

# 4. Newsletter

## ICF Core Sets

July - December 2004

Dear partners and friends of the ICF Core Set project,

In this issue we would like to inform you on the actual status of the ICF Core Set project for chronic conditions, and supply you with a brief summary of ICF Core Sets cooperation studies currently being performed.

With the idea that the prerequisite of the implementation of the ICF and the ICF Core Sets is their worldwide dissemination and with the vision in mind that the ICF Core Sets will be the universal ICF-based tools to describe functioning of patients with different health conditions, we have attended different congresses, conferences and international meetings to present the ICF Core Sets development. A briefing on a few presentations is also included in this issue.

We hope that you enjoy the reading of this 4<sup>th</sup> newsletter.

Kind regards,

Your ICF Core Set Development Team

### **COMING SOON!!!**

Our ICF Research Branch Website is in process, we expect to have it ready in January 2005.

## 1. Project Status

### 1.1. Number of study centers per country

No.	Country	Study Centers
1.	Argentina	1
2.	Australia	3
3.	Austria	4
4.	Brazil	1
5.	Canada	1
6.	China	4
7.	Cyprus	1
8.	Finland	1
9.	France	1
10.	Germany	53
11.	Greece	4
12.	Hungary	15
13.	Ireland	1
14.	Italy	5
15.	Japan	1
16.	Kenya	1
17.	Kuwait	2
18.	Lebanon	1
19.	Lithuania	2
20.	Malaysia	1
21.	Mexico	1
22.	Nigeria	1
23.	Norway	3
24.	Philippines	1
25.	Poland	2
26.	Portugal	4
27.	Romania	3
28.	Russia	1
29.	Serbia	2
30.	South Africa	1
31.	South Korea	1
32.	Spain	2
33.	Sweden	2
34.	Switzerland	8
35.	Netherlands	3
36.	Tunisia	1
37.	Turkey	5
38.	UK	2
39.	USA	3
	<b>Total</b>	<b>149 Centers</b>

## 1.2. Training of Health Professionals

To support all study centers and to improve the standardization of the data collection, we are developing a manual containing additional explanations of some of the definitions of ICF categories, general guidelines on how to quantify the magnitude of the patients' problems, and case examples that help to know when a determine category is applicable for determined patients.

### Training of international study centers

We have received from most study centers the confirmation of receiving the training video and all required material for the execution of the ICF Core Sets Validation Study. We have also learnt from mostly all our study centers, that they have already obtained the approval of the corresponding ethics committees and have started or will soon start the data collection; a few other study centers have submitted the study documentation for approval and upon receipt they will be able to start the data collection.

### Training of German study centers

The last two training workshops at the Ludwig Maximilian University Munich took place on 23.07.04 and on 10.09.04. A total of 46 health professionals attended the meetings. The first external training workshop took place on August 10<sup>th</sup> 2004 at the Rheumatology Clinic of Bad Bentheim, in Niedersachsen, Germany. 33 participants attended this workshop.

A second external training workshop will take place on January 14<sup>th</sup> at the Clinic Rhein/Ruhr, Essen, Germany.

The next three training workshops at the Ludwig-Maximilians-University in Munich will take place on:

- November 26<sup>th</sup>, 2004
- February 25<sup>th</sup>, 2005
- April 22<sup>nd</sup>, 2005.

## 1.3. Data Collection

In order to assure the proper data entry, we have commissioned an external company to perform a double data entry of the data collected within the scope of ICF Core Set Validation Study. **198** Case Record Forms (CRFs) have already been entered into the ICF Core Sets database.

Up to now we have received a total of **251** Case Record Forms:

	International	National	Total
Breast Cancer	10	0	<b>10</b>
Chronic Ischaemic Heart Disease	0	6	<b>6</b>
Chronic Widespreadpain	9	48	<b>57</b>
Depression	0	7	<b>7</b>
Diabetes Mellitus	1	0	<b>1</b>
Low Back Pain	6	17	<b>23</b>
Osteoarthritis	1	0	<b>1</b>
Osteoporosis	3	8	<b>11</b>
Rheumatoid Arthritis	10	0	<b>10</b>
Stroke	16	109	<b>125</b>

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

## 2. Report on further ICF Core Sets studies

### 2.1. *Development of an International Classification of Functioning Disability and Health Core Set in patients with Psoriasis or Psoriatic Arthritis*

#### **Dr. William Taylor (Otago, New Zealand)**

Psoriasis (PS) is a chronic inflammatory skin condition characterized by red, scaly plaques over extensor surfaces and elsewhere, with an unpredictable relapsing and remitting course. It is associated with significant physical and social problems. Psoriatic arthritis (PSA) is an inflammatory arthritis associated with psoriasis characterized by painful swollen joints, spinal involvement, enthesitis and dactylitis. It occurs in about 15% of people with PS and has significant functional and quality-of-life consequences.

