

Report to The NCHS Board of Scientific Counselors
-Review of the NCHS Mortality Statistics Programs-
January 26, 2006

Organization of this Report

This Report provides information resulting from a seven member Panel's review of NCHS mortality activities and programs. It begins with a list of accomplishments, followed by prioritized recommendations which were developed by the Review Panel. The remainder of the report is a summary of the review process and rationale for the various recommendations.

Accomplishments

The NCHS mortality leadership and staff are to be specifically acknowledged and congratulated for the following:

- Being the first CDC/NCHS program to undergo an external review by a panel of professional peers. NCHS' willingness to undergo this review is a landmark action that should serve as a model for other Centers and programs to follow
- Having health scientist and statistician staff committed to data analysis, research, demography, and the production of relevant statistical reports
- Improving the quality assurance and research focuses of the mortality programs, including improved data analysis capabilities
- Expanding research and publication in competitively, peer-reviewed journals
- Encouraging and fostering research by staff
- Developing and promoting (even internationally) the coding and classification systems such as MICAR, ACME, TRANSAX, SuperMICAR
- Serving as a leader in the International Collaborative Effort (ICE)- with the objective to improve quality and international comparability of cause of death statistics
- Serving as a leader in projects such as development of the U.S. Standard Certificate of Death, re-engineering the death registration process, and electronic death registration standards and procedures
- Reliably producing high quality professional reports both on the web and in paper form, the continuance of which is important
- Providing methodological annexes that are very clear and useful for data users
- Engaging in activities and preparing products that are useful to the ten essential services of public health
- Producing, specifically, a comprehensive and high quality Injury Report
- Producing timely preliminary data reports and publishing them on the web
- Providing a work setting and environment that attracts qualified staff who remain in service for long periods of time (stable staff)
- Demonstrating an interest in being more responsive, proactive, and timely in making data available
- Providing candid information to this Review Panel about issues and needs

Recommendations

There are several overarching recommendations, beneath which are specific recommendations that may fall under the umbrella of more than one overarching recommendation. The overarching recommendations are:

Improve data input quality and process

- Strengthen the Federal-State partnership
- Work with NAPHSIS and States to address issues of confidentiality, privacy, and data release and sharing
- Improve understanding of procedures, responsibilities, and issues involved in civil death registration processes conducted by state registrars and integrate registrar input into NCHS programs

Improve data access and dissemination

- Develop a specific analytic/research plan for the NCHS mortality programs
- Strengthen collaborative efforts with other Federal agencies within NCHS/CDC, with other Federal agencies, and with other academic, research, and non-profit entities while reducing redundancy in effort

Implement and follow progress

- Place recommendations in the perspective of full implementation in 5-10 years
- Follow through on recommendations by appointing an ongoing working group with special expertise (including persons skilled in training, vital records registration, systems development, web-based data dissemination, and mortality research) to assist in development of a strategic analytic plan and to monitor progress

Specific recommendations (based on program activity and four evaluation criteria) are listed later in this Report, but for summary purposes, recommendations are listed here in groups that are considered to be **immediate highest priority, high priority, moderate priority, and lesser but important priority**, regardless of specific program or activity area. Although the recommendations are listed in approximate order of priority within each group, numbers are provided for each mainly to facilitate reference during discussion. Numbers and letters in square brackets indicate the section(s) of the evaluation matrix (described later) from which the recommendation is/are derived.

Immediate Highest Priority

1. Establish an implementation working group (IWG) to develop an explicit plan and time table for the refinement and implementation of the recommendations contained in this report. The IWG should include NCHS staff representatives and consultant researchers, state registrars, state center for health statistics representatives, NAPHSIS representatives, physician and medicolegal certifiers of death, and others deemed appropriate. [Over-arching concern]
2. Initiate discussions with state officials through NAPHSIS, for example, and data users about ways of maintaining the NCHS central role while respecting state laws regarding confidentiality, privacy, and data release to ensure that needed and important data may be collected from states, while providing the easiest possible access for data users. It is vital to include researchers in the process so the outcome ensures confidentiality while providing easy access for a range of basic research. This may be accomplished through the IWG. Consideration should be given to using NAS or IOM to provide a broad, national, and federal-state perspective. The continued success of the cooperative health statistics system needs to be ensured, particularly considering changes brought about by the Federal Intelligence Act and the Real ID Act. [3a;15b]

High Priority (to be begun simultaneously and now)

