

Enabling Large-Scale Analysis of Electronic Health Records in Europe: The EHDEN Project

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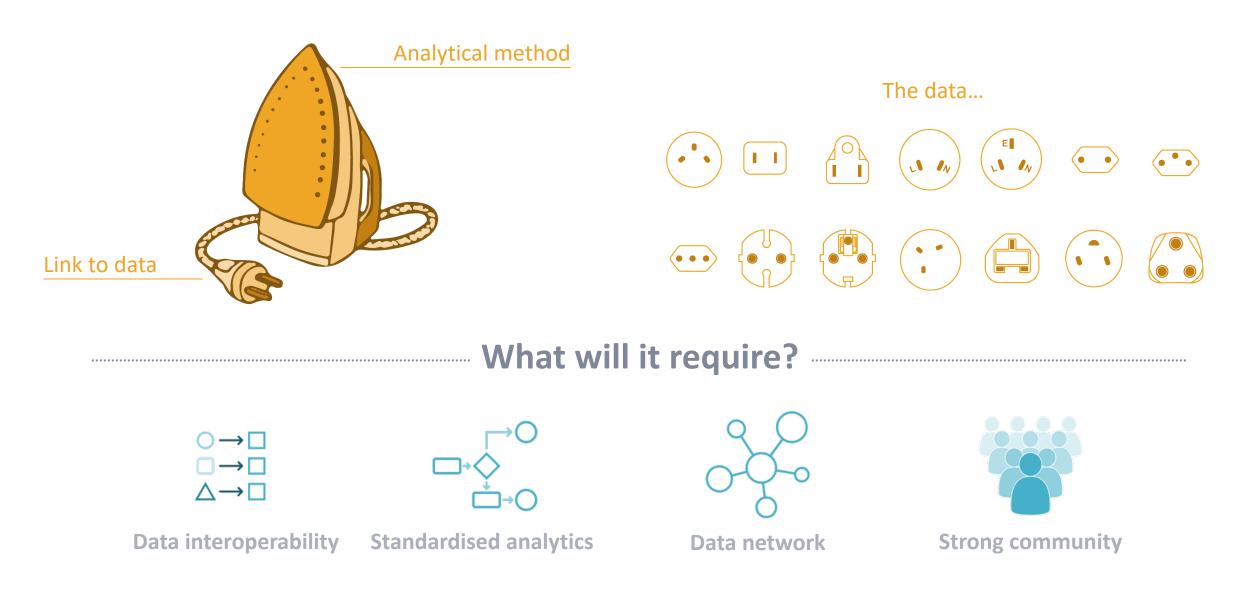
Vision

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 standardized to a common data model

THE CHALLENGES OF REAL WORLD DATA

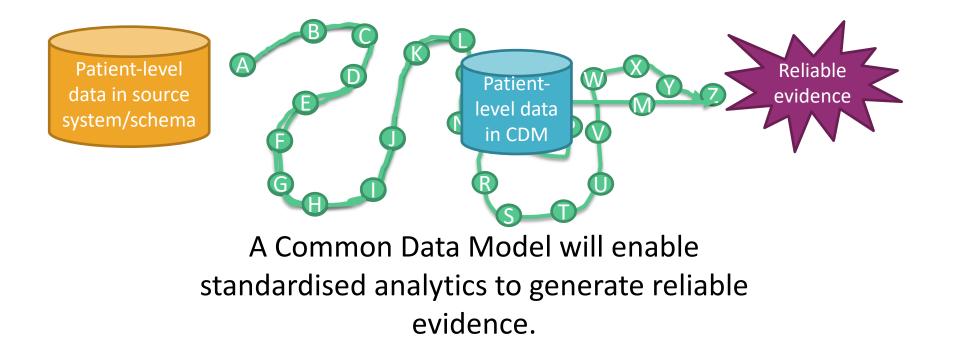


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GENERATING RELIABLE EVIDENCE USING THE OMOP CDM

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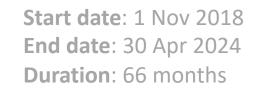












22 partners



EFPIA & Associated partners



Almost €29 million





FEDERATION

Creation of an EU-wide architecture for federated analyses of real world data

HARMONISATION

Harmonise more than 100 million anonymised health records to the OMOP common data model



COMMUNITY

Establish a self-sustaining open science collaboration in Europe, supporting academia, industry, regulators, payers, government, NGOs and others

OUTCOMES

Enabling outcomes driven healthcare at a European level

EDUCATION

The establishment of an EHDEN Academy, webinars and face-to-face training sessions to train all stakeholders



WORK PACKAGE STRUCTURE

WP1: Evidence Workflow Development

Incorporating the use cases for supporting development and validation of the EHDEN sociotechnical approach, inclusive of BD4BO projects

WP2: Outcome Driven Healthcare

Related to all activities specific to e.g. BD4BO projects outcome focus, and ICHOM standards incorporation

WP3: Personalized Medicine

Focusing on the support of outcomes/value based healthcare, inclusive of clinical prediction models, with the incorporation of 'novel' patient data

