

Submission to the Standing Committee on Health, Aged Care and Sport

Parliamentary Inquiry on Long Covid and Repeated Covid infections

By the Australian Long Covid Community Facebook Support Group

November 2022

The following members wished to be named in this submission: Adele Montgomery, Adina Chelom, Airlie Barwell, Alex Andra, Ali Hogg, Alicia Newnham, Allison LM, Amanda Payne, Amelia Crook, Amelia Kerr, Amy Orange, Andrew Gorman-Murray, Angela, Anna D, Anna Ryan, Anna Stacey, Annette Dodd, Avril Holt, Ayla Armstrong, B Oliver, Barbara Cass, Ben Sticpewich, Bethany Wormald, Bev Floyd, Bojan Kovincic, Brittany Williams, Brooke Welgus, Caitlin Smithen, Caroline Ford, Cattie Antionette, Chantal Tsakisiris, Christine, Christine Bailey, Christine, Gunson, Clair Zhang, Colin A Davies, Crystal Grant, Dana Weaver, Danielle, Darren Alan Bilton, David, David Sutton, Deborah Eveniss, Deborah Watts, Debra White, Diana Basso, Donna Bywaters, DP, Dr Helen Balkin, Dr Thomas Andrews, Elise Jones, Elizabeth Hinder, Emma Jane Fitzgerald, Emma Solomon, Erin Godwin, Erin Le Souef, Felicity Gay, Fiona Hook, Fiona McDonald, Fiona Pope, Fiona Sweet-Formiatti, Fran Colman, Francine Murphy, Gaye Kalpus, Gayle, Gemma McDonald, Georgia Goodsell, Georgie Haberfield, Gillian Harvey, Greta Cunningham, H Barker, H. Satchwell, Helen Doyle, Holly, Holly Hayes, Holly Shannon, J Barker, J Bennett, J. Mark Cooke, Jack Flynn, Jacqueline Hardy, Jade Denton, James Irvine, Jane Roman, Jane Tweedy, Janet Rose-Marie, Jayson Cuming, JC, Jeanette Trotter, Jennifer Johnson, Jennifer Ruhno, Jessica Miller, JK Birtus, Jo Wood, Jordan Crane, Judith Apte, Judy Li, Julia Robertson, Julie Collison, Julie Crawley, Julie Savill, Julie Smith, Julie Wurf, Kaitlyn, Karen, Karen, Karen Baker, Karen Dickinson, Karen Henry, Karen Palmer, Karren Hill, Kate Brill, Kate Heintze, Kate Kneebone, Kath Della Vedova, Kathrine Moroney, Kathy Coutts, Kathy Dallest, Katie E, Katie Powell, Katrina Findanis, Katrina Kerkow-Hill, Keira-Lee Leon, Kelly Jeanes, Kelly Linden, Kelly Rimmer, Kendall Parsons, Kerrie Chapman, Kerrie Richards, Kira Evans, Kirk Patston, Koa Webster, Kristen Fraser, Kristen Skinner, Kristie Morrison, Kylie Foot, L Mackay, L Thorsby, Lauren C, Laurin Milsom, Linda Isherwood, Lisa Francis, Lisa Henderson, Lisa Panetta, Lisa R, Louise Bailey, Lucinda, Lucy Beach, Fran C, Lucy Cowie, Luke Hamond Korte, Lynette, M Murray, M Sharma, Madeline Cooper, Margaret Morgan, Margie Moore, Margot Rylah, Marissa Price, Martine van Boeijen, Mary, Mary Jackson, Meg Bryar, Megan Fraser, Melanie Shottenkirk, Melinda Goodrich, Melissa Frankcomb, Melissa Giaquinta, Michelle Answerth, Michelle Johnson, Michelle McDonagh, Michelle Nolan, Michelle Verna, Mirabai Nicholson-McKellar, Miringa Toma, Missing Taxpayer, Naomi Pratt, Natalie Scott, Natasha, Natasha Barry, Nicole Lowes, Nicole McCartney, Olivia Hose, Patricia Powell, Paxton Percy, Penelope, Penny Menezes, Peri Coleman, Phoebe K, Pippa Yeoman, Rachael Taylor, Rachel Fain, Rani Lutwyche, Rebecca Askew, Rebecca Davis, Rebecca Francis, Rebecca Redgwell, Richelle Galvin, RM, Robert, Rocio Saracho, Ruth Newport Birnberg, Sandra, Sandra Collins, Sandra Rew, Sar McFadden, Sara Fuller, Sarah Munzer, Scott Haseler, Sean Simpson, Shakira Wilson, Sharon McGee, Simone Stewart, Siobhan Cichello, Sonja Drexler, Sophie Bryan, Sophie van Reijswoud, Stephanie Wilson, Stephenie Watts, Sue Collins, Sue Hallier, Susan Bishop, Susan Hart, Suzanne La Velle, Tahlie Edwards, Tao Jiang, Tara Barton, Tasmyn Matthews, Tess sorbello, Theresa Sheppard Thomas Ponissi, Toby Seager, Tori Haschka, Tracey Spicer AM, Trish Harrison, Trudy Clutterbok, Valerie Rendle, Vanessa O'Connor, Victoria Leibie, Victoria McGloin, Vivienne Stefanou, Wendy, Su Mon Kyaw-Myint

Executive Summary

This submission represents the lived experience of members of the Australia Long Covid Community Facebook group. In it we present findings from a survey conducted to inform this submission and make recommendations based on our quantitative and qualitative findings. We focussed our submission on TOR 1, 4 and 6 as noted below:

TOR#1. The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;

TOR#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;

TOR#6. Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

Our lived experience of Long Covid

We are predominantly female between the ages of 30-59 years old. Most of us had had two vaccines before we were infected with Omicron after the removal of public health measures on 1 December 2021, and most of us have had only one Covid infection. But of those who have been reinfected, reinfection has tended to make Long Covid symptoms worse.

Long Covid is mainly diagnosed by GPs but there is a significant lack of knowledge and resources regarding the diagnosis and treatment of Long Covid. Long Covid clinics have not been found to be a useful source of information due to inequitable access, long wait times and in some instances poor provider knowledge.

We suffer from a wide range of symptoms, with Fatigue/PEM (Post Exertional Malaise) and cognitive challenges the most common. We seek help with symptom management from a range of (allied) healthcare professionals. Our interactions with the healthcare system are largely not positive and many report minimising and inappropriate treatments.

Long Covid has a significant impact on all aspects of our lives, many of us have had to leave jobs, go on extended leave or work reduced hours. Some of us can no longer work in the occupations we trained for, including healthcare workers, and others have discontinued studies. Many of us are unable to carry out activities of daily living (self care, cooking, shopping, caring for children), and our social and community participation has also been severely affected.

Recommendations

- **See us:** Nationwide data collection to obtain the magnitude and burden of Long Covid in Australia from diagnostic and treatment data, supplemented by representative, national surveys. We also need research on interventions and significant funding for this research.
- **Hear us:** Please listen to our stories through research and data collection.
- **Care for us:** We need education of health and allied health professionals on Long Covid and nationally consistent, high quality, properly funded Long Covid clinics with telehealth access to ensure those in regional and remote areas are not missing out. We also need you to protect us from re-infections which includes making antivirals available and mask mandates.
- **Support us:** People with Long Covid need intensive support including employment support, income support, support for equipment and medications, and support to have suitable workplace adjustments. We also need work environments that are supportive to avoid getting re-infected and to design jobs that accommodate our needs. We have lots to offer and we cut across every section and occupation and industry. There needs to be a nationwide systemic approach.
- **Partner with us:** Work with us to design policy and research. Acknowledge our lived experience. We can be your research and policy partners. Don't make decisions without us.
- **Don't dismiss us:** Please do not minimise Long Covid and Covid-19 infections. We need a vaccine plus strategy.

We provide quotes and responses from individual participants in our submission. They illustrate the points summarised above. The impact of Long Covid is real, significant and requires a more systematic approach if we are to heal as a whole society.

We welcome the opportunity to answer any further questions the committee may have and present at a hearing.

Table of Contents

Executive Summary	2
Our lived experience of Long Covid	2
Recommendations	3
Table of Contents	4
Introduction	5
About the group	5
About the survey	5
Part 1: Group responses	6
Understanding our experience (TOR#1)	6
Who is experiencing Long Covid?	6
Number of Covid-19 infections	7
Testing for initial Covid-19 infection	8
Long Covid Diagnosis	8
Prevalence of Long Covid	8
Long Covid Symptoms	9
Long Covid Treatment	9
Interactions with healthcare services and providers	9
Helpful information sources for Long Covid	10
Impact of re-infections and vaccination on Long Covid	11
Impact of vaccination on Long Covid	11
Understanding the impact on us (TOR#4)	11
Impact on work and income	11
Impact on study	13
Impact on activities of daily living	13
Part 2: Individual survey responses	13
Individual lived experience	14
Shared insights about improving patient-centred care (TOR #6)	15
Educate and support healthcare providers	15
Dignity and care for the whole person	16
Create and sustain ‘Living Guidelines’	17
Improve access to appropriate care and benefits	18
Communicate clearly and collaborate	19
Recommendations	20
See us	20
Hear us	20
Care for us	20
Support us	20
Partner with us	20
Please don’t dismiss us	21
Attachment A: Additional findings from patient led long COVID survey	22

Introduction

As an online support group for Australians who suffer from or care for someone with Long Covid, we are in a unique position to speak to this Inquiry. Due to the debilitating nature of this disease we used a survey to give as many people as possible an opportunity to be heard, and to offer insights into the reality of learning to live with Long Covid.

About the group

The Australia Long Covid Community Facebook group was started in June/July 2020. Founded by three women who saw the need for a peer support group for Australians who still have ongoing symptoms at least four weeks after getting Covid. This is a patient only group, where members can share and compare experiences and information about doctors, tests and treatments. It has become a helpful and compassionate community where people with Long Covid from many walks of life have found solidarity and support.

At the beginning of 2022, the group had 250 members and as of 11 November currently has over 3000 members. It is managed by 5 voluntary administrators, people also sick with Long Covid. We welcome on average 80-100 new members a week. A key theme of posts in the group has been the lack of medical and social support and understanding for the Long Covid experience. The group wanted to contribute to the Parliamentary Inquiry to give an understanding of the lived experience of Long Covid. There is currently no national tracking of Long Covid and the group decided that collecting our members' experiences via survey would give useful qualitative information.

About the survey

The survey was open between 30 September 2022 and 16 October 2022. Questions were developed by group administrators and group members who are researchers with lived experience of Long Covid. Free text responses were also included to give those unable to make a personal submission an opportunity to contribute.

