



## WHO Family of International Classifications (FIC)

# NEWSLETTER

### Editorial Board

Coen H. van Gool, PhD  
 Willem M. Hirs, PhD  
 Marijke W. de Kleijn-de Vrankrijker, PhD  
 Huib Ten Napel, MSc  
 Lany Slobbe, MSc

### Realization and Design

A.C. Alta, Studio RIVM

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### Address

WHO-FIC Collaborating Centre  
 c/o 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 8521  
 Fax: 0031 30 274 4450  
 Website: <http://www.rivm.nl/who-fic>  
 E-mail secretariate: [Lummy.Blomer@rivm.nl](mailto:Lummy.Blomer@rivm.nl)  
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## Public Health Interventions in ICHI

The International Classification of Health Interventions (ICHI) is currently being developed. Once finalised it will join the ICD and ICF as a WHO-FIC reference classification. An overview of the structure, purpose and development of ICHI was presented in the October 2011 issue of this newsletter. Here we focus on the development of a public health classification capability within ICHI.

### Breadth of ICHI

ICHI spans the breadth of the health system, encompassing medicine, surgery, diagnostics, primary care, allied health and rehabilitation, assistance with functioning, nursing, traditional medicine and public health. The inclusion of public health within ICHI will assist in raising the visibility of public health as an important component of health systems, and will provide a basis for the collection of consistent and comparable information on population-level prevention and health promotion activities.

The purpose of ICHI is to provide a framework for comparison of health interventions at local, national and international level, but also to have sufficient detail to enable its use as a classification in its own right. While it will not contain the detail of some national classifications, ICHI will assist countries to align their national classifications, and it will serve as a basis for the development of data tools for international comparisons of the provision and effectiveness of health interventions.

### Three axes to conceptualize interventions

Within ICHI, interventions are conceptualised as being composed of three dimensions, represented by the three axes: Target, Action and Means. Each axis consists of a list of categories organised under headings. Considerable work has been done to develop draft axes, particularly in the areas relating to medical and surgical interventions. Ongoing revision of the axes will occur in an iterative fashion as lists of interventions are developed across the content areas spanned by ICHI.

As it is intended that members of the WHO family of classifications should be used together in the collection of health information, ICHI will not duplicate content present in other classifications. ICHI describes 'What is done to what target, and how'; information on 'who', 'why' and 'where' may be captured using other classifications alongside ICHI.

### What public health interventions should be in ICHI?

Public health activities are often described, funded and reported on at the level of the program. A program may comprise a number of linked and complementary interventions, some of which are delivered at the individual level and others at the group or population level. ICHI will provide a comprehensive list of public health interventions that users can select from to describe a given public health program.

*Continues on page 2*

## Editorial

*“A new spring, a new sound” is a typical Dutch expression and this newsletter is an example of it. We tried again to provide our readers with new information in order to stimulate their work on or with members of the WHO Family of International Classifications.*

*The WHO-FIC Network meeting 2011 in Cape Town supplied a lot of interesting and new information of which several parts are worthwhile to summarize in this newsletter, such as: contributions regarding public health and functioning interventions in the International Classification of Health Interventions (ICHI, the third reference classification of the family, under development).*

*During the meeting two new WHO-FIC centres have been designated: the Japanese centre and the South African centre. See the pictures showing the proud members of both centres (this page), as well as a group photo of all network meeting participants (page 9). In this issue we include a very short overview of papers/posters presented during the meetings, but we refer to the WHO website for the full series of documents and posters and the final meeting report: <http://apps.who.int/classifications/network/meeting2011/en/>.*

*Regarding the ICF a next step was taken in the area of updating by the Functioning and Disability Reference Group (FDRG) and the Update and Revision Committee (URC). A short summary of the working method and the progress of work is provided by the URC co-chair. Of course we include a list of new ICF references. We wonder how to proceed because of the growing length of the list. A possibility could be to announce the update of the list and refer to our website ([www.rivm.nl/who-fic](http://www.rivm.nl/who-fic)) instead of including the full list of new references in the newsletter. Two Dutch contributions inform the readers about research on the relationship between the components of the ICF and about ideas on personal factors in The Netherlands.*

*We regret for not being able to provide new information on the ICD-11 (ICD-11 new release and Alpha evaluation) and the work on functioning properties in the ICD. We hope to be able to publish news on these topics in our next newsletter (autumn 2012).*



*Regarding some other members of the family we do not have substantial information for the time being. Due to unresolved issues WHO prefers to take a rain check for a future publication on the International Classification of Traditional Medicine (ICTM). Also, the development of the ICPS (International Classification of Personal Safety) development has been put on hold by WHO.*

*Enjoy reading and let us know your news!*

### **For information:**

Marijke de Kleijn-de Vrankrijker, WHO-FIC Collaborating Centre in the Netherlands, e-mail: [marijke.de.kleijn@rivm.nl](mailto:marijke.de.kleijn@rivm.nl)

## **Public Health Interventions in ICHI (cont.)**

In determining which interventions should be regarded as public health interventions for the purposes of ICHI, two boundary areas need consideration:

- the boundary between public health and clinical practice;
- the boundary between public health and non-health activities.

### **Public health and clinical practice**

An example of the first boundary would be a campaign to provide oral rehydration therapy for children with diarrhea. Such a program involves delivering many individual interventions, which can be classified using ICHI. But organising the program is a public health intervention and should be coded in its own right. As a general guide, a public health intervention may be identified and classified using ICHI if there are overarching activities in the nature of planning, coordination and targeting that go beyond the normal business of managing individual health services and infrastructure.

Where a public health intervention is characterised by the organised mass delivery of individual interventions (e.g. an immunisation campaign), a coding rule will direct users of the classification to record the appropriate ICHI public health intervention code, plus an additional ICHI code describing the individual intervention(s) delivered, as well as any relevant codes from other WHO-FIC classifications (e.g. ICD, ATC).

### **Public health and non-health activities**

The second boundary arises as an issue when interventions involve activities undertaken outside the health system, but which clearly affect, or protect, population health. Examples include domestic waste removal, sewage treatment, or developing air quality standards. In many contexts such activities are regarded as part of the background infrastructure of society; in others, they are clearly public health interventions.

It will be important for ICHI to provide for the coding of these activities, so that users can record them as public health interventions where appropriate. Coding rules will be drafted to provide some guidance on this, suggesting that consideration be given to whether the intervention is undertaken by people in health occupations, and whether its primary purpose is to improve population health.

### **Current work on public health components of ICHI**

Work is now underway to assemble a comprehensive list of public health interventions. The WHO-CHOICE project, which lists key health interventions for 21 diseases and risk factors, has been used as a starting point. Each intervention is assigned an appropriate Target, Action and Means, and given a descriptive title.

- Targets for public health interventions in ICHI are of three types: health behaviours (e.g. Hygiene, Physical activity), environmental factors (based on ICF Environmental Factors, e.g. Air quality, Flora and fauna), and population/population subgroup (used for campaign type interventions).

- Actions for coding public health interventions are mostly grouped under the heading 'Preventing actions' (e.g. Environmental standards and surveillance, Population screening, Vector control).

- Means for public health interventions are grouped under the heading 'Methods' and align with relevant ICF e-codes. They can be thought of as institutions or instrumentalities of society through which public health interventions are implemented (e.g. Economic services, systems and policies, Health services, systems and policies).

### **Examples of population health interventions in ICHI**

Title: Immunisation campaign

Target: Population

Action: Population immunisation

Means: Health services, systems and policies

(A coding rule would specify that this code should be accompanied by the relevant ICHI individual intervention code, ICD code and ATC code).

