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Working knowledge, uncertainty and ontological politics: An ethnography of UK long covid clinics

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Abstract

Long covid (persistent COVID-19) is a new disease with contested aetiology and variable prognosis. We report a 2-year ethnography of UK long covid clinics. Using a preformative lens, we show that multidisciplinary teams (MDTs) built working knowledge based on shared practices, mutual trust, distributed cognition (e.g. emails, record entries), relational knowledge of what was at stake for the patient, and harnessing uncertainty to open new discursive spaces. Most long covid MDTs performed the working knowledge of 'rehabilitation', a linked set of practices oriented to ensuring that the patient understood and strove to 'correct' maladaptive physiological responses (e.g. through breathing exercises) and pursued recovery goals, supported by physiotherapists, psychologists and generalist clinicians. Some MDTs with a higher proportion of doctors (e.g. cardiologists, neurologists, immunologists) enacted the working knowledge of 'microscopic damage', seeking to elucidate and rectify long covid's underlying molecular and cellular pathology. They justified non-standard investigations and medication in selected patients by

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co-constructing an evidentiary narrative based on biological mechanisms. Working knowledge was ontologically concordant within MDTs but sometimes discordant between MDTs. Overt ontological conflict occurred mostly when patients attending 'rehabilitation' clinics invoked the working knowledge of microscopic damage that had been generated and circulated in online support communities.

KEYWORDS
COVID-19, distributed knowledge, long covid, multidisciplinary teams, ontological politics, working knowledge

INTRODUCTION

Multidisciplinary teams and working knowledge

Working knowledge is complex knowledge that is built, shared and continually revised among a multidisciplinary team (MDT) going about their collective work. It includes the embodied knowledge of clinical experience and practice, various kinds of codified knowledge (e.g. clinical examination notes, test results and practice guidelines, much of which is stored on information systems and accessed digitally), relational knowledge (as in a clinician and patient 'knowing' each other), narrative knowledge (e.g. of the patient's history), and knowledge of the system (e.g. how to cross-refer). It also includes knowledge of what other team members have done (and plan to do), what they are likely to know and how far their contributions can be trusted.

Working knowledge is best studied ethnographically, since it is generated and put to use in real-world actions and interactions. Ellingsen and Monteiro (2003) used ethnography to study working knowledge among MDTs in four departments in a Norwegian hospital. They demonstrated that while the detail of such work differed between specialities, it was always collaborative, knowledge-intensive and involved heterogeneous elements including stories, emails, entries on electronic record(s), and the recounted views of experts beyond the team. Through deliberation involving narrativisation, negotiation, repetition and re-telling, teams explored possible diagnoses, interpreted test results and achieved the collaborative tasks of prioritising, clarifying and mapping what actions needed to be taken, when and by whom. Codified data sources served to record work and also organise, coordinate and delegate it.

Allen's (2014) ethnography in the UK showed that a key element of nursing work was producing 'trajectory narratives' which summarised not just the how the patient's history had unfolded but also the sequence of work done by different team members. Underland's (2010) ethnography of surgical teams in Norway found that much collective knowledge among MDTs developed locally and was built orally through trust and dependence; this oral format bypassed digital information systems and allowed efficient and timely exchange of patient information. Underland and Tjora (2016) showed how in MDT meetings, a 'collective clinical gaze' was

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constructed for each patient on the basis of clinicians' memories, documents, and a consensus-directed discussion among the team members present.

Working knowledge is enacted knowledge. In a classic ethnographic study on the ontology of atherosclerosis, Mol (2002) explored the knowledge that was brought into being as members of the clinical team went about their work. Surgeons, pathologists, nurses and patients all enacted different versions of atherosclerosis using different physical tools and artefacts. These enactments, Mol argued, were 'multiple'. Taken together, they contributed to a rich and layered understanding of what atherosclerosis *is*, and they were ontologically concordant (e.g. the surgeon would acknowledge the pathologist's reality if they were shown arterial plaques down a microscope). Mol and Hardon (2020) subsequently suggested that in some other diseases (notably, COVID-19), the perspectives of different experts can sometimes be ontologically *discordant* since, because of paradigmatic differences, '*even when, say, virologists, clinicians, physicists, epidemiologists, immunologists, economists and sociologists all use the term 'COVID-19', what they actually grapple with is not the same entity*' (page 1).

Timmermans and Buchbinder (2012) drew on the concept of ontological knowledge to show that clinical work in a US genetics clinic achieved ontological transformation of disease categories. In the case of neonatal screening for rare genetic diseases, the reality of clinical work produced a transformed understanding of what a genetic disease *is*—from a clearly-defined and known abnormality in the patient's DNA which produced a fixed phenotypic picture to a possible abnormality indicated by an ambiguous test result, producing variable (if any) clinical manifestations and a shifting picture over time. These authors introduced the term 'bridging work' to depict 'the many activities required to reconcile the promise of technologies with the realities of their implementation' (page 209).

Timmermans et al. (2017) later showed how a key element of working knowledge among MDTs in genetics clinics was the productive exploration of uncertainty. Genetic variants of concern whose significance was uncertain became the focus of collaborative deliberation and action; each variant was afforded its own evidentiary narrative, which was progressively revised based on evolving evidence, further testing, and updated interpretations as teams managed clinical cases. In another ethnography of genetics clinics in Belgium, Kuiper et al. (2023) highlighted how uncertainty in this context exhibited a *duality*: it could be both burdensome (denying the patient a definitive diagnosis) and productive (opening up a discursive space for considering possibilities) (Kuiper et al., 2023).

In sum, ethnographic studies have revealed the working knowledge of MDTs to be multifaceted, distributed, practical, relational, negotiated, emergent, more or less concordant, and constitutive of what a particular disease *is*. In this paper, we present an ethnographic study of working knowledge of a novel disease—long covid—whose ontological status has been a subject of controversy since it was first described by patients in 2020.

