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

Brisbane, Queensland, Australia
14-19 October 2002

Report

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Opening session

Opening

Dr Richard Madden, Head of the Australian Collaborating Centre, the Host Centre for this meeting, welcomed participants. He thanked the Brisbane Planning Committee and staff members of the Australian Institute of Health and Welfare (AIHW), the National Centre for Classification in Health (NCCH) and the Australian Bureau of Statistics (ABS) for their role in organizing the meeting.

Dr Bedirhan Üstün also welcomed meeting participants on behalf of WHO and officially opened the meeting. He extended further thanks to Dr Madden, session Chairs and Rapporteurs for making the meeting possible. He emphasized the importance of classification systems, as the building blocks of health policy.

Election of Officers

A list of proposed Chairs previously circulated at the Manly meeting was agreed upon by meeting participants. The list of Rapporteurs was also endorsed.

Consideration and adoption of the agenda

The draft agenda for the meeting (WHO/HFS/CAS/C/01.01) was agreed.

Strategic planning

Dr Üstün summarized the reports from the WHO-FIC retreat in Cruseilles, France (WHO/HFS/CAS/C/02.90) and the Strategy and work plan from the meeting in Manly, Sydney (WHO/HFS/CAS/C/02.98). He indicated that the report from the Planning meeting is a strategic document, which will be further developed over the course of this meeting.

Dr Madden supported Dr Üstün's presentation. He emphasized the strong consensus among Centre Heads on the need for the electronic version of ICD-10.

Report from the Secretariat on activities since last meeting

André L'Hours reported from the Secretariat on activities since last meeting WHO/HFS/CAS/C/02.04

Discussion points

- The status of the proposed ICD-10-XM was clarified. Dr Üstün stated that the ICD-10 is the standard on which modifications have been developed. The ICD-10-XM will essentially be a library database of modifications from which countries wishing to develop their own modifications can select.

- Regarding the issue of designation of Collaborating Centres, Dr Üstün stated that the formal process for designation is under way. Those Collaborating Centres awaiting formal notice of redesignation continue to be officially considered to be Collaborating Centres. If required they can obtain documentation from WHO confirming that the redesignation is in progress.
- Several Centre Heads stated that designation is essential for obtaining resources to join in WHO-FIC work. Others stressed the urgency for redesignation to ensure their continued resourcing.

Planning Committee arrangements

Dr Madden reported on discussions at Planning on the need to strengthen the existing Planning Committee structure. The current arrangements had worked well (past host Centre, current host Centre, and next host Centre), but would benefit from greater stability and capacity if a small number of additional Centres were included. The Planning Committee now not only plans annual meetings but it is also responsible for overseeing the implementation of the work plan. The Committee undertakes a range of networking and representative activities with WHO and other organizations, and in future will facilitate support for additional Centres. Language and geographic balance suggests five members in all, two Centres in addition to the past, current and forthcoming host Centres. In view of the fact that the 2003 meeting will be co-hosted by the Dutch and German Centres, the Planning Committee will exceptionally be composed of six members. At that time the two additional members will be the North American and Nordic Collaborating Centres. Their participation will be limited to a one-year period. A review of the different possible formats for the Heads of Centres meetings will be undertaken at the next meeting of the Planning Committee in April 2003.

Presentation of terms of reference and work plans of committees and work

The following reports from WHO-FIC Standing Committees were presented:

Family Development Committee: Annual Report (WHO/HFS/CAS/C/02.73) Richard Madden

WHO Mortality Reference Group: A Status Report, 2001–2002 (WHO/HFS/CAS/C/02.38) Donna Hoyert

Subgroup on Training and Credentialing: A Status Report 2001–2002 (WHO/HFS/CAS/C/02.60) Marjorie Greenberg

Annual Report for Update Reference Group (WHO/HFS/CAS/C/02.58) Rosemary Roberts

Annual Report of the Electronic Tools Committee (WHO/HFS/CAS/C/02.45) Michael Schopen

Annual Report of the Implementation of ICD-10 Committee (WHO/HFS/CAS/C/02) Remigijus Prochorskas

Participants were invited to join the sessions of these Standing Committees during the week. In particular, the Update Reference Group and the Implementation of ICD-10 Committee are seeking new members.

Dr Madden formally welcomed Professor Oye Gureje and Dr Debbie Bradshaw, representing the proposed Collaborating Centres in Nigeria and South Africa, respectively.

Actions:

The meeting:

- endorsed the WHO-FIC Strategy and Work Plan (WHO/HFS/CAS/C/02.98)
- noted the importance of committing start-up resources to the development of the electronic version of ICD-10.
- extended the membership and Terms of Reference of the WHO-FIC Planning Committee. The Planning Committee be composed of five Centre Heads to respond to the expanded responsibilities. For 2003, the two additional members are the North American and Nordic Centres who will serve for a one-year period.

Family Development Committee

Breakout session 1

Report of the WHO – WONCA Joint Working Group on the relations between ICD-10, ICF and ICPC-2 WHO/HFS/CAS/C/02.75

Dr Martti Virtanen presented on behalf of the FDC and Dr Niels Bentzen on behalf of WICC (WONCA International Classifications Committee).

WICC will be looking to map ICF to locomotor section of ICPC-2 in the next month or so and expressed a wish to continue the working group next year.

Discussion points

- It was suggested that the 'etiologically neutral' nature of ICF implied that it would not be possible to map ICF with ICPC-2.
- ICD-10 and ICF were not designed to classify Reasons for encounter. The ICPC-2 has the potential to be used in hospitals for people accessing the hospital as a primary care provider.
- WICC is keen to keep the classification intact and not recommend it as a member for reason for encounter only. They are keen to work for another year to align the diagnosis elements more closely with ICD-10.
- The paper explicitly states that ICPC-2 is for family/general practice and not for community health care or other primary care applications. Concern was expressed that there is a focus on one classification for general practice and that there would be a profusion of classifications for other primary care applications.

Dr Richard Madden thanked Dr Virtanen, Dr Schiøler and Dr Hirs for their efforts in the joint working group.

Submission for recognition of the International Classification of External Causes of Injury (ICECI) as a related classification within the WHO Family of International Classifications (FDC) WHO/HFS/CAS/C/02.74

Prof James Harrison on behalf of the ICECI Coordination and Development Group submitted the ICECI for endorsement as a member of the WHO-FIC.

Discussion points

- A preliminary crosswalk between the ICF and ICECI has been considered but had not been carried out on a systematic level.
- WHO suggested that the ICECI version 1.0 should be endorsed only once the alphabetic indexes are complete. The Chair of the FDC suggested that the classification could be endorsed for field-testing and that the index work could continue in the meantime.

Decision:

Propose the ICECI for acceptance, by Centre Heads in a plenary session, as a member of the WHO-FIC as a classification for testing (alpha version).

Australian Classification of Health Interventions adapted for international use (ACHI-I) (Australia) WHO/HFS/CAS/C/02.50

Mrs Linda Best gave an overview of the development of the classification and its current testing in a number of countries. Licensing arrangements need to be considered. NCCH has approached the Australian Department of Health and Ageing to waive the copyright in favour of WHO. WHO has been asked to endorse the ACHI-I as a member of the WHO-FIC.

Discussion points

- There are two purposes for which a classification of interventions is needed. 1) to be made available to those countries that wish to use it for national purposes, and 2) a classification for international reporting.
- There has been no mapping between the ACHI-I and other interventions classifications to see whether it is appropriate for international reporting. The issue of a sentinel list for international reporting is addressed during the meeting. The Nordic Centre will provide a background paper on the mapping issue to be discussed at the next meeting of the Family Development Committee in April 2003.
- There is concern that non-surgical procedures have not been expanded to include enough detail for the needs of the international community. Testing may indicate the areas that need to be expanded.

Decision:

The meeting suggested that the ACHI-I be accepted as an alpha version, for testing.

FDC Breakout sessions 2 & 3

On the ATC (Anatomical, Therapeutic, Chemical) classification system and its use together with ICD (Nordic) WHO/HFS/CAS/C/02.49

Ms Kristina Brand Persson presented the ATC. The ATC is a classification of substances developed and maintained by the WHO Collaborating Centre for Drug Statistics Methodology in Oslo. It is used for drug monitoring; a question is raised as to whether it can be accepted as a related member of the WHO-FIC.

Discussion points

- ATC is used as a national classification for medical drugs in the Nordic countries.. All drugs marketed in these countries are assigned ATC codes.

- The Nordic countries have mandated the classification for use together with ICD. One use of ATC is in hospital morbidity data. National ICD coding guidelines allow for the use of ATC codes to complement, or replace the relevant ICD codes with more specialized ATC codes.
- Updates are issued once a year and are made available at the Oslo Centre website. Publications have to be purchased; however there is a database which can be accessed on line.
- The relationship between the two classifications will need to be made clearer if the classification is to be accepted as a member of WHO-FIC. There is a loose mapping between ICD-10 and ATC.

Recommendation

The FDC would welcome a proposal from the Oslo Centre to include this classification as a related member of the WHO-FIC.

Shortlist of sentinel surgical procedures for international comparisons (Nordic) WHO/HFS/CAS/C/02.68

Prof Bjorn Smedby presented the results of the European Union work on a sentinel list of surgical procedures as a means to compare surgical activity across nations. An overview of the EU project was given, the tentative short list of 18 items presented and the following recommendations made.

- Collaborating Centres should review and test the sentinel procedures list.
- Further discussion on selection of procedures and definitions is needed.
- Mapping to other classifications has to be done, for example ACHI-I.
- The EU Hospital Data Project (HDP) testing experiences should also be taken into account
- After revision it should be considered for international use, possibly at the 2003 meeting.
- This could be used as a reference list.

Discussion points

- It would be easier to test the list if the purpose of the list were clear. The main aim is for hospital activity analysis. It was agreed that a better term is Selected List.
- The method of selecting items for the list, the inclusion and exclusion criteria for the list and the reason for using ICD-9 definitions were discussed. Selection criteria could include the volume of the procedure, cost of the procedure and the public health impact of the procedure.
- Collaborating Centres were offered the possibility to feed back to the EU HDP during the testing phase through the Nordic Centre.

- The Australian Collaborating Centre is keen to test the Selected List and believes that the ACHI-I encompasses all the items in the list.
- Work needs to be done to see the percentage of surgical procedures covered by the Selected List.

Decision:

That a Hospital data subgroup be established to undertake preliminary work to investigate the comparability of international hospital discharge data

That the recommendations of the paper be implemented.

Results of responses to the Survey on Surgical Procedures and Interventions (NACC) (No paper)

Mrs Donna Pickett gave a verbal update from North American. At the Bethesda meeting there was a discussion about whether to repeat the survey on surgical procedures. The testing of the ACHI-I has overtaken the need for a repeat survey.

It was suggested that it might be useful to have more information on the French triaxial classification of procedures.

The WHO Family of International Classifications and its Relationship to Clinical Vocabularies (NACC) WHO/HFS/CAS/C/02.83

Dr Willem Hirs opened discussion by suggesting that this paper is just a start to the work required on the relationship between WHO-FIC classifications and clinical vocabularies.

Discussion points

- Relations with the College of American Pathologists (CAP) (Owners of SNOMED-CT) were discussed, commencing with the presentation at the 2001 annual meeting. The Australian Collaborating Centre contacted SNOMED about the availability of mappings between SNOMED and classifications and the accreditation of maps. There is an issue about whether HoC should limit interest to mappings or to extend interest to vocabularies.
- Pr. Rosemary Roberts relayed an invitation from CAP to work on a map between SNOMED-CT and ICD-10-AM. The Australian National Centre for Classifications in Health (NCCH) is keen to be involved. However, it was agreed that representation at the meeting and use of the ICD for mapping should have endorsement of WHO.
- There are two approaches to mapping: to map from classifications to terminologies, or vice versa. That is to look at items in the classification to see the concepts and terms beneath that could be included in a terminology.

- Concern was expressed that the mapping between ICD-9-CM and SNOMED has not been validated.
- Also concern about the quality of language translations and the public access to maps and the proprietary product. A public use license for the US will not be of benefit for the rest of the world.
- There is a lot of activity around terminologies and UMLS and GALEN also need to be included in the discussions as alternatives to SNOMED.
- There is a sense of urgency in the need for a terminology as the IT industry will not wait for validated tools. An open source terminology could provide competition for the proprietary product.
- A working group should be formed to look at the options, the United Kingdom Centre offered to take the lead and draw up draft terms of reference before the end of the meeting.

Decisions:

That a Vocabulary working group, convened by the United Kingdom Centre, be established to validate mappings between ICD-10 and SNOMED-CT and to consider broader issues of relationships between WHO-FIC classifications and vocabularies.
Based on the recommendations of the Vocabulary working group, WHO will develop, in collaboration with all the parties involved, a protocol for the creation of an international WHO-FIC vocabulary.

Update on the International Collaborative Effort on injury statistics (WHO/HFS/CAS/C/02.34)

There was no presentation; the paper is for information only.

Decisions arising from open discussion on issues raised at the earlier breakout sessions.

Two items of new business for the FDC were identified 1) Classification of health services and 2) Issues of ICD and ICF together.

Decisions:

WHO and WONCA will jointly explore the possibility of developing an ICD-10-PC for broader primary care use.

In this the following tasks are relevant:

- ICD-10-PC & ICF relationship must be examined.
- The WONCA comparative study of ICPC-2 and the Swedish primary care version of ICD-10 be reported. Other countries are invited to do comparative studies.

- FDC should make recommendations for the development of a primary care classification.
- Needs of developing countries must be analyzed

It is recommended that the International Classification of the External Causes of Injury be accepted as an alpha version of a related WHO-FIC classification for testing.

It is recommended that a protocol be developed for testing of the alpha version of the Australian Classification of Health Interventions adapted for International use.

The FDC welcomed the information on the ATC and would welcome a proposal from the WHO CC in Oslo using the protocol for membership of the WHO-FIC as a related classification. The relations between ATC and ICD-10 will need to be clear in the submission.

The meeting welcomes the information about the Technical Aids Classification. The classification has a place within the matrix for the WHO-FIC and its relations with the ICF are very clear. It is recommended that a draft of the revised version be presented to the meeting next year together with a submission for membership according to the protocol; and a clear description of the relationship to the ICF.

The protocol paper is to be revised to reflect the levels and standards for related and derived classifications. WHO processes, once Centre Heads recommend a member, should be elucidated for incorporation in the protocol by the April 2003 FDC meeting.

Nominations to an Expert Group on use of classifications in casemix systems are to be referred to the WHO Classification Assessment and Survey Team by Nov 2002. WHO is to take the lead on developing the plan. FDC will reassess the situation in April 2003.

ICD-10 Implementation Committee

Two main agenda items were agreed:

1. To discuss and, if possible to finalize products in the current work plan, i.e. ICD-10 implementation definition, checklist and the roster of experts
2. To discuss/agree on strategic directions of work for IC and the concrete work plan for the next year with clear responsibilities attached.

Checklist and definition

During the first session on Monday the Canadian experience of implementing ICD-10 was presented (paper WHO/HFS/CAS/C/02.35). It set a logical background for subsequent discussions on the draft generic checklist of essential steps in the process of ICD-10 implementation, including the definition of implementation of ICD-10. A number of suggestions were made for further refinement of the checklist and the definition. It was agreed that the revised paper on the checklist will be circulated by e-mail to the active members of the IC for final comments. The finalized version will be included in the "ICD-10 in a box" package, distributed to WHO Regional Offices and made available via Internet. The purpose of the "Checklist" is to support countries (mainly developing countries) in the planning of ICD-10 implementation process.

As a related issue to the checklist, it was suggested to have a preliminary discussion on the content of the "ICD-10 in a box" – the new product included in the work plan that was developed at the strategic meeting in Sydney, 11-12 October. This was discussed during the second breakout session on Wednesday.

