REPORT

The International Classification of Functioning, Disability and Health (ICF) Core Sets for rheumatoid arthritis: a way to specify functioning

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Today, patients' functioning is a central issue in medicine. Concepts, classifications, and measurements of functioning and health, such as the International Classification of Functioning, Disability and Health (ICF) are of prime importance in clinical practice, teaching, and research. This report compares the contents of three of the most widely used health status measures in rheumatoid arthritis (RA), namely the Health Assessment Questionnaire disability index (HAQ), the Arthritis Impact Measurement Scales 2 (AIMS2), and the Short Form health survey (SF-36) based on the ICF. In addition, their content is compared to the Comprehensive ICF Core Set for RA.

The comparisons illustrate that the different health status measures cover different components, and that they cover the different components with different level of precision. Using the ICF as a reference framework allows a researcher or a recommending instance to see which domains are covered in a specific instrument and, therefore, whether it is necessary to complement the study with other measures. Nevertheless, which specific health status measures to recommend still remains a challenge. If enough care is taken to define "what should be measured", it could form the basis for a solid and stable recommendation, adhered to for many years.

P atients' functioning is a central aspect of the rheumatic diseases. Therefore, concepts, classifications, and measurements of functioning and health are an integral part of clinical practice, teaching, and research,[1] and new developments, such as the International Classification of Functioning, Disability and Health (ICF, formerly ICIDH-2)[2] are of great interest and importance to researchers, clinicians, and clinical teachers.

In contrast to the understanding of the International Classification of Impairment, Disability and Handicap (ICIDH-1),[3] the disease perspective, and even our current understanding of outcomes research, functioning and health are no longer viewed as the consequence of a disease or condition. Functioning is now seen in relation to the health condition, as well as to personal and environmental factors. The relation between functioning (and its components *body functions* and *structures*, *activities* and *participation*) and a health condition or a number of conditions, and personal and contextual factors, is bidirectional. The basis of this new understanding is represented by the model of functioning and disability proposed by the World Health Organization (WHO) (fig 1).[2]

This bio–psycho–social view guided the development of the ICF, which was approved by the World Health Assembly (WHA) as recently as May 2001. With the ICF, not only is an aetiologically neutral framework available but a globally agreed-on language and classification is also available to describe functioning both at the individual and the population levels.

All member states of the WHO are now being called upon to implement the ICF in multiple sectors besides health including education, insurance, labour, health and disability policy, statistics etc.[1] The ICF has to be tailored to suit each of these specific applications.[4]

In the clinical context, the main challenge is the length of the classification which has over 1400 categories. Therefore, chiefly to address feasibility with regard to the number of categories and the user perspective in medicine, which typically takes a condition specific perspective, ICF Core Sets have been developed for many of the most burdensome chronic health conditions, including rheumatoid arthritis (RA).[5] The ICF Core Sets represent a selection of ICF domains or categories from the whole classification which can serve as minimal standards for the reporting of functioning and health in clinical studies and clinical encounters (Brief ICF Core Set) or as standards for multiprofessional, comprehensive assessment (Comprehensive ICF Core Set). The ICF Core Sets are currently undergoing extensive testing and validation in the WHO regions. In the context of a European League Against Rheumatism (EULAR) project, the ICF Core Sets for RA will be tested and validated from the physician, health professional, and patient perspectives.[6]

To implement the ICF in other fields, such as education, insurance, labour, and health and disability policy, further efforts have to be made to tailor the ICF to the needs of the prospective users. The work ahead is, thus, considerable. However, from now on functioning and health can be specified comprehensively in different fields based on one and the same universal framework.

Currently, health status measures, developed over the past two decades, are widely used both in research and clinical practice for describing functioning and health. In some fields, such as rheumatology, function oriented health status measures including the Health Assessment Questionnaire disability index (HAQ[7]) and the Arthritis Impact Measurement Scales 2 (AIMS2[8])—which can be considered as a generic instrument specific for RA—are widely used for assessment, intervention management, and outcome evaluation. They are used to measure the dimensions or study endpoints of "physical function",[9] "physical disability",[10] or "function"[11] as recommended in the core sets for clinical

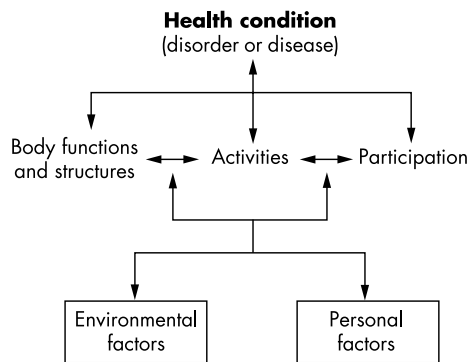...

