IHE EUROPE CONNECTATHON BRUSSELS 2026 MARCH 23/27

March 24, 2026, Brussels

“Connecting primary and secondary use of data in the EHDS: creating the conditions for real data fluidity”,

Workshop Session 2 : Addressing untapped public health needs - The Long Covid example

Reconstructing Patient Care Trajectories from Belgian Health System Metadata.

A cohort of >400 Long Covid patients

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Long Covid Cohort in Belgium



Marc Jamoulle



Johan Van Weyenbergh Rega Inst



Robert Vander Stichele

- **One general practitioner, focussing on Long Covid patients**
- **Using the medical record system Medispring**
- **Following a research protocol of data collection, communication with the patient and with the referring physician**
- **Integrating**
  - Medical record keeping coded in the international Classification of Primary Care
  - Data from the Belgian eHealth Hubs ;
    - lab results, imagery results,
    - discharge letters in PDF, vaccination,Sumehrs if any.
  - Structured patient-filled questionnaires, severity and functional status scores
  - Patient narratives
  - Systematic assessment of symptoms, and codification in Human Phenotype ontology
  - Biosamples for research; Biobank at Rega Institute

=> Since July 2021, gold standard clinical data of more than 400 patients, followed for LC

Objective of this clinical data collection about a new disease

- Focusing on humanistic, holistic partnership for patient care
- Collecting patient expertise
- Exploring the disease trajectories and natural history
- Standardized record keeping
- Comparing phenotypes (symptom clusters) with multiomics biological data
- Ethical safeguards ;

