Proceedings of the International Collaborative Effort on Automating Mortality Statistics, Volume II

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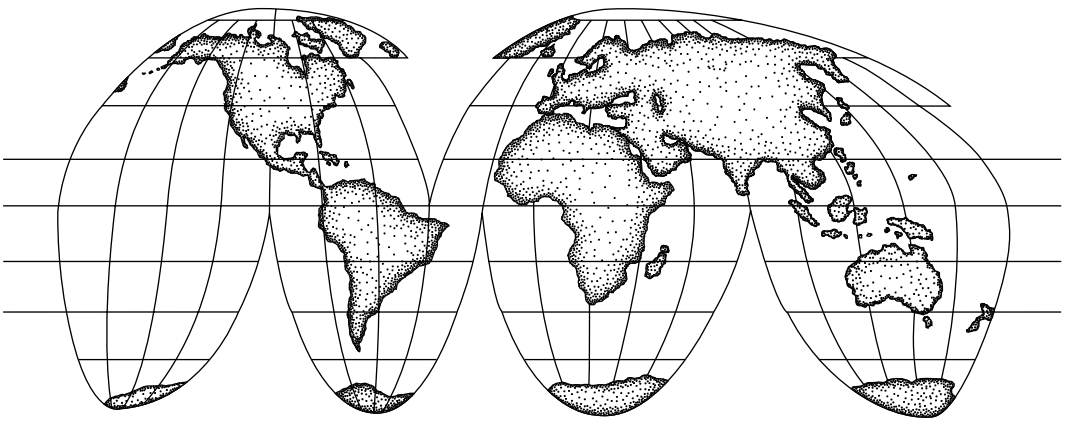

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Preface

The present volume contains presentations delivered at the second plenary meeting of the International Collaborative Effort (ICE) on Automating Mortality Statistics held in Bethesda, Maryland, during September 7–10, 1999. The mission of the ICE is (1) to share knowledge and experience of automated systems for coding mortality information, (2) to develop and improve existing automated systems through international collaboration, (3) to facilitate the transition to ICD-10 for mortality, and (4) to establish mechanisms for technical support of automated systems. At the second ICE, over 70 participants from 25 countries came together to discuss these issues. Progress in all the areas of endeavor that are mentioned above is documented in the Proceedings of the first mortality ICE, held in Washington, D.C., November 12 – 15, 1996, and is available at the NCHS Web site: http://www.cdc.gov/nchs.

Since the first mortality ICE, many of its recommendations have been implemented. A number of these are new activities established by the World Health Organization in connection with maintaining and updating the International Classification of Diseases (ICD). Other activities continue to be under the sponsorship of the ICE. Among the new developments are the following:

- The Mortality Forum—an international on-line discussion group of mortality coding problems supported by the WHO Collaborating Center for the Family of International Classifications for the Nordic Countries.

- WHO's Mortality Reference Group (MRG), a group of mortality experts who review mortality coding and classification problems largely selected from the Mortality Forum and make recommendations to WHO for possible updating. The MRG is supported by the WHO Collaborating Center for the Family of International Classifications for North America.

- WHO's Electronic Tools Committee (ETC)—A committee that is surveying electronic applications to health classification, coding, and dissemination. The ETC is supported by the German Institute for Medical Documentation and Information.

- WHO's Subgroup on Training and Credentialing, which is also supported by the North American Center.

- An electronic bulletin board on mortality automation sponsored by the mortality ICE and supported by the WHO Collaborating Center for the Family of International Classifications for the Australian Center.

- A curriculum on mortality coding and related concepts oriented to automatic coding systems for mortality proposed by the mortality ICE and is conducted for the first time in 2001 by staff of the U.S. National Center for Health Statistics.

The 4-day program of the second ICE was more comprehensive than that of the first meeting, consisting of 11 sessions covering a broad range of topics of relevance to automating of mortality statistics from data collection to data dissemination. These sessions included presentations describing automated coding systems used worldwide, their differences and similarities; bridge-coding between ICD-9 and ICD-10; electronic death registration systems; and progress reports on the recommendations from the previous plenary meeting, among other topics. We are very enthusiastic about the progress generated by this ICE, and we look forward to continuing accomplishments in the future.

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Much of the credit for the success of the conference is due to Kimberley Peters and Kenneth Kochanek of the Mortality Statistics Branch, NCHS.

Finally, thanks to the presenters and authors for their contributions to this volume; please, address individual comments to them (their addresses follow on the next pages). The editors for this volume were Arialdi Minino and Harry M. Rosenberg, of the Mortality Statistics Branch, NCHS. The publication manager was Gail V. Johnson, Publications Branch, NCHS.

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Opening Remarks

Welcome

Harry M. Rosenberg, Ph.D., National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

On behalf of my co-chairperson Sam Notzon and the Mortality ICE Planning Committee, we would like to welcome you to the second plenary meeting of the International Collaborative Effort on Automating Mortality Statistics. We look forward to the next 3 ½ days with you. We hope that they will be interesting and productive as we attempt to improve the international comparability of mortality statistics, and the quality of national mortality statistics through the use of automation.

Before we get underway with our formal presentations, I would like to recognize the persons who have played a major role in planning and organizing the meeting. Kimberley Peters, of the Mortality Statistics Branch, was central to developing the agenda by working directly with the session organizers. Kym also made logistic arrangements with the hotel and with our travel consultants Courtesy Associates. I also want to recognize Ken Kochanek, also of our staff, who has been a very able assistant in planning the meeting and making sure that the planning process went smoothly. A testimony to Kym and Ken's work is that we are here this morning, that the Public Address system is working, and that the coffee is hot. Thanks also to Sam Notzon and to the staff of the Office of International Statistics of the National Center for Health Statistics (NCHS), who provided logistic support, and very importantly, secured a grant from the Open Society Institute, which is funded by the Soros Foundation. The grant enabled participation from some of the Eastern European countries, who could not have been here without the assistance. The grant is also supporting some of the other costs of the meeting. Last, but not least, I want to acknowledge the assistance and the participation of the ICE Planning Committee, who are all listed in the program. They worked very hard to put the meeting together.

I will now turn over the podium to two other persons who will make some opening remarks: Mary Anne Freedman, who is the director of the Division of Vital Statistics (DVS) of NCHS. She will be followed by Ed Sondik, Director of NCHS.

Welcome

Mary Anne Freedman, Director, Division of Vital Statistics, National Centers for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Good morning. It is a real pleasure for me to be here and to see so many of you here. We have over 70 participants from 25 countries at this second meeting of the International Collaborative Effort on Automating Mortality Statistics (ICE). I am enthusiastic about technology and its applications to health data, and about the mortality ICE as a way of collaborating with our international colleagues. NCHS has been developing and applying technology to mortality information for over 30 years. We developed the first ACME program for automatically selecting the underlying cause of death in the early 1970s, applying the data back to1968. Our most recent product is SuperMICAR, which permits the entry of literal text that a physician reports in the cause-of-death section of the death certificate. This text is then converted into codes, which ultimately are processed through the remainder of our software to produce the underlying and multiple causes of death classified by ICD.

The development of SuperMICAR is significant for two reasons: first, we can recover the exact wording that the physician used to describe the causes of death. This is important because cause-of-death codes classified to ICD necessarily lose information. ICD codes often have many inclusions, that is, they subsume a large number of individual, more detailed conditions. In conventional coding, this detail is lost. But with SuperMICAR and the other literal data entry programs used in a number of countries we can retain the cause-of-death detail of the original medical certification and can use the literals for research, analysis, and data requests.

The second reason SuperMICAR is important is that it can interface directly with electronic death registration systems (EDRS). In the EDRS, the physician will directly key his description of the cause of death into the death record. These entries then become direct input into SuperMICAR, which eventually feeds into the ACME program for selecting the underlying cause of death.

I would like to say a few words about the implementation of ICD-10 in the United States. This has been a major effort for us, and it has taken our attention and our resources for over 6 years. As you know, ICD-10 implementation in the United States has a heavy automation component. Automation can be a double-edged sword. On the one hand, we can derive marvelous benefits from it such as more detailed data, higher quality and more timely data, as well as the routine production of multiple cause data for mortality. These are tremendous advantages. The down side is that while automation greatly reduces coding efforts, the costs of system modification and maintenance tend to be high. When we implement a new ICD revision we must modify the decision and modification tables that drive the software. The programming and system work done to implement ICD-10 has been tremendous, running into hundreds of thousands of dollars, and many person-years of efforts by nosologists, statisticians, programmers, and system development staff.

Fortunately, our international partners have helped us to update the mortality decision tables that are the heart of the ACME program. I would like to take this opportunity to publicly thank our colleagues in England, France, Sweden, and Scotland for their great assistance that allowed the U.S. to implement ICD-10 on schedule. The U.S. implemented ICD-10 effective with deaths occurring in 1999. The automated systems are in place at NCHS and in the States,

and we have made them available to a number of countries for review and for adaptation to their own needs. The ICD-10 software is designed for the PC rather than for the mainframe. At present, the programs are DOS-based. Next month we will be releasing the Windows version to our states, and you will be seeing an overview of that system this afternoon.

As you know, the implementation of a new ICD requires retraining of the staff that work with the data. Over the past year we have conducted a massive training effort. We have trained over 300 staff in our state vital statistics programs, and many staff in NCHS as well. Our courses include the traditional underlying and multiple cause of death coding courses and also a new course in ICD-10 coding concepts for statisticians. In addition to that, because the way our systems are maintained—they are maintained at a State level—we have developed a course for the managers of State PC systems. We received tremendous assistance from our Canadian partners. Ms. Patricia Wood, who is a nosologist in Canada, participated in the development of the training materials, and taught several of the underlying and multiple cause sessions. I would like to thank Canada for its assistance in the training. We are also in the process of conducting a comparability study to determine the differences between ICD-9 and ICD-10.

Finally, I would like to just take this opportunity to welcome you again, and to wish you an interesting and a thought-provoking week. I look forward to talking to those of you that I met in the past, and meeting the remainder of you during the week. And I hope that you all enjoy the meeting. Thank you.

Welcome

Edward J. Sondik, Ph. D., Director, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

It is with great pleasure that I welcome you to the second meeting of the International Collaborative Effort on Automating Mortality Statistics, or "Mortality ICE." For many of you this is a return visit; for others, this is your first experience at one of our ICE meetings. The mortality ICE is an example of the National Center for Health Statistics (NCHS) commitment to international and global activities, which is one of the strategic goals of the Centers for Disease Control and Prevention of which NCHS is a part. These collaborative activities over the years have covered a number of areas. The first ICE, which took place15 years ago, was devoted to perinatal mortality statistics; some of you participated in that effort. Subsequently, we have sponsored ICE's in the areas of aging and injury statistics. All of these international collaborative activities have enabled NCHS to work with health statisticians and epidemiologists around the world to better coordinate our research efforts. Earlier this year, we had a very successful meeting of the ICE on Injury.

The purpose of the Mortality ICE is somewhat different from that of the other ICE's. The Mortality ICE is devoted to promoting the international comparability of mortality statistics through the application of technology and automation. The other ICE's, in contrast, have focused on international collaboration on specific research projects. I believe strongly that technology and automation will be one of the most effective approaches to improving the comparability of health data through more coordinated approaches to data collection, to data processing, and to data dissemination. What we see happening every day through the Internet and computer applications is just astonishing. Through email, we can reach our friends and colleagues around the world in minutes. Through the Internet, we can draw on databases and research, again, around the world. And through the power of computer technology and the Internet, we can further standardize national mortality databases to improve their international comparability.

In the United S, NCHS's automation efforts in mortality began in the 1970's when we developed our first software for coding the underlying cause of death. We called that program ACME, which stands for the "Automated Classification of Medical Entities." Since then, we have added three additional inter-related modules for processing mortality data: TRANSAX, MICAR, and SuperMICAR. This software for processing mortality data is already crossing national borders and being adopted or serving as models for other countries. You will be learning more about the systems of the U.S. and other countries during the meeting. We see the dissemination of automation as a major opportunity to improve international comparability of mortality statistics. If the data are coded in similar ways, using automation, then we can at least control one element affecting comparability of mortality statistics across countries.

I am pleased to see that in this ICE, we are also moving into a new area of technology application, namely, electronic data collection, or electronic death registration. We shall have a session devoted to that topic. In the U.S., we are just on the brink of implementing such an electronic death registration system in one State, with other States soon to follow. Electronic data collection for deaths will not only expedite the collection of these data, but also improve the quality of the collected information by including in the software edits, crosschecks, queries, examples, and helps. This has the potential to help physicians in the U.S. obtain instruction on completing cause of death on the death certificate.

In sum, then, we see tremendous opportunities for improving health statistics and the international comparability of mortality statistics through the application of technology and automation. Our purpose during these next 3 days is to share information to further that effort. I want to use this opportunity to thank those involved in this effort: Kym Peters and Ken Kochanek of the Division of Vital Statistics, Barbara Hetzler of the Program Development Staff, and finally the ICE Planning Committee and its co-chairs Harry Rosenberg and Sam Notzon. I also wish to acknowledge the financial assistance of the Open Society Institute sponsored by the Soros Foundation, which made possible the travel of some of our participants from Eastern Europe.

Let me once again welcome you, and wish you a productive meeting, and a very pleasant stay in Bethesda.

Logistics and Goals of the Meeting

Harry M. Rosenberg, Ph.D., National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

By way of background, the mortality ICE, as I like to call it for short, was organized in 1995 by NCHS. Why did we start the ICE? We were stimulated to start the ICE because the international demands on NCHS for assistance in automated coding systems were beginning to overwhelm us. We thought that given this high level of interest we could create a forum to discuss common issues of automation. To proceed, we organized a planning committee comprised of many of the participants who are here today. We had our first meeting in Washington in November 1996, downtown, and that was very successful; the first mortality ICE meeting was attended by over 60 people from 20 countries.

While we had some scientific sessions, the main focus of that meeting was to chart a path. Where did we want to go? What were the issues? What were the problems? Those were developed in 20 discussion groups that were facilitated. The facilitated discussions led to the recommendations that are in your packets. That approach seems to have worked very well.

Six broad topical areas were covered in the first ICE meeting, and around these we have organized the activities of the ICE. The first area that we covered was nosology and the training of nosologists in an automated environment. We recognized that automation was having a tremendous impact on nosologists and mortality medical coders since over 80 percent of the death records in most countries can be handled automatically, rather than manually coded. Yet nosologists are still an essential element for system maintenance, system modification, and for participation in medical research. So what do we do? This is similar to what happened when the power of steam began to be utilized during the Industrial Revolution. Steam power—a new technology—had tremendous impacts on the way things were done and on people who had learned to do business in a certain way prior to that technology.

The second area we talked about was decision tables, which are the core of automated coding systems. They describe acceptable causal relationships between any two medical entities, and they embody the ICD selection and modification rules. We need a way to coordinate international work on decision tables.

Next, data quality: in the context of automation, we want to identify ways to improve the quality of mortality data through editing, querying, identifying and correcting poor certifications, and improving instructions to physicians on how to complete death certificates.

The next area was training for automation support. The use of automation in processing mortality statistics requires new approaches. Not only do medical coders need to know new ways of coding, but they have to become familiar with personal computers, something previously not required in their work. Moreover, there is a need for managers who can assure that the sequential steps in automated processing are carried out properly, and that system problems can be handled expeditiously so that processing can proceed. NCHS just began a new course on PC managers for handling automation in mortality statistics. So we have a new world.

Next, language issues: the first mortality ICE also focused on language issues. When you develop international approaches to automation, there are language issues that affect some parts of the automated systems, but not others. The decision tables are generally not affected by language considerations, because they describe disease relationships in terms of the ICD, not specific to a language. This is true for our underlying cause processing system ACME, as well

as our multiple cause system, TRANSAX. However, there are two "front end" systems, one called MICAR, the other SuperMICAR, which have their counterparts in other countries. To a large degree, the front end components are sensitive to language. In this meeting, we will have some discussion and presentations on how other countries have handled the language issue for the front end of automated systems.

Finally, the last area we talked about in the first ICE meeting was implementation issues. That is, having identified all these problems and issues, how could we make things happen? We developed a number of proposals, one of the foremost of which was to establish a good working relationship with the World Health Organization (WHO). The objectives of the ICE are entirely consistent with the ICD goals of standardizing the collection, processing, and dissemination of mortality and morbidity data among countries. We thus felt that we could get the support of WHO for the ICE, and we are very pleased to inform that we have a key representative from the World Health Organization participating in this meeting, namely, Andre L'Hours.

Have we made any progress? I am happy to report that the ICE has made progress, and I shall go over a few of the things that we have accomplished. Last August we published the Proceedings of the first ICE, of which we have copies available here; they are also available on our mortality Web site. We believe the Proceedings of the first ICE are an important document, not only in assembling a set of scientific papers, but also in creating a permanent record of the recommendations and issues associated with automation.

A notable step forward is the Euro Stat project, which is the European initiative in automation of mortality processing. This project, which is a collaborative effort between France, the United Kingdom, the Netherlands, and Sweden, underscores that important initiatives in this area are occurring in Europe. The ICE strongly supports the collateral activities that started in 1997 in the European Community in automation through Euro Stat. One purpose of the Euro Stat project is to evaluate existing automated systems, and to encourage the use of automation in Europe. Gérard Pavillon, who is at our meeting, will be making a presentation on this project.

The next achievement of the ICE was the establishment of the Mortality Reference Group (MRG) as part of the World Health Organization's ICD program. One recommendation of the first ICE was to establish an updating mechanism for ICD from the mortality point of view, that is, to identify problems of interpretation, errors, and inconsistencies in the ICD, and to propose solutions to these problems. In 1998, the WHO formally endorsed the MRG and identified its membership. A number of the persons at this meeting are charter members of the MRG, which met three times this year, and issued a report to the WHO. This report was presented at the annual meeting of the WHO Heads of Collaborating Centers for the Classification of Diseases in Cardiff, Wales. The MRG began its work by addressing five problems that Lars Age Johansson selected from the Mortality Forum.

The next accomplishment was in the area of training and credentialing. A major source of concern identified at the first ICE is what will happen to nosologists in the future when so many mortality records can be processed automatically, but when nevertheless we need expert nosologists to complement, update, and enhance automated systems. We are very pleased that the World Health Organization and the WHO Center Heads in their new, joint work plan have established a subgroup on training and credentialing to address many of these concerns. Marjorie Greenberg, of NCHS, is the first chair of that subgroup.

Another accomplishment was the identification of the need for an automatic coding systems users group, a recommendation from the first ICE. Such a group is being organized, and you will be hearing more about it in this meeting.

Finally, the ICE is encouraging implementation of automation for mortality throughout the world. Many countries are now moving toward automation, and we will be hearing about those developments during this meeting.

In conclusion, the mortality ICE serves as an international forum for the exchange of information on automation. New ideas can be developed, tested, and evaluated. Those ideas that have demonstrated value can become parts of national systems, within the framework of ICD. That is the direction in which we would like to move. Ultimately, the goal of the mortality ICE is to improve the quality, timeliness, and comparability of international and national mortality statistics. We hope that this meeting can further that cause.

SESSION 1

Overview of Automated Coding S stems

Overview of the National Center for Health Statistics Systems

Harry M. Rosenberg, Ph.D., National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

In the United States the automated coding system has four interrelated components, namely, ACME, TRANSAX, MICAR, and SuperMICAR. ACME is the core of the system and the earliest component. It was developed in the early 1970s to produce underlying cause-of-death data beginning with 1968. The acronym "ACME" stands for the Automated Classification of Medical Entities. The goals of ACME are to:

1. Code the underlying cause of death more consistently than manual coders
2. Simplify data entry and thereby reduce costs
3. Produce multiple cause-of-death data on a routine basis

When we established the system, we succeeded in meeting two of our goals, but not the third. The system is not cheaper. The training aspects of the automated system are not simpler; they are more complex. However, the system can be justified on the grounds that it produces better and more data.

The system works by manually encoding all of the conditions on the death certificate using very explicit data entry rules that require an experienced multiple cause-of-death coder. The codes are entered and then matched automatically against decision tables that identify permissible causal relationships among medical entities for selecting a preliminary underlying cause of death. Then the preliminary underlying cause of death is subjected to the ICD modification and linkage rules for selecting the underlying cause of death that is most suitable for public health purposes. Redundant codes were removed. The ACME is described in detail in NCHS instruction manuals, which are on our mortality Web site.

The next system developed by NCHS is called TRANSAX, whose goal is to produce multiple cause-of-death data. The TRANSAX system uses essentially the same inputs as ACME, and then modifies them in a way most suitable for multiple cause analysis and presentation. There are two sets of output codes, Entity Axis and Record Axis codes.

The Entity Axis codes denote ICD codes as they were entered on the death certificate with the distinction between Part I or Part II, the line, and the position on the line described. The Entity codes are used principally for studies of medical certification assessment.

For example, did physicians put diabetes in Part I or Part II; did they put a chronic disease in Part II; and did they put pneumonia in Part I?

The second set of multiple cause codes are the Record Axis codes, which result from subjecting the Entity Axis codes to the modification and linkage rules. The resultant codes describe the medical certification in terms of all the conditions on the death certificate with terms linked where appropriate. Record Axis codes are used mainly for our tabulation purposes.

The next system is called MICAR. The acronym "MICAR" means Mortality Medical Indexing Classification and Retrieval. Recall that when we established the ACME system, only two of our three goals were fulfilled. The third goal— reducing costs through simplified data entry and training—was not met. MICAR, which we implemented for the first time in 1990, was designed to meet the third goal. MICAR also vastly increases the data retrieval capabilities. The heart of the MICAR system is what we called entity reference numbers or ERNs, which are six-

digit numbers that are assigned sequentially, without any reference to the ICD. For example, Acute Myocardia Infarction is 000001, which has no relation to the ICD; it is just an arbitrarily assigned number.

The use of MICAR requires inputting text from the death certificate in a simplified or "sanitized" fashion. Thus, cancer of the lung is simplified to lung cancer to get a match on the MICAR dictionary, which has several hundred thousand terms.

The benefits of MICAR are that it eliminates using the ICD index for mortality coding or remembering multiple cause-of-death coding rules, some of which are rarely used. Finally, for research and data queries, the MICAR system allows retrieving terms using entity reference numbers. For example, counts of death due to crack cocaine are retrievable even though this term is not on the ICD, but with the ERNs you can retrieve a much higher level of detail.

SuperMICAR is designed to directly use the literal text that the physician put on the death certificate, and having the system produce the multiple and underlying causes of death. We implemented SuperMICAR in 1993 for the first time. SuperMICAR feeds into MICAR, which feeds into ACME and TRANSAX. The advantage of SuperMICAR is that one can actually reconstruct the medical certification of death as the physician reported it.

Thus, in summary, the United States now has a suite of four computer programs for processing mortality data, developed over a period of 25 years. We are still working on the system, and trying to refine it. We can do our job much better with input from international collaborators. The systems do not process all records. ACME can process about 98 or 99 percent of the records; MICAR, about 90 percent; SuperMICAR, about 80 percent. The goal is to get the throughput as close to 100 percent as possible.

Final Report of Automated Coding Systems in Europe

Gérard Pavillon, Head, WHO Collaborating Center for the International Classification of Diseases in the French Language

Introduction

I will present the final report of a survey on causes of death coding in European countries. This work was funded by Eurostat, the statistical office of the European Community. The steering committee of this project included France, United Kingdom, Sweden, and the Netherlands. This project ended in June 1998, and the final report is now available at Eurostat.

Objective

The main objective of the project was to develop recommendations and guidelines to improve European quality and comparability of cause-of-death statistics. This project focused mainly on the coding stage. Another project is on health statistics, including all the aspects of mortality, certification and statistics, but this one focused only on the coding stage, and on the use of Automated Coding Systems (ACS) for medical cause of death.

Tasks

We developed the following tasks in this project. First of all, we tried to describe what is an ACS. Secondly, we made an inventory of coding procedures, manual and automated in the European countries, with an in-depth study of existing automated coding systems. Finally, on the basis of this knowledge, we defined a list of recommendations and guidelines.

The first task is describing what is an ACS. We defined the different functions an ACS should perform: causal death coding, editing, selection of the underlying cause and classification of multiple cause. We made a detailed study, with the help of NCHS, and especially of Harry Rosenberg, of the U.S. system—MICAR, ACME, and TRANSAX.

The second task was developing the inventory of coding procedures in European countries. We made this study on the basis of a questionnaire, including questions on death certificates, certification process, coding process, automated coding systems, and international cooperation on coding programs. We sent out 23 questionnaires to 15 European Union countries, and to 4 other countries. We received 21 questionnaires. The response rate was very good, as you can see. There were more questionnaires than European countries because we sent questionnaires to statistical offices and sometimes, in a given country, there are several statistical offices in charge of mortality data. On the basis of this questionnaire, we made an in-depth study of existing automatic coding systems by an interview of statistical offices using or testing ACS. Those offices were: Catalonia, England, Wales, Italy, Scotland, Sweden, and the Netherlands.

The third task was to develop a set of 30 recommendations and guidelines concerning the implementation, routine processing, and comparability issues of ACS. I will not go through all these 30 recommendations, but I will just underline the recommendations that could be interesting in the context of this ICE, that is, the recommendations that are related to the international quality and comparability of mortality data.

The first recommendation is the use of automated coding systems. We think that ACSs improve international comparability; they also improve the quality of national mortality data over time, and they facilitate easy access to mortality data.

Another recommendation concerns the use of decision tables complying with NCHS ACS decision tables, because most of the countries are already using the NCHS coding system and the decisions tables included in this system are a kind of de facto standard. We also recommend that the decision tables should only be changed on the basis of an international consensus. We recommended developing a set of death certificates that we call a "test deck," with reference coding in order to assess new implementation of ACS.

Finally, we recommended cooperation between member states on ICD-10 implementation and participation with WHO, the Mortality Forum, and the Mortality Reference Group. These cooperations, in my opinion, are one of the more important aspects.

The last recommendation is to create a working group at the European level, open for member states, using or planning to use automatic coding systems with the following goal: to achieve tasks of common interest, to exchange experience, results, methods, and techniques in order to avoid duplicative development of ACS.

Conclusion

As a conclusion, this study gives a definition of ACS, a description of the U.S. software, a picture of the coding processes among member states in 1997, a complete description of the use of ACS, and recommendations and guidelines. We emphasize the need for international cooperation and we propose creation of a working group. The final report was delivered at Eurostat in June 1998.

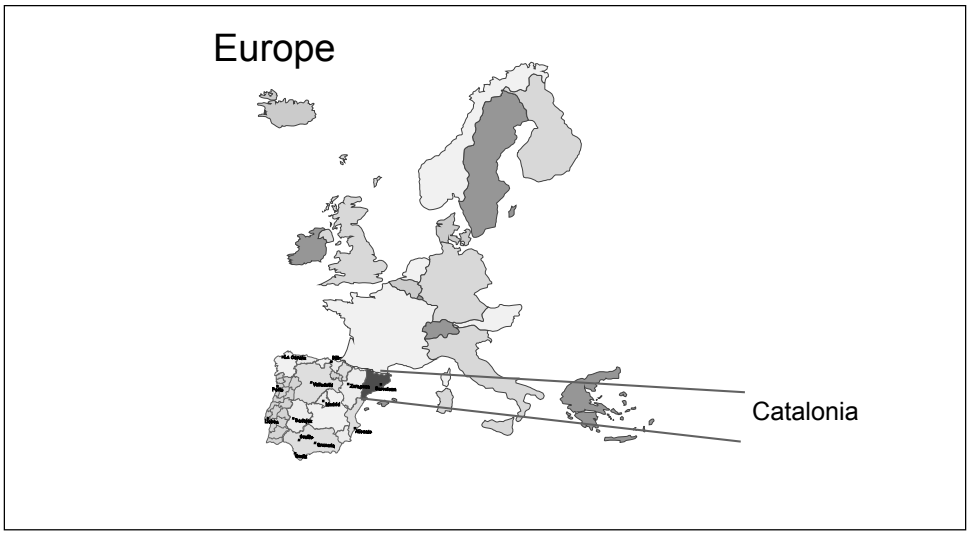
Automated Coding System in Catalonia, Spain

Dr. Gloria Pérez-Albarracín, Chief, Catalonian Mortality Register, Department of Health and Social Security, Spain

Registration and coding deaths

Catalonia is a small autonomous region in the Northeast of Spain and Barcelona is its capital (figure 1). Since the 1980s, a decentralization process began in Spain, which implied that each autonomous community obtained a regional government and parliament with, among others, health policy responsibilities. The decentralized system affects processing, coding, and producing mortality statistics. Currently, the Spanish National Institute of Statistics coordinates and produces national statistics, but each autonomous community is responsible for providing the National Institute with regional mortality statistics.

Figure 1: Catalonia (red) in Spain, Europe



In Spain, global decisions about mortality statistics are taken by national consensus. For example, in 1996, we decided moving to the ICD-10 in 1999. Currently, in the majority of the regional mortality registers the cause of death is selected manually using the coding rules of ICD-9. Only Catalonia and the region of Madrid are coding causes of death by an automated system, but a consensus decision on automated coding has not yet been adopted.

Developing and implementing automated coding of cause of death

Since 1992, the main goal of the Catalonian Mortality Register has been to implement and routinely use an automated system for coding underlying and multiple causes of death, as it was deemed that the automated coding system could improve the reliability of the coding process, reduce the time of training coders, reduce the tedious work of manual coding that can affect the quality of the results, and therefore save time to work in other tasks, e.g. quality control, queries, certification training to physicians, etc. Moreover, the automated system should allow us to record all declared medical entities in order to analyze multiple causes of death.

The automated coding project began in 1992. It entailed reviewing all the documentation about automated systems, interviewing all European mortality registers about their coding systems, and visiting Sweden and England, who had automated systems in a developed phase. Both were using the National Center for Health Statistics (NCHS) automated system, which seemed the most suitable to our needs. As we decided to test this system, in 1993 we sought the advice and expertise from an NCHS expert, Donna Glenn.

In 1994, we made a bridge-coding study between manual and NCHS automated coding system. In 1995, we developed the "DECES neural network system" that is our contribution to the automated system. Finally, 1996 was the first year with full automatically processed data.

The main reason for adopting the NCHS system was the advantage to have the entity reference number (ERN), or what we call the nosological entity of reference as an intermediate code between the literal, i.e., the plain text that physicians write in the death certificates, and the ICD codes. The main drawbacks were the use of English in the dictionary and the dependence on NCHS. Spanish is the main official language in Spain, but there are three other languages (Catalan, Euskera, and Gallego), which are co-official in their respective autonomous communities. Therefore, we needed a recording system that could recognize the literals on death certificates in both Catalan and in Spanish.

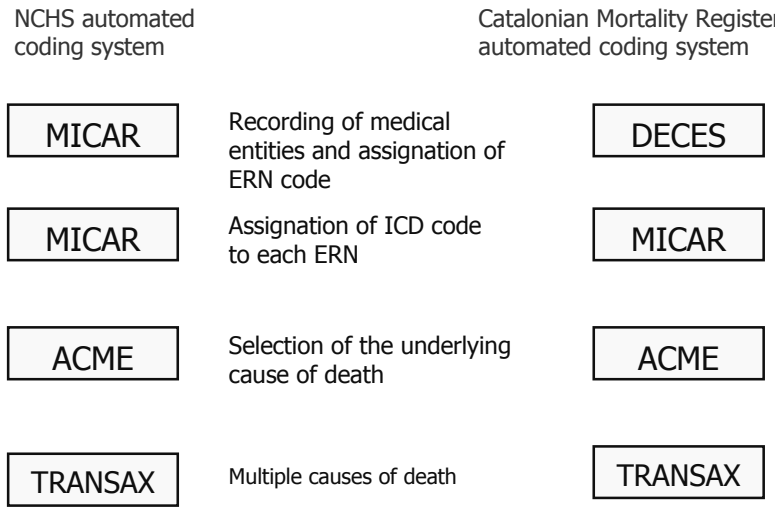
Further, it is worthwhile to remark on the advantage of using an intermediate code (ERN) between the literal of the medical entities and the ICD codes. The ERN is even more precise than ICD codes, it does not change over time, and it allows us to reproduce original medical entities. As is shown (table 1), medical entities with a different etiologic origin like aortic stenosis or aortic insufficiency can not be differentiated in the ICD-9, but now with ERNs this particular case has been corrected in the ICD-10 but others have not.

Table 1. Medical entities, entity reference number (ERN) and International Classification of Diseases (ICD), Ninth and Tenth Revisions. Source of information: Dictionary of MICAR100. NCHS automated coded system.

Medical Entity	ERN	ICD-9	ICD-10
Aortic regurgitation	080384	4241	I351
Aortic endocarditis	080386	4241	I358
Aortic insufficiency	080390	4241	I351
Aortic stenosis	080393	4241	I350

Our system, as presented in figure 2, is using three packages of the NCHS automated system: MICAR200, ACME, and TRANSAX. A specific package for recording medical entities and assigning the ERN was developed: the neural network DECES application, presented in the language issues session of this meeting.

Figure 2: Automated coding systems in the United States and in Catalonia, Spain

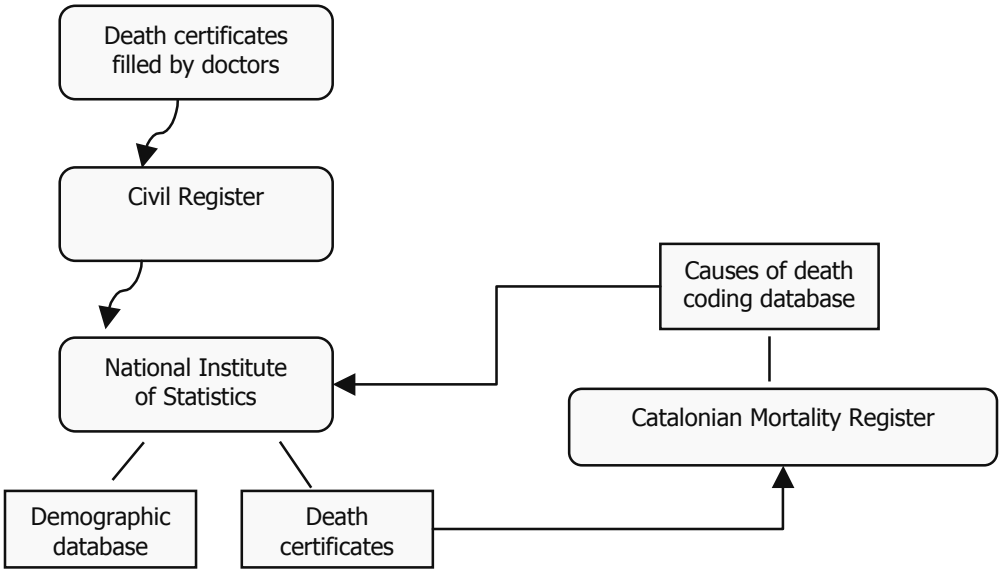


The Catalonian system

The Catalonian mortality information system is as follows (figure 3): Death certificates are filled out by the doctors, who send them to the civil registrar, and then to the National Institute of Statistics, which is responsible for recording the demographic data (age, sex, and occupation). The National Institute then sends to the Catalonian Mortality Register the database of demographic data along with death certificates. We—the Catalonian Mortality Register—code underlying and multiple causes of death, and we send back to the National Institute the database with coded cause-of-death data.

At the end of processing and coding mortality data, the information stored is the original text of the medical entities, entity reference numbers, and the underlying cause-of-death ICD codes, the position and definition of injury of every ICD code, multiple cause-of-death ICD codes, and a monthly 5 percent random sample, which is manually coded to control accuracy of the automated selection of underlying cause of death.

Figure 3: Mortality information system in Catalonia, Spain



Bridge coding study to assess automated coding

The first assessment of the accuracy of the automated coding system was done through a bridge-coding study in 1994. Our bridge coding study consisted in obtaining underlying and multiple causes of death for every death (total amount of 52,180) that occurred in Catalonia in 1994, coded both manually and automatically by the NCHS automated coding system ACME. We aimed to determine the degree of agreement in the underlying cause of death and to calculate death rates using manual and automated underlying cause of death in order to determine changes in death rates by cause of death.

Coders were trained by a nosologist and a physician in the multiple cause-of-death coding rules of NCHS to obtain between-coders reliability of at least 80 percent. Underlying cause-of-death manual coding was considered the standard, and the automated coding system was incorporated in a parallel system that allowed to us to read all ICD codes for every death certificate, to select automatically underlying cause of death by means of ACME, and to link manual and automated underlying causes of death.

From 52,180 deaths that occurred in Catalonia in 1994, a total of 155,649 causes were coded with a mean of 2.9 causes per death certificate. The agreement between manual and automated underlying cause of death when three-digit ICD-9 codes were used was 91 percent. For four digits the agreement was 86 percent.

The agreement when the chapters of the ICD were considered is shown in able 2. The biggest differences are in Ill-defined and Not elsewhere classified causes, in Skin diseases, and in Genitourinary system diseases.

Table 2. Degree of agreement (in percent) of 17 groups of underlying causes of death coded by automated system and manual in Catalonia, Spain

ICD-9 GROUP	Number	%
Infections and parasitic diseases	896	94.4
Neoplasms	9,441	98.0
Endocrine diseases	950	93.8
Blood disorders	148	80.9
Mental disorders	1,115	89.3
Nervous system diseases	707	91.3
Circulatory system diseases	12,848	95.9
Respiratory system diseases	2,794	88.8
Digestive system diseases	1,671	87.0
Genitourinary system diseases	564	82.8
Pregnancy. childbirth and puerperium	1	100
Skin diseases	43	78.2
Musculoskeletal diseases	243	86.5
Congenital	105	89.0
Perinatal period	43	87.8
Not elsewhere classified	162	31.2
External causes	1,779	96.9

When we calculate death rates of specific groups of causes of death differentiated by automated and manual underlying cause of death, we observed differences in rates of Other heart and lung diseases, Pneumonia, Chronic respiratory diseases, Ill-defined and not elsewhere classified (table 3). The rate of Other heart and lung diseases obtained with automated coding is higher than the one manually coded, and vice versa in the group of Ill-defined and not elsewhere classified. This is because in our country cardiac arrest is considered as Ill-defined and is not selected as the underlying cause of death even if another Ill-defined cause is present on the death certificate, whereas in the U.S. cardiac arrest is selected as the underlying cause of death.

Table 3. Mortality rates per 100,000 population for manual and automated coding of specific groups of underlying causes of death. Catalonia, Spain

CAUSES OF DEATH	Manual	Automatic
Intestive infections	0,59	0,74
Respiratory tuberculosi	1,10	1,00
Remainder tuberculosi	0,70	0,64
Remainder bacterial infections	2,90	3,93
Viral infections	0,93	1,76
Remainder infections	0,42	0,77
Leukaemia	6,93	6,57
Remaninder endocrine diseases	4,10	4,35
Chronic rheumatic heart diseases	4,51	3,85
Hypertensive diseases	12,21	10,25
Other heart and lung diseases	75,85	96,86
Cerebrovascular diseases	100,98	96,08
Diseases of veins	11,50	10,72
Respiratory infections	1,86	1,68
Pneumonia	12,39	15,21
Chronic respiratory diseases	40,32	37,54
Gastritis	2,91	2,19
Cirrhosis and other liver diseases	21,32	18,26
Urinary diseases	15,42	14,51
Female genital organs	0,13	0,16
Skin diseases	1,23	1,34
Not elsewhere classified	11,95	4,10
Industry accidents	0,54	0,51

Conclusions

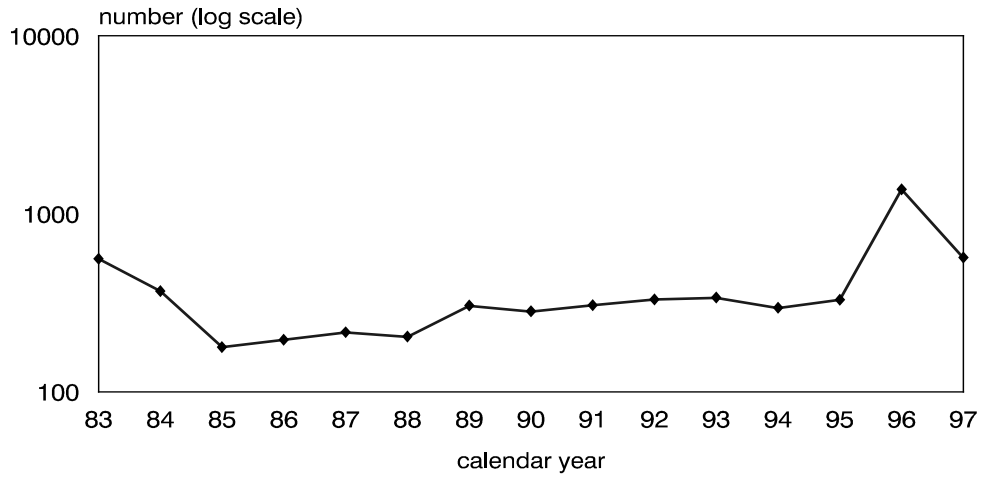
The conclusions are that the limitations of the automatic system are due to the differences in interpretation of the ICD-9 rules. This could modify mortality trends of some causes, for example, infectious diseases and skin diseases. Ill-defined causes need a special mention because in Catalonia and in Spain cardiac arrest has a different treatment as underlying cause than in the U.S., as I will present in a specific session.

In conclusion, the results that we obtained after the bridge coding study for the NCHS automated system in 1994 and the validation study for neural network DECES in 1995 (which is the part of the system that we developed) is that 83 percent of death certificates could be coded by the automated coding system. The full system began to work in 1996. At the moment, the ACS is coding 90–92 percent of all death certificates produced in Catalonia.

The points for discussion are that the purposes of the automated coding system is to assure homogeneity in historical series, and to improve comparability between countries. Differences in interpretation of ICD rules will affect international comparability, and differences with the ACME decision tables will produce changes in mortality trends. In our case, we observed a change in trends when we evaluate the number of deaths due to cardiac arrest. In 1996, the first year of full automated coding with ACME, the amount of cardiac arrest increased

(figure 4). We decided to review these cases manually and we are currently coming back to the level before using automated system.

Figure 4: Number of cardiac arrest evolution as underlying cause of death in Catalonia, Spain



Finally, our recommendations are that a standard international system is necessary for automated coding of the underlying cause of death or multiple causes in order to obtain comparable mortality data. Secondly, a consensus is required on (1) logical sequences and (2) a period to adapt --and this is very important for us-- the local particularities of certification procedures and coding rules interpretations that are not easily modified.

Discussion on the First Three Presentations of Session 1: Overview of Automated Coding Systems

DR. COLE: Susan Cole from Scotland. I would like to ask Dr. Gloria Pérez how you feel about your very interesting cardiac arrest problem, which you obviously regarded as a mode of death and not an underlying cause of death. How do you feel? Do you feel that you are going to be constrained to follow the American interpretation of saying that you died of a heart condition because you had a cardiac arrest? Because I feel with you uncomfortable about this. I suppose I am really asking how much you think that we can persuade with the Americans to part with the ownership of their product?

DR. PÉREZ: Good question. Thank you. I feel very comfortable using ACME decision tables in general, because they will reduce in the future—not now—the variability in trends. But the important thing is reflected in the recommendations that I made. In our country there are some causes of death that physicians wrote that way, and it is very difficult to modify the certification practice.

We cannot use mortality statistics with trend modifications due to coding system, but when is the moment to change? I do not know. I do not know the answer. But I do not feel comfortable giving to our national institute data with this peak on the number of deaths due to cardiac arrest because it is not well coded.

But the thing is when we decide to change the system because we cannot wait to change physicians' knowledge or practice because this is very difficult. Then I think that we need to assume the risk of changing, which means to have modifications in trends due to the ACME decision tables, as in Cardiac arrest.

Maybe the concensus to change is needed for this cause of death and maybe for other causes of death as well. But in the particular case of cardiac arrest, at least for us, this is ill defined and we treat it as such. In general, I think that the decision table is good for our data. I do not know if I have answered your question.

DR. ROONEY: May I comment on that if there is not an immediate question on the same subject? I think this problem with cardiac arrest is one that a lot of the countries were very unhappy with when we started using the American software. I think a lot of these differences may reflect different certification practices in different countries, and may be legitimate in the country where they are being applied.

But I think that we can still get around it, and we are going to talk this afternoon about international cooperation in developing the decision tables. I think this is one of those areas where Gérard Pavillon has pointed out before that it is all very well having the rules, and thinking that we agree how we are applying the rules from the ICD, but unless you actually have a list of every code's relationship with every other code, you may not be applying them in the same way. The way to get around that one, I think, is to change it. And one of the useful things that have come out of this is that it has fed back into the Mortality Reference Group, which involves a lot of the same people, who have the same intention to try and improve mortality statistics.

And I think we want to try and broaden the Ill-defined Rule slightly to take in some of those conditions, which sneaked out of the Ill defined chapter into disease or organ system chapters. At the top of the list is cardiac arrest. If we could agree in the Mortality Reference Group that it should be regarded as ill-defined, then we can get back to the ACME tables as well, I think, cannot we, Harry?

DR. ROSENBERG: Yes. I shall just underscore what Dr. Rooney said. The Mortality Reference Group is making a recommendation to another group called the Update Reference Committee, part of the new, experimental ICD update process. And one of our first recommendations is that some conditions that are now not considered Ill defined, the top of the list being cardiac arrest, be considered Ill defined and subject to that rule.

We are hoping that the Update Reference Committee will endorse the recommendation, and will bring it forward to the Center Heads' meeting next month, and that the Center Heads in turn will support the recommendation, and bring it to the World Health Organization.

DR. PARRISH: I had a question that, I guess, relates to all three talks. It relates to external causes. I know from reading your previous paper that you commented that External Causes are more difficult to get high throughput in terms of accuracy. And I noticed in Spain, Catalonia, you had a very good match between manual and external cause. Was that just for the ones that would actually go through, or were you able to get very high throughputs for external causes as well? Similarly, the same question for the European group, if they had looked at that as well.

DR. PÉREZ: We developed within the DECES system a special module for our external causes of death. The problem with external causes of death is that in Spain they are not always as specific as in the U.S. There are a lot of external causes of death entered as suicide, homicide, or traffic road accident; very general.

The problem with the NCHS entity (ERN) codes is that most of the external causes that are frequent in the U.S. are not frequent in Spain, for example, homicide by guns. We have a lot of death certificates that are rejected because we cannot code them by the NCHS system and we need to code them manually. But in general, it's not a great problem for us.

MR. PAVILLON: In my experience, the problem of external causes is a coding problem; that is, the problem is to find the right code. In France, when we use the automatic coding system Styx, most of the problems of external cause coding found a manual solution in fact.

MR. JOHANSSON: I agree completely. The problem with the external causes is to get the correct multiple codes, and have the multiple codes. Once you have the multiple codes, our manual coding and selection of underlying causes is always identical.

DR. ROONEY: Still on the external causes, our experience in England has actually been a little bit different. It may be that we are not getting the right multiple cause codes in the first place. We actually found that the automated system as a whole did not deal with our external cause deaths adequately at all. I think it is because these deaths get certified and investigated very differently in different countries. Ours have to be certified by coroners, who do it on long, complicated forms, not a simple death certificate. It has bits of information all over the place, not just in the cause-of-death section, including a separate bit for verdict, and a separate bit for how the accident occurred, etc.

You need to take the information from all these places to get the right answer. We code all our external causes of death correctly. We do not put them through the automated system at all, because we found when we did, that we lost about 17 percent of motor vehicle deaths and 20 percent of suicides, which was very cheering for the people who were trying to bring down those rates, but a little unreliable.

DR. JOZAN: First of all, I should like to ask that in such a large country as the United States you have probably more than 2.1 million or 2.2 million deaths per year. Do you have any information regarding the diagnostic differences in States in the United States? I mean between the 50 States of the United States.

I want to clarify: Do you have any information that lets physicians in California, Alaska, or Hawaii approach the positive diagnosis if done different, not in the same way as, let us say, the eastern part of the U.S.? Because I think that international comparability depends not only on a comparative coding approach, but also how physicians fill in the death

certificates in the various countries. It might be that you have your own experience in the United States that would be instructive and informative.

This is one question, because I feel that this is always the first phase of comparability; to educate the physicians. That, for instance, hypertensive disease is hypertensive disease and not hypertensive heart disease. Or what the group of cerebral vascular disease vis-a-vis the hypertensive disease, or chronic and acute myocardial infarction. We always have difficulties in Hungary on how to go ahead with these issues. This is one thing that I wanted to ask you about.

The other is commenting on external causes. External causes are, according at least to my own experience, the soft part of the ICD, because they depend not only on correct diagnosis, but to a certain extent on the culture of the country. I use "culture" as a sociological term. For instance, the diagnosis suicide is not as much of a social issue let us say in the Scandinavian countries or Central European countries as in the Latin countries.

DR. ROSENBERG: I think Peter Józen has made a good point, to isolate the different components of what can affect the comparability of mortality data. Clearly, the only component that we are talking about at this moment is the comparability of coding and processing. However—and that is basically what we are focusing on—your point is excellent, that another general issue, not only in international comparability, but in national comparability is uniformity in completing death certificates.

In the United States we recognize that there are regional variations in the quality of cause-of-death information on death certificates and that there are variations in our mortality statistics that result from that. There are some symptomatic indicators of variations in regional quality. All you need to do is look at the percent of death certificates that are assigned to symptoms and ill-defined conditions.

We have tremendous variations among the States; not only among the States, but among parts of States, rural compared with urban areas in the percent of deaths that are assigned to ill defined categories. Part of the reason for that may not only be variations in physician reporting practices, but also variations in querying incomplete certifications by the health departments. In the United States, but not in every other country, poor medical certifications are queried. The state health department attempts to contact the certifying physician and says: "You said your patient died of cardiac or pulmonary arrest. What was the pulmonary arrest due to?" So that type of variation also plays a role.

Getting back into this regional variation, we know certain medical schools for example, do a much better job in explaining to their students, or subsequently to the residents, how to complete death certificates. But it is, nevertheless, very varied. In some States no one makes an effort to introduce medical students or residents to the correct practice of completing death certificates. So that, indeed, is an important aspect of what we are about. I do not know that we can address that today, but there is an opportunity in automation for improving medical certification practices. That opportunity will lie with the electronic death registration systems in which we can introduce into the system tutorials, edits, and queries, so that if a poor certification is entered on the certificate, the physician can be queried on the spot.

I would say in the future there are great opportunities for improving medical certification. We are trying to do some things to address that in the United States, and let me just mention those. One of the things that we have done is put on our Web site a hot link to a tutorial on completing death certificates, that is, how to write cause-of-death statements.

We also have handbooks that are oriented to physicians on how to complete death certificates. We have printed one-page descriptions on plastic cards on how to complete death certificates and we have distributed over 50,000 to hospitals throughout the United States.

Nevertheless, as I say, there are regional variations, and this is an issue that we can perhaps talk about. I really appreciate your bringing it to our attention, because it does affect comparability.

Swedish MIKADO Coding System

Lars Age Johansson, Senior Executive Officer, Statistics Sweden

Background

Sweden implemented automated coding in two steps: first, the selection of the underlying cause, and then the automated coding of text terms. Our main reason for computerizing the selection of the underlying cause was substantial difficulties with artificial trends in the mortality statistics, due to inconsistent coding. We found that most errors were related to inconsistencies in selecting of the underlying cause of death, and we believed that automated selection of the underlying cause would make that procedure less sensitive.

Statistics Sweden (SCB) also had great difficulties with the timetable for cause-of-death statistics, since several experienced coders left when ICD-9 was introduced. The long time required to train new coders meant that the production of the statistics was much delayed. By introducing a system that would convert the medical terms on the certificates to ICD codes, we hoped to reduce the time and resources required for multiple cause coding.

We studied ACME, the American software for selecting an underlying cause of death, first in 1982 and then again before the introduction of ICD-9 (1986-1987). ACME's selection of the underlying cause agreed with Statistics Sweden's in about 97.5 percent of the cases. This was far above the performance of an average human coder. However, Swedish coding procedures had been thoroughly revised in 1981, and we did not want to upset time trends by introducing new coding practices so soon after the 1981 revision. With the assistance of NCHS, we made some adjustments to the ACME decision tables. After the final modifications (in 1992), ACME and Swedish manual coding agreed in 99.9 percent of the cases. From the introduction of ICD-9 in 1987, we used ACME to check the manually assigned underlying cause code. From 1992, when the decision tables had been adjusted to reflect Swedish coding practices, the selection of the underlying cause of death was left to ACME. However, to monitor the performance of ACME continuously, we assigned underlying causes manually to every third work lot of certificates for another 2 years. From 1995, we coded underlying cause manually only for a small sample of certificates (about 2.5 percent).

SCB experimented with automated coding of free text diagnostic terms first in the late 1970s, and then before the introduction of ICD-9 in 1987. Neither of these attempts was successful, however. In the 1970s, mainframe software used for census coding of occupation was tried, but the language standardization procedures were not sophisticated enough to handle the wide range of variations even in the most common diagnostic terms. For the second attempt (1985-1986) SCB tried to build a PC system. However, the PCs at that time were not capable of storing the large dictionaries required and also could not process the data fast enough.

The Development of MIKADO

The third attempt at a text coding system was launched as a formal project, funded by the Swedish government, in 1989. In the first phase of the project (1989-1991), we collected information on text coding systems via seminars and data bases. We studied three existing coding systems in closer detail:

- AD-DIACOS, a German system used primarily for ICD coding of hospital discharge records

- ACTR, a Canadian system developed primarily for census coding, but built to facilitate adaptations to other uses

- MICAR, an early version of the American software

While ACME obviously met our requirements as for selection of the underlying cause, we could not find any fully satisfactory text coding system. We had set up the following criteria for the text coding module:

- The module must accept the language actually found on the certificates (no specific requirements on the certifiers, no abbreviations or other adjustments at data entry)

- If several conditions are reported in the same field, the module must be able to code them separately

- The module must allow supplementary information to influence the coding

- The computer assisted (interactive) coding must be as similar to manual coding as possible

- The output must be in ACME-compatible format

Of the coding systems available in 1991, none met all these criteria. The AD-DIACOS performed impressively fast, but could not handle code modifications (i.e., that the code for a given term sometimes depends on other information on the certificate, e.g., "brain hemorrhage," which has different codes depending on whether the hemorrhage is recent or old, traumatic or of some natural cause, is in connection with childbirth, or etc). The Canadian system could, in principle, handle the modifications, but the software was not fully operational and Statistics Canada subsequently cancelled the project. The first version of MICAR required the coders themselves to type in the terms to be coded, but SCB wanted to employ professional typists for the keying, and use the coders for the interactive coding only.

By the end of 1991, we decided to develop a multiple-cause coding module of our own. It was decided to work according to the "prototyping" model, i.e., we did not start our project with an attempt to write a complete specification of the coding software. Instead, a primitive prototype was developed very early in the project, and functions and refinements successively added to it. The main part of the work was done by two persons working part-time on the project (50 percent for the first 2 years and 25 percent for the 3rd and 4th year). One was an experienced database programmer, the other a senior coder with previous knowledge of software development. Once the full-scale test was mounted, all coders took part in the evaluation of the software.

A prototype, called AKK, was available in January 1993. After some modifications to the AKK (including renaming it AMK), we started a full-scale test in July 1993. A year later, the

present version (named MIKADO) was introduced. An ICD-10 version of MIKADO has been available since September 1997.

General description

Most certificates are received as paper hardcopies. Approximately 65 percent of the certificates are typed. The contents of the death certificate are keyed in by professional typists, using an application that is not an integral part of the ACS (automated coding system). The typists have no formal medical training, but have long experience of data entry. They have received some in-house training in medical terminology. At first, the typists were told to copy the text exactly as written on the certificate. However, as the typists have gained more experience, they have been instructed to correct obvious mistakes and to make some other edits that will increase the number of matches in the subsequent data processing (such as separating terms with a semicolon). No other edits are permitted at this stage.

We tried optical character recognition (OCR) in 1995, but the outcome was rather disappointing. About 70 percent of the characters were correctly read by the character recognition program, but far more time was needed to find and correct the mistakes than would have been required to key the entire certificate from scratch. However, OCR systems have developed much over the last few years, and a new trial will be conducted in the autumn of 1999.

After keying, the typists run the records through a dummy version of MIKADO, which checks how many of the terms can be found in MIKADO's dictionary. If less than 85 percent of the terms match an expression in the dictionary, the typist has to review and correct the mismatching terms. After typing and correction, the records are exported to the ACS database, named MILAGO. MILAGO, which is written in Paradox for Windows v. 7, is used for storing the records before and after ICD coding, and for data retrieval, such as tabulation and selections. Certificates issued at a forensic institute (at present about 6,000 per year) are sent in electronic form to SCB, and loaded directly into the MILAGO database.

At present, all texts are stored in the MILAGO database, but they are not included in the regular cause-of-death register. No decision has been taken on for how long, and how, the text files will be saved.

Matching strategy

Obviously an efficient text-parsing module is a *sine qua non* for any text coding system. While the number of basic components in medical language is comparatively small, the minor variations are endless. This is well illustrated by the fact that in our first sample of text terms, consisting of 38,720 terms, 32,340 were used only once. In other words, the success of our text coding system would depend very much on the performance of the text parsing components.

Our first plans were to use near-exact matching, which seemed to be the obvious way to avoid inconveniently large dictionaries. The first results were disappointing. We tried different methods, but all yielded a large number of theoretically possible, but unfortunately incorrect dictionary matches. To achieve a reliable match we would have to use a very high threshold value, and we soon realized that exact matching would give the same matches—and much faster.

The explanation of this result, which seems to be at odds with experience from many other automated coding applications, lies probably in the structure of medical language. Medical terms are often compounds of a comparatively restricted set of basic elements. These elements denote, e.g., anatomical site or type of tissue (cervico-, neuro-, myo-, cardio-), or the nature of a disease process (-itis, -oma, -osis, -pathy). Many elements are quite similar, especially in

Swedish spelling, which tends to truncate suffixes ("myocardosis" will be "myokardos") and remove letters that are silent in Swedish pronunciation (e.g., "h" in "cirrhosis" or "p" in "symptom"). Sometimes a single letter makes the whole difference between two quite separate entities, e.g., "arter-" and "artr-" ("artery" and "joint" respectively), or the Swedish words "hjärt-" and "hjärn-" (heart, brain). Moreover, medical terms are often quite long ("kardioartierionefrocerebroskleros"), and essential information on the nature of the disease is often given by the very last syllable ("myocardit," "-it" denotes "inflammation"). This means that word truncation and weighting methods that give higher weight to the early parts of the word will return many incorrect matches.

We therefore decided to base the automatic coding proper (the part of the coding which will not be reviewed manually at a later stage) on exact matching only, but in combination with an extensive text standardization module. In the interactive coding, however, the coder has access to near-exact matching.

The matching procedure proved quite successful. Before standardization, and using direct matching only, about 40 percent of the terms of an average work lot can be found in the MIKADO dictionary. After standardization, a dictionary match is found for about 90 percent of the terms.

Approximately 2 percent of the items to be coded are couched in "ordinary," nonmedical language. In such cases (mainly descriptions of accidents and violence) exact matching is clearly not suitable, and the rate of automatically coded responses is low. Our experiences suggest, then, that exact matching is preferable when scientific terminology is concerned, since such terminology consists of a comparatively small number of basic elements and even small variations can be of crucial importance. Exact matching is not, however, appropriate for coding of responses in ordinary, nonscientific language.

Dictionary of diagnostic expressions

To keep the dictionary reasonably compact and to increase the number of matches, the phrases are standardized prior to matching against the dictionary. The standardization procedure used by MIKADO includes steps such as removal of strings that do not influence the coding, replacement of some strings with synonyms, separation of phrases, alphabetical reordering of words in a phrase, etc. A special feature of the MIKADO is that some strings will be coded separately when they are removed, for example expressions indicating surgery or other forms of treatment, or the duration of a condition. These supplementary codes may be used later to modify the code of the medical condition itself. For a detailed description of the standardization procedure, see the Appendix. The language standardization is defined in a number of tables with a total of about 3,000 records (= instructions on text standardization).

There are two versions of MIKADO's dictionary of diagnostic expressions. One, LEXBAS, contains the expressions in their original, nonstandardized form, whereas in the other (LEXIKON), the expressions have been standardized according to the specifications in the current standardization tables. Thus, an up-to-date version of the standardized dictionary can be prepared whenever the standardization specifications are changed.

Code modification is a salient feature of ICD coding. By this is meant that a medical term may have several different codes, depending on other information on the certificate. Even very common terms, like "heart attack" and "pneumonia," are subject to code modification. Therefore, an important part of MIKADO is the ability to handle such modifications automatically.

For every expression, the dictionary gives a *basic code*, that is, the ICD code to be used if there is no other information on the certificate that modifies the coding. In many cases there is also a *modified code*, i.e., the ICD code to be used if there is indeed information present that influences the coding.

If an expression can have different ICD codes, the criteria for which code is to be used are specified by the *modification variables*. There are 10 of these:

1. The duration of the condition
2. Conditions reported elsewhere on the certificate
3. Recent surgery
4. Complications to surgery
5. Surgery with subsequent complication
6. Complications to recent injury
7. In cases of external violence, possible intent (e.g., suicide, homicide, accident)
8. The age of the deceased
9. The sex of the deceased
10. Specific expressions (text strings) used elsewhere on the certificate

For modifications depending on the basic codes of other reported conditions or on other specific expressions, MIKADO also recognizes 10 different *relations*:

The modifying condition/expression…

1. Immediately precedes the expression to be coded
2. Immediately follows it
3. Immediately precedes or follows the expression to be coded
4. The entities are separated by a word that expresses a causual relationship
5. Immediately precedes or follows the expression to be coded
6. The entities are separated by a word that expresses that neither term is a complete description of the condition without the other
7. Is reported on the same line
8. Is reported on a line above (in Part I)
9. Is reported on a line below (in Part I)
10. Is reported anywhere on the certificate

If an expression can have only one ICD code, there will also be only one record in the dictionary, which will contain only a basic code. If an expression can be coded in several ways, there will be one record in the dictionary for each cause to modify the coding. Each record will have both a basic code and a modified code, and a specification of under what circumstances the modified code will be used rather than the basic one. For example, there is only one record in the dictionary for "alcohol-induced cirrhosis of liver," since no other information on the certificate can modify the coding of that expression. On the other hand, there are five records for "cerebral hemorrhage," reflecting the possibility of coding the hemorrhage as spontaneous, old, traumatic, congenital etc.

Dictionary matrix— Swedish death certificates present three main varieties of medical language: classical Latin, Latin-based Swedish, and Swedish vernacular. While most terms are

couched in Latin-based Swedish, both Classical Latin and vernacular are frequent enough to make their inclusion in the dictionary necessary.

To deal with these parallel sets of terms, and with other kinds of synonyms, we use a system of "dictionary matrixes." For each ICD-10 category, the LEXBAS file contains the full set of possible modifications for one diagnostic term only. This diagnostic term, with its set of modifications, is referred to as the "matrix" for expressions coded to that ICD category. For instance, while "pneumonia" (ICD-10 code J18.9) is coded in the same way as the Swedish expressions "pneumoni" and "lunginflammation," only one of these ("pneumoni") will have records corresponding to the applicable coding modifications of "pneumonia," e.g., postprocedural pneumonia, or chronic pneumonia. The synonyms (e.g., "lunginflammation") will contain a pointer to the matrix, in this case to "pneumoni." When a LEXIKON is produced, MIKADO will, for each expression pointing to a matrix, automatically generate the same set of modifications for the synonyms as for the matrix. So, if "lunginflammation" and "pneumonia" have a pointer to "pneumoni," these expressions will be coded, and if necessary modified, in the same way as "pneumoni."

The nonstandardized dictionary (LEXBAS) of the ICD-10 version now has 8,131 records, of which 6,797 expressions (diagnostic terms) and 1,334 records with modifications of a basic code. The standardized dictionary (LEXIKON) has 15,842 records.

Code assignment—If an expression can be coded in different ways, and consequently there are several dictionary records containing that expression, MIKADO checks for each case whether the conditions specified by the modification variables are met by the circumstances in the present case. If more than one of the dictionary records meet the criteria, the records are ranked according to a set of priority rules. If there is more than one dictionary record with the same rank, and the records give different modified codes, the coder has to determine interactively which dictionary record to use.

MIKADO edits

A consistency check is performed for each assigned ICD code. The checks are specified in table form. The edits are either conditional (for codes that are improbable, but not impossible: for example, plague), or unconditional (for "impossible" codes, like cancer of prostate in a woman). ICD codes can be checked against sex, age, and other ICD codes on the certificates (either that some other code must be present—used for dagger-asterisk codes—or that some other code may not be present, for example that codes from Chapter XV [maternal conditions] may not be used on the same certificate as codes from Chapter XVI [causes of perinatal death]). It is possible to phrase an error message specific to the ICD code, but if no specific error message has been formulated, MIKADO will generate a general error message. At present, there are edits for about 7,000 ICD-10 codes.

When necessary, the procedure also alerts the coder that a certificate has an ill-defined underlying cause of death. If the coder finds that a query to the certifier is necessary, MILAGO will produce a query letter once the certificate is loaded back into the database. Currently, 15 standard letters are available.

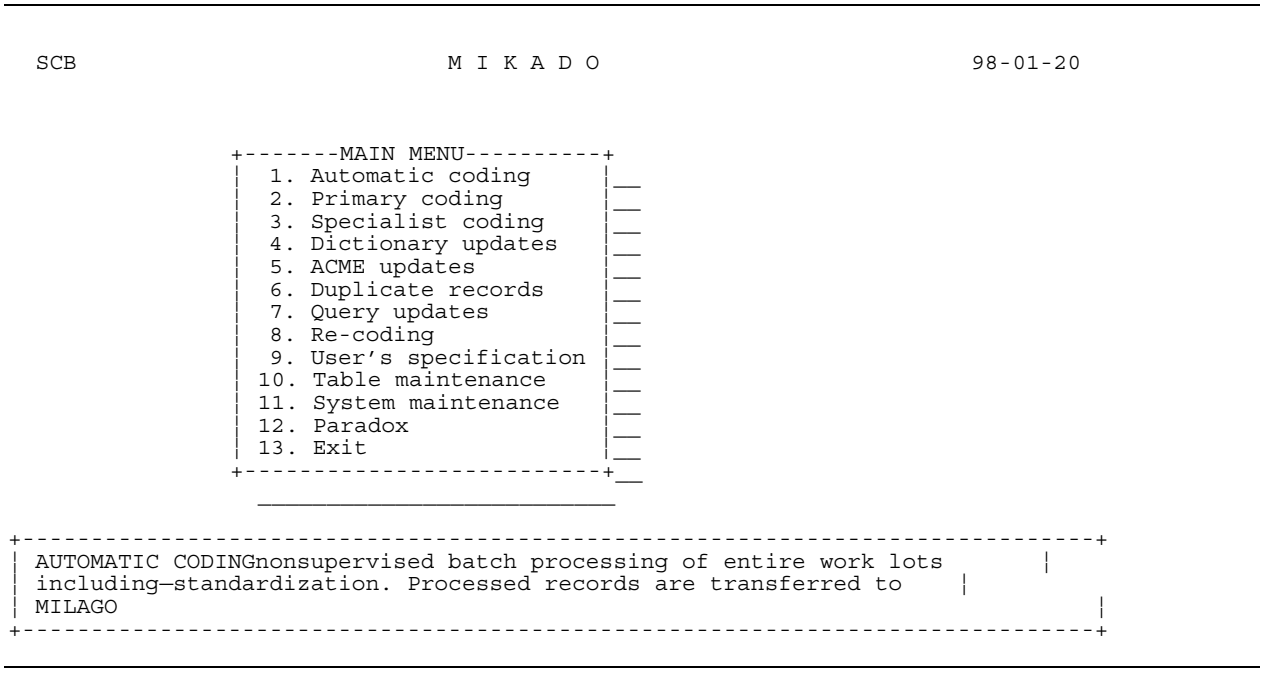
Further checks are performed for consistency between codes from Chapter XIX and XX, and for the use of the ampersand (required by ACME for automated selection of the underlying cause if surgery or violence forms a part of the sequence). Most other variables that the coder can manipulate are subject to entry checks, so that only valid data can be entered. Look up tables, with explanations and help, are available for all items the staff are required to code, such as type of medical examination and place of occurrence.

MIKADO output

The output of MIKADO is a set of ICD codes, arranged according to the ACME specifications. We decided to use ICD codes rather than ERNs (entity reference numbers), since a test proved it quite difficult to match Swedish terms to the terms in the MICAR dictionary. A great number of additional Swedish terms would have been required. We also felt that the MIKADO approach (using standardized text strings instead of arbitrary numbers) would make the system easier to handle. Thus, the output corresponds to the "entity axis" coding performed by MICAR. After MIKADO coding, the data will be exported to ACME for selection of the underlying cause of death, and to TRANSAX, for "record axis" multiple cause coding.