1. Work with states to improve, expand, and expedite homogenous certification, coding and classification procedures *by the states* so that the NCHS emphasis can shift more toward data analysis and research and away from the need to spend considerable staff and resources on correcting or processing incomplete or poor quality data provided by states. The aim is to improve comparability in the production processes of states. [8a;11b]
2. Develop a Master Analytic Plan to prospectively identify data analysis and research projects both internally and externally that foster creative research in the context of current and emerging health priorities, and direct resources to data analysis and research. [11d]
3. Establish closer ties with the various centers of CDC, involving active efforts by NCHS to identify activities to support CDC activities.[11e;12a]
4. Establish closer ties with other federal agencies to reduce redundancy of effort and foster collaboration between NCHS and other agencies, academic centers, and non-profit organizations with mortality projects such as DAWN, CPSC, FDA, SSA, working to integrate the data collected in these programs and provide more comprehensive reports. [3d;11e]
5. Develop a rapid, national mortality reporting surveillance system (including causes of death and not only general mortality). [11c;15h]
6. Evaluate the National Mortality Follow-back Survey (NMFS) program in terms of existing need, usefulness, and cost-effectiveness. Decide whether to continue NMFS or integrate with other comprehensive data collection programs. [3b;3c;9d;14a]
7. Develop an extramural grant program to foster partnerships and collaboration between NCHS and other agencies and researchers. [3f;4a]
8. Work with states and NAPHSIS to improve certification, coding, and classification data and the availability of data from one state to another in a timely manner, and to improve inter-state linkage of birth and death data. Use a variety of means including alternative data sources and demographic analysis to review and improve the accuracy of data on age and other basic demographic measures. [1e;2a;11b;14b]
9. Work with states to improve perinatal information and to bolster the robustness of fetal and infant birth-death information and linkages. [3g]
10. Work to improve and ensure state-to-state comparability of mortality data particularly in regard to cause of death classification. [1e;8b]
11. Continue efforts to decrease the turnaround time required to prepare routine mortality data reports. [2a]
12. Explore alternative methods to increase opportunities for training on proper completion of the death certificate (whether hard copy or EDR) with the goal of improving the quality of data coming into the system. This might include on-line training materials that complement, rather than replace, current training activities. Educational materials and field training staff need to be expanded. [1a;4c;4d]
13. Rethink the methods for reporting major causes of death—especially the 10 leading causes (in view of public health information priorities) and including those for infants. For example, cancer deaths tend to be lumped while cardiovascular deaths are subdivided into categories. More “splitting” may be valuable compared with “lumping.” [9c]
14. Promote the expansion and implementation of Electronic Death Registration (EDR). [1b;4d]
15. Expand the capabilities of the Research Data Center, and review operations, issues, data access and usage to ensure that appropriate data are quickly made available for analysis. [13f;14a]
16. Increase the dissemination and usefulness of multiple cause mortality data and provide the methods of analysis because the concept is complex. [13b;15g;15h]
17. Work with CDC to make the NCHS web site more user-friendly. [13d;13e]
18. Work with CDC to revitalize its Medical Examiner/Coroner Information Sharing Program (MECISP). [11a]

Moderate Priority

1. Improve, through further training of registrars, registrar knowledge of death certification practices, and compliance with coding and classification guidelines to foster more uniform and improved death certification and classification. [5a;7a]
2. Improve, through continued training of NCHS staff, NCHS' knowledge of procedures, responsibilities, and issues involved in civil death registration processes conducted by registrars. [11g]
3. Verify accuracy and validity of basic demographic details and socioeconomic indicators
4. Use existing data sets such as NLMS and NMFS data to assess quality of death certificate data. [1c]
5. Develop further collaboration and links to other mortality data sources such as DAWN, CPSC, and FDA. [3d;11e]
6. Work with states to develop increased flexibility and adaptability of the death certificate so more information can be collected using existing forms and so that the form is responsive to short term needs when new conditions or certification needs arise (this could be facilitated by EDR). [3h]
7. Work with CDC through its EIS officer and other fellow programs to allocate more resources and personnel for vital statistics purposes, including training them on vital statistics issues and assigning them duties in state-based vital statistics programs.
8. Develop a central, organized approach to provide technical information to states, through web-based and other media. [8c;4c]
9. Revise age groupings used to report mortality data, to better reflect populations at risk [9b;15f]
10. Plan mortality reports and classifications so they are geared more toward health issues such as specific chronic diseases amenable to prevention. [9c]
11. Explore possible collaboration with federal and other agencies (such as the Census Bureau, SSA, Population Reference Bureau, and March of Dimes) to increase awareness about mortality trends and disparities. [12a]
12. Develop Fellowships at NCHS related to vital statistics. [12b]
13. Maintain distribution of hardcopy reports. [13a]
14. Increase options for web-based data systems that are more interactive for users, and for data users to create their own queries and tables on-line. [13b;13d]
15. Survey users to determine usefulness of mortality data and needs to improve them. [15a]
16. Review and expand the NCHS role as a liaison or "go-between" between states and researchers to increase and improve the use of data and to assist in addressing state-based issues of confidentiality and data release. [15d]
17. Review the procedures for analyzing and presenting data and results for the oldest ages.[15e;15f]
18. Consider using the WHO model for age-standardization in addition to the current U.S. Standard to facilitate international comparisons. [11f;15f]
19. Explore ways of using multiple cause mortality data to highlight trends in high priority areas of public health; and use multiple cause mortality data in the context of a national rapid mortality surveillance system. [9c;15g]
20. Provide/obtain funding and staff for production of more web-based and hardcopy reports. [16a]
21. Publish more topic-oriented reports, including fetal/perinatal death data. [13c]
22. Encourage the completion of items relating to Hispanic ethnicity and origin group. [14c]

