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WHO Family of International Classifications (FIC)

# NEWSLETTER

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## Contents

ICD Revision - Continued	1
Editorial	2
<b>International organisations</b>	
WHO-FIC Network Meeting Seoul 2009	3
International Organization for Standardization	3
International Classification of Health Interventions	4
APHA annual meeting 2009	4
European Public Health Conference 2009	5
Wonca International Classification Committee	6
<b>FIC around the World</b>	
ICF-CY in Switzerland	7
ICF Personal Factors	8
ICF Train the Trainers course	9
Further development of IMPACT	9
<b>ICF References</b>	10

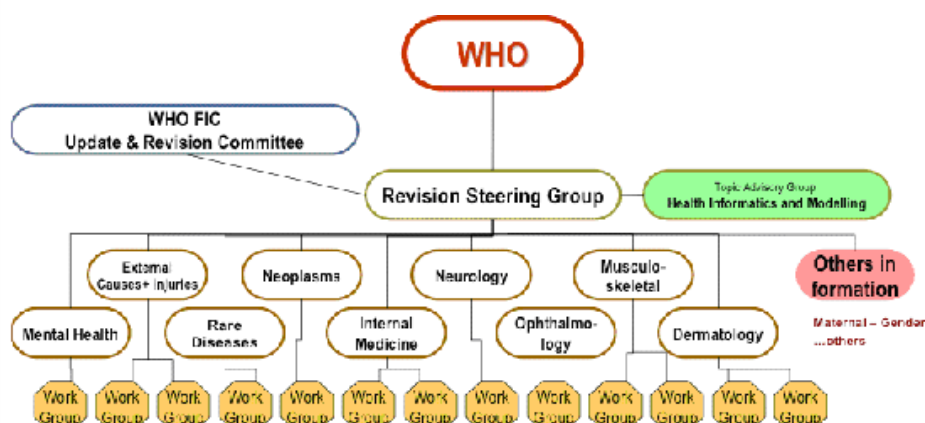
## ICD Revision - Continued

The 2009-1 Newsletter reported the presentation of a draft revision plan for the development of the ICD-11. As the work on the Alpha Draft progressed some more information on the content of the complex work will be given such as the specific goals for the 11th revision of ICD, the basic principles and the content model. The specific goals for the ICD-11 are to:

- formulate a multipurpose and coherent classification,
- serve statistical continuity,
- serve as an international and multilingual reference standard for scientific comparability and communication purposes,
- ensure that ICD-11 will seamlessly function in an electronic health records environment by linking ICD logically to underpinning terminologies, ontologies, and ICD categories defined by "logical operational rules" on their associations and details.

## Electronic use and maintenance

The basic principle is that ICD-11 will be maintained and primarily used electronically, but there will still be a print version, as shown in the goals to serve the various information needs and requirements. It builds on medical knowledge as captured and grouped in its previous versions, especially on ICD-10+. ICD-10+ can be seen as an agreed extension of ICD-10, including classes of local modifications, such as the ICD-10 CM, ICD-10 AM, ICD-10 AM, ICD-10 GM, etc. which they have in common. This means that in the view of WHO these local modifications will serve as input for ICD-11. Additional input will come from reviewers on the WHO-FIC Network, specific Workgroups and from the Topic Advisory Groups (TAGs). The Organization structure of the revision process is shown in the picture below.



## The ICD-11 Organization Structure

Updated versions and the most recent information can be found at: [www.who.int/classifications/icd/](http://www.who.int/classifications/icd/) **ICDRevision**. The content for the ICD-11 will be based on a content model for each class within the classification. This content model contains rubrics, descriptive characteristics and maintenance attributes.

## Examples of Rubrics

TITLE of ENTITY; that is the Name of disease, disorder, or syndrome...

1. Textual definition
2. Synonyms - Inclusion – Exclusion - Index terms

## Examples of Descriptive characteristics

Type (of phenomena), such as:  
Disease, disorder, syndrome, injury, sign/symptom, external cause, reason for encounter;  
Body System(s) (pathophysiology)  
Body Part(s) (anatomical site)  
Manifestation Attributes: Signs & Symptoms, Diagnostic Findings  
Etiology: Causal Mechanisms /Agents  
Genomic characteristics  
Temporal Properties, Severity and/or Extent, Functional Impact and Treatment

## Examples of Maintenance attributes

- A. Unique identifier
- B. Subset, adaptation, and special view flag (1. Primary Care 2. Clinical Care 3. Research 4. Special indices)
- C. Hierarchical relationships: parents and children in ICD structure
- D. Mapping relationships: linkages to other systems like SNOMED etc.
- E. Other rules

The content of textual definition and descriptive characteristics is most fundamental for the ICD-11 as it will state a more specific definition of what a disease is or preferably should be known about a disease. In fact the description will indicate the status of knowledge of a disease term and might in time lead to different layers of knowledge within the classification that are edited and reconciled in a continuous maintenance process.

