

10. Newsletter

ICF Core Sets Validation Study & EULAR ICF Core Sets Validation Study

June 2007

Dear Partners and Friends,

The EULAR and the International ICF Core Sets Validation Studies for chronic conditions are approaching their final spurt. However, many other ICF related studies have just begun or are underway. In this issue, we would like to inform you on the actual status of some ongoing studies. On pages two and three an update on the status of the EULAR and the International ICF Core Sets Validation Studies is provided.

The ICF Research Branch performed two workshops in Asia on February 2007. Dr. Xu Tao from China and Dr. Lydia Latif from Malaysia are reporting on these workshops on pages 4 and 5 respectively.

A very large network of partners have been created in Brazil to disseminate the ICF and the ICF Core Sets based on a web-based system. A report from Dr. Marcelo Ribreto on this project can be found on page 7.

This issue provides a table showing the actual status of the validation studies from the health professional perspective (page 8) and a report on the validation of the “ICF Core Set for Stroke from the patient perspective in *Sweden and Finland*” from Markku Paanalahti (page 9)

The initiation of the “Development of ICF Core Sets for Traumatic Brain Injury” project is provided on page 9. Updates on the ICF Core Sets development projects are to be found on the following pages: *Head and Neck Cancer* on page 10, *Multiple Sclerosis* on page 12, *Spinal Cord Injury* on page 13, *Sleep Disorders* on page 14 and *Ankylosis Spondilitis* on page 15.

The *evaluation and development of clinical outcome measures and instruments in hand osteoarthritis from the perspective of patients* is reported on page 15 followed by a report on the progress of the Measuring Health and Disability in Europe project (MHADIE) and a summary on the MURINET project contained on page 16.

As usual, this newsletter also gives an overview of all actual ICF Core Sets projects and international meetings and includes a list of all new publications and a list of all study centers participating in the on going studies.

All best wishes from Munich,

Your ICF Core Set Development Team

1. EULAR and International ICF Core Sets Validation Study: Project Status

1.1. Number of study centers per country

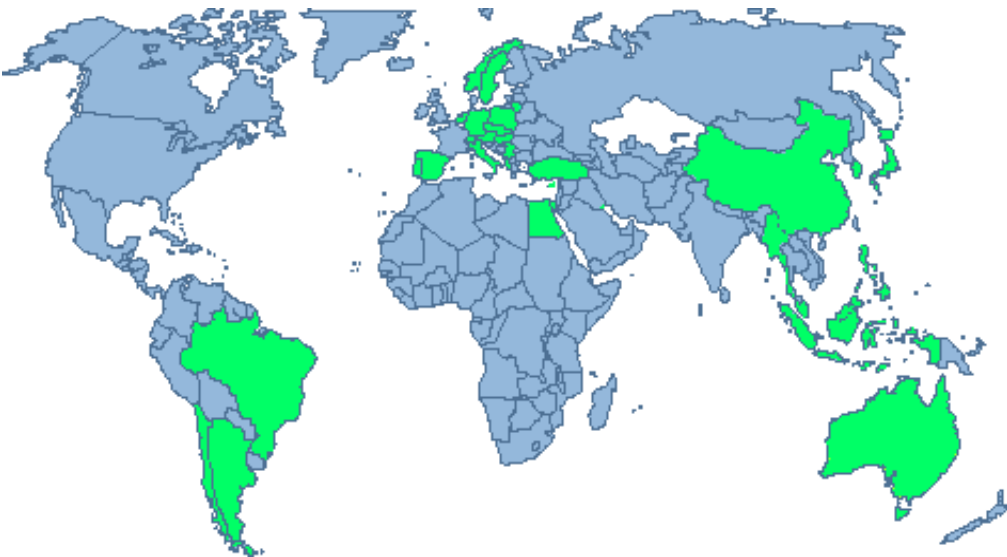
Tab. 1 Number of study centers per country

Country	Study Centers	Country	Study Centers	Country	Study Centers
Argentina	1	India	3	Rep of Macedonia	1
Australia	4	Indonesia	2	Romania	3
Austria	5	Ireland	1	Russia	1
Belgium	3	Israel	8	Serbia	3
Brazil	3	Italy	18	Slovakia	2
Canada	3	Japan	1	Singapore	1
Chile	1	Kenya	1	South Africa	1
China	17	Kuwait	2	South Korea	2
Croatia	1	Lebanon	1	Spain	2
Cyprus	1	Lithuania	5	Sweden	6
Czech Rep	2	Malaysia	16	Switzerland	15
Egypt	1	Mexico	3	Thailand	1
Finland	2	Nigeria	1	The Netherlands	7
France	6	Norway	6	Tunisia	1
Germany	106	Philippines	1	Turkey	13
Greece	6	Poland	11	UK	7
Hungary	15	Portugal	7	USA	3

Currently our network of centers participating in the international validation study comprises 333 Study Centers from 51 countries. Within these centers, 157 European ones are involved in the **EULAR** validation study.

1.2. Data Collection: received data per country

Tab. 2 Received data per country

	Country	CRFs
	Argentina	70
	Australia	8
	Austria	139
	Brazil	109
	Chile	62
	China	85
	Croatia	90
	Cyprus	14
	Czech Republic	20
	Egypt	74
	Germany	1189
	Hungary	426
	Indonesia	39
	Italy	476
	Japan	41
	Kuwait	521
	Lithuania	287
	Malaysia	20
	Netherlands	188
	Norway	202
Philippines	140	
Poland	54	
Portugal	35	
Serbia	788	
Singapore	122	
Slovakia	26	
South Korea	109	
Spain	71	
Sweden	231	
Switzerland	310	
Thailand	40	
Turkey	7	

* Data has been received from countries marked in green.

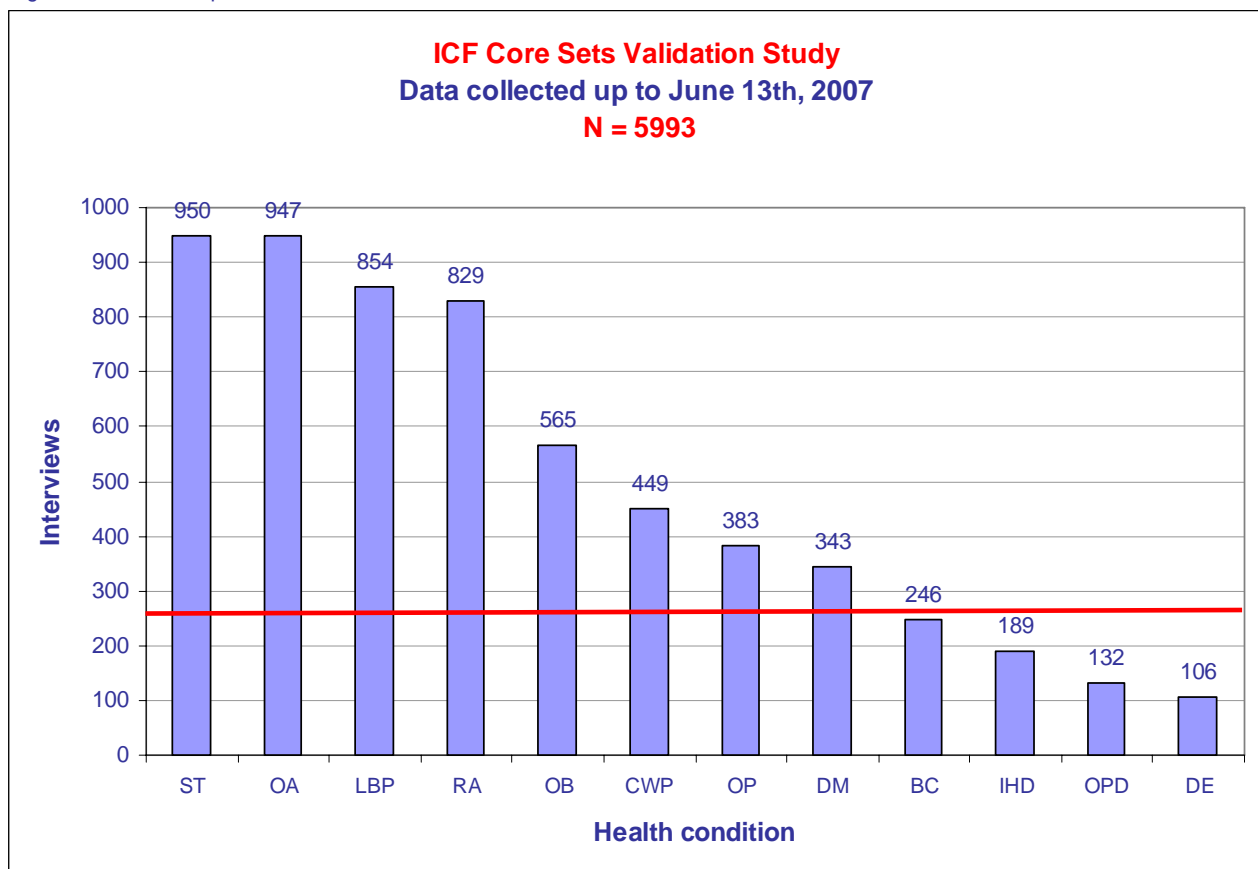
1.2.1. Received data per health condition

