Healthcare Improvement Scotland | Evidence
Advice, guidance and intelligence

COVID-19 rapid evidence review

Managing the long-term effects of COVID-19:

the views and experiences of patients, their families and carers

December 2020

NHS SCOTLAND

Published December 2020

www.healthcareimprovementscotland.org

Contents

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 the management of the long-term effects of COVID-19.

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. This new and emerging condition, which has been described using a variety of terms including ‘long COVID’, can have a significant effect on people’s quality of life. It also presents many challenges when trying to determine the best-practice standards of care based on the current evidence. There is not yet an agreed clinical definition of the condition or clear treatment pathway, and there is a minimal, though evolving evidence base. This review refers throughout to patients with ‘long-term symptoms of COVID-19’ when describing people with this emerging condition.

Methods

Key question

What are the views and experiences of patients, their families and carers about:

- signs and symptoms of post-COVID-19 syndrome
- access to services
- how their symptoms were assessed
- management of symptoms and rehabilitation
- the patient care pathway
- information and support provided
- communication with healthcare professionals?

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

Literature search

The knowledge management team at Healthcare Improvement Scotland identified relevant evidence through systematic searches of the primary and secondary literature up to 29 October 2020 (see appendix 2 for details). Resources searched include bibliographic databases, grey literature sources, and preprint databases.

Results from the literature searches (198 records after de-duplication) were screened for relevance using their titles and abstracts. Two reviewers independently screened all titles and abstracts.

Following screening, potentially relevant studies identified (6 studies[1-6]) were then assessed in full text by two reviewers working independently to determine whether they met the inclusion criteria (see appendix 1). All uncertainties were discussed and referred to a third reviewer if needed. One study was excluded following examination of the full text as it did not use qualitative methods or contain data on direct patient experience. See appendix 3 for the study flow chart of included studies and appendix 4 for a list of excluded studies, with reasons for exclusion.

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 five 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

Thematic synthesis was undertaken on the findings from the five included studies[7]. This involved: (i) independent line-by-line reading of each study by two reviewers to identify initial concepts; (ii) grouping similar concepts into initial descriptive themes and sub-themes, and (iii) generating the final analytical themes. Stage (i) resulted in a total of 138 descriptive themes. These descriptive themes were then grouped into 11 analytical themes using an iterative process, with continuous discussion between reviewers. The iterative process of defining and refining themes and sub-themes resulted in 54 sub-themes being attributed to the 11 analytical themes (see table 2).

Key results

Included studies

A summary of the five included studies[1-5] is presented in table 1. Details of the study citations can be found in appendix 5. All five included studies focused on the experiences and views of patients, with little qualitative evidence on the experiences or views of carers or family members.

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
Assaf *et al.* (2020)[5] [US, UK, Netherlands, Canada, Belgium, France, Other]	Survey circulated to long COVID support groups and through social media Online survey 21 Apr to 2 May 2020 Descriptive statistics for quantitative data; no discussion of analytic approach for qualitative data	Experiences of people with long-term symptoms of COVID-19, and the care available to them	Respondents from multiple countries all with access to different healthcare systems Large proportion of respondents from USA	n=640 Participants recruited predominantly through online support groups (75.4%); other main sources were Facebook (16.9%); friends or family (4.7%) Patients with symptoms lasting >2 weeks 23.1% had positive test; 47.8% not tested 71.7% USA, 12.7% UK 62.7% aged 30-49	Cyclical symptoms experienced unexpectedly for ≥6 weeks Impacts on lifestyle, including physical activity Dismissed or misdiagnosed by medical professionals Sentiment analysis on satisfaction with medical staff – follow ups and check-ins associated with ‘very supportive’; being dismissed or misdiagnosed associated with ‘not supportive’; receiving conflicting	Data aggregation and analysis by people with long-term symptoms of COVID-19 and research expertise Sampling bias

Study [country]	Methods for data collection and analysis	Phenomena of interest	Setting / context / culture	Participant characteristics and sample size	Description of main results	Comments
				76.0% white 76.6% female 57.8% had one or more pre-existing condition 68% moderately to very physically active pre-COVID infection	prognoses and advice associated with 'somewhat supportive' Sentiment analysis on sharing experiences - those who did share were motivated by wanting to help others, to attract more support for sufferers and to educate others; not sharing was driven by a fear of being stigmatised, fear of misleading others and a lack of energy for the potential consequences of sharing Some respondents expressed confusion around ending their isolation periods	

Study [country]	**Methods for data collection and analysis**	**Phenomena of interest**	**Setting / context / culture**	**Participant characteristics and sample size**	**Description of main results**	**Comments**
Kingstone *et al*. (2020)[2] [UK]	Recruitment through social media and snowball sampling Jul to Aug 2020 Semi-structured interviews by telephone or video call (duration 35-90 minutes) Thematic analysis using principles of constant comparison	Explore symptoms that people continue to experience following acute COVID-19 (confirmed or suspected) Understand experiences of primary care support and interventions (if any) that were helpful	General community on Twitter or Facebook	Self-reported persistent symptoms following acute COVID-19 infection n=24 79.2% female Age range 20-68 87.5% white British (2 white other; 1 mixed heritage) 83.3% degree educated (1 O-levels; 1 A-levels; 2 students) 79.2% with underlying condition 79.2% working (PT or FT); 2 retired; 3 not working None hospitalised for COVID-19	Four key themes reported in results: (i) 'hard and heavy work' of enduring and managing symptoms, trying to find answers, and accessing care (ii) living with uncertainty and fear (iii) importance of finding the 'right' GP (iv) recovery and rehabilitation: what would help?	Robust study into experiences of patients with long-term symptoms of COVID-19 People with experience of long-term symptoms of COVID-19 contributed to study design and data analysis One of the research team is an "expert by experience", which may have resulted in bias, however they did not conduct interviews Findings need to be interpreted in context of potentially biased

Study [country]	Methods for data collection and analysis	Phenomena of interest	Setting / context / culture	Participant characteristics and sample size	Description of main results	Comments
						sample of social media users Offered shopping voucher as recompense for time Data collection continued until saturation reached
Ladds *et al*. (2020)[1] [UK]	Individual narrative interview (telephone or video) or participation in an online focus group (two trained facilitators, experiences of symptoms elicited, and positive and negative	Experience of the development, course and resolution of long-term symptoms of COVID-19 What services were accessed (or tried to access), and what were	Community / discharged from hospital or never hospitalised	Total sample = 114 people 55 interviews (40 female/15 male) Median age 48 (range 31-68) 5 hospitalised for COVID-19 (50 not) 59 focus group participants (40 female/19 male)	Five themes: (i) the illness experience (ii) accessing care (iii) relationships (or lack of) with clinicians (iv) emotional touchpoints in encounters with health services (v) ideas for improving services	"The high proportion of women in long COVID support groups may or may not reflect a true gender difference in incidence." For speed only 10 of 55 interviews were fully transcribed, therefore it is unclear if data

Study [country]	Methods for data collection and analysis	Phenomena of interest	Setting / context / culture	Participant characteristics and sample size	Description of main results	Comments
	interactions with health services) Constant comparison method of data analysis	patients' experiences of those services? Ideas for improving the management of the condition and the design and delivery of services		Median age 43 (range 27-73) 6 hospitalised (53 not)		saturation was achieved. Others were selectively transcribed. Webinar offered to all participants with interim findings Unclear how "Ideas for improving services" were derived from patient testimonies. Describing the full sample of patient data: "These findings informed draft quality principles". No quotations provided to directly support these principles

