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WHO Family of International Classifications (FIC)

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Classification and terminology, what is in a name?

The WHO-FIC Network meeting in October 2005 in Tokyo showed five projects on linking between WHO classifications and clinical terminologies:

1. R. Jakob, C. Çelik. Linkages between the ICD and terminologies
2. K. Giannangelo & S. Fenton. Mapping: Creating the Terminology and Classification Connection
3. S. Zaiss, N. Hanser, N. Baerlecken. Comparison of ICHI and CCAM Basic Coding System
4. J.M. Rodrigues, A. Rector, P.E. Zanstra, R. Baud, J. Rogers, A.M. Rassinoux, S. Schultz, B. Trombert, H. ten Napel, L. Clavel, E.J. vander Haring, C. Mateüs. Supporting WHO Classifications with GALEN tools
5. P.E. Zanstra, J.M. Rodrigues, A. Rector, M. Virtanen, G. Surjan, B. Üstün, P. Lewalle. SemanticHealth. A semantic interoperability deployment and research roadmap; see p. 10

M. Virtanen chaired also a round table discussion with terminology experts, such as C. Galinsky (Infoterm), J.M. Rodrigues (from the circle of Galen), K. Spackman (from the circle of Snomed).

In the summary report of the Network meeting it was stated that - "thanks to the developments in informatics today - it is possible to link classifications and terminologies to formalize the representation of knowledge in classifications. The linking of classifications and terminologies is essential to enable IT infrastructure for electronic health records. The linking can be done in various ways including simple tables of correspondence or indexing, and further improved ways of knowledge representation such as in terms of essential features of diseases or decision making rules used in practice." This statement, however, is questionable. Project reports give the impression that the linking is not an easy task, neither conceptually (1-3), nor ontologically (4) or organizationally (5).

For example, the first report conclude:

- The majority of the terms currently in use in the diagnostic definitions of the ICD-10 category F32 Depressive episode, can be linked to the terms in SNOMED-CT, however
 - Such linkages require considerable intellectual work;
 - An automated linking or an automated verification of linkages between ICD-10 and terminologies as SNOMED-CT is not feasible, at present;
 - This situation could be improved imposing a strict terminological control for the definitions in the classification and adding terms to SNOMED-CT.
- Bedirhan Üstün of the WHO CAT team illustrated as the core of the linking problem F32.0 mild depressive disorder: two or three of a range of possible symptoms have to be present for coding F32.0. 17 Snomed codes are needed for 11 symptoms, and even than not all symptoms have got a code (see sheet page 2). Furthermore, 'mild depressive disorders' might be assessed by different sets of symptoms. And a psychiatrist can also avoid that overall title although a set of two symptoms are applicable. Most terminologists would dislike such a coding practice. Naming a client's health problem by a class is what classifications do; it differs in principle from describing a client's symptoms without an overall title.

Rewriting ICD Using SNOMED example of Depressive Disorder F32.0

A.	Low mood	{41006004}
	Loss of interest	{417523004 }
	Low energy	{248274002}
B.	1. Appetite	(decrease, increase) {64379006, 72405004}
	2. Body weight	(decrease, increase) {89362005, 8943002}
	3. Sleep	(decrease, increase) {59050008, 77692006}
	4. Psychomotor	(decrease, increase) {398991009, 47295007}
	5. Libido loss	{8357008}
	6. Low self esteem	{286647002, 162220005}
	7. Guilt, self blame	{7571003}
	8. Thoughts of death ...	
	9. Suicide Ideation	{102911000, 6471006}

Sheet presented by Bedirhan Üstün.

It was noted (cf.. Executive summary) in the round table that "the theory of terminology, confirmed by observations from pilot tests, indicates that it is rather the encapsulated knowledge that could be captured for mapping purposes. Only then can it be ascertained that the concepts are captured uniquely and specifically. This would also provide a stable, language-independent basis for implementation in other languages than English with increased compatibility. The magnitude of the task calls for a formal representation of such knowledge that would allow efficient and reliable machine processing."

It was concluded in the round table that "WHO could take lead role to disseminate and organize health information standards, take a proactive stance for charting the universe of health information standards and establish mechanism of involving member states, multiple stakeholders and use mechanisms established by ISO, CEN and others.... Classifications and clinical terminologies are not alternatives but complementary to each other and should be used in conjunction with appropriate linkages (also known as mappings) based on existing scientific knowledge.

WHO Collaborating Centres will be asked to nominate experts to serve on a terminology reference group. The heads of the German and Nordic Centre will work with WHO CAT to establish this group."

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Editorial

One of the major events last year was the annual meeting of the WHO-FIC network in Tokyo last October. Our Japanese host treated us with an impressive and interesting meeting environment which contributed to the quality and results of the meeting. Of course all classifications of the WHO-FIC have been discussed and we refer the interested reader to the WHO website in order to find details, papers, presentations and posters: www.who.int/classifications/network/meeting2005. A short summary of the highlights of the meeting is presented in this newsletter on page 3-5. A rather new phenomenon in the annual meeting agenda was a round table discussion on the relation between classifications and terminology. Willem Hirs summarized this interesting discussion, to be found on page 1-2 of this newsletter. At international level a terminology reference group will be established. In

the Netherlands we already started a similar activity for our national level. We really believe that the two should be seen together: distinguished but not separated.

An other remarkable issue is the XML Schema based on ClaML developed by the Electronic Tools Committee, which should be adopted as the standard for exchange of WHO-FIC classifications. A contribution by Huib Ten Napel is to be found on page 10.

Persons who are not involved in classifications are confronted with a lot of unknown acronyms and questions. In order to prevent this kind of confusion the Education Committee prepared a document which is included in this newsletter. We hope that this appears to be of help to find the way in the chaos. If certain relevant acronyms or specific questions and their answers are missing, please send them to the chair of the committee, Marjorie Greenberg (<mailto:msg1@cdc.gov>).

As always there are several contributions relating to the ICF included in this newsletter. A surprising paper is contributed by Catherine Sykes on behalf of the Australian ICF team. The team developed a kind of intermediate tool for exchange of information based on different assessment tools. We are interested to see the results of the testing. See page 12.

Another interesting contribution relates to the ethical framework of the ICF prepared by Donal McAnaney from Ireland. This issue took a lot of attention at the time of the ICIDH revision but lost attention during the last few years. We think it is time to consider this issue again and hope this can be a topic for discussion during the next annual WHO-FIC meeting. During the Tokyo meeting an operational plan has been made for the implementation of the ICF within the priority areas (surveys/censuses, clinical and administrative applications, health outcome, policy).

Regarding the International Classification of Technical Aids (new name: Assistive products for persons with disability) ISO9999 we can inform

you that the new version will be distributed by ISO and CEN in due time for final voting by member states. A working group developed crosswalks between ISO9999 and ICF. As soon as possible a document containing these crosswalks will be available for comments through the website of the Dutch WHO-FIC Collaborating Centre.

In the area of ICPC and ICF action is taken in order to produce a mapping between both classifications. Based on the analysis it is to be seen whether the ICF can be (partly) included in ICPC-3. See the contribution from Belgium, page 12 in this newsletter.

A questionnaire about the use of the ICECI will be sent to involved persons. It is intended to make the results of the survey available through our website. The questionnaire (possibly after improvement based on the first replies) will be posted on the website as well in order to enable ICECI users to share their information.

At the start of this new year we wish the readers a prosperous 2006 with a lot of interesting and successful classification experiences. We hope you will enjoy this newsletter and we invite you to send us your information to share with the rest of the WHO-FIC world. Sharing information is important. That is why we prepare this newsletter and why the Education Committee and Implementation Committee started a pilot on the structural collection and distribution on information relating to ICF implementation, educational tools and electronic tools. This is also the reason why the North American Collaborating Centre organizes annual ICF meetings during summertime and why the Australian Collaborating Centre planned to organize an ICF conference at the beginning of February 2006.

We are looking forward to your messages!



