



EHDEN

EUROPEAN HEALTH DATA & EVIDENCE NETWORK

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

OHDSI Community Call

30 August 2022

Julia Kurps, The Hyve

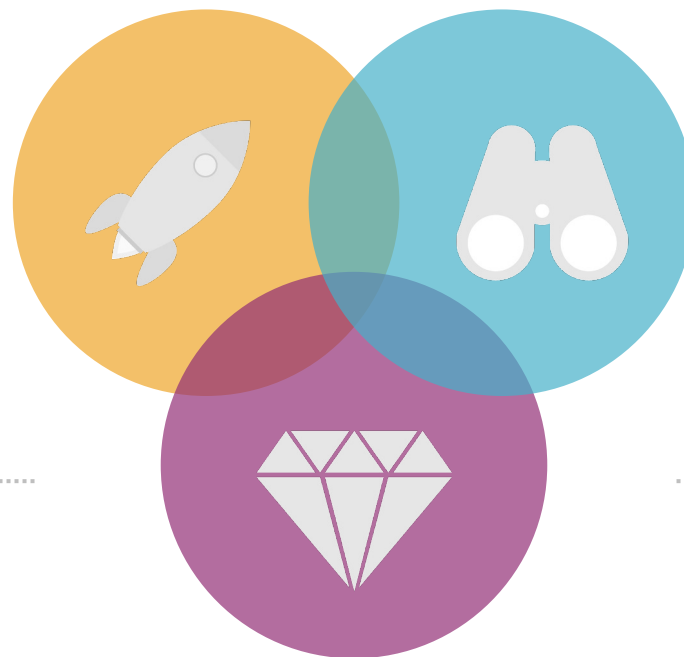




VISION & MISSION

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.**

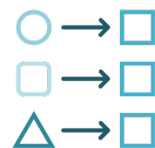
Values

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 EH DEN federated network

Collaboration on consistent **methodologies**

Collaboration with the global **OHDSI** research network

Incorporation of the **ICHOM** health outcome standards

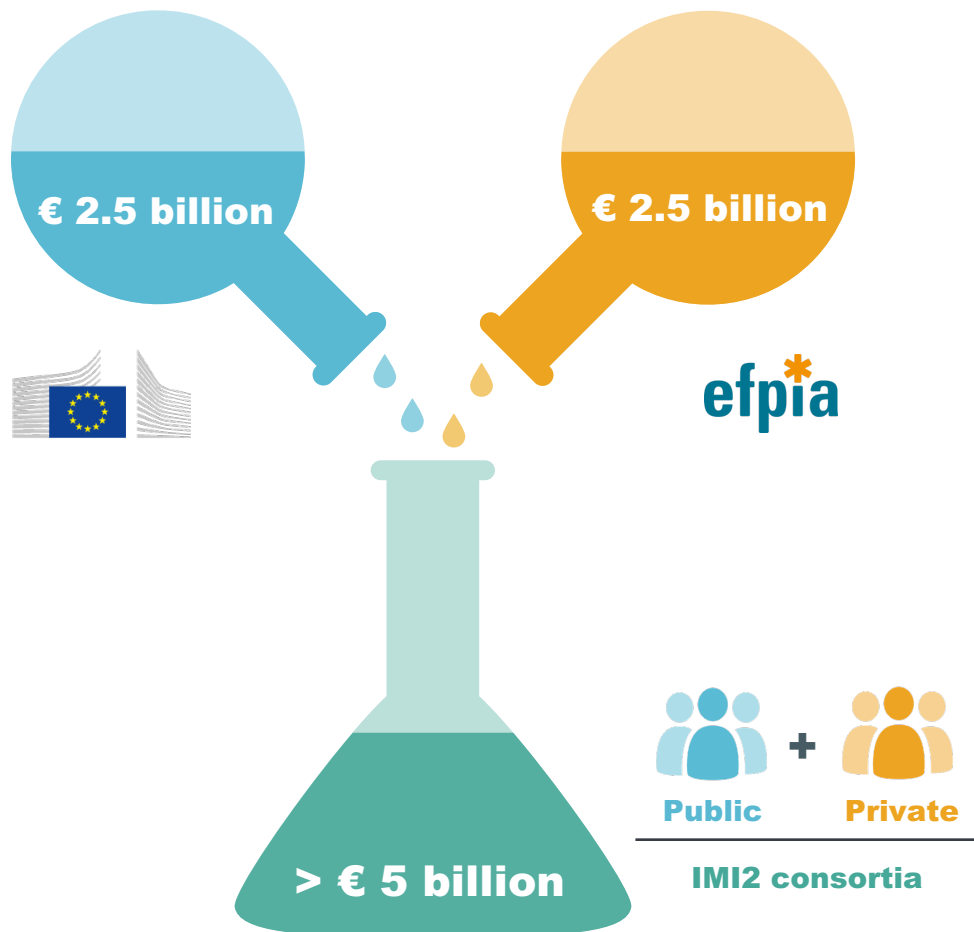
Education & Community



Establishment of the **EH DEN Academy**

Expansion of the **OHDSI network** in Europe

Collaboration on **collective memory** for research use cases



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.



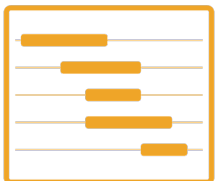
Speed up patient access to innovative treatments.



Improve patient outcomes and safety of medicines.