The remainder of this paper is structured as follows. In Section 'Long covid and the policy response', we give a brief history of long covid and the policy response to it in the UK (with brief mention of other countries). In Section 'Rationale, aim and research question' we list the rationale, aim and research question for our empirical study. In Section 'Methods', we describe an ethnography of 10 long covid clinics across the UK. In Section 'Results', we present data to illustrate how working knowledge is built and enacted by long covid MDTs and explore whether and how it is 'multiple'. Finally, in Section 'Discussion', we reflect on the implications of ontological concordance and discordance.

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Long covid and the policy response

Long covid is a term proposed by patients to describe persistent symptoms after COVID-19 infection (Perego et al., 2020). These include fatigue, breathlessness, palpitations, dizziness, pain, neurocognitive dysfunction ('brain fog'), sleep problems, exercise intolerance, functional disability in daily activities and reduced quality of life (Greenhalgh et al., 2024). The condition typically fluctuates and sometimes produces 'crashes' (profound fatigue and brain fog following physical or mental exertion).

The underlying pathological mechanisms which produce—in some but not all people following acute COVID-19—the symptoms of long covid are multiple and contested. Two explanatory discourses recur in the literature. One focuses primarily on the underlying physical pathology, which it depicts as complex but clearly and consistently demonstrated (Al-Aly & Topol, 2024). In lay language, susceptible people may not be able to kill the virus, and this, accompanied by an unhelpful over-reaction from their immune system, leads to chronic inflammation in the tissues and an abnormal clotting tendency in the blood. This damages the lining of small blood vessels so they do not transmit oxygen or nutrients efficiently, leaving organs such as the brain, peripheral nerves and lungs starved of the molecules they need to function. In this model, the disease becomes known via specialist investigations (e.g. blood tests, scans) which reveal or exclude organ damage. Psychological reactions are seen as secondary to the microscopic damage and resultant functional limitations.

The second explanatory discourse, sometimes referred to as 'biopsychosocial' (Thurner & Stengel, 2023), recognises the existence of biological changes but places greater emphasis on the patient's interpretation of sensory signals (e.g. what they perceive is going on when they feel pain or fatigue), psychological influences (e.g. the patient's personality and cognitive capability) and social ones (e.g. work pressure), which can, according to some versions of the model, combine to produce a downward cycle of confusing physical symptoms, mental anxiety and hopelessness, inactivity, deconditioning and social withdrawal. In this model, the disease becomes known primarily through various questionnaires ('patient reported outcome measures' or PROMs), which produce quantitative scores for different symptoms and functional abilities (Smith et al., 2024).

The ontological uncertainty described above (relating to what long covid is) leads to epistemic uncertainty (how the condition should be researched and investigated), therapeutic uncertainty (how it should be treated), temporal uncertainty (how long it will last in any patient), and ethical uncertainty (what is the right decision in any given case).

Long covid services in the UK, and linked research programmes, have been built on conflicting ontological assumptions.

By late 2020, long covid had been flagged in UK political circles as posing a major challenge for the National Health Service and the economy, with hundreds of thousands of people meeting the formal criteria for diagnosis, many unable to work and some unable to live without support (Office for National Statistics, 2024). NHS England invested £34 million to set up over 80 multidisciplinary long covid clinics in England and £90 million annually to run them. There was no dedicated funding for similar services in Scotland, Wales or Northern Ireland, though some localities established services anyway. Different clinical teams (e.g. respiratory, rehabilitation, pain, infectious diseases, cardiology) stepped forward to lead these services in different localities, so each clinic developed with a unique history, path-dependency and system constraints (Overton et al., 2023). There was initially wide variation in eligibility criteria and investigations and treatments offered, though approaches later converged to some extent.

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An interim clinical guideline, produced at speed in late 2020 (National Institute for Health and Care Excellence, 2020), was uncertain about diagnostic criteria, investigations, treatments and prognosis. Research to update this guideline and inform definitive service models was considered high priority. The UK National Institute for Health and Care Research allocated over £50 million in 2021–2022 to 19 studies covering basic science, epidemiology, diagnostic tests and drug trials. Similar investments were made in other countries.

Many studies are yet to report, but at the time of writing there is a sense of disappointment that few uncertainties surrounding long covid have been resolved through research. Despite hundreds of peer-reviewed papers, scientists and clinicians remain divided over fundamental ontological and epistemic questions such as whether long covid has a biological basis at all.

Rationale, aim and research question

In this paper, we put aside theoretical arguments about the 'facts' of long covid (which we recently addressed in a clinical article (Greenhalgh et al, 2024)) and refocus the research gaze on how the condition is managed in practice. Our particular interest for this paper was how MDTs amass and process an evidence base that is—variously—incomplete, conflicting, contested or non-existent. Our research questions were:

1. How is the working knowledge of long covid developed and enacted in MDTs?
2. How does this working knowledge vary among different MDTs?
3. To what extent are different ontologies of long covid (as enacted in clinics) concordant—and what happens when they are discordant?

METHODS

The LOCOMOTION study

The LOCOMOTION study, funded by UK National Institute for Health and Care Research, was a mixed-methods study from September 2021 to December 2023 which aimed to optimise clinical management of long covid. Eight clinics across England and one each from Wales and Scotland participated. Details of ethics and original study design have been published (Sivan et al., 2022). The 10 participating clinics are summarised in Table 1.

Ethnography was not part of the original design, partly because the study began mid-pandemic. The original plan proposed an online quality improvement collaborative in which participating teams met regularly to agree best practice, set performance goals and share data (Sivan et al., 2022). It quickly became evident that practice (e.g. referral criteria, patient pathways, assessment, treatment and monitoring) varied widely among participating clinics. Research evidence on these topics, while extensive, was hard to interpret and was often perceived as impossible or low-priority to implement locally. To explore these issues further, the study protocol and ethics approval were updated to include ethnographic visits (both online and in-person).

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TABLE 1 Details of participating sites.

