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MEETING OF HEADS OF WHO COLLABORATING CENTRES
FOR THE FAMILY OF INTERNATIONAL CLASSIFICATIONS

Bethesda, MD, USA
21-27 October 2001

REPORT

Contents:

Executive Summary

This summary provides major highlights of the Meeting of the Heads of WHO Collaborating Centres for the Family of International Classifications held in Bethesda, Maryland, USA from 21 to 27 October 2001. Details of the discussions and work done throughout the meeting may be found in the main report and its Appendices 1-10. **A summary of actions to be taken is provided in Appendix 11.**

Opening sessions

Opening remarks were provided by officials from the WHO Collaborating Centre for North America, the United States Department of Health and Human Services, the National Center for Health Statistics, and the Centers for Disease Control and Prevention, the Canadian Institute for Health Information, Statistics Canada, and the Pan American Health Organization. The meeting was officially opened by Dr T. Bedirhan Üstün on behalf of the Director-General of WHO, Dr Gro Harlem Brundtland.

The **objectives** of the meeting were:

- to launch the WHO Family of International Classifications (WHO-FIC),
- to integrate the WHO Collaborating Centres (CCs) for the International Classification of Functioning, Disability and Health (ICF) into the network,
- to reaffirm and augment the joint WHO/CC work plan, including the agreed activities and responsibilities,
- to report on progress and plan the continuing work of the committees,
- to make policy decisions,
- to advance knowledge through scientific sessions,
- to promote international comparability, and
- to evaluate the meeting format and logistics.

This meeting provided for the **official launching of the WHO Family of International Classifications and the ICF,** the newest family member, recently published in the six WHO official languages, together with electronic and Internet versions. Country and region specific launching events will take place between November 2001 and March 2002. The launching period will conclude with the ICF Conference for Ministries of Health in Italy in April 2002.

Photographs of the participants and individual delegations were taken for use in national launchings of WHO-FIC and the ICF. In addition, **interviews** were videotaped with participants about the role of the Centres, the need for training various professions in the use of the classifications, and applications of the classifications in clinical, survey, policy and programme work. These interview tapes will be used in training materials as well as other promotional activities.

The Centre Heads were assured by the WHO secretariat that the official **redesignation of their Centres,** following the WHO moratorium, was scheduled for 2002. They were briefed about plans to create additional Centres, particularly in the African, American and South-East Asian Regions. It was noted that the WHO review of all Collaborating Centres had reaffirmed the value of this network of Centres, which was recognized as exemplary.

Throughout the meeting, concern was expressed about the **lack of resources centrally**, especially for the continuing development work for the ICD. In addition, the organization, facilitation and follow up of the annual meetings have provided a progressively increasing workload. The organization of the 2001 meeting, with almost 100 documents and over 80 participants, has been particularly challenging, not only for the Host Centre, but also for the WHO secretariat.

Reports of committees and work groups

Implementation of ICD-10 Committee

- A list of essential steps for countries implementing ICD-10 and a roster of morbidity and mortality experts will be developed.
- A new Chair was appointed, with the Regional Advisers (RAs) from EURO (Dr Remigijus Prokhorskas) and AFRO (Dr Mounkaila B. Abdou) to serve as Co-Chairs, in close cooperation with WHO/HQ and with the participation of the United Kingdom Centre. Two meetings will be organized in Geneva before the 2002 Centre Heads meeting.
- During discussion about ICD-10 implementation, the secretariat briefed participants about an upcoming meeting of WHO Representatives to countries. It was noted that such a forum would provide a useful opportunity to orient WRs to the work being done on classifications. It may also be beneficial to have members of the Centre Heads Planning Group attend this meeting.

Subgroup on Training and Credentialing

- A needs assessment questionnaire for morbidity and mortality coders will be translated and sent to RAs for distribution to countries.
- The Subgroup will liaise with the ICF group on training issues, and joint activities will be explored.
- The tables of available information on training materials and training capacity for morbidity and mortality coding will be set up on the United States National Center for Health Statistics (NCHS) website, with links to the WHO/HQ, Regional Office and CC sites. A brochure will be developed containing the same information for countries without ready access to the Internet. The secretariat will explore its publication by WHO.
- The joint International Federation of Health Records Organizations (IFHRO)/CC working group held its first meeting, and the following main actions were agreed:
    - An article about this collaboration will be prepared for the IFHRO newsletter.
    - Background papers will be prepared covering relevant definitions, skills, training levels and critical functions of underlying cause mortality and morbidity coders.
    - An assessment of the available training materials will be carried out towards developing a core curriculum.

Update Reference Committee (URC)

- A substantial number of recommendations for updates were reviewed and decisions taken.
- The update process and its frequency were critically reviewed and decisions taken, with both minor and major updates to be implemented every three years.
- The URC secretariat will have access to the clinical consultants who advise WHO to ensure direct clinical input (to be done in collaboration with WHO).

- The updates and database will be posted on the Australian National Centre for Classifications in Health (NCCH) website. Because the updates need to officially belong to WHO in order to be accepted worldwide, WHO will need to import the updates to the WHO website. The dissemination of the changes will come from WHO, and HQ will advise ROs of the existence of the changes.
- The ICD-10 CD-ROM will contain 1999 and 2000 updates and the version will be titled *ICD-10 (2000)*.
- ICD-10 will be placed on the WHO website as a public good. Commercial applications will still require licensing from WHO.
- The importance of a **morbidity meta-database** based on clinical modifications was reconfirmed. This will allow Centres to see the areas of change and to track data internationally. It will also be a resource intensive task and will require additional funding. A teleconference will be held among key persons from the ETC, URC and WHO to discuss feasibility, scope and next steps. For the short term, piecemeal work will be continued by topic (e.g. diabetes mellitus).
- It was recommended that the translator to **map between versions of ICD-10** be done by the WHO secretariat.
- The extensive **changes introduced in ICD-O-3** have significant implications for ICD-10, and these will continue to be addressed by the Update Reference Committee.
- The need to ensure an efficient **mechanism for notification of mortality rules** was emphasized. It was stressed that the updating mechanism and language versions should not be impediments to the implementation of changes. WHO will need to find a solution for this and ensure that changes are disseminated according to the established timetable.
- The impressive work and timetable of the URC, which make it possible to do this fairly complicated work by e-mail, were recognized.
- Though the processes and mechanisms of the URC have been streamlined, those at WHO/HQ have not. The action needed to sanction and disseminate agreed changes to ICD-10 has not occurred. **A clear written policy for updating ICD-10** is needed from WHO for posting and disseminating updates, for providing information and advice to ROs in support of ICD use by countries, for the version control process, and for synchronizing changes to family members.
- It is important that resources be identified at WHO and elsewhere to implement updates on a three-yearly basis and to monitor the update process. Collaborating Centres will take responsibility for their respective translations of updates.
- The plan for this year's process has already been set, and will be evaluated next year.

Mortality Reference Group (MRG)

Three formal papers were reviewed, namely, the annual report of the MRG, the annual report of the Mortality Forum, and a proposal to speed the work of the MRG. In addition, two regular business meetings of the MRG were held at the Centre Heads meeting. It was noted that during the third and highly productive year of the MRG, a total of four meetings were held by teleconference, and considerable work was conducted between meetings. A total of 18 problems were reviewed, seven issues decided, and eight recommendations forward to the URC (one decision was subsequently withdrawn). At the time of the annual report, a total of 10 other issues were under active review. In the Mortality Forum, a total of 329 questions were received from 19 countries. The following main actions were approved:

- To facilitate more expeditious resolution of problems small subgroups will be established, and possible face-to-face meetings may be scheduled between Centre Heads' meetings.
- Smaller subgroups will be established.

- The terms of reference for the MRG will be modified to ensure that members commit to supporting the suggestions presented by the group.
- A re-write of the WHO Trivial conditions Rule was accepted.
- More work will be done on codes for postoperative conditions.
- As a result of a paper on maternal deaths, referred by the WHO Family and Community Health Cluster at the 2000 Centre Heads' meeting, a number of questions have been resolved except one of terminology. A letter will be sent to the Cluster informing them of progress on this issue and discussion on this will continue.

Electronic Tools Committee (ETC)

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

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

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

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

International Classification on Functioning, Disability and Health (ICF)

1. Coding guidelines
- WHO will convene a discussion group on specific coding issues prior to any changes in the existing coding guidelines.
- Examples for coding will be reviewed by WHO.
- WHO and the United Kingdom Collaborating Centre will work out a plan of action for this topic to be circulated by e-mail to the Centres for comment, and consequently, if the need arises, a meeting may be organized in Geneva.

2. Implementation
- WHO will report on the different ways the A&P dimensions are used as information from countries is received, and country data on the use of the options will be posted on the ICF website.
- WHO will report data using the most, or lowest, common option.
- Indexing guidelines will be provided by WHO.

3. Training, outreach and dissemination
- A working group will be established to address: training principles, an inventory of training needs, a catalogue of existing materials and, as a result, an educational plan.

4. ICF adaptations for specific purposes

- The focus of work will be on the development of core sets and criteria for adaptation. Country and discipline specific ICF adaptations will not be encouraged at this stage.
- Information on core sets and adaptations will be exchanged through WHO, and WHO will coordinate criteria development.

5. Measurement

- WHO will post information sent from Centres on the development and use of measurement instruments on its website.
- The work of UNSD's *City Group* on disability measurement needs to be linked to WHO.
- WHO will provide guidance on how to map existing instruments to the ICF, and will update information on WHO-DAS and WHO survey instruments.

6. The use of ICD and ICF together

- It is important to identify commonalities between ICD and ICF, define components in order to clarify differences, and review *same concepts* with different levels of granularity.
- There is a need for national guidance and the use of field experiences.
- The Family Development Committee (FDC) will follow up these issues in consultation with ICF experts.

7. Maintenance and update process

- ICF and ICD are at different stages of development, and their updating processes will therefore be different.
- Information on ICF update requirements will be obtained and evaluated before determining any necessary changes.
- WHO will produce a draft document on updating and maintenance policies for the ICF, and will discuss this with Centres via e-mail and at future meetings.

8. Organizational issues

- There is a need for efficient coordination of meetings, activities and resources.
- It was agreed that annual, joint meetings of ICF with ICD were best at present.
- There is a need for generating resources for ICF work.
- Efforts will be made to work more effectively between meetings, and through the use of existing and *ad hoc* work groups with consideration being given to the creation of a study group for the subjective dimensions of functioning.

9. Additional issues

- There is a need for periodic updates of the WHO website.
- There is a need for precise conditions and technical guidelines to be clearly specified in translation rights agreements with WHO.

Family Development Committee (FDC)

1. Concept of the Family

- The FDC paper on the concept of the family of international classifications will be integrated with the WHO family paper, providing a working document to inform those proposing classifications for WHO-FIC membership.
- Dr Madden and Dr Üstün will develop a draft for discussion.
- Once approved, the paper will be posted on the WHO website.

2. Procedures/interventions

- Three classifications with potential for use as an international classification of health interventions for countries without an interventions classification were identified: the Canadian Classification of Interventions (CCI), OPCS-4 from the United Kingdom, and the Australian Classification of Health Interventions (ACHI). The Australian Centre has prepared a condensed version of ACHI, a subset containing about 1600 codes in a tabular list.
- Criteria were drafted to evaluate candidates for an international interventions classification.
- Two separate priorities were identified:
  - The need for an interventions classification for countries that do not have one.
  - A classification of health interventions that supports international comparisons.
- It was agreed that the former issue is the more important at this time and that the Australian proposal is available to solve an urgent need.
- Next steps:
  - A prototype classification will be developed by the Australian Centre with the amended title *Australian Classification of Health Interventions - adapted for International use*.
  - Additional issues include how to make the classification available, training materials, updating, resource requirements, and availability of assistance with translations.
  - Information will be obtained for countries that have not responded to the survey.
  - Criteria for evaluating potential candidates will be further developed.
- A small working group of the FDC will continue this work. Regional Office representation is desirable. A report will be made to the FDC at its meeting in April 2002.

3. External causes

- Version 1.0 of ICECI has been completed as a final draft, and membership in the WHO Family as a related member is sought.
- The work done on the preparation of indexes revealed some deficiencies in the classification, and WHO does not feel that ICECI can be adopted as a related member until these have been corrected.
- The Violence and Injury Prevention Programme and the CAS Programme will propose to Centre Heads that ICECI be adopted when the work is completed.
- The recommendations of this meeting on possible changes to Chapter XX of ICD-10 will be fed back to the ICECI working group.

4. Relations with WONCA

- A small joint working group will be set up to carry out the recommendations in the paper on the roles of ICPC and ICD:
  - It will include expertise on ICF, ICD and ICPC and will be able to draw on other experts as needed.
  - Electronic communication will be the primary method of work.
  - A preliminary report will be available for the FDC in April 2002.
  - The Dutch Centre will act as secretariat for the group.
- The work with WONCA will be limited to consideration of the use of the ICPC as a classification for reasons for encounter as a possible member of the WHO-FIC.
- A primary care adaptation of ICD-10, for diagnosis and health related problems, will be considered by the FDC, but not in conjunction with WONCA.
- Other reasons for encounter classifications, such as the United States Reason for Visit classification will also be evaluated by the FDC.

5. Joint use of ICD and ICF

- There is a need to examine both classifications closely to identify areas of commonalities or inconsistencies and to propose guidelines and/or revisions.
- It was recognized that some commonalities will be necessary because there are settings where only one classification will be used.
- WHO suggested that the work proceed on the basis that no items be removed from the ICF.
- Centre Heads also questioned whether any items should be removed from the ICD.
- The following actions were suggested:
  - Develop key principles to guide an analysis of commonalities and inconsistencies.
  - Identify areas of commonality and refer them to the URC.
  - Develop a set of guidelines for joint use of ICD and ICF.

Implementation of automated coding systems for mortality

- A brief background of the ICE on Automating Mortality Statistics was provided.
  - At present, the main goal of the ICE is to improve the quality and comparability of international mortality statistics.
- A number of papers relative to automated coding systems for mortality were presented:
  - Automated versus manual selection of the underlying cause of death
  - The automated coding system used in Japan for fetal deaths
  - Results of a global survey of automated systems for coding causes of death
  - A European project that deals with the development of tools of common interest in the field of automated coding systems
- The secretariat stated its full support for the ICE efforts.

Terminologies and mapping with ICD-10 (including SNOMED-CT)

- Representatives of the College of American Pathologists made a presentation about the Systematized Nomenclature of Medicine (SNOMED) and its mapping to ICD.
- The issues of terminologies are important to the work on classifications, and related activities will be included under the quality assurance subcomponent of the joint work plan.
- This work requires a coordinated approach, and standards need to be developed for mapping terminologies to classifications.
- A useful next step would be to assess SNOMED as a clinical index to ICD-10, with maps developed to index terms as well as to codes.
- Comprehensive incorporation of ICF concepts and terms may require the introduction of additional hierarchies, such as for *severity*.
- The quality of the mappings should be evaluated by the proprietors of the classifications.
- Some type of accreditation may be required in the longer term for assurance of the quality of maps from SNOMED and other terminologies to classifications.

Guidelines for hospital morbidity coding

- A small working group on hospital morbidity data will be convened to work towards a short tabulation list for use with ICD-9/ICD-10. The group will:
  - Prepare inventories of national hospital discharge data sets and short tabulation lists.
  - Identify issues that relate to the international comparability of hospital morbidity data.
  - Share information about bridge coding.
  - Solicit papers on these topics for next year's meeting.
- The Nordic Centre will chair the working group.

Improving coordination of vital registration activities at the international and national levels: Options and best practices and other methods of ascertaining mortality and causes of death

- Vital statistics data provide local information and can provide good quality cause of death data that can't be achieved with surveys.
- The UN was congratulated on continuing its efforts to improve vital statistics and civil registration when others, because of the complexities and difficulties involved in this area, have moved towards the use of surveys.
- A resolution will be sent from the Centre Heads to advise WHO on the crucial importance of reliable, timely and internationally consistent vital statistics and complete civil registration systems.

Host Centre presentations

Papers were presented and discussed on the following topics:

- An overview of a United States project to develop a vision of health statistics for the 21st century
- Activities of the ICE on Injury Statistics
- An overview of CIHI activities since the original mandate in 1994

Presentation and discussion of scientific papers

Papers were presented and discussed on the following topics:

- The role of classifications in assessing and improving the performance of health systems
- Influence of DRGs on classification use
- Quality of mortality and morbidity data
- Use of classifications in medical audit
- Conversion from ICD-9 to ICD-10, including comparability factors
- Rehabilitation data

Final business and closing sessions

1. Executive Advisory Group

- The Executive Advisory Group (EAG) will have 12 members, including four members from WHO CCs.
- The WHO secretariat requested nominations for EAG membership by the end of November 2001, after which a short list of candidates will be circulated.
- Topics to be considered by the EAG include a long-term vision for the classifications, education, financial implications and resources, information technology issues, implementation and coordination of the classifications.
- The terms of reference for the group have been drafted. The EAG will provide advice to WHO on all classifications and related matters.

2. Adoption of the joint work plan and meeting report

- The draft joint work plan was introduced and the historical background of its development along with an overview of its format and subcomponents was provided.
- The work plan was critically reviewed and a number of suggestions were made for incorporation into the plan during the week following the meeting. It was formally adopted, pending the amendments delineated at the meeting and pending final review by all concerned.
- It was hoped that sufficient resources would be identified to carry out the activities.
- The draft report of the meeting was critically reviewed, and adopted as amended, as recommended for amendment, and pending receipt of the additional sections to be written.
- The final revised versions of both will be sent from WHO to the Centre Heads and other relevant participants by the second week in November. Additional suggested amendments should be sent back to WHO by the end of November. If this schedule is met, the final documents will be available on the WHO website by the end of the year.

3. Evaluation of the meeting

- The goal of the meeting evaluation discussion was to see how the process could be improved for future meetings. Because of the greater than usual number of participants (over 80), as well as the substantially increased number of papers (almost 100), it was especially important to highlight where improvements could be made.
- Because Centres now have three areas of work to cover (ICD for mortality, ICD for morbidity and ICF), it was suggested that there be no upper limit set for the number of people attending the annual meetings from each Centre.
- In order to control the number of invitations sent to other than Centre or secretariat participants, the Host Centre, in conjunction with WHO Headquarters, will be the only party authorized to issue other invitations.
- In order to ensure adequate time to discuss the papers and their implications, the Centre Heads Planning Group will monitor the papers submitted and assess those to be presented accordingly.
- Poster sessions were proposed as a possible alternative way for papers to be highlighted without actually being presented.
- The Planning Group will work out the details for next year's scientific papers sessions and will ensure a good mix of papers on mortality, morbidity and functioning.

- The increasing cost of conducting the annual meetings is a concern. Joint hosting of the meeting, as will be done by the Dutch and German Centres in 2003, is one way that individual Centres can try to reduce their costs.
- It was suggested that WHO help subsidize, where necessary, countries that will host the annual meetings, and the secretariat agreed that this would be possible.
- Because joint ICD and ICF meetings require an additional number of concurrent sessions, the Planning Group will try to coordinate the sessions in such a way that Centre participants will be able to attend all of the sessions relevant to their areas of work.

4. Place and time of the 2002 meeting

The next meeting of Centre Heads will be held in Brisbane, Queensland, Australia from 13 to 19 October 2002.

Report of the meeting

Opening of the meeting

Ms Marjorie S. Greenberg, Head of the WHO Collaborating Center for the Family of International Classifications for North America, the Host Centre for this meeting, welcomed participants on behalf of the Collaborating Centre, the National Center for Health Statistics (NCHS) and the Centers for Disease Control and Prevention (CDC). She thanked the CDC, NCHS, the Canadian Institute for Health Information (CIHI), Statistics Canada, Health Canada and the Pan American Health Organization (PAHO) for their generous support as co-sponsors of the meeting. Ms Greenberg noted how honoured the Collaborating Centre felt to be able to host this first meeting for the WHO Family of International Classifications and the launching of the International Classification of Functioning, Disability and Health (ICF).