Our Japanese host, Kenji Shuto, and his wife

International Organizations

WHO-FIC Network



WHO Family of International Classifications Network Meeting 2005

Tokyo, 16-22 October

The meeting was attended by 88 international participants from 7 WHO Collaborating Centres and representatives from Ministries of Health or National Statistical Bureaus of over all 16 countries. Agenda, List of participants, and Papers presented in the conference, are available at <http://www.who.int/classifications/>.

The views expressed in these papers are those of the named authors only

and do not necessarily represent WHO's or WHO-FIC Network's views.

The meeting served to review all elements of the WHO-FIC Network and its Committees. The Linkages between Terminologies and Classifications (see p. 1, 2); Case mix Groupings, ICD revision process and ICF applications in multiple sectors received particular attention.

The executive summary of the meeting is used, giving you the highlights of the meeting. Reference is made to several places in this newsletter where specific agenda items are more fully discussed. For Abbreviations and Acronyms throughout this newsletter, developed by the Education Committee, see page 5.

Implementation of ICD-10

A database of the levels of implementation and a Roster of Experts, to be maintained by WHO-CAT, will be available at the WHO Classifications website at the beginning of 2006.

The already existing training materials on ICD from the Brazilian centre and others, and a training tool to be set up by WHO-CAT by October 2006 based on the content of Tendon, will be compiled by April 2007.

The Mortality Reference Group (MRG) will work on the improvement of assessment of ICD implementation for mortality by refining rules and providing assistance.

Updates to ICD-10

The Update and Revision Committee (URC) reached consensus on 36 submissions prior to the meeting, 3 proposals identified errata in the paper version of second edition. The approved changes, to be implemented in 2007, will be posted on the WHO website at the beginning of 2006. It is decided that the existing 'paper based' update mechanisms will be replaced by a 'web based' system that is under development at WHO.

With a view on the situation for avian flu, code J09 Influenza due to Avian influenza virus, has been created and can be used immediately. It will be added in the version 2006 of ICD-10.

The MRG assessed that the programming of an international tool (IRIS) for automated coding based on MICAR and ACME progresses. This collaborative work of the INSERM (France), the Socialstyrelsen (Sweden), NCHS (USA), DIMDI (German) and Statistics Hungary will be available for testing, probably by August 2006. Methods for the manual selection of the underlying cause of death according to the ACME/IRIS algorithm will be developed.

The Education Committee proposed a number of frequently asked questions to be published on the WHO-FIC website, see page 7. The FAQ's relate especially to the development of the International Training and Certification Program for ICD-10 Mortality and Morbidity coders.

The Work group on Hospital Data will continue its work as part of the new Morbidity Reference Group. The origin of the Work group was the EU Hospital Data Project (HDP) aimed at improving hospital statistics with the help of definitions and shortlists. It will be continued as the EU HDP phase 2 under the leadership of Prismant in The Netherlands. Partly through efforts from the Work group several major producers of hospital discharge statistics have now agreed to use the HDP shortlist for diagnoses with only minor agreed modifications, presently known as the EUROSTAT-OECD-WHO hospital morbidity shortlist. The Work group recommends the list to be adopted by WHO as a shortlist for tabulation with the title International Shortlist for Hospital Morbidity Tabulation (ISHMT), to be published on the WHO website.

ICD Revision

WHO has presented the structure for the revision process for the creation of ICD-11. The ICD update and revision processes will proceed in a continuous manner supporting each other. URC will be the overall oversight mechanism to oversee the coordination of work in different chapters.

The revision work will be provided by three main streams:

1. Scientific Stream

It will include evidence based reviews, surveys, validation studies, add-on protocols for existing studies and meta analyses.

2. Clinical Stream

It will ensure clinical utility, linkage to patient reports and to treatment response and deal with phenotypes (gene to behaviour specs).

3. Public Health Stream

It will assess the impact on health systems; service delivery, resource management, reimbursement, accounting, information technology applications and the interactions with terminology.

Five pilot areas were presented by collaborating centres and WHO CAT as revision areas:

- Cystic Fibrosis (North America)
- Diabetes (Australia)
- Lymphomas (Germany)
- External Causes (Nordic Centre)
- Mental Health (CAT)

The centres in charge will report on the results of further activities in the direction of proposals at the Network Meeting 2006.

Specifically in the area of external causes, cooperation with WHO and CCs is sought. In a first meeting the extent of the work, its overwhelming implication on the other chapters of ICD and the need for cooperation with the ICECI as well as with experts in the field of pharmaco-vigilance, substance safety and patient safety were identified.

In the area of Mental Health (WHO-CAT) the work has started together with support of the World Psychiatric Association and the International Union of Psychological Sciences.

Derived and related classifications

Further work within the WHO/WICC group was reviewed in terms of alignment between WHO-FIC reference classifications (ICD, ICF, and ICHI) and the WONCA International Classification of Primary Care (ICPC) which is under revision. The Dutch Collaborating Centre reported on the task of the alignment between ICF and ICPC, see p. 12 .

International Classification of Functioning, Disability and Health

The Implementation Committee endorsed the application of ICF in Health and Disability statistics and had a special debate on the use of ICF by the Washington Group (WG) on Disability Statistics, see for more information: ICF based Surveys and Statistics, p. 15.

In support of ICF implementation the meeting recommended an ICF knowledge network for sharing information on ICF implementation, uses, educational materials and efforts. The final version of the information sharing framework will be hosted on the WHO FIC website with linkages to a mirror website in each of the Collaborating Centres.

For the ICF Children and Youth version, see p. 9.

The meeting recommended adapting the WHO FIC update software platform for ICF. The platform will be hosted on the WHO FIC website. All ICF updated related information generated from implementation projects should be collected through this common mechanism and will be discussed by a. (new) Functional, Disability Reference Group (FDRG).

International Classification of Health Interventions (ICHI)

WHO CAT arranged for extended field tests of ICHI with supporting questionnaires. The meeting took note of the current status of the beta field testing. More than 250 individuals have expressed interest to participate. They come from some 69 countries. Their geographical distribution, however, is uneven. The majority of the reactions came from countries already having a national intervention classification. There is a need to mobilise support, especially in Member States not having such an intervention classification of their own, to ensure that ICHI meets the needs of the health authorities. Translations of ICHI into French and Spanish are being finalized. This will provide WHO with language versions required for communication with countries through official channels.

In parallel, content, scope and nature of ICHI have been scrutinized using various methods, in order to assess the intrinsic value and internal consistency of the classification. It was recognized that efforts in that direction should usefully inform the development of the methodology to be applied to other classifications, especially the 11th revision of ICD. That would also strengthen the role of classifications as building blocks of health information systems as they could benefit, through proper conceptual mappings, from clinical reporting systems such as the EHR, which in turn require standardized terminologies (see further p 1, 2).

WHO-FIC and other fields

The Family of International Classifications is bounded by other systems, such as clinical terminologies (more detailed) and case mix systems (less detailed), that may use international classifications as a reference. The 2005 Network meeting organized two round table discussions: one on terminologies (see p 1, 2) and one on case mix systems.

The round table with international case mix experts discussed the vision of international case mix groupings and the role of WHO and the WHO-FIC Network, see further the Executive Summary of the Network meeting at <http://www.who.int/classifications/>.

Electronic tools

The XML Schema based on ClaML developed by the Electronic Tools Committee should be adopted as the standard for the exchange of WHO-FIC classifications as of this meeting. WHO-FIC centres that use their own classification maintenance systems are encouraged to add functionality for the import and export of classifications according to this XML Schema. WHO and DIMDI should share the development costs for the maintenance and development tool for WHO-FIC classifications and make it available to the WHO-FIC centres for free. WHO-FIC centres not using their own classification maintenance tools should not start the development of their own maintenance tool without having

explored the recommended tool for WHO-FIC classifications.

Organizational affairs

The Network meeting updated its Business plan and Strategy and Work Plan that will be evaluated by the Planning Committee and external advisors in May 2006.

