



Registry Workgroup

Tina Parciak



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



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.



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

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 0



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

[More Details](#)

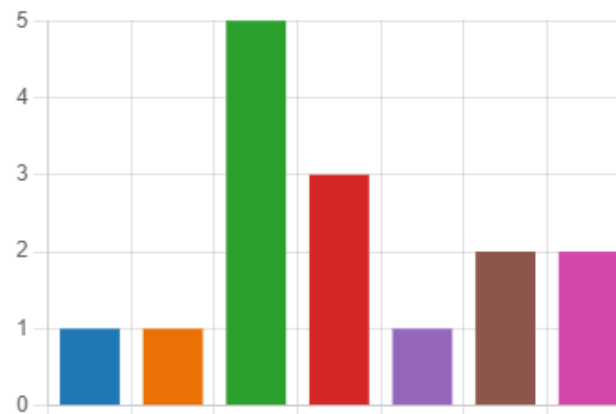
- Data custodian/owner (of regist... 1
- Technical expert (e.g. responsibl... 6
- Researcher (e.g. uses registry da... 4
- Third-party (e.g. industry partne... 1
- Other 4



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

[More Details](#)

- Clinical trial 1
- Post-authorization safety study 1
- Clinician-driven registry (dedicat... 5
- Patient-driven registry 3
- Clinician or patient-driven regist... 1
- Registry consisting of linked dat... 2
- Other 2





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.



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 [mapping](#) from the presented [examples](#) to the OMOP common data model mapping.

→ Mapping conventions

→ Support for transformations within the workgroup.

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

[More Details](#)

● Bi-weekly	0
● Once a month	8
● Once every 3 month	3
● I don't have a preference.	3
● Other	0



ions
D



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