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Negotiation of collective and individual candidacy for long Covid healthcare in the early phases of the Covid-19 pandemic: Validated, diverted and rejected candidacy

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ABSTRACT

This analysis of people's accounts of establishing their need and experiences of healthcare for long Covid (LC) symptoms draws on interview data from five countries (UK, US, Netherlands, Canada, Australia) during the first ~18 months of the Covid-19 pandemic when LC was an emerging, sometimes contested, condition with scant scientific or lay knowledge to guide patients and professionals in their sense-making of often bewildering constellations of symptoms. We extend the construct of candidacy to explore positive and (more often) negative experiences that patients reported in their quest to understand their symptoms and seek appropriate care. Candidacy usually considers how individuals negotiate healthcare access. We argue a crucial step preceding *individual* claims to candidacy is recognition of their condition through generation of *collective* candidacy. "Vanguard patients" collectively identified, named and fought for recognition of long Covid in the context of limited scientific knowledge and no established treatment pathways. This process was technologically accelerated via social media use. Patients commonly experienced "rejected" candidacy (feeling disbelieved, discounted/uncounted and abandoned, and that their suffering was invisible to the medical gaze and society). Patients who felt their candidacy was "validated" had more positive experiences; they appreciated being believed and recognition of their changed lives/bodies and uncertain futures. More positive healthcare encounters were described as a process of "co-experting" through which patient and healthcare professional collaborated in a joint quest towards a pathway to recovery. The findings underpin the importance of believing and learning from patient experience, particularly vanguard patients with new and emerging illnesses.

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1. Introduction

1.1. The "making" of long Covid

When the World Health Organisation declared Covid-19 a pandemic in March 2020, professional and public understandings, whilst rapidly developing, were that Covid-19 caused either symptoms which rapidly resolved or potentially life-threatening illness requiring hospitalisation (especially amongst the elderly and clinically vulnerable). This was enshrined in public messaging during 'lockdowns' to limit virus transmission, when the public was asked to stay home, save lives and protect healthcare systems in the UK, Canada, Australia and elsewhere. The threat of premature mortality and catastrophic strain on healthcare systems was reflected internationally in media reports of escalating cases and deaths, makeshift Covid wards and overworked healthcare staff.

However, soon another picture began to emerge, of people with a bewildering array of longer-term symptoms, even after initially mild symptoms of (assumed) infection. Within six months, Callard and Perego (2021) described long Covid as the first illness to be collectively made by patients finding one another through various social media (e.g. Twitter, www.facebook.com/groups/longcovid), as first-person accounts rendered their persisting and heterogenous symptoms visible and challenged earlier assumptions about the severity and longevity of symptoms. Roth and Gadebusch-Bondio (2022, p2) also noted the importance of collective online advocacy by people with long Covid symptoms, including in the naming of the condition, and identified this as a form of "bio-digital citizenship". They suggest that "online mobilisation of subjective evidence" (p4) by people with longer-term symptoms, including the active engagement of healthcare professionals and "medically literate academics" (p2) who were themselves affected, led to a more rapid and wider acceptance of long Covid than for other contested conditions. Furthermore, the "digital interconnectedness of sufferers" online facilitated a "collective gathering" of patient experience in a "heterogenous and global community" (p6).

Many (e.g., Altmann & Boyton, 2021) have emphasised the unpredictable, relapsing, remitting and diverse symptoms of long Covid which can affect respiratory, cardiovascular, urological, neurological, and gastrointestinal systems; and the lack of information about management and prognosis. A dynamic review highlighted an urgent need for research on (and rapid access to) treatment and management, with "expert by experience" patients as equal partners in setting the agenda (Maxwell, 2021). A review by Macpherson et al. (2022) of the then limited evidence on patient experience (two international surveys and three qualitative studies from the UK) highlighted the lack of knowledge and understanding about long Covid among healthcare professionals and the confusion and anxiety this could create for patients. They noted multiple perceived barriers to healthcare which could make accessing care complex, difficult and exhausting. These findings have been reinforced by more recent papers on patient experience of long Covid (e.g. Rushforth et al., 2021).

1.2. Theoretical framing

When scientific knowledge of a new condition is limited, deciphering patient experience is paramount. Aptly, in relation to an emergent and contested condition such as long Covid, Lian et al. (2021, p7) observe that, in the face of medical uncertainty:

> "… [g]iving people a medical name for their health problems … is the starting point for defining, explaining and acting on illness and for predicting future developments. Nameless ailments … remain indecipherable. Diagnostic uncertainty renders patients incapable of making sense of what is happening to them, what to do, and what to expect, and it prevents clinicians from predicting future developments, which patients often expect and sometimes ask for."

Models of illness behaviour are founded on people's experiences of sense-making of painful and/or disruptive symptoms. In their review of sociological and psychological models, Wyke et al. (2013, p85) suggest the purpose of such behaviour is to "(re)achieve normality in physical or social functioning", drawing on interactions with others, past experiences of symptoms and treatment systems, and knowledge of social norms or expectations of treatments. Healthcare seeking actions, they argue, are "continually evaluated in the light of changes in knowledge, resources or embodied experience." Davison et al. (1991) coined the term "lay epidemiology" for the process by which people make sense of their (risk of) illness, assessing the possibility and probability of becoming ill with particular conditions - for example, the "kind of person who gets heart trouble". Their coronary candidacy theory suggested four outcomes, two explicable ("candidate" who develops heart disease; someone who is not a candidate who never develops heart disease) and two apparently inexplicable (people who do "all the wrong things" yet survive to a ripe old age; those who appear to have no risk factors but succumb to heart disease as "the last person you'd expect"). Others extended this theory to show how factors such as gender are an integral part of the structuring of candidacy (Emslie et al., 2001). A distinct construct of candidacy (Dixon-Woods et al., 2006) was subsequently formulated in relation to healthcare utilisation, and describes how people's *eligibility for healthcare* is a "continually negotiated property" subject to micro- and macro-level influences (e.g. configuration of services). Dixon-Woods et al. argue that:

> "Health services are continually constituting and seeking to define the appropriate objects of medical attention and intervention, whilst at the same time people are engaged in constituting and defining what they understand to be appropriate objects of medical attention and intervention. Access represents a dynamic interplay between these simultaneous, iterative and mutually reinforcing processes" (p1).

But what happens when, as in the case of long Covid in the early years of the pandemic, knowledge is absent or scarce, interactions with others are limited or changed, healthcare resources are subject to unprecedented strain, and expectations of the healthcare system's response to symptoms may be less certain because provision of care is disrupted?

This is the theoretical framing for our analysis of experiences of people who experienced long Covid early in the pandemic – who we refer to as "vanguard patients" here - in their quest for support and treatment from healthcare professionals. Our analysis covers a time in the pandemic when long Covid was a newly emergent illness, with a scant lay or professional epidemiological evidence-base for making sense of often bizarre and life-changing constellations of symptoms, including when long Covid was unrecognised or contested by the medical establishment. We argue that, of the aspects or features (Liberati et al., 2022) of candidacy, four of the seven outlined by Dixon-Woods et al. (2006) are particularly salient: identification of candidacy, navigation of services, permeability of services and adjudication by healthcare professionals. We follow others in recognising the *collective* nature of the "patient-making" of long Covid, arguing that this can be understood as the generation of "collective candidacy".

