

Long COVID as a Revealer of the Vulnerabilities of Contemporary Medicine*

Between Invisible Illness, Scientific Uncertainty, and Health-System Failure

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Abstract

Long COVID is a major revealer of the contemporary vulnerabilities of medicine and health systems. Drawing on clinical experience in family medicine and the longitudinal follow-up of a cohort of more than 450 patients with persistent post-COVID symptoms, this paper examines the changes that this illness imposes on clinical practice, the production of medical knowledge, and the social recognition of suffering.

Long COVID is characterised by multisystem symptoms, often neurocognitive, fluctuating, and difficult to objectify using standard biomedical tools. This situation restores the central importance of the clinical narrative and calls for a renewal of narrative medicine, not merely as a relational tool but as a genuine instrument for producing medical knowledge. When biological biomarkers remain insufficient, patients' accounts themselves become clinical material that can be structured.

The paper therefore introduces the concept of a *terminological biomarker*: a biomarker derived from the semantic structuring of patients' verbatim accounts using clinical ontologies and artificial intelligence. Through the Human Phenotype Ontology (HPO), subjective narratives can be transformed into organised, interoperable, and quantitatively analysable phenotypic data. This opens the way to reverse translational medicine, moving from the patient's narrative towards biological models.

In this context of chronic uncertainty, family medicine regains a central role. Because it works through biographical continuity, narrative listening, and the simultaneous integration of biological, psychological, cognitive, and social dimensions, it appears to be one of the few settings capable of maintaining overall clinical coherence.

Long COVID thus calls for a reconsideration of medical practice from a syndemic perspective, simultaneously connecting the biological, social, economic, cognitive, and political dimensions of illness. The family physician becomes not only a clinician and care coordinator but also an agent of social recognition, a manager of uncertainty, and a contributor to the production of clinical knowledge.

Keywords: Long COVID; narrative medicine; terminological biomarker; family medicine; syndemic approach; quaternary prevention; clinical ontologies; artificial intelligence; medical uncertainty; invisible illness.

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1 Long COVID reshapes the doctor–patient relationship

Long COVID is probably one of the most unsettling medical phenomena of the early twenty-first century. This is not only because it combines extensive suffering with an incomplete scientific understanding, but above all because it simultaneously challenges several implicit foundations of contemporary medicine: evidence, specialisation, the authority of medical knowledge, the doctor–patient relationship, and even the ability of health systems to recognise an emerging disease promptly.

Paradoxically, however, this profoundly disruptive character is also what makes Long COVID scientifically productive. Diseases that challenge medicine are often those that drive it forward. As Thomas Kuhn showed, persistent anomalies that resist dominant interpretative frameworks ultimately lead to the reorganisation of scientific knowledge [1]. By forcing clinicians to move beyond established categories, reconsider their standards of evidence, and rediscover the importance of longitudinal listening, Long COVID both exposes the current limitations of biomedicine and may drive its evolution.

Long COVID, a term initially coined by patients themselves [2], immediately emerged as an invisible illness [3, 4]. It is invisible not because it is imaginary, but because it largely eludes conventional forms of biomedical objectification.

In the aftermath of the pandemic, like many family physicians, I gradually began seeing patients with unusual, fluctuating, sometimes severe clinical presentations that were often difficult to interpret within conventional diagnostic frameworks. What was striking was not merely the diversity of symptoms but the remarkable convergence of their accounts: post-exertional fatigue, fluctuating cognitive disturbances, sensory hypersensitivity, dysautonomia, exhaustion after minimal exertion, sensations of profound energy depletion, and extreme variability in clinical condition within a single day.

Most often following severe or mild acute COVID, and sometimes even after an exposure that had gone unnoticed, patients experience a major biographical disruption in Bury’s sense [5], abruptly interrupting life plans, social activities, and professional identity.

Patients report unexpected cognitive disturbances, extreme fatigue, post-exertional malaise, dysautonomia, diffuse pain, sensory hypersensitivity, and digestive, inflammatory, cardiovascular, or neurological symptoms [6–8]. Few illnesses have generated so many concordant descriptions [9–11] while exposing how poorly prepared health systems were to recognise the lasting consequences of an infection initially regarded as essentially acute [12].

Yet standard medical investigations often yield reassuring results. Biomarkers are unstable or insufficiently sensitive. Conventional imaging may remain normal despite major functional collapse [10, 13]. The paradox becomes almost cruel: the more medicine investigates, the less capable it may sometimes seem of recognising the patient’s illness.

Current diagnostic systems appear to identify fewer than half of cases, thereby obscuring the considerable burden of this chronic illness [14].

The disruption therefore lies not only in the disease itself but also in what it reveals about contemporary medicine: a medicine that performs well when biomarkers are stable or classifications established, but is far more vulnerable when confronted with fluctuating, multisystem symptoms that biological tests fail to detect adequately.

Long COVID thus creates an unusual epistemological situation: patients often describe their illness more consistently than medical categories describe it. This reversal profoundly alters

the traditional balance of the therapeutic relationship. It shifts the centre of gravity of clinical practice towards narrative, longitudinal observation, and the acceptance of uncertainty.

Despite increasing numbers of technical investigations, many patients primarily describe a relational experience of clinical disbelief and invalidation of their lived experience [15]. In this space of uncertainty, clinical listening once again becomes central.

In this sense, Long COVID is not merely a new disease. It is also an epistemological challenge for modern medicine—and perhaps an opportunity for transformation.

1.1 Quaternary prevention and acceptance of uncertainty

By calling for attentive listening to patients’ narratives, Long COVID gives renewed urgency to quaternary prevention. Emerging from reflection on the doctor–patient relationship, quaternary prevention seeks to protect patients from the excesses of medicine: overdiagnosis, overtreatment, unnecessary investigations, false positives, and the excessive medicalisation of life [16, 17]. As incorporated into the WONCA Dictionary of General/Family Practice, it concerns action taken to identify patients at risk of overmedicalisation, protect them from invasive interventions, and offer care that is scientifically and ethically acceptable [18].

In Long COVID, however, the problem takes on a more complex form. Patients feel severely ill but most physicians do not acknowledge their illness. Their lived experience of suffering is silenced, minimised, or even actively denied; many report not being believed and having their symptoms wrongly attributed to psychological causes [15].

The danger lies not only in too much medicine, but also in the medical system’s inability to recognise a disease whose biological characterisation remains incomplete.

