

1st Newsletter

January 2007 - July 2007

The project “*Development of ICF Core Sets for Multiple Sclerosis (MS)*” is progressing fast. With this newsletter, we would like to inform you about the goals achieved during the last seven months.

Preparatory studies

Systematic review

The objective of the systematic review is to identify parameters reported in studies involving patients with MS and published in the last five years (2002 – 2007). The search strategy and the eligibility criteria for the literature search were defined and the relevant literature databases (EMBASE, MEDLINE, CINAHL, PsychINFO, Cochrane Central) were selected. The search was already conducted in May 2007. The abstract check of 2000 randomly selected abstracts is completed. Totally, 354 articles fulfilled the predefined eligibility criteria. The data extraction of these full-text articles is in process. The systematic review is being performed by Sandra Kus and Michaela Coenen at the ICF Research Branch in Munich.



Sandra Kus



Michaela Coenen

Qualitative study

The objective of the qualitative study is to identify the aspects of functioning and health, which are important to individuals with MS. With the support from Dr. Nicolaus Koenig and Dr. Birgit Basedow-Rajwick focus groups and individual interviews are conducted at the Marianne Strauss Clinic in Kempfenhausen (Germany). Up to now six focus groups (28 participants) and five individual interviews were completed. The data analysis is in process. It is expected the data analysis to be finished in November 2007. The qualitative study is performed by Michaela Coenen at the ICF Research Branch in Munich.



Michaela Coenen

Expert survey

The objective of expert survey is to identify the most relevant and typical main issues facing people with MS. The expert survey will be performed as an internet survey to gather the opinion of experts with different health professions (physicians, physical therapists, occupational therapists, nurses, (neuro-)psychologists, speech & language therapists, and social workers). In a first step, a pool of experts is created. In a second step, a random sample is drawn out of this expert pool. When selecting the participants, representativeness of health professions and WHO world regions are considered. In May 2007, the recruitment of health



Michaela Coenen



Andreas Leib

professionals experienced in the treatment of individuals with MS was initiated in collaboration with the Council of Occupational Therapists of the European Countries (COTEC), the World Confederation for Physical Therapy (WCPT), the International Organization of MS Nurses (IOMSN), the Multiple Sclerosis International Federation (MSIF) and its national societies, Rehabilitation in MS (RIMS) and other national and international societies. Over 420 health professionals with different professional backgrounds from over 44 countries have agreed to participate in the expert survey up to now. Within the next weeks we will randomly select participants out of the expert pool and ask them to answer the questions of the internet survey. The data analysis will be started by the end of September 2007. Michaela Coenen and Andreas Leib at the ICF Research Branch in Munich are responsible for the expert survey.

Cross-sectional empirical study

The objective of the empirical study is to describe functioning and health of individuals with MS from a clinical perspective. A workshop on the ICF classification and on the principles of the empirical study took place at the ICF Research Branch in Munich on 14th and 15th May 2007. Forty seven patients have been included in the empirical study up to now. It is planned to complete the data collection in December 2007 with a total sample size of 200 patients. The study is performed in the



Lisa Holper

Andrea Weise

Valens Rehabilitation Centre. Additionally, data are collected at the University Hospital Zurich, Switzerland (Department of Neurology; *Prof. Claudio Bassetti*), the Swiss Multiple Sclerosis Society, Switzerland (*Vera Rentsch*), and the Rehabilitation Centre Quellenhof, Germany (*Prof. Peter Flachenecker*). Lisa Holper at the Valens Rehabilitation Centre (Switzerland) is leading the empirical study; the coordination has been undertaken by Andrea Weise, Valens Rehabilitation Centre.

ICF Consensus Conference

The International ICF Core Set Consensus Conference will be held at the Valens Rehabilitation Centre (Switzerland) on May 2nd to 4th, 2008. Following a multi-stage decision process, the selected experts will agree on the ICF categories to be included in the *ICF Core Sets for MS*.



Presentations & Publications

The project was presented at the joint meeting of the Swiss Society for Neuroscience (SSN), the National Center of Competence Research: Neural Plasticity and Repair (NCCR Neuro), and the Swiss MS Society (see page 4).

Poster presentations will be held at the 80th Congress of the German Society for Neurology (Berlin, Germany, September 12-15, 2007) and the 23rd Congress of the European Committee

for Treatment and Research of Multiple Sclerosis (ECTRIMS) and the 12th Conference of Rehabilitation in Multiple Sclerosis (RIMS) (Prague, Czech Republic, October 11–14, 2007).

Please notice that a short report describing the methods applied in this project will be published in Multiple Sclerosis (<http://msj.sagepub.com>).

The project is being funded by the Hertie Foundation and is a cooperative effort of the Department of Neurorehabilitation at the Valens Rehabilitation Centre in Switzerland, the ICF Research Branch of the WHO at the Ludwig-Maximilian University in Munich, the Classification, Assessment and Surveys (CAS) team at WHO, the Swiss MS Society, the Multiple Sclerosis International Federation (MSIF), the International Society of Physical Medicine and Rehabilitation (ISPRM).

