

Development of ICF Core Sets for Multiple Sclerosis

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Institut Ergotherapie, 2010



International Classification of
Functioning, Disability
and Health

ICF

www.who.int/classifications/icf

Approved by the World Health Assembly in May 2001



ICF is WHO's framework for
measuring health and disability
at both individual and population
levels

While the International
Classification of Diseases ICD
classifies diseases as causes of
death, the ICF classifies health



Dr. Gro Harlem Brundtland
Former Director General, WHO

Bio-medical model of disease

Health Condition
(disease, trauma)



Evaluation of the disease consequences

Integrative model of functioning and disability

Health Condition
(disease, trauma)



Functioning/ Disability

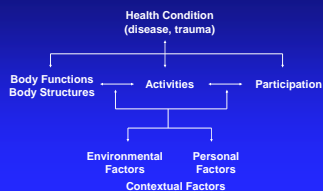


Environmental
Factors

Personal
Factors

Contextual Factors

The biopsychosocial model of functioning and disability



ICF provides an international common language and universal conceptual framework for describing functioning, disability and health

ICF Classification

List of

- mutually exclusive and
- cumulative exhaustive

categories which allows to unambiguously classify, describe and communicate about functioning

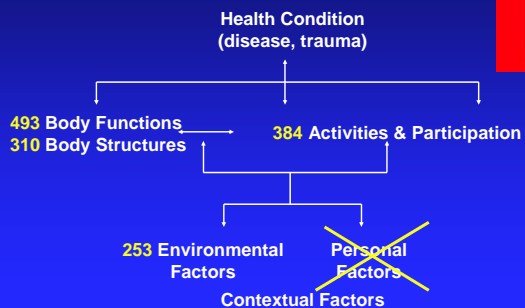
The list is, at least in principle, finite

How many categories do we need to comprehensively describe, classify and communicate the human experience of functioning and disability?

ICF

1454 categories

ICF categories



"To be useful, **practical ICF based tools** need to be tailored to the need of the the users without forgoing the information needed for health statistics and health reporting"



Dr. Bedirhan Üstün
WHO Classification Office Director

Üstün B et al. Common yet specific tools to measure clinical outcomes: ICF Comprehensive Sets and ICF Core Sets. *J Rehab Med* 2004; (44 suppl):7-8.

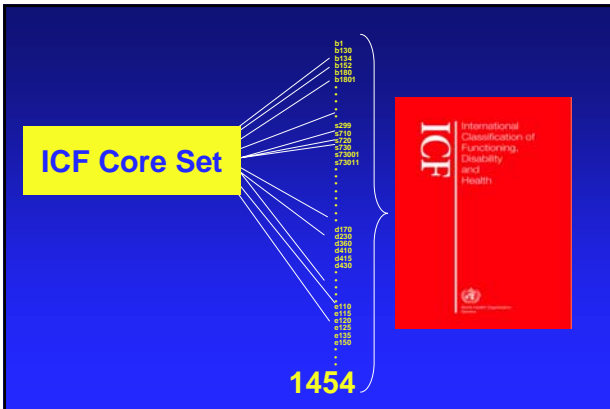
„Tools“ for practical use of ICF

- ICF Checklist
- ICF Core Sets
- ICF Intervention Categories



The **ICF** is the full dictionary of functioning

ICF Core Sets are fractions of the ICF relevant for specific health conditions and / or a specific context



- **Brief ICF Core Sets: 10-15**
 - Research standard and statistics
 - Encounter single professional
- **Comprehensive ICF Core Sets: 70-200**
 - Multi-disciplinary team
 - As few as possible, as many as necessary
- Selection depends on health condition/ specific context

