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LID VAN DE ASSOCIATIE UNIVERSITEIT GENT

Measures within the framework of the  
International Classification of Functioning,  
Disability and Health (ICF)

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Velde

# Patricia and Dominique

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# Nowadays healthcare systems are confronted with important challenges

- § the emerging problem of chronic conditions, with a growing group of patients with multi-morbidity and
- § an increasing older population
- § cure should be replaced by care

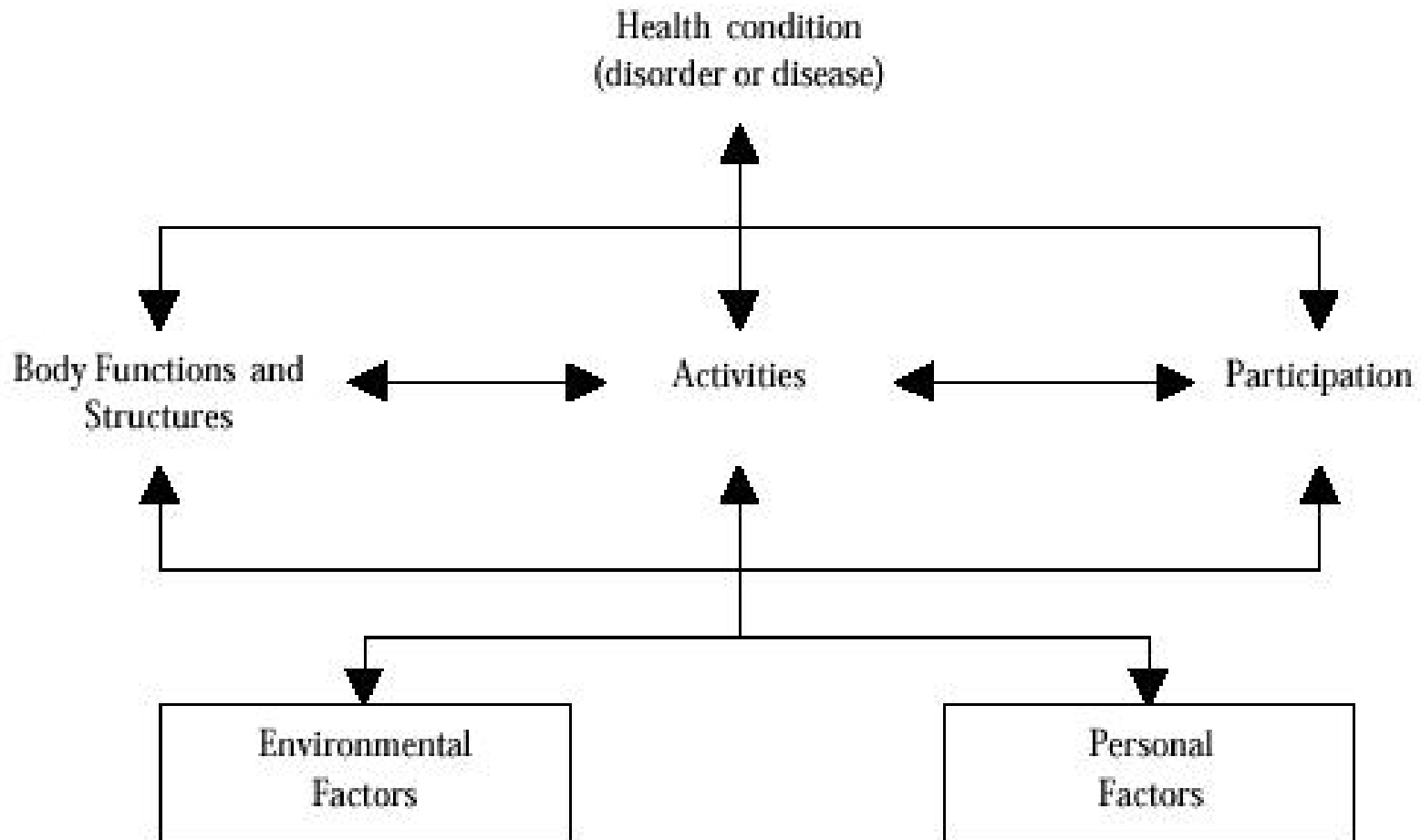
# There is a need for an approach to health,

- § where health is not seen as merely determined by biomedical,
- § but also by a range of economic, psychological, environmental and social factors
- § Less etiology and more emphasis on the consequences
- § Focus on the ability to adapt and self manage (Huber, 2014)

# 'The International Classification of Functioning, disability and Health'

- § represents an inclusive approach that contributes to this bio-psycho-social understanding of health
- § to rate the magnitude of the level of health or to rate the severity of a health problem
- § the advantage to provide
  - § a global language for health, illness and disability
  - § facilitate communication

# The ICF





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## 2 examples of working with the ICF

- ⊗ Measuring performance of activities in the diagnosis of (mild) dementia

- ⊗ Measuring participation

# The advanced Activities of Daily Living tool

## a- ADL tool

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# Diagnostic differentiation between mild and severe forms of cognitive decline based on ADL

## Dementia

- ∅ Cognitive and functional decline
- ∅ Neuropsychological and behavioural problems

∅ Loss of independency

## MCI

- ∅ Cognitive deterioration more than expected for age but not severe enough to warrant diagnosis of dementia

- ∅ b-ADL should remain intact, i-ADL minimal impaired
- ∅ Growing evidence for subtle performance problems in complex ADL

# Evaluation of ADL is problematic ...

**Table 2**  
The Frequency of Use of the Included Questionnaires in the Elderly

Abbreviation of Questionnaire	Number of Records
BI	2562
LB-IADL	1787
KI	534
FAI	156
NEADL	72
FSQ	62
LHS	51
PSMS	49
SMAF	37
LLFDI	35
TMIG-IC	31
GARS	27
WHODAS 2.0 (full version)	26
WDRS-2	25
WHODAS 2.0 (short version)	24
BDQ	23
PAT-D	15
OLDQ	13
TDS	11
LDSQ	10
SF-LLFDI	9
RBFHS	7
EARRS	6
SELF	3

BI, Barthel Index; BDQ, brief disability questionnaire; EARRS, Elderly At Risk Rating Scale; FAI, Frenchay Activities Index; FSQ, Functional Status Questionnaire; GARS, Groningen Activity Restriction Scale; KI, Katz Index; LB-IADL, Lawton and Brody Instrumental Activities of Daily Living Scale; LDSQ, Lambeth Disability Screening Questionnaire; LHS, London Handicap Scale; LLFDI, Late Life Function and Disability Instrument; NEADL, Nottingham Extended Activities of Daily Living scale; OLDQ, Organization for Economic Cooperation and Development Long-Term Disability Questionnaire; PAT-D, Pepper Assessment Tool for Disability; PSMS, Physical Self-Maintenance Scale; RBFHS, Rosow-Breslau Functional Health Scale; SELF, Self-evaluation of life function Scale; SF-LLFDI, Short Form of the Late-Life Function and Disability Instrument; SMAF, Functional Autonomy Measurement System; TMIG-IC, Tokyo Metropolitan Institute of Gerontology Index of Competence; TDS, Townsend Disability Scale; WDRS-2, Winchester Disability Rating Scale-2; WHODAS, World Health Organization Disability Assessment Schedule.

§ Variety of tools

§ But Barthel Index, Lawton and Brody iADL, Katz Index of ADL most often used

§ Shortcomings: no normative data, no consensus level of impairment, poor psychometric properties, no diagnostic accuracy ..