WP4: Technical Implementation

Key priority is socio-technical development of the EHDEN federated framework and relevant services

WP5: Data Workflow Implementation & Service Deployment

Development, oversight and evaluation of the ecosystem development from SME qualification/ certification to data source engagement, OMOP CDM mapping and evaluation

WP6: Outreach and Sustainability

Ensuring the development of value propositions for key stakeholders, and developing the sustainable operational model for EHDEN during and post IMI phase

WP7: Project Management and Dissemination

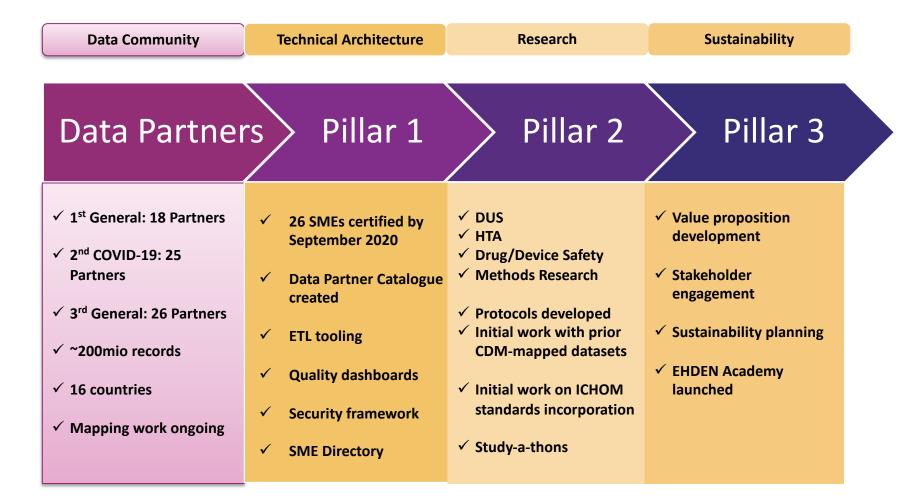
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Concentrating on intra-project project management, internal communications and external dissemination, and responding to IMI deliverables

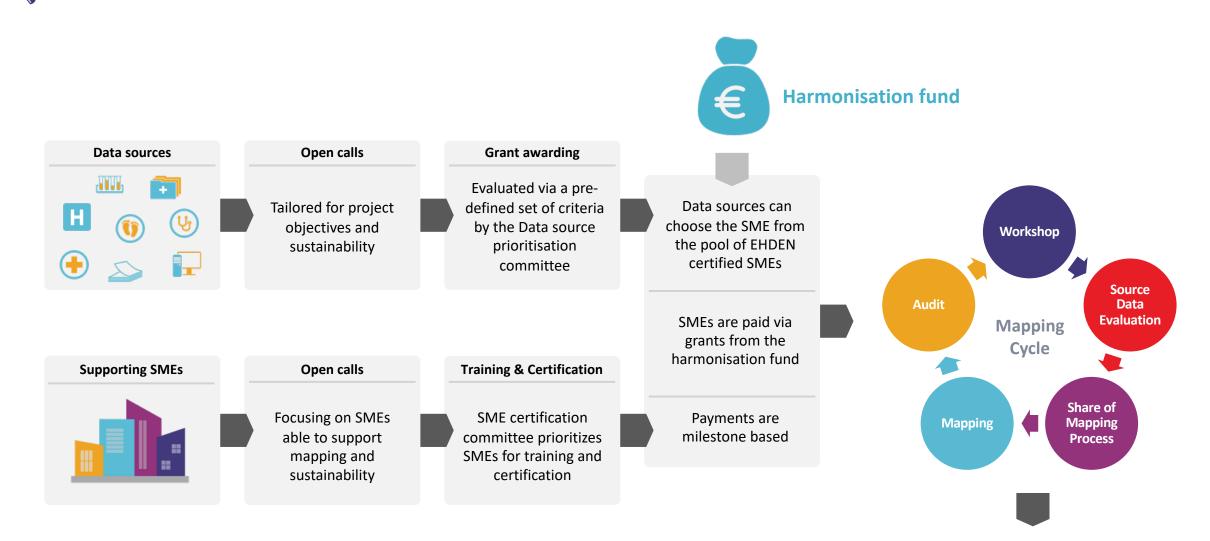


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EHDEN: WHERE ARE WE NOW AFTER 26 MONTHS?



IMPROVING INTEROPERABILITY OF DATA: THE EHDEN CALLS



Mapped data sources are encouraged to be active members of the **EHDEN community**, participating in **research studies**.

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NEED FOR A SUPPORT NETWORK: OPEN CALLS FOR SMES



Q 1st SME Call (n=11)

Q 2nd SME Call (n=15)

14 countries

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(imi)



New SME call opens in March, watch our website and Social Media Channels

SERVICE PROVIDER DIRECTORY



Technical infrastructure services (24)



STACC OÜ

Country: Estonia

Work Languages: English, Estonian

ACC Services: OHDSI Software and Tools, OMOP CDM ETL, Technical infrastructure services, OMOP Standardized Vocabularies

MedicalScan Kft.

