

SUPPLEMENTARY MATERIAL

Supplementary file 1 Inclusion criteria

| Criteria | Notes |
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| Population | Adults and children experiencing new or ongoing symptoms: <ul style="list-style-type: none"> • 4–12 weeks from onset of acute COVID-19 illness • 12 weeks from onset of acute COVID-19 illness |
| Phenomena of interest | Signs and symptoms of post-COVID-19 syndrome Access to services How symptoms were assessed Management of symptoms and rehabilitation 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 experiences, views and perceptions of individuals, families or carers on the factors of interest listed (such as Patient Reported Experience Measures) |
| Settings | Any |
| Sub-groups | Equality groups, 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 or interviews Studies that collect qualitative data from questionnaires / surveys Mixed method study designs (including qualitative element) |
| Countries | Any |
| Timepoints | Any |
| Other exclusions | None |

Supplementary file 2 Sources searched and MEDLINE search strategy

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| UK national health service and government websites |
| Public Health England |
| Public Health Scotland |
| Scottish Government |
| UK Government |
| National/international policy sources |
| European Centre for Disease Control |
| Health Protection Scotland COVID-19 Compendium |
| Guidelines |
| National Institute of Health |
| NICE |
| SIGN |
| Evidence summaries and collections |
| Analytical Collaboration for COVID-19 |
| Cochrane Special Collection |
| COVID-19 Best Evidence Front Door |
| COVID-19 Evidence Reviews |
| Evidence Aid Collection |
| McMaster rapid review database |
| Oxford Centre for Evidence-Based Medicine |
| HTAs |
| ECRI |
| Health Technology Wales |
| National Institute for Health Research |
| NICE |
| Specialist Databases |
| Epistemonikos |
| EPPI Centre: living systematic map of the evidence |
| ProQuest |
| PubMed LitCovid |
| WHO database of publications |
| Preprints |
| bioRxiv |
| medRxiv |
| Research centres/organisations |
| Campbell Collaboration |
| Centre for Qualitative Research |
| Health Foundation |
| King's Fund |
| Patient issues |
| Carers UK |
| Health Talk |
| Involve |
| James Lind Alliance |

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| King's Fund Patient Experience Blog |
| National Association for Patient Participation |
| National Voices |
| Our Covid Voices |
| Patient UK Discussion Forums |
| Patient Views |
| Patient Voices |
| Patients Association |
| Picker Institute |
| Primary literature (bibliographic databases) |
| MEDLINE |
| PsycINFO |
| Web of Science |

Medline search strategy

- 1 exp coronavirus/
- 2 exp Coronavirus Infections/
- 3 ((corona* or corono*) adj1 (virus* or viral* or virinae*)).ti,ab,kw,kf.
- 4 (coronavirus* or coronovirus* or coronavirinae* or CoV).ti,ab,kw,kf.
- 5 ("2019-nCoV" or 2019nCoV or nCoV2019 or "nCoV-2019" or "COVID-19" or COVID19 or "CORVID-19" or CORVID19 or "WN-CoV" or WNCov or "HCoV-19" or HCoV19 or "2019 novel*" or Ncov or "n-cov" or "SARS-CoV-2" or "SARSCoV-2" or "SARSCoV2" or "SARS-CoV2" or SARSCov19 or "SARS-Cov19" or "SARSCov-19" or "SARS-Cov-19" or Ncovor or Ncorona* or Ncorono* or NcovWuhan* or NcovHubei* or NcovChina* or NcovChinese* or SARS2 or "SARS-2" or SARScoronavirus2 or "SARS-coronavirus-2" or "SARScoronavirus 2" or "SARS coronavirus2" or SARScoronavirus2 or "SARS-coronavirus-2" or "SARScoronavirus 2" or "SARS coronavirus2").ti,ab,kw,kf.
- 6 (((respiratory* adj2 (symptom* or disease* or illness* or condition*)) or "seafood market*" or "food market*" or pneumonia*) adj10 (Wuhan* or Hubei* or China* or Chinese* or Huanan*)).ti,ab,kw,kf.
- 7 ((outbreak* or wildlife* or pandemic* or epidemic*) adj1 (China* or Chinese* or Huanan*)).ti,ab,kw,kf.
- 8 "severe acute respiratory syndrome*".ti,ab,kw,kf.
- 9 SARS Virus/
- 10 ("SARSCoV" or "SARS-CoV" or "SARS Cov" or SARScoronavirus or "SARS-coronavirus" or "SARS coronavirus" or SARScoronavirus or "SARS-coronavirus" or "SARS coronavirus").ti,ab,kw,kf.
- 11 Middle East Respiratory Syndrome Coronavirus/
- 12 "Middle East* respiratory syndrome".ti,ab,kw,kf.
- 13 ("MERSCoV" or "MERS-CoV" or "MERS Cov" or MERScoronavirus or "MERS - coronavirus" or "MERS coronavirus" or MERScoronavirus or "MERS-coronavirus" or "MERS Coronavirus" or "camel flu").ti,ab,kw,kf.
- 14 or/1-13
- 15 exp Patient Satisfaction/
- 16 ((patient* or carer* or family) adj2 (experience* or view* or perspective* or preference* or attitude* or expectation* or satisfaction)).tw.

