

5. Newsletter

ICF Core Sets

January - March 2005

Dear partners and friends of the ICF Core Set project,

Many things have happened in the last three months concerning the ICF Core Sets development project. In this issue we would like to inform you on the actual status of the project. In addition, four summary reports describing different national networks established to disseminate and better coordinate the validation studies of the ICF Core Sets regionally are contained.

Furthermore, this newsletter also provides an overview on all actual ICF Core Sets projects. As usual, a list with all participating study centers in the validation study is included.

We hope that you enjoy the reading of this 5th newsletter.

Kind regards,

Your ICF Core Set Development Team

1. Project Status

1.1. Number of study centers per country

No.	Country	Study Centers
1.	Argentina	1
2.	Australia	3
3.	Austria	4
4.	Brazil	1
5.	Canada	1
6.	China	4
7.	Cyprus	1
8.	Czech Republic	1
9.	Finland	1
10.	Germany	71
11.	Greece	5
12.	Hungary	15
13.	Italy	12
14.	Japan	1
15.	Kenya	1
16.	Kuwait	2
17.	Lebanon	1
18.	Lithuania	2
19.	Malaysia	1
20.	Mexico	3
21.	Nigeria	1
22.	Norway	3
23.	Philippines	1
24.	Poland	2
25.	Portugal	4
26.	Romania	3
27.	Russia	1
28.	Serbia	2
29.	South Africa	1
30.	South Korea	1
31.	Spain	2
32.	Sweden	2
33.	Switzerland	13
34.	The Netherlands	4
35.	Tunisia	1
36.	Turkey	5
37.	UK	4
38.	USA	3
	Total	184 Centers

1.2. Training of Health Professionals

Training of German study centers

During the first years' quarter our ICF training team organized 4 workshops for the ICF Core Sets validation study. A total of 60 health professionals were trained. Two training workshops took place at the Ludwig-Maximilians-University in Munich on 25.02.05 and on 22.03.05. For the two external training workshops, we visited Prof. Thilmann in the Clinic Rhein/Ruhr, Essen and Mr. Dirk Bauernschmitt in the Rehabilitationsclinic Bellevue in Bad Soden. The next external training workshop will take place at the Rehabilitationsklinik Küppelsmühle, Bad Orb.

Coming training workshops at the Ludwig-Maximilians-University in Munich are planned on:

- 22. April 2005
- 08. Juli 2005.

We would like to remind you that the training workshops are in German language and herewith we kindly invite you to attend. Please find the registration form attached to this newsletter.

1.3. Data Collection

475 Case Record Forms (CRFs) have already been entered into the ICF Core Sets database.

Up to now we have received a total of **743** Case Record Forms:

	International	National	Total
Breast Cancer	20	18	38
Chronic Ischaemic Heart Disease	5	12	17
Chronic Widespreadpain	24	109	133
Depression	0	12	12
Diabetes Mellitus	20	0	20
Low Back Pain	41	29	70
Obesity	0	0	0
Obstructive Pulmonary Diseases	0	0	0
Osteoarthritis	79	0	79
Osteoporosis	57	8	65
Rheumatoid Arthritis	111	0	111
Stroke	51	146	192
Total	409	334	743

At this point we would like to remind you to send us by regular mail all filled in CRFs.