MedicalSCa

efpia

Country: Hungary

Work Languages: Hungarian, Slovakian, Czech, English, Russian, Ukrainian

Services: OHDSI Software and Tools, OMOP CDM ETL, Technical infrastructure services, OHDSI Training, OMOP Standardized Vocabularies

STACC OÜ

Return to Direct

Street: Narva mnt ACC Number: 2 Post Code: 51008

City: Tartu

Country: Estonia Business Phone Number: ±372 55571567

Business Website Address: https://www.stacc.ee,

silless website Address: https://www.stactiee/

Linkedin: https://www.linkedin.com/company/stacc-software-technology-and-applications-competence-center ?trk=mini-profile

Year of Certification: 2019

Work Languages: English, Estonian

Services: OHDSI Software and Tools, OMOP CDM ETL, Technical infrastructure services, OMOP Standardized Vocabularies

Experience with health data translation:

We have long hands-on technical working experience with working with health related data from various databases and data types like:

- Insurance bills
- Inpatient and outpatient records (HL7), both structured and in free text
- Laboratory measurements (LOINC, free text)
- Trauma registry data
- Wearables data (study specific) performed collection and analysis
 Prescription data

Other expertise :

Focus of our role has varied across datasets. We have a deep experience in all the steps that are needed to get clean and structured data out of the clinical and health related data, also in the analysis of large scale data:

- · Providing support and guidance for initial data anonymization, customized tooling where needed
- Secure data transfer and storage, compliant with various information security baseline controls
- Comprehensive data pipelines handling various stages of data intake and movement with major transformations (CSV & CDA v3 XML into relational DB)
- Free-text analysis and fact extraction using NLP tools
- ETL pipelines (cleaning, structuring, merging)
- Transforming data for speedy access for applications
 Various statistical analyses, data mining, deep learning
- Quality control

E-mail contact for our services: omop@stacc.ee



Small to Medium-sized Enterprises (SMEs) have created business opportunities beyond the EHDEN Data Partner Calls!

ENABLING DATA PARTNERS TO JOIN THE NETWORK

 Three calls have been finalized, including one COVID-19 Call. Two calls per year are foreseen in the project for a total amount of 17 Million Euro financial support. For more information about the Open Calls see the EHDEN website: <u>www.ehden.eu</u>

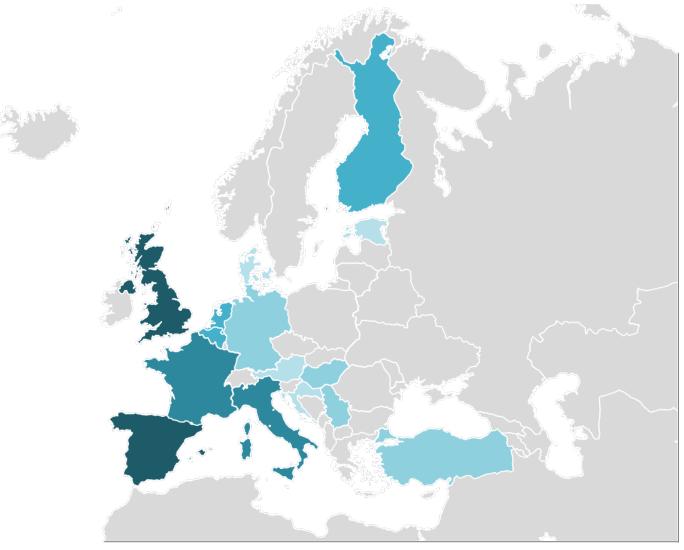
Act	tivity	Max. amount per complexity level in Euro				
		Low	Medium	High		
А.	Create new Data Transformation and Analytical Infrastructure	40.000	70.000	100.000		
В.	Revise Existing Data Transformation and Analytical Infrastructure	30.000	50.000	70.000		
С.	Inspect Completed Data Transformation and Analytical Infrastructure	10.000	20.000	30.000		

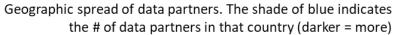
Table 1. Financial support per activity

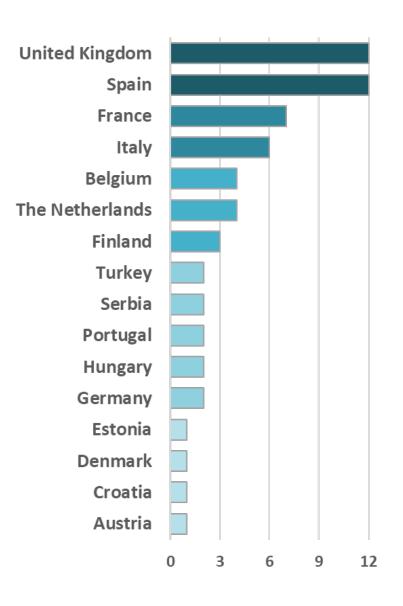
- Data Partners from EU Member States and H2020 countries can apply through online application portal.
- New data partner call opens in April! Watch our website and Social Media Channels



