EHDEN

EUROPEAN HEALTH DATA & EVIDENCE NETWORK

Basel Biometric Society Seminars 2024

Dani Prieto Alhambra

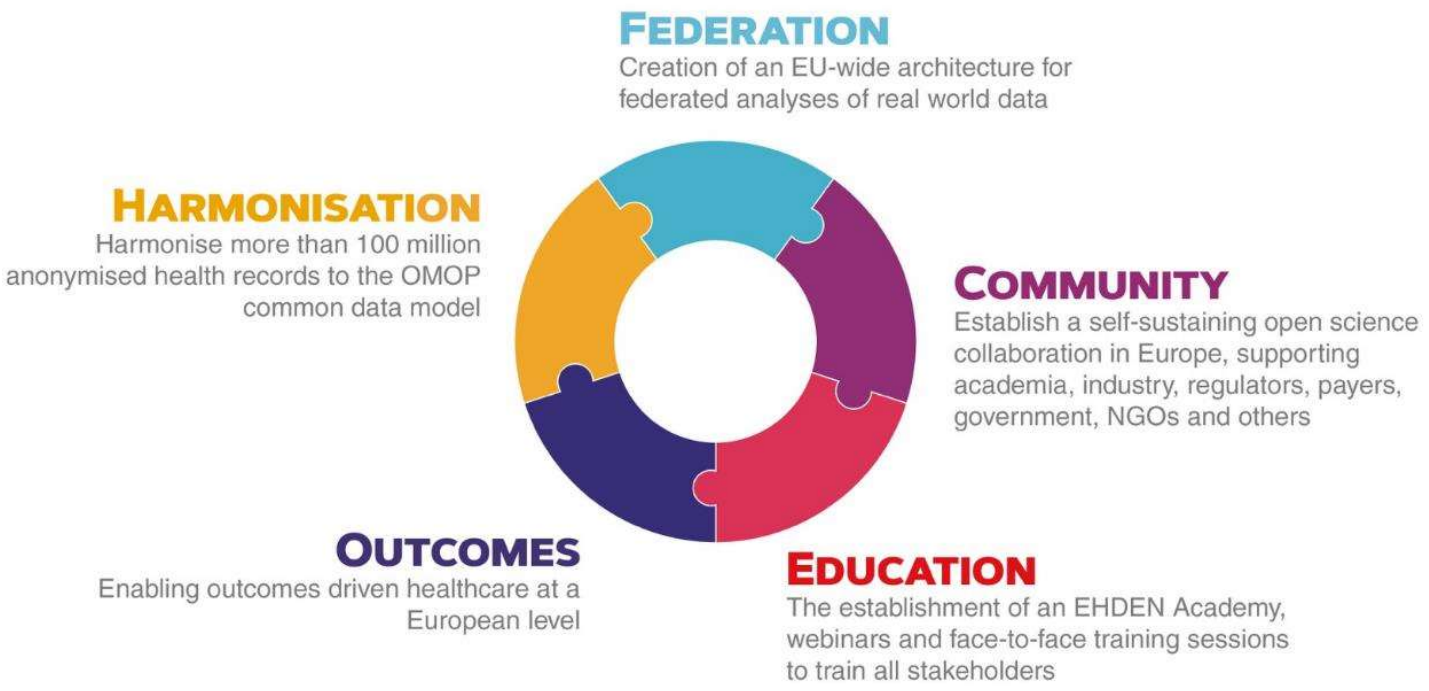
University of Oxford - EMC Rotterdam

imi innovative medicines initiative

efpia

EHDEN IS ABOUT...

Providing 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 (OMOP), significantly speeding up the generation of reliable evidence.



