

COVID-19 rapid evidence review

Case definition (disease trajectory and symptom fluctuation)

The views and experiences of patients, their families and carers

November 2021

© Healthcare Improvement Scotland 2021

This document is licensed under the Creative Commons Attribution-Noncommercial-NoDerivatives 4.0 International Licence. This allows for the copy and redistribution of this document as long as Healthcare Improvement Scotland is fully acknowledged and given credit. The material must not be remixed, transformed or built upon in any way. To view a copy of this licence, visit <https://creativecommons.org/licenses/by-nc-nd/4.0/>

www.healthcareimprovementscotland.org

Contents

Introduction	1
Methods.....	1
Key questions	1
Literature search.....	1
Data extraction.....	2
Quality assessment	2
Data synthesis	2
Key results.....	2
Included studies.....	2
Quality assessment	11
Findings	11
Abbreviations.....	15
Appendix 1: review protocol.....	16
Appendix 2: literature search strategy	20
Appendix 3: study flow diagram	20
Appendix 4: excluded studies	21
Studies excluded at title and abstract screening.....	21
Studies removed at full text screening	21
Appendix 5: citations for included studies	22
Appendix 6: study quality assessment.....	23

Introduction

Healthcare Improvement Scotland conducted a rapid qualitative evidence review as part of the collaborative guideline development work undertaken by the Scottish Intercollegiate Guidelines Network (SIGN), the National Institute for Health and Care Excellence (NICE) and the Royal College of General Practitioners (RCGP) on managing the long-term effects of COVID-19. The rapid evidence review sought patient, family and carer views and experiences relating to disease trajectory and symptom fluctuations to inform two review questions.

The guideline covers the care of people who have signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 4 weeks and are not explained by an alternative diagnosis.

Methods

Key questions

What is the trajectory of post-COVID-19 syndrome (PCS)? Does this differ based on patient characteristics? For example, age, sex, ethnicity, comorbidities, severity of acute COVID-19

Are fluctuating symptoms and episodes of disability features of post-COVID-19 syndrome? Does this differ based on patient characteristics? For example, age, sex, ethnicity, comorbidities, severity of acute COVID-19

The protocol for this rapid evidence review is included in appendix 1.

Literature search

The literature search was conducted by NICE who identified four studies.¹⁻⁴ Of these, one was excluded due to its US context of infectious disease clinic.³ One additional relevant study was added from previous NICE guideline development work.⁵

Data extraction

Two reviewers independently extracted descriptive data on each study (see table 1). Details extracted from the studies included: the country in which the study was conducted, the methods of data collection and analysis used, the phenomena of interest, setting / context / culture, participant characteristics and sample size, and a description of the main results (themes) reported in each paper.

Quality assessment

The four studies used in the qualitative synthesis were critically appraised independently by two reviewers using the CASP qualitative checklist (<https://casp-uk.net/casp-tools-checklists/>).

Data synthesis

Full thematic synthesis was not undertaken due to the limited amount of relevant information which was identified. Key points emerging were summarised.

Key results

Included studies

A summary of the four included studies is presented in table 1.^{1, 2, 7} Details of the study citations can be found in appendix 5.

Table 1: summary of qualitative studies in the rapid evidence review

Study [country]	Methods for data collection and analysis	Phenomena of interest	Setting / context / culture	Participant characteristics and sample size	Description of main results	Comments
Taylor et al 2021 [UK] Subset of a larger study Kingstone et al 2020	Semi-structured interviews. The topic guide was developed by the researchers in collaboration with experts by experience. The topic guide was modified iteratively throughout data collection and analysis. Inductive and interpretive	Experiences of people with persisting symptoms following suspected or confirmed COVID-19 infection in March or April 2020	UK Participants recruited via Facebook and Twitter with snowball sampling	Doctors (n=13, 2 male, 11 white British) Sample size was determined by inductive thematic saturation, which was judged to be the point at which no new codes or themes were developed from the analysis.	Themes: <ul style="list-style-type: none"> • making sense of symptoms • feeling let down • using medical knowledge and connections • wanting to help and wanting to be helped • becoming a more empathic doctor. 	First theme most relevant to this key question. Participants described the unusual and unpredictable nature of their symptoms. <i>'It's weird because one minute, you can walk up the stairs and you can feel fine and the next minute, you walk up and all your muscles are killing you and your heart is batting at 120.'</i>