AFTER THREE CALLS WE SELECTED 60 DATA PARTNERS IN 16 COUNTRIES









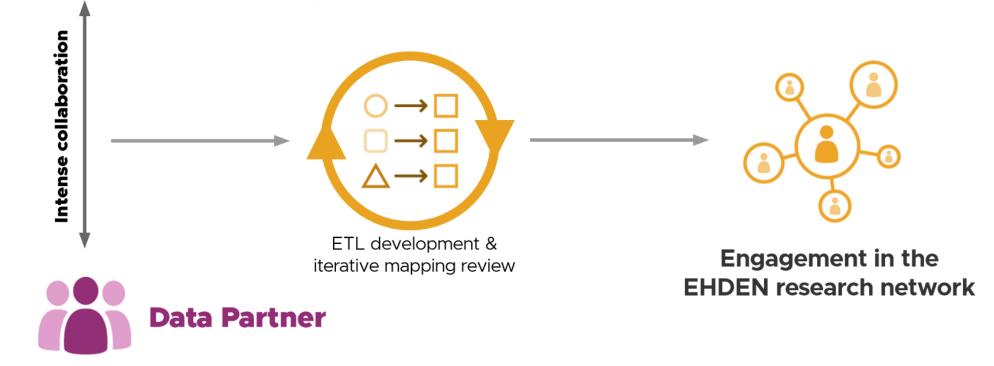
Mapping

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- Taskforce to help data partners with data relevant to COVID to get on the OMOP-CDM
- Taskforce contains EHDEN consortium partners that have extensive expertise in OMOP ETL, as well as certified SMEs



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Huge opportunity to learn about our processes for ETL and quality control.

Interesting to see the diversity in compentences, data readiness, complexity of data, infrastructure needs etc. efpia



Infrastructure and Tool development





»	EHDEN PORTAL	
3	ATLAS ATHome	Ai Home
 ₹ ₹ ₹ € € € € 	 Data Sources Search Concept Sets Cohort Definitions Characterizations Cohort Pathways Incidence Rates Profiles Estimation 	Welcome to ATLAS. ATLAS is an open source application developed as a part of OHDSI intended to provide a unified interface to patient level data and analytics. Documentation Image: The ATLAS user guide can be found here. Getting Started Define a New Cohort Begin performing research by defining the group of people you intend to study Search the Vocabulary Search the different ontologies used to describe patient level data around the world Release Notes ATLAS Version 2.7.8 Release Notes This latest release contains 20 feature enhancements and issue resolutions:
	 Estimation Prediction Jobs Configuration Feedback 	Impossible to delete Feature Analysis Concept set opens with an error PLPPLE import FALED Import of CS doesn't work properly Characterization import skips features Vocabulary switching Create a v2.78 release of Atlas ACHILLES reports and caching Application initialization failed for users without "Atlas users " role export and import of characterization are not compatible. Unable to create new source

- Tool integration in single environment (Single Sign On, Authenication Mechanisms)
- Service Desk Development (Self-service portal, ticketing system, phone number)
- Continuous Security Checks, Server monitoring

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Overview											
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EHDEN Website	v	0	0	0	0	0	0				
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extras	Added documentation files	29 days ago	-T- Abrene 7.0 Election	
inst	Added documentation files	29 days ago	Releases 2	
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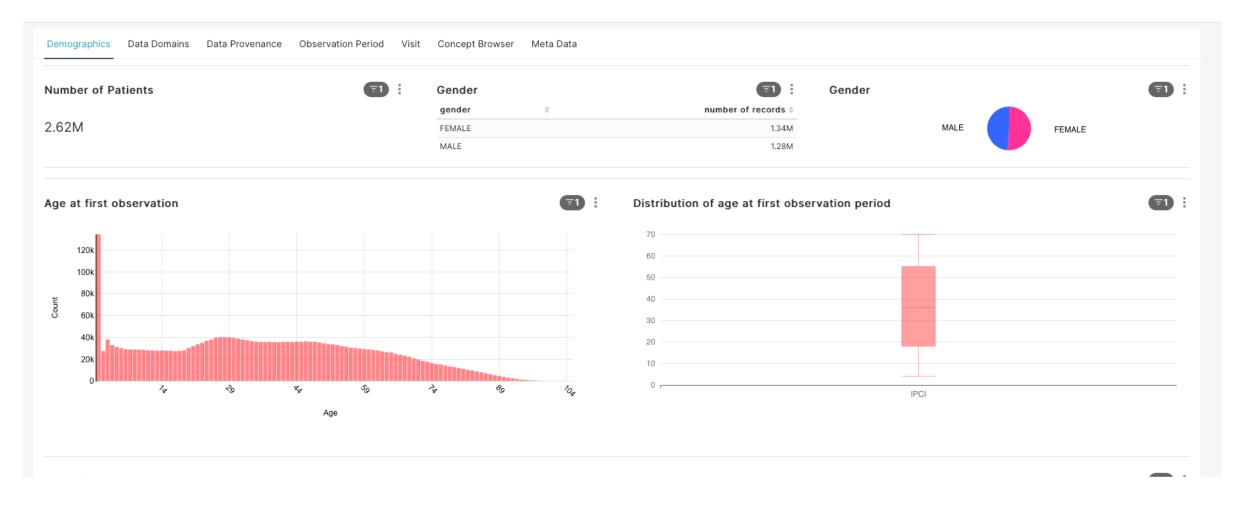
- Based on Achilles
- Extracts all data needed for the visualisations in the data catalogue
- Can easily be extended with additional analysis

