

**WHO FAMILY OF INTERNATIONAL CLASSIFICATIONS
NETWORK MEETING**

WHOFIC/04.094

**Reykjavik, Iceland
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Title: ICD-10 Electronic Tools Committee: Annual Report 2004

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Purpose: for information

Recommendations:

ICD-10 Electronic Tools Committee: Annual Report 2004

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Introduction

At the WHO Centre Heads Meeting in Cardiff in October 1999 it was agreed to convene a committee to support WHO and the WHO Collaborating Centres for the Family of International Classifications in developing policies on electronic classification tools and their dissemination.

This is the fifth annual report of the Electronic Tools Committee (ETC) to summarize the work of the committee in 2004. It puts the results of the current work into the context of the years before. Important new parts have been marked by a sidebar.

Membership

Membership to the ETC is open to any individuals from collaborating organizations who wish to participate actively in the work and aims of the committee. They should submit their names to the Chair (Michael Schopen, schopen@dimdi.de) with copy to the secretariat.

The terms of reference of the ETC are printed in Appendix A.

Meetings

An inaugural meeting was held during the Center Heads Meeting in Cardiff 1999. A second meeting was held during the Center Heads Meeting in Rio de Janeiro in 2000, a third meeting in Bethesda in 2001, a fourth meeting in Brisbane in 2002, and a fifth one in Cologne 2003. Between the annual meetings the committee has communicated via e-mail.

Workplan

1. Establish and improve a communication platform
2. Establish personal links to other organizations and groups working in related areas
3. Survey collaborating centers for existing electronic tools and classify them according to their purpose, availability and dissemination
4. Identify gaps and current needs
5. Establish criteria for the evaluation and accreditation of electronic tools
6. Support WHO to establish an electronic version of ICD-10 in English

Achievements

During the first meeting ETC participants listed all tools known to them and grouped them into a framework (Appendix B). It was agreed to survey all Collaborating Centers to get more detailed information on the existing tools.

Establish a communication platform

The ETC mainly works by e-mail communication. However, alternative ways of communication improving interactivity are to be considered. As a first step towards interactivity, DIMDI has implemented a news server with restricted access as a discussion platform for the ETC. A news server open to the general public has already been operational at DIMDI since 4 years. As this forum for discussion of coding questions has been very well accepted by the German users, it was considered to implement a version with restricted access for the ETC. However, due to network security restrictions access to this news server was not possible from the Collaborating Centers. As it will be easier to install a web based discussion forum than to convince system administrators in different organizations and institutions all over the world to allow the access to a news server, DIMDI will implement a web based discussion forum with restricted access for the members of the ETC.

As of October 2004, the ETC discussion forum has become operational at <http://www.dimdi.de/dynamic/en/klassi/koop/who/forumlogin.html>

To access the forum a user code is necessary. It can be obtained by an informal email to weber@dimdi.de

Establish personal links

Members of the ETC have suggested organizations and institutions working in related areas and people as contact persons to exchange information on their work.

Web Site

A web site has been set up to distribute information about the Electronic Tools Committee and results of its work. It is accessible at

<http://www.dimdi.de/en/klassi/koop/who/etc/index.html>

Survey

For the purpose of this survey the ETC agreed on the following definition of an ICD-10 related electronic tool:

"Software for production, maintenance, and application of ICD or for processing and evaluation of data coded with ICD. Electronic tools can be based on standard software, but need some extra functionality."

A questionnaire on ICD-10-related electronic tools was designed via electronic communication in 2001 and sent out to the Collaborating Centers and other institutions.

The results of the survey are available from the web site of the Electronic Tools Committee at

<http://www.dimdi.de/en/klasi/koop/who/etc/index.html>

Electronic version of ICD-10

During the second meeting of the ETC in Rio de Janeiro in 2000 the discussion revealed that there is a strong need for an electronic version of ICD-10 which is also suitable for integration into database systems. The ETC discussed possibilities to disseminate such an electronic version, whether it should be in the public domain or whether it should be sold by WHO or a commercial company. Members of the ETC agreed to prepare a discussion paper for the meeting in Bethesda in 2001.