Lesser but important priority

1. Examine feasibility of producing more preliminary mortality data including state-based estimates and reports of provisional data on the web prior to availability of complete national data. [2b]
2. Include all military deaths in national statistics as well as deaths of other U.S. Residents which occur abroad. [3e]
3. Provide easy access to ICD codes on-line for certifiers, coders, and researchers. [7d]
4. Disseminate to certifiers information regarding coding and classification procedures and software so that data providers understand the fate of their data. [7a]
5. Geocode locations of residence for decedent and place of injury. [7h]
6. Explore options to improve occupation information for research. [7c]
7. Update the previously published studies and reports of validation studies. [9a]
8. In the context of confidentiality issues, provide masked data for planning research. [15c]

Background Information

In August of 2005, NCHS Director Ed Sondik contacted several individuals to determine their interest in serving on a Panel to review the NCHS Vital Statistics Mortality Programs. Individuals who agreed to serve on the Review Panel included:

Randy Hanzlick, MD (Panel Chair), Chief Medical Examiner, Fulton County, Georgia, and Professor of Forensic Pathology, Emory University School of Medicine, Atlanta

Joann Petrini, PhD, Director, Perinatal Data Center, March of Dimes

Douglas Ewbank, PhD, Research Professor of Sociology, University of Pennsylvania

Richard Rogers, PhD, Director, Population Program, and Professor of Sociology, University of Colorado at Boulder

Robert Schoen, PhD, Hoffman Professor of Family Sociology and Demography, Penn State University

Eric Jougl, PhD, Director of the Centre of Epidemiology on Medical Causes of Death, CapiDc-INSERM, Paris, France

Bruce Cohen, PhD, Director, Division of Research and Epidemiology, Center for Health Information and Statistics, Massachusetts Department of Public Health.

Rob Weinzimer of NCHS served as the NCHS contact for the Review Panel, and **Bill Kalsbeek** was designated as the BSC liaison to the Review Panel.

Initial Procedures

Each reviewer had received a document titled “Proposed Procedure for Reviewing NCHS Programs” which had been prepared by the Board of Scientific Counselors (BSC). In November 2005, NCHS provided each reviewer with a manual titled “Reference Materials: NCHS Vital Statistics Mortality Program Review,” dated November 9, 2005. This 43-page document included:

- An Overview of the Mortality Component of the NVSS
- Budget and organizational structure of NCHS DOVS
- Information about collection and processing of mortality data
- NVSS Products
- A summary of NCHS mortality program research
- Samples of the statistical reports routinely prepared by NCHS/NVSS

On November 21, 2005, Randy Hanzlick implemented an e-mail distribution list consisting of Review Panel members and Rob Weinzimer. All review Panel members were asked to thoroughly review the information provided by NCHS.

After review of information, several panel members had additional questions that were sent to the group and to NCHS for response. On December 7, answers prepared by NCHS staff were sent my e-mail to Review Panel members.

Panel Meeting of December 8/9 2005

The Review Panel met at NCHS headquarters in Hyattsville all day on December 8 and half a day on December 9, 2005. All members were able to attend except Joann Petrini.

Panel members introduced themselves with emphasis on the major emphasis of their daily work, their employer, and description of personal professional interests, and an explanation of how mortality was involved in, or impacted upon their daily work. It was noted that the Panel consisted of producers and users of the data, and was weighted toward “users” of data with one Panel member representing the certifier or data “input” viewpoint. This was viewed as appropriate because a major focus of NCHS is to produce data to be used by others.

A brief discussion of the review process suggested by NCHS was conducted in terms of evaluating activities and products, resource capacity and adequacy, and efforts to improve in the context of current status, scientific quality, and responsiveness. It was noted that suggested procedures provided for flexibility and the Panel determined that it may need to make some modifications in the review matrix. Discussion also occurred regarding the importance of including review of data-related accuracy, completeness, timeliness, accessibility, usefulness, and specificity, as well as abilities to modify data processing and coding/classification procedures to meet urgent or other needs that arise between regularly scheduled revisions of ICD, standard certificates, or other WHO related policies and procedures.

Prior to the Panel meeting, various members had raised questions or issues by e-mail and the nature of these was also reviewed. They included:

- Questions about NCHS efforts to address demographic changes in the population
- Specific questions about coding and classification procedures on the systems used to process data such as ACME, TRANSAX, MICAR, SuperMICAR
- Suggestions that for closely related conditions that have significant interplay, such as hypertension, renal disease, and diabetes, that a “cause cluster” approach might be useful

- Legal concerns that relate to state confidentiality and privacy laws, federal intelligence reform (Federal Intelligence Reform and Terrorism Prevention Act; FIRTPA), and the Vital Statistics Cooperative Program
- A NAPHISIS resolution regarding confidentiality
- Requests for further information about research strategy, follow back surveys, staff qualifications, the nature of users, and the extent of training
- Questions about the review process in the context of public health core functions such as assessment, policy development, and assurance, and the ten essential services of public health which include: monitor health status; inform and empower people; develop policies and plans; link people to health services; evaluate quality; diagnoses health problems; mobilize community partnerships; enforce laws and regulations; assure a competent work force; research for new insights

NCHS provided written responses to these general issues prior to the Panel meeting, and each Panel Member had an opportunity to review them.