    Belgian Patient Doctor contract

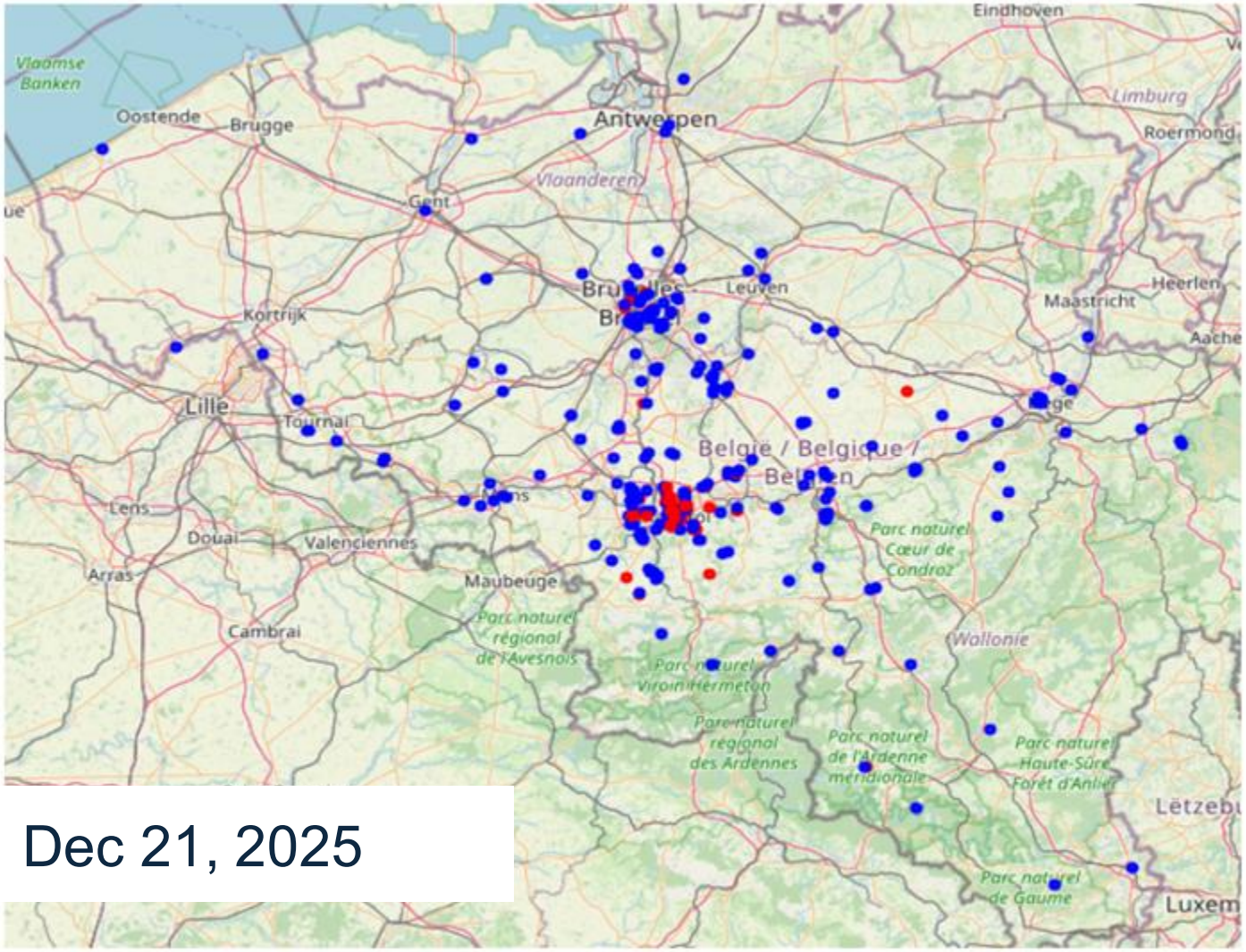
    ULiege Ethical committee approved

    Full informed consent of the patient

    Pseudonymized data

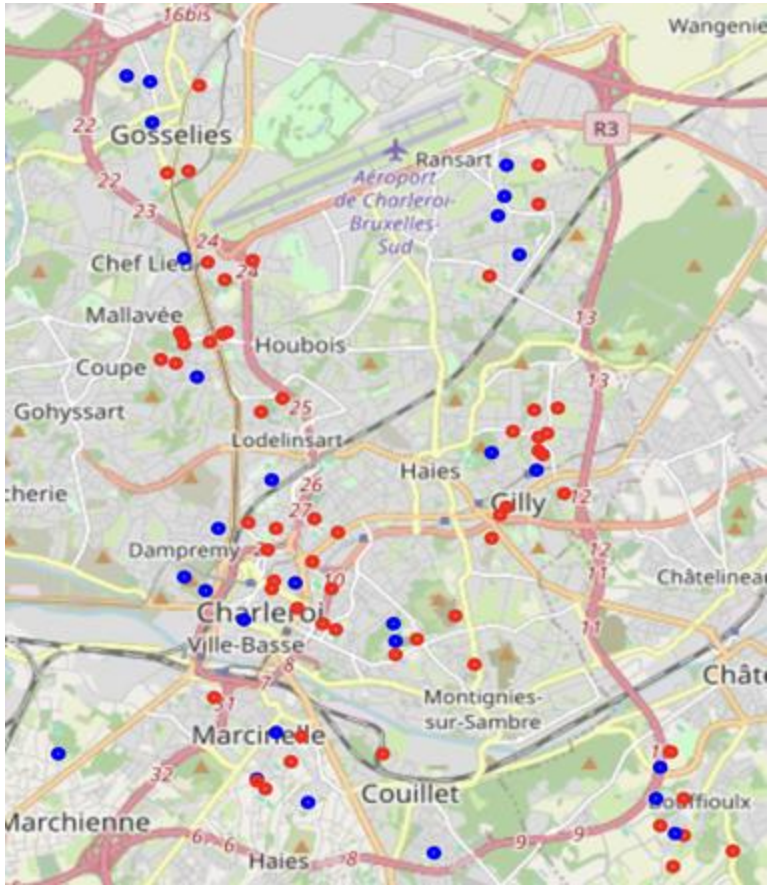
Descritpion of the cohort and some results

Geographical distribution



Dec 21, 2025

Figure 2.2 – Distribution of postal codes for patients consulting for suspected Long COVID. Red: 76 patients from the practice's historical panel. Blue: 249 patients with other primary care physicians. Status as of August 29, 2025 (Courtesy of Tarik Jamoulle, data engineer).



Belgium and Charleroi city maps

LC patients
In red: my patients
In blue: those of my colleagues who came to Charleroi for a consultation (2021–2025)

Demographic characteristics and severity viewed by physician and patients

(as for March 2026)

Global counts

- **Total patients (rows):** 435
- **Rows with no blank cells:** 380

Gender

- **Female (2):** 289 / 430 ≈ **67.2%**
- **Male (1):** 141 / 430 ≈ **32.8%**

ZIP code counts

- **Number of ZIP entries (non-empty):** 410
- **Number of different ZIP codes:** 188