Up to this point we have received a total of **5993** Case Record Forms. 2463 CRFs belong to the EULAR validation study: *European validation of the ICF Core Sets for five musculoskeletal diseases: rheumatoid arthritis, osteoarthritis, osteoporosis, low back pain and chronic widespread pain*. The distribution of data per health condition is presented in the following table and graphic:

Tab. 3 Received data per health condition

	International	EULAR
Breast Cancer	246	
Chronic Ischaemic Heart Disease	189	
Chronic Widespread Pain	449	342
Depression	106	
Diabetes Mellitus	343	
Low Back Pain	854	647
Obesity	565	
Obstructive Pulmonary Diseases	132	
Osteoarthritis	947	512
Osteoporosis	383	269
Rheumatoid Arthritis	829	693
Stroke	950	
Total	5993	2463

Fig. 1 Received data per health condition



ST: Stroke; OA: osteoarthritis; LBP: low back pain; RA: rheumatoid arthritis; OB: obesity; CWP: chronic widespread pain; OP: osteoporosis; DM: diabetes mellitus; BC: breast cancer; IHD: ischaemic heart disease; OPD: obstructive pulmonary diseases and DE: depression.

1.3. Training of Health Professionals

Training of International study centers

1.3.1. Report on ICF training workshop in Wuhan, China

Dr. Xu Tao (Wuhan, China)

A “ICF training workshop” in collaboration among the Hong Kong University, Huazhong University of Science and Technology (Wuhan Tongji Hospital - WHO Collaborating Center for Training & Research in Rehabilitation), the Chinese Journal of Physical Medicine and Rehabilitation and the Ludwig-Maximilian University was held in Wuhan, P.R. China on Feb 1st and 2nd, 2007

Prof. Gerold Stucki, Dr. Alarcos Cieza from the ICF Research Branch of WHO CC FIC at the Ludwig-Maximilian University in Munich, and Prof. Leonard Lee (Hong Kong) were invited to give lectures at the meeting. Approximately 60 participants from throughout China attended the workshop.

One purpose of the workshop was to provide information on ICF and



Figure 2: From left to right: Zhongbi Wu, Gerold Stucki, Fazu Qiu and Dengkun Nan.

the ICF Core Sets. Another one was to facilitate China participating in the ICF Core Sets validation study, which will ultimately lead to a definition of standards for application of ICF in clinical practice and research. Thus the aims and methods of the study and the procedures regarding the data collection were explained in detail.



Figure 3: Participants of the ICF training workshop in Wuhan 1-2nd February, 2007.

40 participants expressed their intention to join the ICF Core Sets for 12 chronic conditions validation study in China, namely: chronic widespread pain , low back pain, osteoarthritis, osteoporosis, rheumatoid arthritis, chronic ischemic heart disease, diabetes, obesity, obstructive pulmonary diseases, depression, breast cancer, and stroke. During the workshop the Chinese implementation committee of ICF Core Sets validation study was established, the committee members are Prof. Leonard Lee (Hong Kong), Prof. Jianan Li (Nanjing), Prof. Xiaolin Huang (Wuhan), Prof. Guo Tiecheng (Wuhan). The Coordinator for the Chinese network is Dr. Xu Tao (Wuhan). The committee together with the coordinator will lead the ICF Core Sets validation study in China during 2007 to collect as many data as possible from the Chinese perspective.

1.3.2. Report from the ICF Training Workshop in Kuala Lumpur, Malaysia.

Lydia A Latif and Nazirah Hasnan (UM, Kuala Lumpur)

The ICF Training Workshop was held for the first time in Kuala Lumpur, Malaysia from February 7-9 2007 at the Putrajaya Marriot Hotel. The workshop was jointly organized by the University of Malaya (UM) and Ministry of Health (MOH), Malaysia represented by the following:

1. Department of Rehabilitation Medicine, Faculty of Medicine , UM (the main ICF study center in Malaysia)
2. Department of Rehabilitation Medicine, Kuala Lumpur Hospital (MOH)
3. Family Health Development Division, Department of Public Health, (MOH)

The training workshop was held in conjunction with Professor Gerold Stucki and Dr. Alarcos Cieza visit to Asia. Kuala Lumpur was their third stop after Wuhan and Bangkok. It was a fruitful meeting conducted by both international as well as the local speakers. This is part of the effort to strengthen the collaboration between the participating study centers in Asia.

The main objectives of the ICF training workshop were to promote the concept of ICF in Malaysia, to expand the ICF Core Set Validation Study to the national level and the use of ICF in Rehabilitation Medicine. For ICF to be accepted and implemented in Malaysia, a WHO member country, the Ministry of Health Malaysia is looked upon as the role player and the workshop was held to introduce the ICF concept to health practitioners across all disciplines and to train participants in the applications of the ICF based on WHO principles. The ICF Training workshop was funded mainly by the Ministry of Health and partially by the University of Malaya. It was officiated by the Deputy Minister of Health, Malaysia.



Fig. 4: YB Datuk Dr Hj Abd Latif B Ahmad, Ministry of Health and Prof. Gerold Stucki.



Figure 5: From left to right: Nazirah Hasnan, Akmal Hafizah, Alarcos Cieza, Lydia A. Latif and Gerold Stucki.

Besides Professor Gerold Stucki, Dr. Alarcos Cieza, there were several local speakers who had been involved in the preliminary ICF work in Malaysia: Assoc Professor Dr Zaliha Omar, Dr Nazirah Hasnan, Dr Asiah Ibrahim and Dr Lydia A Latif.

The training workshop was attended by 90 participants of various health care professions (physician, surgeon, physiotherapist, occupational therapist, nurses, psychologist and many others). To date this has been the most attended ICF training workshop. The feedbacks that were received by the participants were very encouraging and many agreed that the speakers have managed to share a new dimension to the Classification of Functioning, Disability and Health.

The main conclusions of the workshop are:

- 1) The implementation of the concept of ICF by the Ministry of Health
- 2) Recruitments of more study centers throughout Malaysia for the ICF Core set validation study
- 3) To further strengthen and broaden the research area in ICF conducted by the Department of Allied Health, Faculty of Medicine, University of Malaya
- 4) To apply the concept of ICF in various specialty especially Rehabilitation medicine.



Figure 6: Participants of the ICF training workshop in Malaysia, 7-9th February, 2007.

Following the recommendation by Professor Gerold Stucki and Dr Alarcos Cieza, the National Collaboration network for ICF in Malaysia was formed. This includes forming the Steering committee, the Advisory group and the Validation study group.

The following are the summary of the above groups and their tasks:

NATIONAL COLLABORATION NETWORK: ICF CORE SETS VALIDATION STUDY FOR MALAYSIA

I. STEERING COMMITTEE

Dr. Hajjah Asiah Haji Ibrahim and Dr. Mymoon Alias from the Ministry Of Health.

Dr. Nazirah Hasnan and Dr. Lydia Abdul Latif (*University of Malaya*)

and Dato' Dr. Zaliha Omar (*Independent*)

Tasks of Steering Committee

1. Provide guidance to Advisory Group
2. To liaise with ministry and political entities
3. Provide link with ICF Research Branch
4. Decision making – research, publication etc

II. NATIONAL COORDINATOR

Dr. Nazirah Hasnan

III. ADVISORY GROUP

Task of Advisory Group

1. Ensure link to special interest group
2. Ensure group members are well informed on ICF matters
3. Provide input to steering committee
4. Involvement in validation study

1.4. *Dissemination of ICF and ICF Core Sets in Brazil*

Dr. Marcelo Riberto (São Paulo, Brazil)

The dissemination of ICF and the ICF Core Sets in Brazil is the leading objective of a project that has been carried out by the Division of Rehabilitation Medicine, in the School of Medicine at the University of São Paulo, Brazil.