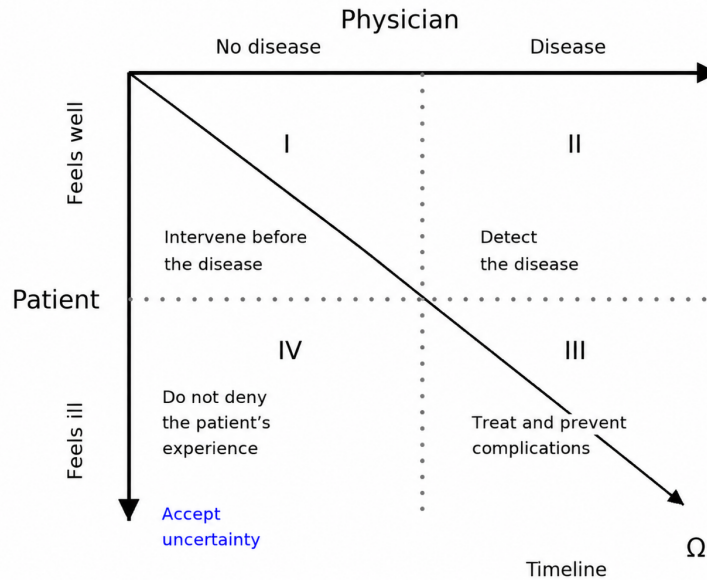


Figure 1: Four fields of the doctor–patient encounter, based on the relationship between lived experience and medical recognition [16]. Physicians seek evidence of disease, while patients may experience illness. Time runs obliquely from left to right, from alpha to omega, from birth to death. Everyone will become ill and die, physicians and patients alike.

In Fig. 1, prevention refers to actions undertaken by physicians to anticipate disease, limit its consequences, or prevent harm caused by care itself. The fourth quadrant represents a more

unsettling situation: patients feel ill while physicians cannot establish the presence of disease. The task is neither to deny the patient's experience nor prematurely resolve diagnostic uncertainty, but to accept the provisional limits of medical knowledge while maintaining recognition and supportive clinical care.

Patients consult because they suffer intensely: exhaustion, cognitive disturbances, diffuse pain, sensory hypersensitivity, or disorganisation of bodily and neurocognitive functions. Yet routine tests are often normal or inconclusive. Medicine enters an especially uncomfortable area of uncertainty.

Two responses are possible. The first is to turn scientific uncertainty into doubt about the patient. In the absence of stable biomarkers, symptoms are gradually psychologised, suffering trivialised, or the illness relabelled as anxiety, burnout, depression, somatisation, or a functional disorder. The result may be a clinical false negative: the disease exists, but the medical system temporarily fails to recognise it.

The second response is to tolerate diagnostic uncertainty without abandoning scientific rigour. As Malterud and colleagues remind us, uncertainty is intrinsic to the nature and complexity of clinical knowledge [19]. Medical history is full of examples in which clinical observation preceded knowledge of pathophysiological mechanisms [20]. Remaining genuinely curious in the face of what is not yet understood is therefore essential.

From this perspective, quaternary prevention means not only avoiding unnecessary examinations and treatments. It also means preventing the harm caused when medicine denies a clinical reality it cannot yet fully objectify [21].

Long COVID thus highlights a deep tension between scientific medicine and the social demand for certainty. When medicine loses its capacity to generate stable explanations, beliefs tend to reappear. An especially unstable space emerges:

- medical denial on one side;
- exaggerated or pseudotherapeutic promises on the other;
- between them, patients desperately seeking a coherent explanation of their suffering.

The family physician's role is essential: neither denying illness for lack of sufficient evidence nor abandoning critical standards, but accepting the limits of current medicine, recognising suffering without inventing false certainties, and sustaining a viable clinical relationship despite uncertainty. Maintaining an investigative stance therefore becomes a particularly rigorous form of science and patient protection.

1.2 From *illness* to *disease*: the elusive recognition of *sickness*

Long COVID often begins as a solitary experience of suffering. Patients know they are ill, yet this reality has no fully recognised place in medical or social categories. The classical distinction between *illness*, *disease*, and *sickness* in medical anthropology is especially relevant here [22].

Illness denotes the lived experience of being unwell: fatigue, cognitive disturbance, internal disorganisation, and loss of self. *Disease* denotes the medical recognition of this suffering as a legitimate clinical entity. *Sickness* denotes social and institutional recognition: the right to rest, social protection, recognition of disability, and professional and administrative legitimacy.

Amid this social and administrative uncertainty, the family physician is often one of the few mediators of recognition. Through continuity of care and biographical proximity, the family

physician can recognise the overall coherence of symptoms that remain scattered across hospital specialties. Where tests are partly normal and specialists see fragments, the generalist can recognise a pathological trajectory.

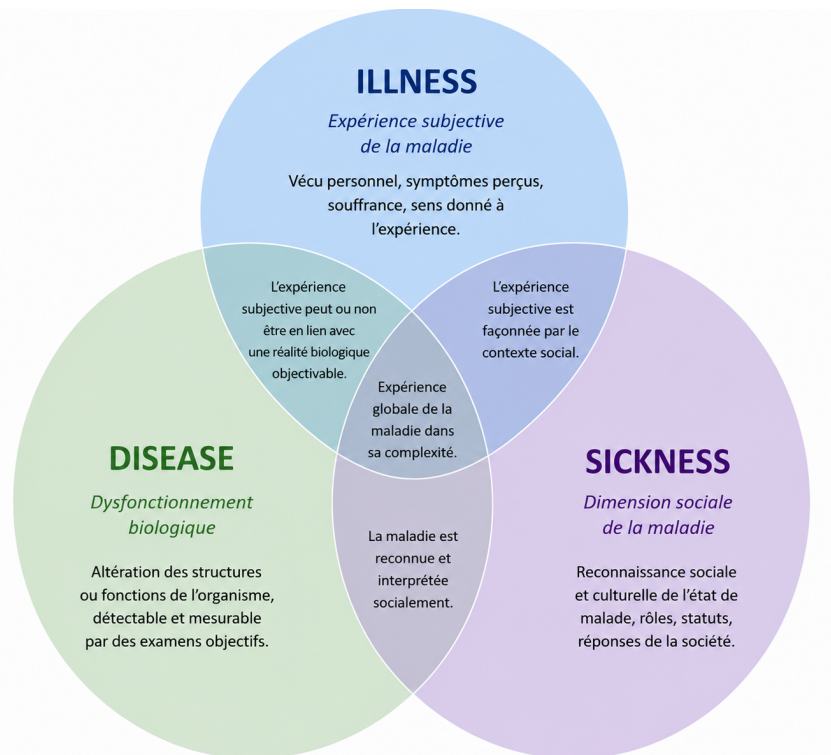


Figure 2: Integration of *illness* (experienced illness), *disease* (medically identified disease), and *sickness* (socially recognised illness), following the anthropological approach of C. Helman [22].

Naming the disease is therefore a major medical act. Writing “Long COVID” in a record, certificate, or report does more than transmit clinical information: it helps move patients from private suffering into recognised medical existence. Medical anthropology has shown how naming and recording a condition gives it social existence. The family physician thus helps transform *illness* into *disease*.

Yet medical recognition does not guarantee *sickness*. Many patients now have a diagnosis without adequate recognition from employers, insurance providers, administrations, or even relatives. They remain precariously recognised medically and insufficiently recognised socially for their suffering to acquire full collective legitimacy.

The family physician’s role extends beyond prescribing and coordinating care to defending the patient’s social legitimacy. Through certificates, reports, disability applications, and exchanges with insurers, employers, and public agencies, physicians contribute to the patient’s right to *sickness*: the right to be socially regarded as genuinely ill.

