The coronavirus papers 1.6

Lasting effects:
Experiences of COVID-19 infections and Long COVID symptoms among Jews in the UK

May 2021

The coronavirus papers comprise a series of reports based on a national survey of Jews across the UK conducted by JPR in July 2020, during the COVID-19 outbreak. The studies look at the effects of the virus on Jewish people's health, jobs, finances, relationships and Jewish lives, and aim to provide Jewish organisations with the data they need to navigate their way through the pandemic, and to help revitalise Jewish life.

1 / Introduction

This is the sixth in a series of short papers investigating how the coronavirus outbreak affected Jews across the UK between the four months from when the government first instituted a nationwide lockdown in March 2020 and the period when the data for this study were gathered in mid- to late July. Each of these papers explores a different theme, variously touching on physical and mental health, socioeconomic situations, community income, Jewish life and caring and support. This paper looks at the extent to which Jews across the UK had experienced COVID-19 symptoms by July 2020, as well as an emergent illness at the time that is now commonly referred to as 'Long COVID.' As the vaccine rollout pushes on in the UK, scientists continue to investigate the longer-term health consequences of a COVID-19 infection for those affected, but here we shed some light on this topic, with particular reference to its impact on Britain's Jewish community in the early stages of the pandemic. By examining this, we hope to help inform the community's response to supporting those who have experienced COVID-19, and particularly those who continue to experience longer-lasting post-viral symptoms.

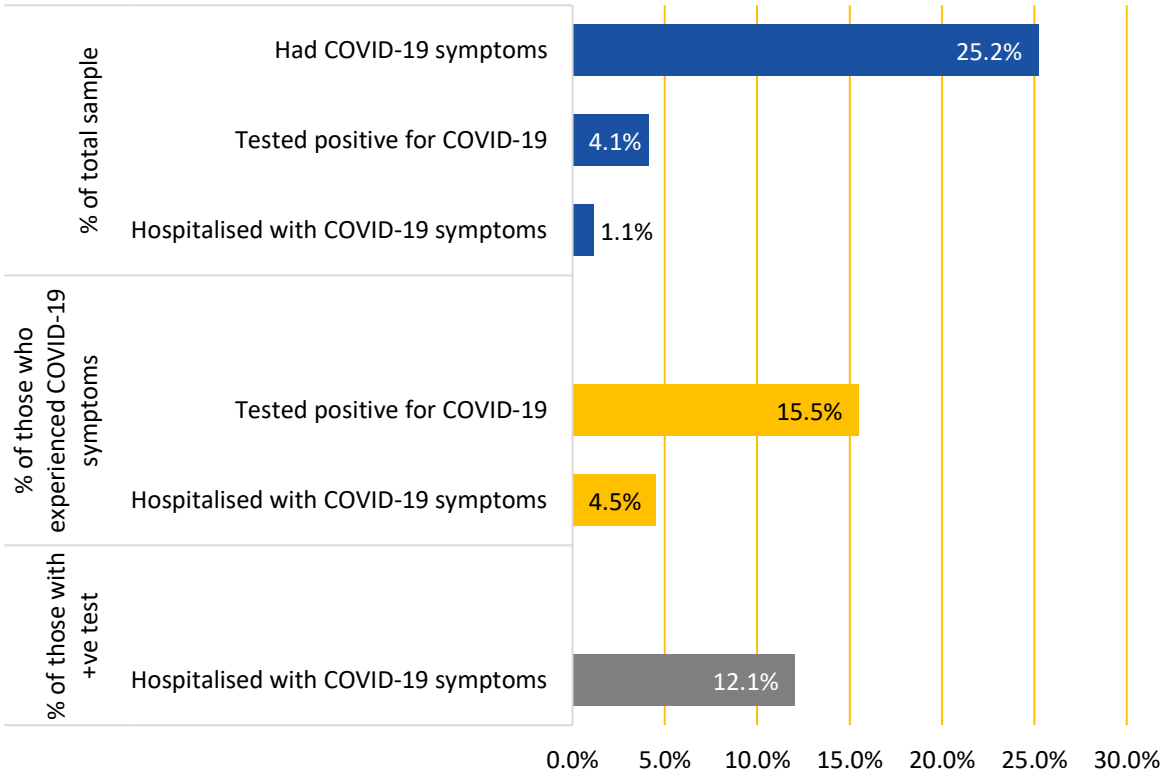
Basic details about the methods used in the survey can be found at the end of this paper, as well as in a longer methodological paper available from JPR.

2 / Estimated prevalence of COVID-19 infections in the Jewish population

First, we need to contextualise the Long COVID data we hold by examining how many people had, or suspect they had had, a COVID-19 (SARS-CoV-2) infection. Widespread testing was not available in Britain during the period up to the survey in July 2020 and so respondents were asked if they had "experienced symptoms that could be caused by coronavirus." Five months into the pandemic, we

found that a quarter (25%) of respondents (aged 16 and above) reported having had COVID-19 symptoms (Figure 1Figure). As with similar studies based on self-reporting of such information, it is possible some misreporting occurred and therefore this figure should be treated with caution. However, even if not all of these were bona fide COVID-19 infections, it is also known that many COVID-19 cases are asymptomatic, so it seems likely that infection was already widespread in the Jewish community by July 2020. Since minimal testing was being carried out at the time in Britain, 4% of the full sample reported having tested positive for COVID-19,[1] rising to 15% of those who reported COVID-19 symptoms.

Figure 1. Proportion who had experienced coronavirus symptoms, tested positive or been hospitalised (aged 16 and above) by July 2020, Jewish population, UK, n=6984