MIKADO's user interface

Main menu:

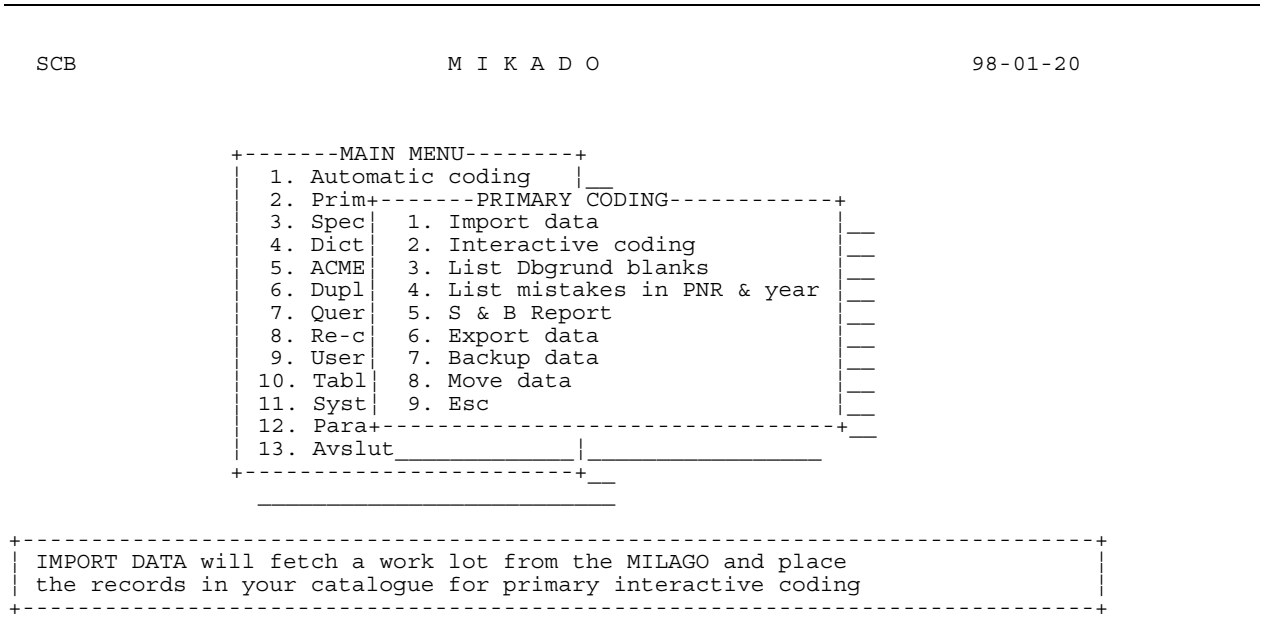


There are two forms of coding: automatic coding, which is run in batches of about 450 certificates, and interactive coding, in which the coders take care of coding problems that MIKADO could not solve in the batch processing. There are several types of interactive coding:

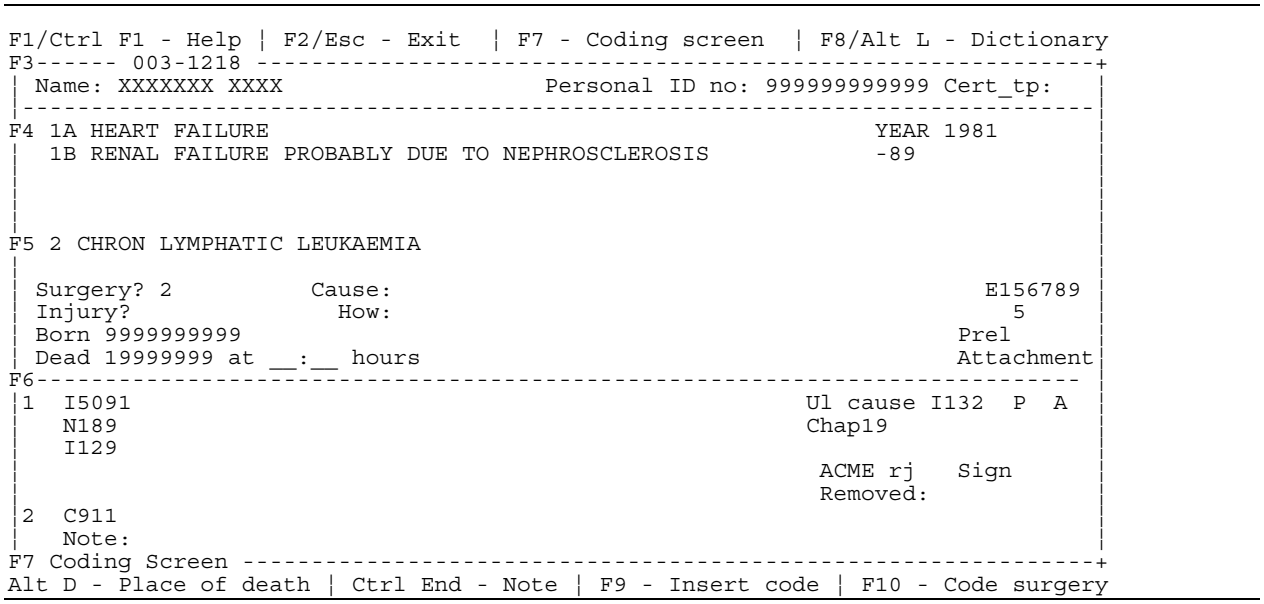
—Primary coding (for all coders)—a first review of all certificates that MIKADO could not code
—Specialist coding (for nosologist coders)—certificates referred to a specialist by another coder
—Dictionary updates (for nosologist coders)—terms not found in the dictionary, and suggested by some of the coders for inclusion
—ACME updates (nosologists)—corrections and other editing of certificates and coding after ACME processing
—Duplicate records (all coders)—elimination of duplicate certificates
—Query updates (nosologists)—editing of certificates after answers from certifiers
—Re-coding (all coders)—independent re-coding for data audits
—User's specification (all coders)—coding of certificates which for some reason do not belong to the production of routine statistics

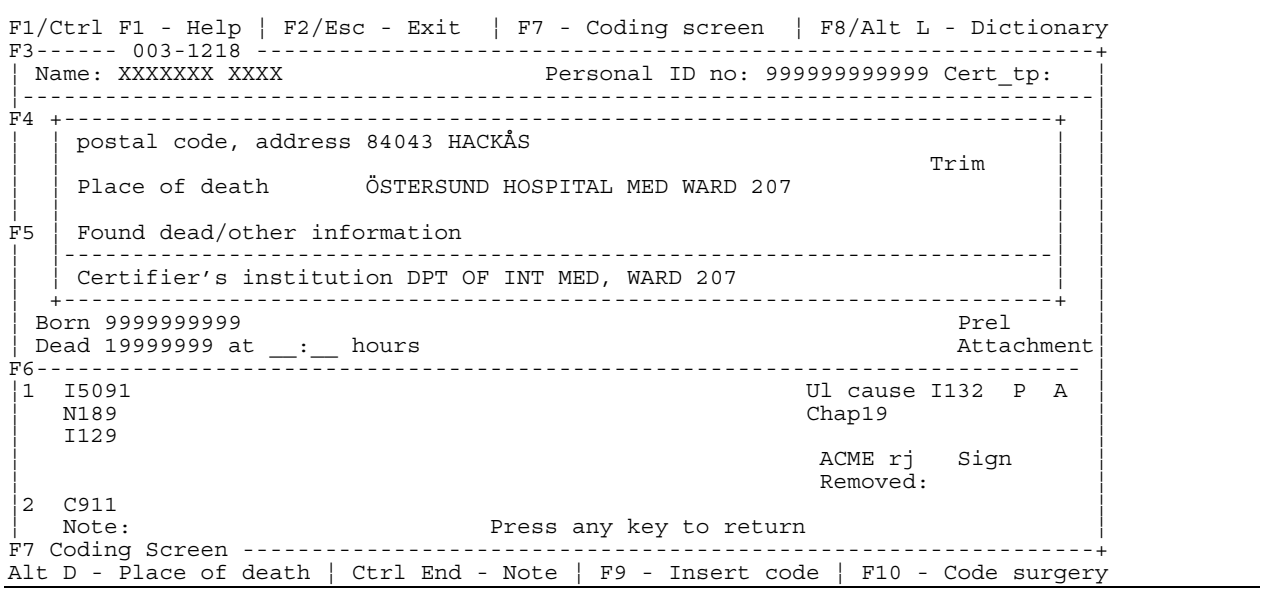
The different types of interactive coding are all fairly similar, and only the Primary coding is described in detail here.

Menu for primary coding:



On the main screen for Primary coding, the identifying particulars are shown, as well as the text from Part I and Part II, and any supplementary information on surgery or violence reported on the certificate. Further information (such as place of death) appears in a special box, if required. The lower section of the main screen is for the ICD codes. We have tried to avoid strong colors, which could strain the users' eyes.





In the interactive coding, the coding suggested by MIKADO is examined interactively by a coder. Any editing is done using a "working copy" of the input text (the “coding screen”), while the original version of the text is stored separately. To facilitate the work of the coder, we have tried to make the interactive coding as similar to manual coding as possible. Thus, the screen layout imitates the certificate form. The coder always has access to the entire text of the certificate, and the operations necessary can be performed in any order the coder prefers. Typically, the review may include operations such as correcting misspellings and supplying codes for expressions not found in the dictionary.

The “coding screen” contains the texts the coder has to work with, and there is one record for each term. The layout is similar to the layout of the MIKADO dictionary, which is also directly available from the coding screen. The coding problems can be solved in any order the coder prefers, as long as there are no unresolved problems left when the coder tries to reload the work lot into the database. Of course, the coder can assign a status code that refers a complicated certificate to a senior coder, in which case MIKADO will accept the certificate as ready for export to the database.

```
F4 - Check Std ¦ F10 - Codes -> Main scr ¦ Esc / F7 - Back to Main Screen
                                                                        H
 HEART FAILURE                              dgn1              ChkMd  Time +4 5
 Line 1A No  1  OK Dbl  10 Pl   A           dgn2              Age    Acute
 BasCode I5099                              dgn3              Sex    Seq
 ModCode I5091                              tx1                      Cong
 SurgCode                                   tx2                      Chron
    Consultant    Surg w compl     Compl of surg   Intent    Compl of injury

 RENAL FAILURE                              dgn1              ChkMd  Time +4 5
 Line 1B No  1  OK Dbl  12 Pl   A     <<*   dgn2              Age    Acute
 BasCode N19                                dgn3              Sex    Seq
 ModCode N189                               tx1                      Cong
 SurgCode                                   tx2                      Chron
    Consultant    Surg w compl     Compl of surg   Intent    Compl of injury

 NEPHROSCLEROSIS                            dgn1              ChkMd  Time   5
 Line 1C No  1  OK Dbl   1 Pl   A           dgn2              Age    Acute
 BasCode I129                               dgn3              Sex    Seq
 ModCode                                    tx1                      Cong
 SurgCode                                   tx2                      Chron
    Consultant   Surg w compl     Compl of surg   Intent    Compl of injury

                  ALL = OK
F1 - Help  ¦ F5 - Standardize and code ¦ F8 - Dictionary ¦ F9 - Remove duplicates
```

From the “coding screen,” the coder can access the dictionary:

```
F2/Ctrl F2 - Back to Coding and bring ICD codes ¦ Alt Q - QUERY ¦ Esc - Back
+--------------------------- DICTIONARY ICD10 -------------------------------+
¦ TextA HEART FAILRE                                              MatrIxM  ¦
¦ Basic Code    I5099                    Place    Act  Standardize  Time     ¦
¦ Modified Code                          dgn1              ChkMd  Acute    ¦
¦     txt1                               dgn2               Age   Seq      ¦
¦     txt2                               dgn3               Sex   Cong     ¦
¦          Surg w compl   Compl of surg   Intent     Compl of injury   Chron  ¦
¦     Consultant                                                           ¦
¦ TextA HEART FAILURE                                             MatrIx M ¦
¦ Basic Code    I5099                    Place    Act Standardize   Time     ¦
¦ Modified Code I5090                    dgn1              ChkMd  Acute 1  ¦
¦     txt1                               dgn2               Age   Seq      ¦
¦     txt2                               dgn3               Sex   Cong     ¦
¦          Surg w compl   Compl of surg   Intent     Compl of injury   Chron  ¦
¦     Consultant                                                           ¦
¦ TextA HEART FAILURE                                             MatrIx M ¦
¦ Basic Code    I5099                    Place    Act   Standardize Time     ¦
¦ Modified Code I5091                    dgn1              ChkMd  Acute    ¦
¦     txt1                               dgn2               Age   Seq      ¦
¦     txt2                               dgn3               Sex   Cong     ¦
¦          Surg w compl   Compl of surg   Intent     Compl of injury   Cron 1 ¦
¦     Consultant                                                           ¦
+--------------------------------------------------------------------------+
F1 - Help ¦ Ctrl S - Scan ¦ F8 - Back ¦ Esc - Back
```

The coder can browse the dictionary in alphabetical or code order, and there are several search facilities available. Expressions not previously included in the dictionary will be copied to a provisional dictionary update file. The provisional dictionary update file will be reviewed by a senior coder and only then included in the dictionary. A "cloning" feature is available, by which it is possible to copy the codes and modification variables (see following) of an expression already included in the dictionary to a new expression. Each time the dictionary is updated, a check is run to ascertain that expressions with the same standardized text have been coded in the same way.

There are several help functions available during coding. There is a general help screen, which lists all hot keys and commands available. There is also context sensitive help. We have

also tried to make any error messages as clear as possible, so that the coder gets a suggestion on what to do next.

The help screen for the Main screen:

```
+-----------------------------------Help-----------------------------------+
| <F2 >         Save the records, return to MENU  <ESC> same                |
| <F1>          Help, this screen or Tablelookup, if available              |
| <F3>          Move to Data                                                |
| <F4>          Move to text in Part I                                      |
| <F5>          Move to text in Part II                                     |
| <F6>          Move to ICD codes                                           |
| <F7>          Move to Coding screen                                       |
| <F8>          Move to dictionary       <Alt> <L> = same                   |
| <F9>          Insert new code, MIKADO moves present codes to the right    |
| <F10>         Mark Surgery/Injury for coding and transfer to Coding Screen|
| <Alt> <D>     Move to Place of death, ZIP code, Place and Hospital        |
| <Alt> <N>     Move to next certificate                                    |
| <Alt> <F>     Move to previous certificate                                |
| <Alt> <O>     Move to next non-coded certificate                          |
| <Alt> <1>     Move to ICD codes -> ICD code for the first term in Part I  |
| <Alt> <2>     Move to ICD codes -> ICD code for the first term in Part II |
| <Alt> <U>     Move to ICD codes -> Underlying cause                       |
| <Alt> <A>     Move to Data -> cause of surgery                            |
| <Alt> <B>     Move to Data -> how the injury was produced                 |
| <Alt> <P>     Move to Data -> Surgery                                     |
| <Alt> <G>     Move to Data -> examination form 5                          |
| <Alt> <E>     Move to ICD codes -> Remove, for S- or B-mark               |
| <Alt> <I>     Suspends check of codes from Chapter XIX and XX             |
+--------------Press a key for more information, Esc for return to certificate-+
```

```
+-----------------------------------Help-----------------------------------+
| <Alt> <F5>    Field View: change the field without erasing with Backspace |
| <Ctrl><F>     Field View: change the field without erasing with Backspace |
|                                                                           |
| <Ctrl><Home> Move to the first field                                      |
| <Ctrl><End>  Move to the last field                                       |
| <Alt><h>     Move to Signature                                            |
| <Ctrl><Z>    Scan for specified certificate number                        |
| <Alt><Z>     Scan for next non-coded certificate                          |
| <Alt><O>     Scan for next non-coded certificate                          |
| <Ctrl><S>    Scan for first certificate marked LATER                      |
| <Alt> <S>    Scan for next certificate marked LATER                       |
| <Ctrl><B>    Scan for first certificate marked REMOVE                     |
| <Alt> <C>    Scan for next certificate marked REMOVE                      |
|                                                                           |
| <Ctrl><X>    Add new text - put the cursor in Part 1 or 2, and then press |
|                           <Ctrl><X>                                       |
| <Shift><F3>  Reverse LATER or REMOVE markings,                            |
| <Ctrl><L>    Medical dictionary                                           |
+---------------------------------------------------------------------------+
```

Help screen for the Coding screen:

```
+-------------------------------------Help-------------------------------------+
| <Esc>         Back to MENU, do not move data                                  |
|                                                                               |
| <F10>         Back to MENU, move all codes to the main screen.                |
|               In doing so you accept the current coding. If you               |
|               wish to change the coding, press F5 to re-code the record       |
|                                                                               |
| <Ctrl><F10>   Re-code all records                                             |
| <F5>          Standardizes the text of the current record and checks the      |
|               Dictionary for a match                                          |
| <Ctrl><F5>    Like <F5>, but suspends the TIME procedure                      |
| <F9>          Remove duplicate dictionary records automatically               |
| <Ctrl><F9>    Remove all duplicate dictionary records, except the current     |
| <Alt><O>      Move to the first non-coded term                                |
| <Alt><G>      Move to BasicCode                                               |
| <Alt><M>      Move to ModifiedCode                                            |
| <Alt><K>      Move to Consultant                                              |
| <Alt><D>      Move to Modification Diagnosis                                  |
| <Alt><T>      Move to Modification Time                                       |
| <Alt><U>      Move to Modification Intent                                     |
| <Alt><A>      Move to Term                                                    |
+-------------------------------------------------------------------------------+
```

```
+-------------------------------------Help-------------------------------------+
| <F8>          Move to Dictionary                                              |
| <Alt> <L>     Move to Dictionary                                              |
| <Ctrl><L>     Move to Medical Dicationary                                     |
| <Ins>         Copies the current record                                       |
|               Note that the record number will change                         |
|                                                                               |
| <Ctrl Z>      Scan for exact phrase or with jokers                            |
| <Alt Z>       Scan next                                                       |
|                                                                               |
| <Ctrl S>      Scan (with automatic insertion of jokers)                       |
| <Alt S>       Scan next                                                       |
|                                                                               |
| <Ctrl> <F>    Field View, change the field without erasing with Backspace     |
|                                                                               |
| <Ctrl><Backspace> Clear entire field                                          |
|                                                                               |
| <Ctrl><U>     Undo, can be used after <Ctrl> <F> or                           |
|               <Ctrl><Backspace>                                               |
|                                                                               |
| "G" in        The record will be referred to a supervisor                     |
| Consultant                                                                    |
+-------------------------------------------------------------------------------+
```

MIKADO and the coders

Initially, several coders had a rather cautious attitude to automated coding. There were fears that ICD coding, which is one of the very few skilled clerical jobs SCB can offer, would be reduced to mere typing. Some coders also feared long monotonous hours in front of the screen with little variety and ensuing stress disorders. After some actual experience of MIKADO, the attitude changed. We made a formal evaluation about one year after the introduction of MIKADO, and at that time, even the initially most hostile coder said it would be unthinkable to return to manual coding. It is essential, though, that the equipment is optimal: the coders need very good monitors, not just standard ones, and also very good chairs and other equipment (desk, lighting, etc.).

The need for expertise has changed. The ACS takes care of all straightforward cases, while the complicated ones still have to be coded interactively. That means that there is no job left for “assistant coders” (persons trained for coding of routine certificates, but with no understanding of the subtleties of ICD coding). There is need for experienced nosologists, as much as before, but for nosologists who know enough of computer jargon to communicate with

the programmers. Conversely, there is also need for programmers who understand the basics of mortality coding. A general conclusion might be that automation has indeed increased the need for expertise, but of a new kind of expertise—people who are "bilingual" in computer and ICD skills.

A great problem with sophisticated automated coding systems is that coding expertise is lost. Since the coders learn that ACME and MIKADO are usually right, they tend more and more to accept the coding suggested by the software, and gradually lose both their ability to code without computer assistance and to evaluate the performance of the ACS. To counteract this, and to maintain the coding abilities that are needed to update the software, the Swedish coders are required regularly to code training sets of certificates manually.

With manual coding, there were more face-to-face discussions among the coders. With automated coding, the coders send problematic certificates electronically to each other. A consequence is that a coder who has a problem with a certificate seldom gets to know how the problem is finally solved. We have tried to address that problem by introducing the possibility of retrieving a single record from the database, and looking at the coding. It presupposes, of course, that the coder who submitted the certificate to a senior coder, keeps some kind of record of problem certificates, and remembers to look them up now and then.

Technical aspects

Each coder him/herself makes the data transactions required for routine work, such as selecting records for interactive coding, and loading them into the database. Two persons have received special in-house training to run more complicated operations, like batch processing of certificates, or data retrieval.

The program code cannot be modified by the staff, only by the consultants who wrote it. The dictionary and language standardization tables have a complicated structure, and at present only the person who designed the MIKADO is able to make the updates.

In 1998, the last year the ICD-9 version was used, the dictionary was considered fairly complete and was updated only twice. There were no changes to the standardization tables. With the ICD-10 version, dictionary updates are performed about once a month. The language standardization tables have been updated four times since the introduction of ICD-10.

MIKADO is written in PAL (Paradox Application Language), which is the programming language supplied with the DOS version of the Paradox database manager. The first versions were written for Paradox v. 3.5; the present version uses Paradox for DOS v. 4.5. MILAGO; the mortality database, is developed in Paradox for Windows, v. 7. The MILAGO (mortality data base) is run under Windows95, and MIKADO in the Windows95 DOS window.

Much work on MIKADO was done while there was still no sufficiently powerful Windows database manager available, and, due to the size and the complicated structure of the application, we have been reluctant to port the application to a Windows-based database manager. We have also run problem-free tests of MIKADO in the Windows NT DOS window. Even so, we will start planning a Windows version in a year or two, mainly because we fear that future versions of Windows will not have a DOS window, or a DOS window with too little space for a complicated application like MIKADO.

MIKADO is PC-based. While each PC has its own copy of MIKADO, and can work independently, any system updates (e.g., loading of certificates to code, new dictionary, new program files) are made through the network. MILAGO is entirely network based.

We use PCs with Pentium processors (350 MHz or more) and a minimum of 32 MB RAM. The MIKADO itself requires about 40 MB of disk space, and uses a further 10 MB while running. The MILAGO uses a PC server with storage capacity for at least 2 years' data.

System performance

To process a work lot (450 certificates) in batch takes about 5 minutes. About 90 percent of the medical terms are coded automatically. For about 65 percent of the certificates, the MIKADO codes every term on the certificate, and no manual review is necessary.

It is important to remember, however, that this does not mean that the coding is now 90 percent (or even 65 percent) cheaper than before. The MIKADO will take care of the straightforward certificates and leave the difficult ones to the coders, who sometimes get the impression that the coding is now slower and more difficult than before. The new technology has also generated several new tasks, such as running the batch jobs and other computer work, and reviewing dictionary updates. Most of this work is done by the coders themselves, and not by IT staff.

The costs of data entry are, of course, substantially higher, and to some extent use up what is saved at the coding stage. Full phrases are both longer and more difficult to type than digit codes, especially since the typists do not always understand the expressions they are copying. Besides, many a doctor's handwriting is as bad as is generally reputed.

The introduction of automated coding has made it possible to work off the backlog we have had since 1987, even though the coding staff have been reduced from eight coders to four. Due to the backlog, however, no financial savings have been made. Presumably, there will be no substantial savings until the current keying of the certificates at Statistics Sweden can be replaced by some form of electronic death certificate.

Percentage of coding errors

In 1992, when we still used manual multiple cause coding, the average coding error (underlying cause, four-character level) was estimated to 7.2 percent. In 1993, after the introduction of AMK, the estimated error was 3.1 percent. Of these, about 0.7 percent were attributable to the automated coding proper, 1.5 percent to the interactive coding, and only 0.3 percent to keying mistakes.

Effects on cause-of-death trends

Underlying cause—For over 3 years, we used ACME in parallel with manual underlying cause coding. For 2 more years, every third work lot of certificates was coded manually, and the manual underlying cause compared to ACME. As a result, we could modify the ACME decision tables to reflect established Swedish coding practice. Thus, there are no visible changes in the Swedish statistics that can be attributed to the introduction of ACME.

Multiple causes— A similar procedure was followed for the MIKADO. We introduced it into the routine production of statistics only after more than a year's full scale testing, which involved parallel manual and automated coding. Thanks to the prolonged test period, we could correct programming and dictionary mistakes that would otherwise have changed the statistics.

Documentation

Since testing and development is still in process, written documentation of the MIKADO is scarce. Full documentation— in Swedish— is included in the program scripts, however, and

specifications— also in Swedish— of central features are available. There are coder and system manager manuals for the ICD-9 version. Similar manuals will be developed for the ICD-10 version as well, but no time schedule has been fixed.

Appendix

Text parsing

When the terms are processed by MIKADO, the first step is to match them “raw” against the dictionary. If there is no match, the following language standardization procedure is applied:

1) Trim blanks— any blanks first and last in the string are deleted, double blanks in the phrases are replaced by single ones.

2) Exceptions— flagging of strings NOT to be standardized in the usual way. Using this feature, e.g., "left" and "right" can be retained in connection with heart failure, where it influences the coding, but deleted in other cases, where it does not.

3) Prefixes and suffixes are removed and replaced.

4) Hyphens are removed or replaced by other characters:
(In this and the following description, "B" stands for blank, "#" for digit, and "@" for letter.)

hyphens first and last in the string are deleted
#B-B# >> #-#
B-B >> B;B
@B-@ >> @B;B@
B-## >> B##
@B-@ >> @B@
@-B@ >> @-B@
#-B@ >> #B@
#-# >> #-#
I-I >> I-I
@-@ >> @@
@-# >> @-#
#-@ >> #-@
@---@ >> @@

5) Deletions— words and strings which do not affect the coding are removed, e.g., "the patient had...,” "probable.”

6) Replacements— spellings and expressions are standardized

7) Full stops— remaining full stops are removed or replaced

Replacement of full stops

full stops first or last in the string are deleted

B.B	>>	B;B
#.#	>>	#□#
B#.@	>>	B#B@
##.@	>>	##B;B@
@.#	>>	@B#
B###.	>>	B;B
.###@.	>>	B;B
B###@.	>>	B;B
B###B@.	>>	B;B
.@.@.	>>	B@B@B
.@.@@.	>>	B@B@@B
.@@.@.	>>	B@@B@B
.@.	>>	B@B
B@.	>>	B@B
.@@.	>>	B@@B
B@@.	>>	B@@B
.@@@.	>>	B@@@B
B@@@.	>>	B@@@B
.@@@@.	>>	B@@@@B
B@@@@.	>>	B@@@@B

any full stop still remaining is replaced by ";"

8) Standardization of phrase separators— strings indicating the beginning or end of a diagnostic expression are replaced by one of four standard separators (";" for enumeration, "*>>*" for a "giving rise to"-type relationship, "*<<*" for a "caused by"-type relationship, *M* for incomplete terms).

9) Surgery— expressions indicating surgery or medical treatment are coded separately and then deleted.

10) The exception sign "#" is removed.

11) If an expression has been deleted in its entirety, it is replaced by a "not known" string.

12) The dictionary is searched for the standardized string.

If still not found:

13) Durations— expressions indicating the onset of or the duration of a condition are removed and, if possible, coded separately. If automated coding of the duration is not possible, the expression is marked for manual duration coding.

14) The dictionary is again searched for the standardized string.

If still not found:

15) All remaining blanks are removed from the standardized string, and a corresponding field in the dictionary (containing the standardized diagnostic expressions with all blanks removed) is searched for a match. If no match is found, the blanks are restored.

16) The words of the phrase are sorted in alphabetical order, and the search is repeated, this time in an alphasorted field.

If still not found:

17) Phrase separation— the string is searched for any standard separator (";", "*>>*" or "*<<*"). If a separator is found, each substring will be standardized as described above (1–16) and a dictionary search performed.

If still not found, or if no phrase separators are found:

Mark the expression for interactive coding.

Update on Automated Coding in England

Dr. Cleone Rooney, Medical Epidemiologist, Office for National Statistics, England

I am just going to tell you how far we have gotten in automating mortality statistics in England and Wales, and I shall also describe some of our future plans. At the moment England and Wales have a mixture of manual clerical activities and automated activities that have to interweave at different stages in processing death records. Certification of cause of death by doctors and coroners is completely manual on paper forms. We are constrained by the law, which only lets us have certain defined forms on which cause of death can be certified. To change that form we actually have to go through Parliament.

The certificate is normally given to the next of kin or some other qualified informant, who takes it to the local registration office to register the death. The legal registration of that death is done electronically onto a PC by the registrar using Registration Service Software (RSS) that was developed by the then Office of Population Centers and Surveys, now the Office of National Statistics. The RSS software produces the official certificates for cause of death for the family to deal with wills, probates, etc. At the same time, the certificate captures the data that we want for statistics, which then goes on to be sent to us centrally, where the cause of death is processed automatically. From there we have regular electronic publications now, as well as paper ones.

Registration Service Software is in use in nearly all the 650 registrar offices in England and Wales now. The very few that do not have it and still do manual registration are very rural areas where the registrar may actually be the postmistress or somebody who registers one or two events a month. With that record volume there is no point in her being computerized, or learning how to use the system. Sometimes in rural areas of Wales, registration is actually done in the registrar's own kitchen at home. Forms are just kept in a drawer in the kitchen.

So 93 percent of all the death registrations now come to us on diskette, floppy disks that are mailed by the registrar every Friday. They arrive sometimes Saturday, sometimes Monday. A certain percent still come in on paper, and we have to type those in. The electronic literal text, exactly what the doctor or coroner wrote, the registrar has to copy exactly and type it in. They have to be able to read it, of course, because most of the certificates are handwritten. The registrars must type exactly what is written on the certificate; that literal text is uploaded from the RSS disk into the national mortality database for mainframe processing. The database in on a mainframe and most of the processing is done in it, via terminals and overnight batches.

The heart of our automated coding is MICAR, ACME, and TRANSAX, which work exactly as in the U.S. We convert the electronic text to ERNs using a software we developed called "TRACER," which does similar things to SuperMICAR, though not in exactly the same way. TRACER takes the text and splits it up into separate entities that are matched to recognized phrases in the MICAR dictionary. The entities get Entity Reference Numbers and provisional ICD-9 codes. That is really the only bit of the coding process that is different from the U.S.

As I mentioned earlier, we do not code external causes using the automated system. External causes have to be coded correctly because they are politically sensitive. Everybody needs to know the number of suicides, homicides, and motor vehicle deaths even though the numbers are relatively small. We have 20,000 deaths a year in total that are certified after a coroner's inquest, and that we code manually to get the external cause. That is out of a total of

about 580,000, so it is not a big problem, and this keeps the coders happy too, because those are nice, difficult ones that maintain coding skills.
We also have about a 20 percent level of rejects, including external causes.

One other thing that is different between the systems of the U.S. and England and Wales is that we use a special certificate recommended in ICD-9 for neonatal deaths and stillbirths. This certificate has lines for the main and other maternal causes, and main and other fetal cause or infant causes of the death or stillbirth, which precludes deriving an underlying cause. Those records cannot go through MICAR and ACME. They only go through TRACER, which gives the text provisional ICD-9 codes, and tells us the position they were in on the certificate, and whether they are maternal or fetal or infant.
The coded data goes back to the national mortality database, which is on the mainframe, including all deaths in England and Wales since the beginning of 1993. The database allows us to update and correct at absolutely any time for any death that occurred since then. For deaths earlier than 1993, we do not bother to correct.

Having this historical database is very useful, because motor vehicle accidents and homicides often delay for very long before we get the final information after all the legal processes are finished. With motor vehicle accidents the median delay is 4 1/2 months, with some information trickling in 2 and 3 years later. We can update these records continuously. Every year we publish updated statistics for the past 5 years or so.

The database also allows linkage of infant deaths and child deaths back to births since 1993. Like a lot of other countries, we used to link infant deaths to the births within the previous year, but now can link deaths up to about the age of 7 years. The child's birth certificate gives us additional information about socioeconomic circumstances of the parents and other things that can be useful for analysis.

For the death database, we get the disks on Friday, and the first statistical outputs are the following Thursday, which are estimates of the total number of deaths registered by age, sex, and a few causes— pneumonia, flu, bronchitis. These estimates are used only for monitoring flu epidemics during very cold weather, etc. We manage to get out some preliminary statistics less than 7 days after the data are sent to us, so we are not dealing with a fine level of accuracy in either the numbers or the causes.

Most of our statistics are based on routine annual extracts stored as separate annual data sets, which are used for most of our paper and electronic publications. We have electronic ones on disk and CDs that we send out every year. Actually, the disks are sent out to district health authorities such as the directors of public health on the decedents in their area. We provide these local authorities much more detailed information about their district population on the annual CDs. We are just starting to put data on our Web site, and it is a little primitive. We can also take ad hoc extracts any time from the model 204 database.

What about our plans for the future? Well, I hope we are going to do some things that will make it all much better. In certification we have talked about the problems of variable quality of death certification, not to say bad. One of the things that we have just started now is a project to develop some electronic training and tutorial materials that we shall put up on the National Health Service (NHS) net so that doctors and medical students can run through exercises on medical certification, and get help about how to certify deaths. We hope to have a mini-course for which doctors can get credit. General practitioners could get a post-graduation education for it if we manage to get it all sorted out.

At the moment the government is reviewing the whole civil registration process— registration of births, marriages, deaths, proof of identity— and how that service is provided to the public, including what it means in terms of citizenship; the review means looking at all the laws and regulations that govern it.

We hope that the review will result in official recognition for the first time since 1836— when death registration began in England and Wales— that one of the functions of death registration is to produce statistics about the number and health of the population. The review may include the law regarding coroners, what they have to investigate and how, which again could help both in the timeliness and also the quality of the information. Thus, we are going to get some legislation that will enable us to improve technology and to modernize the registration system gradually.

In the 1970s, Scotland passed more modern legislation than England and Wales, which lays down the outline in the law, and the rest in regulations that can be changed as and when necessary to reflect more modern knowledge and technology. We need to change our law before we can do that.

In addition, one of the things we would like to do is move to electronic death certification. We are electronic from the point of registration, but the doctor or coroner cannot put the information in electronically yet. Like a lot of other people here, we think that that would have potential to improve the quality of the death certification quite a lot. We could build in some validation checks; could do some querying; and could provide certifying physicians with help files.

We would like to get some direct links between the network that we are going to have for registering deaths, and the NHS network, which is an intranet that links all NHS sites— hospitals, health authorities, doctors offices, etc. With luck, those things would help the timeliness of the data.

We have to change the RSS software for registering deaths, because it is not year 2000 compliant. At this moment, the new version of RSS 2000 is being gradually installed in registrar offices across the country through the year and is being debugged. The old system could run on a PC without a hard disk, swapping floppies; because the registrar, who is employed by local authorities, tends to get cast-off computers.

The new system will be networked, so registrars will be able to send data every day, or rather each time they finish a registration. That would allow some validation at the time when the relatives are still sitting in the office. It will also give registrars access to a lot of databases that we have about legislation, dictionaries, help files, and post code address files, which allows one to give a postal code to any street address in the country, and which is what our geography is built upon. Once you have the post code onto the birth or the death certificate, you can put it into any kind of geography such as local authority, health authority, government region, etc.

Regarding ICD-10 and its implementation— we are behind a lot of you. We shall start coding our deaths to ICD-10 in 2001. We have a lot of work to do, including getting MICAR, SuperMICAR, the coding software from NCHS. We are working with the current versions now, but we need to switch from mainframe to PC processing. That means we have to train the coders to code in a quite different way. Instead of processing big overnight batches and correcting rejects at the different stages that they reject, we shall be taking much smaller batches all the way through on a PC, and dealing with the record all the way through the system. That requires a lot of training. We also have to develop and test all the computer interfaces so that we do not lose deaths through the cracks.

We have to switch from TRACER to SuperMICAR, which involves adding spellings to the dictionaries for SuperMICAR, because the English do not spell the same way as Americans. We still have issues to resolve like the quality of coding for external causes. We presume that we are going to have to go on coding them manually for the foreseeable future, but we hope ultimately to automate them.

We have to work out a way of dealing with the neonatal and stillbirths since they cannot be processed through the NCHS system at all. We do not want to have to redevelop all of TRACER to do it, but we might have to redevelop parts of it. Then we have to decide whether we move that to a PC, or whether we just go to manual coding of these records. Since this involves only about 6 dozen records a year, we may have to process these manually. I hesitate to do that, because I think one of the problems with small numbers is that it is much harder to maintain consistent coding when you are only doing a few records. We also just did not want to make the ICD change at the same time that we changed our input system. Both changes have the potential to change our statistics a lot, and I would like to be able to see the two effects separately if possible. We have to do bridge-coding studies and publish comparability ratios before we start publishing data from the year 2001. We plan to publish the first annual data in May following the data year, but also publish weekly throughout the year. We really want to produce comparability ratios for the users to understand before the ICD-10 data starts hitting their desks.

French Automated Coding System: Styx

Gérard Pavillon, Head, WHO Collaborating Center for the International Classification of Diseases in the French Language (presenter); and Eric Jougla, Service D'information Sur Les Causes Medicales De Deces, SC8-INSERM, France

I will present Styx, the French system for automated coding of causes of death. This system is in its final test phase. A comparison between manual coding, ACME, and Styx will be presented in this afternoon's session. In this session, I will present Styx's functionalities and characteristics.

Styx is a component of the French information system on mortality. This information system was developed by the National Service of Information on Medical Causes of Death, SC8, which is in charge of the production of the mortality statistics in France. The SC8 is included in the French National Institute for Health and Medical Research (INSERM). The information system includes electronic management of death certificates (picture and data), automated coding of death statistics, and matching with sociodemographic data.

First, the death certificate is scanned, and the picture of the certificate is stored on magnetic disks and on CD-ROM. In a second phase, an optical character recognition program codes the personal data: date of birth and date of death, sex, and place of death.

Styx goals

Once these data are captured, Styx can be used. The main goals of Styx are: 1) to automate the coding of causes mentioned on the death certificate and the selection of the underlying cause of death, 2) to store and retrieve the expertise on coding, and 3) to comply with international standards (rules, decision tables). This last point is an important aspect of automatic coding systems.

Styx functions

The functions performed by Styx are the following:

— Coding, which is translating diagnostic text into codes according to the ICD-10. Also included is the editing of diagnoses according to sex and age.

— Underlying cause selection in accordance with the ICD-10 rules of selection and modification tables.

— Explanations on the selection, that is, providing the sequence of applied rules, the conditions of their application, and the decision table relationships used.

— Rejection: in the case of coding issues such as the use of "maybe" relationships or of particular procedures, the death record is identified, as for instance when ill-defined codes are assigned as the underlying cause of death for people under 64 years old.

System characteristics

The architecture of the system includes the Index, the decision tables, the death certificates picture database, and the mortality database with personal data.

The interface of this system offers several features. For instance, the capture of the text of diagnoses reported on the death certificate can be done with the keyboard, but also by vocal capture. Styx can work in batch or in interactive mode. It is possible to make index queries with wild card character. For instance, the query "*infarct*" will list all the diagnoses known in the Index including the string "infarct."

The technical characteristics of Styx are the following: the language used is Microsoft Visual C++ Version 6.0. The database management system used is Microsoft Access 97. Styx requires a Pentium-compatible processor with at least 32 MB RAM. Styx runs with Windows 95, 98, and NT.

Future plans

In the next few months we intend to develop some aspects of Styx. First of all, now that the ACME decision tables are available, they will be included in the Styx database. The system documentation will be written, and we intend to make Styx available for French-speaking countries.

I must add that the system will be used with the 1999 French mortality data for bridge coding. We will code the 1999 mortality data with ICD-9 manually, and automatically with Styx using ICD-10. We do not know at this time if we will code the entire data in ICD-10 or only a sample.

Discussion on the Last Three Presentations of Session 1: Overview of Automated Coding Systems

DR. PARRISH: My name is Gib Parrish, and I work for the Centers for Disease Control and Prevention (CDC), United States. I have a couple of questions: in England you mentioned that a lot of the local registrars have computer systems that have been handed down to them from various groups. Was there any effort made at your national level to provide computers to those people, or is it just that they were available by chance?

DR. ROONEY: This is a complicated legal and governmental tangle. Registrars are employed by local authorities, who are funded by the Department of the Environment. They are professionally responsible to the Registrar General, who is part of the Office for National Statistics, which used to come under the Department of Health, and now comes under the Treasury, because the main statistics that we produce now are retail price indexes and things.

We cannot fund them, and we cannot give them our computers. The local authorities are not interested in registration of births and deaths, they just have a legal requirement to employ registrars, so they do not want to fund them, and we are not allowed to.

We did try, when we were upgrading everybody to Pentiums. We wanted to offload 500 or so of these other computers, and we were told that we absolutely could not do it, that it was not legally allowable.

DR. PARRISH: Then one further question related to that system: You said that you hoped to network those folks so that you could get more real time or daily submissions. Would you "piggy-back" that onto an existing national network, or is that through the Internet, or how would that work?

DR. ROONEY: I think that is going to be another intranet set-up. I do not know physically how it would work, but it has to be a secure network, which can only be accessed by people who have the legal right to access it for the moment. Though there is some talk of having it connected in some ways to the NHS network— which again, has to be a fairly secure intranet in that it has medical data about people on it.

DR. PARRISH: Then my final question actually is for everyone. From what I gathered from your presentations, it sounds like all of your systems store the literal text from the certificate, as well as what eventually comes out. But do you maintain that for archival purposes as well, if one wanted to go back later and recode that using a different system?

DR. ROONEY: Yes, we do. We have to maintain it exactly as it was written on the death certificate, because that is the legal record, that is the register. We also are planning to use that electronic text, for example, in our ICD-10 bridge coding. We will use a year that is already stored.

DR. PÉREZ: For us it is the same. We need to input text for coding, and we may need to have text from the death certificate recovered.

MR. PAVILLON: In the case of Styx, the death certificate is entered as close to the original text, but a little bit standardized.

MR. JOHANSSON: In Sweden we save the original text. We haven't decided for how long as yet. We have used it for bridge coding, for instance. And I think that since so much effort and time is put into processing death certificates, we will think twice about it before we delete those files.

DR. ROONEY: We do use it to produce various statistics too, and answer questions on drugs that are used in poisonings or overdoses or something.

MR. JACKSON: I am Graham Jackson from Scotland. I share the same problem in Scotland that Dr. Rooney referred to about the sort of legislative framework and organizing of the registration service. The one thing that has come to our assistance here is the so-called year 2000 problem, because many of the local authorities have been forced to improve the equipment because that was the cheapest way of sorting out the year 2000 problems.

My question, however, was for Gérard Pavillon, about the bridge coding exercise. Did I understand correctly that you are going to bridge code ICD-10 automatic against ICD-9 manual? So you are going to have the problem of the change of classification, as well as the change from manual to automatic. If you could comment on how you are going to try and disentangle those two factors?

MR. PAVILLON: We will not. We want to assess the change in trends between the ICD-9 manual and the ICD-10 automatic. We accumulate the two aspects, classification and manual *vis-a-vis* automatic coding at the same time. But this is a reality you know.

MR. JACKSON: A single step?

MR. PAVILLON: Yes.

DR. IBRAHIM: My name is Lailanor Ibrahim from Malaysia. We are still using manual coding for our cause of mortality; but for morbidity and in hospitals, we are using the automatic system for the morbidity diagnosis.

I am very astonished about Sweden. Dr. Johansson says that they use ICD-10, yet do not use ERNs. So, is there a difference? That's one question.

And the second is for Cleo Rooney. What is the percentage of TRACER to ICD-9 codes?

MR. JOHANSSON: About the ERNs. We have the ERNs in MICAR. They are of course based on the medical terminology as it looks in English. In Swedish we have in fact three separate sets of medical terms. We shall go back to that in Dr. Pérez' session on Thursday [see Session 8 on Language Issues]. We found that when we tried to match the Swedish medical term to the MICAR ERN register, it found a match for only about one-fourth or one-third of the terms. We would have then to create new ERN numbers for the majority of our terms. We simply found that too much work to do. So instead of using the ERNs, we decided to use the standardized abbreviated expressions for the medical terms rather than the numbers. We found afterwards that perhaps those standardized abbreviations are easier to handle when you work with the system. So I know that we are in the minority here, but we do not regret it at the moment at least.

DR. ROONEY: As far as the accuracy of the TRACER to ICD-9: coding those, we have built it up gradually over a few years. Actually, TRACER is acting as an index to get the phrase as written on the certificate to the right ICD code. I do not think at the moment that we think anything is indexed wrongly. So if it gets a TRACER match, I think it gets the right ICD code.

I cannot remember exactly the percentages. I think about 90 percent of terms, except for the external causes, get a match. The others get rejected, and one of the coders has to match that interactively. The way the TRACER works is that if it does not find an exact match, then it first drops words in a similar way to what SUPERMICAR does. It will drop acute or chronic or severe or that sort of thing, to try to make it match. But if it still does not find a match, then it is rejected for a coder to do it. One thing coders can then do to find a match is browse the TRACER dictionary for the nearest similar phrase. Quite often the reason it does not get a match is because it has been misspelled, because the registrar has to type it in the way the doctor wrote it. If the doctor misspelled it, it is a legal requirement that the registrar misspells it. So quite often the coder just has to fix the spelling, and then find a match.

DR. BAH: I am Sulaiman Bah, of Birth Statistics, South Africa. In South Africa we have the situation where the Home Affairs Office is responsible for registering deaths. And now the certificate has been changed. We have the medical certificate and the registrar of death in one certificate in one

form, but it has two pages. They want to continue to capture all the sociodemographic information, and yet they do not want to capture at all the medical information.

DR. ROONEY: Capturing the information — the words exactly as they are written on the certificate— is part of our registrars' duties. That is an absolute legal requirement. Part of the requirement to have a death registered is to have the cause of death written by a medical practitioner. This has been an absolute legal requirement since 1878. So the registrars in England and Wales know they have to do that. They do not see producing something that you can get statistics from as part of their job; they just write down the words. So it is not up to them to check whether the words are right, or whether that is a likely cause of death in a 15-year-old or anything like that.

DR. KARDAUN: I am Jan Kardaun, from Statistics Netherlands. I have a very down-to-earth question about the presentation by Gérard Pavillon. When you were developing Styx, could you tell how much of an advantage it is? How many additional resources do you need for typing in the text when compared to the previous situation?

MR. PAVILLON: We are not able to say that now, because we are not doing a real application of Styx. We have only applied Styx on samples, and we were two or three persons. I would not be able to compare that to the same work with the same classification ICD-10 done manually by coders, but I think I can compare it to the ICD-9 manual coding. It takes I think 1.5 times additional time to enter the text, and to use the automatic coding system.

MR. JOHANSSON: I could perhaps comment on that as well. In Sweden, we decided that the certificates were not to be typed in by the coders, since the coders were quite often not very good at typing. So we preferred having the certificates typed by professional typists. And we have about 100,000 deaths a year in Sweden. We have needed about two full-time positions to do the typing.

DR. ROSENBERG: My impression from your presentation was that you had a 10 percent reduction in cost when you took into consideration both the data entry and the faster production.

MR. JOHANSSON: Yes, that is right.

DR. KOZIERKIEWICZ: My name is Aaron Kozierkiewicz. I am from Poland. I have a question about the issue of how far the systems that you have developed match the WHO rules for coding and selection of underlying cause of death. I ask this because in two of the cases we have the ACME decision

tables, which probably match WHO directives. But, in two others, you have some separate product. How much do these match the WHO rules for coding, and how comparable are the data?

DR. ROONEY: I think one of the problems is that when we were all doing manual coding, we all thought in our own countries that we were applying the WHO rules as they were written in the books. Only when we do research studies— getting the same certificates coded in different countries, or change over to using something like ACME and compare it to what we were doing— do we discover that we each thought that that rule meant something slightly different. In principle we understood what the rule meant, we were just not applying it the same way.

But Dr. Cole and I will be talking a bit this afternoon about the fact that unless you actually have a complete list of every single code and its relation with every other code, whether you are applying the same acceptable sequences is anybody's guess. I would say in general, countries are not.

So that one of the ways to move toward having more comparable data is to adopt common decision tables. We have to come to a consensus about what is in them, because it will not be exactly what any of us want in every case.

MR. PAVILLON: I think that there are two problems. There is one, which is a problem of rules. There are something like 10 rules, and they are quite well defined, and you can easily translate these rules into an algorithm, and it works. The second aspect is the problem of decision tables; the knowledge that you need to apply these rules. They are not fully defined in ICD-10 Volume 2. All the causal sequences that you need are not defined. So you have to sometime add some knowledge to your system to learn. And the interesting aspect of the ACME decision tables is that they are fully defined. They consider all the cases that you need to apply the ICD-10 rules.

MR. JOHANSSON: I agree with what Dr. Rooney and Gérard Pavillon have said. I think the one great advantage of automated systems that we can systematically look at the differences in how we apply the ICD coding rules. Thanks to the propagation of the automated coding systems, we are now, for the first time ever, in the position of really achieving international comparability in coding. But we have much work to do.

MR. PAVILLON: For instance in ICD-10, I think that the rules on linkages are beyond human capacity. It is impossible to manually apply these rules correctly each time. These rules in themselves are a justification of automated coding systems.

SESSION 2

Implementation of ICD-10 in the United States

Implementation of ICD-10 in the United States

Donna Glenn, Michael Apadula, and Sandy Hemenway, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Presentation by Donna Glenn

Good afternoon. I have been asked to talk about implementation of ICD-10 in the United States. Mary Anne Freedman mentioned that we have been preparing for ICD-10 for the last 6 years. I feel like it has been longer than 6 years, and I do not think it is ever going to end. You have to realize our last ICD conversion was when we went from ICDA-8 to ICD-9 in 1979. At that time we only had ACME and TRANSAX to worry about. In addition, only five of our States had implemented those systems, and very little international attention was paid to the system.

Since 1979, we have developed MICAR and SuperMICAR. We have converted our programs from the mainframe to a PC platform. We have improved and automated our training programs. And, in addition, we have implemented portions of our system in 41 States, and several foreign countries are now using parts of our system. Also, the conversion has been a much larger effort than we anticipated, and there has been a great deal of pressure to implement the system.

This afternoon I am going to outline four areas on which we have concentrated our efforts: 1) Conversion of the decision tables, 2) Revision of the program logic, 3) Revision of the coding manuals, and 4) Development of our training materials. I am not going to spend a lot of time on training because we have another session on training.

Conversion of decision tables and MICAR

We began converting to ICD-10 with our MICAR dictionary, which has approximately 200,000 terms. The use of an ICD-9 to ICD-10 conversion table for automated conversion met with some success; but most of the conversion was done manually, with a nosologist looking at each term and assigning to it an ICD-10 code. Because some judgment was used early in the conversion — judgments about which we have since changed our mind, particularly with the injuries— our dictionary is still being corrected.

Because ICD-10 is so much more detailed than ICD-9, we were concerned that our use of "drop" words would mean that either we had to reject more terms from the dictionary, or we had to determine a way to add these terms to the dictionary. We were fortunate to have the ICD-10 Index, Volume 3, in electronic form, which allowed us to identify our drop words and the corresponding lead term, which we added to the dictionary. Thus, we did not lose throughput because of more detail, but dealing with drop words added time to converting the dictionary. We did not have time to add surgeries to the dictionary. The program itself does not handle surgeries yet.

We had to turn our attention to the ACME decision tables, that is, both the causal relationships and the modification tables. Once again with the causal tables we tried to automatically convert using the ICD-9 to ICD-10 conversion table; however, our nosologists were none too pleased with the results. They basically wanted to convert from scratch. Because of the scope of the job, we called upon England, Scotland, Sweden, and France for help on converting the causal relationship tables. We thank them.

When the causal relationship tables were completed, we began converting the modification tables, which are totally dependent on the ICD classification. The nosologists worked on converting the modification tables from scratch.

When the modification tables had been converted, we addressed the TRANSAX tables, which are totally built upon ACME modification tables. Because TRANSAX is not as important as other parts of the overall system, we just completed the final TRANSAX tables for 2000. The tables for 1999 have not been prepared separately. As the ACME tables were being finalized, we began to work on the MICAR tables. MICAR is driven by a large number of tables for each multiple-cause coding rule in NCHS' instruction manual Part 2B. Some of the rules did not require any extra work. What we call "relating and modifying," the tables converted simply by converting the dictionary. However, because other rules are totally dependent on the ICD classification, we had to generate new rules and new tables. This included the cancers, because they are totally different in ICD-10, and some of what we call "Intent of the certifier" tables.

Revision of the program logic

While our nosologists were working on the decision table changes, our programmers were modifying the program logic. In general, the program logic did not change a great deal, but all the programs had to be changed to some extent for a variety of reasons. It was fortunate that we had to make only a few major changes, because at the same time, our programmers were converting the entire system to Windows.

Revision of NCHS instruction manuals

In addition to the software, we had to rewrite all the NCHS coding manuals. Part 2A is the underlying cause manual; 2B is the multiple cause manual; 2C contains the decision tables used by ACME. While manual Part 2E in ICD-9 included additions or corrections to the Alphabetical Index, in ICD-10 we use the actual ICD-10 Index (Volume 3) and the Tabular List, Volume 1. We call this our Part 2E instruction manual. By making Volumes 1 and 3 part of our instruction manuals, they are easier to read for our nosologists than the WHO volumes.

NCHS instruction manuals parts 2G and 2I are MICAR manuals, which had few changes. Part 2F, our TRANSAX manual, has just been completed for 2000, along with our other year 2000 manuals. 2A, 2B, and 2G will be on our Internet site.

For Part 2C, which is generated directly from the mainframe, only the Introduction is on the Web, but the tables will be put out in an ASCII format flat file with a record format for you to put into whatever program you want. We are unable as yet to put our printed version of the tables on the Internet.

Developing training material

We have spent a great deal of our time creating training materials for coding multiple cause and underlying cause, including pre-classroom material — which deals with basic anatomy, medical terminology, and how to use the ICD index and tabular list. Our plans are to put this material on a CD-ROM, so it can be available for a variety of training formats.

We are also in the process of automating our post-classroom training materials, which are on the PCs for viewing. You can see how a coder learns a rule, applies the rule, and knows immediately whether they have it right or wrong; and if it is wrong, what should have been coded and why.

Conclusion

Our major focus now is to release the Windows version of our software to the States by the end of October. I want to remind our system users that we did not expect the first version of the ICD-10 software to produce as high quality data as our last version of ICD-9 software. When we implemented ICD-9 in 1979, we lost some accuracy at the time, so we expected it with the initial ICD-10 software. In the ACME and TRANSAX tables already completed for the year 2000, we have corrected many errors that were in the 1999 version of the tables.

During November and the first part of December we will correct entries in the MICAR dictionary, add omitted terms, and to correct and add omitted MICAR decision tables. We plan to release the year 2000 tables and the Windows software by the end of December. Once the Windows version of the software is released, we will not support the DOS version because we do not have the resources to support both. In fact, our last DOS version 3.3 is the final DOS version, which will not be updated.

Presentation by Michael Apadula

MICAR and SuperMICAR are data entry packages used to take the text from the death certificate and put it into an electronic format. Both programs will produce a database file that contains the text, and generates the Entity Reference Numbers (ERNs). Both produce the same format file, which is read into MICAR 200, which takes the ERNs and assigns appropriate ICD-10 codes. The output of that process goes into ACME, which produces the underlying cause of death.

The Windows-based version of the mortality medical software is a true 32-bit version that runs on Windows 95, Windows 98, and Windows NT, but not on Windows 3.1. In October we will be releasing the year 2000 software, which will be followed in December with modifications to the decision tables. This will be a Windows version and fully Y2K compliant.

Working with the DOS system, we ported the logic that was needed to assign the ERNs and the ICD-10 codes so there would not be any interpretations or any changes in the code. That was wrapped in an object-oriented programming technique using C++. In the Windows version, we wanted to retain the same look and feel as in the DOS program, because many are familiar with the keystrokes. We tried to come up with a hybrid that would give the maximum throughput, but also conform to the Windows standards.

We have a text-sensitive Help now, so depending on what field one is in, the program will give a brief description of what is expected in the field. The increase in processing codes has helped to speed-up processing. Previously, the dictionary had to be turned on and off. If the dictionary was turned off, the program was used strictly for data entry, not for processing. However, with faster computers and a change in the way we process, the ERN pops up almost immediately. Now, data entry and file processing can occur simultaneously.

Other features of PC MICAR include creating a program, creating a batch, and importing data from an ASCII file. PC MICAR is a predisposed, predefined type of file, so one can enter data or use another program and then import the data. One can also merge files. A large stack of certificates can be divided between two persons who can independently enter the data, and then bring them back together into a single file. The Resort feature is for archived information, which is "zipped," that is, compressed. The information can be restored when needed. Compression minimizes space use by old files.

When entering a batch of information, a header file identifies the lot, the section number, the data year, and the State code. A feature for coder statistics tells how fast the coders are

entering and editing the certificates. Add and delete features are also available. If the dictionary is on, this is not necessary.

Another feature is the ability to print specific certificates or a range of certificates as necessary, but this should be avoided; it is a terrible waste of paper and we should move away from that. We can have an integrated system on a PC that truly moves toward a paperless environment. The back-up file helps archive information for shipping. For States having to report their codes to NCHS in Research Triangle Park, it helps to reduce the file for transmittal.

Another feature does a sequence check that reviews certificate numbers that have been entered to identify duplicates and ensure that no certificates are missing in a certain range. The feature also provides information about the batch that has been entered. Also available is the standard Windows option to set up directories as desired. The dictionary can be on or off; some prefer to leave it on all the time.

A more elaborate Help menu is being developed along the lines of the Windows versions. Although it is not organized at present, all the mini topics are included, and an index. So if one wants to type in "date," it brings up the information on the date.

While PC MICAR is a very useful tool, it requires skill in interpreting the certificate and typing in the information. Some knowledge is involved in data entry. In contrast, SuperMICAR uses a different approach. It presumes that data entry persons have minimal-to-no knowledge of the information in the certificate, and will type in a literal translation of what is reported on the death certificate. The certificate resembles closely the format of the death certificates used in the States. SuperMICAR is a little bit more "intelligent" than MICAR, in that order of words does not matter. It accommodates the literals that the certifier has entered on the death certificate thereby storing the death certificate in the file. Processing, necessarily, is more complex, requiring a natural language processor, which is designed for the English language. The results are the entity and the corresponding entity reference numbers.

As in PC MICAR, SuperMICAR has the capabilities of opening files, importing, exporting, and merging. After processing an entire file, SuperMICAR will cull out certificates that have been rejected for making notes on or correcting misspellings, etc. SuperMICAR allows one to modify records without having to browse the entire file. Reports that are generated during processing include error listings and coder statistics. All the certificates in the file can be printed, which is not encouraged; it is for archiving and shipping purposes.

Another feature is a true "sound-alike" spell checker, so in the English language an "f" and a "ph" have the same sound. A spelling mistake, therefore, is detected not just based on the letters, but rather on the sound of the word.

SuperMICAR also includes a sequence check and options for having version control. Version control gives the user a chance to centralize in one place on the network. A Help menu is provided.

Presentation by Sandy Hemenway

I am here to demonstrate MICAR 200 and ACME. The real strength of the MICAR 200 is invisible to the user: the ERNs come in and the ICD codes go out. The processing code that is in the Windows version is identical to the current ICD-10 version, including the tables and the methodology. It just has a Windows interface in front of it. Those who have used the program are familiar with its ultimate simplicity in that you simply open a file, in this case a SuperMICAR file and process it.

Windows MICAR and ACME have the same reports that the DOS versions had. The MICAR 100 statistics can be viewed and printed, as well as the MICAR 200 statistics. You also have the ability to show MICAR rejects and to format and print them so that notes can be made before coding in ACME.

ACME is a little more complex: the options menu shows the directories where tables and data are stored. While in the DOS version, the coder had to physically type in the date of passage, in the Windows version the user can typically change the data by double clicking on folders like most Windows programs.

When one opens a file that has just been processed, one sees the MICAR test file; the menu options work the same way as they did in the DOS version in that the program forces the user to finish one step before going on to the next. Initially, no processing options are available, because a MICAR reject file exists that requires editing. While the Windows version of the ICD-10 editor is very similar in appearance, a number of additions are advantageous. In the DOS version, the grid was the only place the user could edit the ICD-10 codes. In the Windows version, one can edit in the grid or directly on the entity code line. When you exit the entity code line, the program will update the grid automatically.

After editing the MICAR rejects, the user can proceed to merge the rejects with the ACME input file. Then the file is ready to be processed. One process option is available: process input. The processor in Windows is identical to the one in ICD-10 DOS. After processing in ACME, there is an ACME reject file, which must be edited before proceeding further.

Messages are improved in the Windows version. In the DOS version, the user had the ability to bring up messages after processing, which was a little inconvenient because the user had to get rid of the messages before actually making changes. In Windows, the user can bring up the messages, which cover up the grid, and simultaneously make edits directly on the editing string field. With the message box displayed, the user can scroll through the file, with the messages for each record appearing automatically.

In the example record an underlying cause assigned by ACME was rejected because it was classified as a “maybe” in the table; this means the coder has to verify whether the code is correct. In the example, the first two rejects were for codes 5 and 9. The F7 key allows the coder to go directly to the underlying cause field, which is what the coder will normally edit when coding the rejects.

After reject coding and saving the file, one goes to the processing menu. While the mouse can do the work in the Windows version, all of the hot keys used in DOS have been retained in the Windows version with some minor exceptions, such as where SuperMICAR was using one hot key to delete a record and ACME was using a different one. All the programs are coordinated in that only one key is used to delete a record rather than three or four, depending on which program is being used.

When one edits ACME rejects, they process quickly. When the ACME rejects are completely processed, TRANSAX processing becomes activated. Like MICAR 200, TRANSAX processes with one keystroke; and, like MICAR 200, files provide ACME statistics and TRANSAX statistics that give an idea of the rate of throughput.

Discussion on Session 2: Implementation of ICD-10 in the United States

DR. ROONEY: I have one general question and a few minor ones. Will the year 2000 version with corrections to the tables found during 1999 be available only in Windows?

MS. GLENN: Yes, only in Windows.

DR. ROONEY: So if you want the corrections, it has to be Windows?

MS. GLENN: That is correct; if you want the corrections for this system, you go to Windows, not DOS.

DR. ROONEY: That has just made a major decision for us, thank you.
On a couple of screens, I think it was in MICAR, the date of death is shown as day and month and year in separate fields. What happens when one is processing a death that happened last year?

MR. APADULA: The year is actually part of the header file that identifies the batch of certificates that are being entered. The year is entered one time in the header, so it does not need to be entered again.

DR. ROONEY: Right, but deaths may be registered in January that occurred the year before. For these, one wants the date of death.

MR. APADULA: The data year is the year of occurrence of the death, not the year of registration or the year of processing. If one is processing certificates from December 1998 in January 1999, the header should read "data year 1998."

DR. ROONEY: Death records would be jumbled together and would require sorting.

MS. GLENN: Years of occurrence have to be split. In addition, one has to address the problem of States getting neighboring States' certificates through an "interstate exchange program." In NCHS processing, each batch of death records must be from only one State, because the header information is applied to every single record. Whatever the processing system, NCHS recommends first sorting records by data year and by State of occurrence.

DR. ROONEY: In the "sound alike" spell check, will "anemia" spelled with an "ae" sound like "anemia" spelled with an "e"?

MR. APADULA: That is a function of the dictionary that is used. The dictionary can be modified to support alternative spellings.

MR. JOHANSSON: I have two questions. We recently built DOS ACME into a Windows 95 system, and now have to change to the Windows 95 version of ACME. My first question is: Is the record layout of the input and output files approximately the same?

MS. GLENN: They are the same. The two data entry packages, PC MICAR and SuperMICAR are databases. As soon as data entry is complete they become flat ASCII files; the format has not changed whether one has a Windows format or the old DOS program.

MR. JOHANSSON: My next question is: Can one test ICD coding interactively? If something does not work in ACME and one wants to check for a mistake in the coding, can they interactively change the coding in F1 for what would be the underlying cause, or do they have to put it into a file and run the file through the program?

MS. GLENN: You can process one record at a time. All of the NCHS systems continue to be "batch," as they were on the mainframe. To see what happens to one record, one enters just one record. The system is not truly interactive; so one cannot stop the processing to see what is going on with one record in a batch of 500 and see the messages for that record. That will be a future enhancement.

PARTICIPANT: To take better advantage of MICAR, one has to know the terms of MICAR and the earlier ICD. Is there a classification of the ERNs as ICD text, and does it work, that is, is a single MICAR dictionary available to anyone with the ERNs in it?

MS. GLENN: Because of the pressure to complete the Windows conversion, the latest dictionary will not be available on the Internet until January. The dictionary will have the terms, the entity reference number, an ICD-9 code if one existed, if the term was in the dictionary, and the ICD-10 codes.

MR. RAMIREZ: Good afternoon, I am Paul Ramirez from Mexico. A professional typist can type faster than a coder, but typists may not always be able to understand what is written on the certificate. In Mexico, the medical doctors are not recognized by their legible handwriting. Has anyone tried to measure the errors made by professional typists trying to transcribe this writing from a doctor?

MS. GLENN: While we say that SuperMICAR requires no training, that is not entirely true. Whoever uses SuperMICAR for data entry needs training in basic anatomy and medical terminology simply to read physician's handwriting. Without such training, one person entered the term "cerebral vascular" all the time. Basic training in medical terminology and anatomy does help for SuperMICAR.

One of the States contracts out the data entry of their death certificates. Because the contractor is a private company, they do not use SuperMICAR. NCHS imports the data into SuperMICAR and subjects it to the spelling checker; a certain percentage of records are reviewed to make sure the data are entered correctly.

The people doing the entry do need training to interpret physician's statements about cause of death. If the person doing the data entry cannot read the diagnosis, they can enter the word "illegible." At the national level about every quarter, NCHS isolates every record that has the word "illegible" and sends it back to the States for querying. We may also ask the States to send us the real record and we will try to read it, because we have more experienced people. We have coders who have worked for years from microfilm, which is worse than the real certificate. Sometimes the experienced coders can read records that less experienced coders cannot. We would rather have the coder enter "illegible" than make up a term.

DR. ROONEY: When we started automatic processing we were receiving about 30 percent of our records on paper, and we typed them ourselves. The other 70 percent were typed by local registrars in the local office. The local registrars did much better data entry than the central office because they get used to the handwriting of the doctors in their area. We got far more errors doing data entry centrally at the national level. If you can have data entry done locally, that may be easier. Then the registrar can actually phone the doctor if they cannot read the certificate.

MS. GLENN: In the U.S., we encourage our states to at least do the data entry. While States may not be able to code all the rejects, the States can do data entry and send us the records that have already been entered, and NCHS will code the rejects.

DR. BAH: What are the requirements of SuperMICAR for interfacing a Windows-based data entry program but in a language different from C++?

MR. APADULA: I would recommend that you write your program, export an ASCII file, and import that into SuperMICAR. The format of that ASCII file is in our PC Manager's station. You can write it in whatever you want, and then it comes out to be a 972-character record.

DR. BAH: The second question is: Is it feasible to put ACME/TRANSAX with MICAR into one system, or do you still have to keep them separate, that is, first operating SuperMICAR, and then operating ACME/TRANSAX?

MS. GLENN: Once again, the new PC system is a carry over from our mainframe. Because we keep running out of memory, we keep breaking the system up

into smaller parts. Eventually, maybe with Windows, we can combine the separate components.

DR. IBRAHIM: Do you use the ICD for international comparability, or do you modify whatever you have in the system?

MS. GLENN: No, we do not modify the ICD. We adhere strictly to ICD-9 and ICD-10. For the sake of processing, we have added some "created codes" to facilitate processing, ambivalent conditions, in ACME particularly. Created codes are replaced with the real code before analysis. The created codes just help processing. For example, "Hemorrhage NOS" is our R5800. We use it for the causal tables and the modification tables to work, but as soon as it's through TRANSAX, we will convert that back to R58, which is the real code, so we are consistent with WHO and the ICD.

MR. L'HOURS: Member states of the World Health Organization are bound by an agreement called the International Maintenance Regulations to use the official WHO version of ICD-10 and not an adaptation of that Classification. All the mortality data provided for WHO must be on the basis of either the three- or the four-character level of the Classification. Member states are then free to expand the classification to a five-character and beyond if they so wish, but they must respect the three- and four-character levels as published by WHO.

MS. GLENN: As an aside, when you look through the NCHS codes, any five-digit code is "created code." Rather than come up with a code that would be embedded, we decided to make our created codes five digits so they are easy to find. Whenever you see a five-digit code, drop the fifth digit, and if it is a valid four-digit code, then that is the original ICD code. If it is a valid three-digit code, drop one more digit.

DR. ROONEY: When we were going through some of the codes in MICAR we found some five-digit codes. As far as we could determine, they were there because the causal relationships for different entities within the same ICD code at the fourth-digit were different.

MS. GLENN: That is right.

DR. ROONEY: So they are invented for that, and then disappear again after you have the causal relationships right?

MS. GLENN: It was a question of: Do we want to reject more records, or is there a way to force these through? By using the created codes like the R5800 for Hemorrhage NOS, we could put more records through and get less rejects. We prefer not to get rejects.

DR. ROONEY: Corrected codes are somewhere between an entity code and an ICD code; they give you a bit more detail.

MS. GLENN: In TRANSAX, record axis codes are the multiple cause codes we analyze and the entity axis codes. We keep the created codes only because we have to be able to recreate ACME and rerun it if we want to. However, the created codes are removed from the entity axis field as that record is uploaded to our master file; it is not retained in our master file. The NCHS statistical tapes do not include created codes.

DR. SANTO: I am Augusto Santo from the School of Public Health, São Paulo. Do created codes appear directly in the MICAR dictionary, or do they appear during processing of the death certificate?

MS. GLENN: Created codes appear in the dictionary. In the MICAR dictionary, Hemorrhage NOS, has an ICD-10 code of R5800. Abdominal hemorrhage, is classified to R58.

DR. SANTO: Does the created code depend on the other diagnoses in a sequence in the death certificate?

MS. GLENN: A different type of created code is the MICAR "created term." There is a distinction between the MICAR dictionary itself, which has 100,000 terms, and an artificial dictionary, which has terms created by an application of a rule. An example is a fracture reported due to lying in bed. The fracture from MICAR 100 that would match the dictionary would have an "S" code, a nature of injury code, and an external code. And "while lying in bed" has an Entity Reference Number. MICAR 200 takes the Entity Reference Number that means fracture and, on a lower line, the Entity Reference Number that means lying in bed, and changes these to the Entity Reference Number that means pathological fracture, which is a created MICAR term. Some of the MICAR created terms can get really complex. As a rule as applied, we create more and more terms. A term that is entered as traumatic, after application of the rules, can come out as non-traumatic. This is similar to the pathological fracture. So created codes are used in both system, they are just used a little bit differently in MICAR as compared with ACME and TRANSAX.

SESSION 3

International Cooperation in Decision Table Development

A Comparison and Analysis of ICD-10 Underlying Cause Coding Differences Among Three Coding Systems: Manual Coding, ACME System, and Styx System

Lars Age Johansson, Senior Executive Officer, Statistics Sweden; Gérard Pavillon, Head, WHO Collaborating Center for the International Classification of Diseases in the French Language (presenters); and Margy Trotter, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Gérard Pavillon

Before I begin with our presentation, as I was in charge of the organization of this session, I would like to say that in my opinion and in the opinion of many people decision tables are important for international comparability of mortality data. Even with automatic coding systems, the use of different decision tables will lead to differences in mortality statistics. This is because ICD is incomplete for the application of the mortality coding rules and leaves room for interpretation.

Differences exist between countries in coding habits in the selection of underlying cause of death. The most important problem that creates international differences in the selection of the underlying cause of death is Rule 3. Rule 3 allows one to modify the underlying cause reported by the physician and to choose another cause. Sometimes using Rule 3 is necessary, but we have to know in which situation we are allowed to do that. This is a very important aspect, and it is quite difficult. With the example of Pneumonia coded with ICD-10, this rule can lead to very different results in the statistics among countries.

Another important issue is coding ill-defined causes, for example, Cardiac arrest. Should we consider that Cardiac arrest is an ill-defined condition or not? From the point of view of ICD-10, it is not an ill-defined condition, but for many countries, in particular situations, Cardiac arrest is considered as an ill-defined condition. So there are many differences in selecting the underlying cause that lead to differences in trends and to artificial differences in mortality statistics. Because it will be difficult to have a consensus on these aspects, it is important to involve WHO in the development and update of decision tables.

I shall make an introduction to this subject, and Lars Age Johansson will continue with this presentation. The title is, "The Selection of the Underlying Cause of Death, a Comparison Between France, Sweden, and the United States." Participants in this work were Lars Age Johansson from Statistics Sweden, Eric Jougla from INSERM, Margy Trotter from NCHS, and myself.

