



WHO Collaborating Centre  
for the FIC  
in The Netherlands

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**Published by**

WHO Collaborating Centre for the Family of International Classifications (FIC) in the Netherlands. Responsibility for the information given remains with the persons indicated. Material from the Newsletter may be reproduced provided due acknowledgement is given.

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ISSN: 1388-5138



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WHO Family of International Classifications (FIC)

NEWSLETTER

**Universal Health Coverage within the WHO-FIC Network: Information and Classification**

In the WHO-FIC Network meeting in Beijing – China October 2013, the central theme of the meeting was "Universal Health Coverage: Information and Innovation". The theme has been addressed in several presentations, such as at working group meetings and at the second plenary session during the congress-part of the meeting. Also a poster was dedicated to the subject.

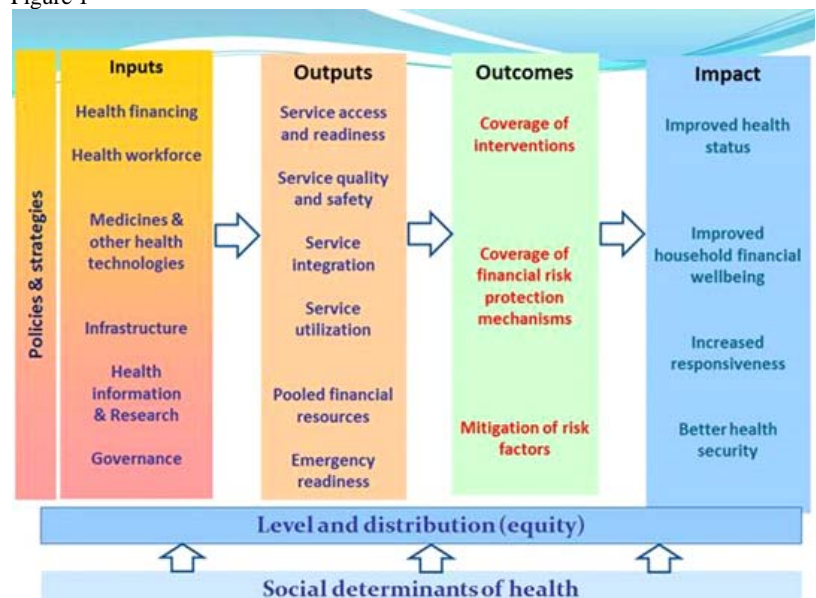
**Universal Health Coverage (UHC) explained**

For the Network, and particularly for the Family Development Committee (FDC) and the Education and Implementation Committee (EIC), it was a first consideration on how the WHO-FIC Network can ensure to assist WHO in measuring progress towards UHC. The first question that arose: what is Universal Health Coverage? Although Universal Health Coverage requires a more elaborated explanation (which can be found on WHO's website on the topic), in short and understandable form it is stated as: "Universal health coverage is to ensure that all people obtain the health services they need without suffering financial hardship when paying for them." This requires: a strong, efficient, well-run health system; a system for financing health services; access to essential medicines and technologies and a sufficient capacity of well-trained, motivated health workers.

**A schema for UHC**

There are six essentials to be named for the coverage of universal health; together they form the input blocks of UHC (figure 1). When it comes to measuring universal health coverage it is about identifying services and interventions or in fact aspects of all six essentials. (This article continues on page 2)

Figure 1



## Editorial

*Our June 2013 newsletter started with a front page article called "A new concept of health; and its relationship with ICF". We published this contribution for several reasons. First of all there is a lot of interest in the Netherlands and abroad for the work carried out by Machteld Huber. Furthermore, we saw a clear relationship with the ICF, which was not recognized enough in her BMJ publication. Finally we think we can use her findings regarding personal factors in the work of our centre in developing a draft list of personal factors in addition to the ICF.*

*During the annual WHO-FIC network meeting in China last October several colleagues mentioned critical remarks regarding the article. However we did not receive any written message; so we invite all readers to send us ([coen.van.gool@rivm.nl](mailto:coen.van.gool@rivm.nl)) their critical remarks as letter to the editor which we can include in the next newsletter. See newsletter 2013-1: [http://www.rivm.nl/who-fic/newsletter/WHO-FIC newsletter 2013-1.pdf](http://www.rivm.nl/who-fic/newsletter/WHO-FIC%20newsletter%202013-1.pdf).*

*The annual WHO-FIC network meeting October 2013 was organized around the central theme: **Universal Health Coverage (UHC)**. That is why we invited Huib ten Napel to prepare a short introductory article for this newsletter regarding UHC in general and Lars Berg to summarize his presentation about this theme related to Sweden. For other documents of the 2013 Beijing network meeting see <http://www.who.int/classifications/network/meeting2013/en/index.html>.*

*A lot of contributions in this newsletter relate to **several members** of the family of classifications, such as translation issues, Asia-Pacific network, eLearning tools (ICD and ICF), rare diseases (ICD, ICF and ICHI). A few contributions are dealing with **specific members**. See for example the article regarding updating of ICD-10, functioning properties in ICD-11, ICD in primary care in Thailand. Progress reports are included on ICHI, ISO 9999 and the Washington Group on Disability Statistics (ICF related).*

*This newsletter is the last one that I have prepared. At the age of 71 I decided to step back as centre head. I will be available as senior advisor to the WHO-FIC Collaborating Centre in the Netherlands for special tasks. Coen van Gool will take over my role. I thank all colleagues for their cooperation and friendship, and wish you all a happy new year.*

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## Universal Health Coverage within the WHO-FIC Network

*(continued from page 1)*

The WHO-FIC suite of classifications can play an important role in measuring the level of universal health coverage and assessing the frontiers. ICD, ICF and ICHI can possibly be used to capture the three dimensions (population, services and costs), but first it needs to be clear to what extent these classifications cover the different aspects of universal health coverage and how this can be done.

### Using the ICF in UHC

The framework within the ICF can serve as what defines a person's health in detail (= health status, including functioning, environment, personal factors and absence or presence of disease or health related problems) from a bio-psycho-social perspective. There also is a need to determine what will be useful in fulfilling the long term information needs required to support universal health coverage.

### Roles for FDC and EIC

The Family Development Committee (FDC) plans to start to assess how the WHO-FIC can be useful for UHC by considering the indicators/objectives of the UHC, and by considering indicators that are currently used by countries that could be relevant to UHC. The data and classifications used for the indicators can then be assessed against the WHO-FIC to determine what changes could be made. Collaborating Centres will be asked to assist the FDC and Education and Implementation Committee (EIC) in identifying and assessing relevant indicators in use in their countries. The recently developed WHO Implementation Database could serve as a central platform to gather the required information, once the relevant aspects have been addressed.

### From ideal to reality

Universal Health Coverage can be seen as an ideal, something to strive and set goals for. In reality there will be frontiers for each of the goals depending on the possibilities within each country's society. The goal then will be to push back the boundaries from a global perspective and as a global effort to attain accessible, available and affordable care for everyone on the planet.

More information on Universal Health Coverage can be found at: [http://www.who.int/universal\\_health\\_coverage/en/](http://www.who.int/universal_health_coverage/en/)

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Jenny Hargreaves, Co-Chair Family Development Committee,  
WHO-FIC Collaborating Centre in Australia.  
Jodee Njeru, Australian Institute for Health and Welfare.

