Our Journey

Where The OHDSI Community Has Been And Where We Are Going

2022 edition

OHDSI

OBSERVATIONAL HEALTH DATA SCIENCES AND INFORMATICS

Publication was written and designed by Craig Sachson. Editorial assistance by Patrick Ryan, Kristin Kostka, George Hripcsak, Martijn Schuemie, Marc Suchard, Jody-Ann McLeggon, Jenna Reps, Peter Rijnbeek, Henrik John, Mui Van Zandt and Chungsoo Kim. Photography shared by the OHDSI community unless specifically credited next to image. Printed by ABGPrint. Thank you to all members of the OHDSI community for all you have done towards improving global healthcare.

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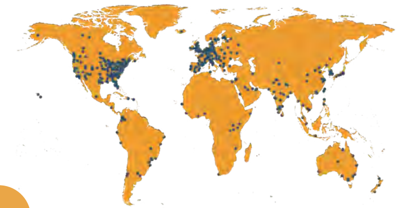
To improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care.



Welcome Letter To The Community

Welcome to the second edition of Our Journey.

This book highlights the Observational Health Data Sciences and Informatics (OHDSI) journey from its inception in 2013—growing out of the Observational Medical Outcomes Partnership (OMOP)—to today.

Our mission, which we repeat often, **is to improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care**. We have created a community of thousands of collaborators, a federated database with approximately 12 percent of the world's population, models and standards for representing that population, and systematic research methods and tools that allow us to generate reliable evidence in health care.

We have turned that system on and begun to produce impactful evidence. We have gotten to the point that policy makers like the European Medicines Agency and medical influencers as represented in journals like

Circulation, Hypertension, JAMA, Lancet, and BMJ have specifically called out OHDSI and its studies and have demonstrated OHDSI's effect on hundreds of millions of people. We've proven what is possible and helped answer some important questions, but we are still just at the beginning of our journey.

Welcome Letter To The Community

With a systematic approach to observational research and an extensive international data network, **we can contribute much more broadly across medicine**.

How have we gotten here, and how can we continue to contribute? **Leadership is the foundation of any initiative, and OHDSI is blessed with many leaders**. OHDSI has done a good job in finding leaders rather than bosses. The mark of a successful group is that it seems to lead itself (see, for example, the Tao of Leadership). Leaders inspire, set examples, and give credit. Put another way, quoting informatician Paul Clayton, we encourage leaders who are nice, bright, and hardworking. **Our leaders are a diverse group, pulling from nations around the world; pulling from industry, academia, and government; and pulling from all career stages from undergraduate to senior figures.**

To foster our open-science community and to improve transparency, **OHDSI has shifted most of its work from informal arrangements to formal workgroups**. OHDSI workgroup leaders have donated their time, creativity, and skills to advance observational research, and OHDSI has more consciously moved to support them through workgroup leadership summits and workshops. Thanks to Paul Nagy and colleagues for being leaders among leaders.

OHDSI recognizes leadership through its annual Titan Awards, which go to those in the community who have contributed greatly in the previous year. The awards include a specific award for Community Leadership, but all our Titan winners are leaders, and our leadership bench includes many more than we can give awards to.

Welcome Letter To The Community

To keep OHDSI healthy, we must expand our leadership as OHDSI grows. OHDSI is therefore looking to find and grow new leaders, especially from its junior ranks. We are an open-science initiative and everyone is welcome.

Leadership also refers to OHDSI's mission-driven responsibility in the field, which is to pull research to be more rigorous and trusted. I use "pull" on purpose, as research must be pulled forward. **You pull towards yourself and push away from yourself, and OHDSI must set the standard for rigorous research, encouraging the broader research community to do the same.**

George Hripcsak

II.

OHDSI Mission and Values

OHDSI Mission and Values

OHDSI Mission

To improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care.

OHDSI Vision

A world in which observational research produces a comprehensive understanding of health and disease.

OHDSI Values

Innovation: Observational research is a field which will benefit greatly from disruptive thinking. We actively seek and encourage fresh methodological approaches in our work.

Reproducibility: Accurate, reproducible, and well-calibrated evidence is necessary for health improvement.

Community: Everyone is welcome to actively participate in OHDSI, whether you are a patient, a health professional, a researcher, or someone who simply believes in our cause.

Collaboration: We work collectively to prioritize and address the real-world needs of our community's participants.

Openness: We strive to make all our community's proceeds open and publicly accessible, including the methods, tools and the evidence that we generate.

Beneficence: We seek to protect the rights of individuals and organizations within our community at all times.

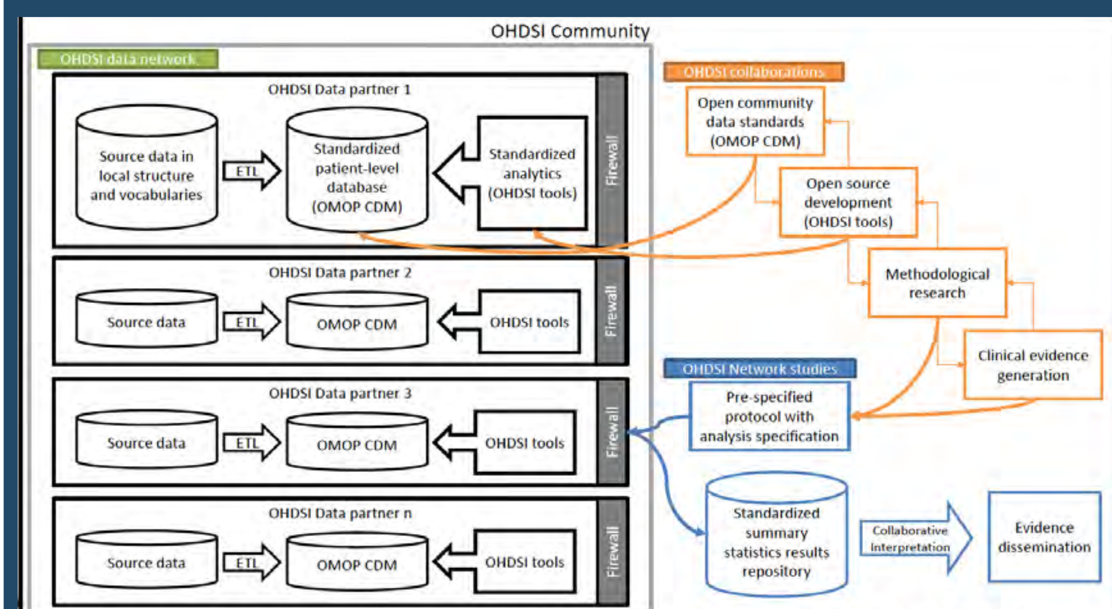
Observational Health Data Sciences and Informatics (OHDSI, pronounced "Odyssey") strives to promote better health decisions and care through globally standardized health data, continuously developing large-scale analytics and a spirit of collaboration though open science.

Founded in 2014, OHDSI is a growing collaborative of more than 3,200 researchers across disciplines (including biomedical informatics, epidemiology, statistics, computer science, health policy, clinical sciences), across stakeholders (including academia, industry, government and regulatory authorities, and health providers), and across geographies (including 80 countries and six continents). OHDSI also has established an international distributed data network that applies one open community data standard and collectively contains data for more than 928 million patients around the world, and has produced a suite of open-source software packages that enables the community to translate that data into reliable evidence.

OHDSI collaborates to establish open community data standards, develop open source software, conduct methodological research, and apply best practices across the OHDSI data network to generate clinical evidence. The OHDSI distributed data network is comprised of data partners who standardize their source data through an extract-transform-load (ETL) into the OMOP Common Data Model (CDM) and apply OHDSI open-source tools securely behind their own firewall.

OHDSI network studies involve researchers collaborating to design analyses

How OHDSI Works



Hripcsak G, Schuemie MJ, Madigan D, Ryan PB, Suchard MA. Drawing Reproducible Conclusions from Observational Clinical Data with OHDSI. Yearb Med Inform. 2021 Apr 21.

OHDSI Mission and Values


Photo by Odelia Ghodsizadeh/CUIMC

The Department of Biomedical Informatics at Columbia University (DBMI) serves as the coordinating center for the OHDSI community.

Located on the Columbia University Irving Medical Center campus, DBMI is both an academic department and an information services partner to NewYork-Presbyterian Hospital, a major healthcare provider in greater New York.

One of the oldest informatics departments in the nation, faculty and students at DBMI have set the path for design of clinical information systems, methodologies in clinical natural language processing, and machine learning over electronic health record data. Faculty research includes the development and evaluation of innovative information technologies, which has led to enhancements in both health and healthcare.

Both faculty and students work in a highly collaborative environment, applying informatics from the atomic level to global populations.

with pre-specified protocol and analysis code which can be executed across the OHDSI data network, allowing aggregate summary statistics (but no patient-level data) to be shared and collectively interpreted and disseminated.

OHDSI's research has been presented across various scientific societies, such as American Medical Informatics Association (AMIA), American Statistics Association (ASA/JSM), and International Society of Pharmacoepidemiology (ISPE), and published in top medical journals, including The Lancet, JAMA, BMJ, PNAS and JAMIA.

Our growing global community is always seeking new collaborators.

Please learn more about OHDSI through this publication and **Join The Journey!**

III.

OHDSI Collaborators

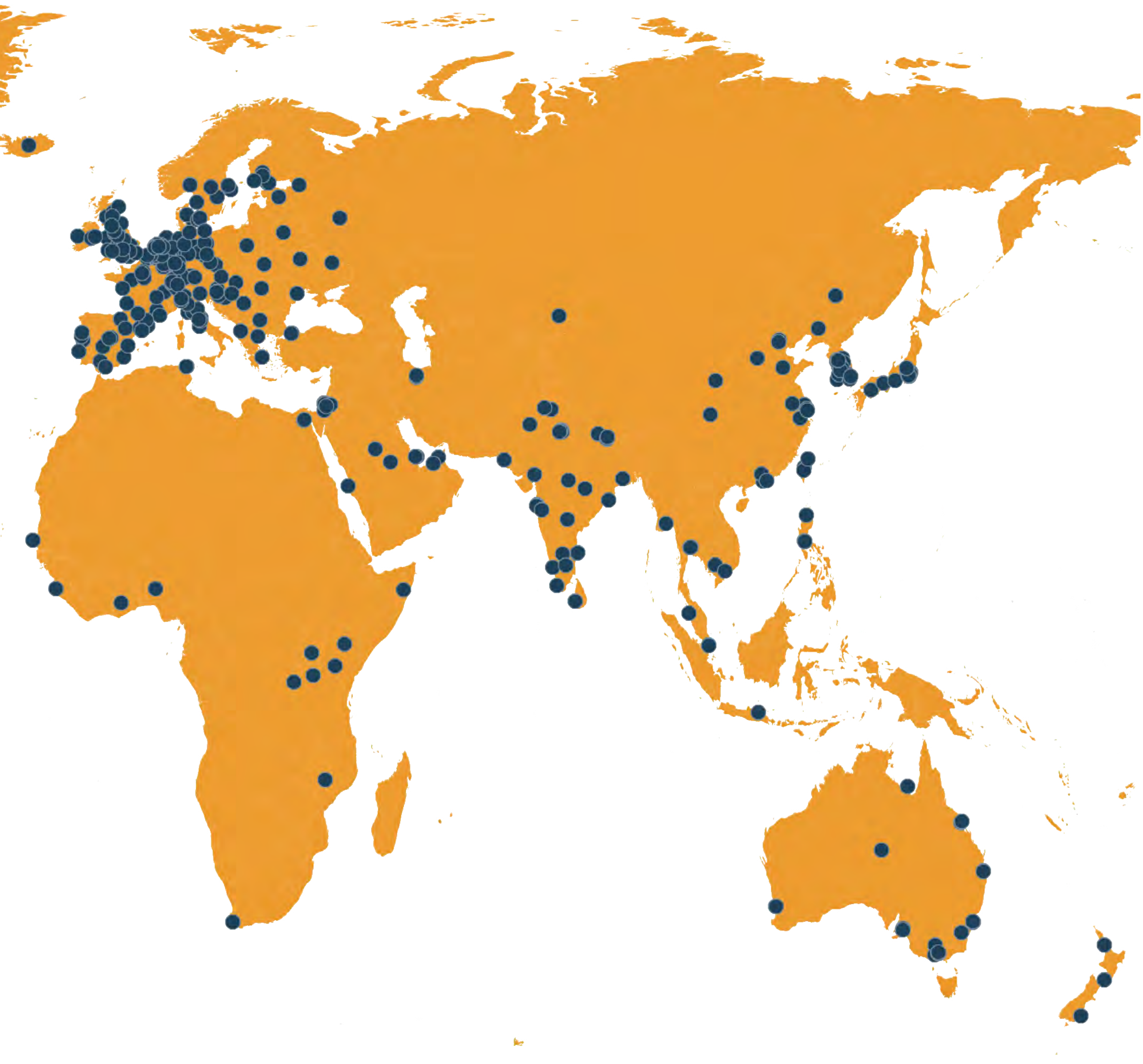
Map of Collaborators

The OHDSI community brings together volunteers from around the world to establish open community data standards, develop open-source software, conduct methodological research, and apply scientific best practices to both answer public health questions and generate reliable clinical evidence.

OHDSI By The Numbers

- 3,266 collaborators
- 80 countries
- 21 time zones
- 6 continents
- 1 community

Our community is ALWAYS seeking new collaborators. Do you want to focus on data standards or methodological research? Are you passionate about open-source development or clinical applications? Do you have data that you want to be part of global network studies? Do you want to be part of a global community that truly values the benefits of open science? Add a dot to the map below and JOIN THE JOURNEY!



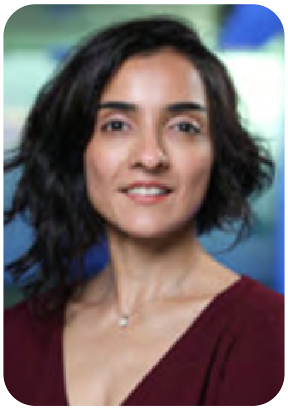
Organizations Involved With OHDSI

OHDSI is a global community of collaborators. Many of the individuals represent organizations who contribute to and benefit from their participation in the OHDSI community. OHDSI is proud to collaborate with the more than 400 organizations listed below, and looks forward to other organizations joining the journey as well.

2Ca-Braga • Aarhus University • AbbVie • Advocate Aurora Health • Agenzia Di Tutela Della Salute Della Provincia Di Bergamo • Ajou University Hospital • Akrivia Health • All Of Us Research Program • Allscripts • AMC Medical Research BV • Amgen • Andrija Štampar School Of Public Health • APDP Diabetes Portugal • Arcadia Inc • ARS Toscana • Asan Hospital • ASCO CancerLinQ • Asociación Instituto De Investigación Sanitaria Biocruces Bizkaia • Assistance Publique - Hopitaux De Paris / Aphp • Assistance Publique Hopitaux De Marseille • Astellas Pharma • AstraZeneca • ASU • AU-EPBRN • AUS Dept of Veterans Affairs • AWS • Az Delta Vzw • Az Klina • Azienda Ospedaliera Nazionale Ss. Antonio E Biagio E Cesare Arrigo Alessandria • Azienda Ospedaliera Universitaria (Aou) Di Modena • Azienda Ospedaliera Universitaria Integrata Verona • Azienda Unità Sanitaria Locale-Irccs In Reggio Emilia • B2I Healthcare • Barts Health NHS Trust • Bayer AG • BCB Medical Oy • Beijing Safe House • Ben-Gurion University • Berlin Institute of Health • Bill & Melinda Gates Foundation • Boehringer Ingelheim • Booz Allen Hamilton • Bordeaux Hospital • Boston Medical Center • Bradford Teaching Hospitals NHS Foundation Trust • Brazilian MOH • Brown University • Bucheon Hospital • Buddhimed Technologies • Caliber • Cancerdatanet Gmbh • Carilion Clinic • Carnegie Melon in Qatar • Case Western CICB • Catholic University of Korea Seoul St. Mary's Hospital • Catholic University of Korea Yeouido St. Mary's Hospital • CDPHP • CEEISCAT (Catalonia) • Cegedim Health Data • Centre Hospitalier Universitaire De Lille • Centre Hospitalier Universitaire De Toulouse • Cerner • Cha University Bundang Medical Center • Charité - Universitätsmedizin Berlin • CHCO (USA) • Cherokee Health Systems • Children's National • CHLA (USA) • Chonnam National University Hospital • CHOP (USA) • CHU Montpellier • Clínica Alemana de Santiago • Clinical Center of Serbia • Clinical Centre of Nis • Cognizant • Columbia University • Columbia University Irving Medical Center • CRHFEI • CSS Denmark • Daegu Catholic University Hospital • Data Integration Centre University Hospital Carl Gustav Carus Dresden • data4life • Databricks • Datasus Ambulatory • DFCI • DHS Los Angeles • DNAnexus • Dongguk University Ilsan Hospital • Dresden University Of Technology • DRG • Drug Safety Research Unit • Duke • Eau Claire Cooperative Health Center • EBMT (EU) • EGCUT • EHDEN • EISBM (Europe) • Eli Lilly & Company • Ephir Inc. • Erasmus MC • European Medicines Agency • Evidera • Evidnet • Ewha Womans University Mokdong Hospital • FIBH12O • FinnGen • Flatiron • Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico • Fondazione IRCCS Istituto Nazionale Dei Tumori • Fondazione IRCCS Policlinico "San Matteo" • Fondazione Poliambulanza • Fred Hutch Cancer Center • Freyr Ltd • Fudan University • Fujitsu • Fundacio Institut D'Inves72tigacions Mèdiques • Fundación Rioja Salud • FUS • GA4GH • Gacheon Gil Hospital • Galilee Medical Center • Gangbuk Samsung Hospital • Gangdong Sacred Heart Hospital • Gangnam Severance Hospital • Geisinger • General Hospital Of Kavala • Georgetown/MedStar Health • Getrude's Children Hospital • Glsmed Learning Health • Google • Great Ormond Street Hospital NHS Foundation Trust • GlaxoSmithKline • Georgia Tech Research Institute • George Washington University • Hanover Medical School (Germany) • Hanyang University Hospital • Harvard • Harvey Walsh Ltd • Hasselt University • HealthVerity • Hebei Mental Health Center • Helix • Helsinki UH CCC Hematology • Hierarchia D.O.O. On Behalf Of University Hospital Centre Zagreb • Health Insurance Review and Assessment Service • HL7 • HM Hospitals • HMAR • Hospital District Of Southwest Finland (Varsinais-Suomen Sairaanhoitopiiri) • Hulafe (Spain) • Hus Datalake Ecareforme Poc • Hwasun Chonnam National University Hospital • IBM T.J. Watson Research Center • Ican School Of Medicine At Mount Sinai • ICON • ICVS (Portugal) • IDIAPJGOL / SIDIAP • Idival • IMASIS • Imperial College Of Science Technology And Medicine • Incheon Sejong Hospital • Indian Society for Clinical Research • Indiana University

School Of Medicine • Inha University Hospital • Innovative Medical Research SA • Inova Health • Institute of Applied Biosciences • Int'l Uni of Health And Welfare • Integraal Kankercentrum Nederland • Intermountain Healthcare • IQVIA • IRST (Italy) • Istanbul Universitesi • Istanbul Universty-Cerrahpasa • Janssen R&D • Janssen Scientific Affairs • Jayne Koskinas Ted Giovanis Foundation • Jiangxi Province • Johns Hopkins University • Johnson & Johnson • Juntendo Uni SOM • Kangwon National University Hospital • Karolinska Institutet • Keck Medicine (USC) • Khoo Teck Puat Hospital • KI Research Institute • King Saud University Medical City • King's College London • Kliničko-Bolnički Centar Zvezdara • Knight Cancer Institute • Konkuk University Hospital • Konyang University Hospital • Korea Advanced Inst of Sci and Tech • Korea University Anam Hospital • Korea University Ansan Hospital • Korea University Guro Hospital • Kyoto University • Kyunghee University Hospital • Kyunghee Medical Center • Kyungpook National University Hospital • Kyushu University Hospital, Japan • Leeds Teaching Hospitals NHS Trust • Leiden MC • LIH (Luxembourg) • Loyola University (NOLA) • LTS Computing LLC • Lundbeck • Lynxcare Clinical Informatics NV • M2GEN • MaineHealth • Marina Salud S.A. • Mass General Brigham • Mayo Clinic • MDV (Japan) • Medaman BV • mederrata • Medibloc • Merck • Microsoft • MIT • MITRE • Momentum AD • Montefiore/AECOM • MS Urban Research Center • MSFP-gGmbH • MSKCC • MSU (MT) • MTPPI • MU Vienna • MUSC / HSSC • Myongji Hospital • Nanfang Hospital • National Cancer Center • National Cancer Hospital East • National Health Insurance Corporation Ilsan Hospital • National Institute of Public Health (Japan) • National University of Hospital (SG_NUH) • NCQA • Nemours • NHIRD • NICE • Northshore • Northwell Health • Northwestern Med • Novartis • Novo Nordisk Inc. • NYU Langone • Odysseus Data Services • OHSU • Okayama University • Oklahoma U • Optimum Patient Care Limited • OSU Medical Center • Outcomes Insights • Oxford • Pareto Intelligence • Paxata • Pedianet • PEDSnet • Peking Union Medical College Hospital • Penn State • PhysioNet • PicnicHealth • Pirkanmaa Hospital District • Plateforme De Données De Santé • Policlinico San Donato S.P.A. • Portuguese Institute of Oncology of Porto • Premier Healthcare • PSMAR (Barcelona) • PSSJD • Pusan National University Hospital • Queen Mary University Of London • RCGP (UK) • Regeneron • Regenstrief Institute • Reliant Medical Group • Roche • Rush UMC • Rutgers • RWJ Barnabas • Sage Bionetworks • SAIL Databank • Samsung Seoul Hospital • Sanford Health • Sanofi • Saudi FDA • SBU (USA) • Semantix • Semmelweis Egyetem • Seoul National University Bundang Hospital • Seoul National University Hospital • SERMAS & FIIBAP • Severance Hospital • Shuanghe Hospital • Siemens Health Services • SIMG (Italy) • SNOMED CT • Snowflake • Soonchunhyang University Hospital • Spectrum Health • Spok • St. Luke's (Idaho) • Stanford University • Stichting Integraal Kankercentrum Nederland • STIZON • Sydney LHD • Taipei Medical University Affiliated Hospital • Taipei Municipal Wanfang Hospital • Takeda • Technical University Sofia • The Hyve • The Roux Institute at Northeastern • The University Court Of The University Of Edinburgh • Tokyo University • Tianjin Anding Hospital • tranSMART • TrialSpark • Tufts • Tulane • U Copenhagen • U Dundee • U Gothenburg • U Hong Kong • U IL Chicago • U Minho • U São Paulo Medical School • U South Australia • U Tartu • U Tsukuba • U Utah • U Witwatersrand • UA-Birmingham • UArkansas • UBuffalo • UColorado Health • UColorado-Anschutz Medical Campus • UCalgary • UChicago • UCincinnati • UCL (UK) • UCLA • UCSF • UFlorida Health • UH Geneva • UHG (USA) • UIO • University of Iowa • UK Biobank • UK-CRIS • UKentucky • UKER • Ulsan University Hospital • U Mass Memorial MC • UMC New Orleans • UMessina • University of Miami • University of Michigan • UMichigan School of Dentistry • University of Minnesota • University of Mississippi MC • UNC Chapel Hill • Unidade Local De Saúde De Matosinhos Epe • Université De Bordeaux • Université De Genève • University College London Hospitals NHS Foundation Trust • University of Pécs • UNMC • UNew Mexico • UNSW Medicine Australia • UPennsylvania • UPittsburgh • URochester • US Department of Veterans Affairs • US Department of Defense • US Food & Drug Administration • US National Cancer Institute • US National Institutes of Health • US National Library of Medicine • USAID • USC (LA) • UTexas-Austin • UTexas-Houston • UTHCS-Houston • UTMC • UVirginia • UWashington (Seattle) • UWisconsin-Madison • Vall D'Hebrón Hospital Campus • Vanderbilt • VCU • Veradigm • Vertex • Vivante Health Software • Vrije Universiteit Amsterdam • Wake Forest • Wanfang Hospital • Washington University • WashU St Louis • Weill Cornell Medical Center • WHO Uppsala Monitoring Centre • Winship Cancer Institute of Emory University • WMichigan USOM • Wonju Severance Hospital • Wonkwang University Hospital • WVU • Yale • Yongin Severance Hospital • Yonsei University • ZOL (Belgium) • ZS Associates

Testimonials From The



There is a lot of energy and good will in the community. It is open, inclusive, and extremely diverse. I get my energy from the community. The enthusiasm and drive to do the right thing and to improve human lives and the possibility to work with such a diverse group of individuals and learn from them excites me and pushes me to do more. I am extremely proud to be a part of this effort.