EHDEN 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

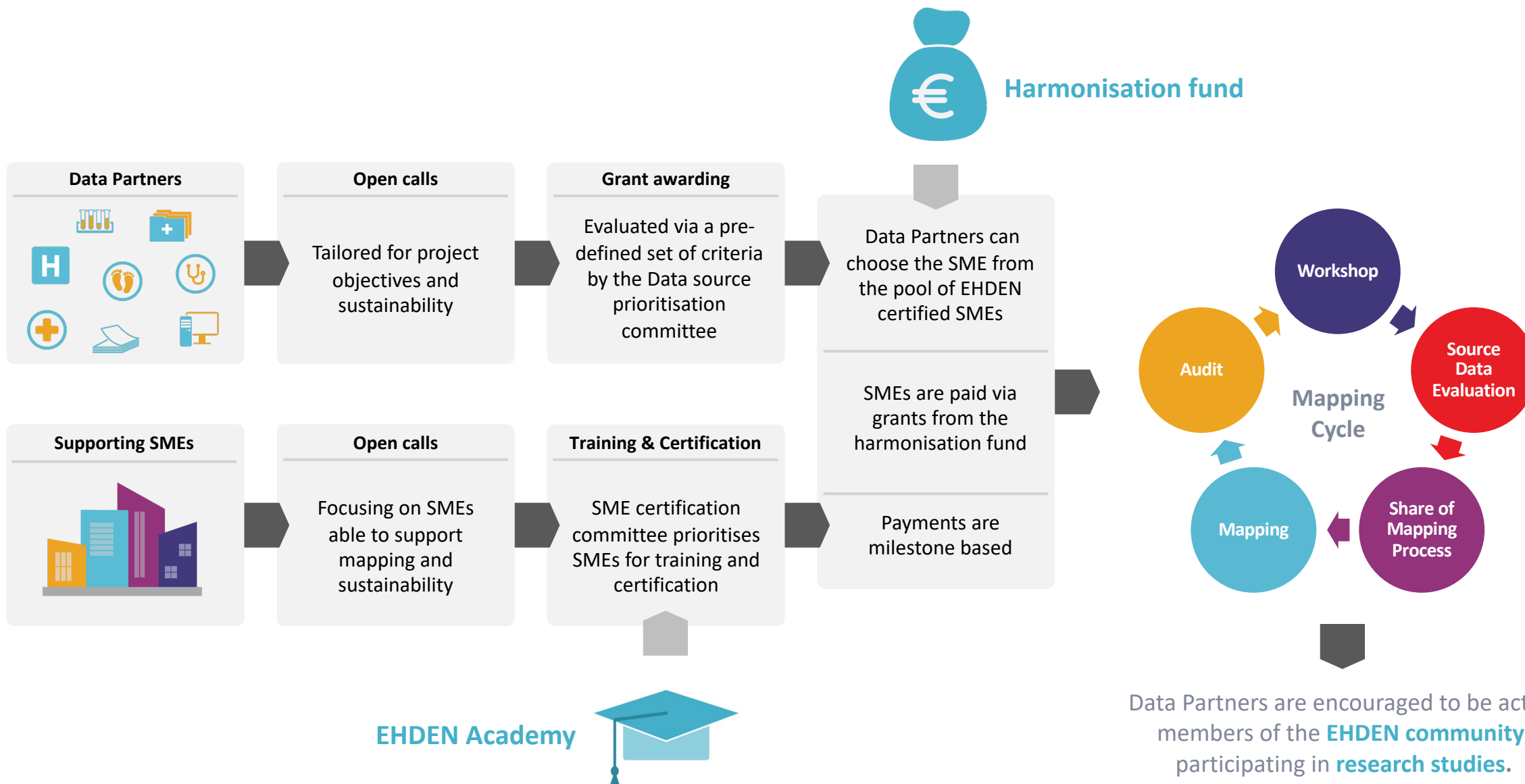


EFPIA Lead





DATA PARTNERS AND SMEs





EUROPE: AN OCEAN OF DATA & A DESERT FOR ANALYSIS





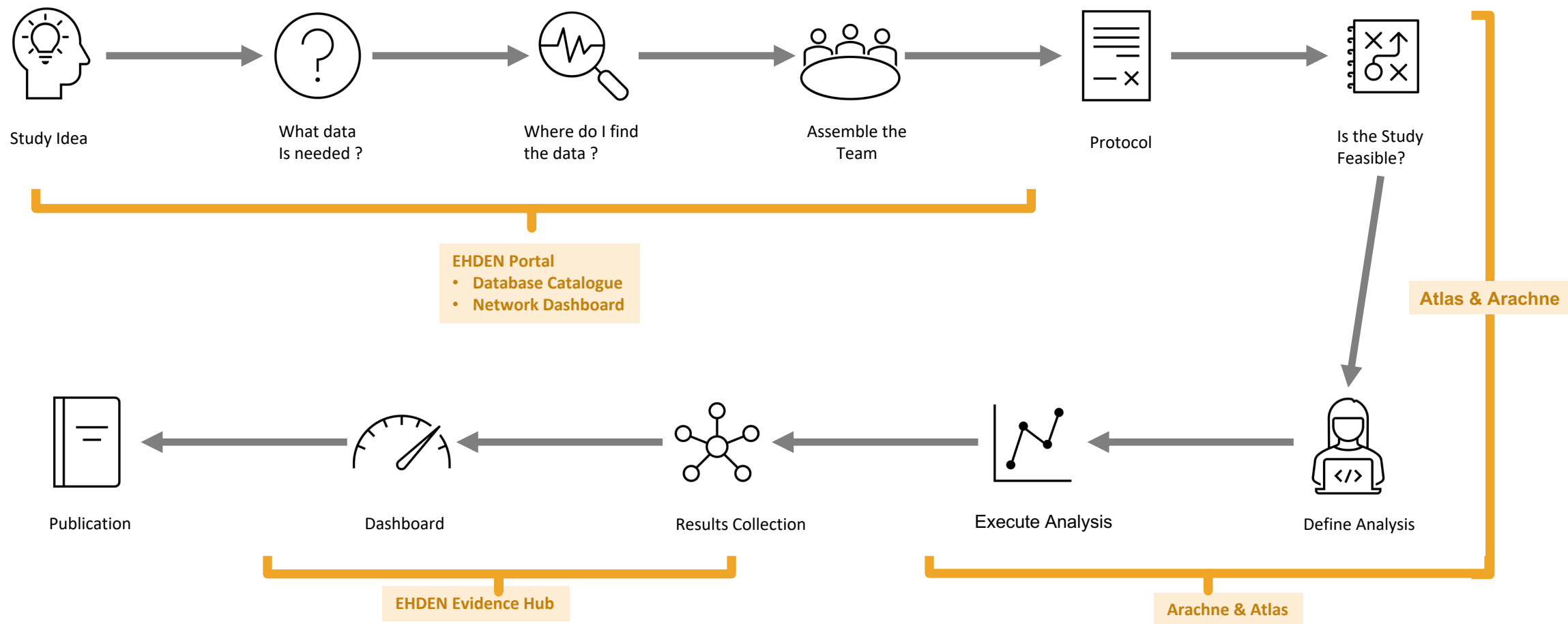
Identify **relevant data** to answer
your **research question**

