

The Possibilities and Challenges of Using CDEs in Making Data AI-Ready and the Future of AI in Achieving Data Interoperability

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SHILEY EYE INSTITUTE
UC SAN DIEGO

The Viterbi Family
Department of Ophthalmology

Disclosures

- National Institutes of Health
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 - OT2OD032644
 - R03EY035824
- Heed Foundation
- The Glaucoma Foundation
- Research to Prevent Blindness
- Optomed (equipment)
- Topcon (equipment; consultant)



Overview

- Using CDEs to make data AI-ready
- Using AI to develop CDEs
- Current efforts and challenges



Why are CDEs and data standards important?

- Clinical interoperability
- Data aggregation / harmonization
- Data sharing

- FAIR = Findable, Accessible, Interoperable, Reusable

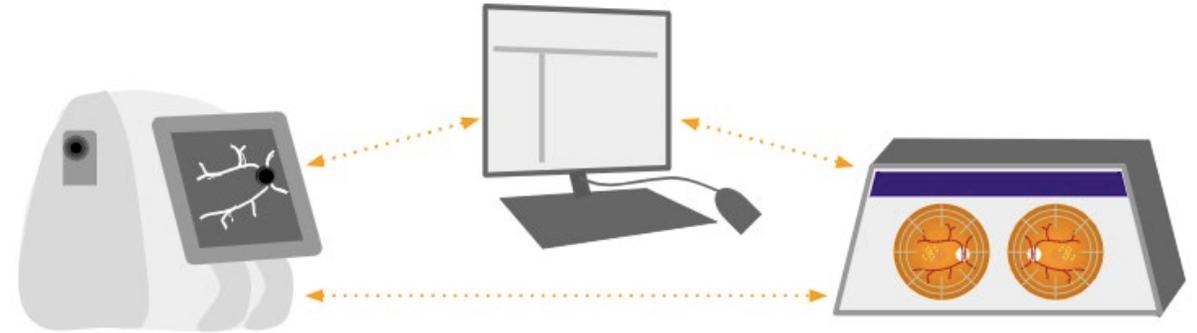
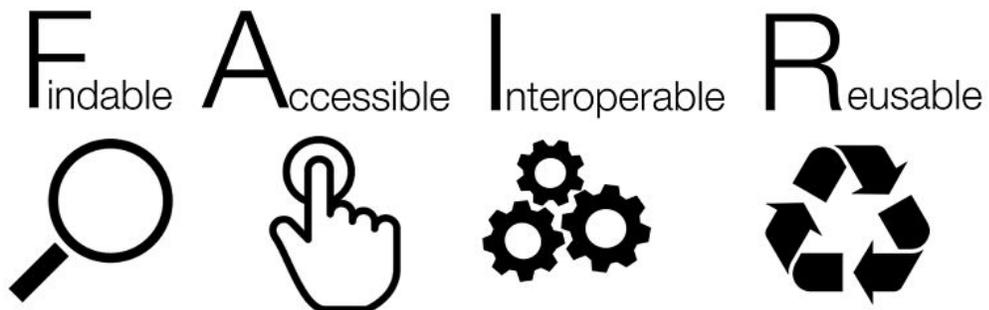
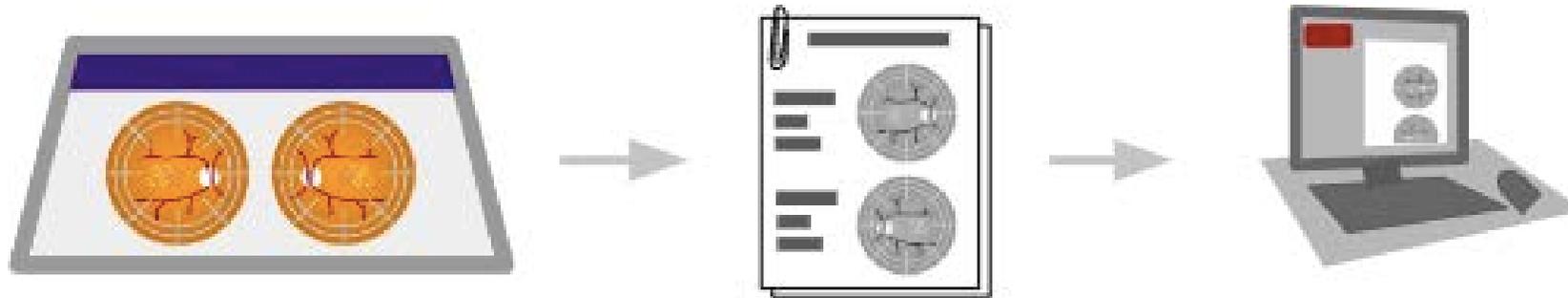


Image credit: Areeba Abid



Clinical Interoperability

Without interoperability standards, high quality data is lost in translation between systems.



