Clinical Registry Efforts in OHDSI

OHDSI Community Call
Sept. 13, 2022 • 11 am ET
# Upcoming OHDSI Community Calls

<table>
<thead>
<tr>
<th>Date</th>
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<tbody>
<tr>
<td>Sept. 20</td>
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Three Stages of The Journey

Where Have We Been?
Where Are We Now?
Where Are We Going?
Congratulations to the team of Joao Rafael Almeida, Joao Paulo Barraca, and José Luís Oliveira on the publication of Preserving Privacy when Querying OMOP CDM Databases in Volume 298 of Studies in Health Technology and Informatics.
OHDSI Shoutouts!

Congratulations to the team of Guohui Xiao, Emily Pfaff, Eric Prud'hommeaux, David Booth, Deepak K Sharma, Nan Huo, Yue Yu, Nansu Zong, Kathryn J Ruddy, Christopher Chute, and Guoqian Jiang on the publication of FHIR-Onlop-OMOP: Building Clinical Knowledge Graphs in FHIR RDF with the OMOP Common Data Model in the Journal of Biomedical Informatics.

Abstract

Background

Knowledge graphs (KGs) play a key role to enable explainable artificial intelligence (AI) applications in healthcare. Constructing clinical knowledge graphs (CKGs) against heterogeneous electronic health records (EHRs) has been desired by the research and healthcare AI communities. From the standardization perspective,
Congratulations to the team of Benoit L Marteau, Yuanda Zhu, Felipe Giuste, Wenqi Shi, Ashley Carpenter, Coleman Hilton, and May D Wang on the publication of *Accelerating Multi-site Health Informatics with Streamlined Data Infrastructure using OMOP-on-FHIR* in the Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC).
OHDSI Shoutouts!

Jenny Lane
@jennifercelane

After a brilliant ACF and DPhil with @ndorms, it's time for a new challenge. I'm looking forward to the challenge of leading surgical research in the international @OHDSI community using #realworld data, joining @BartsBoneJoint as an NIHR Academic Clinical Lecturer.
OHDSI Shoutouts!

Any shoutouts from the community? Please share and help promote and celebrate OHDSI work!

Have a study published? Please send to sachson@ohdsi.org so we can share during this call and on our social channels. Let’s work together to promote the collaborative work happening in OHDSI!
Three Stages of The Journey

Where Have We Been?
Where Are We Now?
Where Are We Going?
## Upcoming Workgroup Calls

<table>
<thead>
<tr>
<th>Date</th>
<th>Time (ET)</th>
<th>Meeting</th>
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</thead>
<tbody>
<tr>
<td>Tuesday</td>
<td>12 pm</td>
<td>Common Data Model Vocabulary</td>
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<tr>
<td>Tuesday</td>
<td>3 pm</td>
<td>OMOP CDM Oncology Outreach/Research Subgroup</td>
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<tr>
<td>Tuesday</td>
<td>6 pm</td>
<td>Eye Care and Vision Research</td>
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<tr>
<td>Wednesday</td>
<td>10 am</td>
<td>FHIR and OMOP Digital Quality Measurements Subgroup (ZOOM)</td>
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<tr>
<td>Wednesday</td>
<td>2 pm</td>
<td>Natural Language Processing</td>
</tr>
<tr>
<td>Thursday</td>
<td>12 pm</td>
<td>HADES</td>
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<tr>
<td>Thursday</td>
<td>12 pm</td>
<td>FHIR and OMOP Oncology Subgroup</td>
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<tr>
<td>Thursday</td>
<td>1 pm</td>
<td>OMOP CDM Oncology Vocabulary/Development Subgroup</td>
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<tr>
<td>Thursday</td>
<td>6 pm</td>
<td>FHIR and OMOP Digital Quality Measurements Subgroup (ZOOM)</td>
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<tr>
<td>Friday</td>
<td>9 am</td>
<td>GIS-Geographic Information System Development</td>
</tr>
<tr>
<td>Friday</td>
<td>10:30 am</td>
<td>Clinical Trials</td>
</tr>
</tbody>
</table>
Paul Nagy Hosts Grand Rounds Sept. 15

Observational Health Data Science and Informatics to Catalyze a Learning Health System
Thursday, Sept. 15
Noon to 1 p.m.

