MEETING OF HEADS OF WHO COLLABORATING CENTRES
FOR THE CLASSIFICATION OF DISEASES

Paris, France
13-19 October, 1998

REPORT

1. Opening of the meeting

Mr. Gérard Pavillon, Head of the WHO Collaborating Centre for the Classification of Diseases in French welcomed participants on behalf of Professor Claude Griscelli, Director of the National Institute of Health and Medical Research (INSERM). He explained that INSERM carries out medical, biological and epidemiological research in some 500 units with 10,000 staff throughout France. The Paris Collaborating Centre supports French language users of health-related classifications in all parts of the world. The Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10) had been used in France for morbidity applications since 1996 and would be used for national mortality statistics as from 1999.

Mr. Eric Jougla, Head of the INSERM Cause of Death Information Service (SC8) in Le Vésinet, where the Paris Collaborating Centre is based, also welcomed participants to the meeting. He noted that SC8 manages the national mortality database and disseminates national statistics as well as initiating specific studies in the context of the national health report. Other activities include collaboration with EUROSTAT on task forces to improve the quality and comparability of health indicators.

The meeting was officially opened by Dr. Christopher J. L. Murray, Director of the WHO Global Programme on Evidence for Health Policy (GPE) on behalf of Dr. J. E. Asvall, Director of the WHO Regional Office for Europe and Dr. Gro Harlem Brundtland, Director General of the World Health Organization.

On the morning of 14 October, participants were also welcomed by Professor Joël Ménard, Director of the Direction Générale de la Santé (DGS), the French ministry of health. Professor Ménard outlined the work that had been carried out in France to introduce new general mortality and neonatal death certificates and in the development of an automated encoding system. Professor Ménard also emphasized the importance of the ICD in international public health and the measurement of mortality and morbidity. He noted with pleasure the fact that a Frenchman, Dr. Jacques Bertillon, had been at the origin of the ICD in the 19th century. He wished participants a successful continuation to the meeting.
2. Election of officers

In accordance with established custom at the annual meetings of Heads of WHO Collaborating Centres for the Classification of Diseases, the Head of the host institution, Mr. Gérard Pavillon was invited to act as Chairperson.

Dr. John Fox, Mrs. Marjorie Greenberg, Professor Ruy Laurenti and Professor Björn Smedby kindly agreed to act as Vice-chairpersons.

Ms. Elizabeth Taylor was appointed as rapporteur, assisted by Mrs. Donnamaria Pickett, A/Prof. Rosemary Roberts, Dr. Cleone Rooney and the secretariat.

3. Consideration and adoption of the agenda

In order to accommodate the other commitments of certain participants, it was decided to combine agenda items 6.6 (Parameters of the family of classifications) and 7.2 (Conceptualization of the family of classifications) and to consider them immediately after discussion of item 5 relating to the Long-term Strategy for the Development and Management of Health-related Classifications. The remainder of the agenda was adopted as presented.

4. Report of WHO classification-related activities

Dr. Murray informed participants of the restructuring which had taken place in WHO headquarters since the new Director General had taken up office on 21 July 1998. He noted the importance which had been placed on the ICD and related classifications as essential tools for public health decision making in this restructuring, an importance which was reflected in the size of the secretariat for the meeting. Dr. Murray expressed the hope that the Centre Heads would appreciate that this was a new WHO with a new commitment.

The restructuring had seen the replacement of Assistant Directors General by Executive Directors (EXDs), each responsible for a “cluster” of programmes. Classification-related activities were included in the cluster of Evidence and Information for Policy (EIP) which included a new Global Programme on Evidence for Health Policy (GPE) of which one of the units, Epidemiology and Burden of Disease (EBD), headed by Dr. Alan D. Lopez, had responsibility, inter alia, for health classifications.

Dr. Lopez, in turn, informed the meeting that Dr. T. Bedirhan Üstün would be the task manager for the area of international classification systems, assisted by a task team including Mr. André L’Hours as Technical Officer, Mrs. Sibel Volkan as full-time secretarial support with sufficient funding to enable recruitment of a half-time technical officer. It was explained that the final WHO organizational structure would be confirmed on 1 November 1998.

The meeting was informed about a moratorium on the creation of WHO collaborating centres which was in place in order to allow a review of the appropriate roles, responsibilities and functioning of such centres in relation to WHO’s overall workplan. This review would include all collaborating centres and input might be sought from those for the classification of diseases which were seen to be models of successful collaboration.
In the report by the secretariat on activities in the past year (WHO/GPE/ICD/C/98.4) it was noted that immediately after the 1997 Centre Heads meeting, the WHO Long-term Strategy for the Development and Management of Health-related Classifications had been updated and forwarded to senior management. Between January and June 1998, classification activities had mainly been dedicated to the preparation of plans of action, programme budgets and alternative scenarios in anticipation of the taking of office of the new Director General.

During March and April of 1998 an In-depth Assessment of the Products and Activities of the Health Situation and Trend Assessment Programme (HST) had been carried out by a team of six external consultants. Participants were informed of the main recommendations of the consultants in document WHO/GPE/ICD/C/98.4. Other activities had included the follow-up of the 1997 meeting and preparation for the 1998 meeting as well as support in the implementation of ICD-10, development of the Third Edition of the International Classification of Diseases for Oncology (ICD-O-3) with the International Agency for Research on Cancer (IARC), the development of the multi-revision, multi-lingual CD-ROM of the ICD, the classification of occupational injuries and other support activities.

5. Long-term Strategy for the Development and Management of Health-related Classifications

The meeting reviewed the revised long-term strategy which had been prepared following the 1997 meeting of Centre Heads (WHO/HST/ICD/C/97.39 REV.1) in relation to the new WHO vision and objectives presented earlier in the meeting. The priorities, as detailed in the document, were reaffirmed.

The restructuring at WHO to bring the work on ICD and ICIDH, two members of the family of classifications, under one task manager raised issues both for the development of overall workplans and the roles of some of the collaborating centres. The work underway in the development of detailed workplans under the restructured WHO was referenced with particular emphasis on the need for input from the collaborating centres in the development of combined and coordinated workplans. A time for this input was allocated later in the meeting (see agenda item 14).

The need for a continuous mechanism for communication and coordination between meetings of Centre Heads was viewed as an important factor in advancing the strategic priorities and the use of task forces and focus groups was suggested by the secretariat as one means to facilitate dialogue and understanding leading to joint vision.

In discussion, the need for flexibility in the frequency of ICD-10 updating was discussed. The schedule for submissions for consideration as agreed at the 1997 meeting was reaffirmed but it was felt that actual updates to the classification might be issued no more frequently than every two or three years. Alphabetic index changes, however, could be made more frequently and made available via the Internet. The issue of the frequency of updating was considered in the context of the impact on all related tools and files as well as on national language versions.
In recognition of the continuing delays in the implementation of ICD-10 worldwide, the meeting reaffirmed its position on ICD-11 as expressed in the report of the 1997 meeting of Heads of Collaborating Centres and in the long-term strategy document: “no consideration should be given to ICD-11 until after the evaluation of the updating mechanism was undertaken and the results considered by WHO and the Centre Heads”.

6. Strategic issues

6.1 Maintenance and updating of ICD-10

The secretariat presented document WHO/GPE/ICD/C/98.40 with proposed changes to the tabular list and to the alphabetical index for ICD-10 as submitted by several collaborating centres. All of the changes to the table of drugs and chemicals in the alphabetical index were suggested by the WHO Collaborating Centre in Australia where it was identified that the drug types in the titles of some ICD-10 rubrics were not reflected in the index.

Although there was general agreement with the proposed changes, further research on the code assignment for Angelman syndrome was specifically requested to ensure that there was consistency between the ICD-10 and its specialty adaptations. It was decided to defer a decision on all of the proposed tabular list changes (and their associated alphabetical index changes) until they had been reviewed by the Update Reference Committee which should begin operating within a short period of time.

In light of the earlier discussion regarding the frequency of updates, it was agreed that the proposed changes to the index should be posted on the Internet by the secretariat as soon as it was practical to do so.

The meeting was advised that nominations had been received for membership on the Update Reference Committee. Based on the plan developed in 1997, the Committee would be chaired by the secretariat. In discussion, the advantage of having a rotational co-chair representing the Collaborating Centres was raised and the Australian Centre volunteered to be the first to serve in this role.

6.2 Mortality reference group

To support the updating mechanism for ICD-10 as well as users of the classification, it had been agreed at the 1997 meeting of Centre Heads to create a Mortality Reference Group as well as an Update Reference Committee. The secretariat reported on the nominations received from the Centre Heads for these two entities. Responses had been received from a number of centres, and the secretariat undertook to establish an E-mail group for each committee, including additional nominations from centres which did not respond in 1997. The two groups were expected to begin functioning shortly.

Dr. Harry Rosenberg, who had agreed to chair the Mortality Reference Group, convened a subgroup of its membership during the present meeting and provided a report on some of its plans and priorities (see Annex I) as well as recommendations for additional members prior to the closure of the meeting.

6.3 Automated encoding
The North American Centre presented a status report (WHO/GPE/ICD/C/98.37) on the International Collaborative Effort (ICE) on Automating Mortality Statistics sponsored by the US National Center for Health Statistics. The over-arching purpose of the ICE is to provide a context within which information can be exchanged on the systematic application of computer technology to the production of mortality statistics, which continue to be key data in both international as well as domestic health statistics. Among the topics covered in the paper were the creation of an ACS (Automatic Coding System) Users Group, international collaboration on developing ICD-10 decision tables, an update on the status of recommendations from the first plenary meeting of the ICE, and preliminary plans for the next plenary meeting tentatively scheduled for the third quarter of 1999.

The group is cooperating with England, France and Sweden in developing decision tables for automated coding software (ACS). Other major issues include the impact of automation on training and numbers of nosologists, data quality and edits, language and implementation issues. The United Kingdom Centre suggested that implications of ACS for morbidity coding also be considered.

The Paris Centre presented a report (WHO/GPE/ICD/C/98.48) on a project on cause-of-death statistics which was funded by the European Community and EUROSTAT. The main objective of the project was to develop recommendations and guidelines that could be used for the application of automated coding systems (ACS) in order to achieve more comparable statistics at the European level. Recommendations and guidelines resulting from the project were based on the examination of existing ACS and on the analysis of requirements when ACS were not implemented for technical or other reasons.