As for the multi-purpose goal; part of the maintenance attributes is the Subset

attribute, which will be placeholders for specific purposes. Based on this principle of attribution is that from a sophisticated electronic version of ICD-11 (as a complex database in ClaML) several views or selections can be taken. This will be called a linearization. These linearizations can be presented as books, e.g. very similar to the known ICD-10 printed or electronic version and for reasons of statistical continuity, containing the familiar codes or conversion to codes. The content of ICD for special purposes will be based on real life Use Cases, which will serve as a blueprint for the usability and coverage. The specified usecases are Mortality, Morbidity, Casemix, Quality and Patient Safety, and Primary Care. We already mentioned the timeline for a first Beta –draft which is planned for 2011, after which Field trials will take place. The official publishing in the six WHO languages is expected for 2014. More detail on the revision process of ICD will follow in subsequent issues.

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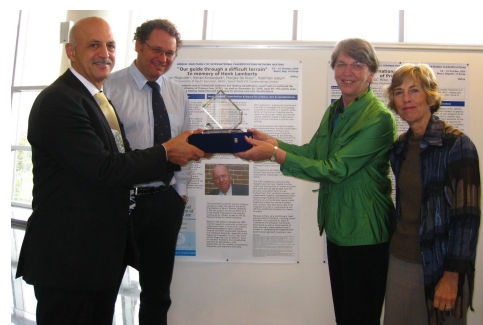
## Editorial

*We are happy to present Coen van Gool as a new member of the editorial board of our newsletter as the successor of Willem Hirs. Coen is now in the warming up stage with Willem as his coach. He is enthusiastic and eager to improve our newsletter. It is good to see new and young persons joining our WHO-FIC collaborating centre taking up (parts of) our tasks.*



Coen van Gool joined the WHO-FIC Collaborating Centre in the Netherlands

*As we mentioned before, Henk Lamberts (father of the ICPC) passed away December 2008 at the age of 68. WHO paid tribute to his life as a leading researcher and his legacy for primary care and classifications at the annual meeting in Korea October 2009. A poster was presented ([http://www.who.int/entity/classifications/network/WHOFIC2009\\_D001p\\_Ma gruderv2.pdf](http://www.who.int/entity/classifications/network/WHOFIC2009_D001p_Ma gruderv2.pdf), please see last page of this newsletter) and a poster session was held in his honour. A specially designed plaque traveled from WHO Geneva, through Korea to Inge Okkes (widow of Henk) in Amsterdam.*



WHO presented Inge Okkes with a plaque honouring the work of Henk Lamberts

*In our newsletter we try to pay attention to all members of the family of international classifications. This time we included developments concerning ICD-11 and ICHI (International Classification of Health Interventions, the third core classification within the family under development), applications of ICF (eligibility procedure in education and use of ICF based instrument IMPACT), contribution to elaborate ICF personal factors, ISO 9999 / ICF harmonization and a progress report on the work of the Wonca International Classification Committee (WICC).*



*Remarkably, there is growing interest for ICF in public health circles in America and Europe; we hope to see more developments here because we feel this is an area where ICF can make a difference!*

*In order to assist the readers to find their way through the papers presented at the WHO-FIC network annual meeting in Korea October 2009, a listing of numbers referring to ICD-10, ICD-11, ICF, ICF-CY, ICHI and ICPC (and primary care) papers and posters is included.*

## International Organizations

### World Health Organization

#### WHO-FIC Network Meeting

10-16 October 2009



The 2009 annual meeting of the WHO Network of Collaborating Centres for the Family of International Classifications (WHO-FIC) in Seoul, Republic of Korea, was hosted by the Korean WHO Collaborating Centre for the WHO-FIC based at the Korean Ministry of Health, Welfare and Family Affairs. Meeting venue was the International Convention Center of the Catholic University of Korea's at the Songsim Campus in Yeokgok Dong / Bucheon (Seoul metropolitan area).

#### Availability of all documents

All documents are published on the website of the 2009 Annual Meeting of the WHO-FIC Network, see <http://www.who.int/classifications/network/meeting2009/en/>. Please see this website for the meeting summary report to overview the results. At the meeting 32 papers and 50 posters were

presented. Out of the 82 presentations, 24 were on the ICD-10, 3 on the ICD-11, 21 on the ICF, 2 on the ICF-CY, 4 on the ICHI, 9 on the ICPC, 7 focused on more than one classification, and 12 were on WHO-FIC related issues.

Classification	Paper no.
ICD-10	2, 3, 5, 9, 10, 16, 17, 30, 31, 32
ICD-11	18
ICF	12, 14, 19
ICHI	20, 21, 22
More than one	4, 11, 26
WHO-FIC related	6, 7, 8, 13, 15, 23, 24, 25, 27, 28, 29, 33

Classification	Poster no.
ICD-10	21 through 26, 29, 30, 37, 38, 44, 47, 48, 50
ICD-11	34, 51
ICF	8, 10 through 19, 31, 33, 36, 40, 41, 45, 46
ICF-CY	32, 35
ICHI	42
ICPC	1 through 7, 27, 49
More than one	9, 28, 39, 43

## International Organization for Standardization (ISO)

### Harmonizing ISO 9999 and ICF

In 2009 the working document N19rev was adapted (including crosswalks ISO 9999 and ICF classes/codes). Also, the process of harmonizing ISO 9999 and ICF was taken a step further.