Out of a total of 2844 members (at that time), 607 completed the survey, giving us a response rate of 21.3%¹. This is fantastic for a Long survey (15-20 mins), with no incentives, in a population suffering significant negative health impacts. A demographic breakdown of survey respondents and comparison with Census 2021 statistics (since a comparison with the general Long Covid population is not possible) is provided at Attachment A.

We acknowledge the limitations of our survey before presenting the findings. We did not have adequate time or resources to get approval from a Human Ethics Research Committee (HREC) and thus we did not reach out specifically to children. We also were unable to test new survey questions with cognitive interviews and pilot testing due to a lack of time and resources. We used the free Google Forms for our survey so could not include data validation and automatic checks while the survey was live. We limited our survey to Facebook group members, rather than opening it to the broader community. This could have led to selection bias as certain age groups do not use Facebook. We also were unable to

¹ The response rate calculation is a rough estimate because some people filled out the survey on behalf of someone else.

include questions about previous health status and pre-existing conditions due to a lack of space. On balance, the survey is fairly representative and captures the Long Covid experience in Australia.

All quantitative analyses were undertaken by Su Mon Kyaw-Myint who takes responsibility for any errors in numbers (including transcribing errors) presented in this submission. We also have not yet conducted modelling to determine factors that predict Long Covid, nor subgroup analyses. We hope that the Committee will allow us to submit a supplementary submission that contains further findings in the new year or allow us to present more information at a face to face session.

In what follows, we address terms of reference 1, 3, and 4. We believe the findings we present should inform research, policy interventions and care for all Australians.

Part 1: Group responses

Understanding our experience (TOR#1)

Who is experiencing Long Covid?

We asked respondents to fill out the survey for each family member with Covid or on behalf of a family member with Covid, noting the challenges of doing a long survey while experiencing Long Covid symptoms. Only 5% of the surveys were completed on behalf of children (0-18 years old). The overwhelming majority (93.1%) completed the survey for themselves.

Noting the limitations of our survey (small sample sizes for the youngest and oldest age groups), the most common age group with Long Covid was the 40-49 years age group (31.8% of respondents). This was followed by 50-59 years age group (23.4%) and 30-39 age group (20.6%). The vast majority with Long Covid were female (84.0%). Similar age and gender distributions were observed in other patient-led studies², suggesting these are likely to reflect a real-world scenario. More information on age, gender and geographical distribution of survey respondents can be found in Attachment A to this submission.

² Medinger, G, Altman, D. The Long COVID handbook. Kindle ed. Penguin Health Handbooks; c2022. Chapter 11, What does recovery look like; p. 219.

While we cannot rule out survey bias, our findings support the literature that the risk of developing Long Covid is higher among women and the middle aged^{3,4,5}. This has been reported in Australian media⁶ and Australian surveys⁷.

Number of Covid-19 infections

In our survey, 86.2% respondents reported having had only one Covid-19 only one time, as reported in the Covid-19 Impact Monitoring Survey⁸. A further 12.5% reported having had Covid-19 twice. Eleven (1.3%) reported having had 3 or more Covid-19 infections.

Most survey respondents (93%) indicated they got Long Covid after their first Covid-19 infection. Twenty three people (3.8%) developed Long Covid after their second infection and seven people reported having Long Covid after their third or more Covid infection. Twelve (~2%) respondents developed Long Covid symptoms after vaccination (see Attachment A, Figure D).

We asked respondents about the date of their first Covid infection as most Australians have had it once only. Only 46 (7.6%) and 47 (7.8%) of survey respondents got their first Covid infection in 2020 and 2021 respectively. The majority of respondents got Covid after 1 Dec 2021 (n=506, 83.5%). Consistent with the burden of infection with Omicron experienced around Australia, 88.1% of respondents had Long Covid after infection with the Omicron variant. Approximately 7% had Long Covid after infection with the alpha strain and a further 3% had Long Covid after infection with the delta variant (Table A-2, Attachment A).

The fact that the bulk of the burden of Long Covid in Australia is from the Omicron wave is due to the dropping of various health protection measures since 1 Dec 2021. While evidence from research showed that the risk of Long Covid is lower after Omicron compared to Delta⁹, we can see that Omicron infections do lead to Long Covid, despite being fully vaccinated. Due to the sheer number of people infected with Omicron, the magnitude of Long Covid from this wave is huge, despite Omicron being milder and the majority of Australians have had two vaccine doses prior to first infection.

³Perlis RH, Santillana M, Ognyanova K, et al. Prevalence and Correlates of Long COVID Symptoms Among US Adults. *JAMA Network Open*. 2022;5(10):e2238804. doi:10.1001/jamanetworkopen.2022.38804

⁴Subramanian, A., Nirantharakumar, K., Hughes, S. et al. Symptoms and risk factors for Long COVID in non-hospitalized adults. *Nat Med* 28, 1706–1714 (2022).

<https://doi.org/10.1038/s41591-022-01909-w>

⁵Bai F, Tomasoni D, Falcinella C, Barbanotti D, Castoldi R, Mulè G, ..., Monforte AD. Female gender is associated with Long COVID syndrome: a prospective cohort study. *Clin Microbiol Infect*. 2022 Apr;28(4):611.e9-611.e16. doi: 10.1016/j.cmi.2021.11.002. Epub 2021 Nov 9. PMID: 34763058; PMCID: PMC8575536.

⁶

<https://www.abc.net.au/news/2022-07-20/younger-active-female-data-reveals-Long-covid-profile/101251352>

⁷

<https://www.roymorgan.com/findings/9107-Long-covid-linked-to-mental-distress-unemployment-and-is-affecting-more-women-than-men>

⁸Biddle, N, Korda, R. The experience of COVID-19 in Australia, including long-COVID-August 2022, c2022, p. 10.

⁹Antonelli M, Pujol JC, Spector TD, Ourselin S, Steves CJ. Risk of Long COVID associated with delta versus omicron variants of SARS-CoV-2. *Lancet*. 2022 Jun 18;399(10343):2263-2264. doi: 10.1016/S0140-6736(22)00941-2. PMID: 35717982; PMCID: PMC9212672.

Testing for initial Covid-19 infection

The vast majority (93%) of Long Covid patients have had their first Covid diagnosis confirmed by either PCR or RATs. There were exceptions for early patients when no RAT or very limited PCR testing was available. Testing was also not available easily during RAT or PCR supply shortages.

Long Covid Diagnosis

The initial diagnosis of Long Covid was most commonly made by GPs (63%), followed by self-diagnosis (30%). We know that clinical diagnosis based on symptoms is accurate for Long Covid diagnosis as reported in a recent study (pre-print)¹⁰ (see Fig E, Attachment A for more info).

Prevalence of Long Covid

By our group's definition, everyone in the group and all survey respondents have Long Covid. We are aware of multiple definitions of Long Covid and present statistics below for two common definitions used in the literature (Figure 1). The bulk (92%) of respondents met the 12-week criteria for Long Covid.

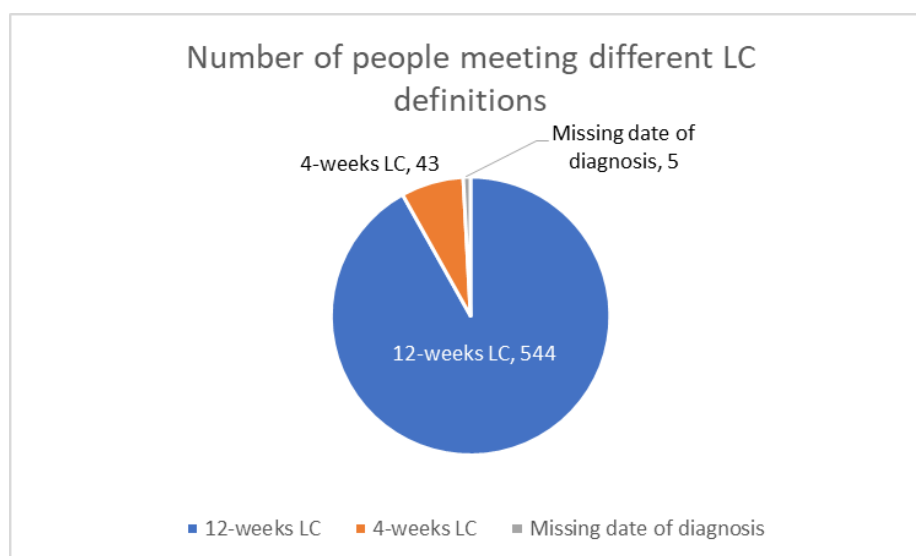


Figure 1. Duration of Covid symptoms

The median duration of Long Covid in weeks was 25.6 weeks and the median duration in days was 200 days.

¹⁰ Klein J, Wood J, Jaycox J, Lu P, Dhodapkar RM, ..., Iwasaki A. Distinguishing features of Long COVID identified through immune profiling. medRxiv [Preprint]. 2022 Aug 10:2022.08.09.22278592. doi: 10.1101/2022.08.09.22278592. PMID: 35982667; PMCID: PMC9387160.

Long Covid Symptoms

Similar to what has been reported in the Long Covid literature¹¹ respondents reported a wide range of symptoms. The most common symptoms were fatigue/PEM, concentration issues, sleep issues, difficulty in information processing and impairments in working memory. The most commonly experienced symptoms also tended to be the most severe symptoms experienced by survey participants. The exceptions were Dysautonomia and tinnitus which were experienced by 33% and 29% of patients respectively. Over 60% of those experiencing Dysautonomia indicated their symptoms were severe and 52% of patients with tinnitus reported their symptom was severe.

Some symptoms such as vision and balance were less common, experienced by 12.5% and 11.2% of respondents respectively. However, the majority of those experiencing these symptoms reported that the effects of the symptoms were severe (64% and 71% respectively). For more information, see Table A-6, Attachment A.

Long Covid Treatment

People sought help from a wide range of health and allied health professionals for diagnosis and treatment of Long Covid. This suggests the need to find answers and trialling different avenues to find help and relief from their wide ranging symptoms.

About two in five have seen a Cardiologist, 21% have been to a Long Covid clinic and a similar proportion have seen a Naturopath (Table A-7, Attachment A). About 12% have been treated as an inpatient at a hospital for their Long Covid symptoms and a third (33%) have been to the Emergency Department. Other commonly sought professionals were Psychologist (24%), Physiotherapist (27%) and Naturopath (20%).

Interactions with healthcare services and providers

A major barrier in the management and treatment of Long Covid is the lack of knowledge among professionals and resources for Long Covid patients. Many are having to rely on their own research to obtain information and treatment. This is further demonstrated below.

