

8. Newsletter

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

January - June 2006

Dear Partners and Friends,

The team of the ICF Research Branch would like to inform you of the progress achieved in different ICF Core Sets projects during the last 6 months.

Since we are at the final stage of the data collection in the EULAR and the International ICF Core Sets Validation Studies, we shall show you the state of the data collection. It is impressive and very motivating to see that the data from 1800 patients have been collected during the last six months. The data from 4014 patients are already in the database. You have contributed to creating the largest existing database containing ICF-based information from clinical populations. We would like to extend our thanks to all of you for this valuable work.

Members of the ICF Research Branch team have been in Hungary, Israel, and Turkey to train collaboration partners in data collection for the EULAR and the International ICF Core Sets Validation Studies. Some of our collaborating partners also participated in a training workshop in Munich. We have summarized all these events for you on pages 4, 5, 6 and 4, respectively.

Beatrix Söhnel from Gothenbur, Sweden, informs us about the clinical application of the Comprehensive ICF Core Set for Stroke in a longitudinal study (page 7) and our collaboration partners in Malaysia describe ICF Core Sets activities that have been carried out in this region (page 12).

We also inform you of the progress made in the validation studies from the health professional perspective (page 8). Approximately 700 health professionals from all over the world have already participated in this process. Our gratitude to all of them!

Monika Scheuringer from the ICF Research Branch and Annlies Boonen from Maastricht provide an update on the progress of the development of the ICF Core Sets for Spinal Core Injury (page 9) and the ICF Core Sets for Ankylosing Spondilitis (page 11).

We also inform you about the progress of the Measuring Health and Disability in Europe project (MHADIE) that is being financed by the European Commission (page 11).

The 2nd Congress of the European Paraplegics Association took place on March 30 and 31, 2006, at the Guido Zäch Institute in Nottwil, Switzerland. Gerold Stucki and Alarcos Cieza were there with two different presentations. A briefly description of this event can be found on page 14.

The 8th OMERACT meeting was held from May 10 to 14 in Malta. Gerold Stucki was there to introduce the ICF. We provide the interesting outcomes of this meeting on page 14.

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

All best wishes from Munich,
Your ICF Core Set Development Team

1. International ICF Core Sets Validation Study: Project Status

1.1. Number of study centers per country

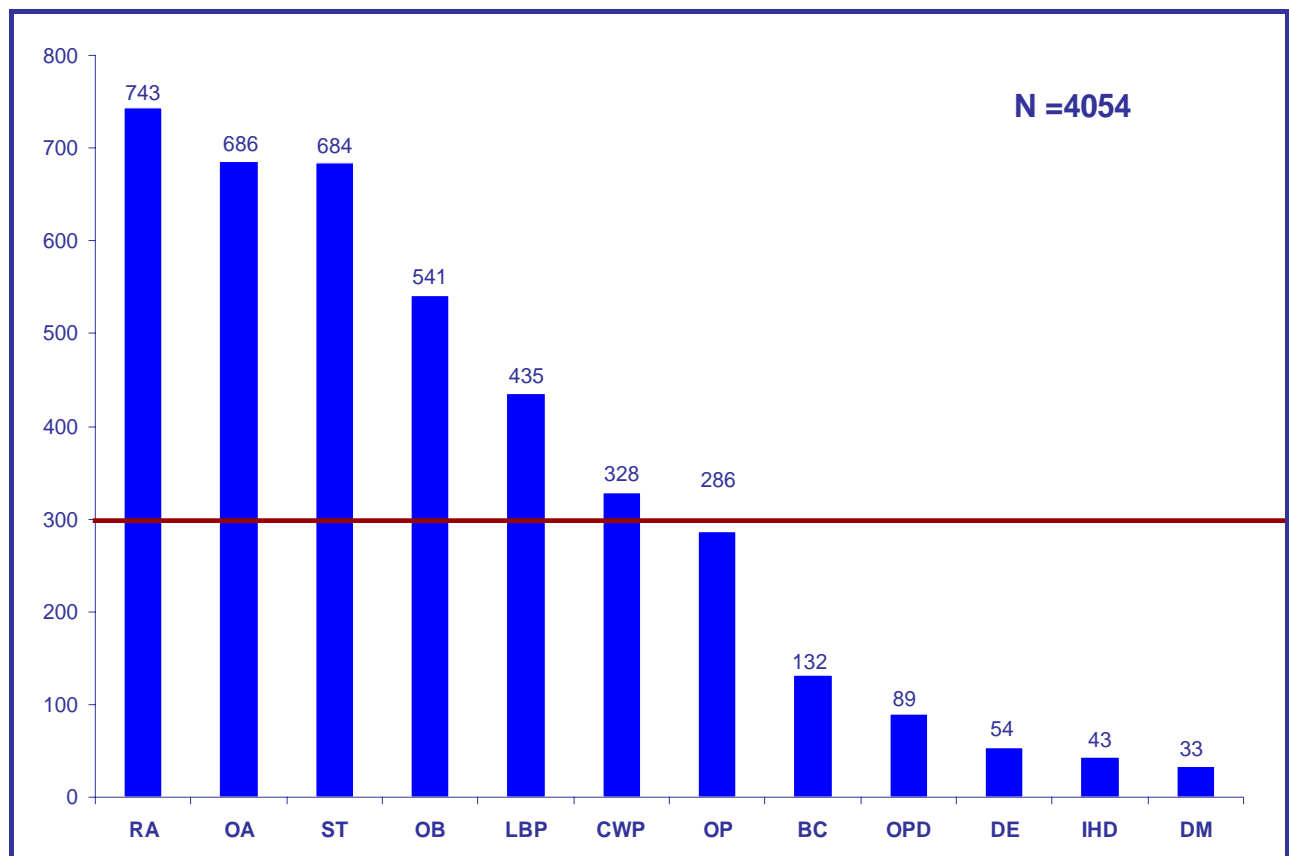
No	Country	N° of Study Centers	No	Country	N° of Study Centers
1	Argentina	1	27	Lithuania	5
2	Australia	4	28	Malaysia	1
3	Austria	5	29	Mexico	3
4	Belgium	3	30	Nigeria	1
5	Brazil	2	31	Norway	6
6	Canada	3	32	Philippines	1
7	Chile	1	33	Poland	11
8	China	4	34	Portugal	7
9	Croatia	1	35	Republic of Macedonia	1
10	Cyprus	1	36	Romania	3
11	Czech Republic	2	37	Russia	1
12	Egypt	1	38	Serbia	3
13	Finland	2	39	Slovakia	2
14	France	6	40	Singapore	1
15	Germany	105	41	South Africa	1
16	Greece	6	42	South Korea	2
17	Hungary	15	43	Spain	2
18	India	3	44	Sweden	6
19	Indonesia	2	45	Switzerland	15
20	Ireland	1	46	Thailand	1
21	Israel	8	47	The Netherlands	7
22	Italy	18	48	Tunisia	1
23	Japan	1	49	Turkey	13
24	Kenya	1	50	UK	7
25	Kuwait	2	51	USA	3
26	Lebanon	1			
Total					303

