



PARLIAMENT OF AUSTRALIA

Sick and tired: Casting a long shadow

Inquiry into Long COVID and Repeated COVID Infections

House of Representatives

Standing Committee on Health, Aged Care and Sport

April 2023

CANBERRA

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Chair's Foreword

Australia hasn't faced a pandemic like this since the Spanish influenza at the end of the First World War. Predictions of an event like the COVID-19 pandemic were being made for many years, yet when it began three years ago many experts were taken by surprise.

Luckily, we have a health system that is resilient and well-resourced, which for the most part was able to deal with important areas of the pandemic and governments across all three levels were able to work together to achieve best outcomes.

Further, with remarkable tenacity and insight, scientists and researchers were able to develop vaccines to reduce the spread and impact of COVID-19, which has helped lead to a global recovery from this debilitating virus. Pharmaceutical companies have worked tirelessly to get access to vaccines as quickly as possible too.

We have health experts across the public spectrum from virologists, infectious disease experts, intensivists, general practitioners (GPs), nursing staff and allied health staff who worked tirelessly to get the best health outcomes for patients.

Special mention needs to be made of our emergency department physicians, nurses and other staff because of their frontline exposure, particularly in some areas to large numbers of patients which stretched resources considerably.

All members of the health system, from GPs to pharmacists, nurses, allied health staff and pathology workers did their duty and helped get through the most acute phases of the pandemic.

Often forgotten in this acute phase was the role of cleaners, retail staff, logistics workers and teachers who worked tirelessly to keep our society moving. As a result, it was often workers within these industries who were at higher risk of being infected by the virus and who in turn, are managing its effects post-infection.

For most of the pandemic, many of us have been in the learning-as-we-go mode and it is apparent that as time has progressed, there is increasing acknowledgement of long-term effects of COVID-19, in terms of long-term complications (such as cardiac, haematological and neurological effects) and it does appear that many people suffer from long-term inflammatory consequences and a new term 'long COVID' arose, which first appeared on social media in May 2020.

Hence, the need for an inquiry looking into long COVID and how Australia manages this going forward. Following discussions with the Minister for Health, the Hon Mark Butler MP, the Standing Committee on Health, Aged Care and Sport announced that an inquiry into

long COVID had been established, titled long COVID and repeated COVID infections, and that from the 5 September 2022, submissions would begin to be received.

The primary focus of this inquiry was our national management of long COVID, with further attention being placed on additional effects of this condition including the economic and mental health impacts, potential treatment and management options, and repeated COVID infections.

It is important to note that during the inquiry, we were hampered by a lack of specific data and the lack of a concise definition of what constitutes long COVID. At the present time, we accept the World Health Organization (WHO) definition as the most useful for clinical practice; however, this may need to be modified as further information becomes available.

It is clear that long COVID is a significant problem and estimates vary, indicating that between two per cent to 20 per cent of those infected with COVID-19 may develop long COVID. Even if it is the lower figure of two per cent, this is still many people requiring help and support.

At this stage it does seem that specific treatments require more evidence of benefit before being specifically recommended, but this will become clearer over time. Certainly, most of the care needs to be provided by the primary care system, such as by GPs, nurses, and allied health professionals.

We will need to help schools, universities, and workplaces adapt to allow the gradual return of people with long COVID. We will also need to train health professionals in how to diagnose and manage long COVID patients.

Mental health issues are clearly an area of concern too, particularly as many suffering from long COVID are aged between 20 and 50 years old and have many concerns, such as family and/or work responsibilities, which place additional stresses on them.

It is important that mental health support is affordable and accessible to individuals, and it is also important that access to support is provided to outer metropolitan, rural and regional areas in an equitable manner.

Further, digital health and telehealth services need to be expanded to cater for individuals who cannot obtain in person consultation or treatments due to their location or mobility issues.

It is also of concern that women seem more likely to be affected by long COVID than men.

Our primary health providers need to be educated on how best to support and diagnose long COVID. The role of specific long COVID clinics as a resource for primary health providers is very important to allow adequate services for major complications, and these clinics may help in providing treatment plans.

These long COVID clinics should also have the ability to refer to specialists and it is also important to fund teaching hospitals to provide these services, as well as encourage

outreach services in outer metropolitan, rural and regional areas to provide these services too.

Clearly, immunisation and reduction in the spread of the virus has an important role in prevention of long COVID. It is important the messaging around this is improved and properly provided to the wider population.

It is important that data about immunisation rates, complications and the rare instances of post-immunisation deaths be collated and investigated, as well as any underlying risk factors.

During our inquiry, many questions were raised about issues relating to the pandemic that were not strictly within our terms of reference.

There is a distinct difficulty in obtaining verifiable data about many of these issues and it is the Committee's view that the development of a national Centre for Disease Control (CDC) within the Department of Health and Aged Care would be the most appropriate mechanism for data collection and linkage with the states and territories.

Likewise, there is much that we do not understand about the virus, such as the fact that it is likely changing from being an acute pandemic virus to now an endemic form.

Research will be very important in helping us understand the best ways and means of managing its ongoing effects, particularly including long COVID. Research should include individuals from Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities and other high-risk groups including those who are immunosuppressed.

A research program should be established to nationally coordinate and fund research into long COVID and COVID-19 generally. This could be led by the Department of Health and Aged Care — ideally the CDC — and should be the for the longer term.

Clearly, there has been a number of issues raised about reducing transmission of COVID-19, such as improving air quality to reduce aerosol spread and this also has reference to broader health outcomes and requires investigation.

We have received many submissions from individuals suffering from Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Whilst there may be some crossover with long COVID, we believe that long COVID is a separate issue to this.

Nevertheless, the ME/CFS community should be supported and researched developed to assist them and provide support.

The topic of the national pandemic response and handling came up often during our inquiry, with the Committee being asked many questions about the Australian Government response to the pandemic and what the future holds for our national plan going forward.

The Committee believes that a wide-ranging summit into the pandemic, as well as the government response, should be held. The summit should also examine what future management of the present pandemic should be. It is imperative that future plans be undertaken at some stage to prepare, prevent and manage future pandemics.

Regarding submissions, I would like to thank all those who made submissions and/or appeared in person, as well as those who have met and discussed with Committee members, for their contribution to this inquiry.

Almost 600 submissions were made, plus many conversations and many questions were asked of the Committee. It is important that our nation, through government, research institutions and healthcare professionals, continue to search for answer and be as transparent as possible in the interest of better healthcare for all.

I would like to thank the Deputy Chair, Melissa McIntosh MP, and the Committee members: Ms Peta Murphy MP, Ms Jenny Ware MP, Ms Anne Stanley MP, Dr Gordon Reid MP, Dr Monique Ryan MP, the Hon Mark Coulton MP and Dr Michelle Ananda-Rajah MP, for their time, dedication, and interest in this important national issue.

There has been a considerable amount of work done to make as much information available to the Committee and this has required a huge effort by the Secretariat.

I would like to thank the Secretariat, particularly Clare Anderson, Kate Portus, Kate Morris, Cassie Davis, and Cathy Rouland. Without their enormous professionalism, diligence, experience and unfailing goodwill and good humour, this inquiry would not have been achievable.

Further, I would like to thank the Minister for Health and Aged Care, the Hon Mark Butler MP, for his support, interest, and guidance throughout this inquiry, particularly his contribution and support for the Terms of Reference.

Lastly, I take full responsibility for any omissions and mistakes, and I do hope that this inquiry will be a good, informative framework for the future.

Dr Mike Freeland MP
Chair

Contents

Chair's Foreword	iii
Terms of reference	xiii
Members	xv
Abbreviations	xvii
List of recommendations	xxi

Report

Introduction	1
About the inquiry	3
Objectives and scope	3
Conduct of the inquiry	4
Acknowledgements	5
Report structure	5
What is long COVID?	7
Overview	7
Current definitions of long COVID	8
World Health Organization definition	9
United Kingdom National Institute for Health and Care Excellence definition	9
What should Australia's definition include?	11
Applicability to clinical and research purposes	11
Consultation on the definition	13
Understanding long COVID	14
Prevalence	14
Clinical features and symptoms	16
Risk factors	20
Groups particularly vulnerable to severe long COVID	21
Prognosis and recovery	22
Committee comment	24

Research and data	27
Overview	27
Current and past research	27
Research quality	28
Regulatory issues	29
Funding.....	30
Suggestions for future research.....	34
Preventative strategies	35
Diagnosis and causes of long COVID symptoms.....	36
Links to other conditions.....	37
Treatments	39
Poorly studied groups.....	41
Children and adolescents	41
Older Australians	42
People with disability	43
Social effects research	43
Impact on key workers	44
Economic impacts.....	45
Mental health.....	45
Data	46
Existing data sets, databases and modelling	47
Issues with current data.....	48
Limited data for groups potentially particularly vulnerable to long COVID.....	49
Suggestions regarding data collection and analysis	51
Classification and coding systems.....	54
Medicare Benefits Schedule and long COVID data	56
Committee comment	57
Research	57
Data.....	58
Lived experiences of long COVID	61
Overview.....	61
Living with long COVID	62

Seeking medical help and specialised care	65
Adverse reactions to COVID-19 vaccines	70
Impacts on employment and income	71
Income support.....	74
Impacts on mental health and social and daily activities	75
Mental health impacts	75
Quality of life and wellbeing – impact on activities of daily living.....	79
Parenting with long COVID.....	81
Changes to roles and responsibilities	82
School and education	84
Committee comment.....	85
Prevention.....	87
Overview.....	87
COVID-19 vaccines	89
Improving public communication to encourage uptake of COVID-19 vaccines.....	93
Adverse reactions to COVID-19 vaccines	95
Antiviral treatments for COVID-19	95
Issues accessing antiviral treatments.....	99
Indoor air quality and ventilation	101
Indoor air quality and ventilation in high-risk settings.....	104
The need for Indoor Air Quality Standards.....	106
International examples of best practice in air quality.....	109
Committee comment.....	110
COVID-19 vaccines.....	110
Antiviral treatments for COVID-19.....	111
Indoor air quality and ventilation.....	112
Responding to long COVID	115
Overview.....	115
Diagnosis	115
Lack of simple and accepted diagnostic procedure	116
Healthcare practitioners’ capability and attitudes	117
Opportunities to improve diagnosis	119

Treatment and management of long COVID	121
Treatments for long COVID	121
COVID-19 antivirals as long COVID treatment.....	122
Current official advice	123
Managing long COVID.....	124
Emerging best practice management	128
Multidisciplinary care	128
Early intervention	130
Self-management.....	131
Settings and models of care	133
Current settings for care	134
Primary care	134
Benefits of primary community care response	135
Drawbacks of primary community care response	137
Long COVID clinics.....	139
Benefits of long COVID clinics	143
Drawbacks of long COVID clinics	144
Models of care	147
Current models of care	147
Strengthening models of care.....	149
Most long COVID managed via primary care	149
Pathways to escalate severe and/or complex cases	151
Tiered model of care.....	153
Alternative proposals	155
Australian Government funding for long COVID care	156
Public hospital funding.....	156
Medicare.....	158
New Medicare item/s for long COVID	159
Chronic disease General Practitioner Management Plans	160
Long COVID eligibility	160
Reducing the 6-month requirement	161
Increasing allied health sessions	163
Team Care Arrangements.....	164

Health workforce: awareness, education and training	165
Importance of long COVID awareness, knowledge and expertise	165
Current communication, education and training	167
Proposals to improve awareness, knowledge and expertise	169
Committee comment.....	172
Recommendations	175

Appendixes

Addendum - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)	179
Appendix A. Submissions	185
Appendix B. Hearings and witnesses	209

List of Tables

Table 5.1	Vaccine coverage by jurisdiction - people aged 16 and over	91
Table 5.2	Vaccine coverage by jurisdiction - people aged 5 to 15	92

List of Figures

Figure 2.1	Long COVID symptom clusters and their overlap	19
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List of Textboxes

Box 4.1	What do people with long COVID tend to experience?	62
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Terms of reference

The House of Representatives Standing Committee on Health, Aged Care and Sport will inquire into and report on:

- 1 The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;
- 2 The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections;
- 3 Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia;
- 4 The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background;
- 5 The impact of long COVID and/or repeated COVID infections on Australia's overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population; and
- 6 Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.



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This committee is supported by staff of the Department of the House of Representatives.



Abbreviations

ABS	Australian Bureau of Statistics
AC	Companion of the Order of Australia
ACHI	Australian Classification of Health Interventions
ACS	Australian Coding Standards
ADLs	Activities of daily living
AIHW	Australian Institute of Health and Welfare
AM	Order of Australia Medal
ANU	Australian National University
AO	Officer of the Order of Australia
AQG	Air Quality Guidelines
ATAGI	Australian Technical Advisory Group on Immunisation
CBT	Cognitive Behaviour Therapy
CEO	Chief Executive Officer
CME	continuing medical education
CO ₂	carbon dioxide
CPD	Continuing Professional Development
DAFF	Department of Agriculture, Fisheries and Forestry
DSP	Disability Support Pension
FHRI	Future Health Research and Innovation Fund
GP	general practitioner
GPMP	general practitioner management plan
GET	Graded Exercise Therapy

HEPA	high efficiency particle air/absorbing filter
HIV/AIDS	Human immunodeficiency virus infection and acquired immune deficiency syndrome
HRQoL	Health-Related Quality of Life
ICD	International Classification of Diseases
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
ICU	Intensive Care Unit
LC	long COVID
MADIP	Multiple Analysis Data Integration Project
MBS	Medicare Benefits Schedule
MDT	multidisciplinary team
ME/CFS	Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
MRI	Magnetic Resonance Imaging
MRFF	Medical Research Future Fund
NACCHO	National Aboriginal Community Controlled Health Organisation
NCET	National Clinical Evidence Taskforce
NCNED	National Centre for Neuroimmunology and Emerging Diseases
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
NHRA	National Health Reform Agreement
NIHR	National Institute for Health and Care Research
NICE	National Institute for Health and Care Excellence
NNDSS	National Notifiable Diseases Surveillance System
PBAC	Pharmaceutical Benefits Advisory Committee

PBS	Pharmaceutical Benefits Scheme
PCC	Post-COVID conditions
PCR	polymerase chain reaction
PHAA	Public Health Association of Australia
PhD	Doctor of Philosophy
PIFS	post-infective fatigue syndrome
POTS	postural orthostatic tachycardia syndrome
PSM	Public Service Medal
PVF	post viral fatigue
RACP	Royal Australasian College of Physicians
RACGP	Royal Australian College of General Practitioners
RAT	rapid antigen test
RMH	Royal Melbourne Hospital
SARS-CoV-2	severe acute respiratory syndrome coronavirus 2
TCA	Team Care Arrangement
TGA	Therapeutic Goods Administration
UK	United Kingdom
UNSW	University of New South Wales
USA	United States of America
VPACS	Victorian Post-Acute COVID-19 sequelae
WHCOVRE	Western Health COVID Recovery Collaboration
WHO	World Health Organization

List of recommendations

Recommendation 1

- 7.1** The Committee recommends that the Australian Government establishes and funds a single COVID-19 database to be administered by the soon-to-be developed Centre for Disease Control to capture data on:
- COVID-19 infections, complications, hospitalisations, and deaths as well as recurrent COVID infections
 - This should incorporate COVID-19 infections in high-risk populations including: hospital-acquired infections (distinguishing this from community acquisition if possible), infections in aged care and other institutions, and infections in Aboriginal and Torres Strait Islander peoples and the immunosuppressed
 - This should also include the collection of data regarding select comorbid conditions and ancestry to identify infections in Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities and the immunosuppressed
 - Long COVID diagnoses including post COVID complications
 - COVID-19 vaccination rates, vaccination side effects and post vaccination deaths
- 7.2** The Committee additionally recommends that the Australian Government explore the use of innovative tools (e.g. artificial intelligence and self-managed care platforms) and data linkage within and between states and territories, to collect this data.

Recommendation 2

- 7.3** The Committee recommends that at the present time the World Health Organization definition of long COVID be used clinically, but that the Australian Government Department of Health and Aged Care work with the states and territories to review this definition as more research and information becomes available.
- 7.4** The Committee additionally recommends developing evidence-based living guidelines for diagnosis and treatment incorporating tiered care including referral pathways, co-designed with patients with lived experience.

Recommendation 3

- 7.5** The Committee recommends that the Australian Government establish a nationally coordinated research program, led by the Department of Health and Aged Care (preferably the Centre for Disease Control), to coordinate and fund COVID-19 and long COVID research.
- 7.6** This funding should be longer term and be nationally coordinated. The funding should aim to better integrate research by fostering greater collaboration rather than fragmentation.
- 7.7** The Committee also recommends that this research have adequate representation from Aboriginal and Torres Strait Islander peoples and the culturally and linguistically diverse population and be adequately funded to achieve these aims. Other vulnerable groups including the elderly, children, people with disability and the immunosuppressed should be represented.
- 7.8** Research programs should span basic science, clinical trials, models of care, health promotion and implementation science.

Recommendation 4

- 7.9** The Committee recommends that the Department of Health and Aged Care updates, focusses, and improves its COVID-19 vaccination communication strategy including by:
- Emphasising the benefit of COVID-19 vaccines in both reducing transmission and illness severity for acute COVID-19 infections and reducing the risk of developing long COVID
 - Encouraging greater COVID-19 vaccination across the Australian population especially among children, young people and people of working age
 - Encouraging immunisation in high-risk groups in particular as the virus becomes endemic
 - Working with the states and territories to develop this health promotion program.

Recommendation 5

- 7.10** The Committee recommends that the Pharmaceutical Benefits Advisory Committee regularly review the benefits of antiviral treatments for COVID-19 in accordance with emerging research with a view to expanding the list of groups eligible to access these treatments through the Pharmaceutical Benefits Scheme (PBS).

- 7.11** The Committee also recommends that antiviral treatments for COVID-19 be approached as a pharmacist-initiated medication to participants eligible under the PBS.
- 7.12** The Committee additionally recommends that the Australian Government review its framework for access to antiviral treatments for COVID-19 to include non-mortality and non-hospitalisation outcomes such as productivity gains, time to illness resolution, return to work and number of health encounters.

Recommendation 6

- 7.13** The aim of the Committee is to ensure people get the support they need, most of which will occur via the primary care network. Accordingly, the Committee makes the following recommendations regarding management:
- Support and education should be provided to general practitioners (GPs) as well as other primary healthcare providers to diagnose long COVID and to help manage those suffering from it. Education for GPs should be coordinated and eligible for Continuing Professional Development (CPD). The Medicare Benefits Schedule (MBS) chronic disease management item number should be reviewed
 - Clinical care should be linked to nationally coordinated research and data collection
 - Funding be provided in partnership with state health departments for selected public hospitals to develop multidisciplinary long COVID clinics linked to nationally consistent referral guidelines for screening patients with challenging long COVID complications
 - Mental health support for those with long COVID must be provided in an affordable, timely and equitable manner, and regular review of mental health issues should be part of GP management noting that the extent of related mental health impacts is still unknown
 - Telehealth and digital health resources be leveraged to make self-management and access to primary care easier
 - Funding be provided so that outreach long COVID clinics can be developed for rural and regional areas, accessible either face to face or via telehealth, as a GP resource.

Recommendation 7

- 7.14** The Committee recommends the Australian Government establish and fund a multidisciplinary advisory body including ventilation experts, architects, aerosol scientists, industry, building code regulators and public health experts to:
- Oversee an assessment of the impact of poor indoor air quality and ventilation on the economy with particular consideration given to high-risk

settings such as hospitals, aged care facilities, childcare and educational settings

- Lead the development of national indoor air quality standards for use in Australia.

While the terms of reference of this inquiry do not cover the content of Recommendations 8 and 9, the Committee received important evidence on these topics throughout its inquiry and makes the following recommendations:

Recommendation 8

- 7.15 The Committee recommends funding be made available for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) research and patient support and that this funding should be allocated in consultation with peak bodies for ME/CFS and with note of the recommendations of the ME/CFS Advisory Committee's 2019 report to the National Health and Medical Research Council.**

Recommendation 9

- 7.16 The Committee recommends, given the multiple questions that have arisen during our Inquiry, that the Australian Government consider a comprehensive summit into the COVID-19 pandemic and Australia's past and current response, including by governments at all levels, with particular consideration to the role of the future Centre for Disease Control.**



1. Introduction

- 1.1 Long COVID and repeated COVID infections are challenges that will confront Australia for the foreseeable future. While only a small proportion of people infected with COVID-19 go on to develop long COVID, this equates to possibly hundreds of thousands of Australians experiencing a medical condition that is poorly understood.
- 1.2 Symptoms of long COVID vary in number and severity. In some cases, long COVID can profoundly impact many aspects of a person's life. Seeking support from health providers for symptoms of long COVID can be challenging as the condition is poorly understood and recognised, and currently, general practitioners (GPs) struggle to know how to diagnose and treat patients with long COVID.
- 1.3 Long COVID can also impact a person's employment and income. People recovering from long COVID may need to work reduced hours or take extended periods away from work to recover, resulting in loss of income. Living with long COVID and its uncertainty can also take a toll on mental health as some people are no longer able to participate in social activities or daily living to the same extent they were before they became unwell.
- 1.4 Like all countries, Australia is still learning about long COVID, including its risk factors and prognosis. The lack of a consistent definition of long COVID at both the international level and nationally is an overarching issue challenging medical research and the Australian healthcare system's capacity to recognise and support people with long COVID.
- 1.5 While research into long COVID is underway in Australia and internationally, significant knowledge gaps remain. Greater funding and improved data are required to facilitate research to better understand various aspects of long COVID: its causes, preventative strategies, how to accurately diagnosis it, potential links to other medical conditions, and treatments.
- 1.6 Evidence received throughout the inquiry highlighted that currently, the only way to certainly prevent long COVID is to avoid any COVID-19 infection. To this end, the Committee turned its attention to how long COVID can be prevented through COVID-19 vaccines, antiviral treatments for COVID-19, and reducing transmission by improving indoor air quality and ventilation.
- 1.7 The inquiry identified that the lack of a standardised procedure for diagnosing long COVID presents a challenge for health practitioners and individuals with long COVID alike. Possible treatments to assist people with long COVID with their recovery are also still unknown, although research is ongoing. In the absence of any specific evidence-based treatments, care is supportive, currently involving managing long COVID symptoms.

- 1.8 The Committee heard about the current settings through which long COVID patients are primarily seeking care: predominantly primary care (GPs and allied health) and hospital-based multidisciplinary long COVID clinics. The Committee considered how patients should receive support for long COVID, Australian Government funding including via Medicare, and education and training for the health workforce.
- 1.9 The Australian Government identified long COVID as one of the three key areas of focus for Australia's COVID-19 response, alongside COVID-19 vaccines and treatments, as part of the *National COVID-19 Health Management Plan for 2023*.¹ This plan emphasised the need to investigate the longer-term effects of the COVID-19 pandemic in Australia.
- 1.10 The *National COVID-19 Health Management Plan for 2023* stated the Australian Government's commitment to develop a long COVID strategy to ensure the Australian health system can best support long COVID patients. In evidence provided to the Committee, Professor Paul Kelly, the Australian Government's Chief Medical Officer, confirmed that this strategy will be finalised after the Committee presents this report.²
- 1.11 While not a focus of the inquiry, the Committee received evidence about adverse reactions to COVID-19 vaccines and evidence regarding Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), which some witnesses and submitters reported is similar to long COVID. The Committee acknowledges that these are legitimate issues that warrant attention. Adverse vaccine reactions to COVID-19 vaccines have been discussed throughout this report where relevant to the broader focus of this inquiry: long COVID and repeated infections. ME/CFS is discussed in an Addendum to this report.
- 1.12 The Department of Health and Aged Care defines COVID-19 as a disease caused by the coronavirus, SARS-CoV-2. Coronaviruses are a large family of viruses that cause respiratory infections.³ This inquiry is focused on long COVID, which is generally understood as ongoing symptoms for three months or longer following an acute COVID-19 infection. Definitions for long COVID are discussed in Chapter 2.
- 1.13 Throughout the inquiry, witnesses and submitters referred to long COVID using different terminology including post-COVID conditions, chronic COVID, post-acute COVID-19, post-acute sequelae of SARS-CoV-2, and 'long-haulers' to refer to people with long COVID. Similarly, when referring to the COVID-19 virus generally, people and organisations used COVID-19, COVID, or SARS-CoV-2 interchangeably.

¹ Department of Health and Aged Care, *National COVID-19 Health Management Plan for 2023*, www.health.gov.au/resources/publications/national-covid-19-health-management-plan-for-2023, viewed 29 March 2023.

² Professor Paul Kelly, Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 8.

³ Department of Health and Aged Care, *COVID-19 disease and symptoms*, www.health.gov.au/health-alerts/covid-19/symptoms, viewed 12 April 2023.

- 1.14 For consistency, this report predominantly uses the terms ‘long COVID’ and ‘COVID-19’. However, where quotes include alternate terminology, this has been retained for accuracy.

About the inquiry

Objectives and scope

- 1.15 On 1 September 2022, the House of Representatives Standing Committee on Health, Aged Care and Sport adopted an inquiry into *long COVID and repeated COVID infections* referred by the Minister for Health and Aged Care, the Hon Mark Butler MP.
- 1.16 The Committee primarily focused on Australia’s management of long COVID. Although repeated COVID infections were a secondary focus of this inquiry’s terms of reference, as the inquiry progressed most of the evidence received related to long COVID. Consequently, the Committee focussed on how repeated infections relate to long COVID. Based on the evidence currently available, it appears that repeated COVID-19 infections may increase a person’s chance of developing long COVID.
- 1.17 Other areas of focus for the inquiry included:
- The patient experience in Australia of long COVID and/or repeated COVID-19 infections, particularly diagnosis and treatment
 - The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID-19 infections
 - Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID-19 infections in Australia
 - The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID-19 infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background
 - The impact of long COVID and/or repeated COVID-19 infections on Australia’s overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population
 - Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID-19 infections, both in Australia and internationally.

Conduct of the inquiry

- 1.18 On 5 September 2022 the Committee issued a media release announcing the inquiry and calling for submissions. The Committee invited submissions from a range of people and organisations with an interest in public health, COVID-19, infectious diseases and chronic diseases. This included federal and state government departments and agencies, industry groups and peak bodies, think tanks, academics, health practitioners, medical research organisations, and the general public.
- 1.19 The inquiry received 566 submissions and an additional 21 supplementary submissions. The full list of submissions presented to the inquiry is at Appendix A.
- 1.20 Of the 566 submissions, 188 were forwarded to the Committee via an online webform independently created and administered by a member of the public. These submissions were generally from individuals with long COVID, or who had family or friends with long COVID.
- 1.21 Given that many submissions contained personal health-related information, the Committee asked individuals who lodged submissions to confirm if they would be comfortable with their submission being published on the Committee webpage. At the request of the submitter, the Committee accepted 273 submissions as name withheld and 12 submissions as confidential. Maintaining privacy over personal health-related information was a common reason cited for these requests.
- 1.22 Unfortunately, the Committee was unable to make contact with 43 submitters to confirm that they had no objections to their submissions being published. These contributions were therefore accepted by the Committee as correspondence.
- 1.23 On 5 December 2022, the Committee published an issues paper for the inquiry.⁴ The purpose of this issues paper was to provide interested parties with an update on the Committee's work to date, and to highlight gaps and areas the Committee intended to examine during public hearings.
- 1.24 The Committee held four days of public hearings:
- 12 October 2022 in Canberra, ACT
 - 5 December 2022 in Liverpool, NSW
 - 17 February 2023 in Canberra, ACT
 - 20 February 2023 in Malvern, VIC.
- 1.25 A list of witnesses and organisations who attended these public hearings is at Appendix B. Transcripts for all public hearings can be found on the Committee's website.

⁴ House of Representatives Standing Committee on Health, Aged Care and Sport, *Issues paper*, www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/LongandrepeatedCOVID/Issues_Paper, viewed 31 March 2023.

- 1.26 The Committee also attended a site visit to the Long COVID Clinic at St Vincent's Hospital in Sydney on 8 December 2022.
- 1.27 The Committee appreciates the strong public engagement in this inquiry, including from many individuals that have not participated in House of Representatives parliamentary committee inquiries previously. Some individuals and organisations have called for the Committee to recommend or discourage specific treatments for long COVID, issue public health advice regarding long COVID, or recommend a detailed model of care. Where possible throughout the inquiry, stakeholders have been informed that as this Committee is a public policy committee, rather than a technical health expert or advisory committee, these types of activities are not within its remit.

Acknowledgements

- 1.28 The Committee would like to thank everyone who provided written submissions and gave evidence at public hearings.
- 1.29 The Committee acknowledges every individual who is experiencing long COVID or being otherwise impacted by long COVID.
- 1.30 In particular, the Committee would like to thank all the individuals who, despite being personally impacted by long COVID, have gone to considerable effort to contribute to this inquiry.

Report structure

- 1.31 The body of this report is structured into six chapters, including this introduction. The final chapter — Chapter 7 — is a list of recommendations:
- Chapter 2 considers existing definitions of long COVID developed by the World Health Organization and the United Kingdom's National Institute for Health and Care Excellence, before exploring suggestions for an Australian definition of long COVID. This chapter also examines what is currently known about long COVID including its prevalence, symptoms, risk factors, and prognosis.
 - Chapter 3 examines research into long COVID and suggested directions for future research. This chapter also looks at existing data collection and data linkage work and discusses how this may be improved.
 - Chapter 4 summarises what the Committee heard about what it is like to live with long COVID. This chapter also includes accounts from people with long COVID about how they sought care for their symptoms, and the impact that long COVID has had on many aspects of their lives.
 - Chapter 5 considers possible tools to prevent long COVID, namely COVID-19 vaccines, antiviral treatments for COVID-19, and measures to improve indoor air quality.

- Chapter 6 discusses how Australia's healthcare system should respond to long COVID, including in relation to diagnosis, treatment and management. This chapter also explores settings of care and models of care for long COVID, and considers the enabling factors of funding, as well as education and training for Australia's health workforce.

2. What is long COVID?

Overview

- 2.1 Different long COVID definitions exist internationally and have become widely used in Australia. However, the Committee observed throughout its inquiry that the absence of a nationally agreed and consistent definition of 'long COVID'¹ in Australia can create unnecessary barriers to providing patients living with the condition the support they need. The lack of a nationally consistent definition can also have implications for healthcare service providers, research, data collection, understanding the impact of long COVID on Australia's overall health system and the development of best practice responses to prevention, diagnosis and treatment.
- 2.2 Many submitters and witnesses to the inquiry called for Australia to agree and implement a consistent definition of long COVID, recognising the challenges associated with responding to an emerging health condition that remains poorly understood and variably defined.² Evidence received by the Committee indicated that achieving this would provide an improved foundation for Australia's policy response and a basis for understanding long COVID's impact on Australian society.³
- 2.3 Many stakeholders shared their ideas for what Australia's definition of long COVID should address, and for what purposes it should be used. For example, some suggested that Australia adopt the World Health Organization's (WHO) definition or the definition developed by the United Kingdom's National Institute for Health and Care Excellence (NICE), while others proposed that the definition should be informed by consultation.

¹ Other terms that have been used in the literature to describe similar symptoms include 'post-acute COVID', 'post COVID', 'late sequela COVID', 'chronic COVID', 'persistent COVID', 'COVID long haulers', and 'post-acute sequelae of SARS-CoV-2' (PASC). Australian Institute of Health and Welfare, *Long COVID in Australia – a review of the literature*, www.aihw.gov.au/reports/covid-19/long-covid-in-australia-a-review-of-the-literature/summary, p. 7, viewed 6 March 2023.

² See, for example: Department of Health (Victoria), Submission 87, pages 1, 3; Burnet Institute, Submission 149, p. 2; Royal Australian College of General Practitioners, Submission 168, pages 4–5; Moderna Australia, Submission 170, p. 2; Avant Mutual Group, Submission 205, p. 4; Australian Healthcare and Hospital Association, Submission 283, p. 2; Pharmaceutical Society of Australia, Submission 293, p. 4; Lung Foundation Australia, Submission 294, p. 22; Rural Doctors Association of Australia, Submission 362, pages 4, 6; BOD Science, Submission 560, p. 2.

³ See, for example: Professor Lena Sanci, Head, Department of General Practice and Primary Care, Melbourne Medical School, The University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 63; Professor Tania Sorrell, Fellow, Australian Academy of Health and Medical Sciences; and Ambassador, Sydney Institute for Infectious Diseases, *Committee Hansard*, Canberra, 17 February 2023, p. 40.

- 2.4 This chapter examines what is known about long COVID to date, including current definitions of long COVID, options for a nationally agreed definition, its prevalence, clinical features and symptoms, risk factors and prognosis.

Current definitions of long COVID

- 2.5 Clinical definitions of long COVID developed by the WHO and NICE are the most widely used in Australia but have limitations.⁴ Professor Paul Kelly, the Australian Government's Chief Medical Officer, told the Committee that both definitions 'are great for research purposes because they are so broad, but in terms of trying to understand [long COVID], we have to get beyond it.'⁵

- 2.6 Both definitions are used throughout Australia. For example, the Department currently uses the NICE definition of long COVID:

The term 'long COVID' is generally used to describe both:

- ongoing symptomatic COVID-19 – COVID-19 symptoms lasting more than 4 weeks
- post-COVID-19 condition/syndrome – COVID-19 symptoms after 12 weeks that are not explained by an alternative diagnosis.⁶

- 2.7 Currently, Australia's states and territories generally use either the WHO definition (the Australian Capital Territory, NSW and Western Australia)⁷, the NICE definition (Tasmania and Victoria)⁸ or a combination of both (Queensland and South Australia).⁹ The Northern Territory uses a more simplified definition: 'Long COVID,

⁴ Department of Health and Aged Care, Submission 196, p. 5. See also, Australian Academy of Science and Australian Academy of Health and Medical Sciences, Submission 165, pages 3–4.

⁵ Professor Paul Kelly, Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 11.

⁶ Department of Health and Aged Care, *Long COVID*, www.health.gov.au/health-alerts/covid-19/testing-positive/long-covid, viewed 1 March 2023. See also: Department of Health and Aged Care, *Getting help for long COVID*, <https://www.health.gov.au/resources/publications/getting-help-for-long-covid>, p. 1, viewed 26 March 2023.

⁷ ACT Government, *Long COVID*, www.covid19.act.gov.au/stay-safe-and-healthy/long-covid, viewed 1 March 2023; New South Wales Government, *Long COVID*, 14 January 2023, www.nsw.gov.au/covid-19/testing-managing/long-covid#toc-what-is-long-covid, viewed 1 March 2023; Department of Health (Western Australia), Submission 273, p. 2.

⁸ Department of Health Tasmania, *Post COVID-19 condition (Long COVID)*, www.health.tas.gov.au/health-topics/coronavirus-covid-19/what-do-if-you-test-positive/post-covid-19-condition-long-covid, viewed 1 March 2023; Department of Health (Victoria), Submission 87, p. 2.

⁹ Queensland Health, *COVID-19 recovery and long COVID-19*, www.health.qld.gov.au/clinical-practice/guidelines-procedures/novel-coronavirus-qld-clinicians/covid-19-recovery-and-long-covid-19, viewed 1 March 2023; SA Health, *Long COVID or post COVID-19 syndrome*, www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/conditions/infectious+diseases/covid-19/health+professionals/covid-19+information+for+general+practice+and+primary+care/long+covid, viewed 1 March 2023.

now known as post-COVID conditions, is when some people continue to feel unwell 3 months after getting COVID-19.¹⁰

World Health Organization definition

2.8 The WHO defines a 'post COVID-19 condition', or 'long COVID' as:

...the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.¹¹

2.9 The WHO states that long COVID 'can affect anyone exposed to SARS-CoV-2, regardless of age or severity of original symptoms.'¹²

2.10 This clinical case definition was developed by the WHO in late 2021¹³ and is widely used throughout Australia, including by the Burnet Institute¹⁴, the University of New South Wales (UNSW) Fatigue Clinic and Research Program¹⁵, and the long COVID clinic operating in the Nepean and Blue Mountains district.¹⁶

2.11 Some submitters and witnesses were of the view that the WHO definition was ambiguous and in need of review. For example, Professor Tania Sorrell contended that the WHO definition was 'too broad' and required 'updating to account for new knowledge', including by factoring in comorbidities that may affect a person's risk of developing long COVID.¹⁷

United Kingdom National Institute for Health and Care Excellence definition

2.12 The set of clinical case definitions developed by NICE identify and diagnose ongoing effects of COVID-19 according to the length of time after acute COVID-19:¹⁸

¹⁰ NT Health, *Long COVID or post-COVID-19 conditions*, health.nt.gov.au/covid-19/managing-covid-19/long-covid-or-post-covid-19-conditions, viewed 31 March 2023.

¹¹ World Health Organization, *Post COVID-19 condition (Long COVID)*, www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition, viewed 28 February 2023.

¹² World Health Organization, *Post COVID-19 condition (Long COVID)*, www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition, viewed 28 February 2023.

¹³ World Health Organization, *A clinical case definition of post COVID-19 condition by a Delphi consensus*, www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1, viewed 7 March 2023.

¹⁴ Burnet Institute, Submission 149, p. 4.

¹⁵ UNSW Fatigue Clinic and Research Program, Submission 289, p. 1.

¹⁶ Dr Archana Sud, Infectious Diseases Physician and Clinical Director Medicine, Nepean and Blue Mountain Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 5. See also: Australian Physiotherapy Association, Submission 126, p. 6; VPACS – Victorian Post Acute COVID-19 Sequelae Research Group, Submission 290, p. 1.

¹⁷ Professor Tania Sorrell, Fellow, Australian Academy of Health and Medical Sciences and Ambassador, Sydney Institute for Infectious Diseases, *Committee Hansard*, Canberra, 17 February 2023, p. 40. See also, Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165.1, p. 7; Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine, Campbelltown Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 34.

¹⁸ Department of Health and Aged Care, Submission 196, p. 5.

Acute COVID-19

Signs and symptoms of COVID-19 for up to 4 weeks.

Ongoing symptomatic COVID-19

Signs and symptoms of COVID-19 from 4 weeks up to 12 weeks.

Post-COVID-19 syndrome

Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.

In addition to the clinical case definitions, the term 'long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).¹⁹

- 2.13 This definition distinguishes itself from the WHO definition as it considers long COVID to be present if symptoms of COVID-19 persist for four or more weeks following the initial infection, rather than twelve weeks stated in the WHO definition. The NICE definition considers persisting symptoms for twelve or more weeks to constitute 'post-COVID-19 syndrome'.
- 2.14 Australia's National Clinical Evidence Taskforce²⁰ employed the NICE definitions of long COVID for the *Australian Guidelines for the clinical care of people with COVID-19*.²¹ The guidelines define long COVID as:
- Signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis. It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body. Post COVID-19 condition may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.²²
- 2.15 The National Clinical Evidence Taskforce (Monash University) explained in its submission that this definition was developed through national expert consensus and

¹⁹ National Institute for Health and Care Excellence, *COVID-19 rapid guideline: managing the long-term effects of COVID-19*, www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742, p. 5, viewed 28 February 2023.

²⁰ The National Clinical Evidence Taskforce is a multi-disciplinary collaboration of 35 member organisations who share a commitment to provide national evidence-based treatment guidelines for urgent and emerging diseases. See, National Clinical COVID-19 Evidence Taskforce, *Caring for people with COVID-19*, www.clinicalevidence.net.au, viewed 28 February 2023.

²¹ Department of Health and Aged Care, Submission 196, p. 6.

²² National Clinical Evidence Taskforce (Monash University), Submission 232, p. 5.

aligns with international guidelines.²³ This definition is also used by the Sydney Children's Hospital Network.²⁴

What should Australia's definition include?

2.16 Many submitters and witnesses shared their ideas with the Committee about how Australia's definition of long COVID should be developed, and what the definition should cover. This section summarises points grouped according to three broad themes that emerged in the debate regarding what Australia's definition of long COVID should consider:

- the need for a definition applicable to both clinical and research purposes
- consultation on the definition
- possible overlap with other post-viral illnesses.

Applicability to clinical and research purposes

2.17 The need for Australia's definition of long COVID to be applicable to both clinical and research purposes was a core theme that emerged from the evidence received throughout this inquiry. Some submitters and witnesses commented on a dichotomy between existing definitions of long COVID and their pertinence to clinical versus research settings.

2.18 For example, Professor Mark Morgan, Chair, Expert Committee for Quality Care, and Co-chair, National Clinical Evidence Taskforce Primary and Chronic Care Panel, RACGP explained that from the perspective of general practitioners (GPs):

Patients don't come to see GPs with long COVID; they come with distressing symptoms and signs. That can be a whole swathe of different conditions that might or might not be related to a previous COVID infection. We take a person-centred view, rather than a labelling view. Clear definitions are required for the research... But from the point of view of treating people, it's about what problems those people are experiencing and what's the best solution for those problems.²⁵

2.19 Professor Morgan also told the Committee that considering a person has long COVID when they have ongoing symptoms for at least four weeks after a COVID-19 infection may be more practical, since current definitions may result in some patients missing their opportunity to have their symptoms treated early. He explained:

...if you wait until 12 weeks before you assign a label of long COVID then you've missed an opportunity to intervene earlier with the sorts of strategies and

²³ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 5.

²⁴ Associate Professor Philip Britton, Staff Specialist, Sydney Children's Hospital Network, *Committee Hansard*, Liverpool, 5 December 2022, p. 20.

²⁵ Professor Mark Morgan, Chair, Expert Committee for Quality Care, and Co-chair, National Clinical Evidence Taskforce Primary and Chronic Care Panel, Royal Australian College of General Practitioners, *Committee Hansard*, Malvern, 20 February 2023, p. 13.

rehabilitation that will work for a lot of people. Having symptoms beyond four weeks is where we start thinking, 'Okay, could this person's distress and symptoms be related to the COVID infection they've had?' That's when you start intervening in that way.²⁶

- 2.20 Some stakeholders emphasised that a nationally agreed and consistent definition of long COVID should be congruent with international definitions so that Australia can continue to make important and meaningful contributions to, and benefit from, global research.²⁷ For example, Professor Bennett said:

...having a consistent case definition that allows us to compare across studies or across time or across populations, because, fundamentally, if you don't do that, it's really hard to compare findings from one study to the next, and even in terms of length of follow-up and how it plays out, even looking at antiviral treatments; different trials follow up people for different periods of time in terms of their symptom resolution.²⁸

- 2.21 Further, Professor Bennett explained that the Public Health Association of Australia (PHAA):

...has gone with the broadest [definition] at the moment because we're still at the early stage. The risk of that is that it's not specific, and that you will include many other conditions where you do have that overlap with a variety of other pre-existing conditions, including other post-viral conditions, that have been noted and understood before. The risk is that, if you dilute it too much, you aren't actually getting the best benefit... I do think that it will evolve [and] that we will have different levels of case definition, some more inclusive, some more specific, as we start to look at this as a constellation of conditions and refine that.²⁹

- 2.22 The National Centre for Neuroimmunology and Emerging Diseases at Menzies Health Institute Queensland, in Griffith University, explained that the evolving definition of long COVID 'significantly hinders diagnosis, health literacy and access to information.'³⁰

- 2.23 The Burnet Institute highlighted the differences between long COVID and post-acute conditions, arguing from the research perspective that:

²⁶ Professor Mark Morgan, Chair, Expert Committee for Quality Care, and Co-chair, National Clinical Evidence Taskforce Primary and Chronic Care Panel, Royal Australian College of General Practitioners, *Committee Hansard*, Malvern, 20 February 2023, p. 14.

²⁷ See, for example: Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165.1, p. 1; Professor Catherine Bennett, Alfred Deakin Professor and Chair in Epidemiology, Deakin University; and Expert Epidemiologist, Public Health Association of Australia, *Committee Hansard*, Canberra, 12 October 2022, p. 31.

²⁸ Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 31.

²⁹ Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Malvern, 20 February 2022, p. 9.

³⁰ National Centre for Neuroimmunology and Emerging Diseases, MHIQ, Griffith University, Submission 215, p. 3.

...the definition of long COVID should include prolonged symptoms as well as post-acute conditions (eg cardiovascular conditions, neurological conditions and diabetes. This definition will need to be used for surveillance and research purposes, including to document the contribution of post-acute COVID to hospitalisation and deaths.³¹

- 2.24 Conversely, the Australian Academy of Science and the Australian Academy of Health and Medical Sciences suggested the Committee consider whether separate definitions for clinical and research settings may be necessary.³²

Consultation on the definition

- 2.25 Noting the evidence emerging from medical literature about long COVID, some submitters identified the need for consultation on the definition of long COVID. For example, the Department of Health in Victoria recommended:

- The Commonwealth should lead the development of nationally consistent case definition, which could be informed by the recent drafting of Care of people after COVID by the National COVID-19 Clinical Evidence Taskforce. This definition should include both 'long COVID' symptoms and post-COVID conditions which may affect multiple organ systems, such as the increased risk of diabetes, heart attacks and strokes.
- A nationally consistent case definition will also support the development of long COVID resources for clinicians and patients.³³

- 2.26 Similarly, the long COVID clinic at St Vincent's Hospital in Sydney recommended that the Australian Government establish an advisory body 'to assist in providing evidence-based information on critical areas such as the definition of long COVID and the role of emerging treatments.'³⁴

- 2.27 Professor Sorrell also underlined the need for the definition to be 'codeveloped or modified in collaboration with lived experience, clinical and diagnostic discipline experts, researchers, public health and health planners, and international colleagues' to ensure it is easily understood and meaningful.³⁵

³¹ Burnet Institute, Submission 149, p. 2.

³² Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165.1, pages 1, 9.

³³ Department of Health (Victoria), Submission 87, p. 3.

³⁴ Long COVID Clinic St Vincent's Hospital Sydney, Submission 287, p. 1.

³⁵ Professor Tania Sorrell, Fellow, Australian Academy of Health and Medical Sciences; and Ambassador, Sydney Institute for Infectious Diseases, *Committee Hansard*, Canberra, 17 February 2023, p. 41. See also: Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165.1, p. 9.

Understanding long COVID

2.28 This section examines what is known to date about the prevalence, clinical features and symptoms, risk factors and prognosis associated with long COVID.

Prevalence

2.29 There is no national registry of long COVID cases in Australia³⁶ and estimates of its incidence and prevalence in both Australia and internationally remain problematic. Efforts to estimate the prevalence are impeded by varying definitions, varying descriptions of symptoms and a reliance on self-reported population-based cohorts.³⁷

2.30 The Burnet Institute considers that five to ten per cent of people in Australia have persisting symptoms for three months, or twelve weeks, after an initial COVID-19 infection.³⁸ Contrary to the submission from the Department, the Burnet Institute was of the view that the nature and prevalence of long COVID in Australia is not unique compared to other countries, 'even after accounting for high levels of vaccination prior to many people experiencing their first COVID-19 infection.'³⁹

2.31 The five per cent estimate is confirmed by several studies.⁴⁰ One Australian study followed 94 per cent of all COVID-19 cases diagnosed in New South Wales (NSW) between January and May 2020 prior to vaccination (2904 cases) and found that approximately five per cent of people had persisting symptoms twelve weeks after their initial infection.⁴¹

2.32 Another study by the Australian National University's Centre for Social Research and Methods and the National Centre for Epidemiology and Population Health published in October 2022 followed the NICE definition of long COVID. This study estimated that '4.7 per cent of adult Australians have had or currently have post-COVID-19 syndrome (symptoms that lasted 3 months or more).'⁴² Referencing this study, the

³⁶ Public Health Association of Australia, Submission 351, p. 5.

³⁷ See, for example: Professor Peter Wark, Submission 134, p. 5; Burnet Institute, Submission 149 (Attachment A), p. 1; Moderna Australia, Submission 170, p. 7; Murdoch Children's Research Institute, Submission, 178, p. 8; National Clinical Evidence Taskforce (Monash University), Submission 232, p. 5; The University of Melbourne – Faculty of Medicine, Dentistry and Health Sciences, Submission 237, p. 5; Lung Foundation Australia, Submission 294, p. 12; OzSAGE, Submission 299, p. 2; The George Institute for Global Health, Submission 514, p. 3.

³⁸ Burnet Institute, Submission 149, p. 1.

³⁹ Burnet Institute, Submission 149, p. 4.

⁴⁰ Department of Health and Aged Care, Submission 196, p. 8.

⁴¹ B Liu et al., 'Whole of population-based cohort study of recovery time from COVID-19 in New South Wales Australia', *The Lancet Regional Health – Western Pacific*, pubmed.ncbi.nlm.nih.gov/34189493/, viewed 6 March 2023.

⁴² N Biddle and R Korda, 'The experience of COVID-19 in Australia, including long-COVID – Evidence from the COVID-19 Impact Monitoring Survey Series, August 2022', *The Australian National University Centre for Social Research and Methods and the National Centre for Epidemiology and Population Health, The Australian National University*, csrcm.cass.anu.edu.au/sites/default/files/docs/2022/10/The_experience_of_COVID-19_in_Australia_-_For_web.pdf, viewed 6 March 2023.

Burnet Institute said that this equates to 500 000 adults with long COVID in Australia three months after infection.⁴³

- 2.33 The Department of Health and Aged Care (the Department) summarised that recent estimates from international studies show between 3.6 per cent to 20 per cent of adults have persisting symptoms for at least twelve weeks after an initial COVID-19 infection.⁴⁴ While less is known about the prevalence of long COVID in children and young people, estimates indicate that between 1.6 per cent and 13 per cent have persisting symptoms for at least eight to twelve weeks.⁴⁵
- 2.34 Although these figures may appear low, the collective number is significant because it applies to the Australian population. Professor Margaret Hellard, Deputy Director of Programs at the Burnet Institute explained:

Depending on which figures you want to look at, it's generally quoted as being around three to five per cent. Some people might call that overs; some people might call that considerable unders... [I]n terms of the precision of it, if you have 10 million people infected, if it's three per cent, that's 300,000 people; if it's five per cent, that's 500,000 people; if it's one per cent, that's 100,000 people—they're all big numbers; if it's more, they're even bigger numbers—who have or have experienced long COVID.

Even if they're overestimates, in a disease where there's a high proportion of the community getting infected, then a small percentage becomes consequential.⁴⁶

- 2.35 The Australian Institute of Health and Welfare (AIHW) published a literature review of the scale and impact of long COVID in December 2022.⁴⁷ The AIHW observed that stricter definitions of long COVID generally led to more modest estimates of its prevalence.⁴⁸ For example:

The prevalence of post-COVID condition (>12 weeks) ranged from 8-17% in studies from the UK. The global prevalence of post-COVID condition was estimated to be 3.7% of all COVID-19 infections and 6.2% of symptomatic infections when only symptoms of fatigue, cognitive problems or shortness of breath were counted.⁴⁹

- 2.36 There is some debate whether international long COVID prevalence studies are applicable to the Australian context. The Department noted several factors that may influence the prevalence of long COVID in Australia:

⁴³ Burnet Institute, Submission 149, p. 5.

⁴⁴ Department of Health and Aged Care, Submission 196, p. 8.

⁴⁵ Department of Health and Aged Care, Submission 196, p. 8.

⁴⁶ Professor Margaret Hellard, Deputy Director, Programs, Burnet Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 19.

⁴⁷ Australian Institute of Health and Welfare, *Long COVID in Australia – a review of the literature*, www.aihw.gov.au/reports/covid-19/long-covid-in-australia-a-review-of-the-literature/summary, viewed 6 March 2023.

⁴⁸ Department of Health and Aged Care, Submission 196, p. 30.

⁴⁹ Department of Health and Aged Care, Submission 196, p. 30.

Australia's experience of COVID-19 differs from other countries who experienced larger outbreaks of the Alpha and Delta variants as well as outbreaks prior to COVID-19 vaccine availability. Australia has relatively high rates of vaccination, which is associated with reduced risk and severity of long COVID. Serological surveys amongst Australian blood donors indicate that around two thirds (65%) of adults in Australia were estimated to have had SARS-CoV-2 by the end of August 2022, compared to 17% in early March 2022 and 46% in early June 2022. Consequently, most people in Australia who have had COVID-19 have been infected with the Omicron variant, which has been the dominant variant in Australia since December 2021. Infection with Omicron has been associated with a lower risk for long COVID than infection with the Delta variant. Therefore, caution should be taken in applying extrapolations based on the experience of other countries to Australia.⁵⁰

Clinical features and symptoms

- 2.37 Long COVID has up to 200 diverse and non-specific symptoms, making recognition and diagnosis challenging. Each experience of long COVID is unique and symptoms can present differently in different people, ranging from mild to severe and persisting for varying periods of time. While progress is still underway to better understand the pathophysiology of long COVID⁵¹, current knowledge indicates that long COVID is multisystem disease.⁵²
- 2.38 According to the Department and the WHO, more than 200 symptoms have been described in the medical literature about long COVID.⁵³ The most frequently reported symptoms include:
- respiratory symptoms: breathlessness, cough
 - cardiovascular symptoms: chest tightness, chest pain, palpitations
 - generalised symptoms: fatigue, fever, pain, reduced activity and functional level, reduced nutritional status and weight loss
 - neurological symptoms: cognitive impairment ('brain fog', loss of concentration or memory issues), headache, sleep disturbance, autonomic dysfunction, peripheral neuropathy issues, dizziness, delirium (in older adults), mobility impairment, visual disturbance
 - gastrointestinal symptoms: abdominal pain, nausea and vomiting, diarrhoea, weight loss and reduced appetite

⁵⁰ Department of Health and Aged Care, Submission 196, p. 8, citations omitted. See also, Royal Australian College of General Practitioners, Submission 168, p. 6.

⁵¹ Department of Health and Aged Care, Submission 196, p. 7.

⁵² See, for example: Australian Physiotherapy Association, Submission 126, p. 13; Department of Health and Aged Care, Submission 196, p. 29; Professor Kerryn Phelps AM, Submission 510, p. 2.

⁵³ Department of Health and Aged Care, Submission 196, p. 6; World Health Organization, *Post COVID-19 condition (Long COVID)*, www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition, viewed 28 February 2023.

- musculoskeletal symptoms: joint pain, muscle pain
- ear, nose and throat symptoms: tinnitus, earache, sore throat, dizziness, loss of taste and/or smell, nasal congestion
- dermatological symptoms: skin rashes, hair loss
- psychological symptoms: low mood, anxiety, intrusive memories, other psychological symptoms.⁵⁴

2.39 The Committee also received evidence regarding less common long COVID symptoms including impaired vision and balance. While these are less frequent, it was reported that these rarer symptoms can be severe.⁵⁵

2.40 Children experiencing symptoms of long COVID describe similar symptoms, particularly pain and fatigue.⁵⁶ The Australian Academy of Science and the Australian Academy of Health and Medical Sciences advocated for a 'specific definition for children... particularly for those under 10 years of age, in whom there may be a potential interaction between long COVID and developmental milestones.'⁵⁷

2.41 The Committee heard about many of these symptoms in submissions from people with long COVID. The Committee also heard that the consequences of living with these symptoms permeate many aspects of life, leading to a range of adverse financial, social, mental health and educational impacts. Some submitters with severe long COVID told the Committee they are unable to leave the house, or unable to walk, due to their symptoms.⁵⁸ These impacts are discussed in more detail in Chapter 4.

2.42 The Royal Australian College of General Practitioners (RACGP) explained:

Patient experiences of long COVID vary but commonalities are present. Common descriptors of long COVID symptoms include fatigue, generalised weakness, brain fog, and reduced concentration and attention span, as well as recurrent respiratory symptoms such as shortness of breath. Beyond these, there are a myriad of other concerning symptoms reported by patients. Many symptoms are consistent with other postviral syndromes and are all pervasive. There is a level of uncertainty as to whether many post-COVID symptoms are an exacerbation of known or unknown preexisting illness from an initial COVID-19 infection or whether long COVID is considered a standalone diagnosis.⁵⁹

⁵⁴ Department of Health and Aged Care, Submission 196, p. 6.

⁵⁵ Australia Long Covid Community Facebook Group, Submission 309, p. 9.

⁵⁶ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, pages 8–9.

⁵⁷ Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165.1, p. 1.