The vast majority of patients (73.4%) said lack of knowledge on Long Covid was a barrier in accessing health care. A lack of services as a barrier to accessing health care (by 60.7% of respondents). Fear/uncertainty was reported as a barrier by 43.5% of respondents.

When seeking care for Long Covid, many patients experienced disbelief by healthcare professionals as well as minimising (Figure 2). Often the symptoms were blamed on anxiety and depression. About two thirds also experienced unwillingness to diagnose Long Covid. The experience of providing outdated treatments when accessing healthcare was also common. More than half the patients also indicated they experienced poor communication.

¹¹ Subramanian, A., Nirantharakumar, K., Hughes, S. *et al.* Symptoms and risk factors for Long Covid in non-hospitalized adults. *Nat Med* 28, 1706–1714 (2022). <https://doi.org/10.1038/s41591-022-01909-w>

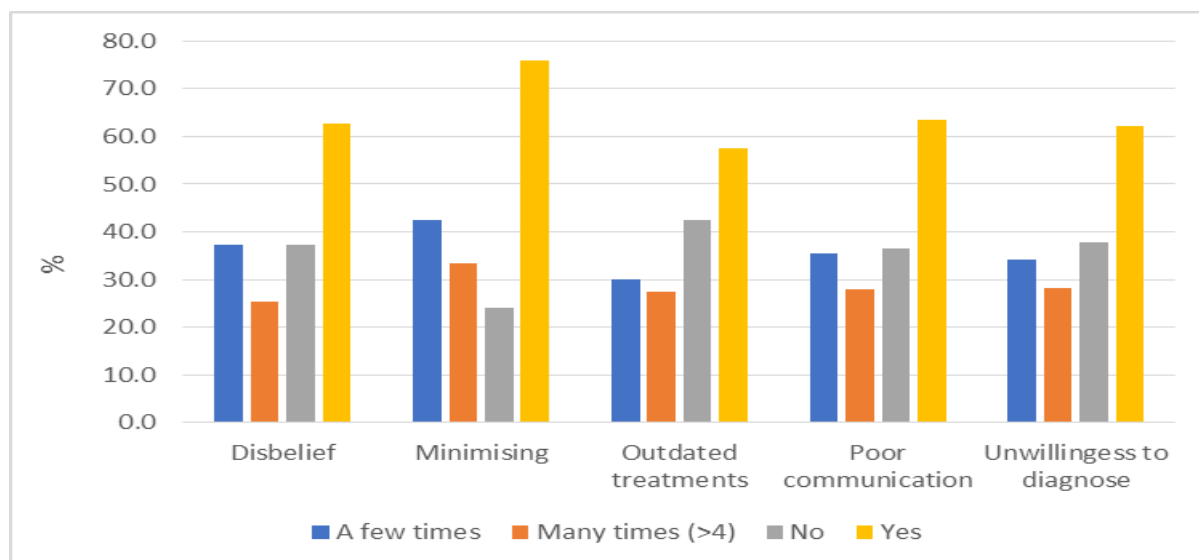


Figure 2. Patients' experience in accessing healthcare services for Long Covid

Helpful information sources for Long Covid

Participants reported that Research Groups, Social Media and GPs/Specialists were the most helpful sources of information on Long Covid. Even for the three most useful information sources, between 10% to 20% of respondents reported these sources as 'not helpful', suggesting improvements are still needed across the board.

Over 70% of participants reported that Long Covid clinics are not a helpful source of information (Figure 3). This may be partly due to the long wait for these clinics and the variation in the quality of these clinics around the country with some offering outdated therapies such as graded exercise therapy and cognitive behavioural therapy.

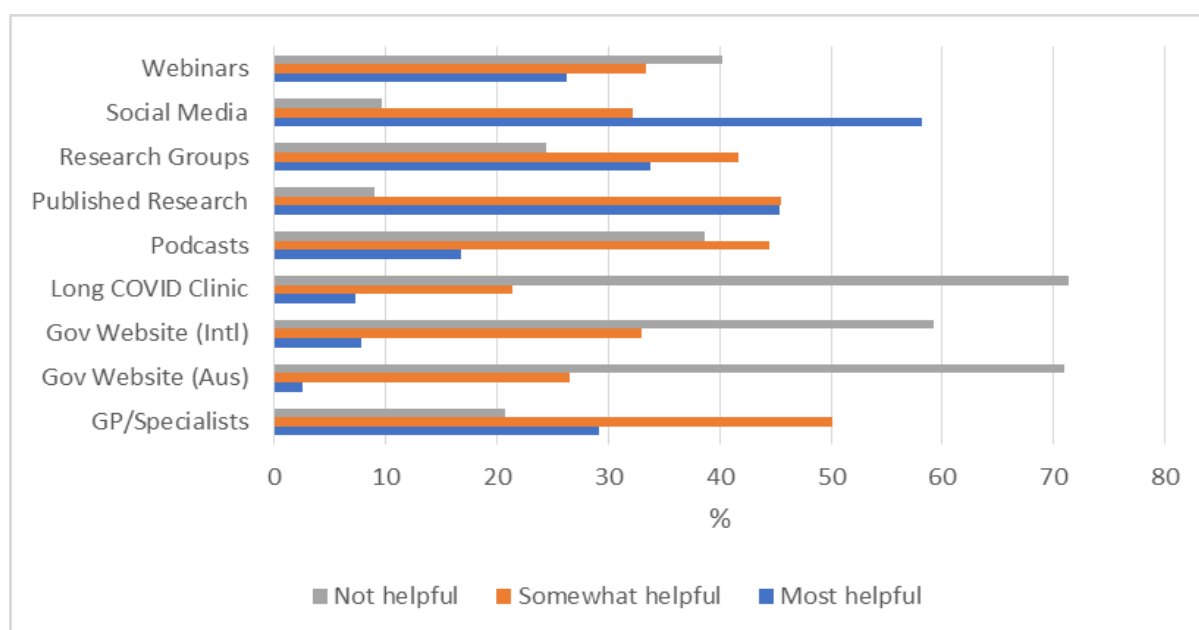


Figure 3. Helpful information sources for Long Covid

Impact of re-infections and vaccination on Long Covid

About 14% of our survey respondents had multiple Covid infections (n=84) and 24 (28.6%) had a non-Omicron strain as their first infection. The majority of those who were reinfected had both their first and subsequent infections during the Long Omicron wave (presumably different sub variants of Omicron).

Among reinfected people, 15.4% indicated symptoms of their second infection was completely different from symptoms of their first Covid infection. One in five reported that symptoms were the same for both infections. The most common experience was that some symptoms were similar between the two infections but some were different (61.9% reporting this).

When asked to compare the severity of infections, one in four reported that their second infection was more severe than their first Covid infection. However, half reported that their second infection was less severe than their first.

The majority of people who were re-infected reported the reinfection made their Long Covid symptoms worse. However, the degree of symptom deterioration varied. Some experienced worsening of only some of their Long Covid symptoms whereas others reported that all their Long Covid symptoms were worse after re-infection. This is similar to the findings in another survey¹² (for more information, see Fig F, Attachment A).

Impact of vaccination on Long Covid

Just over 30% of survey respondents had a Covid vaccination (primary or booster) after developing Long COVID.

Among this group, 55.2% said vaccination had no effect on their Long Covid symptoms (Fig G, Attachment A). About 27% said vaccination made their Long Covid symptoms temporarily worse. About one in ten (9.3%) said vaccination made their Long Covid symptoms permanently worse. A small proportion (2.2%) indicated that their Long Covid symptoms were permanently better after Covid vaccination.

Understanding the impact on us (TOR#4)

Impact on work and income

A significant proportion of Long haulers (11.8%) have lost employment due to Long Covid. A majority (80.1%) reported having a job before Long Covid, fewer (68.3%) currently do.

We found no evidence of changes in the distribution of job type before and after Long Covid. About 17% had their own business and approximately 80% worked for an employer.

We asked about the impact on their (1) pre Long Covid job, and (2) their current job.

¹²

<https://www.Longcovidkids.org/post/a-world-first-effect-of-covid-reinfection-on-people-living-with-Long-covid>

Eight per cent reported being fired or let go from their pre Long Covid job (Figure 4). More than half were absent from their current job (with or without benefits), and 40 per cent were working reduced hours due to the symptoms of Long Covid.

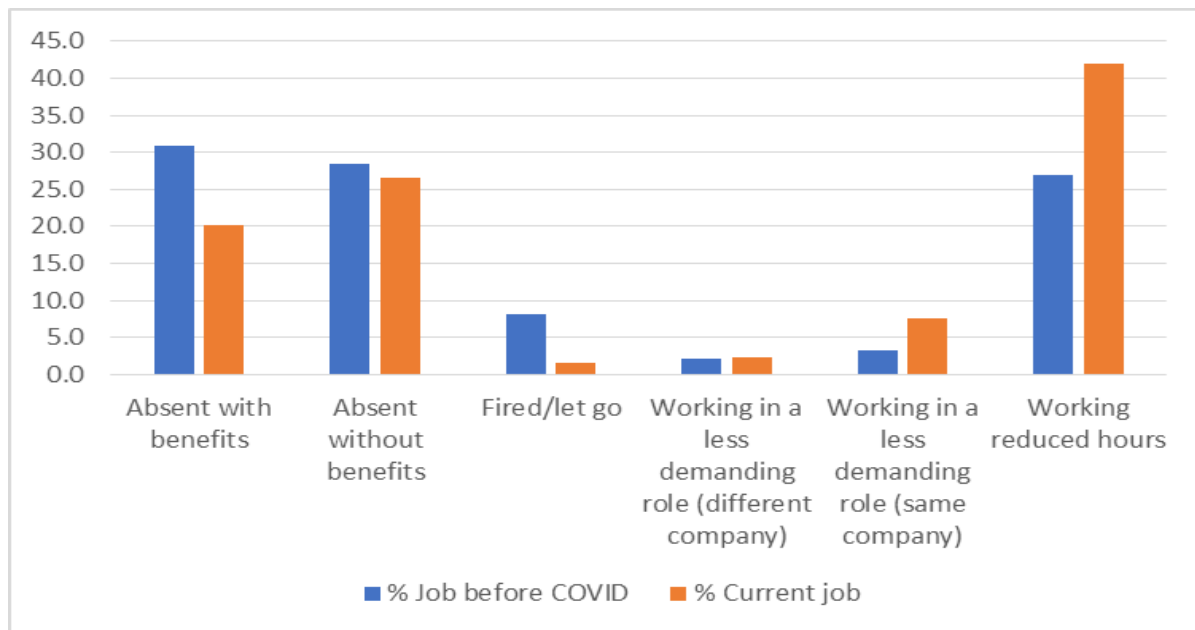


Figure 4. Impact of Long C on current job and job pre-Covid

People were more likely to report being absent with or without benefits in their 'pre- Long Covid' job than in their current job. In their current job, they were more likely to report having to work reduced hours. We note that in many cases respondents may be in the same job for both time points.