We then analyse the experience of our participants, many of whom were amongst the earliest vanguard patients, as they tried to define and assert their own individual candidacy for healthcare in the early stages of the pandemic. Using data from five countries, at various stages of the unfolding of the pandemic in 2020/1 and with differing healthcare systems, we expected many similarities in experiences cross-nationally, in part because of the global interconnectedness engendered by the collective online "making" of long Covid. We argue negative experiences of healthcare interactions of long Covid when it was emerging and contested can be understood as "diverted" or "rejected" candidacy, whereas when candidacy is "validated and affirmed" healthcare interactions are more positive, even in the face of extreme uncertainty about the causes, consequences and prognosis for long Covid. We also draw on developments of the candidacy construct by others (e.g. Macdonald et al., 2016, Kirkpatrick et al., 2018) and an application of the construct to understand access to secondary mental health services in the UK during the pandemic (Liberati et al., 2022).

We conclude by considering whether understanding the making of collective and individual candidacy, and the professional adjudication of candidacy (as rejected, diverted or validated) alongside the accessibility and permeability of services in pandemic times, has cross-national policy and practice implications for healthcare use and interactions for long Covid and other emerging and contested conditions.

2. Methods

This paper draws on ongoing research on experiences of participants with (long) Covid in the UK (n = 30), US (n = 20), Netherlands (n = 10), Canada (n = 6) and Australia (n = 6). Analysis was conducted in 2022; some country teams are continuing to collect data for online platforms for patient experiences of long Covid based on analysis of narrative interviews (see, for example, Long Covid In Adults - Symptoms of long Covid (healthtalk.org)).

2.1. Data collection and sampling

The interviews (n = 72) included in this analysis were undertaken between November 2020 and March 2022 using a comparable narrative and semi-structured approach. All researchers received the same training and support through the DIPEx International collaboration (Ziebland et al., 2020). Specific studies of long Covid are ongoing in the UK, US, Netherlands and Canada; data from Australia and Canada (and additional UK and US data) were from interviews with people with longer term symptoms in broader studies of Covid-19. Convenience sampling was undertaken in Australia given the very low number of cases in 2020. Sampling within most countries will ultimately aim for maximum variation (Coyne, 1997) when country-specific studies complete in 2022/3, with diversity in location, occupational social class, ethnicity, gender and age. Table 1 shows participant characteristics, including when they first became ill with Covid-19 and number of months affected by subsequent symptoms.

Recruitment was through various routes, including clinicians, social media, support groups and snowballing to facilitate diversity in experiences and perspectives. Interviews were conducted online (except in the Netherlands where they were face-to-face) and recorded on audio and/or video according to participant preference. Interviews typically lasted 60–90 min, although some were shorter and/or conducted over multiple sessions if the participant preferred (e.g. due to fatigue); the longest totalled 4.5 h. The first part of the interview invited participants to relate how they first became aware of (long) Covid and their experience of the illness. The second part drew on semi-structured topic guides with various prompts, including questions around their experiences of help-seeking.

Relevant research ethics review and approval was undertaken in each country before data collection.

2.2. Data analysis

Interviews were transcribed verbatim. Transcripts were checked for accuracy and imported into specialist computer software (NVivo [UK, Australia]; ATLAS-ti [NL]; MAXQDA [US, Canada]) for organising textual data for coding/analysis. Our multistage analytical approach was as follows. First, interview accounts were independently analysed by each country team for narrative themes that structured participant experiences. Second, a descriptive write up of initial themes in the UK and a proposed analytical framework based on the UK data were shared with researchers in the four other countries. The UK team met separately with each country team, to allow detailed discussion of each country's data and minimise meetings at antisocial hours. These discussions established many strong commonalities across the data from the five countries. Third, the US, Dutch, Canadian and Australian teams applied the UK conceptual structure to code their own data and shared relevant data extracts in response to the UK team's initial formulation of influences on help-seeking for long Covid; selected extracts from the Dutch data were translated to English. The Dutch extracts were forward and backward translated by two Dutch researchers (NV and AF). Fourth, we undertook another series of online bilateral discussions and face to face meetings between members of the authorship team at a DIPEx International collaborators meeting in May 2022. Following this, the analysis was reworked using the theoretical lens of candidacy, as described above, and the amended analytical framework was shared for critical comment. In the final step, authors from all countries interrogated the redrafted text and analytical framework and confirmed it fully resonated with their data. Subsequent refinements to the line of argument were elaborated, which included searching for any examples that contradicted the main findings. During this iterative process, the data were thus compared and discussed, and the analytical framework was iteratively tested against each country's data and through ongoing dialogue within the author team, in light of existing knowledge, relevant theory and internal peer review. Country teams were asked to highlight any differences in health systems and policies, circumstances of the participants/phase of the pandemic, if relevant for any country-specific observations. Illustrative interview extracts are included in the main text, supplemented by examples from all five countries in Supplementary Table 1.

3. Findings

3.1. Overview

Fig. 1 presents the analytical framework we developed to make sense of people's accounts of having and seeking help for symptoms of long Covid in the relatively early stages of the Covid-19 pandemic, when long Covid was novel and often contested and patients and healthcare professionals alike had limited lay or professional epidemiological knowledge to draw on. In 3.2 below, we give an overview of the types of symptoms experienced, and how a “collective candidacy” was established, principally through vanguard patients' digital interactions through social media. We then discuss people's individual articulation of candidacy and need for healthcare. In 3.3–3.5, we demonstrate how healthcare professionals' adjudication (Dixon-Woods et al., 2006), based on a spectrum of professional knowledge and experience of long Covid, can lead to patients experiencing their claims to candidacy for healthcare as “rejected”, “diverted” or “validated/affirmed”, which in turn affects whether their medical encounters are experienced as negative and undermining or positive and enabling. The most positive healthcare interactions can be experienced as an affirming partnership of discovery in which patient and healthcare professional “co-expert” to learn more about (treatment for) long Covid together. We note here and in Fig. 1 that, as a consequence of these processes, those with the most negative experiences may only be able to find support from health professionals for pathways to recovery and adequate management through resorting to other (e.g. privately-provided) sources of care. This has the potential to further exacerbate health inequality. Although we present these three forms of candidacy as discrete in sections 3.3-3.5 below, it is important to note that there was at times a degree of overlap between rejected and diverted candidacy and between diverted and validated/affirmed candidacy.

3.2. Making sense of symptoms and negotiating collective and individual candidacy in the context of the pandemic

Experiences of initial infection varied considerably. Some described mild illness, whereas others described being “*bedridden*”, "*completely exhausted*" or "*trapped in my own body*" (AUSLC04). In line with other research on experiences of long Covid (see e.g., Callard & Perego, 2021;

Table 1
Participant characteristics grouped by country (ordered by sample size).