The objective of the study was to identify the biases in mortality statistics due to the selection of the underlying cause of death. The death certificates were already coded with ICD-10. This study compares three methods for selecting the underlying cause of death, and it identifies discrepancies due to the differences in application of WHO coding rules. The basic data are a sample of 6,922 death certificates, already coded by Statistics Sweden nosologists, which is to say that this coding is high quality. Three different methods of selection of the underlying cause of death were applied: 1) a manual selection by Statistics Sweden, 2) an automatic selection with the NCHS coding system ACME, and 3) an automatic selection with the automatic coding system Styx. General agreement varies according to the country, but what

is interesting is the general agreement between Sweden, U.S., and France at the four-digit level: 85.5 percent. This is quite good given the fact that the three methods are independent. At three-digit level, agreement is 90 percent, and at chapter level, 95 percent. Lars Age will now present more detailed results on this study.

Lars Age Johansson

I tried to look at the causes of the difference between our three codings. We had a sample of not quite 7,000 certificates. For about half of them, I reviewed those certificates that were coded differently and tried to decide why. When it comes to comparisons between Sweden and the U.S., I had an additional sample of about 11,000 certificates that I have reviewed.

I tried to find out how many errors we made, each one of us. Manual coding in Sweden was less accurate than automated coding; we had almost 2 percent errors in the manual coding, despite our best efforts and the use of two people coding each certificate. I would also say that the figure for the United States is a bit too high. We do not know exactly how much too high, but some of the errors in ACME, when the processing was done, have since been corrected. We have also found some difficulties with Swedish multiple cause coding, which caused some of those errors; but I think both automated systems —ACME and STYX—have performed impressively at this stage.

If one compares differences due to errors in coding or processing to differences caused by interpretation of the ICD, one sees that far more are due to different interpretations of the ICD than due to coding and processing errors. In the last column of Table 1, Sweden and the United States differ at 8.2 percent, and France and the United States differ at 5.9 percent. For 44 certificates all three countries selected a different underlying cause, mainly in the multiple malignant neoplasms. The coding instructions for malignant neoplasms in ICD-10 are extremely complicated.

Problems also occurred with Hypertension, which has quite complicated linkage rules. Hypertension could and should in some cases be combined with, for instance, heart disease, renal disease, et cetera. We also had problems with Chronic obstructive lung disease, where the linkage rules and the specificity rules appear to be inconsistent. And, of course, we had problems with Rule 3 and Pneumonia, that is, cases where the physician said that the underlying cause of death was Pneumonia. According to the new instructions in Volume 2, the coders are not to believe that, and in some cases at least they are instructed to select something else instead. Unfortunately, we do not agree on when to select something else.

Here is a short presentation of the reasons why the three countries selected different underlying causes. We do differ somewhat over the General Principle, but very little compared to pneumonia. In the last column of table 1, Sweden and United States do not agree at all over the Pneumonia and interpretation of Rule 3 as regards the Pneumonia.

Table 1. Different underlying causes (4-digit level) ACME-Styx-Swedish manual coding, by ICD Rule (number and percent)

	ACME-Styx N = 3,802		**Styx-Sweden** n = 3,802		**ACME-Sweden** n = 11,230	
	N	%	N	%	N	%
General Principle	20	(0.5)	11	(0.3)	44	(0.4)
Rule 3: Direct consequence						
- Pneumonia	68	(1.8)	38	(1.0)	364	(3.2)
- Other	51	(1.3)	20	(0.5)	80	(0.7)
Rule A: Ill-defined	6	(0.2)	44	(1.2)	107	(1.0)
Rule B: Trivial	-		-		10	(0.1)
Rule C: Linkage						
- Diabetes	24	(0.6)	15	(0.4)	115	(1.0)
- COLD	20	(0.5)	7	(0.2)	69	(0.6)
- Old myocardial infarction	-		18	(0.5)	51	(0.5)
- Vascular dementia	-		5	(0.1)	18	(0.2)
- Other	21	(0.5)	29	(0.8)	55	(0.5)
Rule D: Specificity	13	(0.3)	8	(0.2)	13	(0.1)
Total	*223*	*(5.9)*	*195*	*(5.1)*	*926*	*(8.2)*

We also have some problems with Rule A, which is about Ill-defined causes, or rather what our definition of an Ill-defined cause is. We also differ somewhat about the Trivial causes. What can you and what can you not die from?

We do have some problems with the linkage, for instance, Diabetes—which is not a great problem from the epidemiological point of view. While we almost always end up with the same three-character category, we almost never select the same fourth-character that specifies the complication of the Diabetes. For Chronic obstructive lung disease (COLD), we end up in the same block most of the time, but very seldom on the same three-character category. We had some Swedish peculiarities regarding Old myocardial infarction. Once upon a time we got a letter from the WHO telling us not to use Old myocardial infarction as the underlying cause of death, but apparently very few other countries got that letter, so we have a slight difference there.

Table 2. Distribution of underlying causes by ACME-Styx-Swedish manual coding, by ICD chapter and age, n = 6922 (number and percentage of average)

ICD	ACME				Styx				Sweden			
Chapter	<65	65+	All	%	<65	65+	All	%	>65	65+	All	%
I	11	57	68	(1.09)	8	52	60	(0.96)	9	50	59	(0.95)
II	409	1541	1950	(1.0)	409	1530	1939	(0.99)	411	1552	1963	(1.01)
III	1	19	20	(1.07)	1	16	17	(0.91)	1	18	19	(1.02)
IV	21	120	141	(1.08)	20	103	123	(0.95)	20	106	126	(0.97)
V	8	218	226	(1.12)	7	176	183	(0.91)	6	191	197	(0.98)
VI	25	131	156	(1.05)	24	128	152	(1.02)	26	112	138	(0.93)
IX	208	3331	3539	(1.01)	210	3301	3511	(1.00)	208	3230	3438	(0.98)
X	22	281	303	(0.77)	21	392	413	(1.04)	22	450	472	(1.19)
XI	19	177	196	(1.01)	20	175	195	(1.00)	20	173	193	(0.99)
XII	1	9	10	(1.07)	1	8	9	(0.96)	1	8	9	(0.96)
XIII	2	23	25	(1.01)	2	27	29	(1.18)	3	17	20	(0.81)
XIV	5	109	114	(1.09)	5	95	100	(0.95)	4	97	101	(0.96)
XVI	1	-	1	(0.75)	2	-	2	(1.50)	1	-	1	(0.75)
XVII	8	2	10	(0.88)	9	3	12	(1.06)	9	3	12	(1.06)
XVIII	1	97	98	(0.96)	1	99	100	(0.98)	1	108	109	(1.07)
XX	10	57	67	(0.94)	12	67	79	(1.11)	10	57	67	(0.94)

Table 2 shows the distribution of the underlying causes according to French, American, or Swedish coding criteria. One can compare the figures for each ICD chapter, but not the chapters with each other. For Chapter 10, which includes pneumonia, the Swedish coding has somewhat higher percents that ACME or STYX. To compensate, ACME has more of almost every other chapter. It is a comfort that differences are not quite as great for deaths at younger ages, that is, below 65. ACME has more infections and more mental disorders, but otherwise the three approaches are approximately at the same level.

France has more deaths in accidents, due to a problem with the Styx system, which cannot handle ampersands, which are quite important in accident coding. So that is an artifact.

During this exercise I have been thinking a bit about the decision tables and their contents. It is quite obvious that the decision tables are an incredible achievement. Some of us have tried to compile decision tables on our own. If you have tried to do that, then you realize what the Americans have actually done, and you are very, very impressed by that. Nevertheless, I believe that there are a few of what I would call critical errors in the decision tables. By critical errors, I mean things that if found by someone who has some kind of medical training, then they will never trust ACME data. For instance, according to the decision tables one cannot get muscular weakness from motor-neural disease, which I suppose many clinicians would find quite surprising. I shall not say that there are very many of such critical errors, but the U.S. should try to find them and correct them as soon as possible. Otherwise, we risk that people who use the statistics will not trust them.

In some cases I have the impression that the decision tables are not quite up-to-date, and that they seem to reflect medical knowledge that we had perhaps 30-35 years ago. Diabetes is an example, where ACME very often links a renal disease in Part 1 to a Diabetes that has just been mentioned anywhere in Part 2. That might have been correct some years ago when we had far more severe cases than we have today. We have a far older population today, and people at an old age have a chance to contract renal diseases from many other causes than diabetes. So I believe that the tables really need some reviewing to reflect current medical thinking. The

problem, of course, is who is to make this review? What criteria would you like to have? And how often to update it? Of course, you cannot update decision tables as soon as someone publishes a new article in some scientific paper, but perhaps one should try to have the tables reflect the major textbooks or something like that.

Differential Codification of Cardiac Arrest

Dr. Gloria Perez-Albarracín, Chief, Catalonian Mortality Register, Department of Health and Social Security, Spain

One of the limitations associated with mortality studies is the quality of the information, which in turn depends on the way in which doctors report the information on the death certificate. Multiple causes of death otherwise may be useful in studies on the quality of certification of causes of death from which practically all mortality statistics are derived.

The main objective of this study is to assess the presence of cardiac arrest on death certificates, and its effect on the total number of causes by means of multiple-cause analysis in Catalonia, Spain, in 1994, 1996, 1997, and in the U.S. in 1994. The second objective is to compare our findings with published data in other countries.

Information sources are the 1994 Multiple Cause-of-Death file that we received from NCHS on CD-ROM, and the Catalonian mortality register multiple cause-of-death files for 1994, 1996, and 1997. Both sources of data were automatically coded using MICAR, ACME, and TRANSAX for underlying and multiple causes of death.

Table 1 shows the differences in the use of Cardiac arrest between the U.S. and Catalonia. In the table we show the total number and percentage of underlying causes of death due to Cardiac arrest and all deaths, both in the U.S. and in Catalonia. We also present Cardiac arrest as contributing to cause of death. Cardiac arrest shows similar percentages (1.2 and 1.5) as underlying cause in both countries, but in Catalonia 25 percent of all contributing causes of death are Cardiac arrest while in the U.S. only 8.7 are contributing. In the U.S., Cardiac arrest is mostly mentioned (59.3 percent) when a cardio-circulatory disease is selected as underlying cause of death (table 2). In Catalonia, it is mentioned in 39.9 percent of the cases where a cardio-circulatory disease is chosen as the underlying cause. Cardiac arrest is also mentioned frequently when the underlying cause of death is a Neoplasm (27.5 percent, table 2).

This may reflect two uses of Cardiac arrest. In Catalonia, we use Cardiac arrest almost systematically in a large amount of death certificates whereas in the United States its use is associated specifically with cardiovascular diseases.

Table 1. Frequency of cardiac arrest as underlying and contributing cause of death in the United States, 1994, and Catalonia, Spain 1994, 1996, 1997

		UCOD		Contributing Causes of death		Multiple Causes of death	
		Number	%	Number	%	Number	%
United States	Cardiac Arrest	28,04	1.2	334,91	8.7	362,95	5.9
	All death	2,282,28 8	100.0	3,860,49 7	100.0	6,142,78 5	100.0
Catalonia	Cardiac Arrest	2,39	1.5	78,40	25.0	80,79	17.1
	All death	160,09 0	100.0	313,15 7	100.0	473,24 7	100.0

UCOD= Underlying cause of death

Table 2. Frequency of cardiac arrest as contributing cause of death to the 17 groups of underlying causes of death in the United States, 1994, and Catalonia, Spain 1994, 1996, 1997

Causes of death	ICD-9 codes	USA Number	USA %	CATALONIA Number	CATALONIA %	*P**
1 Infections	001-139	13,279	3.66	696	0.86	S
2 Neoplasm	140-239	58,076	16.00	22,223	27.51	S
3 Endocrine	240-279	14,154	3.90	3,397	4.20	S
4 Blood disorders	280-289	1,362	0.38	412	0.51	S
5 Mental disorders	290-319	3,497	0.96	3,364	4.16	S
6 Nervous system	320-389	5,487	1.51	2,003	2.48	S
7 Circulatory system	390-459	215,054	59.25	32,250	39.92	S
8 Respiratory system	460-519	27,405	7.55	6,702	8.30	S
9 Digestive system	520-579	10,479	2.89	3,904	4.83	S
10 Genitourinary system	580-629	7,064	1.95	1,635	2.02	NS
11 Pregnancy and childbirth	630-676	30	0.01	1	0.00	NS
12 Skin	680-709	470	0.13	121	0.15	NS
13 Musculoskeletal	710-739	1,218	0.34	592	0.73	S
14 Congenital	740-759	1,165	0.32	238	0.29	NS
15 Perinatal period	760-779	116	0.03	92	0.11	S
16 Ill-defined	780-799	7	0.00	1,488	1.84	S
17 External causes	800-999	4,089	1.13	1,674	2.07	S
Total		362,952		80,792		

S= p value<0.01

As an element for discussion, I present here that Cardiac arrest is a medical entity that doctors tend to report in more occasions than necessary. This over-reporting may be due to: a desire to state more causes of death; a lack of distinction between Cardiac arrest as a mechanism of death and Cardiac arrest as a true cause of death; considering Cardiac arrest an element of the death process; and, considering Cardiac arrest as synonymous with Sudden death.

Another element for discussion is how Cardiac arrest has strongly influenced multiple causes of death. The exclusion of this code has not affected the quality of information—at least in the Catalonian data—because frequently it cannot be considered the underlying cause of death.

Underlying-cause analysis allows Cardiac arrest to be detected only if it was selected as the underlying cause of death. Multiple-cause analysis provides more information about quality in the sense of how this medical entity has been used. There is very little published about the notification of Cardiac arrest in other countries. Without this sort of information, I cannot complete the second objective of this study. It is very difficult to find any data about Cardiac arrest as underlying cause of death because mortality statistics are normally reported at the third-digit level of detail, and the ICD code for Cardiac arrest is a four-digit long code.

Some Aspects of the Translation of the Decision Tables From ICD-9 to ICD-10

Dr. Cleone Rooney, Medical Epidemiologist, Office for National Statistics, England

A lot of the things that I was going to say about international cooperation have probably already come up. I think that the more that we can develop an international consensus on the interpretation of the rules and make sure that that interpretation is embodied in the software, the more the software will be acceptable to a whole range of countries, and therefore the more that the data will be comparable among the countries.

We have already said MICAR and SuperMICAR are becoming the *de facto* international standard for automated indexing and data entry and for mortality medical data processing. ACME is becoming the *de facto* international standard for mortality selection and modification rules. This morning it was stated that the international rules were defined in principle and ACME embodied them. In practice, as Gérard Pavillon just said: "If you do not actually specify every relationship of every code to every other as to whether it is an acceptable sequence or unacceptable as a 'Rule 3' direct sequel, then we may be applying them differently even if we think that we are interpreting them in the same way." No one can keep all those codes in their heads. WHO could not get all those relationships into a printed book, so it is only going to be explicit if we embody the relationships in software. But we need to agree on how to do it.

In ICD-10, some rules are better delineated than others. Problems with linkage exist that I have not even tried, but there are some detailed ICD tables. So, if the code is not there, you do not link it, which is easy. For whether a sequence as written is acceptable or not there is some guidance in ICD-10, which has expanded a bit from ICD-9. But the acceptability of a sequence still depends on clinical judgment, and that tends to be different in different countries. Trivial conditions should be left to clinical opinion and, since they hardly ever get written down, it does not bother us much.

For Ill-defined conditions, however, the rule is very clearly stated. If it is in the chapter of ill-defined conditions, signs, and symptoms, it is ill defined. However, as you heard from Dr. Pérez, ICD-10 has defined it beautifully and clearly, but we went to Rule C and added cardiac arrest and a couple of other things.

The real "nasty" is Rule 3; we have been applying it differently around the world, and we did not realize it. England actually did it differently for several years quite deliberately, but even in the countries that thought they were absolutely following the ICD-9 guidance, there was a lot of variation. So what guidance we are going to take on this rule depends on the country. Try this one: renal failure due to diabetes. Do you link or do you apply Rule 3? In England and Wales we do not like it when death is due to an organ failure without a disease causing it, and so we would have called that a "diabetes with renal complications" using Rule 3. The ACME tables definitely stick with the renal failure if it is written like that, though if one puts in an intervening pathology—and it does not seem to matter very much what the intervening pathology is, as long as it is a renal disease—then both ACME and England and Wales will code the underlying cause as diabetes with renal failure. We still think we are coding it by following Rule 3, but ACME is doing it through linkage.

Another example: a viral pneumonia due to carcinoma of the bronchus. In England and Wales this is treated obviously as carcinoma of the bronchus. Under ICD-9, that was a

pneumonia death through ACME. In ICD-10, it will be a carcinoma of the bronchus, not because we have accepted a real causal relationship there, but because we are ignoring the pneumonia. So we are not all really doing the same things.

We have been thanked profusely for helping to develop the perinatal and congenital decision tables. Particularly in these two chapters, the classification has changed enormously. There is really an expansion in detail. New conditions have been identified that you could not have coded to anything other than "unspecified" before. And conditions have been moved into other chapters all throughout. What was an unspecified code in ICD-9 can now be dealt with in the specified codes in the endocrine chapter, the perinatal chapter, and elsewhere. What has happened in translation to the decision tables was that those "daughter codes" all inherited the relationships that had been assigned to the "parent codes." So we had pages of things that could cause each of them that could be deleted. It might have been appropriate for some of the daughter codes, but certainly not for others.

At the end of the day, I was only checking tables. In fact, Dr. Cole did most of the checking and identified some glaring errors. More errors will certainly become apparent as we look at some real data. In fact, to try and clarify some of the things that we did not understand, Dr. Cole did look at some data and put it through the PC systems on infant mortality data and she will talk to you about that.

We are not going to find all of the things that are wrong on that single exercise. More will turn up from our bridge coding studies, doing our national comparability ratios, and some will come up from the kind of study that Lars Age Johansson and Gérard Pavillon and others have been doing, which entail comparing the way that things are coded in different countries, or even just comparing the data from different countries, and getting things that just do not look right. Such evaluations will make us go back and look at those decision tables.

We are going to find errors in the decision tables, which will be an important method through which the ICD rules and applications are disseminated. We are going to develop consensus on how those rules should be applied gradually, so we need a mechanism for updating and correcting these tables. At the same time as we update them, making them better, we have to make sure that we are clear when they change; because even when you make the decision tables better, you also affect your statistics. While the resultant data may be better, they may not be comparable to last year's data anymore. So we have to be able to measure that process, or at least be aware that this happens. Finally, people using these decision tables need to work very closely with the WHO updating groups to make sure that it is all happening in a coordinated manner.

Comparison of Infant Cause of Death Coding: ICD-9/ICD-10

Dr. Susan Cole, General Register Office for Scotland

We were told this morning that technology had changed the way we worked and thought and behaved. You will see that it did for some, but not for others.

I came into cause-of-death coding because of my longstanding interest in infant mortality. I have long felt that the only way to really understand the data or a problem is to get up to your elbows in it and really feel it with your hands. Just looking at tables will not work. You have to actually work and wrestle and struggle with pieces of paper and things all over the kitchen floor. That, I am afraid is my way of working, and probably it shows in the slides I am going to show you.

Background

The permitted causal sequences of codes allowing the automated coding programs to select the underlying cause of death from ICD-10 Chapters XVI and XVII codes (*Certain conditions originating in the perinatal period* and *Congenital malformations, deformations and chromosomal abnormalities*) were sent to me for checking following a provisional translation from ICD-9 to ICD-10. Errors and extremely unlikely causal sequences were sufficient to give rise to some anxiety about the validity of automated coding for infant deaths. I therefore decided to test the early version of the ICD-10 automated coding systems on the infant deaths in Scotland in 1998, comparing it with the existing selected ICD-9 automatic codes and with manual ICD-10 coding.

What I did—thanks to the technical support from my colleagues in the General Register Office—was to take the 1998 infant mortality statistics from Scotland and put them through our newly-arrived ICD-10 package from Donna Glenn of the U.S. National Center for Health Statistics, without human hands touching them. A total of 320 infant deaths in 1998 had been coded, along with all other deaths, by the ICD-9 coding software from the National Center for Health Statistics. I examined each record individually and manually coded each disease statement to ICD-10 and selected the underlying cause of death according to ICD-10 coding rules in Volume 2 of the International Classification of Diseases (ICD-10). The manual results of coding the 320 certificates were compared with the automated coding from the software. The originally-selected ICD-9 codes and underlying cause of death were also checked.

Results

There appeared to be a few recurring problems, well known to our local coding staff and to the NCHS staff, in the ICD-9 software; these involved conditions either not coded at all, or to an inappropriate code from a chapter other than the perinatal chapter. For example: Necrotising enterocolitis, a fairly common complication of immaturity, was coded incorrectly to 009.0 and not to 777.5. Presumably this was because the condition was not described as such in the ICD-9 Index, but only in the Tabular List. However, Necrotising enterocolitis is in the ICD-10 Index, but the coding problem still existed.

In the main analysis, comparing ICD-10 automated to manual coding, the term "rejected" means a record brought to the attention of the human operator by the computer program. The term "error" means a record with a code or underlying cause of death that I considered to be wrong.

Table 1. Infant deaths coded by both ICD9 and ICD10 software

		Coded to ICD10		
		Rejected	Not rejected	Total
Coded to ICD9	Rejected	90	17	107
	Not rejected	13	200	213
	Total	103	217	320

What was rejected was largely similar in both ICD-9 and ICD-10. Table 1 shows that automatic ICD-10 coding software rejected 13 that were not rejected by the ICD-9 system. Similarly, 17 were rejected by ICD-9 software that were not rejected by ICD-10. About 33 percent of our records were rejected. I thought that the effectiveness of the rejection program in finding problems was probably not all that great, but on the other hand it was pretty good at indicating that there was not a problem.

So I tried to have a look at the records that did have a problem.

Table 2. Errors found in infant death records coded by ICD10 program

	Rejected	Not rejected	Total
Records with an error	69	49	118
Type of error			
- missing code	43	-	43
- wrong code	9	26	35
- underlying cause	2	16	18
- more than one error	15	7	22
Correct records	34	168	202
Total	103	217	320

Table 2 shows that there were three main types of errors:

1. Missing codes: diseases given an entity reference number of 999999
2. Wrong codes: diseases that were coded to an inappropriate ICD-10 code
3. Underlying cause: selection of an inappropriate underlying cause of death, usually by a failure to accept a logical sequence

Some records had more than one type of problem. On the other hand, there were some correct records; 34 correct records that I could not find anything wrong with them. The ICD-10 program found 58 percent (69/118) of errors (sensitivity), and accepted as correct 83 percent (168/202) of the records I judged to be correct (specificity). Many problems were found in almost equal numbers whether they were rejected or not. Obviously, all the missing records had been found among the rejects, and I did not find any missing codes that had not been rejected.

There were no missing codes in the records that were not rejected, but I did find wrong codes, quite a lot of underlying causes that I thought were wrong, etc. So that alarmed me a little bit.

Table 3. Number of causes of death with errors and rejections in infant deaths

Records with:	N. of records	Errors	Rejections	Errors missed
1 code	103	4	1	3
1 code + prematurity*	32	5	4	1
More than 1 code*	185	112	64	48
Total	320	121	69	52

* Mutually exclusive.

The small number of problems with selection of the underlying cause (table 2) is a bit artificial, because quite a lot of the records only had one code. So there was not much possibility of anything going wrong with selecting the underlying cause then. Table 3 shows that of the 320 records, 103 had only one cause of death, 32 had two causes, including prematurity, and 185 (57.8 percent) of the total had two or more other causes of death. Thus, proper selection of the underlying cause could only be assessed on the latter 185 records. Indeed, most of all errors, naturally, arose in these records. The proportion of these records that did have a problem shows this quite clearly. Only 4 percent of the 103 records with only one code had a problem of some kind. One out of four of those was detected by a rejection.

So this gave me quite a feel for the kinds of things that we should be worried about in our own data. I shall give you some examples of some of the problems that I discerned.

Examples of errors

Wrong codes given for exact text causes of death:

	Coded	should be
1. Congenital oesophago-bronchial fistula	J86.0	Q39.2
2. Acute renal failure	N19	N17.9
3. Ventricular septal defect	I51.0	Q21.0
4. Group B streptococcal infection	A49.1	P36.0
5. Pneumothorax	J93.9	P25.1

Let us talk about problems with wrong codes. As an example, we had a statement saying Congenital esophageal bronchial fistula, and it was coded to the chapter on *Diseases of the Respiratory System* –Chapter V; but, in my opinion, it should have been coded in the congenital abnormality chapter –Chapter XVII. The adjectives "congenital" and "acute" lead one to the correct codes in the Index. If you lose the word "acute," it is coded N19, which is Nonspecified renal failure. Yet, a perfectly good code is available for Acute renal failure: N17.9. So there were one or two things like this that were wrong. As for Ventricular septal defect to be coded to I51.0, the text should have the word "acquired" included . For this condition, it would not even have occurred to me to look in the cardiovascular chapter –Chapter IX— for those cases. Even if an adult died of this cause, I would expect it to be congenital. I do think that some problems exist with the presence or absence of the word "congenital."

The remaining two examples are age-dependent and, unless the words "neonatal" or "perinatal" are included in the text, adult codes are selected. Group B streptococcal infection was coded to infections rather than to the section in the perinatal chapter, which quite specifically mentions Sepsis in the perinatal period. Pneumothorax also caused a lot of recurrent problems; there is a pertinent perinatal code that should be used, in my opinion, rather than the code from the respiratory chapter. So those are examples of the coding problems that I had.

Examples of wrong selection of underlying cause

	u/c selected	u/c should be
Example 1		
1.a. Respiratory failure	a	
1.b. Myotonic dystrophy		b
Example 2		
1.a. Pulmonary hypoplasia	a	
1.b. Oligohydramnios		
1.c. Renal agenesis		c
Example 3		
1.a. cardio-respiratory failure		
1.b. hyaline membrane disease		b
1.c. pulmonary hemorrhage	c	

These are three examples of the wrong selection, in my opinion, of underlying cause (wrong sequences). In example 1, there is a clear causal sequence, which is independent of age. In the second example, again, there is a causal sequence of a condition, which is lethal in the perinatal period. No kidneys led to a marked reduction in the amniotic fluid, which in turn, meant that the lungs—normally stimulated by fetal inspiration of the amniotic fluid—failed to develop adequately. In the third example, the automated coding accepted that hyaline membrane disease is caused by pulmonary hemorrhage, when in fact it is a complication.

Conclusion

It was useful to have made the decision to look at all records, as I had not anticipated the extent to which errors could be overlooked.

In any other exercise where automated coding is looked at critically, multiple cause records should be selected, including those that have passed through the system without rejection, as they contain more errors than single cause records. However, the fact that infant deaths records were used in this exercise is probably the key to the high error rate. It is unfair to put the sole responsibility for correct coding on the automated system. It must be underpinned by other edit checks, including age at death. Such a check should reject many records that had been passed in this exercise, but which I found to be in error.

Because many of the infant death records should be coded to the special Chapters XVI and XVII (see ICD-10, Volume 2, page 13) in preference to the anatomical site chapters, it is recommended that special attention be paid these death certificates. Possibly it would be wise to

code them manually until you are quite confident that the automated codes, together with your edit program, can handle them satisfactorily.

Future plans

I would like to finish saying that what I am going to do next is to ask Graham to provide me with another sample of records of different ages. Certainly this exercise has brought home to me quite clearly how much you need extra edit checks in. These are edit checks that must be put in, and there is a series of clear duplicate codes that can be used. We may have an argument about at what stage in the first year of life one can stop using a "P" code and start using another. I do not think it ends at 28 days. I think it goes on for longer than that.

I think there is another problem that goes on into later childhood or possibly early adulthood: the deficit that occurs when a condition is not specified as congenital and is automatically assumed to be acquired. I think there may be a case to argue that whenever the condition is not specified up to a certain age, one should assume it to be congenital. But that, I think, would need to be discussed and talked through as another issue.

Certainly, as far as our office is concerned, we are going to look very closely at infant deaths. We might manually code them for the time being until we get these problems sorted out.

Discussion on Session 3: International Cooperation in Decision Table Development

MS. GLENN: Can I make a couple of comments? First of all, for Lars Age: I appreciate your comments on the tables. We are correcting them and we have a physician who is going to review all the tables and change the ones that need to be changed. I would encourage anybody to give us input on them, but we are well aware that we need the medical support behind it. That will be done sometime during this year.

A comment from Dr. Cole that I wanted to bring up: In the United States our mortality file is composed of two separate files. We have a demographic file and a medical file. When you get the TRANSAX file, there is no guarantee that it is perfect until you match it with the demographic file and do the cross-edits (which compare cause of death with age and with sex). Particularly with MICAR and SuperMICAR, I depend solely on age edits to find the baby errors. I know they are there; but they are the last things we correct because I have a way of finding them. Regardless of the decedent's sex, our edits will pick out the perinatal deaths that have O codes and they will come out as conditional rejects or absolute rejects, at which time they will be corrected.

While we will correct the program eventually, you must realize that with the way our system is presently set up, you need to run cross edits for age, sex, and cause.

DR. ROSENBERG: The WHO Mortality Reference Group (MRG), which was implemented this year and on which many of the panelists sit, is looking at some of these issues. The interpretation of Rule 3 is one of the issues that we are addressing. Rule 3 applied to pneumonia is a very difficult problem, because there are advocates of different approaches. We have not yet achieved consensus on the best way to handle that. We also are looking at perinatal causes of death. Susan Cole very graciously has agreed to assist us working with Cleo Rooney and Donna Glenn to identify baby codes and possibly recommend some changes to the World Health Organization on how they are handled and indexed. Another problem area, and I have to thank Lars Age Johansson for, is giving us very challenging questions in the area of Ill-defined conditions. There the MRG has actually made a recommendation to the World Health Organization.

In the first ICE we did have a session on decision tables. One of the recommendations from the ICE is that an advisory committee comprised of members of WHO collaborating centers should be established to help in the interpretation of decision tables. The committee would report to WHO, which is viewed as ultimately responsible for ICD decisions. The

suggestion was made that the MRG serve in that capacity. So far, we have not put that in the Terms of Reference of the MRG, but it is something that we might want to consider.

This is an evolving and iterative process. We have to figure out how best to do it, and how to do it somewhat conservatively so that we do not lose continuity in mortality trends.

Poster Session I
Poster 1: Experience of Vocal Capture of the Diagnoses Reported on the Medical Death Certificate

Mr. Gérard Pavillon, Head, WHO Collaborating Center for the International Classification of Diseases in the French Language

VOCAL CAPTURE OF THE TEXT OF CAUSES OF DEATH

Gérard PAVILLON

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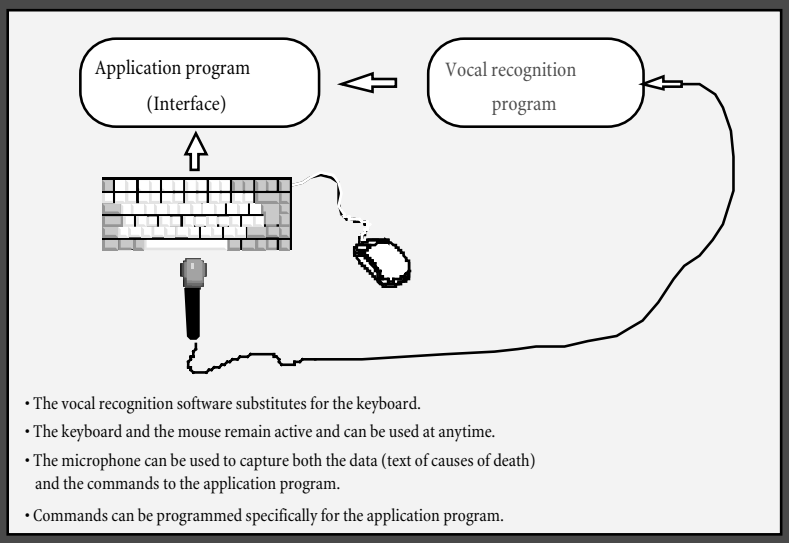
The vocal recognition softwares become now an alternative for the capture of the text of medical causes of death.
This technology has been tested in the French Service of Information on Causes of Death (SC8 - INSERM)

Principle

Two softwares are used: the vocal recognition program that converts speaker's words into ASCII codes and the application program that manages the interface with the user.



- The vocal recognition software substitutes for the keyboard.
- The keyboard and the mouse remain active and can be used at anytime.
- The microphone can be used to capture both the data (text of causes of death) and the commands to the application program.
- Commands can be programmed specifically for the application program.

Advantages

- Very well suited to the medical language (long words with low ambiguity rate)
- Faster than keyboarding (2-3 times)
- Avoids spelling mistakes (except for words with the same pronunciation but different spelling)

Disadvantages

- Speakers must work in rather silent surroundings
- Needs a learning phase for each speaker (about 3 hours)

The vocal capture has been used to test the automated coding software Styx.
It will now be used to code death certificates included in a bridge coding on the 1999 French data.

Softwares used

Vocal recognition software: Dragon Naturally Speaking V3.0 from Dragon System Inc.

Application software: Automated Coding System Styx (SC8-INSERM)

Hardware requirements

PC with a Pentium processor 200MHz and over, 64 Mo RAM, Windows 9x or NT

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Poster 2: The Effect of Query Action on Coded Mortality Data; An Australian Study

Colleen M. Rip-Botha and Maryann Wood, Australian Bureau of Statistics

Introduction

The Australia Bureau of Statistics (ABS), Australia's national statistical agency, processes around 130,000 deaths annually. National statistics on the underlying cause of death have been produced each year since Federation in 1901. Until 1997 the underlying cause of death was classified manually in accordance with the recommendations set out in the World Health Organization (WHO) International Classification of Diseases (ICD). A major new development occurred in 1997 with the implementation of automatic coding procedures. Automation has been made possible by adapting Automated Coding System (ACS) software provided by the National Center for Health Statistics in the U.S.A.

In Australia, deaths are required by law to be registered with the Registrar of Births, Deaths, and Marriages of the State or Territory in which the death occurred. These Registrars hold office under State and/or Territory legislation.

The ABS receives from each State or Territory Registrar details for each death as provided on the Medical Certificate of Cause of Death. Generally, the Medical Certificate of Cause of Death is completed by the attending medical practitioner where the death is due to a natural cause. For deaths that are sudden and unexpected and for most deaths due to external causes, which are subject to coronial enquiry, the death certificate is completed by a coroner.

In Australia, query action plays an integral part in cause of death coding. However, there is little quantification of the effect of query action so a project has been established with the aim of determining:

- The effectiveness of query action in terms of improving the quality of cause of death coding
- Where query action should be specifically targeted
- What resources are ultimately necessary to carry query action out in an efficient and effective manner

The following analysis of 1997 Cause of Death (COD) query action identifies details of resource usage and resulting outcomes. The following analysis was undertaken on a preliminary file, as such some differences may be noted with final figures in publications. A second stage of the project (yet to be completed) will analyze, in detail, how query action effects particular cause of death codes.

Who is the query action directed at?

Query action can be divided into two groups, queries to coroners and queries to doctors.

Queries to coroners:

The initial query results from preliminary information (Medical Certificate of Cause of Death) for coroners cases being nonspecific, nonexistent or unavailable at the time of certification (e.g., unknown cause, awaiting inquest, or poisoning by multiple drugs). Thereafter, a report is received back from the coroner stating the circumstances surrounding the death.

Depending on the report received, a further query may be sent to the coroner requesting more specific information about the circumstances surrounding the death, e.g., Was the poisoning suicide or accidental?

Queries to doctors:

This query generally involves the clarification of nonspecific information recorded on the Medical Certificate of Cause of Death. For example, it may involve requesting a more specific site for bowel cancer, or determining whether a tumor was malignant or benign. Approaches to coroners and doctors contribute to approximately 60 percent and 40 percent, respectively, of all query action.

An education tool currently available for users and certifiers is a certification booklet. The certification booklet aims at providing assistance to medical practitioners in filling out the Medical Certificate of Cause of Death, thus improving data quality and hopefully reducing the need for query action. This booklet has been updated for the introduction of ICD-10. Booklets are distributed to major hospitals (identified by where the most deaths occur) and teaching hospitals. Medical practitioners are supplied the booklet on request. Copies of the booklet are also sent to Coroners; Registrars of Births, Deaths, and Marriages; ABS State and Territory Offices; and other stakeholders who have an interest in the field.

The continuing need to influence certifiers to improve the quality of the Medical Certificates of Cause of Death remains a high priority. As a result, fliers have been produced and are progressively being sent out by Registrars of Births, Deaths, and Marriages to all the hospitals with books of blank Medical Certificates of Cause of Death.

Query action protocol and costs

In 1997, a total of 13,364 (approximately 10 percent) of all records were queried. An automatic query action program, listing the underlying cause of death descriptions and codes to be queried and the text of the query letter, is used to promote consistent query action. The query action procedure used for processing deaths is as follows:

If the reported underlying cause matches a description on the query program, the record is allocated a query flag, and a letter is generated with the query text as shown in the program. The letters are sorted and sent to the certifiers (Medical Practitioner or Coroner). Query letters are generated automatically for States and Territories at the end of each month's processing.

When queries are returned, a final underlying cause of death code is entered into the record on the database replacing the preliminary cause of death code that would have been allocated at the initial stage of coding. If no reply is received, the preliminary cause of death code becomes the final underlying cause of death code.

Additional information is gained without contacting the certifier by reviewing newspaper articles and police reports. This provides extra information about whether the death was accidental or intentional and is used to amend the preliminary cause of death code where no extra detail is able to be obtained from the certifier.

There are a number of reasons why the ABS queries certifiers to the extent that it currently does. These reasons are important when ascertaining the level of success of the query action and the value it adds to the data. The aim of the query action is to:

- Enable proper selection of underlying cause of death
- Improve certification by doctors by identifying COD codes where feedback can be provided to certifiers to improve the quality of their initial certification
- Provide researchers with accurate data—this is particularly important in light of the intensive use made of unit record data in Australia.

Not all Medical Certificates of Cause of Death are queried. Queries are limited to those conditions selected as underlying cause, which are considered to be nonspecific. As a result, queries concerning cause of death are limited to:

Underlying cause cases where the age of death is under 75 years and the following terms are used:

Bowel adhesions
Bowel obstruction
Bronchopneumonia
Cardiac arrest/failure,
Cardiorespiratory arrest/failure
Cerebrovascular disease
Chronic airways disease
Deep leg/calf/other limb vein thrombosis
Embolism
Gastrointestinal bleeding
Heart disease/failure
Nephritis
Peptic ulcer
Peripheral vascular disease
Pneumonia
Pulmonary embolism
Pulmonary thromboembolism
Pulmonary oedema
Renal failure, acute or chronic
Respiratory failure
Septicemia, sepsis
Surgery - reason not stated

Hepatitis	Thromboembolism
Liver/hepatic failure	Urinary tract infection
Meningitis	Vascular disease

Underlying cause cases where regardless of age, the following terms are used:

Leukemia—type unspecified
All external deaths not stated as accidental, suicide, or homicide
Anemia
Carcinoma/Cancer stated as abdominal, intrabdominal, gastrointestinal, bowel, liver, mouth/oral, pharynx, pelvis, skin, throat, uterus or no primary site given, metastatic (no primary site given).
Colitis
Diarrhea
Gastroenteritis
Mesothelioma
Tumor any site

Of the 13,364 queries sent out with respect to deaths registered in 1997, 12,232 return queries were received back. This implies that 1,132 (just over 9 percent) of the queries sent out did not receive any reply. The effect of these unreturned queries will be investigated as part of Stage II of the project.

The total cost of conducting query action for 1997 processing, which includes the sending out of query letters and processing the return queries, was 1,494 hours or 199.2 person days. This amounts to $17,900 (AUD) from a salary budget of approximately $400,000 (AUD) or 4.5 percent of the coding salary budget.

Outcomes of query action
The following 3 tables show the effect of query action on original codes.

Table 1. Number of Queries per Chapter

Chapter	Code Range	Number of Queries	Number of Queries as a % of all queries	Chapter as a % of all records
1 Infectious and Parasitic Diseases	0010 - 1398	247	1.8%	0.9%
2 Neoplasms	1400 - 2399	2,802	21.0%	27.8%
3 Endocrine, Nutritional, and Metabolic Diseases and Immunity Disorders	2400 - 2799	26	0.2%	2.5%
4 Diseases of the Blood and Blood-forming Organs	2809 - 2899	73	0.5%	0.3%
5 Mental Disorders	2900 - 3199	150	1.1%	1.6%
6 Diseases of the Nervous System and Sense Organs	3200 - 3899	106	0.8%	2.0%
7 Diseases of the Circulatory System	3909 - 4599	953	7.1%	41.3%
8 Diseases of the Respiratory System	4609 - 5199	831	6.2%	10.9%
9 Diseases of the Digestive System	5200 - 5799	361	2.7%	2.2%
10 Diseases of the Genitourinary System	5800 - 6299	500	3.7%	2.1%
11 Complications of Pregnancy, Childbirth, and the Puerperium	6309 - 6769	2	0.0%	0.0%
12 Diseases of the Skin and Subcutaneous Tissue	6800 - 7099	14	0.1%	0.1%
13 Diseases of the Musculoskeletal System and Connective Tissue	7100 - 7399	44	0.3%	0.1%
14 Congenital Anomalies	7400 - 7599	10	0.1%	0.1%
15 Certain Conditions originating in the Perinatal Period	7600 - 7799	8	0.1%	0.2%
16 Symptoms, Signs, and Ill-defined conditions	7800 - 7999	2,523	18.9%	2.4%
External Causes	E8000-E9999	4,714	35.3%	5.5%
Total		13,364	100.0%	100.0%

Table 1 analyzes the distribution of queries by ICD chapter. It is evident from the table that the bulk of the queries take place in the External Causes chapter (35.3 percent); Chapter 2 (21.0 percent), and Chapter 16 (18.9 percent). However, the amount of query action is not proportionate to the number of records in each chapter. Chapter 7 accounts for 41.3 percent of all records, but only accounts for 7.1 percent of all queries whereas Chapter 16 accounts for only 2.4 percent of all records but 18.9 percent of queries. This indicates that query action should continue to be targeted to areas where the impact is likely to be statistically significant.

Table 2. ICD Codes Queried Most Frequently

Ranking	Cause of Death	Number of records prior to query action	Number of Queries	Number of Queries as a % of all Queries
1	7999 Other unspecified cause	2,496	2,427	18.2%
2	9289 Unspecified accident	1,272	1,207	9.0%
3	1991 Other malignant neoplasm without specification of site	2,550	893	6.7%
4	1590 Malignant Neoplasm of intestinal tract, part unspecified	831	783	5.9%
5	9138 Accidental mechanical suffocation of other specified means	636	619	4.6%
6	8689 Accidental poisoning by unspecified carbon monoxide	406	406	3.0%
7	4869 Pneumonia, organism unspecified	2,798	401	3.0%
8	8500 Accidental poisoning by opiates and related narcotics	313	300	2.2%
9	9108 Accidental drowning and submersion by other means	292	247	1.8%
10	8199 Motor vehicle accident unspecified	237	237	1.8%
11	9229 Accident caused by unspecified firearm missile	235	234	1.8%
12	8589 Accidental poisoning by unspecified drugs	233	228	1.7%
13	4151 Pulmonary embolism	505	209	1.6%
14	4859 Bronchopneumonia, organism unspecified	1,827	171	1.3%
15	5689 Renal failure, unspecified	677	160	1.2%
16	0389 Sepsis unspecified	626	151	1.1%
17	1990 Disseminated malignant neoplasm without specification of site	188	142	1.1%
18	1552 Malignant neoplasm of liver, not specified as primary or secondary	155	128	1.0%
19	8879 Fracture, unspecified	803	121	0.9%
20	5859 Chronic renal failure	525	121	0.9%
Total		17,605	9,185	68.7%

Table 2 shows that the greatest number of queries take place in the ICD-9 category 799.9 (Other unknown and unspecified cause), with the second largest number occurring in code category 928.9 (Unspecified accidents). These two categories account for 18.2 percent and 9 percent of all queries, respectively. In fact, only 20 codes account for nearly 70 percent of all query action. The other 30 percent are distributed across a large number of codes and further investigation is required (Stage II) to measure the statistical significance of the changes in these codes.

When looking at the top 20 codes queried it is not unexpected to see 18 of the codes have an "unspecified" or nonspecific component to them. This highlights the need to query these codes to ensure the resultant statistics are not dominated by "dump codes." On the other hand codes such as 850.0 and 910.8 are queried due to need to determine the accidental or intentional nature of the death.

Table 3. ICD codes changed most frequently due to queries

Ranking	Cause of Death	Number of records prior to query action	No. of records recoded (a)	Recoded records as a % of all Queries (13364)
1	7999 Other unspecified cause	2,496	2,442	18%
2	9289 Unspecified accident	1,272	1,224	9%
3	1590 Malignant Neoplasm of intestinal tract, part unspecified	831	622	5%
4	9138 Accidental mechanical suffocation of other specified means	636	617	5%
5	1991 Other malignant neoplasm without specification of site	2,550	574	4%
6	8689 Accidental poisoning by unspecified carbon monoxide	406	397	3%
7	4869 Pneumonia, organism unspecified	2,798	288	2%
8	8500 Accidental poisoning by opiates and related narcotics	313	261	2%
9	8199 Motor vehicle accident unspecified	292	230	2%
10	9229 Accident caused by unspecified firearm missile	235	230	2%
11	8589 Accidental poisoning by unspecified drugs	233	215	2%
12	9108 Accidental drowning and submersion by other means	292	211	2%
13	8879 Fracture, unspecified	803	158	1%
14	4151 Pulmonary embolism	505	143	1%
15	5689 Renal failure, unspecified	677	141	1%
16	4859 Bronchopneumonia, organism unspecified	1,827	130	1%
17	0389 Sepsis unspecified	626	121	1%
18	4275 Cardiac arrest	478	111	1%
19	1552 Malignant neoplasm of liver, not specified as primary or secondary	155	111	1%
20	7425 Other specified anomalies of spinal cord	110	104	1%
Total		17,605	8,330	62%

(a) Includes recoded due to query action and or using additional information gathered.

Table 3 takes a slightly different look at the issue by looking at the top 20 codes that change due to query action. As would be expected, there is a high correlation between table 2 and table 3. It can be seen that 18 of the codes occur in both tables, i.e., 18 of the 20 categories that are changed most frequently due to queries are also queried most frequently. The ranking does, however, differ.

As in table 2, the greatest number of changes also occur in the code category 799.9 (Other unknown and unspecified cause), which accounts for 18 percent of all changes, with 9 percent of all changes occurring in the code category 928.9 (Unspecified accidents).

The only two code categories that appear in table 2 but not in table 3 are 199.0 and 585.9, whereas codes 427.5 and 742.5 are included in table 3, but not in table 2.

Future directions

This paper has described the first stage of the query action project. To make the query process more efficient and effective, some steps that can be taken in the short term are to:

- Continue to educate certifiers concerning the level of detail required for adequate coding of causes of death, which are the subject of intensive query action and extensive recoding.
- Review the wording for specific queries and make changes as necessary to ensure adequate information is received.
- Further educate coders to aid their interpretative skills when dealing with specific cause of death codes.

Stage II of the project will involve conducting further analysis of the query action data to track the movement from one code to another following query action and to determine the statistical significance of the changes.

Future steps that could be taken, but will depend on the stage II results, are:

- Devise a step-by-step methodology to allow the review of the effectiveness of query activity annually or every 2-3 years. The feasibility of such a step depends on the ability to produce appropriate management information, and this issue will be considered during the current redevelopment of the Vitals/Causes of Death processing system.
- Examine the viability of continuing with query action for those causes that are currently intensively queried, with reference to the extent of usage of data relating to those causes, by clients.
- Identify if any codes need to be removed from the query program.
- Establish a cut off date near the end of the collection after which time the likelihood of receiving query replies reduces. Determining such a deadline would involve keeping a register of queries dispatched, received and the associated dates toward the end of the collection cycle.

Poster 3: Interactive ICD-10 Coding in Visual Basic

Elsie Mentz, Statistics South Africa

SESSION 4

Panel Discussion on Training for ICD-10

Panel Discussion on Training for ICD-10

Lars Age Johansson (moderator), Senior Executive Officer, Statistics Sweden

For this session, I would like to concentrate on three main points. The first is our experience of ICD training in the automated context: What does it mean to have an automated system? Does that put additional requirements on the coders? Do we need to know more ICD or less; or, is it about the same as before?

The second point: with automated systems, nosologists are now an endangered species. We get fewer and fewer nosologists. Especially in the smaller countries, it is quite difficult to maintain expertise in this field. In a few years, we will simply have to cooperate if we are going to maintain any kind of international comparability in classification of causes of death. What do we do to develop international cooperation, given the quite great differences we have between our countries in how we use the ICD?

Third, I was saying that we are losing nosologists, and it is quite hard to retain the very few nosologists that we have. If we want to keep nosologists, we have to do something about their status. So what can we do toward improving the status of nosologists?

With that, I would like to ask the panel, who represent much experience in this field, to present what they have done in ICD training in their respective countries. And, of course, there are many others in this room who also have lots of experience in this field, and I would ask you to supplement whatever we are saying when we get to the discussion.

Thank you very much. I would like to ask Australia to start with the presentation.

Marelle Rawson, Health Section, Australian Bureau of Statistics

The thing to remember for us Australians —or three things, rather—is that we have a centralized coding unit, and that makes quite a difference. The coders, in fact, all work together. Since 1994, they have been located in one office. We introduced automated coding for ICD-9 in 1997, and we introduced ICD-10 in 1999. So over the 3-year period, we have had a very intensive training from manual to automated and then through to ICD-10.

Having the coders centrally located has been a great advantage for the training program that we have put in place. The first training for the coders was from manual to automated. That was the most difficult transition for the coders. Many of the coders had been within the coding area of the Australian Bureau of Statistics (ABS) for quite some years and had a particular mind set. They did manual coding almost without thinking about it; they had been doing it for so long. Then suddenly, almost from nowhere appeared a new system, which I think some of them saw as being threatening. I think Lars Age or somebody had that on a slide yesterday morning, about an initial hostility, but it did disappear.

When Australia adopted the American ACS system, then two of the coders from Australia came to America to be trained. They were trained specifically in different aspects of the coding system, one specifically in the system itself, and the other one received intensive training for the multi-cause aspect of ICD-9. So we had two experts: a systems expert, and a multi-cause expert; and those two people were, of course, heavily involved in the training then that took place in Australia.

In the Brisbane office, where the coding is done, we have about 12 coders. As I said, some of them are very experienced. Others are, of course, less experienced. They were separated into groups based on their level of experience. The most experienced coders were trained first in the automated system. To some extent it was more difficult to train these because they had a particular mindset.

That group was trained with manuals that we had received from NCHS, and that training was then used as a means of determining how we should make it more appropriate in Australia for the rest of the coders. So that was to some extent an experiment: how to change the manual to "Australianize" it. Once we had finished training the experienced coders, we revisited the training manuals; that is when we Australianized them. We structured them slightly differently. We put more explanation about the underlying rules, so that we changed the manuals based on the experience that we had in the first training session.

The training was spread over a 5-day period: 2 days of system training and then 3 days on the multiple cause groups. At the end of that training, we actually had Australianized versions of the manuals. Then 2 years later, we were moving on to training in ICD-10.

Now, an important thing that happened between the automated coding training and the ICD-10 training was that the office was restructured. Up until 1996, the health and the vital statistics coders worked jointly across those two areas. After automated coding, ICD-10 was introduced and the two sections were separated and coders were invited to go to the area of their choice. That meant that when we started training for ICD-10, we had a self-selected group of coders, and they were the ones that made a commitment to stay within the cause-of-death coding, and that makes a difference when you are training people, because they are the ones that are committed.

We did the training the same way; we had our experienced coders, and we then had to employ new ones. So experienced coders were very experienced, and they had transitional

coding training to go from ICD-9 through to ICD-10, and that was relatively straightforward. That was an easy job to do compared to the training that had taken place 2 years previously; it was transitional coding training for those experienced people. Some of the coders, however, were brand new, as I said. These received full training. They moved into the ABS almost one at a time, so most of those actually received one-to-one training, so that training wasn't conducted in the classrooms. This was very much a product of what was happening in the ABS at the time.

With ICD-10, we have also back coded for 1997 and 1998. What we did then was to employ 15 part-time university students at the end of their third year of health information management course. Once again, they were trained in very small groups, but they were very keen to work with us, very, very keen to expand their expertise in the coding area and to learn more about mortality coding. So we had a very, very—well, not a large group, but a group of very enthusiastic young people with a university background in the area, and they trained brilliantly. They worked Saturday mornings and Monday nights and Tuesday nights on a part-time basis to do the back coding. They were also trained in small groups, not quite-one-to one; but the two people that came to America originally were crucial throughout this training program. They have been the big trainers.

As I said, when we went to automated coding, we Australianized the NCHS manuals, and we have worked with those, and we developed those from ICD-9 through to ICD-10. So I think that perhaps our situation might be quite different from what some of the other countries have experienced. We found training for ICD-10 relatively easy compared to training for automated coding.

Cleone Rooney, Medical Epidemiologist, Office for National Statistics, England

What we have done so far is very different from that. We have not trained coders yet. What we have done is run a course for countries in Europe. We were asked by the European region of WHO and Eurostat to do a training course on how to implement ICD-10 at the national level. Originally, it was Eurostat who wanted us to do a course for Eastern Europe, but in the end, we had 12 countries that came to the course from East and West Europe, so they were coming from multiple language backgrounds, but I am afraid we only taught in English.

We were aiming the course at the people who were responsible at a national level for the overall program of implementing ICD-10 for mortality. So they were people who would have to see that coders were trained, statisticians were trained, computer systems were changed, the users of data were consulted—the whole lot. It was a 1-week residential course, and we had 26 participants.

We were, as I say, trying to deal with the overall requirements for changing over to the new revision in total. We were trying to help train the trainers, who would then be training statisticians, coders, and systems managers.

People who came on the course were sometimes either statisticians or coders, or were people who were in charge of the coders, or the people who were managerially responsible for the process. So, as well as actual coding in ICD-10, we tried to cover some of the principles and methods of good coding, why you needed to do it, and how you needed to do it, and how to plan the whole national program, including designing their own training programs, and how to consult and inform data users, so that they would not suddenly throw up their hands and complain about getting data they did not understand.

Our teaching methods used TENDON for the structure and the content of the ICD. Largely, we had sessions where people could use TENDON on their own and at their own pace, with tutors wandering around answering questions and introducing particular sessions, or sections of it sometimes. Everyone went away from the course with a copy that they could use themselves.

We also had lectures on principles, methods, examples, how to do things, examples of what went wrong last time, that sort of thing, with a lot of discussion. We tried to keep it very open so that there was plenty of time for people to ask all the questions that would come up. And there was very lively discussion.

We also had people breaking into small work groups to work on their own national plans, and so we tended to get those groups then divided up into countries that were doing it manually, countries that were doing it in an automated way, so that they could build up their plans together. The majority of countries that came to the course had centralized national coding of cause of death, but there were a few where it was diffuse. I think that in Germany it was done in 49 different offices, and Poland was staggering; they actually had every single doctor who wrote the certificate coding it himself. So if they continue with that, that is going to be a massive training exercise, but it brought up a lot of interesting issues.

One of the things that was very clear when I was organizing this course was that we have to do these things internationally. You do not have all the expertise in one place. We had tutors from England and Wales—obviously, since we were supposed to be running it—Scotland, the States, and from WHO headquarters. I think you will see all those people in this room, except Bob Israel, who came from the States and who has since retired, and made a tremendous contribution to our training.

Really, that was the only way to get together the experience and the knowledge that was needed for this. That is partly because there are only very small groups of people in any one country who are involved in these processes. It is also partly because it has been 20 years since we last changed revisions with ICD, so there are not a lot of people around who really have that experience that we can draw on.

There are a lot of issues that came up that we discussed then, and that I think are still relevant and will be discussed today. For example, if you are going to be using an automated system, do you need to train people in how to code using the ICD manually without the system, or should you just be training them to use the automated coding system? Do you need some people who can do both? If you do not have anyone who can do it without the system, who develops the next version of the system? But on the other hand, can you keep people going for 20 years just to develop the next system? When you are training people to code manually, should they be using the ACME decision tables to work out where the rules apply, or should they be thinking it through from first principles? It could take a long time, but still may be worth it. Do people really need to learn those principles, or do they just need to learn how to do it through using the automated system? And how do you manage to maintain a level of expertise at a national level when you have only three, four, maybe half a dozen people involved in this work? Again, the question that Lars Age brought up of accreditation and retention of trained coders and nosologists: How do you make this job attractive enough to keep them?

We were also dealing with questions of training statisticians and data users, so that they would be able to cope with change in the classification and the effect it had on their statistics. Obviously, you have to identify who needs this information, then you have to find out what it is they need to know and what sort of products you have to produce for them in terms of comparability ratios, by when they need them, and try to get them interested before the new data comes out. This is not easy. They will ignore you, until they are suddenly confronted with data that they cannot understand. Then they will say: "You did this all wrong." So you have to try and get some interest going, and get people to come along to consultation before that, get them to understand the principles, get them to understand why you are changing it. They often want you to move to a more modern classification. They will complain that the way you are classifying congenital heart defects at the moment is no use at all; it is 30 years out of date. But when you change it, they will say: "I cannot use this, I cannot compare it to last year's." So you have to get them to understand the balance between the two things, and how to use data across that, by working through the principles of bridge coding, production to comparability ratios, how to use the comparability ratios, and what help you are going to be able to give people in interpreting the data.

We found that having an international course had tremendous additional benefits for us. We in England and Wales certainly learned a lot from the participants and the wide range of experience that they had. I think that was the case for the participants, too. They all found that they learned from each other, as well as from the people who were actually training on the course.

The training course established an informal international network of people who could ask each other questions and share the knowledge that they have, and the experience. It is always much easier to send e-mails and to phone people whom you have met than people you have not; and you find out who knows what. So that was very useful for us. It was part of the spirit, I think, for setting up the Mortality Forum. We decided this had been such a useful exchange of information—how do you code this in Poland, how do you code it in Germany, do

you know how to get around this problem—that we wanted to keep that going. Lars Age very kindly set up an e-mail forum for a mortality discussion, which you can now get to through the NCHS web page; a lot of people have found very useful. We certainly find it useful for trying to develop our own test deck of records for training in ICD-10. We found it useful for solving problems in ICD-9. I think participating in the discussions through that forum has been excellent training for our coders and nosologists in how to think through the problems of applying changed mortality selection rules.

Gérard Pavillon Head, WHO Collaborating Center for the International Classification of Diseases in the French Language

I will briefly present the ICD-10 training in French-speaking countries. Several courses were organized by the WHO Collaborating Center for the French ICD and the National Service of Information on causes of death (SC8).

Physicians and nosologists from SC8 are serving as trainers for this program. Courses are based on presentations by teachers and also on the use of TENDON in French; here is where we disseminate the French version of TENDON. The public is mostly composed of health managers, coders in mortality and morbidity, and statisticians and epidemiologists.

The first international course was organized in France in 1996, and three courses took place in Haiti, French Polynesia, and New Caledonia. We are planning, along with the WHO regional office for the East Mediterranean (EMRO), to have several other courses in Tunisia, Morocco, and East Mediterranean countries. Courses with Tunisia and Morocco are more of a collaboration on information systems in mortality; for instance, in Tunisia we are working on the implementation of the new death certificates, and maybe of the use of automatic coding systems.

We are planning to give courses in sub-Saharan Africa but, until now, we have not had any contact with these countries.

Tanya Pitts, Medical Classification Section, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

We conducted ICD-10 conversion training for experienced coders—those who were already trained in ICD-9. Their level of experience varied, some having 20 years of experience, others probably a year or less.

We conducted underlying-cause and multiple-cause conversion training courses from November 1998 through March 1999. The courses included computer-based preclassroom material, which is available on the PC at the back of the room. One week of classroom instruction was also included. Our multiple-cause course had computer-based, post-classroom material, which is also available on the PC.

We conducted seven underlying-cause classes to a total of 117 students. Most of our classes were concurrent sessions. We conducted five multiple-cause classes to 66 students. Julia Raynor and I each taught a class, along with Patricia Wood from Statistics Canada, who graciously assisted us in our training.

We have moved on to deliver our basic underlying and multiple-cause courses for ICD-10. We had a pilot class at the National Center for Health Statistics (NCHS) July 26 - August 6 where we trained eight NCHS employees. This training did include the preclassroom material, book one, which included the anatomy and medical terminology; and, book two, an introduction to the ICD volumes 1 and 3. The latter showed the students how to use the volumes, the arrangements of the volumes, and the conventions that are used within the volumes. It also included some coding exercises. Although this course is not computer-based at this time, my branch chief tells me that it will be computer-based as soon as time permits.

The classroom time lasted 2 weeks. We typically cover our 2B instruction manual from the beginning to the end, and we often have quite a few examples for the students to code. The students worked very hard, and we had 423 examples. We have discovered that these are too many examples, so we will have to cut back on those.

We follow with post-classroom material, which is computer-based. It provides instant feedback, that is, it provides the student with the correct answer and an explanation. It also provides page references in the instruction manual; it is detailed. This is also available in the PC and in hard copy.

We extended the post-classroom material that the student is required to code: it is now 300 records that provide a comprehensive overview of everything included in the instruction manual. We used this to determine how much the student has retained from the 2-week class.

Next is what we call specialty training decks. A deck is a group of records or a group of examples that the students are given to code. The decks contain anywhere from 15 to 50 examples. Some of the decks have four parts, A through D. There are a total of 20 decks arranged in the order of our 2B instruction manual. Each deck deals with a particular part of our instruction manual, such as deck 7, which deals with the neoplasms, and deck 14, which is geared toward the external causes. Each deck has an error rate based on the difficulty of the examples in that deck. The total number of records on all the decks is 2,255 records, so they do quite a bit of post-classroom work; and we have not finished yet.

We also have three qualification decks. Each contains approximately a thousand records, weighted to represent the annual U.S. file; so, therefore it is probably not appropriate for other countries to use. An easy record may have a weight of 100, with more difficult records having a

weight of 5. The student must complete the qualification deck with an acceptable error rate of 6.25 percent or less. Once they have finished the qualification deck and have qualified, they are ready to start their coding process.

There are two more classes planned for the rest of this year: we will be holding a basic multiple cause class at NCHS in the RPT area September 27–October 9, and we also have an underlying cause class planned for October 25– November 5. We have 19 students for our basic multiple cause class, which is probably the largest number that we have ever tried to train at one time, so we will have to see how that goes.

We will plan classes for next year, including a basic multiple-cause and a basic underlying-cause class, as well as an advanced multiple-cause and an advanced underlying-cause class.

On the table at the back of the room we have copies of our material for preclassroom preparation and for conversion. Also available is a complete list of our specialty decks and our qualification decks available.

Andre L'Hours, Epidemiology and Burden of Disease, World Health Organization

Good morning. I started working with the ICD 33 years, 3 months, and 8 days ago, when all one needed was a pile of death certificates, two books and a pencil to do the job; and the training method was called "sitting next to Nelly," because she was the lady who knew the most about it, and who taught you everything that you needed to know.

The WHO's role in training has changed greatly over the years through ICD-6, 7, 8 and 9. We carried out training for trainers by organizing international and regional courses for people who would then go back to their own countries and train their local staff. I think they probably preferred to do it that way so that they could perpetuate their own deviations from international norms. The training was essentially talk and chalk. It wasn't as it is today, when we depend on a system that Dr. Rooney and Gérard Pavillon referred to, which is prepared by the Office of National Statistics and the WHO Collaborating Center for Classification of Diseases housed in London.

We had our first international course for ICD-10 in September 1992, and some 50 people from around the world trained as trainers. The training used the TENDON system, which the trainers took back to their own countries to train their national staff. By the way, within WHO there is a split in responsibility for training: the WHO headquarters has responsibility for training materials, but the actual organization and funding of the training courses is the responsibility of the six regional offices.

Following the course in September 1992, the Eastern Mediterranean regional office organized a course for national coders, and conducted courses in Iran and Mongolia. We find it difficult to refuse to hold courses even when we are not convinced that the country is ready for it. If a minister of health insists on having a course, he or she generally gets one. This was the case in Mongolia. Although the classification had been translated into Mongolian, there was only one copy, and none of the Mongolian doctors knew the medical terminology in Mongolian, because they had all been trained in Russian, so it was a very difficult course to organize.

The regional office of Southeast Asia also has a number of courses for national coders, mainly with the help of the WHO Collaborating Center for the Classification of Diseases in Australia. Next month, they will hold a workshop in Burma on mortality statistics, which will include underlying cause aspects.

The Western Pacific regional office has also held courses in Malaysia and in Brunei. As Dr. Rooney mentioned, a number of ICD-10 courses have been organized there at the request of the regional office for Europe. Also, the WHO Collaborating Center for the Classification of Diseases in the Nordic Countries has carried out a number of training courses for the Baltic States.

The Pan American Health Organization, which is also the WHO Regional office for the Americas, has in fact had a massive training course in Spanish and also in Portuguese throughout the Americas, and trained a very, very large number of coders over a very short period of time.

In terms of training specifically for automated coding, I think the WHO does have a role to play in terms of the part of the training that relates to the principles of the classification and the use of the coding guidelines and the selection and modification rules for mortality. Unfortunately, resources at the Center are very limited. For ICD-8, the staff of the ICD was 16 people, for ICD-9 it was eight people, for ICD-10 it was six people; it is currently two people. So the resources you can put into training activities are quite limited. So as I say, I think we do have a role to play in the purely classification and application of classification aspects.

We look forward to this forum to provide advice and guidance to WHO on specifics related to the automated coding systems. I think there are essentially two posts in WHO that could contribute to this forum: my post, and the post of the medical officer in charge of the WHO mortality database. I think it would be important to get that person involved also in the activities of this forum, as there are important aspects related to the comparison of data coded manually as opposed to data coding according to automated systems.

I have some other notes, but I think they will come up later. Thank you.

Discussion on First Five Presentations of Session 4: Panel Discussion on Training for ICD-10

DR. ROONEY: Amazingly, many doctors have no idea that medical statistics come from the certificate of death. Many of them fill in the certificate and use the statistics, yet do not know that the two are connected, which is dazzling.

We do try to educate them, and we do try to teach them how to fill in the certificate properly, and why filling it in properly matters. It is a constant struggle. There are large numbers of doctors out there filling in certificates, and there are only limited moments at which you can catch them for training, and these are not necessarily always the best moments.

We are trying to train our junior doctors mostly in the first post-qualification year. We do not train medical students, because they are a bit too remote from actually doing the job. The emphasis in England and Wales is for this to be taught not only by epidemiologists or public health departments, but also by pathologists. Very, very rarely do we find clinicians involved in teaching doctors how to fill in death certificates, whereas in fact, most of them are only going to do it in a clinical setting, and that is where they need to learn to do it properly.

Over the last few years we have produced a training pack to be used by general practitioners in medical schools and post-graduate centers. We distributed the pack across the country. These training packs contain various exercises and explain to them the point of sequences and underlying cause.

We also produced a video, and we are now working on an electronic tutorial, which we hope to be able to make available both as a CD and on the National Health Service network, so that people can do it in their own time. It is our hope that if we get it through all sorts of different committees of the GMC, we will be able to award doctors a post-graduate education credit for completing it. We hope this would encourage more of them to complete it. We are trying to let them know that it is there up on a network, and that they could call up and look things up if they are not sure how to fill in the death certificate. But if anyone else has any good ideas about how to get doctors a bit more interested in how to do this properly, I would love them to share this with us.

MR. JOHANSSON: I believe that the general experience of trying to educate doctors is disappointing. You try to teach them how to fill out the certificate, and I think as Dr. Pérez has said in another session, if you check it out a few years later, you find that they have forgotten everything. So I am a pessimist when it comes to educating doctors in filling out the certificates.

I believe what we really have to do is to have far stricter checks at the coding stage.

DR. ROONEY: I think it would be good if we could move some of those checks earlier. Certainly, I have great hopes for electronic certification, and the idea that you could build in the checks, so that they verify the entries. Say a physician enters Bronchopneumonia in Part I and Muscular dystrophy in Part II, and a question pops up and says: "Do not you think that possibly muscular dystrophy actually made this patient susceptible to pneumonia?"

But I think the difficulty with doing that kind of thing is that if you build in too many checks, they will just find a way around it. They will find a phrase that does not get queried, and put it on every single certificate, because that is quick.

MR. JOHANSSON: I think the great problem really is that we try to capture information that the death certificate was never intended for. The death certificate was intended for premature deaths—one disease, one accident that dominates the sequence to death. Now, very often we have multiple causality. That is much more difficult to capture with death certificates. So we try to force the decisions to distort the reality into something that fits into the death certificates, and I believe that many of our quality problems are rooted in that. I think this is a very difficult struggle, and we may have to live with the quality problems that we have.

MR. PAVILLON: I would like to add something about this aspect of training the certifier. In France, we think that an important action is the query, and this is very well demonstrated on the poster of the Australian study, that the queries for incomplete death certificates or death certificates with ambiguous and ill-defined conditions are very important for the training of certifiers.

DR. PARRISH: My name is Gib Parrish, from the Centers for Disease Control and Prevention in United States. I have a short comment on what has just been discussed on the issue of certifiers in England.

As a part of a steering committee that looked at electronic registration of deaths in the United States, we conducted a study in one of the States—Michigan—and looked at the certifiers themselves, and found an interesting bimodal distribution for numbers of certificates that people filled out.

We found a very large number of physicians who complete fewer than three certificates per year, and a very large number of certificates that are completed by very few certifiers; you do not have much in the middle. You have people who are completing tens and hundreds of certificates in a given year; those may be people such as medical examiners, coroners,

people dealing with long-term care facilities, where there are many people dying. Then you also have the people who fill out just the occasional certificate.

So you may have two different groups for targeting training. That may be something to keep in mind, and different approaches might be useful for those different groups.

I also have a question related to Dr. Rooney's presentation. You mentioned discussions of differences in coding between countries such as England and Poland, which I think was the example you gave. Were the major differences related to the terminology that is used in different countries for the same condition? Where, in terms of training, do you find you run into the major problems?

DR. ROONEY: The Poland example I gave was about the doctors having to code their own certificates. Every single doctor who writes a certificate codes it him/herself. They do not have any centralized coding there. So as well as training physicians to fill the certificate, you also train them to code it; and, in theory you have to train them to apply all selection rules. My impression, though, is that by making the certifier do the coding and select the underlying cause, you are circumventing the rules. You are asking them to directly pick which was the most important thing there. Every one of them may interpret it differently. I think they estimated they had over 50,000 people filling in certificates and coding them. That is a problem for training.

DR. KOZIERKIEWICZ: That is right; for 20 years, each doctor certified and coded his own death certificate. A three-digit ICD-9 classification system was used. Starting with 1997, we changed to ICD-10, and we also changed the scheme of coding.

