

ICF CORE SETS FOR RHEUMATOID ARTHRITIS

Gerold Stucki,^{1,2} Alarcos Cieza,² Szilvia Geyh,² Linamara Battistella,^{4,5} Jill Lloyd,⁶ Deborah Symmons,⁷ Nenad Kostanjsek⁸ and Jan Schouten^{9,10}

From the ¹Department of Physical Medicine and Rehabilitation, Ludwig-Maximilians-University, Munich,
²ICF Research Branch, WHO FIC Collaborating Center (DIMDI), IMBK, Ludwig-Maximilians-University, Munich, Germany,
⁴Division of Rehabilitation Medicine, University of Sao Paulo, Brazil, ⁵President Elect of the International Society of Physical and Rehabilitation Medicine (ISPRM), ⁶Department of Health Studies, Brunel University, UK, ⁷ARC Epidemiology Unit, University of Manchester, UK, ⁸Classification, Assessment, Surveys and Terminology Team, World Health Organization, Geneva, Switzerland, ⁹Department of Epidemiology, Maastricht University, Maastricht and ¹⁰Department of Ophthalmology, Maastricht University, The Netherlands

Objective: To report on the results of the consensus process integrating evidence from preliminary studies to develop the first version of a Comprehensive ICF Core Set and a Brief ICF Core Set for rheumatoid arthritis.

Methods: A formal decision-making and consensus process integrating evidence gathered from preliminary studies was followed. Preliminary studies included a Delphi exercise, a systematic review, and an empirical data collection. After training in the ICF, and based on these preliminary studies, relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds.

Results: The preliminary studies identified a set of 530 ICF categories at the second, third and fourth ICF levels with 203 categories on body functions, 76 on body structures, 188 on activities and participation, and 63 on environmental factors. Seventeen experts from 12 different countries attended the consensus conference on rheumatoid arthritis (7 physicians with at least a specialization in physical and rehabilitation medicine, 7 rheumatologists, one nurse, one occupational therapist, and one physical therapist). Altogether 96 categories (76 second-level and 20 third-, and fourth-level categories) were included in the Comprehensive ICF Core Set with 25 categories from the component body functions, 18 from body structures, 32 from activities and participation, and 21 from environmental factors. The Brief ICF Core Set included a total of 39 second-level categories, with 8 on body functions, 7 on body structures, 14 on activities and participation, and 10 on environmental factors.

Conclusion: A formal consensus process integrating evidence and expert opinion based on the ICF framework and classification led to the definition of ICF Core Sets for rheumatoid arthritis. Both the Comprehensive ICF Core Set and the Brief ICF Core Set were defined.

Key words: rheumatoid arthritis, musculoskeletal diseases, outcome assessment, quality of life, ICF.

J Rehabil Med 2004; suppl. 44: 87-93

Correspondence address: Gerold Stucki, Department of Physical Medicine and Rehabilitation, University of Munich, DE-81377 Munich, Germany.

© 2004 Taylor & Francis. *ISSN 1650–1977* DOI 10.1080/16501960410015470 *Tel:* +49 89 7095 4050. *Fax:* +49 89 7095 8836. *E-mail:* gerold.stucki@med.uni-muenchen.de

INTRODUCTION

Rheumatoid arthritis (RA) is a chronic disabling disease. The prevalence of RA in most industrialized countries varies between 0.3% and 1%, whereas in developing countries it is at the lower end of this range (1).

Patients with RA may have a shorter life expectancy (2, 3) and disability in RA patients may be serious. It frequently affects patients in their most productive years and thus disability results in a major economic loss. In a comprehensive review it was found that at least 75% of the total costs of this illness are due to the indirect costs of the relatively high work disability rate. Moreover, the range of costs in the studies is remarkably similar, with direct costs of between \$4 and \$6000 per year in constant dollars and indirect costs of between \$12 and \$24,000 (4).

The RA disease process may lead to impairments in functions and structures of the body including musculoskeletal pain, fatigue, joint stiffness, joint swelling, loss of range of motion, muscular weakness, and joint damage. Such impairments may lead to limitations of physical activities (5) and restrictions in participation (6).

The relationships between impairments, activity limitations and participation restrictions can in turn be influenced by the disease process itself and by contextual factors including social support and job demands (6).