Site (jurisdiction)	Brief description
A (England)	GP-led clinic linked to a teaching hospital. Large core MDT of allied professionals. Hybrid model (virtual or face-to-face).
B (Wales)	Hospital-based clinic run by a respiratory physician and clinical research fellow. No formal MDT support but links with the community recovery team.
C (England)	Entirely virtual community-based clinic jointly led by GP and OT. Large MDT of allied professionals.
D (Scotland)	Hospital and virtual clinic led by a clinical psychologist with a small MDT (infectious diseases consultant, OT, physiotherapist). Mostly virtual (video/phone).
E (England)	Hospital clinic led by respiratory consultant with small MDT (psychologist, OT, physiotherapist). Adjacent clinic run by cardiologist with interest in dysautonomia.
F (England)	Community clinic co-led by allied health professionals with large MDT. Offers virtual, face-to-face and online (group) sessions. Strong emphasis on rehabilitation.
G (England)	Originally a post-hospital respiratory follow-up clinic. Delivered by a large MDT with a weekly cross-speciality virtual meeting.
H (England)	Originally a post-hospital respiratory follow-up clinic; later, amalgamated with CFS/ME service. Nearby tertiary clinic is run by a cardiologist with a special interest in dysautonomia.
I (England)	Hospital service based in a rehabilitation department, led jointly by a rehabilitation consultant and a respiratory consultant. Large MDT oriented mainly to rehabilitation.
J (England)	Multi-tier service. Community clinic led by a GP does in-person assessments; a hospital-based clinic is led by a respiratory physician. Local and regional MDTs meet fortnightly.

Abbreviations: ME/CFS, myalgic encephalomyelitis/chronic fatigue syndrome; OT, occupational therapist; SLT, speech and language therapy.

Data collection

TG and EL (academic general practitioners) and JD (a qualitative researcher in the patient experience) attended 45 MDT meetings (almost all online or hybrid by Microsoft Teams; 49 h of observation). Staff were informed in advance and given the opportunity to object (nobody did). We noted brief demographic and clinical details of cases discussed, dilemmas and uncertainties discussed, and contributions of different staff members.

TG made 13 clinic visits, plus three additional visits to linked services (radiology, pathology, cardiac day unit), comprising 54 h of observation in total. Staff were notified in advance; all were happy to be observed. She shadowed clinicians as they saw patients (usually in a consulting room but occasionally in a gym, seminar room or office; some consultations occurred by telephone or video). Patients were approached by their clinician in advance and given the opportunity to decline (three of 53 patients approached did). After the patient left the room, and guided by our theoretical interest in working knowledge, TG asked the clinician to 'talk me through' particular actions or decisions she had just observed. When invited, she took breaks with staff and talked informally with them.

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Meetings and consultations were not recorded so as to interfere as little as possible with the dynamic. The researcher took notes and typed them up immediately afterwards.

Data management and analysis

Cases discussed in MDTs were logged on a spreadsheet listing age, gender and brief clinical and social details. Typed field notes were collated in a set of Word documents, one for each clinic attended. These were first thematically coded (e.g. flagging 'uncertainty' or 'tacit knowledge') and annotated with reflections to gain familiarity. The main analysis, however, took each patient case as a whole and considered how the concept of working knowledge as previously explored by critical ethnographers (Ellingsen & Monteiro, 2003; Kuiper et al., 2023; Mol, 2002; Nicolini, 2011; Underland & Tjora, 2016) played out and whether it contributed anything new to our emerging synthesis. Using the constant comparative method (Glaser, 1965), an initial synthesis based on the first few cases was refined as new cases were added.

An initial interpretation was written up, summarised in a Powerpoint presentation and shown to three audiences—clinic staff ($n = 15$), long covid patients ($n = 6$) and an academic conference audience in medical humanities ($n \sim 200$). The theoretical model was refined in response to feedback.

RESULTS

Overview of dataset

Clinics varied widely in geography, size, staffing, ethos, population served, modality of delivery and position in the local health economy. Five were located in respiratory outpatient departments, three in rehabilitation, one in infectious diseases and two in community services (Table 1). One was fully virtual (consultations were by telephone or video, with the patient's general practitioner asked to perform any in-person assessments needed). In two, the initial contact was via a long telephone call which served both a clinical function (to obtain a history) and a triage function (to pick up patients who could be referred directly to other specialities). Two clinics had close links with a local cardiology service interested in postural orthostatic tachycardia syndrome (POTS); several had links to specialist chronic fatigue services but in at least one site the long covid clinic *was* the chronic fatigue service. Most clinics were consultant-led; the community clinics were GP-led. In some localities, based on the judgement of the lead clinician (and reflecting team discussion), complex cases could be referred by the local 'tier 2' (community) or 'tier 3' (hospital) MDT to a regional ('tier 4') MDT which had additional specialist doctors (e.g. haematology, cardiology, neurology, psychiatry, immunology). 'Tier 1' refers to patient self-management.

TG observed 50 patient consultations in long covid clinics and TG, JD and EL observed MDT discussions on 244 cases. These 294 patients ranged in age from 18 to 87 (median 48; IQR 40–56); 61% were female. The most common presenting symptoms were fatigue and breathlessness, which often occurred together; many patients had multiple symptoms. Patients discussed at MDT meetings were a somewhat skewed sample: in most clinics, they were people who had not responded to a management plan or for whom a key decision (such as whether to conduct further tests) needed to be made. In just over half (56%) of patients presented in MDTs, one or

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more pre-existing medical diagnoses was mentioned, including asthma, diabetes, arthritis, allergies and mental health conditions; others may have had pre-existing conditions that were not mentioned. Of the 50 clinic patients observed, approximately two-thirds had pre-existing conditions. Contributing social factors (e.g. relationship difficulties, financial problems, history of abuse, loneliness) were flagged by staff in approximately one quarter of patients presented in MDTs and a similar proportion of those seen in clinics.

Below, we describe how working knowledge was constructed and enacted by MDTs and distinguish different kinds of working knowledge in the dataset.

Construction of working knowledge

MDTs drew on diverse knowledge sources, as illustrated by the following case example. As with all cases in this paper, it was compiled from field notes made at a MDT meeting for a long covid clinic and selected because it was illustrative of the dataset more widely. Staff names are pseudonyms and clinical details have been systematically fictionalised from multiple real cases (Willis, 2019).

