

THE EUROPEAN HEALTH DATA & EVIDENCE NETWORK (EHDEN) – SHARING THE OHDSI JOURNEY AND A VISION OF EVIDENCE TODAY, NOT IN SEVERAL TOMORROWS

Hughes, N¹, Prieto-Alhambra, D², Diaz, C³, Rijnbeek, P⁴, on behalf of the EHDEN Consortium

1. Janssen R&D, Belgium 2. University of Oxford, UK 3. Synapse Research Management Partners, Madrid, Spain 4. Erasmus University Medical Centre, Rotterdam, The Netherlands

Background

Europe is an ocean of data, but a desert for analysis. In response to this, the Innovative Medicines Initiative created the public-private partnership programme EHDEN, to run from November 2018 to April 2024. It currently consists of twenty-two partners, split equally with public partners led by Erasmus Medical Centre, and private partners led by Janssen. EHDEN's mission is to create an open science ecosystem via a federated network of Data Partners with locally mapped datasets to the OMOP common data model (CDM), generating timely and reliable evidence at scale to impact on clinical practice for positive patient outcomes.

Development

EHDEN is split into three pillars, (1) evidence generation, (2) sociotechnical architecture, and (3) value proposition, sustainability, and education. In (1), EHDEN has already demonstrated its ability to generate evidence via serial study-a-thons in rheumatoid arthritis, osteoarthritis and knee prosthesis evaluation, and also in response to the COVID-19 pandemic, all in collaboration with international OHDSI colleagues. It will be focusing on expanding this, inclusive also of rapid network studies, as more of its Data Partners complete mapping to the OMOP CDM. A particular focus of the project in (1) is the development of methods and tools for Health Technology Assessment (HTA) studies, and the incorporation of health outcome standards into the OMOP CDM to facilitate rapid deployment and analysis for benchmarking within the standards audit cycles. Initial evaluation work in both areas has been conducted and made public.

As of the date of this abstract, in (2), EHDEN has 98 Data Partners at various stages of completing their mapping to the OMOP CDM, with greater than 400 million records across the European region. In (2), the project has trained and certified 26 small-to-medium sized enterprises (SMEs) in a rigorous consistent ETL methodology to contract with Data Partners and has recently selected 23 additional SMEs across Europe.

Meanwhile, in the architectural build, the overall EHDEN portal, comprising all the tools, dashboards, and processes, is progressing. A metadata driven catalogue of Data Partners will be launched in the project in due course, allied to data characterisation and data quality dashboards. EHDEN is also contributing to wider developments within the OHDSI community and specific work groups, from working with EHR and registry data, through to prediction analytics.

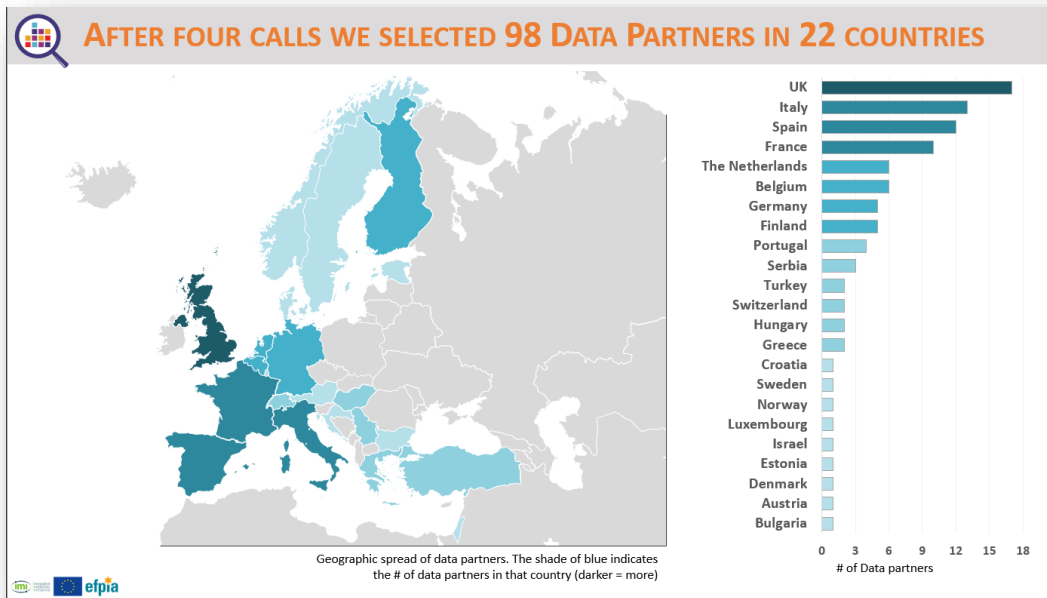


Figure 1: Geographical overview of EHDEN Data Partners mapping to the OMOP CDM

All data, however, is not centralised and always remains local with the Data Partner. The architecture to support the use of standardised analytical tools, such as ATLAS, and the HADES suite, on top of the OMOP CDM-mapped datasets is to be instituted. In pillar (3), the project has developed value propositions for stakeholder engagement, and is working on a sustainable path beyond the project end, coalescing around the launch of a not-for-profit legal entity that will be based in The Netherlands. EHDEN also launched the free, online EHDEN Academy to support education and upskilling for the network and those engaged in ETL (e.g., SMEs) and tools, methods, and skills for researchers. There have been ~1,515 participants enrolled since launch, with ten courses now available, with planning for competency-based learning pathways, linked to the new OHDSI Education working group.

EHDEN is supporting other IMI projects who adopted the OMOP CDM, for instance in prostate cancer (PIONEER), inclusive of their own study-a-thon (March 2021), and patient-reported outcomes observatories (H2O). EHDEN is also providing input into the EU Joint Action, Towards the European Health Data Space (TEHDAS).

Further work

EHDEN worked towards a ‘build, fuel and drive’ philosophy, with the network being built, but reliant on fuelling with real-world data and then driving the resultant engine via studies. To be successful, it has to be based on transparency and trustworthiness, and privacy by design within the EU’s General Data Protection Regulation (GDPR). The project’s Ethics Advisory Board and other experts are working on a code of conduct and framework for federated data networks.

For the second half of the project, EHDEN will continue to add Data Partners to the network, but is expanding our evidence generation. To evaluate the mapping to the OMOP CDM, but also to integrate

and educate new Data Partners, a new 'evidence-a-thon' will be serially conducted, rerunning R packages and widening existing study results dynamically.

Meanwhile, a research operating model, will be refined to accompany the EHDEN not-for-profit in parallel to the remainder of the project, and ultimately superseding it for longer term sustainability. National nodes, or local country networks, are being evaluated within OHDSI Europe and EHDEN to support those countries wanting to embed the federated data network ethos within their own national strategy.

Conclusion

EHDEN is impacting and delivering **now**, and not at the end of the project. A key indicator of success will be the plurality of support for clinical, regulatory, health technology assessment and outcomes decision-making. It is imperative for EHDEN to succeed in supporting the evolution of European digital healthcare, as well as collaborating with OHDSI in Europe and internationally for a global, open science community.

The project looks forward to greening the European analysis desert and transforming it into a flourishing garden for rapid decision-making.

NH010921