Back then, we had 49 coders in 49 districts, and this year we have about 30 coders, because the division of the country changed as well. So the number of coders is decreasing. I hope the quality of the coding is increasing at the same time.

When we were implementing ICD-10, we made a huge effort to educate people. And, of course, this education was directed to coders of mortality. There was a group of about 50 coders, so they had a set of sessions describing the rules of selection of underlying cause of death. Beside that, we also trained about 2,000 people who worked in health facilities. Some of them were doctors and others were statisticians who, in our system, are responsible for the forms and statistical documentation of the institution.

I agree with Lars Age Johansson in that teaching doctors is very complicated, so we decided that we would produce posters, which would be present in each doctor place, in hospitals, and facilities; posters advising them at the moment of certifying.

What Mr. Parrish said is right: a lot of people do certification very rarely. So putting so much knowledge in their heads makes no sense, so a better solution would be to put a poster on the wall and let them see what they should do when they really have to fill in that certificate. We have printed 50,000 posters and put them all over. That is what happened after 1997.

DR. ROONEY: That is very impressive, thank you.

MR. JOHANSSON: With that, we will move on to the subject of future international cooperation. As an example of what one might expect to find if one tries to engage in international cooperation, I will tell you about the training activities in the Nordic and Baltic countries. First, the Nordic WHO Center had a first course in ICD training in 1996. Some people from the Baltic countries and from Poland attended the course. It was a very interesting course because the participants were experts in public health but did not know the ICD very well, since we had to use other classification systems before. My Finnish colleague was also a teacher of that course.

We had many very interesting discussions on the effect of the ICD coding conventions on the statistics that we produced. I think that is the kind of input you need for ICD coding courses, not just how to use the classification; you also have to look at what comes out of the process.

The Nordic group of mortality statisticians decided that we really needed a Nordic mortality coding training, not just each country training in their own codes. And here is where the problems start. Of course, we do not have a common language. Nobody understands Finnish, nobody understands Icelandic. We in Sweden do not understand spoken Danish. Even at our statisticians' meetings, we use English. So how do we explain to people what it all is about?

We also have quite different coding traditions. We in Sweden try to apply the ICD coding rules as precisely as possible. The other countries use the ICD far more freely than we do. There are great differences in the input. Finland, for example, has a case summary on each death certificate. So when they try to code a certificate, they have to check the information in Part I and II against the case summary, and then try to decide which one of them to trust, which is a very complicated procedure. We do not have case summaries in the other Nordic countries, so we do not quite

understand that difficulty. Of course, we cannot advise them on how to approach their activity.

I think this brings us to the question of what can we actually do at the international training. Can we train in detail? Can we just give the general principles? Can the WHO collaborating centers in some way coordinate these matters and take care of these difficulties? I know that Marjorie has some thoughts to share with us on that.

Marjorie Greenberg, Head, WHO Collaborating Center for the Classification of Diseases for North America, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

What I want to talk about today is the WHO Collaborating Centers for the Classification of Diseases. I am representing the North American Center, and we have representatives of various other centers here as well. I want to tell you about their long-term strategy and work plan, and how this relates to the whole issue of training for ICD-10. I also want to talk about our initial efforts in creating a Subgroup on Training and Credentialing, which is just in the process of being established and a few words about next steps.

As you all probably know, the ICD is maintained by the WHO and a network of collaborating centers, formed primarily around language—although the English language is spoken so many different ways that we have the U.K. center, the North American center, and the Australian center. These collaborating centers, the Heads, and other participants meet annually with WHO. They have increasingly been working on cooperative activities that not only take place annually at these meetings, but really go on throughout the year.

In 1997, WHO developed a long-term strategy for health-related classifications that was revised in consultation with the collaborating centers. Then, in 1998, the WHO and the collaborating centers agreed at that meeting to develop a coordinated work plan. The first joint work plan was developed this summer.

The aims of the long-term strategy and the joint work plan are really the same:

- To facilitate international comparison of health information by encouraging wide use of ICD-10 by the year 2003.
- To operationalize the full ICD-10 updating process and its evaluation.
- To define the parameters and promote the development of the family of international classifications, which includes the International Classification of Impairments, Disabilities and Handicaps, and a variety of other specialty classifications.

The joint work plan has five main components. The main point I want to make about them is that training is an important aspect of probably all of them. We are trying to create a common framework for what we call the "family of classifications," trying to define what constitutes a "member" of this family, what the parameters are. This is something we have been working on for a few years, and hopefully we will make some progress in this year with a new work group being formed.

Several people have mentioned how important networking with the users is. I know that this year, in the U.S., Harry Rosenberg and the statisticians that he has been teaching are developing applications, along with quality assurance processes for the classification. I think it is obvious that training is particularly important when you are talking about quality assurance. We are talking about developing applications and networking. So we are interested in training across the spectrum of family classifications, but with the mother classification probably being the ICD-10.

As a result of the interest expressed at each collaborating center meeting, I was asked to establish a subgroup that became known as the "subgroup on training and credentialing," which

is part of the implementation of ICD-10 Committee. This new subgroup recognizes the importance of training for successful implementation of ICD-10, and also responds very directly to recommendations of the first International Collaborative Effort on Automating Mortality Statistics. As Harry Rosenberg mentioned yesterday, I think it is a real example of recommendations being made by this group and your predecessors, and being heard and wanting to respond.

This summer, I drafted some terms of reference. I worked very closely with the coders and nosologists at NCHS, and they were extremely helpful. These terms of reference address two main areas: mortality medical coders and nosologists in an automated environment, and training in a broader sense; training in ICD-10, but also training in the other members of the family of classifications, not only for mortality, but also for morbidity.

But today, I just want to mention what the tasks are that we have identified related to medical mortality coders and nosologists: first, to review the past recommendations that came out of this group. For several of the ones related to training and nosologists, there is a notion that this new subgroup on training and accreditation or credentialing might be able to address some of these issues. We also want to look at the Eurostat recommendations, and any other recommendations that are related to this issue. We want to identify the critical functions of mortality medical coders and nosologists, and conduct a needs assessment, which might be an update of the questionnaire that was done before the previous ICE.

We have been talking about defining the skills and levels of training required all morning. We said that different levels of expertise are needed, so we need to look at what types of expertise are needed and what the progression is from the initial expertise to people who can critique the system continuously, as Lars Age said; and that requires a very high level of expertise.

Another task identified is cataloguing and characterizing the current curriculum of materials to identify gaps; it will be sort of an inventory process, and we really will appreciate your feedback and assistance with that.

Another range of activities is to address the whole issue of the diminishing number of nosologists in an automated environment, and the status of nosologists, and what incentives there are for people to stay in the field, to be current, and to move up the ladder of expertise. Thus, we wanted to explore the possibility of initiating an international organization. This organization would potentially credential medical coders and nosologists, and also represent the profession more broadly as a national or international organization might. We want to explore affiliations with other national and international organizations such as the International Federation of Health Record Organizations, and then we will make recommendations to WHO and the collaborating centers. That will be done initially starting with the meeting in Cardiff next month.

As for next steps, I want to solicit feedback on the Terms of Reference, first from all of you, and then at the collaborating centers meeting in October. We hope to receive the endorsement of WHO and the collaborating centers for moving forward with this work group or subgroup. I do not know if I have permission to recruit members for the subgroup here, but I will anyway. Of course, we will be recruiting participants at the collaborating center at Cardiff, and not all of you will be there. There are many additional countries represented here, and we really will want to reach out as far as we can. So if you are interested in participating in this activity, please let me know.

As I said, we have a very broad work plan, both related to mortality medical coders and to training more broadly, so we are going to have to prioritize the different tasks and develop a work plan for the next year. Again, I seek your advice in that area.

And that is what we are hoping to do at the collaborating centers. I look forward to working with all of you on that.

Andre L'Hours, Epidemiology and Burden of Disease, World Health Organization

Over the years that I have been in contact with groups like this, I became increasingly aware that there seemed to be differences in the status of what used to be called "cause coders" from one national administration to another. Some seem to get the lowest clerical grade that is available within that national administration, and some tend to be involved in the administrative or executive grades that might exist.

Although comparisons are very difficult—because each national administration has its own grading structure—I think it would be interesting to find out at what level within the national administration this work is being done, both for manual and automated coding.

Within WHO, we do have a plan to find out more information about the way in which the data are collected and coded and processed at the national level. This plan is related to the mortality database, and I discussed with Lars Age Johansson the possibility of including a question about the status of nosologists within each country in the letter that would be sent to member states. I think we could then use that to bring pressure on the member states to—along with the idea of having an international federation—improve the career status of nosologists. It is very difficult in most national administrations to keep a person in the same post for a very long time without promoting them. It is also difficult to promote someone who has essentially done the same job for 20 years. It is a "Catch-22" situation: you rely on their expertise, but you have no real facility for improving their remuneration. I think we need to work along those lines.

The problem is that there are too few people doing this job, so there is no career structure available. It can be very frustrating for people who do the job and enjoy it very much, but see their colleagues in other departments in the ministry advance in their careers while they are retained in the same position and the same pay, simply because they are good at what they are doing. I think we need to find out more about the status of the job in general, and try to improve the situation if we can.

Discussion on Last Two Presentations of Session 4: Panel Discussion on Training for ICD-10

DR. IBRAHIM: I do agree that there is a defined level and expertise needed for the training of coders. Usually in developing countries we have very few nosologists. We are pleased to report that, with support from WHO, Dr. Robert Israel came to Malaysia 2 years ago and gave us 2 weeks' training for ICD-10 for Malaysia and Brunei.

DR. KARDAUN: Regarding the status of nosologists in The Netherlands, there are about 10 times as many nosologists not working for the government than those who do. They do hospital discharge coding, and therefore they are neither visible nor organized. In general, they are considered clerical staff. So it could be a point of consideration to join forces, because for mortality coding, the numbers are too small.

MS. RAWSON: In Australia we have about 12 more coders within the Australian Bureau of Statistics. The training that was conducted in the Southeast Asia region was conducted by a person who worked within NCCH, the National Center for Classifications and Health. Recently, the ABS advertised for nosologists to lead the mortality coding team, and guess who we picked up? We picked up the person from NCCH. So we now have her. She is continuing to do the training in Southeast Asia. NCCH has advertised for nosologists, and they had no applicants at all.

Probably within 12 months time, we will cut down from 12 coders to about 6 and run at that level—or so we anticipate. We have the feeling that what we will need to do in Australia then is to sell mortality coding as being part of a more general career, in terms of being a hospital morbidity coder, of which there are many more. They move around, and the good ones become more highly paid. What we had hoped to do was retain perhaps two or three of the ones that seem as though they are committed to the sort of work that they are doing.

They tend to reach the top of the small pyramid of the mortality coders, and they fit quite nicely, and some of them seem to be quite satisfied at that level. Then the others we expect will probably move in and out of mortality as being one step in their career, rather than staying in it for the long term. That is the way that we think we will need to do it in Australia.

DR. ROONEY: As Andre L'Hours was saying, there are differences in the status that nosologists have in different countries. There are also differences in the whole structure of the way that people are employed in the agencies in which they work.

One of the problems for us would be mortality coders, of whom we only have about five at the moment to do our 580,000 deaths a year. But we are automated. They work in civil service. They cannot code hospital data in the civil service. The only coding they can do is mortality coding, so to get promoted within the civil service, they have to do something different.

One or two can progress within the organization. We have had some who have moved into working on the statistical side of mortality data, and another who works on the automated system development and maintenance of the system. But it is not easy to move upwards. Within the civil service, being a specialist in anything is a disadvantage.

DR. COLE: I do not really think that having more morbidity coders as a means of increasing your base or structuring their careers is the answer. I think coding statements, text statements, is skilled, but a comparatively easy skill to learn and teach and to maintain. I think the selection of the underlying cause, which is totally foreign to the morbidity coders, is a much greater skill and requires much greater understanding involving causal sequences and all the rest of it. I do not think that this is a skill that the morbidity coders have.

DR. ROONEY: But they could move between occupations. Someone who had begun as a morbidity coder could then move on to become a mortality coder.

DR. COLE: Yes, I know, but I do not think this is a sort of career structure path answer.

DR. ROONEY: It may be different in different countries. I agree with you about the principle that you cannot just move coders from morbidity to mortality; it is a major training step.

MS. RAWSON: When we advertised the position for manager of the mortality coding unit, the only people that applied (apart from the nosologists in NCCH, who actually had been working part time in the bureau for some years) were morbidity coders. So it seemed as though that was the area where we actually generated some interest. None of them were good enough to do the job, but there are people out there with the right background, who I think would probably be good enough to be able to be trained as mortality coders.

So once we have only six or fewer people, then we will have to look for some way to support a career structure. You may find that some of them will stay within the Australian Bureau of Statistics and then move on, or go to NCCH or RHW, or whatever it happens to be. But there are still just

a small number of agencies that they can go to. So we think we have to look more broadly than that.

DR. ROONEY: But it still comes down to the fact that most countries only have about half a dozen people to do their mortality coding. You need to maintain continuity, you need to constantly improve the standards, and you need to pass on that information to the next group of people. And you need some level of consultation. I was interested in the progress in Poland, the changes that had been made. But they still have 30 coders. Can I ask you a question in the audience, Poland? Are those 30 coders working in 30 separate offices?

MR. L'HOURS: What else do these doctors do? Do they have other functions, or do they only code mortality? Do they have other functions in addition to the coding of mortality?

DR. KOZIERKIEWICZ: Some of them are part time workers.

(Simultaneous discussion.)

DR. ROONEY: It is not always easy to train doctors, as we have discussed before. As a doctor, I can admit this. But I think it is not always easy to train people who have already retired, either. They may feel that they do not need any more training; they can always stop, after all. But I am interested in the fact that a lot of countries are using doctors for coding. I think most of us would not do it for two reasons. One, they are much too expensive and two, they are not very reliable in our experience. They tend to try to interpret what the doctor should have written on the death certificate, rather than actually applying the rules as they are written down in the book and do it the same way every time.

Within the Office of National Statistics, there are about five of us who used to give advice when the coders could not code something, and I have to say that it was inconsistent. The majority of people would say: "Oh, they did not really mean that, he should have written it the other way around." It is not easy. And as I say, I think also doctors are rather too expensive in most countries to have them doing that.

MR. JOHANSSON: Thank you very much. I am afraid we cannot prolong this discussion any more. But as you can see, we have only started. We have lots of things to do, and we hope very much to moderate a subgroup on training and implementation. Thank you very much for your attention.

SESSION 5

Methodological Issues

Methodological Issues

Dr. Cleone Rooney (moderator), Medical Epidemiologist, Office for National Statistics, England

In this session we are going to look at some of the methodological issues. First, Tim Devis from London, one of my colleagues, is going to tell you about using multiple-cause data to try to sort out one of those constant problems of comparability: diabetes deaths. Then we will present four papers about bridge coding and our difficulties about trying to do bridge coding. I hope that a couple of them are actually going to tell us a bit about results, though I have to admit, I will not be presenting results in mine.

So let's start with Tim Devis.

Using Multiple-Cause Data in England and Wales to Measure Artifacts Due to Changes in Selection Rules

Tim Devis, Statistician, Population and Vital Statistics Division, Office for National Statistics, England

This is an ongoing study of recent trends in mortality from diabetes, showing patterns not explainable by simple time trends. We use this to show how the effects of changes in mortality coding rules and organizational changes can affect what we came up with and our understanding of what is going on.

This started as an exercise in the Office of National Statistics to show the potential uses of multiple-cause data and its role in understanding mortality trends. Diabetes was chosen as an example of a condition particularly subject to artifacts, and we are also looking at an associated question with multiple-cause data: How many deaths occur to diabetics and how many due to diabetes as underlying cause? The period studied is 1979 to 1997, but as you will see, we have not actually analyzed every year for everything I will present. The study has two aims: first, What change occurred in diabetes mortality from 1979, and how much of the change was due to artifacts; and second, What do people with diabetes on their certificate actually die of?

I want to mention a paper that Cleo Rooney presented at the previous meeting of this ICE in 1996, in which she looked in general at the issues around automation of coding in England and Wales, and the changes in recent years. If you want to find out more about what has happened in England and Wales and how it has affected us more generally, please refer to the Rooney paper [see "Implementing Automated Coding in England and Wales: How it Affected Mortality Statistics", page 8-1, *Proceedings of the International Collaborative Effort on Automating Mortality Statistics, Volume I*, July 1999]. It is all there, plus discussion. Diabetes is discussed, but not in much detail.

The artifacts especially involve WHO mortality coding Rule 3. For anyone not familiar with what Rule 3 is about, I quote: "if the condition selected by the General Rule or Rules 1 or 2 as the underlying cause can be considered a direct sequel of a condition mentioned elsewhere on the certificate, then select that condition." In the early 1980s, an increasing number of certificates had bronchial pneumonia in Part I, and also reported an important condition in Part II. From 1984, we broadened the application of Rule 3 so that if the tentative underlying condition was 1 of 11 terminal conditions including importantly pneumonia, but also pulmonary embolism, heart failure and so on, and if another major condition was mentioned, then we selected the latter as the underlying cause.

The effect from 1984 was to decrease numbers with a terminal condition and increase those with a major condition, for example, diabetes. A dual coding exercise at the time showed that the mortality from diabetes (ICD-9 No. 250) would have increased by about 44 percent in the first year because of the way we broadened the application of Rule 3.

Secondly, I shall mention automation, which was part of a much larger redevelopment in the early 1990s in the move to automated cause coding. When we implemented automated coding in 1993, it meant moving back to the interpretation of Rule 3 that was in operation before 1984. So we have for the period studied: 1) 1979 to 1983, what might be called "straight Rule 3"; 2) 1984 to 1992, interpretation of Rule 3; 3) 1993, back again to straight Rule 3.

I shall also mention our availability of multiple-cause data. Coding of all causes on the death certificate was carried out in 1985 and 1986. That stopped in early 1987 as an economy,

but was reintroduced in 1993 with automated cause coding. So we have multiple-cause data for these two periods. Mortality shows the increase anticipated for 1984, something like a plateau in 1984 to 1992 and a fall again in 1993. I say "something like a plateau," because other improvements or changes in our methods and coding occurred even during that period. But in 1993, the trend resumes at a higher level than one might have expected from pre-1984 data. On the other hand, the trend is probably still falling, albeit slowly. For age-specific rates, the effect is pretty evident for ages 65 and over. The effects that were there in 1984 to 1992 continued in the later years for the age group 55 to 65 years, but there is not very much evidence of any effect from Rule 3 at younger ages, leaving us with the question: did the application or interpretation of Rule 3 differ for these age groups?

For multiple causes of death, we have data for 1985 and 1986, and for 1993-1997. Multiple cause death rates are a little higher at the very highest ages, 85 years and over, and decline at age 55. For females, rates are at different levels of decline at age 45 and over.

I need to calculate age-standardized death rates for multiple causes in the same way as we did for underlying cause to get a better picture of what is going on overall. However, a rough calculation suggests a slight decline based on multiple-cause information on diabetes. We calculated for each year and for each age a percentage of certificates where diabetes was mentioned. As you might expect from the smaller numbers, there is quite a bit of noise under the younger ages. What comes through is that for 1985 and 1986, levels were substantially above those for 1983 and 1987. This is evident for most of the younger ages.

A similar pattern occurred for females, possibly suggesting some sort of differential age effect of Rule 3. It is only at younger ages where we start to notice the difference. More broadly, we can conclude that if diabetes were given as an underlying cause in the later years, 1993 and 1997, it is a result of a different interpretation of Rule 3.

On the other hand, the number of mentions of diabetes has fallen slightly. We wanted to ask whether this means that the number of diabetics dying is also a little bit down. We do not know whether diabetes has always been mentioned when it should be; hence, we may have an incomplete record on the number of diabetics dying.

Turning to the focus of our investigation —what are diabetics dying of—we looked at the ICD-9 underlying cause number 250 by first digit used for selected years during the 1979 to 1997 period. We examined the fourth digit as a percentage of all digits within the ICD-9 250 code. We measure not the rate at which each occur, but the relative rate amongst those coded to 250. We found that in 1993, there is evidence of some change for 250.0, that is, diabetes without complications. At the same time, 250.3, which is the renal complications, seems to have gone down. There is also some decline for 250.6, which is the peripheral circulatory diseases. Results for males are similar. Our understanding is that 250.3 changed in 1993 when we went to automated cause coding because of the particular interpretation of Rule 3. Up to 1982, we accepted renal failure with diabetes in code 250.3, but with automated cause coding renal failure should be mentioned as one of the diseases caused by diabetes.

Finally, we looked at deaths where diabetes was mentioned, but the underlying cause was assigned to some other condition, for 1985 and 1986, and 1993-1997. For this group of deaths, what is the distribution of other conditions as underlying cause? Amongst males, we saw a gradual decline for heart disease, but also interestingly in 1993 an apparent rise for pneumonia before age 6 years. We suppose those to be related to change in interpretation of Rule 3 again. There is also some emergence of ICD-9 code 443, Other peripheral vascular diseases. At present we are not clear whether this may or may not be due to some artifact. We may also be

handicapped by not having information between 1986 and 1993 to tell us what other factors were at work. For females, some of the same features are showing, that is, for pneumonia and stroke, but not so much of a change for heart disease. The effect for ICD-9 number 443 that I mentioned did not appear.

Methodological Issues in the Design of the United States Comparability Study

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Introduction

I am going to provide you with some basic information regarding the U.S. comparability study. Since the study is in progress and not yet complete, I am going to discuss a little bit of our strategy for completing the study and include our sampling design. I am also going to show you some preliminary comparability ratios that we have calculated from a nonrepresentative sample of records. These are very preliminary data.

Comparability studies have been done in the United States since at least the Sixth Revision of the International Classification of Diseases (ICD) was introduced. The comparability study for ICD-10 will be based on records from the final 1996 mortality file. The comparability study will show ICD-10 tabulation categories compared with ICD-9 tabulation categories, and the approximate quantitative relationship between, for example, the death rate from Diseases of heart in ICD-10 compared with ICD-9. Overall, adjustments made using comparability ratios will facilitate comparative and trend analysis of years in which mortality data was coded according to different revisions of the ICD.

Study design

Design issues

The entire U.S. 1996 mortality file is currently coded by ICD-9. Ideally, this entire file should also be coded by ICD-10. However, given the large size of the 1996 file—a little over 2.3 million records—it is not practical to expect that each and every record will be coded by ICD-10. Three major issues must be taken into account in the design of the comparability study to ensure the representativeness and accuracy of the comparability ratios.

First, the number of records rejected by the automated systems, MICAR and ACME, must be taken into account. Currently, approximately 20 percent of all records are rejected by the ICD-10 automated systems. This leaves over 400,000 records, which must be coded manually. There is neither sufficient time nor resources to code this many records in time for publication of the preliminary 1999 mortality data (Spring 2001). As a result, we plan to release what will be called "preliminary comparability ratios" for 113 selected causes of death. These will be based on a double-coded sample of 1996 records. The ultimate goal is to code the entire 1996 mortality file by ICD-10 and to eventually release a CD-ROM with these data available such that the effect of the new revision on any cause of death may be examined.

Second, since it is impractical to include all rejected records in the initial file, a sample of rejects will be drawn. The previous comparability study examining differences between ICDA-8 and ICD-9 sampled about 137,000 records from the 1976 U.S. mortality file (1). A much larger sample would provide greater statistical stability and greater flexibility in calculating comparability ratios by cause. Therefore, the strategy is to use all of the automatically processed records and all infant records, and to sample from the records rejected by the automated systems. For the purposes of sampling, the NCHS tabulation list of 113 selected causes of death (shown in Appendix I) will be treated as strata. Records rejected by the automated systems by 113 selected causes of death will be sampled using proportional allocation according to how they are

distributed by ICD-9. That is, if a particular cause of death contains 10 percent of all rejected records, then 10 percent of all sampled records will be allocated to this cause of death. For some causes, it may be necessary to collapse adjacent categories or to set a minimum sample size to avoid zero cells. Once the rejected records are sampled, they will be manually coded and added to the automatically processed records. This sample should be representative of the entire 1996 U.S. mortality file.

Third, assessment of statistically significant differences in mortality over time and between groups requires the calculation of variance estimates for the comparability ratios. Since the comparability file is based on a sample of mortality records, comparability ratio estimates will be subject to both random and sampling error. Algorithms for the calculation of variance estimates are currently being created.

Calculation of comparability ratios

The method utilized to calculate comparability ratios is basically the same as that used by previous comparability studies (2–5). Comparability ratios for the preliminary study are based on all deaths occurring in 1996 coded according to ICD-9 and on a sample of the same 1996 deaths coded according to ICD-10. The ratio for a particular cause of death is then calculated with the number of 1996 deaths for that cause coded by ICD-9 in the denominator and the estimated number of 1996 deaths (calculated from the sample) for the comparable ICD-10 cause in the numerator.

If we use less than the entire file, the sample data will be post-stratified to the final 1996 data by age (10-year age groups), race (white, black, other), sex, and cause of death (113 cause list) to increase the precision of comparability ratio estimates. That is, weights will be assigned for each cause-age-race-sex group such that when weighted, group counts in the sample data will exactly equal corresponding group counts in the final data. The weights are calculated as:

$$w_{ijkl} = \frac{N_{ijkl}}{n_{ijkl}}$$

where w_{ijkl} is the weight for cell *ijkl* (deaths for a person of ICD-9 cause *i*, age *j*, race *k*, by sex *l*). i=1,...,113; j=1,...,11; k=1,2,3; and l=1,2. n_{ijkl} is the sample count for cell *ijkl* and N_{ijkl} is the final count for cell *ijkl*. Weights for each cell are calculated based on an ICD-9 classification for cause of death. Note that since we will include all infants in the sample, w_{ijkl}=1.0 for all infant deaths (j=0). In addition, if we use the entire sample, w_{ijkl}=1.0 for all deaths and the weights are unnecessary in the calculation of the comparability ratios and their standard errors. A table of the weights for each cause-age-race-sex group will be reviewed before ratios are calculated.

The comparability ratio for cause *i* (CR_i) is then calculated as:

$$CR_i = \frac{X_i}{N_i} = \frac{\sum_j \sum_k \sum_l (x_{ijkl} w_{ijkl})}{\sum_j \sum_k \sum_l N_{ijkl}}$$

where X_i is the weighted total number of deaths for cause *i* classified according to ICD-10, x_{ijkl} is the sample number of deaths for ICD-10 cause *i*, age *j*, race *k*, and sex *l*, w_{ijkl} is the poststratification weight for the cause-age-race-sex group and N_i is the total number of deaths for cause *i* classified according to ICD-9. Comparability ratios can also be easily calculated for any and all combinations of the cause, age, race and sex variables. For example, comparability ratios for cause *i* and age *j* (CR_{ij}) are calculated simply without summation over *i* and *j*. Comparability ratios for each cause-age-race-sex group (CR_{ijkl}) are calculated with no summation at all.

$$CR_{ij} = \frac{X_{ij}}{N_{ij}} = \frac{\sum_k \sum_l (x_{ijkl} w_{ijkl})}{\sum_k \sum_l N_{ijkl}} \qquad CR_{ijkl} = \frac{X_{ijkl}}{N_{ijkl}} = \frac{x_{ijkl} w_{ijkl}}{N_{ijkl}}$$

Publication plans

We plan to publish mortality data coded by ICD-10 for the first time in the spring of the year 2001 with our preliminary mortality data for 1999. A month or two prior to the release of the preliminary data, we intend to publish our first set of comparability ratios by 113 selected causes of death. Hopefully, by summer of 2002, we will be able to finish the 1996 mortality file and release comparability data that are more detailed along with the CD-ROM that was previously mentioned.

Some very preliminary results

Table 1 shows comparability ratios for the 15 leading causes of death in the U.S. in 1996 and is based on a double-coded data file containing 643,336 records. These data come from 13 States (Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Georgia, Hawaii, Iowa, and Idaho) and the District of Columbia. Further, these data include only those records that were able to be processed by the automated mortality coding systems MICAR and ACME. As a result, these records are not necessarily representative of the entire United States.

Table 1. Preliminary net effects of changing from ICD-9 to ICD-10 (comparability ratios) for the 15 leading causes of death in the United States in 1996
[Data are very preliminary and based on a non-random sample of mortality records for 14 States, N=643,336.]

Cause	ICD-9 codes	ICD-10 codes	Comparability ratio
Diseases of heart	390-398,402,404,410-429	I00-I09,I11,I13,I20-I51	1.02
Malignant neoplasms	140-208	C00-C97	1.00
Cerebrovascular diseases	430-434,436-438	I60-I69	1.04
COPD	490-494,496	J40-J47	1.03
Accidents	E800-E869,E880-E929	V01-X59,Y85-Y86	1.00
Pneumonia and influenza	480-487	J10-J18	0.37
Diabetes mellitus	250	E10-E14	1.03
HIV infection	*042-*044	B20-B24	1.05
Suicide	E950-E959	X60-X84,Y87.0	1.00
Chronic liver disease and cirrhosis	571	K70,K73-K74	1.03
Nephritis, etc.	580-589	N00-N07,N17-N19,N25-N27	1.40
Septicemia	038	A40-A41	1.27
Alzheimer's disease	331.0	G30	1.69
Homicide	E960-E969	X85-Y09,Y87.1	1.00
Atherosclerosis	440	I70	0.98

One rule change in particular will substantially affect the leading causes of death. Rule 3 for both ICD-9 and ICD-10 states if the condition selected by the General rule (or principle) or Rules 1 or 2 can be considered a direct consequence of another reported condition that the other condition should be selected (citations). The ICD-10 version of Rule 3 goes further in stating that pneumonia and bronchopneumonia may be accepted as complications of any disease (citation). For example, pneumonia is often a complication of heart disease, stroke, cancer, and many other diseases. Under ICD-9, pneumonia was likely to have been selected as the underlying cause of death in most cases. Under ICD-10, pneumonia will not be selected in these cases. Hence the very low comparability ratio for pneumonia and influenza in table 1. Increases in heart and cerebrovascular diseases and COPD are primarily due to the change in Rule 3.

Comparability ratios for nephritis, septicemia, and Alzheimer's disease also show significant changes from ICD-9 to ICD-10. Comparability ratios for these causes greater than 1.0 indicate that deaths and death rates for these causes will increase with the revision. The effects of the revision on nephritis and septicemia require further study to understand why these causes will change. However, the almost 70 percent increase in Alzheimer's disease is primarily the result of a change in the way Alzheimer's disease is defined. In ICD-9, Alzheimer's disease was classified as such only if Alzheimer's disease was diagnosed and noted explicitly on the death certificate as a cause of death. In many cases, Alzheimer's or Alzheimer's-type dementia was listed on the death certificate. In ICD-9, the underlying cause of death in these cases was coded to 290.1, presenile dementia. In ICD-10, Alzheimer's or Alzheimer's-type dementia are classified as G30, Alzheimer's disease.

These comparability ratios have important implications for the analysis of mortality trends in the United States. There will be some significant discontinuities in cause of death trends from 1998 to 1999, particularly for pneumonia and influenza, Alzheimer's disease, nephritis, and septicemia. Pneumonia and influenza will drop substantially, while the others will

increase. Care must be taken to explain why these changes are occurring. The change in revision will also have an impact on the ranking of leading causes of death. Based on 1996 rankings, the following changes would occur as shown in table 2. The top four leading causes, heart disease, malignant neoplasms, cerebrovascular diseases, and COPD would remain the same. Diabetes would go from the 7th leading cause to the 5th leading cause. Accidents would drop from 5th to 6th partly because accidents will no longer be tabulated with adverse effects. These will be tabulated as separate rankable causes. Alzheimer's disease would rise from 13th to the 7th leading cause. HIV infection would remain 8th. Pneumonia and influenza would drop from 6th to 9th. Nephritis would rise from 11th to 10th. Chronic liver disease and cirrhosis would drop from 10th to 11th. Suicide would drop from 9th to 12th. Septicemia would drop from 12th to 13th. Atherosclerosis would rise from 15th to 14th. Finally, homicide would drop from 14th to 15th. This drop occurs partly for the same reason that accidents dipped in the rankings. Homicide will no longer be tabulated with legal intervention. Legal intervention is a separate rankable category in ICD-10.

Table 2. Cause of death rankings for the 15 leading causes of death in the U.S. in 1996 under ICD-9 and ICD-10

Rank	ICD-9 Cause	ICD-9 codes	ICD-10 cause	ICD-10 codes
1	Diseases of heart	390-398,402,404,410-429	Diseases of heart	I00-I09,I11,I13,I20-I51
2	Malignant neoplasms	140-208	Malignant neoplasms	C00-C97
3	Cerebrovascular diseases	430-434,436-438	Cerebrovascular diseases	I60-I69
4	COPD	490-494,496	COPD	J40-J47
5	Accidents	E800-E869,E880-E929	Diabetes mellitus	E10-E14
6	Pneumonia and influenza	480-487	Accidents	V01-X59,Y85-Y86
7	Diabetes mellitus	250	Alzheimer's disease	G30
8	HIV infection	*042-*044	HIV infection	B20-B24
9	Suicide	E950-E959	Pneumonia and influenza	J10-J18
10	Chronic liver disease and cirrhosis	571	Nephritis, etc.	N00-N07,N17-N19, N25-N27
11	Nephritis, etc.	580-589	Chronic liver disease and cirrhosis	K70,K73-K74
12	Septicemia	038	Suicide	X60-X84,Y87.0
13	Alzheimer's disease	331.0	Septicemia	A40-A41
14	Homicide	E960-E969	Atherosclerosis	I70
15	Atherosclerosis	440	Homicide	X85-Y09,Y87.1

Conclusions

There will be discontinuities in the trend for some causes of death, particularly for pneumonia and influenza, Alzheimer's disease, nephritis, and septicemia. The effects are substantial enough that the distribution of the 15 leading causes of death for the United States

will be affected. This will cause some initial inconvenience and perhaps some confusion as data users attempt to understand the changes in the context of trend data. The results of the U.S. Comparability Study will be critical in disseminating an adequate explanation of the discontinuities in trend from 1998 to 1999 resulting from the new revision and in estimating the true change in mortality during this period by cause of death.

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Mortality Bridge Coding ICD-9/ICD-10: Preliminary Results from Statistics Sweden's Study

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Sample

For this bridge coding study, we used a random sample of 25,440 Swedish death certificates drawn from the 1996 mortality file. The sample was stratified by the ICD-9 underlying cause (BTL level), with the sampling probability inversely proportional to the frequency of the condition. Consequently, all certificates for rare causes of death have been included in the sample.

Processing

Since the aim was to compare the actual annual files before and after the implementation of ICD-10, and not ideal ICD-9 coding with ideal ICD-10 coding, we decided to accept the ICD-9 coding as we found it in the 1996 sample. In other words, we did not correct errors in the ICD-9 coding encountered during the evaluation process.

When coding the certificates in ICD-10, we used the same production steps as for the general mortality register: routine coding (including manual selection of the underlying cause), specialist review of flagged records, ACME processing, manual review of certificates for which ACME and the manual coder had selected different underlying causes. Data edits (such as compatibility between age, sex, and condition) were applied at all stages of the coding process. Any errors still left were accepted, for the reasons already stated in the preceding paragraph.

Back in 1986, when we did the bridge coding from ICD-8 to ICD-9, we decided to use the bridge coding sample as our training deck for ICD-9. Thus, we first coded the certificates selected for the study, and only then moved on to production coding. This was a mistake. It takes much experience of actual coding to master a new revision of the ICD, and there will inevitably be changes in coding practices until all significant coding problems have been identified and resolved. Consequently, our ICD-9 coding in that study did not quite reflect the way we actually applied the classification during most of the ICD-9 period. Obviously that reduced the value and usefulness of the study. To avoid this problem, we now decided to process the bridge coding sample only after we had coded a full year of ICD-10 data. Even so, we believe that the bridge coding study must be repeated in a few years' time, since international discussions on coding practices will probably lead to changes in international classification instructions, and their effects need to be studied.

We did the main analysis by the European short list (EU65). We used a Swedish adaptation, which has two additional subgroups: Acute myocardial infarction and Motor traffic accidents. We also flagged records included in the computation of the alcohol and drug abuse indexes published in the Swedish mortality yearbook, as well as conditions regarded as "ill-defined" (the rate of "ill-defined" conditions is a rough measure of data quality), and analyzed the impact of the transition to ICD-10 on these three indexes.

Using the sampling probabilities for the ICD-9 underlying cause codes, we then estimated the number of certificates in the EU65 and index groups for a full data year. Confidence intervals will be calculated in the full report, which will be available in autumn 2000.

For additional detail, we also analyzed our coding by the ABC list. This list, which has 214 groups, was developed by the WHO to replace the Basic Tabulation List published in ICD-10 Volume 1.

Results by the European short list

For 93 percent of the material, the underlying cause was coded to the same EU65 group in both ICD-9 and ICD-10. At the highest level of the EU65 list, which approximately corresponds to the ICD chapters, the correspondence was 96 percent.

Some EU65 groups have a comparability ratio far below the average, however. There are several explanations. The most important are changes in the structure of ICD (for example conditions moved from one place in the classification to another), changes in the rules and guidelines for selection of the underlying cause, and changes in Statistics Sweden's interpretation and application of the ICD.

For ICD-9, Sweden used a version of ACME that had been modified to reflect Swedish coding practices. With the implementation of ICD-10, we decided to accept the underlying cause selected by ACME, since ACME is now considered the *de facto* international standard for automated selection of the underlying cause of death. We now select an underlying cause different from ACME's only if we have strong reasons to believe that ACME's decision tables will eventually be modified on that particular point.

Comments on specific short list groups

The numerically most important differences between the ICD-9 and ICD-10 coding are presented below.

· 01 Ch I. Certain infectious and parasitic diseases

Increase, mostly due to the transfer of HIV/AIDS to Ch I from Ch III (Endocrine and immunological conditions, in ICD-9, Sweden used 279.5 for AIDS and 279.6 for other HIV disease). The transfer of Bacteraemia (previously Ch XVI, Symptoms) and Legionnaires' disease (ICD-9: Ch VIII, Respiration) to Ch I also contributes to the increase.

· 03 Meningococcal infection

Decrease, perinatal meningococcal infections are now coded to Ch XVI (Certain conditions originating in the perinatal period).

· 05 Viral hepatitis

Increase, since most cases of chronic hepatitis will now be coded to Ch I (in ICD-9: Ch IX, Digestion).

· 25 Ch III. Diseases of blood and blood-forming organs and certain disorders involving the immune mechanisms

Decrease, two main explanations: HIV/AIDS is now in Ch I (Certain infectious and parasitic diseases), and myelodysplastic syndrome and related conditions now go to Ch II (Neoplasms).

· 28 Ch V. Mental, behavioral disorders
30 Alcohol abuse

Decrease, Alzheimer's disease (with or without dementia) is now classified to Ch VI (Diseases of the nervous system), while Alzheimer's disease with dementia was coded to Ch V in ICD-9. Certain combinations of alcoholism with liver disease now go to Ch XI (Diseases of the digestive system). Accidents due to dementia or other mental disorders are now coded to Ch XX (External causes of morbidity and mortality). Certificates on which drug poisoning has been reported as the underlying cause of death, but with "drug abuse" (ICD-10: F1x.1) mentioned elsewhere, would often go to Ch V in ICD-9. In ICD-10, they will often be coded to Ch XX. HIV and AIDS due to drug abuse was earlier classified as drug abuse deaths (Ch V), but—due to a change in the coding rules—are now coded to Ch I.

· 29 Alcohol abuse

Increase, In ICD-9, alcohol abuse causing a somatic complication was classified to the somatic complication. In ICD-10, however, only certain liver conditions take precedence over alcohol. Acute poisoning with alcohol, reported as the underlying cause of death, is now coded to Ch V, if alcoholism (F10.2) is also mentioned on the certificate, but was coded to Ch XX (External causes of morbidity and mortality) in ICD-9.

· 31 Ch VI. Diseases of the nervous system and the sense organs

Increase, in ICD-9, Alzheimer's disease with dementia was included in Ch V (Mental, behavioral disorders), but all types of Alzheimer are now coded to Ch VI. Changes in the interpretation of Rule 3 ("direct consequence," see below) also bring about that chronic conditions of the nervous system are more often selected as the underlying cause of death.

· 32 Meningitis (other than group 03)

Decrease, mostly due to changes in the interpretation of Rule 3.

· 37 Ch X. Diseases of the respiratory system
39 Pneumonia

Decrease, ICD-10 has new instructions for certificates on which the physician has reported pneumonia as the underlying cause of death. Quite often Rule 3 will be applied, which means that the pneumonia will be regarded as a complication of numerous other conditions, especially of "wasting diseases ... diseases causing paralysis ... communicable diseases and non-trivial injuries." Consequently, many deaths that were classified as due to pneumonia in ICD-9 will be coded to other conditions in ICD-10. Malignant neoplasms and cerebrovascular diseases are prominent among these, but several other conditions are also affected.

· 41 Asthma

Decrease, ACME for ICD-10 applies Rule 3 to asthma far more seldom than the Swedish version of ACME for ICD-9.

· 46 Ch XIII. Diseases of the musculoskeletal system and connective tissue

Increase, main contributions from autoimmune vascular disorders (ICD-9: Ch VII, Circulatory disorders) and gout (ICD-9: Ch III, Endocrine and metabolic conditions).

· 50 Ch XV. Pregnancy, childbirth and the puerperium

Twice as high. An artifact: In ICD-9, most diseases present before pregnancy and childbirth, but aggravated by it, were coded to the "ordinary" chapter for that particular condition in ICD-9. In ICD-10, however, the reverse is true, and the death is coded to Chapter XV. The sample included the case of a woman who died during childbirth due to rupture of a congenital cerebral aneurysm. The death was coded to 430 (subarachnoid haemorrhage) in ICD-9. Since deaths in the ICD-9 block 430-438 (cerebrovascular disease) are quite frequent, such cases have a low sampling probability (0.20), and each case counts for five when the estimates are calculated. Consequently, the transfer of this single case corresponds to five more certificates in group 50, which doubled the estimate for pregnancy-related deaths according to ICD-10.

· 53 Congenital malformation of the nervous system

Increase, due to changes in the application of Rule 3, serious malformations of the nervous system are more often selected as the underlying cause of death.

· 56 Sudden infant death syndrome.

Increase, Sudden infant death syndrome was considered an "ill-defined" cause of death in ICD-9, and was never selected as the underlying cause of death if anything outside Chapter XVI (Symptoms) had been reported on the certificate. Due to a change in Modification Rule A, sudden infant death syndrome is not considered ill-defined in ICD-10 and will be accepted as the underlying cause of death.

· 61 Accidental falls

Sharp decrease. If the cause of death is a fracture, but the cause of the fracture is not mentioned on the certificate (for example "fell," "slipped"), the death is classified as an "unspecified accident" (X59) in ICD-10. In ICD-9, it was coded to the "accidental fall" block (E880-E888).

· 62 Accidental poisoning
65 Poisoning, undetermined intent

Decrease, Poisoning with alcohol (both accidental and undetermined) is now coded to Ch V (Mental, behavioral disorders) if alcoholism is also mentioned on the certificate. Deaths with alcohol poisoning, alcohol dependence and chronic liver disease are often classified to Ch XI (Diseases of the digestive system).

· Alcohol index

The Swedish alcohol index now includes all deaths with poisoning from alcohol, irrespective of the intent. This is to bring the calculation of alcohol index in line with the drug index.

· Drug index

We decided to exclude ICD-10 category T40.4 (Other synthetic narcotics). Dextropropoxifen, which is quite common in suicidal drug poisonings, goes to this category and would affect an increase of the drug index with almost 150 percent, if T40.4 had been included.

Additional detail: Results by the ABC list

In spite of the greater number of groups, the ABC list yielded the same overall agreement between ICD-9 and ICD-10 as the EU65 list: an estimated number of 87,878 out of 93,817 cases (93.6 percent) would have been coded to the same ABC group in both revisions of the ICD. Some of the ABC groups show greater differences, however. Below are comments on larger ABC groups (estimates of more than 30 cases in either revision) for which the two classifications show a discrepancy of at least 15 percent, and which was not detected in the analysis by the European list.

In the ABC list, the groups are designated by three-letter abbreviations. To facilitate orientation within the list, sequence numbers have been added in brackets.

· [5] RET, Respiratory tuberculosis

Increase, mainly due to differences in the application of Rule 3 (current respiratory conditions are more often seen as a consequence of previous respiratory tuberculosis).

· [15] ZBX, Untabulated zoonotic bacterial and other bacterial diseases

Increase, legionnaires' disease has been transferred from 482.8 (Other bacterial pneumonia) in ICD-9 to A48.1 (Legionnaires' disease) in ICD-10.

· [27] HEB, Acute hepatitis B, acute delta-(super)infection of hepatitis B carrier, and chronic viral hepatitis

Large increase (888 percent), mainly due to how the ABC list handles the codes for hepatitis C. The ICD-9 codes 070.4 and 070.5 (Other specified viral hepatitis), which Statistics Sweden used for hepatitis C, are not included in the HEB group, while the codes B17.1 and B18.1 (Acute and chronic hepatitis C, respectively) are. A smaller contribution to the increase comes from a few cases of unspecified chronic hepatitis, which was coded to Ch IX (Diseases of the digestive system) in ICD-9, but to Ch I (Certain infectious and parasitic diseases) in ICD-10.

· [76] SIT, Carcinoma in situ, benign neoplasms of untabulated sites, and untabulated neoplasms of uncertain or unknown behaviour of specified or unspecified sites

Increase, conditions like myelodysplastic syndrome have been moved to Ch II from ICD-9 Ch IV, Diseases of the blood and blood-forming organs. There is a corresponding drop in ABC groups ANA [77] (Anaemias) and BLX [78] (Untabulated diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism).

· [93] CPA, Cerebral palsy and other paralytic syndromes

Increase, due to differences in the application of Rule 3 (see above European list No. 39, pneumonia).

· [104] PTV, Phlebitis, thrombophlebitis, portal vein thrombosis and other venous embolism and thrombosis

Increase, Unspecified thrombosis of deep vessel is coded to I80.2 (Phlebitis and thrombophlebitis of other deep vessel of lower extremities) in ICD-10, but to 453.9 (Other venous embolism and thrombosis, unspecified site) in ICD-9. Technically, the ICD-9 rubric is "unspecified." This means that if another, better specified thrombosis has been reported on the death certificate, Rule D (Specificity) will apply, 453.9 will be discarded and the better specified thrombosis selected instead. If the certificate is coded in ICD-10, on the other hand, Rule D will not apply, since I80.2 is not an "unspecified" rubric. In ICD-10, therefore, I80.2 will be retained as the underlying cause of death. This difference affects many cases of pulmonary embolism reported as due to deep vessel thrombosis.

· [105] CIX, Untabulated diseases of the circulatory system

Decrease, some conditions coded to this ABC group are regarded as "ill-defined" in ICD-10 and cannot be selected as the underlying cause if anything else is reported on the certificate. In ICD-9, they were accepted as underlying cause.

· [112] LUN, Lung diseases due to external agents

Decrease, the new instructions on Rule 3 and pneumonia are also applied to aspiration pneumonia, which is the dominating condition in this ABC group (see above, European list No. 39).

· [123] SCT, Systemic connective tissue disorders

Increase, mainly due to Wegener's granulomatosis and similar conditions, which were coded to Ch VII (Diseases of the circulatory system) in ICD-9 but transferred to Ch XIII (Diseases of the musculoskeletal system and connective tissue) in ICD-10.

· [127] RTI, Renal tubulo-interstitial disease

Decrease, new interpretation of Rule 3: uraemia reported as the originating cause in Part I is now seen as an obvious consequence of a malignant neoplasm in the genitourinary system mentioned in Part II.

· [135] RCD, Respiratory and cardiovascular disorders specific to the perinatal period

Increase, according to a Note in ICD-9, cerebral palsy was preferred to a wide range of perinatal conditions as the underlying cause of death. This Note was removed from ICD-10. Moreover, Rule 3 is now also applied to cases of cerebral palsy, which is seen as an obvious consequence of perinatal cerebral damage. The combined effect of these two changes is a decrease for cerebral palsy and a corresponding increase in certain perinatal conditions.

· [144-155] PED-TRA, Transport accidents

Most ABC groups in this range show considerable differences between ICD-9 and ICD-10. In general, this is an effect of the radical restructuring of the External cause chapter (the E series in ICD-9, Chapter XX in ICD-10), and the ensuing difficulty to find categories that match reasonably well in the two revisions. Even so, the ABC list might need a revision in this area. With the current specifications, the remaining group for transport accidents, [155] TRA, becomes uncomfortably large and encompasses almost two thirds of all transport accidents in our study. In comparison, the corresponding figure according to the European list is 17 percent (all transport accidents minus the motor vehicle accidents).

· [168] AEX, Accidental exposure to untabulated [external] causes

Increase, in ICD-9, Statistics Sweden accepted sequences in which an injury was reported as due to a disease, for example a skull fracture reported as due to a fall caused by an acute myocardial infarction. In ICD-10, a new instruction blocks most such sequences, and injuries are now not accepted as due to a disease.

· [207] UUU, Other specified and unspecified event, undetermined intent

Increase, in most cases due to difficulties with the ICD-10 version of Mikado, Statistics Sweden's software for multiple cause coding. Expressions used in the ICD-9 version to distinguish between undetermined intent and suicide have sometimes been ignored when coding the certificates in ICD-10, with the effect that some cases that were classified as suicides in ICD-9 have been coded as "undetermined" in ICD-10.

· [211] NOS, Complications of medical and surgical care

Increase, in ICD-9, Statistics Sweden used the ICD categories for deaths due to complications of surgical care only if the death certificate clearly stated that a mistake or an accident had occurred. In ICD-10, the corresponding categories are also used for deaths due to "ordinary" complications of surgery, when the cause of the surgery or procedure has not been reported on the death certificate.

· [213] SEQ, Sequelae of external causes of mortality

Increase, see European list No. 39 (pneumonia).

Interchange of Input Files for Automatic Coding Systems SCB/DOSP/SCBX (São Paulo, Brazil) and MIKADO (Sweden): Comparative Study on Underlying Causes of Death

Dr. Augusto Hasiak Santo, Faculdade de Saude Publica, Universidade de São Paulo, Brasil

The participants of this research are Lars Age Johansson, from Statistics Sweden, and from Brazil the following: Celso Escobar Pinheiro from the Informatics Department of the Ministry of Health, Margarete Silva Jordani and Antonio Benedito Marangone Camargo from the Data Analysis System Foundation of the State of São Paulo, and myself.

The idea of this research is to interchange input mortality data files that were designed for different automatic processing systems. The input file designed for a given automatic system would be processed by another system and, from each processing, the resultant underlying causes of death would be compared. About one month ago, I sent a message to Lars Age Johansson with the proposal for this study. Such as the other participants, he was very enthusiastic and agreed with the project for this joint research. We would send to Lars Age a file with records of death certificates from the State of São Paulo, Brazil, prepared to be the input file for the Underlying Cause of Death Selection System (SCB, in Portuguese). The Swedish automatic processing systems MIKADO and ACME would process this file. On the other hand, we would receive the Swedish input file that would be processed by the SCB. The resultant underlying causes of death from each of these input files would be compared with the causes derived from the automatic processing systems for which they were originally designed.

I would like to point out that São Paulo was the first region outside the United States to use the ACME system. Being aware of this fact, other Brazilian States began also to ask for copies of the system. Nevertheless, hardware and computer analysts were not available for all states. The idea was raised for the development of an automatic system designed for microcomputers. Celso Escobar Pinheiro and I developed the SCB microcomputer system in 1993. The Tenth Revision of the International Classification of Diseases (ICD-10) began to be used in Brazil in 1996 for coding causes of death. An adaptation of the SCB system was developed for use with ICD-10. Another adaptation for batch processing called SCB/DOSP/SCBX was developed for the State of São Paulo, where about 230,000 deaths occur during the year. In the same year of 1996, during the first ICE meeting, I proposed that this kind of study with interchange of input files be undertaken. This exercise was done the first time with our own ACME input files with about 130,000 death records. A paper was published about this study: Santo AH, Pinheiro CE, Rodrigues EM. *Comparative evaluation of underlying causes of death processed by the Automated Classification of Medical Entities (ACME) and the Underlying Cause of Death Selection (SCB) Systems*. Revista de Saude Publica, 32 (1):1-6, 1998. (Copy available in the site http://www.fsp.usp.br/~rsp/).

We received an input file from Sweden that included 22,704 records of death certificates. Both MIKADO and ACME systems had processed this file. The resultant underlying causes of death were included in their specific fields. The SCB/DOSP/SCBX system processed this file after certain code adaptations. A new field for the consequent underlying cause was added to each record. The following two tables present the preliminary results of this study. Underlying causes of death were assorted according to the chapters of the ICD-10. The diagonal cells of these tables contain corresponding underlying causes of death that were selected by two different

automatic systems. These cells carry agreements of causes. The comparison of underlying causes of death processed by MIKADO and SCB/DOSP/SCBX resulted in an agreement of 97.0 percent (22,019/22,704) (table 1). The cross-tabulation of causes of death processed by ACME (Sweden) and SCB/DOSP/SCBX systems yielded the agreement of 95.8 percent (21,732/22,689) (table 2).

Table 1. Underlying causes of death selected by MIKADO (Sweden) and SCB/DOSP/SCBX (Brazil) automatic processing systems according to chapters of ICD-10

MIKADO								SCB/DOSP/SCBX									
	1	2	3	4	5	6	9	10	11	12	13	14	16	17	18	20	Total
1	199	5	-	-	-	-	4	3	1	-	-	-	-	-	-	-	212
2	2	5,346	3	2	2	1	20	10	5	1	1	-	-	-	-	2	5,395
3	-	-	43	-	-	-	1	2	-	-	-	-	-	-	-	-	46
4	-	-	-	470	1	-	13	5	-	-	-	-	-	-	-	-	489
5	1	-	-	2	657	2	25	4	-	1	1	-	-	-	-	-	693
6	-	-	-	-	11	409	11	11	-	-	-	-	-	-	-	1	443
9	3	8	-	4	22	11	11,182	16	8	-	-	2	-	-	39	12	11,307
10	14	19	-	2	168	57	38	1,869	1	-	1	1	-	1	-	12	2,183
11	2	5	-	-	3	-	3	3	593	-	-	-	-	-	-	-	609
12	-	1	1	2	1	-	5	2	-	31	1	-	-	-	-	-	44
13	2	-	1	-	2	-	5	6	-	-	75	1	-	-	-	3	95
14	1	2	-	9	-	1	4	-	1	-	-	327	-	-	-	-	345
16	-	-	-	-	-	1	1	1	-	-	-	-	21	-	-	-	24
17	-	-	1	-	-	-	2	-	-	-	-	-	-	58	-	-	61
18	-	-	-	-	-	-	-	-	-	-	-	-	-	-	400	-	400
20	-	-	-	2	2	-	10	2	-	-	1	2	-	-	-	339	358
Total	224	5,386	49	493	869	482	11,324	1,934	609	33	80	333	21	59	439	369	22,704

Table 2. Underlying causes of death selected by ACME (Sweden) and SCB/DOSP/SCBX (Brazil) automatic processing systems according to chapters of ICD-10

ACME								SCB/DOSP/SCBX									
	1	2	3	4	5	6	9	10	11	12	13	14	16	17	18	20	Total
1	210	10	-	-	1	-	-	11	2	-	-	3	-	-	-	-	237
2	-	5,336	3	1	-	-	3	7	4	1	1	3	-	-	-	1	5,360
3	-	2	42	-	-	-	-	8	-	-	-	-	-	-	-	-	52
4	-	3	-	468	8	1	25	47	-	-	-	1	-	-	-	1	554
5	-	1	-	2	773	-	10	42	8	1	-	-	-	-	-	3	840
6	-	-	-	-	29	450	4	20	-	1	-	1	-	-	-	6	511
9	1	21	3	10	49	29	11,261	294	6	4	2	4	-	2	77	17	11,780
10	10	2	1	-	2	-	3	1,431	-	-	-	1	-	-	-	9	1,459
11	2	6	-	1	2	-	2	13	589	-	-	-	-	-	-	1	616
12	-	1	-	-	-	-	3	6	-	26	1	-	-	-	-	-	37
13	-	-	-	-	3	1	7	17	-	-	74	-	-	-	-	2	104
14	1	1	-	9	2	-	5	32	-	-	-	316	-	-	-	1	367
16	-	-	-	-	-	1	-	1	-	-	-	1	21	1	-	-	25
17	-	-	-	-	-	-	-	1	-	-	-	-	-	56	-	-	57
18	-	-	-	-	-	-	-	-	-	-	-	-	-	-	356	1	357
19	-	-	-	-	-	-	-	1	-	-	-	-	-	-	-	3	4
20	-	1	-	1	-	-	-	-	-	-	1	3	-	-	-	323	329
Total	224	5,384	49	492	869	482	11,323	1,931	609	33	79	333	21	59	433	368	22,689

Off-diagonal elements in both tables include underlying causes of death that were assigned to different chapters by automatic systems; these are the disagreements. We are not yet able to say which are right and which are wrong. Only after the study of each singular record and consideration of national mortality guidelines will this decision be possible. Underlying causes of death will be identified at the four-character level, when agreement rates are expected to be lower than the ones observed at chapter level.

The ensuing steps of this research will include the evaluation of the above results and the transference of a Brazilian mortality file to be processed by Sweden's automatic systems.

Comparability Issues and Bridge Coding Methods

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We do not have any results, nor have we even started our bridge coding study yet. We are still trying to design it, and we are very grateful for the inputs and the insight that we are getting from other people in how to deal with some of these issues. We have already talked about why it is important to do bridge coding and the point of getting comparability ratios which compare coding in ICD-9 with ICD-10 in order to look at the time trends. We also have shown that the big differences that one sees are related to changes in the selection rules rather than to other, relatively minor problems. With ICD-10 we have some new codes that did not exist before, and there are going to be some shifts around for inclusions and exclusions. But the big difference is the selection rules and the most prominent of these is Rule 3.

All our comparability studies make independent dual coding of death certificates using both revisions and compare the results. I looked at what people had done in the past and I found the U.S. study for ICD-8 to ICD-9 very useful, even though it was published at a broad tabulation level—which is actually the level at which most people want to look at time trends, anyway. Those tabulation categories are actually more useful than lists of three-digit codes, which are not very useful, or four-digit codes, which are extremely detailed. What is useful about the U.S. study is that it measured the net effect of the change—that is, the number of deaths in the 9th revision divided by the number of deaths in the 8th revision. The U.S. study stratified by age and sex, and included confidence intervals around the comparability ratios. The study provided comparability ratios that one could use.

The study that was done in England and Wales, on the other hand, I found much less useful. England and Wales published numerous tables that showed the detailed movements between one condition and another, so that one had to accumulate them all to get to the total comparability ratio. The effect told one exactly how many deaths moved from other ischemic heart disease into acute myocardial infarction, etc. But the net effect on how to apply this as a ratio was obscure. They did not apply the ratios or do any correcting. The argument was that it was better to wait for the true trends to emerge with time. The changes from the 8th to the 9th revision were not big because there were no real or dramatic changes in the coding rules between ICD-8 and ICD-9. What we saw were little movements between categories due to changes in the inclusion terms and index that accounted for changes in comparability.

We already talked about how the Office of National Statistics (ONS)—then the Office of Population Censuses and Surveys (OPCS)—changed Rule 3 dramatically in 1984 to get rid of all these bronchopneumonia deaths. At that time, we did the proper dual-coding study with comparability ratios.

I shall show the differences between the kind of comparability ratios that result from changing from ICD-8 to ICD-9, with small changes in inclusions and exclusions, compared with the kind of changes that result from changing a rule. Most conditions changed little in the England and Wales and U.S. 8 / 9 comparability studies—about 1 or 2 percent. An exception to this was ischemic heart disease (IHD), which in the U.S. actually had quite a large ratio, and this was very different from the England and Wales figure. We all thought we were doing exactly the same thing for IHD, but apparently were not. Perhaps, comparability is affected even if coding is the same. It is not very easy to explain. The effect of changing Rule 3 in England and

Wales was great. Diabetes went up 20 percent just on that comparability ratio, while pneumonia mortality halved. Pneumonia is a problem that we are all struggling with: Sweden wants pneumonia to go down by 30 percent or 20 percent, while the U.S. will have it decrease by two-thirds under different interpretations of Rule 3 between ICD-9 and ICD-10.

For senile dementia, which is an organic psychosis code to which a large proportion of our deaths were going, comparability showed an increase of two and a half times; from about 4,000 deaths to 9,500. Senile dementia is the biggest cause of death in the mental disorders chapter, so the increase really upset the psychiatrists, who did not like to see that happening.

In the move to ICD-10, we are still struggling a bit. Sweden and the U.S. do not quite agree on what Rule 3 is going to mean, or how to apply it. The wording of the rule is not that different if the condition selected by the General Principle, Rule 1, or Rule 2 is obviously a direct consequence of another reported condition in Part I or Part II. But in ICD-10 a note—which was not there in ICD-9—says that pneumonia and bronchopneumonia may be accepted as complications of <u>any</u> disease. Does that mean accepted as a sequence written down by the certifier as a complication? Or does that mean a broader interpretation? Then ICD-10 goes on to say, in particular, that bronchopneumonia should be assumed to be an obvious consequence of wasting, paralyzing or communicable diseases, or any serious injury. So we have not really quite decided. Are we going to apply this ICD-10 rule to all pneumonias, or is it just to bronchopneumonia? Are we going to assume instead of the pneumonia the death was due to anything else written on the certificate or only to paralyzing diseases, immunosuppressing, wasting, other respiratory diseases?

The WHO Mortality Reference Group is still discussing this, and we have seen what happens with the interpretation currently in ACME. If WHO changes Rule 3, I do not know if we have to redo our bridge coding. If they change it dramatically, for example to Lars Age's interpretation, your results could be rather different, and we might have to repeat the whole exercise.

In bridge coding, one should use the same method of coding used to produce routine data. That is a problem with the Swedish study, because the routine data is going to be automated. The bridge coding is manual.

I did look a little bit more at what happened with the pneumonia deaths in England and Wales when we changed Rule 3 in 1984 in terms of the number of deaths using the ordinary ICD-9 rule, using our special rule, and the rate comparability ratio. What I have done is divide the analysis by the type of pneumonia and by two very broad age groups: under 75 years and over 75. There are two things to note: one is that when we changed the rule, we did not include all pneumonias; we included bronchopneumonia and pneumonia unspecified. We said we would ignore in favor of any other major condition, and we did not restrict what else we would select towards. We restricted what kind of pneumonia to which Rule 3 applied, but we said: any other condition which was not either trivial or ill-defined could be accepted as the underlying cause. One did not have to believe the decedent had a real sickness; one could pick schizophrenia as causing pneumonia, which is "anything." There is essentially no effect on viral pneumonia pneumococcal, lobine pneumonia, or other bacterial pneumonia —practically no effect—because they were not included. However, there is a very big effect on bronchopneumonia.

It is interesting that for bronchopneumonia, the comparability ratio changes with age; it is more extreme in the younger ages. That suggests that for the younger population the certificate had other conditions that could be selected. In fact, almost 70 percent of the records for persons under 75 years had something else that could be selected; whereas, in those over 75 years, only

half had something else that could be selected. Quite a lot of certificates in the very elderly, over 85 or 90 years, just had bronchopneumonia and old age. Since old age is an ill-defined condition, the underlying cause remains bronchopneumonia. The effect is more extreme in those under 75 years than in those over 75, especially for bronchopneumonia.

A larger proportion of deaths in the younger ages are acute pneumonia deaths. These represent about 1,000 deaths out of 8,000, as opposed to 1.5 thousand out of 39,000. When one looks at all pneumonias, the comparability ratio does not differ greatly between those under 75 and those over 75, but there is a difference. So if pneumonia is not the cause of death, what is? In our data, it was mostly chronic debilitating diseases. More generally, however, it is going to depend on the epidemiology of diseases in the country, the practice of certifiers, and the interpretation of Rule 3. The deaths that we lost from pneumonia went to organic psychosis, senile dementia, or diabetes, but the changes were relatively small compared with cerebral vascular disease or stroke, which at 1.08 went up 8 percent. Because stroke is a numerically large cause of death, the increase—numerically slightly bigger than for senile dementia—will be about 10,000 or 13,000 extra deaths.

Another issue that I am trying to think through is the following: Do you adjust old data or new? Ideally, it is nicer to say what the old data would have shown, rather than adjusting new data and undermining peoples' confidence in what one has just produced. However, I am not sure for how long the comparability ratios are valid. People want to look at trends over 5, 10, or 20 years. We do not really know if one can use a ratio calculated on deaths from 1996 or 1997 and apply it to 1984 data.

We should all try to share our experience in bridge coding, but the ratios may not be transferable between countries, because they depend on certificate practice. Rules come into play where the certificate has not been filled in very well; and the way in which doctors complete cause of death varies from country to country.

We used comparability ratios from 1984 to look at the changes during the period. We only prepared comparability ratios once in 1984. The age-standardized death rate per 100,000 population for men did the opposite of what Tim Devis [see Session 5 on Methodological Issues] showed you earlier, with the diabetes going up. Ignoring bronchopneumonia, the rate fell from 1,000 to 400—a large decrease.

The adjustment factor actually looks as if it fits fairly well. For 1993, when we changed the automated system, and, give or take that more pneumonia deaths occur in a cold winter so it moves around a bit, we actually achieved a reasonably good fit across the whole 8-year period. However, for diabetes deaths the age-adjusted death rate using the 1984 comparability ratio does not show a good fit. By 1993, the rate is 15 percent down from1994, so I do not think it is adjusting properly.

One of the reasons the adjustment does not work for diabetes is that the person in charge of the WHO center in the U.K. played around with the way these deaths were coded. He expanded the application of Rule 3 to diabetes, specifically, in 1985 and 1986. As a consequence, large increases occur in 1984, 1985, and 1986, then level off. It is slightly comforting that before the change in Rule 3, during the change period, and after the change to ordinary coding, the trend looks as if it is going in the same direction. While we may not have any idea how many people die of diabetes, the number seems to be decreasing.

For senile dementia, the situation is worse. The adjustment factors do not work; they are 33 percent out by the time we get to that ratio period. We cannot use an adjustment factor from 1984 or 1992 data. It is just not telling me what we need to know. Worse than that, for the

period before the Rule 3 change and the period after it, there appears to be a slight upward trend. For the period adjoining Rule 3, the trend is coming down. Why is it that just by changing the rule this does not just change the absolute number in that year, but the trend? All kinds of complicated things were going on concurrently during this period. Among these was a drift in terminology away from senile dementia to writing Alzheimer's disease. There will be a change in the ICD coding: in ICD-9, selection depends on exactly the order in which terms are written, but the underlying cause ends up coded as one thing or the other if they are both on the certificate. So there was a drift in terminology, and probably a bit of change in the coding. But I do not understand why that should change the direction of the trend.

I am going to leave you with a couple of issues that I think are important for us. In doing bridge coding, comparability ratios are only really useful if one is using the routine kind of coding used for producing the routine statistics. The point of the bridge coding is to help people interpret trends in routine statistics. Bridge coding is not a fancy research exercise. Thus, if we are doing automated coding, we have to use the same decision tables that we are using when we publish the routine data. If we change the decision tables, that means we need to do bridge coding again. We could do bridge coding every year, but it could get a little tedious.

I am not going into other problems in detail. I do think that the sampling method is something that needs more discussion. I am interested that the U.S. and Sweden used cause of death in sampling. I am a bit worried about sampling on cause and ending up with a biased sample: If I sample on the cause in ICD-9, do I really know what all deaths would have ended up in ICD-10 or not? I presume that one can adjust for the sampling fractions used, provided that all causes of death were actually sampled.

I am also a bit worried about not coding for an entire year where we originally said we would. It is 580,000 records or so, most of which have been processed through automated coding, so we only have to manually code the rejects. We also have the advantage that we have the literal texts stored, so we do not have to type it all in again, which saves us a bit of effort.

I had planned to sample the deaths before coding them. I would prefer to have the same sampling fraction for records that code automatically and those that do not, because I think that causes that are rejected are particular. So I am a little bit worried about sampling the rejects and not applying the same sort of sampling frame to the ones that code automatically. But again, it may be that one can get round that. Anyway, I would open the floor for discussion.

Discussion on Session 5: Methodological Issues

DR. KARDAUN: I have a question about the definition of the comparability ratio. I think this creates lots of problems. To clarify what Lars Age said this morning, I am not sure I like this definition, because I think it conceals problems rather than corrects them. In fact, if the comparability ratio is 1.0, then the net effect is null. But I am not sure that you apply the same type of death, and I do not know how to interpret a comparability ratio—we do not know how to interpret a smaller and larger amount. So I think that even though it is more work, we should work with cross-classification rates, which of course, are condensed.

DR. ANDERSON: Yes, I think you are right. Using the net effect does obscure some of what is going on, and so I think it is important not only to show what the net effect is. I think the net effect can be useful to see what is going on in an overall sense, but I think you are right; some sort of matrix does need to be included as well. We plan to do that also.

DR. ROONEY: I am not saying we do not need the detailed information as well. I certainly think that does help us to interpret what is going on. Indeed, if I had more multiple-cause data and put that together with what had transferred in and out of where, I might be able to sort out what was going on with my senile dementia deaths going down, then going up. So yes, I think if it is different deaths that you are counting in one revision than the other, then yes, you may be obscuring the fact that you have actually got different trends going on. But I think the first thing you need is a measure of the net effect to know if of a decline in ischemic heart disease death of 4 or 5 percent that year, 3 percent is due to the classification or is it a real decrease.

DR. ANDERSON: Another interesting thing is malignant neoplasms. If you remember, this cause had a comparability ratio of 1.0, but there is some shifting around within the malignant neoplasms that is not shown in that figure. So you have some deaths going out and some going in, but the net effect is 1.0. So some sort of matrix is necessary to interpret exactly what is going on, but the ratio itself is also very useful.

DR. PARRISH: It seems to me that in these studies, differences could occur as a result of one of two separate things. One is actual changes between two different ICDs in the way a given condition is actually coded within the ICD. Then the other reason could be the algorithm applied to determine the underlying cause. So, my question is: I can imagine that for different conditions, those different causes might apply, or a combination of both. Are you able in some of the comparability studies you are doing to separate those out?

DR. ROONEY: Yes, one difference is that the condition is actually indexed to a different place in the classification. There are new codes for new conditions, like the big block for AIDS now, and there are also moves where things like autoimmune disease in ICD-9 used to go to the immunity chapter and connective tissue disease to the rheumatology chapter. Those both now go to the same code, because we think they are the same thing. So that is a change in the classification.

But if you had a death certificate that had pneumonia in Part I and either autoimmune disease or connective tissue disorder in Part II, with one application of Rule 3, one algorithm, you will end up with the autoimmune disease and with another, you will not. So yes, one is moving individual conditions. For mortality statistics, the one that makes more difference, huge differences, 40-50 percent, tends to be the algorithms, the rules, rather than the individual codes.