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

...

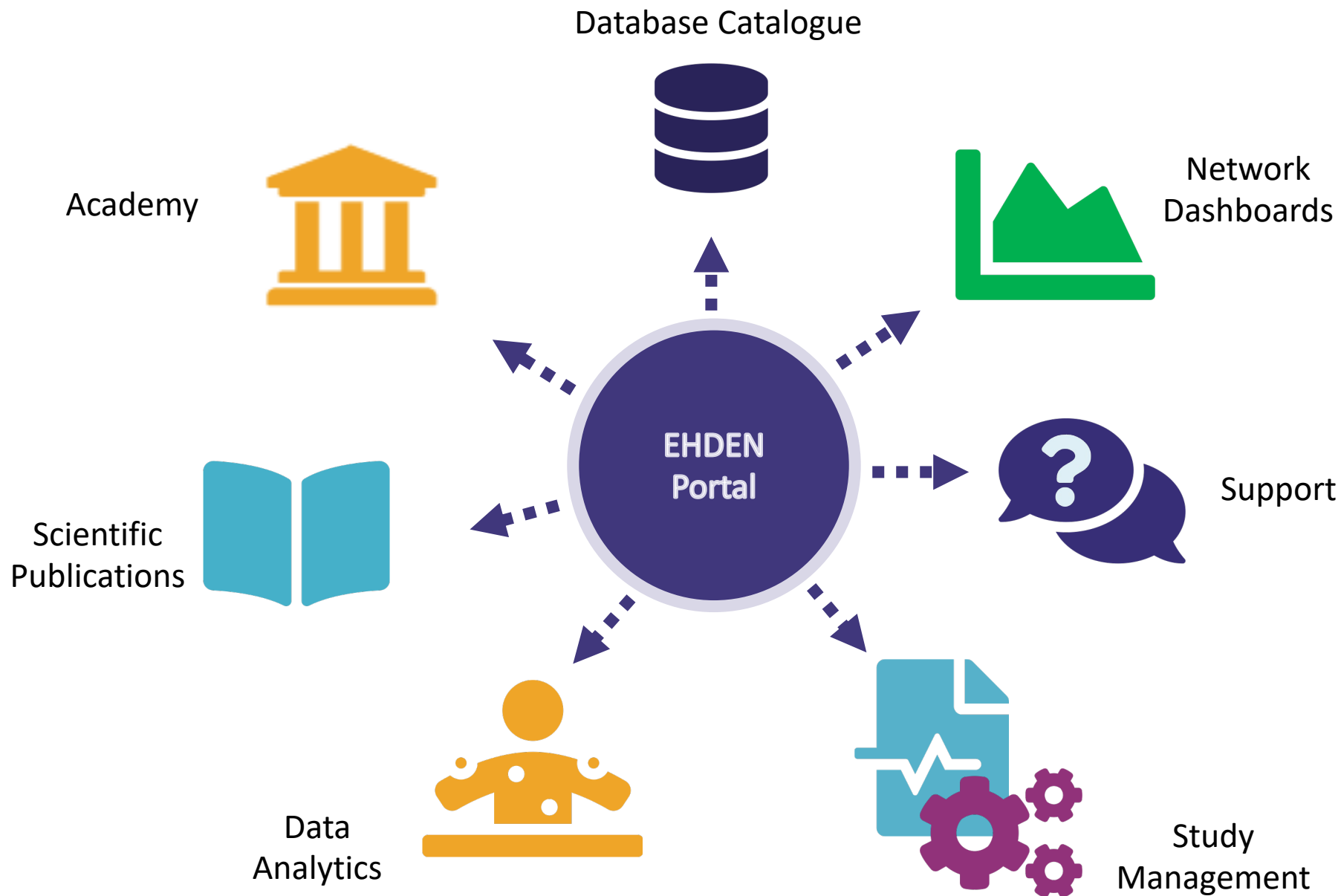


ROLE OF THE EHDEN PORTAL IN THE STUDY WORKFLOW



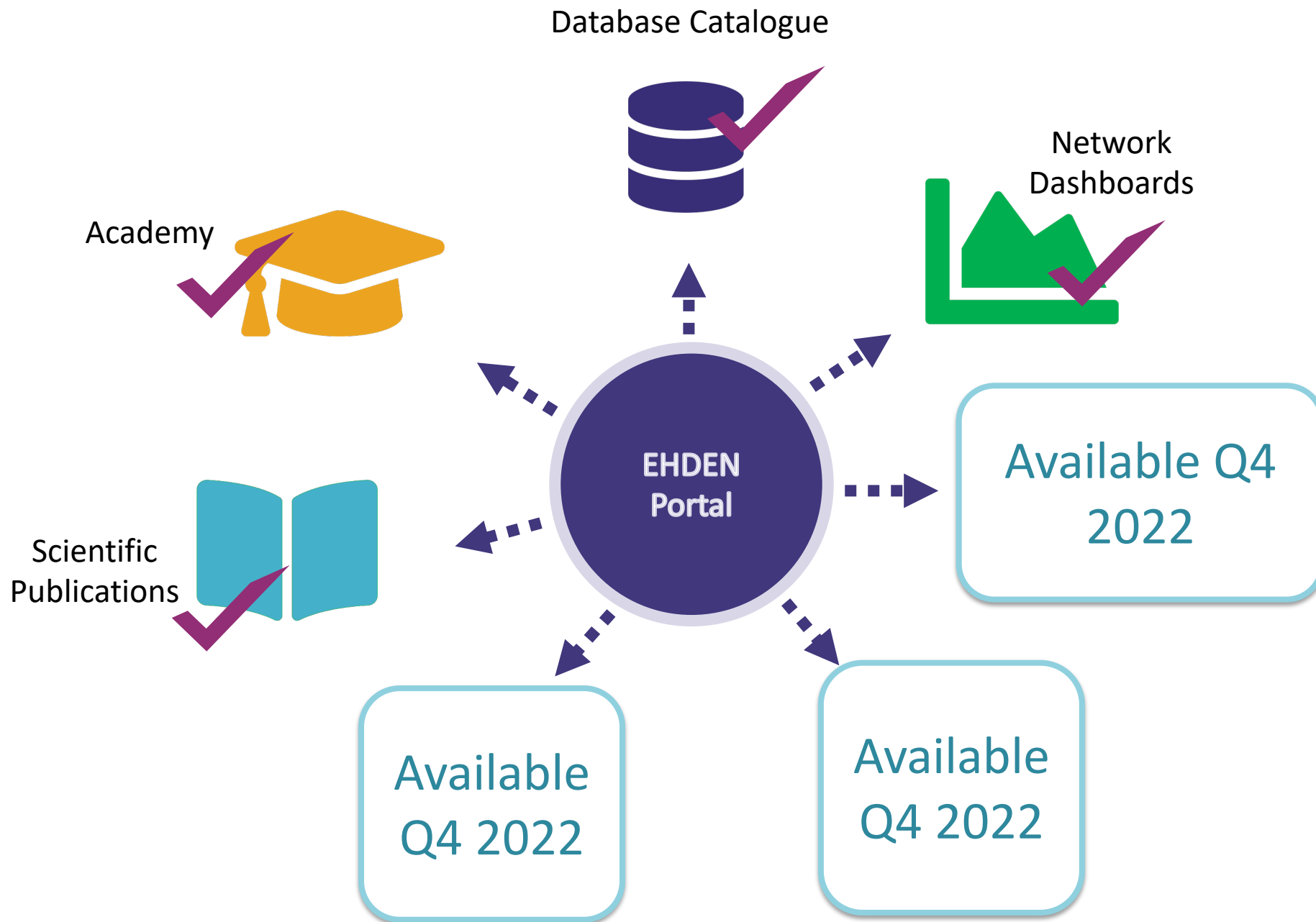