Dr Marcelo Riberto and Dr Linamara Rizzo Battistella lead this project which was awarded with a grant of R\$ 140.000,00 (~US\$70.000) from two governmental organizations: the National Council of Scientific and Technological Development and the National Coordination for the Integration of the Person with Disability. The Brazilian Center for Classification of Diseases and the ICF Research Branch in Munich contributed to develop the didactic material about the topics described below:

The course is 16 hours long, divided in two parts:

1. *ICF concepts:*

- The Family of International Classifications of WHO
- Differences between ICF and ICIDH
- Structure of ICF
- How to use the qualifiers
- Coding exercises

2. ICF Core Sets

- Concept of ICF Core Sets
- Development of ICF Core Sets
- How to rate somebody's functioning
- The validations of ICF Core Sets
- ICF core sets exercises for osteoarthritis, low back pain and stroke
- The Brazilian database of ICF Core Sets

From March to May, 2007, 19 courses were held in 16 cities all around the country, training a total of 570 people. Among those who attended the courses were professors, some policy-makers and prosecuting attorneys. Although some of the participants had had some previous contact with ICF, most of them said that the ICF model was new to them and the opportunity to discuss and have a better understanding was welcome. Some groups also showed interest in participating in the ongoing development of new ICF Core Sets and proposed some other health conditions for which ICF Core Sets should be developed.

Another goal of the project was to develop a Brazilian database on ICF Core Sets. The database is web-based (www.cif.org.br) and accessible with a login and password. According to the user profile, it is possible to add information about a patient or to produce a variety of reports. The structure of the database allows making comparisons between regions of the country and adding new ICF Core Sets very easily.

The objectives of the project, namely training multipliers and developing the database, have been so far achieved. Three other projects are under the same umbrella, each of them comparing functioning and disability of patients with osteoarthritis, low back pain and stroke in different regions of the country.

1.5. Validation of the ICF Core Sets from the perspective of health professionals

The following Delphi studies have been performed or are in process:

Tab. 4 ICF Core Sets. Surveys with experts:

	Physician	Psychologists	Nurses	Occupational therapists	Physical therapists	Social Worker+
Breast Cancer					*	+
Chronic Ischaemic Heart Disease						
Chronic Widespread Pain						
Depression						
Diabetes Mellitus	*					
Low Back Pain	*				√	
Obesity						
Obstructive Pulmonary Diseases	√				√	
Osteoarthritis					*	
Osteoporosis					*	
Rheumatoid Arthritis	√	√	√	√	√	
Stroke	√			√	√	

√ = process completed; * = process initiated

+ = the validation of the ICF Core Sets from the perspective of social workers have been performed in general without referring to any specific health condition.

For more information please contact Inge Kirchberger (Inge.Kirchberger@med.uni-muenchen.de).

1.6. ***Validation of the Comprehensive ICF Core Sets from the Patient Perspective***

1.6.1. *The validation study of the Comprehensive ICF Core Set for stroke in Strömsund Sweden and in Helsinki Finland.*

Markku Paanalahti P.T MSc (Strömsund, Sweden)

After attending an international training workshop at the Ludwig-Maximilian University in Munich, I felt confident to begin with the validation study of the ICF Core Set for stroke from the patient perspective at my hometown in Sweden and even to involve my colleagues at the Rehabilitation Out-Patient Clinic in Helsinki in the research project. The study in Sweden is funded by a grant from the FoU-Jämt (Research and development unit for social services and health care in the county of Jämtland). There is no funding to carry out the study in Finland; my colleagues in Helsinki have committed themselves to interview stroke patients on a voluntary basis. I wish to express my greatest gratitude to them.

In Sweden, the phase of the data collection from stroke patients has been concluded in April 2007. The data of 7 single men, 6 single women and 9 cohabited stroke patients were collected. The transcription of the recordings of the individual interviews has been finished and the phase of data analysis has begun. My supervisor for the study in Sweden is Prof. Katharina Stibrant Sunnerhagen from The Sahlgrenska Academy at Göteborg University, Institute of Clinical Neuroscience and my supervisor for the study in Finland is Kaisa Mannerkorpi, PT, Associate professor Sahlgrenska Academy, Göteborg University, Department of Rheumatology and Inflammation. The data collection from stroke patients in Helsinki will take place during May and June 2007 and will be performed by Anne Pyyhtiä, P.T, Eija Ahonen, Rehabilitation instructor, Mirja Lahtinen, Occupational therapist and Anita Kiesiläinen, Speech therapist from Helsinki University, Central Hospital Rehabilitation Out-Patient Clinic. The same group has also translated the focus group questions into Finnish.

2. Report on further ICF Core Sets development projects

2.1. ***The Development of ICF Core Sets for Traumatic Brain Injury (TBI)***

The first official meeting within the project the development of *ICF Core Sets for TBI* took place recently in Rome during the annual meeting of the World Federation for Neurorehabilitation on June 22nd, 2007. This meeting was initiated and promoted by Alessandro Guistini and involved members from the ICF Research Branch of the WHO Collaboration Centre of the Family of International Classifications, Germany (Gerold Stucki, Alarcos Cieza), the Guttmann Institute, Spain (Montse Bernabeu, Jose Maria Tormos, Sara Laxe and Raquel Lopez), the Ullevål University Hospital, Norway (Erik Bautzholter), the Institute for Rehabilitation, Slovenia (Helena Burger and Klemen Grabljevec), the IRCCS Fondazione "S. Maugen" (Caterina Pistarini), the Department of Rehabilitation in Lungodegenza, Italy (Paolo Boldrimi) and Mauro Zampolini from the Department of Rehabilitation of ASL3 - Regione dell'Umbria.

The project will be a cooperative effort of the Guttmann Institute (Barcelona, Spain), the ICF Research Branch of the World Health Organization (WHO) Collaboration Centre of the Family of International Classifications (DIMDI, Germany), the Classification, Assessment and Terminology (CAT) team and the Disability and Rehabilitation (DAR) team at WHO, the World Federation for Neurorehabilitation (WFNR), the International Society for Physical and Rehabilitation Medicine (ISPRM), and partner institutions across the world.

At this first Rome meeting the three Chairs of the steering committee were agreed on: Anthony Ward (for ISPRM and WFNR), Montserrat Bernabeu (for the Guttmann Institute, Barcelona, Spain) and Gerold Stucki (for the ICF Research Branch Munich, Germany). Additional members of the steering committee were suggested. They will be contacted and invited to join the Steering Committee of the project within the next days.

2.2. Update on the Development of ICF Core Sets for patients with Head and Neck Cancer

Sven Becker, Elisabeth Linseisen, Uta Tschiesner, MD, (Munich, Germany)

We are very pleased to inform you that the data collection for the empirical study and the expert survey have begun and the systematic review and the interviews with patients are about to be finalized. At this point we would like to express our sincere gratitude to all parties concerned for their motivation and enthusiasms.

Uta Tschiesner presented the results of the preliminary study „patient interviews“ at the Otorhinolaryngology Congress in Munich on May 2007.

The protocol paper: „The Development of ICF Core Sets for Head and Neck Cancer“ has been admitted for publication at the *European Archives of Oto-Rhino-Laryngology and Head & Neck*.

The HNC ICF Core Sets international consensus conference will be held from November 22-24, 2007 in Nottwil, Switzerland.

2.2.1. The Systematic literature review

This preliminary study started last summer. The aim of the systematic literature review is to identify which factors of functioning are reported in clinical trials with patients suffering head and neck cancer. The extensive literature review was performed by Sandra Landa and Uta Tschiesner and the results are currently being linked to the „ICF language“ by Edda Amann und Barbara Kollerits.

2.2.2. The individual interviews

The individual interviews with HNC patients have been accomplished. The interviews were conducted by Elisabeth Linseisen in Munich. At this point, the data analyses are being performed. The results reflecting the patient perspective regarding their functioning and disability will be presented at the international ICF Core Set Consensus Conference this autumn.