#### Adaptation of working document

Working document N19 rev (2006) contains a mapping of the divisions (third-level) or subclasses (two-level) of the International Classification of assistive products (ISO 9999) to ICF classes. The mapping was based on product related intended use of assistive products, which is an intrinsic characteristic of assistive products which indicates what the user of the assistive product can and may expect of the assistive product. It does not describe the user, but the product itself! The product related intended use of an assistive product to help blind people in their communication is

'communication' and not '(an impairment in) seeing functions'. The conversion is available as 'Working document' (N19rev) on the Dutch WHO Collaborating Centre website ([www.rivm.nl/who-fic/ISO-9999eng.htm](http://www.rivm.nl/who-fic/ISO-9999eng.htm); click on 'working document' on the right). In March 2010 an update of the document will be available on the website, in which the 2007 version of the ISO 9999 is included and small changes are added. As for the earlier version, we welcome comments on the revised document.

### Further harmonization of ISO 9999 and ICF

There are differences between the subdivision of assistive products in chapter 1 of the list of environmental factors of the ICF and the first level subdivision of the ISO 9999. Earlier proposals were formulated to harmonize the terminology of both classifications (Quebec and New Delhi). Due to uncertainty about the exact meaning of some terms in ICF (such as the term mobility, the terms training, learning and education, and use of the term disability versus disabilities) working group 11 of the ISO/TC173/SC2, entrusted with the administration of the ISO 9999, send a letter to WHO for clarification.

Unfortunately there was no possibility for a representative of FDRG7, (environmental factors), to join the meeting of WG11 in December 2009.

It was decided that the ISO/TC173/SC2/WG11 will formulate a proposal that will be discussed in the FDRG meeting in June 2010. Anticipating the discussion in June there is already a new class, class 31 Assistive products used in employment, included in the DIS version of the fifth edition of the ISO 9999 published in February 2010. This fifth edition will be published at the end of 2011. The results of the discussion in June, when they are 'minor', can be taken up in the 2011 version of ISO 9999; major changes will be included in the 2015 version.

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# International Classification of Health Interventions (ICHI)

## Developing the ICHI

The International Classification of Health Interventions (ICHI) has been included for many years as a reference classification ‘under development’ in the WHO Family of International Classifications (WHO-FIC). The International Classification of Procedures in Medicine (ICPM) was published by WHO in 1978. It was not updated. The rapid growth and evolution of procedures resulted in ICPM becoming outdated. Various countries have developed national classifications of health interventions. These have generally been focused on acute diagnostic, medical and surgical interventions. Some include a wider range, in particular allied health. Some of them have been built on the ICPM.

Limitation in scope is not just an academic question. If only a particular range of interventions is classified, and therefore reported, health policy and funding may be unduly focused on those interventions. Some national classifications have been used in other countries, notably ICD-9-CM Volume 3, although this will become obsolete in 2013. Since 2007, several WHO-FIC members have been developing ICHI. ICHI is designed to be a complete classification, but some countries are expected to seek to extend ICHI to suit their purposes.

## Structure of ICHI

In developing ICHI, an intervention is defined as “A service performed for or on behalf of a client(s) whose purpose is to improve health, to alter or diagnose the course of a health condition or functioning, or to promote wellness.” The classification describes what is done to what target, and how. ICHI will not describe who does the intervention, where it is done, or why. The structure of ICHI consists of three axes:

**-Target** contains the entities on which the action is carried out: anatomy, function, person or group

**-Action** is a deed which is done by an actor to a Target during a healthcare intervention: investigation, treating, managing, informing, assisting or preventing

**-Means** describes the processes and methods by which the action is carried out. These include approach, technique and method.

An ICHI Content Model has been developed, including these three characteristics and also allowing for others that apply to only some interventions. The method for description of Devices has been the subject of substantial debate. Most interventions do not involve a device, and devices change rapidly. Devices can be included in the title of an intervention and as a characteristic in the content model. It is planned that a limited set of terms to describe devices can be identified.

## Next Steps

Several parties are now testing the structure. ICPM content will be a base for these tests, but more modern interventions will be included. After testing, development of an ICHI alpha version can commence. ICHI should be as freely available as other WHO-FIC classifications. A funding plan is under discussion.

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## American Public Health Association (APHA)

### The APHA Disability Section and the ICF

The American Public Health Association (APHA) organizes every year a conference to unite the public health community, professionals and practitioners to exchange information on best practices, latest research and trends in public health. The meeting in 2009 took place in Philadelphia, Pennsylvania and consisted of more

than 1000 scientific sessions, roundtables, poster sessions, institutes and panel discussions; over 4000 scientific papers! The scientific sessions are sponsored by APHA Sections, Special Interest Groups (SPIGS), Forums, and Caucuses.

In 1988 the APHA Caucus on Disablement was established, a forum for experts to identify, discuss and exchange key disability issues and concerns. Over the years the Disability has grown into a Disability Section, an official and influential body of the APHA. The current mission statement of the Disability Section calls for broadening the knowledge base and awareness regarding disability and related phenomena among all public health professions, and to provide advice to APHA on public health policies and programs for prevention and services to enhance the quality of life of persons with disabilities, including increased public and professional awareness.