This function is far from secondary. In societies organised around performance and productivity, institutional recognition of incapacity becomes an issue of power, legitimacy, and sometimes economic conflict. Family medicine therefore involves not only treating disease but also protecting some patients’ very possibility of existing as ill people within society.

2 Long COVID: a socially differentiated disease

Long COVID is not invisible only in a biomedical sense. Its invisibility is also social, because the resources needed to secure recognition are unequally distributed, and epistemic, because classical medical categories still struggle to describe this new condition adequately.

Gender and the invisibility of suffering

Approximately two thirds of patients in our cohort are women, a predominance also described in many studies [23, 24]. Many had spent years establishing themselves in demanding workplaces still shaped by masculine norms of uninterrupted performance, constant availability, and endurance.

Many held positions with high cognitive and relational demands: teaching, healthcare, research, management, administration, intellectual or technical professions. Their social identities were built around competence, autonomy, and the ability to sustain multiple professional and family responsibilities simultaneously.

Then, suddenly, body and mind collapse (Fig. 3). Post-exertional fatigue, cognitive impairment, diffuse pain, and neurological or cardiovascular fluctuations make previously ordinary tasks impossible. Some can no longer attend a meeting, teach for a full day, manage several streams of information, or sustain a stable social presence.

The disease causes a double disruption: they become ill and may also lose the social status they worked for years to achieve. Box 1 illustrates how violently this disruption can be experienced by women who previously struggled to gain professional legitimacy in institutions still marked by implicit gender relations.

Box 1. Patient's words illustrating experienced violence. Woman with Long COVID since 2020

"I am an export manager ... but now I am mentally disabled."

"I was dying alone at home and I felt abandoned."

"The first doctor from the health insurance fund actually shouted at me."

"I could see that nobody was helping me."

"For two years I have felt like a victim of the healthcare system."

"You do not exist; you are nothing but shit."

Dr Jamoulle. Consultation, 2026.

These accounts highlight persistent difficulty in acknowledging women's suffering when it does not fit readily visible biological frameworks [25]. Fluctuating, multisystem, difficult-to-measure symptoms may reactivate historical patterns in which women's complaints are readily psychologised, minimised, or assigned to emotional categories.

Some patients describe progressive social demotion: loss of professional credibility, reduced responsibilities, isolation, partial economic dependence, and even doubts about their own bodily perception after repeated consultations that invalidate their experience. Long COVID thus reveals not only the impact of chronic disease but also persistent social, professional, and epistemic vulnerabilities affecting women.

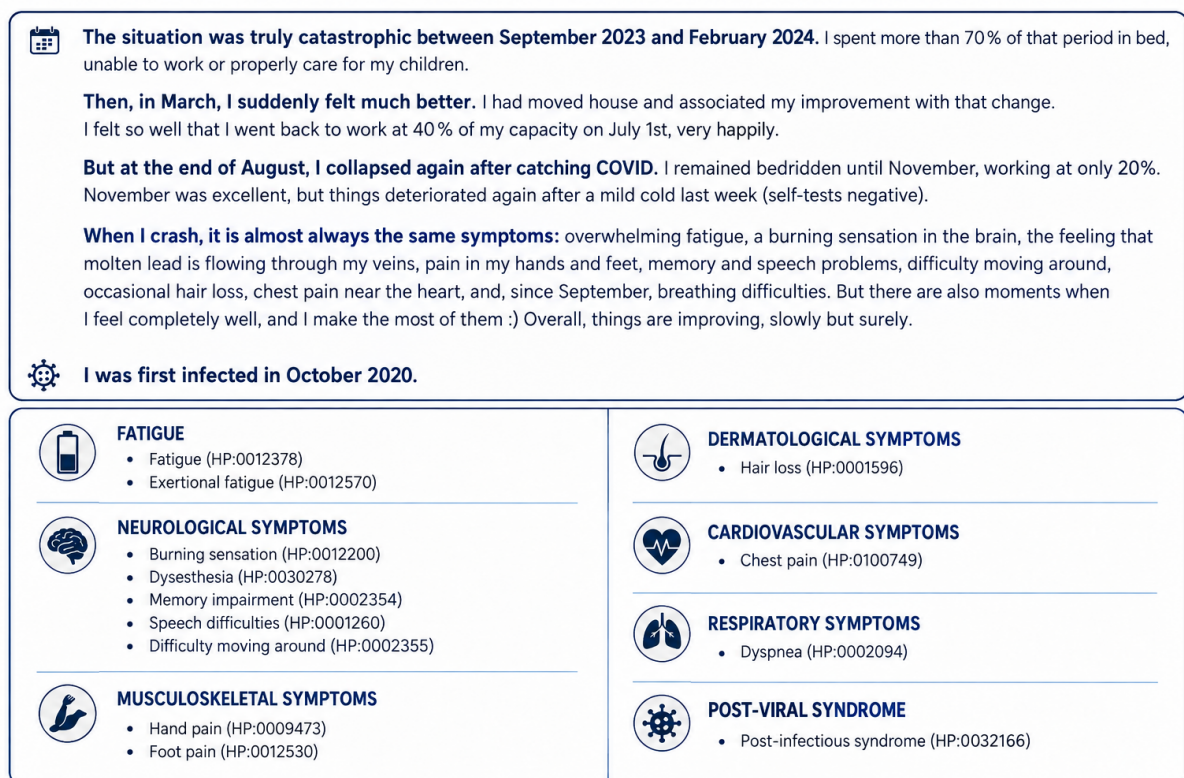


Figure 3: Email received in December 2024 from a woman entering her fourth year of Long COVID. An engineer and mother, previously in excellent health, she developed acute COVID-19 in October 2020 with interstitial pneumonia and pericarditis, followed by further acute episodes. Symptoms reported in the email were identified and classified using the Human Phenotype Ontology (HPO) [26] with ChatGPT-4o. The alphanumeric HPO codes may contain errors.

Inequalities in social and cognitive visibility

Long COVID affects all social groups, but its visibility varies with patients' cultural, professional, and linguistic resources. This inequality is particularly evident in cognitively demanding professions: teachers, researchers, engineers, physicians, lawyers, computer scientists, managers, and advanced students. The disease directly impairs the functions on which their professional identities depend: attention, working memory, cognitive endurance, organisation, processing speed, and multitasking.

These losses are quickly noticeable because they undermine the ability to think, teach, write, decide, or organise. Many recognise the depth of their neurocognitive impairment early and resist reductive diagnoses of burnout, anxiety, or depression, knowing their condition goes beyond ordinary psychological distress.

Paradoxically, their ability to describe deficits precisely may help them obtain medical recognition sooner. They often possess the linguistic, administrative, and cultural resources needed to make their suffering intelligible to institutions.

Socially vulnerable people, by contrast, often face much greater difficulty securing recognition of their decline. They may have fewer means to describe cognitive fluctuation, post-exertional exhaustion, or functional limitations. Their suffering is more easily reduced to vague or psychologising categories: fatigue, fragility, lack of motivation, personal problems, or emotional disturbance.