## Latest News

The ICN eHealth team is keen to identify examples of good **nursing** practice to share among our global community. We received a request for creative and innovative uses of technology in community settings by nurses anywhere in the world to serve as models of good practice. Contact Nick Hardiker, ICN eHealth Programme Director, for more information ([a.r.hardiker@salford.ac.uk](mailto:a.r.hardiker@salford.ac.uk))

Now available at <http://www.who.int/classifications> is the **ICF Practical Manual!** In full: *How to use the ICF; a practical manual for use of the International Classification of Functioning, Disability and Health (ICF); Exposure draft for comment; October 2013; WHO, Geneva.* Comments are to be addressed to [robinsonm@who.int](mailto:robinsonm@who.int) by May 2014.

Enablement is a small agency dedicated to **Community Based Rehabilitation (CBR)**. Main developments within this field build upon the WHO CBR Guidelines and the International Classification of Functioning, Disability and Health (ICF). The ICF sets the direction for disability inclusive developments in the mainstream of society. Functioning of the body, the old medical paradigm, is no longer regarded an end in itself, but the ultimate goal participation of persons with disability in an inclusive and just society. Besides their contributions to research and systems development, core business is capacity building of staff in CBR, varying from fieldworker to government level agents. The 2014 training calendar can be found on <http://www.enablement.nl>. Their newsletter (also on their website) gives an update of new developments, such as a number of courses in the French language. For information: Evert Veldman, [e.veldman@enablement.nl](mailto:e.veldman@enablement.nl).

The Revision Steering Group and WHO Secretariat seriously consider amending the timeline of submitting the **ICD-11** for endorsement by the World Health Assembly to allow more time for field testing in multiple countries and settings, and following up on resulting edits. WHO currently discusses options and scenarios with stakeholders.

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## International Organizations

### Washington Group on Disability Statistics

#### Summary of the 13th Annual Meeting (Amman) and Objectives for the 14th (Buenos Aires)

The main objective of the Washington Group on Disability Statistics (WG) is the promotion and co-ordination of

international co-operation in health statistics focusing on disability measures suitable for censuses and national surveys. The WG has developed a short set of disability measures, suitable for use in censuses, sample-based national surveys, or other statistical formats, for the primary purpose of informing policy on equalization of opportunities. The WG is also developing extended sets of survey items to be used as components of population surveys or as supplements to specialty surveys. The World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) has been used as the basic framework for the development of the sets. All disability measures recommended by the group are accompanied by descriptions of their technical properties and guidance on implementation is provided. A complete overview of the WG including reports from past meetings as well as products and documentation is available at:

[http://www.cdc.gov/nchs/washington\\_group.htm](http://www.cdc.gov/nchs/washington_group.htm)

Below are key issues covered during the 13<sup>th</sup> meeting of the WG, 29-31 October 2013 in Amman, Jordan.

### Methodological Issues Concerning Surveys

The workgroup on the development of an extended set for measuring disability among children and youth (ES-C) presented the work accomplished in the previous year as part of its collaboration with the United Nations Children's Fund (UNICEF). Representatives from the children's workgroup, chaired by members from the Italian National Institute for Statistics (ISTAT), provided a review of the conceptual framework for question development and a proposed set of questions. Presentations were made on the results of the cognitive testing that was completed in Oman, Belize, India, Montenegro and the USA; and a revised Module on Child Functioning and Disability was presented based on these findings. The revised module will be cognitively tested in the USA prior to field testing which is expected to commence early next year (2014). Plans for field testing were discussed, as well as results from some ad hoc field testing that was conducted by Italy on a pre-final version of the module. Field testing was also carried out independently by a group connected with the London School of Hygiene and Tropical Medicine in Cameroon. These results were also discussed.

The representative from UNICEF presented work that has recently begun on measuring facilitators and barriers to school participation. UNICEF also presented its work plan for the development of guidelines and accompanying documentation for the modules developed in collaboration with the WG.

### Country reports

Individual country activities and initiatives were presented by representatives from Argentina, Oman, Italy, and the Pacific Islands Forum Secretariat. These covered results of the 2010 national population census, cognitive and field testing of the child disability module and issues of regional importance to disability measurement and rights.

## New initiatives

There was a presentation on whether and how issues related to mental health could be incorporated into the work of the WG. A proposal was made to create a workgroup to further address this issue and a call has been sent to WG members to identify individuals interested in leading or participating in this workgroup. Interest was expressed in having the WG look into the use of data registers in the compilation of disability statistics. A call will be made to see if there is interest in setting up a workgroup on this topic.

## Plans for the fourteenth meeting

The 14th meeting is scheduled to take place in Buenos Aires, Argentina; 8-10 October, 2014. Objectives for this 14th WG meeting:

- Present the final update of analyses of results of country data collection using the Washington Group Short Question Set (WG SS) and presentation of the published paper
- Review and approve guidelines for analyzing data obtained from the Washington Group Expanded Question Set on Functioning (WS ES-F)
- Present additional work on the Extended Set of Questions on Child Disability (WG ES-C):
  - Present results from analysis of field test data
  - Present the manual for implementation of WG ES-C
  - Adopt final question module
- Review progress in development of measures of facilitators and barriers to school participation for children
- Review progress in the development of extended sets of questions for the general population that address the measurement of environmental factors and participation
- Newly formed workgroups to present on progress of new WG initiatives (if any)
- Review recent activities in disability statistics

## For information:

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## International Organization for Standardization

### New Class Titles in Committee Draft of ISO 9999

ISO 9999, Assistive products for persons with disability - Classification and terminology, is an international standard that classifies assistive products according to their function. Because of the association between assistive products and disability (with co-occurring impairments), ISO 9999 is recognized by WHO as a related member of the WHO Family of International Classifications.

### New ISO 9999 revision completed in 2015

In October 2010, WHO's Family Development Committee recommended future collaboration between the technical

experts of the WHO Functioning and Disability Reference Group 'environmental factors' and ISO 9999 Working Group 12 (WG12) with the objective of harmonizing the two classifications in the content area of assistive products. ISO 9999 has undergone several revisions, and the most recent revision was published in July 2011. Preparation of the next revision of this standard began in October 2011, and the new version will be completed in 2015.