Four countries, France (main contractor), the Netherlands, Sweden and the United Kingdom, worked on the project which started in February 1997. The final report was given to EUROSTAT in June 1998 and is in the process of evaluation. It includes 30 recommendations and guidelines under the following categories:

- objective and advantages of ACS
- technical aspects
- quality assurance
- performance assessment
- language problems
- expertise
- persons
- costs
- maintenance
- quality control
- trends
- expertise and consultation
- decision tables
- software assessment
- international comparison and consensus

The United Kingdom Collaborating Centre reported (WHO/GPE/ICD/C/98.50) on an effort by the Office for National Statistics (ONS) to co-ordinate international co-financing of a
Windows-based version of the automated cause coding system (ACCS) for ICD-10, currently being prepared by US NCHS only in a DOS version. The North American Center reported that this effort had not succeeded in advancing their schedule for such a development. The change from a DOS to a Windows version of their automated coding system is, however, part of the implementation process and is scheduled to be available by the end of 1999. It was noted that software will be available to all users and will be placed on the Internet as it becomes available; US ICD-10 short lists and mortality edits were reported to already be available from the NCHS homepage (http://www.cdc.gov/nchswww).

The Office of the ICD, Japan reported briefly on its 1995 implementation of ICD-10 for mortality reporting. The automated encoding system is based on ACME and runs on a UNIX Operating System.

6.4 Technical infrastructure

There were no papers presented and no specific discussion on this agenda item.

6.5 Publication policy

The secretariat presented document WHO/GPE/ICD/C/98.41. In 1997, WHO was asked to review its publication and pricing policy to ensure ICD-10 and ICD-O were readily available and prices set at an affordable level. At present, only the ICD-10 indexes in English and French will be made available on the Internet. Most international purchases are made under a software agreement with WHO, while countries such as US, UK, France, Canada, Australia and New Zealand have entered into agreements under the WHO copyright policy. For the time being, WHO will not make the tabular list available on the Internet. The German representative noted there was a need to agree on a common document structure for ICD so that exchange is possible (see also agenda item 8.2).

6.6 Parameters of the family of classifications

Three papers authored by the United Kingdom Collaborating Centre (WHO/GPE/ICD/C/98.56, WHO/GPE/ICD/C/98.49 and WHO/GPE/ICD/C/98.55) were presented to the meeting. These documents focused on the need to establish ground rules for inclusion into the family of classifications. The ideas presented in the papers were discussed by the meeting, particularly in light of their attempt to clarify the domains of ICD and ICIDH and other candidates for inclusion into the family of classifications. The link between WHO’s constitutional responsibilities and the classifications, particularly ICD, was noted.

The roles and applications of the ICD and the ICIDH were mentioned in the discussion and it was noted that the ICIDH would be discussed in more detail later in the meeting (see agenda item 12.1). The availability of crosswalks between classifications was cited as important as was the issue of overlap between classifications. The need for standardized definitions for terms across classifications was raised as well as the issue of handling sequelae and of adding severity to classifications. It was felt that there must be a clear delineation of the domain of a specific classification including the purposes for which it should and should not be used. It was noted that the needs of users of the classification and of outputs based on it must be taken seriously. Overall, it was agreed that efforts should be focused on those things which are important to public health.
It was noted that previous efforts had been made to define the criteria for membership into the family of classifications and it was agreed that this issue needed to be pursued urgently. The secretariat undertook to form a subgroup including representation from the Centre Heads to move this issue forward. The work of other standards-setting organizations and available scientific standards, such as ISO 9000 was noted in relation to the need for broader collaboration and cooperation.

In relation to the family of classifications, there was some discussion regarding procedure classifications and primary care classifications such as ICPC. These topics were elaborated further later in the meeting under agenda item 12.

6.7 Multiple cause coding

There were no papers presented on this agenda item. The Paris Centre reported that its work on this issue had temporarily ceased and would recommence in 1999.

6.8 Training

The Venezuelan Centre for the Classification of Diseases (CEVECE), as Collaborating Centre, is the institution in charge of providing material for the International Classification of Diseases, disseminating its use, and training professionals and technicians in Venezuela and all Spanish speaking countries of Latin America. The Centre reported (WHO/GPE/ICD/C/98.59) that it had set up a programme of 23 workshops on the use of the ICD-10 in each of the Venezuelan federal entities, financed by the National Training Program for the Reformation of the Health Sector and the Basic Training Plan in the Administration of Health with the Pan American Health Organization and Project Health. From February to May of 1998, 507 specialists in the use of ICD-10 were trained with an average of 22 students per course. Participants included register and health statistics technicians, clinical and epidemiological medical specialists, and other types of personnel representing the Ministry of Health and Social Assistance, the Venezuelan Institute of Social Security, the Venezuelan Institute of Social Prevention of the Ministry of Education, State Universities, and other institutions.

The meeting was also provided with updates on training activities by meeting participants.

The Paris Centre reported that it was organizing ICD-10 training for French speaking countries with support from WHO and the Regional Offices. It was noted that through PAHO the Centre had provided training in Haiti, although further assistance would be required for African countries.

SEARO is responsible for training of trainers and coders in 10 countries and organized courses for eight of these in Thailand in 1997 with the assistance of the Australian centre’s Brisbane staff. Further courses are planned for 1999.

The secretariat reported on training activities in mental health with the training of 60,000 doctors in Spanish speaking countries. Similar programmes are available for Portuguese speaking countries. The training models have proved useful in other countries and the American Psychiatric Association has sought further information from WHO.
EMRO noted that it had so far organized two inter-country courses on ICD-10 using the English version of TENDON and assisted in preparing and conducting national courses in eight countries. Another inter-country course, using the French language version of TENDON, is planned for 1999. Further training is required for the Eastern Mediterranean Region as well as for African countries in the use of TENDON and in the application of automated systems for coding.

PAHO reported that it is participating in and supporting training for coders and physicians and that work on the development of TENDON-like software is being carried out in the Mexican national centre. In Spain, immediately after the present meeting, a national meeting on epidemiology will cover ICD-10 issues as Spain will introduce the new classification in 1999. A further course was planned to be held in Caracas.

The National Centre for Classification in Health (NCCH) (part of the Australian Centre), in addition to training for ICD-10 coders, is developing educational material for clinicians on the changes in ICD-10-AM compared with the Australian version of ICD-9-CM. The material will be available on the NCCH Homepage and can be downloaded for Powerpoint presentations. The Australian Centre acknowledged the work of Mrs Sue Walker in conducting education programmes for SEARO and Western Pacific Regions. The New Zealand Health Information Service (NZHIS) had organized train-the-trainer courses in ICD-10 for clinical coders in morbidity (ICD-10-AM) and mortality and also reported their involvement in ICD-9-CM training in Singapore.

The North American Center proposed that Education be a theme for next year's Centre Heads meeting and that the theme include working with data users. The Center acknowledged the input from Mrs. Patricia Wood of Statistics Canada who helped develop their training material which would be available within the next few months for mortality ICD coders converting from ICD-9 to ICD-10. In 1999, basic training for new mortality coders will be available as well as a course in principles of coding for statisticians and epidemiologists.

The secretariat raised the need for undergraduate training of doctors in completion of death certificates. In the US, NCHS provides materials and modalities to reach clinicians through the states. There is an Internet site directed at physicians to impart information in tutorial format on the completion of death certificates (http://www.thename.org/main.htm).

The Brazil Centre noted that it distributes 10-12,000 booklets per year to undergraduates and resident medical staff through medical societies and provides 2-3 training lectures per month.
7. Priority themes

7.1 Terminology related to classification and coding

The final report (WHO/GPE/ICD/C/98.26) of the Dutch Classification and Terminology Committee for Health (WCC) was presented and described its activities in standardization in the period 1974-1997. The mission of the Dutch Classification and Terminology Committee for Health (WCC) was the advancement of the one-time recording and exchange of data with regard to health and health care by means of an integrated system for codes, classifications and definitions.

There were three developmental phases with switches of the WCC activity from standards on objects to standards on concepts and then to standards on terms. For an integrated system increasingly more drastic requirements were considered to be necessary in the consecutive phases:

- individual objects need a unique identifier;
- objects have to be distinguished by sets of intrinsic characteristics;
- professional groups determine by consensus on their concepts;
- concepts of professional action have to be defined in terminological phrases;
- all kinds of diagnostic terms, that physicians may be aware of, should refer to a classification if data collection is the purpose (e.g. ICD-10); and
- terms should be analyzed and structured according to their referential meaning.

Since 1998, a new division of tasks between standardization bodies, terminology and maintenance services replaces the WCC activity. The Department for Public Health Forecasting of the National Institute of Public Health and the Environment is maintaining the ICD-10 in Dutch as well as conversions of other health-related classifications to the ICD-10, and has been taking over the terms of reference of the WHO Collaborating Centre for the ICIDH.

Centre Heads agreed that this type of work was a national and international issue. There was discussion on the naming of objects and definition of intrinsic and extrinsic characteristics of entities. However, it was noted that there was still a problem with diagnostic statements. At the European level, WCC and CEN standards have been consulted and need to be operationalized to use the characteristics in certain grammars such as Galen-in-use. Some software is available to handle analytic statements, some non-analytic statements like part-whole relations and causal relations. Recommendations for Centre Heads revolved around the need for agreement on terms, perhaps through more general terminological standards of CEN and ISO and standards on classifications in medical informatics.

The Australian Centre noted that the relationship between the index and tabular list of ICD-10 is important in relating terminologies to ICD-10 and that electronic translation of the classification will allow better appreciation of the three dimensionality of the hierarchy and structure of ICD-10.

The UK centre presented three related papers (WHO/GPE/ICD/C/98.52, WHO/GPE/ICD/C/98.53 and WHO/GPE/ICD/C/98.54) on terminology related to classification and coding addressing aspects of the problems under discussion, particularly confusion about the difference between a nomenclature and a classification. The meeting
agreed that the use of these terms is not clear. The last time that WHO and the Heads of Centres addressed these issues was many years ago. It was agreed that they should be addressed again, and that a subgroup of the Centre Heads, called by the secretariat, should be formed to address this issue and the one of terminologies, their relationship to classifications and to the family. This group should also look at how the family of classifications is conceptualized. Several centres, including Australia, North America, United Kingdom, and that for the Nordic countries as well as the representative from the Netherlands expressed interest in being involved.

It was noted that WHO and the public health community have gradually enlarged their scope of interest from the collection of information about mortality to morbidity and determinants of health and illness. To support these interests, it is necessary to continue to collect traditional vital statistics in a reliable way but to build upon and go beyond this.

Recent developments in electronic technology have made it easier to understand and display the hierarchical structure of a classification in the form of a relational database. The terms can be understood as building bricks, and the structure of the classification as the plan which enables one to build a wall and an entire house from them. The classification thus enables the development of meaningful statistical outputs from the input of individual items in a structured way.

This statistical information, bringing together mortality and morbidity, provides the evidence needed for health policy. Rigorous and consistent use of classification tools is essential to make sense of the information coming from a variety of sources in order to make reliable assessments of the real global burden of diseases.

