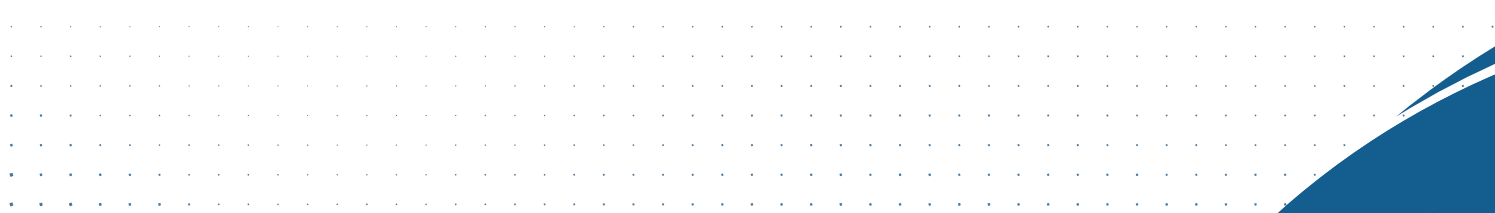




Towards Personalised Assessment and Treatment of Long-COVID: Community Conversation Report

1 June 2022



EVENT REPORT

Towards Personalised Assessment and Treatment of Long-COVID: Community Conversation – 1 June 2022

On 1 June 2022 (6.00pm to 8.00pm), the Western Australian Health Translation Network Consumer and Community Program (CCI) conducted an online Community Conversation in partnership with the Australian National Phenome Centre (ANPC) to discuss lived experiences of those with COVID-19 and Long-COVID.

Number of participants - 16.

Presenter: Professor Jeremy Nicholson (Director, Australian National Phenome Centre, Pro-Vice Chancellor, Health Sciences Murdoch University).

Prof. Nicholson's presentation is highlighted as follows:

- A Systemic disease caused by the SARS CoV-2 b-coronavirus (very like SARS CoV-1). Dangerous new variants continue to appear with increased infectivity.
- Unmitigated, COVID-19 is still a deadly disease and can be passed on asymptotically by aerosol transmission.
- Incubation period variable 2-12 days for original variants (newer variants are faster). Time from infection to first symptoms is about 2 days and from symptoms to severe disease takes 8-10 days. Omicron and variants are super infectious.
- Triple or more vaccination required for full protection especially in older groups. Omicron is still a serious threat to the unvaccinated.
- COVID-19 is much more than just a lung disease – complex multi-system organ failure. Affects children and adults, but lung severity increases with age and background 'conditions. COVID makes every problem you have already worse!
- Long COVID – Incomplete and partial recovery is common. Long COVID can affect anyone and is only partly related to severity.
- There is evidence of increased long-term risks and incidence of Diabetes, Cardiovascular Disease and Neurological diseases at the population level.

This conversation was conducted in partnership with the CCI as part of a Medical Research Future Fund grant (MRFF number 2014349 Molecular phenomic approaches to improve understanding of Post-Acute COVID-19 Syndrome – a biomarker-augmented strategy for risk-based stratification and targeted intervention to improve clinical outcomes). As part of this project, the ANPC and the CCI conducted an online conversation with participants who had lived experience of COVID-19 and Long-COVID. One of the aims of this conversation was to gauge consumer appetite for the application of new diagnostic biomarkers of COVID-19 and Long-COVID for more precise measurement and characterization of disease and symptomatology, including more accurate definition of secondary organ damage and/or disease.

Facilitator:

Deb Langridge – Head CCI Program.

Online community conversation run down process:

- Participants was directed to break-out rooms.
- Facilitators did a quick introduction of the presenter, observers and coordinators.
- Observers in each break-out room collected responses from participants.
- Evaluation and Feedback– a link was sent via email to participants post conversation.

Attendees include Consumer and Community Involvement Program – Lead Facilitator: Deb Langridge, Head of the CCI Program, CCI Coordinators: Ben Horgan, Corinna Musgrave, Kerry Mace, Event Coordinator: Briony Abraham. ANPC Observers including Sze How Bong, Julien Wist and Ruey Leng Loo.