Study [country]	Methods for data collection and analysis	Phenomena of interest	Setting / context / culture	Participant characteristics and sample size	Description of main results	Comments
Martin *et al.* (2020)[3] [UK]	Social network sampling using Meltwater media-monitoring software Data collection 1 Jan to 28 Aug 2020 Sentiment analysis to measure positive, negative and neutral feelings about experiences Discourse analysis using Infranodus software for text network analysis to	Experiences, emotions and practices of people dealing with long-term symptoms of COVID-19 and rehabilitation	Social media: most data from Twitter, with some from Facebook, Reddit, blogs, forums, and other online platforms	Self-reported long-term symptoms of COVID-19 n=7,099 social media users Demographics of people posting across all platforms: 59.4% female 47.4% aged 25-34; 29.1% added 18-24	Negative impacts of competing definitions of COVID-19, mainly: (i) time/duration (ii) symptoms/testing (iii) emotional impact (iv) support & resources	Findings need to be interpreted in context of potentially biased sample of social media users

Study [country]	Methods for data collection and analysis	Phenomena of interest	Setting / context / culture	Participant characteristics and sample size	Description of main results	Comments
	assess themes and patterns					
Maxwell (2020)[4] [UK]	Focus group	Lived experience of long-term symptoms of COVID-19	COVID-19 Facebook group members	Not reported	Four overarching themes: (i) expectations (ii) symptom journey (iii) being doubted (iv) support	Very limited methodological detail provided – only that a focus group was held with some members of the COVID-19 Facebook group Findings need to be interpreted in context of potentially biased sample of social media users

Quality assessment

Critical appraisal of the evidence is presented in appendix 6. Two of the studies used both qualitative and quantitative data analysis to explore patient experiences of long-term COVID-19 symptoms[3, 5]. The qualitative research methods used were interviews and focus groups, with the two studies incorporating quantitative data supplementing these methods with analysis of social media data or a survey that included both open and closed questions.

All five 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. Assaf *et al* (2020), Ladds *et al* (2020) and Martin *et al* (2020) all acknowledged skewed sample characteristics including mainly white ethnicity, over-representation of women, and a generally younger age group[1, 3, 5]. Limited demographic information is provided on study participants, particularly in Maxwell (2020)[4], making it difficult to determine which population groups may have been missed by these studies.

None of the studies described or discussed potential biases arising from the relationship between researchers and study participants. This is despite people with lived experience of long-term COVID-19 symptoms being among the study authors or performing data analysis in both the Kingstone *et al* (2020)[2] and Assaf *et al* (2020)[5] studies.

Four studies had additional limitations. The authors and researchers who analysed the survey data in Assaf *et al* (2020)[5] all had lived experience of long-term symptoms of COVID-19. This participatory research approach represents both a strength and a weakness of this study. Having authors and researchers with experience of long-term symptoms of COVID-19 analyse data is beneficial in bringing lived experience to the interpretation of data. However, it also introduces a potential bias for the same reason. In the study by Kingstone *et al* (2020)[2], participants received a compensation voucher for their time, which may have influenced decisions on whether to participate. Ladds *et al* (2020)[1] only transcribed 10 out of 55 interviews for their analysis, which may have introduced bias to the study if the remaining interviews presented different perspectives/experiences. Finally, Maxwell (2020)[4] reported very limited methodological details, making it difficult to determine how the research was conducted or the number of people involved in the focus group.

There are, however, several strengths of the qualitative evidence. The use of social media and online support groups to recruit participants allowed the study authors to elicit rich experiential data about a recently emerged condition (long-term symptoms of COVID-19). The use of participatory research, as previously noted, could be considered a strength of the experiential literature. Finally, all five studies provide a valuable insight into the lived experiences of patients with long-term COVID-19 symptoms living in the UK.

Analytical themes

Analytical theme 1: experience of symptoms

Evidence from multiple studies showed that patients with long-term symptoms of COVID-19 experienced a far wider range of symptoms than the three symptoms recognised for acute COVID-19 illness (high temperature, new continuous cough and change or loss to sense of smell or taste).

> "From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia." (Maxwell, p8)[4]

In the survey by Assaf *et al* (2020)[5], the top ten most commonly reported symptoms over an eight week period were mild shortness of breath, mild tightness of chest, moderate fatigue, mild fatigue, chills or sweats, mild body aches, dry cough, elevated temperature, mild headache, and brain fog or concentration challenges. In total, over 200 symptoms were reported by survey respondents.

These symptoms varied in severity from relatively mild to potentially life-threatening symptoms that required hospital admission.

> "I was COVID positive in April, thankfully only had mild symptoms and returned to work on the COVID wards after 2 weeks. In the last month, I've been admitted to hospital twice and been diagnosed with hyperthyroidism, mitral valve disease & pericarditis…" (Martin *et al*, p21)[3]

Symptoms fluctuated over time ('coming and going'), with new symptoms appearing at different stages of the illness and in different parts of the body.

> "The symptoms were like a game of whack-a-mole. Different ones would surge at different times and in different places in my body." (Assaf *et al*, p21)[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, p8)[4]

Finally, symptoms were experienced by patients for a prolonged but variable length of time.

> "He was sleeping for about 20 hours a day, 20 hours out of every 24 and he's still sleeping now, five and half months after, he still sleeps an awful lot, sat up, not lay down, sat up, he's just totally exhausted." (Kingstone *et al*, p5)[2]

Analytical theme 2: discordance between patient experiences and official advice or public perceptions

Many study participants reported that their lived experience of long-term symptoms of COVID-19 contrasted with the picture created by official advice. The public perception of the illness is that it is a binary condition – either mild and treated easily at home, or serious and requiring hospitalisation – with no variation or allowances made for ongoing symptoms.

> “So, COVID-19, it’s either a mild infection or you die? No. But no one is prepared to think about us.” (Kingstone *et al*, p8)[2]

> “I think the term "mild" should be removed… I know that people who were admitted to the hospital were worse, but we who stayed home did not have MILD cases in all cases” (Maxwell, p11)[4]

People felt they were led to believe that they would require a short recovery period and would be back at work in two weeks. This was considered to be the norm and expected by employers and the public. The lived experience, for some, was different.

> “After nearly 6 months I have started to feel some improvement, although doing anything remotely physical results in a flare up of symptoms...” (Maxwell, p7)[4]

This discordance between patient experience and official advice/public perception was considered to have a direct effect on the mental and emotional state of those experiencing prolonged illness, often leading to uncertainty about what to do about their symptoms.

> “None of us knew this [the symptoms] because we’re all on our own, in a little bubble, thinking I’m the only one. Why am I the one who has still got it?” (Maxwell, p14)[4]

Analytical theme 3: self management of symptoms

Patients with long-term effects of COVID-19 reported the need to make adjustments to their lifestyle, including pacing themselves and setting realistic goals, in order to self manage their symptoms.

> “…I really have to pace myself… 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 *et al*, p6)[2]

A number of patients described self care in the form of supplements, vitamins, medications, therapeutic massage, and so on.

> “I started taking vitamin D. Had a joint vitamin C and zinc thing, which I didn’t take every day but I took some multivitamins, but then I was a bit unsure really…So

> anyway, then I took nothing for a while, and then I more recently started the vitamin D again, and I'm on B12 just because of all the burning in my feet … and a probiotic and some omega-3." (Kingstone *et al*, p5)[2]

Analytical theme 4: emotional responses from patients and society

Patients described experiencing a range of emotions as part of their illness journey. Anxiety was reported in more than one study and related to multiple aspects of the illness including uncertainty about the cause of symptoms, concern that they may never recover completely, and anxiety due to not being believed by healthcare professionals, family and friends.

