Mapping PROMs data from the Dutch PROFILES registry to the OMOP-CDM - experiences and challenges

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**INTRO**
- Data from the Netherlands Cancer Registry (NCR) is being converted to the OMOP-CDM.
- PROFILES contains patient-reported outcome measures (PROMs) data that is linked to patients in the NCR.
- How do we add this PROMs data to the OMOP-CDM to make the data set even more interesting? OHDSI is not very clear on that.

**METHODS**
Use cases we foresee:
- Specific studies on PROMs data.
- General studies where PROMs data provides additional information about the patient.

A possible solution for adding PROMs data to the OMOP-CDM is outlined in Fig. 1.

**RESULTS**
We mapped the EORTC QLQ-C30 and the Hospital Anxiety and Depression Scale (HADS, see Fig. 2), and added those to our OMOP-CDM.

They both contain question/answer (Q/A) pairs and scores. The latter are calculated from subsets of Q/A pairs.

Examples of mappings are shown in Figs. 3 & 4.

**DISCUSSION**
There are several open questions, to be answered by the OHDSI community:
- Should there be an overarching "PROMs questionnaire filled out" concept that Q/A pairs and scores can be linked to? Yes, that is a good way to group data from a single filled out questionnaire.
- Should Q/A pairs be added to the OMOP-CDM? Should scores?

Yes, they are relevant for specific studies.
- Should Q/A pairs be mapped to clinical concepts?

Yes, always.

Yes, but only if there are no scores (questions are just a tool to determine scores, the latter are the only relevant outcomes).

**CONCLUSIONS**
- A guideline for adding PROMs to the OMOP-CDM does not exist: the OHDSI community should develop conventions for capturing PROMS data in OMOP.
- The vocabulary is very incomplete when it comes to representing PROMS data.

**JOIN US!**
Do you want to collaborate on harmonizing PROMS data in OMOP? Then contact Sebastiaan and join the EHDEN PROMS WG (sebastiaan.van.sandijk@odysseusinc.com)

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**Figure 1. A solution for adding PROMs data to the OMOP-CDM.**

**Figure 2. Example of a PROMs questionnaire: HADS.**

**Figure 3. Example of score mapping: HADS scores.**

**Figure 4. Example of question and answer concepts, and mapping of Q/A pairs: the first two questions of QLQ-C30.**