, Minister for Aged Care, Minister for Sport, 'My Health Record & Improved Health Data to better coordinate care', *Media Release*, 31 March 2016.

115 Dr Richard Kidd, Clinical Lead, Brisbane North Primary Health Network, *Official Committee Hansard*, Brisbane, 18 February 2016, pp 8-9.

The legislation that provides for the national eHealth record system (My Health Record) establishes a privacy regime that generally operates concurrently with Commonwealth, state and territory privacy laws. However, the My Health Record legislation and regulations do place significant new responsibilities and risks on general practices participating in My Health Record. For example, a privacy breach can result in significant fines or criminal penalties. In addition to these obstacles, clinical and functionality issues need to be resolved before My Health Record will become an embedded component of the healthcare landscape and a useful tool for GPs.<sup>116</sup>

- 4.146 Generally, the sharing of patient information, including under the My Health Record system, is based on obtaining patient consent to share relevant information.<sup>117</sup> To this end, the Office of the Australian Information Commissioner provides guidance on how an individual can best manage and safeguard their own My Health Record.<sup>118</sup>
- 4.147 Extending beyond eHealth records, the aggregation of health data for epidemiological and disease trend bases can be achieved with de-identified patient data, so any privacy concerns related to use of that information should be negated.

## Concluding Comment

- 4.148 During the course of the inquiry, the Committee was overwhelmed with the enthusiasm and passion that many clinicians, researchers, patients and providers showed for improving the systems of chronic disease prevention and management in Australia.
- 4.149 The myriad examples of best practice models and programs for educating and involving patients in their own care and wellness, as well as coordinating and participating in the management of their conditions, was a clear indication of the desire to create better systems for chronic disease, both internationally and domestically.
- 4.150 There is also a clear indication that systems developed and implemented to address chronic disease must be based on two clear principles – they must be evidence-based and evaluated, and they must be flexible enough

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116 Royal Australian College of General Practitioners, *Submission 135.1*, p. [3].

117 Victorian Primary Care Partnerships, *Submission 36*, p. 17.

118 Office of the Australian Information Commissioner, 'My Health Records', <<https://www.oaic.gov.au/individuals/faqs-for-individuals/health/my-health-records>>, viewed 12 April 2016.

to apply to the wide range of cultures, populations and service circumstances that the Australian community presents.

### **Chronic Disease Prevention**

- 4.151 The importance of education and awareness in the general population of the lifestyle/risk factors that can contribute to a lot of chronic diseases is evident.
- 4.152 Federal, state and territory governments, peak bodies, private health insurers and interested health care providers currently do a great deal of work in promoting healthy lifestyles or advocating reductions in consumption of tobacco and alcohol. The impacts of tobacco reform in Australia in past decades have been especially relevant to the discussion on how to create chronic disease prevention strategies.
- 4.153 Additionally, the role of health checks and assessments are crucial to potentially identifying early chronic disease or risk factors that may contribute to the onset of conditions in the future.
- 4.154 The argument for an integrated health assessment check for cardiovascular, kidney disease risk and diabetes to be added to the current MBS is a valid one.
- 4.155 The issue of people accessing MBS item 715 health checks through self-identification, when they may not be of Aboriginal or Torres Strait Islander descent was raised a number of times during the inquiry. The Committee believes there is an opportunity for a review of the self-identification process for accessing health checks and the like.

### **Best Practice in Chronic Disease Management**

- 4.156 The 'Healthier Medicare' chronic disease reforms announced on 31 March 2016 embody many of the principles of best practice coordinated care that the Committee has been presented with and considered through the course of this inquiry.
- 4.157 The Australian Government is to be commended on the announcement of the Health Care Home trials, as well as the continued work in the Medicare Benefits Schedule Review, Medicare Compliance Review and Primary Health Care Advisory Group.
- 4.158 The Committee welcomes the intent behind the targeting of these trials to chronic disease patients, as well as the commitment to prioritise Indigenous and rural and remote communities in the trials and wider reforms in train.

- 4.159 The Committee believes these trials are an embodiment of the best practice models considered in the inquiry and support their prioritisation, evaluation and expansion into the future.
- 4.160 The Committee also believes that the current restrictions on clinicians not being able to claim a rebate for a chronic disease management consultation, as well as a general consultation rebate, for the same patient on the same day should be reviewed.

### Data and Chronic Disease

- 4.161 The importance of patient records and associated data related to chronic disease cannot be understated. The continuity and quality of care that stems from consistent patient records, discharge summaries and test results is far superior to that managed by isolated and sometimes indecipherable paper files.
- 4.162 The expansion and promotion of the My Health Record is a welcome step to creating a centre of patient information for coordinated chronic disease care, however, the utilisation of the record by patients and providers must occur for the data to be meaningful for research, analysis and policy development.
- 4.163 Privacy concerns appear to be in the forefront of development of the expansion of eHealth tools and records, so as long as the promotion of patient control of their data and the requisite consent is acquired, then the privacy of such information (including de-identified) data should be assured.
- 4.164 The Committee does feel that the existing health datasets within federal and state government control should be reviewed in regard to analysis and potential combination for the purposes of the National Minimum Data Set or associated data registries.
- 4.165 The AIHW's suggestion for linking of MBS, PBS and RPBS data, with any applicable hospital data appears to have merit and the Committee supports the analysis of any such work.

## Recommendations

### Recommendation 6

- 4.166 **The Committee recommends that the Australian Government examine the inclusion of an integrated health assessment check for cardiovascular, kidney disease risk and diabetes as per that developed by the National**

**Vascular Disease Prevention Alliance, where a patient does not already qualify for an existing assessment and the treating practitioner suspects they are at risk of these chronic diseases.**

### **Recommendation 7**

4.167 **The Committee recommends a review of the self-identification process for accessing health checks and the like.**

### **Recommendation 8**

4.168 **The Committee recommends that the development and implementation of the Health Care Home trials, as part of Healthier Medicare, be prioritised and continue to be developed in consultation with relevant expert panels; and**

**That the outcomes of the trials be evaluated as they occur to inform further coordinated care developments for chronic disease patients and the wider Australian community.**

### **Recommendation 9**

4.169 **The Committee recommends that the Australian Government examine reforms to the Medicare Benefit Schedule to allow for a practitioner to claim a rebate for a chronic disease management consultation and a general consultation benefit, for the same person on the same day.**

### **Recommendation 10**

4.170 **The Committee recommends that the Australian Government examine the feasibility of linking relevant Medicare Benefits Schedule, Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data, with applicable hospital patient data, to create a unified patient dataset, or to consider this link when developing the National Minimum Data Set for Healthier Medicare purposes.**

## Funding Models

### Introduction

- 5.1 At the centre of effective health care for chronic disease is the requirement to have funding and payment models that encourage and incentivise the best chronic disease prevention and health promotion, as well as the best coordinated care.
- 5.2 The health care system in Australia is a robust, yet divided, system of primary and secondary care that mostly treats patient 'transactions' on an individual health concern basis, such as General Practitioner (GP) care for a short-term ailment or a hospital visit for surgery or an emergency, brief recovery, then discharge.
- 5.3 The funding for this system is therefore predicated mainly on a fee for service (FFS) basis. However, the lack of flexibility in such a model and the requirement for flexible patient-centred care, and the funding that supports it, has led to the promotion and introduction of alternative models.
- 5.4 Incentive payments and the ability for bundled payments and alternative systems (such as capitation payments) to increase the benefits for chronic disease care is an increasing focus within the primary health care system, both domestically as well as internationally.

### Fee for Service Models

- 5.5 The current method of payment for GPs, specialists and most other primary health care providers in the Australian health care system is under the FFS model. Under this model, the medical practitioner bills their patients an amount for the provision of an individual service, as

defined and listed in the Medicare Benefits Schedule (MBS), with Medicare paying the practitioner for providing the service. Often the practitioner will charge a gap payment above the MBS fee, though they may 'bulk-bill' Medicare directly with the patient not being required to pay at the time of service at all.

5.6 This model of payment is based on the principle that each item of service is for a 'complete medical service', that each item will provide the complete treatment or service defined by the item descriptor related to that service.<sup>1</sup>

5.7 For example, the item descriptor for a level B standard GP consultation (MBS item 23) is:

Professional attendance by a general practitioner (not being a service to which any other item in this table applies) lasting less than 20 minutes, including any of the following that are clinically relevant:

- a) taking a patient history;
- b) performing a clinical examination;
- c) arranging any necessary investigation;
- d) implementing a management plan;
- e) providing appropriate preventive health care;

in relation to 1 or more health-related issues, with appropriate documentation.<sup>2</sup>

5.8 Many would argue that if a patient were to present with a simple medical complaint, the complete medical service that a consultation such as that outlined above would meet their care needs. However, the complex needs of a patient with chronic disease do not necessarily fit comfortably within the framework of a complete medical service from one service interaction.

5.9 As expressed by Dr Jodi Graham:

FFS is considered to be suitable for short, acute care illnesses, but ill-suited to chronic disease management.<sup>3</sup>

5.10 This view is shared by the Centre for Primary Health Care and Equity:

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1 Department of Health, MBS Online, 'Complete Medical Service', <[http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-Complete\\_Medical\\_Service](http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-Complete_Medical_Service)>, viewed 14 April 2016.

2 Department of Health, MBS Online, 'Item 23', <<http://www9.health.gov.au/mbs/search.cfm?q=23&sopt=I&=>>, viewed 14 April 2016.

3 Dr Jodi Graham, *Submission 1*, p. 2.

Fee for service rewards the frequency and duration of care but does not adequately reward anticipatory, long term co-ordinated care.<sup>4</sup>

- 5.11 The FFS framework of paying medical practitioners to perform individual services has potentially acted as a disincentive to the establishment of integrated care practices,<sup>5</sup> instead making practitioners focus on individual care transactions.
- 5.12 The focus on individual episodes of care has widened in recent years though, as the MBS introduced chronic disease management items (items 721 to 732) intended for 'GPs to manage chronic or terminal medical conditions by preparing, coordinating, reviewing or contributing to chronic disease management plans' (CDMPs).<sup>6</sup>
- 5.13 The CDMPs are intended to help the GP assess and coordinate care for the patient across the spectrum of health care providers, however the allied health sector still feels that the integration between their providers and GPs is fragmented and that this funding does not cater for the required coordination between their sectors:
- The current model of funding, rather than promoting service integration and supporting team-based care, has created "professional silos", which results in medical and allied health professionals working independently of each other, leading to poor overall services and outcomes.<sup>7</sup>
- 5.14 Also, the Royal Australian College of General Practitioners (RACGP) identify that the chronic disease management items, while a move in the right direction to create coordinated care, have some identified shortfalls, with the appropriate allocation of this funding being addressed in their last point:
- No real differentiation between simple and complex chronic disease impacts on patients;
  - Lack of flexibility in tailoring the plans that stem from the items, with excessive red tape to meet requirements;

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4 Centre for Primary Health Care and Equity, UNSW, *Submission 6*, p. 2.

5 Caroline Nicholson, Claire L Jackson and John E Marley, *Best-practice Integrated Health Care Governance – Applying Evidence to Australia's Health Reform Agenda*, Medical Journal of Australia 2014; 201 (3 Suppl): S64-S66.

6 Department of Health, MBS Online, 'Note A36', <<http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=A36&qt=noteID&criteria=chronic%20disease%20management>>, viewed 14 April 2016.

7 Allied Health Professionals Australia, *Submission 77*, p. 3.

- Referrals to allied health professionals is complicated by the requirement to create team care arrangement plans; and
  - The weighting of the rebate payment is on creating the GP management plan, and not on the follow-up monitoring and outcome consultations, where the real outcomes and benefits from chronic disease management can be realised.<sup>8</sup>
- 5.15 While these chronic disease management items are a progressive move, as long as they are still based within the traditional bounds of the FFS MBS system, they will be weighed down with the expectation of being a single fee received for a discrete service, without any real incentive for follow-up treatment or management.
- 5.16 Similar international FFS health care systems to Australia, such as the United Kingdom and Canada, have moved away from a reliance on FFS as the foundation of primary health care, especially for chronic disease care. Some of these systems are outlined later in this chapter.
- 5.17 Similarly, the 'Healthier Medicare' program of reviews and reforms underway by the Australian Government are focused on modernising the current system and bringing more flexibility to health care, not only for chronic disease patients, but all Australians.

## Medicare and the Medicare Benefits Schedule – Building Flexibility

- 5.18 As mentioned throughout this report, the 'Healthier Medicare' review and reform program underway in the Department of Health is intended to 'deliver a healthier Medicare to ensure Australians continue receiving the high-quality and appropriate care they need as efficiently as possible'.<sup>9</sup>
- 5.19 The Primary Health Care Advisory Group (PHCAG) helped deliver the *Better Outcomes for People with Chronic and Complex Health Conditions* report, which is the genesis for the Health Care Home trials announced to commence in July 2017. The PHCAG ceased operation from December 2015.
- 5.20 The Medicare Benefits Schedule Review Taskforce is still ongoing and is tasked with 'considering how the more than 5 700 items on the MBS can

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8 Royal Australian College of General Practitioners, *Submission 135*, p. 7.

9 Department of Health, 'Healthier Medicare', <<http://www.health.gov.au/internet/main/publishing.nsf/Content/healthiermedicare>>, viewed 14 April 2016.

