MEETING OF HEADS OF WHO COLLABORATING CENTRES FOR THE CLASSIFICATION OF DISEASES
Rio de Janeiro, Brazil
15-21 October 2000

Report

1. Opening of the meeting

Professor Ruy Laurenti, Head of the Host Centre, introduced Dr Jarbas B. DaSilva Jnr who welcomed participants on behalf of the Ministry of Health of Brazil. Dr Roberto Becker, Regional Officer for the ICD for the WHO Region for the Americas welcomed participants on behalf of Dr George A. O. Alleyne, Director of the WHO Regional Office for the Americas/Pan American Sanitary Bureau. The meeting was officially opened by Dr T. Bedirhan Üstün on behalf of Dr Gro Harlem Brundtland, Director-General of WHO.

2. Election of Officers

In accordance with the established custom for the annual meeting of Heads of WHO Collaborating Centres for the Classification of Diseases, the Head of the Host Centre, Professor Ruy Laurenti, was invited to act as Chairperson.

Peter Goldblatt (UK Centre), Gerard Pavillon (Paris Centre), Cassia Buchalla (Brazilian Centre), Marjorie Greenberg (North American Centre) and Richard Madden (Western Pacific Centre) agreed to chair specific sessions.

Dr Susan Cole and Mrs Sue Walker accepted responsibility for the coordination of the report of the meeting, with the assistance of other participants.

3. Consideration and adoption of the agenda

The agenda (WHO/GPE/ICD/C/00.01), as amended following the Executive meeting of Centre Heads and the secretariat the previous day, was accepted with the agreement that a degree of flexibility may be required in order to accommodate issues arising during the course of the meeting.

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4. World Health Report 2000 and summary health measures

4.1 World Health Report

With the appointment of a new Director-General of WHO, the World Health Report 2000 no longer focuses on activity reporting as in the past. Instead the emphasis is on the new policy direction, focusing on improving health, responsiveness and fairness in financing of health systems. The concept of ‘stewardship’ of health systems by governments is introduced. The secretariat gave an overview of the report to the meeting, showing some of the summary health measures that had been incorporated for the first time.

Points raised during the discussion after the presentation included:
- Difficulties in collecting information on ‘soft topics’, such as patient satisfaction. Data based on these must be robust enough to withstand critical scrutiny.
- Considerable scientific scepticism has been raised in some countries following publication of the report. It was also noted that some of the countries whose data were utilized in the report were not necessarily representative of their regions. Considerable variation in ‘the most recent year’s data’ that had been analysed was observed.
- The level of Disability Adjusted Life Years appeared to be no more variable than the total life expectancy in different regions. The assumption that disability increases proportionally with increased age appears not to be proved.
- The feeling that the production of reports such as this one will make it imperative that these summary health measures are underpinned by robust instruments such as the ICD. There is the need for the ICIDH to also perform as reliably as the ICD and provide explanatory data on the disability years outlined in the report.

4.2 Uses of Summary health measures: a review of activities and issues, WHO Collaborating Centre for the Classification of Diseases for North America (WHO/GPE/ICD/C/00.52)

The North American Centre made a presentation based on a panel discussion developed for the US National Committee on Vital and Health Statistics, describing activities currently in progress in the United States on summary health measures. There is a huge data overload in some developed countries and it is hoped that summary health measures will go some way to alleviating this problem. The production of the WHO World Health Report 2000 has highlighted implications for the ICD and the ICIDH. Data are not yet of high quality, nor timely in some cases. There are issues surrounding the calculation of summary measures. There are multiple purposes and methods for collecting data, dependent on the uses to which the data are to be put. Work programmes reflect a growing desire for summary measures, to enable a snapshot of where countries are, how they compare and where they are going. There is a growing interest in non-fatal health outcomes and interventions require evidence of efficacy. It is important that these summaries are capable of being disaggregated to the local level, both geographically and by population groups. Some major private companies have approached the Centres for Diseases Control to help with disability adjusted life year analyses in large workforces.

It was suggested that, given the level of interest in this topic, it could become a focus for the 2001 Heads of Centres meeting. Work in progress regarding summary measures needs to be further developed and propagated.

In the discussion that followed, issues were again raised relating to the currently dubious components of the summary measures, and the need for improvements in data quality. Some countries have considerable problems with the calculation of denominators and numerators, in particular the ability to identify an accurate count of subpopulation groups. However it was noted that the search for perfection should not inhibit use of the data in novel ways, and an understanding of their limitations is necessary.
5. Annual Reports of Committees and Working Groups

5.1 Annual Report of the Links with Other Classifications Committee, WHO Collaborating Centre for the Western Pacific (WHO/GPE/ICD/C/00.26)

The Chair of this committee reported on the work undertaken, and the meetings held in the United Kingdom, over the past twelve months. He referred the meeting participants to the paper on issues surrounding the WHO Family of International Health Classifications (WHO-FIC) (WHO/GPE/ICD/C/00.27) and the definitions and models developed by the Nordic Centre. A further paper (WHO/GPE/ICD/C/00.28), prepared by the UK Centre, discusses the issue of the distinction between classifications and terminologies.

The Chair specified issues for discussion that appear later in the agenda for this meeting:
- the concept of the Family of Classifications
- classification of interventions
- external causes – ICECI, Chapter XX of ICD-10
- classifications of primary care – in particular, the approach to WHO made by WONCA regarding the possibility of the inclusion of ICPC in the WHO-FIC, and WHO’s response that further dialogue on this issue is needed.

5.2 Annual Report of the Implementation of ICD-10 Committee, PAHO/WHO (WHO/GPE/ICD/C/00.62)

The apologies of the Chair of this committee for his unavoidable absence were conveyed to the participants. The report presented a review of the status of the global implementation of ICD-10 by 2000. Countries had been surveyed via Regional Offices. Results were as follows:
- AFRO: 6 of 51 countries use ICD-10
- AMRO: 40 of 49 are using ICD-10
- EMRO: 13 of 22 countries have implemented ICD-10
- EURO: 31 of 51 countries have implemented ICD-10
- SEARO: 8 of 10 countries have implemented ICD-10.
- WPRO: 9 of 37 have implemented. It was noted that New Zealand and Fiji are using the Australian modification, ICD-10-AM. Guam and Micronesia plan to use ICD-10-CM.

The reasons given for not implementing ICD-10 ranged from financial problems to lack of trainers and skilled personnel. In discussion, the Western Pacific Centre noted that it had been active in training in the region but that individual countries have not necessarily decided to implement ICD-10. The UK Centre stated that training at the right time is important as materials learnt can rapidly be forgotten if there is a delay prior to implementation. Equally, it is often difficult for funding to be identified at the time that countries feel ready to begin the implementation process. A question was raised as to whether there are plans to repeat this survey on a regular basis? It was indicated that it was hoped that this would be undertaken next year.

5.3 Annual report of the subgroup on Training and Credentialling, WHO Collaborating Centre for North America (WHO/GPE/ICD/C/00.46)

The Chair of the subgroup reported on a teleconference meeting and the e-mail discussions of this group over the past twelve months. There were three major areas of work undertaken by the group:
- a questionnaire was devised to undertake a needs assessment for mortality and morbidity coders and it was planned that WHO be asked to take over its circulation in 2001;
- the various Centres have been surveyed relating to available training materials for ICD-10;
- various national and international organizations had been approached regarding the affiliation and credentialling of mortality and morbidity coders. The International Federation of Health Records Organizations (IFHRO) had expressed interest in this idea and a joint working group will be established to further discuss the proposed phased approach – focusing on underlying cause coding in the first instance, followed by main condition coding and subsequently, multiple causes and
multiple morbidity diagnosis coding. It was noted that there are no standard WHO guidelines for the latter two scenarios and that this may be one of the outcomes of this work.

5.4 Annual Report of the Update Reference Committee, WHO Collaborating Centre for the Western Pacific (WHO/GPE/ICD/C/00.20)

The Chair of this committee prefaced her report by remarking on the enormity of the task to update ICD-10. The implications of a staggered approach to implementation around the world makes updating difficult as do the costs involved in changing and maintaining ICD-10. It is a balancing act to provide a clinically current and credible classification but also one that has stability over time for comparative purposes. The Update Reference Committee (URC) is responsible for recommending changes to the Heads of Centres and also for developing policies on how to manage the update process.

The work of the Committee over the past twelve months has been largely carried out through an e-mail discussion group. The progress made is described in paper ICD/GPE/ICD/C/00.23. 19 members representing six Collaborating Centres are involved in the Committee. A small group at the National Centre for Classification in Health in Australia acts as the secretariat. There is a system for submitting proposals to the committee - 65 suggestions were dealt with in 2000 with 41 still to be considered during this week. The participants were referred to the final recommendations for 2000 (WHO/GPE/ICD/C/00.24) which were to be discussed at the meeting. The method proposed by the North American Centre for evaluating the update process for ICD-10 as discussed during the Cardiff meeting in 1999 has not been taken any further forward. It is planned that this be further considered during this meeting.

In discussions following the presentation, the important balance between implementing the classification and the need for some stability, and the necessity for updating it, was again emphasized. The WHO Regional Office for Europe expressed the view that often comments and recommendations for change will come from countries that have power and influence. Those who are struggling may not have input. There is a need to consider the global effects of changes before making them. The implications of changing and not changing need to be considered by the URC.

The Office of the ICD, Japan queried whether there are any countries that have implemented the new updated version? The North American Centre described the changes made to the automated cause of death coding software to incorporate decisions made regarding Rule A and Rule 3. Six countries use the software at the moment, although it has been distributed to 19 countries.

5.5 Annual Report of the Electronic Tools Committee, DIMDI (WHO/GPE/ICD/C/00.63)

This committee was established in 1999 to develop policies for the electronic tools developed for use with ICD-10. Participants had to date identified the software known to them and utilized a standard recording framework for grouping these tools. However, the workplan has not been progressed due to difficulties experienced over the past twelve months. However, work will be re-established during this meeting.

A question relating to the availability of the WHO multi-lingual, multi-revision CD-ROM of the ICD was raised in discussion. The secretariat noted that the CD-ROM had been updated based on comments received, and will be released within six weeks. It will be available in English, French, Spanish and Portuguese and will include ICD 7,8,9,10. It will be accessible on the WHO web site. The Paris Centre asked about updating of the CD-ROM following the recommendations for change made by the Update Reference Committee. The secretariat agreed that updates to the software would need to be released. Changes made to the classification so far have already been incorporated. It was noted that some way of highlighting changes made to the rules for coding mortality is required. These may be identified specifically in the accompanying documentation.

5.6 Annual Report of the Mortality Forum, WHO Collaborating Centre for the Nordic Countries (WHO/GPE/ICD/C/00.17)

The Mortality Forum is an electronic news group for mortality coding, open to anyone interested in mortality coding. The Nordic Centre moderates the Forum. There are currently 75 members subscribed to the Forum, representing 45 countries/organizations. Problems discussed are rated as great, medium
or minor depending on their potential effect on mortality statistics. 300 problems have so far been discussed by the Forum, of which 76 were considered to have a great impact on the comparability of mortality statistics. Around 10% of the problems have so far been referred to the Mortality Reference Group for further consideration. The UK Centre noted its appreciation of the work of Lars Age Johansson in moderating the Forum. There is now cross-fertilization of issues and problems with the Spanish-language forum run by PAHO.

5.7 Annual Report of the Mortality Reference Group, WHO Collaborating Centre for North America (WHO/GPE/ICD/C/00.17)

This group was established in 1997 and provided its first report at the Cardiff meeting. The Group has held four teleconferences in the past this year and has made recommendations for change based on seven questions submitted from the Mortality Forum and discussed this year. Two proposals for change were made in 1998/99, four submitted to the URC in 1999/00 and two more are to be forwarded to the URC next year. The Group has 19 members from the Collaborating Centres, plus a WHO representative. A further 13 issues have been discussed, without recommendations for changes. The Chair specifically highlighted procedural problems experienced by the MRG, relating to the inability of all Collaborating Centres to participate in teleconferences due to cost. The MRG sought the assistance of WHO to handle this problem. The secretariat noted that a new contract had recently been signed with a commercial telecommunications company, and this may assist people being ‘on line’. Further advice relating to this issue will be provided to Centre Heads within one month.

