



EHDEN

EUROPEAN HEALTH DATA & EVIDENCE NETWORK

An Update

Nigel Hughes

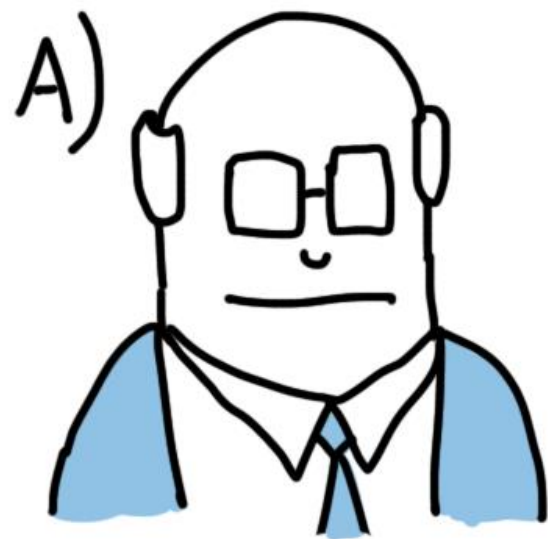
Project Lead, EHDEN
Scientific Director, Epidemiology, Janssen R&D



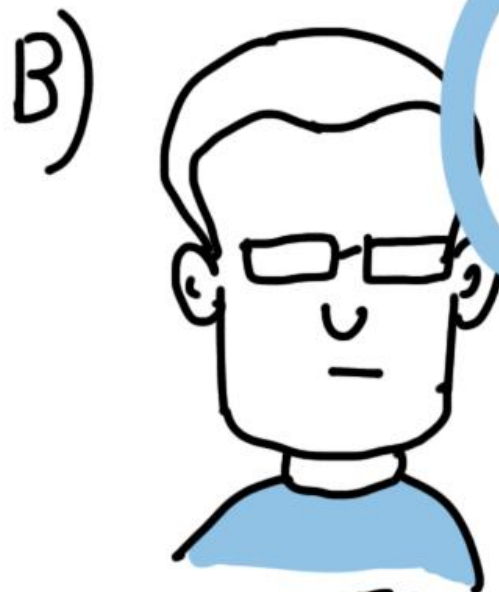


THE PANDEMIC IS A LARGE BOULDER IN THE POND....

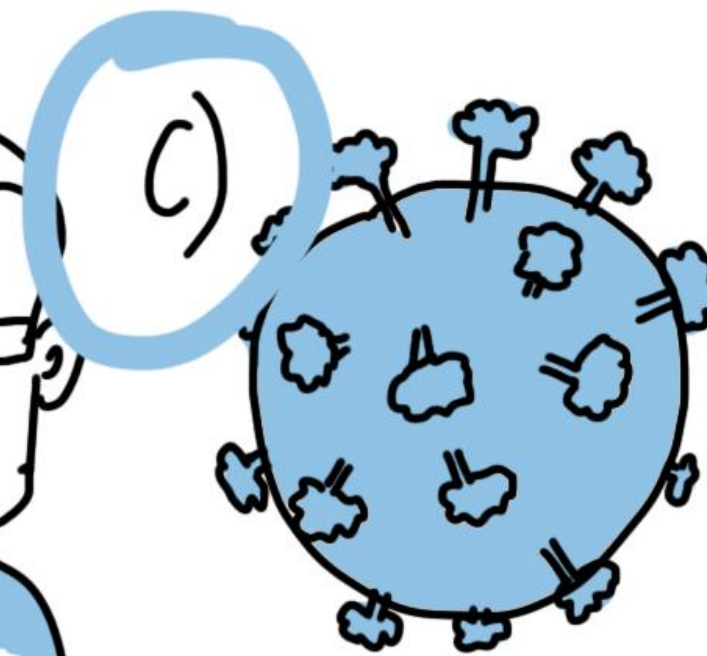
WHO LED THE DIGITAL TRANSFORMATION
OF YOUR COMPANY ?