1.2. Data Collection

Up to now we have received a total of **4014** Case Record Forms:

	International	Germany	Total
Breast Cancer	48	84	132
Chronic Ischaemic Heart Disease	5	38	43
Chronic Widespread Pain	116	205	321
Depression	21	33	54
Diabetes Mellitus	31	2	33
Low Back Pain	319	111	430
Obesity	498	39	537
Obstructive Pulmonary Diseases	60	31	91
Osteoarthritis	619	48	667
Osteoporosis	261	22	283
Rheumatoid Arthritis	731	10	741
Stroke	442	240	682
Total	3151	863	4014

1.3. *Data collected up to May 5 2006 within the EULAR and ICF Core Sets Validation Study*



BC: malignant neoplasm of breast; OPD: obstructive pulmonary diseases; CWP: chronic widespread pain; DE: depression; DM: diabetes mellitus; IHD: chronic ischemic heart disease; LBP: low back pain; OA: osteoarthritis; OB: obesity; OP: osteoporosis; ST: stroke; RA: rheumatoid arthritis.

Sincere thanks to all of you! Please remember that we still need your support to collect data for the following health conditions: breast cancer, ischaemic heart disease, depression, diabetes mellitus and obstructive pulmonary diseases.

1.4. *Training of Health Professionals*

Training of German study centers

Since the beginning of the year our ICF Training team has organized three workshops for the EULAR and the international ICF Core Sets validation studies, a total of 59 health professionals were trained. Out of these workshops, we gained eleven collaboration partners. These study centers will participate in the validation studies for the 12 chronic conditions. All workshops were accredited with 8 vocational training points by the German Medical Association and the German Association of Psychotherapists.

In respond to the circular letter sent to all german study centers asking on the demand on further training workshops, we decided to organize two further ICF Core Sets workshops during the late summer. One will take place at the Fachklinik Wolletzsee in Brandenburg and the second one at the Ludwig-Maximilian University in Munich.

Friday, 01. September 2006

Fachklinik Wolletzsee, Angermünde-Wolletzsee, Brandenburg

Friday, 15. September 2006

Klinikum Großhadern Ludwig-Maximilian University, Munich

We have designed a poster that describes in a simple manner the goals of the study and the relationship between your clinic and the ICF Research Branch within the validation of the ICF Core Sets study. This depiction clarifies the validation study to all clinic staff members and it can facilitate the acquisition of patients. If you are interested, please contact Michaela Kirschneck (Michaela.Kirschneck@med.uni-muenchen.de).

Training of International study centers

Budapest, Hungary

To strengthen the collaboration between the participating study centers in Hungary and the ICF Research Branch, Prof. Lajos Kullman and Dr. Geza Balint invited us to hold an ICF Core Sets validation study training workshop at the National Institute of Rheumatology and Physiotherapy in Budapest on February 10, 2006. Fifteen health professionals attended the meeting - two from Croatia, one from the Slovak Republic and the rest coming from diverse regions in Hungary. The training workshop also familiarised participants with the principles and rules of the data collection within the international ICF Core Sets validation study.



From left to right: G. Bálint, L. Kullmann, S. Pauló, G. Sarlós, C. Varjú, G. Ilosvai, M. Trócsányi, S. Geyh, J. Ortutay, I. Márkus, Z. Pinter, J. Csiki, N. Eberfalvi, P. Takac, R. Csicic and G. Ormos.

Participants in the ICF Core Sets Validation Study Training Workshop in Budapest, February 10, 2006.

Munich, Germany

On March 10, 2006, a training workshop with seven participants was held at the Ludwig-Maximilian University in Munich. Although it was a small group, many countries were represented: Czech Republic, Germany, Italy, Malaysia and Norway. The meeting was very fruitful. All participants have started with the data collection of the ICF Core Sets empirical validation study.



