WHO Collaborating Centre
for the FIC
in The Netherlands

National Institute for Public Health
and the Environment
Ministry of Health, Welfare and Sport

Volume 9, Number 1, 2011

WHO Family of International Classifications (FIC)

NEWSLETTER

An ontology for ICF

Do we need an ontology for ICF, the International Classification of Functioning, Disability and Health? This question might be asked when the ‘O-word’ (ontology) is buzzing within the WHO-FIC community. And why do we need an ontology for the ICF? But first: what is ontology in everyday language?
One description of ontology is: a representation of some pre-existing domain in reality (Rodrigues MIE2006). Representation means: a (more) formal description of the elements by which a domain, and the terminology that is used within that domain, can be understood and described and more important, can be the subject of study. For the ICF domain, this would mean that words and terms are used to express concepts of thought, and these concepts are attached to referents (objects in a broad sense) in the real world.

The ICF, like most other classifications, has not been developed based on formal principles and methods, but is the product of consensus. The words used in the ICF are close to natural language terms, which sometimes are clear but often are ambiguous. Ambiguity can be solved in human communication, computers however cannot deal with ambiguity. The knowledge available in ICF can only be used in an intelligent way if the content and framework of ICF can be expressed in a formal representation.

So we have at least two reasons why we need an ontology for ICF:

- to support an intelligent use of ICF by computers,
- to study the elements of ICF that constitute the domain.

The second reason is in fact the most important one why we need an ontology for ICF. It enables us to fully understand in a formalized way what is in ICF at the moment and check the consistency of every class and subclass, as well as the content within the overarching framework. It also supports us in taking decisions on updates for ICF if we can define ‘something’ in a more explicit manner.

This understanding of ICF is also needed to be able to compare concepts between different classifications or between classifications and terminologies like e.g. ICF and SNOMED CT.
Ontologies are to be used within computers, but ontological thinking is very useful for people who deal with classifications professionally!

For Information
Huib Ten Napel, WHO-FIC CC in the Netherlands
e-mail: huib.ten.napel@rivm.nl

Realization and Design
A.C. Alta, Studio RIVM

Published by
WHO-FIC Collaborating Centre in the Netherlands.
Responsibility for the information given remains with the persons indicated.
Material from the Newsletter may be reproduced provided due acknowledgement is given.

Address
WHO-FIC Collaborating Centre
Centre for Public Health Forecasting
National Institute for Public Health and the
Environment (RIVM), P.O.Box 1,
3720 BA Bilthoven, The Netherlands.
Telephone: 0031 30 274 2039/4276
Fax: 0031 30 274 4450
Website: http://www.rivm.nl/who-fic
E-mail secretariate: Lummy.Blomer@rivm.nl
ISSN: 1388-5138

Contents

International organisations

FIC around the World

Editorial

This issue of our newsletter is completely devoted to ICF related work at international, regional and national level.

The front page article contains an introduction to ontology and ICF. What is ontology and why do we need it? Some readers might be confused, others will be happy to see progress in this area. The ontological approach enables us to understand the ICF in a formalized way, to check the consistency and to support taking decisions on updates of the current ICF.

Several international organizations are in the process of developing and testing measurement instruments in order to enable international comparability of functioning and disability data. They all refer in their own way to the ICF.
You will find reports from:
the Washington Group on Disability Statistics concerning the short and extended set of questions, including reference to the work of the Budapest Initiative,
Eurostat concerning the European Health and Social Integration Survey questionnaire to be used in 2014 and EUPHA about a preconference on functional health in Amsterdam 2010.
After reading the reports we feel the need for a summary document including instruments developed and see a comparison of them mapped towards the ICF. This might improve the understanding of differences and similarities and the reasons why. We recommend the organizations to make this kind of information available. We are prepared to contribute to this work.

At the European level MURINET was a 4-year (2007-2010) European Union funded project related to the ICF and ICF-CY. This newsletter contains a short version of the available information regarding the project aims and results. Reference is given to the website in order to find the detailed information.

A lot of readers asked for information regarding available ICF Core Sets developed by the ICF Research Branch of the German WHO-FIC Collaborating Centre. We include a short overview of them in this newsletter and refer to the relevant website for more information. Furthermore regarding ICF Core Sets a contribution is included about the development of ICF Core Sets for Lymphedema at the Erasmus Medical Centre in Rotterdam, The Netherlands, using the methods of the ICF Research Branch of the German WHO-FIC CC.

An interesting contribution relates to the development of an ICF based instrument in order to measure activities and participation of psychiatric patients (MATE-ICN). It is designed especially for persons with an addiction in order to determine the person's social disintegration.

Finally a lot of ICF references are included in this issue. We invite all readers to send us their articles and papers for inclusion in our reference list (also available through our website: www.rivm.nl/who-fic*).*

For information
Marijke de Kleijn-de Vrankrijker, WHO-FIC Collaborating Centre in the Netherlands.
e-mail: marijke.de.kleijn@rivm.nl

International Organizations

Washington Group on Disability Statistics

Work related to the Budapest Initiative

Until recently, the work of the Washington Group on Disability Statistics (WG) focused primarily on the development of a disability measure (a short set of six questions) suitable for use in censuses. In 2008, a joint meeting of the WG, the Budapest Initiative (BI) and UNESCAP laid the groundwork for the development of extended sets of disability questions suitable for population surveys or as survey supplements. The approach was to first review extant disability questions from other surveys with the goal of expanding upon the six WG short set domains (vision, hearing, cognition, mobility, self care, and communication) to include additional functional domains (upper body functioning, affect, pain, and fatigue) and more information per domain (for example, functioning with and without assistance). To that end, a "Matrix" was created as a framework to guide the development of the extended question sets.

With the backing of UNESCAP, an extended set of questions was cognitively and field tested in 6 south-east Asian countries: Cambodia, Kazakhstan, Maldives, Mongolia, Sri Lanka and Philippines. A second joint WG/BI/UNESCAP meeting convened in May, 2009 to analyze data; and, cognitive and preliminary field test results were presented at the ninth meeting of the WG in Dar es Salaam in 2009. Efforts to finalize an extended set of disability questions were presented at the 10th Meeting of the WG held in Luxembourg in November, 2010.