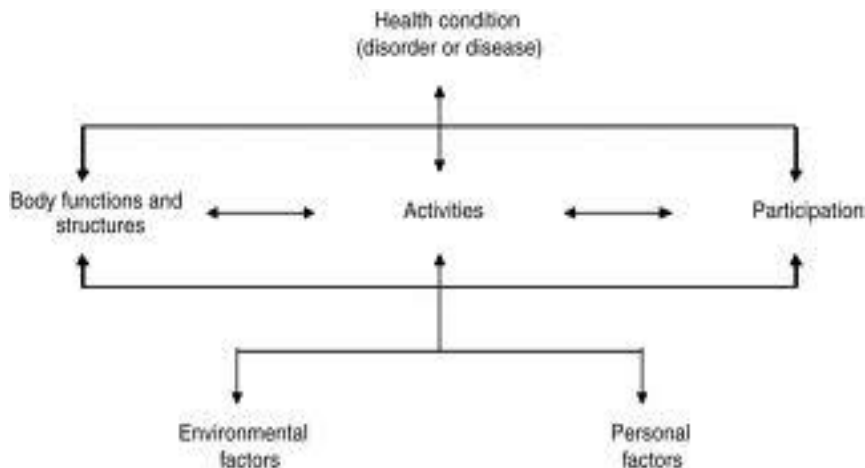
§ But ecological validity and feasible  
(Sikkes, 2012; Yang, et al. 2014)



# a-ADL tool (De Vriendt et al, 2012; 2013; 2014; 2015) Rationale

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

- Framework



WHO, 2001

- ADL-triade (b-, i-, a-ADL) stratified according to complexity and cognitive organization (Reuben, 1989)
  - Person as his own reference
- Differentiation in underlying reasons of impairments
- Severity of the impairment (ICF-qualifiers 0-4)

# Stepwise development of a measurement tool

- Ø Literature study
- Ø Qualitative study to involve target population -> relevant activities -> scoring -> tool 1° draft
- Ø Pilot study for reliability
- Ø More data
  - Ø Discriminative study
  - Ø Convergent validity
- Ø Longitudinal study



# Basic ADL needed to stay alive (Reuben, 1989)



# Instrumental ADL needed to stay independent @home (Reuben, 1989)





# Advanced ADL the 'luxury' items (Reuben, 1989)



Cluster	Activity nr.	Activities	Performance 0/1		Quality of performance		Underlying cause of limited performance			
			0/1	ICF 0/1/2/3/4	Cognitive	Physical	Intrapersonal	Environmental		
1		<b>Sophisticated kitchen activities</b>								
	1	freezing or pickling vegetables	1		1					
	2	baking bread, cakes	1		0	0				
	3	cooking complex meals	1		0	0				
	4	try out new dishes	1		0		0			
	5	making jam	1		0		0			
2		<b>Household appliance and daily technology</b>								
	6	using magnetron								
	7	using dish washer								
	8	using oven	1		1	1				
	9	using coffee machine								
	10	using kitchen aid	1		0	0				
	11	using washing machine								
	12	using drying machine	1		1	1				
	13	playing radio/cd								
	14	playing TV	1		1	1				
	15	using video/dvd								
	16	using a camera	1		1	1				
	17	using a lawn mower	1		1	1				
	18	using a electric saw	1		1	1				
	19	using a high pressure cleaner								
	20	using manuals explaining daily technology								
3		<b>High level gardening</b>								
	21	high level gardening	1		1	1				
4		<b>Cognitive stimulating and intellectual activities</b>								
	22	playing puzzles and brainteasers	1		1	1				
	23	using PC programs	1		1	1				
	24	using internet								
	25	using an agenda	1		1	1				
	26	reading books								
	27	reading educational or professional literature, reading in other languages	1		1	1				
	28	writing books, poems, articles	1		1	1				
5		<b>Craftwork and arts</b>								
	29	making crafts	1		1		1			
	30	playing music instrument	1		1		1			
	31	practicing arts								
6		<b>Complex economic activities and transactions</b>								
	32	electronically banking, paying electronically, using money out of the wall system								
	33	complex administration and banking								
7		<b>Communication activities by using devices or techniques</b>								
	34	using a cell phone	1		4	4	4			
	35	writing a mail or a letter								
8		<b>Sports</b>								
	36	practicing sports	1		4	4	4			
	37	riding bicycle								
9		<b>Transportation by motorised vehicles</b>								
	38	transportation by motorised vehicles								
10		<b>Self development, self realization or self educational activities</b>								
	39	self development, self realization or self educational activities	1		4	4	4			
11		<b>Going on a holiday</b>								
	40	going on a holiday								
12		<b>Caring for or assisting others</b>								
	41	helping (in the business of) the children								
	42	taking care of partner								
	43	taking care of (great) grand children	1		4	4	4			
	44	taking care of pets								
13		<b>Caring for household objects</b>								
	45	caring for household objects								
14		<b>Semi professional work</b>								
	46	semi professional work								
15		<b>Engagement in organised social activities or leisure activities</b>								
	47	organising events								
	48	making and keeping appointments	1		3	3	3			
	49	taking part in meetings, conversations								

Total number of activities relevant for the person: TNA

25

a-ADL Disability Index: a-ADL DI

34

a-ADL Cognitive Disability Index: a-ADL CDI

31

a-ADL Physical Disability Index: a-ADL PDI

21



# 15 clusters – 49 activities

Cluster	Activity no.	Activities	Quality of performance				Underlying areas of functional performance						
			Frequency (%)	ICP (%)	U/L (%)	N (%)	Cognitive	Physical	Interpersonal	Environmental			
1	1	preparation kitchen activities	1	1	1	1	1	1	1	1			
	2	freezing or pickling vegetables	1	1	1	1	1	1	1	1			
	3	baking bread, cakes	1	1	1	1	1	1	1	1			
	4	cooking complex meals	1	1	1	1	1	1	1	1			
	5	dry out new clothes	1	1	1	1	1	1	1	1			
	6	putting jam	1	1	1	1	1	1	1	1			
	2	6	household appliance and daily technology	1	1	1	1	1	1	1	1		
		7	using magnetron	1	1	1	1	1	1	1	1		
		8	using dish washer	1	1	1	1	1	1	1	1		
		9	using oven	1	1	1	1	1	1	1	1		
		10	using coffee machine	1	1	1	1	1	1	1	1		
		11	using clothes drier	1	1	1	1	1	1	1	1		
		12	using washing machine	1	1	1	1	1	1	1	1		
		13	using drying machine	1	1	1	1	1	1	1	1		
		14	using radiator	1	1	1	1	1	1	1	1		
15		using TV	1	1	1	1	1	1	1	1			
16		using wheelchair	1	1	1	1	1	1	1	1			
17		using a camera	1	1	1	1	1	1	1	1			
18		using a lawn mower	1	1	1	1	1	1	1	1			
19		using a electric saw	1	1	1	1	1	1	1	1			
20		using a high pressure cleaner	1	1	1	1	1	1	1	1			
3	10	using tools and equipment	1	1	1	1	1	1	1	1			
	21	high level gardening	1	1	1	1	1	1	1	1			
	4	22	Cognitive stimulating and intellectual activities	1	1	1	1	1	1	1	1		
		23	reading puzzles and brain teasers	1	1	1	1	1	1	1	1		
		24	using IT, computers	1	1	1	1	1	1	1	1		
		25	using internet	1	1	1	1	1	1	1	1		
		26	using an agenda	1	1	1	1	1	1	1	1		
		27	reading books	1	1	1	1	1	1	1	1		
		28	reading educational or professional literature, reading in other languages	1	1	1	1	1	1	1	1		
		29	writing books, poems, articles	1	1	1	1	1	1	1	1		
		5	30	Craftwork and arts	1	1	1	1	1	1	1	1	
			31	making crafts	1	1	1	1	1	1	1	1	
			32	making music, instruments	1	1	1	1	1	1	1	1	
			33	making arts	1	1	1	1	1	1	1	1	
			6	34	Complex economic activities and transactions	1	1	1	1	1	1	1	1
35				maintaining banking, using atm, normally using money out of the wall system	1	1	1	1	1	1	1	1	
36				complex administration and banking	1	1	1	1	1	1	1	1	
37	Communication activities by using devices or techniques			1	1	1	1	1	1	1	1		
38	using a cell phone			1	1	1	1	1	1	1	1		
39	writing a mail or a letter			1	1	1	1	1	1	1	1		
7	40			Sports	1	1	1	1	1	1	1	1	
	41			watching sports	1	1	1	1	1	1	1	1	
	42			riding bicycle	1	1	1	1	1	1	1	1	
	8			43	Transportation by motorised vehicles	1	1	1	1	1	1	1	1
				44	transportation by motorised vehicles	1	1	1	1	1	1	1	1
		45		Self development, self education or self educational activities	1	1	1	1	1	1	1	1	
		46		Self development, self education or self educational activities	1	1	1	1	1	1	1	1	
		47		being on a holiday	1	1	1	1	1	1	1	1	
		48		going on a holiday	1	1	1	1	1	1	1	1	
		49	going for or meeting others	1	1	1	1	1	1	1	1		
		50	helping in the business of the children	1	1	1	1	1	1	1	1		
		51	taking care of partner	1	1	1	1	1	1	1	1		
		52	taking care of special needs children	1	1	1	1	1	1	1	1		
		53	taking care of pets	1	1	1	1	1	1	1	1		
		54	Caring for household objects	1	1	1	1	1	1	1	1		
55		Caring for household objects	1	1	1	1	1	1	1	1			
56		doing professional work	1	1	1	1	1	1	1	1			
57		doing professional work	1	1	1	1	1	1	1	1			
58	Engagement in organised social activities or leisure activities	1	1	1	1	1	1	1	1				
59	organising events	1	1	1	1	1	1	1	1				
60	holding and keeping appointments	1	1	1	1	1	1	1	1				
61	taking part in meetings, conversations	1	1	1	1	1	1	1	1				