Steering committee of the project: Jürg Kesselring, Gerold Stucki, Jenny A. Freeman, Fary Khan, Nenad Kostanjsek, Eija Luoto, John Melvin, Bhim S Singhal, Silvia N Tenenbaum, Alan Thompson



Development of ICF Core Sets for Multiple Sclerosis: a way to specify functioning

Jürg Kesselring, Michaela Coenen, Alarcos Cieza, Nenad Kostanjsek, Gerold Stucki



Valens Rehabilitation Centre, Valens (Switzerland)

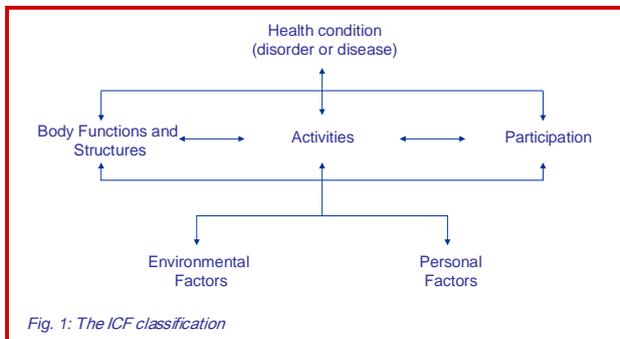
ICF Research Branch of the WHO FIC CC (DIMDI), Ludwig-Maximilian University, Munich (Germany)

Institute for Health and Rehabilitation Sciences (Chairman: Prof. Dr. Gerold Stucki), Ludwig-Maximilian University Munich (Germany)



Background

Multiple sclerosis (MS) can follow a variety of clinical courses and is unpredictable in terms of prognosis. Impairment, activity limitations and participation restrictions are important consequences of MS. Therefore, a widely agreed-upon tool for capturing these complex constructs would be important for the description and assessment of functioning problems of persons with MS as well as for the planning of interventions. With the International Classification of Functioning, Disability and Health (ICF) we can now rely on a globally agreed-upon framework and system for classifying the typical spectrum of problems in functioning of individuals with MS given the environmental context in which they live. The ICF framework is based on a comprehensive and integrative perspective covering functioning and disability with its components Body Structures and Functions, Activities and Participation as well as Personal and Environmental Factors (Figure 1). Since its classification with more than 1400 categories can serve as a reference but is not applicable in clinical practice, tools such as ICF Core Sets are needed to make the ICF useful for medicine.



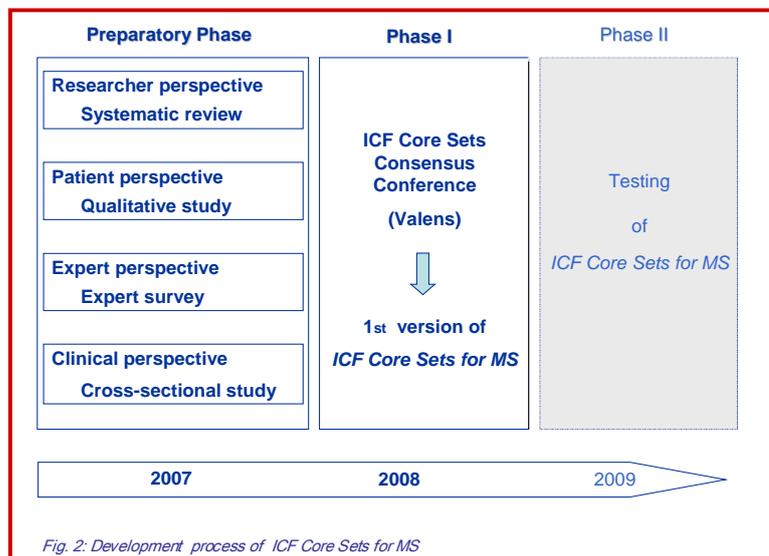
Definition ICF Core Set

List of ICF categories of the International Classification of Functioning, Disability and Health (ICF) that are relevant for individuals with a specific condition or in a specific setting.

Methods

The *ICF Core Sets for MS* will be defined at an international **ICF Core Set Consensus Conference** which will integrate evidence from the following preparatory studies:

- a **systematic review** of measures and outcomes used in studies involving patients with MS and published in the last five years
- a **qualitative study** with individuals with MS using focus groups and individual interviews to identify aspects of functioning and health, which are important to persons with MS
- an **expert survey** via email to gather the opinion of an international pool of experts regarding the most relevant and typical areas to be considered in persons with MS
- a **cross-sectional study** involving 200 patients with MS to describe functioning and health of persons with MS



Cooperation

The development of the *ICF Core Sets for MS* is funded by the Hertie Foundation and is a cooperative effort of the:

- World Health Organization (WHO)
- Department of Neurorehabilitation of the Valens Rehabilitation Centre (Switzerland)
- ICF Research Branch of the WHO Collaboration Centre of the Family of International Classifications (Germany)
- Multiple Sclerosis International Federation (MSIF)
- International Society of Physical Medicine and Rehabilitation (ISPMR)

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