

The Optimise Study: A rapid survey examining frequency, impacts of long COVID and associated concerns

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A rapid survey examining frequency, impacts of long COVID and associated concerns

BACKGROUND

Long COVID is estimated to be costing the Australian economy \$3.6 billion annually.¹ Partly because of the variation in the definition of long COVID, there are varying descriptions of symptoms associated with long COVID and its prevalence (with estimates ranging from 7.5% to 43% depending on the definition applied, follow-up time and population).² The Australian Department of Health and Aged Care considers long COVID to be symptoms associated with COVID-19 infection that remain or develop, four weeks after the initial infection.

The Optimise Study has followed a cohort of around 700 Victorians since September 2020. A rapid survey was conducted between 12 and 21 August 2022 to assess the proportion of Optimise participants who had experienced long COVID, participants' concerns about long COVID and any behaviours they used to mitigate the risk of developing long COVID. There was an optional additional section of the survey completed only by participants who reported having/having had long COVID, asking about their experiences.

Of the 653 Optimise study participants invited to complete the survey, 499 (76%) responded. The participants who completed the survey were representative of the Optimise survey cohort. Fifteen participants completed phone-administered surveys with bilingual data collectors in Mandarin, Arabic or Dinka.

Participants who reported having/having had long COVID were also invited to join a focus group discussion. A total of 20 respondents participated in one of three focus group discussions between 6 and 19 July 2022. The discussions focussed on the nature and duration of their symptoms, access to diagnosis, treatment and information about long COVID, support they had received, and their recommendations for supporting people with long COVID.

SUMMARY OF FINDINGS

Survey findings

- Forty-nine per cent (243/499) of participants had been infected with COVID-19 at least once since the beginning of the pandemic (December 2019).
- Twelve per cent (61/499) of participants reported that they have/have had long COVID.
- Sixty-one per cent (302/499) of participants had friend/s or family member/s who had experienced long COVID. Forty-two per cent (128/302) of these participants reported providing support to friend/s or family member/s with long COVID.
- Participants were most concerned about a family member getting long COVID (46%, 232/499), their own physical health being affected by long COVID (38%, 188/499), and that they might develop long COVID (37%, 187/499).

¹ O'Brien, E. Long Covid Costs Australia Economy \$3.6 Billion a Year: Report, Bloomberg, 10 Sept 2022, available online at:

<https://www.bloomberg.com/news/articles/2022-09-10/long-covid-costs-australia-economy-3-6-billion-a-year-report>

² Chen C, Hauptert SR, Zimmermann L, Shi X, Fritsche LG, Mukherjee B. Global Prevalence of Post COVID-19 Condition or Long COVID: A Meta-Analysis and Systematic Review. *J Infect Dis.* 2022. DOI: 10.1093/infdis/jiac136; National Center for Health Statistics, Nearly One in Five American Adults Who Have Had COVID-19 Still Have "Long COVID", Centers for Disease Control and Prevention, 22 June 2022, available online at: https://www.cdc.gov/nchs/pressroom/nchs_press_releases/2022/20220622.htm

- The risk of developing long COVID motivated survey participants to get vaccinated/stay up-to-date with vaccines (82%, 401/492), maintain physical distancing (73%, 356/491), and wear a face mask outside of their home (71%, 352/493).
- Most participants (62%, 303/492) agreed that to prevent people from developing long COVID, it would be acceptable for the Victorian Government to require wearing a face mask out of their home and 56% (271/488) agreed that it would be acceptable for the Victorian Government to require social distancing in indoor public settings.
- Approximately one-third (29%, 137/480) of participants agreed that the Government was providing adequate information about long COVID and its associated risks.
- Of the 61 participants who reported they have/have had long COVID, 52 completed the additional section on their experiences of long COVID. Of these 52, 43 (83%) said they had long COVID but had not had this diagnosis confirmed by a healthcare professional and nine (17%) reported they had been diagnosed by a healthcare professional.
- Among the 52 participants who have/have had long COVID:
 - Eighty-one per cent (42/52) developed long COVID after their first COVID-19 infection. Since developing long COVID, 6 (12%) had been reinfected once and two (4%) had been reinfected twice with COVID-19.
 - Eight per cent (4/52) had not received a COVID-19 vaccine before developing long COVID. Fifty-six per cent (29/52) had received three vaccine doses before the infection that led to long COVID. Since developing long COVID, 28 (54%) had not received any more vaccine doses.
 - The most common symptom of long COVID reported by participants was fatigue/extreme tiredness (81%, 42/52).
 - The most frequently reported experiences among those with long COVID were reduced exercise (65%, 34/52), followed by reduced socialisation (38%, 20/52) and changes to mood (38%, 20/52).
 - The most common sources of information and support were General Practitioners (GPs) (46%, 24/52), the Internet (33%, 17/52), and friends (17%, 9/52).