- 1 Sophisticated kitchen activities (d6301)
  - 1 Freezing or pickling vegetables
  - 2 Baking bread
  - 3 ...
- 2 Household appliance and daily technology (d6403)
  - 6 using magnetron
  - 7 using dish washer
  - 8 ...
- 15 Engagement in organised social activities or leisure activities (d910, d9250)
  - ...
    - 49 taking part in meetings, conversations.

d6301 Sophisticated kitchen activities (d6301)  
 d6403 Household appliance and daily technology (d6403)  
 d910 Engagement in organised social activities or leisure activities (d910)  
 d9250 Engagement in organised social activities or leisure activities (d9250)

Cluster	Activity nr.	Activities	Performance		Underlying cause of limited performance			
			0/1	ICF 0/1/2/3/4	Cognitive	Physical	Intrapersonal	Environmental
1		<b>Sophisticated kitchen activities</b>						
	1	freezing or pickling vegetables	1		1			
	2	baking bread, cakes	1		0	0		
	3	cooking complex meals	1		0	0		
	4	try out new dishes	1		0		0	
	5	making jam	1		0		0	
2		<b>Household appliance and daily technology</b>						
	6	using magnetron						
	7	using dish washer						
	8	using oven						
	9	using coffee machine						
	10	using kitchen aid						
	11	using washing machine						
	12	using drying machine						
	13	playing radio/cd						
	14	playing TV						
	15	using video/dvd						
	16	using a camera						
	17	using a lawn mower						
	18	using a electric saw						
	19	using a high pressure cleaner						
	20	using manuals explaining daily technology						
3		<b>High level gardening</b>						
	21	high level gardening						
4		<b>Cognitive stimulating and intellectual activities</b>						
	22	playing puzzles and brainteasers						
	23	using PC programs						
	24	using internet						
	25	using an agenda						
	26	reading books						
	27	reading educational or professional literature, reading in other languages						
	28	writing books, poems, articles						
5		<b>Craftwork and arts</b>						
	29	making crafts						
	30	playing music instrument						
	31	practicing arts						
6		<b>Complex economic activities and transactions</b>						
	32	electronically banking, paying electronically, using money out of the wall system						
	33	complex administration and banking						
7		<b>Communication activities by using devices or techniques</b>						
	34	using a cell phone						
	35	writing a mail or a letter						
8		<b>Sports</b>						
	36	practicing sports						
	37	riding bicycle						
9		<b>Transportation by motorised vehicles</b>						
	38	transportation by motorised vehicles						
10		<b>Self development, self realization or self educational activities</b>						
	39	self development, self realization or self educational activities						
11		<b>Going on a holiday</b>						
	40	going on a holiday						
12		<b>Caring for or assisting others</b>						
	41	helping (in the business of) the children						
	42	taking care of partner						
	43	taking care of (great) grand children						
	44	taking care of pets						
13		<b>Caring for household objects</b>						
	45	caring for household objects						
14		<b>Semi professional work</b>						
	46	semi professional work						
15		<b>Engagement in organised social activities or leisure activities</b>						
	47	organising events						
	48	making and keeping appointments	1		3	3	3	
	49	taking part in meetings, conversations						

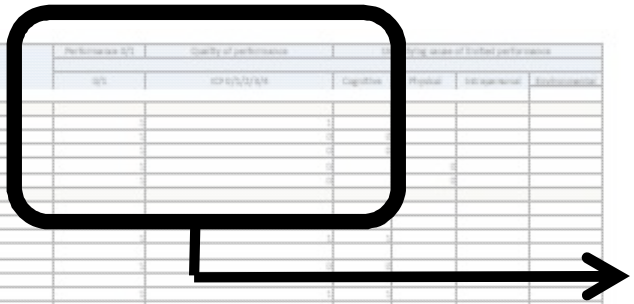
## ICF Chapters

- d1 Learning and applying knowledge
- d2 General tasks and demands
- d3 Communication
- d4 Mobility
- d5 Self-care
- d6 Domestic life
- d7 Interpersonal interactions and relations
- d8 Major life areas
- d9 Community and civic life

Total number of activities relevant for the person: TNA	25
a-ADL Disability Index: a-ADL DI	34
a-ADL Cognitive Disability Index: a-ADL CDI	31
a-ADL Physical Disability Index: a-ADL PDI	21

# The ICF Scores

Code	Activity or Activities	Performance					
		0/1	2/3	4/5	6/7	8/9	10
1	Dependent (other) activities						
2	Personal activities and daily technology						
3	Work and productivity						
4	Education and training						
5	Leisure and sports						
6	Participation in society						



**Performance: 0/1**

**0 No Problem**  
*Completely independently, no help, adequate, flexible, inventive, creative*

**1 Mild Problem**  
*Completely independently, no help, mild limitations: less frequent, more simplified*

**2 Moderate Problem**  
*Independently, sometimes help, less adequate, less result oriented, faults in performance*

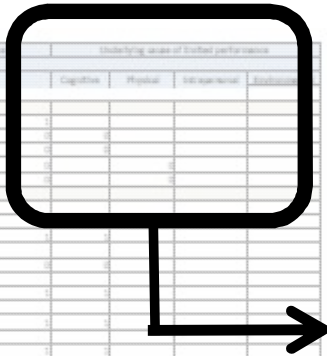
**3 Severe Problem**  
*Completely dependent, continuous help (guiding, support, effective help)*

**4 Complete Problem**  
*No active performance at all*

Total number of activities relevant for the person	38
ICF Disability Index - a-DIS-D	34
a-DIS Cognitive Disability Index - a-DIS-CO	11
a-DIS Physical Disability Index - a-DIS-PI	23

# Underlying causes of limitation

Cluster	Activity no.	Activities	Performance (%)		Underlying cause of limited performance					
			IQ	SP/CL/SL/PL	Cognitive	Physical	Intra-personal	Extraneous		
1	1	Regulation of kitchen activities								
		1	chopping or peeling vegetables							
		2	making bread, cakes							
		3	cooking complex meals							
		4	dry out raw chicken							
2	6	Household appliances and daily technology								
		6	using refrigerator							
		7	using dish washer							
		8	using oven							
		9	using coffee machine							
		10	using kitchen sink							
		11	using washing machine							
		12	using drying machine							
		13	using vacuum							
		14	using TV							
		15	using wheelchair							
		16	using a camera							
		17	using a hair dryer							
		18	using a electric saw							
		19	using a high pressure cleaner							
		20	using vacuum exploring daily technology							
		3	21	High level gardening						
				21	high level gardening					
				4	22	Cognitive, intellectual and intellectual activities				
22	making puzzles and brain teasers									
23	using PC equipment									
5	24	Craftwork and arts								
		24	making crafts							
		25	making wood instruments							
		26	craftwork arts							
		6	27	Complex electronic activities and transactions						
				27	electronic banking, using electronic mails, using games out of the wall system					
				28	using a video camera and hearing					
		7	29	Communication activities by using devices or techniques						
				29	using a cell phone					
				30	writing a mail or a letter					
8	31	Sports								
		31	practicing sports							
		32	riding bicycle							
9	33	Transportation by motorised vehicles								
		33	transportation by motorised vehicles							
10	34	Self development, self education or self educational activities								
		34	self development, self education or self educational activities							
11	35	Living on a holiday								
		35	going on a holiday							
		36	Caring for or assisting others							
		37	helping in the business of the children							
12	38	Caring for household objects								
		38	looking after household objects							
		39	being professional work							
		40	being professional work							
13	41	Engagement in organized social activities or leisure activities								
		41	organizing events							
		42	making and keeping appointments							
		43	making part in meetings, conversations							
		44	making part in meetings, conversations							



*Intrinsic causes*

- cognitive reason
- intra personal reason
- physical reason

*Extrinsic causes*

- social reason
- material reason

Total number of activities relevant for the person 104	104
#-IQ Disability Index - #IQ 20	20
#-SL Cognitive Disability Index - #CL 120	120
#-PL Physical Disability Index - #PL 10	10

