PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	The lived experience of patients with Long COVID: a qualitative study in the UK.
AUTHORS	Thomas, Callum; Faghy, MArk; Owen, Rebecca; Yates, James; Ferraro, Francesco; Bewick, Tom; Haggan, Kate; Ashton, Ruth EM

VERSION 1 – REVIEW

REVIEWER	Humphreys, Helen Sheffield Hallam University, Advanced Wellbeing Research Centre I note that two co-applicants from the larger grant under which this work was funded are current colleagues of mine. However they are not co-authors on this paper and were not to my knowledge directly involved in this piece of work.
REVIEW RETURNED	12-Dec-2022

GENERAL COMMENTS	I commend the authors for this piece of work which I do think makes a worthwhile contribution to the literature on long COVID. I have however made quite extensive recommendations which I hope are constructive. There are some key details missing from your methods section and some confusion about how your analysis was done. I also think your themes would benefit from some further development. In particular, it is not clear what this study reveals about the lived experience over time, which is a missed opportunity of using a diary/longitudinal approach and therefore the discussion is unclear about what this study adds to existing studies and limits clear recommendations/conclusions. I have made some detailed comments on the attached relating to each section of the paper which I hope are useful and received in the encouraging spirit intended.

REVIEWER	Yang, Juntao Chinese Acad Med Sci
REVIEW RETURNED	11-Jan-2023

GENERAL COMMENTS	In this study, COVID-19 patients were asked to keep diaries of their lives for 16 weeks after infection. Based on these records, researchers qualitatively analyzed the impacts of long-COVID on the lives of participants. Researchers identified three main themes, including a need to further understand symptoms and symptom management, the impact upon the quality of life and health status, and the persistence and episodic nature of symptoms affecting physical, mental, and emotional wellbeing. Overall, this study provides many interesting and important insights, but there are still some minor questions that need to be answered.

	1. About the participants 1) There were only 12 participants in this study. How is the sample size determined? Is it enough? 2) Participants were recruited from a Derbyshire Long COVID clinic. Are the findings of this study representative of people in other environments (such as households and workplaces)? 2. About data collection 1) Participants were contacted bimonthly by researchers. However, as stated in the manuscript, "this did influence diary entries, with multiple accounts of site visits and their impact upon symptoms." Why not adjust the contact frequency to reduce this influence? 2) As stated, “researchers in contact with participants had not previously worked with hand-written diaries.” If so, how to ensure that participants got proper directions to complete the diary accurately? 3) Not all COVID-19 patients would develop long-COVID. How to ensure the impacts that participants recorded in their diaries were from long-COVID but not from other causes (such as anxiety during the pandemic, or being influenced by others)?

REVIEWER	Bai, Francesca University of Milan, Department of Health Sciences
REVIEW RETURNED	17-Jan-2023

GENERAL COMMENTS	The authors show the results of a qualitative study to investigate the clinical presentation of long COVID. The aim of the study is currently very interesting and the results of the study are properly presented. I think that the manuscript is suitable for publication. Specifically: the authors could present the methods in more detail, better specifying how the patients filled in the diaries, how the researchers read the diaries and followed up the patients and how the researchers have analyzed the data.

VERSION 1 – AUTHOR RESPONSE

Reviewer #1 responses		
Abstract		
The wording here suggests that participants needed to be currently infected with COVID-19 at time of inclusion – should this read as previous or ongoing?	We thank the reviewer for highlighting this point. This should read as previous or ongoing recovery from COVID-19 infection, and we have subsequently amended the abstract.	Page 2, Line 11.
If the intention of the study is to inform better services and support could the conclusions be made more specific?	The intention of the study was to document the lived experience of patients recovering from a COVID-19 infection with information to inform	Page 2, Lines 18-21.

