Africa Chapter
Chapter Leads: Cynthia Sung, Agnes Kiragga

Purpose

- To strengthen awareness and capacity for data harmonization and analysis using OHDSI tools to meet the data-driven evidence needs of African researchers, health providers, and governments

Teams Meeting Link

Africa Chapter 2025 Objectives and Key Results

Objective 1	Key Result	OKR Lead(s)
Grant funding to expand data in OMOP CDM	• Submit 2 or more grants	Marc Twagirumukiza (Rwanda) Agnes Kiragga (Kenya, Uganda)

Objective 2	Key Results	OKR Lead(s)
OHDSI Africa Symposium on the Continent	• Hold Symposium before end of year: sometime during week of Nov 10 • Identify hosting site: Joint Clin Res Ctr Kampala	Alex Asiimwe (Uganda) Francis Kanyike (JCRC Uganda) David Muyomba (JCRC Uganda)
	• Publicity to achieve >100 attendees	APHRC (Kenya), JCRC (Uganda)
	• Find sponsors • Symposium content: overview, group activity; tutorials, leadership dvpt vision,	? members

Objective 3	Key Results	OKR Lead(s)
Deep dive on ETL/data transformation process	• Group hands-on ETL exercise over ~2 mo	Narem Singh (India)
	• Identify usable data sources on the continent	IQVIA, JCRC, HDSS sites

Africa Chapter 2025 Objectives and Key Results

Objective 4	Key Result	OKR Lead(s)
Propose Africa-specific terminology to add to	Compare local data dictionaries/sources to standardized vocabularies (e.g. CIEL -> ATHENA)	Andy Kanter (USA)
OHDSI Standard Vocabulary	• Identify at least 3 vocabularies to run concept prevalence studies • Create a process for moving the data from CIEL-ATHENA	Bolu Oluwalade (Nigeria), Katherine Johnston (S. Africa)

Objective 5	Key Results	OKR Lead(s)
Conduct learning sessions for different audiences	• Develop customized curricula for MOH vs doctors vs clinical/IT support staff • Hands on use cases relevant for the audience	David Amadi (Kenya) Lars Halvorsen (Norway, Belgium)

Objective 6	Key Results	OKR Lead(s)
Maturity model for ETL implementation	• Outline characteristics of 4-5 levels of maturity	Agnes Kiragga (Kenya), Adam Bouras (Morocco)

Ongoing Activities

- Translation of the Book of OHDSI: French, Arabic, Portuguese, Swahili - Michel Walvarens

- Data Science without Borders Program (Kenya, Cameroon, Senegal)

- BRIDGE PhD/postdoc Training (Rwanda, Kenya, Uganda, S. Africa, Benin, Norway, Belgium, Ethiopia)

Africa Chapter
Chapter Leads: Cynthia Sung, Agnes Kiragga

Biweekly Meeting – Monday 10 AM ET

4 pm WAST; 5 pm CAT/SAST; 6 pm EAT (during **EST**)

Mar 3

US switches to Daylight Savings Time Mar 9

3 pm WAST; 4 pm CAT/SAST; 5 pm EAT (during **EDT**)

Mar 17, Mar 31, Apr 14 . . .

Teams Meeting Link

OHDSI Rare Diseases Working Group

2025 OKR

WG leads:
Xiaoyan Wang PhD
Chunhua Weng PhD

Rare Diseases Working Group

Mission Statement:

To advance the understanding, diagnosis, and treatment of rare diseases through the development and application of open-source analytics tools, standardized data models, and collaborative research.

- Develop and refine methodologies for collaborative rare disease case aggregation within the OHDSI community.
- Support evidence generation over rare diseases within the OHDSI ecosystem.
- Facilitate collaboration across stakeholders, including researchers, clinicians, sponsors, industry partners, and patient advocacy groups, to drive impactful discoveries.

Rare Disease WG 2025 OKRs

WG Leads: Xiaoyan Wang, Chunhua Weng

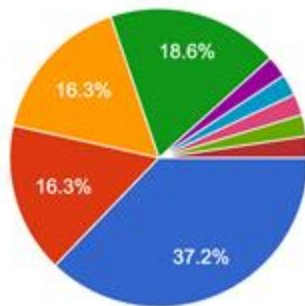**Objective 1**: **Strengthen community engagement and collaboration**

KR1: Form a collaborative team of ~20 active members with expertise in rare disease research, data science, phenotyping and clinical study design.