Asieh Golozar

VP, Global Head of Data Science at Odysseus Data Services, Inc. and Professor of the Practice & Director of Clinical Research at the OHDSI Center, Northeastern University

The values, goals, and people of OHDSI I find incredibly inspiring. The people in OHDSI are highly talented, practical, and collegial. They are always welcoming new people on the journey. OHDSI is a multi-disciplinary community pushing the boundaries of computational observational research so there is always something new to learn. The values of being transparent in our methods and in our software resonate with me in trying to make a lasting impact. I get energized from going to OHDSI meetings because I always meet new people, learn new things, and am part of making a difference in improving healthcare.

Paul Nagy

Program Director for Graduate Training in Biomedical Informatics and Data Science and Deputy Director of the Johns Hopkins Medicine Technology Innovation Center

I often sit in those teleconferences (often late at night or in the wee hours of the morning here in Australia) and marvel at the discoveries and new insights that are shared so openly, the light bulb moments that lead to fabulous discoveries! The work that has been generated in LEGEND and EUMAEUS is important clinically. It can help update clinical guidelines and provide robust evidence for medicine regulators – but for me these landmark studies have also provided critical insights into which methodologies are appropriate under which conditions – especially the value of empirical calibration!

Nicole Pratt

Professor at University of South Australia

There is a saying in Chinese — 酒香不怕巷子深 — which could be translated into 'Good wine needs no bush'.

I really think the reason is because OHDSI has great methodologies, tools, and community support, which are making more and more people adopt OMOP and join the community.

Jing Li

Associate Director of Data Science at IQVIA

OHDSI Community

Although 2020 was a challenging year for most, due to COVID-19, I will remember it for another significant experience as well: the beginning of my collaboration with the OHDSI community. I had the pleasure to participate in scientific research, symposiums, and other collaborative ventures and meet several Titans of the community in person.

ETHONs are a perfect example of how the collective effort of motivated and proactive people can contribute to a greater cause. Thanks to ETHONs and the cooperation with the University Clinical Center of Serbia, I had the opportunity to get better acquainted with the OHDSI toolset and the open-source community around it. In addition, observational studies in which I participated gave me and my colleagues valuable insights and new perspectives for future projects. Through efforts like these, OHDSI enables underrepresented populations to be exposed and contribute to scientific and medical evidence.

After a short time in the community, I felt really comfortable within it and I think it's very easy to advance in it. OHDSI is a community of visionary, forward-looking and persistent people, and their efforts motivate me to improve my skills and contribute more to the community.

Filip Maljković
Lead Programmer at Heliant

In OHDSI I have found an inter-disciplinary community dedicated to making the best use of routinely collected healthcare data to find better treatments for diseases that have greatly affected some of my closest friends and family members. My journey in OHDSI has taken me from being an inspired spectator to co-leading the Open Source Community workgroup with Paul Nagy. Together we are growing OHDSI's open-source software ecosystem and the next generation of OHDSI developers.

Contributing to OHDSI open-source software has been a longtime goal for me and now that it's part of my day job I can say that contributing to open source is more rewarding than I ever thought it could be. The problem with OHDSI is that there are too many amazing projects and people to keep up with, and that's a good problem to have.

Adam Black
Data Scientist at Odysseus Data Services, Inc.

Starting my PhD right before the pandemic started, I got to see the OHDSI community in full action right away during the COVID-19 study-a-thon. Still today, I'm impressed to see so many people from different backgrounds and disciplines work together towards a shared goal.

OHDSI's friendly, supportive and collaborative culture is something I especially appreciate as an early-career researcher.

Furthermore, being able to perform studies on real-world data using the OMOP CDM, thereby re-using tools others created, is a researcher's dream come true!

Aniek Markus
PhD Candidate, Erasmus MC

The Titan Awards

To recognize OHDSI collaborators (or collaborating institutions) for their contributions towards OHDSI's mission, the OHDSI Titan Awards were introduced at the 2018 Symposium and will be awarded for a fifth consecutive year at the 2022 Symposium.

Annually, community members are invited to nominate individuals or institutions they feel have made significant contributions towards advancing OHDSI's mission, vision and values. Once nominations are submitted, the OHDSI Titan Award Committee selects the award winners, and the honorees are announced at the annual symposium.

The award categories, as well as all previous recipients, are listed here.

Data Standards

This Titan Award recognizes extraordinary contributions by an individual, organization, or team in development or evaluation in community data standards, including OMOP common data model and standardized vocabularies

Maxim Moinat
2021 honoree

2021 – Maxim Moinat, The Hyve/ Erasmus University Medical Center

2020 – Clair Blacketer, Janssen Research and Development

2019 – Oncology Workgroup (Michael Gurley, Northwestern University; Rimma Belenkaya, Memorial Sloan Kettering Cancer Center; Robert Miller, Tufts CTSI)

2018 – Vocabulary team (Christian Reich, IQVIA; Anna Ostropolets, Columbia University; Dmitry Dymshyts, Odysseus Data Services)

Methodological Research

This Titan Award recognizes extraordinary contributions by an individual, organization, or team in development or evaluation in analytical methods for clinical characterization, population-level effect estimation, or patient-level prediction

Yong Chen
2021 honoree

2021 – Yong Chen, University of Pennsylvania

2020 – Nicolas Thurin, Université de Bordeaux

2019 – Jenna Reps, Janssen Research and Development

2018 – Martijn Schuemie, Janssen Research and Development; Marc Suchard, University of California, Los Angeles

Open-Source Development

This Titan Award recognizes extraordinary contributions by an individual in design, development, testing, and deployment of open-source software to enable observational analyses

2021 – Adam Black, Odysseus Data Services

2020 – Anthony Sena, Janssen Research and Development

2019 – Pavel Grafkin, Odysseus Data Services

2018 – Christopher Knoll, Janssen Research and Development

Adam Black
2021 honoree

Clinical Applications

This Titan Award recognizes extraordinary contributions by an individual, organization, or team in generating clinical evidence that improves health by informing better health decisions and better care

2021 – Asieh Golozar, Odysseus Data Services

2020 – Jenny Lane, University of Oxford

2019 – Oxford Study-A-Thon (Dani Prieto-Alhambra, University of Oxford; Edward Burn, University of Oxford; Jamie Weaver, Janssen Research and Development; Ross Williams, Erasmus University Medical Center)

2018 – Seng Chan You, Ajou University

Asieh Golozar
2021 honoree

Community Collaboration

This Titan Award recognizes an individual for their collaborative spirit in helping their fellow community members reach their goals.

2021 – Erica Voss, Janssen Research and Development
2020 – Talita Duarte-Salles, IDIAPJGol
2019 – Andrew Williams, Tufts Medical Center
2018 – Kristin Kostka, Deloitte; Mui Van Zandt, IQVIA

Erica Voss
2021 honoree

Community Support

This Titan Award recognizes an individual, team, or organization for their contributions to ensuring the sustainability of the OHDSI community.

Faaizah Arshad
2021 honoree

2021 – Faaizah Arshad, UCLA; Ross Williams, Erasmus University Medical Center
2020 – COVID-19 Support Team**,** Erasmus University Medical Center
2019 – James Wiggins, Amazon Web Services
2018 – Lee Evans, LTS Computing LLC

Ross Williams
2021 honoree

Community Leadership

This Titan Award recognizes an individual for their leadership in advancing the OHDSI mission.

2021 – Mui Van Zandt, IQVIA
2020 – Dani Prieto-Alhambra, University of Oxford
2019 – Peter Rijnbeek, Erasmus University Medical Center
2018 – Rae Woong Park, Ajou University School of Medicine

Mui Van Zandt
2021 honoree

IV.

Collaborative Activities

OHDSI Workgroups

OHDSI's central mission is to improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care. We work towards that goal in the areas of data standards, methodological research, open-source analytics development, and clinical applications.

There are currently 27 active working groups that present opportunities for all community members to find a home for their talents and passions, and to make meaningful contributions. We are always looking for new collaborators.

See an area where you want to contribute? Please **Join The Journey!**

APAC (Asia-Pacific)

Current Participants: 289

Lead: Mui Van Zandt

ATLAS/WebAPI

Current Participants: 226

Lead: Anthony Sena

Clinical Trials

Current Participants: 252

Leads: Mike Hamidi, Lin Zhen

Common Data Model

Current Participants: 596

Lead: Clair Blacketer

Data Quality Dashboard Development

Current Participants: 260

Lead: Clair Blacketer

Early-Stage Researchers

Current Participants: 214

Leads: Faaizah Arshad, Ross Williams

Education

Current Participants: 116

Lead: Nigel Hughes

Eye Care & Vision Research

Current Participants: 40

Leads: Sally Baxter, Kerry Goetz

FHIR and OMOP

Current Participants: 214

Leads: Jon Duke, Christian Reich, Dana Stephenson

Geographic Information System (GIS)

Current Participants: 122

Leads: Robert Miller, Andrew Williams

HADES (Health Analytics Data-to-Evidence Suite)

Current Participants: 262

Lead: Martijn Schuemie

Health Equity

Current Participants: 201

Lead: Jake Gillberg

Healthcare Systems

Current Participants: 430

Lead: Melanie Philofsky

Latin America

Current Participants: 48

Lead: Jose Posada

Medical Devices

Current Participants: 130

Leads: Vojtech Huser, Asiyah Lin

Our workgroups hold meetings, share files, chat asynchronously and more in the OHDSI Microsoft Teams environment. **Collaborators can request access to any workgroup** through an online form available on both OHDSI.org and our main OHDSI Microsoft Teams environment.

Want to learn more? Check out our homepage: **ohdsi.org/ohdsi-workgroups**

Medical Imaging
Current Participants: 114
Leads: Paul Nagy, Seng Chan You

Natural Language Processing
Current Participants: 379
Lead: Hua Xa

Oncology
Current Participants: 241
Lead: Asieh Golozar

Open-Source Community
Current Participants: 118
Leads: Adam Black, Paul Nagy

Patient-Level Prediction
Current Participants: 355
Leads: Jenna Reps, Ross Williams

Phenotype Development & Evaluation
Current Participants: 249
Lead: Gowtham Rao

Population-Level Effect Estimation
Current Participants: 355
Leads: Martijn Schuemie, Marc Suchard

Psychiatry
Current Participants: 115
Leads: Dmitry Dymshyts, Andrew Williams

Registry
Current Participants: 115
Lead: Tina Parciak

Steering Group
Current Participants: 70
Lead: Patrick Ryan

Surgery and Perioperative Medicine
Current Participants: 37
Lead: Evan Minty

Vaccine Vocabulary
Current Participants: 76
Lead: Adam Black

OHDSI Regional Chapters

An OHDSI regional chapter represents a group of OHDSI collaborators located in a geographic area who wish to hold local networking events and meetings to address problems specific to their geographic location.

Africa
Current Participants: 66
Lead: Nega Gebreyesus

Australia
Current Participants: 74
Lead: Nicole Pratt

China
Current Participants: 228
Lead: Hua Xu

Europe
Current Participants: 321
Lead: Peter Rijnbeek

India
Current Participants: new
Lead: Swetha Kiranmayi Jakkuva

Japan
Current Participants: 49
Lead: Tatsuo Hiramatsu

Korea
Current Participants: 55
Lead: Seng Chan You

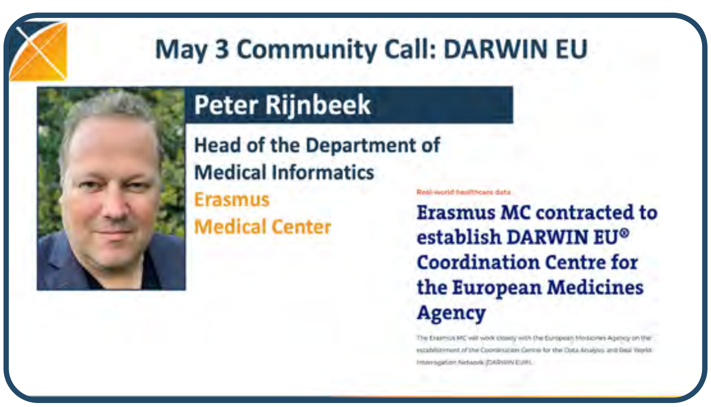
Singapore
Current Participants: 58
Lead: Mengling Feng

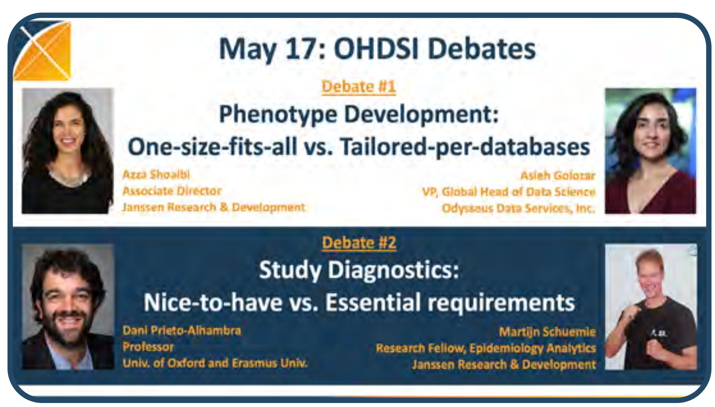
Taiwan
Current Participants: 71
Lead: Jason Hsu

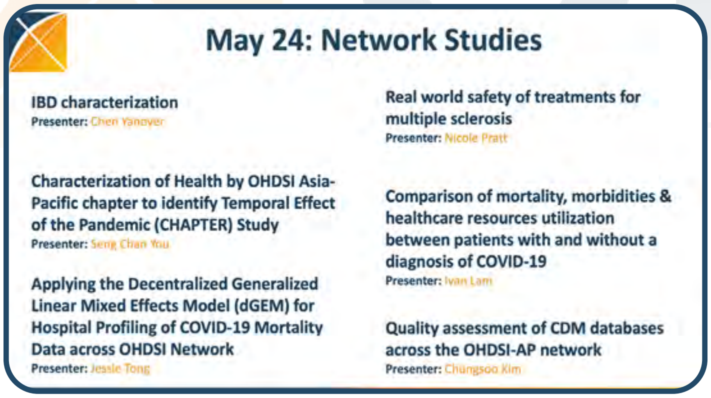
OHDSI Community Calls

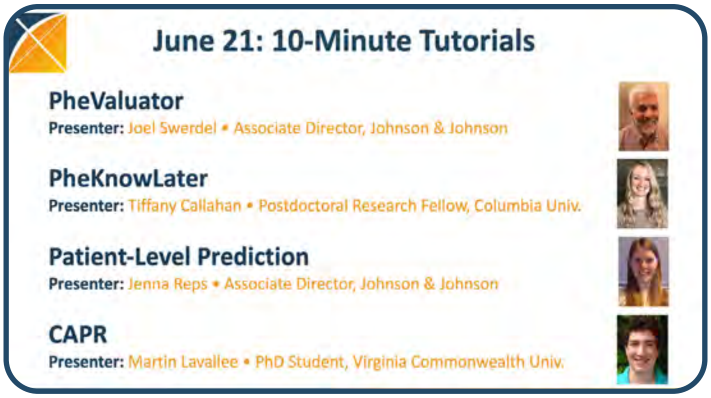
The weekly OHDSI community call is where our global network gathers together to share research, discuss various topics around observational health, keep apprised on community updates, and plenty more. Our weekly calls take place on Tuesdays at 11 am ET and are led by Craig Sachson, and they are both recorded and posted to both OHDSI.org and within our Teams environment.

These pages highlight just a few of the meeting topics from 2022; please check out ohdsi.org/community-calls to learn more about these interactive community gatherings.









How Can You Join Our Calls?

If you are a part of the OHDSI Teams environment, you will receive a weekly calendar invite that includes the upcoming agenda. If you don't have access, the link is on our Community Calls page, which features all recordings and updates from past calls.

Weekly calls are currently held on Tuesdays at 11 am ET. Learn more at our website!

www.ohdsi.org/community-calls

2020 Barcelona study-a-thon, which focused on rheumatoid arthritis

OHDSI Study-A-Thons & Other Events

How does OHDSI go about *empowering a community to collaboratively generate the evidence that promotes better health decisions and better care*?

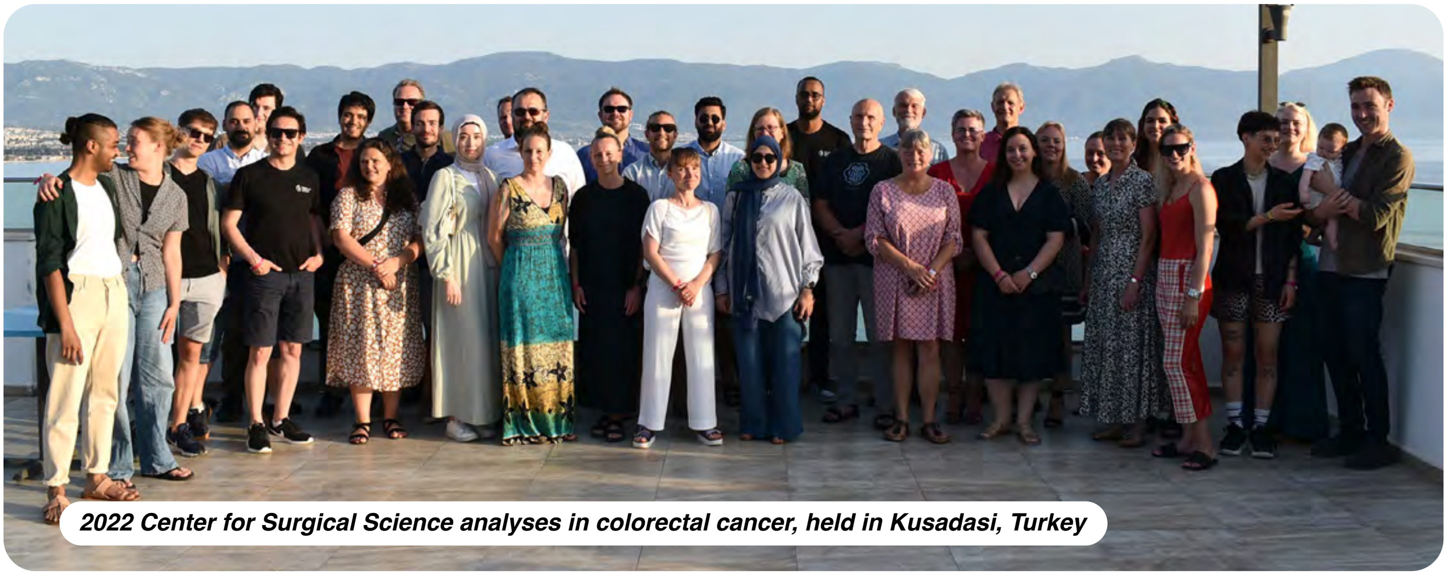
We do it by innovating on what it means to do collaborative research.

The premise of the study-a-thon is simple: bring together a diverse group of researchers aligned on a common question and focus together on collaboratively designing research protocols, executing analyses across databases, and interpreting results over an intense but fun-filled few days.

OHDSI collaborators have held multiple study-a-thons on a wide array of topics, including orthopedic surgery, rheumatoid arthritis, colorectal cancer, cardiovascular prediction, prostate cancer, and COVID-19. Each event has demonstrated our collective ability to accomplish in a short time what may be unimaginable alone, and it has provided further reinforcement of the power of community and the value of multi-disciplinary collaboration.

2022 Sweden EHDEN study-a-thon, which focused on pharmacovigilance


2018 Oxford study-a-thon, which focused on knee replacement surgery


2022 Center for Surgical Science analyses in colorectal cancer, held in Kusadasi, Turkey

2022 Korea Datathon, which focused on several research questions

88 Hours: OHDSI's Signature Moment

OHDSI's COVID-19 work began with the ultimate show of collaboration & community.

The time was originally meant for highlighting OHDSI capabilities, not testing them.

The hours were meant for sharing global research, not sharing *in* global research.

The Observational Health Data Sciences and Informatics (OHDSI) community held a COVID-19 global, virtual study-a-thon March 26-29, 2020, believing that a network of people who valued both collaboration and open science could make a meaningful impact on the current global pandemic.

How? Nobody was quite sure in the moment, but they were confident they would figure it out.

"We chose an ambitious path and relied on our community and infrastructure to lead the way," said Patrick Ryan, Vice President of Observational Health Data Analytics at Janssen Research and Development. "In simple terms, efforts within our community over the past 88 months set the foundation for OHDSI's most important and impactful 88 hours."

The OHDSI community, by definition, is a multi-stakeholder, interdisciplinary collaborative to bring out the value of health data through large-scale analytics. In plainer terms, it's a community of people who volunteer their time and talents for the shared goal of improving healthcare through observational research.

A global network of OHDSI colleagues planned to celebrate recent research initiatives and discuss future efforts during the annual European Symposium at Oxford University in late March of 2020. The symposium was canceled due to the rapidly spreading COVID-19 virus; in its place, the organizing committee planned a study-a-thon, which OHDSI has experienced significant success with several times over.

The twists?

The COVID-19 data was limited (a significant issue for an observational data science network), the needs were immediate, and everybody was staying home.

Those factors would be a hard stop to most, but the virtual OHDSI community has thrived on overcoming obstacles, and there was never a more crucial time to do so again.

Daniel Prieto-Alhambra, Professor of Pharmaco- and Device Epidemiology at Oxford, remembers his OHDSI conversion occurring during one of the afore-mentioned study-a-thon events in 2018. This one had nothing to do with viruses or antibodies; it was about the safety profile of varied knee replacement procedures and ultimately produced a paper published in Lancet Rheumatology.

While that data didn't affect COVID studies 15 months later, the impact of the event stayed with Prieto-Alhambra. He presented on it during the 2019 U.S. Symposium, led another one in Barcelona to focus on rheumatoid arthritis and volunteered to host the global community for the 2020 European Symposium.

"We were thrilled to bring the OHDSI community to Oxford, and we were excited about some new aspects, including new tutorials," Prieto-Alhambra said. "It was crushing to cancel it in the moment, but we quickly looked ahead and saw an opportunity to make the most of our time and talents. From that moment, we never looked back."

88 hours.

That was the time between the global kickoff and closing calls, both of which have combined for more than 2,300 views on YouTube (the entire set of calls and presentations is available at the OHDSI COVID-19 research page). More than 330 people from at least 30 nations registered to collaborate in the event, offering their services in areas like literature review, protocol development, study execution, etc.

Peter Rijnbeek, Associate Professor Health Data Science at the Erasmus University Medical Center in the Netherlands, has a history of bringing together leaders in observational health data science. He hosted the 2019 OHDSI European Symposium, and is leading the recently created EHDEN consortium, which is building a large-scale, federated network of European data sources for the discovery and generation of real-world evidence.

He took a leadership role once again; his Erasmus team set up the Microsoft Teams virtual platform and created 17 different teams that held varied roles throughout the event.

This setup, for example, enabled a group focused on phenotype development to work collaboratively, while also having the ability to connect with teams inside the characterization, estimation and prediction groups as well. When needed, there were support teams for literature review, data support, study design and more.

Your standard study-a-thon might just send various groups to different areas within a shared space. During these 88 hours, that 'space' might have had collaborators from both hemispheres working simultaneously at different points of

More than 300 people from across 30 countries joined a critical journey during a 4-day study-a-thon in March, 2020, wahich set the foundation for OHDSI's work around COVID-19. It was the ultimate sign of collaboration through open science.

a 13-hour time period. From breakfast in one part of the world to dinner in another, determined volunteers didn't stop working together to seek answers during a global crisis.

"OHDSI has always been about people working together to solve common goals, and I am proud our team helped to make this event possible," Rijnbeek said. "We brought the OHDSI world to Erasmus MC in person last year, but it was even more important to bring them together virtually right now."

88 hours.

It is unrealistic to think OHDSI's monumental goals could be accomplished in such a limited time. Early work needed to be done to develop an infrastructure for both the meetings and the OHDSI technical platforms, which happened mainly due to the sustained efforts of Lee Evans, Anthony Sena, and James Wiggins. Beyond that, many of the prioritized questions that would become the primary focus of the four days were determined beforehand.

Community involvement was sought in suggesting such questions, but a group that truly believes in collaborative open science knew this was a time to reach outside the circle. Stakeholders around the world reached out to national governments, public health agencies, and health-related institutions to learn what the most critical questions were right now. That feedback, as well as a literature review process that began days before the study-a-thon, helped the core team provide a framework for the four days.

There was a clear desire to create a multi-nation characterization study of COVID-positive patients, even if the data size was more limited at the moment.