	support and better services a finding of our work. We have amended our conclusions slightly for specificity; however, we have not included information here on services and support as they were not the main objectives of this study.	
Strengths and limitations		
"Diaries allowed participants to open up and reveal nuanced details that, in the presence of a researcher, may not have been documented" – could you provide any examples of this in the discussion to illustrate?	We have included an example of this in the final paragraph of our discussion in-line with an additional comment from Reviewer 1.	Page 17, Lines 24-27.
Could you add that documenting experience over time is a strength of the diary approach? – weaving as part of discussion possibly.	We thank the reviewer for this suggestion. We agree that it is a strength of the study and have touched upon this in the results section and final paragraph of the discussion.	Page 3, Lines 6-8. Page 13, Lines 12-16. Page 17, Lines 27-30.
Introduction		
The introduction section discussing government infection control strategies reads somewhat emotively. I am not clear if you're referring to UK or international policy, some of which differs significantly? I'd suggest this section should be edited so that it focuses on a quick overview of the evidence regarding preventative strategies against long COVID.	We thank the reviewer for identifying the following and we have edited this section and provide a quick overview, citing vaccination as an acute infection preventative strategy as an example.	Page 3, Lines 13-20.
"The Office for National Statistics demonstrates a broad incidence of long COVID in 31 females aged 35-69 years old, and those from lower socioeconomic backgrounds, further evidence of a widening health-inequalities gap" – can you say something more about this – e.g. how much	As part of our revisions, this section of the text has been removed in order to address the previous comment of the introduction. The main aim was to re-structure the introduction to improve the clarity and conciseness.	Pages 3-4.

more likely are these groups to develop Long COVID than other populations? This is pertinent to justification of your sample biased to that group which is presented later. It might also be useful to highlight later whether your sample includes people from lower SES groups.		
You suggest that long COVID symptom profiles are 'unpredictable' but then outline 3 relatively distinct clusters based on the study by Davis et al. Can you clarify how well established these profiles are?	We thank the reviewer for highlighting this point. We have subsequently amended this section to refer to the three symptom profiles without contradicting ourselves by suggesting they are unpredictable. As such, we have removed the latter to improve clarity and conciseness.	Page 3, Line 30 to Page 4, Line 2.
Pg4, 17-19: "Unpredictable symptom profiles could partly explain why individuals with long COVID have struggled to access the support that is needed to help them manage/improve their condition" – can you cite any evidence or this anecdotal?	Our initial reasoning was more so anecdotal, however, as part of the revision to this section of the text, this has been removed to improve the clarity and conciseness.	Pages 3-4.
There is some repetition within the introduction, which I believe could benefit from a re-structure. For example, page 3, lines 25-27 you introduce the idea of complexity in profiling symptoms, but you do not provide any examples of common symptoms or which symptoms typically present together. You then address the issue of health inequalities and then return to the point about symptom profiles on page 4, line 9.	As part of the revision, this section of the text has been restructured in order to improve the clarity and conciseness, and to avoid repetition.	Pages 3-4.
Similarly on page 4, lines 2-3 you highlight a lack of lived experience research but you return to this same point again on lines 22-24. Whilst I agree to an extent, there are a now a number of very well cited qualitative papers on the lived experience and even qualitative syntheses conducted (albeit with relatively few papers included). I think the point you are usefully trying to make is how valuable these qualitative studies are (you might refer to the NIHR dynamic themed review to demonstrate this). Also that the nature of Long COVID which can be longterm for many but also fluctuates over time means that interviewing people with long COVID at a single time point only gives a snapshot, and that there may be value in	We thank the reviewer for their advice and direction. As part of the revision, this section has now been amended to provide a stronger, more concise and clear rationale for the study that focusses on the lack of detailed, longitudinal qualitative studies rather than on a lack of qualitative research in this research area.	Page 4 Lines 13-31.

exploring their experience more longitudinally. I think you're making this point on page 4, lines 29-33 but could do so more convincingly as rationale for this current study.		
You then proceed to outline the benefit of using diaries to understand the experience longitudinally on page 5 lines 1-9. Could you explain what you mean when you say that diaries are a method for "bridging the gap between patients and healthcare professionals?	We have amended the text to explain how diaries help patients remember/recall their experiences independent of recall bias (emphasised by Long COVID associated memory loss) and the emotional difficulty an in-person consultation may have. Ultimately, if patients can report clear experiences at minimal energy/emotional cost through diaries, and healthcare professionals can use the diaries to ascertain clear accounts of the patient experience and their symptoms, this helps bridge a gap where patients cannot explain symptoms and healthcare professionals do not know the full symptom profile of the patient.	Page 4, Lines 26-28.
Methods		
What do you mean by 'recovering in community settings?' – does this mean at home or community hospitals?	We thank the reviewer for highlighting this detail. This does mean recovering at home and so we have changed this to "recovering at home from a COVID-19 infection".	Page 5, Lines 7-8.
Can you very briefly outline the informed consent/recruitment process? Did the Long COVID clinic do the consenting and provide study information or was this done by the research team? How long were participants given to decide whether or not to participate?	Study information was provided by the Long COVID clinic and, if participants wanted to take part, they were passed onto the research team for consenting. We have amended our methods to include this detail. No time-limit was placed on participants to decide whether they wanted to participate or not.	Page 5, Lines 10-13.
What influenced the sample size? How many potential participants were invited and how many responded or declined? Did some express an interest but latterly decide not to participate on reading the full information – it would be useful to get a sense of how appealing/accessible this method of participation was. Did the principle of	We thank the reviewer for this thought-provoking amendment. We have revised the first paragraph of the methods to make clear that recruitment was part of a larger longitudinal 16-week data collection study that was powered by sample analysis techniques. The sample presented here was a sub-	Page 5, Lines 6-10.