THE VISION OF THE EHDEN PORTAL – ONE-STOP-SHOP



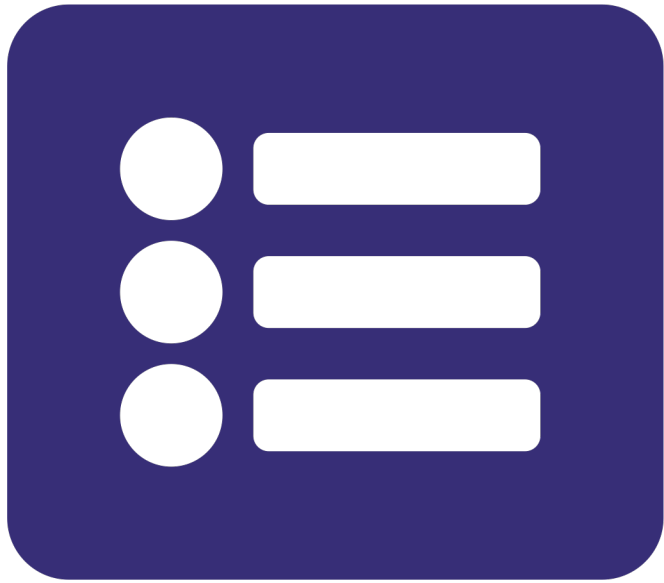


EHDEN PORTAL RELEASED AT EU OHDSI SYMPOSIUM



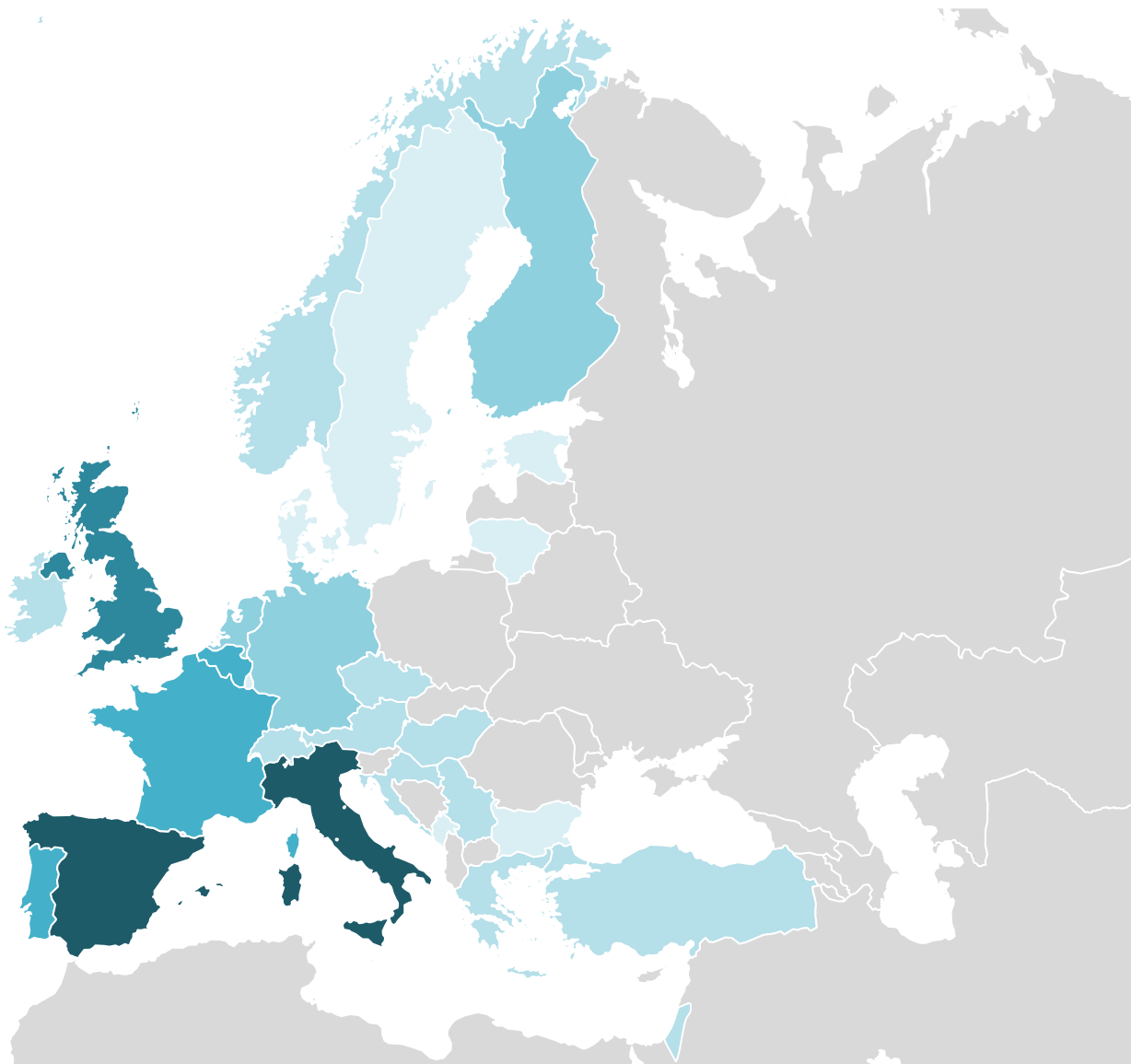


DATABASE CATALOGUE