The Network Structure has 5 standing committees (Implementation, Update and Revision, Education, Family Development, and Electronic Tools). This committee structure reflects the sectors of work in the FIC and form a vertical structure, each one covering all family members. In addition to the existing and successful Mortality Reference Group a few new working groups were suggested for specific topics as horizontal structures across the fields covered by the committee structure: Morbidity Reference Group, Functioning and Disability Reference Group, Terminology Reference Group.

On behalf of the French Collaborating Centre and the Eastern Mediterranean Regional Office (EMRO) and Tunisian WR WHO/CAT informed the meeting that Tunisia agreed to host the next meeting of the WHO-FIC Network from 22-28th October 2006.

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ICECI developments

The next version of the International Classification of External Causes of Injuries (ICECI) will be published in 2006, including minor changes like correction of typos, inclusion and exclusion statements. The current ICECI version is available in English, Spanish and French. All relevant ICECI documents are available on the website (www.iceci.org). In 2006 the ICECI website will be hosted by the Dutch WHO Collaborating Centre for the Family of International Classification and implemented in their website (the current ICECI-website will be linked to this website). At the same the ICECI-part of the website will be upgraded.

In January 2006 a questionnaire will be sent to known users of ICECI. This will lead to insight in who is using ICECI and how ICECI is being used. This information will be made available at the ICECI-website in order to improve the exchange of experiences.

In June 2005 a meeting was organised on the revision of ICD-10 Chapter XX on external causes. It was concluded that ICECI will provide input for improving this part of ICD within a formal procedure.

During the 8th World Conference on Injury Prevention and Safety Promotion in Durban the use of ICECI will be promoted in the WHO booth and by presentations of ICECI-users.

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Abbreviations and Acronyms

Term	Meaning
ABS	Australian Bureau of Statistics
ACBA	Australian Coding Benchmark Audit
ACCS	Automated Cause Coding Software
ACHI	Australian Classification of Health Interventions (Vols. 3 and 4 of ICD-10-AM)
ACME	Automated Classification of Medical Entities
AFRO	Regional Office for Africa of the World Health Organization
AHIMA	American Health Information Management Association
AIHW	Australian Institute of Health and Welfare
AMRO	Regional Office for the Americas of the World Health Organization
ATC/DDD	Anatomical Therapeutic Chemical Classification System with Defined Daily Doses
CAM	Complementary and Alternative Medicine
CAP	College of American Pathologists
CAT	Classifications and Terminology section of WHO Headquarters, Secretariat to the WHO-FIC Network
CBCD	Centro Brasileiro de Classificação de Doenças (Brazilian Collaborating Center)
CCAM	Classification Commune des Actes Medicaux
CCI	Canadian Classification of Health Interventions
CCI	La Classification Canadienne des Interventions

CCSA	Clinical Coders' Society of America	EBM	Evidence-based Medicine	ICD-10-PCS	International Classification of Diseases, Tenth Revision, Procedural Coding System (USA – not yet in use)
CDC	Centers for Disease Control and Prevention (USA)	EBP	Evidence-based Practice		
CEMECE	Centro Mexicano para la Clasificación de Enfermedades (Mexican Center for Classification of Diseases)	EC	Education Committee (WHO-FIC)	ICD-10-XM	International Statistical Classification of Diseases and Related Health Problems, 10th Revision, International Clinical Modification (under discussion)
CEN	European Committee for Standardization	EDI	Electronic data interchange		
CEVECE	Centro Venezolano para la Clasificación de Enfermedades (Venezuelan Center for Classification of Diseases)	EIP	Evidence and Information for Policy (WHO cluster)	ICD-DA-3	Application of the ICD for Dentistry and Stomatology, 3rd Edition
CHIMA	Canadian Health Information Management Association	EMRO	Regional Office for Eastern Mediterranean of the World Health Organization	ICD-Forum	Group for discussions by e-mail of issues related to mortality and morbidity coding and related themes (in English)
CID (CID-10)	Classificação Estatística Internacional de Doenças e Problemas Relacionados à Saúde	ETC	Electronic Tools Committee (WHO-FIC)	ICD-NA	International Classification of Diseases, Neurology Application
CID-O-3	Classificação Internacional de Doenças para Oncologia – Terceira Edição	EU-HDP	European Union Hospital Data Project	ICD-O-2 or 3	ICD for Oncology, 2nd Edition; 0-3, 3rd Edition
CIE	Clasificación Internacional de Enfermedades	EURO	Regional Office for Europe of the World Health Organization	ICE	International Collaborative Effort [on automating mortality statistics, on Injury Statistics] sponsored by NCHS
CIE-10	Clasificación Internacional de Enfermedades y Problemas Relacionados con la Salud	FAQ	Frequently asked questions	ICECI	International Classification of External Causes of Injuries
CIE-O-3	Clasificación Internacional de Enfermedades para Oncología – Tercera Edición	FDC	Family Development Committee (WHO-FIC)	ICF	International Classification of Functioning, Disability and Health
CIE-9-MC	Clasificación Internacional de Enfermedades, 9a Revisión, Modificación Clínica (Spanish version of ICD-9-CM)	FIC	Family of International Classifications	ICF-CY	International Classification of Functioning, Disability and Health, Children and Youth version
CIF	Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud, Classification internationale du fonctionnement, du handicap et de la santé, Classificação Internacional de Funcionalidade, Incapacidade e Saúde	Forum-CIE	Group for discussions by e-mail of issues related to mortality and morbidity coding and related themes (in Spanish)	ICHI	International Classification of Health Interventions
CIHI	Canadian Institute for Health Information	HIMAA	Health Information Management Association of Australia	ICIDH	International Classification of Impairments, Disabilities, and Handicaps (Revised in 2001 and published as International Classification of functioning, Disability and Health)
CIM (CIM-10)	Classification statistique internationale des maladies et des problèmes de santé connexes	HL7	Health Level Seven- one of several American National Standards Institute (ANSI) - accredited Standards Developing Organizations (SDOs) operating in the healthcare arena. Health Level Seven's domain is clinical and administrative data.	ICIS	Institut canadien d'information sur la santé (also CIHI)
CIM-10-CA	Classification statistique internationale des maladies et des problèmes de santé connexes dixieme version, Canada	HOC	Heads of WHO Collaborating Centers for the Family of International Classifications	ICPC	International Classification of Primary Care
CLaML	Classification mark-up language	HRG	Healthcare Resource Group – used in the UK for casemix grouping	ICPM	International Classification of Procedures in Medicine (WHO 1978)
CPT	Current Procedural Terminology (U.S.)	IARC	International Agency for Research on Cancer	IFHRO	International Federation of Health Records Organizations
CRAES	Comité Regional Asesor en Estadísticas de Salud (PAHO Regional Advisory Committee on Health Statistics)	IC	Implementation Committee (WHO-FIC)	IHRIM	Institute of Health Record and Information Management (UK)
CTNERHI	Centre Technique National d'Études et de Recherches sur les Handicaps et les Inadaptations (France)	ICD	International Classification of Diseases	IMIA	International Medical Informatics Association
DATASUS	Departamento de Informática do Sistema Único de Saúde (Brazil)	ICD-9-CM	International Classification of Diseases, Ninth Revision, Clinical Modification (USA)	IND	International Nomenclature of Diseases (Not currently maintained)
DIMDI	Deutsches Institut für Medizinische Dokumentation und Information	ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision	INSERM	Institut National de la Santé et de la Recherche Medicale
DPI	Disabled Peoples International	ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification	INTERCOD	Computer-assisted program for self-instruction for coding mortality and morbidity with ICD-10 developed by the Mexican Center for the classification of Diseases and PAHO.
DRG	Diagnosis-Related Groups	ICD-10-CA	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Canada		
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders – 4 th Edition	ICD-10-CM	International Classification of Diseases, Tenth Revision, Clinical Modification (USA- not yet in use)	ISO	International Organization for Standardization
		ICD-10-GM	International Classification of Diseases and Related Health Problems, Tenth Revision, German Modification	ISO 9999	Technical aids for persons with disabilities. Classification and terminology