During the meeting, a considerable amount of time was spent for questions, answers, and discussion involving Robert Anderson and Charles Rothwell of NCHS. In addition, the Panel heard brief comments from NCHS Director Ed Sondik.

Information gleaned from discussions with NCHS included:

- NCHS differs from other Centers in CDC because of its dual role in registration and production of statistics
- Approximately 56 FTEs are dedicated mainly to mortality programs and about 12% (17M) of NCHS budget is directed toward mortality programs
- The funds available to NCHS to cover actual state costs of providing data are not sufficient
- The CDC move toward “Coordinating Centers” has included NCHS in the process
- Centralization of administrative activities within CDC has adversely impacted the efficiency and timeliness of some NCHS activities and programs
- To comply with emerging federal law regarding intelligence information and to collect/obtain needed information will require a one-time infusion of dollars to implement and continual dollars to maintain
- NCHS seeks guidance to develop research activities and training, and to more specifically direct the activities of the Associate Director of Science which, as the Panel understands it, is a new position not yet filled
- Discussion has occurred as to whether NCHS should become involved in mortality projections
- Further work is needed to address issues of race, ethnicity, and socioeconomic indicators while maintaining consistency with OMB, Census Bureau, and other agencies
- Presently, occupation and industry information is not coded or analyzed
- The goal for “failed” death records (those needing correction) received from states is a failure rate of 5% or below, while currently it runs at about 20%
- A “Research Data Center” (RDC) exists at NCHS which requires permission to access and usually involves charges for use
- The CDC “WONDER” system and others such as “WHISKERS” at NCIPC could be expanded in scope and usefulness through planning with NCHS
- NCHS has collaborated with SSA through development and use of case models for EDR, the development of decennial life tables, and also engages in cooperative projects with the National Cancer Institute, American Cancer Society, Bureau of Justice Statistics, and the Bureau of labor Statistics

- NCHS views as one of its major accomplishments its expanding capability for data analysis
- In the past, the topic of research articles or other publications has been driven to some extent by the personal interest of researchers. This is to be encouraged in the context of also developing a master plan for analysis and research that is aligned with priority needs of NCHS, the key issues of mortality research, and less influence of personal researcher interests.
- Approximately 75% of NCHS staff time is spent preparing mandatory, routine reports and about 10-15% is spent responding to inquiries from the public and other agencies. This leaves about 10-15% of time for specific, non-routine research and analysis projects.
- Outside of NCHS, the data processing capabilities within CDC have declined over the years, practically manifest, for example, in movement away from Epi-Info and other data collection and processing systems

The review process proposed by NCHS included a matrix as shown below:

	Current Status	Quality	Responsiveness
Program Activities and Product	1	2	3
Capacity/Resources	4	5	6
Efforts to improve	7	8	9

After discussion, the Panel decided to modify the review matrix as follows:

	Existing Quality	Current responsiveness	Proactive planning/ effort to improve	Capacity and resources
Certification/Data Input including death certificates and surveys	1	2	3	4
Coding and classification procedures	5	6	7	8
Data aggregation, analysis, and research	9	10	11	12
Dissemination of data and reports	13	14	15	16

For each of the 16 evaluation cells, a decision was made to develop recommendations (underlined) and *rationale* (italics). These are presented below, the numbers referring to the cell in the evaluation matrix shown above.

Certification and Other Data Input

1. Existing quality of certification and other data input

- a) Provide more formalized training in death certification and involve certifying boards and expansion of web-based training. *Both anecdotal and literature based information show that death certification practices are still commonly substandard. Although existing training materials are good, they need to be expanded and taken into the field. The recent NCHS program in Delaware is an example. Suggestions of methods to improve the quality of data on the death certificate provided by physician certifiers include working with hospitals, physician groups, licensure and certifying boards, in addition to expansion of web-based training.*
 - b) Promote the expansion of electronic death registration (EDR), especially at the source of data input. *EDR has the potential to improve the timeliness of mortality data (also useful in the context of a rapid mortality alert system) as well as including on-line training, edit, and, and correction capabilities at the source of data input. It could reduce resources required to manage causes of death.*
 - c) Verify basic demographic details and socioeconomic indicators. *The principles of Shattuck Report of 1850—that diseases and cause of death are associated with demographic and socioeconomic conditions and indicators—seems to have fallen a bit by the wayside. Studies need to be conducted to verify the accuracy, validity, and relevance of demographic details and to assess the capacity of currently collected socioeconomic indicators to provide meaningful mortality information. A good start would be to analyze the educational, race/ethnicity, and occupation/industry data currently being provided, but not necessarily being analyzed or even coded.*
 - d) Assess the quality of death certificate data using existing data sets. *Existing data from the National Longitudinal Mortality Survey and the National Mortality Follow-back Survey could be used to assess the quality of death certificate data. Further work could also be done to directly assess the quality of death certificate data.*
 - e) Foster state to state data comparability, especially in regard to causes of death. *Although the states follow generally uniform procedures for collecting and classifying mortality data, state-based idiosyncrasies in training, registrar philosophies and resources, and other state-specific issues create a milieu that may hamper state- to-state data comparisons. Training needs to be conducted to make more uniform the state-based approaches to certification, which will result in more valid comparisons of data.*
2. Current responsiveness regarding certification and other data input
 - a) Provide more technical support to states regarding timeliness. *At present, the NCHS data production schedule is based on the slowest cog in the wheel. States with lengthy turnaround times hamper the speed at which national data can be assembled. This can only be fixed by providing assistance to states with unacceptable data turnaround times.*
 - b) Examine the feasibility of producing state-based data reports prior to the availability of national data reports. *It seems feasible that state-based mortality data reports—for individual states and aggregates of states—could be produced as data are complete, which would provide useful data prior to the customary 2-year delay currently required to finalize data from all states. This applies to both final and provisional data and these preliminary reports could be made available on the web.*
 3. Proactive planning (efforts to improve) regarding certification and other data input.
 - a) Clarify legal issues pertaining to intelligence reform and Real ID acts. *To have an effective national mortality data system requires that the necessary data can be collected from the states. All barriers created by conflicts in state and federal law need to be addressed and resolved.*
 - b) Consider the role that emerging programs such as the National Violent Death Reporting System (NVDRS) will play. *Programs such as NVDRS are emerging which consist of very*