1. Device collects data and displays it on proprietary visualization software

2. The only way to extract the data from the machine is through low-resolution formats, like printouts

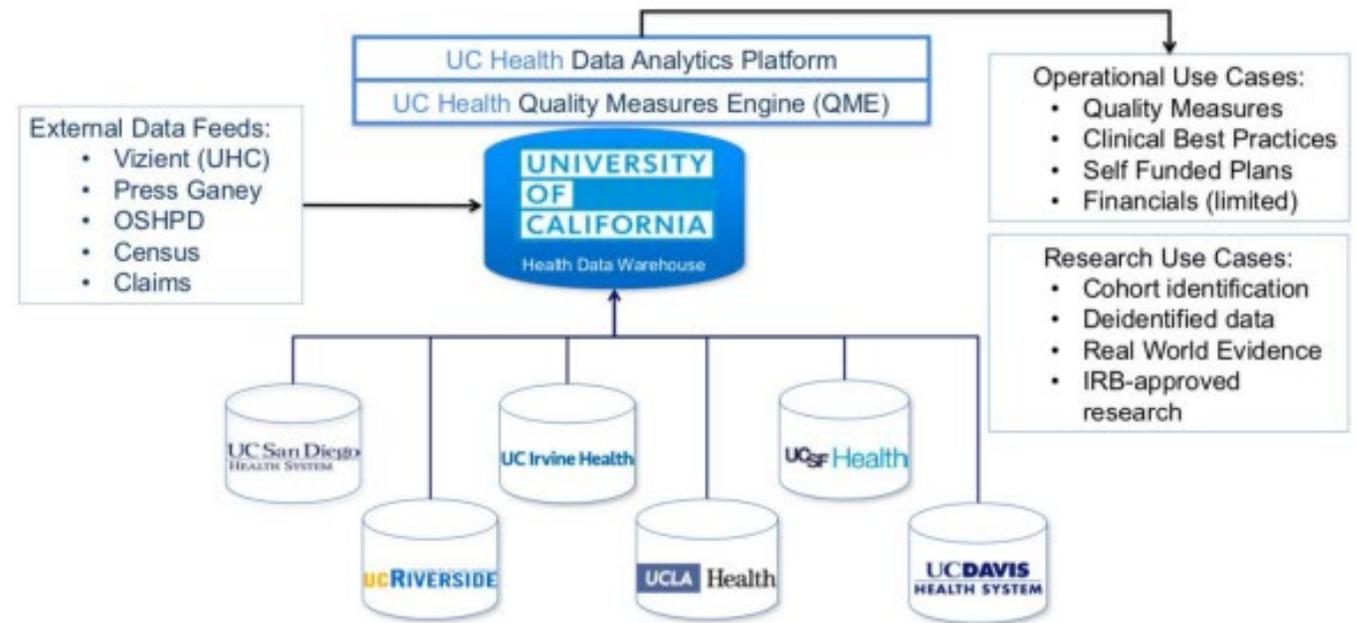
3. Data is uploaded to other systems, but lacks the interactivity and richness of the original data

Image credit: Areeba Abid



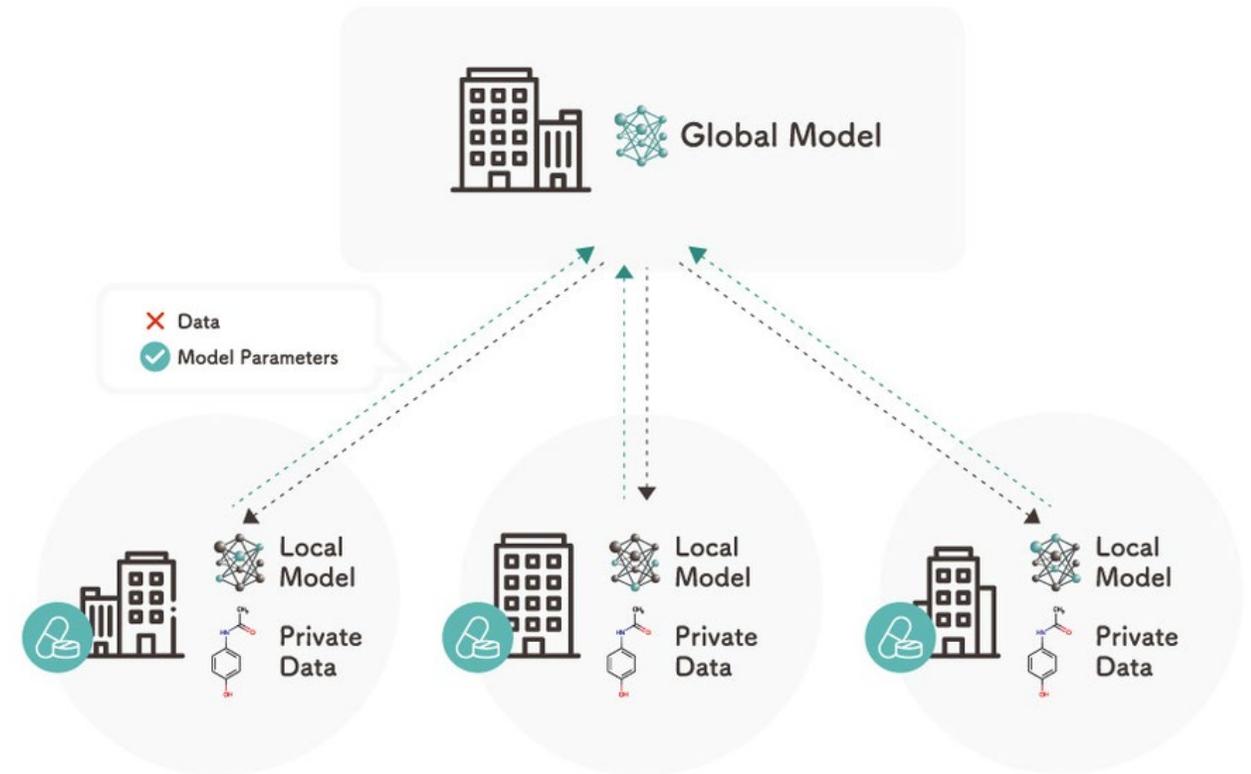
Data Harmonization

- Sufficiently powered research often requires **large sample sizes**
- Research on diverse populations also necessitates **analyzing data from diverse data sources**
- Data standards are needed to **harmonize data into a common data model or shared format** to allow aggregation