MDG	Millennium Development Goals	SEARO	Regional Office for South East Asia of the World Health Organization
MedDRA	Medical Dictionary for Regulatory Activities	SNOMED	Systematized Nomenclature of Medicine
MF	Mortality Forum - Group for discussions by e-mail of issues related to mortality coding (in English)	SNOMED CT	SNOMED Clinical Terms
MICAR	Mortality Medical Indexing, Classification and Retrieval	SNOMED RT	SNOMED Reference Terminology
MIKADO	Swedish automated coding system	STC	Statistics Canada
MMCB	Mortality Medical Classification Branch, NCHS	STYX	French automated coding system
MMDS	Mortality Medical Data System (US automated coding system)	TENDON	Computer-based training package for ICD-10 produced by the WHO Collaborating Centre for the Classification of Diseases, London
MRG	Mortality Reference Group (WHO-FIC)	TRANSAX	Translation of axes – used to create data appropriate for either record-based analysis or person-based analysis
NACC	North American Collaborating Center	UC or UCOD	Underlying cause of death
NCCH	National Centre for Classification in Health (Australia)	UMLS	Unified Medical Language System
NCECI	NOMESCO Classification of External Causes of Injuries	UN	United Nations
NCHS	National Center for Health Statistics (USA)	URC	Update and Revision Committee (WHO-FIC)
NCSP	NOMESCO Classification of Surgical Procedures	WCPT	World Confederation for Physical Therapy
NHS	National Health Service (UK)	WFOT	World Federation of Occupational Therapists
NIC	National Interventions Classification – currently under development but will ultimately replace OPCS-4 for surgical procedures and intervention for the UK	WHO	World Health Organization
NLM	National Library of Medicine (U.S.)	WHO CAT	World Health Organization Classification, Assessment, Surveys and Terminology
NOMESCO	Nordic Medico-Statistical Committee	WHO CC	World Health Organization Collaborating Center
OECD	Organization for Economic Cooperation and Development	WHO-FIC	World Health Organization Family of International Classifications
OMS	Organisation mondiale de la Santé, Organización Mundial de la Salud, Organização Mundial da Saúde	WICC	WONCA International Classification Committee
ONS	Office for National Statistics (UK) Formed in 1996 by a merger of the Central Statistical Office (CSO) and the Office of Population Censuses & Surveys (OPCS)	WONCA	World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (The short name is World Organization of Family Doctors.)
OPCS-4	The Office of Population Censuses and Surveys' Classification of Surgical Operations 4th Revision. The current surgical procedures classification used in the UK	WPA	World Psychiatric Association
OPS (OPAS)	Organization panaméricaine de la Santé, Organización Panamericana de la Salud, Organização Pan-Americana da Saúde	WPRO	Regional Office for Western Pacific of the World Health Organization
PAHO	Pan American Health Organization	XML	Extensible Mark-up Language
RI	Rehabilitation International	YLD	Years of life lived with disability
RIVM	National Institute of Public Health and the Environment (Netherlands)	YLL	Years of life lost through disability, Years of life lost
RUTENDON	Computer-based ICD-10 coding training, in Russian		
SCB	Seleção de causa básica (automated system, Brazil)		

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Marjorie Greenberg addressing to the audience in Tokyo

Additional FAQ's on WHO's Classifications website?

FAQ's on ICD, ICF and purchasing, permissions, copyright, licences and translations are published on www.who.int/classifications//help/en/. The Education Committee of the WHO-FIC Network suggested on the Collaborative Workspace a number of additional FAQ's

- on Collaborating Centres (1),
- on Committees (such as 2),
- on relationships with other organizations (such as 3),
- on the ICD International Training and Certification Program (4-10),
- on ICD-10 (11, 12)
- on ICF (13) and
- on Terminologies (14).

By publishing these FAQ's in the Newsletter, people outside the workspace are kindly invited to participate in the development of this kind of information.

1. What are the WHO Collaborating Centres for the Family of International Classifications?

A WHO collaborating centre is a national institution designated by the Director-General of the World Health Organization to form part of an international collaborative network carrying out activities to support WHO's mandate for work on international health issues through structured programs and priorities. The WHO Collaborating Centres for the Family of International Classifications (FIC) are an international network of expert centres in health classifications, coding, and terminology development. Click on the following link for more information

www.who.int/classifications/network/collaborating/en/index.html.

2. What is the WHO-FIC Education Committee?

The WHO-FIC Education Committee (EC) is one of the six WHO-FIC Committees. This committee assists and advises WHO and the WHO-FIC Network in improving the level and quality of use of the WHO Family of International Classifications in member states by developing an integrated educational strategy. The Committee focuses on raising awareness of the classifications and their applications, standardized training and educational activities for users of the classifications and methods for assessment of coding ability and knowledge. Over the last several years the EC has been responsible for the development of the ICD-10 international training and certification program in collaboration with the International Federation of Health Records Organizations. Click on the following links for more information:

<http://www.who.int/classifications/network/collaborating/en/index.html> or www.cdc.gov/nchs/about/otheract/icd9/nacc_ed_committee.htm

3. What is the relationship between WHO and IFHRO?

The International Federation of Health Records Organizations (IFHRO) is a nongovernmental organization (NGO) in official relations with the World Health Organization (WHO). Click on the following link for more information: <http://www.ifhro.org/>

4. What is the ICD-10 international training and certification program?

This program encompasses international standard ICD-10 curricula for the teaching of ICD-10 morbidity and mortality coders, compilation of “gold standard” core modular approved training packages from multiple sources, and a trainer approval and coder certificate program. The final outcome of this program would be an international training and certification program for ICD coders with an expected effect of higher quality coded data and thus more accurate international and national comparability studies. The target date

for issuing the first international certificates is 2007. For more information click on:

http://www.cdc.gov/nchs/about/otheract/icd9/nacc_ed_committee.htm

5. Why has the international training and certification program been developed?

The WHO-FIC Collaborating Centres and the International Federation of Health Records Organizations (IFHRO) have been working together since 2000 to develop an international training and certification program that will improve the quality of mortality and morbidity data and the status of ICD coders. It is envisioned that this program will also help provide coded data to users for decision-making, resource allocation, and health planning. Receipt of the certificate demonstrates achievement of coding competency within an international framework. Comparable, high quality data ultimately leads to improvement in the health of the world’s population.

6. How is an international certificate obtained?

The specific process to receive an international certificate is under development. Check back in the latter part of 2005 for more information. Will the requirements for obtaining the international certificate be the same for a practicing coder and a new coder? The specific process for practicing coders to receive the international certificate has not been fully developed. It is anticipated a self-assessment and exam will be made available within a specified time period to practicing coders who have not taken an approved training package but would like to qualify for the international certificate. Subject to satisfactory completion they too would receive the international certificate. Check back in the latter part of 2005 for more information.

7. What are the core curricula for the ICD-10 coding training and certification program?

The mortality and morbidity core curricula identify the professional educational requirements for coder education. The curricula are comprised of categories, or knowledge clusters,

that represent broad domains of content. Each category contains specific content areas that training materials are expected to address. The curricula’s purpose is to provide a basis for ICD coder education for all countries, thereby providing appropriate learning experiences that result in the development of the competencies necessary for entry-level mortality and morbidity coding practice. The curricula are an essential element to the construction of training packages that will contribute to more standardized training and coding practice.

8. What are the approved training packages?

The approved training packages are a set of materials from multiple sources that have been approved and meet the requirements of the core curricula. Included in the core training packages are comprehensive assessments for each knowledge cluster in the core curricula. These packages are what approved trainers or nationally recognized educational institutions would use when conducting ICD-10 training.

9. How do educational materials become approved as a module of the training package?

Providers of current training programs on mortality and morbidity coding can apply to have their educational materials assessed by the joint WHO-FIC –IFHRO partnership. Approval will give coders confidence that their coding education program meets the benchmarks set by the Education Committee and IFHRO for high quality teaching and learning. Submission of ICD-10 training materials for consideration may be sent to the American Health Information Management Association, Attention: WHO-FIC/IFHRO, 233 North Michigan Avenue, Suite 2150, Chicago, Illinois, 60601, USA.