Biological invisibility is thus compounded by social and linguistic invisibility. The ability to secure recognition partly depends on being able to name one's own internal disorganisation precisely [2, 3].

Children and adolescents: when illness prevents becoming

And then there are the young.

Approximately 10% of our patients were under twenty at disease onset. Their situation is particularly tragic. Adults losing short-term memory still possess an established past: education, accumulated experience, and a relatively stable identity. But when children or adolescents lose attention, memory, or learning ability precisely when they should be building knowledge, autonomy, and plans for the future, the illness interferes directly with personal development.

Distraught parents describe a genuine cognitive rupture: *“At the beginning of the fifth year of primary school, he seemed to have forgotten much of the fourth-year curriculum and even some of the third-year material.”*

Some can no longer follow a complete lesson, read a few pages, remember simple instructions, or sustain a long conversation. The simplest cognitive efforts become exhausting. Many experience severe post-exertional exhaustion after a school day, sometimes after only a few hours.

These young people rapidly enter a diagnostic odyssey. Because routine biological tests are often normal, symptoms are minimised, psychologised, or reclassified as anxiety, school phobia, a functional disorder, or adolescent depression. Some are referred to psychiatry before their somatic condition has been thoroughly assessed. Holingue and colleagues describe diffuse, complex, multidimensional stigma in paediatric Long COVID [27].

Box 2. Words of an 11-year-old boy with Long COVID

“I sleep much more than before. I used to sleep only at night—now I sleep almost all the time. Even after playing or doing something, I often have to lie down. Sometimes I feel heavy ... [...] ... It’s as if my whole body were crushing me—I don’t know how to explain it—as though I had been crushed ... Sometimes when I climb stairs I get really out of breath, like an old steam locomotive ... [...] ... I have had episodes when I faint: I fall to the ground without realising it—everything goes black, like a buzzing beehive. When I wake up, I realise I have fallen ... [...] ... I used to do well at school. Now I tire quickly. My mum goes over my lessons with me: sometimes I say silly things, like ‘1+1=3’. Then the next day everything is normal again.”

— M. JAMOULLE, consultation 2025

This secondary psychiatrisation has devastating effects. Adolescents feel disbelieved. Parents may themselves be implicitly blamed for maintaining symptoms through presumed maternal overprotection, family anxiety, educational difficulties, or alleged secondary benefits of school absence. Biological suffering becomes social suspicion.

Schools are likewise often poorly adapted to this fluctuating disease. Education still operates largely through binary categories: present or absent, able or unable. Yet Long COVID involves continual variation, with partial remissions followed by abrupt relapses after physical or cognitive exertion.

Few schools have the organisational capacity to adjust schedules, rest periods, cognitive load, or learning methods. Many adolescents gradually disappear from education; some interrupt schooling for months or years, without a clear status, in administrative and medical invisibility.

Long COVID therefore does not merely prevent people from functioning. Sometimes it prevents them from becoming.

Without stable short-term memory, experience is difficult to build. Without accumulated experience, a past becomes difficult to construct. In these young patients, illness directly affects identity formation, autonomy, and the ability to imagine a future.

3 The patient is the expert on this new disease

The medical history—the clinical conversation with the patient—once again becomes a central space for producing clinical knowledge [28].

People with Long COVID often struggle to describe sensations, bodily fluctuations, and functional disruptions that fall outside both their previous experience and conventional medical representations of illness. Their narratives can be fragmented, hesitant, and difficult to interpret precisely because they are trying to articulate a new, unstable physiological experience that remains poorly understood culturally and biomedically.

3.1 The return of the clinical narrative

Behind this apparent disorganisation, many patients develop remarkably detailed observational skills concerning their physiological fluctuations, either in precise accounts or through sophisticated symptom diaries (Fig. 4).

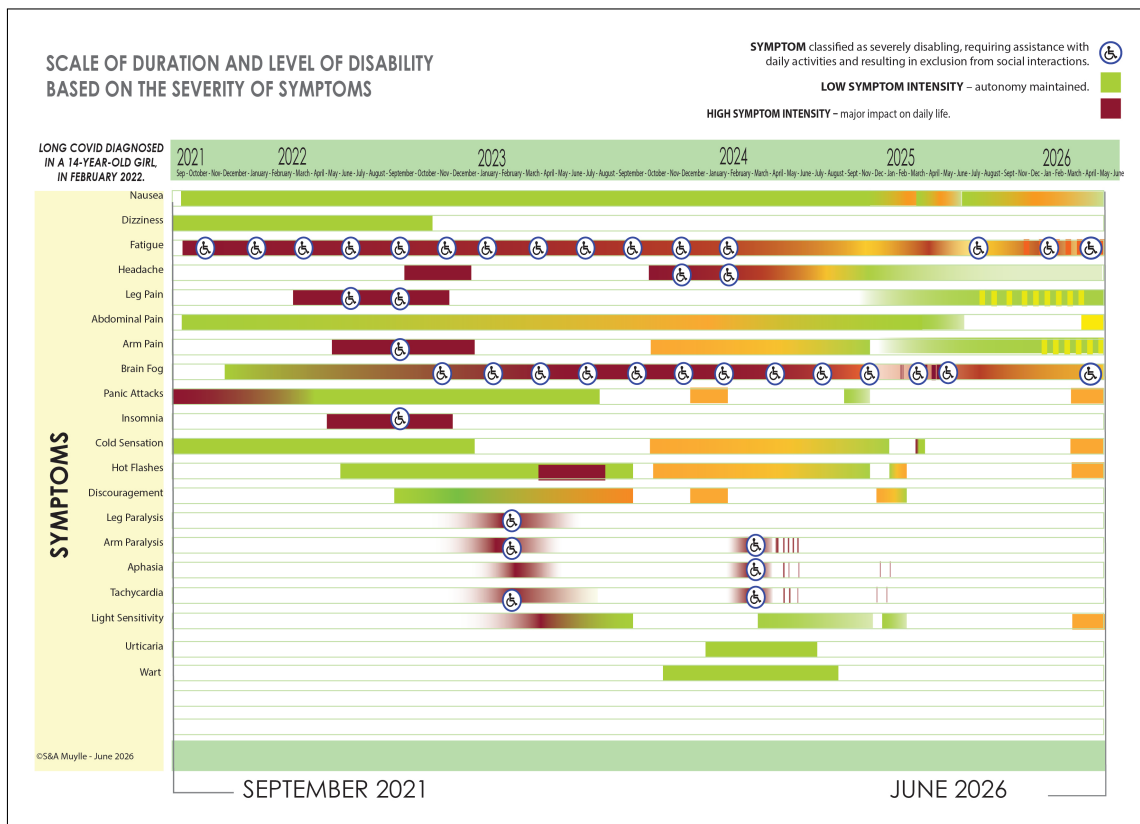


Figure 4: Chart prepared by the patient’s father showing the course of Long COVID symptoms in an adolescent first infected with SARS-CoV-2 in 2021, aged 14. The fluctuations over time are clearly visible. Symptoms shown in burgundy were the most disabling. (Document supplied by the patient with permission for publication.) Dr Jamouille, consultation, 2026.