saturation influence recruitment cessation or did recruitment stop because no one else volunteered?	sample of patients that completed the study. Data from the diaries was monitored continuously and analysed until saturation. At the point of saturation, 17 participants had completed their involvement with 5 participants choosing not to fill out their diaries. Reasoning (not written down) for not completing the diaries included energy (had to prioritise work), remembering to fill in entries, and finding it depressing (made them feel bad looking back at how bad they are each day and having a daily reminder of that).	
How were the diaries completed and stored/shared with research team?	Diaries were completed freely and returned to the research team for photocopying every monthly visit. Participants then handed them back at completion of the 16-week period and were stored securely in a locked room at the University of Derby. Once transcribed, data was stored upon a OneDrive file that was shared between the research team – please see *Researcher Characteristics*.	Page 5, Lines 13-16 and 22-25.
What influenced the use of hand-written diaries as opposed to an electronic format? Were participants given any choice over format of data collection?	A hand-written approach was chosen so to not exclude any participants due to technological difficulties, especially as we were working with a patient group who are older and may not be as savvy with technology. All participants included in this submission chose to keep with hand-written diaries however some subsequent participants in our project have opted to keep electronic diaries for their convenience.	N/A.
What was the rationale for a timeframe of 16 weeks?	The rationale for 16-week timeframe was that it wasn't known when the study was designed how long it would take patients to recover from COVID-19	Page 5, Lines 5-6.

	infection. It was suggested it was a couple months in line with post-viral research. This is not a timeframe we would select for those reasons now and recognise recovery from COVID-19 infection can last month's/years in the cases of, for example, Long COVID. We have now highlighted this in the first paragraph of our methods.	
Researcher Characteristics		
Could you provide detail on the research team that had bimonthly participant contact? E.g. were they part of the long COVID clinical team, or independent?	The research team that had bimonthly participant contact were part of the University of Derby team and not from the Long COVID clinical team. One individual (CT) from this team transcribed, coded and thematically analysed all the diaries.	Page 5, Lines 20-21, 25.
What experience did the research team have in conducting qualitative analysis? Its useful to reflect on how their backgrounds might have influenced their interpretations of the data.	We thank the reviewer for the useful consideration, and we have noted that CT had previous qualitative experience in interview transcription. CT had no previous conceptions of what diaries may reveal from Long COVID patients from previous analysis experience but it could be suggested that by having bimonthly contact with participants CT had already started to form an idea on the themes that would be encountered. To counteract this bias, CT had regular meetings with the research team (MF, RA, RO, JY, and FF) to check the accuracy of the developing themes.	Page 5, Lines 23-26.
PPIE Statement		
"Participants were instructed to freely create their own data that was relevant to their lived experience of COVID-19" – this should be moved to methods section rather than PPI.	We agree with the reviewer that this should be removed from this section and we have placed this in the methods.	Page 5, Lines 14-16.
Was there any lay/public input into the design of the study, development of participant-facing materials etc.	The design of the study was informed by lay/public input in some of our previous clinical research with pneumonia patients which was repurposed for LC patients. Lessons learned from data collection from this research (i.e., a lack of room for additional notes not covered in the data collection paperwork) taught us the importance a diary may have for	Page 5, Lines 29-30.