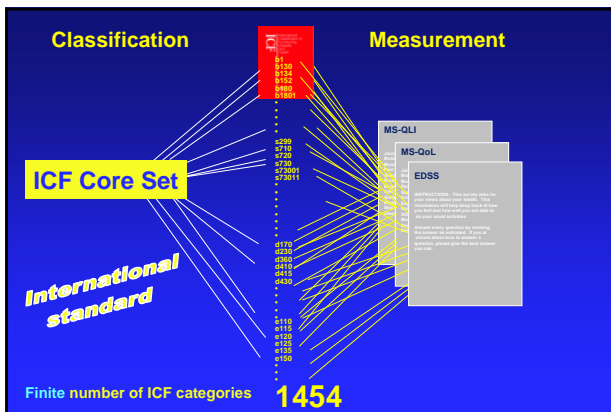
ICF Core Sets

serve as *international standards* regarding

- what to measure
- what to report

ICF Core Sets

- link the ICF to
 - health conditions
 - the world of measurement instruments





Development of ICF Core Sets

Institute for Health and Rehabilitation Sciences
ICF Research Branch, WHO CC FIC Germany
Ludwig-Maximilian University
Munich, Germany

WHO
CAS Team - Classification, Assessment and Standards

Partner-Organisations

Current developments

- Scleroderma – Vienna - EUSTAR, EULAR
- SLE – Vienna - EULAR, OMERACT
- Psoriasis Arthritis – Wellington - GRAPPA, EULAR, OMERACT
- Sleep – Helsinki - WASM
- Multiple Sclerosis – Valens - MSIF
- Traumatic Brain Injury – Barcelona - WFNR
- Bipolar disorders – Barcelona - ISBD
- Vision – Munich - ISLRR
- Migraine/Headache – Milan
- Manual Medicine – Zurich - SAMM
- Oral functioning – Paris
- Work reintegration – Switzerland (SUVA)

Development of ICF Core Sets for MS

World Health Organization (CAS Team)

&

Valens Rehabilitation Centre, Switzerland

&

ICF Research Branch, WHO FIC CC Germany

Ludwig-Maximilian University, Germany

&

Multiple Sclerosis International Federation (MSIF)

&

International Society of Physical and Rehabilitation
Medicine (ISPRM)



ICF research branch

Multiple Sclerosis
International Federation

ICF Core Sets for MS

Preparatory Phase

- Clinical perspective
Empirical study
- Researcher perspective
Systematic review
- Patient perspective
Qualitative study
- Expert perspective
Expert survey

Phase I

International ICF
Consensus
Conference



Phase II

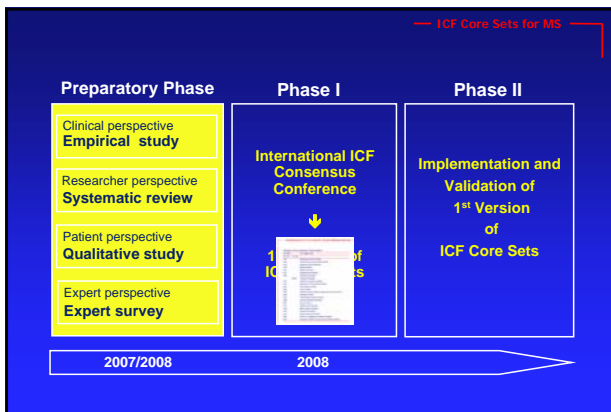
Implementation and
Validation of
1st Version
of
ICF Core Sets

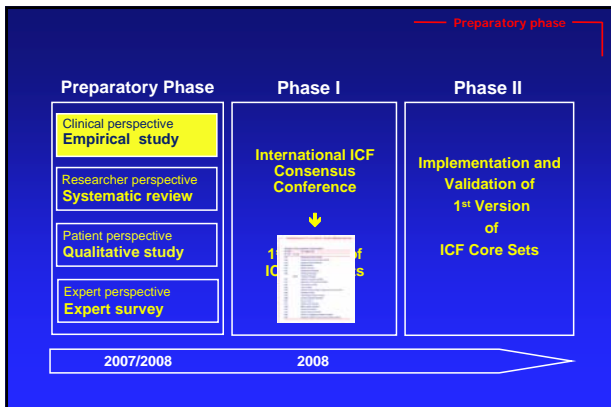
2007/2008

2008

Publikation über gesamtes Projekt

Weise A., Coenen M., Kesselring J., Cieza A.
The development of ICF Core Sets for Multiple Sclerosis. WFOT Bulletin 2008, vol. 57, S. 26-31.





