- Findable, standardized data at scale through the EHDEN Database Catalogue -

OHDSI Community Call
30 August 2022

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**Mission**

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.

**Vision**

Aspire to be the trusted observational research ecosystem to enable **better health decisions**, **outcomes and care**.

**Values**

- Community
- Education
- Sustainability

- Open science
- Quality
- Inclusiveness
OBJECTIVES

**Harmonisation**

Harmonise in excess of **100 million anonymous health records** to the OMOP common data model, supported by an ecosystem of certified SMEs, and technical architecture for a federated network.

**Evidence**

Impact our understanding of, and improvement of, clinical outcomes for patients within diverse healthcare systems in the EU.

**Community**

Establish a self-sustaining open science collaboration in Europe, supporting academia, industry, patient organisations, regulators, payers, government, NGOs and others.
**Foundational Pillars**

**Infrastructure**
- Creation of an **EU-wide** federated network architecture
- **Privacy** by design
- **Data harmonisation** to the OMOP common data model
- Training & certification of **SMEs**

**Research & Outcomes**
- **Use cases** to evaluate the EHDEN federated network
- Collaboration on consistent **methodologies**
- Collaboration with the global **OHDSI** research network
- Incorporation of the **ICHOM** health outcome standards

**Education & Community**
- Establishment of the **EHDEN Academy**
- Expansion of the **OHDSI network** in Europe
- Collaboration on **collective memory** for research use cases
Innovative Medicines Initiative

€ 2.5 billion

€ 2.5 billion

> € 5 billion

IMI2 consortia

Carlos Moedas
EU commissioner for research, science and innovation

“Radical collaboration where multinational companies work together and share data instead of keeping it secret is helping to change the model of the pharmaceutical industry and solve problems more quickly.” (Source)

Accelerate research and development.

Speed up patient access to innovative treatments.

Improve patient outcomes and safety of medicines.

www.imi.europa.eu
EH DEN CONSORTIUM

Start date: 1 Nov 2018
End date: 30 Apr 2024
Duration: 66 months

23 partners

Almost €30 million

Universities, public bodies and research organisations

Academic coordinator

SME & Mid-sized companies

Non-profit organisations

EFPIA & Associated partners
**DATA PARTNERS AND SMEs**

**Data Partners**
- Tailored for project objectives and sustainability

**Open calls**
- Focusing on SMEs able to support mapping and sustainability

**Grant awarding**
- Evaluated via a pre-defined set of criteria by the Data source prioritisation committee

- Data Partners can choose the SME from the pool of EHDEN certified SMEs
- SMEs are paid via grants from the harmonisation fund
- Payments are milestone based

**Supporting SMEs**
- Training & Certification
  - SME certification committee prioritises SMEs for training and certification
- Payments are milestone based

**Harmonisation fund**
- Workshop
  - Audit
  - Mapping
  - Share of Mapping Process

EHDEN Academy

Data Partners are encouraged to be active members of the EHDEN community, participating in research studies.
EUROPE: AN OCEAN OF DATA & A DESERT FOR ANALYSIS
Identify relevant data to answer your research question

What data is available?
From how many patients?
Can I use this data for my research?

...
ROLE OF THE EHDEN PORTAL IN THE STUDY WORKFLOW

Study Idea

What data is needed?

Where do I find the data?

Assemble the Team

Protocol

Is the Study Feasible?

EHDDN Portal
• Database Catalogue
• Network Dashboard

Publication

Dashboard

Results Collection

Execute Analysis

Define Analysis

EHDDN Evidence Hub

Atlas & Arachne

Arachne & Atlas
THE VISION OF THE EHDEN PORTAL – ONE-STOP-SHOP

Academy
Scientific Publications
Data Analytics

Database Catalogue
Network Dashboards
Support
Study Management

EHDEN Portal
EHDEN Portal Released at EU OHDSI Symposium

Database Catalogue

Academy

Scientific Publications

Network Dashboards

Available Q4 2022

Available Q4 2022

Available Q4 2022
Geographical Spread Data Partners

Geographic spread of data partners. The shade of blue indicates the # of data partners in that country (darker = more).
DATABASE CATALOGUE – 67 DATA PARTNERS...AND COUNTING

