Long COVID as a Tracer of Care Fragmentation: Reconstructing Patient Care Trajectories from Belgian Health System Metadata

Running title: Patient Care Journeys in Long COVID

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Abstract

Background: Health systems increasingly face the challenge of managing conditions characterized by diagnostic uncertainty, fluctuating symptoms, and prolonged functional impairment. In such contexts, care organization depends not only on individual clinical encounters but also on how patients move across institutions and specialties over time. Long COVID provides a contemporary case through which to examine how healthcare systems respond to sustained clinical uncertainty in the absence of clearly structured care pathways.

Methods: We conducted an exploratory case-based study in Belgian primary care using routinely generated healthcare metadata combined with clinical records. Three cases were purposefully selected from a cohort of more than 400 patients with long COVID followed since 2021. Care trajectories were reconstructed through manual longitudinal review of primary care documentation and hospital-derived metadata accessible through the Belgian eHealth infrastructure. Descriptive analyses examined institutional dispersion, referral patterns, diagnostic utilization, and travel distance across healthcare institutions.

Results: Care trajectories extended over 39–68 months and involved 7–12 healthcare institutions, 10–21 medical specialties, and 25–81 individual providers per case. Patients underwent repeated cross-specialty referrals and extensive diagnostic investigations without evidence of a stable or coordinated care pathway. Routinely generated metadata enabled the reconstruction and visualization of these trajectories, revealing patterns of institutional dispersion, repeated investigations, and fragmented clinical responsibility across levels of care.

Discussion: In a decentralized Bismarckian health system lacking formal integration mechanisms for long COVID, prolonged diagnostic uncertainty appears to be managed through successive and dispersed care episodes. Reconstruction of trajectories from routinely generated healthcare metadata provides a scalable method for making such organizational patterns visible and for examining how health systems respond to emerging chronic conditions.

Keywords: long COVID; care trajectories; healthcare metadata; care coordination; continuity of care; primary care; health systems governance; health services research

1 Background

1.1 Care trajectories, uncertainty, and the primary care perspective

Health systems increasingly face the challenge of organizing care for conditions characterized by diagnostic uncertainty, fluctuating symptoms, and prolonged functional impairment. In such situations, the effectiveness of care depends less on isolated clinical encounters than on how patients move across institutions, providers, and services over time. Patterns of referral, investigation, and follow-up therefore offer important indicators of how health systems coordinate care, manage uncertainty, and allocate responsibilities across levels of care. Examining these longitudinal movements provides a way to observe how healthcare systems function in practice.

From a primary care perspective, healthcare is inherently longitudinal. General practice operates at the interface of undifferentiated symptoms, evolving diagnoses, and multiple explanatory frameworks. Continuity, coordination, and contextualization are therefore defining functions of primary care rather than peripheral attributes [1–4]. The general practitioner is often the only professional who maintains an ongoing overview of the patient's trajectory across institutions and over time.

From the patient perspective, these trajectories are experienced not as abstract organizational processes but as sequences of consultations, investigations, referrals, and waiting periods that progressively shape everyday life. Fragmentation is therefore not only a structural property of healthcare systems but also a lived experience marked by uncertainty, repeated explanations of symptoms, and fluctuating expectations regarding diagnosis and treatment. Reconstructing care trajectories therefore makes it possible to analyze both the organizational structure of healthcare systems and the experiential journeys encountered by patients.

Patient journey mapping has increasingly been used to reconstruct sequences of care from the patient's perspective [5, 6]. By tracing the succession of encounters experienced by patients, this approach makes visible not only clinical events but also the organizational responses generated by prolonged uncertainty.

When diagnostic categories remain unstable and clinical protocols poorly defined, care trajectories frequently involve iterative referrals, cross-specialty consultations, and shifting interpretations of symptoms. The longitudinal viewpoint of primary care therefore provides a privileged position from which to observe these movements and the organizational patterns they generate.

1.2 Tracer patients and system-revealing trajectories

The concept of a *tracer* originates in the natural sciences, where the movement of a substance within a system reveals its internal structure. In health services research, this logic was adapted through the notion of "tracer conditions," whose management could be used to evaluate the adequacy of healthcare structures and processes [7–9].

Extending this reasoning, a tracer patient can be understood as an individual whose longitudinal care trajectory makes visible how healthcare systems operate in practice [**elli**]. The tracer is not defined primarily by a specific diagnosis or severity level, but by trajectory characteristics: sustained engagement with care, movement across institutions and specialties, and repeated activation of organizational interfaces. What becomes visible through such trajectories is therefore not only a disease process but also the relational, informational, and referral structures mobilized by the patient's circulation through the healthcare system [10].

This systems-analytic use of the tracer concept is particularly relevant in situations of diagnostic uncertainty. Research on medically unexplained symptoms (medically unexplained symptoms (MUS)) has shown how such patients frequently circulate between primary and secondary care, exposing tensions between biomedical specialization and the coordinating role of general practice [11–13]. From a primary care standpoint, these trajectories illuminate how healthcare systems respond when explanatory closure is unavailable.

1.3 Long COVID as a tracer of uncertainty in care organization

Long COVID (LC), defined as persistent symptoms following acute SARS-CoV-2 infection [14, 15], represents a contemporary example of prolonged clinical and organizational uncertainty. The condition may follow severe, mild, or even initially unrecognized infection and is characterized by heterogeneous and fluctuating symptoms that can persist for months or years [16]. Although the absence of routinely available biomarkers and the coexistence of competing explanatory models complicate diagnosis and care planning, emerging biological research has begun to identify potential mechanisms, including patterns consistent with viral persistence [17]. At the same time, several models of care for long COVID have been proposed internationally [18, 19].

Despite these developments, many patients have experienced repeated referrals, fragmented follow-up, and prolonged diagnostic uncertainty [20, 21]. Such trajectories therefore represent not only clinical phenomena but also organizational ones. From a primary care perspective, long COVID patients illustrate how healthcare systems attempt to manage continuity of care under conditions of prolonged uncertainty.

In this study, the care journeys of patients with long COVID are conceptualized as tracers of health system activity. By reconstructing their longitudinal trajectories, it becomes possible to examine how coordination, referral patterns, and informational flows unfold across levels of care.

1.4 Routinely generated metadata and longitudinal reconstruction

Capturing care trajectories poses important methodological challenges. Prospective observation is resource-intensive, while retrospective patient recall is vulnerable to bias. Increasing attention has therefore turned to the secondary use of routinely generated healthcare data to reconstruct trajectories [22–24].

Healthcare metadata—data that describe clinical documents and care events [25]—include timestamps, care settings, document types, and provider identifiers. Although they do not contain clinical narratives, they capture operational traces of healthcare activity and institutional movements. These traces allow reconstruction of the temporal sequencing and institutional dispersion of care events across multiple settings. From a primary care perspective, such metadata provide a means to observe how continuity of care is enacted or disrupted across organizational boundaries.

1.5 The Belgian health system context

Belgium provides a particularly informative context for examining these dynamics. The Belgian healthcare system operates under a Bismarckian model characterized by high accessibility to healthcare providers and the absence of a formal gatekeeping role for general practitioners [26]. Patients may consult specialists directly and choose freely among hospitals and services.