Study aim

To describe functioning as well as environmental factors of individuals with MS from the clinical perspective

Methods

- Multicenter cross-sectional study with 4 study centres in Switzerland and Germany
- Interview, documentation, questionnaires
- Data collection once by one health professional

ICF Core Set Development

	0	1	2	3	4	5	6	7	8	9	C	
d530 Speaking Producing words, phrases and longer passages in spoken messages with literal and implied meaning, such as expressing a fact or telling a story in oral language.												
d535 Producing nonverbal messages Using gestures, symbols and drawings to convey messages, such as shaking one's head to indicate disagreement or drawing a picture or diagram to convey a fact or complex idea.												
d545 Writing messages Producing the literal and implied meanings of messages that are conveyed through written language, such as writing a letter to a friend.												
d550 Conversation Starting, sustaining and ending an interchange of thoughts and ideas, carried out by means of spoken, written, sign or other forms of language, with one or more people one knows or who are strangers, in formal or casual settings.												
d560 Using communication devices and techniques Using devices, techniques and other means for the purposes of communicating, such as calling a friend on the telephone.												
d4 MOBILITY												
d430 Lifting and carrying objects Raising up an object or taking something from one place to another, such as when lifting a cup or carrying a child from one room to another.												
d440 Fine hand use Performing the coordinated actions of handling objects, picking up, manipulating and releasing them using one's hand, fingers and thumb, such as required to fit coins on a table or turn a dial.												

Participants

N	205 participants
Gender	148 female (72%); 57 male (28%)
Age	19 - 76 years; mean 44.7 years
MS form	RR MS = 112 (55%); male 23 (11%) PP MS = 33 (16%); male 13 (6%) SP MS = 60 (29%); male 21 (10%)
EDSS	EDSS 1 – 7.5; mean 3.7 EDSS 1 - 3.5 = 111 (54%) EDSS 4 - 6.5 = 78 (38%) EDSS 7 – 10 = 16 (8%)

Publikation Ergebnisse

L. Holper, M. Coenen, A. Weise et al.
Characterization of functioning in multiple sclerosis using the ICF. Journal of Neurology online-Vorpublikation, September 2009.

Identified ICF categories

Body Functions	40
Body Structures	10
Activities & Participation	57
Environmental Factors (e)	32
Total	139

Candidate ICF categories (2nd level)

Preparatory Phase

- Clinical perspective
Empirical study
- Researcher perspective
Systematic review
- Patient perspective
Qualitative study
- Expert perspective
Expert survey

Phase I

International ICF
Consensus
Conference

↓

1st Version of
ICF Core Sets

Phase II

Implementation and
Validation of
1st Version
of
ICF Core Sets

2007/2008

2008

Study aim

To identify the areas of functioning, disability and health reported in published studies on patients with Multiple Sclerosis (research perspective)

Methods

- MEDLINE, EMBASE, PSYCINFO, CINAHL, CENTRAL
- Published in 2002-2007 in English
- Search terms

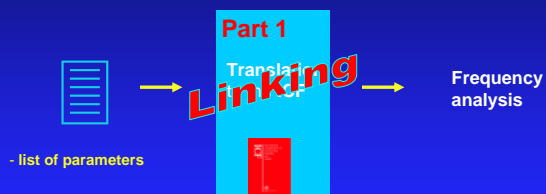
Results

- 5.310 studies
- 1st Eligibility check on abstracts: 1.998 studies
- 2nd Eligibility check on full texts: 354 studies