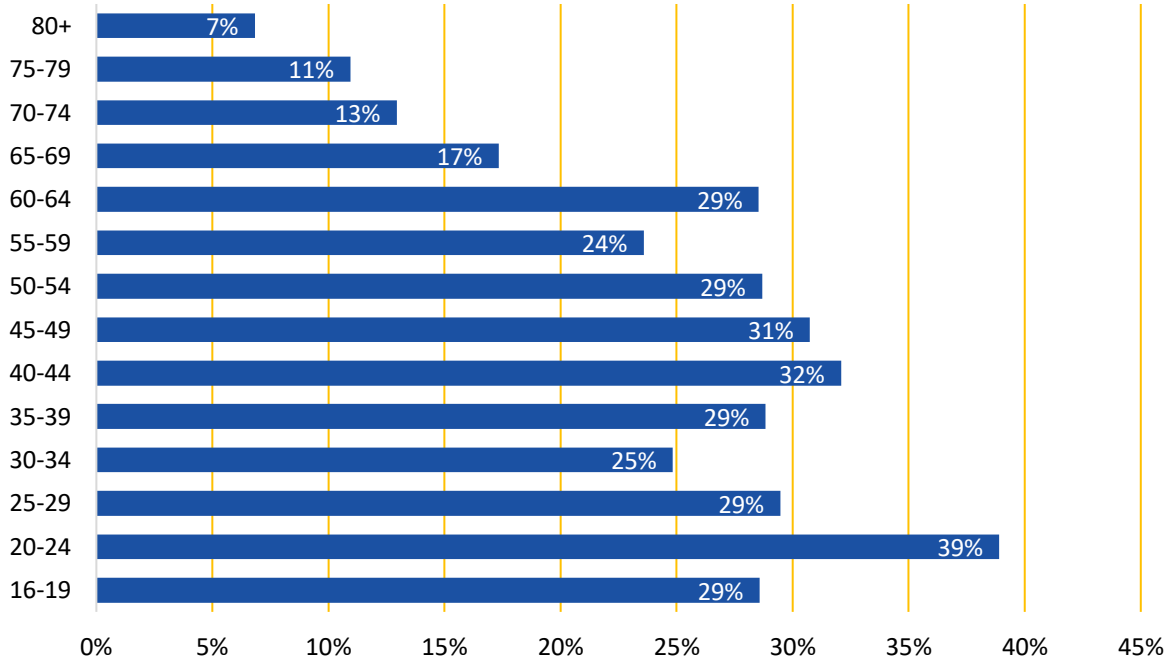
Question: Have you experienced symptoms that could be caused by coronavirus?
Question: Have you ever tested positive for coronavirus?
Question: Have you been in hospital because of coronavirus symptoms?

3 / Groups affected, by age, sex, geography and Jewish identity

JPR data show that men were slightly more likely than women to report coronavirus symptoms (27% versus 24% respectively). Additionally, younger people were more likely to report symptoms than older people (Figure 2). However, there was a notable reduction around the early thirties. Although older people (aged 65 and above) were most likely to be severely affected by coronavirus, we see that they were also least likely to have reported symptoms.

[1] Respondents were not asked if they had tested negative.

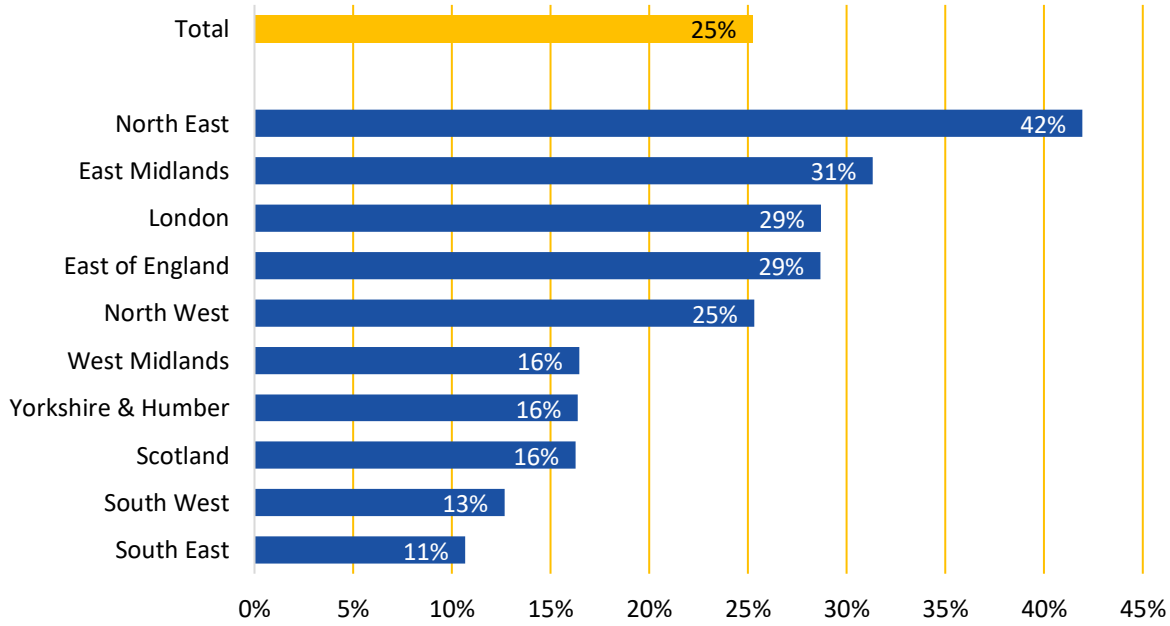
Figure 2. Proportion of each age group reporting coronavirus symptoms, UK Jewish population, July 2020 n=6984



Question: Have you experienced symptoms that could be caused by coronavirus?

Different regions were affected to different degrees. Here we can see that Jews living in the North East were most likely to report symptoms (42%), at a level approaching twice the national average for Jews (Figure 3). This area includes Gateshead, which has a particularly young, strictly Orthodox community (discussed below).

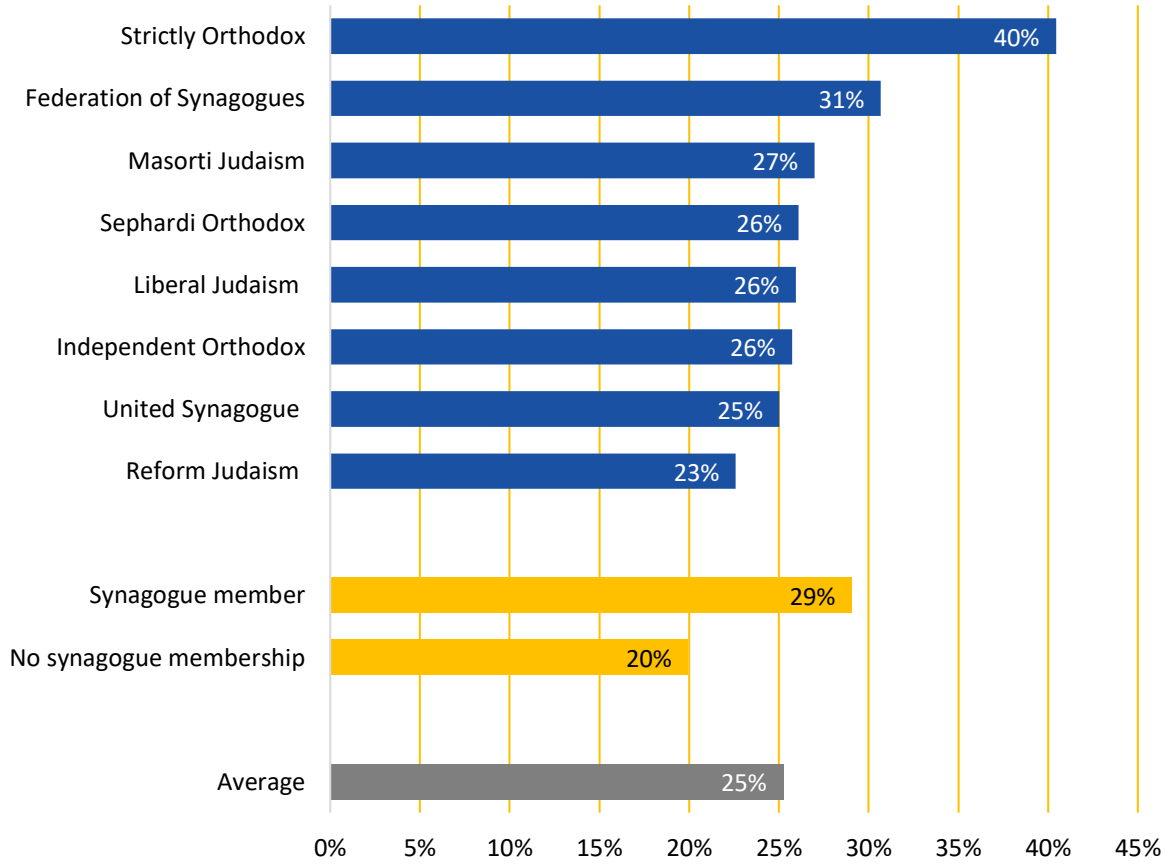
Figure 3. Proportion of each region reporting coronavirus symptoms, UK Jewish population, July 2020 n=6984



