

Access to Death Records to Support Health Research— Some General Background

C. F. Citro, Director, Committee on National Statistics
Revised, October 2, 2014

DISCLAIMER: The information in this document is based on conversations and Internet searches conducted by the author. The document also benefited from comments by NAPHSIS and NIH staff on an earlier version. There are likely still some errors of fact and inference. Nothing in this document should be construed as reflecting the views of any federal agency or other organization or the National Academy of Sciences/National Research Council. The document is intended as background for an invitational meeting. Comments and corrections are welcome.

INTRODUCTION

This document briefly describes research needs for timely, affordable, and user-friendly access to death records and the current status of two major sources of death records maintained by the federal government—the National Death Index (NDI) compiled by the National Center for Health Statistics (NCHS) and the Death Master File (DMF) compiled by the Social Security Administration (SSA). Attachments A and B provide additional information on the NDI and DMF, respectively. Attachment C describes a limited service of the Centers for Medicare and Medicaid Services (CMS) for providing death records for the Medicare-eligible population, and Attachment D describes the initiatives of the National Association of Public Health Statistics and Information Systems (NAPHSIS) to have all of the states—which have the legal authority over vital records—to compile their records electronically. Finally, Attachment E provides additional examples of research needs for access to death records and observations from some researchers on their experiences with available sources of death records.

RESEARCH NEEDS FOR DEATH RECORDS

Timely, affordable, and user-friendly access to records of decedents is vital to important areas of behavioral and social science and medical research. Longitudinal national probability studies of the older population require such access—preferably on a flow basis—in order to determine which sample members may have died since the last follow-up survey. This information helps keep the sample up to date and saves follow-up costs. This information also enables research conducted with survivors to confirm age of the decedent, to investigate end-of-life planning, and to study other policy-relevant topics. The National Institute on Aging's Behavioral and Social Research Division (NIA/BSR), for example, supports several longitudinal studies of older populations that serve as key infrastructure to behavioral and social science research grantees and to the federal government—for example, the Health and Retirement Study (HRS); the National Health and Aging Trends Study (NHATS); the Panel Study of Income

Dynamics (PSID); and the Wisconsin Longitudinal Study.¹ These and other longitudinal surveys greatly benefit from timely, affordable, and user-friendly access to death records.

Clinical trials and prospective cohort studies also require timely, affordable, and user-friendly access to death records—just a few examples of long-running cohort studies funded by NIH, each of which conducts interviews with participants every 2 years, are the Nurses' Health Study I (N = 121,700, begun 1976); the Health Professionals Follow-Up Study (N = 51,259, begun 1986); and the Nurses' Health Study II (N = 116,678, begun 1989).² Such studies have a need, not only for tracking participants in order to save costs on follow-up, but also for documenting a key outcome—namely, death—for research attempting to link treatments or other factors to health outcomes. Frolkis et al. (2009) is just one example of a study that depended on accurate determination of death as the outcome variable.³ See Attachment E for more examples and for researcher observations on sources of death records.

Finally, timely availability of death records can greatly assist health care organizations (hospitals and others) to evaluate the effectiveness of new medical protocols (e.g., new surgical procedures) and quality improvement programs on patient outcomes. Similarly, timely availability of death records is essential for clinical trials to identify adverse events and instances when a trial should be stopped because a treatment has proven harmful.

SOURCES OF DEATH RECORDS

From the beginning of the United States, the states have had the authority and responsibility for recording vital events, including deaths. From Schwartz (2009, p. 78):⁴

In the United States, all vital events are local. What we see as national vital statistics start out as births, deaths, terminations of pregnancy, marriages, and divorces that are registered locally. There are 57 vital registration jurisdictions in the United States: The 50 states, 5 territories (Puerto Rico, U.S. Virgin Islands, Guam, American Samoa, and the Northern Mariana Islands), the District of Columbia, and New York City. Each of the 57 jurisdictions has a direct statistical reporting relationship with the National Center for Health Statistics (NCHS). Some of the states have centralized vital records offices, but most have local registrars who receive, register, and issue certified copies of vital records. There are over 6,000 local vital registrars nationwide.

¹See <http://hrsonline.isr.umich.edu/>; <http://www.nhats.org/>; <http://psidonline.isr.umich.edu/>; and <http://www.ssc.wisc.edu/wlsresearch/> [September 2014].

²See <http://www.channing.harvard.edu/nhs/>; <http://www.hsph.harvard.edu/hpfs/>; and <http://www.channing.harvard.edu/nhs/> [September 2014].

