

Application of the ICF in the planning and reporting of studies

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Overview

- **Introduction into the ICF**
- Applications and Tools
- Applying the ICF in the planning and reporting of studies

Introduction

The ICF

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

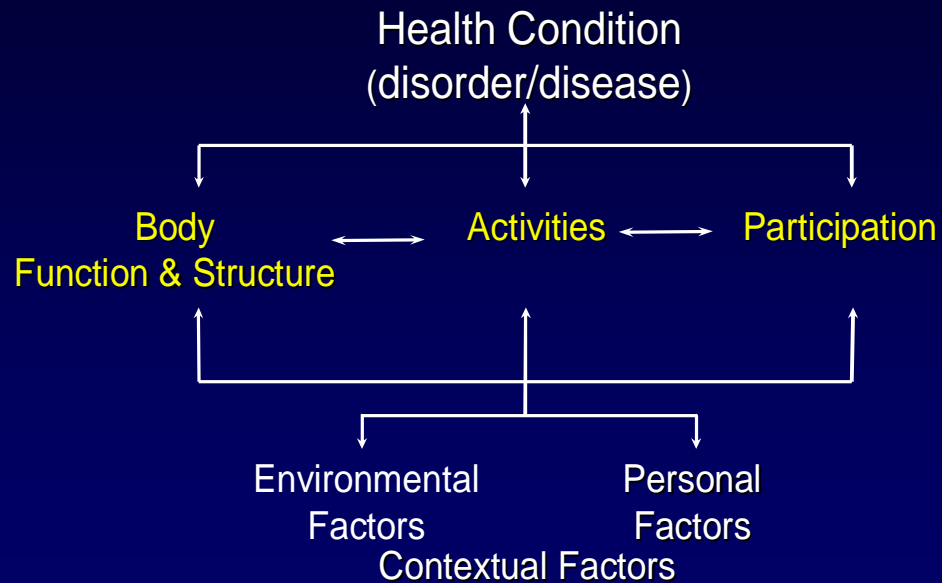
While the **International Classification of Diseases ICD** classifies *health conditions* as causes of death, the **ICF** classifies *health*



Dr. Gro Harlem Brundtland
Former Director General, WHO

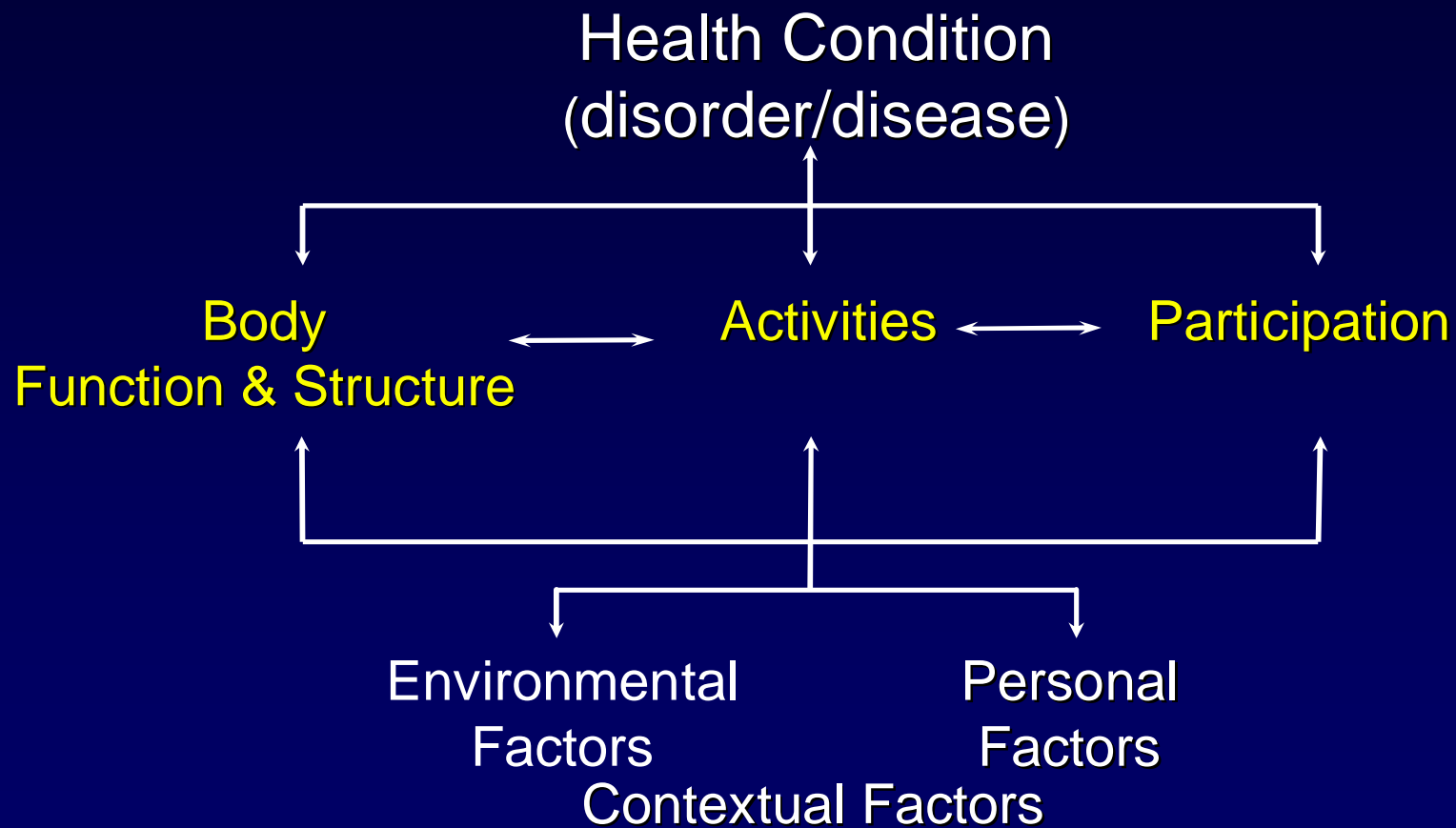
The ICF provides a common **understanding** and **dictionary** of functioning

Framework of Functioning and Disability

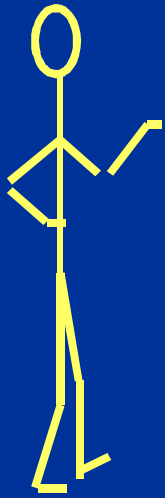


Cieza A, Stucki G. The ICF: its development process and content validity. *Eur J Phys Rehab Med* 2008;44(3):303-314

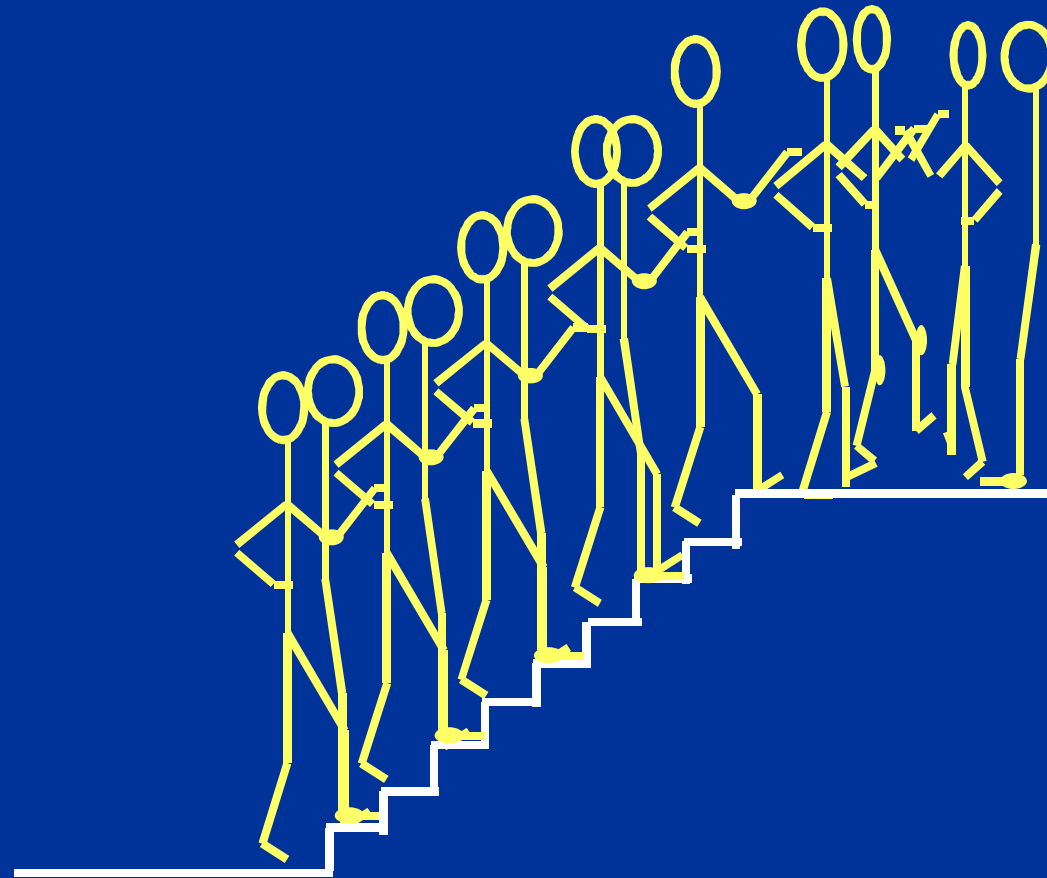
Framework of Functioning, Disability and Health