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Demographics Data Domains Data Provenance Observation Period Visit Concept Browser Meta Data

The concepts browser allows you to search for concepts by name or concept_id in all the data sources you select. No exact number of patients or occurrences are provided but they are rounded up to the nearest multiple of 100. Note that the number of patients and occurrences are for that concept only and does not include the children of that code.

By clicking on the concept_id you can view additional information about the concept in Athena

Concept Browser

Show 10 🛊 entries

Domain Filter	
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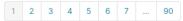
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Integrated Primary Care Information	201826	Type 2 diabetes mellitus	Condition	4483800	4483800
Integrated Primary Care Information	254761	Cough	Condition	2412700	2412700
Integrated Primary Care Information	81902	Urinary tract infectious disease	Condition	2283100	2204900
Integrated Primary Care Information	257011	Acute upper respiratory infection	Condition	2040300	2040300
Integrated Primary Care Information	4223659	Fatigue	Condition	1857100	1788200
Integrated Primary Care Information	194133	Low back pain	Condition	1700100	1700100
Integrated Primary Care Information	317009	Asthma	Condition	1787000	1579300
Integrated Primary Care Information	4131101	Excessive cerumen in ear canal	Condition	1466000	1466000
Integrated Primary Care Information	4037322	C/O: a general symptom	Condition	1460000	1460000





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3-Methylglutaconic aciduria				Condition						100	100	
46, XX true hermaphrodite				Condition						100	100	
4p partial monosomy syndrome				Condition						100	100	
5p partial monosomy syndrome				Condition	100 100					100	100	
ABO incompatibility reaction				Condition						100	100	
Abdominal abscess				Condition	100 100					40.7k		
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The Concept Network Coverage table shows the total number of records (RC) and total number of records including all descendant (DRC) of a specific concept in the full data network.

By clicking on the concept_id you can view additional information about the concept in Athena



how 10 🛊 entries				Search 10670 records	
concept_id	<pre> concept_name </pre>		Databases 🍦	drc ≑	rc
260427	Common cold	Condition	3	7.63M	7.63
316866	Hypertensive disorder	Condition	2	7.63M	5.89
201826	Type 2 diabetes mellitus	Condition	4	5.17M	4.49
254761	Cough	Condition	3	4.06M	4.06
94133	Low back pain	Condition	4	4.59M	41
31902	Urinary tract infectious disease	Condition	4	4.11M	3.91
432795	Traumatic AND/OR non-traumatic injury	Condition	2	9.03M	3.12
260139	Acute bronchitis	Condition	4	3.09M	3.06
24660	Acute tonsillitis	Condition	4	2.95M	2.95
316524	Hematocrit - finding	Condition	1	2.8M	2.8
				2 3 4 5 6	7 1067

Disclaimer: The presented data can be used for an initial feasibility assessment but should not be used for research without involvement of the data custodian





• Maintenance and extension of the ETL Tools

• Tool development to support drug mapping

• Exploring the use of Usagi in a collaborative framework to distribute the mapping effort





EHDEN / CdmInspection

<> Code 🕧 Issues 🏦 Pull requests 🖓 Discussions 🕞 Actions 💾 Projects 💷 Wiki 😲 Security 🗠 Insights 🕸 Settings

²⁹ master → ²⁹ 2 branches S1 tag		Go to file Add file - Code -	About 龄		
PRijnbeek Update README.md 2afb@e5 21 hours ago Image: Second sec			inspection of an OMOP-CDM instance	1 TABLE OF CONTENT	
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The European Health Data and Evidence Network (EHDEN) project has multiple yearly Open Calls for financial