The chart depicts the type and severity of symptoms recorded between ages 14 and 18. From top to bottom: nausea, dizziness, fatigue, headaches, leg pain, abdominal pain, arm pain, brain fog, panic attacks, insomnia, feeling cold, hot flushes, discouragement, leg paralysis, arm paralysis, aphasia, tachycardia, light sensitivity, urticaria, and a wart—a seemingly heterogeneous constellation typical of Long COVID.

These longitudinal observations gradually build dense experiential knowledge. Smartwatches, symptom-tracking applications, and personal physiological sensors make patients continuous observers of their own bodily fluctuations [29]. Some identify exertional thresholds that conventional tests cannot detect, anticipate relapses, or correlate symptoms with sleep disturbance, heart rate, heart-rate variability, or sensory environments. This instrumented self-observation may become a major source of clinical understanding.

Medicine relies not only on identifying biomarkers or imaging abnormalities, but also on listening to human trajectories over time [30]. Repeated follow-up and careful systemic history-taking reveal clinical regularities that fragmented or highly specialised care may miss.

This renewed recognition of clinical narrative quickly clashes with a contemporary medicine largely organised around evidence. When instruments fail to identify disease, doubt is progressively transferred to patients themselves. Their lived experience may be minimised, disqualified, or interpreted through inappropriate explanations, sometimes producing unsuitable therapeutic recommendations.

This tension is especially acute in Long COVID around post-exertional malaise (PEM), now recognised as a central clinical feature [8, 10, 31].

Box 3. Patient's words received via WhatsApp, May 2026

Cardiology consultation *I left this consultation deeply unsettled.*

I tried to explain my Long COVID, my exercise intolerance, and the available scientific evidence on post-exertional malaise and the need not to exceed the threshold of breathlessness.

These points were vehemently rejected. The cardiologist called these recommendations “nonsense” and those who defend them “liars”. She said dysautonomia should mainly be treated through exercise, going beyond breathlessness as part of rehabilitation.

She also questioned some of the treatments prescribed during my follow-up, suggesting that they sometimes resulted from paying too much attention to patients' reported symptoms.

This consultation left me deeply confused because of the striking contrast between these statements and the medical information I had received elsewhere. Message spontaneously sent via WhatsApp by a woman with

severe Long COVID after a specialist cardiology consultation, as part of longitudinal cohort follow-up.

Dr Jamouille, consultations, 2026.

In some patients, physical, cognitive, or emotional exertion provokes a delayed and disproportionate worsening of symptoms, potentially leading to prolonged relapses [31]. Nevertheless, recommendations involving exercise retraining or exceeding physiological limits are still sometimes made, illustrating the persistent gap between emerging knowledge and clinical practice (Box 3).

Alternative diagnoses then emerge: burnout, anxiety, functional disorder, somatisation, depression, or deconditioning. Such labels may serve to reduce clinical uncertainty but risk reversing cause and effect: the psychological and social consequences of chronic disease are reinterpreted as the origin of the symptoms.

A deep tension arises between scientific medicine and the social need for reassurance, disturbing the traditional therapeutic relationship.

For familiar diseases, clinicians use established heuristics built on stable nosological categories, diagnostic routines, and specialised knowledge. Faced with an unfamiliar and poorly understood disease, these inherited heuristics become inadequate or even misleading. As Can-guilhem argued, medical categories are not fixed realities but historical and practical constructions that patients’ lived experience can continually challenge [20].

The clinical encounter can no longer be structured principally around predefined pathological entities. It must begin with patients’ lived experience and the narrative reconstruction of symptoms under uncertainty [19].

The very emergence of a new disease requires new clinical heuristics. Long COVID compels medicine to move beyond established interpretative schemes and progressively construct reasoning based on uncertainty, iterative observation, and collective knowledge-building from patients’ accounts [32, 33].

In this perspective, narrative medicine changes epistemological status. It is no longer simply a relational tool for improving listening and empathy; it becomes a genuine instrument for producing medical knowledge.

When the collective capacity to generate meaning weakens, beliefs tend to reappear. Some consultations become sites of silent confrontation between two vulnerabilities: that of the patient seeking recognition and that of the physician facing the limits of their own conceptual instruments.

3.2 From patients’ narratives to the terminological biomarker

Patients’ narratives therefore acquire particular importance. Physicians often deny, minimise, or devalue them, in part because they are expressed in fragmented, emotional language that fits poorly within traditional biomedical categories. Yet organising these apparently chaotic stories reveals deep clinical knowledge. Patients become the first descriptive experts on this emerging disease.

Combining artificial intelligence, natural-language processing, and appropriate clinical ontologies—especially the *Human Phenotype Ontology* (HPO) [26]—now makes it possible to turn narrative medicine into structured, reusable, interoperable units of knowledge. Subjective accounts can be converted progressively into organised, coded phenotypic data comparable across cohorts.

Moving from narrative to standardised terminology also represents a methodological transition from qualitative to quantitative analysis, illustrated in Fig. 3 and Table 1. The patient’s words, long confined to description or interpretation, can now be integrated into statistical, computational, and biological approaches. Verbatim statements become analysable sets of phenotypes that may be correlated with imaging, transcriptomic, immunological, or functional physiological data.

The principal symptoms of an 11-year-old boy are presented in Table 1, with semantic correspondences between the patient’s verbatim statements and HPO terms. Each code was checked individually and linked to a persistent URL (PURL).

In this view, language itself becomes a source of indirect biological signal. The concept of a *terminological biomarker* emerges: a biomarker derived not from tissue or blood but from semantic structuring of patients’ expressed experience. It is based on statistical repetition of phenotypic patterns in clinical narratives, potentially revealing pathological patterns invisible to conventional biological investigations.

Symptom	HPO (PURL)	Child’s words
Chest pain	HP:0100749	<i>It really hurts in my breastbone</i>
Palpitations	HP:0001962	<i>My heart is beating faster and faster</i>
Syncope	HP:0001279	<i>I realise I have fainted</i>
Cognitive fluctuation	HP:0033630	<i>Sometimes I say that $1+1=3$, then the next day I’m fine</i>
Fatigability	HP:0003388	<i>I’m too tired, so I stop</i>
Post-exertional fatigue	HP:0009020	<i>After playing, I have to lie down</i>

Table 1: Clinical illustration: an 11-year-old boy with post-COVID symptoms since October 2021, no longer attending school. Previously athletic and skilled at strategic video games. HPO codes extracted by AI from the patient’s words and checked manually are clickable and linked to their PURLs. M. Jamoulle, consultation, June 2025.

This opens the possibility of reverse translational medicine: not only from bench to bedside, but also from the patient’s narrative towards biological and statistical models.

The methodological transformation changes more than analytic tools. It also changes the patient’s epistemological position in the clinical relationship and the authority physicians grant to patients’ speech. In many clinical situations—especially when conventional biomarkers are absent or nonspecific—patients’ accounts are still dismissed, minimised, or reinterpreted through psychologising or moral categories.