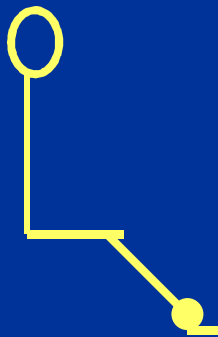
**Body functions
& structures**



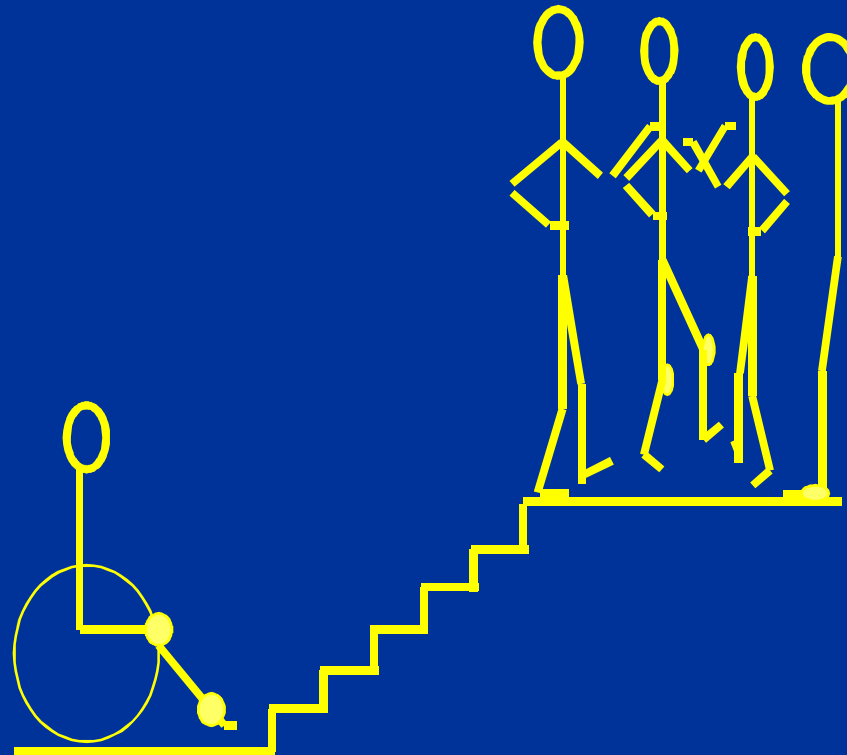
**Activity &
Participation**



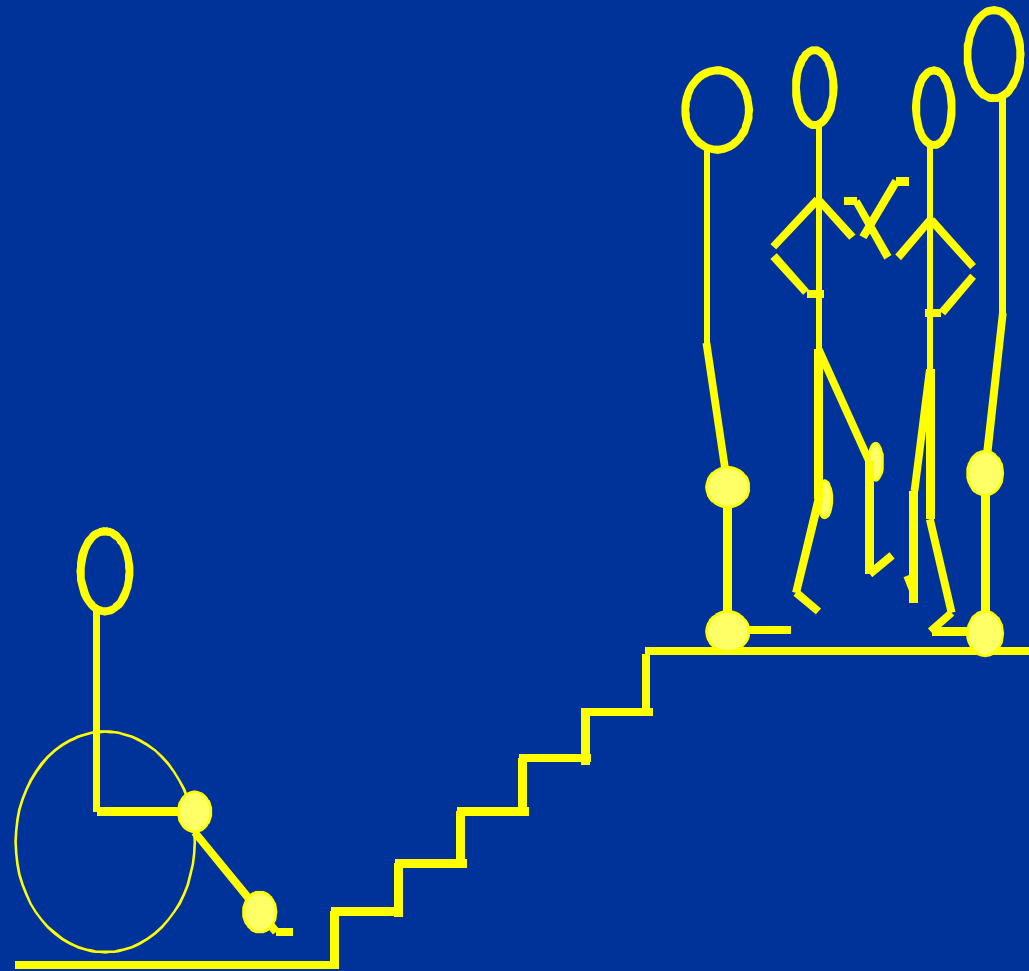
**Impaired
body functions
& structures**



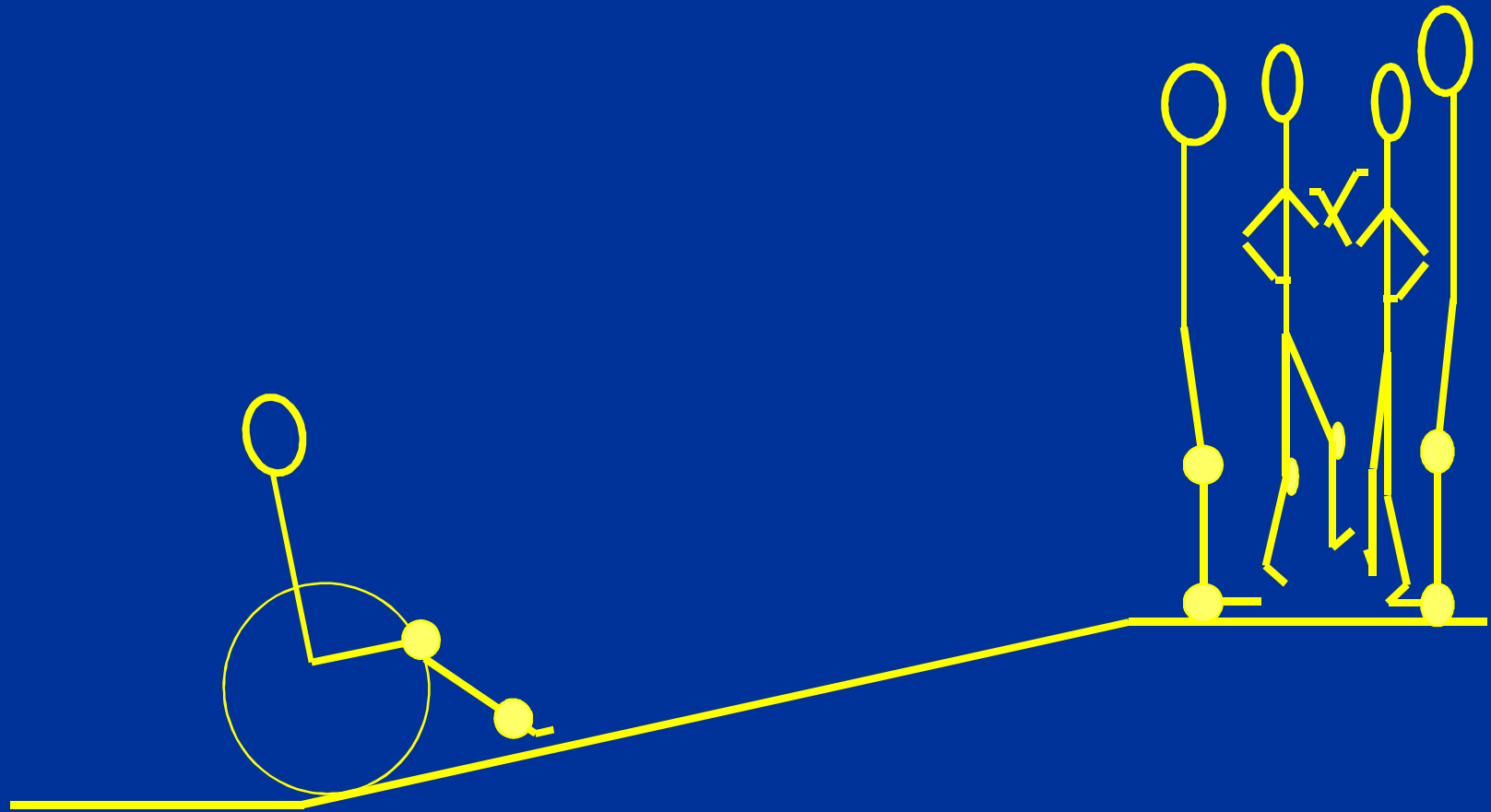
**Limitation in activity
Restriction in participation**