2. ICF Core Sets Networks established

2.1. Greek network for the testing and validation of the ICF Core Sets for chronic conditions

Since the start of the validation study, the Greek centres have made a commitment to participate on the testing and validation of the ICF Core Sets for chronic conditions. Therefore, Professor Xanthi Michael and the Greek Society of Physical and Rehabilitation Medicine decided that it would be most important to create a Greek network to better coordinate the validation studies and to integrate the data and the results from the Greek perspective. To initiate the Greek network Professor Xanthi Michael and the Greek Society of PMR organised a 2 day meeting at the Hygeia Hospital in Athens and invited all members of the Greek Society of Physical and Rehabilitation Medicine, occupational therapists and physical therapists from the currently involved partner institutions. The Greek Ministry of Health was also represented. For the rheumatologic perspective and in the context of the EULAR project Dr. Georgios Kampakis, from the General Hospital of Athens "G.Gennimatas" was invited. A total of 50 persons were introduced to the ICF and the ICF Core Set development by Dr. Alarcos Cieza and Prof. Gerold Stucki from the ICF Research Branch in Munich. Professor Gerold Stucki who is currently also the president of the German Society of Physical Medicine and Rehabilitation was specifically addressing the value of the ICF and ICF Core Sets for clinical practice and Dr. Alarcos Cieza was leading practical workshops. Most importantly, all attendees were carefully introduced into the principles of coding the ICF Core Sets within the validation study. In the context of the meeting a Steering Committee for the Greek network under the leadership of Professor Xanthi Michael was established, leaders for each specific health condition were also named. It was decided that Dr. Nikos Roussos will lead the effort and coordinate the data collection for patients with stroke, Dr. Georgios Kampakis will lead and coordinate the effort of the data collection for rheumatoid arthritis and osteoporosis, and Professor Xanthi Michael will lead and coordinate the effort for patients with low back pain and chronic widespread pain. Dr. Nikos Roussos will explore the possibility to test the ICF Core Set for chronic ischaemic heart disease. There is also the intention to collect a small but relevant number of data on patients with obesity and breast cancer.

The coordinators for the specific conditions will make sure that the agreed number of patients will be met and will work closely with the ICF Research Branch in Munich in regard to the data analysis and possible publications from the Greek perspective.

The workshop was highly interactive and contributed to the dissemination of the ICF and the ICF Core Sets as a most valuable concept and tool both for clinical practice and research.

2.2. The beginning of an Italian Experience on the ICF Core Sets

In 2004, Dott. Alessandro Giustini and his team were successful obtaining a grant from the Italian Ministry of Health to partially finance the ICF Core Sets Validation Study in Italy.

The thereby established Italian network involves 11 study centres. The project started in January 2005 with a meeting with all involved partners at the Scientific Institute of Montescano – Fondazione S. Maugeri, Pavia, Italy. An additional meeting took place in the same location on February 23rd.

The aim of the project is to validate on the Italian population four ICF Core Sets (Chronic Widespread Pain, Obstructive Pulmonary Diseases, Osteoporosis, Stroke) and is coordinated by dr. Maini.

In the first months of the project, the project has focused on the training of the health professional involved in the data collection. The training has been conducted based on the training video provided by the ICF Research Branch and on face-to-face training meetings in each of the study centers.

During the two meetings held in Montescano an intense and rich discussion took place. Many members enlightened the challenges when using the qualifiers' scale. The way how to obtain homogeneous evaluation among different raters with different health professional backgrounds was also a discussed. The question "how to measure" the different ICF categories was a very controversially discussed issue. Since health professional with different backgrounds are involved in the project and different instruments and techniques are available, the question which indicators to use for the judgement of the different ICF categories arose. In order to enhance homogeneity in the data collection an official document in Italian language has been written, which indicates in detail all the emerging issues and the all corresponding solutions collectively proposed. The document has been also sent to the ICF Research Branch in Munich for further consideration.

The data collection will start in April and will last 18 months. At the end of the first year of the study the first partial results will be considered.

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2.3. “ICF Core Sets Validation Study in Norway”

by prof. Erik Bautz-Holter Phd. MD. Department of physical medicine and rehabilitation, Ullevaal University Hospital, Oslo

The health authorities in Norway intent to participate in the development and implementation of the ICF. Several projects are undertaken, among them a multi-centre study with the *ICF Core Sets for Stroke* and *Low Back Pain*. The coordinating centre of the study is Department of Physical Medicine and Rehabilitation at Ullevaal University Hospital in Norway. The study is financed by grants from the Ministry of Social and Health Affairs in Norway and is part of the international WHO project led by professor Gerold Stucki and Alarcos Cieza of the ICF Research Branch at the Ludwig-Maximilians-University in München.