The Group for Research and Assessment in Psoriasis and Psoriatic Arthritis (GRAPPA) was first convened at the American College of Rheumatology meeting in New Orleans, Oct 2002. This group of rheumatologists and dermatologists has made significant progress towards identifying a “core set” of outcome measures for use in different kinds of clinical studies in PSA. This work recently culminated in the 2004 OMERACT (Outcome Measures in Rheumatology Clinical Trials) Conference, in which a research agenda concerning outcome measures in PSA was formulated.

Two important areas of assessment were highlighted at the OMERACT meeting. Firstly, “function” was seen as a vital area but that no condition-specific assessment tools had been developed for use in PSA. Secondly, the ICF concept of “participation” was promoted but that no satisfactory method of measuring this concept had been established. These two areas were seen as important items for the research agenda.

Therefore, a project has been developed in association with GRAPPA and ICF Research Branch of the WHO Collaborating Center for the Family of International Classifications at the German Institute of Medical Documentation and Information (DIMDI), led by Dr William Taylor, University of Otago, New Zealand and Prof. Dr. Wolf-Henning Boehncke, Johann Wolfgang Goethe-University, Frankfurt. The project will follow a similar format to other ICF Core Set studies: phase 1 studies that include a review of existing instruments, Delphi exercise of health professionals, focus groups with patients, and an ICF Checklist study; a phase 2 consensus conference is planned for late Spring 2006 followed by the phase 3 validation project.

Any health-professional interested in psoriasis or psoriatic arthritis is encouraged to contact Dr Taylor ([wtaylor@wnmeds.ac.nz](mailto:wtaylor@wnmeds.ac.nz)) if they would like to contribute to the project, especially the Delphi exercise, which is due to commence in January 2005.

## ***2.2. Development of the ICF Core Sets for Ankylosing Spondylitis***

**Prof. Désirée van der Heijde and Dr. Annelies Boonen (Maastricht, The Netherlands)**

Ankylosing Spondylitis (AS) is a chronic, rheumatic disorder that primarily affects the sacroiliac (SI) joints and the spine. In addition to the spinal manifestations, extra-spinal co-morbidity, comprising peripheral arthritis and enthesitis (in 25% of the patients), uveitis (in 40% of the patients), psoriasis (in 8% of the patients) and inflammatory bowel disease (in 8% of the patients), add to the burden of the disease. The effects of pain, reduced mobility and AS-related comorbidity on functioning are well recognised. Current recommendations by the Assessment in Ankylosing Spondylitis working group (ASAS), regarding outcome assessment in AS, include functioning as a domain of outcome for clinical trials, as well as clinical record keeping. Several disease-specific instruments to assess physical functioning are described in the literature and comprise the Bath Ankylosing Functional Index (BASFI), the Dougados Functional Index (DFI), the Health Assessment Questionnaire modified for the spondyloarthropathies (HAQ-S) and the Revised Leeds Disability Questionnaire (RLDQ). However, these condition-specific measures typically cover only selected aspects of the whole patients' experience associated with AS. Therefore, a project was initiated to develop ICF Core Sets for AS.

This project has been developed in collaboration between the ICF Research Branch of the WHO Collaborating Center for the Family of International Classifications at the German Institute of Medical Documentation and Information (DIMDI) and the Department of Rheumatology at the University Hospital Maastricht, The Netherlands, and is led by Prof. Désirée van der Heijde and Dr. Annelies Boonen of the Department of Rheumatology at the University Hospital Maastricht, The Netherlands.

The Core Set development will follow a similar format to other ICF Core Set studies: phase 1 studies that include a review of existing instruments, Delphi exercise of health professionals, focus groups with patients, and an ICF Checklist study; a phase 2 consensus conference is planned. The conference will be followed by the phase 3 validation project.

The ICF Checklist study of this project has already been completed. First, the ICF Checklist was extended by adding ICF categories identified from the BASFI, the Dougados Functional Index, HAQ-S, and the Revised Leeds Disability Questionnaire (RLDQ). This was done by the standardised and validated process based on content comparison of the specific instruments with the ICF and which is called linking. This procedure resulted in the Extended ICF Checklist for AS. A paper describing the process and results is submitted for publication.

Secondly, the Extended ICF Checklist for AS was applied in 111 patients with AS. This checklist study was done in collaboration among the ICF research Branch in Munich, the Department of Rheumatology at the University Hospital Maastricht, The Netherlands, and the Department of Rheumatology at the Ruhrgebiet Centre for Rheumatology, Herne, Germany. Two trained

assessors collected data using the Extended ICF Checklist for AS in structured interviews. The results showed that the Extended ICF checklist for AS presents a broad view on the functioning of patients with AS. The results of this study have been submitted for publication.