PARTICIPANT: Thank you. My question actually follows on his comments. What I see is, there are two factors that affect the comparability issues. One of them would be the intrinsic factor—with respect to the changing ICD—and the other will be with respect to the coding practice. So there is need to control for one factor to see the effect of the other factor. In that light, I see some danger in the methodology that Dr. Anderson is proposing. If you use automatic coding and then from the rejects you do manual coding, then you have two effects that you are not able to separate. The way I see it is, I think you mentioned that you have to use one consistent coding mechanism to see the effects. If you use two different coding systems, with one manual and another automatic, then the effect will be very broad.

The other comment is: What will be the purpose of these comparative studies across different countries? We have seen that the different coding practices will affect the coding issues, the comparability issues. So really, I do not see the utility of those ratios across countries. Thank you.

DR. ANDERSON: I understand exactly what you are saying about the two different coding systems. However, that is the way we normally code our data in a given year. A certain proportion is coded automatically, and then a certain proportion is coded manually. Those that cannot be processed are coded manually.

So yes, we do have two different systems, but that is our standard practice. So I do not think that that is going to cause us a big problem in terms of getting a representative sample for the United States. The idea is to get a sample of those that are coded using the manual system, and that is what we are trying to do since we do that routinely.

DR. ROONEY: I just want to say that in this room we are all very interested in the processes and how these things are arrived at, and we want to know the detail of what changed and exactly what the reason for each shift was. But the primary function of doing these studies and providing these comparability ratios is for the general public health community using time trend data to be able to tell how much of the change in a year is due to a change in classification. They do not particularly care what part of the change in classification. What they do want to know is: How does the 1999 data compare to 1998 and the 10 years previously? Should I adjust it by 10 percent or by 12 percent or what? So that is what the net effect is for. It is not the perfect answer. It is: What is really happening to ischemic heart disease at a national level and what are the trends?

So what is important is that statisticians are trying to interpret the routine data, so it is important to have the ICD-9 data coded exactly as it was routinely, and the ICD-10 coded as it was routinely. The routine involves shoving it all into the automated system, and then the 20 to 30 percent that the automated system cannot cope with, you have to have some kind of manual intervention. That is the routine system.

I think you are right, but you want the same rules getting applied automatically and manually. We certainly try to achieve that. I am not sure that we always do, but we want to. I think my point is that the kinds of records that are rejected are different from the kind of records that do not. The sampling fraction for that will have to be dealt with carefully.

DR. ANDERSON: Actually, I looked at the distribution of the rejected records, and they are not that different. There are records that are more likely to be rejected; for example, External causes. But the overall distribution is not that different. It is different, but not substantially. So we did not worry too much about designing the sample that way. The only things we would lose are things like surgeries, since almost all surgeries become rejected.

DR. ROONEY: As far as the inter-country generalizability goes, yes, you are right. There are definitely two parts to that. If the two countries are not applying the classification in the same way, then the comparability ratios cannot be interchanged.

Now, in theory, if we are all using this automated system, we are applying them in the same way. I think, however, that there is still a factor that makes them not comparable between countries, which is, that the doctors fill in the certificates differently in different countries. The effect of the rules depends on how the certificate was filled in, the exact words used, how many words were used, what lines they were put on, and that varies a lot.

So I think in general, you cannot take comparability ratios from one country and apply them to another, even if you use the same coding software.

PARTICIPANT: I just had one more comment about the bar coding that is used in Australia plus the bridge coding. I think it would be interesting to see a study that tries to compare the results with respect to addressing the trends. I see you have difficulty in applying the comparability ratios to previous series, so maybe if bar coding is done and then we see that trend as compared with the trend with the comparability ratios, I think it would be an insightful study.

DR. ROONEY: Thank you very much. One more comment.

DR. SANTO: The rejected records and comparability studies should have a different interpretation. We have discussed this, and we have retained it in the first part of the study as being treated differently. Those records that are directly processed will be differentiated from those that were subjected to manual interpretation.

SESSION 6

International Comparisons of Cause of Death

International Comparisons of Cause of Death

Graham Jackson (moderator), Head of Vital Events and NHS Branch, General Register Office for Scotland

Improvements in international comparability are seen as one of the key benefits of moving to automated coding which, of course, has been the theme of this meeting all week. However, in this session, we have two presentations that will serve to remind us that, though automatic coding will help, there are several other factors that have to be considered further.

In the first presentation, we shall hear of work assessing this problem in Europe. Unfortunately, Eric Jougla is unable to be with us as planned, so Gérard Pavillon will stand in. We thank Gérard Pavillon for stepping in on such short notice to make this presentation.

The second presentation will be given by Sam Notzon from NCHS' Office of International Statistics. Dr. Notzon seems to have traveled all over the world and is, therefore, ideally suited for this particular session. Dr. Notzon will describe current mortality in the Russian Federation, a country he has visited. After all our concentration on process it will be very interesting to see some real substance.

So I will just move on immediately now, and ask Gérard Pavillon to describe the work in Europe.

Comparability and Reliability of Cause-of-Death Statistics in Europe

Gérard Pavillon, Head, WHO Collaborating Center for the International Classification of Diseases in the French Language (presenter) and Eric Jougla, Service D'information Sur Les Causes Medicales De Deces, SC8-INSERM, France

Eric Jougla, head of our service, apologizes. I shall make this presentation on European projects on causes of death instead of him, so please be indulgent.

First, it seems useful to locate these projects inside the European Commission work. Since 1997, the European Commission has been deeply involved in the improvement of quality and comparability of public health data. Eurostat (the European Commission's statistical office) has established three task forces on public health statistics: one on health care data with the specific help of Germany, one on health survey data with the help of the U.K., and one on cause-of-death data with the help of France.

In addition to the work undertaken within the Eurostat task force on causes of death, the European Commission Directorate in charge of public health (DGV) supports a project submitted by our agency (SC8 INSERM) to further the study of quality and comparability of European cause-of-death statistics.

Three fields of investigation: production, coding, and certification of mortality statistics

The problems of quality and comparability of cause-of-death statistics are linked to three stages: the certification, the coding, and the production of mortality statistics. On the stage of certification, possible problems involve the availability of the diagnosis and those problems resulting from the comparability of death certificates forms and certification procedures. At the coding stage—and that has been the main issue of this ICE meeting—problems of quality and comparability are linked to the choice of ICD codes and to the selection of the underlying cause. Finally, at the stage of production of mortality statistics, problems of bias may result from different disease groupings and choice of indicators.

The Eurostat task force on causes of death is working on these three fields. The DGV specific project on "quality and comparability improvement in European causes of death statistics" is mainly oriented on the first and third stages.

I will first present projects pertaining to the production of mortality statistics, because that is the stage where European works began concentrating on.

The production of mortality statistics

The main objective of the task force is to standardize the cause-of-death statistics production in Europe. First, the task force has established a short list of 65 causes of death, more specifically adapted to the pathological context of Europe. This short list was definitively agreed upon in August 1998. One of its main characteristics is that the grouping is compatible with ICD-10, ICD-9, and ICD-8, which is necessary to study trends. At the same time, a set of indicators has been defined that is linked to this short list. Additional, more sophisticated indicators are being discussed at the moment.

Eurostat statistics are now published using this short list for years 1994 and 1995 with first basic indicators as numbers, crude death rates, and standardized death rates. These data are presented for all ages and for premature mortality both at national and regional levels for each

country. The regional level permits some interesting analysis. For example, France is divided in 22 regions where indicators are largely different from the North to the South or from the East to the West.

These statistics are available both on paper and on the Web. Eurostat's site (Newcronos) can be accessed with a password obtained from Eurostat.

To go further on the field of the quality of the information, the specific project supported by the DGV has the objective of publishing within 2 years a manual on the quality and comparability of these European statistics. This manual will begin with 14 causes of death (out of the 65) selected by the international expert group as primary public health indicators. The manual will present the Eurostat statistics with maps and comments, summarize the information collected on biases that may affect the international comparisons, propose some corrections in the interpretation of the data, and finally outline recommendations to try to improve the comparability biases. Two kinds of materials are used to produce the manual: a literature review and a questionnaire.

The **literature review** has collected about 700 papers published in the international literature since 1985 on problems of quality and comparability of cause of death statistics. These papers were selected from querying two databases (Embase and Medline) with specific keywords. The papers have been classified according to the 65 causes of death of the short list. Analysis has begun with the 14 selected causes. The first results show that the causes of death most often studied are suicide, accidents, alcohol, and ischaemic heart diseases. Specific international comparability studies are rare; most of the time, analyses concern a single country or a comparison between two countries. A large part of the papers are quite general, discussing the global quality of all causes of death.

The **questionnaire** was sent to experts of each European country (18 countries) at the beginning of November 1999. With maps and tables for each one of the 14 selected causes of death, this questionnaire asks specific questions to each expert about the quality of the statistics, the reasons of biases, the existence of studies on the subject, etcetera.

The coding

A first part of the (Eurostat task force) work on the field of cause-of-death coding has already been completed. You will find a presentation of this study (Final report on Automated coding systems in Europe) in the Session 1 section of this document.

Work is now concentrated on maintaining the knowledge base updated. For example, information on the type of ICD used, planning of ICD-10, bridge coding ICD-9 and ICD-10, codification of multiple codes, and status of implementation of automatic coding system are collected for each country regularly. The analysis of the literature review will provide additional materials (multiple coding methodology between European countries).

The certification

The issue of certification is studied both within the task force and the DGV specific project. Certification is the primary stage in the process of cause-of-death statistics and it is surely the most difficult one to study and to harmonize.

The differences in practices between countries are important. A former questionnaire, analyzed within the task force, had collected basic information on specific certification practices in Europe. It outlined how varied are the death certificate forms (number of lines, additional information collected...) and the certification procedures (ways to query, training practices...).

The new questionnaire included in the DGV project has been sent to each Member State. The items examined in this questionnaire are: death certificate form, infant death certificate, certifiers' training, query practices, confidentiality issues, and ill-defined conditions. The aim is to improve the knowledge on the quality and comparability of certification procedures and to make recommendations for improvement. An additional objective is to collect opinions on the feasibility of implementing European recommendations in each country. As on the other stages of the process, the literature review will produce new material on certification.

Future goals

Our objective for 2002 pertaining certification is to finalize recommendations on the death certificate forms, certification procedures and methods of queries, and on certifier training. Regarding coding, we want to do an evaluation of the experiences with an automated coding system. On the subject of production of statistics, the aim is to disseminate additional indicators and to produce the manual on comparability and reliability of published causes of death (14 selected causes of death).

Addendum to Gérard Pavillon's Presentation: Comparability and Reliability of Cause-of-Death Statistics in Europe

Main features and progress of the project "Comparability and quality improvement in European cause-of-death statistics": agreement of the Commission of the European Communities

Objectives

The project has two main objectives:

* To do research on cause-of-death certification practices among Member States that may lead to concrete recommendations.

* To produce a manual on quality and comparability of cause-of-death statistics in the European Union (based on the Eurostat short list), with the aim to disseminate information to the users and to define recommendations aimed to reduce comparability biases.

Organization

The organization of the project is based on:

* A coordinating team: SC8 INSERM (Cause-of-death statistics, French Office).

* A correspondent network: 15 EU countries and 3 EFTA countries with the participation of representatives from DGV, Eurostat, WHO Europe, and WHO Geneva.

* Two levels of work: a Steering Group (with a limited number of countries working closely with the coordination team) and a Plenary Group with a representative from each Member State.

* Five meetings within 2 years: three meetings of the Steering Group (two in 1999 and one in 2000); two meetings of the Plenary Group (one in 1999 and one in 2000).

Research methods

The investigation is based on two main methods:

* A questionnaire sent to each Member State, including two parts (first part on certification practices and second part on precise analysis of specific causes of death).

* An international literature review of published papers on quality and comparability on causes of death statistics (1985-1997).

Work progress

The organization

* The research team is implemented with Eric Jougla as Project leader, Florence Rossollin as responsible for the coordination, Gérard Pavillon (Head of WHO Collaborating Center on ICD in

French) as expert, and three people working part time on specific aspects (administrative organization, literature review, etc.)

* The correspondent network has been designated with two levels of work:
– the Plenary Group constituted of participants from each Member State (except Lichtenstein). In some countries (Portugal, Spain, and UK), there is more than one expert.

– the Steering Group is organized with eight Member States (Belgium, France, Germany, Norway, Portugal, Spain-Catalonia, Sweden, and the United Kingdom / England + Scotland).

The meetings
* The first meeting of the Steering Group took place in Stockholm on March 26, 1999. All members of the Group were present. The meeting was located in Statistics Sweden headquarters with important participation from Lars A Johansson. The main part of the agenda was a presentation/discussion of the objectives and methods of the project and of the two parts of the questionnaire. The aim was to prepare a final version to present at the Plenary meeting.

* The first meeting of the Plenary Group took place in Paris on June 25, 1999. This meeting was organized back-to-back with the Eurostat Task Force on Causes of Death meeting that was taking place on June 24th in the same location (INSERM headquarters). All Members of the network participated in the meeting except four persons who were excused. Twenty-six (26) people were present from 18 countries or institutions. The two parts of the questionnaire have been largely approved with some constructive corrections made after interesting discussions. The final version takes into account all the corrections of the Plenary Group.

* The second meeting of the Steering Group took place in Luxembourg on December 10, 1999, back-to-back after the meeting of the Eurostat Task Force on Causes of Death that took place on December 9th in the same location (European Commission building). Two main items have been discussed: the first results of the literature review with the example of suicide, events of undetermined intent and unknown and unspecified causes of death, and specific points raised by the Plenary Group about the first part of the questionnaire (Additional information on DC, death certification of the elderly, case history studies, infant death certificate (definitions), feedback to physicians (guidelines, training, queries), main obstacles to queries, confidentiality practices: How to measure consequences?

The questionnaire
The questionnaire (Parts 1 and 2) has been sent to all Member States at the end of October 1999.

Part 1. Investigation in certification practices

* This part of the questionnaire has four specific objectives:
– To acquire knowledge on certification practices among MS
– To measure the influence of differences in certification practices on quality and comparability of causes of death statistics
– To outline European recommendations

– To assess the feasibility of European recommendations

* This part of the questionnaire is presented with six domains: death certificate (medical part), infant death certificate, certifiers' training practices, querying practices, confidentiality, and coverage and ill-defined conditions (prepared by Lars Age Johansson, Statistics Sweden).

* For each domain, the methods consists in analysis of practices in each Member State, opinions on practices in the country, and opinions about European recommendations (contents and feasibility).

Part 2. Investigation in specific causes of death statistics

* The objective of this part of the questionnaire is to measure the influence of Member States' certification or coding practices on the reliability and the comparability of specific cause-of-death statistics in their country.

* The context of this part of the questionnaire is the Eurostat works on cause-of-death statistics (short list of 65 causes of death, first publication of data) and the international literature review.

* The methods consist of:
– Collecting expert opinions on the quality of specific causes of death statistics and on possible improvement (within countries and at European level)
– Presentation of maps for each cause of death
– Common questions relating to each map

* Fourteen pathologies have been selected by the Steering and the Plenary Groups as priorities to be investigated through this part of the questionnaire:

Malignant neoplasm of liver and the intrahepatic bile ducts
Malignant neoplasm of larynx and trachea/bronchus/lung
Malignant neoplasm of breast
Malignant neoplasm of prostate
Diabetes mellitus
Alcohol abuse
Chronic liver disease
Ischaemic heart diseases
Cerebrovascular diseases
Asthma
Unknown and unspecified causes
Transport accidents
Suicide and intentional self-harm
Events of undetermined intent

The international review of literature

The request to the Medline and Embase databases (based on keywords such as "death certificates," "certification," "codification," "accuracy," "reliability," "classification," etcetera) is

finalized. This first request outlines 820 papers with varying significance to the objectives of the work.
* Three hundred and twenty-four papers have been published between 1985 and 1990, 596 since 1991.
* Three hundred and twenty-seven papers are issued from specific studies undertaken in European Union and EFTA countries (127 in UK, 44 in Germany, 29 in France...). The other studies have been mainly issued in the U.S. (270 papers).
* The causes of death most frequently studied are suicide, AIDS, accidents, alcohol, ischaemic heart disease, asthma, and diabetes. A large part of the papers are issued from general studies on all causes of death.

Work is now in progress to analyze methods and results. The results on suicide, events of undetermined intent, and unknown and unspecified causes of death as representative examples of general outlined problems on reliability and comparability have been presented and discussed at the second Steering Group meeting (December 10,1999).

Timetable for the future

The timetable for next meetings has been adopted as following:

- April 28, 2000: Steering Group 3rd meeting in Lisboa.
- June 30, 2000: Plenary Group 2nd meeting in Paris back-to-back with the Eurostat Task Force on causes of death meeting (Thursday, June 29th).
- The final report will be finalized in December 2000.

Improving Mortality Statistics in the Russian Federation

Dr. Sam Notzon, Office of International Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Mortality information currently available for the Russian Federation is not sufficient to meet existing information needs, particularly with the current health crisis in Russia. The summary list of causes of death used for mortality coding and tabulation provides insufficient detail, and numerous data quality problems exist. Concerns about the quality of mortality data led the Russian Government to assign responsibility for the coding of mortality data to the Ministry of Health in 1996. The Ministry of Health in turn decided that cause-of-death data should be coded using the complete list of causes available in the International Classification of Diseases (ICD), rather than the existing Russian summary list of causes. The Ministry has assigned MedSocEconomInform (MSEI) responsibility to implement a national program to code cause-of-death data according to ICD-10. MSEI has begun this activity, working with the WHO Collaborating Center for the ICD in Russia and the WHO Regional Office for Europe (EURO). In addition, the U.S. National Center for Health Statistics (NCHS) will collaborate with MSEI on specific aspects of this national program, as part of the ongoing collaboration on health statistics between NCHS and MSEI.

The collaboration between NCHS and MSEI is part of a program of scientific collaboration between the United States and the Russian Federation known as the Gore-Kirienko Commission. Initially, the NCHS-MSEI collaboration focused on the publication of joint reports on mortality and other health measures in the two countries. These reports have served to underline comparability and quality problems with existing Russian mortality data. Over time, the collaboration between MSEI and NCHS has broadened to include improvements in the quality and variety of health data collected in the Russian Federation.

Current health situation in Russia

The need for accurate and detailed mortality information for Russia has sharpened in the years following the breakup of the Soviet Union. Russia is facing increasingly serious health problems, but a severe economic recession is limiting the government's ability to address these issues. Cardiovascular disease and injury, already major sources of morbidity and mortality in Soviet Russia, have increased sharply in the 1990s. Diphtheria rates rose exponentially from 1990 to 1994, but a national vaccination campaign has since reduced the rate to a relatively low level. The incidence of tuberculosis, sexually transmitted diseases and other communicable diseases have increased many times over since 1990. The result has been an unprecedented rise in adult mortality, leading to a drop in male life expectancy at birth from 64 years in 1990 to less than 58 years in 1994.[1-3] Female life expectancy declined by 3 years, from 74 to 71 years, during the same interval. The situation has improved somewhat since 1994, but life expectancy remains very low by Western standards. Key contributors to the health crisis are, among others, the decline in living conditions, dissolution of social controls, and deterioration of the health care system.

The health problems facing the Russian population are so numerous, and of such daunting proportions, that it is difficult for the Russian government to decide which problems to address first. The same can be said of the many national and international organizations offering

assistance. In such a situation one of the key requirements is accurate information, to identify the most important health problems, to measure improvements in health status over time, and to establish long-term goals for health improvement. The introduction of ICD-10 for the classification of causes of death would be an important improvement in the health statistics system of the Russian Federation.

Disease coding in the Russian Federation

The Russian Federation, and previously the Soviet Union, has not used the entire ICD system for the coding of mortality data, preferring instead to use a simplified coding scheme. The earliest coding list, adopted in 1924, was very close to the Third Revision of the ICD. Since 1965 this list has included approximately 200 causes of death and is similar to the tabulation list of 150 causes of death (the "A-list") developed as part of the 8th Revision of the ICD. Like the 8th Revision A-list, the Russian list has heavy emphasis on communicable diseases, representing almost one-fourth of the total number of causes of death. The Russian coding scheme includes a small set of E-codes, or external cause of injury codes, as well as N-codes, the nature-of-injury categories. The list has been revised at irregular intervals, varying from 223 causes in 1965 to the current level of 185 causes of death. A summary list of causes of death such as the Russian list does provide basic information on the structure of mortality in Russia, but few of the details needed to provide insight into the mortality trends under way in Russia.

The World Health Organization maintains an ICD Collaborating Center for the Russian language in Moscow. The Center is located within Semasko, an agency of the Russian Academy of Medical Sciences that is affiliated with the Ministry of Health. The Russian Collaborating Center is responsible for the translation of each revision of the ICD into the Russian language. In collaboration with EURO, the Russian Collaborating Center also has been providing ICD-10 training to the various NIS countries, including Russia, in recent years.

Problems with mortality information currently available

There have been many limitations to the mortality information available for the Russian Federation, both in the past and present. Chief among these limitations has been the severely restricted list of causes of death, as noted above. Other problems result from deficiencies in the current procedures for coder training, quality control of data coding, and problems with the completion of the medical certification portion of the death certificate. In the past there were problems with the release of information on certain causes of death and on deaths for certain age groups.

Condensing the information available from death certificates into only 185 categories clearly restricts the information available from this resource. Given the realities of the existing system for data coding, however, such a restricted list may be a reasonable approach to cause of death coding. Under the existing system, the medical death certificate, which contains information on the causes of death, is completed by a physician or medical assistant (feldsher). This certificate is taken to the local civil registration office (ZAGS) by relatives of the deceased for completion of the civil registration of death. The local registration office passes on the medical death certificate to the oblast statistical office (Goskomstat), where the cause of death and other information is coded by statisticians or clerical employees. These employees have no medical training and for the most part have received no standardized training on ICD coding procedures. The larger oblasts such as Moscow have one or more staff who specialize in the coding of cause of death information. The coders in the larger oblasts face heavy workloads, as

much as 250 certificates per day. In the smaller oblasts, cause-of-death coders have other responsibilities as well. In either situation, coders also have to deal with physicians' handwriting, which may be difficult to decipher. New cause-of-death coders are typically given on-the-job training by other coders in the oblast statistical office. There is no provision for verification of cause-of-death codes assigned in the oblast office, which combined with the absence of standardized training makes regional coding differences highly likely.

Additional data problems may come from the medical certificate itself. Several studies raise questions about the accuracy of diagnoses of causes of death in Russia, in particular the over-diagnosis of cardiovascular diseases.[4-6] Other studies of the quality of cause-of-death diagnosis in Russia do not support the notion of overreporting of cardiovascular deaths.[7] However, the low levels of mortality in Russia due to causes such as pneumonia and influenza would lead to a reasonable suspicion that some of these deaths are being erroneously assigned to cardiovascular diseases.[2] Other analysts attribute the relatively low levels of mortality in Russia due to many chronic diseases, such as diseases of the endocrine system or the urogenital system, to the overreporting of deaths due to circulatory diseases.[4]

Although the proportion of deaths subjected to autopsies has declined over time, currently about 34 percent of all deaths are autopsied in Russia, a higher proportion than most industrialized countries.[4,8] As in most countries, the bulk of autopsies are performed on deaths due to external causes and to infectious diseases. Also as in most countries, the lowest levels of autopsies are performed on deaths due to the leading causes, neoplasms and cardiovascular diseases. For deaths due to neoplasms and cardiovascular diseases that are not autopsied, the cause of death is usually determined from the decedent's medical history. In cases where the decedent has not had a recent medical examination, the cause of death may be determined from symptoms reported by relatives.[4]

Inaccurate diagnosis of the cause of death may even exist for deaths that have been autopsied. Infant deaths of uncertain cause are routinely autopsied in Russia, especially in the largest cities. Many of these would be considered deaths due to sudden infant death syndrome (SIDS) in Western nations, but few are assigned this cause of death in Russia. The Russian death rate for SIDS was 0.3 per 1,000 live births in the early 1990s, about 1/3 the U.S. rate and about 1/6 the rate in New Zealand.[8,9] Investigations of infant deaths in Moscow and St. Petersburg by Russian SIDS experts identified twice as many likely SIDS deaths as did the autopsies. The low level of reported SIDS deaths appears to be due to the tendency of Russian pathologists to identify a cause of death, no matter how tenuous, for any autopsy they perform.[9]

There also appear to be some incompatibilities between causes of death in the Russian list of causes and those used in other industrialized countries. Of particular note is the Russian use of alcohol poisoning, an external cause of death (ICD-9 code E860) for deaths due to long-term use of alcohol.[10] In most countries, the bulk of alcohol-related deaths are assigned to non-external causes of death, particularly alcohol dependence syndrome (ICD-9 code 303) and nondependent use of alcohol (ICD-9 code 305.0). Incompatibilities probably also exist for other causes of death, including many causes of infant death such as birth trauma and congenital and aspirated pneumonia.[11]

Even for causes of death, which are fully compatible with those used in other countries, the low level of detail limits their usefulness. For example, analysis of causes of childhood deaths in Russia and the United States has shown large excesses of childhood drowning deaths in Russia, as much as 10 times higher for some age groups.[11] However, beyond their classification as drowning deaths, little is known about these deaths in Russia. No information is provided on

the place of death, e.g., bathtub versus lake, and no detail is listed on the circumstances, such as drowning as a result of a boating accident. Programs to reduce these accidental deaths will require such details in order to design effective intervention programs.

Russia continues to use a non-standard definition of live births, seriously understating the level of infant mortality. Before 1993, the Russian definition of a live birth recognized only one sign of life (breathing) as compared to the four signs of life included in the WHO definition. In addition, very preterm infants—those weighing less than 1,000 grams, or less than 28 weeks gestation, or less than 35 centimeters birth length—were only reported as live births if they survived at least 7 days. Although Russia modified their definition to include the four signs of life in 1993, very preterm infants remain unreported as either live births or infant deaths (or even as stillbirths) if they die within the first week of life. Various analysts have estimated that correction for this difference in reporting practice would raise the infant mortality rate by about 25 percent.[12,13] Russian perinatologists argue that it is pointless to report infant deaths that are beyond their ability to save.

Finally, during the era of the Soviet Union information on many causes of death was suppressed. Until 1988, deaths due to cholera, plague, homicide, suicide, and work accidents were included only in the remainder category of "ill-defined" causes. Information on these causes of death was prepared but reserved for use only by selected officials. A Russian analyst who recently gained access to these secret tables reported that in 1970 the male homicide rate for Russia was eight times the average rate for Europe.[14] The Soviet government also suppressed all information on infant deaths from the mid-1970s until 1988. All such restrictions have now been removed and Goskomstat of Russia now provides information on all causes of death for all age groups.

Transition to ICD-10

In 1996, the Russian Government designated the Ministry of Health as the responsible agency for the coding of cause-of-death data, with Goskomstat remaining responsible for the tabulation and publication of vital statistics data. The Ministry of Health in turn made the decision to code mortality data according to the ICD, and to designate the Public Health Institute, or MedSocEconomInform (MSEI) as the implementing agency.

MSEI began the transition with a 1-year experiment using the Ninth Revision of the ICD. Beginning in late 1996, MSEI carried out a "train the trainers" program to establish a pilot program using ICD-9 for cause-of-death coding in three regions of Russia.

The implementation to ICD-10 has already begun, with training courses organized by both MSEI and Semasko. Training courses are planned for four groups of specialists: medical administrators of oblasts and medical chairs and main physicians of oblast hospitals; chiefs of special bureaus of medical statisticians in each region; coder-trainers from each region; and pathologists from each region. The coder-trainers will offer additional training courses in their respective regions.

Certain aspects of the Russian implementation plan differ from the practices of many other countries, and as such deserve mention. First of all, the Ministry of Health intends to use physicians as coders, a practice employed by few other countries. Most countries prefer to use non-physicians as cause-of-death coders because of physicians' tendency to ignore ICD coding conventions. In the case of Russia, this concern is addressed by the second important aspect of this program: namely, that each physician will code the cause of death for all medical certificates of death the physician completes. The use of such a large number of coders raises a variety of

concerns, ranging from the implied demand for training courses and coding manuals to increased needs for verification of coding. The final unique aspect of the Russian ICD-10 plan is that physicians will be trained to code the last-listed cause of death on the certificate as the underlying cause of death, rather than applying the ICD rules for the selection of the underlying cause of death.

The operational plan for ICD-10 coding in Russia designates hospitals as the basic functional units. Each hospital will have a statistical unit responsible for coding activities. For mortality coding, the attending physician will complete the medical certification section of the death certificate and assign an ICD-10 code to the underlying cause of death. The death certificate will then be reviewed in the statistical unit by the facility statistician, and then by the supervising physician, who also must sign the certificate. Death certificates are then sent to the central office of the oblast, where a portion is checked for accuracy. Oblast-level reviewers will contact the hospital to discuss and revise as appropriate any certificates with erroneous information.

The coded certificates will be forwarded to the oblast office of Goskomstat for data processing. Goskomstat will enter the ICD-10 codes into the oblast-level electronic data base, but on an interim basis Goskomstat intends to convert these codes into the existing Russian list of causes of death for the preparation and publication of national tabulations. To justify their plan to retain the current cause-of-death list, Goskomstat cites data quality concerns, among others. However, Goskomstat may begin using the ICD-10 cause data within a short time, as the system matures. In addition, ICD-10 data will remain available for exploitation in electronic form at the oblast level.

The implementation plan for ICD-10 coding in Russia contains provisions that raise serious questions about the data this system will produce. The major concerns are: the use of physicians as coders; self-coding of the cause of death by all physicians completing medical death certificates; and coding of the underlying cause of death without application of the ICD rules for the selection of the underlying cause of death. However, the existing implementation plan, with all of its drawbacks, can be considered as an interim activity laying the foundation for a long-term solution. The following section outlines collaborative activities that the National Center for Health Statistics (NCHS) of the U.S. will undertake with MSEI as part of the ICD-10 implementation plan, and describes one approach to a long-term solution.

NCHS collaboration with MSEI

NCHS will collaborate with MSEI on activities related to the introduction of ICD-10, as part of a broader collaborative program to enhance the quality and scope of Russian health data. The collaboration on ICD-10 activities between these two organizations can be conveniently divided into short-term and longer-term activities.

In the short run, NCHS will collaborate with MSEI on aspects of the training program required for the nationwide introduction of ICD-10. In particular, this collaboration will focus on the development of Russian language ICD training software. NCHS has provided financial assistance to purchase the license for development of a Russian-language version of an existing ICD-10 training software package known as TENDON. MSEI staff are currently working on the translation and programming required to develop the Russian version of TENDON. The training software is designed to complement a standard ICD training course, and will be an important means to ensure consistency of training. The software also will help to ensure staff training over time, as it can be used of refresher courses and for the training of new or replacement coders.

The package will be useful not only in Russia but in other NIS countries as well, many of which are also moving from the short list of causes of death to ICD-10.

NCHS will also assist MSEI with other training-related activities. This assistance will include support for a short training course designed for senior-level administrators that will provide an overview of ICD-10 and the rules for the selection of the underlying cause of death. In addition, NCHS will provide some financial support for the purchase of training equipment and materials.

In the longer term, collaboration may focus on the adaptation for use in Russia of NCHS software for automated coding of mortality data. NCHS used this software for coding during ICD-8 and ICD-9, and has modified the programs to reflect the changes in the 10th Revision. The original programs were designed for a mainframe platform, but the updated software will be designed to run in a desktop computer environment, as a WINDOWS application. If Russia decides to make use of this software, experience in the U.S. and other countries indicates that the programs will be able to successfully code the cause of death for about 80 percent of the certificates. The remaining certificates could be coded by a central staff of skilled medical coders, or nosologists. The result will be a national system to produce cause-of-death data according to ICD-10 coding rules. An additional benefit of the software will be the production of multiple cause of death information.

Summary and conclusions

The Ministry of Health of Russia has begun a program to improve the quality of mortality statistics, in part by coding causes of death according to ICD-10. With the current health crisis in Russia, the additional information thereby produced should provide valuable input to decisions on health interventions, prevention programs, and the like. A review of existing mortality data in Russia identified numerous problems besides the coding scheme used. A particular problem was erroneous causes of death recorded by physicians and feldshers in the medical certificates of death.

The Ministry of Health has authorized MedSocEconomInform to implement a national system for the coding of cause of death data using ICD-10. MSEI has begun implementation, but several aspects of the proposed system have raised concerns, particularly the use of physicians as coders and the decision to have all physicians code the underlying cause of death on all medical death certificates they complete.

NCHS will collaborate with MedSocEconomInform on certain aspects of the implementation plan for ICD-10 coding, supporting in particular the development of Russian language ICD-10 training software. Future NCHS collaboration may include the adaption for use in Russia of NCHS software for automated coding of cause of death. Use of this software would resolve many of the concerns regarding the Russian ICD-10 implementation plan.

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Discussion on Session 6: International Comparisons of Cause of Death

DR. ROONEY: I am very impressed with the attempt to compile a manual on the comparability of the data across Europe. I think that will be very useful, and I certainly think it will be a big advance if you actually manage to get maps or comparative rates, which have annotations about whether they are comparable or not.

We were a little distressed at the ICE on injury to see that Eurostat were perfectly happy to publish comparisons of injury rates, which they knew were probably wrong by a factor of two or three. That is what was published, and they were going to publish it again. But I did wonder, with your suicide data, the map that you showed; was that just suicide, or did it include undetermined injury as well?

MR. PAVILLON: Yes, I think just suicide.

DR. ROONEY: Yes, because I think use of the undetermined category for deaths makes a difference—where you do not get a coroner's verdict nor any opinion on the nature of the injury.

MR. PAVILLON: Absolutely. This is the case in France, for instance. We know why the suicide is under-registered. This is because we do not receive the autopsy reports from certain forensic institutes—Paris, for instance.

DR. ROONEY: In England and Wales, about a third of the probable suicides go down as undetermined injury. That would increase our numbers by another 50 percent or so. And, there are similar problems that we have exchanged information about; homicides, for instance.

Just a couple of comments on Russia. One is, what we found about myocardial degeneration was that in the Moscow deaths after the age of—I think it is 75, but it might even be 70—90 percent of the deaths went down to this one cause? And it basically just means "died, we do not care why." In London, when we look at deaths over the age of 85, we get about 60 percent of deaths coded to bronchopneumonia. So it is the same kind of thing: "it is an old person that died, put down something, nobody will query it." But it is happening when younger in Russia, and they have picked a different cause, I think.

Another interesting cause is SIDS. It is interesting that they are not using it. SIDS is just disappearing as a term in England. I know SIDS death rates are going down, but I have fairly good evidence that people are just not writing it down anymore. They are using some other phrase instead.

DR. NOTZON: I can tell you that in Russia, as I mentioned before, the autopsy rate is still fairly high, and all the infant deaths, definitely all of the unexplained infant deaths, are autopsied. But their pathologists like to say: "If we do an autopsy, we always find a reason; we find the cause." If one finds the cause, it cannot be SIDS. Since SIDS is defined as the absence of all causes, by definition you will not have any SIDS.

DR. ROONEY: In the 1980s, SIDS did increase dramatically, and it seemed to be a transfer from respiratory disease. There has been a lot of publicity over the last few years in England about some SIDS possibly being hidden homicides, and people were very reluctant to write it down any longer, because it upsets the family now.

MR. JACKSON: Dr. Rooney, I can confirm that the suicide chart was indeed just suicides, but there is a separate category in the 65-category list that has been reported, which is the "undetermined." So it will be possible to put the two together. That would help comparisons.

DR. PÉREZ: I agree that certification procedures are very difficult to change, more so than coding procedures.

I want to ask some questions to Dr. Notzon about Russia. It is very surprising not to see neoplasms or such European leading causes of death among the causes listed for Russia, and the peak in number of deaths in 35-44-year-olds is also surprising. What do you think? Is it certification procedures or is it coding procedures, or is it maybe both? Thank you.

DR. NOTZON: First of all, in terms of the leading causes of death, I need to explain something. Cancer is one of the leading causes of death, there is no doubt about that. It is just that the cancer death rate did not increase by much during that interval of rapid rise in mortality. That was what that pie chart was all about; it was trying to define the sources of the rise in mortality. Cancer remains one of the leading causes of death.

The peak in terms of increases in the age group 35-44 was because of external causes of death. That was primarily the source of that. As far as AIDS mortality and other infectious diseases, unfortunately that is also coming. There is an AIDS epidemic that is appearing now in Russia that is going to get much worse before it gets better, and the same is true with tuberculosis. Their estimate is that there may be 100,000 cases of active tuberculosis in Russia right now, a lot of that in the prisons, but nonetheless. So infectious diseases have not been a major issue up to now, other than the news articles about diphtheria, which were newsworthy because they were unusual, but were not a major source of deaths.

DR. COLE: Dr. Notzon, could I ask you a little bit about the medical care available? In Russia, do people have a doctor? Do they have a GP like we would recognize in the U.K.? Do a lot of these doctors meet a patient for the first time when a body is found and they are dead, so that they have no idea what happened? I inferred that from your comments that a history of symptoms is obtained from the relative. That means that the dead person will not ordinarily have had contact with medical services. Is that an issue?

DR. NOTZON: Well, they will not have had contact recently. In fact, they have a great network, particularly in the cities, of neighborhood physicians who still carry out house calls, unlike this country. In theory, it is a great system. The problem now is that they do not have the materials—not so much the physicians themselves, but rather the hospitals. But within the cities, that is not so much of a problem. In the countryside, you have what would be like physician assistants. I am trying to think of a term in English that would be roughly descriptive of them; approximately a physician assistant, maybe a bit less than that. That would be the point of contact in the rural area. But there are certainly people who have not had recent contact, and for them, you are reduced to obtaining symptoms.

DR. COLE: But if that is as you say, there should be hope for the process of medical certification of cause of death, because of knowledge, because they maybe have seen them repeatedly. They should know what is going on. With a relatively high rate of autopsy, even though it is falling, the elements would seem to be there to have good source material for eventually getting over this 175-causes problem.

DR. NOTZON: Eventually, yes. Of course, then the question is, how much detail do you need and for what purpose?

PARTICIPANT: The question is for Dr. Notzon. I think the work is very good. We are going beyond the data to see the possible reasons that will explain the trend. In the demographic literature now, some researchers are giving lots of theories about the high cardiovascular disease in Russia. I remember reading one where they talk about stress, the increased stress, and because of that there is stroke and so on. A lot of theories are going on. So when we come onto what you have done, it throws doubt on all those kinds of theorizing about what is going on there. So I think it is a contribution that we get.

May I also ask: when you partitioned your life expectancy to different causes of death, which method did you use?

DR. NOTZON: I will answer the last question first, which is, I used Arriaga's method for partitioning, which is straightforward. In terms of stress, actually you

raise an interesting question. I would say I started the work on mortality in Russia thinking that stress had nothing to do with it. It is interesting to look at what Russians in the health area think of as the leading factors behind their rise in mortality, and stress is generally listed up towards the top. I would not put it at the top by any means, but I came to appreciate that stress could definitely be a factor. There is a certain amount of literature appearing now about the effect of stress on cardiovascular disease and other diseases, and in particular the area of heart disease as a trigger for myocardial infarcts as a cause of arrhythmias. Again, we hear this about binge drinking and alcohol as a potential cause of arrhythmias. It may be. I would say that, if it is a factor, the increase is just as likely to be due to stress and depression as opposed to alcohol consumption. But at any rate, all of these things tend to work together. I think they reinforce each other, and that is part of the problem. I frankly think it is a bit simplistic to focus just on one issue, because there is plenty of blame and plenty of problems to go around.

MR. PAVILLON: Concerning the mode of computation of the different death rates, I will give you a copy of the slide with the exact formula. But concerning the pertinence of the choice of this mode of computation, I cannot answer you because I am not a specialist. If you have further questions, I can give these questions to Eric Jougla and he can answer you.

SESSION 7

Discussion of Experiences With Implementing Automated Coding

Discussion of Experiences with Implementing Automated Coding

Gary Catlin (moderator), Director, Health Statistics Division, Statistics Canada

This session takes us back into the operations and the process of the automated coding systems. The purpose of this session is to generate discussion, so we are hoping that at the end of a couple of presentations we can have some discussion around the room with the folks at the table.

There are two main presentations that are going to be done, but if there is a little bit of time, I am going to put up a few slides about Canada and the situation in Canada as well. So we will start off with Marelle Rawson, from Australia, describing their experience with automated coding.

An Australian Experience in Implementing Automated Coding (ICD-9 and ICD-10)

Marelle Rawson (presenter), Director, Health Section, Australian Bureau of Statistics, and Malcolm Greig, Australian Bureau of Statistics, National Center for Classification in Health

Introduction

The Australian Bureau of Statistics (ABS) has coded mortality data using ICD-9 since 1979. Some 20 years later in 1999, ICD-10 was introduced. ICD-9 has progressively become less relevant, and the introduction of ICD-10 has been a priority. The significance of the change is unprecedented in recent history, featuring among a host of modifications, a doubling of the number of codes to about 8,000 and a move from a numeric to an alphanumeric code format.

In 1997 the ABS introduced multi-cause mortality coding using United States Automated Coding Software (ACS). This caused complications, such as breaks in series, interfacing with current computer systems, terminology and spelling differences, new coding interpretations and the need for intensive training. Lessons learned in introducing automated coding have strengthened the emphasis on international collaboration. Processing of deaths registered in 1998 for Australia is now complete. This was the last year of mortality coding in ICD-9.

Coding of 1999 data in ICD-10 is progressing well. Plans to "back code" 1997 and 1998 mortality data to ICD-10 will allow data to be available for ICD-10 from 1997 and will facilitate the production of an effective concordance between ICD-9 and ICD-10.

The automated environment

During 1997, the ABS began to code and tabulate all causes and conditions reported on each death certificate using software developed by the National Center for Health Statistics (NCHS) of the United States. The NCHS software has three major components: SuperMICAR/MICAR (Medical Indexing, Classification and Retrieval System), ACME (Automatic Classification of Medical Entities) and TRANSAX (Translation of Axes). These three components have been developed to read the textual entries and convert them into a file containing multi-causes of death in accordance with the ICD-9 coding rules. The ABS receives the textual medical certificate of cause-of-death information in electronic form from the eight State and Territory Registrars of Births, Deaths, and Marriages. The step revolutionized mortality coding and provides the opportunity to significantly improve the consistency of cause of death statistics produced in Australia.

The need for multi-cause statistics

Until 1997, the ABS produced causes of death statistics where only a single underlying cause of death was identified and coded, according to WHO recommendations. The underlying cause is defined as "the disease or injury that initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury." The medical certificate of cause of death, recommended by WHO for international use, was designed to facilitate the selection of the underlying cause. When more than one condition is entered on the death certificate, the underlying cause is selected using the coding rules of the relevant version of the ICD, then the Ninth Revision. The underlying cause is selected so that preventive strategies can be instituted to address that particular cause. Since its adoption in 1948, statistics

based on the underlying cause concept have served the purpose of summarizing international cause-specific mortality statistics into a single index, which has been used to assess trends in causes of death.

However, the current leading causes of death are very different from those that prevailed when the single underlying cause concept was adopted. The leading causes of death in most developed countries have shifted from infectious and parasitic diseases to chronic and degenerative diseases and from infant and child deaths to deaths among the elderly. As the population continues to age, chronic diseases become increasingly more important. Because deaths from chronic conditions commonly occur with a number of concurrent or coexisting conditions, the initiating condition is often difficult to isolate. Some deaths, it has been postulated, cannot occur without the influence of more than one cause. The ability of the single underlying cause statistics alone to accurately summarize the mortality pattern of a population has, therefore, been questioned.

When only a single underlying cause is selected for tabulating cause-specific statistics, we lose other valuable information provided on the death certificate such as the immediate cause of death, causes and conditions that intervene between the underlying and immediate causes of death, and many other contributory causes that were involved but did not directly cause the death. The information lost may be important to the understanding of the process of death. For example, 1997 data for Australia suggest that on average 1.8 causes (and conditions) would be lost per death if only single underlying causes were recorded. The loss of information is a particular problem for deaths attributed to external causes (injury, poisoning, and violence), which are classified to the circumstances of death, rather than according to the nature of injury.

Comparison of manual and automated coding

ACS was developed in the United States and, therefore, uses a United States interpretation of ICD-9 coding rules. In some instances, these differ significantly from the coding rules used previously in Australia when underlying cause was selected manually. As a result of the introduction of ACS, there is now a break in the underlying causes of death series between 1996 and earlier years and 1997, with significant differences for a number of causes of death.

The cause of death most affected is pneumonia and the category of Pneumonia and influenza (ICD codes 480-487) became, in 1997, the fifth leading cause of death. The other causes significantly affected include senile and presenile organic psychotic conditions dementia (ICD code 290), and Alzheimer's disease (ICD code 331.0). Under the previous Australian coding interpretations, many of the deaths attributed to pneumonia in 1997 would have been coded to dementia, Alzheimer's disease, ischaemic heart disease, cardiac dysrhythmias and heart failure, malignant neoplasms, chronic obstructive pulmonary disease and renal failure. Hence, while applying ACS coding interpretations has caused pneumonia deaths to rise, deaths coded to a wide range of other conditions have declined, in particular those due to dementia.

To highlight the differences and to provide a link for underlying causes of death data between 1996 and 1997, the records for more than 34,000 deaths registered in 1997 (representing more than one-quarter of total 1997 deaths) were coded, both manually and automatically. Records selected for the exercise were spread across the year to allow for seasonal influences. Comparability factors were then calculated for groups of causes of death as a means of adjusting data for 1996 and previous years, to allow them to be compared with equivalent data for 1997. Comparability factors of 1.0 or close to 1.0, indicate no significant coding differences between automated and manual coding. Factors of less than 1.0 indicate that automated coding would

assign fewer deaths to that particular cause than would manual coding. Due to the sampling methodology used, reliable comparability factors could not be calculated for individual causes involving only small numbers of deaths. Relative Root Mean Square Errors were calculated to provide a measure of the accuracy of the comparability factors.

An adjusted estimate of the number of deaths attributed to a particular cause can be produced by multiplying the number of deaths attributed to that cause in 1996 (or in earlier years) by its corresponding comparability factor. This adjusted figure can then be more accurately compared with the number of deaths attributed to the same cause in 1997 and enable trends to be more appropriately examined.

Practical issues encountered

As with all systems that are implemented, there are inherent problems with adapting the software to the local environment. The introduction of ACS was not without these problems. A number of these have been overcome in ICD-10 and where applicable, this has been indicated below.

1. Differences in terminology and coding practices were issues of most concern. To partially overcome this problem, a front-end program was built that:

- Changes English spelling into American spelling.
- Reformats Australian-specific terms to get them through the system; e.g., Chronic Airways Limitation and Acute Narcotism.
- Converts a very limited number of terms for which Australia did not agree with the code the United States assigns, e.g,. Merkel Cell Tumor, Myelodysplasia to terms that assign the correct code (note that this no longer applies as there are new codes for these conditions in ICD-10).
- Includes abbreviations that are used differently in Australia than in the United States.

Some differences in coding practice were also identified. Early indications are that the differences in coding practice are not as great in ACS for ICD-10 compared with ACS in ICD-9. In most cases, the United States way of coding has been accepted, particularly multi-cause coding as long as it does not contravene WHO rulings (e.g., 110-118 Mycoses according to ICD-9 rules can be caused by diseases outside Chapter 1, but the United States system does not allow this; we believe this still exists in the ACS ICD-10 version). These coding practice differences usually involve probable/improbable sequences and the use of Rule 3.

Examples of issues encountered include:

- Logic problems with ACME-MICAR decision tables
  Occasionally in ACS for ICD-9 there are cases where the system disallows a logical cause/effect relationship, e.g., liver disease due to alcoholism. There are other cases where WHO says some things are acceptable, but the U.S. system does not allow these. There has been not enough experience yet with ICD-10 and the new system to reliably comment on this. Knowledge of any problems with the decision tables will become evident as editing occurs and will be advised to the NCHS.

- ACS Data Dictionary
  Some diseases are not included in the ACS data dictionary (and hence not recognized) even though they are included in the ICD-10 index. For example, terms like Analgesic Nephropathy, the system will reject the term and a code has to be provided manually at the ACME phase.

  There are also cases where commonly-used Australian terminology such as "chronic airways limitation" or "frailty" cannot be adequately coded by ACS. These cases were corrected under ICD-9 through the use of the front-end addition to the ACS data dictionary, and has also been included in the front end for ICD-10.

- Problems with durations
  As there is no field for duration in Part II the durations mentioned in this part of the certificate are not taken into consideration when the system assigns codes. This impacts on the correct assignment of some codes, for example, cerebrovascular accidents can be coded to current cases when they should be coded to sequelae.

- Neoplasm coding, particularly metastatic carcinomas
  As identified in any coding text and even in Volume 2 of ICD-10, there are a number of ways of describing the same situation for neoplasms. The term metastases can be used to describe:

  - The spread of a neoplasm from a primary site to a secondary site
  - A secondary site
  - A primary site with spread to unknown secondary site(s)

  This ambiguity can provide confusion for the coder and ultimately the system.

- External cause coding
  ACS does not deal well with external causes due to the nature of describing these cases. The circumstances surrounding an accident involves information that is not clearly stated, like a medical term. For example, we can describe a person as having a Myocardial Infarction and understand clearly what disease processes are involved or circumstances. In contrast, a motor vehicle, may take many more words to describe the circumstance or "disease process."

- Myelodysplasia
  This is a relatively new but commonly-used term that is also used for an entirely different disease that is indexed in ICD-9. Special programs had to be run to change the ICD-9 code when it was incorrectly coded to the indexed code. ICD-10 includes a new and separate code and hence this problem no longer exists.

- Infant deaths
  Using ACS, infants over 1 year do not get coded to Sudden Infant Death Syndrome as was done in Australia (up to the age of 4 years).

- Multi-organ failure
  This is a very commonly-used term that has had a lot of discussion on the Mortality Forum. The United States does not code it, but in Australia it is coded to 799.8 (Other ill-defined conditions). Australia will be applying the same rules as the United States for ICD-10, until a decision is made by the Mortality Reference Group on what is appropriate.

- Surgery
  ACS does not deal well with complications of surgery due to the nature of describing these cases. Surgery is not always correctly formatted on the certificate by the clinician. ACS will reject these cases as it cannot always determine the link between the surgery recorded on the certificate and the possible complications of surgery.

2. Integration of the ACS software into the existing Australian processing system—without loss of existing functionality—presented a number of challenges.

For example, there is a commitment in Australia to provide more detailed data on selected causes, e.g., drowning. More detailed flags are set to provide better explanation of the circumstances surrounding the drowning than can be provided by the ICD code. The State-specific data field in the Super MICAR phase has been used to incorporate these flags.

The majority of these challenges were resolved when ACS for ICD-9 was integrated. The introduction of ACS for ICD-10 provided fewer challenges. Most of the new challenges related to the changed edit specifications between the ICD-9 and ICD-10 classifications. Overall the integration of ACS proved to be very resource intensive in both system development and clerical resources.

3. With the introduction of ACS for ICD-9 the existing ABS computer edits had to be modified to include multiple cause codes, including injury data. As the Australian input data is sufficiently detailed, a decision was made to code to the full 4-digit level of the ICD where applicable. This involved extra work as the ACS uses only a limited subset of the 4-digit categories. This is because the United States input data is not sufficiently detailed to code to the 4-digit category in all cases.

This decision has meant a few operational problems as there was a need to strip off the 4th digit when the record axis data was created through TRANSAX and then put the 4th digit back on after the record axis data is produced. For ICD-10 a decision has been that no intervention will occur to add the fourth digits where ACS does not.

4. The introduction of Multi-cause codes required the database and output record structures to be modified. Output tables had to be rewritten to use this new output record structure and to provide additional information related to the multi-cause codes. Decisions about output changes were the result of wide-ranging consultations with clients.

The introduction of ICD-10

ICD-10 for mortality coding is being introduced from the calendar year 1999 and with it, a new version of the Automated Coding System (ACS) software.

ICD-10 differs substantially from ICD-9 with changes including:

- An increase to approximately 8,000 codes in ICD-10 (up from 4,000 in ICD-9)
- Use of a 4-digit alphanumeric code
- Inclusion of three additional chapters
- Rearrangement of some chapters
- Changes to the way certain conditions are classified
- Regrouping of some conditions
- Changes to some coding rules

Some of the implications of these changes are reviewed in the following sections.

Staff impact

ICD-10 mortality coding began from about mid-April 1999 with all coders being fully trained in and familiar with ICD-10 after a few months. With ICD-9 being used for the last 20 years, the changes mentioned above obviously have had a significant effect on coders in regards to training requirements and coding practices.

- Training
  Critical to the successful introduction of ICD-10 was a comprehensive training program. Training began in February 1999 and proceeded through to July 1999. Overview education for non-coders is scheduled for later in 1999.

  Training includes:

  - Transition training for experienced coders
  - Full training for new coders
  - Overview training for non-coders

  Training will consist of:

  - Pre-course familiarization (using TENDON—the United Kingdom software package)
  - Formal course work (practical training)
  - Post course test
  - Specific medical terminology training

Training is being provided by the Australian National Center for Classification in Health (NCCH) and experienced ABS staff and covers both the coding and ACS system use aspects. Educational material for ABS State/Territory Client Service staff and other relevant stakeholders will also be produced.

- Coding impact
  As mentioned above, there are significant changes to the classification structure, codes and coding rules. While the coding is now done in an automated environment, the changes have had a significant effect on coding rates and potentially on the accuracy of

coding, particularly in the early stages of transition. See also 2.3 regarding specific coding issues.

There has been an initial slowdown in coding rates due to the implementation of ICD-10. While this slowdown has been quite significant at the start of coding, coders are reaching a reasonably high rate of coding (compared to ICD-9) fairly quickly. It is anticipated that, over a 12-month period coding rates will revert back to those more comparable with those achieved for ICD-9.

To ensure accuracy of the coding is minimally affected, significant attention has been paid to documentation and quality assurance. Revised instruction manuals for coding and revised software usage manuals have been completed. Particular attention has been paid to the development of appropriate training material.

A simple quality assurance program has been implemented for ICD-10 coding. A basic acceptance testing process has been put in place to check code the work of the staff coding mortality data. At a certain rejection rate the batches of data will be fully re-coded. This process will not only ensure a high level of quality, but will help pinpoint specific areas where further training is needed.

Additionally, system checking well also be undertaken. A random sample of all records will be taken, manually coded, and compared against the corresponding ACS codes. Reasons for differences will be documented and discussed in appropriate forums.

Along with the ICD-10 coding of 1999 data, both 1997 and 1998 data are being "back coded", using the new classification. Detailed procedures have been developed to ensure appropriate "back coding" is completed. Each record from 1997 and 1998 will be coded in ICD-10 and compared with the original ICD-9 code mapped forward to ICD-10. The result of this for each record will be documented, fully identifying the outcome of the comparison.

System impact

The delivery timetable for the ICD-10 version of the ACS software has meant a condensed development timetable in Australia. To cope, a phased approach was taken and has now been completed successfully. The assistance provided by NCHS has been of great value and very much appreciated in Australia.

- System development

A totally new version of the ACS software was required to introduce ICD-10. Version 1 was used to begin early development and integration into the Australian system environment. Version 2 allowed production to begin, although without the TRANSAX component. Version 3 of the software has been tested successfully and is now in production. Edit specifications have been complete and are now included in the production system.

The process to allow data (textual information from the medical certificate of death) to be extracted from the mainframe in ICD-10 format and loaded into SuperMICAR was the first

stage put into production. This allowed back-coding of 1997 and 1998 data to start early. Further enhancement of the local, "front end" dictionary to allow for Australian differences in spelling, terminology, abbreviations, and unique Australian causes of death has been undertaken, but updating will be required on an ongoing basis.

The ACME stage (underlying cause) was then tested. This allowed the ABS to process records through the TRANSAX stage. Once TRANSAX (the output stage of the system) was received and tested, the system was ready to be put into full production. This combined with the new edits that needed writing was completed by July 1999.

By taking a staggered approach to the coding processes, which fitted in with the timing of the delivery of various parts of the ACS software, the timetable for coding 1999 data and back coding 1998 and 1997 has been largely maintained.

The supply of the different versions of the software has not caused any significant problems. Apart from one version of the software with obvious deficiencies that were quickly fixed, the implementation of ACS for ICD-10 has gone smoothly. Most system problems were sorted out as part of the implementation of the ICD-9 version of ACS.

Development of a system for Perinatals coding for ICD-10, which is totally independent of the ACS software has begun and is nearing completion.

- Robustness of the system and the decision tables

Our understanding is that the decision tables were initially produced by using the mapping from ICD-9 to ICD-10. Each decision table was then worked through in detail to ensure that the decision tables worked as planned. It is acknowledged that ICD-10, being so expanded, has caused great complications and complexities in the decision tables.

The experience to date, although on a small number of cases, indicates that the decision tables are quite robust and accuracy is very good. Any changes to the decision tables, if they do need to be made, are expected to be minor and therefore relevant recoding of the affected records should be manageable.

Australia is monitoring the decision tables carefully and will report on areas of concern to NCHS as they arise.

- Maintenance of ACS

Revision to decision tables and updates to ICD-10 will obviously have an effect on ACS. Australia is in agreement with the United States view that the system be kept as stable as possible, particularly during the early years.

However, it is important that problems identified are rectified in the ACS decision tables. Issues concerning the need for changes to coding rules and the timing of any updating will need to be debated by the ACS Users' Group.

External causes, generally speaking, cannot be coded using the automated system. In the short to medium term, it is unlikely that any solution to the external causes issue can be found, (i.e., countries will have to continue to code most of these manually). In the longer term some solution may be possible, but a significant amount of international resources will have to be made available to develop what would be an extremely complex automated process. This issue should be addressed at some future time to determine whether the power of technology can provide a solution.

- WINDOWS version of ACS

Australia will have to move to a WINDOWS version of ACS at some stage, sooner rather than later. Even if the United States produce a WINDOWS version for processing the year 2000 data, it is highly unlikely that Australia will use it for that year. Australia is more likely to want to move to the WINDOWS platform for 2001 processing.

However, it is extremely important that regular advice on development activities is provided to users of ACS. It is also important the international users are given a chance to provide input to development specifications.

International assistance in developing a WINDOWS version has been raised. There are opportunities to work collaboratively on this, but an early request for assistance would be required to allow other countries to consider if and how they may help.

Clients and data suppliers

Stakeholders external to the ABS are also affected by the change. It is of importance that these stakeholders are considered appropriately in the introduction of ICD-10.

- Data suppliers

  Suppliers of mortality data have an important role to play in regards to data quality.

  The certification booklet, produced by the ABS, aims to provide assistance to medical practitioners in filling out the Medical Certificate of Cause of Death, has been updated for the introduction of ICD-10. A total of 15,000 copies have been printed, about 6,000 have already been distributed and more are in the process of being distributed. First priority has been major hospitals (identified by where most deaths occur) and teaching hospitals. Copies of the booklet have also been sent to Coroners, Registrars of Births, Deaths, and Marriages, ABS State and Territory Offices, and other stakeholders who have an interest in this field.

  Articles announcing the introduction of ICD-10, but more importantly asking for medical practitioners to play their part in providing quality data, have been written and provided to major Australian journals. Flyers have also being produced for Registrars to send out to the hospitals with blank Medical Certificates of Cause of Death. The continuing need to influence Registrars to improve the quality of the Medical Certificates of Cause of Death remains a high priority.

- Clients

Because of the significant changes to the structure of ICD, a full redesign of the output produced (including the publication) will be required. There is a need to explain the change from one classification to the new for time series purposes. Both 1997 and 1998 data will be back coded in ICD-10 providing an extra 2 years of time series data for ICD-10, but also providing 2 years of data for calculating the linking between ICD-10 and ICD-9. It is intended to have this linking available at the time of publishing 1999 ICD-10 data. We are also investigating the use of the "parallel coded" sample of 34,000 records used for linking the initial change to ACS, as a possible means of directly linking ICD 10 data to manually-coded, pre-1997 underlying cause data.

The timing of output for 1999 data will be determined once some initial analysis of coding rates has been completed. It is intended to produce educational material for users of mortality data and possibly run a workshop for external clients in the later half of 2000.

The international scene – Australia's role

Australia is committed to multi-cause-of-death coding and, therefore, to an automated coding system. For Australia to continue to produce reliable data, it is keen to take part in international developments related to ICD-10 and the Automated Coding Software (ACS).

As a major user of the ACS, Australia is keen to increase ties and communication with other countries in regards to ICD coding and the automated software. Strengthening contacts will aid in the identification and implementation of best practice for mortality coding and assist in enhancing the international comparability of the cause of death statistics. Improved cooperation can occur and a number of avenues where this is occurring are discussed briefly below.

The Mortality Forum

The Mortality Forum is an email site set up by Sweden to discuss coding and rule interpretation issues in regards to ICD-10. With the introduction of ICD-10 in Australia, ABS is taking the opportunity to increase its contribution to this forum. To do this more effectively, the ABS has designated a senior position to work closely with the NCCH on an ongoing basis, to deal with issues raised and to identify issues that need to be raised, on the Mortality Forum.

As a supplement to the Mortality Forum, the ABS is attempting to increase its direct international contacts as a means of discussing a wide range of operational issues, including matters relating to the interpretation of coding rules and use of the automated coding system. However, the main vehicle for sharing views on the interpretation of coding rules will continue to be the Mortality Forum.

The Mortality Reference Group

The Mortality Reference Group (MRG) has been set up by WHO to review coding and rule interpretation. Sue Walker from NCCH represents Australia on the MRG. ABS and NCCH work cooperatively in providing input to discussions of the MRG.

Initial feelings are that, although there have been some technical communication problems in connecting countries, the discussions have been worthwhile. Australia's ability to contribute directly to the meetings is difficult due to time differences, but some resolution is being negotiated at the moment.

International Collaborating Effort (ICE) on Automated Mortality Coding

Australia sees the role of the ICE on Automated Mortality Coding as imperative to internationalizing ACS. Sharing of experiences and assisting other countries in adopting automated procedures is a high priority.

Automated Coding Software (ACS) User Group

Australia believes strongly that the ACS should be developed to internationally agreed specifications. This would make it more likely that most countries would use it in an untampered form, hence maximizing international comparability. It is now an international product and needs to be further developed and maintained by the international users.

An ACS User Group will be set up under the auspices of ICE. The role of this group should parallel that of the WHO Mortality Reference Group, and it should provide guidance in the development of the ACS software to handle any changes to specific coding rules. Australia is keen to be represented on this group when it is formed.

Research cooperation

There are opportunities to work cooperatively with other countries on specific projects. Areas that require international attention and where Australia in a good position to do some work, or is already doing some work, are:

- Data quality
- Development of the medical certificate
- Query action protocol
- Editing
- Data linkage
- Manual to automatic
- ICD-9 to ICD-10
- Output
- Underlying cause
- Multi-cause
- Perinatal statistics

Australia is keen to pursue joint activities where other countries show particular interests.

The Implementation of Automated Coding in Scotland

Graham Jackson, Head of Vital Events and NHS Branch, General Register, Office for Scotland

I shall be describing the implementation of automated coding in Scotland—an ongoing process that began in 1996.

Factors influencing the change to automated coding

We did consider moving to automated coding as far back as the 1980s, but it was not until the early 1990s that a number of key factors persuaded us that it was worth pursuing this particular approach. The key reasons that lay behind the change to automated coding may be summarized as follows:

- The migration from mainframe to PC-based processing of vital events data; this required a major rewrite of our processing system.
- The development by NCHS of a PC-based version of the automated coding software
- The increased use of electronic registration software in local registration offices; in many ways this was the most important factor. For an increasing proportion of death registrations, we were able to receive all of the registration information electronically—not just the cause of death information, but also the demographic details, doctors' names and addresses, etc.

Key objectives

We were attracted to the use of automated coding for the same reasons that have been mentioned earlier this week by other speakers:

1. Improved consistency in the standards of coding
2. Increased comparability—both within the UK and internationally; within-UK comparability is particularly important because we are often asked to prepare information comparing the four constituent countries of the United Kingdom. It does help to know that we are working on at least a similar basis, if not the same basis, as our colleagues in England and Wales (manual coding is still used in Northern Ireland).
3. The potential for multiple cause coding—we used to keep three causes, in addition to the underlying cause, on our database, but now we retain more information. I say "potential", because to date we have not made significant use of multiple-cause analysis.
4. Faster processing—we were looking for some improvement in throughput. We send weekly provisional information on deaths (and births) to all of our health authorities. As this is used to update hospital and other health service records in their areas, we must code, process and issue the data as quickly as possible.
5. Potential staff/cost savings—again, I use the word potential advisedly here. There is the potential for significant staff, and therefore cost savings. Though to date we have made only modest savings, further savings are on the horizon.

Hardware and software

The automated coding software was integrated with the vital events processing system introduced at the same time. Our system was developed using CA Open Road accessing an

Ingres database. The database is held on a Sequent Unix server and is accessed using TCP/IP over a Novell network using Windows PCs.

Not surprisingly, our system was built around the four NCHS software components about which we have heard a lot this week: SuperMICAR, MICAR, ACME, and TRANSAX. However, in Scotland there are a number of differences in the way we have used this software.

Scottish differences

1. SuperMICAR is not used for data entry. Most of our information is received electronically and it is made available from our database to a mid-point in the SuperMICAR module.
2. Data "grooming." Our coders carry out what we call a data grooming process before the information goes into the automated coding system. For example, spelling may be corrected and discrete terms separated. Harry Rosenberg earlier described such a process as "data sanitizing." At the same time the staff code other aspects of the data, for example occupation.
3. The Super-MICAR spellchecker dictionary has been anglicized. We have added additional spellings that we want to recognize to a key file in the system—what Donna Glenn once referred to as the "big book of deaths." We left all the American spellings there.
4. We have incorporated additional validation checks.
5. We store only 10 of the entity/record axis codes, though the software can generate up to 20.
6. Finally, our system automatically generates a number of "medical enquiries," whereby we write back to the certifying physician for further information.

System implementation

The system went live in 1996. At that time, approximately 85 percent of our death records were being received electronically, the remaining records being keyed up centrally and fed into the system at the same time as the electronic information. Needless to say, there were some teething problems, both in terms of system implementation and the learning process for coders previously used to a completely manual system. Initially there were delays to the provision of weekly and quarterly output. However, we still managed to provide the data for our main statistical publication, the Annual Report of the Registrar General for Scotland, on time. This was published in July 1997. Soon after that the weekly output was back on schedule and the system has been running smoothly since.

Problems

Some problems did arise. One interesting case involved a death coded E-909, "Cataclysmic earth surface movements and eruptions." Now, I have a degree in geography, and I know that Scotland is not on the Pacific Rim or in one of the other earthquake zones, so we investigated further. The text on the death certificate was:

1a. Bronchopneumonia
1b. Immobility
1c. Fractured leg bones
2. Bullous pemphigoid eruption of skin

It was evident that the problem word was "eruption." There have been other problem words:
Pressure—pressure sores or similar terms were sometimes coded to the effects of air pressure.
Intoxication—drug intoxication was sometimes coded to alcohol intoxication.
Shock—there were cases where cardiac shock had been coded to electrocution.
Abuse—child abuse was being coded to drug abuse.

To avoid problems of this sort we carry out text searches on all our records to identify and check potential miscoding. We passed information on these problem words to NCHS who were already aware of some of them; they had also identified a few more of their own. This is clearly the type of information that could be disseminated via the proposed internet forum.

Bridge coding

We carried out a bridge coding exercise based on 1995 data. Preliminary results of this work, based on about 11,500 cases, were presented at the first conference of the ICE on Automating Mortality Statistics (November 1996, Washington). The sample was subsequently increased to 34,000 records and the full results were published as an appendix to our 1996 Annual Report. A copy of the appendix may be found on our Web site (www.gro-scotland.gov.uk).

I shall quickly summarize some of the key results:

1. Eighty-nine percent of deaths were assigned to exactly the same 4-digit ICD9 code.
2. Ninety percent were given the same 3-digit code.
3. Ninety-three percent were coded to the same Block
4. Ninety-six percent were coded to the same Chapter.

These figures are similar to others reported earlier in the week. On a point of detail, I note that our conversion factor for pneumonia was 0.99. This reflects the fact that we did not change our use of Rule 3.

The bridge coding helped us to identify some other minor problems. Here is an example:

1(a) Pulmonary Thromboembolus—Left Vein Thrombosis
Automated coding—415.1 (pulmonary embolism):
Manual coding—673.2 (obstetric blood-clot embolism)

Four deaths, which had originally been coded to Chapter 11 by manual coding, were coded to a completely different chapter by the automated coding system. This happened because our manual coding had been able to take account of the fact that a pregnancy had been involved. All such cases are now reviewed manually.

Some developments since 1996

Electronic registration now covers some 94 percent of all deaths, leaving 6 percent to be keyed centrally. We introduced a new medical certificate of cause of death form at the start of 1999; in line with WHO recommendations, this included the fourth line in Part I. We plan to assess the impact of this change by comparing the data from 1999 with earlier years. This comparison can be carried out independently of our forthcoming move to ICD-10. We have,

rather belatedly, moved to Windows 95 from Windows 3.1; and there has been a lot of Y2K testing for all our systems.

Future plans

We plan to move to ICD-10 in January 2000, possibly using the new Windows version of the NCHS software. Later in 2000, once the system is bedded in, we will move from Windows 95 to Windows NT.

We will carry out a major ICD-9/ICD-10 bridge coding exercise by re-coding all the 1999 records (approximately 60,000) to ICD10. The results of this exercise will be published with our Annual Report for 2000, the first Annual Report with ICD-10 data. We also hope to introduce more structured quality control. Before moving to automated coding, all deaths were double coded. Currently, general double coding has been suspended, though certain key areas such as drug-related deaths are scrutinized in detail. For the future we envisage full double coding of external causes and selective double coding of other causes. Finally, we look forward to having a stable system and the time to analyze the data.

Canada: Issues and Challenges

Gary Catlin, Director, Health Statistics Division, Statistics Canada

I am going to describe a number of the problems or challenges that we have in Canada.

We had 210,000 deaths in Canada during 1997. The death system is very decentralized, so the 10 provinces in 3 territories registered the deaths occurring in their jurisdiction, and we received their registrations at least annually. Some are sent monthly, some quarterly, but at least annually we get data in from each of the provinces and territories.

You will notice that we have a new territory that occupies about half of the previous Northwest territories; the Northwest territories have been split into Nunevet and the Northwest territories. We actually have more deaths of Canadian residents in the U.S. than we have in any of these territories. By the way, we get those deaths to residents through an interchange arrangement with the U.S.