The aims of the study are

1. to contribute to the international database of the ICF Core Sets Validation Study
2. to establish a norwegian database
3. to compare the ICF Core Sets with measures other than those included in the ICF Core Sets Validation Study
4. to establish national and multi-professional competence in the use ICF
5. to implement the knowledge and experiences from the study in the health and social care in Norway
6. to prepare the grounds for further participation in the development of the ICF

Eight medical centres are participating in the study, six in stroke and seven in low back pain. Twelve and ten persons, respectively, with varying professional background (medical doctors, physical therapists, occupational therapists and nurses) will participate in the data collection. A multi-disciplinary project group has prepared the basis for an educational meeting, aiming at developing uniform and adequate procedures of registration. The meeting took place on March 31, 2005.

The data collection will start in April/May 2005 and probably be finished at the end of 2005. The expectation is to include about 200 subjects for each health condition. Each centre will send the questionnaires to the coordinating centre, where they will be properly marked and forwarded to the ICF Research Branch in Munich.

2.4. “The Asian Perspective: Visit from Malaysia”

On February 15th-16th, 2005 Associate Professor Dr. Zaliha Omar head of the Department of Allied Health Sciences, University of Malaya, Kuala Lumpur, Malaysia visited the ICF Research Branch in Munich. Prof. Omar has been an active partner throughout the project “The Development of the ICF Core Sets for Chronic Conditions”; therefore, she is well acquainted with the ICF. Nevertheless, since she will personally train her staff at the University of Malaya for the data collection for the validation study of the ICF Core Sets, one of the main aims of her visit was to be trained in the principles of coding the ICF Core Sets. Prof. Omar will lead and coordinate the validation study in Malaysia for the following conditions: breast cancer, diabetes mellitus, low back pain, osteoarthritis and stroke. She is committed to collect data from ca. 400 patients until the end of the year.

3. Report on further ICF Core Sets studies

3.1. Cross-Sectional-Reliability Study using the Comprehensive ICF Core Set for Low Back Pain

Seraina Obrist (Switzerland)

The overall objective of this study is to examine the reliability of each of the categories contained in the *Comprehensive ICF Core Set for Low Back Pain* (LBP) when they are rated by two different physical therapists.

60 patients from the following study centers will participate in this study: **Klinik Linde AG** , **Rehabilitationsklinik Leukerbad** and **Spitalzentrum Biel**.

In addition to the rating of the degree of the problem of the patients in each of the ICF categories contained in the *Comprehensive ICF Core Set for LBP* using the generic qualifier scale, the two physical therapists will rate how confident they are when rating the corresponding ICF categories (from 0% confident to 100% confident).

The study initiation is scheduled for April 2005 and its completion is planned for November 2005.

4. Report on further ICF project

4.1. *MHADIE Measuring Health and Disability in Europe*

A new framework for supporting health and disability policy development in Europe

Dr. Matilde Leonardi (Italy)

The Italian National Neurological Institute Carlo Besta is the coordinator of innovative European research involving leading international researchers that will allow the European Union to propose to its member countries a new model for disability policy within both health and social contexts.

The kick-off meeting of MHADIE (Measuring Health and Disability in Europe: supporting policy development) took place at the National Neurological Institute C. Besta in Milan on Friday 4 and Saturday 5 March 2005.

This project is of great interest to those concerned with health and disability issues, as well as the larger scientific community. As Dr Matilde Leonardi from the Scientific Direction of the Institute, leader of the research group Public Health, Disability and ICF and coordinator of this important European project, puts it: *“For the first time health and disability issues are approached not merely from a narrow clinical perspective but from one in which environmental, psychological and quality of life aspects of the total lived experience are also taken into account. Understanding how to respond to the needs of people with disabilities means understanding how to influence social and economic policies as well as designing specific tools to combat discrimination and promote social integration and participation, thus enhancing opportunities.”*

The World Health Organisation’s ICF (International Classification of Functioning, Disability and Health) provides a new framework for conceptualising health and disability and will be tested by a group of scientists and researchers from 14 European Union Countries. This study will should yield important results for medical care and social integration, especially for the production of disability statistics.