During this meeting the committee proposed two recommendations for consideration by the Heads of Centers:

Recommendation 1

There is an urgent need for an updated version of all three volumes of the ICD-10. Thus, the Heads of Centers recommend that WHO contact DIMDI in order to obtain necessary support to fulfil this need. DIMDI should collaborate with WHO and those centers that have an electronic version of all three volumes available.

Recommendation 2

The Heads of Centers recommend that WHO, DIMDI and Collaborating Centers work together on promoting the dissemination of updated versions of all volumes of ICD-10 through the Internet in downloadable and accessible form and by CD-ROM. Dissemination should take into account the periodicity recommended by the Update Reference Committee.

These two recommendations were adopted by the Center Heads.

Together with the relaunch of the DIMDI web site in August 2002, web pages with restricted access for WHO and Collaborating Centers have been implemented. Staff of WHO and Collaborating Centers have received a password. These pages give online access to the Tabular List of ICD-10 in English (updates effective in 2003 have been incorporated) and in French (updates not yet incorporated).

During the 2003 WHO-FIC Network Annual Meeting it was decided that the online version of the Tabular List should become accessible to everybody. Thus it was moved to the public access area of the web server.

Meanwhile WHO has also made this web version accessible on their web server at:

<http://www3.who.int/icd/vol1htm2003/fr-icd.htm>

Furthermore, files of the Electronic Version of ICD-10 are available in the restricted area.

Dissemination policies for the ICD-10 electronic version

During the third meeting of the ETC in Bethesda in 2001 problems of dissemination policies for the ICD-10 electronic version had been identified. The aspects concerning the ETC are closely linked to the dissemination issues raised in the URC. The following three recommendations were approved:

Recommendation 3

All successive versions of ICD-10 and mappings should be made available on the Internet free of charge in a read-only format that cannot be edited or used for value-added products.

Recommendation 4

ICD-10 versions (in French and English) should be made available in electronic format suitable for data processing or integration into computer applications, enabling income generation for WHO.

Recommendation 5

Because WHO has the copyright for the ICD, and given the WHO mandate to maintain the classification and that ICD products produce substantial resources, WHO is called upon to provide sufficient resources to appropriately maintain and update the products. The secretariat advised that the issues related to this recommendation should also be taken up by the Centre Heads through the WHO Executive Board and their respective Ministers of Health.

In late 2002 an XML version of ICD-10 prepared for WHO was distributed among the members of the ETC with request for evaluation. The results are available in the "Report of the XML version of ICD-10" and will be presented at the 2003 Annual Meeting in Cologne. It turned out that the quality of the input data was not sufficient, that important parts of ICD-10 were missing and that the granularity of the XML structure was too coarse for a good presentation of the classification. Thus, the work on the electronic version of ICD-10 was based on the SGML files of the English Tabular List and Alphabetical Index available at DIMDI. Details are available in the report mentioned above.

Meanwhile, the following parts of the electronic version are available:

Volumes I, II and III are available in pdf format for printing by WHO. Furthermore, the pdf files have been linked together via ICD codes by Dr. Albrecht Zaiß (Department of Medical Informatics, University of Freiburg) in an ICD-10 browser.

The Tabular List is available in HTML format to everybody on the DIMDI web server and on the WHO web server.

Codes and titles with links to the ICD-10 blocks and chapters and links to the Special Tabulation Lists are available to a closed group (so-called metadata). They can easily be imported into a relational database.

Plain ASCII files with the text of volumes I and III are also available to a closed group. An ASCII file of Volume II is under preparation. Still under preparation is a database version of the classification.

All files are available from the web pages with restricted access for WHO and Collaborating Centers mentioned above.

As the search facilities of the pdf browser are only limited the Australian Collaborating Centre has started to develop another browser based on the technology used for ICD-10-AM. The Australian Centre was provided with SGML files for integration into the browser software.

ICD-10-XM

In spring 2002 WHO and the 2002 planning group for the Center Heads Meeting agreed on a new product called ICD-10-XM.