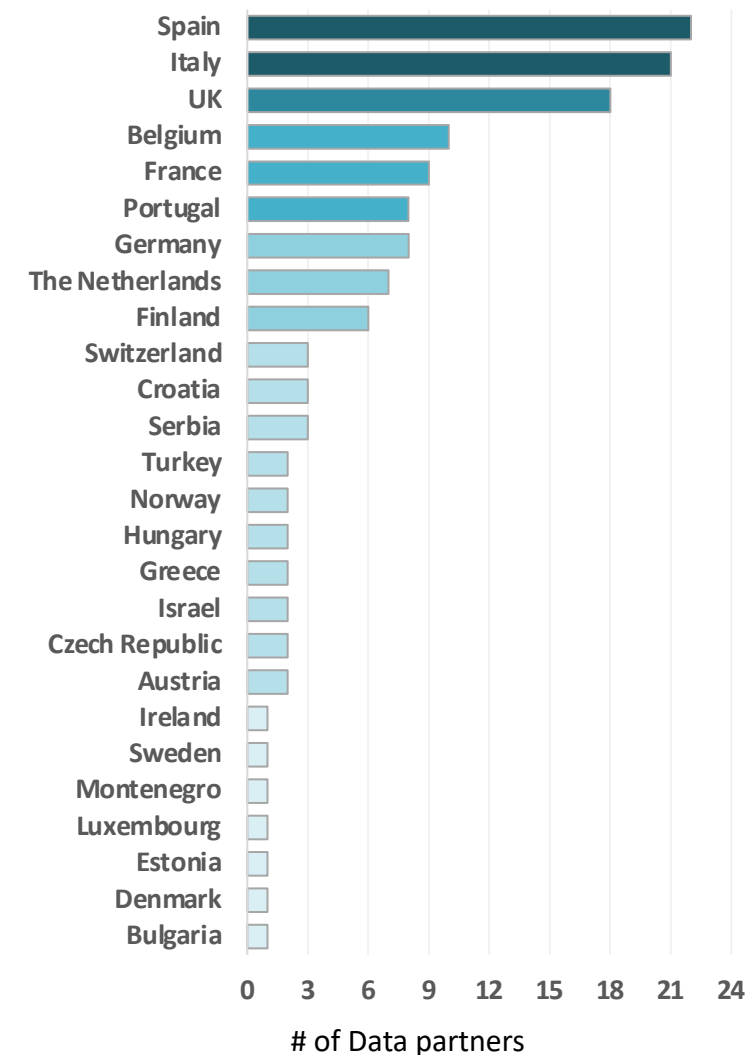
GEOGRAPHICAL SPREAD DATA PARTNERS



Geographic spread of data partners. The shade of blue indicates the # of data partners in that country (darker = more)

