Long COVID Discussion Paper

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WA Primary Health Alliance
Better health, together

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An Australian Government Initiative

Key Messages

- Long COVID is a term used to describe ongoing symptomatic COVID-19 infections where symptoms have persisted for more than four weeks after the initial infection.
- Formal clinical management protocols for the long-term trajectory of post COVID-19 infections are still evolving as Australian based research is conducted on the impact in local populations.
- Current clinical management is focused on investigation and management of reported symptoms.
- The incidence of long COVID symptoms in Australia is likely to be between 5 - 20 per cent with a recent study indicating around 14 per cent of those who have had a COVID-19 infection, had symptoms lasting longer than four weeks.
- While anyone can become ill with long COVID symptoms, those most disadvantaged and/or vulnerable are likely to be most at risk.
- The risk of long COVID symptoms does not appear to decrease with repeated infections however evidence suggests that the recommended vaccination program provides some protection and should continue to be promoted.
- As a complication of long COVID, the number of people presenting with new chronic diseases may increase and those with existing chronic conditions, including mental health conditions, may find their conditions worsening.
- Deferred care will also provide challenges for primary care with delayed cancer and cardiovascular screening, and late presentations of those with newly developed chronic conditions symptoms.
- WA Primary Health Alliance has a role to play as an employer, in primary care support and development, as a commissioner, collaborator and advocate as well as providing up to date information as it comes to hand.

Purpose of the WA Primary Health Alliance Long COVID Discussion Paper

The purpose of this paper is to articulate the current and possible future role of WAPHA in supporting primary care providers in the ongoing management of the condition commonly known as long COVID, from a population health and primary care perspective. Long COVID is believed to develop after an acute infection caused by the virus SARS CoV-2[1] (referred to hereafter as COVID-19). The paper also considers the current understanding of the management of this chronic condition in the primary health care setting. This includes the impact on service provision, role of primary care and the implications for WAPHA as a Primary Health Network (PHN), noting core business functions such as chronic condition management and support for general practice as well as the impact of deferred chronic conditions care and promotion of cancer screening and childhood vaccinations.

It is acknowledged that there may also be implications for other PHN health priority programs such as mental health, Aboriginal health and the Aged Care Program not highlighted in this paper.

[1] The virus that causes a respiratory disease called coronavirus disease 19 (COVID-19). SARS-CoV-2 is a member of a large family of viruses called coronaviruses. These viruses can infect people and some animals. SARS-CoV-2 was first known to infect people in 2019.

What is long COVID?

The term long COVID was likely first coined by a consumer experiencing post-acute COVID-19 infection symptoms, through conversations on Twitter and other social media[2] on 20 May 2020 and through clinical and policy channels in September 2020. While there appears to still be no formally accepted name and definition, at this stage of the COVID-19 trajectory, the collection of symptoms reported has been described in medical literature using terms such as post-acute sequelae of COVID-19, post COVID-19 syndrome, post-acute COVID or long COVID. This paper will use the term long COVID.

The term long COVID is used by the Australian Government Department of Health and Aged Care to describe ongoing symptomatic COVID-19 where the symptom have persisted for more than four weeks after initial infection and post COVID-19 syndrome where symptoms of COVID-19 remain, or develop, long after the initial infection – usually after 12 weeks. Symptoms of what is described as long COVID can last for weeks or sometimes months, and include:

- Extreme fatigue (tiredness)
- Shortness of breath, heart palpitations, chest pain or tightness
- Problems with memory and concentration
- Changes to taste and smell
- Joint and muscle pain

Other reported symptoms include:

- Headache, insomnia, dizziness when standing, pins-and-needles feeling, loss of smell or taste,
- Mental health conditions including exacerbation of pre-existing conditions, depression, and anxiety,
- Joint or muscle pain,
- Cardiac conditions such as myocarditis and stress cardiomyopathy,
- Digestive symptoms, including diarrhoea and stomach pain,
- Blood clots and vascular issues, including pulmonary embolisms, and
- Rashes and changes in the menstrual cycle.

The range of symptoms provides challenges for clinicians in diagnosis of the patient's medical illness, particularly as many of the symptoms could also be caused by another pre-existing diagnosed or undiagnosed condition.