> ".... I was really frightened, terrified and just thought I might die on a couple of occasions ... maybe not "I'm going to die right now", but definitely "I'm never going to get better from this" kind of feeling." (Kingstone *et al*, p8)[2]

> "I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people's symptoms are real and diverse." (Maxwell, p16)[4]

Other emotional responses included a feeling of helplessness and a sense of relief on finding a healthcare professional who believed them. There was also a sense of stigma associated with long-term effects of COVID-19, with patients both experiencing a sense of shame and blame (internally generated stigma), but also expressing a fear that employers and others in the community may stigmatise them for having long-term effects of COVID-19 (externally generated stigma).

Analytical theme 5: effects on self identity, relationships and lifestyle

From the studies that conducted interviews or focus groups it was apparent that for many patients there was a feeling that their self identity had been changed by ongoing COVID-19 symptoms. People reported an impact on how they viewed themselves, before and after COVID-19 illness. There was a feeling they had to reconsider who they were and what they could do within the context of family and work. The phrase "compared with how I used to be" was used by multiple participants[2]. Ladds *et al*[1] (p16) commented on the concept of a "spoiled identity" where an identity as "healthy, independent and successful" was threatened.

Interviews with doctors and other clinicians in one study showed that many were worried about their professional abilities and the impact of cognitive deficits due to long-term COVID-19 on their ability to perform their jobs.

> "[T]he medicolegal aspect is huge and I think possibly certainly feels that way as a GP and it's scary to not be able to recognise potentially where you have deficits because

> if you can’t recognise them then that’s an unknown unknown in what can you do with that.” (Ladds *et al*, p10)[1]

Family members were also considered to have been impacted and were seen as requiring support. One interview participant described the impact her symptoms had on her family and how she felt they didn’t believe her:

> “I think, at first, they just thought, ‘Oh, for god’s sake, she’s napping again’. I feel like I constantly have to explain. I'm just exhausted and I just want to know why I'm so exhausted … I used to enjoy running, and exercising, and stuff like that. I rarely even go on walks now because I know if I walk to the end of the street, they're (lungs) going to start hurting.” (Kingstone *et al*, p5)[2]

Analytical theme 6: healthcare access – barriers and facilitators

Studies reported a general perception among participants that the NHS and doctors were too busy dealing with cases of acute COVID-19 to have capacity to deal with anything else, including patients with long-term symptoms. This was perceived to be a barrier to accessing healthcare. This perception appeared to be strengthened by difficulties people experienced when trying to access primary care, especially if they were seeking a face-to-face consultation.

> “I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful, particularly as I didn’t have, and never have had, a cough or fever” (Maxwell, p12)[4]

> “I was initially contacting a certain GP, and that 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 and that’s how I was being treated…“ (Kingstone *et al*, p7)[2]

In general, study participants found accessing care to be “complex, difficult and exhausting”[1]. This difficulty in accessing care and perceived lack of access, led to patients describing how they felt they had to manipulate the inflexible algorithm-driven systems in order to receive care, which led to feelings of guilt and anger.

> “…did the e-consult – I had to do it a couple of times – I kind of learned to answer the questions to get it to send a message to my GP surgery… If you say you’ve got heart palpitations or breathlessness it’s telling you to call 111 which I didn’t want to do. And so I had to downplay symptoms [laughs] to get through. I cancelled it and did it again." (Ladds *et al*, p12)[1]

Others reported resorting to private healthcare to access tests with the aim of provoking NHS follow up. Some patients felt they needed to conduct their own research and construct their own care pathways, taking the lead in arranging consultations with specialists and circumventing bottlenecks in the system. This was reported as a route often employed by medical professionals who themselves were suffering from ongoing symptoms of COVID-19 and were having difficulty in accessing the care they believed they required[1].

> “I've had to do a lot of this myself, to be honest. It was in the early on stages, I actually rang around the hospitals to see if there was anything, so, but there wasn't anything. I just rang the switch board and said, ‘What’s the deal with people who’ve had Covid?’ But they said nothing. Gosh, yeah, I was desperate. I'm sorry, I'm one of these people who want answers and I wasn't getting any answers” (Ladds *et al*, p12)[1]

Those who reported experiencing long-term symptoms described a perceived lack of support within the system. Some patients described how NHS111 (the national telehealth helpline) had directed them to their GP who then directed them back to NHS111[1]. There was what appeared to be a lack of guidance for those who don’t need to be admitted to hospital but are no longer in the acute phase of the illness. It was suggested by study authors that there was a need for support for patients with long-term symptoms of COVID-19 to help them to self manage their symptoms.

Patients who felt they had received satisfactory care and access to healthcare were generally those who had been offered follow-up appointments and who felt their healthcare providers gave them ongoing support, even if that was only in the form of a video or telephone call.

> “... actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn’t do anything, I just kind of needed to know that I wasn’t losing it really and it was real what I was experiencing, I think so that was really helpful.” (Kingstone *et al*, p8)[2]

Analytical theme 7: telemedicine - limitations and benefits

The use of telemedicine to facilitate interactions with healthcare services was generally perceived by patients to have limitations affecting access to effective healthcare. Remote consulting with primary care was viewed by some patients as potentially limiting direct access to GPs, disrupting continuity of care (people often couldn’t see the same GP every time), and making the communication of symptoms more challenging.

> “The focus when you do get a new GP speaking to you seems to be that they go back to the beginning …. And I think if there was the same GP who we are able to consult regularly they would build a picture of your baseline and I think that’s what’s lost with digital ways of working.” (Ladds *et al*, p11)[1]

Some patients also felt that strict adherence to protocols for telemedicine-delivered care affected patient safety or led to mismanagement of their care.

> “... I remembered ringing my GP from the floor on my lounge laying on my front and kind of saying I’m really short of breath, you know, do you think I should try an inhaler do I need to go back to A&E and I was kind of told well you don’t really sound too out of breath over the phone …. I really felt at that point right if you could see me you would see that I am really like broken” (Ladds *et al*, p14)[1]

One positive view expressed in relation to telemedicine was that it did increase accessibility of primary care during periods of societal restrictions aimed at controlling the spread of COVID-19.

> “My doctor was available via messaging, telephone, and telemedicine. She also contracted COVID-19 so she shared her experience with recovery and it helped me stay calm that I was on the right track.” (Assaf *et al*, p23)[5]

Analytical theme 8: lack of knowledge, information and understanding among healthcare professionals and patients

A common observation among patients with long-term symptoms was the lack of knowledge about long-term symptoms of COVID-19 among the healthcare professionals they encountered. While the reason behind this lack of knowledge was understood there was a general feeling that there needed to be acknowledgement of this within the healthcare community.

> “Well yeah, I feel like there’s a lack of knowledge. And I really wasn’t able to get any answers, I know, you know this is obviously a novel illness. But just even for one doctor to look into it a bit and come back to me, didn’t happen.” (Kingstone *et al*, p7)[2]

> “Not really, just I think all the way through I found doctors that I've come into contact with are just really at a bit of a loss for it. I think at the beginning, particularly when things were going on, and not clearing up it was kind of put on me as just being a strange case ... and my GP was going, “Well, you're just weird, you know”.” (Kingstone *et al*, p7)[2]

Many of the research participants were referred to online support groups by healthcare professionals who recognised the limitations of their own knowledge[1]. There were also reports of conflicting or inconsistent advice from health professionals[4]. Focus group participants suggested they would rather be told that the professional did not have the knowledge required to address their illness.

The absence of knowledge and information about long-term symptoms of COVID-19 symptoms was reported to create anxiety and confusion for patients. Ladds *et al*[1] (p7) reported that confusion felt by people was intensified by the lack of medical knowledge, understanding and guidance from healthcare professionals.

The importance of finding a GP who was understanding, empathetic and who provided support to those experiencing ongoing symptoms was highlighted by Kingstone *et al* (2020)[2]. All participants emphasised the key role of the GP in supporting them at every stage.