⁵⁸ See, for example: Name withheld, Submission 3, p. 5; Name withheld, Submission 75, p. 4; Name withheld, Submission 185, p. 7; Name withheld, Submission 190, p. 3; Name withheld, Submission 197, p. 1; Name withheld, Submission 311, p. 18; Name withheld, Submission 364, p. 1; Emma Quinn, Submission 397, p. 1; Name withheld, Submission 491, p. 6; Name withheld, Submission 533, p. 1.

⁵⁹ Royal Australian College of General Practitioners, Submission 168, p. 4.

2.43 Some witnesses indicated there may be different types or variations of long COVID.⁶⁰ For example, the UNSW Fatigue Clinic and Research Program stated:

...it is clear that a subset of patients after acute COVID-19 infection reporting symptoms of Long COVID have lung or other end-organ damage as a result of pneumonitis, cardiac or neurological injury, or even psychological trauma during the acute illness; or may be experiencing the symptoms as a result of an exacerbation of pre-existing comorbidities. By contrast, it is now clear that another subset of patients with Long COVID have a post-viral fatigue syndrome, albeit with the addition of COVID-related symptoms (e.g., a persistent sensation of breathlessness, or anosmia). This latter subset of patients meet the diagnostic criteria for a post-infective fatigue syndrome (PIFS), that is, a medically- and psychiatrically-unexplained disabling chronic fatigue syndrome, following from documented acute infection, and associated with neurocognitive difficulties ('brain fog'), unrefreshing sleep.⁶¹

2.44 A submission from Ruth Newport stated that 'Long Covid is a broad term for ongoing post Covid symptoms' and suggested that it is generally possible to categorise these symptoms into five subtypes:

- 1 Post-ICU [Intensive Care Unit] syndrome
- 2 Objectively observable organ damage (lung, heart etc)
- 3 Post viral fatigue (PVF, definition used in the first 6 months)
- 4 ME/CFS type (diagnostic criteria require 6 months or more since acute onset)
- 5 a combination of subtypes of 1-4.⁶²

2.45 Dr Anne Fletcher and Dr Luke Fletcher also suggested that long COVID may in fact constitute multiple conditions. They jointly submitted that 'there are likely at least 3 distinct subsets of long COVID disease', and nominated these as:

- 1 patients with organ damage
- 2 patients with post surgery or post intervention complications

⁶⁰ See, for example: Australian Name withheld, Submission 4, p. 7; Name withheld, Submission 120, p. 8; Physiotherapy Association, Submission 126, p. 10; Ms Jennifer Lang, Submission 144, p. 4; Ruth Newport, Submission 231, p. 9; The University of Melbourne - Faculty of Medicine, Dentistry and Health Sciences, Submission 237, pages 2-3, 7-8; Dr Anita White, Submission 238, p. 1; Dr Graeme Exelby, Submission 248, p. 3; Australian Traditional Medicine Society, Submission 271, p. 4; UNSW Fatigue Clinic and Research Program, Submission 289, p. 1; Dr Anne Fletcher and Dr Luke Fletcher, Submission 436, p. 13; Dr Jen Kok, Medical Virologist, Australian Society of Microbiology, Institute of Clinical Pathology and Medical Research, and NSW Health Pathology, *Committee Hansard*, Canberra, 17 February 2023, p. 42; Professor Jeremy Nicholson, Director, Australian National Phenome Centre, and Pro Vice-Chancellor Health Sciences, Murdoch University, *Committee Hansard*, Malvern, 20 February 2023, p. 32.

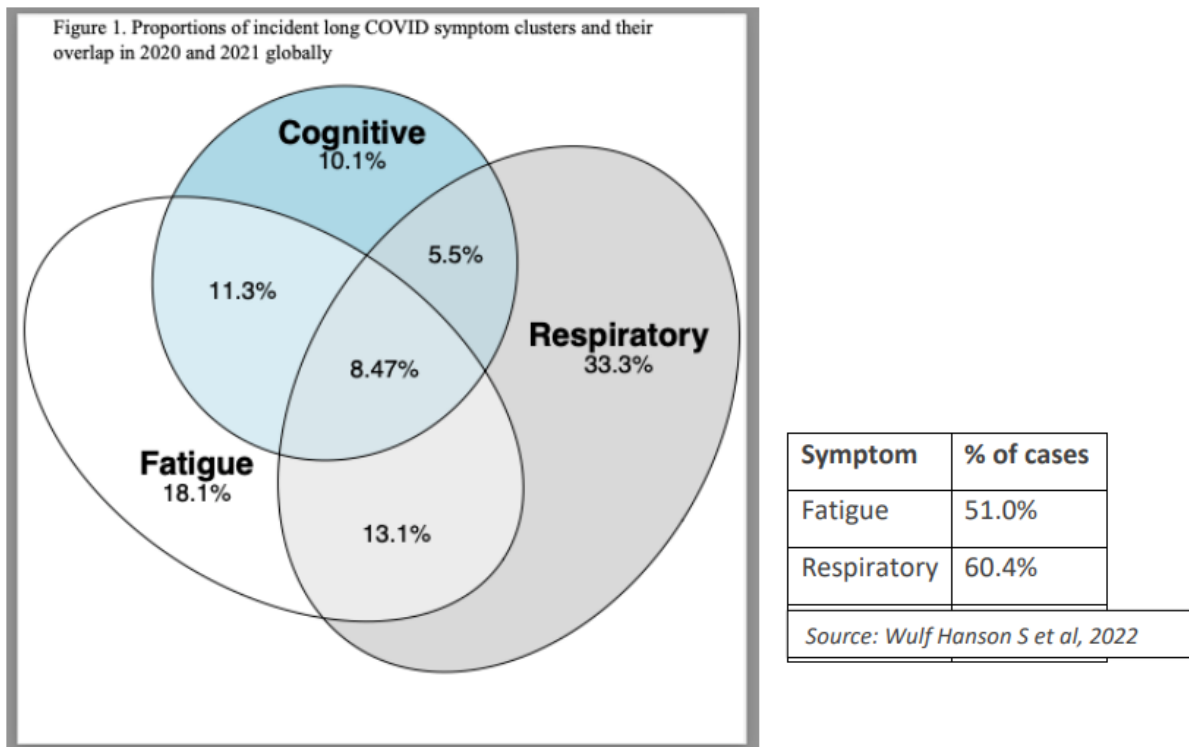
⁶¹ University of New South Wales (UNSW) Fatigue Clinic and Research Program, Submission 289, p. 1, citations omitted.

⁶² Ruth Newport, Submission 231, p. 9.

3 patients with ME/CFS-like illness.⁶³

- 2.46 Allied Health Professions Australia highlighted the findings of a 2022 meta-analysis study that examined the occurrence of three long COVID symptom clusters and estimated the incidence of symptom overlap based on data from 2020 and 2021.⁶⁴ The three types of symptom clusters used in this study were cognitive, respiratory and fatigue. As illustrated in Figure 3.1, the study estimated that many people with long COVID only experienced one of the three symptom clusters but overlap existed:
- 33.3 per cent experienced respiratory symptoms only
 - 18.1 per cent experienced fatigue symptoms only
 - 10.1 per cent experienced cognitive symptoms only.⁶⁵

Figure 2.1 Long COVID symptom clusters and their overlap



Source: Allied Health Professions Australia, Submission 269, p. 4.

⁶³ Dr Anne Fletcher and Dr Luke Fletcher, Submission 436, p. 13.

⁶⁴ S Wulf Hanson et al., 'A global systematic analysis of the occurrence, severity, and recovery pattern of long COVID in 2020 and 2021', medRxivNote [Preprint], doi.org/10.1101/2022.05.26.22275532, viewed 6 March 2023. Note this research is pending peer review.

⁶⁵ Allied Health Professions Australia, Submission 269, p. 4.

Risk factors

2.47 While the exact causes of long COVID remain unknown at this time, several risk factors have emerged that may make a person more likely to develop long COVID. According to the Department of Health and Aged Care these factors include:

- female sex
- pre-existing health conditions (e.g., high blood pressure, asthma, diabetes, obesity)
- psychological stress and pre-existing mental health conditions
- increased severity of initial infection (such as requiring hospitalisation)
- socioeconomic deprivation.⁶⁶

2.48 Asthma Australia pointed out that Aboriginal and Torres Strait Islander peoples are one group at greater risk of developing long COVID due to a higher rate of health comorbidities, and other environmental factors limiting access to care. They explained:

...Aboriginal and Torres Strait Islander people faced disproportionate disadvantage during COVID and are at increased risk of long COVID due to the prevalence of comorbidities. People living in regional, rural and remote areas have their vulnerability compounded due to protracted waiting times, inability to access quality care, specialist treatment and specific investigations.⁶⁷

2.49 There is also growing literature that indicates age, vaccination status, the type of variant of the COVID infection and access to COVID-19 antivirals may also influence the risk of developing long COVID.⁶⁸ For example, RACGP submitted:

GPs have reported greater prevalence of long COVID in patients with existing chronic illness/comorbidities, the elderly and in people living with disability. A greater prevalence in females was noticed. It is also widely acknowledged people from culturally and linguistically diverse backgrounds and those in lower

⁶⁶ Department of Health and Aged Care, Submission 196, pages 7, 30. See also, Institute for Evidence-Based Healthcare, Submission 195, p. 3; National Health and Medical Research Council Centre of Excellence in Treatable Traits, Submission 202, pages 8–9; Name withheld, Submission 228, pages 1–2; Dr Anita White, Submission 238, p. 1; John Curtin Research Centre, Submission 243, p. 4; Australian Patients Association, Submission 256, p. 3; Lung Foundation Australia, Submission 294, p. 11; Australia Long Covid Community Facebook Group, Submission 309.2, pages 1–6; Asthma Australia, Submission 339, p. 6; The George Institute for Global Health, Submission 514, p. 3.

⁶⁷ Asthma Australia, Submission 339, p. 6.

⁶⁸ Department of Health and Aged Care, Submission 196, p. 7. See also, Institute for Evidence-Based Healthcare, Submission 195, p. 14; Lung Foundation Australia, Submission 294 (Attachment 1), p. 6; Australasian College of Nutritional and Environmental Medicine, Submission 434, p. 7; Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 26; Professor Margaret Hellard, Deputy Director, Burnet Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 24; Dr Irani Thevarajan, Infectious Diseases Physician, Victorian Infectious Diseases Service, The Peter Doherty Institute for Infection and Immunity, *Committee Hansard*, Canberra, 12 October 2022, p. 14; Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 10.

socioeconomic communities face additional challenges navigating the healthcare system and accessing timely care and support.⁶⁹

2.50 Professor Catherine Bennett, Chair in Epidemiology at Deakin University explained:

It's very hard to actually determine risk factors because they might be different sets of risk factors associated with these different disease pathways. That's one of the big epidemiological challenges, along with the fact that people are still using different definitions—or we're not trying to delineate different causal pathways within this constellation of conditions that are now starting to emerge and to be understood.⁷⁰

2.51 Risk factors for developing long COVID remains the subject of research. Research into long COVID is discussed in detail in Chapter 3.

Groups particularly vulnerable to severe long COVID

2.52 The Committee received evidence about specific cohorts that may be more vulnerable to developing severe long COVID compared to the general population. This may be due to barriers to accessing healthcare and inadequate management of severe acute COVID-19 symptoms.⁷¹

2.53 The Rural Doctors Association of Australia submitted:

Rural Australians and Aboriginal and Torres Strait Islander people experience higher rates of many chronic illnesses, comorbidities, risky health behaviours and shorter lifespans than people who live in more urban areas. This puts them at higher risk of severe outcomes from COVID-19. An under-resourced rural primary care sector... and hospitals that are not necessarily well equipped to isolate and treat people who have severe COVID illness, together with the “paucity of healthcare and other services in non-metropolitan areas, and the lack of reserve health system capacity, means that it is less feasible to “live with” circulating COVID-19, than in metropolitan areas”.⁷²

2.54 Dr Jason Agostino, Senior Medical Adviser at the National Aboriginal Community Controlled Organisation also emphasised the impacts of long COVID in Aboriginal communities may be more severe ‘due to the high percentage living in poverty or with significant financial stress, the high percentage with high psychological distress

⁶⁹ Royal Australian College of General Practitioners, Submission 168, p. 8. See also, Burnet Institute, Submission 149, p. 8.

⁷⁰ Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 27.

⁷¹ See, for example: Royal Australian College of General Practitioners, Submission 168, p. 8; Public Health Association of Australia, Submission 351, p. 6.

⁷² Rural Doctors Association of Australia, Submission 362, p. 8, citations omitted.

and the higher burden of chronic disease.⁷³ Under reporting of long COVID is likely among Aboriginal and Torres Strait Islander peoples.

- 2.55 National Disability Services told the Committee that the number of people with disability with long COVID cannot be quantified 'due to providers not having the confidence to accurately differentiate between the symptoms as the result of previous COVID-19 infections or related to pre-existing health conditions.'⁷⁴

Prognosis and recovery

- 2.56 Prognosis for people diagnosed with long COVID is uncertain⁷⁵ and there is a lack of conclusive evidence about recovery periods. Many submitters described long COVID as a mass disabling event.⁷⁶

- 2.57 However, evidence is emerging that most people with long COVID will recover.⁷⁷ Associate Professor Louis Irving, Respiratory Physician, Post-COVID Clinic at Royal Melbourne Hospital gave the following example of recovery:

...a lot of patients get better over time, and our most severe patient—in fact, she was the stimulus for setting up this clinic—a young mother working as a medical scientist and leading an incredibly busy life and who was wheelchair- and bed-bound when we first saw her, is completely back to normal after two years. But it has been a long road, and it's required very careful ongoing treatment. Being

⁷³ Dr Jason Agostino, Senior Medical Adviser, National Aboriginal Community Controlled Organisation, *Committee Hansard*, Canberra, 17 February 2023, p. 1.

⁷⁴ National Disability Services, Submission 460, p. 3.

⁷⁵ See, for example: Emerge Australia, Submission 67, p. 8; Dr Anne Fletcher and Dr Luke Fletcher, Submission 436, p. 18; Australian Psychological Society & Phoenix Australia Centre for Posttraumatic Mental Health Ltd, Submission 501, p. 6.

⁷⁶ See, for example: Name withheld, Submission 1, p. 4; Name withheld, Submission 4, p. 1; Name withheld, Submission 18, p. 1; Name withheld, Submission 50, p. 1; Miss Tara Barton, Submission 166, p. 10; Mrs Tori Haschka, Submission 177, p. 3; Name withheld, Submission 221, p. 4; Name withheld, Submission 228, p. 3; Name withheld, Submission 311, p. 28; Name withheld, Submission 312, p. 3; Name withheld, Submission 326, p. 2; Natalia Hodgins, Submission 327, p. 1; Advocacy for Inclusion – Incorporating People with Disabilities ACT, Submission 336, p. 4; Name withheld, Submission 358, p. 2; Australian Federation of Disability Organisations, Submission 486, p. 15; Name withheld, Submission 515, p. 1; Name withheld, Submission 522, p. 1.

⁷⁷ See, for example: Professor Martin Hensher, Submission 175 (Attachment 2), p. 22; Name withheld, Submission 312, p. 2; Inner Melbourne Community Legal & Royal Melbourne Hospital (Allied Health Department), Submission 333, p. 5; Associate Professor Louis Irving, Respiratory Physician, Post-COVID Clinic, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, pages 1-2; Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine, Campbelltown Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 34; Dr Archana Sud, Infectious Diseases Physician and Clinical Director Medicine, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Canberra, 12 October 2022, p. 6; Associate Professor Alex Holmes, Fellow, Royal Australian and New Zealand College of Psychiatrists, Royal Melbourne Hospital, and University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 57; Professor Brendan Murphy AC, Secretary, Department of Health and Aged Care, *Committee Hansard*, Canberra, 20 February 2023, p. 13.

able to reassure people that they're not going to be permanently damaged is part of the management.⁷⁸

- 2.58 The National Clinical Evidence Taskforce (Monash University) said that health prognosis appears to become worse with each repeated COVID-19 infection, emphasising the importance of prevention:

Long COVID follows a SARS-CoV-2 infection, and the impact of SARS-CoV-2 infections (based on available evidence) appears to be cumulative... - i.e. the health prognosis becomes poorer with each additional infection. Thus, aiming towards limiting the number of SARS-CoV-2 infections is a logical way to minimise the potential (and somewhat unknown - at this stage) impact of long COVID and repeated SARS-CoV2 infections.⁷⁹

- 2.59 Professor Steven Faux and Associate Professor Anthony Byrne from the long COVID clinic at St Vincent's Hospital explained:

With respect to the prognosis of the long COVID condition. In our experience the median (most common) time of reporting of improvement in ongoing symptoms varies between strains. Earlier strains like Delta lasting longer than latter strains such as omicron.

At our clinic we are seeing improvements in function and the commencement of a graduated return to work at 6 months. These patients are on the road to recovery by that time, but have not achieved their optimum recovery.

The NSW Dept. of health has quoted a median time for recovery from long COVID from omicron as 4 months and delta as 8 months.

As the syndrome is emerging it is hard to say how long it will take to return to pre COVID levels of function and overall health. The consensus of opinion seems to be 9-12 months or more and in the UK they are considering that long COVID could represent a disability...⁸⁰

- 2.60 Professor Greg Dore, Professor and Epidemiologist at the Kirby Institute suggested that vaccination status may speed up long COVID recovery:

My hypothesis is that people pre-vaccination have a higher risk of long COVID, but also their recovery is more prolonged. I'm still seeing patients that are two years out from acute COVID, with long COVID symptoms. Vaccination clearly reduces the individual risk. But we're seeing a larger number of cases because of how much COVID has been around, but the hypothesis is that the recovery will also be somewhat more rapid in the post-vaccination era.⁸¹

⁷⁸ Associate Professor Louis Irving, Respiratory Physician, Post-COVID Clinic, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2023, pages 1-2.

⁷⁹ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 14, citations omitted.

⁸⁰ Professor Steven Faux and Associate Professor Anthony Byrne, Submission 544.1, pages 1–2.

⁸¹ Professor Greg Dore, Professor and Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 37.

- 2.61 COVID-19 vaccines as a possible method to prevent long COVID is discussed in Chapter 5.
- 2.62 Some submitters and witnesses informed the Committee that prognosis for long COVID may be worse in people with co-morbidities.⁸² For example, Dr Graeme Exelby observed ‘poor prognosis in obesity, diabetes, hypertension, and atherosclerosis.’⁸³
- 2.63 The Committee also heard that the ambiguity regarding prognosis is difficult.⁸⁴ For example, one submitter said:
- The uncertainty of navigating a largely unknown medical condition with untested treatment pathways, unknown timelines, and unknown prognosis has been a significant psychological challenge.⁸⁵
- 2.64 Given this uncertainty, the Rehabilitation Medicine Society of Australia and New Zealand emphasised:
- ...the general health literacy of the public is variable at best, and in order to assist people to live with the uncertainty of the prognosis of long COVID, it is paramount to improve their general understanding of long COVID, its management and prognosis. Further skills need to be taught regarding pacing of activities and living with a measure of uncertainty, that is associated with long COVID.⁸⁶
- 2.65 Self-management tools and resources for individuals with long COVID are discussed further in Chapter 6.

Committee comment

- 2.66 The Committee recognises the need for an agreed and consistent definition of long COVID to be used in Australia and is concerned that its absence may delay diagnosis and prevent patients from accessing necessary treatment, care and support to manage their symptoms. In particular, the Committee is concerned that the patchwork of definitions of long COVID used across each of Australia’s states and territories may lead to inequities in patient access to care.

⁸² See, for example: National Health and Medical Research Council Centre of Excellence in Treatable Traits, Submission 202, p. 9; Dr Graeme Exelby, Submission 248, p. 1; Australian Naturopathic Council, Submission 261, p. 2; Professor Raina Macintyre, Submission 300, p. 2; Advocacy for Inclusion – Incorporating People with Disabilities ACT, Submission 336, p. 5; MSD Australia, Submission 452, p. 6.

⁸³ Dr Graeme Exelby, Submission 248, p. 1.

⁸⁴ See, for example: Name withheld, Submission 153, p. 2; Institute for Evidence-Based Healthcare, Submission 195, p. 3; Relationships Australia, Submission 245, p. 4; Name withheld, Submission 433, p. 1; Mrs Rebecca Adolph, Submission 462, p. 4; Name withheld, Submission 505, p. 2; Health Issues Centre, Submission 529, p. 9.

⁸⁵ Name withheld, Submission 153, p. 2.

⁸⁶ Rehabilitation Medicine Society of Australia and New Zealand, Submission 283, p. 8.

- 2.67 The Committee believes that a nationally agreed and consistent definition of long COVID is a practical solution to improving:
- understanding of the impact of long COVID across Australia's overall healthcare system
 - the utility of research and data regarding long COVID
 - the development of best practice responses to prevention, diagnosis and treatment.
- 2.68 The Committee notes that while there is still much to learn about long COVID and its prognosis, it has heard that many people do recover from this illness. However, recovery can take a prolonged period of time and is associated with biopsychosocial and economic impacts.
- 2.69 The Committee appreciates that the definition of long COVID will need to evolve in accordance with emerging research and is persuaded that it should also evolve to align with international practice. Notwithstanding this, the Committee considers that for now, the WHO definition of long COVID should be used clinically, noting that the decision to initiate treatment would be at the discretion of the clinician who may want to start from an earlier timepoint being four weeks.



3. Research and data

Overview

- 3.1 The evidence before the Committee almost universally called for improved research and data on long COVID.
- 3.2 The Committee heard there has been significant research conducted into long COVID to date, despite considerable challenges facing researchers. These challenges include limited research funding, a lack of quality data and the lack of Australia-specific research centred on our unique experience with the dominance of the COVID-19 Omicron variant, and our high vaccination rates.
- 3.3 While stakeholders specifically identified that substantial progress has been made in areas such as biomarker research, there remain considerable knowledge gaps with respect to other aspects of long COVID. The need for improved data collection on Australian patients with long COVID, and for research regarding treatments, emerged as common themes from the evidence received by the Committee.
- 3.4 This chapter examines completed and ongoing research, suggested directions for future research, and how data collection, linkage and analysis could be improved. It is noted that although this chapter primarily discusses research and data separately, the two are heavily interconnected in practice.

Current and past research

- 3.5 The submissions to this inquiry indicate that many Australian researchers have and are currently investigating a variety of aspects of long COVID, including prevention, symptoms, and treatments. The importance of fostering increased collaboration and Australia-specific research emerged as common themes.
- 3.6 The Committee heard that since the start of the COVID-19 pandemic, ‘Science has moved quickly to build knowledge of COVID-19’.¹ A number of past and current research studies relate specifically to long COVID; there is an international repository of over 10 000 studies on this topic.²
- 3.7 Areas of research regarding long COVID that are currently being, or have been, addressed by Australian researchers include:

¹ Western Health COVID Recovery Collaboration, Submission 493, p. 10.

² Professor Catherine Bennett and Dr Danielle Hitch, Submission 92, p. 2.

- Ventilation³
- Cardiac and respiratory health⁴
- Mental health and social issues⁵
- Cognitive and neurological issues⁶
- Treatment and diagnosis.⁷

3.8 Multiple issues were raised in the evidence as impediments to generalising and relying upon past Australian long Covid research and for conducting new research, such as poor research quality, regulatory issues and limited funding. These points are discussed in more detail below.

Research quality

3.9 The Western Health COVID Recovery Collaboration, a partnership between Western Health and Deakin University including consumers, clinician researchers and academics, suggested that the volume and speed of general COVID-19 research have resulted in quality, accuracy and waste problems:

The majority of published COVID-19 systematic reviews and clinical trials have been evaluated as low-quality, while ‘spin strategies’ that overstate findings have been identified within randomised control trials. Inefficiency and waste are also posing further barriers to research quality, along with diverse interventional controls.⁸

3.10 The Burnet Institute noted that ‘although at least 26 randomised clinical trials of long-COVID therapies are under way, many are too small or lack the necessary control groups to give clear results.’⁹

3.11 Queensland Health was critical of existing long COVID research, observing that it is ‘frequently low quality and not relevant to Queensland’s context of high vaccination rates and recent milder variants. As a result, these publications and reports risk inflating estimates of prevalence, health impacts, and community anxiety.’¹⁰

³ See, for example: Adjunct Professor Giorgio Buonanno, Submission 130, p. 1; Distinguished Professor Lidia Morawska, Submission 304 (Attachment 1), pages 1–4.

⁴ See, for example: Baker Heart and Diabetes Research Institute, Submission 138, p. 2; The University of Melbourne - Faculty of Medicine, Dentistry and Health Sciences, Submission 237, p. 7; National Heart Foundation of Australia, Submission 284, pages 4–5; Lung Foundation Australia, Submission 294, pages 11–12.

⁵ See, for example: Royal Melbourne Hospital, Submission 164, p. 2; Relationships Australia, Submission 245, p. 6; Australian Psychological Society & Phoenix Australia Centre for Posttraumatic Mental Health Ltd, Submission 501, p. 7.

⁶ See, for example: Professor Andreas Suhrbier, Submission 103, p. 1; The Peter Doherty Institute for Infection and Immunity, Submission 291, pages 1–5.

⁷ See, for example: Burnet Institute, Submission 149, pages 14–17; Associate Professor Anthony Byrne, Submission 155, p. 1; Australian National Phenome Centre, Submission 211, p. 5.

⁸ Western Health COVID Recovery Collaboration, Submission 493, p. 10.

⁹ Burnet Institute, Submission 149, p. 16.

¹⁰ Queensland Health, Submission 150, p. 13.

Queensland Health also raised the reliance on retrospective studies as an issue, and advised that ‘There are relatively fewer prospective studies, with most reports drawing from retrospective analysis which introduces significant biases in the recall of experiences and events, and in the selection of controls.’¹¹

- 3.12 The Murdoch Children’s Research Institute identified some major limitations of studies on long COVID including:
- Small numbers of participants
 - Non-standardised methods for identifying and classifying infection and persistent symptoms, including patient reported infection in non-controlled settings, and selection biases
 - Variation in the definition of long COVID and inclusion of symptoms.¹²
- 3.13 Additionally, the Murdoch Children’s Research Institute noted that most long COVID research has been undertaken in adults, and that more research focusing specifically on children and adolescents is needed.¹³
- 3.14 Associate Professor Louis Irving, a Respiratory Physician at the Royal Melbourne Hospital’s Post-Covid Clinic, also emphasised the need to carefully interrogate research relating to long COVID. For example, when commenting on whether the percentage of people with severe COVID symptoms had reduced after widespread vaccination, Associate Professor Irving advised that ‘there is certainly some suggestion that that might be true, although my experience with all the COVID-related publications is that you need to see it a second and a third time before you believe it. There are a lot of early reports that turned out not to be true.’¹⁴

Regulatory issues

- 3.15 The Committee received submissions that discussed aspects of Australia’s regulatory landscape that impeded their long COVID research efforts.
- 3.16 UPcare Group, a botanical drug research and development enterprise, reported that that patent protection activity by large pharmaceutical companies limits related product developments by other researchers. UPcare Group explained:

Small companies that are unable to acquire the resources required to further their product development have only two options: gaining the interest of big pharma or reducing their efforts. This results in research tending to be unidirectional and not multidirectional.¹⁵

¹¹ Queensland Health, Submission 150, p. 6.

¹² Murdoch Children’s Research Institute, Submission 178, p. 8.

¹³ Murdoch Children’s Research Institute, Submission 178, pages 7, 8.

¹⁴ Associate Professor Louis Irving, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 3.

¹⁵ UPcare Group, Submission 270, p. 3.

- 3.17 Professor Andreas Suhrbier, a National Health and Medical Research Council¹⁶ research fellow, told the Committee that his research group waited up to ten months to receive a response to a request to obtain import permits needed for their research.¹⁷ Professor Suhrbier said:

Research into COVID and long COVID has been severely impeded by a series of slow and cumbersome regulatory issues. One of the main problems is obtaining import permits from DAFF [Department of Agriculture, Fisheries and Forestry] now takes well in excess of the prescribed 90 days, even for PC1¹⁸ items like licensed vaccines.¹⁹

- 3.18 Professor Suhrbier explained that these delays make it difficult to participate in collaborative research and development with international bodies.²⁰

Funding

- 3.19 Several submissions raised funding as a critical limiting factor to successful research outcomes.

- 3.20 Dr Sharon Lewin informed the Committee that the current approach to funding research tends to increase fragmentation rather than encourage collaboration. She commented:

Lastly, most of the funding that we did with COVID—and there was quite a bit of additional research funding coming in for COVID—was done in the usual model, meaning breaking people up into small groups and competing with each other. We got a whole lot of small studies, and nothing cohesive. If I could just make the argument for big challenges like this we need strategic funding that brings people together, not breaks them apart and allows small groups to compete against each other.²¹

- 3.21 The National Clinical Evidence Taskforce (NCET), a collaboration of Australia's medical colleges and peak health organisations who provide evidence-based treatment guidelines for urgent and emerging diseases, noted that the Victorian Post-Acute COVID-19 sequelae (VPACS) research group, which formed in February 2021 to share developments in long COVID research, has been operating without Australian Government funding.²²

¹⁶ The National Health and Medical Research Council is an independent statutory agency and the Australian Government's key entity for managing investment in, and the integrity of, health and medical research.

¹⁷ Professor Andreas Suhrbier, Submission 103, p. 1.

¹⁸ Physical Containment (PC) levels refer to the classification of a microbiological laboratory that dictates the type of biological samples the laboratory is permitted to handle. PC1 items require the lowest level of containment.

¹⁹ Professor Andreas Suhrbier, Submission 103, p. 1.

²⁰ Professor Andreas Suhrbier, Submission 103, p. 1.

²¹ Dr Sharon Lewin, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 54.

²² National Clinical Evidence Taskforce (NCET), Submission 232, pages 11–12.

3.22 Professor Mark Morgan, the Chair of the Royal Australian College of General Practitioners' (RACGP) Expert Committee for Quality Care, criticised the decision not to renew the Australian Government's funding for the NCET. According to Professor Morgan, the NCET is:

...the only organisation that has been set up and that is capable of doing this work in Australia...it maintains flow charts and evidence-based recommendations, with 100 per cent consensus of the 35 peak bodies involved in that organisation, including the RACGP. It is world's best practice in evidence generation...²³

3.23 During the public hearing roundtable convened by the Australian Academy of Science and the Australian Academy of Health and Medical Sciences, the Committee heard from multiple witnesses that there is a gap in implementation of knowledge in Australia, with limited funding available to translate scientific findings into the coalface.²⁴

3.24 UPcare Group advised that in the private sphere, there have been 'limited opportunities to raise development capital' for COVID-19 treatment and pharmaceutical research.²⁵

3.25 Other submissions noted the relative lack of funding for long COVID research in Australia when compared with other jurisdictions. The Faculty of Medicine, Dentistry and Health Sciences of University of Melbourne (University of Melbourne) observed that:

Research funding for long COVID in Australia is currently severely underfunded compared to funding internationally, in particular the United Kingdom (UK) and the United States of America (USA). Overseas health authorities are spending billions on tackling long COVID, with innovative research projects for new treatments and comprehensive patient support.²⁶

3.26 However, the Department of Health and Aged Care (the Department) submitted that there has been an overall investment of A\$130 million in COVID-19 research through the Medical Research Future Fund.²⁷ A portion of this has been allocated to long COVID research.²⁸

²³ Professor Mark Morgan, Royal Australian College of General Practitioners, *Committee Hansard*, Malvern, 20 February 2023, p. 13.

²⁴ Various roundtable participants, *Committee Hansard*, Canberra, 17 February 2023, pages 57-60.

²⁵ UPcare Group, submission 270, p. 2.

²⁶ The University of Melbourne - Faculty of Medicine, Dentistry and Health Sciences, Submission 237, p. 6.

²⁷ The Medical Research Future Fund is an ongoing research fund set up by the Australian Government in 2015. Every year, the Government uses some of the net interest from this investment (currently A\$20 billion) to pay for medical research initiatives such as the Clinical Trials Activity Initiative and the Genomics Health Futures Missions, amongst many others. See, Department of Health and Aged Care, *About the MRFF* www.health.gov.au/our-work/medical-research-future-fund/about-the-mrff, viewed on 28 March 2023.

²⁸ Department of Health and Aged Care, Submission 196, p. 11.

- 3.27 The long COVID research projects identified by the Department as being funded through the Medical Research Future Fund were:
- A\$3.4 million to Murdoch University to further its research into improving the understanding of long-term impacts of COVID-19 and develop new models to predict disease progression and tailor treatment
 - A\$1.8 million to University of Melbourne to investigate the effect that SARS-CoV-2 variants of concern may have on the brain
 - A\$3 million to the Australian Institute of Health and Welfare (AIHW), to establish a national linked data platform that integrates COVID-19 case information with a range of relevant existing health datasets
 - A\$2.4 million to University of New South Wales to investigate statin treatment to prevent brain complications as a result of COVID-19
 - A\$2.6 million to University of Melbourne to investigate the use of cardioprotective therapy to manage persistent cardiovascular effects of COVID-19.²⁹
- 3.28 According to the Department, the National Health and Medical Research Council has also funded two projects on long COVID:
- A\$717,305 to the University of Queensland to investigate COVID-19-induced vascular complications: mechanisms and potential therapies
 - A\$904,308 to the University of Queensland for the project 'Targeting neuropilin in SARS-CoV-2 neuronal uptake and transport.'³⁰
- 3.29 The AIHW also provided funding to the Australian National University (ANU) Centre for Social Research and Methods' COVID-19 Impact Monitoring series, which includes a focus on experiences of long COVID.³¹
- 3.30 The Committee heard differing perspectives on where long COVID research funding should be directed. Associate Professor Anthony Byrne, a Respiratory Physician and lead investigator on the ADAPT observational cohort study led by St Vincent's Public Hospital, called for more government funds to support hospital-based research³², whereas the RACGP argued that:

There needs to be a renewed focus on supporting and funding research in general practice. General practice research must be a priority because it is the cornerstone of the health system that provides care to the majority of the population. Currently, less than 1% of National Health and Medical Research Council... competitive funding is awarded to primary health care projects, and less than 1% of funding in the Medical Research Future Fund... 10-year plan is specifically allocated to primary care.³³

²⁹ Department of Health and Aged Care, Submission 196, p. 12.

³⁰ Department of Health and Aged Care, Submission 196, p. 12.

³¹ Department of Health and Aged Care, Submission 196, p. 12.

³² Associate Professor Anthony Byrne, Submission 155, p. 2.

³³ Royal Australian College of General Practitioners, Submission 168, p. 7.

3.31 Professor Brendan Crabb AC, the Director and Chief Executive at the Burnet Institute, recommended better coordination of the Medical Research Future Fund and the National Health and Medical Research Council long COVID projects. He stated:

The reason they're [the Medical Research Future Fund and the National Health and Medical Research Council funding streams] separate is that there's a really important function that needs to be at least conceptually maintained of the different funds. But lacking that overall coordination is a big missed opportunity here, as is potentially the NIHR [National Institute for Health and Care Research]³⁴ type activity that the UK has that is missing ...the MRFF [Medical Research Future Fund]—it has a very conservative disbursement strategy. It's a well over \$20 billion fund now.' It's a \$650 million disbursement each year or something of that magnitude. The aim when it was launched was for it to be a billion dollars a year, and that is still less than 5 per cent of the fund... It has an incredibly conservative approach to disbursement. That was there for a reason at the time but it's no longer as relevant.³⁵

3.32 Other long COVID research funding sources were also identified in the submissions, including private and state government sources. These included:

- Philanthropic organisations such as the Spinnaker Health Research Foundation, the McCusker Charitable Foundation and the Telethon Trust³⁶
- The National Heart Foundation of Australia³⁷
- An 'altruistic donation'³⁸
- The Victorian Government Department of Jobs, Precincts, and Regions³⁹
- The Lung Foundation Australia.⁴⁰

3.33 Evidence from Western Australia (WA) highlighted some critical state government funding being channelled into long COVID research. The WA Department of Health submitted that the WA Government's Future Health Research and Innovation (FHRI) Fund:

...provides a secure source of funding to drive health and medical research, innovation and commercialisation and through these activities, improve the health and prosperity of all Western Australians. The FHRI Fund Strategy which provides a high-level vision and goals for research and innovation has been

³⁴ The National Institute for Health and Care Research is a English funding body that is connected to England's National Health Service. The National Health Service is the publicly funded healthcare system.

³⁵ Professor Brendan Crabb AC, Chief Executive Officer and Director, Burnet Institute, *Committee Hansard*, Canberra, 17 February 2023, p. 59.

³⁶ Australian National Phenome Centre, Submission 211, p. 3.

³⁷ The National Heart Foundation of Australia, Submission 284, pages 4–5.

³⁸ Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 6.

³⁹ Victorian Post-Acute COVID-19 sequelae research group, Submission 290, p. 10.

⁴⁰ The George Institute, Submission 514, p. 3.

refreshed and now includes "Living with COVID-19 and Long-COVID" as a focus area, which will inform future calls for research and innovation proposals.⁴¹

Suggestions for future research

3.34 The Australian Society for Medical Research advised that research needs to characterise the biological and clinical features of long COVID to ultimately inform researchers, health care professionals, patients, and caregivers, and policy makers and to strengthen the development of preventative health strategies, diagnostic tests and new treatments.⁴² Specifically, future research needs to address key issues including:

- How is Long COVID diagnosed?
- Can we predict who will develop long COVID?
- What are the clinical symptoms of Long COVID in the Australian population?
- Are there distinct subtypes (phenotypes) of Long COVID?
- What is the natural history of Long COVID?
- How do the clinical manifestations of Long COVID vary across the lifespan and different demographic groups?
- How do symptoms change over time?
- How are symptoms affected by various interventions, such as vaccines?
- Are there distinct phenotypes among those patients who do not fully recover from initial COVID-19 infection?
- How does SARS-CoV-2 infection initiate development of conditions that evolve over time to cause organ dysfunction or increase the risk of developing other disorders?⁴³

3.35 A common theme that emerged from the evidence was the need for further research regarding long COVID diagnosis and treatment. According to Emerge Australia, a patient organisation for people with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), 'The historic lack of research into post-infection diseases means that hundreds of thousands of Australians with Long COVID also have very few treatment options, and face years of chronic disability.'⁴⁴

3.36 Evidence to this inquiry also raised the need for Australia-specific research due to our comparatively high vaccination rates and the dominance of the Omicron variant. The Australian Academy of Health and Medical Sciences and the Australian Academy of Science advised that:

⁴¹ Department of Health (Western Australia), Submission 273, p. 5.

⁴² Australian Society for Medical Research, Submission 242, p. 2

⁴³ Australian Society for Medical Research, Submission 242, p. 2.

⁴⁴ Emerge Australia, Submission 67, p. 13.

As Australia's path through the COVID-19 pandemic was different from that of most other countries due to early lockdowns until vaccination rates were high, our experience of long COVID may be different. There is a strong case for progressing targeted research specifically within the Australian community.⁴⁵

- 3.37 The submissions indicate that the effect of different variants on the development of long COVID has yet to be determined, and the protective effect of vaccination needs to be further investigated.

Preventative strategies

- 3.38 Several submissions suggested further research be undertaken into means of preventing long COVID.
- 3.39 The Institute for Evidence-Based Healthcare submitted that COVID-19 vaccines have been found to prevent COVID infections, particularly in respect of earlier variants of the virus, and thus would help prevent long COVID. The Institute submitted that what is less clear but 'highly plausible' is whether vaccines reduce long COVID by virtue of reducing the severity of COVID-19 itself and therefore 'trials on vaccination effect for post-infectious and post-long COVID patients should be conducted as a priority.'⁴⁶
- 3.40 Moderna Australia recommended continued investment in vaccination research, as 'Retrospective and prospective surveillance of Long COVID and Repeated Infections in fully and partially vaccinated individuals is required to determine impact of vaccination on the incidence of Long COVID and Repeated Infections as well as the outcomes of these events.'⁴⁷
- 3.41 COVID-19 vaccines and long COVID, alongside other preventative strategies, are discussed further in Chapter 5.
- 3.42 From a research perspective, Professor Lidia Morawska from the School of Earth and Atmospheric Sciences, Queensland University of Technology, confirmed that there is a need for further study regarding pollutant measurement:

There are health-based World Health Organization Air Quality Guidelines (WHO AQG) that apply to both outdoor and indoor air. However, since we cannot routinely measure the pollutants included in the guidelines in every shared indoor environment, we need to identify a set of pollutants that can be measured.

Pollutants originating from human expiration indoors, including pathogens, lead to airborne infection transmission. They are not included in the WHO AQG and it is not feasible to routinely measure pathogens in these environments. Therefore, we need to identify proxy parameters for such pollutants that can be measured.

⁴⁵ Australian Academy of Health and Medical Sciences and the Australian Academy of Science, Submission 165, p. 1.

⁴⁶ Institute for Evidence-Based Healthcare, Submission 195, p. 14.

⁴⁷ Moderna Australia, Submission 170, p. 3.

- 3.43 Professor Robyn Schofield, an Associate Professor of Atmospheric Chemistry at the University of Melbourne, suggested that there is a need for further research into ventilation technologies:

We need research to ensure that we can deal with the fact that we can drive down the cost. We want to have energy efficient buildings. We want to make them resilient to climate change. Outside air, bringing that in all the time, will not always work when we have bushfires or outdoor pollution, for example. We do need to have innovation in this space. We do need to ensure that any technologies that we bring in to solve the problem don't create a new one.⁴⁸

- 3.44 Improved air quality and ventilation controls to prevent COVID-19 infection and thus long COVID was discussed in several submissions, and this is discussed further in Chapter 5 of this report.

Diagnosis and causes of long COVID symptoms

- 3.45 Evidence to the inquiry indicates that research into the pathophysiology of long COVID is needed to diagnose and understand the condition, and develop appropriate treatments.
- 3.46 Associate Professor Anthony Byrne submitted that the 'research and clinical as well as immunological insights from this study have been influencing the research space and [they will] continue to make discoveries into key biomarkers⁴⁹ that correlate with LONG COVID.'⁵⁰
- 3.47 Although the evidence to the inquiry indicates that considerable progress has been made towards identifying long COVID-19 related biomarkers, some ongoing challenges to research in this area were reported.
- 3.48 Professor Jeremy Nicholson, Director of the Australian National Phenome Centre, advised that 'a whole series of really very interesting and potentially very important markers of the disease and long COVID' have been developed. Professor Nicholson further stated that COVID-19 is 'a genetically unstable disease—it probably will never stabilise—so it's going to keep throwing new things at us for years to come. So we need to continue the basic research.'⁵¹
- 3.49 Professor Nicholson further reported that he had difficulty testing disease markers in Australian populations due to lack of different COVID-19 variants in the populations,

⁴⁸ Associate Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne, *Committee Hansard*, Malvern, 20 February 2023, p. 21.

⁴⁹ The term 'biomarker' refers to almost any measurement reflecting an interaction between a biological system and an environmental agent, which may be chemical, physical or biological.

⁵⁰ Associate Professor Anthony Byrne, Submission 155, p. 1.

⁵¹ Professor Jeremy Nicholson, Director, Australian National Phenome Centre, *Committee Hansard*, Malvern, 20 February 2023, pages 32-33.

and noted that Australia lacks an equivalent body to the NIHR, which has funded translational research and driven scientific progress in the UK.⁵²

- 3.50 The Western Health COVID Recovery Collaboration advised that the diverse range of long COVID symptoms ‘is a key challenge to rigorous research’ and cautioned that as a result, ‘Controls may not address the varying trajectories of Long COVID, as symptoms may emerge at different stages of recovery.’⁵³
- 3.51 The Australasian College of Nutritional and Environmental Medicine called for additional research into multiple areas that it suggests may contribute to the long COVID experience: autoimmunity and autoimmune exacerbation, persistent co-infection/inflammation with Epstein Barr Virus, mould, allergy, vector borne illness, and Mitochondrial function and metabolic syndrome.⁵⁴

Links to other conditions

- 3.52 The Committee also received important evidence from health charities, not-for-profit organisations, and medical research institutes about the relationship between long COVID and the potential onset of other medical conditions. The evidence suggested that long COVID could be associated with an increased risk of developing other conditions, but more research is needed on this issue.
- 3.53 Associate Professor Shidan Tosif, a Consultant in General Medicine and Clinical Lead at Melbourne’s Royal Children’s Hospital’s Post-COVID Clinic, shared his experience supporting children with long COVID. He stated that the clinic has not seen ‘that long COVID leads to new immune problems or new medical conditions’, however noted that it is an area currently under research and something the clinic is monitoring for, by trying to conduct long-term follow-up with its patients.⁵⁵
- 3.54 The Victorian Department of Health noted that ‘Studies also suggest that long COVID may be associated with more serious issues such as an increased risk of developing diabetes, cardiac issues such as heart attacks and strokes, and neuropsychiatric symptoms such as insomnia.’⁵⁶
- 3.55 Diabetes Australia told the Committee that ‘Research funding should be made available to further investigate; COVID related new onset diabetes, diabetes related COVID risks, prevention of complications and long COVID and the role of antiviral therapy in prevention of long COVID.’⁵⁷

⁵² Professor Jeremy Nicholson, Director, Australian National Phenome Centre, Committee Hansard, Malvern, 20 February 2023, p. 33.

⁵³ Western Health COVID Recovery Collaboration (WHCOVRE), Submission 493, p. 10.

⁵⁴ Australasian College of Nutritional and Environmental Medicine, Submission 434, p. 8.

⁵⁵ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children’s Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 8.

⁵⁶ Victorian Department of Health, Submission 87, p. 3, citations omitted.

⁵⁷ Diabetes Australia, Submission 209, p. 5.

3.56 The Stroke Foundation also advised that evidence suggests those who experience long COVID have an increased risk of suffering from a stroke, and noted that some neurological symptoms, such as fatigue, are common to both conditions. It indicated that long COVID research could have benefits for other conditions and ‘as more is invested in research to improve our understanding of Long COVID, this should accelerate the development of therapeutic interventions for a range of conditions, including fatigue.’⁵⁸

3.57 The Florey Institute of Neuroscience & Mental Health has been investigating the long-term neurological consequences of COVID-19 and reported that their research suggests:

there are serious long-term consequences of infection in multiple organ systems, such as post-acute COVID-19 syndrome, or ‘long COVID’. There is particular concern around the neurological symptoms including loss of smell and memory complaints. Approximately 80% of those infected with SARS-CoV-2 virus report neurological dysfunction and 30% have persistent symptoms. The long-term implications of these neurological symptoms require careful consideration as many of them are known to be associated with increased risk of neurodegeneration or recognised as part of the prodrome of these disorders.⁵⁹

3.58 The Committee also received evidence indicating a potential link between long COVID and autonomic dysfunction, specifically postural orthostatic tachycardia syndrome (POTS). The Australian POTS Foundation and the Australian Dysautonomia and Arrhythmia Research Collaborative from the University of Adelaide explained that POTS is ‘an autonomic disorder identified by its hallmark manifestation of postural induced rapid heart rate in the absence of blood pressure drop on standing’, and is ‘poorly understood by healthcare providers’. These groups drew the Committee’s attention to research which indicates that there is a high prevalence of POTS in people with long COVID.⁶⁰

3.59 The Baker Heart and Diabetes Institute also informed the Committee about research it is currently conducting into the impact of long COVID on cardiometabolic health. In describing results from one study, the Baker Heart and Diabetes Institute noted that:

Although the main group of participants in this study had symptoms consistent with “Long COVID”, *significant subjective functional impairment was documented in a minority*. Very significant reductions of exercise capacity can be identified among these symptomatic patients, although this is uncommon... Echocardiographic evidence of abnormal cardiac structure and function is uncommon in patients after COVID, and *it seems unlikely that there is a cardiac cause for impaired exercise capacity*.⁶¹

⁵⁸ Stroke Foundation, Submission 338, p. 2.

⁵⁹ The Florey Institute of Neuroscience & Mental Health, Submission 534, pages 2–3, citations omitted.

⁶⁰ The Australian POTS Foundation and the Australian Dysautonomia and Arrhythmia Research Collaborative, University of Adelaide, Submission 167, p. 3, citations omitted.

⁶¹ Baker Heart and Diabetes Institute, Submission 138, pages 1-2.

- 3.60 The National Heart Foundation of Australia suggested that to help improve understanding of long COVID and other cardiovascular (e.g., heart failure), brain and nervous system conditions (e.g., stroke or dementia) caused by COVID-19 infection, 'further investment should be made into dedicated COVID-19 research studies...potentially linked to the existing '45 and Up Study', the largest ongoing longitudinal study of health and ageing in Australia. This would likely be a good investment over the next 5-10 years.'⁶²

Treatments

- 3.61 The evidence suggests that a successful single, or even multidisciplinary cure for long COVID remains elusive. In the face of this, people with long COVID have had to turn to symptom management and treatment strategies, but the success of these remain hard to quantify.

- 3.62 The Burnet Institute advised that there have to date been no published clinical trials evaluating long COVID management strategies, and suggested that studies looking at antiviral treatments of long COVID are needed:

Some of the most logical candidate drugs for long COVID are still not being tested in trials. Several antivirals are used against acute COVID-19. Some researchers think these drugs could ease the symptoms of long COVID, too — particularly as evidence grows that a lingering SARS-CoV-2 reservoir could trigger the condition. But there are still no registered studies directly looking at whether these antivirals — which are expensive and in relatively short supply compared with generic drugs — could ease long-COVID symptoms.⁶³

- 3.63 Professor Crabb AC expanded on the need to fund clinical trials, emphasising the need for research to investigate a variety of treatments:

Well-done trials are still necessary...A really effective pharmacological intervention is likely to be more than just antivirals, in the end. How long does it need to be taken for? Are there any biomarker issues? For example, if you have low cortisol, does it work? What about if you don't have low cortisol? These are the sorts of things that are going to be looked at.⁶⁴

- 3.64 In its submission, the Australasian Society of Clinical and Experimental Pharmacologist and Toxicologists recommended 'a national policy to support drug trials into long COVID that are in alignment with core clinical pharmacology and physiology principles, to ensure safety and efficacy of proposed treatments.'⁶⁵

- 3.65 Associate Professor Nada Hamad, the Director of the Haematology Clinical Trials Unit at St Vincent's Hospital, expressed the view that research is needed into co-

⁶² National Heart Foundation of Australia, Submission 284, p. 2.

⁶³ Burnet Institute, Submission 149, p. 16.

⁶⁴ Professor Brendan Crabb AC, Chief Executive Officer and Director, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 7.

⁶⁵ Australasian Society of Clinical and Experimental Pharmacologist and Toxicologists, Submission 275, p. 1.

designing models of care with long COVID patients. She wrote that ‘Even in the absence of known treatments, it is clear that the model of care that we are accustomed to in clinical medicine, even in multidisciplinary teams, is not effective.’⁶⁶

3.66 Professor Julie Leask, a social scientist, and Penelope McMillan, the spokesperson for ME/CFS Australia, also raised the need for patient experience to inform research into treatments for long COVID.

3.67 Professor Leask stated:

I want to make the case for a systematised look at the lived experience with long COVID that is a research based one that involves talking to people purposefully selected— people across many different strata, not just people who are accessing care but those who can't, such as people in rural and regional areas. That would be very useful from both a qualitative and quantitative perspective in getting a richer understanding of the many ways in which long COVID is affecting different people, including those with a voice and those with less of a voice...⁶⁷

3.68 The Australia Long Covid Community Facebook Group also reiterated that people with long COVID should be part of designing policy and research, given their significant lived experience of the condition. Its submission emphasised: ‘Work with us to design policy and research... Don’t make decisions without us.’⁶⁸

3.69 The National Aboriginal Community Controlled Health Organisation similarly told the Committee that any research among Aboriginal and Torres Strait Islander people be led by Aboriginal and Torres Strait Islander researchers and prioritise sharing of information with the community.⁶⁹

3.70 Penelope McMillan commented that:

The urgency with which we need to invest in research for those treatments is huge... There's a 300-person study that made progress in addressing fibrin amyloid microclots that dramatically improved people's functionality for a very large portion of the cohort using a triple drug protocol—drugs that are readily available, one of which is aspirin. Australian patients are attempting to replicate these results at home using over-the-counter drugs and nutritional supplements that they import from the United States. We need replication so that people don't have to self-medicate, self-treat with things that have been shown to be very likely to be effective.⁷⁰

⁶⁶ Associate Professor Nada Hamad, Submission 335, p. 7.

⁶⁷ Professor Julie Leask, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 50.

⁶⁸ Australia Long Covid Community Facebook Group, Submission 309, p. 20.

⁶⁹ National Aboriginal Community Controlled Health Organisation, Submission 477, p. 3.

⁷⁰ Ms Penelope McMillan, Spokesperson, ME/CFS Australia, *Committee Hansard*, Canberra, 17 February 2023, p. 51.

Poorly studied groups

Children and adolescents

- 3.71 The evidence to the inquiry raised the issue of insufficient research into the potential impact of COVID-19 infections and long COVID in children and adolescents.
- 3.72 One reason this demographic may warrant greater attention in research is that these individuals will likely be affected by the virus over the longest period, given their age.
- 3.73 The Committee also heard that a greater research focus on children and adolescents may also be justified since this group potentially faces higher rates of COVID-19 reinfection.⁷¹
- 3.74 Children and adolescents may be at greater risk of repeated COVID-19 infections due to factors including: their extended time spent in high density settings such as schools, an increased likelihood of being asymptomatic, and this group's lower vaccination rates compared to the adult population (see Chapter 5 for further discussion).⁷² The potential for higher COVID-19 reinfection rates is relevant to long COVID since as previously discussed, repeated infections appear to increase the risk of long COVID.⁷³
- 3.75 The NCET advised that while long COVID research discussions tend to focus on the adult population, the impact on the paediatric population is also worthy of focus:
- It would be prudent to monitor emerging evidence around the potential impacts of long COVID on the paediatric population, who may have to live with outcomes for a longer period of time, with potential ramifications for their health, quality of life, along with associated impacts on the healthcare system and social and economic flow-on effects.⁷⁴
- 3.76 The Murdoch Children's Research Institute called for research into areas relevant to long COVID in children, including:
- The true risk of persistent symptoms caused by COVID infection/s in children and adolescents from well-designed studies and better data.
 - The immune differences of children and adolescents who experience persistent symptoms due to long or repeat COVID infections.
 - The impact of age, disease severity and duration, virus strain, and other factors on the risk of long COVID in children and adolescents.⁷⁵

⁷¹ See, for example: Name withheld, Submission 16, p. 1; Name withheld, Submission 17, p. 1; Name withheld, Submission 31, p. 1; Caroline Molloy, Submission 43, p. 1; Dr Anita White, Submission 238, p. 5; COVID Safe Schools Inc, Submission 306, p. 3.

⁷² See, for example: Australian Education Union, Submission 276, pages 4-5; COVID Safe Schools Inc, Submission 306, pages 3-6.

⁷³ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 14, citations omitted.

⁷⁴ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 14.

⁷⁵ Murdoch Children's Research Institute, Submission 178, p. 9.

- 3.77 The University of Melbourne advised that understanding long COVID in children in particular is important as ‘Symptoms in children are different to those in adults but are poorly recognised. In addition to acute impacts on health, there are also likely consequences of long COVID on social and cognitive development that affect learning with subsequent longer-term impacts.’⁷⁶
- 3.78 The Royal Australasian College of Physicians raised that ‘there are currently no Long COVID cohort studies in Australia focusing on children and adolescents. Vaccination rates of children in the 5-12 year age group continue to be low, and the 6 months to under 5 years age group remaining primarily unvaccinated because vaccination is limited to children at greater risk of severe disease.’⁷⁷

Older Australians

- 3.79 In addition to children, evidence to the inquiry raised that it is important to investigate the effect of long COVID on older Australians (those aged 65 years and over).⁷⁸
- 3.80 The University of Melbourne suggested that ‘Understanding long COVID in older age groups...is a priority as there is a risk that in this age group, symptoms of long COVID (fatigue, brain fog, etc) may not be diagnosed and simply attributed to the effects of ageing or age-related disorders...’⁷⁹
- 3.81 In his evidence, Professor Michael Kidd AM, Deputy Chief Medical Officer, discussed the lack of research into the effect of long COVID on older people, and even the possibility of misdiagnosis or underdiagnosis of long COVID, leading to poorer health outcomes for that cohort of people. He told the Committee:

I did want to reinforce that long COVID in the elderly is one area that we are not looking at or hearing anything about. We looked at the international literature. We had a publication in The Lancet Healthy Longevity at the end of the year. There is very little coming through. One of the worries we have with the elderly, particularly people in aged care, where there have been so many people with COVID-19, is that people may have long COVID which gets misdiagnosed as frailty, and they miss out on the benefits of potential multidisciplinary care which may help them to recover and regain some of the function they may otherwise lose, causing a further deterioration in their health.⁸⁰

⁷⁶ The University of Melbourne - Faculty of Medicine, Dentistry and Health Sciences, Submission 237, p. 3.

