

**WHO Family of International Classifications Network Meeting**  
**Reykjavik, Iceland**  
**24-30 October 2004**

**Executive Summary**

**1. Opening of the meeting**

The WHO Family of International Classifications (WHO-FIC) Network meeting was opened on 24 October 2004 by Mr David Á. Gunnarsson, Dr Sveinn Magnússon, Dr Martti Virtanen and Dr Bedirhan Üstün who welcomed the delegates to Reykjavik and emphasized the importance of the normative role of WHO and the function of classifications as the building blocks for sound health information systems.

The meeting was attended by over 100 international participants from 12 WHO Collaborating Centres and representatives from Ministries of Health or National Statistical Bureaus. The Agenda (annex 1) and the List of participants (annex 2) are attached. Papers presented in the conference are available at the host centre web site (<http://www.nordclass.uu.se/WHOFIC/reykjavik.htm>). The views expressed in these papers are those of the named authors only and do not necessarily represent views or WHO or WHO FIC Network.

**2. WHO-Family of International Classifications**

The meeting served to review all elements of the WHO Family of International Classifications and the work of the WHO FIC Network, including Centres themselves and various committees (Planning Committee, Implementation Committee; Education Committee; Family Development Committee; Electronic Tools Committee). In particular the Business Plan development, ICD revision process and WHO FIC web site received special attention during the meeting.

**2. a. WHO-FIC Business Plan**

The draft Business Plan (WHOFIC/04.004\_A1) was presented by the WHO Secretariat and discussed in plenary on two occasions during the meeting. It was also discussed in the Planning Committee sessions. It outlines what needs to be done to take WHO Classifications and the supporting infrastructure into the 21<sup>st</sup> century and position them in the developing universe of health information - from the patient care end to health statistics. Strategic directions, business drivers, required resources, potential partnerships and future actions are spelled out. It informs existing and future stakeholders about portfolio priorities, and it addresses a number of recognized challenges in making classifications useful for current health initiatives.

The Business Plan was generally very well received and all WHO FIC Network entities and committees put it on their agenda. During the meeting various suggestions and improvements were made to the business plan which was then going to be discussed in a meeting 1-2 November 2004 in Geneva with the participation of the Planning Committee. These were as follows:

- Executive Summary: to specifically point out the action points.
- Risk benefit analysis: The issue of ensuring "sustainability in WHO's classification work" should be addressed. The "business as usual scenario" should be used as a baseline scenario in all risk analysis.
- Information paradox: A graded approach was suggested towards obtaining mortality statistics in all information paradox countries by 2015. The current proposal to the Health Metrics Network is to focus on 4-6 countries in the African Region. Furthermore, efforts to be linked with WHO programmes such as "3by5" and "Stop TB and Malaria" to improve mortality reporting. Additional resource generation from multiple donor agencies for supporting this work will be sought as a network.
- Co-ordination with related sectors and institutions: The links between WHO-FIC and related sectors (e.g. vital registration, labour, welfare, standardization) and respective institutions (i.e. UNSD, ILO (International Labour Organization), ISO (International Organization for Standardization), Eurostat, CEN (European Committee for Standardization)) should be strengthened.
- ICD-Revision: This is a resource intensive effort. If resources were available this activity can generate a huge focus and momentum for developing a better application. However, such efforts should not hinder the usual activities of implementation and regular updating of ICD -10. Evaluation of ICD -10 implementation and update practice should inform the revision process.
- ICF: ICF was regarded as a strong business case. First, using ICF as a common framework for health and disability surveys could lead to substantial savings and more comparable data. Second, using ICF as a health outcome measure can demonstrate the linkage between health and productivity gains. Furthermore, it was noted that ICF serves as a communication and service provision model.
- ICHI: Given the huge expenditures on health interventions, data is necessary to understand the type and frequency of health interventions. It was emphasised that ICHI should be developed following field trials primarily to serve those countries which currently do not have an intervention classification. International comparison lists could be developed based on the common interventions given their public health importance and frequency.
- WHO FIC Terminology Links: Given the advances in Information Technology and terminology work, development and maintenance of classifications hand-in-hand with terminologies is an essential step. This line of development should be explored further with all interested parties.

## **2. b. WHO FIC Committees**

The Planning Committee and each of the WHO FIC committees presented an annual report of its activities:

- Planning Committee (WHOFIC/04.091)
- Implementation Committee (WHOFIC/04.092)
- Family Development Committee (WHOFIC/04.017)
- Update reference Committee (WHOFIC/04.015)
- Education Committee (WHOFIC/04.016)
- Electronic Tools Committee (WHOFIC/04.094)
- Mortality Reference Group (WHOFIC/04.017)

The reports are available on the host centre web site.

## **3. International Classification of Diseases (ICD)**

### **3. a. Implementation**

It was agreed to develop and maintain a database of the levels of implementation across the Family. The Education Committee should liaise with WHO to update the database with the survey information and in particular identify countries with no or only partial implementation of ICD-10.

A report on barriers for implementation in selected countries will be prepared for discussion at the 2005 meeting of the Network. In the long-term a questionnaire on implementation will be sent to the organizations maintaining related classifications. Barriers for implementation go beyond the classifications. This task requires engagement with partner organizations. It was recommended that WHO should initiate discussion with other UN organizations with responsibility for vital registration and those programmes supporting vertical projects. Some reference to this item needs to be incorporated into the Business Plan.

The marketing of the classifications will be developed in line with the work described in the Business Plan. To achieve this, the following lines of action were proposed:

- To formulate a paragraph on why ICD and ICF should be used.
- To develop brochures about the Implementation Committee, ICD and ICF based on those produced by the Education Committee and the ICF in Australia. These brochures would be used for international marketing.
- To review material on the WHO-FIC website to see which entries tie in with the Implementation Committee strategy, particularly the IC entries, and to incorporate material from the new brochures.
- To further develop the final marketing element (WHO cost recovery and pricing) policies in order to entice countries to start implementation. WHO is urged to adopt a flexible pricing policy in this respect.

It had previously been agreed to establish and maintain a Roster of Experts. An updated summary of information on individual experts should be placed on the WHO-FIC website for the benefit of WHO Regional Offices and others.

Tools for implementation, including ICD in a box, need to be enhanced. The range of elements for inclusion in the box, aside from experts, such as resources now on the WHO-FIC website, need to be identified and a checklist of items developed from which the elements needed for each country can be selected by Regional Offices and consultants. National institutions that should be responsible for implementation of vital registration and classification systems in each country need to be identified in co-operation with WHO Regional Offices as well as relevant individuals in those institutions.

### **3. b. Updates**

**The Update Reference Committee (URC)** had three working sessions. A total of 72 proposals for the updating of ICD-10 were considered. Of these, 54 were accepted, 9 were withdrawn, 1 was not supported and 8 were held over for consideration during 2005. The accepted proposals were endorsed by the WHO-FIC meeting. It was recommended that the approved changes that will be implemented in 2006 be posted on the WHO website at the beginning of 2005 (these are contained in document WHO/FIC/04.087 and under URC sessions in the Meeting Report). Actions to be taken included:

- Confirm arrangements for transition of URC responsibilities from the Australian Centre to the North American Centre (CIHI) (ACC, NACC & WHO-CAT)
- Collate and report proposals for updates to ICD-10 including mortality coding rules and guidelines (URC and MRG)
- Inform all users about updates and the dates of implementation (WHO-CAT (English & French translation), PAHO (other translations))
- Make available the main language translations of updates (PAHO and appropriate Collaborating Centres for French, Spanish and Portuguese)
- Preparation for implementation of ICD-10 Third Edition with updates accepted up to 2004 for implementation in 2006 (URC)
- Disseminate updates (WHO-CAT)
- Agree on a plan for conducting an assessment of updating of ICD-10 (URC with IC, WHO-CAT & EC)
- Assessment of updating complete (Planning Committee & WHO CAT)

**Mortality Reference Group (MRG)** met on 21-22 October 2004 in Reykjavik and had a further meeting during the Network meeting. The aim of the MRG is to improve international comparability of mortality data by establishing the standardized application of the ICD for mortality applications. Lars Age Johansson was re-elected as Chair of the MRG for the period 2005-2006. Their recommendations were as follows:

- *External Cause of Injury Mortality Matrix*: should be published to standard WHO tabulations to facilitate statistical analysis with totals of broad Chapter XX groups (accidents, suicides, assaults) given.
- *Leading Causes of Death*: should be continued.
- *Data collection in Information Paradox countries*: should be supported through ICD-10 in-a-box and alternative data collection methods such as verbal autopsy or checklists.

### **3. c. ICD Revision**

The ICD was approved by the International Conference for the Tenth Revision of the ICD in 1989 and adopted by the 43<sup>rd</sup> World Health Assembly in 1990. In the same resolution the article (3) endorsed the need for the establishment of an updating process within the ten-year revision cycle. The revision process which has almost always occurred within 10 year cycles, beginning in 1900, has nevertheless purposefully been deferred for a 20 year interval to be ready by 2010 or thereafter in order to enable a wider implementation of the ICD.