Who is most likely to develop long COVID?

While anyone can become ill with long COVID symptoms after their acute COVID-19 infection, the literature[3],[4],[5] indicates that the following people may be more at risk of developing long

[2] The Social Science and Medicine Journal 2021 states that it is a strong reminder of the importance of the patient narrative, particularly in the diagnosis, care and treatment of those with chronic conditions.

[3] https://www.nature.com/articles/s41591-022-01909-w#:~:text=Among%20the%20cohort%20of%20patients,a%20gradient%20of%20decreasing%20age.

[4] https://www.bmj.com/content/374/bmj.n1648

[5] https://pubmed.ncbi.nlm.nih.gov/35413949/

COVID symptoms. It is important to note that research is continuing and the certainty of evidence may still be low for most risk factors:

- Those with existing chronic illnesses,
- People with high blood pressure, obesity, asthma, and pre-existing mental health condition,
- Those smoking cigarettes or vaping,
- People who have been hospitalised, due to a COVID-19 infection[6] with those admitted to ICU or prolonged hospital stays with COVID-19 in the UK experiencing more severe outcomes (including secondary osteoporosis reported in a recent study),
- Health care workers,
- Older people are more at risk, rising from almost 10 per cent in 18–49-year-olds to almost 22 per cent in those 70 and older. Noting that long COVID can be experienced at any age, it was identified in a Kings College (2020) study that women 50-60 years were eight times more likely to experience lasting symptoms of long COVID than those aged 18–30. Long COVID was also more likely to affect women (14.8 per cent) compared to men (9.5 per cent), although gender was not significant in the older age group and
- Those who experienced more than five symptoms during the first week of illness.

It is known that disadvantaged communities[7] have suffered from the impact of the COVID-19 infection, associated with a higher incidence of risk factors and chronic illness, and it is likely that that they will be more significantly impacted by the effects of long COVID, given the medical and social risks experienced in their families and communities.

These risks include:

- Insecure employment and need to keep working if they do have employment,
- Higher housing density,
- Linguistic diversity, and
- Diminished access to timely, affordable appropriate medical care.

The use of telehealth during the COVID-19 pandemic has been a facilitator as well as barrier to access medical care depending on health literacy and availability of technology.

Research also indicates the risk of some complications such as cardiac or pulmonary complications may not lessen over time. This differs from some other infectious diseases where the risk of complications decreases with increased immunity from immunisation and repeat infections over time. There is also a concerning finding from a study of more than 5.6 million health records in USA that those with 2 or more confirmed infections had more than twice the risk of dying and three times the risk of being hospitalised within six months of their last infection as well as a higher risk for lung and heart problems fatigue, digestive and kidney disorders, diabetes and neurological problems.

[7] https://preventioncentre.org.au/news/chronic-disease-health-equity-and-covid-19/

Incidence of long COVID

The World Health Organization estimates that approximately **10 per cent to 20 per cent** of people experience a variety of mid and long-term effects after they recover from their initial COVID 19 illness. Other recent prevalence estimates suggest that between 3.7 and 20.0 per cent of individuals who experience a COVID-19 infection develop long COVID symptoms. The New South Wales Agency for Clinical Innovation (NSW ACI) advises that in the early trajectory of this disease, it is important to note that prevalence estimates may be linked to study rigour (with a meta-analysis finding that higher study quality was associated with lower prevalence)[8].

WA Positive Cases

Western Australia has recorded a total of 1.19 M positive COVID-19 cases (19 November 2022) with 720 deaths. This is likely to be an estimation only, with a report published by NewsGP suggesting that the COVID-19 positive rate could be at least double the official figures.

However, based on official figures, there could be between 34,353 – 229,023 (3-20 per cent range) people suffering with symptoms of long COVID in Western Australia alone (depending on prevalence rate used).

A total of 83.2 per cent of WA residents aged 16 years or above have completed the recommended three dose vaccination program. The uptake of a winter booster (4th) dose for those 30 years of age and over, as recommended by the Australian Technical Group on Immunisation (ATAGI), has been slow with coverage reported on 17 November 2022 as 30.7 per cent of the eligible population. Sixty per cent of all vaccines administered in WA have been given in the primary care setting.