At Statistics Canada we use MICAR and ACME, and our throughput rate is about 85 percent. Three of the provinces, the largest: Ontario, British Columbia, and Saskatchewan, do their own redeck resolution. Stats-Can does it for the remaining provinces, and for eight of the jurisdictions, all the data is processed at Stats Canada; they just send it in to us. The one remaining province is Quebec. They do all the processing manually. They have never used MICAR or ACME. Due to the language issues, we have never converted the original system into a French system for Quebec, so they are still in the manual stage as we speak.

We have similar issues with English. In Canada we use a little bit of American English, a little bit of United Kingdom English, so we have quite a bit of amalgamation that we are going to be putting in the same. I do not think we have any Australian English, but you never know. But we are going to have to put those things into the dictionary.

We are in the process of translating—creating a French version of the software from NCHS—and we have had somebody working on that for over a year now, almost exclusively. Why are we not using the French version? That is a good question. I think just because we would like to have the same system all across the provinces, but we may go back and look at that at some point.

Regarding our future plans, we are moving to ICD-10 as of January 1, 2000. The plans are to implement MICAR and ACME across all the provinces, the provinces that want to use it. Quebec will start at that point. Some of the other provinces will continue to send it in to Stats Canada.

We are in the same conundrum about the Windows version. We would certainly like to use the Windows version, but time is getting a little short in terms of making a decision about that. So that is a brief summary of where we are in Canada.

Discussion on Session 7: Discussion of Experiences with Implementing Automated Coding

DR. ROONEY: A question for Ms. Rawson. I think you said your perinatal file is separate, and you have a special system for coding that at the moment. Do you use the perinatal death certificate for maternal and fetal causes?

MS. RAWSON: Yes.

DR. ROONEY: I am very interested in talking to you about such a system.

MS. RAWSON: I have no idea how long before it will be ready, but we can talk about that.

DR. ROONEY: If we could work with you on that, that would be wonderful, because we have no idea how we are going to handle our perinatal deaths when we move to ICD-10. That would be really helpful.

MS. RAWSON: That would be good.

DR. ROONEY: Regarding whether to go for the Windows or DOS version, we were limited to DOS because of resistance to having to develop all the interfaces and things. But now that I have heard that the DOS version does not have any of the corrections and the Windows version does, I am very reluctant to stay with the DOS version for the moment.

MR. RADNOTI: My question is for Graham Jackson. If I understand, only 10 causes of death are stored?

MR. JACKSON: Yes.

MR. RADNOTI: What is the selection criterion for these causes?

MR. JACKSON: We keep the underlying cause plus 10 others—and it is the first 10.

MR. RADNOTI: And the second question is: With your system, what percent of the records is coded manually?

MR. JACKSON: It is hard to say. For instance, we allow the external causes to go through the system, but a lot of the deaths that are external causes need some sort of manual intervention. In some instances, we very specifically want to do additional work.

I mentioned drug-related deaths. In such instances, we seek additional information from pathologists, and particularly information on the toxicology. I would say probably around 20 percent of the deaths have some form of manual intervention.

Poster Session 2
Poster 1: Scanning and OCR as Aid for the Cause-Of-Death Statistic

Jan Kardaun, Dept. Statistical Methods, Statistics Netherlands

2nd International Collaborative Effort (ICE) on Automating Mortality Statistics, Bethesda, Sept. 7-10,1999.

1. Current situation
   - 140 k forms / yr, 2 pages, handwritten causes of death
   - Matching of records with a stream from population statistics is necessary
   - Forms are collected and coded manually. Up to 4 causes per case
   - ICD codes + some demographic info is typed in afterwards. Other demographic data are added by record linkage.

2. Before automated coding, the text of the causes have to be entered in some way and to some degree as computer-readable text. After automated coding, automated ranking of underlying and secondary causes, and multiple-cause coding follow.

3. For automated coding, three approaches possible to text entry:
   - Full text verbatim entry of causes
   - Full text stylized entry of causes
   - Full text entry only of the "middle" part of the causes: the very easy ones and the very complicated ones are left for manual coding. This saves somewhat on data entry time.

4. For the first stage of certificate processing, i.e., everything before automated coding, several gains can be reached by using scanning and OCR technology.
[It must be admitted that these gains are also applicable if not followed by an automated coding phase, but these two developments go very well together.]

5. To further decompose the situation, scanning and OCR will be considered separately, even though — again — these two can be very well combined and mixed. OCR requires previous scanning, but scanning does not need to be followed by OCR. Scanning may be followed by OCR: (a) never, (b) later, or (c) for part of a form. If scanning is not followed by OCR, it can be considered to be a modern variant of microfilming.

6. Scanning, making a digital image of a form, and storing the image in a computer, allows "to get rid of the paper" as soon in the process as possible, as all relevant information on the form is present on the image in the computer. These images can be indexed, stored, fetched, forwarded, annotated, and used for data entry easier than a large collection of forms. This has become feasible in recent years by the increased disk and memory storage capacity, by better monitor screens and faster videoprocessing. Normal PC equipment and generally available programs can perform these tasks, while until recently, special (and expensive) equipment and software was needed.

7. As an aside: until recently, scanning was mostly connected in the minds of people with Optical Character Recognition (OCR), because it was too expensive to store the image. The goal

was to perform OCR on each image, and keep only the recognized ASCII text. Now that image storage is cheap, scanning can be considered on its own, or be combined with various degrees of OCR.

8. How cheap is storage of images? Black and white images with 400 dpi resolution (i.e., the quality falls between the current and the previous generation laser printers) are sufficient for almost all purposes of forms processing. If halftones (screens) are used for shaded areas, it can be advisable to use 600 dpi. One page (8.5 x 11"or A4) takes about 1.7 MB, but this can be reduced to 100–150 kb with compression (without loss of detail). Further reductions can be achieved, but these are not considered here. 140,000 death certificates (annual batch in The Netherlands) of 2 pages each are 24 GB. This fits on one disk of US$500. After one or two safety copies are made and stored separately, no frequent backup is needed.

9. So, why are 140,000 image files to be preferred over 140,000 sheets of paper?
Each form is now accessible within milliseconds; several copies can be in use for reading-only at the same time. Parts of the form can be "covered" if privacy rules are advising this. Form images can be transmitted to other locations for consultation. And MOST IMPORTANT, the images can be easily kept in correct order and can be considered "sorted" on multiple keys, while it takes considerable effort and discipline to keep the paper forms sorted (and in merely one sorting order).

10. Some people claim that paper forms have some intrinsic and very important advantages: they can be read everywhere without equipment, can be read with much less strains for the eyes, and it is easy to make notes on them. As far as straining of the eyes, much has improved by better computer monitors, video cards, and LCD screens. Though it remains a matter of personal taste, for the purpose of forms processing (as compared with reading a book) working from screen instead of from paper does not have to degrade work satisfaction. As for making notes on paper: this can be done with images too (of course, using the keyboard in stead of a pen).

11. Working from form images on screen instead of from paper forms has TWO, distinctive advantages for data entry: It allows entering some parts of the data in a first entry round, and other, less urgent parts later (or perhaps never—while keeping this information at hand). All this is possible because forms can be stored and retrieved easily and multiple times, and adding a few fields to an existing record does not incur the overhead of typing in identifying variables to specify the record to which the information is to be added. So, forms that are hard to read or understand, can be sent "upstream," perhaps in several steps, to more experienced layers of coding experts without worrying about the consistency of the form collection.

The other advantage is the possibility to "cut the image into pieces" (which is not possible with the originals) and work on one variable or one kind of variable at a time; e.g., process first all fields that contain dates, or numerical information; or process all forms with only one cause of death mentioned and this in less than 10 words (assuming that these will be mostly easy ones.)

12. What is OCR, what magic can OCR do?
Optical Character recognition takes a bitmap image (in most cases only Black/White) as input, and tries to recognize what the blobs of "ink" mean. In a first step "blocks of text" have to be

selected from the whole image, ignoring smears, spickles, lines, graphs, photos, etc. This block has to be decomposed in line-, word-, and character boxes. The contents of each character box is matched against a "pattern" of admissible characters, which with modern OCR algorithms can recognize an "A" if it looks like an "A." Also "ÄÅÃÂÁÀĂ" should be recognized, but not all software is good at that. Besides accents, punctuation marks can be hard to recognize if the font is too small.

In general, typeset and typewritten text can be recognized fairly well, as well as checkboxes. Handwritten digits have become within the OCR capabilities recently. Handwritten "printed" letters are harder; and normal, cursive handwriting is impossible to recognize.

13. Now we have mentioned all ingredients of these technologies to introduce the notion of "mixed forms," i.e., forms of which some fields can be OCR-ed (mainly checkboxes and numbers or dates, times) and other fields are too hard for OCR (such as handwritten causes of death). This can be combined with a two-step approach: after scanning, the OCR-fields are processed. The unrecognized fields and the handwritten fields are entered manually from the screen image. Or, more traditionally, the cause-of-death fields are read from screen and are coded and ranked manually into ICD numbers.

14. Are all forms suitable for scanning? And for OCR?

The largest improvement of OCR results can be gained by better design and production of the forms. There are many details in the choice of colors, the lining of "answer boxes," the inclusion of a "completion instruction," in the printing prefixes, suffixes, partially filled-in answers, etc., that can make or break the results of OCR. In particular, people have to be coerced to write the digits of a number separately. All this means that in practice a form has to be adapted for OCR, even though the general design and layout can be maintained.

If a form is intended for scanning only (no OCR), there are less constraints. An important constraint is that a multi-page form has to be cut loose before printing.

15. The important role of an ID# on each form.

Because of this need for cutting loose a multi-page form, and the inevitability that a neatly sorted pile of form-pages will get out of order sooner or later, it is mandatory to have on each page an indication (e.g. a number, perhaps in bar code) that uniquely identifies the page and where it belongs. This shifts some of the burden of questionnaire handling from the collecting to the production and distribution phase.

16. How good are the results of OCR?

It depends; so many minor things can spoil it. But, given a well designed form and good scanning and OCR practice, handwritten numbers will have error rates that are comparable to human entry: around 1 percent. Besides errors, OCR programs have also a category "non-recognizable" (which is a rare category for human readers). OCR programs should be able to increase the non-recognized fraction while reducing the error rate. Not all programs offer this feature. If there is some redundancy, e.g. where numbers have to add up, must be a valid date, or are used for matching with other databases, then the error rate can considerably be reduced.

17. What is the relationship between scanning, OCR and automated coding?

A loose one: scanning and OCR are alternative methods for manual data entry. Automated coding needs full text entry. In the case were many forms are typewritten, full text entry by OCR may be cheaper than manual retyping, but it needs a properly designed form. When certificates are mostly handwritten, full text data entry from image/screen can be organized more efficiently because of its flexibility when working from the paper form.

18. What have we done on automated coding since 1996?

For a feasibility study, 1 month's certificates (approx 11,000) were typed in verbatim. By some simple linguistic preprocessing, about 50 percent of the expressions could be recognized from an "expression" list of 1,350 entries, for which ICD-9 and ICD-10 codes were manually added. We started, obviously, with the most frequent expressions. For the given material, single instance expressions were reached with this method. Visual inspection gave the impression that not many more expressions could be reduced to a common subform without making rules for single expressions, which is not easier than coding them individually. Only with more test material, a larger fraction of expressions is likely to occur multiple times. With the same approach, a recognition rate of 2/3 to ¾ can be expected, while the errors in recognition are very low.
In a next step we had a test of multiple-cause coding on 50 percent of the forms that could be recognized completely (a biased sample), using the ACME ICD-9 tables (thanks to NCHS and Statistics Sweden), and found exact correspondence with our normal production coding in 80 percent of these cases.

19. Summing up

It is our intention to arrive at the following situation:

- A modernized certificate (suitable for scanning and OCR) will be introduced.
- Certificates will be scanned immediately after arrival; all further processing will be done from the image (originals will be archived, just in case…).
- Part of the form, including the information for record linkage will be OCR-ed.

Now the project will follow two tracks:

Handcoding and ICD# enter	Automated coding
▪ Forwarding of difficult cases ▪ Repeat coding ▪ Retrieval of images of similar ICD-combinations ▪ Retrieval for research projects	▪ Needs as first step full text entry ▪ Perhaps for efficiency, not for the top-10 causes nor the complex cases ▪ Selecting and ranking of multiple causes

The hand-coding track ensures the continuity of the statistical process. As far as resources allow, the automated coding system can be set up and gradually integrated. For an efficient, automated coding system, a fairly large "learning data base" of medical expressions has to be collected.

Poster 2: Multi-Cause Coding: A Major Step in Improving Mortality Statistics in Australia

John Alexander and David Jayne, Australian Bureau of Statistics

Introduction

In January 1999, The Australian Bureau of Statistics (ABS) published multi-cause of death statistics for the first time. This step, strongly driven by client demand for more comprehensive mortality statistics to provide a basis for medical research, was the culmination of a long process that involved the search for a suitable coding vehicle, the comprehensive testing of the chosen software, and finally, the implementation of the Automated Coding System (ACS) developed and provided by the United States National Center for Health Statistics (NCHS).

Background to Mortality Coding in Australia

Until 1997, the ABS used a "manual" process to code causes of death. With the use of manual coding techniques, resource constraints restricted coding to the "underlying cause of death," which was assigned in line with guidelines laid down by the World Health Organization (WHO). The underlying cause of death is defined as:

"The disease or injury which initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury."

The medical certificate of cause of death, recommended by WHO for international use, was designed to facilitate the selection of the underlying cause. When more than one condition is entered on the death certificate, the underlying cause is selected using the coding rules of the relevant version of the International Classification of Diseases (ICD). The underlying cause is selected so that preventive strategies can be instituted to address that particular cause. Since its adoption in 1948, statistics based on the underlying cause concept have served the purpose of summarizing international cause-specific mortality statistics into a single index that has been used to assess trends in causes of death.

Introduction of the Automated Coding System (ACS) and Multi-cause Coding

In 1997, after considerable research and testing, the ABS finally commenced the implementation of automated coding using the system (ACS) developed and provided by the United States National Center for Health Statistics (NCHS). Apart from the potential this system has for substantially improving the cost effectiveness of mortality coding, it offers several major benefits:

- Through its use of pre-coded logic, it removes much of the subjectivity inherent in any manual coding system. However, a percentage of coding, including the coding of many external causes, still requires manual intervention.
- It also provides the potential to facilitate the production of more internationally comparable mortality statistics, as the use of this software continues to spread to other countries.
- It facilitates the coding of all causes of death (multi-cause coding).

Multi-cause coding is best defined as:

"The coding of all morbid conditions, diseases and injuries entered on the death certificate, including those involved in the morbid train of events leading to the death which were classified as either the underlying cause, the intermediate cause, or any intervening causes, and those conditions which contributed to death but were not related to the disease or condition causing death."

It is understandably the introduction of multi-cause coding, with its potential to reveal the relationships between the various causes, conditions, and circumstances leading to death, which has created most interest in the user community.

The rationale for introducing multi-cause coding

The current leading causes of death are very different from those that prevailed when the single underlying cause concept was first adopted. Over time, the leading causes of death in most developed countries have shifted from infectious and parasitic diseases to chronic and degenerative diseases, and from infant and child deaths to deaths among the elderly. As the population continues to age, chronic diseases become increasingly more important. Because deaths from chronic conditions commonly occur with a number of concurrent or coexisting conditions, the initiating condition is often difficult to isolate. It has been postulated that some deaths cannot occur without the influence of more than one cause. The ability of the single underlying cause statistics alone to accurately summarize the mortality pattern of a population, therefore, has long been questioned.

When only a single underlying cause is selected for tabulating cause-specific statistics, we lose other valuable information provided on the death certificate such as the immediate cause of death, causes and conditions that intervene between the underlying and immediate causes of death, and many other contributory causes that were involved, but did not directly cause the death. The information lost is often important to the understanding of the process of death. This loss of information is a particular problem for deaths attributed to external causes (injury, poisoning, and violence), which are classified to the circumstances of death (E Codes), rather than according to the nature of injury.

The benefits of multi-cause coding

The need for the ABS to introduce multi-cause coding for causes of death has been recognized for some time. Multi-cause coding is currently undertaken in many developed countries (US, UK, France, Sweden, Norway, Denmark, Russia, Latvia, Canada, Japan, and Brazil). Major Australian users, particularly the Australian Institute of Health and Welfare (AIHW), State and Territory Health Departments, the Sudden Infant Death Syndrome (SIDS) Association and a plethora of medical researchers, were anxious for the ABS to provide information based on multiple cause coding. Major benefits of multi-cause coding include:

- A huge increase in the variety of data available for analysis
- An improved product for matching mortality and morbidity data
- An improved product for internationally comparable data

The four hypothetical examples illustrated in Appendix A reflect realistic coding scenarios and serve to clearly illustrate the advantages of multi-cause coding.

A summary of 1997 multi-cause statistics

In 1997, a total of 366,481 causes were coded for the 129,350 deaths registered during the year, resulting in a mean 2.8 causes per death. The mean number of causes of death varied with age of the deceased. The variation was related to changes in the leading cause of death with age and the likelihood that these causes would have more than one contributory condition reported on the Certificate of Cause of Death.

The overall mean number of causes per death for males (2.9) and females (2.8) was similar. However, the mean number of causes per death varied considerably by age group for both males and females. Males aged 45 years and over had a higher mean number of causes per death than females.

The mean number of causes of death varied considerably for different underlying causes of death. Chapter XVI, Sign, symptoms and ill defined condition (780-799) exhibited a mean of just 1.2 while a mean of 4.1 was recorded for both Chapter XII, Diseases of the skin and subcutaneous tissue (680-709) and Chapter XIII, Diseases of the Musculoskeletal system and connective tissue (710-719). Specific causes with a high mean number of causes per death included accidental falls (4.3), drug dependence (4.2), diabetes (3.8) and rheumatic heart disease (3.6).

Underlying causes and contributory causes

For ease of analysis, it is helpful to dissect multi-cause data into underlying causes of death and contributory causes of death. Contributory causes can be considered to be all those causes that appear on the death certificate, but have not been selected as underlying causes.

Of the 129,350 deaths registered in 1997, about 18 percent recorded a single cause of death. Either one or two contributory causes were reported for just over 54 percent of deaths registered during the year, while only a little more than 5 percent of cases reported five or more contributory causes.

Table 1. Deaths, number of causes reported

Causes	Deaths	Proportion of Total Deaths	Causes	Proportion of Total Causes
	No.	%	No.	%
Underlying Only	23,464	18.1	23,464	6.4
Underlying + 1 Contributory	37,355	28.9	74,710	20.4
Underlying + 2 Contributory	32,569	25.2	97,707	26.7
Underlying + 3 Contributory	19,804	15.3	79,216	21.6
Underlying + 4 Contributory	9,491	7.3	47,455	12.9
Underlying + 5 or more Contributory	6,667	5.2	43,929	12.0

The number of times a condition is recorded on death certificates as either an underlying cause of death or a contributory cause gives an indication of its overall relative importance as a multi-cause of death. The following table gives the 10 leading multi-causes of death in 1997 and their corresponding relativity in terms of underlying causes for this year.

Table 2. Leading multi-causes of death

Causes of Death	Multiple Causes No**.	Multiple Causes %	Multiple Causes Rank	Underlying Causes %	Underlying Causes Rank
Ischaemic heart disease (410-414)	39,085	30.2	1	22.5	2
Malignant neoplasms (140-208)	38,894	30.1	2	26.5	1
Cerebrovascular disease (430-438)	19,769	15.3	3	9.4	3
Pneumonia and influenza (480-487)	16,417	12.7	4	3.9	5
Chronic obstructive pulmonary disease and allied conditions (490-496)	14,706	11.4	5	5.0	4
Hypertensive diseases (401-405)	12,005	9.3	6	0.9	17
Nephritis, nephrotic syndrome and Nephrosis (580- 589)	9,741	7.5	7	1.3	11
Accidents & adverse affects(E800-E949)	9,662	7.5	8	3.5	6
Diabetes mellitus (250)	9,528	7.4	10	2.2	8
Diseases of arteries etc (440-448)	9,343	7.2	9	2.3	7
All Causes	129,350				

** Causes can be included in more than one death and hence, will not add to the total number of deaths.

The top three underlying causes, malignant neoplasms, ischaemic heart disease, and cerebrovascular disease are also the major contributory causes in the majority of deaths registered in 1997. On the other hand, it is interesting to note that, while Hypertensive disease and nephritis, nephrotic syndrome and nephrosis together account for less than 3 percent of total deaths classified by underlying cause, they are contributing factors in up to 17 percent of deaths registered in 1997.

In 1997, only about 18 percent of deaths were recorded without a contributory cause. Understanding the association between the underlying cause of death and the various contributory causes is an important element in understanding the totality of various causes and conditions.

Leading underlying causes and their associations with certain contributory causes

Malignant neoplasms (Cancer 140-208), as well as being the leading underlying cause of death, is also the leading cause reported with no contributory causes. Malignant neoplasms were reported as the single cause in 35 percent of deaths due to cancer registered in 1997. Often cancer acts in conjunction with other cancers. In 1997 where cancer was reported as the underlying cause, 23 percent of these deaths also reported one other cancer as a contributory cause, while 4 percent reported two or more other cancers as contributory causes. Pneumonia and Influenza was recorded as a contributing factor in about 8 percent of cancer deaths while other contributory causes commonly associated with cancers included Ischaemic heart disease and Chronic obstructive pulmonary disease and allied conditions, each of which is present in almost 6 percent of cases.

Ischaemic heart disease (410-414) is currently the second most prevalent underlying cause of death in Australia. In 11 percent of cases where Ischaemic heart disease was recorded

as the underlying cause of death, there were no other contributory causes recorded. In a further 33 percent of cases where Ischaemic heart disease was recorded as the underlying cause, it was accompanied by one or more contributory causes attributed to the broad category of circulatory diseases. Circulatory Diseases commonly occurring in these associations were Hypertensive diseases (almost 16 percent) and Diseases of arteries, arterioles and capillaries (over 10 percent).

Eighteen (18) percent of cases assigned an underlying cause of Cerebrovascular disease (430-438) had no other contributory cause recorded. Hypertensive disease was the major contributing cause, being recorded in 21 percent of deaths from Cerebrovascular disease.

Associations viewed by focusing on contributory causes

Ischaemic heart disease is a major contributory cause as well as a leading underlying cause of death. It is a contributing cause in 51 percent of deaths recorded with an underlying cause of diabetes, in 17 percent of deaths recorded with an underlying cause of chronic obstructive pulmonary disease and allied conditions, and in 9 percent of deaths recorded with an underlying cause of cerebrovascular disease.

Hypertensive diseases (401-405) was a contributory cause in over 8 percent of total deaths registered in 1997. Hypertensive diseases were a contributing factor in 22 percent of deaths from diabetes mellitus, 21 percent of deaths coded to cerebrovascular disease, and in 16 percent of deaths classified to Ischaemic heart disease.

Nephritis, nephrotic syndrome, and nephrosis (580-589) was a contributory cause in a considerable number of deaths recorded in 1997. These included diabetes mellitus (19 percent), heart failure (18 percent), and Ischaemic heart disease (6 percent).

Diabetes mellitus (250) was a contributory cause in over 5 percent of deaths registered during 1997. The major causes with which Diabetes mellitus was associated included Ischaemic heart disease, where it was a contributing factor in 9 percent of these deaths, cerebrovascular disease (7 percent) and malignant neoplasms (3 percent).

External causes of death and multi-cause coding

In 1997 in Australia, there were 7,737 deaths due to external causes. Multiple cause data for external causes of death includes external causes (E800-E999), nature of injury (N800-N999), and natural causes (001-799). There were 24,049 multiple causes recorded for deaths from external causes registered in 1997, giving an average of 3.1 causes per death.

Multi-cause coding also has the potential to greatly enhance the understanding of the death, but in a slightly different way than in the case of diseases. Traditionally, the external cause, (indicated by an E-code), describing the event (e.g., a traffic accident, a hanging, a poisoning) is designated as the underlying cause of death. Nature-of-injury codes summarize the results of the event (e.g., in the case of a road traffic accident, the resultant injuries) so their relationship to the underlying cause is intrinsically different to the associations described above for other causes of death. However, by providing insight into the physical harm resulting from the event, they can be used to investigate the potential for survival. In some cases though, very strong associations can be formed, particularly in cases where natural causes are present. For example, pre-existing conditions such as cancer, and severe depression may link closely to cases of suicide or chronic diseases such as diabetes mellitus may hinder the recovery process from an injury causing an infection, which results in septicaemia and death.

Further enhancement to mortality coding in Australia

Multi-cause coding has indeed been a major step in enhancing the usefulness of causes-of-death statistics as a basis for providing researchers with a better understanding of the circumstances associated with mortal events. A further significant improvement will be completed with the adoption of the 10th version of the International Classification of Diseases (ICD-10) for mortality coding, now underway with respect to deaths registered in 1999. Further improvements will be driven by ongoing efforts to improve the quality of certification through further educating certifiers concerning the importance of the process, and by progressive improvements to reporting forms, including the Certificate of Cause of Death. With respect to multi-cause output, there is potential to improve international comparability through the creation of a "standard set" of tables.

Appendices to the Poster "Multi-Cause Coding; A Major Step in Improving Mortality Statistics in Australia"

Appendix A

Example 1

I	CAUSE OF DEATH	APPROXIMATE INTERVAL BETWEEN ONSET AND DEATH
DISEASE OR CONDITION DIRECTLY LEADING TO DEATH ANTECEDENT CAUSES* MORBID CONDITIONS, IF ANY, GIVING RISE TO THE ABOVE CAUSE, STATING THE UNDERLYING CONDITION LAST	A) **CORONARY OCCLUSION** DUE TO (OR AS A CONSEQUENCE OF) B) **CORONARY ATHEROSCLEROSIS** DUE TO (OR AS A CONSEQUENCE OF) C) DUE TO (OR AS A CONSEQUENCE OF) D)	**IMMEDIATE** **5 YEARS**
II *OTHER SIGNIFICANT CONDITIONS* CONTRIBUTING TO THE DEATH, BUT NOT RELATED TO THE DISEASE OR <u>CONDITION CAUSING IT</u> *THIS MEANS THE DISEASE, INJURY OR COMPLICATION WHICH CAUSED DEATH NOT ONLY, FOR EXAMPLE, THE MODE OF DYING, SUCH AS HEART FAILURE, ASTHENIA," ETC.	**EMPHYSEMA** **SMOKING & HEAVY ALCOHOL ABUSE**	**20 YEARS** **MANY YEARS**.

CODES:
Coronary Occlusion 410
Coronary Atherosclerosis 414.0
Emphysema 492
Smoking 305.1
Alcohol Abuse 303

The deceased, who had a history of emphysema for 20 years and symptoms of coronary artery disease for 5 years, died suddenly following a coronary occlusion.

The Coronary Occlusion (410) is selected as the underlying cause due to the linkage rule. Multi-cause coding allows the retention of information on the coronary condition which leads to the coronary occlusion, (i.e., the coronary atherosclerosis). There are a number of conditions that link with 410 (Coronary Occlusion/Myocardial Infarction). These include: Ischaemic heart disease (acute, subacute and chronic), old Myocardial Infarction, Angina Pectoris, Hypertension and Hypertensive Heart and Renal Disease, Conduction disorders and Cardiac Dysrhythmias. Pre-ACS and multi-cause coding, ABS coders would have assigned a combination drug and smoking flag for the smoking and alcohol abuse. However, this flag does not provide the detail made available by multi-cause coding of the conditions of smoking and alcohol abuse. In addition, pre-1997 manual coding would not have captured the information about the chronic condition of the emphysema that would have contributed to the overall debility of the person.

Example 2

I	**CAUSE OF DEATH**	APPROXIMATE INTERVAL BETWEEN ONSET AND DEATH
DISEASE OR CONDITION DIRECTLY LEADING TO DEATH ANTECEDENT CAUSES* MORBID CONDITIONS, IF ANY, GIVING RISE TO THE ABOVE CAUSE, STATING THE UNDERLYING CONDITION LAST	A) **RAISED INTRACRANIAL PRESSURE** DUE TO (OR AS A CONSEQUENCE OF) B) **PRESUMED CEREBRAL TOXOPLASMOSIS** DUE TO (OR AS A CONSEQUENCE OF) C) **AIDS** DUE TO (OR AS A CONSEQUENCE OF) **D) HIV INFECTION**	**48 HOURS** **2 WEEKS** **4 YEARS**
II *OTHER SIGNIFICANT CONDITIONS* CONTRIBUTING TO THE DEATH, BUT NOT RELATED TO THE DISEASE OR CONDITION CAUSING IT *THIS MEANS THE DISEASE, INJURY OR COMPLICATION WHICH CAUSED	**DEPRESSION**	

DEATH NOT ONLY, FOR EXAMPLE, THE MODE OF DYING, SUCH AS HEART FAILURE, ASTHENIA," ETC.		

CODES:
Intracranial Pressure 348.4
Cerebral Toxoplasmosis 130
AIDS 042.9
HIV 044.9
Depression 311

The patient was admitted to hospital with signs of raised intracranial pressure due to presumed cerebral toxoplasmosis. He/she had AIDS and was known to have been seropositive to HIV for at least 4 years. The signs worsened and the patient developed cerebral coning, dying 48 hours after admission.

An underlying cause of 0420 - Human immunodeficiency virus with specified infection (cerebral toxoplasmosis) was assigned. Multi-cause coding provides more specific information about the type of infection the HIV has caused; that is, it provides us with a more detailed history of the progress of HIV. Having this information facilitates the link being made between HIV and the types of infections or complications in which it results.

Example 3

I *DISEASE OR CONDITION DIRECTLY LEADING TO DEATH* ANTECEDENT CAUSES* MORBID CONDITIONS, IF ANY, GIVING RISE TO THE ABOVE CAUSE, STATING THE UNDERLYING CONDITION LAST	**CAUSE OF DEATH** **A) ACUTE MYOCARDIAL INFARCTION** . DUE TO (OR AS A CONSEQUENCE OF) **B) RECENT COLONIC SURGERY** DUE TO (OR AS A CONSEQUENCE OF) C) **ADENOCARCINOMA OF COLON** DUE TO (OR AS A CONSEQUENCE OF) D)	APPROXIMATE INTERVAL BETWEEN ONSET AND DEATH **HOURS** **DAYS** **DIAGNOSED 6 MONTHS AGO**
II *OTHER SIGNIFICANT CONDITIONS* CONTRIBUTING TO THE DEATH, BUT NOT RELATED TO THE DISEASE OR <u>CONDITION CAUSING IT</u> *THIS MEANS THE DISEASE, INJURY OR COMPLICATION WHICH CAUSED DEATH NOT ONLY, FOR EXAMPLE, THE MODE OF DYING, SUCH AS HEART FAILURE, ASTHENIA," ETC.	**ASCITES** **HEAVY SMOKING**	**20 YEARS**

CODES:
Malignant neoplasm of colon, unspecified, 153.9
<u>Nature of Injury</u>
Cardiac complications, 997.1
<u>Multi-cause codes</u>:
Surgical operation and other surgical procedures as the cause of abnormal reaction of patient or of later complication, without mention of misadventure at the time of operation, unspecified, E878.9
Ascites, 789.5

Tobacco dependence, 305.1

The malignant neoplasm is coded as the underlying cause. Under the manual coding regimen, the operation (external cause) reported for this case would have been "invisible." Multi-cause coding also identifies the other significant conditions mentioned in Part II of the Medical Certificate.

Example 4

I *DISEASE OR CONDITION DIRECTLY LEADING TO DEATH* ANTECEDENT CAUSES* MORBID CONDITIONS, IF ANY, GIVING RISE TO THE ABOVE CAUSE, STATING THE UNDERLYING CONDITION LAST	**CAUSE OF DEATH** A) **BRONCHOPNEUMONIA** DUE TO (OR AS A CONSEQUENCE OF) B) **FRACTURE RIGHT NECK OF FEMUR** . DUE TO (OR AS A CONSEQUENCE OF) C) **SENILE DEMENTIA AND DEBILITY** DUE TO (OR AS A CONSEQUENCE OF) D)	APPROXIMATE INTERVAL BETWEEN ONSET AND DEATH **2 DAYS** **1 WEEK** **YEAR**
II *OTHER SIGNIFICANT CONDITIONS* CONTRIBUTING TO THE DEATH, BUT NOT RELATED TO THE DISEASE OR <u>CONDITION CAUSING IT</u> *THIS MEANS THE DISEASE, INJURY OR COMPLICATION WHICH CAUSED DEATH NOT ONLY, FOR EXAMPLE, THE MODE OF DYING, SUCH AS HEART FAILURE, ASTHENIA," ETC.	**NON INSULIN DEPENDENT DIABETES MELLITUS**	

CODES:
Fracture, cause unspecified, E887.9 (Underlying cause)

Nature of Injury
Fracture of neck of femur, unspecified part, closed, 820.8
Other early complications of trauma, 958.8
Multi-cause codes:
Senile dementia, simple type, 290.0
Debility, unspecified, 799.3
Diabetes mellitus, adult-onset type, 250.0

The E- code (887.9) assigned as the underlying cause of death reflects the effects of a fall, an event that is commonly reported for deaths of older persons resulting from external causes. Unfortunately, the code is quite unspecific and provides only very limited information about the death. The additional information provided by multi-cause coding expands the picture considerably. Information on the nature of the trauma sustained helps interpretation of the fatal outcome. The conditions shown as 'multi-cause codes' may have acted as risk factors.

SESSION 8

Language Issues

Language Issues

Gloria Pérez-Albarracín (moderator), Chief, Catalonia Mortality Register, Department of Health and Social Security, Spain

Good morning. It is a pleasure for me to participate in this session. In my opinion, language is an important issue. In 1996, in the first International Collaborative Effort meeting, it was very surprising to me to realize that, even English-speaking countries needed to change the spelling of medical terms in order to use MICAR or SuperMICAR. The question is: What can we do when the language is French, German, Spanish, or Swedish? We would like to discuss this in this session.

Thanks to all panelists, and we begin the session with the presentation of Michal Schopen from Germany.

Electronic Publishing of the German Language Edition of ICD-10

Dr. Michael Schopen, Deutsches Institut für Medizinische Dokumentation und Information (DIMDI), Germany

My presentation is not directly related to automated cause-coding systems, but it is related to how the national language version of ICD-10 can be kept in a computer system in order to make multiple uses of it and perhaps to use it for automated cause-coding systems later.

Let me just say what DIMDI is. DIMDI is the German Institute for Medical Documentation and Information, situated in Cologne. We have been responsible for ICD-9 and for the maintenance of its German language edition for more than 20 years. When we heard that ICD-10 would become subject to annual updates, we had the strong feeling that something had to be changed in the maintenance of this classification.

We felt that a flat ASCII file was no longer sufficient. If we want to promote the classification, then we must meet the needs of our users, and then we must offer files of the classification that can be used for a wide range of products, starting with conventional book printing, going to the production of CD ROM, up to the integration into information systems or coding systems. If we do not want to keep track of classification changes in all these products separately, then we need files that can be transformed automatically into these products.

So, what we need is easy data maintenance in one place, suitable as a single source for a wide range of products, and open to structural changes over the time, being independent of hardware or software.

Is that possible? And if it is possible, how can it be achieved?

Electronic publishing

Electronic Publishing is the use of electronic means to make information available for public consumption. Perhaps this definition is too simple. To make it more complicated, it is the consistent application of certain international standards. One of them is the Standard Generalized Markup Language (SGML), which aims at the logical or semantic representation of documents, independent of their layout. Another standard is the Document Style Semantics and Specification Language—nobody can keep that in mind, so it is abbreviated DSSSL—which aims at the description of the layout of such documents.

So, we have the separation of contents and layout. I will give you a quick example of what that means.

Slide I: An example from Chapter II

CHAPTER II

Neoplasms (C00-D48)

Malignant neoplasms (C00-C97)

Malignant neoplasms of urinary tract (C64-C68)

C67 Malignant neoplasm of bladder

C67.0 Trigone of bladder

C67.1 Dome of bladder

I guess everybody in this room knows what is on this slide. The Tenth Revision of the International Classification of Diseases is a document with a very clear structure. It has chapters, with a chapter title and a coding frame. It has blocks with their titles and their coding frames. And it has categories within these blocks and subcategories within categories.

These logical elements of the classification go along with certain layout features. Category codes are printed in white on a black background, and the coding frame is printed in parentheses, both codes being separated by a dash.

These are nice features, but they are not necessary to understand the classification. We could use other layout means to transfer this information to the reader.

Standard Generalized Markup Language

On the next slide, this document is reduced to mere information and semantics. Information is printed in black, semantics in gray.

Slide II: SGML: markup and text

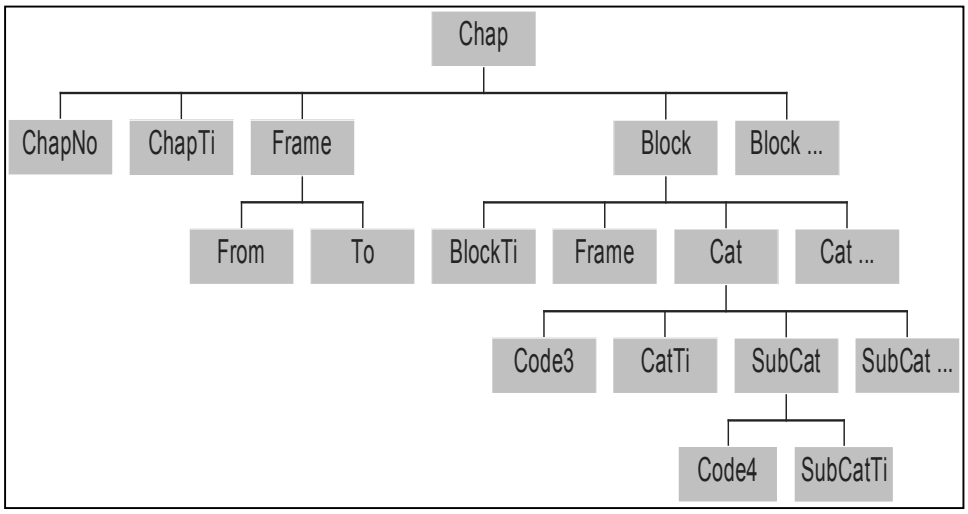
```
<Chap><ChapNo>II</ChapNo>
<ChapTi>Neoplasms</ChapTi>
<Frame><From>C00</From><To>D48</To></Frame>
<Block><BlockTi>Malignant neoplasms</BlockTi>
<Frame><From>C00</From><To>C97</To></Frame>

<SubBlock><SubBlTi>Malignant neoplasms of urinary tract</SubBlTi>
<Frame><From>C64</From><To>C68</To></Frame>

<Cat Prefix="Malignant neoplasm"><Code3>C67</Code3>
<CatTi>Malignant neoplasm of bladder</CatTi>

<SubCat><Code4>C67.0</Code4>
<SubCatTi>Trigone of bladder</SubCatTi></SubCat>

<SubCat><Code4>C67.1</Code4>
<SubCatTi>Dome of bladder</SubCatTi></SubCat>
</Cat></SubBlock></Block></Chap>
```

Let us go through a part of this slide: <Chap> indicates the start of the chapter element, <ChapNo> the start of the chapter number—the chapter number itself being "II"—</ChapNo> marks the end of the chapter number, <ChapTi> the start of chapter title, the title being "Neoplasms," </ChapTi> indicates the end of chapter title. <Frame> marks the start of a coding frame, the first code starts with <From>, it is "C00" and ends with </From>. The next code starts with <To>, it is "D48" and ends with </To>. Finally, the coding frame ends with </Frame>.

If I talk to medical experts, I print information in black and markup in gray. If I talk to computer experts, I print markup in black and information in gray. You are interested in information, computer experts are interested in the structure. They need the markup to process these files.

If you come back to the coding frame, you will see the separation of content and layout. There are no parentheses, and there is no dash proceeding "D48." This information can be kept in a separate file, let us call it a style sheet, and can be added to the document during the production process.

Slide III: Document Tree



If you have such well-structured documents, you can load them into computer memory. This will give access to the whole hierarchy of the document, chapter, chapter number, chapter title, the frame, the children of the frame, the blocks, categories, subcategories, etc.

Now we can ask questions like: "To which chapter does this subcategory belong?" or questions like: "What is the category title for this subcategory?"

Let us sum it up. The text is divided into logical elements. The start and the end of each element is clearly indicated by markup strings—we call them tags—and the elements may be nested to reflect the hierarchy of the classification. The text is not divided into layout units. There is no layout information at all, as layout information would inhibit the reasonable use of this data by a computer, and as layout information can be added later on.

SGML uses only seven-bit ASCII characters and, thus, is easily portable across computer systems, and independent of special software and hardware.

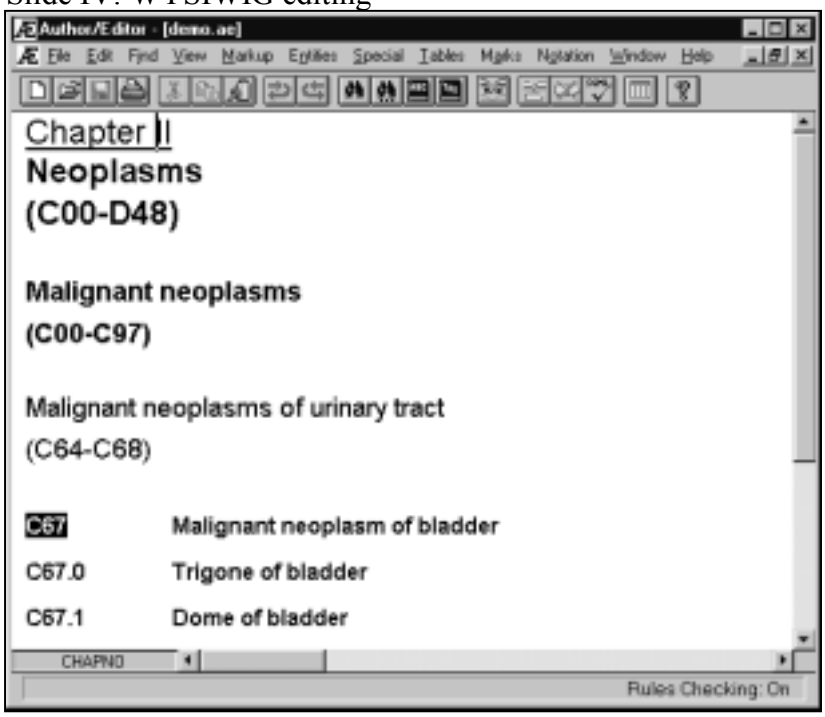
Well, how can we arrive at SGML files? There are two ways. The hard one: you, being the author of ICD-10, have to key in the elements, structural components and special characters. Maybe, for a book of 1,200 pages this is not the easy way. However, we learned that there is so-called auto-tagging software available, by which you can convert your documents from plain ASCII into SGML. Together with the German GMD National Research Center for Information Technology, we used such auto-tagging software to set up the very first SGML files of the German Language edition. It took us less than one week of manual work to arrive at the final files, mainly struggling with the curly braces in the inclusion notes.

After that, we were able to set up a processing environment for these SGML files. What we can do is editing for the maintenance of ICD, formatting for high quality output, and conversion into other data formats.

Production environment

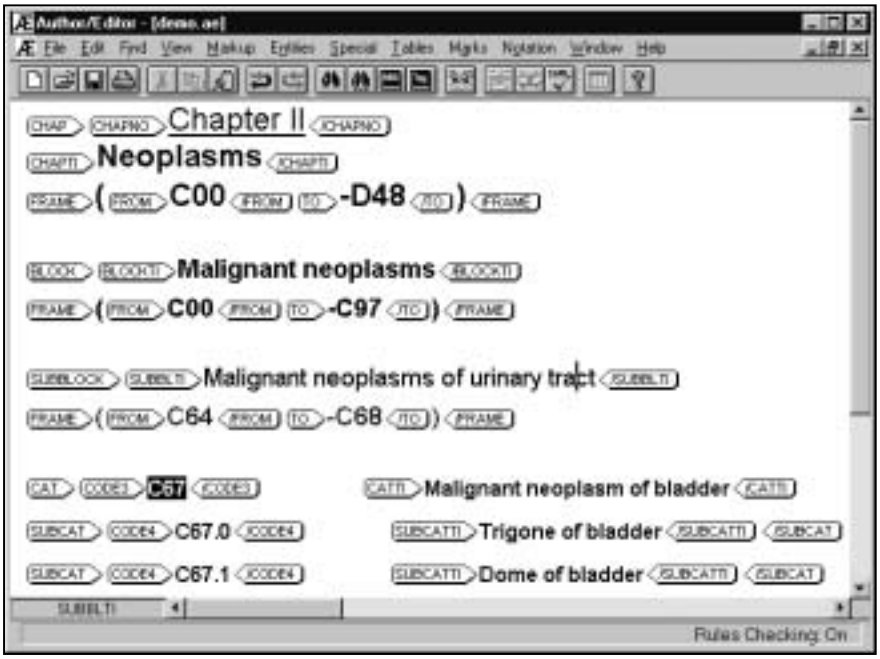
Editing of SGML files is very convenient in a Microsoft-Windows based environment. So, the next slide shows a screen from our SGML editing software.

Slide IV: WYSIWIG editing



It looks like the ICD-10 book. Just by pressing one key, we arrive at a structural view, which gives us the logical elements of the classification. Now we can add elements, delete elements, and make changes to ICD-10.

Slide V: WYSIWIG editing



The next step is formatting. I already said that formatting is based on the Document Style Semantics and Specification Language (DSSSL). At the moment, there is software that supports TeX, Rich Text Format, HTML, and the FrameMaker Interchange Format as output formats. We only use Rich Text Format for ICD-10 and convert that to Postscript, which is used for printing.

Just as an example, this slide shows the German language edition, loaded into Microsoft Word, formatted by a shareware DSSSL engine.

The next step is data conversion. At the moment, we offer HTML files for ICD-10 running on our web server. They can also be used to set up ICD-10 in a hospital intranet.

We still have good old plain ASCII for the traditionalists, and we have the special SGML to SGML conversion—I will talk about it a bit later—to make ICD-10 more suitable for computer systems.

What you should keep in mind is that SGML can be converted to virtually anything. If you decide one day to leave your SGML approach, a change to another system should create no problems. But you probably will never do that.

The next slide shows the German language HTML version on our web server. Again, the layout is very close to the book version, but if you look at the codes and the exclusion notes, they have become hyperlinks now, and you can jump very quickly to any code in the classification by a mouse click without turning pages in a book. There is some navigational framework around it, taking you to the list of the chapters, to the beginning of a chapter, to the block lists in the chapter, and to the preceding or following block.

Electronic version

If we look at the book version, there are certain things that create problems in data processing, mainly in chapters II and XIX.

Slide VI: Print version vs. electronic version

Chapter II Neoplasms (C00-D48)	Chapter II Neoplasms (C00-D48)
Malignant neoplasms (C00-C97)	Malignant neoplasms (C00-C97)
Malignant neoplasms of urinary tract (C64-C68)	Malignant neoplasms of urinary tract (C64-C68)
C67 Malignant neoplasm of bladder	C67 Malignant neoplasm of bladder
C67.0 Trigone of bladder C67.1 Dome of bladder	C67.0 Malignant neoplasm: Trigone of bladder C67.1 Malignant neoplasm: Dome of bladder

We have subcategories that can only be understood together with the category titles. For diabetes or hernias, we have subclassifications that say how to form subcategories. But if you look into the classification, the subcategories are not listed. This is not easy for a computer to process, and we decided to create a special version for computer systems, which we call the electronic version. It provides full titles at the subcategory level, and also explicitly listed subcategories for diabetes, hernias, etc. If you remember the slide with the document tree, then you know it is very easy to ask a question like: "Give me the title of the category," and then you can create these full titles automatically.

The same applies to the subclassifications. In the document tree, you go back to the subclassifications, pick up the fourth character, and you can form your subcategories.

At the moment, we offer the following products: the book version (SGML, HTML, Rich Text Format, and ASCII), and the electronic version (SGML and ASCII). The electronic version is not available in Rich Text Format or HTML, as we think that this does not make much sense.

Errata and meta data file

We use special markup for corrections and updates. This special markup allows us to create the correction lists fully automatically. They were delivered in ASCII, up to the last year. This year, we switched to Rich Text Format and Portable Document Format to make them more readable.

There is another version created automatically, which we call the "meta data file." It is delivered as character separated values (CSV), can easily be loaded into relational database systems and contains the skeleton of the classification—chapters, blocks, categories, subcategories, certain five-character codes. For each level, codes and titles are listed. This file contains special data to produce statistical tabulations, either based on the hierarchy of ICD-10 or

on the Special Tabulation Lists and offers some information on patient sex for quality and consistency checks.

All files are available free of charge from our web server. So, if you do not believe me, pick them up and look at them.

Language independence

The SGML elements can be regarded to be containers for information. This information does not depend on the language. When we realized that—one-and-a-half years ago—we decided to do a little experiment. We took our auto-tagging software and converted WHO's ASCII files of the English version into SGML. Suddenly, all transformation and formatting procedures could be applied to these files without any substantial changes. The only thing we had to change was, for instance, the German word, "Hinweis," into the English word, "Note," or "Exclusiva" into "Excludes." Then we arrived at an English version in HTML and in Rich Text Format.

Just to show you the HTML version, there you are, in English and, again, you get your hyperlinks for the exclusion notes, and you get a navigational framework for easy moving through the classification. When I was able to feed the English HTML version into Netscape and when I followed the first hyperlink, I was so happy that I had a vision, a vision of sharing resources.

If we agree upon a common document structure for ICD, and if we distribute ICD in suitable data formats to all countries, and if we maintain our national language versions in the same data format, then we can share a common pool of transformation and formatting procedures, which are applicable to all national language versions. We could save money and time and offer a wide range of products to meet the users' needs. I am sure that this would be a considerable step forward in the promotion of ICD-10 all over the world. Thank you very much.

Swedish Language Standardization Strategy

Lars Age Johansson, Senior Executive Officer, Statistics Sweden

We started experimenting with electronic dictionaries in Sweden, I think it was in 1988. Of course, computer technology has advanced enormously since then. Perhaps our experiences could be of some use by showing what kind of difficulties one has to cope with when trying to build a dictionary from scratch without the possibility of using a ready-made dictionary from some other country.

First, if we take a look at the kind of language that you might expect to find on Swedish death certificates, the first thing is that we have, in fact, three parallel terminologies on Swedish certificates. We have, first, classical Latin and Greek. That is a historical tradition since the Swedish physicians were trained in Germany.

In the late 1970s, the Swedish parliament issued new legislation saying that everybody has an unconditional right to see the medical records that concern them. By extension, that has been applied to the death certificates as well. The closest relative has the right to see the death certificate. Accordingly, there was a recommendation or a decree from Swedish parliament that the language in the medical records and death certificates must be understandable. So, out goes the Latin.

What came instead was a terminology, something akin of what you have in the English-speaking countries and the romance languages. It is built on Latin and Greek, but you have accommodated it to suit your languages a bit better. But we still have phrases in the classical Latin. There were also quite a few physicians who did not like the new legislation and refused to comply with it.

We also have quite a few certificate terms in vernacular Swedish. That is, terms which are not derived from Latin and Greek, but rather from Germanic or old Norse roots. The problem with these vernacular terms is that they are less precise than the normal medical terminology and very often they seem to fall somewhere in between one, two, or three ICD categories, and it is very difficult to know exactly where to put them. Even so, the language found on death certificates had fairly few basic components, at least compared to normal spoken Swedish.

On the other hand, there are lots of minor variations. In the first experiments we did, we counted about 38,000 expressions. We found that 32,000 were used only once, if you take into account all the variations in spelling, punctuation, et cetera.

Since the variations were quite small, we decided to try near-exact matching. Namely, you had a term you wanted to code, and you started searching the dictionary for something that is as similar to it as possible, and then you hoped it was the same condition. This was done in the early 1990s. You would calculate some kind of fingerprint reference number for all the terms in the dictionary. You would then calculate, according to the same algorithm, a number for the term you wanted to code. Then, you would start the dictionary for the numbers that were closest to the number of the term you wanted to code. The program would then return a list of perhaps 10 terms that would be candidates for the coding. I hope this is clear.

We found, however, that we would very often get similar texts that meant quite different things. We were working with what is called the “threshold value,” which is the numeric difference between the two expressions that you are willing to accept in making this procedure; it

is a measure of the similarity between the two expressions. We found that, to get only correct returns from the dictionary, we had to use such a high threshold value, that we might as well have used exact matching only, and it would even have returned the answer quite faster than the near-exact matching method. So it seemed that even small variations—one single letter, perhaps—could give a term quite a different meaning.

I believe this is due to the structure of medical language. Many medical terms have one part that tells you about the anatomical site of the disease process and another part that tells you about the nature of the disease. The "nature" part is almost always near the end of the word. For instance, in the word "cardiopathy," "cardio" has something to do with the heart. "Pathy" does not say very much, just that it is a disease. "Hepatoma" tells you liver and tumor.

Now, in Swedish, we very often delete the last syllable. We do not say myocarditis, we say myocardite; not pancreatitis, but pancreatite. That means that just the last syllable would specify the disease process. So, obviously, any matching strategy that does not assign a relatively high weight to the last part of the word will not work. Instead, we decided to rely on exact matches only. The terms had to match letter for letter. We also decided that if you wanted to code a phrase, consisting of several terms, every word had to match. That was to avoid the Scottish problem with volcanic eruptions [see Graham Jackson's presentation on *The Implementation of Automated Coding in Scotland*, Session 7]. We found quite often that if you had a phrase of perhaps five words, you could find four of them in the dictionary, but the last word would very often change the meaning of the entire phrase.

Given the problem with all the variations, we also decided to use an extensive text standardization procedure for parsing or sanitizing the input from the death certificate. We removed blanks, hyphens, and redundant words. We have a large set of synonyms, substitutions, et cetera. We take care of the stops. We need all that because the spelling of Swedish medical terminology is extremely unstable at the moment. We have influences from German, from English, from classical Latin, from Greek, very often jumbled together in the same word.

We can make exceptions, of course. For instance, the word "left" and "right" often do not affect the coding. They do in some instances, as for heart failure. So we keep them if the word heart, cardiac, cardio, et cetera, occurs in the phrase.

We have removed from the phrase some of the items that would influence the coding. For example, we have the phrase separators. For some reason, doctors do not always use lines A, B, and C on the death certificate. Instead, they write out in full: "pneumonia due to immobilization caused by rheumatoid arthritis." So, in the coding system, we remove "due to" and "caused by" and store the separate entities in separate variables. Then, when all the coding is done, it will rearrange the codes according to what these phrases mean.

We want to remove, in the same way, anything that has to do with treatment, surgery, procedures and durations. They are stored in separate variables and in some cases will influence which code we will select. We do this in a single step. So, when the coder presses the key for phrase coding, Mikado will first try to find a match in the dictionary. It will then, if necessary, parse the phrase and, finally, it will apply the modifications to the code, if necessary. So, when the coder is finished with a record, he or she will see on the screen exactly the same codes that will go on to ACME. There will be no modifications at a later stage.

With that strategy, we succeeded in ICD-9 in coding about 90 percent of the terms that we found on the certificates. If we were not to use the standardization of the parsing procedure, we would only be able to code about 40 percent. In ICD-10, we have not quite achieved the 90

percent yet. I think with good typing, we will achieve something around 88 or 89 percent, but we manage this with a quite small dictionary.

We have, in our basic dictionary—which does not contain any synonyms—about 6,000 terms. In the expanded dictionary, which does contain the synonyms, we have about 15,000 terms. Still, we get very good results.

The drawback is that the parsing procedure is extremely complicated. It has about 15 steps. We have nine tables containing specifications on how the substitutions, deletions, et cetera, are to be made. It is quite difficult to maintain this procedure. I designed it myself, but I hardly dare to touch it any more, because I do not know what will happen.

Just to conclude this: I have had several questions as to why we do not use the reference numbers. There is nothing dramatic about that. It was simply that we found early on that we would not be able to use the English dictionary. We tried to match Swedish terms in our dictionary to the MICAR dictionary. We got a match for about 30 percent of the terms. Just the work to create new Entity Reference Numbers (ERNs) and figure out what would give the best match for the remaining two thirds proved so much, that we really preferred to build a dictionary of our own. When we did that, we simply found it easier to work with standardized text phrases rather than with numbers. The MICAR dictionary works in very much the same way. The standardized texts have approximately the same functions as the ERNs. Of course, if Sweden had been an English-speaking country, we would have been very grateful for the MICAR dictionary, including the ERNs.

Thank you very much.

French Issues

Gérard Pavillon, Head, WHO Collaborating Center for the International Classification of Diseases in the French Language

Our problem in France is much simpler than in some other countries because we have only one language. Also, we had the advantage that, in France, we had a university-based effort dealing on medical language parsing since the beginning of the 1970s. I was involved in this movement. So for the French index, the development was based on the diagnoses mentioned on death certificates; that is, we built the index from the diagnoses mentioned on death certificates and not from the ICD-10 French index. In this index, diagnoses are stored without extraneous grammatical words. The separation of each diagnosis reported is done manually. For example, for the condition "infarctus du myocarde" in French, we remove the grammatical word "du"—which is an article—and we store "infarctus myocarde."

We keep all the different names or expression of the same disease. For instance, for the same ICD-10 code I21 of myocardial infarction, the database includes at present more than 60 different expressions.

We also have a simple process for abbreviations and synonyms. Besides the main database table, we have a list of synonyms and abbreviations that we can substitute in order to obtain the canonical form of the diagnosis stored in the database. The word "cancer" for instance accepts about 20 synonyms. In the index, only the canonical forms with the word "cancer..." are stored. The other equivalent expressions are generated with the list of synonyms.

We also have a separate table for the codes with an "n-to-n" correspondence between the diagnosis table and the codes table. It means that a code can correspond to several expressions and that one expression can lead to several codes. When a given diagnosis leads to several codes, the final choice depends on other data such as sex or age. For example, P codes are assigned or not depending on the age of the decedent.

Thank you.

DECES: Automated Coding Of Medical Entities by Means of Neural Networks

Gloria Pérez-Albarracín, Chief, Catalonia Mortality Register, Department of Health and Social Security, Spain

Physicians declare the causes of death in literal writing when they certify a death. In order to obtain mortality statistics, it is essential to attach an ICD code to the medical entities declared by physicians.

In 1993 in Catalonia, we adopted the NCHS MICAR dictionary, which is used to record medical entities and to assign the intermediate codes called Entity Reference Numbers (ERNs). After exploring its characteristics, we made some decisions: first, to use ERNs as codes attached to medical entities, which in turn would connect them to ICD codes. Secondly, we decided not to translate the MICAR dictionary because some disease terms may have different interpretations in Spanish and English, making it difficult to find good, direct translations. Moreover, we have two co-official languages in Catalonia (Spanish and Catalan), so we would have had to translate the MICAR dictionary of 140,000 sentences to both languages.

Therefore, we decided to develop our own software for entry and recording of medical entities, which should be able to assign ERNs, allowing us to bypass MICAR 200 and use the other NCHS packages ACME and TRANSAX. We thought then that we needed to find something better than a dictionary for dealing with the problem of two languages. The solution was to develop an expert system based on a neural network that could record literal causes of death and match them to their ERNs. The software was called DECES—that means "death" in Catalan, as well as in French.

The project was developed by a team composed by members of the Catalonian Mortality Register, and by members of the Informatics School of the Polytechnic University of Barcelona. This project was sponsored by the Catalonian Autonomous Government and by the Spanish Ministry of Health.

At the beginning of the project in 1994, we obtained a random sample of 1,500 death certificates and a list of terms of causes of deaths declared by the physicians. These were needed to build the base of the neural network. We obtained 3,882 terms that way. The words of the different terms obtained in the random sample were analyzed from the morphological and semantic point of view. We assigned ERNs to these terms, as chosen from the MICAR dictionary. We decided to assign the ERN to the same medical entity, even if it was differently written, abbreviated, or either in Spanish or Catalan. Then, Acute Myocardial Infarction or AMI or "a. myoc. Infarction," written in different ways, received the same ERN. That way we avoided introducing variants of an ERN for the same disease or medical entity.

A neural network was used to discriminate and classify text entries—in this case, medical entities—by phonological similarities between words. Neural network building must necessarily be gradual. It is virtually impossible to identify the exhaustive set of terms to be incorporated, and it employs a conservative dynamic upgrade that incorporates new sentences without affecting the power of classification of the current set of sentences.

Figure 1 shows how our neural network works. We have the sentence that the physician writes in a death certificate; in this case, brain infarction, cerebral infarct. The system splits the

sentence into two words (cerebral and infarct). These words are connected with the words in the neural network, and the line is activated depending on the degree of similarity or proximity. At the same time, the word inside the neural network, by means of an input value, activates the sentences inside, and at the end of the process, the sentence with a very high weight activates an output; an ERN code.

Figure 1: Normal operation of neural network

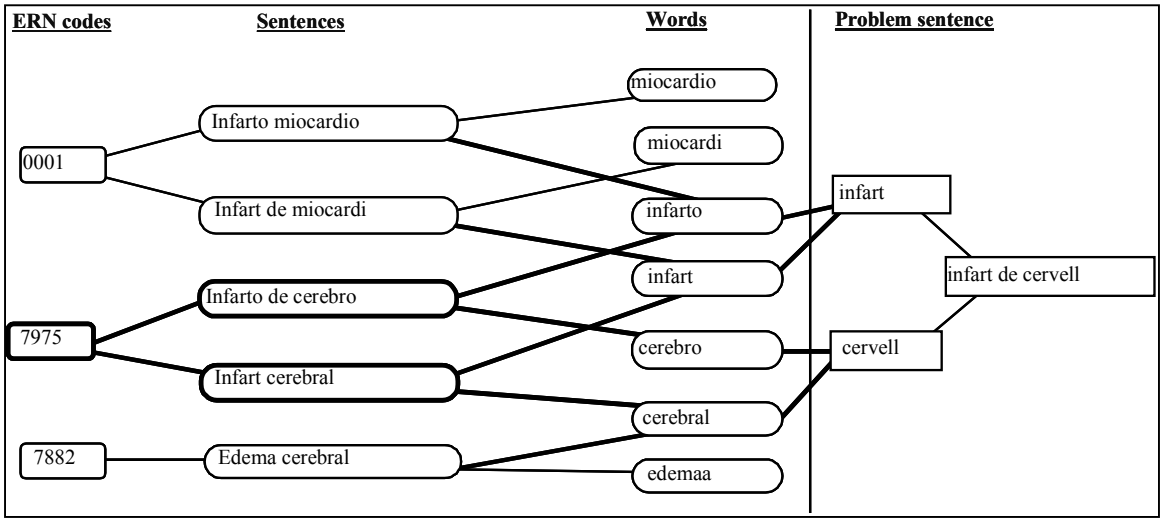
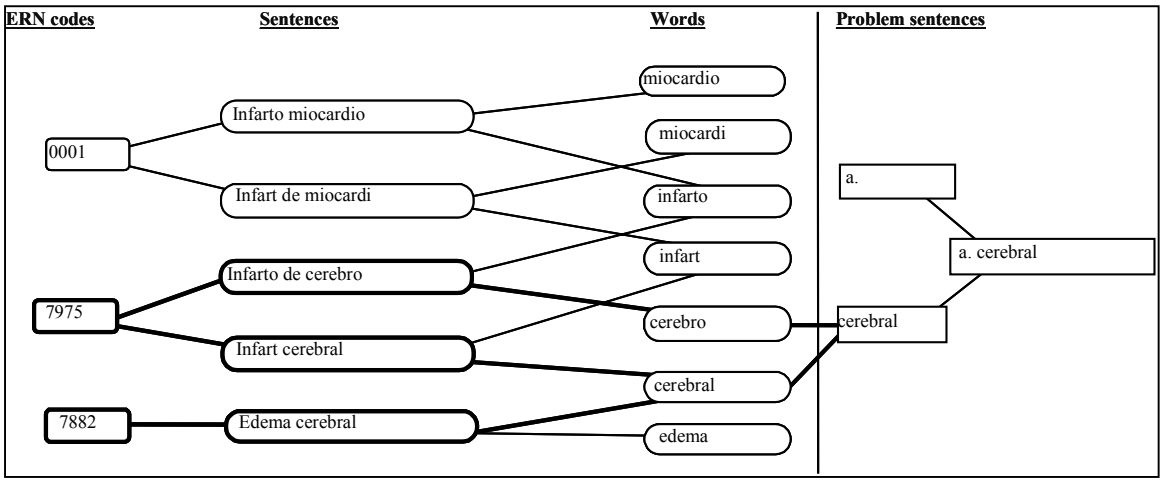


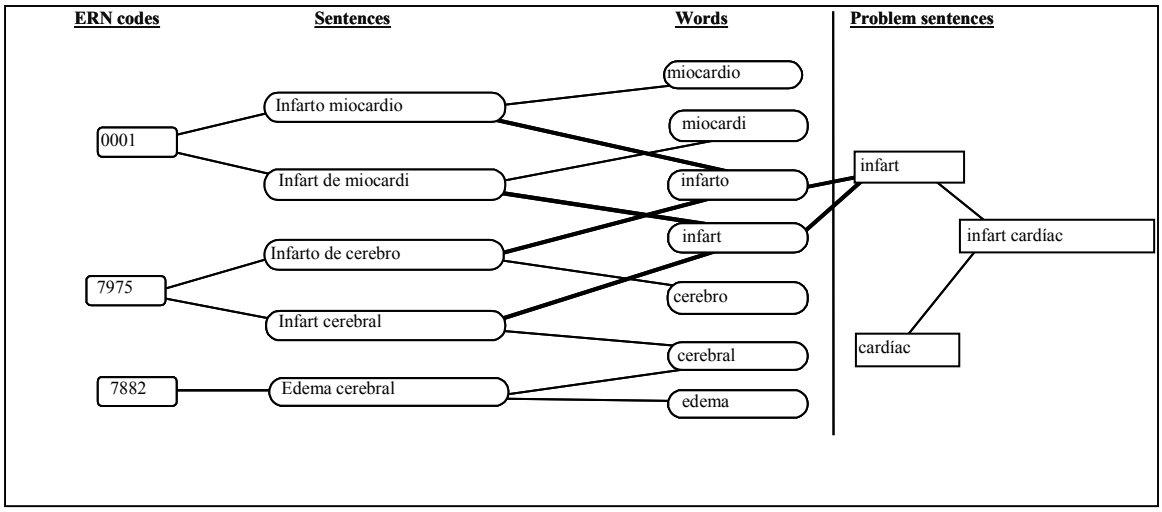
Figure 2 shows an example of abnormal operation of the neural network. In this case the system cannot find enough weight to activate any output for the text "a. cerebral" (a. stands for arterioesclerosis), and it proposes two possible solutions (two ERNs), among which one must be chosen. In such a case, we need to incorporate arteriosclerosis to the knowledge base of the neural network.

Figure 2: Abnormal operation: more than one ERN code activated



Another abnormal operation is when the neuronal network cannot choose the solution because there are a lot of similar sentences and it cannot choose an ERN (figure 3).

Figure 3: Abnormal operation: no ERN code sufficiently activated



The performance of the neural network was checked on a different random sample of 1,067 death certificates. That corresponds to approximately 3.5 percent of all the death certificates in a year in Catalonia. The sample was representative in its sex and age composition, and all medical entities were coded by an expert who was regarded as standard. Overall, 95 percent of all manually coded medical entities in the sample were also coded by DECES, and the total agreement was 94 percent. In table 1, you will see the accuracy indicators where the sensitivity and the predictive positive value were very high and the specificity and negative predictive value was very, very low. In spite of that, the conclusions are that the success rate was 93.2 percent. This figure can only increase asymptotically to approach 100 percent accuracy.

Table 1. DECES neural network accuracy indicators

ACCURACY INDICATORS		95% CI
Sensitivity	94.71	93.93 - 95.47
Positive predictive value	97.75	97.22 - 98.27
Specificity	76.76	71.96 - 81.56
Negative predictive value	57.57	52.70 - 62.40

CI= confidence Interval

Future research into the algorithm aspect of the system should tackle the improvement of overall efficiency. The storage and indexing systems must be rethought so that the automatic

coding time becomes virtually instantaneous. We also need to increase the speed of inclusion of new terms. This, at the moment, is a little bit slow. We are working in increasing the system's decision capacity, and we are exploring other data entry systems, such as scanners and voice recognition.

Thank you very much.

Discussion on Session 8: Language Issues

PARTICIPANT: I would like to know about the neural network system. It seems to me that you do not do any language preprocessing. Is that system also applicable to other languages?

DR. PÉREZ: The Catalonian and the Spanish languages are very similar, and the neural network applies a common language preprocessing to both. It consists of eliminating language particles that do not contain information (articles, prepositions), and then transforming some vowels and consonants. The text is treated in a similar manner as that described by Lars Age.

There are some words that are not so similar and we need the help of another separate table with synonyms. In this table, we have the definitions from Catalan and Spanish. I do not know if such a system could be adapted to other languages. We have not tried it.

PARTICIPANT: Dr. Schopen, did you encounter any copyright problems in your project, converting ICD-10 to electronic publishing?

DR. SCHOPEN: We did not have copyright problems for the German language version because we own the copyright. If you want to see the English version of ICD-10 on the internet, that is not possible, due to copyright restrictions.

PARTICIPANT: Dr. Pérez, I think when you were developing DECES in the first place, you started from actual death certificates and then built up the terms gradually. I think you told us at a previous meeting once that you could do 80 percent of the deaths with about 2,000 terms, something like that. Is that right?

DR. PÉREZ: Yes, it was—approximately 2,000.

PARTICIPANT: So, if you start with the commonest phrases on the death certificate, you can actually develop a dictionary for a given language quite economically. I just think this could be useful for people trying to do it in a lot of other languages. Spanish is used around the world. A lot of other people here are trying to develop it in languages that are not very widely used, and to realize that you do not have to translate 160,000 terms makes it easier.

DR. PÉREZ: Yes, it is true. We are working now with about 4,600 terms inside the system. Now our growth rate is low because we are already coding 90 to 92 percent of all death certificates.

We say that we are now in the "extinction" part of the curve, where infrequent medical terms are being added. We sometimes debate whether to introduce these new items in the system or not.

Maybe the terms we add will be only used once a year or maybe every 3 years, but sometimes we decide to introduce the term. I agree; it is truly a small dictionary.

MR. PAVILLON: I do agree with what Gloria Pérez said. I would like to say something about medical language that may have an effect on the development of such an application: medical language is changing over time. We often see new expressions that we have to include in the index and this procedure must be easy.

PARTICIPANT: Monsieur Pavillon: since you showed that in the French language there are so many diagnoses for myocardial infarction, do you limit your expression to just myocardial infarction or do you have many different expressions for that condition?

MR. PAVILLON: We have many expressions corresponding to the same code, but we store all the different expressions.

MS. ARGAIZ: I am Georgina Argaiz from INEGI, Mexico. I would like to ask how much time does it take for this process to begin. We are initiating our activities in this project, so I would like to know how many years or months we should wait until we can expect to see the first results.

