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longCOVID

Decision support for prediction and management of LCS

LONG COVID EU HORIZON PROJECT

HELENA LIIRA MD, PHD
HUS, COORDINATOR

HOW WE GOT STARTED

- At HUS, the Long Covid clinic started in 2021
- We launched a cohort study to follow the patients clinically
- For the mechanistic EU proposal, we contacted biomechanistic researchers and clinical partners



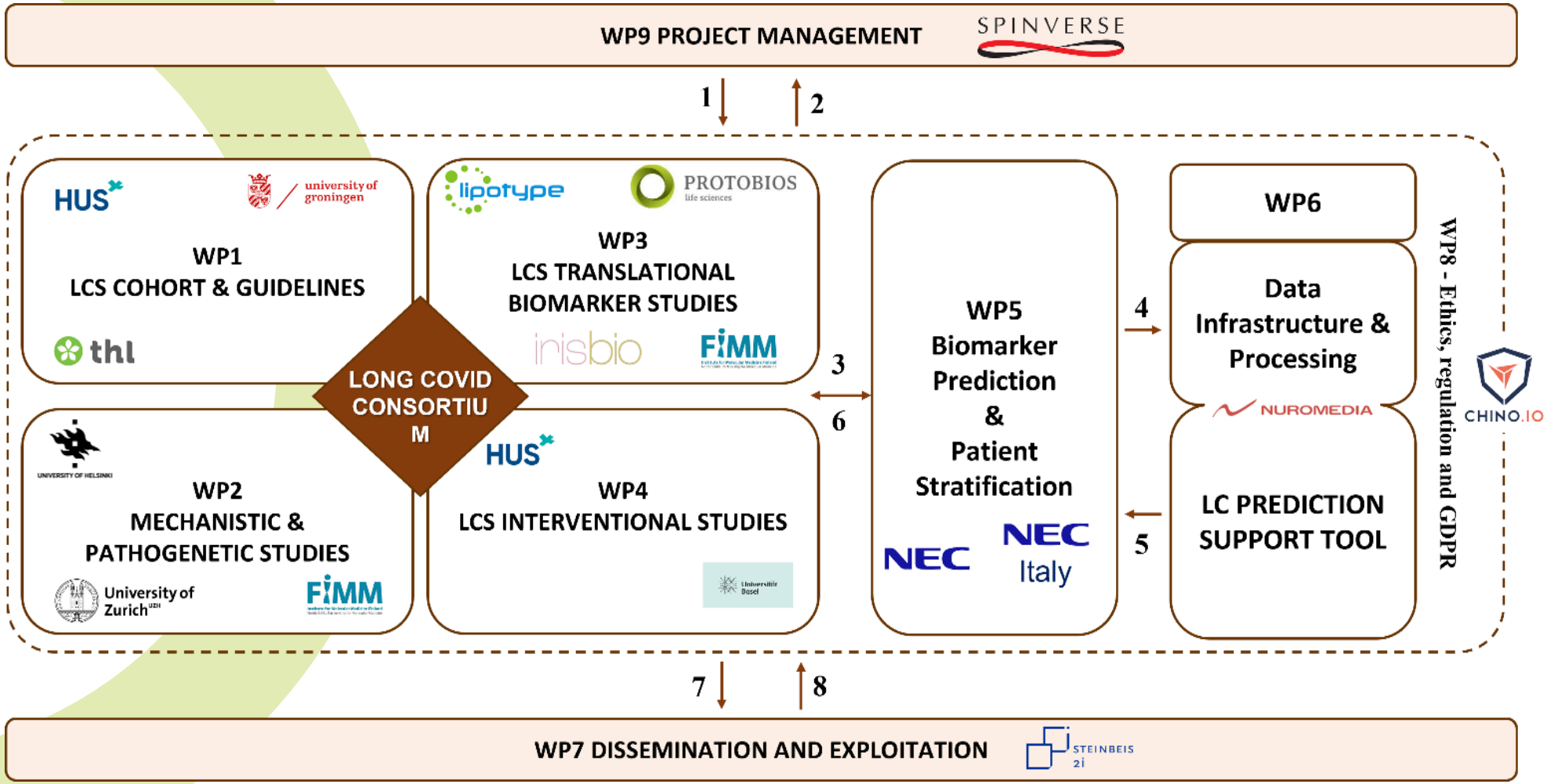


Figure 4: Workplan structure of the project with partners

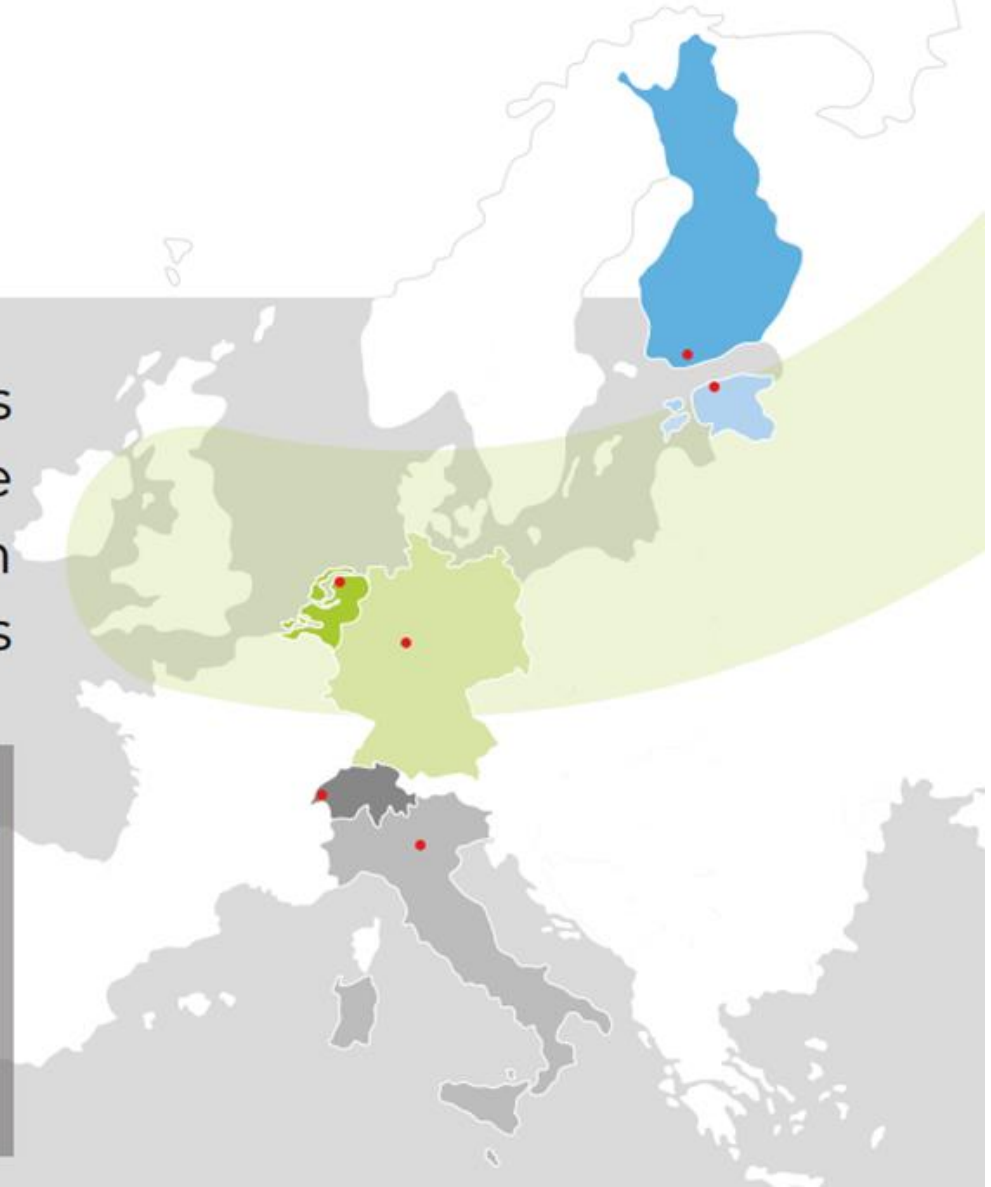
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Countries involved in the consortium & cohorts

Cohort 1 - Registry linkage cohort from the Finnish National Centre for Health and Welfare (NCHW)
Cohort 2 - LC policlinic – HUS
Cohort 3 - ClinCOVID Cohort – UH
Cohort 4 - ICU Cohort –UH

Cohort 5 - Lifelines – Dutch population cohort (UMCG – Groningen)

Cohort 6 - Basel LC Syndrome Cohort (BALCoS) – UNIBAS



DATA MANAGEMENT PLAN

- Originally, Nuromedia, a company in Germany was supposed to provide a data platform for the project.
- However, Lifelines clarified early on that their data would remain in the Netherlands due to data protection.
- When we got started in 2022, there was a strong recommendation from HUS IT that the data would need to be storage in HUS Acamedic, a new safe environment for data.

08.05.2026



HUS Acamedic

HUS Acamedic is a secure, scalable, virtual, audited operating environment that **meets the Finnish Secondary Use Act**.

HUS Acamedic also complies with Findata's regulations and is registered in Valvira's Toini register.