	collecting additional and relevant information.	
How will you support participants to disseminate the findings on your behalf e.g. how will you ensure that they are provided in an accessible and useful format?	We appreciate this is an academic piece and will be shared with those in this field however we do have an established PPIE dissemination plan as part of our work that will assist participants disseminate findings in an accessible and useful format.	N/A.
Data analysis		
What is meant by "extracts"? Did you extract only sections of the diaries which were deemed suitable or relevant, or were the full diaries transcribed? How many people were responsible for coding and thematic development? What research question(s) guided your analysis?	Full diaries were transcribed, and we agree that clarity is required here. We have changed the wording, so it now reads as "Full diaries were transcribed verbatim and…". One person was responsible for coding and thematic development (CT) and we have now stated this in *researcher characteristics.* The main research question that guided our analysis is stated in last sentence of the introduction which is "to capture the lived experience of individuals with Long COVID taking part in a 16-week cohort observation study collected via hand-written diaries."	Page 6, Line 4. Page 5, Lines 22-23. Page 4, Lines 31-33.
Was a recognised method of thematic analysis used? You quantify some of the themes in your results e.g. provide a % of coverage or state how many times a theme occurred – this implies a more quantitative content analysis rather than inductive thematic analysis?	We welcome the reviewer's point here and recognise that the presentation of the results section depicts more of a quantitative content analysis approach. However, the approach from the outset of the analysis was to allow the data to determine our themes and we followed an inductive approach with no word count analysis performed. Percentage coverage of the themes was a late addition to provide context and clarity of theme frequency and how much it impacted patients.	N/A.
How were the steering committee able to comment on accuracy of the sample data?	Regular meetings enabled part of the steering group (MF and RA – not patient facing) and the rest of the research team (RO, FF, and JY) to discuss	N/A.

Do you mean that they reviewed the themes and subthemes? Who were they?	findings and check accuracy. They reviewed raw data and themes as they were presented.	
Results		
You mention the skew towards white females, was this intentional within your recruitment strategy or coincidental/naturally occurring?	This was coincidental/naturally occurring. We have now changed this to "Participant characteristics are detailed in Table 1 and are coincidentally skewed in representation towards white, middle-aged females, and are consistent with research in this area [23]."	Page 6, Lines 14-16.
Instead of the current table 1, it would be more useful to have a table outlining the demographic characteristics of the participants e.g. participant number, sex, age, ethnicity, SES and perhaps how they scored on measure(s) to provide a gauge of the level of severity of their disablement/functional status/perceived QoL.	We thank the reviewer for this comment and have amended Table 1 to include information on SES (Index of Multiple Deprivation (IMD) Decile) and their occupational status; the latter to provide greater scope of their functional status.	Page 6.
The use of percentages and numbers in this section does not fit with your stated analytic approach above – see my point above in methods.	As addressed above, the percentages were added in to provide context and frequency of reported themes. The analytical approach remained inductive despite the late addition of the percentages.	N/A.
Themes		
Being honest, I would suggest that Themes 1 and 2 would benefit from some further development as there is not enough distinction between them and some repetition of subthemes. For example, at different places within both Themes 1 & 2 you address symptoms – nature and severity; triggers and consequences and also support – availability, effectiveness; self-management strategies.	We acknowledge the reviewer's comments and thank them for identifying this overlap. However, we believe to separate this information would not be a true reflection of the patient data. Symptoms and quality of life were very closely related which patients would discuss both together frequently and to dilute the themes by making a greater distinction would misrepresent the data we have collected.	N/A.
Self-treatment – was there any indication within the diaries about where participants got information or ideas about what to try? Trusted sources etc.	We thank the reviewer for this insightful question. This data was not available and highlights a useful point made by the reviewer about a lack of depth from quotes that may have been explored deeper through, for example, interviews.	Page 17, Lines 30-33.

	We have recognised this limitation in the final paragraph of our discussion.	
"Other instances highlight that these experimental treatments resulted in symptom exacerbation" – as both participant quotes refer specifically to oxygen treatment it might be more accurate to state "some" experimental treatments rather than all of them?	We agree with the reviewer's adjustment and the amendment has been made.	Page 8, Line 9.
Page 8, line 17 – it is not appropriate to use the word "unsurprisingly" here – that is a reflection/opinion.	We agree with the reviewer that this language is inappropriate for this section, and we have removed this word.	Page 9, Line 2.
You have used a participant quote about leaving a tap on to illustrate "negative consequences" of seeing friends and family, presumably it is implied that this was due to brain fog but it is not clear from the quote you provide that this was directly related to long COVID.	We agree with the reviewer that this could be made clearer and so we have amended this line to "…served to exacerbate symptoms such as brain fog which had negative outcomes."	Page 9, Lines 2-3.
Theme 2		
Page 10, line 1 – this is a repeat of a quote used earlier	We recognise the quotes highlighted by the reviewer and thank them for their diligence. This was a similar but a separate quote however we recognise that this is unclear and so we have subsequently removed the quote in the second instance and replaced it with a quote regarding walking and breathing from Appendix b.	Page 10, Line 11.
Page 10, line 18 – you say that participants sought others' advice but the illustrative quote is not about actively seeking of advice	We agree with the reviewer's comment. We have changed this to simply state the advice of others has helped and do not state that this was actively sought.	Page 11, Line 1.
Page 10, line 25 – "another interesting finding" – please refrain from giving opinion	We thank the reviewer for spotting this repeated error and we have removed the word "interesting" to refrain from giving an opinion.	Page 11, Line 7.
Theme 3		
Another pillar on which our codes were structured was through the emotions and thoughts of 24 our participants (5% coverage). – what is a coding "pillar"?	We thank the reviewer for identifying this turn of phrase and have changed the wording of this 'theme' to avoid confusion or imply it was reported more than is stated.	Page 12, Line 6.

