# OHDSI Eye Care and Vision Research

ARVO In Person Meeting 5/7/2024

Sign in Sheet: https://tinyurl.com/OHDSI-SignIn



Agenda: https://tinyurl.com/ohdsi-arvo



## Help us cover cost of food!



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## Agenda

- Announcements
- Workgroup overview
- Breakout sessions
- Discussion & next steps

### **THANK YOU!!**

- Aaron and Cecilia Lee for letting us use their space.
- All of you!

### **Announcements**

- Observational Health Data Science and Informatics (OHDSI) Global Symposium is Oct. 22 – 24, 2024 in New Brunswick, NJ
  - Registration is open: <a href="https://www.ohdsi.org/ohdsi2024/">https://www.ohdsi.org/ohdsi2024/</a>
  - Abstracts due June 21, 2024
- Eye Care and Vision Research workgroup virtual meetings are monthly and alternate between Mondays at 4:00 pm ET and Tuesday at 6:00 pm ET
  - Poll for setting new meeting time
  - Changing format of meeting
  - Cancel next meeting on April 14?

Poll for new meeting time. Note: all times are Eastern Time



## **ECAVR Meetings: Proposed Changes**

- Have a theme/topic for each meeting
  - Subgroups
  - External speakers/collaborators
  - Brainstorming sessions
- Post summaries, slides, recordings (if possible) on github site
  - Available to all—not just workgroup members
  - Encourage asynchronous participation/collaboration
- Soliciting ideas for themes/topics
  - What do you want to discuss or learn?
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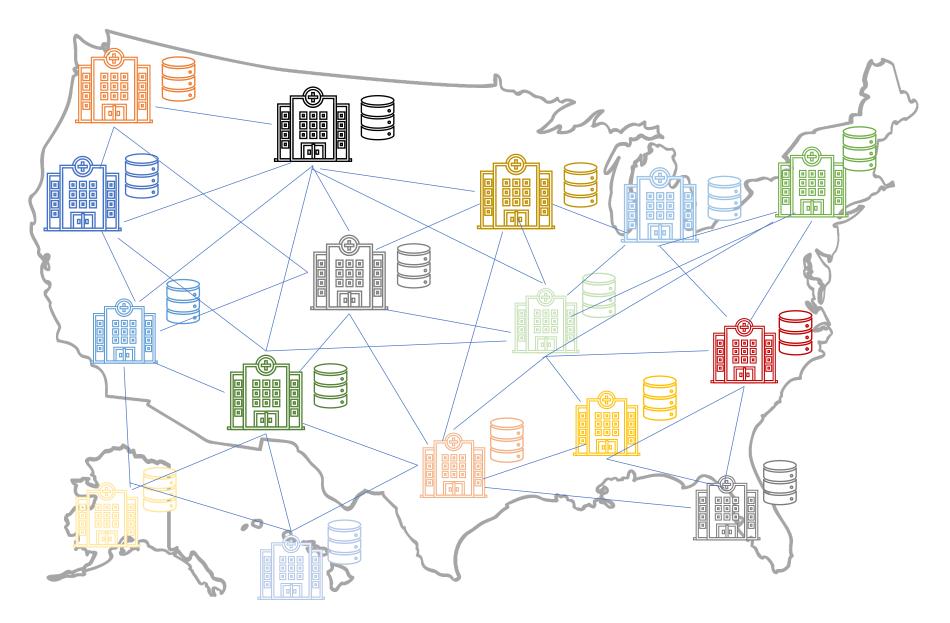
### **ECAVR Overview**

- Started in spring 2022 from AAO Data Standards workgroup
  - Missing eye exam data in All of Us dataset
  - Ophthalmic data concepts missing in OMOP common data model and standardized terminologies
  - Co-leaders: Kerry Goetz, Sally Baxter, and Michelle Hribar
- Part of the Observational Health Data Science (OHDSI) Community focusing on standardizing and using observational health data in research
  - EHR data, claims data
  - Imaging