There was a need to understand the overall safety profile of different drugs being considered in COVID treatment; that included hydroxychloroquine, which became an international fascination after achieving small success in France and then being touted by U.S. President Donald Trump on multiple occasions.

There were crucial prediction questions, which could help healthcare workers make important triage decisions, including which patients would require hospitalization. As each day passed, the challenges facing overwhelmed medical facilities globally were becoming abundantly clear.

Preliminary work with data was necessary as well. Christian Reich led the vocabulary team to develop COVID-related updates on the standardized vocabularies, while Kristin Kostka and Greg Klebanov were among many collaborators working with different sites on either data conversion or analysis support. Seng Chan You and Rae Woong Park collaborated with the South Korean HIRA, which worked with OHDSI to run packages against a more robust set of COVID data than anywhere in the United States. A handful of American institutions, including Columbia and Stanford, signed on to provide deidentified COVID data as well.

"The data owners chose to donate their data for use in these critical studies simply because they want to help," Kostka said. "They share our belief in the power of the OHDSI community, and because of that trust, we are able to generate the world's largest observational studies to help inform decision-making in this major public health issue. I think that's the coolest thing imaginable, and I am so proud to be part of this effort."

Laying the groundwork was the necessary warmup for the sprint that was to come — and the marathon that would follow.

88 hours.

It began Thursday, March 26, at 7 am in Oxford, as Prieto-Alhambra welcomed an international community of people

continued on next page

Collaborative Activities

continued from previous page

to this unique and critical initiative. A panel including Ryan, Rijnbeek and George Hripcsak — chair of the Department of Biomedical Informatics at Columbia University, the coordinating center for OHDSI — discussed the long journey from the formation of OHDSI to this moment, and what they believed could be accomplished over four days.

Subgroup calls immediately followed to set the course for their respective work plans. Teams within characterization, estimation and prediction studies discussed study questions, varied responsibilities, and timetables over the four days; those timetables were dependent on the phenotype group, which had to develop standard cohorts that could be used within all studies.

It was the ultimate team environment.

And the clock was now ticking.

88 hours.

Leadership from institutions including Oxford, Erasmus, Columbia, UCLA, Ajou University, Janssen Research and Development, and IQVIA helped put this event in motion, but OHDSI empowers collaborators at different stages of their own journey to make important contributions.

Jennifer Lane, an orthopedic surgeon pursuing her PhD at Oxford, led the literature review efforts and co-authored the manuscript for the largest safety profile on hydroxychloroquine ever executed. Ed Burn, a recent PhD graduate from Oxford, led the characterization team; he had also served as lead author for the Lancet Rheumatology paper on knee replacement.

Ross Williams, Cynthia Yang and Aniek Markus are each PhD students at Erasmus, and they worked on co-authoring a prediction study that could help critical hospitalization and triage decisions healthcare workers are making daily.

Anna Ostropolets, a PhD student at Columbia, shared in the leadership of the phenotype team and presented on the 114 validated & reviewed cohorts developed and distributed by the team during the closing call.

Many others within academia contributed to the initiative, while global stakeholders from both industry and healthcare agencies provided critical efforts, ranging from protocol design to data support.

"The OHDSI community has an open approach to everything," said Lane, co-lead author of the hydroxychloroquine study, which would eventually be published by Lancet Rheumatology but made its immediate impact as a preprint. "It is based upon clear communication, that all contributions are valuable. Everyone is playing to their strengths, which means that the combined effort is precise in many areas that would be incredibly difficult or impossible within one research group or institution. I have met people who will shape the way I work in the future, both through their leadership and their willingness to help me learn novel research approaches."

Many registrants were newcomers to the OHDSI process who found the idea of a COVID-19 study-a-thon either inspirational and interesting. Their contributions may have been more limited than others over the 88 hours. Some from that group quickly found their footing in the community afterwards and joined studies either developed or brainstormed over the four days.

Covid-19 Study-A-Thon Registrants Span The Globe

Argentina	England	Saudi Arabia
Australia	France	Singapore
Belarus	Germany	South Korea
Belgium	Hungary	Spain
Brazil	India	Sweden
Canada	Israel	Switzerland
China	Italy	Taiwan
Colombia	Netherlands	Ukraine
Croatia	New Zealand	UAE
Denmark	Peru	United States

What You Should Know About The 2020 OHDSI COVID-19 Study-A-Thon

- **More than 330 people from across 30 countries (six continents) registered for the event.**
- **The event took place over 88 hours between March 26-29, and it was coordinated by the Erasmus University Medical Center.**
- **There were 17 concurrent channels on the overall Teams platform, and those channels hosted more than 100 collaborator calls.**
- **There were 12 global huddles, spaced out so collaborators from around the world would have a daily opportunity to hear about community progress.**
- **More than 10,000 publications were reviewed both prior and during the event.**
- **There were 13,000+ chat messages that helped design both 355 cohort definitions and nine protocols, as well as the release of 13 study packages.**
- **The closing call has been viewed almost 1,800 times since it was posted to YouTube.**
- **The OHDSI community has published numerous COVID-19 studies (including in Lancet Rheumatology, Nature Communications, Lancet Digital Health, and The BMJ), and continues that work currently with studies around vaccine surveillance.**

Each person who takes that step strengthens the community.

88 hours.

You've seen that number before? OK, here are a few new ones.

Between the 12 global huddles, there were more than 100 collaborator calls and 13,000 chat messages over 17 concurrent channels (different teams). More than 10,000 publications were reviewed and 355 cohort definitions were defined to lead to the drafting of nine protocols and the release of 13 study packages.

"The real-world evidence we are generating to inform decision-making in this pandemic is the most important thing to come from these four days," Ryan said. "Reflecting on what a community of volunteers achieved in this collaborative setting is humbling. We had a shared goal that mattered to everybody, but OHDSI has a way of attracting good people that you enjoy being around. I don't take that for granted. The people that make up our community are our greatest strength."

It's easy to have that positive feeling on Day 1, or as you reach the close, but to have it in the middle of a four-day marathon is a testament to the energy created organically. The Friday night chat messages and Saturday morning team calls mattered — in that short a time, it all matters — and maintaining focus and enthusiasm powered the process from start to finish.

The 88th hour.

The global closing call was broadcast live to a global audience and provided a series of presentations about how OHDSI arrived at this moment. It was an opportunity to celebrate shared efforts, announce study designs and preliminary findings, and plan for the future.

When Prieto-Alhambra signed off for the final time, COVID-19 did not go away.

OHDSI won't either.

The efforts continued immediately. As protocols continue to be designed or improved, data partners work to run studies and generate evidence. The first manuscript was submitted for peer review two weeks after the final signoff, and more followed.

Generating real-world evidence to improve healthcare has been the OHDSI mission since it officially formed in 2014. This has been a passion project for a global community that expands in both people and analytic capability each year.

Nobody saw this moment coming. But it did, and OHDSI was more ready for it than even the most optimistic collaborator could have imagined.

There were critical discoveries in the first six years, and there are many more to come — including some that will aid global efforts against COVID-19 in the near future.

But those 88 hours stand as a defining moment for OHDSI, and they are a glimpse of this community's potential on the journey ahead.

by Craig Sachson
published April 17, 2020

The Book of OHDSI

Published in 2019, the Book of OHDSI (**book.ohdsi.org**) aims to be a central knowledge repository for OHDSI, and it focuses on describing the OHDSI community, OHDSI data standards, and OHDSI tools.

It is intended for both OHDSI newcomers and veterans alike, and aims to be practical, providing the necessary theory and subsequent instructions on how to design and implement research yourself.

You will learn about the OMOP common data model and standard vocabularies, and how they can be used to standardize an observational healthcare database. You will learn about three analytic use cases for these data: characterization, population-level estimation, and patient-level prediction. You will read about OHDSI's open-source tools and how they can be applied to your data and how you can design and implement your own analyses following OHDSI's best practices.

Martijn Schuemie, who co-led the Book of OHDSI development with David Madigan, introduced the book at the 2019 U.S. Symposium.

Members of the OHDSI community collaborated on documentation efforts for the Book of OHDSI at Case Western Reserve Univ. in Cleveland.

Chapters on data quality, clinical validity, software validity, and method validity will explain how to establish the quality of the generated evidence. Lastly, you will learn how to use the OHDSI tools to execute these studies in a distributed research network.

The Book of OHDSI is available for free online in English, Korean and Chinese, and can also be purchased through Amazon (all links on OHDSI.org).

Thank You To Our Book of OHDSI Contributors

Hamed Abedtash	Mustafa Ascha	Mark Beno	Clair Blacketer	David Blatt
Brian Christian	Gino Cloft	Frank DeFalco	Sara Dempster	Jon Duke
Sergio Eslava	Clark Evans	Thomas Falconer	George Hripcsak	Vojtech Huser
Mark Khayter	Greg Klebanov	Kristin Kostka	Bob Lanese	Wanda Lattimore
Chun Li	David Madigan	Sindhoosha Malay	Harry Menegay	Akihiko Nishimura
Ellen Palmer	Nirav Patil	Jose Posada	Nicole Pratt	Dani Prieto-Alhambra
Christian Reich	Jenna Reps	Peter Rijnbeek	Patrick Ryan	Craig Sachson
Izzy Saridakis	Paola Saroufim	Martijn Schuemie	Sarah Seager	Anthony Sena
Sunah Song	Matthew Spotnitz	Marc Suchard	Joel Swerdel	Devin Tian
Don Torok	Kees van Bochove	Mui Van Zandt	Erica Voss	Kristin Waite
Mike Warfe	Jamie Weaver	James Wiggins	Andrew Williams	Seng Chan You

What Will You Find in The Book of OHDSI?

The OHDSI Symposium

There is nothing quite like an OHDSI symposium.

Whether it is held in the U.S., Europe or Asia, our community has turned the symposium into one of the most anticipated events of the year. The pandemic forced a temporary shift to virtual symposia, but we have been thrilled to return to in-person gatherings this year, beginning with the European symposium in June.

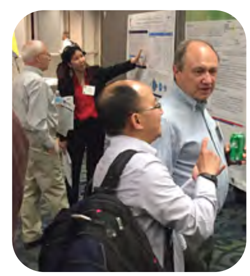
The opportunity to learn from each other and connect as colleagues and friends is unmatched, and our most impactful scientific discoveries are shared at the symposia. We hope you can join us at a future event!

Oct. 20, 2015 • Washington, D.C.




Sept. 23-24, 2016 • Washington, D.C.



Oct. 18-20, 2017 • Bethesda, Md.




Mar. 23-24, 2018 • Rotterdam, Neth.

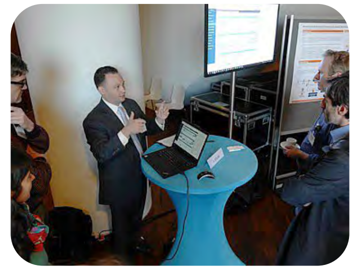



Oct. 11-13, 2018 • Bethesda, Md.



Mar. 29-30, 2019 • Rotterdam, Neth.



June 27-29, 2019 • Guangzhou, China


Sept. 15-17, 2019 • Bethesda, Md.



Dec. 12-14, 2019 • Gwangju, Korea

June 24-26, 2022 • Rotterdam, Neth.

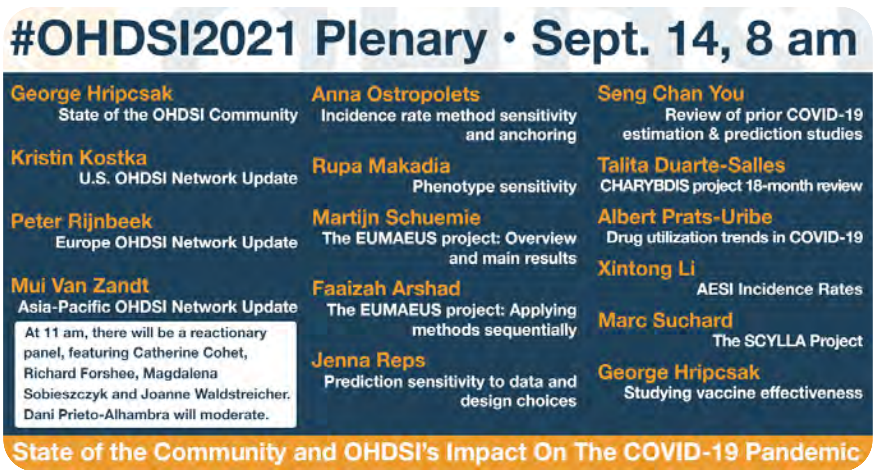


2021 OHDSI Symposium

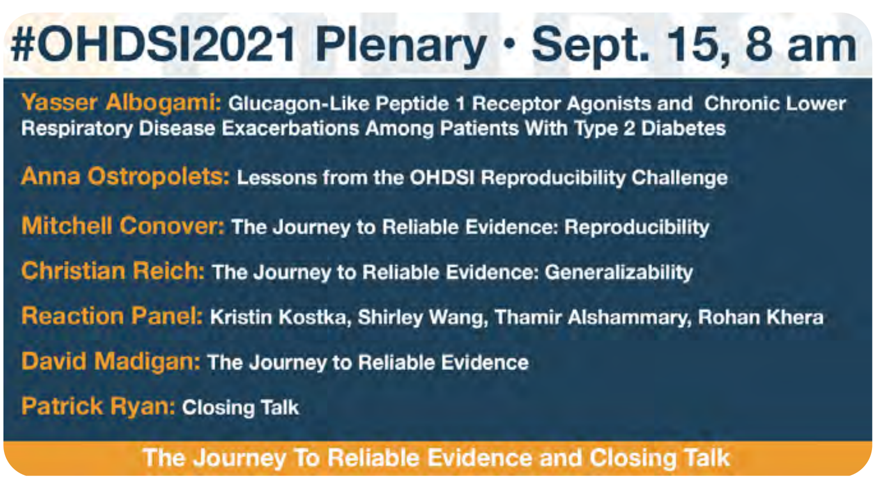
The 2021 OHDSI Global Symposium featured plenary presentations on both OHDSI's Impact on the COVID-19 Pandemic (Day 1), and On the Journey to Reliable Evidence (Day 2). The main days included the State of the Community Presentation, the Collaborator Showcase, and a memorable Closing Ceremony that focused on OHDSI's work through the perspective of a patient.

There were also a pair of activities, including the first OHDSI Reproducibility Challenge workshop, and also a full-day tutorial on building conceptsets.

If you missed it, or wish to watch any of the presentations again, they are all available at ohdsi.org/2021-ohdsi-global-symposium.



The **first plenary (above)** featured the State of the Community presentation, updates from the global OHDSI network, and then a series of talks about OHDSI's impact on the COVID-19 pandemic. The **second plenary (below)** focused on the journey to reliable evidence. Videos from both are available at the symposium homepage on OHDSI.org.



More Highlights from OHDSI2021

• The Closing Ceremony (Patrick Ryan, Jamie Weaver) highlighted the value of observational health research, as a former Titan Award recipient shared his story about appreciating OHDSI's work from the patient's perspective.

• The collaborator showcase received a record number of submissions, and following a peer-review process, there were more than 100 submissions of posters, software demos, and lightning talks; check out page 31 for more on the collaborator showcase.

• The State of the Community (George Hripcsak) highlighted the mission, development and direction of the OHDSI community.

2021 Lightning Talks

Data Quality Dashboard Used to Improve Data Quality in the EHDEN Network
Presenters: Clair Blacketer, Erica Voss

Beyond Clinical: Integrating Research Assay Data into the Observational Health Data Sciences and Informatics Common Data Model (OHDSI CDM) through the Surgical Critical Care Initiative (SC2i)
Presenter: Chandra Almond

Extending the OMOP CDM to store the output of natural language processing pipelines
Presenter: Monica Arrue

Validation of the Genomic Variant Vocabulary against TCGA
Presenter: Denys Kaduk

Evaluating the performance of Austin's standardized difference heuristic in observational cohort studies with varying sample size
Presenter: Mitchell Conover

Leveraging APHRODITE to identify bias in statistical phenotyping algorithms
Presenter: Juan Banda

Assessing the impact of race on glomerular filtration rate prediction
Presenter: Linying Zhang

A Prediction Model Library
Presenter: Ross Williams

Detection of prone positioning in hospitalized COVID patients using NLP
Presenter: Patrick Alba

From metrics to intelligence using the OMOP CDM and Patient-Level-Prediction package as a foundation decision support tool
Presenter: Ismail Gögenur

Detecting PTSD and self-harm among US Veterans using positive unlabeled Learning
Presenter: Christophe Lambert

Revealing unknown benefits of existing medications to aid the discovery of new treatments for post-traumatic stress disorder
Presenter: David Kern

The European Health Data & Evidence Network (EHDEN) Sharing the OHDSI Journey and a Vision of Evidence Today, Not in Several tomorrows
Presenter: Nigel Hughes

Long term outcomes of prostate cancer patients managed by watchful waiting: results from the PIONEER/EHDEN/OHDSI study-a-thon
Presenter: Kees van Bochove, Asieh Golozar

Covid-19 Pandemic impacts on mental health Related conditions Via multi-database network: a Longitudinal Observational study (CERVELLO)
Presenter: Hao Luo

Large Scale Dissemination of OHDSI Methods and Tools: Introducing a New Community Resource, the OHDSI Center at the Roux Institute at Northeastern University
Presenter: Kristin Kostka

2021 Collaborator Showcase Community Contribution Awards

Alberto Labarga: Extending the OMOP CDM to store the output of natural language processing pipelines

Anna Ostropolets: The concept of anchoring in observational study design and its influence

Kimberley Dickinson: Gold or Lead? Adjudicating Differences between CDM Data and Chart Reviews

Kelli Li: Competing risk regression models in cohort studies with the R package Cohort Method

Christophe Lambert: Detecting PTSD and self-harm among US Veterans using positive unlabeled Learning

The EHDEN Academy

The EHDEN Academy (academy.ehden.eu) serves as a free, publicly available online educational resource for anyone working in the domain of real-world data and real-world evidence.

Originating in the European Health Data & Evidence Network (EHDEN) IMI2 project, its goal is to build upon the foundations of that project and its collaboration with the OHDSI community. It is currently used across ~70 countries and has ~2900 enrollees.

The EHDEN Academy is a resource on tools, methods and skills for all those who generate and utilize data, work technically with it (e.g. ETL and mapping), and are involved in methodological development and the use of standardized analytical tools.

Current Courses in the EHDEN Academy

- Getting Started
- EHDEN Foundation
- Introduction to Real World Data & Real World Evidence (non-expert)
- Open Science & FAIR Principles
- Introduction to Data Quality
- Phenotype Definition, Characterisation and Evaluation
- Patient-Level Prediction R for Patient-Level Prediction
- Population-Level Effect Estimation
- Introduction to Usagi & Code Mappings for an ETL
- Infrastructure
- OHDSI in a Box
- OMOP CDM and Standardised Vocabularies
- Extract, Transform & Load
- ETL Learning Pathway: Data Partner & SME Real World Use Cases
- ATLAS
- Health Technology Assessment

Courses In Development

- Regulatory Learning Pathway
- Risk Minimization Management
- Data Quality
- HADES
- Outcome Standards
- OHDSI and Low/ Middle Income 2Countries (LMICs)

The European Health Data & Evidence Network (EHDEN.eu) aspires to be the trusted observational research ecosystem to enable better health decisions, outcomes and care.

Its mission is to provide a new paradigm for the discovery and analysis of health data in Europe by building a large-scale, federated network of data sources standardized to the OMOP common data model and collaborating with OHDSI internationally.

As of the summer of 2022, EHDEN has built a federated network, so far, of 166 data partners from across 27 European nations, and has trained 65 small-to-medium enterprises to support mapping of ~650 million records to OMOP. The EHDEN study workflow portal was made public at the OHDSI Europe Symposium 2022 (portal.ehden.eu) with free access for the Data Partner Catalogue. A startup not-for-profit is being launched for sustainability.

The DARWIN EU® Initiative

The European Medicines Agency (EMA) announced Feb. 9, 2022 that Erasmus University Medical Center Rotterdam has been contracted to establish the DARWIN EU® (Data Analysis and Real World Interrogation Network) Coordination Centre.

Peter Rijnbeek, Chair of the Department of Medical Informatics at Erasmus MC, presented on DARWIN EU during the 2022 OHDSI European Symposium.

The role of the Coordination Centre is to develop and manage a network of real-world healthcare data sources across the EU and to conduct scientific studies requested by medicines regulators and, at a later stage, requested by other stakeholders.

The vision of DARWIN EU® is to give EMA and national competent authorities in EU Member States access to valid and trust-worthy real-world evidence, for example on diseases, patient populations, and the use, safety and effectiveness of medicines, including vaccines, throughout the lifecycle of a medicinal product.

By supporting decision-making on the development, authorisation and surveillance of medicines, a wide range of stakeholders will benefit, from patients and healthcare professionals to health technology assessment bodies and the pharmaceutical industry. Additionally, DARWIN EU® will provide an invaluable resource to prepare for and respond to future healthcare crises and pandemics.

For example, the availability of timely and reliable real-world evidence can lead to innovative medicines becoming more quickly available to patients. Better evidence also supports more informed regulatory decision-making on the safe and effective use by patients of medicines on the market.

Peter Rijnbeek is the Executive Director of the DARWIN EU® Coordinating Center. He is a veteran OHDSI collaborator and Titan Award honoree, and he serves as Chair of the Department of Medical Informatics of the Erasmus MC.

OHDSI, SNOMED International Formalize 5-Year Agreement To Open New Research Opportunities For Research Communities

The OHDSI community and SNOMED International formalized their long-time relationship with a five-year collaborative agreement that will benefit both of their user communities.

SNOMED CT is a core terminology within OHDSI's common data model: Observational Medical Outcomes Partnership (OMOP), allowing the use of other terminologies and classifications through computable linkages.

The collaboration, which officially began in April 2022, provides OHDSI and its user community with comprehensive ontologies on specific healthcare domains and content such as devices, social determinants of health, disease severity scores and modifiers of cancers, as well as better concept definitions and resolutions of composite concepts in large-scale observational research.

In return, OHDSI and its user community can provide SNOMED International with information and feedback on clinical validation, frequency of use data, and validation of SNOMED CT content modeling. Ultimately, continuous feedback shared regarding identified content gaps will benefit both user communities as we move forward together.

The collaboration supports SNOMED International's Member and stakeholder-driven five-year strategy, which includes genomic content collaboration as well as engagement with the research community. The work of OHDSI looks to showcase the use of SNOMED CT for the purposes of data analytics, supporting both healthcare research and audit, with the aim of enhancing healthcare globally.

"Both OHDSI and SNOMED International are working towards creating a healthcare environment that provides both patients and clinicians the real-world evidence needed to make informed and important decisions. SNOMED plays a critical role by delivering the comprehensive health terminologies necessary for OHDSI to generate reliable and reproducible evidence. Our community is thrilled to formalize this partnership so we can continue this important work."

- George Hripcsak
Chair of the OHDSI Coordinating Center at Columbia University.

HL7 International and OHDSI Announce Collaboration to Provide Single Common Data Model for Sharing Information in Clinical Care and Observational Research

Health Level Seven International (HL7®) and the OHDSI network agreed to a collaboration in 2021 to address the sharing and tracking of data in the healthcare and research industries by creating a single common data model. The organizations will integrate HL7 Fast Healthcare Interoperability Resources (FHIR®) and OHDSI's Observational Medical Outcomes Partnership (OMOP) common data model to achieve this goal.

HL7 International CEO Dr. Charles Jaffe, M.D., Ph.D., underscored the significance of this partnership. "The Covid-19 pandemic has emphasized the need to share global health and research data. Collaboration with OHDSI is critical to solving this challenge and will help our mutual vision of a world in which everyone can securely access and use the right data when and where they need it."

The organizations will align their standards to capture data in a clearly defined way into a single common data model. This will allow clinicians as well as researchers to pull data from multiple sources and compile it in the same structure without degradation of the information. This endeavor has global implications with the potential to permit the clinical community to define the elements they need, package and share them in a consistent single structure.

"We are excited to have the OHDSI community join this partnership with HL7 to evolve community standards around observational research and clinical care," said George Hripcsak, MD, MS, OHDSI's coordinating center director. "These standards set the foundation for our mission of global, open-science research, and this partnership will accelerate the development of effective and safe treatments for diseases facing today's global population."

Health Level Seven International is the global authority for healthcare information interoperability and standards with affiliates established in more than 30 countries. HL7 is a non-profit, ANSI accredited standards development organization dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing, and retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services. HL7's members represent approximately 500 corporate members, which include more than 90 percent of the information systems vendors serving healthcare.