> Staff present: Selma (senior respiratory consultant), Vic (newly-appointed respiratory consultant), Eleanor (psychologist), Olga (specialist nurse), Mark (GP), Fatima (physiotherapist), Gemma (community liaison psychiatric nurse).
>
> Olga introduces the case of Mrs Desai, a schoolteacher in her 50s who has had COVID-19 twice (35 and 21 months ago), though the first was unconfirmed. Each time, she had flu-like symptoms, cough, breathlessness, fatigue, altered smell and headache. The fatigue, cough and altered smell have persisted. She improved only minimally on pulmonary rehabilitation. Her history includes sarcoidosis [which can cause lung scarring and fatigue] and hysterectomy 3 months ago for heavy periods. A post-operative blood test showed borderline anaemia but there is no subsequent full blood count available. Olga reports that Mrs Desai was tearful and 'fed up', and said the cough disturbs her husband's sleep. A chest X-ray 5 months ago showed shadowing at the right lung base but no hilar lymphadenopathy. A chest CT scan showed—Olga reads from a report— 'patchy air space opacifications with bronchial mucus plugging and ground glass appearance'. Two months later, the patient had a chest MRI scan which was reported as normal.
>
> Olga directs her question to the respiratory consultants: 'Can we clarify what we need to do? Do we monitor her with another CT? Or do we say that since the MRI shows no sign of scarring, there's no lung damage?'
>
> After a pause, Vic admits 'I'm not sure. Selma, what do you think?'. They realise that Selma has lost connection so Vic ventures a response. 'I know you can get infections that show on CT but not MRI. Did she get antibiotics for her chest infection?'. There is silence while Olga looks through the patient's electronic record: yes, antibiotics were given before the MRI. Vic: 'Give me her hospital number and I'll look at the films'. Olga reads out the number and Vic accesses the relevant image. After studying it, he asks: 'Has she had any issues with swallowing or reflux?' Olga: 'Not that I'm aware of'.

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> Eleanor asks if there is any mental health history. Gemma, who (unlike the others) has access to the patient's community mental health record, says Mrs Desai was seen once, five years ago, for bereavement counselling after her mother died, and improved quickly. Mark asks if the sarcoidosis diagnosis was confirmed. Fatima says she has had an email from the sarcoidosis specialist confirming it and will forward that to him.
>
> Selma has regained connection. She gets up to speed with the story and explains that the clinic is taking part in a trial of multi-organ MRI imaging in long covid, so many patients get scanned. 'But MRI of the lungs is not a validated imaging tool. Because the lungs are full of air, there's not much to scan. If you're not careful, you end up chasing the MRI result instead of treating the patient! From what I know from our MRI experts here, the standard MRI just gives you an assessment of lung volume. To accurately look at the lungs with MRI, you need either a hyperpolarised view or a different gas'.
>
> Everyone nods. Selma has explained well and the way forward is clear: the patient's respiratory status needs to be re-assessed and a repeat CT scan done. Vic, who has already received Fatima's email, agrees to see Mrs Desai at his respiratory follow-up clinic.
>
> (MDT discussion, clinic C)

As expected from previous research on technology-mediated working knowledge (see Section 'Multidisciplinary teams and working knowledge'), there was evidence of codified knowledge (e.g. test results), narrative knowledge (e.g. how some but not all of Mrs Desai's covid symptoms had persisted), experiential knowledge (e.g. Vic has seen infections show on CT but not MRI), distributed knowledge (e.g. Gemma accesses a community record to which other team members do not have access and reads out an extract), knowledge of how far one's own knowledge and that of other team members could be trusted (e.g. Vic, who is relatively new, hesitates to answer Olga's question and his colleagues do not pick up on his tentative answer, but Selma's credible explanation is quickly mobilised to influence the plan), and embedded system knowledge (e.g. that patients with respiratory infections get followed up in the respiratory clinic, not the long covid clinic). There was also evidence of *relational* knowledge (Olga, who has heard Mrs Desai's story and witnessed her suffering, conveys elements of the patient's life-world and what matters to her). Through the discursive work of the MDT, these various knowledge fragments were rendered legitimate and credible, and transformed into a working knowledge that *enabled them to act* (Ellingsen & Monteiro, 2003).

Each knowledge element was assigned different weight and credibility depending on who presented it and how. Selma's caution about the MRI scan result, for example, is persuasive for several reasons. As the senior chest consultant and team leader, she is a highly credible source of this knowledge. She uses imagery ('the lungs are full of air') to illustrate that there is not much tissue to scan with a conventional MRI, narrativisation ('you end up chasing the MRI result') and invokes technical expertise from beyond the group ('our MRI experts here').

Guided by Olga (who frames the case) and Selma (who brings authority), today's MDT ignores Mrs Desai's fatigue and mental health history. But they pick up on the persistent troublesome cough and the mismatch between the recovery they had anticipated and the patient's actual course. By focusing on the chest imaging results and gearing most of the questions

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around those (e.g. whether antibiotics were given, whether the patient has had swallowing problems, which may indicate reflux), the MDT shapes a *collective clinical gaze* (Underland & Tjora, 2016) of a patient whose priority problem is a respiratory condition (most likely an infection) that needs further management rather than (for example) a fatigue and deconditioning problem needing rehabilitation. Findings that do not fit this evidentiary narrative (e.g. the normal chest MRI result, the possible anaemia) are discursively rejected.

The MDT's efficiency in shaping and channelling Mrs Desai's care is striking. Despite her multiple symptoms and complex history, the discussion takes less than 6 min and the question of 'what to do next' is answered to everyone's satisfaction. Of note is the clarity and brevity of the history given by Olga, whose role as lead nurse involves spending an hour documenting a detailed history from each new patient by telephone. TG's earlier observation of Olga's call to Mrs Desai revealed how she had used a structured electronic template flexibly, working skilfully with the patient to co-construct a narrative of how her multiple symptoms fitted together and had developed over time. In this initial call, Olga carefully characterised and probed each symptom ('what *kind* of headache?'; 'what exactly brings on these bouts of severe fatigue?') while also expressing empathy and compassion ('oo that must have been rotten for you'). She clarified which conditions and symptoms predated the infection, the nature of the acute COVID-19 illness (especially, number and severity of symptoms) and how things changed subsequently. At the end, she offered a draft summary and asked the patient to correct any errors and omissions (e.g. how long they had been off work). Through what Lynch et al. (2023) have called 'integrative wisdom', Olga produced an overview which she subsequently presented to the MDT not as a disconnected list of symptoms but as a coherent narrative which conveyed (at least to some extent) her relational knowledge of the patient's own perceptions about the illness and how it affects her life.

