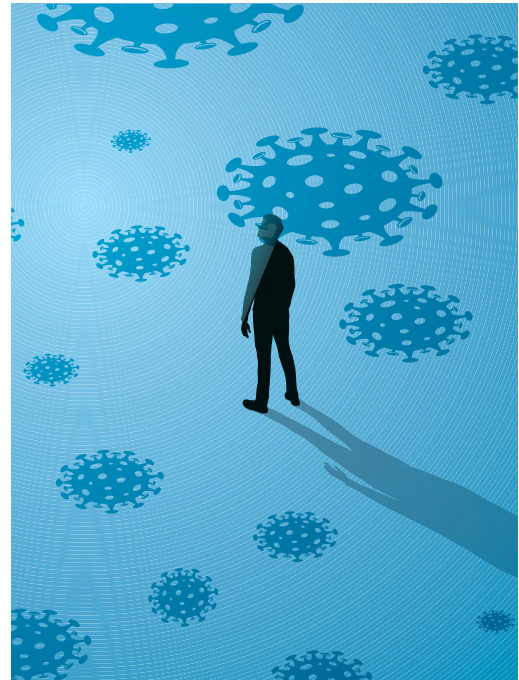


A qualitative study of the general practice experience of diagnosing and managing long COVID: Challenges and practical recommendations



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Background and objective

Patients with prolonged symptoms following COVID-19 infection(s) will increasingly present to general practice. Our research objective was to understand the general practice experience of diagnosing and managing long COVID and to explore recommendations for contributing to the safety and quality of the long COVID response.

Methods

A two-hour qualitative session involving 11 project stakeholders was held in March 2023. The stakeholders included general practitioners as well as representatives from four Primary Health Networks, Outcome Health and the funding body. Transcripts were analysed using qualitative content analysis.

Results

Key challenges and practical recommendations emerged relating to diagnosing long COVID, documentation of COVID-19 infections, ongoing management, screening tools and the need for public health messaging.

Discussion

General practices need more accurate definitions and information about the diagnosis of long COVID. Supporting general practitioners with information to diagnose and manage patients with long COVID is essential. General practice voices need to be heard to enhance our understanding of long COVID and inform policy decisions.

A COVID-19 PANDEMIC MILESTONE was reached on 5 May 2023, when the World Health Organization (WHO) announced that COVID-19 'no longer constitutes a public health emergency of international concern'.¹ With the pandemic evanescent from mainstream media and interest in case numbers protracting to individuals and organisations with a dedicated resolve, attention is now turning towards the longer-term effects of COVID-19 on health and the healthcare system.

In the absence of a universally agreed definition,² patients with prolonged symptoms following a COVID-19 infection are commonly considered to be experiencing 'long COVID'. Long COVID was the matter of an Australian parliamentary inquiry, with the findings released in April 2023 by the House of Representative Standing Committee on Health, Aged Care and Sport in a report titled *Sick and tired: Casting a long shadow*.² The report underscored the crucial need to facilitate research and data to increase our understanding of long COVID and its diagnosis and management. It included recommendations to support general practitioners (GPs) in the management of long COVID in primary care.²

In Australia, symptomatic patients are advised to seek medical advice regarding long COVID from a GP,^{3,4} positioning general practice at the forefront of diagnosing and managing long COVID. This reinforces the importance of the general practice experience of managing long COVID in informing our understanding of the condition. Yet, qualitative research focused on management of long COVID in general practice remains limited to a few European studies^{5,6} and a scoping review,⁷ with a noticeable absence of qualitative studies in the Australian general practice setting.

The aim of the current study was to gain an understanding of the general practice experience of diagnosing and managing long COVID in Australia and to explore recommendations for contributing to the safety and quality of the long COVID response.

Methods

Study context

The current study was undertaken as part of a collaborative research initiative titled 'COVID-19 – Utilising near real-time electronic general practice data to establish effective care and best-practice policy'.⁸ Now in its third year,

the initiative has progressed from researching the effects of the pandemic on general practice (Phase 1 – completed)^{8,9} to focus on long COVID in the general practice setting (Phase 2 – current). Through collaboration and partnership with Primary Health Networks (PHNs; government-sponsored organisations responsible for coordination and delivery of primary health services for a specified geographical region)¹⁰ and digital health developers, Phase 1 of the project identified the effects of the COVID-19 pandemic on many aspects of Australian general practice, including, for example, telehealth,^{11–14} medication prescribing^{12,15} and cancer screening.¹⁶ A detailed description of the translational outcomes from Phase 1 of the project is available in Thomas et al.⁸

As part of Phase 2 of the initiative, the design for the current study stemmed from the methodological framework used in Phase 1, which involved iterative cycles of action research founded on collaboration with key stakeholders, including PHNs, digital health developers and the research team (see Thomas et al⁸ for a detailed description of the methodological framework).

