

# **DARWIN EU® Initiative Annual Report**

**OHDSI Community Call** Nov. 18, 2025 • 11 am ET









### **Upcoming Community Calls**

Date	Topic	
Nov. 18	DARWIN EU 2025 Update	
Nov. 25	Early-Stage Researcher Presentations	
Dec. 2	OHDSI/OMOP Research Spotlight	
Dec. 9	How Did OHDSI Do This Year?	
Dec. 16	Holiday Farewell To 2025	







# Nov. 25: Early-Stage Researcher Workgroup and Presentations





Sumin Lee and Kyulee Jeon, Yonsei College of Medicine

ARKE: An Ontology-Driven Framework for Standardizing Radiology Procedure Terminology Using LLMs and RAG





Markian Hromiak and Jacob Zelko, George Institute of Tecnology

**Exploring Efficient and Scalable OMOP CDM Workflows by Leveraging dbt-synthea** 



Bingyu Zhang, Univ. of Pennsylvania

The Fine Art of Tolerance: Robustify p-value

Calibration in Observational Studies with Partially Valid Negative Control Outcomes











# Three Stages of The Journey

Where Have We Been? Where Are We Now? Where Are We Going?









### **OHDSI Shoutouts!**



Congratulations to the team of Berta Cuyàs, Edilmar Alvarado-Tapias, Eng Hooi Tan, Asieh Golozar, Talita Duarte-Salles, Antonella Delmestri, Josepmaria Argemi, Wai Yi Man, Edward Burn, Carlos Guarner-Argente, Daniel Prieto Alhambra, and Danielle Newby on the publication of Trends in incidence, prevalence, and survival of primary liver cancer in the United Kingdom (2000–2021) in the European Journal of Public Health.

European Journal of Public Health, 2025, ckaf153

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### Trends in incidence, prevalence, and survival of primary liver cancer in the United Kingdom (2000–2021)

Berta Cuyàs<sup>1,2,3,†</sup>, Edilmar Alvarado-Tapias<sup>1,2,3,†</sup>, Eng Hooi Tan<sup>4,0</sup>, Asieh Golozar<sup>5,6</sup>, Talita Duarte-Salles<sup>7,8,0</sup>, Antonella Delmestri<sup>4</sup>, Josepmaria Argemi<sup>3,9,10</sup>, Wai Yi Man<sup>4</sup>, Edward Burn<sup>4,0</sup>, Carlos Guarner-Argente<sup>1</sup>, Daniel Prieto Alhambra<sup>4,8,\*,0</sup>, Danielle Newby<sup>4</sup>

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<sup>2</sup>Medicine Department, Autonomous University of Barcelona (UAB), Barcelona, Spain

<sup>3</sup>Centre for Biomedical Research in Liver and Digestive Diseases Network (CIBERehd), Instituto de Salud Carlos III Madrid, Spain

Centre for Statistics in Medicine, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford, Oxford, United Kingdom

<sup>5</sup>Nemesis Health, New York, NY, United States

<sup>6</sup>OHDSI Center at the Roux Institute, Northeastern University, Boston, MA, United States

<sup>7</sup>Fundació Institut Universitari per a la recerca a l'Atenció Primària de Salut Jordi Gol i Gurina (IDIAPJGol), Barcelona, Spain

<sup>8</sup>Department of Medical Informatics, Erasmus University Medical Centre, Rotterdam, The Netherlands

<sup>9</sup>Liver Unit, Clinica Universidad de Navarra, DNA & RNA Medicine Program, CIMA University of Navarra, Pamplona, Spain
<sup>10</sup>Division of Gastroenterology Hepatology and Nutrition, University of Pittsburgh, Pittsburgh, PA, United States

\*Corresponding author. Botnar Research Centre, Windmill Road, OX37LD, Oxford, United Kingdom. E-mail: daniel.prietoalhambra@ndorms.ox.ac.uk.
\*joint first authors.

