WHO-FIC NETWORK MEETING

Tokyo, Japan
16-22 October 2005

A Strategy for Evaluating ICD-10 Implementation and Updating Process: 2005 Status Report

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Recommendations

- Undertake formal evaluations of how well the key objectives of ICD-10 were supported by the implementation and updating processes.
- The results of these evaluations should guide plans for revision of ICD-10 and implementation of its successor.
- The WHO, in consultation with the WHO-FIC Planning Committee, should be responsible for directing the evaluations, and the evaluations should be incorporated into the WHO Business Plan for Classifications.

Abstract

This paper follows on to papers submitted in Cardiff, Wales (1999); Helsinki, Finland (2004); Reykjavik, Iceland (2004) and Bangkok, Thailand (2005), which put forward proposals for systematically identifying the lessons to be learned from the process of implementing and updating ICD-10. It is suggested that this should be achieved through formal evaluations of how well the key objectives of the classification were supported by the main activities involved in implementation and updating. The intention is to establish what went well and where there were barriers to successfully maintaining and disseminating a current and relevant classification. Thus lessons for the future would be drawn equally from successes and failures. The main output will be a set of recommendations for achieving success in the updating and revision processes in the future, so as to:

- *Improve the level and quality of implementation of ICD coding across member states, particularly achieving expanded coverage of ICD for mortality among the Information Paradox[1] countries*
- *Ensure ICD implementation as part of health information systems (including automated coding systems).*

[1] WHO has identified as a key priority addressing the "information paradox", whereby WHO has the least information for countries with the highest burden of mortality and disability.

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Introduction

WHO has the constitutional mandate to establish and revise as necessary international classifications for diseases, causes of death and other public health parameters. It owns a valuable intellectual property in these international classifications and exercises leadership in supporting classifications as the building blocks of health information systems for the international community. In particular, over the last 100 years, the International Classification of Diseases (ICD) has been the principal building block used by the international community. In 1989, the tenth revision was introduced and, for the first time in the history of the ICD, updating mechanisms were officially established in 1997 and became operational in 1999. Implementing, maintaining and updating ICD-10 are therefore among the top priorities of the World Health Organization Family of International Classifications (WHO-FIC) Network.

The Heads of the Collaborating Centres agreed in 1997 that no consideration should be given to ICD-11 until after an evaluation of the updating mechanisms for ICD-10 had been carried out and the results considered by WHO and the Centre Heads. Furthermore, it was proposed that such an evaluation take place after three years of experience using the updating mechanisms. This paper follows on to papers submitted in Cardiff, Wales (1999); Helsinki, Finland (2003); Reykjavik, Iceland (2004) and Bangkok, Thailand (2005), which put forward proposals for systematically identifying the lessons to be learned from the process of implementing and updating ICD-10. It also describes the results of a preliminary consultation strategy session held at the National Center for Health Statistics, Hyattsville, Maryland, USA on February 9-10, 2005, which was the basis for the Bangkok paper. All earlier papers are available from the authors, as well as a report from the Hyattsville consultation.

A systematic credible evaluation of the updating and implementation process is necessary to assure that the Centre Heads and WHO are accountable to the worldwide community that relies on the International Classification of Diseases. Information from the evaluations also can be used in a feedback loop that includes learning and ongoing improvement to the mechanisms and processes developed. It also can guide the updating process for other members of the WHO-FIC, including the International Classification of Functioning, Disability and Health.

As indicated in the paper presented in Reykjavik, the evaluation should focus on:

Evaluation of implementation

- Experience of implementation in countries that achieved successful implementation
- Barriers experienced by countries that have not fully implemented ICD-10

Evaluation of updating

- Demand for updates
- Limitations of the updating process
- Demand for national modifications
- Achievements of the updating process
- Barriers to full implementation of the updating process

Impact assessment

Implementation of a classification and its subsequent updating is fundamentally about making a difference - improving the accuracy and relevance of clinical and health information, and using the information to improve health. The evaluations therefore also need to look at the extent to which the changes brought about the anticipated improvements in clinical, statistical or other data. They also need to look at the discontinuities and disruption brought about by making the changes. Assessing the magnitude of these is particularly important in considering the frequency with which major updates (and indeed full revisions) should take place in the future. Users of the classification and coded data are important stakeholders for this assessment.