10. How does someone become an approved trainer?

Being a member of a group of approved trainers means you have met certain qualifications and are using a “gold standard” core modular training package. The process for trainer

approval is under development. Check back in the latter part of 2005 for more information.

11. Why is ICD-10 better than ICD-9?
ICD-10 contains an increased number of codes and categories that allow for a more specific and accurate representation of current diseases and related health problems. It also is more consistent with current clinical terminology.

12. Is switching to ICD-10 really necessary?

Yes. Switching to ICD-10 improves the quality of health statistics and healthcare data and maintains worldwide clinical data comparability. The longer one continues to use an earlier version of ICD, the more difficult it becomes to compile and share accurate disease and mortality data at a time when such global data sharing is critical for public health.

13. What are some sources for information about current and potential ICF applications?

The Australian Institute of Health and Welfare has developed a Users Guide. It can be accessed free of charge at <http://www.aihw.gov.au/publications/index.cfm/title/9329>. The NACC ICF Clearinghouse Newsletters are available at <http://www.cdc.gov/nchs/about/otheract/icd9/icfactivities.htm>.

14. Can SNOMED-CT® be used for coding instead of ICD-10?

The two systems are designed for different uses in the healthcare system. ICD-10 is needed to facilitate retrieval of coded data at the desired level of detail depending on the purposes for which the data are being used. SNOMED CT® is designed to work in an electronic health record rather than in the paper-based health record systems. Clinical terminology codes lack the “power of summary” found in classification systems for administrative reporting such as statistical reporting and reimbursement.

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The ICF-CY: a derived classification for children and youth

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) is presently in its final stage of development.

The ICF for children and youth is a derived classification to extend coverage of the main ICF volume for documentation of body functioning, structures, disability and health of children in the first two decades of life. As a derived classification, the ICF-CY is designed to provide a common language of documentation that can be used across disciplines, sectors and countries to advance services, policy and research on behalf of children and youth. The second draft of the ICF-CY provides content to document the characteristics of children and youth of importance for promoting their health, growth and development.

The need: The development of the version for children and youth was carried out in response to the request by WHO for a version of the ICF for universal use with children in health and health related sectors. The need for a version for children and youth was based on recognition that the first two decades of life consist of rapid growth and significant changes in physical, social and psychological development. Further, the manifestations of disability and chronic conditions in childhood and adolescence are different in nature, intensity and impact than those of adults.

The development of the derived version of the ICF for children and youth drew on multiple sources of evidence. These sources included content from (1) international conventions for children and youth; (2) scientific expertise of the working group and consultants; (3) theoretical and conceptual contributions; (4)

research findings; (5) field trial results; (6) findings from related ICF/ICF-CY implementation studies and (7) publications of the work group.

The development activities of the WHO work group have been carried out over the period 2002 to 2005 and supported by the National Center on Birth Defects and Developmental Disabilities of the Centers for Disease Control, USA. Drawing on the guidelines in Annex 8 of the ICF, the version for children and youth was designed to be completely consistent with the organization and structure of the main volume.

The first draft of the ICF-CY was delivered to WHO officials at the WHO-FIC meeting in Cologne in the fall of 2003. This draft version of the ICF-CY was placed on the WHO website in the summer of 2004 for field trials. Responses to surveys and clinical questionnaires were provided by individuals and programs in various countries around the world. Field trial findings and evaluation by the work group

served as the basis for preparing the second draft of the ICF-CY which was submitted to WHO in June, 2005. This second draft is being placed on the WHO website and will remain there for six months to secure comments and suggestions from around the world.

WHO CAT has started the review process which will involve the WHO FIC CCs and selected experts in areas of major changes. Subject to the result of the review process of ICF CY the classification is recommended to be accepted as a WHO-FIC derived classification.

The goal is for the ICF-CY to be approved for publication by WHO and available for distribution in 2006.

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Revision of ClaML: Progress report

In the previous WHO-FIC Newsletter, the revision of the CEN/TS 14463 (Classification Markup Language – ClaML-) has been announced. Also the next steps in the revision process were mentioned. Progress is reported here on three of the steps:

- The preparation of an information and discussion paper for the WHO-FIC network meeting in Japan,

A paper on a XML schema, based on ClaML has been prepared by the experts of DIMDI and experts of the project-team of ClaML, and presented by DIMDI at the WHO-FIC network meeting.

- Consultation of the Electronic Tools Committee

The presentation and discussion on the XML schema based on ClaML, within the meeting of the Electronic Tools Committee, was well received. This resulted in a number of recommendations.

Concerning ClaML directly the recommendation is:

The XML schema based on ClaML developed by the Electronic Tools Committee should be adopted as the standard for the exchange of WHO-FIC classifications as of the Tokyo meeting.

One of the recommendations connected to this first one is: WHO-FIC centres that use their own classification maintenance tools are encouraged to add functionality for the import and export of classifications according to this XML schema.

In the plenary session the recommendations from the Electronic Tools Committee were presented and adopted by the meeting. It was a memorable first time that recommendation from a committee have been accepted with such unanimous support. The Electronic Tools Committee, and more specific the group of experts, was complimented with achieving results in such a short timeframe.

- The preparation of the proposal for revision of ClaML via CEN and ISO

The preparation of the proposal for version 2 of ClaML has been an ongoing activity. Before and after the Tokyo meeting the experts from DIMDI, WHO and the ClaML project team from Nijmegen have been in continuous contact. The timeframe we are setting is: to finish the proposal before December 1 2005. Put the proposal into consultation by CEN for a three months period, and after that complete the proposal for final acceptance early spring 2006.

The proposal contains two parts:

Part A, the normative part, existing of the DTD for classifications in general, and Part B an informative part, existing of a proposal, for WHO-FIC classifications specific. Part B deals with the class kinds and rubric kinds that are required to make the content of WHO-FIC classifications explicit and for internal harmonisation. This Part B needs to be further elaborated in the period up until March 2006.

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SemanticHealth-Project

As of January 1st 2006, the Dutch Centre is leading a new international project on semantic aspects of interoperability of electronic healthcare systems. This project responds to a call initiated at a workshop on this topic organised early 2005 by the Mr. Pierre Lewalle, WHO Geneva, Prof Jean-Marie Rodrigues, Univ. St Etienne and Dr. Ilias Iakovidis EU-DG Infosoc. To efficiently implement e-health to meet the rising needs of mobile citizens, patients and providers, its fragmented interoperability initiatives must come together and coordinate with the increasing need to link clinical data to information from basic biological sciences and evidence of best clinical practice. Considering the need for interoperability at the Member State and cross-border level of the European Union – as expressed in the EU e-Health Action Plan – and for

global interoperability – as represented by WHO – it is necessary to embark on a process that will prompt the divergent initiatives to join forces for the benefit of all citizens.

SemanticHEALTH develops a European and global roadmap for Research and Technology Development (RTD) in health-ICT, focusing on semantic interoperability issues of e-health systems and infrastructures. The roadmap will be based on consensus of the RTD community, and validated by stakeholders, industry and Member State health authorities. It

- identifies key short-term (2-5 years) and medium-term (4-10 years) RTD needs to achieve semantic interoperability of e-health systems (including issues of nomenclatures presently in use, classifications, terminologies, ontologies, EHR and messaging models, public health and secondary uses, and decision support, their relationships, mapping needs, limitations)
- analyses unsolved RTD issues arising in the context of realistic approaches to priority clinical and public health settings (reflecting on models of use, benefits expected, concrete application experience and lessons learned; relevance of open source model)
- takes into account the impact of non-technological (health policy, legal, socio-economic) aspects

The consortium and associated experts represent centres of excellence from four continents and the WHO. The project is lead by Pieter Zanstra from Radboud University Nijmegen Medical Centre (supporting part of the Dutch-FIC-CC).

Next to WHO Geneva, and the University of St Etienne, other consortium members are György Surján, ESKI, Hungary; Martti Virtanen, NCC University Uppsala, Dipak Kalra University College London; Alan Rector University Manchester. The project is supported by Veli Stroetmann, Empirica, Bonn.