³Frolkis, J.P., Pothier, C.E., Blackstone, E.H., and Lauer, M.S. (2009), Frequent ventricular ectopy after exercise, *New England Journal of Medicine* 348(9, February): 781-90.

⁴Schwartz, S. (2009), The U.S. vital statistics system: The role of state and local health departments. Pp. 77-86 in M.J. Siri and D.L. Cork, rapporteurs, *Vital Statistics: Summary of a Workshop*, Committee on National Statistics, Division of Behavioral and Social Sciences and Education, Washington, DC: The National Academies Press. Note that information in the first paragraph of the excerpt is somewhat out of date and not wholly correct. All states maintain centralized vital records, and about 40 percent at present do not have local registration.

Each of the jurisdictions is also a member of NAPHSIS, the National Association for Public Health Statistics and Information Systems. The association was formed in 1933 to provide a forum for the study, discussion, and solution of problems related to these programs in the respective members' health departments. NAPHSIS provides national leadership and advocacy on behalf of its members to ensure the quality, security, confidentiality, and utility of vital records and health statistics, as well as their integral role in health information systems, for monitoring and improving public health.

NAPHSIS represents the interests of jurisdictions on cross-cutting vital records and health statistics matters. These interests include national standards for data collection, exchange, issuance, and verification and electronic systems to collect, maintain, and disseminate records and data in a way that is timely, accurate, and protects confidentiality and security. NAPHSIS creates and fosters communication, best practices, training opportunities, and sharing of information across all jurisdictions. NAPHSIS works to build confidence in the integrity of public health and vital records systems and the data produced.

NAPHSIS also educates and negotiates on behalf of the jurisdictions with NCHS, the Social Security Administration (SSA) and other federal and national partners to ensure fair and equitable support and compensation for all jurisdictions, regardless of size or geographic location.

Cohort and longitudinal studies that began in the 1970s and earlier had to reach out to and negotiate with individual states to locate death records for members of their studies. Since then, there have been two federal agency sources of death records that have obviated the need for researchers to work with individual states. One is the National Death Index (NDI), compiled and maintained by NCHS beginning in 1982 for deaths occurring since 1979, specifically to facilitate research and analysis. The other is the Death Master File (DMF), compiled and maintained by SSA since 1936 to verify benefit status and administer Social Security programs. Since 1980, SSA has made available a public version of the DMF to researchers and others on a timely and inexpensive basis via the National Technical Information Service (NTIS) in the U.S. Department of Commerce. However, recent developments have rendered moot the usefulness of the public DMF.

National Death Index

The NDI is a comprehensive set of U.S. death records that is obtained by NCHS to facilitate research and analysis. NCHS carefully compiles and edits the information, through contracts with the vital registration areas in the United States (50 states, DC, NYC, and the territories). NCHS works with NAPHSIS on standardizing death (and birth) certificates, moving them to electronic form, and similar efforts to improve the system. The NDI includes not only the fact and date of death, but also the cause and other information on the death certificate.

When the agreements were originally reached between NAPHSIS and NCHS regarding the system of death records and the NDI, it was specified that researchers who requested the information would have to (a) submit a research proposal, (b) agree to certify that the records provided to the researcher were destroyed after the research was completed, and (c) provide a list of specific SSNs to NCHS, which would in turn perform a match to the NDI and return only those records that matched. In other words, researchers could not obtain the NDI in its entirety.

NCHS also charged a fee, based on the volume of records sought, to cover the costs of its staff and payments to the states for the records sought, and, historically, each year's additions to the NDI were not available until after a lag of a couple of years.⁵

Recently, and largely in response to SSA's administrative actions that appropriately removed state data from the public DMF and legislation that restricted access to the scaled back public DMF, NCHS undertook to improve the timeliness of the NDI and make other improvements.⁶ Attachment A describes NCHS's goals and progress to date in this effort. With regard to death records specifically, NCHS has said its immediate goal is to be able to release the previous year's death records with the fact of death by June of the following year (starting with June 2014 for 2013 death records). The full NDI with cause of death would come later. Its further goal is to be able to release partial fact of death records by February of the next year (starting in February 2015 for 2014 records)—the release would be partial because not all states transmit their records to NCHS fast enough.

Death Master File

SSA for a number of decades has built its own set of death records, the DMF, which it uses to reduce the problem of continuing to pay benefits after death. To speed up acquisition of death records, specifically the date and fact of death, not the complete death record, which it does not need, SSA obtains information not only from some states, but also directly from some hospitals and funeral homes as well as from family members and other sources (the information from non-state sources is not verified). The DMF currently has over 89 million records.