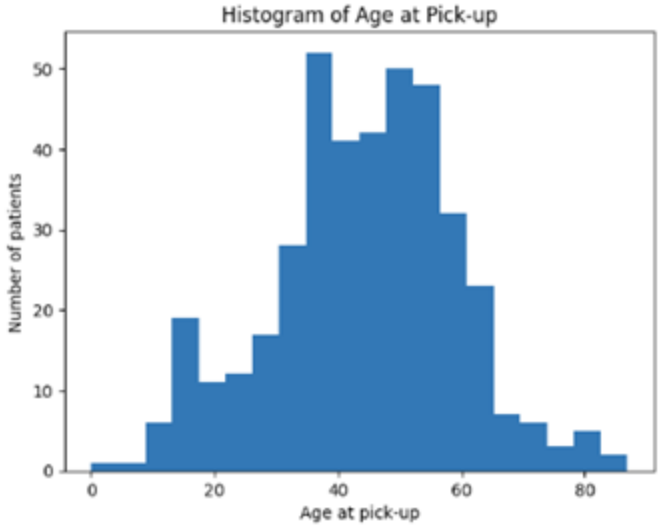
Patient_gp

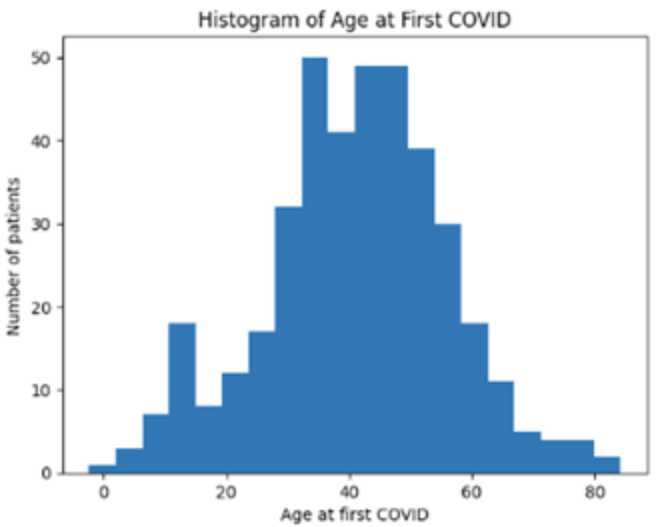
- **Patients of mine:** 82
- **External Belgian patients :** 345
- **Patients from France :** 6

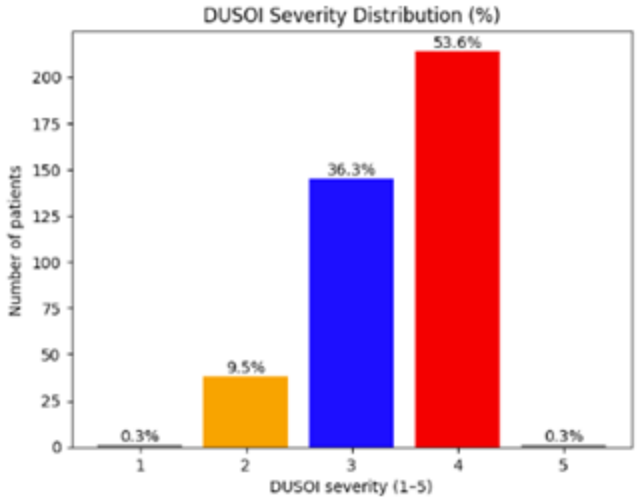
ComParE questionnaires available online 234 (Written ~80)

PROM Coop Charts 357 online

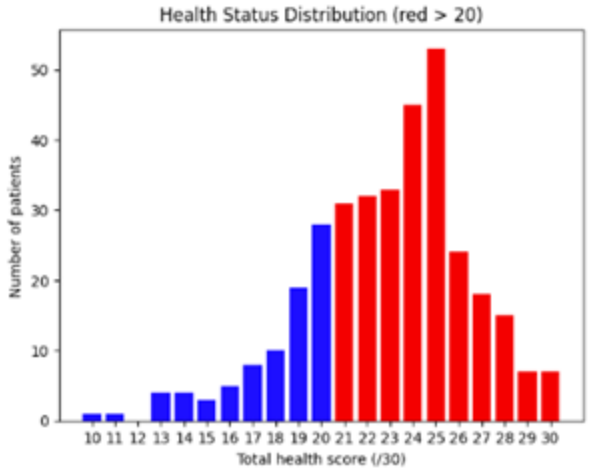
Clinical Report and Patient Migration Format > 350 available