- be aligned with contemporary clinical evidence and practice and improve health outcomes for patients'.<sup>10</sup>
- 5.21 The MBS Review would appear to be a vehicle for looking at the modernisation of the system of FFS payments in Australia, however as highlighted by Kidney Health Australia 'the MBS review is essentially not looking at structural changes'<sup>11</sup>, and the review itself lists 'innovative funding models for people with chronic and complex conditions' as being out of scope and the purview of the PHCAG.<sup>12</sup>
- 5.22 The final element of the 'Healthier Medicare' program is the review of Medicare compliance rules and benchmarks, but this review focuses purely on administrative compliance, measurements and fee information for consumers.<sup>13</sup>
- 5.23 Therefore, outside the completed work of the PHCAG, the reform of the MBS and Medicare to provide more flexible funding options for chronic disease is currently limited to the Health Care Home trials.
- 5.24 Multiple suggestions for MBS reform were made during the inquiry, including, but not limited to:
- Expanding MBS rebates for telehealth activities to include allied health consultations;<sup>14</sup>
  - Creating MBS rebates for health professionals to spend time with families and carers of people with dementia to assess care needs;<sup>15</sup>
  - Increasing the rebate amounts for Nurse Practitioners to continue to be able to support viable general practice;<sup>16</sup> and
  - Creating rebate items for 'lifestyle intervention, including medical nutrition therapy, for pregnant women with gestational diabetes or

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10 Department of Health, 'Medicare Benefits Schedule Review', <<http://www.health.gov.au/internet/main/publishing.nsf/content/mbsreviewtaskforce>>, viewed 15 April 2016.

11 Professor Timothy Usherwood, Member, Kidney Check Australia Taskforce, Kidney Health Australia, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 8.

12 Department of Health, 'About the Medicare Benefits Schedule Review', <<http://www.health.gov.au/internet/main/publishing.nsf/content/MBSR-about>>, viewed 15 April 2016.

13 Department of Health, 'Healthier Medicare', <<http://www.health.gov.au/internet/main/publishing.nsf/Content/healthiermedicare>>, viewed 15 April 2016.

14 Services for Australian Rural and Remote Allied Health, *Submission 115*, p. 3.

15 Alzheimer's Australia, *Submission 98*, p. 3.

16 Australian Nursing and Midwifery Federation, *Submission 110*, p. 5.

obesity during the prenatal period and during the early developmental years of a child'.<sup>17</sup>

- 5.25 However, as can be seen by the focus on MBS item numbers in a lot of these suggestions, as long as the MBS focuses treatment and management principles on the rebates associated with providing care 'transactions', the incentive to provide coordinated care is diminished.

## MBS Rebate Indexation Freeze

- 5.26 As part of the 2014-15 Federal Budget, the Australian Government announced a freeze on the indexation of the majority of MBS rebate rates, along with a number of other payments and programs. The freeze commenced on 1 July 2015.
- 5.27 A number of peak body submitters commented on the negative impact this would have on their association's members or the general care patients may receive as practitioners would have to offset increasing costs elsewhere.<sup>18</sup>
- 5.28 The Royal Australian College of General Practitioners (RACGP) even suggested that the freeze could force some general practices to close, if they could not meet costs and weren't willing to charge a gap payment to their patients.<sup>19</sup> However, this was highlighted as only anecdotal in follow-up information provided to the inquiry.<sup>20</sup>
- 5.29 However, the RACGP also highlighted:
- The Department of Health's report on Medicare statistics shows that 97.3% of general practice health assessments, chronic disease management, mental health care and medication review services were bulk billed in 2014-15.<sup>21</sup>
- 5.30 This statistic only further serves to highlight that reform is required in the way that chronic disease care is funded in Australia. To this end, the Practice Incentive Payments system is just one element of the current health care system encouraging better practice.

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17 Dietitians Association of Australia, *Submission 148*, p. 8.

18 Rural Doctors Association of Australia, *Submission 17*, p. 10; Royal Australian and New Zealand College of Psychiatrists, *Submission 31*, p.4; Optometry Australia, *Submission 59*, p. 9; Victorian Healthcare Association, *Submission 78*, p. 2; Silver Chain Group, *Submission 97*, p. 2; Australian Medical Association, *Submission 107*, p. 2; Australian Nursing and Midwifery Federation, *Submission 110*, p. 17; Royal Australian College of General Practitioners, *Submission 135*, p. 6; Aboriginal Medical Services Alliance Northern Territory, *Submission 153 – Attachment 1*, p. 2; Queensland Government, *Submission 167*, p. 18.

19 Royal Australian College of General Practitioners, *Submission 135*, p. 6.

20 Royal Australian College of General Practitioners, *Submission 135.1*, p. [2].

21 Royal Australian College of General Practitioners, *Submission 135.1*, p. [2].

## Practice Incentive Payments

5.31 The Practice Incentives Program (PIP), introduced in 2001, is aimed at supporting general practice activities that ‘encourage continuing improvement, quality care, enhance capacity, and improve access and health outcomes for patients’.<sup>22</sup> It is administered by the Department of Human Services on behalf of the Department of Health, and consists of Practice Incentive Payments for eleven different areas:

- Asthma Incentive;
- After Hours Incentive;
- Cervical Screening Incentive;
- Diabetes Incentive;
- eHealth Incentive;
- General Practitioner Aged Care Access Incentive;
- Indigenous Health Incentive;
- Procedural General Practitioner Payment;
- Quality Prescribing Incentive;
- Rural Loading Incentive; and
- Teaching Payment.<sup>23</sup>

## Overview of the Practice Incentive Program

5.32 The Asthma Incentive encourages GPs to better manage the clinical care of people with moderate to severe asthma. There are two components to the incentives. The first is a one-off sign-on payment to the practice of \$0.25 per Standardised Whole Patient Equivalent (SWPE). A practice must use a patient register and a recall and remind system, and implement a ‘cycle of care’ for their patients with asthma. The second component is a service incentive payment to the GP of \$100 per patient per year for each completed cycle of care.<sup>24</sup>

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22 Department of Human Services, ‘Practice Incentives Program’, <https://www.humanservices.gov.au/health-professionals/services/medicare/practice-incentives-program>, viewed 11 April 2016.

23 Department of Human Services, ‘Practice Incentives Program’, <https://www.humanservices.gov.au/health-professionals/services/medicare/practice-incentives-program>, viewed 11 April 2016.

24 Department of Human Services, ‘Practice Incentives Program Asthma Incentive Guidelines – October 2013’, <https://www.humanservices.gov.au/sites/default/files/documents/asthma-pip-guidelines.docx>.

- 5.33 The Diabetes Incentive similarly has sign-on and service incentive payments, as well as an outcomes payment for practices reaching a target level of care for patients with diabetes.<sup>25</sup> The Cervical Screening Incentive likewise has sign-on, service incentive and outcomes payments, with a target of 'at least 70 per cent of eligible patients' screened within a 30 month period.<sup>26</sup> The Indigenous Health Incentive also has the same three components.<sup>27</sup>
- 5.34 The GP Aged Care Access Incentive aims to encourage GP services in Residential Aged Care Facilities, with the service incentive payment based on a required number of services provided.<sup>28</sup>
- 5.35 The Procedural GP Incentive encourages GPs in rural and remote areas to provide non-referred procedural services which would normally be specific referral-based specialty services in urban settings, including obstetric deliveries and certain general anaesthetic and surgical services. There are four tiers of payments provided to GPs according to the type and number of services provided.<sup>29</sup> Rural practices also benefit from the Rural Loading Incentive, which recognises the difficulties of providing care in rural and remote areas by providing a loading for practices according to the population of the locality.<sup>30</sup>
- 5.36 The After Hours Incentive gives an incentive payment for practices that provide access to care after hours, considered to be outside 8am to 6pm on weekdays, 8am to noon Saturdays, and on Sundays and public holidays.

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25 Department of Human Services, 'Practice Incentives Program Diabetes Incentive Guidelines – October 2013', <https://www.humanservices.gov.au/sites/default/files/documents/diabetes-pip-guidelines.docx>.

26 Department of Human Services, 'Practice Incentives Program Cervical Screening Incentive Guidelines – July 2012', <https://www.humanservices.gov.au/sites/default/files/documents/cervical-screening-pip-guidelines.docx>.

27 Department of Human Services, 'Practice Incentives Program Indigenous Health Incentive Guidelines – February 2014', <https://www.humanservices.gov.au/sites/default/files/documents/indigenous-health-pip-guidelines.docx>.

28 Department of Human Services, 'GP Aged Care Access Incentive Guidelines – September 2013', <https://www.humanservices.gov.au/sites/default/files/documents/gp-aged-care-pip-guidelines.docx>.

29 Department of Human Services, 'Practice Incentives Program Procedural GP Payment Guidelines – October 2013', <https://www.humanservices.gov.au/sites/default/files/documents/procedural-gp-pip-guidelines.docx>.

30 Department of Human Services, 'Practice Incentives Program Rural Loading November 2013', <https://www.humanservices.gov.au/sites/default/files/documents/rural-loading-pip-guidelines.docx>.

- The rate of payment is based on SWPE and depends on the level of participation.<sup>31</sup>
- 5.37 The eHealth Incentive provides a payment of \$6.50 per SWPE for practices meeting five requirements for adopting eHealth technology.<sup>32</sup> The Quality Prescribing Incentive aims to encourage GPs to 'keep up-to-date with information on the quality use of medicines', rewarding participation in certain activities which promote more effective, quality use of medicines, based on the practice's SWPE.<sup>33</sup>
- 5.38 Finally, the Teaching Incentive encourages practices to train undergraduate and graduate medical students by giving them experience working in general practice. The payments are to compensate for the reduced number of consultations due to the presence of the student.<sup>34</sup>

## The Role of the Practice Incentive Program

- 5.39 A number of submissions and witnesses outlined the role the Practice Incentive Program has in encouraging efficiency and quality care. For example, the Consumer Health Forum supports PIPs as a way of improving coordination and integration of care for people with complex and chronic health needs, and emphasised:
- ...the need for a system of practice incentive payments that recognises the complexity of their case load and provides financial incentives to manage people with chronic diseases in a more holistic way.<sup>35</sup>
- 5.40 The Australian Medical Association stated that the Practice Incentives Program is the 'best place to do those pay for performance' payments, but that it needs to be expanded 'just a little bit so that not just the practice

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31 Department of Human Services, 'After Hours Incentive', <https://www.humanservices.gov.au/health-professionals/enablers/after-hours-incentive>, viewed 12 April 2016.

32 Department of Human Services, 'Practice Incentives Program eHealth Incentive - January 2016', <https://www.humanservices.gov.au/sites/default/files/documents/ehealth-incentive-guidelines.v0.3.docx>.

33 Department of Human Services, 'Quality Prescribing Incentive Guidelines - October 2013', <https://www.humanservices.gov.au/sites/default/files/documents/quality-prescribing-pip-guidelines.docx>.

34 Department of Human Services, 'Practice Incentives Program Teaching Payment Guidelines - December 2014', <https://www.humanservices.gov.au/sites/default/files/documents/teaching-pip-guidelines.docx>.

35 Consumers Health Forum of Australia, *Submission 159*, p. 5.

gets the performance payment but also the actual doctor that does the work'.<sup>36</sup>

- 5.41 The Improvement Foundation stated that:
- ...using a Quality PIP, the Government could gradually increase requirements by focussing on payment for improvement as opposed to payment for performance.<sup>37</sup>
- 5.42 There were several suggestions about expanding the PIPs. For example, the joint submission from the Primary Care Collaborative Cancer Clinical Trials Group, the Clinical Oncology Society of Australia and Cancer Council Australia recommended including the breast and bowel cancer screening programs in addition to the current Cervical Screening Incentive.<sup>38</sup>
- 5.43 Lung Foundation Australia proposed introducing a PIP for patients who have been admitted to hospital with an exacerbation of their lung disease to ensure they are 'discharged with a follow-up plan to ensure appropriate linkage to primary care to manage their condition'.<sup>39</sup>
- 5.44 A number of submissions proposed the use of Practice Incentive Payments (PIPs) to encourage and facilitate the use of Integrated Health Checks (IHCs).<sup>40</sup> The IHC approach is outlined in the submission from the National Vascular Disease Prevention Alliance,<sup>41</sup> and discussed in Chapter 4.
- 5.45 Arthritis Australia stated that an Arthritis Incentive could assist in implementing the Musculoskeletal Primary Health Care Initiative (PHCI) across all Primary Health Networks. Arthritis Australia stated that rolling the PHCI out has 'the greatest potential achieve to improvements and cost savings in [osteoarthritis] care in the short term'.<sup>42</sup>
- 5.46 Other suggestions for additional incentive payments included an optometry incentive<sup>43</sup> and a nutrition care incentive.<sup>44</sup>

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36 Dr Brian Morton, Chair, Council of General Practice, Australian Medical Association, *Official Committee Hansard*, Sydney, 23 October 2015, p. 30.

37 Improvement Foundation, *Submission 179*, p. 5.

38 Primary Care Collaborative Cancer Clinical Trials Group, Clinical Oncology Society of Australia and Cancer Council Australia, *Submission 63*, p. 8.

39 Lung Foundation Australia, *Submission 66*, pp 9-10, 12.

40 Australian Health Promotion Association, *Submission 49*, p. 12; Diabetes Australia, *Submission 102*, pp 3-4; National Stroke Foundation, *Submission 113*, p. 8; National Vascular Disease Prevention Alliance, *Submission 121*, pp 8-9; Kidney Health Australia, *Submission 126*, pp 6-7; Heart Foundation, *Submission 131*, pp 8-9;

41 National Vascular Disease Prevention Alliance, *Submission 121*, pp 7-16.

42 Arthritis Australia, *Supplementary Submission 141.1*, pp 1-2.

43 Optometry Australia, *Submission 59*, p. 10.

- 5.47 Ultimately, practice incentives are intended to encourage practitioners to coordinate and plan care for chronic disease patients in the longer term, rather than treating their illness on a transactional basis.

## Other Funding Models

- 5.48 Along with comments on the current Medicare system and its fee-for-service structure, many submissions and witnesses discussed alternative payment models.

