Data Coordinating Center for the OHDSI Ophthalmic Network: A Proposal for the NEI OHDSI Challenge

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Background

The Observational Health Data Sciences and Informatics (OHDSI) Eye Care and Vision Research workgroup has been standardizing ophthalmic data to the OMOP common data model for use in research over the past 3 years.[1,2] During this time, the workgroup along with the National Eye Institute (NEI) has started to plan an ophthalmic network within the OHDSI Evidence Network. To further the development of this network, the NEI issued a challenge for ideas to advance the network: the NEI Expand OHDSI Initiative for Eye Care and Ocular Imaging Challenge.[3] At OHSU, we prepared a successful submission that described a data coordinating center (DCC) for the network.

Methods

A group of researchers at OHSU met to discuss the motivating use cases for the OHDSI network in order to determine the necessary functionality of a data coordinating center. This group met several times to discuss applications that would use multimodal electronic health record and imaging data, as well as the necessary functionality that would need to be developed.

Results

We identified several use cases for the ophthalmic data network: 1) glaucoma progression rate, a complicated phenomenon to predict in clinical care, but longitudinal multimodal data could provide insights not obtainable otherwise, 2) myopia causes, an international concern given the epidemic of cases, 3) oculomics, a new research area that uses ophthalmic imaging to identify biomarkers for systemic disease as early as possible, 4) a center for model testing and validation, and 5) studies of the social determinants of health and environmental data on ophthalmic disease. We developed a vision for the data coordinating center that included 4 efforts: 1) ophthalmic data tools, 2) external data tools, 3) a study development environment, and 4) organizational groups (see **Figure 1**). We intend for the ophthalmic data tools to transform and standardize eye exam data and images to the Observational Medical Outcomes (OMOP) common data model and modify OHDSI tools for ophthalmic data and imaging. The external data tools will enhance the network with community level social determinants of health and environmental data, as well as external health systems and community health center data. We also think it is important for the DCC to create a study development environment: publicly available datasets for model development and validation, a sandbox environment for development, and a federated learning infrastructure. Finally, we propose that the center will establish multiple organizational groups to guide and support the ophthalmic OHDSI network: a research and data access committee to govern access to the network, an advisory council (including patients) to guide the direction of the network and technical groups of open source developers, OHDSI network experts, and data analysts to develop tools, support sites joining the network, and support the execution of studies within the network.

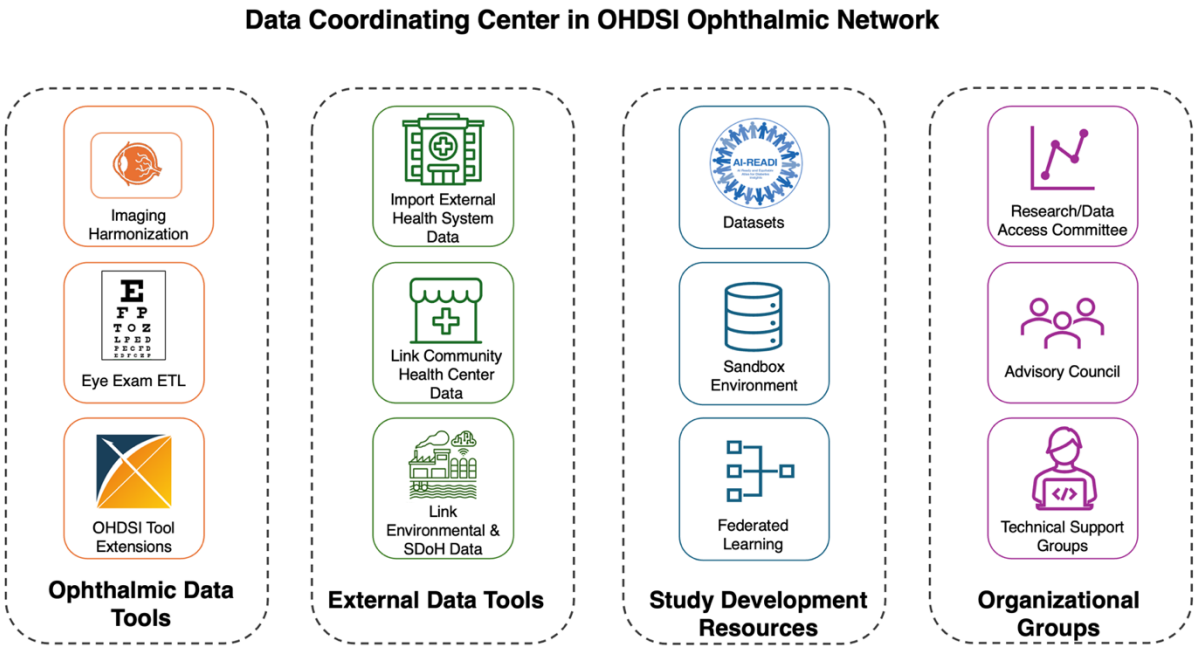

Figure 1: An overview of the structure of the proposed data coordinating center for the OHDSI Ophthalmic Network

Conclusion

The future Observational Health and Data Sciences and Informatics (OHDSI) Ophthalmic Data Network will require a coordinating center to manage the work of adding and using ophthalmic data and images within the network. This data coordinating center will play a pivotal role in the development, implementation, and sustainability of the ophthalmic OHDSI network as well as advance data standardization and tool development for the entire eye care and vision research community. Our proposal for the data coordinating center for the Ophthalmic network received one of the NEI challenge awards and we are currently working on initial steps for implementation of the center.

References

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