

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.

No, irrelevant for studies.

- Should Q/A pairs be added to the OMOP-CDM? Should scores?

Yes, they are relevant for specific studies.

No, only clinical facts and events are relevant.

- 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).

Guideline for adding PROMs to OMOP-CDM nonexistent PROMs vocabulary incomplete

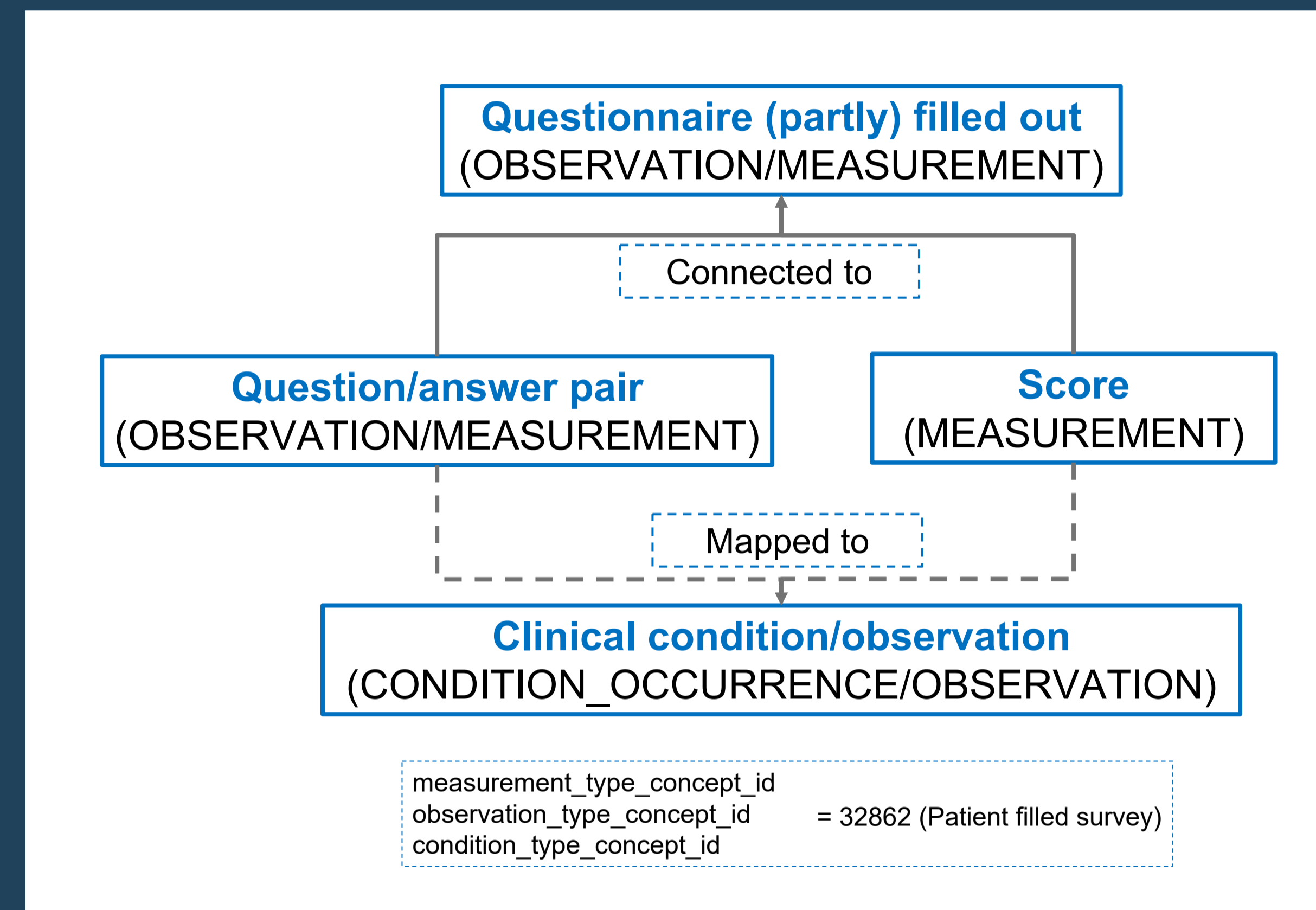


Figure 1. A solution for adding PROMs data to the OMOP-CDM.

Score	Value	Concept ID	Name	Vocabulary
Anxiety score	0-7 (Normal)	do not map		
	8-10 (Borderline abnormal)	4322025	Mild anxiety	SNOMED
	11-21 (Abnormal)	441542	Anxiety	SNOMED
Depression score	0-7 (Normal)	do not map		
	8-10 (Borderline abnormal)	40546087	Depressed mood	SNOMED
	11-21 (Abnormal)	40546087	Depressed mood	SNOMED

Figure 3. Example of score mapping: HADS scores.

Figure 2. Example of a PROMs questionnaire: HADS.

Question	Concept ID*	Answer	Concept ID**	Mapped question/answer	Concept ID***
Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	701340	not at all	45883172	Capable of heavy physical activity	763659
		a little	45876949	?	?
		quite a bit	45884456	?	?
		very much	45885256	?	?
Do you have any trouble taking a long walk?	701341	not at all	45883172	Able to walk	4086870
		a little	45876949	Unable to walk long distances	44792042
		quite a bit	45884456	Unable to walk long distances	44792042
		very much	45885256	Unable to walk long distances	44792042

* OMOP Extension vocabulary, ** LOINC vocabulary, *** SNOMED vocabulary

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

- Should scores be mapped to clinical concepts?
Yes, that is the clinically most important part.
No?
- Should we add negative concepts (no pain)?
Yes, they are relevant observations.
No, this information is not useful in studies.
- Can we use ..._type_concept to indicate patient-reported (vs physician-reported)?
Yes, we do not want to create a whole bunch of new concepts.
No, nobody uses the ...type_concept field in analyses.
- What observation or event date do we associate with the PROMs data ("Did you experience pain in the past month?")?

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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