Status of ICD-10 evaluation activities

Cardiff paper

The Head of the North American Collaborating Center presented a paper at the 1999 Heads of Centre meeting in Cardiff, Wales on "Approaches for Evaluating the Updating Process for ICD-10". The purpose of this paper was to initiate discussions concerning the evaluation and to suggest possible questions to be addressed.

Helsinki paper

The WHO-FIC Planning Committee held a special meeting in April 2004 in Helsinki, Finland to discuss possible revision of the ICD. An issues paper on implementation and evaluation of the updating process by Roberts et al was presented at this meeting. The paper described the

achievements and problems with the updating process from the perspectives of the authors, who included the chairs of the Update and Revision Committee, the Mortality Reference Group and the Education Committee. During this meeting, the group concluded that it was time to begin planning for revision of ICD-10, as mandated by the World Health Assembly, because the process was likely to take many years. It also was agreed that implementation of ICD-10 should be seen as a pathway to the next version. First steps in the process included two main approaches. First, the Update and Revision Committee would coordinate an investigation of particular clinical problem areas in ICD-10 that had not been successfully addressed by the updating process, and, second, the Heads of the North American and UK collaborating centres would prepare a paper on how to move forward a systematic evaluation of ICD-10 implementation and updating.

Reykjavik papers

Goldblatt and Greenberg presented a paper at the 2004 WHO-FIC Network meeting in Reyjkavik, Iceland, on "A Strategy for Evaluating ICD-10 Implementation and the Updating Process". This paper recommended that the WHO-FIC Network undertake formal evaluations of how well the key objectives of ICD-10 were supported by the implementation and updating processes to guide plans for revision of ICD-10 and implementation of its successor. The need for these evaluations was agreed by the meeting participants, and the authors agreed to take the lead in developing the evaluation strategies, with the goal of presenting an options paper for discussion and decisions at the April 2005 meeting of the WHO-FIC Planning Committee.

A second paper presented in Reyjkavik by Walker reported the findings of ICD-10 Coder Needs Assessment Surveys that had been conducted by the WHO-FIC Education Committee. This represented the first known comprehensive view of the coder workforce internationally. The findings included information on ICD-10 implementation status and some barriers to its implementation.

Preliminary consultation

A preliminary consultation strategy session was held in Hyattsville, Maryland on February 9-10, 2005 to frame the purposes, objectives and alternative approaches for the evaluation. The consultation was attended by representatives of WHO (HQ and PAHO), the Australian, North American, and UK Collaborating Centres. Representatives of several other collaborating centres participated in a one-hour conference call on the second day. Tom Chapel, Health Scientist and evaluation advisor at CDC, helped organize and facilitated the consultation. All participants present at the Hyattsville meeting agreed that the evaluations were an important component of the revision process and WHO-FIC Business Plan.

A high level outline of the requirements for a successful evaluation was developed at the February consultation. It was agreed that the evaluations need to be model-based. Discussions suggested a description for ICD-10 implementation and updating, using a global logic model that identifies:

- Inputs, resources and context
- Activities
- Short-term outcomes
- Intermediate outcomes and
- Longer-term outcomes

Participants recognized that the classification and associated processes will have very different purposes and relevance according to the context of the country. For this reason five country scenarios were suggested:

1) Country has no mortality or morbidity data or related resources and infrastructure
2) Country has some data, resources and infrastructure but has not implemented ICD
3) Country has implemented some version of ICD but not ICD-10
4) Country has implemented ICD-10 but not the updates
5) Country has implemented ICD-10 and the official updates

For a particular country, the scenario may differ for mortality and morbidity data.

