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Dear Partners and Friends,

This is the first issue of the ICF Research Branch newsletter. With it, as we previously did with the Newsletter of the Validation Study for 12 Chronic

Conditions, we want to inform you regularly about the new projects of the ICF Research Branch at the Institute for Health and Rehabilitation Sciences at the Ludwig-Maximilian University and about their progress.

This first issue contains a summary of the three international consensus conferences that took place during the last trimester of 2007, reports on further ICF Core Sets development projects, a list of all new publications and a list of all study centers participating in the on going projects and studies.

All best wishes from Munich,  
Your ICF Research Branch Team

## 1. International Consensus Conference on the ICF Core Sets for Ankylosing Spondylitis

*Annelies Boonen (Netherlands)*

From September 5<sup>th</sup> to 8<sup>th</sup>, 2007, the Guido A. Zäch Institute in Nottwil, Switzerland, hosted nineteen health professionals with interest and experience in ankylosing spondylitis (AS) to decide on the Comprehensive and Brief ICF Core Set for this disease.

The three day conference was performed with the financial support and collaboration of the ASsement in Ankylosing Spondylitis working group. Among the 19 participants, 13 were rheumatologists, 3 physiotherapists, one psychologist, one nurse practitioner and one occupational therapist. Fourteen participants were European, two ensured the North-American perspective, two the South-American perspective and one the Asian perspective.

Dr. Annelies Boonen from the University Hospital Maastricht, the Netherlands, and Prof. Jürgen Braun from the Rheumazentrum Ruhrgebiet, Herne, Germany, chaired the conference and led the participants through the consensus building process.



Figure 1: Participants of the AS Consensus Conference in Nottwil.

Finally, 55 second level ICF categories were selected for the Comprehensive ICF Core Set and 19 for the Brief ICF Core Set for AS. All four components of the ICF are represented in both ICF Core Sets for AS. The next step of the process, namely the validation of the agreed-on ICF Core Sets for AS, is about to start. For further information please contact Dr. Annelies Boonen: [aboo@sint.azm.nl](mailto:aboo@sint.azm.nl)

## 2. International Consensus Conference on the ICF Core Sets for Spinal Cord Injury

*Inge Kirchberger (Germany)*

From November 15 to November 18, 2007, the International Consensus Conference on the ICF Core Sets for Spinal Cord Injury (SCI) took place at the Swiss Paraplegic Research in Nottwil, Switzerland. The aim of the conference was to establish ICF Core Sets for patients with spinal cord injury in the early post-acute and in the long-term contexts, respectively.



Figure 2: The Swiss Paraplegic Centre (SPZ), in Nottwil.

34 experts in SCI from six different health professions (physicians, physical therapists, occupational therapists, nurses, psychologists and social workers) and from 31 different countries decided on the inclusion of ICF categories in the Core Sets for SCI following a structured decision-making and consensus process. Their decisions were based on the data gathered in four preparatory studies including an empirical data collection, an expert survey, patient focus groups and a systematic review. The results of these studies were presented by the project coordinators Monika Scheuringer (ICF Research Branch, Germany), Susie Charlifue (USA), Anne Sinnott (New Zealand) and Marcel Post (Netherlands). On the basis of this information the decisions were drawn in five working groups who were led by Wagih El-Masry (UK), Jianan Li (China), Lester Butt (USA), Diana Nix (Switzerland) and Kiley Pershouse (Australia). The group decisions were presented at several plenary sessions and discussed. The discussion was led by Alarcos Cieza (ICF Research Branch, Germany).

As a result of the conference two ICF Core Sets for SCI for each context were developed:

- a Comprehensive ICF Core for SCI for the early post-acute context including a selection of 162 ICF categories and a Brief ICF Core Sets for SCI for the early post-acute context including 25 ICF categories as well as
- a Comprehensive ICF Core for SCI for the long-term context including 168 ICF categories and a Brief ICF Core Sets for SCI for the chronic situation including 33 ICF categories.

The completed development process will be followed by a project phase including an extensive worldwide validation of the first versions of the ICF Core Sets for SCI.