The national eHealth infrastructure connects hospitals, laboratories, and healthcare providers through regional health information hubs and a federal meta-hub, enabling cross-institutional visibility of care events without centralizing clinical content [27]. The ProSanté portal [28] provides healthcare professionals with access to administrative data and federal health applications. These infrastructures make longitudinal trajectory reconstruction technically feasible while also raising questions about how coordination is achieved in the absence of formal gatekeeping mechanisms.

Across Europe, long COVID has been addressed through varying degrees of organizational coordination, including national guidelines, surveillance systems, and multidisciplinary clinics in some countries as early as 2021 [29–35]. Belgium did not implement a comparably structured model. Although the national health insurance institute designated family physicians as responsible for certifying post-COVID condition for reimbursement purposes, this role was not accompanied by clearly defined referral pathways, institutional coordination mechanisms, or dedicated training programs. In practice, primary care therefore assumed de facto responsibility for longitudinal management within a fragmented system.

Conceptual contribution This study proposes a conceptual distinction between three notions that are frequently used interchangeably in health services research. *Care pathways* refer to the intended organization of care defined by clinical guidelines or health system management. *Care journeys* describe the actual sequence of encounters experienced by patients as they move across institutions, providers, and services in real-world settings. *Care trajectories*, in turn, correspond to the analytical reconstruction of these journeys from routinely generated data sources. By mobilizing healthcare metadata to reconstruct longitudinal trajectories, the present study illustrates how real-world care journeys can be made visible and analyzed as indicators of coordination, fragmentation, and health system governance.

1.6 Study objective

Despite growing interest in care trajectories, important gaps remain. Most studies examine long COVID pathways from either clinical or patient-experience perspectives, while fewer analyses address trajectories as organizational phenomena observable through the longitudinal vantage point of primary care. In addition, routinely generated healthcare metadata are often treated as technical by-products of digital systems rather than as meaningful traces of coordination, institutional dispersion, and continuity of care. This study investigates whether such metadata can be used to reconstruct longitudinal care trajectories across institutions and over time within the Belgian health system. Drawing on a primary care cohort of more than 400 patients with long COVID established since 2021 [36], we reconstruct detailed trajectories for three illustrative cases using routinely available metadata combined with clinical documentation. By conceptualizing these patients as tracers of healthcare system activity, the analysis aims to illuminate how referral dynamics, institutional dispersion, and coordination patterns emerge in a decentralized Bismarckian system lacking formally integrated care pathways.

2 Methods

2.1 Study design and case selection

This exploratory study adopted a case-based descriptive design to examine the feasibility of reconstructing longitudinal care trajectories in patients with long COVID using routinely generated healthcare data. Three cases were purposefully selected from a primary care cohort of more than 400 patients followed since 2021 [36–38]. The objective of the study was methodological rather than epidemiological.

Restricting the analysis to three cases was a deliberate epistemic choice. Reconstruction of individual care trajectories required intensive manual examination of heterogeneous longitudinal records originating from multiple institutions and levels of care. Rather than seeking statistical generalizability, the study aimed to reconstruct trajectories in sufficient detail to reveal organizational patterns that may remain obscured in aggregated datasets.

Cases were selected solely on the basis of the availability of sufficiently continuous documentation to allow cross-institutional reconstruction of care events. No selection criteria related to symptom severity, phenotype, or clinical outcome were applied. The selected trajectories were prolonged and institutionally dispersed, providing analytically dense material for examining the structural organization of care. These cases should therefore be interpreted as analytically informative configurations rather than empirically representative samples.

2.2 Setting and data sources

The study was conducted in Belgian primary care using routinely generated clinical data accessed through the general practitioner's electronic medical record (EMR) system (Medispring®). The EMR provides integrated access to two principal sources of information (Figure 1):

- the local electronic medical record (electronic medical record (EMR)), containing clinical data generated by the general practitioner (GP);
- the regional health information hub (regional health information hub (HUB)) [39], which aggregates hospital-derived documents and laboratory reports together with associated metadata and makes them accessible within the EMR.

Two main categories of data were used.

Patient-derived data Patient-derived information included:

- texts and email correspondence between patients and the general practitioner;
- clinical anamnesis (routine physician–patient consultation). Symptom information was obtained during these routine consultations, which form part of standard medical care and were not designed as structured research interviews. No interview guide was developed.

For research purposes, only the symptom-related component of the clinical anamnesis was extracted and analyzed in de-identified form. No personal or identifying information was collected or included in the dataset. These symptom descriptions were subsequently analyzed qualitatively using large language models (LLMs) and ontology-based methods to support the characterization of Long COVID;

- standardized self-administered questionnaires including the COOP/WONCA functional health charts (Charts for functional health assessment (COOP/WONCA)) [40] and the Community of Patients for Research (COMPaRe) long COVID questionnaire [41]. Both instruments are previously published and validated. The French translation of the COOP/WONCA Charts was prepared by the author within the WONCA Classification Committee. The ComPaRe questionnaire is freely available online; an English version is provided in the Supplementary Materials. These questionnaires were administered initially in paper format and, from 2022 onward, via a secure cloud-based form using the patient's alphanumeric identifier (Supplementary Figure S1; Supplementary Material S1);

- the Duke Severity of Illness Index (DUSOI), a clinician-rated instrument assessing overall illness severity across multiple health problems [42].

EMR- and HUB-derived data Clinical documentation and associated metadata included:

- free-text clinical notes and the International Classification of Primary Care (ICPC) diagnostic index within the EMR [43],

- hospital reports, imaging reports, and laboratory documents retrieved via the regional health information hub [39], each accompanied by metadata fields describing document date, document type, healthcare institution, clinical service, and laboratory source.

All data were generated during routine clinical care. No additional clinical interventions or diagnostic procedures were introduced for research purposes

2.3 Data processing workflow

The reconstruction process followed a structured workflow summarized in Figure 1.

Step 1: Pseudonymisation All data were generated during routine clinical care and documented within the EMR during standard patient management. The study did not introduce any additional clinical interventions, diagnostic procedures, or modifications to usual care. Clinical information was subsequently extracted in pseudonymised form and analyzed retrospectively for research purposes.

Step 2: Manual longitudinal review For each case, narrative and documentary sources—including emails, consultation notes, hub-derived documents, and laboratory reports—were reviewed chronologically within authorized clinical systems. No automated extraction or direct database export was performed.

Relevant events were transcribed manually into structured spreadsheet tables. Recorded variables included event date, event type (consultation, laboratory test, imaging examination, referral), institutional context, and transitions between care levels. This review enabled construction of a chronological diagnostic and therapeutic index listing documented health problems and treatments over time.

