How to assess the impact of arthritis on the individual patient: the WHO ICF

G Stucki, T Ewert

The ICF is not only a comprehensive and adequate framework for assessing the impact of arthritis on individual patients but also its impact on populations. The ICF framework and applications such as the ICF Core Sets for rheumatoid arthritis, osteoarthritis, osteoporosis, and low back pain are therefore likely to be used extensively not only in clinical practice but also in outcomes and rehabilitation research, education, health statistics, and regulation.

Assessment of the impact of a disease on an individual patient is different when viewed from the disease perspective than when viewed from the functioning perspective. From the disease perspective, patients’ functioning, disability, and health are seen primarily as the consequences or the impact of a disease or health condition. Medical interventions, including disease modifying antirheumatic drugs, are targeted towards the disease process, and the ultimate goal of these interventions is to avoid the consequences on the individual patient. Assessment of the impact of the disease on the individual patient is necessary to evaluate the outcome of an intervention targeted at the disease process. Measures to assess the impact of the disease on the individual patient and to evaluate the effect of drug treatments or surgical interventions are thus typically condition-specific.

Because aspects of participation or life activities are generally only marginally represented in condition-specific measures, they are often complemented by generic health status measures in clinical studies. The World Health Organisation’s International Classification of Functioning, Disability, and Health (ICF)-based comparisons of the contents covered by generic and condition-specific measures confirmed this difference. Both, the interpretation of condition-specific and generic health status measures are generally based on scales and scores and not on individual items. Also, these measures have not been developed for, and are generally not used in, clinical practice for the assessment of functioning.

From the functioning perspective which is relevant, for example, for rehabilitation, functioning and health are seen as associated with, and not merely as a consequence of, a health condition or disease. Also, functioning and health are not only seen in association with the underlying disease or health condition but also in association with personal and environmental factors. The basis for this understanding is the WHO’s ICF. The ICF will greatly influence clinical practice and research. It will be used as a common language—for example, in multidisciplinary rehabilitation, education of health professionals, documentation, and as platform for the selection and development of new measures. It will promote an in depth understanding of functioning, disability, and health.

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY, AND HEALTH OR ICF

The ICF attempts to achieve a synthesis, thereby providing a coherent view of different perspectives of health from a biological, individual, and societal perspective. It emphasises “building blocks” to form specific models, focusing on more detailed aspects. Therefore the ICF can be seen as a common language for physicians and health professionals, healthcare systems, policies, and patients/clients. The texts that can be created with it depend on the users, their creativity, and their scientific orientation.

Figure 1 demonstrates the interactions between the components of the ICF. It is important to note that the interaction between functioning or disability and a health condition works in both directions, because the presence of the disability may itself modify the health condition.

Health condition refers to any kind of disorder or disease. It may include information about pathogeneses and/or aetiology. There are (possible) interactions with all components of functioning: body functions and structures, activity, and participation.

Body functions are the physiological (and psychological) functions of body systems. Body structures are anatomical parts of the body. Problems in both constructs are impairments, which are defined as a significant deviation or loss (for example, deformity) of structures (for example, joints) and/or functions (for example, reduced range of motion, muscle weakness, pain, and fatigue). The levels of reference are body systems; accordingly, body structures are not considered as organs.

Activity is described as the execution of a task or action by an individual person. It represents the individual perspective of functioning. Difficulties an individual person may have in executing activities are activity limitations (for
example, limitations in mobility such as walking, climbing steps, grasping, or carrying).

*Participation* is described as involvement in life activities. It represents the societal perspective of functioning. Problems an individual person may experience in involvement in a life situation are participation *restrictions*. Limitations and restrictions are assessed against a generally accepted population standard. It records the discordance between the observed and the expected performance. The expected performance is the population norm, which represents the experience of people without the specific health condition (for example, restrictions in community life, recreation, and leisure, but may be in walking too, if walking is an aspect of life participation).