#### Abstract

Primary liver cancer (PLC) remains a global health challenge. Understanding trends in the disease burden and survival is crucial to inform decisions regarding screening, prevention, and treatment. Population-based cohort study using UK primary care data from the Clinical Practice Research Datalink (CPRD) GOLD (2000–2021), replicated in CPRD Aurum. Crude and age-standardized incidence rates (IRs), crude period prevalence (PP), and survival at 1, 5, and 10 years were calculated, and stratified by age, sex, and diagnosis year. The crude IR of PLC was 4.56 (95% CI 4.42–4.70) per 100 000 person-years between 2000 and 2021, with an increase over time across age and sex strata. Sex-specific IR for males was higher than females, 6.60 (95% CI 6.36–6.85) vs. 2.58 (95% CI 2.44–2.74) per 100 000 person-years. Age-standardized IR showed identical trends. Crude PP showed a seven-fold increase over the study period, with PP 0.02% (95% CI 0.019%–0.022%) in 2021, and a 2.8-fold higher PP in males. Survival at 1, 5, and 10 years after diagnosis was 41.7%, 13.2%, and 7.1%, respectively, for both sexes. One-year survival increased only in men, from 33.2% in 2005–2009 to 49.3% in 2015–2019. Over the past two decades, there has been a substantial increase in the number of patients diagnosed with PLC. Despite a slight improvement in median and one-year survival in men, prognosis remains poor. To improve the survival of PLC patients, it is necessary to understand the epidemiological changes and address preventable risk factors associated with liver disease and promote early detection and access to care.











### **OHDSI Shoutouts!**



Congratulations to the team of Melissa Finster, Markus Wenzel and Elham Taghizadeh on the publication of Common data models and data standards for tabular health data: a systematic review in BMC Medical Informatics and Decision Making.

Finster et al. BMC Medical Informatics and Decision Making https://doi.org/10.1186/s12911-025-03267-2

(2025) 25:422

BMC Medical Informatics and Decision Making

#### SYSTEMATIC REVIEW

**Open Access** 

### Common data models and data standards for tabular health data: a systematic review



Melissa Finster<sup>1\*</sup>, Markus Wenzel<sup>1,2†</sup> and Elham Taghizadeh<sup>1†</sup>

#### Abstract

Background The use of health data supports knowledge-based decision-making in healthcare. Common Data Models (CDMs) and data standards facilitate the integration of diverse data sources and enable federated analysis by harmonizing data formats and terminologies.

Methods To determine the best approaches to harmonizing patient data, we undertook a comprehensive literature search, which allowed us to identify the most popular and established CDMs (i2b2, Sentinel CDM, PCORnet CDM, OMOP CDM) and data standards (CDA, HL7 version 2, FHIR, openEHR). We established a set of criteria across the categories of Suitability, Popularity, Adaptability, Interoperability, and Support.

Results The CDMs and data standards are evaluated based on the defined criteria. Overall criteria the OMOP CDM and FHIR scored best. We highlight the strongest CDM and data standard for each criteria category

Conclusion Given the unique characteristics, strengths, and weaknesses of each CDM and data standard, no single global representation can be selected. To promote broad adoption of CDMs and data standards, it is essential to enable transformation between different representations and utilize various formats within a single tool to facilitate their interoperability. Only then seamless data exchange and research across borders can be achieved.

Clinical trial number Not applicable

Keywords Common data model, FAIR-Principles, Data standard, Interoperability, Data harmonization









# Three Stages of The Journey

Where Have We Been? Where Are We Now? Where Are We Going?







### **Upcoming Workgroup Calls**



Date	Time (ET)	Meeting	
Tuesday	12 pm	ATLAS/WebAPI	
Wednesday	1 pm	Perinatal and Reproductive Health	
Thursday	8 am	India Community Call	
Thursday	9 am	Oncology Vocabulary/Development Subgroup	
Thursday	11 am	Themis	
Thursday	12 pm	HADES	
Friday	10 am	GIS-Geographic Information System	
Friday	10:30 am	Open-Source Community	
Friday	11:30 am	Steering	
Monday	9 am	Africa Chapter	
Monday	10 am	Getting Started Subgroup	
Tuesday	10 am	CDM Survey	









### OHDSI Africa Symposium 2025

Nov 10-12 Kampala, Uganda







### Day 1 Tutorial @ JCRC

Session Name	Time	Instructor(s)
OHDSI/OMOP Intro	9:00 – 9:20 AM	Michael Ochola Mui Van Zandt Cynthia Sung
OMOP CDM and Vocabulary	9:20 – 10:00 AM	Sebastian van Sandijk Cynthia Sung Mui Van Zandt
OMOP Conversion Process	10:00 – 10:30 AM	Rachel Odhiambo Freija Descamps Ousmane Diop
Break	10:30 – 10:40 AM	
ETL Exercises	10:40 - 12:00 noon	Pauline Andeso Freija Descamps Reinpeter Momanyi
Lunch	12:00 – 1:30 PM	
Data Quality Dashboard	1:30 – 2:00 PM	Reinpeter Momanyi David Amadi Sebastian van Sandijk
Evidence Generation with OHDSI Tools	2:00 – 3:00 PM 3:15 – 4:15 PM	Edward Burns Anna Saura-Lazaro Mui van Zandt

