Registry Working Group

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Registry Working Group – Roadmap 2022 / 2023

1. **Landscaping of current or to-be OMOPed registries and their use cases**

   i. Definition of "What is a registry?"

   ii. Map of (to-be) OMOPed registries and their use cases

2. **Why use OMOP CDM for registries? (opinions from WG members)**

   i. What is the incentive of using OMOP CDM for registry datasets?

   ii. What is the goal of mapping registry data to OMOP?

Registry WG: Landscaping

OHDSI Registry WG: Landscaping

This form will be used to gather information about ongoing or emerging OMOP CDM transformations of registries (or registry-like cohorts). It serves the purpose of getting an overview of how often the OMOP CDM is used for registries, which use cases are represented in the registries and the aims and status of the transformation. This survey will also help our definition of 'registry' - what is it and what not?

[Disclaimer: All answers will be recorded in the response file in the Registry WG Teams which is visible to all members of the group. No answer is mandatory, please answer only the questions that you are comfortable sharing with the Registry WG members.]

1. What is the name of the registry you are working with/for?

   Enter your answer

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

   ☐ Data custodian/owner (of registry)

   ☐ Technical expert (e.g. responsible for ETL)

   ☐ Researcher (e.g. uses registry data for research purposes)

   ☐ Third-party (e.g. industry partner in a network)

   ☐ Other

3. Please share your understanding of the term 'registry'.

   Enter your answer

4. Why did you join the OHDSI Registry WG? Do you have specific wishes, questions or ideas you want to address or see discussed in the work group?

   Enter your answer

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

   ◯ Bi-weekly

   ◯ Once a month

   ◯ Once every 3 month

   ◯ I don't have a preference.

   ◯ Other

Registry WG: Landscaping

8. Please describe in one sentence the purpose of the registry or link to external resources describing this. 📖

> Enter your answer

9. Please describe the population of the registry. Of whom is data being collected/stored?

> Enter your answer

10. If known, how big is the population within the registry? (Population = Total number of unique individuals with records captured in the registry/cohort)

> Enter your answer

11. What is the geographical origin of the population?

- ○ Specific region
- ○ Specific country
- ○ Several countries, one continent
- ○ Several countries from several continents

14. Is data collection currently ongoing?

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

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

- ☐ Clinical trial
- ☐ Post-authorization safety study
- ☐ Clinician-driven registry (dedicated first or secondary data collection for the registry)
- ☐ Patient-driven registry
- ☐ Clinician or patient-driven registry with linkage to third-party systems, e.g. biobank, health insurance database
- ☐ Registry consisting of linked data only, e.g. extracted from EHR and other database (no dedicated data collection for the registry)
- ☐ Other

16. What were the reasons for transforming the registry's data to the OMOP CDM in the first place?

> Enter your answer

Registry WG: Landscaping

- Survey link was sent to all WG members
- Deadline: 31 August

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3. **Overview of challenges in mapping registry data to OMOP (every stage in mapping process)**

    i. PROMS: Challenges with Questionnaires - how to translate standardized questionnaires?

    ii. Presentations of representatives of registries/SME/network partner

    iii. Document on challenges for the different registries/use cases

4. **Work towards mapping conventions that address those challenges**

    i. How where those challenges solved (retrospect)?

    ii. How could those challenges be solved (prospect)?

    iii. Which of those solutions/suggestions could be considered as a mapping convention?

    Are there differences for disease-specific and disease-agnostic registries (in regards to possible conventions)?

Registry WG

Want to join?
Check out the Working Group registration!

Questions?
Feedback?

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