Universität Augsburg University

Challenges and Opportunities in the Standardized Collection of Functioning Information for Research in Rehabilitation and Healthy Longevity

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I have no conflict of interest to declare.

Functioning information

… is important at all levels of the health system.

Level		Examples
Macro	Policies and programs	Planning, implementation and evaluation of public health programs
Meso	Service provision and payment	Reimbursement Quality management at service and national level
Micro	Persons and health care professionals	Clinical quality management Clinical outcome measurement Goal setting and monitoring

Functioning information

… is available through different data sources.

Level		Data sources
Macro	Policies and programs	Population studies Cohort studies Administrative data Clinical studies Clinical data …
Meso	Service provision and payment	
Micro	Persons and health care professionals	

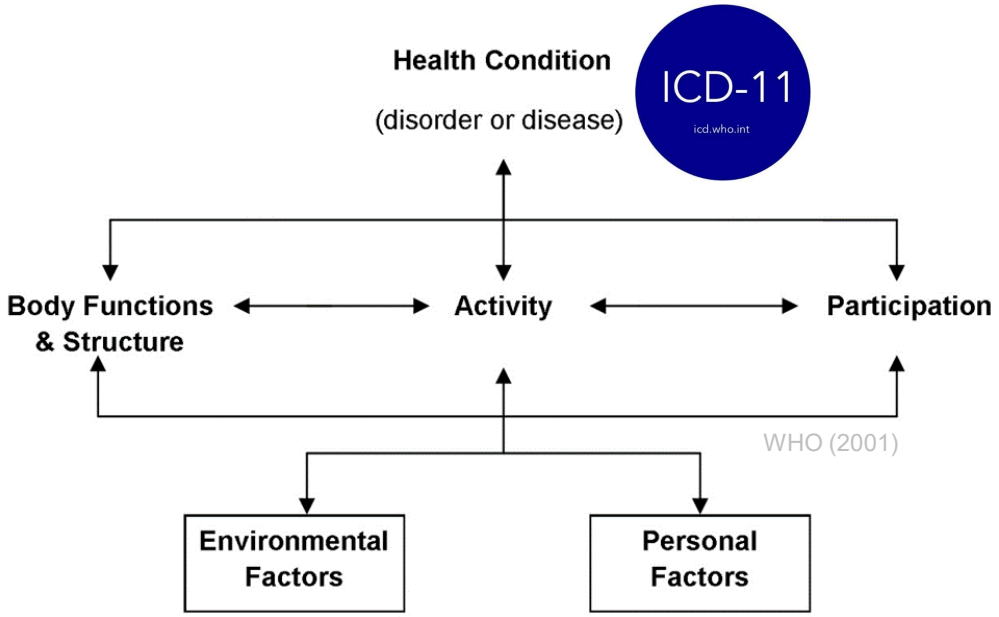
Functioning information

… is collected with various data collection tools.

Level		Methods for data collection
Macro	Policies and programs	Population surveys Registries Health records Patient-reported outcome measures (PROMs) Clinician-administered assessments Clinical tests …
Meso	Service provision and payment	
Micro	Persons and health care professionals	