- comprehensive data collection instruments. The scope of data may, in some ways, supplant the need for other data collection efforts. NCHS should collaborate in programs such as NVDRS to maximize data collection and analytical capability without redundancy in effort.*
- c) Continue to evaluate the potential impact and use of the National Mortality Follow-back Survey. *The NMFS should be assessed to determine the need to continue it in its current form or to change or revitalize its focus for the purposes of research that has public health policy importance.*
 - d) Encourage collaboration with researchers and other agencies to link mortality data to data from other sources. *Many federal agencies have mortality data collection systems. These include, but are not limited to SAMHSA's Drug Alertness Warning Network (DAWN), CPSC's Medical Examiner Coroner Alert Project (MECAP) for unsafe consumer products, FDA's Medical Product and Device Reporting System (MedWatch), NTSB's Fatal Accident Reporting System (FARS), and the BLS' Census of Fatal Occupational Injuries (CFOI). There is a wealth of information among these various databases that could probably be more informative if at least some data were linked. A collaborative effort should occur to achieve such linkages and reduce overlap or redundancy. There needs to be an active mortality linkage system.*
 - e) Incorporate military deaths and deaths of other US residents abroad. *Presently, deaths of military persons occurring outside of the United States are not included in NCHS mortality statistics. These are deaths of U.S. citizens and NCHS should work with DOD to incorporate off-shore military deaths into the national mortality picture. Efforts should also ensure inclusion of deaths of US Residents abroad, such as tsunami victims.*
 - f) Collaborate with funding sources. *Typically, NCHS has only conducted programs that can be funded through its regular budget, which limits what it can do. An active collaboration should be sought with other funding sources to expand the possibility and range of programs and research.*
 - g) Work with states to improve perinatal information. *Although linked perinatal birth and death records exist, the scope and quality of information in such systems is limited. NCHS should work with states to upgrade the standards, scope, and quality of information collected in these systems. With the currently low infant mortality rates, any inconsistencies in the reporting of fetal deaths can seriously affect comparisons across states.*
 - h) Develop flexibility and adaptation of data collection instruments. *Although NCHS mortality data processes must be compliant with WHO recommendations and policies, consideration needs to be given in expanding concepts that remain compliant. For example, the traditional concept of manner of death might be revisited to include new or modified options. The "describe how injury occurred" item might be expanded to promote the reporting of information in natural deaths such as adult sudden deaths, e.g., "collapsed while playing basketball" or "apparently died during sleep." Codes might be developed for important risk factors such as "sharing a sleep surface with an adult" or "unsafe sleep surface" as they relate to sudden unexplained infant deaths.*
4. Capacity and resources related to certification and other data input.
- a) Develop an extramural grant program. *Many agencies such as NIH rely on mortality data to guide the allocation of funds for research or programs. The importance of complete and accurate data is paramount in that respect, yet there are insufficient funds and resources available to evaluate and improve mortality data. Collaboration among NCHS and other agencies and funding sources should be explored to develop a grant program through NCHS in which funding can result in the analysis, validation, and improvement of mortality data.*
 - b) Use EIS officers for vital statistics purposes. *Analogous to the situation in which EIS officers are assigned to state health departments by CDC, the possibility of assigning EIS*

officers to state vital records departments needs to be explored. Such officers could fill many voids related to research, analysis, and training. At the very least, EIS officers need to be trained in the basics of data collection and the importance of rapid processing of data for planning purposes.

- c) Expand staff in the field. In addition to currently available training materials, field staff is needed to provide training in the field for proper completion of the death certificate. Medical schools and other medical institutions do not provide such training and this need can best be addressed through a cooperative approach of NCHS and states. This may involve field staff placed regionally or increasing staff at NCHS who may travel to conduct such activities.
- d) Fund EDR and expand on-line training for death certification. SSA has taken a lead in providing grants to states for the development of electronic death registration (EDR) which also provides a readily available mechanism for on-line training, edits, and correction of data. However, the interest of SSA lays mainly in the fact of death, and only a few states have fully implemented EDR. The quality of cause and circumstance information is of utmost importance and deserves funding from CDC/NCHS as well as other interested agencies which rely on mortality data. The need for funding becomes obvious when one considers that the concept of EDR has existed for a decade, yet only a few states have implemented EDR, especially in light of pending changes to revised federal regulations and emerging concerns about rapid mortality tracking of emerging diseases such as pandemic influenza. Expanding EDR will require increased staff time and error checking, and there will be a need for on-line training to supplement formal courses.