- 5.49 One model that was raised numerous times in submissions and at public hearings is known as capitation. Capitation was defined by the Adelaide Primary Health Network:

Capitation is a way of paying an annual fee to a single practice for the complete care of each patient they have enrolled at their practice. It means that practices can benefit from ensuring that their patients remain healthy and well.<sup>45</sup>

- 5.50 Capitation is used in various jurisdictions around the world. According to the Consumers Health Forum of Australia:

Patient enrolment models are a standard feature of many international healthcare systems including countries such as UK, the Netherlands, Norway, Denmark, New Zealand, Spain and Italy.<sup>46</sup>

- 5.51 Capitation is often discussed in connection with 'bundled' or 'blended' payment models. For example, a funding model may include capitation along with a pay-for-performance system or pay-for-service, or both. Medibank Private supported such a system, stating:

A model that considers blended funding, combining fee-for-service, block funding and performance based payments could be implemented to better support people with chronic disease.<sup>47</sup>

- 5.52 The Adelaide Primary Health Network described how a bundled system might work:

For the prevention and management of chronic disease, a bundled care package can be paid to one entity who then hold the funding and apportions it among the participating care providers for a patient. A care coordinator from that entity, working in

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44 Dr Lauren Ball, *Submission 5*, p. 2.

45 Adelaide Primary Health Network, *Submission 119*, p. 38.

46 Consumers Health Forum of Australia, *Submission 159*, p. 5.

47 Medibank Private, *Submission 43*, p. 12.

partnership with the patient, allows for a cost-effective approach to the implementation of the package.<sup>48</sup>

- 5.53 Support for capitation or a bundled payment funding model has been common through the inquiry in both submissions and at public hearings.<sup>49</sup> The Western Australia Primary Health Alliance commented that there needs to be more flexibility around bundling payments which better link and incentivise collaboration for people with recurring chronic illnesses, particularly those with multiple co-occurring illnesses.<sup>50</sup> This was supported by Professor Alistair Vickery at the Perth hearing.<sup>51</sup>
- 5.54 The Centre for Primary Health Care and Equity at the University of NSW (PHCE) notes that bundled payment models 'provide flexibility to develop innovative ways to deliver care including through other providers and modalities'.<sup>52</sup>
- 5.55 The Australian College of Nursing stated that it supports trialling mixed models of capitation, grants, and outcomes-based payments, and that such models 'deliver a range of incentives that would better support the ongoing, multidisciplinary care that much of the community requires'.<sup>53</sup>
- 5.56 Dr Louisa Hope, a GP in the Castlemaine area of Victoria, suggested a model blending fee for service for some procedures with funding 'per head of patient' or for chronic health patients:

48 Adelaide Primary Health Network, *Submission 119*, p. 39.

49 Rural Doctors Association of Australia, *Submission 17*, p. 9; National Rural Health Alliance, *Submission 67*, p. 12; Royal Australasian College of Physicians, *Submission 81*, pp 4-5; Dr Paul Burgess, *Submission 92*, p. 6; Alzheimer's Australia, *Submission 98 - Supplementary*, p. 6; Australian Nursing and Midwifery Federation, *Submission 110*, pp 17-18; South Eastern Melbourne PHN, *Submission 123*, p. 5; Australian Primary Health Care Research Institute, *Submission 124*, pp 8-9; Arthritis Australia and Australian Rheumatology Association, *Submission 141*, p. 14; Primary Health Tasmania, *Submission 142*, pp 11-12; Department of General Practice, University of Melbourne, *Submission 151*, pp 4-5; NSW Health, *Submission 152*, p. 5; Sydney North PHN, *Submission 155*, p. 2; GMHBA, *Submission 157*, pp 3-4; Consumers Health Forum of Australia, *Submission 159*, p. 5; Queensland Government, *Submission 167*, p. 7; Brisbane North PHN, *Submission 182*, p. 3.

50 Professor Learne Durrington, Chief Executive Officer, Western Australia Primary Health Alliance, *Official Committee Hansard*, Perth, 11 March 2016, p. 19.

51 Associate Professor Alistair Vickery, Primary Health Care, School of Primary Aboriginal and Rural Health Care, University of Western Australia, *Official Committee Hansard*, Perth, 11 March 2016, pp 20, 23.

52 Centre for Primary Health Care and Equity, University of NSW, *Submission 6*, p. 3.

53 Ms Kathleen McLaughlin, Acting Chief Executive Officer, Australian College of Nursing, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 38.

If they were then registered with your clinic and the care stayed within your clinic, you would have a per capita payment for each patient that you were looking after over that year.<sup>54</sup>

- 5.57 Some submissions did raise caution about the capitation or enrolment-based models. The PHCE cautioned that enrolment must be available to all and to ensure that disadvantaged patients do not fall through the cracks.<sup>55</sup> The Australian Primary Health Care Research Institute also emphasised that cherry picking must be avoided and equitable access to service for high-need individuals must be ensured.<sup>56</sup>
- 5.58 Pay-for-coordination (PFC) is another funding model, used in some countries in Europe. The model:
- ...consists of payments to one or more providers to coordinate care between certain care services. It seeks to provide an incentive for the extra effort required by stakeholders to cooperate with one another, share organized, transparent information on healthcare delivery and health outcomes, often set to predefined standards.<sup>57</sup>
- 5.59 The experiences of this type of funding model in European countries is discussed further below.
- 5.60 Pay-for-performance (PFP) offers incentives based on certain performance indicators. It is used in the United Kingdom of Great Britain (UK), introduced in 2004 in the Quality and Outcomes Framework (QoF), in which GPs receive financial rewards if they reach certain targets in quality, process, and outcome. This scheme is discussed further below.

## International Experiences of Alternative Funding

- 5.61 Many submissions and witnesses raised examples of international health care funding models Australia should examine. Most commonly discussed were the systems in the Netherlands, the UK, the United States of America (USA), New Zealand, and the Canadian province of Ontario.
- 5.62 At the public hearing in Perth, Dr Jodi Graham spoke about different systems being used in Europe, tabling an article from *Health Policy*

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54 Dr Louisa Hope, General Practitioner, Mostyn Street Clinic, *Official Committee Hansard*, Bendigo, 18 November 2015, p. 25.

55 Centre for Primary Health Care and Equity, University of NSW, *Submission 6*, p. 3.

56 Australian Primary Health Care Research Institute, *Submission 124*, p. 9.

57 Tsiachristas, A et al, 'Exploring payment schemes used to promote integrated chronic care in Europe', *Health Policy* 113 (2013), pp 297-8.

discussing integrated chronic care in Europe.<sup>58</sup> The article examines several European countries employing pay-for-coordination, pay-for-performance and bundled payment systems. Austria, France, England, the Netherlands, and Germany 'have implemented payment schemes that were specifically designed to promote the integration of chronic care'.<sup>59</sup>

- 5.63 Dr Graham said these European systems 'are basically all pay for coordination and pay for performance', and that they are having 'a lot more success than Australia and the US at the moment'.<sup>60</sup>
- 5.64 The *Health Policy* article described pay-for-coordination schemes in Austria, France, and Germany, and pay-for-performance schemes in England and France, as well as discussing the bundled payment system in the Netherlands.

## The Netherlands

- 5.65 As discussed in Chapter 3, the Netherlands has a public-private hospital system. Dutch residents are required to purchase statutory health insurance from private insurers. The system is financed 'through a nationally defined, income-related contribution, and through community-rated premiums set by each insurer'.<sup>61</sup>
- 5.66 The Dutch system has GPs as the central figure in primary care, with other providers including dentists, midwives and physiotherapists. Hospital and specialist care, other than emergency care, is accessible upon referral from a GP. All citizens are registered with a GP of their choice.<sup>62</sup>
- 5.67 When a Dutch resident with the requisite insurance is diagnosed with a chronic disease, their care can be met by a bundled-payment system. Under the bundled-payment system:
- ...insurers pay a single fee to a contracting entity, the care group, to cover all of the primary care needed to manage a chronic condition. The care groups are often exclusively owned by general

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58 Tsiachristas, A et al, 'Exploring payment schemes used to promote integrated chronic care in Europe', *Health Policy* 113 (2013), pp 296-304.

59 Tsiachristas, A et al, 'Exploring payment schemes used to promote integrated chronic care in Europe', *Health Policy* 113 (2013), p. 296.

60 Dr Jodi Graham, *Official Committee Hansard*, Perth, 11 March 2016, p. 6.

61 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, p. 9.

practitioners who assume both clinical and financial responsibility on the basis of bundled-payment contracts.<sup>63</sup>

- 5.68 These care groups either deliver the care themselves or subcontract to other care providers.<sup>64</sup>
- 5.69 The University of Wollongong (UoW) notes that the service bundles are negotiable by insurers and care groups, and subcontracted services are negotiable by care groups and providers. This allows for flexibility in developing different models, but has also resulted in price variations.<sup>65</sup> These price variations may challenge the community rated basis for insurance costs in the Netherlands, but have continued to work up until now.
- 5.70 The Dutch system is 'disease specific', and started with diabetes, but is being rolled out 'to all chronic diseases'.<sup>66</sup>
- 5.71 The positive effect of this system has been highlighted, for example, by the Australian College of Rural and Remote Medicine.<sup>67</sup>
- 5.72 Studies have found improvements in diabetic care through this system, as well as positive patient experience.<sup>68</sup>
- 5.73 This positive impact was also reported by *Health Policy*:  
 ...the bundled payment scheme was perceived as having a positive structural impact on financing and process delivery of chronic care, increased provider cooperation within the primary care sector, and promoted the integration of financing of different care sectors.<sup>69</sup>
- 5.74 In addition to these benefits, the scheme was seen to have 'improved protocol adherence and record keeping, and promoted competition between health care providers', although it was also reported to have

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63 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peopelcare*, University of Wollongong, 2015, p. 10.

64 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peopelcare*, University of Wollongong, 2015, p. 10.

65 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peopelcare*, University of Wollongong, 2015, p. 10.

66 Dr Jodi Graham, *Official Committee Hansard*, Perth, 11 March 2016, pp 5-6.

67 Australian College of Rural and Remote Medicine, *Submission 76*, p. 8.

68 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peopelcare*, University of Wollongong, 2015, p. 10.

69 Tsiachristas, A et al, 'Exploring payment schemes used to promote integrated chronic care in Europe', *Health Policy* 113 (2013), p. 302.

introduced new financial constraints and failed to decrease the growth of health care expenditure.<sup>70</sup>

## Other European Countries

- 5.75 Austria, France, and Germany have implemented variations of pay-for-coordination (PFC) systems, aiming to promote the use of Disease Management Programs (DMPs) for specific chronic conditions. Austria created 'financial pools' by 'combining 1-2 per cent of the budget of social health insurers with that of regional governments. France initiated 'a negotiation between the social health insurance and the association of GPs'. German health insurers receive a 'fixed fee per patient per year for costs in primary and secondary care', with remuneration for enrolling patients with chronic conditions in DMPs.<sup>71</sup>
- 5.76 Implementation of PFC models has been perceived as 'successful with relatively high uptake in Germany and France', while in Austria it has been seen as less effective, 'as actors did not respond to the incentives with which they were provided'.<sup>72</sup>
- 5.77 France has a PFP scheme in which GPs are rewarded, 'not for specific disease treatments but rather for adequately registered patient records and for following evidence based guidelines'.<sup>73</sup>

## Canada

- 5.78 Ontario, Canada had a fee-for-service system similar to Australia's until it began shifting to a blended model incorporating capitation and pay-for-performance.<sup>74</sup> According to the UoW, Canada over the last decade has had movement towards group practices, with:

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70 Tsiachristas, A et al, 'Exploring payment schemes used to promote integrated chronic care in Europe', *Health Policy* 113 (2013), p. 302.

71 Tsiachristas, A et al, 'Exploring payment schemes used to promote integrated chronic care in Europe', *Health Policy* 113 (2013), p. 299.

72 Tsiachristas, A et al, 'Exploring payment schemes used to promote integrated chronic care in Europe', *Health Policy* 113 (2013), p. 301.

73 Tsiachristas, A et al, 'Exploring payment schemes used to promote integrated chronic care in Europe', *Health Policy* 113 (2013), p. 300.

74 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, p. 1.

...a shift from unitary physician payment methods (mainly fee-for-service) to payment arrangements that include blends of fee-for-service, capitation, salary, or payments per session.<sup>75</sup>

5.79 The blended model in Ontario is:

...an interdisciplinary team essentially paid almost completely – all but 10 per cent – by capitation, and there are incentives for quality primary care management.<sup>76</sup>

5.80 Patients in Ontario belong ‘to a group of doctors... [who] work with allied health professionals and practice nurses’.<sup>77</sup>

5.81 The UoW’s Graduate School of Medicine stated that Ontario’s experience suggested that blended models ‘can provide a favourable balance between productivity and quality in CDM measures in primary care’.<sup>78</sup>

5.82 The UoW also reported that ‘population-based bonuses provide incentives’ for services including ‘Pap smears’, flu immunisations, and cancer screening:

A growing, but still limited, body of evidence suggests that the payment models and incentives introduced in Ontario are improving preventive care delivery, chronic disease management, physician productivity, and access to care.<sup>79</sup>

5.83 The UoW report also found that pay-for-performance incentives have improved care in Ontario.<sup>80</sup>

## United Kingdom of Great Britain

5.84 The UK introduced the ‘Quality and Outcomes Framework’ (QOF) in 2004, offering pay-for-performance contracts to GPs, who are rewarded based on performance indicators across four domains: clinical standards,

75 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, p. 10.

76 Professor Grant Russell, Director, Southern Academic Primary Care Research Unit, Monash University, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 29.

77 Adjunct Professor Michael Moore, Chief Executive Officer, Public Health Association of Australia, *Official Committee Hansard*, Canberra, 21 August 2015, p. 30.

78 Graduate School of Medicine, University of Wollongong, *Submission 16*, p. 1.

79 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, p. 11.

80 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, p. 11.