ICD-10 in a box

The concept of ICD-10 in a box has been discussed and a number of suggestions for the content received. The general consensus of the Implementation Committee was that the content must be at the "gold standard" level. Existing components already in the pipeline are obvious candidates e.g., ICD-10 Manuals in paper and electronic formats, checklist for implementation, training materials in paper and electronic format, roster of experts, automated coding systems. A number of additional components were mentioned as potentially useful, e.g., UNSD Guidelines for vital registration systems development or guidelines for mortality data analysis. However, it was felt that more discussion was required to define the concept and purpose of the "box" e.g., is it for use by experts to disseminate knowledge or for end-users to digest on their own; is this for countries at ground zero i.e., no ICD experience, those who are updating or those who have implemented but have not moved to process, analysis and dissemination of the data, or is this for countries who are using paper versus automated countries?

The secretariat informed the meeting that ICD-10 in a box would be developed as a part of WHO-FIC in a box which will have mortality, morbidity and functioning components. The mortality component will be completed first. For the morbidity and functioning components WHO will explore the possibility of engaging in public-private partnerships as well as involving educational experts.

Roster of Experts

Suggestions for the roster of experts as presented in paper number 18 have been discussed and generally accepted. PAHO (Robert Becker) volunteered to start and maintain the roster.

A number of issues were raised --

- Private versus public
- Individual versus organizations
- CC and WHO affiliations versus others
- Networks of support i.e. CC, WHO Regional Offices and WHO HQ
- Collaboration with the other UN agencies, universities, research networks

The roster will be initiated using the participant lists from the last three meetings of the Heads of Collaborating Centres.

Suggested main directions of work:

1. Continue to monitor the process of ICD-10 implementation, particularly in countries of African and Asian Regions.
2. To encourage and support countries in developing and strengthening their national vital registration systems as an essential background for the ICD-10 implementation for mortality. WHO Regional Offices should be empowered to play a key role in this area.
3. To support the implementation of ICD-10 by developing selected ICD-10 related tools, providing expert support (e.g., for planning or training), maintaining networks to share experiences and information.

Suggested operational work plan for 2002-2003

1. To finalize and disseminate the checklist (EURO)
2. To start the roster of experts (PAHO/AMRO)
3. To carry out the implementation survey in 2003 (AFRO with contributions from other ROs)

4. To start implementing the work plan for “WHO-FIC in a box” (see Strategy and Work Plan for responsibilities):
    - Identification of tools and modules needed for mortality component including technical specifications, design and piloting;
    - Review existing materials and identify gaps;
    - Plan for development of morbidity component;
5. To intensify collaboration with UNSD in order to develop adequate guidelines and joint work plans for strengthening of national vital registration systems in conjunction with ICD-10 implementation (WHO/CAS, AFRO, United Kingdom Centre, others)

Way of working of IC

There are three groups of IC members:

1. The staff of WHO Regional Offices and WHO/HQ that are dealing with ICD issues. This is “ an implementing arm” of the Committee, as Regional Offices have the mandate and obligation to support countries. Unfortunately, the actual involvement of some ROs in this work has been far from satisfactory so far. Appropriate actions by WHO/CAS with the aim to encourage the management of ROs to give adequate attention, resources and priority for ICD-10 implementation in their Regions may help to improve the situation.
2. United Kingdom Collaborating Centre staff. United Kingdom Centre kindly agreed to actively participate in the work of IC and act as secretariat for IC.
3. Participants of IC breakout sessions at the Brisbane meeting that expressed willingness to act as active members of IC.

The IC is chaired by representatives of WHO Regional Offices on a rotational basis. Until 2001 it was PAHO/AMRO. In the period between the Bethesda (2001) and Brisbane meetings, the main work was done by EURO. It was agreed that for the next year AFRO would take the lead.

Decisions:

Ensure that the following issues are covered in the ICD-10 implementation questionnaire:

1 The barriers to implementation of ICD-10.

2 The barriers to consolidating, analyzing and disseminating health information collected with ICD-10.

ICD-10 in a box is a part of WHO-FIC in a box which has mortality, morbidity and functioning as its components.

The mortality portion of the box is to be completed first.

For the development of the morbidity and functioning components WHO will explore the possibility of engaging in public-private partnerships as well as involving educational experts.

Training and Credentialing Subgroup/IFHRO Working Group

Breakout session 1

Three papers were presented during the first session:

- Procedures of Certification of Coders in Mexico (WHO/HFS/CAS/C/02.88)
- International education in coding, clinical documentation and quality assurance (WHO/HFS/CAS/C/02.67)
- ICD-10-AM Third Edition electronic education experience (WHO/HFS/CAS/C/02.52)

Discussion points:

- It is important to recognize formally the technical functions of coders.
- In providing international education in coding, one must also address clinical documentation and quality assurance techniques for coded data.
- Electronic education has many benefits for coders in today's environment, where time and resources are limited. However, it does not replace the importance of face-to-face workshops.

The Subgroup discussed the relationship with the International Federation of Health Records Organizations (IFHRO) and how the collaboration could be enhanced. It was agreed that in order to pursue international credentialing for ICD mortality and morbidity coders, the Subgroup and Working Group will need to develop minimal standards, a core curriculum and an exam. Given IFHRO's limited resources (it is a voluntary organization of other voluntary organizations), the Subgroup will need to develop the work products and seek IFHRO's input and endorsement.

The Subgroup and other meeting participants also discussed expanding the Subgroup work plan to include ICF training issues. The participants agreed that the Subgroup should consider training and credentialing for all the members of the WHO Family of International Classifications (FIC), not just ICD and ICF. In this way, experiences, problems and resources can be shared. However, the current priorities are ICD mortality and morbidity training and ICF training. There was support for a core group of ICF experts joining the Subgroup and developing a training and credentialing work plan for ICF, with an emphasis on training. The group will develop a questionnaire to catalogue and characterize ICF training materials and determine the capacity for ICF training. This could be used to develop an inventory similar to the ones developed for ICD-10.

Actions

1. **In the development of the workplan for the ICF the emphasis should be placed on training. The Subgroup workplan will be expanded to include ICF training and credentialing issues.**

Breakout session 2

The Chair noted that, as all individual papers had been presented in the previous session, this session would be devoted to a review of the work program for the Training and Credentialing Subgroup (WHO/HFS/CAS/C/02.60) and the development of a work program for the next year.

It was noted that the IFHRO representative was unable to attend this meeting for personal reasons, but that an article related to the joint WHO/IFHRO working group had been published in the IFHRO newsletter. It was not known whether there had been any feedback from IFHRO members.

The Needs Assessment questionnaires for ICD mortality and morbidity coders had been translated and circulated during the past year, and approximately 30 responses received. Some countries known to have implemented ICD-10 did not respond, however, the results showed interesting variations between countries in relation to education, service levels and needs for trained coders. Efforts will be made to get responses from some countries in regions that had not responded at all. It was noted that there had been a change in personnel in SEARO and that it had not been possible to get a response from EMRO. The aim of the Needs Assessments is to get information that will be useful to guide the development efforts towards an international standard for training and credentialing.

Actions

2 Feedback from Subgroup members regarding improvements and additions to the Needs Assessment Surveys are to be forwarded to the Chair, as are updates to the responses from countries represented on the T & C Subgroup.

3 The Chair will follow up non-responders and will clarify existing responses, which are unclear.

The matrices on ICD-10 Training Materials and Training Capacity have been posted on the Subgroup's home page, which is part of the North American Collaborating Centre's website (http://www.cdc.gov/nchs/about/otheract/icd9/nacc.htm). The Subgroup agreed that this information should be updated annually.

Actions

4 The Chair will request updates of the information in the matrices from the Collaborating Centres and Regional Offices and update the website accordingly.

The Chair asked whether there is a need to develop a brochure to ensure that people without Internet access can obtain information about the work of the T & C Subgroup. The group thought that the brochure should also include information about the Collaborating Centres themselves.

Actions

5 The Australian representatives will work on content for a brochure and will send the first draft to the Chair for circulation. The North American Collaborating Centre has experts in design who can put the finished product together into a brochure.

6 WHO will be requested to update the information about Collaborating Centres on the WHO-FIC website using information from the brochure.

7 The Chair will investigate the establishment of a List Serv for the Subgroup to facilitate communication.

8 WHO to be requested to post a link from the ICD-10 homepage to the Subgroup homepage; collaborating centres are also requested to do this.

The meeting then discussed the two papers related to Definitions, Skill Levels and Functions for morbidity coders (developed by the United Kingdom Centre) and for mortality coders (developed by the North American Collaborating Centre). The major challenge is to ensure that the terminology used is culturally and internationally appropriate. The documents are aimed at describing best practice and common standards for coding personnel internationally.

Actions

9 Comments on the two papers are to be forwarded to the United Kingdom Centre (Christine Sweeting) and North American Collaborating Centre (Donna Glenn and Amy Blum) within one month (i.e., by mid-November). The Chair will arrange a conference call of the small group working on the documents to discuss future plans.

The Chair then discussed a plan for the WHO/IFHRO/ Working Group of the T & C Subgroup to meet face to face, to progress work on the development of a core curriculum for mortality and morbidity coders. The suggestion was for the

meeting to coincide with the International Collaborative Effort (ICE) on Automated Mortality Data and the Mortality Reference Group meetings to be held in Washington in April 2003, to focus initially on underlying cause mortality coding and to develop a future plan for morbidity and multiple cause coding. The aim is to work towards a report to the IFHRO Congress in October 2004 to seek their endorsement of the proposed international credentialing process and to seek more engagement of IFHRO members. The IFHRO Congress may be preceded by a full face-to-face meeting of the T & C Subgroup in Washington earlier in 2004. Options for funding the two meetings will be explored by the Chair.

Actions

10 The Chair will arrange the face-to-face meetings. The North American, United Kingdom, Nordic and Australian Centres agreed to participate in the April 2003 meeting. The IFHRO co-chair of the Joint Working Group will also be invited.

11 In the context of the WHO-FIC in a box development, the Subcommittee should advise WHO on the curriculum for coding of the underlying cause of mortality at their meeting in April 2003.

A question was raised by the Japanese Centre relating to education for statisticians and data users, as well as data providers. The Automated Mortality ICE is working on collecting booklets and other materials provided to certifiers and discussing standardized international education for providers. It was noted that such education is generally provided through medical schools and specialist colleges.

Actions

12 The T & C Subgroup to maintain a watching brief on training for data producers, eg. Certifiers and health care providers, and data users through joint membership on the T & C Subgroup and Mortality ICE Committee.

The North American Collaborating Centre indicated that a useful publication relating to certification is available from the U.S. National Association of Medical Examiners in hard copy or downloadable from the website http://www.thename.org/CauseDeath/main.htm

The United Kingdom Centre indicated that concerns had been raised in some quarters from experienced coders who feel threatened by the proposed certification or credentialing process. The Subgroup sees the focus as upgrading

skills, not trying to get rid of coders and noted its desire to ensure that the work is seen to be of value to coders.

The concerns were acknowledged and will be taken into account in the development work. The Nordic Centre stressed the need for any examination developed to be pre-tested by members of the Subgroup prior to being released.

The Subgroup spent some time brainstorming ideas relating to requirements for a core curriculum for coders (predominantly mortality coders, although it was acknowledged that many of the issues also relate to morbidity coders). This will be used as the basis for further discussion at the face-to-face meeting in April 2003.

INITIAL THOUGHTS REGARDING EDUCATIONAL NEEDS FOR CODERS

Availability of resource materials, useful references
ACME decision tables or similar

Knowledge of medical science/anatomy and physiology/medical terminology

Uses and users of coded data
International context, history of the classification
International format of medical certificate of cause of death/local format/analysis of differences

Structure of the ICD
How to use different volumes of the ICD
Concept of the underlying cause of death
Appropriate exercises in selection and coding of underlying cause
Rules for coding
Updating mechanisms

Sources of data
Quality of source documents

Querying processes
Editing and validation
Ownership of data quality
Processes for accessing expert advice
Need for querying inappropriate sequencing
Reference to supervisors

Mortality Reference Group

Breakout session 1

Attendance: On Sunday, October 13, 2002, noon-3pm, Lars Age Johansson (Chair: Sweden), Donna Glenn, Donna Pickett, Donna Hoyert, Bob Anderson (US), Robert Jakob (Germany), Susan Cole (Scotland), Sue Walker, Anne Wellington, and Erin Anderson (Australia).

1. The MRG continued discussion of issues deliberated upon at the meeting in Bethesda, May 28-31. The issues were arranged according to the degree of disagreement in e-mails transmitted between June and October. The following issues were discussed:
   a. Question 4 Poisoning
   b. Question 26 HIV and respiratory arrest
   c. Question 60 Primary site unknown (Add a new issue concerning C97 to waiting list for MRG's future consideration)
   d. Question 68 Agent orange
   e. Questions 2-3 Diabetes
   f. Question 5 Fracture
   g. Question 6 Pneumonia
   h. Question 7 Conditions in Part I regarded as a part of the natural history of a disease reported in Part II
   i. Question 9 Which conditions should be considered a cause of dementia
   j. Question 35 "Due to" relationships
   k. Question 72 Narcotism
   l. Question 10 Chronic respiratory failure
   m. Questions 11-12 Pathologic fractures
   n. Questions 17-18 Alcohol
   o. Question 19 Old myocardial infarction
   p. Question 24 Gastroenteritis
   q. Question 27 Tuberculosis
   r. Question 33 Cardiomyopathy
   s. Question 34 Other diseases of pharynx
   t. Question 39-40 Pulmonary embolism
   u. Question 41 Anaemia
   v. Question 43: Decubitus
   w. Question 48: Tobacco

Discussion included outlining next steps to reach resolution and appropriate recommendations to be submitted to the Update Reference Committee.

2. Procedural issues focusing on how to speed up the work of the MRG.
    a. Tighten up process: Head e-mail with statement "Please send comments by 'x' date. No comment indicates assent and commits you to support the decision".
    b. Documentation: Australian members suggest adopting some of the URC documentation procedures (e.g., insert a table listing the countries and print their comments) in the minutes.
    c. Membership: Should we add anyone? We will remove a member who has changed jobs, ask others who don't participate if they wish to be removed, and add Rafael Lozano.
    d. MMDS: Automated system most efficient way to distribute changes but discussions need to look beyond the automated system.

Breakout Session 2

1. The MRG reviewed comments from the WHO secretariat concerning MRG recommendations (#0116, #0117, and #0120) to the Update Reference Committee. The MRG thinks that the recommendation is the best solution for the problems addressed in #0116 and #0117. For each of the recommendations, the MRG is willing to exclude mortality specific note in volume 1.
2. The MRG reviewed the tasks assigned to the MRG in report 02.98 on quality assurance and strategic intent. The MRG discussed what the group needs to do to complete the tasks assigned to us and came up with a plan for proceeding.
3. It was mentioned that the MRG met for 3 ½ hours on Sunday, October 13, 2002.
4. The MRG started reviewing earlier minutes beginning with question 51. The order of issues discussed are as follows:
    a. Question 51- secondary hypertension
    b. Question 52- cerebral atherosclerosis, etc.
    c. Question 54- heart and pulmonary edema
    d. Question 55- diabetes due to pancreatic damage
    e. Question 61- metastatic carcinoma and duration
    f. Question 65- heart disease index inconsistency
    g. Question 70- ileus, meconium
    h. Question 84- further rules and guidelines
    i. Question 8- cases when rule 3 shouldn't be applied

j. Question 14-16- vascular dementia
k. Question 23- primary site implied by "due to" sequence
l. Question 31- legal intervention
m. Question 37- may ill-defined condition block the application of Rule 3
n. Question 44- obvious causes of pneumonia
o. Question 47- alcohol linkages
p. Question 59- metastatic issues
q. Question 62- multiple injuries
r. Question 74- accident assumed cause of injury
s. Question 80- wording
t. Question 75- infarction, transmural

2. Procedural issues focusing on how to speed up the work of the MRG.

The MRG will shift operations from telephone conference calls to face-to-face meetings although e-mail, telephone, and face-to-face methods will all be used. The telephone conferences will focus on asking questions with a more limited scope and on ratifying solutions. E-mails will continue to be used to transmit information, get written comments, and solicit decisions by specific dates. The group will hold two face-to-face meetings annually:

a. Piggyback a 1½ daylong meeting onto the Heads of Centres meeting
b. Hold a 2-3 day meeting sometime around April, which will move around regionally. For 2003, the April meeting can piggyback onto the International Collaborative Effort on Automating Statistics (auto ICE) (to be held April 7-10) in Washington, D.C. There was some discussion that the MRG meeting needed to be held before the ICE meeting because an International Collaborative Effort on Injury Statistics (in Paris) is planned almost immediately after the auto ICE.