7.2 Conceptualization of the family of classifications

This item was addressed under agenda item 6.6 (see above).

7.3 Specialty-based classifications

The Sao Paolo Centre presented a report (WHO/GPE/ICD/C/98.23) on the application of ICD-10 and ICD-DA to oral and maxillo-facial trauma attendances. An analysis was carried out on 2,372 cases in an Oral and Maxillofacial Surgery and Traumatology Service. All the diagnoses were coded by ICD-10 and ICD-DA (Adaptation for Dentistry and Stomatology), 3rd Edition. In 1,117 cases, the ICD-DA had much more specificity; in 978 cases, there was no difference between the two classifications. In the remaining 217 cases, there were no suitable codes in ICD-DA. The authors suggested some additional sub-categories for ICD-DA which would better describe the diagnoses found.

Presentation of this report lead to discussion of which countries are using this adaptation, and whether data collected and classified using the speciality adaptations can really be comparable to data on similar episodes of care classified to ICD-10. Specialists developing their own adaptations may fail to recognise the full scope of the ICD. For example, the ICD-DA had omitted the entire chapter of the Z codes covering other reasons for contact with health services.
The Nordic Centre then presented (WHO/GPE/ICD/C/98.27) a comparison of specialty adaptations, and highlighted some of the problems which may arise in their use. It was apparent that use of specialty adaptations alone, without recourse to the full ICD-10 could lead to gross differences in coding and so to data which were clearly not comparable, though they might appear to be so. For example, the same fifth character codes appear in more than one adaptation, but with different meanings. The meeting discussed whether the Collaborating Centres should have the opportunity to study and comment on proposed adaptations before these were given WHO approval. It was noted that there may be problems of intellectual property rights and commercial sensitivity prior to publication. Centres were asked, however, to advise their constituencies on the use of these adaptations and the interpretation of data produced from them.

It was remarked that the family of classifications includes “unplanned offspring” of the ICD. The advisability of the various adaptations for use in psychiatry - covering specialist clinical, research and primary care settings was discussed. Some countries preparing translations had decided to combine the clinical and research versions. It was noted that there appeared to be a demand for these and other adaptations, and that there was evidence that some of them were being used quite widely. The importance of assessing data based on their use was pointed out.

It was accepted that the secretariat could not be responsible for eliminating overlap or clashes between different specialty adaptations. However, it was felt that clear guidelines should be agreed, promulgated and adhered to. It was noted that although WHO should check their compatibility before approving specialty-based adaptations, this might not be possible with resource constraints. It was agreed, however, that a central database of all existing adaptations should be maintained by the secretariat so that users could search for existing codes and modifications before resorting to the creation of new fifth character extensions. The secretariat expressed an interest in pursuing this initiative.

7.4 Short tabulation lists

The Nordic Centre presented a document (WHO/GPE/ICD/C/98.30) which described the positive experiences of short lists for mortality and morbidity as instruments for statistical continuity within countries and for statistical comparability between Nordic countries using different revisions of ICD. It was noted that the Nordic countries will adopt the EUROSTAT short list for mortality. With this as background, the Nordic Centre suggested that WHO develop short lists for ICD-10 with practical translations back to ICD-9 to be used during the long period of international transition form ICD-9 to ICD-10. Such “coordinated” lists might focus only on selected causes. This development work might be facilitated by enhancing the current WHO “Translator” with one-to-one code conversion choices.

A question was raised regarding WHO plans to use a new list, other than one of those recommended at the ICD-10 Revision Conference, for the publication of mortality statistics. It was noted that, as part of the WHO restructuring, the issue of validation, storage and publication of mortality statistics based on ICD-10 would be reviewed.
8. Implementation of ICD-10

8.1 Current situation

The meeting noted that progress in worldwide implementation of ICD-10 continues to be somewhat slow. A schedule of actual and proposed national implementation dates for ICD-10 was circulated to meeting participants and updated. The revised schedule appears as Annex II of this report.

8.2 National (language) versions

The German Institute for Medical Documentation and Information (DIMDI) presented a paper (WHO/GPE/ICD/C/98.24) on the experience of the electronic publishing of the German language edition of ICD-10. After a thorough analysis of the requirements, DIMDI decided to use the Standard Generalized Markup Language SGML (ISO-8879) for storage and maintenance of the German language edition of ICD-10. The classification is stored as an SGML document - a simple ASCII file with text and additional markup for the logical structure of the classification. SGML documents are independent of any word processing software, operating system or computer hardware. Software for editing, formatting, printing and converting SGML documents is available both in the public domain and commercially.

The report demonstrated the power of SGML and showed how structural markup can be applied to ICD-10 to:
- extract information for consistency checking during the production and update cycle;
- add changes to the classification and extract correction lists;
- link style sheets in order to print the classification;
- map classification elements to database fields to implement an ICD database; and
- transform SGML to HTML to make ICD accessible on the World Wide Web.

The paper pointed out that if all collaborating centres could agree on a common document structure for ICD and if WHO distributed ICD-10 in suitable files, all national language versions could be kept in the same data format. A common pool of utilities for production, consistency checking, transformation and formatting could then be applied to all national language versions. This sharing of resources could produce savings in time, money and labour at WHO and all collaborating centres during their production cycles.

Several advantages for this approach were discussed including: ease of updating the master data and of converting to produce a variety of printed or electronic products; ability to promulgate rapidly via the Internet; incorporation of hot-links to navigate between dagger and asterisk codes, to accommodate exclusions to other codes etc; facility of including educational panels and explanatory notes, and links to volumes II and III.

The paper, which laid out a very clear and far-sighted strategy for exploitation of developments in information technology to produce a very flexible and adaptable electronic master copy in SGML while maintaining firm control over the quality of products derived from it, was greeted with widespread enthusiasm. The participants warmly applauded DIMDI for this far sighted work and for its offer of collaboration.
In response to questions, it was noted that the alphabetical index is also available in SGML form, but has not been converted into HTML yet. The size of the index may be too large for hot links to the tabular list to be practical, because operation would be too slow. The index could be stored as a database, and converted as necessary for users.

The meeting discussed the possibilities of similar approaches for the storage and presentation of classifications in the UMLS and their usefulness in maintaining consistency between language versions of ICD-10 in UMLS. It was noted, for example, that the ICD databases in the UMLS presently did not include links or inclusion/exclusion notes.

The North American Centre presented a report (WHO/GPE/ICD/C/98.39) which summarized the status of ICD-10-CM development and implementation in the United States. It covered modifications made to ICD-10-CM since the 1997 Heads of Centres meeting. Topics focused on several pertinent changes that are due to advancements in understanding the etiology of certain disease entities and the introduction of new standardized definitions.

Discussion ensued on the consultation process and the resultant proposed changes, in particular those relating to the classification of diabetes which would require mapping to ICD-10. The meeting was advised that the American Diabetes Association had decided that the way diabetes should be classified had changed but that these modifications were purely for clinical uses within the United States. The modifications do not extend to mortality where they are often less relevant and where the detail to apply them would rarely be available from death certificates.

The secretariat raised the problems of copyright issues in developing and distributing ICD-10-CM. The National Center for Health Statistics (NCHS) has an agreement with WHO which covers use for US government purposes in the geographic United States of America, and the meeting was told that NCHS had told potential customers outside of the US that they must negotiate their own agreements with WHO. It was mentioned that several US software companies have already negotiated licenses from WHO which cover the use of ICD-10 and clinical modifications. WHO wishes to continue to promote wide use of the classifications in the private sector as well as in government and public health applications.

Canada expressed the concern that proposed changes in ICD-10-CM affect the core classification and may have a serious impact on comparability over time. There was also some discussion about this issue in the context of the interpretation and comparability of case mix grouping (e.g. national DRGs) based on different modifications of the ICD-10 (and varying procedure classifications).

The criteria for identifying a need for modification or updating of ICD-10, as opposed to modifications purely for clinical use, were discussed as well as the sort or amount of change which would indicate a need for a new revision. These had also been discussed at the meeting of Centre Heads in Tokyo in 1996, but participants were not sure whether those criteria had been sufficiently spelled out. It was noted that some additional work in this area will be undertaken as one of the early responsibilities of the Update Reference Committee addressed earlier in the meeting (see agenda item 6.1).

The secretariat expressed its intent to explore the possibility of obtaining extrabudgetary funds to further explore the issues of the modification and application of the classification.
The North American Center reminded the meeting of the different perspectives in morbidity and mortality. A key use of mortality data has always been in time trends, and therefore consistency over time is extremely important so that major classification revisions must be bridge coded. Also, any changes must be incorporated into decision tables of automated coding software and distributed to all users.

Some centres were concerned about the administrative delays in producing the ICD-10-CM. The North American Center emphasized, however, that there was a difference between finalizing the classification, which could then, with WHO approval, be used by others, and obtaining a federal mandate for its implementation in the United States.

With respect to new national language versions of ICD-10, the secretariat noted that Turkmenistan was the only country to have agreed new translation rights since the 1997 meeting of Centre Heads.

9. **The dagger and asterisk system**

There were no papers presented and there was no discussion on this agenda item.

10. **Improvement of health information**

10.1 **Mortality**

The Sao Paulo Centre presented a report (WHO/GPE/ICD/C/98.20) on a study where the medical records of death cases occurring in a University Hospital in the city of Sao Paulo were analyzed and for each case a death certificate was filled in. These death certificates were compared with the original ones filled by the physician who had cared for the patient. In the discussion of the report, a need was cited for the development of general set of descriptions for completion of death certificates.

In a second report (WHO/GPE/ICD/C/98.21), the Sao Paulo Centre described an investigation performed in order to compare the patterns of mortality of the Japanese immigrants to Brazil, and their Brazilian-born descendants, with the existing pattern in Japan and with that of non-Japanese people in the city of Sao Paulo. As a by-product of the investigation, the quality of the completion of the death certificates of immigrants, their descendants, and the non-Japanese was analyzed and the results presented in this paper.

The attempt to link the completion of the certificate with the characteristics of the certifier was seen as a very interesting and excellent study. It was noted that it would not be possible to replicate this study in the United States’ Japanese population because the US death certificates do not contain the decedent’s country of origin and the reporting of race/ethnicity was not seen as an alternative that could yield comparable data.

The Nordic Centre presented two related reports. The first (WHO/GPE/ICD/C/98.32) updated the meeting on the activities of the Mortality Forum since the previous Centre Heads meeting. Issues raised in this paper were referred to the Mortality Reference Group (see agenda item 6.2). The second paper (WHO/GPE/ICD/C/98.33) dealt with the issue of multiple injuries in mortality. In deaths due to external causes, the ICD recommends that the
main injury be coded in addition to the underlying external cause. In ICD-9, the main injury was selected according to a priority list, but in ICD-10 some new coding instructions were introduced, as well as a number of special categories for multiple injuries. The combined impact of these instructions and new categories resulted in precise information on the nature of the injuries being frequently lost. This paper compared statistics based on ICD-9 and ICD-10 coding, and discussed alternative instructions for ICD-10 coding of main injury.