## Lots of Data, but Siloed



### **How Do We Talk to Each Other?**



### **Data Harmonization & Integration**

- Data standardization is key
  - Multiple standardized terminologies in biomedicine
  - E.g. RxNorm for medications, CPT codes for procedures, etc.
- Common data models standardize the storage schema and conventions for data from diverse sources
- Several common data models in the biomedical space
  - PCORnet
  - i2b2
  - OMOP

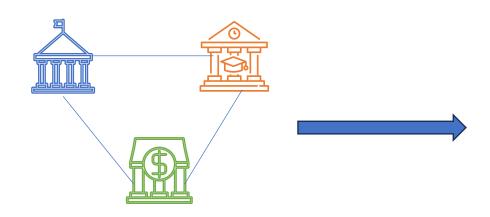






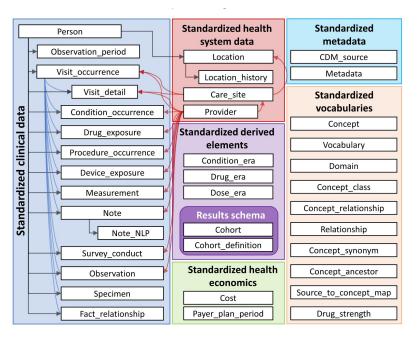
**OMOP: Observable Medical Outcomes** 

**Partnership** 



#### Public – private partnership (2009-2014)

- Goal: study effects of medical products
- Use observational health data
  - Claims data
  - Electronic health record data (EHR)



#### OMOP Common Data Model (CDM)

- CDM standardized structure, content, and semantics of observational data
- Used in NIH data generation projects such as All of Us, N3C, Bridge2Al

## OHDSI: Observational Health Data Sciences and Informatics

- Open source community aims to improve health by collaboratively generating evidence for better health decisions and care
- Maintains/updates OMOP CDM
- Develops/maintains tools for appropriate use of observational health data
- Has supported thousands of studies



# OHDSI By The Numbers 3,266 collaborators 80 countries 21 time zones 6 continents

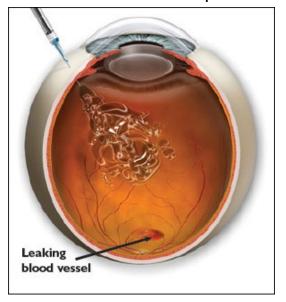
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## Pilot Study (OHDSI SOS Challenge): Intravitreal anti-VEGF and Kidney Failure

- Is the risk of kidney failure associated with intravitreal anti-VEGF exposure in patients with blinding diseases (DR/DME, AMD, VO) different among patients who receive ranibizumab, aflibercept, and bevacizumab?
  - Ranibizumab has much shorter serum elimination (half-life)



Cindy X. Cai MD, MS Johns Hopkins Univ.

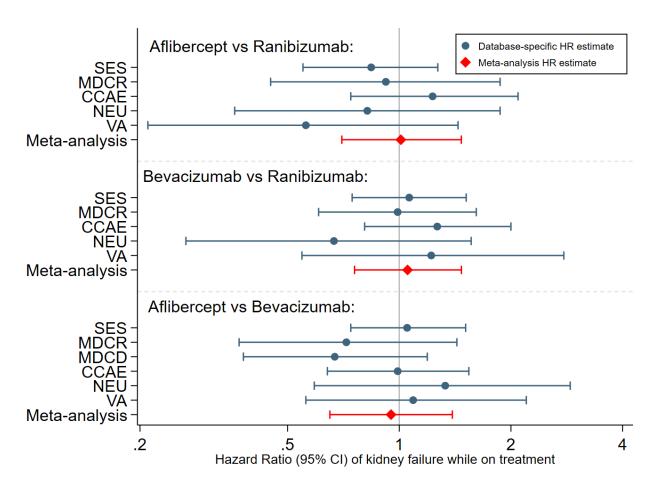


**Question**: Is there evidence for preferentially choosing ranibizumab to lower the risk of kidney failure?

<u>Hypothesis</u>: in pairwise comparisons, lower risk of kidney failure in patients with blinding diseases who are exposed to ranibizumab

