

Eye Care and Vision Research Workgroup: First Year Update

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Background

Although the OMOP Common Data Model (CDM) has been in existence for over a decade, it does not yet completely represent ophthalmic concepts. As the OMOP CDM has been implemented more widely and used in multiple large-scale databases, such as *All of Us* and N3C(1,2), it has become imperative that the eye care and vision research community address the OMOP CDM. The OHDSI Eye Care and Vision Research Workgroup was formed to advance development and implementation of data standards in eye care research that will support studies using observational data for generating evidence to improve vision outcomes.

Methods

In spring 2022, the OHDSI Eye Care and Vision Research Workgroup was formed under the leadership of Kerry Goetz and Sally Baxter. Michelle Hribar joined as a co-lead in October 2022 with the start of her National Institutes of Health (NIH) DATA Scholar appointment. Initial engagement was facilitated by the existing membership of a data standards working group at the American Academy of Ophthalmology (AAO). The initial goals of the workgroup were to perform a comprehensive mapping analysis of data elements, identify gaps in standardized terminologies, and identify motivating use cases that would prioritize which concepts to add to the OMOP CDM. Subgroups focusing on specific sub-specialties of ophthalmology were formed to allow for concurrent efforts to accomplish mapping tasks. Publications, in person meetings at vision research conferences, presentations, and short courses have been ways the group has disseminated the work and fostered interest in the project. Finally, collaborations both within the OHDSI community and external to it ensured that our work was consistent with OHDSI principles and met the needs of eye care and vision science researchers. These collaborations also allowed us to facilitate trainee involvement.

Results

In the first year, the workgroup met 17 times – usually monthly, with a few biweekly meetings in the spring of 2023. There were three in-person meetings (OHDSI Symposium in October 2022, AAO Annual Meeting in October 2022 and the ARVO Annual Meeting in April 2023), with the rest conducted virtually. The workgroup has 122 members, with approximately 40 regularly attending general workgroup or subgroup meetings. The majority of the active workgroup members were clinician-scientists (ophthalmologists and optometrists), with several informaticians and vision researchers. There were 6 subgroups formed to focus on ophthalmic sub-specialties: retina, glaucoma, pediatrics/strabismus, and uveitis, as well as for developing extract transform and load (ETL) scripts and a phenotype for visual impairment. These subgroups have met monthly. An imaging subgroup is being organized for initiation in

October 2023.

The workgroup and sub-groups were highly productive this past year as shown in the timeline in **Figure 1**.

