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How patient experiences can guide the development of Long COVID health policy

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Key Messages

Long Coronavirus Disease (COVID) is a growing public health challenge in Australia. People with Long COVID have a reduced ability to perform their normal daily activities due to debilitating symptoms that affect multiple body systems. However, the burden of Long COVID on people living with the condition and Australia's healthcare system is poorly described, meaning care and support resources cannot be allocated appropriately.

Australia's public health guidance for Long COVID is inconsistent. There is no single, nationally accepted case definition for Long COVID in Australia and public health messaging differs across each state and territory. This complicates an already challenging diagnostic process.

The Australian Government's engagement with Long COVID consumers in decisions about care and policy guidelines has been minimal and patient experience data is scarce. This impacts service accessibility, as well as the health, working life, and quality of life of Australians living with the condition.

Long COVID is also not recognised as a disability in Australia. Such lack of recognition compromises access to necessary care and support services, which are already limited.

To ensure that Australians with Long COVID are recognised and supported with adequate and appropriate person-centred healthcare, social, and disability services, a number of key priority areas must be addressed.

Improved surveillance and consistent public health guidance are essential to accurately identify the burden of Long COVID on Australia's healthcare system and respond accordingly.

Appropriate recognition of the disabling impacts of Long COVID in Australian health policy must be pursued to facilitate access to necessary services and protect people with the condition from discrimination.

Increasing engagement with Long COVID consumers by collecting patient experience data, establishing a consumer advisory group, and co-producing care pathways is vital to developing and delivering person-centred, value-based care for all people with Long COVID in Australia.

Recommendations

1

Identification:

Broaden surveillance by developing a national Long COVID registry, establishing a national minimum data set for chronic illnesses, and expanding electronic health data collection and sharing.

Co-produce accessible and inclusive public health advice about Long COVID using a consensus case definition and consistent terminology.

2

Recognition:

Acknowledge the disabling nature of Long COVID at a federal policy level and within the design and provision of care and support services.

Develop a co-produced approach in consultation with consumers to reduce stigma and discrimination against people with Long COVID in Australia.

3

Consumer engagement:

Understand the care and support needs of Australians with Long COVID by expanding research using appropriate patient-reported experience and outcome measures at a national level.

Establish an intersectional, consumer-driven advisory group for Long COVID to be regularly consulted by policymakers.

Increase care accessibility by adequately resourcing GPs with co-produced care pathways that align with the care and support needs of Long COVID consumers.

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Executive Summary

As a newly emergent chronic, multi-systemic illness and post-infectious health outcome of Coronavirus Disease 2019 (COVID-19), Long COVID is a public health challenge of national significance. By 2022, Long COVID had affected around four million Australians. However, this number – as well as the proportion of Australians who have been exposed to COVID-19 and therefore the risk of developing Long COVID – continues to rise.

Long COVID is responsible for care and support costs, as well as economic losses. As a result of the disabling nature of the illness, people with Long COVID are restricted in their ability to participate in their communities and in the workforce. Due to the profound impact of Long COVID on functioning and daily life, people living with the condition also have complex care and support needs. This involves the coordination of multidisciplinary services, including primary, specialist, and allied healthcare, as well as disability and social support.

The true burden of Long COVID on the Australian healthcare system is not well-understood and is likely underestimated. This is attributable to the absence of a single nationally accepted Long COVID case definition, as well as existing complications with chronic illness surveillance and primary care data sharing in Australia. As a result, the allocation and delivery of services to people with Long COVID are not informed by accurate, real-time data and the care and support needs of Australians with Long COVID are not being met.

People with Long COVID, and the challenges imposed by Long COVID on consumers, are poorly recognised at a federal policy level. Despite advancements in other countries, Long COVID is not regarded as a disability in Australia and a Long COVID advisory group to facilitate consumer engagement with the Australian Government and policymakers does not exist.

No patient experience data has been formally collected from Australians with Long COVID and there has been a lack of co-production with Long COVID consumers in the design and delivery of care and support services. This limited understanding and poor integration of consumers' lived experiences into care pathways and policy compromises the delivery of person-centred, value-based care.

Many of these issues have been identified as existing barriers within Australia's healthcare system affecting people with chronic illnesses in general.

The need for improvements in three key areas have been identified, including – Identification, Recognition, and Consumer engagement. Advancements in these areas must be prioritised to promote and facilitate the best possible health and quality of life for all Australians with Long COVID.

Background

Long Coronavirus Disease (COVID) is a chronic post-infectious illness affecting people who have previously contracted Sudden Acute Respiratory Syndrome-Coronavirus-2 (SARS-CoV-2) – the virus responsible for Coronavirus Disease 2019 (COVID-19). Although much remains unknown about the condition due to its novelty, Long COVID is a multifaceted public health challenge of mounting concern.

Prevalence

As of December 2022, over seven in ten Australians – around 18 million people – had had COVID-19 at least once (Australian COVID-19 Serosurveillance Network, 2023). Close to 30% of Australian adults – around four million people – had experienced or were continuing to experience Long COVID by August 2022 (Biddle and Korda, 2022). Up to 10% of COVID-19 survivors are afflicted by ongoing health concerns for at least three months after COVID-19 (Australian Institute of Health and Welfare (AIHW), 2022h), suggesting that the number of Australians at risk of long-term illness due to COVID-19 could exceed one and a half million. A patient population of this size is comparable to that of diabetes, which affects around 1.3 million Australians and has been regarded as a National Health Priority Area (NHPA) since 1996 (Australian Bureau of Statistics (ABS), 2020-21; AIHW, 1997).

International studies have observed that around 60% of people with Long COVID continue to experience persistent symptoms after six months (Davis, et al., 2021; Kohn et al., 2022), with between 40% and 50% having an illness duration of at least one year

(Fumagalli et al., 2022; Huang et al., 2021). Based on the trajectory that around half of people with Long COVID will not recover within 12 months, more than one in 50 Australians – over half a million people – will experience at least one full year of life lost to post-COVID-19 illness.

Personal accounts from COVID-19 survivors experiencing persistent symptoms began to surface on social media in May 2020 (Callard and Perego, 2021), just two months after the World Health Organization (WHO)'s declaration of the pandemic (WHO, 2020a, 2020b). The potential future burden of Long COVID in Australia was flagged one year later in May 2021 (Hensher et al., 2021). Despite early calls for action, the Australian Government and healthcare system's response to Long COVID in the first three years of the pandemic has been minimal.

Quality of life

People with Long COVID experience poor quality of life and, due to the complex challenges associated with the condition, require multidisciplinary care and support from primary, specialist, and allied healthcare providers, as well as social and disability support services (Aiyegbusi et al., 2021; Centers for Disease Control and Prevention (CDC), 2022; Raveendran et al., 2021; Sorrell et al., 2023).

While the Royal Australian College of General Practitioners' (RACGP) provides guidance for managing Long COVID in general practice (RACGP, 2021), anecdotal evidence indicates that the care and support needs of Australians

with Long COVID continue to be unmet. This lack of recognition of the Long COVID patient experience is likely due to limited ongoing consultation with this cohort, resulting in an absence of a voice in policy and service delivery decisions. This creates barriers to the provision of adequate care and support for all Australians with Long COVID.