UK (n = 30) ID	Gender	Ethnicity	Age	Month of infection	Month of interview	Time affected by symptoms (months)
UKLC01	M	White British	30–39	Apr-20	Apr-21	12
UKLC02	F	White British	40–49	Apr-20	Apr-21	13
UKLC03	M	White British	40–49	May-20	Apr-21	11
UKLC04	F	White British	50–59	Mar-20	Apr-21	13
UKLC05	M	White British	20–29	Mar-20	May-21	14
UKLC06	F	White British	30–39	Mar-20	May-21	14
UKLC07	F	White British	30–39	Mar-20	Jun-21	6
UKLC08	F	White British	30–39	Dec-20	Jun-21	15
UKLC09	F	White British	30–39	Mar-20	Aug-21 Oct-21	19
UKLC10	M	White British	50–59	Mar-20	Aug 21	17
UKLC11	F	Asian British	30–39	Mar-21	Sep-21	6
UKLC12	M	White British	60–69	Mar-20	Oct-21	10
UKLC13	F	White British	60–69	Mar-20 May-20	Jan-22	20
UKLC14	F	White British	50–59	Sep-21	Feb-22	5
UKLC15	F	Bangladeshi	30–39	Dec-20	Mar-21	3
UKLC16	F	Black African	50–59	Feb-21	Apr-21	3
UKLC17	F	Pakistani	30–39	Oct-20	Mar-21	3
UKLC18	F	Malaysian	40–49	Aug-20	May-21	9
UKLC19	F	White Welsh	50–59	Aug-20	May-21	4
UKLC20	F	Black British	50–59	Sep-20	May-21	8
UKLC21	F	Black British	60–69	Dec-20	May-21	5
UKLC22	F	Black Pakistani	30–39	Jan-21	Jul-21	6
UKLC23	F	White American/British	50–59	Jan-20	Sep-21	21
UKLC24	F	Black Caribbean	60–69	Dec-20	Sep-21	3??
UKLC25	F	White English	30–39	Mar-20	Oct-21	18
UKLC26	F	Black British	50–59	Jan-20	Nov-21	25
UKLC27	F	Ashkenazi Jewish	30–39	Mar-20	Nov-21	19
UKLC28	F	White English	20–29	Oct-20	Nov-21	14
UKLC29	F	White British	40–49	Mar-20	Dec-21	21
UKLC30	M	White British	20–29	Mar-20	Mar-21	24

US (n = 20) ID	**Gender**	**Ethnicity**	**Age**	**Month of infection**	**Month of interview**	**Time affected by symptoms (months)**
USLC01	F	Mixed Race: White/Hispanic	20–29	Mar-20	Jan-21	10
USLC02	M	Hispanic or Latino	40–49	Nov-20	Jan-21	3
USLC03	F	Black or African American	40–49	Dec-20	Feb-21	2
USLC04	F	White	50–59	Mar-20	Apr-21	12
USLC05	F	Hispanic or Latino	30–39	Mar-20 (first) Dec 20 (second)	May-21	3 (second infection)
USLC06	M	Hispanic or Latino	60–69	Jun-20	May-21	6
USLC07	F	White	50–59	Nov-20	Jul-21	6
USLC08	F	White	40–49	Dec-20	Jul-21	4
USLC09	F	White	60–69	Oct-20	21-Jul	9
USLC10	F	Arab-American Latina	50–59	Sep-20	Jul-21	6
USLC11	F	White	50–59	Dec-20	Jul-21	4
USLC12	F	White	50–59	21-Jan	Jul-21	6
USLC13	F	White	30–39	Aug-20	Sep-21	6
USLC14	F	White	40–49	Nov-20	Oct-21	5
USLC15	F	White	40–49	Oct-20	Oct-21	6
USLC16	F	White	40–49	Mar-20	Oct-21	18
USLC17	M	White	60–69	May-20	Nov-21	6
USLC18	F	White	50–59	Feb-20	Nov-21	6??
USLC19	F	White	50–59	Oct-20	Dec-21	8??
USLC20	F	Asian	40–49	Mar-20	Jan-22	7

NL (n = 10) ID	**Gender**	**Ethnicity**	**Age**	**Month of infection**	**Month of interview**	**Time affected by symptoms (months)**
NLLC01	F	NL	50–59	Dec-19	Feb-22	25
NLLC02	F	NL	60–69	May-20	Mar-22	22
NLLC03	F	NL	20–29	Mar-20	Jan-22	22
NLLC04	M	NL	40–49	Apr-21	Feb-22	10
NLLC05	M	NL	40–49	Apr-20	Feb-22	10
NLLC06	F	NL	40–49	Mar-21 Dec-21	Feb-22	13
NLLC07	F	Other	40–49	Mar-20	Feb-22	24
NLLC08	F	Other	30–39	Apr-21	Feb-22	10
NLLC09	M	NL	70–79	Apr-21	Feb-22	10
NLLC10	F	NL	60–69	Apr-21	Feb-22	10

CAN (n = 7) ID	**Gender**	**Ethnicity**	**Age**	**Month of infection**	**Month of interview**	**Time affected by symptoms (months)**
CANLC01 (02)	F	White	40–49	Mar-20	Nov-20	8

(*continued on next page*)

Table 1 (*continued*)

CAN (n = 7) ID	Gender	Ethnicity	Age	Month of infection	Month of interview	Time affected by symptoms (months)
CANLC02 (04)	F	White	40–49	Mar-20	Nov-20	8
CANLC03 (05)	F	Caucasian/British Isle	60–69	Apr-20	Nov-20	7
CANLC04 (06)	F	White	40–49	Mar-20	Nov-20	8
CANLC05 (07)	F	Caucasian	40–49	Mar-20	Nov-20	8
CANLC06 (08)	M	Jewish	40–49	Mar-20	Dec-20	9
CANLC07 (11)	F	South-Asian	30–39	Jun-20	Dec-20	6
AUS (n = 6) ID	**Gender**	**Ethnicity**	**Age**	**Month of infection**	**Month of interview**	**Time affected by symptoms (months)**
AUSLC01	F	British	40–49	Mar-20	Dec-20	8
AUSLC02	M	Western European	30–39	Jul-20	Nov-20	4
AUSLC03	F	Eastern European	30–39	Aug-20	Dec-20	4
AUSLC04	F	Australian peoples	60–69	Mar-20	Feb-21	11
AUSLC05	F	Australian peoples	40–49	Jul-20	Mar-21	8
AUSLC06	M	Southern European	40–49	Aug-20	Mar-21	6