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WHO Photo Contest

“Images of Health and Disability 2005/2006”

Main Theme: "Children and Youth" with a special invitation to young photographers

Special Prize: Health & Disability at work

After the successful launch of the WHO Photo Contest in 2002 in conjunction with the release of the *International Classification of Functioning, Disability and Health* (ICF), the World Health Organization invites photographers around the world to participate in the international photo contest -- “Images of Health and Disability 2005/2006”.

The photographers are invited to photograph the notions of health and disability in a variety of ways:

- showing how people and in particular children and youth live with a disease, injury or health condition;
- showing these themes from different perspectives, such as the body, person or societal perspectives;
- capturing health & disability in the working environment;
- illustrating key conceptual features: What is health? Can we measure health? Disability as universal human experience, which cuts across mental and physical conditions.

EXCLUSIVE CALL FOR YOUNG PHOTOGRAPHERS: This year children and youth are invited to send us their photos on health and disability. Two special awards will be given for the best photos: (i) for children up to 12 years old and (ii) for teenagers between 13 and 17 years old.

We strongly encourage you to give your creativity free rein. Further information on Health & Disability and the display of awarded photos from last years photo contest can be found on the ICF website: www.who.int/classifications/icf

There are five categories of submission:

1. Colour photographs (digital or prints)
2. Black and white photographs (digital or prints)
3. Digital Art photographs (images created or drastically manipulated by computer software or electronic filters)
4. SPECIAL CALL category I: Children up to 12 years old. Submissions can be made as colour photographs (digital or prints), black and white photographs (digital or prints) or Digital Art photographs (images created or drastically manipulated by computer software or electronic filters).
5. SPECIAL CALL category II: Teenagers between 13 and 17 years old. Submissions can be made as colour photographs (digital or prints), black and white photographs (digital or prints) or Digital Art photographs (images created or drastically manipulated by computer software or electronic filters).

In each category up to ten photographs may be submitted. For each category the following awards will be given:

1st Prize	1000 US-Dollars + one set of ICF publications
2nd Prize	750 US-Dollars + one set of ICF publications
3rd Prize	500 US-Dollars + one set of ICF publications
Special mentions	100 US-Dollars + one set of ICF publications

The closing date for entries is 31. March 2006. If you would like to take part in the contest by entering a photo, please consult the Competition Rules that follow. Contest winners will be announced prior to the 59th World Health Assembly which will take place in May 2006 in Geneva, Switzerland. The announcement of contest winner will also be posted on the WHO ICF website. A possible compilation of photos could also be published.

FIC around the World

Australia

The Functioning and Disability Unit at the AIHW has recently released the following reports:

Disability Support Services 2003–04: National data on services provided under the Commonwealth State/Territory Disability Agreement.

Please click on the following links to access:

- the media release:
<http://www.aihw.gov.au/mediacentre/2005/mr20050805.cfm>

- the report, which is available for on-line viewing and free download:
<http://www.aihw.gov.au/publications/index.cfm/title/10155>

Alcohol and Other Drug Treatment Services in Australia 2003–04 Report on the NMDS

Click on this link for the media release:
<http://www.aihw.gov.au/mediacentre/2005/mr20050818.cfm>

Click here to view the report or download a copy:

<http://www.aihw.gov.au/publications/index.cfm/title/10162>

Medical Indemnity National Data Collection Public Sector 2003 to 2004

Click on this link for the media release:
<http://www.aihw.gov.au/mediacentre/2005/mr20050729a.cfm>

Click here to view the report or download a copy:

<http://www.aihw.gov.au/publications/index.cfm/title/10140>

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A Functioning and Related Health Outcomes Module (FRHOM)

The purpose of the FRHOM is to collect quantified summary information on the level of functioning of an individual. Information on a person's functioning should enhance data quality for medical purposes. It will complement information on diseases and related health problems in a range of applications (AIHW 2005). Kostanjsek and Üstün (2004) point out that, to overcome the problem where assessment data acquired in one episode of care cannot be carried over to another episode of care involving a different clinical focus, a common framework is needed. This data capture tool is intended to provide that common framework and convey summary information between care providers. It is designed for use in health, clinical and community services and will be tested in these settings. The FRHOM is a new, compact module that can provide a summary that reflects the person's current status across all components of functioning as defined in the International Classification of Functioning, Disability and Health (ICF) (WHO 2001). It is not an assessment tool but draws on information collected from a range of sources, including the person and their carers, clinicians and the usual assessment processes. The information, if gathered over time and by a range of health and community care providers, will result in a complete profile of the person's functioning. The module was developed following extensive mapping of existing items on functioning to the ICF. These items included standardised assessment tools (condition specific and generic), functional outcome, health related quality of life and population survey measures. Details of this work can be found in AIHW 2005.

Methods

The type of testing undertaken will depend on the capacity of the stakeholders to incorporate testing into their existing work programs. There are a range of possible tests, from those

that are simple and have low resource requirements (human, financial and time), to those that are more resource intensive. The types of tests proposed are:

- Structured discussions during committee meetings
- Key informant interviews
- Consensus conference
- Mapping exercises
- Completing FRHOM from case records
- Pilot testing in projects that are about to happen
- Clinical test by interested clinicians
- Testing the FRHOM with existing data

Test materials

1 A document for consultation and testing will be distributed, together with a survey form with a set of key questions, to interested persons to provide feedback to the project team.

2 A FRHOM User's Guide gives information about the purpose of the FHRM and how to collect information. It is envisaged that the User's Guide will be revised in the light of information gained during testing.

3 The set of key questions will form the basis of key informant interviews. Key informants include;

- GPs and other medical practitioners
- Health care providers, such as nurses, allied health professionals and social workers
- Australian Government departments
- State and territory government departments
- Health care consumers and people with disabilities
- Community services providers
- Clinical experts on cardiovascular disease, diabetes and other chronic diseases
- Research experts

4 A set of vignettes is available for coding using the FHRM. Reporting forms for completion by those undertaking the tests have also been developed.

The FRHOM

It comprises four tables for capturing summary information to describe a person's level of functioning:

- Body functioning, qualified by extent;
- Body structure, qualified by extent, location and nature;

- Performance in life areas: activities, qualified by difficulty and need for assistance; and participation, qualified by extent and satisfaction;
- Environmental factors, qualified by extent of influence either as barriers or facilitators to functioning.

Each table represents a component of functioning and has a range of domains and measures of the extent to which that domain is affected. The tables can be seen in the paper (B.5.5) presented in the WHO-FIC Network meeting in Tokyo, 16-22 October 2005, www3.who.int/icd/tokyomeeting/documentlist. In the meeting of the Implementation Committee of the Network, it was emphasised that FRHOM is a data capture tool designed to promote case summaries and communication. It is not an assessment tool for use in just one clinical context and in relation to one health condition. The project team is keen to receive feedback on the approach they are taking to implement the ICF.

References

Australian Institute of Health and Welfare (AIHW) 2005. A Functioning and Related Health Outcomes Module: the development of a data capture tool for health information systems. Canberra: AIHW (forthcoming)

Kostanjsek N, Üstün TB 2004 Operationalizing ICF for Measurement: Calibration, Qualifier, Instruments. Paper presented at the WHO-FIC Network Meeting Reykjavik, Iceland

World Health Organization (WHO) 2001. The International Classification of Functioning, Disability and Health. Geneva: WHO

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Belgium

ICF -ICPC Workshop in Ghent (Belgium), 23 November 2005

In November 2005 at Ghent University, Department of General Practice and Primary Health Care, members of WICC (Wonca International Classification Committee) met with a WHO-FIC representative Marijke W. de Kleijn-de Vrankrijker (WHO Collaborating Centre in the Netherlands). Representatives from four disciplines

(social, mental, occupational, physiotherapeutic) attended the workshop, together with three representatives from WICC and two specialists in informatics in Primary Care.

Aim of the workshop was to make an inventory of what has to be added to the GP's EPR system to be more comprehensive as an instrument in assessing patient's problem, describing risk factors, implementing contextual information and also to make the EPR data useful for communication.