The final version of the extended set of questions was presented to Eurostat (as part of the Budapest Initiative) for inclusion on the European Health Interview Survey (EHIS). The BI, a joint effort of WHO, UNECE, Eurostat and a number of interested countries, has developed a short form questionnaire (BI-M2) intended to provide the basis for comparable standardized information on population health focusing on health state.

The BI defines health state in terms of functioning in a core set of health domains; and, like the WG, the BI has based the development of its questionnaire on a conceptual framework: the International Classification of Functioning, Disability and Health (ICF).

The BI-M2 addresses functional domains that met criteria related to relevance and feasibility as well as certain measurement characteristics. The domains and questions had to be plausible and reasonable, to span the main aspects of health experienced by the population, and to be seen as significant aspects of individuals' health. Furthermore, the parsimonious question set had to be suitable for use in health interview surveys, maintain a consistent meaning in different social contexts, and manifest a reasonable degree of heterogeneity within the population.

Based on the results of multiple rounds of cognitive and field testing, the following functional domains have been included in the BI-M2 questionnaire: vision, hearing, mobility (walking and climbing up or down stairs), cognition (remembering or concentrating), affect (anxiety and depression), pain and fatigue. Two additional domains have been developed and are included in the BI-M2 set as optional: communication and upper body.

In developing survey questions to measure functioning and health state, a notable challenge is to account for the numerous ways that respondents across differing cultures, languages and socioeconomic conditions might interpret and process those questions. The challenge is further heightened because functioning is a particularly complex concept, involving numerous and varied meanings, attitudes and types of experiences across individuals and sociocultural subpopulations. Because social context and cultural circumstances inform the way respondents interpret, consider and ultimately respond to questions, these differences can lead to systematic measurement error in survey data. Rather than interpreting differences in survey estimates as response process bias, they can be wrongfully construed as real differences in the phenomena of study.

In evaluating questions for both the BI and the WG, three large scale evaluation studies were conducted. The first study was an evaluation of the WG short set of six disability questions intended for censuses. Fifteen countries took part in this study: Argentina, Brazil, Congo, Egypt, Gambia, India, Kenya, Lesotho, Mauritius, Mexico, Paraguay, Philippines, Tanzania, Uganda and Vietnam. The results of this first evaluation have been published (see: Miller K, et al. Results of a cross-national structured cognitive interviewing protocol to test measures of disability. Quality & Quantity, 2010 Dec 07). The WG extended set and the BI health state set were analyzed in two separate studies: the UNESCAP Study mentioned above (results available online at: http://www.unescap.org/stat/disability/analysis/); and the Granada Group Study. The Granada Group, consisting of France, Germany, Italy, Portugal, Spain, Switzerland and the US, took a somewhat different approach in looking at the same set of extended questions. While the Group collected cognitive data from qualitative interviews, and analyzed these along the same lines as the UNESCAP project, their approach focused on the further development of question evaluation methodology and best practices in cognitive research methodology.

Based on the results of the cognitive and filed testing from both the UNESCAP region and the Granada Group, the BI has recently recommended that the BI-M2 be included in the 2014 EHSIS as a complete set or section. This would facilitate both international comparability on the individual domains and the computation of summary measures of health state.

WG products are available at:
http://www.cdc.gov/nchs/washington_group.htm

For information
Jennifer H. Madans, National Center for Health Statistics, USA and Washington Group on Disability Statistics
e-mail: JMadans@cdc.gov

The European Health and Social Integration Survey (EHSIS)

Background

On 15 November 2010 the European Commission launched the new European Disability Strategy 2010-2020 (*Ref.1*) which, inter alia, emphasis that EU action will support and supplement Member States' efforts to collect statistics with a view to monitoring the situation of persons with disabilities. Such support is in line with the requirements of the United Nation Convention on the Rights of Persons with Disabilities (Articles 31, 33 and 35) (*Ref.2*) that was ratified by the European Union at the end of 2010.

The UN Convention means a shift in concept for disability from a medical to an integrated, biopsychsocial one, whereby also addressing personal and environmental barriers for social inclusion and participation of disabled people. This new concept is at the centre of the International Classification of Functioning, Disability and Health (ICF). According to definitions used by the ICF, disability is the result of an interaction between people with impairments, ill health or activity difficulties and personal and environmental barriers, which hinder full and effective participation in independent living, or in educational, employment or other opportunities.

The need for statistics on disability as defined by the UN Convention and ICF required the development of a specific survey. Current information on disability from other social surveys conducted within the European Statistical System does not yet follow that new concept, and consequently, does not allow measuring the prevalence of disability in the population or reporting on the situation of disabled people in society as requested. Eurostat, as the Community statistical authority, developed the European Health and Social Integration Survey (EHSIS) (*Ref.3*) that will be implemented in 2012 in all EU-Member States, Iceland and Norway.

Objectives

The European Health and Social Integration Survey (EHSIS) aims to show the extent to which health problems and impairments contribute to a lack of social integration by personal and environmental barriers, whereby health and impairments are regarded as ones of many barriers to social integration. In addition, it allows comparing the situation of people with and without a health problem or impairment as regards the restrictions to social participation that they face in their everyday live.

A major challenge in designing the questionnaire was to decide at which ICF level (chapter, subheading or item) to pitch the questions and to reduce thousands of individual items to a manageable number of questions. This was solved by first focusing on the relevant sections of the ICF: Activity and Participation, Chapters 7-9, and all the Environmental Factors, Chapters 1-5. Bearing in mind the context of disability strategy, two or three main issues in each chapter were identified. The objective was to have a coherent rather than a comprehensive set of questions. Consequently, EHSIS focuses on the key aspects of social integration based on policy needs and uses the ICF as a reference.

EHSIS covers 12 sections:

- The demo-socio-economic background (including the 16 Eurostat core social variables (*Ref.4*) plus 2 additional variables);

- A health component on self-perceived health; existence of a longstanding health condition; longstanding limitations in activities due to a health problem, and a list covering different health problems; basic activity limitation questions such as on seeing, hearing, walking; activities of daily living (ADL) such as on self-care activities, and instrumental activities of daily living questions (IADL) such as on managing money, shopping, using the telephone, housekeeping), and

- 10 domains on important facets of life that enable an individual to be a fully functional and integrated member of society: mobility, transport, accessibility to buildings, education and training, employment, internet use, social contact and support, leisure pursuits, economic life, attitudes and behaviour. For each domain, there is at least one question that establishes whether the respondent experiences barriers in participation.