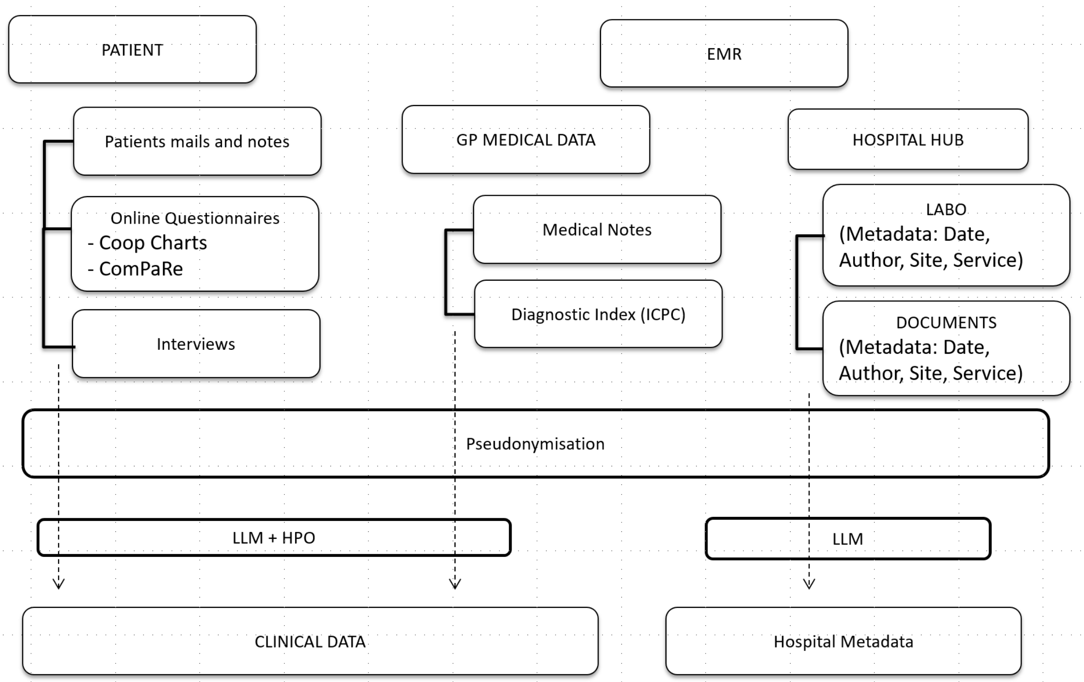

Figure 1: Data sources and processing workflow. Patient-derived materials (emails, clinical anamnesis, and questionnaires) and data extracted from EMR and HUB repositories (general practice records and HUB documents with associated metadata) underwent manual review and pseudonymisation. Clinical information was systematically encoded using the ICPC and Human Phenotype Ontology (HPO) classification frameworks, with structured summarization supported by a large language model (LLM). This procedure generated two analytical outputs: (1) a harmonized clinical dataset and (2) a structured hospital metadata dataset.

Step 3: Clinical structuring and coding Symptom descriptions extracted from narrative sources (pseudonymized emails and clinical anamnesis material) were encoded using the Human Phenotype Ontology (Human Phenotype Ontology (HPO)) [44–46]. Diagnoses and diagnostic hypotheses were indexed using the ICPC classification system [43]. Coding was performed manually by the investigator to ensure semantic consistency across heterogeneous clinical documents.

Hub: RSW

Sumehrs | Schéma de médications | Journal | Laboratoire | Vaccinations | Documents

Date	Type	Auteur	Profil	Site	Service	Acc...	Date accès patient
17/02/2026 08:57	Lien pour démarrer une application externe Link naar CoZo	CoZo	hub			oui	
17/02/2026 08:57	Lien pour démarrer une application externe RSW2 application	RSW	hub	RSW2 Application		Inconnu	
17/02/2026 08:57	Lien pour démarrer une application externe RSW3-Vaccicard	RSW	hub			non	
21/06/2024 06:47	Lien pour démarrer une application externe pacsonweb, PacsOnWeb	[redacted]	médecin	Courcelles - CMS	radiologie	oui	29/06/2024 12:29:10
20/06/2024 11:40	Lien pour démarrer une application externe pacsonweb, PacsOnWeb	[redacted]	médecin	Courcelles - CMS	radiologie	oui	28/06/2024 07:52:04
24/04/2023 22:00	Rapport de contact rapport de consultation	[redacted]	médecin	Hôpital Civil Marie Curie	Maladies infectieuses	oui	24/05/2023 21:00:01
11/01/2023 07:56	Lien pour démarrer une application externe pacsonweb, PacsOnWeb	[redacted]	médecin	Jumet - Dr. [redacted]	radiologie	oui	19/03/2023 21:02:06
04/01/2023 23:00	Procedure result protocole d'examen d'imagerie médicale	[redacted]	médecin	Hôpital Civil Marie Curie	Imagerie médicale	oui	04/02/2023
11/04/2022	Procedure result mn18-cerveau ecd/hmpao	[redacted]	médecin	Hôpital Civil	Médecine	oui	11/05/2022

Figure 2: Patient document metadata (partial view) displayed in the HUB interface. Screenshot of hospital-derived patient data accessible through the Belgian eHealth infrastructure and displayed within the Medispring® clinical software. Visible fields include date and time, document type, author (name removed), professional profile, healthcare site, clinical service, access status, and patient access date (in French).

Step 4: Metadata extraction Metadata describing hospital documents were extracted from the hub interface shown in Figure 2. Visible fields were copied in structured form into spreadsheets. Extracted variables included document date and time, document category, healthcare institution, clinical service, and laboratory identifier.

These variables were used to calculate descriptive indicators including the number of institutions involved, the number of clinical services consulted, laboratory events, and imaging procedures. Visualization of healthcare utilization patterns was generated from these aggregated counts.

Travel distances were estimated by calculating road distances between the patient's postal code and the postal codes of visited institutions using an online mapping service.

Metadata were treated as contextual traces of healthcare activity. Missing values, heterogeneous naming conventions, and inconsistent timestamps were preserved without corrective inference.

Illustrative cost estimates were calculated by applying standardized economic formulas to utilization counts and publicly available unit cost parameters. Actual reimbursement data were not accessed.

Step 5: Computational assistance A large language model (ChatGPT, version 5.2) [47] was used as a technical assistant for processing pseudonymized textual material and structured datasets. Its functions were limited to summarizing chronological sequences of events, verifying internal consistency of event counts, assisting with grouping of document categories, and supporting timeline synthesis and formula-based cost calculations.

The model was not used to generate diagnoses, interpret clinical findings, or produce inferential conclusions.

2.4 Analytical outputs

The reconstruction process generated two complementary analytical outputs:

1. a structured hospital metadata dataset derived from hub traces, enabling visualization of temporal and institutional healthcare trajectories (Table 1 and Supplementary Figure S2);
2. a harmonized clinical dataset integrating patient-reported information and general practitioner documentation encoded using the HPO and ICPC frameworks (Supplementary Table S1).

These datasets allowed descriptive comparison of care trajectories without reassessing diagnoses or reinterpreting clinical decisions.

2.5 Ethical considerations

The study was conducted within an approved clinical research program on long COVID and authorized by the Ethics Committee of the Centre hospitalier universitaire de Liège. All procedures complied with the Declaration of Helsinki and applicable Belgian and European data protection regulations.

Only pseudonymized data were analyzed, and no source documents were exported outside authorized clinical systems. The study aimed to evaluate methodological feasibility rather than to test clinical hypotheses or evaluate therapeutic interventions.

3 Results

This section presents the descriptive findings derived from the reconstruction of care trajectories for three illustrative cases encountered in 2025. Results are organized in four parts: (1) demographic and organizational characteristics, (2) healthcare system mobilization and institutional dispersion, (3) hospital-related trajectories reconstructed from metadata, and (4) supplementary clinical context.

3.1 Demographic and organizational characteristics

Table 1 summarizes the demographic characteristics and healthcare utilization patterns for Cases 318, 407, and 458, based on metadata extracted from their respective records within the regional health information hub. The three patients differed in age, sex, and occupational background but shared a history of prolonged functional impairment and sustained engagement with the healthcare system over multiple years.

Two women and one man were included, reflecting the sex distribution observed in the broader cohort, in which women represent approximately 67% of patients. Observation periods ranged from 39 to 68 months and encompassed multiple acute COVID episodes, vaccination exposures, and extended follow-up.