Decision

The Mortality Reference Group will hold two face-to-face meetings annually

Update Reference Committee

Breakout session 1

The first session consisted of a review and brief discussion of the four papers submitted for this session. The papers included the following:

- Annual report for the Update Reference Committee (WHO/HFS/CAS/C/02.58)
- Implementation of ICD-O-3 from a United Kingdom perspective (WHO/HFS/CAS/C/02.72)
- Data restructuring for the German translation and maintenance of ICD-O-3 (WHO/HFS/CAS/C/02.42)
- Consistency checks for the maintenance of ICD-10 (WHO/HFS/CAS/C/02.43)

1 The presentation of the first report, Annual Report for the Update Reference Committee, reviewed the accomplishments of the group during 2001. Mrs Michelle Bramley presented the report to members of the Update Reference Committee. The Committee maintained its standard of reaching decisions on 65 per cent of submissions received within the same year. The report provided details on the major decisions reached as well as other major work items still under consideration. The Committee decided to take back 15 work items from WHO, owing to the lack of resources within WHO to advance these items.

The report also described enhancements to Table 1, which provides information on version control and update cycle.

Official updates are sent to WHO, and are also available on the NCCH website (http://www.fhs.usyd.edu.au/ncch/who_urc.html). Mr André L'Hours stated that the web page information will also be reproduced on the WHO website.

The URC forum (an e-mail discussion list) was established to encourage discussion of morbidity coding and classification issues between the URC and other collaborating Center representatives, as well as a forum for discussion of URC work items by members of the URC. The forum is rarely used. Two strategies were proposed to improve the use of this tool:

- Establish the WHO ICD-10 URC webpage which outlines the objectives of the URC forum and provides information on how to subscribe to the list. This strategy has been implemented and the website established. By December 2002 this information will also be on the WHO website.

- Seek the cooperation of HoC in disseminating information about the forum to users of the classification.

At the Bethesda meeting in 2001, the URC was asked to write to Dr. Bedirhan Üstün of WHO to request support for the policy of updating ICD-10. The report was sent in December 2001, but no response has been received to date. However, the Chair observed that comments at both the Bethesda meeting and in the first day of the Brisbane meeting appear positive in terms of policy support.

The impact of the WHO-FIC strategy and work plan (WHO/HFS/CAS/C/02.98) on the URC work plan was mentioned. The Chair stated that the Committee will need time to discuss action items for the workplan during the second URC session.

There was no further comment on this presentation. Members approved the Annual Report as circulated.

2 The second report, Implementation of ICD-O-3 from the United Kingdom perspective, was not discussed in detail. Dr Cleo Rooney briefly commented that the paper concerned the simultaneous use of ICD-10, ICD-O-2, and ICD-O-3 and was essentially a plea for better coordination with the introduction of new classifications. However, she noted that the report had been superseded by events (not described).

3 Mr Robert Jakob presented the third report, Data Restructuring for the German Translation and the Maintenance of ICD-O-3. The report reviewed the process followed by the German Collaborating Centre in translating the English version of ICD-O-3 into German. The original file is in WordPerfect format, which presented considerable challenges in converting this file into a database. The report reviewed many of the steps followed in developing the translation, including matching the English file with existing translations into ICD-10, ICD-9, THS and UMLS. Phonetic matching was carried out as well.

The report proposed an alternative and much improved approach, utilizing string unique identifiers and concept unique identifiers to produce multilingual versions of the classification.

The paper was well received. The Chair commented that concept identifiers could be used for mapping morphology from ICD-10 to ICD-O-3. Dr Michael Schopen remarked on the controversy between vocabularies and synonyms. He observed that the approach outlined in the paper bridges the gap between the two, putting vocabulary below the classification. Mr L'Hours mentioned a WHO study that attempted to identify true synonyms between ICD-8 and ICD-9, but the authors ultimately gave up, as they could not reach agreement. Professor

Bjorn Smedby provided a cautionary note from Sweden, where they at one hospital had considered it unnecessary to code in both ICD-9 and ICD-O and only used ICD-O. However, when transferring the data to a central hospital discharge register the codes were truncated, losing important information and making all benign neoplasms malignant.

Mr Lars Age Johansson asked if the approach described in the paper could be used to handle shifts in meaning over time. The authors agreed that this is a problem.

4 Dr Schopen made the fourth presentation, Consistency Checks for the Maintenance of ICD-10. The paper describes routines contained in the SGML-based production system for the German language edition of ICD-10. The routines make use of dependencies between the various components of Volumes 1, 2, and 3 to enforce consistency of the master files and thus consistency of the user files. The dependencies between the three volumes of ICD-10 make it difficult to produce complete updates of the master files, hence computer assistance is essential to reduce updating errors as much as possible. The most complex part of maintenance involves changes to Volume 2. The speaker stressed the importance of identifying all of the redundancies so that they can be included in the system. He also requested the audience to provide all experiences relative to maintenance of ICD-10.

Response from the audience indicated that most groups are still updating their revisions manually. Similar responses were received from Mrs Donna Pickett regarding the ICD-10-CM, Mrs Lori Moskal concerning the Canadian system, and Mr Johansson concerning the work of the MRG.

Ms Kerry Innes raised the question of how to update Volume 2, as the original was done in WordPerfect. Mr L'Hours commented that a reprint of Volume 2 will be required, in part because a section of Volume 2 from the 9th Revision was inadvertently left out. He mentioned that distribution of revised versions of the ICD-10 volumes are complicated by varying stocks of printed copies of each volume. The Chair opined that an electronic update will be the solution to dissemination, but not for everyone. Paper copies of the volumes will still be required for many countries, so electronic updates must be in a format that can be used to print paper copies. Mr Johansson stated that the most efficient way to distribute coding changes was via the U.S. automated coding system.

Mr L'Hours was concerned that changes to the English version only of Volume 2 will affect international comparability of data. Given the complexities introduced by the updating system, Mr. L'Hours mentioned that, in supplying mortality data to WHO, countries will need to mention which version of ICD-10 they are using.

Breakout Session 2

The Chair began the second session with a discussion of the unresolved issues relating to the update process.

1 Correspondence to Dr. T. Bedirhan Üstün re updating process – dated 7 January 2002.

The Chair noted that no response has been received from Dr Üstün to date. To progress certain work items, it is necessary for the URC to seek the advice of the WHO Clinical Groups or Specialty Units or other relevant international bodies such as the International Agency for Research on Cancer (IARC). At the last meeting of the HoC it was agreed that WHO would give the URC secretariat access to these bodies and the Chair sought reassurance from the WHO secretariat that this support is available. Mr L'Hours responded that the clinical advice available from WHO headquarters was not extensive and depended very much on the clinical specialty.

It was decided that all new submissions requesting new codes or restructure of sections of the classification should be accompanied by clinical justification. The process for seeking further clinical advice would then depend on the clinical specialty involved. The submission could be forwarded either to WHO or an international body deemed relevant by the URC.

Action

The URC secretariat agreed to update the URC submission template by adding a section for clinical justification.

2 Correspondence to Dr. T. Bedirhan Üstün re establishment of working group for the classification of mitochondrial disorders – dated 2 May 2002.

The Chair noted that no response has been received from Dr Üstün to date. Mr L'Hours advised that he had not previously seen the letter and he believed that neither had Dr Üstün. He believed that a clinical working group should be established in collaboration with the WHO Headquarters Cluster of Noncommunicable Diseases and Mental Health (NMH).

Action

The URC secretariat agreed to resend the letter to Dr Üstün via e-mail with a copy to André L'Hours

3 Correspondence to the International Agency for Research on Cancer re URC work items Nos. 0015 and 0018 – dated 2 May 2002.

The URC secretariat informed that a response had been received from Dr. Kleihues, Director of the IARC in June 2002. He has forwarded the URC's correspondence to three experts:

- Dr. Guido Sauter, Pathology Institute in Basel, Switzerland (re malignant neoplasm of bladder sphincter)
- Dr Tanya Tavassoli, Gynecological Pathology, Armed Forces Institute of Pathology, Washington, USA (re malignant neoplasm of breast, ectopic site)
- Dr. Philip LeBoit, Clinical Pathology, University of California (San Francisco Campus), San Francisco, USA (re classification of keratoacanthoma).

There has been no response from these experts to date.

Dr. D. M. Parkin, Chief of the Unit of Descriptive Epidemiology, IARC, responded on 12 July 2002. He recalled that the revision committees of ICD-O-3 discussed the issue of ectopic breast tissue. He will consult with the editorial group concerning the URC's proposals and relay their opinion to the committee.

Action

The URC secretariat will keep members informed of any further correspondence.

Following the discussion about issues with the update process, the URC proceeded to a review of the work items specified in the paper WHO/HFS/CAS/C/02.59 URC Worksheets: Recommendations for updates to ICD-10.

Section 1 included 16 recommendations supported by the URC for inclusion in ICD-10 (2004) [minor updates] and ICD-10 (2006) [major updates]. These recommendations had been previously agreed via e-mail and were proposed for ratification.

All were accepted, with the exception of one minor change to URC 0120: *Transitory conditions as underlying causes of death*. In response to Mr. L'Hours concerns about the inclusion of notes in the tabular list that are only applicable to one group of users of the classification, the MRG agreed that the proposed notes in the tabular list mentioning mortality or underlying cause of death coding (Volume 1) be deleted. The remaining changes to Volumes 1 and 2 are to remain as indicated in the worksheets.

Section 2 included 12 recommendations that required further discussion. 6 items were accepted, 2 were withdrawn and 4 were held over and included in the URC work program for 2003.

URC 0002: Procedural complications:

There was mixed support for this proposal. Not all members were convinced of the need to implement the large number of changes to the index and tabular list, especially when the purpose of many of the changes was simply to make consistent the terminology used in the classification.

Decision

Work should continue on clarifying the Volume 2 guidelines. Any changes proposed to the tabular list and index should only reflect corrections to the inconsistencies in the classification. The Australian Centre will progress this work through the URC work program for 2003.

URC 0019: Diabetes mellitus

Members agreed with the North American Centre's recommendations to establish a working group to progress this work item.

Decision

The URC secretariat will establish a working group with membership from Australia, the Nordic Centre, North America, and a diabetologist from WHO Headquarters - Mr L'Hours will provide the URC Secretariat with the contact details. All proposals are to be sent to André and the MRG for comment before distribution to members of the URC.

URC 0025: Organic mental disorder/psychophysiologic disorder or dysfunction

Members agreed that the solution recommended was not appropriate for all users of the classification. Mr L'Hours mentioned that there were plans to align the revision of Chapter V with the development work for DSM-V. Dr Rooney questioned the process for approval of such changes, particularly if those changes involved entire chapters of the classification. After considerable discussion, members agreed that the URC is the appropriate body to approve all changes to the classification and all such submissions should be placed before the URC for ratification.

Action

The Chair will write, through CAS, to the Executive Director of the WHO Cluster

Group involved in this work (NMH) to establish a formal liaison with the URC. André will advise the Chair of the contact details for the Executive Director.

Decision

This work item will be withdrawn pending improvements to Chapter V. In the interim, all members should advise data analysts of the redundancies with F06.9 and F09 and that these two codes should be combined in any review of the data.

URC 0041: Sinus bradycardia

Decision

Members supported Dr Schopen's recommendation that the terms 'sinus tachycardia', 'sinusal tachycardia', 'sinus bradycardia', 'sinoatrial bradycardia', and 'vagal bradycardia' be classified to R00.1. Paroxysmal types of tachycardia are to remain classified to category I47. The URC secretariat will prepare the relevant changes to the tabular list and index for members' consideration in next year's work program.

URC 0065: Organic personality disorder

As this work item relates to URC 0025, the decision is the same.

Decision

This work item will be withdrawn pending improvements to Chapter V. In the interim, all members should advise data analysts of the redundancies with F07.0, F07.8 and F07.9 and that these three codes should be combined in any review of the data.

URC 0082: Corrections to Volume 3 following Dutch translation review

Decision

In relation to item no. 9, members agreed to adopt the index change as suggested by the Dutch Committee on Translation of ICD-10. Members did not support the suggestion to change the index entry for Deformity, mitral, Ebstein's Q22.5 to Deformity, mitral, Ebstein-like Q23.8 because this condition is exceedingly rare and the terminology is imprecise and may cause confusion with Ebstein's anomaly. All other changes accepted as circulated.

URC 0105: Conditions arising in perinatal period

Decision

The additional index entries were accepted as circulated.

URC 0115: Exclusion notes for K56 and P76

Decision

The proposal was accepted as circulated.

URC 0116: Intoxication as underlying cause of death

Decision

In response to Mr L'Hours concerns about the inclusion of notes in the tabular list that are only applicable to one group of users of the classification, the MRG agreed that the proposed notes in the tabular list mentioning mortality or underlying cause of death coding(Volume 1) be deleted. The remaining changes to Volumes 1 and 2 are to remain as indicated in the worksheets.

URC 0117: Selection of underlying cause of death when poisoning and drug dependence are mentioned on the same death certificate

Decision

The same decision applies as for URC 0116.

URC 0121: Classification of cystic fibrosis and related conditions

Dr Rooney expressed concern that some aspects of this submission dealt with measures of severity. Members agreed that the ICD-10 should not incorporate measures of severity.

Decision

Members decided to progress this submission through a working group.

The Australian Centre mentioned the supplementary paper from Cystic Fibrosis Australia in support of this work item and agreed to participate in the working group. Mr L'Hours nominated Victor Boulyjenkov, a geneticist from WHO headquarters and asked to receive a copy of all correspondence from the working group. It was mentioned that Mrs Liliane Heidet from the International Cystic Fibrosis (Mucoviscidosis) Association should also be approached. Members were asked to seek participation from experts within their own countries and advise the URC secretariat of any further nominations.

URC 0140: Inclusion term at K62.8 – Perforation (nontraumatic) of rectum

Decision

The proposal was accepted as circulated.

Section 3 included 5 work items that had been held over for inclusion in the URC work program for 2003. These work items were tabled for members' information only and will be discussed via e-mail next year.

Section 4 included 1 work item that had been withdrawn. Its withdrawal from the work program was accepted.

The final agenda item involved a discussion on the impact of the WHO-FIC strategy and work plan on the URC work plan (WHO/HFS/CAS/C/02.98).

Task: Collate and report proposals for updates to ICD-10.

The time frame was amended to April 2003 to accommodate the MRG's work plan which involves a face-to-face meeting in April.

Task: Make available all the English versions of updates, past and current and cumulative, in both electronic and print versions.

The time frame was amended to April 2003 to accommodate the Electronic Tools Committee's work plan.

Task: Consider separation of updates to tabular lists and instruction manual from updates to the index.