No.	Questions	Participant comments
1.	<p>Are you getting adequate support in your recovery from Long-COVID?</p> <p>Summary of responses:</p> <p>Participants described some of the challenges and experiences of having Long-COVID, including the impact on social and work life, loss of fitness, difficulty in finding helpful medical support, reliance on self-driven recovery, and the importance of acknowledging the disease. There was a lack of preparation and acknowledgement from the health system to cope with Long-COVID, and conflicting information on how to deal with the disease subtypes. The participants experienced a range of symptoms, including headache, nausea, brain fog, slow thinking, and light sensitivity. Traditional medicine and cannabis have been used to manage symptoms. The majority has had difficulty getting appropriate medical attention, with dismissive attitudes from some healthcare providers, conflicting information, and inconsistent test results.</p>	<ul style="list-style-type: none"> • Significant impact on social and work life • Significant loss of fitness • GP not able to help • Fatigue experts had large cost impacts • Lack of acknowledgment of the disease • No support reported by some in Sydney • Self-driven recovery • GP are following self-driven research. • Social media as source of information • Participant reported inability to work for up to 5 months • Headache and nausea • Brain fog and slow thinking • Unable to focus on computer for more than 30 minutes. • Annoyed by light • No preparation from health system to cope with long COVID • Dismissive attitude from GP • 55 symptoms from one participant reported • Participant had to adapt lifestyle to disease • Alternative use of traditional medicine and cannabis

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		<ul style="list-style-type: none"> • Follow-up cardiology appointment scheduled 2 months after initial diagnosis for the management of long COVID symptoms. • Healthcare providers faced uncertainty regarding appropriate treatment measures. • Inconsistent information regarding the recommended actions following a positive diagnosis. • Unpleasant experience with the COVID Care line, as the questions lacked empathy and made one feel as though they were being a burden. • PCR and RAT tests yield divergent results. • Self-monitoring blood pressure due to elevated levels. • Participant had to use an apple watch to monitor vitals such as blood pressure • Participant experienced long term effects such as indigestion and fatigue • Admitted to the hospital via the emergency room, followed by a visit to a general practitioner which proved to be unhelpful. • Participant suffered from dizziness and pain, then went for various medical examinations and was prescribed an antidepressant that exacerbated the condition.
2.	<p>Are you concerned about getting COVID (and Long-COVID) again the future?</p> <p>Summary of responses:</p> <p>Participants experienced various health concerns including shortness of breath, fatigue, and fear of being re-infected. They expressed frustration with policy makers for not taking enough action or implementing the wrong policies, particularly in the context of reopening establishments with no mask restrictions.</p>	<ul style="list-style-type: none"> • Participant experienced shortness of breath and fatigue while suffering from COVID. • Participant was concerned about not being able to go back to work. • They were also concerned about being re-infected. • Policy makers' failure to make timely decisions, inaction or implementation of misguided

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	<p>There were general concerns about the lack of acknowledgement of Long-COVID by healthcare providers and COVID clinics, and frustration with dismissive discourse about the disease. Participants expressed worry about the potential long-term health effects and the impact of the disease on their ability to perform daily activities, including the worry that advice given to them is not appropriate. Participants also expressed increased caution towards infectious diseases in general, with some displaying heightened concerns around crowded areas.</p>	<p>policies, and absence of any restrictions on mask usage."</p> <ul style="list-style-type: none"> • Concerned about any other disease that would trigger COVID symptoms back. • Participants took extensive measures to prevent infection. • The COVID clinic's lack of effort in addressing long-COVID (as evident in their policies and acknowledgment) had caused frustration and anger due to their dismissive discourse. • Debating the decision to get the flu vaccine and being genuinely worried about the potential impact on one's health, particularly concerning the possibility of experiencing the flu for a second time. • Concerned that the flu vaccine could aggravate existing health condition in the case of myalgic encephalomyelitis. The symptoms began 11 weeks after vaccination and have not seen any signs of improvement. • Experienced ongoing fatigue and persistent brain fog, with concerns about lingering side effects • Unable to engage in regular day-to-day activities, leading to concerns about what the future may hold. • Attitude towards infectious diseases includes heightened concern for other infectious diseases. • Feeling increased fear and apprehension, even after being fully vaccinated. • Due to increased anxiety, participants adopt strategies to minimize risk, such as avoiding crowded areas and continuing to wear mask.