Participants were also welcomed by Ms Ghislaine Villeneuve, Chief of Vital and Cancer Statistics in Statistics Canada; Ms Louise Ogilvie, Director of Health Services Information at CIHI; and Dr Edward Sondik, Director of NCHS, all of whom expressed their appreciation for this first expanded family meeting. Dr William Raub, Principal Deputy Assistant Secretary for Planning and Evaluation, welcomed the participants on behalf of Mr Tommy Thompson, the United States Secretary of Health and Human Services, and Dr Carlos Castillo-Salgado welcomed participants on behalf of Dr George Alleyne, Director of PAHO and Regional Director of the WHO Regional Office for the Americas (AMRO). The officials wished participants well for their deliberations and thanked everyone for making the effort to attend the meeting in spite of the recent tragic events. They noted the value of the International Statistical Classification of Diseases and Related Health Problems (ICD) and the ICF to national and international health statistics.

Dr T. Bedirhan Üstün, Coordinator of the WHO Headquarters team on Classification, Assessment, Surveys and Terminology (CAS), officially opened the meeting. He welcomed participants on behalf of Dr Gro Harlem Brundtland, Director-General of the World Health Organization.

After the opening ceremony, photographs were taken of the participants and individual delegations. These photographs will be used in national launchings of the WHO Family of International Classifications (WHO-FIC) and the International Classification of Functioning, Disability and Health (ICF). In addition, it was announced that interviews with participants about the uses of the ICF would be videotaped throughout the week. The tapes will be used in training materials as well as other promotional activities.

Election of Officers

As has been the custom at these annual meetings, the head of the Host Centre, Ms Marjorie Greenberg, was appointed as Chairperson. Dr Richard Madden, Dr Peter Goldblatt, Mr Gérard Pavillon, Professor Bjorn Smedby and Dr Willem Hirs were appointed as Vice-chairpersons. Ms Donnamaria Pickett and Ms Candace Longmire were appointed as Rapporteurs for the meeting, to be assisted by designated participants for individual sessions.

Consideration and adoption of the agenda

The draft agenda for the meeting (WHO/GPE/CAS/C/01.01) was reviewed and accepted with only minor changes in the sequencing of two sessions.

Objectives of the meeting

Ms Greenberg presented the meeting objectives. These were to launch the Family of International Classifications, to integrate the Collaborating Centres (CCs) for the ICF into the network, to reaffirm and augment the joint WHO/CC work plan, including the agreed activities and responsibilities, to report on progress and plan the continuing work of the committees, to make policy decisions, to advance knowledge through scientific sessions, to promote international comparability, and to evaluate the meeting format and logistics.

Launching of the Family of International Classifications

The WHO secretariat presented a paper (WHO/GPE/CAS/C/01.91) about the Family of International Classifications, describing the ICF as a new family member. The final version of the ICF, previously called ICIDH-2, was presented to the WHO Executive Board in January 2001, which recommended that the classification be adopted. A resolution of the 54th World Health Assembly (WHA) in May 2001 endorsed the second edition of the classification. The resolution urged Member States to use the ICF in their research, surveillance and reporting as appropriate, and requested the Director-General to provide support to countries in these endeavours.

In October 2001, the ICF was published simultaneously in the six WHO official languages, together with electronic and Internet versions. In addition to the main volume, there is a short version as well as a multilingual CD-ROM browser with advanced search functions and Internet-based upgrading facilities. Work is continuing on the development of clinical descriptions and assessment guidelines, assessment criteria for research, specialty adaptations including a version for children and youth, and dedicated assessment tools.

Following the launch at the present meeting, country and region specific launching events will take place between November 2001 and March 2002. The launching period will conclude with the ICF Conference for Ministries of Health in Italy in April 2002.
The planning committee for this meeting had requested Professor Ruy Laurenti, in view of his 25 years of experience as Head of the Brazilian Collaborating Centre, to provide a response to the launching of the family. Unfortunately, Professor Laurenti was unable to attend the meeting, and Professor Bjorn Smedby agreed to present Professor Laurenti's paper (WHO/GPE/CAS/C/01.94). The paper covered four main areas: the history of the ICD, the development of the concept of a family of classifications, the history of the ICF, and the role of the Collaborating Centres.

In his paper, Professor Laurenti had expressed his concern about the problems in achieving integration of the present Centres given their differences, but he was not pessimistic because he viewed the situation as a challenge. He concluded his paper as follows: "The network of WHO Collaborating Centres for the ICD has always worked *as a family*, dedicated to *a* classification; now the extended network will work *with a family* of classifications and I expect that the WHO Collaborating Centres for the Family of International Classifications will continue to work as a family."

Professor Smedby said that he was also optimistic about a successful integration of the work on ICD- and ICF-related issues in the new Collaborating Centres for the Family of International Classifications. There has been a growing mutual understanding of the need to apply both traditional disease-focused measures and measures of functioning in order to optimally describe the health situation of populations and individuals. He pointed to the desirability of studying the possibilities for combined use of the ICD and the ICF in different areas. Finally, with reference to the family obligations mentioned in the secretariat's paper, he called for a more balanced way of using WHO resources – in terms of personnel, money and intellectual involvement – with respect to ICD- and ICF-related work.

Report from the secretariat on other activities since the last meeting

In addition to the extensive activities carried out in relation to the ICF as noted above, the WHO secretariat reported on a wide range of other classification related activities (WHO/GPE/CAS/C/01.04). The Third Edition of the International Classification of Diseases for Oncology (ICD-O-3) was published in December 2000. The International Agency for Research on Cancer (IARC) and the International Association of Cancer Registries (IACR) are preparing a French-language version. It is planned to publish CD-ROM versions in both languages. The extensive changes introduced in ICD-O-3 have significant implications for ICD-10, and these have been discussed by the Update Reference Committee.

Work has started on the development of alphabetical indexes for the International Classification of External Causes of Injuries (ICECI) and will continue as resources become available. Support has been provided to the WHO mortality database for the

development of cause, sex and age specific validations for ICD-9 (previously this was only done at the level of the basic tabulation list) and for ICD-10.

Work has continued on the development of CD-ROM versions of ICD with priority being given to the English and French language versions of ICD-10. Work will continue on other versions (ICD-7, ICD-8 and ICD-9) and in other languages (Spanish and Portuguese) as resources permit.

The secretariat has continued to contribute to the activities of the various committees and working groups established to support WHO-FIC activities, including the Update Reference and Family Development Committees. Inquiries from users of the classifications continue to represent a significant workload, as do those from health care professionals, students, software developers and members of the general public.

The organization, facilitation and follow up of the annual meetings of the WHO-FIC Centres have provided a progressively increasing workload over recent years. The organization of the 2001 meeting, with almost 100 documents and over 80 participants, has been particularly challenging, not only for the Host Centre, but also for the secretariat. The secretariat will consult with the Centre Heads Planning Group for the 2002 meeting in order to develop guidelines for documents (software, formats, fonts, etc.), and to better coordinate the issuance of meeting invitations (i.e. for WHO Headquarters and Regional Offices, Centre representatives and other participants). Changing the emphasis of the meeting was also discussed, especially relative to allowing more opportunity for technical discussions and exchange of experiences.

The official redesignation of the Centres by WHO was discussed. The secretariat assured the Centre Heads that their institutions' status as WHO Collaborating Centres was not in jeopardy, and that no existing Centres are being terminated. It was also indicated that efforts by Collaborating Centres to assist countries wherever possible would continue to be appreciated. The process being undertaken at WHO for review and redesignation, as well as about the plans to create additional Centres, particularly in the African, American and South-East Asian Regions of WHO was described. In the meantime, Centre Heads were assured that the current status of their Centres will continue. It was noted that the WHO review of all Collaborating Centres had reaffirmed the value of this network of Centres, which was recognized as exemplary.

Elaboration of the joint work plan

The secretariat introduced the draft joint work plan (WHO/GPE/CAS/C/01.85), noting that the need for a WHO and Collaborating Centre joint work plan had initially been raised at the Paris Heads of Centres meeting in 1998. It described the process of preparation of the first draft and subsequent reviews.

An overview was presented of the format of the joint work plan and its subcomponents. The overall objectives of the collaboration detailed in the plan are for WHO and its Collaborating Centres to work jointly in a coordinated manner on agreed priorities, to

produce outputs based on needs and agreed priorities, to share skills and expertise, and to maximize the return on limited resources.
The work plan is intended to provide a framework for WHO and its Centres in relation to the family of classifications, and will be used in establishing time lines and committing resources to deliver the products. It was noted that the plan contains some activities already being undertaken as well as some that are not currently being done.

It was anticipated that the joint work plan would be adopted at this meeting following the deliberations and recommendations of the plenary sessions and of the committees and work groups, and pending the final draft being seen by the participants. It was hoped that sufficient resources would be identified to carry out the activities delineated in the plan.

Presentations of terms of reference and work plans of committees and work groups

Dr Carlos Castillo-Salgado, Chair of the **Implementation of ICD-10 Committee,** presented information on the status of global implementation of ICD-10. The committee had collected information on the current status through an updated questionnaire to countries and regions on mortality and morbidity implementation. The Regional results were presented, as well as some individual country results.

In the Region of the Americas, all but five countries had implemented ICD-10 for mortality, but the picture for morbidity and health service activity was much more mixed. In the African Region, only five countries had implemented for mortality. In the European Region, 70 countries had implemented for mortality, but fewer for morbidity. Globally, up to half of the countries have not yet implemented ICD-10 for mortality.

Some of the difficulties and obstacles to global implementation were discussed. Chief amongst these for many countries was a lack of resources for training. These included financial resources and the availability of skilled personnel to train coders, statisticians and data users. This situation had been exacerbated in many areas by increased decentralization of information systems. In consequence, larger numbers of personnel in geographically dispersed provinces or regions need to be mobilized and trained.

The implementation committee thus sees a need for continued support and encouragement to countries in many regions to implement ICD-10. The lack of financial resources for training is limiting implementation, even for mortality, in some areas. They saw the training and credentialing subgroup as crucial to achieving this important global task. There is still inadequate infrastructure to support implementation of ICD-10 for vital statistics and health services in many countries. This will require commitment and resources from WHO.

It was remarked that there is a need to keep updating the information on implementation through a regular questionnaire. There is also a need for clear definitions of what *implementation* in a country means, with definitions for morbidity implementation being especially difficult. The questionnaires should include information on whether tabulations

are published nationally or for particular geographic or economic sectors, and also whether the country has bridged the change from ICD-9.

It was noted that PAHO has instituted a discussion forum on the ICD in Spanish. This forum has been very useful in solving coding problems, consolidating concepts and definitions related to the ICD, and improving the standards for data analysis. It has also been a useful mechanism for sharing and increasing skills between countries. In addition, PAHO has collaborated with several institutions in Latin America to develop INTERCOD, an automated, self-instructional, coder-training package available in multiple languages.

Ms Marjorie Greenberg, Chair of the **Subgroup on Training and Credentialing,** noted that the work of this subgroup was closely linked to implementation. She presented the subgroup's annual report (WHO/GPE/CAS/C/01.78), noting that the training and credentialing subgroup had been inaugurated at the Cardiff Centre Heads meeting in 1999, and presenting its terms of reference.

The subgroup had developed a needs assessment questionnaire for mortality and morbidity coders and needed to determine how it could be distributed. The Collaborating Centres and Regional Offices were surveyed on available training materials and capacity to conduct training. The group was exploring the possibility of initiating an international accreditation scheme for cause of death and health service activity coders. The possibility of doing this through affiliation with existing national and international organizations was being explored.

The need for training of statisticians and data users has been discussed, as well as training data suppliers such as doctors certifying causes of death. The subgroup wants to identify common needs and standards for training that could be recognized across national boundaries.

Issues to be discussed this year included whether this group should expand its work plan to include training needs for the ICF, or whether it would be better to have a separate group devoted entirely to addressing training needs for implementing and supporting the ICF. The sessions also needed to consider how to operationalize the proposal for an international training and credentialing programme. Last year a joint working group had been established with the International Federation of Health Records Organizations (IFHRO). The working group would hold its first meeting with the IFHRO co-chair during this meeting.

Dr Richard Madden, Chair of the **Family Development Committee (FDC),** presented the committee's annual report (WHO/GPE/CAS/C/01.51). He thanked the WHO Regional Office for Europe (EURO) and the Nordic CC for hosting committee meetings during the past year. In particular, he thanked Dr Gunnar Schiøler, Ms Donna Pickett, Dr Willem Hirs and Ms Catherine Sykes for their work during the year.

The composition and scope of the Family of International Classifications was briefly discussed. The FDC has strong links to, or is working on, the development of a

classification for interventions for use in countries that do not have a national classification, integrating ICECI, ways of developing Chapter XX of ICD-10, and the consequences of the recent WHA endorsement of the ICF. Joint meetings have been held with the World Organization of Family Doctors (WONCA), with potential for collaboration on the International Classification of Primary Care (ICPC) and other classifications used in primary care.

Professor Rosemary Roberts, Chair of the **Update Reference Committee (URC),** reported on the terms of reference of the URC and its work in the past year. She presented a paper highlighting issues relating to responsibility for maintenance and dissemination of code and rule updates for ICD-10 (WHO/GPE/CAS/C/01.32).

Professor Roberts stated that URC membership consists of 8 Centres, 11 countries, and 21 participants, including three who joined this year, as well as the WHO secretariat. She paid tribute to the contribution of Ms Michelle Bramley from the Australian National Centre for Classifications in Health (NCCH).

The paper set out a method of version control, lists of official updates to date, and the establishment of an e-mail discussion group for morbidity queries. The main achievements in the past year had been to streamline the management of a structured and practical mechanism for updates, with an annual cycle and dates for submissions. This meant that decisions could be progressed more quickly. A database records each work item, progress on it, and decisions made.

Though the processes and mechanisms of the URC have now been streamlined, those at WHO Headquarters have not. The action needed to sanction and disseminate agreed changes to ICD-10 has not occurred. The URC and Mortality Reference Group (MRG) were concerned by WHO's lack of ability to disseminate and control updates. This is causing problems for countries, for specialist adaptations and for other users. There have been no updates posted on the WHO website since 1999. It was felt that a clear policy from WHO was needed on posting and disseminating updates, and providing information and advice to Regional Offices in support of ICD use by countries. A page on the WHO website, or a link from it to a website maintained by one of the Collaborating Centres, is needed. This would provide immediate access to the database of changes approved by the URC and MRG.

Some issues on mappings between versions and information on progress on work items have had to be referred back to WHO (e.g. diabetes, mitochondrial disorders, etc.). These types of referrals might be reduced if the URC had direct access to international specialist clinical advisory groups.

There is a need to ensure compatibility with other members of the WHO-FIC whenever changes or updates are approved. There has been discussion around the possible need to reprint or re-issue updated versions on a five-year basis. This might be achieved largely through electronic dissemination, with paper versions of addenda available to users who need them. Similarly, a database with details of national versions and specialty

adaptations should be available electronically. These issues relate closely to the work of the Electronic Tools Committee.
The URC needs support from WHO so that it can contribute fully to this function of the organization. There is a need for a clear policy from WHO on updating, action on work items, and synchronizing changes to family members. Without this, the resources that have been developed cannot be fully utilized and the URC cannot fulfil its potential to exploit ICD-10 to the full.

It was pointed out that the MRG and URC have made changes and clarifications to the mortality coding rules. NCHS and other Centres have worked hard to incorporate these changes into automated underlying cause coding software. However, there was an issue of parity of access to updates for countries coding cause of death manually, and important issues for the comparability of mortality statistics between countries. Differences in the application of the rules have profound effects, for example, on apparent mortality rates from chronic diseases, when these are selected instead of pneumonias. It is therefore important that these changes also be implemented in manual coding countries via prompt, effective dissemination of URC decisions. The Chair noted that this had been identified as a major policy issue that the meeting must address.

The secretariat pointed out that the demand was clear for rules to be disseminated more widely. The secretariat was working on a document to be put on the WHO website. There were also other items to discuss and resolve after the meeting of the URC. WHO supports the dissemination of automated cause of death coding software. The updating process, however, involves much more than just putting the information on a website. There is a profound lack of resources to carry out necessary updates to the main classification and its supporting tools.

The Chair asked whether the process works in terms of implementing updates globally. Should updates continue to be produced if the support is not available to disseminate and implement them? The fact that this was a major policy issue, with profound effects on the comparability of data across the world, was reiterated.

Dr Harry Rosenberg, Chair of the **Mortality Reference Group,** presented the MRG's annual report (WHO/GPE/CAS/C/01.71). This report sets out the terms of reference and work plan of the MRG, which is part of the updating mechanism for ICD-10, under the aegis of the URC. The MRG concentrates on mortality applications and international comparability of the resultant statistics. Most of the work is conducted by e-mail and regular telephone conferences.

The *Mortality Forum* – an e-mail discussion group - is the entry mechanism for mortality queries, about half of which are resolved without reference to the MRG. Decisions in the MRG are mostly reached by consensus, with resort to voting when consensus is not possible. The problems considered and decisions reached had been outlined in the report. The chair and the meeting offered thanks to Dr Donna Hoyert of NCHS and Mr Lars Age Johansson of the Nordic Centre for organizing the work of the MRG.

In the absence of Dr Michael Schopen, Chair of the **Electronic Tools Committee (ETC)**, Mr Gérard Pavillon, Head of the Paris Centre, presented the ETC's annual report (WHO/GPE/CAS/C/01.24). The report outlined the terms of reference and a short history of the ETC, which first met in Cardiff in 1999 and subsequently in Rio in 2000. The work plan for 2001-04 includes a survey on electronic tools related to the ICD. The annual report of last year's meeting noted the need for an electronic version of ICD-10 that could be incorporated into databases. This would facilitate implementation and updating. It was strongly recommended that someone from the WHO secretariat attend the meeting of the ETC to address how this request could be met. The need to finalize recommendations for tools for electronic dissemination of updates was highlighted. This work must be strongly linked to the URC.

Dr Marijke de Kleijn de-Vrankrijker, Chair of the ICF sessions, addressed the meeting on the status of the **International Classification of Functioning, Disability and Health.** She pointed out that the ICF was a comparatively new classification. There was not yet a committee of the network of Collaborating Centres, like the URC or ICD-10 implementation committee, to take work on the ICF forward. However, several sessions had been scheduled at this meeting, both in breakout and plenary sessions, to plan the programme of work, including responsible parties and dates by which activities need to be done. It was hoped that there would be active participation and collaboration between those working primarily with the ICF and those working with the ICD to forward these aims.

In summary, Ms Greenberg reviewed some of the work to be done during this meeting. She noted that, following the breakout sessions, each working group and committee would report back on the outcome of the breakout sessions, and how these would contribute to developing the overall joint work plan. Centre Heads would also be integrating additional contributions into the joint work plan during the course of the meeting.

Breakout sessions

Individual breakout sessions were organized for the various committees and work groups from Monday afternoon through Tuesday afternoon. A few additional breakout sessions were organized on Wednesday as needed. After conclusion of the breakout sessions, reports of the major issues, findings and recommendations were made back to the plenary sessions. The detailed reports of the breakout sessions for the committees and work groups, except for the Family Development Committee, are included as appendices to the meeting report, and are referenced in footnotes under each subsection of the report back section.

Report back of committees and work groups

The major issues, findings and recommendations made by the various committees and work groups are reported below. However, because the Family Development Committee met for the most part in plenary sessions, the report on its presentations, discussions and recommendations has been provided separately, immediately following this section of the meeting report.

Implementation of ICD-10 Committee[1]

On behalf of Dr Carlos Castillo-Salgado, Dr Margaret Hazelwood reported back on the discussions and recommendations arising out of the breakout session for the Implementation of ICD-10 Committee. The following had been identified by the Committee as actions to be taken during the coming year:

- A definition of the term *implementation* is required to ensure a common understanding of implementation.
- The level of implementation within a country needs to be identified, i.e. if the country is starting from ground zero or, for example, if it is converting from ICD-9 to ICD-10.
- The next round of surveys will include a report on the status of implementation by Region. This is an outstanding action from the 2000 Centre Heads meeting.
- A *must do list/checklist* (essential steps) should be compiled for countries implementing ICD-10.
- A roster of experts is to be compiled for morbidity and mortality expertise.
- A self-training package (INTERCOD) had been developed in multiple languages and is ready for dissemination.
- It was recommended that the committee continue until 2002.
- A new Chair needs to be appointed, possibly from another Regional Office.

