Asia-Pacific (APAC) Regional Updates

OHDSI Community Call
Sept. 10, 2024 • 11 am ET

Upcoming Community Calls

Date	Topic
Sept. 10	Asia-Pacific Regional Updates
Sept. 17	The Book of OHDSI, Five Years Later
Sept. 24	Recent OHDSI Publications
Oct. 1	DARWIN EU® Review
Oct. 8	TBA
Oct. 15	Global Symposium Mad Minutes/Final Logistics
Oct. 22	No Meeting due to Global Symposium
Oct. 29	Welcome to OHDSI

Three Stages of The Journey

Where Have We Been?

Where Are We Now?

Where Are We Going?

OHDSI Shoutouts!

Congratulations to the team of **Ahmed Elhussein, Ulugbek Baymuradov, NYGC ALS Consortium, Noémie Elhadad, Karthik Natarajan and Gamze Gürso** on the publication of **A framework for sharing of clinical and genetic data for precision medicine applications** in *Nature Medicine*.

nature medicine

Article

https://doi.org/10.1038/s41591-024-03239-5

A framework for sharing of clinical and genetic data for precision medicine applications

Received: 22 May 2024

Accepted: 7 August 2024

Published online: 03 September 2024

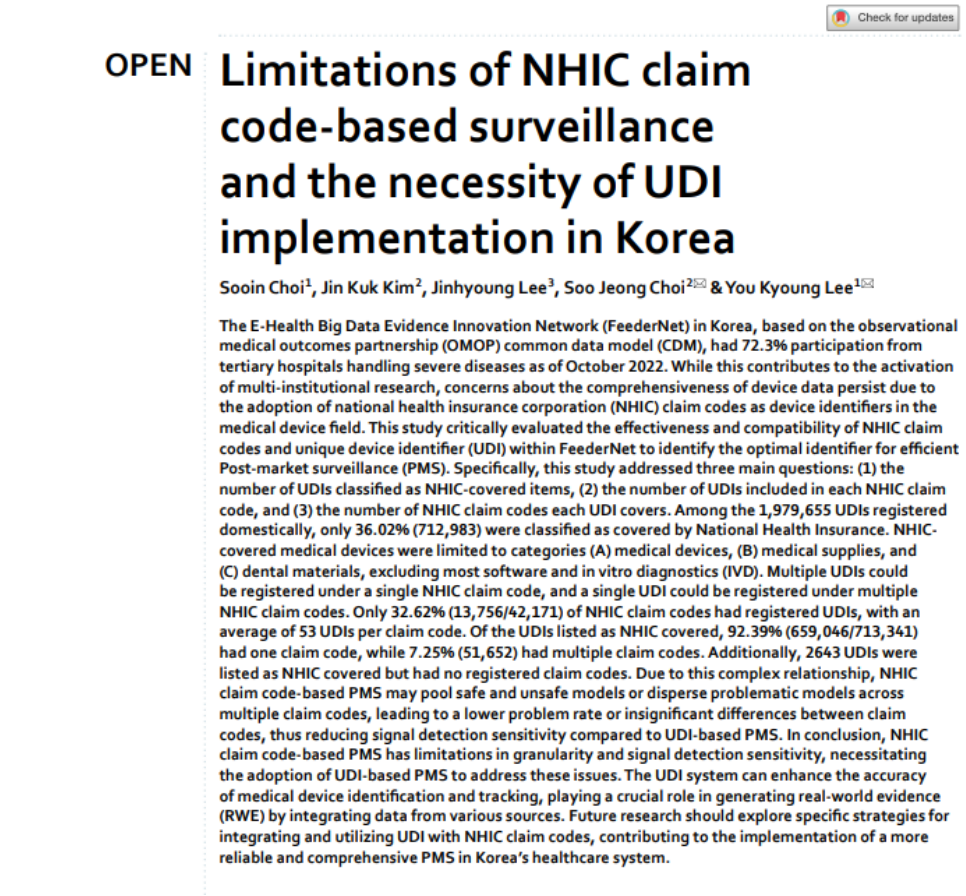
Check for updates

Ahmed Elhussein[1,2], Ulugbek Baymuradov[2], NYGC ALS Consortium*, Noémie Elhadad[1,3], Karthik Natarajan[1] & Gamze Gürsoy[1,2,3]

Precision medicine has the potential to provide more accurate diagnosis, appropriate treatment and timely prevention strategies by considering patients' biological makeup. However, this cannot be realized without integrating clinical and omics data in a data-sharing framework that achieves large sample sizes. Systems that integrate clinical and genetic data from multiple sources are scarce due to their distinct data types, interoperability, security and data ownership issues. Here we present a secure framework that allows immutable storage, querying and analysis of clinical and genetic data using blockchain technology. Our platform allows clinical and genetic data to be harmonized by combining them under a unified framework. It supports combined genotype–phenotype queries and analysis, gives institutions control of their data and provides immutable user access logs, improving transparency into how and when health information is used. We demonstrate the value of our framework for precision medicine by creating genotype–phenotype cohorts and examining relationships within them. We show that combining data across institutions using our secure platform increases statistical power for rare disease analysis. By offering an integrated, secure and decentralized framework, we aim to enhance reproducibility and encourage broader participation from communities and patients in data sharing.

OHDSI Shoutouts!