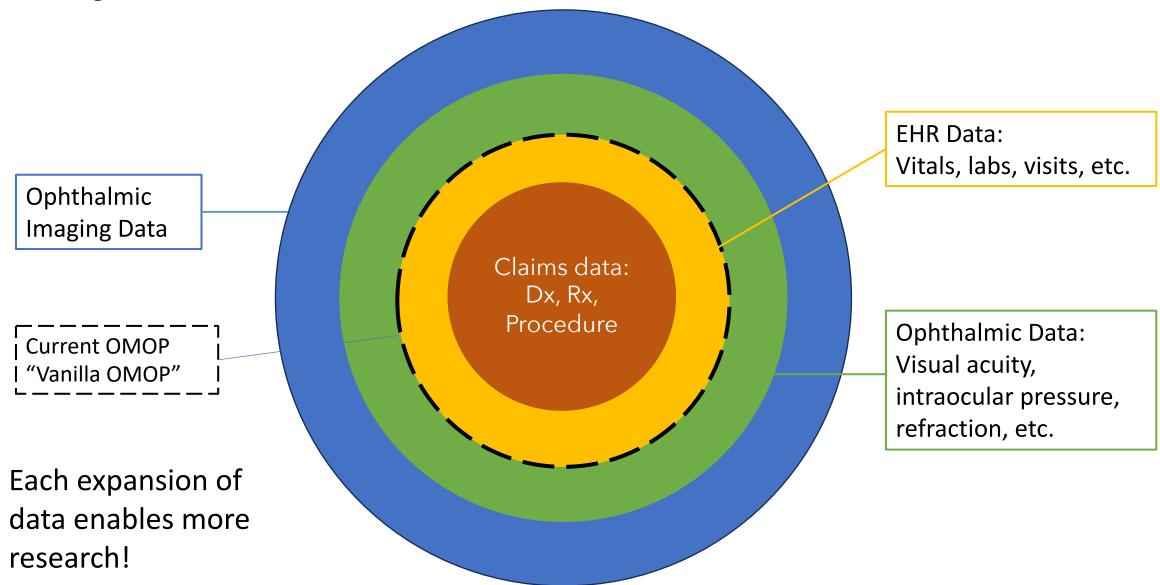
## **Anti-VEGF OHDSI Study: Results**

- 12 databases (6 administrative claims and 6 EHR): 485 million patients
- 6.1 million patients with blinding diseases
  - 37,189 received ranibizumab
  - 39,447 aflibercept
  - 163,611 bevacizumab
  - 1209 kidney failure outcomes
- Standardized incidence proportion of kidney failure: 680 per 100,000 persons
- In all pairwise comparison, the hazard ratio was around 1.0

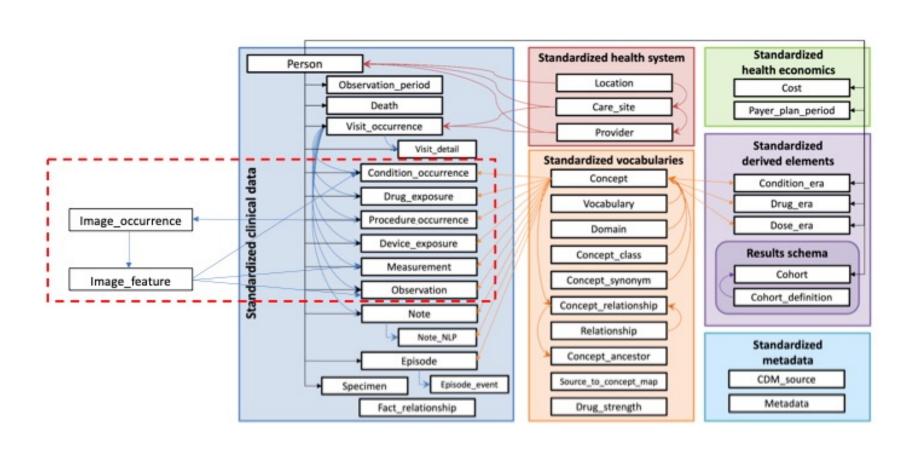


Speed and scale of clinical research projects with data standardization across multiple sites