Johns Hopkins Grand Rounds for Armstrong Institute
Event by Informatics Education - Johns Hopkins University School of Medicine

Thu, Sep 15, 2022, 12:00 PM - 1:00 PM (your local time)
Online
Event link - https://hjhm.zoom.us/j/92600442823
2022 Titan Award Nominees

Congratulations to the 53 individuals or teams who were nominated for a 2022 Titan Award.

The Titan Award recipients will be announced during the closing talk at the 2022 OHDSI Symposium.

Thamir Alshammary | Juan Banda | Adam Black | Fan Bu | Montse Camprubi | Yong Chen | Marcel de Wilde | Frank DeFalco | Egill Fridgeirsson | Jamie Gilbert | Jake Gillberg | Jason Hsu | Nigel Hughes | Yu-Chuan Jack Li | Mik Kallfelz | Andy Kanter | Elisse Katzman | Chungsoo Kim | Greg Klebanov | Chris Knoll | Kristin Kostka | Manlik Kwong | Christophe Lambert | Martin Lavallee | Jing Li | Xintong Li | Star Liu | Ajit Londhe | Aniek Markus | Evan Minty | Paul Nagy | Karthik Natarajan | Aki Nishimura | Anna Ostropolets | Melanie Philofsky | Gowtham Rao | Berta Raventos | Craig Sachson | Martijn Schuemie | Azza Shoaibi | Marc Suchard | Cynthia Sung | Joel Swerdel | May Terry | Don Torok | Cynthia Yang | Jacob Zelko | Center for Surgical Science Prediction study team | LEGEND-T2DM | N3C | Thrombosis w Thrombocytopenia phenotype project team | Vaccine Evidence Workgroup
OHDSI Newsletter Is Available

Publications


The Journey Newsletter (September 2022)

The OHDSI2022 Symposium is less than seven weeks away, and the weekend agenda is available in this newsletter. There will be presentations, the collaborator showcase, a full-day tutorial, workshop activities and plenty more. You can also learn more about our new data partner survey, a new collaborator spotlight, 13 recent publications, several presentations from the past month and plenty more in the latest edition of The Journey! #JoinTheJourney

Objective Diagnostics Plenary, OHDSI Support for Regulatory Agencies Highlight Agenda For 2022 Symposium

Simply returning together for the first time since 2019 would be enough reason to look forward to the 2022 OHDSI Symposium, but there will also be several impactful presentations, the largest collaborator showcase in community history and plenty more activities that will make the Oct. 14-16 weekend a special one.

Where Have We Been?

- Paul Nagy led an informative session on what it takes to build organizational support for adopting the OMOP.COM and OHDSI tools, as well as building organizational capacity for conducting observational research. Video from this panel, which included Karen Mol, Greg Kolansky and Ali Lunde, is available here.
- The third workshop leadership summit of 2022 was held in August and focused on building connections between workshops and maximizing time together at the OHDSI symposium. There are several activities planned during the symposium weekend to strengthen bonds within and between the workshops.
- The first session of the Early-Stage Researchers Speaker Series, Ashish Goyal discussed her career path, how OHDSI has influenced her journey, and shares some tips for moving forward in health data sciences. You can watch it here, and be on the lookout for similar sessions in the future.

Where Are We Now?

