

xShare: Expanding the European EHRxF to share and effectively use health data within the EHDS

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

Innovative workflow: The Long Covid use case

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Patient Story

- In March 2022, Nathalie contracted Covid-19. Although the initial infection was moderate, she never fully recovered.
- She has since experienced chronic fatigue, muscle pain, cognitive difficulties ("brain fog"), and increased stress sensitivity.
- The repeated visits to the GP and specialists were leading to no or contradictory conclusions and Nathalie began to feel very much isolated.
- She was diagnosed with **Post-Covid Syndrome (Long Covid)** by a specialized clinic in Brussels.
- She alternates between working and taking sick leave.
- Nathalie understood then that her data could help the research and tried to identify clinical and public health studies in which he could be enrolled

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Nathalie

Age : 45

lives alone with her teenage son in Namur; Secondary school language teacher (currently part-time due to illness)Education: Master's Degree in Romance Philology

Personality and interests

Curious, persistent, and actively engaged in her health journey.She enjoys reading, listening to science podcasts, and taking gentle walks.

ORGANIZED — DISORGANIZED

EXTROVERT — INTROVERT

EMOTIONAL — RATIONAL

"Lorem Ipsum

Conditions and Problems

Severe chronic fatigue -Concentration and memory issues- Frequent headaches- Joint and muscle pain- Shortness of breath upon exertion-Sleep disturbance

Allergies and Intolerances

No identified issues

Medication & Therapies

Prescribed: Amitriptyline (for neuropathic pain)Vitamin D and B12Paracetamol Occasional anti-inflammatories

Non-prescribed:Natural supplements (magnesium, ginseng)Guided meditation and breathing exercises

History of relevant procedures

Neurocognitive testingPulmonary function testsRegular blood panelsBrain MRI (normal)

Relevant results

Laboratory results

Mild persistent inflammation (CRP 8 mg/L

Mild cognitive impairment on MoCA test

No organ damage identified

Imaging results

Lorem ipsum

Relevant discharge reports

Lorem ipsum

Lorem ipsum

[other health information]

Lorem ipsum

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Sharing my health information

VERY WILLING — VERY UNWILLING

2

Download and Store

wants to keep personal copies of her medical data

Share with health care professional

My reports are automatically shared with all HCP i am in care relatinship with though the national EHR.

Share with trusted one

Yes with my sister

Share for secondary use / research

Open if the project is transparent, anonymous, and secure

[other]

Lorem Ipsum

Lorem Ipsum

How I prefer to interact with Healthcare providers

Prefers in-person consultations for diagnoses and examinations Uses MyHealthViewer to access lab results Appreciates SMS reminders for appointments

Care Professional Concerns

Variety of hard-to-objectify symptoms

Need for multidisciplinary coordination

Fatigue affecting treatment adherence

Risk of psychological isolation

Lack of (updated) reference clinical guideline

Health routines

Daily therapies ad frequency

Respiratory physiotherapy twice per week

Daily mandatory naps

Monthly GP visits,

Occasional Specialist visits

Biweekly psychological visit

Most time consuming or difficult activities

Coordinating care and traveling to Brussels

Dealing with daily tasks (cleaning, cooking..)

My most trusted advisors

My sister, Individuals part of the FACEBOOK support group and my psychologist.

No of HCP that I interact with: 4

GP, Specialised Clinic (pulmonologist, neurologist) , psychologist X

Health goals / Motivation

Stabilize health condition -Regain energy to return to full-time work -Be heard and taken seriously by professionals

Pain Points / Problems

Medical

Invisible symptoms often dismissed

Lack of coordination between providers

Difficulty navigating between GPs, specialists, insurance, and sickness benefits.

Social

The disease has led to isolation due to fatigue and unprevisibility. No possibility of projection- only "coping".

Psychological

Losing self confidence and feeling depressed. Uncertainty about future.

How I feel about these problems?