> "I have to say it was a really powerful experience speaking to the GPs ... the two more recent ones, actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn't do anything, I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing, I think so that was really helpful." (Kingstone *et al*, p8)[2]

Analytical theme 9: desirable features of healthcare services/service delivery

Patients asked for face-to-face assessments; they talked about the need for one-stop clinics with multidisciplinary teams (MDT) who could look at their wide-ranging symptoms and treat them holistically. A case manager to oversee individual patients and ensure that all aspects of their care had been considered was suggested, along with meaningful referral pathways and criteria.

> "What would be most helpful is if all main hospitals could have a Covid clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place, we are having such a range of symptoms that GPs are struggling to know what to do with you" (Maxwell, p17)[4]

> "... there was a view that it would be helpful if people living with Covid19 could have a 'quarter back' or case manager to oversee and coordinate investigations and support services across different medical specialities." (Maxwell, p17)[4]

When asked what features of healthcare delivery or services they would like to see, patients with long-term symptoms spoke about wanting to be listened to, to be believed and understood, and to be offered practical advice on coping.

> "... actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn't do anything, I just kind of needed to know that I wasn't losing it really and it was real what I was experiencing, I think so that was really helpful." (Kingstone *et al*, p8)[2]

Analytical theme 10: social media and support groups

Social media and support groups (online or face-to-face) were valued by patients with long-term symptoms of COVID-19 as opportunities to share experiences, knowledge and resource links with others in a similar situation. Communication through social media and support groups validated patient experiences and provided reassurance they were not alone in their struggle with long-term symptoms.

> “At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it... I actually think that the support group has given more knowledge than the doctors have.” (Ladds *et al*, p15)[1]

However, there were also reports of anxiety and depression triggered by knowledge garnered from these online groups.

> “ …Internet support groups, yeah on the Facebook groups that I'm on, I mean to be honest, I try not to read that group too much because it depresses me, makes me a bit anxious.” (Kingstone *et al*, p6)[2]

Analytical theme 11: seeking acceptance and understanding

Patients expressed a strong desire to find acceptance and understanding about their experiences of long-term symptoms of COVID-19, both among healthcare professionals and family and friends. There was a widespread perception that healthcare professionals doubted patients’ descriptions of long-term symptoms of COVID-19, ignored patient concerns, misdiagnosed symptoms, or were dismissive of patient experiences.

> “There was one GP who just thought it was all anxiety ... she said, "There's nothing wrong with your lungs. This is all anxiety. You must treat your anxiety. There’s nothing wrong with you. How are you going to manage the pandemic if you don't treat your anxiety?“ That was really upsetting because I knew I was short of breath...” (Kingstone *et al*, p7)[2]

> “... one of my friends did say after quite a while, “I’m not being awful, but do you think a lot of it’s in his mind?” and I said “no”. I was quite upset about that…” (Kingstone *et al*, p6)[2]

Patients experienced difficulties in identifying an empathetic healthcare professional who could provide the necessary support. When a patient succeeded in finding an empathetic healthcare professional, they described developing a strong therapeutic bond, and feeling both validated and listened to.

> “... actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn’t do anything, I

just kind of needed to know that I wasn't losing it really and it was real what I was experiencing, I think so that was really helpful." (Kingstone *et al*, p8)[2]

Table 2: summary of key themes relating to the views and experiences of patients, their families and carers

Analytical themes and sub-themes	Summary of sub-themes	Supporting example
Analytical theme: experience of symptoms		
Range of symptoms	Patients described a wide range of symptoms, not all of which were recognised as symptoms of COVID-19.	“The symptoms were like a game of whack-a-mole. Different ones would surge at different times and in different places in my body.“ (Assaf *et al*, p21)[5] “From week four I started to get chest pains and then breathlessness, gradually other symptoms developed including dry mouth, sore tongue, joint pains, fatigue, rash and tachycardia.” (Maxwell, p8)[4]
Severity of symptoms	Symptoms ranged from mild to potentially life-threatening.	“I was COVID positive in April, thankfully only had mild symptoms and returned to work on the COVID wards after 2 weeks. In the last month, I’ve been admitted to hospital twice and been diagnosed with hyperthyroidism, mitral valve disease & pericarditis…” (Martin *et al*, p21)[3]
Duration and lingering nature of symptoms	Symptoms were experienced for a prolonged but variable length of time.	“He was sleeping for about 20 hours a day, 20 hours out of every 24 and he’s still sleeping now, five and half months after, he still sleeps an awful lot, sat up, not lay down, sat up, he’s just totally exhausted.” (Kingstone *et al*, p5)[2]

Analytical themes and sub-themes	Summary of sub-themes	Supporting example
Fluctuating or cumulative nature of symptoms	Patients described symptoms ‘coming and going’, and of new symptoms being added to existing ones over time.	“...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.... After nearly 6 months I have started to feel some improvement, although doing anything remotely physical results in a flare up of symptoms....” (Maxwell, p8)[4]
Analytical theme: discordance between patient experiences and official advice or public perceptions		
Disconnect between official advice and lived experience	Patients found official advice on graded exercise and when to come out of isolation unhelpful and contrary to their lived experience of long-term symptoms of COVID-19.	“Well, one of the things that really bugged me about it was the talking about graded exercise and I’ve learnt from experience that pushing myself even a tiny bit has massive consequences ...” (Kingstone *et al*, p6)[2]
Disconnect between public perception (“labels”) and lived experience	The perception that COVID-19 is a binary illness that is either ‘mild’ or very serious (requiring hospitalisation) was unhelpful and contrasted with patient experience.	“So, COVID-19, it’s either a mild infection or you die? No. But no one is prepared to think about us.” (Kingstone, p8)[2] “I think the term "mild" should be removed… I know that people who were admitted to the hospital were worse, but we who stayed home did not have MILD cases in all cases” (Maxwell, p11)[4]

Analytical themes and sub-themes	Summary of sub-themes	Supporting example
Disconnect between expected/official timeframes and lived experience	Patients expected COVID-19 to last approximately 2 weeks, in line with official estimates, and were then confronted by much longer-term illness. Patients experiencing symptoms beyond the 2-week period are often diagnosed with an alternative condition that more neatly fits the timeframe.	"I was COVID positive in April, thankfully only had mild symptoms and returned to work on the COVID wards after 2 weeks. In the last month, I've been admitted to hospital twice and been diagnosed with hyperthyroidism, mitral valve disease & pericariditis…" (Martin *et al*, p21)[3]
Disconnect between officially recognised symptoms and lived experience	There discordance between the range of symptoms articulated by patients with long-term illness and those officially recognised by authorities as COVID-19.	"....Some of us were misdiagnosed and left at home in life threatening conditions, repeatedly, because we didn't match the #COVID19 symptoms MDs considered relevant. Not a case that the persistence of symptoms in #Long Covid was recognized by patients" (Martin *et al*, p21)[3]
Definitions of COVID-19 and lived experience	Conflicting/competing definitions of COVID-19' lead to confusion, distress and frustration.	"...define Covid-19 bodies in ways that cause confusion, distress and frustration amongst suffers of both short and long Covid-19: for example, as one [Twitter] poster states, 'thought I'd be ill for two weeks, instead it's been half a year'." (Martin *et al*, p6)[3] *[Author quote]*