	thematic approach, applying principles of constant comparison.					<p><i>It's just bizarre.'</i> Deborah</p> <p>Other points about symptoms:</p> <p>Fear around serious pathology that could be missed.</p> <p>Fear of never getting better.</p> <p>Worry about extent to which symptoms were related to psychological factors</p>
Kingstone 2020 [UK]	Semi-structured interviews. Topic guide was developed by the	Explore the symptoms that people with confirmed or suspected COVID-19	UK Participants recruited via Facebook and Twitter	24 Adults with COVID onset March/April 2020 – none had been hospitalised Majority white British	Themes: <ul style="list-style-type: none"> the 'hard and heavy work' of enduring and managing symptoms and accessing care 	First two themes most important to this question.

	<p>research team in collaboration with 'experts by experience'. The topic guide was modified iteratively as data generation and analysis progressed in parallel.</p> <p>Thematic analysis was conducted applying constant comparison techniques.</p>	<p>infection are continuing to experience following recovery from the acute infection, and to understand their experiences of primary care support and which interventions (if any) they have found to be helpful.</p>	<p>with snowball sampling</p>	<p>Unclear when interviews conducted –study submitted Sept 2020</p>	<ul style="list-style-type: none"> • living with uncertainty, helplessness and fear, particularly over whether recovery is possible • the importance of finding the 'right' GP (understanding, empathy, and support needed) • recovery and rehabilitation: what would help? 	<p>Experiencing and enduring persistent symptoms</p> <p><i>I can remember the feeling, you know thinking, "Oh, you know I've managed to get through it" and that's when the fatigue hit ...</i></p> <p><i>And some days bed-ridden, some days you know make it to sort of breakfast to sofa, watch telly.</i></p> <p>Managing symptoms</p> <p><i>He's still sleeping now, five and half months after.</i></p> <p>Most participants described how they had worked out for</p>
--	--	--	-------------------------------	---	--	--

						<p>themselves that they needed to 'pace' their activities in order to conserve what little energy they had.</p> <p>Fear, uncertainty and despair around persisting symptoms.</p>
<p>Maxwell 2000</p> <p>[UK]</p>	<p>Focus group with with some members of the Long Covid Facebook group.</p>	<p>Understanding of the new phenomenon 'ongoing Covid19' in people who do not recover</p>	<p>Unclear/ not specified</p>	<p>Long Covid Facebook members.</p> <p>Likely Sept 2020</p> <p>Query nine participants – identities known but not disclosed.</p>	<p>Four overarching themes emerged:</p> <ul style="list-style-type: none"> • expectations • symptom journey • being doubted • support. 	<p>No detail provided on how analysis conducted.</p> <p>Key point relevant to this question:</p> <p>Covid19 is not always a linear</p>

	Agreed a summary report with them.	after a short period of illness				<p>disease with an acute phase followed by recovery or a steady state rehabilitation. It can be cyclical disease, with symptoms moving round different body systems and fluctuating in severity.</p> <p><i>“If the message hadn’t been [to expect to recover in] around two weeks, I’d have been more cautious at first, ... the doctor I saw in A/E described Covid as the gift that keeps on giving and at four weeks I thought that felt</i></p>
--	------------------------------------	---------------------------------	--	--	--	---

