

# Evidence Network<sub>β</sub> Participation Guidelines

The OHDSI Evidence Network aims to bridge the gap between researchers and organizations by creating an open network of observational health databases. Our primary goal is to ensure that data is utilized more effectively and that research questions are framed and assessed in a structured manner. By joining the OHDSI Evidence Network, organizations and their data sources will gain recognition as leaders in the field, showcased on the OHDSI website. This matchmaker service is a continuous learning process, striving for a future where data and research questions align more appropriately, leading to more significant and impactful health research outcomes. **As this is a volunteer network, Data Partner Organizations are under no obligation to participate in network studies.**

The OHDSI Evidence Network Member agrees not to share any patient information that constitutes protected health information or share confidential business information. It is the intent of the OHDSI Coordinating Center to keep all shared information private, but in the event of an external breach, the OHDSI Coordinating Center is not liable for loss of the information. If an OHDSI Evidence Network Member accidentally shares confidential information, the OHDSI Coordinating Center will delete that information to the extent possible at the time of the discovery of the breach.

## Data Partner Organizations

### What it means to be a Data Partner Organization

A Data Partner Organization is an entity that owns or licenses one or more data sources, which have been converted to the OMOP Common Data Model (CDM) v5.3 or higher. These organizations are interested in using their data to generate evidence supporting network use cases. Membership in the network is voluntary, as is participation in any studies conducted within the network.

### Joining the network as a Data Partner Organization

#### Requirements to join

A DPO must *have* the following to join the OHDSI Evidence Network:

- Observational health data standardized to the OMOP CDM v5.3 or higher
  - The expectation is that the data are already standardized following community-based best practices and data quality assessments
- Data held in a supported SQL environment accessible by the organization

- List of supported SQL environments here:  
<https://ohdsi.github.io/SqlRender/articles/UsingSqlRender.html#translation-to-other-sql-dialects>
- Approval from IRB or other governance entity to share metadata and concept counts with the OHDSI Coordinating Center (OCC)
  - Note: It is up to each individual Data Partner Organization as owner or licensee of data to ensure all appropriate governance requirements are followed.
  - The kinds of agreements necessary to send the aggregate concept counts to the OCC will vary from site to site. For a health system this often includes the IRB and/or the privacy officer
- A resource (individual) who can run a package in R/RStudio against the data

A DPO must *do* the following to join the OHDSI Evidence Network:

- Run the [DbDiagnostics package](#) *executeDbProfile* function to generate metadata and high-level concept counts about each data source
  - The aggregate information gathered by the package is listed here:  
<https://ohdsi.github.io/DbDiagnostics/articles/SummaryStatistics.html>
  - If the [Achilles](#) package was run previously and the results stored this step will take approximately 15-30 minutes, depending on the environment
  - If the Achilles package was not run previously or if the results were not stored this step will take approximately 1-8 hours, depending on the environment.
- Send the resulting information to the OCC via SFTP

**Sending this information to the OCC grants the OCC permission to use this information to support OHDSI Community activities with site name withheld.**

#### Privately held information

Once the metadata and concept counts are sent to the OCC, the direct contact information for organizational representatives and the site-specific concept counts will be held privately. This information will be accessible only by the OCC in a secure environment.

#### Publicly shared information

Only network-level concept counts will be shared as an open public resource. Specifically, this will include the overall network total record count and descendant record count for each concept, as well as the total number of data sources in the network that have at least one record for each concept.



## Upon joining the OHDSI Evidence Network as a DPO

Once a DPO joins the OHDSI Evidence Network by sending the metadata and concept counts for each participating data source to the OCC, they will receive an organizational OHDSI account (@ohdsi.org). This account identifies them as members of the network and will be used for communication within the OHDSI Teams environment to coordinate OHDSI efforts. The email address will not be shared publicly.

Additionally, the organization will receive a report for each data source submitted to the network. This report will compare each data source to others in the network using network-based benchmarks. It will include metrics such as concepts unique to the data source, concepts present in other data sources but missing from the submitted data source, and comparisons of demographic representation.

Organizations will be added to the OHDSI Teams environment to include access to a resource library

## Network Studies

**As this is a volunteer network, DPOs are under no obligation to participate in network studies**, however, each study will follow the same steps to assess potential data sources to contribute evidence and to communicate and solicit interest from DPOs. At that point it is the choice of the DPO if they would like to participate. If so, the DPO must either provide the resources necessary to run the study or work with the researcher/sponsor to provision said resources.

### *Feasibility Assessments*

Researchers will work with the OCC to conduct data diagnostic feasibility assessments to identify which data sources in the network have the building blocks necessary to support their study question.

### *Communication*

Once the potential data sources are identified, an email will be sent to the DPO's OHDSI email address informing them of the opportunity. If the DPO chooses to participate they will work directly with the researcher from that point forward.

Prior to contacting you in relation to a network study, the OCC will:

1. Ensure the persons leading the study have done their due diligence, which includes
  - a. A fully specified draft protocol
  - b. A github repository with all related code and documents

- c. A Data Diagnostics output detailing why a data source has the potential to participate in the study

#### *DPO Resources required*

A DPO will need a resource at their site with R/RStudio installed on their machine, the ability to install and run an R package and access to the data source identified as a candidate for the study. Depending on the study complexity, the person time commitment will vary. For a first-ever study it can range from hours to months, but the general expectation is that there is a learning curve involved. Prior experience is a large factor and the extent to which prior artifacts are reused. Put a list of what might affect the resources required, the level of standardization of the study.

#### *Attribution and Authorship*

If a data source contributes evidence to a manuscript sharing the results of an OHDSI Network Study, it will be listed and attributed according to the guidelines of the data owner or data license. Additionally, at least one member of the DPO will have the opportunity to be listed as a co-author on the manuscript.