This is particularly acute in Long COVID. Fluctuating, invisible symptoms expose people to implicit suspicion of malingering, exaggeration, or seeking alleged secondary social or medical benefits. Their words cease to be a source of clinical knowledge and become an object of doubt.

Personal and professional ethics are then often confused. Professional ethics requires some suspension of individual moral judgement in order to sustain a methodological posture of listening, uncertainty, and clinical investigation. Conversely, when a physician’s personal beliefs about work, suffering, social legitimacy, or psychological normality prevail, scientific inquiry risks becoming an implicit judgement of patient credibility.

The stakes extend far beyond Long COVID. They concern contemporary medicine’s capacity to incorporate knowledge not yet fully objectified. By allowing terminological and statistical structuring of subjective narratives, clinical ontologies and AI could help restore scientific legitimacy to patients’ words—not as absolute truth, but as indispensable empirical material for medical knowledge production.

Collecting primary-care data and extracting knowledge from patient narratives through these methods only achieves its full value within a translational research network organised around patients. Narrative, phenotypic, biological, functional, and social data can then be linked through collaboration among family medicine, clinical specialties, basic science, data science, and the humanities.

The development of the Long COVID Research Network has already been described extensively in our research report [4]. One remarkable phenomenon deserves emphasis: scientists across numerous disciplines are now deeply interested in Long COVID. Immunologists, neurologists, molecular biologists, imaging specialists, bioinformaticians, physicists, statisticians, and AI researchers are investing heavily in this still largely unexplored field.

Paradoxically, engagement from clinical medicine often seems inversely proportional to this scientific interest. While basic science produces increasing numbers of pathophysiological hy-

potheses and experimental findings, a substantial part of the medical profession remains reluctant to recognise the disease’s full clinical reality or reconsider its usual diagnostic frameworks.

4 When healthcare systems themselves produce invisibility

Long COVID exposes not only the limits of contemporary clinical medicine but also the political, organisational, and epistemic vulnerabilities of healthcare systems.

Faced with an unstable and incompletely understood condition, contemporary healthcare structures often fail to provide timely recognition, coordination, and clinical meaning. The disease’s invisibility no longer results solely from the absence of stable biomarkers; it is also produced by institutional arrangements for delivering care.

4.1 Belgium’s political failure to address Long COVID

Six years after the emergence of SARS-CoV-2, several European countries have established specialist centres, coordinated networks, and substantial funding for Long COVID research. The United Kingdom promptly published national guidance [34], funded specialist clinics through the NHS [35], and supported dedicated research through the NIHR [36]. France issued rapid diagnostic and management guidance through the French National Authority for Health [37]. Luxembourg developed an early coordinated strategy combining translational research, multidisciplinary structures, and analysis of socio-economic consequences. Its national CoVaLux programme brings together immunology, public health, social sciences, digital health, and personalised medicine [38].

Belgium’s institutional response, by contrast, has remained exceptionally muted. Whatever the long-term social, health, and economic consequences of Long COVID—already recognised as potentially major by the OECD [39]—political silence has largely prevailed.

Institutional leaders appear afflicted by a kind of collective blindness. It is as though the trauma of the acute pandemic made acknowledging a prolonged chronic crisis politically difficult. Fully recognising Long COVID would mean admitting that, despite the end of emergency measures and apparent social normalisation, the pandemic continues to produce massive, lasting effects, potentially destabilising healthcare, education, employment, and social protection.

It would also mean acknowledging that the pandemic does not belong only to the past, but continues silently to reshape contemporary societies.

The public health insurer did introduce some administrative measures, notably a Long COVID care pathway from 1 July 2022 [40]. Yet this programme remained limited in scale, poorly publicised, administratively unstable, and conceived over a short period, initially one to two years. In the absence of strong political visibility, a coordinated scientific strategy, and sustainable structural funding, these measures proved insufficient to underpin a genuine national policy of translational research, clinical coordination, and social recognition [41].

This lack of governance itself produces invisibility.

4.2 The vertical hospital confronting a transversal disease

Patients nevertheless make extensive use of healthcare services. In Belgium’s open, hospital-centred, competitive system, where patients enjoy direct access to any level of care, they successfully consult numerous specialists, generally according to their predominant symptoms. They

accumulate investigations and undergo sometimes burdensome assessments. Yet they move within a deeply fragmented healthcare system in which each provider principally examines an organ, function, or biological variable and care remains largely organised around organ-centred approaches [42].

The result is often a long and deeply distressing diagnostic odyssey. Patients move from specialist to specialist, accumulating consultations, laboratory tests, imaging, functional investigations, and successive opinions without a comprehensive clinical synthesis ever emerging.

Figure 5 presents one example among hundreds of records reviewed. Fragmentation is almost total: each discipline observes a piece of the picture—tachycardia, dyspnoea, digestive symptoms, diffuse pain, cognitive disturbance, sensory hypersensitivity, reactive anxiety—but nobody manages to reassemble the whole.

Patients thus circulate through a technically sophisticated medical system poorly organised to understand transversal, fluctuating, multisystem disease. As Tan and colleagues observe, a highly specialised healthcare system is not designed for multisystem Long COVID [43].

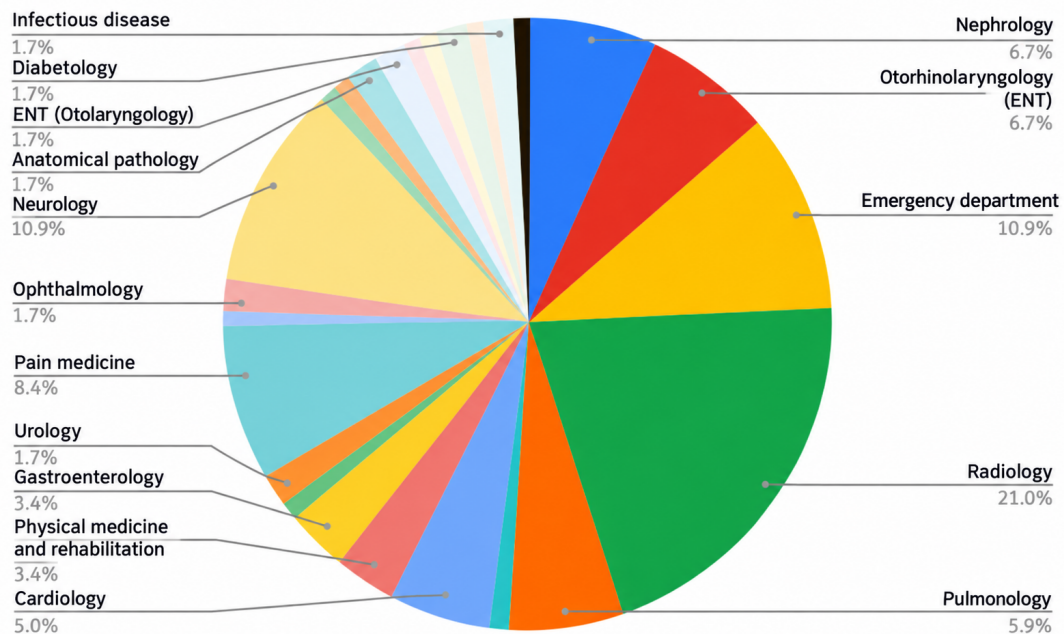


Figure 5: Between December 2020 and August 2025, a senior civil servant who contracted COVID-19 in October 2020 never recovered. Over nearly five years, he attended 18 facilities within four major hospital groups. His care involved 77 providers from 22 medical specialties (excluding clinical laboratory medicine) and an estimated 1,296 km of travel. Despite this extensive diagnostic activity, the diagnoses eventually retained were “major burnout” and “chronic fatigue”. (Source: Walloon Health Network; M. Jamouille, consultation, 2025) [44].