Given the preparations to issue an ICD-11 WHO has initiated a systematic effort for the ICD Revision process to respond to the needs of member states and users, and keep up with new scientific knowledge (Appendix: WHO presentation on ICD Revision). This will be a major evidence-based review process that will address the structural changes and new disease entities and end up in with a final product of user-friendly and scientific ICD-11 as the final product. The revision process will involve multiple parties and professionals and consider the use of classifications at hospitals, primary care and other health care settings such as rehabilitation and long term care. Once the problems and proposed solutions are obtained from different sources, we plan to synthesize them in an evidence -based proposal with transparent rules and knowledge sharing tools. The development will be made in a well-defined database using IT technology and Internet. Various expert groups will be consulted and relevant sections of the classification will be field-tested using field trials.

The WHO FIC Network Meeting adopted the revision process workplan. The Planning Committee had discussed the revision plan in depth in 25 -27 April 2005 in Helsinki and decided to support the ICD Revision Process and the workplan ([http://www.nordclass.uu.se/temp/ICDrevplan\\_Hki.htm](http://www.nordclass.uu.se/temp/ICDrevplan_Hki.htm) ). The work was envisaged in three stages (i) Development of an alpha version of ICD-11; this will be undertaken by a centrally coordinated team (ii) Development of a beta version, based on comments received from extensive consultations on the alpha version. (iii) Field testing of the beta version and development of the final version of ICD-11. The final version would need to be formally endorsed by the World Health Assembly. It was noted that some URC responsibilities have moved into the tasks for the ICD revision process, e.g. updating of specific topics. Other tasks concern testing, arranging of mini-conferences, and to agree on a strategic direction for the revision process discussed at this meeting. A more detailed plan for the revision of ICD should be developed.

This topic will be discussed in more detail in the meeting at the Planning Committee Meeting which will be held in April 2005 in Bangkok. Several Centres expressed interest in taking part in reviewing the evidence and starting the process in the following areas:

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

### **3. d. ICD International Training and Certification Program**

The WHO-FIC Education Committee reported on progress made on an International Training and Certification Program for mortality and morbidity. Nearly 100 countries responded to needs assessment surveys, which identified a variety of barriers to implementing ICD and extensive information on the coding practice worldwide. The meeting approved the standard ICD-10 core curricula for underlying cause-of-death and morbidity coders developed by the Education Committee and endorsed the Business Plan for the training and certification program. The core curricula and business plan had been endorsed by the International Federation of Health Records Organizations (IFHRO) at their 14<sup>th</sup> Congress earlier in the month. A Joint WHO-FIC – IFHRO Committee will take forward much of the work identified in the business plan.

### **3. e Work group on hospital data**

Prof Björn Smedby has led the subgroup for the past two years. The origin was an EU project aimed at improving hospital statistics with the help of shortlists.

- Australia and US will contribute data before end of 2004. There is a database on CD-ROM available for analysis. Japan has also offered data.
- Prof Smedby is to dialogue with the EU HDP group as the EU project continues, to evaluate the data, set up a web village and distribute updated data.
- Hold meeting with the EU group and FDC with participants from OECD, WHO-EURO and other experts from all countries to discuss inconsistencies, issues such as the inclusion of private care, same day care and the use of codes. The results to be presented at the 2005 WHO-FIC Meeting.
- The Planning Committee is to consider if the working group should be expanded to include hospital morbidity coding and multiple coding (incl. dagger-asterisk) with the aim to develop more standardized rules for coding of multiple hospital data.

### **3. f. Derived and related classifications**

#### **Anatomic, Therapeutic, Chemical (ATC) Classification of drugs**

A presentation of ATC and its governance was given by Marit Rønning, Director of the WHO Collaborating Centre for Drug Statistics Methodology in Oslo, Norway.

The WHO Collaborating Centre for Drug Statistics Methodology Oslo would welcome a WHO-FIC observer joining the International working group for drug statistics methodology. The Nordic Collaborating Centre agreed to provide the observer.

The Oslo Centre agreed that they would participate in the activities of the WHO-FIC Network and Network meetings with the aim of improving the alignment between the ATC and other WHO-FIC member classifications.

It was noted that there is no coverage of non-prescription and over-the-counter drugs, including drugs of concern in the ATC.

## **WHO-FIC Primary care classification(s)**

There was acceptance of development of a "WHO FIC Primary Care Classification(s)" as the goal of the collaboration between WHO FIC and the World Organization of Family Doctors (WONCA) International Classification Committee (WICC).

Further work within the WHO/WICC group was encouraged, especially to improve alignment between WHO-FIC reference classifications (ICD, ICF, ICHI) and the WONCA International Classification of Primary Care (ICPC), and also to inform the ICD revision process.

The Dutch Collaborating Centre agreed to take on the task of investigating the alignment between ICF and ICPC.

## **4. International Classification of Functioning, Disability and Health (ICF)**

### **a. Implementation Strategy**

The meeting elaborated and recommended four *strategic directions for ICF implementation*: (i) establish ICF as the official framework for measuring health and disability in the general population (in censuses and surveys) across member states; (ii) institute the ICF as a major health outcome assessment framework at the clinical and service levels in order to quantify health gains of treatment programmes and to understand how health gains translate into productivity gains at the individual and population levels. (iii) mainstream ICF in administrative and clinical information systems including electronic health records and clinical terminologies; (iv) implement ICF in the social policy field by focusing on: aligning the disability certification process with the ICF framework; and developing applications in the areas of education, labour market and law.

A working group is expected to elaborate implementation strategies for the four strategic directions and report them during the next meeting of the Planning Committee in April 2005. Subsequently, demonstration projects relating to the four strategic directions should be identified and facilitated.

In support of ICF implementation the meeting decided to establish an *ICF knowledge network* for sharing information on ICF implementation, uses, educational materials and efforts. A draft template for information sharing has been developed by the Australian CC and should be field tested with all Collaborating Centres and Regional Offices in the first half of 2005. The final version of the information sharing framework should be hosted on the new WHO-FIC website with linkages to a mirror website in each of the Collaborating Centres.

On behalf of the WHO-FIC Network the Planning Committee issued a *statement regarding ICF as the official framework for measuring health and disability* in the general population across member states. The statement welcomed the decision by the Washington Group on Disability Statistics to adopt the ICF as the framework for its work. However, the statement also expressed concern regarding the Washington

Group's development work on disability census questions. Issues of particular concern include the strong focus on impairment questions, lack of evidence-based item selection and weak linkages with health status measurement. The statement noted the WHO-FIC Network's support for the Washington Group in addressing these issues to ensure the correct, optimal and evidence-based use of the classification.

*ICF Training and Education:* The meeting recommended that educational strategies should be aligned with the implementation strategies for ICF. The main focus of educational work should be on increasing awareness. Therefore educational brochures on ICF implementation should be developed and disseminated. Other activities include the stock taking of ICF related educational efforts and material, enhancement of FAQ's on WHO-FIC website and a possible development of generic slide sets and core curricula for users and providers of data.

*ICF Application tools:* The mapping of existing assessment instruments into the ICF framework was identified as one of the priority tasks. The Implementation Committee assigned this task to a small working group, which is expected to carry out the following activities by October 2005: (i) conduct an inventory of existing instrument mappings; (ii) provide information for the development of a mapping typology and decision rules; (iii) provide information for preparing validation protocols. The WHO-FIC collaborative workspace will serve as the platform for this work group.

With regard to the ICF Browser the first update with 8 languages was announced by the WHO Secretariat. A second language update is expected for mid 2005. Further development work on the ICF Coding tool will be conducted by WHO Secretariat in 2005. A survey on identifying gaps and needs for ICF Electronic Tools will be implemented by the North American CC in collaboration with the Implementation and Education Committees.

The meeting took note of a number of ongoing efforts. The study group on subjective dimension was invited to post their annotated bibliography on the WHO-FIC website. Furthermore, they were asked to coordinate their work closer with WHO's work on Quality of Life measures. For the WHO-FIC Network Meeting 2005, reports on work progress were requested on ICF Core Sets projects (German Collaborating Centre), the EC funded project Measuring Health and Disability in Europe, MHADIE (Italian Collaborating Centre/ WHO CAT) and the Washington Group on Disability Statistics.

#### **b. Children and Youth version**

The field testing of the ICF Children and Youth (ICF-CY) has started within ICF-CY work group. The meeting noted the need for extending the field testing beyond the work group to a wider community with particular emphasis on developing countries. Therefore the WHO Secretariat in collaboration with the work group will undertake the following activities: (i) developing and posting a Basic Question protocol together with an ICF-CY marked- up copy (indicating all modifications made) as a database and in pdf format on the WHO-FIC website by December 2004; (ii) official dissemination of ICF-CY beta version with test protocols within WHO and the WHO-FIC Network; (iii) work status report for April 2005 meeting of the Planning Committee and Centre Heads.