Study design and participants

The current research was designed as a qualitative exploratory study aiming to inductively understand the general practice experience of diagnosing and managing long COVID through the experiences of a purposive sample of key project stakeholders and subject matter experts.¹⁷ The qualitative study was held in the early months of Phase 2 of the project to gain an understanding of long COVID challenges to provide context to ensuing quantitative research directions. Collaborating organisations involved in the initiative, which included PHNs in Victoria (Eastern Melbourne PHN and South Eastern Melbourne PHN) and New South Wales (Central and Eastern Sydney PHN and South Western Sydney PHN) and Outcome Health, were asked to nominate a minimum of two representatives to attend a stakeholder research session. Eleven participants attended the session, including six collaborating organisation representatives, four GPs and a representative from the funding body. The attendees had varying roles within their organisations and provided perspectives from general practices and in relation to

the digital health development for general practice. The broader PHN perspective was also shared through the participation of four PHNs across two Australian states (New South Wales and Victoria). One participant had been diagnosed, and was living with, long COVID at the time of the session. The research team attending the session comprised six researchers: four experienced in qualitative research and two in quantitative research. The session was facilitated by a representative from one of the collaborating PHNs. Written informed consent was obtained from all participants. The Macquarie University Human Research Ethics Committee (HREC) Medical Sciences Committee provided project-specific approval (HREC5202067517176).

Data collection

The two-hour stakeholder research session was held online using Zoom (Zoom Video Communications, 2023) on 3 March 2023. With permission from participants, the session was recorded via Zoom's automatic audio transcription. The session was divided into two parts based on the two study aims and was guided by a series of semi-structured questions that had been provided to participants to prompt reflection prior to the session (Box 1). The first hour of the session commenced with a short presentation

from the research team that provided a brief overview of the existing literature and outlined definitions of long COVID, the Australian situation and possible research avenues. The questions for reflection and discussion then served as a semi-structured guide to facilitate open discussion. The second hour of the session commenced with a short presentation of a COVID initiative being undertaken in a participating PHN, which was then followed by open discussion.

Data analysis

Transcripts from the session were quality checked against audio files to correct any transcription errors. This process was performed by one member of the research team who was present during the stakeholder session and, therefore, familiar with the terminology and context of the discussions. The transcripts and chat files were subsequently de-identified by randomly allocating a number to each participant. To further ensure the anonymity of the participants, demographic information was not collected.

Data analysis commenced with de-identified transcripts being independently read and reviewed by two experienced qualitative researchers from the research team (who attended the stakeholder session) for data immersion.

Box 1. Research session: Questions for reflection and discussion

Part I. Outlining the GP experience of long COVID.

What does long COVID mean to you and your practice?

What is the patient experience of long COVID diagnosis and treatment?

In your experience, has there been an increase in any presentation of symptoms over the last year or so?

Has long COVID led to a noticeable increased burden on GP practices?

Part II. Contributing to the safety and quality of the long COVID response.

What do you think is the best advice we can provide for helping to improve the diagnosis and treatment of long COVID?

What type of information (including digital) do you believe is needed to assist the detection, monitoring and care of long COVID?

What is your experience of supporting patients with long COVID?

What type of decision support do you think would be helpful to GPs, PHNs?

How can our partnership contribute to enhancing best practice care?

What do you think is the impact of long COVID on the health system (eg delayed treatment, health screening, aged care, chronic disease care, postponed elective surgery)?

GP, general practitioner; PHNs, Primary Health Networks.

The manifest content of the transcripts and chat files were then analysed using qualitative content analysis,¹⁸ which involved the two researchers independently reading the transcripts and highlighting meaning units (ie words, sentences and meaning statements)¹⁹ and coding the data using emergent codes. Codes were then grouped into similar categories to enable content areas to be defined and described. The two researchers then convened to compare outcomes and resolve any disparities.

Investigator triangulation (ie including more than one experienced qualitative researcher in the data analysis)²⁰ was used to minimise any potential influence of preconceived assumptions that might be held by individual researchers and enhance the trustworthiness of the data analysis. Member checking was also employed, with key stakeholders reviewing the analysed data and providing additional input, clarification and/or confirmation of results.