Data Harmonization

- Even in the absence of direct data sharing/aggregation, we still need standards to harmonize data for **distributed/federated learning**
 - Allows analyses to be conducted across diverse populations while maintaining data privacy



Examples of “misses” where data standards/CDEs would have been helpful

- Project examining telehealth for pediatric ophthalmology – query from UCSF failed at OHSU even though both institutions used the same EHR vendor
- UCI and UCSD share an instance of the same EHR system (same vendor, same installation) but have different codes for surgery tracking – analyses of OR-related time metrics could not be replicated
- The above demonstrate the need for uniform/consistent data naming and storage (even when the same EHR vendor is used!)



Efforts in ophthalmology to develop CDEs

- Bridge2AI / AI-READI (NIH Common Fund dataset)
- OHDSI/OMOP Workgroup in Eye Care and Vision Research



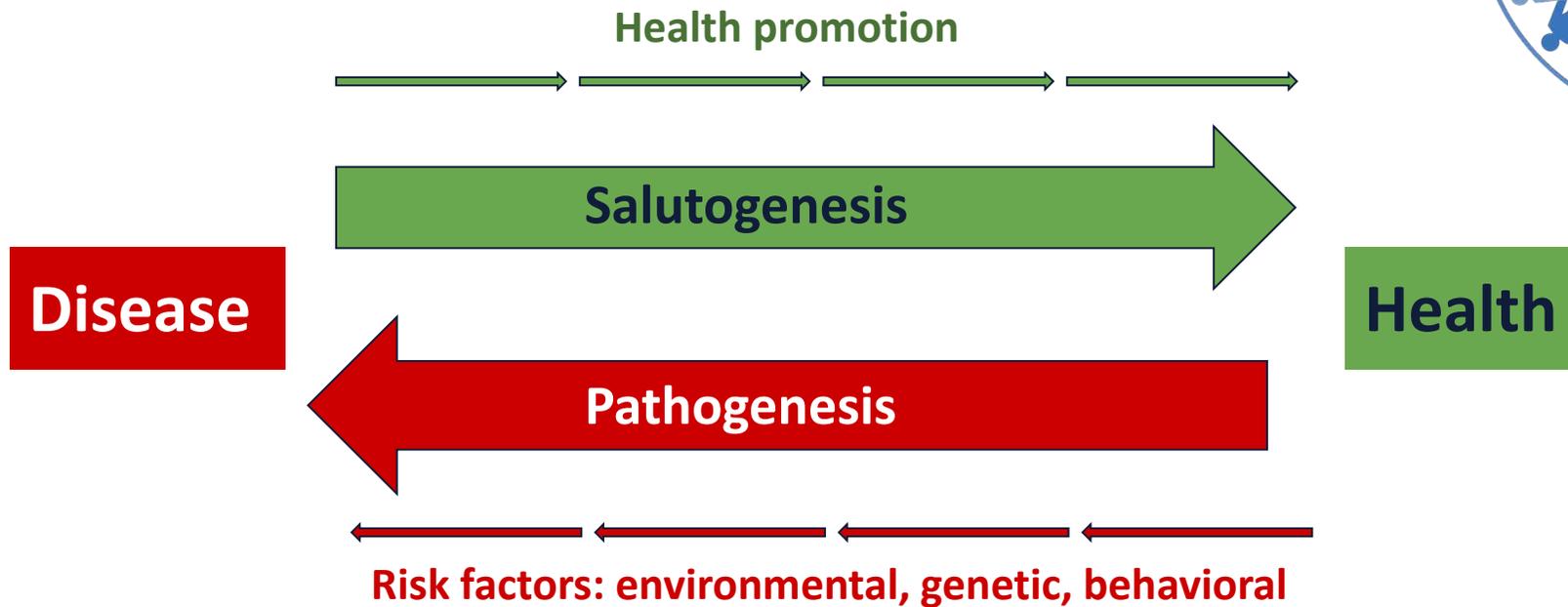
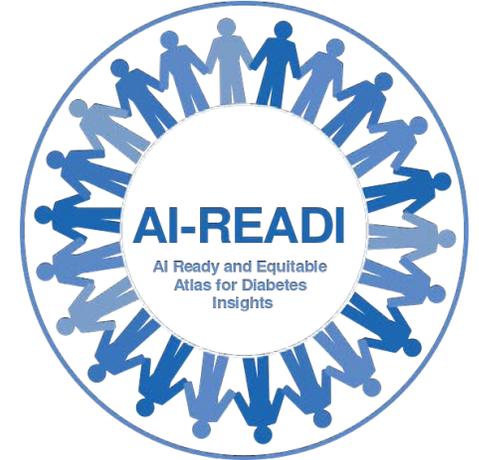
National Institutes of Health (NIH) Bridge2AI Consortium