One of the goals of the co-founders of the APHA Caucus on Disablement was to promote uniform terminology, at that time the International Classification of Impairments Disabilities and Handicaps (ICIDH). At the first business meeting (1988) and the first sponsored scientific session (1989) several disability related models and concepts were presented including the ICIDH. A few years later, an ICIDH training session took place. In 2009 the Disability Section sponsored 20 posters, 17 scientific sessions, and the Disability Section Chair's Forum. Session topics included promoting health and wellness, access to (health) care, disability survey and analysis, mental health, social participation, fostering independence, and measurement issues. In some of the presentations the ICF was applied.

The Disability Section has achieved many goals: influencing APHA policies relevant to disability and securing the commitment of APHA planning committee to enhance accessibility at the annual meetings [<http://www.apha.org/meetings/access>] An Access Guide is in place; assistive

listening devices and American Sign Language Interpreters are provided as requested; computers at the meeting have screen magnification and screen reading software; and an accessibility inventory for annual meeting locations can be found on the APHA website. Yet, there is room for improvement. For instance, presenters using wheelchairs at the 2009 meeting often were hidden behind the computer screen while presenting their PowerPoint slides.

Although there is a growing use of the ICF terminology and applications of the ICF in scientific studies, more work needs to be done in raising the awareness of the ICF and its benefits among APHA members. The inconsistent use of disability clearly hinders the progress of the body of knowledge, and complicates the comparison of findings.

Building on the mission statement of the Disability Section and on observations from the 2009 APHA meeting, the following recommendations were presented to the current Disability Section Chair and Program Chair:

- in planning Disability Section meeting programs, map the proposed presentation titles with the ICF domains
- urge all presenters to report in the abstract of the paper/poster the concepts and related terms of disability used in the study
- recommend the presenters to include a slide at the beginning of the presentation with the definition of disability, and how this definition can be linked to the ICF. Even if a presenter uses another definition of disability it is beneficial to clarify who is included and excluded in the study, to compare and contrast findings with other studies, and to tease out the complex issues of impairments, activity limitations, participation restrictions and the role of environmental and personal factors. If inconsistent definitions are used, that will be an opportunity to further discuss the concept of the term disability

- invite the presenters to devote one slide at the end to “recommendations for future research or action” to stimulate progress in the field
- continue to remind the APHA conference planning committee to make accessibility a priority (see also Design for Accessibility, a Cultural Administrator’s Handbook <http://www.arts.gov/resources/Accessibility/pubs/index.html>, in particular Chapter 7)

Although there is progress promoting the ICF within APHA, the Disability Section can make unique contributions by educating and raising awareness of the ICF at the annual meetings and by urging scholars to apply, test, and foster uniform terminology to broaden the knowledge base and awareness regarding disability and related phenomena among all public health professions.

For more information about the Disability Section, please go to <http://www.apha.org> and click on Sections.

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## **European Public Health Association (EUPHA)**

### **ICF at the 2009 European Public Health Conference**

During the 2<sup>nd</sup> European Public Health Conference in Lodz, Poland, the EUPHA Section on Chronic Diseases held a workshop on health-related functioning in terms of the International Classification of Functioning, Disability, and Health. The workshop was chaired by Iveta Nagyova from PJ Safarik University / Kosice Institute for Society and Health, Kosice, Slovak Republic.

#### **Introduction to the workshop**

Compared to people without chronic diseases, those with chronic diseases report poorer self-rated health and

functioning and more disability. However, results from similar studies using diverse concepts of functioning and disability are often incomparable. To overcome such problems and to establish a common language for describing health and health-related states but also to permit comparisons of health data across populations, the World Health Organization (WHO) introduced the International Classification of Functioning, Disability, and Health (ICF). The workshop described recent and upcoming developments and public health study findings regarding ICF classifications, concepts, and components. The objectives of the workshop were 1) to inform on the latest developments in the ICF and give recent examples of its use, 2) to illustrate the prevalence and changes therein over time of ICF components in patient and general populations, and 3) to raise awareness about health disparities in terms of ethnic differences in ICF components. After an introductory presentation on recent ICF developments, three ICF related topics were presented. An audience discussion focusing on the use of the ICF in everyday practice concluded the workshop.

#### **Recent ICF developments**

Marijke de Kleijn-de Vrankrijker (WHO Collaborating Centre for the Family of International Classifications in the Netherlands) took care of the introductory presentation on recent ICF developments. Extensive use of the ICIDH in rehabilitation and allied health-related practices raised comments, which led to the start of the revision process. This resulted in the launch of the International Classification of Functioning, Disability and Health (ICF) in 2001 which is now in use worldwide in different settings, for different purposes, and is being applied at national and international level. Differences between ICIDH and ICF were highlighted. Furthermore, the ICF Children and Youth version (ICF-CY) was issued in 2007 as the first derived version of the ICF and is considered the first structural contribution to an



ICF updating process. The ICF-CY is designed to record the characteristics of the developing child and the influence of its surrounding environment. Finally, WHO's efforts to support the ICF were discussed.