- organisational standards, patient experience, and additional services.<sup>81</sup> The QOF rewards practices for ‘delivering quality targets and improving data capture’. The funding enables practices to employ nurses to implement the quality initiatives identified, while the data collected contributes to the development of innovative approaches.<sup>82</sup>
- 5.85 The University of Melbourne calls the QOF ‘the largest and most highly developed pay for performance... system in primary care in the world’, noting that it contains important lessons for using PFP to ‘target clinical need associated with socioeconomic disadvantage’. The University of Melbourne stated that an evaluation of the QOF suggests that PFP schemes ‘can contribute to the reduction of inequities in the delivery of clinical care’.<sup>83</sup>
- 5.86 The uptake of PFP was reported as 100 per cent in England, and 30 per cent initially in France before climbing to 90 per cent within three years. The PFP schemes in both England and France led to ‘positive structural changes in chronic care financing and chronic care delivery’.<sup>84</sup> The Better Care Fund was established in 2013 to encourage integrated health and social care. It was established as a single pooled budget to encourage the UK’s National Health Service to work more collaboratively with local government around people, with a focus on reducing hospital admissions and improving financial savings.<sup>85</sup>
- 5.87 The King’s Fund, a UK health policy think tank, was referenced by several submissions.<sup>86</sup> Professor Jeffrey Fuller called the King’s Fund ‘an informative clearing house of research and best practice exemplars’ whose research substantiates the need for long-term thinking.<sup>87</sup>
- 5.88 A 2013 King’s Fund report titled ‘Co-ordinated care for people with complex chronic conditions’ investigated five UK programs of care coordination for people with chronic conditions, identifying key success factors at personal, clinical and service, community, functional, organisational, and system levels.

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81 Tsiachristas, A et al, ‘Exploring payment schemes used to promote integrated chronic care in Europe’, *Health Policy* 113 (2013), p. 300.

82 Sydney North PHN, *Submission 155*, pp 1-2. See also the Royal Australasian College of Physicians, *Submission 81*, p. 5.

83 Department of General Practice, University of Melbourne, *Supplementary Submission 151.1*, p. 5.

84 Tsiachristas, A et al, ‘Exploring payment schemes used to promote integrated chronic care in Europe’, *Health Policy* 113 (2013), p. 302.

85 Cohealth, *Submission 88*, pp 11-12.

86 Professor Jeffrey Fuller, *Submission 22*, p. 2; National Rural Health Alliance, *Submission 67*, p-17-18; South Eastern Melbourne PHN, *Submission 123*, Attachment B; Queensland Government, *Submission 167*, p. 6.

87 Professor Jeffrey Fuller, *Submission 22*, p. 1.

- 5.89 These factors highlighted the importance of a holistic patient focus and dedicated care coordinators. Other key factors included tailored care plans, multidisciplinary care teams, localised care coordination programs and local leadership, and a single source of funding.<sup>88</sup>
- 5.90 One key observation of the report was that ‘success in care co-ordination appears to be the result of a long-term process, facilitated by key local leaders’.<sup>89</sup> Another observation was the importance of context: highlighting this observation in the report, South Eastern Melbourne PHN commented, ‘an approach that works in inner Melbourne would need to be effective on the city outskirts or in a rural area’.<sup>90</sup>

## United States of America

- 5.91 In the United States, the Kaiser Permanente (KP) health care system is held up as an ‘exemplar’ system that has ‘achieved good outcomes in chronic disease management’. The key feature is:
- ...defined populations for which organisations have overall responsibility for health care with a funding model that provides a suite of care that is planned and continuous rather than reactive and episodic.<sup>91</sup>
- 5.92 The KP system is a ‘closed-group model’, and has about eight million members across nine American states and Washington, D.C. It is described as being different from other programs with its strong emphasis on preventive care. The system uses a shared electronic health record system which patients can access. Doctors are salaried rather than paid for service, reducing incentives for unnecessary procedures, and KP also aims to minimise the amount of time spent in hospital.<sup>92</sup>
- 5.93 Studies of the KP model compared to other systems found lower rates of hospitalisation, particularly for ‘preventable hospitalisations and readmissions associated with chronic conditions’.<sup>93</sup>

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88 Goodwin, N et al, ‘Co-ordinated care for people with complex chronic conditions’, King’s Fund (2013), pp 25-27.

89 Goodwin, N et al, ‘Co-ordinated care for people with complex chronic conditions’, King’s Fund (2013), p. 27.

90 South Eastern Melbourne PHN, *Submission 123*, Attachment B.

91 Professor Jeffrey Fuller, *Submission 22*, p. 2.

92 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, pp 11-12.

93 Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplecare*, University of Wollongong, 2015, pp 12, 27.

- 5.94 The 'Kaiser Permanente Pyramid' attempts to target scarce resources towards those most in need by segmenting populations 'into groups to which interventions can be targeted'.<sup>94</sup>
- 5.95 The KP model has a positive reputation outside of the US and was broadly held up in this inquiry as a noteworthy model in submissions and public hearings.<sup>95</sup> South Eastern Melbourne PHN highlighted the early identification of lifestyle risk factors and the role of a 'designated care coordinator'.<sup>96</sup>
- 5.96 It must be acknowledged that the KP system is essentially a coordinated health care commissioner, provider and insurer within the US 'user pays' system, however many of the coordinated care and funding principles that are used by KP can help inform chronic disease care in Australia.

## New Zealand

- 5.97 The Canterbury Model was developed to focus on integrating health and social care as a way of stemming the growing demand for hospital care.<sup>97</sup> The model was developed by the Canterbury District Health Board, in the South Island of New Zealand, and has attracted international attention for achieving better client care pathways.<sup>98</sup>
- 5.98 The focus in the region has been on 'purposefully building up general practice to be able to look after people with complex chronic conditions'. The aim is to keep people out of hospital if they do not need it, to treat them quickly when they do need it, and to discharge them to good community support.<sup>99</sup>
- 5.99 The system has reportedly saved 'more than a million days of waiting for treatment in just four clinical areas in recent years', with fewer patients entering care homes, better and quicker care with less need for hospital

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94 Royal Australian College of General Practitioners, *Submission 135*, p. 4.

95 Metro North Hospital and Health Service, *Submission 9*, p. 1; Graduate School of Medicine, University of Wollongong, *Submission 16*, p. 1; Australian Healthcare and Hospitals Association, *Submission 40*, p. 21; Victorian AIDS Council, *Submission 47*, p. 13; Australian College of Rural and Remote Medicine, *Submission 76*, p. 11; WA Primary Health Alliance, *Submission 180*, p. 10;

96 South Eastern Melbourne PHN, *Submission 123*, Attachment B.

97 The Kings Fund, 'Case study 5: Canterbury District Health Board, New Zealand', <<http://www.kingsfund.org.uk/time-to-think-differently/publications/reforming-nhs-within/case-study-5-canterbury-district-health-board-new-zealand>>, viewed 19 April 2016.

98 Professor Jeffrey Fuller, *Submission 22*, p. 2.

99 South Eastern Melbourne PHN, *Submission 123*, Attachment B.

visits, and a budget that went from NZ \$17m in deficit in 2007 to a NZ \$8m surplus by 2010-11.<sup>100</sup>

- 5.100 While not strictly a funding model, the impact of improved care coordination and avoiding unnecessary treatment and hospital admissions has had a profound impact on the cost of chronic disease care, as outlined above.
- 5.101 One feature of the Canterbury Model is its 'HealthPathways', described as 'local agreements on best practice':
- They are created by bringing together hospital doctors and GPs in order to hammer out what the patient pathway for a particular condition should be. They spell out which treatments can be managed in the community; what tests GPs should carry out before a hospital referral; where and how GPs can access such resources...<sup>101</sup>
- 5.102 This feature has been used as a model for similar approaches in Australia, as discussed in a number of the public hearings and submissions<sup>102</sup> and as highlighted in Chapter 4.

## Concluding Comment

- 5.103 Funding of chronic disease prevention and management in Australia is a complex web of responsibilities, performance measures and outcomes.
- 5.104 At the core of primary health care is the MBS fee for service (FFS) model, delivering episodic care to the vast majority of Australians in an adequate manor to manage their minor health issues, or ongoing care for simpler health issues. However, the adequacy of the FFS model for coordinated prevention and care of chronic disease/s is clearly lacking.
- 5.105 The Committee acknowledges the moves made in introducing chronic disease management items to the MBS in recent years, but the

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100 Timmins, N and Ham, C, 'The quest for integrated health and social care: A case study in Canterbury, New Zealand', *The King's Fund*, p. 6.

101 Timmins, N and Ham, C, 'The quest for integrated health and social care: A case study in Canterbury, New Zealand', *The King's Fund*, p. 21.

102 Mr Matthew Jones, Chief Executive Officer, Murray Primary Health Network, *Official Committee Hansard*, Melbourne, 1 October 2015, pp 55-56; Mr Jason Trethowan, Chief Executive Officer, Western Victoria Primary Health Network, *Official Committee Hansard*, Melbourne, 1 October 2015, p. 57; Professor David Ashbridge, Chair, Western Alliance Academic Health Science Centre, *Official Committee Hansard*, Bendigo, 18 November 2015, p. 19; Ms Megan Clark, Benefits Manager, GMHBA Health Insurance, *Official Committee Hansard*, Bendigo, 18 November 2015, pp 29-31; Centre for Primary Health Care and Equity, University of NSW, *Submission 6*, p. 2; Kidney Health Australia, *Submission 126*, p. 9.

overwhelming opinion expressed in this inquiry is that these MBS items do not go far enough to encourage and incentivise care models that deliver the best outcomes for patients.

- 5.106 The international examples outlined above show that similar international jurisdictions to Australia have either evolved into coordinated, bundled payment systems, or are in the process of doing exactly that, based on the overwhelming evidence that the models of care outlined in Chapter 4 deliver better outcomes, and ultimately better return on investment in care for chronic disease.

### Health Care Homes

- 5.107 The Prime Minister and Health Ministers' joint announcement of the trials of Health Care Homes for chronic disease patients, commencing in July 2017, combines many of the elements of care reform and funding models outlined in Chapter 4 and this chapter. The work of the Primary Health Care Advisory Group (PHCAG), culminating in its *Better Outcomes for People with Chronic and Complex Health Conditions* report, is an indication that the intended improvements from the 'Healthier Medicare' reform agenda is achieving outcomes.
- 5.108 The bundling of payments for Health Care Homes into quarterly payments, to be coordinated and paid to the patients 'home' practice for all required medical, allied health and out-of-hospital services<sup>103</sup> is a welcome reform to the traditional FFS system for the care required by chronic disease patients.
- 5.109 The Committee congratulates the Australian Government for announcing this reform, and while the final detail of the trials is forthcoming, the development of such an initiative can only benefit chronic disease patients into the future.
- 5.110 The Health Care Home implementation advisory group outlined as part of the announcement to 'oversee the design, implementation and evaluation of the trials'<sup>104</sup> has an important job ahead to manage a watershed moment in providing best practice care to chronic disease patients in Australia.

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103 The Hon. Malcolm Turnbull MP, Prime Minister and The Hon. Sussan Ley MP, Minister for Health, Minister for Aged Care, Minister for Sport 'A Healthier Medicare for chronically-ill patients', *Media Release*, 31 March 2016.

104 The Hon. Malcolm Turnbull MP, Prime Minister and The Hon. Sussan Ley MP, Minister for Health, Minister for Aged Care, Minister for Sport 'A Healthier Medicare for chronically-ill patients', *Media Release*, 31 March 2016.

## Moving into the Future

- 5.111 While the Health Care Home trials are a welcome move, the Committee believes that the primary health care system in Australia can aim for more elements of the best practice care and funding models outlined in this report.
- 5.112 Ultimately, the model of care that brings together the best elements of all the theoretical and practical examples outlined contains:
- Blended payments – FFS for ordinary health care needs, bundled and capitation payment methods for ongoing chronic care, as well as salaried chronic care physicians;
  - Pay for performance – rather than pay individual practitioners for a ‘treatment’, measure the outcome of the suite of care provided and pay based on outcome;
  - Chronic Care Methodology and patient-centred care – bringing together the patient, their families, all their required health care providers and coordinating their care, in agreement with the patient themselves;
  - Prevention of disease or progression – incentivise the care and education required of both the patient and their care providers to enable avoidance of, or slow the progression of, chronic disease; and
  - Supported by well-funded and coordinated eHealth systems – expansion of the My Health Record to become the central repository of patient data, augmented by practice data and de-identified central government treatment data, that can be used for performance measurement, as well as research and outcomes-based improvement.<sup>105</sup>
- 5.113 The Australian primary health care system cannot change into a cohesive system of reformed care in a short period. Much like the long-term investment required for creating chronic disease prevention policies work, as outlined in Chapter 4, the time investment required to reform chronic disease management is long-term as well.
- 5.114 Long-term investment in improvements to chronic disease prevention and management is important. The rapid movement from Medicare Locals to Primary Health Networks has challenged the primary health care system to find stability and care continuity, so the continued investment and consolidation in the Primary Health Network model is imperative to measuring success and improving care into the future.

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105 Adapted from the ‘Key Principles Underpinning Cost Effective Models of Primary Care Funding’ outlined in Bonney A, Iverson D and Dijkmans-Hadley B, *A Review of models for financing primary care systems in the Netherlands, Ontario-Canada, United Kingdom and USA: A report for Peoplcare*, University of Wollongong, 2015, p. 29.

- 5.115 The Committee is also of the opinion that the Practice Incentives Program should be examined for potential expansion, along the lines of some of the payments for coordination outlined earlier in this chapter, especially the potential for a PIP for breast, bowel and skin cancer screening, as well as the Integrated Health Check outlined above and in Chapter 4.
- 5.116 These expanded Practice Incentive Programs can then be evaluated to identify improvements to associated chronic disease management.
- 5.117 Additionally, the Committee recommends that the Australian Government continue to fund the evolution and expansion of the My Health Record, managed by the Australian Digital Health Agency from 1 July 2016. The importance of patient-managed care information, as well as the resultant data that can be used to measure successes, failures and outcomes, as identified in Chapter 4, is essential to moving the primary health care system into the future.