Congratulations to the team of **Sooin Choi, Jin Kuk Kim, Jinhyoung Lee, Soo Jeong Choi and You Kyoung Lee** on the publication of **Limitations of NHIC claim code-based surveillance and the necessity of UDI implementation in Korea** in *Scientific Reports*.



scientific reports

Check for updates

OPEN

Limitations of NHIC claim code-based surveillance and the necessity of UDI implementation in Korea

Sooin Choi[1], Jin Kuk Kim[2], Jinhyoung Lee[3], Soo Jeong Choi[2]✉ & You Kyoung Lee[1]✉

The E-Health Big Data Evidence Innovation Network (FeederNet) in Korea, based on the observational medical outcomes partnership (OMOP) common data model (CDM), had 72.3% participation from tertiary hospitals handling severe diseases as of October 2022. While this contributes to the activation of multi-institutional research, concerns about the comprehensiveness of device data persist due to the adoption of national health insurance corporation (NHIC) claim codes as device identifiers in the medical device field. This study critically evaluated the effectiveness and compatibility of NHIC claim codes and unique device identifier (UDI) within FeederNet to identify the optimal identifier for efficient Post-market surveillance (PMS). Specifically, this study addressed three main questions: (1) the number of UDIs classified as NHIC-covered items, (2) the number of UDIs included in each NHIC claim code, and (3) the number of NHIC claim codes each UDI covers. Among the 1,979,655 UDIs registered domestically, only 36.02% (712,983) were classified as covered by National Health Insurance. NHIC-covered medical devices were limited to categories (A) medical devices, (B) medical supplies, and (C) dental materials, excluding most software and in vitro diagnostics (IVD). Multiple UDIs could be registered under a single NHIC claim code, and a single UDI could be registered under multiple NHIC claim codes. Only 32.62% (13,756/42,171) of NHIC claim codes had registered UDIs, with an average of 53 UDIs per claim code. Of the UDIs listed as NHIC covered, 92.39% (659,046/713,341) had one claim code, while 7.25% (51,652) had multiple claim codes. Additionally, 2643 UDIs were listed as NHIC covered but had no registered claim codes. Due to this complex relationship, NHIC claim code-based PMS may pool safe and unsafe models or disperse problematic models across multiple claim codes, leading to a lower problem rate or insignificant differences between claim codes, thus reducing signal detection sensitivity compared to UDI-based PMS. In conclusion, NHIC claim code-based PMS has limitations in granularity and signal detection sensitivity, necessitating the adoption of UDI-based PMS to address these issues. The UDI system can enhance the accuracy of medical device identification and tracking, playing a crucial role in generating real-world evidence (RWE) by integrating data from various sources. Future research should explore specific strategies for integrating and utilizing UDI with NHIC claim codes, contributing to the implementation of a more reliable and comprehensive PMS in Korea's healthcare system.

OHDSI Shoutouts!

The team of **Liwei Wang, Andrew Wen, Sunyang Fu, Xiaoyang Ruan, Ming Huang, Rui Li, Qiuhao Lu, Andrew E Williams, and Hongfang Liu** posted **Adoption of the OMOP CDM for Cancer Research using Real-world Data: Current Status and Opportunities** on a preprint server and seek community feedback.

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Adoption of the OMOP CDM for Cancer Research using Real-world Data: Current Status and Opportunities

Liwei Wang, Andrew Wen, Sunyang Fu, Xiaoyang Ruan, Ming Huang, Rui Li, Qiuhao Lu, Andrew E Williams, Hongfang Liu

doi: https://doi.org/10.1101/2024.08.23.24311950

This article is a preprint and has not been peer-reviewed [what does this mean?]. It reports new medical research that has yet to be evaluated and so should *not* be used to guide clinical practice.

Abstract | Full Text | Info/History | Metrics | Preview PDF

ABSTRACT

Background The Observational Medical Outcomes Partnership (OMOP) common data model (CDM) that is developed and maintained by the Observational Health Data Sciences and Informatics (OHDSI) community supports large scale cancer research by enabling distributed network analysis. As the number of studies using the OMOP CDM for cancer research increases, there is a growing need for an overview of the scope of cancer research that relies on the OMOP CDM ecosystem.

Objectives In this study, we present a comprehensive review of the adoption of the OMOP CDM for cancer research and offer some insights on opportunities in leveraging the OMOP CDM ecosystem for advancing cancer research.

OHDSI Shoutouts!

The team of **Noah Jones, Ming-Chieh Shih, Elizabeth Healey, Chen Wen Zhai, Sonali Advani, Aaron Smith-McLallen, David Sontag, and Sanjat Kanjilal** posted **Reassessing the management of uncomplicated urinary tract infection: A retrospective analysis using machine learning causal inference** on a preprint server and seek community feedback.

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Reassessing the management of uncomplicated urinary tract infection: A retrospective analysis using machine learning causal inference

Noah C Jones, Ming-Chieh Shih, Elizabeth Healey, Chen Wen Zhai, Sonali D Advani, Aaron Smith-McLallen, David Sontag, Sanjat Kanjilal

doi: https://doi.org/10.1101/2024.08.18.24312104

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Abstract | Full Text | Info/History | Metrics | Preview PDF

ABSTRACT

Background Uncomplicated urinary tract infection (UTI) is a common indication for outpatient antimicrobial therapy. National guidelines for the management of uncomplicated UTI were published by the Infectious Diseases Society of America in 2011, however it is not fully known the extent to which they align with current practices, patient diversity, and pathogen biology, all of which have evolved significantly in the time since their publication.

Objective We aimed to re-evaluate efficacy and adverse events for first-line antibiotics (nitrofurantoin, and trimethoprim-sulfamethoxazole), versus second-line antibiotics (fluoroquinolones) and versus alternative agents (oral β-lactams) for uncomplicated UTI in contemporary clinical practice by applying machine learning algorithms to a large claims database formatted into the Observational Medical Outcomes Partnership (OMOP) common

Three Stages of The Journey

Where Have We Been?

Where Are We Now?