### **ICF and Multiple Sclerosis**

Klaske Wynia (Departments of Health Sciences and Neurology, University Medical Center Groningen, University of Groningen, The Netherlands) presented the development and validation process of an assessment tool for people with Multiple Sclerosis, the Multiple Sclerosis Impact Profile (MSIP). Our objective was to describe the process of development and validation of this assessment tool for people with Multiple Sclerosis (MS). The MSIP proved a valid and reliable self-report measure with 36 ICF-items reflecting a broad scope of disabilities and the perception of these disabilities. In clinical practice the MSIP seems to have added value in the enhancement of the role and influence of people with MS during a consultation whilst nurse specialists reported that patients were better prepared and having clearer insight into patients' health problems. The MSIP can be applied in outcome and epidemiological studies. On individual level the MSIP can be applied in clinical practice to enhance the patient role, and as a basis for integrated care planning. The ICF turned out to be a useful classification as a basis for the development of a valid and reliable assessment tool.

### **ICF and Slovak coronary patients**

Iveta Nagyova (PJ Safarik University, Kosice Institute for Society and Health, Kosice, Slovak Republic) presented a study on the level of functioning in terms of the International Classification of Functioning, Disability and Health of non-Roma and Roma coronary patients. Ethnicity has been found to be a factor significantly influencing the subjective perception of the functional limitations level among patients with coronary heart disease, even after controlling for the effect of the socioeconomic status. However, with regard to objective

measure (EF), no ethnic differences were found. The perception of adverse functional status of Roma coronary patients may warrant additional care since this is expected to have adverse effects on quality of life of these patients as well.

### **Activity limitations in the Netherlands**

Coen van Gool (Centre for Public Health Forecasting, National Institute for Public Health and the Environment, Bilthoven, The Netherlands) presented a study on the time trend in the level of functioning in terms of the International Classification of Functioning, Disability and Health among the Dutch older population between 1990-2007 using a meta-analytic approach. Taking all activity limitations together there are no large changes over time. Looking at separate activities, the risk of limitations in climbing stairs based on ADL items is increasing approximately 4% per year and the risk of limitations in getting dressed based on ADL items is increasing approximately 5% per year, whereas trends in activity limitations based on SF-36 items were mainly stable. These results are relevant in the anticipation of care needs of the ageing population. Conflicting developments in underlying determinants of both activity limitations as well as chronic disease will be highlighted in regard of the results.

EUPHA Section on Chronic Diseases. Health-related functioning in terms of the International Classification of Functioning, Disability, and Health. Eur J Public Health 2009, 19 (1): 83-84.

For more information about the EUPHA Section on Chronic Diseases, please go to [http://www.eupha.org/site/section\\_cd.php](http://www.eupha.org/site/section_cd.php). In 2010, the 3<sup>rd</sup> European Public Health Conference will be held in Amsterdam November 10-13. For more information, refer to: [http://www.eupha.org/site/upcoming\\_conference.php](http://www.eupha.org/site/upcoming_conference.php)

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## **Wonca International Classification Committee**

### **Primary care classification and current work of the Wonca International Classification Committee (WICC)**

The International Classification of Primary Care (ICPC) was developed in the 1980s to fit a narrow use case: clinic-based primary care in a developed region, where practice denominators were known, medical records were paper-based, data exchange was limited to letters, following a Western European philosophy of care. ICPC captured in a simple format the essential data of primary care, from the reason for encounter to symptom-based or social problem diagnoses, in the framework of episodes of care.

In 2010 ICPC must be considered a successful classification for primary care. It is now used in over 20 countries, and is the mandated standard for primary care data in 6 countries. However, the primary care use case(s) are now more diverse and more demanding than when it started. Care occurs in many clinical settings, ranging from integrated health systems to community practices to public health in developing countries without infrastructure. There are multiple philosophies of care. In much of the world, electronic patient records are now in routine use and there is a need for interoperability between diverse electronic systems. Primary care classification and terminology must now accommodate additional domains such as clinical and genetic risk factors, multi-morbidity, patients' goals and preferences, and functional status, and link to highly specialized secondary care to enable data exchange and statistical analysis.

### **Need for a primary care information model to guide WICC**

We are in an era in which information technology promises to transform health care, but we do not know how to most effectively use that technology. We can collect immense amounts of

data, but we can not retrieve it or exchange it effectively. Over the past few years, WICC has worked to understand how to integrate the newest generation of classification tools and clinical terminologies in electronic patient records to improve primary health care.

In WICC, we have realized that we can not solve these complex classification requirements without first creating a basic “information model” that provides structure to primary care data. That model must capture meaningful data about people, the problems that affect their health now, the problems that they are at risk to develop, how time affects the care we deliver, and the social context in which that care takes place. We also need to be able to collect and report out data about the quality of care we provide for a growing list of medical conditions.

### Key components of a primary care information model

We are early in this work, but as we see it now, the key components of this model include (see Figure 1):

- Person(s). This component includes demographic, social, and geographic information, some currently captured by paper and electronic records.

<b>Person:</b>
demographics
social structure
goals, preferences
functional status
<b>Problem(s):</b>
RFE as starting point
current/active
severity
<b>Clinical Modifiers:</b>
prevention
risk factors
significant events
<b>Actions (“Process”):</b>
Decisions
Interventions
Plans
<b>Time:</b>
Episode structure
<b>Data import/export:</b>
Exchange protocols

Figure 1: Components of a primary care data model

- Active problems. This is in concept similar to the “problem list” in current practice; these are the health problems currently known to and addressed by the clinician.