MDTs' working knowledge was also evident in individual clinical consultations, as clinicians accessed and incorporated their colleagues' contributions (e.g. by looking at entries on the electronic record or asking questions such as 'how did you get on with the psychologist?').

The duality of uncertainty

Our data revealed how uncertainty could be both burdensome and productive (Kuiper et al., 2023). The many uncertainties around Mrs Desai, for example, (see case example in Section 'Construction of working knowledge'), include whether the first episode of COVID-19 (before testing was widespread) was due to SARS-CoV-2; whether she has had sarcoidosis in the past and whether it is contributing to her failure to improve now; whether her 'borderline' anaemia test should be classified as abnormal; which aspects of her illness are causing the tearfulness and fed-upness; whether these indicate a mental health condition and if so how severe this is; the relative contributions of long covid, sarcoidosis, possible depression, recent surgery, anaemia, deconditioning and other factors to her fatigue; whether she has had antibiotics for her chest infection; whether a CT or MRI scan is better for assessing lung health; whether Vic's hesitant response to this last question should influence the MDT's decision or ignored as unreliable; and—the over-arching uncertainty around which the MDT discussion focuses—the ethical question of what best to *do* for Mrs Desai, given all the above.

Whilst some of these uncertainties are burdensome (it would be good to have a recent full blood count, for example, but the team will have to manage without it today), others are productive. For example, the mismatch between CT and MRI results does not close down

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discussion; on the contrary, it *opens up a discursive space* in which people raise questions about additional symptoms and treatments and are prompted to scrutinise other data on the electronic record. By the end of the 6-min MDT discussion, Olga's succinct articulation of the particular uncertainty on which the patient's management hangs has led the whole team to hone their collective clinical gaze and produce an agreed plan.

We identified several disconfirming examples where uncertainty appeared to play an entirely burdensome and distinctly unproductive role. In all such examples, the preconditions for generating complex, collective knowledge from multiple heterogeneous elements (e.g. multiple staff from different professional backgrounds, multiple knowledge sources including relational knowledge, mutual trust) were not met.

One disconfirming example involved a regular locum doctor who had never attended an MDT meeting. A consultation between this doctor and a patient with cough along with more than 20 other symptoms produced three pages of field notes (and a similar stream of clinical notes) without a coherent narrative. While the doctor showed knowledge and skill in her own specialist clinical area, she did not draw out the narrative of how the condition was affecting the patient or which issues were a priority for them, nor did she pick up on the various contributions of other team members that were documented in the electronic record. Each unexplained symptom or test result was managed without reference to the patient's many other symptoms or to the various knowledge fragments on the record. The patient left the clinic with a long list of further tests and referrals to three different specialities, and expressed confusion as they left the consulting room.

In a less extreme example, a small MDT of only two people (consultant respiratory physician and hospital-based respiratory physiotherapist) sometimes struggled with complex cases whose multiple dimensions might include mental health, speech and language, gynaecology or pregnancy, family relationships, return to work challenges, drug or alcohol use, and wider social issues. Whilst the pair met regularly to deliberate on all these (and more) issues, the knowledge sources to which they had direct access were fewer and more homogeneous, and in many cases the uncertainties remained even after lengthy discussion.

One final example of unproductive uncertainty occurred in an online tier 4 MDT meeting attended mainly by specialist doctors and the allied professionals on their teams; a general practitioner who normally attended was not present. Atypically, neither the person presenting the case nor other MDT members had personally met the patient. The case took more than 30 min to recount and discuss. It was unclear which of the patient's multiple symptoms were troubling them most. Again, the story came across as incoherent; the team found the question of 'what to do next' harder to answer; and the plan for next steps included multiple non-standard investigations and further referrals.

These disconfirming examples serve to underscore how working knowledge, collectively enacted across a diverse MDT, can sometimes produce highly efficient care of this complex condition and streamline investigations. Our findings support a crucial role for relational knowledge (of what is *at stake* for the patient) in reducing uncertainty and honing the clinical gaze in productive directions.

Working knowledge 1: Rehabilitation

> Mr Patel, a clerk in his 40s who has mild asthma, had COVID-19 27 and 9 months ago. The first episode included a brief hospital admission. He has had breathlessness

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and fatigue ever since. Mr Patel is discussed in the pre-clinic MDT, where the ground-glass patches on his chest X-ray are noted to be 'much improved' but there is concern about his scores on three symptom scales—Nijmegen [breathlessness] 27, Epsworth [daytime sleepiness] 15 and PHQ9 [depression] 15—all abnormal. In the clinic, he sees the respiratory physician, physiotherapist, occupational therapist and psychologist in turn. Colin, the physiotherapist, asks how he is feeling. Mr Patel says he used to walk four miles to work and back every day but now commutes by bus. He has trouble taking a deep breath, sighs a lot, and feels he can't breathe out fully. Colin explains that all this, along with his breathlessness score, points to a diagnosis of breathing pattern disorder (BPD): after a nasty infection, the body can get into an unhelpful pattern of 'upper chest breathing' rather than 'tummy breathing'. Correct breathing must be re-learnt. Colin will email him some exercises, and there is an online BPD course which he can join. Mr Patel is keen. Colin adds: 'Some of this is deconditioning. You've lost fitness. It's been years. You've got to give your body time'. Mr Patel then sees Angela (occupational therapist), who asks him which aspects of his job are the most demanding and whether he's asked for reasonable adjustments (e.g. shorter hours, working from home). She suggests self-referring to occupational health at work. He agrees he'll think about this. He moves on to see Anil (psychologist), who begins 'Usually when we get ill or injured, we get less happy and more worried'. Anil asks how long covid has affected Mr Patel's life. He replies that he's had to stop so many things ('I used to enjoy mowing the lawn at weekends'). Anil ventures that the lawn-mowing may have served as a 'meditative activity'. He explains there is an online mindfulness group as an alternative. Again, Mr Patel is keen to sign up. At the post-clinic MDT, the team share their assessments and agree that in view of the long duration of Mr Patel's symptoms, his recovery journey is likely to be slow.