Figure 2

Class	Present ISO 9999 title	New title in the Committee Draft & description
4	Assistive products for personal medical treatment	<b>Assistive product for measuring, supporting, training or replacing body functions</b> Products that monitor or assess a person's medical condition, and products that support, or provide a substitute for, a specific body function
5	Assistive products for training in skills	<b>Assistive products for education and training skills</b> Products intended to provide instruction that improves a person's capacity and performance of physical, mental and social activities with the goal of enhancing the person's participation in all relevant domains (such as communication, self-care, mobility, housekeeping, work, education, and recreation); devices that have a function other than training, but that may also be used for training, should be included in the class covering its principal function
6	Orthoses and prostheses	<b>Assistive products attached to the body for supporting neuromusculoskeletal or movement related functions (orthoses) and replacing anatomical structures (prostheses)</b> <i>Orthoses</i> are externally applied devices used to modify the structural and functional characteristics of the neuromusculoskeletal system; <i>prostheses</i> are externally applied devices used to replace, wholly or in part, an absent or deficient body segment
9	Assistive products for personal care and protection	<b>Assistive products for self-care activities and participation in self-care</b> Products intended to support daily care of oneself, including washing and drying oneself, caring for one's body and body parts, dressing, and protecting one's body
12	Assistive products for personal mobility	<b>Assistive products for activities and participation relating to personal mobility and transportation</b> Products intended to support or replace a person's capacity to move indoors and outdoors, to transfer from one place to another, or to use personal or public transportation
15	Assistive products for housekeeping	<b>Assistive products for domestic activities and participation in domestic life</b> Products intended to support or replace a person's capacity to carry out domestic and everyday actions and tasks, including acquiring a place to live, food, clothing and other necessities, household cleaning and repairing, caring for personal and other household objects, and assisting others
18	Furnishings and adaptations to homes and other premises	<b>Furnishings, fixtures and other assistive products for supporting activities in the indoor and outdoor human-made environment</b> Furniture and other products that can be placed in, incorporated into, or otherwise added to, the built environment to facilitate movement and positioning, including entry and exit, within areas constructed for public and private use.
22	Assistive products for communication and information	<b>Assistive products for communication and information management</b> Products intended to support or replace a person's capacity to receive, send, produce and process information in different forms, including communicating by language, signs and symbols, receiving and producing messages, carrying on conversations, and using communication devices and techniques
24	Assistive products for handling objects and devices	<b>Assistive products for controlling, carrying, moving and handling objects and devices</b> Products intended to facilitate a person's performance of a task requiring the movement or manipulation of an object
27	Assistive products for environmental improvement and assessment	<b>Assistive products for controlling, adapting or measuring elements of the physical environment</b> Products intended to control or modify specific elements of the physical environment or to measure the conditions and components of the natural or physical environment
28	Assistive products for employment and vocational training	<b>Assistive products for work activities and participation in employment</b> Products intended to aid a person in engaging in all aspects of a job, trade, occupation or profession, including vocational training
30	Assistive products for recreation	<b>Assistive products for recreation and leisure</b> Products intended to facilitate a person's participation in any form of play, sports or hobbies or other forms of recreation and leisure

## Steps in harmonizing ISO 9999 and ICF

An important feature of the 2015 version will be that the titles of the classes are adapted using ICF terminology; see the table (based on poster C525 of the Beijing meeting, but with modifications after the meeting [figure 2]). In the 2011 version of ISO 9999 the definition of an assistive product was already changed to make it more in harmony with the ICF terminology. The renaming of the classes is a second step in harmonizing the terminology of ISO 9999 and the ICF. It is the hope that by this change we have made a next step in the harmonization of both classifications, which makes it easier, e.g. for persons with a functioning problem, to browse and find assistive products in national databases, which use the ISO 9999.

### For information:

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## World Health Organization

### Updating ICD-10

The International Conference for the Tenth Revision of the ICD held in Geneva from 26 September to 2 October 1989 recommended that “(...) WHO should endorse the concept of an updating process between revisions and give consideration as to how an effective updating mechanism could be put in place”. The three volumes of ICD-10 were then published between 1992 and 1994 and came into use in WHO Member States as from 1995.

### Update mechanism

Although the first updates to the classification were approved at the annual meeting of WHO Collaborating Centres for the Family of International Classifications in Tokyo, Japan in 1996, the current formal mechanisms to guide the updating process were not established until later. Two separate bodies were established to manage the updating process: the Mortality Reference Group (MRG) and the Update and Revision Committee (URC).

### MRG and URC

The concept for the MRG was developed in 1997, and it began making decisions regarding the application and interpretation of ICD for mortality in 1998. The MRG also makes recommendations on proposed ICD updates to the URC. The URC was established in 2000 and receives ICD-10 update proposals from the MRG and members through the WHO Collaborating Centres for the Family of International Classifications. The URC considers the proposals and submits recommendations on proposed updates to the Heads of Collaborating Centres who, in turn, make recommendations to WHO. Once ratified by WHO, the updates are posted on the WHO website:

<http://www.who.int/classifications/icd/icd10updates/en/index.html>

### Past, present and future

The update process continues during the creation of ICD-11. On average, 100 proposals are submitted annually. Updates are limited to the scope and code structure of ICD-10. There have been multiple categories and codes added over the years, but there have been some requested that could not be accommodated in ICD-10 due to limited code space. Update proposals that cannot be incorporated into ICD-10 are forwarded to WHO for consideration for ICD-11. Some examples of major updates that have successfully been added to ICD-10 include:

- New codes for lymphoma and leukemia
- New codes for drug-resistant micro-organisms
- Emergency updates for severe acute respiratory syndrome (SARS) and the avian flu
- New codes for atrial fibrillation and flutter
- Updated terminology for chronic kidney disease and sepsis
- Incorporation of staging in the codes for pressure ulcers
- New codes for hernias and hemorrhoids
- Specific codes for pancreatitis

### For information:

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Canadian Institute for Health Information  
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### ICF Update process

The ICF update process, which started in 2010, aims at enhancing the classification, based on lessons learned from its current implementation in different countries, and bringing together the ICF and the ICF-CY towards an ICF information model. The process is handled by the Functioning and Disability Reference Group (FDRG) together with the Update and Reference Committee (URC), the WHO and thanks to dedicated ICF experts. The review process is organized on an annual cycle (as shown in the workflow diagram on next page) so as to allow the members of the URC, representatives of each WHO-FIC collaborating centers, to reach a decision, through subsequent voting rounds and discussions, and propose ratification by the WHO-FIC Network Council in occasion of the annual meeting held every year in October.

### Update platform layers

Once a proposal has been entered correctly on the ICF Update Platform, it is reviewed by some members of the FDRG who constitute the Initial Review Group. If the proposal is considered ready to receive comments, all the FDRG members have one month to write a review comment on the Platform. Then follows the “Open Discussion layer” where any ICF expert interested in the process may contribute during one month and by mid-June of each year. Based on previous years’ experience, face-to-face group

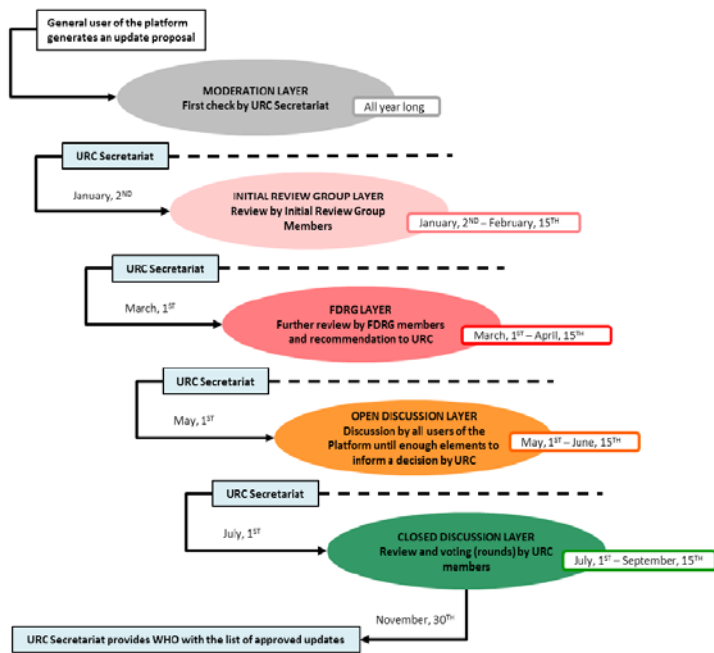


Figure 1. Stages of the review process

discussions are of great help to maximize the possibilities to gain consensus on each proposal. In 2013, three workshops have been organized by the Australian, French and German collaborating centers. In any case, all reviewers in every layer are asked to enter a precise written comment in English on the ICF Update Platform with a clear statement about what they think positive and negative aspects of one proposal are: the clearer, the better for the next reviewers and the FDRG moderator to really comprehend the comment. Each reviewer is also asked to write down a recommendation: either adoption of the initial proposal, adoption of the proposal with specified modifications or rejection of the initial proposal.