KR2: Organize about three knowledge-sharing sessions to foster interdisciplinary collaboration.

KR3: Establish partnerships with key stakeholders, including researchers, clinicians, patient advocacy groups, regulatory agencies, and industry leaders, to enhance research impact.
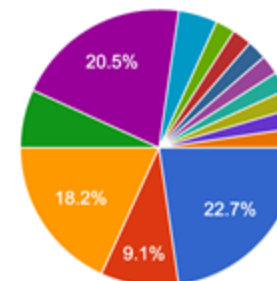

Please indicate your primary affiliation (choose one):
43 responses

- Academic/Research
- Pharmaceutical/Biotech
- Technology/Software
- Consulting/CRO
- Healthcare Provider
- Patient Advocacy Group
- Driving change and adoption of OMOP in Sweden. Engaged in an IHI Call 9 i...
- Health Authority representative (MD)
- Nonprofit Research and Data Coordin...

18.6%
16.3%
16.3%
37.2%

What expertise, skills, or data assets can you contribute to the working group? (Chose one option that fits best)
44 responses

- Clinical and Real-world data (RWD)
- Rare disease research
- Data standardization
- Patient engagement/advocacy
- Statistics, Analytics, AI/ML application...
- Clinical trial design and Pharmacoepid...
- Regulatory science
- Change management, Analytics, Lead...

20.5%
18.2%
9.1%
22.7%

1/2

Rare Disease WG 2025 OKR
WG Lead: Xiaoyan Wang, Chunhua Weng

- **Objective 2 : Enable scalable and reproducible rare disease analytics**

  - **KR1**: Design and initiate a multi-site rare disease study leveraging OHDSI's network and the OMOP CDM.

  - **KR2:** Develop a standardized approach for identifying and integrating hard-to-find rare disease cohorts across multiple data sources.

  - **KR3:** Release preliminary findings and methodological insights to guide future large-scale rare disease research.

- **Objective 3: Integrate Innovative AI Technologies for Rare Disease Research**

  - **KR1:** Evaluate and implement NLP and LLMs for rare disease cohort identification.

  - **KR2:** Develop and test the integration of knowledge graphs and AI-driven knowledge discovery tools for rare disease evidence generation.

  - **KR3:** Release an open-source framework or best practices document for leveraging AI in rare disease studies within the OHDSI community.

Rare Diseases WG Next Meeting

- To join, go to ohdsi.org -> workgroups tab ->
- Select Workgroup - Rare Diseases
- Meeting details:

  Time: 10-11am EST, Feb 28th, 2025

  Meeting Link: Join the meeting now

  Meeting ID: 210 677 103 238

  Passcode: Yw2GJ7pq

  Agenda:
  - Introduce the WG's objectives
  - Discuss priority areas
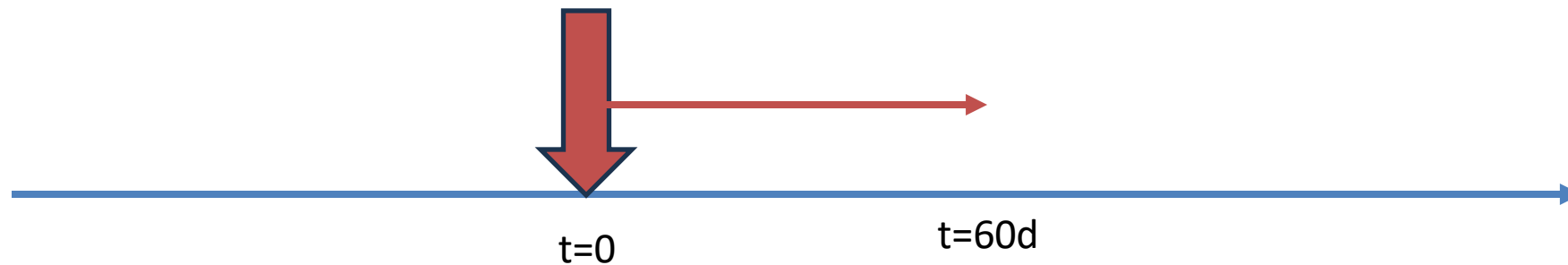 - Identify opportunities for collaboration.