Patient experience

Data on the patient experience of Australians with Long COVID is limited (De Leeuw et al., 2022) and there is no routine mechanism for the views of this cohort to be represented. Where care and support services have been made available, they are often unsatisfactory, poorly accessible, and fail to accommodate for the functional impairments experienced by people with Long COVID (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). This is due to poor consumer engagement and a lack of coproduction in the design and delivery of necessary services (De Leeuw et al., 2022).

Underrepresentation of Long COVID's disease burden due to the lack of coordinated chronic illness surveillance and data collection in Australia further hampers the appropriate allocation and resourcing of necessary care and support services (Angeles and Hensher, 2022; Swerissen et al., 2018).

Inquiry into Long Covid and Repeat COVID Infections

In September 2022, the House of Representatives Standing Committee on Health, Aged Care, and Sport commenced the Inquiry into Long COVID and Repeated COVID-19 Infections. This inquiry provided an opportunity for the lived experience of Australians with Long COVID to be formally documented. Nevertheless, due to the debilitating and limiting nature of the condition, the challenges and needs of many Australians with Long COVID remain unheard (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

The inquiry report, released in April 2023, identifies the pressing need for the lived experiences of people with Long COVID to inform policy and care pathway decisions (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

The impact of Long COVID

Long COVID has profound and multifactorial impacts on people living with the condition, as well as the community. The symptoms of Long COVID can be severe and disabling (Davis et al., 2023; Mehandru and Merad, 2022; Sukocheva et al., 2022), which has implications beyond the physical health of people living with the condition and impacts mental, emotional, and social wellbeing. This also affects communities through the loss of productivity, increased demand on the healthcare system, and economic burden attributable to both financial losses and direct care and support costs (AIHW, 2022b).

There is no cure for Long COVID and pharmacological therapies are limited due to much of the illness' pathophysiology remaining unclear (AIHW, 2022h; Greenhalgh et al., 2022). Consequently, Long COVID is a long-term health condition with significant and diverse impacts on quality of life and minimal treatment options.

Daily living and working life

The symptoms and challenges brought about by Long COVID prevent people living with the condition from engaging in their typical daily activities (Greenhalgh et al., 2022; Vaes et al., 2021; Ziauddeen et al., 2022). Over 85% of Australians with Long COVID reported that their ability to participate in their daily activities had been restricted by the condition (Biddle and Korda, 2022). For some people with Long COVID, this has involved having limited or no capacity to perform activities of daily living, from cooking or cleaning to self-care, such as personal hygiene and dressing

(Fernández-de-las-Peñas et al., 2022; Greenhalgh et al., 2022).

Long COVID also has implications on the working life of people living with the condition (Greenhalgh et al., 2022; House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Nittas et al., 2022). Unemployment due to illness ranges from around 40% to 70% among COVID-19 survivors with ongoing symptoms (Nittas et al., 2022); however, almost nine in ten people with Long COVID report having a reduced capacity to work (Davis et al., 2021).

As of 2023, work absenteeism due to Long COVID equates to nearly \$6 billion in economic losses annually in Australia (Wade et al., 2023). However, as such economic losses do not account for direct costs related to patient care (Australian Health Minister's Advisory Council, 2017), the true financial burden of Long COVID in Australia is likely underestimated.

People with Long COVID also experience relapses or exacerbations of the illness due to insufficient accommodations for symptoms or functional impairments in the workplace, such as a lack of leave rights, unadjusted work demands, and inflexibility in working hours or working conditions (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Kohn et al., 2022).

For some people with Long COVID, the loss of employment and income due to a reduced capacity to work has hindered access to necessary care services and, in severe cases, led to food and housing insecurity (House of Representatives Standing Committee on

Health, Aged Care, and Sport, 2023). The ramifications of financial hardship associated with developing Long COVID place people with the condition at risk of further deteriorations in health (AIHW, 2022e). Preventative, 'upstream' measures that allow people with Long COVID to maximise their engagement in the workforce must be implemented to reduce the burden of Long COVID on patient health, as well as to avoid additional strain on the economy and support services (De Leeuw et al., 2022; House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Kohn et al., 2022). This involves providing accessible financial support for people with Long COVID and enacting appropriate workplace accommodations (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Kohn et al., 2022).

People with Long COVID who have considerable functional impairments or are unable to work have an increased dependency on family and friends, such as for help with activities of daily living and financial support (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Pearson et al., 2022; Skilbeck et al., 2023). New responsibilities associated with caring for a family member or friend with chronic illness can strain carer's health, quality of life, and employment (Winter and Haddock, 2021). Such challenges have been observed among carers of people with Long COVID (Shah et al., 2021).

Mitigating the challenges of Long COVID involves not only supporting Australians with the condition but also their families and communities (Angeles and Hensher, 2022).

Stigma and discrimination

The stigma and discrimination faced by people with Long COVID must be acknowledged. Despite mounting evidence demonstrating the loss of functional capacity among people with Long COVID (Alves de Sousa et al., 2022; Cai et al., 2023; Calvache-Mateo et al., 2023; Hitch et al., 2021; Weigel et al., 2023), prejudiced attitudes and scepticism towards Long COVID are commonly reported by people with the condition (Hossain et al., 2023; Ireson et al., 2022; Russell et al., 2022; Samper-Pardo et al., 2023; Schmachtenberg et al., 2023).

In a study based in the United Kingdom, over 60% of people with Long COVID experienced external stigma directly related to their illness at least some of the time (Pantelic et al., 2022).

In the Australian context, people with Long COVID have been subjected to discrimination in healthcare and employment settings (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). Much of the stigma associated with Long COVID is attributed to the belief that the illness is not a real medical condition and a lack of empathy towards the illness experiences reported by people with Long COVID (Ireson et al., 2022; Samper-Pardo et al., 2023; Schmachtenberg et al., 2023).

Such stigmatisation of Long COVID has led to people with the condition being restricted from necessary care or treatments due to healthcare provider's dismissal of symptoms as being psychological in nature, as well as unsuitable working conditions with no accommodations for health and wellbeing concerns (Hossain et al., 2023; House of

Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Ireson et al., 2022; Kingstone et al., 2020; Schmachtenberg et al., 2023).

Like many other chronic illnesses (Armentor, 2017; Donnelly et al., 2021; O'Donnell and Habenicht, 2022; Pilkington et al., 2020), the invisible nature of Long COVID symptoms has contributed to stigmatisation of the condition (Ireson et al., 2022; Kingstone et al., 2020). People with invisible chronic illnesses inherently face stigma, particularly where there is limited objective evidence of disease (Armentor, 2017; Donnelly et al., 2021; O'Donnell and Habenicht, 2022). Such is the case for Long COVID, in which no single physiological, structural, or functional assessment exists to confirm a diagnosis (CDC, 2022; Davis et al., 2023; Greenhalgh et al., 2022).

Discrimination is known to worsen quality of life among people with chronic illnesses (Australian Health Minister's Advisory Council, 2017; Cockerham et al., 2017). This has similarly been observed among people with Long COVID, particularly regarding mental wellbeing, both internationally and in Australia (Hossain et al., 2023; House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Kingstone et al., 2020).

Consumer engagement is a priority of the *National Strategic Framework for Chronic Conditions* [effective 2017 to 2025] (Australian Health Minister's Advisory Council, 2017); however, this framework does not outline means to address the stigma and discrimination experienced by people with chronic illnesses.