The first update proposals correspond to the modifications included in the Children and Youth version of the ICF (ICF-CY). The ongoing work aiming at elaborating an ontology for the ICF will definitely influence the nature and the content of the next update and revision proposals for this classification.

During 2012-2013, 65 proposals have been sent to the URC with such recommendations. In 2013-2014, still 104 proposals will require comments to gain consensus. Some wait for specific expertise in different areas: some mainly related to Body functions and Body structures, such as bones of cranium (#42), cognitive functions (#57, 58, 62, 63) or digestive functions (#25, 26, 31); others related to play (#39, 185, 212, 213, 176, 178) and education (#160, 210, 211, 217, 163, 165, 167, 175, 180). Other proposals simply require more comments, e.g. the proposal #225 based on the ontology work and questioning two ICF categories that look very similar: Writing (d170) and Writing messages (d345); e.g. a set of proposals related to sensory perception (#204, 230, 231, 232, 235). There are some critical areas of ICF which are at the moment addressed by different update proposals (eg. play). The

URC Co-chair, together with the IRG moderator and some other experts within the WHO-FIC Network, will study a modification of key proposals in order to cluster together existing related proposals under a single item to be processed and discussed in a more efficient way.

If you have ICF expertise and are interested in participating in the process writing review comments or new proposals, you are welcome to register on the Update Platform (<https://extranet.who.int/icfrevision/nr/loginICF.aspx>). The ICF Update Platform User Guide (version 2.0), available on the Platform will then give you more information about the organization of the review and update process.

### Implemented proposals

As an overview of the results of the ICF update process, since the beginning of the process, 69 update proposals have been implemented. The activity “Singing” and the body function “Onset of menstruation” are examples of such implemented proposals. In parallel, 46 update proposals have been rejected by the URC. The number of implemented proposals by year of implementation

2011	13
2012	24
2013	7
2014	25
Total	69

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### ICHI history – development, structure and content

The development of an International Classification of Health Interventions (ICHI) has been progressing since 2007. In the first three years the work has been focused on the classification structure based on a multiaxial system with three independent axes (see below). Since 2010, when the definition of the overall structure of the classification was achieved, the focus of the work lay on the population of a tabular list of interventions. This work has become increasingly important especially for those countries that will be in need of an interventions classification when ICD-9-CM Volume 3, the interventions classification adopted by many countries, is no longer maintained. The demand for international comparisons of health interventions is ever growing, as focus on efficiency, structure and quality of health systems increases.

### Earliest development

The development of the International Classification of Health Interventions (ICHI) started in 2007 discussing an appropriate classification structure and identifying several purposes for ICHI, including to:

- Provide a classification of appropriate scope and detail for use by countries without a national classification
- Provide a base which can be extended to develop more finely grained national or specialty classifications.
- Establish a framework for comparisons of the performance of health interventions in different countries.
- Provide a building block for international casemix development.
- Avoid duplication of effort at national level.

Work on the development of ICHI has been an international process, with members of many WHO-FIC Collaborating Centres contributing.

### ICHI Axes

ICHI has been built around three axes: Target, Action and Means, defined as follows:

- Target: the entity on which the Action is carried out
- Action: a deed done by an actor to a Target during a health intervention
- Means: the processes and methods by which the Action is carried out.

The ICHI framework and structure were finalized in 2010. Content development has been ongoing since then. An alpha draft was released in October 2012, an alpha-2 version in October 2013.

Table 1

Year	Place	Milestone
2011	Sydney	First Version of a tabular list
2011	Cape Town	Two Model chapters as ICHI DRAFT
2012	Freiburg	Reduction: only codes without enumeration to support use as international reference classification
2012	Beijing	Comparison with other Interventions classifications Focus on Completeness
2012	Brasilia	ICHI Alpha 1 in three sections
2013	Paris	Functioning Interventions group: concept for functioning interventions
2013		Review of chapters of Medical/Surgical by original proponent
2013	Uddevalla	Editorial and Coding Rules, Extension codes as for ICD-11, mapping ICHI ICD-9CM Vol. 3
2013	Gland	Review Section I Medical and Surgical: quality checks: titles, annotations and other instructional notes, spelling, assigning ICHI codes to excluded interventions
2013	Beijing	ICHI Alpha 2

The first task besides the development of a framework for ICHI was the definition of a 'health intervention': A health intervention is an activity performed for, with or on behalf of a person or a population whose purpose is to improve, assess or modify health, functioning or health conditions. As already mentioned ICHI has been built around three axes -Target, Action and Means - and the coding scheme comprises a seven-character structure for these three axes. The ICHI framework was finalized in 2010, following a trial that involved pilot content development using a range of interventions from existing classifications. With the structural development in place, attention turned to the development of content for an initial (alpha) version of ICHI. Work continues to progress on ICHI content and encompasses interventions across all functional sectors of the health system, covering primary care, acute care, rehabilitation, functioning, traditional medicine, public health and ancillary services.

Table 2

	Section	Number of classes
I	Medical and surgical Interventions	> 3500
II	Functioning Interventions	> 1.500
III	Public Health Interventions	> 190

### Medical/Surgical Interventions

In 2011, a workshop involving 14 participants drawn from five WHO regions was held in Sydney, Australia, where all interventions in ICD-9-CM Volume 3 were converted to the ICHI structure, and adapted as necessary. Priority was given to diagnostic, medical and surgical interventions. During the Sydney workshop there was general agreement that the level of granularity of ICD-9-CM Volume 3 was largely appropriate for ICHI. This decision limits the detail that can be included in ICHI, but increases the capacity for ICHI to be a successful framework for comparisons across countries. The next step, undertaken by the Chinese Collaborating Centre and reviewed by the Australian and German centres, involved reviewing approximately 4000 concepts and making recommendations regarding content detail. This review involved comparing the draft content with a range of national classifications. Care was taken to ensure consistency across the classification and maintaining a uniform level of granularity.

*Examples of Medical/Surgical Interventions include:*

AHG GD AA Partial excision of parotid gland

AHG GE AA Total excision of parotid gland

### Functioning Interventions

Development of functioning interventions for ICHI also began during the Sydney workshop. To develop the alpha version, substantial content development was undertaken by WHO-FIC network experts, covering allied health interventions and functioning assistance; relevant content in national classifications was reviewed as part of this process. A range of mental health interventions and assistance with support interventions were also added. During 2013, further development of the content and its coverage is being undertaken, along with refinement to the ICHI axes and interventions being made.

*Examples of Functioning interventions include:*

FAK SY BK Personal assistance with memory

FGB AA AH Manual assessment of respiratory muscle function

### Public Health Interventions

Public health content for ICHI was developed during 2011-2013. The ICHI axes include health behaviours and environmental targets necessary to describe public health interventions, as well as relevant Actions and Means. An initial list of public health interventions was generated by systematically examining combinations of Target, Action and Means categories. Further expansion and refinement of the public health interventions to produce a more complete and conceptually consistent classification is ongoing.

*Examples of Public Health interventions include:*

MAQ PA PH Education concerning the health effects of tobacco use, delivered through the media

KBK XA PB Surveillance and enforcement of air quality standards

Work is continuing on finalizing the editorial and coding rules which will assist in the further development and use of ICHI.