- Clinical modifiers. This component includes previously experienced clinical events or risk factors that are important to the care process but are not active clinical problems.

- Actions (process data). This component includes data describing the decisions made in the course of care: laboratory or ancillary service use, referral decisions, procedures performed, pharmacy orders, exception or error reporting, and disposition (follow-up plans).

- Time. The use of the episode structure enables clinical data to be placed in the context of time.

- Data import/export (data exchange protocols). This component enables interoperability of clinical data: for example, the incorporation of important data obtained outside of the practice or structured export of data to assist consultants when referral is made.

The data to fill this model will need to come from multiple classifications and terminologies, some yet to be developed. For example, ICPC can provide the basic structure for the model as well as some of the classification content (RFE, some prevention and problem coding), while ICD and other WHO-FIC classification tools such as ICF or the proposed ICHI can provide other components, and the International Classification of Nursing Practice (ICNP) could supply classification tools for social structure and some interventions. However, there are several areas in which new classifications or terminologies are needed, especially risk factors and patient goals/preferences. SNOMED-CT could eventually provide a highly granular terminology base linked to several of the other classifications to foster data exchange. For this purpose SNOMED-CT content needs to be harmonized with WHO- and other classifications.

This work is still in its early stages, and we expect to refine our model in

the next few months. We look forward to working with WHO-FIC to develop and link these new classification tools.

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## FIC around the World

### Switzerland

#### Launch implementation of ICF-based eligibility procedure in education

Who is entitled to additional resources for their education and how can children be identified in a non-discriminative way? Today, there is a broad consensus that disability should be understood as the result of a complex interaction between a person and his or her environment and not as a characteristic of an individual. Consequentially, it could be presumed that eligibility should also take characteristics of the environment into account. In addition, it is a well established fact that diagnosis cannot predict treatment. Therefore one would expect a move away from one-dimensional, deficit-oriented labels when assessing and planning for learning and development. Some people have therefore suggested that disability categories should be abolished altogether, while others declare that using them causes a dilemma (Wedell 2005).

Switzerland is trying to move forward and overcome this dilemma by replacing fixed criteria with a procedure and by introducing the International Classification of Functioning, Disability and Health, Version for Children and Youth (ICF-CY) as a framework and classification rather than relying on one-dimensional categories. Education systems are not only required to create environments to ensure full participation, they are also mandated to reach goals as stated in the curricula or national standards. In

order to reach these goals, specific environments are created and if the goals set out for the general school population cannot be reached, they are adapted. The procedure is based on the premise that the need for additional resources or support depends not only on the functioning of the child or youth in question, but also on the current environment and the educational goals envisaged. If the child is already taught in a highly resourced environment, few additional resources may be needed. And undoubtedly, more resources will be invested if higher goals are set than if a child or youth is not expected to learn very much.

Switzerland's new eligibility procedure takes these considerations into account and uses different types of information from different sources to reach the decision as to what should be provided for an individual child in addition to the general provision for all children. Unlike traditional ways of establishing eligibility, the information which is then submitted to an independent body is not reduced to a category. Like Mirowsky and Ross (1989) we believe that this process "reduces the signal, but not the noise" or in other words: "diagnosis is a two-part process of gathering information and then ignoring most of it" (Mirowsky & Ross 1989, 17).

While it can be assumed that more information is generated by or available to the persons involved (specialists, school psychologists, teachers, parents), a standardized set of information has been included in the procedure:

- Categorical representation (ICD-10 codes where available or other problem descriptions)
- Functioning (body functions, activity and participation)
- Current environment (professional and family environment – barriers and facilitators)
- Previous experiences and risk factors (in professional and family environment, critical life events)
- Recommended educational and developmental goals
- Recommended professional

environment (e.g. regular school or special school)

- Estimate of requirements (e.g. counseling or environmental adaptations) and needs (e.g. assistance, speech therapy, specialist support); compiled into one quantitative indicator for an over-all level of need.

Additional information on personal factors (age, sex, etc.) and as to why the procedure was initiated is also included. The procedure generates a standardized set of information that is comparable across individuals and educational settings. Parents and students provide information that is included in the procedure and participate in the negotiation process. Therefore, if parents are perceived as part of the problem, this issue has to be broached. Professionals cannot hide behind cryptic wording that de facto dis-empowers parents.

The procedure is not just a bureaucratic act, but a transparent problem-solving process which is formally repeated at least every two years with a view to checking the efficacy and adequateness of the resources provided. A pilot data collection exercise in which over 140 professionals compiled around 450 cases showed that all information required by the procedure was generally available. The application of a common framework to report and share information was welcomed and hopes were expressed that it would boost the quality and comparability of data across settings. It is planned to develop an electronic tool that will facilitate the process of compiling and sharing information. Some of the information generated will be used in the national education statistics. This will enable Switzerland to not only understand the interaction between functioning, provided resources and educational programs, but also to monitor educational progress and the transition into higher education or employment.