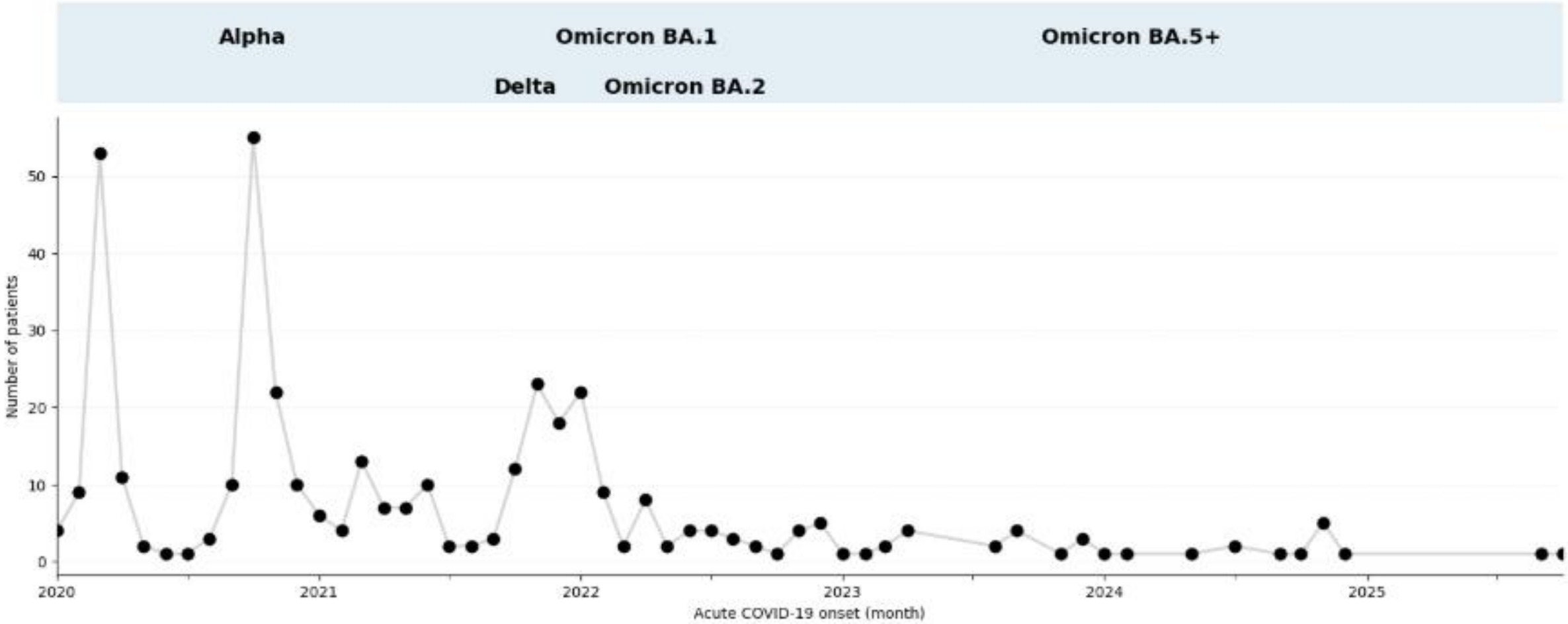


DUSOI results (doctor's view)
I severity (1–5, with 5 = death)
(on 399 patients).