6. Business agenda

6.1 Working Group meetings

Participants started work in their working groups throughout Monday afternoon and continued on Tuesday morning. Reports of the working group meetings were provided to a plenary session on Tuesday afternoon and are included as appendices to this report. The general discussions between participants following the reports are summarized below.

6.1.1 Update Reference Committee (Appendix 1)

The extent of the work undertaken during the year, mainly by e-mail, had been very heavy and the number of unresolved issues still outstanding had made the meeting very detailed. Greater progress in reaching consensus might be made by teleconferencing during the coming year. The recommendations brought forward by the Update Reference Committee were endorsed.

6.1.2 Implementation of ICD-10 Committee (Appendix 2)

There was some discussion of the proposed targets of 2005 for the change to ICD-10 for those countries still using ICD-9, and of 2010 for those countries which had never used the ICD. It was agreed that having a target was advisable, but that the ability to achieve these dates depended on the availability of expert personnel and the financial resources to support them in their work. As more developed countries implemented ICD-10, skilled trainers would become available to help other countries, but finance to support them would be necessary. It should also be remembered that for some countries, vital event registration is far from complete, although this should not be an excuse to delay ICD implementation as this may serve as a catalyst for improvements.

6.1.3 Mortality Reference Group (Appendix 3)

The group discussed the process for disseminating the decisions reached to all users of the classification, and it was agreed that the annual report of the group could be used as a newsletter via the WHO website. Regional Offices could also distribute paper copies to those countries that found Internet access difficult. It was also pointed out that anyone could join the e-mail discussions of the Mortality Forum in English or the group set up in Spanish by PAHO. It would be important to ensure consistency of advice by the nomination to the Mortality Reference Group of a representative of the PAHO Forum.

6.1.4 Training and Credentialling subgroup (Appendix 4)

The secretariat emphasized that WHO could not provide accreditation, but would welcome co-operation between the International Federation of Health Records Organizations and WHO to enhance
the skills of nosologists for both mortality and morbidity training. It would be opportune to pursue this cooperation at next years’ Heads of Centres meeting.

6.1.5 Electronic Tools Committee (Appendix 5)
The coming together of database and SGML tools in the development of national and different language versions of ICD-10 was discussed. Options for disseminating such useful developments, ranging from free access on the Internet to licensing of commercial companies thus inhibiting the widest dissemination, would have to be fully explored.

6.1.6 Links With Other Classifications Committee (Appendix 6)
The results of this working group meeting are reported under agenda item 7.

7. Family of Classifications

7.1 The concept of the Family of International Health Classifications (WHO/GPE/ICD/C/00.27)
The Chair of the Links With Other Classifications Committee clarified that the current concept of the WHO Family of Classifications does not include hybrids (casemix or DRGs) or vocabularies and that the columns in the matrix are still evolving, particularly the column entitled “Settings”. It was suggested that this column might alternatively be retitled “application” or “purpose”.

The Western Pacific Centre expressed concern that the Family concept defined in the paper may be a constraining factor, as it does not appear to relate to the electronic environment. The Committee Chair indicated that the framework described was intended to be overarching with the national level(s) being consistent with the international classification(s).

The WHO secretariat responded that it envisioned the Family concept as a suite of integrated products with the ICD as the first product produced to meet the needs. It was further stated that the Family concept should be developed with a focus on future needs with international comparability becoming the biggest challenge. It was further stated that WHO may have to rethink “classification” and have an open mind on the needs e.g., reference classification versus derived classification versus related classification. This would pertain to current discussions with WONCA regarding ICPC.

The secretariat expressed the importance of having a "suite" regardless of the name that is given to it. It was noted that opening up new areas of the family would be a conceptual change and that it would be a challenge to establish links between derived products and other products (such as a map of SNOMED to the ICD). The secretariat distributed a copy of a document entitled “Measuring and reporting on the health of populations” and suggested undertaking a survey to gather information that is relevant to the ICIDH. Participants expressed caution that implementation of any classification must be from a practical point of view.

7.2 Definitions and concepts related to the Family of International Health Classifications (WHO/GPE/ICD/C/00.37)
There is a need to define “health-related concepts” for reporting health matters and for research. The ICD will not cover the needs of all WHO Member States as some countries have resources sufficient only to treat patients, not for implementation. The Paris Centre noted that definition #3 is a starting point but additional work is needed. The North American Centre noted that the paper advances our thinking in this area. The Centre, however, expressed concern about the matrix in identifying applications in conjunction with settings rather than a continuum of care model that reflects a longitudinal view. The Centre has concerns but no solution. There was a brief discussion about not supporting different classifications for different settings. The Netherlands suggested that the ICD can be used for all kinds of settings and that the title of the column might be more appropriately renamed “purpose”.

Some participants expressed the belief that we must focus on tools that are stable over time and that settings must also be stable over time. It was agreed that further work on this is needed. This is important work and it was suggested that the scope and information needs at the international level should be explored along with the identification of classifications that exist to meet these needs. It was stated that countries may always need to develop relevant materials at a national level but it would be best if an international solution existed.
The Links Chair supported the idea that “settings” could be renamed “purpose” and welcomed suggestions and information to be sent to the Committee to include in the next refinement of the paper. The Links Chair also asked for a mandate to continue to work on the paper and bring it forward for possible adoption at next meeting of Heads of Centres. The meeting concurred.

Discussion was held regarding the status of the Collaborating Centres and their redesignation, with the secretariat clarifying that it is the intention to convene an Executive Committee meeting in February 2001. This item will be placed on the agenda for that meeting.

Discussion ensued regarding the process for carrying workplans forward and the role of the cross-cutting groups already established (Mortality Reference Group and Update Reference Committee). A question was raised as to whether we can extract knowledge from the development of clinical modifications. The secretariat expressed the desire to have the ‘family’ concept formulated around the WHO workplan and is looking for synergy between the work of Collaborating Centres and the WHO workplan.

8. ICIDH-2

The secretariat provided an overview of the revision activities on the ICIDH-2 in the year 2000. In the past year, WHO has been increasingly interested in summary measures of population health. The paper “Measuring and reporting on the health of populations” was tabled as background to the discussion. WHO is promoting the ICIDH-2 internationally as a Main Classification with similar status to the ICD-10. The 2001 version will contain a Main Volume, Clinical Descriptions and Assessment Guidelines, Assessment Criteria for Research, Other Versions (Specialty Adaptations, Children and Youth) and Dedicated Assessment Tools.

Since the Cardiff meeting in 1999, the Beta-2 version has been produced and field tested in over 40 countries. Amongst the contributors were the North American, Australian, French, United Kingdom, the Netherlands and Nordic Collaborating Centres.

Concerns had been expressed relating to the applicability of ICIDH-2 in its current format at a number of international forums. The revision process is in the finalization phase, and is to be discussed at the January 2001 WHO Executive Board meeting, with the view to the submission of a draft resolution regarding the ICIDH-2 to be discussed by the World Health Assembly. The secretariat recommends the endorsement of ICIDH-2 and that it becomes the standard international classification for measuring health outcomes.

The North American Centre then provided an overview of the document WHO/GPE/ICD/C/00.43, highlighting the keen interest in ICIDH-2 and its potential in identifying what can be learned about health along the continuum of life. The North American Collaborating Centre applauded the WHO recognition of the problem with differentiating between Activity and Participation and the need for this issue to be addressed. However, the subsequent basic constructs solution does not address the concerns raised.

Participants raised concerns regarding the future direction of ICIDH-2 with respect to:

- What is its purpose?
- Will it still be useful for multiple purposes?
- What is the content? - at the time of the meeting the latest version was not yet available
- Is the most current version to be field tested?
- What are the roles of the Collaborating Centres in the development and maintenance process?

The Collaborating Centres wish to have continued involvement in the development of ICIDH-2. They would like to have the opportunity to field test the new version that has been produced by WHO. Evidence is required that the new version works better than the Beta-2 version.
9. Mechanism for the periodic updating of ICD-10

The papers WHO/GPE/ICD/C/00.22 and WHO/GPE/ICD/C/00.23 were background to this agenda item.

Concern was expressed about the way in which updates are being endorsed, disseminated and the frequency of their implementation. The process for referral and consultation to the Update Reference Committee is clearly specified but, following the Heads of Centres meeting, there appears to be no systematic way for WHO to handle the further dissemination of changes. This means that there may be problems for countries to change synchronously and to keep pace with version control.

Any classification change impacts on the many language versions of the ICD-10, the multilingual CD-ROM version of ICD-10 and the various electronic systems used in the production of annual statistics.

The World Health Assembly accepted the concept of an updating process between revisions and asked the secretariat to give consideration as to how an effective mechanism could be put in place. Recommendations are made at the Centre Heads meetings. The secretariat undertook to produce a paper making clear the process and timetable for updates. It was agreed that there must be a clear mechanism for active dissemination and not merely passive circulation by publication on the WHO website.

10. Presentation of the Ministerio da Saude Secretaria Executiva DATASUS – Departmento de Informatica do SUS

A presentation was given on the Brazilian activities within the Brazilian Health Care System covering the DATASUS mission, products and use of classifications.

Brazil is the 5th largest country and has the 8th largest economy in the world with a population of 166 million. The major social, economic and epidemiological regional differences were illustrated. The epidemiological and demographic transition includes: growing number of elderly, decreasing fertility, increasing chronic and degenerative diseases (cancer, diabetes, circulatory system diseases) and a decrease in infectious diseases (although this is still an important concern).

The health system has a comprehensive healthcare module, SUS – Sisterma Unico de Saude - and the Informatics Department of the Brazilian Ministry of Health processes the information on health. Their mission statement, main goals and record of the use of data were detailed. Models of the basic data flows were given and details on information dissemination were discussed, including the availability of the Health Ministry homepage, DATASUS homepage and the DATASUS home page data retrieval module. Finally, an overview was given on the history and current use of classifications in Brazil.

A second presentation was given on the Mortality Database System using online data. The database was developed from ACME tables, translating ICD-10 to ICD-9, then re-translating back to ICD-10. It is approximately 98% automated before user intervention is necessary. The screens presented showed how the rules are applied and how the system enables the user to query any code assignment, showing the interactive nature of this database.

11. Classification of procedures

A paper was presented by the Nordic Centre on behalf of the Links Committee. The paper was entitled Tabulation List for International Comparison of Surgical Activities (WHO/GPE/ICD/C/00.26) and was included as Annex 2 of the Links with Other Classifications Committee report. At the Cardiff meeting the committee was tasked to progress the following:

- Develop a protocol for countries that do not have a classification.
- Develop, through a small group, a sentinel list of interventions ensuring both a policy and population focus.
• To look at a broad classification of interventions.

The paper presented is a modification of a draft prepared by the UK Centre for a structure of a classification of health interventions. Examples were presented illustrating the concepts of the paper.

The meeting discussed the fact that this tabulation list only captures surgical activity rather than surgical technique and it is difficult to identify the appropriateness of surgery from the data captured by the tabulation list. The paper advised that there is information that can be gained - it can, for example, show the availability of surgery, although not the surgery itself. The aim of the list was to provide a short, easy tabulation that cannot be achieved if a detailed classification is used.

There was some question as to why a sentinel list was rejected. This discussion has been captured within the papers from the Links with Other Classifications Committee.

The tabulation list was not supported at this point, however it is recognized that an interventions classification is required. Its development should be driven by need. It was agreed that the questionnaire on coding and reporting of surgical procedures and interventions (WHO/GPE/ICD/C/00.68) could inform future discussion on this.

International Classification of Health Interventions

The Western Pacific Centre presented the paper entitled International Classification of Health Interventions (WHO/GPE/ICD/C/00.64), proposing a short version of the ICD-10-AM procedure classification as an appropriate classification for international use. The paper put forward this classification for consideration and potential inclusion in the WHO Family of Classifications and as an alternative to the tabulation list proposed earlier.

The structure of ICD-10-AM was described and the benefits of the updating mechanism that is already in place on a two-yearly basis.