Indicators

The EHSIS will inform on the overall prevalence of disability for persons aged 15 years and older in the EU, Iceland and Norway within private households. Specific disability indicators (barriers for a specific domain), indicators on the (overall or specific barriers) associated with specific health conditions or basic activity difficulties and personal/environmental factors can be analyzed as well as the severity of the disability, either for a specific domain or e.g. in view of the need for specialized equipment or personal help.

References

European Disability Strategy 2010-2020: http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52010DC0636:EN:NOT

United Nation Convention on the Rights of Persons with Disabilities: http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

Information on the project developing EHSIS available at: http://circa.europa.eu/Public/irc/dsis/health/library?l=/reports/disability/edsim_september&vm=detailed&sb=Title

http://epp.eurostat.ec.europa.eu/portal/page/portal/product_details/publication?p_product_code=KS-RA-07-006

For information

Lucian Agafitei, Eurostat. Luxembourg
e-mail: lucian.agafitei@ec.europa.eu
Hartmut Buchow, , Eurostat. Luxembourg
e-mail: Hartmut.Buchow@ec.europa.eu

Towards insights into functional health across countries, report on pre-conference EUPHA 2010 Amsterdam

Variation in health between countries can inform us on the size of health differences that might be prevented and can inform us on how country-specific characteristics (for instance the health care system) are associated with health of the population.

To quantify health differences between groups, we need comparable data on the prevalence of health problems. For the quantification and monitoring of health problems in an ageing population, the prevalence of functioning and disability based on population surveys represents a key indicator, and it is also part of the key statistic ‘healthy life expectancy’. The question is: how do we get good and comparable data. ‘Good’ refers to what we measure, and comparable refers to how comparable we measure it.

In a pre-conference of the EUPHA 2010 attention was paid to the state of science and politics on measuring functional health status across countries. It was organized by the French Public health School EHESP and chaired by Jean-Marie Robine and Martine Bellanger. A variety of themes were introduced by several VIPs, including Nick Fahy (from the European Commission), Richard Klein (from the CDC) and Michael Wolfson (Canadian expert on modeling systems on population health). Specific initiatives that were described to improve the health comparisons between countries were:

- the Budapest initiative/Washington group, presented by Jennifer Madans. These activities have resulted in a short set of 6 items that should be measured in all countries.

- the Study on global AGEing (SAGE), a WHO survey carried out in many countries (China, Ghana, India, Mexico, Russian Federation and South Africa) presented by Manfred Huber.

- OECD projects on (1) trends in severe disability and (2) working age disability, by Gaetan LaFortune.

Progress in the research field includes a lot of awareness of the need for comparable data and how these data will look like. There is for instance consensus on the relevant domains to be part of a Core Set: vision, hearing problems, walking, remembering & concentration, self-care and communication. Much work has still to be done and there is optimism that there will be a time that international comparisons using a Core Set of disability indicators is possible. Until then we have to make the most of currently available - though not ‘perfect’- data. Especially Nick Fahy emphasized that ‘he prefers to have bad data now rather than good data over a period of 20 years’. Ill-health should not be a barrier to participate in society, and with an ageing population we need everybody for a good balance between the working and non-working population.

I agree with Nick Fahy and furthermore; to expect ‘perfect data’ over 10 years might even be to optimistic. Within one country it has been shown that small differences in wording of questions and differences in method of data collection (postal questionnaire vs. face-to-face interviews) affects the actual prevalences of disability. (Picavet & Van den Bos 1996) Standardization of survey methods and questionnaires is a prerequisite for the analyses of time trends and (inter)national comparisons of the prevalence of health problems on the basis of a health survey. International comparisons are even more complicated because differences in languages will have an impact on the results of health surveys. In the Seven Countries Study among elderly men, for instance, it was shown that the category ‘less than moderately good health’ was much more prevalent in Finland than in other countries (Jylha et al 1998) and there was no other explanation than differences in meaning of the wordings.

References

Picavet HSJ & GAM van den Bos. The comparability of survey data on functional disability in the elderly, the impact of some methodological differences. Journal of Epidemiology and Community Health 50, 1996, 86-93

Jylha M, Guralnik JM, Jokela J, Heikkinen E. Is self-rated health comparable across cultures and genders?*J Gerontol B Psychol Sci Soc Sci*. 1998;53:S144-52.

For information
Susan Picavet, RIVM Bilthoven, the Netherlands
e-mail: susan.picavet@rivm.nl

FIC around the World

Europe

List of available ICF Core Sets

Recently an overview of available ICF Core Sets has been published A full list including literature can be downloaded from http://www.icf-research-branch.org/download/finish/5/136.html. For each set references are provided for publication on the study protocol and preliminary studies, publication on the consensus conference, date of the consensus conference, publication on testing and validation and application studies.

For the following contexts and conditions an ICF Core Set is available:

Acute context:
-Cardiopulmonary conditions
-Musculoskeletal conditions
-Neurological conditions

Early post-acute context
-Cardiopulmonary conditions
-Geriatric patients
-Musculoskeletal conditions
-Neurological conditions
-Spinal cord injury

Long-term context
-Amputation
-Ankylosing spondylitis
-Bipolar disorders
-Breast Cancer
-Chronic ischemic heart disease
-Chronic widespread pain
-Depression
-Diabetes mellitus
-Hand conditions
-Head and neck cancer
-Hearing Loss
-Inflammatory bowel disease
-Low back pain
-Multiple sclerosis
-Obesity

-Obstructive pulmonary diseases
-Osteoarthritis
-Osteoporosis
-Rheumatoid arthritis
-Sleep
-Spinal cord injury
-Stroke
-Systemic lupus erythematosus
-Traumatic brain injury
-Vocational rehabilitation

For more information
Melissa Selb, ICF research branch of the German WHO-FIC CC, Nottwil, Switzerland
e-mail: melissa.selb@paranet.ch

MURINET: Multidisciplinary Research Network on Health and Disability in Europe

MURINET was a 4-year (2007-2010), FP6 European Union funded project led by Coordinator Dr Matilde Leonardi (Foundation IRCCS Neurological Institute Carlo Besta, Milan, Italy), with eleven European research institutions and NGOs of people with disability from seven European countries as partners.