## **5. International Classification of Health Interventions (ICHI)**

The meeting was presented with the electronic and printed copies of the ICHI beta version, developed under the auspices of the network by the Australian centre (NCCH) on the basis of the Australian classification (ICD-10-AM). The proposed classification was intended for use as a simpler classification in countries that did not have any classification schemes for interventions.

WHO-CAT agreed to arrange for extended field tests of ICHI. Arrangements have been made to prepare supporting questionnaires. They will be fielded as soon as feedback has been received from the centres.

Several issues that need to be addressed were raised during the meeting. The value of the ICHI contribution has been highly appreciated, but any final version to be proposed to WHO governing bodies for possible adoption should ensure that all Member States have an equal chance to produce high quality data in using the proposed classification as other Member States that use a more comprehensive classification.

It was also emphasized that the scope of the classification should go beyond medical/surgical procedures, given the fact that developing countries are devoting important portions of their limited resources to preventive and other public health interventions, which need to be carefully planned and monitored.

- In practical terms, it was agreed that countries already using larger interventions classifications would map them to the ICHI to assess their compatibility.

## **6. WHO-FIC and terminologies**

The meeting recognized the central role clinical terminologies are to play in the interoperability of systems. Efforts should be made to create synergies between the international classifications as "first generation tools" and clinical terminologies such as SNOMED-CT "second generation tools". Third generation tools are now emerging, adding ontology-based formal concept representation features to the array of instruments that represent clinical knowledge in an appropriate way. This paves the way for a closer integration of information and knowledge sharing tools in a context of true semantic interoperability. Obviously, classifications and clinical terminologies will need to be considered simultaneously for future development.

A number of English-speaking countries have decided to adopt SNOMED-CT as their reference terminology to develop their health information systems. A number of other countries noted the limited suitability of SNOMED-CT in other language spheres and suggested that consideration be given to the emerging third-generation systems that look more promising with regard to multilingual applicability and adaptability to the needs and resources mobilization potential of developing countries.

In the search for a pragmatic solution, it was reported that WHO had had initial contacts with SNOMED-CT representatives for its internationalization. Further discussions would be needed on the details of a possible agreement and technical

improvement in conjunction with WHO products. In light of these developments, the Family Development Committee concluded that its own Terminology working group needed to be replaced by a stronger structure.

## **7. Other issues**

### **Collaborating Centre and Regional Office participation**

Members of the Network noted with regret that of the six WHO Regional Offices, only two (AFRO and AMRO/PAHO) had been able to attend the meeting. In addition, the Chinese, Russian and Spanish language centres had been unable to send representatives.

The WHO secretariat undertook to investigate more flexible solutions, both short and long-term, to enable these delegates to attend the annual Network meetings, including the removal of possible financial obstacles.

### **Place and time for the 2005 Network meeting**

On behalf of the Vital and Health Statistics Division, Statistics and Information Department of the Ministry of Health, Labour and Welfare of Japan, the Director of the ICD Office in Japan informed the meeting that Japan has agreed to host the next meeting of the WHO-FIC Network from 16-22 October 2005.

### **Place for the 2006 Network meeting**

Consideration of proposals for the location of the 2006 meeting will be made by the Planning Committee at its April 2005 meeting. There were four main proposals: North Africa (e.g. Tunisia), Italy, Mexico and South Africa. The meeting supported the general idea of choosing a location in an "information paradox" country.

A proposal was made to decide on a location *before* the next Planning Committee meeting in April 2005 so that representatives from the respective organization could participate in and attend that meeting.

**WHO FAMILY OF INTERNATIONAL CLASSIFICATIONS NETWORK  
MEETING Reykjavik, Iceland 24-30 October, 2004** WHO/FIC/04.001

**Meeting Agenda *Sunday 24<sup>th</sup> October 2004***

**12.30 – 13.30 Planning Committee**

**13.30 –14.00 Break**

**14.00 – 17.00 Meeting of the Heads of Centres**

Report from Helsinki meeting

Other business

**18.30 - 19:00 Registration**

**19.00 - 20.00 Opening Reception at Asmundur Sveinsson Art Museum**

Dr Martti Virtanen, Head, Nordic WHO-FIC Collaborating Centre Dr Sveinn Magnússon, Head of Department, Icelandic Ministry of Health and Social Security, Chairman of the Board of the Nordic Centre Mr David Á Gunnarsson, Permanent Secretary, Icelandic Ministry of Health and Social Security, Chairman of the Executive Board of WHO Dr T Bedirhan Üstün, Head WHO CAT

**Note on Breakout sessions of committees during the meeting:** The committee chairs may change the agenda for the breakout sessions. Thus, certain papers might not be presented in the session(s) they are listed for in the agenda. Some papers are listed for discussion in a breakout session and for presentation in plenary.





***Tuesday 26th October 2004***

**08.30 - 10.30 Breakout Session 2.1** **No.**

**2.1.A Family Development Committee - chair: Richard Madden**

Update on International Classification of Health Interventions Beta Version (WHO CAT) 48

International Classification of Health Interventions Beta Version (Australian Centre) 42

Beyond membership of the World Health Organization Family of International Classifications (Netherlands and Australian Centre) 43

WHO-FIC Development 49

**2.1.B Education Committee - chair: Marjorie S. Greenberg**

Recognition of Clinical Coder Skill Levels within the National Health Service (C Sweeting) 34

The results of questionnaire survey of health information manager in Japan (T Ohi, Y Yokobori, S Yamamoto, M Kimura)

Aspects of developing an educational program for a variety of different professions using ICD-10 (S Weber)

The improvement of the Mortality and Morbidity Statistics: The Brazilian Experience (R Laurenti, Mello Jorge, C M Buchalla) 25

Reaching out to remote locations via videoconference (L Moskal, L Tournay-Lewis)

Discussions on future work

**10.30-10.45 Break**

**10.45 - 12.30 Breakout Session 2.2**

**2.2.A Family Development Committee - chair: Richard Madden**

Adoption of Clinical Vocabulary Standards for the Federal Enterprise (M S Greenberg, D Pickett) 65

Statistical uses of WHO-FIC classifications(R Madden) 47

## ***Tuesday 26th October 2004***

### **2.2.B Implementation Committee (ICD) - chair: Peter Goldblatt**

Generic issues (Implementation of WHO-FIC generic tasks in Strategy and Workplan, Oct 2003) -

ICD issues (Implementation of WHO-FIC ICD tasks in Strategy and Workplan, Oct 2003) -

### **12.30 - 13.30 LUNCH incl demonstration of ICHI**

#### **13.30 - 15.15 Breakout Session 2.3**

**No.**

### **2.3.A Update Reference Committee - chair: Rosemary Roberts**

Issues paper on implementation and evaluation of the updating process (R Roberts, L A Johansson, M S Greenberg, J Rust)

A strategy for evaluating ICD-10 implementation and the updating process (Peter Goldblatt, Marjorie Greenberg) 66

ICD-10-XM (Rosemary Roberts, Bedirhan Üstün, Michael Schopen) 73

Updating/revising specific clinical topics in ICD-10 (R Roberts, J Rust)

Terms of Reference and Workplan

### **2.3.B Implementation Committee (ICF) - chair: Marijke de Kleijn**

Operationalizing ICF for Measurement: Calibration, Qualifier, Instruments (N Kostanjsek, B Üstün) 59

Use of ICF qualifiers - a plan for international collection and exchange of experiences (S Talo, M Ojala, M Virtanen)

ICF measurement and calibration: developments in Australia (C Sykes, Ros Madden, N Fortune)

#### **15.15-15.30 Break**

#### **15.30 - 17.00 Breakout Session 2.4**

### **2.4.A Education and Implementation Committee - Joint session - chair: Marjorie S. Greenberg**

ICF applications: a framework for sharing what we know (N Fortune, Ros Madden, C Sykes)

Discussion paper on Developing an International Education Plan for ICF (M S Greenberg)

## ***Tuesday 26th October 2004***

### **2.4.B Mortality Reference Group - chair: Lars Age Johansson**

The External Cause of Injury Mortality Matrix (L Fingerhut)	67
Leading mortality causes list (A L'Hours, D Ma Fat, R Becker)	89
Leading Causes of Death: A Tool for Health Assessment (H Rosenberg, R Anderson)	88
Terms of Reference and Workplan	

### **17.00-17.15 Break**

### **17.15 - 18.45 Breakout Session 2.5 No.**

#### **2.5.A Education and Implementation Committee - Joint session - chair: Marijke de Kleijn**

ICF Educational Progress and Directions (Ros Madden, N Fortune, S Bullock, C Sykes)	
Video training for the data collection within the scope of validation study for the ICF Core Sets for chronic conditions (A. Cieza, A. Garza, M. Füßl, T. Ewert, G. Stucki)	31
The WHO-DIN ICF training, Basic and Advanced Courses, and the ICF in Italy Project (M Leonardi, A Raggi)	35