The issue of comparability of mortality data was cited by the meeting as an important area for study. It was noted, however, that there was a need to ensure the consistent interpretation of output. With respect to the coding of multiple injuries, the secretariat clarified that ICD-10 Volume 2 contains a section of rules and guidelines specifically for mortality while the instructions in the Tabular List are for all uses. The need to further disseminate training information was seen as a means of improving the situation with respect to several of the problems of coding raised in both of the papers presented by the Nordic Centre.

The Nordic Center noted its plans to create a home page for the Mortality Forum. A summary of the questions and issues raised through the Forum would be forwarded to the Mortality Reference Group regularly for consideration. Recommendations from the Mortality Forum and decisions from the Mortality Reference Group would form part of an annual report to the Heads of Centres.

In another report (WHO/GPE/ICD/C/98.36) the Nordic Centre reported on a comparative study of the collection, processing and publication of mortality statistics in the Nordic Countries with special emphasis on improving inter-Nordic coordination. In 1996, the Nordic Medico-Statistical Committee (NOMESCO) decided to investigate the possibility of improving the comparability of the mortality statistics in the Nordic countries. The working party set up for this purpose has analysed the data collection, classification practices, and distribution of mortality statistics. Differences found were greater than expected. The working party suggested a number of measures to improve comparability, including evaluation of data collection methods, joint training of coders, and regular meetings of statisticians in charge of mortality statistics.

It was noted that the draft report of the NOMESCO study was currently available in Swedish only but that an English translation would be included in the next issue of “Health Statistics in the Nordic Countries”. A discussion followed the presentation of this paper during which the UK Centre cited similar experiences but suggested that the use of automated coding systems could alleviate some of the problems. The United Kingdom Centre mentioned that they would publish, for the first time in 10 years, national multiple cause data using 1996 data coded in ICD-9 and using ICD-6 recommendations for multiple cause tabulation.

The Paris Centre presented a report (WHO/GPE/ICD/C/98.44) on the comparability of causes of death statistics inside the European Community. The report noted that cause-of-death statistics are widely used for inter-country comparison of health characteristics. Procedures for the collection of cause-of-death data are relatively homogeneous between countries (i.e. death certificate models, International Classification of Diseases) but in spite of these common features, important comparability issues remain. Before attempting to measure and interpret inter-country differences in mortality, it is essential to assess these possible biases. This paper presented a review of the results of methodological international comparative cause-of-death studies. The two main steps in the elaboration of mortality statistics,
certification and coding of causes of death, were analyzed and some guidelines aimed at improving the level of future comparability proposed including:

- adoption of the same form of death certificate;
- better training and querying of physicians;
- adoption of the same definition of vital events;
- use of ICD-10 and adoption of uniform automated coding;
- use of multiple cause of death data; and
- use of more operational cause of death indicators.

It was noted that future investigations may focus primarily on indicators specifically useful for health planners (e.g. premature deaths, avoidable deaths) or on causes of death with specific problems of comparability (e.g. suicide, accidental deaths, drug-related deaths). These investigations would be undertaken within the framework of the EUROSTAT task forces on quality and comparability of health indicators within the European Community.

The meeting noted this important work and discussion ensued on the need for the identification of a list of codes throughout ICD-10 for “ill-defined conditions” for the purpose of the consistent application of the underlying cause rules and guidelines. It was noted that thought must be given to the inclusion of those conditions that were classified in Chapter 16 (Signs and Symptoms) of ICD-9 but have been assigned to other chapters in ICD-10.

Other issues that could impact on the quality and comparability of mortality data were noted to include: the use of manual versus automated coding; the integration of forensic evidence (especially that available sometime later) into the death certificates; and the impact of the legal process on the certification and classification of violent deaths. A need to expand the use of automated coding systems was expressed and it was noted that a Spanish-language system had been developed by Catalonia and was available. Mention was made of the International Collaborative Effort (ICE) on Injury Statistics which was also looking at issues related to violent deaths and how the legal processes impact reporting. It was reported that in the United Kingdom the causes of some deaths cannot be resolved until an inquest is held and this may be a year or more after the death.

The United Kingdom Centre provided background on the variation in the collection and processing of mortality statistics across the UK and existing quality control measures, including validity; accuracy and repeatability and provided an abstract (WHO/GPE/ICD/C/98.51) of a report on a project regarding the quality control of mortality statistics. Surveillance of the quality of mortality statistics is an important feature of their interpretability. There is variation in the degree of detail (three- or four-character ICD code or short list) with which the causes of death are presented and of the degree to which data are presented for groups defined by demographic factors such as age, race, sex and place. There is, however, rarely any information in routine sources as to the quality of the underlying data and, therefore, on the extent to which the mortality rates derived from them can safely be used for setting health priorities, estimating life expectancy or potential years of life lost (PYLL) by cause, or simply comparing mortality rates between countries or over time. The UK project was an attempt to identify some of the main remediable causes of variability in the quality of mortality statistics, to devise a strategy for reducing them, and to monitor the effects of any change in the procedures on the mortality statistics over time. It should also
generate a set of indicators that could be routinely published alongside the mortality data in order to improve their interpretation by users.

One of the findings of the project was the need for further checks at various stages of the death registration process. Recommendations of international relevance included:

- the need for validity checks as early as possible in the data collection process, for example age checks against dates of birth and death at registration;
- the routine publication of measures of data quality with the mortality statistics; and
- the need for agreement on an international set of quality measures, for example the percentage of deaths with an ill-defined underlying cause; the percentage of deaths where the underlying cause is not selected by the General Rule (ICD-9) or the General Principle (ICD-10).

An offer was made by the United Kingdom Centre to provide copies of the full report of the project to Centre Heads upon request.

The use of automated coding systems was noted to provide useful data around the application of rules in underlying cause selection, for example the Nordic Centre reported on the production by Statistics Sweden of action statistics concerning the number of times different rules are applied in coding of cause of death.

It was agreed that the Nordic Centre would initiate a discussion on quality measures and report to the 1999 meeting of Centre Heads.

The Office of the ICD, Japan presented a report (WHO/GPE/ICD/C/98.57) on the application of notes in ICD-10 for the interpretation of highly improbable relationships between injuries and conditions coded in other chapters of ICD-10. The discussion centred on the need for international agreement on cases in which injury could be due to a disease. At present, ICD rules confine this relationship to injury due to epilepsy. It was agreed that this issue should be discussed further at the Mortality Forum and the Mortality Reference Group with any suggestions for changes in ICD-10 being directed to the Update Reference Committee for a recommendation to the Centre Heads.

10.2 Morbidity

The Sao Paulo Centre presented a report (WHO/GPE/ICD/C/98.18) on a cross-sectional survey performed in an area of the city of Sao Paulo in order to determine the prevalence of mental disorders. Prevalence was obtained by means of a questionnaire - the Composite International Diagnosis Interview (CIDI) applied by non-physicians. A specific software classified the cases according to the nosologic criteria, using both the DSM-III-R and the ICD-10. Results showed that the CIDI is a very useful tool to be used in interviews performed by lay persons enabling the diagnosis classification of mental disorders according to the ICD-10 criteria.

Discussion centred on the use of the Composite International Diagnostic Interview (CIDI) in mental health research. The tool allows morbidity to be defined in terms of research criteria so that comparisons can be made between and within countries in regard to mental health conditions.
The Sao Paulo Centre reported (WHO/GPE/ICD/C/98.22) that some studies regarding morbidity surveys showed that 40 - 50% of the complaints could not be classified by the disease labels or rubrics in the ICD. The results of a survey performed in an area of the city of Sao Paulo, however, showed that it was possible to code all the complaints using ICD, although approximately 40% of the codes belong to the ill-defined chapter. In a complementary report (WHO/GPE/ICD/C/98.19), using data from a morbidity survey, the cases coded to the "Ill-Defined" Chapter of ICD-9 were compared with their codification by ICD-10. The objective was to quantify how many ill-defined conditions coded using ICD-9 changed to other chapters when coded according to ICD-10. In addition, those remaining in the ill-defined chapter of ICD-10 were evaluated as to whether more or less specificity was available from the ICD-10 codes.

The meeting noted the promising results regarding the applicability of the ICD to survey data. Some discussion focused on the comparative data on mental health prevalence made available through results quoted in two of the papers from the Sao Paulo Centre. It was considered that the difference may arise from the use of different survey instruments and the way in which a question about recent history or experience of disease was asked.

The Nordic Centre reported (WHO/GPE/ICD/C/98.34) on the results of two evaluations of the quality of the data contained in the Swedish national hospital discharge register. The first evaluation was carried out on data from 1986, when ICD-8 was still in use in Sweden. The second evaluation was on data from 1990, three years after ICD-9 was introduced. The studies utilized a research protocol developed at the Centre with the collaboration of the other Nordic countries. This protocol had also been used in a similar Danish study on ICD-8 data from 1990. The protocol allowed differentiation between errors at data entry, errors in the selection of ICD code and in the selection of main diagnosis. The results of the Swedish studies indicated that errors in the selection of main diagnosis were more common in the use of ICD-8 whereas errors in the selection of the code (for the main diagnosis) were more common after the introduction of ICD-9. It was noted that it is intended to repeat the study using ICD-10 after a few years of experience with the new classification.

A great deal of interest was expressed in the results of this study on the reliability of coding the main diagnosis. In discussion of the results, variation in practice between countries concerning who is responsible for the coding and for the choice of the main diagnosis was noted as was variation in the definition and labelling of the “main condition” in morbidity. The United Kingdom Centre commended the distinction made in the Swedish study between errors attributable to doctors and those attributable to clinical coders and recommended that these differences be formalized. The Centre also noted that the United Kingdom had formalized its definition of main diagnosis to comply with the WHO definition.

The Australian Centre reported on the development of the Australian Coding Benchmark Audit to standardize coding audit methods and measurement of coding error in hospitals. It was noted that this audit also makes the distinction between clinical coder error and “system” (doctor) error.