THE CEO



THE CTO



COVID-19

BUSINESSILLUSTRATOR.COM



RARE DISEASES: ~7,000 AFFECTING MILLIONS – COLLECTIVELY COMMON



US¹: Fewer than 200,000 people
Population: ~25-30 million



EU²: <1 in 2000 people
Population: ~30 million

“If a common disease is a series of rare diseases...the challenge is to define traits worth emulating by drugs, and to phenotypically screen a very large population for people with these traits”³

1. <https://rarediseases.info.nih.gov/diseases/pages/31/faqs-about-rare-diseases>

2. https://ec.europa.eu/info/research-and-innovation/research-area/health-research-and-innovation/rare-diseases_en

3. Chung, B.H.Y., Chau, J.F.T. & Wong, G.K.S. Rare versus common diseases: a false dichotomy in precision medicine. *npj Genom. Med.* 6, 19 (2021). <https://doi.org/10.1038/s41525-021-00176-x>



OBSERVATIONAL HEALTH DATA SCIENCES & INFORMATICS (OHDSI)



OHDSI to advance the science of observational research



OHDSI
OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS

- OHDSI is an open science community, founded by scientists at J&J, Columbia University, Stanford, UCLA, Regenstrief Institute, and Iqvia
- OHDSI is an **open multi-stakeholder**, interdisciplinary collaborative with a mission to improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care
- OHDSI is driving development and adoption of **open community data standards, open source analysis software, and open science best practices** within regulators, academia, industry, payors, and health systems

GLOBAL OHDSI NETWORK - Industry, Academia, Government



>2,100

Researchers in epidemiology, statistics, informatics, health policy, and clinical sciences

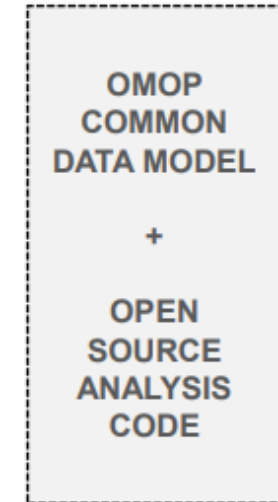
>150

Databases Included

>2B

Patient records Represented

OMOP DRIVING RWE



- A** Clinical Characterization
- B** Population-level effect estimation
- C** Patient-level prediction



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



INNOVATIVE MEDICINES INITIATIVE: EHDEN CONSORTIUM



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



23 partners



Almost €29 million

Universities, public bodies and research organisations

Erasmus MC Academic coordinator
Universiteit Medisch Centrum Rotterdam

Uppsala Monitoring Centre universidade de aveiro

NICE National Institute for Health and Care Excellence TARTU ÜLIKOOL • SISSENS UNIVERSITAS TARTUENSIS 1632 UNIVERSITY OF OXFORD

SME & Mid-sized companies

SYNAPSE RESEARCH MANAGEMENT PARTNERS ODYSSEUS DATA SERVICES INC

The Hyve

Non-profit organisations

EPF European Patients Forum ICHOM

EFPIA & Associated partners

Janssen PHARMACEUTICAL COMPANIES OF Johnson & Johnson Celgene Pfizer Lilly

abbvie Boehringer Ingelheim AstraZeneca

EFPIA Lead SANOFI ucb NOVARTIS SERVIER



EHDEN IS ABOUT...