2.2.3. The empirical study

A training workshop on the ICF, the development of the ICF Core Sets and the detailed procedures for the data collection within the empirical study was held in Munich on May this year. The aim of the workshop was to recruit health professionals from Germany to participate in the empirical study which is coordinated by Elisabeth Linseisen. After receiving the Ethic Commission approvals from different federal states, the data collection has been initiated. The first datasets have been received in Munich and are being entered in our ICF database.

2.2.4. The expert survey

The expert survey is being performed by Sven Becker. The recruitment of health experts on patients with head and neck cancer started on February 2007. Over 120 experts with different professional backgrounds (physicians, nurses, physical therapists, occupational therapists, psychologists, speech/language therapists, and social workers) from 29 different countries accepted participating in the survey. The internet survey was initiated on May 23rd, 2007 and will be finalized by the end of June. Subsequently the answers from the experts will be analyzed.

Health professionals and study centres are invited to actively participate. For further information please contact: [Elisabeth Linseisen](#), [Sven Becker](#) or [Uta Tschiesner](#).

2.3. ***Update on the Development of ICF Core Sets for Multiple Sclerosis***

Jürg Kesselring (Valens, Switzerland), Michaela Coenen (Munich, Germany)

To guide the project “Development of ICF Core Sets for Multiple Sclerosis (MS)” a steering group composed by the following members was established: Jenny A. Freeman, Jürg Kesselring, Fary Khan, Nenad Kostanjsek, Eija Luoto, John Melvin, Bhim S. Singhal, Gerold Stucki, Silvia N. Tenenbaum, and Alan Thompson.

It is our pleasure to inform you that the four preparatory studies of the “Development of ICF Core Sets for Multiple Sclerosis (MS)” are under way:

2.3.1. The Systematic literature review

This study is performed by Sandra Kus and Michaela Coenen at the ICF Research Branch in Munich. The objective of this study 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 in process.

2.3.2. The expert survey

Michaela Coenen and Andreas Leib at the ICF Research Branch in Munich are responsible for the expert survey. The objective of this study 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 an international pool of experts (physicians, nurses, physical therapists, occupational therapists, (neuro-)psychologists, speech/language therapists, and social workers). In May 2007, the recruitment of health 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 Multiple Sclerosis International Federation (MSIF), the Risk and Insurance Management Society (RIMS) and the International Organization of MS Nurses ([IOMSN](#)).

2.3.3. The qualitative study

The qualitative study is performed by Michaela Coenen at the ICF Research Branch in Munich. The objective of this study is to identify the aspects of functioning and health, which are important to individuals with MS. With the support from Dr. Nicolaus König and Dr. Birgit Basedow-Rajwick focus groups and individual interviews are performed at the Marianne Strauss Clinic in Kempfenhausen (Germany).

2.3.4. The empirical study

Lisa Holper at the Valens Rehabilitation Centre (Switzerland) is leading the empirical study; the coordination has been undertaken by Andrea Weise, Valens Rehabilitation Centre. The objective of this 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 from 14th to 15th May 2007. The lecturers were Michaela Coenen and Heinrich Gall from the ICF Research Branch. Lisa Holper and Andrea Weise as well as participants from other ongoing ICF Core Set projects attended the workshop. Please notice that a short report describing the methods applied in this project will be published in *Multiple Sclerosis* (<http://msj.sagepub.com>).

The ICF Core Sets for MS will be defined at the ICF Core Set Consensus Conference to selected experts in the field of MS. It was decided that the International ICF Consensus Conference will be held at the Valens Rehabilitation Centre (Switzerland) on May 2nd to 5th, 2008.

2.4. ***Update on the Development of ICF Core Sets for Spinal Cord Injury (SCI)***

Monika Scheuringer (Munich, Germany)

Health professionals and researchers involved in the preliminary studies of the project in South Africa, were trained by Gerold Stucki and Monika Scheuringer during a workshop at Port Elizabeth (South Africa) from 14th to 15th December 2006. 12 health professionals from the Aurora Hospital and the Nelson Mandela Metropolitan University attended the workshop



Figure 7: Participants of the ICF training course in Port Elizabeth, South Africa, 14th December 2006

Back row from left to right: Gerold Stucki, LeeAnn Pretorius, Jane Weatherall-Thomas, Fairhope Xhoswa, David Levey, Pierre Olivier, Rob Campbell; Kneeleing left to right: Maryna Baard, Lizelle van der Vyver, Ansie Van Zyl; Front row left from right: Vernon Sack, Monika Scheuringer, Marjorie de Bruin, Rushdah Johardien)

In addition, it is a pleasure for me to inform you that the data collection of the four preliminary studies is extremely successful. Over 650 individuals with SCI in 15 study centres have been enrolled in the international Empirical Study. 40 focus groups have been performed in 10 study

centres throughout the world. The data extraction out of 254 studies included in the Systematic Review has been completed. And the analysis of the responses retrieved by the Expert Survey has been finished. The results of these studies will provide valuable information to guide decisions during the consensus conference that will be held at the Swiss Paraplegic Research Nottwil (Switzerland) from 15th to 18th November, 2007, (<http://www.icf-research-branch.org/material/2007/General%20information%20ICF%20Conference%20SCI.pdf>).

The intermediate results of all preliminary studies will be presented in the workshop 'Evaluation of different perspectives on problems experienced by individuals with SCI: report of the project "Development of ICF Core Sets for SCI"' at the 46th ISCoS Annual Scientific Meeting in Reykjavik on June 29th 2007 (<http://www.sci-reykjavik2007.org/main/>).

The abstracts presented at ISCoS are to be found on the appendix I of this newsletter.

2.5. Update on the Development of ICF Core Sets for Sleep

Felix Gradinger (Nottwil, Switzerland)

During the Second Biennial Congress of the World Association of Sleep Medicine (WASM), which was held in Bangkok from February 4 through 8, 2007, the project "the development for ICF Core Sets for sleep" was presented at an ICF Symposium. Even though there were no many participants, the relevant people in the field of sleep medicine attended it, including the president elect from WASM Sudhansu Chokroverty from USA. At the end of the Symposium, all participants made a statement that they endorse the project. Furthermore, a meeting was held with Dr. Markku Partinen, president of WASM, to discuss specific details of the project. The venue and date for the consensus conference were defined; the conference will take place from 28th until 30th of May 2009 in Siuntio, Finland.

The protocol paper "The development of Core Sets for Sleep based on the International Classification of Functioning, Disability and Health" and the "Content comparison of health related quality of life instruments for obstructive sleep apnea" had been accepted for publication in the journal Sleep Medicine.

2.5.1. The expert survey

176 Experts were selected from the overall pool of 380 that gave a positive response to either the first contact/reminder/final call reminder. The 176 questionnaires were sent out on the 24th of April 2007. To date 113 completed questionnaires have been returned.

2.5.2. Systematic literature review

A literature review in order to prepare the literature review of the preparatory phase of the project is currently being performed. The aim of this literature review is to study what has been investigated in the field of sleep in relation to spinal cord injury.

- A highly sensitive search in medline, embase, psycinfo databases has been performed,

resulting in the identification of 23 relevant papers recording on the occurrence of sleep disorders or sleep interferences in SCI study populations.

- A poster presentation of the results will take place under the theme of 'Sleep in Medical Disorders' at the 5th world sleep congress of the WFSRSMS (World Federation of Sleep Research and Sleep Medicine Societies), which will take place from Sept 2-6, 2007 in Cairns, Australia. The authors of the corresponding paper are: F. Gradinger, C. Boldt, S. Geyh, A. Stucki, A. Dahlberg, M. Partinen, F. Michel

2.5.3. Empirical studies

The two empirical studies of the preparatory phase are planned to begin in September or October 2007. The main study centers will be the University Hospital in Zurich (Claudio Bassetti) and Insel Hospital Bern (Matthias Gugger)

Additional study centers can participate in the studies of the preparatory phase. However, it is important to emphasize that no funding is available to support the data collection.

2.6. Consensus Conference for the ICF Core Sets for Ankylosing Spondylitis

The international ICF Consensus Conference on AS will take place from September 5 to September 8th 2007 at the Guido A. Zäch Institute in Nottwil, Switzerland. The goal of the meeting is to develop ICF Core Sets for AS, to be applied in several settings like clinical practice, teaching, and research.