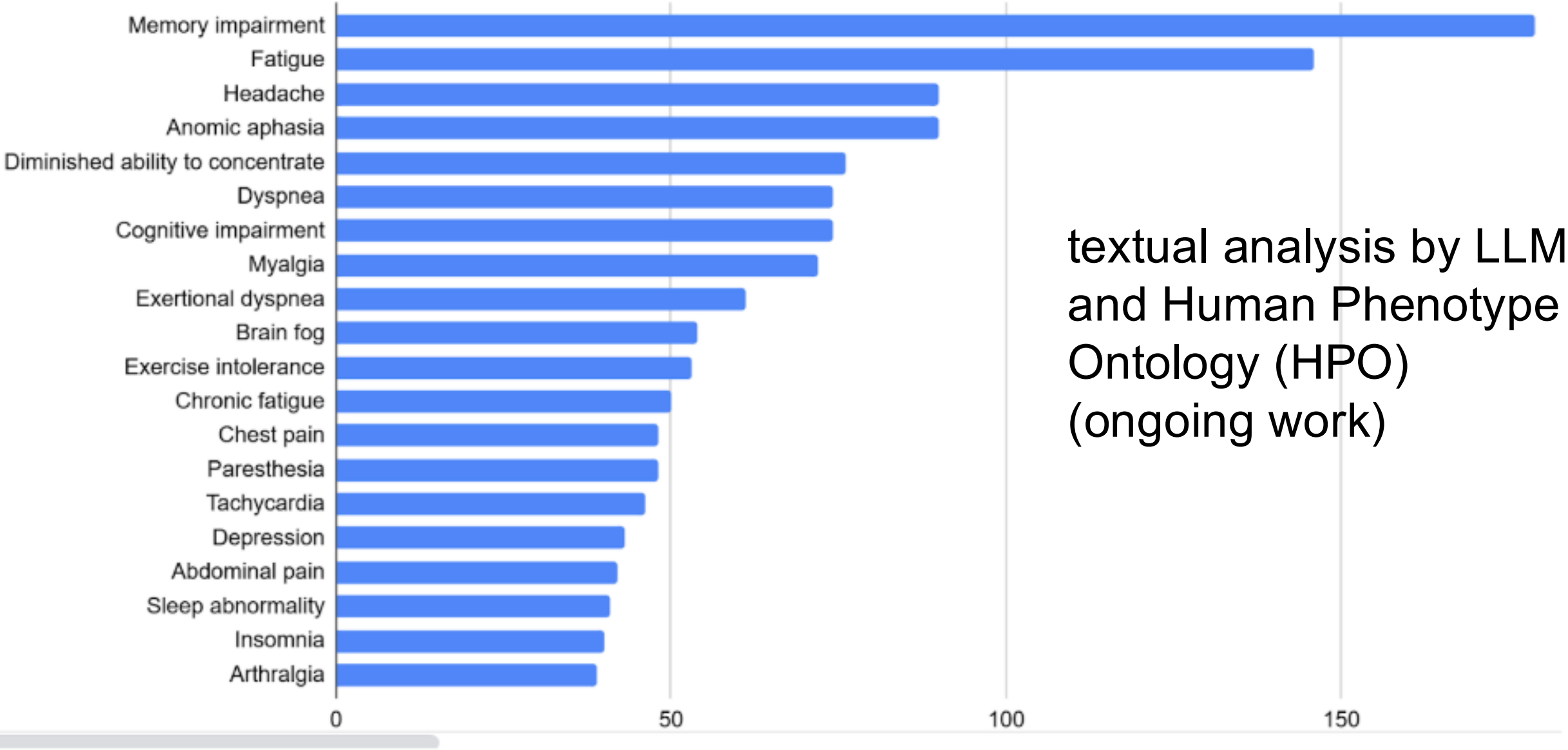
COOP Charts results (patient's view);
Patients with values over 20 are generally unable to work

The cohort as for Decembre 2025: analysing first acute covid date



Temporal distribution of acute COVID-19 onset in the whole patient population.
Monthly distribution of patients according to the date of acute SARS-CoV-2 infection (*first_covid_date*), with the x-axis starting in **January 2020**, corresponding to the onset of the COVID-19 pandemic. Black dots represent observed monthly counts, and the light grey line indicates temporal continuity. The upper timeline shows periods during which major SARS-CoV-2 variants were dominant in Belgium, based on **Sciensano** genomic surveillance data (Alpha, Delta, Omicron BA.1, BA.2, BA.5+). The study population comprised **382 patients**, including 256 females (67.0%) and 126 males (33.0%)., with ages ranging from **7 to 85 years** as for December 20, 2025. (M.Jamoulle, Charleroi,

Phenotypes distribution among 215 patients (preliminary study)



textual analysis by LLM and Human Phenotype Ontology (HPO) (ongoing work)

: Top 20 symptoms, out of 388 different symptoms observed in 215 Long COVID patients, identified using the Human Phenotype Ontology (HPO) based on analysis of patient verbatim reports or consultation notes. Automated coding performed by an LLM (ChatGPT-4o)