⁷⁷ Royal Australasian College of Physicians, Submission 249, p. 9.

⁷⁸ Australian Institute of Health and Welfare, *Older Australians*, www.aihw.gov.au/reports-data/population-groups/older-people/overview, viewed 27 March 2023

⁷⁹ The University of Melbourne - Faculty of Medicine, Dentistry and Health Sciences, Submission 237, p. 3.

⁸⁰ Professor Michael Kidd AM, Deputy Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 12.

People with disability

- 3.82 Around 18 per cent of Australia’s population, or 4.4 million Australians, live with a disability.⁸¹ The AIHW states that many Australians living with a disability are at increased risk of contracting COVID-19 and ‘experiencing more severe health impacts.’⁸² The true impact of this community’s experience of long COVID is still unfolding.
- 3.83 The submission from Advocacy for Inclusion – Incorporating People with Disabilities ACT, a body representing people with disabilities in the ACT, advised:
- Little is known about the increased risk of contracting Long COVID if you are [sic] already have a disability. This is complicated by the failure to identify symptoms or recognise how symptoms present, for example, among people with intellectual disability. Disability support systems are driven by definitions and checklists that allow nonmedical workforces to assess and approve candidates for support services. But those with “invisible illness” rarely meet such criteria.⁸³
- 3.84 Advocacy for Inclusion recommended ‘a research agenda deciphering the multidimensional nature of Long COVID and its connection with pre-existing conditions, its identification, management, and treatment among people with disability, as well as its long-term social and political implications.’⁸⁴

Social effects research

- 3.85 Although everyone is largely aware of the effects of the COVID-19 pandemic on society generally, less is known about the current and future effects of long COVID, from the individual lived experience through to more wide-ranging societal effects.
- 3.86 Relationships Australia reported that their practitioners observed from early in the pandemic that people began to present with an increased range of co-morbidities, and an increased intensity of those co-morbidities. Their practitioners also noted the ‘first onset of domestic and family violence, and increases in harmful gambling, alcohol and other drugs.’⁸⁵
- 3.87 Relationships Australia suggested that to reduce the social effects of long COVID, the government should support research, education and public awareness campaigns to foster and maintain social connection, especially for people living with

⁸¹ Australian Institute of Health and Welfare, *People with disability in Australia*, www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability, viewed on 27 March 2023.

⁸² Australian Institute of Health and Welfare, *People with disability in Australia*, www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/people-with-disability/prevalence-of-disability, viewed on 27 March 2023.

⁸³ Advocacy for Inclusion – Incorporating People with Disabilities ACT, Submission 336, p. 4.

⁸⁴ Advocacy for Inclusion – Incorporating People with Disabilities ACT, Submission 336, p. 4.

⁸⁵ Relationships Australia, Submission 245, p. 2.

disability (including long COVID) and reduce risk of stigma and discrimination in health care, employment, education, cultural, social and recreational activities.⁸⁶

- 3.88 La Trobe University advised that their researchers are investigating media coverage of long COVID, and 'plan to work with patients to understand how well the media is providing their information needs and, through their involvement, to develop best practice guidelines for reporting on Long COVID.'⁸⁷

Impact on key workers

- 3.89 Several submissions also raised concerns regarding the effect of long COVID on health and research workforces.
- 3.90 The Victorian Department of Health noted that absences, sick leave and lost capacity due to long COVID could place pressure on many industries, and called for 'Greater investment in research, including studies on long COVID systemic health impacts, including workforce and how these impact capacity and demand for hospital services.'⁸⁸
- 3.91 Exercise & Sports Science Australia advised that 'Little research evidence is available yet as to the experiences of healthcare service providers in supporting long COVID-19 patients. Anecdotal evidence from Exercise and Sports Science Australia's members suggests that allied health professionals need upskilling (education and training) to better support patients.'⁸⁹
- 3.92 The Western Health COVID Recovery Collaboration also advised that research is needed into the experiences of the allied health, aged care or auxiliary workforces, and noted that the pandemic experiences of this workforce may be different to their medical and nursing colleagues. According to the Western Health COVID Recovery Collaboration, 'Without urgent action, there may be very few people left to provide care for Australians into the future.'⁹⁰
- 3.93 The Australian Council of Deans of Health Sciences recommended that health workforce research be included in a national framework for research into long COVID. It noted:
- Evidence to the Inquiry has already identified that Australia's healthcare workers appear to be particularly at risk of long-COVID. There will also be continuing and growing demand on the health system for access to rehabilitation in community settings for patients with long-COVID.⁹¹
- 3.94 The Committee also received evidence regarding other key workers that may be particularly impacted by long COVID, such as teachers. COVID Safe Schools Inc.

⁸⁶ Relationships Australia, Submission 245, p. 3.

⁸⁷ La Trobe University, Submission 246, pages 2–3.

⁸⁸ Department of Health (Victoria), Submission 87, pages 2–3.

⁸⁹ Exercise and Sports Science Australia, Submission 169, p. 8.

⁹⁰ Western Health COVID Recovery Collaboration (WHCOVRE), Submission 493, p. 7.

⁹¹ Australian Council of Deans of Health Sciences, Submission 183, pages 3–4.

noted that the demographics of the teaching profession align broadly with certain risk factors for long COVID (middle aged females), and in combination with schools being high transmission environments, this puts teachers at risk of developing long COVID.⁹² The Australian Education Union supported this view, reporting that it has received reports of teachers developing long COVID.⁹³

Economic impacts

- 3.95 In their submission to the inquiry, the National Centre for Neuroimmunology and Emerging Diseases (NCNED) noted that no investigations have been conducted into the economic effects of long COVID in Australia, but suggested that the current economic burden of ME/CFS could serve as an example as it is an illness of similar pathology.⁹⁴
- 3.96 The NCNED suggested research should aim to:
- Determine the short, medium and long-term socio-economic costs of Long COVID, and what are the costs to patients specifically
 - Determine the impact of Long COVID on economic burden, including costs incurred due to lack of productivity and loss of work for both health consumers and their carers, access to disability support services, increased visitation to healthcare practitioners, and cost of illness management
 - The impact of Long COVID on low socio-economic status communities and those disadvantaged throughout the COVID-19 pandemic in Australia
 - Consider a report on child and adolescent impact of Long COVID on the Australian economy, including health disparities
 - Consider the impact of Long COVID on the Australian workforce.⁹⁵

Mental health

- 3.97 The detrimental impact on the mental health and wellbeing of those living with long COVID was a common thread throughout the evidence. The evidence indicates that more research is needed into the mental health and cognitive impacts of long COVID.
- 3.98 The Australian Psychological Society and Phoenix Australia Centre for Posttraumatic Mental Health Ltd advised:

International research is currently underway to attempt to understand the neurological underpinnings of long COVID. It is important to note, however, that despite the dedicated efforts from leading researchers, the evidence is still very

⁹² COVID Safe Schools Inc, Submission 306, p. 8.

⁹³ Australian Education Union, Submission 276, p. 7; Australian Education Union, Submission 276.1, p. 2.

⁹⁴ National Centre for Neuroimmunology and Emerging Diseases, Submission 215, p. 13.

⁹⁵ National Centre for Neuroimmunology and Emerging Diseases, MHIQ, Griffith University, Submission 215, p. 14.

much in its infancy...In particular, there is a critical need for more research about treatments for psychological and cognitive symptoms associated with long COVID.⁹⁶

- 3.99 MSD Australia, a subsidiary of Merck & Co., noted that international studies highlighted the psychiatric consequences of long COVID, including post-traumatic stress disorder, anxiety and depression and confirmed the need for further research into long COVID treatments:

The substantial impact of long COVID on patients' mental and physical health was also demonstrated in a cross-sectional study of 1,930 healthcare workers, of which 1,406 suffered from long COVID...Significant differences were reported in physical and mental health scores in those with long COVID versus those without prolonged symptoms...The authors noted these findings highlight the need for effective rehabilitation strategies to improve HRQoL [Health-Related Quality of Life]. In addition, the need for further research to identify treatments that can prevent the development, and subsequent burden, of long COVID was highlighted in a cross-sectional study in Japan. This study demonstrated substantial reductions in HRQoL...in 108 patients experiencing a prolonged symptoms following acute COVID-19...⁹⁷

- 3.100 The Australian Academy of Health and Medical Sciences and the Australian Academy of Science reported that knowledge gaps regarding long COVID include:

potential mental health and neurological impacts of long COVID– these are relevant to all people with long COVID, but researchers believe that children and adolescents may be more susceptible – even among those with no history of mental illness or developmental delay. We need to ensure their experiences are understood, physical symptoms addressed, and if they have lost a level of daily function, the psychological impacts are adequately acknowledged and managed.⁹⁸

Data

- 3.101 Researchers, health agencies and treating practitioners emphasised in their evidence to the inquiry that quality Australian data is needed to understand the prevalence, disease course and social effects of long COVID.
- 3.102 Issues were raised with the current state of data collection, data availability, data quality, and a general lack of existing Australian data. Several submitters made

⁹⁶ Australian Psychological Society & Phoenix Australia Centre for Posttraumatic Mental Health Ltd, Submission 501, p. 7.

⁹⁷ MSD Australia, Submission 452, p. 9.

⁹⁸ Australian Academy of Health and Medical Sciences and the Australian Academy of Science, Submission 165, p. 6.

suggestions as to how this could be improved using tools such as new clinical codes and Medicare Benefits Scheme (MBS) items, overseas models and new technology.

Existing data sets, databases and modelling

- 3.103 The Committee heard about several models and data sets that have already been developed by researchers and government agencies.
- 3.104 The AIHW developed a data set that will link COVID-19 cases collected in state and territory notification systems to existing health data sets, including deaths, hospitals, aged care, immunisation, MBS and PBS data. Current limitations of the data are that there is no detailed information included on an individual's education or level of income, the scope of the linked data is limited to administrative health data sets, and if an individual does not have their positive result registered with a state or territory health department, the individual will not be flagged as having COVID-19 in this dataset.⁹⁹
- 3.105 The Department uses the Multiple Analysis Data Integration Project data from the Australian Bureau of Statistics (ABS) for the 'Understanding socio-demographic cohorts in the COVID-19 Vaccines Strategy' project. The project 'uses deidentified data in the Multiple Analysis Data Integration Project linked to the Australian Immunisation Register dataset to...analyse selected socio-demographic cohorts in the administration COVID-19 vaccines, and allow policy interventions to be targeted accordingly.'¹⁰⁰
- 3.106 Professor Raina MacIntyre, head of the Biosecurity Program at the Kirby Institute, advised the Committee that models of long-COVID projections can be used to test the impact of infection prevention and control strategies on future burden of long-COVID. Professor MacIntyre reported that using a mathematical model, she and her fellow researchers were able to estimate the age-specific burden of long COVID in Australia to October 2023:
- The model estimated that with a vaccine-only policy and no other efforts to mitigate transmission, almost all Australians will be infected at least once in the time window from January 2021 to August 2023. The total people with long-COVID by December 2023 is 1,323,482, with 43,910 of these being children 0.4 [sic] [0-4] years of age.¹⁰¹
- 3.107 Mama Health, an international collaboration of people with backgrounds in economics, information technology and medicine, told the Committee that it is 'engaging with online patient groups and associations, and providing them with an online platform to tell their entire patient story...Their stories are then aggregated to form a community dashboard, visually displaying anonymous data from others just

⁹⁹ Department of Health and Aged Care, Submission 196 (Attachment 1), p. 25.

¹⁰⁰ Australian Bureau of Statistics, *Multi-Agency Data Integration Project (MADIP) Research Projects*, www.abs.gov.au/about/data-services/data-integration/integrated-data/multi-agency-data-integration-project-madip/multi-agency-data-integration-project-madip-research-projects, viewed 22 March 2023.

¹⁰¹ Professor Raina MacIntyre, Submission 300, p. 1.

like them. This dashboard is also available for clinicians and other healthcare players...¹⁰²

- 3.108 Mama Health also advised that it has built a data mining and analysis model to generate data for long COVID research:

Using process mining technology, we organise all individual experiences in a model that mines, in an aggregated way, the most beaten paths of individuals, the roadblocks along their journey and the challenges people face - as reported by them. Such technology also allows us to assess correlations and dependencies among several events (e.g. symptoms and hospitalisation) to identify risk factors impacting patient outcomes.¹⁰³

- 3.109 The Australian Health Services Research Institute reported that the Australasian Rehabilitation Outcomes Centre holds a national database with more than two million rehabilitation episodes of care provided in both the public and private sectors across Australia. According to the Australian Health Services Research Institute, the Australasian Rehabilitation Outcomes Centre has enabled:

the modification of current data sets to facilitate the collection of rehabilitation episodes where the reason for the rehabilitation is post COVID sequelae... [and is] uniquely positioned to play a key role in the collection, analysis and benchmarking of long COVID data in returning people to work, normal functioning and family life.¹⁰⁴

Issues with current data

- 3.110 Although there is some data currently available, evidence to the Committee raised issues with its quality and illustrated the need for more comprehensive and reliable national data regarding long COVID.

- 3.111 Dr Golo Ahlenstiel of the Western Sydney Local Health District discussed the district's COVID-19 data collection platform in his evidence to the Committee. Dr Ahlenstiel advised:

We started data collection pretty much straightaway, and we have our ethics protocol and so on to make sure what we're doing is all appropriate. But I'm really concerned that a lot of our long COVID data comes from either hospital cohorts or cohorts referred to a long COVID clinic. So ultimately both cohorts have a substantial selection bias, either the most severe cohort or the one that has access to someone that refers them to a clinic.¹⁰⁵

¹⁰² Mama Health Technologies gmbH, Submission 313, p. 2.

¹⁰³ Mama Health Technologies gmbH, Submission 313, p. 5.

¹⁰⁴ Australian Health Services Research Institute, Submission 342, p. 3.

¹⁰⁵ Dr Golo Ahlenstiel, Clinical Network Director, Specialty Medicine, Western Sydney Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 11.

3.112 The NCET's submission to the inquiry repeated these concerns about the limited settings in which existing long COVID data has been gathered. It advised:

Existing long COVID clinics have been able to generate crucial data about the prevalence of long COVID secondary care, including data about likely prognosis for people receiving clinical treatment for long COVID in secondary care, **however, this data cannot be extrapolated outside this setting. At the same time there is no comparable data source describing the prevalence of long COVID seen in primary care.** [emphasis added] Without this information it is impossible to understand the true experience or impact of long COVID in Australia.¹⁰⁶

3.113 Professor Paul Kelly, the Australian Government's Chief Medical Officer, emphasised the need for integrated data from across all states and territories, advising that 'the biggest issue we have in infectious diseases is that we do not have notifiable, identifiable disease data at the national level. There are legal impediments to that. There is a long-standing issue. We have been talking to the states again and they are much more interested in doing that.'¹⁰⁷

3.114 Dr Nick Drogenberg, an academic, was critical of the lack of publicly available data to help members of the public and workplaces manage the risk of infection:

...the public is asked to individually manage their risk of infection, but the data they might use to do that, such as testing/case data linked to location, is being removed from public dashboards, and testing and reporting is optional. You can't manage a risk you can't see. And in workplaces staff are not told of other infected colleagues...¹⁰⁸

3.115 Allied Health Professions Australia pointed out allied health practitioners' lack of access to digital health tools that would assist them with caring for long COVID patients, such as My Health Record and secure messaging. It advised that 'Improving allied health digital infrastructure and its integration into primary health care will improve efficiencies for multidisciplinary care of long COVID but also many other chronic conditions.'¹⁰⁹

Limited data for groups potentially particularly vulnerable to long COVID

3.116 The Committee heard that as with the Australian population more generally, there is also a need for more data relating to community groups who are more susceptible to the effects of long COVID.

3.117 Moderna advised that there is a need for data on long COVID and the impact of vaccination in the Australian context, and particularly from Aboriginal and Torres

¹⁰⁶ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 6.

¹⁰⁷ Professor Paul Kelly, Australian Government Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 11.

¹⁰⁸ Dr Nick Drogenberg, Submission 68, p. 2.

¹⁰⁹ Allied Health Professions Australia, Submission 269, p. 23.

Strait Islander people and culturally and linguistically diverse communities where vaccination rates are often lower.¹¹⁰ According to Moderna, ‘This is particularly important given the complexity of Long COVID symptoms, overlaid with different healthcare structures, as well as social policies (lockdown, mandatory masks, workplace vaccination etc.).’¹¹¹

3.118 The National Aboriginal Community Controlled Health Organisation advised that generally data relating to Aboriginal and Torres Strait Islander people and COVID-19 is poor, particularly as the ABS currently does not publish excess mortality data for Aboriginal and Torres Strait Islander peoples.¹¹²

3.119 Kristy Crooks, an indigenous PhD scholar, also advised that there are issues with the collection of data regarding First Nations People:

It's important that the Indigenous status question is being asked of every patient, every visit, every time and that it's available on all pathology forms so we can accurately collect data on First Nations people. We know it's not routinely collected and it varies across jurisdictions. Also, the measures used to gather data for long COVID will systematically exclude First Nations people. For many First Nations people and families, illness is often normalised and they might not recognise that have long COVID and therefore won't seek healthcare. So, lots of First Nations people won't be diagnosed.¹¹³

3.120 In relation to children and adolescents, the Murdoch Children’s Research Institute noted that ‘there is no Australian data on the health, social, educational, and economic impact of long COVID in children and adolescents.’¹¹⁴

3.121 The Australian and New Zealand Paediatric Infectious Diseases Group also noted that ‘current evidence on the burden of post-COVID conditions, including long COVID, in Australian children is lacking.’¹¹⁵ It advised there is a need for ‘high quality, local data on the burden of post-COVID disease in children that is integrated into the health system response. This will also be key to forming a sustainable plan to manage COVID-19 into the future.’¹¹⁶

3.122 National Disability Services submitted that data regarding the effect of long COVID among people living with disability is not readily available, as 7.6 per cent of people under 65 with disability do not see a general practitioner when needed due to cost and people with severe or profound disabilities are also more likely to see multiple practitioners. It observed that ‘Data regarding any case management or collaboration

¹¹⁰ This is confirmed by the Australian Institute of Health and Welfare. See, Australian Institute of Health and Welfare, *Australia’s health 2022: data insights - Chapter 1: The impact of new disease: COVID-19 from 2020, 2021 and into 2022*, www.aihw.gov.au/getmedia/c91a05ef-307f-4c18-8ed3-dfe33d0c603d/aihw-aus-240.pdf.aspx?inline=true, p. 2, viewed 3 April 2023.

¹¹¹ Moderna Australia, Submission 170, p. 12.

¹¹² National Aboriginal Community Controlled Health Organisation, Submission 477, p. 7.

¹¹³ Ms Kristy Crooks, PhD Scholar, APPRISE, *Committee Hansard*, Canberra, 17 February 2023, p. 47.

¹¹⁴ Murdoch Children’s Research Institute, Submission 178, p. 10.

¹¹⁵ Australian and New Zealand Paediatric Infectious Diseases Group, Submission 214, p. 1.

¹¹⁶ Australian and New Zealand Paediatric Infectious Diseases Group, Submission 214, p. 1.

across these groups is not readily available to investigate whether key health risks and needs are being identified and responded to.¹¹⁷

Suggestions regarding data collection and analysis

3.123 Several researchers, organisations and government departments offered advice as to how data collection and reporting could be improved to inform research and policy development regarding long COVID. The evidence to the Committee suggested that Australia could benefit from adopting some practices from other jurisdictions, particularly the UK.

3.124 The Victorian Department of Health advised that what is needed is a 'nationally coordinated approach to data and reporting particularly facilitating alignment of metrics and reporting to underpin best practice, continuous improvement to models of care and update clinical guidelines in line with emerging evidence.'¹¹⁸

3.125 Further, it suggested a coordinated approach, like that adopted by the UK's National Health Service, involving:

- Utilisation of administrative/coding data
- A defined approach to developing the new data required for service planning and decision making (for example: survey/future registries)
- Patient reported outcome measures
- Data on workforce impacts of long COVID, including productivity impacts,
- especially for the healthcare worker segment of the workforce
- Clinical toolkits including patient assessment tools (for example: COVID-19 Yorkshire Rehabilitation Scale¹¹⁹)
- A nationally consistent approach to linking and using relevant data sets for research, planning and monitoring.¹²⁰

3.126 The NCNED referred to technology developed in the USA to help manage long COVID-19. It advised:

Machine learning techniques can be used to analyse high throughput data to provide insights into the impact of Long COVID on health and economy, promoting output of high impact research. Currently, a NIH funded clinical database is using machine learning models to explore de-identified electronic health record data to diagnose Long COVID and identify potential risks.¹²¹

¹¹⁷ National Disability Services, Submission 460, p. 4.

¹¹⁸ Department of Health (Victoria), Submission 87, p. 2.

¹¹⁹ The Yorkshire Rehabilitation Scale is a digital assessment and monitoring tool to remotely manage individuals with persistent COVID systems, used by the United Kingdom's National Health Service.

¹²⁰ Department of Health (Victoria), Submission 87, p. 8.

¹²¹ National Centre for Neuroimmunology and Emerging Diseases, MHIQ, Griffith University, Submission 215, p. 14.

- 3.127 The National Notifiable Diseases Surveillance System (NNDSS) ‘coordinates data on over 70 diseases that present a risk to public health in Australia. This helps us identify trends in diseases, assess the impact of disease control programs and develop policies to reduce the impact of these diseases.’¹²² The NNDSS collates, analyses and publishes disease information via a data visualisation tool, fortnightly reports, annual reports in the Communicable Diseases Intelligence journal and has published datasets for selected diseases from 2009 to 2019.¹²³
- 3.128 The Australian Nursing and Midwifery Federation recommended that the Australian Government include long COVID in the NNDSS’ Notifiable Diseases List and that guidelines should then be endorsed by the Australian Health Protection Principal Committee to include mandatory public reporting.¹²⁴
- 3.129 The NCET expressed concern about the potential overburdening of health professionals with data analysis:
- ClinicalTrials.Gov lists 190 studies underway focused on long COVID and in the past 12 months there were more than 4000 studies on long COVID published. It is not possible for a clinician to evaluate this quantity of data alone.¹²⁵
- 3.130 Further, the NCET recommended that the government continue to fund it to ‘identify, assess, and synthesise up-to-date evidence and convene clinical expertise to develop and sustain recommendations for the clinical care of long COVID in adult and paediatric populations in Australia.’¹²⁶
- 3.131 Guidelines regarding long COVID for healthcare workers are discussed further in Chapter 6.
- 3.132 Pathology testing data was put forward by Pathology Technology Australia as a potential source of long COVID related data. It noted that there is currently no single blood test that can help diagnose long COVID, but some candidate tests (such as Gamma Fibrinogen) correlate with clinical symptoms, and thus could be a useful source of data.¹²⁷
- 3.133 Professor Martin Hensher cautioned against neglecting traditional data collection techniques, such as population prevalence surveys:
- It is possible that a desire to use advanced data linkage assets and techniques may have led to decisions not to use more traditional survey techniques. Unfortunately, data linkage results do not appear to be available yet, and – in any

¹²² Department of Health and Aged Care, *National Notifiable Diseases Surveillance System (NNDSS)*, www.health.gov.au/our-work/nndss, viewed 3 April 2023.

¹²³ Department of Health and Aged Care, *National Notifiable Diseases Surveillance System (NNDSS)*, www.health.gov.au/our-work/nndss, viewed 3 April 2023.

¹²⁴ The Australian Nursing and Midwifery Federation, Submission 210, p. 6.

¹²⁵ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 2, citations omitted.

¹²⁶ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 2.

¹²⁷ Pathology Technology Australia, Submission 244, pages 3, 6.

case – may not be capable of yielding the information actually required to plan for Long COVID policy responses.¹²⁸

3.134 Professor Hensher recommended that the Australian Government direct and provide funding for the ABS and the AIHW to jointly ‘establish a nationwide, monthly population survey of Long COVID prevalence’ across all age groups.¹²⁹

3.135 The University of Melbourne suggested that there needs to be ‘establishment of large data sets of patients with long COVID to enable data linkage’ to enable further long COVID research to occur.

3.136 Further evidence indicates that long COVID datasets could usefully include the following information relevant to long COVID:

- Patient-level data on COVID-19 and subsequent health and healthcare utilisation history¹³⁰
- A registry of patients with long COVID, established with a unique cohort that includes a significant number of cases of post infection illness of a minimum of six months duration who are followed intensively¹³¹
- Data from a self-reporting portal specific for:
 - citizens to anonymously log their experiences of long Covid rates, onset and duration timings, and the mental and physical symptoms/impact citizens experienced and
 - practitioners to log their experiences and incidences.¹³²

3.137 Associate Professor Anthony Byrne suggested that St Vincent’s Hospital could be the custodian of a national long COVID registry, which could collate into a single database the tertiary referral data of Long COVID clinics nationally, adding that:

This would help greatly with data capture, number of patients reviewed, economics, effectiveness, recruitment for national and international clinical trials and of course research from interested parties following appropriate ethics approvals.¹³³

3.138 Suicide Prevention Australia advised that to identify vulnerable and high-risk groups and create better health outcomes for these groups, the Australian Government should collect data on long COVID cases and repeat infection in the community. It recommended the government ‘work with State and Territory Governments,

¹²⁸ Professor Martin Hensher, Submission 175, p. 2.

¹²⁹ Professor Martin Hensher, Submission 175, p. 3.

¹³⁰ Australian Healthcare and Hospital Association, Submission 285, p. 6.

¹³¹ See, for example: Name withheld, Submission 109, p. 3; Minister for Health and Wellbeing, SA, Submission 200, p. 3; Pfizer Australia, Submission 225.1, p. 3; Ruth Newport, Submission 231, p. 7; Name withheld, Submission 341, p. 6; Dr Anne Fletcher and Dr Luke Fletcher, Submission 436, p. 16; Name withheld, Submission 539, p. 14.

¹³² Dr Anne Fletcher and Dr Luke Fletcher, Submission 436, p. 16.

¹³³ Professor Steven Faux and Associate Professor Anthony Byrne, Submission 544, p. 2.

Coroners and the National Coronial Information Service to identify and report on any future suicide deaths where long COVID-19 may have been a contributing factor.¹³⁴

- 3.139 The National Aboriginal Community Controlled Health Organisation recommends publication by the ABS of excess mortality data for Aboriginal and Torres Strait Islander people and that all research and data collection be consistent with the principles of Indigenous Data Sovereignty and aligned with Priority Reform 4 of the National Agreement on Closing the Gap.¹³⁵
- 3.140 Professor Margaret Hellard, the Deputy Director of the Burnet Institute advised the committee that community engagement is essential when it comes to data collection from Indigenous and Torres Strait Islander communities. She emphasised that these communities themselves need to articulate the questions that need to be asked - 'there needs to be a codesigned community component where it's done seriously...' Professor Hellard also noted that co-design data collection is more costly, and needs to be appropriately funded especially for underrepresented groups.¹³⁶

Classification and coding systems

- 3.141 The International Classification of Diseases (ICD) system was developed by the World Health Organization (WHO) and is used in the Australian health care sector to provide an internationally consistent method of classifying all types of patients, their treatment and associated costs. Classification involves the use of coding systems to translate clinical information into useful data sets, which can then be used for developing policies on funding, budgeting and setting costs.
- 3.142 The WHO states that the ICD is important because it provides a 'common language' for recording, reporting and monitoring diseases. This language then allows physicians, nurses, other providers, researchers, health information managers and coders, health information technology workers, policymakers, insurers and patient organisations around the world to 'compare and share data in a consistent and standard way – between hospitals, regions and countries and over periods of time. It facilitates the collection and storage of data for analysis and evidence-based decision-making.'¹³⁷
- 3.143 Specifically, the ICD-10-AM/ACHI/ACS classification system is used for classifying the care of patients admitted to public and private hospitals and consists of:
- International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM) – used to classify diseases, injuries and related health problems

¹³⁴ Suicide Prevention Australia, Submission 203, p. 4.

¹³⁵ National Aboriginal Community Controlled Health Organisation, Submission 477, p. 3.

¹³⁶ Professor Margaret Hellard, Deputy Director, Programs, Burnet Institute, *Committee Hansard*, Canberra, 17 February 2023, p. 53.

¹³⁷ World Health Organization, *Importance of ICD*, www.who.int/standards/classifications/frequently-asked-questions/importance-of-icd, viewed 3 April 2023.

- Australian Classification of Health Interventions (ACHI) – used to classify surgeries, therapies and health interventions
 - Australian Coding Standards (ACS) – guidelines designed for nationally consistent application of ICD-10-AM and ACHI.¹³⁸
- 3.144 The Department advised that two additional codes relating to COVID-19 have been added to the Australian Modification of the ICD-10, being 'History of COVID19 with residual conditions' and 'Post coronavirus disease 2019 [COVID-19] condition'.¹³⁹
- 3.145 Evidence to the inquiry raised the question of whether this classification system is adequate for the purpose of generating accurate long COVID data.
- 3.146 The ABS uses the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10-AM) to code mortality data from state and territory registers of births, deaths and marriages. Once coded, the ABS uses this data to compile excess mortality statistics. According to the ABS:
- Excess mortality measures can account for deaths due to COVID-19, potentially misclassified or undiagnosed COVID-19 deaths, and other mortality that may be indirectly related to the pandemic (e.g. relating to social isolation or changed access to health care).¹⁴⁰
- 3.147 However, the ABS noted that mortality data has limitations as only deaths certified by a doctor are included in the analysis and advised that data from small jurisdictions should be 'interpreted with caution'.¹⁴¹
- 3.148 In its submission, OzSage reported that 'The excess death rate noted by actuaries is largely due to COVID-19 and its post-acute complications, including cardiovascular disease'¹⁴², referring to the 'How COVID-19 has affected Mortality and Morbidity in 2020 & 2021' report by the Actuaries Institute. By analysing the ABS' provisional mortality data, the Actuaries Institute determined that just over half of the excess deaths (10300) for 2022 were due to COVID-19, but considered the pandemic likely played a role in other excess deaths as well, despite this not being reflected in the data.¹⁴³

¹³⁸ Independent Health and Aged Care Pricing Authority, *ICD-10-AM/ACHI/ACS*, www.ihacpa.gov.au/health-care/classification/icd-10-amachiacs, viewed 3 April 2023.

¹³⁹ Department of Health and Aged Care, Submission 196, p. 29.

¹⁴⁰ Australian Bureau of Statistics, *Measuring Australia's excess mortality during the COVID-19 pandemic*, www.abs.gov.au/articles/measuring-australias-excess-mortality-during-covid-19-pandemic#measuring-excess-mortality, viewed 3 April 2023.

¹⁴¹ Australian Bureau of Statistics, *Measuring Australia's excess mortality during the COVID-19 pandemic*, www.abs.gov.au/articles/measuring-australias-excess-mortality-during-covid-19-pandemic#measuring-excess-mortality, viewed 3 April 2023.

¹⁴² OzSAGE, Submission 299, p. 10.

¹⁴³ Actuaries Institute Australia, *Media releases: 6 March 2023: Excess deaths climb to nearly 20,000 for Australia in 2022*, www.actuaries.asn.au/Library/MediaRelease/2023/230306MRCOVID19.pdf, viewed 3 April 2023.

3.149 The AIHW also used the ABS' ICD-10 coded mortality data to determine that since the start of the pandemic there have been 10,279 deaths due to COVID-19, of which 123 were classified as being due to post COVID-19 condition. However, the AIHW also noted that:

In September 2020 WHO activated an...(ICD-10) code for post COVID-19 condition. Analysis of the use of the code in US health care records has shown that the uptake varies widely and currently underestimates the frequency of long COVID. As use of the code becomes more consistent, health care records will provide large and rich sources of data to understand the impact of long COVID, such as patterns of health service use among long COVID patients.¹⁴⁴

3.150 The Australian Private Hospitals Association told the Committee that while private hospitals provide many services that are potentially relevant to long COVID patients, data is scant on the number of long COVID patients admitted to private hospitals as the coding systems do not always capture this as the primary reason for admission.¹⁴⁵

3.151 The Burnet Institute suggested that a definition of long COVID that includes post-acute conditions could 'inform better use of the [International Classification of Diseases] diagnosis code for post-acute COVID... and the medical certification cause of death'.¹⁴⁶

3.152 The Australian Dysautonomia and Arrhythmia Research Collaborative, University of Adelaide and the Australian POTS Foundation jointly submitted that autonomic dysfunction such as postural orthostatic tachycardia syndrome (POTS) has been found to be a common feature of long COVID. They expressed concern that POTS is under recognised by the Australian health sector and frequently coded incorrectly because it does not have a unique ICD code.¹⁴⁷

3.153 The Department advised that the Independent Health and Aged Care Pricing Authority (IHACPA) is currently working with the Commonwealth and states and territories to determine whether more specific codes are required to recognise specialised treatment provided for long COVID, or whether it can be treated through existing classifications.¹⁴⁸

Medicare Benefits Schedule and long COVID data

3.154 The Medicare Benefits Schedule (MBS) is a list of health professional services that the Australian Government subsidises. Each professional service in the MBS is allocated a unique item number, as well as an item descriptor, which outlines the

¹⁴⁴ Australian Institute of Health and Welfare, *Long COVID in Australia – a review of the literature*, www.aihw.gov.au/reports/covid-19/long-covid-in-australia-a-review-of-the-literature/summary, viewed 6 March 2023.

¹⁴⁵ Australian Private Hospitals Association, Submission 555, p. 1.

¹⁴⁶ Burnet Institute, Submission 149, p. 2.

¹⁴⁷ Australian Dysautonomia and Arrhythmia Research Collaborative, University of Adelaide and the Australian POTS Foundation, Submission 167, p. 4.

¹⁴⁸ Department of Health and Aged Care, Submission 196, p. 21.

service requirements. Information about MBS claims including benefits paid, patients and service providers is held by the Department of Health and Aged Care.¹⁴⁹

- 3.155 Several stakeholders raised their concerns with how the MBS operates with respect to treating long COVID. Issues with how the MBS fails to capture long COVID data also became apparent.
- 3.156 The Department reported that it used MBS item data for preliminary work to identify the impact of long COVID. It advised that for the analysis, it needed to use the MBS items for 'COVID-19 Management Service' and prescriptions for antiviral medication as proxy indicators to identify whether a patient was being treated for post-COVID conditions.¹⁵⁰
- 3.157 The Australian Council of Deans of Health Sciences submitted that a barrier to capturing primary healthcare data 'is the difficulty [sic] in extracting consultations related to long-COVID under the MBS chronic disease management items... this task would be more straightforward if there were to be MBS items specifically tailored to the needs of patients with long-COVID'.¹⁵¹
- 3.158 However, changes to MBS items are not likely to be timely. As noted by the MBS Review Taskforce, it can take 12 to 18 months to implement changes as they require:
- regulatory changes
 - mapping changes – advising practitioners, hospitals, insurers and other stakeholders
 - updating IT payment systems
 - updating MBS Online
 - advising stakeholders through webinars and fact sheets.¹⁵²

Committee comment

Research

- 3.159 The Committee recognises that researchers around the globe are conducting research directly related to long COVID and exploring health issues such as excess mortality and post COVID complications including cardiovascular, neurological and endocrine morbidity.

¹⁴⁹ Australian Institute of Health and Welfare, *Medicare Benefits Schedule (MBS) data collection*, www.aihw.gov.au/about-our-data/our-data-collections/medicare-benefits-schedule-mbs, viewed 3 April 2023.

¹⁵⁰ Department of Health and Aged Care, Submission 196, pages 10–11.

¹⁵¹ Australian Council of Deans of Health Sciences, Submission 183, p. 3.

¹⁵² Department of Health and Aged Care, *Medicare Benefits Schedule (MBS) Review*, www.health.gov.au/our-work/mbs-review, viewed 3 April 2023.

- 3.160 The Committee acknowledges the hard work of researchers from Australia and around the world in producing the long COVID data that is available today, and the ongoing work that governments in Australia are undertaking to improve data linkage.
- 3.161 The Committee considers that the current government funding arrangements for long COVID-related research are fragmented and could be better coordinated given our small population relative to other advanced economies. Special consideration should be given to encouraging greater collaboration between researchers and institutes and better leveraging existing publicly funded institutions such as the ABS, to ensure long COVID research is targeted at knowledge gaps and scale.
- 3.162 The Committee suggests consideration should be given to establishing a body focused on integrating research linking basic research with clinical trials and implementation. Consideration should additionally be given to reducing red tape to speed up ethics approvals.
- 3.163 The Committee notes the particular need for research targeted towards understanding the causes of long COVID and supporting clinical trials for potential treatments and preventative interventions. The need for clinical trials is important to best identify evidence-based interventions given the burden long COVID is imposing on the health system.
- 3.164 The Committee also notes with concern the lack of long-term health impact studies on COVID-19 in Australian children, the elderly and Aboriginal and Torres Strait Islander peoples.

Data

- 3.165 The Committee notes that improved data collection is urgently needed encompassing underrepresented groups also. The Committee received evidence that establishes that a great deal of data gathering has occurred and several relevant databases are already in existence, however, there is little integration of these databases and some necessary data is still not being collected. The Committee agrees that there is a strong need for a comprehensive national database that captures broad information relevant to COVID-19, including diagnosed long COVID cases among the Australian population (including children) and long COVID symptoms, as well as management/treatment approaches and outcomes.
- 3.166 The Committee is of the view that, based on the evidence received regarding COVID-19 vaccinations and their potential to reduce long COVID cases or severity, the database should also include vaccination rates of children and adults across Australian states and territories. This will facilitate ongoing public confidence in the COVID-19 vaccines.
- 3.167 The Committee believes that this database should also collect data on COVID-19 vaccination side effects. The Committee has formed this view based on the evidence of some people's experience with adverse reactions to COVID-19 vaccines. This particular data collection could be two-fold – the number of cases where a COVID-19

vaccination is believed to have played a role in a person's death, and the number of cases where people have suffered a significant or severe physical injury as the result of COVID-19 vaccination.

- 3.168 The Committee does not consider any recommendations are required at this time to progress additional long COVID codes considering the evidence provided by the Department of Health and Aged Care regarding ICD-10 AM classifications and ongoing work in this area.
- 3.169 The Committee notes that MBS codes in relation to supporting patients with long COVID are discussed further in Chapter 6. The Committee also notes that the Government has been progressively implementing changes to the MBS in response to the MBS Review Taskforce's recommendations, several of which relate to the management of chronic disease and may assist with the management of long COVID.¹⁵³

¹⁵³ See, Medicare Benefits Schedule Review Taskforce, *An MBS for the 21st Century: Recommendations, learnings and ideas for the future*, www.health.gov.au/sites/default/files/documents/2020/12/medicare-benefits-schedule-review-taskforce-final-report-an-mbs-for-the-21st-century-recommendations-learnings-and-ideas-for-the-future.pdf, viewed 3 April 2023.



4. Lived experiences of long COVID

Overview

- 4.1 The Committee recognises that long COVID itself is the problem: the emergence of this new condition, and our limited understanding of it, has meant that both patients and health care professionals alike have faced an extremely difficult situation and suffered from a lack of information.
- 4.2 The Committee recognises that for those affected, long COVID has impacted many aspects of life. While appreciating that each experience of long COVID is unique, this chapter summarises and highlights common themes of the lived experience of long COVID that the Committee heard throughout the inquiry.
- 4.3 This chapter discusses:
- The experience of seeking medical help and specialised care for ongoing symptoms after COVID-19 infection¹
 - Impacts on people's employment and income
 - Impacts on social activities and daily activities, including roles within the household.
- 4.4 In discussing these themes, many individuals who made submissions told the Committee about how long COVID has also impacted their mental health and wellbeing.
- 4.5 This chapter reflects the experiences of people with long COVID, rather than discussing long COVID from a clinical perspective. Definitions of long COVID, its prevalence, symptoms, risk factors and prognosis are discussed in Chapter 3. The perspectives of health practitioners interacting with people with long COVID are in Chapter 6.
- 4.6 Throughout this chapter, the identities of many individuals who made submissions are not shown as those individuals requested their name be withheld from publication. Given the highly personal nature of many submissions, the Committee was careful to protect individuals' privacy during the inquiry.

¹ The evidence to the inquiry indicates that most people initially seek help from general practitioners, who may refer them to other treatment services such as hospital based long COVID clinics. Patients may also be referred to medical specialists such as cardiologists or directed to allied health professionals.

Living with long COVID

- 4.7 The Committee received an outpouring of evidence from people living with long COVID. Despite this, the Committee heard multiple times that more individuals with long COVID would have liked to make a submission or contribute to the inquiry but were unable to do so due to the severity of their symptoms.²
- 4.8 Although some estimates were mentioned, the number of Australians living with long COVID remains uncertain.³ The prevalence of long COVID is discussed further in Chapter 2.
- 4.9 Professor Paul Kelly, Chief Medical Officer of the Australian Government Department of Health and Aged Care emphasised the importance of hearing and understanding the experience of people with long COVID. He said to the Committee:

What we don't generally have, and you absolutely have... is the really important component of capturing and analysing the shared experience, the lived experience of long COVID. From my perspective, what we want to hear from the committee is a summary of the things that you're hearing, as you've heard from your witnesses.⁴

Box 4.1 What do people with long COVID tend to experience?

While acknowledging that each person's lived experience is unique, the long COVID experience may include some or all of the following:

- Quality of life being impaired (or lost) due to symptoms that include fatigue, headaches, brain fog, low energy levels, and interrupted sleep, diet and exercise
- Bereavement for lives lost or multiple futures lost
- Lost earnings, impacts on household finances, and, in some cases, an inability to work or to extend care to family members including children
- Reduced immunity levels and a sense of vulnerability
- An inability to engage in social activities and sports
- Negative feelings, anxiousness and declining mental health
- Frustration with the lack of answers or consistent advice from healthcare professionals (or cures) that could return the person with long COVID back to better health
- Disillusionment with Australia's health care system.

² See, for example: Name withheld, Submission 234, p. 1; Ms Karren Hill, Administrator, Australia Long Covid Community Facebook Support Group, *Committee Hansard*, Canberra, 17 February 2023, p. 25.

³ Department of Health and Aged Care, Submission 196, p. 9.

⁴ Professor Paul Kelly, Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 8.

4.10 Several organisations and groups provided submissions reflecting on the collective experiences of their members with long COVID.⁵

4.11 A submission from the Brimbank Community-led Long COVID Support Group told the Committee that ‘everything changes’ when a person develops long COVID:

Concentration and focus, memory, stamina, cohesion, general cognitive function are all impaired. There is no certainty as to whether the issue will subside... Everyone suggest [sic] solutions to try and help (from medication, to alternative therapies, to general health and well-being, meditation etc.) but lack of definitive medical certainty is the most stressful factor, added [sic] the multitude of information on the internet, and the lack of brain function to decipher the information that is available.⁶

4.12 The Committee also heard from representatives of the Australia Long COVID Community Facebook Support Group, which had over 3000 members as of November 2022. Ms Karren Hill, an administrator of the group, expressed concern about the prevalence of long COVID in the community and said:

Estimates suggest that in Australia hundreds of thousands of people already have long COVID, and the last wave and the one expected next month are likely to add several hundred thousand more. For many it is a serious, life-changing condition. Our challenges in terms of our health, job, careers, incomes and relationships and our future health outcomes are entirely unknown. ... The scale of its impact in Australia is not always fully recognised. Many of our members are feeling neglected or forgotten. ... This lack of strong data makes it difficult to develop appropriate policy responses and easily dismiss the serious, urgent widespread need.⁷

4.13 The Consumers Health Forum of Australia, an advocacy group on consumer health care issues, reported that consumers were concerned about the long-term economic and social effects of long COVID:

...long COVID will have many ongoing effects for the economy, the health system, government payments and supports, and the whole community. Many people are taking long term sick leave or losing their jobs, returning to part time or lower skilled work, or face permanent disability. Those affected by long COVID will have to rely on government payments and health services, will need more

⁵ See, for example: Consumers Health Forum of Australia, Submission 484, p. 8; Brimbank Community-led Long COVID Support Group, Submission 527, p. 3; Ms Karren Hill, Administrator, Australia Long Covid Community Facebook Support Group, *Committee Hansard*, Canberra, 17 February 2023, p. 25.

⁶ Brimbank Community-led Long COVID Support Group, Submission 527, p. 3.

⁷ Ms Karren Hill, Administrator, Australia Long Covid Community Facebook Support Group, *Committee Hansard*, Canberra, 17 February 2023, p. 25.

paid and unpaid care, and will be unable to fully meet their own responsibilities to provide care for their children and/or others.⁸

4.14 The Committee heard that for a variety of reasons, ‘many are reluctant to seek help.’⁹

4.15 The Australian Psychological Society’s observations of patients attending the long COVID clinic at the Royal Melbourne Hospital identified that common themes included:

- Patients not being believed by peers, family and work colleagues about the impact of their long COVID symptoms and concerned that their experience may be considered ‘malingered’ by health professionals and/or others – a concept known as testimonial injustice.
- Feeling uncertain about the timelines for a likely resolution of their symptoms and the disruption to their life trajectory or identity¹⁰
- Feeling worried about keeping up with their previous work standards and being seen as incapable at work due to the fatigue, cognitive and psychological symptoms they are experiencing
- Difficulty advocating for themselves. Many report that their problem-solving skills have been impacted, and with increased anxiety levels it has been hard for them to ‘navigate the system’ to get assistance and try to make sense of their symptoms alone.¹¹

4.16 Another submitter articulated many of these challenges in their submission, including encountering disbelieving health practitioners. They highlighted how challenging they have found it navigating the healthcare system while unwell, despite relevant experience as a social worker:

Some will act very dismissive. My GP, who knew me for years, rolled their eyes at me, I’m almost certain, and was very dismissive, even though she knew me as a busy mum living a very full and active life and feeling pretty debilitated.

...

I spent a lot of time trying to navigate a system that was super hard normally, but, being as sick as I was... I’ve got a little bit of understanding of how to do that, and it was still really hard.¹²

4.17 The Australian Federation of Disability Organisations noted that ‘Both the COVID-19 pandemic and Long COVID have disproportionately affected vulnerable and marginalised populations, including people with disability.’¹³ They also expressed

⁸ Consumers Health Forum of Australia, Submission 484, p. 8.

⁹ Name withheld, Submission 1, p. 4.

¹⁰ Uncertainty about the prognosis for long COVID is discussed further in Chapter 3.

¹¹ Australian Psychological Society & Phoenix Australia Centre for Posttraumatic Mental Health Ltd, Submission 501, p. 5.

¹² Name withheld, Submission 531, p. 2.

¹³ Australian Federation of Disability Organisations, Submission 486, p. 14.

concern that those who become disabled by long COVID have difficulty accessing mainstream disability supports:

Long COVID can be incredibly disabling, leaving individuals unable to work or complete the basic activities of daily life. In order to access the DSP [Disability Support Pension] or NDIS [National Disability Insurance Scheme], individuals living with Long COVID must prove that they fit the detailed and stringent criteria of each – a nearly impossible task.¹⁴

4.18 Clinicians at the Long COVID Clinic at St Vincent’s Hospital in Sydney described how appropriate treatment and recognition can improve the patient experience:

A number of patients are significantly frustrated by the length of time it takes to make a diagnosis and to achieve a clinical appointment. During the clinical appointment they experience a sense of validation and are often overwhelmed by the recognition that their level of functional loss maybe [sic] caused by symptoms consistent with long Covid. They will then often have medications or tests prescribed and will often commence a tailored activity or movement program as well as see the psychologist face-to-face for education on pacing skills. For patients who live out of area, they will be reassured and referred back to their GP [general practitioner] with a comprehensive letter or referred to a rehabilitation, or pulmonary rehabilitation service in their area.¹⁵

4.19 These themes are discussed in more detail in the next section.

Seeking medical help and specialised care

4.20 The Committee received evidence from individuals about the steps they followed when they realised they were not recovering from their COVID-19 infection as expected, and what happened when they sought medical treatment.

4.21 Many people told the Committee about their experience reporting their ongoing symptoms after a COVID-19 infection to their general practitioner (GP). For example, the submission from the Consumers Health Forum of Australia noted the following common issues:

Issues patients faced included that their regular GP:

- did not accept long COVID as a condition
- did not accept that the symptoms they had were consistent with long COVID
- using outdated clinical guidelines to recommend inappropriate treatment

¹⁴ Australian Federation of Disability Organisations, Submission 486, p. 15.

¹⁵ Long COVID Clinic St Vincent’s Hospital, Submission 287, p. 5

- being concerned that they did not have the experience or [sic] expertise to treat the condition.¹⁶

4.22 Submissions described the length of time taken to receive specialised care after a GP identified long COVID as a possible diagnosis. Many submitters commented that the cost of these services were an additional challenge. For example, Rowena Findlay submitted:

I saw my GP at 3 weeks, he kept reassuring me that because I'd had the 4 vaccinations, the chance of me developing long covid was low. By 6 weeks he wrote me a sick certificate so I could continue to work reduced hours. By 8 weeks we talked about the long covid clinics. He said I had to wait until 3 months before I could apply and that there would probably be a long wait. He suggested going to see an exercise physician privately, which cost about \$100 per 1/2hr session. I wondered what those who couldn't afford it would do. While sessions were good to get me physically moving again, they admit themselves that they don't know a lot about long covid as they are learning along the way like the rest of us. I was completely frustrated by this time.¹⁷

4.23 Another individual with long COVID shared a similar experience:

I have not been able to work for 7 months now. Physical fatigue, mental fatigue, brain fog, memory problems, limb tremors, breathlessness. Our health system is a mess! I had to wait 3 months to see a cardiologist! Multiple costly GP appointments that took up to 2 weeks to get an appointment. Still no help!¹⁸

4.24 Emerge Australia, a national patient organisation for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) which is increasingly also working with individuals impacted by long COVID, discussed the issues regarding access to long COVID clinics. It submitted:

Although Long COVID clinics are operational across Australia, they do not offer all Long COVID patients access to timely medical care. We are hearing from our Long COVID patients that these clinics are difficult to access – many have long wait periods and/or only the most unwell people are admitted.¹⁹

4.25 Submitters also discussed the challenges of visiting a long COVID clinic from a distant location as another barrier to accessing medical help and specialised care for their symptoms. For example, one long COVID patient commented:

My GP has provided really great support during the diagnosis journey, which I am very grateful for. Unfortunately, the area in which I live does not have a long COVID clinic, so I cannot access the specialised clinical services available to long COVID patients in other states... I do not have clarity on other treatments

¹⁶ Consumers Health Forum of Australia, Submission 484, p. 6.

¹⁷ Rowena Findlay, Submission 55, p. 1.

¹⁸ Name withheld, Submission 410, p. 1.

¹⁹ Emerge Australia, Submission 67, p. 8.

that may help me, or what my prognosis is. This is incredibly frustrating and is impacting my mental health.²⁰

- 4.26 Another submission from a family member of a person with long COVID reported a similar inability to access any long COVID clinic:

...my family member has been enduring Long COVID symptoms for over 4-months – with no end in sight. Their Long COVID symptoms include ongoing fatigue, headaches, coughing, breathing problems, trouble sleeping, difficulties focusing on tasks due to fatigue and an ongoing feeling of ill health. My family member has no access to any Long COVID specialised treatment clinics in their area in regional Victoria, with most being located in city/metropolitan areas.²¹

- 4.27 The Committee received evidence that Aboriginal and Torres Strait Islander peoples experience additional barriers accessing care via long COVID clinics. The Aboriginal Medical Services Alliance Northern Territory highlighted the limited health services available in rural and remote areas:

The existing specialist long COVID clinics are not widely available, particularly for Aboriginal and Torres Strait Islander patients in rural and remote areas and have very limited capacity. Aboriginal and Torres Strait Islander people also face additional challenges navigating the healthcare system and accessing timely care and support.²²

- 4.28 One individual discussed the response offered by some GPs to patients seeking help:

My family member has repeatedly visited their GP, requesting further treatment for crippling symptoms. However they were told: “There’s no effective treatment for Long COVID²³ and so many people are going through what you’re going through. This is going to keep happening to a lot of people unless something is done.”²⁴

- 4.29 The Committee heard that given that knowledge of long COVID is still emerging, GPs can be uncertain about how to respond to symptoms associated with long COVID or reluctant to provide a diagnosis. For example, one submission stated:

My GP said that she could not offer medical help for my condition, she had not been given any recommendations from any health department for patients with Long Covid, beyond ruling out any other illness via scans and blood tests. She was however sympathetic and believes I have post covid illness, but won’t

²⁰ Name withheld, Submission 433, p. 1.

²¹ Name withheld, Submission 1, p. 2.

²² Aboriginal Medical Services Alliance Northern Territory, Submission 487, p. 4.

²³ Potential treatments for long COVID are discussed further in Chapter 6.

²⁴ Name withheld, Submission 1, p. 2.

diagnose me with Long Covid until... I am 3 months post covid infection as per the WHO [World Health Organization] recommendations.²⁵

4.30 Another submission stated:

Being a patient suffering Long Covid in Australia is horrendous. Diagnosis is very slow, GPs are hard to book, there is no real knowledge and no real diagnosis. No medication to help symptoms because they are simply thought they will eventually resolve after months of suffering.²⁶

4.31 Several patients with long COVID reported feeling as though their treating practitioners were not listening to them, or not understanding the nature of their illness. Associate Professor Nada Hamad, a physician researcher, described her experience as a long COVID patient. She told the Committee:

I saw several GPs and seven specialists and multiple allied health specialists in a long COVID clinic. No-one, not one person, was able to articulate why this was happening to me, to call it what it is and how long it would last, how to treat it or how to prevent it from getting worse with recurrent infection. In fact I had to advocate very hard for doctors to follow the evidence. I had to present them with the evidence. ... My story would be repeated back to me, or relayed back to me, incorrectly, which I found astonishing, as a doctor.²⁷

4.32 Associate Professor Hamad also expressed the view that many health practitioners were unable to easily access evidence-based information on long COVID due to the time pressures they are under. She recounted:

I understood, given this was a new problem, that everyone was really an experiment. In fact, the evidence was limited, but it was there. You just needed to know where to look and who to ask. No-one had the time...²⁸

4.33 Another submitter described their 'disheartening' experience seeking explanation for their ongoing symptoms after a COVID-19 infection and stated:

My experiences with long Covid have been frightening. I was not prepared for the health issues that occurred after a mild Covid infection. ...doctors have been thorough and performed every test, but when everything comes back 'normal', but you clearly feel like nothing is normal, it's very disheartening. Doctors may then think it's psychological which may certainly be part of it, but it's not the whole story... It's extremely important therefore to feel listened to and understood by your doctor. I've often heard the phrase, 'we don't know enough about it yet'. This provides little comfort to patients who are desperate for answers.²⁹

²⁵ Name withheld, Submission 3, p. 6.

²⁶ Name withheld, Submission 9, p. 1.

²⁷ Associate Professor Nada Hamad, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 21.

²⁸ Associate Professor Nada Hamad, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 21.

²⁹ Name withheld, Submission 505, p. 1.