17 15 or 16
18 14 and 17

Supplementary file 3 Summary of key themes relating to the views and experiences of patients, their families and carers

| Themes and sub-themes | Summary of sub-themes | Supporting example |
|---|--|---|
| 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. | <p>“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 <i>et al</i>)¹⁹</p> <p>“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)¹</p> |
| Severity of symptoms | Symptoms ranged from mild to potentially life-threatening. | <p>“I've been absolutely floored... I've got all sorts of... I've got vasculitis, which I think is a common thing... And I've been left with nerve issues, like really horrible nerve... stabbing pains in my hands and feet and I can't move my toes any more... unfortunately, my journey is far from over.” (Ladds <i>et al</i>)¹⁸</p> <p>“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)¹</p> |
| 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 <i>et al</i>) ¹⁷ |

| 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) ¹ |
| 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 COVID. | "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 <i>et al</i> , p6) ¹⁷ |
| 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 <i>et al</i>) 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) ¹ |
| 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 went back to work too soon and wish I hadn't. Finally had to take a 5 week break in July/ August with the support of my employer. This helped a lot. I have now been back at work for 5 weeks and my symptoms have got worse to a degree." (Davis <i>et al</i>) ¹⁶ |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
|--|---|--|
| Disconnect between officially recognised symptoms and lived experience | There is discordance between the range of symptoms articulated by patients with long-term illness and those officially recognised by authorities as COVID-19. | “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 like a long time, and now five months on it feels like a very long time” (Maxwell, p11) ¹ |
| 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 COVID, patients feel ignored, dismissed, and may be misdiagnosed. | “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. Of course I was anxious, but that was a consequence of the physical symptoms, not the cause! 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) ¹ |
| 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 COVID. | “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 |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| | | B12 just because of all the burning in my feet ... and a probiotic and some omega-3." (Kingstone <i>et al</i>) ¹⁷ |
| 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 <i>et al</i>) ¹⁷ |
| 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 <i>et al</i>) ¹⁷ [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 <i>et al</i>) ¹⁷ |
| 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) ¹ |
| Stigma (externally generated) | Employers and others drive a fear of being stigmatised over long COVID. | "Healthcare staff was fearful and I was turned away with no support" (Assaf <i>et al</i>) ¹⁹ "I had to take two weeks off, had to work from home for four, but had to return for two weeks with fever as my employer would not give me more time [...]." (Davis <i>et al</i>) ¹⁶ |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| 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 <i>et al</i>) ¹⁹ |
| Theme: effects on self-identity, relationships and lifestyle | | |
| Impact on self-identify | Long COVID 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 <i>et al</i>) ¹⁹ |
| Impact on daily life/work | Patients had to alter their physical activity levels to accommodate long COVID 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 <i>et al</i>) ¹⁸ "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 <i>et al</i>) ¹⁷ |
| 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 <i>et al</i>) ¹⁸ [Author quote] |
| Impact on others/relationships | Long COVID 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 |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| | | 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 <i>et al</i>) ¹⁷ |
| 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) ¹ |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| 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 <i>et al</i>) ¹⁷ |
| 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 <i>et al</i>) ¹⁸ |
| 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) ¹ |
| 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 <i>et al</i>) ¹⁹ “I think the message to avoid hospital and the GP unless you had specific symptoms was very unhelpful, |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| | | particularly as I didn't have, and never have had, a cough or fever" (Maxwell) ¹ |
| 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 <i>et al</i>) ¹⁷ |
| 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 <i>et al</i>) ¹⁸ |