From left to right: Dr. Heinrich Gall, Florian Kiuppis, Sybille Schwarz, Dr. Giovanna Garofalo, Monika Sheuringer, Dr. Petra Brtnicka, Szilvia Geyh, Kristin Berge, Dr. Lydia Abdul Latif, Tor-Ivar Karlsen, Dr. Nazirah Hasnan and Alicia Garza.

ICF Research Branch team members and participants in the ICF Core Sets Training Workshop Munich, March 10, 2006.

Raanana, Israel

On March 16 and 17, an ICF Core Sets workshop took place at the *Loewenstein Hospital Rehabilitation Center* under the auspices of Prof. Haim Ring, who is the liaison person of the WHO ICF Research Branch in Israel. Prof. Jacob Hart, Director of the Loewenstein Hospital Rehabilitation Center and Dr. Boaz Lev, Associate Director General at Ministry of Health in Israel supported and were present at the workshop.



From left to right: Prof. Jacob Hart, Dr. Boaz Lez, Prof. Gerold Stucki, Dr. Alarcos Cieza and Prof. Haim Ring

This workshop represented a first step in the creation of an Israeli WHO-ICF Network that will be supervised by Prof. Haim Ring. Around 70 health professionals and physicians with very diverse specializations attended.

This event motivated the initiation of what we call the “Mediterranean Perspective” within the ICF Core Set Validation Study. If enough data are collected in different Mediterranean countries, publications reporting the results of the validation study from the Mediterranean perspective will be submitted to the journal “Europa Medicophysica”.



Participants of the ICF Core Sets Validation Study Training Workshop in Israel, March 16-17,2006.

A follow up meeting led by Prof. Haim Ring took place at the *Loewenstein Hospital Rehabilitation Center* on May 25th , 38 persons attended the session. During the meeting the steps to be followed were established and the tasks to be done were assigned. Resultant to this reunion, data from patients suffering low back pain, osteoarthritis, rheumatoid arthritis and stroke will be collected at eight different institutions in Israel.

Istanbul, Turkey

A training workshop was held in Istanbul on May 5 2006 to strengthen the ICF Core Sets network and to promote their dissemination in different Mediterranean countries. We want to express our deep gratitude to Prof. Gülseren Akyüz from Marmara University Hospital, who hosted the event and invited many health professionals from all over the country to attend the workshop. The widespread interest in the ICF in Turkey was confirmed by the numerous attendees. Forty-nine health professionals and physicians were present and many of them will participate in the empirical validation study of the ICF Core Sets for chronic conditions.

Prof. Haim Ring from the Loewenstein Rehabilitation Center in Israel contributed to the success of the workshop. He opened and closed the event. One of his talks was on the implementation of the ICF in Physical Medicine and Rehabilitation. His presence at this workshop reflects the spirit of the ICF Core Sets validation study, which relies on collaboration and internationality.



Participants in the ICF Core Sets Validation Study Training Workshop in Istanbul, Turkey on May 5 2006.

1.5. *Important information on the data collection for osteoarthritis*

It was originally planned to use the WOMAC questionnaire for the assessment of patients with osteoarthritis in the multicenter validation study of the ICF Core Sets and it is mentioned in the study protocol. Hereby we notify you that only the German version of the WOMAC questionnaire will be used for the validation study of the ICF Core sets for osteoarthritis. The Knee Injury and Osteoarthritis Outcome Score (KOOS) will be used in all other languages, if available (www.koos.nu). Please contact us if you have any questions regarding this matter.

1.6. *Clinical application of the Stroke ICF Core Set in a longitudinal study*

Beatrix Söhnel (Gothenburg, Sweden) beatrix.sohnel@neuro.gu.se

Each year more than 30,000 persons suffer a stroke in Sweden. With almost one million hospital days per year, stroke is the somatic disease responsible for most care days in Swedish hospitals. One year after suffering a stroke, 40-70% of patients are alive, and many survivors face long-term

disability. The input of community nursing homes and nursing services in this sector is high. Good cooperation among the various caregivers is important for the outcome of patient functioning and for its effectiveness. As the ICF provides a universal and comprehensive language, we apply the ICF Core Set for Stroke to investigate how the functioning profiles of stroke patients change during a year-long rehabilitation.

Gothenburg (on the west coast) is the second largest city in Sweden with 490,000 inhabitants in an area of about 450 km², including the surrounding rural area. All acute stroke patients in this district are admitted to the Sahlgrenska University Hospital, which has three departments: Östra sjukhuset (located west), Mölndal sjukhuset (located south) and Sahlgrenska sjukhuset (located central). In 2004, 211 stroke patients were examined on the stroke unit at the Östra sjukhuset, 263 at the Mölndal sjukhuset and 788 at the Sahlgrenska sjukhuset (which has two stroke units: one neurological and one medical).

Within this longitudinal study, patients who are at least 18 years old are recruited 3 ± 5 days after suffering the first acute stroke and followed up after six weeks, three months and one year.

Sixty-two patients have already been included in the study, 35 patients have completed the second time point of assessment and 10 patients, the third. The average age is 72 years. One half is men (average age: 68 years, ranging from 41 to 87 years). The average age of women is 76 years (ranging from 45 to 93 years). Eighty percent were retired at the time of the stroke, and 20% were of working age, which is approximately the normal range of stroke patients in Sweden (around 20% below 65 years of age). Almost half of the sample lived alone when they suffered a stroke. In the acute phase, 52% had problems walking, and 16% could not get out of the bed by themselves. Dressing, as well as washing, was problematic for half of the sample. Half of the sample was worried about the future with their new situation. Health services were seen as a facilitator, and more than two thirds were very satisfied with the health professionals and the care provided.