Mr L'Hours explained the strategic intent of this task. The member countries that need to translate the updates do not use the index for this purpose. They rely purely on the changes to Volumes 1 and 2. Not all members agreed with this statement. Some member countries do use the index for translation purposes. As there was little support for this task, members requested that it be deleted from the WHO work plan.

Task: Establish a process to incorporate updates to ICD-10 onto the WHO website.

The WHO secretariat stated that this would be done by December 2002.

Electronic Tools Committee

Breakout Sessions 1

The meeting discussed the annual report of the committee (WHO/HFS/CAS/C/02.45) which had already been presented at the plenary session on 13 October.

Other papers presented included paper WHO/HFS/CAS/C/02.36 from the North American Collaborating Centre on ICD-10-CA and CCI in database format. This paper described the Canadian process of developing from a Microsoft SQL database in 2000 released for implementation across Canada in 2001 to development of an Oracle database planned for release in 2003. CDs of the classification are released in French and English and there is a two-year updating cycle.

A further formal paper included in this segment was paper WHO/HFS/CAS/C/02.28 (Report on Eurostat Technical meeting on mortality coding systems) presented by the French centre. Six countries in Europe are using automated cause of death coding systems. Some European countries are experiencing difficulties in allocating Entity Reference Numbers for non-English versions. There is a proposal to collect terms from death certificates to develop dictionaries for non-English application of automated cause of death coding systems.

The third paper (WHO/HFS/CAS/C/02.31) was a Report of the Planning Committee on the ICE on Automating Mortality Statistics presented by the North American Collaborating Centre. Previous meetings have been held in 1996 and 1999 and a further meeting is being planned for April 2003. This meeting is to include sessions on electronic tools and data dissemination as well as the core business of the ICE.

Breakout session 2

A formal paper on Modelling of ICD-10-AM was presented by the Australian Centre (WHO/HFS/CAS/C/02.65). The paper described a process being undertaken to make explicit the relationship between the ICD-10-AM tabular list, index and Australian Coding Standards. The modelling has taken specific body systems for diseases and procedures and modelled using classification and clinical principles. A further piece of work consists of rolling out the index of ICD-10-AM to create clinically meaningful concepts and terms which are suitable for mapping to terminologies and which demonstrates the terminological basis of the classification.

This second meeting of the group focussed on the Work plan for the WHO Family of International Classifications, Electronic Version of ICD-10 included in the Strategy and Workplan developed at the Planning meeting (WHO/HFS/CAS/C/02.98). The

first recommendation from that paper is to develop a strategy and time lines to Center Heads and this task occupied most of the time of the committee.

The current situation is that WHO has discontinued distribution of files of ICD-10 on floppy disc and CD-ROM. However, an electronic version of ICD-10 in XML format is soon to be available at WHO. It consists of the three volumes in English without updates. The meeting agreed that members of the ETC should review the XML files and assess whether the semantic structure and granularity are sufficient and whether it can be converted for use on systems within the Collaborating Centres. Following feedback from members, updates are to be included and a meeting held in Geneva to finalize specifications for the electronic version. It was felt that there might be a need for an alternative plan in case the XML version is not appropriate or not a suitable starting point. Members suggested the possibility of using databases from clinical modifications such as those developed in Canada and Australia and strip these back to the core ICD-10 codes. Also, German and French files are available in SGML from DIMDI.

Discussion points

- The importance of version control with the use of an electronic product. It was recommended that there be close coordination with the Update Reference Committee and its update cycle and version labelling conventions.
- There is also a need for electronic versions of ICD-10 to facilitate the development of language versions. DIMDI has versions in SGML in German, French and English. Content and layout are separated so that an identical structure is obtained for all three languages.
- The committee recognized the urgent need for an electronic version of ICD-10, updated. Emphasis should be placed on making available a basic, valid, workable, electronic version of ICD-10, with a second priority being development of more sophisticated tools to support flexible databases for modelling, mapping and terminological development work. Electronic versions should also support generation of lists of changes, mappings and historical trends such as the Chronicle being developed for ICD-10-AM.
- The electronic version of ICD-10 is to be placed on the net (including the WHO website) in read only format. The WHO is to then undertake further work on preparing a database format for information systems which could be sold to generate revenue for WHO.

The possibility of an ICD-10-XM was also presented in principle by Dr Bedirhan Ustun and discussed by the group at the ETC and at other meetings held during the week. ICD-10-XM is a vision to combine existing clinical modifications to allow convergence and exchange of updating clinical principles. The aims of ICD-10-XM is to manage knowledge through electronic representation of ICD-10 and its modifications and to make available the exchange of detail of clinical modifications

to those wishing to develop ICD-10 and to map between clinical modifications. It was also thought that such an exercise would inform the development of ICD-11 and possibly to develop a superset of ICD-10-XM. It was agreed that the core should be ICD-10 with an initial focus on diseases only. Existing clinical modifications such as CM, CA and AM would be included initially, with further modifications being added as they become available (e.g. Thai Modification, French version, Nordic modifications). It is envisaged that countries will retain intellectual property and copyright to modify the classification in their own countries and will receive proportionate revenue if ICD-10-XM is sold as a WHO product.

ETC established an ICD-10-XM Working Group, with initial membership from WHO, Germany, Canada, US, United Kingdom, Nordic Centre, Australia, France, Brazil, Mexico and Thailand. Australia to coordinate this group along with WHO. Dr Ustun undertook to prepare for circulation to members a paper on the aims of ICD-10-XM. Following review by members, Dr Ustun will coordinate creation of a business plan outlining resources required to coordinate the XM functions and their location either at WHO or a Collaborating Centre.

The committee briefly touched on the need for it to coordinate with other related activities such as the development of electronic training materials such as INTERCOD. It was felt that this is particularly important in light of integration of ICD-10 and related education and other materials in ICD-10 in a Box.

The action and timelines for the electronic version of ICD-10 agreed by the committee for the WHO-FIC Strategy and Work Plan are outlined below:

Number	Activity	Responsibility	Deadline
1	Send XML and PDF files to ETC chair	WHO	By 15.11.02
2	Distribute to ETC members and CCs	Chair	By 22.11.02.
3	Analyze usefulness, report back to chair ETC	CCs	By 15.1.03.
4	Convene meeting with WHO staff and ETC members to finalize technical specification	WHO-CAS	By January 2003
5	Produce according to specification: English French Spanish and other WHO languages	 DIMDI DIMDI/Paris CC WHO-CAS/PAHO	 By April 2003 By October 2003
6	Make beta version (read only) available on the internet (pdf) English French Spanish and other WHO languages	ETC ETC ETC	By April 2003 By October 2003
7	Publish final version English	 WHO-CAS	 By June 2003

	French Spanish and other WHO languages	WHO-CAS WHO-CAS	By December 2003
8	Set up dissemination and sales plan	WHO-CAS/Advisory Group	By September 2003

Decisions

The committee confirmed the urgent need for an electronic version of ICD-10
ETC established an ICD-10-XM Working Group, with initial membership from WHO, Germany, Canada, US, United Kingdom, Nordic Centre, Australia, France, Brazil, Mexico and Thailand.
The strategy and timelines for the electronic version of ICD-10 agreed by the committee

International Classification of Functioning, Disability and Health

Breakout session 1

The Chair opened the session and discussed ICF issues that were identified at the Bethesda meeting of WHO Collaborating Centres meeting in October 2001 and at the meeting in Trieste (April 2002). Gaps in addressing these issues in Brisbane were that there are no papers on:

1. Maintenance and update process for ICF
2. Joint use of ICD and ICF together, and
3. Validation of assessment tools to ICF qualifiers

Recommendations

Recommendations
Noting that implementation issues for ICF are different from those related to the ICD, it is recommended that a new subcommittee should be established under the WHO-FIC Implementation Committee to work on ICF Implementation issues;
An ICF retreat to be organized to deal with ICF items
Joint use of ICD and ICF to be the responsibility of the Family Development Committee
The working relationship between WHO, the Centre Heads and the planning group of the Washington City Group should be strengthened and formalized

Actions

Actions
A strategic plan for training to be developed. Because of this, the Terms of Reference of the Training and Credentialing subgroup and the Electronic Tools Committee, to be expanded to include ICF issues and ICF experts
WHO is requested to prepare a policy paper on maintenance and updating of the ICF
The Centre Heads to consider how to proceed with a validation of assessment tools for ICF qualifiers
That, in relation to ICF activities, a formal mechanism be sought to ensure coordination between WHO as custodian of ICF and other UN agencies

The following papers were presented:

1 WHO/HFS/CAS/C/02.33 Washington City Group meeting report (NACC)

The North American Collaborating Centre commented that the conventions for issuing invitations are too rigid in that the proper experts on disability issues and ICF

issues may not be invited to participate. There should be more flexibility in extending invitations to known experts in the field. The Australian Centre commented that the ICF activities of WHO and the UN activities have not been adequately coordinated. He also recommended that a more formal relationship between the Centre Heads and the planning group of the Washington City Group should be developed. The North American Collaborating Centre suggested that the World Health Surveys should be represented at the Washington City group meetings. The WHO Secretariat noted that when invitations are sent to country representatives, WHO invites Ministries of Health, UN Statistical agencies, and national health statistical organizations. Representatives may therefore differ; and a formal mechanism is needed to bridge this gap.

2 WHO/HFS/CAS/C/02.92 Report on Trieste meeting

The WHO secretariat reported on the Trieste meeting. A question was raised about WHO's plan for future ICF meetings. The Secretariat responded that future WHO-FIC meetings will include ICF, as happened in Bethesda and now in Brisbane. This will replace the previous meeting structure, although it was noted that if particular aspects of ICF needed discussions, a specific purpose meeting might be planned. It was also suggested that meetings should not be the only way of conducting business, and that creative ways about accomplishing ICF business should be considered.

Discussion points

- The Australian Centre suggested that the previous list of eight ICF issues from the Bethesda meeting (coding guidelines, implementation, etc.) could be the basis for future planning, for example for the announced ICF retreat proposed for July 2003 (suggested earlier in the day by the WHO Secretariat. The North American Collaborating Centre had mentioned at the strategic planning meeting in Sydney prior to this meeting, that the idea of an International Congress of Classification might be considered.
- The Nordic Centre asked if any ICF updating process has been worked out, and it is not. Richard Madden took exception to the Report on the Trieste meeting, and a part of the presentation, stating that "disability is a decrement in health" as inconsistent with what is said in the ICF book. "The Book is the Book, which was agreed upon", he stressed. The WHO Secretariat noted that the ICF book clearly states that ICF classifies health and health-related states. Therefore, any disability (e.g. impairment of body function or structure, activity limitation or participation restriction) is considered to be a decrement in health.

2 Adapting the ICF for child health systems: a status report (NACC) WHO/HFS/CAS/C/02.41

Dr Rune Simeonsson, Professor, University of North Carolina (Brisbane 41), and Chair on the working group for ICF Children and Youth, reported on the work of the

ICD for Children and Youth. The slides were in more detail than the paper in terms of timetables, scheduled meetings, issues etc.

Discussion points

- The use of ICF among clinicians should be encouraged.
- There was a discussion about the combined use of ICD and ICF and whether clear definitions exist to guide their use in severity assessments in acute care settings.
- The North American Collaborating Center noted that the National Committee on Vital and Health Statistics has encouraged the use of both classifications in the United States to capture a more complete clinical picture.
- Dr. Lozano, Mexico, encouraged the work to be completed "sooner rather than later", because paediatricians in Mexico are interested in ICF, and there is no children's version to give them.
- Regarding the first field trials to be scheduled in extension with the 1st draft in spring 2003, Dr Paul Placek asked whether wide participation was invited as in the ICF field trials. Dr Simeonsson referred to a planned consultation with WHO later on this, and Dr Bedirhan Üstün replied "the wider participation the better".
- Prof Ruy Laurenti, Brazil commented that "child health issues" would be a better title, rather than "child health systems" as suggested in the paper.
- Dr Richard Madden recommended a procedure for final approval of ICF for Children and Youth in the group of Centre Heads of the Family of Classifications, by its finishing in 2004. This issue will be dealt with in WHO consultation scheduled later this year.

Plenary Session - Tuesday 15th October 2002

1 Report on the Eighth Annual North American Collaborating Center Meeting on ICF: Issues and Future Activities (NACC) WHO/HFS/CAS/C/02.37

Ms Diane Caulfeild, North American Collaborating Centre, gave highlights on the Eighth Annual North American Collaborating Centre, meeting on ICF, held in Toronto in June 2002. (Brisbane 37)

Discussion points

- Prof Ruy Laurenti, Brazil asked whether the North American Collaborating Centre, recommended involving professionals with disabilities in implementation, and Diane Caulfeild replied in the affirmative.
- Prof Rosemary Roberts, NCCH, Australia asked about the areas of stroke, asthma and spinal cord injury where ICF and ICD best might be used together, and Ms Caulfeild stated that the presentation of Dr. Stucki's work at the University of Munich, Germany referred to this.

- Dr Placek, North American Collaborating Centre, commented that Dr Simeonsson has done a paper, presented elsewhere, on using ICD and ICF together in children's research.

2 Dissemination of ICF: CODE ICF; North American ICF Clearinghouse; ICF Videos; ICF Curricula in North American Colleges and Universities; and Spring 2003 issue of Health Care Financing Review, WHO/HFS/CAS/C/02.40

Dr Placek, North American Collaborating Centre, presented a paper on five ICF dissemination methods supported by NCHS contracts: Code ICF; North American Collaborating Centre, Clearing House; ICF videos; ICF Curricula in North American Colleges and Universities; and spring 2003 issue of Health Care Financing Review which will examine capturing functional status from administrative records for reimbursement and quality control.

Discussion points

- Dr Madden of the Australian Centre stressed the need for the people recorded and used in the video to have the opportunity to review and to approve their segment in the product, and Dr Placek agreed.
- Dr Notzon, NCHS, recommended that Centre Heads be given another opportunity to review Code ICF before it goes to WHO, and Dr Placek agreed
- Ms Ros Madden, AIHW pointed out that the Australian website will have information on ICF uses, and other Collaborating Centres websites may also have such information, and so they should have hotlinks to each other.
- Dr Placek noted in closing that Code ICF will be a WHO approved product, upon WHO website, and regular updates are anticipated. NCHS has offered to support a Code ICF update effort.

Actions

Actions
North American Collaborating Centre to provide opportunity for those who are on the ICF videos an opportunity to view the product.
North American Collaborating Centre to provide opportunities for CCs to become more involved with the development of Code ICF by commenting on current version and future updates.
Centres with websites with information on uses of ICF consider linking to each other.

3 Coding Guidelines for ICF – Issues That Need Resolving (UK & WHO) WHO/HFS/CAS/C/02.93

The Coding Guidelines paper was presented jointly by Mrs Jane Miller, UK and Dr Üstün, WHO HQ. Each issue was raised by Mrs Miller and responded to by Dr Üstün.

Discussion points

- Dr Üstün referred to the coding guidelines paper as preparatory work which should be seen in the context of the development of an ICF casebook and ICF training material. WHO will explore the possibility of establishing a working group on coding guidelines and to develop Terms of Reference. Coding guidelines may be an independent document or used as a part of training material.
- Mrs Greenberg, North American Collaborating Centre, asked whether the document was "for discussion and reaction, or to move on as a basis for action". Dr Üstün stated that it was a draft to be updated and circulated.
- It was noted that the statement in the coding guidelines paper "The current scheme of expressing the activity and participation component in a single list of life domains and measuring activity as capacity and participation as performance reflects an international consensus on a concept which is clear and meaningful, and to which WHO is bound, needs to be clarified.
- The WHO secretariat clarified that WHO recognizes the ICF information Matrix and Annex 3 as the international consensus but that WHO has chosen the option of measuring activity as capacity and participation as performance. WHO welcomes information on the use of the other options. So far no countries have communicated their national preference.
- After concurring with this comment, it was suggested that the paper, as distributed, would raise unnecessary alarm but that adding comments from the discussion would dispel concerns.
- WHO/CAS asked Centres to provide specific examples to illustrate areas not covered in the coding guidelines, however, it was also felt that some issues could best be addressed and incorporated in training materials.
- WHO/CAS also asked that Centres forward any coding guidelines that they had previously developed for use with ICIDH. It was thought that these guidelines could inform the work of the development of ICF guidelines. It was also noted that the focus of coding differed between ICD and ICF in that ICF focuses on a profile and not an encounter.
- There were varying opinions expressed regarding the need for coding guidelines. Some felt that in order to ensure consistency that guidelines were needed as soon as possible. Others felt that the lack of coding guidelines should not delay use of ICF for coding and that the problems may be in the mind of the coders and not a problem with ICF.