The ICF domains to be included in the ICF Core Set will be selected by an international expert panel during the consensus conference. The expert panel will consist of 21 health professionals of all disciplines that are involved in the management of AS: rheumatologists, physiotherapists, an occupational therapist, a psychologist, a rheumatology specialized nurse and a rehabilitation physician. Based on the results of preliminary studies, the panel will decide on the domains to be included in the ICF Core Sets for AS.

3. Evaluation and development of clinical outcome measures and instruments in hand osteoarthritis from the perspective of patients

Tanja Stamm, MPH, MBA

A project funded by EULAR and DICHOA

Whether outcomes and instruments in hand osteoarthritis (HOA) comprehensively cover issues important to patients has not been evaluated yet. The aim of this project is to evaluate outcomes and instruments from the perspective of patients with HOA from different cultural backgrounds in order to define outcomes relevant to patients with HOA, to improve existing instruments and to develop new instruments. It is important to include the patient perspective because personal values for outcomes may vary between and among patients and professionals. Values of patients

differ considerably across cultures. Therefore, this projects aims to establish a common European understanding of patients with HOA.

Qualitative methodology provides the possibility to explore the perspectives of those who experience the disease (the patient perspectives) and to include these perspectives in the assessment of the disease.

In this study, eight to ten focus groups with HOA patients will be conducted at four different European rheumatology centres. Concepts important to patients will be identified in a 'meaning condensation' analysis of the transcribed text and then linked to the existing outcomes and instruments.

Recommendations for the definition of outcomes, the improvement of existing instruments and the development and validation of new instruments from the perspective of patients will be made.

The following centres participate in the project:

Munich, Germany, Michalea Coenen

Oslo, Norway, Eldri Steen

Newcastle, UK, Fraser Birell and Nicola Marshall

Spenshult, Sweden, Carina Thorstensson Leiden,

Netherlands, Florus van der Giesen, Margreet Kloppenburg, Thea Vliet Vlieland

Vienna, Austria, Tanja Stamm

4. Update on the “Measuring Health and Disability in Europe” (MHADIE) project

All sixteen partners of the MHADIE project met in Zürich, Switzerland, from Mai 30th to June 1st 2007. The meeting was organized and hosted by Prof. Judith Hollenweger from the *Pädagogische Hochschule Zürich*. During the meeting all the partners reported on the milestones accomplished and discussed the next steps. The agenda of the MHADIE European Conference that will be held on November 29th and 30th in Milan, Italy, was also discussed.

For further information on the project and the meeting please visit www.mhadie.it

5. MURINET PROJECT “Multidisciplinary Research Network on Health and Disability in Europe”

Prof. Mathilde Leonardi from the Neurological Institute “Carlo Besta” IRCCS Foundation is the coordinator of MURINET - Multidisciplinary Research Network on Health and Disability in Europe -, a new European Research Project aimed at promoting a new model to develop health and social policies in Europe.

MURINET will form a European pool of experts in health and disability research and management that will be able to combine several multidisciplinary skills within the framework of ICF model.

The kick off meeting of MURINET took place in Milan, Italy, at Palazzo delle Stelline, on February 28th 2007.

As Dr Leonardi reports “our project will involve 40 junior researchers across Europe and internationally, and will form a network of researchers who will be trained to perform state-of-the-

art research in public health and disability. They will be trained to combine several abilities within the framework of ICF and incorporating a solid ethic perspective on health and disability research and policy.”

The 13 European Partners involved in MURINET have a longstanding experience in developing research and promoting new policies based on ICF in social and health fields. They will provide fertile ground for researchers to build up their competences in health and disability.

MURINET will link different operational sectors and build up a multidisciplinary and intersectorial approach to health and disability research and management, joining all the involved stakeholders, from policy makers to clinical professionals, from education to rehabilitation, from ethics to statistics. The ICF model, which will be MURINET’s framework, embodies the principles of full participation, mainstreaming and the universality of disability. It has been developed in close partnership with an Nongovernmental Organization (NGO) representing persons with disability (PwD).

Among the partners of the research group are leading world experts in health and social policy and ICF from Spain, Slovenia, Switzerland, Sweden, Germany, and the Netherlands.

The ICF Research Branch in Munich is one of the 13 partners collaborating in the MURINET project and its tasks belong to the CLINICAL AND REHABILITATIVE area of action. They are the following:

- Identification of instruments used in rehabilitation settings in Europe
- Linking of the identified instruments to the ICF
- Linking of the Standard Classification for Technical and Assistive Devices (ISO 9999) to the ICF
- In collaboration with the Universidad Autonoma de Madrid: Development of ICF Core Sets for Bipolar Disorders
- Provide ICF Courses in collaboration with other partners.

Further information: <http://www.headnetgroup.it/murinet.asp>

6. International Meetings



The 4th World Congress of the International Society of Physical and Rehabilitation Medicine was held in Seoul, Korea, from June 10 to 14, 2007. At the congress, Prof. Gerold Stucki reported among other issues, on the collaboration networks from ISPRM leaders that have been created on different countries to collaborate with the ICF Research Branch in Munich on the development of ICF Core Sets for clinical practice.

7. Actual projects overview

Name	Associations involved	Contact person
Branch Projects:		
ICF Core Sets multicenter international validation study	Partners to be found under: http://www.inif.org/aboutus/partners.htm	Alicia Garza Michaela Kirschneck
EULAR - European validation of the ICF Core Sets for five musculoskeletal diseases	The European League Against Rheumatism EULAR	Alicia Garza Till Uhlig Annelies Boonen, MD, PhD Tanja Stamm, MPH, MBA Valerie Nell
Validation of the Comprehensive ICF Core Set from the Patient Perspective		Michaela Coenen, MPH
Validation of the ICF Comprehensive Core Set from the perspective of Health Professionals		Dr. Inge Kirchberger, MPH
Development of ICF Core Sets for Multiple Sclerosis (MC)	Multiple Sclerosis International Federation	Michaela Coenen, MPH
Development of ICF Core Sets for Manual Medicine	Swiss Association of Manual Medicine (SAMM)	Dr. Inge Kirchberger, MPH
Development of ICF Core Sets for Spinal Cord Injury (SCI)	International Spinal Cord Society (ISCoS) Swiss Paraplegic Research	Monika Scheuringer, MPH
Cooperation Projects:		
Development of an ICF Core Set in patients with Psoriasis or Psoriatic Arthritis	GRAPPA	Dr William Taylor
Development of the ICF Core Sets for Ankylosing Spondylitis	ASessment in Ankylosing Spondylitis (ASAS)	Annelies Boonen, MD, PhD
Development of the ICF Core Sets for Bipolar Disorders	International Society for Bipolar Disorders (ISBP)	Prof. Eduard Vieta
Development of ICF Core Sets for Sleep	Swiss Paraplegic Research	Felix Gradinger
Development of the ICF Core Sets for Lupus Erythematoses (SLE) and Systemic Sclerosis (SSc)	EUSTAR	Tanja Stamm, MPH, MBA
Development of ICF core Sets for patients with head and neck cancer	Deutsche Krebshilfe	Elisabeth Linseisen Uta Tschiesner, MD
Development of ICF Core Sets for Vision	Augenklinik LMU München The International Society for Low-vision Research and Rehabilitation	Dr. Stephan Fröhlich
Measuring Health and Disability in Europe: supporting policy development (MHADIE)	MHADIE	Dr. Alarcos Cieza, MPH Andrea Glaessel (BSc.PT)
Multidisciplinary Research Network on Health and Disability in Europe	MURINET	Dr. Alarcos Cieza, MPH

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

8. New Publications of members of the ICF Research Branch

Braun J, Zochling J, Marker-Hermann E, Stucki G, Bohm H, Rudwaleit M, Zeidler H, Sieper J.
[Recommendations for the management of ankylosing spondylitis after ASAS/EULAR: evaluation in the German language area.]

Z Rheumatol. 2006 Dec;65(8):728-742. German.

PMID: 17119900 [PubMed - as supplied by publisher]

Ewert T, Stucki G.

Validity of the SS-QOL in Germany and in survivors of hemorrhagic or ischemic stroke.

Neurorehabil Neural Repair. 2007 Mar-Apr;21(2):161-8.

PMID: 17312091 [PubMed - indexed for MEDLINE]

Geyh S, Cieza A, Kollerits B, Grimby G, Stucki G.

Content comparison of health-related quality of life measures used in stroke based on the international classification of functioning, disability and health (ICF): a systematic review.