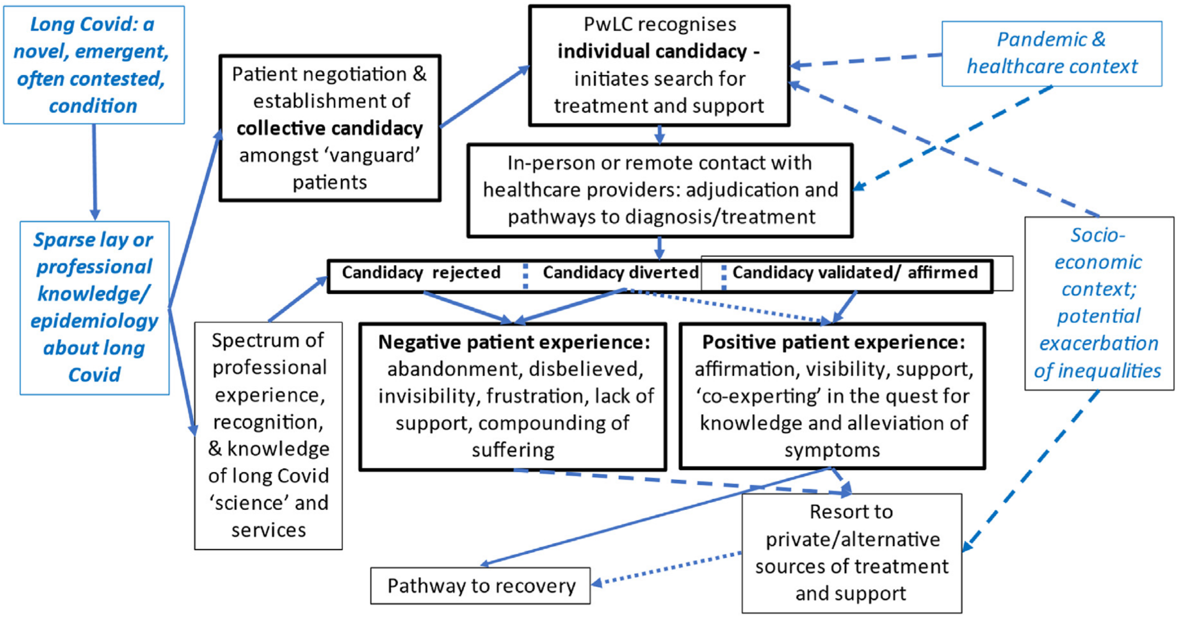

Fig. 1. Patient negotiation and recognition of collective and individual candidacy for healthcare for long Covid, and impact of professional adjudication (rejected, diverted, heard) on patient experience and pathway to treatment and recovery.

Macpherson et al., 2022; Rushforth et al., 2021), participants described how their symptoms fluctuated. Some continued, whilst others disappeared, reappeared, worsened or were compounded by new symptoms. Longer term symptoms included extreme fatigue, "brain fog", breathlessness, cardiac symptoms (e.g., palpitations), dizziness, joint/muscle aches, anosmia, difficulty controlling body temperature, headaches, numbness/pins and needles, problems with vision and many more. Participants, especially the vanguard patients who were affected early in the pandemic when long Covid was new, unrecognised and unknown, said it was hard for them to make sense of their symptoms, not least because of the variety they experienced and their fluctuating occurrence and severity. One described this fluctuation as a "*stinking teaser […] it crushes you because it's like you just want to be you again*" (USLC16). Dissonance with past experience of acute illnesses or infections that followed a linear pathway to recovery could be particularly confusing, causing people to doubt their existing understandings of illness and recovery. For example:

> *[I] would think, 'Okay I'm better now', because this is my experience of being ill […] of so-called respiratory viruses […] So, our experience of being sick […] was that you feel like shit for a few days, and then you get better. Not that you feel like shit for a few days [with Covid-19], you start to feel a little bit better, then you feel like shit again […] it's about a whole new experience of illness that very few people understood […] that suddenly lots of us were going through [and] you're doubting your experience all the time. You come to doubt your knowledge of illness and recovery.* (UKLC23)

Participants commonly referred to their constellation of symptoms as "*life-changing*". For example, UKLC10 described long Covid as a "*completely new condition, that's come out of nowhere, that's turned my life on its head*". The array and severity of symptoms made continuation of people's pre-Covid daily life challenging or impossible ("*pretty much everyday activities suddenly became almost impossible*" AUSLC05). For example, some described disturbing and confusing disruption to taste and smell, crippling fatigue which prevented them from getting out of bed, or how routine tasks (e.g., driving, showering, hanging out washing) could cause their heart rate to soar. Brain fog could render people unable to do their job or day-to-day tasks.

For those affected earliest in the pandemic, the struggle to make sense of their symptoms only began to resolve as they heard of others' suffering. This process was accelerated by people's access to online technologies and media. As vanguard patients began to share their stories and information about symptoms, treatment and support in medical, mainstream and social media, they collectively came to understand their illness as long Covid through a technologically accelerated process of “patient-making” of this novel condition, as others have described (e.g. Callard et al., 2021; Rushforth et al., 2021). As one participant said, “*most of our help has come from online groups which I find extraordinary because I'm not a Facebook user but I've spent a lot of time on there because that's where a lot of the long Covid groups are”* (AUSLC04). As a nascent lay epidemiology (Davison et al., 1991) of long Covid began to coalesce online, inevitably ahead of a scientific understanding given the emergent nature of long Covid as an illness category, people around the world could begin to make sense of their confusing experiences through a shaping of “collective candidacy”.

> *I was questioning my sanity. Am I just making this up, am I just depressed? … [J]oining the slack [online] group was huge, because I discovered that I wasn't alone and there were so many people worldwide that were experiencing the same thing.* (CANLC07)

> *I had no idea what was happening to me … [then] there started to be reports about people having post-Covid syndromes or having episodes of Covid that just seemed to go on and on and on which was just amazing, like a light in the dark because I thought I was going mad and I thought it was something about me. It was just really difficult and then reading more about it, I was like, ‘Okay this is something that happens to people, this is not just about me!’* (UKLC25)

As an understanding of a “collective candidacy” began to gain traction internationally, this could enable a sense-making process through which people could reinterpret their own experience and articulate their *individual* candidacy, as someone needing support for long Covid symptoms. This process involved recognising they were seriously unwell and both in *need*, and *worthy*, of medical care. It was a complex and bewildering process, even for those (like UKLC06 and USLC07) who were doctors themselves:

> *[Y]ou can probably get a sense that a lot of this illness, because it's all been new, a lot of it has just been me trying to work out what on earth is going on. And as a doctor, that has been really, really difficult. I can't imagine what it would be like as a lay person - the neuro stuff, I thought had gotten better, so you know, the phantom smells, the tinnitus, I'd had some strange nerve pain, like a poker in my ear, really bizarre, but it was very, very painful. Strange kind of scalp sensations, as well, but all, all such vague and strange things, I didn't even mention them to, to my GP, because I thought she might think I was completely mad [laugh].* UKLC06

> *“[i]t is scary to me as a healthcare professional, the stuff that people are not telling their docs […] people are so frustrated with their health care, you know health care systems not knowing what to do with […] that they just live at home with these symptoms […] it is really sad*”. (USLC07)

This selective “editing-out” of what people understood to be the most bizarre and implausible symptoms in medical encounters plausibly slowed the development of professional epidemiological understandings of long Covid and contributed to continuing medical scepticism about some symptoms. This scepticism, and people's struggles to assert their individual candidacy, could be compounded for those affected before the widespread availability of testing for Covid-19, as initial infection may never have been confirmed. For example, UKLC23 said: “*Doctors could not make sense [of my symptoms] [… or] help me process what I was going through, because a) they didn't have the time, b) they didn't know what was going on [laughs], and c) I wasn't a valid patient because I didn't have a [positive] test”*.