(Clinic C)

MDTs in most long covid clinics enacted a working knowledge which we call 'rehabilitation', defined by the World Health Organization (2023) as '*a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment*'. They drew—usually implicitly rather than explicitly—on the biopsychosocial model introduced in Section 'Long covid and the policy response'. MDTs sought to help the patient understand the underlying biological processes that the virus had induced, re-learn some aspects of functioning (including overcoming altered physiological responses), and learn to evaluate and accommodate their own fluctuating limitations (especially through pacing—ensuing that they did not over-exert themselves physically or mentally, triggering a 'crash'). Most clinics either required or ordered some basic investigations (e.g. full blood count, chest X-ray). Whilst additional blood tests and imaging were ordered to pursue complications (such as infections) or comorbidities (such as heart failure), long covid itself was assessed and monitored primarily using symptom questionnaires. In some clinics, patients were sent six or more to complete before being seen, and MDT discussions were often codified in the jargon of these instruments and their subscales ('she's gone from 27 to 21').

The working knowledge of 'rehabilitation' mobilised to manage Mr Patel seemed to fit his lived experience and the interventions proposed by team members resonated with him. Many patients improved significantly on this approach (an audit in Clinic D, for example, showed that 92% of patients did) but some did not, as this fictionalised composite example illustrates:

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> Tina (occupational therapist) sighs as she reads from the lengthy electronic record of Mrs Gerraty, a care worker in her 40s we are about to see. The patient had COVID-19 30 months ago and has been severely fatigued with recurring migraines, joint pains and skin rashes ever since. There has been no improvement following an online group programme 'Managing Emotions in Long Covid', but she attended only two of 10 sessions. In the past she has signed up to multiple courses—pulmonary rehabilitation, yoga, mindfulness, pacing, cognitive-behaviour therapy ('she didn't engage')—and had various referrals and investigations, including neurology for the migraine. Today, she scores 21 on the PHQ9 test (suggesting possible depression) and speaks tearfully about three failed attempts to return to the job she had previously enjoyed. She rarely leaves the house now. In the past, Mrs Gerraty had a terrifying ordeal in a road traffic accident where she was trapped in a crushed vehicle unable to breathe properly. Tina listens patiently to Mrs Gerraty's sad story, which she has heard before, and explains that the unfortunate history of chest trauma has made it hard for her to re-learn normal breathing techniques.
>
> Mrs Gerraty, who is a member of an online patient community, wonders if she needs more allergy tests and another head scan (previous investigations were all normal). Later, Tina brings up the case at the MDT meeting. The consultant, Hamish, says 'Right, we should draw a line under physical tests unless something new comes up'. Tina agrees to send a letter to the GP and copy team members in, since 'Working out which team is doing what will be key'.
>
> (Clinic F)

In this case, the team has begun to enact the working knowledge of 'containment'—managing a disabling long-term condition by avoiding referrals and tests which would, they believe, be clinically futile, expensive for the service and potentially misleading. They work to ensure that all providers understand this strategy and convey the same message to the patient and their family.

Patients who were being managed with 'containment' typically had multiple persistent symptoms, had been unwell for years rather than weeks or months and had tragic stories to tell about lost hope and lives not rebuilt. Staff spent a long time listening to these patients' stories but rarely complied with their requests for further referrals or investigations, which they sometimes considered potentially harmful ('medicalising').

Working knowledge 2: Microscopic damage

> Dr Roberts consults by video with Mrs Manning, a 61-year-old woman with long covid and a complex history including diabetes, high blood pressure and depression. Mrs Manning has severe fatigue, brain fog, chest pains on exertion and multiple other seemingly disconnected symptoms. But Dr Roberts sees a pattern. She uses a 'dysautonomia checklist', whose many questions include: Does your heart race when you stand up? Do you have trouble regulating your body temperature? Do you find it harder to swallow your food? Do your legs change colour on standing? Do you sweat more than you used to? Do you get diarrhoea? The answer is yes to all. The patient is especially troubled by a racing heart and dizziness when she stands up.

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Dr Roberts explains to the patient that SARS-CoV-2 can damage the vagus nerve, affecting involuntary functions (e.g. heart rate, blood pressure, temperature regulation, gut movements); this is a form of dysautonomia (symptoms caused by damage to involuntary nerves). She adds that the virus can also interfere with the clotting cascade (various blood proteins), causing endothelitis (swelling of blood capillary linings). This process can block nutrient transfer to the heart muscle (which may explain the chest pain) and brain (which may explain the brain fog). She adds (to the researcher): 'The SGLT-2 inhibitors [diabetes tablets] she's on are endothelial stabilisers. She needs the clotting bundle and an Active Stand Test for POTS [postural orthostatic tachycardia syndrome]. I'll try her on metoprolol [a tablet to slow the pulse]'.

The following week, Mrs Manning attends the cardiac day unit in the city's main hospital. Nurses and junior doctors are busy conducting tests on each patient. These include blood (a 'bundle' of non-standard immunological and clotting tests), an electrocardiograph, and the Active Stand Test in which the patient lies flat for ten minutes and then stands for ten; pulse and blood pressure are measured every minute. If the heart rate accelerates more than 30 beats per minute on standing, this indicates POTS. Mrs Manning's Active Stand Test is positive. Dr Roberts prescribes a test dose of metoprolol (one-quarter the normal dose), which the nurses give; they take observations periodically for the next two hours.

Dr Roberts looks through Mrs Manning's test results, including a myocardial deformation imaging (MDI) or 'strain echo'. She explains that many long covid patients have a normal standard echocardiograph but the strain echo is more sensitive. Mrs Manning's has picked up narrowing of the small blood vessels supplying the heart muscle, suggesting microvascular angina (a rare form of angina that is difficult to detect by conventional tests). A new junior doctor, Ramesh, arrives on the unit; Dr Roberts introduces herself, explains which bloods go in which bottles, and offers to give a talk to Ramesh and his fellow junior doctors.