➔ 269 studies fulfilled the eligibility criteria for further analyses

Parameters extracted: 4744

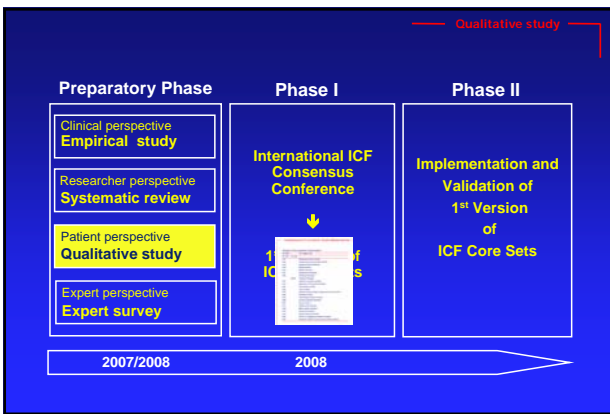
Data analysis



Systematic review

Identified ICF categories

Body functions	66
Body Candidate ICF categories (2nd level)	14
Activities	70
Environmental factors (e)	31
Total	181



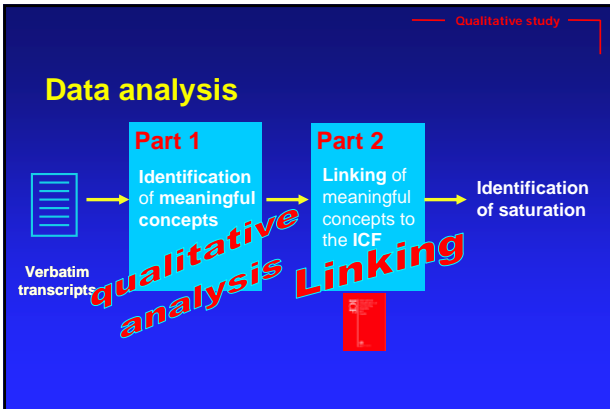
Qualitative study

Study aim

To identify relevant aspects of functioning as well as environmental factors from the patient perspective

Methods

- Focus groups with individuals with MS
- 6 open-ended questions according to ICF components



Qualitative study

Participants

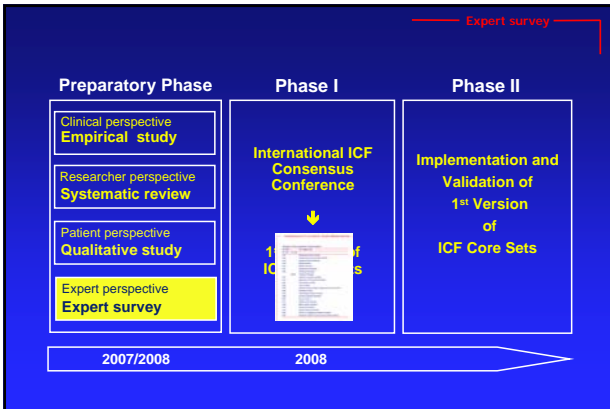
N	27 participants / 6 focus groups
Gender	19 female; 8 male
Age	Median 50 years (28 – 73)
MS form	RR MS n=7 PP MS n=6 SP MS n=14
EDSS	Median 6.5 (2.5 – 8)

Qualitative study

Identified ICF categories

Body Functions (b)	35
Body Structures (s)	--
Activities & Participation (d)	31
Environmental Factors (e)	38
Total	104

Candidate ICF categories
(2nd level)



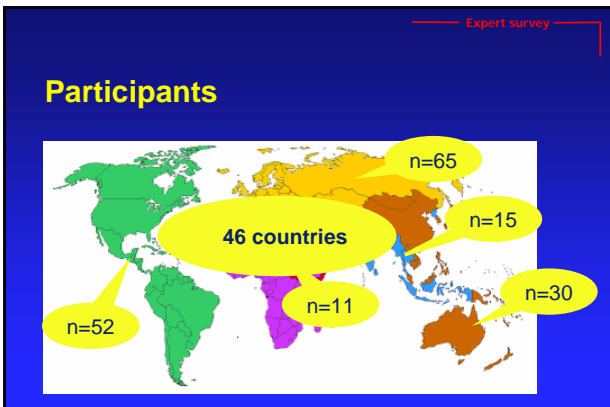
Expert survey

Study aim

To identify relevant aspects of functioning as well as environmental factors from the perspective of health professionals treating patients with MS