"Layers" of Data in OMOP



# OHDSI Proposed Imaging Integration Reference Standard



## **Challenges for Ophthalmic Data**

#### EHR Data

- Data is named and stored differently in different EHRs/institutions
- Ophthalmic data is not completely represented in standardized terminologies or OMOP
- Free text field needs processing to extract values
- Data may only be entered in notes, which requires natural language processing to extract

#### Imaging

- Most ophthalmic imaging is not standardized/fully compliant with the DICOM standard
- Volumetric scans are large and difficult to share
- Tools are needed to use this data in a distributed network

# OHDSI Eye Care and Vision Research Workgroup

- Multidisciplinary group of researchers in eye care and vision research
  - > 140 Ophthalmologists, optometrists, trainees, data scientists, informaticists
- Working to standardize data
  - Mapping eye exam and imaging metadata to standardized terminologies
  - Adding ophthalmic data & imaging to OMOP
- Standardize use of data
  - Phenotype/cohort definitions
  - Analysis & models
- Goal is to support:
  - Data sharing/interoperability
  - Data harmonization
  - Ophthalmic data in pooled datasets such as All of Us and Bridge2Al
  - A distributed network of high quality ophthalmic EHR data & imaging for research

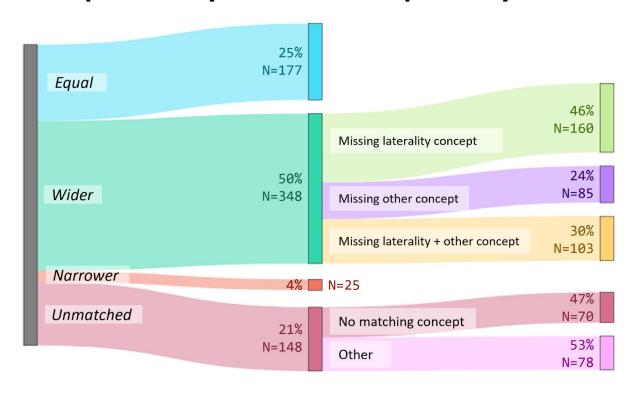
## Workgroup Subgroups

- Retina: Cindy Cai
- Glaucoma: Brian Stagg
- Uveitis: Brian Toy
- Pediatric: Gayathri Srinivasan
- Imaging: Kavi Thakoor
- Implementation (ETL): Will Halfpenny

# First Year Workgroup Accomplishments: Mapping

- Analyzed and mapped > 3700 ophthalmic data elements
- 11 retina condition codes submitted to SNOMED International
- Several glaucoma concepts in discussion with SNOMED
- > 200 visual acuity concepts submitted to LOINC

#### **Epic EHR Eye Exam Concept Analysis**



Cai C.X., Halfpenny W., Boland M.V., Lehmann H.P., Hribar M., Goetz K.E. & Baxter S.L., Advancing toward a common data model in ophthalmology: gap analysis of general eye examination concepts to standard OMOP concepts, Ophthalmology Science (2023), doi:

https://doi.org/10.1016/j.xops.2023.100391.

# First Year Workgroup Accomplishments: Phenotyping

- OHDSI provides tools for defining, using, and publishing patient cohorts or phenotypes
- Our workgroup developed multiple phenotypes:
  - 3 visual impairment
  - 5 diabetic retinopathy
  - 6 uveitis\*
  - 3 new anti-VEGF users\*
  - 1 blinding eye disease\*

ohdsi-studies/
Howoften

Interpretation of the control of the cont

<sup>\*</sup>Submitted to HowOften

# Including Ophthalmic Data in NIH Large Dataset Generation Projects

**Bridge2AI: AI-READI** 

- Collect triple balanced prospective dataset of 4000 diabetic patients
- Working with OHDSI workgroup on adding elements to OMOP
- https://aireadi.org/