Question: Have you experienced symptoms that could be caused by coronavirus?

These findings hint at variation by Jewish identity and, indeed, we can see that strictly Orthodox respondents were most likely to report symptoms (40%), at a level considerably higher than other denominations (Figure 4). Moreover, it is apparent that synagogue members were almost 50% more likely to report symptoms than non-members (29% versus 20%), although this proportion falls to 25% once we exclude the strictly Orthodox. As with age, this may be related to higher levels of social interaction and engagement with Jewish life. However, with the exception of the strictly Orthodox, the type of denomination does not seem to be a major factor. The high prevalence of COVID-19 among strictly Orthodox Jews is increasingly well documented.[2]

Figure 4. Proportion of each synagogue denomination reporting coronavirus symptoms, Jewish population, UK July 2020 n=6984

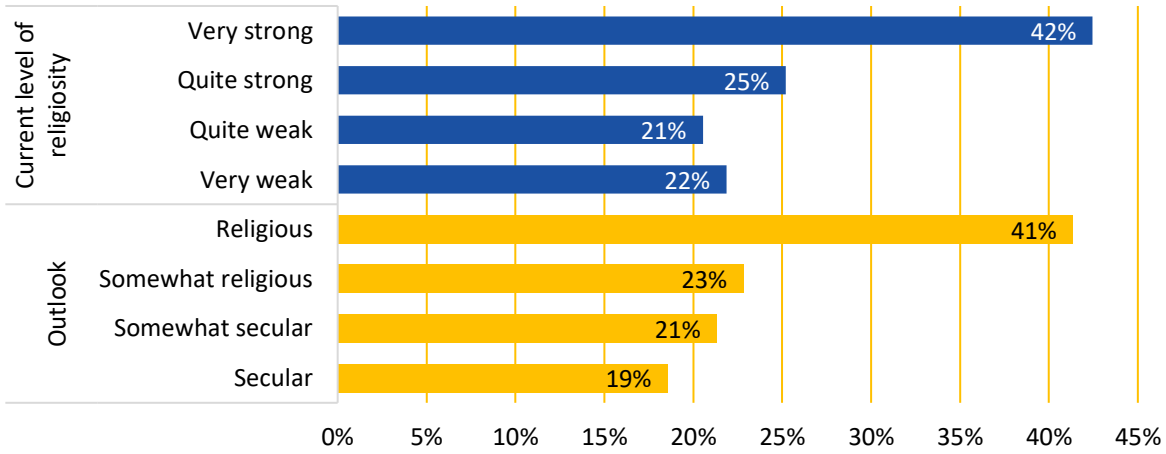


Question: Which, if any, of the following types of synagogue are you currently a member of?

However, synagogue membership *per se* cannot be the whole explanation for the difference. That is because we also see this pattern in terms of non-synagogue members who are 'closely aligned' to particular denominations. In these cases, 52% of respondents 'closely aligned' with strictly Orthodox had experienced symptoms, with those closely aligned with Sephardi being the next most likely at 27%, suggesting that synagogue or communal *involvement* rather than membership is more important. Further, respondents who self-describe as having 'very strong' religiosity or whose outlook is 'religious' were also far more likely to report having had COVID-19 symptoms than other respondents (Figure 5).

[2] See: Gaskell, K.M. et. al., *Extremely high SARS-CoV-2 seroprevalence in a strictly-Orthodox Jewish community in the UK*. London School of Hygiene and Tropical Medicine, February 2021, showing 65% of *haredi* Jews may have had COVID-19 by the end of 2020; see also Patrick Kingsley article in the New York Times (17 February 2021) regarding haredim in Israel, which describes the problem by means of a photo essay.

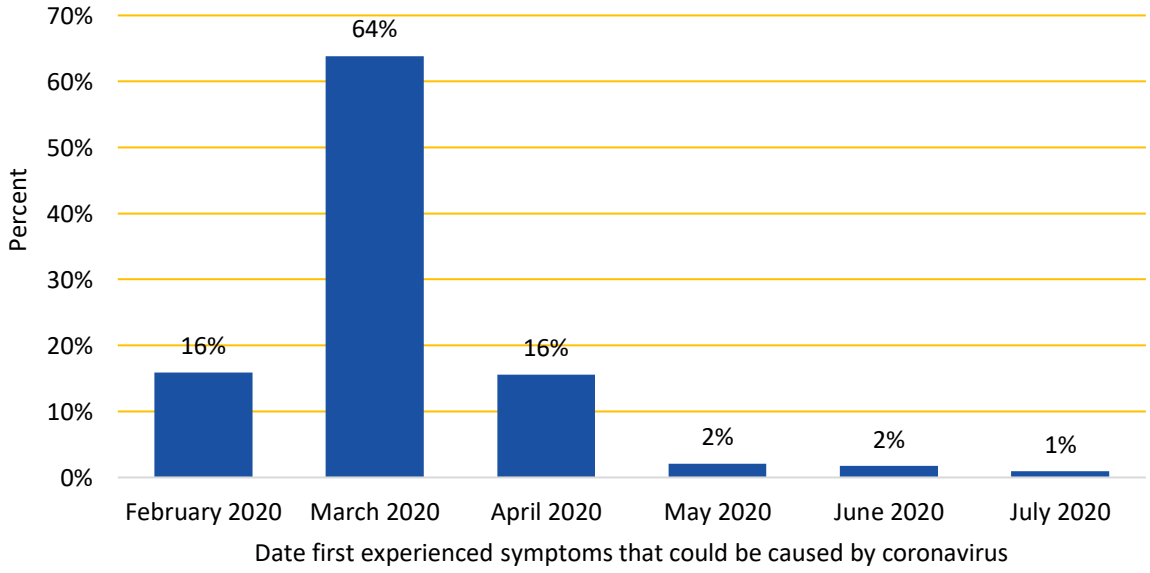
Figure 5. Proportion reporting coronavirus symptoms by religiosity and Jewish/religious outlook, Jewish population, UK July 2020 n=6984



Question: How would you describe your current level of religiosity?
Question: When it comes to your outlook, how do you regard yourself?