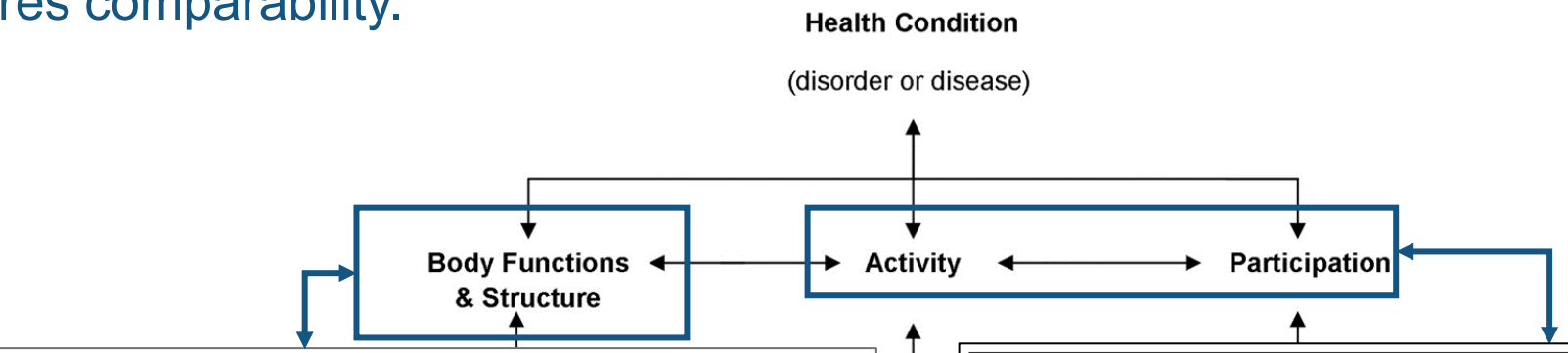
Functioning information

… requires comparability.



Functioning information

… requires comparability.



→ Perspectives:
Biological health
Lived health
Appraisal

	Conventional units	Conversation factors	Metric units
Length	feet	30	centimeters (cm)
Mass	pounts (lb)	0,45	kilograms (kg)
Vitam B12 (Serum)	pg/mL	0,7378	pmol/L
Cholesterol, high density (Serum, plasma)	mg/dl	0,0259	mmol/L
C-reactive protein (Serum)	mg/dL	10	mg/L
…	…	…	…

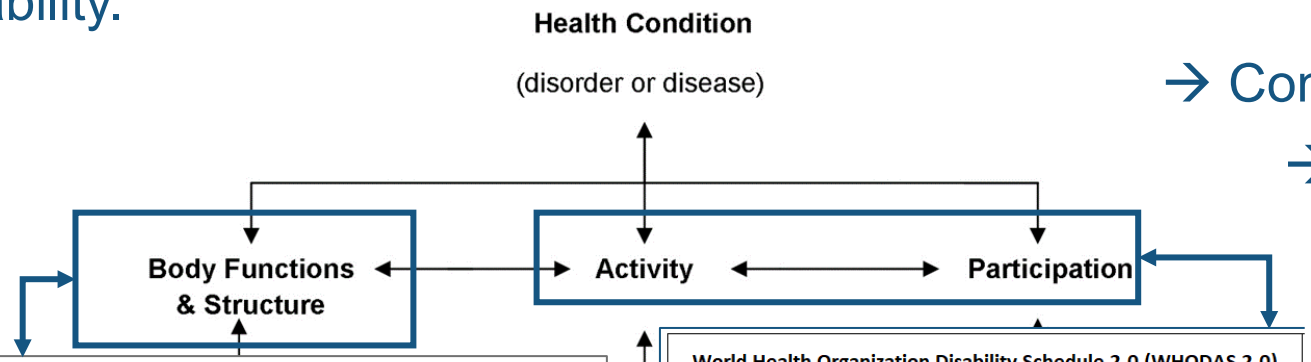
European Health Interview Survey (EHIS)
PL.6 Can you walk 500 metres on a flat terrain without a stick or other walking aid or assistance?

Health Assessment Questionnaire
h. Were you able to walk outdoors on flat ground?

WHOQOL-BREF
15. How well are you able to get around?
17. How satisfied are you with your ability to perform your daily activities?

Functioning information

… requires comparability.



→ Conceptual equivalence

→ Metric equivalence

	Conventional units	Conversation factors	Metric units
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…	…	…	…

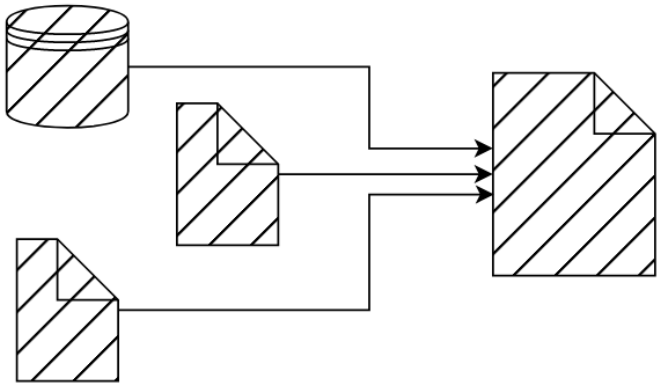
World Health Organization Disability Schedule 2.0 (WHODAS 2.0)
D5.2 Doing your most important household tasks well?
D5.3 Getting all the household work done that you needed to do?
D5.4 Getting your household work done as quickly as needed?