⊙ Unwatch - 5 ☆ Star 1 % Fork 2

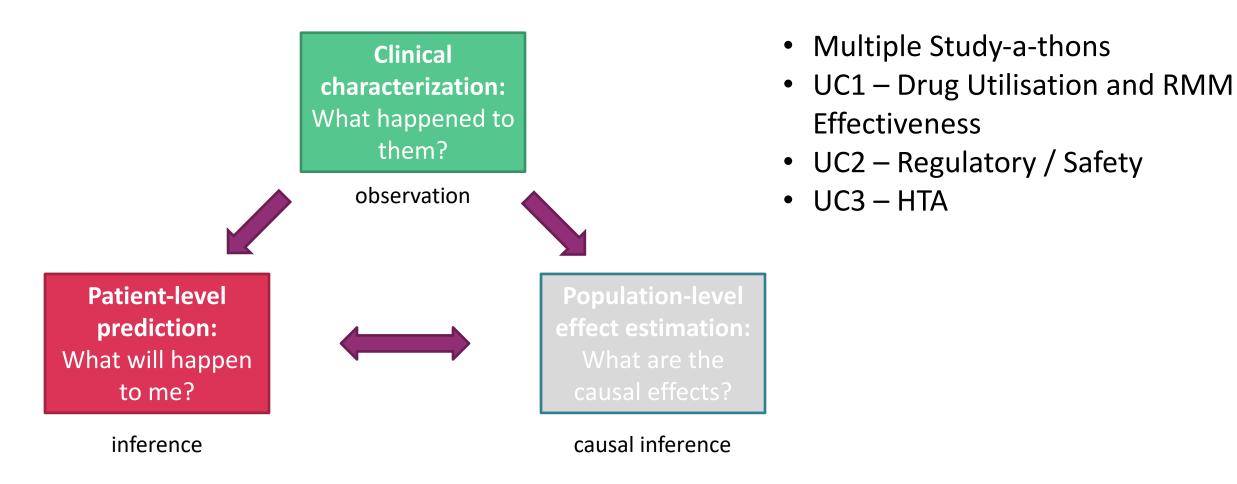
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Research Pillar









METHODS DEVELOPMENT: SOME EXAMPLES

- Pipeline development
 - Heterogeneity of Treatment Effect
 - Natural Language Processing
 - Disease Trajectories
 - Frequent Pattern Mining
 - Learning Curve Research
- Other topics
 - Patient Level Prediction Models Review
 - Explanainable AI



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https://zenodo.org/communities/ehden

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European Health Data and Evidence Network	
Recent uploads	⊥ New upload
Search European Health Data and Evidence Network	Community
December 16, 2020 (1) Project deliverable Open Access EHDEN - D4.5 - Roadmap for interoperability solutions View © Kees van Bochove; Emma Vos; © Maxim Moinat; Sebastiaan van Sandijk; Tess Korthout; Peyman Mohtashani;	EHDEN
The EHDEN project aims to make healthcare data in Europe Findable, Accessible, Interoperable and Reusable (FAIR) at an unprecedented level. This deliverable explores what this entails technically, and how the technical framework of EHDEN, including the OMOP model and the EHDEN Portal, could maximize	EUROPEAN HEALTH DATA & EVIDENCE NETWORK
Uploaded on January 27, 2021	European Health Data and Evidence Network
December 15, 2020 (v1) Preprint Open Access Development and validation of patient-level prediction models for adverse outcomes following total knee arthroplasty	Europe is generating huge amounts of patient-level
Ross D. Williams; Jenna M. Reps; @ Anthony G. Sena; @ Edward Burn; Ying He; Daniel R. Morales; David Culliford; Dahai Y @ Victoria Y. Strauss; @ Talita Duarte-Salles; @ Albert Prats-Uribe; Antonella Delmestri; @ James Weaver; William Sproviero; Danielle Robinson; Henry Morgan Stewart; Belay Birlie; Rafael Pinedo-Villanueva; @ Spyros Kolovos; Luis H. John; Ruth E. Costello; Michel van Speybroeck; Caroline O'Leary; Evan Minty; @ Thomas Falconer; Alison Callahan; Stephe Pfohl; Theresa Burkard; @ Jennifer Lane; @ Peter R. Rijnbeek; Patrick B. Ryan; @ Daniel Prieto-Alhambra;	Yu; diagnoses, medications, laboratory test results, etc., and unstructured data in clinical narratives. The Electronic Health Data and Evidence Network (EHDEN) Consortium leverages these vast volumes of data to improve future clinical practice and
Background Elective total knee replacement (TKR) is a safe and cost-effective surgical procedure for treating severe knee osteoarthritis (OA). Although complications following surgery are rare, prediction tools could help identify those patients who are at particularly high risk who could then be ta Uploaded on January 8, 2021	individual patient outcomes by increasing our understanding of disease and treatment pathways. EHDEN galvanizes transparent and reproducible analytics that generate valid real-world evidence to improve patient care, and enable medical outcomes- based research at an unprecedented scale.
November 27, 2020 (v1) Preprint Open Access Use of dialysis, tracheostomy, and extracorporeal membrane oxygenation among 240,392 patients hospitalized with COVID-19 in the United States	The core of EHDEN is the use of a common data
Edward Burn; S Anthony G. Sena; Albert Prats-Uribe; Matthew Spotnitz; Scott DuVall; Kristine E. Lynch; Michael E Matheny; Fredrik Nyberg; Waheed-Ul-Rahman Ahmed; O Said Alser; Heba Alghoul; Thamir Alshammari; Lizhang; Paula Casajust; C Carlos Areia; Karishma Shah; C Christian Reich; C Clair Blacketer; Alan Andryc; Stephen Fortin; Karthik Natarajan; Mengchun Gong; Asieh Golozar; Daniel Morales; Peter Rijnbeek; Vignesh Subbian; Elena Roel; Martina Recalde; Martina Recalde; Alan Andryc; Stephen I-ottin; Karthik Natarajan; Alena Shah; C Christian Reich; Martina Recalde; Alan Andryc; Stephen Roel; Martina Recalde; Alena Stephen; C C. Lane; David Vizcaya; Jose D. Posada; Nigam H. Shah; Jitendra Jonnagaddala; C Lana Yin Hui Lai; Francesc Xavier Avilés-Jurado; George Hripcsak; Marc A. Suchard; Otavio T. Ranzani; Patrick Ryan; D anal Prieto-Alhambra; Kristin Kostka; Talita Duarte-Salles;	The objective of the EHDEN consortium is to provide all the necessary services that enable a distributed European data network to perform fast, scalable and highly reproducible research, while respecting private regulations, load data performance and