# The a-ADL indices expressed as %

Code	Activity or Activities	Performance 0/1	Quality of performance				Underlying cause of limited performance			
			0/1	0/1/2/3/4	Cognitive	Physical	Inspirational	Psychological		
1	Unrestricted leisure activities									
2	Feeding or picking vegetables									
3	Baking bread, cakes									
4	Washing complex vessels									
5	Drinking raw dishes									
6	Feeding pets									
7	Household appliances and daily technology									
8	Using magnetron									
9	Using dish washer									
10	Using coffee machine									
11	Using coffee machine									
12	Using clothes drier									
13	Using washing machine									
14	Using drying machine									
15	Watching radio/TV									
16	Watching TV									
17	Using video/cd									
18	Using a camera									
19	Using a hair dryer									
20	Using a electric fan									
21	Using a high pressure cleaner									
22	Using internet exploring daily technology									
23	High level gardening									
24	High level gardening									
25	Cognitive stimulating and intellectual activities									
26	Playing puzzles and brain teasers									
27	Using IT applications									
28	Using internet									
29	Using an agenda									
30	Reading books									
31	Reading educational or professional literature, reading in other languages									
32	Writing books, papers, articles									
33	Craftwork and arts									
34	Feeding cats									
35	Playing music instrument									
36	Watching arts									
37	Complex recreational activities and transactions									
38	Electronics: feeding, using, etc. (kettle, using screen net of the wall system)									
39	Complex administration and banking									
40	Communication activities by using devices or techniques									
41	Using a cell phone									
42	Writing a mail or a letter									
43	Sports									
44	Watching sports									
45	Using vehicle									
46	Transportation by motorized vehicles									
47	Transportation by nonmotorized vehicles									
48	Self development, self realization or self educational activities									
49	Self development, self realization or self educational activities									
50	Using an e-mailing									
51	Using an e-mailing									
52	Feeding fish or watching others									
53	Feeding in the house of the children									
54	Feeding care of partner									
55	Feeding care of (great) grand children									
56	Feeding care of pets									
57	Feeding household objects									
58	Feeding household objects									
59	Doing professional work									
60	Doing professional work									
61	Engagement in organized social activities or leisure activities									
62	Organizing events									
63	Using electronic equipment									

**TNA**  
*Total Number of Activities*  
**a-ADL-DI**  
*Advanced Activities of Daily Living Disability Index*  
**a-ADL-CDI**  
*Advanced Activities of Daily Living Cognitive Disability Index*  
**a-ADL-PDI**  
*Advanced Activities of Daily Living Physical Disability Index*





## Interpretation results a- ADL

a-ADL-DI: 68%

a-ADL-CDI: 66,66%

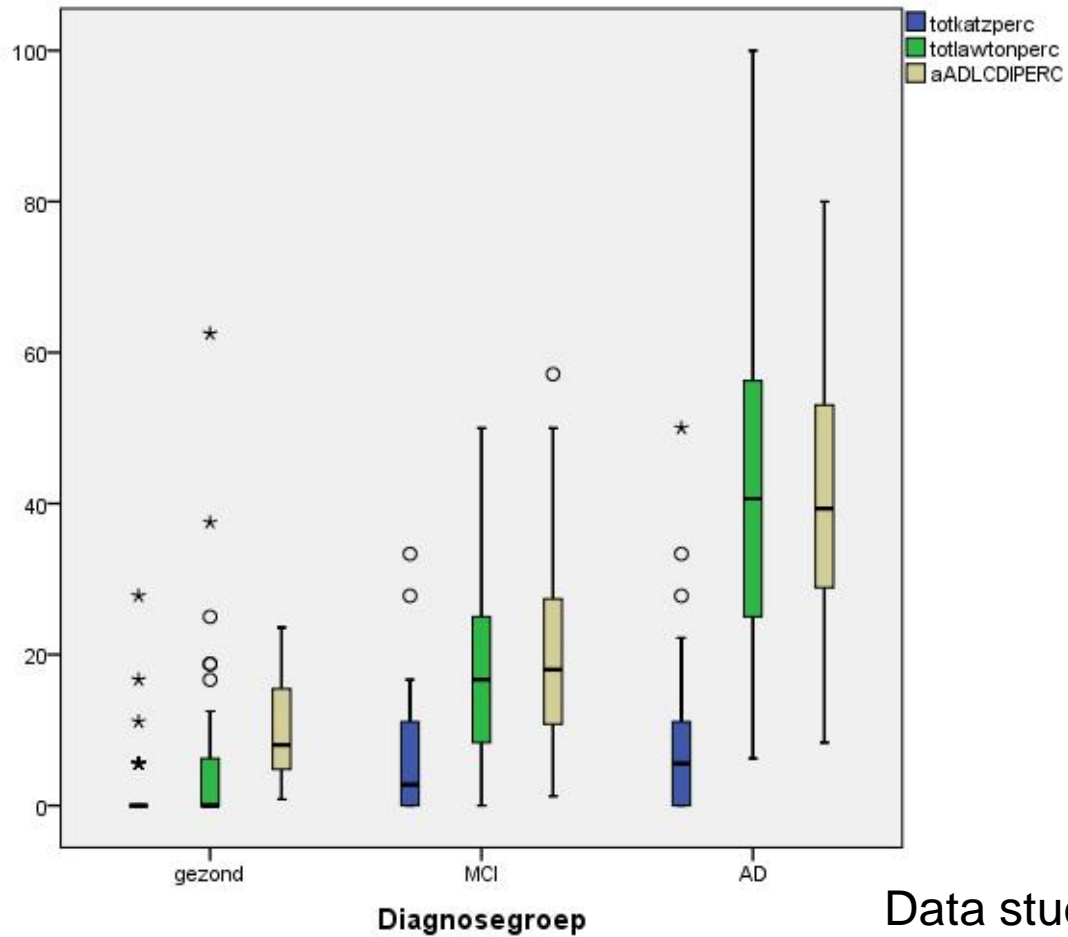
a-ADL-PDI: 9,27%

- the a-ADL-CDI shows clearly functional impairment due to cognitive causes
- No physical causes of impairment as shown by the Physical Disability Index

**Table 2. Discriminative validity of the a-ADL indices between controls, patients with MCI and AD**

	GROUPS	OPTIMAL CUT-OFF	SENSITIVITY	SPECIFICITY	AUC	PPV	NPV
<b>Indices</b>							
a-ADL-DI	C vs. MCI	27.2	75%	80.0%	0.814	79.3%	75.7%
	MCI vs. AD	47.9	71.2%	70.8%	0.802	72.4%	62.6%
a-ADL-CDI	C vs. AD	36.2	94.2%	90.0%	0.949	90.4%	94.2%
	C vs. MCI	14.1	75%	70.0%	0.791	69.4%	75.7%
a-ADL-PDI	MCI vs. AD	27.4	80.8%	70.8%	0.804	72.4%	79.6%
	C vs. AD	22.5	86.5%	94.0%	0.960	94.2%	86.0%
a-ADL-PDI	C vs. MCI	6.1	60.4%	6.0%	0.600	54.5%	61.3%
	MCI vs. AD	9.3	61.5%	64.2%	0.580	65.2%	59.6%
	C vs. AD	7.1	67.3%	72.0%	0.666	72.8%	66.4%

# Hypothesis of functional continuum



Data studie De Vriendt et al.

# Clinimetric properties: methods & results

Psychometric properties		
Feasibility	Time use (n=30) Comprehensibility (n=30)	ü
Face validity	Qualitative study, involvement of patients (n=38)	
Content validity	Prevalence of the a-ADL items (n=68)	ü
Reliability of the scoring system	Distribution of the scores among groups (n=68) Inter rater agreement/reliability (n=28) Agreement patient/proxy (n=24)	ü
Construct validity	Hypothesis correlations with other measures (n=68) Expected differences between groups (n=68)	ü
Discriminative validity	ROC's & Sensitivity and specificity (n=157) Positive and negative predicative values (n=157)	ü
Convergent validity	Compared with Natural Action Test (n=30)	ü



# Predictive value a-ADL-tool

Group	Indices	Overall hit ratio	Sens	Spec	Neg pred value	Pos pred value	AUC
HC/MCI	TNA a-ADL- CDI	80%	77.5%	82%	82%	77.5%	.877
MCI/AD	a-ADL- CDI	79.3%	82.7%	75%	77%	81%	.836
HC/AD	TNA a-ADL- CDI	92.2%	92.3%	92%	92%	96%	.982

*Logistic regression (n=150)*

De Vriendt et al., a-ADL schaal



# Measuring participation as defined by the WHO in the ICF

Dominique Van de Velde, Phd.  
Helsinki – international Week – April 2016

# Introduction

## Defining Participation?

- The WHO's definition of Participation
  - Involvement in a life situation (WHO, 2001, p10)

Domains of participation	
d1	Learning and applying knowledge
d2	General tasks and demands
d3	Communication
d4	Mobility
d5	Self-care
d6	Domestic life
d7	Interpersonal interactions and rel
d8	Major life areas
d9	Community and civic life

# Research questions

- Optimal participation is considered as the ultimate goal of a rehabilitation process (Stucki, 2003).
- Research questions:
  - How is participation measured?
  - How is it operationalized?
  - Are the measurement instruments psychometrically sound?