*Contextual factors* are the factors that together constitute the complete context of an individual person’s life, and in particular the background against which health states are classified in the ICF. There are two components: environmental factors and personal factors.

*Environmental factors* refer to all aspects of the external or extrinsic world that form the context of an individual person’s life and have an impact on that person’s functioning. Environmental factors include the physical world and its features, the human made physical world, other people in different relationships and roles, attitudes and values, social systems and services, and policies, rules, and laws.

*Personal factors* are contextual factors that relate to the individual person such as age, sex, social status, life experiences, and so on.

Risk factors could be described in both personal factors (for example, lifestyle, genetic make up) and environmental factors (for example, architectural barriers, living and work conditions), which are associated with musculoskeletal conditions. Risk factors are not only associated with the onset but also interact with the disabling process at each stage.

*Functioning* and *disability* are umbrella terms. *Functioning* serves as the umbrella term for abilities encompassing body functions and structures, activities, and participation. *Disability* serves as an umbrella term for impairments, activity limitations, and participation restrictions. It can be seen as the negative term of functioning.

A person’s functioning and disability is conceived as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc) and contextual factors. Likewise, there are (possible) interactions with all components of functioning and the contextual factors.

The new ICF replaces the ICIDH, which was first published by the World Health Organisation for trial purposes in 1980. To avoid misunderstandings in the meaning of terminology, it is necessary to replace the definitions that were then used—for example, the definition of “disability” is now different.

**APPLYING THE ICF IN MEDICINE**

The ICF is designed to record and organise a wide range of information about health and health related states. Since the ICF was developed by a worldwide, comprehensive consensus process over the past few years and was endorsed in May 2001 by the World Health Assembly as a member of the WHO Family of International Classifications, it is likely to become the generally accepted framework to describe functioning and health. The widespread interest and acceptance of the ICF is reflected by the increasing number of translations available. The ICF is intended for use in multiple sectors that include education, insurance, labour, health and disability policy, statistics, etc, in addition to health. A special adaptation of the ICF for children is under way. Clinically, it is intended for use in needs assessment, matching interventions to specific health states, rehabilitation, and outcome evaluation.

“*Functioning and disability result from a dynamic interaction between health conditions and contextual factors*”

However, the ICF will have to be tailored to suit these specific uses. Firstly, the joint use of the ICF and the International Classification of Diseases (ICD-10) needs to be considered when applying the ICF to medical practice. For practical purposes and in line with the concept of condition-specific health status measures, it would seem most helpful to link specific conditions or diseases to salient ICF categories of functioning. Such generally agreed lists of ICF categories can serve as Brief Core Sets to be rated in all patients included in a clinical study with a particular condition or as Comprehensive Core Sets to guide multidisciplinary assessments in patients with that condition.

A *Brief ICF Core Set* for a specific condition includes a list of ICF categories with as few categories as possible to be practical, but as many as necessary to be sufficiently comprehensive to describe in clinical studies and possibly clinical encounters the spectrum of abilities that are typically limited in patients with a specific condition. ICF Core Sets also include ICF categories from the component environmental factors. Because there is currently no classification, the personal factors cannot be defined. As the Brief ICF Core Set for a condition is the minimum dataset that will be reported in every clinical study to describe the burden of disease and the influence of environmental factors in a...
In contrast, the Comprehensive ICF Core Set for a specific condition is a list of ICF categories that includes as few categories as possible to be practical, but as many as necessary to be sufficiently comprehensive to describe in a comprehensive, multidisciplinary assessment the spectrum of abilities that are typically limited or not in patients with a specific condition. Preliminary ICF Core Sets for chronic conditions, including rheumatoid arthritis (RA), osteoarthritis (OA), osteoporosis, low back pain, and chronic pain, have been developed jointly by the ICF Research Branch of the German WHO collaborating centre for the family of international classifications (DIMDI) in Munich and the classification, assessment, and surveys team at the WHO headquarters in cooperation with a number of international societies, including EULAR, the Bone and Joint Decade, and the EU health monitor project. Based on the evidence from preliminary studies using empirical data, Delphi surveys, and systematic reviews, the spectrum of categories relevant for patients with RA, OA, osteoporosis, low back pain, and chronic widespread pain, have been derived at international consensus conferences. As an example, table 1 shows the Comprehensive ICF Core Set for the component “body functions” in patients with OA.