Relative to the assignment of a Chair for this committee, it was considered that the Regional Offices would be best placed to fulfil this role. However, the Regional Office representatives expressed concern about the additional workload, and suggested that the issue be referred back to WHO Headquarters. The North America Centre suggested that, for the coming year, the work could be progressed by the Centre Heads Planning Group, because one of the joint work plan goals is ICD-10 implementation.

After further discussion with the WHO secretariat, it was agreed that the Regional Advisers from the WHO Regional Offices for Europe (EURO) and Africa (AFRO) would serve as Co-Chairs of the committee, in close cooperation with WHO Headquarters and with the participation of the United Kingdom Centre. Two meetings will be organized in Geneva before the 2002 Centre Heads meeting.

[1] The detailed report of the committee's breakout session is attached at Appendix 1.

Subgroup on Training and Credentialing[2]

Ms Marjorie Greenberg reported on the two sessions of the Subgroup on Training and Credentialing and the joint International Federation of Health Records Organizations (IFHRO)/CC working group. She reported the main action points agreed at the breakout sessions as follow:

- Needs assessment questionnaire for morbidity and mortality coders will be sent to PAHO for translation into Spanish, French, and Portuguese.
- Subgroup Chair will distribute the questionnaires to other Regional Advisers for distribution to countries.
- Subgroup will liaise with the ICF group on training issues. However, more specific coding guidelines and field experience with applications are needed before an international training and credentialing programme can be established.
- Tables of available information on training materials and training capacity for morbidity and mortality coding will be set up on the United States National Center for Health Statistics (NCHS) website. WHO Headquarters, Regional Offices (ROs) and Collaborating Centres should link to the NCHS site.
    - NCHS will obtain consent from each source to include contact information on the website.
    - NCHS will develop a brochure containing the same information for countries without ready access to the Internet. The secretariat will explore publication by WHO.

The joint IFHRO/CC working group held a productive first meeting with Ms Kathy Brouch, the IFHRO Co-Chair, and the following actions were agreed:

- NCHS will prepare a draft article about this collaboration for the next IFHRO newsletter to assist in recruiting additional IFHRO members.
- IFHRO will provide members with issues of the newsletter, other relevant documents and website information for IFHRO as well as for the American Health Information Management Association (AHIMA).
- NCHS will prepare a background paper covering relevant definitions, skills, training levels and critical functions of underlying cause mortality coders.
- The United Kingdom Centre will prepare a similar paper for morbidity coders.
- IFHRO and NCCH will prepare an assessment tool for analysis of the available training materials.
    - IFHRO and NCCH will initiate an assessment of English language training materials to identify core competencies and best practices.
    - The assessment tool will be sent to relevant persons for applying to non-English language training materials.

[2] The detailed report of the subgroup's breakout sessions is attached at Appendix 2.

The secretariat emphasized the need for consistent linkage to the WHO website. The work of the subgroup was approved.

Update Reference Committee[3]

Professor Rosemary Roberts reported back on the two URC breakout sessions, noting that they had been fruitful despite a long agenda. The following had been agreed following discussion of paper WHO/GPE/CAS/C/01.31:

- Section 1 recommendations supported by the URC for inclusion in ICD-10 (2003) were accepted.
- Section 2 contained six recommendations that were controversial and discussed in detail. Of these, four were accepted, one was rejected and one was amended.
- Section 3 contained items held over to 2003. However, items 104,106,108 and 109 were discussed and accepted.
- Section 4 contained items either not supported or withdrawn. The committee agreed upon the status of these.

There were 12 items originally referred to WHO and therefore held over until next year which may now be part of the general work of the committee in discussion with the WHO secretariat. The committee considered paper WHO/GPE/CAS/C/01.32 that identified the controversial issues and frustration of the committee's work. Professor Roberts reported that some issues had been defused, although some problems still existed. The following items were put forward:

- The version control table will be updated to include the year in which WHO and the Centre Heads accepted the changes for posting on the website.
- The frequency of updates was considered to be too frequent, and imposes an unbearable workload on the URC and WHO. It was agreed that the schedule was in its infancy and that it should be continued and tested. However, some modifications to the cycle will be made.
- Language versions will be changed every three years.
- The French Centre and PAHO had agreed to help with translation.
- The URC secretariat will have access to the clinical consultants who advise WHO to ensure direct clinical input (to be done in collaboration with WHO).
- The Committee had received verbal assurance that WHO supported the policy of updating ICD-10, but had requested this in writing from WHO along with confirmation of the version control process.
- It was agreed that the updates and database would be posted on the NCCH website with links to the WHO website. However, the dissemination of these changes would come from WHO, and WHO Headquarters would advise Regional Offices of the existence of the changes.
- The ICD-10 CD-ROM will contain 1999 and 2000 updates and the version will be titled *ICD-10 (2000)*.

[3] The detailed report of the URC breakout sessions is attached at Appendix 3.

- It was recommended that the translator to map between versions of ICD-10 be prepared by the WHO secretariat. The responsibility for the translation was not agreed, although it was agreed to produce an addendum every three years as a separate publication, to allow changes to be posted.

Other papers had been considered, including those detailing the process and mechanism of the URC and discussions groups.

Professor Smedby stated that the Nordic Centre was impressed by the URC secretariat's work and timetable, which makes it possible to do this fairly complicated work by e-mail. He expressed the Centre's gratitude to the Australian Centre for undertaking this work, and wished a special thanks to be given to Ms Michelle Bramley.

The Australian Centre was queried about the update process as it relates to reporting mortality statistics. Professor Roberts confirmed that the process would be in accordance with the three-year cycle. The WHO secretariat reported that, as there were 65 Member States reporting mortality statistics, there may be some that would not update every three years. Therefore, valid and invalid codes will necessitate careful monitoring.

The United Kingdom Centre emphasized the need to ensure an efficient mechanism for notification of mortality rules. The North American Center supported this and advised that the major changes have implications for both automated and manual coding. The Nordic Centre expressed the importance of this work and noted that the updating mechanism and language versions should not be impediments to the implementation of changes. The WHO secretariat will need to have a solution for this and ensure that changes are disseminated according to the established timetable.

The WHO secretariat reiterated their appreciation of the work done. The proposal to include updates exclusively on the NCCH website could be a problem, and a solution will be found to replicate the same information on the WHO website.

Mortality Reference Group[4]

Dr Harry Rosenberg reported on the discussions and recommendations arising from the MRG breakout sessions. The annual report of the MRG was accepted, the annual report of the Mortality Forum and a paper containing proposals to speed up the work of the MRG were reviewed. The following actions had been put forward by the group:

- To expedite the work of the MRG, a proposal had been made to establish smaller subgroups which was approved.
- The terms of reference for the MRG should be modified to ensure that members commit to supporting the suggestions presented by the group.

[4] The detailed report of the MRG breakout sessions is attached at Appendix 4.

- Information had been provided on a United States proposal proposed codes for a new ICD-10 category to identify terrorism. This received mixed responses. The United Kingdom Centre did not consider that there was a need for this even though some countries have introduced such codes. In the subsequent URC meeting, the secretariat suggested that if such codes were introduced by the United States, they be included in the U Chapter and used as supplementary codes. Discussion was productive and will feed into the general discussion.
- A re-write of the WHO Trivial conditions Rule was accepted.
- It was agreed that more work would be done on codes for postoperative conditions.
- Other issues dealt with included the ambiguous use of the terms "newborn" and "transitory" in relation to categories K56 and P76, guidelines for certain "highly improbable" sequences, the distinction between the similar terms "circulatory insufficiency" and "peripheral circulatory insufficiency", coding of multiple valvular diseases, and a proposal on Sudden Infant Death Syndrome.
- An issue concerning maternal death raised by the WHO Family and Community Health Cluster has not been resolved, although it was considered to be more a semantic rather than a conceptual issue. Discussion on this will continue.

There was no further discussion and the work of the group was approved.

Electronic Tools Committee[5]

Mr Gérard Pavillon reported on the discussions and recommendations of the Electronic Tools Committee. The annual report (WHO/GPE/CAS/C/01.24) had identified the work that was done during 2000. There were two items that had not been completed: collecting material from Collaborating Centres for the electronic versions of ICD-10, and the production and dissemination of a shortened version of ICD-10 to be available on the WHO website in collaboration with the Centres, WHO and DIMDI.

Paper WHO/GPE/CAS/C/01.23 had identified the problems of dissemination policies for the ICD-10 electronic version. Mr Pavillon reported that the problems concerning the Electronic Tools Committee are closely linked to the dissemination issues raised by the Update Reference Committee.

The committee put forward three recommendations for approval:

Recommendation 1: All successive versions of ICD-10 and mappings should be made available on the Internet free of charge in a read-only format that cannot be edited or used for value-added products.

[5] The detailed report of the ETC breakout sessions is attached at Appendix 5.

Recommendation 2: ICD-10 versions should be made available in electronic format suitable for data processing or integration into computer applications for generating income for WHO.

Recommendation 3: To comply with the World Health Assembly policy on updating the classification, it is recommended that resources generated by the sale of the products referred to in Recommendation #2 should be used for the development of content and format of ICD-10.

The secretariat responded that the recommendations were excellent but wished to make the following points:

- WHO supports the public consumption of these tools through other means, for example, the ICF has been made available on the Internet. The WHO secretariat confirmed that ICD-10 would be available in different electronic formats other than ASCII, such as Access. These will be available in the next few months. The North American Center wished the WHO response to Recommendation 1 to be noted and felt this to be important, positive support.
- The secretariat is working on the English and French versions and put forward the suggestion that the relevant countries take on the work for other language versions.
- The secretariat advised that WHO provides a *service* and is not an enterprise as such. With regard to Recommendation 3, WHO is a strong advocate for ICD revenue coming back to the CAS Team, but the World Health Assembly policy is that, when an ICD book that is a best-seller is sold, the revenue is used to support other WHO publication work. The WHO secretariat expressed an interest in looking at a virtual pool of revenues, and suggested that country representatives go back to their respective Ministers of Health to gain support for ICD revenues to reach the CAS Team.

Mr Pavillon responded that Recommendation 2 should remain despite the confirmation from WHO, and that Recommendation 3 should also be retained, as there is still a dichotomy between the ICD being a best-seller and yet there being a lack of resources within WHO to support ICD-10.

The Australian Centre expressed concern about Recommendation 3 on the basis that it was not consistent with the principles of public finance. It was noted that WHO has a responsibility to support the ICD, and it was suggested that this recommendation be reworded to reflect that WHO has the copyright for the ICD and gains substantial revenue from this product. Therefore, WHO should be called on to provide sufficient resources. The North American Center supported this modification. It was therefore agreed that Recommendation 3 be approved with a modification to note that WHO has a constitutional mandate to maintain ICD-10 and that substantial revenues are obtained from this product. WHO should therefore be called upon to provide resources to maintain a high quality product.

The WHO secretariat advised that this should also be taken up by the Centre Heads through the WHO Executive Board and individual country Ministers of Health, etc.

In summary, the following was agreed:

Recommendation 1 approved as submitted by the meeting:
All successive versions of ICD-10 and mappings should be made available on the Internet free of charge in a read-only format that cannot be edited or used for value-added products.

Recommendation 2 approved with some refinement as follows:
ICD-10 versions (in French and English) should be made available in electronic format suitable for data processing or integration into computer applications, enabling income generation for WHO.

Recommendation 3 approved with refinement as follows:
Because WHO has the copyright for the ICD, and given the WHO mandate to maintain the classification and that the ICD products produce substantial revenue, WHO is called upon to provide sufficient resources to appropriately maintain and update the products.

Dr Manuel Mosquera, Head of the Venezuelan Centre, queried the status of INTERCOD, an ICD-10 self-training tool. The PAHO representative advised that this is ready for distribution in multiple languages. The United Kingdom Centre suggested that it would be useful to have a demonstration of the software during the meeting.

International Classification on Functioning, Disability and Health[6]

Dr Marijke de Kleijn de-Vrankrijker presented the issues discussed and the actions to be taken for each of the eight key activity areas. The aim of the sessions had been to identify what future actions need to be taken, who is the responsible party for each, and the time frame within which the activities are to be carried out.

1. Coding guidelines
Issues had been raised relative to further refinement of the existing guidelines, the identification of short- and long-term changes based on empirical evidence, the assurance of international comparability, ensuring the integrity of the ICF, and consideration of user specific needs. It was noted that coding guidelines should be as complete and detailed as necessary. WHO will convene a discussion group on specific coding issues prior to any amendments/enhancements of the existing coding guidelines. Examples for coding will also be reviewed by WHO. It was agreed that WHO and the United Kingdom Collaborating Centre would work out a plan of action for this topic to be circulated by e-mail to the Centres for comment, and consequently, if the need arises, a meeting may be organized in Geneva.

2. Implementation
The need to monitor the use of the ICF by both WHO and the Collaborating Centres, the need to monitor the use of options 1-4 for the activity and participation (A&P)

[6] The detailed report of the ICF breakout sessions is attached at Appendix 6.

dimensions, the recognition of coding guidelines and user guides as integral parts of implementation, and the need for indexing guidelines were the primary issues discussed.
It was agreed that WHO will report on the different ways in which the A&P dimensions are used, as the information is received from countries. WHO will report data using the most, or lowest, common option, and country data on the use of the options will be posted on the ICF website. Indexing guidelines will be provided by WHO. It was agreed that the first step regarding indexing should be to cross reference items (language specific), and that step two would be to develop a substantive index. Comparability of data was an issue that will continue to be discussed at future meetings, including the meeting in April 2002 in Trieste, Italy. The recent report on Classifying and Reporting Functional Status by the United States National Committee on Vital and Health Statistics was noted as a positive example of activities fostering implementation.

3. Training, outreach and dissemination

Issues raised during the discussion included the need for appropriate training to ensure effective implementation, and the considerable resources that will be required for training. The need to avoid duplication of effort was noted. Within this context, the use and exchange of information on training tools (e.g. CODE-ICF and the Australian User Guide) had been emphasized. The need for basic as well as user-specific materials had also been expressed.

Principles for ICF training are to be established and a training plan will be developed. Specific activities will be to post educational materials on the WHO website, to circulate the outline of CODE-ICF among the Collaborating Centres and WHO, and to establish a working group addressing training principles, an inventory of training needs, a catalogue of existing materials and, as a result, an educational plan. This group will liaise with the Subgroup on Training and Credentialing

Over 20 interviews with meeting participants were videotaped by Ms Debra Farmer. Topics for the interviews included the role of WHO Collaborating Centres for the Family of International Classifications in dissemination, the need for training various professions in the use of the classifications, applications of the classifications in clinical, survey, policy and programme work, and how ICF will benefit consumers. The interview tapes will be used in developing ICF training materials.

4. ICF adaptations for specific purposes

Some confusion had been expressed about the word *adaptation*. It was clarified that an adaptation is a *derived* classification (i.e. fully mappable back to the parent classification), rather than a *related* classification (i.e. modified and used for different purposes). Examples to clarify this discussion included that an adaptation would be done for children and youth, while a related product would be developed for rehabilitation terminology. The development of adaptations is to be coordinated and approved by WHO.

It was noted that country- and discipline-specific ICF adaptations would not be encouraged at this stage. The focus of work in this area would be on the development of core sets and criteria for adaptation. Information on core sets and adaptations will be exchanged through WHO, and WHO will coordinate criteria development. The United Kingdom Collaborating Centre will share information on criteria that exist in the United Kingdom.

5. Measurement

The development and use of instruments, the need for mapping existing instruments to the ICF, the need for information exchange, the development of WHO-DAS, and the status of the ICF checklist were topics that had been raised during discussion. It was noted that WHO will post information sent from the Collaborating Centres on its ICF website. The work of the United Nations Statistics Division's *City Group* on disability measurement needs to be linked with WHO. WHO will provide guidance on how to map existing instruments to the ICF and will update information on WHO-DAS and WHO survey instruments. The new checklist is already on the website and is being used by several countries, including Germany and Italy.

6. The use of ICD and ICF together

The importance had been noted of identifying commonalities between the two classifications, defining components in order to clarify differences, and reviewing *same concepts* with different levels of granularity. It was recognized that using the classifications together is important. The need for national guidance (for example coding guidelines) and the use of field experiences were also noted. The Family Development Committee will follow up these issues in consultation with ICF experts.

7. Maintenance and update process

Issues raised included the need for a systematic updating mechanism, the importance of stability of the classification, and the recognition that there must be a distinction between minor and major changes. The issues of updates being reflected in training materials and of keeping the ICF aligned with current terminology had also been addressed. Terminology owners and producers will link with the custodians to which they are mapping.

It was noted that the ICF and the ICD were at different stages of development, and that their updating processes would therefore be different. There will need to be a gradual approach for ICF updates and a need to wait to see what types of updates are required. Information on update requirements should be obtained and evaluated before determining any necessary changes. WHO will produce a draft document on updating and maintenance policies for the ICF, and will discuss this with Centres via e-mail and at future meetings.

8. Organizational issues

The need for efficient coordination of meetings, activities and resources had been emphasized. It was agreed that annual, joint meetings of ICF with ICD were best at

present. However, it was suggested that there may be a need to hold decision/policy-making meetings separately. It was also agreed that there should be a balance between the business and scientific sessions in the meetings, but that the limited time accorded to scientific discussion was a constraint within the joint forum. This situation was recognized by WHO. It was also recognized that there is a need for generating resources for ICF work. It was agreed that future meetings would build on the experience of previous ones, and that efforts would be made to work more effectively between meetings, and through the use of existing and *ad hoc* work groups (e.g. for guidelines and training). There was a proposal initiated by Japan and endorsed by the meeting that there be an *ad hoc* study group for the subjective dimensions of functioning.

9. Additional issues

In addition to the above eight key activity areas, a few other issues had also been addressed. These included the need for periodic updates of the WHO website, and for precise conditions and technical guidelines to be clearly specified in translation rights agreements with WHO. A Nordic Centre paper on structural and terminological issues concerning the ICF by Glen Thorsen and Iver Nordhuus, and the WHO response on how this will be taken into account, will be circulated among the Centres.

Family Development Committee

The Family Development Committee met for the most part in plenary sessions. Hence, there was no separate report of breakout sessions for this committee. Dr Richard Madden opened the session, noting that the annual report (WHO/GPE/CAS/C/01.51) outlined the work of this committee over the past 12 months.

1. Procedures/interventions

Three papers (WHO/GPE/CAS/C/01.57, 01.92 and 01.33) were presented as an introduction to the discussion on classifications for health interventions. These addressed procedures reported to Australia's National Morbidity Database in 1999-2000 using ICD-10-AM, the results of responses to the survey on surgical procedures and interventions, and a proposal for an international classification of health interventions.

Three classifications with potential for modification and use as an international classification of health interventions for countries without an interventions classification had been identified: the Canadian Classification of Interventions (CCI), OPCS-4 from the United Kingdom, and the Australian Classification of Health Interventions (ACHI).

The Australian Centre had prepared a condensed version of ACHI referred to as the International Classification of Health Interventions (ICHI). This version is a subset of ACHI that contains about 1600 codes in a tabular list. The full classification is updated every two years. Maintenance of ICHI would be in conjunction with the full classification. It was noted that ICHI was not intended to replace existing classifications, but it could be used in conjunction with a disease classification, such as ICD-10, in countries without an interventions classification.

The three Regional Office (EURO, AMRO/PAHO and AFRO) representatives at the meeting reported that the demand for an interventions classification was still urgent. The three papers noted above were felt to be especially relevant and were seen to provide a possible solution to an issue that has been on the agenda for some years.

The Nordic Centre suggested that criteria to evaluate candidates for an international interventions classification need to be clarified. In discussion, a draft list of criteria[7] was developed. Two separate priorities were identified:

1. The need for an interventions classification for countries that do not have one.
2. A classification of health interventions that supports international comparisons.

It was agreed that the former issue is the more important at this time. It was noted that the Australian proposal was available to solve an urgent need. The Australian Centre agreed to develop a prototype version incorporating suggestions arising from this meeting, with the amended title *Australian Classification of Health Interventions - adapted for International use*. At the same time, an evaluation of potential candidates will be undertaken.