Qual Life Res. 2007 Jun;16(5):833-51. Epub 2007 Feb 10.

PMID: 17294283 [PubMed - in process]

Grill E, Mansmann U, Cieza A, Stucki G.

Assessing observer agreement when describing and classifying functioning with the International Classification of Functioning, Disability and Health.

J Rehabil Med. 2007 Jan;39(1):71-6.

PMID: 17225041 [PubMed - indexed for MEDLINE]

Grill E, Zochling J, Stucki G, Mittrach R, Scheuringer M, Liman W, Kostanjsek N, Braun J.

International Classification of Functioning, Disability and Health (ICF) Core Set for patients with acute arthritis.

Clin Exp Rheumatol. 2007 Mar-Apr;25(2):252-8.

PMID: 17543150 [PubMed - in process]

Grimby G, Melvin J, Stucki G.

Foreword.

J Rehabil Med. 2007 May;39(4):277-8. No abstract available.

PMID: 17468798 [PubMed - in process]

Kirchberger I, Glaessel A, Stucki G, Cieza A.

Validation of the comprehensive international classification of functioning, disability and health core set for rheumatoid arthritis: the perspective of physical therapists.

Phys Ther. 2007 Apr;87(4):368-84. Epub 2007 Feb 20.

PMID: 17311887 [PubMed - indexed for MEDLINE]

Reinhardt JD, Cieza A, Stamm T, Stucki G.

Commentary on Nordenfelt's 'On Health, ability and activity: Comments on some basic notions in the ICF'.

Disabil Rehabil. 2006 Dec 15;28(23):1483-5; discussion 1487-9. No abstract available.

PMID: 17166815 [PubMed - indexed for MEDLINE]

Reinhardt JD, Hofer P, Arenz S, Stucki G.

Organizing human functioning and rehabilitation research into distinct scientific fields: Part III: Scientific journals.

J Rehabil Med. 2007 May;39(4):308-22.

PMID: 17468803 [PubMed - in process]

Reinhardt JD, Stucki G.

Rheumatoid arthritis and participation the social animal revisited.
J Rheumatol. 2007 Jun;34(6):1214-6. No abstract available.
PMID: 17552052 [PubMed - in process]

Stamm TA, Nell V, Mathis M, Coenen M, Aletaha D, Cieza A, Stucki G, Taylor W, Smolen JS, Machold KP.

Concepts important to patients with psoriatic arthritis are not adequately covered by standard measures of functioning.
Arthritis Rheum. 2007 Apr 15;57(3):487-94.
PMID: 17394177 [PubMed - indexed for MEDLINE]

Stucki A, Stucki G, Cieza A, Schuurmans MM, Kostanjsek N, Ruof J.

Content comparison of health-related quality of life instruments for COPD.
Respir Med. 2007 Jun;101(6):1113-22. Epub 2007 Jan 9.
PMID: 17215114 [PubMed - in process]

Stucki G.

Developing human functioning and rehabilitation research part I: Academic training programs.
J Rehabil Med. 2007 May;39(4):323-33.
PMID: 17468804 [PubMed - in process]

Stucki G.

Developing human functioning and rehabilitation research part II: Interdisciplinary university centers and national and regional collaboration networks.
J Rehabil Med. 2007 May;39(4):334-42.
PMID: 17468805 [PubMed - in process]

Stucki G, Grimby G.

Organizing human functioning and rehabilitation research into distinct scientific fields. Part I: Developing a comprehensive structure from the cell to society.
J Rehabil Med. 2007 May;39(4):293-8.
PMID: 17468801 [PubMed - in process]

Stucki G, Reinhardt JD, Grimby G.

Organizing human functioning and rehabilitation research into distinct scientific fields. Part II: Conceptual descriptions and domains for research.
J Rehabil Med. 2007 May;39(4):299-307.
PMID: 17468802 [PubMed - in process]

Stucki G, Melvin J.

The international classification of functioning, disability and health: A unifying model for the conceptual description of physical and rehabilitation medicine.
J Rehabil Med. 2007 May;39(4):286-92.
PMID: 17468800 [PubMed - in process]

Stucki G, Cieza A, Melvin J.

The international classification of functioning, disability and health (ICF): A unifying model for the conceptual description of the rehabilitation strategy.
J Rehabil Med. 2007 May;39(4):279-85.
PMID: 17468799 [PubMed - in process]

Stucki G, Boonen A, Tugwell P, Cieza A, Boers M
 The World Health Organisation International Classification of Functioning, Disability and Health:
 A Conceptual Model and Interface for the OMERACT Process
 J Rheumatol. 2007 Mar;34(3):600-6.
 PMID: 17343306 [PubMed - indexed for MEDLINE]

Uhlig T, Lillemo S, Moe RH, Stamm T, Cieza A, Boonen A, Mowinckel P, Kvien TK, Stucki GD.
 Reliability of the ICF core set for rheumatoid arthritis.
 Ann Rheum Dis. 2007 Jan 12; [Epub ahead of print]
 PMID: 17223659 [PubMed - as supplied by publisher]

Vieta E, Cieza A, Stucki G, Chatterji S, Nieto M, Sa´ nchez-Moreno J,
 Jaeger J, Grunze H, Ayuso-Mateos JL.
 Developing core sets for persons with bipolar disorder based on the International Classification of
 Functioning, Disability and Health.
 Bipolar Disord 2007; 9: 16–24. ^a Blackwell Munksgaard, 2007

Weigl M, Cieza A, Cantista P, Stucki G.
 Physical disability due to musculoskeletal conditions.
 Best Pract Res Clin Rheumatol. 2007 Feb;21(1):167-90. Review.
 PMID: 17350551 [PubMed - indexed for MEDLINE]

Zochling J, Stucki G, Grill E, Braun J.
 A comparative study of patient-reported functional outcomes in acute rheumatoid arthritis.
 J Rheumatol. 2007 Jan;34(1):64-9. Epub 2006 Nov 15.
 PMID: 17117489 [PubMed - indexed for MEDLINE]

For any questions and for further information please contact:

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APPENDIX I “Development of ICF Core Sets for SCI” Abstracts presented at ISCoS

Abstract Empirical Study:**Title:**

Identification of common problems in functioning of individuals with Spinal Cord Injury using the International Classification of Functioning, Disability and Health (ICF)

Authors:

Susan Charlifue, Monika Scheuringer, Michael Baumberger, Rob Campbell, Apichana Kovindha, Haim Ring, Anne Sinnott, Gerold Stucki

Main institution where the work was done:

ICF Research Branch of the WHO CC FIC (DIMDI), Institute for Health and Rehabilitation Sciences (IHRS), Ludwig-Maximilian University Munich, Marchioninstr. 17, 81377 Munich, Germany

Purpose:

The objective of this international study is to describe functioning and health of individuals with Spinal Cord Injury (SCI) and to identify the most common problems using the International Classification of Functioning, Disability and Health (ICF). The specific aims within the project ‘ICF Core Set development for SCI’ are (1) to identify candidate categories for the ICF Core Sets for SCI for the early post-acute situation and the ICF Core Set for chronic SCI, respectively, and (2) to examine whether ICF categories unique for individuals who differ in the completeness or in the neurological level of SCI exists.

Methods:

This multi-centre study was a cross-sectional survey in samples of individuals with SCI. 264 second level categories of the ICF were used to collect information on patients’ problems.

Results:

The median age in the sample was 42,6 years, 22,2% of the patients were female. 54,9% of the subjects had a complete SCI; 56.3% were paraplegics. 56,8% of the patients were in the chronic situation. 186 ICF categories could be identified as candidate categories for the ICF Core Sets for SCI for the early post-acute situation. 122 ICF categories belong to Part 1 of the ICF including the components Body Functions, Body Structures, and Activities and Participation. 64 ICF categories belong to Part 2 of the ICF including the Environmental Factors. 191 ICF categories could be identified as candidate categories for the ICF Core Sets for the chronic SCI. 127 ICF categories belong to Part 1 of the ICF and 64 to Part 2. 182 ICF categories were common for both, the early post-acute and the chronic situation. 4 ICF categories were identified as unique for the early post-acute situation and 9 ICF categories were identified as unique for the chronic situation. 9 ICF categories could be identified as unique for individuals with incomplete SCI, 8 ICF categories as unique for individuals with complete SCI, 1 ICF category as unique for paraplegics, and 16 ICF categories as unique for tetraplegics.