The study continues until 120 patients have been included and the one year follow-up has been completed.

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

Several international Delphi-studies are being conducted as doctoral and master's theses at the ICF Research Branch in Munich. The following Delphi studies are currently being performed:

1. Validation of the ICF Core Sets for **rheumatoid arthritis** from the perspective of physicians
2. Validation of the ICF Core Sets for **stroke** from the perspective of physicians
3. Validation of the ICF Core Sets for **obstructive pulmonary diseases** from the perspective of physiotherapists
4. Validation of the ICF Core Sets for **obstructive pulmonary diseases** from the perspective of physicians
5. Validation of the ICF Core Sets for **stroke** from the perspective of occupational therapists
6. Validation of the ICF Core Sets for **chronic conditions** from the perspective of social workers

If you want more information on how to undertake a validation study of the ICF Core Sets from the health professional's perspective, please contact Inge Kirchberger (Inge.Kirchberger@med.uni-muenchen.de).

2. Report on further ICF Core Sets projects

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

Monika Scheuringer (Munich, Germany) monika.scheuringer@med.uni-muenchen.de

Pilot study for the empirical study from 22nd to 26th January 2006

Christine Boldt and Monika Scheuringer, both from the ICF Research Branch in Munich, performed interviews with ten individuals treated in the Swiss Paraplegic Centre Nottwil using the case record form developed for the empirical study. The case record form has been modified according to the lessons learned from the pilot study.

International training course at the Swiss Paraplegic Research Centre from 5 April to 6 April 2006

The team of the ICF Research Branch under the leadership of Monika Scheuringer held an international training course in the "Development of ICF Core Sets for SCI" project. The aim of the workshop was to train the regional project coordinators of the WHO regions in the principles of the ICF and data collection procedures of the empirical study and the focus groups. In addition to a systematic review and an expert survey, these studies will provide the evidence background for the international ICF Core Set Consensus Conference.

The regional project coordinators from three WHO regions and health professionals involved in the data collection process, as well as participants from further ongoing ICF Core Sets projects, attended the workshop. A total of 13 participants from 10 different countries were at the Swiss Paraplegic Research at Nottwil from April 5 to 6 2006.



Participants of the ICF training course and members of the WHO CAT team at Nottwil, Switzerland, 6 April 2006 (from left to right: Hansjörg Lüthi, Enea Cominelli, Annelies Boonen, Susan Charlifue, Jan Reinhardt, Alarcos Cieza, Gerold Stucki, Valentina Di Donna, Apichana Kovindha, Üstün, Nenad Kostanjsek, Monika Scheuringer, Christine Boldt, Elisabeth Linseisen, Helga Lechner, Lydia Zufferey, Heinrich Gall, Nazirah Hasnan, Stephan Fröhlich, Anne Sinnott)

The fruitful discussions among the participants resulted in a practical working definition for both “early post-acute” and “chronic” situations and a modification of the open-ended questions used in focus groups.

In a next step, the regional project coordinators will train all health professionals involved in data collection within their WHO region. The worldwide empirical study and the focus groups will start in May, 2006, and it is expected that the data collection should be finished in May, 2007.

The following table gives an overview of the study centres involved in data collection during the preparatory phase:

Name of WHO region	South East Asia Region	Western Pacific Region	Region of the Americas	European Region
Regional Project Coordinator Haim Ring	Apichana Kovindha	Anne Sinnott	Susan Charlifue	Michael Baumberger
Countries Israel	Thailand Malaya India	New Zealand Australia Taiwan/China	Canada USA Brasil	Switzerland Denmark
Study Centers Loewenstein Rehab Center Achuza St. 278 Raanana 43100 Israel Study director: A. Catz	Department of Rehabilitation Medicine Chiangmai Hospital Chiangmai 50200 Thailand Study director: A. Kovindha	Burwood Spinal Unit Burwood Hospital Private Bag 4708 Christchurch New Zealand Study director: Anne Sinnott	GF Strong Rehab Centre 4255 Laurel Street Vancouver, BC V5Z 2G9 Canada Study director: A. Townson	Swiss Paraplegic Centre Nottwil Guido A. Zach Str. 1 6207 Nottwil Switzerland Study director: M. Baumberger
Department of Neurological Rehabilitation At the Chaim Sheba Medical Center Israel Study director: G. Zeilig	Indian Spinal Injuries Centre (ISIC) Sector -C, Vasant Kunj New Delhi - 110070. India Study director: H.S. Chhabra	Auckland Spinal Rehabilitation Centre Auckland New Zealand Study director: Sridhar Atresh	Craig Hospital 3425 S. Clarkson St. Englewood, CO 80113 Denver USA Study director: S. Charlifue	REHAB Basel Im Burgfelderhof 40 4025 Basel Switzerland Study director: M. Mäder
	University Malaya Medical Center Pusat Perubatan Universiti Kuala Lumpur 59100, Kuala Lumpur, Malaya Study director: N. Hasnan	Victoria Spinal Service Melbourne Australia Study director: Angela Chu	University Hospital of Sao Paulo Sao Paulo Brasil Study director: J. Greve	Paraplegic Center Balgrist University Hospital Balgrist Forchstrasse 340 8008 Zurich Switzerland Study director: Volker Dietz
				Clinic for Spinal Cord Injuries Rigshospitalet Havnevej 25 Hornbæk 3100 Denmark Study director: F. Biering-Sørensen
				Orthopädische Universitätsklinik Heidelberg Schlierbacher Strasse 220a 69118 Heidelberg: Study director: HJ Gerner
				Unità Spinale Azienda Ospedaliera Careggi Firenze Viale Pieraccini 17 50139 Firenze Italy Study director: S. Aito

Expert Survey

A survey including health professionals experienced in the care for individuals with SCI is one of the four studies to be performed during the preparatory phase of the project.