Applications (n=283)


 Awarded applications (n=140)





DATABASE CATALOGUE – 67 DATA PARTNERS...AND COUNTING

<<



julia kurps

HOME

CATALOGUE >

DASHBOARD

ACADEMY

EHDEN

PUBLICATIONS

STATUS

PORTAL

ABOUT

HELP

FEEDBACK >

PROFILE

SIGN OUT

EHDEN PORTAL

Free text search EHDEN













≡

Compare ▾ Export ▾

Update: 72

Sorted by: Database Acronym ▾

Select all

 <div>AURIA CLINICAL INFORMATICS</div> <div>ACI</div>	Auria Clinical Informatics at Turku University Hospital Hospital District of Southwest Finland (HDSF)	<div> 765K</div> <div> Finland</div>	<input type="checkbox"/>
 <div>IMR S.A. Innovative Medical Research</div> <div>ADWH IMR</div>	Anonymized Data Warehouse- IMR Innovative Medical Research S.A.	<div> 600K</div> <div> Greece</div>	<input type="checkbox"/>
 <div>Assistance Publique Hôpitaux de Marseille</div> <div>AP-HM</div>	Health Data Warehouse of Assistance Publique - Hopitaux de Marseille Assistance Publique - Hôpitaux de Marseille	<div> 2.79M</div> <div> France</div>	<input type="checkbox"/>
 <div>ARCA</div>	ARCA Cardiology Monasterio Foundation	<div> 50K</div> <div> Italy</div>	<input type="checkbox"/>

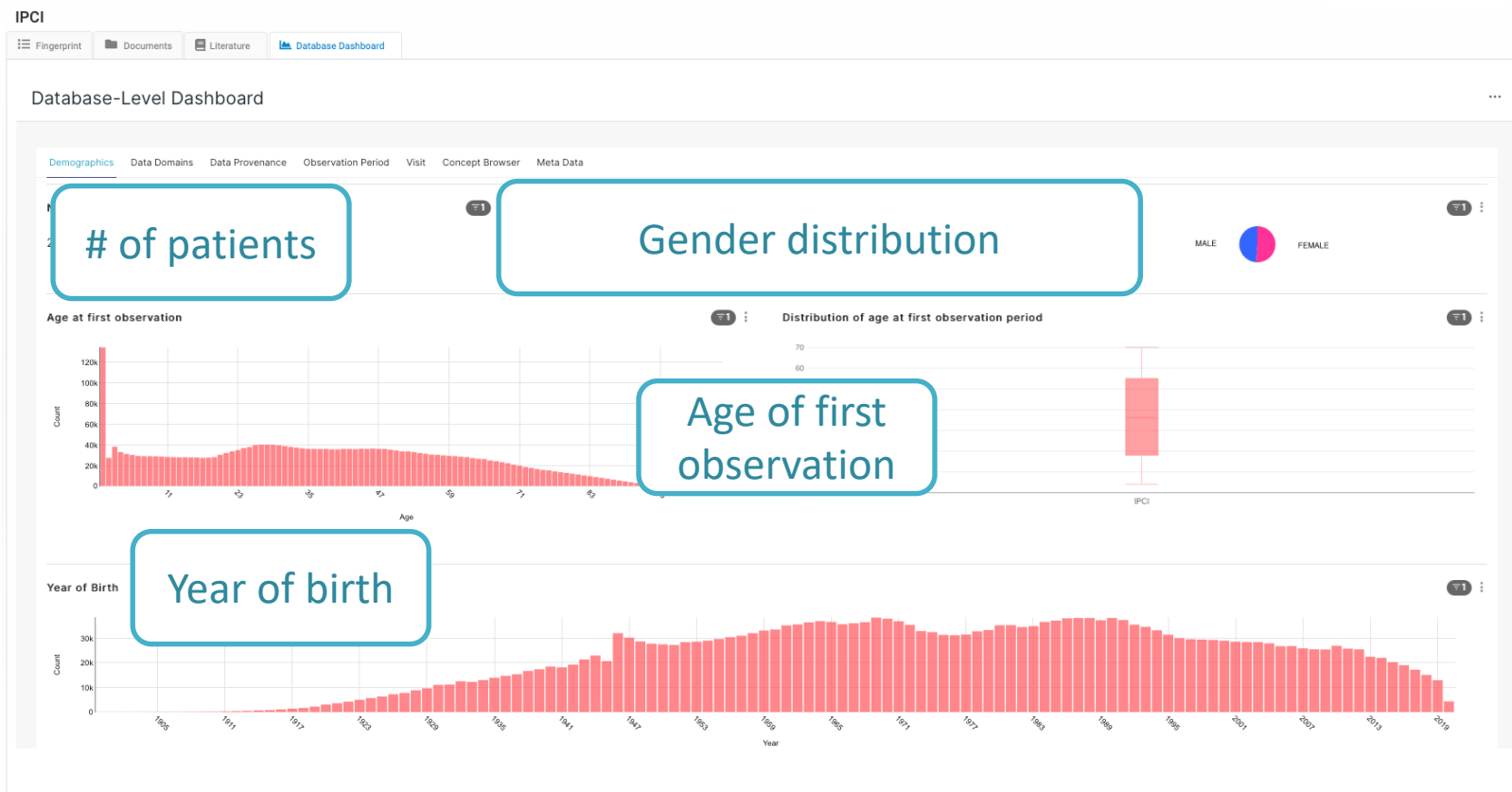
Database Fingerprint



Database Dashboards



- | | |
|--------------------------------------|------|
| 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% |





Close

Order By

Database Acronym



Ascending



Descending

Filter By

Database Acronym

Database Name

Total number of patients

<input type="text"/>	to	<input type="text"/>
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Institution name