OHDSI + Large Community Initiatives

OHDSI is proud to collaborate with large community initiatives around the world, to support the adoption of the OMOP Common Data Model and OHDSI tools, and to advance our shared interests in generating reliable evidence.

Some of these initiatives have been mentioned in previous pages (EHDEN, HL7, SNOMED), while other organizations are highlighted below. If your organization would like to collaborate with OHDSI, please reach out on our forums!

In 2020, OHDSI was awarded a $10 million contract from the U.S. Food and Drug Administration (FDA) to provide support to the Biologics Effectiveness and Safety (BEST) program, which was launched by the FDA Center for Biologics Evaluation and Research (CBER) in 2017.

The lead research team, primarily comprised of OHDSI personnel from Columbia University, UCLA, Northeastern Univaersity and Johns Hopkins University provides support to the BEST system in its mission to conduct safety and effectiveness surveillance of biologic products (vaccines, blood and blood products, tissues and advanced therapeutics).

The All of Us Research Program is inviting one million people across the U.S. to help build one of the most diverse health databases in history.

Researchers will use the data, which is mapped to the OMOP CDM, to learn how our biology, lifestyle, and environment affect health. This may one day help them find ways to treat and prevent disease.

PIONEER is part of the Innovative Medicine Initiative's (IMI's) "Big Data for Better Outcomes" (BD4BO) umbrella program. The BD4BO mission is to improve health outcomes and healthcare systems in Europe by maximizing the potential of Big Data.

OHDSI collaborated with PIONEER in early 2021 on a five-day study-a-thon that investigated the natural history and outcomes of prostate cancer patients managed with watchful waiting.

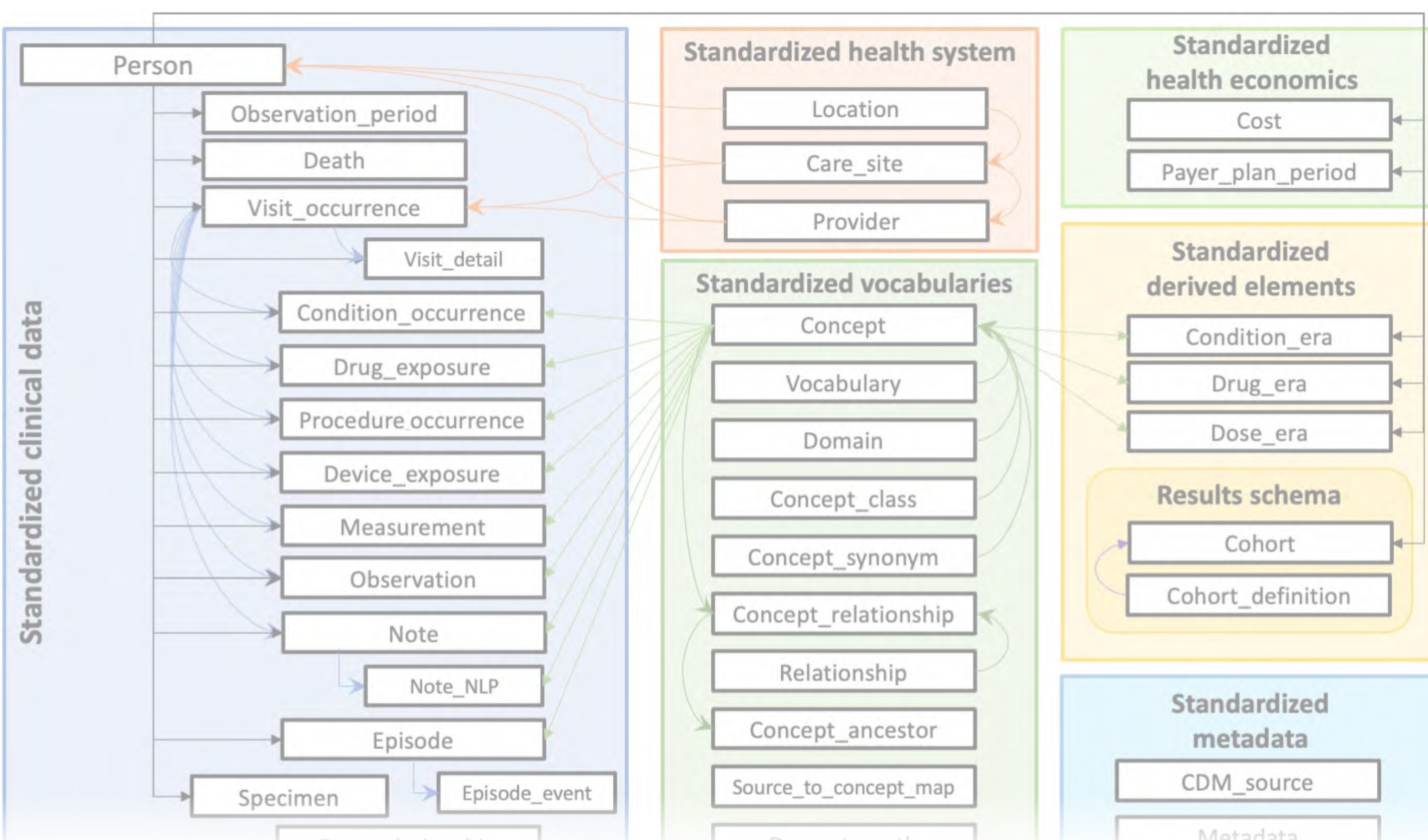
The N3C is a partnership among the NCATS-supported Clinical and Translational Science Awards (CTSA) Program hubs, the National Center for Data to Health (CD2H), and NIGMS-supported Institutional Development Award Networks for Clinical and Translational Research (IDeA-CTR), with overall stewardship by NCATS.
Collaborators are contributing and using COVID-19 clinical data, mapped to the OMOP CDM, to answer critical research questions to address the pandemic.

The Federated E-Health Big Data for Evidence Renovation Network (FEEDER-NET) project was initiated in 2018 with a $10 million budget from the Ministry of Trade, Industry & Energy of Korea.

The main goal is to build a bio-health Big Data ecosystem, centered around an OMOP CDM-based data network. As of August 2021, the FEEDER-NET network included more than 54 million patients.

V.

Data Standards

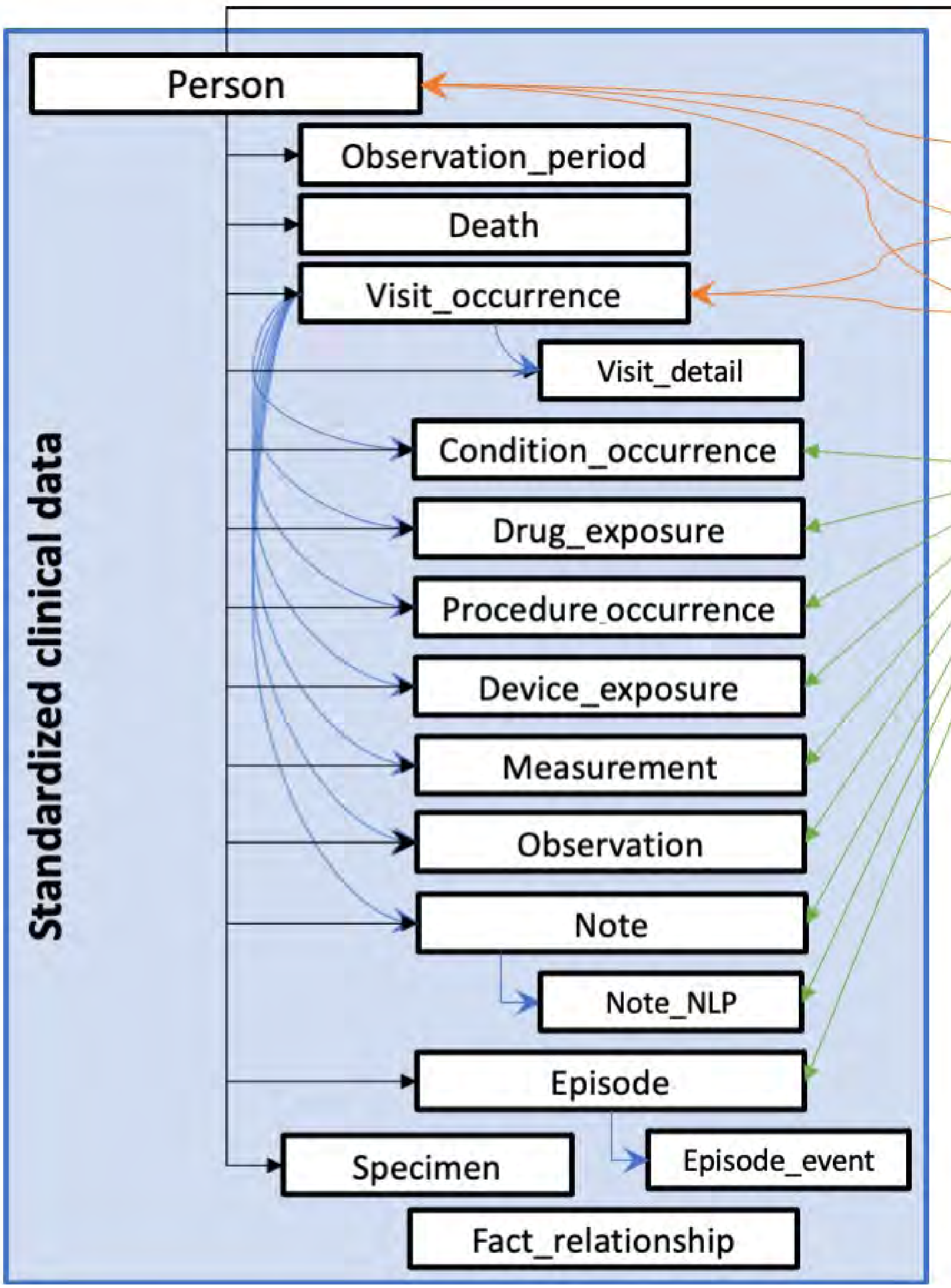


OMOP Common Data Model

The Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM) is an open community data standard, designed to standardize the structure and content of observational data and to enable efficient analyses that can produce reliable evidence.

"The OMOP Common Data Model serves as the foundation of all our work in the OHDSI community, and I'm proud that our open community data standard has been so widely adopted and so extensively used to generate reliable evidence."

- Clair Blacketer
2020 Titan Award for Data Standards recipient



OMOP CDM By The Numbers

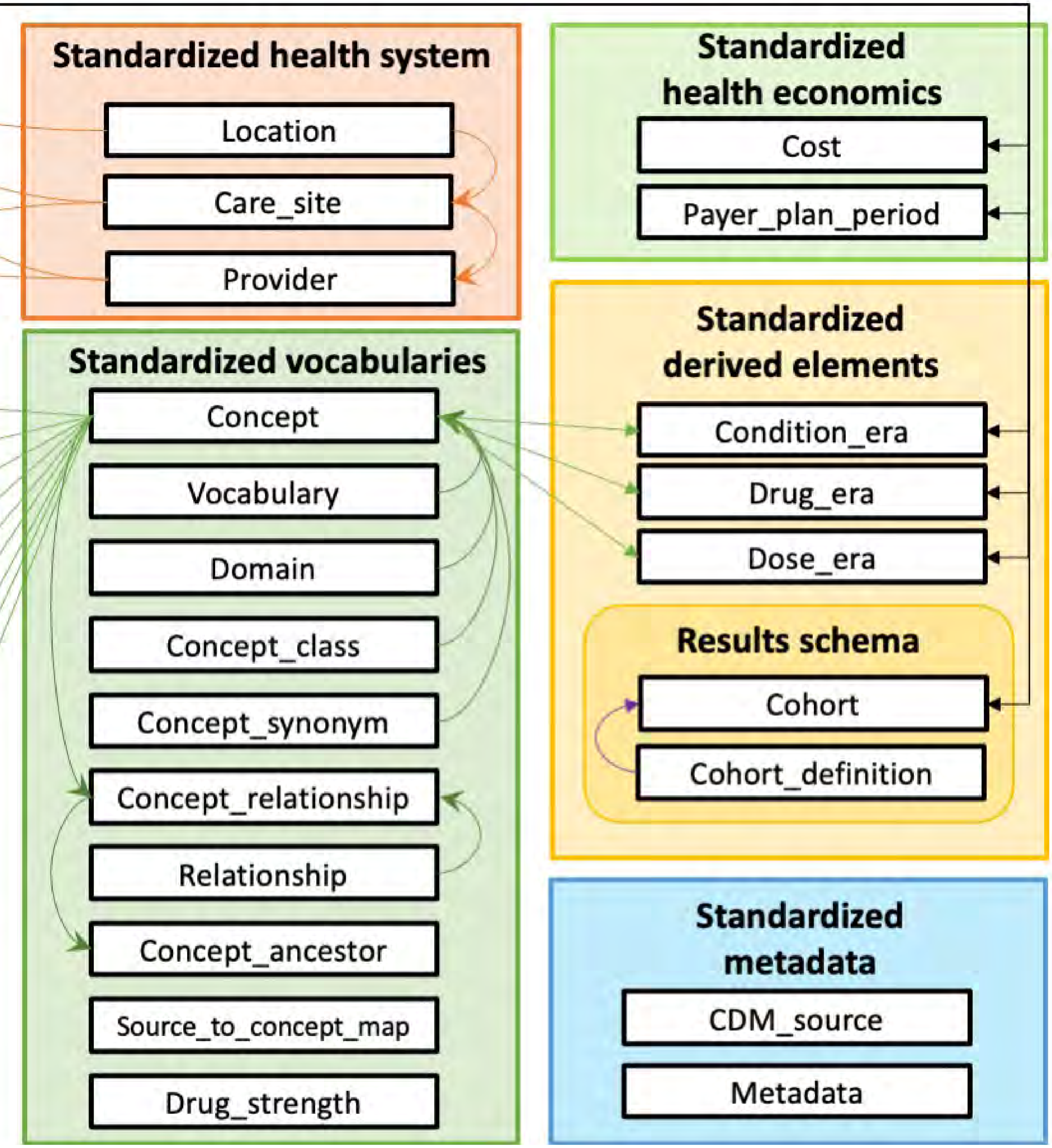
37 tables

- 17 to standardize clinical data
- 10 to standardize vocabularies

394 fields

- 193 with _id to standardize identification
- 101 with _concept_id to standardize content
- 43 with _source_value to preserve original data

1 Open Community Data Standard



OHDSI Data Partners

What does it take to be an OHDSI data partner? Anyone with access to observational data can standardize their database in the OMOP Common Data Model, apply OHDSI's open-source tools, and participate in collaborative research.

Who has already joined the journey and adopted the OMOP CDM? There are currently 453 databases, including 374 electronic health records, 34 registries and 30 administrative claims sources, that come from 41 different countries. Together, these databases represent more than 928 million unique patient records, approximately 12% of the world's population.

Australia (14)
AOA National Joint Replacement Registry
AU-ePBRN (Australian Electronic practice based research network)
AUS Department of Veterans Affairs
Austin Health
IQVIA Australia LPD
Melbourne Childrens Hospital
NPS MedicineWise
Pharmaceutical Benefits Scheme 10% extract
Primary Care GP data (Patron)
Royal Melbourne Hospital and Western Health Hospital Admissions
South Western Sydney LHD
Sydney Childrens Hospital
Sydney Local Health District (LHD)
University of Queensland - Queensland Health

Austria (1)
Medical University of Vienna

Belgium (18)
Az Damiaan Oostende
AZ Delta
AZ Klina
AZ Maria Middelares
Icometrix
IQVIA Belgium LPD
LynxCare
Medaman
Onze-Lieve-Vrouwziekenhuis Aalst-Asse-Ninove
THIN BE
Universitaire Ziekenhuizen KU Leuven
University Hospital Antwerp
University MS Center
University MS Center
UZ Brussel
UZ Leuven
VZW AZ Groeninge
Ziekenhuis Oost-Limburg

Bosnia and Herzegovina (1)
E-MEDIT D.O.O. & Hospital Travnik

Brazil (4)
Centre of Health Data and Knowledge Integration - Cidacs
DataSUS Ambulatory
Hospital Israelita Albert Einstein
IQVIA Brazil

Bulgaria (2)
National Scientific Programme "E-Health in Bulgaria"
SAT Health

Canada (3)
IQVIA Canada EMR
Provincial Health Services Authority (British Columbia)
The Hospital for Sick Children

China (7)
Beijing Anding Psychiatry Hospital
Beijing Smindu Medical Science & Technology CO., Ltd.
Hebei Province Psychiatry Hospital
Jiangsu Province People's Hospital
Nanfang Hospital COVID-19 Research Database (NFHCRD)
Tianjin Anding Psychiatry Hospital
Wonders Information

Colombia (1)
Hospital Universidad del Norte

Croatia (7)
Bács-Kiskun Megyei Kórház a Szegedi Tudományegyetem Általános Orvostudományi Kar Oktató Kórháza
Clinical Hospital Dubrava
Hierarchia & University Hospital Centre Zagreb
IGEA d.o.o. & University Hospital Center Sestre milosrdnice
IN2 d.o.o. & Clinical Hospital Center Osijek
MCS Grupa d.o.o. & Health Care Center of Primorje-Gorski Kotar County
Szabolcs-Szatmár-Bereg Megyei Kórházak és Egyetemi Oktatókórház

Czechia (3)
Czech Myeloma Group
Institute of Rheumatology
OAKS Consulting s.r.o.

Denmark (2)
Aarhus University Hospital Database
Center for Surgical Science (CSS)

Estonia (2)
Estonian Genome Center at the University of Tartu (EGCUT)
University of Tartu

Finland (10)
Auria Clinical Informatics
BCB Medical Ltd.
Finnish Clinical Biobank Tampere
Finnish Hematology Registry/ HUS
Finnish Institute for Health and Welfare (THL)
Hospital District of Helsinki and Uusimaa
Hospital District of Southwest Finland
HUS Datalake eCareforMe POC
Pirkanmaa Hospital District
University of Turku (Prostate Cancer Registry of South West Finland)

France (13)
APHP-EDS
Assistance Publique - Hopitaux de Marseille
Assistance Publique – Hôpitaux de Paris (AP-HP)
Bordeaux University Hospital
CEGEDIM HEALTH DATA
Centre Hospitalier Universitaire de Lille
Centre Hospitalier Universitaire de Montpellier
Centre Hospitalier Universitaire de Toulouse
IQVIA France DA
IQVIA France LPD
Lille University Hospital
SNDS
THIN FR

Germany (11)
CancerDataNet GmbH
Charité - Universitätsmedizin Berlin
European Rare Kidney Disease Registry (ERKReg)
GermanOncology
Hanover Medical School, Germany
IQVIA Germany DA
Krebsregister Rheinland-Pfalz
MS Forschungs- und Projektentwick-lungs-gGmbH
UKER
University Medicine Dresden
University of Ulm, ZIBMT

Greece (4)
Diagnostic & Therapeutic Center Of Athens "Hygeia" Single Member Societe Anonnyme
General Hospital of Kavala
Innovative Medical Research SA
Papageorgiou General Hospital

Hungary (2)
Semmelweis University
University of Pécs

India (1)
Buddhimed Technologies

Ireland (1)
Trinity St James's Cancer Institute, Dublin

Israel (4)
Hadassah OBGYN
Kineret (Ministry of Health medical center network)
Locwise
The Directorate of Government Medical Centers at the Israeli Ministry Of Health

Italy (28)
Agenzia regionale di sanità della Toscana (ARS)
AO Card. G. Panico - Center for Neurodegenerative Diseases and Aging Brain
ASL Roma 1
ATS Bergamo
Azienda Ospedaliera SS Antonio e Biagio e Cesare Arrigo
Azienda Ospedaliera Universitaria Integrata Verona
AZIENDA OSPEDALIERO UNIVERSITARIA SAN LUIGI GONZAGA
Azienda Ospedaliero-Universitaria di Modena
Bambino Gesù Children's Hospital
Basilicata Cancer Registry
Casa di Cura Privata del Policlinico (CCPP)
Fondazione Casa Sollievo della Sofferenza
Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico
Fondazione IRCCS Istituto Neurologico Carlo Besta
Fondazione IRCCS Policlinico San Matteo
Fondazione Istituto Nazionale dei Tumori
Fondazione Poliambulanza Istituto Ospedaliero
FONDAZIONE TOSCANA GABRIELE MONASTERIO PER LA RICERCA MEDICA E DI SANITA PUBBLICA (FTGM)
Grande Ospedale Metropolitano "Bianchi-Melacrino-Morelli"
Inspire-srl
IQVIA Italy LPD
IRCCS Azienda Ospedaliero-Universitaria di Bologna Policlinico di Sant'Orsola
IRCCS Policlinico San Donato
ISMETT
Modena Oncology Center - Azienda Ospedaliera Modena
Pedianet
Società Italiana di Medicina Generale e delle cure Primarie (SIMG)
University Hospital of Parma

Japan (4)
IQVIA Japan Claims
IQVIA Japan HIS
Japan Medical Data Center (JMDC)
MDV (Medical Data Vision)

Luxembourg (1)
Registre National du Cancer du Luxembourg

Montenegro (1)
Clinical Center of Montenegro

Netherlands (12)
Amsterdam UMC
EBMT: The European Society for Blood and Marrow Transplantation
European Clinical Research Alliance on Infectious Diseases (ECRAID) and University Medical Center Utrecht (UMCU)
Harm Slijper
IKNL
Integrated Primary Care Information (IPCI)
National Intensive Care Evaluation foundation
Netherlands Cancer Registry
Pharmo
Stichting VUmc-
STIZON
VieCuri Medisch Centrum

Norway (2)
The Norwegian Cancer Registry
University Of Oslo

Portugal (11)
APDP
Centro Clínico Academico a Braga, Associaçiao (2CA-Braga)
Centro Hospitalar Universitário de Coimbra (CHUC)
CUF
EGAS MONIZ HEALTH ALLIANCE
Hospital da Luz Learning Health
Hospital Distrital de Santarém (HDS)
Hospital do Espírito Santo de Évora
Instituto de Medicina Molecular
Registo Portugues de Doentes Reumaticos
Unidade Local de Saúde de Matosinhos

Republic of Korea (59)
Ajou University Hospital
Asan Medical Center
Bucheon Sejong Hospital
Catholic Kwandong University International ST. Mary's Hospital
Cha University Bundang Medical Center
Chonnam National University Hwasun Hospital
Chonnan National University Hospital
Chungnam National University Hospital
Chungnam National University Sejong Hospital
Daegu Catholic University Medical Center
Dankook University Hospital
Dongguk University Medical Center
Ewha Womans University Medical Center (Mokdong)
Ewha Womans University Medical Center (Seoul)
Gachon University Gil Medical CenterGachon University Gil Medical Center
Gangnam Severance Hospital
Gangneung Asan Hospital
Gyeongsang National University Changwon Hospital
Gyeongsang National University Hospital
Hanyang University Seoul Hospital
Health Insurance Review & Assessment Service
Incheon Sejong Hospital
Inha University Hospital
Jeonbuk National University Hospital
Kangbuk Samsung Hospital
Kangdong Sacred Heart Hospital
Kangwon National University Hospital
Konkuk University Medical Center
Konyang University Hospital
Korea Institute of Radiological & Medical Sciences
Korea University Anam Hospital
Korea University Ansan Hospital
Korea University Guro Hospital
Kyung Hee University Hospital At Gangdong
Kyung Hee University Medical Center
Kyungpook National University Chilgok Hospital
Kyungpook national university hospital
Myongji Hospital
Myongji Hospital (Jecheon)
National Cancer Center
National Health Insurance Service
National Health Insurance Service Ilsan Hospital
Pusan National University Hospital
Samsungmedical Center

Seoul National University Bundang Hospital
Seoul National University Hospital
Severance Hospital
Soonchunghyang University Hospital (Bucheon)
Soonchunghyang University Hospital (Chonan)
Soonchunghyang University Hospital (Gumi)
Soonchunghyang University Hospital(Seoul)
The Catholic University of Korea, Seoul ST. Mary's Hospital
The Catholic University of Korea, ST. Vincent's Hospital
The Catholic University of Korea, Uijeongbu ST. Mary's Hospital
The Catholic University of Korea, Yeouido ST. Mary's Hospital
Ulsan University Hospital
Wonju Severance Christian Hospital
Wonkwng University Hospital
Yongin Severance Hospital