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3.	<p>Would you be interested in a blood test that provides you more information on your health status (with respect to Long-COVID)?</p> <p>Summary of responses:</p> <p>Participants expressed interest in treatment and improved understanding of the underlying cause of Long-COVID. They were also interested in the use of biomarkers to monitor disease and recover although some participants expressed concerns on the exploitation of personal information by insurance companies. Participants wanted comprehensible results so that they can understand how to mitigate symptoms of disease. Participants wanted to know if their mitigation strategies were effective and appropriate. Some participants also preferred more frequent health monitoring.</p>	<ul style="list-style-type: none"> • Participants agreed to get a blood test only if they were provided with clear information and understanding of the purpose and procedure. • Very interested in obtaining proof of infection through blood testing. • Participants were interested in undergoing blood screening to gain insights into potential treatment options. • Interested in understanding the underlying problem in view of finding a treatment. • There was a desire to proactively monitor blood parameters for early detection or prevention of COVID-19 infection. • Participants showed interest in utilizing blood monitoring for the prevention and management of cardiovascular conditions, diabetes, and neurological health. • Participants expressed interest in utilizing biomarkers for monitoring and assessing improvements in their health. • While participants acknowledged the benefits of having indicators to assess the effectiveness of their health-related efforts, concerns arose regarding the potential usage of this information by insurance companies or other entities. • Participants expressed willingness to participate in research for the sake of health benefits. • There was strong appetite for receiving comprehensive information, including both positive and negative results. • Participants emphasized the importance of understanding the implications of blood test results

No.	Questions	Participant comments
		<p>and how to take appropriate action to mitigate any identified issues.</p> <ul style="list-style-type: none"> • The ability to identify disease markers was seen as valuable information for proactive health management. • Having the choice to actively improve health was highly valued by participants. • There was a desire to detect any potential health problems beforehand. • Participants wanted reassurance that the actions they have taken are appropriate and, if necessary, the ability to modify their approach based on the information received. • Participants emphasized the importance of having the freedom to choose their level of involvement in monitoring their health. • The optimal frequency of blood testing should be determined based on the specific markers being monitored and the expected timeframe for observing changes or developments. • More frequent check-ups or tests can provide participants with a sense of assurance that their health markers are actively being monitored.
4.	<p>If this project is successful, should the government be responsible for monitoring Long-COVID?</p> <p>Summary of responses:</p> <p>Participants suggested that independent experts should be responsible for monitoring and collecting data on long-COVID, and the information should be published with transparency and monitored by peers. They expressed a lack of trust in the government for this purpose but believe that the government should be in</p>	<ul style="list-style-type: none"> • Participants expressed a preference for independent experts who are not affiliated with the government to oversee health-related matters. • There was a strong desire for transparency in research findings and publication of results.

No.	Questions	Participant comments
	<p>charge of directing people to adequate treatments. The participants suggested the creation of a central disease centre to collect and monitor data on a national level.</p>	<ul style="list-style-type: none"> • The importance of peer monitoring and evaluation of research was emphasized. • Participants expressed a lack of trust in the government's ability to fulfill certain roles related to health monitoring and treatment. • It was believed that the government should collect data, maintain statistics, and provide appropriate guidance for long-COVID and other health issues. • Participants considered public health to be a significant concern that requires government involvement. • While participants believed the government should be responsible for information dissemination and treatment provision, they emphasize the need for input from various stakeholders, excluding only patients themselves. • Participants suggested the establishment of a central disease center at the national level to collect and monitor health data. • Collaboration and knowledge-sharing within the research and medical community was seen as essential for better understanding and addressing health issues. • Participants emphasized the need for a unified and consistent approach across the federal level in setting up necessary infrastructure and guidelines. • While participants recognized the potential value of international collaboration, they expressed uncertainty about the specific entities or organizations involved. • They believed that the federal government should play a central role in coordinating efforts and implementing policies to mitigate

No.	Questions	Participant comments
		<p>the impact on programs like Medicare.</p> <ul style="list-style-type: none"> • Once research is completed, the responsibility for translation and implementation should lie with the federal government. • Centralization of data is essential, ensuring transparency and enabling the data to be utilized by different states and entities. • The challenge of scaling up interventions or initiatives should be addressed to ensure broader impact and reach. • The government should provide information on self-management strategies for individuals dealing with long COVID. • Information sharing among relevant stakeholders is crucial.
5.	<p>Conclusion:</p> <p>There was a general consensus that more resources were required for Long-COVID monitoring and data collection. The findings of this online community conversation highlighted the need for greater awareness and understanding of Long-COVID and the challenges faced by those who experience it. Participants also expressed strong desire for more accurate monitoring of disease and recovery using precision biomarkers. Participants felt that it was important for healthcare providers and policy makers to acknowledge the disease and provide appropriate support and resources for those who were affected. While independent experts may be best suited to monitor and collect data on long COVID, participants felt the government has a responsibility to ensure that individuals are directed towards adequate treatment and that transparent data centralization is available to all.</p>	