Disability



Functioning



ICF

International
Classification of
Functioning,
Disability
and
Health



World Health Organization
Geneva

Dictionary

1424 categories

**Mutually exclusive
Cumulative exhaustive**

Main challenges

- Operationalizations and practical tools
- Bridge to the world of measures
- Evolution from a second to a third level classification
 - ontological vs hierarchical
 - electronic health record compatible
- Link to the ICD
 - Revision ICD 11 - ontological

Introduction

ICF in the Policy Context

New Emphasis of WHO on Functioning, Disability and Rehabilitation

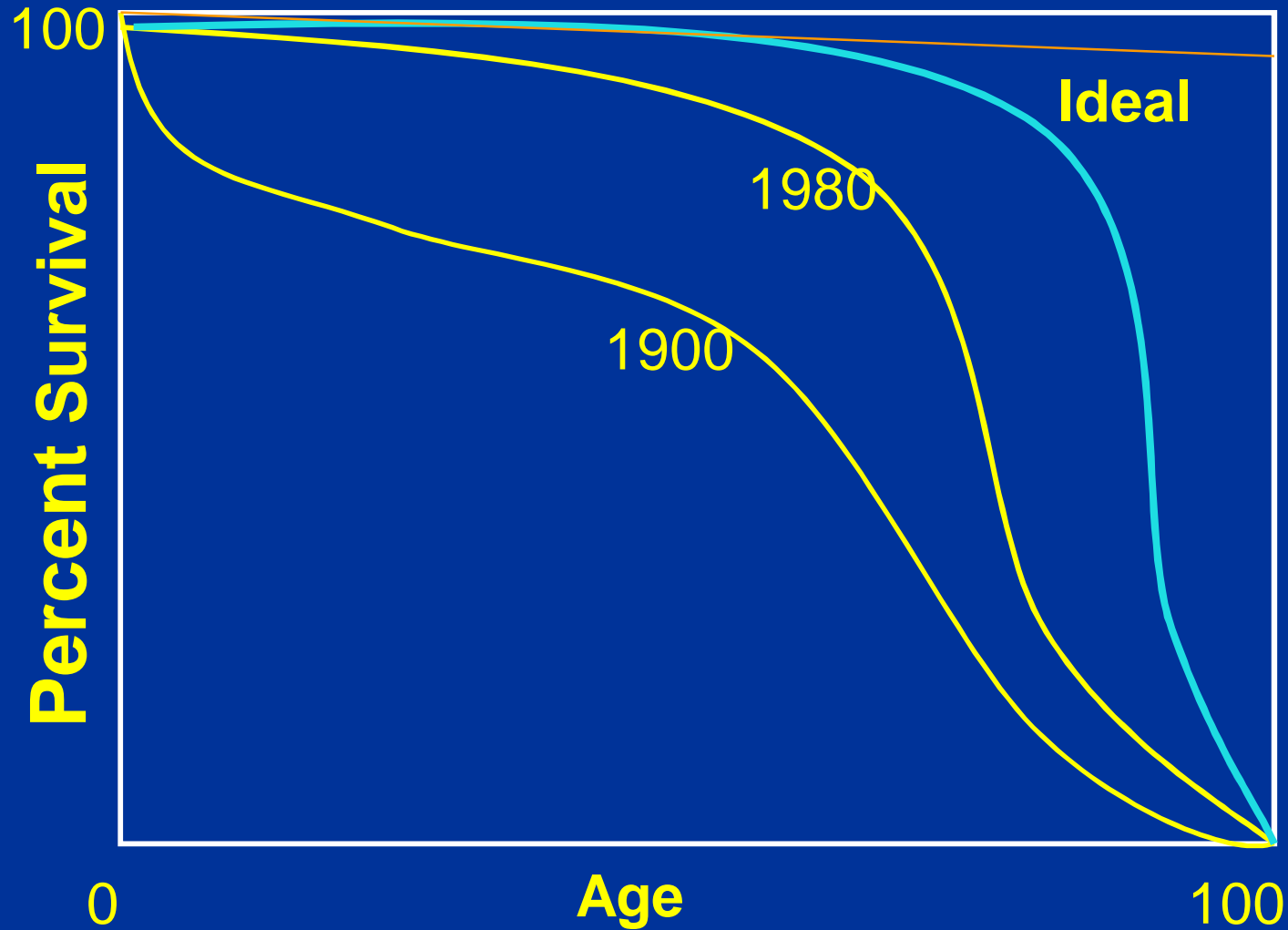
Resolutions by the
World Health Assembly