Respondents who reported experiencing symptoms that could be caused by coronavirus were asked in July 2020 when they first experienced those symptoms. Almost two out of three (64%) said they had first experienced symptoms in March, which was the clear peak of infection in this initial wave of the pandemic. But it is also apparent that more than one in six (16%) said they first experienced symptoms in February 2020 (Figure 6).

Figure 6. Month respondents reported experiencing suspected coronavirus symptoms, UK Jewish population, July 2020 n=1588



Question: When did you first experience symptoms that could be caused by coronavirus?

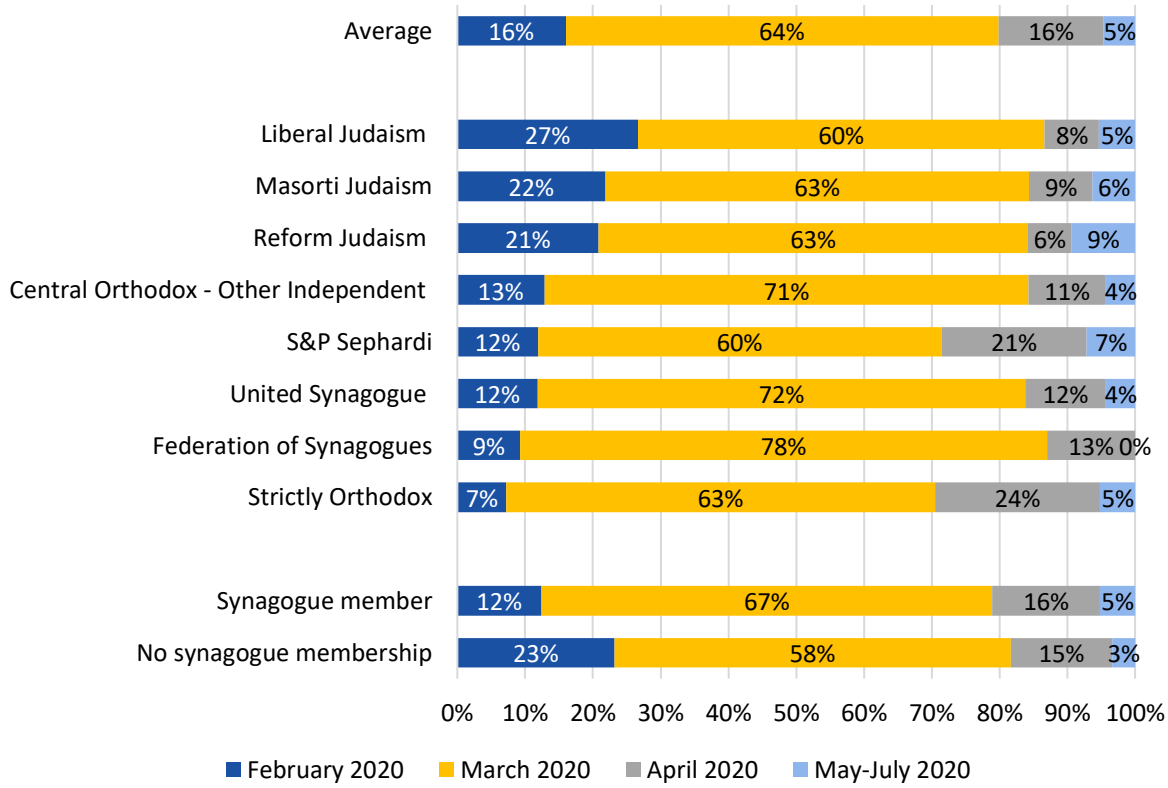
Whilst the most religious Jewish groups were most likely to report having experienced COVID-19 symptoms, it was actually the least religious groups who appear to have experienced them first.[3] For

[3] A brief examination of overseas travel in February and March 2020 did not reveal a strong relationship.

example, relatively high proportions of non-Orthodox denominations reported experiencing symptoms in February: 27% of Liberal Jews, 22% of Masorti and 21% of Reform (Figure 7). By contrast, 7% of strictly Orthodox said they had experienced symptoms at this point. Indeed, a quarter (24%) of this group reports being infected in April, i.e. after lockdown began – more so than any other group identified.

Similarly, one in three (33%) of those who described themselves as 'very weakly' religious said they had symptoms in February 2020, compared with 14% among the 'quite weakly' religious, with the more strongly religious groups being lower still. We see a similar, albeit more nuanced, picture in terms of Jewish religious 'outlook' (i.e. secular to religious scale; not shown graphically).

Figure 7. Month respondents reported experiencing suspected coronavirus symptoms by synagogue denomination and membership, UK, July 2020 n=1588



Question: When did you first experience symptoms that could be caused by coronavirus?

4 / Long COVID

There is now a growing body of scientific research about the long-term effects of a COVID-19 infection on the general population. But when JPR carried out its first COVID survey in July 2020, the term 'Long COVID' had not yet been coined and it was becoming clear that while many recovered fully after about two weeks of sickness, others experienced longer lasting effects. Much of what was known about Long COVID in the very early stages of the pandemic was necessarily based on patients' anecdotes, and in the few peer-reviewed studies, many focused only on patients who were initially hospitalised.[4] Yet we

[4] Huang, C., et. al., '6-month consequences of COVID-19 in patients discharged from hospital: a cohort study,' *The Lancet*, 8th January 2021; Carfi, A., et. al. 'Persistent Symptoms in Patients After Acute COVID-19', *JAMA*, 9th July 2020; Raman, B., et. al., 2020, 'Medium-term effects of SARS-CoV-2 infection on multiple vital organs, exercise capacity, cognition, quality of life and mental health, post-hospital discharge', preprint *medRxiv*, 2020;

now know that even mild cases can lead to longer term symptoms[5] and that there is concern about a societal care burden beyond that of COVID-19 itself.[6]