Next steps:

- Develop a prototype classification (Australian Centre).
- Consider additional issues of how to make the classification available, training materials, updating, resource requirements, and the availability of assistance with translations.
- Get information from countries from which there has been no response to the survey.
- Consider the inclusion of interventions other than surgical.
- Develop criteria for the evaluation of potential candidates.

A small working group of the FDC will continue this work. It was noted that Regional Office representation would be desirable for the working group. A report will be made to the FDC at its meeting in April 2002.

2. External causes

2.1 ICECI as a related classification in the WHO-FIC

The International Classification of External Causes of Injury Version 1.0 has been completed as a final draft, and membership in the WHO Family of International Classifications as a related member is sought. At the Copenhagen meeting of the FDC it was suggested that indexes should be prepared. This work has commenced and has revealed some deficiencies in the classification. WHO does not feel that ICECI can be adopted as a related member until these have been corrected (WHO/GPE/CAS/C/01.90). The Violence and Injury Prevention Programme and the CAS Team will propose to Centre Heads that ICECI be adopted when the work is completed.

[7] The draft list of criteria for evaluating international interventions classifications is attached at Appendix 7.

The ICECI working group was congratulated on its work in this complex area. It was suggested that piloting the classification would be necessary to ensure a satisfactory product. Centre Heads were pleased to note the progress on this classification and looked forward to a proposal for membership in the family at the Brisbane meeting in 2002.

2.2 Changes to Chapter XX

Paper WHO/GPE/CAS/C/01.88 presented a summary of national modifications to Chapter XX of ICD-10 for morbidity applications. Finland and Germany have reduced the number of external cause of injury codes, while Canada, Australia and the United States have expanded them to restore some of the loss of detail that was in ICD-9-CM. Paper WHO/GPE/CAS/C/01.37 illustrated the need for detail. The Australian modification codes for Place of Occurrence and Activity when injured have used some of the vacant U codes.

In ICD-10, the design constraints in Chapter XX limit the ability to expand codes for injury prevention needs. A proposal from the ICECI Technical Working Group to expand the ability to code Activity when injured and Place of Occurrence by using devices similar to those used in the Australian national modification was discussed (WHO/GPE/CAS/C/01.54). There was some opposition to the proposal to use codes in Chapter XX for place and activity, and it was suggested that separate codes, outside of Chapter XX (for example U codes) be used. This would mean that any code in Chapter XX could continue to be used for underlying cause of death.

It was made clear that any proposals for changes to Chapter XX would have to be made through the established mechanism and agreed by the Update Reference Committee. The Committee would consider the various changes made in national versions as well as other suggestions from Collaborating Centres and the ICECI working group in deciding how Chapter XX of ICD-10 might be improved for injury prevention, while retaining its usefulness for mortality applications. The recommendations of this meeting will be fed back to the ICECI working group.

3. Relations with WONCA

Dr Richard Madden welcomed Dr Niels Bentzen, Chair of the WONCA International Classification Committee. Mr Henk Lamberts and Ms Inge Okkes, members of WONCA, attended as observers. A 1999 letter from Dr Higgins, Chair of WONCA, had suggested that the ICPC and WHO classifications be brought together. The matter was discussed at the 1999 Centre Heads meeting and WHO had suggested a joint meeting. This was held in Copenhagen in April 2001. A path forward was agreed, with the first step being a joint presentation at this meeting.

Dr Gunnar Schiøler and Dr Niels Bentzen set out the roles of ICPC and ICD in their paper WHO/GPE/CAS/C/01.53. It was noted that the ICPC could be used as a classification of reasons for encounter, whereas the ICD could not, and that it could also be used to classify diagnoses, although at a courser level of granularity than the ICD.

It was agreed to set up a joint working group to carry out the recommendations in the paper. At the joint meeting in Copenhagen, a recommendation had been made to consider the inclusion of ICF in the Functioning rubric of ICPC. This will be added to the terms of reference of the joint working group.

It was agreed that the group should be small and that the composition of the group should include expertise on ICF, ICD and ICPC, but that it should be able to draw on other experts as needed. Electronic communication would be the primary method of work. A preliminary report should be available for the FDC in April 2002. A meeting of the joint working group could take place in Brisbane (WONCA is meeting in Sydney two weeks earlier). The Chair of the FDC and Dr Niels Bentzen will decide the final composition of the group. The Dutch Centre volunteered to act as secretariat for the group, and Dr Schiøler agreed to continue working with the group.

It was noted that the work with WONCA would be limited to consideration of the use of the ICPC as a classification for reasons for encounter as a possible member of the WHO-FIC. A primary care adaptation of ICD-10, for diagnosis and health related problems, should be considered by the FDC, but not in conjunction with WONCA. However, the joint work with WONCA could include efforts by WONCA to improve alignment between ICPC concepts and ICD-10.

An overview of the United States Reason for Visit (RFV) classification (WHO/GPE/CAS/C/01.69) was presented. The main difference between RFV and ICPC is that the former can be used in emergency rooms and hospital outpatient departments as well as in general practice. It was agreed that reason for encounter classifications would be evaluated by the FDC.

4. Concept of the Family

The Family Development Committee presented a paper on the concept of the family of international classifications (WHO/GPE/CAS/C/01.52). It was agreed that the paper has been substantially improved since the 2000 meeting. The WHO secretariat suggested that this document be blended with the WHO paper (WHO/GPE/CAS/C/01.91) as a working document to inform those proposing classifications for WHO-FIC membership. Publication in the WHO bulletin was suggested, with the FDC to be acknowledged in the authorship. Dr Madden and Dr Üstün will develop a draft for discussion. Suggestions for the merged document included:

- clarification of the term *combination systems*,
- more examples of derived and related classifications to clarify the definitions, and
- clarification of the position of national modifications and translations.

It was agreed that the matrix was a valuable improvement on that presented last year, and there was general approval of the remaining material.

5. Joint use of ICD and ICF

The issue of using the ICD and the ICF together has been identified for some time. Now that there are two reference classifications, the Australian Centre has brought the issue of commonality forward after a moratorium. The paper on the implications of the ICF for the ICD (WHO/GPE/CAS/C/01.55) presented some suggestions for moving forward on this issue. The aim of the paper is to get a mandate for the committee to do further work. That the two classifications are conceptually different was acknowledged, and it was noted that some assistance will be required to take this work forward.

It was agreed that the work on commonalities and inconsistencies should proceed. WHO suggested that this work proceed on the basis that no items be removed from the ICF. The Centre Heads also questioned whether any items should be removed from the ICD. It was recognized that some commonalities will be necessary because there are settings where only one classification will be used. There is still a need to examine both classifications closely to identify areas of commonalities or inconsistencies and to propose guidelines and/or revisions. The following actions were suggested:

- develop key principles to guide an analysis of commonalities and inconsistencies,
- identify areas of commonality and refer to the Update Reference Group, and
- develop a set of guidelines for joint use of ICD and ICF.

In the first instance, the commonality issue is to be confined to the two reference classifications. Other related members of the family (e.g. ICECI and ICD-O) may need to be considered later.

Dr Richard Madden requested that anyone interested in joining the committee contact him. A face to face meeting is planned at the time of the ICF meeting in Italy in April 2002.

Implementation of automated coding systems for mortality

This session was chaired by Mr Gérard Pavillon. Dr Harry Rosenberg, who organized the session, provided a brief background of the International Collaborative Effort (ICE) on Automating Mortality Statistics. The ICE is an activity focused on automated coding and processing of mortality statistics. The ICE participants look at the international collection, processing and dissemination of mortality statistics. Software was the initial focus of the ICE, but the main goal now is to improve the quality and comparability of international mortality statistics. There had been two previous plenary meetings, in 1996 and 1999. The outcomes of those meetings largely influenced the creation of the Subgroup on Training and Credentialing, the Mortality Reference Group and the Electronic Tools Committee. Dr Rosenberg announced the availability at the meeting of the prepublication copy of *Proceedings of the International Collaborative Effort on Automating Mortality Statistics, Vol II* - the report of the 1999 proceedings.

Another product of this effort has been the creation of a curriculum for training in coding causes of death for automation. This is a one-year programme, taught at the NCHS facilities in North Carolina and coordinated by Ms Donna Glenn.

A number of papers were presented[8] at this session. Dr Harry Rosenberg provided some concluding remarks regarding the papers and ensuing discussion. He noted that the Japanese paper had dealt with a system that is somewhat different, and that more details had been requested to be provided at next year's meeting. Specifically, it would be interesting to hear about the completeness and quality of reporting. Within this context, it was noted that the United States has a difficult time obtaining diagnostic information on spontaneous terminations of pregnancy.

Ms Glenn's discussion had indicated the practical issues of maintaining a system and responding to the change requests made to ensure international validity.

It had been suggested, based on the results of the survey reported by Dr Ari Miniño, that perhaps a survey should be conducted annually to track the status of countries.

Mr Pavillon and EUROSTAT colleagues had provided feedback on improving an existing system. The need to reach out to other countries had been addressed, as had the need for European countries to provide technical assistance to other countries. These collective activities help to increase the use of automated systems.

The secretariat provided the following feedback from WHO regarding the presentations and the activities of the ICE: (1) WHO fully supports the efforts of this group, (2) it is important to provide accurate and consistent cause of death and multiple causes of death data, and (3) the decision tables and ICD codes are the common language in this endeavour.

Concern was expressed by the secretariat regarding problems with terminology in other languages, and a few examples were presented of translations that appeared correct in previous versions of ICD but where the meanings were very different. An advantage of an automated coding system is that mistakes can be corrected easier than in a manual system. A disadvantage may be that we gradually lose expertise in many areas, including when a software expert leaves or when coding expertise is not present during a new revision.

For the future, the tables need to be transparent and internationally agreed upon. National tables need to be fully documented as to where they depart from the international tables, so that those comparing data will be aware of this.

Concern was raised concerning the resources needed to attend the training. Although there is no charge for the United States training class, there are still the usual travel and other expenses. Where possible these have been minimized by acquiring accommodations in economical quarters. Training internationally in a central location has

[8] Details of the presentations and discussions of the papers presented are attached at Appendix 8.

been considered, but hardware needs and the transport of training materials must also be considered. In addition, the training in the United States is presently done only in English. These issues will be further addressed by the ICE.

This was noted to have been an excellent initiative and the work of everyone involved was appreciated.

Terminologies and mapping with ICD-10 (including SNOMED-CT)

Dr Richard Madden, Chair of this optional session, noted that the experimental evening meeting was an apparent success, considering the numbers in attendance. He welcomed Dr Diane Aschman, Chief Operating Officer of the College of American Pathologists, and Ms Margo Blakemore, also from the College, who made a presentation[9] about the Systematized Nomenclature of Medicine (SNOMED) and its mapping to ICD.

As highlighted during discussion of the joint work plan, the issues of terminologies were important to the work on classifications, and activities related to terminologies were to be added under the quality assurance subcomponent of the work plan. It was stressed that work related to terminologies would require a coordinated approach, and that standards would need to be developed for mapping terminologies to classifications.

During discussion of the presentation, it was suggested that a useful next step would be to assess SNOMED as a clinical index to ICD-10, with maps developed to index terms as well as to codes. This would allow the index term to be used as the point of entry for ICD coding based on SNOMED terms. There was some discussion of the extent to which ICF concepts and terms were incorporated into SNOMED, for example for use in rehabilitation. Dr Aschman and Ms Blakemore reported that some concepts were likely to have been incorporated, as work had been undertaken on functional and possibly other relevant axes, and work was currently being undertaken to incorporate some nursing terms and terms relating to activities of daily living. Comprehensive incorporation of the ICF may require the introduction of additional hierarchies, such as for severity.

It was also suggested that the quality of the mappings should be evaluated by the proprietors of the classifications. This type of assessment has apparently not been made, but NCHS indicated that it would be interested in undertaking such an evaluation in the future in relation to the ICD-9-CM mappings. Other comments included that the mappings should be transparent, would be more problematic at higher levels of the hierarchies, and could be assessed against manual coding from medical records. Some type of accreditation may be required in the longer term for assurance of the quality of maps from SNOMED and other terminologies to classifications. It was suggested that the meeting consider whether some work on these issues should be specified as part of the joint work plan.

[9] Details of the content of the SNOMED presentation are attached at Appendix 9.

In response to the discussion, Dr Aschman commented that greater collaboration for improved mapping would be welcome, as would working with others to produce SNOMED in other languages and to map it to other classifications, such as ICD-10-CA and the ICF. In concluding the session, Dr Madden thanked Dr Aschman and Ms Blakemore for their interesting presentation.

Guidelines for hospital morbidity coding

Ms Marjorie Greenberg introduced the session, noting the importance of considering health information systems in which classifications are implemented. She noted that hospital discharge data would be addressed at this session, and that vital registration would be the topic at the next session. These subjects are of particular interest to the PAHO Regional Advisory Committee, which includes Ms Greenberg, Professor Laurenti and Ms Violeta Gonzales-Diaz of the UN Statistics Division. Ms Carol Lewis was introduced to the participants as one of the people working on this topic. The session was chaired by Dr Willem Hirs.

Dr Roberto Becker presented a paper on guidelines for a hospital morbidity database (WHO/GPE/CAS/C/01.46). He noted that this paper was to be used as the basis to discuss issues surrounding such guidelines – *not* to develop guidelines and *not* to replace what countries are already doing. Dr Becker noted the problem of data comparability because some countries do not have standardized definitions of the single, main diagnosis and others do not use international definitions. He supported his presentation with results of a survey including 17 countries on coding using hospital discharge data.

Dr Becker presented the three main definitions used for single diagnosis reporting and analysis:

- the condition established after study to be chiefly responsible for occasioning the admission of the patient into the hospital ("reason for hospitalization"),
- the condition treated during the hospitalization considered to be the most important in terms of clinical significance and resources consumed ("main condition"),
- the underlying cause of the condition that occasioned the patient's admission ("underlying cause") .

He noted many differences among countries in how discharge diagnosis is defined and used, who the users are, how the data are disseminated, and how they are tabulated, including the use of many different short lists. He also described the survey findings relating to definitions of single diagnosis, coding practices and data processing. The main survey conclusions were that: (1) the survey questionnaire had not been well understood by some respondents, (2) some countries had multiple uses and multiple databases with differing requirements, (3) there were variations between and within countries in the policies and procedures for coding and in the use of hospital discharge diagnoses, (4) some countries had no standard definition of single diagnosis, and (5) most countries used a national short list or different short lists for tabulation, while two countries used the ICD-10 short list.

Ms Greenberg presented a paper entitled *Designing a Minimum Basic Data Set for Hospital Discharges in the United States* (WHO/GPE/CAS/C/01.82). She described work in this area for the past 30 years, spearheaded by the National Committee on Vital and Health Statistics, and suggested that it might be useful for any international effort.

There was considerable discussion among the participants related to their own and other national experiences as well as to regional experiences with hospital discharge data sets, including quality and completeness of information and biases in coverage. Professor Smedby distributed a paper prepared as part of the European Union's Hospital Data Project. He described the difficulties in achieving comparability of diagnostic patient-level information from various countries. The differences encountered impacted the short lists and could be misleading in terms of analysis. It was noted that short lists need to be constructed to avoid problems with changes in the classifications. The secretariat emphasized the importance of having data for assessing the performance of health systems, specifically identifying variation in coverage of services, and including functional status as well as a consumer view.

The participants agreed that it would not be practical to consider developing a global minimum hospital data set. However, there was considerable interest in extending Dr Becker's work to compilation of a list of data sets being used in countries, the short lists applied, and relevant definitions (e.g. main diagnosis, hospital bed, discharge, etc.). Studying the differences in systems could identify other ways to achieve data comparability, for example through the application of diagnosis-related groups (DRGs).

It was agreed that work on this topic should continue. A small working group should be convened to work towards a short list for use with ICD-9/ICD-10. The group should put together an inventory of national hospital discharge data sets. In addition, it should set out some of the issues that relate to the international comparability of hospital morbidity data, share information about bridge coding, and solicit papers on these topics for next year's meeting.

The Nordic Centre agreed to chair the working group, which will have the development of its terms of reference as an early task. Interest to participate in the group was expressed by the Australian, North American and United Kingdom Centres as well as by PAHO.

Improving coordination of vital registration activities at the international and national levels: Options and best practices and other methods of ascertaining mortality and causes of death

Ms Ghislaine Villeneuve, Chair of this session, introduced the presentation by staff from the United Nations Statistics Division (UNSD), describing activities related to improving the coordination of birth and death registration for the production of vital statistics. Ms Alice Clague began the presentation, remarking that, in honour of the WHO Centre Heads meeting, she was providing the second revision of the publication *Principles and Recommendations for a Vital Statistics System*, which had been released the previous day.

Ms Clague gave an overview of UN activities in this area and described UNSD's 50-year history of compiling, processing and disseminating demographic statistics for all countries and areas of the world. The Division's work includes statistics on births, deaths and other vital events, and developing statistical instruments for improving national capacities in this field. It was noted that the world's knowledge is selective because of varied reporting practices, and that universality and coverage issues are critical elements. Ms Francesca Coullare described the work currently underway to obtain information on how countries evaluate the completeness of vital registration and on the actual level of vital statistics coverage for inclusion in subsequent issues of the UN Demographic Yearbook. Ms Violeta Gonzales-Diaz provided an insight of the activities conducted under the International Programme for Accelerating the Improvement of Vital Statistics and Civil Registration Systems, jointly developed by UNSD, WHO, UNFPA and the International Institute for Vital Registration in 1989 and implemented during the 1990s to enhance technical cooperation to countries in order to strengthen their systems and to facilitate national sustainability.

During the discussion, the secretariat commended UNSD on their work and the improved relations between WHO and UNSD. It was noted that coverage of vital statistics is a critical issue, and that WHO wanted to challenge the meeting to close the gap in coverage and reduce overlap. It was commented that vital statistics data provide local information and can give good quality cause of death data that can't be achieved with surveys. The UN was congratulated on continuing its efforts to improve vital statistics and civil registration when others, because of the complexities and difficulties involved in this area, have moved towards the use of surveys. Continuity of efforts in this direction was acknowledged to be key, but was noted to be an enormous undertaking that required coordination and collaboration at both the national and international levels.

A question was raised about whether resources should be used for coding data in situations where underreporting is high. It was emphasized that problems with the quality and quantity of data should not prevent people from using the data - using the data is the only way to improve it. It was noted that there are several regions in the world, such as Africa and Asia, where vital statistics data are inadequate. It was agreed that improvements in these regions are needed. There was consensus that the local infrastructure must be strengthened in such a way that country-specific as well as international needs are met.

Dr Richard Madden proposed that the Centre Heads develop a resolution to WHO in support of improving civil registration and vital statistics systems. This was agreed, and the resolution would be drafted and circulated to the Centre Heads during the remainder of the meeting. It would be submitted for finalization and adoption during the closing session.

Host Centre presentations

Ms Marjorie Greenberg, Chair of the session, opened by noting a few changes in the agenda. Because several authors of scientific papers were not able to attend the meeting, their papers would not be presented, and only three sessions would be needed for the scientific paper presentations. Therefore it was proposed and agreed that the fourth session of the day would be used to discuss the joint work plan.

As a background to the session, Ms Greenberg explained that the Host Centre had an opportunity to make presentations of interest to the group. This year's presentations would be made by both NCHS and CIHI staff regarding activities in the North American Center.

The first paper (WHO/GPE/CAS/C/01.89), presented by Ms Lisa Broitman of NCHS, provided an overview of a project that was started three years ago. Dr Edward Sondik initiated the plan to develop a *vision for health statistics the United States for the 21st century*. The project was launched with the Health and Human Services (HHS) Data Council as well as the National Committee on Vital and Health Statistics (NCVHS). Many hearings were held around the country, guided in part by the experience of Canada and other countries that had initiated similar projects.

It was noted that a final report is expected to be completed in 2002, and input from this meeting was encouraged. The goals of the project are to develop a vision for United States health statistics in the 21st century, to describe the elements needed to implement this vision, and to set clear criteria for evaluating the health statistics system and its components in the 21st century. Five phases were described: learning from the past and present, identifying themes and components, developing a final vision, drafting a final vision report, and planning in health statistics programmes.

A number of points were raised for discussion following the presentation. Dr Richard Madden offered to share the report of the Australian experience with the United States. Their experience included the development of a plan by NHIMG, endorsed in 1995 and revised in 1999.