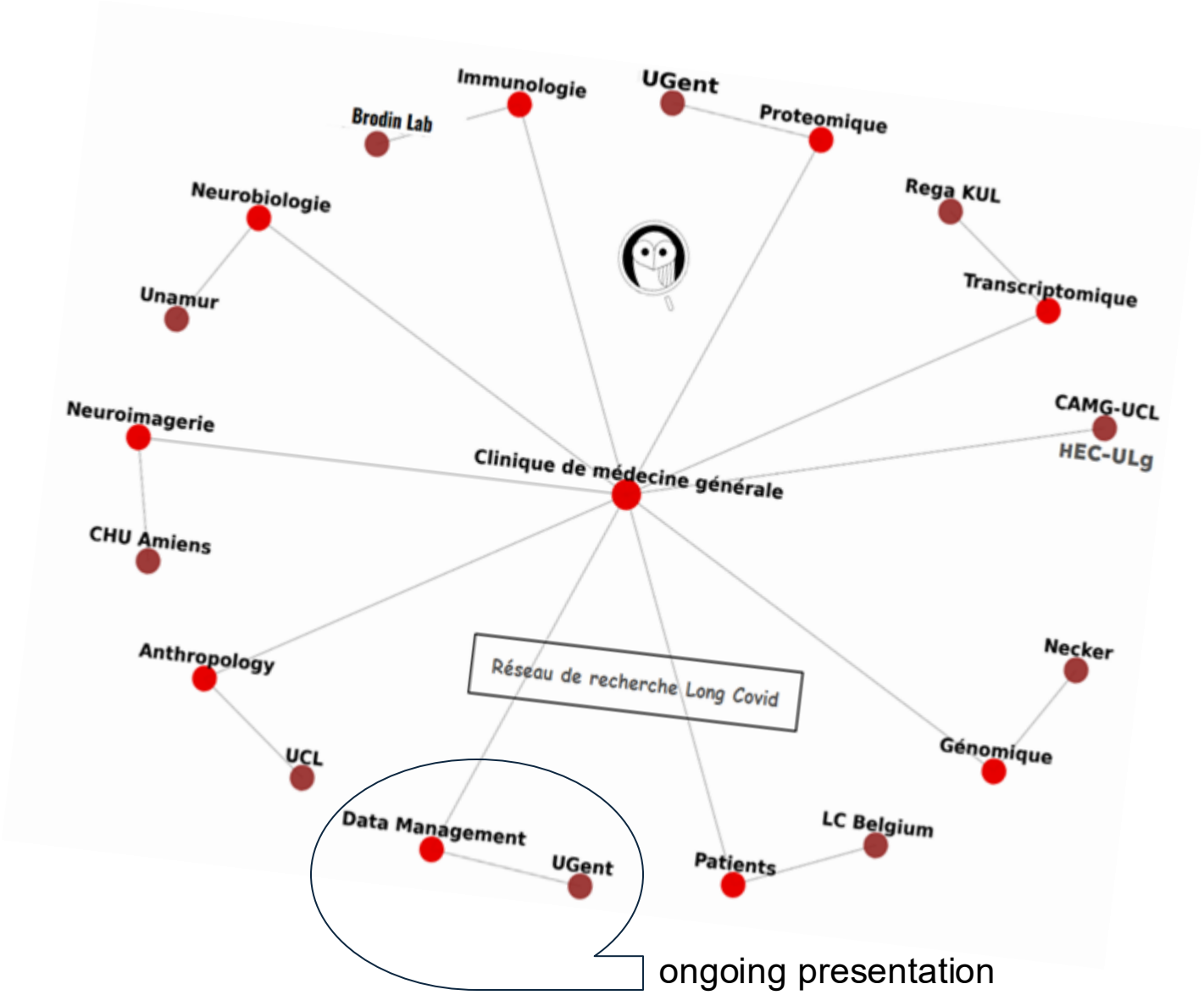
Long Covid Research Network; voluntary, unfunded, links scientists, family doctors, patients, students.

Research network

Multiomics
more than **300** blood samples, biopsies, CSF, sent to Rega Institute (KU Leuven) biobank for in collaboration with numerous labs

Imagery
More than **120** positive SPECT-CT
20 Magnetic Resonance SPECTROSCOPY (Prof Constans , Amiens)

Anthropology
Qualitative analysis
Follow up of patients on 5 years



Jamoulle, M. (Ed.) and the Long COVID Research Network. (2025). Long COVID, invisible illness. Charleroi, Belgium. 147 pp. ORBi — University of Liège. https://orbi.uliege.be/handle/2268/335655

Research results based on internal data set of the cohort

Bibliography of the Charleroi Long Covid Cohort of Dr. Marc Jamoulle

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- Jamoulle, M. (2022). Re: Addressing Post-COVID Symptoms: A Guide for Primary Care. *Journal of the American Board of Family Practice*, *35*(4). https://doi.org/10.3122/jabfm.2022.04.220006
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- *Rodriguez, L., Tan, Z., Lakshmikanth, T., Wang, J., Barcenilla, H., Swank, Z., Zuo, F., Abolhassani, H., Pavlovitch-Bedzyk, A. J., Wang, C., Gonzalez, L., Mugabo, C. H., Johnsson, A., Chen, Y., James, A., Mikes, J., Kleberg, L., Sundling, C., Björnson, M., … Brodin, P. (2024). Restrained memory CD8+ T cell responses favors viral persistence and elevated IgG responses in patients with severe Long COVID (p. 2024.02.11.24302636). medRxiv. https://doi.org/10.1101/2024.02.11.24302636
- *Jamoulle, M., Mignolet, M., Meyts, I., Ladang, A., Nicaise, C., & Weyenbergh, J. V. (2025). *Anticoagulant vs. antiviral therapy, recovery and neurodamage in Long COVID: A real-world prospective cohort study* (p. 2025.02.14.25322178). medRxiv. https://doi.org/10.1101/2025.02.14.25322178
- Jamoulle, M., Louazon, E., Antonacci, T., & Van Weyenbergh, J. (2024). Speed up relief for long COVID through grassroots clinical trials. Nature, 626(8001). https://doi.org/10.1038/d41586-024-00560-4
- *Jamoulle, M., Mignolet, M., Meyts, I., Ladang, A., Nicaise, C., & Weyenbergh, J. V. (2025). *Anticoagulant vs. antiviral therapy, recovery and neurodamage in Long COVID: A real-world prospective cohort study* (p. 2025.02.14.25322178). medRxiv. https://doi.org/10.1101/2025.02.14.25322178