Focus group discussions

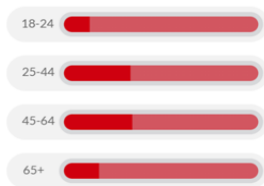
- Some focus group participants with comorbidities found that their chronic conditions tended to worsen with long COVID. Some participants also reported that their usual treatments for their other chronic health conditions were less effective than they had been pre-COVID.
- Participants expressed that long COVID symptoms, in combination with the impact of lockdowns were disrupting their everyday lives including negatively affecting participants' mental health, work and social relationships.
- Participants relied on both formal and informal sources of information, but preferred to access evidence-based resources, especially online. However, they emphasised there was a lack of updated evidence on long COVID.
- Participants highlighted challenges in accessing services due to the healthcare system being under pressure, including difficulties accessing bulk billing and telehealth services.

1. DEMOGRAPHICS OF SURVEY SMAPLE

Of the 499 participants who responded to the survey, 37% (181/499) were aged 45–64 years, 78% (357/499) lived in metropolitan Melbourne, and 13% (67/499) spoke a language other than English at home. Twenty-three per cent (115/499) of participants were healthcare workers. Almost half (49%, 243/499) of the participants had ever tested positive for COVID-19 and 12% (61/499) reported that they have/have had long COVID.

Among the 61 participants who reported having/have had long COVID, 23% (14/61) were aged 25-34 years and 18% (11/61) were aged 18-24 years. One-fifth (20%, 12/61) were current healthcare workers. Sixty-four per cent

(39/61) were born in Australia and 23% (14/61) spoke a language other than English at home. Eighty-four per cent (48/61) lived in metropolitan Melbourne.



37% were aged **45–64**



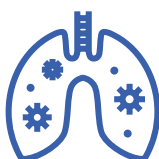
78% lived in **metropolitan Melbourne**



13% spoke a **language other than English** at home



49% **tested positive** for COVID-19 at some point



12% had **long COVID**



23% were **healthcare workers**

2. HISTORY OF INFECTION AND DEVELOPMENT OF LONG COVID

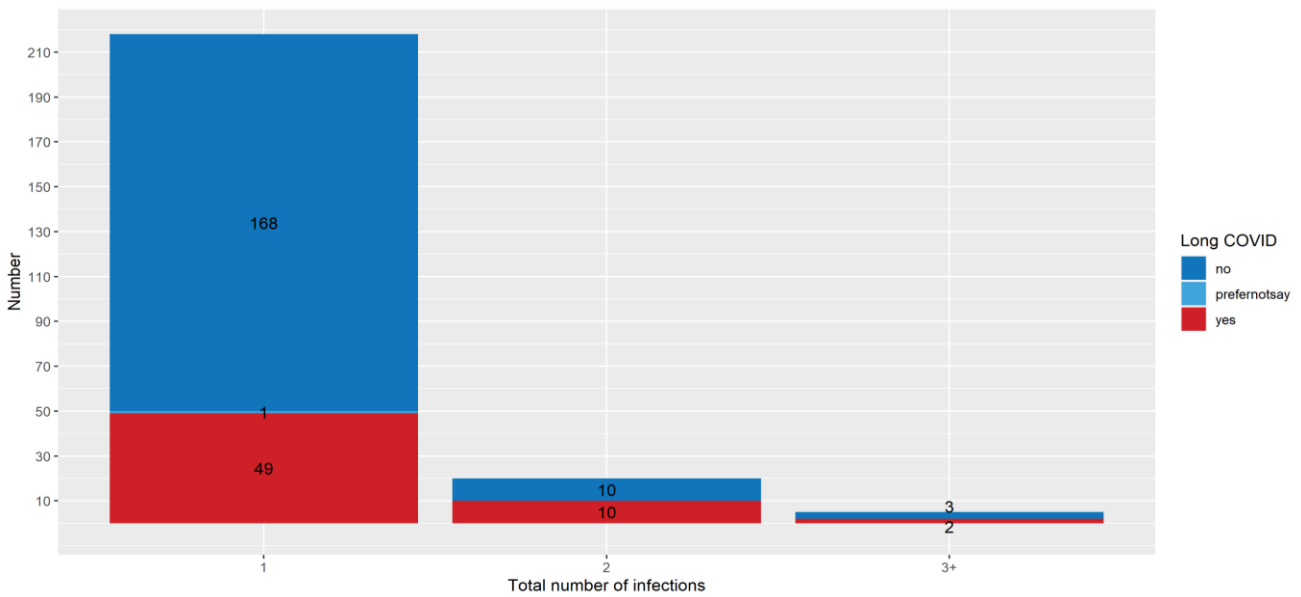
Of the 499 participants, 49% (243/499) reported they had been infected (tested positive) with COVID-19 at least once since the beginning of the pandemic (December 2019). Of the 243 participants who had been infected with COVID-19, 90% (218/243) had been infected once, 8% (20/243) had been infected twice, and 2% (5/243) had been infected three or more times (Appendix Table 1). Of the 243 who had been infected with COVID-19, 14% (35/243) had been infected in the month prior to the survey and 32% (77/243) had been infected in the one to three months prior to the survey. Forty-eight per cent (116/243) had been infected in the four to 12 months prior to the survey.