# Results:

## 10 Measurement Instruments

- Community Integration Measure – CIM (McColl et al, 2001)
- The Keel Assessment of Participation – KAP (Wilkie et al, 2005)
- Community Integration Questionnaire 2 – CIQ2 (Johnston et al, 2005)
- Impact on Participation and Autonomy – IPA(Q) (Cardol et al, 1999)
- Late Life Function and Disability Instrument – LLFDI (Haley et al, 2002)
- Measure of home and community participation – PAR-PRO (Ostir et al, 2006)
- Participation Measure for Post Acute Care – PM-PAC (Gandek et al, 2007)
- Participation Objective, Participation Subjective – POPS (Brown et al, 2004)
- PARTicipation Survey/Mobility – PARTS/M (Gay et al, 2006)
- Participation Scale – P-Scale (Van Brakel et al, 2006).
- Utrecht Scale for Evaluation of rehabilitation –Participation (Post et al, 2012)

# Results:

## How is Participation Operationalized?

Instrument	Aspects measured	Domains of the ICF covered
CIM	Performance	Not based on the ICF domains
KAP	Frequency	5 domains (4.6.7.8.9)
CIQ2	Performance, Satisfaction and Importance	Not based on the ICF domains
IPA	Autonomy, Limitations	Not based on the ICF domains
LLFDI	Frequency, limitations	Not based on the ICF domains
PAR-PRO	Frequency	5 domains (4.6.7.8.9)
PM-PAC	Limitations, duration, satisfaction	8 domains (1.3.4.5.6.7.8.9)
POPS	Frequency, satisfaction and importance	5 domains (4.6.7.8.9)
PARTS/M	Frequency	6 domains (4.5.6.7.8.9)
P-Scale	Limitation	8 domains (1.3.4.5.6.7.8.9)
USER	Frequency, satisfaction, restrictions	Not based in the ICF domains

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# Results: Psychometric Properties

	Content Validity	Internal Consistency	Criterion Validity	Construct Validity	Reproducibility Agreement	Reproducibility reliability	Responsiveness	Floor-Ceiling effects	Interpretability	Overall score
CIM	+	+	-	-	+	0	-	+	+	4
KAP	?	na	+	na	-	-	0	-	+	2
CIQ2	+	+	-	-	+	+	0	+	+	6
IPA	+	+	-	+	+	+	+	-	+	7
LLFDI	+	+	-	0	-	+	-	-	+	4
PAR-PRO	-	+	0	-	0	-	0	+	-	2
PM-PAC	?	+	-	+	+	+	+	-	+	6
POPS	+	0	0	0	0	0	0	0	+	1
PARTS/M	+	+	?	-	?	?	0	0	-	2
P-scale	?	+	0	+	+	+	+	-	+	6

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IPA	+	+	-	+	+	+	+	-	+	7
LLFDI	+	+	-	0	-	+	-	-	+	4
PAR-PRO	-	+	0	-	0	-	0	+	-	2
PM-PAC	?	+	-	+	+	+	+	-	+	6
POPS	+	0	0	0	0	0	0	0	+	1
PARTS/M	+	+	?	-	?	?	0	0	-	2
P-scale	?	+	0	+	+	+	+	-	+	6



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LLFDI	+	+	-	0	-	+	-	-	+	4
PAR-PRO	-	+	0	-	0	-	0	+	-	2
PM-PAC	?	+	-	+	+	+	+	-	+	6
POPS	+	0	0	0	0	0	0	0	+	1
PARTS/M	+	+	?	-	?	?	0	0	-	2
P-scale	?	+	0	+	+	+	+	-	+	6

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IPA	+	+	-	+	+	+	+	-	+	7
LLFDI	+	+	-	0	-	+	-	-	+	4
PAR-PRO	-	+	0	-	0	-	0	+	-	2
PM-PAC	?	+	-	+	+	+	+	-	+	6
POPS	+	0	0	0	0	0	0	0	+	1
PARTS/M	+	+	?	-	?	?	0	0	-	2
P-scale	?	+	0	+	+	+	+	-	+	6

# Results: Psychometric Properties

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IPA	+	+	-	+	+	+	+	-	+	7
LLFDI	+	+	-	0	-	+	-	-	+	4
PAR-PRO	-	+	0	-	0	-	0	+	-	2
PM-PAC	?	+	-	+	+	+	+	-	+	6
POPS	+	0	0	0	0	0	0	0	+	1
PARTS/M	+	+	?	-	?	?	0	0	-	2
P-scale	?	+	0	+	+	+	+	-	+	6

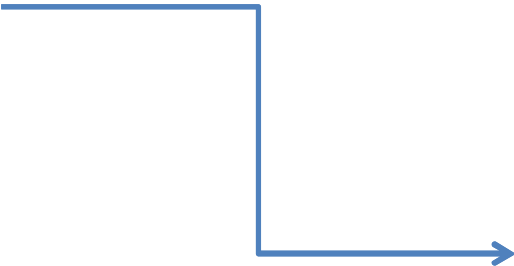
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LLFDI	+	+	-	0	-	+	-	-	+	4
PAR-PRO	-	+	0	-	0	-	0	+	-	2
PM-PAC	?	+	-	+	+	+	+	-	+	6
POPS	+	0	0	0	0	0	0	0	+	1
PARTS/M	+	+	?	-	?	?	0	0	-	2
P-scale	?	+	0	+	+	+	+	-	+	6
USER	+	?	+	?	+	+	0	+	+	6

# Challenge?

**To develop a participation measurement-instrument that**

- includes both subjective and objective variables,
- covers all the domains of participation
- is based on the ICF qualifier scale leading to 1 participation score.

- 
- **0** No participation problem
  - **1** – Mild participation problem
  - **2** – Moderate participation problem
  - **3** – Severe participation problem
  - **4** – Complete participation problem

# Step 1: Item derivation.

- Qualitative research
- How is participation perceived by individuals?

# Results: the determinants

1. The ability to choose a seemingly meaningless occupation
2. The fact that there are other options
3. Being able to perform activities in line with previous experiences
4. Being able to perform activities related to one's own identity
5. Being able to perform activities in order to enhance personal growth
6. Having a feeling or trust in the familiar community
7. The fact that people unconditionally take over necessary tasks
8. The feeling that relatives and other important persons are doing well
9. Experiencing a sense of control by acting
10. Feeling endorsed or valued by acting
11. Experiencing a sense of importance by acting
12. Experiencing the appeal of one's capacities
13. Finding equal identities through acting
14. ...
15. ...



Abstract

Send to:

Int J Rehabil Res. 2010 Dec;33(4):346-55. doi: 10.1097/MRR.0b013e32833cdf2a.

### Perceived participation, experiences from persons with spinal cord injury in their transition period from hospital to home.

Van de Veldea D<sup>1</sup>, Bracke P, Van Hove G, Josephsson S, Vanderstraeten G.

#### Author information

#### Abstract

It is suggested that participation should be achieved at the end of the rehabilitation process. However, there is a lack of consensus on the definition, the conceptualization and the measurement of participation. This study aims to add to the existing body of knowledge of participation by exploring the 'person perceived participation' in individuals with spinal cord injury (SCI). On the basis of the 'grounded theory' approach, in-depth, semistructured interviews were conducted with 11 SCI patients from a rehabilitation cohort in their transition period from hospital to home, to gain an insider perspective on the concept of participation. Results identified three different categories of participation: social participation, occupational participation and socio occupational participation. The participants conceptualize participation as a set of values, including experiencing free choice to perform activities, performing according to the person's identity, experiencing personal growth, belonging by experiencing trust and security, feeling validated, having a sense of control, experiencing a sense of importance and finding equal identities. In conclusion, from a client perspective, participation is a complex, multidimensional construct and can be considered as a dyad between the individual's social interactions and his specific activities performed. Participation was not experienced by the SCI patients as an objective way of performing activities within a societal context or as frequencies of activities performed, but rather as an internal process of negotiation that seemed to be based on balancing personal and societal values.

PMID: 20679902 [PubMed - indexed for MEDLINE]



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Patients' perspectives of a spinal cord injury unit. [SCI Nurs. 1990]

**Review** Participation after spinal cord injury: the evolution of conceptus [J Neurol Phys Ther. 2005]

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The illusion and the paradox of being

# Step 2: Development of the scale.

- Survey: 350 individuals

1. What are the five most important activities that you have performed during the last week?
2. How many time did you spent in each of these activities?
3. Give an appreciation from 1 to 5 for the following statements  
(from 1 totally agree to 5 totally disagree)

$S_1$ : it was completely my choice to engage in this activity.

$S_2$ : I performed this activity (or I was part of it) completely as I wished.

$S_3$ : during this activity I was completely able to be myself.

$S_4$ : this activity was completely self-fulfilling.

$S_5$ : during this activity, I experienced a feeling of complete control

$S_6$ : ...