We then asked more questions about participants' current job and the effect of Long Covid. Over the past month, for the majority of respondents (64.6%), Long Covid affected their job 'every day'. Only 4% reported that Long Covid had no impact on their job over the past month (see Fig H, Attachment A).

About a third reported working zero hours in all their jobs in the last week (Table A-5, Attachment A), and only one in seven with a job was working more than >37.5 hours.

We also asked about actual hours worked vs. expected work hours as people could be working full-time or part-time and working hours alone does not give us the full picture of the impact on employment. One in four said they were not working any of their expected work hours. Less than one in ten (9.3%) reported being able to do their expected hours. Just over 25% were working between 51%-75% of their expected work hours.

We found that flexible or reduced hours and breaks was the most common form of workplace adjustments provided. Almost 40% also had reduced responsibilities. Only one in four reported that peer support was provided (Figure I, Attachment A).

Impact on study

When asked about the frequency of the impact of Long Covid on studying, almost half of those who were studying reported that it was affecting their study everyday. However, almost 30% reported that Long Covid did not have any impact.

The most common impact on studies was being absent (46%). A further third suspended their studies and 16% discontinued their study (Fig J, Attachment A).

Impact on activities of daily living

Most respondents reported that their activities of daily living were affected by Long Covid. Almost all (96.9%) said their ability to do housework was affected with 60% reporting that this was affected 'every day' (Fig K, Attachment A).

Over 90% of respondents also indicated that their ability to cook, and care for others were impaired due to Long Covid. Over 40% reported that Long Covid affected their personal care 'everyday'.

Long Covid had an impact on many other aspects of life, from shopping, volunteering to worship (Fig L, Attachment A). Over 70% reported Long Covid affecting their ability to exercise 'everyday' and 64% reported impact on recreation 'everyday'. The proportions of participants reported 'every day' impact on socialising and shopping were 61% and 50% respectively.

When asked about requesting and accepting help from family and friends, less than 40% of participants reported always feeling well supported. We are unsure if this is because they were reluctant to ask for help all the time (only 16% always asked for help) or if there was a reluctance to accept help all the time.

Part 2: Individual survey responses

Four open ended questions were included in the survey:

- If you could change ONE thing about the process of getting a Long Covid diagnosis, what would it be?
- If you could CHANGE ONE thing about accessing support to manage the symptoms of Long Covid, what would it be?
- Anything else?
- What ONE thing could peak bodies in Australia do to ensure health professionals are kept up to date with rapidly emerging evidence and developing best practice for those living with Long Covid?

In most instances participants used these prompts to progressively tell their story, so responses were analysed per respondent rather than per question. In what follows four participants tell their stories, before many others add their voices to illustrate the dominant themes that emerged from the analysis. Some quotes have been lightly edited for spelling and capitalisation, and square brackets indicate additions to support readability.

Individual lived experience

*I was an international flight attendant and became sick in March 2020. Not being able to get tested in the early days of the pandemic, I was constantly told being sick was due to stress. I find it so frustrating that almost 3 years later I still have to justify my illness. We need more awareness in the medical community that this can happen to anyone. The patients need to be listened to and we are in desperate need of financial support for research and treatment—**Respondent 108.***

*I have been incapacitated for 4 months with severe neurological symptoms pain and paresthesia. Have been unable to work as an ED nurse, have exhausted all leave entitlements and have spent \$5000 thus far looking for answers via GPs, neurologists and ED presentations to no avail. Shame on you all. Spark an interest into LC, the symptoms, treatment and care. Keep abreast of what is known in the UK and US. Stop hiding under a blanket and accept this is debilitating and real!—**Respondent 194.***

*This was very distressing for myself and my family. My mum took me to many doctors because I was fainting and my heart races when standing. At 6 months I'm still waiting to see a specialist to discuss [a] possible POTs diagnosis. The Drs we went to weren't really educated about Long Covid, they didn't see any connection to having Covid. My mum cried a lot because she couldn't find anyone that knew what was going on with my health. I've lost a lot of weight and been very unwell for months. I was referred to St Vincent's Long Covid clinic then redirected to the Hunter area. I was then told the rehab clinic does not help under 18s. I'm still waiting to see a private paediatric doctor as there wasn't a public service available for my age group in the Hunter area. Definitely need more information and support and a service that directs people to Doctors that are comfortable diagnosing LC. This is the worst part when you're struggling with your health and there's an obvious connection to the virus, but doctors minimise the symptoms and blame anxiety. Meanwhile you're stuck with debilitating symptoms that need treatment. I have been unable to attend school for months due to no access to specialist treatment in my area—**Respondent 277.***

*GPs need up to date information on Long Covid and treatment options. I had to do all the research for my husband....[He] has been on the [Long Covid clinic] waitlist for nearly 4 months - he has been told that he will never be bumped up the list... because no one gets better... My husband is a teacher. He had been on leave for 3 months. I'm concerned that when his leave is all used up he will lose his job. He is the principal earner in our home as we have a child with a disability that I care for. Teaching is really strenuous work and there is no option for him to go into light duties. If he could be transferred to a desk job he may be able to return to work but it's not possible for him to be in a room with 27 students all with their own individual learning needs, many of whom are high needs, it is mentally gruelling work and physically exhausting with no recess or lunch breaks due to duties and covering absent staff. Teaching is a nightmare to navigate when you are unwell as there is the added expectation that you actually create and send in the work for classes to complete when you are sick - sheer lunacy to have this expectation that when you call in sick you still have to work at home. Fortunately he has been given leave up until this point without having to set work. I'm so anxious about the future and what will happen when his leave runs out. If he loses his job it will be financial ruin for our family - we will not be able to pay our mortgage and will end up homeless with nothing—**Respondent 274.***

Shared insights about improving patient-centred care (TOR #6)

In what follows, we present quotes illustrating five of the most dominant themes.

Educate and support healthcare providers

Participants overwhelmingly spoke of a lack of understanding of them and their suffering, which they attributed to a lack of provider-knowledge regarding the diagnosis and treatment of Long Covid. Therefore, it is not surprising that the single most often cited action to address this was education and support for healthcare providers, including mandated professional development regarding the validity of Long Covid as a formal diagnosis and access to treatment pathways and guidelines in keeping with current research and best practice from around the world.

As a doctor myself this has been debilitating and I cannot stress enough the need to inform and continue to treat this smartly and reduce the spread of Covid—Respondent 15.

This condition is debilitating and not recognized or researched sufficiently. The GPs do not know what to do and you are left on your own to try and manage. Mine got worse after three infections and I still have had no medical help—Respondent 188.

Be able to see any GP and they would have the knowledge or at least be willing to look into it before dismissing it entirely or insisting it's just mental health and pushing antidepressants—Respondent 224.

Being given access to helpful information about it, from the moment of diagnosis. There's loads, it's taken me 9 months of my own research on my phone, sick in bed to find it. And doctors brush me off saying 'we don't know much yet about Long Covid - because they don't look!—Respondent 191.

Educate GPs that their professional and ethical role does not stop at the limit of their own ignorance. I have not attempted to seek an appointment at a Long Covid clinic because reports from those who have waited months for appointments are mostly of experiencing disappointment—Respondent 195.

Better informed GP's so that they know where to refer after 12 week diagnosis. In SA we have very few expert Cardiologists, Exercise Physios, etc that are experienced in LC, CFS and POTS/OI. This is not sufficient with long waiting lists. More specialists need to be educated to help with the workload. Another Cardiologist sent me away knowing things were not right with me but not knowing how to treat me, literally telling me he did not want to see me again. The waiting time to be diagnosed for LC is 3 months, then being referred and waiting another potential 5 months for specialists. This impacts on a person's mental health as they have no support...are scared, have potentially lost their life...their work, family, social life and income is impacted. It is a dark time with no idea when they will recover. More doctors need to be educated to help with this crisis. I was lucky, I got in early at the start of the Dec/Jan wave and had a great GP who already understood POTS/CFS and did not question me. Others are not so lucky. I guess I am not so lucky that I was so sick with LC....Educate them,

ensure there are clear guidelines, listen to patients and believe they are sick even if their tests all come back clean—Respondent 159.

Dignity and care for the whole person

The second most often cited action to improve patient-centred care was a desire to be acknowledged and treated with dignity. In many instances requests were tempered with an acknowledgement that everyone is coping with uncertainty, including providers. Many of the calls to be treated as a whole person included references to the complex nature of the disease and the challenges experienced in accessing healthcare in a hyper specialised system where effective case management is espoused but very seldom delivered.

When a medical professional believes you and listens to you, it feels like a gift. Sadly not all do—Respondent 167.

Taking this condition seriously. Not making patients feel inadequate and hopeless—Respondent 157.

That we are okay if you don't know the answer but acceptance that LC is a thing and we are not making it up—Respondent 86.

Empathy for everything you lose (work, independence, looking after your family, social life, daily tasks)—Respondent 297.

Drs not looking at the whole situation. E.g., Covid increases cholesterol and thyroid out of normal range. Despite being bed bound and told to restrict exercise, when reviewing blood tests [recommendation] restyled 30 sec later [and] told to manage cholesterol means exercising. When pointing out I couldn't leave bed and asked how that works Dr was baffled! Drs are just looking at singular problems and using old school solutions in isolation, not the whole system impacts—Respondent 153.

I'd like to have been allocated something like a case manager, who has clinical knowledge and perhaps counselling training, who can just 'be there' to help coordinate, guide and inform. I'm fatigued, brain-fogged and trying to hold down my job (sole income earner for my household). So it's hard to find spare energy and headspace to become informed, make sensible decisions, and keep on track. That's probably where a GP should step in but I live in a small town where GPs seem to only have time to dispense medications or order tests - I'm lucky to get a 6 minute conversation. I'm sure they don't start out in medical practice with this intent but I'm guessing the current funding model doesn't help—Respondent 156.

I've had Doctors and Specialists laugh at me - and treat me in a demeaning way - while diagnosing some serious consequences of Long Covid. After telling me I had an aneurysm, one neurologist said, "Just don't go sky-diving or do extreme sports any time soon". This was not a laughing matter. I was horrified—Respondent 190.

