

OMOP CDM for data from multiple sclerosis registries and cohorts?

Possible, but ...

Piloting the Transformation of Multiple Sclerosis Real-World Data to the OMOP CDM: Lessons Learned

Background: OMOP CDM is a promising option for data from MS registries and cohorts as it could enable analysis within and outside the MS community. Since OMOP was not originally designed for registry data, especially of a chronic, relapsing and progressive disease, a piloting transformation for two MS datasets was done.



Lessons Learned

Datasets from MS registries and cohorts differ from EHR data. OMOP CDM lacks features or concepts for such data.

- Differences in data collection methods, the lack of standards and free text fields use.
- Existence of relapses as a disease characteristic
- Existence of many different symptoms and comorbidities without granular information
- Importance of negative or “no evidence of” results in longitudinal follow-up

Standardisation to OMOP CDM can still result in heterogeneous outputs.

- Create a mapping guideline with general transformation rules to promote consistency in OMOP MS databases.
- Additionally, encourage the use of the STEM table for wide formatted data, e.g. registry data, resulting in a simpler and more data-driven ETL implementation.

Exchange of experiences and alignment for registry-type data transformations is necessary.

- Establishment of OHDSI Registry workgroup.
- Identified challenges e.g. survey data, non-valuable answers, linkage of events/fields, observation periods, missing concepts, and patient-reported outcomes.

Transforming data from MS registries and cohorts demands substantial time investment and interdisciplinary knowledge.

- For the use case of MS, a tool will be developed that maps data in a specific format, the MSDA Core Dataset, to the OMOP CDM.
- Lowering the threshold for getting "OMOP-ready" and improving the speed and harmonisation in the mapping process.

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