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# IMPROVING THE COMPLETENESS AND ACCURACY OF THE VITAL REGISTRATION AND VITAL STATISTICS SYSTEM IN THE UNITED STATES

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#### INTRODUCTION

The registration of vital events is not a new phenomenon with some systems in Europe dating back to the 1500's. Even in the United States, some of the early roots were laid in the 1600's. The same can also be said for the use of vital statistics data with the most famous early use by John Graunt of the Bills of Mortality in London in the 1600's. Despite these early beginnings, the vital registration system and the use of the records to produce vital statistics data did not become widespread in the United States until after 1900.

In this paper, I will discuss efforts that have been made to improve both the vital registration system and the vital statistics product derived therefrom, both in terms of completeness and quality. I will limit most of my discussion to efforts directed at improving birth and death registration since those have been the two data systems of most interest and where most of the efforts have been directed. I will discuss some of the early methods used, some things that are currently being done, and some things we hope to accomplish in the future. The one concept that I most want to convey is that efforts to improve the vital registration/vital statistics system can never stop. While the techniques may change, we can never stop the process of evaluating the product and promoting improvements.

#### HISTORY OF VITAL REGISTRATION IN THE UNITED STATES

The vital statistics system had its beginning in western Europe long before Europeans arrived in the United States. Vital statistics, like many other U.S. government systems, followed previously established European patterns in the early years, particularly those of England.

The earliest vital statistics registration law in the U.S. was enacted in Virginia in 1632. This law required that once a year a minister or warden from each parish appear in court on the first day of June to present a register of christenings, marriages, and burials for the previous year. This register covered only those events for which rites were conducted by the church, but in effect, they provided a rough account of births, marriages, and deaths for the area.

In a 1639 law enacted in <u>Massachusetts</u>, two significant modifications were made to the Virginia law. The Massachusetts law required that, (1) government officials, rather than church officials, keep the records, and (2) the records be of births, deaths, and marriages rather than church-related ceremonies. These changes were significant in establishing the present vital statistics registration system.

When the U.S. Constitution was framed, it included a provision

for a decennial census so that congressional representation could be apportioned by population. Consequently, the census was established as a national function. However, provision for a vital statistics system was not made; and therefore, the vital statistics registration system was developed not as a national undertaking but as a local and then State function.

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During the 1700's and early 1800's, there was a growing interest in vital statistics, especially death data. The industrial revolution played a significant role in creating an interest in, and a need for data on deaths.

Generally speaking, registration laws did not keep pace with the need for vital statistics. In 1842, Massachusetts enacted the first law that gave a State agency control over the registration system. Other States and cities followed, but progress was very slow over the next 60 years. Between 1850 and 1900, the only available national vital statistics data were those collected as part of each decennial census.

Before 1900, the role of the Federal Government in promoting and developing the vital statistics system was minimal. Their role mainly consisted of the collection of data during the decennial census. In 1880, the U.S. Bureau of the Census established the "death registration area" which at that time was only composed of two States, Massachusetts and New Jersey, the District of Columbia, and several large cities having efficient systems for the registration of deaths. The Census Bureau obtained copies of actual death certificates from these areas and used these records to supplement data obtained through the Census. This represented the first time that actual death records were used in the United States in the production of national mortality statistics. The practice was repeated in the Census years of 1890 and 1900 with the number of States and cities providing records increasing each The requirements for inclusion in the "death registration vear. area" were that the area had to have a mandatory registration system, that they collect certain data items on their reporting form, and that they register at least 90% of the events. The "birth registration area", established in 1915, had the same requirements for inclusion.

The first U.S. Standard Certificates of Live Birth and Death were developed in 1900. In 1902, the U.S. Bureau of the Census which had previously functioned only in census years, was made a permanent agency of the Federal Government by an act of Congress. This act authorized the Director of the Bureau of the Census to obtain, annually, copies of records filed in the vital statistics offices of those States and cities having adequate death registration systems and to publish data from these records. This authority was brought about because of the realization that the technique of obtaining mortality data through Census in the 1800's was ineffective and that a source of continuous data about what was happening in the country was needed, especially regarding what people were dying from. At that time, not all States had enacted laws requiring the registration of deaths, and in many States the existing laws were poorly enforced. The first Model State Vital Statistics Act was developed in 1907 and was actively promoted by the U.S. Bureau of the Census. The "birth registration area" was officially designated in 1915, and by (1933, all States were providing data to the U.S. Bureau of the census for the production of national birth and death statistics.