“It was felt that WHO should encourage a harmonizing of clinical modifications, leading potentially to an international clinical modification (e.g., ICD-10 XM) that could be used by countries without their own adaptation as well as encourage convergence among modifications. A first step in this direction would be development of a morbidity meta-database of existing clinical modifications, in conjunction with the Electronic Tools Committee. WHO puts its emphasis on this product to build a WHO database and maintain it. This will be done using XML versions of existing ICD modifications. This version will serve as a business application for reimbursement schemes.” (Meeting Summary)

Work on ICD-10-XM will be very much related to the electronic version of ICD-10. DIMDI has SGML files of the English, French and German versions of the Tabular List with identical structure and offers to merge them by ICD codes as a starting point both for an electronic version of ICD-10 and for ICD-10-XM. It is essential to agree on a data structure for ICD-10 to make sure that the Collaborating Centers can work with the files. The chair has contacted members of the ETC from the French, Nordic, UK and US centers to provide files for chapters II and XI as they are used to produce, maintain and publish ICD-10. This material will be analyzed and used for a discussion to agree on a common data structure for the Tabular List.

Maintenance Environment for WHO-FIC Classifications

At the 2003 meeting in Cologne high priority was given to the implementation of a maintenance environment that can be used to update and publish the WHO-FIC classifications. It should be suitable to deliver the classifications on paper, on electronic media and via the Internet and should be capable to generate crosswalks between the different versions of a classification.

Via email communication between WHO and DIMDI and in a face-to-face meeting between WHO and DIMDI on June 22, 2004 in Cologne the basic functionality of such a tool was defined. It was decided to use XML as the format for data storage. Meanwhile, work on this definition has started at DIMDI. A first draft based on the Classification Markup Language ClaML is being discussed in the ETC forum. More

information can be obtained from paper WHOFIC/04.039 that will be presented during the ETC sessions in Reykjavik.

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Papers

The following papers have been developed by Committee members so far:

1. Stahl C, Walker SM, Garrett C, Truran D, Roberts R, Schopen M: Electronic Maintenance of Clinical Classifications: Comparing Two Approaches. WHO/GPE/ICD/C/00.33
2. Rosenberg HM, Kochaenk KD Minino A: Update: International Collaborative Effort on Automating Mortality Statistics. WHO/GPE/ICD/00.70
3. Casey R, Hargreaves J: Mortality and Morbidity Data Dissemination Via Interactive Data Cubes – a new initiative. WHO/GPE/CAS/C/01.63
4. Berglund DJ, Fisher LJ: Developing a Database Version of the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Clinical Modifications (ICD-10-CM). WHO/GPE/CAS/C/01.65
5. Schopen M, Pavillon G, Pickett D: Dissemination Policies for ICD-10. WHO/GPE/CAS/C/01.23
6. Caulfeild D, Renahan M: Development of ICD-10-CA and CCI in Database Format. WHO/GPE/CAS/C/02.36
7. Jakob R: Data restructuring for the German translation and the maintenance of ICD-O-3 WHO/GPE/CAS/C/02.42
8. Schopen M: Consistency Checks for the Maintenance of ICD-10. WHO/GPE/CAS/C/02.43
9. Schopen M, Nelson SJ: ICD-10 and the Unified Medical Language System (UMLS), WHO/GPE/CAS/C/02.44
10. Innes K, Saad P, Roberts R: Modelling ICD-10-AM. WHO/GPE/CAS/C/02.65
11. Caulfeild D, Renahan M: Lessons Learned throughout the Development of Electronic Databases for ICD-10-CA and CCI in Two Languages. WHO/HFS/CAS/C/03.65
12. Ten Napel H, van der Haring EJ: Dutch ICD-10 and ICF in a CEN Technical Standard Format for version control and maintenance. WHO/HFS/CAS/C/03.35
13. Ten Napel H: Applicability of Dutch ICD-10 Electronic tool for publication of ICD-10 updates and control of derived and related classifications. WHO/HFS/CAS/C/03.36
14. Schopen M: Report on the XML Version of ICD-10. WHO/HFS/CAS/C/03.108
15. Hoelzer S, Schweiger RK, Liu R, Rudolf D, Rieger J, Dudeck J: XML Representation of Hierarchical Classification Systems. WHO/HFS/CAS/C/03.95
16. Anderson RN, Notzon FC, Kochanek KD, Miniño AM: International Collaborative Effort on Automating Mortality Statistics: Report of the Third Plenary Meeting. WHO/HFS/CAS/C/03.27
17. Schopen M: Towards an Electronic Version of ICD-10 - A Status Report. WHO/HFS/CAS/C/03.27

Appendix A

Terms of reference

Purpose

Support WHO and the WHO-FIC Network in developing policies on electronic classification-related tools and their dissemination.