Figure 1 The current framework of disability—World Health Organization International Classification of Functioning, Disability and Health (ICF).

studies by the committee on Outcome MEasures in Rheumatoid Arthritis Clinical Trials (OMERACT), WHO/International League of Associations for Rheumatology (ILAR), and American College of Rheumatology (ACR), respectively. Thus, from the perspective of these core sets, "functioning" is implicitly defined by the health areas covered by the health status measures applied. In other words, "what to measure" is defined by the health status measure and therefore by "how to measure". In contrast, the ICF Core Sets for RA define "what to measure" and leave open "how to measure" or which measures to use. The ICF Core Sets for RA can, therefore, be seen as a specification or subset of the dimension "functioning" contained in the core sets of OMERACT, ACR, or WHO/ILAR.

It would, therefore, be helpful to compare the contents of two of the most widely used health status measures in RA, namely the HAQ and AIMS2, and to compare their content with the Comprehensive ICF Core Set for RA.[12] Since generic instruments are also widely used in rheumatology to evaluate effects across conditions, populations, and interventions, the 36 item Medical Outcomes Study Short Form health survey (SF-36),[13] as the most widely used generic health status measure, was also included in the comparison.

HEALTH STATUS MEASURES USED TO COVER "FUNCTIONING"
Arthritis Impact Measurement Scales 2
The AIMS2[8] is an improved and expanded version of the original AIMS.[14] In addition to the original 48 items contained in nine subscales (mobility, physical activity, dexterity, social role functioning, social activity, activities of daily living, depression, anxiety, and pain), the AIMS2 contains 13 items covering the scales arm function, work, and support from family and friends. The questionnaire also includes a problem attribution section with yes/no questions and three new items to assess satisfaction with current level of functioning, specific impact of arthritis on an individual's health status, and prioritisation of three areas in which the patient would most likely achieve improvement.

Stanford Health Assessment Questionnaire disability index
The HAQ[7] measures difficulty in performing activities of daily living retrospectively over the preceding week. There are 20 questions in eight categories of functioning which represent a comprehensive set of functional activities— dressing, rising, eating, walking, hygiene, reach, grip, and usual activities. Each category contains at least two specific components.

Medical Outcomes Study Short Form 36
MOS SF-36[13] is derived from a larger battery of questions administered in the Medical Outcomes Study and is the most widely used general health status measure. It includes eight multi-item scales containing two to 10 items each and a single item to assess health transition. The scales cover the dimensions of physical health, mental health, social functioning, role functioning, general health, pain, and vitality.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH
The ICF[2] contains lists of so called ICF categories organised in three different components:

(1) body functions and structures
(2) activities and participation
(3) environmental factors.

Body functions (b), body structures (s), and activities and participation (d) belong to the part "functioning and disability". Environmental factors belong to the part "contextual factors". Personal factors, which constitute the fourth component of the classification and also belong to the part contextual factors, have not yet been classified. The ICF categories represent the units of the ICF classification. Within the hierarchical code system of this classification, the ICF categories are designated by the letters b, s, d, and e, followed by a numeric code starting with the chapter number (one digit), followed by the second level (two digits) and the third and fourth levels (one digit each). Thus, within each chapter, there are individual two, three, or four level categories.[2]

"Other specified" categories are uniquely identified by the final code 8. These categories allow the coding of aspects not included in any other specific categories. The categories defined as "unspecified" categories (identified by the final code 9) allow the coding of health domains for which there is insufficient information to permit the assignment of a more specific ICF category.

