OHDSI Workgroup Rehabilitation

Ruud Selles & Esther Janssen

18 August, 2026

WG Name: Rehabilitation Workgroup
WG Leads: Esther Janssen & Ruud Selles

Mission statement

Promote better rehabilitation care
by leveraging the OHDSI collaborative to enable
large scale observational rehabilitation research

Two ongoing projects with a central role for OMOP-CDM

- PREPARE is a HaDEA-Horizon European project or rehabilitation care (7 million Euro, nine countries)
- UMBRELLA is an Innovative Health Initiative (IHI) project on stroke care (26 million Euro, 20 public and private parties)
- Both generate (amongst others) federated data platform for sharing ML models, exploiting the OMOP CDM and OHDSI tools

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1. Objective 1: further development of the OHDSI rehabilitation research learning community

2026 Key goals/results:

1. Establish a minimum of 3 workgroup meetings
2. Have at least 25 active working group members
3. Improve collaboration with associated OHDSI WGs to share learning experiences in similar challenges. (e.g., PROM and treatment mapping)

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1. Objective 2: Address challenges and working towards best practices in using OMOP-CDM for rehabilitation research data

2026 Key goals/results:

1. Continue mapping rehabilitation-specific outcome data to the OMOP-CDM (e.g., PROMS)
2. Continue mapping rehabilitation-specific treatments to the OMOP-CDM (e.g., complex treatments, multidisciplinary treatments)
3. Share first experiences with cohort definitions and distributed analyses.

Rehabilitation

1. Speech and language training to improve a person's communication after a brain injury

2. Physical exercise training to improve muscle strength, voluntary movements and balance in persons with stroke or Parkinson disease

3. Modifying an older person's home environment to improve their safety and independence at home and to reduce their risk of falls

4. Educating a person with heart disease on how to exercise safely

5. Preparing a person with an amputation to be able to use a prosthetic and making, fitting and refitting the prosthesis

6. Positioning and splinting techniques to assist with skin healing, reduce swelling, and to regain movement after burn surgery

7. Prescribing medicine to reduce spasticity for a child with cerebral palsy

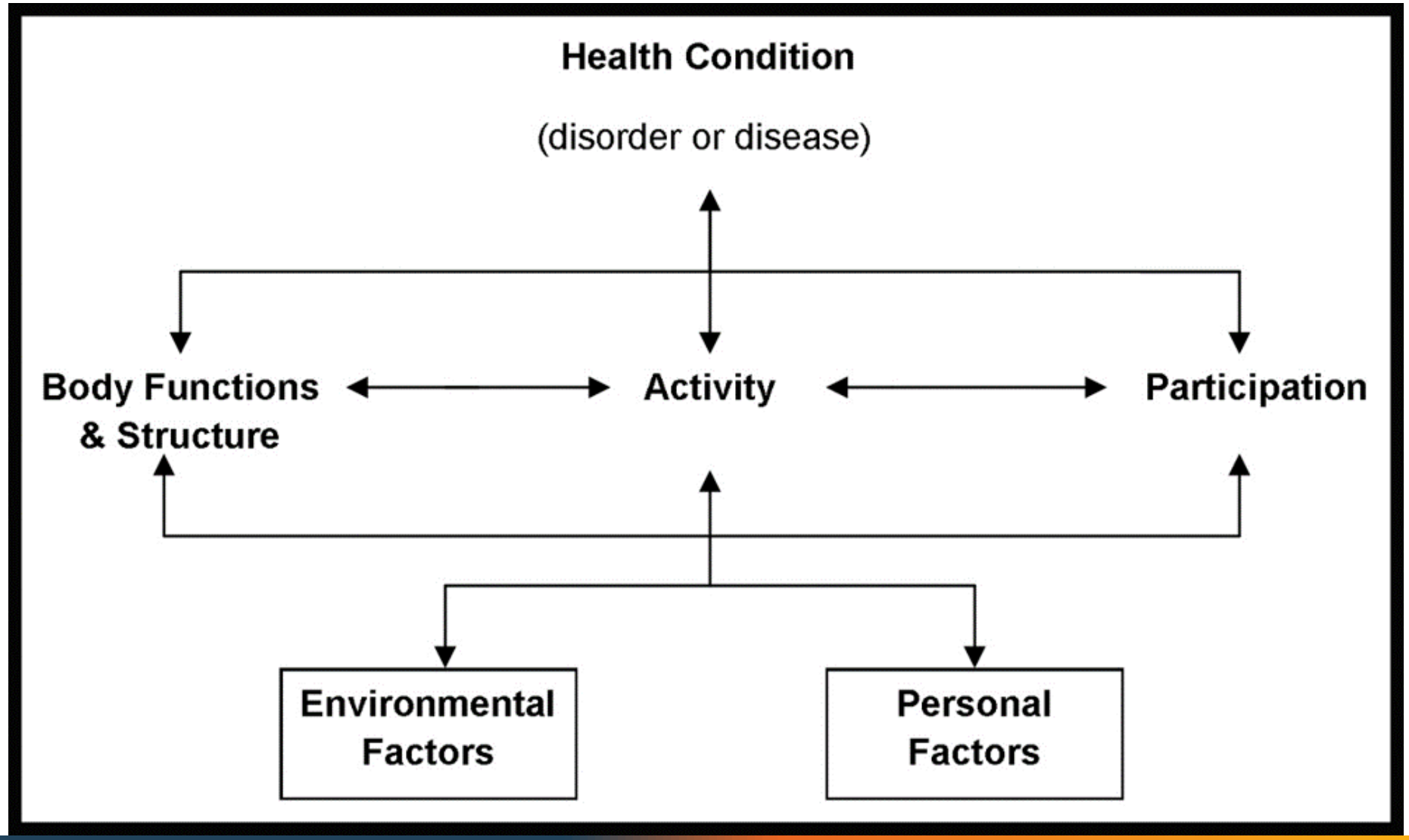
8. Psychological therapies for a person with emotional distress following a spinal cord injury