Feeling abandoned in the healthcare system

Autonomy

Impairment

struggles to maintain stable routines, relies on her support network for help with errands and transport during flare-ups

VERY INDEPENDENT — VERY DEPENDENT

4

Health Literacy: Reads extensively about her condition but finds medical jargon (especially neurological terminology) sometimes difficult

VERY HEALTH LITERATE — VERY ILLITERATE

3

Digital Literacy

PC	2
MOBILE	3
SOCIAL MEDIA	✓
CONNECTIVITY	✓

Support Network

Long Covid Facebook support groups

In case of emergency

My sister is the reference person

Use of health navigation tools

National/Regional apps

MyHealthViewer

sometimes confused by the split between federal and regional systems

HCP apps

NA

PHR apps

Helena APP

[Other tools]

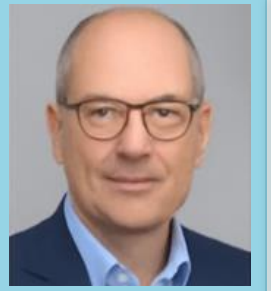
Google Calendar for appointments

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GP Story

- During his years of practice, Dr. Lambert has witnessed many changes in medicine. One of the most challenging in recent years has been the emergence of **long COVID**, which brought new uncertainties for both clinicians and patients. Many patients presented with persistent and diverse symptoms that appeared long after the initial infection, making recognition and diagnosis difficult. At times**, Dr. Lambert found it challenging to identify long COVID or provide adequate support**, and both he and his patients often felt there were few clear answers or coordinated care pathways.
- Over time, **he adapted his approach** by listening more closely to patients, acknowledging uncertainty, and **recognising the importance of patient-reported experiences**. Patients themselves often played a key role in describing symptoms, patterns, and the impact on daily life.
- With the implementation of the **EEHRxF**, Dr. Lambert now sees a positive shift. Patient discovery by relevant authorities — always within the framework of patient consent — has become easier and more transparent. Patients can actively share their data for secondary use, contributing to research and a better understanding of complex conditions such as long COVID. At the same time, both patients and general practitioners feel part of a shared ecosystem, where knowledge develops collaboratively rather than leaving individuals isolated.
- When an alert identifies a potentially relevant patient, Dr. Lambert explains the initiative, supports the completion of PROMs and PREMs through the “yellow button,” and ensures full transparency about the origin and use of the data. For him, this represents a step toward more collaborative medicine, where patients and clinicians work together and patient voices contribute directly to generating new knowledge.

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Dr. Lambert

Age: 59
Location: Liège, Belgium
Education: MD in General Practice, training in psychosomatic medicine
25 years of practice

Personality & Interests:
Empathic, reflective, tech-curious but pragmatic. Enjoys anthropology books, cycling, mentoring.
Community Role: GP with ~1,600 patients; active in regional GP network

Over the past three years, Dr. Lambert has followed an increasing number of patients with post-viral syndromes, including Long COVID.

ORGANIZED — DISORGANIZED

EXTROVERT — INTROVERT

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Role:

Primary care physician, first point of contact for chronic/emerging conditions.

Challenges:

- Managing uncertainty around long COVID
- Avoiding over-medicalization while not dismissing symptoms
- Integrating fragmented specialist reports

Coordination responsibilities

- Consolidates fragmented specialist reports
- Translates specialist findings into understandable information for the patient
- Helps patients navigate administrative aspects (sick leave, insurance forms)
- Monitors the evolution of functional symptoms over time

Opportunities

- Support patient´s active role by checking patients´´s self uploaded data
- Acts a s a bridge between patients and public health authorities interested in contacting patients for specific purposes

Daily Practice:
Morning consultations, EHR dashboard review

Relevant stakeholders:

- Patients
- GPs
- Public health authorities
- Hospitals

Attitude:

- Very supportive of patient empowerment through flagged self-reporting .
- Dr. Lambert verifies compatibilitty of patients for specfific initiatives organized by public health authorities

Goals:

- Better continuity of care
- Contribute to public health surveillance
- Build patient trust through visible impact of their input

Data Sharing activities:

- Reviews EHR
- Checks self-flagged data
- Receives requests for recruiting patients
- Contacts patient to explain recruitment
- Supports PROMs/PREMs completion via “yellow button”

Data Handling:

- Ensures self-reported data is flagged
- Cross-validates but does not overwrite entries

Concerns:

- Administrative overload
- PROMs/PREMs must complement, not replace dialogue with GP
- Lack of structured and validated data
- GDPR compliance & data protection

Routine

- Dr Lambert sees an average of 30 patients per day
- He listens to patient´t´s symptoms and performs medical examinations
- Enters data in EHR
- Prescribes therapies

Frequent symptom patterns observed:

- Persistent fatigue and post-exertional malaise
- Cognitive dysfunction (“brain fog”)
- Headaches and sleep disturbances
- Shortness of breath without clear pulmonary pathology
- Anxiety and emotional distress linked to uncertainty

Approach to medically unexplained symptoms
Dr. Lambert prioritizes:

- Validating the patient’s experience
- Explaining uncertainty without dismissing symptoms
- Avoiding premature psychological attribution
- Providing structured follow-up to reassure patients

Convinced that clinic and medical research must increasingly be both part of any clinician

Becomes « de facto » a **referral person** for many patients lost in errancy.

Regrets lack of (financial) support to consolidate data dn findings and

Use of patient-generated data
Dr. Lambert reviews:

- fatigue scales
- symptom tracking
- cognitive complaints
- functional limitations
- reported through patient apps or questionnaires.

Support Network:
Regional GP network, hospital specialists, public health agency, patient associations.

Digital Tools:

- Online search engine for biomedical and life sciences literature.

- National EHR with yellow button
- PROM/PREM platforms and tools
- Secure public health messaging app

Constraints:

- Limited time per patient
- Mistrust due to history of dismissal in long COVID
- Fragmented insurance & care systems

Care Professional Concerns:

- Variety of hard-to-objectify symptoms
- Need for multidisciplinary coordination
- Fatigue affecting treatment adherence
- Risk of psychological isolation
- Lack of updated clinical guidelines



Jeanne

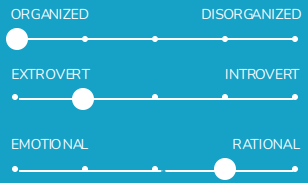
Age: 52

Lives in Paris with her partner.
Current role: Senior Policy Officer at the French Ministry of Health, working on digital health strategy and EU projects.
Education: Master in Public Policy, specializing in health systems and governance

Personality and interests

Enthusiastic, proactive, and analytical. Believes in using digital innovation to empower patients and strengthen healthcare systems.

Enjoys reading European health strategy papers, attending conferences for networking purposes, and cycling on the weekends.



Conditions and Problems (Policy-Level)

- Fragmentation between national, regional, and EU health systems
- Limited resources for national digital infrastructure
- Protect patient data while enabling clinical research
- Complexity of cross-border legal data sharing frameworks
- Align French strategies with EU-level frameworks (EHDS, EEHRxF)

Policy Priorities

- Accelerate France's implementation of the EHDS
- Promote ethical and secure health data sharing
- Strengthen collaboration with patient associations and research bodies
- Support innovative clinical trials through improved data availability
- Position France as a leader in European digital health

Opportunities

- Use tools like the xShare Yellow Button to build citizen trust by giving them agency over data sharing
- Strengthen France's role in Long Covid research by linking national cohorts to EU studies
- Leverage interoperability standards to reduce administrative burden
- Promote AI and advanced analytics while maintaining transparency and ethics

Relevant Stakeholders

- French Ministry of Health
- INSERM, CNRS, and university hospitals
- EHDS implementation projects
- Patient associations and advocacy groups

Attitude towards data sharing

- Strongly supportive of secure, ethical data sharing
- Views initiatives like the xShare Yellow Button as crucial to building trust and empowering patients

Goals for Data Sharing

- Enable recruitment into Long Covid clinical trials and strengthen research for understudied conditions
- Promote secondary use of data for innovation, public health surveillance, and AI development
- Support cross-border collaborations following the EHDS framework
- Demonstrate to citizens the benefits of sharing data
- Ensure France remains a leader in European health data initiatives