Recommendations

1. To revise the paper to reflect the additional clarifications provided during the discussions.

2. WHO to explore the possibility of establishing a Workgroup on Coding Guidelines.
3. Collaborating Centres and countries to submit to WHO ICF data, coding rules, back coding schemes and specific examples to illustrate areas not covered in the coding guidelines .
4. To systematically collect empirical evidence on a number of areas as implementation of ICF continues.
5. WHO to post on their website a list of the schemes being used by each country.

ICF Breakout session Wednesday AM

1 Exploring the Measurement of Participation (Australia) WHO/HFS/CAS/C/02.77

This paper was presented by Ms Samantha Bricknell, Australia.

Discussion points

- Dr Jerome Bickenbach, WHO suggested that Dr David Gray's work and Dr Patrick Fougeyrollas' work are relevant and relate to the ACC work, as are two large Canadian population surveys.
- Dr Satoshi Ueda, Japan, endorsed the study of subjective measures of participation, and asked how the summary measure of Participation was applied. Ms Madden replied that the qualifier was made up of three concepts, frequency, outcome and manner and the summary measure could be applied to any category of participation. This work is being reviewed by the National Community Services Data Committee in Australia

2 Report on the study group on the subjective dimension of functioning and disability (Japan) WHO/HFS/CAS/C/02.30

Dr. Ueda, Japan presented on the Study Group's work on the subjective dimension. (document 30). The audience acknowledged the large number of references in the literature which refer to this topic. The WHO secretariat expressed concern regarding the lack of communication from the Study Group to WHO. As a result, WHO cannot comment on or endorse any recommendation on the work of the Study Group. Some Centres stressed that the work of the Study Group should continue but that communication with WHO should improve. Possibilities for the distribution of results were offered by France, the United States and the Netherlands. Technical assistance for organization of an international meeting would be discussed at a later stage.

3 ICF as a framework for comparing assessment tools in Community Aged Care Programs (Australia) WHO/HFS/CAS/C/02.85

Ms Catherine Sykes, presented on the use of the ICF in Community Aged Care Programmes in Australia. (document 85). Issues that could lead to improving the comparability of data in the programs were discussed.

Discussion points

- Ms Marijke de Kleijn de Vrankrijker asked whether the analytic methods used by many of us, ought to be reconsidered, in the light of the AIHW analysis. Ms Sykes replied in the affirmative.
- Dr Madden of the Australian Centre suggested that special applications of ICF to aged populations may yield special problems and opportunities.

4 The WHO Disability Assessment Schedule (WHO-DAS II) and its relation with ICF (WHO)

Dr Üstün, presented on WHO-DAS II development.

Discussion points

- Ms de Kleijn de Vrankrijker asked that WHO map WHO-DAS-II into ICF categories, and encouraged that more WHO-DAS-II information be placed on the website.
- Dr Madden said that there had been too little communication between the two tents inhabited by Heads of Centres and WHO-DAS II developers.
- Mrs Tóra Dahl asked about WHO-DAS II publications and documentation. Dr Üstün, said more information would be available in a few months.

Organizational Issues

Before closing the session, Ms de Kleijn de Vrankrijker presented the following two options to handle the ICF organizational issues for consideration later in the meeting.

The two options caused comments and discussions which in the following slide is the chair's suggestion for a combined solution. This topic was considered by the Planning committee and the recommendation will be considered at the report back plenary.

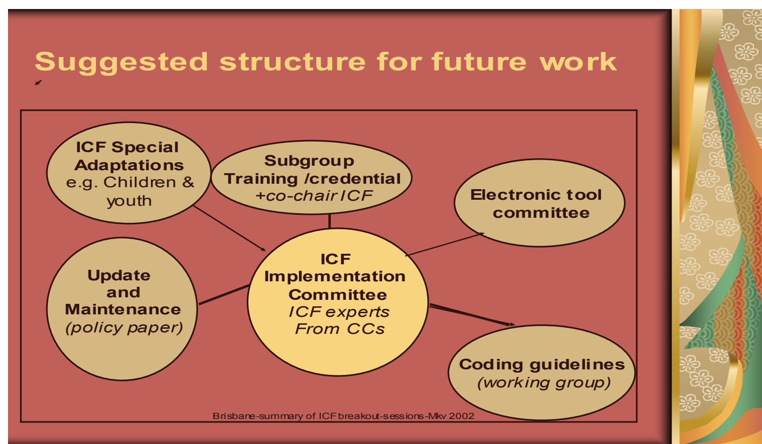
Organisational issues ICF options

- 1. ICF included in multiple committees
- 1.Training
- 2.Implementation
- 3.Maintence and updating
- 4.Coding guidelines
- 5.Electronic tools

- 2. One ICF committee
- Forming an ICF committee, which can cover current and potential issues for a period of e.g. 5 years

+ FDC on ICF/ICD

Brisbane-summary of ICF breakout-sessions-Mkv 2002



Breakout session Wednesday PM

1 Mexican Network for the ICF (Mexico) WHO/HFS/CAS/C/02.87

Dr Rafael Lozano presented on the implementation of ICF in Mexico. Dr Lozano also presented, “The Ibero-american ICF network” on behalf of Dr Vásquez-Barquero as he could not be present. 17 countries are in the network. The goal for 2003 is 80 courses and 1000 experts, 5000 copies of ICF have been distributed and another 5000 copies are needed.

Discussion points

- Dr Placek asked if the Mexican website would be also in English. He replied it would be by end of 2002.
- Mrs Kristina Bränd Persson, Nordic Centre asked about institutional adoptions/approvals of ICF in Mexico. Dr. Lozano replied that a national norm must first be developed.
- Dr Notzon, complimented Dr Lozano on his long range planning approach and asked about their funding. Dr Lozano explained that he hoped to get funding from large hospitals and the private sector.

2 DISTAB Update (NACC) WHO/HFS/CAS/C/02.39

Dr Placek gave an overview of the DISTAB project from its origins to its current work. The aim of the project is to develop methods to produce more comparable disability data from national surveys. The products of the group were presented.

Future activities include:

- Complete the text of the 'tables' report and publish.
- Finish Environment and Participation inventories
- Produce a report on E & P
- Continue links with the Washington City Group meetings
- Quest to improve international comparability of disability data using ICF.

Discussion points

- Dr Üstün, said that the DISTAB work was promising and asked the DISTAB group to submit their data to WHO for further analysis. This was welcomed by Dr Placek.
- Dr Madden praised the DISTAB work and the communications sustained, despite major time zone differences for monthly conference calls.
- It was suggested that more formal links be made between the DISTAB Group and the Washington City Group.

3 The ICF Checklist: development and application WHO/HFS/CAS/C/02.95

Mr Nenad Kostanjsek, gave an over view of the development and application of the ICF Checklist. The checklist was tested during the beta-2 trials with for both case summaries and live case evaluations. The checklist includes 154 codes out of 1423 in the ICF. Multiple sources of information are used, thus clinical judgement is used to complete the checklist.

Future tasks are to refine the anchor points, to link the checklist with population norms and to cross link with assessment tools.

The current version (September 2001) is being used extensively by individuals, in specific projects and the core set project.

A brief outline of the core set project was presented. Early results from the use of the ICF checklist for low back pain indicate fair to good test/retest reliability and concurrent validity with the SF36 body function subscale.

Discussion points

- Dr Placek stated that John Hough, CDC had secured specifications for a handheld palm-pilot version of ICF. He presented a paper at the North American Collaborating Centre meeting in Toronto in June 2002.

- Dr Madden asked whether the design of the slides presented, being the colour of "The Red Book" slides, indicated that it was an official WHO ICF product. Mr Kostanjsek replied in the affirmative and explained that with the Red Book, the CD-ROM, and the ICF checklist showed WHO's intention to present slides and other materials with a "mainstreamed WHO-look".

4 Clinical implementation of the International Classification of Functioning, Disability and Health (ICF): Conceptual and coding approaches (WHO/HFS/CAS/C/02.94)

Dr Bickenbach presented the paper on behalf of Jayne Lux and Geoffrey Reed from the American Psychological Association.

Discussion points

- Ms de Kleijn de Vrankrijker asked whether this work would result in multiple versions of ICF, and Dr Bickenbach replied no. Clinical terms are merely being cross-mapped to ICF.
- Mrs Caulfeild asked if this was designed to be an international standard, to which Jerome replied that it is being developed by American professional associations for their joint use. Other groups within or outside US may or may not decide to use the new manual.
- Mrs Dahl, commented that it is important to stress the multidisciplinary development of manuals rather that single-disciplinary approach, as it will be in conflict with multidisciplinary rehabilitation.

Plenary - International Classification of Functioning, Disability and Health

1 Report on the Eighth Annual North American Collaborating Centre Meeting on ICF: Issues and Future Activities (NACC) WHO/HFS/CAS/C/02.37

Mrs Diane Caulfeild provided information on the eighth annual North American Collaborating Centre Conference on ICF and an overview of the proceedings, content of the conference, and the proposed future activities within the North American Collaborating Centre. Conference papers are available at:
http://secure.cihi.ca.cihiweb/dispPage.jsp?cw_page=event_icf_jun02_e#presentations

Discussion points

- The use of ICF among clinicians should be encouraged.
- There was a discussion about the combined use of ICD with ICF and whether clear definitions exist to guide their use in severity assessments in acute care settings.
- The North American Collaborating Centre noted that the National Committee on Vital and Health Statistics has encouraged the use of both classifications in the U.S. to capture a more complete clinical picture.

2 Coding Guidelines for ICF – Issues that need resolving

Mrs Jane Millar provided a summary of responses to a request for information from Collaborating Centres on the need for coding guidelines. WHO CAS provided comments in response to the issues.

Discussion points

- It was noted that the Coding Guidelines document contains statements that were inconsistent with international consensus. The paper stated that there was international consensus that activity is measured as capacity and participation as performance. However, the international consensus is represented by the narrative that appears in ICF and Annex 3, which allows four options for defining/differentiating activities and participation.
- It was clarified that WHO recognizes Annex 3 as the international consensus but that WHO has chosen the option of measuring activity as capacity and participation as performance. WHO welcomes information on the use of the other options.
- After concurring with this comment, it was suggested that the paper, as distributed, would raise unnecessary alarm but that adding in comments from the discussion would dispel concerns.

- WHO CAS asked Centres to provide specific examples to illustrate areas not covered in the coding guidelines, however, it was also felt that some issues could be best addressed and incorporated in training materials.
- WHO CAS also asked that Centres forward any coding guidelines that they had previously developed for use with ICIDH. It was thought that these guidelines could inform the work of the development of ICF guidelines. It was also noted that the focus of coding differed between ICD and ICF in that ICF focuses on a profile and not an encounter.
- There were varying opinions expressed regarding the need for coding guidelines. Some felt that in order to ensure consistency that guidelines were needed as soon as possible. Others felt that the lack of coding guidelines should not delay use of ICF for coding and that the problems may be in the mind of the coders and not a problem with ICF.

Recommendations

1. To revise the paper to reflect the additional clarifications provided during the discussions.

2. WHO to post on their website a list of the schemes being used by each country.

3. To establish a Workgroup on Coding Guidelines. The group will:

- develop Terms of Reference.
- agree Terms of Reference of Workgroup with WHO.
- develop a set of coding guidelines either as an independent document or as part of training materials.
- explore the development of specialty-specific coding guidelines.

4. To systematically collect empirical evidence on a number of areas as implementation of ICF continues.

5. To invite countries to give ICF data, coding rules and back coding schemes to WHO.

3 Dissemination of Code ICF: Code ICF; North American ICF Clearinghouse: ICF Videos; ICF Curricula in North American colleges and universities; and Spring 2003 issue of Health Care Financing Review

Paul Placek described the five projects he manages, these were:

- Code ICF. Due to be completed and to WHO CAS in three months.
- The North American Clearinghouse monitored by Paul Placek, David Gray and their co-workers. Participants were invited to access the Clearinghouse website and enrol for notification of updates in information.

- ICF videos. Four fifteen-minute videos have been produced. Some of the footage has been included in Code ICF. The four topics are ICF use by consumers, ICF application, Conceptual issues, and Historical development. They are due for release in early 2003.
- A project to collate ICF curricula in North American colleges was described. The information from the project will be available from the Clearinghouse and a report will be presented at the 2003 North American Collaborating Centre meeting on 17 –19 June in St Louis Missouri.
- A special edition of Health Care Financing Review (Spring 2003) will examine capturing functional status for administrative records for payment and quality.

Discussion points

- Those individuals that are used in the video clips need to be able to view their contributions before release.
- Code ICF. The product is to be used internationally, but is being produced as a bilateral project. It will be a WHO product, not representing any nation or agency. There will be a window of opportunity for review before it is put onto the website. There is concern that there has not been independent review of the product. Centre heads were invited to participate in the review. Collaborating Centres should get more involved in commenting on the product.
- WHO will take on the Code ICF. There is no formal mechanism for maintaining and updating the Code ICF.
- The Clearinghouse. Australia will be inviting users to contribute to the Australian website in a parallel process to US product.

Recommendations

1- That the videos produced by the North American Collaborating Centre should be reviewed by those who appear in them prior to their release.

2- That Collaborating Centres become more involved with the development of Code ICF by commenting on the current version and future updates.

3- The meeting should consider a formal mechanism for endorsing and maintaining and updating Code ICF.

4- The meeting should consider the links between national websites so those Collaborating Centres can be aware of international developments.

Plenary - Family Development Committee proposals

Gérard Pavillon stated that the session would be for discussion of the papers, and no decisions would be made.

1 WHO FIC Protocol for endorsement of new family members (WHO/HFS/CAS/C/02.76) Catherine Sykes

There was general approval of the content of the proposed protocol. However, the point was made that copyright and licensing arrangements will need to be addressed. It was suggested that working through the subsequent papers in this session might highlight any issues not adequately addressed in the protocol.

2 Submission for recognition: international classification of external causes of injury (WHO/HFS/CAS/C/02.74) James Harrison

James Harrison invited participants to comment on admission of ICECI as a related classification in WHO FIC. Version 1.1 of the ICECI has recently been released—the data dictionary is complete, but development of the alphabetic index and translation work is still in progress.

The ICECI does not map directly to the ICD, but a coding bridge (a CDC framework) has been used to allow code level comparability between the two classifications.

The view was expressed that it is premature to consider this classification for admission into the Family, as testing is in early stages and there has not been time for proper consideration by Centre Heads.

A question was raised about the extent to which Centre Heads would have input into the maintenance and updating of the classification. James Harrison stated that a paper proposing formalized arrangements for maintenance and updating has been circulated, in which it is proposed that the a group consisting of WHO FIC Centre Heads, WHO Injury Surveillance Centre Heads, and other key groups involved in injury statistics research will be responsible for governance.

While there is a need to establish standards for membership of WHO FIC, there should also be a degree of encouragement for groups developing classifications systems that may be appropriate for inclusion in the Family. The issues raised in this session will contribute to a learning process for the FDC.