Title: Tobacco taxation

Target: Tobacco use

Action: Personal risk reduction

Means: Economic services, systems and policies

Title: Provision of improved water supply

Target: Utilities services, systems and policies

Action: Provision of water

Means: Products and technology

Title: Enactment of laws or regulations concerning safe food management practices

Target: Products or substances for personal consumption

Action: Food safety control

Means: Legal services, systems and policies

Title: Education concerning physical activity, delivered through the media

Target: Physical activity

Action: Education

Means: Media services, systems and policies

Expansion and refinement of public health content within ICHI will draw on other existing lists of interventions, case studies, and input from professionals in the public health field. As this work progresses there will be further review of the axes, adding and modifying categories to better cater for the classification of public health interventions. Editorial rules will be drafted to ensure a consistent approach to the development of interventions within ICHI, and coding rules will be written to provide guidance to users.

### **Next steps**

A progress report on the development of public health content within ICHI was presented at the WHO-FIC meeting held in Cape Town in October 2011. It is planned that an alpha version of ICHI will be presented at the WHO-FIC network meeting in October 2012. Also, we are actively seeking input from public health practitioners and researchers, to assist in the development of public health content in ICHI, and field-testing of the alpha version.

Nicola Fortune

### **For information:**

Richard Madden, University of Sydney, Australia

e-mail: [richard.madden@sydney.edu.au](mailto:richard.madden@sydney.edu.au)

## ***International Organizations***

### **World Confederation for Physical Therapy**

#### **WCPT world conference 2011 report**

The World Confederation for Physical Therapy (WCPT) is the sole international voice for physical therapy, representing more than 350,000 professionals worldwide in physical therapy and related domains through its 106 member organisations. The confederation has been in official relations with the World Health Organization since 1955. At its 2003 General Meeting WCPT endorsed the International Classification of Functioning, Disability and Health (ICF) and at each of its congresses since has included ICF workshops, keynote addresses, platform presentations and networking sessions in the programme.

In June 2011 the world of physical therapy met in Amsterdam for the 16th WCPT congress, and again the ICF was well represented in the programme. Included were:

1. A **focused symposium** entitled Concept to practice: Moving physical therapy forward using the ICF. Alan Jette from the United States of America was joined by Soraya Maart (South Africa), Reuben Escorpizo (Switzerland) and Jiro Okochi (Japan). Following an introduction to the ICF examples of its use to identify environmental barriers to participation among people with disability, in vocational rehabilitation and to develop an assessment instrument for use in geriatrics. Recent efforts and concrete applications of the ICF in physical therapy practice and research were discussed.

2. A **networking session** to facilitate connections between physical therapists with an interest the recent ICF activities at WHO and ICF use in physical therapy. The session was attended by 30 physical therapists from around the world who discussed the relationship of ICF to clinical terminologies and implementation of the ICF in practice.

3. A one day **education session** entitled Principles to practice: ICF tools from the World Health Organization. The session was organised by Janice Miller from Canada and included Catherine Sykes (UK) and Jennifer Jelsma (South Africa) all of whom have worked on WHO classifications for many years. They were joined by Brona McDowell and Claire Kerr (UK) who have used the classification in their research with children with Cerebral Palsy. The session showcased the ICF checklist and WHO-DAS, the ICF eLearning tool and the ICF update platform as well as illustrating ICF use in a range of applications.

4. **Scientific presentations**, both platform and posters, on a multitude of ICF related topics. All abstracts and some presentations can be accessed at: [http://www.wcpt.org/posters\\_and\\_ppts](http://www.wcpt.org/posters_and_ppts).

The range of topics covered in these sessions illustrates the widespread acceptance of the ICF as a valuable tool for physical therapists to describe the outcomes of their practice.

**For information:**

Catherine Sykes, World Confederation for Physical Therapy (WCPT), e-mail: [csykes@wcpt.org](mailto:csykes@wcpt.org)

## International Council of Nurses

### ICN eHealth Programme and the ICNP

The International Council of Nurses (ICN) began developing the International Classification for Nursing Practice (ICNP) in 1989. The visionary goal then was to have a unifying terminology for nursing as electronic health records were gradually becoming a reality. The use of a standard terminology for nursing documentation was seen as an excellent way to generate meaningful, reusable data

that would represent nursing practice and support informed decision-making for clinicians, managers, researchers and policy-makers.

### ICN background

ICN is a federation of 135 national nurses associations, representing millions of nurses worldwide. Founded in 1899, ICN is the world's first and widest reaching international organization for health professionals. ICN works to ensure quality nursing care for all, sound health policies globally, the advancement of nursing knowledge, and the presence worldwide of a respected nursing profession and a competent and satisfied nursing workforce.

### ICN eHealth Programme

In 2011, ICN established an eHealth Programme (<http://www.icn.ch/pillarsprograms/ehealth/>), encompassing the ICNP Programme and the Telenursing Network. This Programme aims to transform nursing and improve health through visionary application of information and communication technologies. ICN integrates eHealth strategies and techniques in its own programmes and projects and also externally among its partners, in both nursing and interdisciplinary organisations. The eHealth Programme has three foci: a technology focus that provides tools and techniques to help meet the eHealth and information needs of nurses, other healthcare workers and patients; a professional focus that promotes best eHealth practice and policy; and a business focus involving collaboration with all stakeholders.

As all aspects of eHealth, eg, telehealth and mHealth, continue to proliferate, electronic documentation of healthcare and interoperability of health data has to be a goal for all providers and citizens. Standard terminologies representing healthcare domains are important for the accuracy of electronic documentation. The attainment of access to care and quality of care can be evaluated using data-based information from standard terminology applications, to the benefit of care recipients, providers, and healthcare systems.

### ICNP – Terminology

ICNP 2011 was released in May 2011, and marked the policy decision to release an updated version every two years. The year would be used as a descriptor, replacing the Version 1.0 (2005) and Version 2.0 (2009) nomenclature. Version 1.0 was the first release to use web ontology language (OWL) in Protégé software environment. The terminology continues to increase in size, in part with new primitive concepts added to the 7-axis model, and in part due to advancements in the development of pre-coordinated statements representing nursing diagnoses, interventions, and outcomes. Figure 1 shows the concepts in ICNP over time. Figure 2 shows the numbers of diagnoses and outcomes, interventions, and primitive concepts within their respective axes in Version 2011.

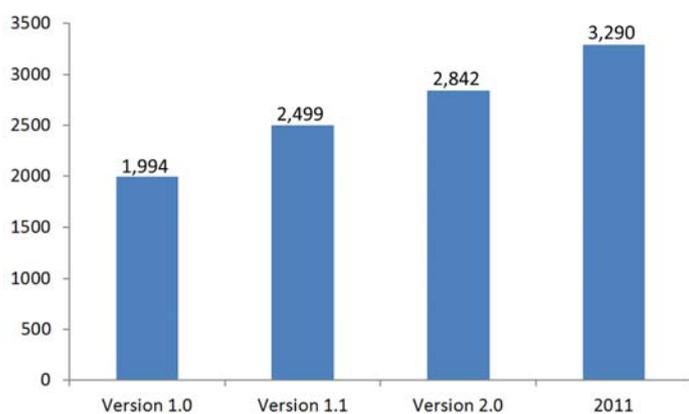


Figure 1. Frequency of ICNP Concepts by Release

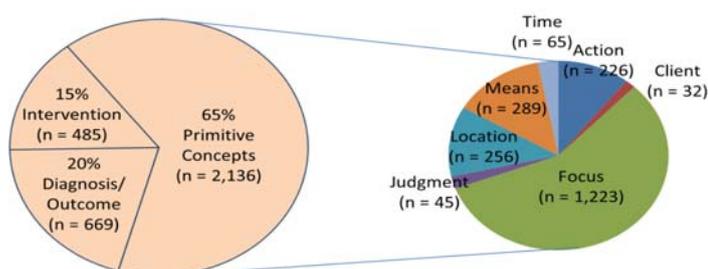


Figure 2. Version 2011 Concepts and Axes

## ICNP and ISO

The continued development of ICNP reflects ISO standards for nursing diagnoses, interventions and outcomes as well as ISO standards for terminologies such as context-free codes, non-redundancy and non-ambiguity. Quality improvement processes are in place using both machine and manual analyses [1], and procedures for style consistency, version management, and mapping have been developed to support terminology maintenance and development. The processes and procedures are reviewed at least annually by the ICNP team for relevance and accuracy.