Surgery and Perioperative WG: 2025 OKR

Feb 25, 2025

Evidence Driven Data Standardization

- Objective: Convert existing surgical cohort assets from non-standard concepts to standard concepts
  - Key Results:
    - Validation completed through peer review of included concepts / source codes
    - Validation completed through population level validation (CohortDiagnostics)
- Objective: Improve vocabulary mappings in the procedural domain (in partnership with the OHDSI Vocabulary Team)
  - Key Results
    - Contribute to LLM enhanced / Manual Review of ICD 10 PCS → SNOMED mappings in the OHDSI vocabulary

Guideline Driven Evidence **Generation** & Dissemination

- Objective: Refine, improve, and disseminate surgical (and outcome) **cohorts**

- Key Results:
  - Complete of Target Surgery Translation to Standard Vocabulary Concepts, and validate. →Updates submitted to Phenotype Library
  - Completion of Outcome Cohort Review →Updates submitted to Phenotype Library
  - Complete phenotype description of at least one surgical cohort (as published paper)

Guideline Driven Evidence **Generation** & **Dissemination**

- Objective: Completion of Surgery Incidence Rate Study
  - Key Results
    - Complete specification and execution of Surgery Incidence Rate study
    - Publication of *at least two* Surgery: Outcome Incidence Rate Papers
- Objective: Specification / Planning of *at least one* surgery related effect estimation or prediction Network study
  - Key Results:
    - Background, proposed methodology, initial cohorts characterized by Jan 2026

Guideline Driven Evidence **Generation** & **Dissemination**

- Objective: Improve Engagement with the Surgery and Periop Medicine Clinical Community
  - Key Results
    - Acceptance of Clinical WG work in at least 3 surgery / perioperative conferences
    - Presentation of broader OHDSI Mission / Capabilities / Methods in at least one Surgery / Periop conference
    - Involvement of (at least) 3 new members from (at least) 3 new surgery / perioperative focused research groups

Collaborative Education / OHDSI Community Collaboration

- Objective: Promote Cross Work Group Collaboration
  - Key Results:
    - Establish 2 strategic Collaborations with other WG
    - 2 Joint meetings in 2025

Surgery and Perioperative WG

Questions? Interest?