METHODOLOGICAL APPROACH TO LINK HEALTH STATUS MEASURES TO THE ICF
The HAQ, the AIMS2, and the SF-36 were linked to the ICF separately by two trained health professionals on the basis of ten linking rules,[15] which enable health status measures to be linked to the ICF in a specific and precise manner. The most important linking rules are rules 2 and 3, which state, respectively, that each item of an outcome measure should be linked to the most precise ICF category and that if one item encompasses different concepts, the information in each concept should be linked. Additionally, two of the ten linking rules require a special annotation. According to rule 6, if the content of an item is not explicitly named in the corresponding ICF category, the "other specified" category has to be applied. Rule 9 states that if the information provided by the item is not sufficient to decide which ICF category should be chosen, this item is assigned "nd" (not definable). Consensus between the two health professionals was used to decide which ICF category should be linked to each item/concept in the three questionnaires. To resolve disagreements between the two health professionals concerning the selected categories, a third independent person with expertise in the concepts and taxonomy of the ICF and who was also trained in the linking rules was consulted.

COMPARISON OF THE HEALTH STATUS MEASURES ADDRESSING FUNCTIONING
In the 128 items of the three health status measures a total of 171 concepts were identified and linked to the ICF. The concepts contained in the items of the health status measures

were linked to 75 different ICF categories—8 categories of the component *body functions*, 57 categories of the component *activities and participation*, and 10 categories of the component *environmental factors*. For 19 items/concepts ''nd'' was used—for example, for items which refer to health or quality of life in general (that is, to items/concepts that refer to all categories contained in the ICF and to none concretely).

Tables 1 and 2 show items using the ICF as a reference with regard to the components body functions and activities and participation. The components body structures and environmental factors are not shown because of limitations of space. The numbers in the columns AIMS2, HAQ, and SF-36 represent the frequency with which the ICF categories were addressed in the corresponding health status measures. Generally, the ICF categories were linked to just one item/concept of a questionnaire, as it is indicated by a ''1'' in the tables. A higher number indicates that either the measure contains a determined concept more than once or that the ICF did not differentiate in greater detail, and, therefore, several items or concepts of items from a specific measure had to be linked to the same ICF category. For example, for the SF-36, the ICF category b152 (emotional functions) was chosen to link a number of different feelings: ''feeling depressed or anxious'', ''emotional problems'', ''very nervous'', ''I felt so down in the dumps nothing could cheer me up'', ''I felt calm and peaceful'', ''I felt downhearted and blue'', and ''Have you been a happy person?''. If there were different categories for different feelings, the named items would have been linked to different categories.

The crosses in the column Comprehensive ICF Core Set for RA correspond to the ICF categories represented in the Comprehensive ICF Core Set for RA, which contains 25

categories in the component body functions and 32 categories in the component activities and participation.

Pain is the leading symptom in patients with RA and one of the key outcome domains recommended by OMERACT.[10] Thus, it is important to note that all instruments address pain at least at the second more general level of the classification. Since pain in RA is typically present in the different parts of the (body's) locomotor system and may specifically involve the joints, and because comprehensive multidisciplinary management of pain relies on an indepth assessment, a number of categories at the third level addressing the different regions and the joints are included in the Comprehensive ICF Core Set for RA. The AIMS2 also addresses pain at this more specific level.

The comparison based on the ICF, therefore, not only provides insight into the bandwidth of the different measures—that is, not only into the breadth of health dimension measurement but also into the thoroughness and depth (fineness of specification) of measurement.[16 17]

Stiffness, in particular morning stiffness, is closely related to pain, but clearly represents a distinct symptom. While stiffness may not add additional information in clinical trials and therefore was not included in the recommendation by OMERACT,[10] it is the first element of the now preferred definition of RA suggested by the ACR.[18] Morning stiffness may considerably hamper activities of daily living; since it may last for hours, activities of daily living may become impossible, difficult, or may take much more time to perform. Thus the assessment of stiffness is an important aspect of multidisciplinary assessment in rheumatological rehabilitation, and sensation of muscle stiffness is included in the comprehensive ICF Core Set as it is also included in the AIMS2.

Table 1 ICF categories of the component ''body functions'' included in the Comprehensive ICF Core Set for RA and frequencies showing how often the body function categories were addressed in the AIMS2, HAQ, and SF-36