Finding Drs who cared enough to explore further than their usual go to tests. That I could have got support (might have prevented stroke three months after being cleared of Covid active infection). Received no follow up care and found out I was

living with dangerously high blood pressure (Covid induced). That I was prescribed statins much earlier as these made a significant improvement to brain fog which persisted for 20 months. [Read] research papers like people with Long Covid do—Respondent 494.

That it not be assumed to be a mental illness or psychological issue, simply because a practitioner does not have an answer. Everyone is too quick to refer to MH services, especially when there has been mental illness in a patient's past. My GP Clinic has behaved APPALLINGLY toward anyone with LC. I have not had access to my GP because they are too afraid that my symptoms are acute Covid infection. Please TAKE THIS SERIOUSLY! We beg you! People in this country need services and support. We need ways of replacing income lost due to this condition. STOP putting your heads in the sand—Respondent 597.

Create and sustain 'Living Guidelines'

Whilst the need for education was paramount, the means through which this would be achieved was often described in terms of access to trusted information. Sometimes this was described in terms of formal criteria, pathways and guidelines. At others it was described as access to a central repository through which providers and patients could access international best practice in an accessible form that is easy to update. More than a few called for 'Living Guidelines' offering access to a mix of the formal and more agile insights into emerging best practice. It is worth noting the strong call for greater engagement with international research and best practice because it reveals a significant lack of trust for Australian practitioners and policy makers amongst Long haulers who have felt the burden for their care has fallen to them. 'Doing it all myself' was a recurrent sentiment expressed by many and it involved all aspects of getting a diagnosis and treating a wide range of relapsing and remitting symptoms over extended periods of time.

Knowing where to get and find support would be a good start. Currently we have an ocean of information out there, a lot of it is bogus and some is useful as the govt has gone quiet on all things Covid it's impossible to know who to believe and who to trust....The front line workers, Doctors, nurses etc should be kept up to date with the numbers of those affected by Covid-19 and Long Covid as from what I am hearing the symptoms can be very different—Respondent 145.

Give the medical profession relevant info on up to date treatments and medications and mandate training in this so we don't get brushed off with the 'we don't know much about Long Covid yet' line. Long Covid clinics or list of relevant LC trained GPs in every town and city with this information—Respondent 191.

Have living guidelines in digital health systems—Respondent 125.

Single set of 'live' clinical guidelines with Medicare Benefits Schedule items to match—Respondent 253.

Create an Australian specific web site with straightforward guidelines to get to a diagnosis—Respondent 341.

Sharing information in one easily accessible site (rather than my GP having to Google information)—Respondent 422.

Communicate better and actually rely on best practice which is evolving so you can't stick with one position—Respondent 212.

I think there needs to be more focus and learning from the research and practical experience of Doctors in other countries. For example the UK is two years ahead in treating Long Covid and we should be learning from their experience and adopting their best practices. Where the knowledge and treatment remains uncertain in this new condition, Doctors need to take a more collaborative approach with the patient; listening and respecting their lived experience—Respondent 143.

Improve access to appropriate care and benefits

Whilst education to increase knowledge about the condition was clearly the priority, improved access to appropriate care and benefits was the second most dominant theme in the responses. This included strong calls for regional access to ensure equity of access for all Australians, reduced wait times, and care and benefits designed for people living with a chronic condition often presenting as a relapsing and remitting disability with marked impacts on one's ability to access to care (e.g., mobility and cognitive challenges).

There is no support, Long Covid Clinics are not available to [every]one, imagine having cancer and [being] told you might get on waiting list and be seen in 12 months so we can obtain data from you, but have no treatments—Respondent 10.

I was a nurse working 70 hours a week during the pandemic. I caught Covid working on the public Covid wards. The only government help I have had is one, one off payment for isolating. This illness has cost me my quality of life, family, friends, partners—Respondent 23.

I cannot afford the medications and treatments I need to stabilise my symptoms and for my quality of life. There is no financial support for sufferers. I cannot access support in my home even though I am often too breathless, fatigued and in pain to clean, cook, do my laundry, brush my hair, etc. I have no quality of life at all since I got Long Covid. I feel completely abandoned—Respondent 201.

I live 45 mins-1hr from medical practitioners. Often extremely fatigued, not able to get to appointments. Phone services would be highly beneficial—Respondent 448.

I would like to access support to manage the symptoms that is available in my area and is comprehensive and thorough, following up to date research so that outdated methods like graded exercise are not what's recommended—Respondent 80.

Greater financial aid to assist in managing this chronic and debilitating disease, as all sick leave and benefits were used up very early and I am ineligible for NDIS or Centrelink payments unless I cease working altogether—Respondent 16.

The thing I would absolutely change...is the way our govt/health depts have limited the supply of antivirals....It makes no sense....if we want to get people active and back to work!—Respondent 162.

Communicate clearly and collaborate

Linking many suggestions for improved care was the need for clear communication: between patients and providers, within primary care practices, between generalists and specialists, across local health care districts, within and across regions, and with international peers and centres of excellence. We cannot wait for best practice to take years to make its way into every corner of Australia, we need for everyone to share knowledge and communicate the best of what is known, in a time of great uncertainty.

Communication is lacking between medical professionals, government and media. So many people are suffering alone and seeking help from the internet because there isn't any help from anywhere else—Respondent 65.

Having all healthcare professionals on the same page - i.e. one professional will give you advice that is the opposite to another professional's advice—Respondent 23.

One flow of communication to the health professionals that encompasses the breadth of symptoms. LC is a total body breakdown. Doctors need to recognise a variety of symptoms to make informed decisions on referring the patient to the next specialist. But equally important there has to be a way for the health professionals to learn from their patients (results/progress/learnings) and feed that info back—Respondent 237.

Please focus on research to understand all the mechanisms and provide treatments. Mostly, get the clear messaging out to stop people becoming infected and getting Long Covid—Respondent 168.

More people talking publicly about it would help to make people with LC feel less alone. The proportion of people affected isn't reflected in the public narrative—Respondent 264.

The most useful advice I have received has been from the Emerge ME/CFS website and organisation and I urge any response to Long Covid to consult ME/CFS patient groups first and foremost.... Consult with Emerge, the ME/CFS peak body who already have the resources available—Respondent 50.

Also need to have a Covid umbrella Organisation such as Cancer Council, Heart Foundation etc—Respondent 73.

Recommendations

See us

Nationwide data collection to obtain the magnitude and burden of Long Covid in Australia from diagnostic and treatment data, supplemented by representative, national surveys. We also need research on interventions and significant funding for this research.

Record acute case numbers at a population level, diagnose those of us with Long Covid and issue a Long Covid Medicare code, provide data on trends that make us visible so others can make informed choices about their long term health outcomes.

We note that PCR testing is again being restricted in Australia and most people are no longer offered a PCR but are provided with a RAT. This is an issue of concern for us.

Hear us

Please listen to our stories through research and data collection. Take the time to listen to us and acknowledge our suffering. We know there are no easy answers. We have no choice, we live with the unknown and inexplicable every day.

Care for us

An absence of knowledge should not equal an absence of care. Leverage best practice from around the world regarding the treatment of Long Covid and other post viral illnesses such as ME/CFS. Educate and support GPs and invest in centres of multidisciplinary excellence in all regions. Take the time to understand the impact of this disease on our ability to access care (e.g. mobility), and the ways in which complex intersecting challenges such as insecure employment, caring responsibilities and other chronic conditions compound the challenges we face and the disadvantages we experience.

Support us

Those of us learning to live with Long Covid need a wide range of support including appropriate leave entitlements, income support, support for equipment and medications including antivirals, and suitable workplace adjustments. We also need safe work environments, which include clean air and appropriate mitigation strategies including mask wearing when necessary to avoid getting re-infected. We have lots to offer and we contribute to every occupation and industry. We need a nationwide systemic approach.

Partner with us

Work with us to design policy and research. Acknowledge our lived experience. We can be your research and policy partners. Don't make decisions without us.

Nothing about us without us. Lived experience is one area where we have knowledge. This knowledge should be used in the development of treatment pathways and in the framing of future research. Talk to us, ask us where we have found help and whom we trust. It's not a

long list but it is a list of the generous and the concerned including emerge.org.au, Long Covid physio, independent research groups, and patient advocacy groups.

Please don't dismiss us

Please do not minimise Long Covid and Covid-19 infections. We need a vaccine plus strategy. We are the price society is willing to pay to return to 'normal'.

Attachment A: Additional findings from patient led long COVID survey

Characteristics of survey respondents

Compared to Census 2021¹³, we had a higher number of respondents from Victoria and the ACT.

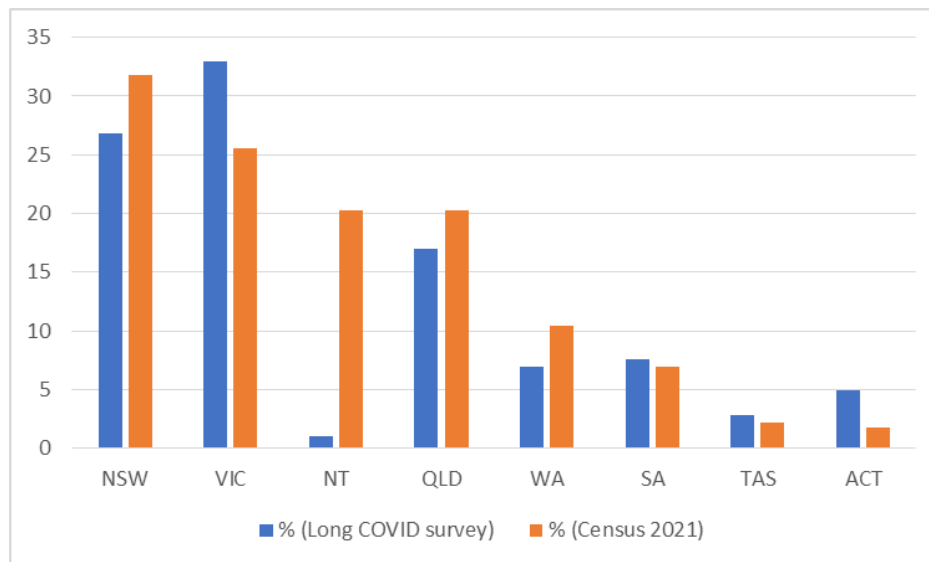


Figure A. State/territory distribution of survey respondents compared to Census 2021

We had a higher proportion of participants in the 30-59 years age groups compared to the Census 2021 population (Fig 2). This may partly reflect the higher prevalence of long COVID around middle age (as reported in many studies). We may be missing people in the oldest age groups due to technological barriers as our survey was conducted online. We note that the two youngest age groups in our survey were not directly aligned with Census 2021 age categories which are 3 to 9 years old and 10 to 19 years old.