Long COVID and Australia's disease burden

The AIHW's burden of disease report for 2022 recognised COVID-19 as the 10th leading contributor to Australia's disease burden and the only infectious disease in Australia's top 25 contributors to the national burden of disease (AIHW, 2022a). In 2022, Long COVID accounted for 10% of the total COVID-19 burden in Australia and almost half of COVID-19's non-fatal disease burden for the year (AIHW, 2022h).

COVID-19 incidence

The cumulative incidence of COVID-19 in Australia, and by inference, the proportion of the population at risk of developing adverse post-COVID-19 health outcomes, like Long COVID, has increased since 2021.

By the end of 2022, the National Notifiable Diseases Surveillance System (NNDSS) recorded close to 10.5 million COVID-19 cases in Australia compared with less than 500,000 diagnosed cases within the year prior (COVID-19 Epidemiology and Surveillance Team, 2023; COVID-19 National Incident Room Surveillance Team, 2022). In fact, the cumulative COVID-19 cases for 2021 totalled less than 190,000 in early December (COVID-19 National Incident Room Surveillance Team, 2021), with the final weeks of the year seeing an influx of cases following the emergence of the Omicron variant in Australia (COVID-19 National Incident Room Surveillance Team, 2022).

Despite cases surging from late 2021, government-mandated restrictions were lifted in April 2022 (DoHAC, 2022a)). Following this, more Australians than ever contracted COVID-19 for the first time. From March to

September 2022, the cumulative incidence of COVID-19 increased from 17% to 65% of the Australian population (Australian COVID-19 Serosurveillance Network, 2022a, 2022b). The Australian Government's lack of measures to control the Omicron variant have been criticised in the Senate Select Committee on COVID-19's final inquiry report (2022).

Long COVID and multimorbidity

Due to the incurable nature of Long COVID, rising case numbers equate to an accumulating population of Australians with complex support needs, exacerbating Australia's existing and future chronic disease burden (Angeles and Hensher, 2022). Given that people with existing chronic conditions are disproportionately affected by Long COVID (AIHW, 2022h; Subramanian et al., 2022; Thompson et al., 2022), the emergence of the condition also threatens to inflate Australia's multimorbidity burden.

People with chronic health conditions have poorer quality of life, increased health service demand and expenditure, and reduced workforce engagement – all of which are exacerbated by multimorbidity (AIHW, 2022b; Australian Health Minister's Advisory Council, 2017). Multimorbidity due to Long COVID is likely associated with increased costs to the Australian Government. However, due to an absence of formal monitoring of Long COVID cases in Australia (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023), the healthcare costs and demands associated with the condition cannot be accurately measured.

The ability of Australia's healthcare system to meet the demands posed by an increasing burden of chronic illness is an existing area of concern (Calder et al., 2019; Primary Health Care Advisory Group, 2015). Each year, over \$38 billion is invested into the management of chronic illness in Australia (Productivity Commission, 2021), yet numerous issues continue to impact the

standard of care received by Australians with chronic illness (Primary Health Care Advisory Group, 2015). These issues include poor resourcing, inequitable access to services, and a lack of continuity of care (Calder et al., 2019; Hitch et al., 2023; Primary Health Care Advisory Group, 2015).

Long COVID is poorly identified

Monitoring the incidence of Long COVID remains an ongoing challenge (AIHW, 2022h; Angeles and Hensher, 2022; Sorrell et al., 2023). This is due to issues with chronic illness surveillance, as well as barriers to accurate and timely Long COVID diagnoses (Crook et al., 2021). Such complications in ascertaining cases of Long COVID are attributable to the absence of consensus diagnostic criteria and incomplete understanding of the condition's pathophysiology (AIHW, 2022h; Davis et al., 2023; Jason et al., 2023; Sorrell et al., 2023).

In this regard, the burden of Long COVID on both Australia's population and healthcare system is likely underrepresented. Consequently, accurate data does not exist to inform the appropriate allocation of resources and the needs of Australians with Long COVID remain unmet.

Surveillance of chronic illness

Chronic illness occupies the majority of Australia's burden of disease (ABS, 2018), yet the ability to formally track and document cases of chronic illnesses is limited (Swerissen et al., 2018). In contrast, communicable diseases have been monitored through the collection of coordinated, real-time data by the NNDSS since 1990 (DoHAC, 2022b).

Paradoxically, the lack of a national repository for chronic illness case data also impacts on post-infectious illnesses, like Long COVID, where the long-term health outcomes are a component of the burden of the infectious disease itself. The impact of notifiable infectious diseases is determined only by acute health outcomes, including hospital

admissions and deaths (AIHW, 2022g). This likely results in the underrepresentation of post-infectious illnesses, including Long COVID, on Australia's disease burden.

The establishment of the Australian Centre for Disease Control will see work to control both chronic and infectious diseases in Australia and will be ideally placed to support the surveillance of Long COVID moving forward.

Health data to monitor chronic illness

In Australia, the standardised collection of data across all chronic illnesses is poor. This is primarily due to a lack of routine sharing of primary care data (including diagnoses and consultations), and a lack of national reporting standards for chronic illnesses (Primary Health Care Advisory Group, 2015; Swerissen et al., 2018). For example, most of Australia's health data sets pertain to acute care settings and not primary care where chronic illnesses are largely managed (AIHW, 2023). National Best Practice Data Sets have been generated for some chronic illnesses identified within Australia's NHPAs, such as cancer, cardiovascular disease, dementia, and diabetes (AIHW, 2023). However, these reporting standards are only recommended and are not mandated (AIHW, 2023).

Barriers to the collection and sharing of health information in primary care have been identified in the 2022 *Strengthening Medicare Taskforce report* and the 2023 Australian Government Productivity Commission's 5-year Productivity Inquiry Report (Australian Government Productivity Commission, 2023; Strengthening Medicare Taskforce, 2022).

The collection of national health data

In Australia, nationally distributed health surveys capture data on select health conditions identified as leading contributors to the burden of disease in Australia (ABS, 2022a), as well as Australia's NHPAs – cancer, cardiovascular disease, injuries, mental health, diabetes mellitus, asthma, arthritis and musculoskeletal conditions, obesity, and dementia (House of Representatives Standing Committee on Health and Ageing, 2013). However, reporting on these health conditions in isolation likely skews reporting of other chronic illnesses, including Long COVID.

Population health data is collected on a national scale via the Census, as well as surveys distributed by the ABS (such as the National Health Survey and Patient Experience Survey (PEX) (ABS, 2022a)). This data is linked with data collected via the Medicare and Pharmaceutical Benefits Schemes (MBS and PBS, respectively), forming the National Integrated Health Service Information Analysis Asset (National Integrated Health Service Information Analysis Asset (NIHSI AA) version 1.0, AIHW Data Quality Statements, Standard 23/09/2022, 766334).

The disease burden of illnesses that fall outside of the NHPAs are captured within the Australian Burden of Disease Study (AIHW, 2021). Since 2011, the Study has been conducted every three to four years, collating health data for over 200 communicable and non-communicable diseases from National Minimum Data Sets (NMDSs), epidemiological studies, and disease registries (AIHW, 2021). As of 2023, Long COVID is yet to be included within this study.

In addition, among the over 100 formally established disease registries in Australia (Australian Commission on Safety and Quality in Health Care (ACSQHC), 2022), a Long COVID, or other post-infectious illness registry, is yet to be developed. Establishment of a post infectious illness registry would aid in the collection of data for inclusion in the Australian Burden of Disease Study.