Twelve per cent (61/499) of participants reported that they have/have had long COVID. Of the 218 participants who had one COVID-19 infection, 49 (22%) reported they had long COVID. Of participants who had two infections, half (50%, 10/20) reported that they had long COVID. Of the five participants who had three infections, two (40%) had long COVID (Figure 1).

Of the 61 participants who reported that they have/have had long COVID, 52 (85%) completed the additional section on their experiences of long COVID. Of the 52 who reported having/having had long COVID, 43 (83%) reported they thought they had long COVID but had not been diagnosed by a healthcare professional and 9 (17%) had been diagnosed by a healthcare professional. Among the 52 respondents with long COVID, 42 (81%) reported developing long COVID after their first infection (Appendix Table 2), and 15% (8/52) were reinfected after developing long COVID. Of these eight participants, six (12%) had one infection and two (4%) had two infections since developing long COVID (Appendix Table 3). Among those with long COVID who completed the additional section on their experiences of long COVID, 56% (29/52) had received three vaccine doses before the infection that led to long COVID. Four participants (8%) had not received a vaccine before developing long COVID (Appendix Table 4). Since developing long COVID, 54% (28/52) had not received any more vaccine doses (Appendix Table 5).

Sixty-one per cent (302/499) of participants had friends or family who had experienced long COVID and of those participants, 42% (128/302) reported providing support to help friend/s or family member/s with long COVID.