ICF code		Comprehensive ICF Core Set for RA	AIMS2	HAQ	SF-36
b130	Energy and drive functions	X			
b1300	Energy level				4
b1304	Impulse control		1		
b134	Sleep functions	X	1		
b152	Emotional functions	X	17		7
b1529	Emotional functions, unspecified		6		1
b180	Experience of self and time functions	X			
b1801	Body image	X			
b2702	Sensitivity to pressure				
b280	Sensation of pain	X		1	2
b2800	Generalised pain	X			
b2801	Pain in body part	X			
b28010	Pain in head and neck	X			
b28013	Pain in back	X			
b28014	Pain in upper limb	X			
b28014	Pain in upper limb				
b28015	Pain in lower limb	X			
b28015	Pain in lower limb				
b28016	Pain in joints	X	5		
b430	Haematological system functions	X			
b455	Exercise tolerance functions	X			
b510	Ingestion functions	X			
b640	Sexual functions	X			
b710	Mobility of joint functions	X			
b7102	Mobility of joints generalised	X			
b715	Stability of joint functions	X			
b730	Muscle power functions	X			
b740	Muscle endurance functions	X			
b770	Gait pattern functions	X			
b780	Sensations related to muscles and movement functions	X			
b7800	Sensation of muscle stiffness	X	1		

AIMS, Arthritis Impact Measurement Scales 2; HAQ, Health Assessment Questionnaire disability index; ICF, International Classification of Functioning, Disability and Health; RA, rheumatoid arthritis; SF-36, Short Form health survey.

Table 2 ICF categories of the component ''activities and participation'' included in the Comprehensive ICF Core Set for RA and frequencies showing how often the activities and participation categories were addressed in the AIMS2, HAQ, and SF-36

ICF code		Comprehensive ICF Core Set for RA	AIMS2	HAQ	SF-36
d170	Writing	X			
d230	Carrying out daily routine	X			2
d360	Using communication devices and techniques	X			
d3600	Using telecommunication devices		1		
d410	Changing basic body position	X			
d4100	Lying down		1	1	
d4102	Kneeling				1
d4104	Standing			2	
d4105	Bending		1	1	1
d415	Maintaining a body position	X			
d429	Changing and maintaining body position, other specified and unspecified			1	
d430	Lifting and carrying objects	X			1
d4300	Lifting		1	1	
d4305	Putting down objects			1	
d4309	Lifting and carrying, unspecified		1		1
d440	Fine hand use	X			
d4400	Picking up			1	
d4401	Grasping			1	
d4402	Manipulating		1	1	
d4403	Releasing			1	
d4409	Fine hand use, unspecified		1		
d445	Hand and arm use	X			
d4452	Reaching		1	1	
d4453	Turning or twisting the hands or arms		1	1	
d4458	Hand and arm use, other specified		3	2	
d4459	Hand and arm use, unspecified				1
d449	Carrying, moving, and handling objects, other specified and unspecified	X			
d450	Walking	X	1	1	
d4500	Walking short distances		1		1
d4501	Walking long distances				1
d4502	Walking on different surfaces			1	
d455	Moving around	X			
d4551	Climbing		3	1	2
d4559	Moving around, unspecified		1		1
d460	Moving around in different locations	X			
d465	Moving around using equipment	X			
d470	Using transportation	X			
d4702	Using public motorised transportation		1		
d475	Driving	X			
d4751	Driving motorised vehicles		1		
d498	Mobility, other specified		2		
d510	Washing oneself	X			
d5100	Washing body parts			1	
d5101	Washing whole body		1	1	1
d5109	Washing oneself, unspecified		1		
d520	Caring for body parts	X			
d5202	Caring for hair		1	1	
d5209	Caring for body parts, unspecified		1		
d530	Toileting	X			
d5308	Toileting, other specified			1	
d5309	Toileting, unspecified		1		
d540	Dressing	X	1	2	1
d5400	Putting on clothes		1		
d5402	Putting on footwear			1	
d550	Eating	X		2	
d560	Drinking	X			
d570	Looking after one's health	X			
d598	Self-care, other specified			1	
d620	Acquisition of goods and services	X			
d6200	Shopping		1		
d6209	Acquisition of goods and services, unspecified		2	2	
d630	Preparing meals	X	1		
d640	Doing housework	X	1		
d6400	Washing and drying clothes and garments		1		
d6408	Doing housework, other specified			1	
d6409	Doing housework, unspecified		1		1
d649	Household tasks, other specified and unspecified		3		1
d660	Assisting others	X			
d699	Domestic life, unspecified			1	
d760	Family relationships	X			
d770	Intimate relationships	X			

Table 2 *continued*

ICF code		Comprehensive ICF Core Set for RA	AIMS2	HAQ	SF-36
d820	School education		1		
d850	Remunerative employment	X	1		1
d859	Work and employment, other specified and unspecified	X	1		2
d910	Community life	X			
d920	Recreation and leisure	X			
d9205	Socialising		4		2
d9208	Recreation and leisure, other specified		1		
d9209	Recreation and leisure, unspecified		1		2
d9300	Organised religion		1		

For abbreviations see table 1.