This is a really insightful theme with some very poignant quotes but I'm not sure the title "emotions" does it justice. For me, this theme highlights the emotions associated with experiencing specific symptoms, but also the enormous impact on personal identity and associated sense of despair felt by participants, compounded by uncertainty about long-term recovery.	We thank the reviewer for recognising the importance of this theme and agree with their comment and have subsequently amended the theme title to better reflect the context of the theme. The theme is now titled "Emotional Impact of Long COVID Symptoms on Personal Identity and Recovery"	Page 12, Lines 4-5.
Theme 4		
This section was a little unclear to me. It stands to reason that the themes would be interconnected, given that adverse symptoms are widely known to affect QoL and emotional state. It is already well documented that Long COVID symptoms can vary and occur episodically, and that they are often exacerbated by activities or exertion.	We thank the reviewer for their comment and agree that previous research has documented the episodic nature of symptoms, and how they are often exacerbated by activities or exertion. We believe our research reaffirms this point but also recognises how these themes do not occur in isolation. We believe this is important to recognise to support the notion that treatment and rehabilitation strategies must facilitate support for all the themes identified, and not in isolation. This is then explained further in the discussion when discussing interdisciplinary work and the range of resources required for Long COVID rehabilitation.	Page 16, Lines 16-25.
I am left wanting to know what has been learnt by asking people to document their experience over time in diary form, or what more has been learnt about how symptoms/experiences change over time. For example, did participants become more or less expert at managing their condition? Did they become more or less hopeful?	We thank the reviewer for highlighting this point and agree more information is needed here as it is a strength of the diary approach. We have now added in some more detail relating to seasonal weather changes that are within the context of Theme 4. We recognise a limitation of this is that the diaries were completed during late summer, and autumnal & winter months, and some of our future work with diaries will include participants recording entries during the warmer seasonal months. We were unfortunately not able to tell if patients became more expert at managing their condition or became	Page 13, Lines 10-16.

	more or less hopeful. Patients did refer to pacing however this did not indicate that they became more expert as often times symptoms would still occur in the following days at a range of intensities.	
Discussion		
Page 13, line 1 – be clear this is the first study known to gather qualitative data longitudinally rather than at one time point, not the first in-depth qualitative study.	We thank the reviewer and agree with their advice. We have amended this to the reviewer's recommendation.	Page 13, Lines 18-19.
Page 13, lines 23-24 "It is well known that patients with chronic diseases will increase activities when they feel able but with little consideration of the consequences". There is plenty of qualitative evidence already published that documents how people with long COVID (and many other LTCs) wrestle with managing daily tasks and activities and to suggest they do not consider the consequences is not representative of the data you have provided. I agree that there is urgent need to understand how volume and intensity affects different individuals. This was documented some time ago (e.g. Humphreys et al., 2021) so it would be a welcome discussion here to reflect on whether/how that understanding has progressed at all.	We thank the reviewer for picking up on this important point and have amended our text so that we highlight that our data indicates consequences are considered but the value of certain activities outweigh that of symptom exacerbation. We have also now made reference to the Humphreys and colleagues (2021) in relation to the above. We also comment on how our data indicates that knowledge and implementation of some form of pacing since this paper has become more widespread and helpful from clinics, but management of volume and intensity is still lacking.	Page 14, Lines 10-17.
Given that participants were recruited via referral from a Long COVID clinic, there is a lack of discussion on how the clinic advised/supported the management of activity load.	We appreciate that this would be useful information to comment on as part of this discussion however this was not shared with the research team from the participants. In many cases participants were waiting for baseline or follow-up appointments to help them with matters such as managing activity load. Therefore, we are unable to comment on how the clinic advised them on this matter other than some found advice helpful. This possibly again identifies a limitation of diary research over, for example, interviews that could ascertain more detail on the topic of activity management.	Page 14, Lines 14-17.
Page 14, line 6: "Following critical illness such as a severe COVID-19 infection" – this could imply that Long COVID follows 'severe	We thank the reviewer for bringing this to our attention. It is not the case that Long COVID would follow just severe infection and we aimed here to compare	Page 14, Line 31.