## Conclusions

In only a few years (2010 – 2013) the ICHI coding framework has been populated with the growing content already covering primary care, acute care, rehabilitation, functioning, prevention and ancillary services. A group of experts from a broad range of WHO Collaborating Centers and Universities provided classification skills, IT and medical knowledge during workshops, phone conferences, and as “homework”. By Beijing 2013 all ICHI content will have been the result of 2 development phases. The content has been built on a sound structure, and has had regard to various national classifications. Granularity is determined by the need for ICHI to serve the dual roles of a stand-alone classification and a framework for international comparisons.

Those interested in assisting in ICHI development are most welcome, contact Albrecht Zaiss<sup>1</sup>, Susanne Hanser<sup>1</sup>, Megan Cumerlato<sup>2</sup>, Linda Best<sup>2</sup>, Andrea Martinuzzi<sup>3</sup>, Nicola Fortune<sup>1</sup>, Richard Madden<sup>2</sup>

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## Functioning Topic Advisory Group (fTAG): the role of the ICF in the process of creating ICD-11, update on activities

The functioning Topic Advisory Group (fTAG) was formed by WHO in 2010 and consists of 10 members, including two Co-Chairs and a Managing Editor. The fTAG is currently focused on four major activities related to ICD-11:

- 1) populating functioning properties in ICD-11;
- 2) identifying ICD-ICF mirror codes;
- 3) developing use cases for ICD-ICF joint use;
- 4) and evaluating the ICD Z-codes.

## Functioning properties

The fTAG’s goal for the first task has been to identify the ICF Activities and Participation (A&P) items, known as functioning properties, related to at least one major entity for each ICD-11 chapter. These functioning properties are intended to complement the standard set that was identified

for use with all disease entities. At present, the functioning properties of 34 ICD-11 disease entities have been identified. Since the WHO-FIC Network Meeting in Brasilia, the fTAG has also become engaged in populating the functioning properties for approximately 100 rehabilitation-related health conditions. The process for accomplishing both tasks was to employ existing ICF Core Sets that have been developed through a standard, rigorous scientific methodology. For ICD-11 chapters where no ICF Core Set existed, the fTAG developed guidelines for a ‘mini-review of the literature’ to populate the remaining functioning properties. Since the Brasilia meeting, 6 rehabilitation-related entities, which were either not a clear health condition — e.g., violence or war or an intervention, i.e., joint arthroplasty — have been deleted from the list. In addition, online tutorials have been conducted to assure that the guidelines are consistently followed. To date, rehabilitation professionals world-wide have been identified who have agreed to populate the functioning properties for 33 of the 83 health conditions. The fTAG continues to seek expert participation for populating the remaining 50 rehabilitation-related health conditions.

## ICD – ICF Mirror codes

In May of 2013, the WHO formalized the mirror coding approach and operationalization for ICD-ICF joint use. This second task for the fTAG work on mirror coding was based on the historical tradition that ICD-10 used certain disability concepts as a common disease or disorder entities, such as for social benefits and rehabilitation. Five ICD-10 disease entities were specified: blindness (H54); deafness (H90); mental retardation (F70-79); learning disability (F84); and paraplegia (G82). These ICD-10 disease entities are also ICF items. In order to facilitate their continued joint use, it was necessary to review whether or not the ICF items continue to be aligned with ICD-11. The first step was to conduct separate, individual reviews in the Republic of South Korea and the United States. The first challenge was to identify the relevant disease entities in ICD-11—some were the same as in ICD-10 and others were revised and located in new chapters, or had been retired. After the semi-structured initial reviews were complete, teleconferences between reviewers were hosted by the Managing Editor and WHO to review the independent determinations and attempt—but not force—consensus. The second challenge was that data entry into the WHO’s Beta version of Morbidity Linearization was continually being updated. After review by fTAG members and relevant TAGs, the recommendations for alignment will be submitted to WHO.

## ICD – ICF Joint use

The third task is the development of a document of use cases for ICD-ICF joint use. There is increasing interest in the use of ICF functioning in health-related reimbursement, disability evaluation and healthcare program eligibility worldwide. The document has evolved through much iteration and is intended to stimulate additional support for



ICD-11 by exemplifying complementary use of ICD and ICF. The document will be submitted to WHO by end 2013.

### ICD-Z codes

The fourth major task of the fTAG is to review ICD-10 Chapter XXI, known as the Z-codes, with a mandate for reviewing the alignment of the Z-code entities with the ICF contextual factors or ICHI categories under development, and making suggestions for a new structure. The Z-codes are used to record health-related circumstances that are not disease entities; these codes contain a mix of concepts, including reasons for encounter, risk factors and interventions. The methodology for this task included scientific literature reviews and reviews of Beta browser comments. Results of the review of 801 ICD-10 chapter XXI categories identified 158 categories related to ICF contextual factors, some of which endorsed the development of the Personal Factors component. Nearly half of the Z-codes (367 or 46%) represented intervention. Another 105 categories pose possibility of being redundant with other ICD-11 codes. The final 171 codes remain under debate. Like the mirror coding of ICD-11 and ICF items, there remains the potential for future mirror coding of the Z-codes with the ICF Contextual factors and with ICHI, once it is fully developed.

The work of the fTAG is multi-faceted and evolves simultaneously with the development of ICD-11. To accomplish its goals, the fTAG highly values and needs the involvement of experts in the WHO-FIC, other ICD-11 Topic Advisory Groups, WHO-FIC Collaborating Centres and the WHO-FIC Academic Centres.

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### News about eLearning tools for users of WHO-FIC classifications

The World Health Organization is the publisher of two flagship classifications, the International Classification of Diseases (ICD) and the International Classification of Functioning, Disability and Health (ICF). With an increasing spotlight on the need for standardised health and disability information to manage initiatives - such as the call for [universal health coverage](#), the [Global Investment Framework for Women's and Children's Health](#), the development of the [Global Health Observatory](#), the [UN convention on the rights of persons with disabilities](#) and the [WHO Disability Action Plan](#) - the use of these classifications to capture the core elements of health information is necessary.

#### Accessible education and training in ICD and ICF

In order to make education and training in ICD-10 and ICF more accessible internationally, the WHO, with experts from various WHO-FIC Collaborating Centres and other

specialty groups, has developed two web-based training tools. The ICD-10 training tool is available for use on line at <http://apps.who.int/classifications/apps/icd/icd10training>. This training tool may also be downloaded from the WHO Classifications Download site for off-line, stand-alone use at <http://apps.who.int/classifications/apps/icd/ClassificationDownloadNR/login.aspx>.

#### ICD-10 training tool

The ICD-10 training tool has been designed for self-learning and also for classroom use. The modular structure of the ICD-10 training permits specific tailoring of the material for different user groups. Different training pathways are recommended, depending on whether the student will use the ICD-10 to assign codes for morbidity or mortality reporting, or is a manager who needs an overview of the classification, or is a doctor who is responsible for the completion of death certificates. Detailed information about pathway selection is given in the introduction of the tool, and in the user guide. The training tool also provides a link to an on line training tool support group so that questions can be raised about the materials with a group of experts. This support group is managed by the WHO-FIC Education and Implementation Committee (EIC). Materials covered in the ICD-10 training tool include an introduction to the classification, how to use the three ICD volumes to locate codes for diagnoses and causes of death, chapter by chapter information with a series of exercises of varying difficulty, morbidity and mortality reporting, confidentiality and ethics, data quality and statistical presentation.