EHDEN BASICS

Start date: 1 Nov 2018
End date: 30 Oct 2024
Duration: 72 months

25 partners

~€30 million

Universities, public bodies and research organisations

Erasmus MC — Academic coordinator

Uppsala Monitoring Centre

universidade de aveiro

NICE National Institute for Health and Care Excellence

Tartu Ülikool

University of Oxford

Small & Mid-sized companies

SYNAPSE Research Management Partners

The Hyve

Odysseus Data Services Inc

Other organisations

EPF European Patients Forum

ICHOM

EFPIA & Associated partners

Janssen — EFPIA Lead

Bayer

Celgene

Pfizer

Lilly

Boehringer Ingelheim

abbvie

Roche

Servier

AstraZeneca

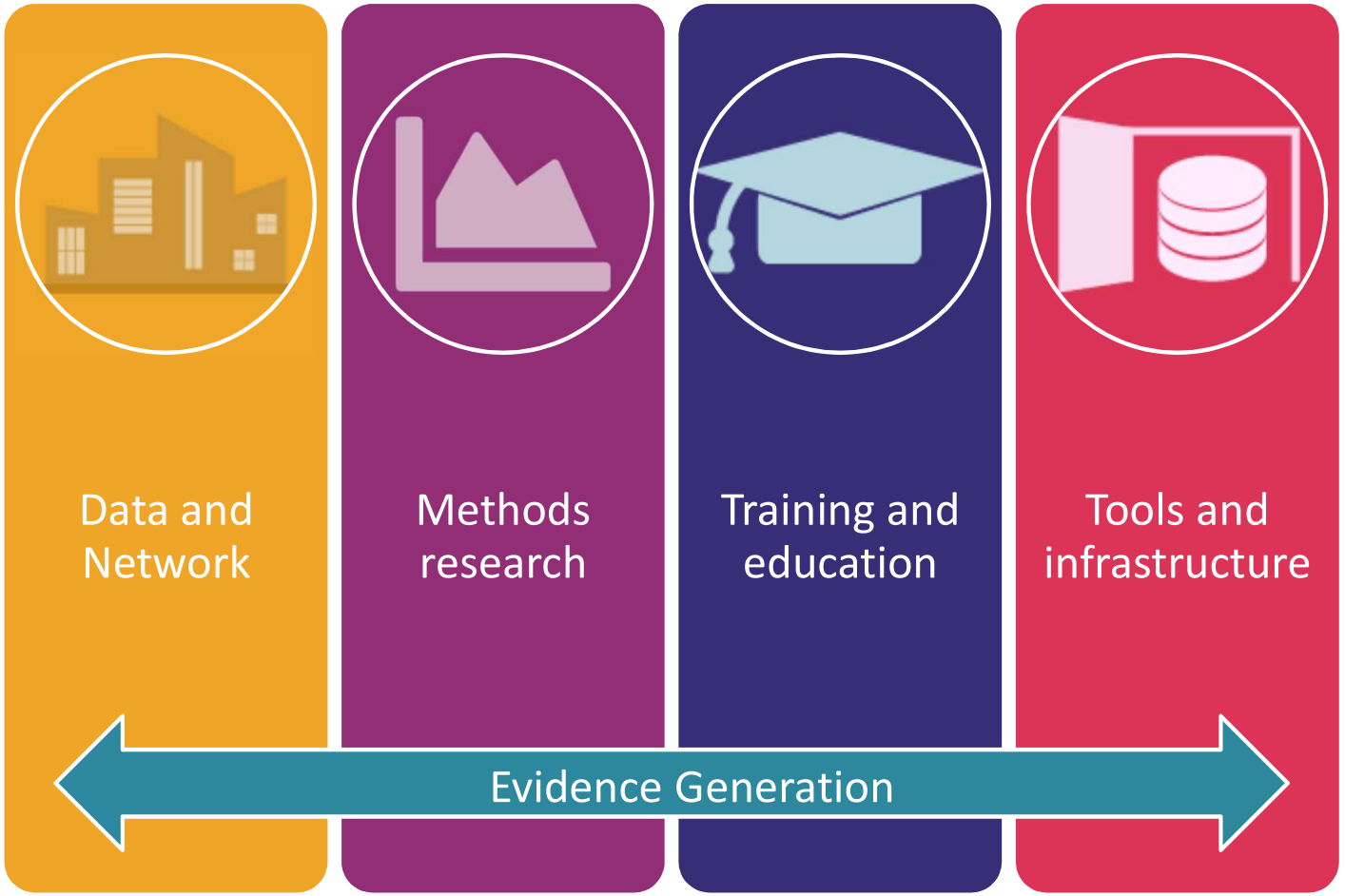
Sanofi

UCB

Novartis

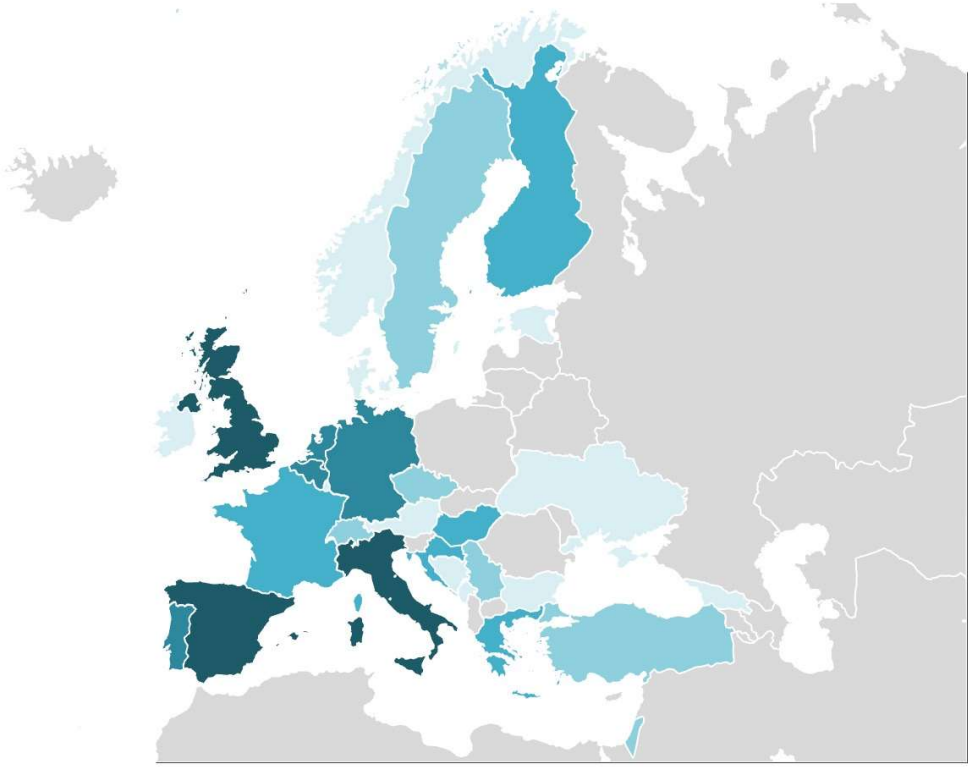
Lundbeck

EHDEN Basics

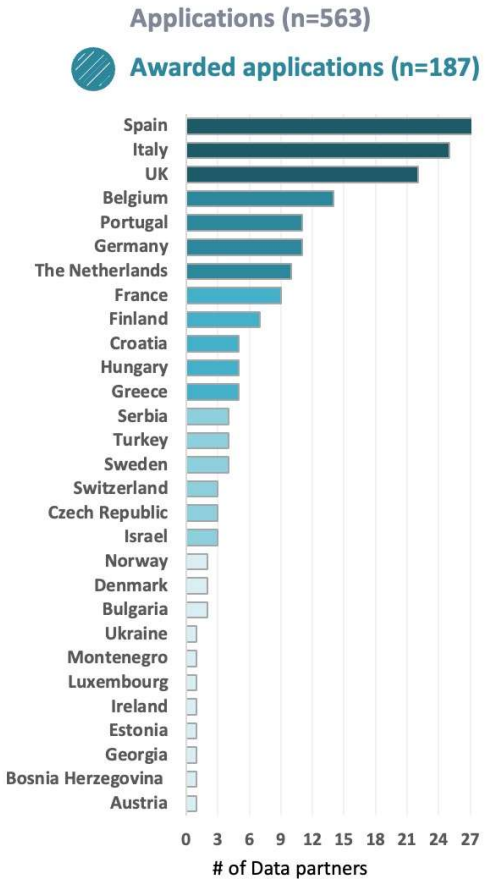


Data Partner Network [After 7 Calls]