#### **2.5.B Electronic Tools Committee - chair: Michael Schopen**

Nomenclatures and Thesauri – Alternatives to the ICD-10 Alphabetical Index? (M Schopen, B Krause)	40
The on-line Response Centre for WHO-FIC Classifications (H Ten Napel, P Zanstra)	41
Demonstration of e-version of ICHI	-

### **2.6 Hospital Data Work Group breakout session- Chair: Björn Smedby**

***Wednesday 27th October 2004***

**08.30 - 09.30 Breakout Session 3.1** **No.**

**3.1.A URC papers related to specific topics of ICD revision process – chair: Rosemary Roberts**

Gastrointestinal endoscopic terminology coding. Get-C; an extension of the ICD-10 (MJM Groenen et al) 90

Problems on classification of the ICD-10, Chapter V (T Maruta, M Iimori) 72

A blueprint for developing the ICD-11 Mental Health Component (J Mezzich) 69

**3.1.B Implementation Committee - chair: Peter Goldblatt**

Terms of Reference and workplan IC organizational issues and next steps -

Other business -

**09.30 - 10.30 Plenary 3.2 - Scientific Papers Chair: Willem Hirs**

ICD-10 Exclusion Notes and Multiple Coding (M Schopen) 78

The use of the dagger-asterisk system in ICD-10 and ICD-9 and in national clinical modifications (B Smedby, O Steinum, M Virtanen) 79

A population survey using ICF-based questionnaire in a suburban city near Tokyo, Japan; with special emphasis on the correlations between objective and subjective dimensions of functioning and disability (S Ueda, Y Okawa) 62

The development of an annotated bibliography on the subjective dimension of functioning and disability (S Ueda, P Welch Saleeby) 58

**10.30-10.45 Break**

**10.45 - 12.30 Plenary 3.3 - Plenary ICF  
Chair: Marjorie Greenberg**

ICF version for Children and Youth: developments & field trial (R Simeonsson, M Leonardi) 51

Assessment of a population of disabled children: method, main results and discussion of ICF-CY (JY Barreyre, C Peintre) 61

Implementation of the ICF in Health Care: Emerging Conceptual Issues (G M Reed, L F Bufka, C Trask) 36

ICF Core Sets for rehabilitation in the acute sub-acute situation (E Grill, T Ewert, C Boldt, M Scheuringer, A Cieza, G Stucki) 60

***Wednesday 27th October 2004***

**12.30 - 13.30 LUNCH incl presentation of papers**

**13.30 - 14.30 Plenary**

**3.4 –WHO-FIC Business Plan –**

**Chair: Martti Virtanen**

**No.**

Draft WHO-FIC Business Plan – introduction and plenary discussion

**14.30 - 15.30 Plenary 3.5 - Cross Family Issues**

**Chair: Marijke de Kleijn**

Disability and its relation to health conditions and other factors  
(X Wen, Ros Madden)

The possibility of the ICF applying to mental disorders (Toshimasa Maruta, Makio Iimori) 71

**15.30-15.45 Break**

**15.45 - 17.00 Plenary 3.6 - ICD revision process**

**Chair: Richard Madden**

ICD revision process - from Helsinki meeting (Michael Schopen)

ICD revision process presentation (Bedirhan Üstün)

Presentation of papers and discussions from URC sessions 2.3.A -- 3.1.B

A strategy for evaluating ICD-10 implementation and the updating process  
(Peter Goldblatt, Marjorie Greenberg)

Updating/revising specific clinical topics in ICD-10 (R Roberts, J Rust)

ICD-10-XM (Rosemary Roberts, Bedirhan Üstün, Michael Schopen)

A blueprint for developing the ICD-11 Mental Health Component (J Mezzich)

**17.00-17.15 Break**

**17.15 - 18.45 Plenary 3.7 - ICD revision process**

**Chair: Richard Madden**

Contd. Presentation of papers and discussions from URC sessions 2.3.A -- 3.1.B,  
papers for noting

Summary and conclusion

***Thursday 28th October 2004***

**08.30 - 10.30 Plenary 4.1 - Report back from Committees**

**Chair: Michael Schopen**

Implementation Committee  
Education Committee  
Electronic Tools Committee

**10.30-10.45                    Break**

**10.45 - 12.30 Plenary 4.2 - Report back from Committees**

**Chair: Michael Schopen**

Family Development Committee

Update Reference Committee

Mortality Reference Group

**12.30 - 13.30                    LUNCH**

**15.00 – 19.00 Guided City Tour & Blue Lagoon Geothermal Spa**

The City Tour ends at Blue Lagoon Spa for swimming and relaxation.

There will be separate transport from the hotel to the conference dinner at Blue Lagoon for participants who do not take part in the City Tour/Spa.

**19.00 – Conference Dinner at Blue Lagoon**

## ***Friday 29th October 2004***

### **08.30 - 10.30 Plenary 5.1 - Scientific Papers**

**Chair: Peter Goldblatt**

	<b>No.</b>
The heatwave in France in August 2003: consequences on the level of mortality and on the evolution of the mortality data system (E Jouglu, G Pavillon)	82
Mortality during the heatwave of August 2003 in England and Wales and the use of rapid weekly estimates (H Johnson, L Cook, C Rooney)	81
The impact of introducing ICD-10 on trends in mortality from cancer and circulatory diseases in England and Wales (C Griffiths, A Brock, C Rooney)	83
Presenting and Analyzing Injury Mortality Data in the United States (R Anderson, A Miniño, L Fingerhut, M Warner)	77
Recent Trends in Fetal Mortality in the United States (D Hoyert, W Barfield, J Martin)	
Explaining Recent Trends in Infant Mortality in the United States (R Anderson, D Hoyert, J A Martin, M MacDorman)	
Trends in homicides in England and Wales: comparison of death registration and police report data (C Rooney, C Griffiths)	84
Bridge coding ICD9-ICD10 and effects on French mortality data (G Pavillon, J Boileau, G Renaud, H Lefèvre, E Jouglu)	80
Automation Seminar for Central and Eastern European Countries (S Notzon, R Anderson)	38

### **10.30-10.45 Break**

### **10.45 - 12.30 Plenary 5.2 - Scientific Papers**

**Chair: Gérard Pavillon**

Enhancing Data Quality through Re-abstraction Studies (M Renahan, A Chapman, S A Wibberley)	
Developing a North American Research Agenda for ICF (P Placek)	
ICF Activities in Canada (D Caulfeild)	
Report of the Tenth Annual North American Collaborating Center Conference on ICF (D Caulfeild, P Placek)	
ICF in Lithuanian: some issues of translation and implementation (A Bagdonas)	21
Other country reports on classification activities	

***Friday 29th October 2004***

**12.30 - 13.30 LUNCH**

**13.30 - 14.30 Plenary 5.3 - Host Centre presentations**

**Chair: Moriyo Kimura**

Development of "injury mechanism" in NOMESCO Classification of External Causes of Injuries (NCECI). Preliminary results. (Nordic NCECI workgroup) 50

Presentation of the Icelandic Accident Registry (IAR) (H B Sigbjörnsdóttir, B Mogensen, S Haraldsdóttir) 74

**14.30-14.45 Break**

**14.45 - 16.45 Planning Committee - Strategy and Workplan**

**16.45-17.00 Break**

**17.00 - 19.00 Planning Committee - Business Plan**

***Saturday 30th October 2004***

**08.30 - 10.30 Plenary 6.1 - Discussion and Adoption of Meeting Documents  
Chair: Martti Virtanen**

Adoption of the Strategy and Work Plan

Discussion of the Business Plan and recommendations

**10.30-10.45                      Break**

**10.45 - 12.45                      Plenary 6.2 - Discussion and Adoption of Meeting  
Documents Chair: Martti Virtanen**

Adoption of the draft report of the meeting

Evaluation of the 2004 meeting

Additional matters

Place, time and topics for the 2005 meeting

Place for the 2006 meeting

**12.45 Closure of the Meeting**

<b>Annex - List of Formal and Background documents</b>	<b>No</b>
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International Classifications in Latvia (Janis Misins)	20
Use of ICPC and ICF together (M W. de Kleijn, I M. Okkes, M Verbeke)	22

## WHO FAMILY OF INTERNATIONAL CLASSIFICATIONS NETWORK MEETING

Reykjavik, Iceland  
24-30 October, 2004

### Final list of participants

#### Participants

**Ms Denise Anderson**

Vital Events Processing Manager  
Hampshire Office for National Statistics, UK Collaborating Centre  
Segensworth Road, Titchfield, United Kingdom  
Phone: +440329813204  
[denise.anderson@ons.gov.uk](mailto:denise.anderson@ons.gov.uk)