| Things patients did to access care | Patients engaged in a number of activities to improve their access to healthcare including: <ul style="list-style-type: none"> • 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. | "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 <i>et al</i>) ¹⁸ |
| 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 <i>et al</i>) ¹⁷ |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| 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 beginningAnd 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 <i>et al</i>) ¹⁸ |
| 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 <i>et al</i>) ¹⁸ |
| 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 <i>et al</i>) ¹⁹ |
| 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 COVID 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 <i>et al</i>) ¹⁷ |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| Lack of knowledge – symptoms | The lack of knowledge around long COVID included uncertainty about the expected symptoms, wanting to learn 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. | “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) ¹ |
| Lack of knowledge – seeking help | Uncertainty about when patients with long COVID 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) ¹ [Author quote] |
| Lack of knowledge – employers | Employers need advice on how to manage employees with long COVID. | “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) ¹ [Author quote] “I have needed more-flexible hours (working remotely) post-COVID. That way, I can rest as needed throughout the day. If I had to return to in-person work at this point, it would be severely reduced hours if at all.” (Davis <i>et al</i>) ¹⁶ |
| Lack of knowledge – management | Lack of knowledge about managing long COVID, 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) ¹ |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| Lack of knowledge – prompts help-seeking from other sources | Lack of widely accessible medical knowledge about long COVID has led to patient reliance on news and social media for information. | “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. So, you know, sixth sense, I actually think that the support group has given more knowledge than the doctors have.” (Ladds <i>et al</i>) ¹⁸ |
| Patients prefer healthcare professionals to admit uncertainty | Patients would prefer healthcare professionals to admit to a lack of knowledge about long COVID. | “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 <i>et al</i>) ¹⁷ |
| 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) ¹ |
| Healthcare structuring – case management | A case manager or single clinician to co-ordinate investigations and the patient care pathway for each patient with long COVID. | “... 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) ¹ |
| 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 |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| | | support after recovering from Covid, or Covid-like symptoms." (Maxwell) ¹ [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) ¹ |
| 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) ¹ [Author quote] |
| Theme: social media and support groups | | |
| Support through sharing experiences | Online support groups and social media provided opportunities for sharing experiences of long COVID. | "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) ¹ |
| Support through sharing knowledge | Online support groups and social media provided opportunities for sharing knowledge and resource links with others coping with long COVID. | "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 <i>et al</i>) ¹⁸ |
| 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 <i>et al</i>) ¹⁸ [Author quote] |
| 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 |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
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| | | 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 <i>et al</i>) ¹⁷ |
| 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 <i>et al</i>) ¹⁷ |
| 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 <i>et al</i>) ¹⁷ "I felt the medical team was dismissive. There were a lot of 'we don't know.' Which is understandable, but difficult." (Assaf <i>et al</i>) ¹⁹ |
| 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 <i>et al</i>) ¹⁷ "Because I've spoken to four different GPs throughout this. I've not found them very helpful..." (Kingstone <i>et al</i>) ¹⁷ |
| Misdiagnosis or dismissal by healthcare professionals | Dismissal of symptoms or misdiagnoses were associated with a negative perception of healthcare. | "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 |

| Themes and sub-themes | Summary of sub-themes | Supporting example |
|--|---|--|
| | | felt like I was nagging them and being a hypochondriac and that's how I was being treated..." (Kingstone <i>et al</i>) ¹⁷ |
| 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 <i>et al</i>) ¹⁷ |