Interest in developing an international research protocol for studies on the quality of morbidity coding was expressed by several centres. The meeting also discussed the interest in and impact on coding quality of the introduction of Diagnosis Related Groups (DRGs) and their use for hospital funding.
The Paris Centre presented a report (WHO/GPE/ICD/C/98.46) on the results of quality controls implemented in 1995 (ICD-9) and 1996 and 1997 (ICD-10) at St. Germain en Laye Hospital. The coding described morbidity on both “primary” (PD) and associated diagnosis (AD). During each six month period, about 100 patient files were sampled to be sure that the ICD coding was accurate and precise enough. The quality control methodology involved having a medical doctor, especially trained in the field of quality insurance and different from the clinician who initially assigned the ICD codes, review the patient record. Results include medical errors (E) and/or imprecisions (I). E was defined as no agreement between codes assigned by clinicians and those used by the medical doctor performing quality control. E might also represent a lack of medical data, affecting PD and AD. In I, disagreements were less significant but, for example, nonspecific .8 or .9 codes could be avoided. Finally, each E or I was discussed with clinical teams and new ICD codes were only maintained if the clinicians agreed.

This paper, which focused on coding quality, also generated a great deal of interest. It was considered extremely useful to have coding errors segregated by cause. It was pointed out that the difference in coding error rate between medical specialties might be due to the size and scope of diseases covered by that specialty. It was noted that the findings in this study supported those found in the Swedish study and that the introduction of ICD-10 may lead to a temporary increase in error rate.

11. Bridge coding and equivalence tables

There were no papers presented under this agenda item.

The Brazil Centre reported briefly on a pilot study involving the dual coding of 6,000 death certificates in ICD-9 and ICD-10. The results showed a decline in mortality from ill-defined conditions and an increase in mortality from respiratory conditions. PAHO reported supporting dual coding studies in two countries which showed little change in broad categories although there was an increase in infectious diseases due to the relocation of the codes for AIDS from Chapter III (in ICD-9) to Chapter I (in ICD-10). The results, based on 5,500 records in each country, were to be published in the epidemiological bulletin of PAHO.

The cost effectiveness of bridge coding was queried. The United Kingdom Centre supported the need for bridge coding and noted that dual coding using ICD-9 and ICD-10 would show greater changes than dual coding using ICD-8 and ICD-9. For example, a study comparing ICD-9 and ICD-10 found an increase in respiratory deaths by 40%. It was noted that a previously reported study from Japan showed a dramatic decline in deaths from pneumonia between ICD-9 and ICD-10. The North American Center also recognized the need for comparability studies (or bridge coding) to be able to interpret changes brought about by the new classification and the associated rules and reported plans to process 1996 cause of death data in ICD-9 and ICD-10 using automated coding even though up to 20% of certificates would have to be coded manually. The United Kingdom Centre also reported plans to bridge code one year's deaths. It was pointed out that if sampling rather than complete recoding is required, the sampling should be on the basis of a characteristic other than the cause of death.

The United Kingdom Centre considered that bridge coding would only be cost effective for mortality data. The Australian Centre reported a dual coding study of 10,000 hospital
discharges using the Australian version of ICD-9-CM and ICD-10-AM. This was part of an impact assessment study regarding the implementation of ICD-10-AM. The results showed no change in the number of codes per record. The meeting was informed that mappings between the Australian version of ICD-9-CM and ICD-10-AM have been made available for downloading from the Australian Commonwealth Department of Health and Family Services homepage on the Internet (see http://www.health.gov.au/casemix/products.htm#mapping).

12. Family of classifications

12.1 International Classification of Impairments, Activities and Participation (ICIDH-2)

The Chairperson welcomed staff members from the French Collaborating Centre for the ICIDH to this portion of the meeting.

Dr Üstün of the secretariat presented an introduction to the ICIDH-2 and outlined WHO’s recent involvement in the revision process. He noted that the change from acute to chronic disease in the epidemiological transition has meant that more people are now living with long term consequences of disease or injury. Health and social services must increasingly answer the needs that creates and there is a requirement to communicate the needs of individuals to policy makers using a common, international language. While the ICD classifies diagnoses of diseases, disorders and injuries, it does not generally cover the consequences and effects that these have on functioning. The ICIDH is intended to fill this gap and to classify outcomes of disease processes and of interventions. It is not a classification of people with disabilities but should describe functioning across the whole population and the whole spectrum of health.

The current draft of the ICIDH-2 sets out three levels of functioning:

<table>
<thead>
<tr>
<th>Impairment</th>
<th>Activity</th>
<th>Participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss or abnormality of body structure or of a physiological or psychological function</td>
<td>Nature and extent of functioning at the level of the person. May be limited in nature, duration and quality.</td>
<td>Nature and extent of a person’s involvement in life situations in relation to Impairment, Activities, Health Conditions and Contextual Factors. May be restricted in nature, duration and quality.</td>
</tr>
</tbody>
</table>

Several changes between ICIDH-1 and ICIDH-2 were noted in the presentation. For example, the concept of a linear causal relationship between impairment, disability and handicap has been replaced with a multifactorial understanding of the interactions between characteristics of the individual and their environment which limit functioning. ICIDH-2 tries to integrate two models: the medical/personal adaptation model and the social/environmental/political model and to establish principles of equity and parity.

The Beta-1 draft of ICIDH-2 was reported to be under field testing in several countries and plans for further development and testing leading up to completion by 2000 were described. It was pointed out that since no real data coded to the new revision are yet available, it remains theoretical. There is a very real need for data to better develop the classification and
to be enable comparisons with the first revision. Some ICIDH-2 training products were noted to be available but dealt largely with introducing and explaining the concepts and framework. They did not yet cover details of how to code using ICIDH-2 or to perform individual case evaluation. It was noted that additional information about the ICIDH-2 was available via the Internet (see http://www.who.int/icidh) and that the current draft and testing protocols might also be downloaded.

The presentation by Dr. Üstün was greeted with enthusiasm. In the discussion it was pointed out that some confusion and unresolved issues still surround the ICIDH such as: the domain of classification; the continuum from diseases and the consequences of treatments; overlaps with the ICD; which information systems will use which classification; whether one must sometimes use both the ICD and the ICIDH or not, and if so, which is primary. It was noted that use of the ICD is not restricted to death but its range is not sufficient to cover all domains of health or needs for health and social care. There is a need to clarify the domains of classification across the whole range of ICIDH and of the ICD. There was some debate over whether the concepts were culturally dependent or could truly be used internationally with the same meaning and sense. Dr. Üstün reported that there were anthropological studies in 14 countries addressing issues of how professionals and people with disabilities conceive health problems.

The North American Center introduced paper WHO/GPE/ICD/C/98.38, but pointed out that it had been written before the annual North American ICIDH revision meeting in Vail, Colorado in early October 1998. Progress made in the year since their 1997 annual meeting in Ottawa, Canada (which followed the 1997 Centre Heads meeting) and on the proceedings in Colorado was reported upon. In North America, results from Beta-1 tests have provided concrete data on the participation and environment domains which clarified many issues. In response to concern that the fast pace of the revision process might not allow sufficient practical testing, a year’s extension was agreed to by WHO and would allow further Beta testing. A task force for children had been established and a contract with WHO for an international task force on environmental aspects had been negotiated.

It was pointed out that work in the United States and Canada suggests that the environmental classification should be a clear fourth dimension rather than be relegated to a part of the participation domain. Papers which outline a skeleton two-digit environmental classification were noted to be available to interested centres from the North American Center. Several meeting participants expressed a need to have two-digit classification for each dimension of the ICIDH-2.

The North American Center recommended continuation of the critical evaluation of ICIDH-2, which does still require further work to make it usable and acceptable, particularly in ensuring that it is written in clear plain English. This is considered absolutely essential to ensure that it is truly understood by users and that it can be successfully translated into other languages while maintaining the same meaning.

The North American Center noted that it would be represented at the ICIDH meeting to be held at WHO headquarters immediately after the present meeting and would communicate the findings from the North American research and discussions, which should be taken into account in re-drafting. They would present firm time-lines for progress and recommend clear
communication to Centres on plans for the ICIDH-2 Beta-2 draft and associated testing protocols which should be circulated by February 1999 in advance of an April 1999 meeting.

Although ICIDH has been used worldwide for research, its use has not permeated service in North America or many other areas yet. The North American Center stated that it remains very committed to the development and use of ICIDH-2 but believes there is still a long way to go.

The French ICIDH Collaborating Centre presented paper WHO/GPE/ICD/C/98.47 which explained the special issues around the ICIDH revision in France where there has been a long tradition of ICIDH interest and application. For example, the need for statistical information on disablement had been recognised by rehabilitation physicians and social and educational administrations and a survey of disability in the elderly in 1978 used the categories but not the full codes of the ICIDH.

French involvement in the development of ICIDH-2 had been difficult to mobilize. Although criticisms of the ICIDH were expressed by many groups, these were not well integrated into the international revision process as the groups tended to oppose rather than to participate constructively. Difficulty in changing to a new revision in France could be anticipated because administrative bodies rely on information they collect using ICIDH-1 (often at the 2 digit level). Recently, there has been a progressive increase in the participation of associations of or for the disabled in the revision process for a variety of reasons, however, some resistance remains. Many find the concepts less clearly defined in ICIDH-2 than in the three dimensions of ICIDH-1 and think that there is both too much detail and too much overlap between dimensions. There is concern that activity and participation may be culturally determined and that the classification is too ethno-centric. The neutrality of the new revision is not seen as being as useful as the ICIDH-1 for defining and articulating service needs, however, some social workers do like the ‘abilities’ aspect. There had also been debate in France about how to classify environmental factors and about whether they should be included in ICIDH. It was felt overall that much more work was needed on ICIDH-2 before it would be at all possible to consider adopting the new revision in France.

Some other centres presented short reports on their work in relation to ICIDH. The Dutch group outlined their work on ICIDH from their annual report (WHO/GPE/ICD/C/98.16) and eight points of concern regarding ICIDH-2 were laid out:

- domain and basic concepts - the reduction of overlap between the ICD the ICIDH and within the ICIDH;
- improvement of the hierarchical structure;
- renewal of the classification of handicaps;
- addition of a list, not a classification, of contextual factors;
- consistency in negative and positive terminology;
- extension of the scope of the classification to cover children, different professional groups, and non-western countries;
- adaptation of the level of detail (providing the ability to use the classification on a higher hierarchical level); and
- revision of the introduction to the classification;

The Dutch group suggested that the current draft is much too detailed and that a need remains for clear definitions of domain and basic concepts, for a simple, clear introduction and
explanation, and for development of the new revision slowly, based firmly on real uses. It was noted that there would be a European meeting on the ICIDH on October 30, 1998 at Amsterdam airport.

The Nordic Centre reported that it had been active in the early phase of ICIDH revision but was not currently operating as collaborating centre for ICIDH although it continued to communicate developments to Nordic and Baltic countries. Central health administrations have not been actively involved with ICIDH except in Sweden and final translation was not planned until a plain English version was available.

