



How do Covid reinfections affect Long Covid?

Results from an internet survey of people with Long Covid

Summary

Long Covid Support and Long Covid Kids surveyed people with Long Covid about their experience of being reinfected with Covid. Responses were received from 484 adults and 112 children and young people. Reinfection worsens the symptoms of Long Covid in the majority those who are still symptomatic. Reinfection causes a recurrence of Long Covid in 60% of those who were in recovery or remission. 89% of respondents first got Long Covid after their first infection, 10% after their second infection and 1% after their third. Most adult respondents had been vaccinated before their second infection.

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SUMMARY

Long Covid Support and Long Covid Kids surveyed people with Long Covid about their experience of being reinfected with Covid.

Responses were received from 484 adults and 112 children and young people (CYP) who had had at least two Covid infections.

Reinfection worsens the symptoms of Long Covid in the majority those who are still symptomatic. Of those who still had Long Covid at the time of reinfection

- 80% had a worsening of symptom severity
- 10% had an improvement in symptom severity
- 85% had either a return of old symptoms or new additional symptoms
- 10% had a resolution or improvement in symptoms

Of those who were in recovery or remission, reinfection causes a recurrence of Long Covid in 60%. Of these 40% said that the second bout of Long Covid was about the same severity as the first time, 32% said it was less severe and 28% more severe.

89% of respondents first got Long Covid after their first infection, 10% after their second infection and 1% after their third. Of those who had had more than two infections, 78% reported that they first had Long Covid after their first infection.

RECOMMENDATIONS

People with Long Covid should be considered as vulnerable to Covid and should be offered antiviral treatment on reinfection.

People with Long Covid should avoid reinfection.

INTRODUCTION

Anecdotally, people with Long Covid have been reinfected and have reported the effects of this. This survey was an attempt to aggregate these experiences to provide some insight into the effect of reinfection with Covid on Long Covid symptoms.

At the time of writing, there is no other published data to show the effects of reinfection on people with a history of Long Covid.

METHODS AND MATERIALS

The online survey service Survey Monkey was used to gather data. The link was promoted via several social media platforms by Long Covid Support and Long Covid Kids. Respondents were not asked to supply any personal or identifiable information so all data are fully anonymous.

The survey was open for 11 consecutive weeks, from Monday 4 April 2022 to 19 June 2022 and all responses were collected in that period.

Questions were predominantly offered as multiple choice although some questions had an option to add a comment if the answer they wanted to give was not an option.

The survey was open to adults and CYP who met the following criteria:

- Have had at least 2 infections with Covid-19
- Have had Long Covid following at least one of these infections
- The first infection was in January 2020 or later

Respondents were able to have another person complete the survey on their behalf. Respondents over the age of 15 were permitted to complete the survey themselves, but those under 15 years were asked to have an adult complete it for them.

A positive SARS-CoV-2 test was not a requirement for participation. This reflects the lack of community testing in the early parts of the pandemic.

SAMPLE CHARACTERISTICS

The survey was completed by 596 people.

Age							
Adults (age 20 – 79)		Children and young people (age 3-19)					
484 (81%)		112 (19%)					
Sex							
-emale Male				Other/Prefer not to say			
All: 460 (77%) Adults: 396 (82%) CYP: 64 (57%)	All:130 (2 Adults: 82 CYP: 48 (All:130 (22%) Adults: 82 (17%) CYP: 48 (43%)		All: 6 (1.0%) Adults: 6 (1.2%) CYP: 0 (0.0%)			
Number of Covid infections							
Two infections	Three infe		ee infections		More than three infections		
All: 505 (85%) Adults: 408 (85%) CYP: 97 (87%)	All: 80 (13 Adults: (1 CYP: 14 (All: 80 (13%) Adults: (14%) CYP: 14 (9.8%)		All: 11 (1.8%) Adults: 10 (2.1%) CYP: 1 (0.9%)			
Hospitalisation in first/ second infection							
Not admitted to hospital	Admitted to hosp	itted to hospital			Sought hospital care but not admitted		
448 (75%)/ 519 (87%)	37 (6.2%)/ 16 (2.	1%)	16 (2.7%)/ 15 (2.5%) 95 (16%)/ 46 (7.7%)				

Table 1 Sample characteristics

Age Distribution

The age categories for CYP were chosen to match those used by the Office for National Statistics in their Coronavirus Infection Survey and cover the age range 0 - 19 years. There was a bimodal distribution with a peak in both the CYP and adult age ranges. The most common age category was 40-44, with 54% of the sample in the age range of 35 - 55. The most common age group in CYP was 12-14. 83% of CYP were in the age range 8 - 16. There were no respondents under the age of 3 or over the age of 79.