Dr Üstün remarked on the WHO concept of stewardship that includes vision, intelligence and policy formulation. He asked whether the consumer side of the equation had been addressed in the United States vision. In response, it was remarked that this had been done at the local level, and that there had been efforts to incorporate consumers' perspectives in the hearings as well.

Dr Edward Sondik provided more details about the project. He noted that such a vision had not previously been articulated in the United States, that strengths and weaknesses in the health statistics system had been identified, and that health in the United States was well covered. However, various agencies publish data differently and in incompatible formats, such as age distributions in surveys. One criticism of the system was a lack of

coordination among agencies. Technology could help with this, but it must be balanced with confidentiality.

Dr Sondik remarked that no single agency in the United States was responsible for health statistics. While NCHS was the official federal agency, along with the census and labor statistics bureaus, many others collect statistics as well, including other components of the CDC and the National Institutes of Health (NIH). A framework therefore needed to be built to allow information to be available and used effectively. A road map and a clear vision on where to go over the next decade were needed. The events of 11 September pointed to the importance of this in terms of tracking sequelae. But the mechanism at present was imperfect. Dr Sondik concluded that he was excited to have the report nearing completion and a book in preparation. He encouraged input from this group through the NCHS website.

Ms Lois Fingerhut of NCHS made the next presentation on activities of the ICE on Injury Statistics (WHO/GPE/CAS/C/01.73). This group has been in existence since 1994, and an overview of the sponsors, purpose and goals of the ICE, as well as the framework, were presented. Ms Fingerhut indicated that work was being done to look at the relationship of ICECI to ICD. Work was also underway regarding compatibility in accordance with the ICD-10 matrix. She noted that multiple cause of death data are underutilized in the United States in the area of poisonings. This has been due to the problem with combinations of drugs in the codes. She gave an overview of the Barrell Injury Diagnosis Matrix, which uses the nature of injury and site of injury as its axes. The individual cells have ICD-9-CM codes in them. A new injury mortality matrix is being developed based on ICD-10 external cause codes. A website located on the NCHS website provides more information on these efforts, as well as the opportunity to join a list-serv (an e-mail list) to discuss these issues in detail with colleagues.

Discussion following the presentation included the suggestion to have a regular report to the Centre Heads on this activity. This work would require priority, and reporting back might help, not just in the classification work, but in the comprehensive work as well. Currently proceedings of the ICE are published on the NCHS website. They are also summarized in the annual report of the North American Collaborating Center. It was remarked that, although it would be easier to look at only the United States issues, work with international colleagues must also be undertaken or considerable information could be missed. Such international collaboration allows the United States to improve their data.

The final paper (WHO/GPE/CAS/C/01.74) submitted for this session was presented by Ms Lori Moskal of CIHI. She provided a brief overview of CIHI activities since the original mandate in 1994. Collaboration was the key, and meetings were held across the country to assess health information needs. There are sixteen databases in CIHI that are briefly described in the paper. Ms Moskal discussed the problems associated with the Provinces using different versions of ICD (ICD-9, ICD-9-CM and ICD-10-CA). She provided a brief description of CCI, the procedure classification for Canada. The goal of their publications is to have CIHI become a household name, with information readily

available to the public. One such effort involves publishing data from the CIHI database that compare regions and cities.

Discussion following this presentation included questions about the feedback received from the public on the government published data. It was stated that there had been varied responses, depending on how positive or negative a region or city had been represented in the publication. With each province being funded separately, there has been a new initiative to look at mortality data to ensure that funding is equitable across the country. There has also been a push to publish local and hospital level CIHI and survey data, as well as a new effort to bring national indicators to the local level. Discussions next year will involve the use of health indicators in allocating funds.

Discussion then shifted to the use of three different classifications at the same time in Canada as well as in Australia, and the associated problems when presenting statistics. This situation has existed in Canada for years. Conversion tables exist for ICD-9-CM back to ICD-9, as well as for ICD-10-CA back to ICD-9 and to ICD-9-CM. Australia had made the decision to map forward (ICD-9-CM to ICD-10-AM) rather than backward, and these are available on the Australian website.

Dr Üstün noted that all of the national modifications would be valuable in identifying the need for updates and modifications to ICD-10, as well as in the future work on ICD-11. It was agreed that a database was needed to identify all of the changes made in national modifications. This would allow other Centres to see the areas of change and to track data internationally. It was felt important to feed these national modifications to the URC in a systematic manner. In this way the URC members could review the modifications and recommend the same or different changes to be applied to the core classification. Within this context, it was noted that France has used ICD-10 for morbidity since 1996, with extensions at the 5th and 6th character.

Presentation and discussion of scientific papers

Mr Gérard Pavillon was Chair of the two sessions for the presentation and discussion of the scientific papers.

The role of classifications in assessing and improving the performance of health systems

The Australian Centre presented a paper (WHO/GPE/CAS/C/01.61) entitled *National information agreements, data dictionaries and quality health and welfare data*. This described the complex method of funding social services by the Commonwealth and State governments. To assist the development of data for reporting purposes, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare (AIHW) have signed four national information agreements. The agreements provide a structure and consultative mechanism to ensure that statistics available nationally are relevant, accurate, reliable and timely. The two data dictionaries for health and community services are compiled by AIHW. There is also a data dictionary on national

housing. Minimum data sets established under the health and housing agreements are obligatory for reporting. It is hoped that the national information agreements and the use of the data dictionaries and the AIHW knowledgebase will result in a more integrated system of health and welfare statistics in Australia.

Influence of DRGs on classification use

The North American Center provided details (WHO/GPE/CAS/C/01.72) of an annotated bibliography on the influence of DRGs and case-mix systems on classification use in the United States, and their impact on the quality of morbidity data. The bibliography includes studies published in the United States since the implementation in 1983 of the prospective payment system for inpatient acute care hospitals (IPPS). Discussion focused on coding experiences in other countries and the consequence of ICD-9-CM being embedded in the DRG system, thus making a transition to ICD-10 more difficult. The bibliography will be posted on the NCHS homepage and updated periodically.

Quality of mortality and morbidity data

Details of the *ICD-10-AM Community Mental Health Manual: A classification for mental and behavioural disorders with glossary descriptions and diagnostic guidelines* (WHO/GPE/CAS/C/01.34) were provided for information by the Australian Centre. It is hoped that the manual will provide a useful tool for community mental health clinicians and improve the quality and consistency of coded morbidity data across mental health services. The manual will be released in January 2002 and come into use in July 2002.

Two papers were presented on the implications for ICD-10 of the publication in December 2000 of the Third Edition of the International Classification of Diseases for Oncology (ICD-O-3). The paper by the Australian Centre (WHO/GPE/CAS/C/01.35) entitled *Inclusion of ICD-O-3 in ICD-10* provided details of how the morphology codes had been included in ICD-10-AM and how the ICD-O-3 changes in behaviour code had been accommodated within the structure of Chapter II. Australia is examining the possibility of replacing Chapter II of ICD-10-AM with the biaxial classification of tumour topography and morphology from ICD-O-3.

The secretariat presented a paper (WHO/GPE/CAS/C/01.40) detailing the changes in ICD-O-3. These include 220 new morphology codes, 378 new terms added to previously existing codes, 134 terms that changed morphology code, six terms that changed from tumour-like lesions to neoplasms, 14 terms that were deleted, and 29 terms that changed behaviour code. The paper proposed that there should be an in-depth review of each change and recommendations made as to whether the change should be included in ICD-10 and, if so, how this should be achieved. If all the changes to the classification were to be accepted, there would also be 732 changes to the alphabetical index. In discussion, the problem was also raised of comparability of data in those countries that use ICD-10 for hospital morbidity and ICD-O in cancer registries.

The North American Center presented a paper (WHO/GPE/CAS/C/01.79) on the classification of inborn errors of metabolism. This discussed the taxonomic issues that will undoubtedly arise as inborn errors of metabolism are found to be the underlying causes of existing diseases. For areas where knowledge is progressing quickly, this will require consideration as new codes are added or new terms are indexed. The update process for ICD-10 must be able to meet future needs and move forward with new advances. Considering these issues in detail at the national and international levels will be important, to enable such advances and ensure comparability over time. In discussing this important well-structured paper, participants preferred the approach of adding detail to the existing classification structure to identify inborn errors of metabolism, rather than moving these disorders to a single chapter.

Use of classifications in medical audit

The United Kingdom Centre presented a paper (WHO/GPE/CAS/C/01.83) entitled *The Role of Classifications in Medical Audit*. The paper gave details of an inquiry into the professional conduct of three doctors involved in the management of the care of children who received complex cardiac surgical care between 1984 and 1995 in a particular hospital. The inquiry used a comparison of key sources of statistical data concerning the nature and outcomes of paediatric cardiac services. The inquiry recognized the contribution that audit can make in improving the quality of care, and considered that it must be given the priority that it needs, and must be underpinned by systematic and reliable systems for collecting and analyzing information which have the confidence of health professionals.

Conversion from ICD-9 to ICD-10, including comparability factors

The Mexican Centre for the Classification of Diseases (CEMECE) presented a paper (WHO/GPE/CAS/C/01.86) entitled *Motor-vehicle Traffic Accidents in Mexico, Changes resulting from implementation of ICD-10*. Mexico implemented ICD-10 for mortality in 1998. Changes to the ICD-10 section for transport accidents had caused some discontinuity with section E810-E819 of ICD-9 which related to motor-vehicle traffic accidents. A number of cases that were classified to E810-E819 in ICD-9 were classified to V09.9 (Pedestrian injured in unspecified transport accident) and V89.2 (Person injured in unspecified motor-vehicle accident, traffic) in ICD-10. This highlighted the importance of selecting the appropriate ICD-10 codes when tabulating motor-vehicle traffic accidents for trend analyses. It was not felt to be appropriate to tabulate transport accidents as a group across revisions as this was not relevant for public health purposes. In discussion of the presentation of new information that included international comparisons, it was pointed out that such problems of continuity are inevitable when a too detailed classification is forced onto data where the required information does not exist. The suggestion was made that to overcome the problems identified in the Mexican paper, *land transport accidents* should be tabulated instead.

The North American Center presented a paper (WHO/GPE/CAS/C/01.77) on the comparability of causes of death between ICD-9 and ICD-10. All 1996 mortality records that had passed through the ACME/MICAR automated encoding software, plus about 14,000 manually-coded records, made a total of 1,852,671 records (about 80 per cent of the total deaths for the year) that were included in the study. The impact of the changes had been sufficient to affect leading causes of death. For some causes, such as cardiovascular disease, age-specific comparability ratios will need to be used. Comparability ratios will also be calculated at the state level. Final results are expected in mid-2002.

The Australian Centre presented a paper (WHO/GPE/CAS/C/01.59) entitled *Concordance and comparability factor information from Australia's ICD-9-CM/ICD-10-AM dual coded hospital morbidity data set*. This paper described a study using a small dual-coded data set to assist data users over the classification transition period, particularly in time-series analyses. The aim was to provide specific information that would be useful for hospital morbidity data-based population health indicators in the national health priority areas of cardiovascular disease, diabetes, injury, mental health and asthma, and on other reasons for admission to hospital where sufficient data are available.

Rehabilitation data

The Nordic Centre presented a paper (WHO/GPE/CAS/C/01.47) entitled *ICF as framework to improve patient discharge information - a study of patients with severe head injuries discharged from intensive rehabilitation care*. The main objective of the study was to improve the quality of information between health care and the social sector at the time of discharge. It was found that the definitions given on item level seem to meet the needs among the multidisciplinary team in order to create a uniform and meaningful terminology in the area of functioning. Difficulties in using the qualifiers have been identified and special coding conventions were designed for trial in this study. The suggested coding conventions in the ICF Final Draft were not considered to be applicable. The final outcome evaluation will be held at the end of 2002, and will include a systematic evaluation of the key points from the study protocol.

The Australian Centre presented a paper (WHO/GPE/CAS/C/01.56) entitled *Principal and additional diagnoses recorded using ICD-10-AM for rehabilitation episodes for admitted patients in Australian hospitals, 1999-00*. The study covered approximately 70,000 rehabilitation separations in public hospitals and 40,000 separations in private hospitals. The principal diagnoses were found not to be helpful in assessing the reason for care as they relate to the type of rehabilitation. Additional diagnoses provided a deeper insight, as they appear to have been either the underlying medical condition or other medical conditions relevant to the episode of care. Discussions are currently being held about a rehabilitation data collection that may eventually be integrated with the mainstream data collections for admitted patients. Hence, the opportunity may exist in the near future to review rehabilitation data collection with a view to making best use of ICD-based, ICF-based and other classifications for data collection.

A paper (WHO/GPE/CAS/C/01.79) on the possible application of the ICF in rehabilitation was presented by the Australian Centre. The information requirements for data collection in rehabilitation are different at each phase, but well encompassed by the ICF, especially for secondary and tertiary rehabilitation. The paper concludes that, together, ICD and ICF could provide a framework for rehabilitation data. It notes that the clarification and separation of the different concepts for which information about rehabilitation patients is required, and the clarification of the respective roles of the ICD and the ICF and other potential members of the WHO Family of International Classifications, are key next steps for a rehabilitation data collection. Tools are also required to assess the severity of disability across the full range of domains of the ICF. New rehabilitation tools, especially proprietary measures not widely available in the public domain, should be evaluated in the context of the ICD/ICF framework.

INTERCOD presentation

During a break in the scientific paper presentations, Dr Carlos Castillo-Salgado provided a demonstration of the INTERCOD software package. This is an automated coder training package that is self-instructional, and available in multiple languages. Considerable interest in the package was expressed by the participants, who appreciated seeing how the software works.

Final business sessions

Ms Marjorie Greenberg, Head of the Host Centre, chaired the final two sessions of the meeting. Prior to review of the joint work plan and the draft report of the meeting, she asked that issues not previously covered in plenary sessions, as well as any additional matters, be brought up for discussion and resolution.

Additional matters

Relative to **updating ICD-10**, it was noted that, although WHO is fully committed to this process, a clear written policy from the organization is needed. In addition, it is important that resources be identified at WHO and elsewhere to implement updates on a three-yearly basis and to monitor the update process. Collaborating Centres will take responsibility for their respective translations of updates.

The dissemination of ICD-10 was another issue requiring clarification, in particular its placement on the WHO website as a public good. The WHO secretariat agreed that this would be done.

The issue of disseminating ICD-10 updates was raised. Professor Rosemary Roberts indicated that updates could be posted on the Australian NCCH website and noted that major changes would be done on a three-yearly basis so that these changes could be tracked. Because the updates need to belong officially to WHO in order to be accepted worldwide, it was agreed that WHO would access the updates from the NCCH website and import them to their own website for wider dissemination.

Professor Roberts noted that much more needs to be done relative to the updating process and to mapping update changes. The plan for this year's process has already been set, and it will be evaluated next year. Other update issues needing consultation with WHO included inborn errors of metabolism, ICD-O-3, diabetes and injuries. A number of these issues require specialist consultation (i.e. major clinical area updates), for example, those relating to diabetes and injury.

The Expert Advisory Group and the role of the Centre Heads in this body were discussed. It was agreed that the name of the group would be changed to **Executive Advisory Group** (EAG), and it was clarified that there would be four representatives from CCs among its 12 members. The WHO secretariat requested nominations for EAG membership, including reasons for the nominations, by the end of November 2001. A short list of candidates will then be circulated. Topics to be considered by the EAG include a long-term vision for the classifications, education, financial implications and resources, information technology issues, implementation and coordination. The terms of reference for the group have been drafted. As an oversight function, the EAG will provide advice to WHO on all classifications and related matters.

Family obligations (of the Centres and of WHO) as raised over the course of the meeting were discussed. The Joint Work Plan should explicate these. A small working group on **hospital morbidity data** had been established. This group will review morbidity short tabulation lists that are currently used as well as hospital discharge minimum data sets, and will determine how better comparability of hospital morbidity data can be achieved. The working group is to be chaired by the Head of the Nordic Centre, with participation from PAHO and the North American, Australian and United Kingdom Centres. The working group could be convened on an *ad hoc* or a long-term basis, and this as well as its specific terms of reference will be determined.

Another morbidity group, the **URC Forum**, which had been functioning primarily within the confines of the URC membership, was also discussed. The URC Forum is an e-mail discussion group on morbidity classification issues that will become open to a wider range of participants (i.e. participants outside the URC). Because this forum was already functional, it was agreed that there is no need to pursue development of a morbidity clearinghouse.

The importance of a **morbidity meta-database** based on clinical modifications was reconfirmed. It was noted that this would be a resource-intensive task and would require additional funding. A teleconference will be held among key persons from the ETC, URC and WHO to discuss feasibility, scope and next steps. For the short term, it was agreed that piecemeal work would be continued by topic (e.g. diabetes mellitus). In this way one or two major areas could be completed each year. Professor Roberts will pursue this incremental approach with Dr Michael Schopen.

Dr Madden reported that the **family concept paper,** *Concept of the family of international classifications* (WHO/GPE/CAS/C/01.52), had been discussed during a session of the Family Development Committee and was generally endorsed. It was

agreed that the paper could be finalized, pending integration with the WHO secretariat's paper on the family (WHO/GPE/CAS/C/01.91), and then could be posted on the WHO website.

The meeting agreed that standards should be developed for mapping between terminologies (such as SNOMED) and the WHO classifications. The issue of accrediting such maps requires consideration.

Resolution on civil registration and vital statistics systems

A draft resolution to be sent to WHO from the Heads of the Collaborating Centres for the Family of International Classifications concerning civil registration and vital statistics systems had been discussed during previous sessions of the meeting. The final draft resolution[10] was carefully reviewed and approved as amended.

Adoption of the joint work plan

The draft WHO/WHO Collaborating Centres Joint Work Plan was critically reviewed. A number of suggestions for amendment were made and these will be incorporated into the plan during the week following the meeting. In particular, it was noted that all activities identified during the meeting are to be included in the work plan. The issues of terminologies and summary health measures were noted to be missing from the plan, and these are to be added under the quality assurance subcomponent. It was stressed that activities related to terminologies would require a coordinated approach, and that standards would need to be developed for mapping terminologies to classifications. The WHO secretariat indicated that this topic could have either e-mail or teleconference discussions as an approach to reaching third parties involved in terminologies.

It was decided that, after the meeting amendments had been made, the final draft of the work plan would be sent to Centre Heads, the WHO secretariat and relevant participants for their final review and comments. Hence, the Joint Work Plan was formally adopted by the Centre Heads, pending the amendments delineated at this meeting and pending final review by all concerned.

Adoption of the draft report of the meeting

The draft Report of the meeting was critically reviewed. A number of suggestions were made concerning the general layout and format of the report, as well as suggested amendments for particular sections. The draft report was adopted by the Centre Heads as amended, as recommended for amendment, and pending receipt of the additional sections to be rewritten.

Ms Greenberg reviewed the time frame for finalization of the Joint Work Plan and the Report of the meeting. She noted that final revised versions of both would be sent from

[10] The Resolution on Civil Registration and Vital Statistics is attached at Appendix 10.

WHO to the Centre Heads and other participants by the second week in November. Additional suggested amendments should be sent back to WHO by the end of November. If this schedule is met, the final documents would be available on the WHO website by the end of the year.

During discussion about the implementation of ICD-10, Dr Üstün had briefed participants about an upcoming meeting for WHO Representatives (WRs) to countries. He noted that such a forum would provide a useful opportunity to orient WRs to the work being done on classifications. He also noted that it may be beneficial to have members of the Centre Heads Planning Group attend this meeting.

Evaluation of the meeting

Ms Greenberg said that the North American Center had been honoured and thrilled to host this first meeting of the Heads of the WHO-FIC Collaborating Centres. She noted that the goal of the meeting evaluation discussion was to see how the process could be improved for future meetings. Because of the greater than usual number of participants, as well as the substantially increased number of papers, it was especially important to highlight where improvements could be made.

It was remarked that, because Centres now have three areas of work to cover (ICD for mortality, ICD for morbidity, and ICF), it would be helpful if there was no upper limit set for any one Collaborating Centre relative to the number of people attending the annual meetings. However, it was noted that it may be necessary to control the number of invitations sent to other than Centre or secretariat participants. It was agreed that the Host Centre, in conjunction with WHO Headquarters, would be the only party authorized to issue other invitations.