This fragmentation creates a paradox: the more extensively patients are investigated, the less visible the coherence of their illness becomes.

The accumulation of normal tests gradually functions as an argument against the reality of the patient’s condition. Without stable biomarkers, scientific doubt is subtly redirected towards the patient. What cannot be objectified tends to be regarded as less real.

A subtle but profound form of epistemic violence develops [3]. The patient is extensively investigated but inadequately recognised. Their lived experience loses legitimacy as negative investigations accumulate. Symptoms become “atypical”, then “functional”, and sometimes implicitly psychological. Some patients ultimately internalise institutional doubt and begin

questioning their own experience of illness.

This violence is all the greater because it arises inside a healthcare system that is visibly active: tests are performed, consultations multiplied, investigations repeated. The problem is not an absence of medicine, but a medicine still primarily organised around biologically stable, localised, and easily defined diseases.

Long COVID thereby exposes structural limits of contemporary biomedicine. Healthcare works effectively when a disease fits established nosological categories, reproducible biomarkers, and clearly localised organ damage. It becomes far more vulnerable when confronted with a condition that is:

- multisystem;
- fluctuating;
- highly symptomatic;
- biologically unstable;
- and still incompletely understood.

Scientific uncertainty may then be transformed into implicit disqualification of the patient. Paradoxically, the more technically sophisticated healthcare becomes, the more difficulty it may have recognising complex forms of suffering.

5 The economy of uncertainty

Long COVID generates not only a health crisis but also a vast economic space.

When an illness remains incompletely understood, without a stable biomarker or validated treatment, a gap develops between patients' suffering and institutional medicine's capacity to respond. That gap rapidly becomes a market.

The pharmaceutical industry is structurally cautious in relation to complex, fluctuating, poorly defined diseases. Contemporary industrial models rely chiefly on stable conditions with relatively homogeneous biological criteria and the potential for standardised therapies. Until a clear therapeutic target emerges, Long COVID remains partly peripheral to industrial strategies.

Conversely, the lack of satisfactory medical answers encourages the growth of parallel health markets: dietary supplements, expensive and often useless "functional" tests, alternative protocols, multiple supplements, microbiome treatments, "detoxification" devices, and insufficiently validated therapies.

This development belongs to a historical context shaped by the US *Dietary Supplement Health and Education Act* (DSHEA) of 1994, which substantially liberalised the dietary supplement market by exempting supplements from many regulatory requirements applied to medicines [45]. In Europe, food supplements are legally classified as foodstuffs, and oversight varies between member states [46].

In this uncertain space, therapeutic models proliferate that implicitly revive older notions of bodily purification or humoral medicine [47]. Contemporary biomedical vocabulary—microbiota, intestinal inflammation, viral persistence, colonocytes, and intestinal permeability—is combined with therapeutic logics inherited from much older traditions.

Box 4 illustrates this hybridisation. A Belgian physician presenting himself as a specialist in “functional and anti-ageing medicine” (sic) proposed to “strip out” the intestine of a woman with Long COVID using Nigari salt (magnesium chloride) at nearly toxic laxative doses. The implicit idea of expelling “bad humours” recalls elements of Hippocratic medicine [47]. Such practices, widely circulated in alternative-health spaces online, often rest on weak scientific foundations and may cause misuse or iatrogenic harm [48]. In this case, the patient ultimately declined the proposed treatment following a medical discussion.

Box 4. Anonymised excerpt from a Belgian naturopathic physician’s report (2022)

“She has intestinal symptoms, so I suspect the virus is multiplying, with viral replication in enterocytes and colonocytes: intestinal Long COVID.

I will therefore strip out her intestine using Nigari salt: five capsules taken together in the morning on an empty stomach before eating, five days a week, stopping at weekends, repeating this four times, and then recolonising the intestine with a high-dose probiotic.”

Report provided by a patient with severe Long COVID for two years.

— M. JAMOULLE, consultation 2022.

Patients thus gradually become consumers of hope. The longer scientific uncertainty persists, the more the market for certainty prospers.

Hybrid forms of medical practice emerge, combining attentive listening with “functional” medicine, naturopathy, extensive laboratory investigations, and multiple supplement prescriptions. Some respond to a genuine relational deficit in conventional medicine. Others principally exploit the vulnerability of patients facing chronic suffering and inadequate institutional recognition.

On function and the meaning of “functional”

A terminological clarification is needed to avoid misunderstanding. In this article, *functional* is used in its strict clinical sense: the patient’s actual ability to act in the world and perform activities of daily living [49]. Functional impairment refers to the concrete consequences of illness for lived existence, not to the absence of a biological substrate. These are the functions assessed using functional outcome measures, including patient-reported outcome measures (PROMs).

This meaning must be distinguished from contemporary uses of “functional” to describe symptoms without an identified organic cause, sometimes implicitly suggesting psychogenesis [50]. It also differs from “functional medicine”, associated with practices that have not been adequately scientifically validated [51].

In Long COVID, the distinction is crucial. Despite frequently inconclusive investigations, patients experience major limitations in cognitive, physical, and social functioning. Rigorous assessment of these limitations becomes central to clinical description and to recognition and legitimization of suffering.

Medical uncertainty is never economically neutral. Every area of ignorance potentially becomes a site of commercial exploitation.

The paradox is profound: the more a disease eludes conventional biomedical instruments, the more vulnerable patients become to competing systems of meaning, care, and therapeutic promises.

Family physicians must navigate a permanent tension. Excessive scepticism drives patients towards parallel markets; excessive credulity exposes them to diagnostic or therapeutic excesses that may be costly, dangerous, and scientifically unsupported.

The physician also becomes a regulator of uncertainty: accepting suffering without abandoning critical judgement, providing support without making promises, and protecting patients without denying their illness.

6 Family medicine, ethical tensions, and a syndemic approach to Long COVID

Long COVID confronts contemporary medicine with two interrelated crises: an ethical crisis in knowledge production and an organisational crisis arising from the extreme organ-centred fragmentation of care. In this setting of chronic uncertainty, family medicine paradoxically regains a central role that is clinical, epistemological, and social.

The disease reveals the limits of a system organised around hyperspecialisation, standardised protocols, and biomedical objectification that may fail to capture complex, fluctuating, multi-system forms of human suffering. Long COVID thus compels us to rethink both how knowledge is produced and how care is delivered.