Coding and Classification

5. Existing quality of coding and classification
 - a) Improve registrar knowledge of and compliance with coding and classification guidelines. Variation exists not only in the capacity of various states, but in the personal viewpoints and philosophies of vital records registrars. Registrar policies may vary from the spirit or intent of NCHS guidelines and may also impact on how deaths are certified through their query procedures and willingness to accept or propensity to reject certain types of reported information. An effort needs to be made to make more uniform the practices of registrars, which will make more uniform the collection of death certificate information among the states.
6. Current responsiveness regarding coding and classification. NCHS does an excellent job in this area and no specific recommendations are offered.
7. Proactive planning regarding coding and classification.
 - a) Disseminate information regarding classification procedures. Aside from nosologists who code and classify information, other users and certifiers would benefit by having a better understanding about the processes used. Training information (in a clear and pedagogical way for a non-specialist user) on the sequence of coding and classification events along with an explanation of what ACME, MICAR, SuperMICAR, and TRANSAX accomplish would be beneficial to the understanding of the “final” data that are available in single cause and multiple cause mortality data sets.
 - b) Geocode locations of residence and place of injury. Currently, the use of data potentially useful for assessing socioeconomic status is suboptimal. The geocoding of residence address and other locations, to the block or smaller geographic level, may be an important item for assessing socioeconomic status and relating that to causes of death. It would be

- necessary to develop procedures whereby these codes could be used without risks to confidentiality, or where this information would be available in the RDC.*
- c) Explore options for improving coding of occupation for use in research. *Although the standard certificate has a place to report occupation and industry information, this information is seldom coded or used despite its potential usefulness.*
 - d) Disseminate ICD Codes. *To understand that classification of disease, it is important for users and suppliers of data to know the codes and ICD rules that are applied to various conditions. In addition to hard copies of ICD code manuals, ICD codes should be made readily available electronically so that certifiers and users who tend to work with certain types of conditions can better appreciate the range and types of codes that apply to that subject matter area.*
8. Capacity and resources regarding coding and classification
- a) Direct resources to data analysis and research. *Resources and staff currently, and necessarily, are allocated to assisting states with high “failure” rates in the mortality data they report. Efforts should be directed at assisting states so that they can provide complete and error-free information that would then free resources and staff to concentrate on data analysis and research. In short, coding and classification needs to occur at the state level so analysis and research can occur at the national level.*
 - b) Develop rigorous procedures for quality control to improve data quality and between-state comparability. *A decentralized system, in which data are provided and processed at the state level, poses obstacles to uniformity in procedures and comparability in data. Specific effort is required to ensure quality and comparability of data.*
 - c) Develop a central approach to providing technical information to states. *There is insufficient daily contact and information exchange between NCHS and the states. Consideration should be given to develop web-based resources such as listservs and other regular communications to promote regular ongoing dialogue, instruction, and technical assistance.*

Data Aggregation, Analysis and Research

9. Existing quality of data aggregation, analysis, and research
- a) Update review of cause of death validations studies. *Most recent cause-of-death validation studies have come from outside of NCHS. NCHS needs to reactivate such studies of its own and update its publication which reviewed such studies published between 1958 and 1980. Causes of death have changed or emerged, and educational effort regarding death certification has also expanded. Studies need to be reviewed and conducted to determine the current strengths and weaknesses of mortality data in order to direct and target efforts at improvement. Simple indicators could be developed to follow and report the quality of data such as % unknown, % imprecise, etc).*
 - b) Review, revise, and expand age groupings and increase the capacity to generate alternative age groupings used to categorize mortality. *As the population ages, and to provide more specific data, NCHS should foster the capacity to present mortality data for a variety of different age groupings, such as 5-year groupings above age 85. Because of increased survival, even at older ages, and because of increased interest in mortality at the oldest ages, we recommend that NCHS consider increasing the ages groups to 100 (from 85) and to 110 (from 100). Current groupings can cause confusion or overlap in age groups, , such as studies that include persons in their early twenties as “teenagers.” Flexibility in data presentation is the key. Such grouping and flexibility could be applied to CDC Wonder if not other routinely published NCHS reports.*