The classification is based on first principles. There is no division between other and unspecified, however this will be reviewed and may be differentiated in the future. The classification could be appropriate for developing countries in that it could be used independently of diagnosis hierarchy and taken at any level.

Currently there is diagnostic information within the procedure information, which is based on the Australian fee schedule. This is currently being changed (though obviously not all diagnoses will be removed eg hernia). The list does include all scheduled procedures, but also input from the Royal Australasian College of Surgeons and public submissions are sought to include procedures that are not covered in the schedule.

A comment was made that when starting from a list of benefits schedule, this means the payment schedule drives the development. It may therefore be hard to find one classification that fulfils the needs of users in different countries.

It was generally agreed that we do not have enough information on procedure classifications available and that this detail is needed before progressing further.

Questionnaire on Coding and Reporting of Surgical Procedures and Interventions

The North American Centre presented the paper Questionnaire on Coding and Reporting of Surgical Procedures and Interventions (WHO/GPE/ICD/C/00.68). The purpose of the questionnaire is to obtain more information on the coding and reporting of surgical procedures/interventions from countries, to enable assessment of those countries that have nothing and to obtain more information on those countries that do use a classification. The by-product of the results could be a comprehensive list of classifications available and relevant contacts to obtain more information.

Comments on the questionnaire are invited and should be forwarded to the North American Centre.
The questionnaire will be made available on the Internet so that it can be completed and e-mailed back.

It was asked whether the approach to getting international data was within the scope of the Electronic Tools Committee and whether the solution might be to map to different systems rather than getting people to implement a standard procedure classification. This was considered not viable due to the enormous amount of work involved.

It was noted that a lot of procedures are already included in the UMLS and common concepts are within the thesaurus. It was agreed that the possibility of using the UMLS to compare country classifications for the purpose of producing a sentinel list should be considered in the future. Whilst this may be useful for developed countries, it would not be useful for other countries. It was also reported that GALEN has software available to map in a logical manner and make comparisons but at a very sophisticated level. The information collected from the questionnaire will be more relevant to those countries that do not have a procedure classification.

It was proposed that it is not the Heads of Centres’ responsibility to make a decision on use of procedure classification but up to the individual countries to determine their own needs.

12. **International Classification of External Causes of Injury (ICECI)**

The following papers were presented on the classification of External Causes of Injury:

- WHO/GPE/ICD/C/00.29
- WHO/GPE/ICD/C/00.47
- WHO/GPE/ICD/C/00.48

The North American Centre presented three papers about the ICECI and updated the meeting on the latest developments. The ICECI working group had suggested to the 1999 Heads of Centres meeting that chapter XX of ICD-10 should be completely replaced by ICECI. Since then, members of the Collaborating Centre have worked closely with the ICECI Working Group to determine the problems with chapter XX and the best way of resolving these.

The North American Centre reported that, at a joint meeting in Amsterdam in September 2000, consensus was reached that Chapter XX needed limited modification. The Chapter XX working group (convened by James Harrison, Australia) will identify in more detail the deficiencies in being able to classify external causes and circumstances of injury, which are important for prevention. The group will produce an interim report by end of March 2001 for consideration by the Heads of Centres and the Links Committee. They will also continue development of full and abbreviated versions of ICECI for use by the injury research community wherever appropriate. They expect to have a complete version of the ICECI tabular list by March 2001.

This consensus was warmly and widely welcomed by the meeting. The participants look forward to further collaboration with the ICECI group to improve the classification of external causes for a wide range of applications.

It was noted that some theoretical gaps in ICD-10, identified through the application of the ICE on Injury Statistics matrix of mechanism and intent, are not really significant. For example, overexertion, animal bites and some other mechanisms are only represented by codes for unintentional/accidental intent. In some cases, though particular intersections of these axes could occur in theory, the likelihood of any cases actually presenting is low enough to justify coding them in ‘other specified’ categories. The North American Centre reported that comparability between ICECI and Chapter XX at the level of groups used for national rates and international comparisons could be achieved through mapping ICECI to this matrix. The meeting felt that the proposals put forward by the ICECI group should be considered as a whole once that group has completed the work, rather than piecemeal. However, there may be some minor, uncontroversial corrections or improvements that could be considered before then by the Update Reference Committee. For example, an additional 4th or 5th digit within the existing three character rubric to distinguish the source of carbon monoxide in poisoning (car exhaust, incomplete combustion in heating appliances etc).
The North American Centre reported the results of a pilot study that tested the reliability of an abbreviated form of ICECI in an Emergency Department setting. The investigators found acceptable reliability and coding times. However, they had had to develop and use a special data collection form, because it was clear that the data items needed for the classification would not be in a standard Emergency Department record. They also developed an index and coding rules for this abbreviated version. They noted the need for a more user-friendly coding manual, more instructions, and clearer rules. A pilot study has also been done in Australia.

13. Collaboration with WONCA

A paper from WONCA (WHO/GPE/ICD/C/00.65) was presented by the Nordic Centre. WONCA has expressed interest in working with WHO and the Collaborating Centres to develop a third ICPC, or an adaptation of ICD-10, for use in primary care.

The secretariat suggested a joint meeting between the Links Committee and WONCA in the future to further explore collaboration. The Chair of the Links Committee agreed that a meeting in 2001 should be arranged and that the secretariat should participate.

14. NordDRG as a casemix tool – importance of the correct use of the primary classifications

The Nordic Centre presented an invited paper on the development of new Nordic DRGs, which are based on ICD-10 and the NOMESCO Procedures classifications. The importance of the correct application of the primary classifications before groupers are used was highlighted. The paper will be made available on the WHO website after the Rio meeting. DRGs were recommended as a topic for a session at the 2001 Centre Heads meeting, and the head of the North American Centre invited the other Collaborating Centres to submit papers on DRGs and related ways of grouping data for that meeting.

Issues discussed by the meeting participants included:

- The overwhelming influence of payment factors in coding practice, and DRG creep
- The relationship of DRGs to the Family of International Health Classifications
- Whether WHO should offer advice about the use of DRGs by Member States.

It was pointed out that there is a wide range of different grouping tools available in different countries, including CMGs in Canada and HRGs in the UK. The North American Centre reiterated the driving influence of funding. DRGs are only used for inpatient care, sometimes including day-cases. Some grouping systems have been developed for ambulatory care.

15. Scientific papers

A series of scientific papers was presented to the meeting.

15.1 Data Quality

Comparing hospital discharge records with death certificates – towards a pragmatic alternative to peer review of medical records (WHO/GPE/ICD/C/00.19)

It is proposed to submit this paper for publication, therefore only the abstract of the paper is reproduced in the meeting papers.

Background and aim of study: In about two thirds of deaths in Sweden, the deceased had been hospitalized during the last year of life. We here compare the official underlying cause of death with the hospital discharge diagnoses, compute the frequency of divergences that cannot be explained by
differences in ICD definitions, and estimate the importance of diagnostic information present in the hospital discharge register, but left out from the death certificates.

Method: We linked individual data from the national hospital discharge register to data from the national cause-of-death register. Using ACME, we then assessed if the official underlying cause of death and the last main diagnosis were medically compatible. We also tested if diagnostic information present in the hospital registers but not on the death certificate would change ACME’s classification of the underlying cause of death.

Results: In one third of cases, divergences between underlying cause of death and last main diagnosis were “incompatible” and could not be explained by differences in definitions. In about 11%, ACME “corrected” the original underlying cause and selected a new underlying cause of death from the hospital discharge data added to the original certificate.

Discussion: Incompatible statements might indicate a quality problem. To evaluate the matter, samples of both incompatible and compatible cases should be studied in closer detail. The “corrections” influence rather few causes of death, but have startling effects on some of them. Therefore, linking hospital discharge data and cause-of-death data might, for some causes of death, result in better mortality estimates.

In discussion during the meeting, other countries indicated that they have found an under-reporting of recent injuries – in the UK, this is in the order of 25% for deaths within one month of fractured neck of femur. Great caution must be exercised in interpreting differences between hospital discharge data and death certificate data, due to the differences in definitions of underlying cause and main condition, and the effect of temporality. Both sources may be correct.

Effect of Cause of Death query action – an Australian study (WHO/GPE/ICD/C/00.34)
In Australia, the selection of records to return for query is made after the first coding is undertaken. Some non-responses may indicate too high a desire for specificity. Query standards may be country-specific. In the UK, there is a data field to indicate that the doctor may be able to supply more specific information later, and these queries are more productive than unprompted queries. This is especially the case for pneumonia and unspecified malignancy in the elderly. In some countries, the problem is not ill-defined causes but unattended death or lay reporting. The ill-defined or imprecise causes of death are probably highly associated with ‘extreme’ old age. The actual perception of that age may differ from country to country.

Quality Information: A pre-requisite for good decision-making (WHO/GPE/ICD/C/00.36)
The type of tool described in this paper has also been used in training for students from Sri Lanka and Thailand, and these countries have used the method to audit local coding in hospitals. France is attempting to develop a similar software program and will be interested to compare the Australian clinical coding tool with its own.

Evaluation of the quality of the medical certificate of cause of death in the Republic of Nicaragua (WHO/GPE/ICD/C/00.39)
This paper was tabled without presentation.

Comparability and quality improvement in European causes of death statistics (WHO/GPE/ICD/C/00.41)
This paper was presented by the Paris Collaborating Centre and was received without comment.

Accuracy of the Information about diagnosis in the discharges of public hospitals in Brazil (WHO/GPE/ICD/C/00.53)
This paper described a preliminary report of a larger exercise on morbidity data quality. It was noted that one problem identified was that late effects of diseases may well be coded to the acute phase.

Evaluation of coders in mortality with ICD-10 in the state of Rio de Janeiro, Brazil (WHO/GPE/ICD/C/00.55)
The large numbers of new mortality coders necessary for devolved local coding, requires a continuous process of training. Decentralization of mortality coding may be a danger to the quality of the coded
data. Authoritative advice on the risks of decentralization should be made available. The Training and Credentiailling subgroup may be able to offer such guidance.

The low status of the coder is inimical to raising the standards of coding quality. It is extremely important to raise the status of coders by credentialling, training and recognition through suitable salary scales.

**Improving the information regarding inadequate terms or incomplete diagnosis in the death certificates (WHO/GPE/ICD/C/00.56)**

Standard letters may not be an entirely appropriate query mechanism for certain certificates, and coders who are responsible for sending out queries may not always recognize an inappropriate query letter. Decentralized coding helps the response rate to queries due to familiarity with certifiers. It was noted that use of letters rather than telephone calls is preferable. Letters are a better training tool for certifiers in recognizing the documentation required by coders. Telephone calls may interrupt the physician or may be made at a time when notes are not available to allow an immediate response. Participants indicated that databases may be changed as a result of querying and it is also useful to have written documentation relating to the reasons for the change.

In Sao Paulo, there is a 50% response rate to an early letter querying the accuracy of a diagnosis of tuberculosis or AIDS, and in 70% of returns the diagnosis is changed. It is important that a senior, perhaps medical, official sends out the letter.

**15.2 Adverse Events**

**Reporting iatrogenic injury in Australia (WHO/GPE/ICD/C/00.30)**

Classifying information about ‘things that go wrong’ in healthcare (WHO/GPE/ICD/C/00.32)

There is a strong political and professional interest in monitoring adverse events in Australia. Reverberations from the Australian paper have swept over several European countries. There are great subtleties in ‘things that go wrong’, ranging from high risk specialties to frank medical malpractice. There must be fairness in analysis or else there will be a retreat from taking risky patients. Quality should be a positive attribute to be monitored, rather than the adverse effects, as the system is often the problem rather than the physician. The Australian Generic Occurrence System is an anonymous notification of events whether there has been a consequential effect on the patient or not.

**Proposed changes to ICD-10-AM to improve adverse events reporting (WHO/GPE/ICD/C/00.31)**

A two day conference will be held in Australia, during which a series of definitions and amendments to the external cause codes relating to adverse events will be proposed and discussed. Any changes might well have far-reaching consequences for mortality. One of the proposals which concerns a possible recommendation to stop dual coding the nature of injury and the external cause, would have to be approached with extreme caution. There is clinical concern that coders are making judgements about the causation of adverse events, and sometimes they assign an external event code to describe a temporal relationship to a procedure, rather than causality.

