Using electronic health records (EHR) data: Data readiness and FAIR principles

# Course organizers

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# Presentations

Presenters and presentations may change.

| **Time**  | **Topic** | **Speaker**  |
| --- | --- | --- |
| 8- 8:30 am | Introduction to Electronic Health Record (EHR) Data & Current Research Using EHR Data in Vision Science | Michelle Hribar, PhD, MS, Oregon Health & Science University (OHSU)/National Eye Institute (NEI) <https://www.ohsu.edu/people/michelle-r-hribar-phd-ms> |
| This talk will set the stage for the course—we will present how data is stored and accessed in the EHR for its primary clinical use, as well as for its secondary use. We will then discuss the different types of available EHR data and the many ways it can be used beyond the primary clinical use. We will provide numerous examples of the secondary use of EHR data in vision science and research, which will illustrate the benefits of using EHR data for research. Finally, we will lead an interactive discussion about the current challenges for the secondary use of EHR. |
| 8:30- 9am | Data Readiness and Bias for Secondary Research Use of EHR Data  | Nicole Wieskopf, PhD, OHSU<https://www.ohsu.edu/people/nicole-g-weiskopf-phd> |
| The reuse of electronic health record (EHR) provide an important completement to traditional clinical research paradigms, with the potential for lower costs and improved generalizability. There are, however, unique challenges associated with the reuse of EHR data, including the fitness and readiness of these data for research, and potential biases that may be present in the data or introduced via study design or analyses. Researchers and clinicians working with EHR data or with results derived from EHR data must be aware of these considerations. In this session attendees will learn the basics of how to define, detect, and characterize EHR data readiness, both broadly and specifically with regards to ophthalmic data. Attendees will also be introduced to common forms of bias that may occur in EHR-based research, including measurement bias, confounding, and collider bias. |
| 9- 9:15am | Discussion of Challenges of Secondary Research Use of EHR Data | Michelle Hribar, PhD, MS, Oregon Health & Science University (OHSU)/National Eye Institute (NEI)Nicole Wieskopf, PhD, OHSU |
| 9:15- 9:30am  | Break (at least 15 minutes)  |  |
| 9:30-9:45am | FAIR Data Principles (Findable, Accessible, Interoperable, and Reusable) and the EHR | Amberlynn Reed, MPH, National Eye Institute (NEI) <https://orcid.org/0000-0001-8249-0581> |
| This presentation will give an overview of the ‘FAIR Guiding Principles for scientific data management and stewardship’. These principles are intended to provide guidelines to improve the Findability, Accessibility, Interoperability, and Reuse of digital assets. The principles emphasise machine-actionability (i.e., the capacity of computational systems to find, access, interoperate, and reuse data with none or minimal human intervention) because humans increasingly rely on computational support to deal with data as a result of the increase in volume, complexity, and creation speed of data. |
| 9:45-10:15am | Healthcare Data Standards | Kerry Goetz, MS, National Eye Institute (NEI) <https://orcid.org/0000-0002-9821-7704> |
| In this part of the educational course, I will cover background on the need for standardization to improve care delivery, public health surveillance, patient access, and research use of healthcare data. The course will outline specific characteristics of a variety of standards. The topics will cover both data standards and health information exchange standards. Use cases from data captured in electronic health records (EHRs), clinical research, and other health information systems will be used to give attendees a better understanding of why there is not a single standard. |
| 10:15-10:45 am | Common Data Models - Fast Healthcare Interoperability Resources (FHIR) & Observational Medical Outcomes Partnership (OMOP) | Sally Baxter, PhD, MSc, Shiley Eye Institute <https://shileyeye.ucsd.edu/faculty/sallylbaxter> |
| In this talk, I will provide an introduction to common data models and extract-transform-load (ETL) processes that convert data into common data model structures. I will then provide additional details about two common data models: Observational Medical Outcomes Partnership (OMOP) and Fast Healthcare Interoperability Resources (FHIR). For OMOP, participants will learn about how to create cohorts, concept sets, and execute analyses, and the benefits of using the OMOP common data model. I will demonstrate some examples of "OMOP in action" and provide some hands-on activities for course participants to learn about publicly available tools. We will also discuss recent activities of the OMOP Workgroup in Eye Care and Vision Research. For FHIR, I will provide an overview of FHIR, including defining resources and demonstrating utility for interoperability and data exchange in a digital health ecosystem. I will describe some use cases and provide some specific applications in ophthalmology. There will be opportunities for interactive discussion throughout the presentation. |
| 10:45- 11:00 am | Discussion of FAIR, Data Standards, Common Data Models | Amberlynn Reed, MPH, National Eye Institute (NEI)Kerry Goetz, MS, National Eye Institute (NEI)Sally Baxter, PhD, MSc, Shiley Eye Institute |
| 11:00- Noon | Future Opportunities and Call to Action | Michelle Hribar, PhD, MS, Oregon Health & Science University (OHSU)/National Eye Institute (NEI) |
| Open discussion about future opportunities. |
| Noon | Adjourn |  |