**Dr Robert Anderson**

Chief Mortality Statistics Branch  
National Center for Health Statistics  
3311 Toledo Road, Room 7318, 20782 Hyattsville, Maryland, U.S.A.  
Phone:  
rmanderson@cdc.gov

**Dr Albinas Bagdonas**

Head of Department and of Laboratory  
Department of Social Work and Laboratory of Special Education, Vilnius University  
Universiteto Str. 3, 903, 01513 Vilnius, Lithuania  
Phone: +37052687253  
albins.bagdonas@fsf.vu.lt

**Mrs Catherine Barral**

Deputy Head  
WHO-FIC Collaborating Centre in France  
236 BIS, RUE DE Tolbiac, 75013 Paris France  
Phone: +331 45 65 59 01  
c.barral@ctnerhi.com.fr

**Jean-Yves Barreyre**

Ile de France Regional Center for Maladjusted Children and Youth /CREAI)  
5 rue Las Cases, 75007 Paris, France  
Phone: +33 145516610  
dir.creai.idf@9online.fr

**Ms Linda Best**

Project Officer  
National Centre for Classification  
PO Box 170, 1825 Sydney /Lidcombe, Australia  
Phone: +61293519461  
l.best@fhs.usyd.edu.au

**Mrs Lynn Bracewell**

National Clinical Classifications Services Manager  
NHS Information Authority  
Kings Court, The Broadway, S0239BE, Winchester, United Kingdom  
Phone: +441962814540  
lynn.bracewell@nhsia.nhs.uk

**Mrs Cassia Maria Buchalla**

Assessor  
WHO Collaborating Center for the FIC in Portuguese  
Av. Dr. Arnaldo 715 room 40  
01246-904 Sao Paulo, Brazil  
Phone: +551130667747  
cmbuchal@usp.br

**Lynn Bufka**

Director, Professional Development  
American Psychological Association  
750 First Street, NE, DC 20002 Washington, U.S.A.  
Phone: +12023365869  
lbufka@apa.org

**Mrs Diane Caulfeild**

Classifications Consultant  
Canadian Institute for Health Information  
377 Dalhousie Street, K1N 9N8 Ottawa, Ontario, Canada  
Phone: +1 613 241 7860  
dcaulfeild@cihi.ca

**Dr Pornarong Chotiwan**

Associate Professor  
Chulalongkorn University, Faculty of Medicine  
Department of Social and Preventative Medicine  
Bangkok, 10330, Thailand  
Phone: +662 256 4000 EXT. 355  
fmedpct@md2.md.chula.ac.th

**Dr Alarcos Cieza**

Group Leader ICF Core Sets Development  
Research Branch of the WHO FIC CC (DIMDI)  
Department of Physical Medicine and Rehabilitation  
Ludwig-Maximilians-University  
Marchioninstr. 15, 81377 Munich, Germany  
Phone: +4989218078216  
acieza@med.uni-muenchen.de

**Dr Susan Cole**

UK WHO-FIC Collaborating Centre  
EH16 5 NP Edinburgh, Scotland  
Phone:  
skcole@granby1880.freeserve.co.uk

**Marie Cuenot**

Researcher  
WHO-FIC Collaborating Centre in France  
236 BIS, Rue de Tolbiac, 75013 Paris, France  
Phone: +33145655902  
m.cuenot@ctnerhi.com.fr

**Leilionas Danielius**

Department of Social Work and Laboratory of Special Education, Vilnius University  
Universiteto Str. 3, 903, 01513 Vilnius, Lithuania  
Phone: +37052687253  
albins.bagdons@fsf.vu.lt

**Thomas Ewert**  
ICF Research Branch WHO FIC CC (DIMDI) IMBK  
University Hospital Munich  
Marchioninstr. 15, 81377 Munich, Germany  
Phone: +499870954077  
tewert@med.uni-muenchen.de

**Kathy Giannangelo**  
Manager  
IFHRO  
11 Redbud Run, Il 62707 Springfield, U.S.A.  
Phone: +12175253502  
kathy.giannangelo@ahima.org

**Ms Sigita Girdzijauskiene**  
Vilnius University  
Universito Str. 3, 903, 01513 Vilnius, Lithuania  
Phone:  
albins.bagdons@fsf.vu.lt

**Ms Donna Glenn**  
Chief, Mortality Medical Classification  
National Center for Health Statistics  
P.O. Box 12214 - Research Triangle, 27709 New York, U.S.A.  
Phone: +19195410369  
DEGlenn@cdc.gov

**Dr Peter Goldblatt**  
Office for National Statistics, UK Collaborating Centre  
1 Drummond Gate, SW1V 2QQ London, United Kingdom  
Phone: +442075335265  
peter.goldblatt@ons.gsi.gov.uk

**Ms Marjorie S Greenberg**  
Head WHO-FIC CC for North America  
National Centre for Health Statistics, Centre for Disease Control and Prevention  
3311 Toledo Road Room 2413, 20782 Hyattsville MD, U.S.A.  
Phone: +1 301 458 4245  
msg1@cdc.gov

**Clare Griffiths**  
Principal Research Officer  
Office for National Statistics  
1 Drummond Gate, B6/08 London, United Kingdom  
Phone: +442075335242  
clare.griffiths@ons.gov.uk

**Dr Marcel Groenen**  
Ikazia Hospital  
Montessoriweg 1, 3083 AN Rotterdam, Netherlands  
Phone: +31102975136  
ouwend@knmg.nl

**Manabu Hasegawa**  
Chief for Working Group  
Health Statistics Office  
1-2-2 Kasumigaseki, Chiyoda-Ku, 100-8916 Tokyo, Japan  
Phone:  
hasegawa-manabu@mhlw.go.jp

**Dr Willem Hirs**

Head WHO-FIC Collaborating Centre in the Netherlands  
National Institute of Public Health and the Environment (RIVM)  
P.O. Box 1, 3720 BA Bilthoven, Netherlands  
Phone: +31 30 2742039  
willem.hirs@rivm.nl

**Dr Donna Hoyert**

Health Statistician  
CDC/National Centre for Health  
Room 7318, MSB, 3311 Toledo Road, 20782 Hyattsville, MD, U.S.A.  
Phone: +1 301 458 4279  
dlh7@cdc.gov

**Dr Robert Jakob**

German WHO Collaborating Centre, DIMDI  
Waisenhausgasse 36-38A, 50676 Cologne, Germany  
Phone:  
jakob@dimdi.de

**Vida Jakutiene**

Department of Social Work and Laboratory of Special Education, Vilnius University  
Universiteto Str. 3, 903, 01513 Vilnius, Lithuania  
Phone: +37052687253  
albins.bagdons@fsf.vu.lt

**Dr Pattariya Jarutat**

Director  
Sirindhorn National Medical Rehabilitation Centre  
11000 Nondhaburi, Thailand  
Phone: +66 02 5914945  
pattariya@health.moph.go.th

**Mr Lars Age Johansson**

Expert adviser  
Nordic Centre for Classifications in Health Care  
WHO-FIC Collaborating Centre in the Nordic Countries  
Department of Public Health and Caring Sciences, Uppsala Science Park  
SE-75185 Uppsala, Sweden.  
Phone: +46733868530  
lars.age.johansson@socialstyrelsen.se

**Moriyo Kimura**

Director, ICD office, MD  
Statistics and information department Minister's secretariat  
Ministry of Health, Labour & Welfare, Japan  
1-2-2, Kasumigaseki, Chiyoda-ku, 100-8916 Tokyo, Japan  
Phone: +81 3 5253 1111  
kimura-moriyo@mhlw.go.jp

**Dr Marijke W de Kleijn-de Vrankrijker**

Centre Head WHO-FIC Centre in the Netherlands  
c/o PO Box 2215, 2301 CE Leiden, Netherlands  
Phone:  
mw.dekleijn@pg.tno.nl

**Dr Ashok Kumar**

Director Central Bureau of Health Intelligence  
Ministry of Health & Family Welfare  
Nirman Bhawan, New Delhi, 110011 India  
Phone: 91 (11) 2379 3175  
drashok@msn.com

**Dr Hassina Lefèvre**

Institut National de la Santé et de la Recherche Médicale  
44 Chemin de ronde, 78116 Le Vésinet Cedex, France  
Phone:  
lefevre@vesinet.inserm.fr

**Mr Richard Madden**

Director  
Australian Institute of Health and Welfare  
6PO Box 570, 2601 Canberra, Australia  
Phone: +61 2 62441101  
richard.madden@aihw.gov.au

**Mrs Ros Madden**

Australian Institute of Health and Welfare  
6PO Box 570, 2601 Canberra, Australia  
Phone: +61 2 62441189  
ros.madden@aihw.gov.au

**Ms Jane Millar**

NHS Information Board Manager  
UK Collaborating Centre NHS  
Aqueous II, Aston Cross, Rocky L, B6 5RQ Birmingham, United Kingdom  
Phone: +4407899791821  
jane.millar@isb.nhs.uk