The development of four ICF Core Sets within 3 days was associated with an enormous workload for the participants and a very tight time schedule. However, all participants accepted this challenge and kept their good mood and motivation until the end of the meeting. The participants actually enjoyed working in multi-professional and multi-cultural groups. Thus, the conference was not only successful in the definition of the ICF Core Sets but contributed to establish a close network of SCI experts worldwide.

For further information please contact Dr. Inge Kirchberger: [Inge.Kirchberger@med.uni-muenchen.de](mailto:Inge.Kirchberger@med.uni-muenchen.de)

### 3. International Consensus Conference on the ICF Core Sets for patients with Head and Neck Cancer

*Uta Tschiesner (Germany)*

The International Consensus Conference on the ICF Core Sets for Head and Neck Cancer (HNC) took place from November 22 to 24, 2007 in Nottwil, Switzerland. The aim of the conference was to decide on a Brief and a Comprehensive ICF Core Set for patients with HNC.

21 experts experienced in the treatment of HNC from five different health professions (physicians, psychologists, physical therapists, nurses and social workers) and from 13 different countries were invited to decide on the ICF categories to be included in each of the two ICF Core Sets for HNC. The structured decision-making and consensus process consisted of discussions in working groups and afterwards, results were presented, discussed and re-voted in the plenary. Decisions were based on the data gathered in four preparatory studies including patient interviews, a world-wide expert survey, a multi-center empirical study and a systematic literature review. The results of these studies were presented by the project team: Uta Tschiesner, Sven Becker, Michalea Coenen, Sandra Kus and Elisabeth Linseisen.



Figure 3: Participants of the HNC Consensus Conference in Nottwil, 22<sup>nd</sup> to 24<sup>th</sup> November 2007

Back row from left to right: Nick Slevine, Kirsten Becker-Bikowski, Andreas Dietz, Sandra Kus, Viktor Bonkowsky, John Fagan, Simon Rogers, Gert Walrave, Ulrich Harreus, Uta Tschiesner, Heinrich Gall, Gerson Mast, Sven Becker, Silvia Neubert, Arun Maiya; Front row left from right: Alarcos Cieza, Gerry Humphris, Sandra Nuyts, Michaela Coenen, Bevan Yueh, Jan Vermorken, Gerry Funk, Keunchil Park, Shulamith Kreitler, Megan Nut, Marek Rogowski, Suhel Hasan, Ashok Shenoy, Elisabeth Linseisen

Each working group consisted of participants from different health professions and from different countries: The first working group was led by B. Yueh (USA) and included V. Bonkowsky (Germany), S. Kreitler (Israel), G. Mast (Germany), M. Nutt (Australia), K. Park (Korea) and A. Shenoy (India). The second working group was led by S. Rogers (UK) and included K. Becker-Bikowski (Germany), G. Funk (USA), S. Hasan (Oman), G. Humphris (UK), N. Slevin (UK) and G. Walrave (The Netherlands). The third working group was led by A. Dietz (Germany) and included J. Fagan (South Africa), U. Harreus

(Germany), A. Maiya (India), S. Nuyts (Belgium), M. Rogowski (Poland) and J. Vermorken (Belgium).

The discussion in the plenary was led by Alarcos Cieza (ICF Research Branch, Germany).



Figure 4: HNC Consensus Conference in Nottwil, Switzerland

As a result of the conference two ICF Core Sets for HNC were developed:

- a Comprehensive ICF Core for HNC for comprehensive, multi-disciplinary assessment including 112 ICF categories as well as
- a Brief ICF Core for HNC including a selection of categories out of the comprehensive Core Set to be assessed in any patient with HNC with 19 ICF categories.

This development process will be followed by a validation phase including extensive worldwide validation of the first version of the ICF Core Sets for HNC. The entire project, including the validation, is designed as an open and integrative process. Anyone interested in participating in the validation process of ICF Core Sets for HNC is highly welcome. For further information, please, contact the project leader: [uta.tschiesner@med.uni-muenchen.de](mailto:uta.tschiesner@med.uni-muenchen.de)

### 4. ICF Core Sets for Bipolar Disorders

*Carolina C. Ávila (Spain)*

We are happy to inform you that the project "Developing the ICF Core Sets for Bipolar Disorders" begun during the Summer of 2007 as a collaboration among the Autonoma University in Madrid, Spain, the ICF Research Branch in Munich, Germany, WHO and the Bipolar Disorder Programme of the Institut Clínic de Neurosciences at the Hospital Clinic from the Barcelona University, Spain.



