RACGP submission: House Standing Committee on Health, Aged Care and Sport inquiry into Long-COVID and repeated COVID infections

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Contents

1. Introduction 3

2. About the RACGP 3

3. Summary 3

4. RACGP response to inquiry 4

4.1. The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment; 4

4.2. The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections; 5

4.3. Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia; 6

4.4. The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background; 8

4.5. The impact of long COVID and/or repeated COVID infections on Australia's overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population; and 8

4.6. Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally. 8

5. Other comments 10

6. Conclusion 11

1.Introduction

The Royal Australian College of General Practitioners (RACGP) is pleased to provide a response to the House Standing Committee on Health, Aged Care and Sport inquiry into long COVID and repeated COVID infections.

General practitioners (GPs) have played a critical role in Australia's COVID 19 response, providing care for COVID positive patients, administering over 50% of the nation's COVID-19 vaccines and now responding to the longer-term effects of the pandemic including long COVID, repeated COVID-19 infections, follow up care missed during lockdowns and increased mental health presentations.

Due to the unprecedented nature of the pandemic, evidence regarding the incidence and spectrum of post–COVID-19 illness and management is evolving and will continue to develop in years to come. However, it is vital that appropriate investments are made and lessons from this pandemic help inform our management of ongoing health and societal impacts, as well as the country's response to future infectious disease outbreaks.

The inquiry into long COVID and repeated COVID infections will help highlight the need for significant support for all facets of the primary and tertiary healthcare systems, and investment in research in this area.

2.About the RACGP

The RACGP is the voice of GPs in our growing cities and throughout rural and remote Australia. For more than 60 years, we have supported the backbone of Australia's health system by setting the standards for education and practice and advocating for better health and wellbeing for all Australians.

As a national peak body representing over 46,000 members working in or towards a career in general practice, our core commitment is to support GPs from across the entirety of general practice, address the primary healthcare needs of the Australian population.

We cultivate a stronger profession by helping the GPs of today and tomorrow continue their professional development throughout their careers, from medical students and GPs in training to experienced GPs. We develop resources and guidelines to support GPs in providing their patients with world-class healthcare and help with the unique issues that affect their practices. We are a point of connection for GPs serving communities in every corner of the country.

Australia's GPs see more than two million patients each week, and support Australians through every stage of life. The scope of general practice is unmatched among medical professionals.

Patient-centred care is at the heart of every Australian general practice, and at the heart of everything we do.

3.Summary

Long COVID and repeat COVID-19 infections are having, and will continue to have, a significant impact on Australians and the Australian healthcare system. GPs are experiencing increased workloads as well as increased practice and personal expenses, which is impacting on practice viability and personal wellbeing.

The RACGP recommends:

- GPs are acknowledged as being best placed to provide coordinated care for patients with long COVID
- current inadequacies in the Medicare Benefits Schedule (MBS) to support patients with long COVID must be addressed

- an agreed definition of long COVID be established as an essential component of a plan to support appropriate assessment, diagnosis and management
- that inequities be addressed to ensure all patients, irrespective of location or social factors, have access to best-practice medical care and support
- long COVID data is captured in primary care to understand the breadth and impact of this chronic condition in Australia and standards are implemented to create consistent clinical coding to support consistent data capture in electronic medical records
- funding is directed to general practice research into long COVID, with GPs leading this research and the interpretation of primary care data.

4.RACGP response to inquiry

4.1. The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;

"I work in an area of disadvantage with a cohort of patients with multiple co-morbidities. My suspicion is that long COVID symptoms and signs in my population are likely under-reported, under-detected and under-managed" – General Practitioner, Metropolitan New South Wales

Patient experiences of long COVID vary but commonalities are present.

Common descriptors of long COVID symptoms include fatigue, generalised weakness, brain fog, and reduced concentration and attention span, as well as recurrent respiratory symptoms such as shortness of breath. Beyond these, there are a myriad of other concerning symptoms reported by patients. Many symptoms are consistent with other post-viral syndromes and are all pervasive.

There is a level of uncertainty as to whether many post-COVID symptoms are an exacerbation of known or unknown pre-existing illness from an initial COVID-19 infection or whether long COVID is considered a standalone diagnosis.