9. Social skills training for persons with schizophrenia, autism spectrum disorders or disorders of intellectual disability.

10. Training a person with vision loss in the use of a white cane

11. Working with a patient in intensive care to improve their breathing, prevent complications and speed their recovery after critical illness

International Classification of **Functioning**, Disability and Health (ICF)



Rehabilitation outcomes

PROMs & CROMs

Body functions & structures
Examples:
Muscle strength
Pain perception
Joint mobility
Posture
Mental capacity

Activities
Examples:
Walking ability
Moving around
Transfers
Balance
Handling stress
Dressing

Participation
Examples:
Working ability
Community life
Leisure time
Social life

External factors
Examples:
Spouse
Employer
Housing
Climate
Air quality

Personal factors
Examples:
Age
Sex
Income
Coping style
Motivation

PREPARE in a nutshell

PREPARE REHAB

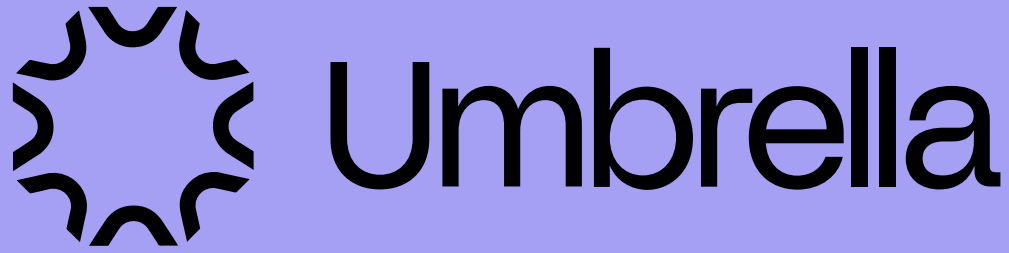
European Commission

HORIZON 2020

9 pilot cases

PREPARE data

				Clinical database	1	2	3	4	5	6	7	Total included	
				diagnosis	X	X	X	X	X	X	X	7	
				clinician reported outcome measures	X	X	X	X	X		X	6	
				complex multimodal rehabilitation	X	X		X	X			4	
				exercises		X	X		X		X	4	
				volume of exercise treatment		X	X		X			3	
	Outcomes	Impairment	body functions	pain	X	X		X	X	X	X	6	6
				other	X	X		X	X		X	5	
			body structures		X	X		X	X	X		5	
		Activities	gait				X	X	X	X		4	5
			activity level			X		X	X			3	
			activities of daily life				X	X	X	X		4	
			donning/doffing orthoses & prostheses			X		X	X			3	
			falls					X	X			2	
		Participation	*return to work*		X			X	X			3	3
		Discharge planning	use of walking aids					X	X	X		3	3
			care giver burden						X	X		2	
			discharge destination					X		X		2	
		PROs: Patient Reported Outcomes	*quality of Life*		X	X	X		X	X	X	6	7
			satisfaction		X	X	X	X			X	5	
			change in complaints		X		X				X	3	
			general physical and mental health		X	X				X		3	
			disease-related physical health			X				X		2	
		PREMs: Patient Reported Experience	*experience of the care process*		X						X	2	2
				Total variables	9	9	5	12	12	10	6	median 9	
				Categories included	4	3	2	5	5	4	3	median 4	
			day of verticalization							X		1	
				Total variables	7	6	4	6	12	11	8	median 7	
				Categories included	4	4	2	4	5	5	5	median 4	
				Total variables	14	10	5	14	10	10	14	median 14	
				Categories included	7	7	5	7	8	8	9	median 7	



The Umbrella Project

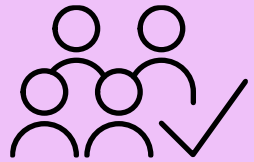
AND THE ROLE OF OMOP

IN A NUTSHELL

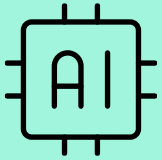
Our ambition:

Revolutionising
Stroke Care in Europe

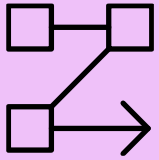
1 Enhanced stroke care for patients leading **to better health outcomes**