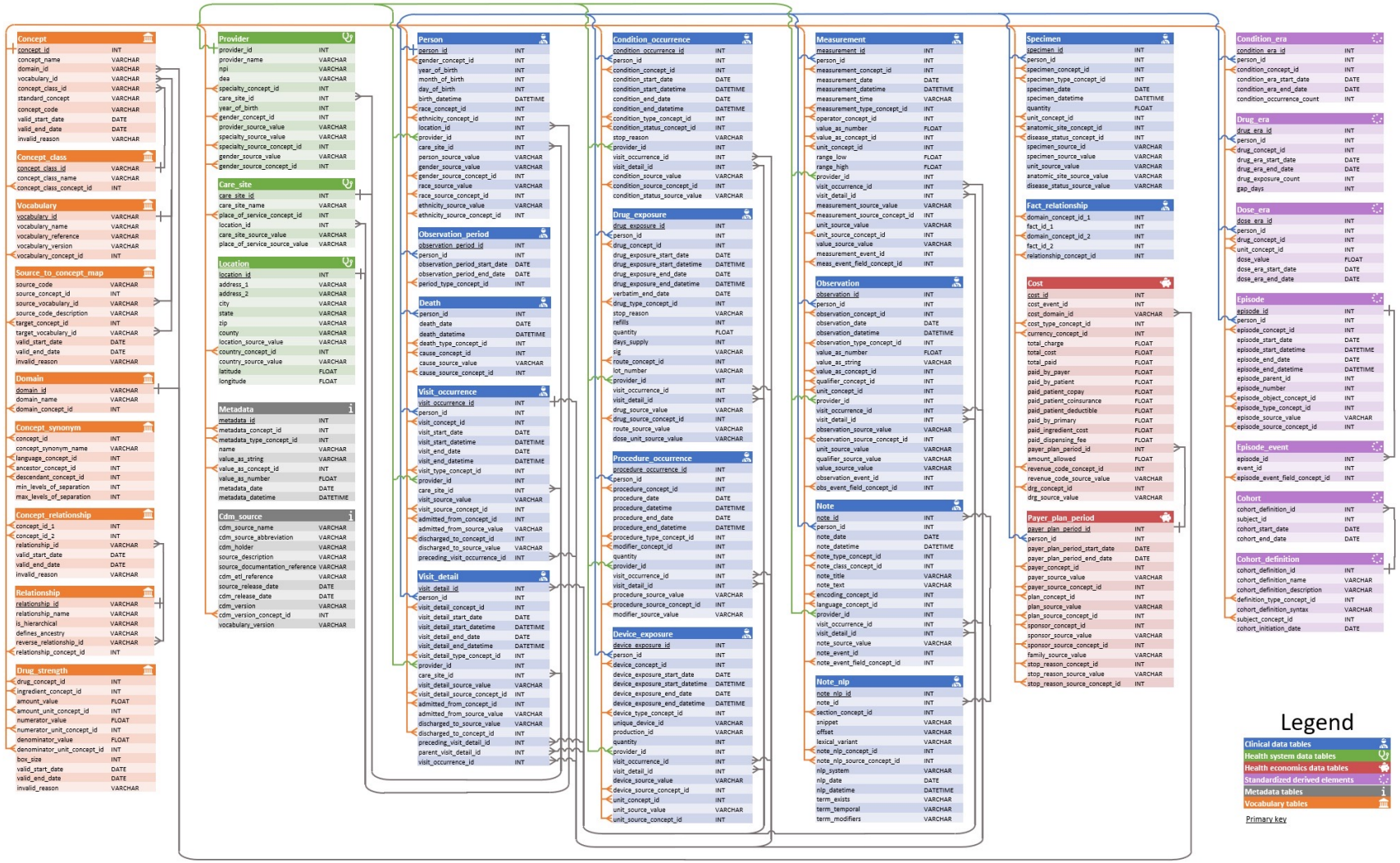
Where Are We Going?

Upcoming Workgroup Calls

Date	Time (ET)	Meeting
Tuesday	12 pm	Common Data Model Vocabulary Subgroup
Tuesday	12 pm	Generative AI and Analytics
Wednesday	9 am	Patient-Level Prediction
Wednesday	12 pm	Health Equity
Wednesday	2 pm	Natural Language Processing
Wednesday	4 pm	Joint Vulcan/OHDSI Meeting
Thursday	9:30 am	Network Data Quality
Thursday	10:30 am	Evidence Network
Thursday	12 pm	Strategus HADES Subgroup
Thursday	7 pm	Dentistry
Friday	9 am	Phenotype Development & Evaluation
Friday	10 am	GIS-Geographic Information System
Friday	11:30 am	Clinical Trials
Friday	11:30 am	Steering Group
Friday	11 pm	China Chapter
Monday	10 am	Africa Chapter
Monday	10 am	CDM Survey Subgroup
Monday	11 am	Data Bricks
Monday	2 pm	Electronic Animal Health Records

Evidence Network Update

OMOP Common Data Model 5.4



Titan Award Nominations Close FRIDAY!

The Titan Awards have been handed out annually since 2018 to recognize OHDSI collaborators (or collaborating institutions) for their contributions towards OHDSI's mission.