https://www.ehden.eu/datapartners/



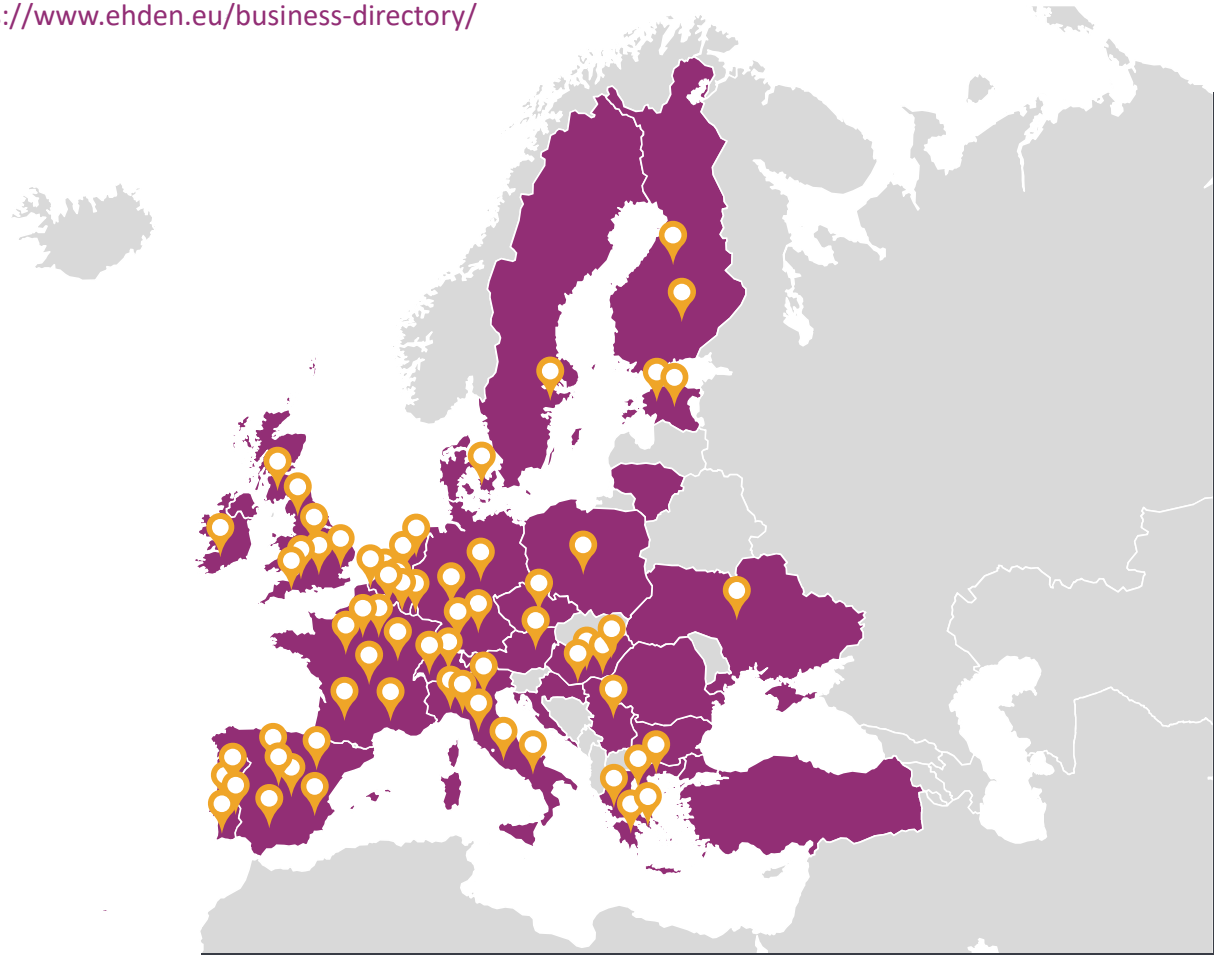
Geographic spread of data partners. The shade of blue indicates the # of data partners in that country (darker = more)



~850 million records being mapped to OMOP CDM in 29 European countries

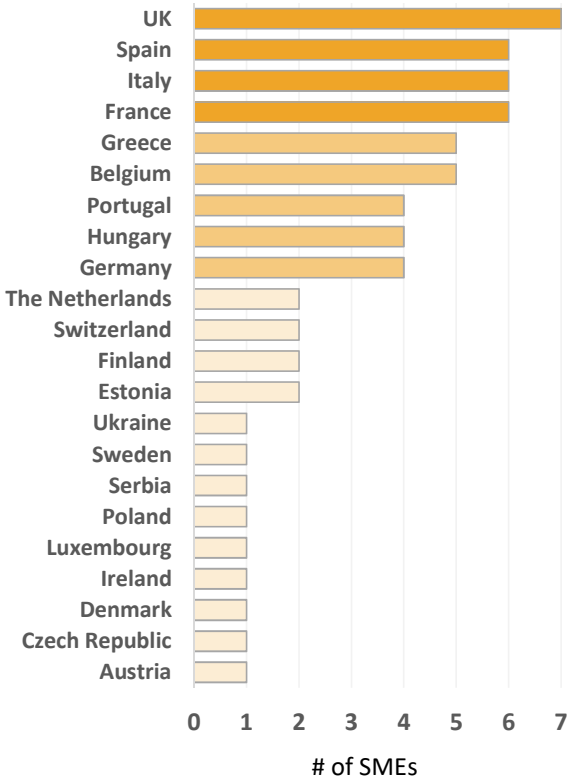
SME Network [after 4 Calls]

https://www.ehden.eu/business-directory/

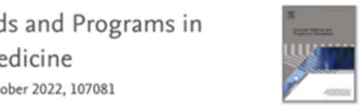


Certified SMEs (n=64)

Applications (n=143)



METHODS: MANY PUBLICATIONS. SOME EXAMPLES…



Computer Methods and Programs in Biomedicine

Volume 225, October 2022, 107081

TreatmentPatterns: An R package to facilitate the standardized development and analysis of treatment patterns across disease domains

Aniek F. Markus [a], Katia M.C. Verhamme [a, b], Jan A. Kors [a], Peter R. Rijnbeek [a]

Show more

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https://doi.org/10

Under a Creative

Highli

Proceedings of Machine Learning Research 182:1–25, 2022 Machine Learning for Healthcare

Why predicting risk can't identify 'risk factors': empirical assessment of model stability in machine learning across observational health databases

Aniek F. Markus A.MARKUS@ERASMUSMC.NL
Department of Medical Informatics
Erasmus University Medical Center
Rotterdam, The Netherlands

Peter R. Rijnbeek P.RIJNBEEK@ERASMUSMC.NL
Department of Medical Informatics
Erasmus University Medical Center
Rotterdam, The Netherlands

Jenna M. Reps JREPS@ITS.JNJ.COM
Janssen Research and Development
Raritan, New Jersey, United States

> Semin Arthritis Rheum. 2022 Oct;56:152050. doi: 10.1016/j.semarthrit.2022.152050. Epub 2022 Jun 15.