**Summary of adverse event reporting in the United States (WHO/GPE/ICD/C/00.49)**

The North American centre apologized for the lack of a paper and indicated that it will be posted on the WHO website at the conclusion of the meeting. The issue of legal liability makes accurate documentation and coding of adverse events very problematic in the US.

**Complications of medical and surgical care (adverse events) in the mortality and morbidity statistics in Brazil (WHO/GPE/ICD/C/00.54)**

There are great problems with adverse events in mortality reporting, both as far as specifying the actual sequence of events, and also concerning the rules for coding. In the UK, there is a confidential enquiry into perioperative deaths. Any investigation that uses ICD codes to identify adverse events must have a parallel case investigation. There are also problems in death reporting because nothing is done. Even though the statistics do not represent the true level of adverse events, the sentinel event may indicate a trend. Actual reporting may change as a result of publicity and so even trend data may not be useful. The use of multiple cause coding is certainly useful in mortality data but the issue of incompleteness is still a difficulty and denominators may not be available.
Adverse event reporting in routine hospital discharge statistics based on ICD-10 in the Nordic countries (WHO/GPE/ICD/C/00.60)
The analysis of the comparative study between Finland and Sweden shows similar results to those from other countries. The ICD is manifestly not good enough to meet the needs of bodies currently investigating adverse events in health care. Morbidity coding seems especially difficult. The responsibility of Collaborating Centres should be to suggest amendments to codes and to coding rules to facilitate the identification of these adverse events. It was suggested that further multinational studies need to be undertaken.

15.3 Bridge coding and comparability

Comparability of cause of death between ICD-9 and ICD-10 – preliminary results from US mortality data (WHO/GPE/ICD/C/00.45)
The published results of bridge coding will be in the form of Tabulation lists (113 selected causes for general deaths and 130 selected causes for infant deaths) and will show comparability ratios and confidence intervals. These will be available by the end of 2000. The records used in bridge coding will consist of the whole of 1996 deaths, rather than a sample, in about a year’s time. For this year, a sample of 1996 rejected records, and all of the remaining 80% of automatically coded records will be used. Australia is in the process of double coding three years’ worth of data. The effects of Rule 3 changes were discussed. Scotland is bridge coding 1999 deaths as are England and Wales.

Mortality bridge coding ICD-9/ICD-10: preliminary results from a Statistics Sweden study (WHO/GPE/ICD/C/00.66)
The Rule 3 change produced a 20% decrease in pneumonia deaths in Sweden, but after the amendment of Rule 3 (as accepted by the Heads of Centres) this large fall should be reduced. It was pointed out that the changes proposed by the Mortality Reference Group makes bridge coding difficult.

For manual coding, some early impressions indicate that Rule 3 changes have not been implemented in all countries. This emphasizes that each country must use its own data in order to bridge code, and that bridge coding should be done in the same way as routine coding.

15.4 Clinical modifications

Development of the International Statistical Classification of Diseases and Related Health Problems, 10th revision, Canada (ICD-10-CA) and the Canadian Classification of Interventions (CCI) (WHO/GPE/ICD/C/00.50)
Implementing ICD-10-CA and CCI across Canada (WHO/GPE/ICD/C/00.51)
These papers were presented together by the North American Centre. The name ‘modification’ gives rise to confusion, as the ICD is not modified but enhanced. There was some criticism of the use of the term ‘ICD’ for surgical procedure classifications being developed by some individual countries.

15.5 Emerging issues for classification

Criteria for cross-referencing clinical vocabularies and classifications such as ICD (WHO/GPE/ICD/C/00.28)
Six to 10 test sites are piloting the SNOMED clinical terms and the new electronic record system in the United Kingdom. There are close contacts with the College of American Pathologists. The use of clinical terms has been shown not to make the quality of information any worse at the very least. The cross-mapping work between the clinical term codes and the ICD is highly skilled. It takes at least 18 months to train a skilled coder. The GALEN project does not look as though it will be helpful with the SNOMED-ICD mapping.

The mapping tables are freely available within the UK, and a finished product will be released worldwide by the end of 2001. The mapping and maintenance of the SNOMED codes are the responsibility of the National Health Service in England for the United Kingdom version. For the rest of the world, the College of American Pathologists will be responsible for maintenance. Both of these
bodies maintain close collaboration. There is also cooperation with the UMLS and the National Library of Medicine in the USA.

Classifying genetic disorders – aetiology and manifestations (WHO/GPE/ICD/C/00.61)
Both the aetiology and the manifestation should be coded but there are problems with longstanding, well-known diseases – like arteriosclerotic heart disease – these may have a genetic basis but require an environmental factor before the condition is expressed. It perhaps will be necessary to consider preventive aspects - where the disease is always expressed in the presence of a genetic disorder, the identification of the genetic disorder is important, but where the environmental factor is more important, the manifestation should be identified. There is a clear need to address the issues contained within this paper, but perhaps a future course of action may be along the direction of dual coding in a similar manner to the dagger and asterisk system.

15.6 Definitions and standards

ICD-10 definitions relating to maternal mortality – rationales for proposed modifications (WHO/GPE/ICD/C/00.40)
As this paper involves a change to Volume 2, the proposals should be referred to the Mortality Reference Group. Sympathy was expressed with the wish to simply count a death during, or within 42 days, of the end of the pregnancy – the pregnancy-related death. This concept is allowed for in Volume 2. The issue is primarily a tabulation problem, rather than a coding issue. It is a big change to call the concept a maternal death.

15.7 Other

Introduction of the new tabulation list for communicable diseases in Japan (WHO/GPE/ICD/C/00.38)
ICD-10, on the whole, is better for the identification of infectious diseases and drug-resistant organisms compared with ICD-9. However there are continuing problems with identifying some drug-resistant organisms raised in some countries. The Update Reference Committee is considering a recommendation to utilize a ‘U’ code for these and will circulate a firm proposal.

Maternal deaths: analysis of a new variable in Brazilian death certificates (WHO/GPE/ICD/C/00.57)
Although the initial introduction of the new death certificate with a pregnancy question did not greatly improve reporting (only by about 15%), there had been no accompanying information distributed with the new certificates. It was thought that this lack of information might have been the reason for the less than expected improvement. In the United States, it was noted that in the 16 states that had implemented a pregnancy question, there had been a 40% increase in the ascertainment of maternal deaths.

Patterns of mortality in Sao Paulo municipality at the beginning and end of the twentieth century measured according to ICD-1 (1901) and ICD-10 (1996) (WHO/GPE/ICD/C/00.58)
The Brazilian Centre presented this interesting paper. The Western Pacific centre reported that they had also attempted to show trends of disease for certain causes throughout the twentieth century. During this exercise studying the changes within the ICD, from the first to the tenth revisions, has been extremely interesting. The evolution of the ideas behind disease classification could be seen with, for example, the first appearance of hypertension in ICD-4. In this edition, hypotension was grouped with hypertension.

There have been considerable methodological changes in the names and concepts in the aetiology of disease. The UK Centre offered to act as a centre for international comparisons for those countries that could contribute 100 years of data.

The information about circumstances of the external causes in death certificates (WHO/GPE/ICD/C/00.59)
In the US, there is space for the medical examiner to provide a narrative about the external cause. The Brazilian centre believes that future collaboration with the legal authorities will help to further improve
this information. In Sweden and Finland, there is also the ability to use free text about the external cause. Newspapers can also provide ancillary information for mortality coders.

PAHO Regional Advisory Committee on Health Statistics (CRAES) subcommittee for the ICD and the Family of Classifications (WHO/GPE/ICD/C/00.67)
Other countries expressed an interest in joining in the suggested e-mail discussion group to be created by PAHO.

16. Reports of the classification-related activities of WHO and the Centres
The reports of the Collaborating Centres were accepted as distributed. The report of the WHO secretariat (WHO/GPE/ICD/C/00.04) was tabled and discussed.

17. Adoption of the draft report of the meeting
The draft report was considered and accepted as amended.

18. Additional matters
18.1 The Centre Heads endorsed the recommendations of the Links Committee (Appendix 6).
18.2 It was noted that no discussion had taken place on the joint workplan.

It was pointed out that the Collaborating Centres struggle with their own resources, endeavouring to carry out the plans originally agreed in Copenhagen in 1997. The priorities of the Collaborating Centres remain:

• The implementation of the ICD
• Updating of the ICD
• The definition of the parameters of the family and the prioritization of work on other family members.

The demands placed on the Centres increase the strains. This is exemplified by the request to the Beijing Centre to take on the responsibilities for the ICIDH, when it is struggling to implement ICD-10 in its huge country.

It was regretted that there has been no review of the proposed future work of the individual centres and how these will impact on the joint workplan.

19. Place, time, themes and agenda for next meeting
The secretariat made a final presentation on the discussions with individual Collaborating Centres and the redesignation of the Centres.

Future meetings of the Heads of Collaborating Centres are planned for:

2001 Washington DC
  Themes: Family of Classifications, Summary Measures of Population Health
2002 Australia
2003 Germany, in collaboration with the Netherlands

Thanks were given to the WHO Collaborating Centre for the Classification of Diseases in Portuguese for the excellent organization and an extremely interesting meeting.
Appendix 1 Update Reference Committee Report

Chair: Rosemary Roberts
Rapporteur: Kerry Innes

1. Ratification of the Committee structure, work programme and membership document
   The tabled document was ratified.

2. Ratification of the proposed ICD-10 updates – 1998 [ICD-10 (2000)]
   The tabled document was ratified as these changes already appear on the WHO website

3. Ratification of the proposed ICD-10 updates – 1999 [ICD-10 (2001)]
   The document was not available to the meeting but had been approved by URC consensus prior to the meeting.

4. Consideration of the following recommendations for change:

4.1 Supported recommendations:
   Twenty-two (22) recommendations were ratified for inclusion in ICD-10 as URC consensus had been reached on these items prior to this meeting. Of these 22 items, eight are designated as major changes and will therefore be introduced in 2003. The remainder will be included in the 2002 changes. The details are as follows:

   **Agreed minor changes for ICD-10 (2002):**
   0004 Unspecified mental retardation
   0005 Android pelvis
   0006 Self mutilation
   0007 Osteoporosis
   0008 Antagonist
   0013 Personal history of chronic resp condition
   0033 Injury to fascia
   0036 Drug abuse counselling or surv.
   0038 Torsion of Morgagni’s hydatid
   0048 Note 4.1.9 Rule A – Senility and…
   0051 Note 4.2.2 – highly improbable – point (a)
   0058 Lichen sclerosus of ext. gen. Organs
   0059 Bullous impetigo
   0062 Block W85-W99 Exclusion note

   **Agreed major changes for ICD-10 (2003):**
   0003 Influenza vaccine, adverse effect
   0009 Meningococcal vaccine
   0047 Note on pneumonia for SR 3
   0050 Note 4.2.2 highly improbable (n)
   0056 Charcot’s arthropathy
   0057 Gestational hypertension
   0061 Pulmonary hypertension of newborn
   0063 Atypical pneumonia