> With the increase in social programs in the 1930's and the entry of the United States into World War II in 1941, the need for vital records by individuals for legal purposes increased dramatically. During World War II, there was even discussion about making the vital statistics registration system a federal system. It was decided, however, to leave the system in the hands of the States, but the Federal Government would provide more assistance to the States to promote improvements.

> In 1946 responsibility for the vital statistics program at the federal level was transferred from the U.S. Bureau of the Census to the U.S. Public Health Service V This transfer brought about the creation of the National Office of Vital Statistics (NOVS) within the U.S. Public Health Service. The NOVS was created to provide a single locus of authority for vital records at the Federal level.

Since 1950, attention has been focused on improving the quality of vital statistics and making them more useful and widely available. Interest in vital statistics widened when State and Federal agencies, challenged to define needs for and effects of various State and Federal health and welfare programs, began looking for pertinent and reliable statistics on which to base judgments. The registration certificates assumed new importance as they were looked to as a source of credible national vital and health statistics for use by all levels of government institutions and the general public. Demand for this information increased and research was undertaken on how best to apply it to the rapidly developing data processing technology.

In (1960), the NOVS was merged with the National Health Survey to establish the Mational Center for Health Statistics (NCHS). The NCHS is responsible for collecting statistics on a broad range of health related subjects, including the annual collection of data from records of births, deaths, marriages, and divorces. The vital statistics function at the Federal level is still housed in the NCHS.

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# OPERATION OF THE UNITED STATES VITAL REGISTRATION/VITAL STATISTICS SYSTEM

<u>The vital statistics system</u> in the United States is <u>a State</u> <u>operated-State controlled system</u>. <u>There is no Federal law</u> <u>mandating the registration of any vital event</u>. As indicated above, when the U.S. Constitution was framed it did not include a provision for the registration of vital events. Because under the U.S. form of government any authority not specifically granted to the Federal Government automatically falls to the States, <u>the responsibility for the registration of vital events</u> became a State responsibility.

When it became apparent in the late 1800's and early 1900's that a system needed to be established to provide a continuous source of information about the population through a birth and death registration system, the decision was made to work through the States to develop comparable systems in all States rather than changing the Constitution and bringing such systems under the control of the Federal Government. Therefore, we have a system in which each of the individual States controls the system and the Federal partner provides guidance and assistance through a cooperative arrangement. It is a system which might not be expected to work efficiently, but, through the willingness of both the States and the Federal Government to work together for the common good, it has been and continues to be remarkably successful.

In an effort to ensure that the information collected by the various States is as uniform as possible, the Federal Government and the States work cooperatively to develop standard reporting forms that are recommended to the States as models for the development of their reporting forms. The first standards were developed in 1900 and they have been revised periodically since (the most recent revision was in 1989). The standards are designed to include the minimum information needed to meet legal needs and to produce statistical data to meet both national and State needs. States frequently add additional items that are of interest for statistical purposes within their area. However, most state reporting forms conform very closely to the standards in terms of content.

Another tool to promote uniformity is the <u>Model State Vital</u> <u>Statistics Act and Regulations</u>. Like the standard certificates, the Model Act is developed jointly by the states and the Federal Government and is designed to serve as a guide to the states in the development of their vital statistics Taws. While not all states have Taws that completely conform to the Model, most are similar in concept. The most recent revision of the Model Act was in 1992. In the process of developing standards and recommendations for the states, the guidelines from the World Health Organization (WHO) are carefully reviewed. Our definitions and reporting requirements are in essential agreement with the recommendations from the WHO.

One of the unique aspects of the U.S. registration system is that the responsibility for completing and filing the various vital records is **not** placed on the family. Rather our laws require that certain professionals involved with the event be responsible for obtaining the information and filing the records with the appropriate authorities. In the case of birth, the responsibility is generally assigned to the hospital where the birth occurs (approximately 98% of all births occur in hospitals). For those not occurring in a hospital, the attendant at the birth (physician or midwife) is responsible for the birth certificate. For deaths, the responsibility for ensuring that the certificate is completed and filed is placed on the funeral director hired by the family to arrange for the disposition of the body. This is effective since the disposition of almost all deaths are arranged through these professional funeral directors.

The physician who attended the decedent for the event leading to death or, if death was due to an external cause, the medical examiner or coroner is required to complete the medical certification of cause of death. The cause of death is included on the same document so it is the responsibility of the funeral director to get the form to the appropriate certifier and to retrieve it after the cause-of-death section is completed. The certificate is then filed with the appropriate authorities.