**Ms Janice Miller**

Consultant  
North American Collaborating Centre  
341 Sherwood Drive, K1Y 3X2 Ottawa Ontario, Canada  
Phone: +16137297885  
miller.janice@sympatico.ca

**Mrs Lori Moskal**

Consultant Classifications  
Canadian Institute for Health Information  
377 Dalhousie St, K1N 9N8 Ottawa ON, Canada  
Phone: +1 613 241 7860  
lmoskal@cihi.ca

**Birthe Frimodt Møller**

MD, Senior Researcher, Expert Adviser  
National Institute of Public Health & Nordic WHO-FIC CC  
Svanemollevvej 25, 2100 København Ø, Denmark  
Phone: +45 3920 7777  
bfm@niph.dk

**Francis Notzon**

Director, International Statistics Program  
National Centre for Health Statistic  
3311 Toledo Road, 20782 Hyattsville, Maryland, U.S.A.  
Phone: +1 301 458 4402  
snotzon@cdc.gov

**Dr Rob Ouwendijk**

Ikaziz Hospital  
Montessoriweg 1, 3083 AN Rotterdam Netherlands  
Phone: +31102975136  
ouwend@knmg.nl

**Mr Gérard Pavillon**

Head WHO-FIC Collaborating Centre France  
Institut National de la Santé et de la Recherche Médicale  
44 Chemin de ronde, 78116 Le Vésinet Cedex, France  
Phone: +33134802462  
pavillon@vesinet.inserm.fr

**Carole Peintre**

Ile de France Regional Center for Maladjusted Children and Youth /CREAI)  
5 Rue Las Cases, 75007 Paris, France  
creai.idf@9online.fr

**Ms Kristina Bränd Persson**

Assistant Centre Head  
Nordic Centre for Classifications in Health Care  
WHO-FIC Collaborating Centre in the Nordic Countries  
Department of Public Health and Caring Sciences, Uppsala Science Park  
SE-75185 Uppsala, Sweden.  
Phone: +46 18 611 3591 / +46 18 542656  
kristina.brand.persson@nordclass.uu.se

**Mrs Donnataria Pickett**

Medical Classification Administrator  
National Center for Health Statistics  
311 Toledo Road, Room 2337, 20782 Hyattsville, U.S.A.  
Phone: +1 301 458 4434  
dfp4@cdc.gov

**Mrs Tanya Pitts**

Medical Classification Trainer  
National Center for Health Statistics  
P.O. Box 12214 - Research Triangle, 27709 New York, U.S.A.  
Phone: +19195410369  
TPitts@cdc.gov

**Dr Paul Placek**

Statistician  
National Center for Health Statistics  
3311 Toledo Road, Room 2414, 20782 Hyattsville, U.S.A.  
Phone: +1 301 458 4437  
pjp2@cdc.gov

**Mrs Julia Raynor**

Medical Classification Trainer  
National Center for Health Statistics  
P.O. BOX 12214 - Research Triangle, 12214 New York, U.S.A.  
Phone: +19195410369  
JRaynor@cdc.gov

**Dr Geoffrey Reed**

Assistant Executive Director  
American Psychological Association  
750 First Street, NE, DC 20002, 4242 Washington, U.S.A.  
Phone: +12023365968  
gmreed@apa.org

**Ms Mea Renahan**

Manager Classifications Standards  
Canada Institute for Health Information  
90 Eglinton Avenue East, Suite 300, ON M4P 2Y3 Toronto, Canada  
Phone: +1 416 181 1616  
mrenahan@cihi.ca

**A/Prof Rosemary Roberts**

Associate Professor/Director  
National Centre for Classification in Health  
University of Sydney  
PO Box 170, 1825 Sydney/Lidcombe, Australia  
Phone: +61 2 9351 9461  
r.roberts@fhs.usyd.edu.au

**Dr Cleone Rooney**

Medical Epidemiologist  
Office for National Statistics & UK Collaborating Centre  
Room B7/04, 1 Drummond Gate, SW1V; 2QQ London, United Kingdom  
Phone: +442075335254  
cleo.rooney@ons.gov.uk

**Patricia Welch Saleeby**

Visiting Assistant Professor  
University of Missouri  
One University Blvd, Lucas Hall 583, MO 63121 St. Louis, U.S.A.  
Phone: +13145164654  
saleebyp@umsl.edu

**Dr Gunnar Schiøler**

Consultant Classifications  
National Board of Health, Denmark  
Jagtvej 208, 2tv, DK-2100 København Ø, Denmark  
Phone:  
gs@dadlnet.dk

**Dr Michael Schopen**

Head  
German WHO-FIC Collaborating Centre, DIMDI  
Waisenhausgasse 36-38A, 50676 Cologne, Germany  
Phone: +49 221 4724 325  
schopen@dimdi.de

**Mr Rune Simeonsson**

FPG Child Development Institute  
Sheryl Mar Bldg. Rm 253  
521 S.Greensboro St, 27599 Chapel Hill, U.S.A.  
Phone:  
simeonsr@mail.fpg.unc.edu

**Ms Piret Simmo**

Project Manager Classifications  
Health Dep. Ministry of Social Affairs  
Gonsiori 29, 15027 Tallinn, Estonia  
piret.simmo@sm.ee

**Prof Björn Smedby**

Expert Adviser  
Nordic Centre for Classifications in Health Care  
WHO-FIC Collaborating Centre in the Nordic Countries  
Department of Public Health and Caring Sciences, Uppsala Science Park  
SE-75185 Uppsala, Sweden.  
Phone: +4618542656  
bjorn.smedby@nordclass.uu.se

**Dr Olafr Steinum**

Expert Adviser  
Nordic Centre for Classifications in Health Care  
WHO-FIC Collaborating Centre in the Nordic Countries  
Jordfall 420, 45197, Uddevalla, Sverige  
Phone: +46 522650172  
olafr@swipnet.se

**Mrs Christine Sweeting**

Clinical Classification Adviser  
NHS Information Authority  
King 's Court The Broadway, S023 9BE Winchester, United Kingdom  
Phone: +44 96 2814 540  
christine.sweeting@nhsia.nhs.uk

**Ms Catherine Sykes**

Australian Institute of Health & Welfare  
6 PO Box S70, 2601 Canberra, Australia  
Phone: +61 2 62441129  
catherine.sykes@aihw.gov.au

**Dr Seija Talo**

Development Manager, Expert Adviser Nordic WHO-FIC CC  
Stakes Information/Classification Center  
Koivuharjunk 25, 20660 Littoinen, Finland  
Phone:  
seija.talo@stakes.fi

**Dr Huib ten Napel**

Deputy Head  
WHO-FIC Collaborating Centre in the Netherlands  
Dr Duchateastraat 87, 5571 DB Bergeijk, Netherlands  
Phone:  
tl355655@tiscali.nl

**Dr Glen Thorsen**

Expert Adviser  
Norwegian Centre for Health Informatics (KITH) & Nordic WHO-FIC CC  
Sukkerhuset, 7489 Trondheim, Norway  
Phone: +4773598600  
glen.thorsen@kith.no

**Maruta Toshimasa**

Associate Professor  
Dep. of Psychiatry, Tokyo Medical University  
6-7-1 Nishi-Shinjuku, Shinjuku-Ku,  
160-0023 Tokyo, Japan  
Phone: +81333426111  
t-maruta@bd5.so-net.ne.jp

**Dr Satoshi Ueda**

Advisor  
Japanese Society for Rehabilitation  
Nakazato 3-77-20, Kiyose, 204-0003 Tokyo, Japan  
Phone:  
sat.ueda@nifty.com

**Mrs Sue Walker**

Associate Director  
National Centre for Classification in Health  
Queensland University of Technology  
Victoria Park Road Kelvin, 4059 Brisbane , Australia  
Phone: +161738645873  
s.walker@qut.edu.au

**Dr Stefanie Weber**

German Collaborating Centre, DIMDI  
Waisenhaus Gasse 36-38a, 50676 Köln, Germany  
Phone: +492214724485  
weber@dimdi.de

**Dr Martti Virtanen**

Head of Centre  
Nordic Centre for Classifications in Health Care  
WHO-FIC Collaborating Centre in the Nordic Countries  
Metsänvirtiantie 8 B, FIN-02720 Espoo, Finland  
Phone: +35 850 667 28 / +46 18 611 3580  
martti.virtanen@nordclass.uu.se

**Dr Ulrich Vogel**

Member medical Classification Se, DIMDI  
Waisenhausgasse 36-38a, 50676 Köln, Germany  
Phone:  
vogel@dimdi.de

**Ms Patricia Wood**

Mortality Classification Specialist  
Health Statistics Division, Statistics Canada  
Main Building, Room 2200, K1A 0T6 Ottawa Ontario, Canada  
Phone:  
patricia.wood@statcan.ca