### **2.3. Development of ICF Core Sets for Aids, Tuberculosis and Malaria**

#### **Nenad Kostanjsek (Switzerland)**

ICF Core Sets for Aids, Tuberculosis and Malaria are being developed under the leading of Nenad Kostanjsek from The Classification, Assessment, Surveys and Terminology Unit, WHO. We will provide you with more information in our next issue. If you require more information on any of these ICF Core Sets in the meantime please contact directly Nenad Kostanjsek (kostanjsekn@who.ch).

### **3. Publications**

Borchers M, Cieza A, Sigl T, Kollerits B, Kostanjsek N, Stucki G.

**Content comparison of osteoporosis-targeted health status measures in relation to the International Classification of Functioning, Disability and Health (ICF).**

Clin Rheumatol. 2004 Sep 14 [Epub ahead of print]

Stucki G, Cieza A.

**The International Classification of Functioning, Disability and Health (ICF) Core Sets for rheumatoid arthritis: a way to specify functioning.**

Ann Rheum Dis. 2004 Nov;63 Suppl 2:ii40-ii45.

The supplement of the Journal of Rehabilitation Medicine with the title „ICF CORE SETS FOR CHRONIC CONDITIONS“ has been released. July Supplement No. 44



### **ICF CORE SETS FOR CHRONIC CONDITIONS**

Abstracts are to be found under:

[http://taylorandfrancis.metapress.com/app/home/issue.asp?wasp=fc22  
yntmrgdvvt7g9j4k&referrer=parent&backto=journal,5,26;linkingpublicati  
onresults,1:104919,1](http://taylorandfrancis.metapress.com/app/home/issue.asp?wasp=fc22yntmrgdvvt7g9j4k&referrer=parent&backto=journal,5,26;linkingpublicati<br/>onresults,1:104919,1)

## **4. Presentations**

### ***4.1. International Symposium on Measurement and Evaluation of Outcomes in Rehabilitation, Stockholm, Sweden***

The ICF Core Sets project was presented by Dr. Alarcos Cieza and Prof. Gerold Stucki within the scope of the symposium "Measurement and evaluation of outcomes in rehabilitation". The symposium, which was sponsored by the Journal of Rehabilitation Medicine (Foundation for Rehabilitation Information) as part of the UEMS European Board of Physical and Rehabilitation Medicine postgraduate program, took place in Stockholm from 27<sup>th</sup> to 28<sup>th</sup> September 2004.

During the symposium an up-to-date review of methodological aspects on evaluation and measurements of outcomes in rehabilitation exemplified by clinically used methods and instruments was presented. In addition criteria for appropriate choice of methods and instruments were discussed.

### ***4.2. ISOQoL 2004, Hong Kong***

During the annual conference of the International Society for Quality of Life Research (ISOQoL) held from October 16 to October 19, 2004 at the Hong Kong Academy of Medicine in Hong Kong; Dr. Alarcos Cieza held a workshop on the International Classification of Function Disability and Health (ICF) and its application in clinical practice and research. The aim of this workshop was to introduce the contents and structure of the ICF, as well as the bio-psycho-social model, which is the basis of the classification. The ICF Core Sets – tools to implement the ICF in clinical practice and research – were presented in detail. Also the development process of the ICF Core Sets was presented.

Since Health Related Quality of Life (HRQoL)- and ICF-based approaches will often be used concurrently in clinical practice, research, and health reporting, it is essential for clinicians and researchers to understand the relationship between HRQoL instruments and the ICF. The process of linking HRQoL instruments to the ICF, which makes possible the content comparisons among instruments, was introduced in detail. The usefulness of such a linkage process in identifying the best measures to most efficiently cover the required categories of functioning in studies was also discussed.

### ***4.3. WHO FIC Network Meeting, Reykjavik, Iceland***

At the WHO FIC meeting held on 24-30 October 2004, Dr. Alarcos Cieza presented the training video for the ICF Core Sets validation study as well as the way in which the corresponding users have evaluated it.

All WHO Collaborating Centers participating in the meeting were provided with a training video and it will be used in different contexts.

Within this meeting, an initiative was created for the development of further training videos including more case studies than rheumatoid arthritis. We hope to be able to send you more training videos very soon.