- The agenda for the OHDSI 2022 Symposium was recently announced. This document lists the full agenda for the main conference, including all planned presentations, as well as the lightning talks and software demos for the Collaborator Showcase. A later version will include the 100+ posters that will also be presented at the showcase. If you haven’t already registered for any of the events, please visit our Symposium homepage and secure your spot at our biggest event of the year.
#OHDSI2022 Agenda

OHDSI 2022 Symposium
Oct. 14-16, 2022
Bethesda North Marriott Hotel & Conference Center

Main Conference Agenda • Oct. 14

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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</thead>
<tbody>
<tr>
<td>7:30 am - 8:30 am</td>
<td>Registration and Pre-Breakfast</td>
</tr>
</tbody>
</table>
| 9:00 am - 10:00 am | State of the Community  
                      | George Hipsceak, Columbia University  
                      | presentation of 2020, 2021 In Awards                                    |
| 10:00 am - 10:45 am | Workgroup and Chapter connections  
                      | workgroup chapter leads will be distributed across the venue and available for networking to share activities and progress and connect for future collaborations |
| 10:45 am - 12:15 pm | Plenary: Objective Diagnostics: A pathway to provably reliable evidence  
                      | Martin Schumee, Johnson & Johnson                                       |
| 12:15 pm - 1:00 pm | Buffet Lunch  
                      | buffet in exhibit space                                                 |
| 1:00 pm - 2:00 pm | Presentations: OHDSI support for regulatory authorities  
                      | moderator: Jody-Ann Mcleaggin, Columbia University  
                      | “US FDA/CDER: Performance of vaccine safety surveillance methods” Fan Bi, UCLA  
                      | “Korea Ministry of Food and Drug Safety: Replication of clinical trials in electronic health records” Seung-Chan You, Yonsei University  
                      | “European Medicines Agency: DARWIN EU” Peter Ryboeck, Erasmus MC         |
| 2:00 pm - 3:00 pm | Collaborator Showcase, Round 1  
                      | • Poster presentations with poster walks  
                      | • Software demonstrations  
                      | • Exhibitors                                                            |
| 3:00 pm - 4:00 pm | Collaborator Showcase Lightning Talks  
                      | moderator: Kristen Kostka, Roxa Institute at Northeastern University  
                      | “Disentanglement of IOPC codes using free-text and active learning to improve concept mappings” Tom Seinen, Erasmus MC  
                      | “OHDSI Phenotype Februle: lessons learned” Azza Shoabi, Johnson & Johnson |

OHDSI Speed Dating

3:00 pm - 4:00 pm
Ballroom DE (continued)

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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</table>
| 4:00 pm - 5:00 pm | Collaborator Showcase, Round 2  
                      | • Poster presentations with poster walks  
                      | • Software demonstrations  
                      | • Exhibitors                                                            |
| 5:00 pm - 6:00 pm | Closing Talk: Building A Healthier World Together  
                      | Patrick Ryan, Johnson & Johnson, Columbia University  
                      | • 2022 Titan Awards  
                      | • Group photo at conclusion                                            |
| 6:00 pm - 7:00 pm | Networking Reception                                                  |

Register Here:  
ohdsi.org/ohdsi2022symposium/

#JoinTheJourney  

bit.ly/OHDSI2022-Agenda
OHDSI 2022 Symposium
Oct. 14-16, 2022
Bethesda North Marriott Hotel & Conference Center

Full-Day Tutorial • Oct. 15
An Introductory Journey From Data To Evidence

In this tutorial, we will introduce participants to steps along the journey from data to evidence using the OHDSI Common Data Model, OHDSI tools and scientific best practices in each 60-minute segment. The class will learn the conceptual framing of the problem and approach to the solution. Then, the class will have the opportunity to have hands-on exposure to design and implementation of analyses and interpretation of results. The course will be motivated by a real-use case using observational data to generate evidence about the relationship between an exposure and outcome, and will highlight how the use of OHDSI tools and practices can enable such learning.

This class is designed for newcomers to the OHDSI community who are looking for a high-level summary across a wide range of topics covered within the OHDSI community. It is also designed for those in the OHDSI community who may be focused in one particular area of the journey who want exposure to the other areas, so they can better understand how their work contributes to the big picture, and advances the mission to improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care.

The tutorial will be held in White Oak A.