Current recommendations regarding assessment of the disease and disease consequences, for example in trials of anti-rheumatic drugs include the recommendation to measure function mainly referring to physical function (7). Accordingly, measures of function such as the Health Assessment Questionnaire (HAQ) (8), the Arthritis Impact Measurement Scales (AIMS) (9), or the McMaster Toronto Arthritis Patient Preference Disability Questionnaire (MACTAR) (10) are increasingly used in RA studies (11).

However, condition-specific measures, arguably with the

exception of the AIMS (9, 12), which can be considered a generic instrument specific for RA, typically cover only selected aspects of the whole patient experience associated with RA. Also, the measures vary quite considerably regarding the concepts included (13). It is also important to recognize that these measures have been developed to measure the disease consequences but not to measure functioning and health not only associated with the disease process of RA but also with environmental and personal factors (14). Therefore, these measures may not be ideal for rehabilitation where functioning and health is not primarily an outcome but the starting point in the diagnosis or the assessment of a patient.

It would therefore be valuable for teaching, clinical practice and research to define what should be measured to represent comprehensively the experience of patients with RA. To achieve this goal, we need a comprehensive framework and classification, which can serve as a universal language understood by health professionals, researchers, policymakers, patients, and patient organizations.

With the approval of the new International Classification of Functioning, Disability and Health (ICF, formerly ICIDH-2 http://www.who.int/classification/icf) (15), we can now rely on a globally agreed framework and classification to define the typical spectrum of problems in functioning of patients with RA. For practical purposes and in line with the concept of condition-specific health status measures it would thus seem most helpful to link specific conditions or diseases to salient ICF categories of functioning (16). Such generally-agreed-on lists of ICF categories can serve as Brief ICF Core Set to be rated in all patients included in a clinical study with RA or as Comprehensive ICF Core Set to guide multidisciplinary assessments in patients with RA. The objective of this paper is to report on the results of the consensus process integrating evidence from preliminary studies to develop the first version of the ICF Core Sets for RA, the Comprehensive ICF Core Set and the Brief ICF Core Set.

METHODS

The development of the ICF Core Sets for RA involved a formal decision-making and consensus process integrating evidence gathered from preliminary studies including a Delphi exercise (17), a systematic review (18), and an empirical data collection, using the ICF checklist (19). After training in the ICF and based on these preliminary studies relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds. Seventeen experts (7 physicians with at least a specialization in physical and rehabilitation medicine, 7 rheumatologists, 1 nurse, 1 occupational therapist, and 1 physical therapist) from 12 different countries attended the consensus process for RA. The decision-making process for RA involved 3 working groups with 4–5 experts each. The process was facilitated by the condition co-ordinator for RA (JS) and the 3 working-group leaders (LB, JL, DS).

The tables on the preliminary studies presented to the participants included 530 ICF categories (203 on *body functions*, 76 on *body structures*, 188 on *activities and participation*, and 63 on *environmental functions*) at the second, third, and fourth levels.

RESULTS

Tables I–IV show the ICF categories included in the Comprehensive ICF Core Set. Table V shows the ICF categories included in the Brief ICF Core Set, as well as the percentage of experts willing to include the named category in the Brief ICF Core Set. The total number of categories in the Comprehensive ICF Core Set is 96, and the total number of categories included in the Brief ICF Core Set is 39. In the component *body functions* and *body structures* 8 categories at the third and 12 categories at the fourth level were included in the Comprehensive ICF Core Set, respectively. No categories at the third and fourth levels were included in the Brief ICF Core Set.

Comprehensive ICF Core Set

The 96 categories of the Comprehensive ICF Core Set are made up of 25 (26%) categories from the component *body functions*, 18 (19%) from the component *body structures*, 32 (33%) from the component *activities and participation*, and 21 (22%) from the component *environmental factors*.