Figure 1 Age distribution of respondents

Country of respondents

Responses were gathered from people in 30 countries. Just under half of respondents were in England at the time of the first infection. 374 (63%) were in the United Kingdom (including Northern Ireland). The next most common country was the USA (16%). The 'Other' category includes 22 other countries.

Country	percentage	number
England	48%	289
USA	16%	94
Scotland	9.2%	55
Wales	4.5%	27
Ireland	4.4%	26
France	2.0%	12
Netherlands	1.7%	10
Canada	1.3%	8
Other	13%	75

Table 2 Country at time of first infection

Date of Infection

Data are presented as infection per quarter. The total number is only 593 because some respondents made an error in writing the date, giving dates which were in the future. 43% of first infections were in the first quarter of 2020. 79% of second infections happened in quarter 3 of 2021 or later, with 46% of second infections occurring in the first quarter of 2022. This probably reflects the higher rate of immune evasion of the Omicron variant.



Figure 2 Date of first and second infections (N=593)

Test Status

Testing status changed markedly between the first and second infections because the majority of respondents were those who had their first infection in the first wave in the community for whom tests were not available. In the second infection 84% of respondents had had a positive test, either by PCR or LFT, up from 38% in the first infection.



Figure 3 Test Status of respondents in first and second infections

Vaccine Status

The majority of respondents, 82%, had not had any vaccine before their first infection. This reflects the predominance of respondents from the first pandemic wave. Slightly more CYP than adults, 87% versus 81% had not received any vaccine before the first infection.



Figure 4 Number of vaccines/ booster received before first infection

Respondents were asked how many vaccines and boosters they had received between the first and second infections. Here, there is a marked difference between CYP and adults, which reflect the phased roll outs for vaccines starting with adults only, and delays in regulatory approvals for

vaccines for children. 71% of CYP had received no vaccine between first and second infections, compared to 26% in adults.



Figure 5 Number of vaccines/booster received between first and second infection

RESULTS AND DISCUSSION

Severity of acute infection comparing 1st and 2nd

For the majority of infections, 58%, the severity of the second acute infection was less severe than the first. There was a difference between adults and CYP, with adults more likely to have a less severe second acute infection than CYP, 61% versus 43%. This may reflect the fact that far fewer CYP had had a vaccination by the time of their second infection.



Figure 6 Severity of second infection compared to the first.

How reinfection affected Long Covid in people who still had Long Covid symptoms at the time of reinfection

Type of symptoms with reinfection

523 respondents still had LC at the time of their first reinfection. Of these, 41% had additional new symptoms with their reinfection, 45% had a return of some old symptoms and 23% had no new or additional symptoms. The total is greater than 100% as the categories are not mutually exclusive. Fewer CYP report a return of some old symptoms than adults, 28% versus 48%.



Figure 7 Effect of reinfection on type of symptoms of Long Covid.All N = 523; Adults N=430; CYP N=93

Severity of Long Covid Symptoms with reinfection

For 80% of respondents, reinfection made at least some of their Long Covid symptoms worse. For 23%, all of their symptoms were made much worse. A minority,15%, reported that reinfection made no difference to their Long Covid symptoms. The total reporting that reinfection made some or all of their symptoms better or caused them to resolve was 11% overall. Here there is a marked difference between adults and CYP, being 12% of adults and 6.5% for CYP. Again, it is potentially because few CYP had been vaccinated by the time of their reinfections. Percentages sum to more than 100 because categories are not mutually exclusive. For example, it is possible for some symptoms to be improved while others are made worse.