- 4.34 Some individuals told the Committee they feel that their health practitioners are ignoring their symptoms. For example:

Since my first bout of COVID, I have had continued pain and numbness in my chest and shoulder. The pain varies between total numbness and burning agony, but never fully disappears. I have had cognitive confusion, headaches and extreme fatigue, dizziness and breathlessness. MRIs [magnetic resonance imaging scans] and blood tests have shown nothing of concern, and doctors appear to just be ready to ignore it.³⁰

- 4.35 Mrs Rebecca Adolph, a nurse with long COVID, discussed her difficulty in trying to obtain timely and effective treatment and the financial burden of seeking care:

General Practitioners are reluctant to diagnose long covid... I understand they are wanting to rule out other health conditions before diagnosing long covid. The cost of increased GP visits, referrals to Specialists and cost of medical tests is also impacting. The prognosis is unknown, and after living with long covid for 8 months now, and not having any resolution in my ongoing symptoms, it is hard to see the light out of this tunnel. There is a lack of support for people suffering with long covid. Doctors say that the key is to pace yourself and rest, however as a busy working mum, I don't have that luxury.³¹

- 4.36 In response to the lack of treatment options offered by health practitioners, some individuals have searched for their own solutions.³² For example, one individual said:

I was diagnosed quickly by my GP (4 weeks after initial infection), and for the first several months was told to 'wait it out.' Unsatisfied with this, I visited many different health care providers... Through trial and error of different medications, I was able to find things that relieved my symptoms.³³

- 4.37 However, another submitter with long COVID highlighted that self-help was not an option available to everyone citing the financial barriers to care:

My GP listened to what I had to say and said she had other patients have said similar. I have joined some Long covid Facebook groups. But I don't know where to look or turn for information and don't have the money to try different options.³⁴

³⁰ Name withheld, Submission 506, p. 1.

³¹ Mrs Rebecca Adolph, Submission 462, p. 4.

³² Potential treatments for long COVID, including recommendations not to use unproven therapies outside of guidelines or randomised trials with appropriate ethical approval, are discussed in Chapter 6.

³³ Name withheld, Submission 73, p.2.

³⁴ Name withheld, Submission 259, p. 1.

Adverse reactions to COVID-19 vaccines

- 4.38 The Committee heard from some submitters that vaccination related illness can sometimes present as a long COVID-like syndrome.³⁵ Adverse reactions to COVID-19 vaccines are also discussed in Chapter 5.
- 4.39 It is noted that some individuals experience asymptomatic SARS-CoV-2 infections³⁶, and it is therefore not possible to definitively rule out exposure to the virus in patients that report an adverse vaccine reaction.
- 4.40 For example, Professor Kerry Phelp AM told the Committee about examples of people developing symptoms mirroring long COVID after receiving a COVID-19 vaccine despite no known infection with the virus:

Within this group of vaccine injured individuals, there is a diminishing cohort of people who have symptoms following immunisation, many of which are similar to Long COVID (such as fatigue and brain fog), but who have not had a COVID infection. These people would be an important subset or control group for studies looking into the pathophysiology, causes of and treatments for Long COVID.

It is possible that there is at least some shared pathophysiology between vaccine injury and Long COVID, possibly due to the effects of spike protein.³⁷

- 4.41 Similarly, COVERSE Ltd suggested that adverse reactions to COVID-19 vaccines could be mistaken for long COVID, given the 'significant' overlap in symptoms.³⁸ COVERSE Ltd also highlighted the lack of social and medical support available to people that have experienced an adverse vaccine reaction:

...most of the vaccine-injured people in Australia have faced derision from public figures and unconscionable gaslighting and bullying by doctors, work colleagues, friends, and even from family. ... For many of us, despite our best efforts to stay connected and request help, other vaccine-injured people are our main source of support, resources and hope.³⁹

- 4.42 One submitter who was diagnosed by their GP as having 'long COVID-like symptoms' after receiving the COVID-19 vaccine told the Committee:

For the record, prior to my injury I was (and remain) pro-vaccination, and I still support COVID-19 vaccination; it is just unfortunate that I am part of a small proportion of people vaccinated for COVID that subsequently suffer 'long COVID-like' symptoms.

...after my second COVID vaccination I began experiencing significant neuropathic pain in my arms and legs, together with significant post-exertion

³⁵ See, for example: Name withheld, Submission 121, p. 2; Professor Kerry Phelp AM, Submission 510, p. 8; COVERSE Ltd, Submission 516, p. 2; Dr Melissa McCann, Submission 547, p. 5.

³⁶ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 16.

³⁷ Professor Kerry Phelp AM, Submission 510, p. 10.

³⁸ COVERSE Ltd, Submission 516, p. 2.

³⁹ COVERSE Ltd, Submission 516, p. 8.

fatigue. This has had a major impact on my work and home life; I went from being a fit, very active and busy professional to leading a slow and sheltered life, where my energy and activities are seriously limited and my quality of life is poor.

While I am lucky to have an excellent GP, in the ensuing 18 months I have been on a merry-go-round of testing, specialist visits and trialling various treatments; I have had to organise all of this myself, in spite of lengthy waiting lists for specialist visits (6 to 8 months is normal). While Medicare has subsidised some costs, I remain out of pocket many thousands of dollars (not counting lost income during this period); I shudder to think the impact this condition has on people unable to self-fund their care as I have.

A general physician specialising in “hard cases” recently diagnosed me with ‘long COVID-like symptoms’, though he was not able to provide any treatments beyond what I had already identified myself. While some medications (in particular low dose naltrexone for fatigue) have provided a degree of respite, I still have no sense of when or even if I will recover.⁴⁰

Impacts on employment and income

4.43 Many individuals with long COVID described to the Committee how their illness has impacted their employment and income. Some submitters said that they needed to reduce their work hours due to their illness and others had to stop working completely depending on the severity of their symptoms. This has negatively impacted their financial situations.

4.44 For example, Karen Johnston told the Committee that she can no longer work due to long COVID and as a result needs financial assistance from her elderly parents:

The impacts have absolutely destroyed my life in all areas... My health is longer the same, I cannot work to earn money or go out for very long. My struggle affects my elderly parents who have to help me out financially as Centrelink is not enough and they end up without money as well. ... The impact of Long Covid on my family I believe has caused so much grief that I fear it will never be the same again and our quality of life is over.⁴¹

4.45 A submission from Theresa Sheppard discussed similar challenges:

Financially I am going backwards. I am no longer able to work and am receiving Centrelink benefits. This pays my rent and puts basic food on the table, but does not allow for other bills such as phone/internet, electricity, school fees, clothing, sports activities for my boys and medical expenses.⁴²

⁴⁰ Name withheld, Submission 121, p. 1.

⁴¹ Karen Johnston, Submission 423, p. 1.

⁴² Theresa Sheppard, Submission 421, p. 2.

- 4.46 One individual described how their long COVID symptoms have impacted their ability to perform at work:

Where previously it was easy for me to do my job, which is demanding and requires managing many priorities, now I constantly find it a struggle. It's hard for me to think straight and listen to people when they talk, pay attention, read or concentrate. I am now forgetful and struggle to articulate my thoughts clearly.⁴³

- 4.47 Another submitter said they resorted to using their leave entitlements to cover the time they were unable to work due to long COVID:

I tried to work part time with reduced hours, but was unable to bear the chest pain. I have used up all my accrued sick leave, and I'm on my last week of annual leave, so my income is about to disappear.⁴⁴

- 4.48 The Committee heard that people employed on a casual basis and not entitled to sick leave who have long COVID are particularly financially impacted. One submitter described their family member's experience:

As a casually employed staff member in Aged Care they did not have access to any paid sick leave. As a casually employed staff member, they were unable to earn his usual income for over 2-weeks, and as a result needed to seek out support from friends and family to cover urgent expenses. ... After additional rest they returned to work, despite not feeling fully recovered – and this was primarily due to pressure and a lack of understanding from their employer, plus the pressure of staff to return due to chronic staff shortages in Aged Care.⁴⁵

- 4.49 Another submitter who had to reduce their work hours due to long COVID said they had to use their superannuation to cover living costs:

As a self-employed part-time worker, I still don't have income protection, and as a full-time mum of 4, I had very little superannuation and I took it all out when Covid shut down all my work...

Now with Long Covid, I have to cut down my work to just a few counselling clients a week, due to fatigue and other symptoms. Even counselling on Zoom is exhausting. I don't want to go onto JobSeeker as I can still work a little, and don't know if I could receive JobSeeker as I don't want to apply for work I cannot do. I don't have superannuation or income protection.⁴⁶

- 4.50 In addition to people with long COVID sometimes needing to forego income due to their illness, the Committee also heard about the financial impacts of seeking medical help. For example, Felicity Gay submitted:

⁴³ Name withheld, Submission 25, p. 1.

⁴⁴ Name withheld, Submission 27, p. 1

⁴⁵ Name withheld, Submission 1, p. 2.

⁴⁶ Name withheld, Submission 3, p. 6.

I estimate Long Covid has cost me around \$10,000 in medical expenses and \$30,000 lost income... I used to work full time. I attempted to work part-time after getting Covid but after 2 months had to stop work completely. I didn't work for 5 months. I attempted to return to part-time work at the start of October but haven't managed more than a few hours a week.⁴⁷

- 4.51 One submission suggested that workplaces should adjust to make it possible for a person with long COVID to return to work:

There are no guidelines on return to work and workplace accommodations for people with long COVID. No one knows what to do. There is still a lot of administrative burden and a lack of understanding about the realities of living with Long COVID. There are already excellent return to work models... but these need to be tailored to the individual and for long COVID. More importantly, there needs to be nationwide awareness and recognition that people need a suitable return-to-work plan and workplace accommodations.⁴⁸

- 4.52 Some people with long COVID have successfully negotiated reduced work hours with their employer. For example, one submitter told the Committee:

I am really lucky to be working at a supportive workplace. They have been understanding from the beginning, always telling me to prioritise my health and choose what hours work for me. I am now working about 7 hours a day but needing to have a rest in the middle (I do 3.5 hours at home, 1 hour rest, 3.5 hours at the office). While this isn't too different to a full day and I am lucky that I can manage challenging and demanding work, I find it mentally very hard to not be able to do a 'normal' day at the office. I really love my work and look forward to getting back to my previous hours.⁴⁹

- 4.53 The Committee heard that if there is a large number of long COVID cases, many individuals may not be able to work to their full capacity. The Victorian Department of Health noted the potential productivity implications of long COVID:

Anecdotally, local clinicians report that individuals with significant long COVID symptoms have a substantial reduction in their ability to carry out normal daily activities such as attend work or carer duties. This has a broader impact on sectors that are depending on a stretched workforce.⁵⁰

⁴⁷ Felicity Gay, Submission 30, p. 1.

⁴⁸ Name withheld, Submission 83, p. 6.

⁴⁹ Name withheld, Submission 74, p. 4.

⁵⁰ Department of Health (Victoria), Submission 87, p. 9.

Income support

- 4.54 Given these impacts on employment and income, many submitters called for specialised income support for people diagnosed with long COVID.⁵¹ For example, the Brimbank Community-Led Covid Group recommended:

Centrelink special Income support for GP diagnosed long COVID sufferers, non-means-tested, for at least up to 12 months, while sufferers are unable to work due to this disease, to alleviate immediate family and financial stress, and support services to help sufferers adjust to new work or work [sic] approaches, or potential pathway to disability support for those severely impacted and unable to work at all.⁵²

- 4.55 Inner Melbourne Community Legal and the Royal Melbourne Hospital (Allied Health Department) made a similar recommendation:

Long COVID patients need access to proper income support to make ends meet until they recover. The stress of struggling to pay the bills, to pay the rent or mortgage, only makes recovery more difficult.

- a. Workers eligible to make a workers' compensation claim need support to access help;
- b. People who are not eligible to access workers' compensation need a special COVID income support payment to make ends meet until they recover; and,
- c. More funding and increased access is needed for people to receive social work support, legal support, and financial counsellors assistance early to alleviate the financial and mental stress that can be a consequence of long COVID.⁵³

- 4.56 Other submissions suggested that people with long COVID should be eligible to access the National Disability Insurance Scheme and/or the Disability Support Pension.⁵⁴

- 4.57 The Australian Council of Trade Unions specifically recommended income support for people with long COVID who do not have access to sick leave or are employed casually.⁵⁵

⁵¹ See, for example: Long Covid Australia Collaboration, Submission 235, p. 4; Australia Long Covid Community Facebook Group, Submission 309, p. 3; Name withheld, Submission 491, p. 24; Brimbank Community-Led Covid Group, Submission 527, p. 4; Name withheld, Submission 547, p. 2.

⁵² Brimbank Community-Led Covid Group, Submission 527, p. 4.

⁵³ Inner Melbourne Community Legal & Royal Melbourne Hospital (Allied Health Department), Submission 333, p. 5.

⁵⁴ See, for example: Emerge Australia, Submission 67, p. 2; Name withheld, Submission 115, p. 3; Name withheld, Submission 172, p. 3; Name withheld, Submission 229, p. 3; OzSAGE, Submission 299, p. 10; Advocacy for Inclusion - Incorporating People with Disabilities ACT, Submission 336, p. 6; Name withheld, Submission 449, p. 1; Group of ME/CFS Patient Advocates, Submission 470, p. 3; Australian Federation of Disability Organisations, Submission 486, p. 15; Health Issues Centre, Submission 529, p. 3.

⁵⁵ Australian Council of Trade Unions, Submission 251, p. 2.

Impacts on mental health and social and daily activities

- 4.58 Many people with long COVID who wrote to the Committee said that reduced ability to participate in social activities and to perform everyday tasks impacts their mental health and quality of life. Their evidence also noted the impacts ongoing illness can have on parents with young children and carers.
- 4.59 Submissions discussed how these impacts can extend to household and family members who are called upon to provide care or to work additional hours, placing relationships with family and friends under pressure.
- 4.60 Some individuals with long COVID described feeling vulnerable in social settings and being concerned about further COVID-19 infections.
- 4.61 Lastly, the Committee heard that the challenges related to long COVID could affect educational opportunities.

Mental health impacts

- 4.62 The Committee was concerned to hear from many individuals about the negative impact of long COVID on their mental health.
- 4.63 The submissions from people living with long COVID included troubling insights into their experiences of declining mental health. Their comments included:
- I am depressed thinking about the lost friendships and the strained relationship with my husband... My mental health has deteriorated as I grieve the person who I used to be, not knowing if I will ever be that person again.⁵⁶
 - The frustration and sadness I feel on a daily basis that I am unable to live how I used to is beginning to affect my mental health. It is a lonely illness, one that lacks support, and also, I feel is poorly recognised and is still being accepted.⁵⁷
 - My mental health is deteriorating as I feel absolutely useless.⁵⁸
 - I am very anxious about re-infection... It has made social interaction very difficult as I'm continually scared of contracting the virus again and the ongoing implication of being unwell for a long period. My mental health has suffered greatly as a result.⁵⁹

⁵⁶ Name withheld, Submission 375, p. 1.

⁵⁷ Mrs Rebecca Adolph, Submission 462, p. 4.

⁵⁸ Name withheld, Submission 52, p. 1.

⁵⁹ Damien Wood, Submission 56, p. 1.

- I had also become depressed as my life was dramatically altered, and was fixated on long Covid. That I'm [sic] turn impacts on your family members and social and mental well-being.⁶⁰
- My mental health has taken a massive hit during this entire ordeal. I've been seeing a psychologist weekly for the past 12 months. I had to be admitted to a mental health facility for three weeks to help me try and cope with what I was dealing with. I am now on antidepressant medication and will be for the foreseeable future.⁶¹

4.64 Multiple witnesses and submitters reported that long COVID is generally associated with poor mental health, including mental health conditions such as anxiety and depression.⁶²

4.65 Among those who advocate that there is an increased risk of mental health difficulties among people with long COVID, different perspectives were heard over whether these are caused by long COVID itself, individuals' experiences of social isolation and stigma related to long COVID, and/or may be an exacerbation or reappearance of mental health issues that existed prior to the development of long COVID.

4.66 The Department of Health and Aged Care's submission explained that while evidence about the mental health impacts of long COVID is still emerging:

Many symptoms have been linked to long COVID, including fatigue, which studies suggest is among the most common and debilitating symptoms. It is known that fatigue can worsen symptoms of depression and anxiety and, in turn, depression and anxiety can worsen fatigue. Further, there is some evidence that people with pre-existing mental distress, including depression, anxiety, worry, perceived stress and loneliness, may be at increased risk of both developing long COVID and experiencing impairment in activities of daily living due to long COVID.⁶³

4.67 Associate Professor Alex Holmes, a member of the Victorian Post-Acute COVID-19 sequelae research group, reported that there is currently a limited understanding of the frequency and severity of psychological symptoms potentially associated with long COVID, since 'robust population studies are not available.' However, he outlined that relevant key learnings to date include:

- Long COVID is not primarily a psychological condition.
- Some individuals with long COVID are fearful that, in the absence of abnormal test results, health professionals will conclude that the

⁶⁰ Name withheld, Submission 505, p. 2.

⁶¹ Jason Woodyatt, Submission 485, p. 2.

⁶² See, for example: Royal Australian and New Zealand College of Psychiatrists, Submission 176, p. 2; Department of Health and Aged Care, Submission 196, p. 12; The University of Melbourne – Faculty of Medicine, Dentistry and Health Sciences, Submission 237, p. 6; Australian Psychological Society & Phoenix Australia Centre for Posttraumatic Mental Health Ltd, Submission 501, pages 6, 7.

⁶³ Department of Health and Aged Care, Submission 196, p. 14.

condition is psychological or 'all in their head'.

...

- A degree of anxiousness, uncertainty, concern about current and future implications, increased attention to physical symptoms and cognitive difficulties is normal.

...

- Individuals with more severe symptoms sometimes feel alienated, isolated, abandoned and not listened [sic] to.⁶⁴

4.68 Associate Professor Holmes added that 'A minority of individuals with long COVID may develop a secondary psychological disorder' in response to long COVID.⁶⁵

4.69 The Royal Australian and New Zealand College of Psychiatrists also noted that some individuals with long COVID will develop mental health issues:

COVID-19 can lead to a wide range of deleterious health effects. While most people recover well, some will go on to develop serious mental health conditions. Repeated COVID-19 infection and/or the development of long COVID-19 has extended this risk of psychological trauma.⁶⁶

4.70 In its submission, the Australian Psychological Society & Phoenix Australia Centre for Posttraumatic Mental Health Ltd noted that multiple factors could explain the presence of anxiety in long COVID patients, such as 'it being an aftereffect of the infection itself', an exacerbation of existing anxiety driven by the implications of long COVID, and/or an effect of any traumatic experience associated with the COVID-19 infection itself such as being in an Intensive Care Unit (ICU).⁶⁷

4.71 As discussed in Chapter 3, research is underway that aims to understand the neurological factors relevant to long COVID. However at the current time, the Committee heard that there is insufficient evidence indicating whether psychological and cognitive issues associated with long COVID 'have a clear biological basis', or are in fact a secondary response to long COVID itself or related factors.⁶⁸

4.72 Multiple individuals with long COVID expressed a frustration about healthcare practitioners attributing their long COVID symptoms to psychological factors such as anxiety or depression. For instance, two individuals quoted in the submission from the Australia Long Covid Community Facebook Support Group said:

This is the worst part when you're struggling with your health and there's an obvious connection to the virus, but doctors minimise the symptoms and blame

⁶⁴ Associate Professor Alex Holmes, Psychological Aspects of Long COVID, VPACS – Victorian Post acute Covid-19 sequelae research group, Submission 290, p. 19.

⁶⁵ Associate Professor Alex Holmes, Psychological Aspects of Long COVID, VPACS – Victorian Post acute Covid-19 sequelae research group, Submission 290, p. 20.

⁶⁶ Royal Australian and New Zealand College of Psychiatrists, Submission 176, p. 2.

⁶⁷ Australian Psychological Society & Phoenix Australia Centre for Posttraumatic Mental Health Ltd, Submission 501, p. 7.

⁶⁸ Royal Melbourne Hospital, Submission 164, p. 2.

anxiety. Meanwhile you're stuck with debilitating symptoms that need treatment...—Respondent 277

[I wish I would] Be able to see any GP and they would have the knowledge or at least be willing to look into it before dismissing it entirely or insisting it's just mental health and pushing antidepressants—Respondent 224⁶⁹

- 4.73 Mr Robin Austin, a member of the Australia Long COVID Community Facebook Group argued that mental health issues are a response to long COVID, and that the lack of information about long COVID was a core contributor to poor mental health outcomes for people with long COVID. He stated:

The important point is that there are a lot of mental health problems with long COVID, but fundamentally that is brought on by the long COVID. Secondly, someone said, 'We shouldn't over diagnose because that could make people's mental health worse.' For me, and I think for a lot of people—from all the comments I read on the Facebook page, the posts—it is the lack of diagnosis, the lack of information that's causing the mental health problems.⁷⁰

- 4.74 Lived Experience Australia, a national representative organisation for Australian mental health consumers and carers, noted the potential for loneliness and isolation among long COVID patients with mental illness:

This population disproportionately experience social exclusion and limited social networks, unemployment and fewer opportunities for educational and social participation, discrimination and stigma, and loneliness. Social connection and participation, and having meaningful and purposeful activity, are central to recovery from mental health conditions. Long COVID has hindered recovery for many individuals already disadvantaged by these issues.⁷¹

- 4.75 The Committee also heard that treating practitioners can have difficulty separating the symptoms of pre-existing mental illnesses from those of long COVID. One submitter reported:

When I finally got in to see the doctor, they tried to shoehorn me into a depression diagnosis (which would have enabled them to send me straight to the psychiatry outpatient's clinic) and refused to consider any alternatives or order further testing. I believe that was due partly to their own excessive workload, but also due to common misconceptions that chronic fatigue is always a symptom of either depression or a functional disorder. I tried to advocate for myself, as I have been depressed in the past and have studied enough psychology myself to understand the difference between clinical depression and fatigue. However, it

⁶⁹ Australia Long Covid Community Facebook Support Group, Submission 309, p. 14.

⁷⁰ Mr Robin Austin, Member, Australia Long Covid Community Facebook Support Group, *Committee Hansard*, Canberra, 17 February 2023, p. 31.

⁷¹ Lived Experience Australia, Submission 23, p. 6.

was clear that this doctor would rather drop the matter altogether than explore other options...⁷²

- 4.76 One submitter suggested that treating practitioners' inability to distinguish between long COVID and mental health conditions may cause anxiety among people with long COVID:

That to me is truly frightening that messaging can be so wrong that medical professionals are not believing [patients]. There is far too much GASLIGHTING from doctors with Long COVID. Too many of them think it is anxiety related when it is not. In fact, these types of doctors cause secondary anxiety for patients because they are pigeon holed and dismissed.⁷³

Quality of life and wellbeing – impact on activities of daily living

- 4.77 Many submissions described how long COVID can have broad impacts on a person's quality of life and wellbeing. For example, some submitters told the Committee that they were no longer able to undertake home duties, go out into the community or exercise.

- 4.78 One submitter with long COVID explained their family has taken on household duties:

My health issues suffered after contracting Covid-19 have affected my family as they need to take on a lot more responsibility and work for the household. It's impacted their ability to live a normal life due to my sickness.⁷⁴

- 4.79 Another submitter described how they are no longer physically able to participate in the community with their children:

Since having COVID, I feel like I am a shell of who I was. Prior to COVID, we were a very active family and we would go on hikes, to the park, zoo, museum and other outings. ... Post-COVID, I am no longer able to take my children on an outing... as I physically cannot manage walking more than a few 100 meters without becoming short of breath, experience chest pain and heart palpitations.⁷⁵

- 4.80 A submission from Thomas Murdock discussed how long COVID affected his ability to exercise and socialise:

Every part of my life has been affected by long covid. I used to easily run 5kms in 20 minutes, but a few months ago I wouldn't have been able to manage 20 minutes of gentle walking. ... My social life was also strongly impacted by this fatigue. For about 4 months I couldn't manage going out most days, and when I did it was only minor things... Talking with anyone was hard because of the fatigue, but also because of my concentration levels and memory loss. Mid

⁷² Name withheld, Submission 542, p. 4.

⁷³ Name withheld, Submission 539, p. 12.

⁷⁴ Name withheld, Submission 9, p. 1.

⁷⁵ Name withheld, Submission 433, p. 1.

conversation I would just zone out, or sometimes I'd forget what we were talking about.⁷⁶

4.81 Another individual with long COVID described the impact of their brain fog:

The brain fog still comes and goes and in my mind that is the most terrifying part even more than the exhaustion. ... I worry about being out of the house for more than a couple of hours or being far from home. Some days the whole thing just makes me cry. I know this isn't sustainable long term and I hope it is going to start getting better soon.⁷⁷

4.82 Another submitter told the Committee about how long COVID prevents them from shopping and cooking:

I had just graduated university and was preparing to enter the workforce full time. Then I caught covid. I was unwell for roughly 10 days with a cough, extreme body aches, headaches, sore throat, and fatigue. Since then, I have not been the same. More than six months on, I still get exhausted doing basic things like grocery shopping and cooking. ... I have been unable to move out of home as I need help and support from my family to do day-to-day things, like changing the sheets on my bed.⁷⁸

4.83 Theresa Sheppard describes the impacts of her long COVID fatigue leading to social isolation:

On a good day I can move from my bed to the couch, I can make myself a cup of tea and maybe put clothes in the washing machine before needing to lie down. On a bad day, I don't get out of bed and I sleep/rest with no stimulus i.e. no tv, no reading, no music, no phone. Everything I do uses energy I don't have. Due to these symptoms, my social interactions have reduced to barely nothing.⁷⁹

4.84 The Committee was concerned to hear that long COVID has also caused some individuals to defer major personal decisions or milestones. For example, Courtney Baker said they have postponed personal milestones as a result of their long COVID:

...doctors tell me they don't know if or when I will get better. I am getting married next year and have stopped planning since I don't know if I will be well enough.⁸⁰

4.85 Another individual shared that they and their partner deferred trying to have a second child until they recover from long COVID:

⁷⁶ Thomas Murdock, Submission 473, p. 1.

⁷⁷ Name withheld, Submission 6, p. 1.

⁷⁸ Name withheld, Submission 73, pages 1–2.

⁷⁹ Theresa Sheppard, Submission 421, p. 1.

⁸⁰ Courtney Baker, Submission 57, p. 1.

We were trying for a little brother or sister before I got COVID and that's now been put on hold until I get better. That's really actually quite sad for us, but hopefully I'll be better soon and we'll be back on track with that.⁸¹

Parenting with long COVID

4.86 The Committee received submissions from parents who reflected on the challenges of parenting while they are sick with long COVID. Some submitters expressed regret that they were no longer able to do many of the activities that they used to enjoy doing with their children prior to developing long COVID.⁸² Others discussed new reliance on other family members to take on caring roles.⁸³

4.87 The Committee received a submission from Angela O'Connor, a neuroscientist no longer able to work due to long COVID. Ms O'Connor commented:

I am 36 and have two small children who I am barely able to parent any longer; I feel like a crushed shell of a human being who will only become more of a burden to her family and the health system as I age. My body now requires enough maintenance and care that it is similar to having another toddler in the household.⁸⁴

4.88 Another submitter said:

I can't take my children to their multiple appointments each week, social events or even play with them. This breaks my heart the most! Reading books together was a regular bedtime routine and I can't even do that with them.⁸⁵

4.89 Rowena Findlay told the Committee about how she could no longer attend her sons' sporting activities due to her long COVID symptoms:

I'm a mother of 2 primary school boys, who I use to take to sporting activities most nights, now my husband was having to do this. Driving made the fatigue worse. I would sometimes push a little too hard and then have to stay in bed for 2 or 3 days. By 12 weeks the fatigue lifted, but the brain fog is still present. The brain fog gets a little better every week. Multitasking is still hard, especially by the end of the day.⁸⁶

4.90 Another submission said that they required in-home help:

I'm unable to work. I'm unable to look after my 3 young children. My children have missed school on occasion as I couldn't get them ready, or get them to

⁸¹ Name withheld, Submission 531, p. 1.

⁸² See, for example: Name withheld, Submission 410, p. 1; Lisa Brereton, Submission 442, p. 4; Name withheld, Submission 506, p. 1.

⁸³ See, for example: Name withheld, Submission 41, p. 1; Name withheld, Submission 52, p. 1; Name withheld, Submission 147, p. 1; Nicole Blackford, Submission 408, p. 1; Name withheld, Submission 505, p. 2.

⁸⁴ Angela O'Connor, Submission 86, p. 1.

⁸⁵ Name withheld, Submission 410, p. 1.

⁸⁶ Rowena Findlay, Submission 55, p. 1.

school. I'm unable to cook/clean or even look after myself, needing food to be prepared for me, as well as my family. We therefore require in-home help to look after me, to look after my kids, as well as complete basic household tasks. I've become a significant burden to my friends and family, as well as our community as we require so much help just to do the most basic things.⁸⁷

Changes to roles and responsibilities

- 4.91 In addition to looking after children, submissions noted the pressure that long COVID often places on other household members to keep households running. For example, one submitter explained:

I can't work, I can't look after my 3 young kids. My husband has become carer to me, and we're juggling help from our friends, family and paid services just to keep our family fed and clean. Along with the financial stress of suddenly not working, the emotional stress on my family is huge.⁸⁸

- 4.92 Angela O'Connor described how her inability to earn an income, contribute to household chores and help with children's activities has placed pressure on her partner:

My partner – who currently works two jobs – has had to take over my share of chores around the house, cook all the time, and drive me around to appointments... My husband is now the sole bread winner and likely will continue to be for the remainder of our lives, which puts a lot of pressure on him. My children no longer have an active, involved parent; I am not capable of taking them out to play sport or do fun activities or even just attend friends' birthday parties.⁸⁹

- 4.93 The Committee heard that these pressures can negatively impact relationships with family and friends:

My immediate family have had to carry the load physically, mentally and financially... my parents believe that covid isn't real and that I should just get over it. It has very negatively impacted my relationship with my parents who are antivaxxers and believe only misinformation. I rarely see my friends anymore and I can't go out much anymore as I am worried about catching covid again.⁹⁰

- 4.94 Even with supportive family and friends, some individuals reported difficulty with their social lives. One submitter advised:

I am lucky to have really close and supportive friends, family and housemates. I could not do it without them. They have all cooked, shopped, cleaned and driven me around, while I can do these things, it's not to the same extent. I am really

⁸⁷ Name withheld, Submission 401, p. 1.

⁸⁸ Name withheld, Submission 52, p. 1

⁸⁹ Angela O'Connor, Submission 86, p. 1.

⁹⁰ Name withheld, Submission 383, p. 1.

grateful for everything they have done. No one has ever questioned how I'm feeling. It is hard to maintain a social life.⁹¹

- 4.95 Another person described how being ill with long COVID disrupts their caring responsibilities:

A big impact of long COVID is on caring. I am also now unable to care for my elderly parents who have many health issues. I was providing a lot of care to them before I got COVID. Now all I can do is apologise for not being there for them when they need me.⁹²

- 4.96 Carers Australia commented on research regarding shifts in caring responsibilities brought about by the pandemic, and noted that caring responsibilities cannot always be re-allocated:

A recent report by the International Alliance of Caring Organisations... found that nearly one in three (29%) carers in the Asia Pacific region started their responsibilities as a result of the pandemic, higher than the global average. This will be exacerbated if there are no other family members or friends able to provide these roles, or there are many people impacted within the household. It should not be assumed that the community will 'step up' or that other family will step-in because 'it's what family should do' - the demands of the caring role often go beyond what would normally be expected of these relationships.⁹³

- 4.97 Some submissions commented on how long COVID could negatively impact social lives by making a person fearful of being reinfected with COVID-19 in social settings. For example, one individual reported:

The impact has been profound. I am unable to perform basic daily tasks... I'm so concerned about what yet another infection will do to me that I have ceased socialising in most settings.⁹⁴

- 4.98 Damien Wood described that he experienced severe symptoms for 10 to 12 weeks after a COVID-19 infection, and that he is concerned about it occurring again. He submitted:

I am very anxious about re-infection... It has made social interaction very difficult as I'm continually scared of contracting the virus again and the ongoing implication of being unwell for a long period. My mental health has suffered greatly as a result.⁹⁵

⁹¹ Name withheld, Submission 74, p. 4.

⁹² Name withheld, Submission 83, p. 6.

⁹³ Carers Australia, Submission 502, p. 4.

⁹⁴ Name withheld, Submission 50, p. 1.

⁹⁵ Damian Wood, Submission 56, p. 1.

- 4.99 Another submission echoed similar concerns about COVID-19 reinfection exacerbating their long COVID symptoms and the risks of acquisition from school aged children. They stated:

I feel like I still need to limit my life and interactions in case I catch it again and the long term effects are made worse. I still mask and limit public spaces, but both infections were originally brought home from a school setting by my children, where there are no preventative measures in place. This has left me feeling incredibly anxious that eventually a subsequent infection will either leave me completely disabled or dead.⁹⁶

School and education

- 4.100 Some submissions discussed how long COVID has impacted their engagement at university and their ability to complete their studies as planned.⁹⁷ For example, Courtney Baker, a psychologist and person with long COVID, submitted:

I was active and healthy. I had to quit one job, stop my phd [PhD] and am now on unpaid leave from my remaining job. My income has been slashed and I am spending a lot of money on doctors and treatments.⁹⁸

- 4.101 One submission from a carer of a school-aged child with long COVID stated:

...my previously high achieving and engaged child was so unwell that she was regularly absent from school and was unable to participate fully or concentrate even when she was at school. She frequently missed extra-curricular and social activities either because she was too unwell or concerned about how much worse she would feel in the hours/days afterwards. ...her teacher has been understanding; acknowledging the substantial fatigue, pain, brain fog, concentration and memory issues that were not present in term 1.⁹⁹

- 4.102 The Committee also heard that the school performance of children of parents with long COVID could be negatively affected. One submission advised:

My 7-year-old's teacher reported a significant change in behaviour from my 7 year old at school, even without her knowing I was unwell. The impact affects every part of our lives.¹⁰⁰

- 4.103 A submission from Jamie Walker explained how long COVID has impacted their university studies:

⁹⁶ Name withheld, Submission 506, pages 1–2.

⁹⁷ See, for example, Jamie Walker, Submission 34, p. 1; Name withheld, Submission 53, p. 1; Name withheld, Submission 162, p. 7; Name withheld, Submission 182, p. 1; Name withheld, Submission 240, p. 2; Name withheld, Submission 426, p. 1.

⁹⁸ Courtney Baker, Submission 57, p. 1.

⁹⁹ Name withheld, Submission 422, p. 1.

¹⁰⁰ Name withheld, Submission 52, p. 1.

Most of the impacts are being able to get out of bed to attend my university classes, some days I find myself passing out asleep in class, other days I'm crashing into bed the moment I get home. As a carer for one of my family members, it makes it difficult not only to me but to them, as I'm supposed to be able to care for them, but the added exhaustion has made me feel like I'm lugging around a ball and chain attached to all my limbs.¹⁰¹

Committee comment

- 4.104 The Committee acknowledges individuals who are experiencing long COVID themselves or otherwise being impacted by long COVID.
- 4.105 The Committee recognises the challenges and hardship for people affected. Long COVID has sizeable impacts on productivity and livelihoods. More can be done to increase awareness about long COVID in the general community and the medical profession specifically.
- 4.106 The Committee notes that while some symptoms and impacts from long COVID were common themes in the evidence, there is variation in symptoms depending on individual circumstances.
- 4.107 Later in this report the Committee has made a range of recommendations informed by these testimonies. The Committee appreciates the courage of those who came forward to share their valuable experiences and perspectives.
- 4.108 Although adverse vaccine reactions are not the focus of this inquiry, the Committee acknowledges that although very rare, these do occur. This issue is discussed further in Chapter 5.

¹⁰¹ Jamie Walker, Submission 34, p. 1.

5. Prevention

Overview

- 5.1 Long COVID only occurs after a COVID-19 infection. If a person has not been infected with COVID-19, then they cannot develop long COVID. As the search for a possible cure for long COVID continues, the Committee recognises that at this stage, prevention is the best way to mitigate against long COVID.
- 5.2 Australia's healthcare system is jointly run by all levels of government (federal, state and territory, and local).¹ The Australian Government continues to cooperate with states and territories to support the response to COVID-19. In particular, the Australian Government is taking a national leadership role to provide COVID-19 vaccines, facilitate access to antiviral treatments for COVID-19, and support the distribution of rapid antigen tests (RATs).²
- 5.3 Throughout the pandemic, the Australian Government recommended various methods to protect people from COVID-19 infection. These methods included COVID-19 vaccination, antiviral treatments for people at risk of severe illness from COVID-19, COVID-19 testing by polymerase chain reaction (PCR) or RATs, mask wearing, physical distancing, hygiene, and guidance about visiting high-risk settings.³
- 5.4 The committee received evidence that emphasised that the best way to prevent long COVID is to prevent an initial COVID-19 infection.⁴ For example, Professor Margaret

¹ Department of Health and Aged Care, *The Australian health system*, www.health.gov.au/about-us/the-australian-health-system, viewed 16 March 2023.

² Department of Health and Aged Care, *Our response to the pandemic*, www.health.gov.au/health-alerts/covid-19/government-response, viewed 16 March 2023.

³ Department of Health and Aged Care, *Protect yourself and others from COVID-19*, www.health.gov.au/health-alerts/covid-19/protect-yourself-and-others, viewed 16 March 2023.

⁴ See, for example: Mrs Mary Klestadt, Submission 2, p. 3; Name withheld, Submission 97, pages 1, 4; Mark Leonard, Submission 146, [p. 2]; Burnet Institute, Submission 149, p. 2; Name withheld, Submission 162, p. 12; Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, pages 1, 9; Professor Martin Hensher, Submission 175 (Attachment 1) p. 6; Pfizer Australia, Submission 225, p. 4; National Clinical Evidence Taskforce (Monash University), Submission 232, pages 16, 19; Long COVID Australia Collaboration, Submission 235, p. 4; Pharmaceutical Society of Australia, Submission 293, pages 3, 7; OzSAGE, Submission 299, p. 18; Pathology Technology Australia, Submission 244, pages 3, 7; AstraZeneca, Submission 247.1, p. 2; Australia Long Covid Community Facebook Group, Submission 309.2, p. 3; Professor Linda Slack-Smith, Submission 320, p. 1; Australian Medical Association, Submission 328, p. 5; Associate Professor Nada Hamad, Submission 335, p. 10; Dr Anne Fletcher and Dr Luke Fletcher, Submission 436, p. 19; Aboriginal Health Council of South Australia, Submission 439, p. 6; Name withheld, Submission 440, p. 4; Name withheld, Submission 467, p. 4; Australian Federation of Disability Organisations, Submission 486, p. 16; Dr Benjamin Veness, Submission 492, pages 1, 6–7; Name withheld, Submission 494, p. 2; Professor Kerry Phelps AM, Submission 510, p. 14; Professor Tania Sorrell, Fellow, Australian Academy of Health and Medical Sciences,

Hellard, Director of Programs at the Burnet Institute, argued that while we don't have a full understanding of long COVID, the most effective way to avoid it is to 'try and stop COVID and reduce the number of COVID infections.'⁵

5.5 This position is supported by the National Clinical Evidence Taskforce on COVID-19 (NCET), which recommended the Australian Government clearly communicate to the public and to health care providers 'that prevention of COVID-19 is the most-effective method of preventing long term health issues' resulting from the virus.⁶

5.6 However, this is difficult to achieve without access to other preventative methods given the highly infectious nature of current Omicron variants circulating in the community.⁷ The NCET summarised:

With the shift away from mandated mask use and regular reporting of COVID-19 cases, and the recent removal of the requirement for isolation following confirmed infection, people may have the highly inaccurate impression that COVID-19 is "over". There is a lack of messaging that potential health risks related to COVID-19 continue to be relevant and that vaccines, mask use in crowded indoor spaces, testing and isolation are still a valuable way to decrease the transmission of SARS-CoV-2, and mitigate the impact of long COVID.⁸

5.7 The importance of mask wearing, physical distancing, hygiene and taking other health precautions when visiting high-risk settings cannot be underestimated. However, the enforcement of these health measures is largely at state and territory government discretion, and to varying extents, now a matter of individual responsibility.

5.8 This inquiry focused on long COVID from a federal health perspective. Accordingly, this chapter focuses on methods to prevent long COVID that are influenced by Australian Government decision-making, including:

- COVID-19 vaccines
- COVID-19 antiviral treatments
- indoor air quality and ventilation.

5.9 Information presented in this chapter is based on current knowledge and literature available to the Committee. Research on long COVID is discussed in more detail in Chapter 3.

and Ambassador, Sydney Institute for Infectious Diseases, *Committee Hansard*, Canberra, 17 February 2023, p. 39; Professor Geoff Hanmer, Director, OzSAGE (and Adjunct Professor within the School of Architecture at the University of Adelaide), *Committee Hansard*, Malvern, 20 February 2023, p. 22.

⁵ Professor Margaret Hellard, Deputy Director, Programs, Burnet Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 23.

⁶ National Clinical Evidence Taskforce (Monash University), Submission 232 (Attachment 1), p. 14.

⁷ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 19.

⁸ National Clinical Evidence Taskforce (Monash University), Submission 232 (Attachment 1), p. 16.

COVID-19 vaccines

- 5.10 The Committee heard that COVID-19 vaccines may be an effective tool to prevent long COVID by reducing the severity and duration of acute COVID-19 infections. Professor Greg Dore from the Kirby Institute explained that people:

...with more severe, acute COVID were more likely to have long COVID. [However, having] said that, most of the people with long COVID had what is described as mild, community managed COVID, and that's certainly what we're seeing now with the omicron wave.⁹

- 5.11 Vaccines may also help to prevent the spread of COVID-19 in the community and reduce the risk of repeated COVID-19 infections.¹⁰ As stated above, the evidence suggests that reducing overall COVID-19 infections in the population should reduce the incidence of long COVID.

- 5.12 There is emerging evidence that COVID-19 vaccines may prevent or reduce the severity of long COVID.¹¹

- 5.13 However, the extent to which COVID-19 vaccines may be effective in preventing long COVID remains the subject of medical research. In December 2022, the Australian Institute of Health and Welfare published a literature review on long COVID and summarised:

The overall picture suggests that 2 vaccination doses could reduce the risk of long COVID between 6% and 26%. Severity of acute COVID-19 infection is a major risk factor for long COVID... and it is plausible that the observed association between vaccination prior to COVID-19 and development of long COVID could be due to the reduction of severe disease during the acute infection...¹²

- 5.14 Professor Brendan Crabb AC, Director and Chief Executive at the Burnet Institute, emphasised to the Committee that in addition to preventing COVID-19 hospitalisations and deaths, vaccines:

...do two other things. One is that it looks like they reduce the incidence of long COVID. The exact number is pretty variable, and you can see why. There are a

⁹ Professor Greg Dore, Professor and Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 36.

¹⁰ See, for example: Pfizer Australia, Submission 225, p. 4; Professor Margaret Hellard, Deputy Director, Programs, Burnet Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 23; Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 10.

¹¹ See, for example: Dr Jason Agostino, Senior Medical Adviser, National Aboriginal Community Controlled Organisation, *Committee Hansard*, Canberra, 17 February 2023, p. 3; Professor Brendan Murphy AC, Secretary, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 9.

¹² Australian Institute of Health and Welfare, *Long COVID in Australia – a review of the literature*, www.aihw.gov.au/reports/covid-19/long-covid-in-australia-a-review-of-the-literature/summary, p. 16, viewed 16 March 2023.

lot of variables: different vaccines, different immune status in which you're vaccinated and, of course, different variants. But somewhere in the 10 to 50 per cent range of reduction in long COVID is where the current evidence is.

The second thing about vaccines is that they do actually reduce transmission. There's a lot of discussion about vaccines not reducing transmission... The most likely thing that vaccines are doing is reducing the viral load. We don't talk a lot about viral load. If any of us in this room get infected today, we might say, 'We've got COVID,' but we didn't get COVID. We don't often say, 'How much COVID did we get?' Less COVID is almost certainly better than more COVID, more virus. If it takes five days for the virus to reach a certain load in your body instead of two days, that's a lot better. Your immune system has had a chance to kick in and your chances of post-COVID sequelae are probably less.¹³

- 5.15 Dr Lucas de Toca, First Assistant Secretary, National COVID-19 Vaccine Program at the Department of Health and Aged Care (the Department) commented on the role that COVID-19 vaccines may play in preventing long COVID. Dr de Toca explained that 'studies that look at whether vaccines prevent long COVID... don't tend to account for the cases averted by vaccination, so they probably underestimate the impact of vaccination on the prevention of long COVID.'¹⁴
- 5.16 Most of Australia's population has now been vaccinated against COVID-19. As of 22 March 2023, 96.2 per cent of Australians have received two doses of the COVID-19 vaccine. In total, 65 492 360 vaccine doses have been administered nationally.¹⁵ Statistics and information about eligibility for the COVID-19 vaccine discussed in this report are current at the time writing. The Committee encourages people to monitor advice from the Department of Health and Aged Care for updates regarding eligibility and booster doses.¹⁶
- 5.17 Table 5.1 shows the percentage of people according to jurisdiction who have received first, second, third and fourth doses of the COVID-19 vaccine. These figures show that uptake of vaccines has reduced with every booster announcement.¹⁷

¹³ Professor Brendan Crabb AC, Director and Chief Executive, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, pages 4–5.

¹⁴ Dr Lucas de Toca, First Assistant Secretary, National COVID-19 Vaccine Program, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 13.

¹⁵ Department of Health and Aged Care, *Vaccination numbers and statistics*, www.health.gov.au/our-work/covid-19-vaccines/vaccination-numbers-and-statistics, viewed 30 March 2023.

¹⁶ See: Department of Health and Aged Care, *Who can get vaccinated*, www.health.gov.au/our-work/covid-19-vaccines/who-can-get-vaccinated, viewed 13 April 2023.

¹⁷ See also, Professor Paul Kelly, Australian Government Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 9. See also, AstraZeneca, Submission 247, p. 2.

Table 5.1 Vaccine coverage by jurisdiction - people aged 16 and over

Jurisdiction	% People with at least one dose	% People with two doses	% People eligible with three doses	% People eligible with four doses (aged 30+) ¹⁸
National	97.6%	96.2%	72.4%	45.2%
New South Wales	97.3%	96.0%	70.6%	46.7%
Victoria	98.3%	97.1%	74.5%	43.1%
Queensland	93.6%	92.2%	65.5%	47.9%
Western Australia	96.7%	95.5%	83.3%	39.5%
South Australia	93.8%	92.1%	76.2%	48.8%
Tasmania	95.4%	93.7%	74.7%	52.1%
Australian Capital Territory	97.1%	95.7%	80.8%	52.7%
Northern Territory	88.6%	86.6%	79.5%	28.3%

Source: Department of Health and Aged Care, Vaccination numbers and statistics, 22 March 2023.

- 5.18 Booster doses of the COVID-19 vaccine are important to prevent waning immunity against the rapidly mutating COVID-19 virus.
- 5.19 On 8 February 2023 the Hon Mark Butler MP, Minister for Health and Aged Care, announced that from 20 February 2023 all adults who have not had a COVID-19 booster or a confirmed case in the past six months are eligible for a COVID-19 booster, irrespective of how many doses that person has received.¹⁹ Additional boosters for people under the age of 18 have not yet been announced, except where children aged 5 to 17 have health conditions that would put them at risk of severe illness.²⁰
- 5.20 Although COVID-19 vaccines are widely available and accessible, data suggests that many people are not electing to receive additional doses for which they are eligible. Professor Crabb AC suggested that this may be due to people becoming less aware of the risks associated with COVID-19 infections as the pandemic continues and commented on a general lack of motivation experienced by many people who received their first two doses but ‘don’t see the benefit’ in receiving booster doses.²¹

¹⁸ People aged 30 and over have been eligible for a fourth dose since 11 July 2022. See: the Hon Mark Butler MP, Minister for Health and Aged Care, ‘Expanded eligibility for fourth COVID-19 vaccine dose’, *Media Release*, 7 July 2022.

¹⁹ The Hon Mark Butler MP, Minister for Health and Aged Care, ‘All adults now eligible for a 2023 COVID-19 booster dose’, *Media Release*, 8 February 2023.

²⁰ The Hon Mark Butler MP, Minister for Health and Aged Care, ‘All adults now eligible for a 2023 COVID-19 booster dose’, *Media Release*, 8 February 2023.

²¹ Professor Brendan Crabb AC, Director and Chief Executive, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 5.

- 5.21 The Committee also heard about low uptake of vaccines for children. The Australian Government currently recommends vaccination for everyone in Australia aged five years and over with some caveats.²² In February 2023, the Australian Technical Advisory Group on Immunisation (ATAGI) announced that children aged five to 15 years old with either medical comorbidities that increase their risk of severe COVID-19, or disability with significant complex health needs, should consider a booster dose of the COVID-19 vaccine.²³
- 5.22 COVID-19 vaccination is only recommended for children aged six months to under five years who are severely immunocompromised, or have disability, as well as those who have complex and/or multiple health conditions that increase their risk of severe COVID-19.²⁴
- 5.23 Table 5.2 shows the percentage of children and adolescents aged five to 15 years old who have received first and second doses of the COVID-19 vaccine. Statistics on the uptake of booster doses for this group are not available.

Table 5.2 Vaccine coverage by jurisdiction - people aged 5 to 15

Jurisdiction	% People with at least one dose	% People with two doses
National	58.8%	50.8%
New South Wales	57.1%	50.4%
Victoria	63.3%	54.6%
Queensland	50.6%	42.8%
Western Australia	60.6%	50.6%
South Australia	60.4%	52.2%
Tasmania	65.2%	57.5%
Australian Capital Territory	80.4%	74.2%
Northern Territory	55.8%	44.4%

Source: Department of Health and Aged Care, Vaccination numbers and statistics, 22 March 2023.

- 5.24 Dr Brendan McMullan, Paediatric Infectious Diseases Specialist at the Sydney Children's Hospitals Network, told the Committee about some of the possible factors that may explain low vaccine uptake for children and adolescents. Dr McMullan explained:

...there is perhaps a perception among parents that the benefit of vaccination now is somewhat more limited if their child has had COVID. There's also... been

²² Department of Health and Aged Care, *COVID-19 vaccines*, www.health.gov.au/our-work/covid-19-vaccines, viewed 16 March 2023.

²³ Australian Technical Advisory Group on Immunisation, *ATAGI 2023 booster advice*, www.health.gov.au/news/atagi-2023-booster-advice, viewed 10 March 2023.

²⁴ Department of Health and Aged Care, *COVID-19 vaccines for children*, www.health.gov.au/our-work/covid-19-vaccines/who-can-get-vaccinated/children, viewed 13 April 2023.

some hesitation in the community about COVID vaccines. And of course, the vaccine rollout happening in a stage process has meant that as the age of the child comes down, the rollout of the vaccine has been later and later. So by the time we got around to being able to vaccinate five- to 12-year-olds, and certainly the under-fives, many people's perceptions of the dangers of COVID... had waned.²⁵

- 5.25 COVID Safe Schools Inc informed the Committee that the message that COVID-19 is mild for children may be another factor explaining the slow uptake of vaccines for this cohort.²⁶

Improving public communication to encourage uptake of COVID-19 vaccines

- 5.26 As noted above, emerging research indicates that COVID-19 vaccines may prevent or reduce the severity of long COVID. As a result, many submitters and witnesses called for improved public health messaging to encourage uptake of the COVID-19 vaccine, especially for the 20- to 50-year-old cohort.²⁷
- 5.27 This message is consistent with the findings of the review of COVID-19 vaccine and treatment procurements completed by the Hon Professor Jane Halton AO PSM in September 2022. The review stated that to maximise coverage and reduce confusion around COVID-19 vaccines, it is important to 'align key public messaging, public health goals, and high-level COVID-19 vaccine policy.'²⁸
- 5.28 Professor Margaret Hellard, Deputy Director, Programs at the Burnet Institute explained that Australia '...would benefit from a vaccine program... to engage with people to get the vaccine.'²⁹
- 5.29 The Australian Patients Association told the Committee that public communication regarding COVID-19 vaccinations needs to be improved:

In Australia and around the world, the most effective management for preventing Long COVID is vaccinations and ensuring all Australians are up-to-date with their boosters. A cornerstone to this aspect of management is public education about

²⁵ Dr Brendan McMullan, Paediatric Infectious Diseases Specialist, Sydney Children's Hospitals Network, *Committee Hansard*, Liverpool, 5 December 2022, p. 24.

²⁶ COVID Safe Schools Inc, Submission 306, p. 31.

²⁷ See, for example: Department of Health (Victoria), Submission 87, p. 11; Moderna Australia, Submission 170, p. 3; Name withheld, Submission 231, p. 8; AstraZeneca, Submission 247, p. 2; AstraZeneca, Submission 247.1, p. 2; Australian Patients Association, Submission 256, p. 6; Pharmaceutical Society of Australia, Submission 293, p. 7; Rural Doctors Association of Australia, Submission 362, p. 7; Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 32.

²⁸ The Hon Professor Jane Halton AO PSM, *Review of COVID-19 vaccine and treatment purchasing and procurement*, 19 September 2022, pages 3–4.

²⁹ Professor Margaret Hellard, Deputy Director, Programs, Burnet Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 21.

the importance, efficacy and safety of vaccinations, as well as general education for patients about how Long COVID- 19 is safely managed at this point in time.³⁰

- 5.30 Professor Catherine Bennett, Chair in Epidemiology at Deakin University, emphasised that better evidence about the protections offered by COVID-19 vaccines would incentivise uptake.³¹ Professor Bennett said that long COVID should be a key part of public communication:

It's something I always include just so that people can be mindful of the benefits of avoiding reinfection... [Y]our initial symptoms aren't necessarily a predictor of your potential for long COVID. People who might have had an infection and it was mild are less aware, less concerned and less likely to be contemplating vaccination, but in fact, if they have another infection, it might not be as mild, or it might still be as mild but it might be a precursor to long COVID.³²

- 5.31 Another submitter made a similar point and recommended the Australian Government 'make the prevention of long COVID an explicit goal of Australia's vaccination program.'³³

- 5.32 Similarly, Moderna Australia also advocated for the Australian Government to encourage uptake of COVID-19 vaccines, noting that early data suggests that vaccination reduces long COVID symptoms. Moderna argued that if this data is confirmed, it will be important for the management of long COVID to ensure that 'all eligible Australians remain up to date with their vaccinations.'³⁴ Moderna suggested that:

Possible approaches could include continuing communication campaigns about the importance and value of vaccines in lessening risks of Long COVID to assist in preventing vaccine fatigue, as recommended by the Halton Review.³⁵

- 5.33 AstraZeneca echoed this sentiment, and submitted:

...given the known benefit of prophylaxis (vaccines or antibodies) in preventing SARS-CoV-2 infection and reducing severe COVID-19 illness, we strongly endorse the implementation of a sustained public campaign to encourage greater vaccine booster uptake and the availability of options for the prevention and treatment of COVID-19.³⁶

³⁰ Australian Patients Association, Submission 256, p. 6.

³¹ Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 32.

³² Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 32.

³³ Name withheld, Submission 142, p. 1.

³⁴ Moderna Australia, Submission 170, p. 3.

³⁵ Moderna Australia, Submission 170, p. 3.

³⁶ AstraZeneca, Submission 247, p. 2.

Adverse reactions to COVID-19 vaccines

- 5.34 The Committee received a small body of evidence from people in the community who are concerned about, and/or report having experienced adverse reactions to COVID-19 vaccinations.
- 5.35 Some submitters and witnesses expressed that their adverse reactions to the COVID-19 vaccination included either the development of new symptoms mirroring long COVID, or a worsening of existing long COVID symptoms.³⁷
- 5.36 Dr de Toca from the Department of Health and Aged Care told the Committee that these reports regarding adverse vaccine reactions remain the subject of research:
- What is a worsening of long COVID symptoms becomes a little bit difficult in that context. That involved a very small number of people. The majority of the studies show either no difference or a slight improvement [from COVID-19 vaccines] on long COVID outcomes. ...we have not seen, either in studies or in the data reported to the TGA [Therapeutic Goods Administration], long COVID onsetting after vaccination. We have not seen evidence of that.³⁸
- 5.37 Lived experiences of adverse reactions to COVID-19 vaccines are discussed in Chapter 4.

Antiviral treatments for COVID-19

- 5.38 Antiviral medicines help stop a virus infecting healthy cells or multiplying in the body.³⁹ The Committee heard that antiviral treatments for COVID-19 may be an effective tool to prevent long COVID by reducing the severity of acute COVID-19 illness.⁴⁰
- 5.39 The Department reported there is currently no conclusive evidence that antiviral treatments prevent long COVID.⁴¹ However, it noted that severity of illness during acute COVID-19 infection is ‘an important predictor of long COVID’ and acknowledged emerging evidence that COVID-19 antiviral treatments may have a protective effect against long COVID.⁴² The Department continues to monitor relevant studies.⁴³

³⁷ See, for example: Name withheld, Submission 121, p. 2; Professor Kerry Phelps AM, Submission 510, p. 8; COVERSE Ltd, Submission 516, p. 2; Dr Melissa McCann, Submission 547, p. 5.