Nominations for the 2024 Titan Awards are now open. **Please complete your nominations by our Sept. 13 deadline!**

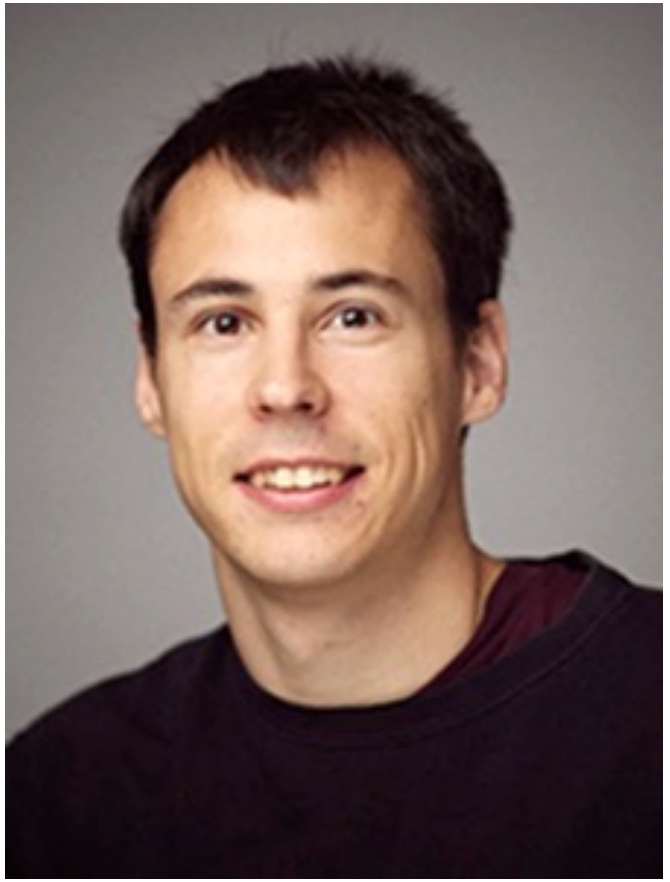
ohdsi.org/titan-awards

Next CBER Best Seminar: Tomorrow!

Topic: Observational methods for COVID-19 vaccine effectiveness research: an empirical evaluation and target trial emulation

Presenter: Martí Català Sabaté, Medical Statistician and Data Scientist, University of Oxford

Logistics: 11 am – 12 pm EST, Zoom webinar



ohdsi.org/cber-best-seminar-series

2024 Global Symposium

Oct. 22-24 • Hyatt Regency Hotel, New Brunswick, N.J.

Registration is OPEN for the 2024 OHDSI Global Symposium. Collaborator Showcase notifications are taking place this week. Agendas and tutorial/workgroup schedules are posted.

Tuesday: Tutorials
Wednesday: Plenary/Showcase
Thursday: Workgroup Activities

ohdsi.org/OHDSI2024

2024 India Symposium

Oct. 5 • Jio World Convention Centre, Mumbia

2024 APAC Symposium

Dec. 4-8 • Marina Bay Sands & National University of Singapore (NUS)

Preliminary Dates To Know

Oct. 6: Collaborator Showcase Submission Deadline
Oct. 7-24: Collaborator Showcase Submission Review
Oct. 31: Notification of Acceptance

Symposium Agenda

Dec. 4: Tutorial at NUS
Dec. 5-6: Main Conference at Marina Bay Sands
Dec. 7-8: Datathon at NUS

Registration Information is coming soon!

ohdsi.org/APAC2024

The Center for Advanced Healthcare Research Informatics (CAHRI) at Tufts Medicine welcomes:

Cavin Ward-Caviness, PhD

Senior Computational Biologist in the Public Health and Integrated Toxicology Division of the US Environmental Protection Agency

'Successes and Lessons Learned from Integrating Environmental Data into Diverse EHR Resources'

September 26, 2024, 11am-12pm EST
Virtually via Zoom

Please contact Marty Alvarez at malvarez2@tuftsmedicalcenter.org for calendar invite or questions.

TuftsMedicine
Tufts Medical Center

#OHDSISocialShowcase

MONDAY

OHDSI in Africa and Partnerships with European Institutions

(Cynthia Sung, Agnes Kiragga, Kofi Agayre, OO Aluko, David Amadi, Daniel Ankrah, Chidi Asuzu, Adam Bouras, Geert Byttebier, Aize Cao, Ahmed El-Sayed, Chris Fourie, Yacob Gebretensae, Nega Gebreyesus, Jay Greenfield, Lars Halvorsen, Jared Houghtaling, Katherine Johnston, Andrew S. Kanter, Mack Kigada, Sylvia Muyingo, Maureen Ng'etich, Michael Ochola, Henry Ogoe, Bolu Oluwalade, James Orwa, Mariette Smith, Amelia Taylor, Marleen Temmerman, Jim Todd, Marc Twagirumukiza, Daniel M Wanga, Andrew Williams and the OHDSI Africa Chapter)

The Africa Chapter is raising awareness of OHDSI in Africa to improve interoperability and promote collaboration across Africa and globally

OHDSI in Africa and Partnerships with European Institutions

Cynthia Sung[1*], Agnes Kiragga[2*], Kofi Agayre[3], OO Aluko[4], David Amadi[2], Daniel Ankrah[5], Chidi Asuzu[6], Adam Bouras[7], Geert Byttebier[8,9], Aize Cao[10], Ahmed El-Sayed, Chris Fourie[11], Yacob Gebretensae[12], Nega Gebreyesus[13], Jay Greenfield[14], Lars Halvorsen[15], Jared Houghtaling[15,16], Katherine Johnston[17], Andrew S. Kanter[18], Mack Kigada[19], Sylvia Muyingo[2], Maureen Ng'etich[2], Michael Ochola[2], Henry Ogoe[20], Bolu Oluwalade[21], James Orwa[22], Mariette Smith[17], Amelia Taylor[23], Marleen Temmerman[9,22], Jim Todd[24,25,26], Marc Twagirumukiza[9], Daniel M Wanga[2], Andrew Williams[16] and the OHDSI Africa Chapter