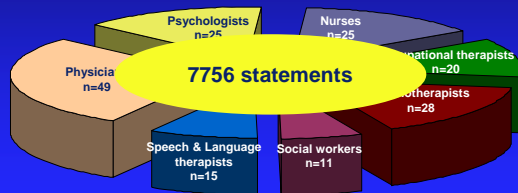
Methods

- International internet survey
- Health professionals from different WHO world regions experienced in the treatment of MS

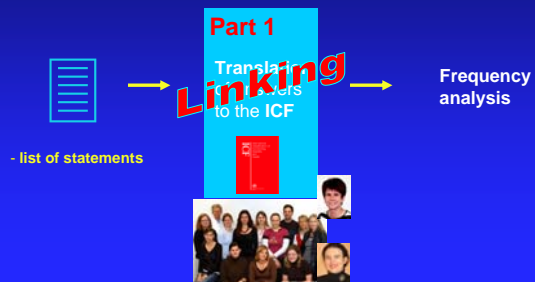


Participants

N	173 health professionals
Gender	113 female (65%); 60 male (35%)
Age	Mean 44.9 years (27 – 83)
Years of experience	Mean 13.4 years (5.0; 50.0)



Data analysis

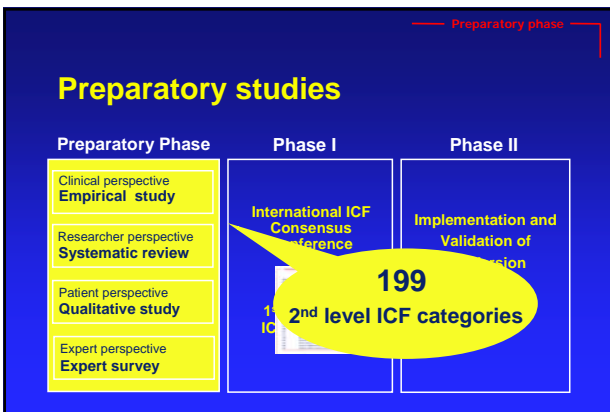


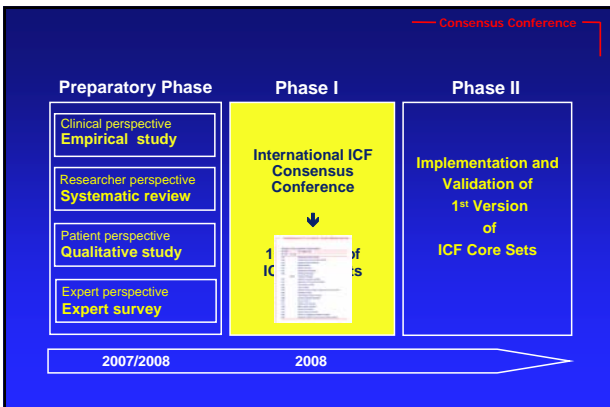
Expert survey

Identified ICF categories

Body Functions (b)	51
Body Structures (s)	21
Activities and Participation (d)	57
Environmental Factors (e)	47
Total	176

Candidate ICF categories
(2nd level)





Development of ICF Core Sets for MS Consensus Conference

Valens Rehabilitation Centre, Switzerland
Valens, May 2 – 4, 2008



Consensus Conference

During the conference ...

a decision-making and consensus process takes place to decide on



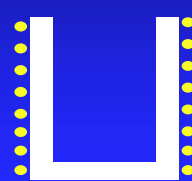
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graph TD
    A[ICF Core Sets for MS] --> B[Comprehensive ICF Core Set]
    A --> C[Brief ICF Core Set]
    
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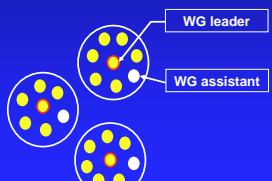
Consensus Conference