The Sao Paolo Centre noted that it had not been involved with ICIDH in the past but intended to begin in 1999. The number of health professionals requesting advice about this classification had been increasing in Brazil. These include occupational and physical therapists and specialists in rehabilitation, as well as health and social administrations.

The overlaps between domains of ICIDH and between it and ICD were discussed. French research had identified several types of overlap including: same words and significance; same words, but different meaning; and different words but the same meaning. It had been concluded that these might not really present a problem if the classifications were not used together. The North American Center reported that in the United States the ICIDH was used primarily as a research tool where overlap was not so important but that it would matter more in routine use in health services - especially outcomes and impact on functioning.

There was a plea for simplicity from SEARO where use of ICD-10 at the three-character level is the most that can be expected. For ICIDH to be useful in the Region, it must be able to be used at a one or two digit level. The United Kingdom Centre suggested that one or two digit use was at odds with neutrality since it was only meaningful if a negative meaning was assumed. The question was also raised as to whether the current complexity of ICIDH-2 was a bar to translation especially for languages used only in one or two countries.

Dr. Ouakrim of EMRO noted that the conceptual framework of the ICIDH was agreeable, however, he asked whether the ICIDH could really be considered international, if it was not well adapted or practical for use in developing countries, and whether any such countries were using it. It was noted that there is a demand for information on disability in developing countries but this classification is considered too complicated.

In responding to the discussion, the secretariat suggested that ICIDH is not a self explanatory classification, education and training are needed for its use. The participation of collaborating centres for both ICD and ICIDH had been crucial up to now and would continue to be so. Existing collaborating centres for the classification of diseases may be expected to have the family of classifications in their future terms of reference but ICIDH needs to be owned by the collaborating centres, not imposed. Centres were asked to submit any data they have in ICIDH-1 to the secretariat for further research on problems of continuity in transition.

Objections to the ICIDH-2 were noted to be largely from an ideological and advocacy point of view. While domain names are neutral, each dimension has positive and negative directions. The negative aspect can be used to define needs and for advocacy. The level of specificity or detail in ICIDH-2 had been demanded by specialists but it has been put into a hierarchy so that a lower level can be used when appropriate. For example, a four page check
list exists which can be used without reference to detailed classification. It was noted that South Africa is doing a 13,000 households survey of disability using this classification.

With respect to the inclusion of environment as an axis in the ICIDH, this was noted to present some conceptual difficulties because the unit has been person, whereas environment pertains to a different level.

The secretariat warned that centres which do not translate the ICIDH-2 until the revision process is finished cannot contribute to development of the new revision. Plans for a project base of proposals and of potential funders and donors where WHO would broker exchanges were mentioned.

The United Kingdom Centre pointed out that overlap between classifications does exist and needs to be managed. It depends on the application or the sphere in which the classifications are being used, not on specific chapters of the ICD or conditions. There need to be rules for the application of a classification and the ability to produce comparable data between places and times. Rules and testing should be application specific and testing should be in specific settings, not just in research applications. To maintain the “family” it is important that any overlap be clear and that concepts identified in both classifications be consistent.

It was noted that Canada is developing integrated health information systems and tended to view ICD and ICIDH as a single classification across a continuum of information. The United States have learned from Canada in this sphere. The secretariat was congratulated on attracting funding for development of ICIDH-2, and hope was expressed that same could be done for the ICD in future.

The issues and concerns raised by participants were noted for inclusion in the discussions at the ICIDH meeting scheduled to take place in Geneva the week following the present meeting.

### 12.2 Classification of medical procedures

The Nordic Centre presented a paper (WHO/GPE/ICD/C/98.29) on the creation of a short list based on the Nordic Classification of Surgical Procedures which from 1999 will be used in all the Nordic countries. The short list is needed for the annual Nordic Health Statistics. The paper clearly showed the difficulties which arise when there is a change from one classification to another. Procedures and descriptions of them vary more over time and between places than do diagnoses. This makes comparability across either more difficult and a short list alone cannot solve this problem.

There was some discussion about the issue of procedure classifications, their scope, content and intended application. It was noted that the Nordic Classification included only surgical procedures while many national/regional classifications have broader content. The intended application of such classifications, including use for physician billing purposes (at the national or sub-national level), was seen as an important factor in their design.

The meeting was told that Canadian Classification of Diagnostic, Therapeutic, and Surgical Procedures (CCP), which was used with ICD-9, was also revised recently. A draft of the new Canadian Classification of Health Interventions (CCI) was produced on CD-ROM and a
revised Version 1.2 was noted to be about to be issued. The classification includes all procedures - not just surgical procedures - and is intended for use across the continuum of health information.

The United Kingdom Centre pointed out that there was a need to define what is meant by a surgical procedure (the OPCS-4 used in the UK was said to be one of the few classifications to do so) and an “intervention”. These definitions also define the boundaries of the data. It is not possible to compare total rates of surgical intervention between countries, because these limits have not been defined. It was noted that the US defines surgical procedures, not in the classification itself, but in instructions for data collection and uniform standards for medical records. Canada has defined surgical interventions within the CCI, the definition is included in their CD-ROM.

The meeting discussed whether WHO should produce an international classification of procedures. Was there a need, and if so, how should it be formulated and addressed? It was noted that this question had been addressed before, including a discussion at the Revision Conference. Mention was made of the many recently developed or revised classifications of procedures for national or regional application and it was suggested that it might be better for WHO to produce a list of sentinel operations defined in precise terms - a short, well-defined list of procedures for international comparisons of statistics with data to be coded locally using national classifications and extracted according to WHO definitions.

The position expressed at the 1997 Centre Heads meeting and captured in the Long-term Strategy was provided for the information of the meeting participants. There was general agreement with the conclusions of last year’s meeting: not to spend WHO’s limited resources on an international classification as such but that there is some need to clarify requirements for international comparisons and how to meet these. The Nordic Centre offered to provide assistance in this area.

12.3 Lay reporting of health information

There were no papers presented on this agenda item. Considering lay reporting as a very important system for developing countries, however, the representatives of EMRO and SEARO requested that the Heads of Collaborating Centres consider the item as one of priority items in the agenda for their 1999 meeting. It was suggested that a paper on this topic be solicited.

12.4 Specialty-based adaptations of ICD-10

There were no papers presented on this agenda item but there had been discussion during the meeting (see agenda item 7.3).

12.5 Primary care classifications

Professor Pierre Lombrail of the French National School of Public Health (ENSP) presented a paper (WHO/GPE/ICD/C/98.45) on the primary care “Kasugraphie” of 300 causes
developed by Austrian Professor R. N. Braun. Professor Braun identified and classified 300 cases observed in general practice having a regular frequency of distribution. Each case is defined by the conjunction of inclusion criteria which determine the nosologic frame and by “demarcation” criteria which contribute to its delimitation. The classification contains an element to reflect the level of uncertainty often present in the relatively short encounters in general practice:

- A: isolated symptom (e.g. cough)
- B: pattern of symptoms (e.g. secondary catarrh)
- C: clinical disease patterns
- D: diagnosis (proven etiology)

Isolated symptoms (A) are, apart from a very limited number of exceptions, superimposable with those of ICD-10 and therefore do not present any coding difficulty. As a general rule, the pattern of symptoms (B) is sufficiently clear to allow coding in ICD-10. However, some symptom patterns are not described in ICD-10 and would, therefore, require the creation of additional rubrics. Most of the cases falling into the category of clinical disease patterns (C) are also codable in ICD-10 if one allows the inclusion of conditions without biological proof.

The meeting was informed that a mapping from the Braun classification to ICD-10 would be published soon.

In discussion, participants acknowledged the problems of etiologic uncertainty in primary care, however, as they had no previous knowledge of this classification, the Head of the Paris Centre was asked to obtain more details including a full bibliographic reference and a copy of the mapping to ICD-10 when this became available. The matter could then be discussed on a more informed basis at a future meeting.

12.6 International Classification of External Causes of Injuries (ICECI)

The WHO Collaborating Centre on Injury Surveillance provided a progress report (WHO/GPE/ICD/C/98.58) on the International Classification for External Causes of Injuries (ICECI). This paper described the aims and scope of the ICECI, its structure and relationship to the ICD-10 chapter on external causes (Chapter XX) and the plans for further development. The current draft will be field tested including:

- checking compatibility with ICD-10;
- testing the hierarchy and the codes for mutual exclusivity and adequacy for purpose (including the completeness of instructions and clarifications);
- checking the utility and acceptability of operational definitions with relevant international agencies and sectoral interests (e.g. traffic, work, consumer products, violence control);
- and
- identifying the size of the efforts and costs to be invested in collecting routine information in accordance with the protocol and in a variety of settings.

Collaborating Centres for the Classification of Diseases were invited to comment on the draft and to provide suggestions for the testing. It was hoped that a report on the results of the testing would be presented to the next meeting of Centre Heads. The next version of the ICECI will be presented to the 5th World Conference on Injury Prevention in March 2000.
The meeting also received a report (WHO/GPE/ICD/C/98.43) prepared by the Nordic and North American Centres on the Round Table Discussion on the draft International Classification for External Causes of Injury (ICECI) which was held during the Fourth World Congress on Injury Prevention and Control on May 17, 1998 in Amsterdam, The Netherlands. The ICD Centre Heads were represented at this session by Martti Virtanen (Nordic Centre) and Donnamaria Pickett (North American Center).

The four main issues discussed at the Amsterdam meeting regarding the current draft were:

- whether it responds sufficiently to demands for better tools in view of studying injuries and their causes;
- whether it fits with contemporary practice and current conceptual frameworks;
- whether it provides a suitable framework for the further development of ICD-10; and
- whether it is an appropriate tool for injury surveillance in various health settings and in different parts of the world.

The Nordic Centre had prepared a background paper discussing where compatibility between Chapter XX of ICD-10 and ICECI is relevant, emphasizing the different domains of the two classifications.

During discussion, the Centre Heads expressed their concern regarding the way the work on the ICECI was progressing and the poor communication that existed between parts of the secretariat and the Working Group, even though the secretariat was officially represented on that group. The secretariat was asked to ensure, in conjunction with the responsible headquarters unit, that there was better coordination in the future. The Nordic and North American Centres agreed to continue their role of liaison between the Working Group and the Centre Heads.

13. Other topics

The German Institute for Medical Documentation and Information (DIMDI) presented the Centre Heads (WHO/GPE/ICD/C/98.25) with details of the nature and function of the institute. DIMDI was founded in 1969 as an institute within the scope of the Federal Ministry of Health. DIMDI runs a large computer host service providing access to a broad collection of life sciences databases, searchable via all major communication networks with DIMDI’s retrieval system “grips”.