## 5. Study Centers

<b>Argentina</b>	
<b>Hospital San Juan Bautista</b> Calle Dr. Julio Herrera 432 Barrio Judicial 4700, Catamarca <i>Dr. Sergio Miguel Toloza</i>	
<b>Australia</b>	
<b>Braeside Hospital</b> Rehabilitation Medicine Locked bag 82, Wetherill Park 2164 New South Wales <i>Dr. F. Köhler</i>	<b>Lourdes Hospital, Health and Aged Care Services</b> Rehabilitation Medicine NSW 2830 Dubbo <i>Dr. Jagdish Maharaj</i>
<b>University of Melbourne</b> Victorian Rehabilitation Research Institute Poplar Road 3052 Melbourne, Victoria <i>Prof. Dr. Peter Disler</i>	
<b>Austria</b>	
<b>Donauspital</b> Physical Medicine & Rehabilitation Langobarelenstrasse 122 A-1220 Wien <i>Dr. Christine Prager</i>	<b>Kaiser-Franz-Josef-Spital/ SMZ Süd</b> Institut für Physikalische Medizin Kundratstrasse 3 1100 Vienna <i>Prof. Dr. Michael Quittan</i>
<b>University Clinic for Physical Medicine and Rehabilitation</b> Währinger Gürtel 18-20 1090 Wien <i>Prof. Dr. Veronika Fialka-Moser</i>	<b>Univ. Klinik für Innere Medizin</b> Physical Medicine Anichstr. 35 6020 Innsbruck <i>Dr. Paul Lüth</i>
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<b>Hospital das Clinicas, School of Medicine, University of Sao Paulo</b> Rehabilitation Medicine Rua Diderot, 43 - Vila Mariana 04116-030 Sao Paulo <i>Prof. Dr. Linamara Rizzo Battistella</i>	
<b>Canada</b>	
<b>McGill University Health Centre (Royal Victoria Hospital)</b> Clinical Epidemiology R4.29, 687 Pine Ave W. H3A 1A1 Montreal, Quebec <i>Prof. Nancy Mayo</i>	
<b>China</b>	
<b>Peking Union Medical College Hospital, Chinese Academy of Medical Sciences</b> Department of Endocrinology Wang-Fu-Jing St. 100730 Beijing <i>Prof. Dr. Heng Wang</i>	<b>Sun Yat-sen University, The Second Affiliated Hospital</b> Department of Rehabilitation Medicine No 107 Yan Jiang West Road 510120 Guangzhou <i>Prof. Dr. Tiebin Yan</i>
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<b>France</b>	
<b>University Hospital of Dijon</b> Physical Medicine & Rehabilitation 23 rue Gaffarel 21034 Dijon <i>Prof. Jean Marie Casillas</i>	
<b>Germany</b>	
<b>Ambulantes Rehabilitations Centrum Grevenbroich</b> Montanusstr. 54 41515 Grevenbroich <i>U. Liefländer</i> <i>Dipl. Psych. K. Reinard</i>	<b>ANR Bonn</b> Graurheindorfer Str. 149 a 53117 Bonn <i>H. Lorenzen</i>
<b>Augusta-Medical-Clinic</b> August-Bebel-Str. 8 45525 Hattingen <i>Dr. med. J. Bachmann</i>	<b>Bayerisches Rheuma- und Orthopädie-Zentrum</b> Medizinische Kliniken Kaiser-Karl V. - Allee 3 93077 Bad Abbach <i>Prof. Dr. med. H. Menninger</i>
<b>BfA Rehabilitationsklinik Seehof Abt. Verhaltenstherapie</b> Lichtenfelder Allee 55 14513 Teltow / Berlin <i>Prof. Dr. med. M. Linden</i> <i>Dipl. Psych. St. Baron</i>	<b>Deegenbergklinik</b> Innere Medizin, Orthopädie, Kardiologie Burgstraße 21 97688 Bad Kissingen <i>Prof. Dr. Deeg</i>
<b>DGPMR</b> Kurze Strasse 2 37073 Göttingen <i>Dr. med. M. Wiezoreck</i>	<b>DRK Schmerz-Zentrum</b> Auf der Steig 16 55131 Mainz <i>Prof. Dr. med. H-R. Casser</i> <i>Dr. med. M. Legat</i>
<b>Edertal Klinik</b> Fachklinik für Psychosomatik und Verhaltensmedizin Ziergartenstrasse 9 34537 Bad Wildungen <i>PD Dr. med. U. Michalak</i>	<b>Fachklinik Allgäu</b> Pneumologie Peter-Heel-Str. 29 87459 Pfronten <i>Dr. med. C. Müller</i>
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<b>Geriatrische Rehabilitationsklinik der AWO</b> Kantstr. 45 97074 Würzburg <i>Dr. med. W. Swoboda</i>	<b>Hedon Kliniken</b> Hedonallee 1 49811 Lingen <i>P. Thiele</i> <i>Prof. Dr. med. T. Mokrusch</i>
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## 6. Attachments

Workshop Registration Form