## C-Space and ICNP

The C-Space platform (<http://icnp.clinicaltemplates.org/>) supports ICNP development, dissemination and translations. The ICNP browser is available for research or education purposes, and shows the primitive concepts in the 7 axes as well as the diagnoses/outcomes (DC) and interventions (IC). ICNP can be downloaded in different formats, depending on the user's needs, eg, an entities (concepts) table, ICNP subsets, or the ClAML representation. Fourteen translations of ICNP are also available on C-Space.

The development of ICNP catalogues or subsets in collaboration with expert nurses for selected topics is the primary means by which new concepts and pre-coordinated diagnosis and intervention statements are added to ICNP [2]. ICNP catalogues are clinically relevant subsets developed by subject matter experts in collaboration with ICNP experts. Additional experts validate each catalogue's content prior to final release. Two early catalogues were on Adherence [3] and Palliative Care [4]; the pre-coordinated

statements from these catalogues are now on C-Space. The Community Nursing [5] and Nursing Outcome Indicators [6] catalogues are available from ICN in-print (narrative content plus pre-coordinated statements) and on C-Space (pre-coordinated statements).

## ICNP and Related Terminologies

ICNP is a related member of the WHO Family of International Classifications, supporting aim of harmonizing ICNP with other WHO-FIC terminologies. A recent study examined to what extent the ICF and ICNP could be mapped to facilitate unambiguous communication across health settings and professionals [7]. Less than half of 946 ICF concepts (46%) were able to be mapped to ICNP primitive concepts. ICF concepts were more granular than ICNP concepts in the areas of human functioning and body structures. A mapping exercise between ICNP nursing interventions and ICHI was completed recently. 278 ICNP interventions were mapped with the ICHI codes (target, action and means) with most interventions having equivalence with ICHI means or actions or both; fewer equivalences between interventions and targets were found. The findings of these studies warrant further research, with the suggestion that clinically relevant subsets for documentation of care could use multiple terminologies to give users the necessary breadth and depth of options for describing diagnoses, interventions and outcomes. Using this same reasoning, it could be useful to use ICD concepts in clinically relevant subsets so that, for example, medical diagnoses such as diabetes or pancreatitis could be included in the array of options provided to nurses for their documentation.

The harmonization agreement between ICN and the IHTSDO is the basis for mapping of ICNP and SNOMED-CT. A pilot study using 239 ICNP diagnostic codes, or problems found that 222 (92%) were identified as semantically equivalent to concepts for SNOMED-CT. The work continues, with ICNP experts mapping all of the ICNP diagnostic codes (669) with SNOMED-CT. Given that the use of SNOMED-CT in electronic health records is increasing, the mapping of ICNP is important in that nursing-related data from those systems can be extracted and re-used for comparison of nursing decision-making and nurse sensitive patient outcomes analysis within and across countries worldwide.

## Key messages

This article described the International Council of Nurses and the ICN eHealth Programme, with an emphasis on the International Classification for Nursing Practice. The ICNP terminology was designed to represent nursing practice to include nursing diagnosis, intervention and outcome concepts. ICNP continues to increase in size, with continued development of clinically relevant subsets and mapping with other terminologies. The ongoing work with ICF, ICHI and SNOMED-CT, and the potential for augmenting ICNP Catalogues with concepts from other WHO FIC

terminologies, holds great promise for implementation of interoperable systems worldwide.

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#### For information:

Claudia C. Bartz, International Council of Nurses  
e-mail: [cbartz@uwm.edu](mailto:cbartz@uwm.edu)

## International Federation of Health Information Management Associations (IFHIMA)

### Update on IFHIMA activities

Greetings to all of you in the WHO-FIC community who are reading this message!! As the current President of IFHIMA, I am happy to provide an update of the activities of IFHIMA, the International Federation of Health Information Management Associations. We are currently 14 months out from the next IFHIMA Congress, the 17th Congress, scheduled in Montreal, Canada on May 13-15, 2013.

Plans are very much underway with significant information already on the IFHIMA web site, [www.ifhima.org](http://www.ifhima.org). We hope many of you are making plans to attend, and to contribute papers or posters.

### IFHIMA congress details

Registration for the 17th Congress is already open. If you go to our web site, there is a link that will send you right to the Canadian site for the latest information on the Congress. Watch for the deadlines for the abstract submission, and scholarship opportunities. Also, you can go directly to the Congress web site at [www.ifhimacongress2013.com](http://www.ifhimacongress2013.com). Please plan on arriving in Montreal by Friday May 10, 2013, as there will be some pre-meetings on Saturday, as well as the General Assembly on Sunday. The official opening of the Congress will be on Monday the 13th of May, 2013.

### Current activities

The activities of IFHIMA currently are very numerous. Our initiatives continue to be in the areas of HIM education, advancing the Electronic Health Record, promoting Data Quality and Data Management, and working on the Needs of Developing Countries. To that end we are working on publishing on the web site a comprehensive list of HIM education opportunities worldwide. This master list is being compiled by Yukiko Yokobori of the Japan Hospital Association. Also, development is underway for two new education modules for our web site—one in Privacy and Confidentiality and one for the development of the Electronic Health Record.

### IFHIMA executive board

Our work on the Executive Board of IFHIMA this year is outstanding. The IFHIMA Europe group, with the good work of Past President Lorraine Nicholson, is making great strides on many fronts, including the AHAIP true European Innovation Partnership focusing on enabling ageing EU citizens to lead healthy, active and independent lives. Lorraine, with the assistance of Carol Lewis of the US, has also worked on streamlining the guidelines for countries wishing to establish an HIM association. Additionally, we will be participating in EHealth Week in Copenhagen in May of 2012.

Other directors and board members have been equally as busy—all their activities are too numerous to mention in this report, but the web site contains detail on the activities of our executive board in the Western Pacific, Africa and the Eastern Mediterranean, The Americas, and South East Asia. You'll find their names and emails on this letterhead. A big thank you goes out to Angelika, Lorraine, Joon, Marci, Stuart, Yukiko, Sallyanne and Darley.

Our membership Chairman is Darley Petersen from Denmark. She has worked extensively with AHIMA in the US to refine and facilitate the membership processing. Certificates are now presented to all individual members, something that is important to our members in developing countries. The entire membership process has been updated, including timing of dues invoices for countries and members.

### IFHIMA Newsletter

The Global News is our excellent newsletter that is produced by the President-Elect of IFHIMA, Angelika Haendel from Germany. All of you have access to this newsletter from our web site. Just click on the tab for Global News. This comprehensive and informative newsletter contains articles, and information from our members. The most current issue is March of 2012; however, previous issues are on the web site awaiting your review.