Analytical themes and sub-themes	**Summary of sub-themes**	**Supporting example**
Impact of disconnect between officially recognised symptoms and lived experience	As a consequence of the mismatch between officially recognised symptoms and lived experience of long-term symptoms of COVID-19, patients feel ignored, dismissed, and may be misdiagnosed.	".....Some of us were misdiagnosed and left at home in life threatening conditions, repeatedly, because we didn't match the #COVID19 symptoms MDs considered relevant. Not a case that the persistence of symptoms in #Long Covid was recognized by patients" (Martin *et al*, p21)[3]
Analytical theme: self management of symptoms		
Self care and lifestyle adjustment	Patients attempted various forms of self care, such as taking supplements, and made adjustments to their lifestyle, for example by reducing physical activity, to accommodate long-term symptoms of COVID-19.	"I mean initially I started taking vitamin D. Had a joint vitamin C and zinc thing, which I didn't take every day but I took some multivitamins, but then I was a bit unsure really … my husband's quite anti-vitamin use … So anyway, then I took nothing for a while, and then I more recently started the vitamin D again, and I'm on B12 just because of all the burning in my feet … and a probiotic and some omega-3." (Kingstone *et al*, p5)[2]
Pacing and goal setting	The importance of pacing yourself and setting realistic goals was highlighted by patients.	"…I really have to pace myself… 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 *et al*, p6)[2]

Analytical theme: emotional responses from patients and society		
Helplessness	Long-term symptoms were associated with a feeling of helplessness.	“Most participants continued the discussion after the digital recorder was turned off, emphasising their own feelings of helplessness, but also alluding to the uncertainty and helplessness that GPs had admitted to” (Kingstone *et al*, p5)[2] *[Author quote]*
Anxiety	Patients described anxiety about the prospect of not recovering, uncertainty over the cause of symptoms, not being believed, and some of the content they read on online support groups.	“.... I was really frightened, terrified and just thought I might die on a couple of occasions ... maybe not “I’m going to die right now”, but definitely “I’m never going to get better from this” kind of feeling.” (Kingstone *et al*, p8)[2]
Relief	A sense of relief was associated with finding a healthcare professional that believed the patient.	“I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people’s symptoms are real and diverse.” (Maxwell, p16)[4]
Stigma (externally generated)	Employers and others drive a fear of being stigmatised over long-term symptoms of COVID-19.	“Healthcare staff was fearful and I was turned away with no support” (Assaf *et al*, p47)[5]
Stigma (internally generated)	Patients experienced a sense of shame and blame consistent with stigma.	“Fearful of people around me finding out and overreacting / treating me differently” (Assaf *et al*, p46)[5]

Analytical theme: effects on self-identity, relationships and lifestyle		
Impact on self-identify	Long-term symptoms of COVID-19 affected self identity as a healthy, independent individual, and resulted in patients comparing themselves with a pre-COVID version of self.	“I have not had strength to return to physical activity. I did work in my house and 2 days later had a fever again after being 12 days fever free.” (Assaf *et al*, p20)[5]
Impact on daily life/work	Patients had to alter their physical activity levels to accommodate long-term symptoms of COVID-19 and found cognitive symptoms prevented a return to work.	“I'm trapped, in that I can't park that far away and walk [to the shops] like I normally would because I can't do hills. I can just, in the last couple of weeks, I can do gentle inclines now, but I sort of grind to a halt on a hill. So, it's very limiting.” (Ladds *et al*, p8)[1] “I wasn’t just fogged, I was confused. I had a very difficult encounter as a result of just being confused about things and that took a long time to resolve. I love words and I enjoy the business of communicating, and I felt that part of my life was lost. Really, I just did admin, I didn’t do anything that required clear thinking.” (Kingstone *et al*, p7[2]
Impact on self - reduced confidence	There was a sense of loss of confidence in professional abilities among some patients.	“Doctors and other clinicians …. described how their symptoms and the accompanying prognostic uncertainty …. had also stripped them of confidence in their professional abilities.” (Ladds *et al*, p9)[1] *[Author quote]*

Impact on others/relationships	Long-term symptoms of COVID-19 had an impact on family members as well as patients.	"I think, at first, they just thought, "Oh, for god's sake, she's napping again." I feel like I constantly have to explain. I'm just exhausted and I just want to know why I'm so exhausted …. I used to enjoy running, and exercising, and stuff like that. I rarely even go on walks now because I know if I walk to the end of the street, they're [lungs] going to start hurting." (Kingstone *et al*, p5)[2]
Analytical theme: healthcare access – barriers and facilitators		
Barrier - testing	Challenges were experienced with accessing testing (for long-term symptoms or COVID-19 diagnostic testing).	"... My worst and scariest experience with this illness was in week 6, when I was rushed to A&E as I had a sudden relapse of symptoms and found myself gasping for air, with the top of my head numb and tingling and a headache so blinding that I couldn't keep my eyes open. I got worse in the hospital and was shaking visibly, so much so that the nurse couldn't perform an ECG as I just couldn't stay still. Despite having been diagnosed with suspected Covid by my GP and a doctor in a Covid clinic (swab testing wasn't available to the public at the time) and told I had pleurisy during a visit to A&E two weeks earlier, the doctor on duty didn't take this into account. Instead, he dismissed me with anxiety, advising a course of anti-depressants, and chose not to investigate these concerning symptoms further. ….I would later learn from a

		neurologist that what I experienced on that day were clear neurological symptoms that should have been investigated promptly. To be brushed off like this when so little was known at the time of the damage Covid can cause was disheartening and very upsetting.“ (Maxwell, p15)[4]
Barrier – primary care	Difficulties accessing primary care, particularly face-to-face or through the ‘total triage’ system were a barrier to healthcare access	“I was initially contacting a certain GP, and that GP literally just went “you need to stay at home and rest, there’s nothing we can do”, a.....so I started contacting a different GP, in the same practice, and it’s the same outcome, they can’t do anything else but he seems to be interested and wants to know what’s going on.” (Kingstone *et al*, p7)[2]
Barrier – effort involved	Accessing healthcare was complex, difficult and exhausting for patients.	“One day I had blue finger nails and I wasn’t cold …. and I phoned the GP and the GP answer phone said if you’ve got any of the signs of, of Covid please ring 111 and so I rang 111 and, I live in [city with high incidence of Covid-19] I don’t know if that makes any difference but I was put on hold and after over an hour, an hour and twenty minutes nobody answered so I just put the phone down …..” (Ladds *et al*, p10)[1]
Barrier – specialist referral	Few patients managed to obtain a referral to a specialist.	“...three of the referrals my GP made (two respiratory and one neurology) were refused by two different hospitals on the grounds that a) they only checked

		Covid confirmed patients b) that they needed extra tests which weren't done on me at A&E" (Maxwell, p17)[4]
Perceived barrier – healthcare professionals being busy	There was a perception that healthcare professionals are too busy caring for patients with acute COVID-19 to be able to provide care for patients with long-term symptoms.	"At this point, most physicians and researchers are so overwhelmed treating the covid19 patients who are at risk of immediate death, that they don't have the ability to even recognize that people like me exist...." (Assaf *et al*, p43)[5] "I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful, particularly as I didn't have, and never have had, a cough or fever" (Maxwell, p12)[4]
Perceived barrier – healthcare entitlement	Patients had a perception that they were not entitled to healthcare for long-term symptoms of COVID-19.	"....I guess I felt a bit like I was ineligible for health care now. I felt like I'm just going to have to live with this at home and no one will come and see me and, you know, I'm just, yeah. It was a horrible feeling." (Kingstone *et al*, p7)[2]
Facilitator – follow-ups & check-ins	Regular follow up or check-in with patients with long-term symptoms was viewed as a positive aspect of healthcare.	".... I think for the first five days after I called her she had a daily check in call with me to monitor how I'm doing so it was like a ten minute phone call every day for the first five days" (Ladds *et al*, p13)[1]
Things patients did to access care	Patients engaged in a number of activities to improve their access to healthcare including:	"did the e-consult – I had to do it a couple of times – I kind of learned to answer the questions to get it to