Although academic papers are beginning to appear,[7] evidence is still being gathered, not least because the number of people who have been affected by Long COVID has not been tracked as closely as the number who have had an initial COVID-19 infection.[8] For a working definition of Long COVID, one team of experts has suggested it is "a collection of symptoms that develop during or following a confirmed or suspected case of COVID-19, and which continue for more than 28 days."[9] It is thought that about one in three people with COVID-19 have symptoms that last longer than the typical two weeks.[10] One international web-based study found that Long COVID is associated with 205 symptoms affecting multiple organs, with the most frequent symptoms reported six months after the initial infection being fatigue (75% to 80%), post-exertional malaise (69% to 75%), and cognitive dysfunction (52% to 59%).[11]

In the UK, it was not until November 2020 that the NHS announced it would launch a network of specialist clinics to provide assistance to long-term sufferers,[12] and in February 2021, the government awarded a £18.5 million research investment into the condition.[13] There have also been recent calls for the government to recognise Long COVID as an occupational disease.[14] ONS estimated in January 2021 that as many as 300,000 people in the UK may be suffering from Long COVID.[15]

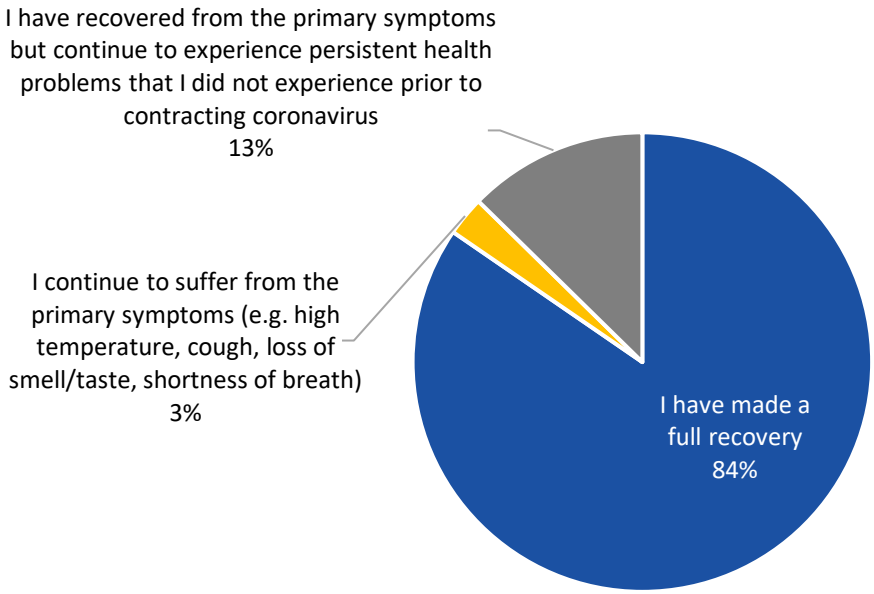
While we know that British Jews suffered a particularly high level of mortality in the first wave of the pandemic,[16] we also know that the vast majority of those who said they experienced COVID-19 symptoms were not hospitalised with the disease (see Figure, page 2). Therefore, like most 'long haulers' (a term also used to describe sufferers of Long COVID), Jews with Long COVID have also been missed out in studies that have focused on discharged hospital patients.

As we have seen, JPR asked respondents whether they had "experienced symptoms that could be caused by coronavirus?" All of those who responded in the affirmative (25% in Figure above, n=1,588) were then asked a follow-up question about their recovery. The majority (84%) reported that they had "made a full recovery" from the primary symptoms of their diagnosed or suspected coronavirus

[5] Gale, J., 'Even Mild Covid-19 Infections Can Make People Sick for Months', *Bloomberg*, 7 October 2020.
[6] Campbell, D. 'NHS may face a million long Covid patients after pandemic', *The Guardian*, 6th March 2021.
[7] Huang, et. al., op. cit.; Sudre, C. H., et. al., 'Attributes and predictors of Long-COVID: analysis of COVID cases and their symptoms collected by the Covid Symptoms Study App', preprint *medrXiv,* 2020; Carfi, et. al., op.cit.
[8] Alwan, N. A. 'Surveillance is underestimating the burden of the COVID-19 pandemic', *The Lancet*, 27th August 2020.
[9] Davis, H. E., et. al., 'Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact', p.2, preprint medRxiv, 2020.
[10] LaVergne. S. 'How many people get 'long COVID' – and who is most at risk?' *The Conversation*, 18 February 2021.
[11] Davis, et. al., op. cit.
[12] National Health Service, 'NHS launches 40 'long COVID' clinics to tackle persistent symptoms', 15 November 2020.
[13] National Institute for Health Research, '£18.5 million awarded to new research projects to understand and treat long COVID', 18 February 2021.
[14] 'Long Covid: MPs call for compensation for key workers', *BBC News*, 18 February 2021.
[15] Office for National Statistics, 'Updated estimates of the prevalence of long COVID symptoms', 21st January 2021
[16] Staetsky, L. D. and Paltiel, A. (November 2020), *COVID-19 mortality and Jews: A global overview of the first wave of the coronavirus pandemic, March to May 2020*. London: Institute for Jewish Policy Research.

infection, but a further 13% said they continued to experience "persistent health problems," and 3% said they "continued to suffer from the primary symptoms" (Figure 8).[17]

Figure 8. Proportion of those who had experienced COVID-19 symptoms who had recovered or continued to experience health problems, UK Jewish population aged 16 and above, N=1588



Question: Have you made a full recovery from the primary symptoms of your diagnosed or suspected coronavirus infection?

However, 13% cannot be considered the final indicator of Long COVID among JPR respondents. That is because most[18] of those who said they "continued to suffer from the primary symptoms" first became infected before May 2020, i.e. at least five weeks earlier. Yet Long COVID is currently defined as any symptoms that persist or emerge *three weeks* after the initial infection (since most people recover in about two weeks).[19] We know this because we also asked respondents when they first experienced their initial symptoms, and recalculating the data to include these individuals indicates that, in total, 15% of respondents who experienced symptoms that could have been caused by coronavirus were exhibiting Long COVID symptoms in July 2020.