The research hypothesis within the Long Covid Research Network

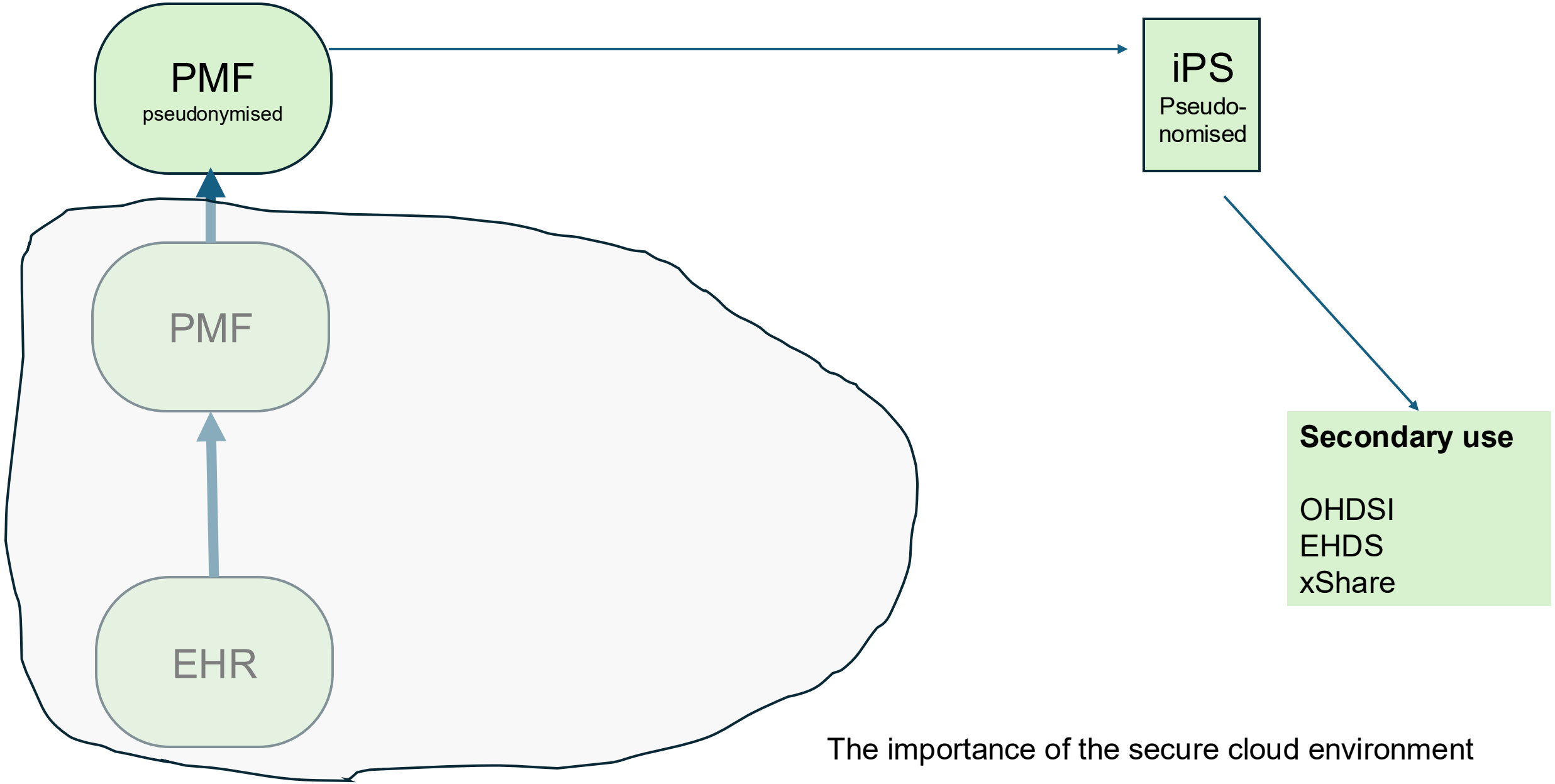
Our research hypotheses

Long COVID is a chronic viral disease, severely disabling, fluctuating, neurotropic, and multisystemic.