	• taking the lead in arranging consultations and "circumventing bottlenecks” • deliberately manipulating inflexible algorithm-driven systems to access referrals • accessing private healthcare to prompt NHS follow up, conducting their own research and constructing their own care pathways.	send a message to my GP surgery… If you say you’ve got heart palpitations or breathlessness it’s telling you to call 111 which I didn’t want to do. And so I had to downplay symptoms [laughs] to get through. I cancelled it and did it again." (Ladds *et al*, p12)[1]
Analytical theme: telemedicine - limitations and benefits		
Limitation – remote consultation	Remote consulting was found to limit access to GPs and to restrict communication of symptoms.	“... reassure me are things where I need my body actually checking which I don’t think you could check online, you can’t check for blood clots online, you can’t check for neurological damage online can you?’ (Kingstone *et al*, p9)[2]
Limitation – lack of continuity	Loss of continuity of care was particularly impactful on patients with complex presentations.	“The focus when you do get a new GP speaking to you seems to be that they go back to the beginning ….And I think if there was the same GP who we are able to consult regularly they would build a picture of your baseline and I think that’s what’s lost with digital ways of working.” (Ladds *et al*, p11)[1]

Limitation – protocolised care	Strict adherence to protocols in the telemedicine context affected patient safety and led to mismanagement.	“... I remembered ringing my GP from the floor on my lounge laying on my front and kind of saying I’m really short of breath, you know, do you think I should try an inhaler do I need to go back to A&E and I was kind of told well you don’t really sound too out of breath over the phone …. I really felt at that point right if you could see me you would see that I am really like broken” (Ladds *et al*, p14)[1]
Benefits - accessibility	Positive experiences of accessing GPs through telemedicine.	“My doctor was available via messaging, telephone, and telemedicine. She also contracted COVID-19 so she shared her experience with recovery and it helped me stay calm that I was on the right track.” (Assaf *et al*, p23)[5]
Analytical theme: lack of knowledge, information and understanding among healthcare professionals and patients		
Lack of knowledge - healthcare professionals	There is a perceived lack of knowledge about long-term symptoms of COVID-19 among healthcare professionals.	“...I think all the way through I found doctors that I've come into contact with are just really at a bit of a loss for it. I think at the beginning, particularly when things were going on, and not clearing up it was kind of put on me as just being a strange case ... and my GP was going, “Well, you're just weird, you know”.’ (Kingstone *et al*, p7)[2]
Lack of knowledge – symptoms	The lack of knowledge around long-term symptoms of COVID-19 included uncertainty about the expected symptoms, wanting to learn	“None of us knew this [the symptoms] because we’re all on our own, in a little bubble, thinking I’m the only

	about living with COVID-19, uncertainty about the cause of symptoms, a lack of understanding about the fluctuating nature of symptoms and lack of knowledge about recovery from long-term symptoms.	one. Why am I the one who has still got it?" (Maxwell, p14)[4]
Lack of knowledge – seeking help	Uncertainty about when patients with long-term symptoms of COVID-19 should seek medical help.	"...combined with the UK government message to stay away from health services unless very ill, left many people uncertain about when they should seek help." (Maxwell, p12)[4] *[Author quote]*
Lack of knowledge – employers	Employers need advice on how to manage employees with long-term symptoms of COVID-19.	"Advice on the range of symptoms and duration was also needed by employers who are unclear what to expect of those with ongoing effects." (Maxwell, p18)[4] *[Author quote]*
Lack of knowledge – management	Lack of knowledge about managing long-term symptoms of COVID-19, resources available locally for patient rehabilitation, and about recovery from prolonged illness.	"I finally had a respiratory appointment three months later, over the phone (not over a video link). I was .... recommended graded exercise. When I then saw a rehabilitation physiotherapist, she said no, we are not going to do graded exercise because that would be counterproductive for you. " (Maxwell, p13)[4]
Lack of knowledge – prompts help-seeking from other sources	Lack of widely accessible medical knowledge about long-term symptoms of COVID-19 has led to patient reliance on news and social media for information.	"In the absence of sufficient and widely accessible medical knowledge surrounding Long Covid (as opposed to Covid-19 more generally) ..... news and social media have taken its role as an important if not

		the only information resource on Long Covid." (Martin *et al*, p11)[3] *[Author quote]*
Patients prefer healthcare professionals to admit uncertainty	Patients would prefer healthcare professionals to admit to a lack of knowledge about long-term symptoms of COVID-19.	"She just listens a little bit more to what I'm saying and she's much more willing to say, "Of course, we don't really know what's going on because it's a new virus." She doesn't try to pretend that she understands what's going on, which is good." (Kingstone *et al*, p8)[2]
Analytical theme: desirable features of healthcare services/service delivery		
Healthcare structuring – one stop clinics with face-to-face assessment of symptoms by multidisciplinary teams	Patients wanted a 'one-stop' clinic with multidisciplinary teams there to assess symptoms affecting a wide range of body systems.	"What would be most helpful is if all main hospitals could have a Covid clinic that had experts from respiratory, cardiology, rheumatology, neurology, physiotherapy etc, so you could go along for half a day and see people from these different departments, they can refer you for tests and you can get a plan in place, We are having such a range of symptoms that GPs are struggling to know what to do with you" (Maxwell, p17)[4]
Healthcare structuring – case management	A case manager or single clinician to co-ordinate investigations and the patient care pathway for each patient with long-term symptoms of COVID-19.	"... there was a view that it would be helpful if people living with Covid19 could have a 'quarter back' or case manager to oversee and coordinate investigations and support services across different medical specialities." (Maxwell, p 17)[4]

Healthcare structuring – MDT rehabilitation	Assessment by a multidisciplinary rehabilitation team was proposed.	"... the British Society of Rehabilitation Medicine notes there are people who were never admitted to hospital but who still have ongoing needs for rehabilitation support after recovering from Covid, or Covid-like symptoms." (Maxwell, p 19)[4] *[Author quote]*
Individual - acceptance of patient experiences by healthcare professionals	Empathetic health professionals that accepted patient experiences were desirable to individuals.	"I finally found a GP who took me seriously last Saturday when I was at the point of crying talking to her, just understanding that people's symptoms are real and diverse." (Maxwell, p16)[4]
Individual - practical coping strategies	Patients wanted practical advice on coping strategies.	"... members understood that there were no magic cures, but were looking for practical advice on coping strategies that go beyond basic advice." (Maxwell, p17)[4] *[Author quote]*
Analytical theme: social media and support groups		
Support through sharing experiences	Online support groups and social media provided opportunities for sharing experiences of long-term symptoms of COVID-19.	"when I found the Long Covid Facebook group that I realised I wasn't alone, thousands of people were in the same situation. Knowing this helped enormously." (Maxwell, p8)[4]
Support through sharing knowledge	Online support groups and social media provided opportunities for sharing knowledge and resource links with others coping with long-term symptoms.	"At least I know I'm not alone. And I think people who actually have had the disease tend to know a little bit more about it... I actually think that the support group has given more knowledge than the doctors have." (Ladds *et al*, p15)[1]

Validation of experiences	Patients found validation of their experiences in communication with others through online support groups.	"many participants – both men and women – found that online peer support groups offered the greatest source of support through shared experiences, knowledge and validation." (Ladds *et al*, p14)[1] *[Author quote]*
Analytical theme: seeking acceptance and understanding		
Perception of being doubted by healthcare professionals	Healthcare professionals were perceived to doubt patient symptoms were related to COVID-19 and to doubt symptom severity.	"There was one GP who just thought it was all anxiety ... she said, "There's nothing wrong with your lungs. This is all anxiety. You must treat your anxiety. There's nothing wrong with you. How are you going to manage the pandemic if you don't treat your anxiety?" That was really upsetting because I knew I was short of breath..." (Kingstone *et al*, p7)[2]
Perception of being doubted by friends and family	There was a perception that friends and family doubted patients because symptoms were not always obvious.	"... one of my friends did say after quite a while, "I'm not being awful, but do you think a lot of it's in his mind?" and I said "no". I was quite upset about that…" (Kingstone *et al*, p6)[2]
Perception of being ignored	Patients felt that their condition was not given the recognition that it deserved.	"So, COVID-19, it's either a mild infection or you die? No. But no one is prepared to think about us." (Kingstone *et al*, p8)[2] "I felt the medical team was dismissive. There were a lot of 'we don't know.' Which is understandable, but difficult." (Assaf *et al*, p43)[5]