Conclusions:

This study is a first step towards the development of ICF Core Sets for individuals with SCI and provides the information to guide decisions on which type of ICF Core Sets for SCI to proceed with.

Abstract Expert Survey:**Title:**

Identification of relevant aspects of functioning in individuals with Spinal Cord Injury from the health professional perspective: an international Expert Survey

Authors:

Monika Scheuringer, Christine Boldt, Inge Eriks, Szilvia Geyh, Alexandra Rauch, Alarcos Cieza

Main institution where the work was done:

ICF Research Branch of the WHO CC FIC (DIMDI), Institute for Health and Rehabilitation Sciences (IHRS), Ludwig-Maximilian University Munich, Marchioninstr. 17, 81377 Munich, Germany

Purpose:

The objective of the Expert Survey was to identify problems in functioning relevant to individuals with Spinal Cord Injury (SCI) from the health professional perspective. The specific aim within the project 'ICF Core Set development for SCI' is to identify candidate categories for the ICF Core Sets for SCI for the early post-acute situation and the ICF Core Set for chronic SCI, respectively.

Methods:

A worldwide internet survey including samples of nurses, social workers, physical therapists, occupational therapists, physicians, and psychologists with expertise in the treatment of people with SCI. We used open-ended questions asking for the problems experienced by individuals with SCI and for environmental factors and personal factors affecting the every-day life of individuals with SCI. The participants' answers were linked to the categories of the ICF using standardized linkage rules.

Results:

From the 243 randomly selected health professionals, 51.4% of them participated in the expert survey. The median age of the participants was 40.0 years, 62,7% were female. The median number of years of professional experience was 16.0. 337 out of the 1.454 ICF categories could be identified as candidate categories for the ICF Core Sets for SCI for the early post-acute situation. 283 ICF categories belong to Part 1 of the ICF including the components Body Functions, Body Structures, and Activities and Participation. 54 ICF categories belong to Part 2 of the ICF including the Environmental Factors. 371 out of the 1.454 ICF categories could be identified as candidate categories for the ICF Core Sets for the chronic SCI. 307 ICF categories belong to Part 1 of the ICF and 64 to Part 2. 285 ICF categories were common for both, the early post-acute and the chronic situation. 52 ICF categories were identified as unique for the early post-acute situation and 86 ICF categories were identified as unique for the chronic situation.

Conclusions:

This study is a first step towards the development of ICF Core Sets for individuals with SCI and indicates a need to develop different ICF Core Sets for individuals with SCI in the early post-acute situation and in the chronic situation, respectively.

Abstract Focus Groups:**Title:**

Identification of problems in functioning related to Spinal Cord Injury from the individuals' perspective: an international focus group study

Authors:

Anne Sinnott, Monika Scheuringer, Susie Charlifue, Apichana Kovindha, Hansjörg Lüthi, Manuel Zwecker, Vernon Sack, Michaela Coenen, Alarcos Cieza

Main institution where the work was done:

ICF Research Branch of the WHO CC FIC (DIMDI), Institute for Health and Rehabilitation Sciences (IHRS), Ludwig-Maximilian University Munich, Marchioninstr. 17, 81377 Munich, Germany

Purpose:

The objective of this qualitative study was to explore the aspects of functioning and health relevant to individuals with spinal cord injury (SCI) using the focus group technique.

Purpose:

The objective of this qualitative study was to explore the aspects of functioning and health relevant to individuals with Spinal Cord Injury (SCI) using the focus group technique. The specific aim within the project 'ICF Core Set development for SCI' is to identify candidate categories for the ICF Core Sets for SCI for the early post-acute situation and the ICF Core Set for chronic SCI, respectively.

Methods:

We used six open-ended questions asking for the problems of individuals on body functions and body structures, activities and participation. In addition, the individuals were asked about environmental factors

and personal factors affecting their every-day life. The focus groups were digitally recorded and transcribed verbatim. The meaning condensation procedure was used to identify the meaningful concepts contained in the focus groups. In a next step, the meaningful concepts were linked to categories of the International Classification of Functioning, Disability and Health (ICF) according to established linking rules.

Results:

298 out of the 1.454 ICF categories could be identified as candidate categories for the ICF Core Sets for SCI for the early post-acute situation. 230 ICF categories belong to Part 1 of the ICF including the components Body Functions, Body Structures, and Activities and Participation. 68 ICF categories belong to Part 2 of the ICF including the Environmental Factors. 349 out of the 1.454 ICF categories could be identified as candidate categories for the ICF Core Sets for the chronic SCI. 243 ICF categories belong to Part 1 of the ICF and 106 to Part 2. 217 ICF categories were common for both, the early post-acute and the chronic situation. 81 ICF categories were identified as unique for the early post-acute situation and 132 ICF categories were identified as unique for the chronic situation.

Conclusions:

Focus groups are a useful method to identify relevant aspects of functioning and health from the individuals' perspective. This study is a first step towards the development of ICF Core Sets for individuals with SCI and provides the information to guide decisions on which type of ICF Core Sets for SCI to proceed with.

Abstract Literature Review:

Title:

Systematic review of parameters reported in published studies focusing on Spinal Cord Injury

Authors:

Marieke Wollaars, Monika Scheuringer, Marcel W Post, Szilvia Geyh

Main institution where the work was done:

De Hoostraat Revalidecentrum, Rembrandtkade 10, 3583 TM Utrecht, The Netherlands

Purpose:

The objective of the systematic literature review is to identify parameters reported in published studies focusing on spinal cord injury (SCI), and to identify and quantify the concepts contained in these parameters using the ICF as a reference.

Methods:

Electronic searches of Medline, EMBASE, PsycINFO, and CINAHL from 2000 to 2005 were carried out. In a first step, the abstracts of a random sample of the retrieved studies were checked. In a second step, data on the reported parameters and certain characteristics of the included studies were extracted. In a third step, the parameters and their underlying concepts were specified. These concepts were then linked to categories of the International Classification of Functioning, Disability and Health (ICF) using standardized linkage rules.

Results:

From the 6.681 abstracts retrieved, 2.204 were randomly selected (32.9%). 254 of these selected studies met the inclusion criteria (11.5%). In a next step, 1.997 different parameters were retrieved. The specification of the concepts contained in these parameters and the linking of these concepts to ICF categories is under way.

Conclusions:

This study will show whether the ICF provides a valuable reference to identify and quantify the concepts of parameters reported in studies focusing on SCI. Our results may indicate a need to define and to agree on 'what should be measured' in SCI research to allow for a comparison of patient populations.

APPENDIX II Lists of Study Centers participating in the projects

Study Centers EULAR and International ICF Core Sets Validation Study

New Study Centers are grey shadowed.

EULAR Study Centers are marked with a thick blue frame.

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>	Centre for Rheumatic Diseases, University of Melbourne Level 4 Clinical Services Bldg. RMH Grattan St Parkville, Melbourne 3050 Victoria <i>Dr. Richard Osborne</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>
Medical University of Innsbruck Clinical Department of Internal Medicine, Rheumatology Unit <i>Prof. Manfred Herold</i>	University Clinic for Physical Medicine and Rehabilitation Währinger Gürtel 18-20 1090 Wien <i>Prof. Dr. Veronika Fialka-Moser</i>
Univ. Klinik für Innere Medizin Physical Medicine Anichstr. 35 6020 Innsbruck <i>Doz. Dr. Erich Mur</i>	
Belgium	
Bone and Cartilage Metabolism Unit CHU Centre – Ville <i>Prof. Jean-Yves Reginster</i>	Kuleuven Department of Rheumatology <i>Prof. Frank Luyten</i> <i>René Westhofen</i>
University of Liege Department of Public Health, Epidemiology and Health Economics <i>Prof. Olivier Bruyère</i>	