SSA's contract with the state vital registrars and its enabling statute (see Attachment B) limit the uses to which SSA's data may be put—that is, uses for SSA, other executive branch program agencies, and state program agencies are strictly for such purposes as reducing benefits fraud and program administration.⁷ SSA currently has MOUs with the following federal agencies for their use of the full DMF (i.e., including information from the states and other sources): Railroad Retirement Board (monthly updates), Federal Retirement Thrift Investment Board (monthly updates), Defense Manpower Data Center (monthly updates), Centers for Medicare and Medicaid Services (weekly updates—see Attachment C), IRS (weekly updates), Pension Benefit Guaranty Corporation (weekly updates), Department of Veterans Affairs (weekly updates), and Office of Personnel Management (weekly updates).⁸

From 1980 until recently (November 2011), consistent with a FOIA settlement, SSA also provided access to a public version of the DMF through the National Technical Information

⁵Funding from the National Cancer Institute enabled the NDI to get off the ground.

⁶NIA put together a coalition of agencies, including NIA, other NIH institutes, the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Quality and Research (AHRQ), to provide funding for this improvement effort.

⁷SSA's authorizing legislation (section 205r—see Attachment B) also includes "statistical and research uses," but it is not clear whether this pertains solely to statistical and research uses by agencies that have approval to obtain DMF files for benefit payment administration.

⁸See U.S. Government Accountability Office (November 2013), *Social Security Death Data—Additional Action Needed to Address Data Errors and Federal Agency Access*, GAO-14-46, Washington, DC (p. 41).

Service (NTIS) in the U.S. Department of Commerce. Facilitated by development of the Electronic Death Registration System (EDRS—see Attachment D), data from the states that were not independently verified from another source were added to the public DMF starting in 2002, although that should not have been done per SSA's contract with the states and statute. NTIS in turn provided updates to the public DMF on a weekly, monthly, or quarterly basis to non-government subscribers, including researchers, credit companies, and life insurance companies.

In response to concerns about tax fraud, especially the use of SSNs of recently deceased children, SSA took a look hard at its agreement with the states, which was predicated on state laws, and determined that it should have never included state records in the public DMF provided to NTIS in the first place.⁹ Since then, SSA has provided to NTIS only the death records obtained from non-state sources, such as funeral directors. Deletion of state records in the version of the public DMF significantly affects the public DMF coverage (see Attachment B).

Section 203 of the Bipartisan Budget Act of 2013 (signed into law on December 26, 2013, see Attachment B) requires that NTIS make the non-state data available to the public for specific purposes and under specific conditions, designed to continue to reduce tax fraud and related identify theft. It contains a provision restricting access to the NTIS version of the DMF any earlier than 3 years after to the data of death, with the exception that earlier access can be provided to "certified" persons. NTIS issued a *Federal Register* notice, March 26, 2014, on the interim certification process that it has set up (see <http://www.gpo.gov/fdsys/pkg/FR-2014-03-26/pdf/2014-06701.pdf>), looking toward a process for the long term that takes into account the views of a full range of stakeholders. Given that state records will not be restored to the public DMF, its usefulness to researchers is limited.

Attachments:

- A—NCHS Progress on the NDI
- B—Developments on the SSA DMF
- C—CMS Provision of Death Records
- D—NAPHSIS's Electronic Initiatives Relevant to Death Records
- E—Examples of Research Needs for Death Records and Observations on Existing Sources

⁹The state laws that govern access to vital records differ considerably in how tightly they restrict access—some state laws severely restrict reuse of records, while other state laws impose fewer restrictions. This diversity among state laws is a primary reason why agreements negotiated through NAPHSIS with federal agencies for access to state vital records are themselves highly restrictive. There is also a difference between federal law regarding the privacy of death information and state laws (and among state laws). The federal Privacy Act of 1974 excludes deceased individuals from federal privacy protection. In contrast, many states accord legal protection to death records, including the fact of death, for long periods of time. (Similarly, the Privacy Rule for the Health Insurance Portability and Accountability Act of 1996 protects individually identified health information for 50 years after death.)

ATTACHMENT A—NCHS PROGRESS ON THE NDI

I: NVSS Improvements [from http://www.cdc.gov/nchs/data/factsheets/factsheet_nvss_improvements.html, April 2014]

National Vital Statistics System

The National Vital Statistics System (NVSS) provides the nation's official vital statistics based on the collection and registration of birth and death events at the state and local level. This system contains information on all births and deaths in the United States and provides the most complete and continuous data available to public health officials at the national, state and local levels, and in the private sector.