- Generating **new flagship biomedical and behavioral data sets** that are ethically sourced, trustworthy, well-defined, and accessible
- Developing **software and standards** to unify data attributes across multiple data sources and across data types
- Creating **automated tools to accelerate the creation of FAIR** (Findable, Accessible, Interoperable, and Reusable) and ethically sourced data sets
- Providing resources to disseminate data, ethical principles, tools, and best practices
- Creating **training materials and activities for workforce development** that bridges the AI, biomedical, and behavioral research communities



AI-READI (AI Ready and Equitable Atlas for Diabetes Insights)

- Data Generation Project part of a large US National Institutes of Health (NIH) initiative called “Bridge2AI”
- Goal: To create a multidimensional, ethically-sourced dataset in diverse people for studying salutogenesis in Type 2 diabetes



AI-READI



AI-READI

Continuous Glucose Monitoring



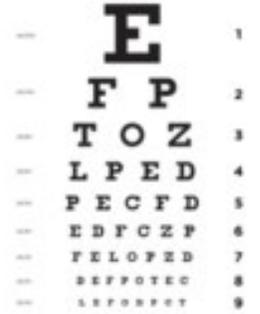
Activity/Heart Rate Monitoring



Surveys



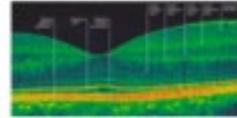
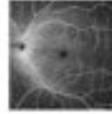
Visual Function



Ophthalmologic Imaging



Fundus
Photography
OCT
OCTA
FLIO



Open Source Data

Cognition



Genetics + Banking

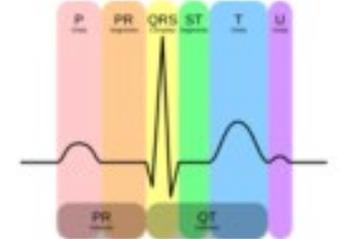


Depression

Environmental Sensing



EKG



Bloodwork/Urine



Medical History



Demographics/ Vitals



Data standards in AI-READI

Module Members

Meet the people behind the scenes who make it all happen.



Aaron Lee

C. Dan and Irene Hunter Endowed
Professorship



Christopher Chute

Professor and CRO



Julia Owen

Program Manager



Qilu Yu

Biostatistician



Stephanie Hong

Senior Healthcare Informatics
Analyst



- Strong emphasis on standardizing all data elements
- Alignment with FAIR Data Principles
- Using existing standards where available
- Developing new standards for those data elements without existing representation
- Healthsheets metadata
- Data documentation/user guides



OMOP Eye Care and Vision Research Workgroup Goals

- Advance **representation of ophthalmic data elements** in OMOP and source vocabularies
 - General, cross-specialty data elements (e.g., visual acuity)
 - Also subspecialty domains
 - Glaucoma
 - Retina
 - Pediatrics
 - Uveitis
- Implement **transformations of source data to OMOP** for ophthalmology
- Develop a **distributed data network** with representation of diverse communities



Gap Analysis of Eye Exam Elements in the EHR

The screenshot displays the Epic EHR interface for a patient named Armando. The main content area shows an eye exam form with the following sections:

- External:** Includes fields for Right and Left eyes, with checkboxes for 'Ext' and 'nl'.
- Slit Lamp:** Includes fields for Right and Left eyes, with checkboxes for 'L/L', 'C/S', 'Cornea', 'AC', 'Iris', 'Lens', and 'Vitreous'. A pink box highlights the 'AC' field, and an arrow points to a brown box labeled "Fields".
- Fundus:** Includes fields for Right and Left eyes, with checkboxes for 'Disc', 'C/D Ratio', and 'Macula'. An arrow points to a brown box labeled "Fields".

On the right side, there is a detailed section for the 'Anterior Chamber Right Eye' with various findings and their corresponding values:

- Cell: 1+, 2+, 3+, 4+ (None)
- Fibrin: (None)
- Flare: (None)
- Flat: (None)
- Gas bubble: (None)
- HypHEMA: Layered, Total (None)
- Narrow angle: (None)
- Shallow: (None)
- Tube: K touch, Iris touch (None)
- Vitreous strands: (None)

Annotations include a brown box labeled "Values" pointing to the value selection buttons (1+, 2+, 3+, 4+) for Cell and Flare, and another brown box labeled "Fields" pointing to the checkboxes for AC and Disc.