Figure 8 Effect of reinfection on severity of Long Covid symptoms. N = 523

How reinfection affected Long Covid in people who were in recovery or remission from Long Covid symptoms at the time of reinfection

96 people reported having been in remission or recovered at the time of reinfection. Of these, 60% got Long Covid again and 40% did not get Long Covid again at their second infection. There were only 11 CYP in this group so it was not possible to do a separate analysis to compare Adults and CYP.

How were the symptoms of second bout of LC compared to the first bout.

In the second bout of Long Covid most respondents, 93%, reported that at least some symptoms were the same as the first bout. For just under half, the symptoms were the same as the first bout.



Figure 9 Comparison of types of symptoms of second bout of Long Covid compared to the first. N = 96

How was the severity of second bout of LC compared to the first bout.

For 40% of respondents, the second bout of Long Covid was about the same severity as the first time. The proportion reporting less severe was 32%, and more severe 28%.



Figure 10 Comparison of severity second bout of Long Covid compared to the first. N = 96

After which infection did respondents first get Long Covid

Respondents were asked to say which of their infections first resulted in Long Covid. The large majority reported that it was after their first infection. This is probably because most of the recruitment was done in social media groups for Long Covid, in which those who got Long Covid in the first pandemic wave predominate. Overall, 89% of respondents contracted Long Covid after the first infection, 10% from the second and 1% from the third. No respondents reported contracting Long Covid from fourth or fifth infections. The main difference between Adults and CYP is that twice as many CYP first contracted Long Covid from their second infection. It is not known why this is, but it may reflect the lower rates of vaccination at the time of the second infection in CYP.



Figure 11 Which infection first caused Long Covid

The majority of respondents had only had two infections. Of the 91 people who reported 3 or more infections, 71 (78.0%) first got Long Covid from the first infection, 15 (16.5%) from the second infection and 5 (5.5%) from the third infection.

Effect of vaccines on Long Covid

Respondents were asked to say what effect vaccines had had on their Long Covid. Of the 432 who responded, the largest portion, 39%, said that vaccines had no effect on their Long Covid. A further 33% said it affected their Long Covid but that the effect was temporary.

There was a marked difference in the percentage of adults (36%) and CYP (65%) who reported that no effect on their Long Covid. Responses for the other categories should be treated with some caution as only 55 CYP in total answered this question.



Figure 12 Effect of vaccines on Long Covid. All N = 432; Adults N = 377; CYP N = 55

LIMITATIONS

The main limitations of the present study are that it is retrospective and the respondents are selfselected, therefore, may be biased. Full demographic data were not collected, therefore it is not possible to judge the socioeconomic status of the respondents with respect to the general population.

The strength of the study is the relatively large sample size and the fact that this the research has been initiated by patients. Notwithstanding the potential bias of the sample, it does represent people's real-life experiences and is intended to provide indicative data to guide future research. The study is not intended to be an end in itself, but to open up a hitherto unexplored area in Long Covid research, and to pool the combined real-life experiences of hundreds of people to point to the need for the consequences of reinfection to be considered in people with Long Covid. It can be considered a hypothesis generating study and we would urge researchers wishing to conduct prospective studies in this area to consider some of the issues revealed in the study.

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AUTHORS

This work has been designed, conducted, analysed and written up by members of Long Covid Support and Long Covid Kids. They are all people with lived experience of Long Covid. All work has been done on a voluntary basis.

Long Covid Support was founded in May 2020 by people with Long Covid and is a charity registered in England & Wales. The charity's work spans four key areas: peer support, advocacy, work and employment rights, and research involvement. Their online forum facilitates peer support for over 50,000 people in over 100 countries. The mission of LCS is to provide support for people with Long Covid and to advocate for awareness, research and treatment.

Long Covid Kids was founded in October 2020 by people living with Long Covid. In 2021 LCK became the first UK-based international registered charity advocating for families, children and young people living with Long Covid. Currently supporting 10,000 families, LCK's vision is to achieve recognition, support and recovery for Long Covid and related illnesses in children and young people. Their mission is to increase understanding, aid early diagnosis and improve response and intervention.