³⁸ Dr Lucas de Toca, First Assistant Secretary, National COVID-19 Vaccine Program, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 14.

³⁹ New South Wales Government, *COVID-19 antivirals – your questions answered*, www.nsw.gov.au/covid-19/testing-managing/antivirals#toc-what-are-antivirals, viewed on 29 March 2023.

⁴⁰ See, for example: Mr Colin Kinner, Submission 186, p. 5; Australian Pathology, Submission 206, p. 3; Name withheld, Submission 228, p. 7; National Heart Foundation of Australia, Submission 284, p. 5; OzSAGE, Submission 299, pp. 2–3; Professor Kerry Phelps AM, Submission 510, p. 11.

⁴¹ Department of Health and Aged Care, Submission 196, p. 21.

⁴² Department of Health and Aged Care, Submission 196, pages 31-32.

⁴³ Department of Health and Aged Care, Submission 196, p. 21.

- 5.40 Research into if and how antiviral treatments may prevent long COVID is ongoing. The Public Health Association of Australia highlighted the findings of emerging research indicating that antivirals may decrease the risk of developing long COVID by reducing the severity of COVID-19, and stated:

...in Australia, antivirals are mostly only prescribed to persons with vulnerabilities, particularly elderly populations; therefore there is minimal understanding of the benefits and risks associated with allowing younger and non-at-risk populations access to antivirals. The availability of antivirals to people at low risk should be reviewed and any subsequent decisions should be supported by the evidence. More diverse, long-term research of multiple population groups is required to investigate antiviral treatment of acute COVID and its impact on reinfection and Long COVID.⁴⁴

- 5.41 A recent study found that in people with at least one risk factor for severe COVID-19 illness, the use of Paxlovid® was associated with reduced risk of post-COVID complications.⁴⁵

- 5.42 Dr Anthony Kelleher, Director at the Kirby Institute, outlined one mechanism through which antiviral treatment may prevent long COVID:

...it [long COVID] might be due to the chronic persistent presentation of antigen to the immune system and that the resultant stimulation of the innate immune system, and it is plausible that, if you clear antigen more quickly by starting an antiviral early, you could turn off that innate immune response earlier and therefore truncate the condition—if it is that innate immune response that's driving the symptomatology—by turning off viral production and therefore reducing antigen production more rapidly... I think it is plausible that treatment with an effective antiviral that reduces antigen load rapidly would logically reduce the amount of persistent antigen that's there and also truncate any innate immune response, because that's been driven by the presence of the foreign antigen.⁴⁶

- 5.43 In considering the potential use of antiviral treatments to prevent long COVID, it is relevant to bear in mind the arrangements under which new medicines are listed on the Pharmaceutical Benefits Scheme (PBS) and subsidised.

- 5.44 The Pharmaceutical Benefits Advisory Committee (PBAC) is an independent expert body appointed by the Australian Government and established by the *National Health Act 1953* (Cth).⁴⁷ It recommends to the Minister for Health and Aged Care drugs for

⁴⁴ Public Health Association of Australia, Submission 351, p. 8, citations omitted.

⁴⁵ Y Xie et al., 'Association of Treatment With Nirmatrelvir and the Risk of Post-COVID-19 Condition', doi:10.1001/jamainternmed.2023.0743, viewed 13 April 2023.

⁴⁶ Dr Anthony Kelleher, Director, Kirby Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 39.

⁴⁷ Department of Health and Aged Care, *Pharmaceutical Benefits Advisory Committee (PBASC) Membership*, www.pbs.gov.au/pbs/industry/listing/participants/pbac, viewed 22 March 2023.

listing on the PBS and vaccines. New medicines cannot be listed on the PBS unless the PBAC makes a positive recommendation.⁴⁸

- 5.45 There are currently two oral antiviral treatments for COVID-19 approved and available in Australia: molnupiravir (Lagevrio®) and nirmatrelvir and ritonavir (Paxlovid®).⁴⁹ Lagevrio® and Paxlovid® can currently be prescribed to eligible patients by a general practitioner (GP), physician or nurse practitioner for access through the PBS for a cost of A\$30.⁵⁰
- 5.46 As of 18 November 2022, 367 480 prescriptions for antiviral treatments had been dispensed via the PBS.⁵¹ Based on current criteria, Pfizer estimated 4.2 million Australian adults are eligible to access antiviral treatments via the PBS.⁵²
- 5.47 Currently, the following groups may be eligible for antiviral treatments via the PBS:
- 70 years of age or older, regardless of risk factors and with or without symptoms
 - 50 years of age or older with 2 additional risk factors for developing severe disease or have had past a COVID 19 infection resulting in hospitalisation
 - First Nations person, 30 years of age or older and with 1 additional risk factor for developing severe disease
 - 18 years of age or older and moderately to severely immunocompromised.⁵³
- 5.48 From 1 April 2023, people aged 60 to 69 years with one risk factor for severe illness can access Paxlovid® via the PBS.⁵⁴
- 5.49 For the purpose of determining eligibility for COVID-19 antivirals via the PBS, risk factors include if the person:
- lives in residential care (aged or disability)
 - has disability with multiple comorbidities and/or frailty
 - neurological conditions, including stroke, dementia and demyelinating conditions

⁴⁸ Department of Health and Aged Care, *Pharmaceutical Benefits Advisory Committee (PBASC) Membership*, www.pbs.gov.au/pbs/industry/listing/participants/pbac, viewed 22 March 2023.

⁴⁹ Department of Health and Aged Care, Submission 196, p. 20.

⁵⁰ Department of Health and Aged Care, Submission 196, p. 20.

⁵¹ MSD Australia, Submission 452, p. 4.

⁵² Pfizer Australia, Submission 225.1, p. 5.

⁵³ Department of Health and Aged Care, *Oral treatments for COVID-19*, www.health.gov.au/health-alerts/covid-19/treatments/oral, viewed 7 March 2023.

⁵⁴ The Hon Mark Butler MP, Minister for Health and Aged Care, 'Expanded access to subsidised oral antiviral Paxlovid and other COVID-19 supports', *Media Release*, 30 March 2023.

- respiratory compromise, including [chronic obstructive pulmonary disease], moderate or severe asthma (requiring inhaled steroids), and bronchiectasis, or caused by neurological or musculoskeletal disease
- heart failure, coronary artery disease, cardiomyopathies
- obesity ([body mass index] > 30 kg/m²)
- diabetes type 1 or 2, requiring medication for glycaemic control
- renal failure ([estimated glomerular filtration rate] < 60 mL/min)
- cirrhosis
- reduced, or lack of, access to higher level health care and lives in an area of geographic remoteness classified by the Modified Monash Model (which categorises an area according to geographical remoteness and town size) as Category 5 or above.⁵⁵

5.50 In relation to COVID-19 antiviral eligibility via the PBS, moderately to severely immunocompromised' currently means:

Any primary or acquired immunodeficiency including:

- haematologic neoplasms: leukaemias, lymphomas, myelodysplastic syndromes, multiple myeloma and other plasma cell disorders
- post-transplant: solid organ (on immunosuppressive therapy), haematopoietic stem cell transplant (within 24 months)
- immunocompromised due to primary or acquired (HIV/AIDS) [human immunodeficiency virus infection and acquired immune deficiency syndrome] immunodeficiency.

Any significantly immunocompromising condition(s) where, in the last 3 months, the patient has received any of these treatments:

- chemotherapy or whole-body radiotherapy
- high-dose corticosteroids (\geq 20 mg of prednisolone per day, or equivalent) for at least 14 days in 1 month, or pulse corticosteroid therapy
- biological agents and other treatments that deplete or inhibit B- or T-cell function...
- selected conventional synthetic disease-modifying anti-rheumatic drugs...

Others with very high-risk conditions, including:

- Down syndrome
- cerebral palsy

⁵⁵ NPS MedicineWise, *Changes to COVID-19 oral antiviral PBS eligibility criteria – July 2022*, www.nps.org.au/radar/articles/changes-to-covid-19-oral-antiviral-pbs-eligibility-criteria, viewed 17 March 2023.

- congenital heart disease
- thalassemia, sickle cell disease and other haemoglobinopathies.

Any significantly immunocompromising condition(s) where, in the last 12 months, the patient has received rituximab.

People with disability with multiple comorbidities and/or frailty.⁵⁶

- 5.51 Patients not belonging to one of the groups eligible to access antiviral treatments through the PBS can seek private prescriptions at a cost of approximately A\$1100.⁵⁷ Current advice from the Department discourages doctors and pharmacists from providing antiviral treatments via private prescriptions ‘to ensure that patients who meet the PBS criteria can access the treatments when they need...’⁵⁸

Issues accessing antiviral treatments

- 5.52 The Committee heard about various issues regarding access to antiviral treatments for COVID-19 in Australia.
- 5.53 As mentioned earlier in this chapter, antiviral treatments can be prescribed to eligible patients via the PBS by a GP, physician or nurse practitioner. Given that it is recommended that antiviral treatments be commenced within the first five days of symptoms onset to be effective⁵⁹, timely access to a GP, physician or nurse practitioner is critical.
- 5.54 The Pharmacy Guild of Australia submitted that ‘the United States, Canada and New Zealand allow pharmacists to initiate oral COVID antiviral treatments’ and called for the same access to be granted to pharmacists in Australia. The Pharmacy Guild of Australia recommended:

The community pharmacy network should be effectively used to provide patients with timely access to oral COVID antivirals. The Guild believes that enabling oral COVID antivirals to be pharmacist-initiated medications will improve patient access and extend access and use throughout Australia, including in rural and remote areas, leading to a decreased burden on public hospital emergency facilities and other health services.⁶⁰

- 5.55 As indicated by the PBS antiviral eligibility criterion outlined above, being diagnosed with long COVID does not make a person eligible to access subsidised antiviral treatment via the PBS.

⁵⁶ NPS MedicineWise, *Changes to COVID-19 oral antiviral PBS eligibility criteria – July 2022*, www.nps.org.au/radar/articles/changes-to-covid-19-oral-antiviral-pbs-eligibility-criteria, viewed 17 March 2023.

⁵⁷ Department of Health and Aged Care, *Pharmaceutical Benefits Scheme - A-Z medicine listing – Viewing by Drug*, www.pbs.gov.au/browse/medicine-listing, viewed 14 March 2023.

⁵⁸ Department of Health and Aged Care, *COVID-19 oral treatments*, 1 January 2023, p. 6.

⁵⁹ The Pharmacy Guild of Australia, Submission 337, p. 4.

⁶⁰ The Pharmacy Guild of Australia, Submission 337, pages 2–3.

5.56 Some submissions disagreed with this and advocated that people with long COVID should be eligible to access antiviral treatments through the PBS. One submitter described the current eligibility criterion to access subsidised antivirals as ‘clunky and over restrictive’ and called for ‘those with Long COVID to be explicitly listed as being eligible for antivirals, in situations where COVID is contracted again.’⁶¹

5.57 Many of these submissions advocating for broader access to antivirals were from people with long COVID who expressed their fears about repeated COVID-19 infections.⁶² For example, one submitter explained:

Antivirals should be made available to those who have long Covid when they have another Covid-19 infection. If I am reinfected again, I am not eligible for antivirals, as long Covid is not currently considered as a significant underlying health condition by the government. Long Covid needs to be included on the list of eligible conditions to access antivirals. There is research that antivirals, such as Paxlovid, can lessen the risk of developing long Covid.⁶³

5.58 OzSAGE, who describe themselves as a multi-disciplinary network of Australian experts from a broad range of sectors relevant to the well-being of the Australian population during and after the COVID-19 pandemic, agreed that people with long COVID often want antivirals to prevent ‘potential further exacerbation of their condition’, but that any long COVID-related disability they have is not recognised. OzSAGE elaborated:

Patients may face significant costs if not in the limited subgroup currently eligible for subsidised antiviral medication. Antiviral therapies are not available to those who have had prior severe COVID-19 infection, despite evidence that SARS-CoV-2 can persist in the body long after acute infection.⁶⁴

5.59 The Committee received evidence indicating that this inability to access subsidised antivirals negatively impacts some individuals with long COVID. Bethany and Matthew Wormald highlighted in their submission that inability to access antiviral treatments limits various aspects of their lives:

We have been told that it would be dangerous to get a new Covid 19 infection, while suffering from LC [long COVID], but do not qualify for Paxlovid should a

⁶¹ Name withheld, Submission 233, p. 4.

⁶² See, for example: Name withheld, Submission 12, p. 8; Name withheld, Submission 13, p. 1; Name withheld, Submission 75, p. 4; Name withheld, Submission 83, p. 6; Name withheld, Submission 162, p. 9; Name withheld, Submission 189, p. 2; Name withheld, Submission 229, p. 3; Ruth Newport, Submission 231, p. 7; Name withheld, Submission 233, p. 5; Name withheld, Submission 234, p. 10; J.T. Smith, Submission 281, p. 3; OzSAGE, Submission 299, p. 10; Name withheld, Submission 303, p. 1; Australia Long Covid Community Facebook Group, Submission 309, p. 3; Name withheld, Submission 326, p. 1; Name withheld, Submission 347, p. 1; Mr Jonathan Munro, Submission 360, p. 1; Name withheld, Submission 375, p. 1; Michelle Yang, Submission 395, p. 1; Name withheld, Submission 505, p. 3; Name withheld, Submission 533, p. 3; Associate Professor Nada Hamad, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 22.

⁶³ Name withheld, Submission 221, p. 4. See also, Name withheld, Submission 298, p. 1; Name withheld, Submission 488, p. 4.

⁶⁴ OzSAGE, Submission 299, p. 10.

positive test occur. This limits ability to socialise, exercise, work, volunteer and most importantly to access treatment for [long COVID] in facilities full of sick people.⁶⁵

- 5.60 The Committee also heard from a submitter with long COVID who spoke about their fear of having to restart their recovery after repeated COVID infections:

One of my major fears is getting covid a second time and having to start the recovery from long covid all over again. There would appear to be some evidence that antivirals may help protect people from getting long covid... I realise not all the evidence is in, but I think as a preventative measure, those who have been diagnosed with long covid should be eligible for antivirals, regardless of their age or other health status.⁶⁶

- 5.61 It was unclear whether many submitters were aware that antivirals could be accessed privately off the PBS. However, at least some individuals did recognise this, but expressed concern at the cost. A submission from a person who developed long COVID symptoms after an acute COVID-19 infection highlighted the difficult choice they would need to make if reinfected:

As a fall back I have a prescription for Paxlovid, but if I fill it, I'm not entitled to cover under the PBS, as I'm under 70, not diagnosed as disabled and not considered immunocompromised I will have to pay \$1000.00. This is money I will have to find on credit, but if my health deteriorates as a result of unprotected reinfection I will lose much more than that.⁶⁷

- 5.62 Antiviral medication as a potential treatment for people with ongoing long COVID symptoms is discussed in Chapter 6.

Indoor air quality and ventilation

- 5.63 COVID-19 was not recognised as an airborne virus by the World Health Organization (WHO) until April 2021 – more than one year into the pandemic.⁶⁸ The Committee heard that as a result of this delay, the importance of safeguarding air quality and ventilation has been overlooked in Australia's response to managing COVID-19.

- 5.64 As mentioned previously in this chapter, the evidence suggests that at present the most effective method of preventing long COVID is to prevent an initial COVID-19 infection. The Committee therefore considered how improving indoor air quality and ventilation may play a key part in preventing acute and repeated COVID-19 infections, with the aim of ultimately preventing long COVID.

⁶⁵ Bethany and Matthew Wormald, Submission 11, p. 2.

⁶⁶ Name withheld, Submission 147, p. 4.

⁶⁷ Name withheld, Submission 3, p. 8.

⁶⁸ Royal Australian College of General Practitioners, 'A *welcome step*' WHO acknowledges aerosol spread of COVID-19, www1.racgp.org.au/newsgp/clinical/a-welcome-step-who-acknowledges-aerosol-spread-of, viewed 22 March 2023.

- 5.65 Responsibility for monitoring and managing air quality in Australia is predominantly split between state, territory and local governments. However, the Australian Government has a role in the National Construction Code, which covers minimum ventilation requirements for new buildings, building work, new plumbing and drainage systems.⁶⁹ The National Construction Code is given legal effect by building regulatory legislation in each state and territory.⁷⁰
- 5.66 Australia's states and territories have, throughout the pandemic, developed guidance on ventilation and air quality to assist with reducing COVID-19 transmission.⁷¹ However, implementing this guidance is voluntary and different jurisdictions have taken different approaches, resulting in inconsistencies across Australia.
- 5.67 Professor Crabb AC was of the view that the delay in recognising the airborne transmission of COVID-19 and the lack of controls to manage this was a 'big failure' in the pandemic response.⁷² He elaborated:

There is a real opportunity there to do something practical that's going to help but also send a positive signal. No social licence is needed for clean air. There are tricky regulations and so on, but countries are tackling this in a step-wise manner, sometimes just regulating that all you have to see is the quality of the air; you don't have to do anything but you have to display the quality of the air in a venue. These sorts of things send strong signals to the population now that breathing clean air is very important.⁷³

⁶⁹ NSW Department of Planning and Environment, *National Construction Code*, www.planning.nsw.gov.au/policy-and-legislation/buildings/national-construction-code, viewed 23 March 2023.

⁷⁰ See: National Construction Code, 2019, Volume Two Amendment 1, ncc.abcb.gov.au/editions/2019-a1/ncc-2019-volume-two-amendment-1/part-38-health-and-amenity/part-385-ventilation, viewed 22 March 2023.

⁷¹ See, for example: ACT Government, *COVID-19 guidance on ventilation*, www.covid19.act.gov.au/stay-safe-and-healthy/covid-19-guidance-on-ventilation, viewed 2 March 2023; Department for Education South Australia, *Statement on ventilation in schools*, www.education.sa.gov.au/department/media-centre/our-news/statement-ventilation-schools, viewed 2 March 2023; Department of Health (Tasmania), *Best Practice COVID-19 Workplace Safety: Ventilation fact sheet*, www.health.tas.gov.au/publications/best-practice-covid-19-workplace-safety-ventilation-fact-sheet, viewed 3 March 2023; Department of Health (Western Australia), *Information on COVID-19 and building ventilation*, www.health.wa.gov.au/~media/Corp/Documents/Health-for/Infectious-disease/COVID19/COVID-19-ventilation-in-buildings.pdf, viewed 2 March 2023; New South Wales Government, *COVID-19 guidance on ventilation*, www.nsw.gov.au/covid-19/business/guidance/ventilation, viewed 2 March 2023; Queensland Department of Education, *Managing air quality*, www.education.qld.gov.au/initiatives-and-strategies/health-and-wellbeing/workplaces/safety/managing-air-quality, viewed 2 March 2023; WorkSafe Queensland, *Improving ventilation in indoor workplaces*, www.worksafe.qld.gov.au/news-and-events/newsletters/esafe-newsletters/esafe-editions/esafe/april-2021/improving-ventilation-in-indoor-workplaces, viewed 2 March 2023; Victorian Government, *Ventilation*, www.coronavirus.vic.gov.au/ventilation, viewed 2 March 2023.

⁷² Professor Brendan Crabb AC, Director and Chief Executive, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 5.

⁷³ Professor Brendan Crabb AC, Director and Chief Executive, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 5.

- 5.68 The Committee heard from many submitters and witnesses who expressed concerns that poor indoor air quality and ventilation are unnecessarily contributing to or exacerbating COVID-19 transmission in a variety of settings, including workplaces.⁷⁴
- 5.69 The Committee heard from three ventilation experts, each of whom highlighted the risks of poor indoor air quality and how it enables transmission of COVID-19.⁷⁵
- 5.70 Associate Professor Robyn Schofield from the University of Melbourne told the Committee that '[b]asically all COVID transmission events have occurred indoors' and added:

That's the cost of our inaction. The benefits and co-benefits [of potentially improving indoor air quality] are huge: productivity, educational success and performance enhancement, and a reduction in the population disease burden of this disease. We need safe indoor air for all. What the last three years of the pandemic have taught us is that our indoor air won't be improved for all without standards, education, monitoring and action.⁷⁶

- 5.71 Distinguished Professor Lidia Morawska from the Queensland University of Technology explained how that speaking and breathing can spread the virus:

Overall, if we are talking about this virus, SARS-CoV-2, smaller particles contain a higher load, particles smaller than one micrometre—not an individual small particle but as a body, because they are in the vast majority. Smaller particles come from the deeper parts of the respiratory tract, the location of the virus. By contrast, larger particles have less virus because they originate from the mouth,

⁷⁴ See, for example: Name withheld, Submission 1, pages 4–5; Name withheld, Submission 13, p. 1; Name withheld, Submission 17, p. 1; Name withheld, Submission 25, p. 1; Name withheld, Submission 28, p. 4; Caroline Molloy, Submission 43, p. 2; Name withheld, Submission 46, p. 3; Name withheld, Submission 51, p. 1; Name withheld, Submission 71, p. 1; Name withheld, Submission 77, p. 1; Name withheld, Submission 104, p. 2; Ms Amelia Kerr, Submission 139, pages 4–5; Name withheld, Submission 141, p. 2; Burnet Institute, Submission 149, p. 2; Name withheld, Submission 162, pages 14–15; Name withheld, Submission 171, p. 4; Name withheld, Submission 174, p. 3; Name withheld, Submission 185, p. 8; Mr Colin Kinner, Submission 186, p. 7; Name withheld, Submission 194, p. 9; Name withheld, Submission 204, p. 3; Name withheld, Submission 207, p. 3; Name withheld, Submission 217, p. 2; Name withheld, Submission 218, p. 2; Brian Jackson, Submission 223, p. 1; Name withheld, Submission 228, p. 6; Ruth Newport, Submission 231, p. 7; Dr Anita White, Submission 238, pages 6–9; John Curtin Research Centre, Submission 243, pages 2, 9; Australian Council of Trade Unions, Submission 251, p. 8; Associate Professor Robyn Schofield, Submission, 254, pages 1–11; Professor Jeremy Howard, Submission 263, pages 1–8; Professor Geoffrey Hanmer (Director at OzSAGE and Adjunct Professor within the School of Architecture at the University of Adelaide), Submission 274, pages 1–18; Australian Education Union Federal Office, Submission 276, pages 3–4; Name withheld, Submission 282, p. 6; Peri Coleman, Submission 296, p. 2; OzSAGE, Submission 299, pages 2–7, 19; Distinguished Professor Lidia Morawska, Submission 304, pages 1–3.

⁷⁵ Professor Geoffrey Hanmer, Director, OzSAGE (and Adjunct Professor within the School of Architecture at the University of Adelaide), *Committee Hansard*, Malvern, 20 February 2023, pages 22–26; Distinguished Professor Lidia Morawska, School of Earth and Atmospheric Sciences, Queensland University of Technology, *Committee Hansard*, Malvern, 20 February 2023, pages 26–30; Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne, *Committee Hansard*, Malvern, 20 February 2023, pages 18–21.

⁷⁶ Associate Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne, *Committee Hansard*, Malvern, 20 February 2023, p. 18.

where there's less of the virus. Again, speaking and breathing are the main source of the small viruses.⁷⁷

- 5.72 Professor Geoff Hanmer, Director at OzSAGE (Adjunct Professor within the School of Architecture at the University of Adelaide), argued the need to 'implement physical options' to reduce the airborne transmission of COVID-19.⁷⁸ He said that wherever possible, people should be continuing to work from home and dine outdoors, events should be held outdoors, and people continue to use masks – 'the key element is ensuring that shared indoor air is clean.'⁷⁹
- 5.73 Associate Professor Schofield also explained that the last assessment of the economic cost of poor indoor air quality was completed by Commonwealth Scientific and Industrial Research Organisation in 1998.⁸⁰ She said that at that time, it was estimated that poorly ventilated indoor spaces cost Australia \$12 billion per year; an amount which would have increased during the COVID-19 pandemic:⁸¹

I imagine the cost of it through the pandemic would be much higher because it would start to factor in all of the transmission events that brought about death. If we consider that most of the COVID transmission events happened in the indoor environment and you bring in all of those deaths, that is a really large number. The benefit of doing something to the air for productivity, for school test scores and for a healthier society are very large. One of my first recommendations was that analysis needs to be done because people say, 'It's too hard; it's going to cost too much.' It's not too hard. It will cost a lot, but the cost of inaction is huge.⁸²

Indoor air quality and ventilation in high-risk settings

- 5.74 The Committee heard from some submitters and witnesses about how poor indoor air quality and ventilation exacerbated COVID-19 transmission in high-risk settings, including schools and aged care facilities.
- 5.75 Adjunct Professor Giorgio Buonanno wrote to the Committee about indoor air quality and ventilation in school settings, and to share the results of his study that investigated ventilation and COVID-19 transmission in Italian schools:

⁷⁷ Distinguished Professor Lidia Morawska, School of Earth and Atmospheric Sciences, Queensland University of Technology, *Committee Hansard*, Malvern, 20 February 2023, p. 26.

⁷⁸ Professor Geoff Hanmer, Director, OzSAGE (and Adjunct Professor within the School of Architecture at the University of Adelaide), *Committee Hansard*, Malvern, 20 February 2023, p. 22.

⁷⁹ Professor Geoff Hanmer, Director, OzSAGE (and Adjunct Professor within the School of Architecture at the University of Adelaide), *Committee Hansard*, Malvern, 20 February 2023, p. 22.

⁸⁰ Associate Professor Robyn Schofield, Submission 254, p. 2. See also, Department of Climate Change, Energy, the Environment and Water, *Indoor air*, www.dcceew.gov.au/environment/protection/air-quality/indoor-air, viewed 22 March 2023.

⁸¹ Associate Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne, *Committee Hansard*, Malvern, 20 February 2023, p. 19. See also, Department of Climate Change, Energy, the Environment and Water, *Indoor air*, www.dcceew.gov.au/environment/protection/air-quality/indoor-air, viewed 22 March 2023.

⁸² Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne, *Committee Hansard*, Malvern, 20 February 2023, p. 20.

We investigated the strength of association between ventilation and SARS-CoV-2 transmission reported among the students of Italy's Marche region in more than 10,000 classrooms, of which 316 were equipped with mechanical ventilation. We explored the relative risk associated with the exposure of students in classrooms.

Findings: For classrooms equipped with mechanical ventilation systems, the relative risk of infection decreased with the increase in ventilation: classrooms with good mechanical ventilation reduced the likelihood of infection for students by 80% compared with a classroom with only natural ventilation.

The conclusion is clear - predictable ventilation of classrooms is a very effective measure which reduces risk of transmission of any airborne disease. I know the findings can be applied to any buildings which are occupied by many people for extended periods.⁸³

- 5.76 Professor Hanmer, Director at OzSAGE (Adjunct Professor within the School of Architecture at the University of Adelaide), described weaknesses of naturally ventilated spaces:

When it is not too cold, too hot or too noisy, the window or windows are open. But the reality is that, in most climates... there's a problem: too cold, too hot, too noisy, too polluted or too unsafe. Windows are closed and there's no ventilation. Basically, natural ventilation equates to no ventilation in situations like this. Of course, there is a disclaimer: 'no ventilation' means 'minimal ventilation', because there is always some penetration of air into the building.

...there's not enough ventilation, even if windows are open. But the very big problem is that energy invested in heating and cooling is lost. As a society, we cannot afford to invest more energy. We need to do it smarter.⁸⁴

- 5.77 COVID Safe Schools Inc echoed this point and submitted that schools with improved indoor air quality and ventilation had lower transmission of COVID-19 compared to the broader community. COVID Safe Schools Inc provided an example of low COVID-19 cases found in schools and childcare facilities with improved ventilation in Baden-Württemberg Germany.⁸⁵

- 5.78 Further, Ms Karen Armstrong, Acting President at Covid Safe Schools Inc argued:

The cost of installing this equipment should not be seen as a luxury... Air monitoring and filtration equipment should be seen as being as necessary as smoke alarms and fire extinguishers in public buildings...

[...]

...ideally what we want is a situation...where ultimately we have HVAC facilities in every classroom. That would be the ideal. In fact a school infrastructure

⁸³ Adjunct Professor Giorgio Buonanno, Submission 130, p. 1.

⁸⁴ Professor Geoff Hanmer, Director, OzSAGE (and Adjunct Professor within the School of Architecture at the University of Adelaide), *Committee Hansard*, Malvern, 20 February 2023, p. 27.

⁸⁵ COVID Safe Schools Inc, Submission 306, p. 21, citations omitted.

investment where that could be rolled out would be the best possible scenario. In the short term, though, there could be sensible and very cheap and relatively easy things to do. In the short term, we need teachers to have the windows open and we need the teachers to be educated about how to use HEPA [high efficiency particular air/absorbing] filtration. In Victoria, you're probably aware, HEPA filters were rolled out, one for every classroom. There were some problems with that implementation, largely to do with education, and this is part of the problem. So ideally we would have, in the short term, air monitors and HEPA filters in the classrooms while the HVAC was being rolled out.

But we also need—and this is the critical thing—education. Staff need to be made to understand why they're using it and how to make it work. We read all the time, and I know through personal experience, that the HEPA filters often aren't turned on. You have a situation where the teachers don't know where to put them. The filters aren't replaced. The windows aren't left open with the HEPA filters on, which, by the way, even the WHO has said needs to happen: you need the change of air as well as the air being filtered if you're going to use that. It's the main way of managing the clean air.⁸⁶

- 5.79 Professor Hanmer, Director at OzSAGE (Adjunct Professor within the School of Architecture at the University of Adelaide), told the Committee that the current number of COVID-19 related deaths in aged care in Australia – about 300 so far in 2023 – is unacceptable, and he suggested that poor ventilation in aged care facilities is playing a part:

During the second winter wave in Victoria, about 700 residents died in residential aged care facilities. In the cold Melbourne winter, windows were shut, ventilation was minimal and COVID was able to accumulate in the air, a bit like smoke. When an infected person entered a facility it proved impossible to stop the infection spreading. An examination of the scientific literature at the time, including papers from Professor Morawska, showed that the probable reason for the high level of infections was airborne transmissions, exacerbated by low ventilation...

Many aged care residents died then and are continuing to die because the people who make recommendations on infection control are too stubborn to admit their early advice was wrong, despite abundant evidence to the contrary.⁸⁷

The need for Indoor Air Quality Standards

- 5.80 Noting the risk presented by poor indoor air quality and ventilation, many submitters and witnesses recommended that Australia establish national Indoor Air Quality Standards to improve the safety of indoor spaces and reduce transmission of

⁸⁶ Ms Karen Armstrong, Acting President, Covid Safe Schools Inc, *Committee Hansard*, Malvern, 20 February 2023, pages 38–39.

⁸⁷ Professor Geoff Hanmer, Director, OzSAGE (and Adjunct Professor within the School of Architecture at the University of Adelaide), *Committee Hansard*, Malvern, 20 February 2023, p. 22.

COVID-19 and other infectious diseases.⁸⁸ These standards would be separate from the air quality and ventilation requirements set out in the National Construction Code.

5.81 Professor Morawska made several recommendations to the Committee regarding the establishment of Indoor Air Quality Standards for consistent use across Australia's states and territories:

1. Establish a consistent national regulatory infrastructure for Clean Indoor Air for Australians through the Federal Cabinet working with the States and Territories through the National Cabinet
2. Establish an interdisciplinary panel of experts, including scientists, engineers, architects and medical and public health professionals tasked with developing a foundation for [Indoor Air Quality] standards that can be legislated and enforced.
3. Legislate the [Indoor Air Quality] standards
4. Mandate that all new buildings are designed to meet the standards
5. Review and improve the existing building design and building engineering standards, regulations and codes to ensure that they enable compliance with the [Indoor Air Quality] standards.
6. Establish a national fund enabling the rollout of indoor environment modernisation measures addressing both immediate emergencies as well as a long-term transition process towards all public interiors meeting [Indoor Air Quality] standards.⁸⁹

5.82 Professor Morawska said that these standards must:

...prescribe concentrations of indoor selected pollutants[,] be enforceable, monitored in every public space and legislated, and regulations sufficient and effective as a part of HVAC [heating, ventilation and air-conditioning] system must be an element of enforcement of these standards and regulations for public spaces. This must be supplemented by disinfection to control airborne infection transmission.⁹⁰

5.83 Associate Professor Schofield highlighted the human right to a clean, healthy and sustainable environment, which was recognised by the United Nations General Assembly in July 2022.⁹¹ Highlighting the need for standards to enable monitoring, she said:

How do we ensure that this right is met for everyone? If you don't set standards and monitor those quantities, you're not managing that resource. Air is arguably the most important resource that we consume. Food standards generate

⁸⁸ See, for example: Name withheld, Submission 1, p. 5; Name withheld, Submission 17, p. 1; Name withheld, Submission 25, p. 1; Name withheld, Submission 46, p. 3.

⁸⁹ Distinguished Professor Lidia Morawska, Submission 304.2, pages 41–43.

⁹⁰ Distinguished Professor Lidia Morawska, School of Earth and Atmospheric Sciences, Queensland University of Technology, *Committee Hansard*, Malvern, 20 February 2023, p. 28.

⁹¹ Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne, *Committee Hansard*, Malvern, 20 February 2023, p. 18.

compliance through education. They monitor for compliance, and there is a clear response to noncompliance. We need this for air. We need a litmus test telling us that the air is safe, given the occupancy and the use of a space. This is what CO2 [carbon dioxide] monitoring gives us...

We also need to regulate how much fresh air is coming in from outside... That's about 14 litres per second per person... We need to be really careful about airflows. Here, in this space [Malvern public hearing venue, Cabrini Hospital], it's very good. You've got air coming in and then the air exhausting there. The pathways are short. It's not coming in over there and coming through me to there, like the confluence of a river. That's what we need to be very careful of.⁹²

- 5.84 Professor Hanmer, Director at OzSAGE (Adjunct Professor within the School of Architecture at the University of Adelaide), also advocated for the establishment of Indoor Air Quality Standards and explained current ventilation requirements set out in the National Construction Code:⁹³

...the National Construction Code requires a new building to be constructed with either natural or mechanical ventilation. If a building is naturally ventilated, the [National Construction Code] requires windows with the area of their openable elements to be five per cent of the floor area, regardless of the intensity of the occupancy of the space. ...no laws or regulations require building operators to open the windows. Nearly all our schools, childcare centres, community centres, churches, medical waiting rooms, pharmacies and residential aged care facilities are naturally ventilated...

...with some simple tweaks to settings, nudged along by a regulator and some regulations, most of these buildings can perform acceptably. We urgently need a national standard for indoor air quality and a national indoor air standards code. This could operate like the national Food Standards Code referenced in the National Construction Code, with regulation by both state and territory governments, and enforcement by local government. In New South Wales, for example, the New South Wales Food Authority directly looks after high-risk issues, while hygiene and food standards at the local hamburger joint are monitored by local government. Most states are similar.⁹⁴

- 5.85 Another submitter made a similar recommendation that indoor air quality standards are needed for every indoor space such as day care centres, schools, libraries and businesses, 'the same way we have food safety standards that prevent the transmission of diseases such as gastroenteritis.'⁹⁵

⁹² Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne, *Committee Hansard*, Malvern, 20 February 2023, p. 18.

⁹³ The National Construction Code is a performance-based code that sets minimum required levels for 'safety, health, amenity, accessibility and sustainability of certain buildings.' See: Australian Building Codes Board, *National Construction Code*, ncc.abcb.gov.au/, viewed 22 March 2023.

⁹⁴ Professor Geoff Hanmer, Director, OzSAGE (and Adjunct Professor within the School of Architecture at the University of Adelaide), *Committee Hansard*, Malvern, 20 February 2023, pages 22–23.

⁹⁵ Name withheld, Submission 46, p. 3.

- 5.86 Associate Professor Schofield also addressed the issue of the cost of establishing Indoor Air Quality Standards, suggesting that more research into indoor air quality and ventilation would assist with bringing down costs:

We need research to ensure that we can deal with the fact that we can drive down the cost. We want to have energy efficient buildings. We want to make them resilient to climate change. Outside air, bringing that in all the time, will not always work when we have bushfires or outdoor pollution, for example. We do need to have innovation in this space. We do need to ensure that any technologies that we bring in to solve the problem don't create a new one.⁹⁶

- 5.87 Professor Hanmer, Director at OzSAGE (Adjunct Professor within the School of Architecture at the University of Adelaide), said the benefits of improved ventilation would 'far outweigh the costs, including improvements in productivity, learning and general health, not to forget reducing COVID infections and mortality.'⁹⁷

International examples of best practice in air quality

- 5.88 Some submitters and witnesses discussed measures adopted in other countries seeking to improve air quality and ventilation. In particular, the Committee heard about measures in Belgium, Ireland, New Zealand and the Netherlands as examples of best practice.⁹⁸ For example, OzSAGE submitted:

Clean indoor air is essential to mitigate repeat SARS-CoV-2 infections and resultant long COVID. Peer countries are moving to set targets for unfiltered indoor CO₂ levels (as a proxy for ventilation) in public spaces, such as schools, restaurants, and workplaces. For example, Belgium has recently passed legislation that requires all public places to monitor their indoor air quality and install a CO₂ monitor that is visible to the public. In New Zealand, all schools have been supplied with a CO₂ monitor and air purifiers are used when ventilation is insufficient. Australia should follow by mandating and championing indoor air quality standards and other clean indoor air technologies. More cost effective is investment in safe indoor air and other mitigations.⁹⁹

⁹⁶ Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne, *Committee Hansard*, Malvern, 20 February 2023, p. 21.

⁹⁷ Professor Geoff Hanmer, Director, OzSAGE (and Adjunct Professor within the School of Architecture at the University of Adelaide), *Committee Hansard*, Malvern, 20 February 2023, p. 23.

⁹⁸ See, for example: Lisa Kava, Submission 157, p. 4; Donna Cicca, Submission 192, p. 1; Barbara Romeril and Marg Hutton, Submission 201, p. 5; Professor Quentin Grafton, Submission 208, pages 2, 15; Name withheld, Submission 227, p. 2; John Curtin Research Centre, Submission 243, p. 2; John Curtin Research Centre, Submission 243.1, p. 1; Professor Geoff Hanmer (Director at OzSAGE and Adjunct Professor within the School of Architecture at the University of Adelaide), Submission 274, p. 4; Name withheld, Submission 282, p. 6; OzSAGE, Submission 299, p. 3; Name withheld, Submission 365, p. 3; Name withheld, Submission 445, p. 1; Name withheld, Submission 463, p. 4; Dr Benjamin Veness, Submission 492, p. 4; Mr Christopher Jones, Submission 498, p. 3; Name withheld, Submission 503, p. 9; Name withheld, Submission 542, p. 8; Ms Karen Armstrong, Acting President, Covid Safe Schools Inc, *Committee Hansard*, Malvern, 20 February 2023, p. 38.

⁹⁹ OzSAGE, Submission 299, p. 3.

5.89 Another submitter told the Committee of progress in Belgium and Ireland:

Recently, the Belgian government recognised the importance of healthy indoor air, finding a legal framework to improve air quality: all publicly accessible premises (including bars, restaurants, cinemas, theatres and gyms) must monitor their indoor air, display CO2 readings, and have a "ventilation plan." Ireland is also taking serious steps to address indoor air quality: their Health and Safety Authority has drawn up a new code of practice to ensure workplace air quality, and this will be signed into law next year. Australia must do the same. In the short term, the government must acknowledge the importance of good ventilation in public indoor spaces and provide clear guidance on this...¹⁰⁰

Committee comment

5.90 The Committee believes that preventing COVID-19 infection is, based on current information, the most effective method to prevent long COVID. Consequently, the Committee considers that there is opportunity for Australia to respond to long COVID and reduce future cases by more effectively promoting COVID-19 vaccines, expanding access to antiviral treatments for COVID-19, and improving indoor air quality and ventilation.

COVID-19 vaccines

5.91 The Committee notes emerging evidence that suggests COVID-19 vaccines prevent long COVID by reducing community transmission and the chance of severe acute COVID-19 illness.

5.92 The Committee commends all Australians for achieving high double dose national vaccination rates amongst the adult population. However, the Committee notes that a diminishing percentage of Australian adults over the age of 16 have received each additional COVID-19 vaccine booster that is available to them. The Committee further observes that just over 50 per cent of children and adolescents aged between five and 15 have received two doses of the COVID-19 vaccine.

5.93 Accordingly, the Committee is concerned that the limited uptake of COVID-19 vaccines may represent a missed opportunity to reduce and mitigate the future prevalence and severity of long COVID cases. Although long COVID is not common, it is real and millions of Australians could potentially be increasing their protection against it simply by receiving additional COVID-19 vaccinations, which are readily available and free. The Committee thus encourages all Australians who are eligible to keep up to date with booster doses.

5.94 The Committee appreciates the ongoing work undertaken by the Department of Health and Aged Care to facilitate the vaccine rollout and ensure the ongoing supply of COVID-19 vaccine booster doses. However, the Committee considers that the

¹⁰⁰ Name withheld, Submission 228, p. 8, citations omitted.

Department must urgently improve its public communication to encourage all Australians who are eligible for the COVID-19 vaccine to keep up to date with booster doses as they are announced.

- 5.95 Further, the Committee strongly believes that the Department of Health and Aged Care should work with the states and territories to improve public campaigns informing Australians of the benefits of COVID-19 vaccines. These campaigns should emphasise the role that COVID-19 vaccines have in reducing transmission and illness severity of acute COVID-19, and thus potentially in preventing long COVID. These campaigns should be updated to reflect emerging research regarding vaccines and long COVID.
- 5.96 The Committee notes the Minister for Health and Aged Care recently released a new campaign to encourage uptake of COVID-19 vaccines prior to the 2023 winter season.¹⁰¹
- 5.97 The Committee recognises the importance of ensuring that future public health campaigns on this topic are accessible and reach vulnerable groups in regional, rural and remote areas and culturally and linguistically diverse communities.
- 5.98 The Committee would like to emphasise that the issue of adverse reactions to COVID-19 vaccinations was not within the terms of reference, nor a focus of this inquiry. However, the Committee acknowledges the small body of evidence received from people in the community telling of theirs or a loved ones' experience of an adverse physical reaction after receiving a COVID-19 vaccination. The Committee acknowledges that adverse vaccine events, although very rare, do occur.
- 5.99 The Committee encourages anyone who suspects they may have had an adverse reaction to a COVID-19 vaccine to report this to a health professional, a relevant state or territory health department, the NPS MedicineWise Adverse Medicine Events line or directly to the Therapeutic Goods Administration.¹⁰²

Antiviral treatments for COVID-19

- 5.100 The Committee notes that research on antiviral treatments for COVID-19 and whether they prevent long COVID is evolving.¹⁰³
- 5.101 However, the Committee acknowledges there is some clinical evidence on the effect of antiviral treatments, which suggests that these treatments may in certain populations reduce the severity of acute COVID-19 illness. Given that increased

¹⁰¹ See: Department of Health and Aged Care, *COVID-19 and vaccines campaign advertisements*, www.health.gov.au/our-work/covid-19-vaccines/campaign/covid-19-and-vaccines-campaign-videos/covid-19-and-vaccines-campaign-advertisements, viewed 12 April 2023.

¹⁰² See: Therapeutic Goods Administration, *Reporting suspected side effects associated with a COVID-19 vaccine*, www.tga.gov.au/products/covid-19/covid-19-vaccines/covid-19-vaccine-safety-monitoring-and-reporting/reporting-suspected-side-effects-associated-covid-19-vaccine, viewed 8 March 2023.

¹⁰³ See, for example: Y Xie et al., 'Association of Treatment With Nirmatrelvir and the Risk of Post-COVID-19 Condition', doi:10.1001/jamainternmed.2023.0743, viewed 13 April 2023.

severity of initial infection (such as requiring hospitalisation) may put a person at risk of developing long COVID the Committee recognises the logic that antiviral treatments may play a role in preventing long COVID.

- 5.102 The Committee notes though that it also heard from people who experienced mild symptoms during their initial COVID-19 infection, which later developed into long COVID. Given this, the extent to which antiviral treatments may prevent long COVID is unconfirmed.
- 5.103 Despite this, the Committee agrees that access to antiviral treatments should be expanded so that as many Australians as possible have an opportunity to reduce the severity of their acute COVID-19 infections, and potentially reduce the risk of experiencing long COVID.
- 5.104 The Committee notes that decisions regarding the eligibility of individuals to access antiviral treatments require a positive recommendation by the Pharmaceutical Benefits Advisory Committee, an independent expert body, and as such are not within the sole discretion of the Minister for Health and Aged Care.
- 5.105 The Committee supports the recommendation of the Pharmacy Guild of Australia to enable pharmacists to initiate COVID-19 antiviral treatments and notes that such arrangements exist in the United States of America, Canada and New Zealand. This would ease the pressure on GPs and assist people who are not able to easily access an appointment with a GP within the first five days of their COVID-19 infection. This will also improve patient access to COVID-19 antiviral treatments and extend access and use throughout Australia, including in rural and remote areas, leading to a decreased burden on public hospital emergency facilities and other health services.

Indoor air quality and ventilation

- 5.106 The Committee shares the frustrations of many submitters and witnesses that the WHO's delay in recognising COVID-19 as an airborne virus ultimately weakened the initial global response to the pandemic. However, the Committee urges the Australian Government from this point on to consider improving Australia's approach to managing indoor air quality and ventilation. The Committee believes that this will help mitigate the impacts of long COVID and repeated infections, and positively benefit the health of all Australians beyond the COVID-19 pandemic in readiness for subsequent airborne threats such as smoke and pathogens.
- 5.107 The Committee wishes to emphasise that this report does not purport to traverse in any detail Australia's framework or standards around air quality and ventilation, as the Committee only received a small volume of evidence on these issues.
- 5.108 What the Committee did hear was compelling evidence that poor indoor air quality and ventilation leads to increased risk of COVID-19 infection. The Committee is convinced of the role that good air quality and ventilation play in preventing the transmission of COVID-19, and therefore in preventing long COVID and repeated COVID infections.

5.109 Thus, the Committee is of the view that the Australian Government needs to act quickly to establish consistent indoor air quality regulation, working with the states and territories, while taking advice from ventilation and multidisciplinary experts and following international best practice.

5.110 The Committee believes that national Indoor Air Quality Standards would be beneficial.



6. Responding to long COVID

Overview

- 6.1 Long COVID is still a relatively new condition, which is not yet fully understood. It is consequently unsurprising that the Committee received considerable evidence about issues and inconsistencies in terms of access to care and models of care for long COVID in Australia.
- 6.2 Some of the issues that will be discussed in this chapter include:
- Current challenges and opportunities for improving the diagnosis, treatment and management of long COVID
 - Current and potential models of care for long COVID, in particular the roles of primary care - including general practitioners (GPs) and allied health professionals – and specialist multidisciplinary long COVID clinics
 - Current Australian Government funding to support the care of long COVID patients, as well as calls for new or amended funding
 - Awareness, education and training regarding long COVID for Australia’s health workforce.

Diagnosis

- 6.3 As discussed in Chapter 4, the Committee heard from many individuals who have either experienced significant difficulty obtaining a formal long COVID diagnosis or been unable to do so.
- 6.4 Professor Michael Kidd AM, the Deputy Chief Medical Officer of the Department of Health and Aged Care (the Department), expressed concern about the potential underdiagnosis of long COVID:
- The feedback that I get from our colleagues is that some people are seeing lots of people with long COVID and some people are seeing very few people with long COVID. I am concerned that people may be being missed.¹
- 6.5 When someone with long COVID does not receive a timely diagnosis, this can lead to negative outcomes, such as delayed access to treatment and stress.

¹ Professor Michael Kidd AM, Deputy Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 13.

- 6.6 People who cannot obtain a long COVID diagnosis from a healthcare practitioner may self-diagnose. A survey of 607 people with long COVID found that 30 per cent were initially self-diagnosed with long COVID.²
- 6.7 An accurate diagnosis of long COVID is important, because as the Australian Academy of Science and the Australian Academy of Health and Medical Sciences jointly noted:
- It is important to exclude alternative explanations... when diagnosing long COVID. This is crucial to enabling health professionals to determine the most appropriate treatments and management approaches.³
- 6.8 Apart from the lack of a nationally consistent definition for long COVID (discussed in Chapter 2), the evidence received suggested that there are two major challenges to diagnosing long COVID:
- the lack of a widely available diagnostic test, and
 - medical practitioners' poor confidence to make the diagnosis.
- 6.9 These points, and suggestions from witnesses and submitters to improve the timeliness and consistency of long COVID diagnoses, are covered below.

Lack of simple and accepted diagnostic procedure

- 6.10 The Committee heard from many submitters and witnesses that there is currently no simple and widely accepted diagnostic test for long COVID, making the condition difficult to diagnose.⁴
- 6.11 NSW Health explained:

There is no definitive test for long COVID which means it is a diagnosis of exclusion and it is therefore difficult to be precise. COVID-19, like many other viral illnesses can cause lingering symptoms and after-effects. It can be challenging to determine the point at which these constitute long COVID.

² Australia Long Covid Community Facebook Group, Submission 309, p. 8.

³ Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, pages 7–8.

⁴ See, for example: Professor Greg Dore, Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 34; Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 12; Dr Golo Ahlenstiel, Clinical Network Director, Specialty Medicine, Western Sydney Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 11; Dr Benjamin Gerhardy, Respiratory Physician, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 2; Dr Jen Kok, Medical Virologist, Australian Society of Microbiology; Institute of Clinical Pathology and Medical Research; and NSW Health Pathology, *Committee Hansard*, Canberra, 17 February 2023, p. 42; Burnet Institute, Submission 149, p. 14; Queensland Health, Submission 150, p. 5, citations omitted; Department of Health and Aged Care, Submission 196, p. 21; Royal Australasian College of Physicians, Submission 249, p. 6; NSW Health, Submission 272, p. 6.

Additionally, long COVID includes a range of different clinical profiles – from mild to severe; with single or multiple symptoms, reoccurring or continuous illness, with varying impacts on breathing, circulation, and inflammatory responses. It can be difficult to tell the difference between long COVID and similar conditions such as chronic fatigue syndrome.⁵

- 6.12 Due to the large number of possible long COVID symptoms – the Burnet Institute acknowledged there are ‘up to 200 symptoms in 10 organ systems’⁶ – ruling out other conditions is particularly challenging.
- 6.13 The diagnosis of exclusion approach can be time consuming. Dr Benjamin Gerhardy, a respiratory physician with the Nepean and Blue Mountains Local Health District, explained that due to the need to conduct investigations and exclude other possible explanations, ‘...making the diagnosis [of long COVID] can’t be done very quickly...’⁷
- 6.14 Another problem associated with the current diagnosis of exclusion approach is the potential for healthcare practitioners to conduct excessive testing, at a cost to taxpayers and/or the patient. This risk was acknowledged by the National Clinical Evidence Taskforce (NCET), which recommended that ‘to avoid adding burden to the person’, healthcare practitioners ‘limit investigations to those that are necessary for determining care.’⁸
- 6.15 This situation likely contributes to patients’ reported delays and difficulties and cost associated with receiving a diagnosis. The Royal Australian College of General Practitioners quoted a GP who observed:

I believe that there is great difficulty in diagnosing long COVID resulting in diagnostic delay and subsequent management. I believe this to be a major factor impacting the patient experience.⁹

- 6.16 The Royal Australasian College of Physicians also acknowledged the negative impact this has on patients:

With no diagnostic test available, individuals are often left understandably frustrated as to how to manage their symptoms or where to seek assistance.¹⁰

Healthcare practitioners’ capability and attitudes

- 6.17 The Committee heard various perspectives regarding healthcare practitioners’ capability, willingness and confidence to diagnose cases of long COVID.

⁵ NSW Health, Submission 272, p. 6.

⁶ Burnet Institute, Submission 149, p. 14.

⁷ Dr Benjamin Gerhardy, Respiratory Physician, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 3.

⁸ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 19.

⁹ Royal Australian College of General Practitioners, Submission 168, p. 4.

¹⁰ Royal Australasian College of Physicians, Submission 249, p. 6.

- 6.18 Some healthcare practitioners reported that long COVID clinics or GPs are respectively ‘pretty good’ at diagnosing long COVID.¹¹
- 6.19 However, the Committee heard many reports from individuals with long COVID that some healthcare practitioners are reluctant to make the diagnosis.
- 6.20 For example, the Australia Long Covid Community Facebook Group conducted a survey with 607 of its members and found that:
- When seeking care for Long Covid, many patients experienced disbelief by healthcare professionals as well as minimising... Often the symptoms were blamed on anxiety and depression. About two thirds [of those surveyed] also experienced unwillingness to diagnose Long Covid.¹²
- 6.21 Some experts and peak bodies also echoed concerns about there being a reluctance to diagnose long COVID. Professor Steve Wesselingh, President of the Australian Academy of Health and Medical Sciences, acknowledged that:
- ...there's also a lot of people out there who are either worried/afraid of making the diagnosis or for a variety of reasons [are not making the diagnosis] and are therefore not helping their patients or sending their patients elsewhere.¹³
- 6.22 The Australian Healthcare and Hospitals Association noted anecdotal reports from its members suggesting that:
- ...the lack of consistent diagnostic, referral and treatment pathways for people with long COVID has resulted in some primary care and allied health service providers (private businesses) actively choosing not to treat people suffering from long COVID.¹⁴
- 6.23 One factor that may be relevant is whether healthcare practitioners have sufficient education and training to support patients with long COVID. This is discussed later in this chapter in the section titled ‘Health workforce: awareness, education and training’.
- 6.24 Another factor that could influence healthcare practitioners’ perspectives on diagnosing long COVID is whether they see a practical utility of the diagnosis, given there is currently no known treatment and supporting the patient therefore involves managing their symptoms (see the section ‘Treatment and Management of long COVID’ for further discussion).

¹¹ See, for example: Associate Professor Lou Irving, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 45; Professor Steve Wesselingh, President of the Australian Academy of Health and Medical Sciences, *Committee Hansard*, Canberra, 17 February 2023, p. 45.

¹² Australia Long Covid Community Facebook Group, Submission 309, p. 9.

¹³ Professor Steve Wesselingh, President of the Australian Academy of Health and Medical Sciences, *Committee Hansard*, Canberra, 17 February 2023, p. 45.

¹⁴ Australian Healthcare and Hospitals Association, Submission 285, p. 5.

- 6.25 A diagnosis of long COVID may hold greater clinical benefit in the future if treatments are identified. Professor Michael Kidd AM, Deputy Chief Medical Officer of the Department, considered this possibility:

There are people who may present, as we mentioned earlier, with other symptoms, as part of the spectrum. That gets managed. As long as it's being managed, that's probably the most important thing that happens... As we understand more, if there are tests available, and if there are more treatments available, we will get more understanding about who will benefit the most from the multidisciplinary interventions.¹⁵

Opportunities to improve diagnosis

- 6.26 The current diagnostic approach, as referenced above, could lead to multiple suboptimal outcomes including some people not receiving a diagnosis, delayed diagnoses, unnecessary diagnostic tests being conducted, and excessive ambiguity for healthcare practitioners. Multiple suggestions were received throughout the inquiry as to how the diagnosis of long COVID could be improved, and some of these potential issues addressed.

- 6.27 First, the Committee heard that a diagnosis is important for demystifying long COVID. Associate Professor Nada Hamad, a physician living with long COVID, stated:

One of the first things they talk about in the UK [United Kingdom], in the papers on guidelines, is that you must document it as long COVID. You must write it down. I still don't have it written down anywhere in my documentation. There is a reluctance to call it or look at it. It is because we keep talking about, 'Oh, it's just a bunch of symptoms. It's really hard to figure out.' But it actually isn't. We know that people with chronic illnesses manifest in different ways, but if we keep talking about how difficult and how nebulous it is, we will never move on.¹⁶

- 6.28 In terms of specific avenues for improvement, the Committee heard that standardising the diagnostic assessment process or developing a diagnostic model would assist. Professor Greg Dore, an epidemiologist at the Kirby Institute, explained:

It's a very difficult diagnosis because there's no easy diagnostic test... That assessment process could be somewhat standardised in terms of the tests that are ordered, the investigations that are covered and the referral pathways that are utilised.¹⁷

- 6.29 While discussing long COVID priorities, Professor Steve Wesselingh also called for a diagnostic model. He advocated:

¹⁵ Professor Michael Kidd AM, Deputy Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 13.