4.2 Items for further discussion
   The remaining 41 proposals were then considered with the following results:

<p>| Supported | 9 | Major | These will be implemented in 2003 |
| Not supported | 11 | Minor | These will be implemented in 2002 |
| Held over | 10 |
| WHO action | 11 | These items need further discussion or action by the URC members before a decision can be made |
| | | These items require further action by WHO before a decision can be made |</p>
<table>
<thead>
<tr>
<th>URC Ref No and Title</th>
<th>Major</th>
<th>Country</th>
<th>Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>0001 Papillary necrosis</td>
<td>UK</td>
<td></td>
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</tr>
<tr>
<td>0002 Procedural complications</td>
<td>Aust</td>
<td></td>
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</tr>
<tr>
<td>0010 Trembles</td>
<td>UK</td>
<td></td>
<td>Not supported</td>
</tr>
<tr>
<td>0011 Kussmaul’s respiration</td>
<td>Major</td>
<td>UK</td>
<td>Supported</td>
</tr>
<tr>
<td>0012 Palatal incoordination</td>
<td>UK</td>
<td></td>
<td>Not supported</td>
</tr>
<tr>
<td>0014 Biliary colic</td>
<td>UK</td>
<td></td>
<td>Not supported</td>
</tr>
<tr>
<td>0015 Malignant neoplasms</td>
<td>UK</td>
<td></td>
<td>WHO</td>
</tr>
<tr>
<td>0016 Tophi gout</td>
<td>Minor</td>
<td>UK</td>
<td>Supported</td>
</tr>
<tr>
<td>0017 Appendix testis</td>
<td>Aust</td>
<td></td>
<td>WHO</td>
</tr>
<tr>
<td>0018 Keratoacanthoma</td>
<td>Aust</td>
<td></td>
<td>WHO/IARC</td>
</tr>
<tr>
<td>0019 Diabetes mellitus</td>
<td>Aust</td>
<td></td>
<td>WHO/MRG</td>
</tr>
<tr>
<td>0020 Mitochondrial disorders</td>
<td>UK</td>
<td></td>
<td>WHO</td>
</tr>
<tr>
<td>0021 Retropertitoneal fibrosis</td>
<td>UK</td>
<td></td>
<td>Not supported</td>
</tr>
<tr>
<td>0022 Frozen pelvis, male and female</td>
<td>Major</td>
<td>UK</td>
<td>Supported</td>
</tr>
<tr>
<td>0024 Peyronie’s disease</td>
<td>UK</td>
<td></td>
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</tr>
<tr>
<td>0026 Drug resistant microorganisms</td>
<td>Major</td>
<td>Aust</td>
<td>Supported</td>
</tr>
<tr>
<td>0027 Reticuloscarcoma</td>
<td>Aust</td>
<td></td>
<td>WHO/IARC</td>
</tr>
<tr>
<td>0028 Ross river fever</td>
<td>Aust</td>
<td></td>
<td>Not supported</td>
</tr>
<tr>
<td>0029 TMJ disorders</td>
<td>Germany</td>
<td></td>
<td>WHO</td>
</tr>
<tr>
<td>0030 Sacroiliac joint</td>
<td>Germany</td>
<td></td>
<td>WHO</td>
</tr>
<tr>
<td>0031 Ankylosing spondylitis</td>
<td>Germany</td>
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<td>WHO</td>
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<tr>
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<td>Germany</td>
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<td>0035 Degeneration, corticostriatal-spinal</td>
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<td>Germany</td>
<td>Supported</td>
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<td>0037 Snapping hip</td>
<td>Germany</td>
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<td>Held over</td>
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<td>0039 Extrapulmonary systemic mycobacterial inf</td>
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<td></td>
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</tr>
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<td>0040 Overactive bladder</td>
<td>North America</td>
<td></td>
<td>WHO</td>
</tr>
<tr>
<td>0041 Sinus bradycardia</td>
<td>Aust</td>
<td></td>
<td>WHO</td>
</tr>
<tr>
<td>0042 Hantaan virus with pulmonary manifestaion</td>
<td>Brazil</td>
<td></td>
<td>Held over</td>
</tr>
<tr>
<td>0043 Ca of middle ear &amp; resp system</td>
<td>Brazil</td>
<td></td>
<td>Not supported</td>
</tr>
<tr>
<td>0044 Agents acting on muscle &amp; resp system</td>
<td>Brazil</td>
<td></td>
<td>Not supported</td>
</tr>
<tr>
<td>0045 Cerebral palsy</td>
<td>Aust</td>
<td></td>
<td>Held over</td>
</tr>
<tr>
<td>0046 Aetiology/manifestation codes</td>
<td>Aust</td>
<td></td>
<td>Held over</td>
</tr>
<tr>
<td>0049 Note 4.2.2 “highly improbable” (m)</td>
<td>Minor</td>
<td>MRG</td>
<td>Supported</td>
</tr>
<tr>
<td>0052 Intraventricular haemorrhage</td>
<td>Aust</td>
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<td>Held over</td>
</tr>
<tr>
<td>0053 Dementia in hypothyroidism</td>
<td>Minor</td>
<td>Aust</td>
<td>Supported</td>
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<tr>
<td>0054 Cleft lip and palate</td>
<td>Germany</td>
<td></td>
<td>Held over</td>
</tr>
<tr>
<td>0055 Diagnostic and therapeutic procedure</td>
<td>Germany</td>
<td></td>
<td>Not supported</td>
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<td>0060 Laryngomalacia</td>
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<td></td>
<td>Held over</td>
</tr>
<tr>
<td>0064 Suicidal ideation</td>
<td>Aust</td>
<td></td>
<td>Held over</td>
</tr>
<tr>
<td>0065 Organic personality disorder</td>
<td>Major</td>
<td>Aust</td>
<td>Supported</td>
</tr>
</tbody>
</table>

4.3 Item 0023 Abscess of Pouch of Douglas proposed by the UK had not been supported by URC – no further work is required.

5. Ratification of the proposed ICD-10 updates – 2000 [ICD-10 (2002)]
Ratification of the tabled document was deemed unnecessary. The table will be updated with the minor recommendations supported at this meeting and circulated to the URC members for proofing.

6. Code expansion-numbering conventions/the level of detail warranted internationally
The participants agreed that this is not appropriate for international discussion and that the countries introducing additional characters should discuss this issue between themselves.
7. Establishing links with IARC for decisions on neoplasm/morphology coding
The secretariat advised that they have existing links with IARC in regard to issues of neoplasm/morphology coding through the Unit of Descriptive Epidemiology. There was discussion about the URC's role in regard to oncology changes to ICD-10 and it was agreed that the secretariat will draft a proposed solution for how changes in ICD-O-3 should be reviewed for inclusion in ICD-10. This proposal will be circulated to URC members for discussion.

8. Dissemination of updates and changes made by the MRG and the URC
This item was held over for discussion in a subsequent plenary session.

9. Evaluation process
It was agreed that recommendations need to be screened more effectively before presentation to the Heads of Centres meeting.

It was also agreed that recommendations should be referred to the WHO clinical groups when 'international' clinical advice is deemed necessary to evaluate a proposal. This will ensure that clinical advice received from a particular country has international credibility prior to consideration by URC members.

It was also agreed that the URC should engage in a continuous discussion process via e-mail and teleconference to reduce the burden of decision making at the Heads of Centres meeting.

The possibility of using a voting system to ratify recommendations was discussed but it was agreed that a process of consensus is preferable.
Appendix 2
Implementation of ICD-10 Committee

Chair: Margaret Hazlewood (representing Carlos Castillo-Salgado)
Rapporteur: Sue Walker

The Chair welcomed participants and invited discussion points for the meeting. It was determined to focus on the Terms of Reference set in Cardiff in 1999, to review progress to date and to consider issues raised in the report of global ICD-10 implementation status (WHO/GPE/ICD/C/00.62).

The Committee discussed the timing of implementation, particularly in countries where vital registration processes are poor or non-existent. It was noted that full enumeration is not necessarily a prerequisite for the introduction of ICD-10 – in fact, introducing ICD-10 may serve as a catalyst for improvements in this area. Support for processes relating to vital registration was stated to be a responsibility of United Nations Statistical Division.

Recommendations:

1. The goal for the global implementation of ICD-10 for countries that are upgrading from ICD-9 is 2005.
2. Countries that are implementing the ICD for the first time should be encouraged to implement the 10th revision.
3. The goal for the global implementation in the countries covered by 2. above is 2010.
4. A well-documented implementation checklist for both categories of implementation is required and is to be developed. This may be a booklet that amplifies the points outlined in the report of the Cardiff meeting.
5. Further work is required to validate the existing data relating to the global situation on ICD-10 implementation.

The Implementation committee reviewed its achievements against its stated Terms of Reference.

1. conduct a regular international stocktake of ICD-10 activities
   1.1. review the current situation with regard to ICD-10 implementation
       • done, through the survey coordinated by PAHO
   1.2 review current processes for implementation
       • review not done, although it was recognized that the experiences of the Paris Centre in providing support for Tunisia could be utilized for this purpose
2. review of training materials
   • the training and credentialling subgroup has worked on this area and has developed and circulated a survey instrument and compiled the results
3. review of the capacity of Regional Offices to implement ICD-10
   • review not done
4. sharing of experiences relating to implementation
   • not done - the group noted that work on the implementation checklist would assist with this Term of Reference.

Other issues discussed by the Implementation Committee:

- sharing of post-implementation experiences

Post implementation evaluation studies, such as bridge coding, data quality studies and comparability studies, should be reported at the annual Heads of Centres meetings. It was suggested that the reports of such studies could be posted on the WHO web site as a central repository and a resource for countries wishing to conduct similar work.

- support for the concept of Collaborating Centres ‘adopting’ a country to provide implementation assistance
The issue here is the allocation of resources – not necessarily financial – and the provision of longer term support and a close relationship between a particular Collaborating Centre and one or more countries.

Priority support for AFRO was noted as a necessity, highlighted through the data provided in response to the implementation questionnaire. EMRO also requires assistance although there has been considerable difficulty contacting an appropriate person in the Regional Office. The Paris Centre is willing and able to provide support for the French-speaking nations in these regions.

- It was suggested that Collaborating Centres should identify existing ICD trainers within their jurisdictions, and that this list be available as a resource for countries considering training.

- The use of coded data should be encouraged as a means of identifying quality problems and improving coding quality. There is a need to share methodologies for quality assessment. It was suggested that this be a topic of discussion for the 2001 meeting. The Paris Centre was encouraged to further report on its activities relating to mortality data quality, being jointly conducted with Eurostat.

The group discussed the ongoing requirement for the work of the committee and predicted a bright but busy future.

The Implementation Committee reconvened to develop a work program for 2000/2001. Three major projects were identified as achievable priorities:

1. validation of information about the existing global implementation status
   1.1 results of a survey conducted under the auspices of PAHO to be circulated at the Rio meeting with a request that it be updated as necessary. Changes made should be annotated to indicate the name of the person making the change.
   1.2 the updated results to be sent to Regional Offices and Collaborating Centres for confirmation.
   1.3 A further survey to be conducted in 2003 (to confirm the progress towards the 2005 goal) and 2006 (to identify whether the goal was met and to highlight progress towards the 2010 goal).
   ACTION: PAHO

2. development of implementation checklists
   2.1 development of checklists for morbidity implementation in countries previously utilizing ICD-9. National implementation plans to be gathered from relevant countries (eg Australia, Canada, the UK) and a template developed.
   ACTION: Collaborating Centre for North America (through Louise Ogilvie, Canada)

   2.2 development of checklists for mortality implementation in countries previously utilizing ICD-9. National implementation plans to be gathered from relevant countries and a template developed.
   ACTION: UK Collaborating Centre (through Peter Goldblatt)

   2.3 development of checklists for mortality implementation in countries which have not previously used the ICD.
   ACTION: Paris Collaborating Centre (through Gérard Pavillon's experiences in Tunisia)

   2.4 development of checklists for morbidity implementation in countries which have not previously utilized the ICD.
   ACTION: PAHO (through Roberto Becker)
Action items 2.1-2.4 timetable:

Information regarding national implementation checklists to be forwarded to nominated contact person by end December 2000

1st draft of generic implementation checklists to be developed by nominated persons January – March 2001

Draft implementation checklists to be forwarded to Carlos Castillo-Salgado, PAHO for circulation to Committee members by end of March 2001

Consideration by Committee members and direct feedback to nominated persons April – May 2001

Comments to be incorporated by nominated persons and submission of checklists for discussion at 2001 Heads of Centres meeting June-July 2001

3. support for implementation in EMRO and AFRO

3.1 investigate how to involve the Regional Offices for EMRO and AFRO in the plans of their constituent nations to implement ICD-10 – WHO secretariat to be asked to nominate an ICD-10 focal point in each Regional Office, in particular these two regions

ACTION: Chair of Implementation Committee, PAHO

3.2 letter to be written to AFRO, indicating the committee’s support and understanding of the issues raised in this region’s response to the implementation questionnaire and promoting the implementation of ICD-10 as a means of improving comparability of data. Although constrained by a lack of financial resources, the committee is willing to assist wherever possible.