For each scenario, the participants defined the types of questions that should be asked in relation to the logic model and the uses to be made of the information gathered. Specific questions were identified, along with data collection methods and sources. Some of the information already has been collected by the Network and WHO through Needs Assessment questionnaires, the Update Reference Committee and other sources, as indicated above. However, the participants in the consultation agreed that new data collection will be required through structured questionnaires, structured interviews with some country representatives and regional offices, and possibly focus groups. The group identified as a particular challenge collecting costs of implementation and ongoing maintenance and estimating the cost of implementing a future revision.

Necessary tasks envisaged were as follows:

- Complete the internal WHO-FIC Network evaluation
- Develop evaluation design options
- Refine questions for each scenario
- Develop draft survey instrument with skip patterns
- Elaborate sources and methods
- Develop a sampling and fieldwork plan for each scenario
- Estimate resources needed

- Conduct data collection and analysis

The participants concluded that the principal users of the evaluation findings will be the WHO-FIC Network. However, the World Health Assembly, national statistical organizations, international donors and others in the international health and data standards community also are expected to be interested in the results. As a formative evaluation, research on how to make the "product" a better match for market needs can be used to develop incentives for implementation and updating by more countries. As an implementation evaluation, the findings can be used to improve current efforts and establish "best practices" for the next revision. Finally, as an effectiveness evaluation, the findings can provide accountability to funders and also data to persuade slow to adopt countries to implement the classification and its updates.

Bangkok paper

As agreed in Reykjavik and drawing on the above consultation, Goldblatt and Greenberg prepared a paper for the 2005 mid-year meeting of the Planning Committee in Bangkok, Thailand, on "Design Options for Evaluating the ICD-10 Implementation and Updating Processes". This paper described the results of the consultation and made the following recommendations:

- The WHO-FIC Planning Committee should be responsible for directing formal evaluations of how well the key objectives of ICD-10 were supported by the implementation and updating processes
- The evaluations should include desk based assessment of existing materials, targeted questionnaires and visits to a sample of countries, selected according to the level of implementation and updating achieved.
- The WHO-FIC Planning Committee should determine which aspects of the evaluations might be carried out by the WHO-FIC Network, recognizing this may require additional resources, and which should be carried out externally
- Funding should be sought to finance the evaluations, so as to ensure timely and high quality products

During the discussion of the paper in Bangkok, members of the Planning Committee expressed appreciation for the work accomplished to date and asked the Head of the North American Collaborating Center (NACC) to carry out an additional task prior to the 2005 WHO-FIC Network meeting. This involved gathering information from a sample of members of the Network on their ability to answer the types of questions on the implementation and updating processes that had been developed during the consultation.

Post-Bangkok data collection

The authors reviewed and refined the questions included in the Bangkok paper and developed two questionnaires (see appendixes 1 and 2), which were sent to the members of the Planning Committee for their completion or further distribution. Respondents were not asked to provide actual answers to the questions (e.g., what resources were needed to implement ICD-10 in

country) but rather to indicate one of the four options:

1) Information is readily available to collaborating centre or respondent
2) Information could be obtained quite readily from other sources
3) Considerable effort or additional resources would be needed to obtain this information
4) Respondent is unaware of data sources for the information

Comments on each question also were solicited.

There were several reasons why actual answers to the evaluation questions were not solicited. The principal reason was that the questions identified during the consultation were quite open-ended; obtaining answers to these imprecise questions would result in non-comparable data that would be difficult to analyze and interpret. It was always intended that the questions would serve as the basis for developing a more refined questionnaire with standardized response categories. The Planning Committee understood that there were no resources identified to refine and field the questionnaire instruments and report on the results in time for the 2005 Network meeting; however, the members felt that it would be useful to explore the ability of collaborating centres to answer the questions in the future.