Across cases, care trajectories involved numerous institutions, specialties, and healthcare providers. No uniform referral sequence or identifiable standardized pathway was observed. Instead, the reconstructed trajectories illustrate prolonged interactions with the healthcare system characterized by repeated consultations across multiple specialties and extensive diagnostic investigations.

Table 1: Characteristics and reconstructed healthcare utilization of three illustrative cases

Item	Case 318	Case 407	Case 458
Observation period	Jul 2020–Aug 2025	Jul 2022–Aug 2025	Mar 2020–Nov 2025
Months of observation	62	39	68
Sex	Male	Female	Female
Age at index COVID (y)	48	27	35
Occupation	Executive	Independent artist	Mental health therapist
Belgian region	South-East	North-East	Central
Index acute COVID date	Jul 2020	Jul 2022	14 Mar 2020
PCR-confirmed date	23 Jan 2021	24 Jul 2022	Not available (Mar 2020)
Work-related exposure	Yes	Yes	Yes
Acute COVID episodes (n)	1	3	5
Start of follow-up in study setting	Aug 2025	Sep 2025	Nov 2025
Vaccination (doses)	2	5 (severe adverse effect)	3
Institutions (n)	12	8	7
Specialties (n)	21	17	10
Providers (n)	81	25	39
Labs (n)	5	6	10
Lab results (n)	77	15	44
Standard imaging (n)	95	26	65
Advanced imaging (n)	2	1	1
Estimated minimum theoretical cost (€)	19,210	11,540	5,350
Estimated distance travelled by the patient (km)	1,296	580	1,112

PCR testing was not systematically available during the early phase of the COVID-19 pandemic in Belgium.

3.2 Healthcare system mobilization and institutional dispersion

The reconstructed trajectories reveal substantial mobilization of healthcare resources across institutional, geographic, and specialty dimensions. Patients circulated between 7 and 12 healthcare institutions and interacted with between 25 and 81 individual healthcare providers.

After consolidation of typographical and linguistic duplicates in the metadata, these interactions corresponded to the involvement of more than ten and up to twenty-one distinct medical specialties depending on the case.

Patients travelled considerable cumulative distances to access care, ranging from approximately 580 km to 1,296 km. These movements reflect successive consultations across multiple Belgian hospital institutions before convergence, at different stages, toward the same general practice clinic in the Charleroi region, where longitudinal follow-up resumed.

Biological investigations ranged from 15 to 77 laboratory events per case, originating from three to nine laboratories. Each event corresponded to a separate document accessible through the regional health information hub. Because the available metadata did not allow grouping of analyses by sampling episode, each document was treated as an individual event.

Imaging utilization ranged from 26 to 95 conventional radiological examinations per case, in addition to one or two nuclear medicine procedures. Using a standardized illustrative cost estimation approach, cumulative hospital-related expenditures exceeded 10,000 € in certain trajectories.

Patient perspective Beyond institutional dispersion and diagnostic utilization, the reconstructed trajectories correspond to prolonged personal experiences of uncertainty and repeated clinical encounters. Patients described cycles of consultation, investigation, and referral extending over several years. Diagnostic tests were frequently repeated across institutions, and consultations often concluded without a definitive explanation for symptoms. Patients also reported repeatedly recounting their medical history when consulting new specialists, reinforcing a perception of discontinuity in care.

When the reconstructed trajectory visualizations were later presented to patients, several expressed surprise at the cumulative number of institutions, investigations, and consultations involved in their care. The graphical reconstruction transformed dispersed experiences into a coherent narrative, allowing both patients and clinicians to recognize patterns of fragmentation that had previously remained implicit.

3.3 Hospital-related care trajectories

Supplementary Figure S2 provides a visual chronological reconstruction of hospital-related healthcare events derived from metadata available through the regional health information hub.

These visualizations display the temporal distribution, frequency, and institutional dispersion of hospital encounters without artificial grouping into episodes of care. Institutional labels correspond to the original hub metadata and were normalized only for analytical clarity, highlighting the heterogeneity of routinely generated administrative data.

Across cases, the reconstructed trajectories reveal repeated diagnostic investigations, cross-specialty referrals, and extended periods of clinical uncertainty. No stable institutional care pathway could be identified.

In the Belgian context of unrestricted access to specialist care, patients may consult specialists directly and choose hospitals according to their symptoms or preferences. Within each institution, clinicians typically pursue diagnostic evaluation using locally available technologies and prevailing standards of practice. When investigations fail to produce definitive findings, patients are often referred back to their general practitioner or directed toward another specialty.

Patients who perceive these responses as inconclusive may subsequently seek additional consultations elsewhere. In the absence of a designated coordinating structure, no single actor assumes responsibility for integrating these successive encounters. Care progression therefore emerges from the cumulative effect of individual consultations and patient-initiated movements rather than from an explicitly organized pathway.

3.4 Supplementary clinical characteristics

Supplementary Table S1 presents detailed clinical characteristics for the three cases, including symptom profiles, functional impact, selected biological and imaging findings, diagnostic labels, and standardized coding using ICPC and HPO terminologies.

The purpose of this table is to document the clinical complexity accompanying the reconstructed care trajectories. It provides the clinical context underlying the extensive institutional mobilization described above without reassessing diagnoses or establishing causal relationships. Instead, it situates the organizational findings within the clinical realities that led to repeated consultations and investigations.

Importantly, the clinical workflow, documentation procedures, and data acquisition methods applied to these three cases are identical to those used across the broader primary care cohort, ensuring methodological consistency.

3.5 Participation in multi-omics research

Between 2022 and 2025, one patient from the cohort participated in a multi-omics research program conducted by the Laboratory for Clinical and Evolutionary Virology and the Immunology Research Service at the Rega Institute for Medical Research, KU Leuven (Leuven, Belgium).

Written informed consent was obtained in accordance with institutional ethical approvals. Blood samples were collected and stored within the KU Leuven biobank infrastructure for subsequent multi-omic analyses. Findings from these investigations have been reported elsewhere [17, 48–50].

Synthesis of empirical findings Taken together, the reconstructed trajectories reveal prolonged and institutionally dispersed care processes characterized by repeated diagnostic investigations and cross-specialty referrals. Across the three cases, patients circulated between multiple hospitals, laboratories, and medical services over several years without evidence of a stable or coordinated care pathway. The metadata-based reconstruction highlights how prolonged clinical uncertainty was managed through sequential encounters distributed across institutions rather than through integrated care structures. These trajectories therefore provide an empirical illustration of how healthcare systems respond to emerging chronic conditions in the absence of formally organized coordination mechanisms.

4 Discussion

Long COVID as a tracer of organizational uncertainty

This study shows that long-term care journeys of patients with Long COVID can be reconstructed through the combined analysis of routinely generated healthcare metadata and primary care clinical records. The reconstructed trajectories reveal extensive institutional dispersion, repeated cross-specialty referrals, and a progressive accumulation of diagnostic investigations over several years. Despite sustained engagement with the healthcare system, no coherent or intentionally structured care pathway was identifiable.

Rather than reflecting coordinated management, these trajectories illustrate how prolonged diagnostic uncertainty is redistributed across existing institutional structures. Diagnostic exploration is progressively delegated from one specialty or institution to another, producing a chain of investigations that mobilizes considerable clinical and technological resources without necessarily generating an integrative clinical interpretation.