infection' – is that the case/how do you define 'severe'?	how emotional difficulty of critical illness is comparable with that of Long COVID. We believe that we make a distinction in what type of infection precedes Long COVID when we refer to the prevalence of Long COVID as comparable between hospitalised (severe) and non-hospitalised (non-severe). To avoid confusion and improve clarity, we have now changed this to simply "Following critical illness, it can be commonplace…".	
You discuss the need for psychological/emotional support, in particular 'acceptance' of a new baseline to reduce negative impact of comparison with healthy individuals. What might this support look like or be informed by? E.g. specific psychological/sociological theories of illness, specific therapeutic models or approaches? Are there examples of this used in other more established long-term condition groups that could be learnt from e.g. persistent pain, MS, HIV?	We thank the reviewer for their comment and agree that expansion on this point would be useful. We have subsequently given an example of a support methods that have been useful in managing ME/CFS (a chronic condition similar to Long COVID).	Page 15, Lines 8-11.
A significant section of the discussion advocates for an interdisciplinary approach embedded in systems science and the specific involvement of SEM professionals. Can you be more specific about what relevant expertise skills these professionals offer/which specific long COVID care needs they can support with (and what other types of professionals would be needed to ensure people's other care needs are effectively supported – e.g. psychological services or wellbeing practitioners?)	We thank the reviewer for their comment and have amended this section to focus on clinical exercise specialists and how their skills are well-placed to support Long COVID support. We have also noted the importance for a broad range of rehabilitation specialists to support the broad symptom profile Long COVID patients present.	Page 16, Lines 11-18.
I also think this section would be greatly improved with discussion about what models of care are currently being offered/how effective these have been to date, both across the UK and internationally. Again, any reflection on how multi-disciplinary or interdisciplinary care has been most effectively (or not!) offered for other long-term conditions? Can you make any suggestions about how a 'buffet style' approach model of care would work in practice / be delivered consistently across	We thank the reviewer for their advice. We have made amendments to this section to include the reviewers comments.	Page 15, Line 30 to Page 16 Line 7.

different parts of the UK to ensure equity of access?		
I welcome your discussion section reflecting on inclusivity in research for people from minoritized communities. I'd suggest that this needs to be extended beyond race/ethnicity to include other under-represented characteristics such as low SES, young people, etc. Could you reflect here on how your study design and recruitment procedures might have influenced your sample or could have been more inclusive? E.g. was it permissible to complete the diary in a language other than English?	We agree with the reviewer's comments that research in this area and our own has underrepresented other groups such as young people and lower SES groups, and have included these groups within this section of our discussion. In our ongoing data collection, we have been able to recruit younger people (20's) however given the time commitment of our ongoing project we understand how it may be more difficult for working age patients to take part in our 16-week study. A possible way around this would be to offer the diary independent of the 16-week bimonthly contact. Further, we could offer the option of completing an online diary format, as the reviewer picked up on earlier, so that it is a more accessible to participants. We refer the reviewer to table 1 for the addition of Index of Multiple Deprivation (IMD) Decile to demonstrate that data does indeed lack participants from lower SES. We agree that our study design could be made more accessible to these groups (I.e., sending diaries to individuals in these underrepresented groups without the need to take time away from commonly associated responsibilities of people working in these groups to attend the university). However, given the diaries were part of the larger trial this was not possible for this project. It was not permissible to complete the diary in a language other than English however this is a consideration for future work using diaries.	Page 17, Line 4. N/A. Page 6. N/A.