MURINET linked up in a multidisciplinary and intersectoral approach to health and disability research and management institutions that have been cooperating for 10 years in national and international projects related to the International Classification of Functioning, Disability and Health (ICF) and its children and youth version ICF-CY. The project created a pool of European experts in health and disability research and disability management, all of whom brought together a variety of research skills. More than 25 junior and senior researchers from several professional backgrounds and from Europe, Australia, Canada, Africa, USA were trained in Murinet multidisciplinary Consortium.

Aims

The project had the following aims:
- to identify the needs of people with disability and to plan interventions in light of the biopsychosocial model of ICF
- to operationalise ICF for research and practical implementation by applying the ICF model in different settings (clinical and rehabilitative environments, child health, psychology and educational field, and ethics and human rights)
- to reorient disability-related clinical practice and policy by exploring the validity of the various continua of functioning and disability
- to explore the practical consequences of an ICF-inspired intervention strategy in which all interventions are designed to increase participation, by means of environmental facilitation or increased functional capacity.

MURINET encouraged participation in meetings, short-term exchange visits and interactions among European institutions through an attractive Research and Training programme. This approach facilitated early-career exposure to different techniques, methods and scientific approaches.

Areas

MURINET project comprised four different areas that were interconnected within the 3 main objectives:
- applying ICF Model
- explore health and disability continuum
- design interventions.

Area 1, Clinical and Rehabilitation, concerned research that furthers our understanding of the basic biomedical and rehabilitative sciences of functioning and disability. Clinical applications of ICF and ICF-based tools – specifically the ICF checklist, WHO DAS II and ICF Core Sets – in different clinical populations were the methodology to determine the extent to which these assessment tools are valid, clinically sensitive and reliable.

Area 2, Child Health, psychology and education, involved research on issues of conceptualization and measurement of functioning and disability in focusing on educational and early childhood interventions settings. The rationale here was to identify relevant information needed to describe the nature and extent of disability with a special focus on major life areas and environmental factors relevant to children.

Area 3, Health and disability information for policy: featured ICF as the conceptual model for organizing and reporting information about functioning and disability in order to use a common framework for quantifying levels of health and disability in measurement exercises. In addition the ICF was the common language in terms of which this information is to be expressed such that there are no ambiguities in communication.

Area 4, Ethics and human rights, encouraged original research on ethical issues as applied to functioning and disability. Specific ethical considerations also arise for individuals who are unable to consent or who are otherwise vulnerable to abuse. Since ethical issues arise at both the individual and population levels, ICF training in ethics and research were designed to cover both the clinical or individual levels, and the systemic or population level.

Project's steps

MURINET Project has been running since 2007 with the aims of identifying the needs of persons with disability and planning interventions in the light of the biopsychosocial model of the ICF and of the UN Convention of Rights of people with disability, operationalizing the ICF model in different settings (clinical and rehabilitative environments, child health, psychology and educational field, and ethics and human rights), with the ultimate aim of improving

health and disability research and policy across Europe, and reorienting health and disability-related clinical practice and policy by exploring the validity of the various continua of functioning and disability, grounded in the ICF model.
The MURINET closing Conference on the 1st of December 2010 in Bruxelles presented the key results of this extraordinary network that has trained researchers from very different backgrounds.
On the 2nd of December 2010 the results of the European Multidisciplinary Research Network on Health and Disability in Europe (MURINET Day) were presented in a multicountry European event in Italy (Milan Catholic University), Germany (Hamburg), Romania (Bucarest), Spain (Madrid), Sweden (Jönköping), Switzerland (Zurich), Slovenia (Ljubljana) The speakers were researchers that, from all over Europe, have been trained within EU MURINET project for the past four years.

Results

25 Researchers out of 422 applicants from all over the world joined this European training network. All MURINET researchers, from different professional backgrounds, have been trained to understand the UN Convention for the Rights of people with disability as well as the ethical issues related to health and disability policy and to use ICF as a common language and framework.
ICF has provided the theoretical foundation for this research by emphasizing the need to look at the complete lived experience of disability, but also by offering a common language that links together clinical and rehabilitative services, population data collection, and other health-related services, such as education and employment. On account of the classifications and terminology of the ICF, moreover, all stakeholders were able to speak the same language, to collect data that are comparable – across disciplines, sectors, and languages – and to describe the lived experience of disability as it is actually experienced and considered as a universal experience of human condition.

This is a summary. The full article on the MURINET project, including an extensive overview of participants, project outcomes and literature references can be found at http://www.rivm.nl/who-fic/newsletter/May2011-1MURINET.pdf. More information on MURINET can be found at: http://www.murinet.eu/

For more information
Dr Matilde Leonardi, Foundation IRCCS Neurological Institute Carlo Besta, Milan, Italy
e-mail: Matilde.Leonardi@istituto-besta.it

The Netherlands

MATE-ICN: Applying the ICF in the Measurement of Activities and Participation of Psychiatric Patients

To match persons to treatment modalities and to evaluate treatment for patients with chronic, psychiatric disorders, measuring human functioning (i.e., activities and participation) is as vital as measuring symptoms of psychopathology. Existing instruments for measuring activities and participation differ enormously, however, in the aspects of functioning that they cover and the domains of functioning they assess. Some, like the General Assessment of Functioning (GAF) and the Health of the Nation Outcomes Scale (HONoS), are very broad and general. Others, like the Camberwell Assessment of Needs (CAN), refer only to certain aspects of functioning. The WHODAS, whose final version was recently launched, is more differentiated, but is not intended for psychiatric patients in particular. We, therefore, devised the MATE-ICN, tested its psychometric properties, and launched it for general use in 2007 (Schippers et al., 2007).

The MATE-ICN (*Measurement of Addictions for Triage and Evaluation – ICF Core Set and Needs)* is based entirely on the ICF, and identifies (a) the extent of limitations in activities and participation, (b) environmental factors that affect a person's functioning, and (c) the need for care that results from limitations in participation and lack of support. The MATE-ICN is generally intended for assessing chronic, psychiatric patients, and is part of the MATE, that is designed especially for persons with an addiction. The MATE-ICN is used to (a) determine the person's degree of social disintegration that is relevant for triage decisions about the level of care and kind of support that should be provided, and (b) evaluate changes in functioning across time.