Given the periodic nature of national health data collection in Australia, health surveys administered to Australians are unable to capture real-time data. Hence, any fluctuations in the burden of chronic illnesses between reporting periods, such as the emergence and prevalence patterns of Long COVID, are not captured.

For example, the National Health Survey recurs every three years and was last distributed from August 2020 to June 2021 (ABS, 2022b). Therefore, data contained within the survey omits the majority of Australia's Long COVID cases, which emerged as a result of the Omicron wave from November 2021 to March 2022 (Angeles and Hensher, 2022).

Long COVID surveillance

Long COVID data is a routinely collected and shared by the United Kingdom (Office for National Statistics, 2023) and the implementation of a Long COVID registry has commenced in New Zealand (University of Auckland, 2023).

In 2022, the AIHW established the COVID-19 Register and Linked Data Set, synthesising NNDSS, MBS, and PBS data with immunisations, deaths, and information recorded within hospital NMDSs relating to COVID-19 (AIHW, 2022c). Although the linkage

of MBS and PBS data provides a proxy measure of health outcomes after COVID-19, as there are no billing items specific for Long Covid (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). While classification codes have been developed for Long COVID, including within the WHO's International Statistical Classification of Diseases and Related Health Problems (ICD), Eleventh Revision ("RA02 Post COVID-19 condition" Tenth Revision, Australian Modification ("U07.4 Post Coronavirus Disease 2019")(AIHW, 2022h), such codes are specific for use in hospital settings and are not recorded within the COVID-19 Register and Linked Data Set.

As a result, MBS and PBS expenditure attributable to the management of Long COVID cannot be accurately monitored and the AIHW's COVID-19 Register and Linked Data Set, in its current form, is not appropriate for tracking the cases and burden of Long COVID in Australia effectively (Angeles and Hensher, 2022).

In addition, the removal of COVID-19 testing mandates, combined with the increasingly endemic nature of SARS-CoV-2 has complicated the documentation of COVID-19 cases and therefore those at risk of developing Long COVID within the COVID-19 Registry and Linked Data Set.

Analysis of electronic health records has identified differences in both data density and granularity across case definitions and between healthcare providers (Zhang et al., 2023). This highlights the need for standardised case definitions in clinical practice, as well as education for healthcare

providers regarding Long COVID diagnoses and appropriate coding.

Improving surveillance of Long COVID will also rely on the expansion of chronic illness monitoring in Australia. Establishing an NMDS for chronic illnesses and broadening the collection of national health data to consider chronic illness in its entirety have previously been recommended by the Primary Health Care Advisory Group (2015), Thorpe and Sweeney (2019), and Angeles and Hensher (2022). This must now be given priority. The AIHW's development of the National Primary Health Care Data Collection, as well as the recommendations from the Strengthening Medical Taskforce and Productivity Commission to improve My Health Record data accessibility and increase healthcare provider participation should also be supported.

Monitoring the impact of Long COVID

Establishing a Long COVID registry is necessary to enable comprehensive investigation into the impact on Australians living with the condition.

The Australian Government Department of Health and Aged Care prioritises research into the health and quality of life of Australians with Long COVID as part of the four-year *Post-Acute Sequelae of COVID-19 Research Plan* (DoHAC, 2023b). This research plan, which is supported by the Medical Research Futures Fund (MRFF), seeks to gather data specific to Australian patients. Such data can assist in informing healthcare planning in the interim while a Long COVID registry and established chronic illness and primary care data sharing practices are developed.

Long COVID public health guidance for Australians

In Australia, public health messaging around Long COVID was communicated relatively slowly by both federal and jurisdictional health departments, with the risk of developing Long COVID not being publicly addressed until the third year of the pandemic. The health system response was timelier in other OECD countries, like Singapore and the United

Kingdom, which released public health guidance about Long COVID several months before advice about the condition was published by the Australian Government (Singapore Government Ministry of Health, 2020; United Kingdom Department of Health and Social Care, 2020, 2021).

Australia's Long COVID public health guidance

To the best of the authors' knowledge, the earliest documented Long COVID public health guidance from an Australian health body was released by the RACGP in December 2020. The RACGP's *Patient resource: Managing post-COVID-19 symptoms* factsheet provides self-management and care-seeking advice for people with persistent COVID-19 symptoms (RACGP, 2020). However, terminology pertaining to Long COVID is omitted and no minimum illness duration is specified.

The Department of Health and Aged Care's first formal media release of Long COVID guidance for the Australian public, including typical symptoms and advice about vaccinations, was not published until April 2022 (DoHAC, 2022d).

The *Getting help for Long COVID* factsheet, which provides more detailed advice regarding healthcare service access for people with the condition (DoHAC, 2022c), was distributed by the federal health department in August 2022.

Long COVID and COVID-19 recovery webpages were also established by Healthdirect Australia and developed for each of the federal and jurisdictional health departments. However, most of these resources were published in late 2022. By this time, around 18 million Australians had experienced COVID-19 at least once (Australian COVID-19 Serosurveillance Network, 2023).

As of 2023, the available Long COVID public health guidance distributed by Australian health departments and health bodies remains variable and uncoordinated. The terms used to describe Long COVID, timeframes for recovery and the minimum illness duration before Long COVID is considered, and care seeking advice fluctuate across the health departments (as summarised in Appendix 1).

Long COVID guidance lacks clarity

Accessing clear and consistent care-seeking guidance for Long COVID is an internationally-reported challenge (Hossain et al., 2023). Similarly, in Australia, the discordance of information between state and territory health departments creates uncertainty around when the possibility of Long COVID diagnosis should be considered, and when care should be sought.

Care-seeking advice for COVID-19 recovery and Long COVID across Australian jurisdictions

Health departments with shared guidance about COVID-19 recovery include the federal, Australian Capital Territory, Victorian, and Northern Territory health departments, being that:

- Acute COVID-19 illness typically lasts a few weeks.
- People who have had COVID-19 should consult a GP if ongoing symptoms are of concern.

New South Wales, Queensland, South Australia, Western Australia, and Tasmania each have unique Long COVID guidance with limited similarities.

Across the breadth of information provided by Australia's health departments (Appendix 1), it is unclear whether persistent COVID-19 symptoms lasting between four and 12 weeks, also known as Ongoing Symptomatic COVID-19 (National Institute for Health and Care Excellence (NICE), 2022), should be classified as Long COVID.

The federal, Australian Capital Territory, and South Australian health departments provide guidance for people experiencing residual COVID-19 symptoms that have persisted for less than three months. However, there is little information about the typical illness progression or care available for people experiencing Long COVID symptoms for less than three months in other states and territories.

Uniquely, the Northern Territory specifically defines people with COVID-19-related symptoms persisting for less than three months as 'still recovering from COVID-19'.

The lack of consistent information across public health guidance for Long COVID hinders Australians from having the equal opportunity to make adequately informed decisions about their health (De Leeuw et al., 2022). This has been an existing concern in Australia throughout the pandemic, whereby people from vulnerable populations were observed to have reduced COVID-19 health literacy attributable to a lack of inclusivity and accessibility in public health messaging (McCaffery et al., 2020).