It is not simple to compare these figures directly with other studies due to different methodologies, timeframes and the evolving understanding of the health issues being measured. However, the Office for National Statistics (ONS) has recently issued experimental estimates about the prevalence of Long COVID in the national UK population (aged 2 and above), tracing data since October 2020. These show that 22% of those who had *tested positive* for COVID-19 reported symptoms five weeks later, and 10% reported symptoms twelve weeks later.[20] Another study, which was mainly UK-based, has found 13% reported symptoms lasting more than 28 days, 5% more than 8 weeks and 2% more than 12 weeks.[21]

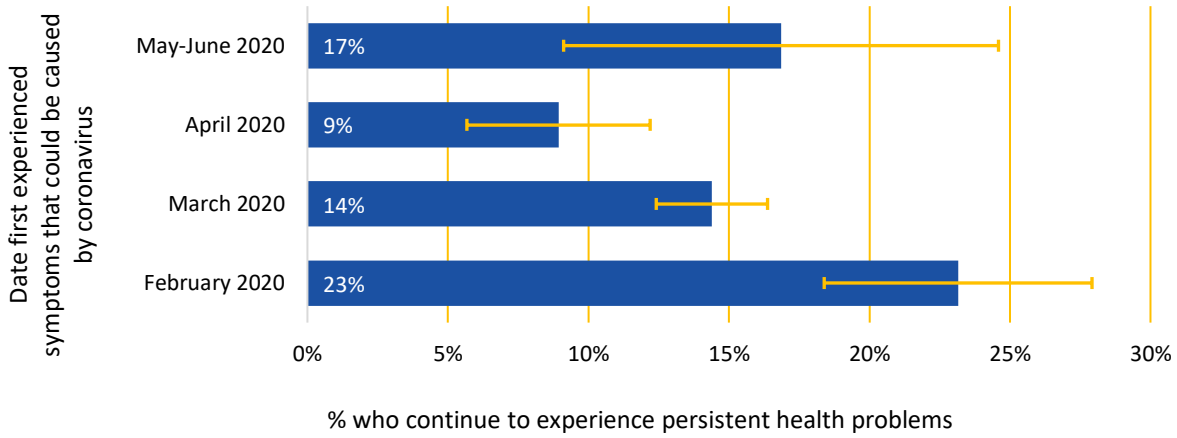
[17] Unfortunately, this Long COVID estimate is likely to be understated, as first, anyone with Long COVID who was initially asymptomatic or otherwise unaware that they had had a COVID-19 infection was not asked about longer-term issues. Second, those who had experienced longer term health problems, but which had resolved by the time of the survey, were also not asked this question.
[18] The proportion was 87%.
[19] LaVergne, February 2021, op. cit.
[20] Office for National Statistics, 21st January 2021, op. cit.
[21] Sudre, C.H., Murray, B., Varsavsky, T. et al. 2021 'Attributes and predictors of long COVID', *Nat Med* (2021).

All of this therefore suggests that Britain's Jewish population has been affected by Long COVID to a similar degree as the general population.

In Figure it was shown that, as of July 2020, before testing was widely available in the UK, 15% of Jews who suspected they had had a COVID-19 infection had tested positive. 22% of this group reported Long COVID symptoms (the same proportion found by ONS), compared with 14% among those who had not tested positive.

JPR data suggest that of those who said they first experienced symptoms that could be caused by coronavirus in February 2020, almost a quarter, 23%, said they continued to experience persistent health problems at least five months later (i.e. in July 2020) (Figure 9). This shows that Long COVID symptoms can persist for several months. However, the pattern was uneven. The majority (64%) of suspected Jewish COVID-19 cases occurred in March 2020 (see Figure, page 5 above), but of these, a lower proportion, 14%, reported Long COVID symptoms four months later. It is not clear why those infected more recently were less likely to report ongoing health issues, especially given the experimental ONS data indicate the opposite is occurring in the national population. The broad 95% confidence intervals on the February and May-June datapoints suggest this may be a statistical aberration but it must also be reiterated that the two surveys have different methodologies and examine different time periods. Clearly, more work is required to understand this better.

Figure 9. Proportion who continued to suffer persistent health problems (Long COVID) by date first experienced COVID-19 symptoms, UK Jewish population aged 16 and above, N=1588



Question: When did you first experience symptoms that could be caused by coronavirus?

5 / Long COVID symptoms by sex, age, and preexisting health conditions

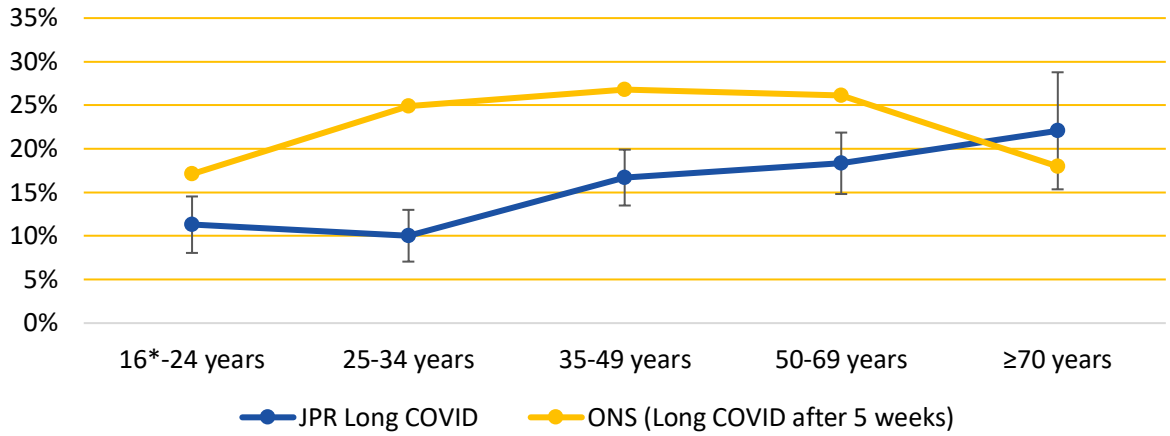
The experimental data from ONS suggests that there is a slight gender difference, with 21% of men and 24% of women exhibiting Long COVID symptoms five weeks after infection based on a sample of just over 9,000 individuals who had ever tested positive.[22] We did not observe this in the JPR survey, which showed that 15% of men and 15% of women reported Long COVID symptoms.

Recent ONS findings show a peak in the middle aged groups, and a lower prevalence in the younger and older age groups (Figure 10). However, the JPR data suggest that the likelihood increases with age: i.e. older Jewish people who experienced symptoms consistent with COVID-19 are more likely

[22] Office for National Statistics, 'Updated estimates of the prevalence of long COVID symptoms', 21 January 2021.

than younger Jewish people to report Long COVID health concerns. While it is not clear why there is a difference here it must be reiterated that the two methodologies are (necessarily) different. Further, the confidence interval for Jewish people in the oldest group (70 years and above) is wide and encompasses the ONS datapoint, so this value may be a statistical aberration.