Figure 5: Universidad Autonoma, Madrid.

The protocol paper "Developing core sets for persons with Bipolar Disorder based on the International Classification of Functioning, Disability and Health" was published in Journal Bipolar Disorders and a poster

exposing some preliminary results was presented at the "3<sup>rd</sup> Biennial Conference of the International Society for Bipolar Disorders" in Delhi, India in January 2008.

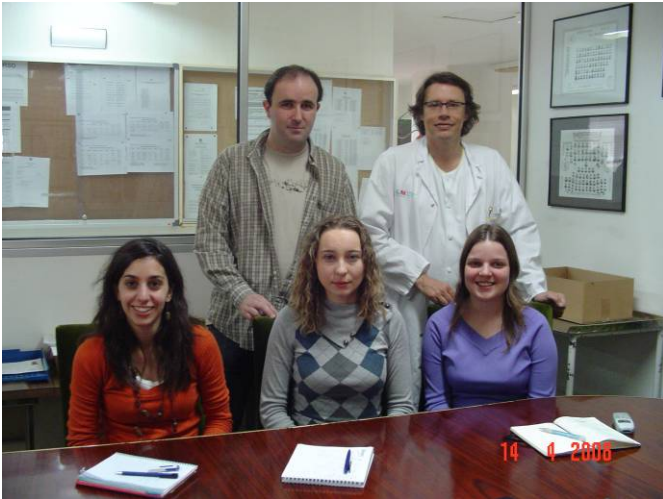


Figure 6: Team members Madrid: Back row from left to right: José Luis Ayuso, Roberto Nuevo. Front row left from right: Marta Miret, Maria Cabello and Carolina Avila.

In the next lines, we inform you about the state of affairs in the project.

#### **Expert Survey**

After recruiting health professionals from all six different WHO-world regions to participate in this study, we recently started the online expert survey and are currently gathering answers from experts on Bipolar Disorders. We would like to thank all experts that participated so far for their collaboration.

Additional experts willing to participate are encouraged to contact us at: [carolina.avila@uam.es](mailto:carolina.avila@uam.es).

#### **Systematic Literature Review**

An electronic search was conducted in MEDLINE® and PsycINFO® for articles on bipolar disorders published between 2000 and 2006 (both included). The abstracts of all retrieved articles have already been screened for inclusion according to pre-agreed criteria and parameters contained in the included articles are currently being retrieved.

#### **Empirical Studies**

Data on patients with bipolar disorder based on the ICF are being collected at the Hospital Clinic in Barcelona (Prof. Vieta) and the Hospital Universitario de la Princesa in Madrid (Prof. Ayuso-Mateos).

#### **Qualitative Studies**

To address the patients' perspective in the process of developing the ICF Core Sets for BD individual interviews are being performed at the La Princesa Hospital in Madrid with individuals suffering from Bipolar Disorder type I and II in an euthymic state.

#### **5. ICF Core Sets for Hand Conditions**

A new project to develop ICF Core Sets for hand conditions was launched last month at the ICF Research Branch after receiving a positive response from the German Social Accident Insurance "Deutsche Gesetzliche Unfallversicherung" (DGUV) for funding the project. This is a cooperative effort among the Institution for Statutory Accident Insurance and Prevention in the Health and Welfare Services (BGW), Hamburg, Germany, the Department of Hand Surgery, Plastic- and Microsurgery, Burns Unit at the Hospital of Workmens Compensation (BUK) Hamburg, Germany, the ICF Research Branch of the WHO at the Ludwig-Maximilian University in Munich and the Classification, Assessment and Surveys (CAS) team at WHO.

If you require further information, please do not hesitate to contact Sandra Kus, leader of the project ([sandra.kus@med.uni-muenchen.de](mailto:sandra.kus@med.uni-muenchen.de)).

#### **6. ICF Core Sets for Multiple Sclerosis**

*Michaela Coenen (Germany)*

The project "Development of ICF Core Sets for Multiple Sclerosis (MS)" is a cooperative effort of the Department of Neurorehabilitation at the Valens Rehabilitation Centre and the ICF Research Branch\*. It is our pleasure to inform you that the four preparatory studies of the project are coming to an end. At this point, we would like to express our sincere gratitude to all parties concerned for their cooperation and enthusiasm.