From the patient's perspective, these processes translate into prolonged and often exhausting care journeys. Repeated consultations, parallel investigations, and shifting clinical hypotheses generate uncertainty and practical burdens that extend beyond the clinical sphere, affecting professional activity, family life, and psychological well-being. The trajectories reconstructed here therefore reveal not only an organizational phenomenon but also a lived experience of fragmentation.

Within the Belgian healthcare system examined, prolonged clinical uncertainty appears to be managed primarily through sequential and loosely connected episodes of care rather than through integrated organizational responses. Because the trajectories reconstructed in this study derive exclusively from routine care data, they provide a direct observation of how the system operates under ordinary conditions, without the structuring effects of research protocols or dedicated pilot programs. The patterns observed therefore reflect the system's default organizational response in the absence of structured integration mechanisms.

These empirical observations can also be interpreted in light of disciplinary structures within contemporary medicine. Each medical specialty operates within specific epistemic and technological frameworks that define which clinical phenomena become visible and interpretable. When investigations fail to produce findings that are meaningful within a given disciplinary domain, diagnostic interpretation frequently stops at those boundaries. What becomes apparent in such situations is the absence of a transversal clinical position capable of integrating dispersed observations into a coherent account of the patient's condition. As Foucault argued in *The Birth of the Clinic*, the visibility of disease is historically and institutionally constructed through the organization of medical knowledge [51]. In this sense, Long COVID acts as a tracer condition that reveals how contemporary healthcare systems manage persistent diagnostic uncertainty.

Gendered dimensions of care journeys

A gendered dimension is also visible in the reconstructed trajectories. Women are consistently reported to be disproportionately affected by post-acute and chronic conditions [52, 53], including Long COVID. In the present cohort, women represented 67% of cases. This distribution must be interpreted within the broader context of well-documented gender bias in medicine, where women's symptoms are more frequently minimized, psychologized, or attributed to non-organic causes [54–56].

The coexistence of higher female prevalence and diagnostic uncertainty may therefore reflect a structurally coherent dynamic. A larger number of women enter care pathways because of higher disease prevalence, while gendered interpretative frameworks may simultaneously contribute to prolonged diagnostic investigation and referral. Under these conditions, biological vulnerability and sociocultural dynamics intersect to shape longer and more institutionally dispersed care journeys.

Such dynamics can contribute not only to diagnostic delay but also to experiences of delegitimization within healthcare encounters. From a feminist disability perspective, chronic exhaustion, fluctuating functional limitations, and social dependency intersect with gendered expectations regarding productivity and caregiving roles. As Smith et al. note, these intersections may amplify experiences of disbelief and marginalization among patients living with Long COVID [57]. The trajectories reconstructed here therefore illuminate how biomedical uncertainty and social dynamics combine to shape the lived experience of chronic illness.

Healthcare metadata and the visibility of fragmentation

The metadata interface examined in this study (Figure 2) reveals several structural inconsistencies within the organizational data layer. These include multilingual labels, heterogeneous naming conventions for clinical services, exposure of internal system identifiers to end users, and the mixing of administrative and clinical entries within the same interface. Such variability suggests the absence of a unified organizational reference model and limited semantic normalization across institutional systems.

Healthcare metadata thus participate in a particular regime of visibility. They allow institutional movements of patients to be traced across services and organizations, yet they simultaneously obscure the absence of coordination between those encounters. Digital infrastructures therefore do more than document healthcare activity: they also shape how fragmentation becomes visible and interpretable.

These dynamics are closely related to broader governance arrangements in health systems. In centralized Beveridge-type systems, integrated national infrastructures have historically facilitated standardized information systems and stronger organizational accountability [58, 59]. In contrast, Bismarckian systems such as Belgium rely on negotiated coordination between multiple actors, including insurers, hospitals, and professional groups [60, 61]. Information systems in such contexts often evolve in a heterogeneous and partially interoperable manner [62, 63], complicating the reconstruction of care trajectories and obscuring the systemic logic underlying patient movements.

Although the present observations are grounded in the Belgian context, similar patterns may arise in other health systems characterized by institutional plurality, diagnostic uncertainty, and digitally mediated coordination. Comparative research would be required to determine the extent to which these mechanisms operate across different organizational environments.

More broadly, the modeling of care trajectories through graph-based representations presupposes shared conceptual definitions of fundamental entities such as persons, healthcare organizations, and clinical services. Without such semantic alignment, relational modeling risks reproducing ambiguity rather than clarifying it. Ontological frameworks such as Systematized Nomenclature of Medicine–Clinical Terms (SNOMED-CT) offer potential solutions by providing structured representations of clinical actors, roles, organizations, and processes.

Visualization, narrative continuity, and clinical meaning

The reconstruction and visualization of individual trajectories (Supplementary Figure S2) played a role that extended beyond simple description. By transforming dispersed metadata into structured temporal representations, visualization altered the epistemic status of the data. Events that appeared routine when viewed in isolation became evidence of institutional dispersion and repeated investigation when assembled into a longitudinal structure.

This transformation also had a reflexive impact on the clinical perspective. The visual consolidation of trajectories echoed patients' accounts of fragmented and incoherent care experiences. Visualization therefore functioned as a form of epistemic intervention: it did not generate new clinical information but reorganized existing traces in a way that made structural fragmentation perceptible.

Addressing such fragmentation requires responses at both clinical and organizational levels. Clinically, attentive listening and reconstruction of the patient's narrative remain essential when diagnostic categories are unstable. Oliver Sacks emphasized how careful attention to lived experience can restore coherence in complex neurological conditions [64]. In situations where explanatory models remain uncertain, narrative continuity may help counterbalance the fragmentation produced by disciplinary specialization.

At the organizational level, structured approaches such as the Chronic Care Model proposed by Wagner provide a framework for coordinated management of complex chronic conditions [65, 66]. Such models emphasize proactive follow-up, multidisciplinary collaboration, and shared information infrastructures, offering potential pathways toward improved coordination for patients with Long COVID and similar conditions.

Toward scalable trajectory analysis

The reconstruction process described here also points toward the possibility of scaling trajectory analysis beyond individual cases. The Medispring® software used in this study allows the export of patient records in standardized formats such as the Patient Migration Format (PMF) and Software Migration Format (SMF). These files contain structured and unstructured clinical information, including physician notes, diagnostic indices, and hospital documents retrieved through the HUB infrastructure.

When aggregated across multiple patients and pseudonymized using natural language processing techniques, such datasets could enable systematic analysis of care trajectories at population level. Automated de-identification tools, such as those developed by the Assistance Publique–Hôpitaux de Paris (AP-HP) [67], can remove identifying information from clinical text while preserving medically relevant content. More recent approaches combine de-identification with automated phenotypic extraction using ontologies such as the HPO, as illustrated by the ClinFly framework [68].

When sufficiently large datasets become available, analytical techniques such as Group-Based Trajectory Modelling (GBTM) could be applied to identify clusters of patients with similar care trajectories [69]. Such analyses could contribute to evaluating patterns of healthcare utilization and identifying organizational bottlenecks in the management of complex chronic conditions.

Policy implications

The findings of this study suggest that routinely generated healthcare metadata may constitute a valuable resource for monitoring care continuity and institutional dispersion in complex chronic conditions. Because these data are produced as part of routine clinical activity, they provide a scalable and relatively low-cost means of observing system performance.