						<p><i>like a long time, and now five months on it feels like a very long time”</i></p> <p>The biggest challenge for many was not the individual symptoms, but their unpredictability and the dashed hopes of recovery after a few good days:</p>
Ladds 2020 [UK]	<p>Narrative interviews with prompts and focus groups (3-12 participants).</p> <p>Partial transcription to identify</p>	<p>How do people with long Covid (including those who were never hospitalised) experience the development,</p>	<p>UK participants recruited from Twitter and Facebook</p>	<p>55 interviews + 59 focus group participants (n=114). 74% white British. 70% males. Median age 46 (range 23-73)</p> <p>People with symptoms developed between February and</p>	<p>Themes:</p> <p>a confusing illness with many, varied and often relapsing-remitting symptoms and uncertain prognosis</p> <p>a heavy sense of loss and stigma</p>	<p>The first theme is the most relevant to this key question.</p> <p>Participants with long Covid described symptoms in every part of the body</p>

	initial themes – with these refined refined using the constant comparative method.	course and perhaps resolution of the illness over time?		<p>July 2020 following an acute illness consistent with Covid-19.</p> <p>symptoms continued beyond 3 weeks.</p>	<p>difficulty accessing and navigating services</p> <p>difficulty being taken seriously and achieving a diagnosis disjointed and siloed care (including inability to access specialist services)</p> <p>variation in standards (e.g. inconsistent criteria for seeing, investigating and referring patients)</p> <p>variable quality of the therapeutic relationship and possible critical events</p>	<p>which were sometimes severe or fluctuating, made worse by the uncertain prognosis and stalled recovery, all of which combined to make this a frightening, confusing and debilitating illness. Many were unable to make sense of their suffering – an experience intensified by absence of medical knowledge or guidance. They described being trapped in a cycle of small improvements followed by setbacks which</p>
--	--	---	--	---	---	--

						were physically and emotionally stressful, with no clear prospect of full recovery.
--	--	--	--	--	--	---

Quality assessment

Critical appraisal of the evidence is presented in appendix 6. The qualitative research methods used were interviews and focus groups.

All studies recruited participants through social media and/or online support groups. This convenience sampling arguably resulted in biased samples since people who are active on social media or online support groups are likely to differ from the general population (for example, younger age) and may be more vocal about their experiences of COVID-19. All acknowledged skewed sample characteristics including mainly white ethnicity, over-representation of women, and a generally younger age group.

None of the studies described or discussed potential biases arising from the relationship between researchers and study participants.

Findings

Context

All four qualitative studies were conducted during Autumn 2020 and recruited participants who were experiencing persisting symptoms following suspected or confirmed COVID-19 infection. Although perceived recovery from the acute infection was within the scope of these studies it is unlikely that participants who had fully recovered following a period of persisting symptoms would have been included so this aspect of disease trajectory is not encompassed.

How do patients describe their experience of fluctuating symptoms and disease trajectory?

Reported symptoms varied in both range and severity, and fluctuations in symptoms was a commonly described aspect of the disease trajectory. One study described how patients reported being ‘trapped in a cycle of small improvements followed by setbacks which were physically and emotionally stressful, with no clear prospect of full recovery’.²

This concept of a cyclical pattern of symptoms was evident in two of the other studies.^{4, 5}

“I currently feel I am living in a “Covid” cycle of symptoms (fever, cough and metallic taste), extreme fatigue and brain fog then a few days of normality. Slowly, after nearly six months I am slowly beginning to see more ‘normal’ days but as soon as I begin to feel better the cycle starts again.” (Maxwell p10)⁵

“I went through this cycle of feeling a bit better... I thought I’d gradually try and increase my exercise tolerance in my garden... but I’d get to the point where I literally couldn’t walk another step, it was like my battery had run out. It wasn’t just fatigue, it was the weirdest thing...” (Taylor, p835)⁴

In one study of doctors, the participants described symptoms as both unusual and unpredictable.⁴ These aspects together lead to concern, confusion and difficulties making sense of symptoms.¹ Another study noted that where people have a wide range of interconnected symptoms, even if not individually severe, they can collectively leave people severely debilitated.⁵

“ from week four I started to get chest pains and then breathlessness, gradually other symptoms developed.....The following weeks were frightening as symptoms fluctuated; sometimes thinking that you were improving and then very disheartening when they returned.” (Maxwell, p7)⁵

What is the impact of the fluctuating symptoms and disease trajectory?