Development and external validation of prediction models for adverse health outcomes in rheumatoid arthritis: A multinational real-world cohort analysis

Cynthia Yang [1], Ross D Williams [2], Joel N Swerdel [3], João Rafael Almeida [4], Emily S Brouwer [3], Edward Burn [5], Loreto Carmona [6], Katerina Chatzidionysiou [7], Talita Duarte-Salles [8], Walid Fakhouri [9], Antj, Lembe Kullamaa [13], J, Henry Morgan Stewar, Carmen O Torre [17], K, Daniel Prieto-Alhambr

Affiliations + expand

PMID: 35728447 DO

Free article

> JAMIA Open. 2022 Mar 16;5(1):ooac021. doi: 10.1093/jamiaopen/ooac021. eCollection 2022 Apr.

Trajectories: a framework for detecting temporal clinical event sequences from health data standardized to the Observational Medical Outcomes Partnership (OMOP) Common Data Model

Kadri Künnapuu [1], Solomon Ioannou [2], Kadri Ligi [1 3], Raivo Kolde [3], Sven Laur [1 3], Jaak Vilo [1 3 4], Peter R Rijnbeek [2], Sulev Reisberg [1 3 4]

Affiliations + expand

PMID: 35571357 PMCID: PMC9097714 DOI: 10.1093/jamiaopen/ooac021

Free PMC article

Abstract

Background: Identific
outcomes remains a n
variety of adverse hea
monotherapy.

Abstract

Objective: To develop a framework for identifying temporal clinical event trajectories from Observational Medical Outcomes Partnership-formatted observational healthcare data.

Materials and methods: A 4-step framework based on significant temporal event pair detection is described and implemented as an open-source R package. It is used on a population-based Estonian dataset to first replicate a large Danish population-based study and second, to conduct a disease trajectory detection study for type 2 diabetes patients in the Estonian and Dutch databases

> Drug Saf. 2022 May;45(5):563-570. doi: 10.1007/s40264-022-01161-8. Epub 2022 May 17.

Using Iterative Pairwise External Validation to Contextualize Prediction Model Performance: A Use Case Predicting 1-Year Heart Failure Risk in Patients with Diabetes Across Five Data Sources

> Int J Med Inform. 2022 Jul;163:104762. doi: 10.1016/j.ijmedinf.2022.104762. Epub 2022 Apr 12.

Logistic regression models for patient-level prediction based on massive observational data: Do we need all data?

Luis H John [1], Jan A Kors [2], Jenna M Reps [3], Patrick B Ryan [3], Peter R Rijnbeek [2]

Affiliations + expand

PMID: 35429722 DOI: 10.1016/j.ijmedinf.2022.104762

> BMC Med Inform Decis Mak. 2022 May 25;22(1):142. doi: 10.1186/s12911-022-01879-6.

Learning patient-level prediction models across multiple healthcare databases: evaluation of ensembles for increasing model transportability

oss D Williams [# 2], Martijn J Schuemie [3], Patrick B Ry

): PMC9134686 DOI: 10.1186/s12911-022-01879-6

models that are accurate could help aid medical decisi
often contain temporal medical data for large and diver
ble to learn prognostic models using the large observati
gnostic model undesirably worsens when transported t
al setting). In this study we investigate different ensemb

> BMC Med Res Methodol. 2022 Jan 30;22(1):35. doi: 10.1186/s12874-022-01505-z.

Seek COVER: using a disease proxy to rapidly develop and validate a personalized risk calculator for COVID-19 outcomes in an international network

Ross D Williams [# 1], Aniek F Markus [# 1], Cynthia Yang [1], Talita Duarte-Salles [2], Scott L DuVall [3], Thomas Falconer [4], Jitendra Jonnagaddala [5], Chungsoo Kim [6], Yeunsook Rho [7],

> J Am Med Inform Assoc. 2022 Apr 1

Trends in the conduct and reporting of clinical prediction model development and validation: a systematic review

Cynthia Yang [1], Jan
Alexandros Rekkas
Peter R Rijnbeek [1]

Affiliations + expar

PMID: 35045179 P

Free PMC article

> Knee Surg Sports Traumatol Arthrosc. 2022 Sep;30(9):3068-3075. doi: 10.1007/s00167-021-06799-y. Epub 2021 Dec 6.

90-Day all-cause mortality can be predicted following a total knee replacement: an internationa network study to develop and validate a prediction model

Ross D Williams [# 1], Jenna M Reps [# 2], OHDSI/EHDEN Knee Arthroplasty Group;