**Ms Yukiko Yokobori**

Head of Distant Training Division  
Japan Hosp. Association  
13-3 Ichibancho Chiyoda-ku, 102-8414 Tokyo, Japan  
Phone:  
yokobori@jha-e.com

## Host Centre Observers

### **Lars Berg**

Medical Director, MD  
Swedish National Board of Health and Welfare, Centre for Epidemiology  
SE-106 30 Stockholm, Sweden  
Phone: +46 8 5555 3221  
lars.berg@socialstyrelsen.se

### **Guðrún Kr. Guðfinnsdóttir**

Project Manager  
Division of Health Statistics, Directorate of Health  
Austurströnd 5, IS-170 Seltjarnarnes, Iceland  
Phone +354 510 1900  
gudkr@landlaeknir.is

### **Sigríður Haraldsdóttir**

Head of Division  
Division of Health Statistics, Directorate of Health  
Austurströnd 5, IS-170 Seltjarnarnes, Iceland  
Phone: +354 510 1900  
shara@landlaeknir.is

### **Asbjørn Haugsbø**

Senior Adviser, MD  
Directorate for Health and Social Welfare  
P.O.Box 8054, 0031 Oslo Norway  
Phone: +4724163236  
aha@shdir.no

### **Ms Lilja Sigrún Jónsdóttir**

Hagstofa Islands  
Borgartúni 21A, 150 Reykjavík, Iceland  
lilja.jonsdottir@hagstofa.is

### **Sveinn Magnússon**

Head of department, MD  
Ministry of Health and Social Security & Nordic WHO-FIC CC  
Vegmúla 3, 108 Reykjavík, Iceland  
Phone: +354 545 8781  
sveinn.magnusson@htr.stjr.is

### **Mr Johannes Nielsen**

Head of Secretariat  
NOMESCO  
Islands Brygge, 2300 København S, Denmark  
Phone: +5457222762  
mail@nom-nos.dk

### **Iver Nordhuus**

Senior Advisor  
Norwegian Centre for Health Informatics (KITH)  
Sukkerhuset, 7489 Trondheim, Norway  
Phone: +4773598600  
iver.nordhuus@kith.no

**Dr Matti Ojala**

Senior Medical Officer, Expert Adviser  
National Research and Development Centre for Welfare and Health (Stakes)  
Lintulahdenkuja 4, 00531 Helsinki, Finland  
Phone: +358 9 39672153  
matti.ojala@stakes.fi

**Stefi Stabell Wetteland**

Adviser  
Norwegian Centre for Health Informatics (KITH) & Nordic WHO-FIC CC  
Sukkerhuset, 7489 Trondheim, Norway  
Phone: +4722067519  
stefi.wetteland@kith.no

**Host Centre Support Staff****Ms Awring Koyi**

Project Assistant  
Nordic Centre for Classifications in Health Care  
WHO-FIC Collaborating Centre in the Nordic Countries  
Department of Public Health and Caring Sciences, Uppsala Science Park  
SE-75185 Uppsala, Sweden.  
Phone: +46 18 611 3566  
awring.koyi@nordclass.uu.se

**Ms Gunilla Pettersson**

Project Assistant  
Nordic Centre for Classifications in Health Care  
WHO-FIC Collaborating Centre in the Nordic Countries  
Department of Public Health and Caring Sciences, Uppsala Science Park  
SE-75185 Uppsala, Sweden.  
Phone: +46 18 611 3572  
gunilla.pettersson@nordclass.uu.se

**Special Invitees****Prof Niels Bentzen**

Chair of WICC  
WONCA (WICC)  
Olastu, Byneset, 7074 Spongdal, Norway  
Phone: +4790051349  
niels.bentzen@medisin.ntnu.no

**Prof Juan Enrique Mezzich**

Consultant  
World Health Organization  
175 East 96 ST, Apt. 5L, New York NY, 10128 U.S.A.  
Phone: +17183345094  
juanmezzich@aol.com

**Marit Rønning**

Director  
WHO Collaborating Centre for Drug Statistics Methodology  
Norwegian Institute of Public Health  
P.O.Box 4404 Nydalen, 0403 Oslo, Norway  
Phone: +4723408158  
marit.ronning@fhi.no

## **WHO Secretariat**

### **Dr Roberto Becker**

Pan American Health Organization  
525 23rd Street. NW, 200374 Washington, DC, U.S.A.  
Phone: +12029743131  
Fax: +12029743674  
beckerro@paho.org

### **Jaume Canela**

Acting Chief of Measurement and Health Information System Unit  
Pan American Health Organization  
525 23rd Street. NW, 200374 Washington, DC, U.S.A.  
Phone: +12029743484  
canelaja@paho.org

### **Mr André L'Hours**

Technical Officer  
World Health Organization  
Avenue Appia, 20, 1211 Geneva 27, Switzerland  
Phone: +41227912843  
lhoursa@who.int

### **Mr Nenad Kostanjsek**

Technical Officer  
World Health Organization  
Avenue Appia, 20, 1211 Geneva 27, Switzerland  
Phone: +41227913242  
kostanjsekn@who.int

### **Dr Edoh Soubey-Alley**

Regional Advisor  
Health Information Systems, Division of Health Systems and Services Development  
WHO/AFRO  
PO Box 06 Brazzaville, Congo.  
Phone: +4724139263  
soubeye@afro.who.int

### **Pierre Lewalle**


World Health Organization  
Avenue Appia, 20, 1211 Geneva 27, Switzerland  
Phone: +412279224  
lewallep@who.int

### **Mrs Doris Ma Fat**

Statistician  
Measurement and Health Information Systems (MHI)  
World Health Organization  
Avenue Appia, 20, 1211 Geneva 27 Switzerland  
Phone: +41 22 791 2841  
mafatd@who.int

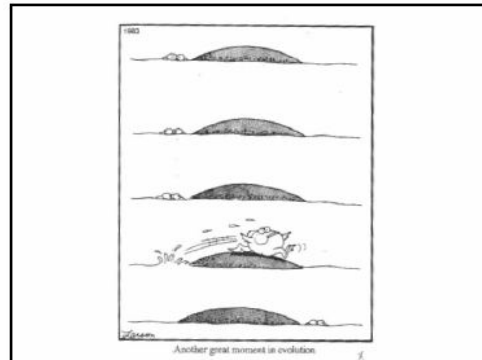
### **Dr Tevfik Bedirhan Üstün**

Coordinator  
World Health Organization  
Avenue Appia, 20, 1211 Geneva 27, Switzerland  
Phone: +41227913609  
ustunb@who.int



**ICD Revision Process:  
towards ICD -11**

Dr. T. B. Üstün  
WHO

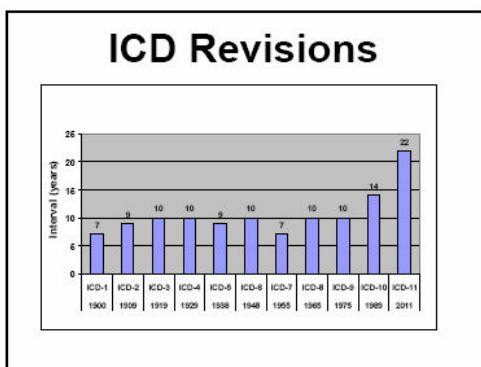


**Cologne – Helsinki – Reykjavik  
Planning for Revision**

- **Continuous life cycle**
  - Knowledge Management
    - strategic vision - purpose - users - policy
    - recognition of need & perspective: how & when
  - Software release methodology
- **Beyond Prejudgement: conservatism vs novelty**
  - undermining the ICD-10, ICF ?
  - New = better ?; Old = better ?
  - Marketing strategy
  - Credibility management
  - backward compatibility
  - real response to need
- **systematic evaluation**
  - impact, process
- **serious planning for revision**
  - needs, resources, timeline, customers, partners

**Key Drivers**

- **Mandated by WHA and EB**
- **Respond to consumer-needs**
  - Clinicians, Administration, Patients, families; Data-users
- **Keep up with new scientific knowledge**
  - **New Diseases**, Treatments, Terminology ...
  - Corrections: pruning and grafting, deletions
  - Change in rules, guidelines, conventions ...
- **Compatibility within the WHO-FIC members**
  - ICF, ICHI, ICECI, ICD-O...
- **Creation of an improved network and dissemination**
- **Better implementation within Health Information Systems**
  - Electronic Health Record, Clinical Terminologies, Mortality Database



## UP-dating vs Re.vision

- **UPDATING:**
  - Build on ICD-10
    - Corrections, quick fixes of problems
    - Insertion of further detail
    - New terms
    - Harmonization
  - Cumulative updates
    - **ICD-10 Second Edition (2004)**
- **REVISION**
  - More than Update:
    - Difficult to update conditions
      - Mitochondrial diseases, Cystic Fibrosis, Diabetes Mellitus
    - Structural changes
    - New concepts ...

