

ICF Core Sets Newsletter

July – September 2003

1. Project overview

The ICF Core Sets project is a collaboration project between the World Health Organization (WHO) and the ICF Research Branch, WHO FIC, Germany, at the University of Munich. The core partner organizations of the project are:

The International Society of physical and Rehabilitation Medicine,

The German Society for Rehabilitation Research,

The Austrian, German and Swiss Society of Physical Medicine and Rehabilitation,

The Swiss Physical Therapy Association,

The Bavarian Scientific Research Network in Rehabilitation

Eular, and

The Bone and Joint Decade.

Two phases with their respective aims can be distinguished in this project (figure 1).

Phase I, which has already been completed, aimed to select the ICF categories to be included in the different ICF Core Sets. This selection took place in three international consensus conferences that were held at Seon's monastery, near Munich. During these conferences experts from all over the world derived the spectrum of prototypical ICF categories in a variety of 12 health conditions (see below) based on the results of preliminary studies using empirical data from 1000 patients, international Delphi surveys and systematic reviews.

The first ICF Core Sets conference on low back pain, osteoarthritis, osteoporosis and rheumatoid arthritis took place from April 26 to April 29, 2002 under the participation of a panel of 80 experts from 28 countries.

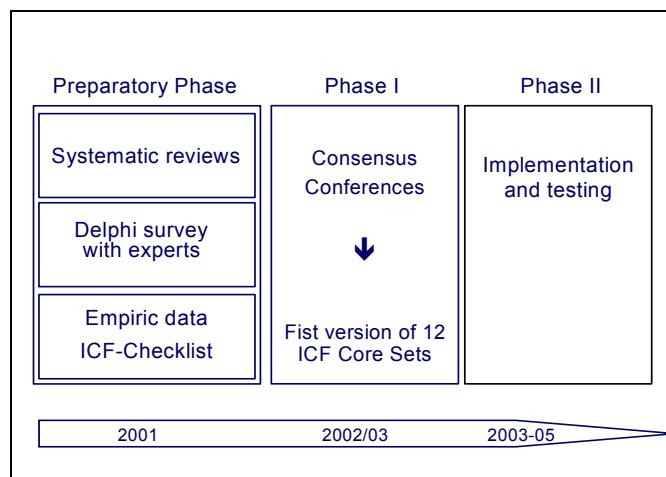
Depression, chronic widespread pain, obesity and stroke were the conditions to work on during the second ICF Core Sets conference, on which 140 experts from 28 countries participated from January 31 to February 3, 2003.

The third ICF Core Sets conference on breast cancer, diabetes mellitus, chronic ischaemic heart disease and obstructive pulmonary disease was held from May 30 to June 2, 2003 under the participation of a panel of 78 experts representing 22 countries. Regarding the decision-making and consensus process followed during the conferences, please find attached under point **3** of this newsletter the report of one of the participants,

Prof. Dr. Zhou Xiaonan from China, to the Peking Union Medical College Hospital, where she works at the department of internal medicine.

Phase II of the project aims to implement and test the Core Sets developed during phase I. This objective will be accomplished within the scope of an international collaboration, which is introduced in more detail in the next paragraph of this newsletter.

Figure 1: Phases of the ICF Core Set Project



2. Phase II: First effort of INIF

In the Phase II of the project a network of organizations from all over the world which are interested in the implementation and testing of the of the 12 pilot ICF Core Sets developed during phase I of the project will work together within the so called INIF (International Initiative for Functioning and Health).

The first effort of the INIF will be the implementation and testing of the pilot ICF Core Sets on the basis of an international multicenter study, which will start by the end of November for the health conditions low back pain, osteoarthritis, osteoporosis, rheumatoid arthritis and chronic widespread pain. The study involving patients with the remaining health conditions will start during the first quarter of 2004.

The ICF Research Branch, WHO FIC, Germany, at the University of Munich will be responsible for the coordination of all institutions involved in the INIF and for providing all required information and material.

All organizations, which have notified their interest in the implementation and testing of the ICF Core Sets will be part of the INIF and will receive a Collaboration Agreement by the end of September.

If you are interested in joining the INIF for the implementation and testing of the ICF Core Sets, and haven't had the opportunity to notify us, please fill in the attached "Association Intent Form" and send it back to us.