There was discussion about the need to limit the number of papers to be presented at future meetings, to ensure adequate time to discuss the papers and their implications. It was noted that the papers should be read by participants prior to their formal presentation, and that the Chair of the session should bring up specific discussion points when introducing a paper. It was also noted that only papers pertaining to the areas of work in the Joint Work Plan and that have key points for decision making should be presented, with the exception of the scientific paper sessions. The Centre Heads Planning Group will monitor the papers submitted and assess those to be presented accordingly. Poster sessions were mentioned as a possible alternative way for papers to be highlighted without actually being presented.

The need for papers to be circulated well in advance of the meeting was stressed. Papers that do not reach the secretariat by the specified deadline will be not be able to be presented. It was suggested that scientific papers for presentation could be limited to 20, preferably on multidisciplinary topics, and that these could be presented in plenary sessions on the Tuesday of the meeting. The Planning Group will work out the details for next year's scientific papers sessions and will ensure a good mix of papers on mortality, morbidity and functioning.

Participants were requested to send themes to be considered for next year's scientific papers to Dr Richard Madden, Head of the Centre hosting the 2002 meeting.

The increasing cost of conducting the annual meetings was discussed. Joint hosting of the meeting, as will be done by the Dutch and German Centres in 2003, is one way that individual Centres can try to reduce their costs. It was suggested that WHO could help subsidize, where necessary, countries who plan to host the annual meetings, and the secretariat agreed that this would be possible.

It had been agreed that the ICD and ICF Centres would continue to meet together on an annual basis. Because joint meetings require an additional number of concurrent sessions, it was noted that the Centre Heads Planning Group would need to be sensitive to this. The group will try to coordinate the sessions in such a way that Centre participants will be able to attend all of the sessions relevant to their areas of work.

The meeting participants recognized and expressed their appreciation for all of the scientific papers submitted for this meeting. It was noted that any papers not presented during this year's scientific discussions, depending on their relevance, could be updated and resubmitted for presentation at the 2002 meeting.

The meeting participants also expressed their appreciation to the rapporteurs for their tremendous efforts during the week. The rapporteurs for the meeting included Lynn Bracewell, Catherine Sykes, Cleone Rooney, Beth Fisher, Tyringa Ambrose, Lori Moskal, Barbara McLean, Jenny Hargreaves, Jerome Bickenbach, Jane Millar, Ching Choi, Donnamaria Pickett, Candace Longmire and André L'Hours.

Place, time, themes and agenda for the 2002 meeting

Dr Richard Madden briefed participants about the 2002 meeting of Centre Heads that will be held in Brisbane, Queensland, Australia from 13 to 19 October 2002. He also provided hotel and other useful information to the participants. As mentioned previously, participants have been requested to send suggested themes for scientific papers to Dr Madden.

Closing remarks

Dr Madden, on behalf of the participants, thanked the North American Center for hosting the meeting. He noted that it had been a memorable meeting in a memorable city. He invited everyone to Brisbane for the 2002 meeting. Ms Greenberg expressed her appreciation to everyone from the North American Host Centre and from WHO and PAHO for their support and hard work. Copies of the ICF signed by the participants were presented to Ms Greenberg and to Dr Üstün.

Appendix 1: Implementation of ICD-10 Committee

Chair: Dr Carlos Castillo-Salgado

The breakout session for this committee opened with a review of the status of ICD-10 implementation globally as well as by WHO Regions and for selected countries. Dr Castillo-Salgado noted that progress in implementation has been slow over the past several years, and cited lack of available human resources and weak political commitment as two of the primary contributing factors.

A number of discussion points were raised by participants during this session. Topics included the need for a definition of *implementation*; the need to differentiate between the various levels of implementation as well as between countries developing basic infrastructure versus those converting to ICD-10 from other versions of the ICD; the differences and overlaps in morbidity and mortality training needs, training materials and resources; the lack of resources for implementation (both funding for training and capacity building for trainers internationally); the lack of user-friendly briefing materials on the implementation process, and implementation differences for centralized versus decentralized systems and the difficulties of each.

In summary, the committee suggested that the following activities be considered by the Heads of Centres during their plenary session:

1. The term *implementation* should be *clearly defined*, with reference to the various levels of implementation at which countries may be.

2. The *status of implementation information* should be further clarified as to whether countries are at the basic level of implementation, or whether they have already implemented an earlier version of ICD and now would like to convert to ICD-10. Obtaining information about incentives for implementation could also be ascertained. Within this context, key persons should review the questionnaire used to obtain this information.

3. A *must do list/checklist* (essential steps) for countries should be developed relative to the implementation of ICD-10, using the Canadian and United Kingdom tools as examples.

4. A *roster of experts* should be developed and maintained, including information about the person's area(s) of expertise (morbidity, mortality, automated systems, etc.), his/her skill level, and his/her availability. This roster should be made readily available to all countries, and should facilitate matching the appropriate experts to countries requiring external assistance. WHO should provide assistance in linking relevant funders, appropriate experts, and countries. Also, an inventory of available training materials should be created.

5. The *continuation of the Implementation of ICD-10 Committee* is needed, but modifying the process of its ongoing functions should be considered, including the feasibility of functioning as a WHO website/web page which is continuously updated about available resources, status of implementation, etc.

6. A *new Chair* needs to be appointed for the Committee since PAHO/AMRO is no longer able to carry out this role. Another WHO Regional Office, WHO Headquarters or a Collaborating Centre may be considered for this role.

7. The PAHO *INTERCOD* multilingual self-training tools and the WHO multilingual ICD-10 CD-ROM should be made readily available for wide dissemination.

Appendix 2: Subgroup on Training and Credentialing

Chair: Ms Marjorie Greenberg

The breakout session of this subgroup was opened with a review of the work plan and what had been accomplished during the past year, with reference to the subgroup's annual report (WHO/GPE/CAS/C/01.78). The status of work on the *needs assessment survey for coders* in each country was discussed. It was reported that the questionnaires were finalized, but that circulation of the surveys had been delayed until appropriate translations could be done. It was noted that the questionnaires are rather long and that certain questions would not be relevant or not be able to be answered in some countries. It was decided that the questionnaires should stay as they are, and that national authorities should be directed to complete as many of the questions as possible.

It was suggested that the questionnaires for this survey could be routed from the Chair of the Subgroup to the appropriate WHO Regional Advisers and then on to their counterparts at country level. The counterparts could be responsible for completing the morbidity coding questionnaires, and could forward the mortality coding questionnaires to the appropriate government person. For countries in the Region of the Americas, PAHO will be responsible for translating the questionnaires into Spanish, French and Portuguese. The Portuguese version will be sent to the Sao Paolo Centre for review and the Spanish version to the Caracas Centre. These language versions of the surveys will also be made available to the AFRO Regional Office for distribution.

It was suggested that the *tables on training materials and capacity* compiled from the questionnaires on this subject be put on a website so that the information is readily available. NCHS volunteered to set up a website for this purpose. The NCHS site will be linked to WHO Headquarters, Regional Office and CC sites. Contact information for all sources of the training materials, along with consent of the sources, will be obtained so that people accessing the website will be able to contact the sources directly. NCHS (Ms Donna Glenn) will prepare a brochure about the training materials so that this information can be disseminated to persons not having ready access to the Internet. The secretariat will explore the publication of the brochure by WHO.

Issues involved in *coordinating ICD training activities along with those for ICF* were discussed. It was noted that CODE-ICF provides information about what ICF is and how to use it, but that more extensive guidelines are needed before a comprehensive training programme can be developed. These should include coding guidelines for more than survey applications, as well as a variety of case records as coding examples. WHO will work with the United Kingdom Centre to organize a meeting to discuss development of the guidelines.

It was agreed that this subgroup would liaise with the ICF group on training and credentialing matters. It was stressed that any draft coding guidelines should be sanctioned by WHO and that they should be field tested before being applied. It was noted that more specific coding guidelines and field experiences with applications are

needed before an international programme for ICF coding and credentialing can be established.

The subgroup did not plan any formal involvement in training in procedure coding.

Ms Kathy Brouch, a member of the International Federation of Health Records Organizations (IFHRO), was introduced to the participants as the IFHRO co-chair on the *joint IFHRO-CC working group for training and credentialing of clinical coders*. The second breakout session of the subgroup constituted the first meeting of the joint working group. Ms Brouch described the organization and functions of IFHRO, noting that it covers health information management issues in general, including coding. Their membership consists of national health record associations from around the world as well as individual memberships.

The present meeting of the joint working group will be reported in the next IFHRO newsletter. The North American Center volunteered to prepare a draft article about this collaboration. Ms Brouch agreed to forward issues of the IFHRO newsletter from January 2001 to all group members, along with other relevant documents on training and credentialing of morbidity coders. It is anticipated that this exchange of information would foster increased memberships in IFHRO as well as recruitment of IFHRO members to the Joint Working Group. Ms Brouch will also provide participants with website information for IFHRO and the American Health Information Management Association (AHIMA), so that they may access other relevant information on training and credentialing.

Ms Brouch provided information about the activities being considered and issues being discussed by the joint working group, including levels of credentialing. Information was shared by participants about the situations in various countries relative to mortality coding, and their needs for training and/or credentialing. It was noted that an international credentialing system would have to be responsive to both international and national needs, and to both manual and automated coding environments. Credentialing different levels of expertise was noted to be a possible incentive for career advancement for coders.

There was considerable discussion about defining the various levels for credentialing, what prerequisites were needed relative to clinical knowledge, etc., what terms should be used, and what core training in coding would be required. The need for a standard international curriculum was noted.

It was decided that a number of activities could be carried out soon in order to move this process along. These will be done relative to underlying cause mortality coding training and credentialing using three levels (entry/beginning, intermediate, advanced/nosologist), with reference to the possibility of a fourth or specialist level that includes informatics.

Ms Sue Walker of NCCH has begun work on the assessment of available training materials to identify core competencies and best practices. This work requires an assessment tool to be developed soon so that it can progress. Ms Brouch will work with Ms Walker on developing this tool and applying it to the English-language materials. The assessment tool will be forwarded to Dr Manuel Mosquera and Dr Rafael Lozano so that they can translate the instrument and apply it to the training materials available in Spanish. It will also be forwarded to other appropriate Centres for translation and application. Ms Walker and Ms Brouch will then be responsible for the overall analysis.

It was suggested that a background paper be prepared covering relevant definitions, skill and training levels, and critical functions of underlying cause mortality coders. The North American Center volunteered to draft this paper. The United Kingdom Centre volunteered to prepare a similar background paper for morbidity coders in preparation for future activities relative to their credentialing.

It was agreed that communication among the joint group members as well as much of the work of this group could be done primarily through e-mail and telephone conferences.

Appendix 3: Update Reference Committee (URC)

Chair: Professor Rosemary Roberts

Professor Roberts began the session with a review of the committee's *Annual Report* (WHO/GPE/CAS/C/01.26) that was approved as circulated. She noted that there have been improvements to the version control/update cycle. The session focused on a review of the work items and papers on the agenda. It was emphasized that there was a considerable amount of work to be done this year, and that decisions made at this meeting will reach WHO in time for the 2003 version update. The following papers were considered by the Committee: WHO/GPE/CAS/C/01.26 to 01.32, 01.62, 01.75 and 01.84.

The work of the URC has been accomplished to date via e-mail and the annual meetings of the Heads of Centres. Due to the vast difference in time zones and distance, teleconferences have been difficult to organize. The group agreed that the work of the URC should continue in this manner. The Mortality Reference Group (MRG), however, will continue to hold teleconferences. The excellent work of Ms Michelle Bramley was formally recognized, and due to the quality of this work, the URC may continue to function through the use of e-mail. This could change if the need arises.

Action: In regard to the table describing version control for ICD-10, it was agreed that another column would be added to the table indicating the year in which decisions are taken by Heads of Centres.

The WHO secretariat was asked for reassurance that the URC recommendations would be posted on the WHO website. The secretariat responded that each update must be put on the website in two official languages, English and French. The organization has been working on a CD for three years and every year the URC brings new updates. The French language version must be checked to ensure there are no discrepancies, but WHO agrees that the updates should be posted as soon as possible.

The Chair noted that there was an approved updating process in place, and that the barrier to prompt dissemination of the updates must be removed so the rest of the world would have access to the updates. There have been two hard copy ICD-10 versions available in the United Kingdom, the original ICD-10 and one with the 1998 updates printed within the publication. The 1999 updates have been approved by the URC and WHO. The Paris Centre is ready to help with translation when necessary, as users need assurance that they are receiving an official version in French. WHO will try to have this done within the expected time frame.

Implementation of URC recommendations made at previous meetings have been an issue for the last three to four years due to lack of resources at WHO. There is still no Internet version. There are many unresolved technical issues that make the production of an electronic version difficult.

A paper on updating ICD-10 (WHO/GPE/CAS/C/01.32) was presented. There was discussion about the issue of what steps need to be taken to receive WHO's sanction and to achieve dissemination of the changes approved by the URC (mortality/morbidity). The Nordic Centre noted that the secretariat had during this meeting already verbally agreed that WHO would sanction the work of the URC.

If the ICD-10 updating work of the URC was accepted as policy, there need to be enough resources for WHO to take URC recommendations forward. The secretariat's statement was appreciated, but written confirmation was required that indicates WHO's readiness to disseminate the recommendations. In an effort to decide how the URC might make this process work, it was suggested that the Collaborating Centres assist WHO by delegating the tasks of disseminating as well as maintaining updates to the URC secretariat.

Action: The URC will formally contact the WHO secretariat seeking written endorsement of support for the process of updating ICD-10. WHO agreed to include the 2000 changes on the updated CD-ROM, to be called ICD-10 2000.

Discussion ensued about changing the updating cycle to every five years to make it more practical. Another suggestion was to reduce the number of updates by not bringing forward issues that do not affect the integrity of the classification. (e.g. the use of the terms postoperative and post-procedural). It was suggested that minor changes could be corrected every three years along with the major changes. The Chair responded that the main issue is that all countries understand and interpret the classification the same way. The current plan, only three years old, has not been given a thorough trial.

Action: Leave the current recommendation and version cycle on the table. If it is found, after further trial, to be impractical, it can be revised at a later meeting.

Action: The Head of the United Kingdom Centre requested that the secretariat document the sequence of events and the work that needs to be done by WHO, and to indicate which functions might be shared.

A paper entitled *Development and dissemination of periodic updates to the Tenth Revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10)* (WHO/GPE/CAS/C/01.84) was presented. The secretariat reported that there is no mechanism in place to notify users that updates have been posted on the website. It was agreed that the cycle must be publicized. There was also a need identified to inform those responsible for developing specialty applications and those who hold licence agreements to modify ICD-10.

Discussion followed about the possibility of the URC secretariat helping with the dissemination of the updates. The WHO secretariat thought that the URC secretariat might post changes and the URC database on the NCCH website, with a link to the WHO website and web page relating to the corrigenda and update process. It was also suggested that perhaps only the major changes (every three years) need to be translated.

Actions:

- The URC will persevere with the existing plan.
- Minor changes will be posted on an annual cycle (to be reviewed).
- Only major changes will be translated.

Action: The URC secretariat will write a letter to the WHO secretariat seeking appropriate action that will include the second recommendation of paper WHO/GPE/CAS/C/01.32, i.e. "That WHO provide access, via this (URC) web page, to the database of URC work items (which records each work item of the URC, the progress of the work and the decisions made)." This may include transmission from the URC secretariat to WHO via web page link or other electronic means. WHO Headquarters will, in turn, notify the Regional Offices and Collaborating Centres about the changes, to avoid reprinting or purchasing of outdated versions.

The CD version has not yet been completed. It currently includes updates approved at the 1997 Heads of Centres meeting and is the official 1999 version of ICD-10. After discussion, it was agreed that the release of the CD will incorporate the 2000 updates and will be called ICD-10 2000.

Action: The release of the CD will be delayed so that all changes approved in 1998 may be incorporated. This CD will be titled *ICD-10 (2000)* and will be published in 2002.

Dissemination of the updates is still an issue. Updating tables is a concern as changes to ICD-10 impact other members of the WHO Family of Classifications. A translator will be required to track the changes from one version to another. Possible solutions were:

- Confine updates to every five years.
- Confine updates to electronic versions.
- Disseminate updates (addenda) in booklet format which could be produced every three years.

Action: It was agreed that WHO would publish an addenda in hard copy and electronic format every three years (at major update).

In response to an issue raised by the URC secretariat, it was agreed that WHO would give the URC secretariat access to international clinical consultants and organizations such as IARC so that compatibility can be ensured between URC decisions and work being done for other relevant publications such as ICD-O-3.

For paper WHO/GPE/CAS/C/01.31, *URC Worksheets including Recommendations for Updates to ICD-10,* **Section 1- Recommendations supported by the URC for inclusion in ICD-10 (2003)** - was proposed for ratification. Twenty-six (26) tabled work items had been discussed extensively and agreed via e-mail discussion. These work items were accepted.

Section 2- Recommendations to be discussed - Four (4) items were accepted, 1 was rejected and 1 was amended:
URC No. 0034: Decision: Inclusion at S76.1 should include mention of tendon
S76.1 Injury of quadriceps muscle and tendon
Patellar ligament (tendon)

URC No. 0046: Etiology manifestation compatibility between index and tabular listings
Decision: Accepted as circulated.

URC No. 0079: Anaemia in myelofibrosis
Decision: Follow United States and DIMDI's recommendation and use codes D47.1+ and D63.0*.

URC No. 0085: Splenosis
Decision: Splenosis is similar to endometriosis in that splenic tissue can be found elsewhere in the body. Splenosis will be classified to D73.8.

URC No. 0088: Health supervision and care of other healthy infant and child
Decision: Do not modify this code title. Infants or children that are not healthy should have other codes applied.

URC No. 0105: Conditions arising in the perinatal period
Decision: This proposal to add a new section to the index (as tabled) was approved. It could be included in the update booklets, but will require translation.

Action: The United States has this index in electronic format and will forward it to WHO.

Section 4 – Recommendations not supported or withdrawn
Accepted as circulated. Work items are withdrawn.

Section 3 – Recommendations to be held over and included in URC work for 2002
The MRG has requested that the URC look at four issues in this section.

URC No. 0104: Initial request was made to clarify instructions in Volume 2. Accepted.

URC No. 0106: MRG had concerns about the impact of automated coding. The following wording was developed in agreement with Japan: "The medical practitioner or other qualified certifier should use his or her clinical judgement in completing the medical certificate of cause of death. Automated systems must not include lists or other prompts to guide the certifier as these necessarily limit the range of diagnoses and therefore have an adverse effect on the accuracy and usefulness of the report."

URC No. 0108: Decision: Agreed.

URC No. 0109: Issue of clarification and applicability of the list
The list needs to have ambiguity removed to ensure international comparability and should be included as an appendix in Volume 2. A suggestion has been made by the Portuguese Centre to add *impetigo for infants over 1 year of age*. Decision: Agreed. Add the minor change for impetigo.

WHO Progress Report on the 2000 report
The following items have not yet been addressed: malignant neoplasm of corpus callosum, appendix testis, diabetes mellitus, mitochondrial disorders, organic mental disorders, reticulosarcoma, exclusion note for temporomandibular joint disorders, sacroiliac joint, ankylosing spondylitis, overactive bladder, sinus bradycardia, and organic personality disorder.

It was agreed that the URC secretariat and WHO would discuss the possibility of including some of these issues in the ongoing work of the URC with advice from WHO.

Paper WHO/GPE/CAS/C/01.62*, Issues in the frequency of updating classifications – the Australian experience*, was presented by Ms Jenny Hargreaves and was well received. Paper WHO/GPE/CAS/C/01.75*, WHO Update Reference Committee E-Mail Discussion Group*, was presented for information only.

NCHS presented a paper for information and feedback on external cause codes for acts of terrorism. It was pointed out that it would be very difficult to define terrorism as opposed to acts of war or homicide. The interpretation of the act may vary by country depending on the current political situation. The MRG will take these comments under advisement as the proposal is still under discussion in the United States.

Infection due to drug resistant microorganisms: It was agreed that the U code to be used for infection due to drug-resistant microorganisms should be clarified by the URC secretariat.