Fifteen of the 25 categories of the component *body functions* are at the second, 5 at the third and 5 at the fourth level of the classification. The 15 categories at the second level represent 13% of the total number of ICF categories at the second level in this component. Most of the *body-functions* categories belong to

Table I. International Classification of Functioning, Disability and Health (ICF) – categories of the component body functions included in the Comprehensive ICF Core Set for rheumatoid arthritis

ICF code		ICF category title	
2nd	3rd		
b130		Energy and drive functions	
b134		Sleep functions	
b152		Emotional functions	
b180		Experience of self and time functions	
	b1801	Body image	
b280		Sensation of pain	
	b2800	Generalized pain	
b2801		Pain in body part	
	b28010	Pain in head and neck	
	b28013	Pain in back	
	b28014	Pain in upper limb	
	b28015	Pain in lower limb	
	b28016	Pain in joints	
b430		Haematological system functions	
b455		Exercise tolerance functions	
b510		Ingestion functions	
b640		Sexual functions	
b710		Mobility of joint functions	
	b7102	Mobility of joints generalized	
b715		Stability of joint functions	
b730		Muscle power functions	
b740		Muscle endurance functions	
b770		Gait pattern functions	
b780		Sensations related to muscles and movement functions	
b7800		Sensation of muscle stiffness	

Table II. International Classification of Functioning, Disability and Health (ICF) – categories of the component body structures included in the Comprehensive ICF Core Set for rheumatoid arthritis

ICF code		ICF category title	
2nd	3rd		
s299		Eye, ear and related structures, unspecified	
s710		Structure of head and neck region	
s720		Structure of shoulder region	
s730		Structure of upper extremity	
	s73001	Elbow joint	
	s73011	Wrist joint	
	s7302	Structure of hand	
s73021		Joints of hand and fingers	
s73022		Muscles of hand	
s750		Structure of lower extremity	
	s75001	Hip joint	
	s75011	Knee joint	
	s7502	Structure of ankle and foot	
s760		Structure of trunk	
	s7600	Structure of vertebral column	
	s76000	Cervical vertebral column	
s770		Additional musculoskeletal structures related to movement	
s810		Structure of areas of skin	

Table III. International Classification of Functioning, Disability and Health (ICF) – categories of the component activities and participation included in the Comprehensive ICF Core Set for rheumatoid arthritis

ICF code	ICF category title			
d170	Writing			
d230	Carrying out daily routine			
d360	Using communication devices and techniques			
d410	Changing basic body position			
d415	Maintaining a body position			
d430	Lifting and carrying objects			
d440	Fine hand use			
d445	Hand and arm use			
d449	Carrying, moving and handling objects, other			
	specified and unspecified			
d450	Walking			
d455	Moving around			
d460	Moving around in different locations			
d465	Moving around using equipment			
d470	Using transportation			
d475	Driving			
d510	Washing oneself			
d520	Caring for body parts			
d530	Toileting			
d540	Dressing			
d550	Eating			
d560	Drinking			
d570	Looking after one's health			
d620	Acquisition of goods and services			
d630	Preparing meals			
d640	Doing housework			
d660	Assisting others			
d760	Family relationships			
d770	Intimate relationships			
d850	Remunerative employment			
d859	Work and employment, other specified and			
	unspecified			
d910	Community life			
d920	Recreation and leisure			

Table IV. International Classification of Functioning, Disability and Health (ICF) – categories of the component environmental factors included in the Comprehensive ICF Core Set for rheumatoid arthritis

ICF code	ICF category title		
e110	Products or substances for personal consumption		
e115	Products and technology for personal use in daily living		
e120	Products and technology for personal indoor and outdoor mobility and transportation		
e125	Products and technology for communication		
e135	Products and technology for employment		
e150	Design, construction and building products and		
	technology of buildings for public use		
e155	Design, construction and building products and		
	technology of buildings for private use		
e225	Climate		
e310	Immediate family		
e320	Friends		
e340	Personal care providers and personal assistants		
e355	Health professionals		
e360	Other professionals		
e410	Individual attitudes of immediate family members		
e420	Individual attitudes of friends		
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members		
e450	Individual attitudes of health professionals		
e460	Societal attitudes		
e540	Transportation services, systems and policies		
e570	Social security services, systems and policies		
e580	Health services, systems and policies		

chapter 7 neuromusculoskeletal and movement-related functions (8 categories). Only 2 of those categories are at the third level of this classification, namely b7102 mobility of joints generalized and b7800 sensation of muscle stiffness. Chapter 2 sensory functions and pain is also represented by 8 categories, whereas only b280 sensation of pain is at the second level, and the remaining 7 categories are specifications of b280 sensation of pain at the third and fourth levels. Chapter 1 mental functions is represented by 5 categories, 1 of which, b1801 body image, is at the third level of the classification. Chapter 4 functions of the cardiovascular, haematological, immunological and respiratory systems is represented by 2 categories, chapter 5 functions of the digestive, metabolic and endocrine systems, and chapter 6 genitourinary and reproductive functions are represented by 1 category at the second level, respectively.