There are several significant advantages to having the records completed and filed by someone other than the family. First it reduces significantly the number of persons who must be informed of their legal responsibilities and trained in the proper completion of the records. The completion of the records is perceived as a part of the responsibility of these individuals in their professional relationship with the family or the individual. Also, since most of these individuals are licensed in some manner by the States, the licensure process can be used, if necessary, to exert pressure on them to properly do their job of completing the forms. From a statistical standpoint, this process allows for the collection of vital research data on the same form and at the same time as the legal information is obtained. In addition to the cause-of-death information on the death certificate, we collect a wide range of medical and health information on the birth certificate. It makes for a more efficient process and, by tying the provision of the statistical information to the legal requirement to file the birth or death certificate, we obtain information much more completely and Since information from the legal portion is also timely. important for statistical purposes, we do not have to worry about linking two different systems together to produce our vital statistics data.

As indicated in the historical overview, the Federal Government has been publishing vital statistics data since the mid 1800's and has been using State vital records as a source since 1880. In the early years, copies or abstracts of the actual records were obtained and the data that was needed was extracted. Beginning in (1972) the Federal Government began working with the States to obtain data in an electronic format. We now obtain virtually all of our information in this manner. Our contracts with the States require that they provide the information to us ? in our format and according to our coding specifications. In return, the States are reimbursed for the federal share of collecting and processing these data. There are a number of advantages to the new arrangement: It gets rid of duplication of effort since the information will only be keyed once, not twice as it was in the past; the States are more familiar with their records and are likely to do a better job of capturing the information; and the contracts provide significantly more money to the States than they received when they were providing copies of the records (a portion of this money is supposed to be used in programs to improve the quality of the data).

#### TECHNIQUES TO BRING ABOUT IMPROVEMENTS

There are a number of things that have contributed to improvements in the quality and completeness of both the registration of vital events in the United States and in the quality of the information obtained through the system. As with the system as a whole, efforts to effect improvements are a joint effort of the individual States working through the Federal Agency having responsibility for national statistics (currently the National Center for Health Statistics).

The decision by the Federal Government to work through the States to promote the establishment of a vital registration system and to use this system as the source of national vital statistics data dictated that the States would always be the principal agent for bringing about improvements. However, the Federal Government recognized that they must provide assistance and guidance. This has been how the system has operated for almost 100 years in the United States. It is truly a system that relies on the willingness of the Federal and State partners to work together to meet a common goal.

There is one point that must be kept in mind when working to improve a system - the audience must be convinced of the value of the product to them if we are to expect them to cooperate. **Utilization** is the single most important factor in bringing about improvements in the system. If the public knows they need the vital record now and into the future for some legal purpose or to obtain some benefit, they will make sure it is registered. If the policy makers and researchers know that our data are of value to them in making decisions on resource allocation or to identify and explain a problem, they will support the collection of the data. If the records are not important to the public and if the data are not important the system will not be successful. The focus of the efforts to improve both completeness and quality must be on convincing the public, the providers, and the users of the value of the records and the data to them.

Involvement of persons involved with the event who are not members of the family in the registration process - Because of the way the vital registration system is organized in the United States, the responsibility for completing and filing the vital record is not on the family. The hospital where the birth occurs or the attendant at the birth is responsible for completing the birth record; the funeral director handling the disposition of the dead body and the physician in attendance at the death are responsible for the death certificate. Since the registration is made a part of the duties of these professionals, we do not have to rely on the family to remember to register the event. This is especially true should a child die shortly after birth. The family may feel that there is no need to bother since the child is dead. The other advantage of involving persons other than the family is that it makes it possible to obtain statistical data that would not be available from the family.

It may not be practical for other countries to implement a similar process for registering the event but those involved with the event can still be involved in the process. Requiring hospitals, clinics, midwives, etc., who deliver babies to send lists of all deliveries and some information about these deliveries can be an invaluable check on registration completeness as well as a source of statistical information not available from the family.

**Develop informational materials for distribution** - Over the years in the United States a variety of pamphlets and other informational documents have been developed and distributed. These have been designed to inform the parents about the importance of birth registration to them and their child and to alert them to the information they would need to provide when the birth certificate is being completed. The focus of the materials has been on the importance of the information to the individual or the family.