ACTION: Chair of Implementation committee, PAHO

3.3 Once advice is received from the secretariat regarding the focal point for ICD in EMRO, send a letter of request for information relating to implementation of ICD-10 in that region. If no response, follow up with the secretariat to indicate the difficulties the committee is having in obtaining any response and the problems that this raises in terms of data collection, comparability and reporting. If still no way of contacting the region is identified, bring this issue to the attention of the Heads of Centres at the 2001 meeting, with the view to recommending that the Director-General be made aware of the problem, given that WHO has a mandate to implement and support the ICD-10 internationally.

ACTION: Chair of Implementation committee, PAHO

Recommendation:

The Implementation committee recommends that the opportunity presented by the planned discussion of the Family of International Health Classification and summary health measures at the next World Health Assembly, be also utilized to make mention of the importance of the collection of high quality and standardized data relating to health through the use of the ICD-10. Special mention should be made of the difficulties being experienced in communicating with AFRO and EMRO and the subsequent gaps in international mortality reporting.
Appendix 3 Mortality Reference Group

Chair: Harry Rosenberg
Rapporteur: Cleo Rooney

The Mortality Reference Group (MRG) determined the following agenda items for discussion:
1. Review and corrections to annual report
2. Workplan for 2000-2001
3. Dissemination of decisions and advice
4. Size and composition of Group
5. Use of pick-lists or drop down lists in death certification
6. Mechanism for updating Decision Tables in automated systems

Review and corrections to annual report

The secretariat congratulated Harry Rosenberg, Lars Age Johansson, and Donna Hoyert on producing such a clear and informative report of the activities of the MRG in the past year. Minor corrections to the wording of the annual report were agreed. The title of table 1 is to be changed to ‘Decisions made by the MRG…’, from ‘Issues considered by…’ The revised version will be made available on the WHO website. It was pointed out that while the Group had made a decision on coding maternal mortality, that issue was not fully resolved. The Chairperson pointed out that the text of the report indicated that the issue of maternal mortality had not been fully resolved and might be addressed again in the future. It was not considered necessary to amend Table 1, which showed actions that had been taken.

Workplan for 2000-2001

Some areas of current concern were raised:

- Coding of drug and alcohol related deaths, poisonings and intoxications
- Coding of ‘indirect’ maternal deaths
- Issues about HIV raised by Dr. Richard Selik of the U.S. Centers for Disease Control and Prevention
- The work of the Update Reference Committee (URC) on the classification of Diabetes

The important contribution of deaths from acute alcohol poisoning and other effects of alcohol on the mortality crisis in the Newly Independent States of the former USSR was discussed. Dramatically different patterns of alcohol-related mortality in different countries were noted. The need to ensure the comparability of these data for public health is clear. Equally, interest in deaths related to drugs and poisonings is high. Several international bodies, including EUROSTAT and EMCDDA, are either seeking guidance on coding such deaths or planning to provide it themselves. There are a number of outstanding questions about the use of the F codes for substance abuse or dependence, when ‘acute intoxication’ should be used and when a poisoning codes from chapters XIX and XX should be used. The MRG will bring together all the queries and problems related to these causes of death, and consider them together so as to produce comprehensive, coherent guidance.

It was apparent that there are differences in interpretation of whether all disease deaths related in time to pregnancy should have a pregnancy-related code as their underlying cause. The secretariat suggested that all such deaths fell within the definition of ‘indirect maternal deaths’ and should be coded to chapter XV. The UK felt that where a directly lethal disease predated pregnancy, and its course was unlikely to have been altered by the pregnancy, the underlying cause should be the disease. The MRG decided to examine this more fully, with examples from a variety of countries.

Dr Selik has identified some issues in coding deaths related to HIV and AIDS. He is seeking the opinion of the wider community of AIDS physicians and epidemiologists on the range of malignant neoplasms and infectious diseases which should be assumed to be due to HIV / AIDS for the application of Rule 3. The results of this consultation will be considered by the MRG in due course.
The group agreed that it would be important to keep up to date with any changes in recommendations for describing or classifying diabetes mellitus and how these might impact on coding of death certificates. In particular, the URC is asked to inform the MRG of any instructions or recommendations they make.

Members agreed to review the outstanding questions listed in paper WHO/GPE/ICD/C/00.18 by Lars Age Johansson, and the issues above, and to rank them in order of priority. The group will then collate these and decide the order of work for the coming year. These would be integrated into the existing problem sets that are being worked on by the group (a total of 13 issues).

**Dissemination of decisions and advice**

Many of the questions considered by the MRG arise from problems sent to the Mortality Forum by coders. If these go though the whole update process, the original inquirer may not get an answer for a very long time. The MRG discussed the possibility of producing a newsletter for participants. However, it was decided that it would be more efficient just to inform all participants and inquirers that the annual reports of the MRG would be made available on the WHO Website. The WHO Regional Office for Europe suggested that the Regional Offices should promulgate this information to countries in their regions.

**Size and Composition of the MRG**

It was agreed that participation in the Mortality Forum run by Lars Age Johansson of the Nordic Centre should be open to anyone who wanted to join. The Internet address should be advertised through Regional Offices and the WHO website. This has been a valuable educational resource and helps to improve comparability of coding between countries. The working language is English. It was suggested that the countries of the English-speaking Caribbean might wish to join this forum. PAHO runs a similar forum in Spanish, which has wide participation throughout Latin America. PAHO and the Nordic Centre will continue to cooperate in their forums to ensure consistent advice in the two languages and exchange of knowledge and ideas.

Membership of the MRG will continue to be limited to nominees of Collaborating Centres. It was suggested that Japan and the Spanish-language Centre in Caracas might wish to nominate members to ensure full representation of countries using these languages.

**Use of pick-lists or drop down lists in death certification**

The Chairperson reported that some information technology suppliers producing systems for electronic death certification in the USA were including drop-down lists of causes of death for completing the medical certification of death, as well as lists to interpret common abbreviations, as noted in paper WHO/GPE/ICD/C/00.70. The MRG is unanimous in condemning this practice. It is essential that causes of death continue to be reported by physicians and coroners in their own words. Such lists will grossly distort mortality statistics and stifle further development of understanding of disease sequences and terms. The UK Centre reported that similar problems had been noted with default values or drop-down lists for other variables (e.g. country of birth, whether post-mortem was done and place of death) when death registration was automated in the UK. It was also pointed out that though the danger of such lists was greatest with automation, it could be a problem in paper systems as well.

The MRG has written a paragraph to be added to Volume II of ICD-10, making clear the need to record cause of death accurately and not to use such lists. This will be promulgated through the WHO website, Collaborating Centres and Regional Offices. The recommended paragraph – to be inserted in ICD-10, Vol. 2, p. 31, at 4.1.3, after the last sentence of the second paragraph, is as follows:

**The medical practitioner should use his or her clinical judgement in completing the medical certificate of cause of death. Lists of diseases or conditions should not be used to influence the reporting of any of the direct or antecedent causes of death.**
Mechanism for updating Decision Tables in automated systems

It is essential to have a clear, open, and reliable method for updating the decision tables used in automated coding to apply the mortality rules. A mechanism, also described in paper WHO/GPE/ICD/C/00.70, was presented schematically by the Paris Centre and agreed by the MRG. The decision table updates would occur not more often than once a year. The process could be initiated by any of three sources: the Mortality Reference Group, the Mortality Forum, or the ACS Users Group. The MRG could take actions in the following ways:

(a) through the traditional channel of the URC,
(b) through an emergency short cut by securing WHO informal agreement through the secretariat,
(c) directly if the update did not concern the ICD,
(d) the Mortality Forum could effect an update if there were a clear consensus in the Mortality Forum, and if the update did not concern ICD. (There would be merit in referring this to the MRG for informational purposes, so that WHO, Collaborating Centres and member countries could be systematically apprised of changes to the decision tables), and
(e) through the ACS Users’ Group, with the concurrence of the nosology staff of the U.S. National Center for Health Statistics. (Again, it would be desirable to work through the MRG for informational purposes).
Appendix 4 Training and Credentialling subgroup

Chair: Marjorie Greenberg
Rapporteur: Louise Ogilvie

The Chair welcomed participants to the meeting. The following three agenda items were proposed and agreed to:

- review of Subgroup on Training and Credentialling Terms of Reference;
- review and discussion of three key action items arising from the Cardiff meeting; and
- update on International Collaborative Effort (ICE) on Automating Mortality Statistics with regard to training activities.

Review of Terms of Reference

The terms of reference were reviewed to determine if they were still relevant. The status of specific work activities was also discussed. The Subgroup agreed that the terms of reference were still relevant and did not require further amendments. Specific comments that arose during the discussion of activities include:

- 1.1 and 1.3 – The North American Centre was unable to carry out work in identifying the critical functions, skills and levels of training for medical coders/nosologists; this will be carried out over the next year.
- 1.2 – Needs assessment questionnaires for mortality and morbidity have been drafted and were sent out to members of the Subgroup for review.
- 1.4 – Educational and training curricula questionnaire was sent to Collaborating Centres; responses were collated and presented to this Heads of Centres meeting.
- 1.5 – TENDON was identified as a WHO training tool.
- 2.1 and 2.2 – The recommendations of the ICE on Automating Mortality Statistics and the Eurostat Project were circulated to members of the Subgroup; The Chair will re-circulate these to the group.
- 3.2 and 3.3 – the North American Centre to assist with the identification of groups requiring training in completion of source documents, as well as specifying the purpose of the training; this work will proceed over the next year.
- 3.6 – Training for other members of the Family of International Health Classifications was identified as a future activity; training on an International Classification of Procedures could be included as a future activity if work evolves in this area.

During the discussion, PAHO raised the question as to whether Caribbean countries could be affiliated with a WHO Collaborating Centre. It was agreed that this should be further discussed with the secretariat.

Needs Assessment for Mortality and Morbidity Medical Coders

The needs assessment questionnaires for mortality and morbidity medical coders have been circulated to the Subgroup members for review and comment. Participants were asked to review the draft documents again and send comments to the Chair. An item for inclusion in the questionnaire regarding the capacity of centres to conduct training both within and outside their Collaborating Centre was discussed. It was also suggested that in-service training for coders be added to the questionnaire. The revised questionnaires will be sent to WHO which will then distribute these as part of a planned WHO questionnaire. It is hoped that the survey can be distributed and the information collated before the 2001 Heads of Centres Meeting.

Survey of Collaborating Centres to Catalogue and Characterize Current Educational and Training Curricula and Modules

The survey was distributed to Collaborating Centres and results compiled. The Chair will follow up on known information gaps and will also send the survey to Regional Offices. Participants were asked to review the results and provide feedback. The revised copy of the questionnaire results will be posted on the WHO website. In addition, it was recommended that a paper version of the questionnaire results be available in the form of a brochure. This will be explored with the WHO secretariat. Members
expressed their appreciation to the North American Centre for taking the lead on this work and the production of a comprehensive and useful report.

It was noted during the discussion that the licence for the TENDON software application has expired. This product can be purchased from the Office for National Statistics in the UK.

The role of a Morbidity Forum and/or Morbidity Reference Group to support morbidity data collection was briefly discussed and will be brought forward during the plenary session.

**International Process for Credentialling Medical Coders and Nosologists**

The Western Pacific Centre reported that the quadrennial International Federation of Health Record Organizations (IFHRO) Congress was recently held in Melbourne, Australia. Sue Walker presented the Subgroup’s proposal regarding the possible affiliation of mortality and morbidity medical coders/nosologists with IFHRO and its national affiliates to both the Grand Council and the Executive Committee of IFHRO. The objectives of the affiliation would include the promotion of support, training and career advancement for medical mortality and morbidity coders and nosologists. The concept was supported, and three members of IFHRO have volunteered to participate in a new joint Working Group to further work on this topic. A number of members from the Collaborating Centres/WHO Regional Offices also agreed to participate on the Working Group (North American, Nordic, UK, PAHO). It was recommended that this Working Group be jointly chaired by IFHRO and WHO Collaborating Centres. S. Walker (Collaborating Centres) and K. Brouch (IFHRO) were recommended as co-chairs. Work will primarily occur by e-mail and some conference calls. The Subgroup supported the phased in approach for this work, beginning with underlying cause-of-death coding, then moving on to main condition for morbidity, and later to multiple causes of death and secondary conditions, respectively. It was also agreed that the Working Group would keep the Subgroup members informed of progress over the next year. In terms of next steps, it was agreed that S. Walker will contact K. Brouch and during a subsequent plenary session, other Collaborating Centres/Regional Offices will be asked to volunteer members to join the new Working Group.