The first of the two modules of the MATE-ICN (MATE Module 7) consist of 19 domains selected from the ICF component *Activities and Participation*. For each of these domains, the MATE-ICN assesses the following: (1) The degree to which the person's activities and participation are limited (ranging from *not at all* to *completely*), and (2) the amount of support that is provided to the person (from *none* to *completely*) in each of ten domains, and (3) for 15 domains concerning the need for care, (a) whether or not the interviewer feels that the person is in need of care, (b) whether or not the person himself or herself feels in need of care, and (c) whether or not the agency is willing and able to provide the care that is needed. The second module of the MATE-ICN (MATE Module 8) assesses the influence of four factors selected from the ICF component *Environmental Factors* that either facilitate or interfere with the person's recovery. These factors are: people in the immediate environment of the person being interviewed (especially if the person has suffered a personal loss), societal attitudes, legal affairs, and other factors. Module 8 assesses the degree of positive or negative effect that each factor has (from *none* to *completely*). When the influence is negative, the need for care is also assessed as in Module 7, 3a-3c.

To field test the instrument in a treatment-seeking population, test–retest interviews were administered by researchers and clinicians to (a) monitor feasibility, (b) assess construct validity against related instruments, and (c) evaluate the dimensional structure of the MATE-ICN (Schippers et al., 2010). The research was conducted in a large, regional substance-abuse treatment centre in the Netherlands and at the Municipal Health Service of Amsterdam. A total of 945 treatment-seeking patients were recruited during routine intakes, and 159 of them were interviewed twice. Thirty-two problem drug users were also recruited from the Amsterdam cohort studies of problem drug users. Interview completion time was reasonably short, and there were relatively few missing data. The factor structure of the ICF-related modules revealed a three-factor model with an acceptable fit. Interrater reliability ranged from 0.75 to 0.92 and was satisfactory, but interviewer test-retest reliability ranged from 0.34 to 0.73, indicating that some of the subscales needed to be improved. Concurrent validity was indicated by significant correlations (> 0.50) between the ICF-related modules and the WHO Disability Assessment Schedule II (WHODAS II) and the brief version of the WHO Quality of Life instrument (WHOQOL-BREF).

We concluded that the MATE can be used to allocate patients to substance-abuse treatment. Because it is a comprehensive but flexible measurement tool that is also practical to use, the MATE is well suited for use in a heterogeneous population. The MATE (including the MATE-ICN) has now been accepted as the standard instrument for intake and evaluation (routine outcome monitoring) in the majority of Dutch addiction treatment centres. The MATE is in the public domain (www.mateinfo.nl) and has been published along with extensive instructional manuals and training materials. Because we aim to use the MATE internationally, English, German, and Spanish versions have been developed and are available.

References

Ref. 1: Schippers, G. M., Broekman, T. G. and Buchholz, A. (2007).MATE. Handleiding en protocol. Nijmegen: Bêta Boeken.

Ref. 2: Schippers, G. M., Broekman, T. G., Buchholz, A., Koeter, M. and van den Brink, W. (2010). Measurements in Addictions for Triage and Evaluation (MATE): An instrument based on the World Health Organization family of international classifications. Addiction, 105, 862-871.

For more information

Gerard M. Schippers, Arkin and Academic Medical Centre, Amsterdam
e-mail: **gschippers@xs4all.nl**
Theo G. Broekman ,Bureau Bêta, Nijmegen
e-mail: **broekman@beta.nl**

Development of ICF Core Sets for Lymphedema

In 2010 a project has been started to come to Core Sets for Lymphedema. This project will be executed as a cooperative effort from Erasmus Medical Centre, Department of Dermatology, Rotterdam and the Dutch Institute of Allied Health Care, Amersfoort, both in The Netherlands. The project will be guided by a steering committee composed by the following members: Robert Damstra MD, PhD (Department of Dermatology, phlebology and lympho-vascular diseases, Nij Smellinghe Hospital, Drachten, The Netherlands), Yvonne Heerkens PhD (Dutch Institute of Allied Health Care, Amersfoort, The Netherlands), Dorine van Ravensberg PhD, PT (Dutch Institute of Allied Health Care, Amersfoort, The Netherlands), Janine Hidding MSc, PT (Dutch Association for Physical Therapists in Lymphology), Huib Ten Napel MSc (WHO-FIC Collaborating Centre, Centre for Public Health Forecasting, National Institute for Public Health and the Environment (RIVM), Bilthoven, The Netherlands) and Professor Martino Neumann MD, PhD (Department of Dermatology, Erasmus Medical Centre, Rotterdam, The Netherlands).

The prevalence of lymphedema is not exactly known because it is not a regular registered disease. The number of patients worldwide is estimated at about 140-250 million (*Ref. 1*).
An important basis for the optimal management of lymphedema is an in-depth understanding, systematic examination and sound measurement of its consequences at different levels. To achieve this goal, the ICF can serve as a comprehensive framework and classification of an universal language understood by health professionals, researchers, policy makers, patients, and patient organizations. The International Society for Lymphology (ISL) mentions the importance of the (use of) the ICF in their latest revision of their lymphedema consensus document (*Ref. 2*)].

Lymphedema is defined as an abnormal accumulation of fluid and protein in the body tissues as a result of a dis balance between the flow and the discharge of fluid.
Lymphedema is a chronic disorder, that often begins slowly. It can occur in both upper and lower limbs as well as midline (head ,neck and thorax). It can be sub-divided into primary and secondary lymphedema.
Primary lymphedema is inherited at birth. The lymph vessels and/or nodes, have not been well constructed, which results in an insufficient flow and discharge of the lymph fluid. This can occur in the entire body, but it is most common in the lower limbs.
Secondary lymphedema is inflicted. The lymph vessels and/or nodes have been damaged or removed. Examples are upper limb edema after a breast operation for mamma carcinoma, edema of the lower limb after a gynaecological operation and edema after the removal of a melanoma. In these operations, the lymph glands have been removed,

which results in damage of the lymph vessels and pressure on the fluid discharge. Patients, who receive radio and /or chemotherapy after the operation , have an increased chance of acquiring lymph oedema. Secondary lymphedema can also be caused by serious wounds, infection, joint operations etc.

Patients with lymphedema suffer from pain, swelling and disturbed feelings in the affected body parts. Often activities of daily life are limited, e.g. walking, personal care and household. Patients should live with certain regimens such as cautiousness with open wounds and taking care not to overburden themselves.