<table>
<thead>
<tr>
<th>Time</th>
<th>Title</th>
<th>Faculty</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30 am</td>
<td>Registration/Lite Breakfast (White Oak Foyer)</td>
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<tr>
<td>8:30 am</td>
<td>Overview of the OHDSI Journey: where are we going?</td>
<td>Patrick Ryan</td>
</tr>
<tr>
<td>9:00 am</td>
<td>OHDSI Common Data Model and vocabulary</td>
<td>Clair Blacketer</td>
</tr>
<tr>
<td>9:30 am</td>
<td>Energy Break</td>
<td></td>
</tr>
<tr>
<td>10:00 am</td>
<td>OHDSI: A database into OHDSI: CDIM</td>
<td>Helmar Philoosky</td>
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<tr>
<td>10:50 am</td>
<td>Break</td>
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<tr>
<td>11:00 am</td>
<td>OHDSI: A database into OHDSI: CDIM</td>
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<tr>
<td>11:50 am</td>
<td>Buffet Lunch</td>
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<tr>
<td>12:00 pm</td>
<td>Phenotype Evaluation</td>
<td>Swetham Rao</td>
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<tr>
<td>1:00 pm</td>
<td>Energy Break</td>
<td></td>
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<tr>
<td>1:30 pm</td>
<td>Phenotype Evaluation</td>
<td></td>
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<tr>
<td>2:00 pm</td>
<td>Characterization</td>
<td>Krista Koska</td>
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<tr>
<td>2:30 pm</td>
<td>Energy Break</td>
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<tr>
<td>3:00 pm</td>
<td>Estimation</td>
<td>Martin Schuemie</td>
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<tr>
<td>3:30 pm</td>
<td>Energy Break</td>
<td></td>
</tr>
<tr>
<td>4:00 pm</td>
<td>Prediction</td>
<td>Jenna Reynolds</td>
</tr>
<tr>
<td>4:30 pm</td>
<td>Recap of the OHDSI Journey: Where do we go from here?</td>
<td>George Hipposak</td>
</tr>
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</table>

Collaborator Showcase

Poster Presentations

Software Demos

OHDSI 2022 Symposium
Oct. 14-16, 2022
Bethesda North Marriott Hotel & Conference Center

#OHDSI2022 Agenda

www.ohdsi.org

@OHDSI

#OHDSI2022-Agenda

bit.ly/OHDSI2022-Agenda
Registration is OPEN for #OHDSI2022!

The 2022 OHDSI Symposium will be held Oct. 14-16 at the Bethesda North Marriott Hotel & Conference Center.

www.ohdsi.org/ohdsi2022symposium
2022 OHDSI Symposium

Oct. 14-16 • Bethesda North Marriott Hotel & Conference Center

We are thrilled to announce that registration for the 2022 OHDSI Symposium, which will be held Oct. 14-16 at the Bethesda North Marriott Hotel & Conference Center, is now open!

It is so exciting to bring our community back together this fall. Our collaborator showcase will return; please click the link to see how you can take part in our poster presentations, software demos and lightning talks. The full agenda for our conference is still being developed, so please continue to check the OHDSI website (www.ohdsi.org) and our social platforms for updates as we plan for the 2022 Symposium.

The main conference will be held Friday, Oct. 14. A full-day tutorial will be held Saturday, Oct. 15, while other community activities will be held both Oct. 15 and Oct. 16.

Symposium Registration Details

Friday, Oct. 14 – Main Conference

Registration Fee: $900

* This is an open and inclusive event. If the registration fee represents a burden to you, please contact symposium@ohdsi.org.

Should you need to make changes or cancel your registration ticket, please follow the instructions you will receive on your Eventbrite confirmation upon registration completion. Please note that tickets can be refunded up until 7 days prior to the event. Eventbrite fees are not refundable.

Register For The Main Conference • Friday, Oct. 14

Saturday, Oct. 15 – Full-Day Tutorial: An Introductory Journey From Data To Evidence

Registration Fee: $500

* This is an open and inclusive event. If the registration fee represents a burden to you, please contact symposium@ohdsi.org.