(Field notes, Clinic J)

This case is from a tertiary cardiology service specialising in POTS which takes referrals from the main long covid clinic locally as well as from other specialists and GPs. It illustrates the working knowledge of 'microscopic damage', which is explicitly biomedical, based on mechanistic reasoning about molecular and cellular processes, and oriented around specialised tests requiring advanced technical knowledge to interpret. The MDT is more hierarchical, with a clinical consultant (in this case, a cardiologist) making all the decisions, based on discussions with specialist colleagues such as radiologists, neurologists and pharmacologists; junior team members carry out the tests. Their collective working knowledge is built through practices on the day unit and didactic expert-to-novice teaching.

The evidentiary narrative constructed for each patient is typically complex, involving multiple biomarkers and speculation about molecular, cellular, endothelial and pharmacological mechanisms. Refining this evidentiary narrative can involve solving mysteries and explaining false clues (e.g. a standard test may be reported as normal, but a more sophisticated test is deemed necessary to confirm or exclude a particular pathology).

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Dr Roberts described Mrs Manning as 'POTS-y' (referring to the dysautonomic syndrome of postural orthostatic tachycardia) and also as 'coagulopathic' (that is, having a tendency to form blood clots). She explained that other long covid patients in this clinic were more 'MCAS-y' (referring to the acronym for 'mast cell activation syndrome', in which a particular sub-set of immune cells become over-active, releasing the chemical histamine and triggering various allergic pathways), requiring a low histamine diet and antihistamine medication. Others had a more autoimmune picture (in which the patient makes antibodies against their own tissues), requiring immune suppressant medication, or suffered 'MECFS' (myalgic encephalomyelitis and chronic fatigue syndrome, a disabling condition characterised by profound fatigue, possibly due to persistent viral infection and considered by some to overlap with long covid). Whilst each phenotype had a different causal pathway, said Dr Roberts, they overlapped and coexisted in many long covid patients.

The working knowledge of 'microscopic damage', with its associated specialist tests and mechanistic explanations, was rarely brought into play (and was sometimes actively dismissed) in the tier 2 long covid clinics. In contrast, some tier 3 and all tier 4 meetings, which featured multiple doctors from different specialities, were often centred on such knowledge as specialists suggested immunological, haematological or radiological investigations to help solve a mystery set of symptoms. Sometimes, the mystery would be solved through discussion but sometimes—especially when the relational knowledge component was sparse—the uncertainty remained and the presenting clinician was advised to order more tests or seek another specialist opinion.

Ontological conflicts among MDTs

While we did not encounter a single example of overt ontological conflict among staff *within* a MDT, members of particular MDTs sometimes emphatically dismissed approaches taken by *other* MDTs and services. This is illustrated by two contrasting examples from our dataset:

> Dr Roberts introduces me to a health professional in their 30s with disabling tachycardia on standing who has arrived in a wheelchair. We watch as the patient completes the Active Stand Test, which is dramatically abnormal, confirming (for Dr Roberts) the diagnosis of POTS. She is not surprised, and explains how the patient had been 'fobbed off' with a one-size-fits-all rehabilitation package in a previous clinic but needs to be fully investigated. 'Let's face it', she reflects, 'you can't 'rehabilitate' a thrombotic endothelitis!'.
>
> (Field notes, Clinic J [specialist cardiology])

> Dr Smyth presents the case of Mrs Jenkins, a care worker in her 50s with fatigue who has been seen in multiple specialist clinics, some privately. 'Cardio[logy] diagnosed POTS with sweet nothing in the way of evidence. They put her on ivabradine [heart drug]. It's annoying. When she came to us, we did the Active Stand Test. It was normal!' Some staff roll their eyes; some laugh. Donna, the occupational therapist, reports: 'Once we got down to the nitty gritty, she got tearful and said she was struggling. Cardio hadn't dealt with her fatigue or her mood or sort her return to work. So when that surfaced, we did all the long covid stuff: ENO [a breathing exercise programme], pacing, and cutting down her hours at work. She's miles better!'
>
> (Field notes, Clinic E [tier 3])

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The above quotes illustrate how 'rehabilitation' teams dismissed 'microscopic damage' enactments and vice versa. But it is worth commenting that the Active Stand Test for POTS, initially dismissed by many of the former teams as 'over-medicalising' patients, gradually became more widely used in most 'rehabilitation' clinics. However, staff in such clinics tended to explain abnormal Active Stand Test results using biopsychosocial terminology (e.g. in terms of altered physiological feedback loops) rather than in terms of microscopic damage to the autonomic nerves (as in Dr Roberts' 'damage to the vagus nerve' in Section 'Working knowledge 2: Microscopic damage' above).

The working knowledge of patient communities

Many patient participants were members of online long covid communities, which had emerged early in the pandemic at a time when doctors were unfamiliar with this new condition. Communities included a high proportion of health and care professionals, reflecting the demographics long covid, and were heavily skewed to university-educated white women (Ziauddeen et al., 2022). The heterogeneous knowledge generated and published by these communities included narratives of complex and fluctuating symptom patterns (Perego et al., 2020; Rushforth et al., 2021; Russell et al., 2022), online symptom surveys (Ziauddeen et al., 2022), and practical suggestions for how to deal with 'medical gaslighting' (the term used by patients to convey clinicians' power-charged dismissal of their symptoms or explanations) (Au et al., 2022; Russell et al., 2022).

Broadly speaking (but not invariably), online long covid communities enacted a 'microscopic damage' working knowledge, reflecting previous findings that people with contested diseases often seek biomedical explanations for legitimacy (Dumit, 2006). Our dataset contained many examples of patients who invoked such knowledge to request additional tests geared to elucidating a personal evidentiary narrative of molecular and cellular causes for their symptoms (see example of Mrs Gerraty in Section 'Working knowledge 1: Rehabilitation'). Some patient participants (mostly doctors or scientists) were already taking steroids, antihistamines, anticoagulants, immune suppressants or antivirals, variously sourced.