Concerns and Barriers

- Ensuring GDPR compliance and national data protection law oversight
- Risks of misuse of patient data
- Fragmentation between national, regional, and EU systems
- Avoiding duplication of projects across EU
- Lack of long-term financial sustainability for data-sharing platforms

Enablers to Advocate For

- Citizen-centric tools like the xShare Yellow Button
- Interoperability standards and data exchange formats
- Data governance frameworks that balance privacy with research use

Routines

- Daily scans of EU and national health policy briefs
- Strategy meetings with the Ministry of Health and National Data Protection Authority
- Public consultations with patient associations
- Reviews of Long Covid project reports and dashboards

Decision Drivers

- Evidence from data pilots and real-world case studies
- Alignment with EU Commision regulations
- Budget feasibility and sustainability
- Political support
- Public trust and societal acceptance

Problems

- Overlapping projects with unclear coordination
- Need to translate technical jargon into policy / scientific language
- Limited resources for implementation
- Administrative burden for care providers
- High expectations from patient groups and researchers

Behavioural Traits

- Collaborative and consensus-driven, but firm on ethical issues
- Prefers structgured briefs to long presentations
- Open to innovation but cautious about scalability

Autonomy

- Significant influence in shaping France's digital health strategy
- Must balance between EU obligations and national political priorities

Policy Literacy

- Knowledge of EU health data governance, GDPR, and national law
- Familiar with interoperability frameworks (EEHRxF, HL7 FHIR)
- Tracks progress of EU-funded projects

Digital Literacy

- Comfortable with digital dashboards, secure data platforms, and policy portals
- Relies on technical staff for detailed programming and system architecture analysis

Support Network

- Ministry of Health colleagues in digital health and clinical trials
- EU-level working groups
- Patient associations
- Policy think tanks and OECD/WHO advisors

Use of policy navigation tools

- HealthData@EU platform for interoperability monitoring
- French national digital health dashboards
- Stakeholder consultation platforms
- Legal reference databases for GDPR/EHDS compliance

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The xShare Long Covid scenario

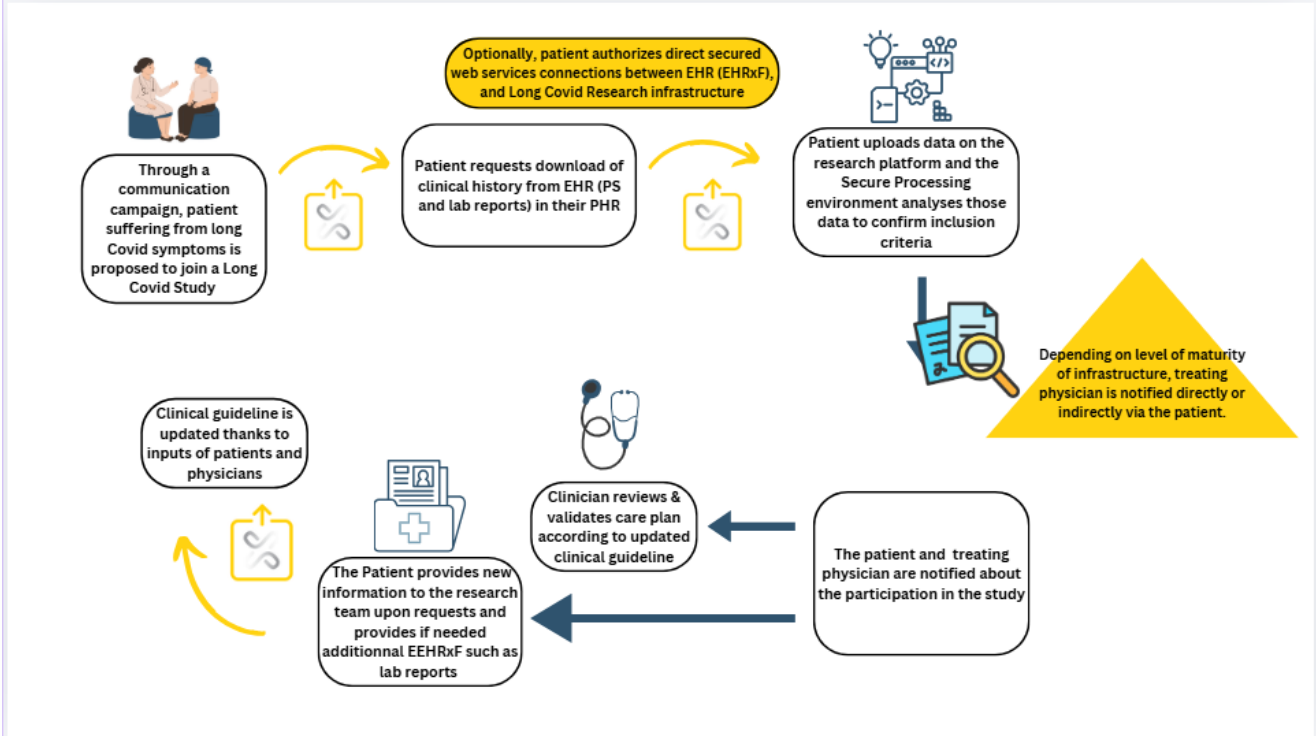
- In the xShare project, we explored various options – long COVID, hypertension and long-term pharmacovigilance. One example was **the capacity to identify patients who have possibly been affected by long COVID**. These patients are often faced with conflicting diagnoses and a lack of adequate follow-up.