Vaccination Protection

Opinion varies as to whether the vaccinations protect against the development of long COVID. However The Lancet January 2022, suggests that those in the UK who are vaccinated (two doses) are less likely to report long COVID. The King's College London also found that the odds of developing symptoms that last longer than four weeks reduced by 50% post vaccination. This reinforces the need to encourage people to complete the recommended course in Australia.

What has WAPHA done?

For the past two years, WAPHA has provided a comprehensive PHN response to managing the COVID-19 pandemic. At first with the vaccination program, dissemination of information and clinical advice during the acute response phase and now through provision of equipment and delivering services as part of the Living with COVID Program. It is now facing the recovery and transition phase noting that new SARS-CoV-2 variants and infections are likely to occur, and subsequent updated vaccines recommended for the foreseeable future. Review of WAPHA's response by the Living with COVID Program team provides useful insights for WAPHA's consideration in the ongoing public health challenges of the COVID 19 pandemic.

[8] https://aci.health.nsw.gov.au/__data/assets/pdf_file/0004/695983/Evidence-Check-Post-acute-sequelae-of-COVID-19.pdf

Clinical Management

Clinical management of long COVID will change as more is understood about the aetiology, epidemiology and evaluation of treatment and current research. There are a range of studies occurring with various levels of rigour. It is likely that recommended diagnosis and treatment will alter as higher quality studies report their findings[9].

When patients are presenting with range of symptoms that may or may not represent long COVID, general advice for clinicians based on the anecdotal evidence, reviewed for this paper, centres around the following recommendations:

- To listen to patients - there is a significant variance in the number of symptoms reported by those presenting, within excess of 100 reported symptoms. Expertise is coming from patient experiences,
- It is important to highlight that evidence is constantly evolving and medical management will change as research relevant to the Australian cohort is published,
- Investigate symptoms and provide the care patients need, acknowledging the individuality of each patient and consideration of intersectional[10] factors such as gender, health, economic status, and other social determinants of health,
- This is a perfect opportunity to provide patient centred care provided by a multi-disciplinary team – both clinical and social support are required,
- Lifestyle factors such as rest, nutrition and pacing physical activity together with more structured rehabilitation (in some cases) and mental health support are important to manage symptoms such as fatigue, emotional stress, and
- Data collection at the practice level is critical to gaining a better understanding of the disease.

WAPHA's HealthPathways GP Clinical Editors are regularly reviewing clinical evidence and considering the need for a long COVID pathway on an ongoing basis.

In the interim, HealthPathways WA has added a section to the COVID-19 Assessment and Management pathway called 'After Acute Illness' which provides clinicians with advice around the monitoring and management of ongoing symptoms; timing of elective surgery and COVID-19 vaccination recommendations. The section links to other resources from the COVID-19 Evidence Taskforce, ACI living evidence on the post-acute sequelae of COVID-19 and RACGP guidelines for adult patients with post-COVID-19 conditions. Searching long COVID on the HealthPathways WA site will direct clinicians to the forementioned pathway with all information in one place.

In Western Australia, the default service for the care of people reporting long COVID symptoms is general practice with subsequent referral to the relevant specialty for the symptom of main concern if required. This may, at times, involve more than one referral. Partnerships between the WAPHA, RACGP and other key agencies to support and training for general practice, allied

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9 https://aci.health.nsw.gov.au/__data/assets/pdf_file/0004/695983/Evidence-Check-Post-acute-sequelae-of-COVID-19.pdf

10 Intersectionality' refers to the ways in which different aspects of a person's identity can expose them to overlapping forms of discrimination and marginalisation. Aspects of a person's identity can include social characteristics such as: gender, sex, ethnicity, residency etc. https://www.vic.gov.au/understanding-intersectionality

health (including mental health) and specialists services to develop and deliver an integrated, person-centred care approach may assist to reduce the cost, travel and psychological stress related to patients seeking ongoing health care from multiple providers.

There is also now a trial public health clinic available at Bentley Health Service for those with long COVID symptoms. The clinic, led by a physiotherapist, is open to residents of the East Metropolitan Health Service over the age of 16 years. A GP referral is required to access the service which is a pilot for six months. It is likely that further clinics across the State will be required specifically for those community members experiencing long COVID symptoms.