Eight of the 18 categories of the component *body structures* are at the second, 3 categories at the third and 7 at the fourth level of the classification. The 8 categories at the second level represent 14% of the total number of ICF categories at the second level in this component. Sixteen of the 18 categories of the *body-structures* categories belong to chapter 7 *structures related to movement*, whereas 5 categories are specifications at the third and fourth level of the second-level category s730 *structure of upper extremity*, 3 are specifications at the third and fourth levels of s750 *structure of lower extremity* and 2 are specifications at the third and fourth levels of s760 *structure of trunk*.

The 32 categories of the component activities and partici-

Table V. International Classification of Functioning, Disability and Health (ICF) – categories included in the Brief ICF Core Set for rheumatoid arthritis and percentage of experts willing to include the named category in the Brief ICF Core Set. 50% represents a preliminary cut-off. >50% is shown in bold typeface

		ICF	
ICF component	%	code	ICF category title
Body functions	100 100 85 70	b280 b710 b730 b455	Sensation of pain Mobility of joint functions Muscle power functions Exercise tolerance functions
	65	b780	Sensations related to muscles and movement functions
	15	b770	Gait pattern functions
	5 5	b134 b740	Sleep functions Muscle endurance functions
Body structures	100 100 85	s750 s730 s710	Structure of lower extremity Structure of upper extremity Structure of head and neck region
	70	s720	Structure of shoulder region
	15	s810	Structure of areas of skin
	10	s760	Structure of trunk
	5	s299	Eye, ear and related structures, unspecified
Activities and	90	d450	Walking
participation	<u>90</u>	d850	Remunerative employment
	75 75	d440	Fine hand use
	75 65	d410 d445	Changing basic body position Hand and arm use
	65	d230	Carrying out daily routine
	45	d430	Lifting and carrying objects
	40	d470	Using transportation
	30	d540	Dressing
	30	d510	Washing oneself
	30	d920	Recreation and leisure
	25	d770	Intimate relationships
	10	d859	Work and employment, other specified and unspecified
	5	d550	Eating
Environmental factors	92 92	e310 e580	Immediate family Health services, systems and
	69	e355	policies Health professionals
	69	e115	Products and technology for personal use in daily living
	62	e570	Social security services, systems and policies
	38	e155	Design, construction and building products and technology of
	23	e540	buildings for private use Transportation services, systems and policies
	23	e120	and policies Products and technology for personal indoor and outdoor
	15	e110	mobility and transportation Products or substances for personal consumption
	8	e150	Design, construction and building products and technology of
			buildings for public use

pation are all at the second level of the ICF hierarchy. They represent 27% of the total number of ICF categories at the second level in this component. Most of the *activities and participation* categories belong to chapter 4 *mobility* (12 categories) and chapter 5 *self-care* (7 categories). However, all 9 chapters of this component are represented in the Comprehensive ICF Core Set. Chapter 6 *domestic life* is represented by 4 categories, chapter 7 *interpersonal interactions and relationships*, chapter 8 *major life areas*, and chapter 9 *community*, *social and civic life* by 2 categories, respectively. Chapter 1 *learning and applying knowledge*, chapter 2 *general tasks and demands*, and chapter 3 *communication* are all represented by 1 category.

The 21 categories of the component *environmental factors* are all at the second level of the ICF hierarchy. They represent 28% of the total number of ICF categories at the second level of this component. Most of the *environmental factors* categories belong to chapter 1 *products and technology* (7 categories), chapter 3 *support and relationships* (5 categories) and chapter 4 *attitudes* (5 categories). However, all 5 chapters of this component are represented in the Comprehensive ICF Core Set. Chapter 5 *services, systems and policies* is represented by 3 categories and chapter 2 *natural environment and human-made changes to the environment* is represented by the category e225 *climate*.

Brief ICF Core Set

With respect to the categories at the second level contained in the Comprehensive ICF Core Set, the Brief ICF Core Set includes 8 (53%) categories from the component *body functions*, 7 (88%) from *body structures*, 14 (44%) from *activities and participation*, and 10 (48%) from *environmental factors*.