[1]Duke-NUS Medical School SGP [2]African Population Health Research Center KEN, [3]Nayaho Medical Center GHA, [4]Obafemi Awolowo University NGA, [5]Korle-Bu Teaching Hospital GHA, [6]Duke Medical School USA, [7]CDC USA, [8]Medaman BV BEL, [9]Ghent University BEL, [10]Meharry College of Medicine USA, [11]Western Cape Provincial Health Data Centre ZAF, [12]Sapienza University of Rome ITA, [13]USAID USA, [14]CODATA FRA, [15]EdenceHealth NV BEL, [16]Tufts University School of Medicine USA, [17]University of Cape Town ZAF, [18]Columbia University, USA, [19]Digulab KEN, [20]Publicis Sapient GHA, [21]Children's Hospital of Philadelphia USA, [22]Aga Khan University KEN, [23]Malawi University of Business and Applied Science MWI, [24]London School of Hygiene and Tropical Medicine GBR, [25]Catholic University of Health and Applied Sciences TZA, [26]National Inst for Medical Research, TZA *Chapter Co-leads

Background

Africa faces significant health challenges from a high burden of infectious diseases, maternal health issues, and rising incidence of non-communicable diseases. African governments are striving to establish efficient systems for sharing health data and promoting interoperability among various repositories as health data are increasingly migrating to electronic data capture. The OHDSI framework for data standardization and collaboration through a federated approach, as well as the extensive suite of programs for quality checks, visualization and rigorous analysis of observational data can accelerate efforts of African entities to strengthen health information systems and analyze large health data sets, both within and across African countries, to generate evidence for improving health systems and patient care, in a manner that is privacy protecting, transparent in methodology, and economical through use of open-source tools.

Methods

Africa Chapter members are spreading awareness of OHDSI to other African researchers, health data custodians and government officials, using the Value Proposition document written by Chapter members in 2023. Chapter members have begun the process to obtain permission to do an OMOP ETL of a specific healthcare database in their country. At Chapter meetings, more experienced members are transferring their knowledge and experiences, as well as introducing synthetic datasets, to give members who are new to OHDSI an opportunity to become familiar with OHDSI tools. The OHDSI Africa chapter is seeking to build collaborative relationships with other data science programs such as DS-I Africa, African Open Science Platform and VODAN.

Results

African countries represented among OHDSI Africa chapter members

- Institutions in Rwanda, Kenya, Malawi, Tanzania, and South Africa have created OMOP versions of local health data.
- The LAISDAR project located at the Rwanda Biomedical Center contains 3.6 million unique subjects in OMOP CDMs transformed from OpenMRS and OpenClinic EMRs at 15 hospitals.
- The INSPIRE network at the African Population Health and Research Centre (APHRC) carried out ETLs to the OMOP CDM using data from the Health and Demographic Surveillance System in Kenya, Tanzania and South Africa.
- APHRC is collaborating with UK institutions The Alan Turing Institute and London School of Hygiene and Tropical Medicine, CODATA (France), I-DAIR (Switzerland) and institutions in Cameroon, Ethiopia and Senegal on a Wellcome Trust funded project "Data Science Without Borders", which will conduct research using data harmonized to the OMOP CDM.
- The Virus Outbreak Data Network (VODAN) Africa has established data science partnerships in 12 African countries and invited OHDSI Africa Chapter members to meet at Leiden University (Belgium) on 04 Jun 2024 to discuss a plan for collaboration.

Conclusion

Awareness of OHDSI is growing in Africa with several African institutions successfully implementing the OMOP CDM and OHDSI tools. Several OHDSI Africa Chapter members are poised to do OMOP CDM implementations at their institutions. Despite the availability of vast amounts of health data in Africa, these remain siloed in different organizations and captured in varying formats and terminologies. Facilitating knowledge transfer from experienced OHDSI members, within Africa and globally, to those less familiar with OHDSI tools, will expedite interoperability and capacity building in Africa. **Funding is urgently needed to empower African scientists to lead this transformative effort.**

OHDSI

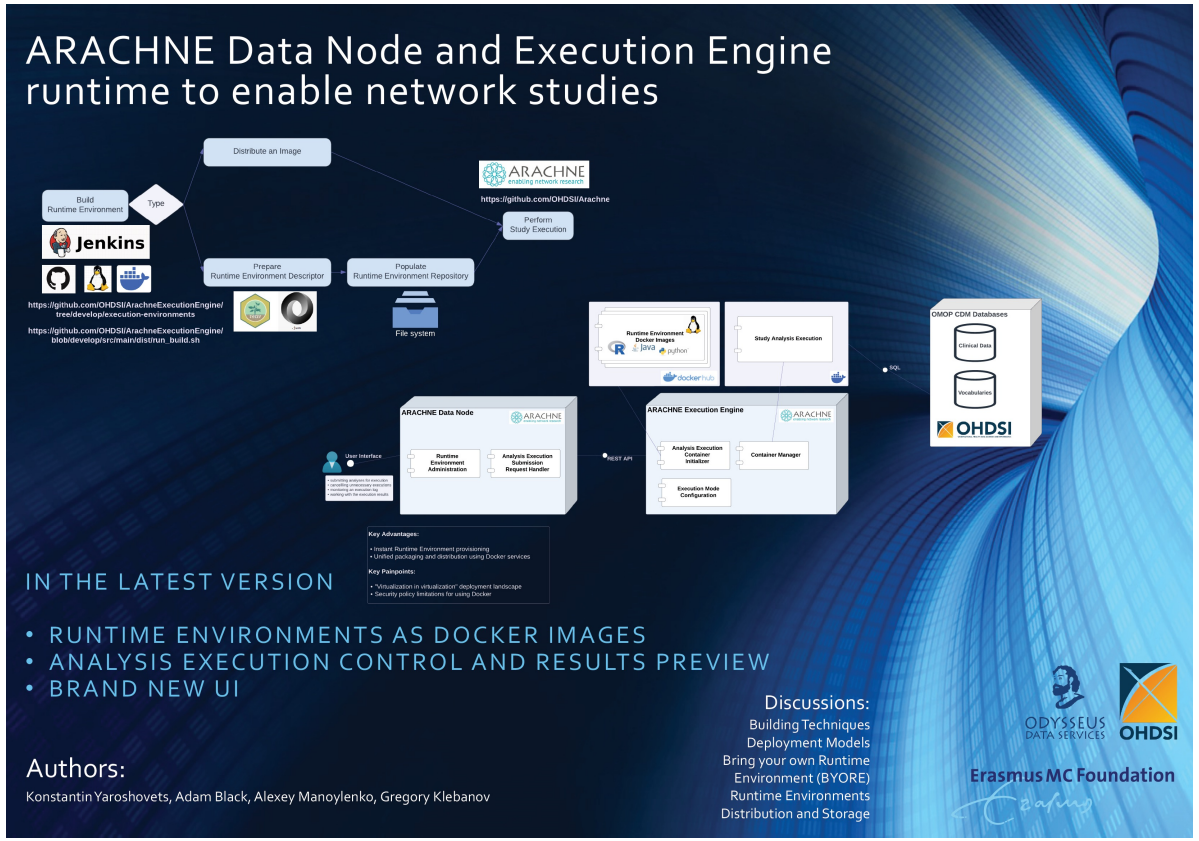
Join the OHDSI Africa Chapter biweekly meeting Monday at 10 AM ET