#### **Systematic review**

Totally, 354 articles of 2000 randomly selected abstracts fulfilled the predefined eligibility criteria. The identification of parameters reported in these full-text articles is completed. Within the next weeks the identified parameters will be linked to ICF categories.

#### **Qualitative study**

Six focus groups (28 participants) and five individual interviews were conducted at the Marianne Strauss Clinic in Kempfenhausen (Germany). The data analysis is in process.

#### **Expert survey**

The expert survey was performed as an internet survey to gather the opinion of physicians, physical therapists, occupational therapists, nurses, (neuro-) psychologists, speech & language therapists, and social workers. Initially an expert pool of 505 health professionals was identified. A stratified sample of 182 potential participants was drawn considering the criteria health profession and WHO world region. One hundred three health professionals from 46 countries filled in the questionnaire (95%). Totally, 7.551 different answers could be retrieved from the expert survey. Health professionals and researchers involved in the linking of the retrieved answers were trained by Michaela Coenen during a workshop at the ICF Research Branch from September 24th to 26th 2007. The linking of the

answers to ICF categories and data analysis will be completed in March 2008.



Figure 7: Participants of the MS training workshop in Munich, 24<sup>th</sup> to 26<sup>th</sup> September 2007

Back row from left to right: Michaela Coenen, Andreas Weidmann, Susanne Borkert, Tanja Übel, Kathrin Allgöwer, Andrea Fritz, Andreas Leib, Andrea Wiedenmann, Andrea Fahlböck; Front row left from right: Lena Spitzer, Andrea Glässel, Katrin Schorer, Petra Bauer (not on the foto: Eike Hirschmann)



Figure 8: Participants of the MS training workshop in Munich, 24<sup>th</sup> to 26<sup>th</sup> September 2007

Back row from left to right: Kathrin Allgöwer, Johanna Karner, Susanne Borkert, Eike Hirschmann, Andrea Fritz, Michaela Coenen, Andreas Leib, Andrea Fahlböck, Andrea Wiedenmann; Front row left from right: Lena Spitzer, Katrin Schorer, Andrea Glässel, Sandra Kus, Petra Bauer (not on the foto: Tanja Übel)

### **Cross-sectional empirical study**

Two hundred and five patients were included in the empirical study. The study was performed at the Valens Rehabilitation Centre, the University Hospital Zurich, Switzerland (Department of Neurology), the Swiss Multiple Sclerosis Society, Switzerland, and the Rehabilitation Centre Quellenhof, Germany.

### **ICF Consensus Conference**

The International ICF Core Set Consensus Conference will be held at the Valens Rehabilitation Centre

(Switzerland) from May 2nd to 4th, 2008. Following a multi-stage decision process, 21 selected experts will agree on the ICF categories to be included in the ICF Core Sets for MS.

For further information please contact Dr. Michaela Coenen: [Michaela.Coenen@med.un-muenchen.de](mailto:Michaela.Coenen@med.un-muenchen.de)

### **Presentations & Publications**

Poster presentations were 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).

The protocol paper: „Developing the ICF Core Sets for multiple sclerosis to specify functioning“ has been published in *Multiple Sclerosis* (<http://msj.sagepub.com/cgi/content/abstract/1352458507082615v1>).

\* funded by the Hertie Foundation

### **7. ICF Core Sets for Traumatic Brain Injury** *Sara Laxe (Spain)*

After the first meeting in Rome May 2007 within the framework of the World Federation for Neurorehabilitation and after being trained in the workshop at the WHO Collaborating Branch in Munich October 2007, we are happy to inform you that we are working hard in the development of the ICF Core Sets for Traumatic Brain Injury.

This project is coordinated at the Institut Guttmann (Dr. Sara Laxe and Raquel Lopez) and is a cooperative effort of the ICF Research Branch of the WHO at the Ludwig-Maximilians University Munich, the Classification, Assessment and Surveys (CAS) team at WHO, the International Society of Physical Medicine and Rehabilitation (ISPMR).



Figure 9: Institut Guttmann, Barcelona, Spain.