The 8 categories of the component *body functions* represent 7%, the 7 categories of the component *body structures* 13%, the 14 categories of the component *activities and participation* 12% and the 10 categories of the component *environmental factors* 14% of the total number of ICF categories at the second level in their respective components.

All ICF categories taken into account in the final decision process are presented in Table V. However, a preliminary cutoff was established at 50% to reflect majority opinion.

DISCUSSION

The formal consensus process integrating evidence from preliminary studies and expert knowledge at the first ICF Core Sets conference led to the definition of the Brief ICF Core Set and the Comprehensive ICF Core Set for multidisciplinary assessment in patients with RA.

The Comprehensive ICF Core Set for RA is one of the largest ICF Core Sets developed for the 12 most burdensome chronic conditions. The fact that 96 categories covering all components and covering all 9 chapters of the component *activities and participation* were included in the Comprehensive ICF Core Set reflects the multiple and important impairments, limitations and restrictions of activity and participation involved, as well as the numerous interactions with environmental factors.

Consistent with the main organ systems involved in RA, neuromusculoskeletal and movement-related functions

(chapter b7), as well as to *structures related to movement* (chapter s7) are broadly covered.

Pain is the leading symptom in patients with RA and one of the key outcome domains recommended by OMERACT (7). Accordingly, the second-level ICF category b280 sensation of pain was selected into the Brief ICF Core Set. Since pain in RA is typically present in the different body parts of the locomotor system and may specifically involve the joints, and because comprehensive multidisciplinary management of pain relies on an in-depth assessment, a number of categories at the third-level addressing the different regions and the joints were included in the Comprehensive ICF Core Set. Consistent with this differentiated selection of pain categories, the consensus panel also selected the categories for the component body structures in great depth. In addition to the most important medium and large size joints, also the fourth-level categories joints of hand and fingers (s73021) and muscles of hand (s73022) were included in order to address the important involvement of the small joints. To address the potentially lethal changes of the cervical vertebral column (s76000) this category of the fourth level was also included.

Closely related to pain, but clearly a distinct symptom, is stiffness and particularly "morning stiffness". While stiffness may not add additional information in clinical trials and therefore was not included in the recommendation by OMERACT (7), it is the first element of the now preferred definition of RA suggested by the American College of Rheumatology (20) and has been included in some RA-specific measures, such as the self-administered Rheumatoid Arthritis Disease Index (21). Morning stiffness may importantly hamper activities of daily living. Due to morning stiffness, which may last for hours, activities of daily living may become impossible, difficult or may take much more time. Accordingly, the assessment of stiffness is an important aspect in the multidisciplinary assessment in rheumatological rehabilitation and therefore sensation of muscle stiffness (b7800) was included in the Comprehensive ICF Core Set.

Patients with RA may also suffer from problems related to *energy and drive functions* (b130), *sleep functions* (b134) and *emotional functions* (b152), which are not specific to RA but typical for a systemic inflammatory condition. Therefore, these categories were included in the Comprehensive ICF Core Set. Despite improved but often extensive treatment options, which unfortunately are only available to selected patients, RA may still lead to the deformity of small, medium size and large joints as well as atrophy of muscles. Together with body changes related to medication effects, e.g. corticosteroid intake, this often leads to a significantly altered *body image* (b1801) and *self-experience* (b180) over time which need to be addressed in a multidisciplinary assessment.

Some of the experts felt that co-ordination represented by the ICF category b760 *control of voluntary movement functions* should be included in the ICF Core Sets. Since the definition is relating more to neurological aspects not primarily relevant for patients with RA and since other categories including *gait* *pattern function* (b770) may represent the issue, b760 *control of voluntary movement functions* was not included in the Comprehensive ICF Core Set.

Together with pain, limitations and restrictions in *activities and participation* may be most relevant to patients with RA. This is reflected by the fact that this component is represented by 32 categories addressing key issues for patients with RA, including independence in activities of daily living, and participation in work and leisure activities.

Closely related to the changes of body functions and alterations of body structures, activities participation of the hand and arm were a major point of discussion. The expert panel included the categories fine hand use (d440), hand and arm use (d445), as well as lifting and carrying objects (d430), which were considered related but all distinct and relevant. The fact that all these categories are not only selected into the Comprehensive ICF Core Set but also into the Brief ICF Core Set reflects the importance of the abilities relating to hand, arm and upper extremity in patients with RA. In a similar discussion about the redundancy of categories concerning mobility, a number of related categories, including walking (d450), moving around (d455), moving around in different locations (d460), moving around using equipment (d465) using transportation (d470), and driving (d475) were all included in the Comprehensive ICF Core Set. However, only walking (d450) and using transportation (d470) were selected into the Brief ICF Core Set.