1 Mapping to OMOP

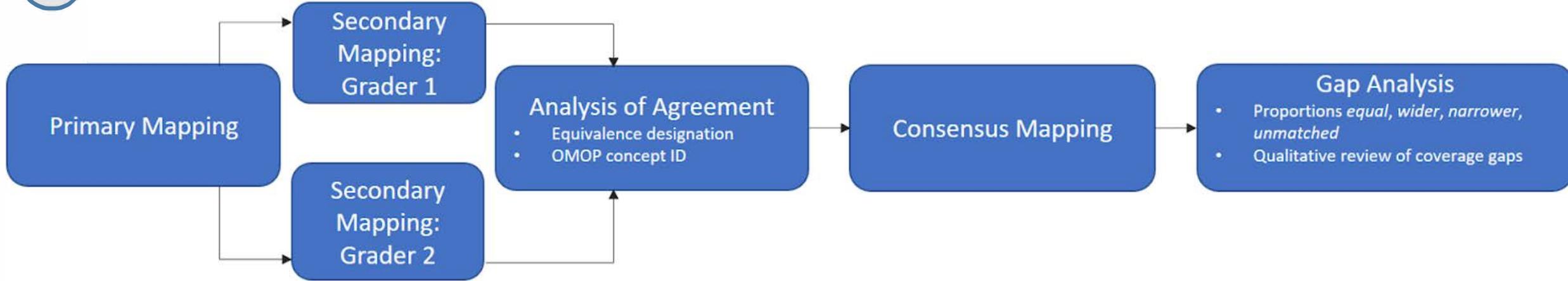
A

B

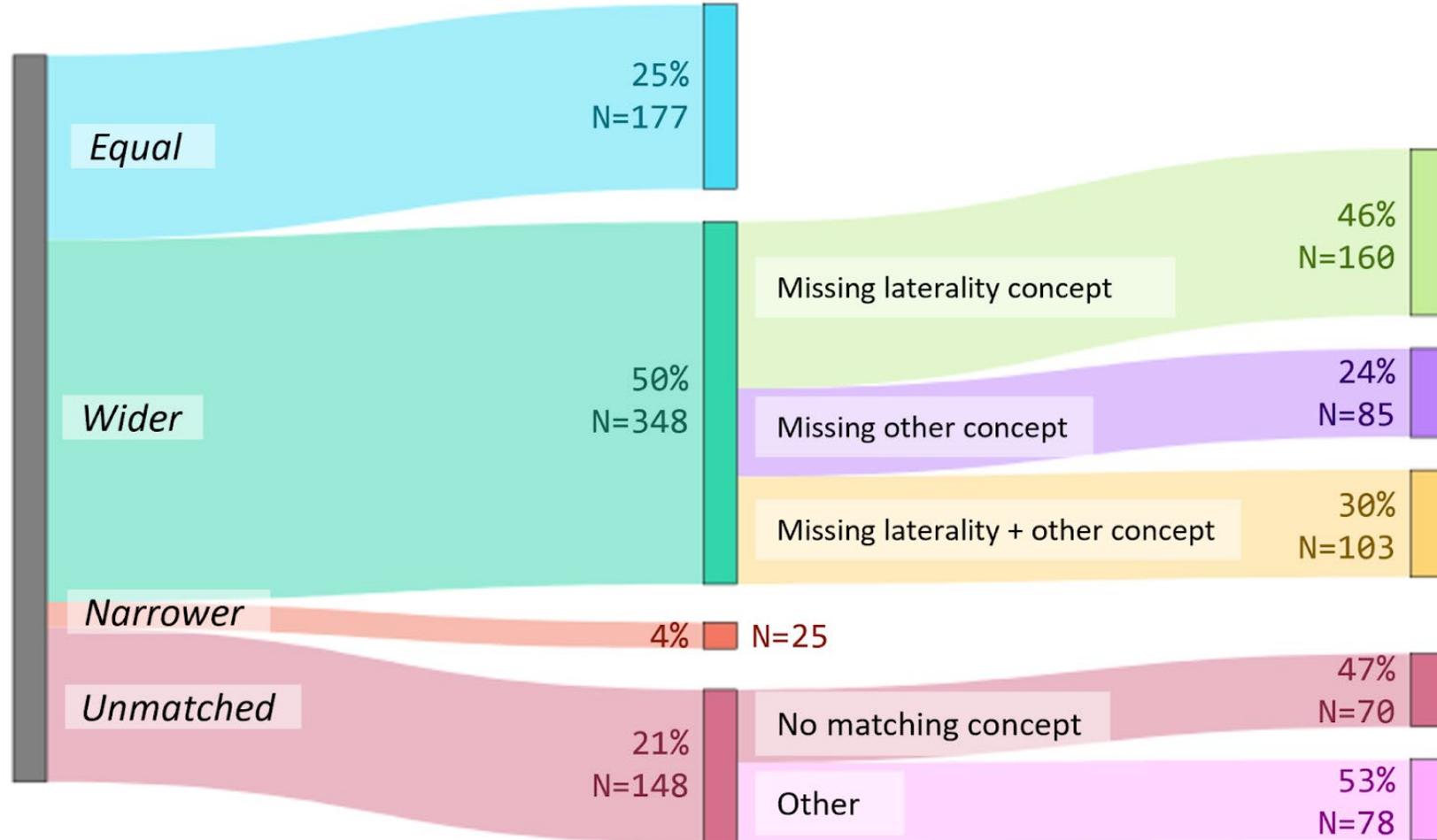
C

Source EHR Data Element	Target (OMOP) Concept Name	OMOP Concept ID	Vocab	Equivalence	Explanation
Tonometry Right Eye	Intraocular pressure of right eye	44813337	SNOMED	Equal	
Visual Acuity, Right Eye Distance CC	Corrected visual acuity	4288368	SNOMED	Wider	Missing laterality, missing concept - does not include "distance" specification
Right Eye Lids: Hordeolum - Upper	Hordeolum internum of upper eyelid of right eye	762357	SNOMED	Narrower	EHR source code does not specify "internal"
Extraocular Movements: Right Eye Superior	NA	NA	NA	Unmatched	No matching concept