Starting point was Chapter Z ("Social Problems") in ICPC-2 and the mapping of ICF to ICPC-2. First drafts of mapping ICPC-ICF have been made already but have to be improved and tested. Marijke de Kleijn gave a practical frame to create a mapping proposal. Rewriting the chapter Z in ICPC-2 could be an important step forward. This will be part of the discussion in developing ICPC-3 by WICC. Not the entire mapping of ICPC-ICF belongs to chapter Z, but the focus in this workshop was on social, mental and occupational problems, together with physiotherapeutic issues.

ICPC-2 and ICD-10 are already mapped and implemented in the Belgian EPR. The Belgian GP's also have a bilingual (Dutch/French) thesaurus with a list of about 45.000 "clinical labels", all double encoded ICPC/ICD.

ICF at this point is the next classification to be added to the system. The task of the representatives of the different disciplines at this workshop was to look what is still missing in these classifications for use in Primary Care. So a list can be created of items to be added when chapter Z will be rewritten.

A distinction has to be made between information to be added to the classifications and information to be added to the EPR. Information to be added to the EPR is independent of describing the patient's problem at that time, but important to register in function of a surveillance task. The future of communication, administrative management and the

evolution to patient participation in the EPR registration has to be taken into consideration in developing new tools. Agreements have been made to make an inventory of existing tools in the different disciplines, to explore what is missing in ICPC/ICD/ICF and the Belgian Thesaurus, and secondly make a choice of what has to be implemented.

The work will be done separately within the different disciplines, followed by integration in a next phase.

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Ireland

Is the current Ethical Framework for the ICF sufficient?

The current statement of ethics in relation to the ICF comprises of an introduction and eleven short and concise statements about the ethical issues that need to be addressed in the application and dissemination of the Classification. The areas covered include respect and confidentiality, the clinical use of the ICF and the social use of the ICF. Fundamentally, the guidelines are predicated on the premise that every scientific tool can be misused or abused (Annex 6). The stated aspiration is that attention to the guidelines will reduce the risk that the ICF will be used in disrespectful or harmful ways.

The core principles at the heart of the Guidelines include an acknowledgement of the inherent value & autonomy of the person, a prohibition on the labelling or categorization of people, the requirement for full knowledge and informed consent on the part of the participant and the safeguarding of privacy and confidentiality. In clinical use, the guidelines place a responsibility on the clinician to explain to clients the purpose for which the classification is being used, to support and encourage the active participation of the person and the use of the classification in a holistic way.

The social use of the classification should be about collaboration, choice, support and enhanced participation. It should not be about the restriction of rights or entitlements and there should be no assumption of homogeneity.

It is legitimate to question whether or not these brief guidelines are sufficient to support the ethical global deployment and dissemination of what is a very powerful classification. It is also legitimate to query the priority assigned to the Ethical Guidelines by the WHO itself when it sees fit to be able to drop them from the short version of the classification. In the absence of a justification for this editorial decision, one might well assume that either ethics did not rate as a high enough priority for inclusion in the short version or that the omission was the result of an oversight. Whatever the reason, the omission sends a very unhelpful message to people with disabilities and their advocates. This is particularly so in a context in which there has been little or no public activity or debate in relation to the ethical risks associated with the use of the classification nor have the ethical guidelines formed a core element of training courses or presentations on the ICF, that I have come across.

Surely there is an onus on those who support the global application of the ICF to provide more detailed guidance on how ethics should be incorporated into the development and application of instruments and tools based on the ICF. There is a critical requirement for the international community to take on board the very real concern of people with disabilities and their advocates that the ICF has the potential to be deployed in ways that may not be in the best interests of vulnerable people. This concern needs to be addressed not simply through a static statement of an ethical code but through a dynamic process of ethical decision-making that is incorporated as a core element of the Classification. The ethical framework and guidelines must be considered as an integral part of the use of the tool and, in any

future publications of the Classification, should be presented in the introduction and highlighted.

In order to stimulate discussion and debate about the issues and to emphasise the need for the prioritisation of ethical issues in global discourse about the ICF, a number of concerns are discussed here.

Inequalities of power: the Individual and the ICF

The main ethical concerns with regard to the use of the ICF arise from inequalities of power. The ICF is a very 'powerful' Classification, which is generally understood and applied by professionals on behalf of people who are in many cases vulnerable. The power of the ICF emanates from a number of sources. Specifically, the ICF has **descriptive and explanatory power** in so far as it is possible to use it to document and explain why individuals or groups of individuals are experiencing activity limitations and/or participation restrictions. It has **linguistic power** in that it provides a unique opportunity to communicate across linguistic boundaries, cultures and jurisdictions. It has **professional and academic power**. The ICF is likely to become incorporated into the research practice of researchers and academics and the professional practice of doctors, social workers, psychologists and other allied health professionals. It has the potential to be used within the legal system by lawyers and judges to determine the outcome of legal cases.

The ICF will accrue **institutional, administrative and regulatory power** as government departments, authorities and agencies begin to adopt it as the basis for decision-making in relation to the allocation of resources, the determination of eligibility, the application of procedures and political decision making. In an environment where the application of national disability strategies has given rise to the development and implementation of a range of legal instruments to protect and promote people with disabilities within society, the ICF can provide a

practical format for the production of regulatory instruments.

Finally and most importantly the ICF has **consensual power**. It has been developed through a discourse between the World Health Organisation and Disabled Persons International. It is currently on trial. DPI has made a conditional decision to support the ICF in the medium term. This decision has repercussions at national level for disability activists and Centres for Independent Living. The ultimate success or failure of the ICF depends upon the way in which the Classification is utilised. In its own terms, it is a part of the environment that has the potential to be used to disable people with reduced function either inadvertently or intentionally. Equally, it can be the cornerstone of creating inclusive processes that enable people with disabilities to participate to the full in mainstream society.

Inequalities of power can arise from a wide variety of factors. The complexity of the ICF in itself creates a barrier to self-advocacy and to personal empowerment.

- Personal Vulnerabilities

Inequalities of power can arise from a range of factors including personal vulnerabilities. For example Age - people can be very young, even at the foetal stage of development, or very old and approaching senility; Gender - people can be at risk of double discrimination on the basis of gender and of disability; Health - people who are not well and experiencing pain or other symptomatology may have difficulty in coming to terms with the ICF; or Genetic Inheritance - people with clearly identified conditions, some of which have not manifested themselves as yet, have the potential to be classified prematurely using the ICF.

- Economic, social and cultural imperatives:

There is a range of issues facing society that are high on the agendas of many Member States. The ICF could provide States with a tool to begin to address these issues. For example, it

is highly likely that the ICF will be used to address the issue of costs associated with disability.

- Technological vulnerability:

With the introduction of Personal Identification Numbers (PINs), the ICF provides a systematic methodology for computerising all information about an individual in relation to their current status. Once information has been coded and stored within an information management system, it can be used to calculate probabilities of outcome, estimate return on investment in relation to certain conditions, specify those for whom certain interventions are counter indicated and to implement programmes and mechanisms that can have substantial implications in terms of personal costs for individuals with reduced function and their families.

In order to ensure that the ICF is ethically applied and deployed across Member States and across disciplines, a number of steps must be implemented.

1. A clear and comprehensive Code of Practice must be developed and endorsed by WHO
2. It must be ensured that all professionals are trained in, and have committed to, the Ethical Code of Practice
3. Professional associations must incorporate the ICF Ethical Code of Practice into their own ethical guidelines
4. People with disabilities, families and carers must be educated and made aware of the Ethical Code of Practice and their rights under the Code
5. National and international ethical monitoring structures must be put in place
6. The Guidelines must be reviewed and augmented to address beneficence, competence, social justice and extended responsibility.

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The Netherlands

ICF based surveys and statistics

There are several activities relating to the development of internationally comparable question sets for the measurement of Functioning and Disability in censuses and surveys. All of them intend to use the ICF as the framework. But what does it mean and how is the use of the ICF applicable for surveys? And second: how is coordination of these activities at world and regional level to be realized in order to prevent different recommendations for the measurement of functioning and disability in surveys sent to countries? First of all we present a short (not limitative) over-view of current activities in this area.