Health authorities could potentially use existing eHealth infrastructures to develop trajectory-based monitoring tools capable of identifying patterns of fragmentation and coordination gaps. In settings where formal care pathways are absent or weakly defined, such tools could help inform organizational reforms aimed at improving integration across institutions and levels of care.

More broadly, tracer-based trajectory analysis may provide a pragmatic framework for evaluating how healthcare systems respond to conditions characterized by prolonged diagnostic uncertainty. By making institutional movements visible, such analyses offer a way to translate dispersed data traces into actionable insights for healthcare governance.

Limitations

Several limitations should be considered when interpreting these findings. First, the analysis is based on three purposefully selected cases and was not intended to provide statistically representative estimates of healthcare utilization. The objective of the study was methodological and exploratory: to demonstrate the feasibility of reconstructing longitudinal care trajectories using routinely generated healthcare metadata. The cases were selected because they contained sufficiently continuous documentation to allow cross-institutional reconstruction.

Second, the metadata available through the regional health information hub provide information on the occurrence and institutional context of healthcare events but do not capture the full clinical reasoning underlying each encounter. As a result, the reconstruction describes patterns of healthcare utilization and institutional dispersion rather than evaluating the appropriateness of individual diagnostic or therapeutic decisions.

Third, the Belgian healthcare context, characterized by unrestricted access to specialist care and the absence of formal gatekeeping mechanisms, may influence the degree of institutional dispersion observed in these trajectories. Although similar patterns may exist in other decentralized healthcare systems, the generalizability of the findings to different organizational contexts requires further comparative research.

Finally, trajectory reconstruction relied partly on manual review and transcription of heterogeneous clinical documents. Although this approach ensured contextual interpretation of records, it may limit scalability. Future work combining standardized data exports, automated pseudonymization, and computational trajectory analysis could allow the approach demonstrated here to be applied to larger patient populations.

5 Conclusion

This pilot study demonstrates that routinely generated healthcare metadata, when interpreted alongside primary care clinical records, can be used to reconstruct long-term care trajectories in patients with long COVID. The trajectories observed reveal repeated circulation across institutions and specialties, accumulation of diagnostic investigations, and shifting clinical responsibility over time. Rather than reflecting coordinated pathways, these patterns suggest that prolonged clinical uncertainty is frequently managed through dispersed and sequential care episodes.

Although healthcare metadata do not contain clinical narratives, they capture the temporal structure and institutional dispersion of care. When combined with the longitudinal perspective of primary care, these data make visible organizational patterns that would otherwise remain difficult to observe, including fragmentation, duplication of investigations, and weak coordination across services. The findings also highlight the central but often under-documented role of general practitioners in maintaining continuity and attempting to integrate dispersed elements of care.

Beyond the specific context of long COVID, trajectory reconstruction from routinely generated data provides a methodological framework for examining how healthcare systems respond to emerging chronic conditions characterized by diagnostic uncertainty. In this perspective, patients with long COVID function as tracers of institutional dynamics: their prolonged movement across services exposes structural limits in coordination and accountability. These trajectories, however, represent more than organizational patterns. They reflect lived experiences of illness marked by uncertainty, functional decline, professional disruption, and repeated medical encounters. Long COVID thus reveals not only systemic fragmentation but also the human and economic consequences of delayed institutional adaptation within technologically advanced healthcare systems.

List of acronyms

AP-HP Assistance Publique–Hôpitaux de Paris

COMPaRe Community of Patients for Research

COOP/WONCA Charts for functional health assessment

DUSOI Duke Severity of Illness Index

EMR electronic medical record

GBTM Group-Based Trajectory Modelling

GP general practitioner

HPO Human Phenotype Ontology

HUB regional health information hub

ICPC International Classification of Primary Care

LC Long COVID

MUS medically unexplained symptoms

SNOMED-CT Systematized Nomenclature of Medicine–Clinical Terms

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Author Contributions MJ conceived the study, collected and analyzed the data, and drafted the manuscript. RVS and AI contributed to methodological guidance, interpretation of findings, and critical revision of the manuscript. All authors approved the final manuscript and agree to be accountable for the work.

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Ethics Approval All patients whose medical records were included in this study are managed within the Belgian patient–doctor contractual framework and provided informed consent for the anonymized use and publication of their personal data. The study protocol was reviewed and approved by the Ethics Committee of the University Hospital of Liège, Belgium (approval number 2022/23).

Data Availability Data supporting the findings of this study are available from the corresponding author upon reasonable request. No personally identifiable information was collected or included in the dataset.

Use of Generative Artificial Intelligence During the preparation of this manuscript, generative artificial intelligence (AI) tools were used solely to assist with language editing, clarity of expression, and organization of text. In addition, a large language model (ChatGPT, version 5.2) was used as a computational assistant for structured summarization of pseudonymized textual material, verification of internal consistency of event counts, and support for formula-based calculations as described in the Methods section.

AI tools were not used for study design, data collection, interpretation of results, or the formulation of scientific conclusions. All AI-assisted outputs were critically reviewed, verified, and edited by the authors. The authors take full responsibility for the accuracy, integrity, and originality of the manuscript.

Supplementary Material

This table provides descriptive clinical information to document the context in which care journeys unfolded. Data are reported as documented in medical records and patient-reported sources and were not used for comparative or inferential analyses. The table is intended to support interpretation of organizational and care pathway data presented in the main text.