2 Harness the potential of **AI-based technologies** to advance stroke management

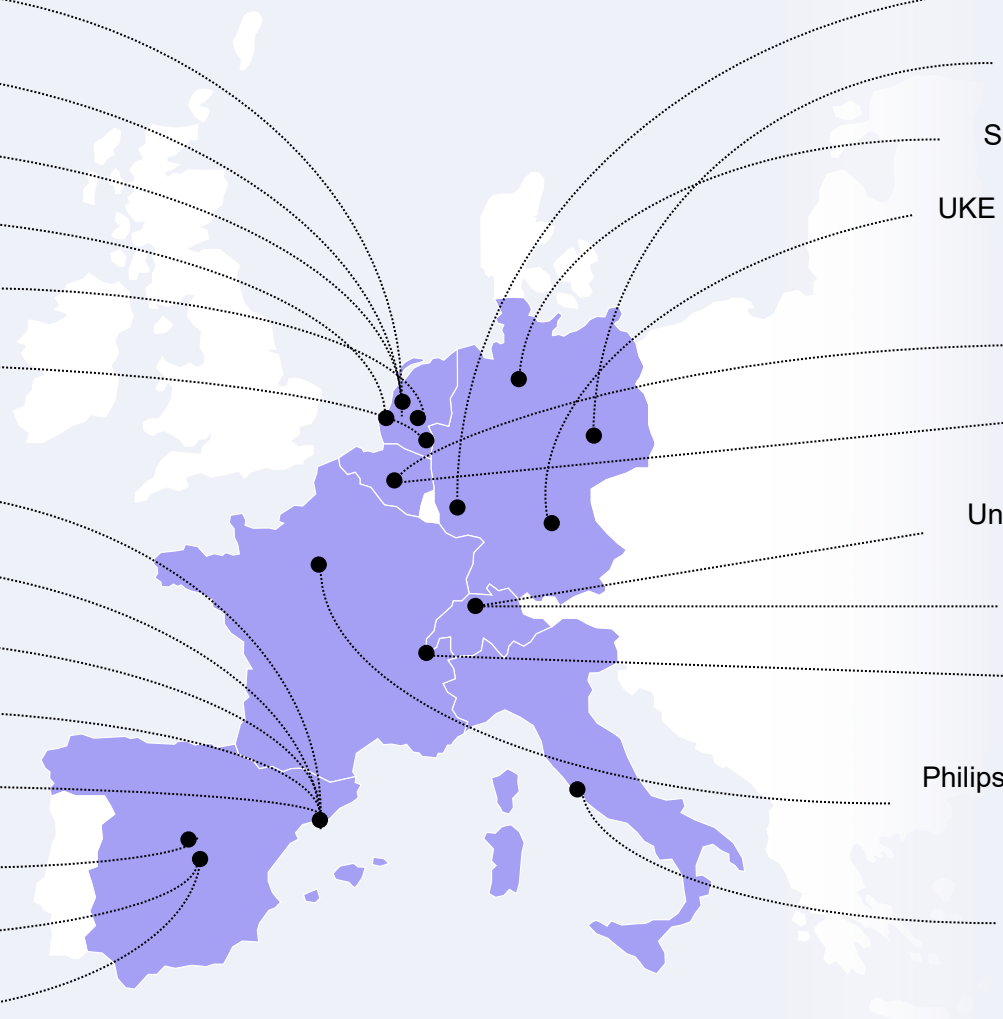


3 Integrated industry solutions for **coordinated decision-making** and efficient stroke care