The protocol paper "Development of core sets for persons with traumatic brain injury based on the International Classification of Functioning, Disability and Health" is currently being prepared.

### **Expert Survey**

An expert survey will be conducted online to gather opinions from health professionals around the world about the most important and relevant aspects to traumatic brain injury.

### **Systematic Literature Review**

An electronic search was conducted in MEDLINE®, PsycINFO®, EMBASE and CENTRAL databases for articles on Traumatic Brain Injury that have been published between 2002 and 2007 (both included) and the abstracts of all the retrieved articles were screened for inclusion according to pre-agreed criteria. Dr. Sara Laxe and Dr. Giovanna Mitchell ([slaxe@guttmann.com](mailto:slaxe@guttmann.com)) are conducting this study.

### **Qualitative study**

Focus groups with patients with TBI and/or their families will be performed to address the patient's perspective. This study will be started in April 2008.

### **Empirical Studies**

We have done a systematic literature review in order to decide which are the most common outcome scales used in Traumatic Brain Injury to prepare the case record forms for the study. We will be glad to have other hospitals collaborating with us. This study will be conducted by Dr Sara Laxe and Raquel Lopez ([slaxe@guttmann.com](mailto:slaxe@guttmann.com), [rlopez.investigacio@guttmann.com](mailto:rlopez.investigacio@guttmann.com)).



Figure 10: Dr. Sara Laxe



Figure 11: Raquel López

## **8. ICF Core Sets for Sleep**

*Felix Grading (Nottwil, Switzerland)*

The protocol paper of the project "Developing ICF Core Sets for persons with sleep disorders 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" have been preliminarily published online in July 2007 in a special section of the international journal *Sleep Medicine* called "World Health Organisation (WHO) – World Association of Sleep Medicine (WASM) Recommendations"

### **Expert Survey**

From the overall pool of 380 that gave a positive response to either the first contact/reminder/final call reminder to the initial pool of approx. 2700 experts contacted from all the WHO regions and the disciplines involved in Sleep Medicine care 176 Experts were selected. The 176 questionnaires were sent out on the 24th of April 2007 and the deadline for the final call reminder was the end of October 2007. All in all 123 completed questionnaires have been returned. The data collection has consequently been terminated and all the meaningful concepts within the answers of the experts have been extracted. The linking of these meaningful concepts to the categories of the ICF started in January 2008.

### **Systematic Literature Review**

A literature review with the aim to study what sleep-related variables have been investigated in the field of spinal cord injury has been conducted.

- A highly sensitive search in medline, embase, psychinfo databases was 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 took place with great success 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), on Sept 2-6, 2007 in Cairns, Australia.

### **Empirical Studies**

The two empirical studies (qualitative study with focus groups / empirical-quantitative study with individual interviews using the extended ICF-checklist) of the preparatory phase began in January 2008. In order to identify the extension categories to the ICF-checklist a systematic review and a linking process was also performed. In this process 104 distinct sleep questionnaires have so far been identified through reviews and international guidelines in sleep medicine practice and research. The main study centers for conducting the interviews are the sleep centers of the University Hospital in Zurich (Claudio Bassetti, Ramin Khatami) and the Insel-University Hospital in Berne (Matthias Gugger, Johannes Mathis). Additional study centers can participate in the studies of the preparatory phase. If you are interested please contact Felix Grading: [felix.gradinger@paranet.ch](mailto:felix.gradinger@paranet.ch)

## 9. ICF Core Set for Visual Impairment / Low Vision

*Dr. Stephan Froehlich (Germany)*

As a collaborative project among the Department of Ophthalmology at the LMU, the Classification, Assessment and Surveys (CAS) team at WHO, and the ICF Research Branch, the ICF Core Sets for Visual Impairment are currently being developed.