# Step 3: Structure of the scale.

- Exploratory Factor Analysis
  - 3 subscales:
    - Activities leading social appreciation
    - Activities according to choices and wishes
    - Delegated activities
- Internal consistency:
  - Cronbach's Alpha:  $\alpha$ : 0,79 – 0,83
  - Item total correlation: 0,57 – 0,80



Abstract ▾

Send to: ▾

Eur J Phys Rehabil Med. 2015 Nov 27. [Epub ahead of print]

## Measuring participation when combining subjective and objective variables; the development of the Ghent Participation Scale (GPS).

[Van de Velde D<sup>1</sup>](#), [Bracke P](#), [Van Hove G](#), [Josephsson S](#), [Viaene A](#), [De Boever E](#), [Coorevits P](#), [Vanderstraeten G](#).

### Author information

#### Abstract

**BACKGROUND:** The ICF reflects a bio-psycho-social paradigm and is increasingly used in outpatients rehabilitation settings. The component of participation is in the ICF the manifestation of a bio- psycho-social reasoning. Different participation measures have already been developed and were operationalized through objective and/or a limited set of subjective variables, but keeping them as separate concepts. There is still need for a generic participation instrument including both objective and all relevant subjective variables resulting in one participation score.

**OBJECTIVE:** To develop a generic participation measure based on objective and subjective aspects and leading to one final score; the Ghent Participation Scale (GPS). Additionally it was the aim to explore whether the GPS has a good internal validity by means of factorial validity and homogeneity and whether the GPS is feasible and interpretable.

**DESIGN AND SETTING:** Cross-sectional study: 130 former rehabilitation outpatients with various conditions. Item derivation for the GPS was based on qualitative research. The participants administered the GPS in the third week after discharge from the Ghent University Hospital. An exploratory factor analysis was performed to determine underlying dimensions. Statistical coherence was expressed in both item-total correlations and in Cronbach's  $\alpha$  coefficient.

**RESULTS:** An exploratory factor analysis showed 3 underlying dimensions within the GPS: (1) performing activities according to preferred choices and wishes, (2) social appreciation and acceptance by performing activities and (3) the need to delegate activities explaining 55.8% of the total variance. The results show a good to strong homogeneity (item-total ranged from 0.58 to 0.80) and a strong internal consistency (Cronbach's  $\alpha$  ranged from 0.76 - 0.92).

**CONCLUSION:** The results of this preliminary validation study suggest that the GPS appears to be a valid measure to rate participation. Further research and more and more powerful psychometric models such as Rasch Analysis or Item Response models are needed to establish a psychometrically sound instrument.

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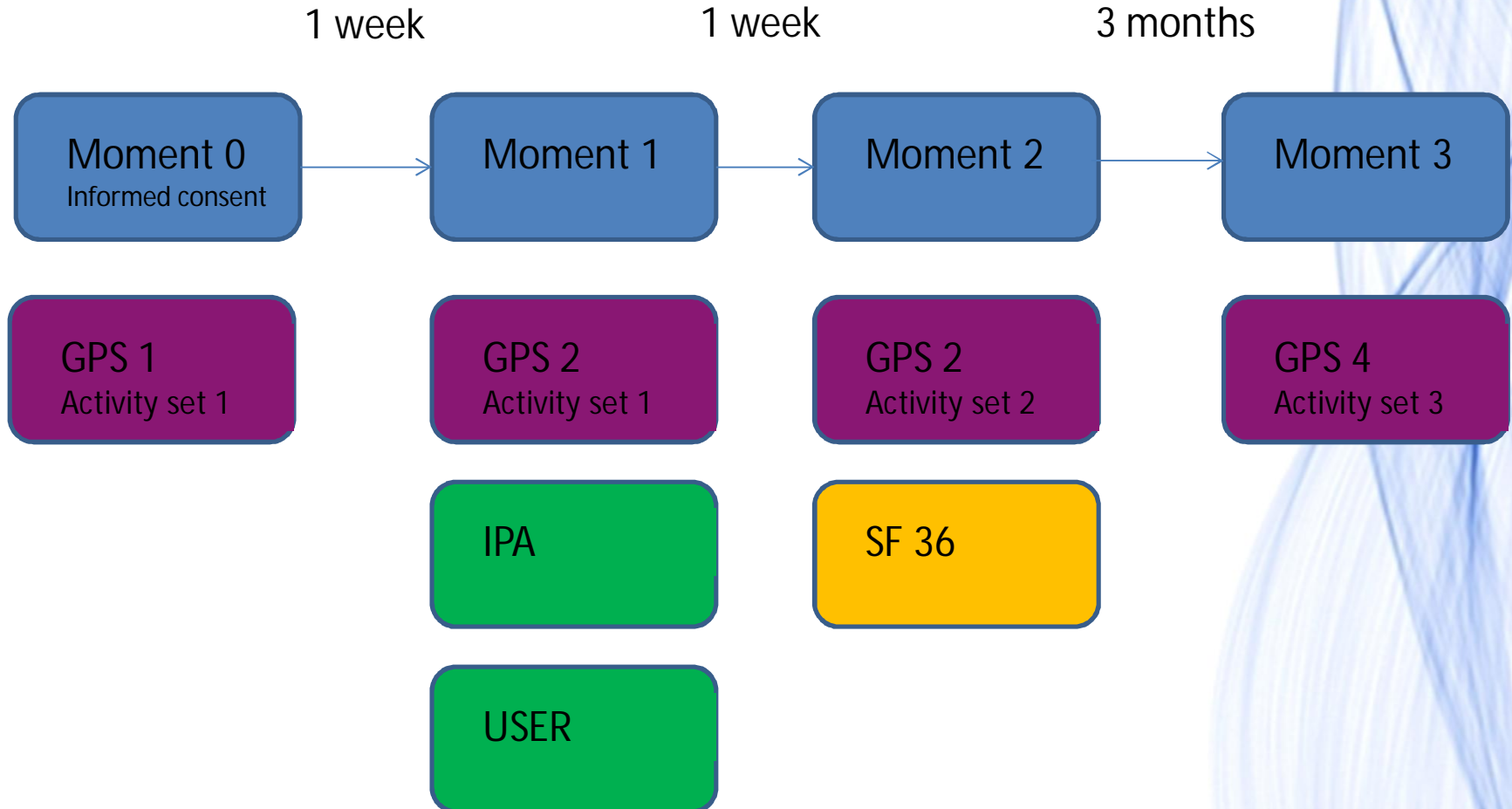
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measuring[All Fields] AND
participation[All Fields] AND
subjective[All Fields] AND ("goals"
[MeSH Terms] OR "goals"[All Fields]
OR "objective"[All Fields]) AND
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# Step 4: testing the Psychometrics

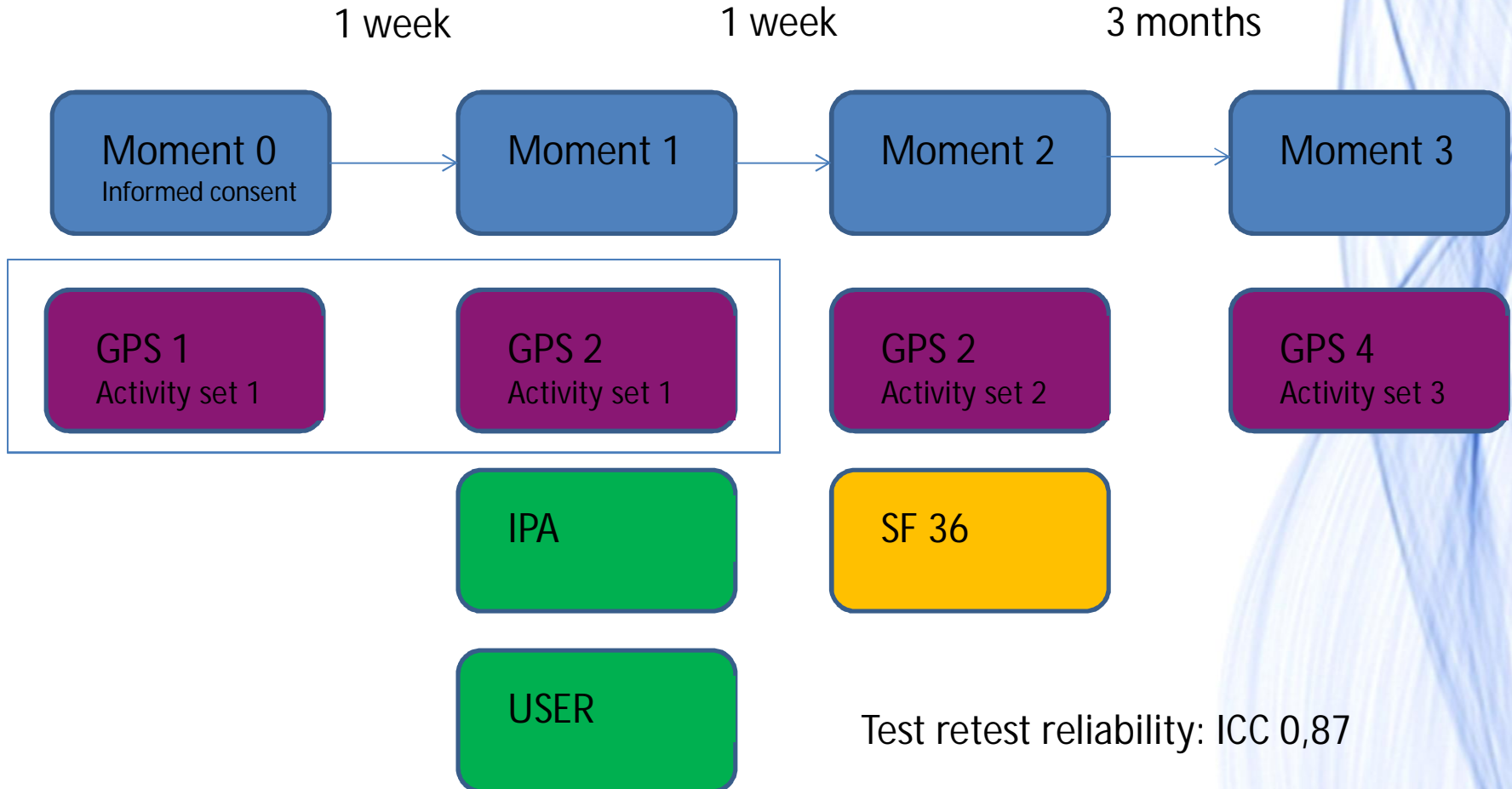
Participants: 365 individuals from 6 rehab centers, with different health conditions