DR. PÉREZ: I could say 2 months, but it actually takes years. With this project, the design and all the development took 2 years. We began in 1994. In 1995, we made the initial evaluation and in 1996 we began with full coding, so it took 2 years.

MR. JOHANSSON: In Sweden it was about the same. I think it took us 2 or 3 years to build a dictionary and to build the standardization tables to achieve those 90 percent of matches.

On the other hand, when we converted from ICD-9 to ICD-10, we made—just like in Catalonia—frequency counts. We counted which terms in the dictionary we used most frequently. We coded the terms that had been used at least three times into ICD-10. That reduced the dictionary size to about 4,000. That took us about 4 months.

MR. PAVILLON: It is difficult to answer to this question, because we were not working full time on this program. I would say that the index, the application and the database took us less than 1 year. At this point we have more than 4,000 expressions, leading to a potential of 20,000 expressions with the table of synonyms and expressions, and we cover 85 percent of the deaths. I think that we will be obliged to have about 6,000 expressions to cover more than 90 percent of the deaths.

PARTICIPANT: About your system, you have about 30,000 deaths a year. In Mexico, we have 400,000 deaths a year. I want to know how much time it takes you to process the 30,000 deaths. A second, related question: What is the cost for delaying or slowing the program, delaying the process?

DR. PÉREZ: We process monthly batches and we have 5,000 each time that we code. The throughput time is four or five hours. For us, that is a little slow. It depends on the machine that you have or the network that you have and the cost of the software. I think this was very expensive for Catalonia. I am not sure, but I think maybe the development did cost approximately $50,000.

PARTICIPANT: We have had a pilot project in The Netherlands, also building a dictionary with the most common expressions. We had almost the same approach. The dictionary approach had an additional attractive: now I was able to show the coders how to do it. They see the dictionary and the substitution rules and they can understand how it works, even though they cannot see the computer program. That takes away a lot of their skepticism. This is easier for anybody who is not a computer scientist.

MR. JOHANSSON: I would just like to add to that, in Mikado, which has a screen where you can follow the process, we start with the full expression. Then Mikado specifies what happens, step by step. So, if something goes wrong, it is not that difficult to find out where it goes wrong.

The problem is that if we try to correct a parsing error, it might go wrong for other phrases. So, we need to process a couple of thousand certificates any time you change anything in the parsing tables, to see that you end up with the same codes.

SESSION 9

Electronic Death Registration S stems

Electronic Death Registration Systems

Kimberley Peters, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Welcome. In this session, we are going to be talking about electronic death registration and certification. First, we will have Pam Akison from New York State, here in the United States. Then we will have Graham Jackson from Scotland. If we can hold all the questions until the end of the session, we might be able to cover comparability and contrast between the two systems.

Electronic Death Registration in New York State

Pamela J. Akison, Director, Bureau of Production Systems Management, New York State Department of Health

When we discuss electronic death registration systems (EDRS) we are talking about the actual capture of information and the building of a system to create no longer a paper record, but an electronic death certificate, with the full force and legality of law.

Issues

Our considerations when we began the EDRS project were many. First of all, our users—in particular, our funeral directors—were complaining to us that the paper-based system was very burdensome to them; that it is very difficult to create and file a death certificate in the required amount of time, and that this was also imposing hardship on the families, in some cases. Another issue, of course, is the need for the data and the accessibility to the data in a timely manner, and to improve the quality of the data, both in transcription but also in original capture of good data from the sources. So, officially, we want to reduce the amount of data entry. Our resources are continuing to decline, so we thought an electronic system was certainly the way to proceed. The timeliness needs of our data users, including the National Center for Health Statistics, are forever increasing. Not only do we want better data, we want a system that can support very rapid—almost instantaneous—reporting and management capacities. But the main consideration is that we are not just creating data for public health purposes, but we are also creating legal documents.

We had to make sure that the technology for making this a court-certifiable document was available. For that, the key thing is the assurance that the people who are entering the information and are signing the document are who they say they are. We had to change our laws a bit to accept electronic certification of identity. A primary consideration is that in the past, as a department of health, we have always been concerned with the final document, and transcribing the data from that document.

We realize that to really satisfy the needs of everybody involved in the process of death registration—not just us—we needed to look at the entire system of death registration. Then, of course, we had just come through the task-force process, spearheaded by NCHS, on re-engineering the death registration system. Out of that process arose many standards and recommendations that we wanted to ensure were built into our system. Finally, we wanted EDRS to be easily maintainable, something that was not going to become so difficult that it would become useless as we make our transition to the next revision of the U.S. Standard Certificate of Death.

Because we wanted to have this system-wide consideration, we created an EDRS Partnership committee of all types of participants, as well as our in-house team, to represent our own needs. The partnership committee advised us to an enormous extent on procedural and operational issues that we really had not been completely aware of in terms of the interactions between funeral directors which, in our country, are the primary responsible party for ensuring that the death information is collected and represented on the death certificate by all other parties, including the physicians. We found out that we did not understand necessarily the business. One thing that was very obvious was that we were not going to be able to mandate that

all participants use our system. It was just not politically acceptable in our State to say, "If you do not use this system, you cannot do a death certificate." We wanted to make sure that we incorporated capacities in the system that would attract people to its use, that is, more of a "carrot" than a "stick" mentality in our development. For example, since funeral directors are the liaison between the family of the decedent and the death registration process, they wanted to be able to use the system to order certified copies for the family. So, that was something we built into the process, again, to make it attractive for funeral directors. It took 2 or 3 years, just in the planning stages, to really think through all the issues and go back and forth with our users.

System design

I am going to talk about some of the elements of the system design. First of all, I know that in the U.S., the process of death registration is different from that of other countries. I want to talk about what all the different roles are. First of all, our role in the N.Y. Department of Health, is to ensure that the network and the software is available at all times. This is a very radical departure from our previous involvement, because we have actually become part of the process now. If the system is not available, and a death certificate needs to be filed very quickly, it is on our shoulders to make sure that it is available to those users. So, it is a much more directly responsible operational role.

Institutions—both hospitals and funeral homes—are responsible, practically, for the information on our certificate, on the admission, the length of stay, and the dates related to that institutional stay. The funeral director is responsible for ensuring that the entire certificate is completed by all other parties, and that it is filed with the local registrar. The family is not directly involved in having to take the certificate to a local office; the funeral director acts as the agent of the family. The physician, the medical examiner, or coroner is the party responsible for the cause of death. In the case of the medical examiner or coroner, the injury information is also required.

From a functional point of view, we had to make the EDRS very flexible. We found out that in every small locality, there are different ways of doing business. In New York State, we have 1,500 local registrars who are charged with filing death certificates. That is not common in most States in the United States. New York State is akin to some developing countries in the numbers of small jurisdictions. On a trip to India a few years ago I found that New York State has more in common with India than with Colorado. So, the EDRS has to be very flexible and support those business needs. One of the aspects of flexibility is that a funeral director may be the person who starts the certificate, or an institution might start the certificate. The parties have to be able to communicate with each other about the status of that certificate.

As I said before, we were not going to mandate use of the EDRS so that not all participants would necessarily be using it. But we did not want a system that would penalize those who chose to use it. Consequently, the EDRS supports partial entry of a death certificate and then subsequent manual processing after that. We do that by dropping the partially-completed certificate to paper, or just printing a partially-completed certificate, locking the record, and then allowing that partially-completed certificate to wind its way through the system.

Non-sequential entry of information is even possible. Sometimes a physician may be the first person to enter any information on a death certificate. For instance, in an emergency room, in an accident situation, a resident in the emergency room might be able to go into the EDRS, enter the information about the cause of death, and then notify whoever else is involved, and

essentially be done with it at that point. So, the electronic death certificate is not necessarily going to be initiated by a funeral director.

The other thing about flexibility is that physicians, as well as funeral directors, often find themselves in different hospitals or different offices, and the system is not wedded to a particular PC; it is on the Internet. If the physician or funeral director have their digital certificate loaded, they can access the system from any of many different personal computers, maybe one at home or in their own office or at the hospital.

Because it is a system approach, communication is very important. Everybody in the system registers, not only who they are—to make sure they are valid users— but the persons themselves register their phone number, their fax number, their e-mail address, perhaps their beeper number, or any type of communication device that they choose to use. They then tell the system what their preferred mode of communication is, because some of the communication in the system is automatically generated and invokes their preferred mode of communication.

Connectivity and security

The EDRS began as a very tightly contained Internet solution. The N.Y. Department of Health spent years developing a network that allowed hospitals and other public health agencies to dial into our system and use the Internet protocols, but there was no direct connection with the Internet. When we came up with the idea for electronic death registration, and realized the literally potentially tens of thousands of participants in a system like this, this forced the Department to address the issue of direct connectivity to the Internet for this purpose.

The many potential participants obviously brought many security considerations to the forefront. The most direct kind of security is ensuring that the Internet site is an HTTPS site or that it uses the secured socket layer, which encrypts every movement of data between a browser on a client's station and a server, uniquely, every time a new session is begun. That is our first line of defense from people randomly trying to sniff the transmissions. Of course, everybody attempting to use our system is assigned a user ID and password, and we have a firewall that protects our data from the point of contact with the front end of the system. We have gone several steps further, and we have put what we call our "filter" on. Between the system operation and our very highly confidential data, we watch every command that traverses the firewall to make sure that it is not a command that is illegitimate or being spawned by a hacker. We make sure that each command is just a very straightforward sequel statement that will not bring back more than a single request or do any harm to the database. Waiting for this filter to work correctly has been a real challenge and one of the reasons why we have been very slow in moving forward.

When you move to the Internet, you do not have the same kind of flexibility as when you develop a regular PC application. PC applications are very robust and have all sorts of edits and error traps and things like that. We do not want to give that up so we have invoked, wherever possible, the same types of error traps and edits in our Internet solution.

At the client level, we use JAVA script to make sure that, for instance, dates are reasonable dates, that fields that are mandatory have been filled out; that is, very straightforward things. Subsequently, I will talk about some of the cause-of-death edits.

At the server, we have two types of edits that we use. We have a lot of business rules about who can do what and who can write to this field, and what if this person has already written and this kind of thing. Those are all rules that are based in what we call "middleware." Then, we additionally have rules in our database itself, about valid codes that can be stored in a

given column and so on and so forth. The database is a relational database. We try to incorporate edits and controls at every stage that we can.

Standards

In terms of standards (and I was very happy to hear the presentation from Michael Schopen about the SGML standards and I applaud the movement toward standards), we tried to incorporate, wherever possible, the standards based on the re-engineering task force on death registration. We use other standards wherever possible. Internet standards are used, TCPIP, and so on. We want to work toward incorporating format standards for death records or death certificates. To that end, we need to collaborate with everybody involved in the business, including the international standards organizations. I see this as an opportunity to move toward XML solutions. XML is a subset of SGML; it supports both transmission of data directly between computers as well as internet display.

Digital signatures

Earlier, I mentioned digital signatures. These are not images of your signature, but rather, they are the public key, private key solution. It is a mathematical algorithm. Like two pieces of puzzle, they both are needed to unlock the information. This verifies the authenticity of the text in transmission, assuring that nothing has been changed in transmission. In this application, that is probably not a very large risk. Digital signatures ensure that the text received is identical to the text that was sent. And, most importantly for us, digital signatures ensure the identity of the sender, above and beyond the password and the user ID. Currently, we are asking that users obtain a digital signature from a particular vendor in this country called Verisign. Ultimately, the State, looking at all sorts of different electronic commerce applications for government, is looking at contracting with some company to become what is called the digital signature authority for New York. That means that everybody who wants to be on this system would provide to the certificate authority sufficient information to assure their identity, and then receive their key into the system.

Flexibility

I have talked about flexibility and a very flexible system. There have to be a lot of controls built into the system, including controlling the right access to the different fields. For instance, in the scenario where the physician might actually be the first person to write elements of the certificate, he or she might also have entered the name of the individual. In fact, the funeral director is responsible in the U.S. for ensuring that the name is correct. So, every field has been designated with an absolute authority, and every person who is involved has some level of authority in relation to that field. One of the key aspects about our application is this control structure, which we use for a lot of things. We call it the authority table, but it really drives the control over the system. The funeral director controls all the demographic information. The physician, the medical examiner or coroner, controls cause of death and injury. The institution controls information relating to stay, the medical record number, and the admission dates.

Printing certificates

As I said, the EDRS is not mandated; there will be printed certificates, either partially or completely finished certificates. Printing was a challenge because we want the certificate, when it is printed, to look identical to a paper certificate that we fill out from scratch. Our solution was

not to print the HTML from the screen, because that would change, depending on all sorts of settings in the individual's local software, in their browser, and in the settings in their printer. Every time the death certificate is printed, the record is locked and no more entry can be made to the electronic record to ensure that we do not have two conflicting sets of data. Once a request is made to print, a print file is returned from the server. You cannot print directly from the screen. We do that by generating a postscript file and turning that automatically into a .PDF or portable document format. No matter what printer you are using or what system you are using for your browser, the document will look identical. If a partial record is printed, the digital signature will be represented as a printed name, and a control number, an associated code with that document. From that point on, the incomplete sections can be filled out manually.

Cause of death

On cause-of-death reporting, the screen looks identical to the entry on a paper certificate. The wording is the same. The purpose of this system was to make it as easy as possible to have nothing look particularly unlike the current system, in order to minimize our training needs. The JAVA scripts that we have in the browser on site for cause of death are based on the standards from the task force to re-engineer the death registration system. These JAVA scripts are somewhat limited, simply because of the nature of Internet applications. However, we look for a list of unacceptable terms, such as cardiac arrest with no other information in the subsequent lines. If that is what has been entered when they submit the form, it comes back with an error message telling them that that is not sufficient, they need to add more information.

There is, of course, much help information that users can link to: the NCHS Web site, a web site maintained by our National Association of Medical Examiners, and others. We try to take advantage of the flexibility of the linkages in the Internet, for example, to pop up new screens of training. We perceive training opportunities as one of the huge benefits of an Internet solution, as people increasingly interact directly with their Internet applications.

We do not have any pick lists or any drill down kind of logic for assigning a cause of death. It is all simply the information, the strings of information that are currently entered on the record. In the future, there will be the direct integration with SuperMICAR, taking the responses from the physician, running them through SuperMICAR, and then presenting something back to the physician.

One of the open questions in a relationship is, what is the degree and type of feedback that should be given to the physicians. We have had a lot of discussion about not having physicians write to coding systems. You want physicians to provide the best cause of death.

Another issue is the capacity to incorporate all those rules into a web application. When you are on an Internet application, all that information is loaded to your computer on that transaction. We are talking about enormous sets of rules here that cannot be loaded to an application every time you do a death certificate. A balance needs to be struck between the types of edits that can be built effectively into a web application.

Development

In terms of development, we out-sourced development, because we really did not have the skills in-house. We knew that there would be a large learning curve and we wanted to take advantage of this to train our staff and to do some technology transfer to my staff. We also had competing priorities with the Y2K problem in which our programmers were very heavily involved. So what did we do? We did not ask for a software package to be developed; we asked

for programming services, that is, to come in and work with us as a team and to take our business rules and help us translate those into code.

Demonstration

I do not have a live demonstration, unfortunately, but I am going to show you some of the screens from our system to give you a sense of what the New York State EDRS looks like. Our main menu is on the vital records home page. The user enters his or her user ID and password to first log into the system. The system checks to see whether or not it is a valid user requesting entrance; it also checks what this user's role is. In this case, it came back and said: "You are a physician." The user's title is "physician." As a physician, there may be several different roles that the user is playing in the system. The user may be an attending physician and the decedent was his or her patient. The user may be designated by a non-physician coroner to represent the coroner as a physician. So, there are a lot of different types of roles for even a physician. Consequently, the user has to be very specific.

Once that is done, the user can choose to begin a new record or update information on an existing case. Every record is assigned a unique case number that is used in communication between individuals to allow them to very quickly and easily get into and add new information to a case.

Because the system is so flexible, many times two individuals may start a case, not knowing that somebody else has already started it. We have a lot of logic in place that identifies if somebody tries to start a new case that has already begun. If so, is the person who is doing this just ignorant that the case was already begun, or are they actually trying to enter into a case that they should not have access to? There is a very fine line between flexibility and control. What we determined as a reasonable solution was that, if a case had already been started by, say, a funeral director, and a physician tries to begin the case again; if no physician has touched that case, we let him or her in. We let them see the information the funeral director has entered, and we let them enter the cause of death. However, if one funeral director has already begun a case, and a second one comes in and tries to begin it again, we warn them that it has already begun. We show them the name of the funeral director to allow them to reconcile who really should be filing this record.

We were told by the industry that many times different members of the family go to different funeral homes, resulting in a conflict. Sometimes it is unintentional; sometimes it is intentional. This is an example of the type of business rule that we had never considered at the Department of Health before, but we tried to build into the system. We try to make sure that any conflicts that may happen in the process can be handled by people in the field. We do not feel that we are in a position to intervene in those types of conflicts. Thus, we allow the system to let them transfer a case from one individual to another if a potential conflict has arisen and has been resolved.

Various people can review the document; anybody who has access to the document can review it. If you are a local registrar who is going to file the certificate, the option for you, when you review it, is to accept it for filing or to reject it, and to send some message back to the funeral director explaining why you are rejecting it.

The upload and download functions allow people to maintain the data locally on their systems, or if anyone wants to create the data and then upload to us, it allows them to do that. Cases can be referred in New York State to a medical examiner or coroner by almost anybody, so we allow that to happen very easily.

The last options featured in the system are business-related. If you want to find another participant by entering their name or their license number, and if you want to find out their phone number, the system is almost like a large directory of all the participants. It allows you to view or change your own information so you can self maintain your phone number, your fax number, and so on. We do not allow system participants to change their own names or their license numbers, because those things are controlled by our department as licensing authorities. To order copies of the death certificate is really just a mechanism to allow the funeral directors to communicate with local registrars.

To begin a new record, the system allows you to enter the name, the gender, the date of death, and the county of place. If that is not enough to uniquely identify somebody, that is, if this information is so common that two records are found with the same information—an unlikely thing to happen—a message will ask for additional information to help identify a unique individual. We have done analyses on our existing data, and this has proven to be unique.

We try to make the screens look very intuitive. We found out during our testing that if a person was already familiar with using the Internet and they got to this point, it was very intuitive and they just went on and entered the data. The most difficulty we had was with people who were not familiar with use of the Internet.

The left-hand column we call our case menu. It allows users to branch to other parts of the record for which they may not be directly responsible, but which they wish to check out or view. The system also has some special functions; for instance, it has a screen that a funeral director would fill out, giving them an option to file the record with the registrar. Also on the left-hand menu are options to alert other participants, to show other participants on the case, to print the record, and so on.

When the system prints, it looks almost identical to our paper death certificates. This is being brought back from the Acrobat plug-in that is freely available for everyone in the world. It gives final control over the way documents look. If this were to be printed as a final document, then the rest of the record would be locked and it would continue to be filled out as a hardcopy.

Another screen shows extraneous support services that the system has. For example, if the person had clicked on "show me the other participants in the case," it would list the funeral director that is currently available. If other people had entered information, for example, if a physician had already entered information, there would be information about that physician. This aids and abets the communication between the participants, by phone, fax, or e-mail.

Another screen allows the user to proactively alert somebody. If, for instance, a person dies in a hospital and the family says, "I want to use this particular funeral home," or "please notify the person's doctor," they can use this system to do automatic notifications. We have a lot of different help menus and help screens in the system.

Status of system

In terms of implementation, the system has been internally operative for over a year. We are working out our final security measures. A lot of changes have been made to those filters and security pieces that the system needed reworked. We have every anticipation that we will go into production this fall.

We are going to begin an evaluation process. We have thought about how to evaluate the system. We want to look at the percentage of all the potential participants that are using the system. That is very important. If, in a given county or part of your State, only 5 percent of the people want to use the system, then it is not going to be very effective. Another evaluation

method is to determine the percentage of all deaths that are reported through the system and then, of course, to obtain user feedback.

Difficulties and challenges

Right now, the biggest challenge is the flexibility that we have built in, and that we have these mixed-mode records; ones that have been partially completed electronically, and partially completed manually. We have a strategy for entering those manually-entered components and linking them back with the already-entered components. It involves a combination of imaging and explicit versions of the form that will be noted on each form.

What do we perceive will make the EDRS successful? Good communications among the participants, and our ability to support the users in terms of training and ongoing questions. A critical mass of users in a given region will be necessary before the EDRS actually attains its value and, of course, the system has to be reliable, so that people have trust that it will do what is needed for them and confidence that it will be available. This will build up over time.

Goals

In closing, our goals in terms of benefits to the State, were as follow: more timely and better data, reduction in data entry, streamlining cause-of-death coding by providing literals in electronic format, and eventually printing legal copies by the local registrars.

The benefits to the participants are the following: flexibility in terms of non-sequential entry of information, eliminating the problems of physical distance and work schedules in a very tight time line, and the communication options. We need a burial permit in New York State before you can bury somebody. In addition to printing the certificates, you can print the burial permit.

Electronic Registration in Great Britain: Scottish Perspective

Graham Jackson, Head of Vital Events and NHS Branch, General Register Office for Scotland

Introduction

I will briefly describe the introduction of electronic registration in Scotland, and highlight the many benefits that it has brought us in the field of vital statistics generally, and mortality analysis in particular. As the title and the agenda suggest, this is very much a Scottish perspective. However, much of what I will say also holds true for England and Wales, whose move to electronic registration predated ours by a few years. Our registration systems have much in common. Moreover, I believe they will have much in common with many other systems elsewhere in the world. I hope, therefore, that my presentation will complement that of Pam Akison.

The General Register Office for Scotland

The General Register Office for Scotland (GROS) was set up by an Act of Parliament in 1854. Compulsory civil registration started the following year. The head of the department is known as the Registrar General. In addition to civil registration, the department is also responsible for demographic information such as population estimates and population projections, and, every 10 years, for the census of population carried out in Scotland, although on the latter we work very closely with the Office for National Statistics in London.

The responsibility for administering civil registration is divided between the Registrar General, based in Edinburgh, and the local councils. The Registrar General has the statutory duty to prescribe registration forms such as the certificates and the forms on which the details are supplied to the registrars, and also to set various fees associated with the production of extracts, etc.

Following the latest reorganization (in 1996) there are now 32 councils; and it is the councils who employ the 360 local registrars and provide their premises and IT equipment. So we cannot dictate particular standards of IT equipment. The local registrars deal not just with the registration of deaths, but also births, stillbirths, and marriages. In fact, it is the registrars themselves who conduct civil marriages in Scotland. This multifunctional role of the registration office is something we have to bear in mind when designing our registration systems. There are generally similar arrangements for registration in England and Wales.

The legislative background

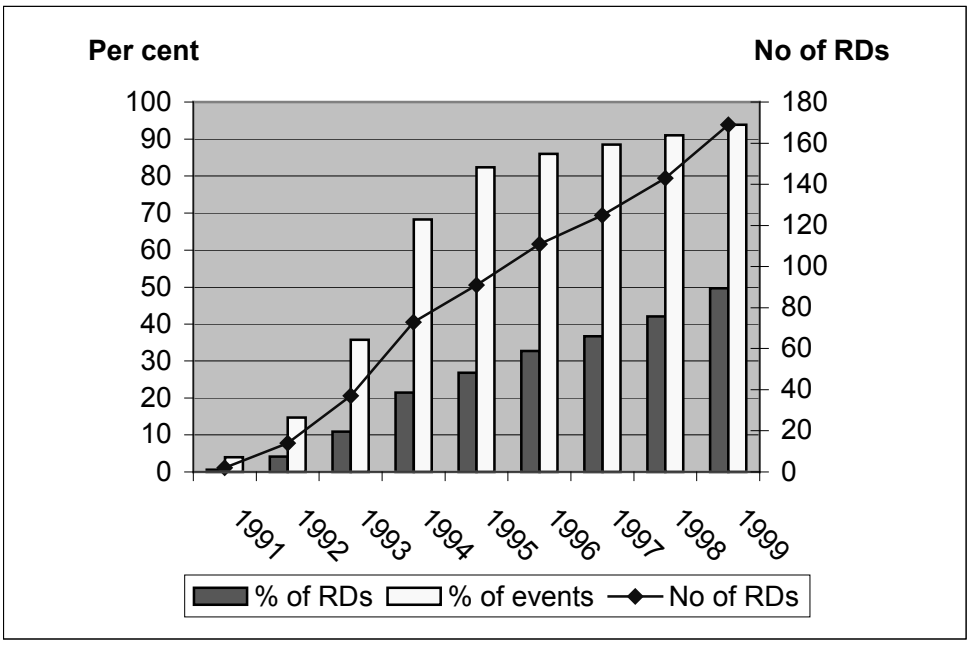
The legislation relating to registration in Scotland is post-war. It is slightly more flexible than that in England and Wales in that it allows us to make modest changes to the forms that we use without having to seek fresh legislation. For example, we were able this year to introduce a new medical certificate of cause of death for completion by doctors without recourse to fresh legislation. As recommended by WHO, this new form includes a fourth line in Part I of the cause of death information.

For the future, things will probably be slightly more straightforward because new legislation will be handled by our new Scottish parliament, which was reconvened this year after 282 years; something of which we are all very proud.

The Computerization of Local Registration Offices (COLRO)

This project started in 1988 and initially it drew quite heavily on experience in England and Wales where similar work had been started in the mid-1980s. However, because of the differences in the methods of work, we decided to develop a completely separate software system for Scotland. An initial trial site in Edinburgh went live in 1991, and since then, the number of registration districts computerized has increased significantly, to the point where 94 percent of events are handled electronically. That is all events—including births and marriages. Chart 1 shows the take up of electronic registration during the1990s.

Chart 1. Take-up of Scottish Registration Software (SRS)



Though the percentage of events registered electronically is now over 90 percent, the percentage of registration districts that have been computerized has barely reached 50 percent. We currently have some 170 manual registration districts, virtually all in remote rural areas. Most of these are staffed by part-time registrars and 145 of these districts deal with fewer than 100 events per annum.

Technical aspects—hardware

Because we started in the early 1990s, and because of the different standards of equipment that were available in the registration offices, we had to go for a fairly low-tech, lowest common denominator, approach. Even the current version will run on a 386 system with 4Mb of memory, although happily we do not think there is anyone out there still using such low power computers. A benefit of the work done to avoid potential Y2K problems was that many councils upgraded their systems across the board.

For registration extract purposes—that is, for the production of official legal extracts of the certificate of death, birth, or marriage—there has to be an output standard. Currently, our output standard is an HP LaserJet 4 with PCL 5 software and drivers.

Technical Aspects—software

The Scottish Registration Software (SRS) is DOS based. This has helped to ensure that it will run on low power PCs. SRS is mainly written in CA Clipper, although a number of other products, which work in the Clipper environment, were used to complete the project. Some sites are networked, some are not. Originally, there was a 50/50 split between LAN Manager and Novell. Now the sites are mainly Novell, although some use Windows NT.

The software deals with births, deaths, and marriages (but not stillbirths, for which manual returns are still used). The registrar keys in the information. For death registrations, the information is mainly provided by the "informant," who is usually a close relative. The informant will also have a certificate of cause of death provided by a doctor.

The software is a fairly basic DOS system, but it does have pop-up help and pop-up prompts, from which the registrars can select particular categories such as: relationship of the informant (spouse, son, daughter, etc.) or country of birth. Additionally, some of the most frequently used addresses, such as hospitals, can be input automatically; and age is calculated from the date of birth.

Following the collection of the data by the registrar, the informant is given the opportunity to check all of the information provided screen by screen. The registrar may also choose to contact the doctor to clarify any points arising from the medical certificate of cause of death. Indeed, there are a number of options that allow the registrar to go back into the system to make corrections or to annotate records.

Data collected on deaths

A wide range of information is collected at the registration of a death, and we decided to collect as much as possible electronically. The list below summarizes the data collected:

- Forename(s), surname, sex, date of birth, marital status, occupation, usual residence, country of birth
- Date, time, and place of death; full cause of death text, post-mortem indicator, pregnancy indicator
- Name and address of certifying doctor and, if different, deceased's own doctor
- Details about parents and, where appropriate, spouse or former spouse

It is interesting to note that entering the full cause-of-death text is only a relatively small part of the data entry process. Although it may involve some complicated terms and having to decipher some poor handwriting, it is not seen as a particular burden. Some of the information collected does not appear on the official register (i.e., it is not part of publicly available information). It is collected under separate legislation, which allows us to collect additional demographic detail for use in aggregate population statistics.

SRS data transfer

There is nothing groundbreaking here and there is certainly scope for introducing a more sophisticated approach as we move into the 21st Century. The data are submitted by mail on diskette. The files are encrypted, and we have provisions for the rapid supply of a back-up file should something go missing or be damaged in the post or if the file becomes corrupted. The manual offices submit paper returns, again by mail, and these are keyed in our office in Edinburgh by skilled data preparation staff. As I mentioned earlier, this is now down to 6 percent of events.

The benefits of electronic data capture of cause of death etc.

It has proved very useful to collect all this information electronically. I shall outline some of the main benefits.

- Input to the automated coding process

The main benefit for research and statistics is undoubtedly the ability to input the cause of death text to the automated coding process. Indeed, without the prior introduction of computerization in the registration offices, we would not have introduced the automated coding system that we now use.

- Medical enquiries

It is also very helpful to have all the text-based data for use in medical enquiries. We send out enquiries to the certifying doctor in about 8 percent of cases. This is done to get more specific information, or for further clarification, or if we consider that the information originally supplied is insufficient. We are now able to print out letters automatically giving the reason for the request and the full original text; and, of course, the doctor's name and address are also available electronically. We get responses to about 80 percent of the enquiries.

- Output for research studies

This is a very interesting use. We are able to supply medical researchers with the full text on cause of death for named individuals. This is only allowed for studies that have been vetted by the appropriate medical ethics committees and our own privacy advisory committee. For many studies the information is supplied for people who have been "flagged" on our National Health Service Central Register (NHSCR). The NHSCR is a quasi-population register maintained by GROS for the Health Service in Scotland. The best current example of such a study is a follow up of people who served in the armed forces during the Gulf War. They are all flagged on the NHSCR and, should one of these people die, we automatically generate a form giving cause of death information and pass this on to the relevant researchers.

- Text searches on cause of death

This is something we find very useful for ad hoc exercises; for instance, when we are asked how often "hypothermia" is mentioned on death certificates. There are quite a few pressure groups who regularly ask us for information of this sort. We may also want to look for occurrences of specific drugs, such as methadone or paracetamol.

We have also been able to analyze the terminology used on the certificates. A recent example of this relates to the terminology used for cot deaths. The director of the Scottish Cot Death Trust was concerned that the terminology used by doctors had changed in recent years. An analysis of the cause of death text confirmed this. Whereas the term "sudden infant death syndrome" had been used quite frequently until a few years ago it had generally been replaced with terms such as "sudden and unexpected death in infancy", without the use of the word syndrome, or even reverting to vague terms such as "undetermined" or

"unascertained." (Under our coding conventions, virtually all of these deaths would have been coded to ICD-9 798.0.)

The next steps

First, we have been considering a number of options for the noncomputerized offices, for example faxing and scanning, though the necessary hardware costs make such approaches difficult to justify. Secondly, and more likely, is the electronic transmission of data from the computerized offices to our central office, either by phone or the Internet. Beyond that, we will begin to consider the options for electronic death certification rather than just electronic death registration. This, I believe, is some years away.

Discussion on Session 9: Electronic Death Registration Systems

MR. RADNOTI: I am interested in the encryption methods used for the transmission of data.

MS. AKISON: It is a game of "leap-frog," I think. It is constantly being challenged. I have heard that, just recently, hackers have developed a way to break into the public key, private key encryption fairly readily, although it takes a lot of resources to do that. I would have to say that the best thing to do is to try and stay educated about what the technology is, and use the highest level.

You have to do a risk assessment. In our case the risk assessment follows this argument: is the likelihood that a given record being transmitted through the Internet is going to be captured and decrypted any greater than —with all the overhead and resources—the risk that paper records with the handwritten information be intercepted. It comes down to a true risk analysis and a judgment.

MS. AHONEN: It was really fascinating to hear the presentation of Pam Akison. So, I am very interested in your solutions.

I guess it has taken some dollars to build it. I want to know how much work you have done, how many working hours, years. I would also like to know whether your system and your solutions are government-owned. Can they be loaned?

MS. AKISON: I am glad you asked the question. That was a very important part of our decision in New York, that we wanted it to be an open system. That is why we contracted with a company to come in and basically augment our labor. We have, in fact, given the software to the State of New Jersey. There are additional costs because New Jersey's rules are different from New York's rules. It is a State-based system. So, they contracted with somebody to change it to fit what their laws and rules were.

We are not a software company, but we are happy to provide the software to people and let them change it however they see fit. I do feel obligated to say, however, ours is not the only State that has done some experimentation in this area. There are four or five, maybe six different States that have done something with electronic death registration. In a couple of cases, and actually in Canada, they have done different types of things, and these are products that are sold by vendors. There are other options out there. They are not quite like the one that we have developed in New York in terms of just a straight Internet solution, but I feel remiss in not saying that there are other options out there.

This is the way that we proceeded, and that was our goal, to make it an open system, because we cannot do everything. I know in New Jersey they are looking at adding some capacity to the system, and then we want to borrow back what they add, so that we can all gain from that.

That was our philosophy and, yes, it took us a long time. I had probably one full-time programmer working on it for nearly a year, maybe 75 percent of her time. Then it did cost a couple hundred thousand dollars beyond that in contracting costs.

DR. ROONEY: I was very interested in the different approaches to querying. I know the constraints that we have in the United Kingdom, that the certificate has to be on paper, et cetera. It is quite nice to be able to at least send out the query letters automatically. I wondered, with your real-time querying, have you any experience of how the doctors receive that, and whether it has had an effect on the information you are getting?

MS. AKISON: It is vastly premature, unfortunately. Maybe the next time this meeting convenes. The best that I could say is that the physicians that participated in our beta test were very interested in doing it themselves, but that was kind of self selective. They wanted to be part of the test; they were interested in it.

My concern and my anticipation is that what will, in fact, happen will be that staff in the physician's office are actually the ones who enter the information, based on what the physician says to them.

The way we have it set up is that we do support that. We let that happen, but it is not a certification. The physicians have to at least get on and view it and submit it themselves, even if they have not physically typed it themselves. The same responses will come back when they try to submit it, even if they have not typed it themselves. It is really premature to say what kind of effect it has had.

MR. JACKSON: In some instances we will have the name and address of the consultant as well as the certifier. The certifier might be quite a junior doctor working certain times of the day, for instance, in the hospital. When we send our medical inquiries back, we in many instances do get responses from a more senior doctor, or the person who had actually seen the deceased in the later stages of the illness that caused the death. Sometimes that does give us a little bit of extra information that you might not get from a system that is too immediate.

MS. AKISON: I would just like to augment what Graham just said, because I think that is a very important point. This does not mean that one is moving away from traditional processes as well. It does not mean that we would not in

addition have a query system—a formal query system—as well. I think it would be a mistake to just say, "well, this is good enough."

DR. LE: I have a question and a comment. Knowing that the registration system is available to multiple users at multiple sites, I wonder how this will affect the actual filling of certificates for sensitive conditions—for example, HIV—and how that will affect the viewing of these conditions by family members or maybe just family acquaintances who happen to be nearby at the time.

The next one is the question. You mentioned that the current system can impose hardship on the family. Can you elaborate on what those hardships are?

The last thing is just a comment about the filling out of the entry of the cause-of-death statement: I think the more open the system is, the more it will encourage the certifiers to fill out those statements.

MS. AKISON: In terms of sensitive data, the system is fully capable of preventing people without a need to know to see information. However, in New York State, we do not have any laws to support the restriction of information to the people who need to know. In other words, the funeral director, the physician, the institution, as well as the local registrar, all have the legal capacity to see all of the data on the death certificate. Certainly the funeral directors, when we talked about suppressing some of the information so they could not see it, felt very strongly that they should always see what the cause of death is, and I understand what their concerns are. The system design, if the laws were different, would certainly support suppression of information. For instance, we have done a birth system in the same mode, and local registrars cannot see the medical information on the birth record. So, it is just a matter of what the laws require; the system is capable of suppression.

In terms of the hardship on the family, all I was talking about is that in some cases it is very difficult to get the death certificate filed in a timely manner in order to get the burial permit and get the person buried, the decedent buried. There have been times when it has actually put a change in the plans of the family, just because the process is so cumbersome. That is all I meant by the hardship.

DR. BAH: I have three short questions for Pam Akison. First: the date [year] of death. I notice it only allowed two digits.

MS. AKISON: That was an old screen.

DR. BAH: The second question is: How many copies of the certificate can be accommodated by the system, one or multiple?

MS. AKISON: If you are completing part of it, there are two options. You can print a draft for review or storage in medical file or whatever, and you can print many draft copies—anybody on the record can print a draft. Once you print the final copy, one. Now, sometime in the future, I think what Graham is doing at the local registrar's or the local council's offices—the ability to print mini-transcripts—would be possible, but one copy of the final certificate.

DR. BAH: The third one is: Have you thought about the cheating aspects, for example, with respect to insurance and so on, if people want to technically kill someone? Have you thought about this?

MS. AKISON: Yes, we are from New York, so we have a lot of issues like that. We never forget it. That was foremost in our minds. You know, how could the system be fooled. We tried to think of all different manners of control.

One thing I did not mention was that every week, once the system is in production, a report will be sent in a different mode—not electronically, probably initially just through the mail—saying: "These are the documents this week that you worked on. If you do not think you worked on this document, let us know right away," so there is a different mechanism for controlling.

If somebody is posing as Dr. Smith, Dr. Smith is going to say: "I did not file a record for Joe Jones." Then we will know. Then we will have a chance. We have given a lot of thought to that issue and tried to put a lot of cumulative controls in the system to help. I am sure there are a lot more that we could do.

DR. KOZIERKIEWICZ: On that same issue: Is it legally acceptable in the United States that that certificate only be signed with use of an electronic signature? Is there no requirement that a person sign his own document with hand signature?

The second question is: In *USA Today* there is an article about the Senate considering legislation regarding privacy of medical information in the United States. How do you think that affects your issues?

MS. AKISON: In terms of the digital certificates, it is a State-by-State question. It is based on each State's laws. In the State of New York, we did not have a law that said you could sign something using electronic means, so we passed a regulation. Our laws were not particularly restrictive, but we were not comfortable with what they said, so we had a regulation passed that allowed it. Subsequently, the State of New York passed legislation

that said: "Unless there is some specific law prohibiting it, signatures can be done electronically." We are following the suit of several other States that are way ahead of us on that.

In terms of the privacy of medical records, we are watching that legislation. We have to be very careful that it does not go too far in restricting public health purposes. I know NCHS is watching it, and our association of vital records is watching that legislation very carefully. Whenever there is an issue that we are uncomfortable with, we try to reach out to the Congress and let them know that this is not something that you want to throw away. There are a lot of forces working to ensure that this will be protected, and I am confident that it will.

DR. ROONEY: On that same point, we have fairly strict rules on medical confidentiality, but the death certificate in England is not a medical document. It is a legal document, and it is a record that exists in the registration system, and it is a public legal document, and nobody can restrict that. That is the law. The laws are different. It is not a medical document.

MS. AKISON: It is not a medical document here either. Sometimes a legislation might say something about cause-of-death information. All of a sudden, somebody says: "Wait a minute, that is on a vital record too, does that apply?" It gets very confusing. We have to be very careful that they do not bridge into arenas that they do not really tend to bridge. That is an education process.

DR. IBRAHIM: I am Lailanor Ibrahim from Malaysia. Does your system have a software for analysis?

MR. JACKSON: If you mean the analysis of the data, no, it does not. We just pass on the text and all the information. It is all process, essentially.

DR. IBRAHIM: The analytical aspect is separate?

MR. JACKSON: It is different, yes. Our system is used as an input to the analytical process that starts with the automated coding process in the case of the information on deaths.

We get from the same source the information from births, which we use for our files on birth statistics as well, and that is processed in exactly the same way, on a weekly basis.

Many of our outputs are actually linked. We provide outputs of births and deaths, for instance, to the local health authorities on a weekly basis, for them to keep their records up to date, etc. All the processing is done centrally. This is a comprehensive detail collection exercise, and we try to

be as comprehensive as possible. We now extract as much as we can get from that system and try to use it in as many ways as possible.

DR. IBRAHIM: The second question is: How do the local operators from different localities send data to you? Do you have a linkage network, or is it sent by diskettes, or is it sent to you by any other means?

MR. JACKSON: The information is sent weekly by diskette currently, by mail.

MR. DEVIS: I have one question for Graham Jackson. I was very impressed in your presentation, because it sounds very similar to what I do myself. Particularly, the registration software, it had a lot of similarities to the software we use. I had a query about defaults used in your software. About 3 years ago we found that deaths registered by doctors where post-mortems were being conducted were going down dramatically. This was simply because there was a default that enabled registrars to do that. Once we fixed that, they started coming up again. I wondered whether this was a problem with software that you have used?

MR. JACKSON: There have been instances where the registrar has been able to skip over a field and has done this in a repetitive way, which we have been able to pick up. The one I can think of was, I think, "country of residence." It is pre-entered as "Scotland" for obvious reasons. There have been occasions where people have skipped over that inadvertently. By looking at the addresses, we can find out that the information was probably incorrect. There have been cases where we have had to go back and remind them.

MR. DEVIS: But you have not had to adjust the software to amend it?

MR. JACKSON: I think there has been at least one instance where we have had to force the software developers to put something in where previously there was a default, to avoid the sort of problem you are talking about. We start off with the software to try and develop something that makes the task of the registrar more straightforward. Registrars are not trained keyers, although they obviously use computers on a daily basis. We try to have as much pre-entered or that can be picked from lists to minimize this. I guess there is a danger, if you put in defaults too often, that they can be lazy, or just in a rush they can miss out something.

MR. DEVIS: I think there is a general message that there are some things where you have to expect them to think themselves about what they are putting in, rather than just pressing the next button.

MR. JACKSON: Yes, sometimes they will try to cheat the system for a particular reason. In Scotland, the legislation requires that a death or a birth be registered either at the place of the usual residence or in the registration district where the

event occurred. We have had instances recently where someone has come back from abroad to have a birth in Scotland, and perhaps stayed with parents on a temporary basis, but the birth has been in another nearby town with a maternity hospital. The local registrar has allowed that birth to be registered, say, at the mother's parent's address, which is in a different area, and we get conflicting information on our returns, where we have a usual residence of outside Scotland, but we have a usual residence address which is Scottish. Sometimes we have to edit these, and sometimes we have to write fresh instructions for the registrars. In that instance, they were not doing what they should have been doing.

SESSION 10

Recommendations From the 1996 Meeting

Recommendations from the 1996 Meeting

Dr. Sam Notzon (moderator), Office of International Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

The objective of this session is to discuss progress on the recommendations developed at the first meeting of the mortality ICE. For those of you who participated, you remember how long and hard we worked on the recommendations. It is a good time to take stock on the recommendations.

We have six different topics with a different panelist for each topic. The panelists will introduce the topic, summarize the recommendations, and make comments or discussion. Then, we are going to open the topic to the floor, asking for comments. I ask you to think about whether activities in your country are relevant to the recommendations.

Nosology and the Training of Nosologists

Joyce Bius, Medical Classification Section, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

These were the recommendations developed in the first mortality ICE for topic Number One, "Nosology and/or the training of nosologists in an automated environment":

1. *NCHS should provide a standard definition of a nosologist.*

Such a definition was proposed at the 1996 meeting. This definition states "that nosologists have achieved high levels of expertise in the practice of medical coding, in interpretation and in application of ICD classifications, and the training and qualification of new medical coders, and in the implementation of special projects on causes of death."

2. *Countries should take steps to strengthen the skill and expertise of nosologists and medical coders, including courses and seminars. An international ICD-10 coding course, accreditation, and curriculum standards should be developed by WHO.*

August 1999, the WHO Center Heads Joint Work Plan of 1999 established a credentialing and training subgroup that could address these issues.

3. *Countries should strengthen and increase the status, career advancement, and public recognition of contributions of nosology. An international society of nosologists could be created by WHO and ICE.*

In August 1999, the WHO Center Heads Joint Work Plan of 1999 established a credentialing and training subgroup that could address these issues.

4. *With the use of the automated system, fewer but more highly skilled nosologists are needed. Countries should increase the awareness of the need for nosological expertise.*

5. *To address the declining number of nosologists, countries should consider cross training.*

Is it such a bad idea to train statisticians as nosologists, or combine nosological duties with other staff responsibilities? We have heard of countries in which that is already being done. In June 1998, at the ICE planning meeting, the training of nosologists and how to raise their status was discussed. Some questions that we need to ask ourselves are: If WHO sponsors a certificate, what will it mean? Should the ICE involve nosologists in trying to come up with a solution for these issues? Can the ICE set up a mechanism to address these recommendations? Perhaps the issue of nosologists can be a theme of the Center Heads meeting.

It was proposed that for the WHO Center Heads meeting, a paper specifically on training and nosologists be presented. The paper would mention the number of nosologists, the trend in the number of nosologists, and the impact of the trend on updating ICD and on future changes in ICD.

It is important to continue training and to expand training for coders and nosologists. The ICE can first review the information from the Eurostat study, and then look at the questionnaire paper from the first ICE meeting. An author from the ICE

planning committee could do a first draft of this paper and e-mail it to other members on the planning committee for comment. Authorship of the paper could be representatives from the WHO Collaborating Centers on the ICE planning committee.

To finish this review and somewhat update, the WHO Center Heads Joint Work Plan of 1999 established a very important credentialing and training subgroup that could address these issues.

Discussion on Topic "Nosology and the Training of Nosologists"

DR. COLE: Having poured scorn the other day on the idea that medical record coders could move into death certificate coders, I think I am going to shift my position ever so slightly from the point of view of some kind of society or skills. I know that there is a very enthusiastic and probably a reasonably large volume of medical records staff with an international group that is quite active. I wonder if it would be possible for them to sort of spawn or take under their wing a kind of subgroup of super-specialists, mortality coders, having the same basic interests in accuracy and coding and skills without, perhaps, the interest in the rules and the selection of underlying cause. I cannot help feeling that if ICE should create an international society, you create something that is too artificial. It really has got to be a group of people with the self-interest to create and promote. I cannot see where else the relatively few death nosologists would go, unless it could be slotted into the medical records establishment.

MS. GREENBERG: What Susan Cole is suggesting is definitely one of the things we are thinking about. I think even if we were able to form some type of separate group, it would absolutely have to affiliate with a larger organization that has a greater critical mass and a whole history of professional association.

There are a few people who participate in the Collaborating Center meetings, who are very active in the International Federation of Health Record Organizations. I have somebody on my staff also who has been participating in that. That is something we definitely want to look into. We certainly have a very active health information management association here in the U.S., the national affiliate of the International Health Records Organization. I think that even the title of that group, the American Health Information Management Association—which used to be the American Medical Records Association—gives you an idea of how they are looking to expand their area of interest and diversify by moving into the whole area of health information management. That offers some opportunities, too, particularly since we are talking about nosologists in an automated environment.

MS. FREEDMAN: I would just like to suggest that we be very careful in the language we use when we describe what nosologists do and their qualifications. I am particularly concerned about the word "coding" that we have used in the recommendations, and describing folks as "coders." One of the things that we have found in working with our personnel specialists in the United States is that this is one of the characteristics that hold people back. No matter how complex the system, if you describe someone as applying coding rules, it does not convey professional status. We have been talking about using the term "medical classification specialist," as opposed to calling them "coders." I would suggest that we may want to think about other ways to get the idea across about what not only the expert nosologists do, but also the journeyman-level folks who actually produce our data.

DR. NOTZON: Do not go away, Mary Anne, because I am going to ask you a question. Recommendation Number One concerns the definition of a nosologist. It has "coding" or coding-like terms. Are you saying that it would be best to drop those terms from the definition or rephrase them in some way?

MS. FREEDMAN: I think we might want to think about recasting those.

MR. JOHANSSON: I would like to add another recommendation to those that we have, and that is one about international cooperation on ICD training.
Since the number of nosologists is getting smaller and smaller, especially since the smaller countries find it quite difficult to train new nosologists, we need to develop some kind of network for international training. I cannot suggest the particular phrasing right now, but we should try to include a recommendation like that.

DR. NOTZON: You mean beyond the training that WHO provides through the regional centers?

MR. JOHANSSON: I believe so, yes: a network of specialists who have experience in the classification of mortality.

DR. IBRAHIM: This is my first time attending this ICE meeting. I would just like to add recommendation Number Five. Because the number of nosologists is declining, countries should consider cross training employees, for example, statisticians. Thus, in developing countries we have a few statisticians around, but we have a number of medical record officers who could become the coders.

Besides that, we can also train the medical assistants or the nurses or the sisters in the hospital to become the coders. That is our experience in the developing countries, especially in Malaysia.

DR. NOTZON: So, you do cross training.

DR. IBRAHIM: Yes.

DR. NOTZON: I wonder if there might be some danger in that. If one places multiple demands on the same person, one may restrict their ability to do a good job of either. I assume that is a problem you have had to deal with in Malaysia as well.

MS. BIUS: What is mentioned here goes along with what Mary Anne Freedman is saying about raising the status of nosologists. It is hard in Personnel's eyes to change the classifications if nosologists do not do some other things. You have got to put some duties other than classifying records using ICD.

DR. ROSENBERG: Lars Age proposed a recommendation. I wonder if we want to refine that and take a quick vote on it so that, in fact, it can become a recommendation of the ICE that we would carry forward.
And should we follow up on Mary Anne Freedman's recommendation on the definition, that we be careful about the wording? Is it best that we have a group that formulates the definition and sends it out for review? What should we do procedurally?

MS. GREENBERG: If you are asking how the group wants to respond to these, I do think that what Lars Age Johansson mentioned would definitely be within the scope of the training and credentialing group. Is there any feedback from the group that I might be able to get concerning the plans for the training and credentialing subgroup and the terms of reference that I could take to Cardiff? It could be helpful to have some kind of feedback.

DR. NOTZON: Let me start with Lars Age Johansson. Could we ask you to just draft something very quickly along the lines of your recommendation? If you could do that before the end of the discussion, then we could propose it here. Alternatively, we could do it following the meeting. Now, Marjorie Greenberg, your meeting is not for a few weeks yet. We could certainly survey the group by e-mail and get comments regarding Marjorie's suggestion of incorporating nosologists in a medical records professional society. We will draft something and circulate it to all of you and ask for responses, so that Marjorie has something to take to the Center Heads meeting.

MS. GREENBERG: On the issue that Mary Anne Freedman raised about the definition: Would the group like to refer that back to this training and credentialing group? We could look at that as part of our charge.

DR. NOTZON: If there is no objection from the audience, and I do not see any—it looks like universal approval—then we will do that. If we have no further comment on the first set of recommendations, we will move to the second one, and I change hats and "become" Eric Jougla.

Decision Tables

Dr. Sam Notzon, Office of International Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services (for Eric Jougla)

This discussion concerns the decision tables, their logic, and mechanisms for updating them. We have debated this topic during this meeting.

1. *NCHS will develop consensus decision tables to improve comparability across countries, with the help of other countries.*

The update notes on a number of instances of cooperation in developing or reviewing the decision tables; and, in particular, that some countries are helping to review the ICD-10 decision tables, and that in the WHO Center Heads Joint Work Plan of 1999, there was established an automated coding system user subgroup.

2. *Countries should test decision tables and algorithms for specificity and clarity.*

3. *NCHS should create a test deck for countries and systems comparison on ICD codes and multiple causes.*

The update is that Sweden and England will provide such test decks to NCHS.

4. *Countries should use bridge coding to assess a number of changes from ICD-9 to ICD-10, from manual to automatic coding, and to compare any subsequent changes made to ICD-10.*

Of course, we have a couple of instances where countries have made two changes at the same time, from ICD-9 to 10 and from manual to automatic coding, which is its own special case.

5. *The ICE should work to develop uniform rules for external-causes comparisons, because of the difficulties inherent in making these comparisons across countries.*

The update notes that the ICE planning committee recognizes a need to implement priorities on nature-of-injury conditions, and it is not a simple field in which to standardize, by any means.

6. *To encourage countries to participate in a beta test of ICD-10 software, and to provide feedback to NCHS on problems that they run into. It then calls on NCHS to make appropriate adjustments to the software.*

The update notes that the ACS users group will deal with many of these issues, and that as of August of 1999, NCHS has received feedback from Australia.

7. *Developers of automated systems should make decision tables that they use broadly in all countries.*

The update notes that England, France, Scotland, and Sweden have assisted in developing ICD-10 decision tables for the United States ACS system.

We have talked here also about the availability of decision tables for the United States. While they are not posted on the Web site, as you all know, you just have to contact Donna Glenn if you want copies of those.

8. *An advisory committee should be established to help in the interpretation of decision tables, which would report to WHO.*

The update notes that the Mortality Forum is now operational; the Mortality Reference Group as well. They will help in the interpretation of the decision tables.

9. *The ICE should develop a process to recognize differences in the interpretation of the rules and to disseminate information on international differences.*

We have heard a fair amount about international differences in coding rules. The updates provide some detail on the process whereby recommended changes in the rules are developed within the WHO Mortality Reference Group, forwarded to the Update Reference Committee, and then passed on to the WHO Secretariat, which shall make the final decisions on these ICD changes.

Discussion on Topic "Decision Tables"

MR. SIMS: It seems to me that recommendation Number Eight—which talks about an advisory committee for the interpretation of decision tables, and the annotation there talks about reporting through the Mortality Reference Group. The comment at the end indicates that this activity can be added to the terms of reference and work plan for the Mortality Reference Group. It all seems to me to make sense; it all links the process to WHO authority for the ICD. But shouldn't we perhaps formulate a recommendation that encapsulates that last sentence formally for somebody to take to the Heads of Center meeting in Cardiff so that this can, in fact, be considered as a recommendation from this ICE meeting?

DR. NOTZON: That sounds reasonable to me. Do we have any other comment or follow up on that? I think we would all be happy to ask you to draw up that recommendation, and include it in your discussion at the Center Heads meeting for formal approval within the WHO framework.

I would like to comment that so many of these recommendations are feeding very nicely into the WHO system, which is what we all wanted from the beginning. Obviously, this is the way we all want to work. It is nice to see an example of an outside organization meshing well with the WHO organization on an activity that is crucial to all of us.

Data Quality and Editing

Donna Hoyert, Division of Vital Statistics, National Center for Health Statistics,Centers for Disease Control and Prevention

Topic three is data quality and editing:

1. *Automated coding is a step toward improving data quality, consistency, and comparability, but is not the only step. To improve data quality, the quality of certification must also improve. Countries can help physicians complete more accurate death certificates by:*

   A. Using a querying system for corrections as an educational tool
   B. Sending letters to physicians explaining how to certify deaths in specific cases
   C. Exploring ways to make the system more accessible for physician input, for example, like an electronic death certificate
   D. Training doctors with a PC-based interactive system which includes test cases, for example, the National Association of Medical Examiners' "Cause-of-Death Tutorial" that is available on the web
   E. Conducting quality control of medical certification through peer review

The first update says that the U.S. NCHS Web site has included a link to the National Association of Medical Examiners tutorial. NCHS has also developed a tutorial that includes help screens and some basic edits that can be incorporated into versions of electronic death certificates on which various states are working.

2. *WHO should recommend that questions on death certification, including the concepts of sequence and underlying cause, be incorporated into medical board examinations, implying that it will be added to the curriculum, and that receiving continuing medical education credit be a possibility.*

The ICE planning committee suggested that at their next meeting the Center Heads make recommendations to WHO tying medical certification into the global burden of diseases.

3. *Countries should pursue ways to handle constraints on budgets, time, resources, and legal issues, which restrict their ability to query physicians.*

4. *The use of literal text entry should be used to reduce the likelihood of coders or typists changing the input to avoid error messages.*

5. *Countries should use final edits of age, sex, and cause of death to verify consistency and validity among variables on the death certificate.*

6. *Countries should make edit procedures broadly available.*

The update on recommendation Number Six is that NCHS is placing vital statistics instruction manuals that describe coding and processing procedures on the NCHS Web site.

7. *Ways to improve data quality through format, content, and instructions of the death certificate should be considered whenever countries revise their death certificates.*

8. *The ICE on automating mortality statistics should establish a group to review the algorithms to interpret the ICD rules. The group will focus on clarification and specification.*

The update is that the Mortality Reference Group will play that role.

Discussion on Topic "Data Quality and Editing"

DR. COLE: There are two things that I want to say: one is that very many of our death certificates are signed by junior doctors, who change jobs and hospitals quite frequently. When we were sending out queries to the doctor who had filled in and signed the death certificate, the doctors were quite frequently gone away, or they were being forwarded to a new hospital, where the poor chap had no access to the original record and really could not help us at all.

So, in the 1990s, we put the consultant's name—a much more stable character, the career doctor who was in charge of the junior doctor—in the query. We address or we ask the query be passed on to him. I think this has improved quite a bit both the volume of responses and the quality of responses that we get back for our query.

The other thing is that we have started this year a sort of "checkbook." I am sure you have the same kind of thing; you keep the basic information in the hospital, and the torn-off bit of medical cause of death on the death certificate is handed to the relative, who takes it to the registrar to do the process that Graham Jackson [see Session 9 on Electronic Death Registration Systems] spoke about this morning. I do not know how universal that is.

We have comprehensively revised the seven or eight pages that are a preface to this checkbook that is kept on all the wards, and also have a summary of the guidance notes immediately facing the certificate when it lies open and the doctor is filling in. Whether this will make a bit of difference, I do not know; we hope that it will help a little bit.

The recommendations for post-graduate medical education played in our favor because doctors in what we call pre-registration (the first year after qualifying) now have to be given tutorials. The post-graduate tutors, who are the senior and consultant doctors who are responsible for organizing these, are actively looking out for modular packages to deliver bits of tutorial and education.

They received quite enthusiastically a pack of exercises for the completion of death certificates. We are hoping that by this variety of means we will get some improvement.

DR. NOTZON: I was about to ask, before Susan Cole made her statement, if there was any country that had had success in convincing physicians—or medical schools—to include instruction on completion of medical certification as part of the medical education process. It sounds like you have done that in Scotland.

DR. COLE: It was always a part of the public health courses… the boring bit. I think that when people are coming up to final exams, when they have the dramas of real medicine and blood and gore, filling out death certificates is dead boring, and they are not going to do it for a year or two. There is no point in doing it.

I think that teaching the interns just as they are starting—when they actually have to fill a death certificate and they think, "my goodness, what do I have to put down?"—that is the time to catch them. That is why I was pleased to get it inserted at that stage.

DR. NOTZON: About the form that you have adjacent to the medical certification form, a sort of "cheat sheet" that provides information; it sounds similar to the plastic form that we in the U.S. use, which has had reasonable success.

MR. PARRISH: I have four comments. One is on recommendation Number 1-C. What might be done is to update this to now give a couple of specific examples, such as the work that Pam Akison presented this morning [see Session 9 on Electronic Death Registration Systems], in terms of electronic death certification. That might be a nice update to do.

The second comment is that because I was not involved in the first ICE meeting, I do not understand the comment that follows Recommendation Two, "make recommendations to WHO tying medical certification into the global burden of disease." Some clarification as to what is being talked about here might be helpful to the naive outsider in interpreting that.

I am trying to understand Recommendation Four: "use of literal text entry should be encouraged." Does this mean the use of literal text entry, when it is done electronically, should be encouraged? It might be helpful to say: "the use of literal text entry into electronic systems or when it is captured electronically should be encouraged."

Finally, Recommendation Eight seems to have a significant relationship to the whole group of recommendations under Topic Two (Decision Tables). It is not clear to me how it is different from the others.

DR. NOTZON: That is a fair question, and I do not have the answer. To me, it seems to reflect overlap as well. I think the various groups that met at that first meeting found that their recommendations did tend to overlap to a certain extent. Maybe Dr. Rooney would have an additional comment on that.

DR. ROONEY: In general some of this is written in jargon that will only be understood by people who happened to be there, or who are using these systems which use these phrases. That second part in italics in Recommendation Two is supposed to mean that the ICE group thought that it was important that we try to get the WHO to realize the importance of the whole system of medical certification and cause of death and vital registration in providing the information that was required to measure the global burden of disease. Global burden of disease is one of WHO's big programs now. It is just to say: "you cannot do that properly without this underpinning; therefore, let us do some infrastructure strengthening and encourage people to certify cause of death properly, collect this information in a reliable way, code it well, and look at how comparable and how useful it is." That way, it has a higher priority in WHO.

DR. NOTZON: If I understand the subtext correctly, that could also be interpreted to provide additional support to ICD functions within WHO.

DR. ROONEY: I believe so, yes. Part of it was recognizing that the classification and measurement section really need the resources to do the job properly if you want the data to be reliable at the end of the day.

About the Mortality Reference Group, it has been established as a working group of the WHO Heads of Collaborating Centers. Its function is to advise the Heads of Centers, countries, and users of the ICD on the interpretation of the ICD in a mortality context; how things should be coded, how the rules should be applied, and any updating that is needed or any corrections of errors. We are functioning, and we are meeting tomorrow morning.

The ICE Users' Group, on the other hand, is sorting out what is in the decision tables. The ICE Users' Group and the Mortality Reference Group have to make sure that they have all got the interpretation right enough and the same. As I was saying in my previous talk, the application of the rules for a lot of us is going to be through those decision tables.

DR. NOTZON: Do we have any more comment on the recommendations in this section? I think that is a reasonable recommendation, that we reword these so that they are understandable to the outsider who is not part of this group.

DR. ROONEY: On the recommendation about developing tutorial material and tutorials in the style of the National Association of Medical Examiners' tutorial, it has been apparent in discussions that there are several countries currently working on similar things. We are working on one in England and Wales, and I think Canada as well is working on one. It would be very useful if we exchanged transferable information on those; the WHO-type instructions are transferable. Obviously, each country has different laws about what needs to be referred to a medical examiner, that sort of thing. So, we could probably strengthen each other's material by exchanging.

DR. NOTZON: What I would suggest is that we slightly modify the text of this recommendation to say that all countries exchange information to assist in the further development of these tutorials.

DR. ROONEY: Maybe next time we all get together, we can have a session on electronic training.

DR. NOTZON: Before we move on to the next set of recommendations we are going to call on Geoff Sims to come up and read the text that he has prepared regarding Recommendation Number Nine in the second topic group on decision tables.

MR. SIMS: What I tried to do is ensure that, however recommendations are developed in relation to decision tables, they are fed through the Mortality Reference Group into the WHO process. So, my recommendation reads as follows: "That the role of the Mortality Reference Group, in advising WHO Heads of Centers and others on the interpretation of ICD coding of mortality, should encompass the operation of decision rules in automated coding systems." I recommend that that be a recommendation from this ICE meeting to the Heads of Centers meeting in Cardiff.

Technical Support

Dr. Susan Cole, General Register Office for Scotland

1. *NCHS will provide training on automation support to the best of its ability.*

2. *Countries who have already received automation support training should work to strengthen networks with each other.*

3. *Each country is encouraged to try to understand their own automated systems and to be able to change their systems when needed.*

4. *Countries should recognize that two types of support skills are needed for: (1) daily operations and general computer skills, and (2) systems and platform support, including training. Systems and platform support personnel will need to be highly skilled in computer applications.*

5. *Each country's site should have a daily operations support person.*

6. *Each country will be responsible for general computer training.*

7. *Technical support of automation should be hierarchical:*
   - *Local*
   - *State*
   - *Country*
   - *Region*

8. *Developers of automated systems should include useful and understandable messages in their systems.*

9. *Developers of automated systems should document changes in their system and inform users of these changes.*

10. *The ICE on Automating Mortality Statistics should explore ways of reimbursing NCHS for training and support time.*

11. *Countries should provide medical coders and nosologists with computer training along with their nosological training.*

Canada provided assistance to the United States in conversion training.

Discussion on Topic "Technical Support"

DR. COLE: I will start by saying what we in Scotland have done. We are very lucky in that we have an extremely able systems analyst who started off as a coder. She really has an insight into the whole problem. Certainly, with the advantage of having a coder turned systems analyst, I feel reasonably confident that Adele does understand the system, and can really help us in installing it.

MR. JOHANSSON: I understand your situation completely. In Sweden, when we developed MIKADO, the programmer had to learn some ICD coding to understand what he was to do with it. The person working with him—myself—had to learn some programming to be able to tell him what to do. So, you really have to know a bit of both.

DR. ROONEY: It is important that the general daily debugging skills that help computer systems work for all of us are important, as well as the deeper knowledge of the platform and the system as a whole. It is also very important that there be somebody available all the time; this is not a part-time job that you come by and do on a weekly basis.

Within the office for our computer applications, we do have a very good training department. When we changed to the automated system, our coders received training on how to use the package via our computer department. This facility for lifting the level of expertise is as important from the technical side as coding and nosology are on the coding side.

MS. BIUS: What people were trying to get across was that NCHS will try to provide backup technical support, but that the different states or countries have to have good enough local support to be running day-to-day and week-to-week locally. There is no point in thinking that you can use automated coding if you cannot provide that level of technical support, whether that is nationally or in provinces. NCHS is not like Microsoft, for example, where they have thousands of people answering the phone all the time. So, it is up to the states to be running week-to-week solutions, and then to make the occasional call to NCHS.

DR. NOTZON: Of those countries that are currently operating automated coding systems, what sort of hierarchies do you have in place?

DR. ROONEY: While I am up, I will say what we do. We only code in one place for the whole country. We have support that keeps us going most of the time, nationally. Again, we sent our systems support manager to a course at North Carolina's RTP just recently, which she found very useful. We do have to get help from NCHS several times a year.

DR. PÉREZ: I do not need so much technical support from NCHS at the phase that we are now, but yes, in the initial phases we did. I think there are a lot of manuals about the procedures that are very good, but we needed to do a lot of our own work. But now that the system is working, we do not need so much technical support from NCHS.

DR. ROONEY: You do need technical support to run your operation, your own technical support.

DR. PÉREZ: Yes, but not so much either; it is only a few problems in managing data or something like that.

DR. NOTZON: The coding that you perform in Catalonia is centralized; is that correct?

DR. PÉREZ: Yes, and we have a team for informatics personnel who work for us. The system is good enough to not need much technical support.

DR. BAH: There are some other areas in which NCHS could probably delegate some responsibility; that is, some other countries have gone further ahead in incorporating the NCHS system into their own environment. That is something that NCHS does not necessarily have a lot of expertise in, because they developed the model system, so to speak, and then it was incorporated into other systems. So, maybe, if other countries want to go another route, they could probably seek advice from one of those countries that have gone that route, maybe Australia or Sweden.

DR. NOTZON: Actually, this was part of the master plan. The idea is that there is so much interest in automated coding systems that it outstrips the ability of the National Center for Health Statistics to provide assistance. The hope was that other countries that currently have this body of expertise would be willing and able to share that with countries that are interested in acquiring it.

If I can make one more comment: Mexico is one country here that would have to think about the notion of a hierarchy. Mexico is a large country both in terms of population and in terms of territorial expanse, with a diversified coding system that takes place in a number of different regions of the country. Any other large countries that have regional coding centers are going to have to think about this.

DR. COLE: The next two recommendations appear to go together. One of them I very warmly support.

I was once in charge of maternity and child health morbidity data in Scotland. We had a very elaborate editing system, and we were responsible for trying to guide the medical records staffs in hospitals. In

some of the records that were rejected when I was in charge of infant mortality data, I did not get a message to point me in the direction of the problem. It would have been helpful to people who are having to try to resolve these queries to get a clear message as to what was wrong with the record.

I also certainly endorse documenting changes so that when we are looking back we can trace them to new versions of the coding system that are improperly documented. It is amazing how quickly historical knowledge dies and goes away. It is very important to have a long-term firm record of what is going on. It may be very boring to do it, but it is terribly important.

May I ask somebody like Lars Age Johansson or Gérard Pavillon, people who have done so much in their own systems, how do you get on with documenting and dating changes and having useful and friendly messages so that people know what is going on?

MR. JOHANSSON: Thank you, Dr. Cole. I would rather start with your question about the error messages. We have the MIKADO error messages, which tell the coder what to do if a record, for some reason, cannot be accepted by the system. We have also tried to include code-specific error messages such as: "this code cannot be used for people lower than 1-year of age," et cetera. We have not been able to write such messages for the entire ICD yet, but that is certainly our ambition.

As for the documentation, I was talking to Michael Apadula about how very difficult it is to maintain a good standard of documentation if you have very few people working with the system. If something does not work, you try something else. You perhaps make some temporary changes and after some time you cannot even say which parts of the program code are in operation and which part is not.

As I said, the documentation in MIKADO is deplorable. We have full documentation in the program code itself, but it would take some knowledge to be able to assess it. We are planning a Windows version, and we will certainly try to make better documentation when we do that. We have a database system which we use for storing the deaths, and it has excellent documentation—the date of every change, etcetera. That is what we will try to do with the MIKADO as well.

DR. PÉREZ: I am sorry, but we are not users of this system. In the case of manuals or documents or messages and so on, in this we have the help, and it is very useful to understand. We have also a manual that specifies all messages and so forth in the hardware. For the moment, we have not changed anything inside, because we are developing some parts of this.

DR. NOTZON: Dr. Pérez, I have a question for you now. In your work, as your system learns and expands, do you have a "test deck" of records that you can run through the system to get a sense for any changes—unexpected or unintended changes—that have taken place?

DR. PÉREZ: That is not exactly what we are doing. We are randomly taking a sample and comparing the samples; but we do not have one set—the same set—going through the system, no.

DR. NOTZON: But you do test it to see what the ramifications are.

DR. PÉREZ: Yes, randomly.

DR. NOTZON: I heard this morning from some of the group from North Carolina that they have a standard test deck that is used whenever they make changes to the dictionary, because many of those changes can have unexpected and unintended consequences.

DR. PÉREZ: That is a very good recommendation.

MR. APADULA: I have one comment to make about the ICE's last recommendation. About 2 years ago, when we took over the development of the MICAR suite of software, we instituted a version control system for the development of the software and the tables.

So, we have a history that includes dates and comments. We have not gone ahead and published those, but will make it available if it is needed. By the way, Microsoft Source Save is an excellent tool for keeping that type of information.

DR. COLE: Then we come to the final recommendation in this particular section which, as I recall, is one which came up from the floor in the last meeting.

We are in gratitude to NCHS, because of their incredible generosity in sharing all the work that they have done with great expense over many years. In fact, 2 years ago we almost gave you money, but then in the end you turned it down. I hope that perhaps reimbursing will also include cash, but certainly the work that we can all share and grow by. I think that we should all be willing to work with each other, because doing work helps us in our own understanding, and it is a very profitable exercise for everyone.