¹⁶ Associate Professor Nada Hamad, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 23.

¹⁷ Professor Greg Dore, Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 34.

If we could very quickly develop a relatively simple model with the right tests to exclude the diagnosis of other diagnostic opportunities, but also then lead to the diagnosis and share that widely with primary care, I think that would be probably the most helpful aspect.¹⁸

- 6.30 Professor Brendan Crabb AC, Chief Executive Officer and Director of the Burnet Institute concurred. He suggested: ‘At a high level, the most important [thing] is being able to diagnose the different forms of long COVID, assess the risk associated with each and, of course, come up with a treatment plan for each.’¹⁹
- 6.31 Multiple witnesses also referenced that in the future there may be new tools to help effectively and accurately diagnose long COVID utilising biomarker research (see Chapter 3 for further discussion).²⁰
- 6.32 Professor Jeremy Nicholson, Director of the Australian National Phenome Centre, explained to the Committee that biomarker research conducted by him and his colleagues was recently able to predict who would develop long COVID. Professor Nicholson told the Committee that ‘We think that in the future we’ll be able to predict systematic subsets of long COVID as well.’²¹
- 6.33 Professor Crabb AC commented that in the future, testing for long COVID biomarkers could form part of the long COVID diagnosis process:
- For diagnosis... we’ll start off quite clinically and, as biomarkers improve-
biomarker research... we’ll be able to add those concrete biomarkers into clinical
[diagnostic assessments].²²
- 6.34 The Burnet Institute submitted that such a tool would have significant benefits, including that it could ‘be easily deployed in medical practices across the world, at low cost.’²³
- 6.35 Dr Jen Kok, Medical Virologist, Australian Society of Microbiology; Institute of Clinical Pathology and Medical Research; and NSW Health Pathology, also saw value in biomarker tests for long COVID. At the same time, he acknowledged that further research is needed:

¹⁸ Professor Steve Wesselingh, President of the Australian Academy of Health and Medical Sciences, *Committee Hansard*, Canberra, 17 February 2023, p. 45.

¹⁹ Professor Brendan Crabb AC, Chief Executive Officer and Director, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 3.

²⁰ See, for example: Professor Greg Dore, Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 34; Dr Jen Kok, Medical Virologist, Australian Society of Microbiology; Institute of Clinical Pathology and Medical Research; and NSW Health Pathology, *Committee Hansard*, Canberra, 17 February 2023, p. 42; Professor Brendan Crabb AC, Chief Executive Officer and Director, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 3.

²¹ Professor Jeremy Nicholson, Director, Australian National Phenome Centre, *Committee Hansard*, Malvern, 20 February 2023, p. 31.

²² Professor Brendan Crabb, Chief Executive Officer and Director, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 3.

²³ Burnet Institute, Submission 149, p. 14.

...it would be very elegant if we did have a biomarker or a set of biomarkers to test people for long COVID. I don't think we're quite there yet, and there are different syndromes, if you like... If you have pulmonary predominant long COVID versus neuropredominant long COVID, those sets of biomarkers potentially could be very different.²⁴

- 6.36 The Australian Academy of Science and the Australian Academy of Health and Medical Sciences also suggested 'structured clinical assessments and laboratory investigations for conditions or disease that may be confused with long COVID' to exclude other conditions. They further argued that 'This would require our health system to support increased and standardised screening and a workforce with the knowledge and capacity to undertake these assessments.'²⁵

Treatment and management of long COVID

- 6.37 The Royal Australasian College of Physicians summarised the current situation, when it noted that 'Knowledge about Long COVID is still emerging and therefore treatment and support options provided are limited at present.'²⁶
- 6.38 This section reflects evidence received regarding the current state of treatments and management of long COVID in Australia. It first discusses the current lack of any evidence-based treatments and considers potential emerging treatments. Then, current and emerging best practice for the management of long COVID symptoms are discussed.

Treatments for long COVID

- 6.39 Many witnesses and submitters highlighted that there are currently no known, evidence-based treatments for long COVID.²⁷ As Professor Crabb AC put – 'At the moment, we don't have medical solutions and technical solutions to long COVID.'²⁸
- 6.40 However, the Committee received evidence from many individual members of the public, as well as some healthcare practitioners and medical researchers, about emerging treatments being studied for the condition. These included medications

²⁴ Dr Jen Kok, Medical Virologist, Australian Society of Microbiology; Institute of Clinical Pathology and Medical Research; and NSW Health Pathology, *Committee Hansard*, Canberra, 17 February 2023, p. 42.

²⁵ Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, p. 8.

²⁶ Royal Australasian College of Physicians, Submission 249, p. 6.

²⁷ See, for example: Associate Professor Alex Holmes, Fellow, Royal Australian and New Zealand College of Psychiatrists; Department of Health (Victoria), Submission 87, p. 3; Minister for Health and Wellbeing, SA, Submission 200, p. 7; Royal Melbourne Hospital; University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 50; Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 9.

²⁸ Professor Brendan Crabb AC, Chief Executive Officer and Director, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 1.

such as Aspirin, Naltrexone and antihistamines, and vitamins or minerals such as vitamin C, vitamin B, zinc and magnesium.²⁹

- 6.41 The Australia Long Covid Community Facebook Group identified 33 specific treatments that its' members had trialled, further illustrating the breadth of potential treatments being discussed. This group noted that 'many potential treatments (those requiring prescription, healthcare professional involvement) are not readily available to Long COVID patients in Australia'.³⁰
- 6.42 Noting a need to improve access and information regarding long COVID treatments, the Australia Long Covid Community Facebook Group proposed running more clinical trials of potential treatments, and educating health professionals of simple, cost-effective treatments.³¹
- 6.43 As discussed in Chapter 2, some consider long COVID to be an umbrella term that may in fact encompass multiple conditions or symptomatic clusters. If this is found to be the case, it is possible that some overarching treatments may be effective for all affected individuals, and/or different treatments may be needed for different symptom presentations. Professor Dore explained:
- ...I think the solution will be some therapeutic interventions. There'll probably be different interventions for different clusters. I think a neurocognitive cluster, for example, will need a specific intervention. There may be some immunological interventions that are much more broadly focused, in terms of trying to dampen down the hyperactive immune response.³²
- 6.44 The need for research and clinical trials into treatments for long COVID is discussed in Chapter 3.

COVID-19 antivirals as long COVID treatment

- 6.45 The Committee was particularly interested in evidence regarding the potential for COVID-19 antivirals to be used to treat long COVID.
- 6.46 Chapter 5 discusses the potential use of COVID-19 antivirals as a preventative measure in relation to long COVID, both in terms of preventing the development of long COVID or preventing individuals with long COVID from being reinfected. Chapter 5 also outlines the regulatory framework under which COVID-19 antivirals are listed on the Pharmaceutical Benefits Scheme.
- 6.47 In Australia, there are two oral antiviral treatments for COVID-19 currently available: molnupiravir (Lagevrio®) or nirmatrelvir and ritonavir (Paxlovid®). Neither of these

²⁹ Dr Colin McQueen, Submission 308, p. 1; Lisa Brereton, Submission 442, pages 3–4; Name withheld, Submission 9, p. 1; Ms Rose Stuart-Smith, Submission 193, p. 3; Australian Traditional Medicine Society (ATMS), Submission 271, pages 2, 6, 10–11; Ms Penelope McMillan, Spokesperson, ME/CFS Australia, *Committee Hansard*, Canberra, 17 February 2023, p. 51.

³⁰ Australia Long Covid Community Facebook Group, Submission 309.3, pages 1, 4.

³¹ Australia Long Covid Community Facebook Group, Submission 309.3, pages 1–2.

³² Professor Greg Dore, Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 35.

antivirals is currently authorised or approved for use as a treatment for long COVID, although the Department continues to monitor relevant emerging research.³³

- 6.48 Multiple individuals with long COVID noted the potential for antivirals to treat long COVID symptoms and/or called for access to antivirals for this purpose.³⁴ For example, one submitter stated: 'Although the treatment is relatively new, there are emerging case studies about the use of the antiviral Paxlovid in treating long COVID.' This submitter described two case studies with single individuals that suggest antiviral treatment may reduce long COVID symptoms.³⁵
- 6.49 The Committee heard from Pfizer Australia about two studies that are currently underway, which will evaluate the potential for Paxlovid® antivirals to be used as a treatment for people with long COVID.³⁶
- 6.50 However, as the Public Health Association of Australia noted, 'more research is required' regarding the use of antivirals as a treatment for long COVID.³⁷
- 6.51 The Burnet Institute summarised the current theory and state of research regarding antivirals as long COVID treatment:

Several antivirals are used against acute COVID-19. Some researchers think these drugs could ease the symptoms of long COVID, too — particularly as evidence grows that a lingering SARS-CoV-2 reservoir could trigger the condition. But there are still no registered studies directly looking at whether these antivirals — which are expensive and in relatively short supply compared with generic drugs — could ease long-COVID symptoms.³⁸

Current official advice

- 6.52 The Committee appreciates that suggestions regarding potential treatments for long COVID are intended to help people who are experiencing poor health and associated hardship. The Committee notes that people seeking potential treatments may be doing so because of the current absence of any established, evidence-based treatments. However, while the Committee does not intend to issue any health advice in this report, it does note the sensible evidence from the Australian Patients Association and OzSAGE, which suggests that experimenting with untested medications or other interventions may be harmful as there is the potential for over-dosing, misuse, and interactions with other drugs.³⁹ This is why potential treatments

³³ See, for example: Department of Health and Aged Care, Submission 196, p. 20; Pfizer Australia, Submission 225.1, p. 6; Therapeutic Goods Administration, *Paxlovid*, www.tga.gov.au/resources/auspmd/paxlovid, accessed 24 March 2023; Therapeutic Goods Administration, *Lagevrio*, www.tga.gov.au/resources/auspmd/lagevrio, viewed 24 March 2023.

³⁴ See, for example: Name withheld, Submission 147, p. 4; Name withheld, Submission 221, p. 4; Name withheld, Submission 298, p. 1; Name withheld, Submission 488, p. 4.

³⁵ Name withheld, Submission 311, p. 24.

³⁶ Pfizer Australia, Submission 225.1, pages 5–6.

³⁷ Public Health Association of Australia, Submission 351, p. 8.

³⁸ Burnet Institute, Submission 149, p. 16.

³⁹ Australian Patients Association, Submission 256, p. 6; OzSAGE, Submission 299, p. 9.

undergo rigorous testing in pre-clinical and clinical phases including through clinical trials pathways.

- 6.53 The Royal Australian College of General Practitioners cited advice from the NCET's 'Australian guidelines for the clinical care of people with COVID-19' (the guidelines).⁴⁰ These guidelines currently recommend:

In patients with continuing symptoms after COVID-19, do not use unproven therapies outside of guidelines or randomised trials with appropriate ethical approval.⁴¹

- 6.54 Detailed advice regarding some of the potential long COVID treatments proposed throughout the inquiry is available via the NCET guidelines⁴², and on the Australian Government's healthdirect website.⁴³ Individuals seeking health advice are encouraged to contact their GP.

Managing long COVID

- 6.55 This section discusses approaches to managing long COVID. It is noted that in some instances, witnesses and submitters appear to have used the term 'treatment' to refer to activities that would be technically classified as management or supportive care, as they aim to control or reduce (rather than fully resolve) long COVID symptoms.

- 6.56 Given that there are currently no known effective treatments, healthcare practitioners supporting patients with long COVID aim to manage their symptoms and provide supportive care.

- 6.57 This means that the current goal is to effectively manage long COVID symptoms, rather than treat (i.e. cure or fully resolve) the condition. Associate Professor Alex Holmes from the Royal Australian and New Zealand College of Psychiatrists pointed out the difference between management and treatment:

Essentially, there are no effective treatments... People talk about care and treatment as if they're the same thing... In five or 10 years time maybe that will change, but we need to acknowledge that mostly we're... helping people deal with an awful event that isn't getting better.⁴⁴

⁴⁰ Royal Australian College of General Practitioners, Submission 168, p. 10.

⁴¹ National Clinical Evidence Taskforce, *Australian guidelines for the clinical care of people with COVID-19*, app.magicapp.org/#/guideline/L4Q5An/section/jN222G, viewed 24 March 2023.

⁴² National Clinical Evidence Taskforce, *Australian guidelines for the clinical care of people with COVID-19*, app.magicapp.org/#/guideline/L4Q5An/section/jN222G, viewed 24 March 2023.

⁴³ Healthdirect, *Medications for treating COVID-19*, www.healthdirect.gov.au/covid-19/medications#not-approved, viewed 24 March 2023.

⁴⁴ Associate Professor Alex Holmes, Fellow, Royal Australian and New Zealand College of Psychiatrists; Royal Melbourne Hospital; University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 50.

- 6.58 The Committee was informed that there is currently no conclusive evidence about how to best manage long COVID.⁴⁵
- 6.59 The Burnet Institute noted ‘there have been no published clinical trials evaluating long COVID management strategies.’⁴⁶ The guidelines from NCET further state that:
- Evidence for specific management of post COVID-19 is not available.
Established symptom management approaches are likely to be beneficial.⁴⁷
- 6.60 In the absence of any evidence-based management approaches specific to long COVID, the Committee heard descriptions of the general approaches that healthcare practitioners are taking. For example, Professor Shidan Tosif, a Consultant of General Medicine and Clinical Lead at the Melbourne Royal Children’s Hospital’s Post-COVID Clinic, described:
- The mainstay of our management is supportive, holistic care with symptom control and assessment of treatable complications. What we try to do is hear the patient's story and validate the experience of the family, which is often a very challenging and anxiety-provoking experience for the child and the parents. We utilise our clinical experience with other post-viral fatigue syndromes, such as chronic fatigue syndrome and myalgic encephalitis. On a case-by-case basis we recommend activity management through, for example, pacing or prioritising activities, focusing on sleep, graded physical activity, prioritising school and social engagement, and trying to set limits around areas such as screen time. We sometimes do use medications when needed. I would say it's fairly rarely, but they are at times needed for symptom control. We monitor for other complications such as autonomic instability and weight issues.⁴⁸
- 6.61 Like Associate Professor Tosif, Associate Professor Irving from the Royal Melbourne Hospital’s Post-Covid Clinic for adults also highlighted that patient validation is an important part of providing care. He told the Committee:
- ...we based our model of care on exactly what GPs do in terms of validating symptoms, supporting the patient, not dumping the patient but keeping in touch with them and then using targeted tests or targeted referrals to rule out the very occasional, nasty thing, such as myocarditis or Pes [pulmonary embolisms] or asthma, and so on.⁴⁹

⁴⁵ See, for example: Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine, Western Sydney Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 12; Dr Benjamin Gerhardy, Respiratory Physician, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 2; Royal Melbourne Hospital, Submission 164, p. 2.

⁴⁶ Burnet Institute, Submission 149, p. 15.

⁴⁷ National Clinical Evidence Taskforce, *Australian guidelines for the clinical care of people with COVID-19*, app.magicapp.org/#/guideline/L4Q5An/section/jN222G, viewed 24 March 2023.

⁴⁸ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children’s Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 8.

⁴⁹ Associate Professor Lou Irving, private capacity, *Committee Hansard*, Canberra, 12 October 2022, p. 4.

- 6.62 The Committee also heard examples of health practitioners providing evidence of their long COVID patients' symptoms and/or advocating on behalf of their patients to facilitate appropriate adjustments or support from employers, health insurance companies and other relevant bodies.⁵⁰
- 6.63 These aspects of patient management – acknowledging patient symptoms and experience and advocacy to facilitate their access to care and engagement with employers - align with some of the key values that the NCET identified via focus groups as important for long COVID patient care.⁵¹
- 6.64 Although following established symptom management strategies is useful guidance for many healthcare practitioners, the current lack of evidence regarding long COVID may make this difficult in areas such as psychological support. Psychologists from the COVID Recovery Clinic at the Royal Melbourne Hospital drew the Committee's attention to:
- ...the lack of evidence based psychological and cognitive treatments and interventions for long COVID, causing difficulties for both clinicians and patients. Clinicians indicate that it is difficult not having strong evidence about whether the psychological and cognitive issues have a clear biological basis, or if they are secondary responses/reactions to the other factors of long COVID (medical complications, fatigue etc).⁵²
- 6.65 The psychologists from the COVID Recovery Clinic further explained:
- This impacts on the types of psychoeducation the psychologists can provide to patients, and whether their first line of treatment approaches should be restorative/symptom targeted or acceptance/compensatory based.⁵³
- 6.66 A common theme throughout the evidence was the need to manage long COVID patients as individuals and identify appropriate interventions for their symptoms on a case-by-case basis. Associate Professor Tosif illustrated this tailored approach with paediatric long COVID patients:
- It really comes down to a case by case assessment and trying to, firstly, optimise all the nonpharmacological means through which the child may have benefit—through those measures I discussed earlier. In some children where they perhaps have pain as a prominent symptom—headaches is a common one. After we have tried simple analgesia, if the headache is really impacting their function and quality of life then we may consider something similar to what we would use for migraine prophylaxis, for example.⁵⁴

⁵⁰ Associate Professor Lou Irving, private capacity, *Committee Hansard*, Canberra, 12 October 2022, p. 4; Professor Lena Sanci, Head, Department of General Practice and Primary Care, Melbourne Medical School, The University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 50.

⁵¹ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 7.

⁵² Royal Melbourne Hospital, Submission 164, p. 2.

⁵³ Royal Melbourne Hospital, Submission 164, p. 2.

⁵⁴ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 9.

- 6.67 The Committee also received evidence that rehabilitation services may play a role in helping some patients with long COVID.⁵⁵
- 6.68 The World Health Organization, as cited by the Rehabilitation Medicine Society of Australia and New Zealand, defines rehabilitation as a ‘set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment...’.⁵⁶ A number of healthcare professions provide rehabilitation services including specialist rehabilitation doctors, physiotherapists, occupational therapists, speech therapists, psychologists, dieticians and social workers.
- 6.69 The NCET guidelines recommend that- ‘In patients with persistent symptoms or functional impairment following COVID-19, begin rehabilitation as soon as possible, as appropriate to the individual’s circumstances, setting and tolerance.’ The guidelines further note that rehabilitation services which could be appropriate may include physical or occupational therapy, speech and language therapy, vocational therapy, neurological rehabilitation or dietary interventions.⁵⁷
- 6.70 The Department’s advice, titled ‘Getting help for long COVID’, similarly notes that depending on an individual’s symptoms, it may be appropriate for their GP to refer them to health professionals for various rehabilitation services.⁵⁸
- 6.71 The Committee heard that this advice is being put into practice by many healthcare practitioners. For instance, the Long Covid Clinic at St Vincent’s Hospital in Sydney outlined that:
- The management approach taken is based on general rehabilitation principles and the principles of managing treatable traits such as breathlessness, fatigue and cognitive impairment. Diagnostic review also forms part of the services of the clinic.⁵⁹
- 6.72 Other healthcare practitioners also discussed the importance of rehabilitation services via allied health professionals. Dr Benjamin Gerhardy, a respiratory physician with the Nepean and Blue Mountains Local Health District, commented that from his experience ‘The mainstay of therapy at the moment is getting patients to be involved with physiotherapists and occupational therapists.’⁶⁰

⁵⁵ Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 5.

⁵⁶ Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 5, citations omitted.

⁵⁷ National Clinical Evidence Taskforce, *Australian guidelines for the clinical care of people with COVID-19*, app.magicapp.org/#/guideline/L4Q5An/section/jN222G, viewed 24 March 2023.

⁵⁸ Department of Health and Aged Care, *Getting help for Long COVID*, www.health.gov.au/sites/default/files/documents/2022/11/getting-help-for-long-covid_0.pdf, viewed 24 March 2023.

⁵⁹ Long Covid Clinic St Vincent’s Hospital Sydney, Submission 287, p. 4.

⁶⁰ Dr Benjamin Gerhardy, Respiratory Physician, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 7.

- 6.73 Associate Professor Holmes shared a similar view, commenting that ‘The hero ingredient is in fact the exercise physiologists.’⁶¹
- 6.74 However, many witnesses and submitters contested the appropriateness of exercise as part of a management approach for long COVID patients and suggested it may in fact be harmful.⁶²
- 6.75 Professor Anne Holland, Head of Post COVID Service and Head of Respiratory Research at Alfred Health and Professor of Physiotherapy at Monash University, suggested there is an evidence gap regarding the ‘role of exercise rehabilitation or graded exercise therapy’ in managing long COVID. Professor Holland noted:

Certainly, there are people for whom the graded exercise therapy interventions are not helpful and can be harmful, but there’s also I think a group of people with long COVID perhaps with persistent respiratory disease for whom those interventions are actually quite helpful.⁶³

- 6.76 Relevantly, the NCET guidelines state:

In patients with post-exertional fatigue, use a conservative physical rehabilitation plan involving consultation with physiotherapy or exercise physiology for cautious initiation and pacing of activity or movement.

For most patients gradual return to exercise as tolerated may be beneficial.

Additional caution and specialist review should be sought before commencing exercise programs in patients who are known to have myocarditis. Clinicians should assess whether exercise exacerbates symptoms, and adjust rehabilitation plans as necessary...⁶⁴

Emerging best practice management

- 6.77 Throughout the inquiry the Committee received evidence indicating that multidisciplinary care, early intervention, and self-management approaches (for appropriate patients) may all constitute best practice management of patients with long COVID.

Multidisciplinary care

- 6.78 The Rehabilitation Medicine Society of Australia and New Zealand submitted that since most individuals with long COVID have multiple symptoms, multidisciplinary

⁶¹ Associate Professor Alex Holmes, Fellow, Royal Australian and New Zealand College of Psychiatrists; Royal Melbourne Hospital; University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 50.

⁶² See, for example: Emerge Australia, Submission 67, p. 17; Sian Webster, Submission 279, p. 4; CFS Patient Advocates, Submission 470, p. 10; Name withheld, Submission 229, p. 1; Robin Austin, Submission 499.1, p. 4.

⁶³ Professor Anne Holland, Head of Post COVID Service, Head of Respiratory Research, Alfred Health, Professor of Physiotherapy, Monash University, *Committee Hansard*, Canberra, 17 February 2023, p. 49.

⁶⁴ National Clinical Evidence Taskforce, *Australian guidelines for the clinical care of people with COVID-19*, app.magicapp.org/#/guideline/L4Q5An/section/jN222G, viewed 24 March 2023, citations omitted.

care (which involves healthcare practitioners from different disciplines) will often be required.⁶⁵

- 6.79 Many submitters and witnesses either recommended or are implementing multidisciplinary rehabilitation care arrangements for patients with long COVID.⁶⁶ For example, the Royal Melbourne Hospital informed the Committee that it has found a multidisciplinary approach beneficial:

A multidisciplinary team (MDT) approach has been very helpful in the RMH [Royal Melbourne Hospital] COVID Recovery Clinic, given the variety of symptoms in people presenting with long COVID. As such an MDT approach is recommended as best practice...⁶⁷

- 6.80 Ms McConnell, a physiotherapist leading the Royal Melbourne Hospital's allied health-led long COVID clinic, further described what their multidisciplinary approach looks like:

We have a 12-week multidisciplinary program that we run for patients that is very much tailored to the unique needs of the individual patients. We have a physiotherapist, an exercise physiologist, a clinical psychologist, a neuropsychologist, a social worker and so on. So we have quite a large array, and patients are referred to the disciplines that they need to best treat their symptoms.⁶⁸

- 6.81 The Long Covid Clinic at St Vincent's Hospital also outlined its use of multidisciplinary case conferences:

Every patient consulted is discussed at the multidisciplinary case conference, which includes specialist physicians in rehabilitation respiratory medicine as well as psychologists' physiotherapists and our clinical nurse consultant. Treatment plans are developed based on combined experience and available resources. Specialists in [particular] areas such as psychiatry and cardiology are invited to the clinic to allow us to present specific cases and to obtain information, referral pathways, and up to date research and opinion for management.⁶⁹

- 6.82 The Department noted that multidisciplinary care is also being employed by many other countries. It submitted:

⁶⁵ Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 12.

⁶⁶ See, for example: Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 11; Western Health COVID Recovery Collaboration (WHCOVRE), Submission 493, p. 16; Australian Physiotherapy Association, Submission 126, pages 12-14; Burnet Institute, Submission 149, p. 15; Dr Irani Thevarajan, Infectious Diseases Physician, Peter Doherty Institute for Infection and Immunity, *Committee Hansard*, Canberra, 12 October 2022, p. 18.

⁶⁷ Royal Melbourne Hospital, Submission 164, p. 3.

⁶⁸ Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 2.

⁶⁹ Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 4.

Most of the international approaches to the management of long COVID identified at Attachment C involve a multidisciplinary team providing care through community health clinics, general practice, rehabilitation programs, or COVID-19 clinics. This multidisciplinary team may include GPs, specialist doctors, and allied health professionals.⁷⁰

6.83 The NCET also supported multidisciplinary care, advising the Committee that:

Best practice would include a multidisciplinary team. This could be accessed through general practice, community health, rehabilitation programs or post-COVID-19 clinics, where these are available.⁷¹

Early intervention

6.84 The benefits of early intervention to manage long COVID symptoms was a theme that ran throughout the inquiry. Like with any health condition, not receiving timely support for long COVID negatively impacts an individual's recovery, potentially allows untreated symptoms to worsen, and/or causes additional stress and suffering.

6.85 Illustrating this point, the Royal Melbourne Hospital submitted:

Psychologists in the RMH COVID Recovery Clinic have noticed that those presenting with the longest duration of long COVID symptoms, appear to be having the more entrenched issues with their mental health and functional cognitive difficulties. Once symptoms are entrenched, including resulting patterns of behaviour change, these can be harder to remediate through therapy/intervention.⁷²

6.86 Beyond helping affected individuals, ensuring people with long COVID have early access to care may have broader positive effects. Professor Margaret Hellard, Deputy Director of Programs at the Burnet Institute, noted the financial benefits of early intervention. Professor Hellard expressed the importance that:

... they [patients] actually get the care that they require and they don't have to wait months and months, because that is a cost to the community. The moment somebody is not actually engaging in their family life, their social life and their work life, that's a cost anyway. It's costing us money, so it's a false economy to not do that.⁷³

6.87 Multiple submitters advocated for early intervention for people with long COVID.⁷⁴ The Western Health COVID Recovery Collaboration argued:

⁷⁰ Department of Health and Aged Care, Submission 196, p. 20.

⁷¹ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 20.

⁷² Royal Melbourne Hospital, Submission 164, p. 3.

⁷³ Professor Margaret Hellard, Deputy Director of Programs, Burnet Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 22.

⁷⁴ See, for example: Royal Melbourne Hospital, Submission 164, p. 3; Victorian Post acute Covid-19 sequelae research group (VPACS), Submission 290, p. 7.

In the absence of health promotion and/or prevention, early intervention in the disease course of Long COVID is urgently [needed]. Ideally consumers would receive rehabilitation and other supports as soon as it becomes clear they are experiencing sustained problems, and some jurisdictions include symptoms lasting longer than 1 month in their case criteria. Early referral for rehabilitation is recommended in the World Health Organisations Clinical Management of COVID-19 Living Guideline but is predicated on the availability of services. Without rapid access to the care they need, consumers experience aggravated deconditioning, loss of valued roles and social isolation as they remain on waiting lists for many months – all of which further impact on their potential to achieve optimal recovery.⁷⁵

Self-management

- 6.88 Many submitters and witnesses advocated for self-management resources and tools for patients with less severe long COVID symptoms, in addition to support for multidisciplinary care and early intervention.⁷⁶
- 6.89 As outlined in Chapter 2, although the prognosis for people with long COVID is not yet clear, at least some long COVID cases involve symptoms on the milder end of the spectrum. The Committee heard that for this group of patients, a self-management approach, via online tools and information, is likely to be appropriate.
- 6.90 Dr Danielle Hitch, a Senior Lecturer in Occupational Therapy at Deakin University, reported that much of the attention and resourcing for long COVID focuses on individuals with severe symptoms. While acknowledging that addressing this group is important, she states that:

...addressing the needs of people with milder long COVID is critical also. Even a five per cent reduction in function is significant in the short and longer term... People with milder long COVID usually don't meet the criteria for the long COVID clinics, so they are kind of falling into a gap at the moment.⁷⁷

⁷⁵ Western Health COVID Recovery Collaboration (WHCOVRE), Submission 493, p. 15, citations omitted.

⁷⁶ See, for example: Department of Health (Victoria), Submission 87, p. 12; Exercise & Sports Science Australia, Submission 169, p. 7; Murdoch Children's Research Institute, Submission 178, p. 10. Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 9; Associate Professor Philip Britton, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 47; Professor Lena Sanci, Head, Department of General Practice and Primary Care, Melbourne Medical School, The University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 50; Professor Anne Holland, Head of Post COVID Service, Head of Respiratory Research, Alfred Health, Professor of Physiotherapy, Monash University, *Committee Hansard*, Canberra, 17 February 2023, p. 56; Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine, Western Sydney Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 12; Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine, Campbelltown Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 35; Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 4.

⁷⁷ Dr Danielle Hitch, Senior Lecturer in Occupational Therapy, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 28.

- 6.91 The NCET recommends that healthcare practitioners utilise education and skills training, to support patients with long COVID to self-manage their symptoms.⁷⁸ The Committee heard that some healthcare practitioners, such as the Post-COVID Clinic at the Melbourne Royal Children’s Hospital, are already supporting a self-management approach for patients with mild functional impact.⁷⁹
- 6.92 The Committee received evidence emphasising that while self-management approaches have merit, they will not be suitable for all long COVID patients. Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine at Campbelltown Hospital, discussed whether allied health support could be outsourced to self-management systems. Dr Nguyen said:
- I guess it comes back to what the symptoms are. If it's general fatigue symptoms, I feel a lot of them can be self-managed... There may be some specific symptoms in terms of breathlessness where there may be disordered breathing patterns, where a specific form of rehab may be useful, and in that case some expertise in terms of managing some of the more complex breathing disorders may be useful. But, for the majority of patients with long COVID symptoms, an approach where there's self-management tools, where there's pacing strategies [management of activity to avoid over-exertion] and education around how to manage those... would be quite useful...⁸⁰
- 6.93 Dr Nguyen further commented that self-management resources need to:
- ...be easy to understand, potentially allow for individualisation of treatment approaches based on symptoms and functional impact, be scalable, be cost-effective, and provide guidance on how, when and where to get further help.⁸¹
- 6.94 The need for self-management resources and information to be accessible for culturally and linguistically diverse and Aboriginal and Torres Strait Islander populations was also mentioned.⁸² The Rehabilitation Medicine Society of Australia and New Zealand additionally noted that self-management resources would likely be of most benefit to individuals with ‘reasonable education standards and adequate health literacy.’⁸³
- 6.95 While self-management may sound like it does not involve contact with a healthcare practitioner, Associate Professor Holmes suggested that there may be a need for a

⁷⁸ National Clinical Evidence Taskforce, *Australian guidelines for the clinical care of people with COVID-19*, app.magicapp.org/#/guideline/L4Q5An/section/jN222G, viewed 24 March 2023.

⁷⁹ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children’s Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 8.

⁸⁰ Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine, Campbelltown Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 35.

⁸¹ Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine, Campbelltown Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 34.

⁸² Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 11; Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine, Campbelltown Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 34.

⁸³ Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 11.

GP to facilitate and provide supportive care to patients with long COVID utilising a self-management approach.⁸⁴

- 6.96 Throughout the inquiry some submitters and witnesses cited the United Kingdom's (UK) 'Your COVID Recovery' digital program as an example of international best practice for supporting long COVID patient self-management and advocated for Australia to adapt the UK version or develop something similar.⁸⁵
- 6.97 Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine at Western Sydney Health District, told the Committee that the UK 'Your COVID Recovery' digital program and the COVID-19 Recovery Course are 'an efficient way of doing things and also being able to get things out for the population.'⁸⁶ He advised that the UK has an open access platform, and providers can grant patients access to a program of up to 12 weeks, which provides additional resources and support.
- 6.98 Ms Carly McConnell, ReCOV Team Leader at the Royal Melbourne Hospital, also complimented the UK's 'Your COVID Recovery' program. She described that the program allows patients to enter and monitor their symptoms and communicate with the relevant health service. Ms McConnell suggested that:

A great way of scaling our [long COVID clinic] service up would actually be to triage the milder symptoms into a program like that so that they can self-manage, and then the tertiary services can really focus their resources where they're needed more, in severe disease.⁸⁷

Settings and models of care

- 6.99 When people with long COVID engage with Australia's healthcare system, they typically do so via primary care (entry level services such as GPs), specialist long COVID clinics, and/or allied health providers.
- 6.100 This section first discusses the various roles that primary care (including GPs and allied health) and long COVID clinics play in supporting patients with long COVID and considers benefits and drawbacks of the current approaches. Some apparent inconsistencies in long COVID care across Australia are examined, including regarding the roles and operations of long COVID clinics.

⁸⁴ Associate Professor Alex Holmes, Fellow, Royal Australian and New Zealand College of Psychiatrists; Royal Melbourne Hospital; University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 50.

⁸⁵ See, for example: Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, p. 8; Victorian Post acute Covid-19 sequelae research group (VPACS), Submission 290, p. 20.

⁸⁶ Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine, Western Sydney Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 12.

⁸⁷ Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 4.

6.101 The current state of affairs in terms of models of care for supporting long COVID patients are then considered, and potential opportunities to improve models of care for long COVID patients are discussed.

Current settings for care

Primary care

6.102 The current advice from the Department is that people with persistent symptoms after COVID-19 should seek first advice from their GP. The Department further advises that:

It is likely that many symptoms can be managed through primary care services, including GPs and allied health professionals such as physiotherapists, occupational therapists, dietitians, speech pathologists, psychologists, social workers and exercise physiologists.⁸⁸

6.103 The NCET supports GPs being the first port of call. It submitted that:

General practitioners are well placed to undertake initial investigations and diagnosis of long COVID, including determining if symptoms are related to or exacerbated by comorbid conditions. In some instances, patients may require additional assessment by more than one specialist to exclude other conditions contributing to their symptoms.⁸⁹

6.104 The issue of whether GPs are appropriately funded to manage long COVID patients is discussed later in this chapter in the section titled 'Australian Government funding for long COVID care'. Likewise, whether GPs have the relevant knowledge, education and training to effectively support long COVID patients is discussed in the section titled 'Health workforce: awareness, education and training'.

6.105 The Committee heard different perspectives on whether GPs are equipped to support long COVID patients from a demand perspective.

6.106 The Australian Medical Association called for greater support for general practice. It argued that:

GPs will be on the front line and will need appropriate resourcing to manage the expected increase in [long COVID] patients. GPs cannot be expected to take on this additional burden with no additional resources as they have throughout the pandemic.⁹⁰

⁸⁸ Department of Health and Aged Care, 3 November 2022, *Getting help for Long COVID*, www.health.gov.au/sites/default/files/documents/2022/11/getting-help-for-long-covid_0.pdf, p. 19, viewed 24 March 2023.

⁸⁹ National Clinical Evidence Taskforce (Monash University), Submission 232, pages 19–20.

⁹⁰ Australian Medical Association, Submission 328, p. 1.

6.107 The South Australian Minister for Health and Wellbeing, the Hon Chris Picton MP, shared this view that long COVID is likely to result in an increase in patients seeking care. Citing self-reported data from long COVID patients in the UK that indicates a considerable number have symptoms for one to two years after their COVID-19 infection, Minister Picton stated that this supports GPs taking a central role. He said:

Given that a large proportion of Long COVID patients have such chronic symptoms, it reinforces the ideal position of primary care to support the majority of these patients, while the resource-intensive multidisciplinary acute sector teams care should be reserved for a minority of complex and severe patients.⁹¹

6.108 However, Queensland Health presented a different view. Its submission outlined that a focus group convened to advise on the demand and design of support services for people with long COVID, advised that it did not currently observe a significant demand in primary care services. Queensland Health noted that the focus group further advised that ‘the management of long COVID did not warrant the establishment of tertiary specialist services in Queensland’s context’, and instead suggested that long COVID ‘be managed within primary care’.⁹²

6.109 Thus, the Committee heard some perspectives or forecasts regarding high numbers of people being severely impacted by long COVID and requiring care, and others anticipating a lesser impact on Australia’s healthcare system. In some instances, these varying forecasts may explain the different views regarding whether general practice currently has the capacity to effectively support long COVID patients. In other instances, regardless of disagreement on the prevalence or prognosis of long COVID, some stakeholders agreed that primary care is well placed to manage the majority of long COVID cases.

6.110 Relevant to long COVID, community based care is generally considered to include allied health practitioners. As discussed under the section ‘Managing long COVID’, allied health often plays a role in supporting patients with long COVID. This includes allied health involvement via GP referrals.

6.111 Noting that GPs and allied health are often both involved in supporting long COVID patients, Allied Health Professions Australia reported that allied health practitioners consider GPs as ‘central to managing long COVID patients at many stages of their care’. Allied Health Professions Australia further advocated that GPs should also ‘help coordinate and structure an effective multi-disciplinary plan for the patient’.⁹³

Benefits of primary community care response

6.112 The Committee heard various reasons why primary care should play the central role in supporting people with long COVID.

⁹¹ Minister for Health and Wellbeing, SA, Submission 200, p. 6.

⁹² Queensland Health, Submission 150, p. 7.

⁹³ Allied Health Professions Australia, Submission 269, p. 18.

6.113 Professor Mark Morgan, Chair of the Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, NCET's Primary and Chronic Care Panel, noted that GPs are well suited to provide coordinated care for long COVID patients because there are GPs across the country, they are reasonably accessible, and GPs as generalists are 'able to manage a multisystem disease, which has psychosocial impacts.'⁹⁴

6.114 Professor Bennett noted that from a practical point of view, GPs are likely to be where many individuals with long COVID symptoms first seek help, regardless of any official models of care or government advice. She explained:

People won't necessarily know that they have long COVID. They may not even know they've had a COVID infection, particularly if they had a very mild or asymptomatic or atypical COVID infection. They might not even know that it could be long COVID. So I actually think, just thinking about it from a referral point of view, that you have to support this from the GP level up...⁹⁵

6.115 Given the role they play, another potential consideration is that GPs may have greater knowledge of a patient's history than other healthcare practitioners. The Royal Australian College of General Practitioners mentioned that: 'GPs are experts in providing patient-centered, continuous, and coordinated care. GPs know their patients, their medical history, backgrounds, social and mental health circumstances.' At the same time, they cautioned that:

General practice cannot work in isolation to provide effective long COVID management, particularly for more complex cases of long COVID and, other medical specialists and allied health professionals must be engaged in a coordinated manner.⁹⁶

6.116 Noting this idea that GPs are often a trusted healthcare practitioner, the Hon Chris Picton MP, the South Australian Minister for Health and Wellbeing, reported that GPs may consequently be appropriately placed to support long COVID patients who experience any related mental health concerns. Minister Picton stated that:

...a range of mental health disorders have been reported in patient cohorts recovering from COVID-19... primary care GPs are well placed to leverage the trusted steady relationships with their patients, in conjunction with psychologists and mental health support programs, to support patients in their mental health recovery over the long term.⁹⁷

6.117 Dr Kenneth McCroary, a GP and Director of Macarthur General Practice, noted that GPs also often have experience managing post-viral syndromes and people with

⁹⁴ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 13.

⁹⁵ Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 32.

⁹⁶ Royal Australian College of General Practitioners, Submission 168, pages 8–9.

⁹⁷ Minister for Health and Wellbeing, SA, Submission 200, p. 6, citations omitted.

chronic illness.⁹⁸ Given the current advice is to utilise established symptom management approaches⁹⁹, such experience may be transferrable to long COVID patients.

6.118 Another potential advantage that GPs may have over more specialised colleagues is being more integrated within the local community. For instance, while discussing challenges conducting effective community outreach with culturally and linguistically diverse populations from a long COVID clinic perspective, Dr Gardiner observed that 'patients often go to the GPs that speak their native language'.¹⁰⁰

6.119 Throughout the inquiry and as previously noted, the Committee received evidence that self-management approaches and/or management via primary care (specifically GPs) are likely to be appropriate and effective for many long COVID patients.¹⁰¹ If this is correct, using primary care to manage lower-risk, less complex cases of long COVID may avoid escalating patients to specialists unnecessarily.

Drawbacks of primary community care response

6.120 However, the Committee also received evidence regarding multiple disadvantages of utilising GPs to manage people with long COVID.

6.121 First, as outlined in the previous section titled 'Healthcare practitioners' capability and attitudes', the Committee heard that some individuals have found GPs to be unable or unwilling to diagnose and support patients with long COVID.

6.122 As another issue, multiple submitters and witnesses noted that it can be challenging for people to attend an appointment with their GP due to attendance often involving out-of-pocket expenses and/or their limited availability.

6.123 Dr Archana Sud, an Infectious Diseases Physician and Clinical Director Medicine at the Nepean and Blue Mountains Local Health District, noted that out-of-pocket fees would probably be an issue for some individuals, and would represent a barrier for lower socioeconomic populations.¹⁰²

6.124 Dr McCroary, a GP and Director of Macarthur General Practice, agreed there is often 'difficulty in attending' a GP, and attributed this to 'the increased crisis that general practices are facing in terms of numbers and particularly distribution.' Dr McCroary

⁹⁸ Dr Kenneth McCroary, Director, Macarthur General Practice, *Committee Hansard*, Liverpool, 5 December 2022, p. 46.

⁹⁹ Burnet Institute, Submission 149, p. 15.

¹⁰⁰ Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine, Western Sydney Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 14.

¹⁰¹ See, for example: Department of Health and Aged Care, *Getting help for Long COVID*, www.health.gov.au/sites/default/files/documents/2022/11/getting-help-for-long-covid_0.pdf, p. 19, viewed 24 March 2023; Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine, Campbelltown Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 35; Queensland Health, *Submission 150*, p. 7; Minister for Health and Wellbeing, SA, Submission 200, p. 5; Dr Kenneth McCroary, Director, Macarthur General Practice, *Committee Hansard*, Liverpool, 5 December 2022, p. 48.

¹⁰² Dr Archana Sud, Director, Infectious Diseases Physician, Clinical Director Medicine, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 7.

further observed that 'it's going to cause a lot of challenges and a put a lot more burden on our hospital system and emergency presentations if people are expected to pay these out-of-pocket funds.'¹⁰³

6.125 The Rural Doctors Association of Australia submitted the issue of shortages of practitioners in rural areas as another potential challenge with relying upon GPs.¹⁰⁴

6.126 Thus, as Dr Danielle Hitch commented 'Not everyone has a GP. Not everyone accesses their GP either.' Dr Hitch emphasised that given there are different groups with long COVID that have different needs and different access to care:

Having a range of options is more likely to actually reach all Australians or the vast majority.¹⁰⁵

6.127 From a patient perspective, the Committee heard that some individuals find seeking help via a GP slow and expensive. For instance, Dr Kyaw-Myint, an individual with long COVID, commented:

Everything is so siloed. You get referred to so many specialists. The specialist writes back to the GP. Sometimes you wait six months to see a specialist. You don't get to even speak to the specialist again because you have to wait another six months... I don't feel like GPs are the answer. We need multidisciplinary centres of excellence for long COVID.¹⁰⁶

6.128 During a public hearing, another individual with long COVID, Ms Karren Hill, noted that GPs are under tight time constraints¹⁰⁷, which may impact their ability to communicate efficiently with specialists.

6.129 In addition to the aforementioned broader issues with accessing GPs, the Committee heard that some GPs may not have the necessary expertise to support long COVID patients. Mr Robin Austin, a person with long COVID, shared his perspective:

My understanding has always been that you need the GP as the first port of call. If it's relatively simple, the GP works with you and fixes your problem. But if it's complex, they need to refer you to specialists. When it's complex and mysterious, there is no way that most GPs will ever begin to be able to address that with you on their own. They need to refer you to the specialists who are working on this all day, every day, learning as they go, so that we have access to the best knowledge, the best international knowledge. My wonderful GP will never begin

¹⁰³ Dr Kenneth McCroary, Director, Macarthur General Practice, *Committee Hansard*, Liverpool, 5 December 2022, p. 47.

¹⁰⁴ See, for example: Rural Doctors Association of Australia, Submission 362, p. 2.

¹⁰⁵ Dr Danielle Hitch, Senior Lecturer in Occupational Therapy, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 33.

¹⁰⁶ Dr Su Mon Kyaw-Myint, personal capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 26.

¹⁰⁷ Ms Karren Hill, Administrator, Australia Long Covid Community Facebook Support Group, *Committee Hansard*, Canberra, 17 February 2023, p. 27.

to be able to get anywhere near that. He needs to be able to say... 'Go to the experts in the multidisciplinary clinic'.¹⁰⁸

Long COVID clinics

6.130 A major theme throughout the inquiry was the establishment of long COVID clinics in some parts of the country, to provide services to patients with long COVID. This section first provides a brief overview of where these long COVID clinics are, what roles they play, and the services they provide. Various benefits and drawbacks of these long COVID clinics as raised throughout the inquiry are then discussed.

6.131 Long COVID clinics typically provide specialist, dedicated and multidisciplinary services to people with long COVID, and are connected to a tertiary hospital. The Australian Patients Association referenced that 89 long COVID clinics have been set up around Australia, in both rural and urban settings.¹⁰⁹

6.132 At least six Australian states and territories have established one or more long COVID clinics.¹¹⁰

6.133 At the time of writing Tasmania does not appear to have any long COVID clinic.¹¹¹ The Northern Territory has not established any, and the Northern Territory Department of Health explained the rationale for this decision:

Currently, there is no centralised long COVID referral pathway or multidisciplinary long COVID service in the NT. This decision was made due to the NT context where there is remote community focus on primary care management of patients with multidisciplinary input through in-reach and out-reach models of care. The current models of multidisciplinary care for chronic disease are therefore ideally accessed for these patients in community, rather than establishing urban teams which require additional staffing and travel of patients or staff.¹¹²

6.134 The Northern Territory Department of Health elaborated:

The best practice approach for the management of long COVID has been described as a dedicated multi-disciplinary long COVID service. In our context, from a financial, service and patient perspective, having a centralised service for such a large and remotely spread potential pool of patients long term is not the

¹⁰⁸ Mr Robin Austin, Member, Australia Long Covid Community Facebook Support Group, *Committee Hansard*, Canberra, 17 February 2023, p. 27.

¹⁰⁹ Australian Patients Association, Submission 256, p. 2.

¹¹⁰ See: ACT Government, *Post-COVID Recovery Clinic*, www.canberrahealthservices.act.gov.au/services-and-clinics/services/post-covid-recovery-clinic, viewed 27 March 2023; NSW Health, Submission 272, p. 10; Queensland Health, Submission 150, p. 7; Minister for Health and Wellbeing, SA, Submission 200, p. 2; Department of Health (Victoria), Submission 87, p. 7; Department of Health (Western Australia), Submission 273, p. 4.

¹¹¹ It appears that Tasmania does not have any long COVID clinic, although the Tasmanian Department of Health has launched a Post COVID-19 Navigation Service. See: Department of Health (Tasmania), *Post COVID-19 Navigation Service*, www.health.tas.gov.au/post-covid-19-navigation-service, viewed 27 March 2023.

¹¹² Department of Health (Northern Territory), Submission 253, p. 3.

preferred model. In our context skilling primary care and outreach multi-disciplinary teams to identify and undertake initial management supported by urban specialists (including by telehealth) is a more sustainable model for the NT.

As our understanding of the regional and local impact of long COVID across the NT emerges it may be that a focussed model is developed.¹¹³

- 6.135 Other countries including the Belgium, Canada, France, Germany, Spain, the UK, and the United States have also reportedly established specialist long COVID clinics.¹¹⁴
- 6.136 Throughout the inquiry the Committee heard from multiple long COVID clinics operating around the country. These clinics can differ in multiple ways, including in terms of:
- The referral pathways to access the clinic and admission criteria
 - The clinic's role, in particular whether a clinic is designed to provide initial assessment and diagnosis of patients, and/or support and facilitate specialist care for patients with more severe symptoms; and
 - The variety of health disciplines incorporated within the clinic.
- 6.137 Funding for long COVID clinics is discussed later in this chapter in the section titled 'Australian Government funding for long COVID care'.
- 6.138 Many long COVID clinics that provided evidence to the inquiry advised that they either require or prefer a referral from a GP to attend the clinic.¹¹⁵
- 6.139 However, some long COVID clinics accept a wider range of referrals. For example, the Post-COVID Clinic at the Melbourne Royal Children's Hospital accepts referrals from GPs, other internal areas of the hospital, other hospitals, hospital emergency departments, and even interstate referrals.¹¹⁶ In addition to GP referrals, the Royal Melbourne Hospital's allied health-led long COVID clinic also accepts self-referrals from hospital staff.¹¹⁷
- 6.140 Another point of difference between long COVID clinics was the admissions criteria they set for patients. Some long COVID clinics only accept referrals for individuals who live within the relevant catchment area. For instance, the temporary long COVID clinic being trialled at Bentley Health Service in Western Australia 'requires referral from a general practitioner (GP) for people who live in the catchment area.'¹¹⁸

¹¹³ Department of Health (Northern Territory), Submission 253, p. 5.

¹¹⁴ Department of Health and Aged Care, Submission 196, pages 19, 35; Pfizer Australia, Submission 225.1, p. 4.

¹¹⁵ See, for example: Department of Health (Western Australia), Submission 273, p. 4; Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 4.

¹¹⁶ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 9.

¹¹⁷ Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 5.

¹¹⁸ Department of Health (Western Australia), Submission 273, p. 4.

6.141 Others, such as the Royal Melbourne Hospital's allied health-led long COVID clinic, will accept referrals for patients outside their hospital's catchment area if the patient's area does not have a comparable service.¹¹⁹

6.142 Similarly, some long COVID clinics require that patients are diagnosed with long COVID by their GP before they can attend the clinic. The long COVID clinic at St Vincent's Hospital is one such example, and additionally requires that patients have undergone certain tests prior to admission. It explained:

Patients cannot be admitted to the clinic unless they have been referred by a GP and a diagnosis of long Covid has been made. This indicates that the diagnosis is one of exclusion. Other comorbidities that the patients suffering with are optimally managed. Tests that need to be completed prior to admission include a chest x-ray, a D-dimer test, and a CRP. Further the Yorkshire long Covid questionnaire must be completed online... Communication with the patient needs to be undertaken as well as communication with the GP either online or by telephone.¹²⁰

6.143 In contrast, other long COVID clinics described that their approach includes assessing and diagnosing long COVID cases. Associate Professor Shidan Tosif, a Consultant of General Medicine and Clinical Lead at the Melbourne Royal Children's Hospital's Post-COVID Clinic, outlined that:

Our approach is to assess children according to a standardised definition for PCC [Post-COVID conditions, i.e. long COVID]. We consider PCC what we call a diagnosis of exclusion, which means we have to evaluate at times for other medical and mental health diagnoses which may present in a similar way, with similar symptoms, before confirming the diagnosis.¹²¹

6.144 Related to differences in the approach to diagnosis, is whether the individual clinics view their role as being to support early intervention in cases of long COVID, and/or to manage complex and/or severe cases of long COVID.

6.145 Associate Professor Tosif explained that the Post-COVID Clinic at Melbourne's Royal Children's Hospital aims to 'take more of an assessment and early management role'. He noted that 'We would try and prioritise seeing those children early and provide some initial assessment and advice and try to set them up as soon as possible for self-management where we can.'¹²²

6.146 In contrast, some other long COVID clinics exclusively aim to be a specialist service for patients with severe long COVID symptoms or complex needs, meaning that

¹¹⁹ Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 5.

¹²⁰ Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 4.

¹²¹ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 8.

¹²² Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 12.

these clinics would not see most patients with mild long COVID symptoms. For instance, under South Australia's state-wide long COVID model of care, only 'patients with substantial disability or uncertain diagnoses' are referred to hospital long COVID clinics.¹²³

- 6.147 The Committee also heard of alternative approaches to support long COVID patients without establishing long COVID clinics. For example, Western Sydney Local Health District described that its 'approach to-date has really been to support general practice with access to existing sub-specialty clinics and services. We have yet to establish a long COVID clinical service.'¹²⁴
- 6.148 Another area in which long COVID clinics are not consistent is in terms of the health disciplines that lead the clinics and are incorporated within them.
- 6.149 Dr Danielle Hitch, a Senior Lecturer in Occupational Therapy at Deakin University, noted that: 'Some of the long COVID clinics are allied health led, and they're the key rehabilitation experts for chronic and complex conditions.'¹²⁵
- 6.150 Two examples of this approach are the allied health-led long COVID clinic at the Royal Melbourne Hospital that runs in conjunction with a respiratory service, and Western Australia's temporary long COVID clinic.¹²⁶ Both of these allied health-led long COVID clinics are led by physiotherapists.
- 6.151 The Long COVID clinic at St Vincent's Hospital is different; it is led co-led by a respiratory physician and a rehabilitation physician.¹²⁷
- 6.152 The Committee also heard that some long COVID clinics have internal staff from a range of disciplines. For instance, the Royal Melbourne Hospital's allied health-led multidisciplinary long COVID clinic includes a range of allied health professions including 'a physiotherapist, an exercise physiologist, a clinical psychologist, a neuropsychologist, a social worker...'.¹²⁸ The Long COVID clinic at St Vincent's Hospital, by contrast, has fewer allied health practitioners in-house: a clinical psychologist, physiotherapist, and clinical nurse.¹²⁹
- 6.153 The Committee heard that where some long COVID clinics may not have allied health or specialists such as cardiologists in-house, they often have relationships

¹²³ Minister for Health and Wellbeing, SA, Submission 200, p. 5.

¹²⁴ Dr Golo Ahlenstiel, Clinical Network Director, Specialty Medicine, Western Sydney Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 12.

¹²⁵ Dr Danielle Hitch, Senior Lecturer in Occupational Therapy, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 27.

¹²⁶ Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 4; Department of Health (Western Australia), Submission 273, p. 4.

¹²⁷ Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 3.

¹²⁸ Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 2.

¹²⁹ Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 3.

with rehabilitation services and specialists at the hospital, through which patients can receive support where necessary.¹³⁰

Benefits of long COVID clinics

6.154 One benefit of long COVID clinics is that they should facilitate the health practitioners working there to develop expertise and specialise in supporting long COVID patients. Through focusing on a single condition there is also potentially a greater opportunity for long COVID clinics to collect relevant data and contribute to and stay abreast of emerging research.

6.155 Brimbank Community-Led Long Covid Group emphasised these benefits of a specialist and dedicated service, recommending that:

Specialist Long COVID clinics rather than GPs or the already stretched hospital system are best placed to provide a dedicated, caring and specialist approach and a significant source of important community data on his disease, that in our opinion must be maintained.¹³¹

6.156 As an example of how long COVID clinics may facilitate long COVID research, the clinic at St Vincent's Hospital reported close research ties with the ADAPT study, and that it is supporting an ongoing research project to identify outcomes and qualitative approaches to the management of long COVID patients.¹³²

6.157 Another advantage of long COVID clinics from the patient perspective is that these often provide more affordable access to care, including in some instances from allied health professionals and specialists.

6.158 Long COVID patients often encounter out-of-pocket expenses to access allied health services in the community¹³³, however as outlined above, these services may be free if accessed as part of a long COVID clinic.

6.159 Dr Irani Thevarajan noted that accessing specialists is a significant challenge for some Australians:

Getting access to a cardiologist, getting access to respiratory physicians, getting access to a psychiatrist and a neurologist—I can't imagine that they would be easy areas for someone who has socioeconomic limitations.¹³⁴

6.160 In addition to supporting better patient access to care in a financial sense, the Committee also heard that long COVID clinics may be easier for patients to

¹³⁰ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 12.

¹³¹ Brimbank Community-Led Covid Group, Submission 527, p. 2.

¹³² Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 6.

¹³³ Allied Health Professions Australia, Submission 269, p. 4.

¹³⁴ Dr Irani Thevarajan, Infectious Diseases Physician at the Peter Doherty Institute for Infection and Immunity, *Committee Hansard*, Canberra, 12 October 2022, p. 16.

physically attend and may enable greater coordination of care among treating healthcare practitioners.