UN: Under the aegis of the UN a so-called city group, the Washington Group on Disability Statistics (WG), is in charge with the development of a short set for the measurement of disability in censuses and extended sets for the measurement of disability in national population based surveys. Both are intended to improve cross national comparability of disability statistics. So far the WG developed a draft short set including 6 questions on seeing, hearing, walking and climbing steps, remembering and concentrating, self care, communication. So this set is mainly relating to body functions and (some basic) activities. The set has been used and is going to be used in several countries in South America and Africa for cognitive and field testing. The extended sets are still under development; at least one (not yet accepted) proposal includes the use of the WHS-17 and the WHO-DAS-12 as an extended set. A second set could include more participation and environmental factors related questions. On the longer term it might be possible to develop a short set on participation and environmental factors.

The UN planned in the census program 2010 to include the measurement of disability including the recommended questions from the Washington Group.

WHO: WHO and UNESCAP carried out disability pilot studies in de ESCAP region. The questionnaire encompasses

the short set of the Washington Group, WHS-17, WHO-DAS-36 and the short Australian census question set on need for assistance. It is expected that WHO and UNESCAP will start a similar project in the ESCWA region.

Eurostat: At the level of the EU a set of modules relating to health, health care and health determinants. The modules are intended to be implemented in national surveys in order to improve the cross national comparability of health and disability statistics at the European level. The European Health Status Module (EHSM) encompasses questions such as diseases, mental health, functions, activities and a few participation questions on participation. This module was available for field testing in 2005; experiences will be analyzed in order to finalize this module. In 2006 a module on functioning/ disability including more extensive participation issues and environmental factors will be developed. For this module Eurostat is aiming at synchronization with the Washington Group results.

UNECE/WHO/EUROSTAT: An initiative taken by the UNECE in cooperation with WHO and Eurostat includes the development of a measurement instrument for health state. Items mentioned as to be included are: vitality/fatigue, cognition (memory, concentrating, thinking, problem solving), affect, anxiety, vision, hearing, pain and discomfort, mobility, dexterity, social relationship including communication.

ICF relation

Although all activities mentioned above indicate to use the ICF as the framework, the relationship is not very clear in all situations. This has been discussed by the WHO-FIC network

during the annual meeting last October in Tokyo. As a result it was found that the use of the ICF in surveys should mean at least:

- use of correct ICF terms, concepts and definitions;
- use of the correct ICF scheme;
- use of the full spectrum of the ICF (e.g. covering all components but not necessarily all classes of course).

We recommend all involved persons and organizations to see what this could mean for their work.

Need for coordination

It is clear that countries will not be able to use different measurement instruments dealing with at least partly the same items in one national survey; budget and space/time in questionnaires/interviews do not allow to do so. For that reason it is recommended to try to synchronize the questionnaires: questions dealing with the same issue should be the same or can be a specification of each other; questions dealing with similar issues but different components of the ICF (e.g. body function compared to activity) should reflect the differences. A complete matrix using the ICF as a ruler and crosswalking the initiatives/questionnaires mentioned above is presented as an Attachment to the annual report of the WHO-FIC Implementation Committee 2005, paper number B.5-8, to be found at www.who.int/classifications/network/meeting2005.

All responsible persons are invited to take this recommendation into account in order to create realistic recommended measurement instruments and cross national comparable functioning and disability statistics.

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	Seeing/vision	Hearing
WG short set	Difficulty seeing even with glasses	Difficulty hearing even with a hearing aid
WHS-17	Seeing/recognizing a person; seeing/recognizing object	Hearing someone; hearing a conversation
UNECE/WHO/Eurostat	Vision	Hearing
EHSM Eurostat	Seeing newspaper print with./without glasses/ see a face	Hearing a conversation with several people; hearing a conversation with one person

Two examples of questions dealing with the same or similar issue

Emancipation for people with disability by means of evaluation

For many years, the kind of help offered to mentally disabled people was defined by the vision of the professionals who knew what was good for their clients. It was a matter of "you get what you are offered".

Towards the end of the eighties and the beginning of the nineties, pressure by parent organisations brought about a change in this process. These groups managed to persuade the authorities that they wished the care offered for their disabled child to be based not only on the request for help from the child but also on the needs of the family.

The government shared this vision and obliged the various institutes to adjust their offer of care to suit the client. A very important aspect was the introduction of the Personal Budget: this budget gave the clients the financial means to buy their own care.

The introduction of this kind of care motivated the Province of Groningen in the early nineties to support a group of parents with mentally disabled children in the town of Ter Apel with the development of living accommodation for their children. The initiative came about in collaboration with Stichting Humanitas DMH, which champions a society in which people with disability actively shape their own life and also take responsibility for living with each other. This is applied to services in the areas of well being, living and care. Because this initiative was so new, the Stichting Humanitas DMH was, among others, supported by the Education Faculty of Groningen University.

To get a good insight into the needs of the client and to offer the right kind of help in the right place it was necessary to make a detailed study using an extensive questionnaire. This was the beginning of the development of the Evaluation Scale (in Dutch: Taksatieschaal).

During the following years, this Evaluation Scale was developed into an instrument in which the practical and socio-emotional skills of the client are assessed by means of 450 questions. The questions are divided into 9 sections, e.g.:

- 1 Practical skills in the personal sphere
- 2 Practical skills in the domestic sphere
- 3 Practical skills in the community
- 4 Intellectual skills
- 5 Personal skills
- 6 Social skills, individual traits
- 7 Social skills, social functioning
- 8 Special areas focussed on serious behaviour problems
- 9 Special areas focussed on epilepsy

A specialist institute that serves people with light mental impairment and serious behaviour problems drew up the questions under section 8 together with specialists and practitioners in this field. For the questions concerning epilepsy, the same process was applied using an extensive inquiry with the "Stichting Epilepsie Instellingen Nederland". Neurologists, behaviour specialists and management also contributed.

Questions, based on the concepts used by neurologists concerning the types of attacks, were developed to ascertain the safety of independent living.

Finally the same process was applied to people with profound multiple disabilities.

What distinguishes the Evaluation Scale and what makes it unique is that after each question a time assessment is fixed. This determines the amount of time needed for the support of the client. The support time needed is combined with the desired structure of the future living situation, which must create sufficient safety. This process has been automated completely. The time assessment is based on the practical experiences of the care workers. Up to now about 3500 Evaluation Scales have been used and 90% of the client network identifies with the result. It can be presumed that the reliability of the results is more than 90%.

Clients have information available with which they can indicate their care requirement and so consequently buy care provision. Based on measured information, they know what they need and they have control. When he or she then buys the necessary care armed with a personal budget the emancipation process is strengthened even further.

To give people with disability control over their own lives seems obvious but it is not an easy task. The Evaluation Scale a marvellous instrument for them

to give form to their own lives and it is suitable for several user groups.

The client completes the questionnaire (with parents, care workers, and behaviour experts). The answers are fed into the computer. The results are then compared with the existing profile of the client and the requirement for care. As a result, there is not only a method, but also a procedure that includes the client.

In practical terms, some people with mental disability do not always understand the written text and often more information is needed. Spoken text, signs, illustrations, or a combination of all three will enhance the written word. This is a good reason to develop a multimedia version of the Evaluation Scale.

The Evaluation Scale will ensure the quantity and quality of the care to be offered to the client as follows:

- Measurement of possibilities and limitations
- Mapping of the phase of the development process
- Revealing the existing skills and the desires of the client to retain skills or to develop them further
- The evaluative use of the Scale to measure progress or deterioration

The framework of the International Classification of Functioning, Disability and Health (ICF) shows the classifications which form the standardised understanding of human functioning and the problems associated with it. With the help of the ICF, human functioning can be described from various perspectives: those of human functioning, human behaviour and as a member of society.

The various components of the Evaluation Scale were compared with those of the ICF. This comparison will bring the Evaluation Scale into harmony with the ICF and will possibly contribute to improving the ICF. In order to learn more about international developments we will be pleased to contact researchers involved in the same field.

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