Figure 1: Number of people with long COVID by number of infections

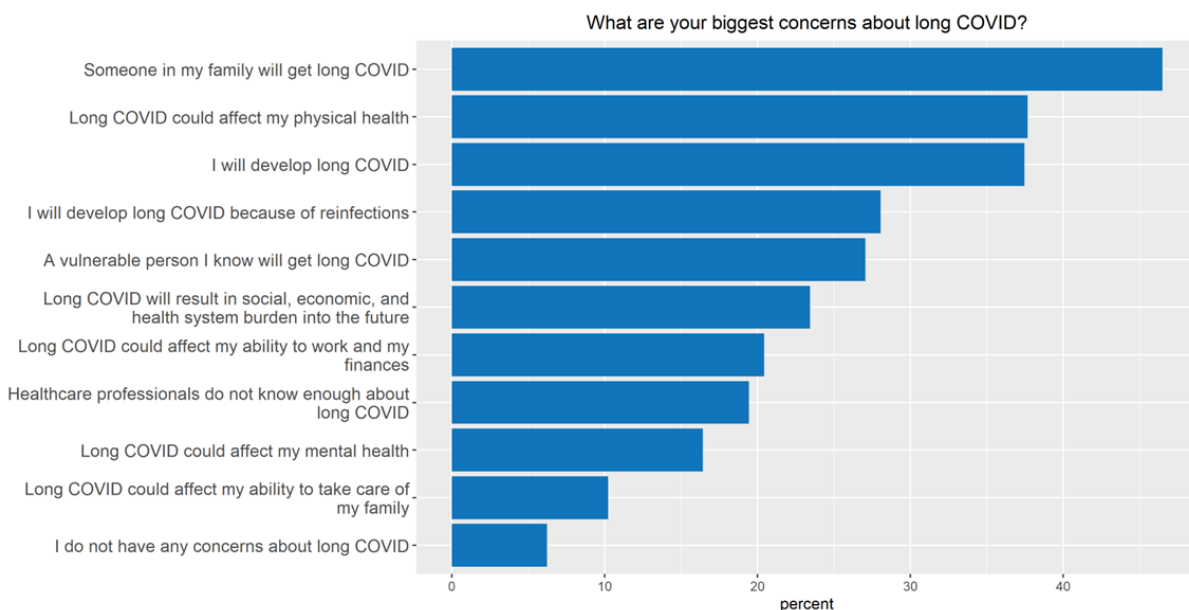


3. CONCERNS ABOUT LONG COVID

We asked all participants (n=499) about their three biggest concerns regarding long COVID. Participants were most concerned about a family member developing long COVID (46%, 232/499), and a vulnerable person they knew developing long COVID (27%, 135/499; Figure 2).

Participants were also concerned about their own risk of long COVID; 38% (188/499) were concerned that long COVID could affect their physical health, 37% (187/499) were concerned that they would develop long COVID, and 28% (140/499) were concerned that they would develop long COVID because of reinfection. In addition, almost one in five (19%, 97/499) participants were concerned that healthcare professionals do not know enough about long COVID and 23% (117/499) of participants were concerned about the impacts of long COVID on wider society and the economy.

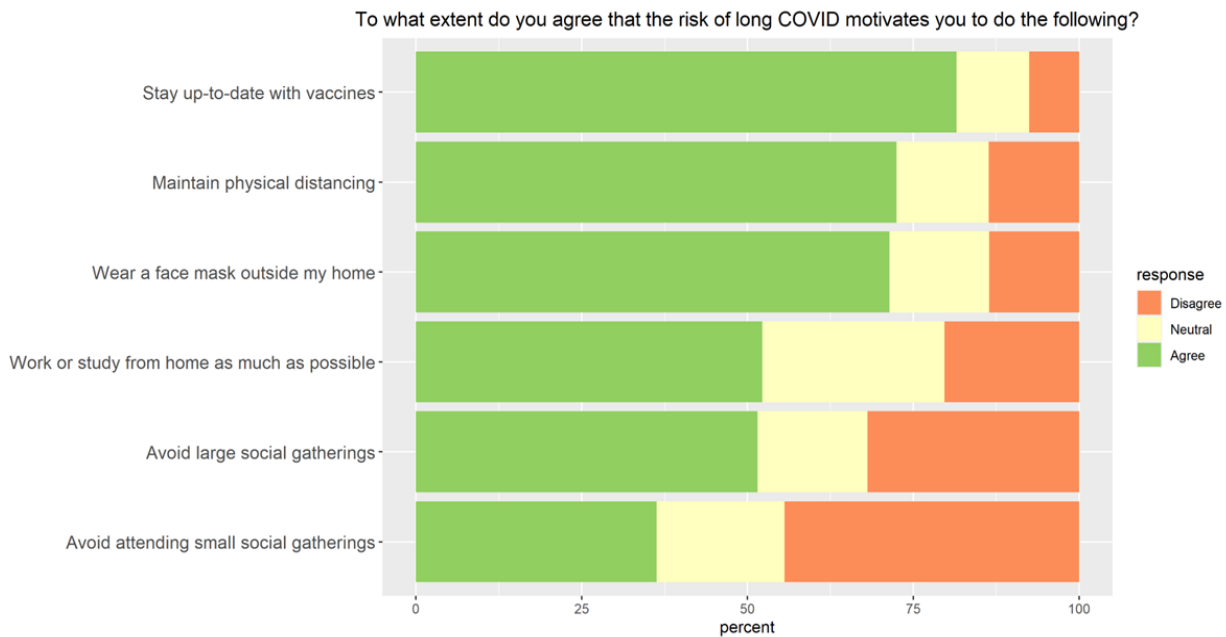
Figure 2: Greatest concerns about long COVID among participants



4. BEHAVIOURS TO MITIGATE THE RISK OF DEVELOPING LONG COVID

All participants (n=499) were asked about any actions they had taken or changes they had made to their behaviours to mitigate the risk of developing long COVID (Figure 3). Eighty-two per cent (401/492) of participants reported that the risk of long COVID motivated them to get vaccinated/stay up-to-date with vaccines. In addition, the risk of long COVID also motivated behaviours relating to physical distancing (73%, 356/491), mask-wearing when outside the home (71%, 352/493), choosing to work and/or study from home as much as possible (52%, 247/473), and avoiding large social gatherings (52%, 255/495).