- 6.161 Ms Karren Hill and Dr Su Mon Kyaw-Myint, two individuals with long COVID, respectively commented that long COVID clinics are ‘one place to go’, and that ‘it’s not as tiring going to one place.’¹³⁵ Ms Hill further outlined the benefits of long COVID clinics:

They [long COVID clinic staff] talk between themselves about what treatment plan they would put forward... You would hope that over time they will get more knowledge about overseas, because we seem to be behind with what’s happening with research. They will get to know what is happening. They may apply it. They may see a pattern of patients where something is working or not.¹³⁶

Drawbacks of long COVID clinics

- 6.162 Some witnesses and submitters took a different view and highlighted various drawbacks of long COVID clinics. For example, the Australian Long Covid Community Facebook Group reported that of its 607 members surveyed:

Over 70% of participants reported that Long Covid clinics are not a helpful source of information... This may be partly due to the long wait for these clinics and the variation in the quality of these clinics around the country with some offering outdated therapies such as graded exercise therapy and cognitive behavioural therapy.¹³⁷

- 6.163 The long wait lists to access long COVID clinics was a common criticism throughout the inquiry.¹³⁸
- 6.164 Multiple long COVID clinics acknowledged that they were struggling to meet patient demand, and their wait lists were growing.¹³⁹ For instance, the long COVID clinic at St Vincent’s Hospital reported that as of November 2022, its respiratory physician and rehabilitation physician are respectively booked out until April and October 2023.¹⁴⁰

¹³⁵ Ms Karren Hill, Administrator, Australia Long Covid Community Facebook Support Group, *Committee Hansard*, Canberra, 17 February 2023, p. 27; Dr Su Mon Kyaw-Myint, personal capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 26.

¹³⁶ Ms Karren Hill, Administrator, Australia Long Covid Community Facebook Support Group, *Committee Hansard*, Canberra, 17 February 2023, p. 27.

¹³⁷ Australia Long Covid Community Facebook Group, Submission 309, p. 10.

¹³⁸ See, for example: Australian Healthcare and Hospital Association, Submission 285, p. 5; Brimbank Community-Led Covid Group, *Submission 527*, p. 1; Name withheld, Submission 348, p.1; Mrs Melinda Border, Submission 184, p. 2; Name withheld, Submission 347, p. 1; Madeline Cooper, Submission 371, p. 1.

¹³⁹ See, for example: Minister for Health and Wellbeing, SA, Submission 200, p. 7; Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 4.

¹⁴⁰ Long Covid Clinic St Vincent’s Hospital Sydney, Submission 287, p. 8.

6.165 Associate Professor Tosif noted that he expects the waitlist for the long COVID clinic operating out of the Royal Children's Hospital in Melbourne to continue to grow, since it 'can take some time for the recognition of post-COVID conditions'.¹⁴¹

6.166 Dr Zinta Harrington, Head of the Department of Respiratory and Sleep Medicine at Sydney's Liverpool Hospital, noted that wait lists are a common problem for specialist clinics. She commented that from her perspective:

I think speciality clinics create workflow problems in terms of bottlenecks. I have six different speciality clinics, all with long waiting lists. If we create another one then it will find a long waiting list too.¹⁴²

6.167 Dr Harrington further questioned whether long COVID clinics are the most appropriate solution to managing long COVID patients. In querying this, Dr Harrington noted that relevant contextual factors include that specialist clinics are 'highly expensive' to taxpayers, and the lack of evidence-based treatments or specific symptom management strategies for long COVID. Dr Harrington explained:

I do think that there's been a jump to creating a solution that's not necessarily tailored to the problem... If there were something very specific that the hospital only could provide, then I think we should provide it...¹⁴³

6.168 Apart from the wait lists, the Committee received some evidence questioning the idea that long COVID clinics do possess specialist expertise in managing long COVID. In its submission, the UNSW Fatigue Clinic and Research Program describes itself as the only specialist service in Australia 'with expertise to diagnose and manage patients with Long COVID or other post-infective fatigue states... notwithstanding the birth of many 'Long COVID clinics' with uncertain expertise in evidence-based management' post-infection fatigue.¹⁴⁴

6.169 Whether or not long COVID clinics do in practice provide effective and coordinated multidisciplinary care was also contested. Associate Professor Nada Hamad noted that in her experience long COVID clinics did not provide well-coordinated care. She commented:

...I am in a long COVID clinic. I can tell you, from my perspective and in my opinion, the model of care in a long COVID clinic does not work. It includes a combination of clinicians who don't talk to each other. The systems don't talk to each other. They each manage their own system. I got multiple conflicting advice from various clinicians because they're still working in their own silo.¹⁴⁵

¹⁴¹ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 11.

¹⁴² Dr Zinta Harrington, Head, Department of Respiratory and Sleep Medicine, Liverpool Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 31.

¹⁴³ Dr Zinta Harrington, Head, Department of Respiratory and Sleep Medicine, Liverpool Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 31.

¹⁴⁴ UNSW Fatigue Clinic and Research Program, Submission 289, p. 2.

¹⁴⁵ Associate Professor Nada Hamad, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 22.

6.170 Some witnesses additionally noted that long COVID clinics may not be accessible to all people, and there are indications that they are predominantly being accessed by those with greater health literacy and/or who are English-speaking.

6.171 Dr Jason Agostino, Senior Medical Adviser at the National Aboriginal Community Controlled Health Organisation, expressed concern that standalone long COVID clinics ‘will likely be difficult to access for many Aboriginal and Torres Strait Islander peoples’.¹⁴⁶

6.172 Dr Hitch expressed similar concern, and observed that:

the specialist long COVID clinics... can be inaccessible for some, especially ...people living in poverty, people from culturally and linguistically diverse backgrounds, and marginalised communities generally...¹⁴⁷

6.173 The Committee heard some reports indicating that these concerns may be warranted. Associate Professor Tosif commented from the perspective of the Post-COVID Clinic run out of Melbourne Royal Children’s Hospital:

...I do fear that we're seeing, potentially, those higher health-literate and English-speaking families that are able to recognise this condition and access services. It does raise concerns for us about the awareness of this condition more broadly in children and their families who are culturally diverse with non-English-speaking backgrounds. I don't think we are yet seeing a broad enough representation in our clinic of what we should be seeing in some of those groups, who may not have access or the awareness due to the barriers of language and health literacy.¹⁴⁸

Ms McConnell echoed similar concerns in relation to the Royal Melbourne Hospital’s allied health-led long COVID clinic and respiratory service:

... I think both of our services are quite open to selection bias, being that we're located within the hospital. I would comment, from our perspective, we see around one-third of our patients being staff, but we're advertised within the hospital. When we look at our population as a whole, only two per cent require an interpreter. Clearly, the messaging is getting out to our staff and our English-speaking, educated, health-literate population but potentially not to our non-English speaking population. So I think we're quite heavily biased in that regard...¹⁴⁹

¹⁴⁶ Dr Jason Agostino, Senior Medical Adviser, National Aboriginal Community Controlled Health Organisation, *Committee Hansard*, Canberra, 17 February 2023, p. 1.

¹⁴⁷ Dr Danielle Hitch, Senior Lecturer in Occupational Therapy, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 27.

¹⁴⁸ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children’s Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 11.

¹⁴⁹ Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 4.

6.174 Dr Benjamin Gerhardy, a respiratory physician with the Nepean and Blue Mountains Local Health District, noted that their long COVID clinic also shared this concern:

... the group that it feels like we are missing, just from seeing the patients who come to the door every day, is the non-English speaking groups because we just don't get very many. We know that a lot of them have had COVID, and some of them quite severely. So I do feel like our clinic doesn't adequately capture the disease burden that's in the community with regard to that group...¹⁵⁰

6.175 Some submitters also raised people living in rural or remote communities not having physical access to long COVID clinics as an issue, since these are predominantly based in metropolitan centres.¹⁵¹ It is noted that while this is a challenge, many long COVID clinics conduct services via telehealth.¹⁵²

Models of care

6.176 As outlined above, the Committee received evidence highlighting multiple issues and inconsistencies regarding the ability of people with long COVID to access effective and efficient care.

6.177 This section accordingly discusses current models of care by which Australia's overall healthcare system delivers care to long COVID patients, and subsequently considers opportunities for improvement.

Current models of care

6.178 This chapter previously highlighted inconsistencies both among and between primary care providers, specifically GPs, and long COVID clinics. These inconsistencies include different conceptualised roles and different services provided to long COVID patients. This section considers system-wide models of care, including pathways by which long COVID patients navigate different settings of the healthcare system.

6.179 Commenting on the broader models of care for patients with long COVID, the Victorian Post acute Covid-19 sequelae research group observed that:

At present long COVID care is offered through a range of models of care that have been established by individual organisations and clinicians to meet the needs of people with long COVID. There is however much variation across these models, lack of a systematic approach and an absence of clear pathways between these models for patients whose care needs change.¹⁵³

¹⁵⁰ Dr Benjamin Gerhardy, Respiratory Physician, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 6.

¹⁵¹ Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, p. 7, citations omitted; Australian Healthcare and Hospital Association, Submission 285, p. 5.

¹⁵² See, for example: Minister for Health and Wellbeing, SA, Submission 200, p. 5; Ms Carly McConnell, ReCOV Team Leader, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 5.

¹⁵³ Victorian Post acute Covid-19 sequelae research group (VPACS), Submission 290, p. 3.

- 6.180 A review of the submissions received from Australian state and territory health authorities demonstrates the lack of a national approach to supporting long COVID patients.
- 6.181 South Australia is the only state or territory that reported it has developed a model of care setting out care pathways for adult patients with long COVID. Key aspects of South Australia’s model of care include:
- Comprehensive initial assessment of patients with suspected Long COVID by the GP, including thorough history, examination, and investigations to exclude alternative causes for the symptoms.
 - An estimation of the severity and functional limitation of symptoms, with these factors primarily guiding the degree of intervention the patient will need.
 - The promotion of supported self-management strategies for all patients.
 - Referral of patients with substantial disability or uncertain diagnoses to Long COVID clinics in hospitals. The clinics have access to physicians from multiple disciplines, diagnostics and therapy teams. In addition, they have access to programs provided by specialist rehabilitation teams...
 - The hospitals provide outreach activities and centralised telehealth (assessment) telerehabilitation services for rural and remote clients to ensure equitable access to specialist rehabilitation teams.¹⁵⁴
- 6.182 NSW Health advised that it is currently developing a model of care for long COVID. Its submission further notes that:
- NSW Health has a state-wide approach in place which provides evidence based clinical management guidance for primary care providers with local referral escalation pathways and specialist services based on need.¹⁵⁵
- 6.183 In Victoria, the Victorian Department of Health informed the Committee that there is work underway to:
- better identify demand for long COVID support
 - map the service models of existing clinics supporting long COVID patients; and
 - develop state-wide criteria for referrals to multidisciplinary services for long COVID patients.¹⁵⁶
- 6.184 The evidence received from the Western Australian Department of Health and Queensland Health does not mention any model of care for long COVID patients.¹⁵⁷

¹⁵⁴ Minister for Health and Wellbeing, SA, Submission 200, p. 5.

¹⁵⁵ NSW Health, Submission 272, pages 9–10.

¹⁵⁶ Department of Health (Victoria), Submission 87, p. 7.

¹⁵⁷ Department of Health (Western Australia), Submission 273; Queensland Health, Submission 150.

- 6.185 However, the submission from Queensland Health recommends that ‘Primary Care is the main setting for the management of patients experiencing a longer recovery from COVID-19’ and notes that additional support is required for better ‘access to community allied health services, to which GPs could refer patients for symptom management (rather than a dedicated long COVID-19 service).’ Queensland Health additionally states that it ‘continues to monitor the demand across its health system for long COVID services.’¹⁵⁸
- 6.186 The Northern Territory Department of Health’s submission outlined that long COVID patients are being managed via primary care, with possible multidisciplinary support via ‘in-reach and out-reach models of care’, and/or specialist support – including via telehealth- as required.¹⁵⁹

Strengthening models of care

- 6.187 The Committee received considerable evidence outlining potential ways to create or improve models of care to better support long COVID patients.
- 6.188 The Australian Academy of Science and the Australian Academy of Health and Medical Sciences observed that ‘Australia can improve access to healthcare for patients experiencing long COVID and develop better and clearer care pathways within the health system.’¹⁶⁰
- 6.189 The NCET agreed, and stated that currently there is ‘no clear pathway for patients and their care team to determine the most appropriate setting of care and how to facilitate transition between these settings.’¹⁶¹

Most long COVID managed via primary care

- 6.190 The need for primary care, in particular GPs, to manage the majority of individuals with long COVID was a theme that ran throughout the inquiry.
- 6.191 The NCET noted that its guidelines recommend a ‘biopsychosocial approach to care, within the local context’ for patients with long COVID, given the large range in symptoms.¹⁶² The NCET further recommends that:

¹⁵⁸ Queensland Health, Submission 150, pages 3, 8.

¹⁵⁹ Department of Health (Northern Territory), Submission 253, pages 2, 5.

¹⁶⁰ Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, p. 2.

¹⁶¹ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 9.

¹⁶² A biopsychosocial approach ‘systematically considers biological, psychological, and social factors and their complex interactions in understanding health, illness, and health care delivery.’ See: The University of Rochester Medical Center, *The Biopsychosocial Approach*, www.urmc.rochester.edu/medialibraries/urmcmedia/education/md/documents/biopsychosocial-model-approach.pdf, viewed 29 March 2023.

The primary health care team is well placed to coordinate person centred care and should remain a central point in the care team along with the person's carer or significant other.¹⁶³

6.192 Many witnesses and submitters assumed a pragmatic view that primary care managing most long COVID patients was the most practical solution.

6.193 For instance, Dr Zinta Harrington, Head of the Department of Respiratory and Sleep Medicine at Liverpool Hospital, noted that specialist clinics generally have long wait lists, and that GPs are generally more accessible. She stated:

I think it [support for people with long COVID] belongs in primary care... The way to deal with a big problem is to diversify the people who can then address that problem. The more practitioners you have, you don't have an access problem.¹⁶⁴

6.194 Professor Greg Dore, an Epidemiologist with the Kirby Institute, agreed and commented that 'I think a lot of it has to be managed in primary care... We can't manage it all through so-called centres of excellence... we do want most of it to be able to be managed at the primary care level.'¹⁶⁵

6.195 Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine at Western Sydney Health District, further agreed, stating that '...our belief is that the general practices are the gatekeepers or the primary people who need to be involved with this.'¹⁶⁶

6.196 Dr Gardiner additionally noted that 'A lot of the patients, we know, can be treated at scale', and raised the potential for many patients to be managed more efficiently, using online self-management resources and/or support.

6.197 The potential for supporting many individuals with milder long COVID symptoms via self-management tools and resources is discussed earlier in this chapter in the section titled 'Self-management'.

6.198 The Victorian Department of Health generally noted that a major benefit of most long COVID care being provided in primary health care settings is that this will 'assist in reducing hospital care and emergency department presentations for most low-risk, long COVID cases.'¹⁶⁷

6.199 While many discussed the merits of primary health care leading the management of most long COVID patients, the Committee heard that there may be insufficient information available setting out models of care for patients that initially see their GP

¹⁶³ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 20.

¹⁶⁴ Dr Zinta Harrington, Head, Department of Respiratory and Sleep Medicine, Liverpool Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 31.

¹⁶⁵ Professor Greg Dore, Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 41.

¹⁶⁶ Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine, Western Sydney Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 12.

¹⁶⁷ Department of Health (Victoria), Submission 87, p. 6.

but require additional support. The Australian Healthcare and Hospital Association submitted that:

In Australia, service models for long COVID in primary care are not well (if at all) established, with GPs in many areas highlighting the absence of referral pathways from general practice to specialised long COVID supports for patients presenting with long COVID symptoms. This is problematic given that Australian Government advice recommends seeing your GP if you are experiencing long COVID symptoms.¹⁶⁸

Pathways to escalate severe and/or complex cases

6.200 Multiple submitters and witnesses highlighted that while primary care settings could support many long COVID patients, there needs to be pathways for escalating patients with more severe symptoms and/or complex needs, such as multimorbidity (the presence of multiple diseases and medical conditions in a single person).

6.201 The Committee also received evidence that these pathways need to be clear. One individual submitter with long COVID expressed that there is a 'Lack of clarity on care pathways and what it means to be a long covid clinic' and noted that both patients and healthcare practitioners could benefit from clear information 'on what these services are and are not.'¹⁶⁹

6.202 Some of the evidence emphasised a general need for escalation options. For instance, Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine at Campbelltown Hospital commented:

We acknowledge that, even though primary care in communities is where most patients with long COVID should be managed, and our primary care colleagues are doing as much as they can with what they have, they cannot do it on their own and will need support from secondary and tertiary care providers for some patients. The question remains how to best provide these services for the number of patients who may actually need them.¹⁷⁰

6.203 Professor Catherine Bennett, Chair in Epidemiology at Deakin University, similarly noted that referral pathways will be important given emerging research indicates that long COVID can sometimes involve more complex symptoms. She advised that:

There has to be a balance between looking after people with more generic symptoms where they can be supported or can self-manage with good guidance and those with more advanced neurological symptoms. Another study has just come out talking about 44 different neurological syndromes or disorders associated with COVID. So you probably need a balance between some specialisation so that you can refer people to clinics where there are medical

¹⁶⁸ Australian Healthcare and Hospitals Association, Submission 285, p. 4, citations omitted.

¹⁶⁹ Name withheld, Submission 190, p. 1.

¹⁷⁰ Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine, Campbelltown Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 34.

experts who understand—whether it is thinking about it from a cardio or neuro point of view, for example.¹⁷¹

- 6.204 Others specifically argued that specialist long COVID clinics should exist as a referral pathway for patients requiring specialist and/or multidisciplinary support. The Royal Australasian College of Physicians told the Committee that:

It is recognised that most post-COVID issues resolve and are managed via primary care. However, for ongoing or more severe issues, patients will require access to specialist multidisciplinary clinics or ‘Long COVID clinics’ run collaboratively across medical specialties.¹⁷²

- 6.205 Professor Morgan outlined that a model of care wherein most long COVID cases are managed in primary care and complex or high needs cases are escalated to a long COVID clinic, would make sense given the nature of long COVID. He explained:

Long-COVID clinics will pull together expertise and would be a convenient place for GPs to refer the most severe or troubling people with long-COVID symptoms, who need that level of expertise that’s been gathered, and equipment and testing facilities, within long-COVID clinics. It’s very similar to the way we interact with other specialist providers. We manage the majority in general practice, but we need to be able to refer to other people when symptoms are particularly severe or need equipment and testing that’s not available in general practice. Having a one-stop shop makes a lot more sense for a multisystem disease state than trying to refer a person to a multitude of separate care providers.¹⁷³

- 6.206 The Department also considered that long COVID clinics could play a role for supporting those most impacted by long COVID. The Department’s Secretary, Professor Brendan Murphy AC, said:

We feel that they [long COVID clinics] probably have a very narrow role for a small subset of quite long-standing and very disabled people who need intensive, highly specialised care. Most people are probably best managed in primary care. We’ve said that most people, we believe, will recover, with supportive care... There is probably a role for these clinics regarding a small proportion of people.¹⁷⁴

- 6.207 As discussed in the section ‘Drawbacks of long COVID clinics’, there are often long wait lists for patients to access these services. Triage long COVID patients so that only those with more severe or complex needs are referred to long COVID clinics is

¹⁷¹ Professor Catherine Bennett, Chair in Epidemiology, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 33.

¹⁷² Royal Australasian College of Physicians, Submission 249, p. 6.

¹⁷³ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners’ Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce’s Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 16.

¹⁷⁴ Professor Brendan Murphy AC, Secretary, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 13.

one way to improve wait lists. Another option would be to open additional long COVID clinics or increase funding for existing clinics to enable additional staffing (see 'Public hospital funding' section later in this chapter for further discussion).

6.208 Different views were heard on the number of long COVID clinics that should be established across Australia. Some advocated for additional long COVID clinics, potentially including in regional areas.¹⁷⁵

6.209 The Australian Medical Association similarly called for additional long COVID clinics, but warned that careful consideration and planning needs to be undertaken regarding the impact this would have on the workforce. It advised:

More dedicated Long COVID clinics will also assist with the management of these conditions, however these must be planned with the whole health system in mind. Too often we have seen new services established which have required significant staff. These staff have come from other services, at times leaving the existing services unable to manage. Australia has a total health workforce shortage right now, and we must sensibly manage our limited resources.¹⁷⁶

6.210 From the perspective of an existing specialist service, the long COVID clinic at St Vincent's Hospital recommended 'Specialist long COVID clinics that operate in a small number of centres in each state.'¹⁷⁷

Tiered model of care

6.211 Extending calls for clearer referral pathways from primary care, some witnesses and submitters emphasised that a tiered model of care would be effective and efficient for supporting long COVID patients.¹⁷⁸ In general, proposals for a tiered model of care involved:

- self-management resources and tools initially
- then if required, GP management potentially including multidisciplinary care; and
- if further support was required, escalation to specialist care (potentially again including multidisciplinary care) via long COVID clinics or other means.

6.212 One group recommending a tiered model of care was the NCET. It recommended endorsing and supporting:

... a model of care delivery that involves a tiered approach to providing clinical care. Most patients with long COVID will not require specialist care. Many of these patients will be able to self-manage their clinical care. However others, will require clinical care from a general practitioner, and others still will require more

¹⁷⁵ See, for example: Royal Australasian College of Physicians, Submission 249, p. 4; Rural Doctors Association of Australia, Submission 362, p. 4.

¹⁷⁶ Australian Medical Association, Submission 328, p. 5.

¹⁷⁷ Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 2.

¹⁷⁸ See, for example: Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 11.

intensive multidisciplinary care involving the primary care team plus allied health and a variety of specialists....¹⁷⁹

6.213 The NCET specified that primary care should play a coordination role. It explained:

A tiered model of care (similar to that used for COVID-19) could be employed across the healthcare system, notably coordinated within primary care, to avoid unnecessary burden on the patient and health system and to guide patient-centred and appropriate clinical care.¹⁸⁰

6.214 Evidence outlining the benefits of a tiered model of care highlighted that this would be sensible and pragmatic in terms of both financial viability and health workforce limitations.

6.215 Professor Anne Holland, Head of Post COVID Service and Head of Respiratory Research at Alfred Health and Professor of Physiotherapy at Monash University, noted that triaging only long COVID patients with higher needs to specialist long COVID clinics would reduce demand and thus make the clinics more affordable to run. She commented:

We've talked today about being able to make a diagnosis in primary care and people being confidently able to do that, then having self-management resources available that will help most people, along with the messaging about recovery, and then a pathway into a specialist service if you need it. If we know that only a small number of people are going to need that pathway, because there are other things available, that will make it easier for state health to keep those [long COVID clinics] open.¹⁸¹

6.216 Professor Morgan pointed out that reducing the number of people with long COVID seeking to attend long COVID clinics would improve access for those patients who do require greater support. He said:

I don't believe you could set up a system of long-COVID clinics that has equitable access for everybody. It would largely be an excessive resource for people with mild conditions, and therefore interfere with access by people with severe conditions.¹⁸²

6.217 Dr Gardiner echoed that triaging long COVID patients based on their needs is essential to manage costs, maintain efficiency, and work within existing health workforce constraints. He told the Committee:

¹⁷⁹ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 9.

¹⁸⁰ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 20.

¹⁸¹ Professor Anne Holland, Head of Post COVID Service, Head of Respiratory Research, Alfred Health, Professor of Physiotherapy, Monash University, *Committee Hansard*, Canberra, 17 February 2023, p. 62.

¹⁸² Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 16.

We're certainly looking at an approach like the UK and providing particularly some virtual rehab, and we'd like the GPs to be the centre of that...

And then there could be a very targeted long COVID clinic side of things... I think the big target of that would be for those with multiple medical comorbidities and for those with a lot of impact in their daily life, so we'd triage them... If we don't do that, then we certainly wouldn't be able to manage demand. It'd be quite expensive and fairly inefficient. And, quite frankly, we'd never be able to get the allied health and other resources available to do any of this.¹⁸³

6.218 Western Sydney Local Health District's Dr Ahlenstiel suggested that for a long COVID model of care to be 'financially viable and sustainable', it will need to involve telehealth and involvement from the primary health networks, since there are only a limited number of specialists around.¹⁸⁴

6.219 It was also mentioned that if long COVID clinics continue to be utilised, it is important that these conduct outreach with other health care settings, 'so that everyone can benefit from the specialist knowledge that's being developed through those.'¹⁸⁵

Alternative proposals

6.220 Over the course of the inquiry the Committee also heard various alternative suggestions to either strengthen existing models of care or create new models. Some of these are mentioned below.

6.221 Dr Danielle Hitch told the Committee about a model of care for patients with long COVID developed by the Western Health COVID Recovery Collaboration and co-designed by people experiencing the condition. Dr Hitch described that:

...we've co-produced a model of care with people who have long COVID. It's called the discovery model. Our consumer partners were clear that they wanted access to care in their local communities; they didn't want to have to travel and they wanted something that was just around the corner, if possible. They also wanted options that met their individual needs. So, the model is founded on care coordination, rather than a new long COVID clinic. It's about linking people with existing local services and supports—healthcare supports as well as beyond health care, because long COVID impacts every part of daily life. So, as part of the model we also have things like education, cultural participation and employment relationships—all of those sorts of things.¹⁸⁶

¹⁸³ Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine, Western Sydney Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 18.

¹⁸⁴ Dr Golo Ahlenstiel, Clinical Network Director, Specialty Medicine, Western Sydney Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 12.

¹⁸⁵ Dr Danielle Hitch, Senior Lecturer in Occupational Therapy, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 27.

¹⁸⁶ Dr Danielle Hitch, Senior Lecturer in Occupational Therapy, Deakin University, *Committee Hansard*, Canberra, 12 October 2022, p. 27.

6.222 The Western Health COVID Recovery Collaboration’s submission noted that this model of care includes an online self-management component, which is currently being developed.¹⁸⁷

6.223 Queensland Health also advocated for a model of care including greater community allied health services, ‘to which GPs could refer patients for symptom management (rather than a dedicated Long COVID-19 service).’¹⁸⁸

Australian Government funding for long COVID care

6.224 This section considers Australian Government funding particularly relevant for long COVID health care. Broader funding for Australia’s healthcare system is not within the scope of this inquiry.

Public hospital funding

6.225 Given long COVID clinics were a major point of discussion throughout the inquiry, it follows that the Committee also received evidence regarding funding arrangements for these clinics.

6.226 The Committee heard that as long COVID clinics were generally set up by individual hospitals and local health networks, the funding arrangements for these clinics vary.

6.227 For example, Associate Professor Irving, Respiratory Physician at the Royal Melbourne Hospital’s Post-Covid Clinic, told the Committee that initially the hospital’s respiratory outpatient service expanded to cover the long COVID clinic. Associate Professor Irving described how the clinic’s funding arrangements had evolved since it first started:

...more recently it's a Medicare clinic, and we're billing item numbers. The integrated allied health service is being funded by the hospital for 12 months and then being reviewed. It's only in the credit to the hospital to do it. To be fair, quite a few of the early patients were our own staff and that was our incentive.¹⁸⁹

6.228 The long COVID clinic at The Royal Children’s Hospital in Melbourne also utilises a mixture of core hospital funding and Medicare bulkbilling.¹⁹⁰

6.229 The long COVID clinic at St Vincent’s Hospital reported that its respiratory physician and rehabilitation physician are funded in kind only, and its psychologist is also funded in kind provided by the Department of Pain Medicine within the hospital.¹⁹¹

¹⁸⁷ Western Health COVID Recovery Collaboration (WHCOVRE), Submission 493, p. 15.

¹⁸⁸ Queensland Health, Submission 150, p. 7.

¹⁸⁹ Associate Professor Lou Irving, private capacity, *Committee Hansard*, Canberra, 12 October 2022, p. 5.

¹⁹⁰ Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children’s Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 11.

¹⁹¹ Long Covid Clinic St Vincent’s Hospital Sydney, Submission 287, p. 3.

6.230 Despite variations in funding, the Committee heard repeatedly that a key challenge for the long COVID clinics was unstable, short-term funding. Dr Brendan McMullan, a Paediatric Infectious Diseases Specialist with Sydney Children's Hospitals Network, noted that sufficient resourcing to support children with long COVID is a challenge:

... particularly in terms of coordination of support for post-COVID conditions and the lack of dedicated funding. The work that the group of clinicians have managed to achieve over the past almost three years has been almost entirely as a sort of coalition of the willing. People have been going above and beyond to do this work, obviously recognising the importance of it and being very happy to contribute, but with a lack of dedicated funding. There is a real sustainability issue there. There are other places around the world that have invested in coordinating long COVID care, like in the United Kingdom, which has included dedicated funding for paediatrics as well.¹⁹²

6.231 Acknowledging the current funding instability, multiple submitters and witnesses called for greater funding for long COVID clinics.¹⁹³

6.232 Some of these calls came from health practitioners working at long COVID clinics. For instance, Dr Gerhardy who works at the Nepean and Blue Mountains Local Health District's long COVID clinic, mentioned at a public hearing in December 2022 that:

We have issues with ongoing funding. For example, at the moment our clinic is funded only until the end of this year, meaning we'll lose at least two physicians, as well as our essential administrative staff, as we head into 2023, and I'm sure our clinic is not the only one in this position.¹⁹⁴

6.233 The Department's submission explained the responsibilities of the Australian Government and state and territory governments in relation to public hospitals, out of which most long COVID clinics are based. The Department noted that:

State and territory governments are responsible for the public health system, including public hospitals and community clinics. They continue to have a role supporting people who have long COVID by providing access to outpatient services, including multidisciplinary long COVID clinics. Some private hospitals have also established long COVID clinics.

The Government is working with state and territory governments to better understand the services provided by multidisciplinary long COVID clinics,

¹⁹² Dr Brendan McMullan, Paediatric Infectious Diseases Specialist, Sydney Children's Hospitals Network, *Committee Hansard*, Liverpool, 5 December 2022, p. 23.

¹⁹³ See, for example: Royal Australasian College of Physicians, Submission 249, p. 67; Australian Healthcare and Hospitals Association, Submission 285, p. 6; Long Covid Clinic St Vincent's Hospital Sydney, Submission 287, p. 3; Australian Medical Association, Submission 328, p. 5; Australian Federation of Disability Organisations, Submission 486, pages 13-14; Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead, Post-COVID Clinic, The Royal Children's Hospital, *Committee Hansard*, Canberra, 12 October 2022, p. 9.

¹⁹⁴ Dr Benjamin Gerhardy, Respiratory Physician, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 1.

including whether demand is being met and any additional demand for primary health care services arising from long COVID.¹⁹⁵

6.234 The Australian Government contributes funds to the states and territories for public health services under the *2020-25 National Health Reform Agreement (NHRA)*.¹⁹⁶

The Department explained that:

Under the National Health Reform Agreement (NHRA), the state and territory governments have committed to providing eligible patients with the choice to receive public hospital services free-of-charge, on the basis of clinical need and within a clinically appropriate period. Decisions regarding access to public hospital services and determining the appropriate treatment of individual patients rest with states and territories, individual hospitals and the doctors involved.

Public hospital services provided for the treatment of long COVID, including in an outpatient setting, attract a funding contribution from the Commonwealth under the NHRA.¹⁹⁷

6.235 Under the NHRA, the Australian Government's total funding contribution to public health services is capped at 6.5 per cent a year.¹⁹⁸

6.236 The Victorian Department of Health proposed that the Australian Government provide 'Additional funding of demand growth in public health services (unconstrained by the 6.5 per cent growth cap) to ensure adequate care for long COVID without negatively impacting other hospitalisation care needs.'¹⁹⁹

Medicare

6.237 Under Medicare, the Australian Government pays for some or all of the costs of various medical services, including those provided in public hospitals. The Medicare Benefits Schedule (MBS) lists professional services that the Australian Government subsidises, under specific items.

6.238 Given Medicare is one of the Australian Government's major levers to support public health in Australia, the Committee was interested to hear evidence regarding to what extent Medicare was supporting long COVID patients accessing care, and proposals for potential improvements to the system. This section discusses aspects of the Medicare system particularly relevant to long COVID: calls for one or more new MBS

¹⁹⁵ Department of Health and Aged Care, Submission 196, p. 20.

¹⁹⁶ Department of Health and Aged Care, 9 February 2022, *2020–25 National Health Reform Agreement (NHRA)*, www.health.gov.au/our-work/2020-25-national-health-reform-agreement-nhra, viewed 29 March 2023.

¹⁹⁷ Department of Health and Aged Care, Submission 196, p. 20.

¹⁹⁸ Department of Health and Aged Care, 9 February 2022, *2020–25 National Health Reform Agreement (NHRA)*, www.health.gov.au/our-work/2020-25-national-health-reform-agreement-nhra, viewed 29 March 2023.

¹⁹⁹ Department of Health (Victoria), Submission 87, p. 2.

items specifically for long COVID, discussion regarding MBS Chronic disease GP Management Plans and Team Care Arrangements.

New Medicare item/s for long COVID

6.239 The Committee heard some calls for a new MBS item – or items - specifically for long COVID. Dr Su Mon Kyaw-Myint, speaking in a personal capacity, suggested this and noted that from her perspective, it would be ‘easy’ to add a new Medicare item for long COVID.²⁰⁰

6.240 The Victorian Department of Health recommended the creation of multiple new MBS items – that is ‘Specific MBS long COVID items to support access to primary care for patients including items for essential affordable allied health services.’²⁰¹

6.241 The Victorian Department of Health also separately advocated for changes to chronic disease management plans to enable greater access to allied health care for individuals with long COVID (this is discussed further below). It noted that in the event relevant changes to chronic disease management plans were not supported, Victoria would alternatively support the introduction of ‘a specific long COVID care plan MBS item.’²⁰²

6.242 In its submission, Queensland Health stated that it saw a need for greater funding for long COVID patients to access allied health support. Queensland Health commented that the current MBS CDM plans (which are discussed below), would not be suitable for long COVID patients as they anticipate the person being sick for at least six months. Queensland Health cautioned against associating long COVID with chronic disease and suggested that an alternative funding arrangement facilitating access to allied health, potentially similar to the existing MBS CDM items, be established.²⁰³

6.243 The Australian Government Department of Health and Aged Care affirmed that, like most health conditions, there are no specific MBS items for the treatment or care of individuals with long COVID. The Department noted that:

Individuals with long COVID can access existing MBS items for the treatment of their condition, including time tiered GP general attendance items. If clinically appropriate, GPs can also refer patients to relevant specialists for treatment. Specialist doctors also have access to a range of general consultation items.²⁰⁴

6.244 Professor Morgan, representing the Royal Australian College of General Practitioners, argued that from a GP perspective amending the current MBS items would be a better solution rather than creating a new MBS item for long COVID. He explained:

²⁰⁰ Dr Su Mon Kyaw-Myint, personal capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 29.

²⁰¹ Department of Health (Victoria), Submission 87, p. 2.

²⁰² Department of Health (Victoria), Submission 87, p. 7.

²⁰³ Queensland Health, Submission 150, p. 7.

²⁰⁴ Department of Health and Aged Care, Submission 196, p. 19.

The current system, with enhancements, would be better than a new Medicare item number for a single disease definition, because one problem you have then is how well that label fits the person in front of you that needs your help. You end up with the label being stretched to fit the needs of the person, or people missing out on care. I'd much rather see an enhancement through access to additional resources by tweaking the numbers that are currently available...²⁰⁵

6.245 Proposals for a new long COVID-specific MBS item to aid in data collection are discussed in Chapter 3.

Chronic disease General Practitioner Management Plans

6.246 Under the current Medicare system, people with long COVID may be eligible for MBS Chronic disease GP Management Plans (GPMP). The Department outlined the general eligibility requirements:

To be eligible for CDM [chronic disease management] items a person must have at least one medical condition that has been present (or is likely to be present) for at least six months or is terminal. The CDM items enable GPs to plan and coordinate the health care of patients with chronic or terminal medical conditions. GPs may refer patients for up to five MBS subsidised allied health services per calendar year under a GP Management Plan and Team Care Arrangement. There is no list of eligible conditions. Whether an individual meets the eligibility requirement of having a chronic or terminal condition is a clinical judgement for their GP.²⁰⁶

6.247 Multiple submitters and witnesses raised the potential for GPMPs to be used to support patients with long COVID. Dr Archana Sud, an Infectious Diseases Physician and Clinical Director of Medicine at the Nepean and Blue Mountains Local Health District, commented that 'GP care plans [GPMPs] could be encouraged, and they might help them [patients] to access at least some allied health help.'²⁰⁷

6.248 However, the Committee received evidence regarding various issues and/or deficits relating to the current GPMP MBS items.

Long COVID eligibility

6.249 The Committee received evidence indicating that there is significant confusion among GPs over whether it is reasonable to create chronic disease GPMPs for patients suspected of having long COVID.²⁰⁸

²⁰⁵ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 14.

²⁰⁶ Department of Health and Aged Care, Submission 196, p. 19.

²⁰⁷ Dr Archana Sud, Infectious Diseases Physician, Clinical Director Medicine, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 7.

²⁰⁸ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel,

- 6.250 Professor Morgan indicated that issuing advice clarifying the situation could be a short-term fix that would improve long COVID patients' access to care.²⁰⁹
- 6.251 The core issue is that, as reflected in Chapter 2 of this report, the prognosis for long COVID patients, that is how long their illness will persist and the likelihood of recovery, is unclear. This presents an issue because the use of MBS chronic disease GPMP items requires the GP to forecast whether the patient's condition is likely to last for at least six months.
- 6.252 The Australian Healthcare and Hospitals Association outlined the ambiguity of the current situation:
- Chronic disease GP Management Plans... and Team Care Arrangements... present a mechanism through which GPs are seeking to provide more coordinated joined up care for those experiencing long COVID. However, to be eligible for these MBS items patients must have a chronic medical condition which has been, or as the case is more likely to be, the condition must be present for at least six months. Together with nationally inconsistent definition of long COVID and a limited evidence base, health professionals face considerable difficulty determining if the experience of long COVID symptoms actually persist past 6 months. As such, many people are left to experience debilitating symptoms for 6 months before they are able to access subsidised coordinated support for long COVID.²¹⁰
- 6.253 The Royal Australian College of General Practitioners advised the Committee that it sought clarity in late 2021 regarding whether the MBS chronic disease GPMP items could be used for managing patients with long COVID, and was told that - "whether a patient is eligible for a [chronic disease management] service or services is essentially a matter for the GP to determine using clinical judgement".²¹¹
- 6.254 However, the South Australian Minister for Health and Wellbeing, the Hon Chris Picton MP, described the current situation as 'ambiguous' and recommended explicit confirmation be issued that long COVID is a condition eligible for MBS chronic disease GPMPs.²¹²

Reducing the 6-month requirement

- 6.255 As previously stated, to access MBS chronic disease GPMP items for long COVID, the patient must have had long COVID for at least six months or be likely to have long COVID for at least this period.

Committee Hansard, Malvern, 20 February 2023, p. 15; Australian Medical Association, Submission 328, p. 15; Royal Australian College of General Practitioners, Submission 168, p. 9.

²⁰⁹ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 15.

²¹⁰ Australian Healthcare and Hospitals Association, Submission 285, p. 4, citations omitted.

²¹¹ Royal Australian College of General Practitioners, Submission 168, p. 9.

²¹² Minister for Health and Wellbeing, SA, Submission 200, p. 2.

6.256 Professor Michael Kidd AM, Deputy Chief Medical Officer of the Department, outlined the current functioning of the MBS chronic disease GPMP items for long COVID patients. He stated:

The chronic disease item numbers are not enacted until six months after someone has been diagnosed with a chronic condition. Of course, with the current definition that we have, that's three months after people may have been diagnosed with long COVID. That means that access to subsidised allied health, psychology and so forth, is not readily available to people. Those who can afford to pay for it can access it; those who can't afford to do so within that three-month period miss out, which obviously is inequitable.²¹³

6.257 The previous section highlighted that due to an absence of clear guidance and research regarding the prognosis for long COVID patients, some GPs are hesitant to utilise MBS GPMP items for long COVID patients that have not yet been sick for six months.

6.258 Some submitters and witnesses advocated for amending the MBS GPMP items to allow for these to be used for patients with long COVID who have been sick for at least three months (rather than six).²¹⁴

6.259 Professor Lena Sanci, Head of the Department of General Practice and Primary Care at Melbourne Medical School at the University of Melbourne commented that allowing long COVID patients to access MBS GPMP items 'even earlier' than three months would be beneficial.²¹⁵

6.260 At a public hearing with the Department, the viability of amending the MBS chronic disease GPMP items to allow these to be utilised for long COVID patients who have been sick for three months (as opposed to six) was discussed. Professor Brendan Murphy AC, Secretary of the Department, informed the Committee that this proposal:

...would require a change of Medicare policy. It would require approval of government and it would require costing and finance assessment. It's certainly possible. It would be tricky to do it for just one condition because you'd then open the door to lots of other people who may have less than a six-month, debilitating condition. It would be a complex issue to deal with. It's certainly feasible.²¹⁶

²¹³ Professor Michael Kidd AM, Deputy Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 13.

²¹⁴ Department of Health (Victoria), Submission 87, p. 13; Allied Health Professions Australia, Submission 269, p. 20; Professor Andrew Lloyd, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 46; Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 16.

²¹⁵ Professor Lena Sanci, Head, Department of General Practice and Primary Care, Melbourne Medical School, The University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 47.

²¹⁶ Professor Brendan Murphy AC, Secretary, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 13.

Increasing allied health sessions

- 6.261 The current MBS chronic disease GPMP items allow for a maximum of five subsidised allied health sessions each calendar year.²¹⁷
- 6.262 A recurrent suggestion throughout the inquiry was to increase the number of subsidised allied health sessions available to long COVID patients per annum under a MBS chronic disease GPMP.²¹⁸
- 6.263 Allied Health Professions Australia argued that the current limit of five allied health visits each year ‘results in sub-optimal, fragmented care for long COVID patients.’ Allied Health Professions Australia further suggested that the limit of five sessions requires patients to ‘ration’ their allied health services and stated that increasing the number of subsidised allied health visits would grant health practitioners ‘more scope to improve the quality of multidisciplinary care.’²¹⁹
- 6.264 The Committee heard that the limit of five subsidised allied health visits per calendar year is particularly challenging for people with long COVID who:
- are experiencing severe symptoms²²⁰
 - are experiencing multisystem symptoms (for instance, respiratory and cognitive symptoms), requiring support from different allied health providers²²¹
 - have existing chronic conditions and may have accordingly used up their subsidised allied health visits²²²
 - are financially disadvantaged and unable to pay for additional, non-subsidised allied health sessions.²²³
- 6.265 One GP from rural Victoria, quoted by the Royal Australian College of General Practitioners in its submission, articulated his challenge supporting some of the abovementioned long COVID patient cohorts to access allied health. The GP explained:

²¹⁷ Services Australia, 6 December 2022, *Chronic disease GP Management Plans and Team Care Arrangements*, www.servicesaustralia.gov.au/chronic-disease-gp-management-plans-and-team-care-arrangements?context=20, viewed 29 March 2023.

²¹⁸ Department of Health (Victoria), Submission 87, p. 13; Royal Australian College of General Practitioners, Submission 168, p. 9; Minister for Health and Wellbeing, SA, Submission 200, p. 2; Allied Health Professions Australia, Submission 269, pages 16–23; Australian Healthcare and Hospitals Association, Submission 285, p. 4; Professor Mark Morgan, Chair, Royal Australian College of General Practitioners’ Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce’s Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 14.

²¹⁹ Allied Health Professions Australia, Submission 269, pages 16, 19, 21.

²²⁰ Allied Health Professions Australia, Submission 269, p. 21.

²²¹ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners’ Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce’s Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 14.

²²² Department of Health (Victoria), Submission 87, p. 13; Minister for Health and Wellbeing, SA, Submission 200, p. 2; Royal Australian College of General Practitioners, Submission 168, p. 9.

²²³ Minister for Health and Wellbeing, SA, Submission 200, p. 2.

Most of my long COVID patients already have other chronic diseases and their five Medicare rebated allied health sessions have already been allocated or used. It's vastly insufficient for someone who is simultaneously unable to earn an income because of their illness and requires expensive regular allied health input to maximise their recovery.²²⁴

- 6.266 Noting these concerns, Allied Health Professions Australia advocated for allowing long COVID patients with MBS chronic disease GPMPs to access the initial five allied health sessions, then, subject to ongoing review by their GP to check efficacy, access up to 10 extra allied health visits.²²⁵

Team Care Arrangements

- 6.267 In addition to chronic disease GPMPs, the MBS also includes items relating to Team Care Arrangements (TCAs). TCAs are for chronic health conditions that require a multidisciplinary team. For the purpose of a TCA, the multidisciplinary team includes the patient's usual medical practitioner and at least two other collaborating health or care providers.²²⁶
- 6.268 Allied Health Professions Australia commented that 'Care coordination is highly valuable in assisting patients to navigate their healthcare, particularly for chronic and complex conditions such as long COVID.'²²⁷ For this reason, a TCA may be useful for some individuals with long COVID.
- 6.269 However, Allied Health Professions Australia identified that one issue with the current TCA arrangements is that the patient's treating practitioner (GP) must invite other people providing multidisciplinary support to the patient (such as allied health providers) to participate in the case conference. Since many GPs have 'stretched resources', they may find this difficult to organise.²²⁸
- 6.270 The Committee further heard from Professor Morgan that the MBS TCA items are 'clunky and difficult' because they require the patient's multidisciplinary team members to be available at the same time.²²⁹ Professor Morgan proposed that the utility of these MBS TCA items for supporting long COVID patients could be improved by allowing multiple one-on-one coordination meetings, in instances where convening all relevant parties at once is not possible.

²²⁴ Royal Australian College of General Practitioners, Submission 168, p. 9.

²²⁵ Allied Health Professions Australia, Submission 269, p. 22.

²²⁶ Services Australia, *Chronic disease GP Management Plans and Team Care Arrangements*, www.servicesaustralia.gov.au/chronic-disease-gp-management-plans-and-team-care-arrangements?context=20, viewed 29 March 2023.

²²⁷ Allied Health Professions Australia, Submission 269, p. 21.

²²⁸ Allied Health Professions Australia, Submission 269, p. 21.

²²⁹ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 16.

6.271 It was previously noted that there is a lack of clarity over whether patients with long COVID symptoms who have been sick for less than six months can be considered as having a 'chronic condition' for the purpose of accessing MBS chronic disease GPMPs. The Royal Australian College of General Practitioners informed the Committee that this same issue exists with the MBS TCA items.²³⁰

Health workforce: awareness, education and training

6.272 The Committee heard a wide range of evidence regarding the level of awareness of long COVID, and relevant education and training, for Australia's health workforce.

6.273 The Committee also received evidence regarding the need to support individuals with long COVID by making available relevant information. This issue is discussed earlier in this chapter in the section titled 'Self-management'.

Importance of long COVID awareness, knowledge and expertise

6.274 As discussed throughout this report, long COVID is a relatively new condition. The Australian Medical Association cautioned that 'we are still learning more about long COVID and new diagnostic criteria and treatment protocols are emerging for review every day.'²³¹

6.275 Consequently, it is unsurprising that many healthcare workers, from GPs to allied health and the tertiary hospitals, have gaps in their knowledge regarding long COVID. Professor Crabb AC of the Burnet Institute observed that:

There are definitely gaps in the knowledge of clinicians... But that is just reflective of the community knowledge gap; it is a global problem. I don't think it's something to beat ourselves up about. We need to recognise just how significant it is. The full-frontal acknowledgement of the significance of long COVID, for example by this committee, starts a process by which those groups say, 'Right, we need to learn more.' Then they become receptive to what is on offer from an educational point of view.²³²

6.276 Many individuals with long COVID reported a need to provide education and support for healthcare practitioners regarding long COVID.²³³ Dr Nada Hamad, a physician, described her personal experience while seeking help for long COVID, which included not being heard, being dismissed, and receiving advice not based on available evidence from various health practitioners. Professor Hamad stated:

²³⁰ Royal Australian College of General Practitioners, Submission 168, p. 9.

²³¹ Australian Medical Association, Submission 328, p. 10.

²³² Professor Brendan Crabb AC, Chief Executive Officer and Director, Burnet Institute, *Committee Hansard*, Malvern, 20 February 2023, p. 6.

²³³ Australia Long Covid Community Facebook Group, *Submission 309*, p. 15.

I am here to tell you that, while this is disappointing, it is not a doctor failure; it is a system failure. Doctors are not equipped to deal with this level of uncertainty and lack of education, and are just as susceptible to public narratives and societal pressures as anyone else. If we are told, 'COVID is just a cold, not exceptional and nothing to worry about,' they believe it. If you don't give them access to diagnostic tools and treatment options, they will not use them. They are prone to bias like everybody else.²³⁴

- 6.277 The Australian Academy of Science and the Australian Academy of Health and Medical Sciences agreed that there are currently significant gaps, reporting that 'Health professionals do not have enough information to fully understand the condition, how to identify it and how to manage or refer their patients.'²³⁵
- 6.278 To rectify the situation and better support long COVID patients, many individuals and organisations called for greater awareness raising, education and training for primary care practitioners including GPs and allied health professionals, as well as medical specialists.²³⁶
- 6.279 The Australian Healthcare and Hospitals Association specifically advocated for 'nationally consistent' advice, education and training for healthcare practitioners, 'to upskill on long COVID diagnostic and treatment approaches and deliver care that better aligns with their values as healers'.²³⁷
- 6.280 As discussed in the previous section titled 'Settings and models of care', a major theme raised by a majority of witnesses and submitters was the necessity for primary care to support and manage the majority of individuals with long COVID. The Committee heard repeatedly that if this is to occur, there needs to be a particular focus on greater awareness raising, education and training regarding long COVID targeted at primary care practitioners.²³⁸
- 6.281 Dr Ahlenstiel, the Clinical Network Director at the Western Sydney Local Health District, reported that in his experience, GPs are 'quite keen to manage their patients... But obviously, like anyone else, they need to first be trained in how to manage those patients. The last thing you want to do is put your patient into harm's way.'²³⁹

²³⁴ Associate Professor Nada Hamad, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 21.

²³⁵ Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, p. 5, citations omitted.

²³⁶ See, for example: Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ), Submission 283, p. 9; Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, p.8.

²³⁷ Australian Healthcare and Hospitals Association, Submission 285, p. 5, citations omitted.

²³⁸ See, for example: Department of Health (Victoria), Submission 87, p. 6; Associate Professor Anthony Byrne, respiratory physician, St Vincent's Hospital, Submission 155, p. 2; Australian Academy of Science and the Australian Academy of Health and Medical Sciences, Submission 165, p. 8; Allied Health Professions Australia, Submission 269, p. 17; Professor Greg Dore, Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, pages 34, 41–42.

²³⁹ Dr Golo Ahlenstiel, Clinical Network Director, Specialty Medicine, Western Sydney Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, p. 16.

6.282 Dr Zinta Harrington, Head of the Department of Respiratory and Sleep Medicine at Liverpool Hospital, expressed a somewhat different view that there may be sufficient information available, but time for health practitioners to engage with it may be an obstacle. She commented:

I think there's terrific information available. I think as part of your submissions, you've had access to the New South Wales department of health resources. The Critical Intelligence Unit resources have regular updates. I think Coronacast is great. We have departmental meetings. The PHN [Primary Health Network] organised a webinar for the GPs on long COVID in, I think, just the last three months. I think there is access. The availability is there. It's time that's probably the greatest barrier.²⁴⁰

Current communication, education and training

6.283 The Committee received evidence regarding information sharing, and education and training specifically relevant to long COVID that is being offered to health practitioners across Australia. Given the large amount of work underway, it is not possible to mention this all here. As such, this section highlights only a few examples.

6.284 However, the Committee acknowledges that various parts of Australia's healthcare system including the Australian Government, state and territory governments, Primary Health Networks, Local Hospital Networks, long COVID clinics, and peak bodies representing health practitioners including college, are all actively working to build the health workforce's awareness, knowledge and expertise regarding long COVID

6.285 At the Commonwealth level, Professor Kidd AM, Deputy Chief Medical Officer, advised that the Department is actively and regularly engaging with peak bodies, primary health networks and other relevant stakeholders to disseminate messaging regarding long COVID to relevant parts of the health workforce.²⁴¹

6.286 The Committee heard that a vast range of activity is occurring within state and territory governments to build health practitioners' understanding and management of long COVID.

6.287 For instance, the South Australian Minister for Health and Wellbeing, the Hon Chris Picton MP, advised that the South Australian Department of Health and Wellbeing is working to support GPs by regularly sharing updates, producing a comprehensive Long COVID assessment guideline, conducting webinars, and producing long COVID clinical fact sheets. Minister Picton also noted that South Australia's state-wide Long COVID Clinical Advisory Group has endorsed a long COVID definition for the state

²⁴⁰ Dr Zinta Harrington, Head, Department of Respiratory and Sleep Medicine, Liverpool Hospital, *Committee Hansard*, Liverpool, 5 December 2022, pages 31–32.

²⁴¹ Professor Michael Kidd AM, Deputy Chief Medical Officer, Department of Health and Aged Care, *Committee Hansard*, Canberra, 17 February 2023, p. 12.

and developed a South Australian long COVID model of care, which will assist practitioners.²⁴²

6.288 Queensland Health reported that it has summarised information and guidance about long COVID for clinicians on a webpage, which includes links to other recommended clinical guidance.²⁴³

6.289 Meanwhile, the Committee heard that NSW Health's Critical Intelligence Unit maintains an online living evidence table on long COVID, which 'ensures that the most up to date information is available to clinicians.'²⁴⁴

6.290 Dr Harrington informed the Committee that the Primary Health Networks are also playing an active role. She commented that as part of the Primary Healthcare Network's Clinical Council, she has been:

... supporting and witnessing the PHNs [Primary Health Networks] development of a long COVID pathway... which helped decide which patients would benefit from specialist referral; and their peer education sessions, webinars to promote GP recognition of the management of long COVID.²⁴⁵

6.291 Dr Archana Sud, an Infectious Diseases Physician and Clinical Director Medicine at the Nepean and Blue Mountains Local Health District, described how the long COVID clinic she works at was also supporting local GPs by holding education and question-and-answer sessions, as well as liaising closely with Primary Health Networks to develop guidance on how to make a diagnosis of long COVID, and when to refer patients to specialist services.²⁴⁶

6.292 Many peak bodies representing health disciplines are also contributing to raising awareness, educating and training their members regarding long COVID. For instance, the Royal Australian College of General Practitioners has developed guidelines on 'Caring for patients with post-COVID-19 conditions'.²⁴⁷ However, it was acknowledged that embedding these guidelines within general practice is an ongoing challenge.²⁴⁸

6.293 Multiple peak bodies have also contributed via the NCET. The NCET brings together 35 organisations representing various Australian healthcare professionals, 'to identify

²⁴² Minister for Health and Wellbeing, SA, Submission 200, p. 4.

²⁴³ Queensland Health, Submission 150, p. 10.

²⁴⁴ NSW Health, Submission 272, p. 9, citations omitted.

²⁴⁵ Dr Zinta Harrington, Head, Department of Respiratory and Sleep Medicine, Liverpool Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 28.

²⁴⁶ Dr Archana Sud, Director, Infectious Diseases Physician, Clinical Director Medicine, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, pages 6–7.

²⁴⁷ Royal Australian College of General Practitioners, *Caring for patients with post-COVID-19 conditions*, www.racgp.org.au/clinical-resources/covid-19-resources/clinical-care/caring-for-patients-with-post-covid-19-conditions/introduction, viewed 30 March 2023.

²⁴⁸ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 14.

and rapidly synthesise emerging research in order to provide national, evidence-based guidelines.²⁴⁹

6.294 Since the beginning of the COVID-19 pandemic in 2020, the NCET advised that it:

...has been gathering and synthesising data to inform best practices clinical care for the treatment of long COVID. Our approach involves daily searches for evidence, appraisal of this evidence and development of recommendations for clinical care.... The Guideline is approved by the NHMRC (National Health and Medical Research Council) and endorsed by 35 health care organisations across Australia.²⁵⁰

Proposals to improve awareness, knowledge and expertise

6.295 Despite the current efforts to assist healthcare practitioners to provide efficient, effective and evidence-based care to people with long COVID, the vast majority of submitters and witnesses called for more to be done.

6.296 Multiple suggestions were received for how the Australian Government could raise greater awareness and improve healthcare practitioners' knowledge and expertise of long COVID. Some of these are discussed below.