Supplementary Figure S1 — COOP/WONCA Charts

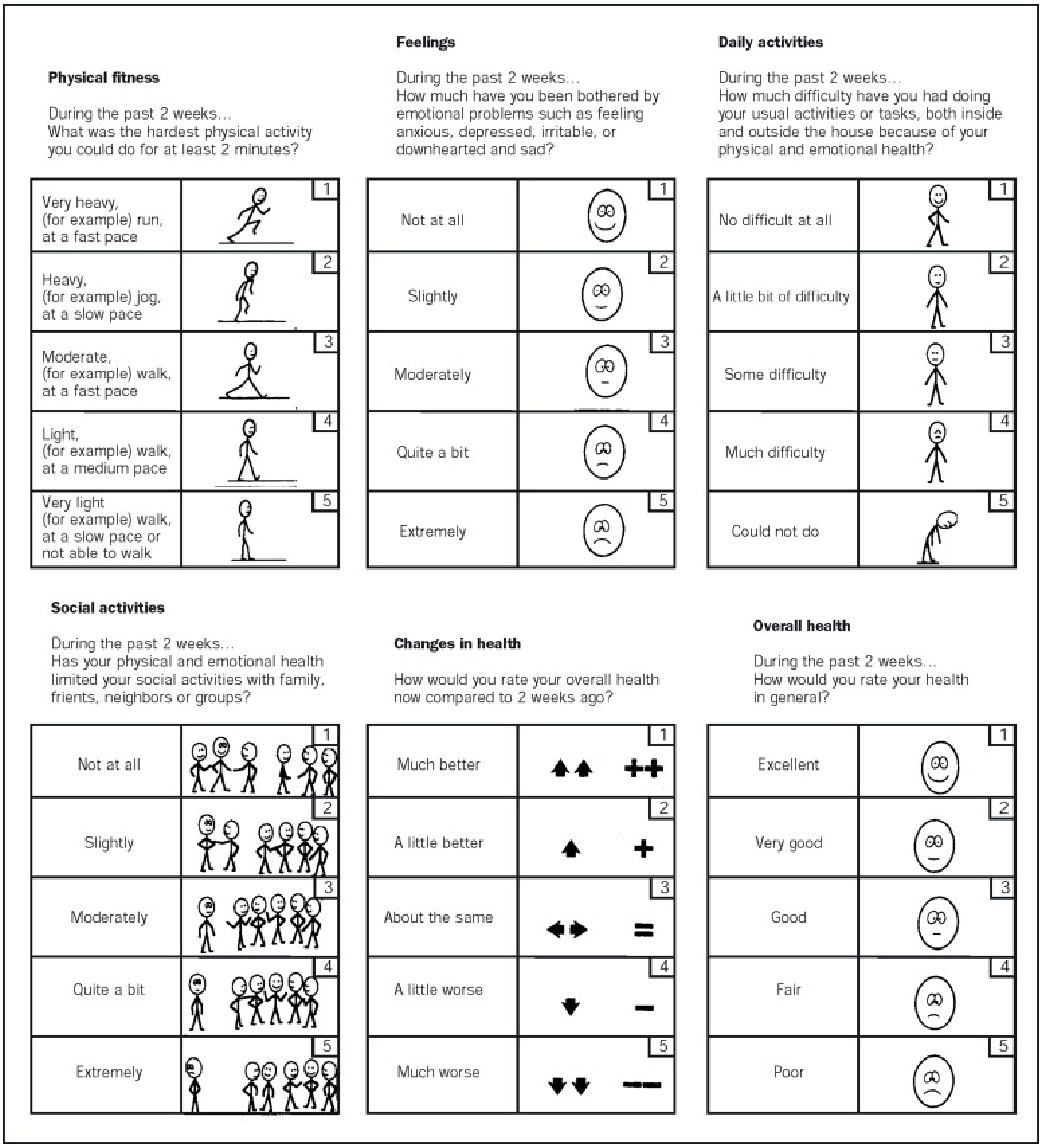

Figure S1: COOP/WONCA Charts for Functional Health Assessment. The COOP charts were originally developed by the Trustees of the Dartmouth COOP (Primary Care Cooperative Information Project) and subsequently endorsed and disseminated by WONCA through the work of the WONCA International Classification Committee [40, 70]. The charts are a patient-reported outcome measure of functional health status. Scores range from 6 (very good health) to 30 (extremely severe impairment). The French-language version was used in this study [71].

Supplementary Material S1 — Long COVID Clinical Questionnaire (English translation)

Foreword. The patient-facing version of this questionnaire is administered online in French via Google Forms as part of routine clinical care. The present English version is provided for transparency and methodological documentation. The content and structure correspond exactly to the instrument used in practice.

The questionnaire serves two purposes: (1) systematic symptom documentation to support clinical evaluation, and (2) structured data capture for phenotypic encoding using the Human Phenotype Ontology (HPO) within the reconstruction framework described in the Methods section. Responses are recorded under a pseudonymized alphanumeric identifier.

Dear patient,
You have requested my opinion regarding your current health status. The evaluation of an emerging disease requires collecting detailed and structured information. With your consent, I will consult your medical record through the Réseau Santé Wallon. Please answer the questions below and use the identifier sent to you by email.

General information

Identifier: MGA.xxx **Date of first contact:**
Age: **Sex:**
Occupation (including retired):
Primary care physician:
Regular specialist(s):
Long COVID care pathway: ☐ No ☐ Yes **Start date:**

Pre-existing health status

Significant health problems prior to COVID-19:

COVID-19 vaccination

Vaccinated: ☐ No ☐ Yes
Post-vaccination reaction: ☐ No ☐ Yes
Type: ☐ Local ☐ Systemic (fever, malaise, etc.)
Brief description:

Acute COVID-19

Date of first infection:
PCR confirmation: ☐ No ☐ Yes **Date:**
Multiple infections (dates and type of PCR/antigen tests):
Major acute symptoms:
Workplace exposure: ☐ No ☐ Yes
Duration of work leave:
Currently on work leave: ☐ No ☐ Yes

Long COVID

Diagnoses considered before Long COVID:
Who suggested Long COVID and when:
Main long COVID symptoms (brief description):
Specific treatments already undertaken (e.g., hyperbaric therapy, vagus nerve stimulation):

Symptoms (COMPaRe questionnaire, AP–HP)

Instructions: Tick the symptoms experienced. Underline those that are still present. See the original questionnaire at COMPaRe Long COVID (AP–HP).

Neurological ☐ Headache
☐ Brain fog / concentration difficulties
☐ Dizziness
☐ Paresthesia
☐ Memory impairment
☐ Loss or change of smell
☐ Loss or change of taste
☐ Word-finding difficulty
☐ Reduced sensitivity
☐ Tremor
☐ Balance disturbance
☐ None

General ☐ Fatigue
☐ Chills (with or without fever)
☐ Sleep disturbance
☐ Mood changes / irritability / low mood
☐ Muscle aches
☐ Weight loss
☐ Loss of appetite
☐ Sweating
☐ Drowsiness
☐ Sensitivity to heat or cold
☐ Hot flashes
☐ None

Chest ☐ Shortness of breath
☐ Palpitations / arrhythmia
☐ Chest pain or burning
☐ Cough
☐ Chest tightness
☐ None

Musculoskeletal ☐ Muscle pain
☐ Joint pain
☐ Back or neck pain
☐ Heavy legs / edema
☐ None

Digestive ☐ Abdominal discomfort
☐ Diarrhea
☐ Nausea / vomiting
☐ None

ENT ☐ Sore throat / difficulty swallowing
☐ Tinnitus
☐ Nasal congestion
☐ Ear pain
☐ Hearing impairment
☐ None

Skin and hair ☐ Hair loss
☐ Rash
☐ Dry skin
☐ Discoloration of fingers/toes
☐ None

Eyes ☐ Dryness / irritation
☐ Blurred vision
☐ Photophobia
☐ None

Vascular / lymphatic ☐ Circulatory disturbances
☐ Spontaneous bruising
☐ Blood pressure abnormalities
☐ Swollen lymph nodes
☐ None

Genitourinary ☐ Gynecological symptoms
☐ Urinary symptoms
☐ None

Free comments

Symptoms or information not captured above:

Figure S2: Healthcare utilization patterns by case: institutions, medical specialties, and laboratories.