#OHDSISocialShowcase

TUESDAY

ARACHNE Data Node and Execution Engine runtime to enable network studies

(Konstantin Yaroshovets, Adam Black, Alexey Manoylenko, Gregory Klebanov)



#OHDSISocialShowcase

WEDNESDAY

How metadata empowers MedDRA hierarchies and mappings

(Mikita Salavei, Oleg Zhuk, Vlad Korsik, Alexander Davydov)

How metadata empowers MedDRA hierarchies and mappings

Mikita Salavei[1], Oleg Zhuk[1], Vlad Korsik[1], Alexander Davydov[1]
[1]Odysseus Data Services Inc., Cambridge, MA

Background: MedDRA, short for Medical Dictionary for Regulatory Activities, is a comprehensive medical terminology specifically developed for classifying adverse events and other crucial medical information, predominantly utilised within clinical trials and pharmacovigilance practice. Its integration with SNOMED CT, a cornerstone medical terminology in OHDSI Standardized vocabularies, offers substantial potential for augmenting healthcare research endeavours.

Lately, the compatibility between MedDRA and SNOMED in OMOP was hindered by a limited number of direct 'Maps to' links, constructed to align concepts based on their semantic similarity, often with varying levels of granularity. However, with the February 2024 OHDSI Vocabulary release[1], mapping metadata (inspired by the SSSOM model[2]) has been utilised to enhance the precision of mappings and to establish hierarchical links between MedDRA and SNOMED.

Methods: Our approach encompasses the utilisation of both internal resources within OHDSI, such as previously built MedDRA-SNOMED mappings and internal AI-augmented mapping approach, as well as tapping into external sources including the Unified Medical Language System thesaurus, MedDRA-SNOMED bidirectional mappings from the Maintenance and Support Services Organization, and ICD10-MedDRA mappings. To streamline the process, all identical MedDRA concepts with differing variants of potential mappings to SNOMED were methodically grouped and subjected to manual review by medical terminologists to discern the most optimal mapping choice with the help of a Common Data Environment (CDE)[3]. For each finalized variant of mapping, a unique relationship_id_predicate was defined as metadata, capturing three levels of semantic similarity: 'Maps to equivalent', 'Maps to uphill', and 'Maps to downhill' (Table 1).

The result of the mapping process involved the creation of hierarchical links between MedDRA and SNOMED based on the metadata, ensuring integration of two medical terminologies within the OMOP framework into a single hierarchy.

Table 1. Description of metadata relationship_id_predicates and typical examples of MedDRA-SNOMED mappings

Relationship_id full	Description	Concept name	Vocabulary	Relationship_id	Relationtionship_id_predicate	Concept code	Concept name	Vocabulary
Maps to equivalent	Standard full equivalent 'Maps to" with no data loss. The two terms are intended to refer the same thing	Adrenocortical insufficiency acute	MedDRA	Maps to	equivalent	766986002	Acute adrenal insufficiency	SNOMED
		Congenital pulmonary hypertension	MedDRA	Maps to	equivalent	1010627004	Pulmonary hypertension due to developmental abnormality	SNOMED
Maps to uphill	The source concept is a narrower term than the target concept. Data loss happens. Typical scenario when no exact match can be found	Anastomotic ulcer haemorrhage	MedDRA	Maps to	uphill	74474003	Gastrointestinal hemorrhage	SNOMED
		Anastomotic ulcer haemorrhage	MedDRA	Maps to	uphill	447408004	Ulcer of anastomosis	SNOMED
		Groin infection	MedDRA	Maps to	uphill	40733004	Disorder due to infection	SNOMED
		Groin infection	MedDRA	Maps to	uphill	118936007	Disorder of inguinal region	SNOMED
Maps to downhill	Rare scenario when the source concept is broader than the target concept. It should not happen generally if not stated otherwise	Suture rupture	MedDRA	Maps to	downhill	217008000	Suture failure during surgical operation	SNOMED
		Epstein-Barr virus test	MedDRA	Maps to	downhill	408219003	Epstein-Barr virus serology	SNOMED

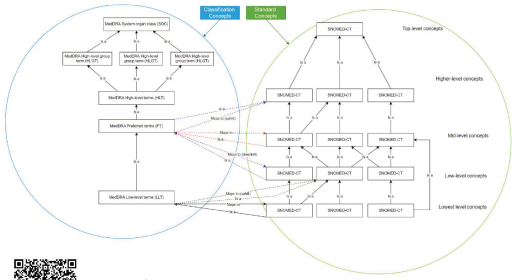
Results: Our primary focus centred on the Preferred Term (PT) level of MedDRA concepts due to their enhanced suitability for analytics needs. In addition, we add and improve Lowest Level Term (LLT) mapping. This work led to the addition of 10,189 PT and 2,874 LLT mappings of concepts to the OHDSI standardized vocabularies (as per February 2024 release).