Fear

Research participants reported feelings of fear surrounding their ongoing COVID-19 symptoms. Some of the fear was generated by this being a novel disease, which doctors were openly admitting they knew little about.

“....(the) GP literally just went ‘you need to stay at home and rest, there’s nothing we can do’ and that frustrated me because it didn’t seem like they were being caring, it felt like I was nagging them and being a hypochondriac...” (Kingstone, p7)¹

In some cases, this fear led to people becoming concerned that their symptoms were indicative of an illness that was more serious and were being overlooked or incorrectly linked with COVID-19.

“I guess I was frightened that I had an ongoing illness that was going to be chronic, and that also there was some serious pathology going on that was being missed...” (Kingstone, p7)¹

“I’ve actually spent this morning in [the emergency department] because I thought I’ve never had a positive diagnosis of [COVID 19]. I’ve been unwell for, what 10 weeks now, I need to make sure it’s nothing else and I’ve not actually been examined at any point.” (Ladds, p61)²

Similarly, Maxwell (2020) reported that the uncertainty around the cause of their symptoms and the restricted access to diagnostics left people feeling isolated and uncertain about whether or not concurrent disease was being missed.⁵

For some this was compounded by the difficulty obtaining face-to-face appointments with GPs, and they feared that online or telephone appointments could result in symptoms being overlooked. People also missed the therapeutic relationship generated by traditional appointments and the reassurance provided by face-to-face contact. This seemed to be

particularly pertinent in people who felt the disease affected their judgement and their ability to communicate. However, there was also general recognition that remote consultation was necessary during the pandemic.

“I’ve not actually physically seen my GP face-to face on any of these occasions...and then I come off the phone quite dissatisfied.” (Ladds, p61)²

People felt the need to seek out their own answers and find their own ways in which to navigate the disease as medicine was not providing them with formalised treatments and protocols. Many people reported doing this via social media and online support groups. Many felt that these groups helped them understand their symptoms and validated their fears in a way GPs and the medical community had not.

Uncertainty

Uncertainty was a recurring topic that emerged from the literature. This stemmed from the fact that many participants were dealing with symptoms that didn’t seem to fit the pattern of disease progression which they, and the professionals expected.

“....She said, ‘Well we don’t’ know what to do with long COVID. What we’re doing at the moment is what we always do in these situations, we’re ruling out other things but if the answer ends up being Long COVID we don’t know...” (Ladds, p61)²

Limited information and knowledge around symptoms

These feelings of fear and uncertainty were underpinned by a lack of information and knowledge around the long-term effects of COVID-19, its fluctuating symptoms and its treatment. Maxwell (2020) reported that people believed that this lack of information and knowledge affected the way medical professionals interacted with them and the advice they were given, many feeling that the advice was that they should have recovered within a few weeks of the initial infection.⁵ This mismatch between the reality faced by patients and the expectations health professionals’ had around the progression of the disease left many feeling uncertain and anxious.

“Well yeah, I feel like there’s a lack of knowledge. And I really wasn’t able to get any answers...” (Kingstone, p7)¹

Attempts to manage symptoms

The research shows that, in light of the limited official information, people were searching out a variety of ways to deal with the feelings of uncertainty, the fluctuating symptoms, and the disease progression. Social media groups were found, for some people, to be a good source of information around how to manage their symptoms. Some people turned to

complementary medicine such as acupuncture, massage, vitamin supplements, or specialist diets such as the anti-inflammatory diet or the anti-histamine diet.