Other materials have been developed to inform the person or facility charged with the completion of a document about their obligations, to provide instructions on the proper completion of the document, and to indicate the reason the various items are included on the record. This latter inclusion is especially important since in the United States our vital records include both legal and statistical information. While those completing the forms may understand the importance of the legal items for the individual or the family, they may not always understand the importance of the information that is being collected solely for statistical purposes.

Over the years these materials have taken many forms. In the early years of the registration system, much of the material was directed at the general public to educate them and to encourage them to ensure that the records were completed and filed by the appropriate individuals. Since our registration system for births and deaths is now virtually complete, the focus of most of our current informational material is directed at the persons and facilities who have responsibilities for the registration of the The National Center for Health Statistics produces a events. series of Handbooks that provide instructions for completion of the items on the various certificates and justification of the information included. These Handbooks are directed at organizations and individuals who have responsibilities in the registration process: <u>Physicians</u>, <u>Funeral Directors</u>, <u>Medical</u> Examiners/Coroners, and <u>Hospitals</u>. In addition, we have handbooks on marriage and divorce registration, the reporting of induced terminations of pregnancy, and guidelines for completing the occupation and industry items on the death certificate. Copies of these handbooks are provided free of charge to the various State vital statistics offices for distribution within their State (some States develop their own handbooks using the NCHS handbooks as models).

One of the major areas of concern regarding the quality of data has been with cause of death. While the handbooks provide instruction, they are not always accessible to the physician when Common of the not willing to take the time to look up the Instructions in a handbook. Therefore, we have developed a one Face page Taminated instruction sheet on "Instructions for a page laminated instruction sheet on "Instructions for Completing the Cause of Death Section of the Death Certificate." Again, these have been provided free of charge to the States and have received wide distribution to hospitals and other locations within the States. Physician reaction to the laminated sheet has been very positive and it is hoped that it will result in improvements in the quality of cause-of-death data. Work is currently underway on another laminated sheet on "Instructions for Completing the Cause-of-Death Section for Injury and Poisoning" and it will be ready for distribution by the end of 1994. As the title indicates this flyer will provide instructions for those deaths due to external causes (accidents, injuries, and poisonings).

**Training -** As with other programs designed to improve completeness and quality, the responsibility for training programs rests primarily with the individual States. The National Center for Health Statistics provides some training tools and staff will, on occasion, participate in the training programs The tools provided by the Federal Government include the (handbooks and (aminated sheets) mentioned above. We have also developed four videos that provide instruction on the proper completion of vital records. One of the videos provides instruction on the completion of the birth certificate and is intended for use in training hospital personnel. Three of the videos provide instruction on the completion of the death certificate: One is for funeral directors and deals primarily with the personal information on the death certificate; one is for physicians on the completion of the cause-of-death section; and the other is for medical examiners and coroners and also deals with cause of death but is specific to those types of cases requiring medical/legal investigation. Each of these videos is approximately 20 minutes in length. We have also developed an audio tape providing instructions on the completion of the cause-of-death section which is approximately 10 minutes long. All of these items are provided free of charge to the States.

The level of training varies considerably from State to State. In some there are training programs conducted every year and for a variety of participants. Regrettably, in some States there is virtually no training. The availability of resources is generally the reason for the difference. The training programs are directed toward those individuals and organizations that have responsibilities related to the registration of vital events. Almost all deal with birth and death. Only occasionally do they include a discussion of marriage and divorce. Since most States have a local registran with whom birth and death records are filed before they are sent to the State, all training programs include this group of individuals. Others frequently included are hospital personnel and funeral directors. Over the years, numerous efforts have been made to include physicians but with only limited success. It is for this reason that the area where the greatest need for improvement in the quality of our data is in cause of death.

The training programs generally focus on the following:

- 0 A discussion of problem areas that have been identified, either through discussion with the participants or through a review of the records that have been received by the State;
- 0 Going over the various records and ensuring that the participants understand the various items and how they are supposed to be completed;
- 0 A discussion of the uses of the various items. This is especially important for the statistical items since their

value may not be as obvious as the legal items; A review of any recent changes in procedures caused by new legislation or a change in policy.

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The National Center for Health Statistics also offers some training programs for the States. There are three types of courses offered: (1) Nosology courses for State cause-of-death coders; (2) a general vital statistics course designed for persons at the State and local level involved with the production of vital statistics; and (3) a vital registration course designed for persons at the State and local level involved with the registration of vital records. These courses are designed to promote uniformity and quality in coding procedures, in statistical practices, and in registration procedures.