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

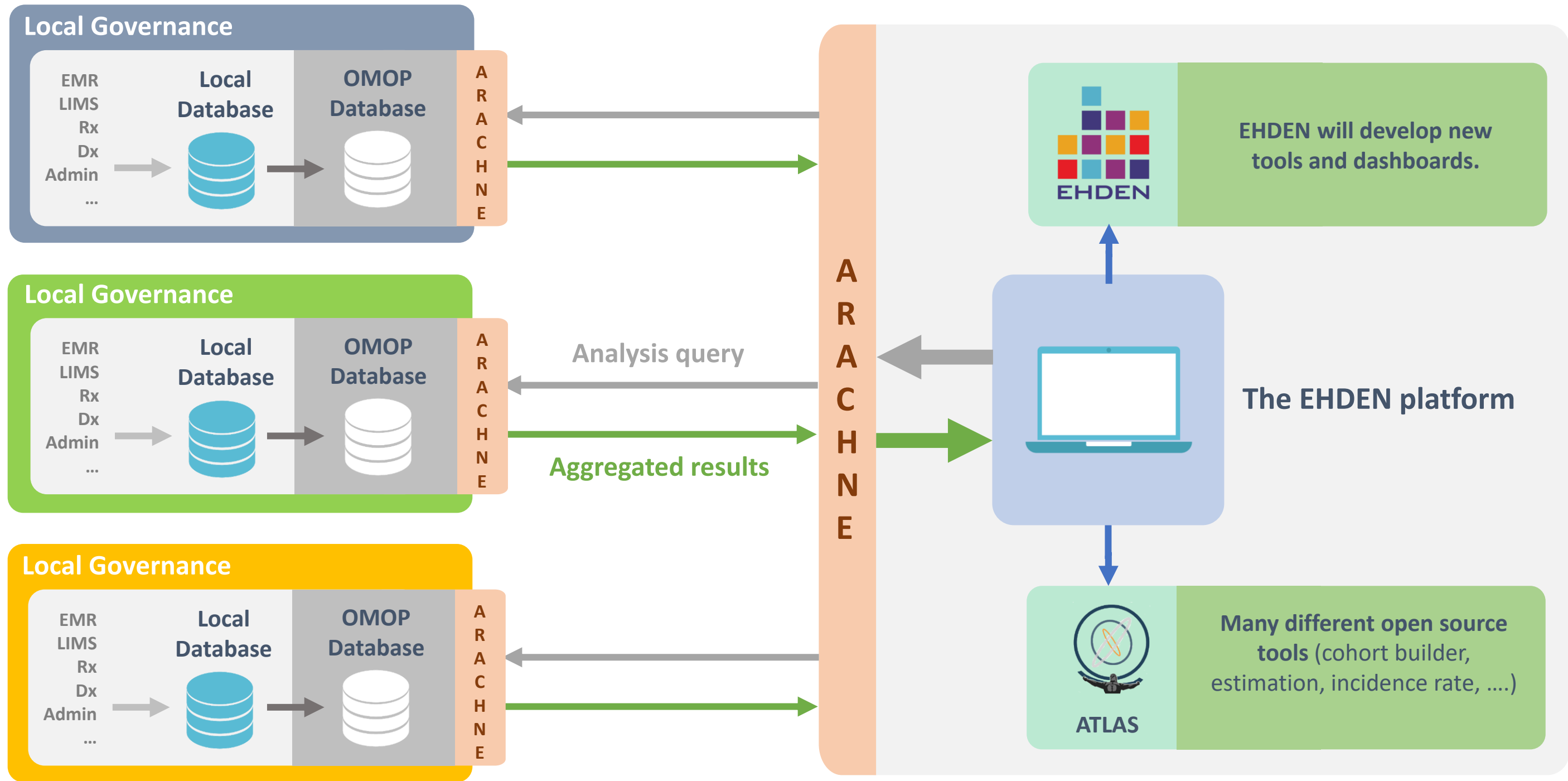
OUTCOMES

Enabling outcomes driven healthcare at a European level

