DEVELOPMENT OF ICF CORE SETS FOR PATIENTS WITH CHRONIC CONDITIONS

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Objective: The objective of the ICF Core Sets project is the development of internationally agreed Brief ICF Core Sets and Comprehensive ICF Core Sets.
Methods: The methods to develop both ICF Core Sets, the Comprehensive ICF Core Set and the Brief ICF Core Set, involved a formal decision-making and consensus process integrating evidence gathered from preliminary studies and expert opinion.
Results: The results regarding the development of the ICF Core Sets for 12 health conditions (chronic widespread pain, low back pain, osteoarthritis, osteoporosis, rheumatoid arthritis, chronic ischemic heart disease, diabetes mellitus, obesity, obstructive pulmonary diseases, breast cancer, depression, and stroke) are presented in this supplement.
Conclusion: Both, the Brief ICF Core Sets and the Comprehensive ICF Core Sets are preliminary and need to be tested in the coming years based on a standardized protocol in close cooperation with the ICF research branch of the WHO FIC CC (DIMDI) in Munich and the CAS team at WHO. The final goals are valid and globally agreed tools to be used in clinical practice, research and health statistics.

Key words: health, rehabilitation, classification, ICF.

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Medicine and, more specifically, rehabilitation is dedicated to optimizing patient functioning and health. Accordingly, concepts, classifications and measurements of functioning and health are an important key to clinical practice, teaching, and research (1) and new developments, such as the International Classification of Functioning, Disability and Health (ICF, formerly ICIDH-2: http://www3.who.int/icf/icftemplate.cfm) (2) are of great interest to researchers, clinicians, and clinical teachers.

The ICF is designed to record and organize a wide range of information about health and health-related states. Since the ICF has been developed in a worldwide, comprehensive consensus process over the last 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 ICF is intended for use in multiple sectors that include, besides health, education, insurance, labour, health and disability policy, statistics, etc. In the clinical context, it is intended for use in needs assessment, matching interventions to specific health states, rehabilitation and outcome evaluation.

However, the ICF will have to be tailored to suit these specific uses (3). Firstly, the joint use of the ICF and the International Classification of Diseases (ICD-10) needs to be addressed when applying the ICF to medical practice. The WHO considers the ICF and the ICD-10 to be distinct but complementary classifications. According to this view, which is shared by rehabilitation medicine, patient functioning and health are associated with, but not merely a consequence of a condition or disease. For practical purposes and in line with the concept of condition-specific health status measures (4), it would thus seem most helpful to link specific conditions or diseases to salient ICF categories of functioning (3). Such generally-agreed-on lists of ICF categories can serve as *Brief ICF Core Sets* to be rated in all patients included in a clinical study with a condition or as *Comprehensive ICF 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 typical spectrum of problems in functioning of patients with a specific condition. Since it is intended that the categories of the Brief ICF Core Set for a condition serves as a minimum data set that will be reported in every clinical study to describe the burden of disease in a comparable way across studies, the list needs to be as short as possible. Instead, 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 typical spectrum of problems in functioning of patients with a specific condition. Obviously, this list will be considerably longer than the Brief ICF Core Set.

The objective of the ICF Core Sets project is the development of internationally agreed Brief ICF Core Sets and Comprehensive ICF Core Sets. The ICF Core Sets project is a joint project of the ICF Research Branch of the German WHO FIC collaborating centre at the University of Munich and the CAS team at the WHO together with partner organizations worldwide (3). The 12 conference reports in this supplement describe the development of the ICF Core Sets for 12 chronic conditions with a high burden of disease.

The methods used to develop both ICF Core Sets, the Comprehensive ICF Core Set and the Brief ICF Core Set, involved a formal decision-making and consensus process integrating evidence gathered from preliminary studies and expert opinion. For each health condition, the preliminary studies included a *Delphi exercise* (5), which represents the expert view, a *systematic review* (6–10) on outcomes used in randomized clinical trials, which represents the view of researchers performing studies, and an *empirical data collection*, using the ICF checklist representing the perspective of patients undergoing inpatient or outpatient rehabilitation (11). Based on these preliminary studies relevant ICF categories were identified. The lists of these identified categories represent the starting point of the decision-making and consensus process that took place in three different consensus conferences.

Based on the literature on consensus building and teamwork (12), the 3 ICF Core Sets Consensus Conferences were organized at a quiet monastery situated in a pleasant landscape, distant from cities and distractions. The 1st, 2nd, and 3rd International ICF Core Sets Consensus Conferences took place on April 26–29, 2002, January 31 to February 3, 2003, and at May 30th to June 2nd, 2003, respectively. The 1st conference was on low back pain, osteoarthritis, osteoporosis, and rheumatoid arthritis, the 2nd conference on chronic widespread pain, depression, stroke, and obesity, and the 3rd conference on breast cancer, diabetes mellitus, obstructive pulmonary diseases, and chronic ischaemic heart disease.

To ensure expertise and broad representation within the context of a feasible and affordable decision-making process, (i) formal co-operation with appropriate organizations were established, (ii) clinicians involved in the preliminary studies were invited, (iii) international and regional societies (or working groups) were identified and their members contacted, (iv) opinion leaders in the different health conditions were identified and invited, and (v) experts in the fields of functioning and health, quality of life, health statistics, and public health from developing countries were contacted by the WHO and invited to the conference.

During the conference, the first meeting consisted of a half-day training workshop, in which all participants were familiarized with the ICF framework and classification (2) and informed about the evidence from the preliminary studies. Participants were provided with summary sheets containing both the identified ICF categories and the results of the preliminary studies.

The ICF categories to be included in the ICF Core Sets were then identified in an iterative decision-making process with discussions and voting. In the process, ICF categories which were either clearly relevant or irrelevant according to pre-set decision rules were excluded from further discussion. The focusing on the remaining controversial categories was thereby facilitated. Immediate feedback on the voting results during the whole decision-making and consensus process was performed.

The decision-making process consisted of two major parts. In the first part, the participants were requested to select the Comprehensive ICF Core Set according to the above definition. In the second part, the participants were requested to select the Brief ICF Core Set. This second part involved exclusively the categories of the Comprehensive ICF Core Set. Data concerning the voting and ranking processes were continuously entered in MS Excel 2000 throughout the conference. Descriptive statistics were used to examine the frequency with which the experts endorsed the different ICF categories for inclusion in the ICF Core Sets. The results are presented in 12 conference reports of this supplement.

Both, the Brief ICF Core Sets and the Comprehensive ICF Core Sets are preliminary and need to be tested in the coming years in different countries and regions, subsets of patients with varying patient and condition characteristics, healthcare settings, and from the perspective of the different professions involved in the care of patients. The testing will be based on a standardized protocol in close co-operation with the ICF research branch of the WHO FIC CC (DIMDI) in Munich and the CAS team at WHO. The final goal is valid and globally agreed tools to be used in clinical practice, research and health statistics.

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