#### All of Us Dataset

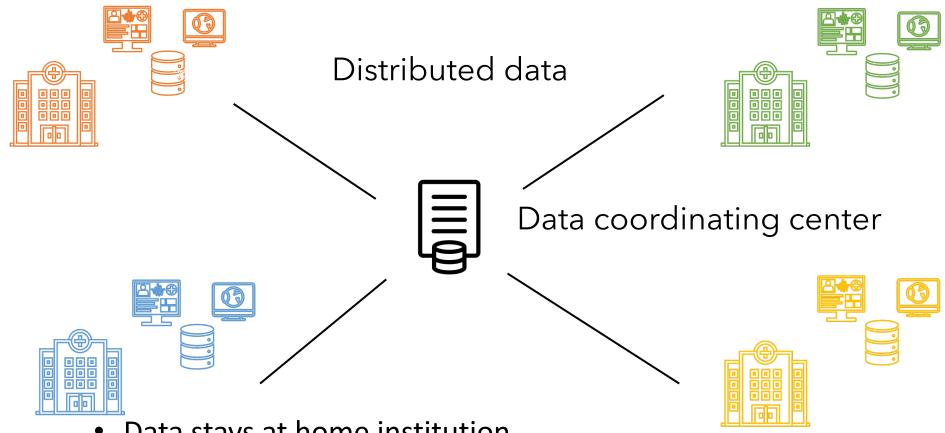
- NEI-NIBIB All of Us Workshop 2023 was initial step towards integrating ocular data & imaging into All of Us
- Proposing a pilot study at 4 sites







## **Goal: Build OHDSI Ophthalmic Data Network**



- Data stays at home institution
  - Avoids legal & privacy challenges of sharing data
  - Data is accessed through tools & federated learning
- Multimodal: Systemic & Ocular EHR data + Ocular imaging

# Potential Use Cases of Standardized Ophthalmic Data

- Extension of clinical trials
- Validation of AI models
- Real world outcomes of treatments
- Systemic risk factors for eye disease and its progression
- Oculomics
- Rare disease studies
- Prevalence of eye disease
- Health care access/equity

## Impact of Data Standardization

- Ophthalmic data & imaging is in data generation projects such as All of Us, Bridge2Al
- Ophthalmic data network allows for discovery beyond clinical trials
- Large, diverse dataset supports the breadth, quality, & reliability of research
- Distributed data network supports FAIR principles & NIH Data Science Strategic Plan
- Data and image standardization improve data interoperability for clinical care, quality measurement, as well as research

### **Get Involved!**

- Join our OHDSI workgroup
- Join the weekly OHDSI community calls

#### **OHDSI Workgroup Page**



www.ohdsi.org

#### **OHDSI Community Calls Page**



### **Breakout Sessions**

- Imaging
- Network studies brainstorming
- Grant & funding planning

## **Imaging**

- Overview of proposed reference standard
- Challenges for implementing standard, using images
  - Consistent pre-processing, segmentation, cropping
  - Harmonization of metadata and measurements
  - Viewing images at different sites
- Opportunities for innovation
  - Tools
  - Infrastructure for federated learning
  - Pilot projects (e.g. putting datasets into standard)
- Guiding use cases

Action items: Pilot project idea, tools needed, initial steps

## **Network Studies Brainstorming**

- Overview of network studies
  - Steps of study
  - Examples of studies
- Brainstorm ideas
  - "Vanilla" OMOP
  - + eye exam data
  - + eye exam data & imaging
- Next steps
  - Phenotypes
  - Identify missing concepts

Action items: List of possible network studies

## **Grant & Funding Planning**

- Funding opportunities
- What would funding allow us to do?
- Who is interested? What institutions?
- Ideas
  - Small size
  - Large size
- Timeline

Action items: Mechanisms, what budget items need funding

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## **FHIR Workshop**

- Hands-on workshop for learning FHIR
- Registration is open for the May 30, 1:00pm EST event at <a href="https://bit.ly/2024-05-fhir-workshop">https://bit.ly/2024-05-fhir-workshop</a>.



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