Three members of the Executive Board of IFHIMA—Marci MacDonald, Joon Hong, and I attended the WHO-FIC

Education and Implementation Committee meeting in Washington, DC in the US in March. Three IFHIMA members have sat on this workgroup for the past 7 years or so and provided valuable input from the HIM profession to the Committee, especially in mortality/morbidity coding.

IFHIMA is a virtual organization, made strong by the member countries and individual members. The web site reveals the contact person in each country and is a very good resource for anyone desiring more information about the organization. Our web master, Julie Wolter in the US keeps our web site very current.

Best regards,

Margaret

**For information:**

Margaret Skurka, Indiana University Northwest, USA  
e-mail: [mskurk@iun.edu](mailto:mskurk@iun.edu)

## IRIS

### **An international system for automated cause of death coding**

Mortality data are widely used in medical research, for monitoring of public health and for planning and evaluation of health interventions. These data are comprehensive, available from a wide range of countries, collected on an ongoing basis and cover long periods of time. This is why the International Classification of diseases (ICD), published and maintained by the World Health Organisation (WHO), stipulates standards for data collection, coding, classification, statistical concepts and tabulation.

### **ICD and automated coding**

The ICD is now used by more than 100 countries. However, several studies have shown that comparing mortality data over time and between regions and countries offers many challenges. The complexity of mortality coding has led to the use of computers to apply the ICD instructions for the selection of the underlying cause of death. The main advantages are 1) rules and guidelines are fully specified in the program and 2) the program will apply these rules systematically without variation through time. Moreover, if countries use the same software, the data comparability will be greatly increased. Also, the introduction of an international Automated Coding System (ACS) for mortality often leads to a critical evaluation of local coding practices, which further contributes to improvement of mortality data quality and comparability.

### **Need for single coding**

Several countries are using the US system for mortality coding called the Medical Mortality Data System (MMDS). But because an important part of the MMDS depends on the language used for causes of death certification, most non-

English-speaking countries (e.g., Sweden, France, Hungary, Italy and Mexico) use only those parts of the MMDS that are language independent, and have developed their own equivalents of the language-dependent components. This limits the usefulness of computer programs for improving international comparability. Therefore, the importance of developing a single coding system that can be used internationally is apparent. In this context several countries have been working on the Iris project

### **Iris system**

The Iris system is an ACS developed through international collaboration and that can be easily adapted to any language. Iris is fully compatible with the WHO rules and guidelines for mortality coding. To ensure international comparability, Iris has been developed in close cooperation with the Mortality Reference Group and the developers of the pioneering US ACS system MMDS. Iris offers an intuitive interface based on the international death certificate form. Causes of death can be entered either as ICD codes for the conditions mentioned on the certificate, or as free text. Iris applies the ICD rules to select an underlying cause. If the data are entered as free text, Iris assigns an ICD code to the expressions by matching them to a dictionary of diagnostic terms. Powerful tools for text standardization are available, which greatly increases the efficiency of the text matching. Further, Iris provides detailed explanations on how the system arrived at the multiple and underlying cause codes.

Over the last few years there has been a growing interest in Iris and Iris has now been implemented in Catalonia, the Czech Republic, France, Israel, Germany, Luxembourg, Norway and Sweden. Many other countries are in the process of implementing Iris, for example Austria, Belgium, Brazil, Canada, England and Wales, Finland, Hungary, Ireland, Italy, Morocco, Netherland, Poland, Slovenia, South Africa, Spain and Switzerland.

### **Current status**

Iris is developed and maintained by a core group including the five pioneer countries France, Germany, Hungary, Italy and Sweden. The core group members share the work between them, including implementation of ICD updates. Several improvements are under development and a new version will be available by summer 2012. Other new projects aim at adapting Iris to special uses, for example to register deaths at the local level and to register data collected by verbal autopsy questionnaires. However, Iris is already available in a stable version, which can be downloaded from the Iris website ([http://www.cepidc.inserm.fr/inserm/html/IRIS/iris\\_project.htm](http://www.cepidc.inserm.fr/inserm/html/IRIS/iris_project.htm)). To avoid differences resulting from local adaptations, and thereby compromising international comparability of mortality data coded by Iris, the source code is not open. The core group is currently investigating the possibility to set up a more permanent structure for maintenance and development of Iris in the future, although the details are not yet finalized.

## European support for IRIS

In 2009, Eurostat financed an 18 months project that allowed the core group to organize meetings and training courses for other European users. This created an active community of European users, now joined by several non-European countries. Feedback from the users' group is important in developing the Iris system further, both as concerns interface and functionalities. Especially, advice from the users' group has been essential in implementing ICD-10 updates, and it will have an important role to play in adapting Iris to ICD-11. The Iris core group looks forward to developing the Iris system further in close cooperation with international users.

G rard Pavillon, on behalf of Lars Age Johansson and Stefanie Weber

### For information:

G rard Pavillon, INSERM, France  
e-mail: [Gerard.Pavillon@inserm.fr](mailto:Gerard.Pavillon@inserm.fr)

## ALTER

### European Journal of Disability Research - Revue europ enne de recherche sur le handicap

Since December 2007, ALTER-European Journal of Disability Research provides social scientists, academics, postdoctoral and doctoral students a new opportunity to publish works in the field of disability, in two languages, English or French. ALTER is a, peer-reviewed scientific quarterly, published by Elsevier, supported by the French Federative institute for disability research (INSERM) and sponsored by ALTER-International society for the history of disability. Located in Paris, the Journal is international in its readership and subscribers, the regions of the world where disability issues are examined and its cross-disciplinary editorial board whose members belong to the international scientific and academic network on disability. ALTER appeals to researchers, academics, students, policy makers, field professionals and all parties concerned with disability.

### Scope of the journal: A cross-cutting and cross-disciplinary approach of disability

ALTER aims to account for the broad picture of current cutting-edge international research on disability. In domains as varied as education, health, policies and politics, economy, employment, sports, sexuality, etc., disability raises compelling issues that research investigates. ALTER publishes in-depth articles in all humanities and social sciences disciplines (sociology, psychology, anthropology, legal, political or gender studies, demography, history, epistemology...). Each issue contains five original articles (9 000 words each) which can be a theoretical approach, a field research or related to the lived experience of disability, an experimentation or a methodological proposal, a report on a work in progress, an

analysis of a disability policy... You will find also several other sections such as key-texts revisited, book reviews, announcements of scientific events related to disability, summaries of recently defended doctoral dissertations. At [http://www.elsevier.com/wps/find/journaleditorialboard.cws\\_home/714030/editorialboard](http://www.elsevier.com/wps/find/journaleditorialboard.cws_home/714030/editorialboard) a list of members of the editorial board can be viewed. You can also have a look at the top ten cited articles:

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As members of WHO-FIC collaborating centres, you will find familiar topics and authors such as:

- The relevance of the International Classification of Functioning, Disability and Health (ICF) to mental disorders and their treatment. Geoffrey M. Reed William Spaulding D. Lynn F. Bufka (Vol.3, n 4, Sept.-Dec. 2009)
- United Nations Convention on the Rights of Persons with Disabilities. Moving towards substituted or supported decision-making? Article 12 of the Convention on the Rights of Persons with Disabilities. Nandini Devi, Jerome Bickenbach, Gerold Stucki (Vol.5, n 4, Sept.-Dec.2011)