Impact of COVID-19 infections complications and long COVID on chronic disease management

Prior to the COVID-19 pandemic, Australia had a high incidence of chronic diseases and the associated risk factors such as obesity, hypertension and lack of physical activity. It was also known that those most disadvantaged experience higher rates of chronic diseases than the general population[11].

The evidence is emerging that those with chronic diseases have more severe outcomes post COVID-19, however there is also evidence that those with no pre-existing risk factors or chronic illness can also develop chronic illnesses such as a post viral fatigue syndrome, diseases of the heart, lungs, nervous and endocrine system, and mental health conditions such as anxiety, depression, and post-traumatic stress disorders[12],[13] across cohorts who were hospitalised or non-hospitalised. It is likely that this will result in in "permanent functional impairment"[14]. All these patients will require long term management through their GP.

Research is now also emerging that older patients (over 60 years of age) surviving COVID-19 infections appear to have higher levels of cognitive decline[15],[16]. These findings will require further analysis of the future dementia burden in the Australian population.

The estimation of burden of disease due to the COVID-19 pandemic in Australia, is constantly changing, making it challenging to respond proportionate to the current population health risk. The University of New South Wales study followed 94 per cent if all COVID-19 cases diagnosed in NSW January – May 2020 and assessed that 5 per cent of the cohort experienced symptoms 3 months later. The Deeble Institute modelling suggested in April 2021, that in WA that the long COVID cases per GP FTE may be between 0.03-0.06[17]. However, based on the number of COVID positive cases in WA since March 2020, this rate is likely to be considerably higher.

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[11] https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/chronic-disease/overview

[12] Deeble Issues Brief No. 40: Managing the long-term health consequences of COVID-19 in Australia | Australian Healthcare & Hospitals Association (ahha.asn.au)

[13] https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/covid-long-haulers-long-term-effects-of-covid19

[14] https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-022-13169-x#ref-CR10

[15] https://jamanetwork.com/journals/jamaneurology/fullarticle/2789919

[16] https://aaic.alz.org/releases_2021/covid-19-cognitive-impact.asp

[17] Deeble Issues Brief No. 40: Managing the long-term health consequences of COVID-19 in Australia | Australian Healthcare & Hospitals Association (ahha.asn.au)

Deferred Care due to the COVID-19 Pandemic

We also know that many community members during the peak of the COVID-19 pandemic delayed cancer screening and visits to GPs and other primary care services such as Aboriginal Community Controlled Health Services (ACCHS) for the regular check-ups and care. This may have been due to factors such as lockdowns, perception of risk, financial distress, the post COVID-19 infection recovery period, and reluctance to use modalities such as telehealth, resulting in possible delayed diagnoses of cancer and chronic conditions[18],[19],[20],[21].

The main challenges now confronting general practice will be[22]:

- Delayed cancer screening – breast, bowel and cervical,
- Delayed other screening and preventative care such as assessing and managing cardiovascular risk,
- Late presentations of chronic conditions such as diabetes and cardiovascular conditions,
- Exacerbation of mental health conditions, and cognitive decline, and
- Sexual health issues including late presentation of sexually transmitted diseases requiring more ongoing complex care.

It is also likely that, due to the deferment of elective surgery, reduced capacity as a result of service closures and a reduction in resources during the COVID-19 pandemic, existing health conditions requiring surgical treatment may have been further exacerbated, with patients needing more complex symptom management in the general practice setting.

What can WAPHA do?

WAPHA is funded by the Australian Government[23] with a mandate to:

- Commission health services to meet the needs of people in their regions and address gaps in primary health care,
- Work closely with general practitioners and other health professionals to build the capacity of the health workforce to deliver high-quality care, and
- Integrate health services at the local level to create a better experience for people, encourage better use of health resources, and eliminate service duplication[24].

There are key functions relevant to WAPHA's mandate, in the pandemic response that can support the internal organisation and primary health care practice management of long COVID.