ICD-10  
Update



ICD-11

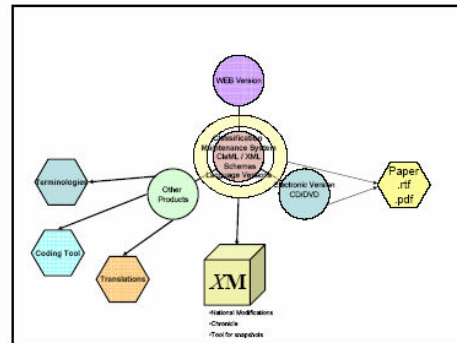
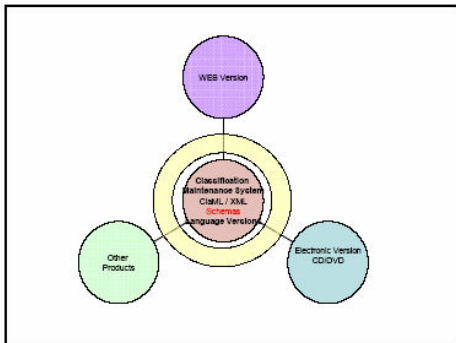
Insurers and carefree. Surely, left hand didn't know what the right was doing.

## “Revision” of ICD

- Design requirements for compatibility **within family**
  - relatively major changes in chapters, blocks
  - re-coding / elimination of whole sections
- Design requirements for **implementation tools**
- Incorporation of **new elements** of classification
  - **genetic information?**
  - Linkage to interventions - procedures
  - **joint use of ICD-ICF & ICHI...**
- **Visioning ICD-11** in the emerging **e-health applications**

## DESIDERATA for ICD-11

- Compatibility with **National Classification schemes**
  - Bottom-up perspective
- **Multiple coding schemes** for:
  - Mortality
  - Morbidity
  - Epidemiology
  - Administration
- **Translatability**
  - ? Local language relevance
- User-friendliness
- Application tools
- Development in a technical database with metadata



## Technical Aspects

- Development in a database environment
  - XML – classification mark-up language
  - Meta data
- Definitions, Diagnostic features
- Inclusion and exclusion
- Extension and Collapsing of codes
- Index
- Mapping
- Specialty extensions – Oncology, Mental Health.
- Hierarchy of coding rules
  - Main cause, Multiple cause,...
- Links with the Family Members
- Data Quality Tools

## Issues raised in this meeting for ICD Revision

- MORTALITY: Short Mortality List(s)
- MORBIDITY: Compilation of micro-data
- Dagger & asterisk
- Evidence based revision process
  - Scientific literature on taxonomy
  - Administration requirement for better management
- updates: **what has/& has not been addressed ?**
- User demand and response to need
  - change in national classifications
    - ICD - XM
    - DSM -V
    - Other classification systems: Chinese, Cuban, Latin American...

## Basic Questions

- Mortality vs. Morbidity

If you are **NOT DEAD**, we are **NOT INTERESTED**



"Fill out this tag and attach it to your big toe."

## Basic Questions

- Mortality vs. Morbidity
- Statistical Reporting
  - vs. Administration
  - vs. Epidemiology & Services Research
  - vs. Clinical Decision-making
- Others:
  - Continuity vs. breaks
  - Distinction of **Disease** categories
    - and other entities: Reasons for encounter

## Key Inputs

- Evaluation of ICD-10 Implementation Process
  - ICD-10 Update Process



### Key Inputs

- Evaluation of ICD-10 Implementation Process
  - ICD-10 Update Process
- **ICD-10 XM**
- Family Congruence
  - ICF
  - ICD Derived classifications: **ICD-O 3** and others; ICD-XM
  - ICD Related classifications: ICECI, **iCPC**
  - ICHI (implications)
- IT & Standards requirements
  - Terminology Links - **mappings**
  - ISO standards + HL7
- Structural amendments
  - **XVII, XX, XXI** - Distinction: Diseases; Signs, symptoms; interventions

### Work Streams

1. **Epidemiological Stream**
  - Surveys
  - Validation Studies
  - Add-on protocols for existing studies
  - Meta analyses
2. **Clinical Stream**
  - Clinical utility - linkage to patient reports
  - Treatment Response
  - **Phenotypes**: gene to behaviour specs
3. **Knowledge Management & Sharing**
  - WEB based tools for open access and commentary on
    - Disease Categories, Definitions and Criteria
    - Structured Discussion Forums
  - Evidence based systematic reviews & Knowledge Base
  - ICD Journal online
  - Translation tools

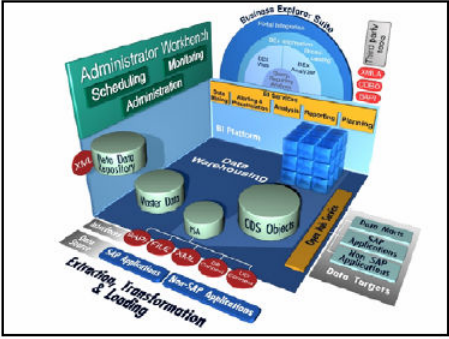
### Involvement Strategy

- **International:**
  - Multiple countries
  - Multiple languages
  - Multiple health care systems
- **Multiple Parties & Professionals**
  - Different clinical specialties, nursing & midwifery; other professionals
  - Different health care aspects:
    - primary care
    - home care
    - rehabilitation
    - long term care
  - Consumers from different sectors

### Structure for Revision Process

- Central revision team
  - Coordination
  - Editing
  - IT
- **Network of Centers**
- **WHO Regional Offices** and Technical Programs
- International Expert Groups
- Annual Revision Meetings
- Partners
- Specialty Reference Groups

➤ Permanent Knowledge Portal



## Knowledge Portal

Web of ICD Revision

*WEB based tools for open access and commentary*

- Evidence based systematic reviews
  - Clinical Use:
  - Epidemiology, demography and public health
- Knowledge Sharing
  - All ICD Chapters:
    - Disease Definitions and Criteria
    - comment threads
  - Structured Discussion Forums
  - Field Trials: *Global Practice Networks* to test the proposed codes, definitions...
  - Classifications *On-line Journal*
- *Personalized selections in an interconnected electronic environment*
  - Actionable information – alerting, planning, query, reporting & analysis
  - Collaboration (Executive, Knowledge worker, User)

## ICD Revision Process


- Drafting Rules
  - Taxonomic Guidelines
  - Definition, Diagnosis and Indexing / mapping guidelines
- Drafting Overall Structure
- Drafting Individual Chapters
- Overseeing the TOTAL ICD
  - ALPHA Draft – structured comments
  - BETA Draft – field testing
- Final Draft
  - **WHA Approval**

## Revision Business

- Environment/Context
  - Barriers & Facilitators
- Agents
  - WHO FIC Network, Partners, Competitors
- Product
  - ICD-11, supporting materials
- Market Analysis
  - ICD-10 countries
  - New users
- Operational Plan & Business Model
- Financial Statements
- Risks
- Presentation- Communication - Approval

## Development Strategy

- Marketing analysis
  - Consumer needs
  - Stakeholder involvement
- Communication Strategy
  - Invitation to Member States
- Resource Mobilization
  - Human resources
  - Financial resources
  - IT resources
- User involvement
  - Technical experts, clinicians
  - Administrators
  - Consumers




## Packaging the Final Product

- Update & Compatibility Package:
  - Use in Mortality Database (time series / bridge coding...)
  - Use in other national applications
- Training Materials
- Implementation Materials
  - Coding Tool
  - Linkage to IT Systems - e-Health Record (terminologies)
- Trainers' Network
- Data Quality Tools

## Working Principles

- Shared leadership
  - Network recognition – responsibility - accountability
- Network consensus building
  - Differences surfaced
  - Multi-party agreement
- Process / task oriented
- Empowerment of interested parties / accountability / transparency

## Field Trials

### e-Questionnaires within a Global Practice Network

- **Relevance**
  - Appropriate coding – fit for purpose
  - Scientific accuracy
  - Guidance for case-management
- **Coverage**
  - Comprehensiveness, missing elements
- **Utility**
  - Feasibility, benefits
  - Explanatory power: need, costs, utilization
  - User acceptance: barriers
- **Trends**
  - Statistical time series
  - Bridge-coding studies
  - Projections
- **Translations**
- **Computer Applications**
  - Links with other IT tools
  - Mapping with Terminologies

## Tentative Timeline

- ICD-11 by ...
  - 2004/5: International Consultations for blueprint
  - 2005 : Start of multiple streams of workplan
  - 2006 : **Alpha version**
  - 2007 : Commentaries and consultations
  - 2008 : **Beta version & Field Version**
  - 2009 : Field trials
  - 2010 : Final version for public viewing
  - 2011 : **WHA Approval**
  - 2013+ **implementation**