minty@ohdsi.org

t=0

t=60d

Meetings: Last Wednesday of Every Month
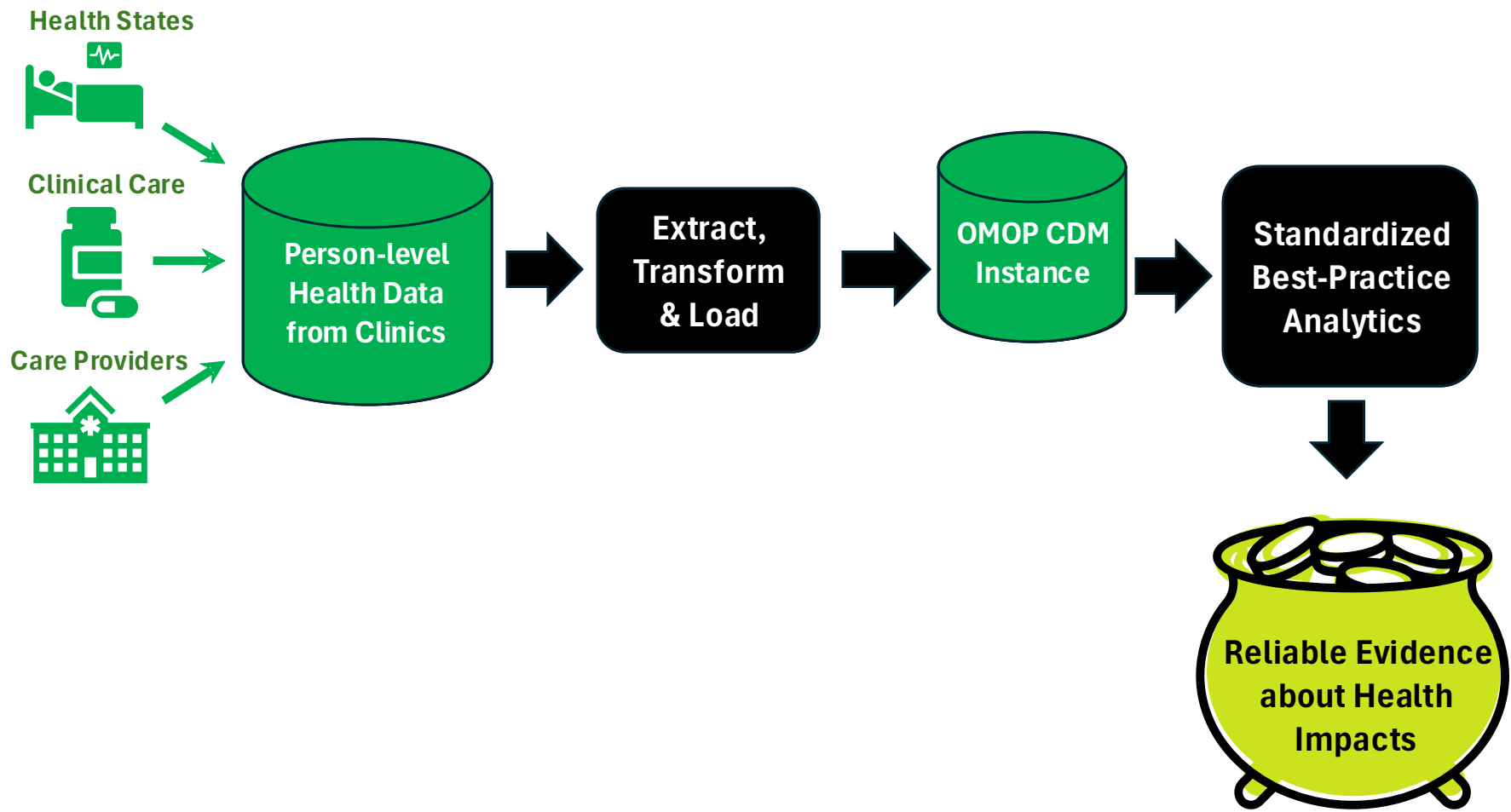7am PST / 8am MST / 10am EST / 3pm BST / 4pm CET.
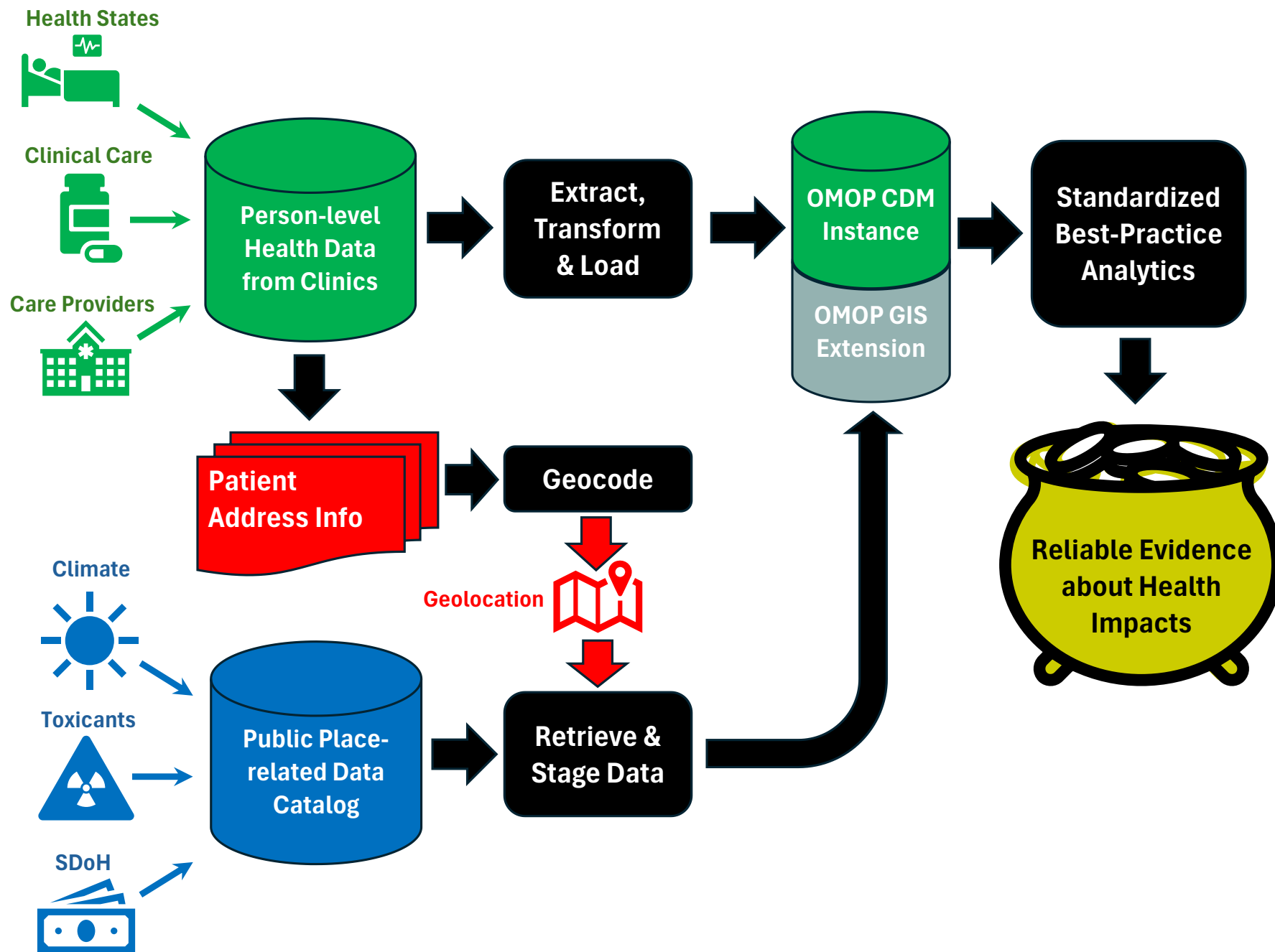
OHDSI GIS Workgroup

