Registry Workgroup

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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. EHDPEN)
  – (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
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- 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.
"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**”
14. Is data collection currently ongoing?

- Yes, but it has a defined end point: 2
- Yes, and it will continue without: 5
- No: 2
- Unsure: 0

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

- Clinical trial: 1
- Post-authorization safety study: 1
- Clinician-driven registry (dedicated): 5
- Patient-driven registry: 3
- Clinician or patient-driven registry: 1
- Registry consisting of linked data: 2
- Other: 2
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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 transforming registry data to the OMOP common data model with regards to challenges in mapping.
  → Mapping conventions
  → Support for transformations within the workgroup.

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

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

More Details
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