“I have gone all out on the quackery, which I never thought I would because I’ve never been that person. I’ve had acupuncture a few times. I am under a dietician and I’m taking all sorts of weird and wonderful supplements.” (Taylor, p838)⁴

Pacing of effort was also found to be helpful for some as a way of conserving energy for specific activities:

“Yeah and I really have to pace myself and I can’t do...I couldn’t do two or three household chores back to back, I have to do a chore, sit down for 15, 20 minutes and then do the next which frustrates me...” (Kingstone, p6)¹

Abbreviations

CASP	critical appraisal skills programme
GP	general practitioner
NICE	National Institute for Health and Care Excellence
RCGP	Royal College of General Practitioners
SIGN	Scottish Intercollegiate Guidelines Network

Appendix 1: review protocol

Question 1: What is trajectory of post-COVID-19 syndrome (PCS)? Does this differ based on patient characteristics? For example, age, sex, ethnicity, comorbidities, severity of acute COVID-19

Criteria	Notes
Population	Adults and children experiencing ongoing symptoms beyond the duration of acute COVID-19 illness (>4 weeks)
Exposure	<ul style="list-style-type: none"> History of SARS-CoV-19 infection which has been laboratory-confirmed or History of symptoms suggestive of acute COVID-19 illness
Comparators	Not applicable
Outcomes	<p>Time of referral to PCS services</p> <p>Signs and symptoms experienced at time of follow up (These include physical, cognitive, psychological and psychiatric symptoms)</p> <p>Patient reported outcomes such as:</p> <ul style="list-style-type: none"> Self-reported recovery Changes in symptoms Changes in functioning and disability using WHO ICF framework Duration of symptoms Severity of symptoms <p>Proportion of people with alternative diagnoses</p> <p>Number of people diagnosed with PCS (SNOMED and READ codes)</p>

	<p>Time to diagnosis with PCS (including time to coding with SNOMED and READ codes)</p> <p>Evidence of end organ damage</p>
Settings	Any
Subgroups	<p>Diagnostic status of acute COVID-19 (e.g., confirmed or high clinical suspicion)</p> <ul style="list-style-type: none"> • Treatment setting for acute COVID-19, including: <ul style="list-style-type: none"> ○ Hospitalised for acute COVID-19 ○ Non-hospitalised for acute COVID-19 ○ Care or residential homes • Severity of initial COVID 19 illness (using definition in the NICE NG191 guideline) • Comorbidities • Characteristics such as age, sex ethnicity, disabilities included in the EIA • Vaccination status • SARS-CoV-2 variant
Study types	<p>The following study design types for this question are preferred. Where these studies are not identified, other study designs will be considered.</p> <p>Preferred:</p> <ul style="list-style-type: none"> • Systematic reviews of cohort studies • Cohort studies (prospective or retrospective) • Cross-sectional studies • Qualitative studies • Mixed methods studies
Countries	Any

Timepoints	At least 4 weeks from initial acute COVID-19 illness onset
------------	--

Fluctuation of symptoms in post-COVID-19 syndrome

Question 2: Are fluctuating symptoms and episodes of disability features of post-COVID-19 syndrome? Does this differ based on patient characteristics? For example, age, sex, ethnicity, comorbidities, severity of acute COVID-19

Criteria	Notes
Population	Adults and children experiencing ongoing symptoms beyond the duration of acute COVID-19 illness (>4 weeks)
Exposure	<ul style="list-style-type: none"> History of SARS-CoV-19 infection which has been laboratory-confirmed or History of symptoms suggestive of acute COVID-19 illness
Comparators	Any or no comparator
Outcomes	<p>Signs and symptoms experienced at the time of follow-up (These include physical, cognitive, psychological and psychiatric symptoms)</p> <p>Time to recovery from any ongoing COVID-19 symptoms.</p> <p>Time to recurrence of any symptoms</p> <p>Number of recurrences of any symptoms</p> <p>Triggers for recurrence of symptoms</p>