The universal approach embodied in the ICF is a major paradigm shift in our understanding of disability, one that emphasizes the need to integrate individual functioning with the complete physical and social environment, incorporating the full lived experience disability and linking together health and social participation issues policy concerns. The project will develop policy recommendations and guidelines that Italy and the rest of the European Union will be able to use for their policy planning and development.

In this 3-year project Italy will play a leading role as the coordinating country. In addition, the Labour and Welfare Ministry of Italy is implementing a pilot project “ICF and Labour Policies” that is developing a new approach to work related issues as they apply to people with disabilities and which is currently being tested in 25 provinces throughout all regions of the country.

MHADIE will develop a framework to influence and support new European policy guidelines on health and disability through statistical, clinical and experimental research, and will use ICF as a cross-cutting universal framework and international standard.

Among the partners of the research group “Public Health, Disability and ICF” led by Dr Matilde Leonardi from the Scientific Direction of the National Neurological Institute C. Besta are the World Health Organization, the **ICF Research Branch at the Ludwig-Maximilians-University**, the European Federation of Neurological Associations and leading world experts in health and social policy and ICF from Spain, Slovenia, Switzerland, Sweden, Rumania, Ireland, Germany, Czech Republic as well as the Family and Social Solidarity Department of Regione Lombardia, the Regional Health Agency of Regione Friuli Venezia Giulia, Don Gnocchi Foundation, CF Consulting and the Disability Italian Network (DIN).

5. Actual projects overview

Name	Stand	Contact person
<i>Branch Projects:</i>		
ICF Core Sets multicenter international validation study	International data collection for 12 chronic conditions is being performed for the validation of the first version of the ICF Core Sets.	Dr. Alarcos Cieza, MPH Alarcos.Cieza@med.uni-muenchen.de Alicia Garza Alicia.Garza@med.uni-muenchen.de Andrea Glaessel Andrea.Glaessel@med.uni-muenchen.de Michaela Kirschneck Michaela.Kirschneck@med.uni-muenchen.de
EULAR - European validation of the ICF Core Sets for five musculoskeletal diseases	The study material has been sent to 25 European centers to begin the data collection.	Dr. Susanne Schwarzkopf Susanne.Schwarzkopf@med.uni-muenchen.de
Validation of the Comprehensive ICF Core Set for Rheumatoid Arthritis from the Patient Perspective	The focus groups with rheumatoid arthritis are concluded; analysis and publications are in process.	Michaela Coenen, MPH Michaela.Coenen@med.uni-muenchen.de
Validation of the ICF Comprehensive Core Set for Rheumatoid Arthritis from the perspective of Health Professionals	The studies regarding the validation of the ICF Core Sets for Rheumatoid Arthritis from the perspective of physical therapists and occupational therapists have been concluded. The studies regarding the validation of the ICF Core Sets for Rheumatoid Arthritis from the perspective of psychologists, and nurses are currently being performed.	Dr. Inge Kirchberger, MPH Inge.Kirchberger@med.uni-muenchen.de
<i>Cooperation Projects:</i>		
Development of an International Classification of Functioning Disability and Health Core Set in patients with Psoriasis or Psoriatic Arthritis	The preliminary studies are in process.	Dr William Taylor wtaylor@wnmeds.ac.nz
Development of the ICF Core Sets for Ankylosing Spondylitis	The preliminary studies are in process.	Annelies Boonen, MD, PhD aboo@sint.azm.nl
Measuring Health and Disability in Europe: supporting policy development (MHADIE)	Project started on January 2005.	Dr. Alarcos Cieza, MPH Alarcos.Cieza@med.uni-muenchen.de

For more information visit our website: www.icf-research-branch.org

6. New Publications

Cieza A, Stucki G.