### Instructors



Mui van Zandt **IQVIA** 



Michael Ochola **APHRC** 



**Duke-NUS** 



Cynthia Sung Sebastian van Sandijk **EPAM** 



Rachel Odhiambo **APHRC** 



David Amadi LSHTM & APHRC



Freija Descamps EdenceHealth



Ousmane Diop **IRESSEF** 



Pauline Andeso APHRC



Ed Burn Oxford



Reinpeter Momanyi APHRC



Anna Saura Lazaro Oxford



### Tutorial Group Photo @ JCRC





### Day 2-3 Symposium @ Mestil Hotel





### Day 2-3 Symposium @ Mestil Hotel



**Dr. Cissy Kityo**Executive Director
Joint Clinical Research Center

**Paul Mbaka,** Asst Commissioner Dept Health Information, MOH





**Brenda Nakazibwe**Sci, Tech & Innovation Secretariat
Office of the President, Uganda



### 2025 OHDSI Africa Symposium Group Photo

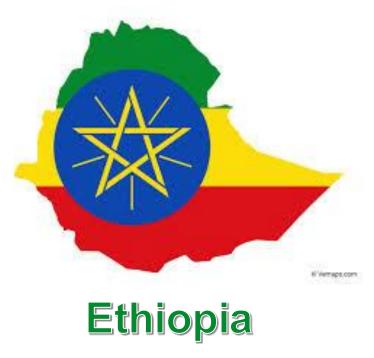




### Next OHDSI Africa Symposium









# India Symposium











# APAC Symposium: Dec. 6-7

#### <u>Day 1 (December 6) – Tutorial at Room 102, Dongxia Yuan Building (Zheng-Cai Cuiju Teaching Building)</u>

#### Morning Session

- 09:00-09:20 Introduction of OHDSI/OMOP
- 09:20-10:00 OMOP CDM and Vocabulary
- 10:00-10:30 OMOP Conversion Process
- 10:40-12:00 ETL Exercises

#### Afternoon Session

- · 13:30-14:50 OHDSI Analyses: Building Cohorts & Hands-on
- 14:50-15:30 CohortDiagnostics and Population-Level Estimation
- 15:50-16:30 Interpreting Results

#### Day 2 (December 7) - Main conference at Room A100, 1F, Student Center

#### Session 1 - From Global to Regional Impact: OHDSI across APAC & Africa

- 09:00 09:15 Opening Speech
- 09:15 09:45 Keynote Speech from OHDSI Global
- 09:45 10:45 APAC Regional Chapter Updates
- 10:45 11:00 OHDSI Africa

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- 10:45 11:00 OHDSI Africa

#### Session 2 - From Research to Reflection: 2025 APAC Studies and Lessons Learned

- 11:15 11:30 2025 APAC Study 1 by Fudan University
- 11:30 11:45 2025 APAC Study 2 by Peking University
- 11:45 12:00 2025 APAC Study 3 by University of Science and Technology of China (USTC)
- 12:00 12:10 Journal's Perspectives
- 12:10 12:30 Panel Discussion

#### Session 3 - From Regional Insights to Local Challenges: Real-World Evidence and OHDSI/OMOP in China

- 13:30 14:30 Collaborator Showcase: Lightning Talks
- 14:30 14:45 Real-World Evidence Talk 1
- 14:45 15:00 Real-World Evidence Talk 2
- 15:00 15:15 Real-World Evidence Talk 3
- 15:30 15:50 Real-World Evidence Using OHDSI/OMOP
- 15:50 16:10 Panel Discussion: Opportunities and Challenges Using OHDSI/OMOP for Real-World Evidence in China
- 16:10 16:50 Closing & Networking