3 International Classifications of Health Interventions—ICD-10-AM (ACHI) and its subset, ACHI-I (WHO/HFS/CAS/C/02.50) Linda Best

ACHI-I is a short classification based on ACHI, developed for countries who do not have their own classification and who do not require or cannot support the level of detail given in the parent classification (ACHI). It is also proposed that ACHI-I could

be used as a basis for international comparison/reporting of procedures and interventions. A pilot version has been distributed for testing. There has not yet been any attempt to map ACHI-I to other similar classifications currently in use. The classification will be available regardless of whether it becomes a member of the Family.

Some participants indicated that ACHI-I could be used as a prototype for a standard international classification of health interventions, after further testing and development. However, other participants expressed reservations.

4 Classification of technical aids for persons with disabilities: neighbour or member of the family? (WHO/HFS/CAS/C/02.91) Marijke de Kleijn-de-Vrankrijker

ISO 9999 is a classification of technical aids used by people with disabilities. The classification has undergone three revisions since 1992 and will undergo a fourth in 2003–2004, with terms and references being adapted to the ICF.

It was generally agreed that ISO 9999 complements the ICF and would fit into the FDC matrix. It was agreed that further work is required to determine 'what it means to be a member of the Family'.

Actions

The meeting suggested that an alpha testing protocol be developed for the ACHI which is to be named ICHI. The protocol should be presented at the next Heads of Centres meeting.

Plenary - International Classification of Diseases – 10th revision

1 Impact of the implementation of ICD 10th revision on Diabetes Mellitus mortality trends in Mexico (WHO/HFS/CAS/C/02.86) (Dr R Lozano (Mexico))

Discussion Points

- The United Kingdom representative commented on the interesting points that the paper had raised – in particular on how the multiple cause analysis can be useful. It showed clear differences between the United Kingdom and Mexico in the selection of underlying cause of death: In Mexico 5/6th of death certificates with diabetes mentioned had it selected as the underlying cause, whereas only a quarter were the underlying cause in England.
- Comments were made around Rule 3. The Mortality Reference Group had decided that rule 3 reselection from pneumonia did not apply to diabetes because it was not classed as a wasting or paralyzing disease.
- Further analyses of multiple cause data from a variety of countries are needed to help the Mortality Reference Group develop guidelines for applying the mortality rules with regard to diabetes, to improve the comparability of mortality statistics between countries.
- The North American Collaborating Centre representative re-iterated the value of multiple cause data and expressed an interest in comparing data from Northern Mexico with bordering US states.
- The North American Centre representative also enquired about the prospect of routine multiple cause coding and analysis in Mexico.
- Dr Lozano stated that the use of ICD-10 will improve consistency. Some previous studies had shown high prevalence of diabetes but low mortality. In Mexico coding is done manually, so only a small sample of multiple cause data was available for analysis. The results should be viewed with caution.

2 An adjustment factor for estimating the maternal mortality ratio (WHO/HFS/CAS/C/02.23) (Pr. R Laurenti, Brazil)

Professor Laurenti outlined the difficulty encountered in Brazil in measuring maternal deaths and highlighted concerns regarding under-reporting of maternal deaths and also misclassification of maternal deaths.

3 Comparability of cause of death between ICD-9 and ICD-10 (WHO/HFS/CAS/C/02.61) (Mr R Anderson (NACC))

Discussion points

- The work progresses the preliminary comparability study using 1996 mortality records, results of which were published last year and are available on the Internet.
- The new study includes the 20% of deaths which needed manual coding and had been excluded from the earlier publication.
- The United Kingdom Centre representative stated that although multiple cause is still difficult to interpret, it could be useful to understand changes in underlying cause mortality rates. An example was given of prostate cancer and linkage with other cancers mentioned on the death certificate so that the underlying cause became 'malignant neoplasm of multiple primary sites' – C97 (ICD-10).
- The United Kingdom Centre representative said that the ICE on injury statistics would be looking at multiple cause data to explain changes in external causes. In particular, to help disentangle the reduction in deaths assigned to falls, and the large increase in 'accidental exposure to unspecified factors' (X59). They will be analyzing nature of injury codes to assist in this work.
- ICD-9 had a precedence list for selecting a 'main injury' in addition to the external cause. This has been recommended since ICD-6, but few countries routinely tabulate deaths from accidents and violence by main injury. Further work is needed on how to select the main injury in ICD-10, but WHO should consider asking countries to submit mortality data by main injury, as well as by external cause.

Recommendation

That the need for comparability studies should be included in the ICD-10 implementation checklist being developed by the Implementation Committee.

4 Use of ICD-10-AM for reporting diagnoses and external causes relevant to Indigenous health issues (WHO/HFS/CAS/C/02.80) (Ms J Hargreaves (ACC))

Discussion points

- It was pointed out by the presenter that the location of the hospital had an effect on quality of data collected on indigenous status. These data were generally better in areas with large indigenous populations.
- The Mexican representative said that in Mexico there are 15 million indigenous people but there is insufficient information as not all have access to health facilities.

- It was noted that in Australia external cause and injury data are not well linked so that it is difficult to analyze associations between these two data items.

5 A recommended shortlist for comparisons of hospital discharge statistics in the European Union (WHO/HFS/CAS/C/02.48) (Prof B Smedby (Nordic Centre))

The author reported on the work of the EU Hospital Data Project on a recommended shortlist of diagnoses for use in international comparisons of hospital data that could handle the problem with diagnoses being coded according to ICD-9 in some countries and ICD-10 in some others. The analyses of national test data performed by an Expert Group showed the importance of taking into account also organizational differences (eg. Regarding reporting of day care) and differences in national coding practices and guidelines. The shortlist is based on three character ICD-10 codes but mapping of ICD-9 codes to the shortlist groups may require four-digit codes. The definitions of the shortlist groups were presented in the paper as well as national test data from four European countries.

Discussion points

- It was noted that similar work had been undertaken in Australia and agreed with the external cause code rationale.
- DRG data had been reviewed as part of the study in particular the OECD data but was not included as it was not at all comparable between countries.

Recommendations

1. Collaborating Centres should review the EU recommended shortlist and test it with data from other countries.
2. The Centre Heads Meeting in 2003 should revise the list based on such a review and recommend it for international use

Plenary - International Classification of Functioning, Disability and Health

1 ICF User Guide (WHO/HFS/CAS/C/02.78)

Ros Madden, from the Australian Institute of Health and Welfare, opened this session explaining that the Australian ICF User Guide was a draft document and invited comments on it from ICF experts across the world. It has been developed to compliment the ICF classification – to help Australians understand the ICF, support consistent use, discuss potential uses and applications. It is part of a suite of tools which includes data dictionaries and a training strategy.

Included in this presentation was a description of what the document is, who might use it and its content. Ros focused then on section 5 – Activities and Participation: application in Australia – which discusses the WHO options for the use of these domains and the view that options 'b' and 'd' are useful to Australia at this point with the need to work on qualifiers. Environmental factors and their interaction with A & P. Ros concluded with reiterating the need for evidence on the use of ICF and particularly wants comment on table 5.3.

Section 10 of the User Guide is devoted to examples of ICF applications in Australia, and 3 of these were presented. Jemma Skeat presented The use of the ICF framework in an allied health outcome measure: Australian Therapy Outcome Measures (AusTOMs), Sean Tweedy presented Applying the ICF to classification for disability sport: an example from disability athletics and John Walsh presented ICF and accident compensation in Australia.

Discussion points

Discussion focused on the applications rather than the User Guide itself.

- A question was raised about validation between AusTOMs and the Barthel scale – Jemma confirmed that they had not looked at this area as yet.
- Some discussions took place related to compensation, the current state of the industry and how ICF experts are aiming to open the dialogue with them including a major meeting of accident compensation schemes at which Ros Madden will be presenting ICF.
- There were discussions about the use of environmental factors in both the AusTOMs work and with relation to the classification in disability sport.

2 Application of ICF in the World Health Survey Programme

This was presented by Bedirhan Ustun, WHO.

This development underpins the need to understand the full breadth of health experience, and is fully described in the submitted paper. There is a fundamental need to look beyond mortality based indicators of health to include the positive aspects, does the health system cover the population with the appropriate interventions, what is the cost and what are the benefits?

It has also been recognized with this work the need for good training for surveys and a rigorous check on the quality of the data collected – at the site and once delivered to WHO. Its approach is modular and takes up to 90 minutes to do. It uses 8 core domains from ICF, selected after review of research, survey instruments and cross-cultural applicability study. 71 surveys have been undertaken in 61 countries, with 185,369 respondents – with sampling being done as multistage cluster. To date, it has only been undertaken with adults.

Future work includes work on measuring the quality of improvement in the data, seeking to try to combine census, surveys and service data, and also increasing the coverage across members states, extending the survey to children and youth, geo-coding which can lead to sub-national comparisons and collection of additional data. Details of the work and the questionnaire can be found at www.who.int/whs.

Discussion points

- It was suggested that ICF leads would like to see the coding across to ICF, and it was made clear that the crosswalk is available. It will also be an opportunity to look at the use of ICF and its applicability – this will be available in a database which will build as move from piloting.
- The size of the sampling was questioned and how survey was done in individual countries. The cost is high for any survey, so have followed the EU approach to sampling size. The key important point for the Heads of Centres was the relationship to ICF and actually getting feedback on the coding and use in this survey.

Report back of committees and workgroups

Implementation of ICD-10 Committee

Dr Mounkaila Abdou delivered the report of this committee.

Discussion points

- A recommendation was accepted to add two questions to the questionnaire to better understand the difficulties developing countries may encounter.
    1. What are the barriers to implementation of ICD-10?
    2. What are the barriers to collection, analysis and dissemination of information?
- Further discussion ensued around the proposed "ICD-10 in a box". It was made clear that this is not a quick fix. Many countries may require longer-term support. A point was also raised about the possibility of WHO working in conjunction with the UN to determine methods of implementing ICD-10 in more countries.

Decisions

Decisions
1. It was agreed to add two questions to the questionnaire.
2. A roster of experts in ICD-10 implementation will be maintained by Dr Roberto Becker and PAHO.
3. The United Kingdom Centre will act as Secretariat for the Implementation of ICD-10 Committee

Update Reference Committee

The report of this committee was delivered by Mrs Michelle Bramley.

Discussion points

- A question was raised about the final approval of updates by WHO and it was explained that while acceptance is obtained at the Heads of Centres meeting each year, WHO does a final check of updates. Full approval is confirmed by placement of the updates on the website.

Electronic Tools Committee

Associate Professor Rosemary Roberts delivered this report.

Discussion points

- Dr Schopen noted that an electronic version of ICD-10 that includes all the updates to the classification to date is crucial. It is a necessary prerequisite to many other tasks such as “ICD-10 in a box” and ICD-10-XM.

Decision

All actions and time lines for the production of the electronic version in French and English, that were agreed in Manly be adhered to.

Mortality Reference Group

The Chair of this committee, Mr Lars Age Johansson delivered this report.

Discussion points

- Quality assurance is an international issue and it is important to determine the application of the classification in vital registration and in mortality statistics.

Family Development Committee

Dr Richard Madden provided the report of the Family Development Committee. Comments from delegates were welcomed after each topic area in the report.

Discussion points

- A question was raised about the relationship of Anatomical Therapeutic Chemical Classification (ATC) with the WHO. It was clarified that the ATC is the product of the WHO Collaborating Centre for Drug Statistics Methodology in Oslo, Norway. It was requested that the copyrights regarding ATC be clarified.
- Dr Peter Goldblatt presented the preliminary terms of reference for the Vocabulary Work Group. Peter welcomed comments and volunteers for the work group. The Dutch Collaborating Centre North American Collaborating Centre, Australia and Germany indicated that they would participate. Questions were raised regarding the relationship between vocabulary and nomenclatures as well as the WHO work on nomenclatures. It was clarified that vocabularies are inclusive of nomenclatures. It was also clarified that International Nomenclature of Diseases (IND) was the only WHO-related work on nomenclatures and that it was terminated about 10 years ago due to lack of funding. IMP was not part of the WHO but associated with the WHO. Questions were also raised regarding the accreditation of mappings and the implications of this.
- Prof Bjorn Smedby confirmed that the Nordic centre would lead the work on the Hospital Data Working Group. The following Centres and countries volunteered to be part of the group: Australia, New Zealand, the United States, PAHO, the United Kingdom, Brazil, Mexico and Venezuela. Canada and South Africa indicated that they would need to confirm their participation after the Brisbane meeting.
- An issue was brought forward about the use of acronyms at the meeting and the challenges that this presented for first time delegates. Mrs Marjorie Greenberg suggested putting an organizational structure of the committees as part of the final report. In addition, a glossary of terms could be created. It was suggested that this information could also be placed on the WHO web site.

International Classification of Functioning, Disability and Health

Ms Marijke de Kleijn-deVrankrijker provided a report on the International Classification of Functioning, Disability and Health (ICF) Committee deliberations. Marijke requested that the WHO respond to the organizational issues related to the committee structure for ICF as well as the ICF retreat.

The WHO secretariat responded that the desire to integrate ICF work within the present committee structure was driven by:

- the WHO-FIC policy of creating WHO-FIC Centres, meetings and subsequently a WHO-FIC committee structure; and
- The need to keep the number of committees to a minimum due to resource constraints and efficiency concerns

As a result, all existing committees should be renamed as WHO-FIC committees and should have ICF-specific subcommittees where appropriate.

With respect to the ICF retreat, the WHO secretariat indicated that WHO is still discussing the agenda. The focus of the agenda will be on ICF implementation and filling in the work plan for ICF.

Ms de Kleijn-de Vrankrijker requested the strategic plan for ICF be added as an agenda item for the retreat.

Discussion points

- A number of concerns were raised by Mrs Tóra Dahl and Ms Ros Madden regarding the WHO's unwillingness to have a stand-alone ICF committee on a temporary basis until the completion of the strategic plan. It was noted that:
- ICF is still in its early stages and as such, it has different issues than ICD-10;
- ICF resources are scarce and it will be difficult to find resources to participate in the current committee structure; and
- The existing committee structure was developed for ICD-10 and not ICF.
- Dr Madden indicated that the agreement reached with the WHO was a compromise position that could meet everyone's needs.
- Mrs Greenberg indicated that the objective of the next year is to flesh-out a work plan for ICF. Once that is completed, a way will be found to carry out the proposed plan. Some fluidity will be required in terms of structures. However, we may need to consider how to bring more resources.

Sub-Group on Training and Credentialing

Mrs Greenberg provided the report on Sub-Group on Training and Credentialing. The report was well received. As part of the report Mrs Greenberg requested that those who had not responded to the Needs Assessment Questionnaires do so.

Mrs Greenberg thanked Mrs Diane Caulfeild, Mr Garry Waller and Mrs Sue Walker for serving as rapporteurs.

Discussion points

- Dr Madden indicated that he was uncomfortable about the meeting being planned in Washington, in April 2003, as it would be difficult for Australians to attend.
- Mrs Greenberg indicated that the Washington meeting would be primarily focused on mortality and underlying causes of death and that she would withdraw any inferences about work on ICF at that meeting from the report on the Sub-Group on Training and Credentialing.
- Mrs Greenberg stated that it was agreed that a core group on ICF develop a work plan on training and credentialing. Dr Madden indicated that any work on ICF training and credentialing should be done in matrix fashion with the Implementation sub-committee on ICF.
- Mrs Greenberg indicated that she would organize a meeting to discuss ICF training needs and linkages.

Plenary - Scientific Papers

During the discussions following the presentations in this session, the following issues were noted.

1 ICD-10 and the Unified Medical Language System (UMLS) (WHO/HFS/CAS/C/02.44)

Technical barriers to the inclusion of the electronic version of ICD-10 in the UMLS vocabulary are the print conventions used by ICD, including bullet points, curly brackets and the indentation structure in the Index. The two former conventions were eliminated in the US for ICD-10-CM because their database could not handle them.