Figure 3: Behaviour changes to reduce the risk of developing long COVID among participants

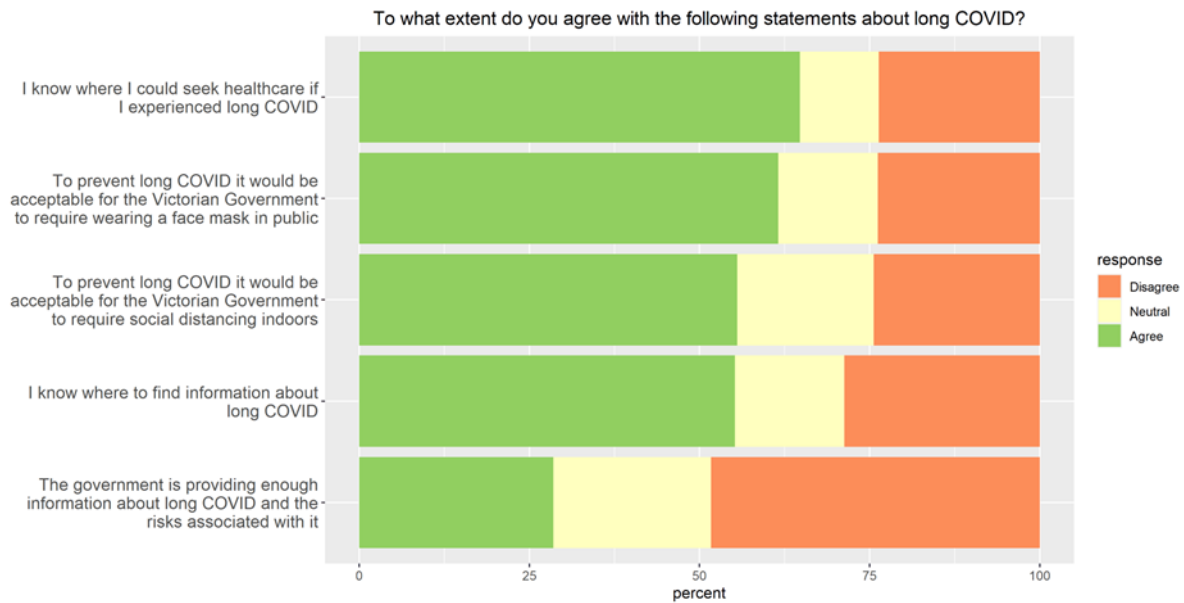


5. ATTITUDES TOWARDS THE VICTORIAN GOVERNMENT'S MITIGATION MEASURES

We asked all participants to indicate to what extent they agreed with statements about the Victorian Government's mitigation measures and the availability of information about long COVID.

Most participants agreed that it would be acceptable for the Victorian Government to require wearing a face mask out of home (62%, 303/492) and to require social distancing in indoor public settings (56%, 271/488) to prevent long COVID (Figure 4). Nearly two-thirds (65%, 312/482) of participants agreed that they knew where to find information about long COVID. Approximately one-third (29%, 137/480) of participants thought the Government was providing adequate information about long COVID and its associated risks.

Figure 4: Attitudes toward the Government's risk mitigation measures and information provision