2 Tiered Review & Gap Analysis



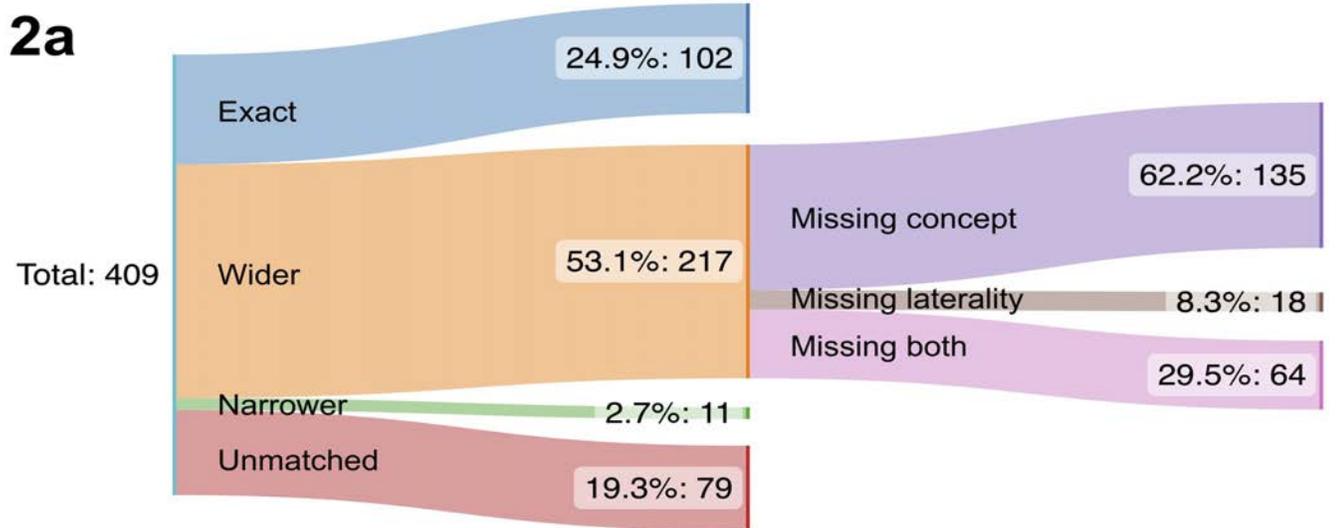
Gaps in representation of ophthalmic data elements - Epic



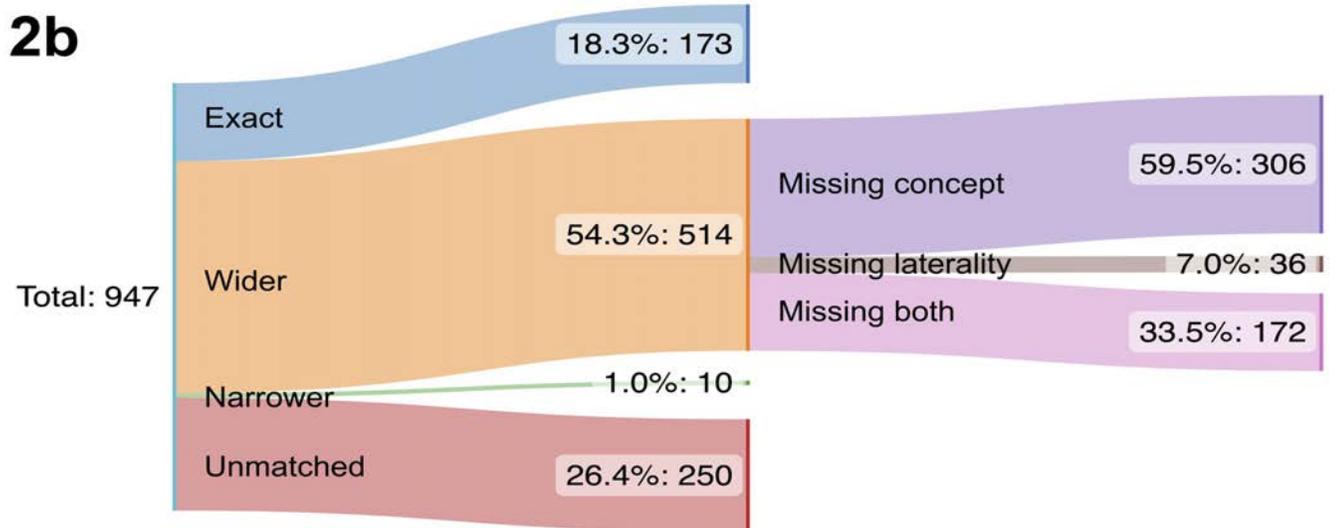
Gaps in representation of ophthalmic data elements - Cerner

Sankey diagrams for match type breakdown for (a) default Cerner module and (b) local Cerner module

2a



2b



	Area of Conceptual Gap	
Component of Ophthalmic Examination	Partial Matches in OMOP (designated <i>wider</i> with missing concepts)	No Matches in OMOP (designated <i>unmatched</i>)
Visual Acuity (VA)	Type of chart used for VA testing: Snellen - Linear Snellen - Single Snellen - Blocked	Type of chart used for VA testing: Numbers - Linear Numbers - Single Numbers - Blocked
Intraocular pressure (IOP)	Method of measurement: Tonopen Palpation	Target IOP right eye Maximum IOP right eye
Gonioscopy	Grading of gonioscopic findings (e.g. wide open angles)	Type of mirror used for gonioscopy (e.g., Sussmann, four mirror)
Anterior slit lamp examination	Exam findings such as cystic bleb	Exam findings such as glaucoma drainage device implant
Fundoscopy examination	Exam findings such as size, characteristic, and location of drusen	Exam findings such as geographic atrophy, lacquer crack, retinal pigment epithelium mottling, normal right macula