### Submissions

You are invited to submit manuscripts on line at: <http://ees.elsevier.com/alter/> or submit other pieces that would fit in one of the above mentioned rubrics, at: [alter@elsevier.com](mailto:alter@elsevier.com). Would you be working within a network on a specific topic, you may then wish to coordinate a special issue of 5 articles as Guest Editor. Do not hesitate to submit your project at: [alter@elsevier.com](mailto:alter@elsevier.com). Here are some examples of special issues:

- Disability and birth at stake. Vol. 5, n 1 (Jan.-March 2011)  
<http://www.sciencedirect.com/science/journal/18750672/5/1>
- Amartya Sen's capability approach to re-think disability policies: the case of the Tuscany region (Italy) Vol. 5, n  3 (Sept.-Dec.2011).  
<http://www.sciencedirect.com/science/journal/18750672/5/3>
- Current Trends and Development in Global Disability Research. Vol.2, n 1, (Jan.-March 2008).  
<http://www.sciencedirect.com/science/journal/18750672/2/1>

### Annual conference: NEW!!

Aiming at connecting disability stakeholders and researchers to current knowledge on disability issues, ALTER- European Society for Disability Research, stemming from ALTER's Editorial Board, organizes July 5th and 6th in Paris, its first annual conference, linked with the annual Editorial Board meeting. If you wish to receive the conference program and registration form, let us know at: [alter@elsevier.com](mailto:alter@elsevier.com).

### Subscription

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**For information:**

Catherine Barral, ALTER Associate editor, Ecole des Hautes Etudes en Santé Publique, Paris  
e-mail: [Catherine.barral@ehesp.fr](mailto:Catherine.barral@ehesp.fr)

## Overview of WHO-FIC Network Meeting

### 29 October – 5 November 2011

The 2011 annual meeting of the WHO Network of Collaborating Centres for the Family of International Classifications in Cape Town, South Africa, was hosted by the Medical Research Council of South Africa. Meeting venue was the Southern Sun Cape Sun hotel.



### Availability of all documents

All meeting documents are published on the website of the 2011 Annual Meeting of the WHO FIC Network, see <http://apps.who.int/classifications/network/meeting2011/en/>. Please see this website for the meeting summary reports to overview the results. At the 2011 network meeting 22 papers and 58 posters were presented. Out of these 80 presentations, 19 were on ICD, 26 on ICF, 10 on ICHI, and 25 were on WHO-FIC related issues. Two presentations are highlighted below.

### COURAGE in EUROPE Project

There is a need to measure health, environment and social networks of the ageing population and their impact on quality of life and well-being to produce comparable data throughout Europe. The COURAGE in EUROPE Project, which is funded by the European Commission within the Seventh Framework Programme, will develop and validate cross-nationally measures of health and health-related outcomes for an ageing population. The ICF theoretical framework is defined as the background against which these comparable data on determinants of health and disability in ageing will be collected. The poster (D006p) by Matilde Leonardi et al. is entitled: Understanding ageing and determinants of health and disability in ageing to guide public health policies: the COURAGE in EUROPE Project.

### Knowledge representation on disability: world to win

A cursory analysis of the usage of the concept of disability in two reports provided by UNESCO and UNICEF suggests that there is no shared conceptual understanding between WHO-FIC and other UN agencies and therefore little chance for a common knowledge representation to evolve. The representation of knowledge around “disability” is very heterogeneous and often conceptually incompatible. The organisations are aware of this situation and perceive the lack of a common framework to link data to information and to knowledge as a major problem. Ways to overcome this problem include collectively creating concept maps. This can visualise the different conceptualisations and initiate a process of collective reasoning to create more consistent knowledge based across a broader area of application. The paper (D005) by Judith Hollenweger is entitled: Bridging the gap between WHO-FIC and other Families of the United Nations: the example of UNESCO and UNICEF.

**For information:**

Coen van Gool, WHO-FIC Collaborating Centre in the Netherlands, e-mail: [coen.van.gool@rivm.nl](mailto:coen.van.gool@rivm.nl)

## International Classification of Functioning, Disability, and Health

### Updating the ICF

Mandate of the World Health Organization (WHO) and the WHO Family of International Classifications (WHO-FIC) Network is the maintenance of international classifications on health. This maintenance is principally done by updating. The updating of a classification is a crucial process, which determines the survival of the classification itself. Ensuring that a classification is regularly updated to reflect the necessities of its users is necessary so that the classification is effectively used over the years. The Update and Revision Committee (URC) supports the WHO-FIC network in this task of updating. It coordinates the whole classifications update process, from submission of update proposals by reference groups and other sources to final approval of proposed updates by the WHO-FIC Council.

### Two lines of work

The International Classification of Functioning, Disability and Health (ICF) is one of the reference classifications of the WHO-FIC. The update process of ICF is conducted along two different lines of work: the realization of a foundation ICF, i.e., the merging of the derived classification ICF-CY into ICF, and the provision of annual updates to ICF. The ICF update process started in 2010 when it was decided to run the merging of ICF-CY into ICF. So far, the work has mainly focused on the realization of the foundation ICF, by reviewing and, if necessary, adapting ICF-CY items to ensure their suitability in order to be incorporated into ICF. However, in addition to proposals derived from ICF-CY, which are treated as update

proposals, proposals related to ICF items have also been considered.

### **Web-based update platform**

The entire update process is managed through a web-based platform, thus ensuring standardization of submission, review, decision on, and implementation of update proposals. This web-based tool allows contributors from around the world to work collaboratively and makes the process transparent as each contribution is visible to all users. The platform is accessible to any person, who can register and become a user, from the following link: <https://extranet.who.int/icfrevision/nr/loginICF.aspx>  
The update platform is structured in layers. During the proposal review process, each proposal goes through the different layers before reaching the final stage. Moving the proposal from one layer to the next is done by the URC Secretariat.

The four ICF update platform layers are the following:

1. *Moderation Layer*: it is a filter layer in which all proposals are screened by the URC secretariat for appropriateness.
2. *Closed Group Layer*: in the ICF update platform there are two closed groups, the Initial Review Group (IRG) and the Function and Disability Reference Group (FDRG).
  - a) *IRG layer*: in this layer, a dedicated group of FDRG experts perform a first review of the proposals following the recommendations and principles reported in the Recommendations for Initial Reviewers, a document which combines a reviewer's checklist and a list of good practices, and in the ICF Update Platform User Guide. The FDRG, together with WHO, nominates the coordinators of the IRG. Their role is to streamline the process and to inform the URC Secretariat when the review work is completed.
  - b) *FDRG layer*: the update proposals are reviewed by all FDRG members. The aim is to decide whether a proposal should be approved, approved with modification, or rejected. The recommendation is generally expressed by the IRG coordinators on behalf of the FDRG co-chairs and is communicated to the URC Secretariat.
3. *Open Discussion Layer*: the proposals can be seen by all users of the platform, who can comment on the proposal itself or on the recommendation made by the FDRG. At this stage, which is a key step for the transparency of the process, collaborating experts of the FDRG can add revision remarks, while the author of the proposal can, if necessary, respond to the remarks made by the reviewers.
4. *Closed Discussion Layer*: the members of the URC make a decision on the proposals taking into account the IRG reviews, FDRG recommendations, and comments made in the Open Discussion Layer. The discussion is catalyzed by rounds of vote set up by the URC Secretariat. The voting procedure is used to stimulate on-line discussion by the members of the URC.