Functions

1. Agree on the scope and definition of 'electronic tools'
2. Cover tools which are only for morbidity, mortality or functioning as well as ones with a more general application or for joint use
3. Work closely with other WHO-FIC Committees, such as the Education Committee, on overlapping areas
4. Establish liaison with other organizations/groups working in electronic classification such as the ICE on Automating Mortality Statistics, the Eurostat automated coding group or the UN Expert Group on International Economic and Social Classifications
5. Establish criteria for the evaluation and accreditation of electronic classification-related tools
6. Survey existing tools and identify gaps
7. Evaluate such tools on behalf of WHO or oversee such evaluation in some circumstances
8. Needs assessment.

Structure and working methods

The committee should have an integrated mandate of WHO-FIC electronic tools although the nature and phase of different members of WHO-FIC may differ in different countries. The Committee should be responsible to develop generic, overall principles that will apply to all members of the WHO-FIC. If necessary different sub committees may be formed on ICD, ICF and other WHO-FIC classifications so as to address different issues.

The structure of the Electronic Tools Committee should involve 10-12 permanent members that will primarily devote their time in actually developing methods and application of the tasks in the field.

Membership to the ETC is open to any individuals from collaborating organizations who wish to participate actively in the work and aims of the committee. They should submit their names to the Chair with copy to the WHO-FIC secretariat.

The chair should preferably be a single person to emphasize the integration of WHO-FIC implementation.

The committee shall draw up a workplan, which lists in detail aims, activities, deliverables, timelines and responsibilities.

Working methods should include e-mail and more interactive ways of electronic communication, conference calls and meetings, including an annual meeting during the WHO-FIC Network Annual Meeting. Official meetings of the committee must be held in conjunction with international WHO-FIC meetings.

Electronic Tools Sub-committees

Within the structure and mandate of the WHO-FIC Electronic Tools Committee, sub-committees for individual classifications can be established as the need arises. Sub-Committees assist and advise WHO on electronic tools matters which are specific and unique to the individual classifications.

The sub-committees shall specify the WHO-FIC Electronic Tools Committee functions for the respective classification in detailed workplans. The workplans shall list in detail aims, activities, deliverables, timelines and responsibilities

Working methods should include e-mail and more interactive ways of electronic communication, conference calls and meetings, including an annual meeting during the WHO-FIC Network Annual Meeting. Official meetings of the sub-committee must be held in conjunction with international WHO-FIC meetings.

Committee members should give a commitment to work on both, committee and sub-committee tasks.

Appendix B

A Framework for ICD-Related Electronic Tools

Electronic Versions of ICD-10

- Electronic Index
- ICD-10 Metadatabase System
- Web-Version of ICD-10
- WHO Multilingual CD-ROM

Automated Cause Coding Systems (Mortality)

- ACME – MICAR100 – MICAR200 – SuperMICAR – Transax
- Styx
- SCB
- DECES
- Mikado

Other Applications

- PesqCID
- Hospital Encoding Systems
- WHO Multilingual CD-ROM
- Crosswalks
- Relation/Mappings to other vocabularies (UMLS, Galen, Read-Codes etc.)
- Software for validation, aggregation, tabulation, retrieval

Electronic Training Tools

- TENDON (several languages) and other
- INTERCOD
- Training material in electronic form (NCHS)
- Need for representation format for training cases as basis for a knowledge base

Data Capture Tools

- Electronic Death Registration and Certificate
- Cancer Registration
- Data Entry Systems for Hospitals
- Data Entry Systems for Primary Care

Analytic Tools

- Geographical Information Systems
- Statistical Data Dissemination Systems

Dissemination and Communication Tools

- Web-Sites
- Majordomos
- Literature on the ICD

Other Tools

- Assembly in Health Record
- Optical Character Recognition and Vocal Capture