Responses to the questionnaires distributed were received from Australia, Canada, Finland, France, Germany, UK, US and PAHO (for Caribbean countries). Sue Walker, who has conducted training throughout the Western Pacific region, also submitted a response to the updating questionnaire for Samoa. (See appendix 3) The results of these questionnaires can be summarized as follows:

- The majority of respondents answered that information on the vast majority of questions was either readily available to the Collaborating Centre or could be obtained quite readily from other sources. This was especially true for the "input-related" questions and held for both mortality and morbidity implementation and updating.
- Respondents did indicate that considerable effort or additional resources would be needed to obtain some of the information sought. There was at least one response in this category for 43% of the implementation questions and 74% of the updating questions. The questions for which the most respondents selected this option were the "outcome-related" ones. For these questions, in particular, some consultation would be needed with data users. The same was true for the question about how ICD-10 can be changed to be more responsive to the country's situation.
- Respondents were aware of data sources for almost all of the questions.
- Comments provided on specific questions confirmed that many of the questions (e.g., what resources are needed or what training is needed) were too general or vague and needed further definition.

As noted above, Sue Walker, who has conducted training in a number of countries that currently use ICD-10, submitted a response to the updating questionnaire (morbidity) for Samoa. She reported that the Ministry of Health in that country was totally unaware of the updating process prior to her visit. She further indicated that in almost every case, a country representative would need to be contacted to obtain the actual answers to the questions and

suggested several possible contacts.

Conclusions from Post-Bangkok Data Collection

This small effort indicates that information probably could be collected directly from Network members (who, for the most part, represent scenario 5) for many of the questions identified by the preliminary consultation. However, first the data collection instrument would have to be turned into a proper survey with response options specified. Some questions would need to be clarified, others eliminated, and skip patterns would need to be included to route respondents through the questionnaire. The comments received provide clear pointers to where this would be necessary. Outcome-related questions would receive limited responses unless the country had resources to query users and other stakeholders.

Unfortunately, this has provided little information about whether and how countries outside of the Network (scenarios 1, 2, 3 and 4) would respond to the questions. It is unlikely that sending questionnaires to these countries, even if contact information were available, would result in a good response. In-person interviews in a sample of the countries probably would lead to the most useful data. Regional offices and international trainers might be able to suggest appropriate contacts. However, without gathering this information, it is unlikely that uptake of the next version of ICD or its updates will be any better than the experience with ICD-10.

Next steps

Based on the above activities and analysis, the following next steps are required:

- The Update and Revision Committee should complete its internal evaluation of the updating process.
- The questions should be refined for Network countries, and fully defined questionnaires should be developed to collect the substantive, comparable information needed for an evaluation.
- All Collaborating Centres should be requested to complete the questionnaires for at least one, and preferably all, countries covered by the respective Centre. This should be done for both implementation and updating and for both mortality and morbidity uses.
- Based on the results from the above internal evaluation, the questions should be further refined and questionnaires developed for countries in scenarios 1-4.
- A sample should be drawn of countries in each of scenarios 1-4, and a field work plan should be developed. (The Bangkok paper suggests different approaches for stratifying countries into different scenarios and designing the sample.)
- The interview protocol should be piloted in at least one country for each scenario.
- The full field work should be carried out, with sample size dependent on available resources.
- All results should be synthesized and a final report prepared.

With the possible exception of the first task, all of the tasks described above will require some external resources. It is evident that dedicated staff or contractors are needed to coordinate the evaluation components and synthesize the information obtained. This can not be done by volunteers from the Network. It is possible that Network survey experts could complete the development work on the questionnaires but, to date, no volunteers have come forward to indicate their willingness to do this. Although, again, volunteers from the Network might also be able to conduct some of the interviews, their expenses would need to be covered, at the very least. Because this is a major effort, critical to the future maintenance and implementation of ICD, the WHO, in consultation with the WHO-FIC Planning Committee, should be responsible for directing the evaluations, and the evaluations should be incorporated into the WHO Business Plan for Classifications.