The objective of the expert survey is to explore the expert perspective on problems relevant to individuals with SCI. Up to 40 physicians, psychologists, nurses, physiotherapists, occupational therapists, and social workers from each of the six WHO regions will be requested to participate in an e-mail survey. The participants will be asked to fill in a questionnaire with five open-ended questions.

We have started the recruitment of health professionals for the so-called “expert pool” in May, 2006. Persons from 230 identified institutions specialised in the care of individuals with SCI from 59 different countries worldwide have been contacted. They were asked to name health professionals of their institution, who would be interested in participating in this worldwide study. In a next step, a random sample from this expert pool is drawn. An e-mail including the survey questionnaire will be sent to the selected health professionals in June/July, 2006.

For further information, please contact Monika Scheuringer (monika.scheuringer@med.uni-muenchen.de)

2.2. Update on the development of the ICF Core Sets for ankylosing spondylitis

Dr. Annelies Boonen (Maastricht, the Netherlands) aboo@sint.azm.nl

The development of the Core Sets for AS has made good progress. To identify the most typical and relevant categories of the ICF according to the perspective of health professionals in patients with AS, an international expert survey was conducted using the Delphi technique. Data were collected in three rounds. Answers were linked to the ICF and analysed for the degree of consensus. Of the 267 experts invited, 126 agreed to participate, and 73 participated in the three rounds. The results of the exercise have been submitted as an abstract for the Spondyloarthritis Congress in Ghent.

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

All sixteen partners of the MHADIE project met in Prague from May 31 to June 3, 2006. The meeting was organized and hosted by Prof. Olga Svestkova M.D. from the Department of Rehabilitation Medicine at Charles University. During the meeting all the partners reported on the milestones accomplished during the first half of 2006 and discussed the next steps.

This meeting in Prague was also the frame of a very significant event, namely, a one-day meeting with outstanding speakers to discuss the international debate around the definition of disability.

Astonishingly, there is no uniform conception of disability that policy makers in different countries – or even within the same country – can use to plan health and social policy. This is one reason why despite the efforts of the Organization for Economic Co-operation and Development (OECD),

the United Nations Statistics Division (UNSTAT) and EUROSTAT, prevalence rates of disability across countries and regions are markedly different. UNSTAT reports that there is 60-fold difference in the disability prevalence rates among its reporting countries.

Keeping in mind that a definition of disability is essential to develop health and social policy for people with disabilities, MHADIE partners discussed and prepared an ICF-based definition of disability together with EC members, Advisory Board members and experts from several EU countries.

The following speakers with the corresponding talks were present during the meeting:

Matilde Leonardi, MHADIE Coordinator	EU MHADIE Project presentation
Somnath Chatterji, WHO	Functioning and disability in statistics in Europe
José-Luis Ayuso, Universidad Autónoma de Madrid	Functioning and disability in clinical in Europe
Judith Hollenweger, Pädagogische Hochschule Zürich	Functioning and disability in children in Europe
Nenad, Kostanjsek, WHO	Functioning and disability issues in the world
Wallis Goelen, EU Commission	Participation and integration in Europe
Giampiero Griffo, European Disability Forum	Participation and integration in Europe
Thorsten Afflerbach, Council of Europe	Disability Action Plan
Kevin McCarthy, EU Commission	Research supporting policy program in EU

For further information, please contact us alarcos.cieza@med.uni-muenchen.de

3. The Malaysian experience

Dr. Lydia Abdul Latif (Kuala Lumpur, Malaysia) lydialatif@um.edu.my

Work on the ICF has generated worldwide interest, including Malaysia. It has provided a platform for international collaboration in research for academic excellence and clinical practice. The collaboration between the ICF Research Branch in Munich and Malaysia started in 2004 and is ongoing. It was initiated by Associate Professor Dato Dr Zaliha Omar, who attended the Consensus Conferences for musculoskeletal and internal conditions, respectively.

The Faculty of Medicine of the University Malaya (UM), the premier and oldest university in Malaysia is spearheading the ICF work in Malaysia. The Rehabilitation Medicine Unit, Department of Allied Health Sciences (AHS) is the official study centre for the ICF Validation Study in Malaysia.

To date, various activities have been conducted to promote the ICF work in Malaysia. These include:

1. Organizing workshops:

The Department of AHS has conducted two workshops for disseminating the worldwide development of the ICF and the ICF Core Sets. The initial workshop was aimed to present an overview of the ICF concept to the various health-care professionals, mainly in Rehabilitation Medicine, and to introduce the various research opportunities that can be undertaken.

The most recent workshop conducted on the April 5, 2006, was jointly organized by the Ministry of Health (MOH), Malaysia. The workshop chairman, Dr Asiah Ibrahim, Head of Rehabilitation Medicine, has assured MOH commitment in supporting ICF work conducted by the University of Malaya. The participants in the workshop included Rehabilitation Medicine Physicians from Malaysia and other health-care professionals.