The social and emotional impacts are significant with some sufferers unable to engage in usual activity, family interactions, employment, sport and exercise. As well as the physical and emotional toll of long COVID on sufferers, many patients are significantly financially impacted due to an inability to work or provide care as a result of illness and out-of-pocket fees to access services.

Key barriers identified for people with long COVID accessing assessment, diagnosis and treatment are poor patient awareness of long COVID presentation, lack of access to medical and allied health appointments and out-of-pocket fees. Confusion and frustration are often terms used by both patients and clinicians regarding navigation of long COVID assessment, diagnosis and treatment.

"I believe that there is great difficulty in diagnosing long COVID resulting in diagnostic delay and subsequent management. I believe this to be a major factor impacting the patient experience" – General Practitioner, metropolitan New South Wales

Furthermore, there is concern amongst our members that an acceptance of long COVID in the community, in the absence of a formal diagnosis, will result in a reluctance to address symptoms to determine their cause, resulting in

missed opportunities for early assessment and diagnosis of other illnesses. Delays in accessing appropriate care will come at a significant cost to the community.

“Patients in general seem to feel they have to 'get on with it', and there is an assumption that nothing can be done. Many patients push on, don't seek help and do not rest which seems to exacerbate the problem” – General Practitioner, rural New South Wales

There is currently no clear trajectory for disease profile and outcomes of long COVID. Management of common non-specific multisystem post-viral symptoms will usually be pragmatic and symptomatic with patients being supported to maximise their personal wellbeing through diet, exercise and sleep. In a time where many people expect modern medicine to provide a ‘quick-fix’ the slow recovery from COVID-19 for some people can be a cause of great uncertainty and result in heightened anxiety.

“[My patients with long COVID feel] insecure, anxious and isolated… they are not sure about where to obtain information and resources about treatment” – General Practitioner, metropolitan Western Australia

The RACGP recommends:

- all patients, irrespective of location or social factors, have access to best-practice medical care and support
- best practice models of care are established, as per priorities outlined in section 4.6, through a mix of access through appropriately funded and resourced general practices and dedicated long COVID clinics, with extended access to MBS-funded allied health sessions.

4.2. The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections;

Agreed definition and guidelines for long COVID

While the World Health Organization (WHO) has developed a clinical case definition of *post COVID-19 condition*, there remains a lack of a formal agreed definition of long COVID, which has created uncertainty for patients and clinicians. An agreed definition for the purposes of clinical coding in general practice is necessary to support management and facilitate research.

Despite operating in an environment where the available evidence is minimal, the disease burden unclear and management pathways are still evolving, GPs are well positioned to support patients with long COVID, and to work collaboratively with other medical specialists and allied health professionals as required. GPs are adept in supporting patients with experiences of post-viral illness. However, the lack of an agreed definition and specific guidelines for the diagnosis and management of long COVID are barriers to timely and appropriate care.

Evidence based guidance is needed to differentiate management of ongoing COVID-19 symptoms before and after meeting the time threshold for ‘long COVID’ (generally accepted as ongoing symptoms three months from the onset of initial infection).

The RACGP recommends:

- an agreed definition of long COVID is as an essential component to support appropriate assessment, diagnosis, and management
- up-to-date evidence-based guidelines are developed and maintained (for example by continuing to fund the National Evidence Clinical Taskforce).

Accessibility to services

Existing specialist long COVID clinics are not widely available, particularly for patients in rural and remote areas, and have every limited capacity. GPs are also reporting long wait times for review and input by other medical specialists and allied health professionals, acknowledging the entire healthcare system is playing catch up due to deferred treatments, reduced health screening and postponed elective surgery due to the pandemic.

Personal and professional impacts

The impacts of long COVID are not only felt by the patient but by the healthcare team supporting them. The time burden in supporting patients with long COVID is impacting GP workload, their ability to take on new patients, and the financial viability of practices. .

As with navigating and responding to rapid changes in the early days of the COVID-19 pandemic, time-poor GPs with competing demands are now navigating emerging evidence, assessment and treatment options and inconsistent referral pathways, which comes at an intellectual and emotional cost.