ohdsi.org/apac2025











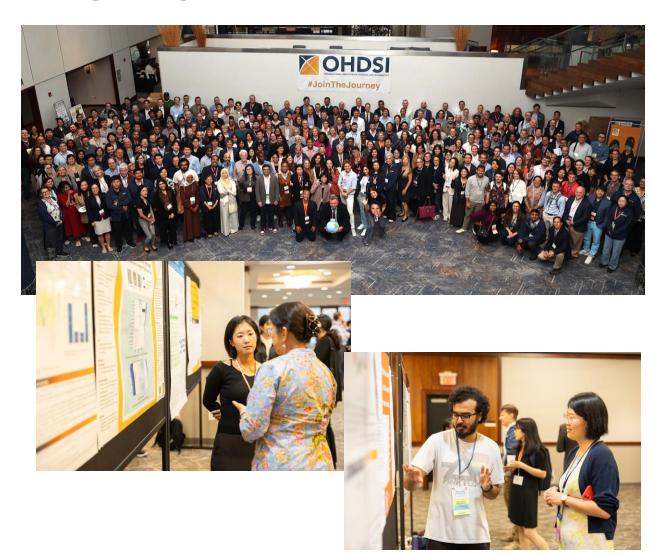




# 2026 Global Symposium

The 2026 OHDSI Global Symposium will return to the Hyatt Regency Hotel in New Brunswick, N.J., on Oct. 20-22.

More details to come.









# **Tutorials Homepage**

#### **OHDSI Tutorials**

Education is at the heart of OHDSI's mission, and these tutorials showcase the community's commitment to sharing knowledge. Developed and taught by OHDSI faculty, they highlight tools, standards, and best practices that empower collaborators at every level to engage in open science and generate reliable evidence.

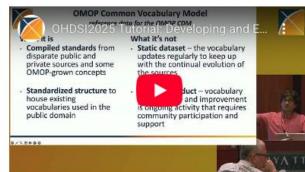
#### 2025 Global Symposium

An Introduction to the Journey from Data to Evidence Using OHDSI



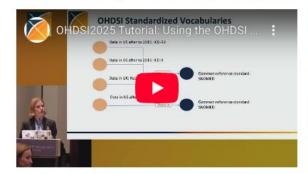
Faculty: Erica Voss, Yong Chen, Katy Sadowski, Nicole Pratt, Roger Carlson, Chongliang (Jason) Luo

Developing and Evaluating Your Extract, Transform, Load (ETL) Process to the OMOP Common Data Model



Faculty: Clair Blacketer, Karthik Natarajan, Evanette Burrows, Max Adulyanuksol, Maxim Moinat

Using the OHDSI Standardized Vocabularies for Research



Faculty: Anna Ostropolets, Vlad Korsik, Polina Talapova, Masha Khitrun

Population-Level Effect Estimation Applications to Generate Reliable Real-World Evidence



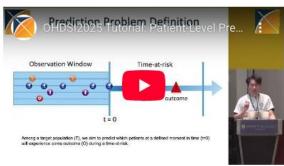
Faculty: George Hripcsak, Martijn Schuemie, Linying Zhang, Tara Anand

Clinical Characterization Applications to Generate Reliable Real-World Evidence



Faculty: Patrick Ryan, Aniek Markus, Hsin Yi "Cindy" Chen, Azza Shoaibi

Patient-Level Prediction Applications to Generate Reliable Real-World Evidence



Faculty: Jenna Reps, Egill Fridgersson, Ross Williams

ohdsi.org/tutorials













### Monday

**PREPARE-Rehab:** Personalized rehabilitation via novel AI patient stratification strategies using the OMOP-CDM standard

(Carlotte Kiekens, Esther Janssen, Lisa Hoogendam, Ruud Selles, Philip van der Wees, Alberto Negrini, Stefano Negrini and the PREPARE group)

PREPARE-Rehab helps establish best practices for applying OHDSI tools in rehabilitation, and the extension of standardized vocabularies and CDM domains to increase its usefulness for applications in biopsychosocial domains

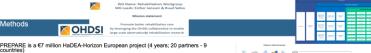
Personalized rehabilitation via novel AI patient stratification strategies using the OMOP-CDM standard

- Rehabilitation is a complex, multimodal, collaborative person-centered process.
- Clinical decision support systems (CDSSs), like prediction models, aid shared decision-making (clinicians and patients)
- Many health conditions lack validated prediction models; existing models often use simple statistics and small datasets
- Current models lack Application Programming Interface for integration of new data and continuous improvement.