## Recommendations

### Recommendation 11

- 5.118 **The Committee recommends that the Australian Government commit to providing consistent support and funding for the establishment of Primary Health Networks or similar into the future, to enable consistent development and support for chronic disease prevention and management.**

### Recommendation 12

- 5.119 **The Committee recommends that the Australian Government examine the current Practice Incentives Program with the aim that it be expanded to include programs for breast, bowel and skin cancer screening, as well as the Integrated Health Check developed by the National Vascular Disease Prevention Alliance; and**
- That these programs, as well as the existing Practice Incentive Programs, be evaluated and measured to identify improvements to management of chronic disease.**

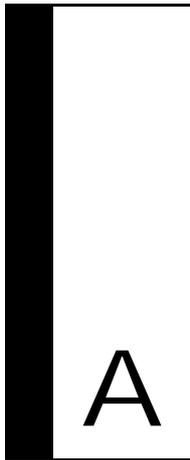
**Recommendation 13**

- 5.120 **The Committee recommends that the Australian Government continue to prioritise funding of the evolution and expansion of the My Health Record to support improvements in the prevention and management of chronic disease, as well as the wellness of all Australians.**

Steve Irons MP  
Chair

3 May 2016





## Appendix A - Case Study on Tick-Borne and Lyme-Like Diseases

### Background

Lyme disease or Lyme borreliosis is a tick-borne illness caused by the bacterium *Borrelia burgdorferi*. The condition causes a wide range of symptoms, including fever, headache, fatigue, sore muscles and joints, and a characteristic skin rash known as *erythema migrans*.<sup>1</sup> Later symptoms of untreated Lyme disease can include severe joint pain, facial palsy, heart palpitations, dizziness or shortness of breath, and short-term memory problems, among others.<sup>2</sup> According to the Lyme Disease Association of Australia (LDAA), the disease 'can degenerate to a chronic state and can be fatal if left untreated'.<sup>3</sup>

Lyme disease is carried by ticks belonging to the *Ixodes* genus. Although several *Ixodes* species do exist in Eastern Australia, there has been no recognised evidence of these carrying *Borrelia burgdorferi*.<sup>4</sup> The Australian *Ixodes holocyclus* is known to cause tick paralysis, tick typhus, and allergic reactions.<sup>5</sup> Research being conducted by Professor Peter Irwin at Murdoch University has found one case of *Borrelia* 'of

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- 1 NSW Health, 'Lyme Disease', [http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme\\_disease.aspx](http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx), viewed 16 March 2016.
  - 2 Centers for Disease Control and Prevention, 'Lyme disease - Signs and Symptoms of Untreated Lyme Disease', [http://www.cdc.gov/lyme/signs\\_symptoms/index.html/](http://www.cdc.gov/lyme/signs_symptoms/index.html/), viewed 16 March 2016.
  - 3 Lyme Disease Association of Australia, *Submission 85*, introductory letter, p. 1.
  - 4 NSW Health, 'Lyme Disease', [http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme\\_disease.aspx](http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx), viewed 16 March 2016.
  - 5 NSW Health, 'Lyme Disease', [http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme\\_disease.aspx](http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx), viewed 16 March 2016. The *Ixodes holocyclus* is known to cause tick paralysis, tick typhus, and allergic reactions.

the relapsing fever group' in an *Ixodes halocyclus* tick, but has not found *Borrelia burgdorferi*.<sup>6</sup>

A growing number of Australians are being diagnosed with tick-borne or Lyme-like illnesses and showing symptoms consistent with Lyme disease, including many who have never left Australia.<sup>7</sup> The LDAA has been notified of 1 494 cases of individual Australian residents with tick-borne or Lyme-like disease, from 625 tick bite locations across Australia.<sup>8</sup>

## Defining Tick-Borne or Lyme-Like Diseases

The LDAA, the Country Women's Association of New South Wales (CWA of NSW), and Dr Richard Schloeffel commented that the term 'Lyme disease' is inappropriate.

The Lyme Disease Association of Australia (LDAA) stated 'Lyme' is too narrow and that 'Lyme-like illness' is appropriate in the absence of some other name.

Ms Alex Patson commented that the term 'Lyme disease' is more appropriate in the American context.<sup>9</sup> Dr Richard Schloeffel commented that it is only properly called Lyme disease if contracted in America, and suggested the term 'Borreliosis and Co-Infection with Multi System Disorder' or something similar would be more appropriate.<sup>10</sup>

The view that a name other than Lyme disease should be adopted was supported by the CWA of NSW,<sup>11</sup> Sarcoidosis Lyme Australia,<sup>12</sup> and the Karl McManus Foundation (KMF).<sup>13</sup>

The KMF also stated that 'the other borreliosis infection which is endemic in the world is relapsing fever', stating:

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6 Professor Peter Irwin, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4. See also Murdoch University, 'Researchers closer to ending debate around Lyme disease and ticks in Australia', <http://media.murdoch.edu.au/researchers-closer-to-ending-debate-around-lyme-disease-and-ticks-in-australia>, viewed 16 March 2016.

7 Dr Richard Schloeffel, *Submission 162*, p. [2].

8 Lyme Disease Association of Australia, 'The Stats', <<http://www.lymedisease.org.au/stats/>>, viewed 16 March 2016.

9 Ms Alex Patson, Lyme Disease Association of Australia, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

10 Dr Richard Schloeffel, *Submission 162*, p. 2.

11 Ms Annie Kiefer, Country Women's Association of New South Wales, *Official Committee Hansard*, Sydney, 18 September 2015, p. 19.

12 Sarcoidosis Lyme Australia, *Submission 166*, p. 5.

13 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 2.

Given that Peter Irwin's work has shown that there is a relapsing fever *Borrelia* in Australian ticks, it is even more important for us to focus on that rather than on Lyme.<sup>14</sup>

For the sake of consistency and clarity, this report uses the term 'tick-borne or Lyme-like disease'.

## Current Australian Research

The Department of Health established the Clinical Advisory Committee on Lyme Disease (CACLD) in 2013 to advise the Chief Medical Officer on the evidence for tick-borne or Lyme-like disease in Australia, diagnostic testing, treatment, and research requirements. In regard to these diseases, the Department of Health stated:

Through regular communication and correspondence, the department has gained a deeper appreciation and real concern for those Australians experiencing these chronic, debilitating symptoms, which they associate with a tick bite. We wish to remain engaged with the patient and medical community to continue to find, share and understand the evidence associated with this medical conundrum.<sup>15</sup>

Professor Peter Irwin, who was part of the CACLD, has been leading a team at Murdoch University which has developed a new method of detecting the DNA of bacteria inside ticks. They have recently found *Borrelia* DNA on a tick taken from a wild echidna. Professor Irwin emphasised that this was found only in one tick out of 196, and that '*Borrelia burgdorferi* has never been found [in Australia].'<sup>16</sup> Professor Irwin suggested that it is likely Australia has something unique.<sup>17</sup>

There is broad agreement that further research into the causes of tick-borne illnesses in Australia is essential. The Royal Australian College of General Practitioners (RACGP) stated:

We recognise that in Australia there is a Lyme-like illness with no consistent causative organism, very little epidemiology, unstructured treatment and poor evidence about outcomes of current management. There is a great need for further research into what can be a very

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14 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 2.

15 Dr Gary Lum, Department of Health, *Official Committee Hansard*, Sydney, 18 September 2015, p. 3.

16 Professor Peter Irwin, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

17 Professor Peter Irwin, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

disabling condition for patients. The college would support anything in that direction.<sup>18</sup>

Dr Richard Schloeffel 'strongly support[s]' the view that further research and 'rigorous science' is needed.<sup>19</sup>

## Incidence

The incidence of tick-borne or Lyme-like diseases in Australia is difficult to determine. Dr Richard Schloeffel identified as a 'tentative projection of 102 000 [people] in Australia with chronic borrelial infection'.<sup>20</sup> Dr Schloeffel also stated that 'we have no idea how many people may have symptoms that fit this category', emphasising that tick-borne or Lyme-like disease is not a notifiable condition,<sup>21</sup> but stated that he currently has '400 patients with borreliosis or related illnesses'.<sup>22</sup>

The Department of Health (DoH) stated that tick-borne or Lyme-like disease has previously been assessed and was not added to the list of nationally notifiable diseases. The Department of Health explained this was due to a lack of a good case definition and consensus about the cause of the disease.<sup>23</sup> The DoH also suggested that a case definition would need to be developed.<sup>24</sup>

The KMF stated that part of the difficulty of determining incidence of tick-borne or Lyme-like diseases is due to the non-specific symptoms and unreliable diagnostics of these diseases.<sup>25</sup>

The RACGP indicated it could not know how widespread tick-borne or Lyme-like disease is as no research has been undertaken into the disease in the Australian context.<sup>26</sup>

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18 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Committee Hansard*, Sydney, 18 September 2015, p. 5.

19 Dr Richard Schloeffel, *Submission 162*, p. 4.

20 Dr Richard Schloeffel, *Submission 162*, Attachment B, p. 4.

21 Dr Richard Schloeffel, *Submission 162*, p. 2.

22 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 6.

23 Dr Gary Lum, Department of Health, *Official Committee Hansard*, Sydney, 18 September 2015, p. 19.

24 Dr Gary Lum, Department of Health, *Official Committee Hansard*, Sydney, 18 September 2015, p. 19.

25 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 2.

26 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Official Committee Hansard*, Sydney, 18 September 2015, p. 7.

## Diagnosis

Tick-borne or Lyme-like disease can be diagnosed based on symptoms, physical signs such as the *erythema migrans* or 'bulls-eye' rash, and the possibility of exposure to ticks infected with *Borrelia*. Laboratory testing is undertaken in later stages of the illness. In Australia, a common method of diagnosis of tick-borne illnesses involves an 'ELISA' screening test<sup>27</sup> which, if positive, is confirmed by a 'western blot' or 'immunoblot' test.<sup>28</sup>

Dr Richard Schloeffel suggested the current use of the ELISA test is 'inadequate to assess whether the patients have Borreliosis', and that a better guide is the western blot test or a Polymerase Chain Reaction (PCR) test.<sup>29</sup> Dr Schloeffel described the diagnosis process for some of his patients who have acquired and were diagnosed with Lyme disease overseas. This typically involves 'appropriate testing with approved labs' in Germany or America, using immunoblot or PCR testing but not ELISA testing.<sup>30</sup>

Australian Biologics, a commercial laboratory, stated that it undertakes tests for tick-borne illness which return positives for the *Borrelia* bacteria. Australian Biologics stated that, using immunoblot and EliSpot testing,<sup>31</sup> it gets positives from patients, including from patients who have never left the country.<sup>32</sup>

Australian Biologics has found 'probably five to six types of *Borrelia*' bacteria. Ms Jennie Burke from Australian Biologics stated that they have found 'close to - not quite a perfect match; close to' *Borrelia burgdorferi* in Australian ticks.<sup>33</sup>

One of the symptoms of Lyme disease is a characteristic 'bulls-eye' rash called *erythema migrans*. The LDAA indicated that in other countries the presence of this rash is a 'pathognomonic' sign warranting an immediate diagnosis of Lyme disease, but that this advice is not generally followed in Australia. The LDAA stated:

In other countries Lyme disease is diagnosed on clinical signs alone if a 'bullseye' (EM) rash is present. The bullseye rash is known as a 'pathognomonic' sign that warrants an immediate diagnosis of Lyme disease as it is unique to Lyme disease; this is a CDC-agreed diagnostic

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27 Enzyme-linked immunosorbent assay.

28 NSW Health, 'Lyme Disease', <[http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme\\_disease.aspx](http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx)>, viewed 16 March 2016.

29 Dr Richard Schloeffel, *Submission 162*, p. 3.

30 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, pp 6-7.

31 An ELISPOT (enzyme-linked immunospot) assay is a modification of the ELISA test.

32 Ms Jennie Burke, *Official Committee Hansard*, Sydney, 18 September 2015, pp 1-2.

33 Ms Jennie Burke, *Official Committee Hansard*, Sydney, 18 September 2015, p. 6.

position, negating the need for any diagnostic test. In Australia we don't educate doctors about this sign.<sup>34</sup>

## Co-infections

The LDAA stated that tick-borne or Lyme-like disease is often contracted with co-infections, as ticks are able to transmit more than one pathogen. According to the LDAA, 55 per cent of patients with tick-borne or Lyme-like disease reported being diagnosed with at least one co-infection. This is a much higher rate than that reported in the USA.<sup>35</sup>

Dr Schloeffel lists ten groups of co-infections associated with tick-borne or Lyme-like disease, including: relapsing fever,<sup>36</sup> *rickettsias*,<sup>37</sup> and chronic viral infections including HIV.<sup>38</sup>

## Treatment

### Antibiotics

In cases where patients do test positively for tick-borne or Lyme-like disease, a common experience is for patients to be treated with a short course of antibiotics. The LDAA stated that infectious diseases specialists commonly follow the Infectious Diseases Society of America (IDSA) practice guidelines. However, the LDAA stated that this is 'seen as vastly inadequate by any medical professional that is educated and experienced in treating Lyme-like disease'.<sup>39</sup>

The LDAA stated that longer term treatment is required in cases where patients have co-infections.<sup>40</sup> The LDAA also identified the complexity of treatment

34 Lyme Disease Association of Australia, *Submission 85*, p. 2.

35 Lyme Disease Association of Australia, *Submission 85*, p. 2.

36 Dr Schloeffel described his experience with relapsing fever working in Papua New Guinea: 'I think this picture of evolving *Borrelia* relapsing fever would fit the pattern, because it fits the symptom of the patient. When I trained originally I worked in Papua New Guinea in malaria and TB and leprosy... I would look at some of these patients, and they were like they had malaria because they had these relapsing fevers and these funny chronic symptoms where every day, or every third day, they had a massive night sweat where they would completely saturate the bed.' Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 7.

37 Rickettsial infections are transmitted to humans by ticks and fleas and fall into one of three groups: spotted fever, typhus, and scrub typhus. Dr Richard Schloeffel, *Submission 162*, Attachment B, pp 3-4.

38 Dr Richard Schloeffel, *Submission 162*, Attachment B, pp 2-4. See also Dr Richard Schloeffel, *Submission 162*, Attachment A, pp 1-2.