DR. NOTZON: I think Harry will agree with me in saying that reimbursement in kind is certainly as welcome as other and, perhaps in many ways, preferable, and we would welcome that.

DR. ROONEY: I think the cooperation on developing and checking the decision tables was a good move in that direction. I think the more that we can build on that kind of cooperative working, so as not to have to duplicate things in different countries and get it done more efficiently, the better we will get this done. Plus, we can feel that we have an ownership in the final product as well. It does require a certain amount of commitment of resources from our parent institution and ourselves, and also recognition that you have to go on working in this area for a while. One cannot just send a person to a meeting this year and then next year say, "Oh, no, they cannot have foreign travel again, so we will send somebody else who has not worked in the area." Sharing work is as good as sharing money.

DR. NOTZON: Let me just make a couple of comments about Dr. Rooney's remark. One of them is that we would have had more collaboration earlier had NCHS asked for it. Number two, I like to use this example of the work on the decision tables as a perfect example of international collaboration. I am not sure whether anyone ever sat down and figured out how much it would have cost NCHS to do the work that the four countries provided to us, but it saved us a substantial amount of money and time. I think we are all better off for it, for having the work come from a variety of countries and perspectives. I think the NCHS system is a better product as a result.

Language Issues

Dr. Jaume Domenech, Catalonian Mortality Register, Departament de Sanitat i Seguretat Social

Our primary concern is the MICAR dictionary and correct assignation of ERNs to medical terms. The problem is: What is the correct assignation and reference number to medical terms that can have different meanings? One problem is that there are medical entities without a reference number in the MICAR dictionary—vascular dementia, for example. I do not know whether the term has been incorporated to the latest MICAR version or not, and whether it extends across cultures. So, is there a good correlation between the expressed cause of death and the reference number code?

System users must explore language problems by assuming the possibility of interpretation and word variance. It is also necessary to increase efforts to reach a higher level of consensus within the medical associations about the necessary standardization of the medical language, and in understanding the diffusion of the existing language-sensitive computer programs.

More on these language problems is in the recommendations that were provided in 1996.

1. *WHO and the Collaborating Centers should provide technical support and act as clearinghouses. They might also provide help with networking within countries and give assistance in translation.*

Canada and France have initiated a dictionary of common diagnoses. The Pan American Health Organization and Catalonia have provided technical assistance in Latin America.

2. *Although countries should be responsible for their own changes, language groups should share translations.*

3. *The ICE on Automating Mortality Statistics should assist countries in sharing their experience of system revisions. They should also work to increase networking between countries undergoing system revisions.*

4. *The most updated medical dictionaries should be used in updating translation of the MICAR and super MICAR dictionary.*

5. *Translation should aim at translating ERNs, assuring that it is always possible to enter ACME through ICD codes.*

6. *Translators should translate dictionary terms according to frequency so that the most frequently used terms are translated first.*

7. *Countries should involve a nosologist when writing these dictionaries.*

8. *Before translating the MICAR dictionary, countries need to understand how MICAR works and how to create their own dictionary from scratch. Countries should start with a sample of their death certificates, not with the MICAR dictionary.*

For some countries, the translation of MICAR was a stumbling block in creating their own dictionary. This is why each country needs to understand how MICAR works and how to create dictionaries from scratch. One country took a sample of their most frequently coded causes and began their own dictionary, which will include about 6,000 terms when they are finished. Another country also used the most frequently occurring terms, which represent about 82-85 percent of their cases, but had some difficulty resolving the remaining cases.

Discussion on Topic "Language Issues"

DR. NOTZON: Do we have any general comments on this?

DR. PÉREZ: About Recommendation One: I do not know what the source of this information is, but we are not involved in providing technical assistance in any Latin American country at the moment.

DR. NOTZON: That was one of my questions, and you have answered it already.

DR. PÉREZ: In Recommendation Eight, we emphasized in 1996 that it is necessary to understand the MICAR dictionary before beginning any process. That is very important. We go on to say that we possibly would include 6,000 terms in our dictionary. At the moment, we are including 4,600 terms. In 1996, we had no estimate of the size of this.

Another comment: I spoke with Michael Apadula today about how in the French, Swedish, and Catalonian systems we are "sanitizing" the medical texts—we eliminate prepositions, we change some words, we reformat the structure, etcetera. He thought that maybe it would be interesting to produce some kind of document about this procedure in order to supply this information to the other countries that may need it.

DR. NOTZON: This sounds like it should be a further recommendation, then. I do not know how the other countries feel about that, but that certainly makes sense to me. Gérard and Lars, does that makes sense to you? Would you be able to work jointly on that?

MR. L'HOURS: I have a problem related to several of the recommendations on this topic. It is in connection with the use of the word "translation" and "translator." Nobody should be translating anything. In medical terminology, there are many of what the French call "false friends." A term appears to be the same or similar to a term that exists in a different language, yet it has a completely different meaning in that language. In ICD-9, we worked with

English and French in the WHO headquarters, and there were 33 other language versions. The translators are those preparing language versions. We had this problem with ICD many years ago: "angina," meaning *angina pectoris*, was translated into Russian as "angino," which is sore throat. We need to be very careful about these "false friends" that exist in medical terminology.

To give you further examples, "anthrax" in English is an infectious disease, whereas in French it is a carbuncle—or rather in French as spoken in France, because in Canadian French, anthrax is an infectious disease the same as in English. Creutzfeld-Jakob disease in French is Jakob Creutzfeld disease, and it always was, until the recent publicity about it, when the French have been attracted by the English terminology now, and they cannot call it Jakob Creutzfeld; they have to call it Creutzfeld-Jakob. I think it has happened in other languages as well. In Spanish and Portuguese, where the new doctors are learning more and more of their information from the English, terms are really deformed by the English terminology so their traditional terminology disappears. There are many examples of this. We need to be very, very careful, in preparing these dictionaries, so we do not fall into these traps that we know exist.

It is a very good idea that people from the same language groups should share information, so that the Slav languages and the Romance languages should share their dictionaries. Problems that exist in French may also exist in Spanish and Portuguese.

DR. NOTZON: I have a question for the Canadian representative about making use of the work in France on the MICAR dictionary. I heard yesterday that that has not been done, but you are thinking about it. Would anybody care to make a comment?

MR. CATLIN: We have had some discussions, Gérard Pavillon and I, about sharing information. We are going to initiate cooperation both in training and sharing of indexes this fall.

MR. PAVILLON: I do agree. Those collaborations can have two points: sharing the index, and the update of ICD-10.

About the medical text processing document that Dr. Pérez spoke about, this is the idea: Provided that we standardize the entry of the diagnosis, could we conceive of a system that could be language-independent, with a classical approach? We could try to answer this question with Gloria Pérez and Lars Age Johansson. I think of a coding system that accepts standardized expressions at entry with perfect matching. It could produce the codes according to certain constraints, such as sex, age, other codes present on the death certificates, etcetera. I do not know for certain, but it

seems to me that it is possible. Is it possible to come up with such a system that could be language-independent? If so, it would be very useful to have it as a general tool; simple, but general.

MR. JOHANSSON: I think that is a very good idea. I should say that many of the ideas for text parsing that we use within MIKADO actually came from a Canadian project called "ACTR." We used the preliminary report of this project, where they described the different steps to use in parsing, and we then incorporated that in our system. We did some changes, of course, but the interesting thing with the Canadian system is that it was planned to be general, that is, to be used both for English and French. So, I suppose it would be possible to make some kind of general strategy for language parsing.

DR. NOTZON: I think that would be of use to a variety of countries. Lars Age, I had one other question regarding the effort to standardize language among physicians. You talked this morning about the problems that you have with the variety of language that is used by different physicians. Is there an attempt now to standardize, that is, to convince physicians to speak in one language, at least the new physicians who are coming on?

MR. JOHANSSON: I think that the difficulty in trying to restrict the language that physicians use is that you would not catch any developments in medicine. There are new diseases emerging and there are fashions in terminology as well. I do not think we should try to correct that.

DR. COLE: Excuse me for translating what I think you mean. I think he was trying to persuade the older physicians from speaking Latin and Greek.

DR. NOTZON: That is what I meant.

DR. COLE: And you cannot persuade them to do this, or do you have to wait until they die out?

MR. JOHANSSON: What we have seen from the statistics suggests that they are dying out.

DR. NOTZON: Another issue is, where do the physicians in each country receive their training? I think you mentioned this morning that some of them were trained in Germany? Is that correct?

MR. JOHANSSON: They were not trained in Germany, but we had German textbooks up to the Second World War.

DR. NOTZON: Certainly there is some exchange between the United States and Canada in terms of medical training. In a sense, it is a good thing that you have people bringing back information from the other system. It tends to tie the two groups together to a certain extent.

Implementation Issues

Pnina Zadka, Health Social & Welfare Statistics, Central Bureau of Statistics

1. *The ICE on Automating Mortality Statistics recognizes the importance of WHO in coordinating and providing leadership in automation relative to the classification of cause of death. WHO should continue in this leadership role.*

2. *NCHS, as well as other countries who develop automated systems, should emphasize the transfer of expertise and methodology, not just products.*

3. *NCHS will establish a web presence for automated systems.*

4. *The ICE on Automating Mortality Statistics will establish a user group.*

The recommendation for the creation of an automated systems users group was presented at the 1997 WHO Center Heads meeting. The users group, established by NCHS, offers technical assistance and systems support, input to software development and general information sharing with news and updates of ICD-9 and ICD-10. This group works closely with the Mortality Reference Group to ensure that decisions are reflected in general software design.

5. *The ICE on Automating Mortality Statistics should establish an e-mail network for the general sharing of news, ideas, and questions. This e-mail network would be open to all countries using automation as well as those who are considering moving toward automation.*

6. *The ICE on Automating Mortality Statistics encourages the establishment of language-based e-mail groups.*

Now, what has happened since 1996? WHO has taken steps toward establishment of an ACS users group, subgroup. The MICAR dictionaries for ICD are all available on the NCHS mortality Web site. The manuals are also available now on the Web site, and this Web site continues to develop and include more information that is readily available for everybody. France and Canada have established an e-mail group for the French version of ICD-10.

Discussion on Topic "Implementation Issues"

DR. PÉREZ: We have an e-mail group in Spain for the mortality registry. It is part of the implementation of ICD-10. It is a very active group. Another group is being organized by Roberto Becker from PAHO, which is similar to the Mortality Forum. It is in English, Spanish, and Portuguese, and it is also for the ICD-10 implementation.

MR. JOHANSSON: I have to confess that I had not heard about the ACS User Subgroup until today, but I hope that this group will soon come into more tangible existence.

I think the mortality forum and other groups are a really efficient way to work. I mean, you can send questions to people all over the world and you get answers in a week or so. It would be very nice to have an e-mail group on automated coding. I am not quite sure that these two groups should be the same, because we are discussing somewhat different issues. However, more or less the same people would be active in both groups. We should first determine whether we will need two groups or if one group will do.

MR. L'HOURS: The reason that Lars Age Johansson had not heard of this group before is that it has just been incorporated in the joint WHO—WHO Collaborating Centers work plan that was developed last month. It is going to be presented to the Center Heads meeting that starts on the 17th of October. Unofficially, it has been established, and it will be confirmed next month, we expect.

DR. NOTZON: I receive the e-mail messages from Roberto Becker's users group. They sent to me, and I translated them for Marjorie Greenberg. The group seems to be working reasonably well, and they are getting many responses to questions that are raised, and are resolving issues that concern coders across Latin America.

MR. PAVILLON: Just a detail on Recommendation Six: France and Canada have established contacts, but not an e-mail group, to discuss the French version of ICD-10 and its implementation.

DR. ROONEY: On the establishment of this users' group as well: you are right, Lars Age, it has not been generally established and working yet. It is not the same as either the Mortality Reference Group or the ICE. Within the joint work plan that is being discussed and is going to be presented in Cardiff meeting are several work groups or areas of priority for work groups, and then subgroups within that. Within the Electronic Tools Committee, there is a subgroup for a users' group of people using automated systems; the idea being to exchange information, and for that to be a route through which WHO and the collaborating center network can have an input into the content of decision tables. Also, a users' group will extend the whole idea of international cooperation, so that when you find an error in the decision tables, you feed it back and they correct it, then it goes out again to all the users. We keep trying iteratively to make it better. It has been established in somebody's head, and it is going to be established in fact, and have a membership.

MR. JOHANSSON: I wonder whether it would be possible to compile some kind of a status list including which countries have automated coding, and which countries are planning to introduce it, at what stage they are, etcetera? Maybe there is something like this already out there? That could help quite a lot in establishing contact between people working in automated coding.

DR. NOTZON: We could go a long way toward doing that before this meeting is over if we could hear from each of the countries present before we break tomorrow at noon. We would know about their current situation and their plans for the future. You can give those to me, and then I would pass that on to Lars Age Johansson. I agree, I think that would be very useful.

MS. AKISON: I am not sure where this comment fits in, but I would like to bring up as a potential topic something to which I alluded earlier and see if others agree. We are starting to move into situations where we can envision automated coding as being in the back end of real-time systems. I am concerned about the nature of the feedback that we give to the users—not to our coding staff, but to the physicians who are actually entering this information in. It is something that we have talked about in the United States to some degree, but it is very important because it is part of training; it is part of the decision tables; it is part of a lot of things. I do not know where it fits, but I think it is a very important issue, and I would like to bring that up and see if there is any interest in addressing that in the different user groups, or as a recommendation, or with WHO.

DR. COLE: I cannot remember who said that somebody who filled in the death certificate was absolutely astonished that that was where the country knew the leading causes of death. When you read the kind of problematic death certificates that are brought to my attention, you could weep. Somehow, you want to be able to say to the doctor immediately: "that is a logical sequence," or "that is not a logical sequence." If you could ask the physician: "Do you really mean that in the national cause-of-death statistics you want to say that 'operation for hernia' is a cause of death?"; they would probably answer, astonished: "Now, really say, in your national statistics, this patient will be attributed to this cause? Is that what you mean?" You know, I think that might be the kind of question to ask, a fairly simple, standard question that might start to make the neurons, the synapses, jump.

DR. ROSENBERG: This so-called disconnect between filling out death certificates and producing national statistics is something that we have been aware of in the United States for some time. We held two workshops on improving the quality of medical certification of death, one in 1989 and one in 1991. One of the recommendations that came out of that, which we have tried to implement, is that in every news release, and in every article that we write that has mortality statistics in it, we state right at the very beginning: "This

information is from death certificates, completed by physicians, medical examiners, and coroners." We make the statement extremely visible, and we ask the States, in their own publications, to do the same. I would not say this policy is implemented uniformly and always successfully, but it is a way to impress the medical community and say: "It is very important for you to know that what you are doing is the basis for national and State statistics." There are ways to educate the physician community.

MS. ZADKA: Harry, do you think a newsletter that is distributed through a medical association would help?

DR. ROSENBERG: I think articles that go to professional societies and State medical societies are useful, but where it would really have an impact is if it were to appear on the first page of the Washington Post or the front page of the New York Times, saying: "AIDS mortality decreased by 20 percent, this information is from death certificates completed by physicians." Then they would know.

DR. ROONEY: I think that is absolutely true. That is the connection you are trying to make. They see the dramatic trends, yet they do not know where they come from, and they do not realize that the data relies on them. What we have done with some other systems in England is to feed back to the people who fill in the forms every 6 months or so, the statistics of the country, and how many forms the individual has filled, or how the statistics of the physician's hospital are almost identical to, or higher or lower than for the nation. It would be tricky to do the same thing with mortality statistics on an individual physician level, partly because they do not complete enough certificates, but maybe it could be done at the county level.

DR. NOTZON: For certain procedures, like cesarean section, there has been an attempt to inform the hospitals and doctors of their rate of delivery by that particular procedure. In at least some States in the United States there has been an effort over time to provide feedback from the State vital statistics to the hospitals, to the local communities.

MS. AKISON: We have tried reporting something that is actually interesting, like what the locality's heart disease rate is. As well, one could get feedback that says: "You have the highest rate of incompletely-filled certificates," and just turn people off.

DR. NOTZON: I think that has been done as well.

Poster 1: The Effect of Changing From Manual to Automated Coding; Australian Results

Malcolm Greig and Sue Walker, Australian Bureau of Statistics

Introduction

In 1997 the ABS introduced multi-cause mortality coding using United States Automated Coding Software (ACS). This caused complications such as, interfacing with current computer systems, terminology and spelling differences, new coding interpretations and the need for intensive coder training. This paper looks at the statistical quantification of the change.

Comparison of manual and automated coding

ACS was developed in the United States and, therefore, uses United States interpretations of ICD-9 coding rules. In some instances, these differ significantly from the coding rules used previously in Australia when underlying cause was selected manually. As a result of the introduction of ACS, there is now a break in the underlying causes of death series between 1996 and earlier years and 1997, with significant differences for a number of causes of death.

To highlight the differences and to provide a link for underlying causes of death data between 1996 and 1997, the records for more than 34,000 deaths registered in 1997 (representing more than one-quarter of total 1997 deaths) were coded, both manually and automatically. Records selected for the exercise were spread across the year to allow for seasonal influences. Comparability factors were then calculated. An adjusted estimate of the number of deaths attributed to a particular cause can be produced by multiplying the number of deaths attributed to that cause in 1996 (or in earlier years) by its corresponding comparability factor. This adjusted figure can then be more accurately compared with the number of deaths attributed to the same cause in 1997 and enable trends to be more appropriately examined. Relative Root Mean Square Errors were calculated to provide a measure of the accuracy of the comparability factors.

The estimates of the comparability factors will be slightly biased when estimating for a "rare" cause of death code (i.e., a code which is only used in small or very small numbers in any year). This is caused by the possibility of selecting no death records in the sample, which when manually coded, would have been assigned that code. This means that rather than working out Variances, Standard Errors and Relative Standard Errors, Mean Square Errors (MSEs), Root MSEs, and Relative Root MSEs are calculated, respectively. These are close substitutes, but will be slightly higher than the measures they replace.

In addition, in working out the Relative Root MSEs, it has been assumed that the death records selected for dual coding were randomly chosen. In fact, 3 months were selected to represent the population, and all the records relating to those months were dual coded. The affect of this approach has been analyzed and has shown that the results calculated from the sample closely conform to those that would have been obtained from a random sample.

Comparability factors of 1.0 or close to 1.0, indicate no significant coding differences between automated and manual coding. Factors of less than 1.0 indicate that automated coding would assign fewer deaths to that particular cause than would manual coding.

General results

Comparability factors were calculated at both the 3- and 4-digit levels of the ICD. Information at the 3-digit level is provided to users where standard errors are suitably low. Information at the 4-digit level is used for ABS internal analysis only. A selected set of factors is shown and commented on below.

Table 1. Comparability factors, general results

Cause of death and ICD code	Comparability factor
All causes	1
Chapter I Infectious and parasitic diseases (001-139)	1.05
Chapter II Neoplasms (140-239)	0.99
Malignant neoplasms (140-208)	0.99
Lip, oral cavity and pharynx (140-149)	1.04
Digestive organs and peritoneum (150-159)	0.99
Oesophagus (150)	0.99
Stomach (151)	0.99
Colon (153)	1
Rectum, rectosigmoid junction and anus (154)	0.99
Liver and intrahepatic bile ducts (155)	1.04
Pancreas (157)	1
Trachea, bronchus and lung (162)	1
Bone, connective tissue, skin and breast (170-175)	0.98
Melanoma of skin (172)	0.99
Breast (174, 175)	0.99
Ovary and other uterine adnexa (183)	1.01
Prostate (185)	0.99
Bladder (188)	0.97
Other and unspecified sites (190-199)	0.99
Brain (191)	0.99
Lymphatic and haematopoietic tissue (200-208)	1
Leukaemia (204-208)	0.96
Benign and unspecified neoplasms (210-239)	0.9
Chapter III Endocrine, nutritional and metabolic diseases and immunity disorders (240–279)	0.97
Diabetes mellitus (250)	0.94
Chapter IV Diseases of blood and blood-forming organs (280–289)	1.12
Chapter V Mental disorders (290–319)	0.84
Senile and presenile organic psychotic conditions (290)	0.38
Drug dependence (304)	1.03
Chapter VI Disease of the nervous system and sense organs (320–389)	0.88
Hereditary and degenerative diseases of the central nervous system (330–337)	0.86
Alzheimer's disease (3310)	0.84
Chapter VII Diseases of the circulatory system (390–459)	0.98
All heart disease (393–398, 402, 404, 410–414, 415, 416, 420–429)	0.99

Rheumatic fever and rheumatic heart disease (390–398)	0.89
Hypertensive disease (401–405)	0.93
Ischaemic heart disease (410–414)	0.99
Acute myocardial infarction (410)	0.99
Diseases of pulmonary circulation and other forms of heart disease (415–429)	0.99
Heart failure (428)	0.94
Cerebrovascular disease (430–438)	0.95
Diseases of arteries, arterioles and capillaries (440–448)	0.99
Atherosclerosis (440)	0.88
Aortic aneurysm (441)	0.99
Chapter VIII Diseases of the respiratory system (460-519)	1.21
Pneumonia and influenza (480-487)	2
Chronic obstructive pulmonary disease and allied conditions (490-496)	0.94
Emphysema (492)	0.97
Asthma (493)	0.98
Chapter IX Diseases of the digestive system (520–579)	0.99
Diseases of oesophagus, stomach and duodenum (530-537)	1.01
Ulcer of stomach and duodenum (531-533)	0.97
Chronic liver disease and cirrhosis (571)	0.96
Chapter X Diseases of the genitourinary system (580-629)	1.03
Nephritis, nephrotic syndrome and nephrosis (580-589)	0.88
Renal failure (584-586)	0.86
Chapter XI Complications of pregnancy, childbirth and the puerperium (630-676)	1
Chapter XII Diseases of the skin and subcutaneous tissue (680-709)	0.99
Chapter XIII Diseases of the musculoskeletal system and connective tissue (710-739)	0.97
Chapter XIV Congenital anomalies (740-759)	1.09
Chapter XV Certain conditions originating in the perinatal period (760-779)	0.92
Chapter XVI Symptoms, signs and ill-defined conditions (780-799)	0.74
Supplementary Chapter XVII Accidents, poisonings and violence external causes (E800-E999)	1.01
Accidents (E800-E949)	1.02
Motor vehicle traffic accidents (E810-E819)	1
Accidental falls (E880-E888)	1.03
Accidental drowning and submersion (E910)	0.99
Homicide (E960-E969)	1.03

As can be seen from the table, the key change is with regard to the treatment of pneumonia and influenza. Specific areas that were affected as a consequence of this were Senile and presenile organic psychotic conditions, Hereditary and degenerative diseases of the central nervous system and Alzheimer's disease. (See the next section for a detailed analysis.)

Within Chapter IV, the 3-digit code 298, Other nonorganic psychosis has a comparability factor of 46.17 (manual 6, ACS 277). This is due to the Australian rule of coding any case with dementia over 65 as Senile dementia. ACS only assigns a code, 290.0 (Senile Dementia), if that

exact term is mentioned on the certificate, i.e., ACS does not take the age into consideration when coding dementia.

Many of the differences are due to the Australian interpretation of Rule 3, e.g.:

- Category 415 Acute pulmonary heart disease, which includes pulmonary embolism, has a comparability factor of 2.12 (manual 41, ACS 87). Manually, Australia would have assigned a condition from Part II for the Pulmonary Embolism, if query action provided no extra information.

- Category 507, Pneumonitis, which includes aspiration pneumonia, has a comparability factor of 2.75 (manual 24, ACS 66).

- Category 599, which includes Urinary Tract Infection, has a comparability factor of 2.71 (manual 45, ACS 122).

There were a number of other large comparability factors, but most involved very small occurrences and high standard errors.

Pneumonia—a case study in Australia

The cause of death most affected by automated coding for Australia was pneumonia with the category of pneumonia and influenza (ICD codes 480, 487) becoming, in 1997, the fifth leading cause of death. Causes consequently and significantly affected include senile and presenile organic psychotic conditions dementia (ICD code 290), and Alzheimer's disease (ICD code 331.0).

Variation in the coding of pneumonia is largely due to the non-application in ACS of the 1984 Australian ruling that,

"If the death was of a person who was 75 years of age or over and pneumonia was reported on the lowest line in Part I and a serious disease was included in Part II of the death certificate, the underlying cause would always be coded to the serious disease in Part II."

If there was more than one serious disease listed in Part II, the first mentioned disease was chosen. This was an Australian interpretation of how Rule 3 should be implemented.

However, the ICD-9 version of ACS does not apply Rule 3 in this way. There are no clear guidelines about how to use Rule 3 in ICD-9 in such cases, thus, Rule 3 in ICD-9 is very much open to interpretation. [Note: The introduction of ICD-10 will again change the interpretation, but, although ACS logic does not revert to coding in the same way as Australia did prior to 1997, it moves closer to that previous interpretation]

There are quite a number of codes affected by the change of interpretation for Pneumonia. In the linking exercise, of the 1,512 deaths coded to pneumonia (480-486) under ACS, 682 (45.1 percent) were similarly assigned under manual coding. Of the remainder, the following proportions were manually coded to:

- 44 (2.9 percent) malignant neoplasms
- 33 (2.2 percent) diabetes

- 165 (10.9 percent) senile and presenile psychotic conditions (dementia)
- 32 (2.1 percent) Alzheimer's
- 27 (1.8 percent) Parkinson's disease
- 92 (6.1 percent) ischaemic heart disease
- 91 (6.0 percent) cardiac dysrhythmias and heart failure
- 36 (2.4 percent) chronic obstructive pulmonary disease
- 29 (1.9 percent) other diseases of the respiratory system
- 37 (2.4 percent) renal failure

The remaining 16 percent of deaths were widely spread in small numbers across a range of other causes. Hence, while applying ACS coding interpretations has caused pneumonia deaths to rise, deaths coded to a wide range of other conditions have declined, in particular those due to dementia.

A more detailed breakdown of the comparability factors for Pneumonia with relevant RRMSEs is given in the following table. Also included is an indication of the corresponding actual movements for each broad type of Pneumonia. The comparability factors and the actual movements match reasonably well, considering the well established expectation within the health sector that the number of Pneumonia deaths may vary considerably from year to year.

Table 2. Pneumonia: comparability factors and their reliability

ICD Code	Manual Codes Number	Automated Codes Number	Compara-bility Factor	Actual 1996/1997 movement	Relative Root MSE %	Confidence Interval-Lower Bound	Confidence Interval-Upper Bound
480	26	23	0.88	0.67	9.25	0.72	1.05
481	53	79	1.49	1.82	9.89	1.2	1.79
482	41	37	0.9	1.08	5.38	0.81	1
483	9	12	1.33	2.06	14.25	0.95	1.71
485	215	534	2.48	3.12	4.55	2.26	2.71
486	363	827	2.28	3.42	3.52	2.12	2.44
480 – 486	707	1,512	2.14	2.88	2.42	2.04	2.24

The low Relative Root Mean Square Error (RRMSE) for the comparability factors relating to Pneumonia are low and the comparability factors should therefore be considered to be accurate.

ICD-10 ACS allows for a much more flexible relationship between Pneumonia and other conditions than does the ICD-9 version of the software. In addition, although the interpretation of Rule 3 in the new version of ACS does not incorporate any age relationship such as the one previously existing in Australia under manual coding, it does build in a very much wider relationship between Pneumonia and other causes. The likely result is that deaths from Pneumonia will reduce substantially with the introduction of ICD-10, and deaths from other causes, which are recognized in the logic as being capable of causing Pneumonia, will increase.

The actual results cannot be predicted so careful monitoring of the output of the system will be undertaken. Dual coding of 2 years data will provide an excellent link.

The Mortality Reference Group (MRG) Meeting is also addressing the question:

"What is the most appropriate way to apply Rule 3 with respect to Pneumonia?"

The group has agreed to restrict the types of Pneumonia to broncho and hypostatic Pneumonia, but was unable to reach a consensus about restricting conditions that would be appropriate direct sequels. Views varied from taking a narrow interpretation of Rule 3 whereby Pneumonia reported as the originating cause is considered as a direct consequence of wasting or paralysing diseases only, to a broad application where Pneumonia can be considered as a direct consequence of any non-symptomatic, non-trivial condition.

Based on Swedish studies, Lars Age Johansson has suggested rephrasing Rule 3 along the following lines:

- For persons 75 years of age or more, Pneumonia (any type) should be seen as a direct consequence of any condition
- For persons under 75 years of age, Pneumonia (any type) should be seen as a direct consequence of wasting diseases and diseases causing paralysis.

This is very similar to the Australian approach pre-ACS. In Australia, though, cases are queried in regards to Pneumonia for those aged 75 and under, in cases where a non-trivial condition or conditions is/are listed in Part II of the Certificate of Cause of Death.

Poster 2: A Multivariate Analysis to Evaluate the Effects of Automated Coding in Mortality by Cause; An Overview on Regional Differences in Italy

Luisa Frova , S. Bruzzone, A. Battisti, S. Marchetti, and R. Crialesi

Introduction

Every year the Italian National Institute of Statistics (Istat) collects, processes, and publishes data on mortality by cause of death. For every death that occurs in Italy a certificate of death has to be filled. Therefore, sociodemographic variables, such as sex, marital status, educational level, etc. and epidemiological information are available. The epidemiological information refers to all the different fatal or nonfatal diseases and, when it applies, the traumatic circumstances that occurred to the individual before death.

Data published by Istat refer to the underlying cause of death, i.e., the one that has mostly contributed to death. The selection and coding of the underlying cause (based on information from the death certificate) is one of the most delicate and demanding phases of the mortality data production.

Before 1994 the underlying cause of death was manually selected and coded by specialized Istat personnel, on the basis of the "selection rules" recommended by the World Health Organization. Recently, Istat has adopted a new coding system for death: automated coding has replaced manual coding starting with deaths occurring in 1995. Currently, 77 percent of deaths are coded by means of a revised version of MICAR-ACME software.

The aim of this paper is to evaluate the impact that automated coding has on mortality by cause statistics in Italy. Therefore, a double coding (both manual and automated) was done on a large number of deaths that occurred in 1995. In order to better understand if differences observed in the two coding systems, a multidimensional analysis is done.

Automated vs. manual coding: descriptive results of "bridge coding"

Deaths that occurred in 7 months of 1995 (January, February, March, May, July, September, and November) were selected, and both an automated and manual coding process was done on each form. Therefore, 323,204 individual forms were considered. However, automated coding was successful only in 77 percent of cases; that is, 245,999 individual forms were automatically coded. Deaths due to AIDS, injury, and poisoning were not included in this analysis because, for this type of deaths, management and operating problems were found in the automated coding software. Therefore, the analysis includes natural deaths according to the automated coding; that is, deaths coded in conformity with IX International Classification of Traumatism and Death Cause Diseases with codes below 800.0 and different from code 279.1 (the Italian way of coding AIDS). A descriptive comparison between the coding procedures can be made using information at an individual record level.

Of the 245,999 individual records examined, 71.7 percent showed an exact concordance by the two coding methods at the fourth digit level in the code assigned. This percentage of concordance increases at the third digit level (77.2 percent) and is even higher at a group level (89.3 percent).

Although on the whole concordance is remarkable, variation can be found between disease groups. Concordance at group level is very high for neoplasms, major coronary events, and circulatory system. As far as neoplasms are concerned, exact concordance at third and fourth

digit is very high: 90.3 percent and 86.7 percent, respectively. In cardiovascular diseases, the concordance is high for major coronary events, but it considerably decreases for the other circulatory system diseases. In fact, concordance percentage is more than 80 percent in the former, both at third and fourth digit. On the contrary, in the latter, the lowest percentages are about 64 percent (table 1).

Table 1. Concordance at individual record levels between automated and manual coding

Diseases (ICD IX Rev.)	Method of coding		Concordance			Concordance (%)*		
	Manual	Auto	group	III digit	IV digit	group	III digit	IV digit
Infectious (1-139)	734	1,148	461	405	369	62.8	55.2	50.3
Neoplasms (140-239)	70,793	69,089	67,923	63,912	61,344	95.9	90.3	86.7
Major coronary events (410-414)	37,413	37,013	33,418	31,829	30,725	89.3	85.1	82.1
Other circulatory diseases (390-409; 415-459)	81,781	82,340	73,053	55,793	52,285	89.3	68.2	63.9
Respiratory system (460-519)	16,556	17,484	13,779	10,626	10,384	83.2	64.2	62.7
Digestive system (520-579)	12,517	11,539	10,287	9,613	8,516	82.2	76.8	68.0
Other diseases** (code < 800)	26,205	27,386	20,819	17,618	12,697	79.4	67.2	48.5
Total causes	**245,999**	**245,999**	**219,740**	**189,796**	**176,320**	**89.3**	**77.2**	**71.7**

* Percentage is equal to the ratio of concordant cases (at group, at III digit, at IV digit) to manual coding cases.
** AIDS is not included.

Main results from previous works

In a previous work (Crialesi R. et al., 1998), a logistic model was used to better understand differences between the two coding methods.

Main results can be summarized as follow:

- The two coding methods are not dependent on demographics characteristics of the dead (sex, age, and geographical area of death).
- The main differences between the two coding methods depend on the type of pathology and on complexity of the pathologic picture recorded on the certificate of death.
- Discordance increases with number of pathologies reported.
- The highest discordance is recorded for infectious diseases and for respiratory system diseases.
- For neoplasms, the two methods of coding are highly concordant even if the pathologic picture is complex (e.g., more than five diseases).

Examined data allow us to state that concordance between the two coding methods is greater for the most widespread diseases as they are well-known by certifying doctors (facilitated in certifying death and in form filling) and Istat coders.

Discordance between manual and automated coding could be caused by the coder, who does not always evaluate in an objective manner the “placing order” for initial cause, intermediate cause or complication, fatal cause, and other important morbidity conditions recorded in death certificate.

In the above-mentioned study, the geographical analysis was limited to four large Italian areas (North-East, North-West, Center, South, and the Islands) and territorial differences between the manual system and the automated system were not highlighted.

The certifying of death and regional differences

A greater territorial desegregation was necessary in order to determine whether territorial differences actually exist. A detailed regional level was chosen for this reason, and the phenomenon was studied subdividing the Italian territory into 20 sub-areas. A preliminary, descriptive analysis of certain variables such as sex, age of death, number of pathologies and mortality by cause is necessary in order to analyze possible territorial differences. Furthermore, the territorial distribution of these indicators depends on the accuracy in filling out the certificate of death and answering health question, as well as on the demographic characteristics of the reference population. The territorial changes in the form filling and certifications can be influenced by the professional experience of the doctor and the subjective diagnosis of the morbidity process.

Regional differences in the variables can be observed in a preliminary descriptive analysis. Marche, Liguria, Molise, and Toscana are the regions with an older age-structure; in other words, a higher percentage of deaths over 75 years old. On the other hand, Campania, Lombardia, and Lazio record the lowest percentages of such deaths.

Territorial differences can also be observed for the number of pathologies on the death form. Toscana, Basilicata, Calabria, and Sicilia (60.8 percent to 65.4 percent of forms with 1–3 pathologies) have the highest percentage of certifying doctors or coroners declaring 1 to 3 pathologies, while the highest percentage of those declaring more than five pathologies are in Lazio, Trentino Alto Adige, Friuli Venezia Giulia, and Sardegna (from 7.33 percent to 8.49 percent).

A similar regional distribution of the two coding systems can be recorded through an analysis of deaths by large groups of causes; some differences are found only in pathologies with a lower concordance, even on a group level (infectious diseases group). The regions with the highest number of cases of mortality by infectious diseases are Friuli Venezia Giulia, Marche, Piemonte and Valle d'Aosta, Trentino Alto Adige, and Sardegna. Considering the manual coding system, the overall percentage of cases of death by infectious diseases varies, in these regions, from 0.59 percent to 0.37 percent. Campania and Sicilia are the regions where this percentage is lower, respectively 0.18 percent and 0.19 percent.

Automated coded deaths give a slightly different picture. According to this distribution, a higher number of cases of deaths by infectious diseases is recorded in Marche (0.71 percent) and high values—not shown by the manual coding system—are also recorded in Umbria and Lombardia (0.66 percent and 0.59 percent).

The lowest percentage is recorded in Campania and Sicilia for both coding systems (respectively manual coding: 0.18 percent and 0.19 percent—automated coding: 0.33 percent and 0.37 percent). In the North East regions in particular, a high percentage of neoplasm can be observed (percentage of cases on the total mortality in the range 33–28 percent). Campania, Sicilia, and Molise are favoured (percentage of cases on the total in the range 20.8–22.7 percent).

The Southern regions record a higher percentage (compared to the Northern ones) for circulatory system diseases. The only exception, compared to the other Northern regions, is Trentino Alto Adige; in fact, a very high percentage of deaths for major coronary events is recorded in this region (about 22 percent on the total, against a national percentage of around 15 percent).

The Southern regions, along with Piemonte, Valle d'Aosta, and Friuli Venezia Giulia, have a high number of deaths by respiratory system diseases (percentage of cases between 7.5

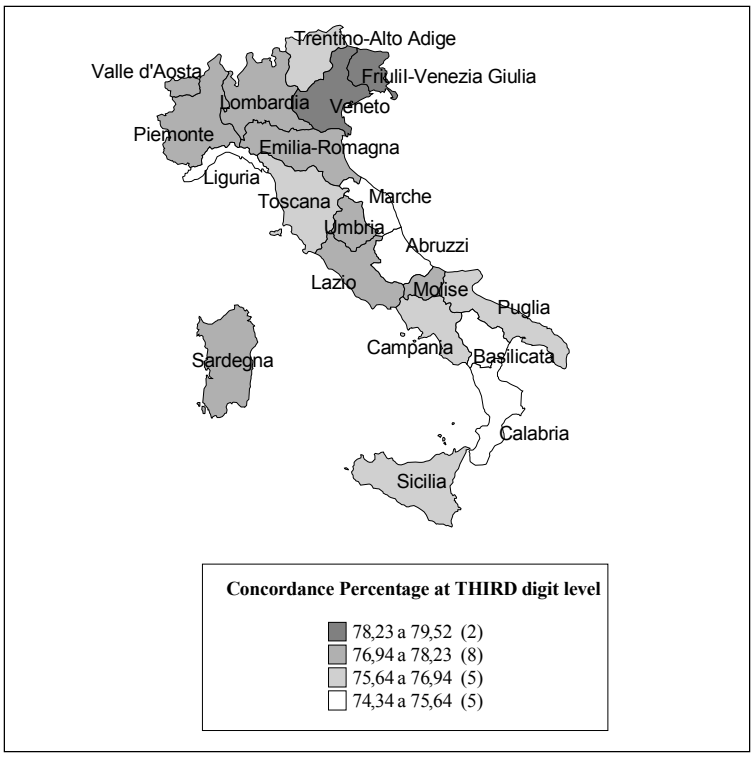
percent and 8.5 percent). The highest percentage of cases for digestive system diseases is in Campania (6.5 percent), while the lowest percentage is in Toscana (3.6 percent).

Manual vs. Automated coding: concordance at third and fourth digit. A map of the Italian regions

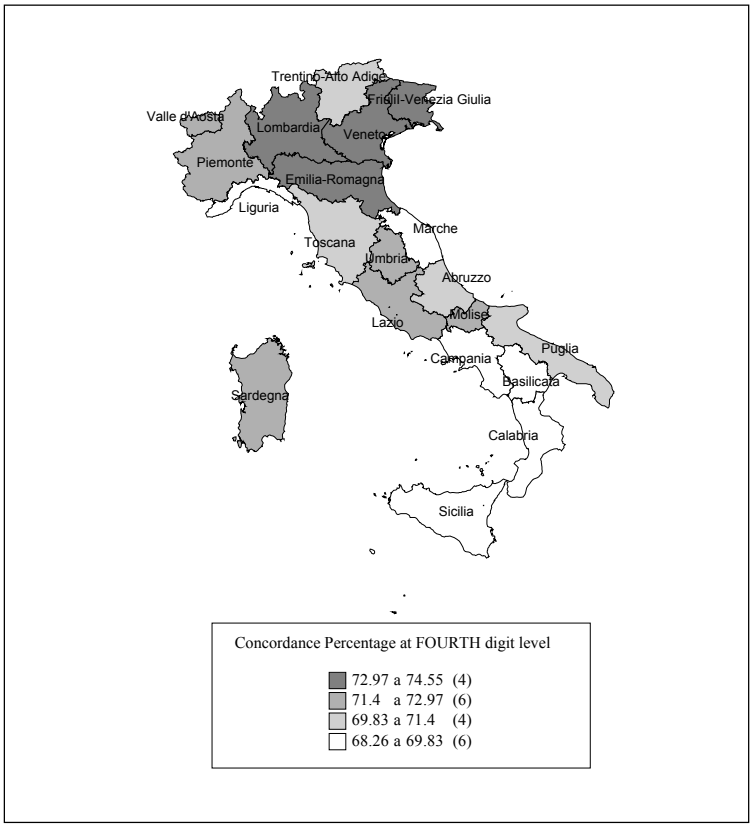
Analyzing the concordance percentage between the two coding systems at group, at third digit and fourth digit levels in the 20 Italian regions, the variability of these indicators is quite low in the first case (3 percentage points), and it is higher when the precision level of the indicator is increased (5 percentage points for third digit concordance and 6.3 percentage points in fourth digit concordance). The region with the lowest concordance percentage is Basilicata (group concordance 88.4 percent, at third digit level 75.1 percent, at fourth digit level 68.3 percent against Italian average of respectively 89.3 percent, 77.2 percent, 71.7 percent), while the regions with the highest percentage are Piemonte and Valle d'Aosta (90.7 percent, 77.9 percent, 72.9 percent) and Friuli Venezia Giulia (89.2 percent, 79.5 percent, 74.5 percent), (figure 1).

The territorial concordance analysis shows that, along with Basilicata, the most disadvantaged regions are Liguria, Marche, Abruzzo, Calabria, and Sicilia. On the other hand, the North East regions record the highest concordance percentage at the third and fourth digit, Trentino Alto Adige is an exception with similarities with the Central and Southern regions.

Figure 1. Concordance percentage at III and IV digit level: a map of the Italian regions



Note (figure 1): The values near the legend labels, between brackets, indicate the number of regions contained in the groups



Discordance between manual and automated coding: a territorial analysis

Findings from the analytical study have been synthesized in order to complete the analysis of the territorial differences of mortality, giving an overall evaluation of the regional differences of mortality between the two coding systems. For this reason, a Principal Components Analysis on the complete matrix of the most suitable indicators in illustrating the regional differences has been conducted. The input matrix for an individuals—variables Factorial Analysis can be likened to a cloud made up of 20 points (Italian regions) within the space of the 49 variables. The variables considered (including variables of descriptive analysis) are for the most part concordance measures stratified by cause of death and number of pathologies recorded on the death form. The Principal Components method enabled the selection of four principal factors explaining 62.8 percent of the total variability. Table 2 and figures 2, 3, 4, concerning the planes resulting from the 2 X 2 combinations of the first four factors, illustrate the results using the method.

Table 2. Description of Principal Components referring to continuous active variables and to active units

Factorial axis	Variables	Correlation	Mean value
First (25.5%)[a]	Concordance at IV digit	-0.94	71.3
	Concordance at III digit	-0.91	76.8
	Concordance at III digit, 4-5 diseases	-0.86	72.5
	Concordance at group, 4-5 diseases	-0.83	86.1
	Concordance at IV digit, 4-5 diseases	-0.83	65.9
	Concordance at IV digit, 1-3 diseases	-0.82	76.4
	Concordance at IV digit, more than 5 diseases	-0.80	56.2
	% of 1-3 diseases	0.45	57.1
Unit (coordinates)	Veneto (-5.5), Friuli (-5.0), …, Calabria (5.9), Basilicata (7.4)		
Second (16.7%)[a]	Concordance at III digit, digestive system	-0.83	82.6
	Concordance at group, digestive system	-0.81	88.7
	% of 1-3 diseases	-0.78	57.1
	% of more than 5 diseases	0.74	6.1
Unit (coordinates)	Campania (-5.1), Sicilia (-4.8), …, Marche (4.2), Trentino Alto Adige (6.9)		
Third (11.2%)[a]	Concordance at III digit, respiratory system	-0.56	59.6
	Ratio M/A[b], respiratory system, more than 5 dis.	0.47	111.7
	Concordance at goup, infectious diseases	0.52	38.8
	Concordance at III digit, infectious diseases	0.60	35.1
Unit (coordinates)	Trentino Alto Adige (-2.5), Campania (-2.2), …, Sardegna (2.3), Molise (8.6)		
Fourth (9.5%)[a]	Concordance at III digit, major coronary events	-0.49	85.8
	Concordance at group, major coronary events	-0.48	89.8
	Ratio M/A[b], major coronary events, more than 5 dis	0.50	100.3
	% of death over 75 years old	0.53	62.5
	Ratio M/A[b], other circulatory diseases, 4-5 diseases	0.57	100.4
Unit (coordinates)	Trentino Alto Adige (-5.5), Sardegna (-3.5), …, Umbria (3.1), Liguria (4.0)		

a: Percentage of total variability.
b: M=Manual coding, A=Automated coding.

The interpretation of the factors is given by the correlation analysis between the variables and the factorial axes (table 2). The first factorial axis (figure 2) can be defined as a "global concordance" axis since it is strictly correlated (relation in reverse proportion) with the group concordance, at III and at IV digit, without distinction by cause, independently from the number of pathologies in the certificate of death. Therefore, the first axis seems to be reproducing a picture similar to the previously observed territorial diagram (figure 1), showing a higher concordance in the Northern regions, except for Liguria, and, on the contrary, a lower concordance in the Central and Southern regions. The correlation of the variable "percentage of 1–3 diseases written in the certificate of death" with the first axis ($r = 0.45$) enables the peculiarities of the Calabria and Basilicata regions to be highlighted: in fact, not only do they have, on average, lower concordance levels, but they also stand out for the reduced number of pathologies in the sanitary part of the certificate of death.

The second factorial axis (figure 2) illustrates the variability between the two coding systems due to mortality for digestive system diseases (concordance at group and concordance at III digit, digestive system). The variable "percentage of more than 5 diseases," inversely correlated to the concordance, also contributes to determine the factor. The second axis partly explains the difference between Trentino Alto Adige, Marche, Liguria and the national average values. In fact, in these regions, a reduced concordance in the digestive system group and a high percentage of forms with over five pathologies is reported. Campania and Sicilia are on the other end of the axis. Although their general concordance is lower than the national average (concordance at III digit is respectively of 76.4 percent and 76 percent, while the Italian one is 77.2 percent), their concordance of the two coding systems for the digestive system diseases is quite satisfactory (concordance at III digit is respectively of 87.1 percent and 85.7 percent), while the Italian one is 83.2 percent).

The third factorial axis illustrates a variability not highlighted in the first factorial plane (Axis 1 x Axis 2). As seen in figure 2, Molise occupies a "neutral position" in the 1st plane, next to the origin of the axis and to Italy unit. Instead, in the 2nd factorial plane (Axis 1 x Axis 3, figure 3) this region is different due to the following characteristics:

- Higher concordance at group and at III digit for infectious diseases
- Lower concordance at III digit in respiratory diseases due to a greater proportion of manually coded cases in forms with a complex nosological picture (more than 5 diseases).

Sardegna is in a similar situation, although its position is more closely related to respiratory diseases mortality.

The fourth factorial axis can be called the "mortality by circulatory diseases" axis and in particular of the major coronary events. Positive coordinates of the fourth axis correspond to a lower concordance between the two coding systems calculated for mortality for major coronary events (at III digit and at group level). The regions on the positive semi-plane (Axis 1 x Axis 4) are Liguria, Umbria, and Marche. On the negative semi-plane Sardegna and Trentino Alto Adige can be found. The lower concordance can be partly explained with the different structure by age of death in Liguria and Marche: these two regions have a substantial percentage of deaths over 75. The clinical situation in the elderly is generally more complex, in fact, with the increase of age, there is also an increase in the number of diseases and therefore, the certification of death becomes more burdensome.

Figure 2. Principal components analysis: 1st Factorial Plane: Axis 1 “Global Concordance” x Axis 2 “Digestive System Diseases”

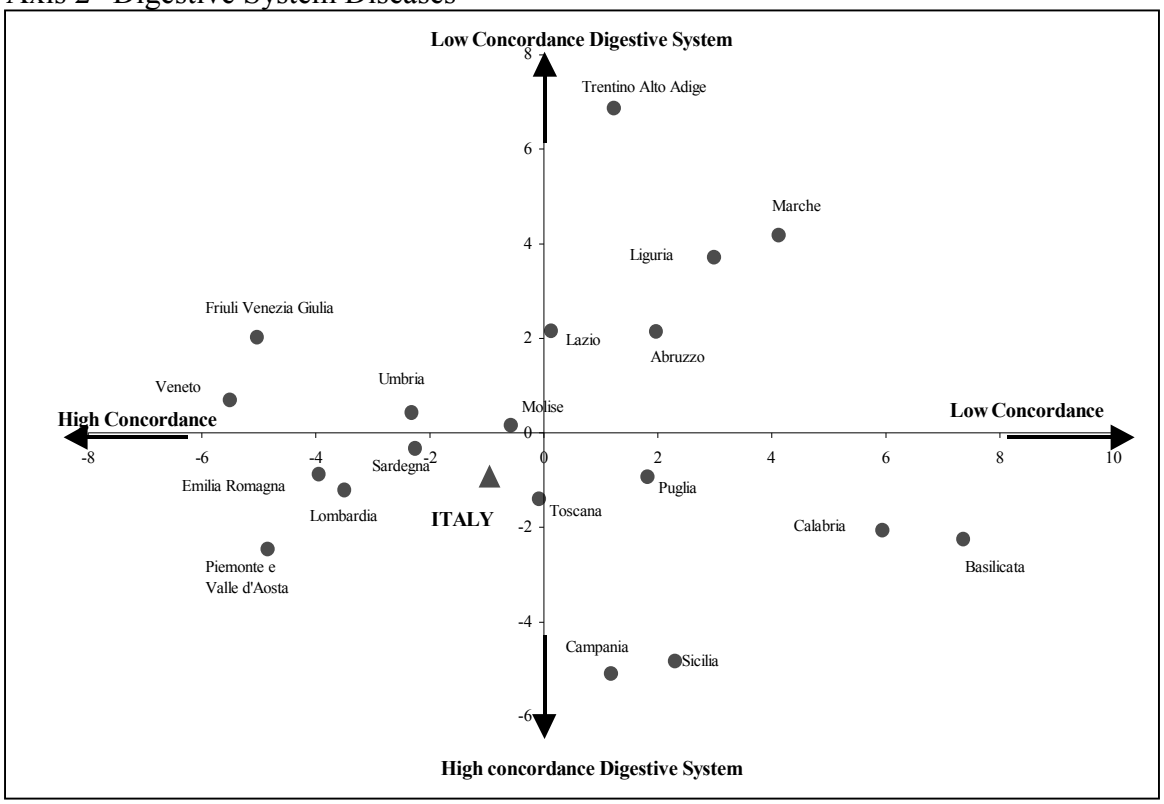


Figure 3. Principal components analysis: 2nd Plane: Axis 1 “Global Concordance” x Axis 3 “Infectious and Respiratory System Diseases”

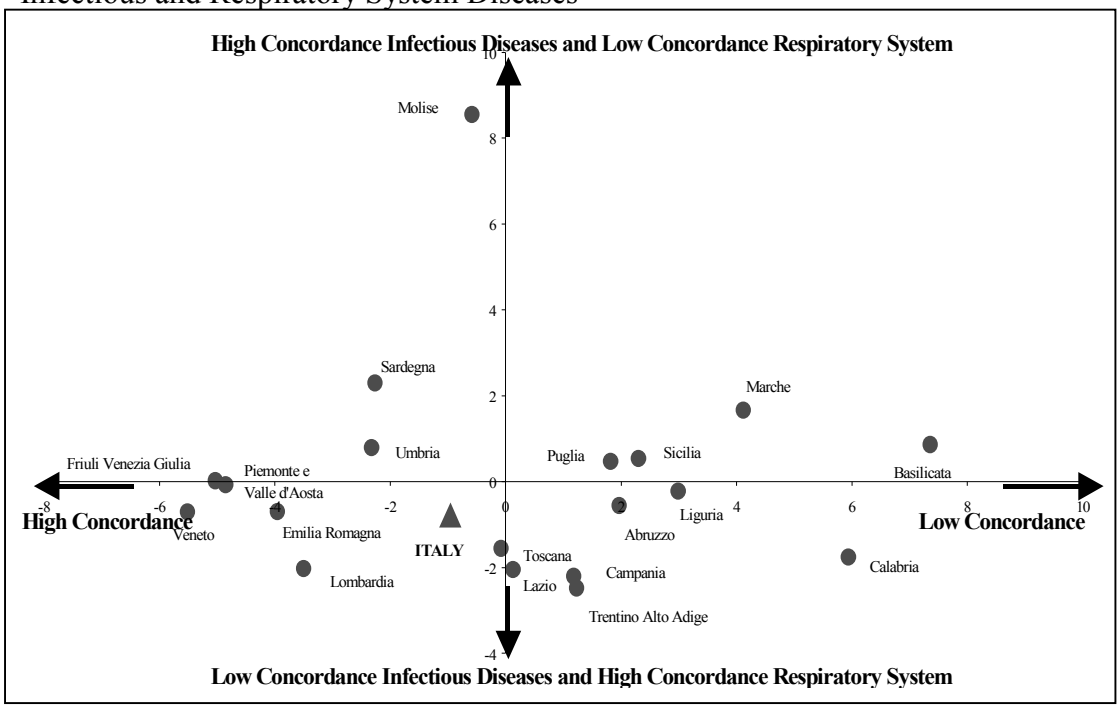
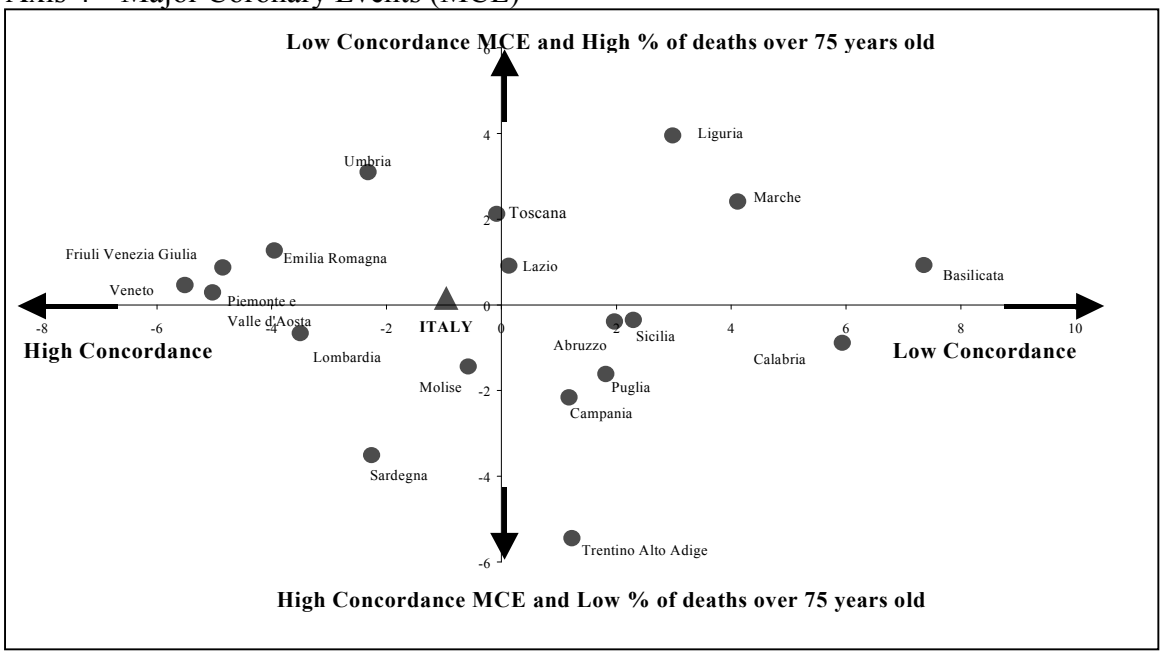


Figure 4. Principal components analysis: 3rd Factorial Plane: Axis 1 “Global Concordance” x Axis 4 “ Major Coronary Events (MCE) ”



Final remarks

In previous research we have found that the two coding methods are not dependent on demographics characteristics of the dead, and that the main differences depend on the pathology type (concordance is greater for the most widespread diseases as they are well-known by certifying doctors and Istat coders) and on complexity of the pathologic picture recorded on the certificate of death.

The aim of this paper was to analyze geographical differences. Therefore, a territorial desegregation was considered and a multidimensional analysis with reference to place of death (subdividing the Italian territory into 20 sub-areas) has been done. The main results can be briefly summarized as follow:

- The region with the lowest concordance percentage is Basilicata, while the regions with the highest percentage are Piemonte and Valle d'Aosta and Friuli Venezia Giulia.
- The analysis shows that, along with Basilicata, the most disadvantaged regions are Liguria, Marche, Abruzzo, Calabria and Sicilia. On the other hand, the North East regions record the highest concordance percentage at the third and fourth digit, Trentino Alto Adige is an exception with similarities with the Central and Southern regions.

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SESSION 11

The Function of the Users' Group and the Role of NCHS

The Function of the Users' Group and the Role of NCHS

Donna E. Glenn, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

I want to talk to you a little bit about training, because several people have asked me about it. We would like to start off with the end part if it, that is, a multiple-cause training class that will be international. A couple of requirements will be, of course, that the participants be English-speaking and English-reading, because all our material is in English. We would have this course in the late summer or fall, and that is primarily because of the temperature in North Carolina. We are not sure if some of the cooler-liking people would survive the temperature and humidity of North Carolina. In the spring, we would have a class that we call a "PC managers' class." If someone in your shop, your division, your country is going to be operating an automated system, in particular any part of the NCHS system as the base, then send someone in the spring ahead of your coders, and have them learn from NCHS how we have the automated system setup, how we expect it to be run, and why coding is done a certain way, so that when your coders return to their functions, they will have an idea of where they fit in and will not be totally lost. If you have been using the NCHS system for a long time, then the PC managers' course may not be necessary; but, for the new users who are implementing automated systems, we really would encourage attending this training. The PC managers' class will last about 3 days. The multiple-cause coding class lasts 2 weeks; it is vigorous and strict in terms of content. There will be homework at night and over the weekend. We shall limit this class to 12 trainees. The class would be given at our Research Triangle Park (RTP) facility in North Carolina. We will arrange hotels close to our building and provide transportation back and forth. While there will be no charge to attend the class, trainees would be responsible for their transportation, their hotel room, and their per diem. About a month before class, we do send pre-classroom material to all students, so we have to know early on who is coming to take the class.

To repeat, there are two classes: one for your systems persons, or the person who is overseeing your automated system—not necessarily a programmer, but someone that is overseeing the system, so they will be able to help the coders know where they fit in the system. In the 2-week period for training the coders, we really do not spend a lot of time telling coders where they fit into the system. With the amount of training we do, we do not have the time for it. I ignored underlying-cause training, because almost every country has such training. Our underlying-cause training is basically no different from the training that you have had through your other areas.

Another aspect of training is the qualification deck. In our training, the qualification deck is weighted to represent the U.S. annual mortality file. I think each country should prepare their own qualification deck.

When you sign up for the class, I shall ask that you send us a copy of your certificate, so we can be prepared for any differences that might be in your certificate relative to the U.S. Standard Certificate of Death (for which the coding training is designed).

On the ACS User's Group, I really have no preconceived ideas of how we want to set this up. I would like a discussion group where people can ask questions and get answers from those

that use the system. For example, when a country in Africa asks about building ACME into their cause-of-death coding program, I send them to Lars Age Johansson of Sweden, because we have never integrated ACME into other systems. On front ends, particularly for Spanish-speaking people, I usually refer them to Gloria Pérez of Catalonia, because she has developed front ends for ACME in a language other than English. Thus, I would like to have a users' group where all parts of the system are open for discussion. I have a volunteer who is actually going to lead this: Tim Devis has agreed to set it up.

Discussion on Item 11: The Function of the Users' Group and the Role of NCHS

MR. DEVIS: Yesterday, I approached Donna Glenn about the users' group, because in Australia we are keen to see it started. Australia has been using the automatic coding system now for some time; we have been really pleased with the good support from Donna, her team, and other people in the U.S., to help us to introduce the system and to use it. Because many countries are using automatic coding, it is a very good time to press for the establishment of a users' group that can share experiences from many countries in applying the system. Mrs. Glenn said she would actually appreciate the opportunity to take a lower profile, or a less intensive role in the users' group.

I have no detailed thoughts about exactly how to go about it, except to say that I think it would be good if a consortium of countries that are using the system got together to organize the users' group and became the drivers of that group. I have very little in my mind about terms of reference that would be established except to say that we will need to have a close relationship with the Mortality Reference Group. There would be matters that arise from users' group discussions that ought to go to the Mortality Reference Group and perhaps be referred to WHO if there were indeed problems identified with the ICD and its application. So it would be important that these relationships be included in the terms of reference. Another matter that would need to be included in the terms of reference is that the users' group would provide an opportunity to identify issues that need attention in the system, so the users would not just be able to help each other to understand and apply the system, but have a channel for feedback to the U.S. for further development of the system. Apart from that, it could be a matter for the users' group itself, or for a group of countries that were interested, to develop terms of reference at our preliminary meeting. Australia, as one of the users of the system, would be very interested to play a role in that, and to become part of a coordinating group.

DR. COLE: Would there be anything wrong with setting this up similarly to our coding question group and Mortality Reference Group? The Mortality Forum, whereby you had a series of e-mail addresses from the participating people and fired off questions that could be answered by anybody, and the answers circulated to anyone? This would seem to be a useful way of spreading the news around in a relatively simple way. We know that the Mortality Forum works quite well.

MS. GLENN: We do know that it works, because it has worked for Lars Age. However, I know it is also a lot of work on Lars Age's part to send e-mails back out.

MR. JOHANSSON: Yes, I think it is a good model for these kinds of groups. You can get responses from all over the world and from people who have somewhat different expertise. On the other hand, it does take some work to run the group. You have to compile the lists of the group, et cetera; but if somebody is prepared to do it, I think that it is a very good model.

DR. ROONEY: The Mortality Forum has not moved to being a listserve, which we have for the Injury ICE. I think the listserve may reduce the work a little bit. If you have people who are members of a formal listserve group, anyone can post questions and answers on a bulletin board, and then anyone can get into it at any time to get messages automatically. The listserve may be less work, but it requires somebody who actually knows how to do that.

MR. JOHANSSON: The reason why I do not use a listserve for the Mortality Forum is that I want to keep track of what is going on, since one of the functions of the forum is to find difficulties in the ICD and the application of ICD. I find it quite useful to review the answers and the questions manually, compile reports, et cetera, then feed them on to the Mortality Reference Group. You could do that for the listserve as well; but I think the temptation would be very great just to let the group mind its own business.

MS. RAWSON: We are very keen to be one of the drivers for the group. I want to ask Lars Age the role that he plays for the Mortality Forum and whether that role could be played by a small group of countries that were also equally interested in being involved? We do not have the resources to do the enormous job that I understand that you do with the Mortality Forum.

I have to dub in Graham Jackson, who said that the users' group would be a good collaborative effort. So I actually took that as Scotland volunteering alongside with Australia to be heavily involved. So the question is, rather than just one country, one person being the driving force, do you think the model would work to have three or four or whatever countries put their hands up, and let them be able to do it in some way as a group, because I think that seems like an enormous job for one person. If it ends up being one person, I would actually rather have one country doing the job. We certainly would like to be one of a small group and not the driving force, because we do not have the resources.

MR. JOHANSSON: Of course, several countries or people could share the job of reviewing what happens in the group, extract things that we would like the NCHS to take a closer look at, for instance, in evaluating the system. But I think that, technically, the group itself has to be placed in one computer and one computer only, so that you do not have duplication of address lists with slightly different members, slightly different formats that will not convert, et cetera. So the technical matters ought to be run from one place, but the contents of it could be reviewed by several people.

DR. CATLIN: I have a question for Donna Glenn: Would you anticipate in the U.S. that some of the States would be members of the users' group?

DR. GLENN: We have debated that. I am not sure how I would answer that. We definitely are starting a more interactive e-mail with our States, based on a PC managers' class that we taught, where we are now in touch with the technical people. I have to give some thought regarding international participation from the States. I am not saying "no," and it is an open discussion for us, too. I worry about giving them a lot of choice. We want them to code our way.

DR. CATLIN: So the idea would be that it one representative of a country would funnel information from states or provinces up to this ACS Users' Group.

DR. GLENN: In your case, probably yes, because you have the same type of setup that we do.

DR. CATLIN: We are certainly enthusiastic about this idea.

Closing Remarks

Closing Remarks

Mary Anne Freedman, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

On behalf of Dr. Sondik and myself, I would like to thank you all very much for coming, for your participation in this meeting, and for making it such an interesting, informative, and productive week.

It is apparent from all we have heard this week that there is a lot of activity going on in the automation area in mortality, and that activity is growing and continuing. I also think that this ICE has accomplished at least a part of its intent, a very large part: that of increasing international awareness of the automation opportunities and of developing collaborative efforts to work together. The efforts that we have seen are obviously continuing as we move forward.

I am also very pleased that WHO has accepted this group's activities and has incorporated many of them into its work plans. Some of the recommendations that this group made at its first meeting have been institutionalized within the framework of the WHO center heads and their ICD activities. This speaks not only to our objective of working with WHO, but also to the relevance of the work that this group has been doing within the automation area. Several of our recommendations are part of the new WHO Center Heads' Work Plan, such as the Mortality Reference Group, the Training and Credentialing Group, and the Automation Users' Group. This is a direct outcome of this ICE, and I think it is something that everyone here should be proud of.

I would like to talk for a minute about NCHS' commitment to this. We very much feel that it is important for us to be working with you on a systematic approach to supporting the international use of automation software. We have been a bit remiss about this in the past, primarily because of resource issues. We really could not begin thinking about some of these issues until this meeting because, quite frankly, we have been consumed over the course of the past year and a half with the implementation of ICD-10 in the United States. As we move beyond that, I think we can continue to work with you on some of the issues related to training, the users' group, and support of our software elsewhere. Donna Glenn announced this morning the training program that we would like to institute on a modest basis, at least initially.

I would like to take a minute to recognize some of the people who worked very hard to make this a successful meeting: first of all, the Planning Committee. We thank you for the preparation of an excellent agenda and for your recommendations about how we should proceed here. There were a good number of people: the session organizers and speakers; many of whom gave multiple presentations and put a lot of effort and thought into the sessions. Barbara Hetzler and Patricia Drummond manned the registration desk, and we thank them for their efforts. Also, Carla Battle from Courtesy Associates, who handled all the international travel. I would like to thank Sam Notzon, who is a co-chair of the conference and was very instrumental in obtaining the funds to travel participants from so many countries to the meeting. Kim Peters and Ken Kochanek were responsible for much of the preparation work for the meeting. They handled the logistics, they worked on the program, and they made sure everything was running smoothly. I think that Kim and Ken did a wonderful job, and should share a large part of the credit for the meeting's success. And, of course, we have to thank Harry Rosenberg, who continues to be a moving force behind this project.

In closing, I would like to thank you again for being part of this ICE. I hope the meeting was as productive for you as it was for us at NCHS. I wish you all a good trip home. I hope you have an opportunity, if you are not leaving immediately, to see a little bit of the Washington area. And I look forward to continuing to work together with you, as we proceed to automate mortality systems throughout the world. Thank you very much.

Closing Remarks

Dr. Sam Notzon, Office of International Statistics, National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

I have worked with four different ICE groups over the years in my role in the international office at NCHS. Most of you surely know by now that there is more than this one ICE group that NCHS participates in, or has done so in the past. I cannot help but compare this group with the others. Let me tell you about some of the differences that I have found. The first one, which I think is very striking, is how smoothly this meeting has gone. The credit goes to Kim Peters and Ken Kochanek. They deserve congratulations from all of us here, because they have done a terrific job. Another way in which this ICE differs from the others is that it is focused more on the production of data, rather than on the analysis of data, which has been the focus of the other international collaborative efforts on perinatal and infant mortality, on aging, and on injury statistics. So that is a difference, but I think it is a valuable difference. It is something obviously that we all think is important. Clearly, the analysts amongst us appreciate what is happening. One reason that we are involved in this is that by automating systems, we are improving the comparability of data across countries, something that we think is important and I think you all do as well. If I am not mistaken, and this is another difference, this is the largest number of countries that have been represented in one of these meetings. I am counting 23 to 26. It is impressive to see this interest around the world. Repeating a little bit of what Mary Anne Freedman said, I will say that although all of the ICEs have had an interest in working with WHO, I think this one has gone the farthest in meshing its activities with WHO interests and responsibilities. I think we are all very pleased with the way that has turned out.

I mentioned yesterday how pleased I was to see the results from our collaboration on the decision tables. I think it is a classic example of international collaboration and certainly we at NCHS appreciate this, because this made a huge difference to us in terms of resources and, most particularly, in terms of timing.

Finally, I will say that I am happy to see that NCHS is about to embark on some real international training in this area. For so long we were so focused on implementing the 10th Revision of the ICD and modifying the automated system, that we just did not have the time or the resources to even think about this area, much less actually address it. I am very pleased to see that we are at the point where we can begin to actively involve other countries.

So I would have to say overall, I am really pleased with the way this meeting has gone. It is a reflection on Harry, on Kim and Ken, and on everyone that has worked on the planning committee. I think they all deserve congratulations.

Closing Remarks

Harry M. Rosenberg, Ph.D., National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services

Yesterday, when we went over the recommendations from the first ICE, I got a really good feeling that we were on the right track, and that we are making progress. This is a wonderful project in which to be involved, and you are a marvelous group of folks with whom to work. It is a great experience at the personal level; it is great at the professional level.

I want to thank the presenters, who I believe gave incredibly high-quality presentations. This was a high-caliber, important meeting, intellectually stimulating, and very gratifying. I think it is a great contribution. So, my thanks to you.

What are we going to do for the future? I think the next step is going to be that the planning committee for the ICE will probably convene in the spring of the year 2000 and reflect on what we have accomplished and where we want to go next. Our first plenary meeting was 3 years ago. I am not sure exactly when the next plenary meeting will be, whether we will have it in 2 or 3 years. And we do not know what the agenda will be, because it is truly a collaborative effort. What we try to do is see what the emerging issues are, and we try to address those. So, in this meeting we moved somewhat hesitatingly perhaps into the area of electronic death registration—which is a new area for us—and maybe we will be able to report on the work of the automation users' group, and maybe we will be able to talk a little bit more about our successes and our progress in electronic death registration, and the interface between electronic death registration, electronic processing, and electronic data dissemination. I believe that that is part of the future. I see it as a continuum. So our hope is that in the spring, we will be able to get together a small group as we have almost every year since 1995, and come up with an appetizing program for the future.

Thanks again. The meeting is adjourned.