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## The Netherlands

### Can psychological theory help to elaborate personal contextual factors within the International Classification of Functioning, Disability and Health (ICF)

Personal contextual factors in the ICF are characterized as 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 state (World Health Organization, 2001). Personal factors are not classified in the ICF but are critical in understanding the lives of individuals with disabilities (Schmitt, et al., 2009). The ICF gives little guidance on how to address these personal factors. Psychological theory may be helpful in providing guidance in our understanding of personal contextual factors in disability.

The conceptualization of disability as behavior enables the application of theories of behavior and behavior change to describe, explain and reduce disability (Johnston, 1996). Previously, the input of psychology was focused on the emotional sequelae of disability rather than disability per se. Within the disability as behavior paradigm psychological theory, focused on emotions and/or on cognitions, is used to explain disability. Social cognition models such as the Theory of Planned Behavior have been used to explain the factors that act to influence behavior such as activity limitations (Dixon, Johnston, Rowley, & Pollard, 2008). The belief systems defined within the social cognition models can be regarded as personal factors that motivate behaviors, including activity and activity limitations. The



motivational constructs in the Theory of Planned Behavior can act as process variables that mediate the relationship between body structure or body function and activity. A direct relationship between body function and activity was found and an indirect relationship via motivational beliefs (Schröder, et al., 2007). This integrated model explains more variability in disability than either the ICF or psychological theory alone (Dixon, et al., 2008). However, this evidence is more elaborated for cognitive theories than for emotional theory and more elaborated for activity limitations than for participation restrictions.

Since the ICF is premised on the assumptions of biopsychosocial theory and the constructs of activity and participation are defined in terms of behavior, using psychological theory to elaborate personal contextual factors is complementary to other well developed parts of the ICF without duplication. Psychological theory provides a stronger theoretical basis for the personal contextual factors and the process variables that link the constructs body function, activity and participation. Consequently integrating psychological theory opens up different possible interventions to reduce disability. This possibility is especially important for people with chronic conditions that are not amenable to change by biomedical interventions.

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### **ICF Train the Trainers course**

In April 2010 the third group of ICF Trainers received a certificate from the head and trainer of the Dutch Centre after a group presentation of their individual learning results. The Dutch Train the Trainers course has been developed based on adult education, which includes high levels of self direction, group interaction, and distant learning guided by professional tutors and ICF experts. The course is given over a period of about 16-18 weeks.



The 14 new trainers are all working at the Centre for Needs Assessment (CIZ) at Driebergen and Utrecht. They are working at several departments of the CIZ institute in the area of policy development for the institute, care needs assessment consultancy, or in education for co-workers. We congratulate them all!

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### **Further development and applications of 'IMPACT', an ICF-based instrument**

The International Classification of Functioning, Disability and Health (ICF) provides the most recent and comprehensive model of human functioning and disability. IMPACT (ICF Measure of Participation and ACTivities) was developed from 2002 (Perenboom et al., 2006) because of a lack of a measure that accurately reflects the ICF. The Participation and Activity parts of the ICF cover all areas of daily life. IMPACT is a generic self-report measure to describe functioning and disability independent of health condition, usable in large-scale epidemiological and outcome studies.

IMPACT was designed as a 2-level instrument. Level 1, the screener part, covers all ICF activity and participation chapters with a limited number of items and can also be used as an independent measure (IMPACT-S). The reliability and validity of IMPACT-S was tested and found sufficient (Post et al., 2008). Level 2 consists of a series of more specific items in 21 modules. These modules are linked to items in IMPACT-S.

#### **Current version of IMPACT**

Based on the study of Post et al. (2008), IMPACT was further developed resulting in the following characteristics:

- IMPACT-S has been slightly adapted into its current final form. Two items have been merged into one and IMPACT-S now consists of 32 (18 activity and 14 participation) items covering the 9 ICF activity and participation domains. Some examples have been re-formulated to match the related items in level 2 modules.
- IMPACT-S has been translated into English.
- Level 2 of IMPACT has been completely redesigned, and its items now match the lower-level ICF categories. Cognitive testing procedures were applied in 15 healthy people and 15 people with

- physical disability to reach a feasible level 2 questionnaire. The sensitivity and specificity of IMPACT-S as a screener for Level 2 were tested in 24 persons with a variety of disability and was found to be sufficient (Van der Heijden, 2008)
- IMPACT (level 1 and 2, Dutch version) is made available on the internet, hosted by TNO. Respondents are provided a login code to [tno.nl/Impactvragenlijst](http://tno.nl/Impactvragenlijst). First, the respondent answers all level 1 items. If any disability is reported the corresponding level 2 items are presented. They can complete the questionnaire in one or several sessions and they can subsequently print an IMPACT profile; a report (Pdf) of their answers to the IMPACT items.
  - The responsiveness of IMPACT-S for outcomes of rehabilitation is being tested in 500 rehabilitation outpatients from four Dutch rehabilitation centers.

### Adding impairments to IMPACT

As part of a government funded project, IMPACT is currently expanded with items related to body functions and structures. Cognitive testing procedures are applied.