Hence, even as collective candidacy for long Covid took root internationally (perhaps not as quickly as implied by Roth and Gadebusch-Bondio (2022)), some found their individual candidacy even more difficult to assert in the face of organisational changes to restrict virus transmission or pressures on health systems during the pandemic. As some wrestled with the validity of their candidacy, participants often emphasised their previous good health, their infrequent past resort to medical care or time off work for illness, pandemic-related pressures on the healthcare system or the futility of help-seeking for a novel illness. For example, a UK participant said:

> *I'm not someone […] who's been off sick, not someone who's actually suffered with ill health particularly in my life. And then to be back and forth to the GP is really uncomfortable. Just because I don't want to put any pressure on the … the health service [… it] is quite awful to come and approach a GP and say, ‘I'm really tired’ […] I just feel like I'm becoming a hypochondriac […] an annoying patient that is saying ‘I don't feel well’ and there's no real … and they'll be like, ‘What's wrong?’ And I'm like, ‘Well I don't really know’ […] because you do feel like, well what are they going to do? They've already done [some tests] […] What else could there be that could be offered?* (UKLC09)

Analyses of participants' accounts in some countries revealed the ways that they were managing the task of balancing responsible healthcare service use (i.e., not “wasting” the doctor's time, not using scarce resources without just cause) against taking responsibility for their own health (seeking investigations into possible long-term damage to their bodies caused by long Covid) and a sometimes desperate need for explanations, support and treatment. The morally charged nature of this balancing act could be intensified by the fact that the pandemic was adding pressure to already stretched health services and the knowledge that Covid was causing life-threatening illness or death for others. Such considerations caused some participants to repeatedly question if their own healthcare service demands were justifiable. It was common for participants to follow up ways in which they felt they had not been supported with a comment which downplayed their need for help as compared to others with more severe illness (although this was not evident to the same extent in data from the Netherlands):

> *There wasn't any screening by your GP, by the surgery nurse, nothing. Nothing at all. [erm] And obviously I don't wanna, I don't wanna say in-depth of care as some […] had to be induced into a coma and had to be hospitalised. They are the priority. Even with all of that, if some people we know have died. But it just felt as though there was a gap.* (UKLC21)

However, while acknowledging that those experiencing more acute illness should be prioritised, participants emphasised the importance of acknowledging, and planning for, those with long Covid too; one described the lack of support as “*galling*” (UKLC10). This desire to fill the support void for long Covid can be seen as part of their efforts to draw on and shape a collective candidacy for long Covid.

Across the five countries, there were many accounts of negative and unsatisfying, frustrating or unhelpful healthcare encounters, but also some positive accounts. We now go on to discuss how these can be understood in relation to rejected, diverted and validated/affirmed candidacy.

3.3. Rejected candidacy

The data included many examples of participants' claims to individual candidacy being adjudicated then rejected, at least initially, by healthcare professionals. Participants' accounts suggest this happened in various ways, from health professionals telling patients that long Covid did not exist, to patients being left with the impression that healthcare professionals, certainly during the early stages of the pandemic, were at a loss as to how to deal with their claims to candidacy. Many participants recounted feeling disbelieved by some of the healthcare professionals they encountered. For example, CANLC06 said one junior hospital doctor told her “*it was all in my head and it was anxiety”*. She challenged the doctor who called in a superior who said “*it was not in my head, that it was very real, they just couldn't prove it”*. UKLC05 reported presenting to the emergency department with severe chest pain, after being encouraged to do so at an earlier visit, and being told it was likely a symptom of his long

Covid and he should just take Paracetamol [a commonly used pain killer]. This left him feeling "*very let down […] I don't feel believed*". UKLC10 was told by a respiratory specialist "*I don't believe in long Covid*" and was then frustrated when subsequently a neurology specialist said: "*I think you have long Covid, and when it does turn out to be long Covid, I really don't know what we can do about it*".

Often participants described a compounding of their symptoms and suffering in their struggle to establish their need for, and get, healthcare. AUSLC06 was told by his primary care doctor to seek help from Covid doctors at the hospital who, in turn, told him "*Your [primary care doctor] should be able to look after you*". He found this "*frustrating […] you've burnt up more of your energy"*. Participants who felt their symptoms had not been sufficiently investigated spoke of ongoing fears that Covid had inflicted lasting damage to their body and their struggle to have their fears allayed by diagnostic testing. For example, USLC07 said "*There are times when I was like [asking healthcare professionals] '[do] You just want to CAT scan? Like, I just want my brain checked. I want to make sure that my brain is okay'*".

Some participants (including some who were medically trained) said they understood the difficult position that healthcare professionals found themselves in when faced with patients whose symptoms they could neither explain nor effectively treat. UKLC06, a doctor herself, said "*it was difficult for the [primary care doctor] to know what to do with people like me, because it was a new condition, there was no service set up specifically for it*". However, there were many participants who experienced a sense of abandonment when pathways to healthcare seemed impermeable (Dixon-Woods et al., 2006), when their claims to candidacy were rejected (adjudicated as not credible) or when their accounts of symptoms were believed but there was no clear investigative or treatment pathway.

> *[The process of searching for pathways to care] was difficult and frustrating […] I called [names four cities]. I left messages. I got no responses. Finally, with the [city] free clinic, I was able to get in with them, but it took over a week […] [W]hen I was there, I had two people [nurse and doctor] in the room […] they looked at my chart […] and x-rays [and I asked] 'When can I get back to work?' And they just basically laughed and were like, 'You can't work. You're on oxygen.' And I didn't really get any like, any plans to help […] I was supposed to hear follow-up from them in about a week [… but] I still have not, to this day, heard from them.* (USLC13)

> *[T]hey sent me home because they said everything, all my tests were normal. And you're like well I know I'm far from normal here [laughs] but equally I know that you can't help me […] it was just really weird. So you're kind of abandoned basically.* (UKLC29)

Many participants presented themselves as frustrated, angry or defeated. Their accounts suggest that they were particularly angry at being left alone to understand their condition and find ways to recover their former health. One participant called this *"DIY GP-ing [um] and I think for the people that don't have any medical knowledge it must be awful"* (UKLC13).

> I went to a neurologist […] he says, 'Yes, you just have to learn to live with it.' And you are kicked out and yes then I became very angry with, 'Yes, you should learn to live more with that pain you have' or whatever. And then I had a second opinion from a second neurologist, he says well he says, […]'Yes, you have to learn to live with it […] but also learn to deal with it.' […] But then you still want to know, where does it come from? (NLLC02)

> *I would literally like want to bang my head when I left my doctor's office. Like what a waste of my time […] they had no clue […] don't feel like they're very educated, and they're not very compassionate. Like this is new to everybody […] I went from being a perfectly healthy person […] to being so sick […] they're like 'I don't know what to tell you. Everything looks good. You look, physically you look great.' But I don't feel great. There's something going on inside […] she's like, 'Well, do you think I missed something?' 'I don't know. You're the doctor […] You're not helping me. You're not informing me. You know, I don't understand' […] I go online. I'm like […] 'I should have that checked', you know. And so, but she just doesn't understand why I want to do that […] they're [medical profession] all like, 'Ooh, long haulers, no way, we don't know anything.' [LAUGHING] Their hands are up in the air […] I kind of feel like, you know, back in the '80s when HIV first came out […] it's like, 'Oh, my God, you got some like weird disease going on. Like what's wrong with you?' You know, and nobody wants to understand or take the time to figure it out.* (USLC16)

Thus, those who experienced rejected candidacy felt either overlooked, invisible and discounted, or actively disbelieved and challenged ("*I don't believe in long Covid*") when their strange, often fluctuating, constellations of symptoms defied some healthcare professionals' understandings of how Covid-19 could manifest after the acute stage of infection.