### **Final approval**

The URC Secretariat prepares a list of the proposals for which a full consensus has been achieved during the voting rounds and submits it to the URC for approval during the WHO-FIC annual meeting. During the annual meeting, all the controversial proposals are discussed face to face in order to come up with a decision, which can be one of four types: approved, approved with modification, rejected, and withheld for further discussion. The decision of the URC is then submitted to the WHO-FIC Council for ratification. The approved update proposals are published on the WHO website by the end of January of the year following the ratification. The updated ICF database is also made available to the Collaborating Centres who require it in order to update their ICF-based information systems. Since the beginning of the ICF update process, 37 update proposals have been approved. Thirteen were approved in 2010 and 24 in 2011. At present (April 11, 2012), there are still 177 items under evaluation (Ten newly added into the IRG layer, 104 under review in the FDRG layer and 63 receiving further input in the Open Discussion layer).

### **Quality control**

The updating of ICF is not an easy task. New or modified items have to effectively add additional value to ICF while preserving the style and harmonization of the classification. Therefore, it has to be ensured that the rationale provided for each update proposal is supported by evidence of the underlying need, in terms of clinical or public health utility. Moreover, definitions of new codes have to be written clearly and unambiguously and examples should have a full explanatory role ensuring cross-cultural relevance. The knowledge on functioning has thus to be informed by classification principles in order to qualify the new or adapted ICF items as valid and reliable classification entities.

All URC members participating in the discussion can review and comment on all proposals, recommending, if necessary, alternatives or modifications to the initial proposal and providing useful input to the review process. Therefore, besides coordinating the ICF update process, the URC also plays a key role in preserving consistency of ICF content and structure.

### **Work ahead**

From a more technical point of view, the first two years of work on updating ICF have shown that the process needs refinement in terms of establishing the roles and deadlines in the different steps. In the current year, the following timeline has been adopted: IRG review of proposals by April 3, FDRG review from April 4 to April 22, open discussion from April 30 to May 31, and closed discussion and voting rounds from June 11, 2012 on.

### **For information:**

Francesco Gongolo, co-chair URC  
e-mail: [francesco.gongolo@regione.fvg.it](mailto:francesco.gongolo@regione.fvg.it)

## International Classification of Health Interventions (ICHI)

### A Developing ICHI makes more contact with ICF

In the last year the WHO-FIC community has devoted considerable effort to the new International Classification of Health Interventions (ICHI), especially the members of the Family Development Committee under the co-chairmanship of Richard Madden from the Collaborating Centre for the WHO-FIC in Australia. ICHI, describing and classifying procedures in medicine, is a long standing project of WHO, with its roots in 1978, would complete the trinity of reference classifications together with ICD and ICF, and will include interventions from the fields of medicine, surgery, diagnostics, primary care, nursing, traditional medicine, public health, rehabilitation, and allied health sciences.

### Functioning properties in ICHI

Members of the Functioning and Disability Reference Group paid special attention to interventions typically performed in the context of rehabilitation programs, which are now found in a small portion of chapter 16 of ICD-9-CM volume 3. Health interventions are described in the ICHI by their target, the type of action, and the means by which that action is performed. Targets are organized following the ICF structure, identifying the anatomical site (body structure), the physiological function (body functions) or more complex aspects of functioning (e.g. mobility, self care or personal interaction, as represented by the ICF component activity and participation). The ICF component "Environmental Factors" however is not represented among the target options, nor among the means or actions.

### Environmental Factor as Target of intervention

The goal of rehabilitation interventions is to optimize human functioning even in the context of a persisting impairment or a significant reduction in capacity to execute activities or to participate in life situations. Even though some rehabilitation interventions may target body structures (e.g. muscle trophism) or functions (e.g. voice articulation), most interventions target activities or participation. In the process of assigning ICHI labels to the existing items in ICD-9-CM chapter 16 and to other intervention lists (such as the Thai ICD10-TM chapter 17 list of rehabilitation, physical therapy and related procedures, and the Canadian Classification of Health Interventions chapter 6.sc and 7.sc) it became increasingly evident that in many instances the target of intervention was not identifiable within the available list. The most appropriate label would be provided however by an environmental factor. In the provisional transcoding exercise of ICD-9-CM items with ICHI labels completed by Andrea Martinuzzi and Thorsten Meyer, 21 % of the interventions typically performed in rehabilitation would need an «e» target. For example in the "Organization of appropriate food for a person by a nutritionist" the intervention is aiming to improve

functioning related to the digestive system and also various aspects of activities and participation, however the immediate target is Food (e1100): an Environmental Factor. Similarly, when providing a ramp for mobility, the intervention is aiming to improve various domains of activities and participation, but the immediate target is the environmental barrier. In some instances «e» codes would be useful as Means, when the desired outcome (e.g. autonomy in mobility) is pursued by modifying environmental aspects (e.g. Training in use of see eye dog for the blind).

### Proximal versus remote

It may be argued that even though the immediate (proximal) intervention targets an environmental factor, the final (remote) target could be found among some of the existing codes reflecting body functions, structures or activity and participation: For example, one may act on the environment to make adaptations for accessibility (e.g. modifying the design or construction of a building), but the final "remote" goal is to allow persons with problems in mobility to move around freely. This line of reasoning however presents two major problems:

- 1) It would fail in term of consistency with the way in which targets are identified for other interventions, for which always the most proximal, directly addressed target is considered (e.g. in an operation for coronary bypass the target will be the coronary artery even though the final aim is to improve myocardial blood supply).
- 2) It would frequently lead to multiple "remote" targets, all of whom potentially addressed by the same intervention (e.g. by providing training to a care giver on management issues for a dependent person the targets may indeed encompass a wide array of categories in activities and participation of the cared for person).

### Further discussion

The issue of including «e» targets and means into the ICHI draft was discussed at the 2011 WHO-FIC meeting in Cape Town, and raised much interest. This inclusion could open a potential cross talk with other existing international classifications and denomination systems, and could also provide a solid bridge towards the area of public health, opening ICHI to a wider and inclusive horizon. The next appointment for discussion on ICHI is the mid-year meeting of the WHO-FIC Family Development Committee due in Beijing next July. On that occasion a growing and more comprehensive ICHI draft will be presented and discussed.

### For information:

Andrea Martinuzzi, E. Medea Scientific Institute, Research Branch of the Italian WHO-FIC Collaborating Centre  
e-mail: [andrea.martinuzzi@cn.lnf.it](mailto:andrea.martinuzzi@cn.lnf.it)  
Thorsten Meyer, Hannover Medical School, Germany  
e-mail: [meyer.thorsten@mh-hannover.de](mailto:meyer.thorsten@mh-hannover.de)

# ***FIC around the World***

## **North America**

### **PROMIS**

#### **Patient Reported Outcome Measurement Information System: PROMIS®**

Over the past few years collaboration between members of the WHO-FIC Functioning and Disability Reference Group (FDRG) and investigators from the US National Institutes of Health (NIH) the Patient Reported Outcomes Measurement Information System (PROMIS) has been established to improve harmonization of efforts. The purpose of this report is to provide an overview of PROMIS, as well as a summary of the progress made to date on the harmonization between our groups, and plans for the future.

#### **Overview of PROMIS**

PROMIS ([www.nihpromis.org](http://www.nihpromis.org)) is an ongoing U.S. National Institutes of Health initiative designed to create a set of item banks measuring self-perceptions of adults and children about their health and illness experiences. The initial focus of the network was on the development of PRO instruments that captured health outcomes considered as important clinical research trial endpoints. Given this purpose, the PROMIS framework reflects specific measures framed in the ways that patients (and proxy reporters) organize their health-related experiences and perceptions - the constructs underlying person/patient-reported outcomes (PRO's). The uniqueness of PROMIS® lies in four key areas:

- 1) Comparability: measures have been standardized so there are common domains and metrics across conditions, allowing for comparisons across domains and diseases;
- 2) Reliability and Validity: all metrics for each domain have been rigorously reviewed and tested;
- 3) Flexibility: PROMIS can be administered in a variety of ways, in different forms;
- 4) Inclusiveness: PROMIS encompasses all people, regardless of literacy, language, physical function or life course.