Furthermore, hierarchical links, denoted by 'Is a' and 'Subsumes' relationships, were systematically constructed based on the following principles.

In cases of complete semantic correspondence between MedDRA and SNOMED concepts, the MedDRA concept was strategically positioned above its corresponding SNOMED counterpart. However, in cases of incomplete correspondence, diverse scenarios emerged wherein the MedDRA concept could be hierarchically higher (downhill mapping to SNOMED) or lower (uphill mapping to SNOMED) compared to the corresponding SNOMED concept.

Finally, a hierarchy between MedDRA and SNOMED / OMOP Extension has been constructed with 25,623 'Is a'/'Subsumes' links (Figure 1)

Figure 1. Hierarchical links between MedDRA and SNOMED vocabularies constructed based on metadata



Scan QR code to view eposter

Conclusion: The strategic emphasis placed on harnessing metadata to enhance MedDRA mappings and establish new hierarchies within the OMOP framework signifies a notable step forward in OMOP terminology improvement. MedDRA, retaining its status as a classification vocabulary, serves dual purposes within this framework. Firstly, it facilitates the mapping of source data from MedDRA codes to OMOP Standard concepts, leveraging 'Maps to' and 'Maps to value' links. Secondly, MedDRA codes are utilized as classification concepts for constructing concept sets based on hierarchical links. This is the first example of mappings metadata implementation in OHDSI vocabulary development process with a practical effect on the content in the official release.

References:
1. https://github.com/OHDSI/Vocabulary-v5.0/releases/tag/v20240229_1709217174.000000
2. O. Zhuk, A. Ostropolets, N. Matentzoglu, M. Haendel, D. Gabriel, A. Davydov, C. Reich Community Contribution to the OHDSI Vocabularies, User-Level QC and a New Entity Mapping System SSSOM, Conference: OHDSI European Symposium 2023.
3. I. Zherko, M. Nerovnya, M. Kallfelz, A. Davydov Common data environment for source vocabularies mapping, Conference: OHDSI European Symposium 2022.

#OHDSISocialShowcase

The Data2Evidence platform: facilitating **healthcare research** through better **data discovery and governance.**

OHDSI

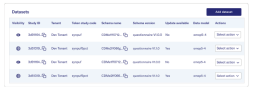
THURSDAY

Enhancing Clinical Data Management and Utilization with the Data2Evidence Platform

(Karthik Seetharaman, Santan Maddi, Satish Anbazhagan, Afreen Sikandara, Brandan Tan, Alicia Jing Wen Koh, Peter Hoffmann)

Enhancing Clinical Data Management and Utilization with the Data2Evidence Platform

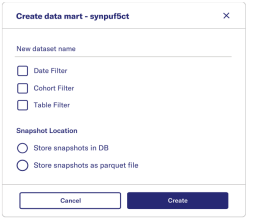
Background: Storing and managing multiple large OMOP datasets in an organization with numerous users poses significant challenges in storage, security, and IT expertise. Moreover, given the large number of data sets, it is often challenging for researchers to navigate and find relevant data. Our software platform, Data2Evidence, is designed to facilitate the streamlined management and analysis of clinical data in the OMOP CDM.



Enabling Data Discovery and Evaluation in Dataset Collections

The system administrators can flexibly define and modify the metadata stored for each dataset. Moreover, our solution allows the administrator to run existing OHDSI tools for data characterization and data quality on demand and store the results per dataset.

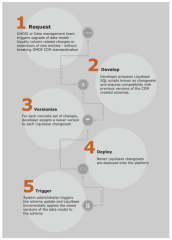
Our solution also provides the researcher with a comprehensive overview of the datasets in an easy-to-use web interface allowing them to make informed decisions. This includes information such as the metadata, schema version, data characterization, and data quality reports for each dataset. Users can search across this information and free text to get the relevant dataset.



Improving Governance and Security through Targeted Data Use

Our platform supports typical and more complex workflows to request and grant access to the dataset. It also integrates with existing identity providers and data governance systems in the organisation.

New data subsets (data marts) can be created by filtering by timeframes, patients matching a specific phenotype and specific entities and attributes. The new subset is created from the primary dataset based on the defined filter criteria. The isolation of the new subset begins at the database layer to ensure clear governance and boundaries. This empowers researchers to work with the minimum necessary data while safeguarding information about patients with specific diseases and filtering out sensitive information in data sets.



Easier Data Model Evolution

During the lifecycle of a dataset, it is expected that changes to the existing data model are required with each new version of the OMOP CDM which is not trivial. Also, it might be expected to make these changes only on certain datasets in the platform while keeping the others as is.

To address this challenge, our platform has a robust integrated schema evolution solution. Developers define "changesets" (SQL scripts) and the software maintains a comprehensive record of applied changesets, thereby facilitating the update or rollback of changes to the database.