		N/A.
I appreciate the limitations of journal word count but would welcome a short addition to your discussion on the merits and limitations of the diary approach, given that it is the key factor in the originality of this paper. Generally your quotes are short compared to studies using interviews, is this reflective of the style that participants recorded their thoughts – does it mean a lack of depth/richness? Were there many instances where more context or clarification would have been desirable but not possible due to the method? In the strengths and limitations section you state "Diaries allowed participants to open up and reveal nuanced details that, in the presence of a researcher, may not have been documented" – can you give any examples?	We thank the reviewer for this recommendation and an additional section has been added prior to our conclusions. We believe by making this point that it would add value and provide perspective on future use of this research method. We have also subtly touched upon how, by being able to complete the diary at any time, this has highlighted a strength of our study which is enabling data to be recorded over a larger time period to enable an entry when the participant is ready to complete one. As expected, this along with some of the other amendments to the discussion have increased the word count of this manuscript considerably. We would welcome advice on how to make the manuscript more concise if appropriate.	Page 17, Lines 24-33.
Reviewer #2 responses		
About the participants		
There were only 12 participants in this study. How is the sample size determined? Is it enough?	We thank the reviewer for this important consideration. Recruitment was part of a larger longitudinal data collection 16-week study that was powered by sample analysis techniques. The sample presented here was a sub-sample of patients that completed the study. Data from the diaries was monitored continuously and analysed until saturation.	Page 5, Lines 6-10.
Participants were recruited from a Derbyshire Long COVID clinic. Are the findings of this study representative of people in other environments (such as households and workplaces)?	We thank the reviewer for their comment. Participants were recruited from the Long COVID clinic however they were referred to this site through GP referrals and included a range of patients who were recovering at home with some of whom had returned to work. We have amended Table 1. to show the socio-economic and occupational status of our participants to provide more	Page 5, Lines 10-13.

	context of their background and functional status. Furthermore, the demographic details from table 1 are consistent with COVID-19 research participants as identified in the results and discussion sections.	Page 6 Page 6, Lines 15-16 and Page 17, Lines 3-5.
About data collection		
Participants were contacted bimonthly by researchers. However, as stated in the manuscript, "this did influence diary entries, with multiple accounts of site visits and their impact upon symptoms." Why not adjust the contact frequency to reduce this influence?	Alike to our previous answer participant size number, recruitment was part of a larger longitudinal data collection 16-week study that had strict bimonthly contact. The sample presented here was a sub-sample of patients that completed the study. Furthermore, after reflection on the reviewers' comment and our group discussions, we decided that bimonthly contacts did not influence diary entries any more than any other activity may have done in their everyday lives and so we amended this passage in the methods section to state that bimonthly contact only had a "limited" impact.	Page 5, Lines 6-9. Page 5, Lines 21-22.
As stated, "researchers in contact with participants had not previously worked with hand-written diaries." If so, how to ensure that participants got proper directions to complete the diary accurately?	Instructions simply included asking participants to document information they perceived relevant to their lived experience – this was intentionally kept simple to ensure proper direction. We have also now included information on how the diaries were returned and data was recorded from participants in light of Reviewer 1 comments. Any queries from patients that patient facing members could not answer were	Page 5, Lines 14-16.

	referred to supervisory research team members (MF and RA) who had greater experience with qualitative research methodology.	
Not all COVID-19 patients would develop long-COVID. How to ensure the impacts that participants recorded in their diaries were from long-COVID but not from other causes (such as anxiety during the pandemic, or being influenced by others)?	Participants were recruited from a Long COVID Clinic and so were evaluated by medical professionals to ensure they had symptoms consistent with Long COVID and not simply symptoms from other causes. In most instances, patients had been referred by their GP's and had confirmed previous COVID-19 infection.	N/A.
Reviewer #3 responses		
The authors could present the methods in more detail, better specifying how the patients filled in the diaries, how the researchers read the diaries and followed up the patients and how the researchers have analysed the data.	We thank the reviewer for their important recommendations. As a result of this specific advice and from all reviewers, the methods section has been significantly improved.	Page 5, Line 1 to Page 6, Line 12.

VERSION 2 – REVIEW

REVIEWER	Humphreys, Helen Sheffield Hallam University, Advanced Wellbeing Research Centre Colleagues of mine are co-applicants on a wider grant associated with this work but were not directly involved in this study.
REVIEW RETURNED	06-Mar-2023

GENERAL COMMENTS	I am very sorry that I cannot recommend this paper for publication in its current form. The originality of the paper is in the analysis of longitudinal qualitative data but the discussion does not clearly explain whether anything new or different has been learnt about the lived experience of long Covid by adopting this method (nor whether it has confirmed previous reports). The reported themes are unclear leaving the reader struggling to interpret the key findings. If the authors are determined not to undertake further work to develop their themes (which I think they should), perhaps they might consider adding some subthemes to the narrative and using more informative theme names. Some of the points I asked for clarification on have not been updated in the manuscript. For example, in their response to reviewers the authors have responded to a comment about explaining sample size and reasons for attrition from or declining invitations to the study, however this detail has not been added to the manuscript. This detail would provide the reader with important information from which they could draw conclusions about potential selection biases within the sample and also the appeal of the diary method to potential participants.