3.4. Diverted candidacy

As part of their care, symptoms often required investigation and tests, to rule out alternative explanations, which was often portrayed by participants as reassuring because these diagnostic explorations allayed nagging fears that another serious illness, such as cancer, underlay their symptoms. This can be understood as an appropriate part of the process of adjudication of candidacy by the healthcare professional. Sometimes, however, this testing for other illnesses was felt to undermine or invalidate participants' lived experiences as people with long Covid:

> *I needed – it would have been good for [the doctor] to say to me 'I want you to understand that even though this may all be attributable to Covid, we still have to go through the process of ruling out other serious things, like heart disease or whatever is known already within the medical system'. That would have gone a long way to validate my experience, to foster a greater sense of trust when my trust in the medical system had already been so compromised because of the way that I had been treated all along.* (CANLC02)

> *You know a lot of people in the long Covid community, we've all been through this thing of going for the tests that are available, the chest x-rays and ECGs, doctors turn around and say, 'There's nothing wrong with you, you're fine' because […] they don't- test for the right things. They don't-test for the kinds of damage, they cannot reveal the kinds of damage that are going on in your body […] they're not calibrated to show the sorts of things that would indicate disease, then then, the doctors are telling you you're fine […] But those are the only tests that are available […] in primary care, and the system's not geared up for finding it.* (UKLC23)

Others argued that the investigation of symptoms was frustrating because they rarely felt any further forward in understanding their symptoms and were exhausted by the burdensome process of seeking help and investigations.

> *[A] lot of people were looking for medical answers, getting testing, you know, a lot of it. And I think [laughs] 99% of the people didn't get any good answers. They were already exhausted and went to get this testing, and these testings made them even more exhausted. But they didn't get any answer [or …] any good medication that worked.* (USLC18)

For some, clinician-directed investigations of symptoms were interpreted as a curtailed exercise in ruling out a limited number of alternative diagnoses rather than a continuing exploration or quest that led to a greater understanding of their long Covid symptoms and future management. In such cases, participants said they felt their symptoms were "*put down to*" other conditions; or as one participant said, healthcare professionals would "*put [symptoms] in boxes that exist*" (UKLC06), and further investigation could then cease. This was the case for UKLC10, who said that "*some of the medical professionals I engaged with were very nervous about, labelling [my symptoms] as long Covid, but really comfortable labelling [them] as chronic fatigue [syndrome].*" CANLC04 said that her symptoms were attributed to allergies by her doctor and she was told not to worry. An alternative diagnosis may not even have been clearly communicated, as for USLC14: *"it wasn't until I had actually gone back into my notes to realize that he actually had diagnosed me with something but never even bothered telling me what that was."*

By far the most common way in which participants' claims to candidacy was diverted, was by healthcare professionals attributing the cause of their sometimes complex, bizarre and changing symptoms to psychological origins, such as anxiety. The extracts below demonstrate how participants presented themselves as frustrated and dismayed by their individual candidacy being diverted in this way. They also implied that this was a challenge to collective candidacy, in some cases. Not only did this response from healthcare professionals make participants' efforts to assert their candidacy more of a struggle, it deterred some participants from actively seeking medical help:

> *[T]hat's what's happened to other people [symptoms put down to psychological origins] [...] 'Well, it's just anxiety, [um], stop watching the news, stop being in these groups, you know, you're not going to make yourself better with that' But it's not anxiety. I mean, they may well have anxiety. A lot of people with long Covid have anxiety and depression and all sorts of issues, but that's because they've got long Covid and they're not being listened to and there's nobody helping us. So, [laughs] you know, most people would be anxious and depressed. It's, it's, come ... it's part of it, it's not instead of it. (*UKLC04)

> *"And, ah, I think during that process, because there was nothing wrong in my tests, it was implicated to me on multiple occasions that it's just anxiety. And, um, I do appreciate that anxiety is a real condition, and many people are suffering from it, and it's horrible. However, I don't think this really applies to me, because there was no reason for me to feel stress, other than not getting help, and not being really treated like this is a physical condition that is happening to me. (*AUSLC05)

> *[A] lot of people were getting, like you know, answers like, 'It's all in your head' [laughs]. It's like you're too, you're like, you know, anxiety is causing this kind of phantom symptoms. But like I knew that myself, I was the last person, one of the last person I think would create phantom symptoms, because I try to ignore my pain [laughs], and I try to power through with everything. So, yeah, after reading that [I didn't try to find a doctor].* (USLC20)

Analysis of participants' accounts suggested that when they were subject to doctors diverting their (or other long Covid sufferers') claims to candidacy in this way, it served to compound their suffering, could act as a barrier to further help-seeking and was referred to as medical "gaslighting" by some participants.

3.5. Validated or affirmed candidacy

Although examples of negative healthcare interactions were plentiful across participants' accounts, there was evidence of more positive help-seeking experiences from participants' perspectives. Participants placed great value on interactions where their claims to candidacy were validated and affirmed by healthcare professionals, even when people with long Covid acknowledged the lack of their own or collective medical knowledge of causes, prognosis and appropriate treatment pathways for long Covid. The following extracts demonstrate the strength of participants' responses to feeling they had been listened to, believed and taken seriously in healthcare encounters:

> *My GP is fantastic. He listens to me, he knows that I'm a healthcare worker myself [...] he doesn't have any answers, like he doesn't know what's going on either. But, but at least he hasn't told me it's all in my head, and that it's all anxiety, and he, you know, has been very clear that if I'm talking about it, then it's a real thing, and hasn't tried to dismiss me.* (AUSLC03)

> *I can't say enough about how amazing [appointment at post-Covid clinic] was. The doctor [...] is probably the best provider I've ever been in contact with. He just, he listened to absolutely everything I had to say, every weird symptom that I thought was unrelated. You know, he listened to everything and then would tell me, 'Nope, that's all part of it'.* (USLC10)

Participants also valued their candidacy being affirmed and validated by healthcare professionals referring to other patients with long Covid. For example, UKLC04 said a breathing specialist had told her she had worked with "*loads of long Covid*" patients with similar symptoms.

Alongside the importance of their claims to candidacy being listened to, validated and affirmed, participants' accounts suggested they also valued feeling that healthcare professionals were professionally curious about long Covid and engaged in trying to understand its mechanisms and how to treat it. UKLC04 said she had asked specifically to see a doctor at her primary care practice who was keeping up to date with emerging long Covid research. She stressed the need "*to have an open mind."* UKLC02 said it was important that honesty about what healthcare professionals did and did not know, was "*accompanied by an earnest wish to help me with it and keep helping me with it [...] and she's not going to abandon me halfway through*". Some participants indicated that they felt part of *a joint quest* for understandings and solutions alongside their healthcare professional. UKLC05 described this as "co-experting" and accounts provide evidence of the value of being treated as *partners* as their healthcare professional(s) tried to navigate a pathway to recovery:

> *[My GPs] have been absolutely brilliant in terms of responsiveness, supportive, kind of taking what I'm saying and acting on it but also kind of if I'm asking for, for stuff to be considered, like I say, I'm on that, that [social media] group, if I see something else the doctor isn't particularly aware of [...] and I propose that, she takes that away, validates it and comes back [...] there was no ... no need to convince her, like I explained honestly and frankly what I was experiencing. She could come back to me and say, 'Yeah, this is what I've heard from you. Do you agree?' [...] So, yeah, really kind of co-experting essentially, you're the expert on your own body, the doctor's the expert on what we can do about that.* (UKLC05)