¹³ <https://www.abs.gov.au/statistics/people/people-and-communities/location-census/latest-release>

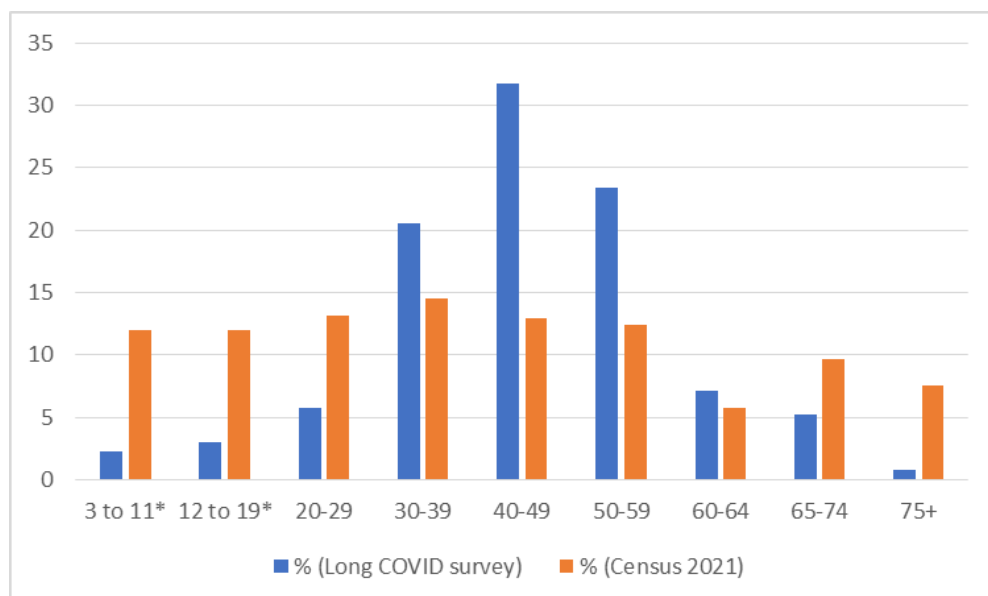


Figure B. Age distribution of survey respondents compared to Census 2021

The vast majority of survey respondents were females. We think this partly reflects the higher prevalence of long COVID among females.

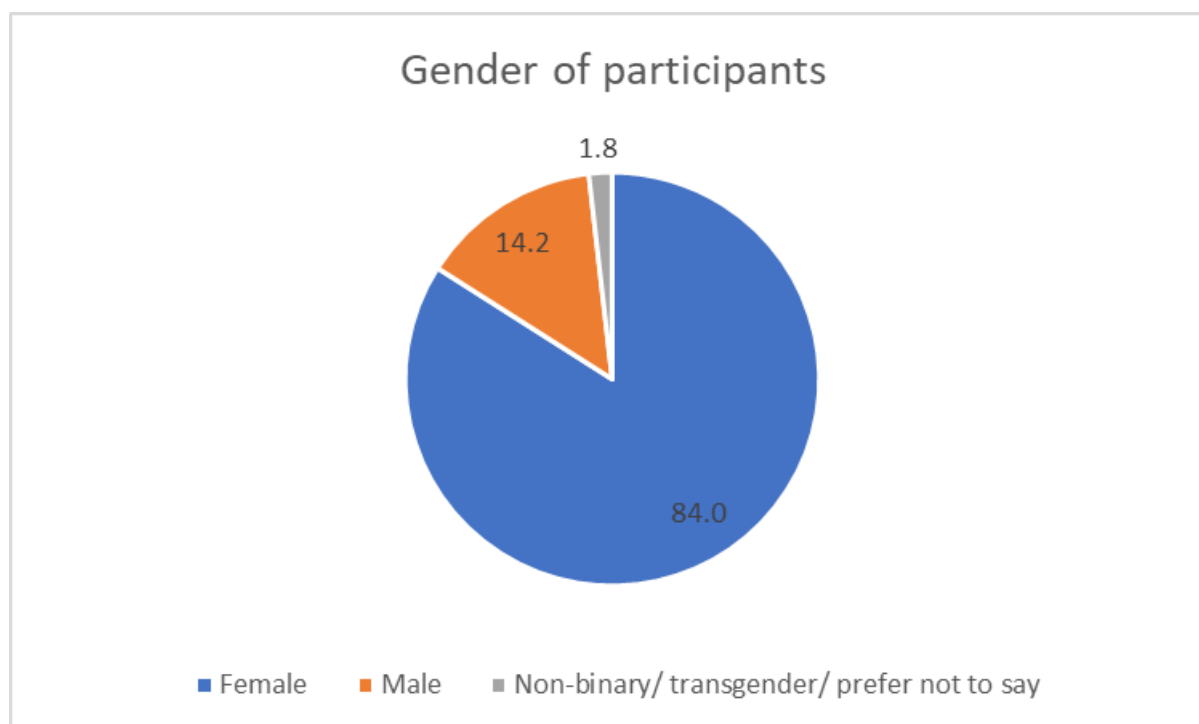


Figure C. Gender distribution of survey respondents vs. Census 2021

Supplementary survey findings

Table A-1. Who are you completing this survey for?

Q1. Who are YOU completing this survey for?	Freq .	Percent
Child (0-18 years)	31	5.1
Myself	565	93.1
Parent	1	0.2
Partner	9	1.5
Adult child (19 years or older)	1	0.2
Total	607	5.1

Table A-2. Which infection caused long COVID?

Derived from the date of first COVID infection	Freq .	Percent t
	1	
Alpha Wave 1	31	5.1
Alpha Wave 2	11	1.8
Missing date	7	1.2
Between Alpha and Delta	4	0.7
Delta	18	3.0
Omicron	535	88.1
Grand Total	607	100

Table A-3. Number of COVID-19 infections

Q7. NUMBER of COVID-19 infections?	Freq .	Percent t
One	523	86.2
Two	76	12.5
Three	5	0.8
Four	1	0.2
Five or more	2	0.3
Total	607	100

Table A-4. Testing status of first COVID infection

COVID testing	Freq.	Percent t
NEGATIVE but symptoms following close contact with a confirmed case	11	1.8
No test, symptoms WITH a clinical diagnosis	23	3.8
No test, symptoms WITH a positive ANTIBODY test	2	0.3
No test, symptoms WITHOUT a clinical diagnosis	8	1.3
Positive PCR	269	44.3
Positive RAT	294	48.4
Grand Total	607	100.0

Table A-5. Hours worked last week among those who currently have a job

Hours worked last week	Freq .	Percent
Zero hours	154	31.9
1-7.5	53	11.0
7.51-15	71	14.7
15-22.5	51	10.6
22.51-30	61	12.6
30-37.5	26	5.4
>37.5	67	13.9
Total	483	100.0

Table A-6. Long COVID symptoms: presence/absence and severity

Symptoms	% Severe (among those who have experienced the symptom)	% who have experienced this symptom
Fatigue/PEM	68.32	98.32
Concentration	40.07	96.8
Sleep	37.67	90.48
Information Processing	33.03	93.48
Working Memory	32.97	93.98
Dysautonomia	32.82	61.16
Joint Pain	29.8	79.61
Muscle weakness	29.45	84.75
Breathlessness	28.94	87.28
Tinnitus	28.52	52.24
Headaches	28.4	86.21
Anxiety	28.25	85.42
Word Finding	28.02	90.29
Muscle Pain	27.92	83.33
Tachycardia	27.19	62.64
Mobility	25.77	75.27
Palpitations	24.94	77.78
GI Issues	24.79	65.02
Migraines	24.76	57.07
Chest Pain	23.61	72.55
Depression	22.95	77.6
Sexual dysfunction	22.71	45.89
Menstruation	22.46	34.31
Dizziness	21.8	83.68
Allergies	21.07	50.45
Ears	17.91	47.86
Paraesthesia	15.31	40.19
Nausea/Vomiting	14.24	57.47
Tremors	13.55	45.64
Vision	12.53	64.11
Skin Rashes	12.5	41.8
Diarrhoea	11.45	53.8
Balance	11.2	70.68
Fainting	8.45	26.25

Table A-7. Treatment tried for long COVID

Treatment type	% tried treatment
Acupuncture	29.7
Alternative Medicine	47.1
Antibiotics	37.7
Anticoagulants	9.3
Antihistamines	71.5
Anti-inflammatories	65.8
Aspirin	36.8
Beta-blockers	20.6
Cardiac (Other)	15.5
CBD Oil	11.1
Colchicine	8.6
Corticosteroids	33.0
Hyperbaric Oxygen Therapy	2.7
IV Vitamins	11.9
Low Dose Naltrexone	11.6
Massage	41.3
Melatonin	43.8
Nutraceuticals	15.4
Occupational Therapy	19.3
Pacing	73.1
Physiotherapy	47.9
Pre/Probiotics	59.3
PPIs (reflux)	29.6
Speech Therapy	4.6
SSRIs	29.1
Therapy (psychological)	38.3
Traditional Chinese Medicine	9.6
Vagus Nerve Stimulation	22.8
Vitamins (oral)	87.3

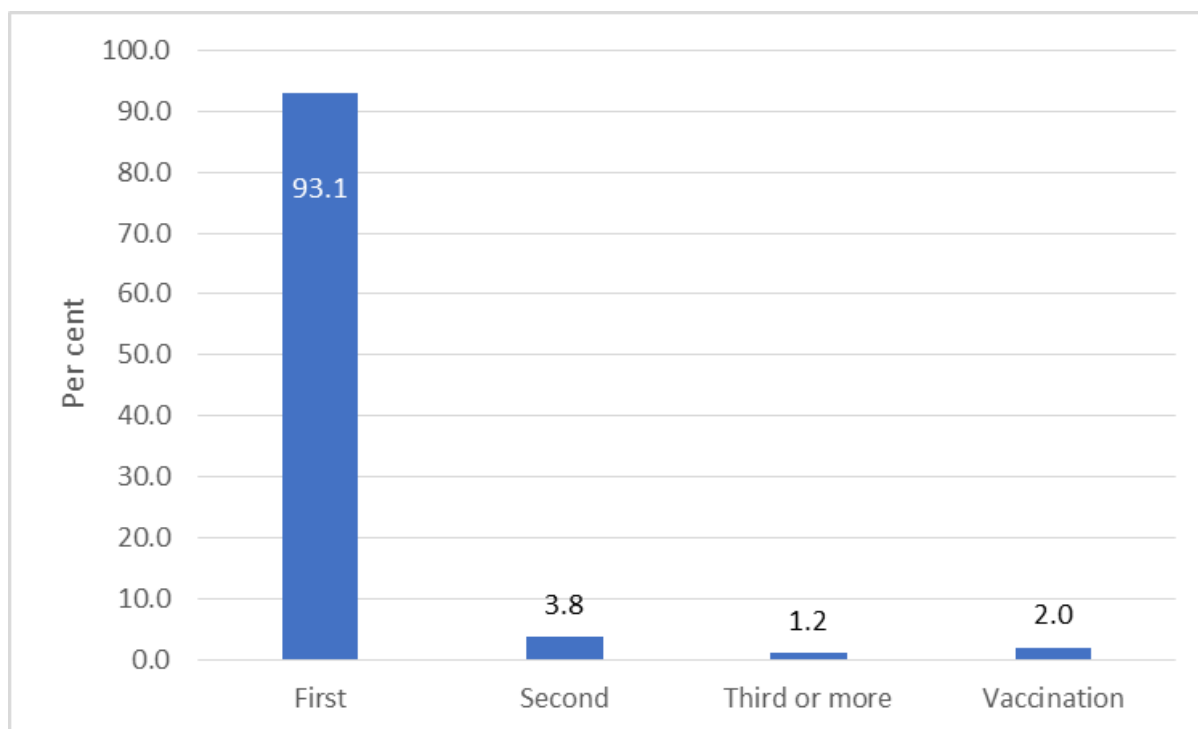


Figure D. After which infection did long COVID start?