Difficulties finding empathetic healthcare professionals	Challenges were described in finding healthcare professionals willing to show empathy and accept patient experiences of symptoms.	“I was initially contacting a certain GP, and that 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 *et al*, p7)[2] “Because I’ve spoken to four different GPs throughout this. I’ve not found them very helpful...” (Kingstone *et al*, p8)[2]
Misdiagnosis or dismissal by healthcare professionals	Dismissal of symptoms or misdiagnoses were associated with a negative perception of healthcare.	“Some of us were misdiagnosed and left at home in life threatening conditions, repeatedly, because we didn't match the #COVID19 symptoms MDs considered relevant.” (Martin *et al*, p21)[3]
When available strong empathetic relationships with healthcare professionals provides strong therapeutic relationships	A minority of patients reported strong therapeutic relationships involving listening, empathy, validation, honesty and arranging tests and follow up.	“... actually just the experience of being heard and feeling like somebody got it and was being kind about it, but you know it was okay that they couldn’t do anything, I just kind of needed to know that I wasn’t losing it really and it was real what I was experiencing, I think so that was really helpful.” (Kingstone *et al*, p8)[2]

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Acknowledgements

Healthcare Improvement Scotland would like to acknowledge the contribution of colleagues from NICE in reviewing and commenting upon the protocol for this review and draft and final reports.

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Abbreviations

CASP	critical appraisal skills programme
EIA	equality impact assessment
FT	full-time
GP	general practitioner
ISSG	information specialist sub-group
MDT	multidisciplinary team
NA	not applicable
NICE	National Institute for Health and Care Excellence
PREMS	patient reported experience measures
PT	part-time
RCGP	Royal College of General Practitioners
SIGN	Scottish Intercollegiate Guidelines Network
USA	United States of America

Appendix 1: review protocol

Review question 9: What are the views and experiences of patients, their families and carers about:

- signs and symptoms of post-COVID-19 syndrome
- access to services
- how their symptoms were assessed
- management of symptoms and rehabilitation
- the patient care pathway
- information and support provided
- communication with healthcare professionals?

Table 3: review protocol

Criteria	Notes
Population	Adults and children who are experiencing new or ongoing symptoms: 4–12 weeks from onset of acute COVID-19 illness 12 weeks from onset of acute COVID-19 illness
Factors of interest	signs and symptoms of post-COVID-19 syndrome access to services how their symptoms were assessed management of symptoms and rehabilitation the patient care pathway information and support provided communication with healthcare professionals
Comparators	Not applicable

Outcomes	The outcomes will be generated using emergent coding, but are expected to include the following: Experiences, views and perceptions of individuals, families or carers on the factors of interest listed (such as PREMS).
Settings	Any
Subgroups	Groups as defined in the equality impact assessment (EIA) for example, age, gender, ethnicity Diagnosis of COVID-19 (e.g. confirmed or high clinical suspicion) Duration of symptoms
Study types	Systematic reviews of qualitative studies Qualitative studies that collect data from focus groups and interviews Qualitative studies that collect data from questionnaires/surveys Mixed method study designs (including qualitative evidence that matches the above study designs only)
Countries	Any
Timepoints	Any
Other exclusions	None

Appendix 2: literature search strategy

Information Scientists at Healthcare Improvement Scotland conducted two systematic literature searches. One search aimed to identify qualitative literature on patient/carer views and experiences relating to COVID-19 without restriction on the duration of symptoms. The second search sought quantitative evidence reporting on views and experiences relating to long-term effects of COVID-19. Both searches sought to identify primary and secondary published, unpublished and grey literature. A full list of resources searched is available on request.

In databases not specific to COVID-19 research, search results were limited to 2020 as the year of publication. All search results were limited to English language.

The search for qualitative literature applied adapted versions of the qualitative research filter by DeJean *et al* (2016)[8] and a filter for patient experience literature developed by combining terms from papers by Selva *et al* (2017)[9] and Wessels *et al* (2016)[10]. The quantitative literature search used the combined Selva-Wessels filter. All original filters are available on the ISSG filters resource. The adapted filters are available on request.

The Information Scientists excluded records relating to views or experiences of healthcare for conditions other than COVID-19 during the pandemic, to acute episodes of COVID-19 illness, and records relating to the views of healthcare staff who were not also patients.

Table 4: databases searched

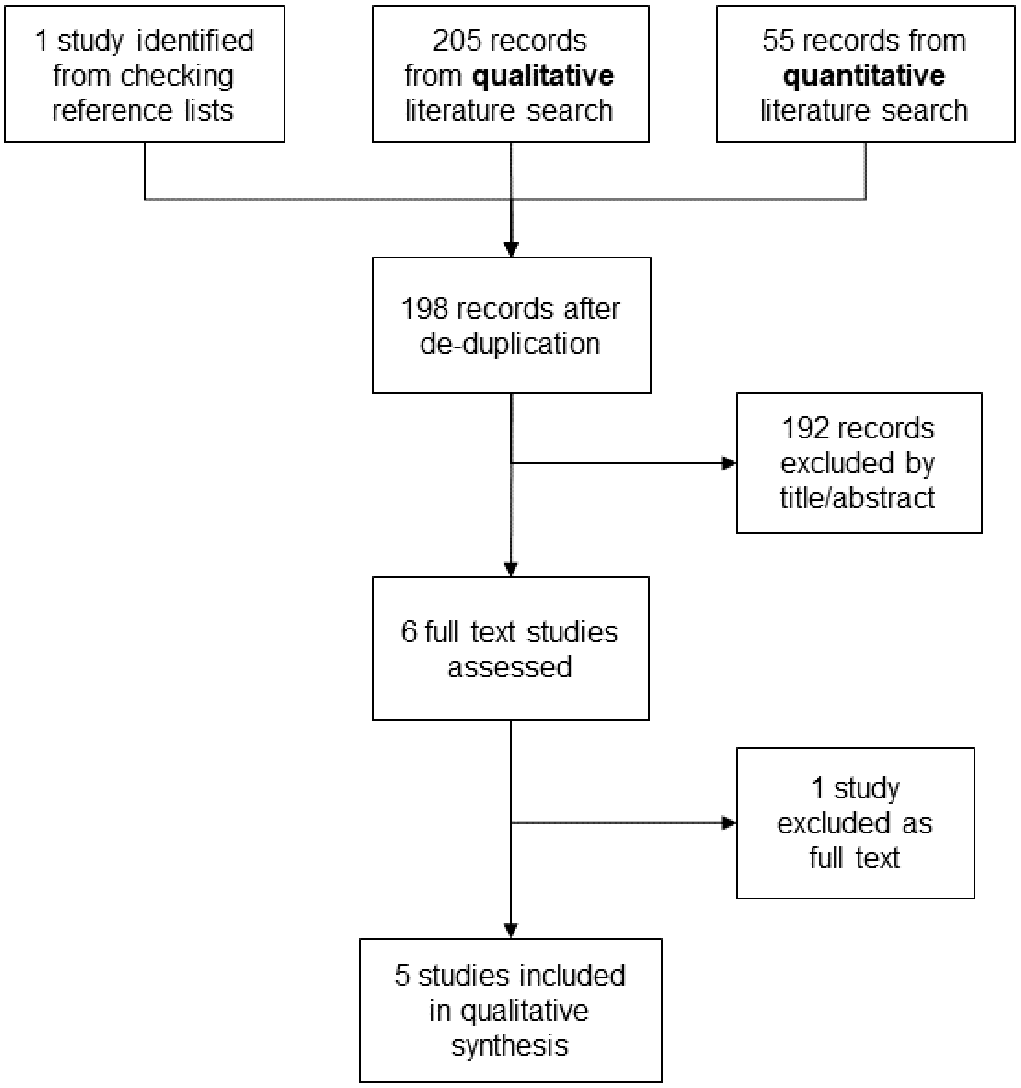
Database	Platform	Segment searched
Pubmed LitCov	Pubmed	All
WHO database of publications	-	2020, English language
Proquest COVID	Proquest	All
Epistemonikos	-	2020, English language
MedRxiv	-	2020, English language
bioRxiv	-	2020, English language
Medline	Ovid	2020, English language
PsychInfo	Ovid	2020, English language