Public health guidance about Long COVID must be harmonised across the states and co-produced with consumers to ensure the distribution of equitable and accessible health information to all Australians (De Leeuw et al., 2022; Hensher et al., 2021), which is a right

identified in the ACSQHC's *Australian Charter of Healthcare Rights* and a component of the *National Safety and Quality Health Services (NSQHS) Standards* (ACSQHC 2020, 2021). The development of inclusive community health education is also an objective of the *National COVID-19 Health Management Plan for 2023* (DoHAC, 2022e); however, this goal should be reflected more broadly.

A standardised case definition that is accepted across Australian jurisdictions will also allow the burden of Long COVID to be more accurately monitored as data collection measures are expanded, such as the development of a Long COVID registry and improved primary care data sharing.

The legitimacy of Long COVID

In Australia, Long COVID is poorly recognised across policy, health care, employment, and social settings (Angeles and Hensher, 2022). For the most part, this is due to the legitimacy of Long COVID and its disabling nature being poorly acknowledged. As such, the Australian Government, healthcare system, and community services have taken few measures to accommodate and mitigate the challenges and burdens experienced by people with Long COVID. Consequently, Australians with Long COVID have not been afforded the opportunity to receive the necessary care and support that is required to facilitate improved health outcomes, as well as the ability to engage in work and daily activities.

Over the period of the pandemic (11 March 2020 – 5 May 2023), no explicit changes were made to Australian healthcare policy to support the delivery of services, financial aid, or workplace accommodations for people with Long COVID. While the *National COVID-19 Health Management Plan for 2023* has identified the need to develop a strategic framework for Long COVID that underpins care and support services for people with the condition, it is still yet to be developed (DoHAC, 2022e; House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

Nevertheless, healthcare frameworks and policies relevant to chronic illness (but not specific to Long COVID) existed prior to the pandemic and have the capacity to support approaches to Long COVID across health and community services. These frameworks include the 2015 *Better Outcomes for People*

with Chronic and Complex Health Conditions (Primary Health Care Advisory Group, 2015), the *National Strategic Framework for Chronic Conditions* [effective 2017 to 2025] (Australian Health Minister's Advisory Council, 2017), and the 2021 *Innovations in Care for Chronic Conditions Health Conditions* (Australian Government Productivity Commission, 2021), which provide rationale for the provision of care and support services for people with Long COVID.

The disabling nature of Long COVID

In Australia, Long COVID is not recognised as a disability. This is despite the functional limitations associated with the condition meeting disability definitions (Hereth et al., 2022), including those outlined in Australian policy and legislation, as well as international guidelines (see Australian and international definitions of disability below).

Australian definitions of disability

Australian Institute of Health and Welfare (2022d)

Disability is an umbrella term for any or all the following:

- a) Impairment: problems in body function or structure;
- b) Activity limitation: difficulties in executing activities;
- c) Participation restriction: problems an individual may experience in involvement in life situations.

Australian Public Service Commission (2019)

Persons are considered to have a disability if they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities. This includes episodic conditions if they are likely to recur.

Disability Discrimination Act 1992 (Cth s 4, latest version 20 December 2022, C2022C00367)

Disability, in relation to a person, means:

- a) total or partial loss of the person's bodily or mental functions; or
- b) total or partial loss of a part of the body; or
- c) the presence in the body of organisms causing disease or illness; or
- d) the presence in the body of organisms capable of causing disease or illness; or
- e) the malfunction, malformation or disfigurement of a part of the person's body; or
- f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour; and includes a disability that:
- h) presently exists; or
- i) previously existed but no longer exists; or
- j) may exist in the future (including because of a genetic predisposition to that disability); or
- k) is imputed to a person.

To avoid doubt, a disability that is otherwise covered by this definition includes behaviour that is a symptom or manifestation of the disability.

International definitions of disability

United Nations Convention on the Rights of Persons with Disabilities (2006, Treaty Series, 2515, 3)

Persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments, which (in interaction with various barriers) may hinder their full and effective participation in society on an equal basis with others.

World Health Organization International Classification of Functioning, Disability, and Health (2002)

Disability is an umbrella term for impairments, activity limitations and participation restrictions.

The lack of recognition of the disabling nature of Long COVID has resulted in Australians with the condition being excluded from accessing disability support services. This has also hindered people with Long COVID from being supported by accommodations to which people with disability are entitled in Australia.

Long COVID has been formally recognised as a disability in other OECD countries. For example, the United States has classified Long COVID as a disability under the *Americans with Disabilities Act 1990*, *Rehabilitation Act 1973*, and *Affordable Care Act 2010* since 2021 (United States of America Department of Health and Human Services, 2021). Long COVID is also considered a disability in the United Kingdom under the *Equality Act 2010* following a case of unfair dismissal relating to Long COVID in 2022 (*Burke v Turning Point Scotland*, 2022, 4112457/2021)

Long COVID and disability status

As part of Australia's National Disability Insurance Scheme (NDIS), formal care from support workers is available for people with long-term and permanent illnesses such as rheumatoid arthritis, dementia, and multiple sclerosis (National Disability Insurance Agency, 2022). However, the absence of recognition of Long COVID as a disability, means that Australians with the condition are not eligible for subsidised disability support services. When services are not subsidised, people – particularly those already enduring financial strain – are more likely to forego necessary care and support and face worsened health consequences (Callander, 2023). Going without care and support services due to income loss has been reported among Australians with Long COVID (House of

Representatives Standing Committee on Health, Aged Care, and Sport, 2023), which threatens to further exacerbate poor health outcomes.

The lack of recognition of Long COVID as a disability also hinders people with the condition from formally entering flexible employment arrangements. Workers with disability are entitled to such arrangements (Fair Work Act 2009 (Cth) s 65 div 4, latest version 10th March 2023, C2023C00054), which are utilised by 20% of employed people with disability at least once per week (AIHW, 2022i). This flexibility supports continued workforce participation for people living with disability (AIHW, 2022i). As Long COVID is associated with functional impairments, poor perceptions of health, and disruptions to employment and income, establishment of disability status and accompanying flexible work entitlements for people with Long COVID is critical to support positive health and wellbeing outcomes.

Engagement in life activities, health equality, and income support are captured as priority areas within *Australia's Disability Strategy 2021-31* (Department of Social Services, 2021), which provides an ideal framework for identifying appropriate supports for Australians living with Long COVID.

Administrative processes

General practice is the first point of contact for people with chronic illness, including people with Long COVID (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023); yet, administrative burdens have created barriers to accessing primary care services (Song et al., 2019). Impaired

physical functioning – a feature of Long COVID – has been reported as a notable hindrance to attending in-person GP appointments (Song et al., 2019) and people with Long COVID typically plan days designated to care consults to ensure they are well enough to access services (Kohn et al., 2022). While telehealth consults have increased accessibility to primary care for people with Long COVID, this also facilitated healthcare provider's questioning of the legitimacy of patients' symptoms (Macpherson et al., 2022).

Burdensome administrative processes have also restricted access to disability support

In a submission to the Productivity Commissions Review of the National Disability Agreement 2019, people with myalgic encephalomyelitis/chronic fatigue syndrome (a chronic, multi-systemic illness with a similar illness presentation to Long COVID) reported ceasing attempts to access the NDIS due to the overwhelming and complex nature of the application process (Reilly and Buchanan, 2018).