39 Lyme Disease Association of Australia, *Submission 85*, p. 2.

40 Lyme Disease Association of Australia, *Submission 85*, p. 2.

pathways due to the 'different infections and different manifestations' patients in Australia present with.<sup>41</sup>

The complexity of treating tick-borne or Lyme-like diseases was articulated by Dr Richard Schloeffel, who has treated patients with these illnesses. Dr Schloeffel stated:

The type of treatment that we do is not just about throwing antibiotics at patients.... It is about management and giving the patient an understanding of their illness, making a proper diagnosis, sorting out their mental state and making sure they have carers and community support. It is about providing them with advice about how they should change their diet or improve their eating patterns, providing adequate supplementation for foods and for things that they may require as part of the treatment but also as a result of the treatment. So they will be on vitamins and supplements and other things, which they have often already started because they have already seen six or seven naturopaths before they see you. Then depending on their diagnosis, very gently and slowly, there is an antibiotic protocol. I have many antibiotic protocols, because every patient is different.<sup>42</sup>

Dr Schloeffel emphasised the importance of not 'bombarding' with doses of antibiotics that are too high.<sup>43</sup> This view was shared by the Australasian Society for Infectious Diseases (ASID), which stated:

...it is of no benefit to the patients to treat them long term with antibiotics, which can be potentially harmful and certainly will not help chronic symptoms that are not due to bacterial infection. In the absence of a specific diagnosis, this, I would suggest, is malpractice, if it is not supported by any laboratory diagnosis.<sup>44</sup>

The ASID also stated that most professional bodies in endemic areas have guidelines advising 'short-term antibiotic therapy usually for two weeks', in which time the 'vast majority of patients' will improve.<sup>45</sup>

The RACGP highlighted its concern about antimicrobial resistance to prolonged use of antibiotics and stated:

...we have to be concerned about antimicrobial resistance, as already mentioned, in conditions which may be related to the overuse of antibiotics. Although people are seemingly getting some benefit from

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41 Lyme Disease Association of Australia, *Submission 85*, p. 3.

42 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 13.

43 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 17.

44 Professor Lyn Gilbert, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

45 Professor Lyn Gilbert, *Official Committee Hansard*, Sydney, 18 September 2015, p. 15.

this anecdotally, we also have to be aware that some patients will be having adverse effects because of long-term antibiotic use.<sup>46</sup>

The KMF commented that in some cases 'the patient has prolonged antibiotic treatment and they can end up with adverse effects from the antibiotics'.<sup>47</sup>

The KMF and LDAA stated, however, that antibiotic treatment would be inadequate if it was not long enough. The KMF stated:

...a short-term treatment [of antibiotics] will not be adequate to actually decrease the bacterial load so that the immune system can take over defeating the infection.<sup>48</sup>

The LDAA stated that international Lyme experts and Lyme-treating doctors in Australia agree that 'four weeks is simply not long enough'.<sup>49</sup>

Dr Schloeffel stated that there are two approaches in the USA to treating Lyme disease: the Centers for Disease Control (CDC) recommends a short course of treatment while the International Lyme and Associated Diseases Society (ILADS) recommends a longer period of therapy.<sup>50</sup>

### Other Treatments

Dr Schloeffel, in addition to antibiotic treatment, is also involved in treatment using hyperthermia, a method used in Germany in which the body is heated for nine hours to 41.7 degrees in an intensive care unit. Dr Schloeffel stated that over 1 000 Australians have travelled to Germany to receive this particular treatment, which 'seems to be very effective'.<sup>51</sup>

The RACGP stated that as it advocates for evidence based practice it 'cannot support many of the treatments currently being used or advocated', regardless of 'whatever success individual doctors have with their patients'.<sup>52</sup>

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46 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Official Committee Hansard*, Sydney, 18 September 2015, p. 16.

47 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 14.

48 Dr Mualla McManus, Karl McManus Foundation, *Official Committee Hansard*, Sydney, 18 September 2015, p. 14.

49 Ms Sharon Whiteman, Lyme Disease Association of Australia, *Official Committee Hansard*, 18 September 2015, p. 3.

50 Dr Richard Schloeffel, *Submission 162*, p. 3.

51 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 17.

52 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Official Committee Hansard*, Sydney, 18 September 2015, p. 16.

## Living With Tick-Borne or Lyme-Like Disease

Several first-hand accounts of Australians living with tick-borne or Lyme-like disease symptoms outlined the debilitating effects their condition has on their lives. Common to all those affected is the long-term nature of their conditions.

Comments from Ms Lynn Rees are a typical representation of the effects of tick-borne or Lyme-like disease on sufferers. Ms Rees recounted her ongoing treatment for the disease and the personal cost:

...even after nearly four years of active treatment, I continue to be ill, though with appropriate treatment I am recovering slowly. My two children, now teenagers, can barely remember when I was an intelligent, healthy and fit mother, and my marriage of 18 years recently collapsed due to the impacts of this disease. The personal cost to my life and career and the impacts Lyme disease has had on my family have been profound.<sup>53</sup>

Ms Elaine Kelly also related a long-term illness, having been sick for 15 years since travelling to endemic areas.<sup>54</sup>

Mrs Michelle Wheeler outlined how debilitating tick-borne or Lyme-like disease is, speaking of her inability to function and care for her family, and of being bedridden most days.<sup>55</sup>

Mr Christopher Walker described how he was diagnosed with a range of different illnesses over a decade before receiving a clinical diagnosis of borreliosis. Mr Walker, similarly to Mrs Wheeler,<sup>56</sup> spends \$5000 a month on treatment.<sup>57</sup>

Mr Walker's experience of visiting multiple doctors and receiving various diagnoses was shared by other witnesses. Dr Schloeffel stated that many patients 'often seen multiple specialists and have multiple tests'.<sup>58</sup> Ms Rees stated that she received 'numerous diagnoses' over four years, including:

...chronic fatigue, systemic lupus erythematosus, post-traumatic stress disorder, anxiety, depression and perimenopause.<sup>59</sup>

Ms Alex Patson and her two children contracted the condition at the same time after bushwalking in Newcastle.<sup>60</sup> Ms Patson described symptoms including word-block, neurological issues, Parkinson's shakes, arthritic pain, muscle and

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53 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, p. 27.

54 Ms Elaine Kelly, *Official Committee Hansard*, Sydney, 18 September 2015, p. 28.

55 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

56 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

57 Mr Christopher Walker, *Official Committee Hansard*, Sydney, 18 September 2015, p. 28.

58 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 17.

59 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, p. 27.

60 Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, pp 29-30.

bone pain and stiffness. At one point Ms Patson also recounted how at one point she lost the use of one arm, could not lift a cup or brush her teeth, could not walk, talk, or get changed.<sup>61</sup>

Ms Patson also related her experience of having to visit multiple specialists before being diagnosed with a tick-borne disease.<sup>62</sup>

Ms Gabrielle Stevens' two daughters developed a tick-borne or Lyme-like illness, and as a consequence they have missed much of their schooling.<sup>63</sup> This was also the case for Ms Patson's children.<sup>64</sup>

Another experience some people described was the necessity of travelling to Europe to receive treatment. Ms Stevens lived in Europe for over a year with her children, who underwent treatment in the Netherlands, Germany, and the Czech Republic.<sup>65</sup>

Mr Walker was advised to travel to Germany for treatment but was too sick. He began receiving treatment in Australia and recovered to a point where he no longer needed to travel to Germany for treatment.<sup>66</sup>

The need for many patients to travel to Europe is a great financial burden in addition to the cost of the treatment itself. Dr Schloeffel estimated that overseas blood tests cost between \$1000 and \$2000 per patient.<sup>67</sup> Additionally, Dr Schloeffel stated that patients who use supplements have an additional cost of \$600 a month for a minor treatment to several thousand a month. Dr Schloeffel estimated treatment costs 'between \$20 000 and \$50 000 a year per patient'.<sup>68</sup>

Ms Rees stated her costs after four years of treatment are nearly \$80 000.<sup>69</sup> Mrs Wheeler stated the cost of her illness is about \$5000 a month on average and has cost her family their life savings.<sup>70</sup>

Mrs Wheeler also explained the social burdens in addition to the financial costs that people with tick-borne or Lyme-like disease can face, sharing her experience of stress, anger, sadness, guilt, and depression.<sup>71</sup>

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61 Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

62 Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, pp 29-30.

63 Ms Gabrielle Stevens, *Official Committee Hansard*, Sydney, 18 September 2015, p. 31.

64 Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

65 Ms Gabrielle Stevens, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

66 Mr Christopher Walker, *Official Committee Hansard*, Sydney, 18 September 2015, p. 28.

67 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 13.

68 Dr Richard Schloeffel, *Official Committee Hansard*, Sydney, 18 September 2015, p. 18.

69 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, p. 27.

70 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

71 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

Ms Stevens related a similarly exhaustive experience and a 'huge emotional impact', saying her family 'often are afraid' and how they 'hate to see the children suffer'.<sup>72</sup>

Another recurring experience among Australians living with tick-borne or Lyme-like disease is stigma, including a lack of recognition of their condition in the medical profession.

Ms Rees stated her concern about the lack of acceptance of this disease in Australia, contrasting that with her experience with her employer, who accepts her condition and has 'taken a proactive role' in supporting her.<sup>73</sup>

Mr Walker also expressed concerns about lack of recognition among the medical profession. Referring to the controversy around the contraction within Australia, he said:

Whether it is contracted here or overseas is irrelevant as to whether the individual is deserving and entitled to being properly treated.<sup>74</sup>

This broad lack of recognition was also discussed by Mrs Wheeler<sup>75</sup> and Ms Stevens,<sup>76</sup> and Ms Kelly stated that 'treating GPs have no peer support and no back-up medical support services'.<sup>77</sup>

## Concluding Comment

As outlined in this case study, the Committee has received evidence from individuals, advocacy groups, and doctors demonstrating the extent of the difficulties presented by tick-borne or Lyme-like diseases.

The Committee acknowledges the suffering endured by many Australians living with these conditions. They can be debilitating and last for many years. Due to the uncertainty in the medical community about the existence and type of tick-borne or Lyme-like disease and associated conditions in Australia, many patients face a frustrating process before being diagnosed and treated appropriately, if at all. This often involves visiting multiple doctors and sometimes requires travelling to America or Europe. These costs as well as the ongoing costs of treatment and the resulting loss of employment create a significant financial burden on those with the condition. There is also significant cost to a patient's family members.

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72 Ms Gabrielle Stevens, *Official Committee Hansard*, Sydney, 18 September 2015, p. 31.

73 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, pp 27-28.

74 Mr Christopher Walker, *Official Committee Hansard*, Sydney, 18 September 2015, p. 28.

75 Mrs Michelle Wheeler, *Official Committee Hansard*, Sydney, 18 September 2015, p. 26.

76 Ms Gabrielle Stevens, *Official Committee Hansard*, Sydney, 18 September 2015, p. 31.

77 Ms Elaine Kelly, *Official Committee Hansard*, Sydney, 18 September 2015, pp 28-29.

The Committee is aware of the ongoing discussion about the definition of 'Lyme disease' and whether Lyme disease is something that can be contracted within Australia. The Committee acknowledges the concerns about misdiagnosis,<sup>78</sup> and the possibility of overuse of antibiotics.<sup>79</sup>

The Committee acknowledges the lack of recognition of tick-borne or Lyme-like diseases within the medical community. This was highlighted in the evidence from people living with tick-borne or Lyme-like diseases, who experience a lack of recognition and stigma from much of the medical profession until they find a 'Lyme-literate'<sup>80</sup> doctor.

One of the consequences of the lack of attention tick-borne or Lyme-like disease has received in the medical community is that very little is known about the incidence of these diseases throughout Australia. The fact that tick-borne or Lyme-like disease is not a notifiable disease was raised in the evidence as a hindrance to knowing more about the disease in this country and the scale of the disease as a social problem. The lack of consensus about the definition was cited as a main reason for tick-borne or Lyme-like disease not being a notifiable disease.

The Committee acknowledges the research efforts of the CACLD and the work being done by Professor Irwin and his team at Murdoch University. Professor Irwin's recent discovery of *Borrelia* DNA on a tick taken from an echidna may yet prove to have significance for further research into Lyme-like and other tick-borne illnesses in humans.

However, there is wide agreement on the need for further research. The CACLD's 'five research priorities', mentioned in the case study, should continue to generate further research activity. The Committee recommends that the Australian Government continue to pursue advances in relevant policy and relevant research areas as per the following recommendation.

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78 Dr Stephen Graves, Royal College of Pathologists of Australasia, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4; Professor Lyn Gilbert, Australasian Society for Infectious Diseases, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

79 Professor Nigel Stocks, Royal Australian College of General Practitioners, *Official Committee Hansard*, Sydney, 18 September 2015, p. 16; Professor Lyn Gilbert, Australasian Society for Infectious Diseases, *Official Committee Hansard*, Sydney, 18 September 2015, p. 4.

80 Ms Lynn Rees, *Official Committee Hansard*, Sydney, 18 September 2015, p. 27; Ms Alex Patson, *Official Committee Hansard*, Sydney, 18 September 2015, p. 30.

## Recommendation

### Recommendation 14

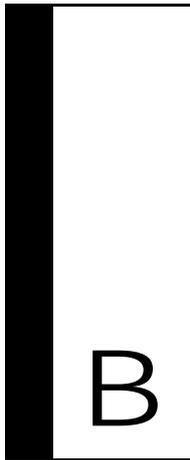
The Committee recommends that the Australian Government consider:

- developing a case definition for tick-borne and Lyme-like illnesses for addition to the national notifiable disease register;
- developing protocols of diagnosis and treatment for tick-borne and Lyme-like diseases; and
- continuing to prioritise the research areas identified by the Clinical Advisory Committee on Lyme Disease.