2001 International
Classification of Functioning,
Disability and Health (ICF)

2005 Disability, including
prevention, management and
rehabilitation

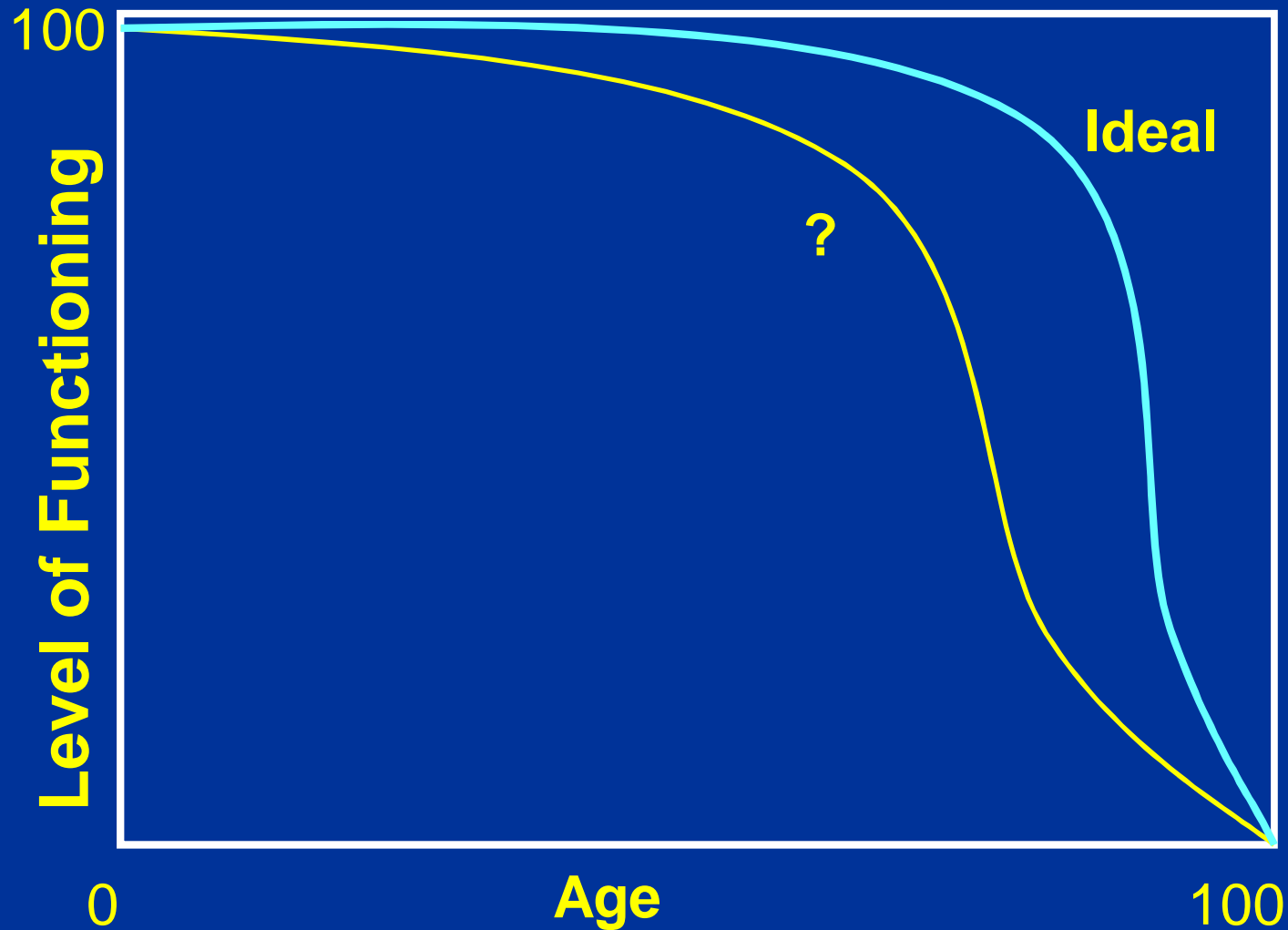


#1 Public Health Goal: Survival



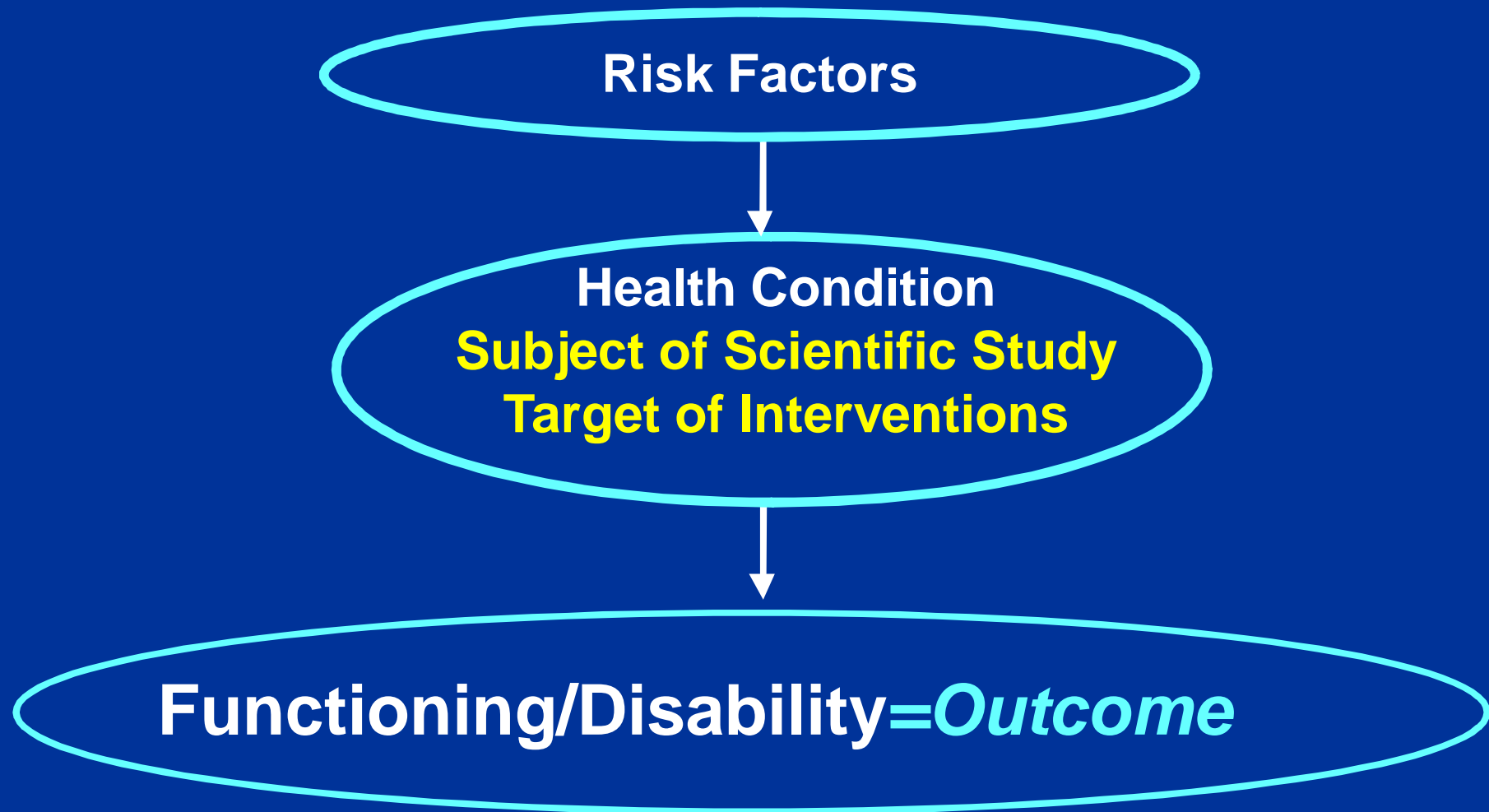
Fries JF, NEJM, 1980, 130

#2 Public Health Goal: Functioning



The Biomedical Perspective

Preventive and Curative Strategy



The Integrative Perspective

Rehabilitative and Supportive Strategy

Health Condition **ICD**
(disease, trauma, ageing, congenital anomalies)



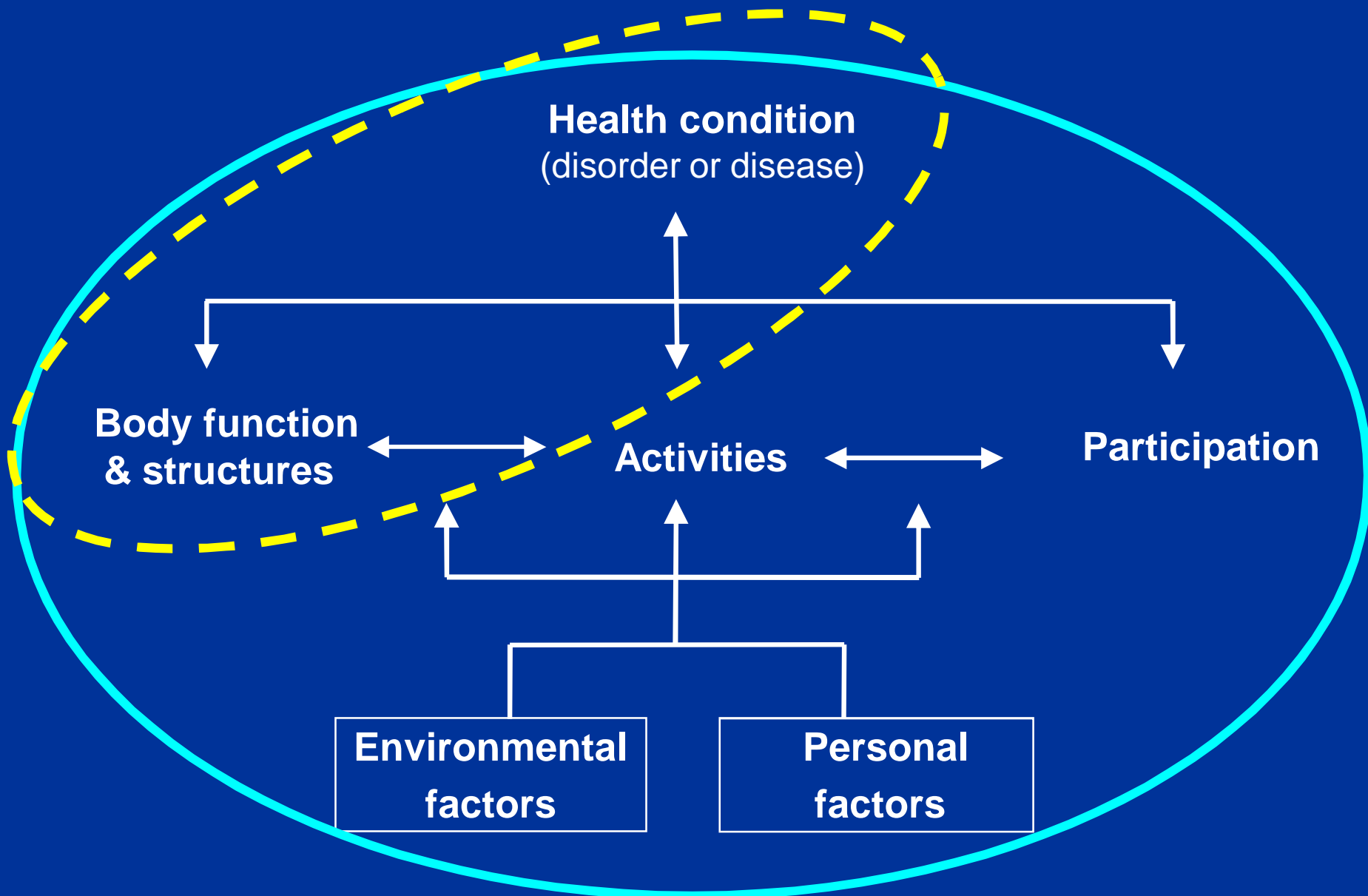
Functioning=Human Experience **ICF**
Subject of Scientific Study
Target and Outcome of Interventions