EDUCATION

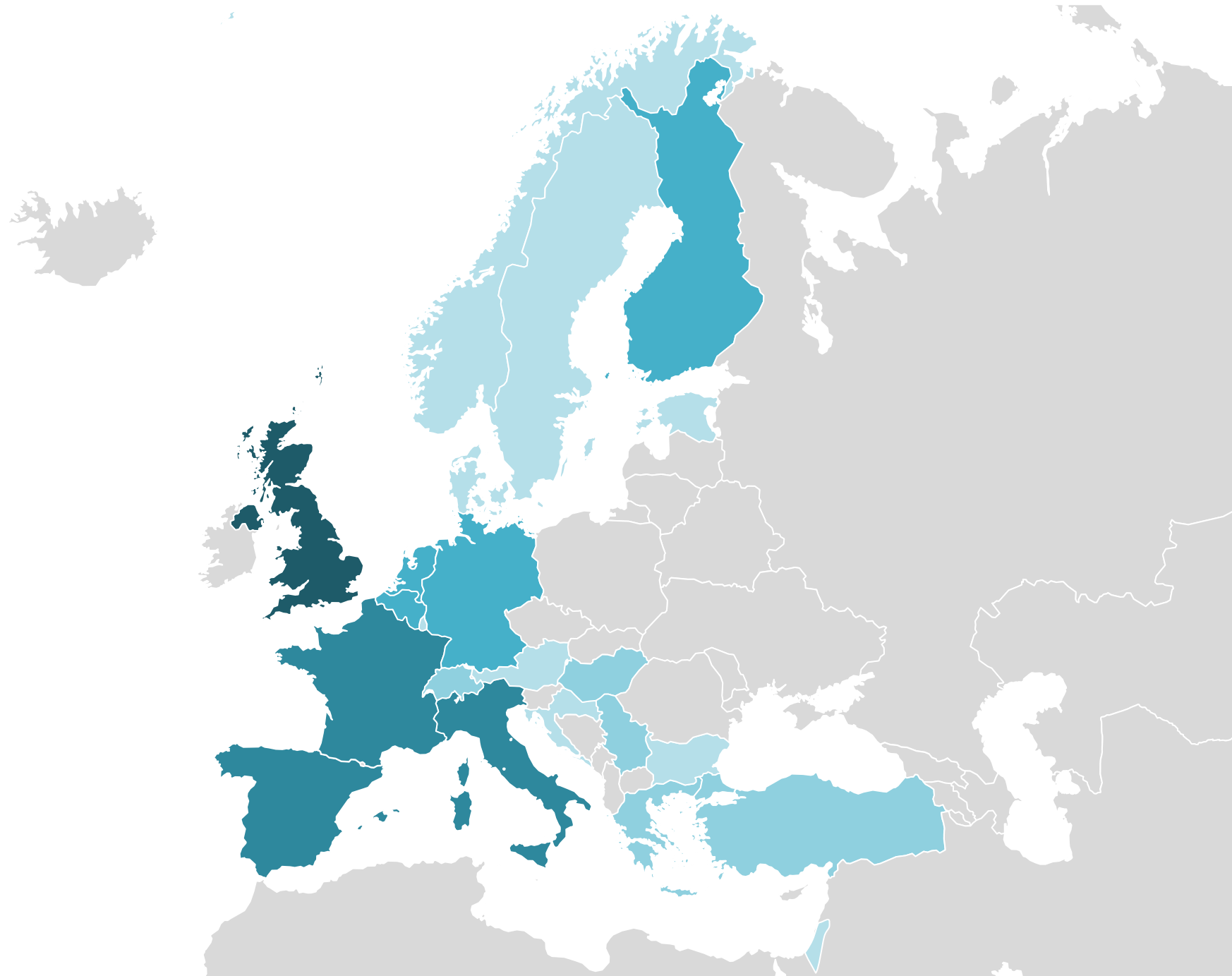
The establishment of an EHDEN Academy, webinars and face-to-face training sessions to train all stakeholders