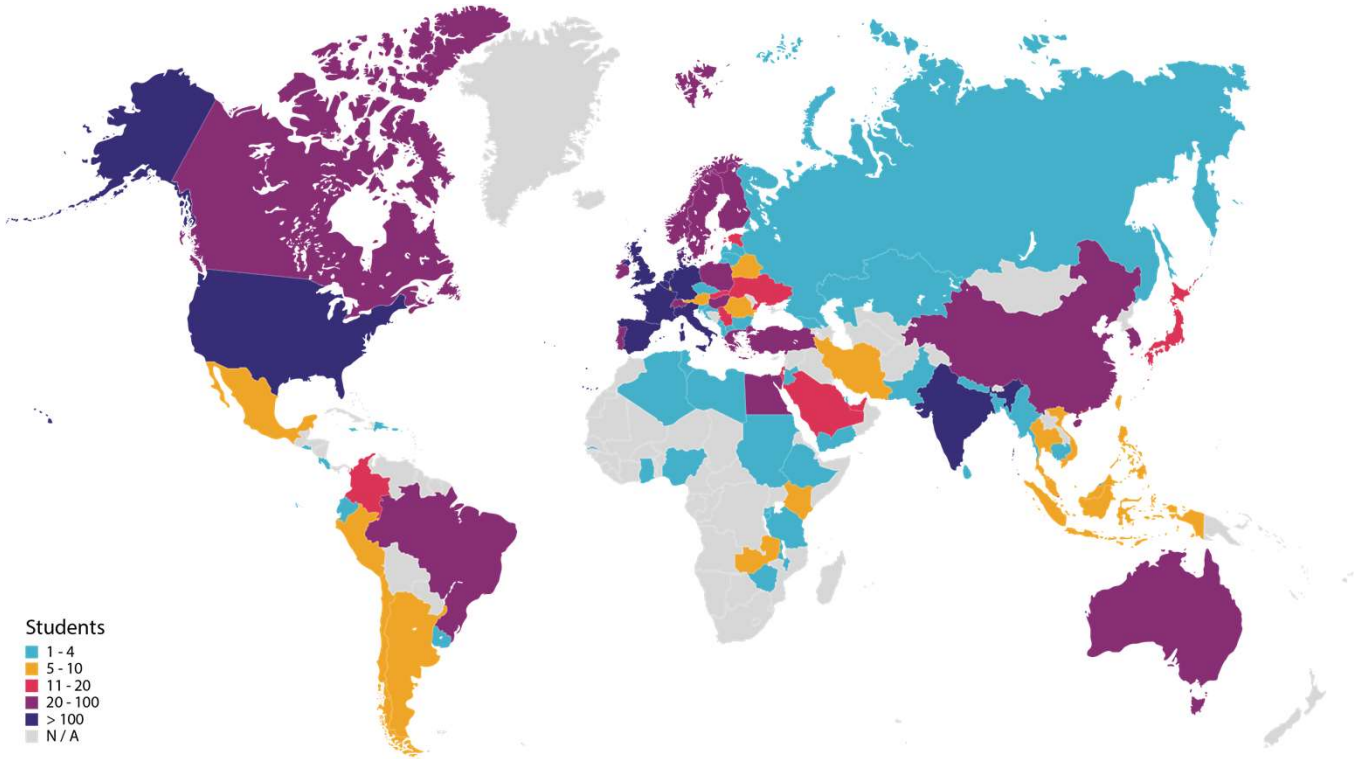
TRAINING: EHDEN ACADEMY – FREE ONLINE TRAINING FOR ALL

19 courses covering:

- EHDEN Academy
- SKILLS
- TOOLS
- METHODS

and a course for **non-experts**

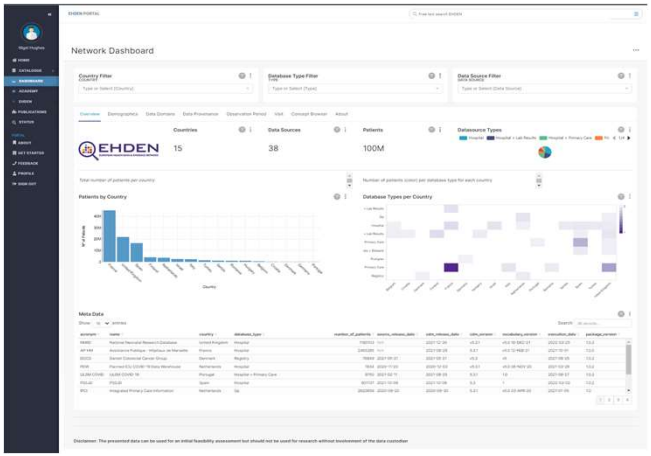
> 4,000 students



Also used as a training program for certification of SMEs to support Data Partners mapping their data to the OMOP CDM

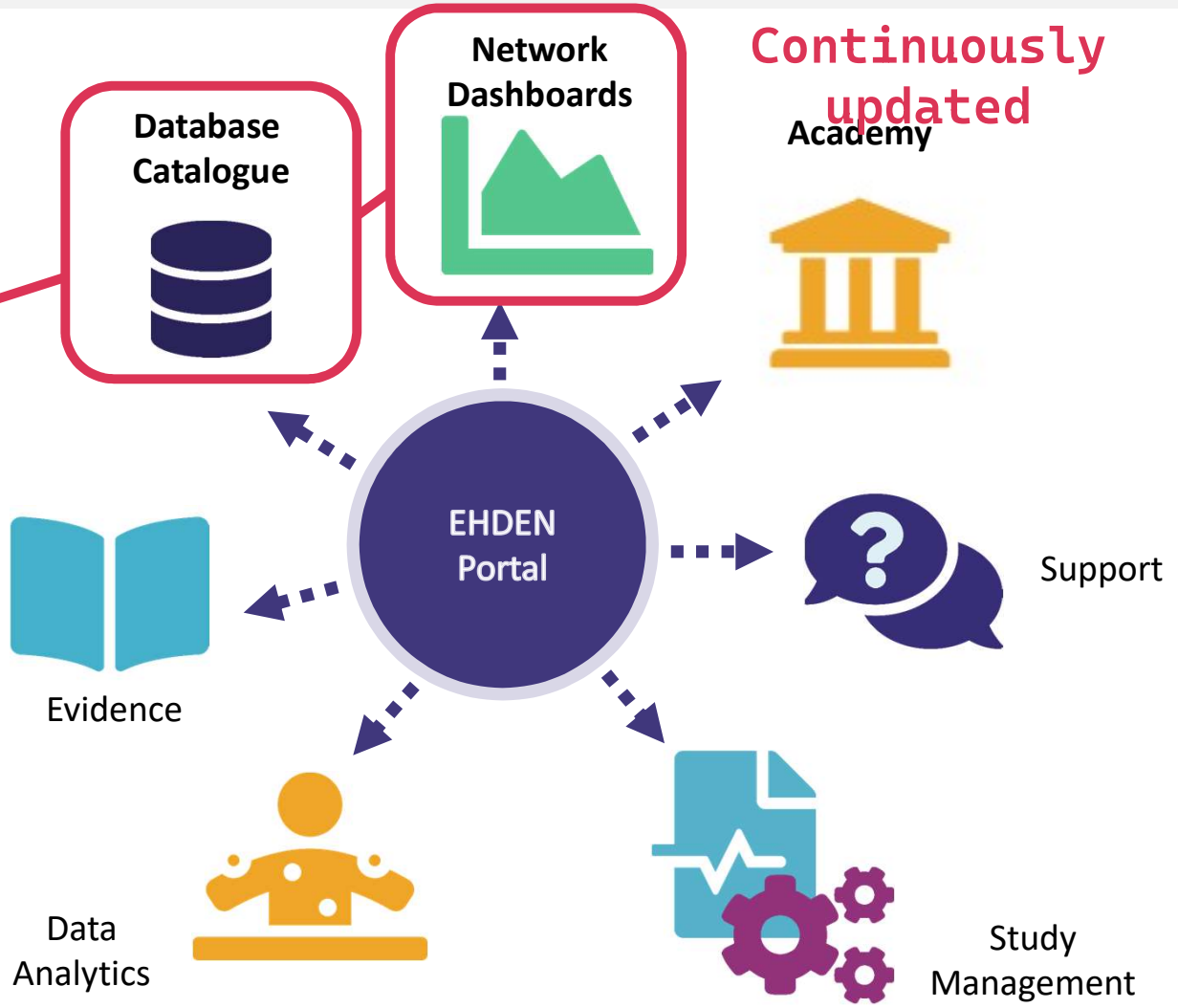
TOOLS: THE EHDEN PORTAL – ONE-STOP-SHOP LAUNCHED 24 JUNE 2022

https://www.ehden.eu/ehden-portal/



Free Enrolment!