Furthermore, DIMDI is responsible for:

- a national information system and a European database on medical devices;
- the implementation and operation of the national drug information system and of an information system on food-monitoring;
- the operation of the social database of the statutory health insurance companies with disease information;
- the implementation and operation of an information system for economic evaluation in health care;
- the publication, in German, of official classifications, nomenclatures and thesauri including:
  - International Classification of Diseases (ICD-9 and ICD-10)
  - German procedure classification system (OPS-301)
  - Universal Medical Device Nomenclature System (UMDNS)
  - Medical Subject Headings (MeSH)
The North American Center provided the meeting with an update on the activities of the International Collaborative Effort (ICE) on Injury Statistics (WHO/GPE/ICD/C/98.42). The report described the proceedings of the working group meeting of the International Collaborative Effort (ICE) on Injury Statistics held May 16-17, 1998 in Amsterdam, The Netherlands in conjunction with the 4th World Injury Conference. The formal agenda included presentations on:

- injury classification schemes;
- the development of the International Classification of External Causes of Injury (ICECI);
- the development of a multi-country questionnaire related to injury mortality certification and registration with a view to identifying differences that could affect injury specific death rates;
- the transition to ICD-10; and
- discussion of developing a matrix of the injury diagnosis according to the site of the injury, and how to include injury severity as part of a classification.

14. Reports of activities of the WHO Collaborating Centres for the Classification of Diseases

In presenting the reports of their activities, the Collaborating Centres were asked by the secretariat to identify: their priority areas for the future; activities where they could provide support to WHO Headquarters, Regional Offices and others; and areas where the centres themselves would require assistance. This information would then be used in developing the WHO workplan for classification-related activities.

The Australian Centre (WHO/GPE/ICD/C/98.5) reported that ICD-10 would be implemented for mortality in Australia and New Zealand in 1998/1999. Also in 1999 there would be the first updating of ICD-10-AM. Support would be provided to Member States in the Western Pacific and South-East Asian Regions of WHO though funding for these activities would have to be provided by the countries and the Regional Offices. The Australian Institute of Health and Welfare (AIHW) would carry out Beta testing of ICIDH-2 and also prepare a comparison of the "overlaps" between ICD-10 and the impairments section of ICIDH-2. Other planned activities included: contributing to the development of the ICECI; the use of ICPC Plus in morbidity surveys; development of the Australian Clinical Thesaurus; mapping of the Australian procedure classification short lists; and the development of indicators of coding quality. The Centre also expressed the desire to work with WHO on the further elaboration of the classification of complications of care and adverse events in hospitals and with DIMDI in preparing electronic versions of ICD-10-AM. New Zealand reported plans for the implementation of ICD-10-AM from November 1998 through March 1999.

The Sao Paulo Centre, in addition to the activities contained in its report (WHO/GPE/ICD/C/98.6) would continue its work in training coders to use ICD-10 for mortality and morbidity and the preparation of didactic material. Support would also be provided to the national mortality system, particularly for multiple cause analysis and in accuracy of cause of death studies. During 1999 some support would also be required for ICIDH activities, while there was good support from PAHO/AMRO, the Centre would need to improve cooperation with AFRO and EURO to enable collaboration with the lusophone countries in those regions.
The Beijing Centre (WHO/GPE/ICD/C/98.7) had completed publication of ICD-10 in Chinese in June 1998. Work over the next year would mainly concentrate on extending the application of ICD-10 in hospitals, responding to technical queries from existing users of the classification, the provision of courses in clinical epidemiology and the improvement of cause of death statistics. A computer program and database for conversion between ICD-9 and ICD-10 should be completed during 1999. Regional Office support would be required for a number of these activities.

The United Kingdom Centre (WHO/GPE/ICD/C/98.8) had developed a detailed workplan and a copy of this would be forwarded to the other Centre Heads. Work was continuing toward the establishment of a national clinical coding qualification and the Centre would also host the 1999 Centre Heads meeting, probably in Wales.

The Paris Centre (WHO/GPE/ICD/C/98.9) identified skills and expertise in mortality and morbidity applications as well as epidemiology and information technology. Training would be provided to other French-speaking countries, however, this would require the support of WHO headquarters and the Regional Offices for Africa, Europe and the Eastern Mediterranean. Future work would include the development of electronic tools and methodological work in relation to mortality databases, quality control, international comparability and multiple cause analysis.

The priority of the Kuwait Centre (WHO/GPE/ICD/C/98.10) was to extend the implementation of the ICD-10 to all 19 countries of the Eastern Mediterranean Region. Only eight countries were currently using the classification. Regional Office support was required in the provision of training for coders and physicians in the three languages (Arabic, English and French) used in the Region. Efforts would also be required to improve data quality.

The Centre for the Nordic countries (WHO/GPE/ICD/C/98.12) had extended its activities for providing information and training to Estonia, Latvia and Lithuania. A major activity was the updating of the various Nordic health-related classifications. Contributions to WHO will be made through continued maintenance of the Mortality Forum and participation in the Mortality Reference Group and the Update Reference Committee as well as acting as liaison between Centre Heads and ICECI and ICIDH-2. The Centre would also like to contribute to the development of indicators for health interventions as well as standards for quality studies in morbidity coding. The Nordic Centre also indicated its intention to emphasize non-published classification literature including information on training material and computerized aids in its bibliographic work. The Centre considered the rapid dissemination of decisions and development of a practical conversion between ICD-9 and ICD-10 to be the major requirements from WHO.

The North American Centre (WHO/GPE/ICD/C/98.13) informed the meeting that ICD-10 would be introduced for the automatic encoding of mortality in the United States for data year 1999. Within the context of the International Collaborative Effort (ICE) on Automating Mortality Statistics, several countries, including the United Kingdom, Sweden and France, were assisting NCHS in preparing the decision tables that will be used. Work would continue on the development of ICD-10-CM, including the associated information technology tools and products for implementation. Considerable support would be provided by the Centre in relation to the development of ICIDH-2. The Centre would also ensure the chairmanship of
the Mortality Reference Group and provide members for this group and the Update Reference Committee. The secretariat was asked to indicate whether support in other areas was required as the workplans were developed. In terms of support required by the Centre from WHO, this was seen to relate mainly to the provision of an effective programme for the maintenance of the ICD-10 core classification and the ability to respond in a timely way to issues and questions. The Canadian Institute for Health Information (CIHI) offered to make an international contribution in relation to its partnership for telematics and informatics as well as in the areas of the classification of medical procedures and external causes of injuries.

The Caracas Centre (WHO/GPE/ICD/C/98.14) reported plans for an evaluation of the application of ICD-10 through samples of hospitals separations at the regional level and of death certificates within Latin America. Workshops on ICD-10 would continue at the national and international levels.

The Office of the ICD, Japan (WHO/GPE/ICD/C/98.5) reported that it would be working towards wider application of ICD-10 in Japan, particularly in private hospitals. ICD-O-2, ICIDH-1 and ICPM had already been translated into Japanese. Work was ongoing to publish the application of ICD-10 to dentistry and stomatology (ICD-DA-3) and it was planned to prepare a Japanese version of the application of ICD-10 to neurology (ICD-10-NA).

The Dutch Department for Public Health Forecasting (WHO/GPE/ICD/C/98.16) would be participating in the revision of the ICIDH and preparing the Dutch language version for field testing. It was noted, however, that the final draft in English was required before further work could be carried out. Other areas of involvement would include concepts related to the family of classifications and the distribution of a quarterly newsletter on the use and revision of the ICIDH and the commentaries and implementation of ICIDH-2, assessment tools, etc.

The German Institute for Medical Documentation and Information (DIMDI) reported (WHO/GPE/ICD/C/98.17) that ICD-10 version 1.1 had been released and introduced for mortality statistics. All coders were trained in two courses together with the Federal Statistical Office. Another series of three sessions for the discussion of coding experiences and problems was scheduled to be held in November 1998. The implementation of ICD-10 for morbidity coding was still outstanding due to political reasons. An updating mechanism for ICD-10 in Germany had been set up. The efforts to create a special version of ICD-10 for the outpatient sector of the German health care system (ICD-10-SGBV) have come to an end and version 1.1 was published.

DIMDI takes part as adviser in a research project compiling a collection of now 100,000 diagnostic terms coded with ICD-10. This synonym file will be used as a dictionary for automatic coding systems and as a supplementary file for ICD databases. The German procedure coding system, OPS-301, was reported to be undergoing a minor revision. A working group was established to investigate whether the German OPS-301 could be replaced by the new ICD-10-PCS and which modifications would be necessary.

Version 3.0 of the Medical Subject Headings (MeSH 1998) was published in February 1998. The Universal Medical Device Nomenclature System (UMDNS) Version 1.0 of 1996 was undergoing substantial enhancement by addition of several thousand German synonyms.
It was felt by the meeting that, in view of DIMDI’s considerable expertise in information technology, the institute had a major role to play in assisting other centres to achieve the same standard of excellence.

Representatives of the three WHO Regional Offices in attendance also provided information about their activities and future plans.

SEARO reported plans to continue to train ICD-10 trainers with a few training courses carried out in Thailand and Myanmar with the support of the Australian Centre. Short training courses in health information management including the use of ICD-10 were also planned. It was noted that most of the SEARO countries are interested in training and implementation of a classification of procedures (interventions) and would like WHO to coordinate the development of an international classification. SEARO also reported their intent to initiate activities to improve vital registration and cause of death certification processes in selected countries of the Region as well as to begin a quality “review” of morbidity coding. Interest in a completed three-character version of ICD-10 was expressed, particularly for use in sentinel public hospitals in this region.

PAHO/AMRO reported on its activities with several countries in the Region for ICD-10 implementation and vital statistics improvement and noted plans to continue work in these areas as well as in the use of data, the development of short lists for the identification of leading causes of death and in ICIDH-2.

EMRO reported plans to increase the use of ICD-10 in the Region. Efforts had been made since 1994 to increase national awareness and to foster a culture regarding the use of data on causes of death and morbidity that could support health policy strategies at the national level. Some training has been undertaken using TENDON. In order to increase ICD-10 implementation, however, the countries in the Region need the completed three-character version which is a less sophisticated classification more suitable for these countries. In addition, it was noted that lay reporting is very important in the Region. Collaborating Centres were asked to continue to consider the needs of developing countries in their work.

The secretariat thanked the participants for all of the information provided and indicated that it would be utilized in the development of the workplan presently underway. Areas of potential increased collaboration with the Centres and with other UN organizations as well as in the area of informatics were identified.

15. Other business

15.1 Additional matters

There were no additional matters raised for discussion.

15.2 Place, time and agenda for next meeting

The United Kingdom Centre agreed to host the 1999 meeting, to be held in Cardiff, Wales, during the week beginning 17 October.
With respect to the format of the 1999 meeting, reference was made to an agreement in principle at the 1997 meeting to consider shortening the meeting to fit within a working week (no more than five days). There was discussion on this issue, particularly from the perspective of producing, reviewing and accepting a draft report of the meeting. It was agreed that this issue should be resolved by the secretariat in consultation with the host of the 1999 meeting and the other members of the Executive Group of Centre Heads.