Following the standard procedure of ICF Core Sets development, the preliminary studies have been launched. Cornelia Lackerbauer is engaged with the literature review now starting the data extraction after having concluded the abstract checking. We estimate to finish this part by the summer this year. Danny Loyola and Juliane Leissner are performing the patient interviews within the empirical studies. About 100 interviews have been performed up to now. Major parts of the other studies will be started this year as well, i.e. the focus groups and the expert survey. For further information please contact Dr. Stephan Froehlich: [Stephan.Froehlich@med.uni-muenchen.de](mailto:Stephan.Froehlich@med.uni-muenchen.de)

## 10. International & EULAR ICF Core Sets Validation Study for 12 different chronic conditions

*Alicia Garza (Germany)*

The data collection for the empirical validation study for chronic conditions is coming to an end. The data collection will be finished during the summer of 2008. Up to now we have received data from 119 study centers throughout the world. The distribution of the study centers per WHO region is as follows:

Eastern Mediterranean Region: 10%  
European Region: 76%  
Region of the Americas: 4%  
South East Asia Region: 1%  
Western Pacific Region: 9%

The following figure shows the number of study centers in each WHO Region that have collected data during the study.

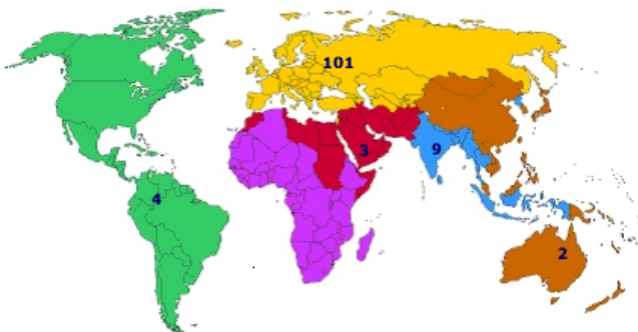


Fig. 12: Number of study centers per WHO world region.

Currently all data, that has been received is being cleaned and prepared for the analyses at the ICF

Research Branch. There have been already several teams from collaborating study centers who have started, with the support of the ICF research team in Munich, national analyses and even some have published the results on data collected for the international validation study. This is the case of Dr. Feng Xie from Singapore, who collected data from patients suffering knee osteoarthritis within this study and had already published the results in the paper: "Validation of the Comprehensive ICF Core Set for Osteoarthritis (OA) in Patients with Knee OA: A Singaporean Perspective." in the Journal of rheumatology.

### 10.1. Validation of Comprehensive ICF Core Sets from the patient perspective

Using the validation of Comprehensive ICF Core Set for RA as a case in point, a protocol was developed to validate ICF Core Sets from the patient perspective to be used for different health conditions and in different countries. In the meantime several researchers have started the process of validating ICF Core Sets for different health conditions using the protocol (see table on page). For the studies in foreign countries listed below the open-ended questions were translated according to a standardized translation procedure. For further information please contact [Alicia.Garza@med.uni-muenchen.de](mailto:Alicia.Garza@med.uni-muenchen.de)

### 10.2. Validation of the ICF Core Sets from the perspective of health professionals

The main question is whether the interventions applied to patients with a specific health condition by different health professionals and the intervention-related effects on the patients' functioning and well-being are represented in the ICF categories selected for the corresponding ICF Core Sets. This approach is being pursued with an international survey of experts (physicians, physical and occupational therapists, nurses, psychologists and social workers) according to the Delphi method.

Interested persons please contact Dr. Inge Kirchberger: [Inge.Kirchberger@med.uni-muenchen.de](mailto:Inge.Kirchberger@med.uni-muenchen.de)



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

Tab 1 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.

### 11. The use of the ICF Core Sets for the appraisal of patients suffering low back pain and chronic widespread pain

In collaboration among the ICF Research Branch and the German Pension Insurance (Federation) of different federal states an 18 month project was started early this year. The aim of the study is to verify if the ICF Core Sets can provide a basis for the appraisal of patients suffering low back pain and chronic widespread pain. The appraisal of patients based on the bio-psycho-social model of the ICF will allow a systematic assessment of functioning and disability and will lead to the standardization of the medical opinion files, facilitating the communication between physicians and insurance companies.