**Environmental
Factors**



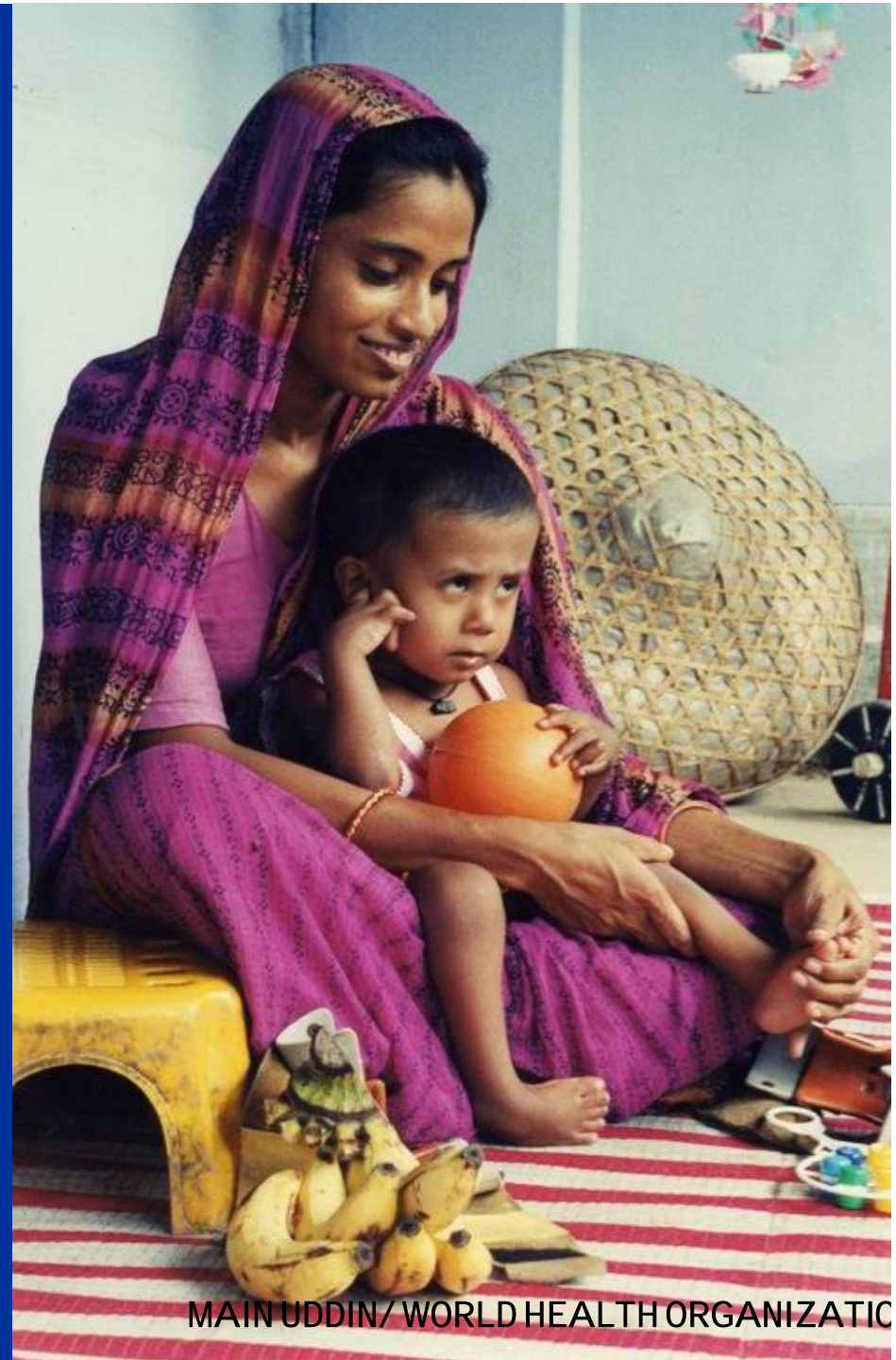
**Personal
Factors**



Partial Perspective (Biomedical Aspects) vs
Comprehensive Perspective (Integrative Model)

UN

Convention on the Rights of Persons with Disabilities



MAIN UDDIN/ WORLD HEALTH ORGANIZATION

Introduction

Who is Who

WHO's CTS Team

Responsible for
Classification,
Terminology and
Standards at WHO

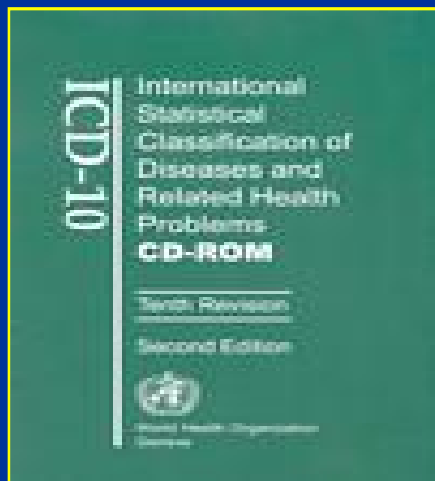
*Bedirhan Üstün and
Nenad Kostansjek*



WHO FIC CC Network

Network of the **C**ollaboration **C**enters for the **F**amily of **I**nternational **C**lassifications

4 Committees and 4 Reference Groups



FDRG

Functioning and Disability Reference Group

- 1 Principles of use, coding rules and guidelines
- 2 ICF update
- 3 ICF implications for ICD
- 4 Measurement and statistical use of the ICF
- 5 Educational materials
- 6 Ethical issues and ICF
- 7 Environmental factors
- 8 Terminology / electronic health records

ICF Research Branch

German WHO FIC CC (DIMDI)

Steering Group

Jerome Bickenbach, Alarcos Cieza, Gerold Stucki
www.icf-research-branch.org; Newsletter

Development of the ICF

Personal Factors, Ontology

Applications and Tools

ICF Core Sets and Instruments

Operationalizations of ICF Categories

Mapping / Linking Methodology

Implementation

Use of the ICF in Cochrane Reviews!

Introduction

Implementation



Home
About WHO
Countries
Health topics
Publications
Data and statistics
Programmes and projects
DAR Home
Policies
Medical care and rehabilitation
Community-based rehabilitation (CBR)
Assistive devices / technologies
Capacity building

Disability and Rehabilitation Team (DAR)

[About us](#) | [Information resources](#) | [Media centre](#) | [Related links](#)

[WHO](#) > [Programmes and projects](#)

Disability and Rehabilitation

An estimated 650 million people live with disabilities around the world

WHO's role is to enhance the quality of life, and promote and protect the rights and dignity of people with disabilities through local, national and global efforts. WHO guides and supports countries to increase awareness about disability issues, improve disability data, scale up public health programmes and community-based initiatives that promote health and rehabilitation and make assistive devices available to persons with disabilities. A six-year plan directs WHO's efforts.



WHO/Bernard Franck

- :: [WHO's key activities](#)
- :: [WHO action plan 2006-2011 \[pdf 49kb\]](#)

NEWS

8 April 2008
Task Force to mainstream disability across WHO
[Full text](#)

5 April 2008
Convention promoting and protecting the rights of people

UPCOMING EVENTS

19 - 22 May 2008
UN Convention on the Rights of Persons with Disabilities: a Call for Action on Poverty, Lack of Access and Discrimination. Addis Ababa, Ethiopia
[Leonard Cheshire Disability website](#)

HIGHLIGHTS

[The Convention on the Rights of Persons with Disabilities has entered into force Statement by the Assistant Director-General, Noncommunicable Diseases and Mental Health](#)

[World Report on Disability and Rehabilitation Concept paper \[pdf 98kb\]](#)

[WHO Newsletter on Disability and Rehabilitation: Issue No. 4 English \[pdf 1.29Mb\]](#)

PHOTO GALLERY



[Images of health and disability](#)

- **Disability statistics**
- **Eligibility determination**
- **Assignment to and evaluation of health services**
- **Professional practice**
 - Endorsements: WCPT, WFOT, ISPRM
 - Documentation: APTA – Form
- **Education**
 - Medicine and health professions
- **Research**
 - Rehabilitation Journals (Author Guidelines)
 - Grant applications
 - **Cochrane Collaboration ?! – Strong Use Case**

MHADIE

A European Coordination Action for Policy Support

Hosted by EPP-ED



**EPP-ED Hearing on
Measuring Health and Disability in Europe:
supporting Policy Development**



HIGH LEVEL CONFERENCE

European Parliament
Brussels

16 September 2008

**Write a letter with
your suggestions!**

**J Rehab Med 2007;
Vol. 39, Issue 4:
<http://jrm.medicaljournals.se/issue/39/4>**

Journal of Rehabilitation Medicine
Vol 39 2007 Supplement 46

Journal of REHABILITATION MEDICINE

ISSN 1650-1977

Official journal of the

- UEMS European Board of Physical and Rehabilitation Medicine
- European Academy of Rehabilitation Medicine
- International Society of Physical and Rehabilitation Medicine (ISPRM)

Supplement No. 46
Special issue 007

**THE ICF: A UNIFYING MODEL FOR
THE CONCEPTUALIZATION,
ORGANIZATION AND DEVELOPMENT
OF HUMAN FUNCTIONING AND
REHABILITATION RESEARCH**

Editors:

Gunnar Grimby, John Melvin and Gerold Stucki

The Non-profit Foundation for
Rehabilitation Information

www.medicaljournals.se/jrm

Overview

- Introduction into the ICF
- **Applications and Tools**
- Applying the ICF in the planning and reporting of studies

Development of ICF Core Sets *Standards and Tools for Practice, Research and Statistics*

**ICF Research Branch
WHO FIC CC Germany (DIMDI)**

**World Health Organization
&
ISPRM and other Partner Organizations
&
International Collaboration Network 51 countries,
300 centers**





b1
b130
b134
b152
b180
b1801
.

s299
s710
s720
s730
s73001
s73011
.

d170
d230
d360
d410
d415
d430
.

e110
e115
e120
e125
e135
e150
.