- c) Gear mortality reports and classifications toward health issues. *Although the “top ten,” “leading,” or “selected” causes of death traditionally reported are useful for historical comparisons, there is a need to devise new reporting structures which are geared to current health issues or public health needs. For example, emerging infections are currently an issue of concern. Perhaps a data reporting system could include a list of “Sudden Unexplained Deaths due to Infectious Agents” or “Deaths reported to involve obesity.” These groups should not necessarily attempt to measure the total attributable deaths, but could be constructed as indicators of changing importance.*
 - d) Use the NLMS and National Mortality Follow-back Survey to assess death certificates. *Studies should be conducted to determine their usefulness for determining the quality of death certificate information*
10. Current responsiveness regarding aggregation, analysis, and research. *Based on available resources and priorities, the Panel views NCHS as being already very good in this area and improving. No specific recommendations are offered.*
11. Proactive planning regarding data aggregation, analysis, and research.
- a) Work with CDC to revitalize its Medical Examiner/Coroner Information Sharing Program (MECISP). *Medical examiners and coroners play a critical role in regard to vital statistics and public health. First, they certify almost all deaths involving injury or poisoning as well as deaths that are sudden, unexpected, and initially unexplained. Second, with the hospital autopsy rate being very low in the United States, most autopsy-based death certifications are performed by medical examiners and coroners. Third, many federal programs, such as NVDRS and DAWN to name just two, rely heavily upon medical examiner and coroner data. Fourth, by virtue of their positions in local communities and their dealings with physicians and health care agencies, medical examiners and coroners are in a good position to educate physicians and others regarding death certification. Fifth, medical examiners and coroners investigate many deaths involving minorities and populations underserved by the health care system. The CDC’s Medical Examiner/Coroner Information Sharing Program, established in 1986, was designed to facilitate communication and data sharing among the medical examiner, coroner, and public health communities. Now, MECISP is completely unfunded and nearly defunct. NCHS needs to work with CDC, the National Association of Medical Examiners, the International Association of Coroners and Medical Examiners, and state-based medical examiner and coroner organizations to revitalize the MECISP program. The revitalization may even include establishment of a Medical Examiner/Coroner Coordinating Center within CDC to interface with the death investigation community and the many public health and vital statistics programs that involve it.*
 - b) Improve timeliness of reports. *As discussed earlier, NCHS needs to work with states to make mortality data more timely, correcting the problem of state-based delays in mortality reporting.*
 - c) Develop a Rapid Mortality Surveillance System. *Delays intrinsic to the current data collection system render NCHS data suboptimal for the detection of emerging or urgent public health problems. Whether accomplished through EDR or other mechanisms, a rapid mortality surveillance system needs to be developed without creating redundancy in reporting burden (for instance, to monitor emerging disease-related mortality such as that due to avian flu). EDR may be helpful in this regard.*
 - d) Develop a master analytic plan and conduct more research. *In the past, the topic of research articles or other publications has been driven to some extent by the personal interest of researchers. This is to be encouraged in the context of also developing a master plan for analysis and research that is independent of personal researcher interests. This plan needs*

- to prospectively outline research goals, focus, and scope with the goal of fostering more research, reflecting both internal and external priorities. Additional research should become feasible if the burden of coding and classification is transferred from NCHS to the states. The Panel does not believe that projections should be included within the scope of the initial master analytic plan.*
- e) Develop joint analysis ventures with other CDC Centers, Federal Agencies, researchers, academic centers, and non-profit organizations. *The capacity to analyze and meaningfully use mortality data will be enhanced through cooperative effort that includes shared funding, staff, and other resources. Joint analysis should also reduce or eliminate redundancy of effort.*
 - f) Stress the importance of inter-state and international collaborations and promote comparability of data. *Effort should be expended to promote inter-state and international comparability of data so that research and programs may be better targeted (perhaps developing a routine set of quality indicators in the routine).*
 - g) Study, provide training for, and improve NCHS understanding of the civil death registration process and related issues. *Mortality data are collected and provided by registrars and thorough knowledge of their work, capabilities, and limitations is paramount to the missions of NCHS. NCHS should study this and provide in-house training to NCHS staff to improve expertise in this area.*
12. Capacity and resources regarding data aggregation, analysis, and research
- a) Leverage resources. *Collaborative ties could be increased and duplication of effort among agencies needs to be reduced. Close working alliances, which can provide a synergistic effect, should be developed with agencies such as the Census Bureau, SSA, and Population Reference Bureau. The PRB produces educational and informational materials and thus provides another way in which NCHS can communicate with and disseminate information to the research and lay public. Formal partnerships with universities need to be expanded. Research collaboration both within CDC and externally needs to be strengthened. Leveraging is absolutely necessary in the face of increased costs and inadequate funding within individual agencies and institutions.*
 - b) Develop NCHS Research Fellowships. *Most NCHS activities are carried out by NCHS staff. A formal Vital Statistics Fellowship program should be developed and implemented to provide staff for analysis and research and to build linkages with outside researchers and agencies.*

Dissemination of Data and Reports

13. Existing quality of report and data dissemination
- a) Maintain hardcopy reports. *Although the availability of reports and data on the web is important, there is a need for researchers and others to continue to receive hardcopy reports. The receipt of certain hardcopy reports serves as a flag that new data are available, whereas it is more difficult to search for and find new data on the web. Researchers also value hardcopy reports as readily available library and reference materials.*
 - b) Enable users to create their own tables. *The needs and interests of researchers and other inquirers are difficult to predict. Expand the capacity to produce electronic data made in a format that allows users to create their own tables based on selected criteria or variables.*

