IHE® CONNECTATHON WEEK
EUROPE

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BRUSSELS

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

Tuesday 24 - 9.00 – 12,30

xShare
EHR Xchange Format

Co-funded by
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The current healthcare data ecosystem remains fragmented, with limited alignment between clinical, research, and public health data standards. The European **xShare** project addresses these issues by linking EHDS1 (primary use) and EHDS2 (secondary use).

It documents "only once" practices in four EU Member States—approaches that aim to reuse clinical data for secondary purposes. While fully integrated infrastructures show potential, challenges remain around semantic quality, provider buy-in, and resistance from data providers especially if multiple parallel data collection systems remain operational.

xShare has also studied major public health data flows and mapped them to the six EHDS primary use domains (prescriptions, dispensations, patient summaries, lab reports, imaging, and discharge summaries). This work includes "IPS+R" (International Patient Summary for Research), which outlines data needed for clinical, public health, and population-level use cases. From these, for public health, **xShare** has prioritized three priorities: healthcare associated infections, antimicrobial resistance and cancer.

xShare has been in close contact with the organisations who play a central role in the data collection process of those three priorities and has invited them to join this plugathon to discuss the new opportunities offered and the challenges ahead. Together with clinicians and medical information officers, we will also consider the impact on the data collection process with the perspective to reach near-real time monitoring, at least for the key variables.

But there is more, the EEHRxF may also support new innovative workflows in support of public and population health with the active participation of the patient such as in the case of Long Covid. Together with public health analyst, SDOs and clinicians, we will discuss how the EEHRxF can support active patient discovery which can then lead to an interactive and dynamic knowledge consolidation process.

This Workshop brings thus together representatives of the entire value chain - including the patient- to discuss innovative and sometimes disruptive data workflows which hold the promise of significant new benefits both for the patient and society.

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Agenda:

9:00- 9:15 **Welcome and Introduction. Luc Nicolas – EHTEL – xShare WP4 co-lead**
This introduction will briefly outline the lessons learnt from implementation projects aiming at collecting data at the source for secondary use in Belgium, Finland and Denmark.

9:15- 10:45 **Part 1: Fluidifying current major current workflows**
In this first session we will focus on the datasets which are already collected in all EU Member States, such as those related to infectious diseases.

Moderation by Eugenia RINALDI- Charité- Germany
Speakers:
Representatives from the following initiatives and organisations will discuss
European Centre for Disease Prevention and Control (ECDC): The EU Public Health authority perspective on standardisation of infection-related data
National Institute for Public Health and the Environment - The Netherlands - (RIVM): key interoperability requirements for early outbreak detection.
European Society of Clinical Microbiology and Infectious Diseases - study group dedicated to advancing AI, data standardization and interoperability in infectious disease (ESGAID): Highlighting the challenges of interoperability in microbiology data.
Academic and Research Network of Slovenia (ARNES): Reflecting on the need for standardisation for NCDs.
BioMérieux -world leader in clinical microbiology : reflecting on the use of OMOP is in microbiology.
CHR Haute Senne Hospital - Belgium: Reflecting on best strategies to connect hospital EHR in near real time to secondary use of data.
Health Level 7 Europe (HL7): Reflecting on wide profiling including primary and secondary use of data for specific health domain.
SNOMED International: Reflecting on global terminology mapping and links between terminologies such as SNOMED-CT and data models.

10:45 – 11:15 **Coffee break**

11:15- 12:30 **Session 2: Addressing untaped public health needs- The Long Covid example.**
Can the EHDS help us to identify untapped needs and problems in our health system and how can the patient play a key role to propose innovative answers to those needs?
The session will compare the different approaches followed by Public Health researchers and clinicians to address this issue and will discuss if and how the EEHRxF can help identifying citizens and patients who meet specific clinical criteria. It will also dicuss how to collect patients' inputs in a both actionable and meaningful way.

Moderated by Stefano Dalmiani- Fondazione Toscana Gabriele Monasterio (FGTM)- Italy
Participants:
The Belgian Long Covid GPs cohort: Robert Vander Stichele – University of Ghent and I~HD- Belgium: will present the innovative approach followed by a cohort of Belgian GPs led by MD Marc Jamoulle, MD, PhD which published “Long Covid, invisible disease”. The report documents its approach and findings with the direct involvement of a cohort of 307 patients.
The Long Covid project: This EU project led by Helsinki University Hospital (HUS) in Finland relies on 6 Long Covid cohorts (4 in Finland, 1 in the Netherlands and 1 in Switzerland). It main innovation is related to AI-ba-sed biomarker discovery on multimodal data and it proposes a Long Covid data portal to collect the data for LCS research and is developing novel methods for harmonizing and accessing integrated data.
Post-Covid Netherlands Network (PCNN) - TBC- Led by Leiden University Medical Center, this network is a national partnership bringing together (university) hospitals, patient associations, paramedical partners and organizations such as the RIVM
SNOMED-CT- Portugal: Licínio Kustra Mano will provide inputs on how SNOMED-CT can help incorporating patient inputs such as observations.
Patient Expert Center - Belgium: Stefan Gijssels will provide his input on empowering the patient to become a key health data provider.