Administrative requirements associated with support services, such as in-person assessments, prolonged assessment times, and the gathering and collation of extensive information (Barr et al., 2020), do not accommodate for the physical and cognitive impairments experienced by people with Long COVID, thereby further restricting access to necessary care and support. This is complicated by the scarcity of available services, extended wait times for specialists (and Long COVID clinics), and issues with care affordability (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

Healthcare providers

Stigmatisation by healthcare providers not only appears to be the most commonly reported form of discrimination towards people with Long COVID (Ireson et al., 2022;

services. Concerns have already been raised about the inappropriateness of eligibility criteria for disability services and their inability to reflect the challenges experienced by people with Long COVID (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

The pathway to accessing support services, like the NDIS, has been described as complicated, arduous, and burdensome for people already in need of support (Barr et al., 2020; Mellifont et al., 2022).

Macpherson et al., 2022; Russell et al., 2022; Samper-Pardo et al., 2023; Skilbeck et al., 2023), but is of particular concern, as this can lead to the provision of poor, inadequate care and adverse health outcomes. People with Long COVID have reported that discrimination, including the invalidation of patients' experiences and dismissal of symptoms, has jeopardised the safety of care and delayed care access, precipitating worsened health outcomes (Au et al., 2022; Hossain et al., 2023; House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Kingstone et al., 2020).

Stigmatisation and discrimination in healthcare settings is a two-fold problem, as Long COVID is also associated poor mental health and internal stigma due to the psychosocial impacts of acquiring a chronic illness (Pantelic et al., 2022; Russell et al., 2022; Samper-Pardo et al., 2023). Internal stigma about one's

condition can lead to feelings of shame, guilt, embarrassment and alienation, and exacerbate the burden of living with chronic illness (Earnshaw and Quinn, 2012). As a result, healthcare providers have a responsibility to validate the experiences of people with Long COVID (NICE, 2022; RACGP, 2021). To support the best outcomes for people with Long COVID, it is therefore essential that healthcare providers validate and affirm the experiences of people living with the condition.

The workplace

People with Long COVID, internationally and in Australia, have reported difficulty in continuing employment due to a lack of adjustments in the workplace to accommodate for their condition (Hossain et al., 2023; House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023; Schmachtenberg et al., 2023). The resulting decrease in income creates further financial strain and, in some cases, has prohibited access to necessary, non-subsidised care for Australians with Long COVID (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

Although some non-government organisations have provided guidelines for employers to support people with Long COVID (Altius Group, 2023; Rehab Management and Diversity Council Australia, 2022), the Australian

Government is yet to provide a framework for Australian workplaces that could support employees with the condition.

A lack of recognition of Long COVID in health policy is linked to discrimination in employment settings, particularly the failure to recognise the impact of the functional impairments associated with Long COVID on working capacity (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). People with Long COVID have the right to be protected from discrimination in employment settings (WHO, 2022); and mitigating the stigma and discrimination towards Long COVID must involve recognition of the disabling nature of the condition in policy and practice.

Equitable access and treatment in employment settings are recognised in both the preliminary *National Stigma and Discrimination Reduction Strategy* (Australian Government National Mental Health Commission, 2022) – which remains, as of 2023, in development – and the Australian Government *Australia's Disability Strategy 2021-31* (Department of Social Services, 2021). These strategies can provide guidance to Long COVID policy development, including the development of a consumer-designed approach to reducing stigma and discrimination, which must be a component of the Long COVID national strategic plan.

The right to health

All people have the right to the equitable opportunity to achieve the “highest attainable standard of health” (International Covenant on Economic, Social, and Cultural Rights, 16 December 1966 (entry into force 3 January 1976); WHO, 1946). Australia is responsible for upholding this right to health as a member state of the WHO and as a party to the International Covenant on Economic, Social, and Cultural Rights of 1966 (Australian Treaty Series 1976 No 5, (entered into force 10 March 1976), ATS 5).

The best possible patient health outcomes are achieved when the best possible care is provided (DoHAC, 2019), which can be broadly defined as care that is both cost-effective and meets consumers’ needs (ACSQHC, 2019).

To ensure that consumers’ needs are met in the provision of healthcare and support services, policy decisions that dictate care funding and access must be guided by the active engagement of consumers, as well as detailed patient experience data (ACSQHC, 2010; Australian Health Minister’s Advisory Council, 2017).

Collaboration between consumers, healthcare providers, and policymakers is underscored as the cornerstone to providing high-quality, safe, and value-based care in the *Clinical Governance Standard* and the *Partnering with Consumers Standard* within the NSQHS Standards developed by the ACSQHC and in the WHO’s *Global Strategy on People-Centred and Integrated Health Services* (ACSQHC 2021; WHO, 2015).

Patient-reported measures

The routine collection of data via patient-reported experience and outcome measures (PREMs and PROMs, respectively) among Australians with Long COVID is integral to the development of person-centred care pathways, guiding funding towards services and implementing appropriate health policies for Australians with Long COVID (Hitch et al., 2023).

Collecting care safety and quality data is an expected standard of health care services in Australia (ACSQHC, 2010; ACSQHC, 2012; AIHW, 2022f); yet, patient-reported experience and outcome data is scarce for Australian’s with chronic illness (AIHW, 2020), including Long COVID.

PREMs

The capacity to collect data via PREMs in Australia is limited not only among people with Long COVID but chronic illness in general. Some patient experience data is collected nationally by the ABS via the PEx (ABS, 2022d). However, this data is collected periodically rather than in real-time and does not capture specific chronic illnesses outside of Australia’s NHPAs or leading disease burden contributors, such as Long COVID. Data captured by the PEx also largely pertains to care access with few measures to evaluate care quality and safety (ABS, 2022d).

Primary care centres in Australia also collect some patient-reported experience data; however, much of this data is unpublished and therefore poorly utilised in informing

developments in care quality and safety (ACSQHC, 2023; Song, 2020). A number of PREMs are available to assess patient experiences and continuity in primary care among Australian chronic illness cohorts (ACSQHC, 2023; Bull et al., 2019; Sartore et al., 2022). For example, these include:

- Care Coordination Quality Measure for Primary Care (Agency for Healthcare Research and Quality, 2016);
- Consumer Assessment of Healthcare Providers and Systems Clinician and Group (Agency for Healthcare Research and Quality, 2013);
- Patient Assessment of Chronic Illness Care (Glasgow et al., 2005; Taggart et al., 2011); and,
- Patient Partnerships in Care (Powell et al., 2009).

However, as of 2023, none of these instruments have been validated in an Australian cohort of people with Long COVID (Angeles and Hensher, 2022). Existing PREMs have also been criticised for their lack of inclusivity and accessibility for people from vulnerable populations (Sartore et al., 2022).

Australia's capacity to collect patient-reported experience data must be expanded for people with Long COVID and chronic illness populations in general. Such data enables understanding of the needs of patients, permits care safety and quality to be evaluated and monitored, and therefore is essential to ensure the provision of high-quality, value-based care (Zurynski et al., 2021).

PROMs

In 2022, the International Consortium for Health Outcomes Measurement (ICHOM) established a set of PROMs to assess health outcomes among people with acute COVID-19 illness (ICHOM, 2022); however an outcome set specific for Long COVID is yet to be developed.

