EHDEN: Approach & Strategy

Courtesy of: Peter Rijnbeek & Nigel Hughes

Project Coordinator and Project Lead
Patient-level data in source system/schema

- Complete documented specification that fully describes all data manipulations and statistical procedures
- Full analysis code that executes end-to-end (from source to results) without manual intervention

**GOAL:** to implement a large sustainable data network (+100m records) in Europe to generate reliable evidence for patient care that is transparent and fully reproducible
Why is this not current practice?

• **Interoperability** of data: different structures, different terminologies

• **Standardized analytical pipelines** are needed

• **Services** are needed to build an active data network to answer clinically important questions in a timely manner

• A strong **community** is needed covering all of Europe that collaboratively will improve patient care
A COMMON DATA MODEL AND STANDARDIZED VOCABULARIES

- Use of a **common data model** splits the journey into two segments: 1) data **standardization**, 2) **analysis** execution
- **CDM** creates opportunity for re-use of data curation and analysis step
**Vision:** The European Health Data & Evidence Network (EHDEN) aspires to be the trusted observational research ecosystem to enable better health decisions, outcomes and care.

**Mission:** Our mission is to provide a new paradigm for the discovery and analysis of health data in Europe, by building a large-scale, federated network of data sources standardised to a common data model.

**Values:**
- Diversity
- Excellence
- Education
- Openness
- Perseverance
- Beneficence
- Reproducibility
- Sustainability
- Efficiency
- Community
- Quality
- Coverage
Open Calls
- Series of in-project calls across the EU
- Tailored for project objectives and sustainability

Open Calls
- Continuous open call across the EU
- Focusing on SME representation to support mapping and sustainability

‘Grants’
- ‘Grants’ are provided via milestone payments to Data Sources
- SMEs will support Mapping Cycle and be paid via the Data Source ‘grant’, following certification by EHDEN
• Build the infrastructure to enable federated studies on an unprecedented scale in Europe
• Leverage and further develop OHDSI and other tools for high quality analyses
• Use Case driven development
• Ensure interoperability on a global level
BUILDING THE ECO-SYSTEM: OUTCOMES

• Incorporation of outcome standards (ICHOM)
• Supporting outcomes-based research and medicine
• Demonstrate the additive value of EHDEN through use cases
BUILDING THE ECO-SYSTEM: ECOSYSTEM

- A trusted **federated data network** expanding beyond EHDEN’s lifetime
- European-wide network of **certified SMEs**
- Enable new and **augmented health services** during and after EHDEN
- Stimulate active **collaboration** within the community
- **Sustainability** is a responsibility of all stakeholders
KEY COMPONENTS FOR EHDEN

OUTCOMES

Build
Fuel
Drive
Technology
Engagement
Outreach
EHDEN Work Package Structure

WP1: Evidence Workflow Development

WP2: Outcome Driven Healthcare

WP3: Personalized Medicine

WP4: Technical Implementation

WP5: Data Workflow Implementation & Service Deployment

WP6: Outreach and Sustainability

WP7: Project Management and Dissemination

Build
Fuel
Drive
EHDEN’s Three Pillars & Foundations

Infrastructure

Research

Outcomes

Bioinformatics & Tooling

Epi/Statistics/Methods & Use Cases

Communications

Processes & Calls
PILLAR ONE: BUILD

INFRASTRUCTURE
**EHDEN IS NOT A BLANK CANVAS PROJECT....**

- EHDEN will utilise the best from prior and current (IMI) projects and platforms to develop its own infrastructure.
- It will be developing its federated framework, but also analytical tooling and processes to support observational research in the EU, closely associated with the OHDSI EU/Global Open Science/Open Source collaboration.

We have the main developers of most tools in the consortium and are closely collaborating with the development teams.
PILLAR TWO: RESEARCH
EHDEN CAN FACILITATE UNPRECEDENTED RESEARCH IN EUROPE

- There is a very active global research community around the OMOP-CDM (OHDSI) -> Example is the Oxford Study-A-Thon
- Our task is to facilitate this at scale in Europe and add additional tools and methods to the current stack
- In EHDEN research will drive the development of the eco-system with respect to tool and processes, but also to build the necessary trust

**Quality Control** on all steps in the pipeline is needed, starting at source data, ensuring the transformation to the CDM is valid, ensure the analytical pipeline has build in quality measures, etc.

**Result dissemination** that enables others to add new insight on their data after study publication
PILLAR THREE: OUTCOMES

• Use data derived from standard, internationally-accepted metrics to enable a learning healthcare system

• Our data standardization effort could facilitate this at scale