> *"The pressure of trying to be a specialist in a new area without funding (time needed to sort out what we can do for patients) has led me for the first time in my career of 30 years to plan my resignation and find other work. This is serious!!!" – General Practitioner, Northern Territory*

It must also be acknowledged that GPs and their teams are not immune from the health concerns they treat and make up a portion of the population affected by long COVID, as sufferers themselves.

4.3. Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia;

As an evidence-based profession, research is critical to our understanding and management of long COVID.

> *"No data = no idea" – General Practitioner, rural Queensland*

The RACGP has been a member of the National COVID-19 Clinical Evidence Taskforce since its inception and recognises the importance of their support for Australia's healthcare professionals through the provision of continually updated, evidence-based clinical guidelines. The prioritisation and synthesis of emerging international research on this topic, and grading of this research to provide guidelines, is a crucial undertaking to enable healthcare providers to best manage initial COVID illness and long COVID.

Due to the unprecedented nature of the pandemic, evidence regarding the incidence and spectrum of post–COVID-19 illness and its management is evolving and will continue to develop in years to come. Key to developing this understanding is research into long COVID and repeat COVID infections, with an increased focus on the Australian context.

Australia is fortunate to have a highly vaccinated population and through its initial 'test and trace' strategy maintained low cases numbers throughout 2020 and 2021 before widespread vaccination was possible. This has resulted in reduced applicability of some research data from countries such as the United States and the United Kingdom, which experienced severe outbreaks in unvaccinated communities.

A key theme from member feedback is the need to better define long COVID to enable accurate data collection and interpretation and guide the development of best-practice guidelines; not simply lay out the gravity of the problem.

Other key themes identified by GP members when considering research in this area include:

- broad data collection across the healthcare spectrum, including general practice, not just data specific to hospital settings and long COVID clinics
- the importance of GP inclusion in interpreting primary care data
- understanding the correlation between vaccination (initial and booster) and long COVID prevalence and severity
- understanding the correlation between repeated COVID infections and long COVID prevalence and severity
- the correlation between different variants and long COVID
- the impact of antiviral treatments on long COVID
- data-linkages of diagnostic tests confirming COVID-19 infection with large collections of data from sources such as electronic health records
- effective management regimes for long COVID.

Funding must be prioritised to embed outcomes from research findings into best-practice care, so benefits are realised for both patients and clinicians.

Accurate data on the prevalence and severity of long COVID is vital to informing public policy and reducing public complacency as to the impacts of COVID infection, even following vaccination.

Australia needs a data driven plan to manage COVID-19 and long COVID, now and into the future. Data allows us to set targets and measure outcomes.

There is widespread acknowledgement many cases of COVID-19 in the community will not be captured in data sets due to a lack of initial testing or not self-reporting a positive test result. Poor awareness and understanding of long COVID may mean many patients will not present for such and therefore not be captured in data, even if a mechanism to do so is in place.

General practice research

The RACGP supports the re-introduction of funding for high-quality longitudinal studies in general practice. One of the key challenges facing general practice is the lack of evidence generated through these long-term studies, such as the now discontinued Bettering the Evaluation and Care of Health (BEACH) and Medicine in Australia: Balancing Employment and Life (MABEL) studies.

There needs to be a renewed focus on supporting and funding research in general practice. General practice research must be a priority because it is the cornerstone of the health system that provides care to the majority of the population.

Currently, less than 1% of National Health and Medical Research Council (NHMRC) competitive funding is awarded to primary health care projects, and less than 1% of funding in the Medical Research Future Fund (MRFF) 10-year plan is specifically allocated to primary care.

Significant MRFF funding for COVID research was directed towards vaccine and antiviral development in 2020 and 2021. Now that the focus of the pandemic has shifted, research funding into long COVID should be directed to general practice where much of the patient care is being undertaken.

The COVID-19 pandemic has highlighted the lack of a practice-based research network (PBRN) framework as a significant gap in Australian primary care research capacity. In the United Kingdom, researchers rapidly established through PBRNs a large trial in primary care looking at treatment for mild to moderate coronavirus. It is unlikely that Australia could rapidly implement a large-scale national trial in this way, without a framework, infrastructure, and linkages between individual PBRNs. We need to be able to rapidly generate evidence from primary care where the majority of health care is undertaken, and this would facilitate larger studies relevant to long COVID.