4 Better healthcare decisions with **improved integrated data access**

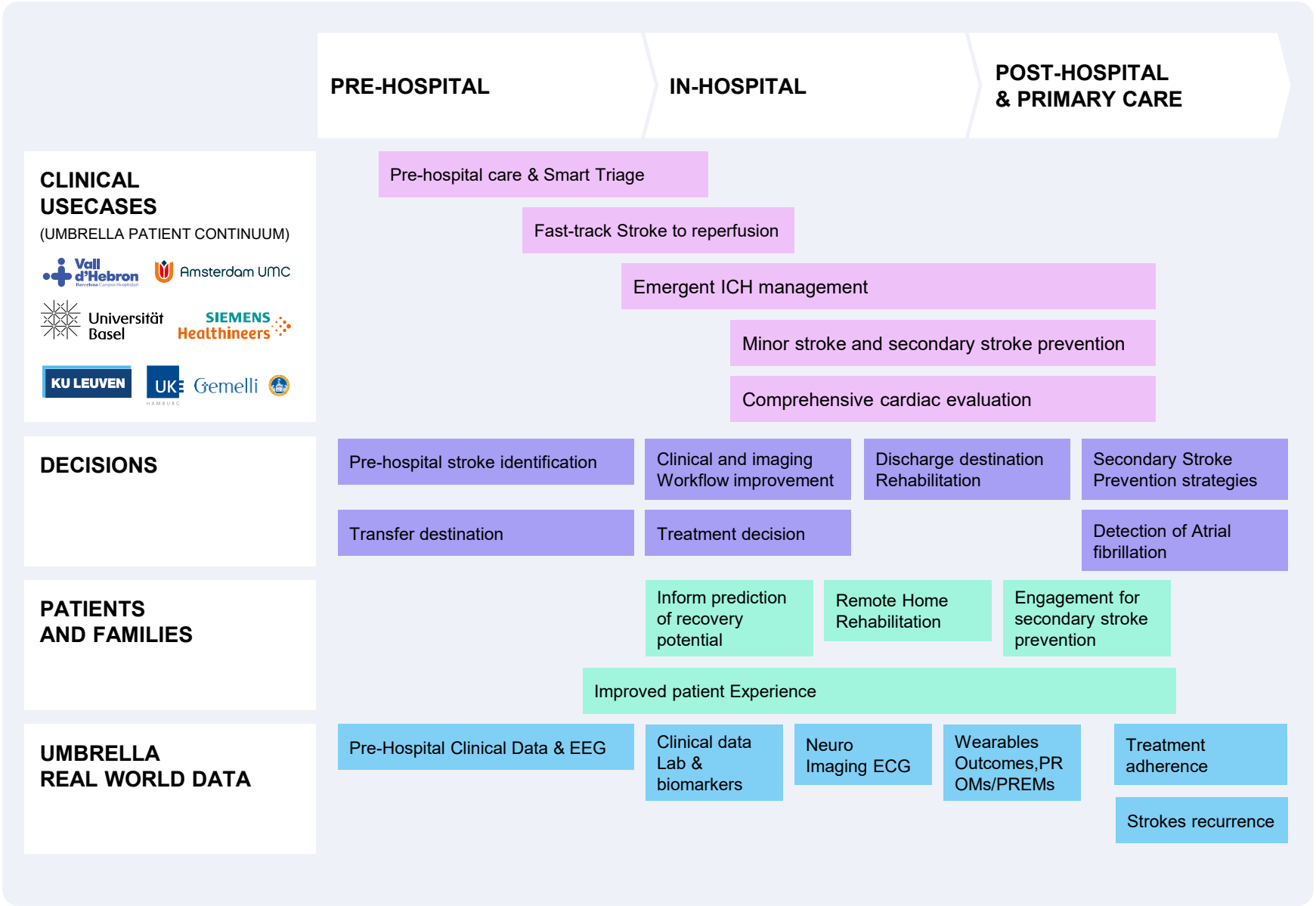
5 Standardise, harmonise and integrate in a federated manner **real-world stroke data**