Appendix 4: Mortality Reference Group

Chair: Dr Harry Rosenberg

Dr Harry Rosenberg opened the meeting, noting that two members of the MRG were unable to attend, Mr Lars Age Johansson and Dr Michael Schopen. Documents were distributed for the group's reference, including the proposed agenda, which was approved. Ms Donna Glenn requested that input be provided on the causal table of what other diseases can be caused by peripheral vascular disease. Dr Cleo Rooney and Dr Susan Cole agreed to help her with this new agenda item, freeing up more group time. The following papers were by the committee: WHO/GPE/CAS/C/01.19, 01.20, 01.21 and 01.71. Dr Rosenberg had added a United States paper about a terrorism classification to the agenda.

Dr Hoyert reviewed the *WHO Mortality Reference Group Annual Report of WHO MRG* (WHO/GPE/CAS/C/01.71) She noted that the MRG had a highly-productive and busy third year; it had met four times by teleconference, communicated extensively by e-mail, done considerable work outside the committee meetings, and comprehensively documented its activities. During the third year, a total of 18 problems were reviewed by the MRG; a total of seven issues were decided, and eight decisions were forwarded to the URC for further action. Two additional issues were resolved after the year 2000-2001 recommendations were submitted to the URC, and one decision was subsequently withdrawn from the URC. At the time the annual report was prepared a total of 10 other issues were under active review, and additional issues were discussed at the Centre Heads' meeting (see below). The MRG report noted its concern about the timely and effective distribution of URC decisions, including those involving mortality coding and classification. The annual report was accepted as presented.

In Mr Johansson's absence, Dr Rosenberg reviewed the *Annual Report of the Mortality Forum* (WHO/GPE/CAS/C/01.19), pointing out that 329 questions from 19 countries had been received from December 1996 to June 2000. No submissions to the MRG were received from the summer of 2000 to the present due to the backlog of issues. It was agreed that the MRG is not designed to respond to coding questions quickly as desired by many practising coders. Coders with immediate concerns should call an appropriate person in their national office for a decision at that time so they can continue with their work. International advice is available through the two mortality forums in English and Spanish. The Latin American Forum has over 200 participants and interacts with the Mortality Forum, being especially helpful with idiomatic problems involving Spanish or Portuguese.

Dr Rosenberg also presented the paper (WHO/GPE/CAS/C/01.21) by Mr Johansson which addressed the need to speed up the work of the MRG. Mr Johansson suggested the development of smaller subgroups made up of members of the larger MRG. These subgroups could meet together face to face to discuss some of the coding problems and distribute a proposal among the group members for their responses. This idea was generally well received. Although Australian delegates expressed concerns about this

method because it limits valuable input from each region of the world, they stated that they would not object, given the current backlog, the need to resolve some of the many longstanding issues, and the opportunity to comment at the regular MRG meeting. Other suggestions were to have several different subgroups whose members were geographically located nearby or who had interest in a particular topic. Another possibility would be to rotate members of the subgroup to get a diversity of views. Concern was expressed about inhibiting the unity of the group by developing different layers with the addition of subgroups. It was noted that while there was merit to this overall suggestion, transport may be a problem and it would definitely need an organizer to pull it all together.

After review of the two formal papers, the MRG proceeded to its regular meeting agenda, beginning with a procedural item: because of problems in approving and commenting on MRG recommendations that had gone forward to the URC, a change in the MRG terms of reference was agreed upon, committing members and their Centres to support the recommendations of the MRG. Hopefully, this will promote consistency among group members and eliminate objections being raised after a proposal has been forwarded to the URC.

Information was distributed outlining proposed codes for a new ICD-10 category for terrorism, developed by the United States National Center for Health Statistics, to facilitate statistical tabulation and analysis. This suggestion stems from the events in the United States of 11 September 2001. It was noted that some countries have such codes while others, experiencing such activities, find the existing homicide codes adequate. It was ultimately felt that the proposed terrorism codes were difficult to endorse on an international basis , because different countries have varying definitions of the term *terrorism*. Sometimes a terrorist event could be interpreted as a war operation or insurrection and may be coded as such, or it could be reported as a homicide. (In the subsequent URC meeting, the secretariat suggested that if the United States introduced such codes, they be placed in the U chapter rather than in the main classification, and that they be used as supplementary codes (multiple causes) rather than as the underlying cause of death.) It was noted that the date and place of death could be isolated statistically to identify terrorist deaths.

Ms Wood and Ms Raynor presented a rewrite of the Trivial conditions Rule from Volume 2 to make the ICD-10 rule more consistent with the ICD-9 rule. There had been concern that the wording of this rule would cause it to be used more in the 10th Revision than in the 9th. This revision clarifies important issues such as providing a definition for *more serious condition*, and noting that when a trivial condition causes any other condition, Rule B does not apply. Because some members had been struggling with just these types of issues, the rewrite was gratefully accepted by the group.

At a previous meeting, Dr Susan Cole had ambitiously offered to assign postoperative codes but ran into many problems in doing so. For example, abscess contains four columns of codes assigned by site. Because the code assignments also need to be

programmable, Ms Donna Glenn will work with her on terms that will be less specific and more general. The end result may be more practical than ideal.
The group spent some time looking at maternal issues, one of which was the question of whether external causes should be included as maternal deaths. Ms Tanya Pitts and Ms Julia Raynor agreed to work with Dr Susan Cole on items that needed a nosologist's input. With respect to the recommendations of the WHO Family and Community Health Cluster on maternal mortality presented at the 2000 meeting of Centre Heads, objection had been expressed from the Brazilian Center regarding use of the term *pregnancy-related death* and *pregnancy-associated death*. The group agreed on a reasonable definition, i.e. *deaths occurring during pregnancy or puerperal period*, but did not come up with an agreeable substitute for the objectionable terms.

The group agreed to a second meeting in order to take advantage of the rare opportunity to meet face to face. By the close of the meeting, 17 people were in attendance, including Mr Lars Age Johansson, participating by telephone. The group was able to look at 7 of the 13 possible discussion items from the agenda.

The first item of discussion involved the ambiguous use of the term *newborn*. The group agreed that neither "transient" nor "transitory" would be used with newborn codes because these are morbidity terms. Either a general note will be added to Volume 2 or a note will be added at each category affected by this concept. Ms Donna Glenn will provide Dr Susan Cole with a list of terms having "transient" in them for her to see the type of documentation that would be most appropriate. Dr Roberto Becker will work with her on this as well.

Another issue concerned the use of the terms *newborn*, *perinatal* and *neonatal*. After much discussion, the participant who had originally raised this issue felt his concern had been sufficiently addressed.

There was concern involving two conditions in Volume 1 that seem to be mutually exclusive - K56 and P76. The group accepted a proposal from Dr Susan Cole to move the exclusion to the four-character level, thus eliminating the confusion. A proposal to clarify the highly improbable guideline regarding cerebrovascular diseases due to digestive diseases or endocarditis was reviewed. Mr Johansson will review his research notes to determine why intracranial haemorrhage was not mentioned in the revision and communicate with Ms Julia Raynor on this. This topic will be resolved at the next meeting.

Concern was expressed regarding the term *circulatory insufficiency* versus *peripheral circulatory insufficiency*. It seemed illogical for the general term to be coded to I99 and then the very similar but more specific term to be assigned to R579, an ill-defined category. When the group was reminded that a previous MRG decision had made I99 ill-defined as well, it was recognized that this proposal was actually no longer an issue.

There seemed to be differences of opinion regarding the coding of multiple valvular diseases. When caused by a non-rheumatic condition such as arteriosclerosis or diabetes,

should they remain in the rheumatic category or become non-rheumatic based on their origin? Dr Cleo Rooney agreed to work on the Volume 1 notes to clarify this issue. Ms Donna Glenn will provide her with codes representing valvular diseases.

Maternal conditions were further discussed during the meeting. Mr Johansson was advised that, based on the previous discussion this week, the exclusion notes in Volume 1 for O categories were to be used as a guide for determining which conditions would not receive a maternal code. The group also agreed to leave ICD-10 as is for maternal mortality definitions and not make the changes suggested by the WHO Family and Community Health Cluster. A proposed morbidity code to cover sequelae of direct and indirect obstetric causes (O94) was reviewed by the group and it was generally felt to be irrelevant for our purposes. The MRG feels that this proposal has no impact on mortality coding and Volume 2 of ICD-10. The MRG agrees with the secretariat that the title needs to be modified to clearly indicate that it is not to be used for underlying cause coding.

A discussion about the reduction in the number of SIDS cases revealed that the decrease may be due to changes in reporting. One example would be more thorough postmortem exams that offer a better diagnosis. The group did not support a proposal, submitted by Dr. Hanzlick, representing a United States SIDS Diagnosis Work Team of a federally-sponsored SIDS and Infant Death Support Program, to interpret certain types of reporting as SIDS deaths. A reply letter needs to be drafted and reviewed by the group.

Appendix 5: Electronic Tools Committee (ETC)

Acting Chair: Mr Gérard Pavillon

In the absence of Dr Michael Schopen, Mr Gérard Pavillon chaired this third meeting of the Electronic Tools Committee. Six papers were submitted for review. However, papers WHO/GPE/CAS/C/01.22 *(Consistency Checks for the Maintenance of ICD-10)* and WHO/GPE/CAS/C/01.25 *(ICD-10 and the Unified Medical Language System (UMLS))* by DIMDI were not presented because the author was not able to attend the meeting. The Committee considered the following papers: WHO/GPE/CAS/C/01.23, 01.24, 01.63 and 01.65.

Mr Pavillon presented *The Annual Report of the Electronic Tools Committee* (WHO/GPE/CAS/C/01.24). The tasks for the year 2001 listed in the work plan of the committee had been completed, with the exception of the collection of material from Collaborating Centres on electronic versions of ICD-10. Concerning the electronic version of ICD-10, the recommendations in the annual report had been adopted last year in Rio by the Heads of Centres. These recommended that WHO and the CCs collaborate to produce and disseminate updated versions of ICD-10 through the Internet in accessible and downloadable form. It did not appear that these recommendations were fully implemented. Participants mentioned the importance of this project for the ICD-10 update process and reaffirmed these recommendations for 2002.

A paper entitled *Mortality and Morbidity Data Dissemination Via Interactive Data Cubes – a new initiative* (WHO/GPE/CAS/C/01.63), was presented by the Australian Centre. This paper presented a system for analyzing mortality and morbidity data via data cubes. The software for the morbidity data allows the user to present large amounts of data in various forms, and includes basic information on the ICD-10-AM (Australian Modification) classification.

The North American Center presented a paper entitled *Developing a Database Version of the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Clinical Modifications (ICD-10-CM)* (WHO/GPE/CAS/C/01.65). This paper addressed the development of an ICD-10 database. This database will allow updating, editing, and querying of ICD-10-CM. In addition, export in various formats would also be possible.

Mr Pavillon presented a paper entitled *Dissemination Policies for ICD-10* (WHO/GPE/CAS/C/01.23), prepared by DIMDI This paper was written to promote discussion on dissemination policies for the ICD-10 electronic version and to recommend a strategy to WHO. The paper examined three scenarios for ICD-10 electronic dissemination and puts forward three recommendations. After extensive discussion, the committee proposed the following ***recommendations*** to be adopted by the Heads of Centres:

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

2. ICD-10 versions should be available in electronic formats suitable for data processing or integration into computer applications for generating income for WHO.

3. To comply with the World Health Assembly policy on updating of the classification, it is recommended that resources generated by the sale of the products referred to in Recommendation #2 should be deployed for the development of content and format of ICD-10.

In addition, participants agreed that it was essential to the updating process that an evaluation of alternative technologies for ICD-10 database management be conducted as soon as possible.

Appendix 6: International Classification of Functioning, Disability and Health

Chair: Dr Marijke de Kleijn de-Vrankrijker

The breakout sessions on the ICF were chaired by Dr Marijke de Kleijn de-Vrankrijker. The aim of the sessions was to identify what future actions need to be taken, who is the responsible party for each, and the time frame within which the activities are to be carried out. A number of papers (WHO/GPE/CAS/C/01.55, 01.60, 01.64, 01.67, 01.68, 01.70, 01.87 and 01.93) addressing ICF issues were presented. Two annual reports (WHO/GPE/CAS/C/01.66 and 01.95), while not presented, were used for reference. These papers, together with documents on the eight key activity areas, including WHO/GPE/CAS/C/01.41, provided the basis for discussion. For each of the eight main areas addressed, presentations and discussions were directed to the issues to be addressed, an inventory of actions to be taken, the parties involved in the work, and other relevant issues.

1. Coding guidelines

Issues were raised relative to further refinement of the existing guidelines (e.g. capacity and performance, standard environment, and qualifiers), the identification of short and long-term changes based on empirical evidence, the assurance of international comparability, ensuring the integrity of the ICF, and consideration of user-specific needs.

It was noted that coding guidelines should be as complete and detailed as necessary. WHO will convene a discussion group on specific coding issues prior to any amendments/enhancements of the existing coding guidelines. Examples for coding will also be reviewed by WHO. It was agreed that WHO and the United Kingdom Collaborating Centre would work out a plan of action for this topic to be circulated to the Centres by e-mail for comment, and consequently, if the need arises, a meeting may be organized in Geneva.

2. Implementation

The need to monitor the use of the ICF by both WHO and the Collaborating Centres, the need to monitor the use of options 1-4 for the activity and participation (A&P) dimensions, the recognition of coding guidelines and user guides as integral parts of implementation, and the need for indexing guidelines were the primary issues discussed.

WHO will report on the different ways the A&P dimensions are used, as they receive such information from countries. WHO will report data using the most, or lowest, common option. Indexing guidelines will be provided by WHO, and country data on the use of the options will be posted on the ICF website. It was agreed that the first step regarding indexing should be to cross reference items (language specific), and that step two would be to develop a substantive index. Comparability of data was an issue that will continue to be discussed at future meetings, including the meeting in April 2002 in Trieste, Italy. The recent report on Classifying and Reporting Functional Status by the United States National Committee on Vital and Health Statistics was noted as a positive example of activities fostering implementation.

3. Training, outreach and dissemination

Issues raised during the discussion included the need for appropriate training to ensure effective implementation, and the considerable resources that will be required for training. The need to avoid duplication of efforts was noted. Within this context, the use and exchange of information on training tools (e.g. CODE-ICF and the Australian User Guide) were emphasized. The need for basic as well as user-specific materials was also expressed. Principles for ICF training are to be established and a training plan will be developed. Specific activities will be to post educational materials on the WHO website, to circulate the outline of CODE-ICF among the Collaborating Centres and WHO, and to establish a working group addressing training principles, an inventory of training needs, a catalogue of existing materials and, as a result, an educational plan. This group will liaise with the Subgroup on Training and Credentialing.

Over 20 interviews with meeting participants were videotaped by Ms Debra Farmer. Topics for the interviews included the role of WHO Collaborating Centres for the Family of International Classifications in dissemination, the need for training various professions in use of the classifications, applications of the classifications in clinical, survey, policy and programme work, and how the ICF will benefit consumers. The interview tapes will be used in developing ICF training materials.

4. ICF adaptations for specific purposes

Some confusion was expressed about the word *adaptation*. It was clarified that an adaptation is a *derived* classification (i.e. fully mappable back to the parent classification), rather than a *related* classification (i.e. modified and used for different purposes). Examples to clarify this discussion were that an adaptation would be done for children and youth, while a related product would be developed for rehabilitation terminology. The development of adaptations is to be coordinated and approved by WHO.

It was noted that country and discipline specific ICF adaptations would not be encouraged at this stage. The focus of work in this area would be the development of core sets and criteria for adaptation. Information on core sets and adaptations will be exchanged through WHO, and WHO will coordinate criteria development. The United Kingdom Collaborating Centre will share information on criteria that exist in the United Kingdom.

5. Measurement

The development and use of instruments, the need for mapping existing instruments to the ICF, the need for information exchange, the development of WHO-DAS, and the status of the ICF checklist were topics raised during the discussion. It was noted that WHO will post information sent from the Collaborating Centres on its ICF website. The work of the United Nations Statistics Division's *City Group* on disability measurement needs to be linked with WHO. WHO will provide guidance on how to map existing instruments to the ICF and will update information on WHO-DAS and WHO survey

instruments. The new checklist is already on the website and is being used by several countries, including Germany and Italy.

6. The use of ICD and ICF together

The importance was noted of identifying commonalities between the two classifications, defining components in order to clarify differences, and reviewing *same* concepts with different levels of granularity. It was recognized that using the classifications together is important. The need for national guidance (for example coding guidelines) and the use of field experiences were also noted. The Family Development Committee will follow up these issues in consultation with ICF experts.

7. Maintenance and update process

Issues raised included the need for a systematic updating mechanism, the importance of stability of the classification, and the recognition that there must be a distinction between minor and major changes. The issues of updates being reflected in training materials and of keeping the ICF aligned with current terminology were also addressed. Terminology owners and producers will link with the custodians to which they are mapping.

It was noted that the ICF and the ICD were at different stages of development, and that their updating processes would therefore be different. There will need to be a gradual approach for ICF updates and a need to wait to see what types of updates are required. Information on update requirements should be obtained and evaluated before determining any necessary changes. WHO will produce a draft paper on the updating mechanism and will discuss this with Centres (via e-mail and at future meetings).

8. Organizational issues

The need for efficient coordination of meetings, activities and resources was emphasized. It was agreed that annual, joint meetings of ICF with ICD were best at present. However, it was suggested that there may be a need to hold decision/policy making meetings separately. It was also agreed that there should be a balance between the business and scientific sessions in the meetings, but that the limited time accorded to scientific discussion was a constraint within the joint forum. This situation was recognized by WHO. It was also recognized that there is a need for generating resources for ICF work. It was agreed that future meetings would build on the experience of previous ones, and that efforts would be made to work more effectively between meetings, and through the use of existing and *ad hoc* work groups (e.g. guidelines and training). There was a proposal initiated by Japan that there be an *ad hoc* study group for the subjective dimensions of functioning.

9. Additional issues

In addition to the above eight key activity areas, a few other issues were also addressed. These included the need for periodic updates of the WHO website, and for precise conditions and technical guidelines to be clearly specified in translation rights agreements with WHO. The Nordic Centre paper on terminology, and the WHO response on how this will be taken into account, will be circulated among the Centres.

Appendix 7: Draft list of criteria for evaluating potential international classifications of health interventions

- A classification for use in developing countries should not be too complex.
- It should be possible to make a short/sentinel list.
- It should meet the requirements of international reporting.
- Other classifications in use should be able to map to the preferred reporting categories.
- It should be decided whether to limit the classification to surgical procedures or include all health interventions.
- An index is essential.
- It should be relatively easy to update and insert new codes.
- Translations should be done.
- The level of detail of medically-oriented and non-medical health interventions should be similar.
- All possible procedures should be able to fit within the limited number of classes.
- It should be easy to use without technology.
- There should be a maximum of 400 reporting classes.
- It should be a low maintenance classification.

Appendix 8: Presentations and discussions on automated coding systems for mortality

Ms Donna Glenn presented a response to the paper by Mr Lars Age Johansson entitled *Automated versus manual selection of the underlying cause: Differences between ACME and Swedish manual underlying cause coding* (WHO/GPE/CAS/C/01.18). In the background section of the paper, it was noted that Sweden began using the ACME system with ICD-9 in 1987. During the time that the ICD-9 ACME was used, the decision tables were modified to reflect Swedish coding practices. ICD-10 was implemented in Sweden in 1997. In the interest of international comparability, Sweden decided not to make any national modifications to the decisions tables. At the same time, NCHS expressed willingness to review the decision tables in cooperation with international users. The Swedish paper presented 22 examples of differences between Swedish manual coding and the ACME system.

All of these examples were reviewed. Eleven (11) of the 22 were caused by omissions in the 2001 ACME decision tables which have been incorporated into the 2002 version. Two (2) were withdrawn as potential changes. The remaining nine examples have been referred to the Mortality Reference Group (MRG) for adjudication. Items requiring further discussion were generally related to:

1. Cases where there is a difference of opinion regarding the causal relationship between diseases.
2. Cases where there is a difference of opinion regarding linkages. It was noted that NCHS only uses linkages provided for in the ICD, i.e. linkages are not created. Where additional linkages may be desirable, the MRG is asked to determine if a new linkage should be created within the ICD.