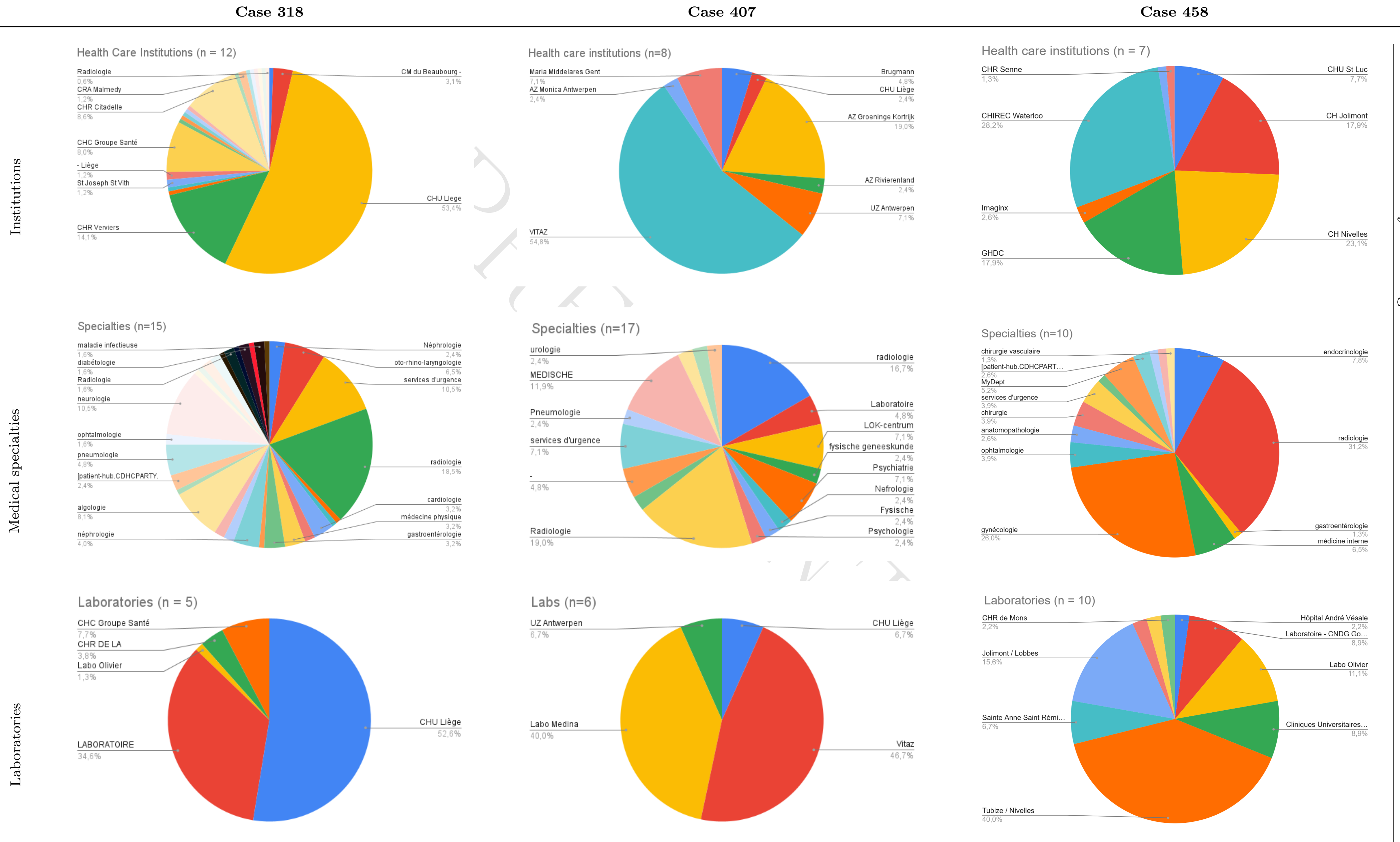

Table S1: Detailed clinical characteristics of three illustrative cases

Clinical data	**Case 318**	**Case 407**	**Case 458**
Sex	Male	Female	Female
Age at first COVID-19 episode (years)	48	27	35
Occupational status	Complete work cessation for 5 years	Work interruption denied by insurance fund; appeal ongoing	Part-time employment
Diagnostic labels found in medical reports	Major burnout; chronic fatigue	Fibromyalgia	Burnout
BMI	29.3	27.3	48.1
DUSOI severity index[1]	4	4	3
Technetium brain scintigraphy	Ongoing	Areas of poorly systematized hypofixation, notably frontal and bilateral parietal regions, and the lateral aspect of the anterior pole of the right temporal lobe	Heterogeneous cortical uptake across the cortex, particularly in the left frontal region; microangiovascular involvement reported
Notable biological findings	Low-titer speckled antinuclear antibodies; creatinine 1.3 mg/dL	B-cell and NK-cell lymphopenia with preserved CD4/CD8 ratio	Euglobulin lysis time: 1111 min (reference range 100-174)
COOP/WONCA score (PROM)[2]	27/30 (04 Mar 2025): poor perceived health, limited to light efforts, severe emotional impact, unable to perform usual activities, impaired social life; health status unchanged	24/30 (02 Sep 2025): fairly poor perceived health, limited to light efforts, moderate emotional impact, major difficulty with usual activities, moderately impaired social life; slightly worsened health	19/30 (14 Nov 2025): good perceived health, able to perform very light efforts, moderate emotional impact, some difficulty with usual activities, moderately impaired social life; health status unchanged
Index diagnosis (ICPC)[3]	L99 Cervical intervertebral foraminal stenosis (03/2015) U99 Mild renal insufficiency (03/2017) K86 Hypertension (03/2017) A77 COVID–19 (10/2020) A77 Long COVID–19 (08/2025)	A80 Accident injury (02/2004) P29 Autistic traits (11/2020) U85 Horseshoe kidney (02/2021) A85 Vaccination adverse effect (12/2021) A77 COVID–19 (07/2022) A77 COVID–19 (07/2025) A77 Long COVID–19 (09/2025) N71 Encephalitis (11/2025)	T82 Obesity, bypass (11/2010) A75 Mononucleosis (12/2014) A77 COVID–19 (03/2020) A77 COVID–19 (09/2020) A77 COVID–19 (11/2020) A77 COVID–19 (07/2022) A77 COVID–19 (12/2023) K86 Hypertension (11/2024) A77 Long COVID–19 (11/2025) N71 Encephalitis (01/2026)
HPO phenotypes (terms)[4]	Chronic fatigue; Cognitive impairment; Impaired concentration; Memory impairment; Brain fog; Dizziness; Tremor; Ataxia; Paresthesia | Insomnia; Non-restorative sleep; Nightmares; Decreased endurance; Post-exertional malaise | Anxiety; Panic attacks; Increased stress sensitivity | Hypoacusis; Tinnitus | Dyspnea; Tachycardia; Palpitations; Chest tightness | Nausea; Abdominal discomfort; Weight loss; Anorexia | Myalgia; Arthralgia; Bone pain | Hyperhidrosis; Cold intolerance | Ear fullness | Alopecia; Xerosis; Visual blur	Impaired concentration; Short-term memory impairment; Memory impairment; Word-finding difficulties; Unsteady gait; Orthostatic dizziness; Falls | Fatigue; Unrefreshing sleep; Excessive daytime sleepiness | Migraine; Visual blur; Hearing impairment | Palpitations; Tachycardia | Arthralgia; Myalgia; Back pain; Foot pain; Generalized pain | Abdominal pain; Abdominal distention; Diarrhea; Constipation; Lactose intolerance | Eczema | Menstrual irregularity	Cognitive impairment; Memory impairment; Aphasia; Vertigo | Fatigue; Hypersomnia | Depression | Hyposmia; Phantosmia; Hyperacusis; Blurred vision | Palpitations; Dyspnea | Myalgia | Menorrhagia; Urinary frequency; Recurrent urinary tract infections | Decreased libido; Lactose intolerance

[1] **DUSOI**: clinician-rated measure of overall illness severity (score range 0–4; higher scores indicate greater severity).
[2] **COOP/WONCA**: Patient-reported outcome measure assessing perceived health status, functional capacity, emotional well-being, daily activities, social functioning, and perceived change in health (score range 6–30; higher scores indicate poorer health).
[3] **ICPC**, as routinely used in Belgian primary care; diagnoses are reported as documented in medical reports, with dates indicating first documentation.
[4] **HPO**: Human Phenotype Ontology terms describing the main reported phenotypic features, extracted from patients' narratives, clinical anamnesis, and medical reports using a large language model; terms are listed descriptively for readability.