Field program - One of the most positive programs instituted by the States in the past 20 years to improve the quality and completeness of vital statistics data is the "field program." The persons in the field program are assigned the duty of working directly with all persons and organizations involved with the registration function to address problems as they arise and to provide continuous guidance on the proper completion of the various documents. They play an integral part in the arrangements for and conduct of training programs. They follow closely reports on the quality and completeness of records that are being filed so they can identify problems early and take action to solve them. They spend a significant amount of their time "in the field" providing instruction, answering questions, and trouble shooting. These field representatives have had a significant impact on improvements in the completeness and quality of the vital statistics data.

Workshops - Much concern has been expressed about the quality of cause-of-death data. In 1989 and again in 1991, the National Center for Health Statistics, in cooperation with the U.S. National Committee on Vital and Health Statistics, convened a workshop of persons representing interested organizations to discuss steps that might be taken to improve cause-of-death statistics. Among the associations represented were the American College of Physicians; the American Geriatric Society; the American Hospital Association; the American Medical Association; the American Medical Record Association; the Association of American Medical Colleges; the College of American Pathologists; the International Association of Coroners and Medical Examiners; the National Medical Association; and the National Association of Medical Examiners. The workshops focused on what needed to be done to improve cause-of-death data in the United States and the consensus was that training programs for physicians had to be The following are some of the specific recommendations improved. made to improve physician education programs:

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## Physician Training

It is essential to convey the importance of cause-of-death information and to provide an overview of the process during medical school training. Educational materials should be tied to the appropriate and relevant clinical topics and linked with research on mechanisms of disease and death.

Residency is considered the key time for educating physicians on cause-of-death reporting. Educational efforts should begin at the orientation of new residents and should be focused on the resident's first completion of a death certificate.

Continuing medical education, either through self-study or other course work, on completion of the death certificate should be considered as a requirement for relicensure and/or medical society membership.

Continuing medical education modules should be developed for practicing physicians. These modules should be tied to clinical research and problem areas.

Training should be targeted to physicians who complete a significant number of death certificates in their practice. A study should be undertaken to determine which physicians certify deaths.

Medical examiners and coroners are a resource for training on cause-of-death certification in medical schools and can also serve as a resource to State Registrars and hospitals by serving as consultants, reviewing death certificates, and providing feedback to certifiers.

Local health officers also can serve as a resource to States for querying cause of death.

Assuring accurate completion of the death certificate is part of continuous quality improvement in the hospital. There should be one or more focal points in the hospital for assuring proper completion of death certificates.

The role of the medical records department in fostering accurate cause-of-death reporting in the hospital should be increased.

Completion of training in cause-of-death certification should be a requirement for staff privileges.

Hospitals should facilitate submission of amendments to death certificates after autopsy findings are received.

The usefulness of death certificate information for individual programs and specialties, from both a clinical and research perspective, must be marketed to the physician community. A medical media "blitz" is needed.

States should develop action plans for improving cause-of-death certification and convene planning meetings with the interested parties in their respective States.

## Evaluation and Software Development

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There should be a total reevaluation of how medical information is collected through the death certificate. This would include evaluation of alternative designs for the medical certification of cause-of-death and for the order of reporting underlying and contributing causes.

Uniform software for completion of the death certificate, for use by all jurisdictions, should be developed. The new software should be interactive and user (physician) friendly. Although aimed at proper completion of the certificate, the new software should also be educational.

Software should be developed for completing the entire death certificate. Several modules should be considered to meet needs of various users and producers of death certificates.

The first module undertaken should be the medical module, focusing on the cause-of-death certification by the physician.

Hospital autopsy data should be incorporated into the process.

System design requirements for the medical module should be developed within 2 years; the medical module should be operational by 1996.

The National Center for Health Statistics should coordinate the development of the interactive approach and software. Medical examiners and coroners, physician organizations, the National Funeral Directors Association, States, and the Association for Vital Records and Health Statistics are all key players in development and implementation of the medical module.

The model state vital statistics act and regulations, which currently are undergoing review and revision by the States and NCHS, should take into consideration collection and issuance of death information through electronic means. While progress has already been made and some of the recommendations have been implemented, much work remains to be done to achieve the quality of cause-of-death data we desire.

The laminated sheets mentioned earlier were an outgrowth of the workshops. The NCHS has also awarded a contract to try to find out more about physician knowledge and attitudes toward death registration. This should provide information to assist in developing or improving training programs. It may also lead to changes in the design or content of the death certificate if it is found that the current form is a problem. The report on this study is due in 1995 and we would anticipate that it will be helpful in bringing about improvements in cause-of-death data.