Steve Irons MP  
Chair

3 May 2016





## Appendix B – Submissions

- 1 Dr Jodi Graham
- 2 GPpartners
- 3 Professor Mark Nelson
- 4 Flinders Human Behaviour and Health Research Unit
- 5 Dr Lauren Ball
- 6 Centre for Primary Health Care and Equity, UNSW
- 7 Mrs Kim Crowe
- 8 Name Withheld
- 9 Metro North Hospital and Health Service
- 10 Mrs Yvonne Hughes
- 11 Ms Kitty Lobert
- 12 Latrobe Community Health Service
- 13 Mr Robert Little
- 14 Name Withheld
- 15 Multiple Sclerosis Network of Care Australia and Chronic Cerebro Spinal Venous Insufficiency Australia
- 16 Graduate School of Medicine, University of Wollongong
- 17 Rural Doctors Association of Australia (RDAA)

- 18 Sarah Jansen, APD
- 19 Haemochromatosis Australia
- 20 Royal Flying Doctor Service (RFDS)
- 21 Australian College of Nurse Practitioners
- 22 Professor Jeffrey Fuller
- 23 Lifestyle Medicine Institute
- 24 Exercise and Sports Science Australia
- 25 Health Insurance Restricted Membership Association of Australia (HIRMAA)
- 26 Australian Health Service Alliance
- 27 Health Network Northern Territory
- 28 Dr Johanna Lynch
- 29 Mr Ian Watts
- 30 ISIS Primary Care
- 31 The Royal Australian and New Zealand College of Psychiatrists
- 32 Pharmaceutical Society of Australia
- 33 Lymphoedema Action Alliance
- 34 Dr Susan Boucher
- 35 Australian Pain Society
- 36 Victorian Primary Care Partnerships
- 37 beyondblue
- 38 Dental Hygienists Association of Australia
- 39 Australian College of Optometry
- 40 Australian Healthcare and Hospitals Association
- 41 Professor Libby Roughead
- 42 Osteoporosis Australia

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- 43 Medibank Private
- 44 Prima Health Solutions Pty Ltd
- 45 Indigenous Eye Health, University of Melbourne
- 46 Australian Association of Social Workers
- 47 Victorian AIDS Council
- 48 Name Withheld
- 49 Australian Health Promotion Association
- 50 Ms Elizabeth Bartlett
- 51 Rare Voices Australia
- 52 Australian Pain Management Association
- 53 WentWest Limited
- 54 Western Victoria Primary Health Network
- 55 Australian Dental Association
- 56 Pharmacy Guild of Australia
- 57 Healthways Australia
- 58 The Royal Australian and New Zealand College of Ophthalmologists
- 59 Optometry Australia
- 60 Diabetes NSW
- 61 Confidential
- 62 University of Sydney, Discipline of Physiotherapy
- 63 Primary Care Collaborative Clinical Trials Group, Clinical Oncology Society of Australia and Cancer Council Australia
- 63.1 Primary Care Collaborative Clinical Trials Group, Clinical Oncology Society of Australia and Cancer Council Australia
- 63.2 Primary Care Collaborative Clinical Trials Group, Clinical Oncology Society of Australia and Cancer Council Australia
- 64 The Peninsula Model

- 65 Cancer Australia
- 66 Lung Foundation Australia
- 67 National Rural Health Alliance
- 68 Mr Tan Nguyen
- 69 Royal Society for the Blind
- 70 Confidential
- 71 Primary Health Care Limited
- 72 Carrington Health
- 73 CRANaplus
- 74 Confidential
- 75 Australian Unity
- 76 Australian College of Rural and Remote Medicine
- 77 Allied Health Professions Australia
- 78 Victorian Healthcare Association
- 79 SANE Australia
- 80 Rural Doctors Workforce Agency
- 81 The Royal Australasian College of Physicians
- 82 Arthritis and Osteoporosis Victoria
- 83 Associate Professor Lynette Mackenzie, University of Sydney
- 84 Confidential
- 85 Lyme Disease Association of Australia
- 86 Ms Margaret Fleuren
- 87 Dr Chris Bollen
- 88 cohealth
- 89 Vision 2020 Australia

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- 90 Ms Alanna Watson
- 91 Sydney Nursing School, University of Sydney
- 91.1 Sydney Nursing School, University of Sydney
- 92 Dr Paul Burgess
- 93 Australasian Society of Lifestyle Medicine
- 94 Country South Australia Public Health Network
- 95 Eastern Health – Yarra Valley Community Health
- 96 Painaustralia
- 97 Silver Chain Group
- 98 Alzheimer's Australia
- 98.1 Alzheimer's Australia
- 99 Midwifery and Maternity Provider Organisation Australia (MMPOA)
- 100 Western Health
- 101 Mrs Vicki Allan
- 102 Diabetes Australia
- 103 Ms Emma Bird
- 104 Ahmo Garden
- 105 Consumer Reference Group Blue Mountains GP Network
- 106 Australian College of Nursing, Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, Australian Primary Health Care Nurses Association, Maternal, Child and Family Health Nurses Australia, Australian College of Mental Health Nurses
- 106.1 Australian College of Nursing, Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, Australian Primary Health Care Nurses Association, Maternal, Child and Family Health Nurses Australia, Australian College of Mental Health Nurses
- 107 Australian Medical Association
- 108 Private Healthcare Australia

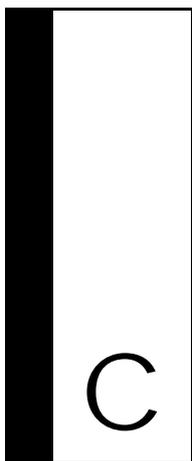
- 109 Australian Diabetes Educators Association
- 110 Australian Nursing and Midwifery Federation (ANMF)
- 111 Public Health Association of Australia
- 112 Australian Women's Health Network
- 113 National Stroke Foundation
- 113.1 National Stroke Foundation
- 114 Foundation for Alcohol Research and Education (FARE) and the Public Health Association of Australia (PHAA)
- 115 Services for Australian Rural & Remote Allied Health
- 116 Health Care Consumers' Association of the ACT Inc.
- 117 Victorian Health Promotion Foundation (VicHealth)
- 118 Speech Pathology Australia
- 119 Adelaide Primary Health Network
- 119.1 Adelaide Primary Health Network
- 120 Victorian Council of Social Service
- 121 National Vascular Disease Prevention Alliance
- 122 HCF
- 123 South Eastern Melbourne Primary Health Network
- 123.1 South Eastern Melbourne Primary Health Network
- 124 Australian Primary Healthcare Research Institute
- 125 Australasian Podiatry Council
- 126 Kidney Health Australia
- 127 Australian Institute of Health and Welfare
- 128 Name Withheld
- 129 National Home Doctor Service
- 130 Australian Psychological Society

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- 131 National Heart Foundation of Australia
  - 132 Palliative Care Australia
  - 133 Northern Territory Department of Health
  - 134 Confidential
  - 135 Royal Australian College of General Practitioners
  - 135.1 Royal Australian College of General Practitioners
  - 136 Rehabilitation Medicine Society of Australia and New Zealand
  - 137 Occupational Therapy Australia
  - 138 Australian Diabetes Society
  - 139 Health Issues Centre
  - 140 Australian Orthotic Prosthetic Association
  - 141 Arthritis Australia and Australian Rheumatology Association
  - 141.1 Arthritis Australia and Australian Rheumatology Association
  - 142 Primary Health Tasmania
  - 143 Department of Health (Commonwealth)
  - 143.1 Department of Health (Commonwealth)
  - 143.2 Department of Health (Commonwealth)
  - 144 Bupa
  - 145 Australian Physiotherapy Association
  - 146 Dr Thomas Wenkart
  - 147 Australia and New Zealand Society for the Developmental Origins of Health and Disease
  - 148 Dietitians Association of Australia
  - 149 Garvan Institute of Medical Research
  - 150 Melbourne Research Alliance to End Violence against Women and their Children

- 151 Department of General Practice, University of Melbourne
- 151.1 Department of General Practice, University of Melbourne
- 152 NSW Health
- 153 Aboriginal Medical Services Alliance of the Northern Territory
- 154 Southern Academic Primary Care Research Unit
- 155 Sydney North Primary Health Network
- 156 Ms Emily O'Sullivan
- 157 GMHBA Health Insurance Ltd
- 158 Karl McManus Foundation
- 159 Consumers Health Forum of Australia
- 160 Western Alliance Academic Health Science Centre
- 161 Dr Rosemary Panelli
- 162 Dr Richard Schloeffel
- 163 Mostyn Street Clinic
- 164 La Trobe University Rural Health School
- 164.1 La Trobe University Rural Health School
- 164.2 La Trobe University Rural Health School
- 165 National Herbalists Association of Australia
- 166 Sarcoidosis Lyme Australia
- 167 Queensland Government
- 168 Murrumbidgee Primary Health Network
- 169 The George Institute for Global Health
- 170 The Brain Foundation
- 171 Name Withheld
- 172 Royal Australian and New Zealand College of Radiology

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- 173 Department of Health and Human Services Victoria
- 174 Name Withheld
- 175 Dr Victoria McCartney
- 176 Ms Sharon King
- 177 Waminda - South Coast Women's Health and Welfare Aboriginal Corporation
- 178 Illawarra Health and Medical Research Institute, University of Wollongong
- 179 Improvement Foundation
- 180 Western Australian Primary Health Alliance
- 181 Centre of Research Excellence in Quality and Safety in Integrated Primary-Secondary Care, University of Queensland
- 182 Brisbane North Primary Health Network
- 183 Dragon Claw
- 184 Australian General Practice Network
- 185 Dr Lisa Akison
- 186 Mrs Joanne O'Donoghue
- 187 Bendigo Health
- 188 Grattan Institute
- 189 Stroke and Disability Information (Hunter) Inc
- 190 TROG Cancer Research
- 191 Confidential
- 192 Confidential
- 193 Hunter New England Local Health Network
- 194 Australasian Association of Academic Primary Care
- 195 Dr John Ward





## Appendix C – Exhibits

1. HCF
  - 1) Confidential
    - a) *Impact of a Chronic Disease Management Program on Hospital Admissions and Readmissions in an Australian Population with Heart Disease or Diabetes, 2013*
    - b) *Research Article: Long-term impact of a chronic disease management program on hospital utilization and cost in an Australian population with heart disease or diabetes, 2015*
    - c) *Telephone case management reduces both distress and psychiatric hospitalization, Australian and New Zealand Journal of Psychiatry 2009.*
2. Department of Health  
*Better Outcomes for People with Chronic and Complex Health Conditions through Primary Health Care: Primary Health Care Advisory Group Discussion Paper, August 2015*
3. Services for Australian Rural and Remote Allied Health  
*Investigating the Efficacy of Allied Health: Reducing Costs and Improving Outcomes in the Treatment of Diabetes, Osteoarthritis and Stroke, Virginia DeCourcy, Australian National Internships Program, Semester 2, 2014*
4. Ms Laurann Yen, Australian Primary Health Care Research Institute  
*Article: Tackling chronic illness with smart devices, The Economist Intelligence Unit, Jessica Twentyman, July 2015*
  - a) *Article: The impact of chronic illness on workforce participation and the need for assistance with household tasks and personal care by older Australians, Health and Social Care in the Community, February 2011*
  - b) *Article: Time spent on health related activity by older Australians with diabetes, Journal of Diabetes & Metabolic Disorders, 2013*

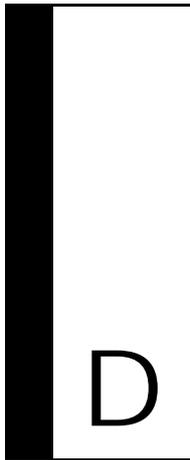
- c) Article: *Consultations with complementary and alternative medicine practitioners by older Australians: results from a national survey*, BMC Complementary and Alternative Medicine, 2013
- d) Article: *Health work by older people with chronic illness: how much time does it take?* Chronic illness, 2013
- 5 The Royal College of Pathologists of Australasia  
*Position Statement: Diagnostic Laboratory testing for Borreliosis ('Lyme Disease' or similar syndromes) in Australia and New Zealand, February 2014*
- 6 Lyme Disease Association of Australia  
*Lyme Disease Roundtable Brief, September 2015*
- 7 Australian Biologics Testing Service Pty Ltd  
*Package of Information on Testing for Borrelia Species*
- 8 Royal Australian College of General Practitioners  
*Vision for general practice and a sustainable healthcare system, September 2015.*  
a) *Vision for general practice and a sustainable healthcare system: summary document.*
- 9 Public Health Association of Australia  
*Modified Monash Model, Questions and Answers.*  
a) World Health Organization: *Draft comprehensive global monitoring framework and targets for the prevention and control of noncommunicable diseases, March 2013.*
- 10 The Australian Psychological Society Limited  
*Media Release: Medibank targets primary care involvement to help tackle chronic disease, 22 May 2015*  
a) *Evaluation Report of the Diabetes Care Project, written by McKinsey and Company, June 2015*  
b) *Preventative program aimed at modifying risk factors*  
c) *American Human Development Report: The Measure of America 2013–2014*
- 11 Medibank Private  
*The Care Suite of Integrated Health Care Programs*
- 12 Department of General Practice, The University of Sydney  
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- a) *Case for Action – Proposal to NHMRC, A Comprehensive type 2 diabetes prevention program, Research Translation Faculty Diabetes Mellitus Steering Group, September 2014*
- b) *Taking Control: Supporting People to Self-Manage Their Diabetes, All Party Parliamentary Group for Diabetes, UK, March 2015*
- 15 WentWest Limited  
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- 16 Brain Foundation  
*Brain Foundation, Funding brain research: Increasing Awareness, brochure*
- a) *Fact Sheet: Understanding Migraine*
- 17 Kidney Health Australia  
*Kidney Health for All: A report on policy options for improving Aboriginal and Torres Strait Islander Kidney Health*
- a) *Submission to the Senate Standing Committee on Community Affairs: Out-of-pocket costs in Australian healthcare*
- 18 HCF  
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- a) *Quality improvement report, Improving primary care in Australia through the Australian Primary Care Collaboratives Program: a quality improvement report, 12 July 2012*
- b) *The eCollaborative: using a quality improvement collaborative to implement the National eHealth Record System in Australian primary care practices, 12 June 2014*
- 21 University of Wollongong (Prof Andrew Bonney)  
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- 22 The Pharmacy Guild of Australia  
*A Healthy Future: An enhanced role for community pharmacy.*
- 23 Professor Linda Tapsell, Illawarra Health and Medical Research Institute  
*Australian National Preventive Health Strategy 2014. Obesity: Prevalence Trends in Australia, Evidence Brief.*
- 24 Australian Health Promotion Association  
*'How can the Australian Government save thousands of lives and billions of dollars, every year?'*, August 2013
- 25 Lung Foundation Australia  
*Asthma in Australia: with a focus on chronic obstructive pulmonary disease, 2011*
- a) *Graph taken from OECD Reviews of Health Care Quality, 2015*
- 26 Dr Jodi Graham  
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b) *Moore B, Miskovski K, Stupar M and Ng H, Reducing the Prevalence of Alzheimer's Disease: modifiable risk factors or social determinants of health?, Alzheimer's Australia NSW, April 2015.*
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- 29 Dr Tracy Brown  
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- 30 Confidential