The aim is to develop Core Sets for lymphedema using the method of Professor G Stucki , ICF Research Branch of the Collaboration Centre of the Family of International Classifications (DIMDI, Germany) at the Ludwig-Maximilians-University in Munich, Germany.

References

Ref. 1: Földi M, Földi E, Kubik S (eds). Textbook of Lymphology. Munchen, Urban and Fischer,2003

Ref. 2: Lymphedema Consensus Document 2009. International Society for Lymphology. Tucson.

For more information

Peter Viehoff MSc, PT , Project leader (Department of Dermatology, Erasmus Medical Centre, Rotterdam, The Netherlands)
email: p.viehoff@erasmusmc.nl

ICF References

2788 Alma MA, Mei SF van der, Melis-Dankers BJ, van Tilburg TG, Groothoff JW, Suurmeijer TP.*Participation of the elderly after vision loss*. Disabil Rehabil, 201

2814 Becker S, Kirchberger I, Cieza A, Berghaus A, Harréus U, Reichel O, Tschiesner *U Content validation of the comprehensive ICF core set for Head and Neck Cancer (HNC)*: The perspective of psychologists Content validation of the comprehensive ICF core set for Head and Neck Cancer (HNC): The perspective of psychologists. Psycho-Oncology, 2010 19(6) 594-605

2760 Bemis-Dougherty A *Practice Matters: What is the ICF?*. Magazine of Physical Therapy, 2009 17(1)

2829 Chen M, Yang C, He D, Zhang S, Jiang B *Soft Tissue Reduction During Open Treatment of Intracapsular Condylar Fracture of the Temporomandibular Joint: Our Institution's Experience.* Journal of Oral and Maxillofacial Surgery, 2010

2757 Cibulka MT, White DM, Woehrle J, Harris-Hayes M, Enseki K, Fagerson TL, Slover J, Godges JJ *Hip Pain and Mobility Deficits - Hip Osteoarthritis*: Clinical Practice Guidelines Linked to the International Classification of Functioning, Diasability and Health from the Orthopaedic Section of the American Physical Therapy Association. J Orthop Sports Phys Ther, 2009 39(4) A1-A25

2812 Dempsey L, Skarakis-Doyle E *Developmental language impairment through the lens of the ICF*: An integrated account of children's functioning. Journal of Communication Disorders, 2010

2820 Ding X, Reimann S, Timrott K, Gutenbrunner C, Schwarze M, Fischer MJ *Comparison of the ICF core set for cardiopulmonary conditions in the acute hospital setting among different types of transplant patients.* , 2010

2831 Ding X, Reimann S, Timrott K, Gutenbrunner C, Schwarze M, Fischer MJ *Comparison of the ICF core set for cardiopulmonary conditions in the acute hospital setting among different types of transplant patients*. International Journal of Rehabilitation Research, 2010

2813 Dreinhöfer KE, Schwarzkopf SR *Outcome assessment in geriatric trauma.* Unfallchirurg, 2010

2791 Escorpizo R, Ekholm J, Gmünder HP, Cieza A, Kostanjsek N, Stucki G *Developing a Core Set to Describe Functioning in Vocational Rehabilitation Using The International Classification of Functioning, Disability, and Health (ICF).* J Occup Rehabil, 2010

2807 Escorpizo R, Stucki G, Cieza A, Davis K, Stumbo T, Riddle DL *Creating an Interface Between the International Classification of Functioning, Disability and Health and Physical Therapist Practice*. Phys Ther., 2010

2780 Escorpizo, R., Ekholm, J., Gmünder, H.-P., Cieza A, Kostanjsek N, Stucki, G *Developing a Core Set to Describe Functioning in Vocational Rehabilitation Using The International Classification of Functioning, Disability, and Health (ICF).* Journal of Occupational Rehabilitation, 2010 1-10

2806 Farias da Guarda SN, Cohen LG, Cunha Pinho M da, Yamamoto FI, Marchiori PE, Scaff M, Conforto AB Farias da Guarda SN, Cohen LG, Cunha Pinho M da, Yamamoto FI, Marchiori PE, Scaff M, Conforto AB *Interhemispheric Asymmetry of Corticomotor Excitability After Chronic Cerebellar Infarcts*. Cerebellum, 2010

2774 Farias da Guarda SN, Cohen LG, Cunha Pinho M da, Yamamoto FI, Marchiori PE, Scaff M, Conforto AB *Interhemispheric Asymmetry of Corticomotor Excitability After Chronic Cerebellar Infarcts*. Cerebellum, 2010 1-7

2755 Freedman VA *Adopting the ICF Language for Studying Late-life Disability*: A Field of Dreams?. J Gerontol A Biol Sci Med Sci, 2009 64A(11) 1172-1174

2801 Garin O, Ayuso-Mateos JL, Almansa J, Nieto M, Chatterji S, Vilagut G, Alonso J, Cieza A, Svestkova O, Burger H, Racca V, Francescutti C, Vieta E, Kostanjsek N, Raggi A, Leonardi M, Ferrer M, Consortium M *Validation of the World Health Organization Disability Assessment Schedule (WHODAS-2) in patients with chronic diseases*. Health Qual Life Outcomes, 2010 8(1) 51

2769 Giannangelo K, Bowman S, Dougherty M, Fenton S *ICF: Representing the Patient byond a Medical Classification of Diagnoses*. Perspectives in Health Information Management, 2005 2 (7) 1-9

2758 Godges JJ, Irrgang *ICF-based Practice Guidelines for Common Musculoskeletal Conditions*. J Orthop Sports Phys Ther, 2008 38(4) 167-168

2822 Grötzbach H *Defining therapy goals: Paternalistic or cooperative?* L.O.G.O.S. Interdisziplinair, 2010 18(2) 119-126

2784 Gudat W, Nürnberg W *Holistic approach to in-patient dermatological rehabilitation*. Hautarzt, 2010 61(4) 310-316

2754 Guralnik JM, Ferrucci L *The Challenge of Understanding the Disablement Process in Older Persons*. J Gerontol A Biol Sci Med Sci, 2009 64A(11) 1169-1171

2825 He D, Yang C, Chen M, Bin J, Zhang X, Qiu Y *Modified Preauricular Approach and Rigid Internal Fixation for Intracapsular Condyle Fracture of the Mandible*. Journal of Oral and Maxillofacial Surger, 2010 68(7) 1578-1584