**International Collaborative Effort on Automating Mortality Statistics**

The North American Centre informed the Subgroup of an international training programme being developed for automated mortality coding systems. This programme will consist of three-week on-site training modules (approximately two) over the course of one year, as well as pre and post training at the student’s place of work. The training for the on-site modules will be held at the NCHS Facility in Research Triangle Park, North Carolina in the US. The programme is to begin in the spring of 2001 and will initially accommodate 6-9 students. There will be no charge for this programme, however students will be required to cover their own travel and accommodation costs. The training programme will take a “train the trainer” approach. This training is viewed as an international program versus a US programme. The relationship of this work and the new joint Working Group described above will need to be further explored by the newly-formed Working Group.
Appendix 5 Electronic Tools committee
Chair: Michael Schopen
Rapporteur: Peter Goldblatt

The committee considered the following papers:

- Electronic Maintenance of Clinical Classifications: Comparing Two Approaches (WHO/GPE/ICD/C/00.33)

The paper compared two methods of storing the ICD electronically, as a tool for maintaining and developing classifications. The two methods used were as a Microsoft Access database (developed by the NCCH in Australia to support ICD-10-AM) and as an SGML document (developed by DIMDI in Germany to support the German-language edition of ICD-10). Both ways of storing the ICD electronically had advantages over holding the classification as a word processing file, enabling searches to be performed more effectively, improving the tracking of changes and providing flexibility in producing a wide range of products. While Access is more familiar to many staff, SGML provides greater granularity. Using software such as BALISE it is possible to move between these two types of files. Production of files for web publishing can be achieved with both systems. The use of electronic versions of the classifications was therefore recommended, using either a database or an SGML document.

The main issue raised in the meeting was how to disseminate the electronic classification information and at what price. Options include making it an internationally available public good, creating a consortium to sell it and generate income for WHO and Collaborating Centres or to let an outside developer produce it and carry all the risk. Although there is an important distinction to be made between use for research and statistics or use for commercial gain, it is difficult to prevent unauthorized commercial exploitation in these circumstances.

While electronic versions make it easier to provide updates, it has proved difficult to ensure that users take up these updates (e.g. by downloading from the Internet).

Update: International Collaborative Effort on Automating Mortality Statistics (WHO/GPE/ICD/C/00.70)

The report of the International Collaborative Effort (ICE) on automating Mortality Statistics identified the following:

- Concern at the use of “pick list” functionality to cause of death certifications. The ICE will recommend to the Mortality Reference Group that ICD-10 Volume 2 should include a paragraph warning against the use of pick lists in medical certification of death. This issue was also discussed by the Mortality Reference Group and an appropriate paragraph drafted.

- A systematic process is proposed for updating decision tables and for documenting changes, to ensure that these get to users. This will be recommended to the Mortality Reference Group.

- An international curriculum in ICD-10 coding oriented to ACS was proposed and is likely to be implemented by the US in 2001.

- Options for establishing an ACS bulletin board are being explored.
Recognizing the urgent need for an electronic version of the ICD-10, the committee proposed two recommendations for consideration by Heads of Centres:

**Recommendation 1**

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

**Recommendation 2**

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

These recommendations stemmed from a need for a searcher (browser) and for different languages to be available to users for this purpose. The importance was highlighted of having the history of update changes available on the system, with the dates at which these became effective. The electronic index should be available in different English spellings, to facilitate searching.

The committee will be sending out a questionnaire to all Collaborating Centres on the availability of electronic tools relating to the ICD. For the purpose of this questionnaire, the committee agreed on the following definition of electronic tools for the proposed questionnaire:

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

It was agreed that the next steps to proceed with the workplan were to:

- set up an e-mail network in the next few days (Michael Schopen)
- circulate draft questionnaire before Christmas 2000 (Michael Schopen)
- write paper on dissemination policy for electronic versions of ICD-10 (Donna Pickett, Gérard Pavillon, Sandra Mitchell, Michael Schopen)
- agree on the structure and languages for a multilingual database, through a face-to-face meeting of technical experts in 2001.
Appendix 6 Links with Other Classifications committee

Chair: Richard Madden
Rapporteur: Lynn Bracewell

The Links Committee met on two occasions during the meeting, and reported on each topic in its work programme during the plenary sessions.

The purpose of the committee is fully captured in the Terms of Reference. The committee was tasked to prepare a paper to take forward the concept of a WHO Family of International Health Classifications (WHO-FIC).

The Chair opened the session by thanking the United Kingdom Centre for hosting two meetings of the Links Committee in London during the year, and providing the services of Dr John Ashley to assist the Committee. He then introduced the summary paper entitled The concept of the Family of International Health Classifications (WHO/GPE/ICD/C/00.27) which proposes a means by which the scope of the WHO-FIC may be defined. The paper focuses on the background and defines the problems. The proposed concepts within the paper were described, including the essential criteria for compliance as a member of the Family: nature, scope and application/settings, the components of each and aspects of terminologies described as different levels of granularity, such as:

- Vocabularies (natural language)
- Classifications
- Hybrids (groupings).

The paper proposes that the family of classifications includes ICD, ICIDH-2 (ICPC, ICECI) but does not include vocabularies or hybrids, however the committee acknowledged the ‘characteristics’ of the classifications identified is not necessarily complete.

The scope of the family of health and health-related classifications were presented in a matrix format covering the dimensions and settings, family and area of applications. It was stressed that this is a first draft, it is work in progress and comments are very important. The two-dimensional matrix shows that each cell should have, in principle, one classification in each cell. The Chair asked that, if anyone wished a copy of the matrix to complete the cells, this could be provided. Comments are welcomed and should be returned to the Western Pacific Centre.

The second paper was presented by the UK Centre entitled Criteria for cross referencing clinical vocabularies and classifications such as ICD (WHO/GPE/ICD/C/00.28). It explores the nature of classifications and clinical vocabularies including the relationships between them, and the UK’s work in this area, the stability of vocabularies and aggregation, using cross references and the need for classification rules. The need for clear and accurate cross-references between the dynamic vocabulary and the stable, fixed classification structures such as ICD was emphasized. Construction of good quality maps requires trained professionals to develop cross walks and this idea was supported by the group. The paper recommends that WHO should consider the need for national governments to be responsible for accrediting maps between vocabularies and ICD used to generate statistical data for governmental use.

The third paper was presented by the Nordic Centre on behalf of the Links Committee. The paper was entitled Definitions and Concepts related to the Family of International Health Classifications (WHO/GPE/ICD/C/00.37). It is an attempt to understand the definitions and concepts, such as ‘classification’. It is by no means a final decision of the committee, but a discussion paper. The models presented are not necessarily complete but attempt to distinguish these different elements. It does not show the process of how to construct a classification but rather tries to identify the concepts and the relationships.

The Nordic Centre contributed a further idea relating to the family of classifications for health care based around need and what should be included:

- Laboratory investigations
- Procedures
- Functional status
- Problems of care
- etc.

Comments:

- Concern was expressed that the concept of a ‘family’ of classifications could be constraining in the light of clinical terminologies.
- The ICD index is a structured vocabulary and therefore within the concepts of the paper would be excluded from the family. There is a need to consider the structure of the classification.
- A suggestion was put forward relating to the need to define reference terminology and interface terminology.
- If the index is regarded as a national index rather than an international index, this goes against the conventions built into the classification.
- The Nordic Centre reported that an Electronic Patient Record will be introduced in Denmark in the next 4-5 years. However, clinicians/nurses cannot be expected to learn another language (in order to extract data at the end) and there is a possibility that the data do not accurately describe what it should be. Therefore the translation is key and it was suggested that we cannot expect this to be done at an international level - it has to be a national responsibility. It is stressed there is a big step from vocabularies to classifications or modifications. It is important to use the classifications with all the rules and conventions, but it is a lot of work and it would not be possible to make an international mapping.
- A query was raised in relation to clinical modifications: was there any role for this group to network, sharing information to ensure international comparability? The secretariat advised that, from a WHO perspective, international comparability is key.
- Interest was expressed about this view, and the group was asked if it could assist and learn from each other.
- How for our next meeting, can we improve/progress work between terminology/SNOMED/ICD? What could enrich our knowledge? The North American Centre acknowledged that a lot of work and real progress had already been made in this area.

Action:

- It was agreed that the paper on clinical vocabularies/classifications should be expanded and a translation made of the UK Centre’s paper into Figure 1 of the different health care models/interface models presented by the Nordic Centre (indicating the mapping in the diagram). The paper to also identify differences between classifications and vocabularies.

Tuesday 17 October 2000 – meeting with the WHO Secretariat

A meeting was convened between the committee members and Bedirhan Üstün (representing the WHO secretariat) who had expressed that the paper was not satisfactory for WHO's needs. The idea of the Family was closest to the model illustrated by the Nordic Centre. The secretariat envisages a suite of tools for the family concept and sees the foundation of such a family as ICD and ICIDH-2 (which is coming of age).

The Chair advised that the matrix is crucial and the Nordic Centre's version also fits within the matrix. At this first stage the committee has only developed the theory but does not cover practicalities.

The secretariat discussed the need to package the ‘Family’ differently and come up with international comparability of information. A series of slides was presented to cover the issues.

- Primary aim: international comparability of health information
- Basic principles: scientific and transcultural
- Interrelated use: coherent, agreed and appropriate
- Versatility: responds to current developing health information needs of different users.

WHO sees the ICD as an etiological framework with ICIDH-2. This is seen as a proprietary view rather than a conceptual view.
• Foundation classes: categories of conceptual and metric equivalence
• Coding Rules: transparent and reliable
• Standards: uniform and meeting ISO standards

Axes of settings should be coherent with each other, aggregate to different groups and be fit for purpose. Discussion took place on the settings/application/purpose and the need to ensure that the final proposal is adhered to.

The secretariat advised that we have to meet ISO standards as far as possible.

How does one define ‘Family’?

• Parent and off-spring with a common ancestry and lineage
• Shared goals and values: long-term commitment towards living together under one roof
• Related homologous entities: such as Indo-European language group
• Evolutionary status: below order, above genus
• Vertical columns of periodic table (family of inert gases)

The secretariat advised that the UN system of classification identifies classifications as:

• Core
• Derived
• Related.

ICD and ICIDH-2 have been accepted as core health classifications.

The concept of the existing international families and national families of health classifications was discussed and seen as useful. National families should be consistent with the international family.

Adaptations of ICD are derived classifications within the WHO family. Drilling down will identify such additional specialist classifications.

Summary of discussions

Following the comments on the concept of the WHO Family of International Health Classifications (WHO-FIC) during the plenary session of the meeting, the Committee concluded as follows.

• There was general acceptance of the identification of three categories of terminologies:
  - Vocabularies
  - Classifications
  - Hybrids

• A distinction should be made between the potential terrain for health classifications and the WHO Family of International Health Classifications. The former is designed to include all existing and potential health classifications. The latter includes
  - the core health classifications (ICD and ICIDH),
  - adaptations and national modifications of the core classifications, and
  - other classifications of which WHO is the proprietor or where the proprietor has a formal relationship with WHO in respect of that classification.

• The index of a classification such as ICD may have a dual use as a vocabulary for a separate purpose, and may be altered for this purpose

• An additional criterion for a classification is stability over time; a vocabulary will necessarily need to change as rapidly as required to meet the needs of its users.

The Committee invites further comment (addressed to the Head of the Western Pacific Collaborating Centre) on Paper WHO/GPE/ICD/C/00.27, to be provided by 15 January 2001. The Committee proposes that it submit a further paper to the 2001 Centre Heads meeting, which should include draft text for insertion in the introductions of WHO health classifications.
Interventions

The Committee identified two specific tasks:
1. Proposing an interventions classification suitable for use by countries not wishing to develop a national classification
2. Comparison of intervention data among countries using national classifications.