The ICF Core Sets for RA, OA, osteoporosis, low back pain, and chronic widespread pain are preliminary and need to be tested in coming years in different countries and regions, in subsets of patients with varying characteristics, in healthcare settings, and from the perspective of the different professions involved in the care of patients. The primary goal of the testing is to examine the validity of the ICF Core Sets. It will be examined whether the ICF Core Set categories are relevant to different patient populations across regions and whether there are relevant categories not yet included. The testing will be conducted in close cooperation with the ICF Research Branch of the WHO FIC CC (DIMDI) in Munich and the CAS team at the WHO. From 2004 to 2006 interested institutions and organisations are encouraged to participate. For example, in Europe the testing will be conducted in a project supported by EULAR. Based on the results of the testing, a final version will be approved in 2007.

To deal with the issue of application, a number of initiatives—for example, by the Australian WHO Collaboration Centre and the American Psychology Association—are currently developing manuals of practical descriptions of the ICF category titles and descriptors and manuals describing how to understand more precisely the content and the consequent measurement of a category. For the linkage of the ICF categories to measures and, more specifically, psychometrically developed health status measures, so called linkage rules have been developed.

HOW TO USE THE ICF AND ICF CORE SETS IN CLINICAL PRACTICE
The ICF framework is increasingly used in clinical practice to structure patient problems, particularly in multidisciplinary care and for rehabilitation purposes. Physicians and health professionals can use the ICF framework and the ICF Core Sets to identify and document patients’ complaints when taking a patient history and to identify and document clinical findings of a clinical examination. The ICF Core Sets may be particularly useful not only for trainees but also for experienced clinicians because physicians may underestimate patients’ functional problems.
The use of an ICF model sheet\textsuperscript{22} based on the ICF framework is a most useful way to understand the relationship between selected target problems and impaired body functions and structures and psychosocial and environmental factors which exacerbate or help to minimise them (fig 2). Figure 2 illustrates how the ICF components can be used to structure patient problems (listed in the upper section “Patient’s perspective”) as well as findings, and observations by the rehabilitation team (listed in the lower section “Health professional’s perspective”). Lines between the selected target problems from the patient’s perspective (circled in the upper section) and impaired body functions and structures as well as the given personal and environmental factors (circled in the lower section) denote their suggested relationship. Please note that the wording denotes patient’s words or special medical terms and not text from the ICF categories. In this example, the problems become the initial treatment goals. The multiprofessional rehabilitation team attempts to reduce pain and increase the walking distance. These may be the limiting factors for the patient’s other activity limitations and participation restrictions, which could be examined in the next rehabilitation cycle. The treatment goals define the selected measures. For this example a visual analogue scale of pain and recording of the maximum walking distance are adequate. The use of an ICF model sheet and the ICF Core Sets which are tailored to specific conditions can be used to improve the internal reporting and documentation and to structure multidisciplinary care.\textsuperscript{24}

**FUTURE OF THE ICF IN CLINICAL PRACTICE, EDUCATION, RESEARCH, HEALTH STATISTICS, AND REGULATION**

For the first time in the history of medicine there is now have a universally agreed conceptual framework and classification for functioning, disability, and health. The current adoption of the ICF by clinicians and health professionals, researchers, health authorities, healthcare providers, and insurers is likely to trigger a number of important developments.\textsuperscript{1} Any language influences the way people think. Because the ICF now includes contextual factors, which interact with the components body functions and structures, activity, and participation it is likely that people who work with the ICF will increasingly consider these factors and interactions. Also, the now neutral terms body functions and structures, activity, and participation as compared with the previous “negative” terms impairment, disability, and handicap may stimulate a more positive view and bring a more resource oriented perspective into rehabilitation.