2761 Helgeson K, Russell Smith Jr A *Process for Applying the International Classification of Functioning, Disability and Health Model to a Patien With Patellar Dislocation*. Physical Therapy, 2008 88(8) 956-964

2781 Hinsch KD, Zick C *International classification of function, disability and health (ICF)*: Basis for cutaneous rehabilitation management. Hautarzt, 2010 61(4) 294-301

2759 Howard D, Nieuwenhuijsen E, Saleeby P *Health promotion and education:* Application of the ICF in th US and Canada using a ecological perspective. Disability and Rehabilitation, 2008 30 (12-13) 942-954

2778 Huang YZ, Rothwell, JC, Lu CS, Wang J, Chen RS *Restoration of motor inhibition through an abnormal premotor-motor connection in dystonia*. Movement Disorders, 2010 25(6) 696-703

2808 Huber JG, Sillick J, Skarakis-Doyle E *Personal perception and personal factors*: incorporating health-related quality of life into the International Classification of Functioning, Disability and Health. Disabil Rehabil, 2010

2817 Jaecks P, Hielscher-Fastabend M *Pragmatics and aphasia*. Sprache Stimme Gehor, 2010 34(2) 58-62

2827 Jaecks P, Hielscher-Fastabend M *Pragmatics and aphasia*. Sprache Stimme Gehor, 2010 34(2) 58-62

2753 Jette AM *Beyond Dueling Models*. J Gerontol A Biol Sci Med Sci, 2009 64A(11) 1175-1176

2752 Jette AM *Toward a Common Language of Disablement*. J Gerontol A Biol Sci Med Sci, 2009 64A(11) 1165-1168published ahead of print July 1165-1168

2816 Kneidl, O *Pragmatic disorders while stuttering*. Sprache Stimme Gehor, 2010 34(2) 80-83

2800 Kuhlow H, Fransen J, Ewert T, Stucki G, Forster A, Langenegger T, Beat M *Factors explaining limitations in activities and restrictions in participation in rheumatoid arthritis*. Eur J Phys Rehabil Med, 2010 46(2) 169-177

2790 Linden M, Baron S, Muschalla B *Relationship between Work-Related Attitudes, Performance and Capacities according to the ICF in Patients with Mental Disorders*. Psychopathology, 2010 43(4) 262-267

2805 Lindner HY, Nätterlund BS, Hermansson LM *Upper limb prosthetic outcome measures: review and content comparison based on International Classification of Functioning, Disability and Health*. Prosthet Orthot Int, 2010 34(2) 109-128

2798 Liptak GS, Kennedy JA, Dosa NP *Youth with Spina Bifida and Transitions:* Health and Social Participation in a Nationally Represented Sample. J Pediatr, 2010

2793 Logerstedt DS, Snyder-Mackler L, Ritter RC, Axe MJ *Knee pain and mobility impairments: meniscal and articular cartilage lesions*. J Orthop Sports Phys Ther, 2010 40(6) A1-A35

2775 Mandrusiak A, Giraud D, MacDonald J, Wilson C, Watter P *Muscle length and joint range of motion in children with cystic fibrosis compared to children developing typically*. Physiotherapy Canada, 2010 62(2) 141-146

2767 Mayo NE, Poissant L, Ahmed S, Finch L, Higgins

J, Salbach NM, Soicher J, Jaglal S *Incorporating the International Classification of Functioning, Disability and Health (ICF) into an Electronic Health Record to Create Indicators of Functioning*: Proof of Concept the SF 12. J Am Med Inform Assoc, 2004 11 514-522

2794 McCormack J, McLeod S, Harrison LJ, McAllister L *The impact of speech impairment in early childhood: Investigating parents' and speech-language pathologists' perspectives using the ICF-CY*. J Commun Disord, 2010

2770 McDougall J, Horgan K, Baldwin P, Tucker MA, Frid P *Employing the International Classification of Functioning, Disability and Health to enhance services for children and youth with chronical physical health*. Paediatr Child Health, 2008 13(3) 173-178

2799 Ménoni V, Lucas N, Leforestier JF, Dimet J, Doz F, Chatellier G, Tréluyer JM, Chappuy H *The readability of information and consent forms in clinical research in France*. PLoS One, 2010 5(5) e10576

2782 Mhalla A, Andrde DC de, Baudic S, Perrot S, Bouhassira D *Alteration of cortical excitability in patients with fibromyalgia*. Pain, 2010 149(3) 465-500

2766 Moriello C, Byrne K, Cieza A, Nash C, Stolee P, Mayo N *Mapping the stroke impact scale (SIS-16) to the International Classification of Functioning, Disability and Health*. J Rehabil Med, 2008 40 102-106

2803 Msall ME *Developing preschool surveillance tools for adaptive functioning*: Lessons for neuro-oncology. Eur J Paediatr Neuro, 2010

2771 Mueller M, Lohmann S, Thul P, Weimann A, Grill E *Functioning and Health in patients with cancer on home-parenteral nutrition: a qualitative study*. Health and Quality of Life Outcomes, 2010 8-41

2792 Mutlu A, Akmese PP, Gunel MK, Karahan S, Livanelioglu A *The importance of motor functional levels from the activity limitation perspective of ICF in children with cerebral palsy*. Int J Rehabil Res, 2010

2756 Nat. Committee on Vital and Health Statistic/Department of Health and Human Services *Classifying and Reporting Functional Status*. Nat. Committee on Vital and Health Statistic/Department of Health and Human Services,

2750 Nationale Raad voor de Volksgezondheid/Werkgroep Classificaties en Coderingen *Rapport vooronderzoek fysiotherapie*. Nationale Raad voor de Volksgezondheid/Werkgroep Classificaties en Coderingen, 1987

2824 Nürnberg W, Breuel K, Haffner D *Preventive care and rehabilitation for children and adolescents.* Monatsschrift fur Kinderheilkunde, 2010 158(3) 254-261

2834 Nürnberg W, Vieluf D *ICF-based rehabilitation of chronic atopic diseases*. Allergologi, 2010 33(6) 271-278

2786 Nürnberg W Special features of dermatologic rehabilitation for children and adolescents. Hautarzt, 2010 61(4) 302-309