The ICF category d240 handling stress and other psychological demands was discussed in the context of the important psychosocial factors that may influence the RA disability process. However, the expert panel decided that emotional functions (b152) sufficiently represent the major aspects of this issue. In addition, the category d570 looking after one's health was included in the Comprehensive ICF Core Set, referring for example to the importance of patients' compliance with medical advice or managing diet. Since a loss of productivity is a major problem in RA, the experts selected d850 remunerative employment not only into the Comprehensive ICF Core Set, but also into the Brief ICF Core Set.

It is significant that 21 categories representing 22% of the categories of the Comprehensive ICF Core Set belong to the component *environmental factors*. The experts selected categories for the ICF Core Sets to address 4 main topics of special importance with regard to the influence of *environmental factors* on patients' functioning. These 4 topics were the availability, the effects, and the quality of treatment and healthcare services, issues related to work disability, features of the home environment and social support.

The availability, the effects, and the quality of treatment and healthcare services clearly have an essential impact on functioning in patients with RA. The expert panel considered ICF categories form various chapters as related to this important issue. Both, *health care services, systems and policies* (e580) as well as *social security services, systems and policies* (e570) may be seen as responsible for creating the terms and conditions for the availability and the quality of RA care. Both categories were included therefore not only in the Comprehensive ICF Core Set, but also in the Brief ICF Core Set. In particular, the knowledge and experience of specialists in the field of RA may have great influence on patients' outcome (22-24). Thus, categories such as health professionals (e355) and attitudes of health professionals (e450) were included in the Comprehensive ICF Core Set. Issues related to the effects of drug treatment in RA were subject to controversial discussions during the consensus conference. While non-steroidal anti-inflammatory drugs reduce pain and inflammation, and disease-modifying anti-rheumatic drugs in addition may reduce tissue damage, the toxicity of these substances remains a serious problem (25). Moreover, the availability and also the costs of medication were points of discussion. The low agreement on the inclusion of the ICF category e110 products or substances for personal consumption for the Brief ICF Core Set can thereby be explained.

As patients with RA often have to deal with consequences of work disability (26), experts considered various environmental factors as important barriers or facilitators with regard to patients' employment status. The experts took into account specific assistive devices, the accessibility of buildings, and the possibility of reaching the place of work by means of transportation as key environmental factors having considerable impact on RA patients' ability to work. Accordingly, the ICF categories e135 products and technology for employment, e150 design, construction and building products and technology of buildings for public use, e120 products and technology for personal indoor and outdoor mobility and transportation and e540 transportation services, systems and policies were included in the Comprehensive ICF Core Set. Except for the ICF category e135, these categories were also selected for the Brief ICF Core Set for RA.

Features of the home environment (e155 design, construction and building products and technology of buildings for private use) and assistive devices described by the category e115 products and technology for personal use in daily living were chosen by the expert panel to be included in both ICF Core Sets. Adaptations in patients' homes and aids are often referred to in studies on the financial burden of RA (27, 28), but can also serve as indicators for disability outcome (29).

Finally, the experts selected categories for the ICF Core Sets that address the essential issue of social support and its influence on RA patients' functioning (23, 24, 30, 31). Altogether 10 categories from the ICF chapters e3 *support and relationships* and e4 *attitudes* entered the Comprehensive ICF Core Set, reflecting the experts conviction that the patients' social context has a strong impact on RA-related functioning and health. Two categories were then included in the Brief ICF Core Set, support by the *immediate family* (e310) having the highest rate of expert agreement in the component of the *environmental factors*, but also the category *health professionals* (e355), already mentioned before, was included in the Brief ICF Core Set. However, no category from the chapter e4 *attitudes* was selected for the Brief ICF Core Set.

It is interesting to note that the panel of experts did not identify problems of patients not contained in the ICF. This emphasises the comprehensiveness and the validity of the ICF classification, which was based on a painstaking international development process. The Comprehensive ICF Core Set for multidisciplinary assessment and the Brief ICF Core Set in RA as disease specific adaptations of the ICF may be used in future to facilitate clinicians and researchers efforts to incorporate a patient-oriented, multilevel comprehensive view in their everyday practice.