- · Many clinical rehabilitation variables lack appropriate concepts in existing vocabularies, indicating the need to
- Overlapping data across clinical cases offers a chance to establish uniform mapping for rehabilitation data.
- The WHO's International Classification of Functioning Disability and Health (ICF) framework supports the extension of existing vocabularies and class hierarchy
- · Extending CDM domains may improve mapping of rehabilitation data, including (PROMs) and long-term
- accuracy in rehabilitation and for many chronic conditions
- Comparisons between different cases will guide the newly

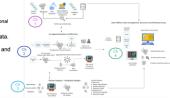
Lessons learned from the OMOP CDM implementation in pilot case "Scoliosis during growth (ISICO)"

- · Extending the ETL (Extract, Transform, Load) to transform data from MySQL to PostgreSQL was crucial for OHDSI tool compatibility and long-term maintainability.
- Many rehab-specific concepts need to be added to OHDSI Athena, after discussion and consensus in our community
- Recording therapy sessions and other rehabilitation interventions, including compliance or device changes was challenging, as well as results of questionnaires.
- A dedicated OHDSI CDM set of concepts for non-
- pharmacological prescriptions is lacking. The rehabilitation processes and the databases used to construct the CDSS were compared for commonalities and distinctions, using Excel files and piloting GUIDE-Rehab.



- Applies machine learning (ML) to 9 large-scale patient datasets.
   Uses federated approach for real-world, routinely collected data.

- Creates prediction and stratification Machine Learning strategies for rehabilitation dat
- Validates models through nine clinical demonstration pilots.



complexities of rehabilitation care.

By addressing gaps in existing vocabularies and fostering collaboration within the OHDSI community, this project advances standardized data mapping and machine learning applications in rehabilitation

The initiative lays a foundation for scalable, interoperable solutions that enhance personalized patient stratification and prediction models to ultimately improve clinical outcomes across diverse rehabilitation settings

This may be of interest for other fields dealing with chronic conditions

















### **Tuesday**

**Transforming clinical data** from innovative European **Cancer Precision** Medicine projects: The **PRIME-ROSE Example** 

(Maria Martin Agudo, Henk van der Pol, Gabriel Bratseth Stav, Tina Kringelbach, Katarina Puco, Åsmund Flobak, Hans Gelderblom, Kjetil Taskén, Eivind Hovig and Gro Live Fagereng)

**OMOP CDM enables transforming** aggregated data in a **European** clinical trial **network** in precision cancer medicine

Transforming clinical data from innovative European Precision Cancer Medicine projects: The PRIME-ROSE SE Example

Background: PRIME-ROSE has established a European Precision Cancer Medicine Trial network, where partners share clinical trial data. Merging this data results in aggregated patient cohorts defined by tumor type, biomarker and treatment. The aim is to generate evidence linked to the feasibility of indication expansion and efficient treatments in terms of clinical outcome and cost-effectiveness in precision cancer medicine. Cross-border data sharing accelerates the completion of patient enrollment and subsequent data analysis. Standardizing the data to OMOP CDM enables clear cohort analysis and facilitates further cross-border data sharing

### Methods

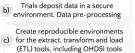
The data aggregation group is working on the implementation of a pipeline to enable fast and accurate standardization of aggregated data



Define common variable set

pact public health and so economic aspects

Methods 1: Data flow, ETL pipeline and evidence generation Cross-border data sharing



(ETL) tools, including OHDSI tools Cohort data analysis for evidence generation



#### Results

variables including 42









Conclusions: This work will contribute to demonstrate how standardized data can improve crossborder data sharing. As an example, PRIME-ROSE seeks for additional partnerships inside and outside Europe, and the project will benefit from transforming clinical data into OMOP CDM standards. Data generated in this project may become an invaluable resource for producing evidence to inform public health efforts, leading eventually to improved patient care.





Tina Kringelbach, Katarina Puco, Asmund Flobak, Hans Gelderblom, Kjetil Taskén, Eivind Hovig and Gro Live Fageren

















### Wednesday

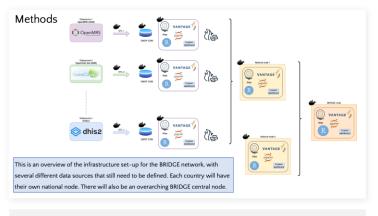
**Advancing Epidemiological** Research in Africa: Federated Infrastructure, Data Harmonization, and Knowledge **Transfer for Scalable Public Health Insights – Technical** contribution of the BRIDGE **NETWORK** project

(Emma Gesquiere, Lars Halvorsen, Claude Mambo Muvunyi, Marc Twagirumukiza, **Pascal Coorevits)** 

Technical contribution to a more robust and accessible evidence-based data network for public health and epidemiology in Africa

Advancing Epidemiological Research in Africa: Federated Infrastructure, Data Harmonization, and Knowledge Transfer for Scalable Public Health Insights -Technical contribution of the BRIDGE NETWORK

Background: Epidemiological research relies heavily on high-quality, standardized data to analyse disease patterns and inform public health policies and interventions. However, variability in health information systems and data formats hinders interoperability and large-scale (inter)national studies. To address these challenges, the BRIDGE Network aims to empower infectious disease experts to drive research from and for sub-Sahara Africa through creation of an innovative scalable training program that leverages data harmonisation and federated research infrastructure. Knowledge transfer of the technical processes across institutions and countries will ensure the network is sustainable for future research studies.