2832 Ogoshi Y, Nakai A, Mitsuhashi Y, Araki C *Proposal of the school children support system using ICF to communicate with the teachers, the specialists and the guardians, requiring special support education*. EEJ Transactions on Electronics, Information and System, 2010 130(4) 631-632

2762 Okochi J, Utsunomiya, Takahashi T *Health measurement using the ICF*: Test-retest reliability study of ICF codes and qualifiers in geriatric care. Health and Quality of Life Outcomes, 2005 3(46)

2772 Ostir GV, Granger CV, Black T, Roberts P, Burgos L, Martinkewiz P, Ottenbacher J *Preliminary Results for the PAR-PRO*: A Measure of Home and Community Participation. Arch Phys Med Rehabil, 2006 87 1043-1051

2804 Otr OV, Reinders-Messelink HA, Bongers RM, Bouwsema H, Van Der Sluis CK *The i-LIMB hand and the DMC plus hand compared*: a case report. Prosthet Orthot Int, 2010 34(2) 216-220

2787 Pedro-Cuesta J de, Comín Comín M, Virués-Ortega J, Almazán Isla J et al *ICF-Based Disability Survey in a Rural Population of Adults and Older Adults Living in Cinco Villas, Northeastern Spain*: Design, Methods and Population Characteristics. Neuroepidemiology, 2010 35(1) 72-82

2776 Pigini L, Andrich R, Liverani G, Bucciarelli P, Occhipinti E *Designing reasonable accommodation of the workplace:* A new methodology based on risk assessment. Disability and Rehabilitation. Assistive Technology, 2010 5(3) 184-198

2826 Pragmatic disorders while stuttering Kneidln O *Pragmatic disorders while stuttering. Sprache* Stimme Gehor, 2010 34(2) 80-83

2789 Ptyushkin P, Vidmar G, Burger H, Marinček C, Escorpizo R *The International Classification of*

Functioning, Disability and Health (ICF) in vocational rehabilitation and disability assessment in Slovenia: state of law and users' perspective. Disabil Rehabil, 2010

2809 Raggi A, Brunani A, Sirtori A, Liuzzi A, Berselli ME, Villa V, Ceriani F, Leonardi M *Obesity-related disability*: key factors identified by the International Classification of Functioning, Disability and Health. Disabil Rehabil, 2010

2795 Rauch A, Escorpizo R, Riddle DL, Eriks-Hoogland I, Stucki G, Cieza A *Using a Case Report of a Patient With Spinal Cord Injury to Illustrate the Application of the International Classification of Functioning, Disability and Health During Multidisciplinary Patient Management*. Phys Ther, 2010

2764 Resnik LJ, Allen SM *Using International Classification of Functioning, Disability and Health to understand challenges in community reintegration of injured veterans.* Journal of Rehabilitation Research & Development, 2007 44(7) 991-1006

2763 Resnik LJ, Plow M, Jette A *Development of CRIS: Measure of community reintegration of injures service menbers*. Journal of Rehabilitation Research & Development, 2009 46(4) 469-480

2768 Scarini N, Worral L, Hickson L *The ICF and third-part disability*: Its application to spouses of older people with hearing impairment. Disability and Rehabilitation, 2009 31(25) 2088-2100

2819 Schmich J, Porsche J, Vogel M, Kuny R, Mannsberger U, Lorenzl S, Levin J, Ziegler W *Everyday communication in dysarthria:* A self-report questionnaire Everyday communication in dysarthria: A self-report questionnaire. Sprache Stimme Gehor, 2010 34(2) 73-79

2783 Schwarzkopf SR, Grill E, Dreinhöfer KE *Introduction to the International Classification of Functioning, Disability and Health (ICF*). Unfallchirurg, 2010 1-5

2796 Street J, Lenehan B, Berven S, Fisher C *Introducing a New Health-Related Quality of Life Outcome Tool for Metastatic Disease of the Spine*: Content Validation Using the International Classification of Functioning, Disability, and Health; On Behalf of the Spine Oncology Study Group. Spine, 2010

2802 Lemberg I, Kirchberger I, Stucki G, Cieza A *The ICF Core Set for stroke from the perspective of physicians*: a worldwide validation study using the Delphi technique. Eur J Phys Rehabil Med, 2010

2797 Thole K, Chalmers J, Ettinger RL, Warren J *Iowa intermediate care facilities*: an evaluation of care providers'attitudes toward oral hygiene care. Spec Care Dentist, 2010 30(3) 99-105

2765 Threats TT *Access for persons with neurogenic communication disorders*: Influences of Personal and Environmental Factors of the ICF. Aphasiology, 2007 21(1) 67-80

2773 Threats TT *The Complexity of Social/Cultural Dimension in Communication Disorders*. Folia Phoniatrica et Logopaedica, 2010 62 (4) 158-165

2751 Threats TT *The ICF and speech-language pathology*: Aspiring to a fuller realization of ethical and moral issues. Int. Journal of Speech-Language Pathology, 2010 12 87-93

2749 Thuis IM, Swets-Cronert FA *Eindrapport 'Bijstelling van de ICIDH voor de Logopedie'*. Centraal Begeleidingsorgaan voor de intercollegiale toetsing, 1997

2777 Upadhyay B, Parveen Dhaker AK, Kumar, *A Ethnomedicinal and ethnopharmaco-statistical studies of Eastern Rajasthan*, India. Journal of Ethnopharmacology, 2010 129(1) 64-86

2815 Üstün B, Kennedy C *What is "functional impairment"?* Disentangling disability from clinical significance. Postepy Psychiatrii i Neurologi, 2009 18(3) 217-221

2785 Wehrmann J *Dermatologic-psychosomatic rehabilitation*. Hautarzt, 2010 61(4) 317-322

2810 Whyte, J *Directions in brain injury research: From concept to clinical implementation*. Neuropsychological rehabilitation, 2009 19(6) 807-823

2830 Zaghi S, Freitas Rezende L de, de Oliveira LM, El-Nazer R, Menning S, Tadini L, Fregni F *Inhibition of motor cortex excitability with 15 Hz transcranial alternating current stimulation (tACS).* Neuroscience Letters, 2010

2779 Zang J *Quantitative, qualitative and psychosocial assessment of Stuttering*. Forum Logopaedie, 2010 24(2) 6-11