> *[When I finally saw the long-haul doctor] that was so wonderful because it was just validation. Like, yeah, this is happening. You know, and he knew the right tests, and he knew the right meds to treat my symptoms. And, you know, why it was happening, and we even had conversation like because [...] there's lots of theories out there about why this is happening, you know, scientists and doctors and things that are addressing it. [...] So, you know, it was good to talk to him about it and him to understand. You know, that was, [um] helped with the fear.* (USLC17)

Participants' accounts also suggest that validated and affirmed candidacy should be reflected in the ways that healthcare services are provided for long Covid patients so that the burden of pursuing investigations and care does not fall on the patient. In particular, they felt it important that care pathways should be better coordinated and easier for people with debilitating fatigue and brain fog to navigate. UKLC02 suggested "*one person maybe having ownership over a patient's case*" would serve to smooth experiences for long Covid patients, and other participants from the Netherlands said they would have been helped by having support from a healthcare professional who acted as a "case manager". Similarly, UKLC06 suggested ways in which existing long Covid clinics could be improved:

> ... some of the clinics that have popped up [...] have an [occupational therapist], and a physio[therapist], and maybe a psychologist. And whilst those things can be helpful, you know, people [with long Covid] have acute medical problems. So having the different specialties, that are primarily affected [a neurologist, cardiologist and respiratory physician] would be really helpful, with a knowledge of, of what's going on, and how to treat.

4. Discussion

4.1. Summary of main findings in context

In this paper, we revisit and extend Dixon-Woods et al.'s (2006) concept of candidacy, by arguing that preceding patients' *individual* claims to candidacy is recognition of their condition through the generation of a *collective* candidacy by vanguard patients. We suggest that, whilst long Covid is a novel, emergent condition, the most salient aspects of candidacy are identificiation, navigation, permeability and particularly adjudication. Using data collected in 2020-2 from participants from five countries which were at various stages of the pandemic, we have shown many similarities across these countries in people's accounts of their experience of help-seeking for long Covid. Our participants' experiences of often bewildering, disabling, life-changing and fluctuating but persistent constellations of symptoms align with the findings of other studies and the growing understanding and recognition of long Covid (Subramanian et al., 2022). Vanguard patients' sense of reassurance as they experienced the realisation that they were neither alone nor "going mad" when they discovered others' similarly bizarre and unexpected experiences, largely through online communities, reflects other accounts of the early pandemic. Roth and Gadebusch-Bondio (2022, p1) describe the importance of a "collective gathering" of experience which transformed "patients' .. subjective experience [of long Covid] into a collective one"; Callard and Perego (2021) heralded the collective nature of the "patient-making" of long Covid; and Rushforth et al. (2021, p7) describe how their participants articulated "a rich description of the diverse manifestations of a grave new illness [and] a shared account of rejection by the healthcare system".

Here, we have argued that the experience of participants across several studies and countries can be understood as not just the making and naming of an emergent condition, but its transition from the unknown and invisible to the decipherable (Lian et al., 2021). Most prior work on candidacy (defined by Dixon-Woods et al. (2006, p1) as the process through which "people's eligibility for healthcare is determined between themselves and health services") has been conducted on known or established conditions (e.g. cancer and heart disease (Macdonald et al., 2016)), hence our highlighting of the generation of a *collective* candidacy which precedes *individual* candidacy. Long Covid has provided a real-time example of how this happens with new and emergent conditions, in this case a largely technologically enabled or accelerated patient-led generation exemplifying the increasing importance of digital interconnectedness of an emerging community of people with long Covid across social and national boundaries.

In considering how doctors negotiate uncertainty in clinical encounters, Lian et al. (2021, p7) note that "Illness is a life-changing experience that deprives the ill person from taken-for-granted routines and habits and reveals aspects of human existence that often go unnoticed. These experiences put us in a state of vulnerability". Our participants' accounts powerfully recount the disruption of the taken-for-granted because of their long Covid symptoms and the vulnerability that both vanguard and later patients with long Covid experienced as they attempted to navigate various healthcare systems in the midst of the pandemic, when healthcare systems (as many aspects of day-to-day life at a societal level) were themselves overwhelmed and disrupted. Lian et al. go on to suggest that in the face of medical uncertainty, "the main source of patient contention is the *ways in which doctors engage with patients, not the lack of biomedical knowledge per se*" (p7, emphasis added). Given the uncertainty inherent when emergent conditions have limited foundations in lay and professional epidemiological evidence, and the difficulties that many described in navigating what could seem like impermeable systems, at a time when many with long Covid have a dearth of physical, mental and cognitive resources, it is perhaps not surprising that their experience of healthcare professionals' adjudication of their candidacy (Dixon-Woods et al., 2006) is so strongly aligned with how negative or positive patients' experience of healthcare was. The people who felt dismissed, unheard, unworthy or invisible in their dealings with healthcare professionals (i.e., those whose candidacy was perceived to have been rejected after adjudication), described the most negative reactions (e.g., anger, frustration, hopelessness, dejection). The experience of "diverted" candidacy could be interpreted as an appropriate quest for alternative explanations, or a different kind of dismissal of people's experience. This had perhaps its most negative connotations when people felt that their symptoms were seen as being "just" a manifestation of anxiety or other mental health conditions. Being listened to, believed, validated and affirmed was experienced as positive by those who encountered this in their medical interactions - even in the face of healthcare professionals' professed uncertainty about the causes, consequences, best management and prognosis for long Covid. Its importance was strongly emphasised by the majority. The similarities internationally, in symptom stories and the impact of healthcare professionals' responses, underlie the particular importance of active and attentive listening and response in healthcare interactions for patients where care pathways, like the underlying conditions, are themselves emergent or medically unexplained.

It is pertinent to note, that our participants' accounts relate to times when many health systems were under extreme strain due to the demands of caring for hospitalised patients whose acute manifestations of Covid symptoms were life-threatening. For this reason, we suggest that it may make sense to interrogate other aspects of Dixon-Woods' candidacy framework (appearances, offers and resistance, and operating conditions and the local production of candidacy) when the acute disruption and overwhelming of health systems by Covid-19 has largely abated. In their study of the application of the construct of candidacy to understand access to secondary mental health services in the UK during the pandemic, Liberati et al. (2022, p1) discuss how macro-level changes affected identification of candidacy:

> "Macro-level changes, including an increased emphasis on crisis and risk management and adapted risk management systems, produced effects that went far beyond restrictions in the availability of services: they profoundly re-structured service users' identification of their own candidacy, including perceptions of what counted as a problem worthy of attention and whether they as individuals needed, deserved, and were entitled to care".

Arguably all negotiations of illness and health care are imbued with some moral undertone, and our data included many examples of patients acknowledging the strains on healthcare systems and staff imposed at the height of the Covid pandemic, and the undoubted needs (candidacy) of those who were suffering from life-threatening symptoms. These featured across the data, including in accounts (e.g. from the UK and US) where healthcare systems are very differently structured. This will be an important area to revisit in accounts of patients diagnosed with long Covid later in the pandemic.