	# databases in Database Catalogue	# databases in Network Dashboard	# countries	# patients	# users
OHDSI EU 2022	67	35	15	~ 44 Mio	~ 400
OHDSI EU 2023	118	90	23	~ 149 Mio	~ 900
	76%	157%	53%	238%	125%
Total number at end of project	187	187	29		



EVIDENCE GENERATION EXAMPLE: LONG-COVID STUDY-A-THON

13 Data Partners

BIGAN Big Data in Healthcare, Aragon

CHU Montpellier

CPRD

Instituto de Investigación Sanitaria La Fe

- GOLD
- AURUM

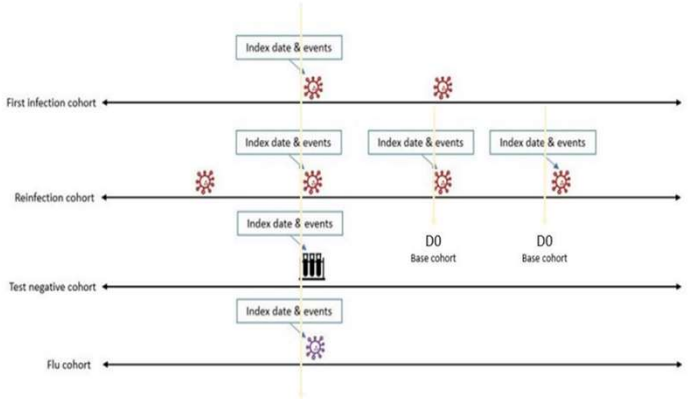
IMIM Parc de Salut MAR Barcelona — Institut Hospital del Mar d'Investigacions Mèdiques

Tartu Ülikool 1632 Universitas Tartuensis

UiO : Department of Pharmacy University of Oslo

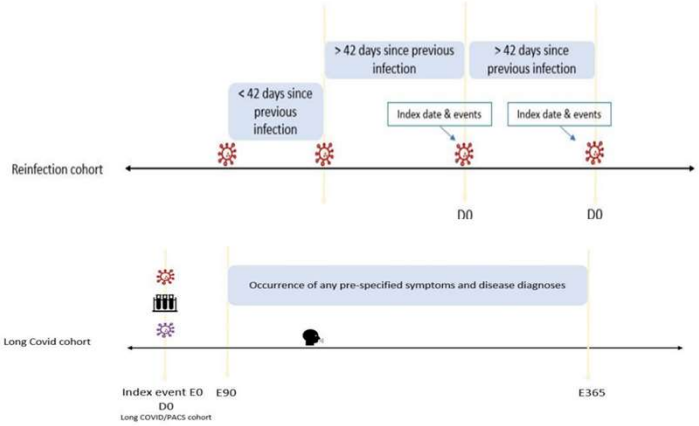
SIDIAP

ADDITIONAL DPs (online) Pharmetrics+, IQVIA (USA), HSD (Italy), Ajou University (S Korea)



	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY
8.45-9.00		COFFEE			
9.00- 10.30		9.00-9.30 Intro to Github (Data Scientists) All: Presentation of Results for 1 DB	Break out session in 3 groups	Break out session in 3 groups	All: Review results from additional analyses and manuscripts together
10.30-11.00	Technical Help desk	Coffee break			
11.00-13.00		Break out in 3 groups: (1) Descriptive epi (2) Drug utilisation (3) Clusters and trajectories	Break out session in 3 groups	Break out session in 3 groups	All: Closure; Next steps beyond this study-a-thon (publication) Lunch from 12.00
13.00-14.00	LUNCH				
14.00- 15.30	Welcome and Introductions	Manuscript discussion Break out session in 3 groups	All: Progress update	All: Progress update	
15.30- 16.00	Coffee break				
16.00- 17.00	Introduction of the databases Form expert teams for the rest of the week	All: Update and Summary of Plan for the next days	Break out session in 3 groups	Break out session in 3 groups	
		Evening: Dinner		Evening: Dinner	

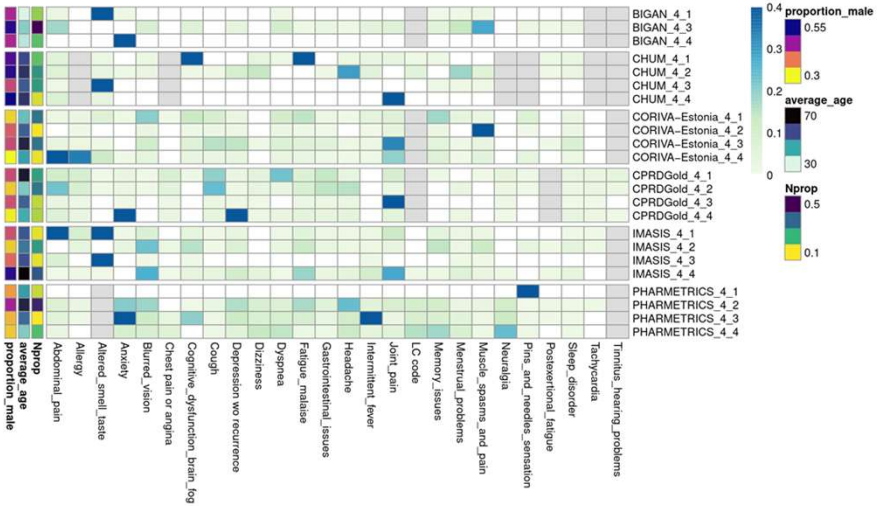
	Team 1	Team 2	Team 3	Team 4
Work Package	Incidence	Characterisation and DUS	Clustering and Trajectories	Technical Experts
Lead	**FRANK**	**ANNIKA**	**KIM**	**MARTÍ and ED**
Long COVID Experts	Roger	Cora	Lourdes	
Clinical Experts	[Dani]	Miguel-Angel	Raúl	
			[Dani]	
Data Sciences	Juan Manuel	Núria	Raivo	Aki
	Jaime	Dominique	Alvaro	
	[Ed]	Laura	[Martí]	
Pharmacists		Nhung		
		Theresa		
Epidemiologists	Kristin	Johnmary	Talita	
	Alicia	Bernardo	Daniel	
	Anneli		Gregoire	
	Jessie			