- c) Be more proactive in adding new types of information or reports. *By virtue of current staffing and resources, the majority of effort is spent on producing the regularly published reports. A plan needs to be developed to produce more specialized reports or databases.*
 - d) Pursue interactive systems. *Systems such as CDC WONDER are somewhat static and limited in the ways they can be used. Data within such systems need to be more accessible and detailed, and presented in a way that is more interactive with the user.*
 - e) Make the NCHS web site more user-friendly. *Although the NCHS web site contains much valuable information, it is not particularly easy to navigate. A more intuitive and user friendly front needs to be developed.*
 - f) Review the Research Data Center (RDC). *A formal review of the RDC should be conducted to review issues related to its approaches and access to data. Explore alternatives to the use of the RDC as a means of making data more widely available while still protecting confidentiality of the data.*
14. Current responsiveness regarding data and report dissemination. *In view of current constraints, the Panel feels that NCHS has an excellent performance record in this area and has just three recommendations.*
- a) Make supplemental data from the 1993 NMFS available through the RDC. *Some data from the last NMFS were collected but not released to the research public, including autopsy results and drug tests. Such unique and important data could have great scientific value and should be released to the RDC.*
 - b) Ensure that the basic national mortality statistics are published in a timely fashion. *Efforts need to be undertaken to decrease the turnaround time required to publish mortality data and life expectancy reports.*
 - c) Expand collection and research efforts regarding minorities. *The population of Hispanic/Latinos is growing, and selected health conditions and causes of mortality may be quite different between various race/ethnicity groups such as African-Americans, Asian Americans, Native Americans, Hispanics, and other minority groups.*
15. Proactive planning regarding data and report dissemination
- a) Survey users. *Although the formation of the Review Panel is one way to survey users, more formal surveys of data users need to be performed to ascertain the strengths and weakness of mortality data and areas that need to be improved.*
 - b) Hold a formal national meeting to discuss data confidentiality, privacy, and sharing issues. *Developing federal legislation, in the context of existing and emerging state laws regarding data, may pose serious obstacles to the collection or provision or needed data. The Panel recommends that a meeting be held in the context of the National Academy of Sciences to find creative new approaches to issues of data confidentiality and release.*
 - c) Provide masked data for planning research. *A masked data set, available in a timely fashion, would allow researchers to develop research strategies that could then be applied to the complete data set at the RDC or through other mechanisms that protect confidentiality.*
 - d) Serve as a liaison between states and researchers. *NCHS could serve as a liaison or “go-between” between states and researchers to assist in providing or obtaining data needed for research purposes. Researchers would have a common place to go (NCHS) when making requests for data and assistance.*
 - e) Examine data quality for persons over age 85 and review analytical procedures for analyses of data. *Current mortality data are aggregated into a group of persons 85 years of age and older. The increased attention paid to mortality at the oldest ages raises new issues of data quality and appropriate analytic methods. As the population ages, more age-specific data may be valuable. Also, few studies of data accuracy have been done regarding very old*

people. In particular, it is important to ensure that states apply consistent rules for assigning cause of death. Smaller population sizes at each age and rapid mortality increases with age may require different methods of analysis rather than those used for the rest of the population, as may the existence of frequent co-morbid conditions. Studies of data accuracy may be useful not only when interpreting data, but may provide information or strategies that could improve the certification of such deaths.

- f) Consider using the WHO model for age-standardization in addition to the current U.S. Standard to facilitate international comparisons. Although current reporting methods include age adjustments for the U.S. population, the reporting method does not allow easy comparison to other countries. Methods should be developed to also report data using the WHO method of age adjustments.
- g) Disseminate multiple cause mortality data. In the past, most publications have presented single cause mortality data. In reality, in many age groups, there are quite commonly co-morbid conditions. Efforts should be expended to develop methodologies, to publish more multiple cause mortality data and to make it more available electronically. For example, this might involve the development of a short standard list of causes such as “heart disease with mention of diabetes.” One Panel Member was unable to use this file because of a reported error which may not yet have been corrected. The use of multiple causes on publicly available tape needs to be enabled, and short lists need to be developed that could supplement the traditional 10 leading causes of death.
- h) Use multiple cause mortality data in the context of a rapid surveillance system. To maximize the usefulness of a rapid mortality surveillance system, it should include multiple cause mortality data. This is important because a specific underlying cause of death may not be reported but could be detected through its manifesting as an immediate cause of death or other significant condition. For example, “dehydration,” “diarrheal illness” and “rectal hemorrhage” might be a tip off to *E coli* colonic infection that went unreported on the death certificate.

16. Capacity and resources regarding data and report dissemination

- a) Provide more support for web based and hardcopy publications. Hardcopy reports should remain to be published. Additional topical reports should be prepared and published such as reports of risk factors, chronic diseases, and fetal/perinatal deaths. Expansion of data and reports on the web should be pursued.

Preparation of Final Report

Immediately following the Panel’s meeting of December 8-9, the Panel Chair prepared a draft report and provided it to each Panel member for review and comment. Suggested edits were incorporated to the extent possible. Several versions of revised drafts were then sent to the Panel members prior to January 26, and the draft was reviewed by a state registrar. On January 26, 2006, the Panel met again at NCHS and prepared its final written report and PowerPoint report summary to be presented to the BSC on the afternoon of January 26, 2006.

Respectfully submitted January 26, 2006,
On behalf of the Mortality Programs Review Panel,

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