5.2. Strengths and limitations of the study

A significant strength of our study is the use of identical rigorous methods of data collection in several countries (Ziebland et al., 2020). This has enabled the analysis of a large number of robustly collected and analysed qualitative interviews (n = 72). To our knowledge, this is the first study that has examined experiences of help-seeking amongst people with long Covid that has drawn on data from multiple countries, albeit four of them anglophone countries. We were also able to interview an ethnically diverse sample. Another strength is our iterative approach to analysis and verification of the analytical framework that we developed. As the analytical framework is the result of critical input from authors in countries with varied healthcare systems, it is likely to be generalisable to other high income countries. We recognise the need for comparable work on patient experience in low and middle income countries. A further strength is the identification and empirical substantiation of concepts, which has enabled us to contribute to theorisations of health and illness (e.g. vanguard patients, adjudication, collective candidacy, and individual candidacy as validated, diverted or rejected), including in relation to new and emergent illness.

One limitation of the paper is the differing number of interviews from participating countries. Covid as an emergent illness penetrated some countries (e.g. UK and USA) faster and more broadly than others (e.g. Australia), reflecting differences in public health control measures during early parts of the pandemic. Also, the nature of illness narratives is that they are, of necessity, retrospective and others have noted the ways in which narratives may be "honed" (Rushforth et al., 2021) as people with long Covid (as with other conditions) will have "rehearsed" their journey with long Covid through multiple recantations for both medical and non-medical audiences. On one hand, this could be interpreted as a limitation; alternatively, this can also be understood as the product of a long period of sense-making by participants. We acknowledge too that what patients take away from healthcare encounters may differ from the perspective or intent of the care provider. We also acknowledge that people who choose to take part in qualitative interview studies may not be representative of the wider population in various ways.

5. Conclusion

Paying close heed to the experience of vanguard patients and how they generate collective candidacy is paramount in the context of new, emerging and contested health conditions, as exemplified by the experience of people who developed long Covid at the earliest stages of the pandemic. This can not only alleviate the alienation and suffering of those with bewildering and disruptive constellations of symptoms, but may accelerate pathways to lay and medical knowledge about aetiology, management and recovery through a process of "co-experting". At the very least, professional adjudication of patient accounts that leads to them feeling listened to and believed (i.e. validates and affirms candidacy) may significantly improve patients' experiences, particularly whilst the science on pathways to recovery is being developed.

Author contribution statement

Alice Maclean: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing - original draft; **Kate Hunt**: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Validation, Writing - original draft; **Ashley Brown**: Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing - review & editing; **Jane Evered**: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Validation, Writing - review & editing; **Anna Dowrick**: Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing - review & editing; **Andrea Fokkens**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing - review & editing; **Rachel Grob**: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing - review & editing; **Susan Law** Supervision, Validation, Writing - review & editing; **Louise Locock**: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Writing - review & editing; **Michelle Marcinow**: Formal analysis, Methodology, Project Administration, Resources, Writing - review & editing; **Lorraine Smith**: Conceptualization, Formal analysis, Methodology, Project Administration, Resources, Writing - review & editing; **Anna Urbanowicz**: Formal analysis, Methodology, Project Administration, Resources, Writing - review & editing; **Nientje Verheij**: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing - review & editing; **Cervantee Wild**: Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing - review & editing.

Ethical review

UK: NHS Health Research Authority [IRAS 112111; minor amendments 22].

USA: The study was determined exempt by the University of Wisconsin-Madison Institutional Review Board.

Netherlands: Approved by the Central Review Committee of the Medical Ethical Committee (Research Registration Number 202100710).

Australia: Approved by University of Sydney Human Research Ethics Committee #2020/401.

Canada: Reviewed by Trillium Health Partners Research Ethics Board (Mississauga, Canada) ID#1003.

Declaration of competing interest

The authors have no competing interests to declare.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ssmqr.2022.100207.

References

Altmann, D. M., & Boyton, R. J. (2021). Decoding the unknowns in long covid. *BMJ, 372*, n132.

Callard, F., & Perego, E. (2021). How and why patients made Long Covid. *Social Science & Medicine, 268*, Article 113426.

Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing, 26*(3), 623–630.

Davison, C., Smith, G. D., & Frankel, S. (1991). Lay epidemiology and the prevention paradox: The implications of coronary candidacy for health education. *Sociology of Health & Illness, 13*(1), 1–19.

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology, 6*, 35-35.

Emslie, C., Hunt, K., & Watt, G. (2001). Invisible women? The importance of gender in lay beliefs about heart problems. *Sociology of Health & Illness, 23*(2), 203–233.

Kirkpatrick, S., Locock, L., Farre, A., Ryan, S., Salisbury, H., & McDonagh, J. E. (2018). Untimely illness: When diagnosis does not match age-related expectations. *Health Expectations, 21*(4), 730–740.

Lian, O. S., Nettleton, S., Wifstad, Å., & Dowrick, C. (2021). Negotiating uncertainty in clinical encounters: A narrative exploration of naturally occurring primary care consultations. *Social Science & Medicine, 291*, Article 114467.

Liberati, E., Richards, N., Parker, J., Willars, J., Scott, D., Boydell, N., Pinfold, V., Martin, G., Jones, P. B., & Dixon-Woods, M. (2022). Qualitative study of candidacy and access to secondary mental health services during the COVID-19 pandemic. *Social Science & Medicine, 296*, Article 114711.

Macdonald, S., Blane, D., Browne, S., Conway, E., Macleod, U., May, C., & Mair, F. (2016). Illness identity as an important component of candidacy: Contrasting experiences of help-seeking and access to care in cancer and heart disease. *Social Science & Medicine, 168*, 101–110.

Macpherson, K., Cooper, K., Harbour, J., Mahal, D., Miller, C., & Nairn, M. (2022). Experiences of living with long COVID and of accessing healthcare services: A qualitative systematic review. *BMJ Open, 12*(1), Article e050979.

Maxwell, E. (2021). *Living with long Covid19. Second review*: Nihr. Available at: https://evidence.nihr.ac.uk/themedreview/living-with-covid19-second-review/. (Accessed 31 August 2022).

Roth, P. H., & Gadebusch-Bondio, M. (2022). The contested meaning of "long COVID" – patients, doctors, and the politics of subjective evidence. *Social Science & Medicine, 292*, Article 114619.

Rushforth, A., Ladds, E., Wieringa, S., Taylor, S., Husain, L., & Greenhalgh, T. (2021). Long Covid – the illness narratives. *Social Science & Medicine, 286*, Article 114326.

Subramanian, A., Nirantharakumar, K., Hughes, S., Myles, P., Williams, T., Gokhale, K. M., Taverner, T., Chandan, J. S., Brown, K., Simms-Williams, N., Shah, A. D., Singh, M., Kidy, F., Okoth, K., Hotham, R., Bashir, N., Cockburn, N., Lee, S. I., Turner, G. M., … Haroon, S. (2022). Symptoms and risk factors for long COVID in non-hospitalized adults. *Nature Medicine, 28*(8), 1706–1714.

Wyke, S., Adamson, J., Dixon, D., & Hunt, K. (2013). Consultation and illness behaviour in response to symptoms: A comparison of models from different disciplinary frameworks and suggestions for future research directions. *Social Science & Medicine, 86*, 79–87.

Ziebland, S., Grob, R., & Schlesinger, M. (2020). Polyphonic perspectives on health and care: Reflections from two decades of the DIPEx project. *Journal of Health Services Research and Policy, 26*(2), 133–140.