#### ICF eLearning tool

The ICF eLearning tool is currently being finalized and will also be available on the WHO classifications website in the near future. Also designed for self-learning, this tool includes an introductory module which covers the aims and uses of the ICF, the ICF bio-psycho-social model that underpins the classification, the structure of the classification, how to code with the ICF and the use of qualifiers and other components of the ICF. Real world examples are included, as are a variety of exercises to facilitate learning.



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# ***FIC around the World***

## **Asia Pacific Network**

### **7th Meeting of the WHO-FIC Asia-Pacific Network in Bangkok, Thailand**

The WHO-FIC Asia-Pacific Network (APN) held its 6th meeting in Bangkok, Thailand, on July 18 and 19, 2013. The APN, a regional network of the wider WHO-FIC Network, was launched in 2006 to promote regional cooperation in the implementation of the WHO Family of International Classifications (WHO-FIC) and improve health information management in the region. This year's meeting in Bangkok was the first APN meeting in three years after the last meeting in Tokyo in 2010. Bangkok also became the first city to host an APN meeting in a country outside Japan that was not held in conjunction with the annual WHO-FIC Network Meeting.

The meeting had the attendance of 37 people from India, Indonesia, Korea, Thailand, Japan, Hong Kong, Malaysia, Myanmar, Laos, and the Regional Office for South-East Asia (SEARO) of World Health Organization (WHO). Dr. Bedirhan Üstün of the WHO Geneva also participated via video conference facility. Dr. Thet Thet Mu of Myanmar's Ministry of Health became the first representative from that country to take part in an APN meeting.

This year's meeting marked the designation of Thailand as the Collaborating Centre for the WHO-FIC, in the presence of senior officials from Thailand's Ministry of Public Health, including Dr. Sapon Mekthong, Deputy Permanent Secretary, and Dr. Suwat Kittidilokkul, Director of the Bureau of Policy and Strategy. Dr. Wansa Paoin, the Head of the Collaborating Centre, outlined the centre's future activities at the meeting.

The meeting also saw Dr. Hiroyoshi Endo, the new Co-Chair of the APN, preside over an APN meeting for the first time. Dr. Endo was appointed Co-Chair following the annual WHO-FIC Network Meeting in Brasilia in 2012, succeeding Dr. Kenji Shuto of Japan to serve alongside Professor Sukil Kim of Korea as Co-Chair. Currently a professor at Tokyo Women's Medical University, he served in Japan's Ministry of Health, Labour and Welfare and has experience working in the WHO Western Pacific Regional Office and the WHO headquarters in Geneva.

#### **Meeting highlights**

The Asia-Pacific Network entered the second phase of development as a regional network after the first phase that focused on the creation and establishment of a network. The meeting covered such topics as ICD/ICF implementation, health information systems in the respective countries, development of health interventions and traditional medicine classifications, the DRG case mix system, the international coding exam, and education and training of

coders. In particular, the meeting highlighted ongoing intra-regional support, both bilateral and multilateral, in providing education and training to physicians and coders in developing countries. This included the efforts of Thailand and India to educate and train physicians and coders from Laos and Myanmar, Japan's effort to assist health information managers in India and Indonesia, and joint effort of SEARO and Australia to organize 3-month training for medical record technicians in Myanmar. South Korea held a week-long education workshop in Mongolia in cooperation with WPRO. With South Korea providing expertise, the Mongolian government the funding, and WPRO managing the project, this kind of three-way contribution could serve as a model for international cooperation. Moreover, the Indian Collaborating Centre offered to make its training centers available for countries in the region.



Challenges faced by developing countries included lack of resources, infrastructure, trainers, and staffing. Prior to the meeting, the APN secretariat had distributed to the participating countries questionnaires for the WHO-FIC Implementation Database, which is being developed by WHO in cooperation with the Collaborating Centre for the WHO-FIC in the Netherlands. The analysis of the responses underscored the above point. Improving verbal autopsy was another issue, as a large proportion of deaths occurred outside medical facilities. A SEARO study also identified poor quality of cause of death data in the Southeast Asia region, one reason for which was a relatively small percentage of causes of deaths that were medically certified among registered deaths.

Dr. Üstün of WHO provided an update on the ICD revision via video conferencing and discussed with APN members about the network's participation in the revision process, including review of the draft version, translation, and field trials.

#### **Future steps**

The network discussed and agreed on three sets of tangible actions for a strategic work plan covering the next two years, as follows:

- Develop a common education module for the Asia-Pacific modeled on the Core Curriculum of the WHO-FIC Network's Education and Implementation Committee (EIC);

- Make a list of available ICD training resources in the region, including regular training programs, train-the-trainer programs, and advanced courses; and
  - Create an Asia-Pacific version of ICD-10 shortlist.
- Members agreed that an ICD-10 shortlist would be particularly useful for developing countries. As a first step, the Co-Chairs and Thailand will meet to compare and analyze ICD-10-TM for PCU, an existing Thai shortlist, and Japan's draft shortlist by the end of the year.

In terms of the network's organization, a decision was made to abolish the Health Information System Working Group and rename the Mortality Working Group and the Morbidity Working Group as Mortality Use Committee and Morbidity Use Committee, respectively. Malaysia agreed to host the 7th WHO-FIC Asia-Pacific Network Meeting in 2014.

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## South Africa

### The importance of accurate translation

The essence of having a Family of International Classifications is that somehow the classifications and codes should mean the same to all people who use them, regardless of language, culture or education. In a world in which the dominant language is English, it is easy to forget how difficult it is to ensure equivalence of translated versions of the classifications. Based on the experience of translating the ICF Checklist and other related instruments into isi-Xhosa (South Africa), Shona (Zimbabwe) and Kinyawanda (Rwanda), we conclude that it is possible to ensure that translations are appropriate and culturally sound for use by those who speak African languages. However, it requires a demanding and rigorous process of forward and backward translation, punctuated by consensus meetings to not only identify the linguistic correct version, but also the most culturally appropriated phrasing.

### Cross-cultural conceptualization

English is rich, simple and a very explicit language, which allows both generalization and at the same time, specification and precision. Difficulties with conceptualization of health concepts cross-culturally, semantic equivalence (the transfer of meaning across languages) and specific idiomatic expressions were encountered. In some cases no equivalent word could be found in the target language. Finding an appropriate word for disability which was not demeaning was difficult in isi-Xhosa. The group decided to 'borrow' a Nguni word from isi-Zulu, which is a neutral term for disability which was not insulting. In this way translation can lead to a change in language use and possibly ways of thinking about issues

related to disability. In other cases, one English construct could be translated into two separate phrases. There are two isiXhosa words meaning to lift and carry objects, one referring to picking up a child or person and the other to lifting objects and the translators had to choose one over the other. It was difficult to discriminate between disability and impairment and in the isi-Xhosa version the same word was used for both. In Kinyarwanda the phrase 'problems of the body' was finally agreed upon by team consensus.

### Inappropriate

Some words were judged to be insulting and inappropriate. In Kinyarwanda it would be embarrassing to ask someone if they were cohabitating and ultimately it was translated by 'living with someone for a short time'. The choice of word for urination was difficult in isi-Xhosa. Certain words are used as euphemisms in order to show respect in specific contexts. Different colloquial words are used for males and females. Finally a more direct but less "polite" word was chosen as everyone would understand this.