The organizers of the consensus process took great care in the selection of the experts and were successful in recruiting 17 experts with different professional backgrounds and from 8 different countries. Nevertheless, the results of any consensus process may differ with different groups of experts. This emphasizes the importance of the extensive validation of this first version of the ICF Core Sets from the perspectives of different professions and in different countries. The first version of the ICF Core Sets will also be tested from the patients' points of view and in different clinical settings. Thus, the extent to which the level of specification of the categories selected suffices to describe the prototypical spectrum of problems in functioning of patients with RA (e.g. b455 exercise tolerance functions instead of b4552 fatigability) will be addressed. It is important to note that this first version of the ICF Core Sets is only recommended for validation or pilot studies.

The testing and validation of the Comprehensive ICF Core Set will show whether the currently-selected categories are frequent and relevant enough to be maintained. Similarly, some ICF categories currently included in the Comprehensive ICF Core Set, but not in the Brief ICF Core Set, may be selected in the final Brief ICF Core Set after testing. This will be the case, if they are extremely frequent and also if they are of particular relevance from the patients' perspective. An example is *energy and drive functions*, which is included in the Comprehensive ICF Core Set, but not in the Brief ICF Core Set. *Energy and drive functions* was identified at OMERACT VI as an area of particular importance to patients with RA (32).

ACKNOWLEDGEMENTS

We thank the Bone and Joint Decade, the European League against Rheumatism (EULAR), the EU Monitor Project and OMERACT for their support for this project.

We are most grateful for the contributions made by the following experts attending the conference: Daina Andersone, Daniela Fuchs, Edwin Hanada, Mieke Hazes, Ofer Keren, Klaus Leistner, Leonard Li, Yu Mengxue, Girish Mody, Lucien Portenier, Carlos Eduardo G. Rangel, Susanne Rauh, Helga Streibl and Wang Yi-Peng.

REFERENCES

 WHO Technical Report Series, No. 919. The burden of musculoskeletal conditions at the start of the new millenium. Geneva: World Health Organization; 2003.

- Wolfe F, Mitchell DM, Sibley JT, Fries JF, Bloch DA, Williams CA, et al. The mortality of rheumatoid arthritis. Arthritis Rheum 1994; 37: 481–494.
- Grimstadt-Kvalvik A. Mortality in rheumatoid arthritis. Rheumatol Eur 1996; 25: 9–14.
- Yelin E, Wanke L. An assessment of the annual and long-term costs of rheumatoid arthritis. Arthritis Rheum 1999; 42: 1209–1218.
- Stucki G, Brühlmann P, Stucki S, Michel BA. Isometric muscle strength is an indicator of self-reported physical functional disability in patients with rheumatoid arthritis. Br J Rheumatol 1998; 37: 643–648.
- Fransen J, Uebelhart D, Stucki G, Langenegger T, Seitz M, Michel BA. The ICIDH-2 as a framework for the assessment of functioning and disability in rheumatoid arthritis. Ann Rheum Dis 2002; 61: 225–231.
- Boers M, Tugwell P, Felson DT, Van Riel PL, Kirwan JR, Edmonds JP, et al. World Health Organisation and international league of associations for rheumatology core endpoints for symptom modifying antirheumatic drugs in rheumatoid arthritis clinical trials. J Rheumatol 1994; 41: 86–89.
- Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. Arthritis Rheum 1980; 23: 137–145.
- Meenan RF, Mason JH, Anderson JJ, Guccione AA, Kazis LE. AIMS 2. Arthritis Rheum 1992; 35: 1–10.
- Tugwell P, Bombardier C, Buchanan WW, Goldsmith CH, Grace E. The MACTAR Questionnaire – an individualized functional priority approach for assessing improvement in physical disability in clinical trials in rheumatoid arthritis. J Rheumatol 1987; 14: 446–451.
- Fransen J, Stucki G. Current use of health status instruments in randomised controlled trials on patients with rheumatoid arthritis. Dis Manage Health Outcomes 1998; 3: 271–277.
- Meenan RF, Gertman PM, Mason JH. Measuring health status in arthritis: the Arthritis Impact Measurement Scales. Arthritis Rheum 1980; 23: 146–152.
- Stucki G, Sigl T. Assessment of the impact of disease on the individual. Best Pract & Res Clin Rheumatol 2003; 17: 451–473.
- 14. Stucki G, Ewert T, Cieza A. Value and application of the ICF in rehabilitation medicine. Disabil Rehabil 2002; 24: 932–938.
- World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: WHO; 2001.
- Stucki G, Cieza A, Ewert T, Konstanjsek N, Chatterji S, Bedirhan Ustun T. Application on the International Classification of Functioning, Disability and Health (ICF) in clinical practice. Disabil Rehabil 2002; 24: 281–282.
- Weigl M, Cieza A, Andersen A, Kollerits B, Amann E, Füssl M, Stucki G. Identification of the most relevant ICF categories in patients with chronic health conditions: a Delphi exercise. J Rehabil Med 2004; 36: suppl 44: 12–21.
- Brockow T, Cieza A, Kuhlow H, Sigl T, Franke T, Harder M, Stucki G. Identifying the concepts in outcome measures of clinical trials on musculoskeletal disorders and chronic wide spread pain using the