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>	Santa Casa de Sao Paulo Serviço de Fisioterapia Rua Domiciano Rossi 300 Ap. 32 09726-121 Sao Paulo <i>Dr. Eduardo de Melo Carvalho</i>
Brazil	
Universidade Federal do Rio de Janeiro Hospital Universitário Clementino Fraga Filho Serviço de Medicina Física e Reabilitação Av. Brigadeiro Trompowski, s/n 2 andar Ilha do Fundão Rio de Janeiro <i>Prof. Dr. Carmen L Natividade de Castro</i>	
Canada	
Institute for Work & Health Health Services Research 481 University Ave Toronto M5G 2E9 Ontario <i>Dr. Jaime Guzman</i>	McGill University Health Centre (Royal Victoria Hospital) Clinical Epidemiology R4.29, 687 Pine Ave W. H3A 1A1 Montreal, Quebec <i>Prof. Nancy Mayo</i>
McGill University Jewish General Hospital Division of Rheumatology Suite A216, 3755 St. Catherine Rd. H3T 1E2 Montreal, Quebec <i>Dr. Murray Baron</i>	
Chile	
Hospital Clinico, Universidad de Chile Physical Medicine and Rehabilitation Santos Dumont 999 <i>Dr. Carlo Paolinelli Grunert</i>	
China	
Affiliated Taihe Hospital of Yunyang Medical College Department of Rehabilitation Medicine Renmin Southroad 32 442000 Hubei Shiyan <i>Ass Prof. Feng Jin Cai, Ass Prof. Gang Wang Ass Prof. Hai feng Li, Ass Prof. Xiaohu Zhu, Ass Prof. Yuanhong Xu</i>	Beijing Cancer Hospital Department of Medical Oncology No.52 Fucheng Road, Haidian District 100036 Beijing <i>Dr. Lijun Di</i>
First Affiliated Hospital of Nanjing Medical University Rehabilitation Department 300 Guangzhou Road 210029 Nanjing <i>Dr. Xiao Lu, Dr. Guangxu Xu, Dr. Kaisheng Yin, Dr. Tong Wang, Dr. Zhongli Jiang, Dr. Xiaojun Zhu</i>	First Hospital of Beijing University Department of Physical Medicine and Rehabilitation No. 8 Xi Shiku Street, West District 100034 Beijing <i>Ass Prof. Xie Bin</i>
Fujian College of Traditional Chinese Medicine PMR and Acupuncture & Massage Fuzhou 350180 Fujian <i>Dr. Xiangbin Wang, Lishan Huang</i>	Guangdong Provincial Work Injury Rehabilitation Center Rehabilitation Department Conhua Hotspring 105# 510970 ConHua <i>Dr. Liu Siwen</i>

China	
Huazhong University of Science and Technology PMR No. 1095 Jiefang Avenue 430030 Wuhan Hubei <i>Dr. Tao Xu, Ms Ting Zhang, Prof. Chunjing You, Prof. Shiyong Yu, Prof. Xiaonan Tao, Prof. Xiaolin Huang</i>	Jiangsu Province Hospital Department of Geriatrics 300 Guangzhou Road 210029 Nanjing <i>Dr. Chuanwei Zhou</i>
Nanfang Hospital of Nanfang Medical University Department of Rehabilitation Medicine North Avenue of Guangzhou 1838 510515 Guangzhou <i>Dr. hong Zhang Jian</i>	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>
South-West Hospital, The Third Military Medical University Department of Rehabilitation Medicine 38# Gao-Tan-Yan St. 400038 Chong Qing <i>Dr. Yin Qing</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, Dr. Lv Xiao</i>
The Longgang Centre Hospital of Shenzhen Rehabilitation Medicine No. 1228 Shenhui road, Longgang District 518116 Shenzhen, Guangdong <i>Dr. Chunfeng Ran</i>	The Second People's Hospital Affiliated to Fujian College of TCM Rehabilitation Center No. 13 Hudong Branch Road 350003 Fuzhou <i>Dr. Shizhong Wang, Prof. Lidian Chen</i>
The Third Affiliated Hospital of Sun YatSen University Department of Rehabilitation Medicine Tianhe Road No. 600 510630 Guangzhou <i>Ass Prof. Xiquan Hu</i>	Tongji Hospital, Tongji Medical College Department of rehabilitation Medicine 1095 Jiefang Street 430030 Wuhan <i>Ass Prof. Dr. Tiecheng Guo, Dr. Shao Bin</i>
Tung Wah Hospital, University of Hong Kong Division of Rehabilitation, Dept. Of Medicine 12 Po Yan Street Sheung Wan, Hong Kong <i>Dr. Leonard S.W. Li</i>	
Croatia	
Vuk Vrhovac University Clinic Diabetes, Endocrinology and Metabolic diseases Zagreb <i>Dr. Mirjana Pibernik-Okanovic</i>	
Cyprus	
Limassol Center of Physical & Rehabilitation Medicine Physical and Rehabilitation Medicine 43, Vassilis Michaelides Str. 3026 Limassol <i>Dr. Nicolas Christodoulou</i>	
Czech Republic	
Charles University in Prague Department of Rehabilitation Medicine First Faculty of Medicine Albertov 7 Prague 2, 12800 <i>Olga Svestkova M.D., Ph.D. Dr Jiri Votava</i>	Institute of Rheumatology Na Slupi 4 <i>Prof. Jiri Vencovsky Dr. Hana Jarosova</i>

Egypt	
Al Azhar University Department of Rheumatology <i>Prof. Hammoud Hesham Salah</i>	
Finland	
National Public Health Institute Department of Health and Functional Ability <i>Dr. Markku Heliövaara</i>	ORTON Research Institute Foundation for Invalids Tanholantie 10 FIN-00280 Helsinki <i>PhD, docent Juhani Smolander</i>
France	
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CHU-Lapeyronie Service d'Immuno-rhumatologie <i>Dr. Jacques Morel</i>	Rangueil University Hospital Department of Rheumatology <i>Prof. B. Mazières</i>
University of Nice Department of Rheumatology Academic Hospital L'Archet I <i>Prof. Liana Euller-Ziegler</i>	University Francois Rabelais, Medical Faculty Service du Rhumatologie Hopital Trousseau <i>PR Pierre Valat</i>
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Stand 20.11.06

Study Centers: Development of ICF Core Sets for spinal cord injury

Name of WHO region	
Eastern Mediterranean Region:	
Regional Project Coordinator	Haim Ring
Countries	Israel
Study Centers:	Loewenstein Rehab Center Israel Study director: A. Catz
	Department of Neurological Rehabilitation The Chaim Sheba Medical Center Israel Study director: G. Zeilig
South East Asia Region:	
Regional Project Coordinator	Apichana Kovindha
Countries	India Malaysia Thailand Vietnam
Study Centers	Department of Rehabilitation Medicine Chiangmai Hospital Thailand Study director: A. Kovindha
	Handicap International Vietnam Vietnam Study director: Eric Weerts
	Indian Spinal Injuries Centre (ISIC) India Study director: H.S. Chhabra
	University Malaya Medical Center Pusat Perubatan Universiti Kuala Lumpur Malaya Study director: N. Hasnan
Western Pacific Region:	
Regional Project Coordinator	Anne Sinnott
Countries	New Zealand Australia
Study Centers	Burwood Spinal Unit Burwood Hospital Private Bag 4708 Christchurch, New Zealand Study director: A. Sinnott
	Auckland Spinal Rehabilitation Centre Auckland, New Zealand Study director: S. Atresh
	Victorian Spinal Cord Service Melbourne, Australia Study director: D. Brown
Region of the Americas:	
Regional Project Coordinator	Susan Charlifue
Countries	Canada USA Brazil
Study Centers	ICORD GF Strong Rehab Centre 4255 Laurel Street Vancouver, BC V5Z 2G9 Canada Study director: A. Townson

	Craig Hospital 3425 S. Clarkson St. Englewood, CO 80113 Denver, USA Study director: S. Charlifue
	University Hospital of Sao Paulo Sao Paulo Brasil Study director: J. Greve
European Region:	
Regional Project Coordinator	Michael Baumbergert
Countries	Switzerland Denmark Germany Italy
Study Centers	Swiss Paraplegic Centre Nottwil Switzerland Study director: M. Baumberger
	REHAB Basel Switzerland Study director: M. Mäder
	Paraplegic Center Balgrist University Hospital Balgrist Switzerland Study director: V. Dietz
	Clinic for Spinal Cord Injuries Rigshospitalet Denmark Study director: F. Biering-Sørensen
	Orthopädische Universitätsklinik Heidelberg Study director: HJ Gerner
	Unità Spinale Azienda Ospedaliera Careggi Firenze, Italy Study director: S. Aito
African Region:	
Regional Project Coordinator	Robert Campbell
Countries	South Africa
Study Centers	Aurora Hospital South Africa Study director: R. Campbell

Stand 10.06.07

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Stand 04.05.06