The RACGP recommends:

- funding is directed to general practice research into long COVID, and GPs must lead this research and the interpretation of primary care data.

4.4. The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background;

"I think the long-term health & socioeconomic impacts will be huge. I have seen the benefit of early GP support & multidisciplinary input, reassurance by specialists & lack of financial pressure correlating with better outcomes - we need investment now to help our community for the future" – General Practitioner, metropolitan Victoria

The impacts of long COVID are far reaching and cannot be underestimated. However, without data on its prevalence and severity we cannot know the true cost of the illness on individuals and their communities.

GPs have reported greater prevalence of long COVID in patients with existing chronic illness/comorbidities, the elderly and in people living with disability. A greater prevalence in females was noticed. It is also widely acknowledged people from culturally and linguistically diverse backgrounds and those in lower socioeconomic communities face additional challenges navigating the healthcare system and accessing timely care and support.

These observations align with emerging evidence. As indicated in 4.3, improved data collection and research will confirm this and assist in guiding targeted management for specific patient cohorts.

4.5. The impact of long COVID and/or repeated COVID infections on Australia's overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population; and

In the 2022 RACGP *General Practice: Health of the Nation* report, GPs reported COVID-19 (particularly the impact of long COVID) as one of the top emerging health issues of concern for GPs, alongside mental health, chronic illness and obesity and lifestyle.

In another recent survey of GP members, 91% of respondents felt the financial viability of private healthcare providers such as general practice will be somewhat or significantly impacted by long COVID.

Healthcare resources are finite and competing priorities have always been an aspect of care provision. When an emerging issue such as long COVID arises, resources need to be redirected, impacting other aspects of care provision through reduced appointment capacity, longer consultation times and delays in accessing referred services.

4.6. Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

GPs play a critical role in a patient's journey through the healthcare system, often acting as the central point of contact, coordination, education, and trust. General practice cannot work in isolation to provide effective long COVID management, particularly for more complex cases of long COVID and, other medical specialists and allied health professionals must be engaged in a coordinated manner.

GPs are experts in providing patient-centered, continuous, and coordinated care. GPs know their patients, their medical history, backgrounds, social and mental health circumstances. They provide high-quality care for patients with long COVID. However, there is a general practice crisis in Australia and governments must commit to correcting the underfunded system to better support patients to access GP services.

The MBS, which provides patient rebates to access healthcare and is a funding source for general practice, has not kept pace with economic changes and the financial realities of providing primary healthcare. Patient rebates were never set at an appropriate level, and GPs are still contending with lost funding from the Medicare rebate freeze which lasted six years (four for standard GP consults).The current system continues to undervalue the skill and expertise of GPs and encourages rapid throughput rather than longer, high quality patient consultations, which is a crucial component of caring for patients with long COVID.

In a recent survey of GP members, priorities for establishing best practice models of care for long COVID included:

- improved funding for current MBS item numbers, particularly for longer consultations, including longer telehealth consultations
- increasing the number of MBS-funded allied health sessions for patients with chronic disease (currently capped at five sessions per calendar year)
- dedicated funding to establish long COVID clinics with a focus on equity of access for people in rural and remote communities.

GPs report confusion over the use of GP Chronic Disease Management items – GP Management Plan (MBS item 721) and Team Care Arrangements (MBS item 723) – in the context of long COVID, which "*apply for a patient who suffers from at least one medical condition that has been present (or is likely to be present) for at least six months or is terminal*."

Due to the presentation of patients with long COVID earlier than six months from initial illness and the unknown sequalae of long COVID and likely recovery time, there is some hesitancy in utilising these item numbers, therefore reducing patient access to early, subsidised and coordinated multidisciplinary care, and the opportunity to reduce the burden of disease. The RACGP sought clarity from AskMBS in late 2021 on the use of these items for management of long COVID and were told that "whether a patient is eligible for a [chronic disease management] service or services is essentially a matter for the GP to determine using clinical judgement". However, the unique circumstance of long COVID requires further clarity on the use of these item numbers in this context to provide surety to clinicians and essential access to appropriate services for patients.