THE EHDEN FEDERATED DATA NETWORK

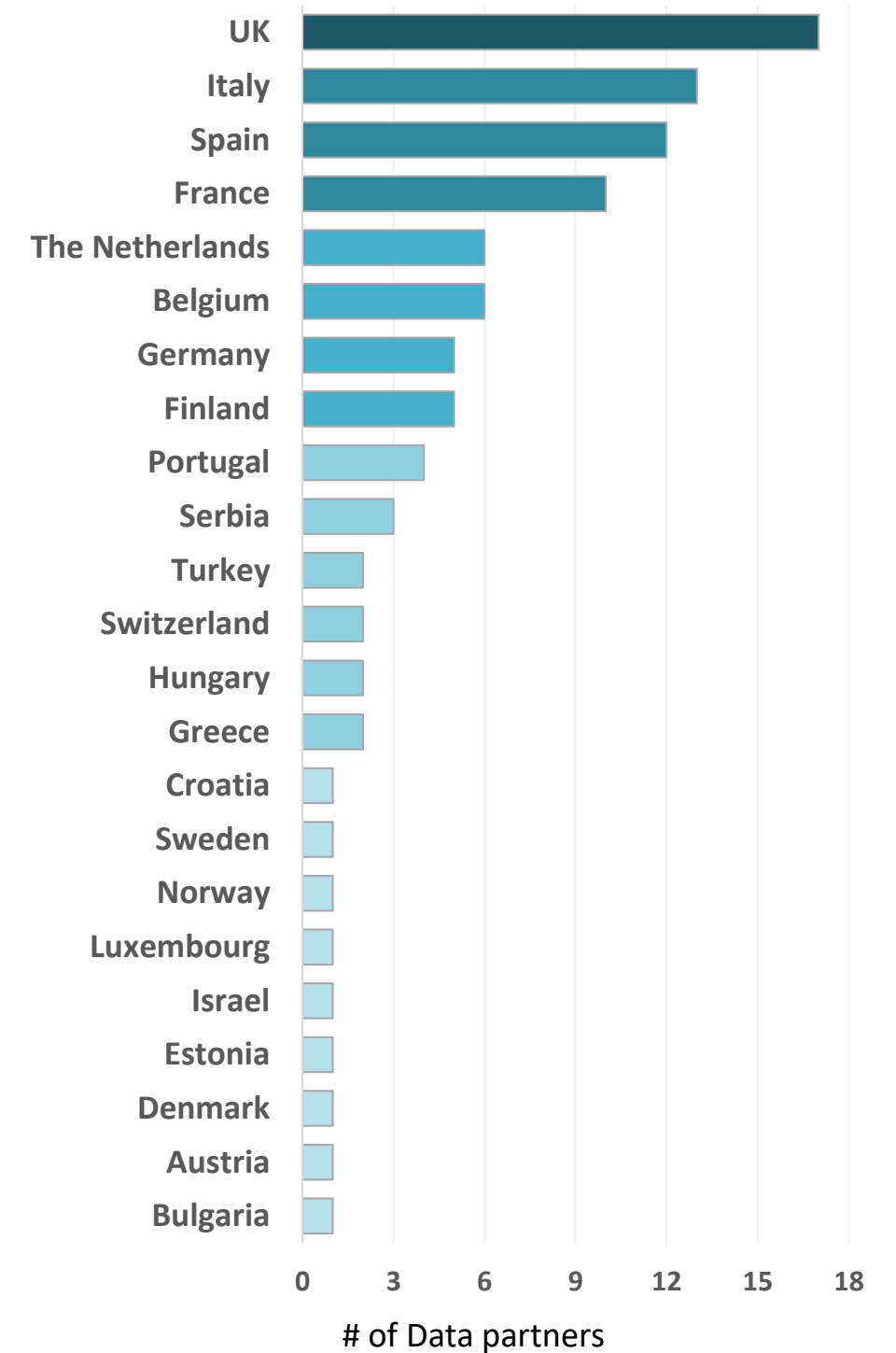




AFTER FOUR CALLS WE SELECTED 98 DATA PARTNERS IN 23 COUNTRIES



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



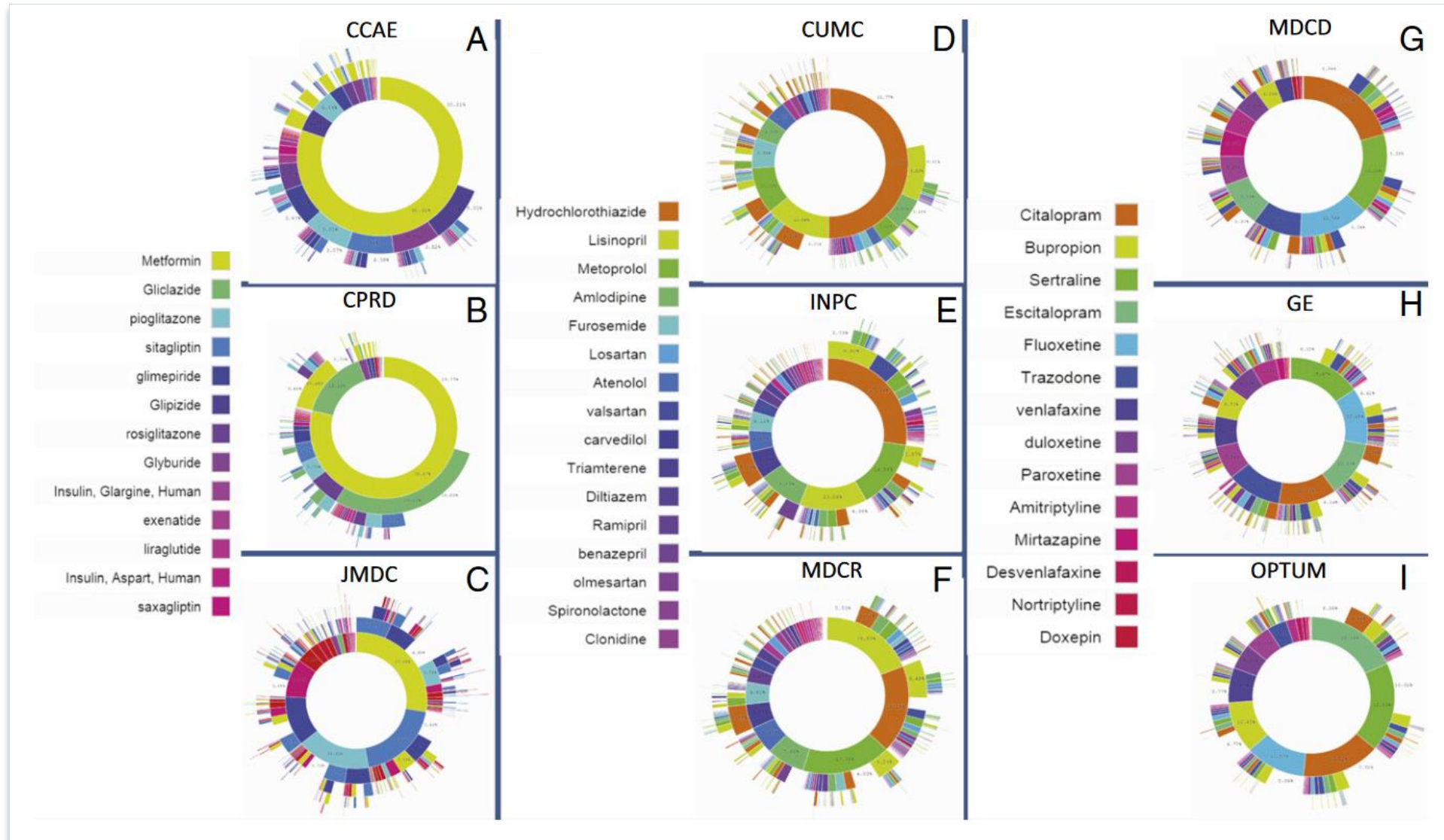


LARGE-SCALE OBSERVATIONAL RESEARCH IS FEASIBLE

T2 Diabetes Mellitus

Hypertension

Depression



11 Data sources



4 Countries



> 250 million patients

“Characterizing treatment pathways at scale using the OHDSI network.”

George Hripcsak et al. - PNAS (2016)27:7329–7336



EHDEN IS IMPACTFUL TODAY

- Now ending our third year
- We are building one of the largest international collaborative research networks on the planet within OHDSI
- We need to think regional and global in scale for 'rare' and 'common' diseases
- EHDEN has contributed to the understanding and response of COVID-19
- We are informing, educating and working with a remarkable network
- Numerous projects are benefitting from our expertise, knowledge and skills
- Project will end in 2024, but we will continue as a new legal entity



www.ehden.eu



[@IMI_EHDEN](https://twitter.com/IMI_EHDEN)



[IMI_EHDEN](https://www.linkedin.com/company/IMI_EHDEN)



github.com/EHDEN



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