## Appendix D – Hearings and Witnesses

### **Tuesday, 18 August 2015 – Canberra**

#### **Private Healthcare Australia**

Hon. Dr Michael Armitage, Chief Executive Officer

### **Friday, 21 August 2015 – Canberra**

#### **Department of Health**

Ms Janet Anderson, First Assistant Secretary, Health Services

Dr Lisa Studdert, First Assistant Secretary, Population Health and Sport  
Division

Ms Helen Catchatoor, A/g Assistant Secretary

#### **Australian Psychological Society**

Professor Mike Kyrios, President

Dr Louise Roufeil, Executive Manager, Professional Practice

#### **Alzheimer's Australia**

Professor Graeme Samuel AC, National President

Ms Carol Bennett, Chief Executive Officer

#### **Cancer Council Australia**

Professor Sanchia Aranda, Chief Executive Officer

Professor Geoffrey Mitchell, Advisor, Clinical, Clinical Oncology Society of  
Australia & Primary Care Collaborative Clinical Trials Group

Mr Paul Grogan, Director, Public Policy

**Public Health Association of Australia**

Adjunct Professor Michael Moore, Chief Executive Officer

Ms Danielle Dalla, Policy Adviser

**Rural Doctors Association of Australia**

Dr John Hall, Vice President

Ms Jennifer Johnson, Chief Executive Officer

**Services for Australian Rural and Remote Allied Health**

Mr Rod Wellington, Chief Executive Officer

Ms Cathy Maloney, NSW Network Co-ordinator

**Australian Primary Health Care Research Institute**

Associate Professor Terence Findlay, Head of Programs

Ms Laurann Yen, APCHRI Head ANU

**Friday, 18 September 2015 – Sydney**

**Dr Gary Lum, Specialist Medical Advisor, Medical and Scientific Advisory Unit, Office of Health Protection, Department of Health**

**Professor Peter Irwin, Associate Professor in Small Animal Medicine, Murdoch University**

**Ms Sharon Whiteman, President, Lyme Disease Association of Australia**

**Dr Mualla McManus, Director, Karl McManus Foundation**

**Professor Lyn Gilbert, Past President, Australasian Society of Infectious Diseases**

**Professor Nigel Stocks, Faculty Board Member, Royal Australian College of General Practitioners (via teleconference)**

**Dr Stephen Graves, Spokesman, Royal College of Pathologists Australasia**

**Dr Richard Schloeffel, General Practitioner**

**Ms Annie Kiefer, State Secretary, Country Women's Association of New South Wales**

**Ms Jennie Burke, Director, Australian Biologics**

**Australians Living with Lyme Disease**

Ms Elaine Kelly  
Ms Alex Patsan  
Ms Lynn Rees  
Ms Gabrielle Stevens  
Mr Christopher Walker  
Ms Michelle Wheeler

**Thursday, 1 October 2015 – Melbourne****Victorian Department of Health and Human Services**

Professor Robert Thomas, Chief Adviser Cancer, Principal Investigator  
Care Point  
Ms Josephine Beer, Relationship Manager, CarePoint Trial

**Kidney Health Australia**

Ms Anne Wilson, Managing Director and Chief Executive Officer  
Mr Luke Toy, General Manager, Public Affairs  
Professor Timothy Usherwood, Member of the Kidney Check Australia  
Taskforce

**Beyondblue**

Dr Stephen Carbone, Policy, Research and Evaluation Leader  
Ms Carolyn Nikoloski, Policy Advisor

**SANE Australia**

Mr Jack Heath, Chief Executive Officer  
Ms Rebecca Halpin, Director of Policy and Partnerships

**Royal Australian College of General Practitioners**

Professor Morton Rawlin

**Southern Academic Primary Care Research Unit**

Professor Grant Russell, Director

**Allied Health Professions Australia**

Ms Lin Oke, Executive Officer  
Mr Damian Mitsch, Director

Ms Glenys Wilkinson, Director

**Australian College of Nursing**

Ms Kathleen McLaughlin, Acting Chief Executive Officer

**Congress of Aboriginal and Torres Strait Islander Nurses and Midwives**

Ms Colleen Gibbs, Senior Policy and Research Officer

**Australian Primary Health Care Nurses Association**

Ms Karen Booth, President

**Maternal, Child and Family Health Nurses Australia**

Dr Julian Grant, President

**Australian College of Mental Health Nurses**

Ms Kim Ryan, Chief Executive Officer

**University of Melbourne Department of General Practice**

Professor Jane Gunn, Head of Department

Associate Professor John Furler, Research Fellow

**Health Issues Centre**

Mr Danny Vadasz - Chief Executive Officer

Ms Sophy Athan, Chair, Board of Governance

**South East Melbourne Primary Health Network**

Ms Anne Lyon, General Manager - Primary Health Services, Acting Chief Executive Officer

**Western Victoria Primary Health Network**

Mr Jason Trethowan, Chief Executive Officer

**Murray Primary Health Network**

Mr Matt Jones, Chief Executive Officer

**Medibank Private**

Mr James Connors, Head of Government and Regulatory Affairs

Ms Lucinda Bilney, Senior Strategy Manager

**BUPA**

Ms Natalie Dubrowin, Head of Health Programs & Quality

Dr Robert Grenfell, National Medical Director

**Friday, 23 October 2015 – Sydney****Arthritis Australia**

Ms Ainslie Cahill, Chief Executive Officer

Ms Franca Marine, Policy and Government Relations Manager

**Australian Rheumatology Association**

Mr Chris Drummer, Chief Executive Officer

**Osteoporosis Australia**

Dr Greg Lyubomirsky, Chief Executive Officer

Ms Melita Daru, Marketing Manager

**Brain Foundation**

Mr Gerald Edmunds, Secretary-General

**National Stroke Foundation**

Dr Erin Lalor, Chief Executive Officer

Ms Rebecca Smith, Director, Policy and Advocacy

**Diabetes Australia**

Professor Greg Johnson, Chief Executive Officer

Ms Taryn Black, National Policy and Program Director

**Australian Diabetes Society**

Professor Sof Andrikopoulos, President

Professor Sophia Zoungas, President Elect

**HCF**

Dr Shaun Larkin, Managing Director

**Australian Medical Association**

Dr Brian Morton, Chair – AMA Council of General Practice

Mr Warwick Hough, Policy Director – General Practice, Legal Services and Workplace Policy

**Garvan Institute**

Professor John Mattick, Executive Director

**Centre for Primary Health Care and Equity**

Professor Mark Harris, Executive Director

**Sydney Nursing School**

Professor Donna Waters, Dean

Associate Professor Heather McKenzie, Associate Dean (Academic)

Dr Lis Neubeck, Senior Lecturer

**Central and Eastern Sydney Primary Health Network**

Dr Michael Moore, Chief Executive Officer

**Hunter New England Central Coast Primary Health Network**

Mr Graeme Kershaw, Acting Chief Executive Officer

**Murrumbidgee Primary Health Network**

Mrs Nancye Piercy, Chief Executive Officer

**Sydney North Health Network**

Dr Magdalen Campbell, Chair

**WentWest Limited**

Adjunct/ Associate Professor Walter Kmet, Chief Executive Officer

Dr Walid Jammal, GP Leader

**Wednesday, 18 November 2015 – Bendigo****Bendigo Community Health Service**

Ms Kim Sykes, Chief Executive Officer

Mr Callum Wright, Executive Director

**La Trobe Rural Health School**

Professor Amanda Kenny, Professor of Rural and Regional Nursing

Professor Teresa Iacono, Professor of Rural and Regional Allied Health

**Western Alliance**

Professor David Ashbridge, Chair

Dr Renee Otmar, Business and Communications Manager

**Mostyn Street Clinic**

Dr Louisa Hope, General Medical Practitioner

**GMHBA**

Ms Megan Clark, Benefits Manager

**Bendigo and District Aboriginal Health Cooperative**

Mr Shane McLennan, General Manager of Health and Wellbeing

Ms Amy Clark, Clinical Practice Program Manager

**Friday, 12 February 2016 – Bomaderry****University of Wollongong Graduate School of Medicine**

Professor Andrew Bonney

**South Coast Medical Service Aboriginal Corporation (South Coast AMS)**

Mr Craig Ardler, Chief Executive Officer

Ms Jo Naughton, Senior Manager Health Services

**South Coast Women's Health and Welfare Aboriginal Corporation (Waminda)**

Ms Faye Worner, Chief Executive Officer

Ms Hayley Longbottom, Senior Aboriginal Primary Health Worker

**Illawarra Health and Medical Research Institute**

Senior Professor Linda Tapsell, Lead Investigator for Health Track Program

**Ms Pieta Newport, private citizen**

**Mrs Margaret Smith, private citizen**

**Dr Victoria McCartney, general practitioner**

## **Thursday, 18 February 2016 – Brisbane**

### **Darling Downs & West Moreton Primary Health Network**

Mr Ken Murphy, Chief Executive Officer

Dr Roland Owen, Board Director

### **Brisbane North Primary Health Network**

Dr Richard Kidd, Clinical Adviser

### **Brisbane South Primary Health Network**

Dr Peter Adkins, Senior Clerical Adviser

### **Central Queensland, Wide Bay, Sunshine Coast Primary Health Network**

Dr Peter Dobson, Chair of the Board

### **Asthma Australia and Lung Foundation Australia**

Mr Mark Brooke, Chief Executive Officer, Asthma Australia

Mrs Heather Allan, Chief Executive Officer, Lung Foundation Australia

Professor Ian Yang, Chair, COPD Guidelines Committee

### **Australian College of Rural and Remote Medicine**

Ms Vicki Sheedy, Director of Strategic Development

### **Centre of Research Excellence**

Professor Claire Jackson, Director

Professor Geoffrey Mitchell, Professor of General Practice and Palliative Care

## **Friday, 19 February 2016 – Tumbi Umbi**

### **The Glen – Central Coast Alcohol and Drug Rehabilitation Centre**

Mr Joe Coyte, Chief Executive Officer

### **Waratah Medical Services**

Dr Wolf du Plessis, General Practitioner

Ms Sue Maher, Practice Manager

### **Hunter New England and Central Coast PHN**

Mr Richard Nankervis, Chief Executive Officer

**Mr Graham McGuiness, Board Member, various local health organisations**

## **Tuesday, 23 February 2016 – Canberra**

### **Pharmacy Guild of Australia**

Mr David Quilty, Executive Director

Mr Anthony Tassone, President (Victorian Branch), National Councillor

## **Friday, 4 March 2016 – Adelaide**

### **Royal Australian College of General Practitioners**

Dr Robert Menz, Corlis Fellow for South Australia

### **Australian General Practice Network**

Dr Rodney Pearce AM, Chairperson

### **Adelaide Primary Health Network**

Mr Malcolm Ellis, Development & Commissioning Executive Manager

### **Country South Australia Primary Health Network**

Mr Kim Hosking, CEO

Dr Alison Edwards, Chair

### **Improvement Foundation**

Mr Colin Frick, Chief Executive Officer

Dr Dale Ford, Principal Clinical Adviser and Chair

### **Australian Health Promotion Association**

Ms Michelle Herriot, Vice President

Ms Melanie Smith, Director

### **Flinders University, Human Behaviour & Health Research Unit**

Professor Sharon Lawn

### **Royal Flying Doctor Service**

Mr Martin Laverty, Chief Executive Officer

## **Friday, 11 March 2016 – Perth**

**Dr Jodi Graham, Consultant anaesthetist and Medical administrator**

### **HBF Health Limited**

Mr Rob Bransby, Managing Director

### **Western Australia Primary Health Alliance**

Adjunct Associate Professor Learne Durrington, Chief Executive Officer

Ms Chris Kane, General Manager, Strategy and Policy

### **University of Western Australia School of Primary, Aboriginal and Rural Health Care**

Professor Alistair Vickery

### **360 Health + Community**

Mr Paul Hersey, Chief Executive Officer

## **Thursday, 31 March 2016 – Newcastle**

### **Hunter New England Local Health District**

Dr Penny Webster

### **Lake Macquarie Private Hospital**

Mr Ian Maytom, Chief Executive Officer

Mr Kahunni Sneddon, Social Worker

### **Alzheimer's Australia NSW**

Mr Brendan Moore, General Manager for Policy, Research and Information

### **University of Newcastle School of Medicine and Public Health**

Professor Dimity Pond, Professor of General Practice

### **Stroke and Disability Information Hunter**

Mrs Judy Webb-Ryall, Coordinator

### **Dr Tracy Brown**

**TROG Cancer Research**

Mrs Joan Torony, Chief Executive Officer and Research Manager

Dr Fiona Hegi Johnson, Radiation Oncologist

Ms Melissa Crain, Quality Assurance Manager

**NIB Health Funds**

Dr Justin Vaughan, Group Executive Benefits and Provider Relations