Results

Stakeholder discussion regarding experiences of diagnosing and managing long COVID in general practice highlighted four key challenges, outlined below.

1. Diagnosis is delayed due to the need to first exclude other possible causes of symptoms, as there is a broad array of symptoms linked to COVID-19 infection:

... we notice people are still searching for another reason before they commit to long COVID. So people have seen a respiratory physician, a cardiologist, a neurologist, and no one knows what's going on, and then maybe someone will put the word long COVID on their file. So I think there is a significant delay in diagnosis. (Participant 10 [P10])

... uncertainty of diagnosis. And is this long COVID? Is (this) something else? ... So, I think, really, the uncertainty for general practitioners is the most difficult thing, and you know, being able to be confident that that is the diagnosis. Particularly when there's a bit of a delay in that symptomatology coming forward. (P2)

2. It is difficult to establish if and when a patient had a confirmed COVID infection

due to declines in self-testing and laboratory testing, reporting and documentation:

If you don't have a diagnosis of COVID, it's hard to make a diagnosis of long COVID ... And I'm just seeing more and more people, certainly going forward, not bothering to test at all ... The RATs aren't accurate, and then no one wants to go and have a PCR. (P4)

'Have you had COVID? Could this be after your COVID?' - And often they don't know because they're not testing anymore or they're using quite poor-quality RAT tests and getting negative results. And even when you encourage them to do their PCRs, they don't. (P10)

3. Consistency and consensus are lacking on long COVID diagnosis and management strategies, and their effectiveness:

There's no good consensus on diagnosis, as we've discussed. There's no good consensus on treatment. (P1)

Lack of education and knowledge on how do you then manage these symptoms. (P10)

Targeted education and information about self-care, really is that efficacious for management? Whereas our rehabilitation supports, do they make a difference in actually improving those long COVID symptoms in that sort of 12-week to 12-month period? Does that actually make a difference? (P2)

4. There are limited referral options and extensive wait times for referred patients, with no specialist guidance or support for patient management in the meantime:

Long COVID clinics aren't seeing people quickly at all. (P1)

It is so hard to get anyone in, you know. You can send referrals, and you never hear back. (P4)

The discussion exploring recommendations for contributing to the safety and quality of the long COVID response led to the identification of five proposed practical suggestions to help address the identified challenges, outlined below.

1. Guidelines providing precise definitions and symptoms are needed to arm

practitioners with the knowledge and confidence to diagnose patients with symptoms indicative of long COVID:

We really need to give GPs a lot more information about accurate definitions and diagnosis. (P2)

The assessment, the initial management for long COVID should be standardised across states. You know, and possibly Australia ... I don't think it's clear ... about the standardised of - these are the clear criteria to diagnose. These are the important things not to miss. (P4)

2. Easy-to-apply guidelines and screening tools are needed that are relevant to the Australian context, communicated to practitioners through channels they engage with or embedded as decision support tools:

You know, whether it's electronic or paper, or whatever. Is there a way that we could come up with a tool that would be useful for Australian GPs in an Australian context to say, well, maybe this is a way to look at long COVID. And maybe even if you're referring off to a long COVID clinic, you know that you could say, well, actually, this guy's got a, he's got a 10 out of 10 on his long COVID clinic referral form. Let's get them in fast. (P7)

A guideline that people can follow to help them make that diagnosis and flow chart. There's some pretty good resources made by the BMJ and the UK for specific long COVID subsets of patients ... Having a local version of those. (P10)

3. Coordinated, multidisciplinary approaches to long COVID patient management must be adopted:

Because you do need the multidisciplinary care. Every, you know, we can refer to a psychologist, to an exercise, or a physio, or you know. But (patients) need a one stop shop. So they don't have to (coordinate) that. Because they're just too tired to do it. (P4)

We need to also support our allied health practitioners. They need the support to actually, and the education to be able to, then take over those rehab avenues. (P2)

4. Public health messaging is needed to raise awareness about 'what is long COVID' to assist public understanding of symptoms and when to see a GP:

Some public health messaging about the whole thing would be a good idea ... You know, long COVID, the word 'long' is the first, most important part of the whole thing. It's not, you're still sick in the short term; it's a long-term problem. But I think it's just basically trying to raise awareness for people. (P1)

My cohort in the elderly population, I see much more stoic and tolerant of a lot of these symptoms and don't necessarily report them. (P4)