EVIDENCE GENERATION: EXAMPLE OUTPUTS

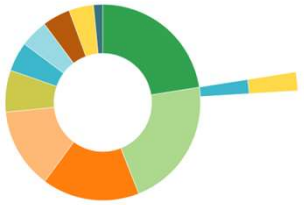
Long COVID characterisation

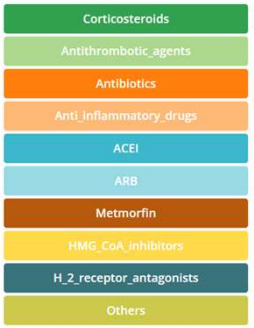
Preliminary clusters identified using Latent Class Analyses across 4 databases



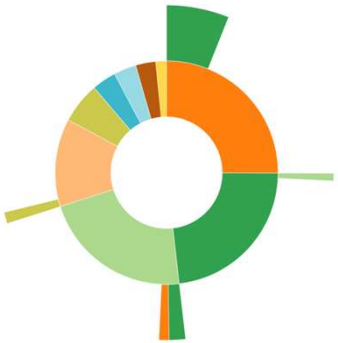
SUNBURST PLOTS

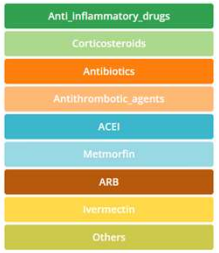
Treatments after COVID-19 diagnosis in the NL and the UK





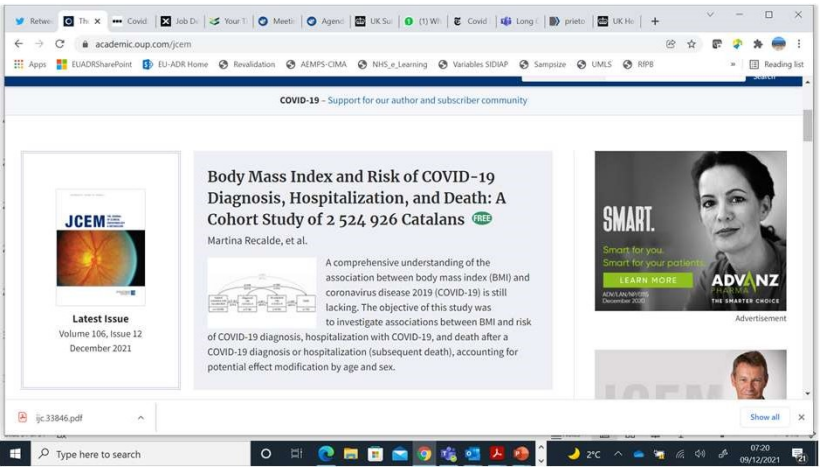
CPRD GOLD



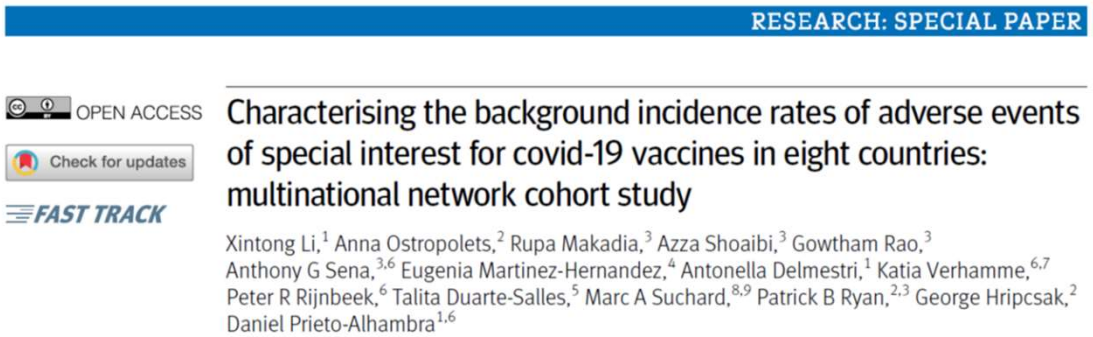


IPCI

ACADEMIC/SCIENTIFIC IMPACT: ~70 METHODOLOGICAL & SCIENTIFIC PUBLICATIONS



BMI in COVID-19: JCEM pick of the week!!