2. Participation in the Worldwide Empirical Study:

This has been the core activity for the ICF work in the faculty. The main researcher, Dr Lydia Abdul Latif, Rehabilitation Medicine Physician and a lecturer from the Department of AHS initiated the empirical study for validation of the ICF Core Sets for breast cancer and low back pain. A research grant was obtained from the China Medical Board, which is one of the main research funders in the faculty.

3. ICF workshop and attachment with the ICF research team at the Ludwig-Maximilian University, Munich, Germany.

Demonstrating the high level of team commitment and interest, Dr Lydia and Dr Asiah attended the ICF training workshop held recently in Munich. Travel expenses were provided by their respective organizations in recognition of the work that has already been accomplished. The meeting with the ICF Research Branch team members was a very enriching experience, provided greater depth of knowledge of ICF work and has generated further collaboration. The training workshop was very useful as it provided clearer guidelines, clarification on study designs and ensures uniformity of the work conducted.

4. Development of ICF Core set for Spinal Cord Injury (SCI).

Dr Nazirah Hasnan, Head of Unit, Department of AHS, who has special interest in Spinal Cord medicine, attended the International Training Course at the Swiss Paraplegic Research from April 5 to 6, 2006, for Development of the ICF Core Sets for SCI. She will be part of the team performing research for the SCI group here.

5. On going and future activities:

- Continue with Worldwide Empirical Survey for breast cancer and other conditions.
- Generate further research grants to conduct Worldwide Expert Survey for physician in treating Breast Cancer
- Participate in research for the development of the Core Sets for SCI
- Discuss the development of other ICF Core Sets, e.g. amputee patients, with the ICF research branch team members
- Conduct ICF workshop for the ASEAN region in Kuala Lumpur, Malaysia, together with the members from the ICF research branch.

The ICF Research Branch in Munich has been very supportive and has provided overwhelming assistance for the work done here in Malaysia. Hopefully the work undertaken in Malaysia can help promote ICF within the region.

4. Presentations

4.1. *Second Congress of the European Paraplegics Association Nottwil, March 30 and 31, 2006*

The European umbrella organisation of the national self-help associations of Spinal Cord Injury (SCI) applies itself to protect and promote the interests of people with spinal cord injuries. Within this organization it is particularly important to create relationships among the individual national representative organizations of SCI to work together in questions related to SCI.

At the Second Congress at the Guido Zäch Institute in Nottwil, Prof. Gerold Stucki and Alarcos Cieza held two talks on the application of the ICF in clinical practice and research. Both presentations can be downloaded from our homepage (www.icf-research-branch.org).

4.2. **OMERACT**

OMERACT 8 was held in Malta from May 10 to 14, 2006. The OMERACT initiative is an informal international network, consisting of working groups and gatherings interested in outcome measurement across the spectrum of rheumatology intervention studies. OMERACT strives to improve outcome measurement through a data driven, interactive consensus process. An organizing committee with members from three continents, Scientific & Business

Advisory Committees, international opinion leaders and hard-working participants strive towards consensus on guidelines and recommendations.

One of the core initiatives of OMERACT is the definition of relevant domains for outcome evaluation in different types of interventions. OMERACT has, therefore, developed a specific process, including the so-called “OMERACT filter” (truth, discrimination and feasibility). According to this process, it is essential to first define what to measure before defining how to measure.

One domain stands out as relevant for all OMERACT Core Sets across musculoskeletal conditions. This is the domain “functioning”. However, lacking an agreed conceptual framework in the past, the domain of functioning could not rely on a consistent terminology and conceptual model. Furthermore, what aspects of the domain of functioning are relevant was not explicitly



defined. Instead, the content of what is relevant within the domain of functioning is implicitly left to the content of a recommended measure.

The ICF with its conceptual model, terminology and specification of categories within a selected domain provides a useful reference for defining OMERACT domains. The ICF Core Sets developed with the WHO can provide guidance for what to measure within an OMERACT domain. Finally, the linkage of candidate measures to the ICF using the established linkage rules allow easy comparison of measures and evaluation of truth (does the measure address the ICF categories or what is considered relevant in a certain domain?). OMERACT groups, which are currently in the process of defining OMERACT Core Sets (psoriasis, fibromyalgia) or are embarking on such a development (e.g. gout) are considering the adaptation of the ICF as their reference conceptual model, the development of ICF Core Sets to specify the OMERACT domain “functioning” and the use of ICF linkage in the comparison and selection of measures or in the development of new measures of the domain functioning.

Gerold Stucki, who has been working with OMERACT for many years and has learned much from the OMERACT initiative for the development of ICF Core Set, gave a plenary talk at the introductory session of OMERACT 8. He talked to many people involved in the ICF Core Set development who are also involved in the OMERACT process during the meeting. The OMERACT process could be seen as a model that makes use of the development of the ICF, the ICF Core Sets and the ICF linkage of measures. The team at the ICF Research Branch in Munich and many of our collaborating partners working in the field of musculoskeletal conditions are looking forward to close collaboration with OMERACT in the future.