This ensures a consistent state of the database across multiple deployments including development, testing, and production systems. The flexibility to apply changes to specific datasets also allows users to take sufficient time to amend their analysis scripts based on these changes in the CDM schema.

Karthik Seetharaman[1], Santan Maddi[1], Satish Anbazhagan[1], Afreen Sikandara[1], Brandan Tan[1], Alicia Jing Wen Koh[1], Peter Hoffmann[1]

[1]D4L data4life Asia Limited

D4L

#OHDSISocialShowcase

FRIDAY

Baseline characterization and treatment pathways of patients with Alport Syndrome across geographies: Exploring a rare disease in a multi-database retrospective cohort study

(Katrin Manlik, Glen James, Andrea Scalise, Charlie Scott, Daloha Rodriguez Molina, David Vizcaya)

Alport syndrome, a rare genetic kidney disease, shows **notable gender and regional differences** in patient characteristics. Multi-database studies using OMOP Common Data Model are an excellent opportunity to gain **insights into rare diseases.**

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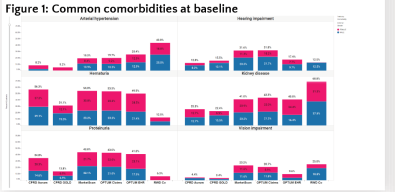
Background: Alport Syndrome (AS) is a rare genetic kidney disease that usually manifests in early childhood. Mutations in the COL4A3, COL4A4 and COL4A5 genes lead to defective collagen production. Consequently, patients may present with hematuria, proteinuria or progressive loss of kidney function leading to kidney failure in addition to ocular abnormalities and hearing loss.

Results: Overall, **1819 AS patients** were identified from **6 databases** across **3 countries**. In the **US**, patients were diagnosed with AS around the age of 20. **Male patients** were 7–10 years **younger** than females at index date. In the **UK**, patients were diagnosed with AS in their early teens, in **Japan** around the age of 24. Common comorbidities at baseline can be found in figure 1.

Table 1: Demographics

Variable	CPRD Aurum EHR	CPRD GOLD EHR	MarketScan Claims	OPTUM Claims	OPTUM EHR	RWD Co EHR Claims
Country	UK	UK	USA	USA	USA	Japan
Patient Count	158	58	585	314	688	16
Female %	52.5	41.4	54.7	51.3	57.6	56.2
Age at diagnosis (in years)						
Overall Median (IQR) Age	13 (8–28)	14 (7–25)	19 (10–29)	19 (10–32)	23 (13–32)	24 (17–26)
Female Median (IQR) Age	16 (9–30)	14 (9–30)	23 (12–32)	24 (11–33)	27 (18–33)	24 (24–25)
Male Median (IQR) Age	11 (6–24)	14 (5–18)	16 (9–26)	16 (9–25)	17 (9–28)	23 (4–26)

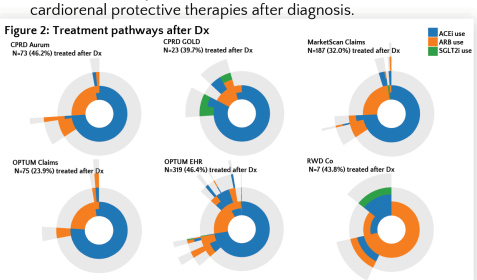
Figure 1: Common comorbidities at baseline



We assessed medications typically used to treat patients with AS:

- **Angiotensin-converting enzyme inhibitors (ACEi)** was the most frequently used 1st line therapy **in US and UK** – around 3/4 of patients.
- **Angiotensin receptor blockers (ARBs)** was the second most frequently used 1st line therapy in US and UK – nearly 1/4 of patients, but most frequently used in **Japan**.
- **Sodium-glucose transport protein 2 inhibitors (SGLT2i)** were rarely used in the AS population.
- **Less than half of patients** with AS were **treated** with cardiorenal protective therapies after diagnosis.

Figure 2: Treatment pathways after Dx

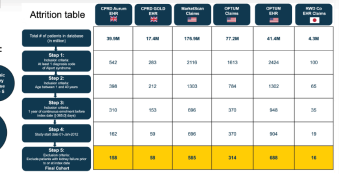


Methods:

- A longitudinal retrospective cohort study
- 6 OMOP databases from 3 countries
- Study start date 01-JAN-2012
- Inclusion criteria:
  - ✓ 1 diagnosis code for AS
  - ✓ age between 1 and 40 years at index
  - ✓ at least 12 months of continuous enrolment
- Exclusion criteria:
  - ✓ prior kidney failure before or on index

Figure 3: Inclusion & Exclusion criteria and Comorbidities of interest

Attrition table



Conclusions: This study demonstrates that the use of data sources standardized to the **OMOP CDM and using OHDSI tools provides an excellent opportunity to gain insights into rare diseases** across multiple geographies and healthcare settings in a standardized approach where contemporary real-world evidence is scarce. It provides **new insights into the demographics, clinical characteristics, and treatment utilization of patients with AS**. These data may be useful to gain knowledge about the disease, provide better support to clinicians and healthcare providers and most importantly, improve patient's quality of life.

Katrin Manlik[1], Glen James[2], Andrea Scalise[3], Charlie Scott[2], Daloha Rodriguez Molina[1], David Vizcaya[3]

1 Bayer AG, Berlin, Germany
2 Bayer plc, Reading, UK
3 Bayer Hispania S.L., San Joan Despi, Spain

katrin.manlik@bayer.com

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

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Three Stages of The Journey

Where Have We Been?

Where Are We Now?

Where Are We Going?

Sept. 10: Asia-Pacific Updates

Jason Hsu

Taiwan Chapter

Seng Chan You

Korea Chapter

Keiko Asao

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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