Once the collaboration agreement has been signed by the responsible parties, the ICF Research Branch of Munich University will provide in English language the study protocol, patients' information sheet and patient consent form together with a document which testifies that all named documents have been approved by the Ethics Committee of the Ludwig-Maximilians-University in Munich and by the Ethics Committee of Bavaria [District Medical Council].

The Case Record Forms (CRFs) containing the ICF Core Sets, the CRFs for the patients (self-administered questionnaires) as well as proper instructions on the data documentation will also be provided by the ICF Research Branch of Munich University.

The ICF Research Branch of Munich University will keep very close contact with all the organizations of the INIF and will inform them regularly on the progress of the study.

2.1. Partner Organizations (associated):

- Eular
- Portuguese Society of Physical Medicine and Rehabilitation
- The Austrian, German and Swiss Society of Physical Medicine and Rehabilitation
- The Bavarian Scientific Research Network in Rehabilitation
- The Bone and Joint Decade
- The German Society for Rehabilitation Research
- The International Society of Physical and Rehabilitation Medicine (ISPRM)
- The Swiss Physical Therapy Association

2.2. Partner Organizations (statement of interest):

- American Academy of Physical Medicine and Rehabilitation
- American Society of Neurorehabilitation for Stroke
- Austrian Occupational Therapy Association
- Center for Diabetes and Metabolic Diseases, Italy for Diabetes mellitus
- European Network of Physiotherapy in Higher Education
- EUSOMA for Breast Cancer
- Federal Association of Self-Employed Physiotherapists - IFK e.V.
- Hellenic Society of Physical Medicine and Rehabilitation
- International Association for the Study of Obesity for Obesity
- International Federation of Social Workers
- International Society for Bipolar Disorders for Depression
- Ministry of Health, Mexico
- National Center for Rehabilitation Medicine, Fiji
- National Institute for Medical Rehabilitation, Hungary for Stroke, LBP and CWP
- ORTON Research Institute, Finland
- Pan American Health Organization
- Peking Union Medical College Hospital, China
- Rehabilitation Clinic of Felix Spa, Romania
- Russian Academy for Social Medicine and Rehabilitation
- The Japanese Association of Rehabilitation
- The Swedish Association of General Practice
- University Hospital Elias, Romania
- University of Ibadan, Nigeria
- University of Malaya, Malaysia
- University of Medicine of Hanover, Germany
- University of Melbourne, Australia

3. Report on the 3rd ICF Core Sets Consensus Conference by Prof. Dr. Zhou Xiaonan from China

The 3rd ICF Core Sets Consensus Conference was held in Kloster Seeon Germany from May 30 to June 2, 2003. More than 80 experts from 22 countries attended the conference. Prof. Wang Heng and Associate Prof. Zhou Xiaonan from The Peking Union Medical College Hospital supported by WHO have attended the conference. The purpose of the conference is to make the ICF more practical in clinical use. We tried to cut off the ICF categories, which are not very closely related to the patients with breast cancer, chronic ischaemic heart disease, diabetes mellitus or obstructive pulmonary disease.

The experts of every special area were divided into three small groups. The experts in small groups discussed and voted to decide which ICF category should be kept or cut off. If more than 80% of the experts in the small group agreed to keep the category, it would be painted to green; If more than 80% of the experts in the small group agreed to cut off the category, it would be painted to red; If more than 20% and less than 80% of the experts in the small group agreed to keep or cut off the ICF category, it would be painted to yellow. Then three small groups in one special area came together. If there were different opinions on one category the experts in different groups had to explain why they choose to include or to exclude a category.

Then the three groups would go back to their own rooms to discuss and vote again the categories without agreement among the three groups. This kind of procedure had been repeated for four to five times. At last we got the conclusion. Dr. Wang Heng worked in the Diabetes Mellitus (DM) group. She said: "There are 40 millions DM patients in China. Part of them suffered from vascular complications, which could result in disabilities or even death. It is very important disease in China and in the world. We cut off a lot of categories and only keep 10 to 15 categories in each domain under DM. Whether those categories are useful or not we will see in the future. And we will correct and improve them in our clinical practice."

In other three special areas the conclusions are similar. This conference is very successful. The arrangement is wonderful. It might take a long time to make doctors in China know something about ICF. Before we spread ICF in China I hope I can correct and modify the Chinese version of ICF first after the English one completed.

Dr. Zhou Xiaonan

4. How to contact us

For any questions and for further information please contact:

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5. Attachments

“Association Intent Form”