Country

Last Update

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 DASHBOARDS - OVERVIEW



Countries

15

Data Sources

35

Update: 38

Patients

44.2M

Update: 100M

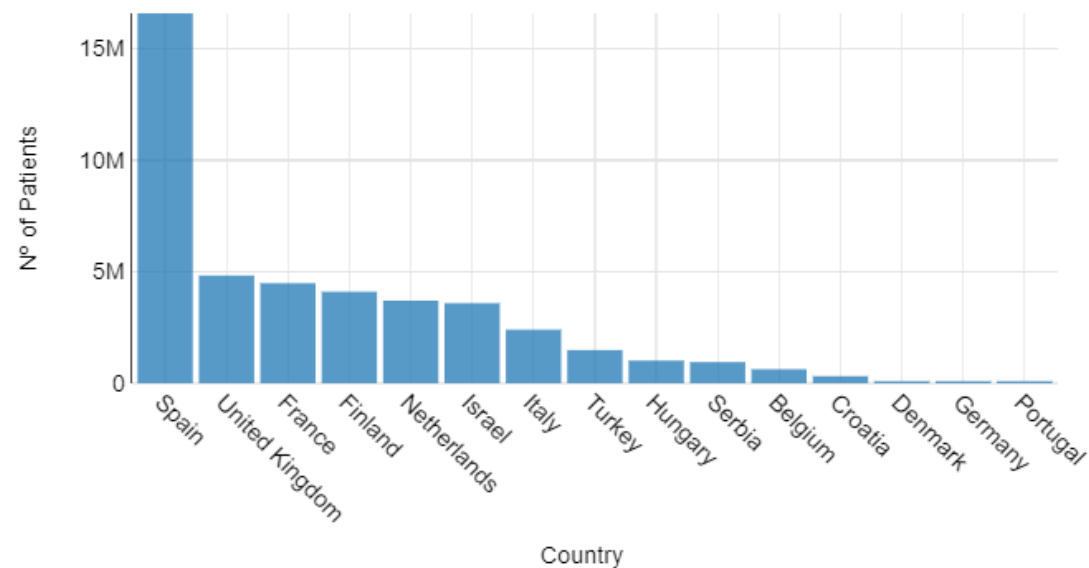
Datasource Types

Hospital Hospital + Lab Results Hosp 1/4



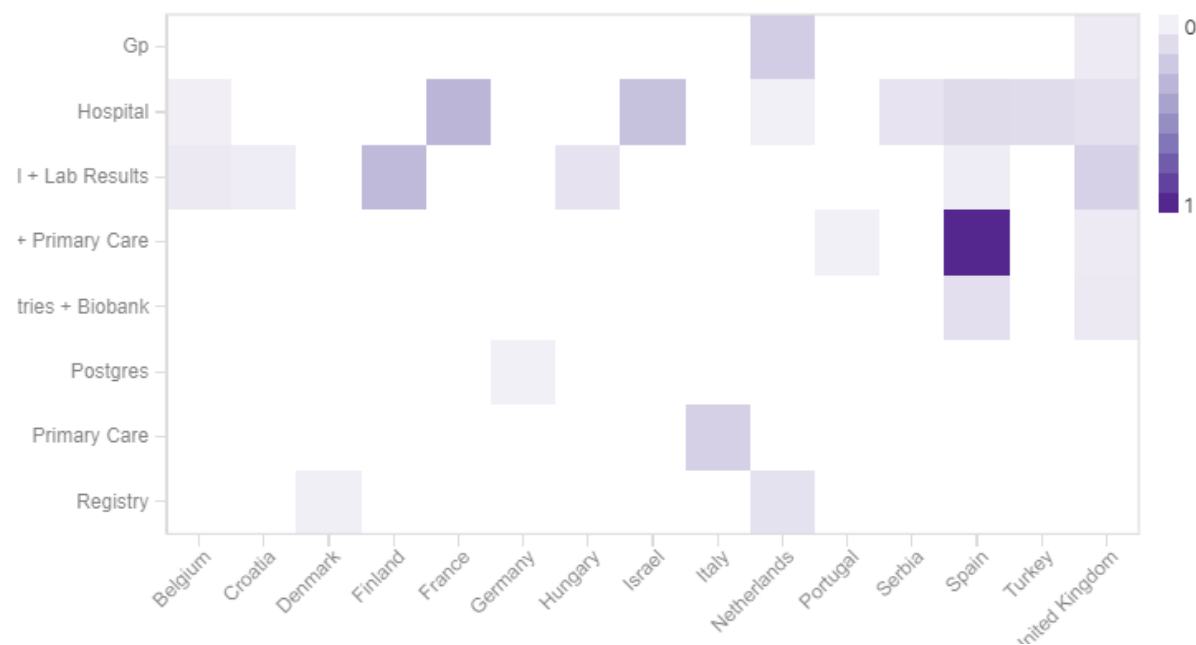
Total number of patients per country

Patients by Country



Number of patients (color) per database type for each country

Database Types per Country





FILTER TO FIND RELEVANT DATA

The image shows three filter panels arranged horizontally. Each panel has a header with icons and a title, followed by a dropdown menu.

- Country Filter:** Header with three flags (blue, orange, purple). Title: "Country Filter". Dropdown label: "COUNTRY". Input: "Type or Select [Country]".
- Database Type Filter:** Header with icons of a doctor, a flask, and a hospital. Title: "Database Type Filter". Dropdown label: "TYPE". Input: "Type or Select [Type]".
- Data Source Filter:** Header with three database cylinders (orange, blue, purple). Title: "Data Source Filter". Dropdown label: "DATA SOURCE". Input: "Type or Select [Data Source]".