On a similar note, long COVID patients with other chronic illnesses have often already exhausted their five subsidised allied health sessions, limiting their access to appropriate care.

> *"Most of my long COVID patients already have other chronic diseases and their five Medicare rebated allied health sessions have already been allocated or used. It's vastly insufficient for someone who is simultaneously unable to earn an income because of their illness and requires expensive regular allied health input to maximise their recovery" – General Practitioner, rural Victoria*

The RACGP recommends:

- the current inadequacies in the Medicare Benefits Schedule (MBS) to support patients with long COVID must be addressed.

5.Other comments

Ensuring provision of evidence-based care

General practice has a role in providing evidence-based long COVID advice and guidance to patients to protect from low value or harmful tests and apparent cures. This role extends to selecting patients who are most likely to benefit from multidisciplinary clinics and other specialist services.

The National COVID-19 Clinical Evidence Taskforce currently recommends: "*In patients with continuing symptoms after COVID-19, do not use emerging or unproven therapies outside of randomised trials with appropriate ethical approval".*

COVID-19 and existing chronic disease management

The impact of COVID-19 on existing chronic disease management has been profound. This is a combination of reduced attention to chronic disease management by the community during the height of the pandemic and direct impacts of COVID-19 infection exacerbating chronic diseases. The impacts may include reduced cancer screening, monitoring of heart disease and diabetes and reduced self-care – all of which will be felt for years to come.

There is opportunity, now, to promote and fund the general practice response to this crisis. Potential solutions could include resources to support preventative health assessments for the broader population conducted by the primary care team. Currently these are funded just once for people aged 45-50 years and annually for people aged 75 years or older.

There needs to be increased investment in general practice to better support IT systems, employment of skills mix within general practice, and workforce interventions, to address the current general practice crisis.

Data integration with general practice clinical information systems from other providers

The RACGP has long advocated for improved interoperability within the Australian healthcare system to support the seamless transfer of information between patients, their GP and others involved in their healthcare.

GPs are often the "information managers" for patients and rely on other healthcare organisations to provide additional details regarding diagnosis, treatments, management plans and outcomes. Sharing results from investigations conducted outside of general practice, both for initial COVID-19 test results and subsequent investigations for the diagnosis and management of long COVID, would better support continuity of care. This principle is transferable to all aspects of healthcare.

Data integration of patient information should be a priority for the entire healthcare sector to ensure improved efficiencies and provision of safe quality care.

Ongoing consumer awareness

The RACGP acknowledges a degree of new and repeat COVID-19 infection is inevitable, however, reducing cases of initial infection is the best measure to reduce the likelihood of long COVID.

While public health measures are being wound back, they must remain available for use when required and be flexible and appropriate to the current COVID environment. Accessible and culturally and linguistically appropriate health promotion/education, combined with ongoing vaccination will better control the spread of COVID-19. Community complacency must be challenged through continued information on and awareness of the benefits of simple measures such as hand washing and mask wearing and remaining up to date with COVID vaccinations.

6.Conclusion

GPs and general practice teams have worked harder than ever under trying circumstances to continue caring for their patients during this unprecedented global pandemic.

The RACGP hopes the lessons from the COVID-19 and long COVID response will highlight the longstanding need for improved funding to support general practice, which will enable ongoing patient access to high-quality and safe care. This pandemic has highlighted the critical role GPs play in Australia's healthcare system, and this must not be jeopardised.

The general practice response to this pandemic is far from over, with the real impact of COVID-19 and its lasting impacts on individuals, communities, our healthcare system, and healthcare workers unlikely to be fully realised for years to come. GPs will continue to be front and centre in the response but must be appropriately supported.

Just as they did with COVID-19, GPs and their teams will be front and centre in the response to any future pandemic and disease outbreak. The RACGP is keen to continue working productively with all levels of government to ensure GPs are appropriately and consistently included in pandemic preparedness, response, and recovery across Australia.

The RACGP looks forward to contributing to further discussions around the Australian response to COVID-19 and long COVID.

Should you have any questions or comments regarding the RACGP's submission, please contact Ms Joanne Hereward, Program Manager, RACGP Practice Technology and Management at joanne.hereward@racgp.org.au