	<p>Severity of symptoms at the time of follow-up</p> <p>Onset of new symptoms at the time of follow-up</p> <p>Referral for investigations based on symptoms</p> <p>People with alternative diagnoses</p> <p>Number of people diagnosed with PCS (SNOMED and READ codes)</p> <p>Number of recurrences</p> <p>Readmission to hospital or attendance at other acute care facilities</p> <p>Changes in functioning and disability using WHO ICF framework</p>
Settings	Any
Subgroups	<p>Diagnostic status of acute COVID-19 (e.g., confirmed or high clinical suspicion)</p> <ul style="list-style-type: none"> • Treatment setting for acute COVID-19, including: <ul style="list-style-type: none"> ○ Hospitalised for acute COVID-19 ○ Non-hospitalised for acute COVID-19 ○ Care or residential homes • Severity of initial COVID 19 illness (using definition in MAC guideline) • Underlying or pre-existing conditions • Characteristics such as age, sex ethnicity, disabilities included in the EIA • Vaccination status • SARS-CoV-2 variant

Study types	<p>The following study design types for this question are preferred. Where these studies are not identified, other study designs will be considered.</p> <p>Preferred:</p> <ul style="list-style-type: none"> • Systematic reviews of cohort studies • Cohort studies (prospective or retrospective) • Cross-sectional studies • Qualitative studies • Mixed methods studies
Countries	Any
Timepoints	At least 4 weeks from initial acute COVID-19 illness onset
Other exclusions	None

Appendix 2: literature search strategy

Available from NICE

Appendix 3: study flow diagram

Available from NICE

Appendix 4: excluded studies

Studies excluded at title and abstract screening

Available from NICE

Studies removed at full text screening

Table 3: studies rejected at full text screening

Study	Reason for exclusion
Rodriguez Edda I S-R, Maiorana A, Peluso Michael J, Hoh R, Tai V, Fehrman Emily A, et al. Characterizing the COVID-19 illness experience to inform the study of post-acute sequelae and recovery: a qualitative study. medrxiv preprint.	US study conducted in context of infectious disease clinic setting.

Appendix 5: citations for included studies

Ladds E, Rushforth A, Wieringa S, Taylor S, Rayner C, Husain L, et al. Persistent symptoms after Covid-19: qualitative study of 114 "long Covid" patients and draft quality principles for services. BMC Health Serv Res. 2020;20(1):1144. Epub 2020/12/22.

Kingstone T, Taylor AK, O'Donnell CA, Atherton H, Blane DN, Chew-Graham CA. Finding the 'right' GP: a qualitative study of the experiences of people with long-COVID. BJGP Open. 2020;4(5). Epub 2020/10/15.

Maxwell E. Living with Covid19. National Institute for Health Research. 2020.

Taylor AK, Kingstone T, Briggs TA, O'Donnell CA, Atherton H, Blane DN, et al. 'Reluctant pioneer': A qualitative study of doctors' experiences as patients with long COVID. Health Expectations. 2021;24(3):833-42.

Appendix 6: study quality assessment

criteria	CASP	Yes/No/ Can't tell	Comments
Study: Taylor <i>et al</i> 2021 (Kingstone <i>et al</i> 2020)			
Was there a clear statement of the aims of the research?	Yes		Aims clearly stated.
Is a qualitative methodology appropriate?	Yes		Qualitative methodology highly appropriate as exploring participants' experiences. Qualitative methodologies are suitable for this study due to the exploratory nature of the research questions, which seek to reveal perspectives and understandings, and interpret the experiences of people with COVID-19.
Was the research design appropriate to address the aims of the research?	Yes		Qualitative methodology, with semi-structured interviews. Good justification provided at start of methods section for choice of qualitative methodology.
Was the recruitment strategy appropriate to the aims of the research?	Yes		Recruitment strategy involved social media (Facebook & Twitter) and snowball sampling. Appropriate strategy to recruit sample in short timeframe but may be biased (social-media users and arguably more vocal individuals, largely self-identified as having long COVID). Bias not discussed by authors - focus on effective strategy with Twitter being particularly fruitful.
Was the data collected in a way that addressed the research issue?	Yes		Methods appropriate and clearly described. Topic guide modified iteratively. The topic guide was developed by the research team in collaboration with 'experts by experience' (people who were suffering with persistent symptoms) in one-to-one discussions with one author, and at a Clinical Commissioning Group support group in which the author participated. Data collection continued until the research team members were confident that saturation, at a thematic level, had been reached.
Has the relationship between researcher and participants been adequately considered?	Can't tell		Little reflexivity - told that one of the authors is also a long term COVID-19 sufferer but no discussion of potential bias.