perform data standardization, analytical pipelines,



Community Building and Sustainability



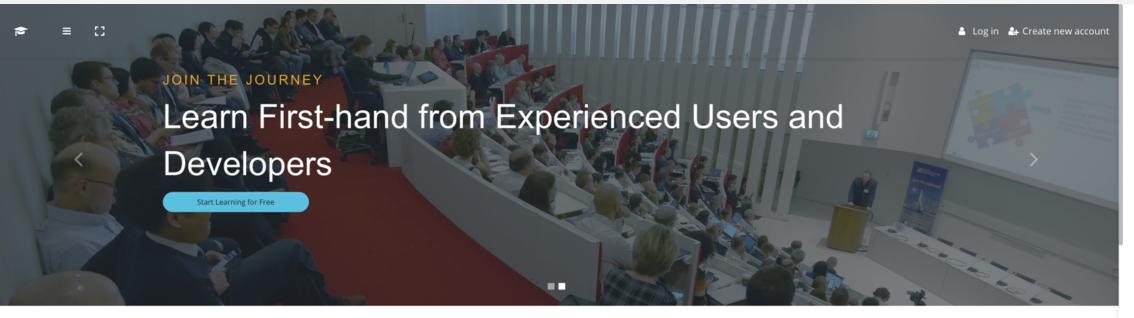


- Stakeholder Workshops, e.g. with HTA bodies
- EHDEN Webinars
- Collaboration with other European Projects
- Interaction with regulators
- Interaction with European Commission
- Providing educational resources



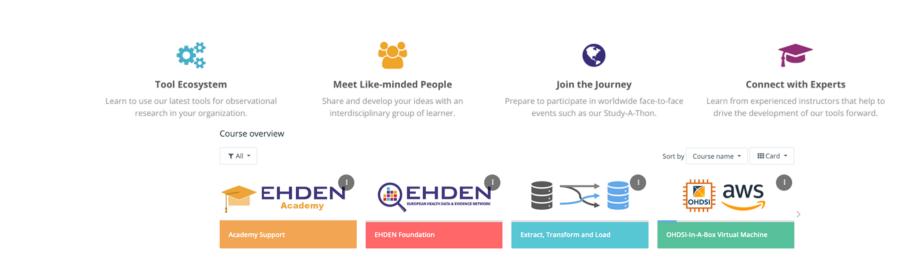


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Learning for Anyone, Anywhere

On-demand training and development programs developed by the OHDSI and EHDEN community.





Now

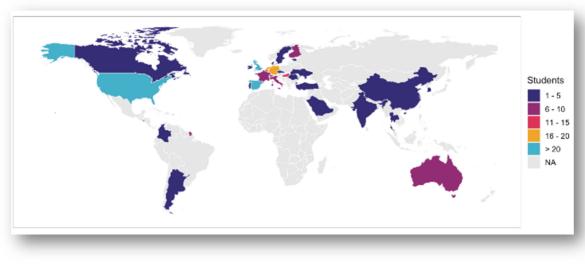
- Free education in observational research from the perspective of OHDSI
- Modular training along Learning Paths
- Link to the OHDSI global community
- Supports EHDEN's SME training/ certification & Data Partners programme

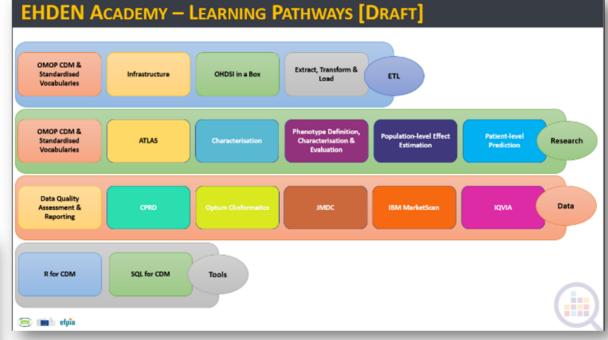
Opportunity

- Forum engagement and community development to extend EHDEN and OHDSI
- Engagement by potential partners and sponsors in Academy development and community
- Scientific standard communicated for observational research within OHDSI framework
- Insights generation on research community's education and practice
- Future educational institution with clear remit and formal qualifications