**Exhibit on cause-of-death** - After the 1989 workshop, the NCHS, in cooperation with other organizations, developed an educational exhibit addressed to physicians on the importance of accurate cause-of-death certification. In addition to providing instruction on the completion of the cause-of-death section, the exhibit emphasizes the many uses of mortality data for policy and research purposes. The exhibit is designed to be shown at physician association meetings and to date has been shown at 10 such meetings. In addition, a smaller version of the exhibit has been developed and offered to the States for use at State level meetings and several States have already availed themselves of the offer. Our plans are to continue taking this exhibit to medical association meetings as long as it appears to be of interest to the attendees.

**Ouerving** - One of the oldest techniques used by the States to improve the quality and completeness of information is to query (contact) the reporting source when a certificate is filed with missing or inconsistent information. The purpose of the query is to obtain the missing information or to clarify the While it would be preferable that the certificate inconsistency. be filed correctly to begin with, this helps ensure that the data are correct before official statistics are released. The guery program can also serve as a training tool since it does alert providers when they are doing something wrong or when they are providing inconsistent information. Hopefully they will be more careful and thorough in the future. To assist States with their query program, the National Center for Health Statistics has developed two instruction manuals to provide guidelines. One of the manuals deals only with cause-of-death while the other provides guidance for the other items on the death certificate as well as all items on the birth certificate. These manuals have been helpful in bringing about uniformity and consistency in State query programs.

Automation - Birth - Automation is beginning to have an impact on

the quality, completeness, and timeliness of vital statistics data in the United States. In the past 10 years, the States have begun to implement electronic birth certificate (EBC) systems in their hospitals. These systems allow hospital personnel to enter the birth certificate information on a computer rather than using a typewriter to complete the document. This process is much quicker and easier for the hospital since corrections can be made on the computer **before** the certificate is printed and mistakes The software also includes defaults for can be avoided. repetitive information (such as facility name and address) so that it does not have to be retyped for each certificate. The most important aspect of the systems from a data quality standpoint, however, is that the quality control edits employed by the State to check records when they are received in the State Vital statistics office are now incorporated into the software at the hospital. Therefore, the certificate is checked by the edits before the paper copy is printed or the record is transmitted to the State. This has almost eliminated the need for querying inthose hospitals using the electronic systems. In addition, the State vital statistics office receives an electronic version of the certificate removing the need for almost all data entry for the record.

The use of EBC programs is growing and we expect that almost all births will be registered through such systems within the next few years. While they do not solve all of the data quality problems, they do solve many of them and are resulting in significant savings in time in the hospitals as well as the State vital statistics offices.

We are also beginning to explore ways electronics could be used to get information needed for the birth certificate (especially the statistical information) from the source of prenatal care to the hospital more efficiently. While we feel the overall quality of data on the birth certificate is good, we know that some information is not included or is not complete either because the birth registration clerk cannot locate it in the medical record or the medical record is not available. Our efforts in this area are just beginning but it appears to be the logical next step in our attempt to improve the quality of natality data.

**Death** - Because of the complexity of the death registration system, development of an electronic death certificate (EDC) has lagged behind the development of the EBC. Currently only one State has an operational EDC system. In the registration of a death, the funeral director has the overall responsibility for ensuring that the certificate is completed and filing it with the registrar. Specifically they are responsible for obtaining the personal information about the decedent. The attending physician, medical examiner, or coroner is responsible for completing the cause-of-death information. In addition, when deaths occur in a hospital or other institution the hospital or institution will sometimes assist with obtaining the information for the certificate, especially the cause-of-death information. Because of the number of individuals involved in the completion of each certificate and the logistical problems involved with each, the development of an EDC will be more complex than the EBC. Currently the National Center for Health Statistics is working on the development of a prototype EDC that will provide the States with guidance in the development of a system within their State. When completed, the prototype will have two parts the personal information and the cause-of-death information. Our intent is to develop a system that, like the EBC, will edit the certificate as it is being completed, including the cause of In addition, we plan to include instructions for the death. completion of the various items as a part of the "help" feature Special emphasis will be given to the of the package. instructions for the cause-of-death section. It is too early to speculate on how an EDC will be installed in the various States.

It is hoped, however, that the NCHS prototype will be helpful in setting the specifications. It is currently being tested in two areas and their experience will be extremely helpful to NCHS in making improvements in the prototype. There is currently much interest in an EDC system and we anticipate that States will begin developing and installing these systems very soon.