Have ethical issues been taken into consideration?	Yes	Ethical approval from University ethics committee - appropriate as not recruited via NHS. Research ethical by current standards - social media posts for recruitment followed by information sheet & written informed consent - consent reconfirmed at start of interview - confidentiality implied (audio recordings sent to professional transcription service, codes used for analysis & reporting, participants should not be identifiable from article).
Was the data analysis sufficiently rigorous?	Yes	Data analysis described and applied thematic analysis cited. Two researchers analysed data, saturation discussed, although there could be more clarity around how themes were identified. Good spread of participant quotes used.
Is there a clear statement of findings?	Yes	Findings clearly presented and flow from the raw data (quotes). Findings answer research question. The findings used mostly quotes which is appropriate for applied thematic analysis - descriptive. Appears credible from use of quotes, two researchers, feedback from participants and other experts by experience (people with COVID-19). Illustrative data are provided to support the analysis; data extracts are identified by participant number with sex and age reported in brackets for context.
How valuable is the research?	-	Results are valuable - provides insight into experiences of long COVID which are to date under-researched. Experience of long-term COVID-19 and accessing care can be used by healthcare professionals to inform support/management of people with long COVID and help healthcare professionals to understand the condition. The findings from this study will provide important contributions to the development of flexible, person-centred interventions for people recovering and rehabilitating from COVID-19.
Study: Ladds <i>et al</i> (2020)		
Was there a clear statement of the aims of the research?	Yes	Sets out rationale for the work and three questions to be answered.

Is a qualitative methodology appropriate?	Yes	Question about what services accessed could be answered using survey techniques, but other aims are to describe experiences and to measure beliefs about service design which are clearly served by qualitative approaches.
Was the research design appropriate to address the aims of the research?	Yes	Use of focus groups and interviews appropriate to gather qualitative information; tried to adjust for under-represented groups. Interim broad thematic analysis and then use of constant comparative methods; informed by relevant theories."
Was the recruitment strategy appropriate to the aims of the research?	Yes	Social media call and direct contact with support groups. Snowballing and eligibility screening. Additional steps taken to correct gender and ethnicity skew. Drew on social media to get to a group of individuals for which there was no other group established.
Was the data collected in a way that addressed the research issue?	Yes	Focus groups and interviews appropriate for gathering the necessary data. Interviews were not based upon prespecified questions as narrative wanted - this seems appropriate. Focus groups - appropriate number of participants (3 to 12) and timing (90 mins), participants could leave if tired; two trained facilitators. First ten interviews transcribed in full and used to identify themes; subsequent interviews only transcribed in part but seems reasonable and justified. Focus groups transcribed in full. Patients were involved in data analysis and also checking data.
Has the relationship between researcher and participants been adequately considered?	Can't tell	Does not specifically mentioned role of researchers, although notes that participants were involved in all aspects of the study. Research overseen by an independent advisory group with patient representation and a lay chair which met 3-monthly. The study was planned, undertaken, analysed and written in collaboration with people with long COVID.
Have ethical issues been taken into consideration?	Yes	Ethical approval was sought and received. Consent was collected either by email or verbally at the beginning of the audio or videotape. Participants informed of right to withdraw or change testimony at any stage.