- Amsterdam UMC — Amsterdam, NL
- Eatris Eric — Amsterdam, NL
- Nico-Lab — Amsterdam, NL
- Erasmus MC — Rotterdam, NL
- Philips Medical Systems — Best, NL
- Trianect — Utrecht, NL
- Fundació Eurecat — Barcelona, ES
- Nacar Studio — Barcelona, ES
- Nora Health — Barcelona, ES
- Teamit Research — Barcelona, ES
- Vall d'Hebron — Barcelona, ES
- Daiichi Sankyo España — Pozuelo de Alarcón, ES
- Astrazeneca — Madrid, ES
- Johnson & Johnson, ES
- Allm EMEA — Düsseldorf, DE
- Penumbra Europe — Berlin, DE
- Siemens Healthineers — Forchheim, DE
- UKE Hamburg-Eppendorf — Hamburg, DE
- KU Leuven — Leuven, BE
- SAFE — Brussels, BE
- Universitätsspital Basel — Basel, CH
- University of Basel — Basel, CH
- CERN — Geneva, CH
- Philips France Commercial — Suresnes, FR
- Gemelli Hospital — Rome, IT

Umbrella Project Structure

UMBRELLA offers a comprehensive, holistic, multi-centre approach to closing gaps along the stroke care pathway.



Exploring the Application of the Observational Medical Outcomes Partnership Common Data Model to Multi-site Stroke Rehabilitation Research Data

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Mapping PROMs to the OMOP-CDM: Insights and Lessons from the ICHOM Hand and Wrist Conditions Standard Set and the PROMOP H2O Project

Authors: Lisa Hoogendam, Laura Verbeij, Aniek Markus, Harm Slijper, Adnan Jouned, Florian Katsch, Marko Todorovic, Marta Ferri Peradalta, Romain Tching Chi Yen, Andreas Kremer, Sofia Bazakou,, Tanja Stamm, Georg Duftschmid, Renske Los, Ruud Selles

Brief Report

Mapping PROMs to the OMOP-CDM: Insights and Lessons from the ICHOM Hand and Wrist Conditions Standard Set and the PROMOP H2O Project

PRESENTERS: **Lisa Hoogendam & Aniek Markus**

INTRO:

- In the context of Value Based Health Care, it is important that outcome measurement also includes the patient's perspective.
- We compared two independent mapping initiatives to identify potential solutions and open questions to use PROMs in the OMOP CDM framework.

METHODS:

1. *Mapping initiatives*

Xpert Clinics ICHOM Hand and Wrist Conditions Standard Set

ICHOM defines global standard sets of outcome measures that matter most to patients, in 2021 this set was implemented at XC and later mapped to the OMOP CDM as part of the EHDEN project. The set consisted of ~200 PROM

To enable the use of PROMs in large-scale evidence generation, OHDSI community standards are needed answering the following questions:

How do we capture laterality and temporality in questions?

How do we represent negative responses?

POTENTIAL SOLUTIONS:

1. Creating custom concept_ids to exactly match the PROM questions
2. Using existing concept_ids and adding qualifier_ids to the mapping to make the match more specific.

1. Use an appropriate concept for the questions in concept_id and "No" (Concept ID: 45878245) in value_as_concept_id.
2. For observations, qualifier_concept_id may be used to represent negation with concepts like "No history of" (Concept ID: 4032324).
3. Employ concepts that inherently express negation, e.g. "No history of malignant tumor of breast" (Concept ID: 45763684).

1. Translate Likert scale answers to "Grade x on a scale of 1 to 5".
2. Map the actual answers, e.g., "never", "sometimes", "always".