As of 2023, one Long COVID-specific PROM has been developed: the Modified COVID-19 Yorkshire Rehabilitation Scale (Sivan et al., 2022). However, this instrument has not yet been validated in an Australian cohort. Existing PROMs that, although not specific to the condition, are relevant for the manifestations of Long COVID are also poorly utilised and there is a lack of patient outcome data among people with Long COVID that has been collected using validated measures (Jason et al., 2023).

A standardised and validated approach to evaluating patient-reported outcomes among people with Long COVID should be pursued in Australia. This is essential to characterise the burden of Long COVID on health outcomes, which can be used by the Australian Governments and service providers to direct funding and services (Angeles and Hensher, 2022).

Qualitative data

Qualitative patient experience data among Australians with Long COVID is also lacking. The need for further collection of this data must be emphasised. Published evidence of the perspectives and lived experiences of people with Long COVID is available from other countries, including the United Kingdom (Ireson et al., 2022; Kingstone et al., 2020),

Spain (Samper-Pardo et al., 2023), and Germany (Schmachtenberg et al., 2023).

Perceptions of recovery among Australians with Long COVID are documented (Hitch et al., 2023); however, published qualitative data pertaining to healthcare service access and experiences with healthcare service providers among people with Long COVID in Australia is limited. Collection of qualitative patient experience data, in conjunction with adequate consumer representation and co-designed approaches to care, must be pursued to enable the Australian healthcare system to respond to Long COVID in proportion to the needs of people with the condition. However, the collection of such data is omitted from the *Post-Acute Sequelae of COVID-19 Research Plan* (DoHAC, 2023b).

Vulnerable populations

The role of social determinants in the development of Long COVID has not been definitely established (AIHW, 2022h; Lukkahatai et al., 2023); yet, the inequities faced by people from vulnerable populations likely worsen health disparities for those who develop Long COVID (Berger et al., 2021; De Leeuw et al., 2022). This has been acknowledged in the 2022 report on the Inquiry into Long COVID and Repeated COVID-19 Infections (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). As of 2023, the Australian Government has not implemented specific health policies to protect vulnerable populations from developing Long COVID, nor have they provided additional support for people from vulnerable populations who develop Long COVID. For example, no measures were implemented to ensure the

accessibility of vaccines for people with disability (Senate Select Committee on COVID-19, 2022).

Vulnerable populations have also been underrepresented in Australian Long COVID research (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). Recommendations to improve data collection among vulnerable populations have been proposed and must be prioritised to provide appropriate public health interventions and support (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). An intersectional, consumer-driven approach for engaging all Long COVID consumers, including those from vulnerable populations, is recommended to ensure these populations have the opportunity to achieve their highest possible health and quality of life (De Leeuw et al., 2022).

Consumers

The representation and involvement of people with Long COVID in the design and implementation of policies related to the care and support provided to people with the condition in Australia have been poor (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

Consumer advisory groups have been established within parliament to communicate the lived experiences and concerns of specific groups and act as a conduit between affected populations and policymakers; however, an advisory group for Long COVID is yet to be established (Allard et al., 2022). Such an advisory group has already been established in New Zealand (Te Whatu Ora Health New Zealand, 2023), which had a relatively similar

experience of COVID-19 when compared with Australia (Biddle and Korda, 2022). This lack of consumer engagement has resulted in misalignment between the care provided and the care needed for people with Long COVID in Australia.

Long COVID has impacts beyond those living with the condition (Pearson et al., 2022; Skilbeck et al., 2023; Sorrell et al., 2023) and an intersectional Long COVID advisory group that equitably represents all Long COVID consumers, including their families, support workers, and advocates, must be established to ensure that public health interventions are appropriate, value-based, and person-centred. This advisory group must be consulted regularly and consider vulnerable populations so that any measures that are implemented, including the design and provision of care services, are inclusive of these priority groups and reflective of their values and goals (Sorrell et al., 2023).

Establishing a consumer advisory group to inform the development of co-designed living clinical guidelines and care pathways for the management of Long COVID should also be pursued (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). Best practice approaches to facilitating consumer contribution to living guidelines are provided by the Australian Living Evidence Consortium, which has already overseen the development of co-designed living guidelines for the management of stroke, COVID-19, inflammatory arthritis, and diabetes in Australia (Australian Living Evidence Consortium, 2022).

Accessibility of care

Despite formal recognition that managing Long COVID requires holistic, multidisciplinary care (RACGP, 2021), Australians with Long COVID have reported that services are poorly integrated and there exists multiple barriers to access (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

Rising medical expenses and the cost of living have impacted the ability of Australians to access healthcare (Zurynski et al., 2021). In 2022 to 2023, almost half of the Australians visiting a GP paid out-of-pocket fees with only 51.7% reporting that services were always bulk-billed – the lowest percentage within the last decade (DoHAC, 2023a).

Similarly, in 2021 to 2022, waiting times to access specialist healthcare were deemed unacceptable by almost 30% of people with a long-term health condition – the highest proportion on record (ABS, 2022c).

Existing barriers to care in Australia, such as the decreasing number of bulk-billing GPs, an inefficient approach to repeat referrals, and systemic issues with service integration and care continuity (Prime et al., 2020; Swerissen et al., 2018), further limit accessibility of services for Australians with Long COVID.

As GPs and specialists have a prominent role in the management of chronic and complex health conditions, including Long COVID, decreasing accessibility of these services has a considerable impact on the health and quality of life of Australians living with chronic illness (Song et al., 2019; Zurynski et al., 2021).

Long COVID clinics

In Australia Long COVID clinics consisting of multidisciplinary care services, were first established in 2022. However, protracted waiting times hindered timely access to care for many Australians with Long COVID (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

Throughout the pandemic, no Long COVID clinics were established in Tasmania or the Northern Territory and those established in other jurisdictions were largely restricted to major cities (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). Poor accessibility of necessary healthcare services for people living outside of metropolitan areas has existed as an enabler to geographical health disparities in Australia prior to the pandemic (Swerissen, et al., 2018; Whitehead, et al., 2018).

The services comprised within Australia's active Long COVID clinics are also not standardised or consistent across clinics, with some (such as the Royal Adelaide Hospital's Long COVID Assessment Clinic (Government of South Australia, 2022)) consisting of multidisciplinary specialist and allied healthcare services and others (like the Wesley Hospital Long COVID Clinic (The Wesley Hospital, 2022)) providing only allied healthcare services. There have also been reports of poor care continuity within Long COVID clinics (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

The Commonwealth funding agreement for public hospitals, which supported government-run Long COVID clinics, was

discontinued on 31st December 2022 (Hewett, 2022), despite more Australians than ever being exposed to developing the condition in 2022 (Australian COVID-19 Serosurveillance Network, 2022a, 2022b). This has led to a number of Long COVID clinics, including the Royal Melbourne Hospital's ReCov and Austin Health's ReCOVary programs, being dissolved and further reduced the already limited services available for Australians with Long COVID.

Conclusion and recommendations

In Australia, Long COVID has affected more than one in 25 people (Australian COVID-19 Serosurveillance Network, 2023; Biddle and Korda, 2022) and has left more than 1.5 million Australians at risk of long-term chronic illness. In May 2023, the WHO removed the COVID-19 pandemic status as a Public Health Emergency of International Concern (WHO, 2023). However, existing understanding of multi-systemic post-viral illnesses suggests that Long COVID will likely be a perpetuating public health challenge (Blomberg et al., 2022; Davis et al., 2023; Owens, 2022), particularly as SARS-CoV-2 becomes endemic (House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023).