Priority themes for the agenda of the 1999 meeting were also addressed. In addition to the items on the “standing agenda” for meetings of Heads of Collaborating Centres, it was agreed that the following items would be considered priorities for 1999:

- ICD-10 implementation and promotion including developing country needs, such as lay reporting, as well as education and training;
- definition of the “family”;
- mortality and morbidity data use including quality issues and transition strategies, such as short lists and conversion tables.

The Sao Paulo Centre agreed to host the 2000 meeting at a place and time to be decided.

**Action summary**

**All Collaborating Centres**

- review and provide input to secretariat workplan on request
- submit any data classified to ICIDH-1 to the secretariat for use in the revision process
- comment on the draft of the ICECI and provide suggestions for testing
- submit morbidity issues for Update Reference Committee to secretariat for distribution and coordination
- submit mortality issues for Mortality Reference Group to secretariat for distribution and coordination
- work with secretariat to establish common document structure for distribution of ICD-10 files
- consider the issue of lay reporting as a priority item for the 1999 Centre Heads meeting
- submit abstracts of documents proposed for 1999 Centre Heads meeting to secretariat no later than 14 May 1999
- submit documents for 1999 Centres Heads meeting to United Kingdom Centre and to secretariat no later than 17 September 1999 (N.B. documents to be circulated by the secretariat must reach the secretariat by 1 September 1999)

**Australian Centre**

- initiate the development of an international research protocol for studies on the quality of morbidity coding with interested centres
- provide co-chair for Update Reference Committee
- work with the secretariat on further elaboration of the classification of complications of care and adverse events in hospitals

**Nordic Centre**

- create a home page for the Mortality Forum
• initiate a discussion on quality measures in mortality and prepare a report for the 1999 Centre Heads meeting
• provide assistance to the secretariat in the development of a list of sentinel operations
• continue to provide a liaison between the ICECI Working Group and the Centre Heads

North American Centre
• continue to provide a liaison between the ICECI Working Group and the Centre Heads

Paris Centre
• obtain more details on Braun classification including full bibliographic reference and mapping to ICD-10
• Centre Head to follow up on business from 1998 Centre Heads meeting with the secretariat

United Kingdom Centre
• provide copies of the report on the quality control of mortality statistics to other centres upon request (see WHO/GPE/ICD/C/98.51)
• provide copies of detailed work plan to other centres and the secretariat
• Centre Head to review abstracts of documents proposed for 1999 Centre Heads meeting with secretariat and prepare draft agenda
• Centre Head to confer with secretariat in development of annotated agenda for 1999 Centre Heads meeting (to be available to participants at the meeting)

Secretariat
• develop a workplan for classification-related activities incorporating input received from Centre Heads
• establish subgroup including representation from Centre Heads to define the criteria for membership into the family of classifications and the issue of terminologies and their relationship to classifications and to the family
• establish task forces and focus groups as necessary to elicit input and promote communication
• research classification of Angelman syndrome in other classifications, particularly specialty-based adaptations
• operationalize Update Reference Committee
• establish e-mail group for Update Reference Committee and Mortality Reference Group
• enforce guidelines in the development of specialty-based adaptations
• establish a central database of the detailed codes and descriptions of all existing adaptations of ICD-10
• develop short lists for ICD-10 with practical translations back to ICD-9 for use during the transition to ICD-10
• enhance the WHO Translator with one-to-one code conversions
• explore the possibility of obtaining extrabudgetary funds to address issues of modification and application of ICD-10
• develop a list of ICD-10 codes for “ill-defined” conditions for the purpose of applying underlying cause rules and guidelines
• produce a list of sentinel operations, defined in precise terms, for international comparison purposes
• solicit a paper on lay reporting for 1999 Centre Heads meeting
• distribute call for documents for 1999 Centre Heads meeting to all Collaborating Centres no later than February 12, 1999
• establish the format for the 1999 Centre Heads meeting in conjunction with United Kingdom Centre and Executive Group of Centre Heads
• review abstracts of documents proposed for 1999 Centre Heads meeting with United Kingdom Centre Head, draft agenda for meeting, and disseminate to all Collaborating Centres by approximately 18 June 1999
• disseminate any documents for 1999 Centre Heads meeting in sufficient time to ensure they reach participants no later than 30 September 1999 (documents may be those prepared or translated by the secretariat or disseminated by the secretariat on behalf of Collaborating Centres)
• confer with United Kingdom Centre Head in development of annotated agenda for 1999 Centre Heads meeting (to be available to participants at the meeting)
• ensure, in conjunction with the responsible WHO headquarters unit, better coordination and communication on development of the ICECI
• ensure the rapid dissemination of decisions
• complete the three-character version of ICD-10
• identify and communicate needs for additional support from collaborating centres
• work with collaborating centres to establish common document structure for distribution of ICD-10 files

WHO Regional Offices
• liaise with collaborating centres regarding training, based on language needs
• contribute to paper on lay reporting for 1999 Centre Heads meeting

Update Reference Committee
• finalize criteria for updates to ICD-10
• review and comment on ICD-10 updates as presented to 1998 Centre Heads meeting
• submit recommendations for ICD-10 updates to be considered by 1999 Centre Heads meeting by 2 August 1999

Mortality Reference Group
• become operational based on report of subgroup at 1998 Centre Heads meeting
• address issues raised through the Mortality Forum (see WHO/GPE/ICD/C/98.32)
• address the issue of highly improbable relationships between injuries and conditions coded in other chapters of ICD-10 (see WHO/GPE/ICD/C/98.57)
• submit application and interpretation decisions for 1999 Centre Heads meeting by 2 August 1999

Annex I

NOTES ON A MEETING OF THE ORGANIZATIONAL SUBGROUP, MORTALITY REFERENCE GROUP, PARIS, OCTOBER 14, 1998
This is a report of the meeting of the organizational subgroup of the Mortality Reference Group held at the Centre Heads meeting in Paris on October 14. In attendance were Lars Age Johansson, Cleone Rooney, Michael Schopen, Donna Pickett, André L’Hours, and Harry Rosenberg.

André L’Hours provided a list of persons who have been nominated by their respective Centres to the Mortality Reference Group which was established in concept at the 1997 Centre Heads meeting in Copenhagen. Additional members were identified either if there is no existing WHO Centre and their expertise in mortality warranted their membership. The membership includes the following: Sue Walker (Australia), Hilkka Ahonen (Finland), Donna Glenn (USA), Donna Pickett (USA), Tanya Pitts (USA), Julia Raynor (USA), Harry Rosenberg (USA), Lars Age Johannson (Sweden), Patricia Wood (Canada), Cassia Maria Buchalla (Brazil), Ruy Laurenti (Brazil), Michael Schopen (Germany), Gloria Perez (Catalonia, Spain), Cleone Rooney (England), and André L’Hours (WHO).

Reference was made to the basic report on the Mortality Reference Group (MRG), contained in the Centre Heads Report for 1997 (WHO/HST/ICD/C/97.65, pages 31-33), which includes the general concepts and principles for the operation of the MRG, as well as a schematic which shows its relationship to the other key groups that will be involved in the ICD-10 Updating Mechanism; these are the Mortality Forum, the Update Reference Committee, the national organizations, the WHO Collaborating Centres, the Centre Heads meeting, and the WHO Secretariat. One correction was made in the schematic, namely, that the WHO Collaborating Centres can provide input directly to the MRG. The revised schematic is shown as Appendix I to this report.

It was agreed that the key dates for the updating process need to be spelled out more clearly. The timing of the process is shown in Appendix II. It is recognized, in addition, that official implementation of changes will be made in _clusters_ of about three years. That is, proposed changes will be accumulated for three years, then disseminated; then accumulated for three more years, then disseminated, etc. The updating deliberative process, in contrast, will be continuous, and decisions made by the Centre Heads and WHO on an annual basis.

It was agreed that the MRG will meet electronically, as it were, about three times a year, in August, April, and early December. A prioritized but limited set of problems will be sent out electronically to all the members. They will be given one month to review the problems and make their individual recommendations. The responses will be tallied and the statistical and substantive responses sent out to the individual members. This will be followed by a _virtual meeting_, which will be held as a conference call, to be held at 4 p.m., London time. The member from Australia cannot participate in the telephone conference because of time differences, so it was agreed that results of the telephone conference will be sent to Sue Walker (Australia) to determine if she agrees or disagrees. If the group reaches a consensus on change, its recommendation will be sent to the Update Reference Committee for further consideration. If the group does not reach consensus, its differences will be summarized and then forwarded to the Update Reference Committee for further action.

In their review of any problem, the MRG committee members will be advised to consult with whomever they choose, and make their recommendation based on their best professional judgement and experience. The process of decision making will be by consensus.

The MRG proposes to use the following criteria in screening candidate issues:
(1) What is likely to be the effect on international comparability;
(2) How many deaths are involved;
(3) What are its policy or epidemiological implications; and
(4) Is it restricted to some language groups or is it more general?

It was pointed out that there is a large accumulation of problems for consideration. Lars Age Johannson has agreed to prioritize these and put them in “bite size” pieces for the first iteration of the MRG’s work, which is being viewed as a “pilot” to help the MRG develop a smoothly functioning process. Lars Age’s list will include a frequency count of deaths that might be involved in the particular problem.

Related Items:
The Mortality Forum, which is a discussion group of mortality coding problems -- by ListServ -- maintained by the Nordic Centre is open to all interested persons in the topic. To participate contact Lars Age Johannson at the Nordic Centre. Currently, the Mortality Forum is archived through the Website of the U.S. National Center for Health Statistics (see Mortality Home Page). It is expected that the Mortality Forum will be accessible through the Nordic Centre Website within the coming year.
NOTES ON A MEETING OF THE ORGANIZATIONAL SUBGROUP, MORTALITY REFERENCE GROUP, PARIS, OCTOBER 14, 1998

APPENDIX I

APPENDIX II

KEY DATES IN ICD-10 UPDATE PROCESS:

April, August, December of Year X  Problems are sent to MRG members
May, Year X+1  Decisions are made by MRG
June, Year X+1  Decisions are sent to Update Reference Group
July, Year X+1  Decisions are made by Update Reference Group
August, Year X+1  Decisions are sent to Centre Heads
September, Year X+1  Decisions are made by Centre Heads
September, Year X+1  Decisions are communicated to WHO
October, Year X+1  Decisions announced at Centre Heads meeting
### Annex II

**Actual and Proposed Implementation Dates of ICD-10 - October 1998**

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