1. Precoordinated pairs (e.g., for the EQ5D-5L).
2. Linking questions to a questionnaire via observation_event_id.
3. Considering sending out a questionnaire as an encounter and map this to the visit table. Link the questions to the visit.

1. Linking questionnaires to visits using the visit_occurrence_id.
2. Not explicitly linking the questionnaires to moments in the care pathway, but deriving this from time since treatment.

1. In token-based survey software (e.g., LimeSurvey), the status of the token can be added to the OMOP-CDM (e.g., "completed", "missed", "open - can be

Challenges in rehabilitation

When multiple initiatives aim to standardize rehabilitation data

- **Duplicate efforts**
- **Inconsistent use of existing vocabularies**
- **Many custom concepts**
- **Inconsistent mapping to the CDM**
- **Lack of rehabilitation-specific domains**
- **Many non-dichotomous outcomes, including patient-reported measures**

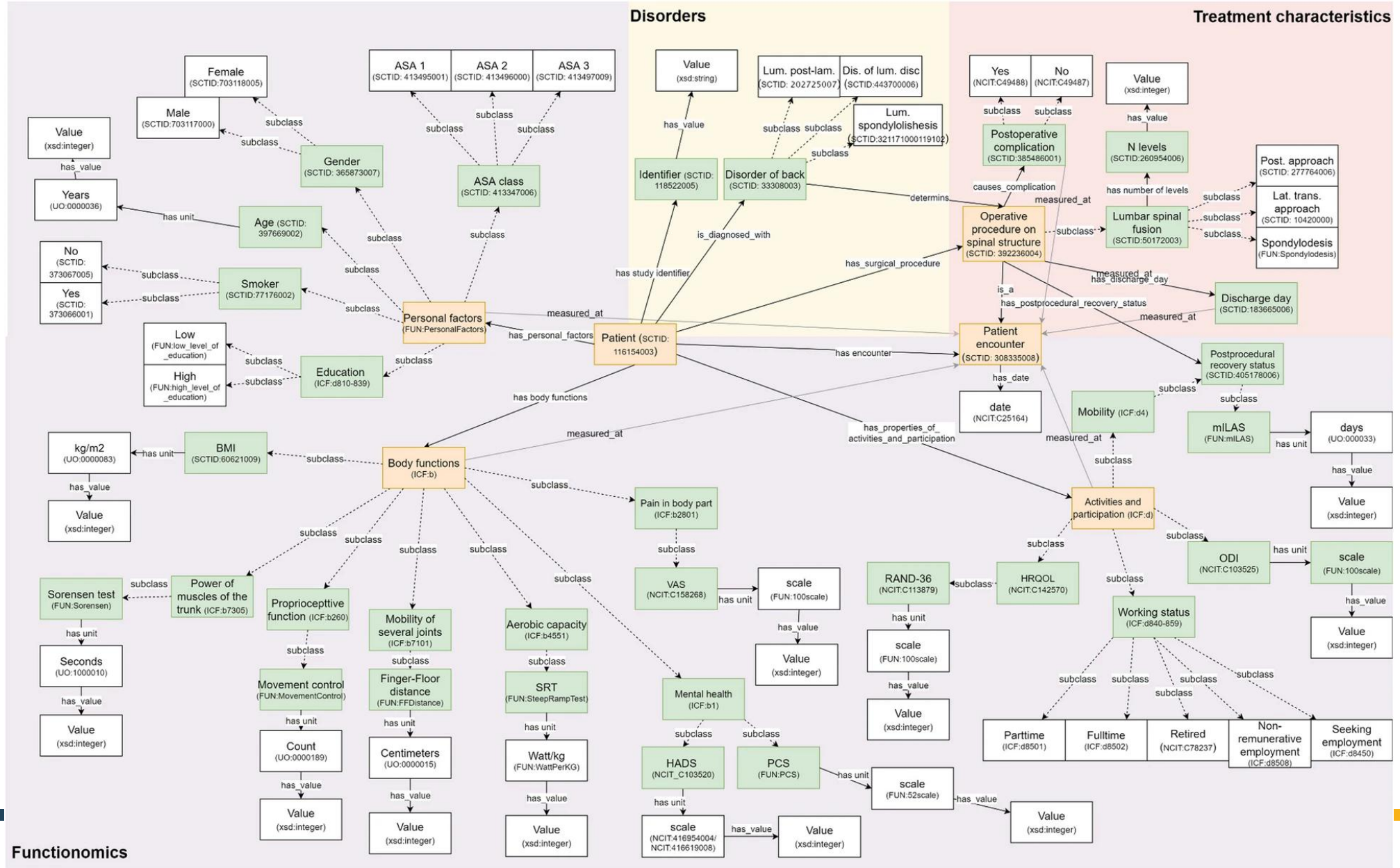
Rehabilitation vocabularies

Class	Preferred Ontology	Secondary Ontologies
Disease	SNOMED	ORDO, ICD10/11
Outcomes	ICF (not in Athena)	SNOMED, LIONC
Treatment	ICHI (not in Athena)	SNOMED, CPT4

Mapping outcome data

Source value	Source code	Source Vocabulary	OMOP Vocabulary Version	Standard Concept_ID	Standard Concept_Name	CDM_Field
jamar_position2_right	jamar_position2_right	Pulse	v20221031	40490816	Jamar hydraulic hand dynamometer	observation_concept_id
jamar_position2_right	jamar_position2_right	Pulse	v20221031	4302584	Structure of right hand	qualifier_concept_id
jamar_position2_right	jamar_position2_right	Pulse	v20221031	9529	kilogram	unit_concept_id
pinch_key_left	pinch_key_left	Pulse	v20221031	4089160	Key pinch	observation_concept_id
pinch_key_left	pinch_key_left	Pulse	v20221031	4309650	Structure of left hand	qualifier_concept_id
pinch_key_left	pinch_key_left	Pulse	v20221031	9529	kilogram	unit_concept_id
pinch_key_right	pinch_key_right	Pulse	v20221031	4089160	Key pinch	observation_concept_id
pinch_key_right	pinch_key_right	Pulse	v20221031	4302584	Structure of right hand	qualifier_concept_id
pinch_key_right	pinch_key_right	Pulse	v20221031	9529	kilogram	unit_concept_id