Decision-making and consensus process

Plenary sessions



Working group sessions



Working groups

WG room	B351	B352	B005
WG leader	<u>F. Khan</u>	<u>J. Freeman</u>	<u>D. Miller</u>
WG members	A. Hassan E. Månsson L. M. Renom G. A. Stuijbergen S. Sungkarat C. Vaney	B. Anderseck F. Cáceres M. Govaerts J. Hinrichs C. Stevens A. Vogt	S. Chitnis P. Flachenecker P. Hoang J. Jansa L. Vahter E. Willoughby
WG assistant	S. Kus	L. Holper	C. Sabariego

Results

Prel. Comprehensive ICF Core Set for MS

138 ICF categories

Preliminary Brief ICF Core Set for MS

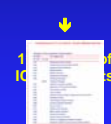
37 candidate ICF categories

Preparatory Phase

- Clinical perspective
Empirical study
- Researcher perspective
Systematic review
- Patient perspective
Qualitative study
- Expert perspective
Expert survey

Phase I

International ICF
Consensus
Conference



Phase II

Implementation and
Validation of
1st Version
of
ICF Core Sets

2007/2008

2008

Implementation & Validation

- Manual
- Empirical study (Fary Khan/Australia?)
- Australian qualitative study
- Delphi studies with
 - physicians (Stephanie Berno)
 - occupational therapists (Andrea Wiedenmann)
 - physiotherapists (Andrea Wiedenmann)
 - psychologists (Michaela Coenen)
 - nurses (Andreas Leib)
 - speech & language therapists (Marta Renom Guiteras)

Preliminary Comprehensive ICF Core Set for MS: 138 categories

	Total
Body functions	40 (29.0%)
Body structures	7 (5.1%)
Activities & Participation	53 (38.4%)
Environmental factors	38 (27.5%)
Total	138

Activities & Participation: 53 categories

d110	Walking	d110	Teaching oneself
d155	Acquiring skills	d520	Caring for body parts
d160	Focusing attention	d530	Talking
d163	Thinking	d540	Choosing
d166	Reading	d550	Eating
d170	Writing	d560	Drinking
d175	Solving problems	d570	Looking after one's health
d177	Making decisions	d620	Acquisition of goods and services
d210	Understanding a single task	d630	Preparing meals
d210	Understanding multiple tasks	d640	Caring for oneself
d230	Carrying out daily routine	d650	Caring for household objects
d240	Handling stress and other psychological demands	d660	Assisting others
d300	Speaking	d710	Basic interpersonal interactions
d310	Communication	d720	Complex interpersonal interactions
d360	Using communication devices and techniques	d750	Intimate social relationships
d410	Changing basic body position	d760	Family relationships
d415	Maintaining a body position	d770	Intimate relationships
d420	Transferring oneself	d825	Vocational training
d430	Lifting and carrying objects	d830	Higher education
d440	Fine hand use	d845	Acquiring, keeping and terminating a job
d445	Hand and arm use	d850	Remunerative employment
d450	Walking	d860	Basic economic transactions
d465	Moving around	d870	Economic self-efficacy
d465	Moving around in different locations	d910	Community life
d465	Moving around using equipment	d920	Recreation and leisure
d470	Using transportation	d930	Religion and spirituality
d475	Driving		

**Brief ICF Core Set for MS
(37 categories)
can serve as a worldwide agreed-upon:**

- Research standard: minimum data will be collected and reported about with regard to this diagnosis
- Clinical standard: minimum data will be collected and reported during encounter with a single professional

**Comprehensive ICF Core Set for MS
(138 categories)
can serve as a worldwide agreed-upon:**

- Checklist for observation & questioning
- Guideline for choosing relevant measurements/ observation tools
- Guideline for developing missing measurements
- Guideline for reporting & documenting in a multi-disciplinary setting
- Checklist for dividing tasks in a multi-disciplinary setting
- Guideline for structure of saving clinical data that is comparable for research worldwide
- ...