However, it must first be acknowledged that mitigating the spread of COVID-19 is critical to managing the future burden of Long COVID on both consumers and the healthcare system (Hensher et al., 2021; House of Representatives Standing Committee on Health, Aged Care, and Sport, 2023). Prevention, together with an improved understanding of the risk factors for Long COVID after SARS-CoV-2 infection, are integral to reducing the future prevalence of Long COVID in Australia (Al-Aly et al., 2022; Angeles and Hensher, 2022; Hensher et al., 2021).

Recommendation 1: Improve the identification of Long COVID

Care seeking guidance for people with ongoing COVID-19 symptoms and the risks associated with developing Long COVID must be clearly conveyed in public health messaging to

empower all Australians to make adequately informed health decisions.

This must be underpinned by improved identification and monitoring of Long COVID cases in Australia. Such advancements are necessary to enhance our understanding of the Long COVID's epidemiology, as well as the healthcare, disability, and social service needs of Australians with the condition.

The following recommendations are proposed:

- Standardise Long COVID terminology and definitions used in public health messaging across all jurisdictions.
- Codesign Long COVID public health guidance with consumers to ensure all Australians have equitable access to high-quality and accurate health information.
- Develop a national registry composed of people with Long COVID referred from primary care centres to track Long COVID's burden on the Australian healthcare system.
- Establish a national minimum data set for chronic illnesses and increase primary care data accessibility via the AIHW's National Primary Health Care Data Collection to capture all chronic illness diagnoses and healthcare interactions.
- Expand the collection and integration of electronic health data via My Health Record by increasing healthcare provider engagement, as well as data accessibility.

Recommendation 2: Recognise Long COVID as a disability

The challenges of living with Long COVID, including discrimination and stigma, must be recognised and appropriately addressed in Australian health policy and service administrative processes. Achieving this requires the formal recognition of the disabling nature of Long COVID.

The following recommendations are proposed:

- Develop, via consultation between the Department of Health and Aged Care and Long COVID consumers, a co-designed approach to reducing stigma and discrimination to be included within the national strategic plan for Long COVID.
- Acknowledge the disabling nature of Long COVID in Australian health policy to afford people with the condition access to subsidised disability support services and workplace accommodations that are necessary to achieve the highest possible health, quality of life, and workforce engagement.
- Co-design the administrative processes associated with and the delivery of disability support services with Long COVID consumers to ensure that necessary care is accessible, safe, and of high quality.

Recommendation 3: Increase stakeholder engagement with Long COVID consumers

To ensure that all policy and care pathway decisions are informed by the lived experiences of Long COVID consumers and that care and support services are person-

centred and value-based, Long COVID consumers must appropriately and inclusively be represented.

This must be underpinned by: 1) improved patient-reported experience and outcome data collection; 2) increased consumer engagement in the development of relevant health policies; and 3) co-produced care and support services.

The following recommendations for these three priority areas are proposed:

- Support research into the validation of PREMs and PROMs among Australians with Long COVID as a component of the Department of Health and Aged Care's national strategic plan for Long COVID.
- Investigate the lived experiences of Long COVID consumers via a nation-wide cohort study (facilitated by the development of a national Long COVID registry) and promote continued data collection as part of the Department of Health and Aged Care's national strategic plan for Long COVID following the ascertainment and validation of appropriate PREMs and PROMs.
- Develop and deliver person-centred models of care and referral pathways to multidisciplinary healthcare, disability support, and social support services that align with the needs of Long COVID consumers via collaboration between policymakers, consumers, and healthcare providers.
- Co-design inclusive research strategies and tailored care pathways for people from vulnerable populations via collaboration with consumers to further understand and subsequently mitigate

additional challenges faced by vulnerable populations, thereby avoiding further health inequities.

- Establish an intersectional, consumer-driven Long COVID advisory group that can be regularly consulted by policymakers within Department of Health and Aged Care.

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Appendix 1. Long COVID and COVID-19 recovery advice provided by Australia's health departments.

Health department	Long COVID terms used	Minimum illness duration	COVID-19 recovery and Long COVID onset	Long COVID recovery time	Resource
Federal	Long COVID comprising Ongoing Symptomatic COVID-19 and Post-COVID-19 Condition or Post-COVID-19 Syndrome.	Four weeks.	Acute COVID-19 illness recovery is typically a few weeks. Consult a GP if ongoing symptoms are of concern.	Three to four months for Post-COVID-19 Condition. No specific recovery timelines for Ongoing Symptomatic COVID-19.	Long COVID
Australian Capital Territory	Post-Acute Sequelae of COVID-19, Post COVID Conditions, or Long COVID.	Four weeks.	Acute COVID-19 illness recovery is typically a few weeks. Consult a GP if ongoing symptoms are of concern.	A few months for Post COVID Conditions. No specific recovery timelines for Ongoing Symptomatic COVID-19.	ACT Gov Long COVID Recovering from Long COVID

Health department	Long COVID terms used	Minimum illness duration	COVID-19 recovery and Long COVID onset	Long COVID recovery time	Resource
New South Wales	Long COVID.	Three months.	Acute COVID-19 illness recovery is typically a few days. Advice about Long COVID onset is otherwise limited.	Three to four months.	NSW Gov Long COVID Testing and managing COVID-19
Northern Territory	Long COVID or Post COVID Conditions.	Three months.	Acute COVID-19 illness recovery is typically one to two weeks. Consult a GP if symptoms are of concern or if have not improved after six weeks.	No advice provided.	NT Gov Long COVID Managing COVID-19
Queensland	Long COVID or Post-COVID Condition.	Three months.	Acute COVID-19 illness recovery is typically one to two weeks but can take up to several months. Advice about Long COVID onset is otherwise limited.	No advice provided.	QLD Gov after COVID-19 Recovery from COVID-19

Health department	Long COVID terms used	Minimum illness duration	COVID-19 recovery and Long COVID onset	Long COVID recovery time	Resource
South Australia	Ongoing Symptomatic COVID-19 and Long COVID or Post COVID-19 Syndrome.	Four weeks.	Consult a GP if experiencing ongoing symptoms four weeks after the initial positive COVID-19 test result or if believed to be experiencing Long COVID.	No advice provided.	SA Gov Long COVID
Tasmania	Long COVID or Post COVID-19 Condition.	Three months.	Acute COVID-19 illness recovery is typically a few weeks but can take up to several months. Consult a GP if experiencing ongoing symptoms 12 weeks after the initial positive COVID-19 test result to discuss access to the Post COVID-19 Syndrome Navigation Service.	No advice provided.	Tas Gov Long COVID; Recovery from COVID-19

Health department	Long COVID terms used	Minimum illness duration	COVID-19 recovery and Long COVID onset	Long COVID recovery time	Resource
Victoria	Long COVID.	No minimum illness duration. "Long COVID" is described as ongoing COVID-19 symptoms (without a minimum duration) or new symptoms that present weeks or months after the initial COVID-19 episode.	Acute COVID-19 illness recovery is typically from a few days to a few weeks. Consult a GP if experiencing Long COVID symptoms.	Typically within 12 months but can take up to 24 months.	VIC Gov Long COVID
Western Australia	Long COVID or Post COVID-19 Condition.	Three months.	Consult a GP if believed to be experiencing Long COVID.	One year.	WA Gov COVID-19

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