[18] https://www.cancercouncil.com.au/news/covid-19-and-the-impact-on-cancer-outcomes-in-australia/

[19] https://www.mja.com.au/journal/2022/216/9/impact-covid-19-chronic-disease-management-primary-care-lessons-australia

[20] https://www.abs.gov.au/statistics/health/health-services/patient-experiences-australia-summary-findings/latest-release

[21] https://www.canceraustralia.gov.au/about-us/news/first-data-impact-pandemic-14-cancer-types-2020

[22] https://nwmphn.org.au/news/the-deferred-care-pandemic-finding-the-joy-in-business-as-unusual/

[23] https://www.health.gov.au/initiatives-and-programs/phn/what-phns-are

[24] https://www.health.gov.au/initiatives-and-programs/phn/what-phns-do

The review of lessons learnt from the COVID-19 Pandemic authored by Central and Eastern Sydney PHN also provide some useful insights into what may be expected of PHNs in the future management of pandemics and applied to the long COVID syndrome[25].

As an employer

- Continue to support all WAPHA staff to keep their vaccinations up to date based on their eligibility,
- Encourage known effective public health measures, such as staying at home when sick, good hand hygiene, mask wearing, physical distancing and choosing carefully whether to attend crowded events. The consequence of not doing this may lead to increasing number of COVID cases and the burden of disease resulting from long COVID[26], and
- Continue to acknowledge and support the mental health burden of managing the COVID-19 pandemic on WAPHA staff members and the need to develop innovative well-being programs and recruitment and retention strategies to deal with reduced clinical services, burn out and high staff turnover.

In support of primary care development

- Continue to support the COVID-19 vaccination program through general practice and public health campaigns.
- Continue to provide up to date information and training opportunities as well as identified future needs on long COVID including a possible option for a Community of Practice to share learnings.
- HealthPathways WA development of a long COVID pathway for primary care as appropriate and in partnership with other lead health agencies.
- Facilitate the use of data/information systems in general practice to identify people with long COVID to assist with scheduling review appointments.
- Promotion of use of MBS Items such as GP Chronic Disease Management Plan, Team Care Arrangement, Long Consultation, Health Assessments, Diabetes Cycle of Care, Allied Health item numbers, My Health Record and collection of data related to long COVID through practice management software,
- Seek funds and implement general practice Quality Improvement Projects focused on deferred care for chronic disease management, vaccinations, cancer screening and cardiovascular risk,
- Encourage and support multidisciplinary team care and the extended role of allied health staff at the top of their scope where appropriate e.g., occupational therapists, social workers, non-prescribing pharmacists, practice nurses to support the likely increased demand on GP services to provide care for those reporting long COVID symptoms and chronic disease management, and
- Promote and support the use of technology to facilitate coordinated chronic conditions care such as e-referrals, e-prescribing, telehealth, and remote monitoring.

[25] https://www.cesphn.org.au/preview/communications-1/3508-covid-19-challenges-and-opportunities-for-primary-care/file

[26] https://theconversation.com/reinfection-will-be-part-of-the-pandemic-for-months-to-come-each-repeat-illness-raises-the-risk-of-long-covid-186733

As a commissioner

- Continue to support the delivery of primary health care based on the Quintuple Aim of healthcare with a focus on equity of access and sustainability particularly in the WA Country PHN,
- Acknowledge and plan for increased incidence of chronic conditions such as diabetes and cardiovascular disease as complications of the COVID-19 acute infection as well as frailty and social isolation leading to poor health outcomes, particularly for those hospitalised due to contracting COVID-19[27],
- Acknowledge and plan for the increased numbers of patients already with chronic conditions presenting with additional risk factors due to a delay in access to services during the COVID-19 pandemic including later stage cancer diagnoses,
- Consider appropriate models of care for those suffering from long COVID (including acknowledgement as a chronic condition[28]consistent with the national definition) and other chronic conditions in the primary health care setting including:
    - Integrated person centred, health care,
    - Health navigation,
    - Increased multidisciplinary care planning,
    - Increased access to specialists and co-location of GP and specialist services,
    - Building capacity to allow GPs to manage higher risk patients in their practices where appropriate and
    - Innovation including the use of remote monitoring, online coaching, AI apps and self-reporting[29]. Technology successfully used during the COVID-19 pandemic should now be seriously considered as business as usual.
- Acknowledge and support the mental health burden of managing the COVID-19 pandemic on service providers and the need to develop innovative well-being programs and recruitment and retention strategies and secure funding to deal with reduced clinical services, burnout, and high staff turnover. Many frontline health care staff may also be suffering from long COVID symptoms[30]. Providing chronic disease care in rural and remote regions will required well-resourced and supported multidisciplinary teams [31] .
- Consider further longer-term commissioning, co-commissioning, and co-funding services. There will be an increased need for chronic disease management, mental health, Aboriginal health, and aged care services to support increased demand by those with acute and long COVID and post COVID-19 complications resulting in permanent disability, particularly where there is limited access to specialist services e.g., telehealth accessible in remote locations,
- Support primary health care services such as Aboriginal Community Controlled Health Services to develop appropriate models of care for their community members that are also applicable to mainstream services caring for Aboriginal and Torres Islander community members, and