“The language of the ICF will influence the way people think”

The ICF as common language for functioning will probably change multiprofessional communication. As illustrated under the section ICF in clinical practice, the ICF will become the basis for multiprofessional patient assessment, goal setting, intervention management, and evaluation. Because rehabilitation is part of the continuum of care from acute to community care, the ICF seems to be a new meaningful way to communicate across the continuum—for example, when transferring a patient. The ICF may also improve communication between patients and health professionals. It will be easier for patients to understand their functioning and health, rehabilitation goals, and an intervention plan based on a language they and their proxies can understand.

Similarly, the ICF will become an important part for the education of rehabilitation doctors and nurses, physical, occupational and speech therapists, psychologists, social workers, and other rehabilitation professionals. Indeed, the ICF now forms part of a number of curriculums for physicians and health professionals world wide.

The ICF is already having an important impact on rehabilitation and outcomes. Currently we are faced with “competing” instruments in many areas. Mapping of items to the ICF \textsuperscript{5, 20} provides a unique opportunity to standardise items and instruments. The results of these studies show, that with few exceptions, the content of the generic and condition-specific health status measures is represented by the ICF categories and, therefore, the ICF can serve as the common framework when comparing health status instruments.

The components of the ICF are the basis for research into their interactions and will lead to a better understanding of functioning, disability, and health.\textsuperscript{25} Most importantly, the components are a practical framework for designing longitudinal prognostic studies on the negative and positive factors related to functioning and health in people with a specific health condition or within a specific context.

Finally, the ICF will be used by health agencies, healthcare providers, and insurance providers in many ways. It will, for example, be used for expert opinion or as a framework to develop expert systems, case management, health reporting and health statistics, quality assurance and benchmarking, healthcare planning, and case management. The ICF may also be used for the development of prospective payment systems. In all these situations, a mass of information must be handled and analysed. Redundant data collection must be avoided and decisions need to be made based on relevant data. The ICF provides a framework for data collection\textsuperscript{26} and a terminology for comparable data\textsuperscript{27} for all aspects centring around functioning.

The research community or regulatory agencies may use the ICF and ICF Core Sets to define what should be measured when reporting a clinical study or when defining the minimal requirements to be met for approval. In rheumatology, the ICF Core Sets can complement current rheumatological Core Sets.\textsuperscript{28} These rheumatological Core Sets are not ICF based and typically include the domains “inflammation” as measured by an acute phase reactant and “destruction” as measured by an x ray score. Rheumatological Core Set domains such as “pain” or “vitality” can be easily linked to respective ICF categories. It is more difficult to link a less well defined domain such as “function”. “Function” can include many different aspects and not each health status instrument includes the same aspects. Based on the ICF and the ICF Core Sets it is possible to define the categories that should be covered by a measure of “function”. To first define what categories should be covered when referring to the rheumatological domain function and only then to decide how to measure these categories would indeed follow the accepted principles of how to define rheumatological Core Sets.\textsuperscript{28} ICF Core Sets could therefore complement the current rheumatological Core Sets when defining functioning.

In conclusion, the ICF is an exciting landmark for the assessment of the impact of arthritis on the individual patient. The ICF is not only a comprehensive and adequate framework for assessing the impact of health conditions on an individual person but also its impact on populations. The ICF framework and applications such as the ICF Core Sets for RA, OA, osteoporosis, and low back pain are likely to be used in clinical practice, outcomes and rehabilitation research, education, health statistics, and regulation.

**ACKNOWLEDGEMENT**

We acknowledge Susanne Zaisserer for her contribution to the ICF model sheet example.


