



Building a European Children's Health Data Space

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An urgent need for timely and safe data sharing

- **Small numbers of complex pediatric and rare diseases patients per country**
 - ▶ Limited ability to conduct research, develop new therapies, and improve patient outcomes
- **Limited real-world data for newer expensive therapies**
 - ▶ Health technology assessment (HTA) bodies lack data and processes to evaluate treatment outcomes
- **Need for more engagement with Medtech industry & innovation ecosystems**
 - ▶ Large data sets are needed to leverage benefits of artificial intelligence and machine learning and support innovation
- **Many countries only have one or two children's hospitals**
 - ▶ Shared data are necessary for benchmarking to improve system performance and efficiency



PHEMS by the numbers

3-years

October 2023 - September 2026

7 M€

Funded through Horizon Europe and UK Research & Innovation

14
partners

Including hospitals, universities, technology, and biotech companies

Coordinated by



Partners



Hospitals and Universities



Technical and Business



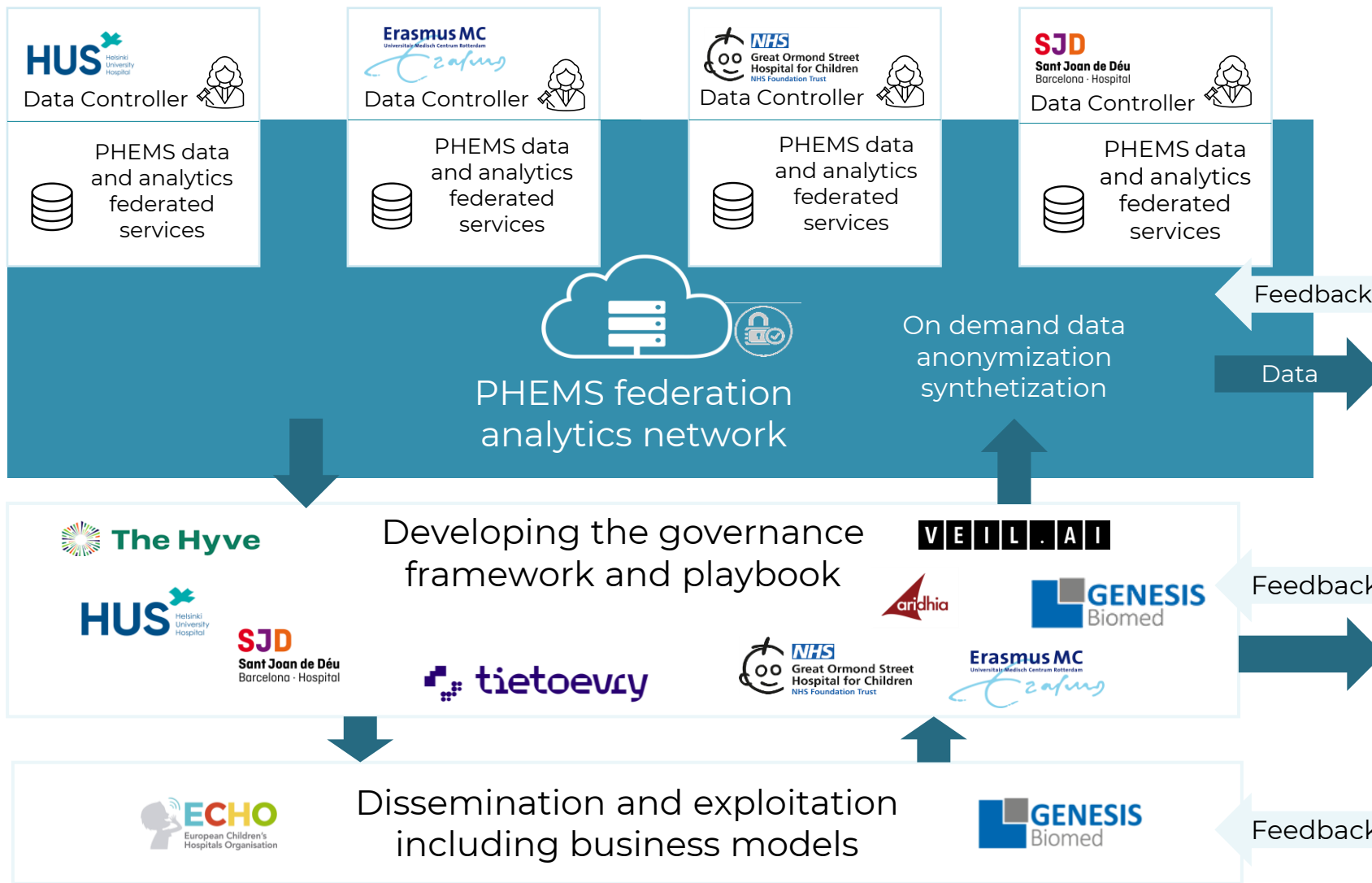
PHEMS transcends boundaries, supporting access and use of health data between children's hospitals and across borders

Objectives

- Increase access to health data while protecting patient privacy
- Advance federated health data analysis through predictive modelling and machine learning
- Enable on-demand generation of shareable synthetic and anonymized datasets
- Demonstrate the value of the data ecosystem using three clinical use cases in four countries

The project will create a **decentralized and open health data ecosystem** consisting of **technical components** and **governance frameworks**, empowering institutions to **collaborate without relinquishing control** over their data.

Project Overview



Validating the results

Clinical validation of synthetic data vs. raw data

Clinical Use case 1: Cardiology patients operation management

Clinical Use case 2: Pediatric Intensive Care Unit (PICU) Sepsis



Clinical Use case 3: Hematology; hemophilia



Validation of governance framework and playbook



Children's University Hospital Latvia

Evaluating the business models and accessibility through Hackathons



Demonstrating impact: clinical cases

1

Cardiology operations benchmarking

Supporting **creation of benchmarking standard** and **promote a culture of benchmarking** across pediatric cardiac institutions, enabling **the adoption of 'best-practice' across institutions**

Led by Great Ormond Street Hospital for Children (GOSH)

2

Pediatric Intensive Care Unit Sepsis

Investigating the benefits of the federated ecosystem to **develop, train and test algorithms to predict sepsis** on a large scale between pediatric intensive care units in four large European children's hospitals

Led by Sant Joan de Déu Barcelona Children's Hospital (HSJD)

3

Hematology - hemophilia

Developing and testing a machine learning-based prediction algorithm to improve treatment for pediatric patients with **hemophilia A or B**

Led by Erasmus University Medical Center Rotterdam (Erasmus)

The clinical cases use OMOP harmonized pediatric data from different hospitals, contributing to new clinical and organizational knowledge



Project Organisation



WP1 Project management and coordination

WP5 Governance and playbook, including privacy & cybersecurity

WP2 Platform architecture implementation

WP3 Data processing functions



WP4
Clinical use
case &
validation

WP7 Ethics
Requirements

WP6 Communication, dissemination, and exploitation

Thank you!



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