Figure 10. Proportion who continued to suffer persistent health problems (Long COVID) by age, UK Jewish population aged 16 and above^ and the general population aged 17 and above, n=1588

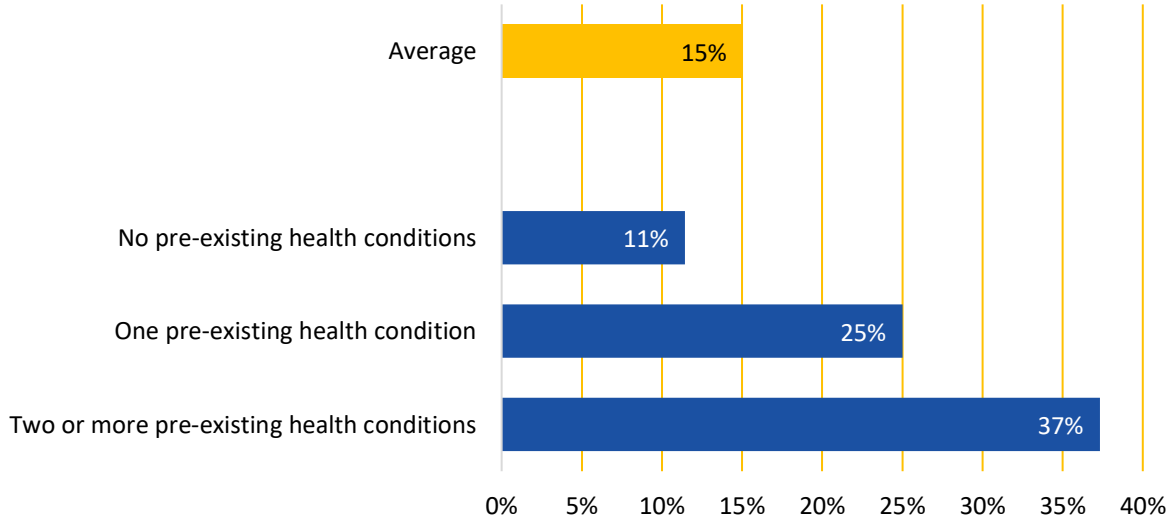


^ Error bars show 95% confidence intervals of the JPR data

* ONS data start at age 17.

JPR respondents who had preexisting health conditions*, were far more likely to report Long COVID than those without such preexisting conditions (Figure 11). Even having just one such condition meant respondents who had had a suspected coronavirus infection were more than twice as likely to report Long COVID (25% versus 11%).

Figure 11. Proportion who continued to suffer persistent health problems (Long COVID) by number of preexisting health conditions*, UK Jewish population aged 16 and above, n=1588

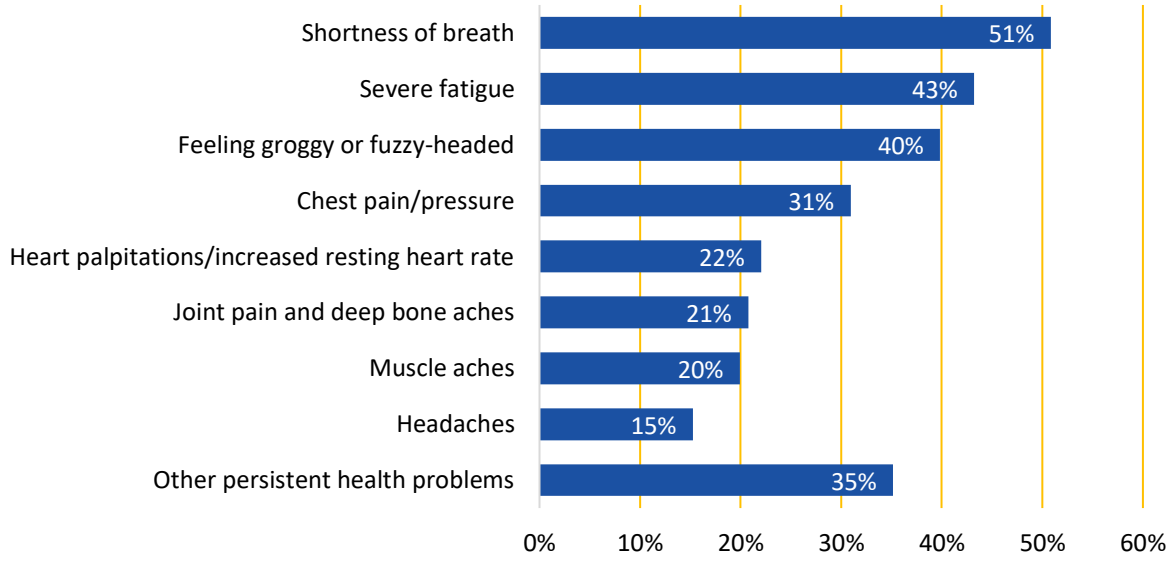


* *Question: Do you currently have a long-term condition(s) that makes you particularly susceptible to serious effects from coronavirus?* [Answer options: Angina or long-term heart condition, Asthma or long-term chest condition, Autoimmune disease (e.g. MS, lupus), Cancer, Diabetes, Other long-term condition].

6 / Type and severity of Long COVID symptoms[23]

As noted,[24] Long COVID is associated with a bewildering array of symptoms, and some commentators have pointed out these may also fluctuate and relapse.[25] JPR presented respondents with a list of possible symptoms they may have experienced, along with an 'other' write-in option. The most commonly reported issue was shortness of breath affecting half of sufferers (51%), followed by 'severe fatigue' affecting 43% (Figure 12). Two out of five (40%) said they felt 'groggy or fuzzy-headed' and 31% experienced chest pain or pressure. One in three (32%) experienced just one persistent health problem, and a further 20% experienced two such problems, but almost half of those who reported longer term effects (48%) experienced three or more persistent health problems.

Figure 12. Type of symptoms reported among those with Long COVID, UK Jewish population aged 16 and above, n=211 per item



Question: What persistent health problems have you been experiencing that you did not have before the initial onset of your symptoms?