Romania (1)
Thin Ro

Saudi Arabia (1)
Saudi Food and Drug Authority

Scotland (1)
HIC Dundee

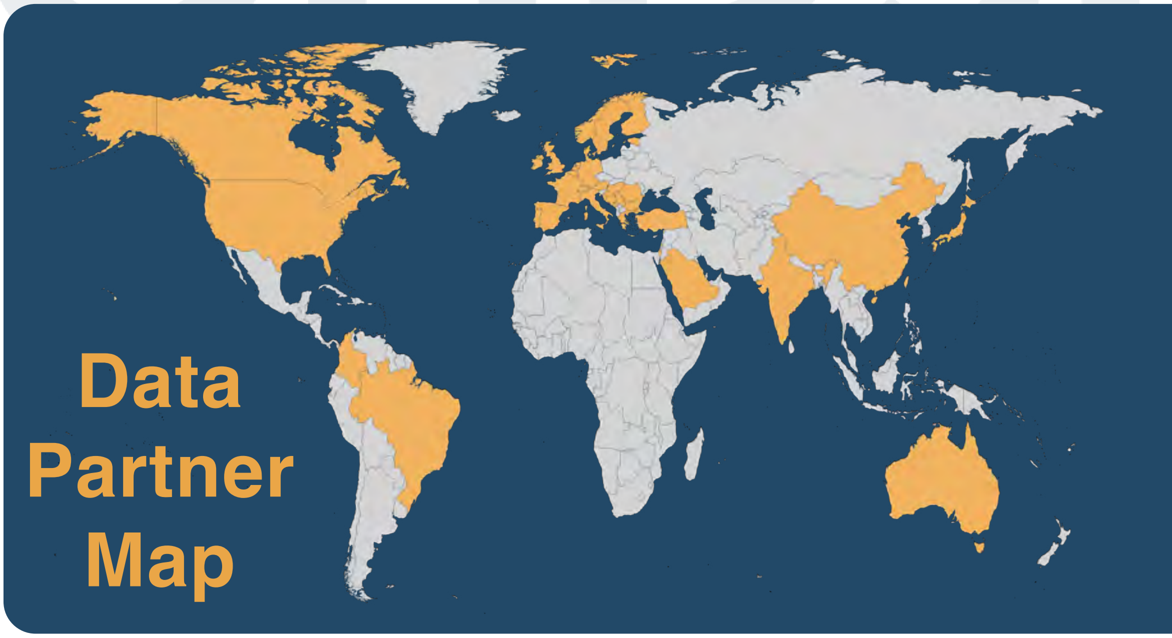
Serbia (5)
Clinical-hospital center Zvezdara
Kliničko-bolnički centar Zvezdara (Clinical-hospital center Zvezdara)
Primary Healthcare Center Zemun
University Clinical Center of Niš
University Clinical Center of Serbia

Singapore (3)
Growing Up in Singapore Towards healthy Outcomes (GUSTO)
Khoo Teck Puat Hospital (SG_KTPH)
National University Hospital Singapore

Spain (37)
Agencia Española de Medicamentos y Productos Sanitarios, AEMPS
BIOCRUCES BIZKAIA HEALTH RESEARCH INSTITUTE
Consellería de Sanidade
Consorci Corporació Sanitària Parc Taulí
Consorci Mar Parc de Salut de Barcelona (PSMAR)
CORPORACIÓ SANITARIA PARC TAULI
FISABIO-HSRU
Fundació Institut d´Investigació Sanitària Illes Balears
Fundació Institut d'Investigacions Mèdiques (FIMIM)
Fundacion de Investigacion Biomedica del Hospital Universitario 12 de Octubre
Fundación para la Investigación Biomedica INCLIVA
FUNDACION PARA LA INVESTIGACION DEL HOSPITAL UNIVERSITARIO LA FE DE LA COMUNIDAD VALENCIANA (HULAFE)
Fundación para la Investigación del Hospital Universitario La Fe de la Comunidad Valenciana (HULAFE)
Fundación para la Investigación e Innovación Biosanitaria en Atención Primaria (FIIBAP)
Healthcare Service of the Principality of Asturias
HM Hospitals
Hospital del Mar (HMAR)
Hospital Sant Joan de Déu
Hospital Universitario 12 de Octubre
INFOBANCO12
Information System of Parc de Salut Mar (IMASIS)
Institut Català d'Oncologia
Instituto Aragonés de Ciencias de la Salud (IACS)
IQVIA Spain LPD
Marina Salud (Hospital de Denia)
Parc Sanitari Sant Joan de Déu
Pedro Mallol
Research Institute - Hospital de la Santa Creu i Sant Pau
Rioja Salud
Servicio Cántabro de Salud and IDIVAL
Servicio Madrileño de Salud
Servicio Navarro de Salud Osasunbidea (SNS-O)
The Information System for Research in Primary Care
The Information System for Research in Primary Care – Hospitalization Linked Data (SIDIAP-H)
Vall d'hebron Hospital Campus
Vall d'Hebrón Hospital Campus
Virgen Macarena University Hospital

Sweden (2)
MEB KI
Swibreg

Switzerland (5)
CancerDataNet



Data2time
Geneva Cancer Registry
HUG and SCQM
Institute of Social and Preventive Medicine, University of Bern

Taiwan (5)
NHIRD
Shuang Ho Hospital
Taipei Medical University Clinical Research Database (TMUCRD)
Taipei Medical University Hospital
Wanfang Hospital

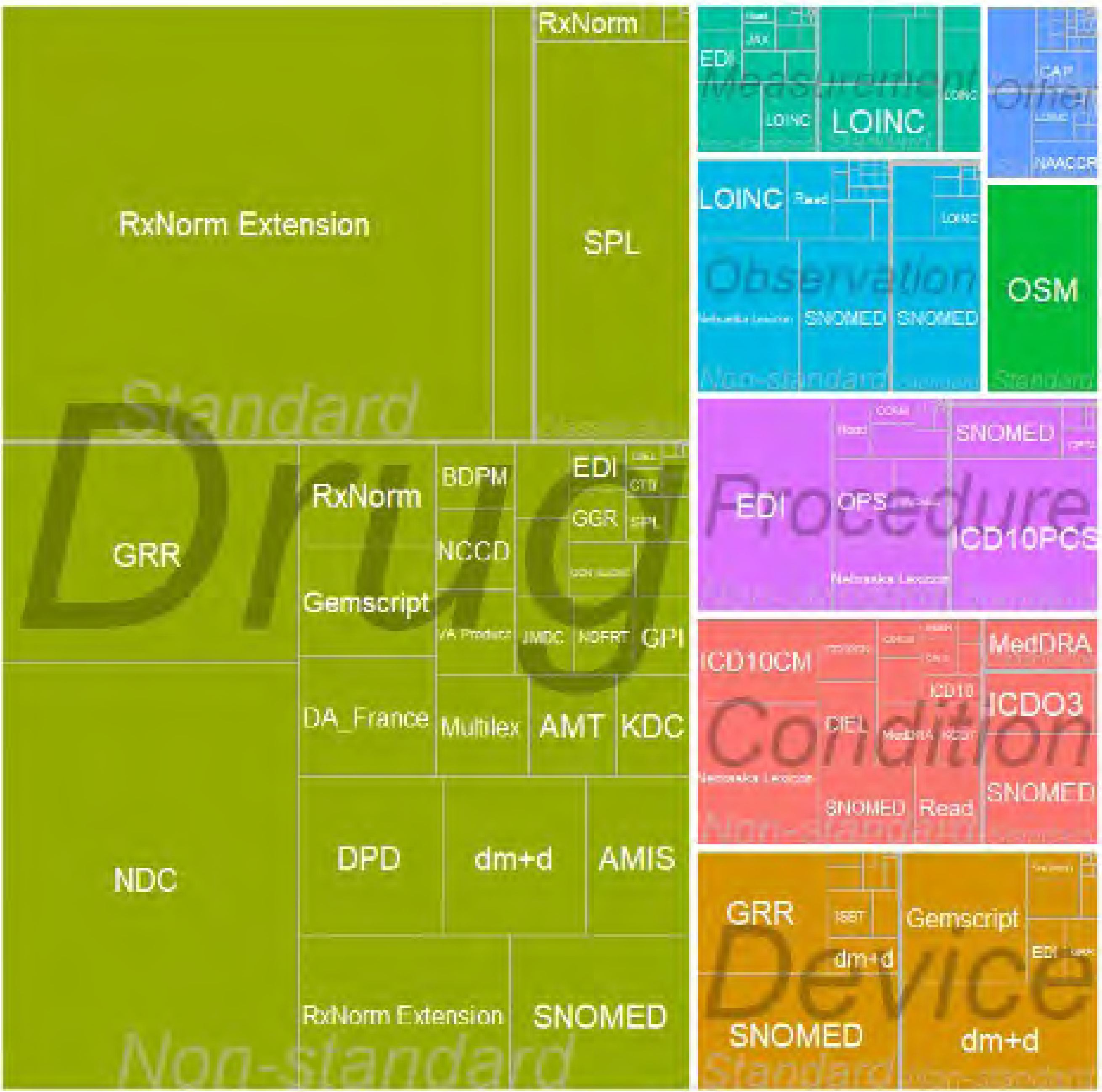
Turkey (2)
Istanbul University Istanbul Faculty of Medicine
IUC Cerrahpaşa TIP Fakületesi

United Kingdom (26)
Akrivia Health
Barts Health NHS Trust
Clinical Practice Research Datalink (CPRD GOLD)
Clinical Practice Research Datalink Aurum (CPRD Aurum)
Connected Bradford
DataLoch
GOSH
Harvey Walsh Ltd
King's College London
Leeds Teaching Hospitals
OPEN Health
Optimum Patient Care Limited
Queen Mary University of London
Royal College of General Practitioners Research and Surveillance Centre
SAIL Databank
THIN UK
UCL
UK Biobank
UK Integrated Medical Record Database (IMRD) THIN
UK National Neonatal Research Database
UKCRIS
University College London CALIBER
University College London Hospitals
University College London Hospitals NHS Foundation Trust
University of Edinburgh
University of Edinburgh DataLoch

United States (136)
1up health
Advocate Aurora Health & University of Madison Health Non-Muscle Invasive Bladder Cancer
Advocate Aurora Health COVID Database
All of Us Research Program
ALTAMED (University of Southern California)
Atrium - Wake Forest Baptist Health
Blue Health Intelligence
Boston Medical Center
Brown University - Rhode Island HIE
C-Path
Carilion Clinic
Case Western
Cerner HealthFacts
Cherokee Health Systems
Children's Hospital of Colorado
Children's Hospital of Los Angeles
Children's Hospital of Philadelphia
Children's National
Columbia University Irving Medical Center
CRHFEI
DARTNet Institute: CER2 Study
Decision Resources Group (DRG)
Department of Health Services - Los Angeles
Duke University
Eau Claire Cooperative Health Center
Flatiron - OSCER
Geisinger Health System
George Washington University
Georgetown University ARIA
Georgia Tech Research Institute
GeriOMOP
Harvard University Mass General Brigham
HealthVerity
IBM(R) MarketScan(R) Commercial Claims (CCAE)
IBM(R) MarketScan(R) Medicare Supplemental Database (MDCR)
IBM(R) MarketScan(R) Multi-State Medicaid Database (MDCD
Icahn School of Medicine at Mount Sinai
Indiana University School of Medicine / Regenstrief Institute
Inova Health System
IQVIA US Ambulatory EMR
IQVIA US Hospital Charge Data Master (CDM)
IQVIA US Oncology EMR
IQVIA US Open Claims
IQVIA US PharMetrics Plus
Johns Hopkins Unversity
Keck Medicine of University of Southern California
Loyola University New Orleans
Maine Medical Center
Mayo Clinic
Medical University of South Carolina
Medicare Research Identifiable Files
MedStar Health
Memorial Sloan Kettering Cancer Center
Momentum AD
Montefiore Medical Center (Albert Einstein College of Medicine)
N3C
Nemours Children's Health System
NorthShore University HealthSystem
Northwestern Medicine Enterprise Data Warehouse (NMEDW)
NYC-CDRN
NYU Langone
OCHIN (Oregon Community Health Information Network)
Ochsner Medical Center
Oklahoma University
One Fact Foundation Payless Health
Optum© De-Identified Clinformatics(R) Data Mart Database - SES & DOD
Optum© de-identified Electronic Health Record Dataset (PANTHER)
Oregon Health & Science University
Pareto Intelligence
PEDSnet
Penn State
Premier Healthcare Database
QueensCare - Los Angeles
Reliant Medical Group
Rhode Island Quality Institute
Rush University Medical Center
Rutgers
Shriners Children's
Spectrum Health West Michigan
STAnford medicine Research data Repository (STARR)
Stony Brook
Surveillance, Epidemiology, and End Results Program (SEER): B-Cell
TCC - Los Angeles
The Healthcare Cost and Utilization Project (HCUP), Nationwide Inpatient Sample (NIS)
The National Health and Nutrition Examination Survey (NHANES)
The Ohio State University Medical Center
TrialSpark
Tufts MC Research Data Warehouse (TRDW)
Tulane
UMass Memorial Medical Center
UNC Chapel Hill
University Medical Center New Orleans
University of Alabama at Birmingham
University of Arkansas
University of Buffalo
University of California Health
University of California, Davis
University of California, Irvine
University of California, Los Angeles
University of California, Riverside
University of California, San Diego
University of California, San Francisco
University of Chicago
University of Cincinnati
University of Colorado
University of Colorado, Anschutz Medical Center
University of Illinois Chicago
University of Iowa
University of Kentucky
University of Miami
University of Michigan
University of Minnesota
University of Mississippi Medical Center
University of Nebraska Medical Center
University of New Mexico Health Sciences Center
University of Pittsburgh
University of Pittsburgh - Banner
University of Rochester
University of Texas Houston
University of Texas Medical Branch
University of Texas Southwestern Medical Center
University of Utah
University of Virginia
University of Washington
University of Wisconsin Madison
US Department of Defense
US Department of Veterans Affairs
UTPhysicians
Vanderbilt University
Veradigm Health Insights Data - Allscripts
Veradigm Health Insights Data - Practice Fusion
Virginia Commonwealth University
Wake Forest University
WashU St Louis
Weill Cornell Medicine/NewYork-Presbyterian Hospital (East Campus)
West Virginia University
Winship Cancer Institute of Emory University

OHDSI Vocabularies

The OHDSI vocabularies allow organization and standardization of medical terms to be used across the various clinical domains of the OMOP common data model, and enables standardized analytics that leverage the knowledge base when constructing exposure and outcome phenotypes and other features within characterization, population-level effect estimation, and patient-level prediction studies.



This treemap shows all concepts in the OHDSI vocabularies, organized by domain (color) and vocabularies (boxes sized by the number of concepts).

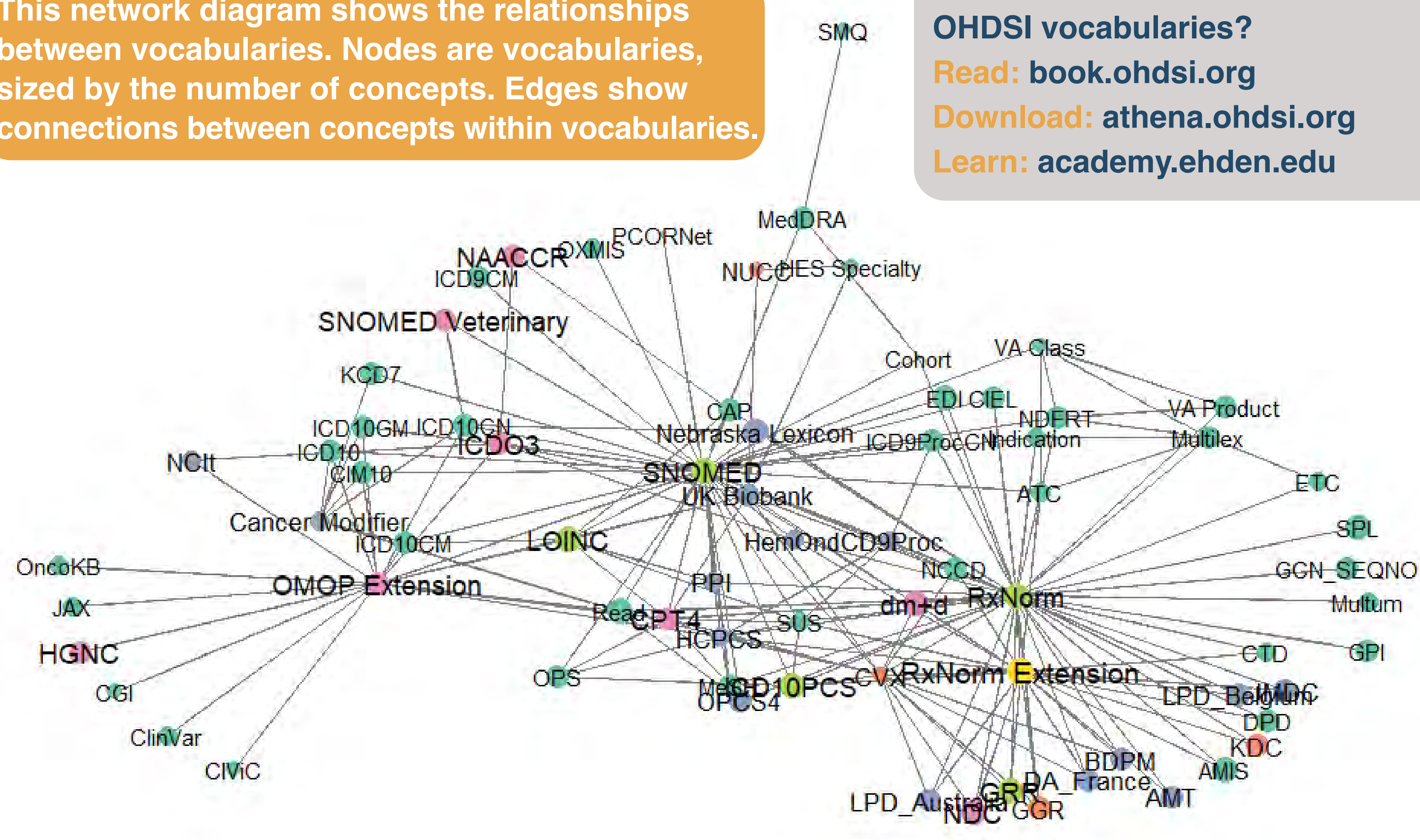
OHDSI Vocabularies By The Numbers

as of v5.0 • Sept. 9, 2022

- **10,218,572 concepts**
  - **3,549,524 standard concepts**
  - **780,207 classification concepts**
- **135 vocabularies**
- **42 domains**
- **81,243,356 concept relationships**
- **85,241,004 ancestral relationships**
- **3,268,183 concept synonyms**

1 Shared Resource to Enable Data Standards

This network diagram shows the relationships between vocabularies. Nodes are vocabularies, sized by the number of concepts. Edges show connections between concepts within vocabularies.



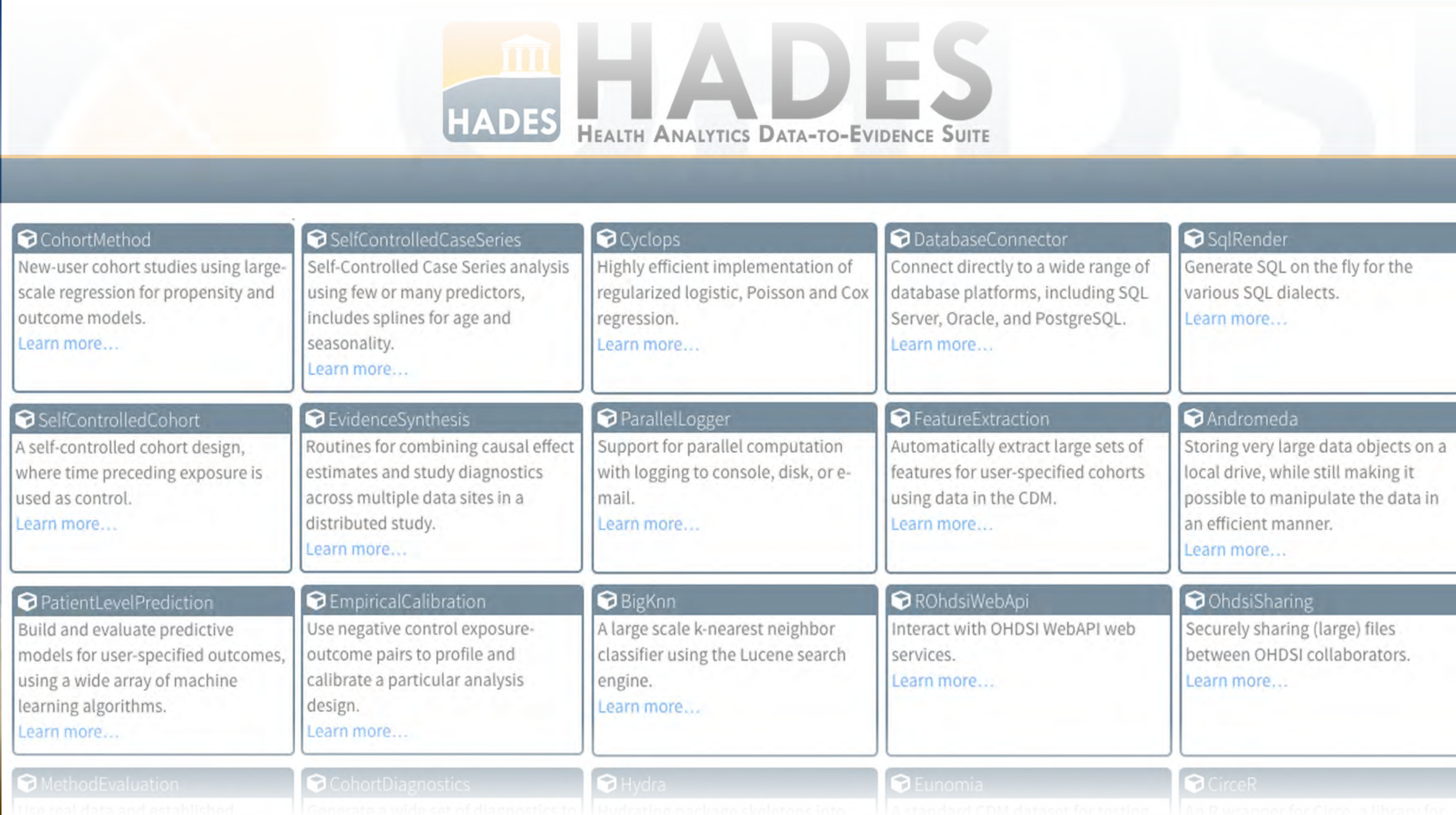
Want to learn more about the OHDSI vocabularies?
Read: book.ohdsi.org
Download: athena.ohdsi.org
Learn: academy.ehden.edu

"If we really want to achieve global collaboration, we need more than just standardizing data format. We have to establish a shared understanding of data meaning and speak the same language when expressing clinical ideas. The OHDSI vocabularies is a community resource that makes it possible to work to reach this common goal."

- Christian Reich
2018 Titan Award for Data Standards recipient

The open-source tools that empower OHDSI research are not only available to the community, but they are DEVELOPED by the community. Leaders within our global network, including 2018 Titan Award recipient Martijn Schuemie (pictured), have developed the foundation for OHDSI collaborators to engage in robust, reliable and reproducible observational health research.

VI. Open-Source Software



HADES

HADES is a set of open source R packages for large scale analytics, including population characterization, population-level causal effect estimation, and patient-level prediction.

The packages offer R functions that together can be used to perform an observation study from data to estimates and supporting statistics, figures, and tables. The packages interact directly with observational data in the OMOP Common Data Model, and are designed to support both large datasets and large numbers of analyses.

Each package includes functions for specifying and subsequently executing multiple analyses efficiently. HADES supports best practices for use of observational data as learned from previous and ongoing research, such as transparency, reproducibility, as well as measuring of the operating characteristics of methods in a particular context and subsequent empirical calibration of estimates produced by the methods.

Learn more about the individual HADES packages in this section.

Population-Level Estimation

CohortMethod

This is an R package for performing new-user cohort studies in an observational database in the OMOP Common Data Model.

EvidenceSynthesis

This R package contains routines for combining causal effect estimates and study diagnostics across multiple data sites in a distributed study. This includes functions for performing meta-analysis and forest plots.

SelfControlledCaseSeries

This is an R package for performing Self-Controlled Case Series (SCCS) analyses in an observational database in the OMOP Common Data Model.

SelfControlledCohort

This package provides a method to estimate risk by comparing time exposed with time unexposed among the exposed cohort.

Patient-Level Prediction

PatientLevelPrediction

This is an R package for building and validating patient-level predictive models using data in the OMOP Common Data Model format.

EnsemblePatientLevelPrediction

This is an R package for building and validating ensemble patient-level predictive models using data in the OMOP Common Data Model format. The package expands the OHDSI R PatientLevelPrediction package to enable ensemble learning.