Another problem was that examples may not be appropriate for the context. The WHODASII item Staying by yourself a few days was uncorrelated with other self-care items when used in a large scale survey in Rwanda, most likely due to the situation being very uncommon within the context of large extended families. Quantification of impact posed problems in all three languages and it was difficult to identify words that would distinguish between mild and moderate.

The translation process is time-consuming but if the ICF is to be used across cultures and languages, it is an essential part of the process of standardizing the conceptualization of functioning and disability. It is well worth doing properly.

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## Sweden

### Universal Health Coverage – some Swedish aspects

The WHO goal of Universal Health Coverage (UHC) is to ensure that all people obtain the health services they need, without suffering financial hardship when paying for them ([http://www.who.int/universal\\_health\\_coverage/en/](http://www.who.int/universal_health_coverage/en/)). The health system has to be well-run with access and sufficient well-trained health workers. One of the UHC essentials is the information provided in the Global Health Observatory (GHO). This is a common gateway to the wealth of WHO data and statistics.

## Global Health Observatory

The GHO gives an excellent opportunity to compare health statistics for regions and countries. An easy way is to start with a look at the own country profile. These profiles are available in pdf format, condensed in two A4 pages. In the Swedish profile (<http://www.who.int/gho/countries/swe.pdf>) Sweden is compared with the WHO European Region. For some indicators global averages are also available. For further study, the GHO site gives almost too many possibilities to make comparisons!

Overall there are very positive results for the presented indicators for Sweden, compared with the rest of Europe. Some examples: Life expectancy is high for both sexes. Child and maternity mortality rates are very low, and so are Tuberculosis and HIV prevalence's. The number of physicians per population is higher than the average in Europe.

However, some data were not available for Sweden. For example information on tobacco use for ages 15+ is not available, while the European region can report these data. But, are these statistics and results enough to fulfill all UHC goals? To study that, we have to use additional sources of information. Some examples:

1) The drinking water is in the Swedish health profile said to be 100 percent improved. But this statistics is only true for and related to the inhabitants that have access to municipality provided water. About 15 percent of the inhabitants in Sweden use their own private wells. A study in 2007 showed that about 20 percent of that water was unfit for drinking, and another 60 percent fit, but with remarks. Despite recent changes the regulations will continue to be unclear with two Authorities responsible.

2) The Swedish awareness of UHC seems to be low. For example no hits at all on the Web site of the Swedish National Board of Health and Welfare. The National Institute for Health and Welfare in Finland have 38 hits on their Finnish site, and 27 hits on their English and Swedish pages.

3) Medication for the elderly have recently showed a use of too much drugs and many interaction problems.

4) A current discussion is the influence of New Public Management (NPM) in Health Care, mandatory time-consuming coding and reimbursement systems leading to unnecessary care, wrong focus and less availability for the chronic patients. These discussions originated with four articles in the Swedish Newspaper Dagens Nyheter ("Daily News") by the author and journalist Maziej Zaremba and a following book Patientens pris ("Price for the Patient"). These discussions are now followed up with four sessions at the Annual General Meeting of the Swedish Society of Medicine in December 2013.

5) Use of Adjusted Clinical Group (ACG) for reimbursement in Primary Health Care has distorted correct coding of diagnoses and is therefore lively debated at present.

6) Despite 30 years of national "priority" there are still a significant lack of family physicians and psychiatrists. An investigation in 2013 showed that 4800 fully employed family physicians were working, but to achieve the national goal 1400 more were needed. Quite many doctors and also nurses now work for employment agencies. They are hired by the county councils (responsible for health care) and work in short term periods, which is much more expensive and result in less or no continuity of care.

7) There is a constant lack of hospital nurses and midwives (especially during summer vacation, worse every year). The nurses work in Norway (better paid, better working conditions) or leave health care work.

Conclusion: there is still a long way to go to fully achieve Universal Health Coverage in Sweden.

This newsletter contribution was based on a presentation in the Family Development Committee session October 13, during the WHO FIC Annual Network Meeting in Beijing 12-18 October 2013, and can be read in conjunction with the front page article.

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## Thailand

### ICD for Primary Care Unit in Thailand

ICD-10-TM for PCU is a new version of the International Classification of Diseases and Related Health Problems, 10th revision, Thai Modification which was implemented for use in all primary care units in Thailand since 2009. Its second version was published in the year 2012. The PCU version is a simplified version of ICD-10-TM which enables nurses and public health staff to do easier ICD coding than the original version. The PCU staff feels more competent when using ICD-10-TM for PCU to do ICD coding and could code it more correctly. Hence ICD coding errors rate were reduced, comparing with the use of original version.

### Implementation of ICD-10 in Thailand

Thailand has been using the International Classification of Diseases and Related Health Problems – ICD since the year 1950 [1]. We used ICD-7, and later ICD-8, for mortality coding and statistics before ICD usage for morbidity coding and statistics began in 1963. ICD-9 was used during 1980-1993 before implementation of ICD-10 in 1994.

**ICD-10 Clinical Modification in Thailand – ICD-10-TM**  
Modification of ICD-10 in Thailand happened after the ICD office discovered that some medical doctors in Thailand

added more terminal digits to ICD-codes to make it “more specific”. Because ICD-10 did not include codes of common diseases in Thailand (for example: necrotizing fasciitis, green pit viper poison snake bite, Dengue shock syndrome etc.) and doctors demands increased very fast, the Ministry of Public Health in co-operation with medical schools, medical associations and other stakeholders started ICD-10-Thai Modification since 2000. A committee was formed by a group of medical experts from every subspecialty of medicine and a group of ICD coders to do comprehensive jobs of reviewing demands for new codes, creating new ICD index entries, assigned new ICD code as necessary. After pilot testing for four years, Ministry of Public Health adopted ICD-10-TM to be used in morbidity coding in Thailand since 2005 until now [2].

### Universal Health Coverage

UHC system in Thailand started in 2000 after a sudden change in government policy regarding health care. The system was fully implemented in 2002 and operated by the National Health Security Office since then. Now 75% of the Thai people were health insured by the UHC scheme while the rest (25%) were health insured by other scheme (Civil Servant, Social Security or Private Health Insurance). When a person got illness, the primary care unit in the village or sub-district level will take care of the patient. In Thailand, 10,068 primary care units around the country were operated by general practitioner nurses and/or public health staffs with no doctor in the unit. After service, the patient reason for encounter or diagnosis in the medical record will be coded using ICD-10 and the data will be sent to the health statistics office at the province level within 24 hours.

### Development of ICD-10-TM for Primary Care Units

In the year 2007, the Thai Health Coding Center, Ministry of Public Health, Thailand conducted an ICD coding quality assessment program. Sample of ICD codes from primary care units in two provinces were assessed and error rate of 70-90% was found. The most common type or errors were invalid and incorrect codes. The PCU staff also complained that they did not get the complete ICD book set to do coding correctly, so they produced their own “short list” of diagnosis assigned to ICD code. When the auditors checked their ICD short lists, they found so many errors code assignment in those short lists. So many groups of PCU staff were trained to use the full version of ICD book set to do ICD coding, most of them could be trained but they usually complained that the full version of ICD book set was too complicated for them. Given by that fact, it was obvious that a simplified version of ICD was required for usage in the primary care unit. In the year 2008, the ICD-10-TM for PCU version was developed with the main objective of making the ICD-10-TM easier for use in the primary care unit. Four methods of modification to make simpler ICD-10-TM are; 1) Reduction of number of total codes in ICD volume one, 2) Eliminate of complexity, for example: the dagger and asterisk system, 3) Reduction of index terms in the alphabetical index, 4) Addition of self

directed learning book into the new ICD-10-TM for PCU book set. Table 1 shows the difference in some aspects between the original ICD-10-TM and the PCU version.