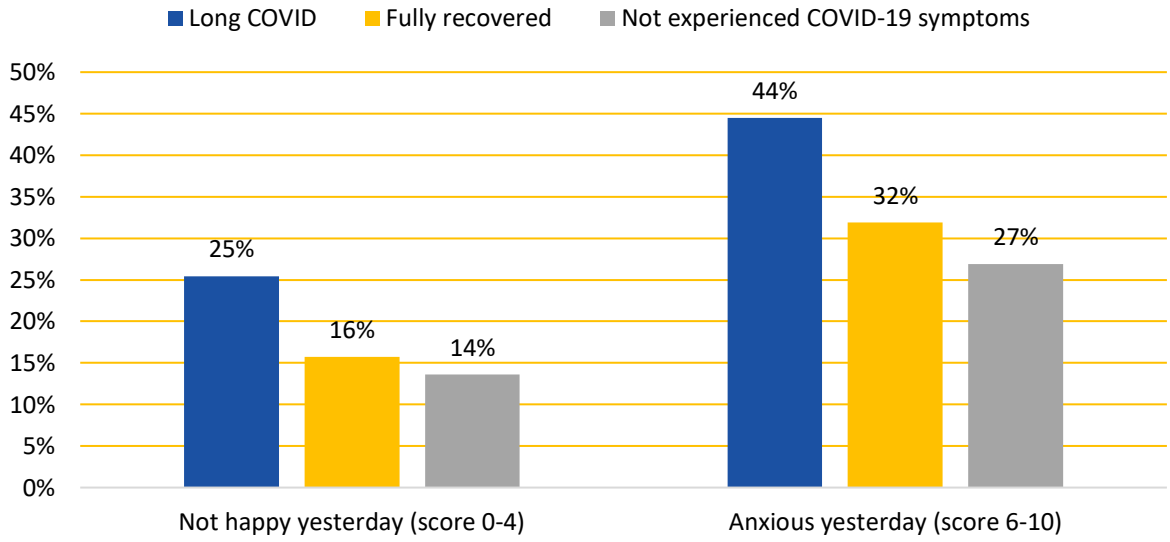
Many other persistent health problems were mentioned by respondents in the write-in box of the questionnaire, including: cough, hair loss, kidney pain, memory deterioration, nerve damage, sore throat, loss of taste and smell, and voice affected/difficulty speaking. Separately, ONS's experimental Long COVID dataset also examined this issue, and whilst not directly comparable with the JPR numbers, found that 'fatigue' was the most common problem, followed by 'cough' and 'headache'.[26]

JPR respondents reporting Long COVID were also asked to subjectively assess the severity of their symptoms.[27] Most (58%) described them as mild, but 35% said they were moderate and for 7% they were severe.[28]

[23] This section does not include those who said they were *currently* (July 2020) suffering COVID-19 symptoms but who also said they were infected before June 2020 (i.e. they had Long COVID).
[24] Davis H et al 2020 op cit.
[25] Alwan, N. A. 'A negative COVID-19 test does not mean recovery', *Nature*, 11 August 2020.
[26] Office for National Statistics, 21 January 2021, op. cit.
[27] Question: And overall, would you describe these persistent health problems as mild, moderate or severe?
[28] n=211.

Finally, it is clear that Long COVID may be detrimental to one's health in other ways. Respondents with Long COVID were both much less happy and rather more anxious than those who had recovered from their COVID-19 symptoms and those who had never had any symptoms to start with (Figure 13).[29] This link has also been noted more widely and is one of the main concerns about the long lasting impacts of the pandemic.[30] Indeed, it is one the main reasons the government is funding the NIHR project.[31]

Figure 13. Proportion who said they were not happy yesterday (score 0-4) and who were anxious yesterday (score 6-10), among Long COVID sufferers and those who had recovered from COVID-19 (n=1588), plus all other respondents (n=5396), UK Jewish population aged 16 and above



Question: Overall, how happy did you feel yesterday? [0 - Not at all happy to 10 - Completely happy].
Question: Overall, how anxious did you feel yesterday? [0 - Not at all anxious to 10 - Completely anxious].

7 / Conclusion

As we learn more about Long COVID we will work to fill in the many gaps that remain in our understanding of what is increasingly looking like one of the main long-term health legacies of the coronavirus pandemic. Simple questions such as what characterises Long COVID, how long it lasts, who is most vulnerable, and perhaps most important of all, how to recover from it, are still poorly understood one year after it emerged as a distinct health problem.

That it remains poorly understood was made clear in the findings of Parliament's recent All-Party Group on Coronavirus, which has called for better measurement of the problem, improved recognition of it as a medical condition by the medical community, as well as increased research funding and better information for employers and GPs.[32]

In this context, the data gathered by JPR must be understood as a modest contribution to our understanding of a serious health issue confronting the population as a whole, which, of course, includes the Jewish community. Looking ahead, as more and more people in Britain are vaccinated

[29] This differential was also noted in our report on mental welfare. See Graham, D., Lessof, C. and Boyd, J. *Hidden effects: The mental health of the UK's Jewish population during the COVID-19 pandemic*, London: Institute for Jewish Policy Research, p.15.
[30] Raman, et. al., 2020, op, cit.; Gale, 2020, op. cit.
[31] National Institute for Health Research, 2021, op. cit.
[32] All-Party Group on Coronavirus, Interim Report December 2020, Sections 4.1 and 4.2

against COVID-19, dealing with the burden of Long COVID could become an important task for Jewish community welfare groups and health professionals.

Long COVID will be a topic in JPR's next national survey, which will help us to build on what we have already learnt in order to provide the Jewish community with greater information about this issue so that it can better plan and provide for the welfare of Jews in the UK.

/ Methodological note

These results are based on an online survey of Jewish people aged 16 and over living in the UK. A total of 6,984 individuals who took part are included in this analysis. They responded variously to emails and e-newsletters sent out by a wide range of Jewish communal organisations and synagogues, or to messaging through social media, word of mouth, or referrals from other survey participants. Five £100 shopping vouchers were offered as an incentive. Since this report focuses on household financial wellbeing, we present findings based on household representatives rather than all individuals. To achieve this, we selected 3,807 household representatives from the 6,984 respondents, representing a random sample of Jewish households across the UK.

The questionnaire was developed by JPR, drawing on a range of existing surveys, including some newly created to respond to COVID-19. It was programmed in-house using Confirmit software and formed part of a wider panel recruitment process. Except for a handful of individuals who requested telephone interviews, the survey was completed online, by computer, smartphone or tablet, from 9-31 July 2020, including a short piloting process. The median time taken to complete the survey was 25 minutes.

The survey data were cleaned and weighted to adjust for the age, sex, religious affiliation/denomination and geographical profile of the Jewish community in the UK based on 2011 Census data. Statistical analysis was carried out using IBM SPSS Version 26, and the text in this report focuses wherever possible on findings which are statistically significant. A more detailed methodological report will be available at www.jpr.org.uk.

/ Acknowledgments

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We also thank the many people across the UK who gave up their time to complete the COVID-19 survey and to support our research. We know their time is precious, so we are particularly grateful to them for sharing their thoughts and experiences.

/ About the Institute for Jewish Policy Research (JPR)

The Institute for Jewish Policy Research (JPR) is a London-based research organisation, consultancy and think-tank. It aims to advance the prospects of Jewish communities in the United Kingdom and across Europe by conducting research and informing policy development in dialogue with those best placed to positively influence Jewish life. Web: www.jpr.org.uk.

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