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Annual Report 2005 of the Mortality Forum

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Abstract

Since 1996, when the Mortality Forum was set up, the MF has received and discussed 532 questions on classification of causes of death. Of these, 47 were received since July 2004. The discussions demonstrate the need for international coordination: of 433 issues there has been substantial disagreement on 232. A total of 189 issues have been forwarded to the Mortality Reference Group. Since July 2004, 20 new issues have been sent to the MRG.

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Annual Report of the Mortality Forum

The English Office for National Statistics arranged a course on the implementation of ICD-10 in mortality statistics in September 1996. The course was attended by statisticians and coders from thirteen countries. This provided a unique opportunity for people to exchange views and experiences. The participants wished to stay in touch, and so the idea of an e-mail newsgroup on ICD-10 mortality coding was born. The Nordic WHO Collaborating Centre took responsibility for the administration of the group, which was later given the name "Mortality Forum". The Forum now has about 100 members, representing more than 50 different countries or institutions.

The Forum has a simple questions-and-answers design. Questions related to the use of ICD-10 in mortality are sent to the moderator, Lars Age Johansson (lars.age.johansson@socialstyrelsen.se, or mortforum@nordclass.uu.se), who then forwards them to all members of the Forum. The members are invited to submit comments to the moderator, who then compiles them and passes them on to the group once a week. The complete correspondence, and an index, is now accessible from the Nordic WHO-FIC Centre homepage [<http://www.nordclass.uu.se/>].

Since 1999, the Mortality Forum cooperates with the Spanish-language Latin American ICD Forum ("Forum-CIE"), and questions of particular interest are now circulated in both fora.

From December 1996 to June 2005, the Forum received 532 questions on mortality coding from 35 countries or institutions. On average, each question is discussed for eight weeks.

The number of regular contributors is fairly small compared to the number of members in the group, but several other countries have expressed a lively interest in the discussions.

The Forum has considered a wide variety of questions. Some refer to general principles for using the ICD and not specific to mortality coding, e.g., how to use Chapter XVI (conditions originating in the perinatal period), and how to interpret non-precise medical terms, e.g., tumour, immunosuppression. Others refer to the rules and guidelines specific to mortality coding, e.g., a "highly improbable" sequence of events reported by the certifier, which conditions the coders are to regard as "ill-defined", or the rationale behind some of the coding instructions.

If anything, the Mortality Forum clearly demonstrates the need for international coordination of coding procedures. Even countries who pride themselves on following the ICD instructions often code quite differently. Of 433 questions with comments from more than one country, there has been substantial disagreement on 232. Some of the problems might have little impact on international comparability, but there are still 40 cases where the coding differences we have discovered might cause epidemiologists serious trouble. In another 109 cases, differences might cause noticeable, if not dramatic, discrepancies in the statistics.

Among those who have submitted comments, one might discern two different approaches to the ICD manuals: a "literalist" approach, where the coder follows

the ICD manual to the letter, and an "intentionalist" approach, where the coder attempts to understand what the ICD wants to achieve with the coding instructions, and then codes accordingly. The literalist approach will certainly produce more consistent national statistics, but the coding becomes extremely dependent on the exact wording of the English version of the ICD. A literalist coding based on a translation of ICD-10 - perhaps with an alphabetical index which is not based on Volume 3 of the English version - could produce a quite different result. The intentionalist approach is not quite so dependent on the exact wording, but (as has been seen in the discussions) different countries may arrive at distinctly different interpretations. It seems, therefore, that none of these approaches is the ideal one, and that some type of agreed-upon compromise is needed.

Another classical problem also encountered in the discussions is the tension between rule-based coding and coding based on medical knowledge and experience. To the conscientious nosologist, coding arguments based on medical expertise and experience are neither here nor there. It is impossible for any person - nosologist or physician - to have an in-depth knowledge of all aspects of contemporary medicine, and coding based on personal medical experience is bound to be subjective and will vary considerably from person to person. In the interest of stable and comparable statistics, it is therefore preferable to base the coding on strictly observed rules. However, it is important that the coding instructions are, as far as possible, based on current medical consensus. If the gap between medical opinion and nosological procedures becomes too great, there is a substantial risk that the medical profession will eventually lose confidence in mortality statistics.

Members of the Forum very early expressed their concern that no decisions are taken - the Forum just noted the differences, and/or that the ICD instructions on some point need clarification. A procedure to arrive at an international consensus on how to interpret the instructions of the ICD was therefore proposed to, and endorsed by, the Centre Heads Meeting in Copenhagen 1997. Accordingly, a Mortality Reference Group (MRG) was established at the Centre Heads Meeting in Paris 1998, and the majority of the problems identified in the Mortality Forum have been forwarded to the MRG.

Appendix: Mortality Forum Statistics

Table 1. Number and importance of submitted problems

Period	Importance			All
	Great	Medium	Minor	
2004-07-01 - 2005-06-30	4	29	14	47
2003-07-01 - 2004-06-30	4	23	30	57
2002-07-01 - 2003-06-30	4	33	21	58
2001-07-01 - 2002-06-30	4	18	19	41
2000-07-01 - 2001-06-30	10	20	12	42
1999-07-01 - 2000-06-30	37	17	16	70
1998-07-01 - 1999-06-30	7	50	26	83
1997-07-01 - 1998-06-30	26	48	38	112
1996-12-01 - 1997-06-30	6	8	8	22
<i>All</i>	<i>102</i>	<i>246</i>	<i>184</i>	<i>532</i>

Table 2. Agreement between participants - questions discussed by Forum members

Agreement?	Importance			All
	Great	Medium	Minor	
No	40	109	83	232
Yes	42	103	56	201
Reply from one country only / discussion not concluded	20	33	46	99
<i>All</i>	<i>102</i>	<i>245</i>	<i>185</i>	<i>532</i>

Table 3. Problems forwarded to the Mortality Reference Group

From period	Importance			All
	Great	Medium	Minor	
2005-07-01 - 2005-06-30	3	16	1	20
2003-07-01 - 2004-06-30	-	8	-	8
2002-07-01 - 2003-06-30	4	22	17	43
2001-07-01 - 2002-06-30	26	53	11	90
2000-07-01 - 2001-06-30	0	0	0	0
1999-07-01 - 2000-06-30	4	1	0	5
1998-07-01 - 1999-06-30	2	8	0	10
1997-07-01 - 1998-06-30	3	4	1	8
1996-12-01 - 1997-06-30	3	2	0	5
<i>All</i>	<i>45</i>	<i>114</i>	<i>30</i>	<i>189</i>