Task 1

A questionnaire has been developed by the North American Centre to serve the dual purpose of:

1. Ascertaining the level of detail required by countries that do not already have a classification of interventions
2. Ascertaining the intervention classifications currently used.

The questionnaire was tabled during the Centre Heads meeting. Any comment on the content of the questionnaire should be forwarded to Donnamaria Pickett by 31 October 2000. The Committee agreed that the scope should not include ‘interventions’ where the patient is not present (such as laboratory tests). The questionnaire, when finalized, will be distributed to Regional Offices and Collaborating Centres (in conjunction with the training needs questionnaire). The Committee will consider the results of the survey when available, and report its conclusions to Centre Heads.

Task 2

The Western Pacific Centre presented a paper (WHO/GPE/ICD/C/00.26) proposing a summary version of ICD-10-AM for use in countries which do not currently have an intervention classification.

It was noted that many procedures are already included in the UMLS and common concepts are within the thesaurus. It was agreed that the possibility of using the UMLS to compare country classifications for the purpose of producing a sentinel list should be considered in the future. Whilst this may be useful for developed countries, it would not be useful for other countries. It was also reported that GALEN has software available to map in a logical manner and make comparisons but at a very sophisticated level.

A subgroup of the Links Committee will put forward a statement of intent for progressing a sentinel list for international comparison. Members of the subgroup are Alain Lellouch, Donna Pickett (convenor), Kerry Innes, Louise Ogilvie, Martti Virtanen, Alan Davies.

External Causes of Injury

The Committee welcomed the positive response from the subgroup convened by James Harrison (Australia) to the invitation to bring forward suggested changes to Chapter XX of ICD-10. The Committee will seek further input from the subgroup by the end of March 2001.

Links with WONCA

Following Dr Üstün’s letter to WONCA, Gunnar Schioler will approach WONCA to arrange a discussion in April 2001. ICD Centres wishing to join this discussion should advise Gunnar as soon as possible. The Nordic and Australian centres have indicated their interest. The WHO secretariat should be invited. Martti Virtanen will prepare a paper for WONCA explaining the work of the committee.

2001 Meeting of the Committee

The Nordic Centre has offered to host a face to face meeting in Copenhagen during the week 23-27 April 2001. The primary aim of the meeting will be to prepare the new paper on the conceptual basis for the WHO Family of International Health Classifications. The WONCA discussion should occur during this week.
Action summary

Secretariat

Make summary health measures a focus of the 2001 meeting of Centre Heads

Circulate questionnaire on needs assessment for mortality and morbidity coders for the Subgroup on Training and Credentialling

Investigate ways of ensuring that all Centres are able to participate in Mortality Reference Group teleconferences and report back within one month

Place the status of the Collaborating Centres and their redesignation on the agenda of the Executive Committee meeting to be convened in February 2001

Produce a paper on the mechanism for the periodic updating of ICD-10 making clear the process and timetable for updates

Draft a proposed solution for the incorporation of ICD-O-3 changes in ICD-10

Use the opportunity presented by the planned discussion of the Family of International Health Classifications and summary health measures at the next World Health Assembly to make mention of the importance of the collection of high quality and standardized data relating to health through the use of the ICD-10. Special mention should be made of the difficulties being experienced in communicating with AFRO and EMRO and the subsequent gaps in international mortality reporting

Advertise the Internet address of the Mortality Reference Group on the WHO website and through the Regional Offices

Discuss with PAHO the affiliation of the Caribbean countries with a Collaborating Centre

Work with DIMDI and Collaborating Centres on promoting the dissemination of updated versions of all volumes of ICD-10 through the Internet in downloadable and accessible form and by CD-ROM. Dissemination should take into account the periodicity recommended by the Update Reference Committee

Consider the need for national governments to be responsible for accrediting maps between vocabularies and ICD used to generate statistical data for governmental use

All Centres

Provide comments on the questionnaire on Coding and Reporting of Surgical Procedures and Interventions (document 00.68) to the North American Centre

Identify existing ICD trainers within their jurisdictions who could be used as a resource for counties considering training and inform the secretariat

Review and provide feedback on the matrices produced from the Survey of Collaborating Centres to Catalogue and Characterize Current Educational and Training Curricula and Modules to the Chair of the Subgroup on Training and Credentialling

Submit responses to the Survey to the Chair if this has not already been done

Send comments on the two-dimensional matrix for the Family of International Health Classifications to the Western Pacific Centre
Provide comments (addressed to the Head of the Western Pacific Collaborating Centre) on Paper WHO/GPE/ICD/C/00.27, by 15 January 2001

**United Kingdom Centre**

Act as a centre for international comparisons of mortality data for those countries able to provide long time series

**Implementation of ICD-10 Committee**

**Repeat the survey on implementation in 2001**

**validation of information about the existing global implementation status**
results of a survey conducted under the auspices of PAHO to be circulated at the Rio meeting with a request that it be updated as necessary. Changes made should be annotated to indicate the name of the person making the change. The updated results to be sent to Regional Offices and Collaborating Centres for confirmation. A further survey to be conducted in 2003 (to confirm the progress towards the 2005 goal) and 2006 (to identify whether the goal was met and to highlight progress towards the 2010 goal)

**development of implementation checklists**
development of checklists for morbidity implementation in countries previously utilizing ICD-9. National implementation plans to be gathered from relevant countries (eg Australia, Canada, the UK) and a template developed. *(Collaborating Centre for North America (through Louise Ogilvie, Canada)*

development of checklists for mortality implementation in countries previously utilizing ICD-9. National implementation plans to be gathered from relevant countries and a template developed. *(UK Collaborating Centre (through Peter Goldblatt)*

development of checklists for mortality implementation in countries which have not previously used the ICD. *(Paris Collaborating Centre through Gérard Pavillon’s experiences in Tunisia)*

development of checklists for morbidity implementation in countries which have not previously utilized the ICD. *(PAHO through Roberto Becker)*

Information regarding national implementation checklists to be forwarded to nominated contact person by end December 2000

1st draft of generic implementation checklists to be developed by nominated persons January – March 2001

Draft implementation checklists to be forwarded to Carlos Castillo-Salgado, PAHO for circulation to Committee members by end of March 2001

Consideration by Committee members and direct feedback to nominated persons April – May 2001

Comments to be incorporated by nominated persons and submission of checklists for discussion at 2001 Heads of Centres meeting June-July 2001

investigate how to involve the Regional Offices for EMRO and AFRO in the plans of their constituent nations to implement ICD-10 – WHO secretariat to be asked to nominate an ICD-10 focal point in each Regional Office, in particular these two regions *(Chair of Implementation Committee, PAHO)*

letter to be written to AFRO, indicating the committee’s support and understanding of the issues raised in this region’s response to the implementation questionnaire and promoting the implementation of ICD-10 as a means of improving comparability of data. Although constrained by a lack of financial resources, the committee is willing to assist wherever possible. *(Chair of Implementation committee, PAHO)*
once advice is received from the secretariat regarding the focal point for ICD in EMRO, send a letter of request for information relating to implementation of ICD-10 in that region. If no response, follow up with the secretariat to indicate the difficulties the committee is having in obtaining any response and the problems that this raises in terms of data collection, comparability and reporting. If still no way of contacting the region is identified, bring this issue to the attention of the Heads of Centres at the 2001 meeting, with the view to recommending that the Director-General be made aware of the problem, given that WHO has a mandate to implement and support the ICD-10 internationally. *(Chair of Implementation committee, PAHO)*

**Links Committee**

Organize a meeting with WONCA during 2001

It was agreed that the paper on clinical vocabularies/classifications should be expanded and a translation made of the UK Centre’s paper into Figure 1 of the different health care models/interface models presented by the Nordic Centre (indicating the mapping in the diagram). The paper to also identify differences between classifications and vocabularies

A subgroup will put forward a statement of intent for progressing a sentinel list of interventions for international comparison. Members of the subgroup are Alain Lellouch, Donna Pickett (convenor), Kerry Innes, Louise Ogilvie, Martti Virtanen, Alan Davies

Seek further input from the subgroup on external causes of injury by the end of March 2001

Gunnar Schioler to approach WONCA to arrange a discussion in April 2001. ICD Centres wishing to join this discussion should advise Gunnar as soon as possible. The Nordic and Australian centres have indicated their interest. The WHO secretariat should be invited. Martti Virtanen will prepare a paper for WONCA explaining the work of the committee

The Nordic Centre to host a face to face meeting in Copenhagen during the week 23-27 April 2001. The primary aim of the meeting will be to prepare the new paper on the conceptual basis for the WHO Family of International Health Classifications. The WONCA discussion should occur during this week

**Mortality Reference Group**

Members agreed to review the outstanding questions listed in paper WHO/GPE/ICD/C/00.18 by Lars Age Johansson, and the issues above, and to rank them in order of priority. The group will then collate these and decide the order of work for the coming year. These would be integrated into the existing problem sets that are being worked on by the group (a total of 13 issues)

**Electronic Tools Committee**

set up an e-mail network in the next few days (Michael Schopen)

circulate draft questionnaire before Christmas 2000 (Michael Schopen)

write paper on dissemination policy for electronic versions of ICD-10 (Donna Pickett, Gérard Pavillon, Sandra Mitchell, Michael Schopen)

agree on the structure and languages for a multilingual database, through a face-to-face meeting of technical experts in 2001.
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List of Documents

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WHO/GPE/ICD/C/00.5 Annual Report from the WHO Collaborating Centre for the Classification of Diseases in the Nordic Countries, 2000
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Update Reference Committee, Committee structure, work programme and membership

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Update Reference Committee, 2000 - Proposed updates to ICD-10 (2002)

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Status report on the work of the "Chapter XX" group, James Harrison, Australian Institute of Health and Welfare

Reporting iatrogenic injury in Australia, Jenny Hargreaves, Australian Institute of Health and Welfare

Proposed changes to ICD-10-AM to improve adverse event reporting, Rosemary Roberts, Kerry Innes, Sue Walker, Julie Rust, National Centre for Classification in Health

Classifying information about things "that go wrong" in healthcare, William B Runciman, Australian Patient Safety Foundation, Department of Anaesthesia and Intensive Care, Royal Adelaide Hospital


Development of an Encoder for Perinatal Mortality Coding - An Australian Project, Maryann Wood, Australian Bureau of Statistics

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Definitions and concepts related to the Family of International Health Classifications, G Schioler, Nordic Centre
Introduction of the new tabulation list for communicable diseases in Japan, Yasushi Mochizuki, Kazuhito Shirayoshi, Tetsuo Hirako, Ministry of Health and Welfare, Japan

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Development of the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Canada (ICD-10-CA) and the Canadian Classification of Interventions (CCI), WHO Collaborating Center for the Classification of Diseases for North America

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<td>WHO/GPE/ICD/C/00.66</td>
<td>Mortality bridge coding ICD-9/ICD-10: preliminary results from a Statistics Sweden study, Lars Age Johansson, WHO Collaborating Centre for the Classification of Diseases in the Nordic Countries and Statistics Sweden</td>
<td>Lars Age Johansson, WHO Collaborating Centre</td>
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<td>PAHO Regional Advisory Committee on Health Statistics (CRAES), Subcommittee for the ICD and the Family of Classifications, Dr Roberto Becker, Pan American Health Organization</td>
<td>Dr Roberto Becker, Pan American Health Organization</td>
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<td>WHO/GPE/ICD/C/00.68</td>
<td>Questionnaire on Coding and Reporting of Surgical Procedures and Interventions, WHO Collaborating Centre for the Classification of Diseases for North America</td>
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<td>Update: International Collaborative Effort on Automating Mortality Statistics, Harry M. Rosenberg, Kenneth D. Kochanek, and Ari Mininio, for the WHO Collaborating Center for the Classification of Diseases for North America</td>
<td>Harry M. Rosenberg, Kenneth D. Kochanek, and Ari Mininio, WHO Collaborating Center</td>
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### Background documents

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<td>Background03.doc</td>
<td>WHO Collaborating Centres, General Information, WHO Department of Research Policy and Cooperation, Geneva, May 2000</td>
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