Update: 72

- **Auria Clinical Informatics**
  - Acronym: ACI
  - Description: Auria Clinical Informatics at Turku University Hospital Hospital District of Southwest Finland (HDSF)
  - Location: Finland
  - Population: 765K

- **Anonymized Data Warehouse IMR**
  - Acronym: ADWH IMR
  - Description: Innovative Medical Research S.A.
  - Location: Greece
  - Population: 600K

- **Health Data Warehouse of Assistance Publique - Hôpitaux de Marseille**
  - Acronym: AP-HM
  - Description: Assistance Publique - Hôpitaux de Marseille
  - Location: France
  - Population: 2.79M

- **ARCA Cardiology**
  - Acronym: ARCA
  - Description: Monasterio Foundation
  - Location: Italy
  - Population: 50K
COMPONENTS OF THE DATABASE CATALOGUE

Database Fingerprint

1. Database Description (20/20) 100%
2. Contact Details (10/10) 100%
3. Technical Details CDM (5/5) 100%
4. Data Governance and Ethics (9... 100%
5. Publications (2/2) 100%

Database Dashboards

- # of patients
- Gender distribution
- Age of first observation
- Year of birth
Explore the catalogue

- Is a certain database part of the EHDEN network?
- Which database has the highest patient counts?
- Find all databases from France
- Find the database with the most recent updates
NETWORK DASHBOARD
NETWORK DASHBOARD - OVERVIEW

Countries: 15  
Data Sources: 35  
Patients: 44.2M  
Update: 38
Update: 100M

Total number of patients per country

Patients by Country

Database Types per Country
**Use case examples**

- Geographical spread
  Identify all EHDEN data partners from *France*

- Range of Source data systems
  Identify data partners that can provide *GP data*
Distribution of age at first observation period
GETTING STARTED

Network Dashboard at a Glance

Total number of datasources and patients in the network
- Use the country/database type/data source filter to restrict the selection

Getting access to the Network Dashboard
- Enter credentials on the EHDEN portal (https://portal.ehdenu.eu)
- Select the Network Dashboard icon on the left panel

1. Understanding gender or year of birth or age coverage
   - Go to the tab ‘Demographics’
   - Gender distribution is shown in the top pie chart
   - Age at first observation is presented in tabular format, bar chart and boxplot
   - Year of birth is presented as bar chart.

2. Understanding what data are available for one or more data sources
   - Go to the tab ‘Data Domains’
   - The ‘Average number of records per person’ indicates how many records per entity type are available. Use in conjunction with the above filters to select on country/database type or data source
   - The pie chart gives the total number of records per entity type

3. What is the source of the data?
   - Go to the tab ‘Data Provenance’
   - The pivot table ‘Visit Type Pivot’ gives a count per entity type of the respective concept types e.g. EHR problem list entry, primary or secondary condition, hospitalisation cost record etc.

4. What is the available observation period?
   - Go to the tab ‘Observation Period’
   - Check the second graph – cumulative observation time
   - Click in the legend on a single item to select/deselect
   - Double-click to select a single data source

5. Which data sources do contain a particular concept?
   - Go to the tab ‘Concept Browser’
   - In the concept type, start typing part of the text string
   - Select the concept that you want to search for
   - Hit APPLY
   - In the pivot table you can see approximately total number of records and descendant number of records. Further down, you see a graphical representation

Nice-to-know
1. Knowing the last update per datasource
   - On the landing page of the network dashboard
   - Scroll to the bottom – meta data view
   - Cutoff date from the source data: source_release_date
   - CDM date: cdm_release_date

2. Filtering results and other tricks
   - Option A: top filters for selection on country/database type or data source
   - Option B: When a legend is displayed, individual items can be selected/unselected or double-click – select a single item from another list

3. Maximize your graph
   - When a graph is not readable: click on the icon and select ‘maximise graph’ from the pop-up
More data partners will be added
Submission deadline DP Call #6 just closed

Integration with Data Analytics and Study Management capabilities

Implementation of Service desk for study requests

Add other data sources in OMOP CDM

And that’s just the beginning...
Welcome – We are Open

Register your account today at

Portal.EHDEN.eu

And start exploring high quality real world data from

> 100 M patients
from 15 European countries