1424



ICF Core Sets

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

link the ICF to the ICD

The ICF is the full dictionary of functioning

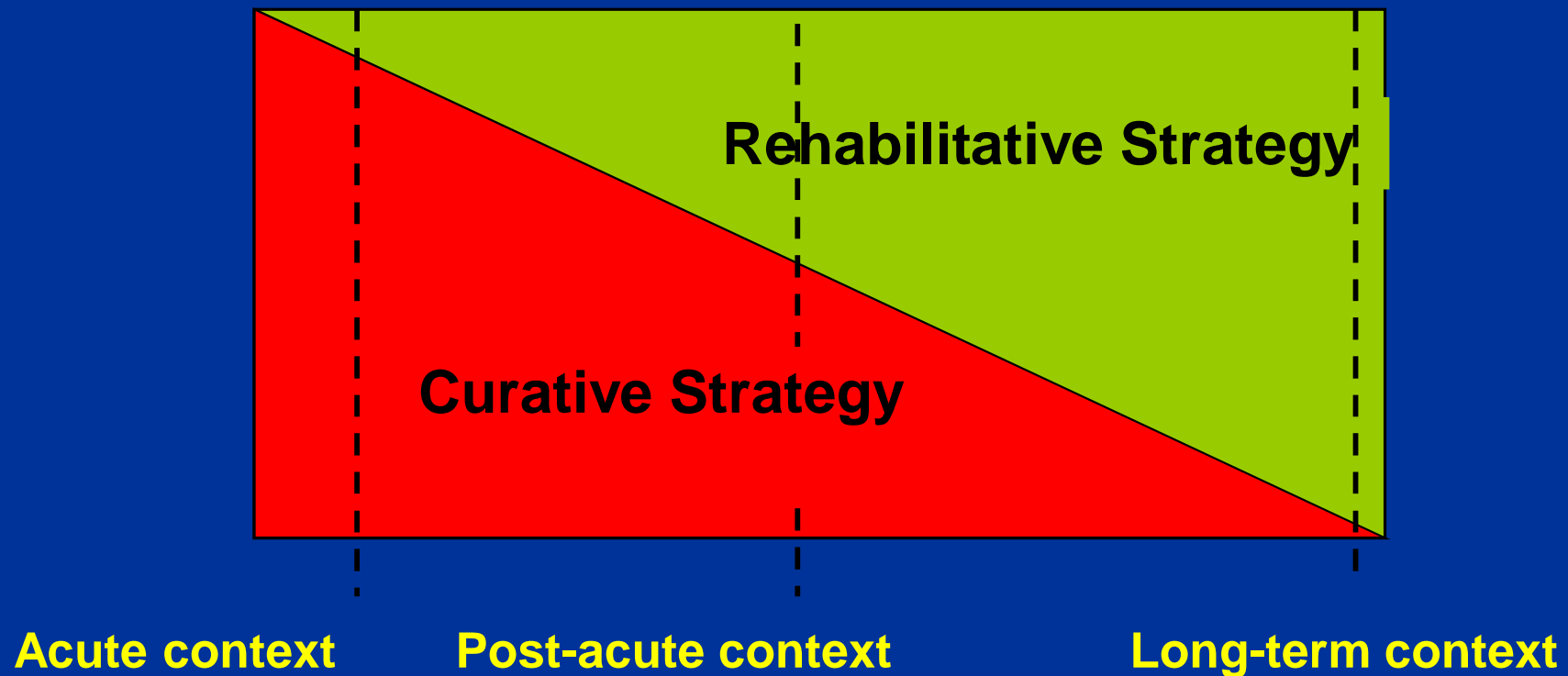
The ICF Core Sets are fractions of the ICF relevant for specific health conditions and/or a specific context

Activities & Participation – RA

- d450 Walking
- d850 Remunerative employment
- d440 Fine hand use
- d410 Changing basic body position
- d445 Hand and arm use
- d230 Carrying out daily routine
- d430 Lifting and carrying objects
- d470 *Using transportation*
- d620 Acquisition of goods and services
- d920 Recreation and leisure
- d640 Doing housework
- d540 Dressing
- d630 Preparing
- d475 Driving
- d530 Toileting
- d550 Eating

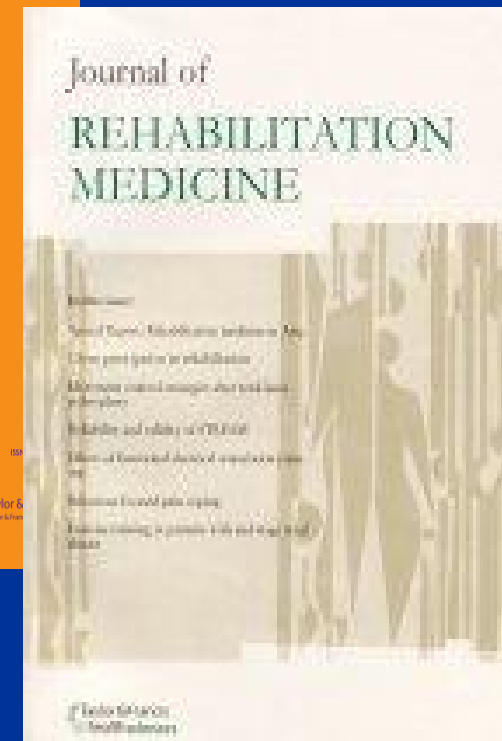
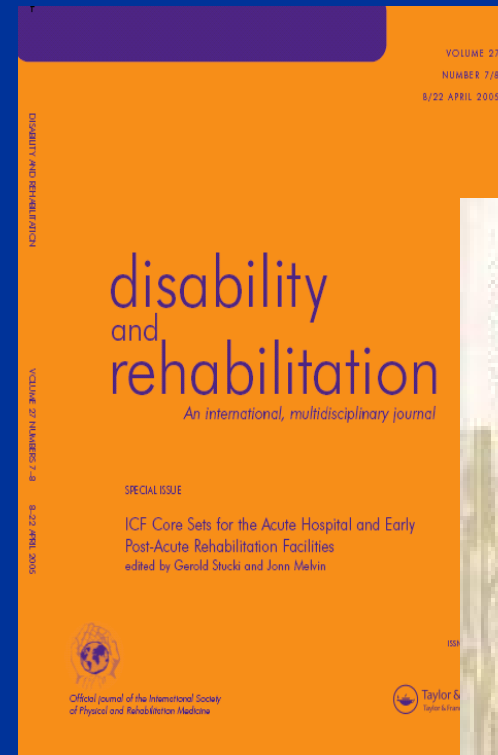
8 out of 393
Brief ICF Core Set

The Service and Care Continuum



ICF Core Sets

- Acute Context
- Post-acute context
- Long-term context (Chronic conditions)
- Generic – 2009



Development of ICF Core Sets

Preparatory Phase

Focus groups
Patient's
Perspective

Empirical
multicenter study

Experts' survey via
email

Systematic
literature review

Phase I

International ICF
consensus
conference

⇒

1st version of the
ICF Core Sets

Phase II

Broad Testing and
validation
of the 1st version
of the
ICF Core Sets

Year 1

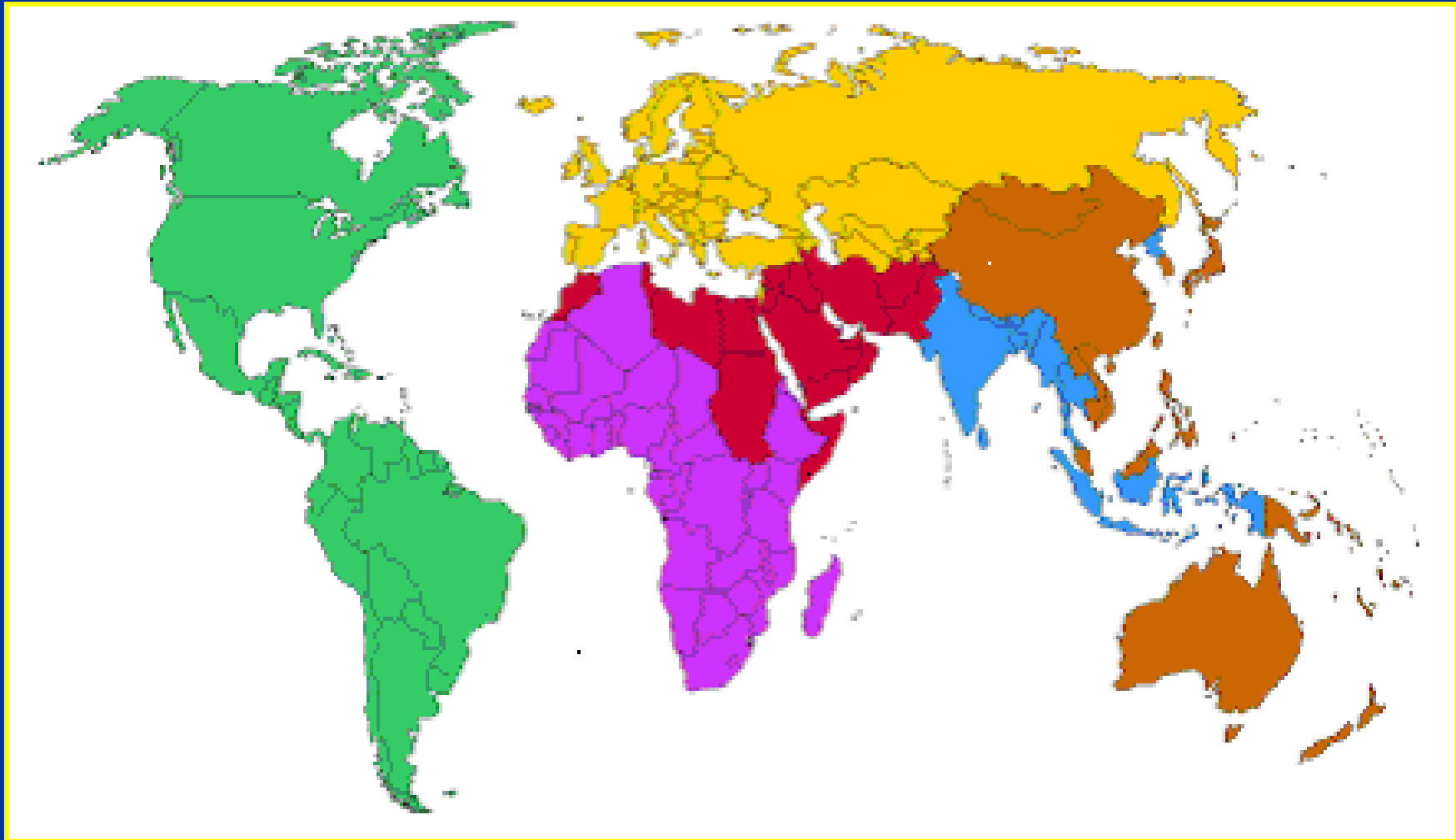
Year 2-3

Year 5



Testing and Validation

6 WHO Regions, 50 Countries, 300 Study Centers



ICF Core Sets for Chronic Conditions

Chronic widespread pain

Low back pain

Osteoarthritis

Osteoporosis

Rheumatoid arthritis

Chronic ischemic heart disease

Diabetes

Obesity

Obstructive pulmonary diseases

Depression

Breast cancer

Stroke

Current Developments

Amputation	Sydney	Australia
Ankylosing Spondylitis	Maastricht	Netherlands
Bipolar disorders	Barcelona	Spain
Hearing	Stockholm	Sweden
Migraine	Milan	Italy
Multiple Sclerosis	Valens	Switzerland
Oropharyngeal Cancer	Munich	Germany
Psoriasis Arthritis	Wellington	New Zealand
Scleroderma	Vienna	Austria
SLE	Vienna	Austria
Sleep	Helsinki	Finland
Spinal Cord Injury	Nottwil	Switzerland
Traumatic Brain Injury	Barcelona	Spain
Vision	Munich	Germany
Vocational Rehab	Bellikon	Switzerland