Conclusion: This work aims to enhance the efficiency and reproducibility of public health research in Africa by establishing a robust research framework. The integration of OMOP CDM with federated analysis enables scalable, privacy-preserving studies, fostering international collaboration and accelerating evidence generation. These findings will provide valuable insights to the broader OHDSI community and demonstrate effective knowledge transfer within a large-scale international consortium























### **Thursday**

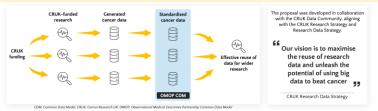
**Developing** a strategy for the standardisation of **Cancer Research UK** funded data

(Jasmine Handford, Charlotte Moss, Joseph Day, Gemma Codner, Andrew Blake, Mieke Van Hemelrijck)

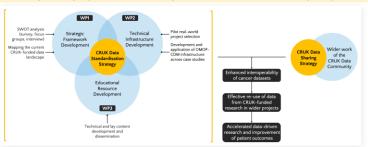
#### Developing a strategy for the standardisation of Cancer Research UK funded data

The opportunity: Cancer Research UK (CRUK) funds -£400 million of research per year, with each project using or generating valuable cancer data. However, the collective impact of this research could be amplified by standardising the data produced, e.g., by using a common data model (CDM), facilitating its re-use in a wide range of future projects.

#### We aim to inform a strategy for OMOP-CDM adoption across CRUK-funded research



#### Our planned programme of work comprises three interconnected work packages



#### Interim findings highlight a variety of barriers and enablers for OMOP-CDM adoption



The impact: Alongside wider work to facilitate effective data sharing, this strategy for OMOP-CDM adoption across CRUK-funded projects will drive progress against the CRUK Research Strategy and Research Data Strategy, enabling large scale data integration, accelerating data-driven cancer research, and improving patient outcomes



Jasmine Handford, Charlotte Moss, Joseph Day, Gemma Codner, Andrew Blake, Mieke Van Hemelrijck

















### **Friday**

**RAG-Enhanced LLM** Pipeline for Semantic **Mapping of Context**based Features to **OMOP Vocabulary** 

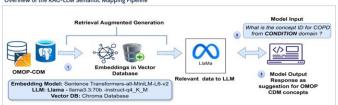
(Sariga Kakkamani, Frederic Jung, Joeri Verbiest, Liesbet Peeters)

**Accelerating Feature Extraction with AI-Powered** RAG-LLM: Automated Concept Mapping to **OMOP-CDM Vocabulary.** 

Title: RAG-Enhanced LLM Pipeline for Semantic Mapping of Context-based Features to OMOP Vocabulary

Background: Observational health data are often standardized to the commonly used OMOP-CDM standards. This enables us to carry out efficient analyses that can generate reliable evidence. However, understanding these standards and vocabulary terms requires medical knowledge, along with OMOP-CDM expertise. This makes feature extraction crucial, particularly for users without domain expertise

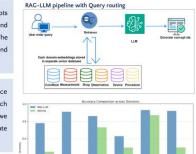
Overview of the RAG-LLM Semantic Mapping Pipeline



Method: In the end-to-end pipeline: (1) OMOP concepts stored in a vector database. (2) User input is encoded and compared against pre-generated embeddings (3) The top-k most semantically similar matches are retrieved and LLM generates context-aware concepts as suggestions.

Results: The pipeline achieved improved performance over the OHDSI tool Athena. With the proposed approach in addition to the suggestions on matching concepts we get explanation on which concepts are more appropriate

Conclusion: The proposed tool mainly focuses on aiding the Al model developers to evaluate their software with a focus or



Mapping Accuracy for RAG-LLM pipeline















# Where Are We Going?

Any other announcements of upcoming work, events, deadlines, etc?







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# Nov. 18: DARWIN EU Update











### The weekly OHDSI community call is held every Tuesday at 11 am ET.

**Everybody** is invited!

Links are sent out weekly and available at: ohdsi.org/community-calls-2025