Should you need to make changes or cancel your registration ticket, please follow the instructions you will receive on your Eventbrite confirmation upon registration completion. Please note that tickets can be refunded up until 7 days prior to the event. Eventbrite fees are not refundable.

Register For The Full-Day Tutorial • Saturday, Oct. 15

Saturday, Oct. 15 and Sunday, Oct. 16 — Community Activities

A highlight of the OHDSI Symposium will be a full weekend of workshop activities and meetings within the Bethesda North Marriott Hotel & Conference Center. You are now able to register for any workshop sessions as long as there is no overlap between any two sessions—registration is free, but please do so early as this will be first-come, first-served due to room capacity.

See The Schedule & Agenda For Workshop Activities • Weekend of Oct. 15-16

Hotel Information and Sleeping Room Block

Hotel: Bethesda North Marriott Hotel & Conference Center
Address: 4701 Marriott Road, Rockville, Maryland, 20852
Hotel Main Number: (301) 332-8200
Reservations Toll Free: (877) 312-7772
Reservations Local Phone: (301) 332-8200

This year, OHDSI is holding a sleeping room block for the nights of Oct. 13 and 14 with a special room rate of $179 plus taxes. Please note that all sleeping rooms are on a first-come, first-served basis. To help us in the planning process, we ask that you do not cancel your hotel room ordered through the OHDSI Room Block. If you must cancel, please let us know prior to Thursday, Sept. 1, so that we can offer the room to others who may need one. Once the room block is full, or if specific nights are sold out, you may make additional room reservations go the hotel’s website or by calling the hotel phone number above. Please note that OHDSI is not holding any sleeping rooms on Saturday, Oct. 15. Therefore, please call the hotel phone number or make this reservation online should you plan to stay Saturday night.

ohdsi.org/ohdsi2022symposium
Talita Duarte-Salles, a 2020 OHDSI Titan Award honoree, recently announced an opening for a post-doc to join her Real World Epidemiology group at the The Institut d’Investigació en Atenció Primària Jordi Gol (IDIAPJGol).

The application deadline is Sept. 18, 2022. More information and an application link will be available on the community calls page.

**Job Description Post-Doctoral Researcher**
**“Institut d’Investigació en Atenció Primària Jordi Gol”**

The Institut d’Investigació en Atenció Primària Jordi Gol i Gurina is looking for a postdoctoral researcher to join the Real-World Epidemiology (RWEpi) research group led by Dr. Talita Duarte-Salles. The RWEpi research group is a multidisciplinary team including epidemiologists, statisticians, clinicians, data scientists, and pre- and post-doctoral researchers with extensive experience in analysing and interpreting large, real-world data from different countries. Our main goal is to generate reliable scientific evidence by using routinely collected data from different settings of the healthcare system. We are currently involved in a number of national and international studies focused on the understanding of the natural history and determinants of multiple diseases/conditions (e.g. cancer, COVID-19, obesity, mental health, etc), the safety and effectiveness of new medicines and vaccines, and the implementation of methodological approaches to analyse and evaluate the quality of real-world data. We are also particularly interested in population subgroups such as the pediatric and pregnant women populations, being recently able to link a large cohort of mother and child electronic healthcare records from primary care in Catalonia; as well as understanding health inequalities, and the role of lifestyle and urban environmental exposures on health.
Common data environment for source vocabularies mapping

A common data environment approach can streamline source vocabulary processing for repetitive processes, harmonize and enrich mapping, speed up the process of data reuse.