Both NCHS and Sweden agree that the longstanding use of the ACME system has influenced the interpretation of the ICD rules and guidelines. Therefore, NCHS urged more countries that are still using manual coding to submit records for adjudication by NCHS.

On an ongoing basis, the ACME decision tables are only updated once a year, while MICAR and SuperMICAR are updated no more than three times a year. However, when serious errors that affect the underlying cause of death coding are uncovered in these programs, a corrected version is released with the recommendation that users reprocess all data affected by the previous program. In the year 2000, there were six updates made to correct errors. In 2001, only two versions of the programs have been released. In 2002, it is hoped that NCHS will release system updates on the planned schedule without the need for intermittent versions to correct serious errors.

Users of the United States Mortality Medical Data System (MDDS) that includes SuperMICAR, MICAR, ACME and TRANSAX are encouraged to send questions to Ms Donna Glenn. A response will be prepared as quickly as possible. Any disagreements with the table will be referred to the MRG for adjudication.

Discussion points following the presentation included the fact that the ACME decision tables are a standard. They represent a powerful and useful tool for the international comparability of mortality data and allow more consistent data over time. A question was raised as to whether the 2001 ACME system included the new version of Rule 3 for pneumonia. It was clarified that when the 2001 (Direct Sequel) tables for pneumonia were developed, if another rule such as linkage or specificity was applicable, this was taken into consideration. However, the 2002 tables reflect the implementation of Rule 3 as revised.

Paper WHO/GPE/CAS/C/01.76 discussed the automated coding system used in Japan for fetal deaths. It presents an overview of the organization of vital statistics in Japan, where there is a specific death certificate for fetal deaths. Coding rules are inferred from the ICD-10 guidelines and through the study of individual cases. Multiple causes of death are coded including both maternal and fetal conditions.

Participants noted that this work was very interesting, and requested that a presentation of the results be provided at next year's Centre Heads meeting.

Dr Ari Miniño presented a paper (WHO/GPE/CAS/C/01.80) that summarized results of the survey of automated systems for coding causes of death. The intent was to give an account of the use of automated coding systems globally.

During discussion following the presentation, it was noted that this had been a necessary and comprehensive survey, and that it had provided a good picture of global use of automated coding systems. It was agreed that selecting cause with the tables is a complex problem which was compounded by language differences. Communication in areas not represented in the survey needs to be addressed further. This was noted to be harder to do in some areas. There had been some communication with countries that have been training in the United States and some countries that have established communication with the United States. It was noted that this could be worked on further. In addition, it was noted that some other users of ACME are also required to assist with the training, and that new trainees are needed for the international training courses.

It was stressed that, although automated coding systems may reduce the number of staff required to code causes of death, it is important to have these staff trained to a higher level. The remaining coders must be able to guide and direct the implementation and improvement of automated coding systems.

The training course conducted by NCHS for international participants is designed to *train the trainers* so that each country has the capacity to prepare its own courses. In 2001, the following schedule was used:

- Multiple cause coding (3 weeks)
- Software PC managers (optional, 1 week)
- Underlying cause coding, including a session on the use of ICD-10 for statisticians (3 weeks)

There were breaks between the multiple cause training and underlying cause training to allow trainees to determine how best to use the material provided and whether to continue with the next session. The optional PC Managers seminar has been offered after each three week session.

Coding of external causes is difficult and there will usually be differences due to how each country investigates those causes. Hence it is difficult to develop coding standards for external causes. However, because these causes represent a relatively low percentage of total deaths, they do not substantially affect the statistics.

The final paper (WHO/GPE/CAS/C/01.81), presented by Mr Gérard Pavillon, described a European project funded by the Statistical Office of the European Community (EUROSTAT). This project deals with the development of tools of common interest in the field of automated coding systems.

Appendix 9: Presentation on SNOMED

Presenters: Dr Diane Aschman
Ms Margo Blakemore

Dr Aschman thanked the meeting for the opportunity to make the presentation and began by noting that she would describe how SNOMED and its mapping to ICD could be used to meet data analysis challenges. She noted that, in the ideal world, clinical data would be captured once, and then be available for multiple uses, requiring flexibility of expression, interoperability in electronic messages, specificity suited to care management, and collapsibility for billing and statistical reporting purposes. During the presentation and discussion, she reported that SNOMED:

- is a concept-based reference terminology with multiple levels of granularity.
- is currently being developed as SNOMED-CT in collaboration with the United Kingdom's National Health Service, incorporating the latter's clinical terms (formerly the Read codes), and is to be released in January 2002.
- has a broad content encompassing about 300,000 terms.
- has a structure which means that terms can be the children of multiple families (for example, *pneumonia in anthrax* is a child of *anthrax* and of *bacterial pneumonia*), and have multiple other relationships (for example, *has topography of*, *has morphology of* and *has cause*).
- allows for data retrieval for a range of purposes based on any of these computer readable relationships or links.
- does not include NOS or NEC categories, with higher levels in the hierarchies available to be used when sufficient information is not available to assign specific codes.
- allows for the use of multiple synonyms for terms, but analysis of a concept accessible using any synonym.
- can cross geographical/language barriers due to its use of codes but, as yet, is only being translated into Spanish.
- can be used for case finding, possibly more efficiently than the ICD.

Dr Aschman also described the work on mapping from SNOMED to the ICD, undertaken in recognition of the continuing need for classifications for statistical reporting and billing purposes, and the need to present the data in mutually-exclusive categories for these purposes. Maps had been undertaken for ICD-9-CM and ICD-O (V2), and are being developed for ICD-10. In addition, some alpha testing (assessing structures) had been undertaken with ICD-10-AM. The maps have been to codes (not index terms), have been designed to be flexible, and have been categorized in terms of specificity and priority for manual consideration. The need for complex maps, for example requiring *qualifying* concepts, had been identified, but was not currently being met. Such complex maps would need to be developed for fully-automated mapping. The maps to ICD-9-CM were currently being evaluated in a remapping exercise being undertaken by AHIMA.

Appendix 10: UN Resolution

RESOLUTION ON CIVIL REGISTRATION AND VITAL STATISTICS

The Heads of Collaborating Centres for the WHO Family of International Classifications have a broad interest in promoting and developing internationally comparable health statistics. Good quality information on the health of the population of Member States compiled by United Nations and other international bodies is essential for policy development and resource distribution.

A reliable flow of information on births and deaths is an essential component of health statistics. The Centre Heads welcomed a presentation on UN efforts to improve vital statistics, and the civil registration systems that underpin them, at their meeting in Bethesda, MD, USA on 25th October 2001.

The Centre Heads resolved to advise WHO of their views on the crucial importance of reliable, timely and internationally consistent vital statistics, and to ask the WHO to advise the UN Statistical Commission of their position. Centre Heads agreed to advise their respective national statistical agencies of their position, and to urge the agencies to pursue the issue of improved vital statistics through the UN Statistical Commission.

Centre Heads recommend that:

1. Reliable, timely and internationally consistent statistics on births and deaths (vital statistics) are an essential component of information needed to promote soundly based policy development and resource distribution.

2. Complete registration of births and deaths is essential for the production of national birth and mortality statistics. Demographic surveys can be a useful complement to national vital statistics but are not a substitute for a complete vital registration system.

3. Mortality statistics should include cause of death coded and classified according to ICD-10. WHO and Collaborating Centres will make every effort to assist countries to implement ICD-10 for mortality.

4. Centre Heads commended the efforts to date of the UN Statistical Division, regional commissions and the United Nations Population Fund to assist the registration and vital statistics activities in countries, and noted that further work is needed in many countries. Centre Heads also noted the need for readily available training material, for technical assistance to countries (including resources for development in the country), and for the development of appropriate systems to monitor quality.

5. Centre Heads requested the UN Statistics Division to provide an update on progress in the development of national civil registration and vital statistics systems to the annual Collaborating Centre meetings.

Appendix 11: Action summary

Secretariat

Provide logistical and financial support to countries for the implementation of ICD-10 with the support of the Subgroup on Training and Credentialing (Regional Offices).

Develop a clear policy on posting and disseminating updates, and providing information and advice to Regional Offices in support of ICD use by countries. Create a page on the WHO website, or a link from it to a website maintained by one of the Collaborating Centres, to provide immediate access to the database of changes approved by the URC and MRG.

Establish a roster of international specialist clinical advisory groups who can advise the Update Reference Committee so that compatibility can be ensured between URC decisions and work being done for other relevant publications such as ICD-O-3.

Make the PAHO INTERCOD multilingual self-training tools and the WHO multilingual ICD-10 CD-ROM readily available for wide dissemination.

Explore the possibility of publishing a brochure on training materials.

Work with the United Kingdom Centre to organize a meeting to discuss the development of coding guidelines for ICF.

Collaborate with the CCs to produce and disseminate updated versions of ICD-10 through the Internet in accessible and down-loadable form.

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

Make ICD versions available in electronic formats suitable for data processing or integration into computer applications for generating income for WHO.

Conduct an evaluation of alternative technologies for ICD-10 database management as soon as possible.

Include the 2000 changes on the updated CD-ROM so that it will be called ICD-10 2000.

Document the sequence of events and the work that needs to be done by WHO in relation to the dissemination of updates to ICD-10 and indicate which functions might be shared.

Notify the Regional Offices, Collaborating Centres and other interested parties about the updates to ICD-10 to avoid reprinting or purchasing of outdated versions.

Devise a methodology for tracking changes from one version of ICD-10 to another.

Publish an addendum to ICD-10 in hard copy and electronic format every three years (at major update).

Convene a discussion group on specific ICF coding issues prior to any amendments/enhancements of the existing coding guidelines. WHO and the United Kingdom Collaborating Centre will work out a plan of action for this topic to be circulated to the Centres by e-mail for comment.

Report on the different ways the A&P dimensions of ICF are used, as information is received from countries. Report data using the most, or lowest, common option. Provide indexing guidelines, and post country data on the use of the options on the ICF website.

Provide guidance on how to map existing instruments to ICF and update information on WHO-DAS and WHO survey instruments.

Produce a draft paper on the updating mechanism for ICF and discuss this with Centres (via e-mail and at the Italy meeting).

Post the final report of the meeting on the WHO website by 28 December 2001.

Implementation of ICD-10 Committee

Keep information on implementation up to date through a periodic questionnaire that should include information on whether tabulations are published nationally or for particular geographic or economic sectors, and also whether the country has bridged the change from ICD-9.

Clearly define the term *implementation*, with reference to the various levels of implementation at which countries may be.

Develop a *must do* list/checklist (essential steps) for countries relative to the implementation of ICD-10, using the Canadian and United Kingdom tools as examples.

Develop and maintain a roster of experts, including information about the person's area(s) of expertise (morbidity, mortality, automated systems, etc.), his/her skill level, and his/her availability. This roster should be made readily available to all countries, and should facilitate matching the appropriate experts to countries requiring external assistance. WHO should provide assistance in linking relevant funders, appropriate experts, and countries. Also, an inventory of available training materials should be created.

EURO and AFRO Regional Advisers will serve as Co-Chairs of the committee in close cooperation with WHO Headquarters and with the participation of the United Kingdom Centre. Two consultations will be organized in Geneva before the 2002 Heads of Centres meeting.

Subgroup on Training and Credentialing

Needs assessment questionnaires should be routed from the Chair of the Subgroup to the appropriate WHO Regional Advisers and then on to their counterparts at the country level. The counterparts could be responsible for completing the morbidity coding questionnaires, and could forward the mortality coding questionnaires to the appropriate government person. PAHO will be responsible for translating the questionnaires into Spanish, French and Portuguese for their own countries. The Portuguese version will be sent to the Sao Paolo Centre for review and the Spanish version to the Caracas Centre. These language versions of the surveys will be made available to the AFRO Regional Office for distribution.

Place the tables on training materials and capacity compiled from the questionnaires on the NCHS website so that the information is readily available. The site will be linked to the WHO Headquarters and Regional Office sites as well as to CC sites. Contact information for all sources of the training materials, along with consent of the sources, will be obtained so that people accessing the website will be able to contact the sources directly. NCHS (Ms Donna Glenn) will prepare a brochure about the training materials so that this information can be disseminated to persons not having ready access to the Internet.

The present meeting of the joint working group will be reported in the next IFHRO newsletter. The North American Center will prepare a draft article about this collaboration. Ms Brouch agreed to forward issues of the IFHRO newsletter from January 2001 to all group members, along with other relevant documents on training and credentialing of morbidity coders.

Ms Brouch will provide participants with the websites for IFHRO and AHIMA so that they may access other relevant information on training and credentialing.

Ms Sue Walker of NCCH has begun work on the assessment of available training materials to identify core competencies and best practices. This work requires an assessment tool to be developed soon so that it can progress. Ms Brouch will work with Ms Walker on developing this tool and applying it to the English-language materials. The assessment tool will be forwarded to Dr Manuel Mosquera and Dr Rafael Lozano so that they can translate the instrument and apply it to the training materials available in Spanish. It will also be forwarded to other appropriate Centres for translation and application. Ms Walker and Ms Brouch will then be responsible for the overall analysis.

The North American Center will prepare a background paper covering relevant definitions, skill and training levels, and critical functions of underlying cause mortality coders. The United Kingdom Centre will prepare a similar background paper for morbidity coders in preparation for future activities relative to their credentialing.

Subgroup will liaise with the ICF group on training issues. However, more specific coding guidelines and field experience with applications are needed before an international training and credentialing program can be established.

Update Reference Committee

Contact the WHO secretariat formally seeking written endorsement of support for the process of updating ICD-10.

Write a letter to the secretariat seeking appropriate action to provide access to the database of URC work items (which records each work item of the URC, the progress of the work, and the decisions made).

Discuss with WHO the possibility of including some of the unaddressed items (malignant neoplasm of corpus callosum, appendix testis, diabetes mellitus, mitochondrial disorders, organic mental disorders, reticulosarcoma, exclusion note for temporomandibular joint disorders, sacroiliac joint, ankylosing spondylitis, overactive bladder, sinus bradycardia, and organic personality disorder) in the ongoing work of the URC with advice from WHO.

Decide on an appropriate U code for infection due to drug resistant microorganisms.

The version control table will be updated to include the year in which WHO and the Heads of Centres accepted the changes for posting on the website. Language versions will be changed every three years. The French Centre and PAHO agreed to help with translation.

Mortality Reference Group

Create a smaller subgroup to speed up the work of the MRG

Dr Susan Cole and Ms Donna Glenn to work together to assign codes to postoperative conditions.

Ms Tanya Pitts and Ms Julia Raynor to work with Dr Susan Cole on items related to maternal issues that need a nosologist's input.

Ms Donna Glenn to provide Dr Susan Cole with a list of perinatal terms having *transient* or *transitory* in them for her to see the type of documentation that would be most appropriate. Dr Roberto Becker will work with her on this as well.

Mr Johansson to review his research notes to determine why intracranial haemorrhage was not mentioned in the revision of the *highly improbable* guideline and communicate with Ms Julia Raynor on this.

Dr Cleo Rooney to work on the Volume 1 notes to clarify the issue of the coding of multiple valvular diseases. Ms Donna Glenn will provide her with codes representing valvular diseases.

Draft a reply to Dr Hanzlick regarding the reporting of SIDS deaths to be reviewed by the group.

The terms of reference for the MRG should be modified to ensure that members commit to supporting the suggestions presented by the group.

More work was agreed to be done on postoperative codes.

The issue of maternal deaths has not been resolved, although it was considered to be more a semantic rather than a conceptual issue. Discussion on this will continue.

International Classification of Functioning, Disability and Health (ICF)

Establish principles for ICF training and develop a training plan. Specific activities will be to post educational materials on the WHO website, to circulate the outline of CODE-ICF among the Collaborating Centres and WHO, and to establish a working group on training principles, an inventory of training needs, a catalogue of existing materials, and, as a result, an educational plan.

Develop core sets and criteria for the preparation of country and discipline specific sub-sets of ICF. Exchange information through WHO. The United Kingdom Collaborating Centre to share information on criteria that exist in the United Kingdom.

Family Development Committee

Procedures/interventions

The Australian Centre agreed to develop a prototype interventions classification incorporating suggestions arising from the meeting, with the amended title Australian Classification of Health Interventions - adapted for International use. At the same time, an evaluation of potential candidates will be undertaken.

Develop criteria for evaluation of potential candidates.

Get information from countries from which there has been no response to the survey.

Consider the inclusion of interventions other than surgical.

Consider additional issues of how to make the classification available, training materials, updating, resource requirements, and availability of assistance with translations.

A small working group of the FDC will continue this work. It was noted that Regional Office representation would be desirable for the small working group. A report will be made to the FDC at its meeting in April 2002.

External causes

Inform the ICECI working group of the recommendations of the meeting.

Relations with WONCA

Set up a joint working group to carry out the recommendations of the meeting with the consideration of the inclusion of ICF in the functioning rubric of ICPC as part of the terms of reference

The Chair of the FDC and Dr Niels Bentzen to decide the final composition of the group.

The Dutch Centre to act as secretariat for the group.

Limit work with WONCA to the consideration of the use of the ICPC as a classification for reasons for encounter as a possible member of the WHO-FIC.

Concept of the Family

Dr Richard Madden, on behalf of the Committee, and Dr T. Bedirhan Üstün to develop a draft paper for discussion initially by merging the FDC paper (WHO/GPE/CAS/C/01.52) with that prepared by the secretariat (WHO/GPE/CAS/C/1.91) as a working document to inform those proposing classifications for membership of WHO-FIC. Publication in the WHO bulletin was suggested with the FDC acknowledged in the authorship.

Use of ICD and ICF together

Follow up the identification of commonalities between ICD-10 and ICF, defining components in order to clarify differences and review same concepts with different levels of granularity in consultation with ICF experts, and refer to the Update Reference Committee.

Develop a set of guidelines for joint use of ICD and ICF.

Implementation of automated coding systems for mortality

Office of the ICD, Japan to consider presenting a paper on the results of the automated coding system used in Japan for fetal deaths during the 2002 meeting.

Conduct an annual survey to track the status of use of automated encoding systems.

Guidelines for hospital morbidity coding

Draw up a list of data sets being used in countries, the short lists applied, and relevant definitions (e.g. main diagnosis, hospital bed, discharge, etc.) for hospital morbidity statistics.

Establish a working group to work towards a short list for use with ICD-9/ICD-10 to be chaired by the Head of the Nordic Centre, with the participation of PAHO and the North American, Australian and United Kingdom Centres.

All Centres

Propose nominations, including reasons for the nominations, for EAG membership by the end of November 2001.

Send suggested themes for the scientific papers for the 2002 meeting to the Head of the Australian Centre.

Provide comments on the draft report of the meeting as well as on the joint work plan to WHO by 30 November 2001.

North American Center

Send the alphabetical index of perinatal conditions in electronic format to WHO.

United Kingdom Centre

Work with the secretariat to organize a meeting to discuss the development of coding guidelines for ICF.

Office of the ICD, Japan

Take the lead role in work on the subjective experience of disability (the Australian Centre has expressed interest in being a part of the working group).

Executive Advisory Group

Topics to be considered by the EAG include a long term vision for the classifications, education, financial implications and resources, information technology, and coordination. As an oversight function, the EAG will provide advice to WHO on all classifications and related matters.

Joint work plan

The issues of terminologies and summary health measures were noted to be missing from the plan, and these are to be added under the quality assurance subcomponent.

Centre Heads Planning Group

Monitor the papers submitted for consideration at the annual meetings and assess those to be presented accordingly.

Work out the details for the 2002 scientific papers sessions and ensure a good mix of papers on mortality, morbidity and functioning.

Consider those scientific papers not presented at the 2001 meeting and identify those that could be updated and resubmitted for presentation at the 2002 meeting.

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WHO/GPE/CAS/C/01.05 Annual Report 2001 from the WHO Collaborating Centre for the Classification of Diseases in the Nordic Countries

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WHO/GPE/CAS/C/01.18 Automated versus manual selection of the underlying cause of death: Differences between ACME and Swedish manual underlying cause coding, Lars Age Johansson, WHO Collaborating Centre for the Classification of Diseases in the Nordic Countries

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