	I am confused by uses of terms such as ‘checking’ and ‘accuracy’ in the methods section and under researcher characteristics. How can diaries be “checked” if participants were free to record whatever they wanted? How can themes be “checked” for accuracy? There is no right or wrong theme but rather a need for transparency and reflexivity about how these themes were arrived at and whether they are a credible representation of the data – hence my earlier comments about adding detail into the methods section such as how reflexivity/researcher triangulation was managed, the professional backgrounds of the research team, further details about data analysis methods and the use of quantitative coding. This detail is not just my personal preference but a requirement listed on the SRQR checklist to encourage clear and transparent reporting of qualitative research. Other points: • A reference is needed to explain how ‘saturation’ is being defined as this term is variably operationalised in qualitative research. • Detail about who did the coding and thematic development listed under Researcher Characteristics belongs in method/data analysis section.

VERSION 2 – AUTHOR RESPONSE

Reviewer #1 responses		
Methods		
“Some of the points I asked for clarification on have not been updated in the manuscript. For example, in their response to reviewers the authors have responded to a comment about explaining sample size and reasons for attrition from or declining invitations to the study, however this detail has not been added to the manuscript.”	We had originally responded to the reviewers’ comments but did not include this information because of how far beyond we had gone from the recommended word count. We have now included this information.	Page 5, Lines 10-12.
“I am confused by uses of terms such as ‘checking’ and ‘accuracy’ in the methods section and under researcher characteristics. How can diaries be “checked” if participants were free to record whatever they wanted? How can themes be “checked” for accuracy?	We thank the reviewer for their comment and have amended our manuscript to inform the reader more clearly that transcriptions were checked for accuracy – meaning it was checked that CT had accurately transcribed the diaries and had not included information that was not there.	Page 6, Lines 7-8.
There is no right or wrong theme but rather a need for transparency and	We thank the reviewer for their guidance on this matter and have	Page 6, Lines 4 & 10-15.

reflexivity about how these themes were arrived at and whether they are a credible representation of the data – hence my earlier comments about adding detail into the methods section such as how reflexivity/researcher triangulation was managed, the professional backgrounds of the research team , further details about data analysis methods and the use of quantitative coding.”	amended our manuscript to include detail of not only the researchers previous experience with working with chronic condition populations but also being open about their experience with these methods and what roles did they have during the data analysis. We have also included how these findings were checked with patient representatives.	
“A reference is needed to explain how ‘saturation’ is being defined as this term is variably operationalised in qualitative research.”	This reference has now been included into our manuscript.	Page 5, Line 10.
“Detail about who did the coding and thematic development listed under Researcher Characteristics belongs in method/data analysis section.”	We thank the reviewer for this instruction and have now included this in the data analysis section.	Page 6, Lines 4-5.
Results		
“The reported themes are unclear leaving the reader struggling to interpret the key findings.” “If the authors are determined not to undertake further work to develop their themes (which I think they should), perhaps they might consider adding some subthemes to the narrative and using more informative theme names.”	We thank the reviewer for their comment and worked on amending the results section by adjusting theme titles and including some subthemes titles to guide the reader through the context of the theme.	Page 6, Lines 20-22; Page 7, Line 2; Page 8, Line 3; Page 9, Lines 3 & 16; Page 10, Line 6; Page 11, Line 5; and Page 12, Line 1.
Discussion		
“the discussion does not clearly explain whether anything new or different has been learnt about the lived experience of long Covid by adopting this method (nor whether it has confirmed previous reports).”	We thank the reviewer for their comment and agree we can add more clear examples of how the diaries reaffirm and/or add to previous knowledge. We have amended the manuscript discussion to include these points.	Page 14, Lines 16-18; Pages 14-15, Lines 31-2; Page 15, Lines 23-25; Page 16, Lines 9-11; Page 17, Lines 20-24. Page 18, Lines 16-22.

	We have also made reference in the right-hand column to examples of where we already state our diary findings have confirmed previous reports from the previous submission.	Page 14, Lines 12-13, 24-27, 29-31; Page 15, Lines 5-6, 9-10, 15-16; Page 17, Lines 28-29.