[27] https://ccforum.biomedcentral.com/articles/10.1186/s13054-021-03794-0

[28] https://www.health.gov.au/resources/publications/national-strategic-framework-for-chronic-conditions

[29] https://www.publish.csiro.au/PY/pdf/PY20095

[30] https://pubmed.ncbi.nlm.nih.gov/33830208/

[31] https://www.mja.com.au/journal/2022/216/9/impact-covid-19-chronic-disease-management-primary-care-lessons-australia

- Provide up to date information on long COVID to WAPHA service providers through webinars, newsletters, and other media channels as it becomes available.

As a partner and collaborator

As a key peak body in the primary health care sector, WAPHA has a role to play in participating in cross sector and health advisory taskforces focussing on health system planning, including development of chronic conditions models and increased resources to meet the needs of local communities and priority groups.

WAPHA can also share learnings with other PHNs such as the North-Western Melbourne PHN, Central and Eastern Sydney PHN, RACGP and others who have progressed the development of HealthPathways and other resources to support the primary care of patients with long COVID.

Investment, research, regional planning, and coordination should be ongoing for the next pandemic and the likely challenges and higher demand on services including:

- Funding models no longer fit for purpose with less GP practices willing to bulk bill for their services[32],[33],
- Non viability of single or small general practices due to high costs and staffing shortages, and
- Chronic disease management, alcohol and other drugs programs and walk in and online mental health services, rehabilitation and social support services and programs into the future.

As an information provider

Support primary health care providers with up to date and accurate information on long COVID through webinars and other educational forums, social media channels, and supporting increased community health literacy with easy-to-understand patient information readily available in multiple languages. This includes accessing already available resources suitable for distribution to primary health care providers.

Support and promote public health campaigns to encourage the community to access vaccinations, seek care, cancer, and chronic conditions screening, targeting those most at risk.

As an advocate

Provide information as it becomes available to WAPHA Board and Executive members to ensure their understanding of emerging trends and implications for WAPHA is current and can assist in advocating for an increased system wide response to providing care of those with long COVID.

This advocacy may also include acknowledging the need for and support increased funding through MBS items for team-based care (limited number of allied health consults and payment for chronic disease management plans especially for those patients with long COVID chronic illness), improving access to primary health care in rural areas, appropriate care for people at

[32] https://www.healthed.com.au/clinical_articles/something-needs-to-give/

[33] https://www1.racgp.org.au/newsgp/professional/drop-in-national-bulk-billing-rate-signals-increas

risk of poorer health outcomes, support for self-management and funding reform through avenues such as the Primary Health Care 10 year Plan and the Strengthening Medicare Taskforce.

There is also an urgent need for consistent, systematic collection of better primary health care data and analysis to understand the aetiology, prognosis, duration, treatment, and population-based implications of long COVID in future years including impact on the most disadvantaged, relationship with the social determinants of health and identifying the required service provision to regional, rural, and remote communities.

Disclaimer:

The information presented in this paper may change at any time, due to further research and understanding of the impact of long COVID in the Australian setting. Much of the current research/evidence originates from large studies overseas where the trajectory of the COVID-19 virus differed greatly with the Australian response, given early Australian border closures, social isolation and other rigorous public health measures and the significant vaccination program prior major outbreaks.