Advancing toward a common data model in ophthalmology: gap analysis of general eye examination concepts to standard OMOP concepts

Cindy X. Cai, MD, MS   • William Halfpenny, MB, BChir, MEng  • Michael V. Boland, MD, PhD • Harold P. Lehmann, MD, PhD • Michelle Hribar, PhD • Kerry E. Goetz, MS • Sally L. Baxter, MD, MSc • [Show less](#) • [Show footnotes](#)

[Open Access](#) • Published: August 25, 2023 • DOI: <https://doi.org/10.1016/j.xops.2023.100391>

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Ocular Health and National Data Standards: A Case for Including Visual Acuity in the United States Core Data for Interoperability (USCDI)

Sally L. Baxter, MD, MSc   • Amberlynn A. Reed, MPH • April Maa, MD • Michael V. Boland, MD, PhD • Durga S. Borkar, MD, MMCI • Eric N. Brown, MD, PhD • Flora Lum, MD • Kerry E. Goetz, MS • [Show less](#)

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Data Standards in Eye Care

Article initiated by: [Sally L. Baxter, MD, MSc](#)

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OMOP Eye Care and Vision Research Workgroup: How to Join



The screenshot shows the OHDSI website header with the logo and navigation menu. The 'Workgroups' menu item is highlighted. Below the navigation is a section titled 'OHDSI Workgroups' with a dark blue background. The text in this section describes OHDSI's mission and the purpose of the workgroups. A call to action is provided: 'See an area where you want to contribute? Please Join The Journey!'. Below this is a section titled 'Join Our Workgroup Efforts!' with two buttons: 'Join A Workgroup' and 'Weekly Workgroup Meeting Schedule'. At the bottom, there is a section titled 'Get To Know The OHDSI Workgroups' with a small paragraph of text.

OHDSI
OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS

Who We Are ▾ Updates & News ▾ Standards Software Tools ▾ Network Studies ▾ Community Forums ▾ Education ▾ New To OHDSI? ▾

Community Calls ▾ Past Events ▾ **Workgroups ▾** Our Journey: Where We Have Been & Where We Are Going (PDF) Community Dashboards ▾

This Week In OHDSI Support & Sponsorship ▾ 2023 OHDSI Events ▾ Github YouTube Twitter LinkedIn Newsletters ▾

OHDSI Workgroups

OHDSI's central mission is to improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care. We work towards that goal in the areas of data standards, methodological research, open-source analytics development, and clinical applications.

Our workgroups present opportunities for all community members to find a home for their talents and passions, and make meaningful contributions. We are always looking for new collaborators. Learn more about these workgroups by checking out this page.

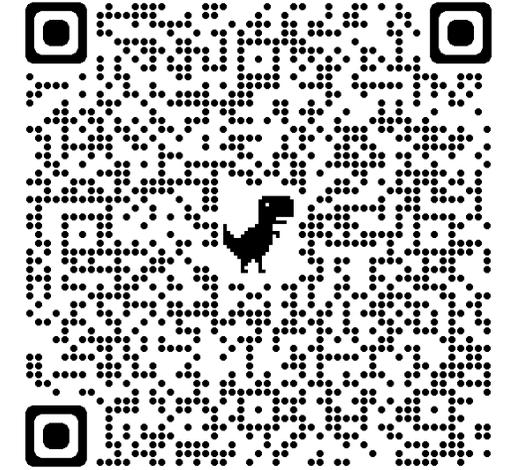
See an area where you want to contribute? Please Join The Journey!

Join Our Workgroup Efforts!

[Join A Workgroup](#) [Weekly Workgroup Meeting Schedule](#)

Get To Know The OHDSI Workgroups

Workgroups present updates on the weekly OHDSI community calls at least one time per year. The most recent update is posted below, as well as their announced objectives and key results for 2023, and the latest number of workgroup members and leads. Please get to know the exciting research happening around the community and [join any workgroups that interest you](#).