- Identifying patients, who have either been diagnosed as having long COVID or who are affected by symptoms associated with the condition, **would enable the patients to be oriented towards adapted dedicated structures, to build longitudinal cohorts and consolidate knowledge and clinical guidelines with the direct support and input of the patients**.

- Ideally, this initiative would require access to repositories which include data from a global population. Even pending the complete implementation of the EHDS Regulation, however, **the yellow button will enable citizens to become active contributors to knowledge update and consolidation and hence of treatment improvement**.

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The xShare long covid use case



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IHE EUROPE CONNECTATHON BRUSSELS 2026 MARCH 23/27

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Addressing untapped public health needs: The Long Covid example

24 March 2026 | 11.15 – 12.45 CET



Carmen Van Looy
Flemish Authority



Robert Vander Stichele
University of Ghent & I~HD



Bianca Boxma-de Klerk
EPI – LUMC



Helena Leera
Helsinki University Hospital



Stefan Schrek
EU Commission – DG Sante

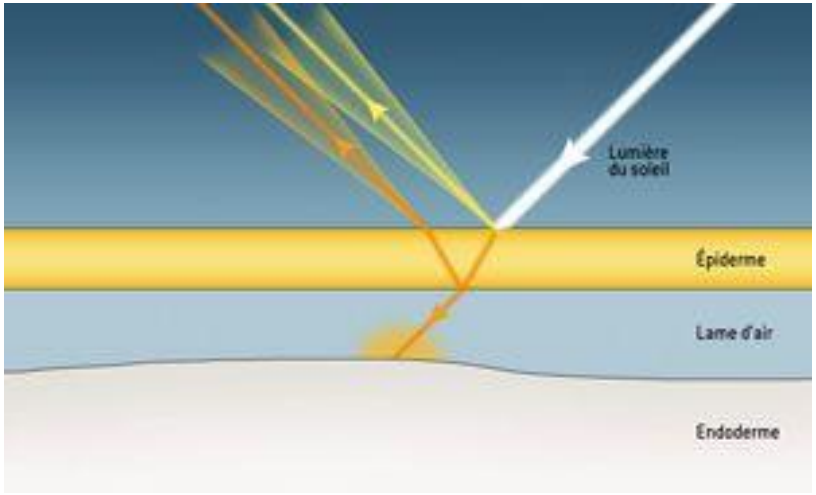
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Implementers Advancing Digital Health and Care Transformation

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THANKS





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