Cohort Construction

CAPR

This is an R package to develop and manipulate OHDSI cohort definitions. This package assists in creating a cohort definition that can be compiled by circe-be using CirceR. Cohort definitions developed in Capr are compatible with OHDSI ATLAS. Additionally the package allows for development of cohort design components, sub-items of a cohort design that are meant to be reusable and mutable to assist creating cohorts in study development.

CirceR

A R-wrapper for Circe, a library for creating queries for the OMOP Common Data Model. These queries are used in cohort definitions (CohortExpression) as well as custom features (CriteriaFeature). This package provides convenient wrappers for Circe functions, and includes the necessary Java dependencies.

CohortGenerator

This R package contains functions for generating cohorts using data in the CDM.

PhenotypeLibrary

This is a repository to store the content of the OHDSI Phenotype Library. These phenotype/cohort definitions have undergone an OHDSI best practice process by the Phenotype Development and Evaluation workgroup. Definitions that have graduated through this process are published in this repository, and are thus considered high quality cohort definitions.

Evidence Quality

CohortDiagnostics

This is an R utility package for the development and evaluation of phenotype algorithms for OMOP CDM compliant data sets. This package provides a standard, end to end, set of analytics for understanding patient capture including data generation and result exploration through an R Shiny interface. Analytics computed include cohort characteristics, record counts, index event misclassification, captured observation windows and basic incidence proportions for age, gender and calendar year. Through the identification of errors, CohortDiagnostics enables the comparison of multiple candidate cohort definitions across one or more data sources, facilitating reproducible research.

EmpiricalCalibration

This R package contains routines for performing empirical calibration of observational study estimates. By using a set of negative control hypotheses we can estimate the empirical null distribution of a particular observational study setup. This empirical null distribution can be used to compute a calibrated p-value, which reflects the probability of observing an estimated effect size when the null hypothesis is true taking both random and systematic error into account, as described in the paper Interpreting observational studies: why empirical calibration is needed to correct p-values.

Also supported is empirical calibration of confidence intervals, based on the results for a set of negative and positive controls, as described in the paper Empirical confidence interval calibration for population-level effect estimation studies in observational healthcare data.

MethodEvaluation

This R package contains resources for the evaluation of the performance of methods that aim to estimate the magnitude (relative risk) of the effect of a drug on an outcome. These resources include reference sets for evaluating methods on real data, as well as functions for inserting simulated effects in real data based on negative control drug-outcome pairs. Further included are functions for the computation of the minimum detectable relative risks and functions for computing performance statistics such as predictive accuracy, error and bias.

Kheiron Contributor Cohort

Paul Nagy and Adam Black, leads of the Open-Source Community workgroup, founded the Kheiron Contributor Cohort in 2022 as a way to welcome and mentor new developers in the OHDSI community. The first cohort included 25 individuals who committed 10% of their time for a year to join the journey with the open-source community, and the cohort has already made positive impacts on OHDSI tools. The cohort has hosted workshops, learned from developers around the community and made strong connections. Paul and Adam plan to lead a new cohort next year, and more information about that will be shared when available.

Supporting Packages

Andromeda

AsynchroNous Disk-based Representation of MassivE DAta (ANDROMEDA) is an R package for storing large data objects. Andromeda allow storing data objects on a local drive, while still making it possible to manipulate the data in an efficient manner.

BigKNN

This is an R package implementing a large scale k-nearest neighbor (KNN) classifier using the Lucene search engine.

Cyclops

Cyclops (Cyclic coordinate descent for logistic, Poisson and survival analysis) is an R package for performing large scale regularized regressions.

DatabaseConnector

This R package provides function for connecting to various DBMSs. Together with the SqlRender package, the main goal of DatabaseConnector is to provide a uniform interface across database platforms: the same code should run and produce equivalent results, regardless of the database back end.

Eunomia

Eunomia is a standard dataset in the OMOP (Observational Medical Outcomes Partnership) Common Data Model (CDM) for testing and demonstration purposes. Eunomia is used for many of the exercises in the Book of OHDSI. For functions that require schema name, use 'main'.

FeatureExtraction

This is an R package for generating features (covariates) for a cohort using data in the Common Data Model.

Hydra

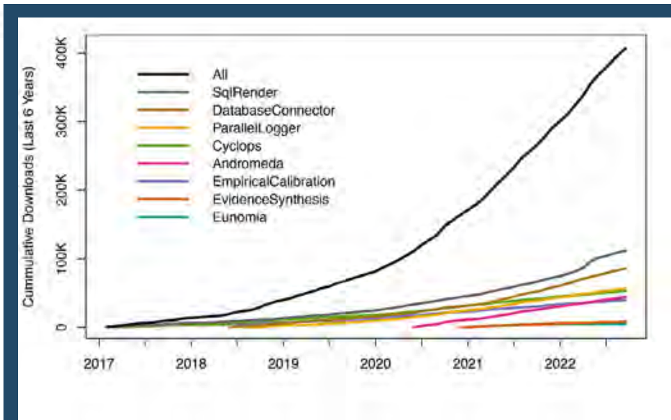
This is an R package and Java library for hydrating package skeletons into executable R study packages based on specifications in JSON format.

IterativeHardThresholding

IterativeHardThresholding is an R package for performing L_0-based regressions using Cyclops.

OhdsiSharing

This is an R package for sharing data between OHDSI partners.



The eight HADES packages shown above have been released on CRAN and have been downloaded more than 400,000 times.

ParallelLogger

Support for parallel computation with progress bar, and option to stop or proceed on errors. Also provides logging to console and disk, and the logging persists in the parallel threads. Additional functions support function call automation with delayed execution (e.g. for executing functions in parallel).

ROhdsiWebApi

ROhdsiWebApi is a R based interface to 'WebApi' (OHDSI RESTful services), and performs GET/PULL/POST/DELETE calls via the WebApi. All objects starting from R or output to R - are analysis ready R-objects like list and data.frame. The package handles the intermediary steps by converting R-objects to JSON and vice versa. To ensure r-objects are analysis ready, the objects are type converted where possible, e.g. date/date time are converted from string to POSIXct.
This package makes reproducible research easier, by offering ability to retrieve detailed study specifications, transport study specifications from one instance to another, programmatically invoke the generation of a sequence of steps that are part of a study, manage running studies in batch mode.
An example of a WebApi endpoint is "http://server.org:80/WebAPI".

SqlRender

This is an R package for rendering parameterized SQL, and translating it to different SQL dialects. SqlRender can also be used as a stand-alone Java library and a command-line executable.

HADES

Health Analytics Data-to-Evidence Suite

Certain factors for the success of an open-science community like OHDSI are more obvious than others. When hundreds of people come together to research a common cause, or studies are run against millions of patient records in a global database, it becomes clear that something impactful is happening.

One critical factor in OHDSI's ability to perform rigorous, ground-breaking analyses lies under the surface, but it holds an equally important role in the overall community mission.

A core foundation for OHDSI is open-source software development, and a small group of community collaborators, led by Martijn Schuemie, has generated a collection of analytics tools that enable research both in and out of the OHDSI community.

HADES — the Health Analytics Data-to-Evidence Suite — is a set of (currently) 25 open-source R packages for large scale analytics, including population characterization, population-level causal effect estimation, and patient-level prediction, as well as supporting packages that are critical throughout the journey of observational research. The packages offer a robust set of functions that together can be used to perform all the steps required to conduct a network study, from connecting to a database, translating queries into the appropriate SQL dialect, generating cohorts and extracting features, fitting large-scale statistical models, compiling results for meta-analysis and empirical calibration, and enabling exploration through interactive visualization dashboards.

The packages interact directly with any observational data in the OMOP Common Data Model, and are designed to support network research across large datasets with millions of patients and billions of observations, as well as smaller populations. HADES scales to enable large numbers of analyses so that researchers can systematically explore populations and hypotheses across a range of outcomes.

These packages, available on the HADES home page (ohdsi.github.io/Hades), have empowered at least 34 network studies. These include the OHDSI LEGEND study on hypertension, CHARYBDIS, hydroxychloroquine safety, the ongoing work with COVID AESI characterization, and many more. All packages are developed and released as open-source tools at github.com/OHDSI. Amongst the HADES ecosystem, all packages are made open source and publicly accessible through the OHDSI GitHub repository. Additionally eight packages are available on CRAN (The Comprehensive R Archive Network, a public repository for all R users). These eight HADES packages on CRAN and have been downloaded more than 400,000 times (see graphic, opposite page).

"Our community, and observational researchers in general, owe an enormous debt of gratitude to Martijn and the HADES team for leading this effort," said Provost and Senior Vice President for Academic Affairs at Northeastern University David Madigan, who is leading efforts around the new OHDSI Center at the Roux Institute. "Open-source development within the OHDSI community is the quiet force that is impacting important evidence that can save lives, and it shouldn't be taken for granted."

Beyond network studies, HADES allows researchers to conduct analyses locally. It supports best practices for use of observational data as learned from previous and ongoing research; for example, the population-level estimation methods have been extensively evaluated using the OHDSI Methods Benchmark, as published in the Harvard Data Science Review.

Researchers can learn how to use HADES through documentation found in the Book of OHDSI (ohdsi.github.io/TheBookOfOhdsi/).

"We are very proud of the impact that HADES continues to make on real-world evidence generation," said Schuemie, who leads the HADES workgroup. "Our team develops, tests and continuously monitors a set of tools that empowers global research using best practices developed within our community."

OHDSI's reach has expanded recently, including its role supporting the FDA BEST program in vaccine surveillance, as well as informing best practices in the recent EMA revision of its guidelines. Researchers continue to join the community, and the breadth of work has expanded as collaboration efforts have matured. But for success to follow these positive developments, the HADES foundation and team continues to need greater support.

A small portion of the community maintains the set of packages, and one consistent HADES objective is to diversify the leadership within the ecosystem. There are several ways that OHDSI collaborators can support this critical piece of the puzzle. Developers can contribute by helping develop and test code. Users of the tools can help with testing, user documentation and other training resources. Those with the means can provide financial support to help pay for developers specifically focused on open-source development. Anybody can contribute ideas as part of the HADES workgroup.

Just as every piece of the HADES toolset has aided the growth of OHDSI, every small contribution from the community can aid the advancement of HADES.

"Open-source development within the HADES ecosystem has been critical to our growth and success as a community," said George Hripcsak, Chair and Vivian Beaumont Allen Professor of Biomedical Informatics at Columbia, the coordinating center for OHDSI. "Martijn and the HADES team have done extraordinary work to put us in position to run observational health studies that make a difference to patients around the world, but we can't overlook the burden on this small core of our community who have enabled this growth. I believe we have people who are generous with both their time and talents to help take HADES to a sustainable level as we continue to mature as a community."

Package Maintainers

Martijn Schuemie
BigKnn, CohortMethod, DatabaseConnector, EmpiricalCalibration, EvidenceSynthesis, MethodEvaluation, ParallelLogger, SelfControlledCaseSeries, SqlReader

Anthony Sena
CohortGenerator, FeatureExtraction, HYDRA

Jamie Gilbert
CohortDiagnostics, SelfControlledCohort

Gowtham Rao
PhenotypeLibrary, ROhdsiWebApi

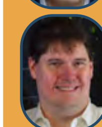
Jenna Reps
EnsemblePatientLevelPrediction, PatientLevelPrediction

Marc Suchard
Cyclops, IterativeHardThresholding

Adam Black
Andromeda

Frank DeFalco
Eunomia

Lee Evans
OhdsiSharing



Christopher Knoll
CirceR

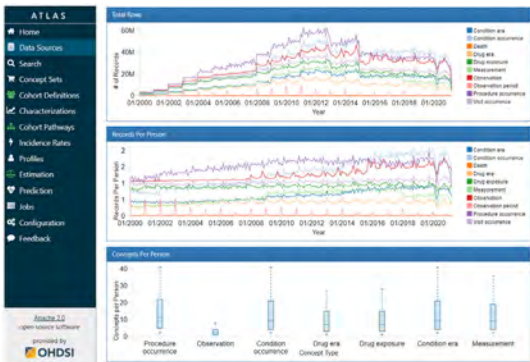
Martin Lavalee
CAPR

Peter Rijnbeek
PatientLevelPrediction

ATLAS

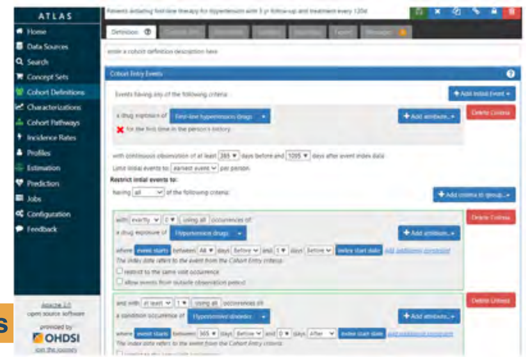
ATLAS is a free, publicly available, web-based tool developed by the OHDSI community that facilitates the design and execution of analyses on standardized, patient-level, observational data in the OMOP CDM format.

Enabling A Journey From Data To Evidence



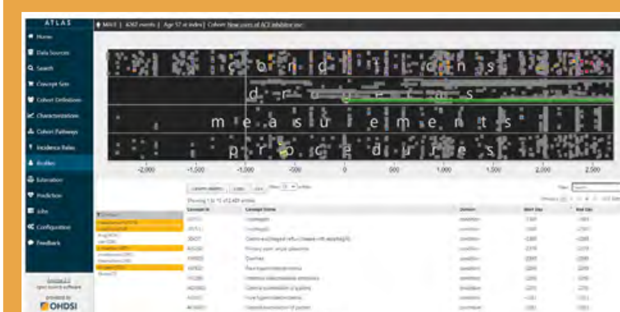
Explore Data

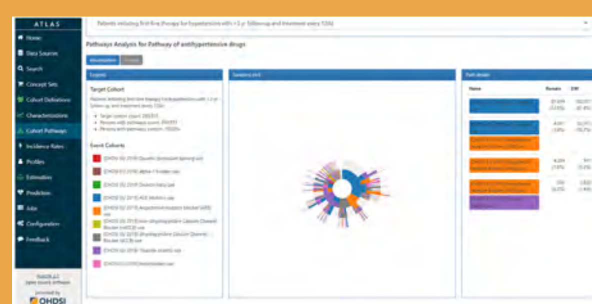
Design Analyses

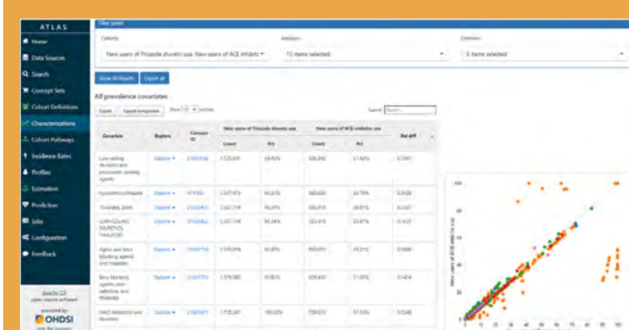


Produce Code

Generate Evidence







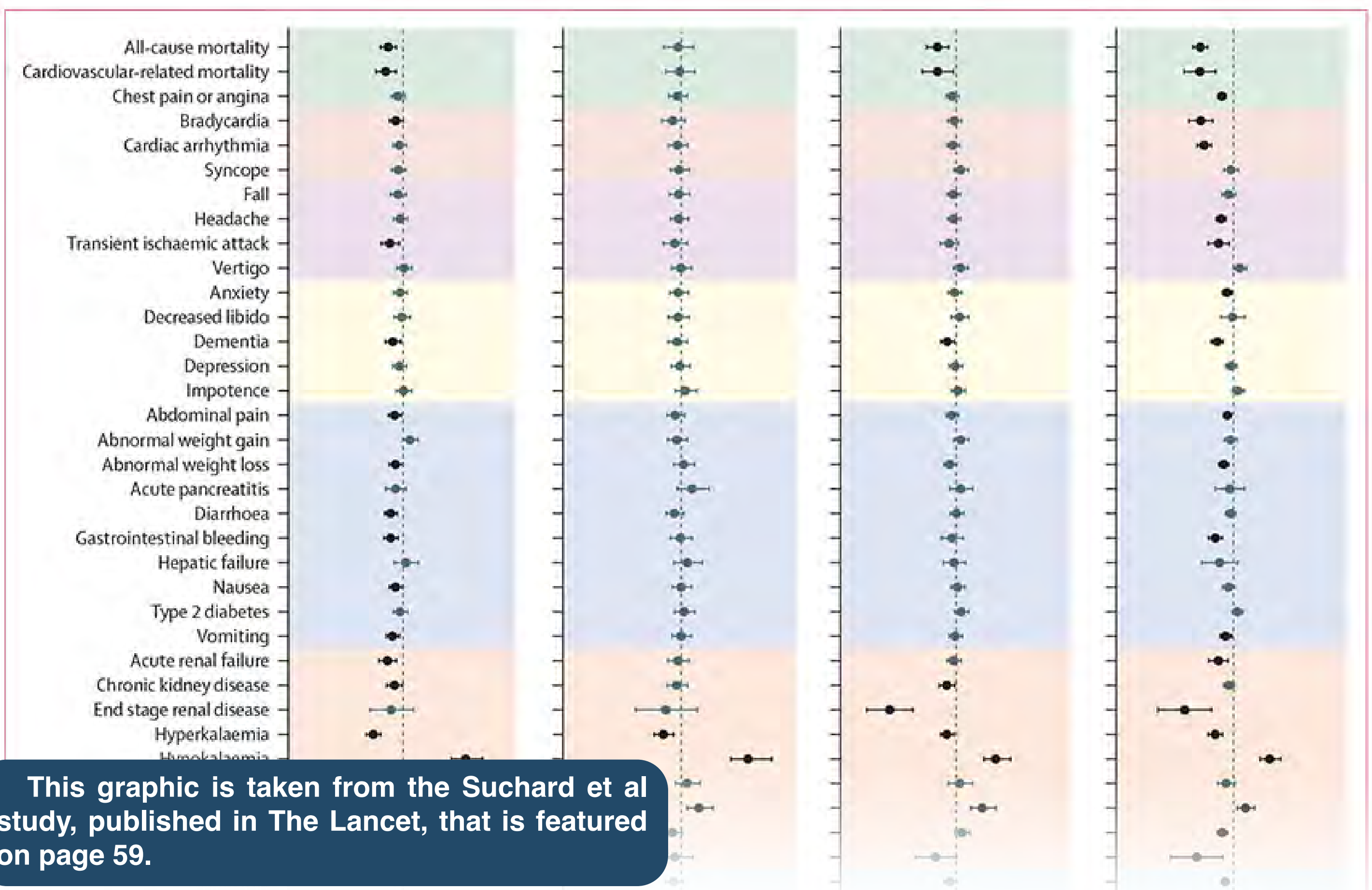
"ATLAS makes it possible for everyone in the OHDSI community to collaboratively design high-quality observational studies and produce reproducible code that can be shared and executed on OMOP CDM databases around the world."

- Christopher Knoll
2018 Titan Award for Open-Source Development recipient

Want to learn more about ATLAS?

Experience: atlas-demo.ohdsi.org/
Download: github.com/ohdsi/atlas
Read: book.ohdsi.org/
Train: academy.ehden.eu

VII. Methods Research



This graphic is taken from the Suchard et al study, published in The Lancet, that is featured on page 59.

Empirical Calibration

Methodological research is a foundational aspect of OHDSI work. We seek to evaluate the performance of analytics methods so we understand when they can be appropriately applied and how confident we can be in the reliability of the evidence we generate. This research has provided the empirical evidence to allow OHDSI to establish best practices for the design and implementation of population-level effect estimation, as applied for safety surveillance and comparative effectiveness research.

Negative controls – exposure-outcome pairs with no causal relationship – offer a powerful diagnostic to evaluate the reliability of a population-level effect estimation study. By applying the same method on the same data to a large collection of negative controls, one can determine if there is systematic error in the analysis, whether due to selection bias, confounding, or measurement error. Empirical calibration is a statistical procedure developed by OHDSI collaborators to use the error distribution estimated from negative controls and correct the original study statistics – point estimates, confidence intervals, and p-values – to restore their nominal operating characteristics and allow for a more honest interpretation of what really has been learned from observational data.

Research Article

Statistics in Medicine

Received 12 November 2012, Accepted 3 July 2013 Published online in Wiley Online Library

(wileyonlinelibrary.com) DOI: 10.1002/sim.5925

Interpreting observational studies: why empirical calibration is needed to correct p-values

Martijn J. Schuemie,[a,b*†] Patrick B. Ryan,[b,c] William DuMouchel,[b,d] Marc A. Suchard[b,e] and David Madigan[b,f]

Figure 2. Calibration plots. Each subplot shows the fraction of negative controls with $p < \alpha$, for different levels of α. Both traditional p-value calculation and p-values using calibration are shown. For the calibrated p-value, a leave-one-out design was used.

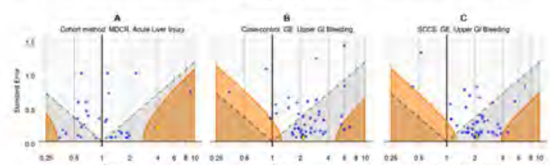


Figure 3. Traditional and calibrated significance testing. Estimates below the dashed line (gray area) have $p < 0.05$ using traditional p-value calculation. Estimates in the orange areas have $p < 0.05$ using the calibrated p-value calculation. Blue dots indicate negative controls, and the yellow diamond indicates the drugs of interest: isoniazid (A) and sertraline (B and C).

Empirical confidence interval calibration for population-level effect estimation studies in observational healthcare data

Martijn J. Schuemie[a,b,1], George Hripcsak[a,c,d], Patrick B. Ryan[a,b,c], David Madigan[a,e], and Marc A. Suchard[a,f,g,h]

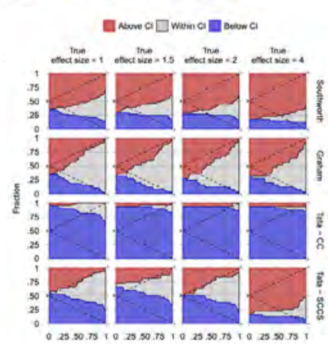


Fig. 2. The fraction of controls where the true hazard ratio is above, within, or below the CI for various widths of the CI. The dashed lines indicate the boundaries of a perfectly calibrated and centered estimator.

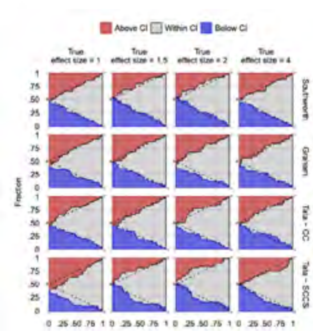
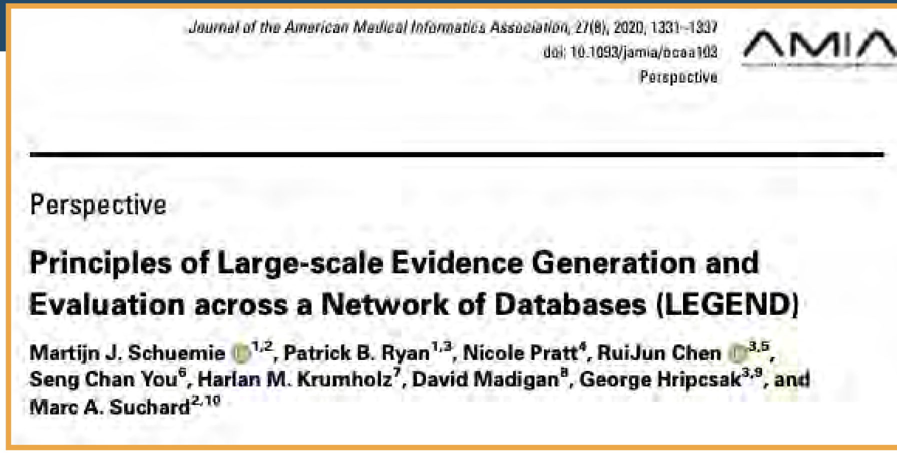


Fig. 4. The fraction of controls where the true hazard ratio is above, within, or below the calibrated CI for various widths of the CI. The dashed lines indicate the boundaries of a perfectly calibrated and centered estimator. Fractions were computed using leave-one-out cross-validation.

LEGEND in Principle

LEGEND (Large-scale Evidence Generation and Evaluation across a Network of Databases) applies high-level analytics to perform observational research on hundreds of millions of patient records within OHDSI's international database network.

LEGEND is based on 10 guiding principles that were published in JAMIA (August, 2020) and are listed below.