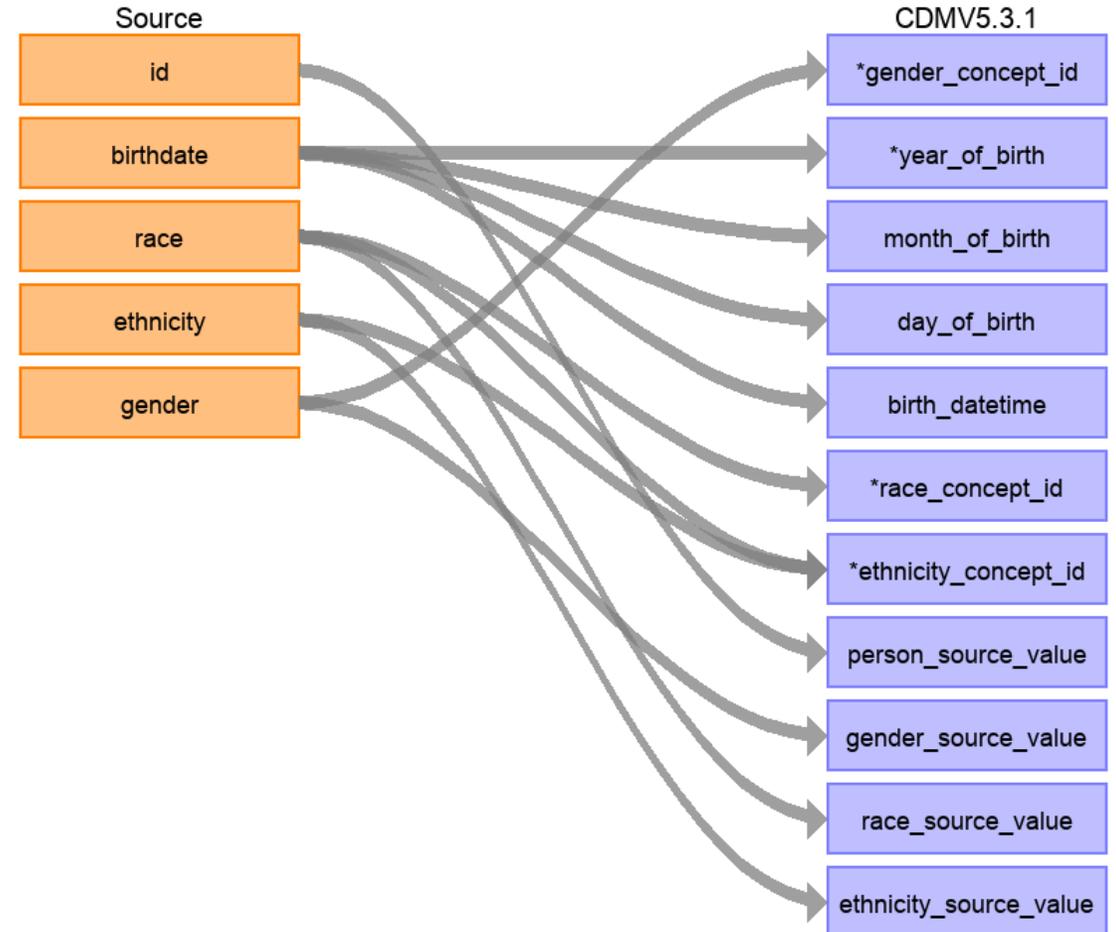


**Sign-up Sheet for
OHDSI Workgroups**



Using AI to develop CDEs

- Very nascent work; not mature research in our field yet
- Mapping efforts have been very **manual and labor-intensive** to date
- We have used existing **tools from OHDSI to semi-automate the process** (e.g. USAGI, RabbitInaHat)
- Currently exploring using AI (LLMs) to help with mappings, ETLs, and generating data documentation/user guides
 - Transparency is a key concern



Current Challenges

- **Lack of standardized representation of concepts related to many areas of ophthalmology**
 - Particularly in eye examination findings (diagnoses and procedures are better represented)
- Even in areas where standards do exist (e.g. visual acuity), **current representations may not account for many of the possible modifiers and their combinations**
- **Lack of standard phenotypes / cohorts**
- **Clinician demand is needed to drive vendor engagement**



Current Challenges

- Developing CDEs often requires **multi-stakeholder engagement and consensus-building**, which can be time-consuming (and can be difficult to coordinate busy clinicians)
- Also reliance on **standards bodies** which have variable bandwidth for engagement
- **Limited IT resources** for transforming data into common data models or standardized formats
 - Lack of strong incentives for subspecialty domains
- Building **long-term sustainability** (largely volunteer effort)



Future Directions



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Data Sources for Evaluating Health Disparities in Ophthalmology

Where We Are and Where We Need to Go

Sally L. Baxter, MD, MSc,^{1,2} Kristen Nwanyanwu, MD, MBA,³ Gary Legault, MD,⁴
Aaron Y. Lee, MD, MSCI⁵

Data provide an opportunity to discover disparities and inequities that may otherwise be unrecognized. Within the American Academy of Ophthalmology (AAO) Task Force on Disparities in Eye Care, the Leveraging Data Sub-task Force was charged with identifying data sources to study health disparities in eye care and to leverage data to advance health equity. We evaluated large data sources to determine their strengths, deficiencies, and relative accessibility in relation to the likelihood of identifying eye care disparities. We highlight the current challenges with these data sources and review key recommendations for improving future sources for studying health disparities in eye care. *Ophthalmology* 2022;129:e146-e149 © 2022 by the American Academy of Ophthalmology

- **Collect more data** from existing sources
- Collect data using **standardized tools and definitions**
 - Enables data sharing
 - Enables federated learning
- **Democratize access** to datasets
- **Ensure trust** in data collection
- Create and fund **new datasets**
- Educate and build a **diverse workforce**



Ongoing Efforts

- AAO Standards Workgroup
- OHDSI OMOP Workgroup in Eye Care & Vision Research
- Ophthalmology FHIR/HL7 Implementation (“Eyes on FHIR”)
- NIH Bridge2AI Initiative
- NEI Data Scholar Program
- NIH Common Data Elements Initiative
- SNOMED Clinical Reference Group in Ophthalmology
- DICOM Working Group 9 (Ophthalmology DICOM workgroup)
- EHR and Imaging Device Vendor Engagement



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- Flora Lum, MD
- AAO Data Standards / Interoperability Workgroup
- OMOP Eye Care & Vision Research Workgroup Members
- Many others!