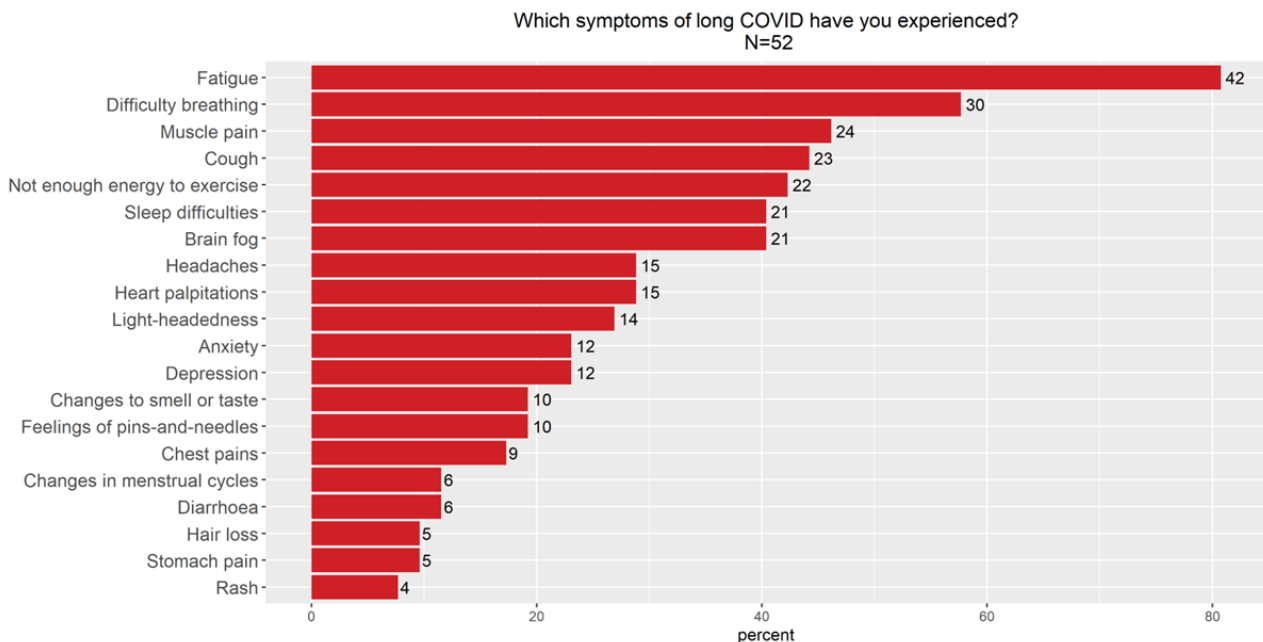
6. SYMPTOMS OF LONG COVID

Participants with long COVID were asked to indicate the severity of their long COVID symptoms when they were at their worst. Thirty-eight per cent (20/52) of these participants reported that their symptoms were mild at their worst, 35% (18/52) reported that they had moderate symptoms, and 27% (14/52) reported that their symptoms were severe.

Participants with long COVID (n=52) were asked to indicate all symptoms they had experienced. The most common symptoms reported were fatigue/extreme tiredness (81%, 42/52), shortness of breath or difficulty breathing (58%, 30/52), muscle pain (46%, 24/52), and cough (44%, 23/52; Figure 5).

A considerable proportion of participants reported experiencing anxiety (23%, 12/52), depression (23%, 12/52) and sleep disturbances (40%, 21/52).

Figure 5: Symptoms of long COVID



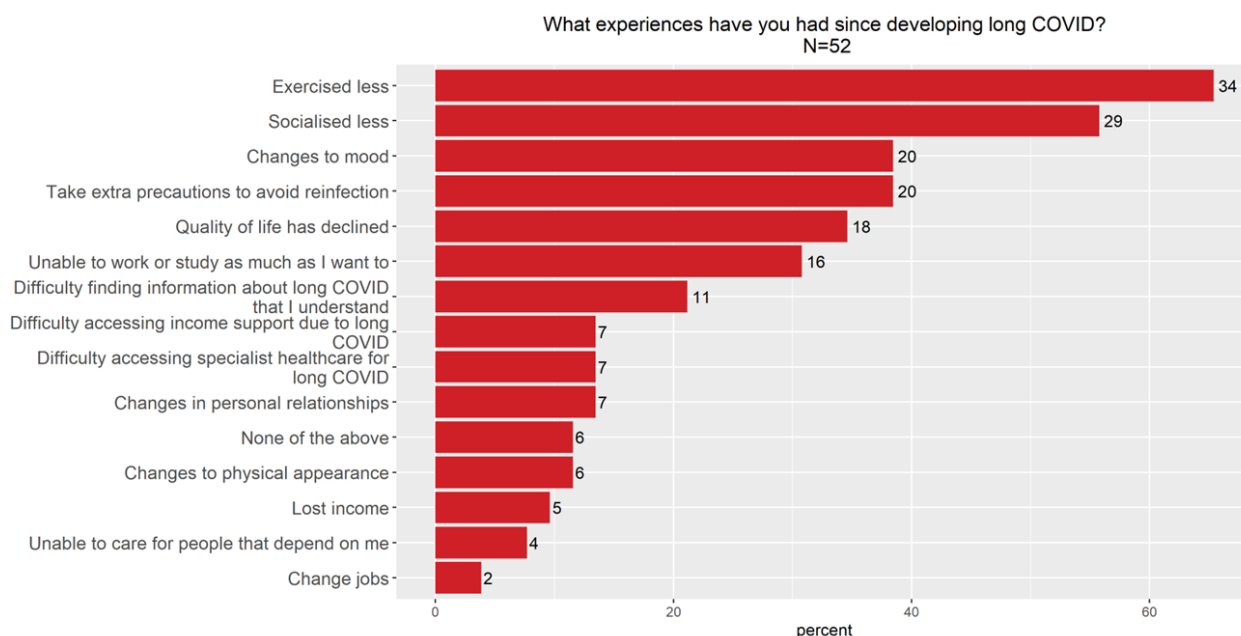
7. EXPERIENCES OF LIVING WITH LONG COVID