The contents of 600 randomly selected medical opinion files will be analyzed. The identified concepts will be translated into the language of the ICF. This so-called "Linking" will be performed by social evaluators and by members of the ICF Research Branch. The results of the study will verify whether all relevant information

within the medical opinion files is contained in the ICF Core Sets for low back pain and chronic widespread pain. For further information, please contact: [Michaela.Kirschneck@med.uni-muenchen.de](mailto:Michaela.Kirschneck@med.uni-muenchen.de)

### 12. Case studies to describe the implementation of the ICF in rehabilitation practice

To apply the ICF and ICF Core Sets in rehabilitation practice ICF tools needed to be developed. These tools aim to facilitate the understanding and descriptions of the individual's functioning in rehabilitation management and provide an ICF based documentation which contributes to multidisciplinary team approaches. To illustrate the use of these ICF tools in rehabilitation practice the case studies project was initiated at the Swiss Paraplegic Research (SPR) in October 2006. The Swiss Paraplegic Research aims to contribute to optimal functioning and social integration, health and quality of life of people with Spinal Cord Injury (SCI) through clinical and community oriented research ([www.paranet.ch/sw39033.asp](http://www.paranet.ch/sw39033.asp)).



#### Methods - Case studies

The aims of the Case study project are

- to illustrate the use of ICF tools in a structured rehabilitation management based on the Rehab-Cycle
- to demonstrate a patient-oriented rehabilitation approach based on the individual's perspective suffering from SCI

In the project, persons suffering from SCI by different reasons and varying in age, gender, cause and severity of disease, are accompanied and monitored during a specific time in a specific rehabilitation phase. Since patients with SCI and the involved health professionals are faced with a lot of physical, psychological and social challenges, the Case studies aim to cover a broad spectrum of these challenges, from biological to psychological and environmental aspects. To satisfy the broad spectrum altogether 20 cases will be described and published on a publicly available website.

The use of ICF tools (namely ICF Assessment Sheet, the ICF Categorical Profile, ICF Intervention table and ICF Evaluation display) is illustrated in the steps of the rehabilitation processes (assessment, assignment, intervention and evaluation) in each of the cases. Additional information about the ICF and the ICF tools is also available at the website.

To foster an educational approach the readers of the website are invited to check their knowledge about the

ICF and SCI within answering open questions and specific quizzes.

The website is open to public access; the first four cases are already uploaded:

<http://www.icf-casestudies.org/>

For further information, please contact [Alexandra.Rauch@paranet.ch](mailto:Alexandra.Rauch@paranet.ch)

### 13. Project completion: "Measuring Health and Disability in Europe" (MHADIE)

MHADIE research has demonstrated the feasibility, utility and value of the ICF as a model for harmonising data across populations and sectors in Europe. Such data assist countries in developing realistic, evidence-based and effective social policies for persons with disabilities that will achieve equality of opportunities and full participation. MHADIE results will facilitate a comprehensive description of disability, an evidence based definition of domains of disability and a baseline reference population for comparisons, thereby increasing the EU capacity of analysis as requested by the EU disability Action Plan 2006-2007. In this way, inequalities can be described and measured by the difference between opportunities for participation of persons with and those without impairments experience. These inequalities represent unmet resource and service needs linked to impairments, including needs created by discriminatory policies and practices. Identification of disability inequalities is also mandated by the recently approved UN Convention for the Rights and Dignity of Persons with Disabilities.

By providing a common framework for defining and measuring disability, MHADIE's results help to improve the accuracy and comparability of estimates of prevalence of impairments and disability Europe wide. The methodology used and the system developed during the research period have allowed the harmonisation of disparate data sets collected at national and international levels. This has led to an integration of existing statistical information systems across nations, sectors and life span.

### 14. ICF Core Set Development Workshops

Two training workshops on the methods to be followed for the *Development of ICF Core Sets* took place on October 16<sup>th</sup> and 17<sup>th</sup>, 2007 and on 25<sup>th</sup> and 26<sup>th</sup> of February 2008 at the Institute for Health and Rehabilitation Sciences in Munich. The contents of the two-day workshop were: 1) an introduction into the ICF, 2) general information on the process for the Development of the ICF Core Sets and 3) detailed information on the preliminary studies: patient interviews, literature review, empirical study and expert survey.

Nineteen participants coming from Australia, France, Germany, Italy, Norway, Slovenia, Spain, Sweden and Switzerland attended the meeting in October. Many of

the attendees are already collaborating in the development of ICF Core Sets for traumatic brain injury; some others are interested in developing ICF Core Sets for Amputees. Interest was shown in other areas as hand functioning, oral functioning as well as hearing impairment.