Generic ICF Core Set

Common Metric
applicable

*across world regions
across health conditions
along the continuum of care
over the course of life*

*Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustun BT, Stucki G.
Identification of candidate categories of the ICF for a Generic ICF Core Set
based on regression modelling
BMC Med Res Methodol. 2006; 6:36*

Overview

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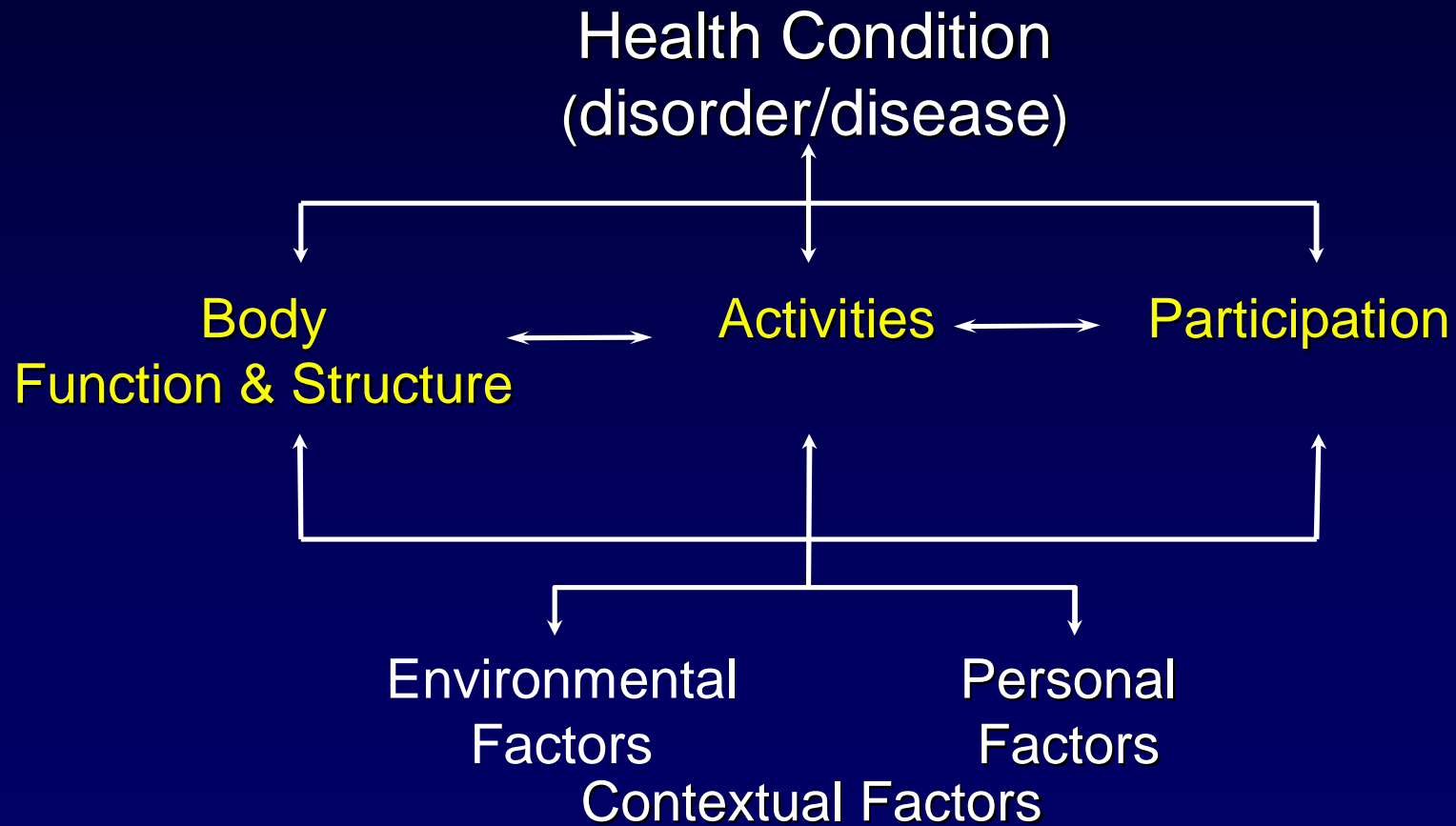
ICF in the Planning of Studies

1. What to measure – Conceptually
2. What to measure – Specifically
3. How to measure
4. Coding intervention targets and goals
5. Coding the variables of the analysis

ICF in the Planning of Studies

1. **What to measure – Conceptually**
2. What to measure – Specifically
3. How to measure
4. Coding intervention targets and goals
5. Coding the variables of the analysis

Identify the ICF components relevant for the study



The OMERACT Example

- RA Physical disability
- AS Physical function
- OA Physical functioning
- OP QoL
- SLE Health related QoL
- SCL Function and health related QOL

*Stucki G, Boonen A, Tugwell P, Cieza A, Boers M.
The ICF: A conceptual model and interface for the OMERACT process.
J Rheumatol. 2007;34(3):600-606*

What to measure - Conceptually

- Ensure communication of considered domains in a language every person in the world can immediately understand
 - patients and clients; practitioners; researchers; payers and providers; policy makers
 - across world regions
 - across professional and scientific disciplines

What to measure - Conceptually

- Ensure that all study-relevant domains are considered („study information model“)

ICF in the Planning of Studies

1. What to measure – Conceptually
- 2. What to measure – Specifically**
3. How to measure
4. Coding intervention targets and goals
5. Coding the variables of the analysis

What to measure – Specifically

Generic ICF Core Set

Minimum Standard for all studies

Ensure comparability and interpretability across all studies

ICF Core Set - Condition / Context specific

Recommended

Ensure comparability and interpretability across similar studies

Stucki G, Boonen A, Tugwell P, Cieza A, Boers M.

The ICF: A conceptual model and interface for the OMERACT process.

J Rheumatol. 2007;34(3):600-606

What to measure - Specifically

- **Identify / Select additional ICF categories**
 - not covered by the **Generic or Specific ICF Core Sets**
 - known to be determinants, confounders/covariates of study outcomes

ICF in the Planning of Studies

1. What to measure – Conceptually
2. What to measure – Specifically
- 3. How to measure**
4. Coding intervention targets and goals
5. Coding the variables of the analysis

How to measure

- Select suitable measures by mapping and comparing candidate instruments

Cieza A et. al.

ICF linking rules: an update based on lessons learned. Journal of Rehabilitation Medicine 2005;37(4):212-218

Does a candidate instrument address specified ICF categories ?

Patient-oriented instruments
Clinical tests

ICF Core Set

ICF International Classification of Functioning, Disability and Health

- b1
- b130
- b134
- b152
- b180
- b1801

- .
- .
- .
- s299
- s710
- s720
- s730
- s73001
- s73011
- .
- .
- .
- d170
- d230
- d360
- d410
- d415
- d430
- .
- .
- .
- e110
- e115
- e120
- e125
- e135
- e150
- .
- .