Web of Science Core Collection	-	2020, English language
Cinahl	EBSCOHost	2020, English language

Database strategies

Full details of database search strategies are available on request.

Appendix 3: study flow diagram



Appendix 4: excluded studies

Studies excluded at title and abstract screening

A full list of articles excluded at the screening of titles and abstracts stage is available on request.

Studies removed at full text screening

Table 5: studies rejected at full text screening

Study	Reason for exclusion
Singh SM, Reddy C. An analysis of self-reported longcovid symptoms on Twitter. medRxiv. 2020. DOI: 10.1101/2020.08.14.20175059	Did not use qualitative methods or contain data on direct patient experience of long COVID.

Appendix 5: citations for included studies

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Appendix 6: study quality assessment

Table 6: critical appraisal of studies using the CASP qualitative checklist

CASP criteria	Yes/No/ Can't tell	Comments
Study: Assaf *et al* (2020)[5]		
Was there a clear statement of the aims of the research?	Yes	Clearly stated aim.
Is a qualitative methodology appropriate?	Can't tell	Qualitative approach was appropriate as the survey aimed to understand patient views and perspectives. However, much of the survey was quantitative, with qualitative data being generated through open questions in the survey.
Was the research design appropriate to address the aims of the research?	Can't tell	Surveying a sample of people is an appropriate research design. However, there is little discussion about exactly what type of data would be gathered and how it would be analysed. The survey aimed to capture experiences but mostly used closed questions resulting in mainly quantitative data collection.
Was the recruitment strategy appropriate to the aims of the research?	Yes	Survey distributed through support groups and social media channels (convenience sample). Potential for bias as people in support groups or social media discussing COVID-19 may have particularly strong views or different experiences of disease to those not participating in these groups. Biases introduced by the convenience sampling are discussed in the study.

CASP criteria	Yes/No/ Can't tell	Comments
Was the data collected in a way that addressed the research issue?	Can't tell	Data collected via online survey but no information given about the questions, and the response options. No discussion of data analysis undertaken and consequently of data saturation.
Has the relationship between researcher and participants been adequately considered?	No	This constituted participatory research, so by its very nature, those collecting and analysing the data had potential conflicts of interest - their involvement is both a strength and a weakness. Survey conducted and analysed by patients with COVID-19 who also have a background in research and data analysis. There is no discussion of steps taken to mitigate against potential biases. The over-representation of some groups within the survey respondents is noted but attempts to reach a wider group will be part of the next iteration of the research.
Have ethical issues been taken into consideration?	Can't tell	Not directly applicable as survey conducted in open fora and social media platforms. There is no mention of ethical approval being sought.
Was the data analysis sufficiently rigorous?	Can't tell	Details of how the data from the survey were analysed is not provided. Minimal qualitative analysis - even the qualitative section is summarised in a quantitative manner. Quotes provided to support findings in both qualitative and quantitative sections of the survey.
Is there a clear statement of findings?	Can't tell	Results of the quantitative elements of the survey are clearly presented with graphs and charts. Quotes are presented from open responses. The quantitative findings are summarised at the start of the report. There is no summary of qualitative findings.

CASP criteria	**Yes/No/ Can't tell**	**Comments**
How valuable is the research?	-	Findings relate to an important area for which information on the experiences of this group of individuals is much needed. Most respondents were from the U.S.A. (71.7%), followed by the U.K. (12.7%). May differ from UK population in terms of their experience of the healthcare system, most will be responding in relation to a very different healthcare system from the UK. The majority of respondents were between the ages of 30 and 49 (62.7%), and female (76.6%). As such they may not be representative of the entire population of interest. This approach is especially important for COVID-19 because patients experiencing symptoms are in need of timely research and content relevant to them that is not currently available due to the newness of this virus.
Study: Kingstone *et al* (2020)[2]		
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.

CASP criteria	Yes/No/ Can't tell	Comments
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).

CASP criteria	Yes/No/ Can't tell	Comments
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 *et al* (2020)[1]		
Was there a clear statement of the aims of the research?	Yes	Sets out rationale for the work and three questions to be answered.

CASP criteria	Yes/No/ Can’t tell	Comments
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

CASP criteria	**Yes/No/ Can't tell**	**Comments**
		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: Martin *et al* (2020)[3]		

CASP criteria	Yes/No/ Can't tell	Comments
Was there a clear statement of the aims of the research?	Yes	Clearly stated aims and objectives on first page. Research question stated on page 4. Importance and relevance clearly articulated.
Is a qualitative methodology appropriate?	Yes	Exploring people's experiences therefore qualitative methods are appropriate. This study involves some quantitative data as social media analytics presented as well as discourse analysis of the posts.
Was the research design appropriate to address the aims of the research?	Yes	Design appropriate to gathering data on a recent phenomenon.
Was the recruitment strategy appropriate to the aims of the research?	Yes	Appropriate convenience sample for the aim of the study. Biased sample (UK social media users - mainly Twitter) which is not discussed by researchers - this may represent a specific (vocal) subgroup of COVID-19 sufferers. Sample skewed towards young people (76.5% aged 18-34).
Was the data collected in a way that addressed the research issue?	Yes	Provide details of data collection using media monitoring software and detailed list of keywords and hashtags used. Data collected over 8-month period. Appears to be a robust methodology.
Has the relationship between researcher and participants been adequately considered?	Can't tell	Not disclosed (e.g., whether authors are COVID-19 sufferers themselves and have particular bias or whether they have posted to any of the social media sites used). Possibly a relationship is not relevant to this study since analysing retrospective data from social media.

CASP criteria	Yes/No/ Can't tell	Comments
Have ethical issues been taken into consideration?	NA	Used data already in public domain (social media posts). Authors do mention that with Facebook they only analysed at overview level (number of posts) due to ethical and restricted access reasons (open groups only).
Was the data analysis sufficiently rigorous?	Can't tell	Sentiment analysis (quantitative) and discourse analysis using text network analysis software to measure themes and patterns. No detail provided on whether 1 or 2 researchers conducted analysis but appears to be comprehensive.
Is there a clear statement of findings?	Yes	Findings included list of 7 topics of discussion found on social media sites and discussion of key themes.
How valuable is the research?	-	Provides insight into issues being experienced and discussed by COVID-19 sufferers that can help inform definitions and understanding of the condition. Findings need to be interpreted in context of potentially biased sample. Authors provide summary points placing findings in context of existing evidence and highlighting value of results.
Study: Maxwell (2020)[4]		
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.

CASP criteria	**Yes/No/ Can't tell**	**Comments**
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.

CASP criteria	Yes/No/ Can't tell	Comments
How valuable is the research?	-	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.

Published December 2020

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