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

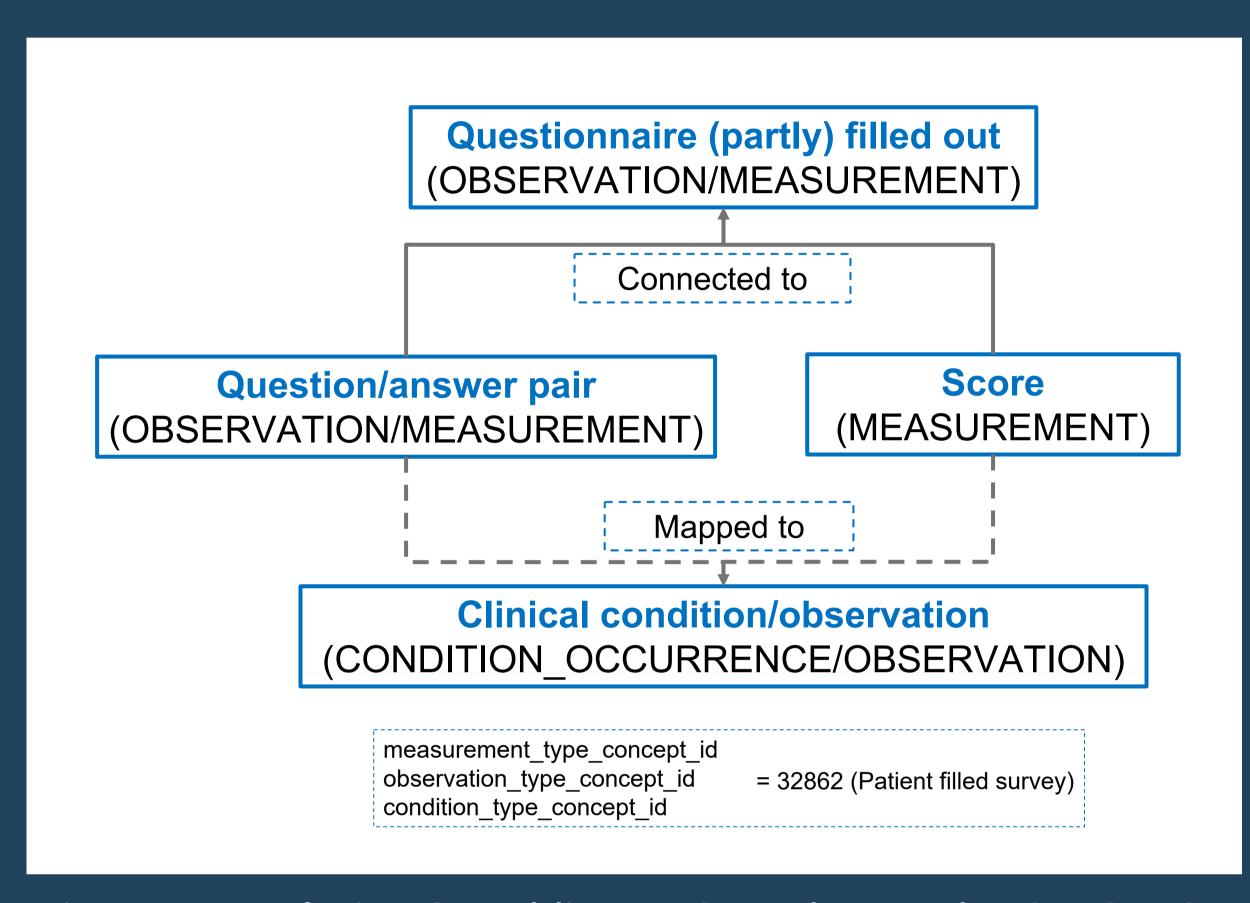


Figure 1. A solution for adding PROMs data to the OMOP-CDM.

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.

I feel tense or 'wound up': Most of the time A lot of the time From time to time, occasionally Not at all I still enjoy the things I used to	3 2 1 0		I feel as if I am slowed down: Nearly all the time Very often Sometimes
A lot of the time From time to time, occasionally Not at all I still enjoy the things I used to	2		Very often
From time to time, occasionally Not at all I still enjoy the things I used to	1		
Not at all I still enjoy the things I used to	0		Sometimes
I still enjoy the things I used to	0		
			Not at all
enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
Definitely as much		0	Not at all
Not quite so much		1	Occasionally
Only a little		2	Quite Often
Hardly at all		3	Very Often
I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
	3		Definitely
Yes, but not too badly	2		I don't take as much care as I should
A little, but it doesn't worry me	1		I may not take quite as much care
Not at all	0		I take just as much care as ever
I can laugh and see the funny side			I feel restless as I have to be on the move:
•		3	Very much indeed
			Quite a lot
			Not very much
			Not at all
		U	I look forward with enjoyment to
mind:			things:
	0		As much as I ever did
	1		Rather less than I used to
			Definitely less than I used to
Only occasionally	3		Hardly at all
I feel cheerful:			I get sudden feelings of panic:
		3	Very often indeed
		_	Quite often
			Not very often
		0	Not at all
I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
Definitely	0		Often
Usually	1		Sometimes
Not Often	2		Not often
Not at all	3		Very seldom
	Only a little Hardly at all I get a sort of frightened feeling as if something awful is about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all I can laugh and see the funny side of things: As much as I always could Not quite so much now Definitely not so much now Not at all Worrying thoughts go through my mind: A great deal of the time A lot of the time From time to time, but not too often Only occasionally I feel cheerful: Not at all Not often Sometimes Most of the time I can sit at ease and feel relaxed: Definitely Usually	Only a little Hardly at all I get a sort of frightened feeling as if something awful is about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me 1 Not at all 0 I can laugh and see the funny side of things: As much as I always could Not quite so much now Definitely not so much now Not at all Worrying thoughts go through my mind: A great deal of the time A lot of the time 1 From time to time, but not too often Only occasionally I feel cheerful: Not at all Not often Sometimes Most of the time I can sit at ease and feel relaxed: Definitely Usually 1	Only a little Hardly at all I get a sort of frightened feeling as if something awful is about to happen: Very definitely and quite badly Yes, but not too badly A little, but it doesn't worry me Not at all I can laugh and see the funny side of things: As much as I always could Not quite so much now Definitely not so much now Not at all Worrying thoughts go through my mind: A great deal of the time A lot of the time From time to time, but not too often Only occasionally I feel cheerful: Not at all Not often Sometimes Most of the time I can sit at ease and feel relaxed: Definitely Usually Definitely Usually

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

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.

- 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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