In public health terms, its impact is as significant as that of multiple sclerosis.

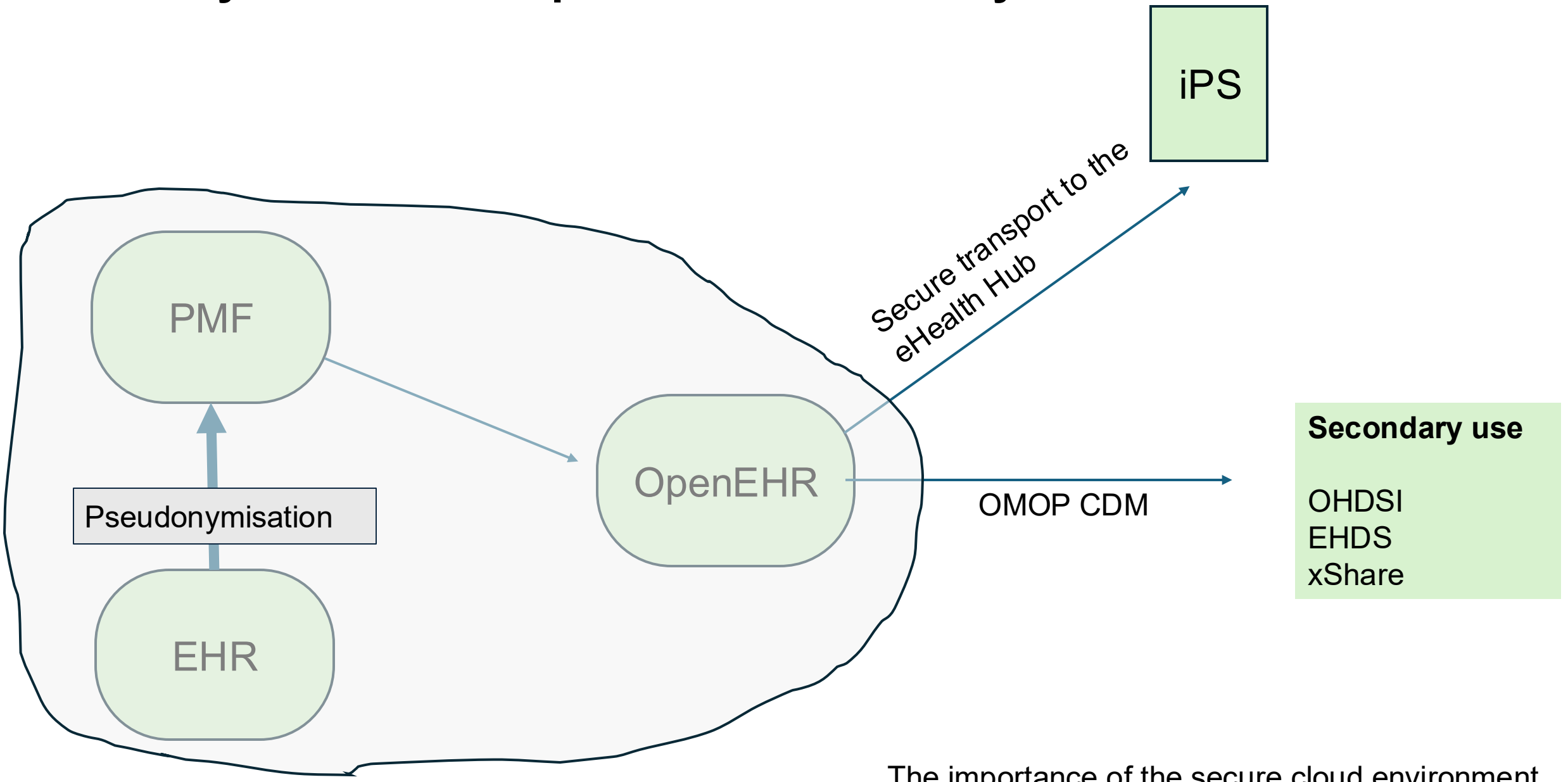
Perspectives on sharing clinical data for secondary use

Current pathway for secondary use



The importance of the secure cloud environment

Pathway under development for secondary use



The importance of the secure cloud environment

Requirements for sharing these data for secondary use with the EU initiatives (xShare, EHDS) and OHDSI

- Development of safeguards for privacy and ethical conduct
- Guaranties for maintenance of the cohort
- Further standardisation of the primary data with multi-terminology
- Expansion to other practices

Thank you contact ; Robert.VanderStichele@UGent.be