GIS Workgroup: Mission

Improve the health of populations by generating reliable evidence from integrated geospatial and person-level health data.

- Climate
- Toxicants
- Regional policies
- Social determinants of health
- ...

Health States

Clinical Care

Care Providers

Person-level Health Data from Clinics

Extract, Transform & Load

OMOP CDM Instance

Standardized Best-Practice Analytics

Reliable Evidence about Health Impacts

GIS Workgroup: 2024 Accomplishments

- **Released GIS Extension to OMOP Schema**
  - https://ohdsi.github.io/GIS
- **Released draft vocabulary for standard representation of geospatial attributes that affect health:**
  https://github.com/OHDSI/GIS/tree/main/vocabularies
  - GIS Vocabulary
  - Exposome Vocabulary
  - SDoH Vocuablary
- Tested GAIA Core schema and code for ETLing geospatial data
- Developed flexible data cataloging approach
- Developed flexible geocoding approach
- Transitioned to a flexible use case-driven management structure
- Developed roadmaps for key infrastructure components

GIS Workgroup: 2025 Goals Infrastructure

- Roadmap for GAIA
- Roadmap for vocabulary
- Roadmap for cataloging
- Roadmap for geocoding
- Roadmap for containerization

GIS Workgroup: Use cases

- Climate and HIV mortality in Africa (Inspire)
- Temperature and health (Boston area test case for vocab validation)
- SDoH and intensive care (Bridge2AI)
- Geocoding accuracy (CLAD)
- Anaphalaxis incidence linkage to geospatial exposures (Linying Zhang)
- Highway bufferzone association with pulmonary outcomes
- Various informatics milestones relate to the toolchain

GIS Workgroup: Meeting times

- The primary meeting takes place on Fridays at 10 a.m. Eastern US

OHDSI Workgroup
Objectives and Key Results (OKR)

NLP Workgroup

Hua Xu

NLP Workgroup Purpose

NLP WG exists to promote the use of textual information in electronic health records (EHRs) , to facilitate the generation of evidence for observational studies.