Table 1

Important Aspects	ICD-10-TM original version	ICD-10-TM for PCU
Number of total ICD Codes	~35,000 codes	~1,900 codes
Pages of the alphabetical index	401	123
Dagger and asterisk system	Yes	No
Complex words and symbol	Yes	No
Additional code system	Yes	No

### Implementation of ICD-10-TM for PCU

Development of ICD-10-TM for PCU finished in July 2009 after the beta version test was completed. The first version was published in August 2009 [3] which included three books, volume 1: the tabular list, volume 2: the alphabetical index and volume 3: the self-directed learning book. First phase implementation was completed by the end of the year 2009 in 10 pilot provinces, country wide implementation was finished in the year 2010. Initial feedback data from the user show acceptance of use by most of the PCU staff and they felt more competent to do ICD coding using the new tools.

The second version of ICD-10-TM for PCU [4] was published in the year 2012. In this version the book set contained four books, volume 1: the tabular list and index, volume 2: the procedure codes, volume 3: the guideline for diagnosis data input and initial ICD codes, volume 4: the standard codes for home and community health care services. Volume 2 to 4 of the book set provide new tools for the PCU staff. Volume 3 included flowchart to diagnosis and initial ICD codes of the most common group of diseases and services found in the PCU. This volume made ICD coding in common cases more easier than the first version.

The PCU ICD Coding quality assessment was conducted annually, latest assessment in 2013 show that overall coding error rate was in the range of 10-20% . Although the error rate was not so low but it show improvement of coding quality when compared to the high error rate in the year 2007. Coding errors still occurred in nearly all PCU due to frequent replacement of the PCU nurses or public health staff who do the ICD coding with the new staff who still do not get training of ICD-10-TM for PCU coding.

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## The Netherlands

### Rare diseases: a holistic approach for classifying and coding

Rare diseases should be classified and coded in such a way that the often complex and diverse nature of most rare diseases are respected and recognized as much as possible. This is probably true for any disease, but especially for rare diseases, often combining many medical conditions and physical and mental problems, most often from birth or early childhood. It is therefore important to have a holistic approach to health and practicing medicine. The precise and correct diagnosis is very important, but also the level and way of functioning and the specific treatment a patient with a rare disease is receiving. This is conceivable by combining three WHO FIC classifications: ICD, ICF and ICHI. The combined use of ICD, ICF and ICHI will have added value because it will describe the patient as a whole, not just from a medical point of view. The patient will ultimately benefit from the (combined) insight into the specific medical and personal needs of an individual with a rare disease. Therefore the level of functioning, as well as the medical diagnosis and treatment should be classified, coded and stored together, preferably in a central registry for rare diseases.

### ICD

In 2012 Robinson concluded that ICD-10 includes nearly 500 rare diseases, only about 240 of which have a specific ICD code. He also concluded that with roughly 8,000 named RDs and at least 100 new RDs characterized yearly, this means that less than 3% of RDs have codes in the ICD-10. “Correspondingly, rare diseases have been largely invisible in national mortality and morbidity statistics.” Robinson 2012. Some, but not many rare disease can be classified by using the alphabetical index (Part III of ICD-10). Other rare diseases are classified at a too general level, with codes not specific enough to recognize the rare disease or are misclassified altogether. For both diagnostic- and research purposes this situation should be improved regarding ICD-10 and ICD-11 if we want to be able to gather more knowledge on rare diseases.

Currently ORPHANET (<http://www.orpha.net>) has linked about 85% of the total number of Orphanet codes to ICD-10 codes (mostly at the deepest possible ICD level of e.g. Q80.1 and G11.1). This should be coordinated with the work done by the WHO-FIC Update and Revision Committee. Related activities by ORPHANET should lead to a consistent representation of rare diseases in ICD-11.

The question is whether all rare diseases will be covered and how this will be visible in the new ICD version.

### ICF

Improvement of treatment and care for persons with rare diseases is obtained by standardization of measuring functioning according to the ICF. Nowadays there is no standardized measurement instrument available. Development of a new measurement instrument is not feasible because of practical reasons (8000 rare diseases!). We recommend to explore the possibility of applying the General ICF core set and the existing instrument called IMPACT (based on A and P of the ICF), and evaluate the coverage of the instruments regarding functioning aspects of persons with rare diseases. Another possibility could be to use the ICF checklist and ask representatives of patient organizations and professionals to score relevant codes for rare diseases and see whether a common set of classes can be recognized. This work can lead to a better understanding of rare diseases and also lead to ICF update or revision proposals.

### ICHI

Early detection and prevention of rare diseases are generally considered important and recognized as such. We therefore recommend studying the relationship between rare diseases and laboratory interventions presented in ICHI. Because of the importance of functioning we also recommend to check whether interventions focusing at functioning (relevant to rare diseases) are clearly presented in ICHI.

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## How fit are ICD and ICF for their purposes?

My last feat of arms was finishing the Dutch translation of the ICD-10 training tool. Being so close to the meaning of this classification for the statistical description of morbidity and mortality, urges me to deliberate shortly on the basic thought of William Farr more than 150 year ago.

### Terminologies, taxonomy, and nosology

I spent a lot of my working life to the importance of using terminologic rules, taxonomic principles, and nosologic knowledge in ICD-related classification developments. However, all of this is less important in view of two main purposes of ICD: counting deaths or discharged patients according to their underlying cause or hospital discharge diagnosis. Often there is comorbidity, other morbid conditions or specific conditions contributing to death or

hospital care, but these data are only a by-product of the main assessments. The individual object, a death or discharged patient, is classified. ICD is primarily a purpose-oriented classification of objects, not per se a classification of medical knowledge.

### Reality check

This imperative counting of cause of death and discharge diagnosis is required by reality. People end up in hospital as well as die for totally different reasons. Farr proposed in 1856 that for "(...) epidemiological purposes, statistical data on diseases should be grouped in the following way:

- epidemic diseases
- constitutional or general diseases
- local diseases arranged by site
- developmental diseases
- injuries" (ICD-10, Vol. 2)

Furthermore, this reality is viewed by a variety of medically trained professionals with diverging diagnostic methods and medical language conventions in different countries. The training tool will certainly help coders to order the chaos of data these people delivered.

Conclusion: a linguistic reality of standardized syntaxis and semantics of medicine with rules, principles and knowledge might be helpful, even necessary, but will never be sufficient for the reality morbidity and mortality statistics want to capture.

### ICF as linguistic cover

The ICF can be viewed upon as a linguistic cover of functioning of the individual object, being able to assess body function and structure, domains of activity and participation, and taking account of environmental factors. However, it is not a measurement instrument like ICD. Death or discharge diagnosis is the same for every individual, regardless age, but functioning changes during life time. The reality is that the functioning of children and youth are primarily defined by the natural process of physical and mental development, and functioning of the elderly by ditto aging. There is also an enormous variation in what people of all ages can and will do, and thus in the functioning they perform. The problems in functioning they experience, are the result of that reality. Still you count objects, the functioning as a characteristic of a number of individuals, if you want to measure the burden of a specific functioning problem. ICF also is primarily a purpose-oriented classification of objects. The fit of ICF is in the operationalization of reality by measurement instruments of specific functioning potentialities and problems.

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