Understanding functioning, disability, and health in rheumatoid arthritis: the basis for rehabilitation care.

Curr Opin Rheumatol. 2005 Mar;17(2):183-9.

PMID: 15711233 [PubMed - in process]

Dworkin RH, Turk DC, Farrar JT, Haythornthwaite JA, Jensen MP, Katz NP, Kerns RD, Stucki G, Allen RR, Bellamy N, Carr DB, Chandler J, Cowan P, Dionne R, Galer BS, Hertz S, Jadad AR, Kramer LD, Manning DC, Martin S, McCormick CG, McDermott MP, McGrath P, Quessy S, Rappaport BA, Robbins W, Robinson JP, Rothman M, Royal MA, Simon L, Stauffer JW, Stein W, Tollett J, Wernicke J, Witter J; IMMPACT.

Core outcome measures for chronic pain clinical trials: IMMPACT recommendations.

Pain. 2005 Jan;113(1-2):9-19. No abstract available.

PMID: 15621359 [PubMed - in process]

Michel BA, Stucki G, Frey D, De Vathaire F, Vignon E, Bruehlmann P, Uebelhart D.

Chondroitins 4 and 6 sulfate in osteoarthritis of the knee: A randomized, controlled trial.

Arthritis Rheum. 2005 Mar;52(3):779-86.

PMID: 15751094 [PubMed - in process]

Stamm TA, Cieza A, Machold KP, Smolen JS, Stucki G.

Content comparison of occupation-based instruments in adult rheumatology and musculoskeletal rehabilitation based on the International Classification of Functioning, Disability and Health.

Arthritis Rheum. 2004 Dec 15;51(6):917-24.

PMID: 15593365 [PubMed - indexed for MEDLINE]

7. Study Centers

New Study Centers are grey shadowed.

Argentina	
Hospital San Juan Bautista Calle Dr. Julio Herrera 432 Barrio Judicial 4700, Catamarca <i>Dr. Sergio Miguel Toloza</i>	
Australia	
Braeside Hospital Rehabilitation Medicine Locked bag 82, Wetherill Park 2164 New South Wales <i>Dr. F. Köhler</i>	Lourdes Hospital, Health and Aged Care Services Rehabilitation Medicine NSW 2830 Dubbo <i>Dr. Jagdish Maharaj</i>
University of Melbourne Victorian Rehabilitation Research Institute Poplar Road 3052 Melbourne, Victoria <i>Prof. Dr. Peter Disler</i>	
Austria	
Donauspital Physical Medicine & Rehabilitation Langobarelenstrasse 122 A-1220 Wien <i>Dr. Christine Prager</i>	Kaiser-Franz-Josef-Spital/ SMZ Süd Institut für Physikalische Medizin Kundratstrasse 3 1100 Vienna <i>Prof. Dr. Michael Quittan</i>
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Brazil	
Hospital das Clinicas, School of Medicine, University of Sao Paulo Rehabilitation Medicine Rua Diderot, 43 - Vila Mariana 04116-030 Sao Paulo <i>Prof. Dr. Linamara Rizzo Battistella</i>	
Canada	
McGill University Health Centre (Royal Victoria Hospital) Clinical Epidemiology R4.29, 687 Pine Ave W. H3A 1A1 Montreal, Quebec <i>Prof. Nancy Mayo</i>	
China	
Peking Union Medical College Hospital, Chinese Academy of Medical Sciences Department of Endocrinology Wang-Fu-Jing St. 100730 Beijing <i>Prof. Dr. Heng Wang</i>	Sun Yat-sen University, The Second Affiliated Hospital Department of Rehabilitation Medicine No 107 Yan Jiang West Road 510120 Guangzhou <i>Prof. Dr. Tiebin Yan</i>
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Czech Republic	
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Finland	
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8. Attachments

Workshop Registration Form