Conclusion

The authors have completed their work in designing the evaluation of ICD-10 implementation and updating and proposing strategies for carrying out the evaluations. Although they are willing to serve in an advisory capacity to future efforts, they have concluded that dedicated resources are now needed to accomplish credible evaluations.

For this reason, they have recommended that WHO assume responsibility for directing and resourcing the evaluations, because the Planning Committee does not have this capacity.

Appendix 1

Questions on Implementation of ICD-10

Collaborating Centre:

Country:

Mortality ___ Morbidity___

Respondent:

	Question	*Check if Information is readily available to Collaborating Centre or respondent*	*Check if Information could be obtained quite readily from other sources*	*Check if considerable effort or additional resources would be needed to obtain this Information*	*Check if unaware of data sources for information*	*Comments*
	Input Related					
1	What resources are needed to implement ICD-10 in country?					
2	What kind of expertise is needed?					
3	What kind of training is needed?					
4	What is the legal framework?					
5	What is the administrative structure?					
6	Where did resources to implement current system come from?					
7	If no system is in place, where would					

	Question	*Check if Information is readily available to Collaborating Centre or respondent*	*Check if Information could be obtained quite readily from other sources*	*Check if considerable effort or additional resources would be needed to obtain this Information*	*Check if unaware of data sources for information*	*Comments*
	resources to implement come from?					
8	How are mortality or morbidity data currently coded and reported?					
9	What is the extent of coverage for coded data in the country (death certificates or hospital discharge data)?					
10	Where (which agency) houses the systems for death registration, mortality statistics, hospital discharge data?					
11	Which barriers to implementation are key ones?					
12	Which barriers are short-term ones and					

	Question	*Check if Information is readily available to Collaborating Centre or respondent*	*Check if Information could be obtained quite readily from other sources*	*Check if considerable effort or additional resources would be needed to obtain this Information*	*Check if unaware of data sources for information*	*Comments*
	which are long-term ones?					
13	Is translation a barrier?					
14	Are there changes in larger environment that will have a positive or negative impact on moving implementation forward?					
15	Are there programs that need coded ICD-10 data?					
16	Are there champions in country for the use of ICD-10? If so, describe their positions and influence.					
17	Who makes decisions about implementation?					

	Question	*Check if Information is readily available to Collaborating Centre or respondent*	*Check if Information could be obtained quite readily from other sources*	*Check if considerable effort or additional resources would be needed to obtain this Information*	*Check if unaware of data sources for information*	*Comments*
18	Are international mandates to implement acknowledged by decision-makers? Are they motivators?					
19	Is the death registration process linked with a death tracking system?					
20	What is the current IT infrastructure of the country?					
	Activity Related					
1	Does the country need technical assistance for ICD-10 implementation? If so, what kind of assistance is needed and by whom?					
2	Does country need help in setting up basics or modernizing					

	Question	*Check if Information is readily available to Collaborating Centre or respondent*	*Check if Information could be obtained quite readily from other sources*	*Check if considerable effort or additional resources would be needed to obtain this Information*	*Check if unaware of data sources for information*	*Comments*
	a basic system?					
3	What assistance with advocacy is needed?					
4	How can the product (ICD-10) be changed to be more responsive to country situation?					
5	Does country consider ICD-10 better than ICD-9?					
6	Has the change to ICD-10 met country's expectations?					
7	Would country implement its current version of ICD if had it to do over TODAY? Was it worth it? Costs and benefits?					
8	Does country prefer incremental periodic changes to the system					

	Question	*Check if Information is readily available to Collaborating Centre or respondent*	*Check if Information could be obtained quite readily from other sources*	*Check if considerable effort or additional resources would be needed to obtain this Information*	*Check if unaware of data sources for information*	*Comments*
	or seismic changes every 10 or more years?					
	Outcome Related					
1	What purposes does ICD-10 serve for country?					
2	How is country currently using the mortality or morbidity data collected through its systems?					
3	Is morbidity data used in reimbursement and if so, what is the impact? (morbidity only)					
4	Has country examined validity/comparability					