6.1 Ethical tensions and translational research

This research developed gradually, without advance planning or dedicated funding. When the first cases emerged, nothing suggested the eventual scale of the problem, the numbers affected, the persistence of post-COVID symptoms, or the need to build a scientific structure around them.

Action research requires flexibility and continuous reflection [koshy2005action]. Successive observations and partial findings continually change the work's direction, creating new methodological and conceptual challenges. An interdisciplinary research network gradually emerged around the realities observed in clinical practice [jamouille2023exploring]. This process mobilised expertise in clinical medicine, social science, multi-omics, advanced imaging, terminology, medical informatics, and data science. The informal network became the *Long COVID Belgium Research Network*.

This can be described as participatory action research [reason2008sage], based on continual adjustment between methods and findings through reciprocal learning among patients, clinicians, and researchers.

The ethical questions extend far beyond data confidentiality and practical research organisation. A rapidly developing, practice-based research initiative naturally raised difficulties of compliance with the General Data Protection Regulation (GDPR), secure data storage, and organising a scientific activity that had neither been anticipated nor funded. Yet these practical issues are secondary to deeper tensions surrounding the production and circulation of knowledge.

Long COVID has placed clinician-researchers in an unusual position. Close involvement in translational research can provide early access to biological hypotheses or promising findings from virology, immunology, and molecular biology [52, 53]. Yet such knowledge is frequently provisional, unpublished, or restricted by scientific competition, intellectual property, and economic interests associated with biomedical discoveries [54–56].

Action research creates an additional challenge: its development cannot be fully predicted in advance. Hypotheses change in response to the field, new symptoms emerge, collaborations form, unexpected methodological tools become necessary, and some initial lines of investigation reach dead ends. With a new disease such as Long COVID, research advances through successive adjustments following clinical observations and exchanges among patients, clinicians, and researchers. This makes it particularly difficult to apply ethical protocols fixed completely from the outset [57–59].

Field teams consequently face a difficult conflict of loyalties. Patients participate directly in research by contributing blood, data, and clinical narratives, yet clinicians sometimes cannot share emerging information before formal validation. This asymmetry is particularly sensitive in Long COVID, where many patients have already experienced abandonment or institutional denial.

Physicians are caught between competing obligations: scientific caution, academic loyalty, respect for validation processes, and the moral duty to be transparent with patients desperate to understand what is happening to them. Premature disclosure risks spreading fragile hypotheses or creating unrealistic expectations; complete silence may be experienced as yet another form of medical silence.

The contemporary contradictions between the logic of care, the economics of research, and the governance of scientific knowledge production become plainly visible.

6.2 The role of the family physician in a syndemic approach

Within this disciplinary compartmentalisation, family medicine paradoxically regains central importance.

Long COVID exposes the limits of a healthcare system built around hyperspecialisation. Each specialist observes one fragment: the neurologist the cognitive disturbances, the cardiologist the tachycardia, the respiratory physician the dyspnoea, the gastroenterologist digestive symptoms, and the psychiatrist reactive anxiety. But the disease moves between organs, fluctuates over time, and combines biological, cognitive, emotional, and social dimensions. The patient becomes the only place where all symptoms coexist.

Very few medical structures are organised to understand this whole.

Because family medicine works through biographical continuity, long-term care, narrative listening, and simultaneous attention to social, cognitive, and bodily dimensions, it remains one of the few settings capable of sustaining clinical coherence despite institutional fragmentation.

Family physicians see not merely an impaired function or dysfunctional organ but a human trajectory progressively falling apart: memory loss, withdrawal from employment, social isolation, family exhaustion, and collapse of identity. Where hyperspecialised care separates, family medicine reconnects.

This synthesising role is especially important in emerging or complex diseases, when biomarkers remain incomplete and pathophysiological understanding is partial. Clinical coherence then depends not only on instrumental objectification but also on linking stories, time courses, fluctuations, and subtle signs.

Family medicine regains a major epistemological function: maintaining provisional clinical intelligibility in situations where biomedical science has not yet stabilised its explanatory models.

The family physician becomes less a mere source of referrals and more an agent of synthesis in a system that has lost the ability to conceive of certain contemporary forms of illness as wholes.

For Long COVID, this role extends well beyond technical coordination of care. It also maintains continuity of meaning for patients whose social, professional, and sometimes cognitive existence is becoming fragmented.

Family medicine thus appears not as a residual or peripheral form of medicine but as one of the last clinical spaces capable of connecting, simultaneously, the biological, psychological,

spiritual, cognitive, social, economic, narrative, and political dimensions of illness.

This goes beyond a merely “holistic” view or attention to the “whole person”. As Fig. ?? shows, Long COVID involves dynamic interactions between biological processes, social vulnerabilities, institutional arrangements, economic constraints, cultural representations, and biographical trajectories. This entanglement exceeds classical notions of medical holism. It calls for a syndemic approach in the sense described by Singer and Clair: biological and social dimensions of illness interact to aggravate one another within a shared system of vulnerability [60, 61].

Long COVID ultimately reminds us that some complex diseases can only be understood if there is a clinical setting capable of thinking together what healthcare institutions have gradually learned to separate.

Conclusion

Long COVID is not merely a new chronic post-infectious condition. It is a broad indicator of the contemporary conditions under which medical knowledge is produced, suffering receives social recognition, and healthcare systems are politically organised.

It exposes the limits of medicine based exclusively on objectification, the fragilities of hospital hyperspecialisation, the social effects of biological invisibility, cultural asymmetries between physicians and patients, and the difficulty healthcare systems face in adapting to a new disease.

Long COVID ultimately reminds us of an old truth that has become difficult to hear within modern technological systems: a disease can be real before it is fully explained.

Perhaps more profoundly, it reminds us that societies do not recognise illness simply because sufficient biological evidence exists, but because they are willing—politically, scientifically, and morally—to transform collective suffering into a legitimate medical reality.

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Use of artificial intelligence

Generative artificial intelligence tools were used during manuscript preparation to improve style, readability, and some linguistic or graphical formulations, including preparation of this English version.

All concepts, hypotheses, clinical analyses, anthropological interpretations, and scientific positions presented in the manuscript remain exclusively those of the author.

Acronym	Meaning
COVID	<i>Coronavirus Disease</i>
HAS	<i>Haute Autorité de Santé</i> (French National Authority for Health)
HPO	<i>Human Phenotype Ontology</i>
AI	Artificial intelligence
INAMI	<i>Institut National d'Assurance Maladie Invalidité</i> (Belgian National Institute for Health and Dis)
NHS	<i>National Health Service</i>
NIHR	<i>National Institute for Health and Care Research</i>
OECD	<i>Organisation for Economic Co-operation and Development</i>
PEM	<i>Post-exertional malaise</i>
PROM	<i>Patient-reported outcome measure</i>
PURL	<i>Persistent Uniform Resource Locator</i>
GDPR	<i>General Data Protection Regulation</i>

Acronyms and abbreviations

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