### Current and future applications of IMPACT

- The internet version of IMPACT is currently applied as part of a diagnostic tool in a regional indication agency for persons with traumatic brain damage. About 250 clients will be asked to report on the items of IMPACT before they visit the agency for further diagnostics.
- In 2009, the Dutch Council of the Chronically ill and the Disabled (DCCD) funded a project for identifying characteristics of chronically ill persons who reported that they would not benefit from a law indicating those who could get a lump sum as compensation for extra costs of daily living due to their chronic illness. Chronically ill persons could go to a disclosures office where they could fill in a questionnaire including IMPACT-S. Results were reported by TNO and

presented by the DCCD to Dutch parliament in order to change inclusion criteria to get a lump sum.

- The Dutch Ministry of Welfare Health and Sports initiated a project to study the inclusion criteria for this law. In this study, TNO applies IMPACT-S including items on bodily functions and anatomical characteristics to evaluate the current inclusion criteria. At least 1200 respondents will be included in the study and the results will be reported in December 2010.

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# "Our guide through a difficult terrain" In memory of Henk Lamberts

10 – 16 October 2009  
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**Abstract** Henk Lamberts was an influential academic and leading classification expert who co-authored the International Classification of Primary Care (ICPC). He died on December 29, 2008, aged 68. This poster pays tribute to his life as a leading researcher and his legacy for primary care and classifications.

## Introduction

Henk Lamberts was born on 13 July 1940 in Rotterdam, a month after the invasion of the Netherlands. His father was a solo general practitioner and member of the Dutch resistance who subsequently became a Labour member of parliament.

Henk Lamberts himself became a regional councillor in Rijnmond in 1963, two years before his graduation from the Medical School of Rotterdam, and subsequently city councillor in Rotterdam. He went on to found the Ommoord Health Centre and group practice in Rotterdam, an important and innovative centre of primary care and family practice.

Here he created one of the first multi-disciplinary primary care teams in Europe. Henk Lamberts left Rotterdam for the University of Amsterdam in 1984, where he remained professor and chairman for more than 10 years. Then he became a full time research professor until his retirement in 2005.

His written legacy to the world of general practice includes three text-books and hundreds of articles. He received several prestigious prizes and awards for his innovations and research in family medicine: he was honorary member of the Dutch College of General Practitioners, member of the US Institute of Medicine, recipient of the Maurice Wood award of the North American Primary Care Research Group in 2005, and he was made honorary fellow of the World Organization of Family Doctors (WONCA) in 2007.

## Henk Lamberts contribution & legacy for primary care & classifications

His work in community oriented primary care, which he started in Ommoord and continued in Amsterdam, required the development of a new analysis tool, a statistically valid classification designed specifically for the clinical, behavioural, and social circumstances of family medicine and incorporating the nature of health-care management for health in the community.

As part of this development activities Henk Lamberts co-authored the:

- International Classification of Health Problems in Primary Care (ICHPPC) published in 1975,
- International Classification of Health Problems in Primary Care (ICHPPC-2) published in 1979,
- International Classification of Health Problems in Primary Care -2- defined. Inclusion criteria for the use of the rubrics of ICHPPC-2-defined, published in 1983
- International Classification of Primary Care (ICPC), published in 1987.



After publication, subsequent development was ICPC is translated into 22 languages, accepted by the WHO as a member of the family of international classifications for reason for encounter, widely used for the routine collection of data on episodes of care in several countries in primary care settings

Among the projects that Henk Lamberts was passionate about was the classification of mental disorders in primary care. Although the general area of mental disorders is dominated by psychiatrists, Henk Lamberts never shied away from his articulate and well-reasoned arguments that what was appropriate in psychiatry was not necessarily right in primary care.

With sensitivity to the kinds of patients seen in primary care, their presenting complaints, and unique primary care practice parameters, he eloquently described and compared three classification systems for mental disorders in primary care the International Classification of Diseases Primary Care Version (ICD-10-PC), the Diagnostic and Statistical Manual Primary Care Version (DSM-IV-PC), and the International Classification of Primary Care (ICPC).

The ICPC classification approach also helped to provide new insights into the onset and development of mental disorders that could only be appreciated from the primary care patient point of view. Furthermore, Prof. Lamberts' primary care classification insights complemented major epidemiologic findings that showed that primary care is the *de facto* mental health treatment system for mental disorders; thus, primary care physicians need to be integrally involved in understanding and refining classification systems for mental disorders.

Because primary care practitioners treat patients with all disorders, including mental disorders, it is important for them to understand the biological, mental and behavioural as well as social aspects of these disorders. Henk Lamberts was a pioneer in recognizing the integrated bio-psycho-social approach in primary care.

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Obituaries: Henk Lamberts - Influential academic who classified encounters in primary care, *BMJ* 2009;338:b1747

This work Henk Lamberts and his colleagues carried out under the aegis of the World Organization of Family Doctors (WONCA). It was the product of years of effort by a World Health Organization international working party, initially funded by the US National Center for Health Statistics.

Based on the patient's perspective, ICPC uses the reason for encounter as the main ordering principle. Coming from a Family Medicine perspective, Henk Lamberts ensured that ICPC emphasized symptoms and complaint diagnoses, especially at the beginning of episodes of care when more precise diagnoses may be difficult. Such an approach enabled a more longitudinal approach to classification, with appreciation for the interplay of symptoms, diagnoses, and treatment over time.