6.297 Professor Dore, an Epidemiologist with the Kirby Institute, outlined where he sees that more effort is needed, including education and training around how primary care engages with long COVID patients. Professor Dore stated:

I think education and training at the primary care level is essential. There's obviously been some done by the college of GPs and various other organisations. I think we need a big effort in trying to get primary care to better understand the requirements of long-COVID assessment; better understand what's potentially available on the management front; and develop... some standardised referrals pathways, who needs to be referred and so forth. To really put a concerted effort into that education and training at the primary care level, and engagement—as I said, a lot of patients come to me and they've been somewhat dismissed. I think that's an exposure issue for people at the primary care level—with some education and training and making them part of the solution.²⁵¹

6.298 Regarding training, some witnesses suggested that supporting long COVID specific continuing professional development (CPD)²⁵² training for clinicians like GPs would

²⁴⁹ National Clinical Evidence Taskforce, *About the taskforce*, clinicalevidence.net.au/about-the-taskforce, viewed 30 March 2023.

²⁵⁰ National Clinical Evidence Taskforce (Monash University), Submission 232, p. 19, citations omitted.

²⁵¹ Professor Greg Dore, Epidemiologist, Kirby Institute, *Committee Hansard*, Canberra, 12 October 2022, p. 42.

²⁵² The Royal Australasian College of Physicians defines Continuing Professional Development (CPD) in a healthcare context as consisting of a range of activities undertaken to maintain clinical skills and knowledge, as well as competence in the delivery of patient-centred care. Royal Australasian College of Physicians,

be one way to encourage uptake, since undertaking regular CPD is a requirement for many health professions.

6.299 Professor Julie Leask suggested that a practical option may be ‘to ask the college to prioritise CME-awarded [continuing medical education, similar to CPD] educational sessions around long COVID...’.²⁵³

6.300 Professor Morgan also proposed encouraging CPD training on long COVID. He suggested that:

It would be very good value for the taxpayer to... fund the production of CPD products that are high quality, and then make them available at no cost. Unlike other clinicians within hospital systems, GPs fund their own CPD and have to fund the time they take away from their practices. That could be addressed. It would be fantastic if the training and the self-maintenance of GPs' knowledge was valued in the system and by the system as a public necessity.²⁵⁴

6.301 The Australian Long Covid Community Facebook Group echoed calls for targeted CPD but went one step further and suggested ‘...mandated professional development regarding the validity of Long Covid as a formal diagnosis and access to treatment pathways and guidelines in keeping with current research and best practice from around the world.’²⁵⁵

6.302 Professor Lena Sanci proposed that Primary Health Networks should conduct training on long COVID since they receive funding to educate primary care practitioners in their area, and noted that there is need for state-level public health units to coordinate training with Primary Health Networks.²⁵⁶

6.303 The Victorian Department of Health advocated for the Australian Government to ‘Lead the development of nationally consistent training and support of GPs and other healthcare workers in primary care to optimally diagnose, treat and manage people with long COVID.’²⁵⁷

6.304 Additionally, Victoria’s Department of Health recommended that the Australian Government:

- Implement a national GP advice line to support best practice diagnosis and care

Continuing Professional Development, www.racp.edu.au/fellows/continuing-professional-development, viewed 19 April 2023.

²⁵³ Professor Julie Leask, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 63.

²⁵⁴ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners’ Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce’s Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 15.

²⁵⁵ Australia Long Covid Community Facebook Group, Submission 309, p. 10.

²⁵⁶ Professor Lena Sanci, Head, Department of General Practice and Primary Care, Melbourne Medical School, The University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 63.

²⁵⁷ Department of Health (Victoria), Submission 87, p. 12.

- Promote resources including agreed referral criteria to specialist care via PHNs [Primary Health Networks] and professional groups²⁵⁸

6.305 Perhaps the most recurrent specific proposal to improve health workforce awareness, knowledge and expertise of long COVID was that up to date, evidence-based guidelines to support healthcare practitioners working with long COVID patients should be developed and maintained.²⁵⁹

6.306 The NCET made the case for why clinicians require centralised and evidence-based guidance for long COVID. The NCET noted that it is challenging to develop and maintain up to date guidance given the ‘rapidly evolving and complex’ evidence regarding long COVID. The NCET elaborated:

We currently know little about long COVID, however, research is emerging which will add to the growing body of evidence and help us to understand more about the condition and how it may be best managed. Studies researching long COVID tend to be complex, and interpretation of the results requires high level appraisal and synthesis skills. Furthermore, understanding how individual study results contribute to the whole evidence-base requires broad knowledge of the topic. New research is likely to continue to emerge for the foreseeable future, and mechanisms need to be in place to support clinicians to ensure they are able to provide consistent, evidence-based practice.²⁶⁰

6.307 Professor Morgan observed that Australian Government funding for the NCET was not renewed, and expressed disappointment since the NCET is ‘world’s best practice in evidence generation’, and the ‘research, the care-delivery systems and the evidence-based guidelines [that NCET develops] won’t just be benefiting long COVID but also other post-viral syndromes and chronic fatigue states that cause so much distress in the community.’²⁶¹

6.308 The NCET recommended that the Australian Government continue to fund it ‘to identify, assess, and synthesise up-to-date evidence and convene clinical expertise to develop and sustain recommendations for the clinical care of long COVID in adult and paediatric populations in Australia.’²⁶²

6.309 Dr Kyaw-Myint, an individual with long COVID, emphasised that for any guidelines regarding long COVID ‘It is crucial to have consumer input’ to reflect patient voice. Dr Kyaw-Myint further indicated that patients may be able to meaningfully contribute to

²⁵⁸ Department of Health (Victoria), Submission 87, p. 12.

²⁵⁹ See, for example: Department of Health (Victoria), Submission 87, p. 12; Royal Australian College of General Practitioners, Submission 168, p. 5; Australia Long Covid Community Facebook Group, Submission 309, p. 17; Professor Mark Morgan, Chair, Royal Australian College of General Practitioners’ Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce’s Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 15.

²⁶⁰ National Clinical Evidence Taskforce (Monash University), Submission 232, pages 4, 6.

²⁶¹ Professor Mark Morgan, Chair, Royal Australian College of General Practitioners’ Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce’s Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 13.

²⁶² National Clinical Evidence Taskforce (Monash University), Submission 232, p. 2.

guidelines, since many individuals with long COVID have ‘read all the resources, all the articles. We have been keeping track of all the treatments: what works, what doesn’t work.’²⁶³

Committee comment

- 6.310 As noted in Chapter 1, the Committee reiterates that its purpose for this inquiry is to make public policy recommendations regarding long COVID. The Committee is not a technical health advisory committee, and as such it is not appropriate for it to issue health advice regarding the diagnosis and/or treatment of long COVID, propose a detailed model of care, or undertake other such actions. However, the Committee has carefully considered evidence received and through this report makes a number of recommendations that it believes will support a better Australian healthcare response to long COVID.
- 6.311 The Committee recognises that there is currently a limited understanding of long COVID. It is unknown why some people develop long COVID and not others, how to diagnose it accurately and efficiently, how to treat it, and how to best manage the symptoms. The Committee acknowledges how challenging these circumstances are for individuals with long COVID and their loved ones.
- 6.312 The Committee also recognises that this situation is challenging for healthcare practitioners, who often do not have answers to their patients’ questions.
- 6.313 Although there is not yet a clear picture regarding the prevalence of long COVID in Australia and the likely prognosis for those individuals that develop it, the Committee is encouraged by indications that the majority of long COVID cases will involve milder symptoms that do not require specialist care. At the same time, the Committee accepts that some individuals will be more severely impacted by long COVID. Long term severe impacts do not seem to be the norm, with most patients recovering albeit over different periods of time. Regardless, all individuals with long COVID deserve appropriate support and care.
- 6.314 In relation to current settings of care and models of care, it is evident that there are significant inconsistencies across Australia in who manages long COVID patients, and the care they receive.
- 6.315 The Committee considers that given it is likely only a minority of long COVID cases will require specialist care, most individuals with long COVID should be supported via primary care. The Committee sees that there is a role for specialist, multidisciplinary long COVID clinics in supporting individuals with severe symptoms and/or complex needs.
- 6.316 However, the Committee notes that long COVID clinics that are hospital-based are not scalable and will create more bottlenecks. Consequently, the Committee considers that these long COVID clinics should be limited in number, to provide care

²⁶³ Dr Su Mon Kyaw-Myint, personal capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 26.

(via telehealth or in person) to triaged patients, while minimising the impacts of these clinics on the broader health workforce. The Committee additionally proposes that specialist long COVID clinics should be seen as centres of excellence and engage in research regarding long COVID and conduct education outreach activities with other healthcare settings to disseminate their knowledge and expertise.

6.317 The Committee considers that there is great heterogeneity in managing long COVID with pros and cons to all models. A one size fits all approach may not work for some jurisdictions because of geography, workforce, demands on the system etc.

6.318 In general, the Committee sees benefit in a tiered model of care approach, which could allow individuals with long COVID to access appropriate care proportionate to their needs.

6.319 The Committee believes that there may be a role for the Department of Health and Aged Care to convene a working group including states and territories to assist with developing guidelines and models of care.

6.320 The Committee sees that community-based care is in most instances ideal provided it is supported with education, timely specialist input, adequate remuneration, connectivity, self-management tools and guidelines.

6.321 The Committee also sees a need to provide greater support to healthcare practitioners supporting long COVID patients, in particular primary care. The Committee considers that this should be achieved via:

- Support and education for GPs and other primary healthcare providers to diagnose long COVID and manage patients
- Development of living guidelines codesigned with patients
- Support for multidisciplinary long COVID clinics across Australia, as a tertiary referral pathway
- Support for the establishment of outreach long COVID clinics for rural and regional areas
- Provision of mental health support for people with long COVID
- Leveraging of telehealth and digital health resources to help people with long COVID self-manage and access primary care.

6.322 The Committee notes that this inquiry received some evidence suggesting that broader problems with Australia's healthcare system, such as health workforce issues, pose challenges for effectively responding to long COVID.²⁶⁴ While it is

²⁶⁴ See, for example: Australian Medical Association, Submission 328, p. 7; Dr Benjamin Gerhardy, Respiratory Physician, Nepean and Blue Mountains Local Health District, *Committee Hansard*, Liverpool, 5 December 2022, pages 2–3; Dr Zinta Harrington, Head, Department of Respiratory and Sleep Medicine, Liverpool Hospital, *Committee Hansard*, Liverpool, 5 December 2022, p. 31; Dr Kenneth McCroary, Director, Macarthur General Practice, *Committee Hansard*, Liverpool, 5 December 2022, pages 47–48; Dr Jason Agostino, Senior Medical Advisor, National Aboriginal Community Controlled Health Organisation, *Committee Hansard*, Canberra, 17 February 2023, pages 1–2; Professor Lena Sancı, Head, Department of

beyond the scope of this inquiry to explore Australia's overall healthcare system, or make recommendations regarding the broader system, the Committee encourages the Department of Health and Aged Care to consider issues raised during this inquiry in the context of ongoing reforms to the healthcare system.²⁶⁵

- 6.323 The Committees also observed that throughout the inquiry many submitters and witnesses raised a host of issues and various questions regarding Australia's response to the COVID-19 pandemic broadly. In many instances, these broader issues or questions were only tangentially related to long COVID. The Committee recognises the importance of a comprehensive look at the COVID-19 pandemic and Australia's response, and that this could inform future responses. However, the Committee considers that given this inquiry's targeted focus upon long COVID, a broader mechanism is needed to conduct this work.

General Practice and Primary Care, Melbourne Medical School, The University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 50; Professor Martin Hensher, private capacity, *Committee Hansard*, Canberra, 17 February 2023, p. 50; Professor Andrew Baillie, Professor of Allied Health, University of Sydney, *Committee Hansard*, Canberra, 17 February 2023, p. 62; Professor Mark Morgan, Chair, Royal Australian College of General Practitioners' Expert Committee for Quality Care, & Co-chair, National Clinical Evidence Taskforce's Primary and Chronic Care Panel, *Committee Hansard*, Malvern, 20 February 2023, p. 15.

²⁶⁵ See, for example: Department of Health and Aged Care, *Strengthening Medicare Taskforce*, www.health.gov.au/committees-and-groups/strengthening-medicare-taskforce, viewed 3 April 2023.



7. Recommendations

Recommendation 1

- 7.1 The Committee recommends that the Australian Government establishes and funds a single COVID-19 database to be administered by the soon-to-be developed Centre for Disease Control to capture data on:
- COVID-19 infections, complications, hospitalisations, and deaths as well as recurrent COVID infections
 - This should incorporate COVID-19 infections in high-risk populations including: hospital-acquired infections (distinguishing this from community acquisition if possible), infections in aged care and other institutions, and infections in Aboriginal and Torres Strait Islander peoples and the immunosuppressed
 - This should also include the collection of data regarding select comorbid conditions and ancestry to identify infections in Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities and the immunosuppressed
 - Long COVID diagnoses including post COVID complications
 - COVID-19 vaccination rates, vaccination side effects and post vaccination deaths
- 7.2 The Committee additionally recommends that the Australian Government explore the use of innovative tools (e.g. artificial intelligence and self-managed care platforms) and data linkage within and between states and territories, to collect this data.

Recommendation 2

- 7.3 The Committee recommends that at the present time the World Health Organization definition of long COVID be used clinically, but that the Australian Government Department of Health and Aged Care work with the states and territories to review this definition as more research and information becomes available.
- 7.4 The Committee additionally recommends developing evidence-based living guidelines for diagnosis and treatment incorporating tiered care including referral pathways, co-designed with patients with lived experience.

Recommendation 3

- 7.5 The Committee recommends that the Australian Government establish a nationally coordinated research program, led by the Department of Health and Aged Care (preferably the Centre for Disease Control), to coordinate and fund COVID-19 and long COVID research.
- 7.6 This funding should be longer term and be nationally coordinated. The funding should aim to better integrate research by fostering greater collaboration rather than fragmentation.
- 7.7 The Committee also recommends that this research have adequate representation from Aboriginal and Torres Strait Islander peoples and the culturally and linguistically diverse population and be adequately funded to achieve these aims. Other vulnerable groups including the elderly, children, people with disability and the immunosuppressed should be represented.
- 7.8 Research programs should span basic science, clinical trials, models of care, health promotion and implementation science.

Recommendation 4

- 7.9 The Committee recommends that the Department of Health and Aged Care updates, focusses, and improves its COVID-19 vaccination communication strategy including by:
- Emphasising the benefit of COVID-19 vaccines in both reducing transmission and illness severity for acute COVID-19 infections and reducing the risk of developing long COVID
 - Encouraging greater COVID-19 vaccination across the Australian population especially among children, young people and people of working age
 - Encouraging immunisation in high-risk groups in particular as the virus becomes endemic
 - Working with the states and territories to develop this health promotion program.

Recommendation 5

- 7.10 The Committee recommends that the Pharmaceutical Benefits Advisory Committee regularly review the benefits of antiviral treatments for COVID-19 in accordance with emerging research with a view to expanding the list of groups eligible to access these treatments through the Pharmaceutical Benefits Scheme (PBS).

- 7.11 The Committee also recommends that antiviral treatments for COVID-19 be approached as a pharmacist-initiated medication to participants eligible under the PBS.
- 7.12 The Committee additionally recommends that the Australian Government review its framework for access to antiviral treatments for COVID-19 to include non-mortality and non-hospitalisation outcomes such as productivity gains, time to illness resolution, return to work and number of health encounters.

Recommendation 6

- 7.13 The aim of the Committee is to ensure people get the support they need, most of which will occur via the primary care network. Accordingly, the Committee makes the following recommendations regarding management:
- Support and education should be provided to general practitioners (GPs) as well as other primary healthcare providers to diagnose long COVID and to help manage those suffering from it. Education for GPs should be coordinated and eligible for Continuing Professional Development (CPD). The Medicare Benefits Schedule (MBS) chronic disease management item number should be reviewed
 - Clinical care should be linked to nationally coordinated research and data collection
 - Funding be provided in partnership with state health departments for selected public hospitals to develop multidisciplinary long COVID clinics linked to nationally consistent referral guidelines for screening patients with challenging long COVID complications
 - Mental health support for those with long COVID must be provided in an affordable, timely and equitable manner, and regular review of mental health issues should be part of GP management noting that the extent of related mental health impacts is still unknown
 - Telehealth and digital health resources be leveraged to make self-management and access to primary care easier
 - Funding be provided so that outreach long COVID clinics can be developed for rural and regional areas, accessible either face to face or via telehealth, as a GP resource.

Recommendation 7

- 7.14 The Committee recommends the Australian Government establish and fund a multidisciplinary advisory body including ventilation experts, architects, aerosol scientists, industry, building code regulators and public health experts to:
- Oversee an assessment of the impact of poor indoor air quality and ventilation on the economy with particular consideration given to high-risk

settings such as hospitals, aged care facilities, childcare and educational settings

- Lead the development of national indoor air quality standards for use in Australia.


While the terms of reference of this inquiry do not cover the content of Recommendations 8 and 9, the Committee received important evidence on these topics throughout its inquiry and makes the following recommendations:

Recommendation 8

7.15 The Committee recommends funding be made available for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) research and patient support and that this funding should be allocated in consultation with peak bodies for ME/CFS and with note of the recommendations of the ME/CFS Advisory Committee's 2019 report to the National Health and Medical Research Council.

Recommendation 9

7.16 The Committee recommends, given the multiple questions that have arisen during our Inquiry, that the Australian Government consider a comprehensive summit into the COVID-19 pandemic and Australia's past and current response, including by governments at all levels, with particular consideration to the role of the future Centre for Disease Control.



Dr Mike Freeland MP

Chair

19 April 2023



Addendum - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

- 1.1 Throughout the inquiry the Committee received evidence regarding Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), a poorly understood illness.
- 1.2 Although this inquiry was focused on long COVID, given the volume of evidence regarding ME/CFS received, the Committee considers it is useful to acknowledge and discuss this topic.
- 1.3 In general, the evidence about ME/CFS fell into two categories, which are discussed in this addendum:
 - A possible overlap between long COVID and ME/CFS, in terms of their definitions and/or symptoms¹
 - Individuals' experiences with ME/CFS, which some submitters and witnesses argued were relevant to inform a response to long COVID given apparent similarities between the conditions.

Possible overlap between long COVID and ME/CFS

- 1.4 The Committee heard about a possible overlap in the definitions and symptoms of long COVID and ME/CFS.
- 1.5 The National Centre for Neuroimmunology and Emerging Diseases, Menzies Health Institute Queensland, Griffith University observed that 'current working definitions [of long COVID] are not yet specific and overlap significantly with other post-infectious fatigue syndromes.'²
- 1.6 This point was echoed by Ms Elisa Holgate, a person with ME/CFS, who submitted '[w]ith such a vague definition, Long Covid could be considered a sub-group of ME/CFS, and it is likely that many Long Covid patients will eventually be included in ME/CFS if they do not recover, or suffer relapses.'³

¹ See, for example: Emerge Australia. Submission 67, p. 1; Ms Elisa Holgate, Submission 85, p. 1.

² National Centre for Neuroimmunology and Emerging Diseases, MHIQ, Griffith University, Submission 215, p. 3.

³ Ms Elisa Holgate, Submission 85, p. 1.

- 1.7 The Committee also heard about possible overlap in symptoms reported by people living with ME/CFS and long COVID. For example, Emerge Australia noted post-exertional malaise⁴ as a core feature of ME/CFS and highlighted that this is also a symptom frequently reported by people with long COVID.⁵ A group of ME/CFS patient advocates also stated that almost half of people diagnosed with long COVID meet the diagnostic criteria for ME/CFS.⁶
- 1.8 Clinical evidence about a possible overlap between ME/CFS and long COVID is not yet clear. At this stage, many people with long COVID show improvement in symptoms and functioning after varying periods of time,⁷ but this appears to be less common for people living with ME/CFS. For example, Professor Lena Sancı, Head, Department of General Practice and Primary Care, Melbourne Medical School at the University of Melbourne, told the Committee that she was aware of patients who saw their GP with ongoing symptoms eight weeks after testing positive for COVID-19 and ‘around a quarter’ of those patients recovered before twelve weeks.⁸ However, this is only one indication and Professor Sancı noted that many people are struggling to get an appointment with their GP.
- 1.9 Further, Dr Irani Thevarajan, Infectious Diseases Physician, Victorian Infectious Diseases Service, The Peter Doherty Institute for Infection and Immunity, told the Committee that while there are some common themes between ME/CFS and long COVID, including that both are complex conditions that can affect multiple organs, they cannot necessarily put them into the same category.⁹
- 1.10 Professor Steven Faux and Associate Professor Anthony Byrne from the long COVID clinic at St Vincent’s Hospital told the Committee that despite similarities in the symptoms of long COVID and ME/CFS, there are important differences. They stated that ‘long COVID is the condition that occurs following a single, specific, novel corona virus’ (COVID-19) while ‘ME/CFS is a consequence of another virus’ such as the Epstein-Barr virus.¹⁰
- 1.11 Professor Faux and Associate Professor Byrne also explained that long COVID patients tend to experience persisting respiratory symptoms, which ‘is not the case in ME/CFS.’ They additionally pointed out ‘important immunological differences’ between patients with these conditions:

⁴ Post-exertional malaise is a worsening of symptoms such as fatigue, pain and cognitive impairment following physical or mental effort. See, Emerge Australia, Submission 67, p. 5.

⁵ Emerge Australia, Submission 67, p. 5.

⁶ Group of ME/CFS Patient Advocates, Submission 470, p. 6.

⁷ See, for example: Associate Professor Louis Irving, Respiratory Physician, Post-COVID Clinic, Royal Melbourne Hospital, *Committee Hansard*, Canberra, 12 October 2023, p. 1; Associate Professor Alex Holmes, Fellow, Royal Australian and New Zealand College of Psychiatrists, Royal Melbourne Hospital, and University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 47.

⁸ Professor Lena Sancı, Head, Department of General Practice and Primary Care, Melbourne Medical School, The University of Melbourne, *Committee Hansard*, Canberra, 17 February 2023, p. 50.

⁹ Dr Irani Thevarajan, Infectious Diseases Physician, Victorian Infectious Diseases Service, The Peter Doherty Institute for Infection and Immunity, *Committee Hansard*, Canberra, 12 October 2022, p. 18.

¹⁰ Professor Steven Faux and Associate Professor Anthony Byrne, Submission 544, pages 1–2.

In unpublished data, we have shown that the Kyneuranine pathway... is increased in Long COVID but not ME/CFS patients. Published data... shows that the [Kyneuranine pathway] is clearly associated with neurocognitive impairment [sic] in Long COVID patients. This impairment [sic] (brain fog) may not be obvious and was diagnosed on specific neuropsychological testing... This persisted for 12 months in our study and DID NOT IMPROVE over that time.¹¹

- 1.12 The Australian Institute of Health and Welfare's (AIHW) literature review on long COVID covered this topic. Noting potential links made between long COVID and ME/CFS in terms of similarities in symptoms and a possible association with viral infections, the AIHW stated that:

...further research is needed to investigate the relationships between the 2 conditions and care should be taken not to conflate the 2 conditions until more is understood.¹²

- 1.13 The AIHW also noted:

...ongoing symptoms post infection is not limited to long COVID and ME/CFS. Various other infections have been known to cause chronic symptoms collectively referred to as post-acute infection syndromes.¹³

- 1.14 The Committee notes the clinical parallels between ME/CFS and long COVID. However, in the absence of strong evidence establishing that these are the same condition, the Committee agrees with the AIHW that these conditions should not be conflated.

Experience of people with ME/CFS

- 1.15 The Committee heard from many people with ME/CFS, who described their experiences seeking medical treatment and specialised care as individuals with a poorly understood condition.

- 1.16 Emerge Australia submitted that Australia was:

...unprepared for Long COVID, because the medical profession has long neglected and ignored patients with post-infection disease. The scale of the COVID-19 pandemic, and subsequent numbers of Long COVID patients, has been so large the world has been forced to acknowledge what the ME/CFS

¹¹ Professor Steven Faux and Associate Professor Anthony Byrne, Submission 544, p. 2.

¹² Australian Institute of Health and Welfare, *Long COVID in Australia – a review of the literature*, www.aihw.gov.au/reports/covid-19/long-covid-in-australia-a-review-of-the-literature/summary, p. 34, viewed 6 March 2023.

¹³ Australian Institute of Health and Welfare, *Long COVID in Australia – a review of the literature*, www.aihw.gov.au/reports/covid-19/long-covid-in-australia-a-review-of-the-literature/summary, p. 34, viewed 6 March 2023, citations omitted.

community, and clinicians and researchers in the field, have long known: post-infection disease is real and devastating.¹⁴

1.17 ME/CFS Australia, a peak body for patient-led ME/CFS organisations, noted in its submission that:

Evidence continues to indicate that people with ME/CFS are disparaged by many health practitioners, experiencing stigma that impacts the health and well-being of those affected and undermining the prevention, early diagnosis, management and health outcomes of the condition... There is no designated specialty for ME/CFS, so diagnosis and management usually take place in primary care. Doctors, nurses and allied health practitioners in General Practice need to be supported by information, education and tools to deliver both early diagnosis and effective ME/CFS care.¹⁵

1.18 Ms Alice Rumble's submission shared her experience as a patient seeking help from her GP for post-viral illness. She said that GPs are ill-equipped to manage post-viral illnesses such as ME/CFS or long COVID. Mrs Rumble believes this means:

- Patients are required to keep attending Doctor's appointments until they strike on someone with personal interest or experience in ME or LC [long COVID], delaying patients getting treatment and putting a strain on overstretched GP clinics and specialists;
- There is a high risk of patients being dismissed or undermined by Doctor's [sic] who are out of their depth – posing a risk that patients will stop trying to seek treatment and believe it is 'their fault' (I have personal experience of Doctor's suggesting I would 'bounce back' or that I may have a mental illness, without conducting any mental health assessments. I know of many patients who are told they are imagining their symptoms or that they have caused them by their lifestyle factors)
- GPs are vulnerable to suggestions from practitioners running 'fatigue' or 'long COVID clinics' and may not have any understanding of how dangerous the treatment offerings at these clinics are.¹⁶

1.19 Ruth Newport raised the mental health challenges that come with the experience of living with debilitating chronic symptoms without constructive support from health practitioners. She said in her submission:

Depression and anxiety is not the cause of my illness. If I'm depressed about anything, it is because I've spent a substantial part of the year being ignored and or dismissed by doctors who haven't kept up-to-date with the research on ME/CFS and Long Covid. I have lived with complex chronic illness for all my adult life so dealing with dismissive medical professionals is not a new

¹⁴ Emerge Australia, Submission 67, p. 2.

¹⁵ ME/CFS Australia, Submission 541, pages 7–8.

¹⁶ Ms Alice Rumble, Submission 184, p. 1.

experience for me. Unfortunately, it also appears to be a common experience for many others I've met in the Australia Long Covid Community.¹⁷

1.20 ME/CFS patient advocates argued that there is a need for greater GP education around both ME/CFS and long COVID. They advised that GPs have very little knowledge of ME/CFS and noted that the ME/CFS Advisory Committee's 2019 report and recommendations to the National Health and Medical Research Council (NHMRC) to improve this have not been actioned, despite an undertaking to do so.¹⁸

1.21 In its report to the NHMRC Chief Executive Officer (CEO), the ME/CFS Advisory Committee recommended that the NHMRC:

- Provide clinicians with ME/CFS health care resources including clinical guidelines based on the latest evidence
- Develop a clinical pathway within clinical guidelines for ME/CFS management and effective patient support
- Collaborate nationally to improve clinician awareness of ME/CFS and to disseminate and implement clinical resources.¹⁹

The CEO's response to this report advised that the NHMRC should develop clinical guidelines on ME/CFS, but needed to identify a funding source.²⁰

1.22 Although this inquiry was focused upon long COVID rather than ME/CFS, the Committee acknowledges the challenges that individuals with ME/CFS in Australia face.

¹⁷ Ruth Newport, Submission 231, p. 4.

¹⁸ National Health and Medical Research Council, *CEO Response – Open Letter to stakeholders*, www.nhmrc.gov.au/file/14680/download?token=gVFrWphN, viewed 30 March 2023.

¹⁹ National Health and Medical Research Council, *Report to the NHMRC Chief Executive Officer*, April 2019, p. 25.

²⁰ National Health and Medical Research Council, *CEO Response – Open Letter to stakeholders*, www.nhmrc.gov.au/file/14680/download?token=gVFrWphN, viewed 30 March 2023.



A. Submissions

- 1 *Name Withheld*
- 2 Mrs Mary Klestadt
- 3 *Name Withheld*
- 4 *Name Withheld*
- 5 *Name Withheld*
- 6 *Name Withheld*
- 7 *Name Withheld*
- 8 Robert Heron
- 9 *Name Withheld*
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- 22 *Name Withheld*
- 23 Lived Experience Australia Ltd
- 24 Ree Taylor
- 25 *Name Withheld*
- 26 *Name Withheld*
- 27 *Name Withheld*
- 28 *Name Withheld*
- 29 Adam Williams
- 30 Felicity Gay
- 31 *Name Withheld*
- 32 Peter Nenadovic
- 33 Mary Symons
- 34 Jamie Walker
- 35 *Name Withheld*
- 36 Warren Milward
- 37 *Name Withheld*
- 38 *Name Withheld*
- 39 *Name Withheld*
- 40 *Name Withheld*
- 41 *Name Withheld*
- 42 Michael Williams
- 43 Caroline Molloy
- 44 Georgina Taylor
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- 51 *Name Withheld*
- 52 *Name Withheld*
- 53 *Name Withheld*
- 54 *Name Withheld*
- 55 Rowena Findlay
- 56 Damian Wood
- 57 Courtney Baker
- 58 Julieanne Mathieson
- 59 Simon Leck
- 60 Jason Betson
- 61 *Name Withheld*
- 62 *Name Withheld*
- 63 Dr Stephen & Sarah Duckett
- 64 *Name Withheld*
- 65 Scott Symington
- 66 *Name Withheld*
- 67 Emerge Australia
- 68 Dr Nick Drengenberg
- 69 *Name Withheld*
- 70 *Name Withheld*
- 71 *Name Withheld*
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- 81 *Name Withheld*
- 82 *Name Withheld*
- 83 *Name Withheld*
- 84 *Name Withheld*
- 85 Ms Elisa Holgate
- 86 Angela O'Connor
- 87 Department of Health (Victoria)
- 88 *Name Withheld*
- 89 Martine Van boeijen
- 90 Felicity Nelson
- Attachment 1
- 91 Alexis Misko
- 92 Professor Catherine Bennett and Dr Danielle Hitch
- 93 *Name Withheld*
- 94 *Name Withheld*
- 95 Macarthur General Practice
- Attachment 1
 - Attachment 2
- 96 *Name Withheld*

- 97 *Name Withheld*
- 98 Debbie Kilroy
- 99 *Name Withheld*
- 100 Linda Mason
- 101 Bethany and Matthew Wormald
- 102 Victoria Cameron
- 103 Professor Andreas Suhrbier
- 104 *Name Withheld*
- 105 *Name Withheld*
- 106 *Name Withheld*
- 107 *Name Withheld*
- 108 Matthew Altus
- 109 *Name Withheld*
- 110 *Name Withheld*
- 111 *Name Withheld*
- 112 Dr Pippa Yeoman
- 113 *Name Withheld*
- 114 *Name Withheld*
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- 119 *Name Withheld*
- 120 *Name Withheld*
- 121 *Name Withheld*
- 122 *Name Withheld*

- 123** *Name Withheld*
- 124** Mrs Laura Bridgman
- 125** Amy Jones
- 126** Australian Physiotherapy Association
- 127** *Name Withheld*
- 128** Prevention United
- 129** *Name Withheld*
- 130** Adjunct Professor Giorgio Buonanno
- 131** *Name Withheld*
- 132** *Name Withheld*
- 133** Mr Jack Flynn
- 134** Professor Peter Wark
- 135** Maureen Shelley
- 136** Colleen Rowe
- 137** *Name Withheld*
- 138** Baker Heart and Diabetes Institute
- 139** Ms Amelia Kerr
- 140** *Name Withheld*
- 141** *Name Withheld*
- 142** *Name Withheld*
- 143** Private Healthcare Australia
- 144** Ms Jennifer Lang
- 145** Australasian Integrative Medicine Association
- 146** Mark Leonard
- 147** *Name Withheld*
- 148** *Name Withheld*

- 149** Burnet Institute
- Attachment 1
- 150** Queensland Health
- 151** *Name Withheld*
- 152** *Name Withheld*
- 153** *Name Withheld*
- 154** *Name Withheld*
- 155** Associate Professor Anthony Byrne
- 156** Michelle Thompson
- 157** Lisa Kava
- 158** Katrina Findanis
- 159** Alicia Newnham
- 160** *Name Withheld*
- 161** *Name Withheld*
- 162** *Name Withheld*
- 163** *Name Withheld*
- 164** Royal Melbourne Hospital
- 165** Australian Academy of Health and Medical Sciences and the Australian Academy of Science
- 165.1 Supplementary to submission 165
- 166** Miss Tara Barton
- 167** Australian POTS Foundation and the Australian Dysautonomia & Arrhythmia Research Collaborative
- 168** Royal Australian College of General Practitioners (RACGP)
- 169** Exercise & Sports Science Australia (ESSA)
- 170** Moderna Australia
- 171** *Name Withheld*

- 172** *Name Withheld*
- 173** *Name Withheld*
- 174** *Name Withheld*
- 175** Professor Martin Hensher
- Attachment 1
 - Attachment 2
- 176** Royal Australian and New Zealand College of Psychiatrists (RANZCP)
- 177** Mrs Tori Haschka
- 178** Murdoch Children's Research Institute
- 179** Occupational Therapy Australia
- 180** Faculty of Pain Medicine
- 181** Ms Alice Rumble
- 182** *Name Withheld*
- 183** Australian Council of Deans of Health Sciences
- 184** Mrs Melinda Border
- 185** *Name Withheld*
- 186** Mr Colin Kinner
- 187** *Name Withheld*
- 188** Rachel Nelson
- 189** *Name Withheld*
- 190** *Name Withheld*
- 191** *Name Withheld*
- 192** Donna Ciccio
- 193** Ms Rose Stuart-Smith
- 194** *Name Withheld*
- 195** Institute for Evidence-Based Healthcare

- 196** Department of Health and Aged Care
- 196.1 Supplementary to submission 196
- 197** *Name Withheld*
- 198** *Name Withheld*
- 199** *Name Withheld*
- 200** Minister for Health and Wellbeing, SA
- 201** Barbara Romeril and Marg Hutton
- 202** National Health and Medical Research Council Centre of Excellence in Treatable Traits
- 203** Suicide Prevention Australia
- 204** *Name Withheld*
- 205** Avant Mutual Group
- 206** Australian Pathology
- 207** *Name Withheld*
- 208** Professor Quentin Grafton
- 209** Diabetes Australia
- 210** Australian Nursing & Midwifery Federation
- 211** Australian National Phenome Centre
- 212** *Name Withheld*
- 213** *Name Withheld*
- 214** Australian and New Zealand Paediatric Infectious Diseases Group (ANZPID)
- 215** National Centre for Neuroimmunology and Emerging Diseases, MHIQ, Griffith University
- 216** Australian Naturopathic Council
- 217** *Name Withheld*
- 218** *Name Withheld*
- 219** *Name Withheld*

- 220** *Name Withheld*
- 221** *Name Withheld*
- 222** Sophie van der Linden
- 223** Brian Jackson
- 224** Alana James
- 225** Pfizer Australia
- 225.1 Supplementary to submission 225
 - Attachment 1
- 226** *Name Withheld*
- 227** *Name Withheld*
- 228** *Name Withheld*
- 229** *Name Withheld*
- 230** Immunisation Coalition
- 231** Ruth Newport
- 232** National Clinical Evidence Taskforce (Monash University)
- Attachment 1
- 233** *Name Withheld*
- 234** *Name Withheld*
- 235** Long Covid Australia Collaboration
- 236** Australasian Sleep Association and Sleep Health Foundation
- 237** The University of Melbourne - Faculty of Medicine, Dentistry and Health Sciences
- 238** Dr Anita White
- 239** *Name Withheld*
- 240** *Name Withheld*
- 241** Carers NSW Australia
- 242** Australian Society for Medical Research

- 243** John Curtin Research Centre
- 243.1 Supplementary to submission 243
 - Attachment 1
 - Attachment 2
- 244** Pathology Technology Australia
- 245** Relationships Australia
- 246** La Trobe University
- 247** AstraZeneca
- 247.1 Supplementary to submission 247
- 248** Dr Graham Exelby
- 249** Royal Australasian College of Physicians
- 250** OneCAM
- 251** Australian Council of Trade Unions
- 252** Zurich Financial Services Australia Limited
- 253** Department of Health (Northern Territory)
- 254** Associate Professor Robyn Schofield
- 254.1 Supplementary to submission 254
- 255** Australian Council of State School Organisations Limited
- 256** Australian Patients Association
- 257** *Name Withheld*
- 258** *Name Withheld*
- 259** *Name Withheld*
- 260** *Name Withheld*
- 261** *Name Withheld*
- 262** Confidential
- 263** Professor Jeremy Howard
- 264** Confidential

- 265** Confidential
- 266** *Name Withheld*
- 267** Mr Darren Ails
- 268** *Name Withheld*
- 269** Allied Health Professions Australia
- 270** UPcare Group
- 271** Australian Traditional Medicine Society (ATMS)
- 272** NSW Health
- 272.1 Supplementary to submission 272
- 273** Department of Health (Western Australia)
- 274** Professor Geoff Hanmer
- 275** ASCEPT Clinical Pharmacology Special Interest Group
- 276** Australian Education Union Federal Office
- 276.1 Supplementary to submission 276
- 277** *Name Withheld*
- 278** *Name Withheld*
- 279** Sian Webster
- 280** Matthew Johnson
- 281** J.T Smith
- 282** *Name Withheld*
- 283** Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ)
- 284** National Heart Foundation of Australia
- 285** Australian Healthcare and Hospital Association
- 286** Dr Christian Allen
- 287** Long Covid Clinic St Vincent's Hospital Sydney
- 288** The Society of Hospital Pharmacists of Australia

- 289** UNSW Fatigue Clinic and Research Program
- 290** VPACS - Victorian Post acute Covid-19 sequelae research group
- Attachment 1
- 291** The Peter Doherty Institute for Infection and Immunity
- 292** *Name Withheld*
- 293** Pharmaceutical Society of Australia (PSA)
- 294** Lung Foundation Australia
- Attachment 1
 - Attachment 2
- 295** *Name Withheld*
- 296** Peri Coleman
- 297** Chelsea Shiambi
- 298** *Name Withheld*
- 299** OzSAGE
- 300** Professor Raina Macintyre
- 301** *Name Withheld*
- 302** *Name Withheld*
- 303** *Name Withheld*
- 304** Lidia Morawska
- 304.1 Supplementary to submission 304
 - 304.2 Supplementary to submission 304
 - Attachment 1
- 305** *Name Withheld*
- 306** Covid Safe Schools Inc
- 306.1 Supplementary to submission 306
- 307** Associate Professor Chris O'Callaghan
- 308** Dr Colin McQueen

- 309** Australia Long Covid Community Facebook Group
- 309.1 Supplementary to submission 309
 - 309.2 Supplementary to submission 309
 - 309.3 Supplementary to submission 309
 - 309.4 Supplementary to submission 309
- 310** Georgina Haberfield
- 311** *Name Withheld*
- 312** *Name Withheld*
- 313** Mama Health Technologies gmbH
- 314** Libby Crothers
- 315** Rare Cancers Australia
- 316** *Name Withheld*
- 317** *Name Withheld*
- 318** *Name Withheld*
- 319** Ms Ella Barnard
- 320** Prof Linda Slack-Smith
- 321** *Name Withheld*
- 322** *Name Withheld*
- 323** *Name Withheld*
- 324** Children and Young People with Disability Australia
- 325** *Name Withheld*
- 326** *Name Withheld*
- 327** Natalia Hodgins
- 328** Australian Medical Association
- 329** *Name Withheld*
- 330** *Name Withheld*
- 331** *Name Withheld*

- 332** *Name Withheld*
- 333** Inner Melbourne Community Legal & Royal Melbourne Hospital (Allied Health Department)
- 334** Australasian College for Emergency Medicine
- 335** A/Professor Nada Hamad
- 336** Advocacy for Inclusion - Incorporating People with Disabilities ACT
- 337** The Pharmacy Guild of Australia
- 338** Stroke Foundation
- 339** Asthma Australia
- 340** Drs Rae Duncan and Claire Taylor
- 341** *Name Withheld*
- 342** Australian Health Services Research Institute (AHSRI)
- 343** *Name Withheld*
- 344** *Name Withheld*
- 345** *Name Withheld*
- 346** *Name Withheld*
- 347** *Name Withheld*
- 348** *Name Withheld*
- 349** *Name Withheld*
- 350** *Name Withheld*
- 351** Public Health Association of Australia (PHAA)
- 352** *Name Withheld*
- 353** Kathy Anderson and Dr Katherine Kenny
- 354** Jamie Lawler
- 355** *Name Withheld*
- 356** *Name Withheld*

- 357** *Name Withheld*
- 358** *Name Withheld*
- 359** *Name Withheld*
- 360** Mr Jonathan Munro
- 361** *Name Withheld*
- 362** Rural Doctors Association of Australia (RDAA)
- 363** *Name Withheld*
- 364** *Name Withheld*
- 365** *Name Withheld*
- 366** Alyssa Mobbs
- 367** *Name Withheld*
- 368** *Name Withheld*
- 369** *Name Withheld*
- 370** *Name Withheld*
- 371** Madeline Cooper
- 372** Mark Newnham
- 373** Lauren Beasley
- 374** Russell Bach
- 375** *Name Withheld*
- 376** *Name Withheld*
- 377** Elisha Londrigan
- 378** Kelly Turner
- 379** Sue La Velle
- 380** *Name Withheld*
- 381** Julie Smithers
- 382** *Name Withheld*

- 383** *Name Withheld*
- 384** Kelly Jeanes
- 385** Nic Goodrich
- 386** Mark Cooke
- 387** Jo O'Connor
- 388** *Name Withheld*
- 389** *Name Withheld*
- 390** *Name Withheld*
- 391** Rebecca Davis
- 392** *Name Withheld*
- 393** Tracey-ann Doe
- 394** Jennifer Munday
- 395** Michelle Yang
- 396** *Name Withheld*
- 397** Emma Quinn
- 398** Jessica Lee
- 399** Narelle Molineux
- 400** *Name Withheld*
- 401** *Name Withheld*
- 402** Gina Bamford
- 403** Elizabeth Robison
- 404** Natalie Gooch
- 405** *Name Withheld*
- 406** *Name Withheld*
- 407** *Name Withheld*
- 408** Nicole Blackford

- 409 Meg Bryar
- 410 *Name Withheld*
- 411 *Name Withheld*
- 412 *Name Withheld*
- 413 Elise Jones
- 414 *Name Withheld*
- 415 Dr Koa Webster
- 416 Brighde Collins
- 417 *Name Withheld*
- 418 Larissa Ryan
- 419 Jac Carolan
- 420 *Name Withheld*
- 421 Theresa Sheppard
- 422 *Name Withheld*
- 423 Karen Johnston
- 424 *Name Withheld*
- 425 Janet Watson
- 426 *Name Withheld*
- 427 *Name Withheld*
- 428 *Name Withheld*
- 429 Ms Lorraine Vogel
- 430 Universities Australia
- 431 *Name Withheld*
- 432 Tim Fulluck
- 433 *Name Withheld*
- 434 Australasian College of Nutritional and Environmental Medicine (ACNEM)

- 435 *Name Withheld*
- 436 Dr Anne Fletcher and Dr Luke Fletcher
- 437 *Name Withheld*
- 438 Alanna Cloy
- 439 Aboriginal Health Council of South Australia
- 440 *Name Withheld*
- 441 *Name Withheld*
- 442 Lisa Brereton
- 443 *Name Withheld*
- 444 *Name Withheld*
- 445 *Name Withheld*
- 446 Gary Smithwick
- 447 *Name Withheld*
- 448 *Name Withheld*
- 449 *Name Withheld*
- 450 Govinda Lange
- 451 Cate Everleigh
- 452 MSD Australia
- 453 Lannen Stapleton
- 454 *Name Withheld*
- 455 *Name Withheld*
- 456 *Name Withheld*
- 457 *Name Withheld*
- 458 *Name Withheld*
- 459 Caroline Veitch
- 460 National Disability Services

- 461** *Name Withheld*
- 462** Mrs Rebecca Adolph
- 463** *Name Withheld*
- 464** Robert Olney
- 464.1 Supplementary to submission 464
- 465** Dr Brett Lidbury
- 466** *Name Withheld*
- 467** *Name Withheld*
- 468** Mrs Christine Murdock
- 469** Ms Eliza Charley
- 470** Group of ME/CFS Patient Advocates
- 471** Maree Candish
- 472** *Name Withheld*
- 473** Thomas Murdock
- 474** *Name Withheld*
- 475** *Name Withheld*
- 476** *Name Withheld*
- 477** National Aboriginal Community Controlled Health Organisation
- 478** Valsamma Eapen
- 479** *Name Withheld*
- 480** Michael Tiffin
- 481** Carly James
- 482** Federation of Community Legal Centres (Victoria) Inc.
- 483** Miquette Abercrombie
- Attachment 1
- 484** Consumers Health Forum of Australia

- 485** Jason Woodyatt
- 486** Australian Federation of Disability Organisations
- 487** Aboriginal Medical Services Alliance Northern Territory
- 488** *Name Withheld*
- 489** Amy Lee
- 490** Bernadette Young
- 491** *Name Withheld*
- 492** Dr Benjamin Veness
- Attachment 1
 - Attachment 2
- 493** Western Health COVID Recovery Collaboration (WHCOVRE)
- 494** *Name Withheld*
- 495** *Name Withheld*
- 496** *Name Withheld*
- 497** *Name Withheld*
- 498** Mr Christopher Jones
- 499** Robin Austin
- 499.1 Supplementary to submission 499
- 500** Sean Kirby
- 501** Australian Psychological Society & Phoenix Australia Centre for Posttraumatic Mental Health Ltd
- 502** Carers Australia
- 503** *Name Withheld*
- 504** Rachel Alice
- 505** *Name Withheld*
- 506** *Name Withheld*
- 507** *Name Withheld*

508 Kathryn Gill

509 Tracey Foster

510 Professor Kerry Phelps AM

511 Ms Gaye Walker

512 *Name Withheld*

513 *Name Withheld*

514 The George Institute for Global Health

515 *Name Withheld*

516 COVERSE Ltd

- Attachment 1

517 *Name Withheld*

518 Medtronic

519 Confidential

520 Confidential

521 Confidential

522 *Name Withheld*

523 Paul Brisbane

524 Confidential

525 Confidential

526 Confidential

527 Brimbank Community-Led Covid Group

528 *Name Withheld*

529 Health Issues Centre

530 Confidential

531 *Name Withheld*

532 *Name Withheld*

- 533** *Name Withheld*
- 534** The Florey Institute of Neuroscience & Mental Health
- 535** *Name Withheld*
- 536** James Mancey
- 537** Confidential
- 538** Emeritus Professor Robert Raison
- 539** *Name Withheld*
- 540** Professor Searle Stoneway
- 541** ME/CFS Australia Ltd
- 542** *Name Withheld*
- 543** AFRM Claims Advocacy (ACA)
- 544** Professor Steven Faux and Associate Professor Anthony Byrne
- 544.1 Supplementary to submission 544
 - 544.2 Supplementary to submission 544
 - 544.3 Supplementary to submission 544
 - Attachment 1
 - Attachment 2
 - Attachment 3
 - Attachment 4
- 545** Mr Bruce Sedgwick and Ms Sophie Sedgwick
- 546** *Name Withheld*
- 547** Dr Melissa McCann
- 548** *Name Withheld*
- 549** Kate Pannifex
- 550** *Name Withheld*
- 551** Ian Henschke
- 552** *Name Withheld*

- 553** *Name Withheld*
- 554** GAMA Healthcare Australia
- 555** Australian Private Hospitals Association
- 556** Carers Tasmania
- 557** *Name Withheld*
- 558** *Name Withheld*
- 559** Michelle O'Brien
- 560** BOD Science
- 561** Dr Adrian Wentzel
- 562** *Name Withheld*
- 563** Michael Bailey
- 564** *Name Withheld*
- 565** *Name Withheld*
- 566** Confidential



B. Hearings and witnesses

Wednesday, 12 October 2022 – Canberra

Royal Melbourne Hospital (by videoconference)

- Associate Professor Louis Irving, Respiratory Physician, Post-Covid Clinic
- Ms Carly McConnell, ReCOV Team Leader

Royal Children's Hospital (Melbourne) (by videoconference)

- Associate Professor Shidan Tosif, Consultant, General Medicine, and Clinical Lead Post-COVID Clinic

Peter Doherty Institute for Infection and Immunity (by videoconference)

- Dr Irani Thevarajan, Infectious Diseases Physician, Victorian Infectious Diseases Service

Burnet Institute (by videoconference)

- Professor Margaret Hellard, Deputy Director, Programs

Deakin University (by videoconference)

- Professor Catherine Bennett, Chair in Epidemiology
- Dr Danielle Hitch, Senior Lecturer in Occupational Therapy

Kirby Institute (by videoconference)

- Professor Greg Dore, Professor and Epidemiologist
- Dr Anthony Kelleher, Director

Monday, 5 December 2022 – Liverpool

Nepean Hospital

- Dr Benjamin Gerhardy, Respiratory Physician, Nepean and Blue Mountains Local Health District
- Dr Archana Sud, Infectious Diseases Physician and Clinical Director Medicine, Nepean and Blue Mountains Local Health District

Westmead Hospital

- Dr Golo Ahlenstiel, Clinical Network Director, Specialty Medicine, Western Sydney Local Health District

- Dr Brett Gardiner, Clinical Network Director, Subacute and Ambulatory Medicine, Western Sydney Local Health District

Sydney Children's Hospital Network (by teleconference)

- Associate Professor Philip Britton, Staff Specialist
- Dr Brendan McMullan, Paediatric Infectious Diseases Specialist

Liverpool Hospital

- Dr Zinta Harrington, Head, Department of Respiratory and Sleep Medicine

Campbelltown Hospital (by teleconference)

- Dr Tuan-Anh Nguyen, Head of Department, Senior Staff Specialist, Rehabilitation Medicine

Ingham Institute for Applied Medical Research

- Professor Les Bokey, Director of Research, South Western Sydney Local Health District; and Director, Ingham Institute for Applied Medical Research

Macarthur General Practice (by teleconference)

- Dr Kenneth McCroary, Director

Tharawal Aboriginal Corporation (by teleconference)

- Ms Melinda Bell, Executive Assistant

Friday, 17 February 2023 – Canberra

National Aboriginal Community Controlled Health Organisation

- Dr Jason Agostino, Senior Medical Advisor

Department of Health and Aged Care

- Professor Brendan Murphy AC, Secretary
- Professor Paul Kelly, Australian Government Chief Medical Officer
- Professor Michael Kidd AM, Deputy Chief Medical Officer
- Dr Ruth Vine, Deputy Chief Medical Officer, Mental Health
- Dr Lucas de Toca, First Assistant Secretary, National COVID-19 Vaccine Program

Mr Bruce Sedgwick and Ms Sophie Sedgwick, private capacity

Associate Professor Nada Hamad, private capacity (by videoconference)

Australia Long Covid Community Facebook Group

- Mr Robin Austin, private capacity (by videoconference)
- Ms Karren Hill, private capacity

- Dr Su Mon Kyaw-Myint, private capacity

Session on lived experience of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (by videoconference):

- Ms Michelle O'Brien, private capacity
- Ms Christina Stenseth, private capacity
- Ms Cindy Wu, private capacity
- Ms Penelope McMillan, Spokesperson, ME/CFS Australia

Roundtable of experts jointly convened by the Australian Academy of Science and the Australian Academy of Health and Medical Sciences:

- Professor Craig Anderson, George Institute for Global Health (*by videoconference*)
- Professor Andrew Baillie, Professor of Allied Health, University of Sydney
- Associate Professor Philip Britton, private capacity
- Dr Allen Cheng, private capacity (*by videoconference*)
- Professor Brendan Crabb, Chief Executive Officer and Director, Burnet Institute
- Ms Kristy Crooks, PhD Scholar, APRISE (*by videoconference*)
- Professor Maria Crotty, Professor of Rehabilitation, Aged and Extended Care, Flinders University
- Professor Margaret Hellard, Deputy Director, Burnet Institute
- Professor Martin Hensher, private capacity
- Professor Anne Holland, Head of Post COVID Service and Head of Respiratory Research, Alfred Health; and Professor of Physiotherapy, Monash University
- Associate Professor Alex Holmes, Fellow, Royal Australian and New Zealand College of Psychiatrists; Royal Melbourne Hospital; and University of Melbourne
- Associate Professor Louis Irving, private capacity
- Professor Chennupati Jagadish, President, Australian Academy of Science
- Dr Jen Kok, Medical Virologist, Australian Society of Microbiology; Institute of Clinical Pathology and Medical Research; and NSW Health Pathology
- Professor Dennis Lau, private capacity
- Professor Julie Leask, private capacity
- Dr Sharon Lewin, private capacity (*by videoconference*)
- Professor Andrew Lloyd, private capacity
- Dr Sarah Lynar, Infectious Diseases Physician, Royal Darwin Hospital; and Department of Health, Northern Territory (*by videoconference*)

- Dr Kristine Macartney, Fellow, Australian Academy of Health and Medical Sciences (*by videoconference*)
- Dr Gail Matthews, private capacity (*by videoconference*)
- Ms Penelope McMillan, Spokesperson, ME/CFS Australia (*by videoconference*)
- Professor Jodie McVernon, Director, Doherty Epidemiology, The Peter Doherty Institute for Infection and Immunity; Professor, University of Melbourne; and Royal Melbourne Hospital
- Professor Adrian Miller, Deputy Vice-President, Indigenous Engagement, Central Queensland University (*by videoconference*)
- Professor Jeremy Nicholson, Pro Vice-Chancellor, Health Sciences, Murdoch University; and Director, Australian National Phenome Centre
- Ms Michelle O'Brien, private capacity (*by videoconference*)
- Distinguished Professor Ingrid Piller, Centre for Workforce Futures, Macquarie University (*by videoconference*)
- Professor Lena Sanci, Department of General Practice and Primary Care, Melbourne Medical School, University of Melbourne
- Professor Kirsty Short, University of Queensland
- Professor Tania Sorrell, Fellow, Australian Academy of Health and Medical Sciences; and Ambassador, Sydney Institute for Infectious Diseases
- Ms Christina Stenseth, private capacity (*by videoconference*)
- Professor Steve Wesselingh, President, Australian Academy of Health and Medical Sciences
- Ms Cindy Wu, private capacity (*by videoconference*)

Monday, 20 February 2023 – Malvern

Burnet Institute

- Professor Brendan Crabb AC, Director and Chief Executive

Public Health Association of Australia (PHAA) (by videoconference)

- Professor Catherine Bennett, Alfred Deakin Professor and Chair in Epidemiology, Deakin University; and Expert Epidemiologist, PHAA
- Professor Caroline Miller, Vice-President, Policy, PHAA

Royal Australian College of General Practitioners (RACGP)

- Professor Mark Morgan, Chair of the RACGP Expert Committee for Quality Care and Co-chair of the National Clinical Evidence Taskforce Primary and Chronic Care Panel

Associate Professor Robyn Schofield, Associate Professor of Atmospheric Chemistry, University of Melbourne

Professor Geoffrey Hanmer, Director, OzSAGE

Distinguished Professor Lidia Morawska, School of Earth and Atmospheric Sciences, Queensland University of Technology (by videoconference)

Professor Jeremy Nicholson, Director, Australian National Phenome Centre; and Pro Vice-Chancellor Health Sciences, Murdoch University

Covid Safe Schools Inc (by videoconference)

- Ms Karen Armstrong, Acting President
- Mr Peter Vogel, Legal Advisor

Australian Education Union Federal Office (by videoconference)

- Mr Kevin Bates, Federal Secretary