THE EHDEN ACADEMY AS A NEW GLOBAL EDUCATIONAL RESOURCE

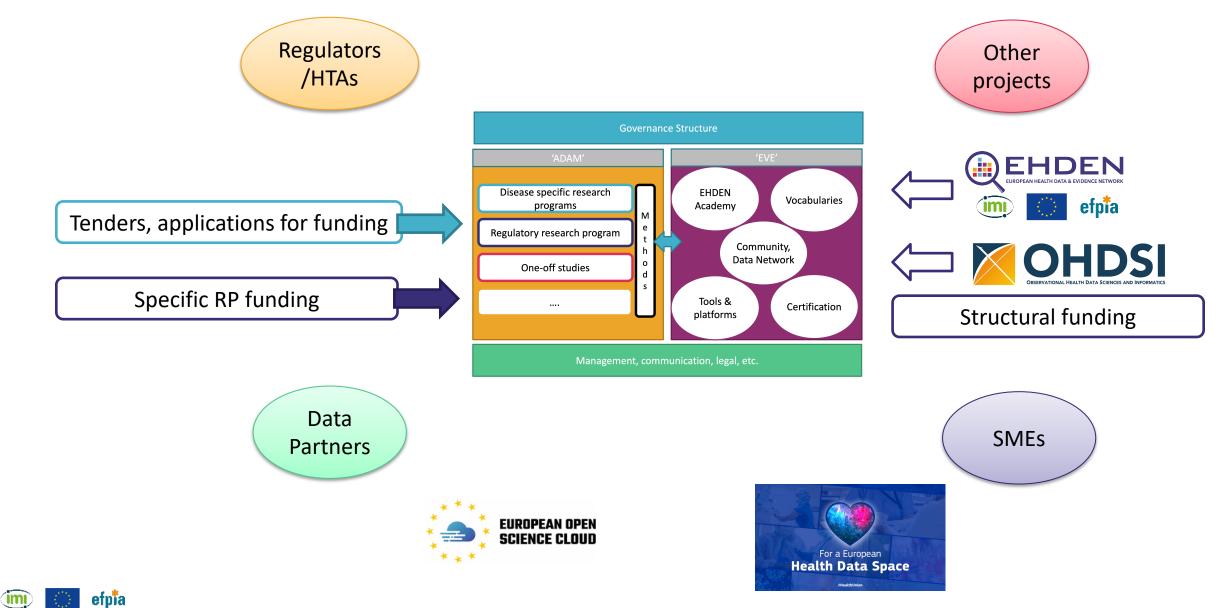
- As of 8th February ~800 participants enrolled with ~50% active in the last 14 days
 - Major concentration in US, UK and Spain
 - Focus driven by EHDEN SME Learning Pathway in Europe
 - European SME marketplace developing (sustainability)





- Focus now is on content development in 2021
- Learning pathways developed from modules created by OHDA and Erasmus Medical Center
- https://academy.ehden.eu

SUSTAINABILITY: THE EHDEN INSTITUTE

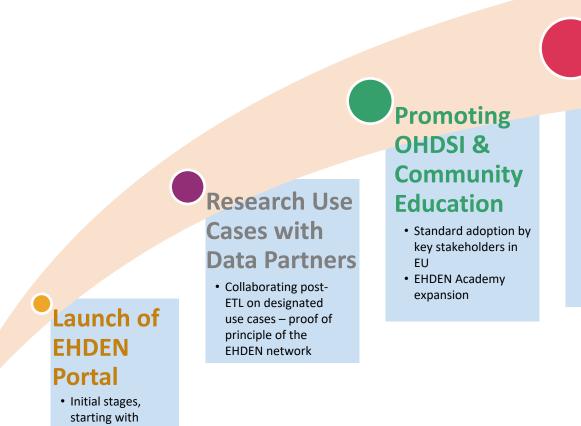


CLEAR OBJECTIVES IN EHDEN YEAR 3

Catalogue

efpia

Imi



Launch of EHDEN Institute sustainability

- New legal entity
- Parallel to EHDEN project
- Development of research operating model and future business model

And much more...



- We are all cognisant of the impact of the COVID-19 pandemic
- OHDSI is evolving and expanding. Countries are adopting the OMOP CDM, e.g. Denmark, Germany as are other IMI projects (e.g. BD4BO, EU-PEARL, H2O, et al)
- From a PEST analysis now:
 - Political: Instability
 - Economic: Global Shock
 - Social: Negative Trends
 - Technology: Networks Expanding
- EHDEN has grown as a thought leader in this dynamic environment
- EMA and EU Commission plans very convergent with EHDEN
- We are on track to support observational research in a sustainable, federated, open science network for the future



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