5. Clear and consistent documentation of long COVID diagnosis is needed in clinical notes to facilitate long-term tracking and management of the condition, for better patient care and translational research:

Without that, that information, we're not going to get the data. Without the data, we're not going to be able to help people. (P10)

Discussion

The qualitative stakeholder session undertaken in the current study provides a valuable preliminary understanding of the challenges facing general practice and practitioners in the diagnosis and management of long COVID. The key challenges identified were associated with delayed diagnosis due to first needing to exclude other possible causes of symptoms; difficulty establishing if and when a patient had a confirmed COVID infection due to declines in self-testing, laboratory testing, reporting and documentation; a lack of consistency and consensus on long COVID diagnosis and management strategies and their effectiveness; and limited referral options and extensive wait times for referred patients, with no specialist guidance or support for patient management in the meantime.

Long COVID diagnosis and management is a matter of worldwide concern. Our findings of delayed diagnosis due to excluding other possible causes and lack of consistency in management strategies are echoed in similar findings of 'uncertainty' reported

within the limited existing literature.^{7,21} Establishing if and when a patient had a confirmed COVID infection due to declines in self-testing, laboratory testing, reporting and documentation likely represents an emergent challenge from the past year as the pandemic emergency abates,²² life returns to the 'new normal' and general practice emerges as the touchpoint for patients with persistent COVID-19 symptoms. Declines in testing and a lack of documented COVID-19 infection status will likely be an added impediment to the future clinical diagnosis of long COVID.

Practical suggestions from our study to help address the long COVID diagnosis and management challenges in general practice include the establishment of: (1) guidelines that provide precise definitions and symptoms to arm practitioners with the knowledge and confidence to diagnose long COVID; and (2) easy-to-apply guidelines and screening tools relevant to the Australian context. Since our study, the Australian parliamentary inquiry into long COVID has recommended that for Australian healthcare, 'the World Health Organization definition of long COVID be used clinically ... (but) ... to review this definition as more research and information becomes available'.² Evidence-based guidelines, developed by the Australian National Clinical Evidence Taskforce to provide diagnostic guidance on COVID-19 (including the management of patients with ongoing symptoms), reiterate the use of the WHO definition but highlight that challenges in synthesising evidence nonetheless remain due to the considerable variation in the definitions of long COVID used across studies.²³ Thus, use of standardised and precise definitions remains a key goal that must be addressed to aid the development of long COVID diagnosis and management guidance.

Other practical suggestions emerging from our study, including the need for coordinated, multidisciplinary approaches to long COVID patient management and the need for public health messaging are reflective of reports in the literature of fragmented care,²¹ the requirement for multidisciplinary care,⁷ a need for patient information on long COVID⁶ and the need for guidelines and screening tools.⁶ To contribute to the safety and quality of the long COVID response, our study identified the need for clear and consistent documentation

of long COVID diagnosis in clinical notes to facilitate long-term tracking and management of the condition for better patient care and translational research. This finding concurs with Bachmeier et al,⁶ whose recommendations from a qualitative study, based on interviews with GPs in Germany, recognised the role of routine data in contributing to improving practice in the management and treatment of long COVID and its potential for use in medical research. Further research in both Australia and internationally is needed to understand the persistent and emerging challenges facing general practice and GPs in the diagnosis and management of long COVID, including strategies being used to address these challenges.

Strengths and limitations

Our study presents findings from a previously unexplored context in Australian general practice. However, as the study is specific to the Australian healthcare setting and involved participants from the states of Victoria and New South Wales only, the generalisability of results might be limited. The purposively sampled stakeholder group represents a small sample, and the results reflect the opinions and experience of the study participants. March 2023 represents a period in the pandemic when restrictions were lifted, life was returning to pre-pandemic conditions and general practice was the first point of contact for patients with persistent symptoms. These circumstances represent a different epoch in the pandemic compared to earlier studies in 2020–2021 and are a strength of our study.

Conclusion

The primary care system will have an essential role in supporting long COVID patients,² and general practice will play a key part in facilitating ongoing research and understanding of long COVID within both Australian and international contexts. Our research findings provide direction for improving the long COVID response in the primary care setting. General practices need more information about accurate definitions and diagnosis of long COVID, and support for GPs with the information required to diagnose and manage patients with long COVID is essential. General practice voices need to be heard to enhance

our understanding of long COVID and to help inform long COVID policy decisions. Understanding the patient voice and the healthcare challenges experienced by patients living with long COVID is an important area of future research.

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