Was the data analysis sufficiently rigorous?	Yes	Have put yes, but mostly likely due to constraints of the word count, there is limited information given; no real explanation of how the theories used to explain the data were chosen. Note potential limitation that only the first 10 interviews were transcribed in full, with selected parts of others added for speed. Analysis informed by multiple theoretical constructs.
Is there a clear statement of findings?	Yes	Without seeing the raw data, it is difficult to be entirely clear whether the findings reflect the information gathered, however they are explicit and clear. The 'fit' of the data with existing theories is discussed. No discussion of credibility and conflicting evidence was only presented for one theme. Unclear whether examples selected to emphasise chosen themes or if data were unanimous.
How valuable is the research?	-	While the authors acknowledge the shortcomings in the range of participants within the sample studied, the sample seems wide enough to at least start to guide practice in this area. Excellent discussion of results in theoretical contexts.
Study: Maxwell (2020)		
Was there a clear statement of the aims of the research?	No	There is no clear statement of the aims of the research. Text suggests that the aim is to gather experience to inform others and improve understanding around the issues of long-term symptoms of COVID-19.
Is a qualitative methodology appropriate?	Yes	Aimed to capture the experience of people with long-term symptoms of COVID-19.
Was the research design appropriate to address the aims of the research?	Can't tell	Only detail is that a focus group was held - no methodology description included in publication and no details described. Number of patients involved not stated. Sampling / recruitment methods not stated.
Was the recruitment strategy appropriate to the aims of the research?	Can't tell	No details provided. It appears to be a convenience sample of people in COVID-19 Facebook group – this would facilitate fast recruitment but most likely a biased sample (of Facebook users).
Was the data collected in a way that addressed the research issue?	Can't tell	Focus group used, but no details given for data collection, saturation, conduct of group, researcher role, etc.

Has the relationship between researcher and participants been adequately considered?	Can't tell	No information included.
Have ethical issues been taken into consideration?	Can't tell	No details provided.
Was the data analysis sufficiently rigorous?	No	No analytical methodology. Themes described but unclear how these were synthesised. Several quotations used in each theme with narrative interpretation of the participants' views included. No clear link between summary statements and the number of participants who provided them.
Is there a clear statement of findings?	Yes	Findings presented clearly with good range of participant quotes - no detail on credibility or way of judging credibility. Clear description of themes, but mixture of attribution of views of individuals and views of the whole focus group. Majority of themes were not supported by examples in favour of and contrary to overall theme.
How valuable is the research?	N/A	Although scant detail on methodology and methods this does provide useful information on people's experiences of living with long-term symptoms of COVID-19. The authors do justify their approach based on the lack of research conducted to date.

Healthcare Improvement Scotland

Edinburgh Office	Glasgow Office
Gyle Square	Delta House
1 South Gyle Crescent	50 West Nile Street
Edinburgh	Glasgow
EH12 9EB	G1 2NP
0131 623 4300	0141 225 6999

www.healthcareimprovementscotland.org

References

1. Kingstone T, Taylor AK, O'Donnell CA, Atherton H, Blane DN, Chew-Graham CA. Finding the 'right' GP: a qualitative study of the experiences of people with long-COVID. *BJGP Open*. 2020;4(5). Epub 2020/10/15.
2. Ladds E, Rushforth A, Wieringa S, Taylor S, Rayner C, Husain L, *et al*. Persistent symptoms after Covid-19: qualitative study of 114 "long Covid" patients and draft quality principles for services. *BMC health services research*. 2020;20(1):1144.
3. Rodriguez Edda I S-R, Maiorana A, Peluso Michael J, Hoh R, Tai V, Fehrman Emily A, *et al*. Characterizing the COVID-19 illness experience to inform the study of post-acute sequelae and recovery: a qualitative study. *medrxiv preprint*.
4. Taylor AK, Kingstone T, Briggs TA, O'Donnell CA, Atherton H, Blane DN, *et al*. 'Reluctant pioneer': A qualitative study of doctors' experiences as patients with long COVID. *Health expectations : an international journal of public participation in health care and health policy*. 2021;24(3):833-42.
5. Maxwell E. Living with Covid19. National Institute for Health Research. 2020.