The common data environment should contain the most complete set of source data, structured across each vocabulary by code, code_description, frequency of occurrence of each concept and the whole group.
#OHDSISocialShowcase This Week

**Create Analytical panel based on ATLAS definitions**

**From ATLAS to predictive modeling CDM data extracting & Study preparations**

**Lead:** Guy Livne

**TUESDAY**
Utilising real-world evidence for health technology assessment: development of a cancer survival use case

Lead: Ravinder Claire

OBJECTIVES

- We compared potential outcomes of the Dashboard: academic experts, HTA decision makers, industry experts and patients. It is expected that potential outcomes, benefits and harms of the intervention, and relevant clinical information would be most useful to them.
- Some of the potential outcomes identified from the literature can be found in Figure 1.

DESCRIPTION

- The development of this survival analysis tool will demonstrate a potential benefit of OHDSI and EHDEN tools to address priority areas of HTA agencies and industry stakeholders.
- The main strengths of this use case are likely to be a large sample size and the observational nature of the data, meaning its results will be representative of real world clinical practice.
- The development of the EHDEN Cancer Survival Data Dashboard will allow alternative parametric functions for survival estimation to be explored in different cohorts.
- The Dashboard will help guide health technology reimbursement decisions based on HTA for the example of informing comparator survival estimates for patients with small cell lung cancer, or estimating survival estimates from a clinical trial in the most relevant, real-world population.
- Other identified priority areas for HTA with potential use in future EHDEN use cases in other disease areas.

Ravinder Claire1, Janie Elvin2, Dilak Chassany1, Catherine Nadkarni1, Ed Burns1, Caren Gatterman1

1 National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme, Institute of Translational Medicine, University of Liverpool, Liverpool, UK

1 Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton, ON, Canada

1 Centre for Health Economics, University of York, York, YO10 5DD, UK

2 Department of Health Economics, School of Health and Related Research, University of Sheffield, Sheffield, UK

SUPPORT

- We have access to potential data sources of the Dashboard: academic experts, HTA decision makers, industry experts and patients. It is expected that potential outcomes, benefits and harms of the intervention, and relevant clinical information would be most useful to them.
- Some of the potential outcomes identified from the literature can be found in Figure 1.
Applying k-anonymity and l-diversity in OMOP CDM databases

Lead: João Almeida

METHODS
- k-anonymity limits the information released based on generalization and suppression of data concepts, as well as the number of equivalence classes.
- l-diversity reduces bias by ensuring that sensitive data values are sufficiently diverse.

RESULTS
- We considered some tables of the OMOP CDM.
  - Tables in the group ‘Standardized vocabularies’ and ‘Standardized laboratory elements’ were omitted.
  - Key attributes, quasi-identifiers and sensitive attributes were masked to apply the privacy-preserving techniques.

THURSDAY

Applying k-anonymity and l-diversity in OMOP CDM databases

Lead: João Almeida

Sharing aggregate data?
Robust anonymization through privacy-preserving techniques.
OMOP CDM/ATLAS allows identifying Neurofibromatosis Type 1 patients with an Optical Pathway Glioma in the Electronic Health Record database of a clinical site.

Leveraging this approach to a federated site network provides the potential to identify patients matching trial eligibility criteria on large scale and to refine criteria as appropriate.
Where Are We Going?

Any other announcements of upcoming work, events, deadlines, etc?
Three Stages of The Journey

Where Have We Been?

Where Are We Now?

Where Are We Going?
Sept. 13: Clinical Registry Efforts in OHDSI

How clinical registries and OHDSI can benefit from each other
Presenter: Paul Nagy • Program Director for Graduate Training in Biomedical Informatics and Data Science, Deputy Director of the Johns Hopkins Medicine Technology Innovation Center

How to adapt a manual clinical registry to OMOP
Presenter: Matt Robinson • Assistant Professor, The Johns Hopkins University School of Medicine

How to lower the ETL barrier going to OMOP with Perseus (Demonstration)
Presenter: Zachary Wang • Graduate Student, Johns Hopkins (2022 Kheiron Cohort member)

Lowering the deployment burden with the cloud
Presenter: Lee Evans • Owner, LTS Computing LLC

Distributed Machine Learning Using OMOP
Presenter: Emily Pfaff • Research Assistant Professor, University of North Carolina at Chapel Hill