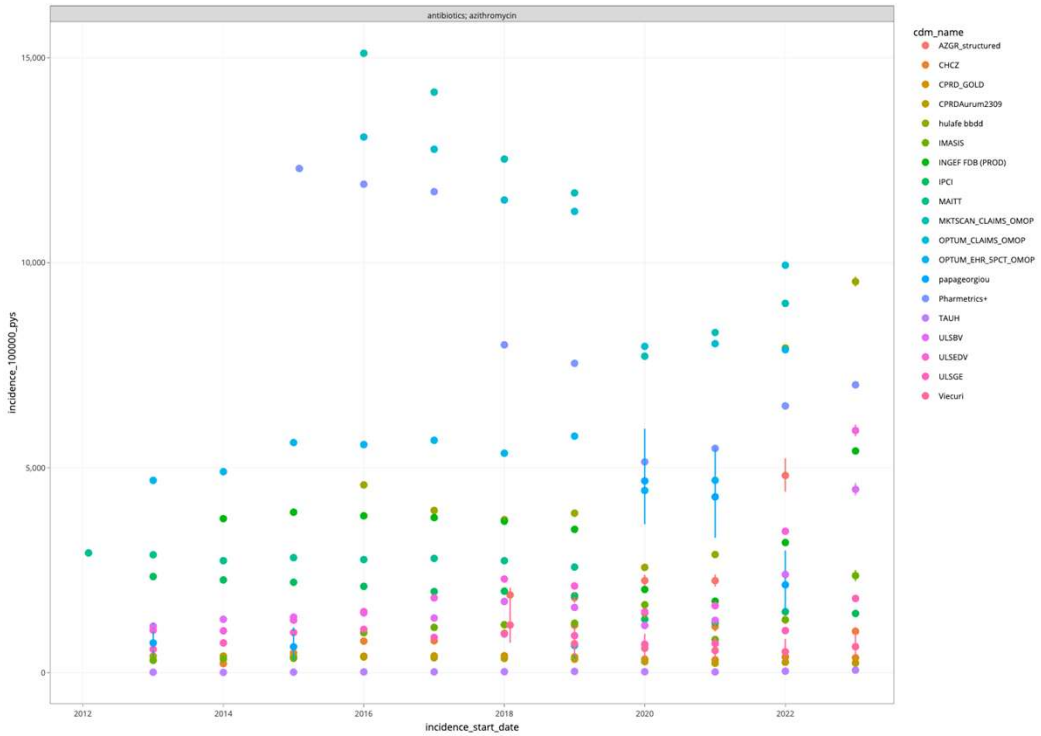


https://zenodo.org/communities/ehden/search?page=1&size=20&q=&type=publication&subtype=preprint&subtype=article

EVIDENCE GENERATION: A STRIKING UPCOMING STUDY

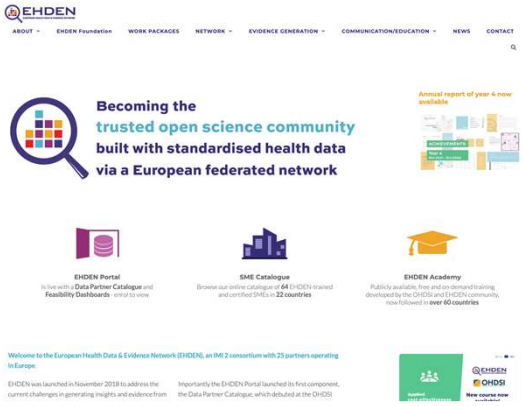
- **EHDEN Mega-Study**
  - *To describe the incidence and prevalence of medicines with suggested shortages between 2015 and 2023*
  - *To characterise incident users of medicines with suggested shortages between 2015 and 2023*

Database name	Persons in the database	Number of observation periods	OMOP CDM vocabulary version
AZGR_structured	68,918	67,532	v5.0 16-JAN-23
BARDENA	1,972,272	1,972,272	v5.0 23-JAN-23
BG	501,065	501,065	v5.0 04-FEB-22
CHA CAN	214,443	208,183	v5.0 16-JAN-23
CHCZ	588,650	779,119	v5.0 04-FEB-22
CPRD_GOLD	17,267,137	17,267,137	v5.0 31-AUG-23
CPRDAurum2309	44,851,398	44,851,398	v5.0 31-AUG-23
CPRDAurum50	1,377,783	1,377,783	v5.0 23-JAN-23
hulafe bbdd	2,371,896	1,920,548	v5.0 23-OCT-21
IMASIS	1,066,675	1,066,675	v5.0 31-MAY-23
IncPrev_UZB_structured	19,218	19,048	v5.0 16-JAN-23
INGEF FDB (PROD)	9,111,064	9,111,064	v5.0 29-FEB-24
IPCI	2,817,331	2,817,331	v5.0 31-AUG-23
ITF_CDM	899,515	899,515	v5.0 17-JUN-21
MAITT	149,364	149,364	v5.0 23-JAN-23
MEGA	49,011	49,011	v5.0 20-APR-21
MEGA	49,011	49,011	v5.0 16-JAN-23
MKTSCAN_CLAIMS_OMOP	176,890,290	202,823,163	v5.0 23-JAN-23
NCR	2,514,888	2,514,888	v5.0 31-AUG-23

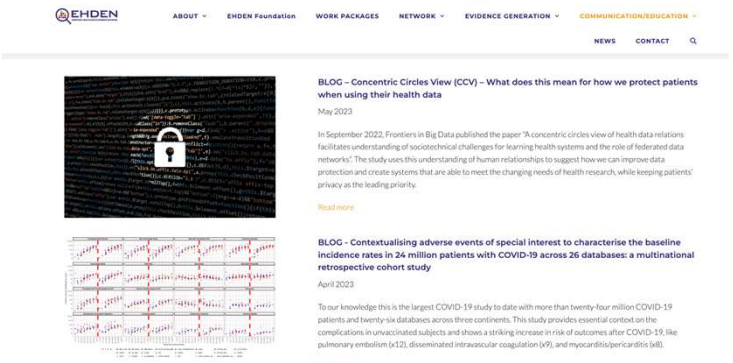


EHDEN AS A CONNECTED COMMUNITY

1 Webpage with all the latest news



2 Monthly BLOG



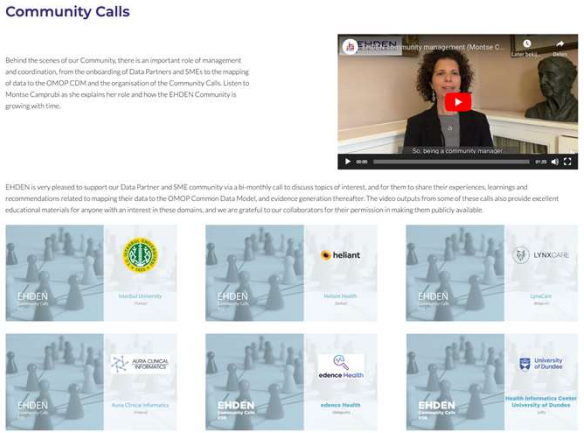
3 Podcast

THE VOICE OF EHDEN
EUROPEAN HEALTH DATA & EVIDENCE NETWORK
Ethics, Legal & Social Implications

THE VOICE OF EHDEN
EUROPEAN HEALTH DATA & EVIDENCE NETWORK
season 4

4 Social media

5 Meetings dedicated to our Community



FUTURE OF EHDEN

- Need for high-quality RWE increasing and recognised by all stakeholders.
- Project's legacy needs to be sustained and further developed.
- IMI consortium construct creates huge opportunities to fuel and build this system but enabling it for external collaborations requires a different focus of resources.
- Acting on sustainability now is the best way to ensure smooth and progressive transition to a project after-life.
- Legal entity in the Netherlands established in late 2021 (EHDEN Foundation)
- Consistent with the EHDEN project's vision, workplan and results
- Flexible and scalable by design to prepare for the future