**Training tools** - In our continuing efforts to develop training materials for physicians on completing the cause-of-death, we are exploring the development of a computerized training module. The concept would be to provide case histories on the computer and have the physician complete the cause-of-death for each on the computer. The program would then evaluate the cause given by the physician and provide feed-back. We believe the concept to be viable and staff are currently working on it. While I cannot give a specific time frame, we should have something that we can give to the States to disseminate within the next one to two years. If we are successful, such a training aid should be extremely helpful.

**Publicity** - A very effective technique for improving the completeness of registration and the quality of data is through the media. The secret is to determine who we need to reach and how best to do so. In the early years of our registration system, the general public needed to be educated about the importance of registering a birth or death. This was done through posters in doctors offices, pamphlets distributed through doctors or local health departments, information booths set up in places where large numbers of people were in attendance (county of State fairs, for example), and in some cases through radio announcements. The intent was to inform them of the importance / of registering the event and of the value of the records to the individual or the family. Now that our registration completeness is almost 100%) the focus of the publicity is directed toward those who have responsibility for providing information for the records or for filing the This is done generally through articles in journals or records. newsletters that reach these individuals and which discuss the value and uses of the records or the data derived from them. When talking to physicians, it is very helpful to be able to show them an article from one of their journals either talking about the value of the data from birth or death records or using data from these records. The same applies to others involved in the registration process, as well. And these same articles can be very helpful in explaining to the general public why certain items of information are being collected. Even though the family does not register the birth or death, they provide much of the information for the documents and they do have questions about why certain information is being asked. Having examples of uses to show when questions arise is extremely helpful.

A number of States have developed newsletters which serve as a communication avenue with people and organizations involved with the registration system and, to a lesser extent, users of the vital statistics data. Some of the newsletters are directed to a specific audience (several States have a newsletter that deals with the electronic birth certificate program and they are sent to those hospitals participating in the EBC program). Most of the newsletters are more general in nature and are designed to inform a wide range of persons and organizations. Among the topics covered are law changes; personnel changes; and a discussion of a current problem or issue that has been brought to the attention of the State staff. In a few of the States they include a "score board" on the timeliness of reporting from the various areas of the State. The intent is to create an atmosphere of competition that will result in improvements in getting the records to the State office on time. States have found these newsletters to be a relatively inexpensive mechanism to maintain lines of communication within the vital statistics community and to promote improvements in timeliness and quality of reporting.

**Using Other Sources to Check Quality of Vital Statistics Data** -Surveys can be an effective and cost-efficient mechanism to obtain statistical data not available through the vital statistics system. These surveys can also be helpful in examining the quality of data collected through the civil registration system. In the United States, we conduct periodic surveys using both the birth and death records as sampling trames. The information collected in the survey includes some items that are also on the registration document. This provides us a good measure of the quality of our data and is helpful in identifying potential problems that need to be addressed. Since birth certificates in the U.S. are completed by hospitals, another technique to check on quality is to compare the information in the hospital records with that on the birth certificate. This can be an effective mechanism to identify problems in the procedures used in the hospital to prepare the birth certificate. However, despite the effectiveness of the process in identifying problems and improving data quality, it is expensive and time-consuming and only a few of our States have been able to use it.

**Confidentiality and Quality** - In the vital statistics system we collect extensive amounts of very valuable information that, we hope, will lead to improvements in the quality of life of the citizens of our country. Much of this information is of a personal nature and could be embarrassing if it is improperly used or released. It is critical that adequate safeguards be employed to protect the information from improper or inappropriate disclosure if we are to expect the providers to provide complete and accurate information. These safeguards are needed not only on the individual documents but also on the statistical information.

In the United States, State confidentiality laws vary somewhat and in some of the States anyone can obtain a copy of any birth or death certificate. However, all States provide protection for the information on the birth certificate collected for "medical and health use only." In addition, some of the States are now limiting who can obtain a copy of a death certificate showing cause of death. These restrictions are designed to protect personal privacy and to assure those providing the information that confidentiality will be maintained. Without these protections, it is unlikely that we could continue to collect the type of information currently available through our vital statistics system.

One word of caution, however, about restrictions on access to the information - they should never be so stringent that legitimate research is prevented. A mechanism should be in place to review requests for records or data and to allow those research projects that meet established criteria. Vital records and vital statistics data are valuable resources that must be used to be effective in improving the health of our citizens.