We asked participants with long COVID (n=52) about their long COVID related experiences such as their daily activities, relationships, mental health and finances.

The most frequently reported experience was reduced exercise (65%, 34/52), followed by reduced socialisation (38%, 20/52), and changes to mood (38%, 20/52; Figure 6). Thirty-eight per cent (20/52) of participants reported that they took extra precautions to avoid reinfection. One-third (31%, 16/52) of participants reported that they were unable to work or study as much as they wanted to.

Barriers to access to information and support for long COVID were reported by a smaller proportion of participants with long COVID, including difficulties in finding information about long COVID that they understand (21%, 11/52), difficulties in access to income support due to long COVID (13%, 7/52), and difficulties in getting specialist healthcare for long COVID (13%, 7/52).

Figure 6: Impact of long COVID on the lives of participants with long COVID



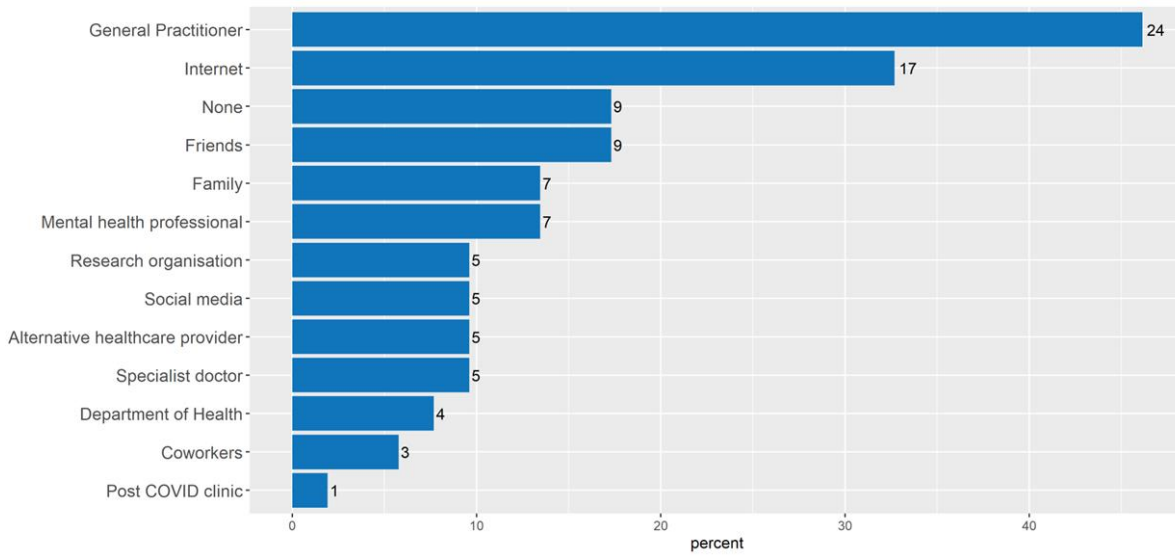
8. ACCESS TO INFORMATION & SUPPORT FOR LONG COVID

We asked participants with long COVID (n=52) which resources they used to seek information and/or support for long COVID. GPs were the most common information source, used by 46% (24/52) of participants. This was followed by seeking information from an Internet search (33%, 17/52), friends (17%, 9/52) and family (13%, 7/52; Figure 7).

Participants also reported seeking information and/or support for long COVID from other healthcare providers, including mental health professionals (13%, 7/52), alternative healthcare providers (10%, 5/52), and the Department of Health (8%, 4/52). Nine (17%) participants said that they had not sought any information or help for long COVID.