- Develop standard representations for clinical text and NLP output data
- Build methods and tools to facilitate textual data processing
- Conduct cross-institutional studies and disseminate best practice of using textual data for real world evidence generation

NLP 2025 Objectives and Key Results

Objective 1: Conduct multi-site clinical studies that utilize both structured and textual data

Key results

1. Characterizing the Anticancer Treatment Trajectory and Pattern in Patients Receiving Chemotherapy (Oncology) – annotation guideline development
2. Predictors of diagnostic transition from major depressive disorder to bipolar disorder: a retrospective observational network study (Psychiatry) – revising the protocol
3. Social Determinants of Health and Treatment Outcomes in Type 2 Diabetes: A Multi-Site Analysis of LEGEND-T2DM study – finalizing SDoH factors and subset of Treatment-Comparator-Outcome pairs

Objective 2: Open source LLMs for information extraction from clinical notes

Key results

1. Development of Kiwi - An LLM-based Clinical Information Extraction System
2. Expanding Kiwi for open-source community development

Objective 3: Knowledge dissemination

Key results

1. Monthly presentations on NLP advances (~ 30 attendees on average in 2024)
2. Book of OHDSI – NLP Chapter Textbook -> Cookbook

OHDSI Medical Device WG - Device ID Data subgroup

Subgroup Leads: Asiyah Lin

- **Year 2025 OKR: Deep dive into OHDSI vocab – device & procedure**
  – Complete the medical device terminology manuscript and submit for publication
  – Establish the medical device branch in OHDSI device vocab.

- **Achieved in 2024**
  – OHDSI annual symposium poster
  – Deepened collaboration with Korea group (Seng Chan You et al.) and Vocab WG (Alex Davydov, Oleg Zhuk)
  – Manuscript drafted (led by Seojeong Shin et al.)

OHDSI Medical Device WG
- Device-Generated Data subgroup
Subgroup Leads: Andrew Williams, Manlik Kwong

- **Year 2025 OKR:**
  - Develop standard strategy for managing and representing features waveform and other device-generated data.

- **Achieved in 2024**
  - Clarify OMOP Standard concept coverage gaps for features from 12-lead ECG Data and ICU monitor data
  - Demonstrate the strategy for supporting OHDSI standardized analytics across integrated EHR and waveform/"numerics" data

OHDSI Medical Device WG
- Device Adverse Event subgroup
Subgroup Leads: Michael Matheny

- **Year 2025 OKR:**

  Develop plan for comparative effectiveness network study based on OHDSI site data availability & interest

- **Achieved in 2024**
  - Engaged Korea group for collaboration
  - Established the VA and Vanderbilt's capacity for medical device RWE research

What have we done in 2024?

Goal: Enabling Observational Cancer Research

- Step 1.
  - Reviewed the Oncology use case at the OHDSI European symposium
  - Identified the use case requirement and surveyed 26 data partners

	Base Dx	Metastasis	Stage	Grade	Lymph nodes	Others (specify)	-Omics	Regimens	Radiation	Surgery	Extent	Dynamic	Episode of care	Death
Use case requirement	0.93	0.57	0.66	0.13	0	0	0.38	0.46	0.16	0.08	0.11	0.39	0.1	0.56
Vocab readiness	1	1	1	1	0.5	0.5	1	1	0.3	0.5	0.9	0.9	1	1
Model readiness	1	1	1	1	1	1	1	1	0.1	1	1	1	1	1
Available data/algorithm	0.77	0.65	0.79	0.69	0.48	0.58	0.40	0.69	0.50	0.62	0.46	0.35	0.31	0.69
Data Partners with data	20	17	20.5	18	12.5	15	10.5	18	13	16	12	9	8	18

- Step 2. Systematically assess the data readiness for oncology evidence generation

Oncology WG in 2025

Goal: Enabling Observational Cancer Research

Community support and collaboration	High quality oncology OHDSI data network	Evidence generation
1. Oncology wiki update 2. Oncology chapter in the book of OHDSI	1. Oncology data readiness assessment 2. Fixing the impediments 3. Use case driven vocab improvement	1. Guideline driven evidence generation 2. Oncology WG studies 3. Regular use case repo update

Themis working group

2025 OKRs

Themis Mission & Ethos

The goal of Themis is to provide conventions on how source data should be standardized to the OMOP CDM to support the OHDSI community to generate the evidence that promotes better health decisions and better care. When there is ambiguity on how data should be inserted into the CDM, Themis will examine the issue, create a convention and document it.