HUS Acamedic operates **on the public internet, virtually around the world** if necessary, so it also enables global research. HUS Acamedic is available not only for the public sector, but also for the private sector.

HUS Acamedic currently offers three virtual desktops on default to all groups to navigate the (operating) environment. The options are Microsoft Windows, Linux Ubuntu and HPC Linux (high performance computing). Virtual desktops run as Citrix virtual desktops.

The Long Covid Acamedic hosts all clinical & omics data of Finnish and Swiss patients

DATA HARMONIZATION

- We did not use OMOP or Snomed to code the data
- Harmonizing the data across data from two countries has been feasible

AI BASED BIOMARKER DISCOVERY

- Our partner NEC, a global technology company has performed the AI-driven analytics in HUS Acamedic
- Unfortunately, a biomarker seems not feasible
- There are several, disparate biological signatures
- Our challenge is to interpret whether they are signals of the mechanism or rather consequences of the lifestyle changes of long Covid

FAIR IMPLEMENTATION

- HUS Acamedic ensures full compliance with data protection and governance requirements
- Metadata are publicly available
- Data are accessible to external researchers through a formal application and approval process
- Access is granted within the secure environment (no data download)

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THANK YOU FOR YOUR ATTENTION

Helena Liira
HUS
Helena.liira@hus.fi

/ LinkedIn / Twitter www.longcovidproject.eu