Figure 7: Sources of information or support for long COVID

Where have you accessed information or support for your long COVID?
N=52



FOCUS GROUP INSIGHTS

Survey participants who reported long COVID (ongoing COVID-19 symptoms for over four weeks following onset of COVID-19) were invited to participate in one of three semi-structured focus group discussions. The focus groups were conducted between 6 and 19 July 2022 involving 20 participants. The group discussions were facilitated by researchers from the University of Melbourne and Burnet Institute. Participants discussed the nature and duration of their symptoms, access to diagnosis, treatment and information about long COVID, the types of support they had received, and their recommendations for supporting people with long COVID.

SYMPTOMS OF COVID-19 AND LONG COVID

- Participants reported a wide range of symptoms and varying levels of severity of both COVID-19 and long COVID.
- Participants reported challenges in obtaining a clear diagnosis and effective treatment for their symptoms.
- Some people with comorbidities found that their chronic condition worsened (e.g., Attention deficit/hyperactivity disorder, arthritis, cancer, depression, endometriosis, HIV, kidney deficiency, and sinusitis).
- In addition to symptoms relating to cognitive function (e.g., brain fog), fatigue, respiratory symptoms and changes to smell and taste, some participants also reported feeling weaker and getting sick more often.

MENTAL HEALTH AND WELLBEING IMPACTS OF LONG COVID

- Long COVID symptoms, in combination with the impact of lockdowns were disrupting people's everyday lives including negatively affecting participants' mental health, work, and social relationships. Participants reported often feeling exhausted, misunderstood, anxious or fearful, frustrated, and isolated.
- Participants found the focus groups helpful in providing a rare opportunity to connect with other people with long COVID, alleviating feelings of isolation.
- Participants raised the need for increased mental health support beyond the increase to Medicare funded mental health sessions given the need for ongoing support due to long COVID.

ACCESSING INFORMATION ABOUT LONG COVID

- Participants relied on both formal and informal sources of information, but preferred to access evidence-based resources, especially online. However, they emphasised there was a lack of evidence on long COVID and its treatment.

BARRIERS TO HEALTHCARE ACCESS FOR LONG COVID

- Participants reported receiving little follow-up or support for their long COVID. There was concern about a lack of information tailored to people from culturally and linguistically diverse communities.
- Participants were aware that the healthcare system was under a lot of strain and healthcare workers were experiencing high levels of burnout.
- Participants also noted that long COVID clinics were at full capacity and found that telehealth consultations were more limited than earlier in the pandemic and that many doctors have stopped bulk billing.

HEALTHCARE RECEIVED FOR LONG COVID

- GPs and other health professionals had a crucial role in helping participants feel supported and validated. Previous experiences with healthcare services (positive and negative) greatly influenced patients' sense of being heard and patients' willingness to accept that they had long COVID.
- Participants also highlighted that long COVID clinics were a very useful resource for those who could access them.

WORKPLACE SUPPORT FOR LONG COVID

- Participants discussed the need for support at the workplace and for those people who had lost their source of income due to long COVID.
- Some participants reported having supportive teams and supervisors, others reported not being able to access sick leave and having to go back to work and fulfill long hours and night shifts.

PARTICIPANT RECOMMENDATIONS

- Participants' recommendations for supporting people with long COVID included:
 - Facilitating access to healthcare;
 - Providing more information about long COVID for healthcare workers and the general population;
 - Facilitating access to mental health services and peer support groups;
 - Establishing workplace support measures;
 - Providing additional support to people from culturally and linguistically diverse communities, people with previous physical and mental health conditions, and patients who are also healthcare workers.

Appendix

Table 1: Number and proportion of infections among 243 participants who had COVID-19 infections

	Number	Percent (%)
1 infection	218	90
2 infections	20	8
3 or more infections	5	2

Table 2: Number and proportion of infections prior to developing long COVID among 52 participants with long COVID-19

	Number	Percent (%)
1 infection	42	81
2 infections	7	13
3 or more infections	3	6

Table 3: Number and proportion of infections since developing long COVID among 52 participants with long COVID

	Number	Percent (%)
No infection	42	81
1 infection	6	12
2 infections	2	4
stop testing	2	4

Table 4: Number and proportion of COVID-19 vaccines taken prior to developing long COVID among 52 participants with long COVID

	Number	Percent (%)
No vaccine	4	8
1 vaccine	2	4
2 vaccines	15	29
3 vaccines	29	56
4 vaccines	2	4

Table 5: Number and proportion of vaccines taken since developing long COVID among 52 participants with long COVID

	Number	Percent (%)
No vaccine	28	54
1 vaccine	11	21
2 vaccines	5	10
3 vaccines	4	8
4 vaccines	4	8

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