2 The Australian General Practice vocabulary and the ICD-10-Am index: parsing and classification issues (WHO/HFS/CAS/C/02.54)

This paper was presented by the National Centre for Classification in Health in Australia. It was suggested that the terms used by GPs may well relate to the vocabulary used by Resident Medical Officers in hospital discharge summaries.

3 Australian coder workforce: an update survey (WHO/HFS/CAS/C/02.66)

This paper was presented by the National Centre for Classification in Health in Australia. It was reported that in Germany doctors traditionally have coded their own notes without any special coding training but that since the DRG system had been introduced for reimbursement, there is now serious consideration being given to the development of clerical staff as trained coders. It was agreed that it would be interesting to compare accuracy before and after such a coding change.

Several other countries are considering similar surveys of their coder workforces. The Australian Centre offered to share its coder survey so that international comparisons may be facilitated.

4 Differences in the selection of the underlying cause of death: Coding seminars in the Nordic-Baltic region (WHO/HFS/CAS/C/02.47)

In discussion it was revealed that the same exercise had been carried out in Brazilian States, and that the results were very similar to those found in the Nordic/Baltic countries. The main problem in carrying out comparative studies in different countries was one of language.

5 Updating the ONS (OPCS) hierarchical classification of causes of still birth and death in infants for ICD-10 (WHO/HFS/CAS/C/02.70)

In discussion of the WHO recommended perinatal death certificate, very few countries represented in the meeting were using it. PAHO reported that three countries in the region had moved in the opposite direction and used the international death certificate for fetal deaths.

6 The clarification of an underlying cause of death declared as an "incomplete" diagnosis (WHO/HFS/CAS/C/02.26)

7 An investigation for the clarification of ill-defined conditions declared as underlying cause of death. (WHO/HFS/CAS/C/02.22.)

In discussion it was reported that in Mexico the number of ill-defined diagnoses is increasing, and may be due to the single ill-defined cause of cardiac arrest.

8 The definitions of "Live birth" and "Fetal death" and the influence in the estimations of rates (WHO/HFS/CAS/C/02.25)

9 Senility as the underlying cause of death (WHO/HFS/CAS/C/02.27)

It was reported that in many countries there are pressures to allow "senility" as a valid underlying cause of death, with suitable age restrictions. If it remains an ill-defined cause of death, this may make doctors 'invent' a more acceptable, but less accurate, cause.

10 The underlying causes of death among HIV patients (WHO/HFS/CAS/C/02.64)

It was noted that more people with HIV are now dying of complications of therapy, which poses a problem for coding the underlying cause of death. It was suggested that the rules should probably not be altered to allow the application of Rule 3 to select HIV from part II in these cases. Using complication of drug therapy as the underlying cause would also result in a loss of detail.

1 Proposed Guidelines for Accessibility at WHO-FIC meetings (NACC), WHO/HFS/CAS/C/02.62.

The North American Centre proposed that the recommendations be adopted by HOC for future meetings.

Discussion points

- The Brazilian centre congratulated them and asked permission to translate the guidelines into Portuguese.
- The Dutch Centre reminded delegates that information about accessibility should be sent to all participants with the meeting papers.
- The Nordic centre said that it was often useful to send delegates with mobility difficulties a map or plan of the venues, including layout and dimensions of rooms. This helped them to work out for themselves whether there might be any problems and how to circumvent them.
- The meeting was reminded of the importance of making arrangements in advance for any special transport needs to and from airports, stations, hotels and meeting venues.
- The Australian Centre pointed out that there were national guidelines in Australia, and that we should be sure to meet guidelines in the country in which the meeting was to be held. They suggested that we should always take into account the need to meet the access needs of delegates and potential delegates. However, there was also a need to be flexible because of the high cost of fully compliant hotels, and the danger of preventing some centres from hosting meetings. They recommended a resolution on the principle of ensuring adequate accessibility, but referring the detail to the planning committee.
- The North American Centre stressed the need to encourage participation, and ensure any barriers are overcome.

2 Proposals for modernization of the Civil Registration system in England and Wales (UK), WHO/HFS/CAS/C/02.51.

The United Kingdom Centre described the current system in England & Wales, including the limitations posed by legislation based on paper documents, and proposed modernization, which had to take account of developments in the field of rights and protections in the European Union.

Discussion points

- Issues around linkage to other administrative records; consent from next of kin, or prospectively from individuals before death; provision of information that is essential to establish identity and voluntary information provided for other purposes; confidentiality; data quality, validation at source and effects on time trend statistics, and the value of

being able to pilot changes before introducing them nationally were discussed.

The Brazilian centre presented 3 papers:

3 Fall as a cause of death in the elderly population (Brazil), WHO/HFS/CAS/C/02.21,

4 The specification of the circumstances of the accident or violence in cases of death due to external causes, WHO/HFS/CAS/C/02.24,

5 Level of accuracy in filling out death certificates at the civil servant's hospital in the state of Sao Paulo, Brazil

Discussion points

- The United Kingdom Centre (Scotland) asked whether the same or a different physician was completing the certificate. As it is the same physician is was suggested that this may place too much emphasis on accuracy of medical records.

6 The Quality of Suicide Mortality Data, (France) WHO/HFS/CAS/C/02.29.

Discussion points

- The United Kingdom Centre said that many countries have some problems with vital statistics data on deaths investigated outside the medical/vital statistics system, by police, courts etc. Biases are different in different countries so data are not comparable between countries. The need to be able to update and footnote data on WHO site to correct these deficiencies was suggested.
- The WHO European Regional Office said that it was possible to correct the data on their website. However, a country had to re-send the whole annual file with the corrections. It was not possible for them to deal with partially updated information, or to include recommendations about adjusting national data, such as the additions a proportion of the undetermined intent and unknown cause deaths to estimate the true suicide rate.

7 Quality activities for morbidity and mortality coding. (Australia), WHO/HFS/CAS/C/02.

Discussion points

- The United Kingdom Centre said that these activities would provide useful background for the modernization of vital registration in England and Wales.

8 Summary of Hearings on Transition to ICD-10-CM and ICD-10-CM PCS: Issues and Future Steps, (NACC) WHO/HFS/CAS/C/02.84.

9 Specificity in ICD-10 AM, (Australia) WHO/HFS/CAS/C/02.51.

Discussion points

- The North American centre complimented the researchers on the methods of their study. The US will consider doing similar studies. Work on why clinicians were not using the distinctions available in the 4 character asthma codes is in progress

10 Use of ICD-10-AM for reporting 'mental health related' admitted patient care (Australia), WHO/HFS/CAS/C/02.79

Discussion points

- Rosemary Roberts asked whether there were differences in codes used in specialist psychiatric services compared to general? Schizophrenia was more common in mental health services and depression in general and private services.

11 The Chronicle: the history and evolution of ICD-10-AM WHO/HFS/CAS/C/02.55.

Discussion points

- Discussion centred on the importance of documenting changes methodically, and the good example set by the Australian Centre. The URC agreed to consider using the same sort of electronic documentation once an electronic version of ICD-10 becomes available.

12 The history of health statistics in Japan, (Japan) WHO/HFS/CAS/C/02.89

The Japanese Centre presented an historical perspective on health statistics. There was lively discussion about the wealth of demographic, sociological and health information that had been collected since the 7th century.

Two New Centres in Africa, introduced themselves and described their backgrounds and plans. The first headed by Dr. Oye Gureje is based in the Department of Psychiatry at the University of Ibadan in Nigeria, and the second headed by Dr. Debbie Bradshaw is in the Medical Research Council of South Africa and University of Cape Town.

Guest speaker: Dr David Filby

Dr Madden introduced Dr David Filby, Executive Director, South Australian Department of Human Services, and Chair of Australia's National Health Performance Committee. Dr Filby presented the following in relation to Australia's National Health Performance Framework:

- National Health Performance Committee (NHPC)
- Outline of the National Health Performance Framework (NHPF)
- Issues faced by the NHPC
- International efforts in area of health performance frameworks
- Implications of the framework for future indicators
- Data development within Australia

Dr Filby outlined the history of the NHPC, which was formed in 1999 at the request of the Australian Health Minister's Conference. The National Health Minister's Benchmarking Working Group was the predecessor to the NHPC, but only related to acute public hospitals. The performance framework developed by the Benchmarking Working Group was based on effectiveness and efficiency only.

Dr Filby reported that the NHPC aimed to develop a broader performance framework. This was done through discussion papers, workshops and examining the goals and objectives of the State and Territory governments through examining principal funding agreements, for example. These goals were also mapped against the WHO goals of improving health etc. Dr Filby also stated that the frameworks developed in other countries were examined, including those from the US, the United Kingdom and Canada. He noted that the Canadian Health Roadmap Framework was used as the basis for the Australian framework.

Dr Filby outlined the performance frameworks that are in use in Australian States and Territories and stated that international health performance frameworks had been developed by the WHO, OECD and ISO. He also stated that the NHPF was consistent with the matrix for the WHO-FIC.

Dr Filby then described the NHPF. He noted that it consists of three tiers, but that it is not hierarchical. The tiers are Health Status Outcome, Determinants of Health and Health System Performance. Dr Filby also described the criteria used to select the performance indicator framework and outlined some of the issues surrounding the framework, for example that it is limited to around 40 high level indicators and that there is a need for further discussion on ways to link indicators across the framework.

Dr Filby illustrated how the NHPF was used in reporting to Australian Health Ministers and showed examples of the data contained in the 2001 Report.

In conclusion Dr Filby noted that the NHPF provides a consistent basis for reporting, a structure for indicator development and benchmarking and a basis for influencing and comparing at the international level.

Following the presentation there was some brief discussion about whether 40 indicators are enough, about whether much weight had been given to disparities and inequalities in the development of the framework and about a whole of government approach. The lack of composite indicators within the framework was also noted.

Host Centre Presentations

1. The role of the Australian Bureau of Statistics in health and related statistics - Dennis Trewin WHO/HFS/CAS/C/02.82

Mr Trewin explained that the Australian Bureau of Statistics (www.abs.gov.au) is Australia's national statistical agency, providing statistical services for the Federal and State and Territory governments. The Bureau's functions, which Mr Trewin described as a 'national statistical service' are to collect, collate, analyze and disseminate statistics, and to play a role in coordination of statistical activities in Australia. The Bureau covers all subject matter areas, however, other agencies are also playing increasingly important roles, for example, the Australian Institute of Health and Welfare in health-related statistics.

Mr Trewin provided a brief overview of the Bureau's role in health statistics, which includes the population census, basic demographic work, population surveys (including the National Health Survey), business surveys (including those covering private hospitals and general practitioners), cause of death statistics and a range of special surveys and analytical work related to Indigenous health.

The National Statistical Service was described as fostering cohesion through activities such as the development of comprehensive information development plans that spell out data needs, data availability and gaps, and the roles and responsibilities of stakeholders. Other relevant activities include the Bureau's directory of statistical sources, work to develop classifications and methodologies and support for statistical work conducted outside the Bureau.

Health has provided a good example of an area that has been the subject of productive collaborative efforts in Australia, with the preparation, within the arrangements of the National Health Information Agreement, of information development plans for health status, health services, Indigenous health, and public health; coordination of State-based CATI survey methodologies, agreements on the use of classifications and definitions. These have facilitated production of comparative data such as included in the AIHW's *Australia's Health 2002*.

Mr Trewin concluded by noting that a recent meeting of the UN Statistical Commission had requested WHO to strengthen its coordination of statistical work, and posed the question of whether the role of the Collaborating Centres should extend beyond classification to wider statistical issues, to assist the WHO in this area.

2. Better health and welfare – the role of the Australian Institute of Health and Welfare Richard Madden, Director, Australian Institute of Health and Welfare

Dr Madden presented an overview of the Australian Institute of Health and Welfare, noting that it had been established in 1987, and had support from Australia's Commonwealth government, and the governments of the eight States and

Territories. He explained that its mission is 'to improve the health and well-being of Australians, we inform community discussion and decision making through national leadership in developing and providing health and welfare statistics and information.' (www.aihw.gov.au)

Much of the Institute's work is undertaken under the auspices of Australia's National Health Information Agreement. This agreement, established by the Commonwealth, the States and Territories, the Institute and the Australian Bureau of Statistics has been in existence for 10 years and has provided a stable basis for the development and coordination of national health statistics. It is overseen by a management group, which reports to the Australian Health Ministers' Advisory Council, and for which the Institute provides secretariat services. The management group has three standing committees – the National Health Data Committee, the Expert Group on Health Classifications and the National Advisory Group for Aboriginal and Torres Strait Islander Health Information and Data. Its roles include approving classifications and definitions used in National Minimum Data Sets and management of a work program encompassing a range of coordination and infrastructure development activities.

Dr Madden briefly explained the Institute's health-related activities, outlining its key data collections and statistical outputs, which include those relating to hospitals, general practice, cancer registrations, child protection, injuries and disability services. He highlighted work in hospital statistics (which is central in informing debate in this area), disability service statistics (in which use of a statistical linkage key allows estimation of numbers of clients accessing services), the registration of new cases of diabetes (which has allowed estimates of the incidence of type 1 diabetes to be made), the development of algorithms to estimate incidence of coronary heart disease using hospital morbidity data, and work to plan for a survey to include physical measures of health.

3 Comparing the Health of Indigenous Populations of Australia, New Zealand, the USA and Canada - Ian Ring WHO/HFS/CAS/C/02.81

Dr Ring presented a paper on international comparisons of Indigenous health and noted that Indigenous health was of tremendous concern in Australia. He noted that there were some practical difficulties in presenting international comparative data on Indigenous health. For example, changes in individual codes and in chapter structures for ICD-9 and ICD-10, and differences in manual and automatic coding; the meaning of 'Indigenous' in different countries and the completeness of identification; and difficulties with matching numerator and denominator populations.

He noted that there were gaps in life expectancy between Indigenous and non-Indigenous people in Canada, the USA and New Zealand, and noted that the gap was 20 years in Australia.

Dr Ring then presented some trend data on death rates for these countries and stated that there has not been any real reduction in mortality rates for Indigenous

Australians, but that there had been reductions for Indigenous peoples of Canada, the USA and New Zealand.

Dr Ring then presented data showing that most of the extra deaths for Indigenous Australians were from circulatory diseases, injury and poisoning, respiratory diseases and neoplasms. He also showed that injury and poisoning was the cause of most of the extra deaths for Indians in the USA and that circulatory diseases were the cause of most of the extra deaths for Maoris.

Dr Ring outlined some current and future issues for Indigenous health. These included the establishment of International systems for monitoring and comparison through trends and patterns, learning from the International experience and the use of information to improve the health of indigenous peoples both nationally and internationally.

Following the presentation there was discussion about the identification of Indigenous people internationally. It was suggested that perhaps a measure of socio-economic disadvantage may be more useful than the identification of Indigenous people. The subjective nature of self-reported health status was also raised.

Invited Speaker – Harry Rosenberg

Approaches to Implementing ICD-10 for Vital Statistics Harry Rosenberg WHO/HFS/CAS/C/02.63

Dr Rosenberg has recently retired from the United States National Centre for Health Statistics, and from the chair of the Mortality Reference Group. He began his presentation by expressing his pleasure at having been involved in the work of the MRG and of the Collaborating Centres, and with his career at NCHS in mortality statistical work.

Dr Rosenberg briefly outlined his vast experience in mortality statistics in the US and internationally, which included the implementation of ICD-9 and ICD-10 in the US.

He explained that he saw two institutional forces for change relating to ICD. First was the shifting emphasis from uses relating to mortality to non-mortality uses. Second was the impact of computer technology. He presented a range of recommendations for the WHO to consider which reflected these two forces and his experiences with mortality statistical work. The recommendations cover national training, international training, the use of automation, international technical assistance, coordination at the national level between vital registration activities (UN) and classification standards (WHO) and the role of the WHO.

