

Registry Workgroup

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in ohdsi



Purpose of the Registry WG

- Registries contain valuable real-world data whose potential could be increased by transforming it to the OMOP common data model.
- Registry data might face additional challenges compared to data coming from electronic health care records.
 - For example, registry data often consists of data that does not come from EHR (alone) and uses other standards, if any, than those that are widely used in EHR.
- As a group we aim to identify these challenges and align approaches to transform registry data to the OMOP CDM.



Purpose of the Registry WG

- Reasons of transforming registry data to OMOP CDM:
 - Become part of projects / networks (e.g. EHDEN)
 - (Inter)national research / collaboration
 - Enrichment or validation of own studies with (linked) OMOPed data
 - Automation and lowering physician burden for data collection
 - Make registry data more FAIR
 - Create standardized analysis across databases in a more transparent way with more reliable results
 - Privacy by design

Members' voices



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2022 Achievements of the Registry WG

- We successfully constituted the Registry WG out of the former UK Biobank WG and gathered interested, motivated OMOP collaborators.
- Kick-started with a survey to get the first impressions of the group's members, focus and ideas.
- We had several talks from different registries who transformed their data to the OMOP CDM and discussed the challenges.

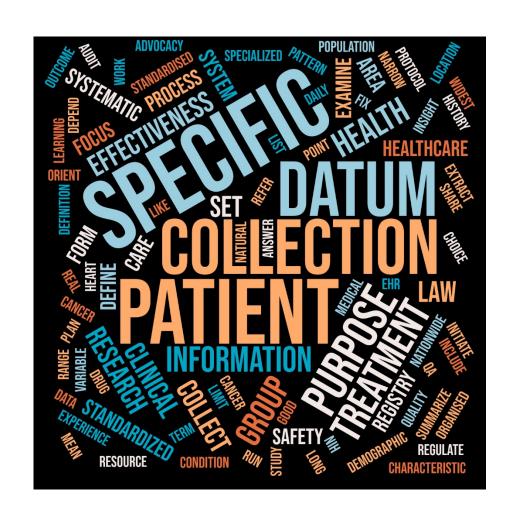


Get to know the Registry WG - Survey

"What is a registry?"

"a collection of standardized information about a group of patients who share a disease or experience". (NIH)

- "A structured data set with specific variables collected for a specific set of patients."
- "organised collection of defined and standardised health data on a specific disease or patient population"
- "A centralization of clinical data about patients across multipole locations with a standardized data collection protocol and generally a list of questions to answer."
- "long-term data collection system on a group of person with a specific disease or condition and established for a specific purpose"
- "Systematic collection of health information about individuals and regulated by law."
- "high quality platform"
- "Extracted and summarized EHR data"





Get to know the Registry WG - Survey

14. Is data collection currently ongoing?

More Details

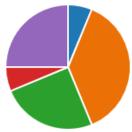
- Yes, but it has a defined end point 2
- Yes, and it will continue without ... 5
- No 2
- Unsure



2. How would you describe your role associated with this registry and/or the OMOP CDM best?

More Details

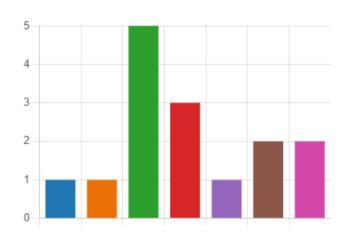
- Data custodian/owner (of regist... 1
- Technical expert (e.g. responsibl... 6
- Researcher (e.g. uses registry da... 4
- Third-party (e.g. industry partne... 1
- Other



15. What describes the type of your registry best? (multiple answers possible)

More Details

- Clinical trial
- Post-authorization safety study
- Clinician-driven registry (dedicat... 5
- Patient-driven registry
- Clinician or patient-driven regist... 1
- Registry consisting of linked dat... 2
- Other





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OKR 2023 (Q1-2) of the Registry WG

 Our main objective for the first half year 2023 is to establish a regular meeting routine of at least a meeting/presentation every 2 months.

 Move ahead with the from the presented ex the OMOP common d mapping.

Once a month
Once every 3 month
I don't have a preference.



→ Mapping conventions

→ Support for transformations within the workgroup.

More Details

Bi-weekly

sions

5. What are your preferences for the frequency of the Registry WG meeting?

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OKR 2023 (Q1-2) of the Registry WG

- Our main objective for the first half year 2023 is to establish a regular meeting routine of at least a meeting/presentation every 2 months.
- Move ahead with the following objective of drawing up conclusions from the presented experiences of / challenges in transforming registry data to the OMOP common data model.
 - → Mapping conventions for alignment (2023/2024)
 - → Support for transformations within the workgroup

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