- Test-retest reliability
- Construct validity
- Discriminative validity
- Responsiveness
- Interpretability

# Protocol?

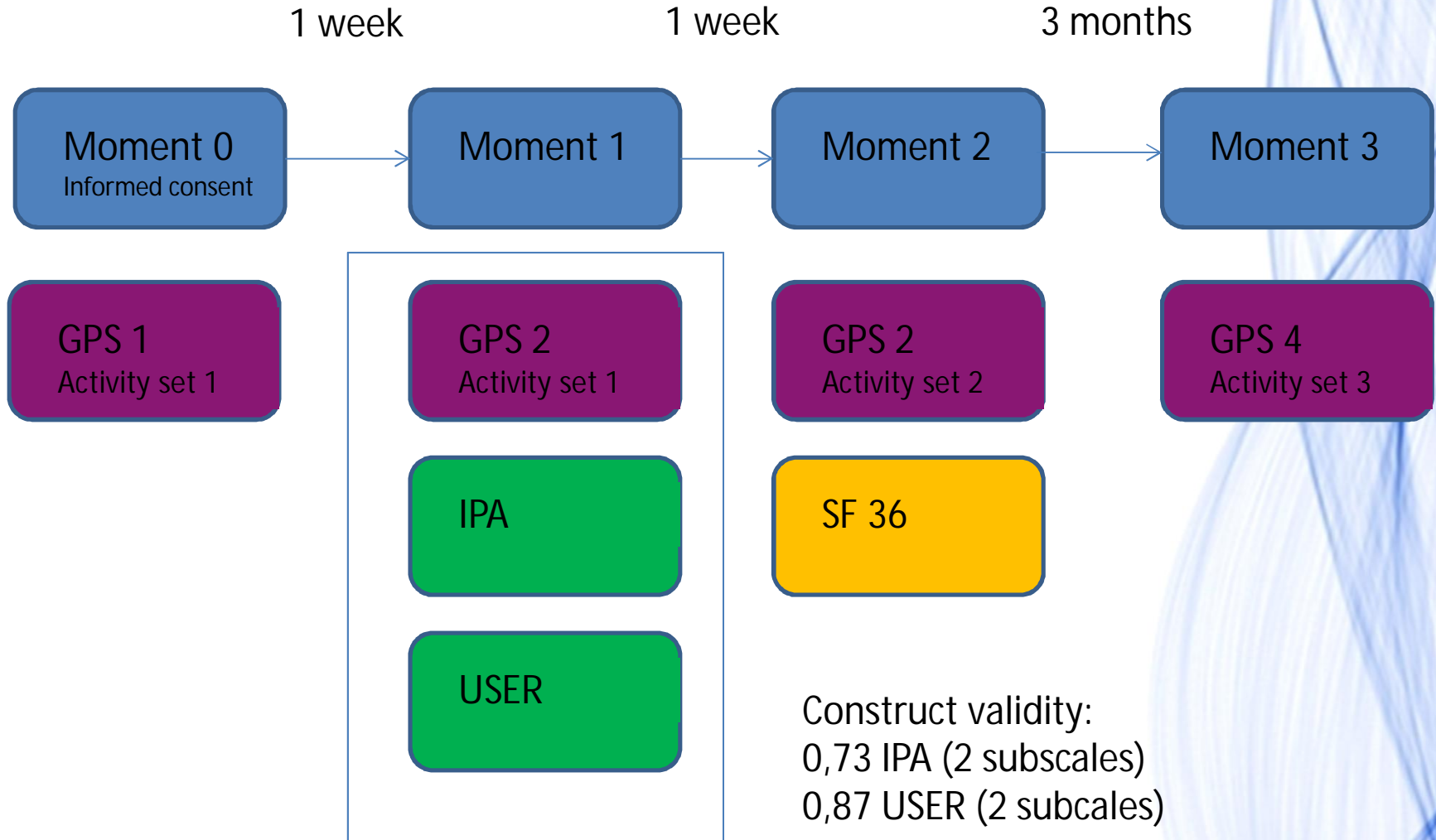


# Protocol?

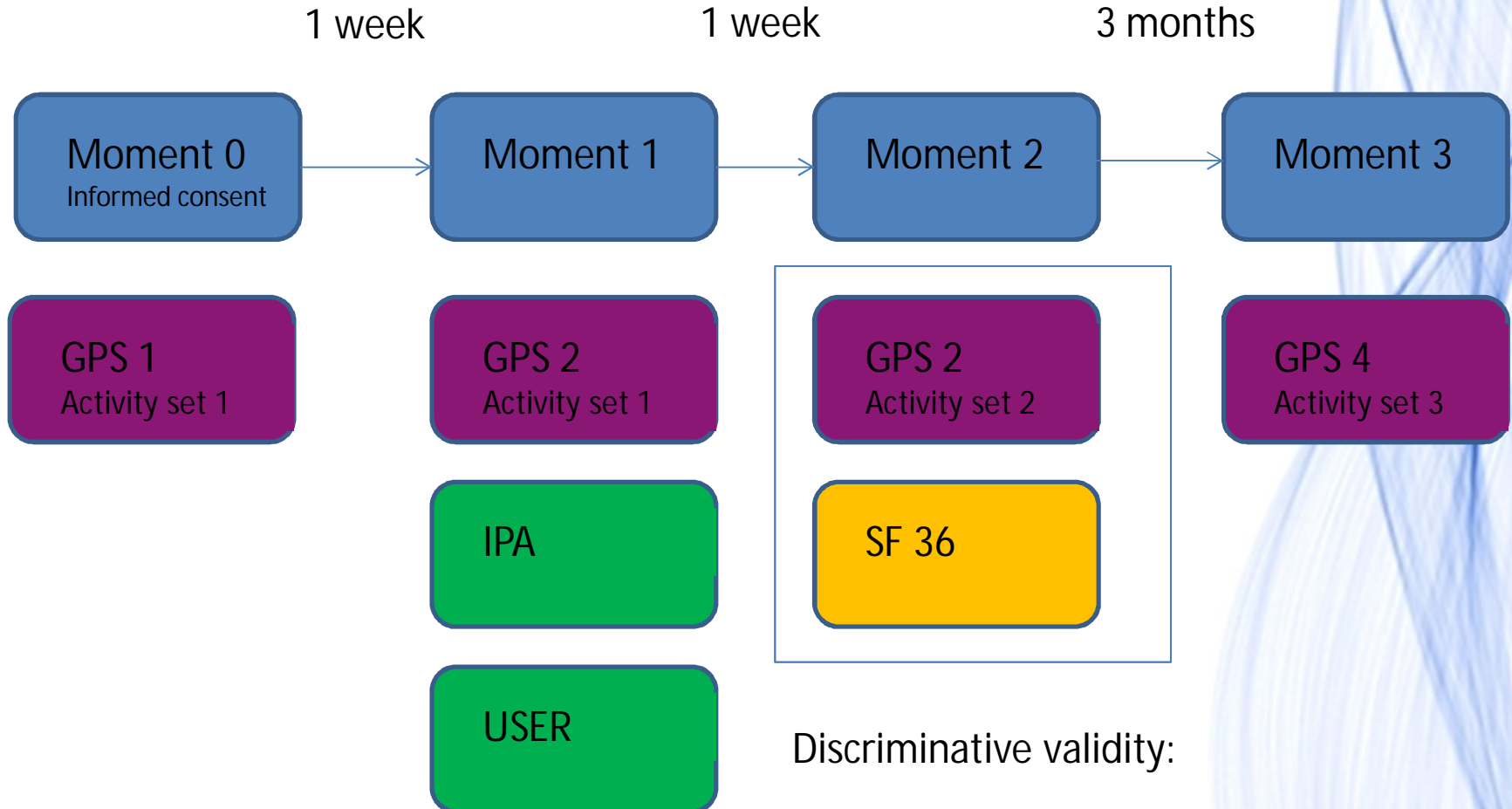




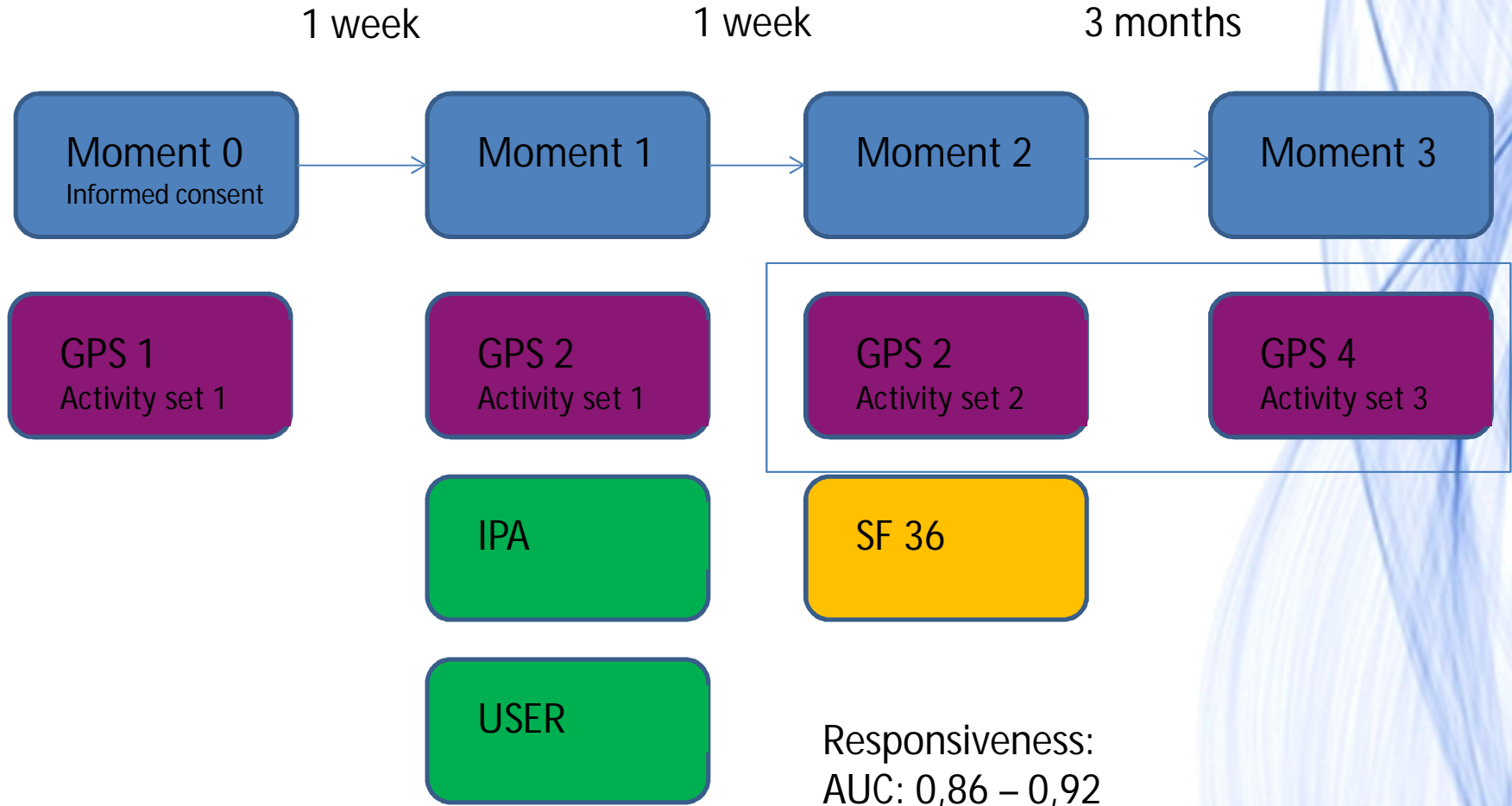
# Protocol?



# Protocol?



# Protocol?



# Interpretability:

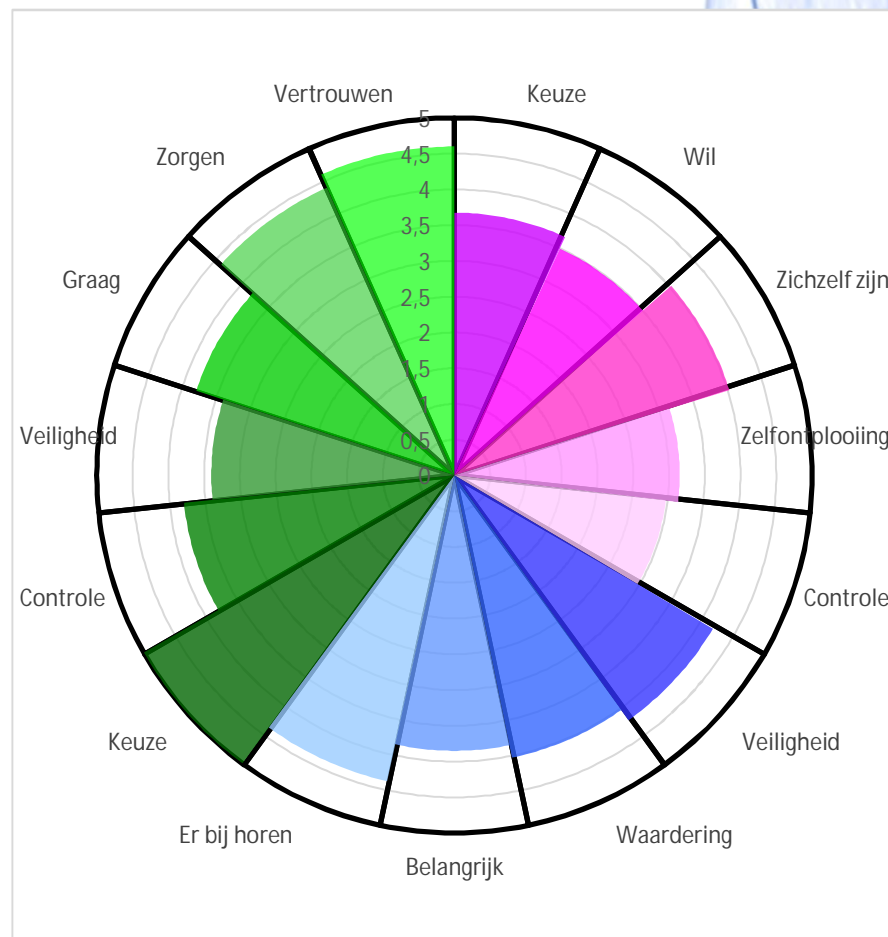
**One Participation score: 65,50%**

**According to the ICF Qualifier: 2**

- Moderate participation problem.

## Conclusion:

The study resulted in a **generic participation measure**, the GPS. The GPS has **strong psychometric properties** and is **easy to interpret**. The GPS enhances the ability for practitioners to **evaluate the effectiveness of their interventions** regarding participation.



# To conclude

§ It is possible

§ To measure within the ICF:

§ With less emphasis on the etiology but more emphasis on the consequences

§ On both levels of activities and participation.

§ It depends on the way you operationalize the concepts.





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Who wants to join us in our  
scientific work?

# Process of translation and adaptation of instruments

- § WHO guidelines: focus on cross-cultural and conceptual, rather than on linguistic/literal equivalence
- § Following steps:
  - § Forward translation
  - § Expert panel Back-translation
  - § Pre-testing and cognitive interviewing
  - § Final version
  - § Documentation



# Questions?

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