Others were keen to obtain these drugs from long covid clinics. One scientist patient, for example, sent several emails to the lead consultant asking them to reconsider prescribing an off-label immunosuppressant drug for brain fog that had been turned down previously. The scientist set out what they felt was a highly plausible biological mechanism for why the drug might work, citing a particular class of receptors on microglial cells (in the brain) and an impact on regulatory T cells (in the immune system).

Such requests for mechanism-based tests and treatments were generally viewed as inappropriate by clinicians working to a rehabilitation logic. In contrast, clinicians who worked in specialist clinics were often sympathetic to them, though not uncritically so; some disclosed that they were members of online long covid communities themselves because they or a family member had (or had had) the condition.

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DISCUSSION

Summary of main findings

This ethnographic study has revealed how MDTs in most long covid clinics built working knowledge by combining multiple kinds of formal and informal knowledge and harnessing uncertainty to open up discursive spaces. The working knowledge performed in most such clinics was 'rehabilitation', supported by physiotherapists, psychologists and generalist clinicians. When patients showed little or no improvement, the team either shifted to 'containment' or referred the case to a more biomedically-oriented MDT. In the latter, which invariably featured the epistemic power of several specialist hospital doctors, team actions and interactions followed the working knowledge of 'microscopic damage', predicated on an assumption of physical pathology at molecular level and used to justify extensive specialist investigations and pharmacological interventions.

A novel finding from this study, which we believe has far-reaching implications for services, was that *relational* knowledge of what was at stake for the patient was crucial to drawing out a unique trajectory narrative to inform management of long covid's complex and varied manifestations. Absent such knowledge, both the evidentiary narrative and the answer to the question 'what to do next?' were often unclear.

Comparison with previous literature

Our findings affirmed many of the features of working knowledge previously demonstrated by others (see Section 'Multidisciplinary teams and working knowledge'), including its collaborative and heterogeneous nature (Ellingsen & Monteiro, 2003), the key role of narrativizing (Allen, 2014), the importance of interpersonal trust (Underland, 2010), and how a collective clinical gaze could be honed through discussion (Underland & Tjora, 2016). Building on work by Underland (2010), we have shown that oral knowledge-building can occur very effectively in the virtual environment, where participants can bring codified knowledge into play rapidly by accessing electronic resources (e.g. a stored report), reading out selected extracts and using narrative and imagery to make these knowledge fragments credible and relevant. The oral medium and informal ethos of MDTs also allowed members to convey relational knowledge about the extent of suffering and what was at stake for patients and their families.

We also affirmed previous findings that uncertainty may play a productive role in MDTs by prompting collective reflection and abductive reasoning (Kuiper et al., 2023; Timmermans et al., 2017). Patients often had dozens of different symptoms which waxed and waned unpredictably, and many had comorbidities. MDT discussions were typically focused on creatively surfacing and exploring various kinds of uncertainty. These discursive spaces sometimes facilitated and legitimised the integration of tacit and relational knowledge with codified knowledge such as symptom questionnaires. In specialist tertiary centres, multiple biomarkers were routinely measured but—as Timmermans and Buchbinder (2012) showed in genetics clinics—the meaning of these test results was often uncertain (a 'normal' result may be a false negative; an abnormal result may not correlate with the clinical picture). Hence, these biomarkers had to be interpreted along with physiological tests and the patient's narrative to produce a mechanistic explanation of what was *possibly* or

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probably going on at microscopic level, which then guided the choice of further tests and treatments.

Building on work by Mol (2002) on ontological concordance in atherosclerosis and by Mol and Hardon (2020) on ontological discordance in COVID-19, we showed a high level of ontological concordance *within* any particular MDT (all members were broadly aligned on the kind of working knowledge enacted, at least overtly) but marked discordance *across* MDTs (see examples in Section 'The working knowledge of patient communities'). The main source of overt ontological conflict in our dataset was when patients invoked the 'microscopic damage' working knowledge of an online community to request tests and treatments that clashed with the 'rehabilitation' working knowledge being enacted by clinic staff.

In these days of patient-centred research and experience-based service design, and in the face of evidence of microscopic damage in long covid (Al-Aly & Topol, 2024), it is tempting to conclude that the rehabilitation working knowledge in play in most clinics is ontologically deficient, anachronistic and should be replaced with a more biomedical approach. However, an alternative perspective is that the working knowledge of rehabilitation does not deny the existence of damage; it just centres the clinical gaze and the work of the team on the whole person rather than the endothelium. The key clinical question, perhaps, is 'in which patients, and to what extent, does the clinical gaze need to shift to a more mechanistic, molecular level of explanation?'.

Conclusion

More than four years into the COVID-19 pandemic, long covid remains a poorly understood condition whose origins and management are bitterly contested. The working knowledge of 'rehabilitation' enacted in most long covid clinics leads to significant improvement in many patients. But it is now evident that long covid plays out as an intractable long-term condition in some patients. A proportion of these are referred to a specialist clinic (e.g. POTS) or discussed at hospital based, biomedically oriented MDT meetings, leading to further investigations and mechanism-driven management using the working knowledge of 'microscopic damage'. For others, the management logic shifts from 'rehabilitation' to 'containment'.

This ethnographic study was not designed to answer the question of how patients with long covid should be managed clinically. However, our findings suggest that further work on clinical pathways and referrals within the service, particularly for patients who are not responding to rehabilitation, might take on board how particular well-established patterns of working knowledge within an MDT could limit the productive harnessing of uncertainty and the options considered in particular cases.

AUTHOR CONTRIBUTIONS

Trisha Greenhalgh: Conceptualization (lead); data curation (lead); formal analysis (lead); funding acquisition (lead); investigation (lead); methodology (lead); supervision (lead); visualization (lead); writing – original draft (lead); writing – review & editing (equal). **Julie Darbyshire**: Data curation (equal); investigation (equal); writing – review & editing (equal). **Emma Ladds**: Data curation (equal); investigation (equal); writing – review & editing (equal). **Jackie Van Dael**: Methodology (equal); writing – review & editing (equal).

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DATA AVAILABILITY STATEMENT

Qualitative data are available to research teams on reasonable request.

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