#### **Use of PROMIS**

The current PROMIS framework structure and corresponding definitions can be found at [www.nihpromis.org](http://www.nihpromis.org). PROMIS measures can be used as primary or secondary endpoints in clinical studies of the effectiveness of treatment, and PROMIS® tools can be used across a wide variety of chronic diseases and conditions and in the general population. When used with traditional clinical measures of health, PROMIS® tools allow clinicians to better understand how various treatments might affect what patients are able to do and the symptoms they experience.

#### **Psychometrics**

All PROMIS item banks are calibrated using item response theory models – providing efficient measurement of the underlying health constructs and a common metric across all items within each construct. This calibration makes computer adaptive testing possible, in which precise estimation can be reached by using only few informative items, and scores can be compared even when respondents are not asked the same items. Test developers also have the freedom to choose specific items that must be asked to ensure capture of an aspect of the construct considered of importance (e.g. mobility on stairs to determine home care supports).

PROMIS has many assessment options available to measure self-reported health for clinical research and practice. PROMIS assessment instruments are drawn primarily from calibrated item banks (sets of well-defined and validated items) measuring concepts such as pain, fatigue, physical function, depression, anxiety and social function. These calibrated item banks can be used to derive short forms (typically requiring 4-10 items per domain or sub-domain), or computerized adaptive testing (CAT; typically requiring 4-7 items per domain or sub-domain depending on the stopping rules set up by investigators). PROMIS profiles are available for investigators to capture general health, which consists of fixed numbers of items from multi-domains/sub-domains, are also available.

#### **Current status**

As of April 2012, PROMIS has developed 46 IRT calibrated self-reported item banks and three scales, which consist of fewer items, for adults and children. Eight item banks and one scale are available for parent proxy. We anticipate in completing the calibration of another 10 item banks by the end of 2013. Most PROMIS item banks/scales and associated short-forms are available for use in the public domain through Assessment Center ([www.assessmentcenter.net](http://www.assessmentcenter.net)). Assessment Center can be utilized for computer, web-based or paper administration, as well as inclusion in other electronic data collection platforms. Current efforts are also underway to support the inclusion of PROMIS measures in electronic health record platforms. PROMIS items are available in multiple languages (a complete list can be found at <http://www.nihpromis.org/measurements/translations>)

#### **PROMIS and WHO-FIC Harmonization Activities**

PROMIS concepts are most closely linked with concepts contained in the ICF framework, and harmonization efforts have included conceptual and item/category level comparison between the frameworks. While conceptual similarities clearly exist between these 2 frameworks, a few important differences exist. One difference between the 2 frameworks stems from the original intended purpose of each. PROMIS focuses on measures that have been highly prioritized as clinical research and practice outcomes, and was broadly envisioned as a means to standardize and

advance PROs based on the application of item response theory. The ICF was developed to meet the need for a common, international means of describing human functioning, health and disability by classifying health, non health and environmental factors that contribute to one's level of disability. The ICF excels at providing a broad landscape of health. PROMIS excels at providing granularity within targeted areas of health outcomes that were considered high priorities to advance PRO measurement. The ICF provides a system for organizing the components of the biological aspects of health, health related outcomes and the non-health related person and environmental aspects (environment). PROMIS more heavily focuses on the subjective experience of health in terms of affective, cognitive, functioning, and well-being experiences, with fewer measures of non-health concepts than included in the ICF.

### Summary

The bodies of work of both PROMIS and ICF have and will advance the measurement and understanding of health and functioning. Although the frameworks for PROMIS and ICF share a common goal of supporting measurement, they approach the task differently, and such differences provide opportunities for synergy and measurement advancement. The broad scientific community has a role to play, ensuring that the strengths of each system are highlighted, and that the complementary areas are built upon to further advance the fields of health functioning and disability measurement and intervention. Currently a series of publication, co-authored by WHO, FDRG and PROMIS members and investigators, are in progress that provide detailed mappings between PROMIS adult and pediatric concepts and measures at the conceptual and item levels are underway. Ultimately such complementary efforts will lead to improved systems for comprehensive health outcome measures.

### For information:

Carole Tucker, Temple University, Philadelphia PA, USA  
 e-mail: [carole.tucker@temple.edu](mailto:carole.tucker@temple.edu)  
 Jin Shei Lai, Northwestern University, Chicago IL, USA  
 e-mail: [j-slai@northwestern.edu](mailto:j-slai@northwestern.edu)

## The Netherlands

### An empirical exploration of the relations between the health components of the ICF

In January 2012, we reported in the International Journal Disability and Rehabilitation the results of a quantitative study into the relations between the health components of the ICF (<http://dx.doi.org/10.3109/09638288.2011.647233>). This study is rather unique as it is, to our knowledge, the first one to investigate these relations in a general way, not aimed at a specific chronic condition.

### Instruments

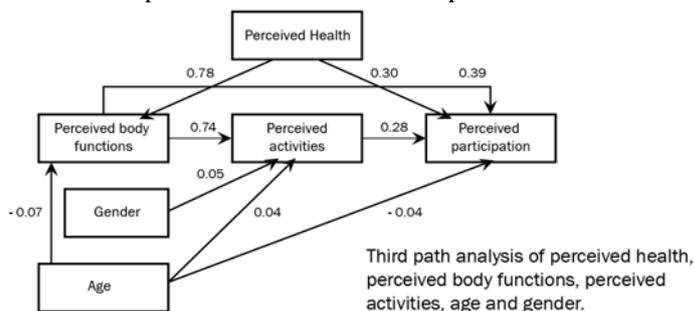
Health condition was measured by number of chronic conditions reported, body structures and functions by an ICF based instrument IMPACT-BF, containing 39 items on body structures and functions. Activity and Participation were measured by IMPACT-S, an ICF-based questionnaire with 32 items. Age and gender were used as personal factors. Also included was the single-item question on perceived or self-rated health. The study did not contain questions on external factors.

### Methods

Data were collected by an internet survey among 2941 individuals with at least one chronic disease or disorder. Path analysis was used to quantify the relations with Participation as the final denominator. We tested three models: one with the number of chronic conditions as an indicator of health condition, one with perceived health as an indicator of the health condition and one with the number of chronic conditions as an indicator of the health condition and perceived health as part of the personal factors.

### Results

In all three models the relations between the health components of the ICF could be established, except a direct relation between health condition and activities. All three models showed a good fit, but the model with the best fit was the one with perceived health as an indicator of health condition (see figure 1). The numbers in figure 1 present the standardized parameters of the path-analysis and should be interpreted as: a change of 1 standard deviation in one variable results in a change in standard deviation in the size as presented by the parameter. Thus: a change of 1 SD in Perceived health results in a change in SD of 0.30 in Participation. All variables included in the model account for 0.77% explained variance of Participation.



From this study we conclude that Participation as perceived by the respondents is strongly associated with respondents perception of his/her own health and less with the number of chronic conditions.