Dr Rosenberg concluded that the forces of change can and should be harnessed to improve the ICD and the quality and comparability of international health statistics.

During discussion of this paper, Dr Üstün thanked Dr Rosenberg for his input into the work of the WHO-FIC network over the years, and said that Dr Rosenberg's work will long be remembered and his contribution will be greatly missed.

Annotated Agenda

Monday 14th October 2002

Time	Item	Document
09.00 – 9.30	**Registration and Coffee**	
09.30 - 12.30	**Opening** Dr Richard Madden (Host Centre)	
	Dr T Bedirhan Ustun (WHO)	
	Election of Officers	
	Consideration and adoption of the agenda	WHO/HFS/CAS/C/02.01
	• Report from the Secretariat on activities since last meeting	WHO/HFS/CAS/C/02.04
	• Report on WHO-FIC retreat (March 2002)	WHO/HFS/CAS/C/02.90
	• Strategy and Work Plan (October 2002)	WHO/HFS/CAS/C/02.98
	Presentation of terms of reference and work plans of committees and work groups	
	• Family Development Committee: Annual Report (ACC)	WHO/HFS/CAS/C/02.73
	• WHO Mortality Reference Group: A Status Report, 2001-2002 (NACC)	WHO/HFS/CAS/C/02.38
	• Subgroup on Training and Credentialing: A Status Report 2001-2002 (NACC)	WHO/HFS/CAS/C/02.60
	• Annual report for Update Reference Group (ACC)	WHO/HFS/CAS/C/02.58
	• Annual report of the Electronic Tools Committee (Germany)	WHO/HFS/CAS/C/02.45
	• Annual report of the Implementation of ICD-10 Committee (WHO)	WHO/HFS/CAS/C/02.102
12.30-13.30	**Lunch**	
13.30 - 14.45	**Breakout Sessions**	
	International Classification of Functioning, Disability and Health (ICF)	
	• Opening discussion setting the direction for the ICF sessions (Dutch)	WHO/HFS/CAS/C/02.101
	• Washington City Group report (NACC)	WHO/HFS/CAS/C/02.33
	• Report on the Trieste meeting (WHO)	WHO/HFS/CAS/C/02.92
	• Adapting the ICF for child health systems: a status report (NACC)	WHO/HFS/CAS/C/02.41
	Implementation of ICD-10 Committee	
	• Implementation of ICD-10-CA and CCI – A Checklist (NACC)	WHO/HFS/CAS/C/02.35
	• Global summary of the ICD-10 implementation status in 2002	WHO/HFS/CAS/C/02.19
14.45 – 16.00	**Breakout sessions**	
	Subgroup on Training and Credentialing and IFHRO Committee	
	• Subgroup on Training and Credentialing: A Status Report 2001-2002 (NACC)	WHO/HFS/CAS/C/02.60
	• Procedures of Certification of Coders in Mexico (Mexico)	WHO/HFS/CAS/C/02.88

• International education in coding, clinical documentation and quality assurance.(Australia)	WHO/HFS/CAS/C/02.67
• ICD-10-AM Third Edition electronic education experience. (Australia)	WHO/HFS/CAS/C/02.52

Update Reference Group

• Annual report for Update Reference Group	WHO/HFS/CAS/C/02.58
• Implementation of ICD-0-3 from a United Kingdom perspective (UK)	WHO/HFS/CAS/C/02.72
• Data Restructuring for the German Translation and Maintenance of ICD-O-3 (Germany)	WHO/HFS/CAS/C/02.42
• Consistency Checks for the Maintenance of ICD-10 (Germany)	WHO/HFS/CAS/C/02.43

16.00 – 16.15

Break

16.15 - 17.30

Breakout sessions

Family Development Committee

• Annual report of the FDC (Australia)	WHO/HFS/CAS/C/02.73
• Report of the WHO – WONCA Joint Working Group on the relations between ICD-10, ICF and ICPC-2	WHO/HFS/CAS/C/02.75
• Submission for recognition of the International Classification of External Causes of Injury (ICECI) as a related classification within the WHO Family of International Classifications (FDC)	WHO/HFS/CAS/C/02.74
• International Classification of Health Interventions – ICD-10-AM (ACHI) and its subset, ICHI (Australia)	WHO/HFS/CAS/C/02.50
• Classification of technical aids for persons with disabilities: neighbour or member of the family? (Dutch)	WHO/HFS/CAS/C/02.91
• The WHO FIC: a protocol for endorsement of new family members (FDC)	WHO/HFS/CAS/C/02.76

Electronic Tools Committee

• Annual report of the Electronic Tools Committee	WHO/HFS/CAS/C/02.45
• Development of ICD-10-CA and CCI in Database Format (NACC)	WHO/HFS/CAS/C/02.36
• Report on Eurostat Technical meeting on Automated Coding Systems for mortality (France)	WHO/HFS/CAS/C/02.28
• Report of the Planning Committee of the International Collaborative Effort on Automating Mortality Statistics (NACC)	WHO/HFS/CAS/C/02.31

18.15 **Tour of Parliament House, Opening of the meeting and Reception**

Sponsor – Queensland Health

Tuesday 15 October

8.30 – 10.30

Plenary

- Report on the Eighth Annual North American Collaborating Center Meeting on ICF: Issues and Future Activities (NACC) — WHO/HFS/CAS/C/02.37
- ICF Coding Guidelines (UK & WHO) — WHO/HFS/CAS/C/02.93
- Dissemination of ICF: CODE ICF; ICF Videos; ICF Curricula in North American Colleges and Universities; and North American ICF Clearinghouse (NACC) — WHO/HFS/CAS/C/02.40

10.30 – 11.00

Break

11.00 – 12.30

Plenary

- Submission for recognition of the International Classification of External Causes of Injury (ICECI) as a related classification within the WHO Family of International Classifications (FDC) — WHO/HFS/CAS/C/02.74
- International Classification of Health Interventions – ICD-10-AM (ACHI) and its subset, ICHI (Australia) — WHO/HFS/CAS/C/02.50
- Classification of technical aids for persons with disabilities: neighbour or member of the family? (Dutch) — WHO/HFS/CAS/C/02.91
- The WHO FIC: a protocol for endorsement of new family members (FDC) — WHO/HFS/CAS/C/02.76

12.30-13.30

Lunch

13.30 – 15.15

Plenary

- ICD 10 effects in the statistics of Diabetes Mellitus in Mexico (Mexico) — WHO/HFS/CAS/C/02.86
- An adjustment factor for estimating the maternal mortality ratio (Brazil) — WHO/HFS/CAS/C/02.23
- Comparability of Cause of Death between ICD-9 and ICD-10 (NACC) — WHO/HFS/CAS/C/02.61
- Use of ICD-10-AM for reporting diagnoses and external causes relevant to Indigenous health issues (Australia) — WHO/HFS/CAS/C/02.80

15.15 –15.45

Break

15.45 – 17.30

Plenary

- ICF User Guide (Australia) — WHO/HFS/CAS/C/02.78
- Application of ICF in the World Health Survey Program (WHO) — WHO/HFS/CAS/C/02.97
- Recommended shortlist for comparisons of hospital discharge statistics in the European union (Nordic) — WHO/HFS/CAS/C/02.48

Breakout Session

Mortality Reference Group

• WHO Mortality Reference Group: A Status Report, 2001-2002 (NACC)	WHO/HFS/CAS/C/02.38
• Annual report from the Mortality Forum (Nordic)	WHO/HFS/CAS/C/02.46
• Results of the ICD-10 bridge coding study England and Wales (UK)	WHO/HFS/CAS/C/02.71
• Using WHO mortality data for international comparisons. (Australia)	WHO/HFS/CAS/C/02.53

17.30 – 18.30 **ICE - Automated Coding**

Wednesday 16 October

8.30 – 10.15

Breakout Sessions

International Classification of Functioning, Disability and Health (ICF)

• Exploring the Measurement of Participation (Australia)	WHO/HFS/CAS/C/02.77
• Report on the study group on the subjective dimension of functioning and disability (Japan)	WHO/HFS/CAS/C/02.30
• ICF as a framework for comparing assessment tools in Community Aged Care Programs (Australia)	WHO/HFS/CAS/C/02.85
• The WHO Disability Assessment Schedule (WHO-DAS II) and its relation with ICF (WHO)	WHO/HFS/CAS/C/02.96

Implementation of ICD Committee

• A roster of experts on ICD-10: suggestions for development and maintenance	WHO/HFS/CAS/C/02.17
• The checklist of essential steps/actions to be taken by countries in the process of ICD-10 implementation	WHO/HFS/CAS/C/02.18

10.15 – 10.45

Break

10.45 – 12.30

Breakout Sessions

Family Development Committee

• The WHO Family of International Classifications and its Relationship to Clinical Vocabularies (NACC)	WHO/HFS/CAS/C/02.83
• Results of responses to the Survey on Surgical Procedures and Interventions (NACC)	No paper
• On the ATC (Anatomical Therapeutic Chemical) classification system and its' use together with ICD (Nordic)	WHO/HFS/CAS/C/02.49
• Shortlist of sentinel surgical procedures for international	WHO/HFS/CAS/C/02.68

Time	Item	Document
	comparisons (Nordic)	
	• Update on International Collaborative Effort on Injury Statistics (NACC)	WHO/HFS/CAS/C/02.34
	Electronic Tools Committee	
	• Modelling ICD-10-AM (Australia)	WHO/HFS/CAS/C/02.65
12.30-13.30	**Lunch**	
13.30 – 15.00	**Breakout sessions**	
	International Classification of Functioning, Disability and Health (ICF)	
	• Mexican Network for the ICF (Mexico)	WHO/HFS/CAS/C/02.87
	• DISTAB Update (NACC)	WHO/HFS/CAS/C/02.39
	• The ICF checklist: Development and Application (WHO)	
	• Clinical Implementation of the International Classification of Functioning, Disability and Health: Conceptual and Coding Approaches (WHO)	WHO/HFS/CAS/C/02.94
	Subgroup on Training and Credentialing and IFHRO Committee	
15.00 – 15.30	**Break**	
15.30 – 17.30	**Breakout sessions**	
	Update Reference Committee	
	• URC worksheets: recommendations for updates to ICD-10	WHO/HFS/CAS/C/02.59
	Family Development Committee	
	• Discussion - Report of the Strategic Planning Meeting	
17.30 – 18.45	**Guest speaker – David Filby**	
19.30	**Dinner – River Canteen**	
	Sponsors – Australian Institute of Health and Welfare and National Centre for Classification in Health	

Thursday 17 October

8.30 – 10.00

Plenary - Host Centre Presentations

- The role of the Australian Bureau of Statistics in health and related statistics - Dennis Trewin — WHO/HFS/CAS/C/02.82
- Better health and welfare – the role of the Australian Institute of Health and Welfare - Richard Madden — WHO/HFS/CAS/C/02.06
- Comparing the Health of Indigenous Populations of Australia, New Zealand, the USA and Canada - Ian Ring — WHO/HFS/CAS/C/02.81

10.00 – 10.30

Invited Speaker

- Approaches to Implementing ICD-10 for Vital Statistics - Harry Rosenberg — WHO/HFS/CAS/C/02.63

10.30 – 11.00

Break

11.00 - 12.30

Report back of committees and workgroups

- Implementation of ICD-10 Committee
- Update Reference Committee
- Electronic Tools Committee
- Mortality Reference Group

12.30-13.30

Lunch

13.30 – 15.15

Report back of committees and workgroups

- ICF
- Subgroup on Training and Credentialing
- Family Development Committee

15.15 – 15.30

Break

15.30 – 17.30

Plenary - Presentation and discussion of scientific papers

- ICD-10 and the Unified Medical Language System UMLS. (Germany) — WHO/HFS/CAS/C/02.44
- The WHO Family of International Classifications and its Relationship to Clinical Vocabularies (NACC) — WHO/HFS/CAS/C/02.83
- The Australian General Practice vocabulary and the ICD-10-Am index: parsing and classification issues (Australia) — WHO/HFS/CAS/C/02.54
- Australian coder workforce. An update survey. (Australia) — WHO/HFS/CAS/C/02.66
- National Coroners Information System (Australia) — WHO/HFS/CAS/C/02.57
- The clarification of an underlying cause of death declared as an “incomplete” diagnosis (Brazil) — WHO/HFS/CAS/C/02.26

	• An investigation for the clarification of ill-defined conditions declared as underlying cause of death. (Brazil)	WHO/HFS/CAS/C/02.22
	• Differences in the selection of the underlying cause of death: Coding seminars in the Nordic-Baltic region (Nordic)	WHO/HFS/CAS/C/02.47
	• The definitions of "Live birth" and "Fetal death" and the influence in the estimations of rates (Brazil)	WHO/HFS/CAS/C/02.25
	• Updating the ONS (OPCS) hierarchical classification of causes of still birth and death in infants for ICD-10 (UK)	WHO/HFS/CAS/C/02.70
	• Senility as the underlying cause of death (Brazil)	WHO/HFS/CAS/C/02.27
	• The underlying causes of death among HIV patients (Brazil)	WHO/HFS/CAS/C/02.64

Friday 18 October

8.30 – 10-.15

Plenary - Presentation and discussion of scientific papers

• Proposals for modernization of the Civil Registration system in England and Wales (UK)	WHO/HFS/CAS/C/02.69
• Use of ICD-10-AM for reporting 'mental health related' admitted patient care (Australia)	WHO/HFS/CAS/C/02.79
• Summary of Hearings on Transition to ICD-10-CM and ICD-10-CM PCS: Issues and Future Steps (NACC)	WHO/HFS/CAS/C/02.84
• Specificity in ICD-10-AM. (Australia)	WHO/HFS/CAS/C/02.51
• The specification of the circumstances of the accident or violence in cases of death due to external causes (Brazil)	WHO/HFS/CAS/C/02.24
• Level of accuracy in filling out death certificates at the civil servant's hospital in the state of Sao Paulo, Brazil (Brazil)	WHO/HFS/CAS/C/02.20
• Quality activities for morbidity and mortality coding. (Australia)	WHO/HFS/CAS/C/02.56
• The Quality of Suicide Mortality Data (France)	WHO/HFS/CAS/C/02.29
• Fall as a cause of death in the elderly population (Brazil)	WHO/HFS/CAS/C/02.21
• Proposed Guidelines for Accessibility at WHO-FIC meetings (NACC)	WHO/HFS/CAS/C/02.62
• The Chronicle: the history and evolution of ICD-10-AM (Australia)	WHO/HFS/CAS/C/02.55
• The history of health statistics in Japan (Japan)	WHO/HFS/CAS/C/02.89

10.15 – 10.30

Break

10.30 – 12.00

Plenary - Presentation and discussion of scientific papers (Continued)

12.30 - **Lunch and river trip to Lone Pine Koala Sanctuary**

Sponsor – Australian Bureau of Statistics

The ferry departs Pier 3, Queens Wharf Road, North Quay (a 12-minute stroll from Royal on the Park). Boarding will be at 12.15 for a 12.30 departure. A buffet lunch will include a choice of main courses, salads, breads and deserts, tea, coffee and orange juice. Other drinks may be purchased from the bar. On return, boarding will be at 15.45 for departure at 16.00. The ferry will arrive back at Pier 3 approximately 18.00

Saturday 19th October

8.30 – 10.15	**Adoption of the draft report of the meeting**
10.15 – 10.30	**Break**
10.30 – 12.30	**Adoption of the Strategic Plan**
	Adoption of Joint Work Plan
	Evaluation of the meeting
	Additional matters
	Place, time, themes and agenda for the 2003 meeting
	Venue for the 2004 meeting

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