5. Actual projects overview

Name	Stand	Contact person
<i>Branch Projects:</i>		
ICF Core Sets multicenter international validation study	International data collection for 12 chronic conditions is being performed for the validation of the first version of the ICF Core Sets.	Alicia Garza Alicia.Garza@med.uni-muenchen.de Michaela Kirschneck Michaela.Kirschneck@med.uni-muenchen.de
EULAR - European validation of the ICF Core Sets for five musculoskeletal diseases	The data collection in numerous European countries for five musculoskeletal conditions is being performed for the validation of the first version of the ICF Core Sets in Europe. Reliability and sensitivity-to-change analyses using the ICF Core Set for Rheumatoid Arthritis are being performed at the National Resource Center for Rehabilitation in Rheumatology under the lead of Dr. Till Uhlig. The validation of the ICF Core Set in a very early rheumatoid-arthritis cohort is being performed at the Vienna Medical University, division of rheumatology under the lead of Dr. Valerie Nell.	Alicia Garza Alicia.Garza@med.uni-muenchen.de Till Uhlig Till.Uhlig@diakonsyk.no Valerie Nell valerie.nell@meduniwien.ac.at
Development of ICF Core Sets for Spinal Cord Injury (SCI)	The preliminary studies are in process.	Monika Scheuringer mailto:Monika.Scheuringer@med.uni-muenchen.de
Validation of the Comprehensive ICF Core Set for Rheumatoid Arthritis from the Patient Perspective	The focus groups with rheumatoid arthritis are concluded; publications have been released.	Michaela Coenen, MPH Michaela.Coenen@med.uni-muenchen.de
Validation of the ICF Comprehensive Core Set from the perspective of Health Professionals	The study regarding the validation of the ICF Core Sets for Rheumatoid Arthritis from the perspective of physicians are currently being performed. The studies regarding the validation of the ICF Core Sets for Stroke from the perspective of occupational therapists and physicians are currently being performed. Regarding the validation of the ICF Core Sets for Obstructive Pulmonary Disease, a study with physical therapists is currently being performed and a study with physicians will start soon.	Dr. Inge Kirchberger, MPH Inge.Kirchberger@med.uni-muenchen.de
<i>Cooperation Projects:</i>		
Development of an ICF Core Set in patients with Psoriasis or Psoriatic Arthritis	The preliminary studies are in process.	Dr William Taylor wtaylor@wnmeds.ac.nz
Development of the ICF Core Sets for Ankylosing Spondylitis	The preliminary studies are in process.	Annelies Boonen, MD, PhD aboo@sint.azm.nl
Development of the ICF Core Sets for Lupus Erythematodes (SLE) and Systemic Sclerosis (SSc)	The preliminary studies are in process.	Tanja Stamm, MPH, MBA tanja.stamm@meduniwien.ac.at
Measuring Health and Disability in Europe: supporting policy development (MHADIE)	Project started on January 2005.	Dr. Alarcos Cieza, MPH Alarcos.Cieza@med.uni-muenchen.de Andrea Glaessel (BSc.PT) Andrea.Glaessel@med.uni-muenchen.de

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

6. New Publications of members of the ICF Research Branch

Aringer M, Stamm TA, Pisetsky DS, Yarboro CH, Cieza A, Smolen JS, Stucki G.

ICF core sets: how to specify impairment and function in systemic lupus erythematosus.
Lupus. 2006;15(4):248-53.

Coenen M, Cieza A, Stamm TA, Amann E, Kollerits B, Stucki G.

Validation of the International Classification of Functioning, Disability and Health (ICF) Core Set for rheumatoid arthritis from the patient perspective using focus groups.
Arthritis Res Ther. 2006 May 9;8(4):R84 [Epub ahead of print]

Stamm T, Geyh S, Cieza A, Machold K, Kollerits B, Kloppenburg M, Smolen J, Stucki G.

Measuring functioning in patients with hand osteoarthritis--content comparison of questionnaires based on the International Classification of Functioning, Disability and Health (ICF).

Rheumatology (Oxford). 2006 May 2; [Epub ahead of print]

Stucki A, Borchers M, Stucki G, Cieza A, Amann E, Ruof J.

Content comparison of health status measures for obesity based on the international classification of functioning, disability and health.

Int J Obes (Lond). 2006 Apr 4; [Epub ahead of print]

Weigl M, Cieza A, Kostanjsek N, Kirschneck M, Stucki G.

The ICF comprehensively covers the spectrum of health problems encountered by health professionals in patients with musculoskeletal conditions.

Rheumatology (Oxford). 2006 Mar 27; [Epub ahead of print]

Grill E, Uus K, Hessel F, Davies L, Taylor RS, Wasem J, Bamford J.

Neonatal hearing screening: modelling cost and effectiveness of hospital- and community-based screening.

BMC Health Serv Res. 2006 Feb 23;6:14.

Sigl T, Cieza A, Brockow T, Chatterji S, Kostanjsek N, Stucki G

Content comparison of low back pain-specific measures based on the International Classification of Functioning, Disability and Health (ICF).

Clin J Pain. 2006 Feb;22(2):147-53.

Stamm T, Machold K, Aletaha D, Stucki G, Smolen J.

Clinical outcome measures in hand osteoarthritis from the patient perspective.

Z Rheumatol. 2006 Feb 22; [Epub ahead of print] German.

Stier-Jarmer M, Liman W, Stucki G, Braun J.

Structures of acute rheumatic care.

Z Rheumatol. 2006 Feb 16; [Epub ahead of print] German.

Weigl M, Angst F, Aeschlimann A, Lehmann S, Stucki G.

Predictors for response to rehabilitation in patients with hip or knee osteoarthritis: a comparison of logistic regression models with three different definitions of responder.

Osteoarthritis Cartilage. 2006 Feb 27; [Epub ahead of print]

Zochling J, Bonjean M, Grill E, Scheuringer M, Stucki G, Braun J.

Systematic review of measures and their concepts used in published studies focusing on the treatment of acute inflammatory arthritis.