Use case examples

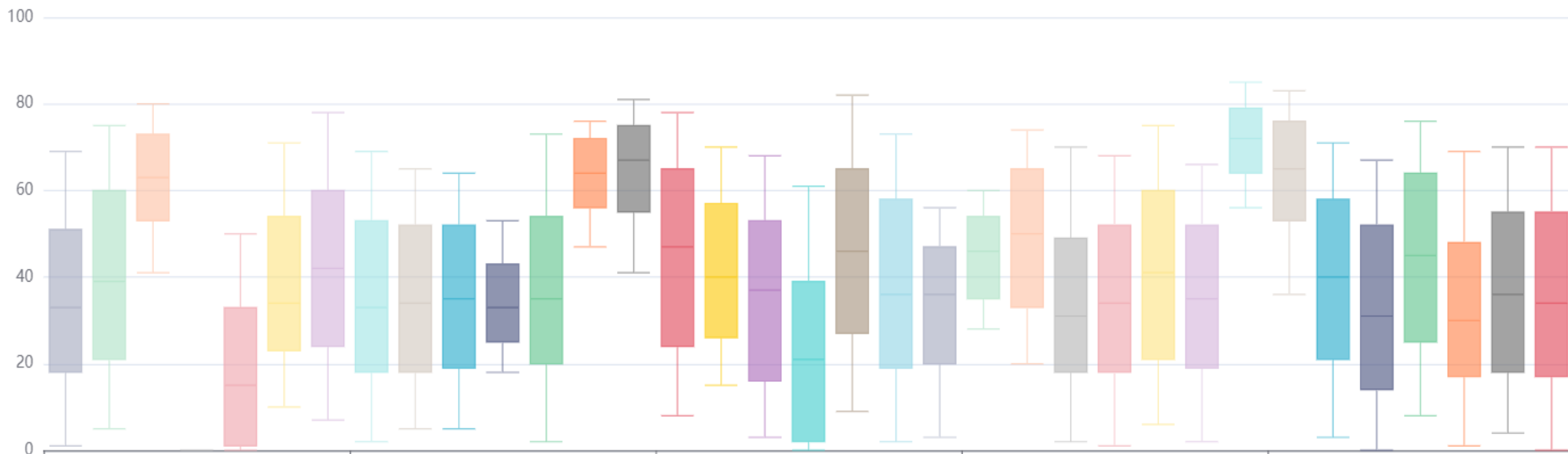
- Geographical spread
Identify all EHDEN data partners from *France*
- Range of Source data systems
Identify data partners that can provide *GP data*



NETWORK DASHBOARDS – BROWSE – EXPLORE - DISCOVER

[Overview](#)[Demographics](#)[Data Domains](#)[Data Provenance](#)[Observation Period](#)[Visit](#)[Concept Browser](#)[About](#)

Distribution of age at first observation period





GETTING STARTED

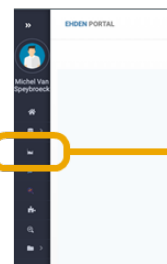


EHDEN
EUROPEAN HEALTH DATA & EVIDENCE NETWORK

Network Dashboard at a Glance

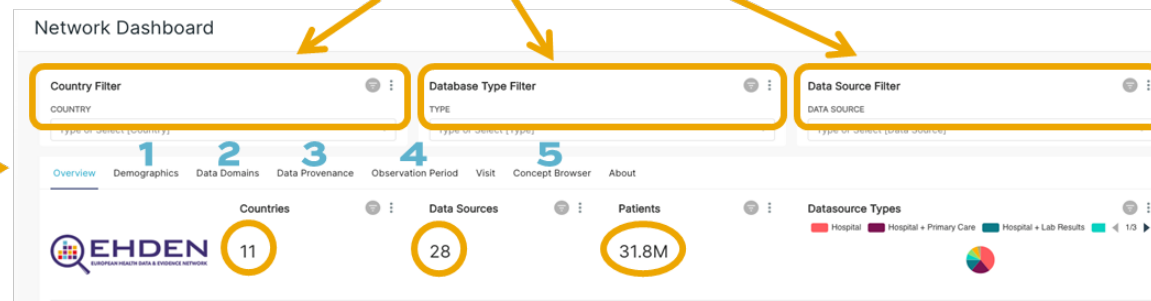
Getting Access to the Network Dashboard

- Enter credentials on the EHDEN portal (<https://portal.ehden.eu>)
- Select the **Network Dashboard** icon on the left panel



Total Number of datasources and patients in the network

- Use the country / database type / data source filter to restrict the selection



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, hospitalization cost record etc.

4

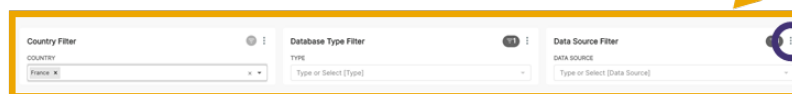
What's the available observation period?

- 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 approx. 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

acronym	name	country	database_type	number_of_patients	source_release_date	cdm_release_date
ULSM COVID	ULSM COVID-19	Portugal	Hospital + Primary Care	9750	2021-02-11	2021-08-25
Parc Sanitari Sant Joan de	PSSJD	Spain	Hospital	601107	2021-10-08	2021-10-08
IPC	Integrated Primary Care Information	Netherlands	Gp	2620859	2020-09-20	2020-09-30
HIC	HIC Data	United Kingdom	Hospital + Lab Results	1910220	2021-01-25	2021-01-27
H120 EHDEN	H120 EHDEN	Spain	Hospital + Primary	2891589	2021-06-07	N/A

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



AND THAT'S JUST THE BEGINNING...



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





WELCOME – WE ARE OPEN



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