#### CONCLUSION

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Maintaining quality and completeness of the vital registration and vital statistics system is a continuous and never ending process. All who are involved in the process must be convinced that what they are doing is important. While the fact that there is a legal mandate that they do something can be helpful, that alone is not enough. They must be convinced of the worth of what they are doing. Obviously the more useful the record is to the individual or their family the more likely it is that the record will be filed. Therefore, it is important that the birth and death record become the principal document for proving age and for establishing the fact of death for settlement of estates. In the United States, a copy of a birth record has long been a requirement for proving age for school entrance and this makes the family aware of the importance of the document. **Utilization** is critical to ensuring registration completeness.

It is equally important that the value of the statistical information be shown to those who must provide it. Documenting programs that have used the data to bring about improvements in the health or quality of life of the community is very important in convincing physicians and others to provide the information. In the United States, there continues to be much concern about the infant mortality rate. One of the selling points we have used for the information collected on the birth certificate is that it is very helpful in the study of adverse birth outcomes, especially of infant deaths. Obviously, many other examples can be used but the important issue is to explain why the information is needed and, most important of all, make sure that it is made available to those who need it.

Over the nearly 100 years of the vital registration system in the United States, many techniques have been used to inform and educate those involved in the registration process. As our society has changed so have the techniques. The important factor, however, is that we have continued to seek better ways to reach our audience. The fact that the birth and death record are so important to the individual and their family is invaluable to insuring complete registration. The fact that we collect and disseminate statistical information that is invaluable to the public health and demographic communities insures the collection of high quality statistical data. Our goal now is to make the product even better and more valuable and we will never cease striving for that goal.

# **REFERENCES AND SOURCES**

- National Center for Health Statistics. Physicians' Handbook on Medical Certification of Death: DHHS Publication No. (PHS) 87-1108. September 1987.
- National Center for Health Statistics. Hospitals' and Physicians' Handbook on Birth Registration and Fetal Death Reporting: DHHS Publication No. (PHS) 87-1107. October 1987.
- 3. National Center for Health Statistics. Funeral Directors' Handbook on Death Registration and Fetal Death Reporting: DHHS Publication No. (PHS) 87-1109. September 1987.
- National Center for Health Statistics. Medical Examiners' and Coroners' Handbook on Death Registration and Fetal Death Reporting: DHHS Publication No. (PHS) 87-1110. October 1987.
- National Center for Health Statistics. Handbook on Marriage Registration. DHHS Publication No. (PHS) 88-1111. April 1988.
- 6. National Center for Health Statistics. Handbook on Divorce Registration. DHHS Publication No. (PHS) 88-1116. April 1988.
- National Center for Health Statistics. Handbook on the Reporting of Induced Termination of Pregnancy. DHHS Publication No. (PHS) 88-1117. January 1988.
- National Center for Health Statistics. Guidelines for Reporting Occupation and Industry on Death Certificates. DHHS Publication No. (PHS) 88-1149. March 1988.
- 9. National Center for Health Statistics. Instruction Manual Part 20, Cause-of-Death Querying, 1985.
- National Center for Health Statistics, Model State Vital Statistics Act and Model State Vital Statistics Regulations, 1992 Revision. DHHS Publication No. (PHS) 94-1115. February 1994.
- 11. Tolson GC, Barnes JM, Gay GA, Kowaleski JL. The 1989 Revision of the U.S. Standard Certificates and Reports. National Center for Health Statistics. Vital Health

Stat 4(28). 1991.

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- 12. National Center for Health Statistics. Instruction Manual Part 18, Guidelines for Implementing Field and Query Programs for Registration of Births and Deaths, 1993.
- 13. Report of the Workshop on Improving Cause-of-Death Statistics. October 15-17, 1989.
- 14. Report of the Second Workshop on Improving Cause-of-Death Statistics. April 21-23, 1991.
- 15. Vital Statistics of the United States: History and Organization of the Vital Statistics System; Vol I, 1950:2-19.
- 16. Report of the Panel to Evaluate the U.S. Standard Certificates and Reports, April 1986.
- 17. Taffel SM, Ventura SJ, Gay GA. Revised U.S. Certificate of Birth-New Opportunities for Research on Birth Outcome. BIRTH 16:4, December 1989.
- 18. Freedman MA, Gay GA, Brockert JE, et al. The 1989 Revisions of the U.S. Standard Certificates of Live Birth and Death and the U.S. Standard Report of Fetal Death. American Journal of Public Health 1988; 78:168-172. February 1988.