pinch_twopoint_left	pinch_twopoint_left	Pulse	v20221031	4088678	Tip pinch	observation_concept_id
pinch_twopoint_left	pinch_twopoint_left	Pulse	v20221031	4309650	Structure of left hand	qualifier_concept_id
pinch_twopoint_left	pinch_twopoint_left	Pulse	v20221031	9529	kilogram	unit_concept_id
pinch_twopoint_right	pinch_twopoint_right	Pulse	v20221031	4088678	Tip pinch	observation_concept_id
pinch_twopoint_right	pinch_twopoint_right	Pulse	v20221031	4302584	Structure of right hand	qualifier_concept_id
pinch_twopoint_right	pinch_twopoint_right	Pulse	v20221031	9529	kilogram	unit_concept_id
education_level	education_level	SNOMED	v20250227	4022643	Educational achievement	observation_concept_id
physical_activity_level	physical_activity_level	SNOMED	v20250227	44808782	Level of physical activity	observation_concept_id
House walker (walking only indoor)	House walker (walking only indoor)	SNOMED	v20250227	4058146	FITT activity level 0; no mod/vig acti	value_as_concept_id
Community walker (independent for > 500 me	Community walker (independent for > 500 meters)	SNOMED	v20250227	46285111	Less than 150 minutes of moderate	value_as_concept_id
Regular (walking 20-30 minutes/day outdoors)	Regular (walking 20-30 minutes/day outdoors)	SNOMED	v20250227	46285110	At least 150 minutes of moderate in	value_as_concept_id
Sport/palestra	Sport/palestra	LOINC	v20250227	1619864	Physical activity at least 30 minutes	value_as_concept_id
Wheelchair bound	Wheelchair bound	LOINC	v20250227	46237985	Wheelchair bound or bedridden unl	value_as_concept_id

Establishing new concepts & mappings



Challenges in rehabilitation work group

- **Small community, largely related to the 2 EU projects**
  - **How to maintain momentum?**
- **Many issues we struggle with may also be discussed in other workgroups**
  - **How to organize this? Should we consider merging or collaborating?**
- **We need to proceeed from data preparation to study execution**

Next steps

- Connect with other WGs and combine efforts on
  - PROM mapping
  - Contextual data mapping: GIS
  - Complex interventions

- Development of lower-level concepts of ICF and ICHI