International Classification of Functioning, Disability and Health as a reference. J Rehabil Med 2004; 36: suppl 44: 30–36.

- Ewert T, Fuessl M, Cieza A, Andersen A, Chatterji S, Kostanjsek N, Stucki G. Identification of the most common patient problems in patients with chronic conditions using the ICF checklist. J Rehabil Med 2004; 36: suppl 44: 22–29.
- Arnett FC, et al. The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. Arthritis Rheum 1988; 30: 315–324.
- 21. Stucki G, Liang MH, Stucki S, Bruehlmann P, Michel BA. A selfadministered Rheumatoid Arthritis Disease Activity Index (RADAI) for epidemiological research: psychometric properties and correlation with parameters of disease activity. Arthritis Rheum 1995; 38: 795–798.
- MacLean CH, Louie R, Leake B, McCaffrey DF, Paulus HE, Brook RH, et al. Quality of care for patients with rheumatoid arthritis. JAMA 2000; 284: 984–992.
- Ward MM, Leigh JP, Fries JF. Progression of functional disability in patients with rheumatoid arthritis. Associations with rheumatology subspecialty care. Arch Intern Med 1993; 153: 2229–2237.
- Ward MM, Leigh JP. Marital status and the progression of functional disability in patients with rheumatoid arthritis. Arthritis Rheum 1993; 36: 581–588.
- Fries JF. Current treatment paradigms in rheumatoid arthritis. Rheumatol 2000; 39: 30–35.
- 26. Albers JMC, Kuper HH, van Riel PLCM, Prevoo MLL, Van't Hof MA, van Gestel AM, et al. Socio-economic consequences of rheumatoid arthritis in the first years of the disease. Rheumatol 1999; 38: 423–430.
- Van Jaarsveld CHM, Jacobs JWG, Schrijvers AJP, Heurkens AHM, Haanen HCM, Bijlsma JWJ. Direct cost of rheumatoid arthritis during the first six years: a cost-of-illness study. Br J Rheumatol 1998; 37: 837–847.
- Gabriel SE, Crownson CS, Campion ME, O'Fallon WM. Indirect and nonmedical costs among people with rheumatoid arthritis and osteoarthritis compared with nonarthritic controls. J Rheumatol 1997; 24: 43–48.
- 29. Young A, Dixey J, Cox N, Davies P, Devlin J, Emery P, et al. How does functional disability in early rheumatoid arthritis (RA) affect patients and their lives? Results of 5 years of follow-up in 732 patients form the Early RA Study (ERAS). Rheumatol 2000; 39: 603–611.
- Evers AWM, Kraaimaat FW, Geenen R, Jacobs JWG, Jijlsma JWJ. Pain coping and social support as predictors of long-term functional disability and pain in early rheumatoid arthritis. Behav Res Ther 2003; 41: 1295–1310.
- Waltz M, Kriegel W, van't Pad Bosch P. The social environment and health in rheumatoid arthritis: marital quality predicts individual variability in pain severity. Arthritis Care Res 1998; 11: 356–374.
- Kirwan J, Heiberg T, Hewlett S, Hughes R, Ahlmen M, et al. Outcomes from the Patient Perspective Workshop at OMERACT 6. J Rheumatol 2003; 30: 868–872.