	Question	*Check if Information is readily available to Collaborating Centre or respondent*	*Check if Information could be obtained quite readily from other sources*	*Check if considerable effort or additional resources would be needed to obtain this Information*	*Check if unaware of data sources for information*	*Comments*
	issues? Whose responsibility is this?					
5	How has use of the coded data impacted on allocation of health resources?					
6	How (else) has use of ICD system paid off for country in health-related outcomes?					
7	If not using ICD-10, would purposes would it serve for country?					
8	What is the impact of LACK of implementation?					
9	What benefits are most desired from a system like ICD-10?					

Appendix 2

Questions on Process for Updating of ICD-10

Collaborating Centre:

Country:

Mortality ___ Morbidity___

Respondent:

	Question	*Check if Information is readily available to Collaborating Centre or respondent*	*Check if Information could be obtained quite readily from other sources*	*Check if considerable effort or additional resources would be needed to obtain this Information*	*Check if unaware of data sources for Information*	*Comments*
	Input Related					

1	How aware are decision makers of the updates to ICD-10 and the process for making them and implementing them?					
2	How aware are data producers of the updates and the process for making them and implementing them?					
3	How aware are data users of the updates and the process for making them and implementing them?					
4	What resources are needed for implementing the ICD-10 updates in country?					
5	What kind of expertise is needed?					

6	What kind of training is needed?					
7	What is the legal framework for implementing updates?					
8	What is the administrative structure for implementing updates?					
9	Are there champions for updating ICD-10 and implementing the updates? If so, describe their positions and influence.					
10	Which barriers are key ones?					
11	Which barriers are short-term ones and which are long-term ones?					
12	Is translation a barrier?					
13	Are there changes in larger environment that will have a positive or negative impact on moving implementation of updates forward?					

14	Are there programs that need data based on latest updates?					
15	Who makes decisions about implementation of updates?					
16	Are international mandates to update and implement updates acknowledged by decision makers? Are they motivators?					
17	Where do resources to implement updates come from?					
	Activity Related					
1	Does the country need technical assistance for implementation of ICD-10 updates? If so, what kind of assistance is needed and by whom?					
2	What assistance with advocacy is needed?					
3	What is cycle in country for incorporating updates?					
4	Has the country implemented the most recent updates posted on the WHO website?					

5	Does country participate in the WHO-FIC ICD update process?					
6	Who, if anyone, is responsible for dissemination of updates etc in country?					
7	Do updates have an adverse impact on analyses and trends?					
8	How does country address version control with limited resources?					
9	Is the current international update process meeting country needs?					
10	How can the product be changed to be more responsive to country situation?					
11	How can process be changed to be less costly, hard, or burdensome to country?					
	Outcome Related					
1	What is the impact of LACK of implementation of updates?					

2	For what uses and purposes would/does ICD-10, periodically updated, work for country?					
3	Has country examined validity/comparability issues related to periodic updates? Whose responsibility is this?					
4	How important do decision makers think updates are?					
5	How important do producers of data think updates are?					
6	How important do users of data think updates are?					

Appendix 3

		Respondents to Evaluation Questionnaires		
Country/Collaborating Centre	Questions on Implementation of ICD-10 for Mortality	Questions on Process for Updating ICD-10 for Mortality	Questions on Implementation of ICD -10 for Morbidity	Questions on Process for Updating ICD-10 for Morbidity
Australia	x	x	x	x
Australia/Samoa				x
Canada	x	x	x	x
Finland	x	x	x	x
France	x	x		
Germany	x	x	x	x
PAHO/Caribbean	x	x	x	x
UK			x	x
USA	x	x	x	x