We follow the FAIR principles: Findable, Accessible, Interoperable and Reusable. *FAIRR - reproducible*

Themis makes decisions for the good of the whole community. We must compromise. We can always revisit and modify the convention. Don't let perfect be the enemy of great. And interoperability between different OMOP CDMs is great!

Themis 2024 accomplishments

✓ Establish a formal project management process

✓ Establish a repository for Themis conventions

2025 Objectives

Objectives:

1. Have one central location for OMOP CDM conventions

2. Succinct list of active issues

Objective 1 & key results

Objective #1: Have one central location for OMOP CDM conventions

Key results: Incorporate resources from other OHDSI standards into Themis documentation

❖ The Themis convention library will contain or link to formal CDM expansions

❖ The Themis convention library will link to domain specific WG documenatation

Objective 2 & key results

Objective #2: Succinct list of active issues

Key results: Clean up current GitHub issues

- ❖ Archive
- ❖ De-duplicate

Themis working group details

- ❖ Located in MS Teams

- ❖ Meetings: 1st & 3rd Thursday at 10 am Eastern Time

- ❖ All are welcome!

- ❖ #JoinTheJourney

CDM SURVEY
SUB-WORK GROUP

MISSION STATEMENT

The CDM Survey Sub-Workgroup is a collaborative effort to unlock the potential of survey data within the Observational Health Data Sciences and Informatics (OHDSI) framework. We aim to develop a standardized approach for integrating survey data into the OMOP Common Data Model (CDM). This will be achieved through the development of standards, tools, and best practices to transform survey questions and responses into the CDM format. This, in turn, will empower researchers to conduct more robust analyses across diverse datasets, ultimately leading to richer insights and improved health outcomes.

OBJECTIVES AND KEY RESULTS 2024

✓ Establish the CDM Survey Subgroup
✓ Landscape Assessment
➢ Development and Testing – use cases and value proposition
❑ Find and Apply for Future Support

ESTABLISH STANDARDIZED MAPPING FOR HIGH-USE CLINICAL SURVEYS

- **Key Results**

  - Identify 3 to 5 high-use clinical surveys (e.g., PHQ-9, GAD-7, Asthma Control Test, SF-36, PROMIS)

  - Develop standardized mapping guidelines for each of these identified surveys

  - Collaborate with the OMOP Vocabulary Working Group to develop necessary vocabulary elements for these surveys in OMOP CDM where needed

  - Publish these standardized mappings on the OHDSI GitHub, ensuring accessibility for the community

ENHANCE COMMUNITY ENGAGEMENT AND CONTRIBUTION

- **Key Result**

  - Create a repository for survey mapping contributions from the community on the OHDSI GitHub

  - Host a webinar or workshop to discuss progress, share best practices, and gather feedback from the community

  - Develop and distribute a guide on how community members can contribute their survey mappings and experiences

FOSTER COLLABORATION WITH OTHER RELEVANT GROUPS AND INITIATIVES

- **Key Results**
  - Establish regular communication and joint meetings with the OMOP Vocabulary Working Group to address vocabulary needs for surveys
  - Initiate collaborations with groups such as the PhenX Toolkit community, HL7 Behavioral Health Project Group, Psychiatry Workgroup, etc. to align efforts and share resources
  - Present the workgroup's progress and findings at relevant conferences and community calls to raise awareness and gain insights

DEVELOP AND IMPLEMENT MAPPING TOOLS AND RESOURCES

- **Key Results**

  - Identify and evaluate existing tools for mapping survey data

  - Develop a user-friendly tool or set of tools that facilitate the mapping of survey data to OMOP

  - Pilot the tools with at least three different survey datasets and gather feedback for improvements

  - Document and publish a user guide for the tools, including case studies from the pilot

SECURE FUNDING AND RESOURCES FOR SUSTAINED EFFORT

- **Key Result**

  - Identify potential funding sources and grant opportunities to support the workgroup's initiatives

  - Develop and submit grant proposals to secure funding

  - Establish partnerships with academic institutions and industry stakeholders to leverage additional resources and expertise

Nicole Gerlanc, PhD

Data Analyst Lead, Connect Study

Trans-Divisional Research Program

Division of Cancer Epidemiology and Genetics

National Cancer Institute

Email: nicole.gerlanc@nih.gov

CDM Survey Subgroup Wiki https://github.com/OHDSI/CdmSurveySubWg/wiki