WHOQoL

Join Mob Mus Pain Stab Emo Eng Gait Stiff Mus Sext Slee

NHP

SF-36

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

What to measure
Finite number of categories

How to measure
Infinite number of items and instruments

1424

How to measure

- Select suitable measures by mapping and comparing candidate instruments
- **Make sure that all selected ICF categories are measured**
- **Make sure that specific categories are properly measured**
 - level of precision and detail

ICF in the Planning of Studies

1. What to measure – Conceptually
2. What to measure – Specifically
3. How to measure
4. **Coding intervention targets and goals**
5. Coding the variables of the analysis

Coding intervention targets and goals

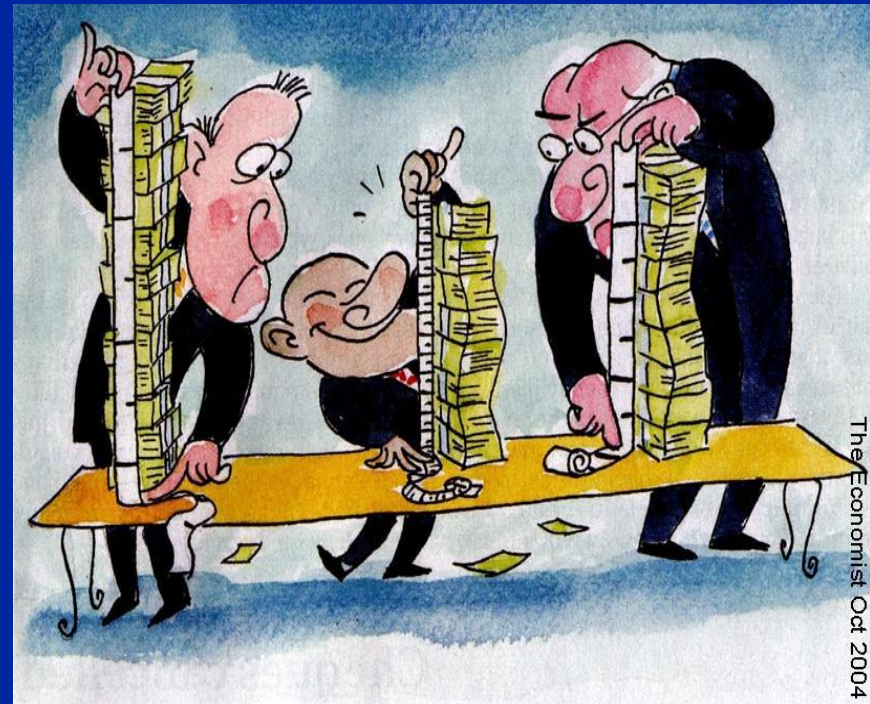
- Link the intervention targets and goals to the ICF

ICF in the Planning of Studies

1. What to measure – Conceptually
2. What to measure – Specifically
3. How to measure
4. Coding intervention targets and goals
5. **Coding the variables of the analysis**

ICF in the Reporting of Studies

- **ICF Core Sets** serve as minimal international standard what to measure and report
- The **ICF Qualifier (0-4)** serves as quantitative reference scale



ICF Qualifier

0	NO problem (none, absent, negligible...)	0-4 %
1	MILD problem (slight, low...)	5-24 %
2	MODERATE problem (medium, fair...)	25-49 %
3	SEVERE problem (high, extreme...)	50-95 %
4	COMPLETE problem (total...)	96-100 %

Example Report – Single Patient – Use of the ICF Qualifier

Assessment												
Long-term goal: Fully independence (Living, job, etc.)											0	
Program goal: Independence in Activities of daily living											0	
Cycle goal 1: d4 Mobility											1	
Cycle goal 2: d5 Self-care											0	
Cycle goal 3: d9201 Sport											2	
		ICF Qualifier									Goal value	
ICF categories		4	3	2	1	0						
b265	Touch function											
b28013	Pain in back ¹											0
b525	Defecation functions											
b620	Urination functions											
b7101	Mobility of several joints ^{1,2}											0
b7303	Muscle power functions in lower half of the body											
b735	Muscle tone functions ¹											1
b750	Motor reflex functions											
b755	Involuntary movement reaction functions ^{1,2}											0
b7603	Supportive functions of the arms - resource ^{1,2}											0.R
b7800	Sensation of muscle stiffness (M. ischiocurale) ^{1,2}											0
s810	Structure of areas of the skin - at risk											0
d410	Changing a basic body position ¹											0
d4153	Maintaining a sitting position ^{1,2}											0
d4200	Transferring oneself while sitting ¹											1
d465	Moving around using equipment ¹											1
d4751	Driving a car ¹											0
d510	Washing oneself ²											0
d520	Caring for body parts ²											0
d5300	Regulating urination ²											0
d5301	Regulating defecation ²											0
d540	Dressing ²											0
d9201	Sport ³											2
		4	3	2	1	0	1+	2+	3+	4+		
e1151	Assistive product: Chair cushion ¹											0
e1201	Assistive product mobility: wheelchair, car ¹											0
e155	Design and construction of private building											2
e5700	Social security services											4+
e5750	General social support services											3+
pf	Knowledge											2+
pf	Acceptance of disease											0

Bold letters: Intervention targets; ^{1,2,3} : Illustrate relation to Cycle goals 1,2,3

Qualifier Mapping

Example Vision Scales

ICF Severity Scale	Duration	Intensity	Frequency	Vision scale
0 = none	≤ 4%	Not noticeable	Never	18-20/20
1 = mild	< 25%	Slight alteration in functionin	Rarely	16-17/20
2 = moderate	≥ 25%	Medium alteration in function	Occasionally	12-15/20
3 = severe	> 50%	High alteration in functioning	Frequently	04-11/20
4 = complete	> 95%	Total alteration in functioning	Constantly	0-3/20

ICF in the Reporting of Studies

- Profile across ICF categories
- % of persons with a limitation vs no limitation in functioning
- Table 1: Person and condition characteristics
- Table X: Results

ICF Qualifier



**Clinical Test
Patient-oriented Instrument**

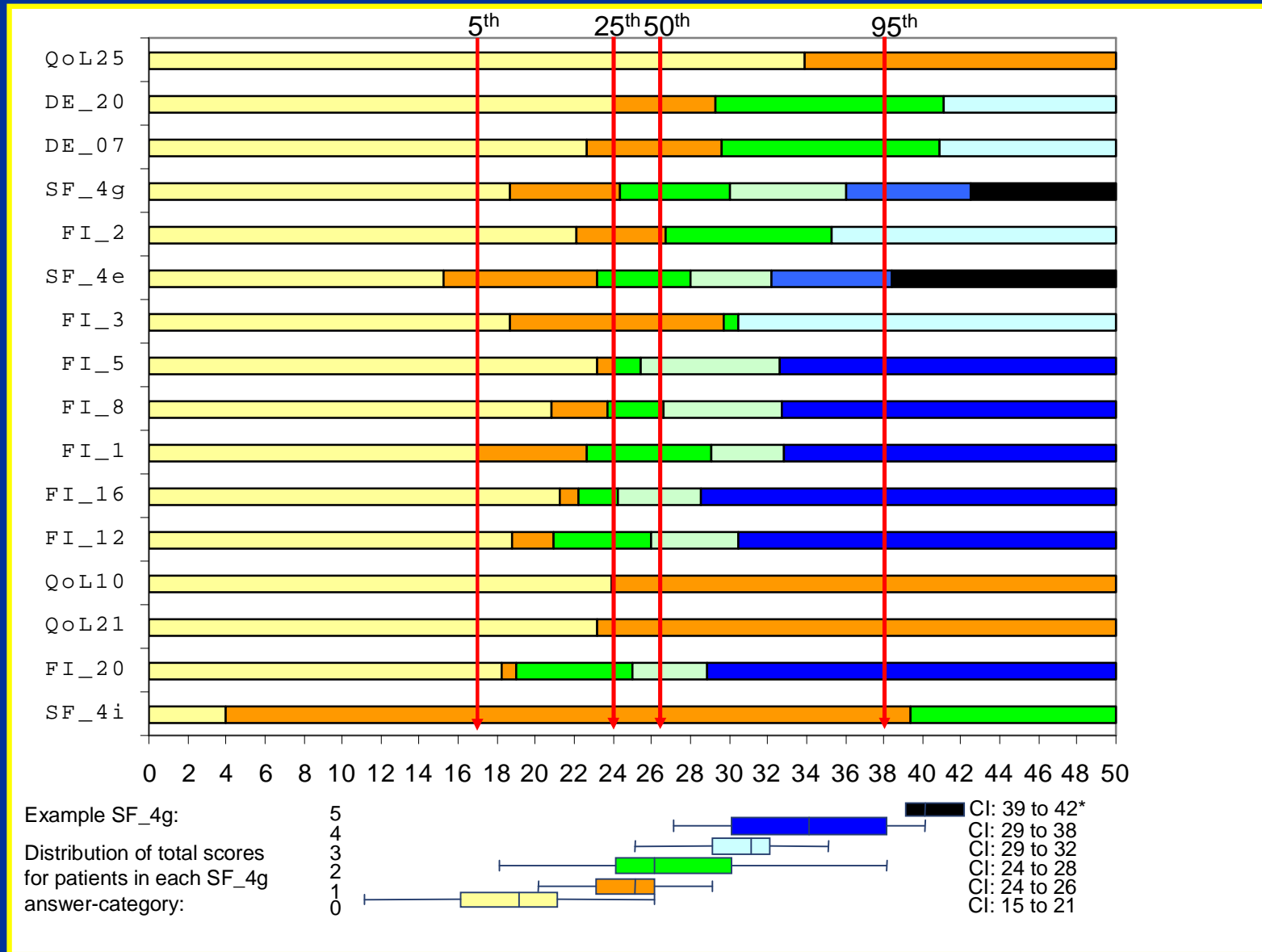
**ICF category reference scale
(Interval scale)**

Cieza A et.al.

*Items from patient-oriented instruments can be integrated
into interval scales to operationalize categories of the ICF*

J Clin Epidemiol; in press

ICF category reference scale



Threshold map ,Energy and drive functions‘

ICF in the Reporting of Studies

- Use codes of ICF categories for the reporting of results

Implementing the ICF in the planning and reporting of studies

- Editors of Journals in Rehabilitation Medicine
 - Initiative JRM and EJPRM for **Author Guidelines**
 - involvement of editors of other journals envisioned
- Cochrane Collaboration - Suggestion
 - Discussion paper inviting case examples
 - Demonstration project with invited case examples
 - Tentative Guidelines recommended for a test phase
- Grant agencies
 - Demonstration project envisioned