Figure 13: Participants of the ICF Core Set Development workshop in Munich, 16<sup>th</sup> and 17<sup>th</sup> October 2007  
Back row from left to right: E. Kraft, L. Peyrin, A. Leib, E. Baütz-Holter, K. Grabljevec and L. Fava. Middle row: A. Cieza, R. Tate, Y. Bucher, E. Linseisen, U. Cizman, D. Faulks, C. Johansson, B. Aiachini, S. Laxe, S. Kus, R. Lopez, A. Garza, S. Landa and G. Stucki. Front row: U. Sveen, H. Lüthi, M. Garcia, S. Kleemann, C. Roe and P. Boldrini

The workshop which took place last February was attended by twenty health professionals from many different countries, namely, Austria, Canada, Czech Republic, France, Germany, Hungary, Switzerland, UK and USA. Oral pain, dementia and children disability were the main areas of interest within the participants.



Figure 14: Participants of the ICF Core Set Development workshop in Munich, 25<sup>th</sup> and 26<sup>th</sup> February 2008  
Back row from left to right: G. Rivier, G. Stucki, S. Wadle, P. Jaegher, V. Krutsch, A. Mohagheghi, I. Prime, P. Ryckx, M. Schindl, S. Szczecianna, A. Al-Khodairy, S. Kus, V. Schiariti, L. Garcia, M. Coenen, I. Kirchberger, I. Schäfer, E. Simoncsics, C. Sabariego, H. Matlasová, J. Kupková. Front row: A. Garza, S. Mackensen, R. Escorpizo and A. Cieza

The ICF Research Branch will offer similar workshops periodically. The workshops will be planned depending on the demand; if you are interested in attending such a meeting please contact: [alicia.garza@med.uni-muenchen.de](mailto:alicia.garza@med.uni-muenchen.de).

**APPENDIX I New Publications of members of the ICF Research Branch:**

Allet L, Cieza A, Burge E, Finger M, Stucki G, Huber EO.

Intervention categories for physiotherapists treating patients with musculoskeletal conditions on the basis of the International Classification of Functioning, Disability and Health.

Int J Rehabil Res. 2007 Dec; 30(4): 273-280.

PMID: 17975446 [PubMed - as supplied by publisher]

Stamm TA, Bauernfeind B, Coenen M, Feierl E, Mathis M, Stucki G, Smolen JS, Machold KP, Aringer M.

Concepts important to persons with systemic lupus erythematosus and their coverage by standard measures of disease activity and health status.

Arthritis Rheum. 2007 Oct 15; 57(7): 1287-95.

PMID: 17907225 [PubMed - indexed for MEDLINE]

U. Tschiesner · A. Cieza · S. N. Rogers · J. Piccirillo · G. Funk · G. Stucki · A. Berghaus

Developing core sets for patients with head and neck cancer based on the International Classification of Functioning, Disability and Health (ICF)

Eur Arch Otorhinolaryngol (2007) 264: 1215–1222

van Echteld I, Cieza A, Boonen A, Stucki G, Zochling J, Braun J, van der Heijde D

Identification of the most common problems by patients with ankylosing spondylitis using the international classification of functioning, disability and health.

J Rheumatol. 2006 Dec; 33(12): 2475-83. Epub 2006 Oct 15.

Jurg Kesselring, Michaela Coenen, Alarcos Cieza, Alan Thompson, Nenad Kostanjsek, and Gerold Stucki

Developing the ICF Core Sets for multiple sclerosis to specify functioning

Multiple Sclerosis 2007, doi: 10.1177/1352458507082615

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Xie F, Lo NN, Lee HP, Cieza A, Li SC.

Validation of the Comprehensive ICF Core Set for Osteoarthritis (OA) in Patients with Knee OA: A Singaporean Perspective.

J Rheumatol. 2007 Oct 15; [Epub ahead of print]

PMID: 17937460 [PubMed - as supplied by publisher]

Weigl M, Cieza A, Cantista P, Reinhardt JD, Stucki G.

Determinants of disability in chronic musculoskeletal health conditions: a literature review. Eur J Med Phys. 2007 Nov 9; [Epub ahead of print].

**APPENDIX II Lists of Study Centers participating in the projects:**

- a) ICF Core Sets for chronic conditions: international validation study

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<b>Austria</b>
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**b) ICF Core Sets for HNC: international validation study**

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