Journal of the American Medical Informatics Association, 27(8), 2020, 1331–1337
doi: 10.1093/jamia/ocaa103
Perspective

AMIA

Perspective

Principles of Large-scale Evidence Generation and Evaluation across a Network of Databases (LEGEND)

Martijn J. Schuemie[1,2], Patrick B. Ryan[1,3], Nicole Pratt[4], RuiJun Chen[3,5], Seng Chan You[6], Harlan M. Krumholz[7], David Madigan[8], George Hripcsak[3,9], and Marc A. Suchard[2,10]

1. LEGEND will generate evidence at a large scale. Instead of answering a single question at a time (eg, the effect of 1 treatment on 1 outcome), LEGEND answers large sets of related questions at once (eg, the effects of many treatments for a disease on many outcomes). **Aim:** Avoids publication bias, achieves comprehensiveness of results, and allows for an evaluation of the overall coherence and consistency of the generated evidence.

2. Dissemination of the evidence will not depend on the estimated effects. All generated evidence is disseminated at once. **Aim:** Avoids publication bias and enhances transparency.

3. LEGEND will generate evidence using a prespecified analysis design. All analyses, including the research questions that will be answered, will be decided prior to analysis execution. **Aim:** Avoids P hacking.

4. LEGEND will generate evidence by consistently applying a systematic process across all research questions. This principle precludes modification of analyses to obtain a desired answer to any specific question. This does not imply a simple one-size-fits-all process, rather that the logic for modifying an analysis for specific research questions should be explicated and applied systematically. **Aim:** Avoids P hacking and allows for the evaluation of the operating characteristics of this process (Principle 6).

5. LEGEND will generate evidence using best practices. LEGEND answers each question using current best practices, including advanced methods to address confounding, such as propensity scores. Specifically, we will not employ suboptimal methods (in terms of bias) to achieve better computational efficiency. **Aim:** Minimizes bias.

6. LEGEND will include empirical evaluation through the use of control questions. Every LEGEND study includes control questions. Control questions are questions where the answer is known. These allow for measuring the operating characteristics of our systematic process, including residual bias. We subsequently account for this observed residual bias in our P values, effect estimates, and confidence intervals using empirical calibration. [7,8] **Aim:** Enhances transparency on the uncertainty due to residual bias.

7. LEGEND will generate evidence using open-source software that is freely available to all. The analysis software is open to review and evaluation, and is available for replicating analyses down to the smallest detail. **Aim:** Enhances transparency and allows replication.

8. LEGEND will not be used to evaluate new methods. Even though the same infrastructure used in LEGEND may also be used to evaluate new causal inference methods, generating clinical evidence should not be performed at the same time as method evaluation. This is a corollary of Principle 5, since a new method that still requires evaluation cannot already be best practice. Also, generating evidence with unproven methods can hamper the interpretability of the clinical results. Note that LEGEND does evaluate how well the methods it uses perform in the specific context of the questions and data used in a LEGEND study (Principle 6). **Aim:** Avoids bias and improves interpretability.

9. LEGEND will generate evidence across a network of multiple databases. Multiple heterogeneous databases (different data capture processes, health-care systems, and populations) will be used to generate the evidence to allow an assessment of the replicability of findings across sites. **Aim:** Enhances generalizability and uncovers potential between-site heterogeneity.

10. LEGEND will maintain data confidentiality; patient-level data will not be shared between sites in the network. Not sharing data will ensure patient privacy, and comply with local data governance rules. **Aim:** Privacy.

Methods Research

LEGEND in Action

LEGEND (Large-scale Evidence Generation and Evaluation Across a Network of Databases) principles have been applied to studying the effects of treatments for depression, hypertension, and COVID-19, and are being applied to Type 2 diabetes.

The clinical impact of LEGEND has already been observed, with important evidence that promotes better health decisions published in Lancet, JAMA Internal Medicine, and Hypertension.

Journal of the American Medical Informatics Association, 27(8), 2020, 1268–1277
doi: 10.1093/jamia/ocaa124
Research and Applications

AMIA

Research and Applications

Large-scale evidence generation and evaluation across a network of databases (LEGEND): assessing validity using hypertension as a case study

Martijn J Schuemie,[1,2] Patrick B Ryan,[1,3] Nicole Pratt,[4] RuiJun Chen,[3,5] Seng Chan You,[6] Harlan M Krumholz,[7] David Madigan,[8] George Hripcsak,[3,9] and Marc A Suchard[2,10]

JAMA Internal Medicine | Original Investigation

Comparison of Cardiovascular and Safety Outcomes of Chlorthalidone vs Hydrochlorothiazide to Treat Hypertension

George Hripcsak, MD, MS; Marc A. Suchard, MD, PhD; Steven Shea, MD; RuiJun Chen, MD; Seng Chan You, MD; Nicole Pratt, PhD; David Madigan, PhD; Harlan M. Krumholz, MD, SM; Patrick B. Ryan, PhD; Martijn J. Schuemie, PhD

IMPORTANCE Chlorthalidone is currently recommended as the preferred thiazide diuretic to treat hypertension, but no trials have directly compared risks and benefits.

OBJECTIVE To compare the effectiveness and safety of chlorthalidone and hydrochlorothiazide as first-line therapies for hypertension in real-world practice.

DESIGN, SETTING, AND PARTICIPANTS This is a Large-Scale Evidence Generation and Evaluation in a Network of Databases (LEGEND) observational comparative cohort study with large-scale propensity score stratification and negative-control and synthetic positive-control calibration on databases spanning January 2001 through December 2018. Outpatient and inpatient care episodes of first-time users of antihypertensive monotherapy in the United States based on 2 administrative claims databases and 1 collection of electronic health records were analyzed. Analysis began June 2018.

EXPOSURES Chlorthalidone and hydrochlorothiazide.

MAIN OUTCOMES AND MEASURES The primary outcomes were acute myocardial infarction, hospitalization for heart failure, ischemic or hemorrhagic stroke, and a composite cardiovascular disease outcome including the first 3 outcomes and sudden cardiac death. Fifty-one safety outcomes were measured.

RESULTS Of 730 225 individuals (mean [SD] age, 51.5 [13.3] years; 450 100 women [61.6%]), 36 918 were dispensed or prescribed chlorthalidone and had 149 composite outcome events, and 693 337 were dispensed or prescribed hydrochlorothiazide and had 3089 composite outcome events. No significant difference was found in the associated risk of myocardial infarction, hospitalized heart failure, or stroke, with a calibrated hazard ratio for the composite cardiovascular outcome of 1.00 for chlorthalidone compared with hydrochlorothiazide (95% CI, 0.85-1.17). Chlorthalidone was associated with a significantly higher risk of hypokalemia (hazard ratio [HR], 2.72; 95% CI, 2.38-3.12), hyponatremia (HR, 1.31; 95% CI, 1.16-1.47), acute renal failure (HR, 1.37; 95% CI, 1.15-1.63), chronic kidney disease (HR, 1.24; 95% CI, 1.09-1.42), and type 2 diabetes mellitus (HR, 1.21; 95% CI, 1.12-1.30). Chlorthalidone was associated with a significantly lower risk of diagnosed abnormal weight gain (HR, 0.73; 95% CI, 0.61-0.86).

CONCLUSIONS AND RELEVANCE This study found that chlorthalidone use was not associated with significant cardiovascular benefits when compared with hydrochlorothiazide, while its use was associated with greater risk of renal and electrolyte abnormalities. These findings do not support current recommendations to prefer chlorthalidone vs hydrochlorothiazide for hypertension treatment in first-time users was found. We used advanced methods, sensitivity analyses, and diagnostics, but given the possibility of residual confounding and the limited length of observation periods, further study is warranted.

THE LANCET

Comprehensive comparative effectiveness and safety of first-line antihypertensive drug classes: a systematic, multinational, large-scale analysis

Marc A Suchard, Martijn J Schuemie, Harlan M Krumholz, Seng Chan You, RuiJun Chen, Nicole Pratt, Christian G Reich, Jon Duke, David Madigan, George Hripcsak, Patrick B Ryan

Summary

Background Uncertainty remains about the optimal monotherapy for hypertension, with current guidelines recommending any primary agent among the first-line drug classes thiazide or thiazide-like diuretics, angiotensin-converting enzyme inhibitors, angiotensin receptor blockers, dihydropyridine calcium channel blockers, and non-dihydropyridine calcium channel blockers, in the absence of comorbid indications. Randomised trials have not further refined this choice.

Hypertension

Comparative First-Line Effectiveness and Safety of ACE (Angiotensin-Converting Enzyme) Inhibitors and Angiotensin Receptor Blockers: A Multinational Cohort Study

RuiJun Chen, Marc A. Suchard, Harlan M. Krumholz, Martijn J. Schuemie, Steven Shea, Jon Duke, Nicole Pratt, Christian G. Reich, David Madigan, Seng Chan You, Patrick B. Ryan, George Hripcsak

Comprehensive Comparative Effectiveness and Safety of First-Line β-Blocker Monotherapy in Hypertensive Patients

A Large-Scale Multicenter Observational Study

Seng Chan You, Harlan M. Krumholz, Marc A. Suchard, Martijn J. Schuemie, George Hripcsak, RuiJun Chen, Steven Shea, Jon Duke, Nicole Pratt, Christian G. Reich, David Madigan, Patrick B. Ryan, Rae Woong Park, Sungha Park

Starting On The Most Popular Hypertension Drug Isn't Most Effective, Per OHDSI's LEGEND Study

Thiazide diuretics demonstrate better effectiveness and cause fewer side effects than ACE inhibitors as first-line antihypertensive drugs, according to a report published Oct. 24, 2019, in The Lancet. The study factors insurance claim data and electronic health records from 4.9 million patients across nine observational databases, making it the most comprehensive one ever on first-line antihypertensives, and it provides additional context to the 2017 guidelines for high blood pressure treatment developed by the American College of Cardiology (ACC) and American Heart Association (AHA).

Collaborators within the OHDSI network produced the paper **"Comprehensive comparative effectiveness and safety of first-line antihypertensive drug classes: a systematic, multinational, large-scale analysis"** as part of the collaborative's ongoing LEGEND (Large-Scale Evidence Generation and Evaluation across a Network of Databases) project, which applies high-level analytics to perform observational research on hundreds of millions of patient records within OHDSI's international database network.

OHDSI researchers believe LEGEND will continue to significantly enhance how real-world evidence is used to study important healthcare questions that impact millions of patients worldwide.

First-Line Thiazide Diuretic Users Experience 15% Fewer Adverse Cardiovascular Outcomes Than ACE Inhibitor Users

The 2017 ACC/AHA guidelines on antihypertensives recommend initiating hypertension (high blood pressure) treatment with prescription medications from any of five drug classes, including both thiazides and ACE inhibitors. Within the LEGEND project, ACE inhibitors produced both worse cardiovascular outcomes and worse side effects than thiazides.

First-line thiazide new-users experienced three major medical outcomes (heart attack, hospitalization for heart failure, and stroke) at an approximate 15% lower event rate than those who began treatment with an ACE inhibitor. Furthermore, among potential side effects associated with first-line hypertensive drugs, ACE inhibitor new-users experienced a higher rate of 19 potential side effects — and a lower rate of 2 — than thiazide diuretic new-users.

In spite of these differences, the majority of patients from this study who initiated treatment were prescribed ACE inhibitors (48%) over thiazides (17%); the results, however, indicate that over 3,100 major cardiovascular events could potentially have been avoided had those approximately 2.4 million ACE inhibitor new-users chosen a thiazide diuretic instead.

Filling The Evidence Gaps

"The LEGEND project attempts to fill the evidence gaps in treatment choices that randomized controlled trials (RCTs) leave unanswered," said lead author Marc A. Suchard, MD, PhD (University of California, Los Angeles). "We were able to compare all antihypertensive drug classes against each other at a massive scale and in a transparent and reproducible manner to study what patients worry about. Heart attack. Stroke. Heart failure. Drug safety. LEGEND synthesizes real-world evidence to determine how different drug classes impact the people who have to choose between them."

"We did not execute our study to prove one particular drug class was most effective," Suchard added. "Instead, we used the high-level analytics and best practices developed within OHDSI to study all of these drug classes against each other and openly report on all possible comparisons. Researchers can then interpret specific results in the context of their own research questions."

The paper also reported that non-dihydropyridine calcium channel blockers proved inferior to the four other first-line antihypertensive drug classes recommended in the 2017 guidelines; other classes included are angiotensin receptor blockers and dihydropyridine calcium channel blockers.

A LEGEND-ary Approach To Observational Science

"LEGEND is a unique, sophisticated approach to using observational data in a way that is reliable, rich and relevant," Suchard said. "With the availability of existing health data available, we can start to answer important clinical questions in a reproducible manner."

The LEGEND Hypertension project used state-of-the-art causal methods to address both observed confounding and residual bias. Covering patients from July 1996 to March 2018, the study filled in evidence gaps that were unavailable for the 2017 ACC/AHA guidelines. The RCTs from those guidelines factored approximately 31,000 users of either thiazide diuretics or ACE inhibitors, far fewer than the approximately 3.2 million new-users available in the LEGEND project.

"LEGEND is a novel approach that could transform the way we use real-world evidence in healthcare," said senior author Patrick Ryan, PhD, Adjunct Assistant Professor of Biomedical Informatics (Columbia University). "Rather than inefficiently conducting bespoke analyses one-question-one-method-one-database-at-a-time, leaving us vulnerable to various threats to scientific validity, LEGEND provides a systematic framework that can reproducibly generate evidence by applying advanced analytics across a network of disparate databases for a wide array of exposures and outcomes."

"We were able to compare all antihypertensive drug classes against each other at a massive scale and in a transparent and reproducible manner to study what patients worry about. Heart attack. Stroke. Heart failure. Drug safety. LEGEND synthesizes real-world evidence to determine how different drug classes impact the people who have to choose between them."

- Marc Suchard

2018 Titan Award recipient for Methodological Research

The Journey To Reliable Evidence

Clear specification of the prediction task:

- **Target Population: patients at risk**
- **Outcome: medical event to predict**
- **Time-at-risk (TAR): interval to predict if outcome will occur**

Design and Extraction

Study design

Case-control prone to misclassification and should be avoided; use cohort design

The patient-level prediction journey is more than just classification...

Loss to follow-up

Excluding non-outcomes lost to follow-up can bias the data

Feature extraction

Feature lookback can make an impact on model performance if it is too short (<180 days)

Join the PLP journey
PLP GitHub:
github.com/OHDSI/PatientLevelPrediction

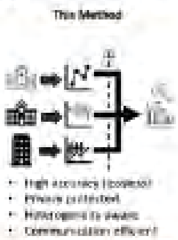
"Patient-level prediction can make a huge impact on the way we deliver medicine, but a lot more work is needed to ensure quality models are developed. OHDSI is leading research to establish best practices, answering important questions that will ensure future predictive models generate reliable evidence."

- Jenna Reps
2019 Titan Award for Methodological Research recipient

With Patient-Level Prediction

Model Development

Learning across datasets



Models can be learned across datasets while maintaining privacy

Test/Train split

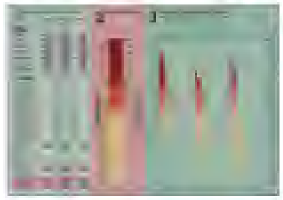
The design used to pick hyper-parameters and estimate internal validation matters, even with big p and big n data.

Sample size

Learning curves provide a way for model developers to determine whether they have sufficiently sized data

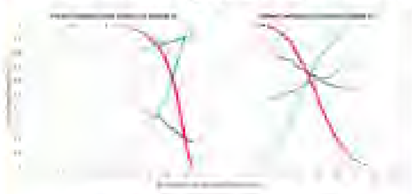
Model Evaluation

Model usability



Simple score-based models are easier to apply and can be benchmarked against large-scale models

Visualizing performance



A simple plot with the operating characteristics for all cut-offs informs model usefulness

Network validation

The OHDSI network enables large-scale external validation and improves our understanding of models

Applications

Bipolar

Mortality

Infection MI, Stroke

Fall Risk

Join The PLP Journey

PLP GitHub: github.com/OHDSI/PatientLevelPrediction

Members of the OHDSI community have published many papers together. Often, these studies are first showcased at our annual OHDSI Symposia, like the 2019 event pictured here. These events also provide opportunities for networking, which leads to new collaborations, and new collaborations lead to new evidence generation that impacts patients around the world.

VIII. OHDSI Publications

nature COMMUNICATIONS

ARTICLE

https://doi.org/10.1038/s41467-022-29160-4 OPEN

Check for updates

DLMM as a lossless one-shot algorithm for collaborative multi-site distributed linear mixed models

Chongliang Luo[1,2], Md. Nazmul Islam[3], Natalie E. Sheils[3], John Buresh[3], Jenna Reps[4], Martijn J. Schuemie[4], Patrick B. Ryan[4], Mackenzie Edmondson[1], Rui Duan[1,5], Jiayi Tong[1], Arielle Marks-Anglin[1], Jiang Bian[6], Zhaoyi Chen[6], Talita Duarte-Salles[7], Sergio Fernández-Bertolín[7], Thomas Falconer[8], Chungsoo Kim[9], Rae Woong Park[9,10], Stephen R. Pfohl[11], Nigam H. Shah[11], Andrew E. Williams[12], Hua Xu[13], Yujia Zhou[13], Ebbing Lautenbach[1,14,15], Jalpa A. Doshi[16,17], Rachel M. Werner[16,17,18], David A. Asch[16,17] & Yong Chen[1]✉

frontiers | Frontiers in Pharmacology

Vaccine Safety Surveillance Using Routinely Collected Healthcare Data—An Empirical Evaluation of Epidemiological Designs

Martijn J. Schuemie[1,2,3]*, Faaizah Arshad[1,3], Nicole Pratt[4], Fredrik Nyberg[5], Thamir M Alshammari[6], George Hripcsak[1,7], Patrick Ryan[1,2,7], Daniel Prieto-Alhambra[8,9], Lana Y. H. Lai[10], Xintong Li[11], Stephen Fortin[2], Evan Minty[10] and Marc A. Suchard[1,3,12]

Drug Safety (2022) 45:685–698
https://doi.org/10.1007/s40264-022-01187-y

ORIGINAL RESEARCH ARTICLE

Phenotype Algorithms for the Identification and Characterization of Vaccine-Induced Thrombotic Thrombocytopenia in Real World Data: A Multinational Network Cohort Study

Azza Shoaibi[1,2] · Gowtham A. Rao[1,2] · Erica A. Voss[1,2] · Anna Ostropolets[2,3] · Miguel Angel Mayer[4] · Juan Manuel Ramírez-Anguita[4] · Filip Maljković[5] · Biljana Carević[6] · Scott Horban[7] · Daniel R. Morales[7] · Talita Duarte-Salles[8] · Clement Fraboulet[9] · Tanguy Le Carrour[10] · Spiros Denaxas[11] · Vaclav Papez[11] · Luis H. John[12] · Peter R. Rijneek[12] · Evan Minty[13] · Thamir M. Alshammari[2,14] · Rupa Makadia[1,2] · Clair Blacketer[1,2] · Frank DeFalco[1,2] · Anthony G. Sena[1,2] · Marc A. Suchard[2,15] · Daniel Prieto-Alhambra[16] · Patrick B. Ryan[1,2]

ELSEVIER

Journal of Biomedical Informatics
Volume 134, October 2022, 104204

Original Research

Adjusting for indirectly measured confounding using large-scale propensity score

Linying Zhang, Yixin Wang, Martijn J. Schuemie, David M. Blei, George Hripcsak

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https://doi.org/10.1016/j.jbi.2022.104204

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BMC Medical Research Methodology

RESEARCH Open Access

Seek COVER: using a disease proxy to rapidly develop and validate a personalized risk calculator for COVID-19 outcomes in an international network

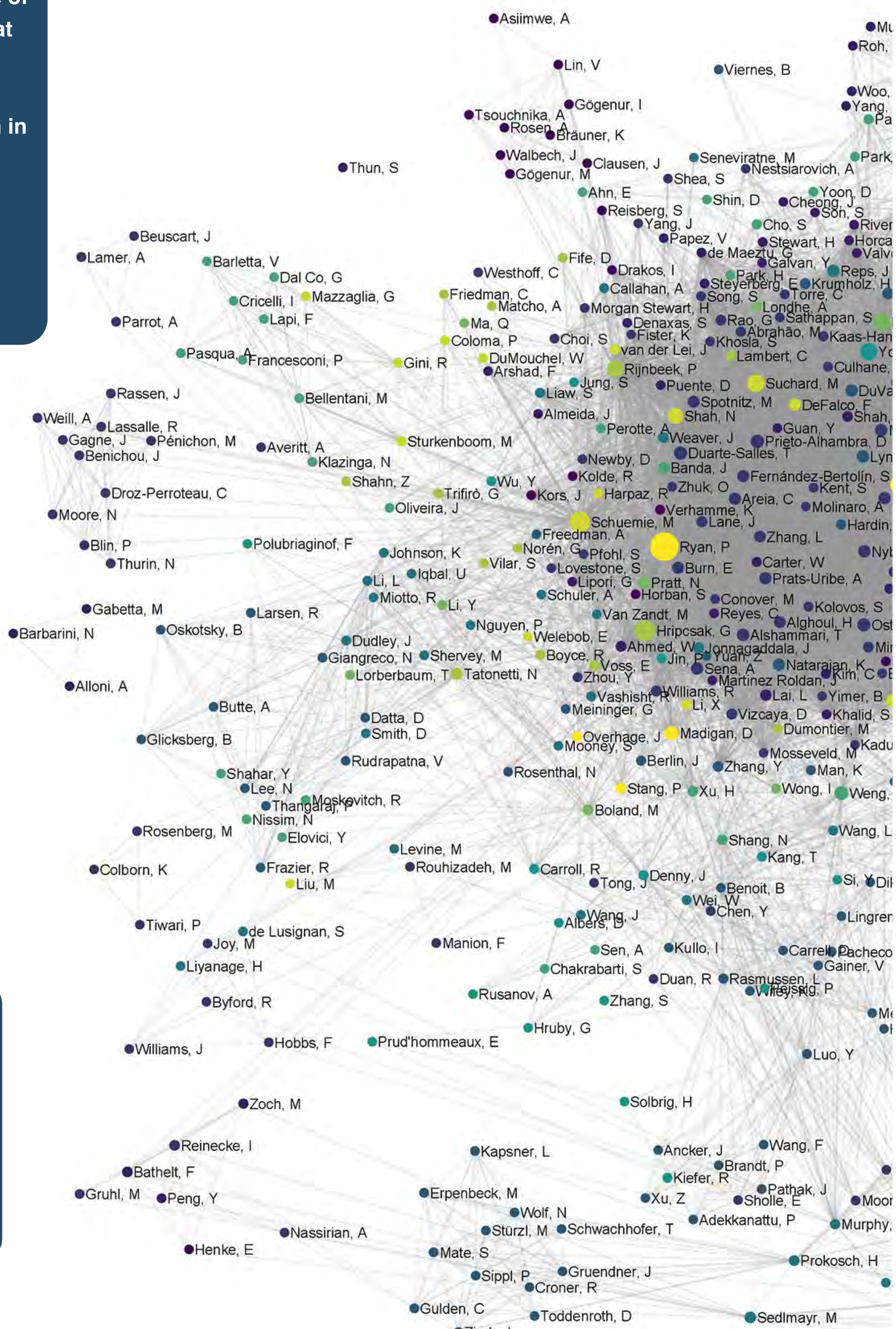
Ross D. Williams[1†], Aniek F. Markus[1†], Cynthia Yang[1], Talita Duarte-Salles[2], Scott L. DuVall[3], Thomas Falconer[4], Jitendra Jonnagaddala[5], Chungsoo Kim[6], Yeunsook Rho[7], Andrew E. Williams[8], Amanda Alberga Machado[9], Min Ho An[10], María Aragón[2], Carlos Areia[11], Edward Burn[2,12], Young Hwa Choi[13], Iannis Drakos[14], Maria Tereza Fernandes Abrahão[15], Sergio Fernández-Bertolín[2], George Hripcsak[4], Benjamin Skov Kaas-Hansen[16,17], Prasanna L. Kandukuri[18], Jan A. Kors[1], Kristin Kostka[19], Siaw-Teng Liaw[5], Kristine E. Lynch[3], Gerardo Machnicki[20], Michael E. Matheny[21,22], Daniel Morales[23], Fredrik Nyberg[24], Rae Woong Park[25], Albert Prats-Uribe[12], Nicole Pratt[26], Gowtham Rao[27], Christian G. Reich[19], Marcela Rivera[28], Tom Seinen[1], Azza Shoaibi[27], Matthew E. Spotnitz[4], Ewout W. Steyerberg[29,30], Marc A. Suchard[31], Seng Chan You[25], Lin Zhang[32,33], Lili Zhou[18], Patrick B. Ryan[27], Daniel Prieto-Alhambra[12], Jenna M. Reps[27†] and Peter R. Rijnbeek[1*†]

Collaborations Within

In this chapter, you will see both the depth and wide range of peer-reviewed publications that our community has produced over the last decade. How has OHDSI accomplished so much in so little time?