Clin Rheumatol. 2006 Apr 22; [Epub ahead of print]

7. Study Centers 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>	
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Univ. Klinik für Innere Medizin Physical Medicine Anichstr. 35 6020 Innsbruck <i>Doz. Dr. Erich Mur</i>	
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University of Liege Department of Public Health, Epidemiology and Health Economics <i>Prof. Olivier Bruyère</i>	
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BfA Rehabilitationsklinik Seehof Abt. Verhaltenstherapie Lichtenfelder Allee 55 14513 Teltow / Berlin <i>Prof. Dr. med. M. Linden</i> <i>Dipl. Psych. St. Baron</i>	BfA Klinik Hochstaufen Fachabteilung Kardiologie und Gastroenterologie Herkommerstraße 2 83457 Bayerisch Gmain <i>Dr. Kai Christof Weber</i> <i>Dr. Günter Haug</i>

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<p>Drei Burgen Klinik Psychologische Abteilung Zum Wacholder 55583 Bad Münster <i>Dipl.-Psych. Christa Wiedemann</i></p>	<p>DRK Schmerz-Zentrum Auf der Steig 16 55131 Mainz <i>Prof. Dr. med. H-R. Casser</i> <i>Dr. med. M. Legat</i></p>
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<p>Franz von Prümmer Klinik Bahnhofstr. 16 97769 Bad Brückenau <i>Martina Baumann-Hillenbrand</i></p>	<p>Friesenhörn-Nordsee-Kliniken Medizinische Abteilung Möwenstr. 170 ff 26434 Wangerland <i>Dr. med. St. Berghem</i> <i>H. Janßen</i></p>

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<p>Klaus Miehke-Klinik Rheumatologie Leibnizstr. 23 65191 Wiesbaden <i>Dr. med. W. Bolten</i></p>	
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<p>Klinik Hoher Meissner Orthopädie Hardtstraße 36 37242 Bad Sooden-Allendorf <i>Dr. med. A. Wagner</i></p>	<p>Klinik Herzoghöhe Kulmbacher Str. 103 95445 Bayreuth <i>Dr. med. J. D. Kargus</i></p>
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<p>Klinik Roseneck Med. Psychosomatik Am Roseneck 6 <i>Dr. med. A. Hillert</i></p>	<p>Klinik Porta Westfalica Steinstr. 65 32547 Bad Oeynhausen <i>Dr. med. M. Gassmann</i></p>
<p>Klinik St. Irmingard Health Promoting Hospital - WHO Osternacher Str. 103 83209 Prien am Chiemsee <i>Dr. med. U. Hildebrandt</i></p>	<p>Klinik und Poliklinik der Physikalischen Medizin und Rehabilitation Universität München Marchioninstr. 15 81377 München <i>Prof. Dr. med. G. Stucki</i></p>
<p>Klinikum Berchtesgadener Land Psychosomatische Medizin und Psychotherapie Malterhöh 1 83471 Schönau am Königssee <i>Dr. med. O. Jerke</i></p>	<p>Klinikum Staffelstein Orthopädische Klinik Am Kurpark 11 96231 Bad Staffelstein <i>Dr. med. St. Middeldorf</i></p>
<p>Klinikum Bremen-Ost Institut für Physikalische und Rehabilitationsmedizin Züricher Str. 40 28325 Bremen <i>Dr. Rudolf Siegert</i></p>	<p>Landeslinik Teupitz Buchholzer Str. 21 15755 Teupitz <i>A. Hamann</i></p>
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<p>Medizinische Hochschule Hannover Institut für Balneologie und Medizinische Klimatologie Carl-Neuberg Str. 1 30625 Hannover <i>Univ.-Prof. Dr. med. Gutenbrunner</i></p>	<p>Medical Park St. Hubertus Sonnenfeldweg 29 83707 Bad Wiessee <i>Dr. med. K. Botchen</i></p>
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<p>Praxis für Physikalische Medizin und Rehabilitation Kurze Straße 2 37073 Göttingen <i>Dr. med. Wiezoreck</i> <i>Frau Kuhnert</i></p>	<p>Psychosomatische Fachklinik Hochsauerland Zu den drei Buchen 2 57392 Schmallenberg <i>Dr. med. J. Schneider</i></p>
<p>Psychosomatische Klinik Buching Rauchenbichl 87642 Halblech <i>Dr. med. W. Müller</i></p>	<p>Rehabilitationsklinik FRANKEN der BfA AHB-Kliniken Berliner Str. 18 95138 Bad Steben <i>Dr. med. S. Rennert-Pisternick</i></p>
<p>Reha-Klinik Bellevue Brüder-Grimm-Str. 20 63628 Bad Soden-Salmünster <i>D. Bauernschmitt</i> <i>Dr. med. Maximilian Statt</i></p>	<p>Rehaklinik für Kardiologie & Angiologie Ostseeallee 103 23946 Ostseebad Boltenhagen <i>Dr. med. J. Bolte</i></p>
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<p>Rehabilitationsklinik Park-Therme E.-Eisenlohr-Str. 6 79410 Badenweiler <i>D. Bauernschmitt</i> <i>Dr. F. Frankenhauser</i></p>	<p>Rehabilitationsklinik Nordfriesland Wohldweg 9 25826 St. Peter- Ording <i>D. Bauernschmitt</i> <i>H. Albrecht</i></p>

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Stand 16.06.06

8. Study Centers ICF Core Sets for Early Rehabilitation Validation Study

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9. Study Centers “Measuring Health and Disability in Europe” (MHADIE) project

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Stand 04.05.06

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