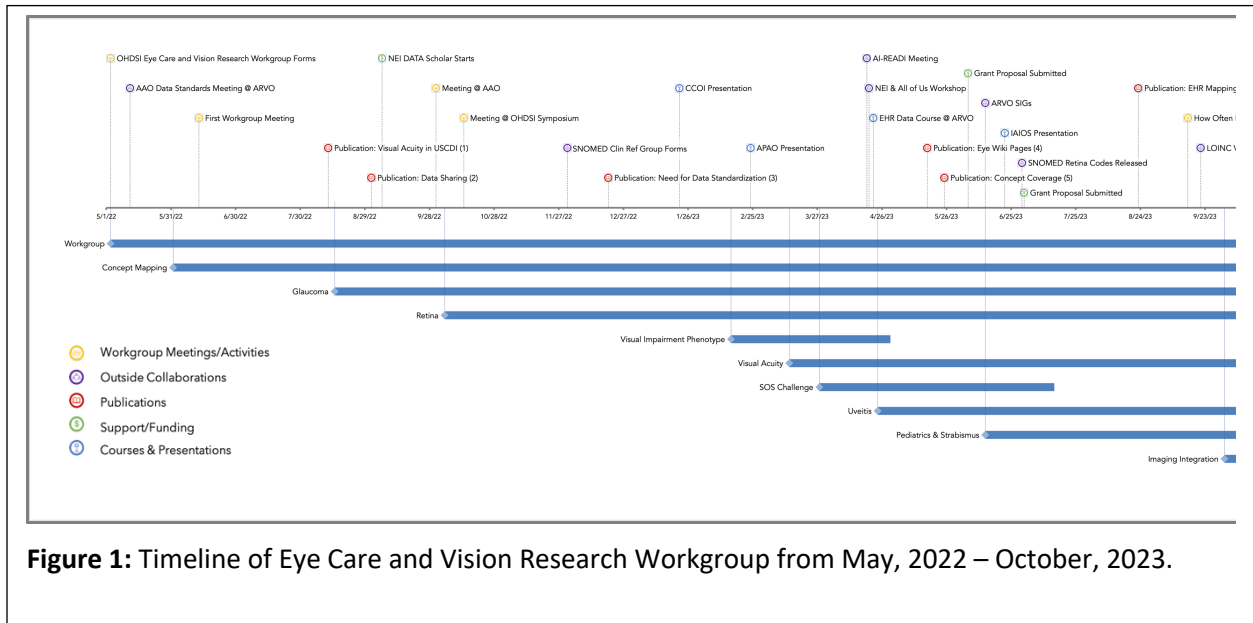
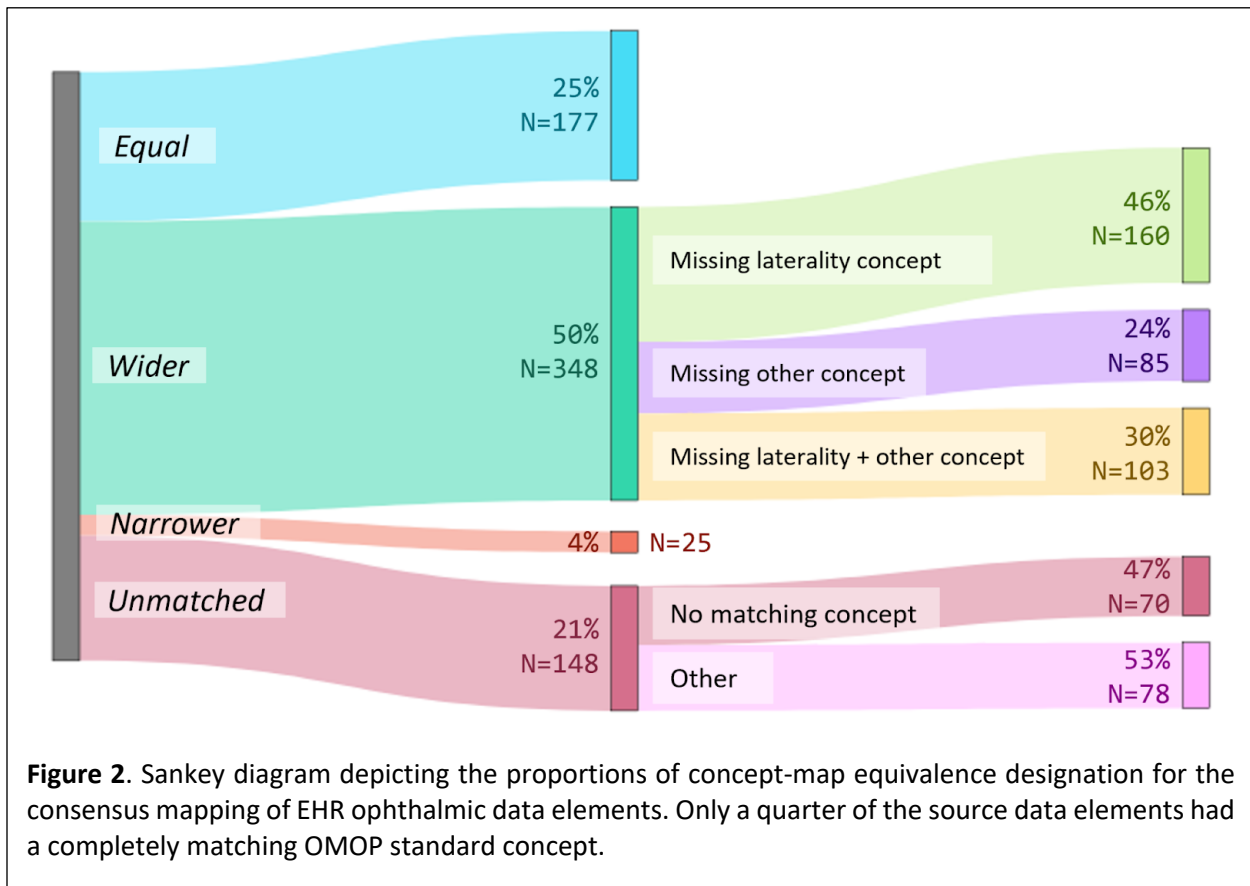


Figure 1: Timeline of Eye Care and Vision Research Workgroup from May, 2022 – October, 2023.