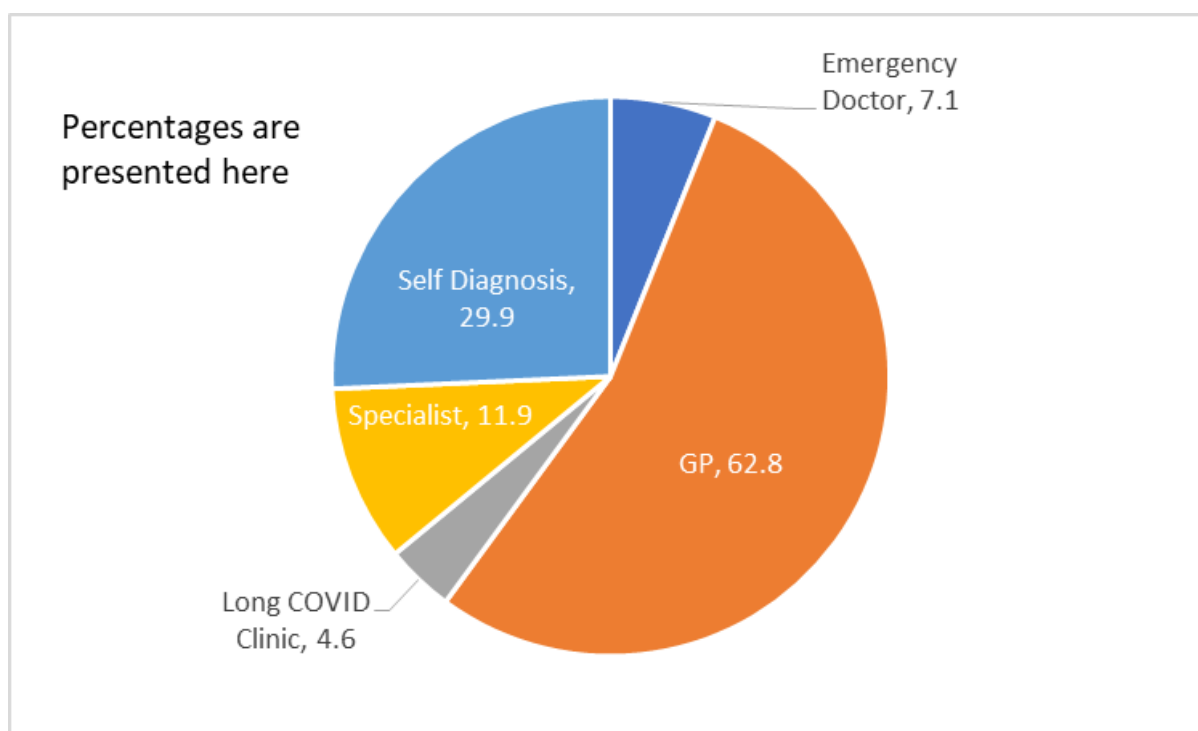


Figure E. Who made the initial Long COVID diagnosis?