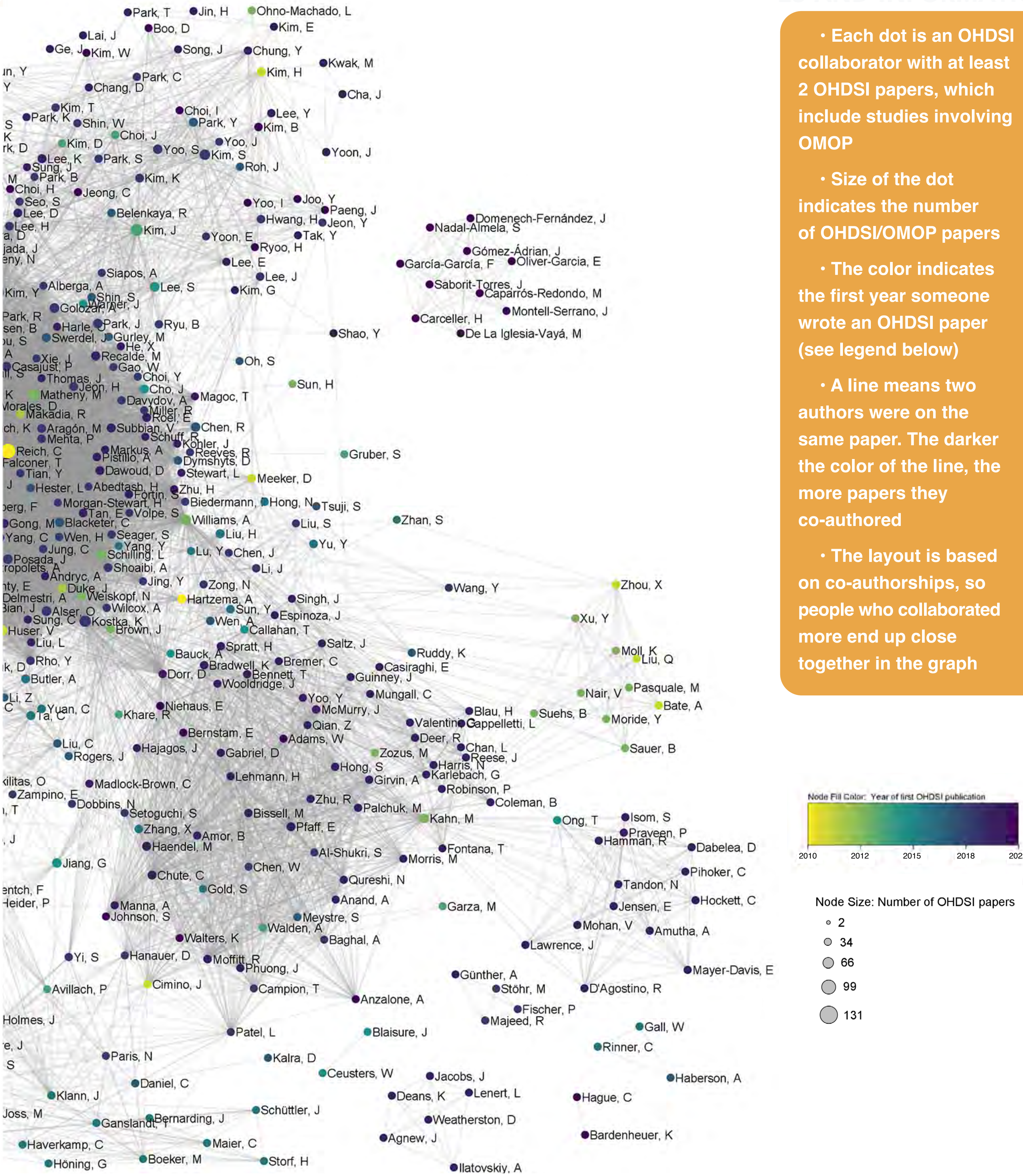
We work together.

This graphic highlights just how much our community collaborates to produce high-quality observational research.



Since our community writes many, MANY papers together, this graphic can't have everybody in the perfect spot. But it clearly shows how the culture of **'we' over 'me'** has powered OHDSI to incredible heights.

Our OHDSI Community



- Each dot is an OHDSI collaborator with at least 2 OHDSI papers, which include studies involving OMOP
- Size of the dot indicates the number of OHDSI/OMOP papers
- The color indicates the first year someone wrote an OHDSI paper (see legend below)
- A line means two authors were on the same paper. The darker the color of the line, the more papers they co-authored
- The layout is based on co-authorships, so people who collaborated more end up close together in the graph

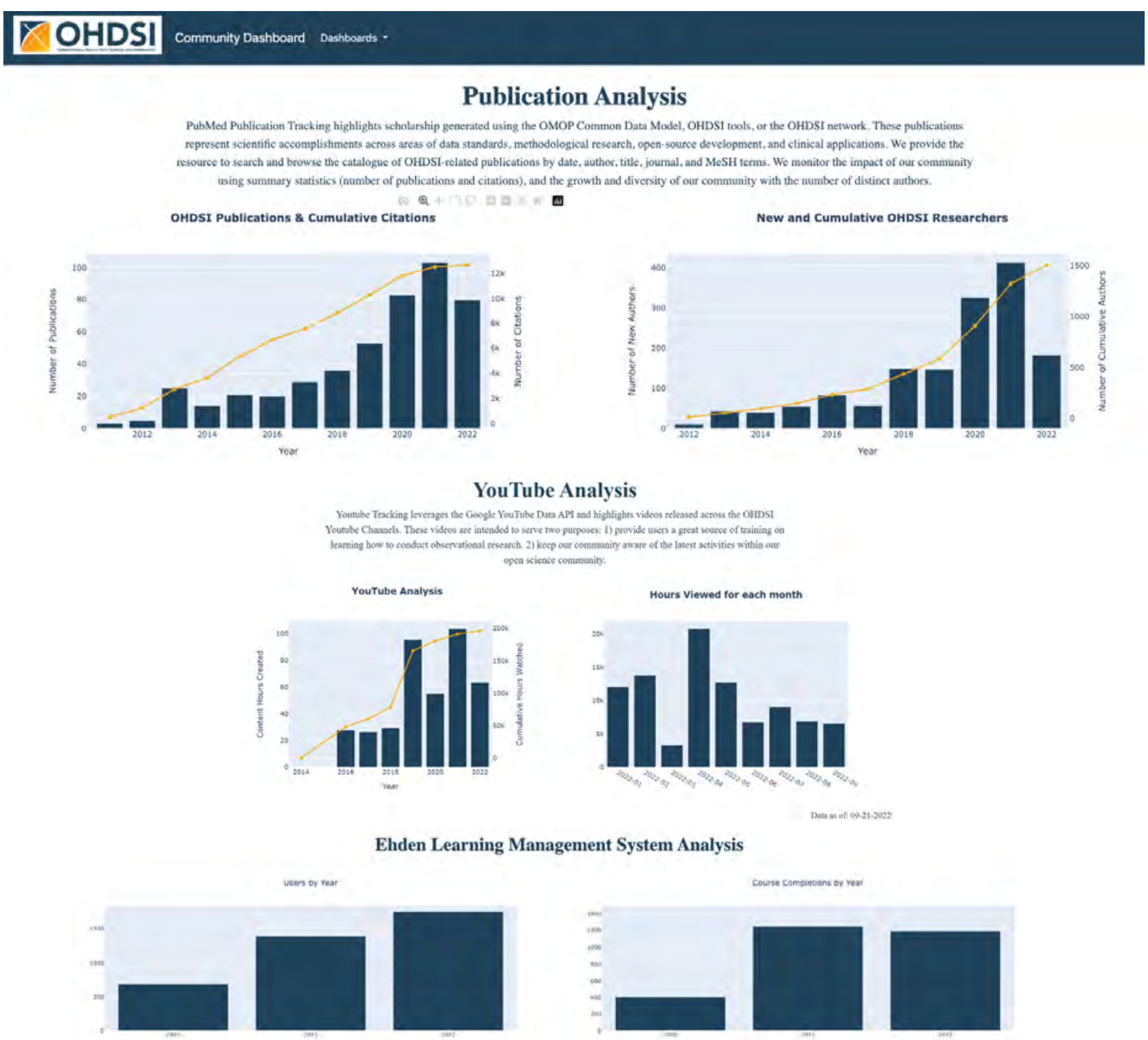
Community Dashboard

The OHDSI Community Dashboard is a tool to highlight the progress we are making toward our mission and the collective accomplishments and impact of our community. A goal of the dashboard is help our community identify how members can see the OHDSI ecosystem as an interconnected system to make a larger impact.

PubMed Publication Tracking highlights scholarship generated using the OMOP Common Data Model, OHDSI tools, or the OHDSI network. These publications represent scientific accomplishments across areas of data standards, methodological research, open-source development, and clinical applications.

There are also dashboards monitoring YouTube video tracking and EHDEN course tracking.

Thank you to the team of Paul Nagy, Star Liu, Jody-Ann McLeggon, Asieh Golozar, and Adam Black for their leadership in developing this dashboard.



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≤ 2013	2014	2015	2016	2017	2018	2019	2020	2021	Thru Sept '22
33	14	21	20	29	36	53	83	103	83

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OHDSI Publications

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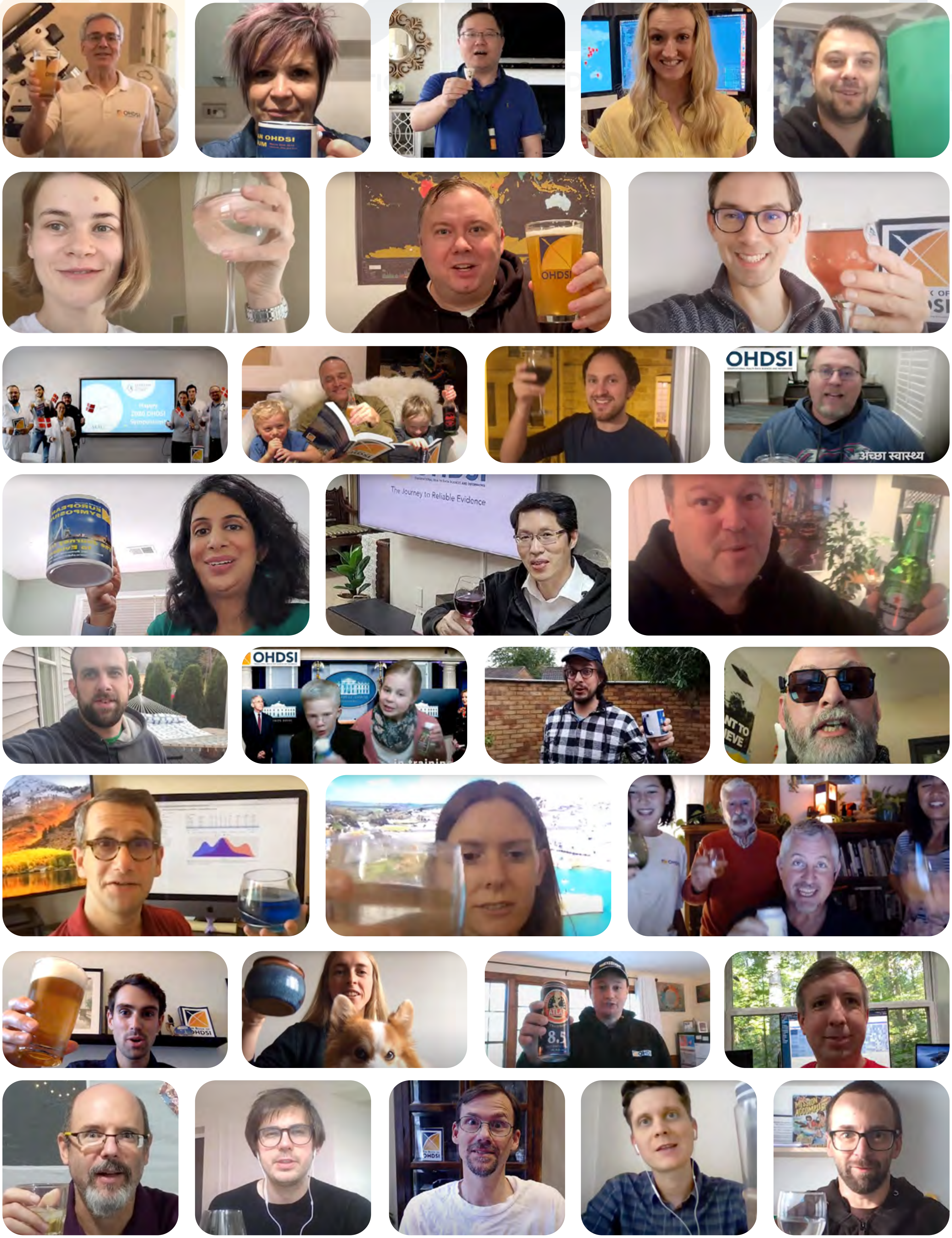
X. Join The Journey

Artwork by OHDSI collaborator Sarah Seager

Cheers, From The OHDSI Community!

2020 threatened to pull people apart, but the OHDSI community came closer together. Volunteer researchers from around the globe joined forces to study COVID-19 and other critical healthcare concerns. Collaboration in the spirit of open science drove us to do far more together than anybody could have done alone.

We also had a lot of fun in the process. To close our 2020 Global Symposium, we created a virtual "cheers" to celebrate our shared successes. To all of you who have done so much for the community, and to those of you who will join our future endeavors, CHEERS!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A favorite part of every OHDSI Symposium is the closing talk, given by Patrick Ryan. Naturally, we figured the appropriate way to end this annual report was a closing letter from Patrick.

Thank you for Joining The Journey with OHDSI!

Since as long as I can remember, I have loved sports. I love that sport is a meritocracy: at the start of any match, everyone has an equal chance to win. I love that there are objective criteria to determine success, clear rules that everyone must follow to play the game, clear goals to accomplish (like actually scoring goals!). At the end of any match, everyone knows who has won and lost.

Growing up, I especially loved playing team sports. Be it soccer, baseball or basketball, if there was a game to be played, I wanted to be in the action. I loved the competition, but I also enjoyed the comradery. I enjoyed the practices where we worked to improve our individual skills and also tried to perform better as a team. We would run drills one-on-one, two-on-two, five-on-five, each trying to focus on specific interactions between teammates. We'd rehearse set plays over and over to make sure everybody knew their role and were ready to execute. By gametime, we'd try our best to apply what we learned and see if we were good enough to earn the win. Together as a team, we shared the 'thrill of victory or the agony of defeat.'

While I loved playing on teams, I was acutely aware that I was never one of the best players. On the soccer pitch, I wasn't fast, didn't have the best drilling skills, couldn't kick it the furthest. On the basketball court, I wasn't tall, still wasn't fast, couldn't jump, wasn't much of a shooter. My dad often coached me while I was young, and he was also acutely aware of my lack of ability. He taught me two things: 1. You can't control how naturally talented you are, but you can control how much work you put in to try to get better; 2. You shouldn't focus just on yourself, but think about how you can help make your team better.

Fast forward many years later, Craig Sachson and I coached the Killer Dragons (they came up with their own name!), a U-10 soccer team in Ithaca, N.Y. Our team was comprised of all the 'leftover' kids who weren't selected by any of the other teams in the league. We knew they weren't the fastest, didn't have the best dribbling skills, couldn't kick it the farthest. We wanted to instill that same love of the game that we had, to get them to enjoy both the competition and the practices together. We wanted them to understand the value of team and the importance of teamwork. I don't remember all the practice drills or game scores that season, but I'll never forget when the Dragons scored their first (and only) goal during the final game, which came after a couple successful passes up-field between teammates. Watching those kids come together to celebrate their shared accomplishment is a memory I'll never forget.

For me, there's nothing like the rush of team achievement, that feeling when you declare "we did it" and you celebrate and recognize how everyone came together to make it happen.

Herb Brooks, head coach of the 'Miracle on Ice' 1980 US hockey team that won Olympic gold, said, "When you pull on that jersey, you represent yourself and your teammates. The name on the front is a hell of a lot more important than the one on the back." When a team has a shared purpose, it can have a powerful effect. Teams typically strive for common goals which are more ambitious than those that can be accomplished by individuals alone. Setting sights on a bigger objective can be motivating, but it can also feel intimidating on your own. With the support of a team, however, that shared objective can be broken into smaller pieces, and the specific tasks and contributions can seem more manageable and far less intimidating. When individual activities serve as building blocks, and teammates orchestrate how those blocks fit together, the team itself can build something great together.

Teamwork scales accomplishment. One person can only do so much, no matter how talented or productive she is. You can't play all positions on the field at once. Collaboration is hard, and it takes practice to figure out how to work together most effectively. Once those relationships are made and trust in teammates is formed, it becomes more comfortable to divide-and-conquer. The World Cup takes place later this year, and it represents one of the great team competitions in the world. Players like Messi, Ronaldo and Neymar are recognized around the globe, but none can win for their home countries on their own. You don't win one on eleven, no matter how special the one might be. A winning team needs a great striker, versatile midfielders, strong defenders and a dependable goalkeeper. Despite having different individuals having different responsibilities and different skills within different position groups, the team works as one and builds on each other's successes. There is no 'me' or 'you', there is only 'we.' Championships are often determined by the togetherness of the team.

I was quite struck and inspired when Martijn Schuemie introduced the analogy of the CERN Large Hadron Collider to our community (see image, right). More than 10,000 scientists across hundreds of universities and labs came together to build the world's largest and highest- energy particle collider, and they have collaboratively conducted a wide range of large-scale experiments to answer some of the most fundamental questions in physics, such as detecting the Higgs boson. CERN is a marvel of modern engineering in terms of scale and precision, but it also required tremendous innovations in computing. Leaders in their respective disciplines could have chosen to focus on their own areas of interest, continuing to make incremental progress and producing quality scholarship in their local domains. Instead, they chose a path of multi-disciplinary collaboration, contributing their expertise — often a small part of the bigger whole — to collectively enable transformational advances in science that no one individual or lab could possibly have the resources or capabilities to achieve alone. Together, they have published thousands of papers, often with thousands of co-authors, providing compelling evidence toward explaining phenomena across the universe. Part of the CERN mission is to "unite people from all over the world to push the frontiers of science and technology, for the benefit of all." **Imagine the thrill of being part of this team and playing your part, no matter how small, in something so big.**


The CERN team

What is our sport? Who is our team? How do we win?

I believe wholeheartedly in the potential for real-world evidence to fundamentally transform medicine by putting the collective learnings from past patient experience into practice for future patient care. I am confident that using observational data to characterize disease natural history and treatment utilization patterns from around the world, estimate the safety and comparative effectiveness of medical interventions, and predict health outcomes in populations of interest can empower patients and providers to make more informed, evidence-based and personalized treatment decisions. I also recognize that transformative change won't happen overnight and can't be completed by one person alone. I remain passionate about OHDSI's mission, "to improve health by empowering a community to collaboratively generate the evidence that promotes better health decisions and better care."

I believe the only way that our open-science community can succeed is through effective teamwork. If our sport is generating reliable evidence and our objective is to improve the lives of patients around the world, then that is a team I want to be on. That is a game I want to win.

Our team — the OHDSI community — already has a solid foundation. We have tremendous depth, with 3,266 collaborators on the field. We have incredible talent at all the key positions, with world-leading experts in open community data standards, open-source development, methodological research, and clinical applications guiding the way. A key strength of our team is diversity: we have strong representation across geographies, across disciplines, and across stakeholder communities. Our team has already demonstrated some of what we're capable of:

- Together as a team, **we have established an open community data standard** that is now used by more than 450 organizations in more than 40 countries around the world.
- Together as a team, **we have developed a rich suite of open-source analytics tools**, with a subset of the HADES packages having been downloaded >400,000 times by the broader research community.
- Together as a team, **the EHDEN community has certified 47 small-to-medium size enterprises in best practices for data standards and OHDSI tool configuration**, amassing a core group capable of supporting health care institutions around the world on their journey to evidence using the OMOP CDM and OHDSI analytics.
- Together as a team, **we have empirically evaluated the performance of alternative causal inference methods for comparative effectiveness and safety surveillance**, establishing the LEGEND principles for conducting large-scale analyses within disease areas of interest.
- Together as a team, **we have established best practices for patient-level prediction and built advanced machine learning tools** to train and validate models across our network.
- Together as a team, we **have created a textbook, 15 courses and >400 hours of educational content** to train the broader research community on best practices in data standards and analysis
- Together as a team, **we have published 475 scientific articles and generated evidence that has directly impacted clinical guidelines and regulatory policy**.

Yet, I would contend that our team is still just learning how to play together.

We have many members in our community watching from the sideline, wondering if they should start to play and if the juice will be worth the squeeze. We have many data partners who have joined the journey by converting their data to the OMOP CDM, but relatively few who have contributed to an open network study. We have many users of OHDSI tools, but a much smaller number of contributors willing to communicate issues, recommend enhancements, develop solutions, and support their fellow colleagues in their appropriate use. We have innovated in the area of phenotype development and evaluation, but have only begun to build a shared library of cohort definitions for expanded use across our community. We've completed an impressive number of OHDSI network studies, but many more studies remain isolated to a specific data source or institution. We have many workgroups that have made progress on their local ambitions, but haven't yet coordinated all the activities to align with an over-arching objective.

I'm excited for what's possible if we all work as one team with a shared sense of purpose, each of us focusing our efforts to make our own contributions toward a common goal. **Brick by brick, when we put it all together, we can build something profound. We can build a healthier world together.**

I can't imagine a sweeter victory.

Patrick Ryan

How Can You Join The Journey?

Our community has set both the foundation and the highest of standards for global collaboration around observational research. We continue to make real differences in healthcare, and we are doing it through transparent and reproducible science. We also recognize that there is so much more to be done, and so much more that we can do.

If you are inspired by what you read in this book, if you want to learn more about methods research or open-source development, if you have a clinical question you believe needs answering, or if you want to join a community of people dedicated to the team sport of observational health data sciences and informatics, we have a place for you.

How can you get started?

Step One: Join The OHDSI Forums (forums.ohdsi.org)

Connect with other OHDSI collaborators on our community forums and start discussing how you can help us inform medical decision-making, or simply follow discussions that are interesting to you and learn about the work happening within our global community.

Step Two: Join Our Workgroups & MS Teams Environment (ohdsi.org/ohdsi-workgroups)

OHDSI has 27 active workgroups that always seek new collaborators. Our workgroups present opportunities for all community members to find a home for their talents and passions, and a place to make meaningful contributions. Our workgroups collaborate inside the OHDSI MS Teams environment; a form to join our Teams environment is available here: bit.ly/Join-OHDSI-Teams.

Step Three: Join Our Community Calls (ohdsi.org/community-calls/)

Join collaborators around the world each week during our OHDSI Community Call, held Tuesdays at 11 am ET within our Teams environment. Following weekly updates, we have a variety of call formats, including research presentations, workgroup updates, discussions, debates and more. These calls are recorded, and you can access them (as well as the meeting link) at our Community Calls page.

Step Four: Continue To Learn About OHDSI

Learn about OHDSI tools and research processes in a variety of ways.

• The Book of OHDSI (which is also translated into both Korean and Chinese) is a community-developed resource with information for every step of your journey: ohdsi.github.io/TheBookOfOhdsi

• Check out the EHDEN Academy, a set of free, on-demand training and development courses. These are open to anybody, but we always encourage new OHDSI collaborators to use this resource to learn about best practices towards our mission of improving health by empowering a community to collaboratively generate evidence that promotes better health decisions and better care: academy.ehden.eu

• Our OHDSI News page keeps you informed of recent news, publications, upcoming studies and more, while also profiling collaborators and providing other updates: ohdsi.org/ohdsi-news-updates

• Check out the OHDSI YouTube page (youtube.com/c/OHDSI) for many community-developed learning resources, including tutorials, research presentations and more. Follow OHDSI on both Twitter (@OHDSI) and LinkedIn (OHDSI) to keep updated on community research and follow the #OHDSISocialShowcase to see the research shared at our annual symposia.

Join The Journey

Your journey with OHDSI has started. Your interest in our global community is the first step in making a difference in global health. There is no limit to the impact you can make, and you can do so in a supportive, positive and fun environment. We invite you to search our website, post to the forum, join us in Teams, check out our GitHub (github.com/OHDSI), or reach out to us over email (contact@ohdsi.org).

Thank you for Joining The Journey with OHDSI!

OHDSI

Join The Journey

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