Specifically, the workgroup:

1. Performed gap analyses on data elements important for each sub-specialty using EHR data fields and textbook indices as reference lists. For the analysis of EHR fields shown in **Figure 2**, roughly 75% of terms do not have equivalent representation in standardized terminologies; some of the terms are missing entirely while others are incomplete (e.g., missing laterality). This work has now been published(3).
2. Added missing terms to source vocabularies. Several members of the workgroup are collaborating with the Ophthalmology Clinical Reference Group in SNOMED International to improve the coverage of terms. They have submitted requests for adding new terms related to intraocular pressure (IOP), gonioscopic grading, and diagnosis codes for retinal conditions that were not previously represented. These new retinal codes were released in June 2023. Work for the new glaucoma concepts (IOP, gonioscopic grading) is ongoing. Concepts related to visual acuity

measurements have been submitted to LOINC.



3. Participated in the OHDSI Save our Sisyphus Challenge. One workgroup member, Cindy Cai, submitted a research question for a network study and was one of four projects selected for the challenge. Dr. Cai's project analyzed data from patients who had received intravitreal anti-VEGF injections (injections into the eye for treating retinal diseases), comparing the hazard ratio for kidney failure with 3 different anti-VEGF agents. Anti-VEGF systemic medications have known risks for kidney failure, so it has been assumed that intravitreal injections can have similar adverse systemic reactions. Because one agent (bevacizumab) is significantly cheaper than the other two (ranibizumab & aflibercept), these studies could help improve cost-effectiveness for patients and payors.
4. Developed phenotypes for diseases as a way of prioritizing standardization of clinical concepts. As part of the SOS challenge, phenotypes for patients who were new users of 3 anti-VEGF agents injected intravitreally and for patients with blinding eye disease were developed. The uveitis subgroup developed 6 phenotypes for different uveitis conditions. Both the SOS challenge and uveitis phenotypes were submitted to OHDSI's How Often. There is ongoing work in the glaucoma subgroup to develop phenotypes for primary open-angle glaucoma (POAG), which does not currently have a consensus definition among experts. The visual impairment (VI) subgroup developed and investigated 3 different methods of identifying VI.
5. Published work advocating for better standardization of ophthalmic data. Workgroup members

have been involved with standardization efforts in ophthalmology for decades and have been effective at calling for more standardization(4–8) over the past year. In addition, two publications about the various mapping activities were published(3, 9).

6. Disseminated ophthalmic data standardization efforts and results through the EyeWiki supported by the AAO(10-13). By providing the rationale and process for standardizing data on this popular website for eye related information, we hope to garner more support within the ophthalmic clinical and research community.
7. Taught courses regarding data standards in ophthalmology to the broader vision research community. This included a half-day course focused on secondary use of electronic health record data and three different Special Interest Group (SIG) sessions (advancing ocular data standards in OMOP, glaucoma standards, and retina standards), all held in association with the ARVO 2023 Annual Meeting.
8. Collaborated with the trans-NIH Bridge2AI Initiative to ensure standardized representation of ophthalmic data elements in OMOP for one of the Bridge2AI Data Generation Projects.
9. Included trainees in workgroup activities and engaged with interns from the NIH Bridge2AI/AI-READI Skills and Workforce Development Module.

Conclusion

The OHDSI Eye Care and Vision Research workgroup has had a productive first year and is looking forward to making even more progress in ophthalmic data standardization over the next year. The focus for the coming year will be on completing the mapping and planning for a future of networked sites, developing repositories of information helpful for ETL processes across sites, integrating ophthalmic imaging, and continuing to add concepts across a range of ocular subspecialties. Funding opportunities will also be pursued to facilitate sustainability of workgroup efforts.

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