Short Form Health 36 (SF-36)
Does your health now limit you in these activities?
3) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports
4) Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
5) Lifting or carrying groceries

Patient-Reported Outcomes Measurement Information System (PROMIS) Physical Function Short Form 8b
1 Are you able to do chores such as vacuuming or yard work?
2 Are you able to go up and down stairs at a normal pace?
3 Are you able to go for a walk of at least 15 minutes?
4 Are you able to run errands and shop?

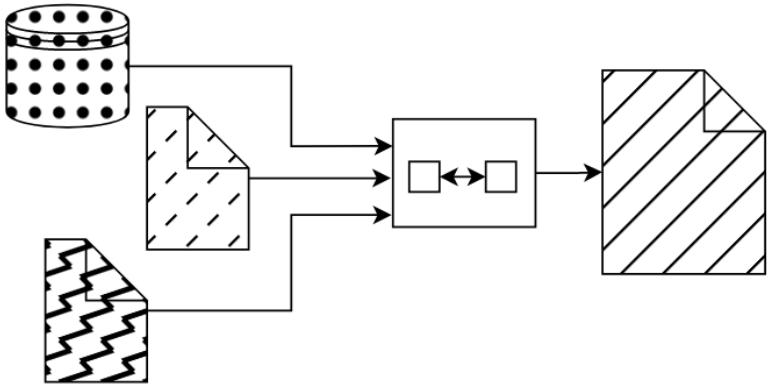
Functioning information

… standardizing data collection



- ⊕ Assessments and reporting are unified
- ⊖ Requires change in practice
- ⊖ Loss of comparability of data over time

… standardizing reporting

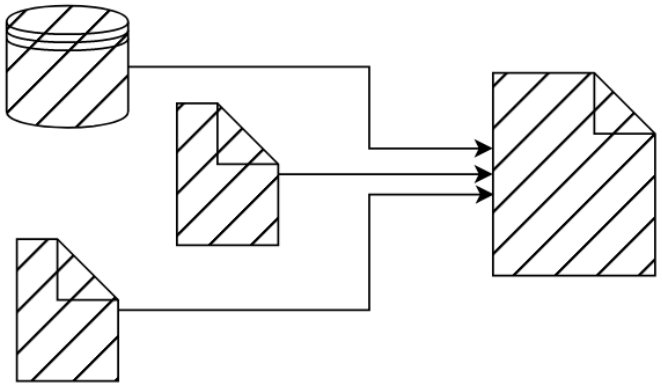


- ⊕ Allows to continue existing data collection tools
- ⊕ Enables comparability of data over time
- ⊖ Requires transformation

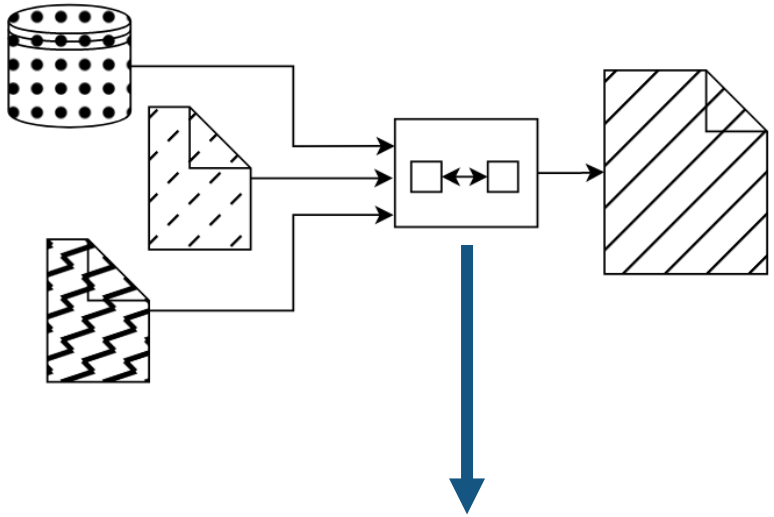
Maritz et al. (2020)

Functioning information

… standardizing data collection



… standardizing reporting



Concept equivalence: *ICF Linking Rules*

Cieza et al. (2019)

Metric equivalence:

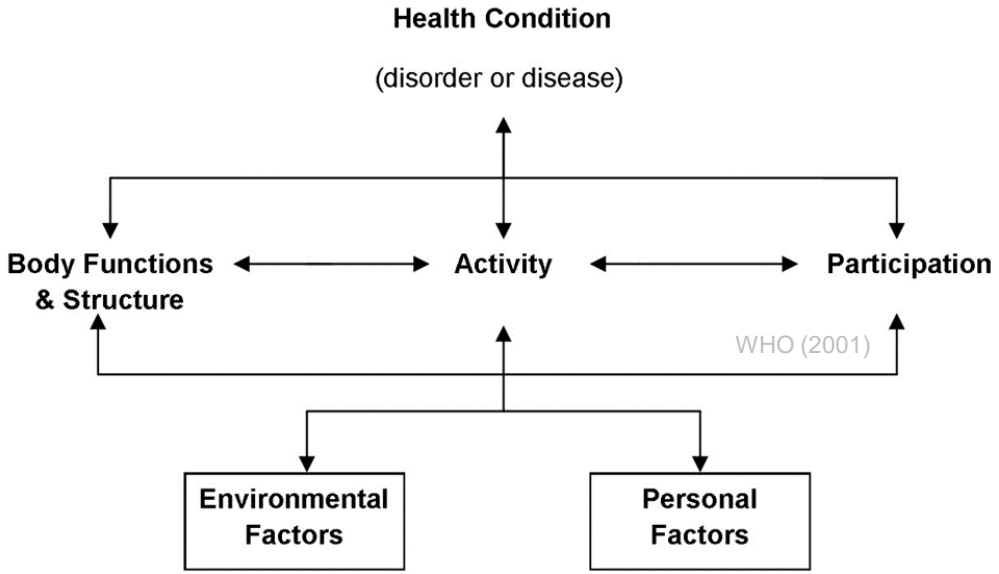
Instrument equating using Rasch measurement model

Andrich (2013)

Maritz et al. (2020)

Functioning

… is multidimensional.



Extent ICF categories in the ICF sets were covered by the Clinical Assessment Tools with and without the additional ICF categories identified in the Patient interviews:

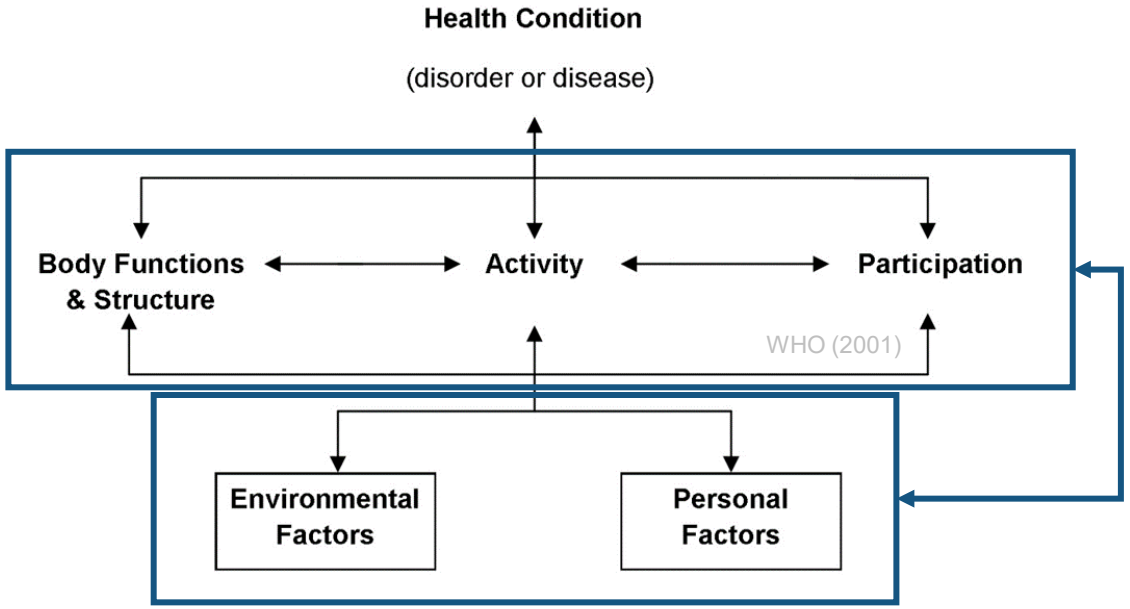
		ICF sets vs. CATs			ICF sets vs. CATs + PI		
Phase of care	ICF components	CATs (*n*)	ICF sets (*n*)	Coverage (%)	CATs and PI (*n*)	ICF sets (*n*)	Coverage (%)
Acute	B	2	9	22.2	6	9	66.7
	D	0	21	0	7	21	33.3
	E	0	12	0	8	12	66.7
	Total	2	42	4.8	21	42	50.0
Post-acute	B	9	13	69.2	11	13	84.6
	D	10	23	43.5	21	23	91.3
	E	5	13	38.5	10	13	76.9
	Total	24	49	49.0	42	49	85.7
Early long-term	B	8	12	66.7	10	12	83.3
	D	9	22	40.9	16	22	72.7
	E	5	13	38.5	10	13	76.9
	Total	22	47	46.8	36	47	76.6
Late long-term	B	5	15	33.3	12	15	80.0
	D	1	24	4.2	10	24	41.7
	E	0	14	0	10	14	71.4
	Total	6	53	11.3	32	53	60.4