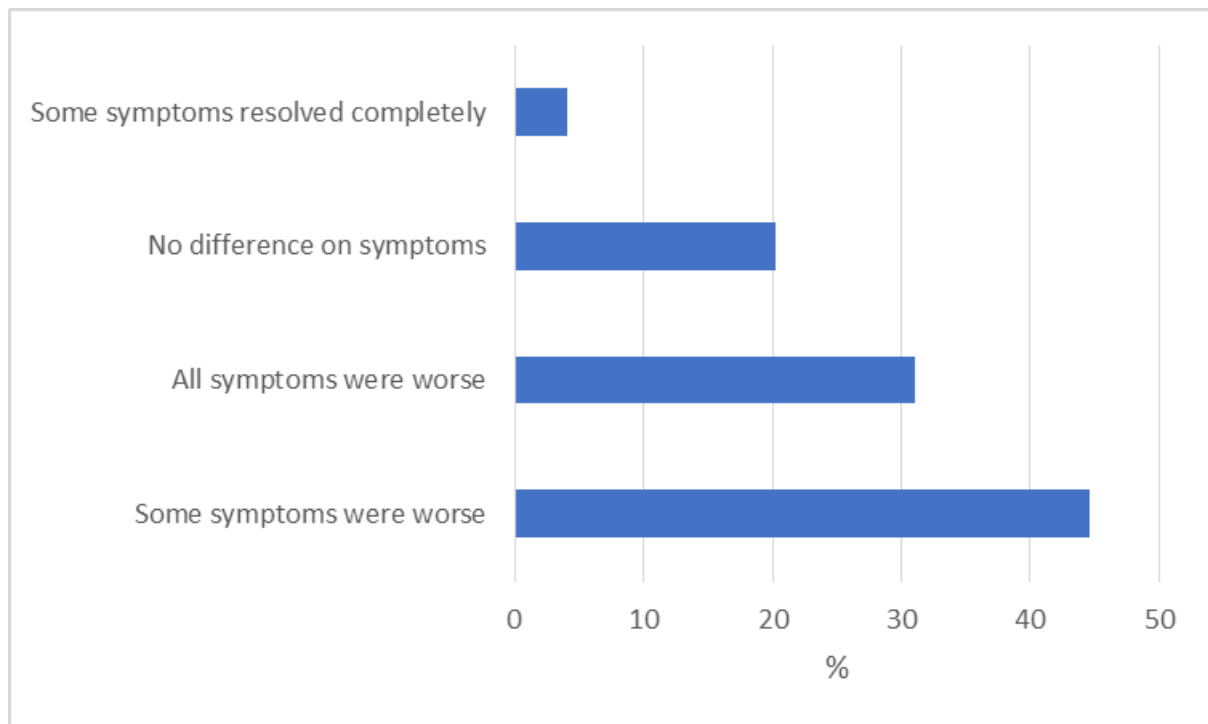


Figure F. The effect of COVID re-infection on Long COVID symptoms

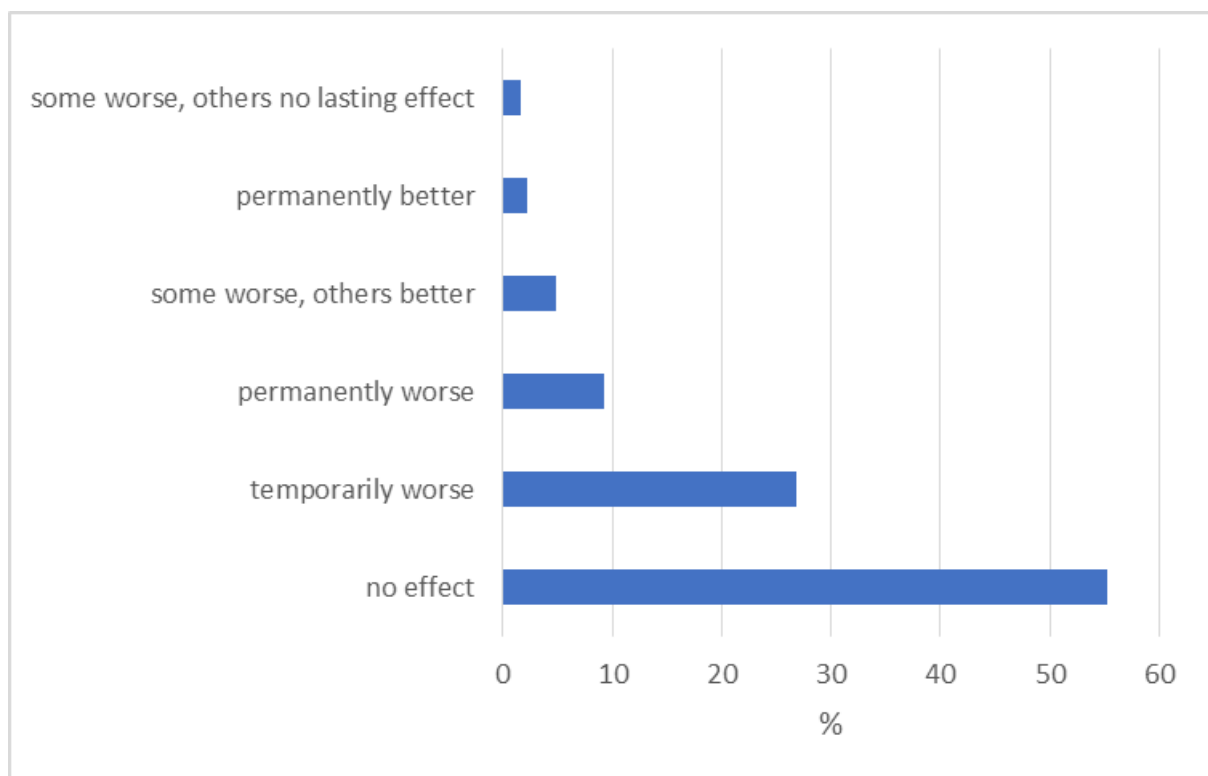


Figure G. Effect of vaccination on Long COVID symptoms

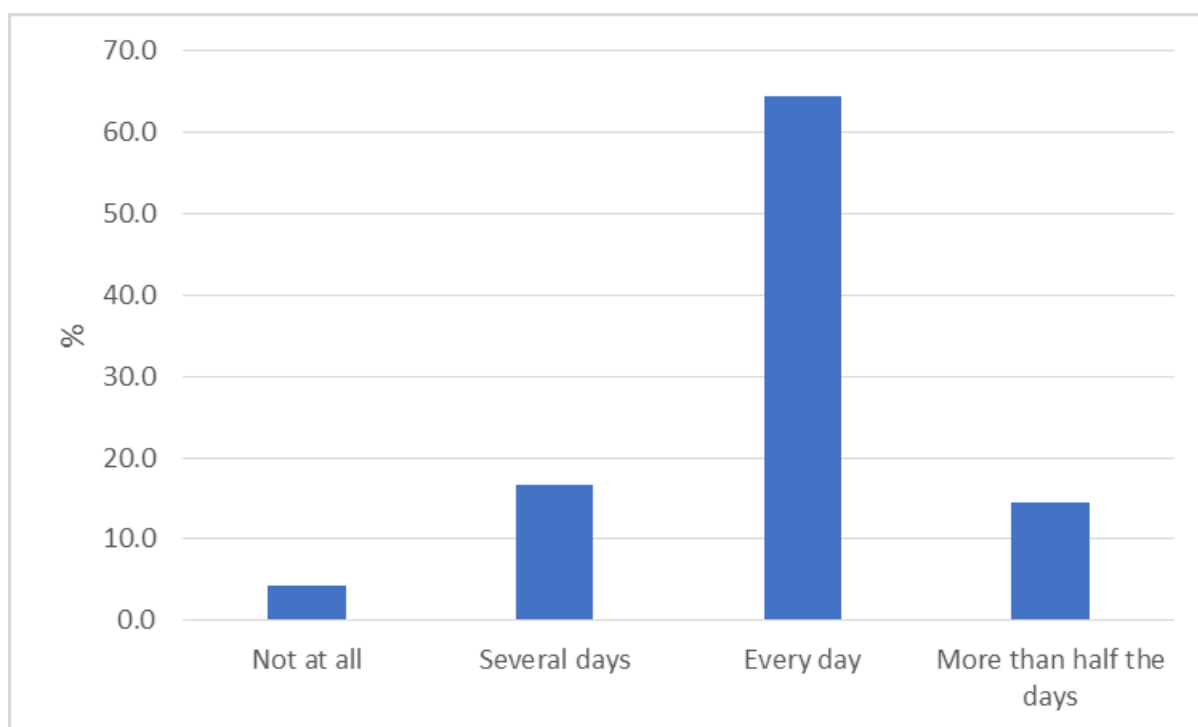


Figure H. Over the past MONTH, how often have Long COVID symptoms affected your employment?

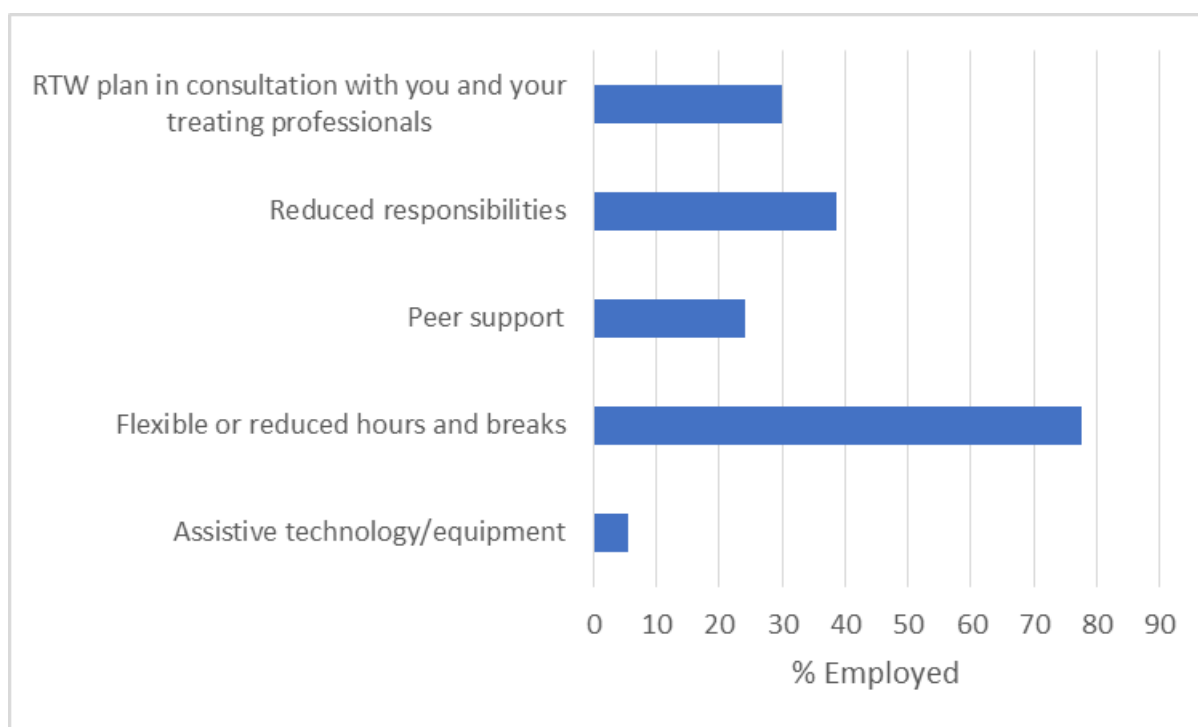


Figure I. Workplace adjustments and accommodations (multiple responses accepted)

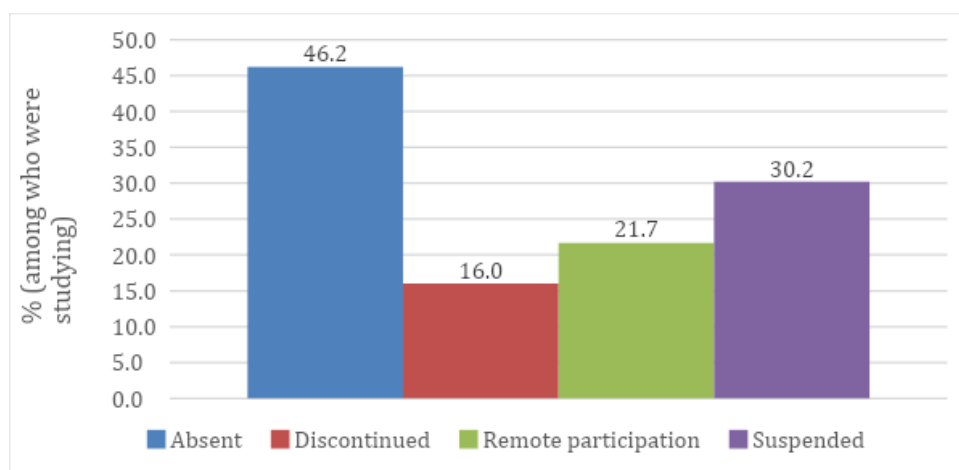


Figure J. Impact of Long COVID on study

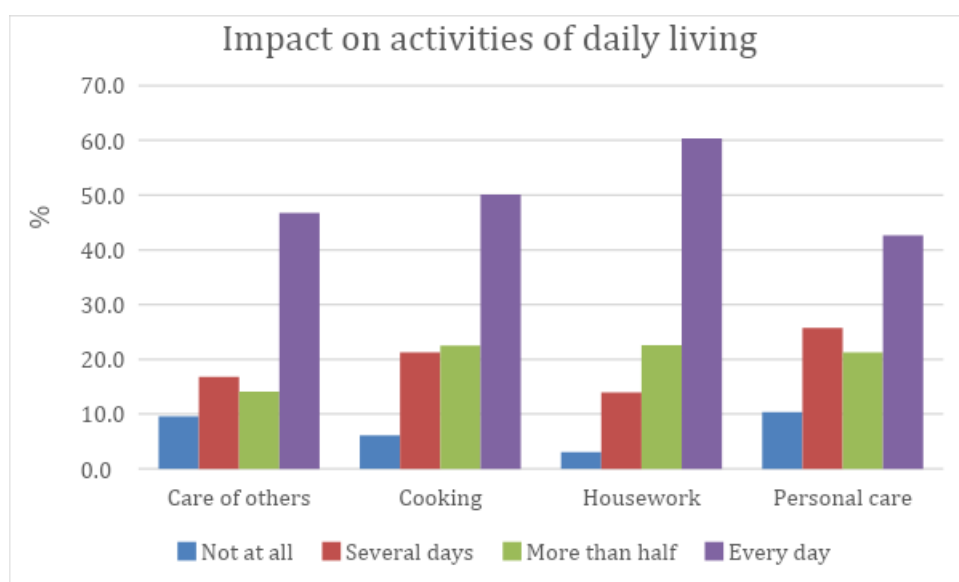


Figure K. Impact of Long COVID on activities of daily living

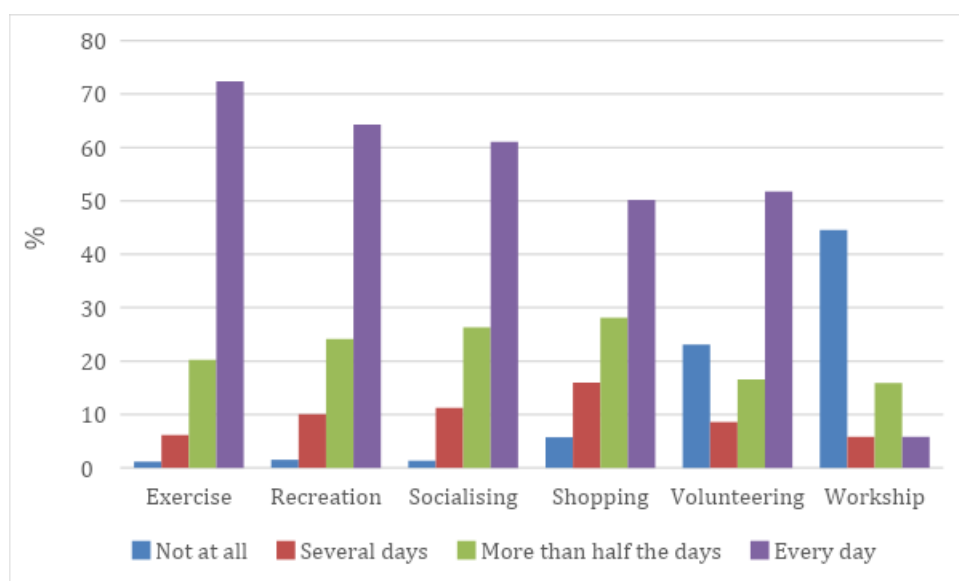


Figure L. Impact of Long COVID on other areas of life