Patients with RA may also develop problems related to energy and drive functions, sleep, and emotional functions, which are not specific to RA but typical for a systemic inflammatory condition. These categories are included in the Comprehensive ICF Core Set. Nevertheless, whilst sleep and emotional functions are covered by the AIMS2, energy level is only covered by the SF-36.

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 in the Comprehensive ICF Core Set. This is also reflected by the fact that the two health status measures included in the content comparison also cover a very broad range of categories within the component activities and participation.

Carrying out daily routine is exclusively covered by the SF-36. Aspects of mobility are extensively represented in the two other health status measures, the AIMS2 being the measure that covers it most broadly with the highest number of different ICF categories and with the highest precision in distinguishing, for example, many different modalities of fine hand use such as picking up, grasping, manipulating and releasing.

All three measures cover walking, the SF-36 distinguishing between short and long distances, the AIMS2 specifying exclusively short distances, and the HAQ walking on different surfaces. With respect to self-care, the AIMS2 and the HAQ cover a wide range of categories, whereas the SF-36 only includes washing the whole body and dressing. At least one of the categories included in the chapter domestic life is covered in all three measures, but the AIMS2 cover this area in more detail than the HAQ and SF-36.

None of the measures contains interpersonal interactions and relationships. It is important to emphasise that the social functioning scale of the SF-36 covers ''social activities with family, friends, neighbours, or groups'', which, based on the ICF framework, are linked to ''socialising''. Further aspects of recreation and leisure are also included in the AIMS2 but not in the HAQ.

Loss of productivity is a major problem in RA. Therefore the Comprehensive ICF Core Set contains d850 remunerative employment. Again, in contrast with the HAQ, only the AIMS2 and the SF-36 cover aspects of work.

DISCUSSION
Comparison of the health status measures illustrates that the different instruments cover different components, and that they cover the different components with different levels of precision. It also becomes clear that functioning as defined in the ICF is a very broad concept. Therefore, it is no surprise that the ICF Core Set for RA, which was developed based on the ICF, covers a much broader spectrum of categories than, for example, the HAQ. The HAQ is an instrument that exclusively covers the component activity and participation. The AIMS2, which can be considered a generic health status measure specific to RA, also covers aspects of the component body functions, particularly emotional functions, sleep functions, pain and stiffness. In addition, it covers activities most relevant to patients with RA, like fine hand use, hand and arm use, or preparing meals and doing housework in more detail than the HAQ.

It is also interesting to note the categories considered relevant and, therefore, included in the ICF Core Set for RA are not covered by the other instruments. Examples of these ICF categories are drinking, writing, and using communication devices. The ICF Core Set for RA addresses categories such as muscle power, which cannot be measured by self-administered health status instruments.

As pointed out earlier in this report, recommending a specific measure to cover a dimension such as functioning requires both the definition of the underlying domains and an analysis of the domains contained in the different instruments. Otherwise, some domains not covered by a specific instrument, but nonetheless relevant, may not be considered in a study. For example, when recommending the HAQ, one should be aware that sleep would not be covered and that when recommending the AIMS2, sleep would be covered. Use of the ICF as a reference framework allows a researcher or a recommending instance to see which domains are covered in a specific instrument and, therefore, whether it is necessary to complement the study with other measures.

Which specific health status measures to recommend remains a challenge. New health status measures are being developed, and new versions of existing measures are constantly evolving with respect to their contents and psychometric properties. Therefore, any recommendation regarding a specific instrument is soon likely to be outdated.

To avoid this problem, at least to some extent, it would be preferable to first define ''what should be measured'' and only then to recommend how to measure it or which instrument to use. Indeed, this approach has been successfully applied in rheumatology by the OMERACT group.[10] However, it has not yet been applied for the specification of the dimension ''function''.

If enough care is taken to define ''what should be measured'', it could form the basis for solid and stable recommendations, adhered to for many years. On the basis of the valid set of recommended categories to be measured, the best available measurement options can be tested against this set and then recommended.

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