CATs clinical assessment tools, *PIs* Patient interviews, *B* body functions, *D* activities and participations, *E* environment factors.

Pongpipatpaiboon et al. (2020; pg. 8)

Functioning

… is interactive.

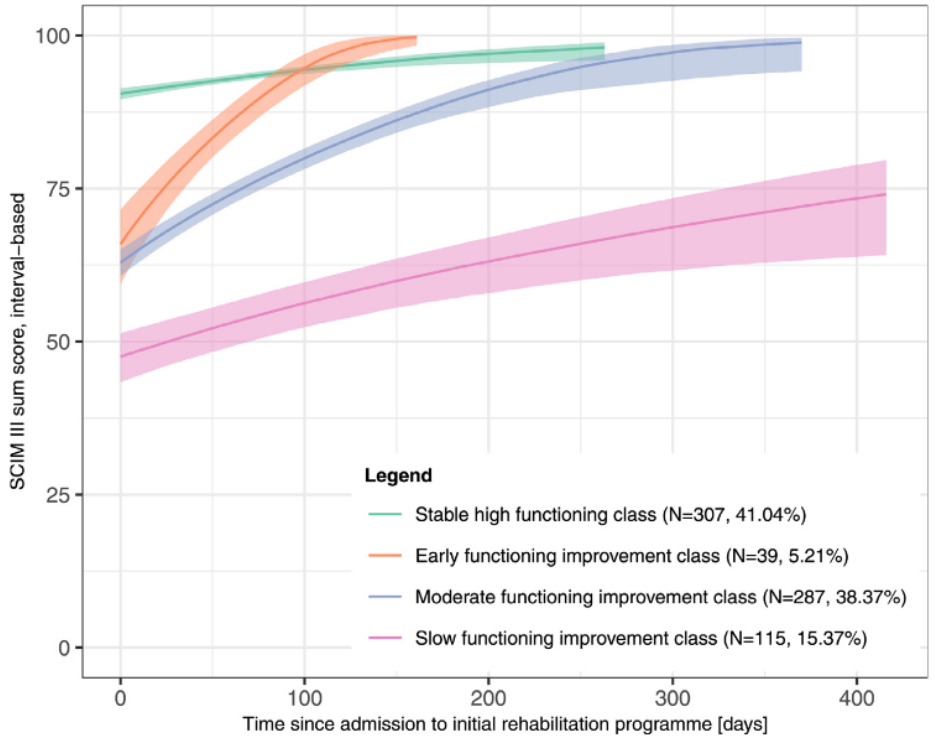


Lived health is an outcome of the interaction between a person‘s capacity and the environment.

→ Role of contextual factors in dis-/en- ablement process

Functioning

… is continuous.



Hodel et al. (2021; pg. 9)

→ Interpretability:
e.g. minimal clinically important difference (MCID)

In Conclusion: *Challenges and Opportunities*

Functioning information …

… is important at all levels of the health system.

Functioning …

… is multidimensional.

… is interactive.

… is continuous.

Functioning, as the main outcome of rehabilitation, uniquely positions rehabilitation as a health strategy at the intersection of various disciplines and fields of practice.
The related information needs to reflect and enable living up to this claim.

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