Rom Perenboom, on behalf of Gert Jan Wijnhuizen, Francisca Galindo Garre, Yvonne F Heerkens, and Nico van Meeteren

### For information:

Rom Perenboom, TNO, Leiden  
 e-mail: [rom.perenboom@tno.nl](mailto:rom.perenboom@tno.nl)

## Dutch medical spelling reform

Since 2004, Dutch WHO-FIC collaborating centre members have been working on the Dutch translation of the ICD-10. In 2011 they inspired the linguist Van den Eerenbeemt, editor of the monolingual Dutch medical Pinkhof dictionary, to compose, advocate and disseminate a custom spelling reform geared at medical professionals reading and speaking Dutch.

### Dutch spelling rules fall short in medicine

These centre members, whilst translating tens of thousands of English diagnostic terms into Dutch, were asked to 'Dutchify' to some extent intricate multiword Greco-Latin terms commonly used in medicine. They observed that official spelling rules set up for general, layman's Dutch may fall short for complex medical terms. Applying these rules lead to expressions that are acceptable to the lay reader but definitely not to the medical professional. They wanted the Dutch ICD-10 to comply orthographically with the new Pinkhof edition due later that year. It was therefore decided to consult the Pinkhof editor. Van den Eerenbeemt joined the team for a day's translation work and was invited to comment on terminographic challenges resulting from current spelling rules. He was already quite familiar with these spelling inconsistencies, which first arose in 1995 when stark spelling rules on notably eponyms (Down syndrome) and acronyms (ECG, AIDS, DES) were introduced into the Dutch language.

### Proposing a spelling alternative

It thus became clear to both parties that neither the Dutch ICD-10 nor the new Pinkhof edition would gain any credibility if there were differences in spelling. Strictly applying standard spelling rules to the ICD would result in spelling forms found controversial by ICD users and the dictionary. In the past decade most MDs, who are largely accustomed to English word forms, appear to be unwilling and/or unable to adhere to standard spelling rules. This, among others, prompted the editor to suggest introducing a set of new, custom spelling rules for use by medical professionals. Such practice is already customary for Dutch biologists, who are allowed to use 'de Kraai en de Eik' (the crow and the oak) rather than 'de kraai en de eik'. The 'heretical' move of proposing a set of spelling rules differing from the nation's standard spelling is an uncommon challenge, requiring medical and linguistic expertise as well as diplomatic skills. By combining solid linguistic arguments with fine examples of spelling controversies, Van den Eerenbeemt succeeded in convincing the Dutch State Spelling Board to allow the authoritative Pinkhof to prescribe both additional and optional spelling forms differing from those regulated by the official State spelling glossary.

### Providing a choice

From now on, medical professionals writing and reading Dutch have a choice between writing 'maak 2 12

afleidingen-ecg's bij dit brugadasyndroom' and 'maak 2 12-afleidingen-ECG's bij dit Brugada-syndroom'. An Anglophone reader will know which spelling fits best in the average MD's vocabulary. Van den Eerenbeemt explains in Pinkhof Geneeskundig woordenboek ([www.pinkhof.nl](http://www.pinkhof.nl)) this newly attained spelling freedom available for Dutch healthcare professionals in some thirty elaborate articles on medical linguistics and pragmatics. The spelling reform has since been welcomed by the leading Dutch medical journal *Nederlands Tijdschrift voor Geneeskunde*.

Arnoud van den Eerenbeemt, Editor of Pinkhof Medical Dictionary

### For information:

Huib ten Napel, WHO-FIC Collaborating Centre in the Netherlands, e-mail: [huib.ten.napel@rivm.nl](mailto:huib.ten.napel@rivm.nl)

## Personal Factors in the ICF

As it is indicated in the scheme of the ICF, functioning and disability of a person can be influenced by his/her health condition, environmental factors and personal factors. However, the 2001 version of the ICF does not contain a list of personal factors, only a definition and some examples, as no consensus was reached about the inclusion of a list of personal factors in the ICF. In the 2001 version of the ICF the definition for Personal Factors is: "Personal factors are the particular background of an individual's life and living, and comprise features of the individual that are not part of a health condition or health states."

### Examples

On page 17 of the ICF 2001 the following examples of personal factors are given: gender, race, age, other health conditions, fitness, lifestyle, habits, upbringing, coping styles, social background, education, profession, past and current experience (past life events and concurrent events), overall behavior pattern and character style, individual psychological assets and other characteristics, all or any of which may play a role in disability at any level. On page 214 of the ICF 2001 the following examples are given: age, gender, social status, life experiences.

### Several attempts to list personal factors

Although no consensus was reached about the subdivision of personal factors in the development process of ICF, most researchers are convinced that a list of personal factors can help in describing the factors influencing functioning and disability. There are several research groups with great interest in the composition of a list of personal factors to be used in statistics, research and education. Conversion of assessment instruments to the ICF have generated an increasing amount of concepts that can be classified as a personal factor and a gross list of personal factors was already composed by Geyh et al. (*Disability and Rehabilitation* 2011;33 (13-14):1089-102), based on a systematic review and content analysis of the literature.

Although it is our opinion that not all the concepts on this list are 'real' personal factors, the list gives a nice picture of the concepts that might be candidates for future inclusion in a list of personal factors to be added as part of the ICF.

### **Five category provisional list of personal factors**

Based on several (research) projects and adaptations of the ICF for specific health professions, experts from the ICF-team of the Dutch WHO-FIC Collaborating Centre have composed a provisional list of personal factors. The list consists of five subcategories:

1 *Sociodemographic factors / general personal data*; such as age, gender, nationality, country of birth, language, religious affiliation, ethnicity, genetic kit, economical background, education, partnership and marriage, position in family, income, major life events, life course. These are data which are included often in research as independent variables influencing the outcome of e.g. an intervention.

2. *Psychological assets / mental factors*; such as self-efficacy, coping style, locus of control, attitude, health literacy, learning style, psychosocial carrying capacity, perceived stress, expectations, purpose in life, quality of life / life satisfaction. Although these factors are very relevant and already present in the examples of personal factors in the ICF 2001 version, discussion is still needed about the possible overlap with 'mental functions' (chapter 1 of the Classification of Functions).

3. *Personal factors related to disease / disorder*; such as coping with illness, attribution, illness behavior, compliance to therapy, illness beliefs / cognitions, acceptance, comorbidity. These personal factors are related to the disease of the person and indicate his or her way of dealing with the disease/disorder and with the consequences of the disease/disorder.

4. *General lifestyle (behavior)*; such as movement habits, smoking habits, use of alcohol, use of drugs, use of medication, dietary habits, safety habits, sunbathing habits, relaxation behavior. Lifestyle is a widely used concept and includes behavior related to 'habits' with respect to moving, smoking, eating, drinking, recreation etc.

5. *Work-related personal factors*; such as occupation / profession, occupational status, personal meaning of work, commitment to work, need for absenteeism, job satisfaction, work history, occupational style, ambition, attachment to company, employability, intention for turnover (work), intention to return to work, need for work. Although work (such as work circumstances and work content) is an environmental factor, there are also personal factors related to work which will influence whether or not a person will participate in (paid) employment.

Some of the examples indicated above can be further subdivided, such as coping styles and life events. It is our opinion however that for really understanding functioning and disability of a person, a list of personal factors is

necessary. We therefore welcome and highly appreciate comments and additions from other experts / researchers using the ICF.

### **For information:**

Yvonne Heerkens, Dutch Institute of Allied Health Professions, e-mail: [heerkens@paramedisch.org](mailto:heerkens@paramedisch.org)

Dorine van Ravensberg, Dutch Institute of Allied Health Professions, e-mail: [vanravensberg@paramedisch.org](mailto:vanravensberg@paramedisch.org)

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