Examples from the NVSS include teen births and birth rates; preterm birth and infant mortality rates; leading causes of death; and life expectancy. Vital statistics have diverse uses - they serve as a base for public health, social service, and economic planning and program development and are used to track progress toward health goals.

Improvements to the NVSS

Each year, the NVSS collects information on 6.5 million birth, death and fetal death events occurring in the 57 U.S. vital registration areas (50 states, New York City, District of Columbia, and five U.S. territories). NCHS also works with each vital registration area and the National Association for Public Health Statistics and Information Systems (NAPHSIS) - representing state vital statistics' offices - to collect vital registration data and to improve **timeliness** and **data quality**.

Efforts to improve vital records are ongoing - they involve NCHS support of states in implementing electronic birth and death registration systems and completing the implementation of the 2003 revised standard certificates in all jurisdictions. Electronic birth and death records will improve timeliness of data, allow for transfer of data between states, and integrate vital statistics with public health surveillance systems. As of 2013, NCHS completed the funding of remaining states seeking assistance for development and/or implementation of a web-based electronic birth registration system (EBRS). Similar progress has not been made with electronic death registration systems (EDRS). As of 2013, 37 of the 57 vital registration areas have an operating EDRS, although most of these systems are not operating statewide and most data providers (physicians, funeral homes) are not using them to enter the death information.

Registration areas are also implementing a revised birth certificate based on the 2003 U.S. Standard Certificate of Live Birth. At the start of 2014, 10 vital registration areas still need to implement the revised birth certificate; all areas are expected to implement the revised birth and death certificates by January 1, 2015. In 2012, new 5-year contracts with the vital registration areas were signed that promote improved timeliness and quality. For the first time, these contracts allowed NCHS to fund special projects to enhance the timeliness and quality of the vital statistics system. Projects were funded to:

- Implement new electronic birth registration systems (EBRS) and complete the establishment of EBRS in every state.

- Test the feasibility of electronic data exchange between vital registration systems and electronic medical records.
- Improve physician participation with electronic death registration.
- Assist in the development of electronic death registration systems and increase the percentage of physicians signing death certificates using the electronic system.

Improved Timeliness

Timeliness of data for the preliminary and final vital statistics reports is calculated from the time records are received from the vital registration areas, processed and closed, to publication on the web.

- To allow for timely public health planning and response, NCHS releases preliminary birth and mortality data when it has received 95 percent or more of all records from vital registration areas.
- Preliminary birth data for 2012 were released five months after the end of data collection.

Improved Data Quality

NCHS works to improve data quality through special studies, and expanded outreach to physicians and others completing birth and death certificates. Recent projects to improve data quality include:

- The 2003 Revisions of the U.S. Standard Certificates for live birth, death, and fetal death. These revisions encourage uniformity in data collection across registration areas. State adoption of the revised certificates enhances the ability to analyze and track crucial indicators, including demographic characteristics, health care utilization, and outcomes such as Cesarean delivery.
- Improved data transfer systems developed between vital registration areas and between vital registration areas and NCHS.
- Data standards developed to transfer data between electronic medical records and vital registration systems.
- Web-based tutorials to assist physicians in completing death certificates.
- Automated coding systems for cause of death developed to speed data availability.

II: Latest Data Available from the NDI

[from: <http://www.cdc.gov/nchs/ndi.htm>, September 2014]

National Death Index

The 2013 NDI [Early Release File](#) is available for ROUTINE searches.
[View table of completion status by state.](#)

The 2012 NDI Final File has a few remaining issues. Please check back periodically for release date announcement

The National Death Index (NDI) is a centralized database of death record information on file in state vital statistics offices. Working with these state offices, the National Center for Health Statistics (NCHS) established the NDI as a resource to aid epidemiologists and other health and medical investigators with their mortality ascertainment activities.

- **Assists investigators in determining whether persons in their studies have died** and, if so, provide the names of the states in which those deaths occurred, the dates of death, and the corresponding death certificate numbers. Investigators can then make arrangements with the appropriate state offices to obtain copies of death certificates or specific statistical information such as cause of death. **Cause of death codes may also be obtained using the NDI Plus service.**
- **Records from 1979 through 2011** are available and contain a standard set of identifying information on each death. Death records are added to the NDI file annually, approximately 12 months after the end of a particular calendar year.
- The NDI service is **available to investigators solely for statistical purposes in medical and health research.** The service is *not* accessible to organizations or the general public for legal, administrative, or genealogy purposes.

How to Use the National Death Index: Steps in the Process

1. Download the National Death Index (NDI) Application Form. Allow approximately 2 to 3 months for your application to be reviewed and approved.
2. If questions arise as you are completing a DRAFT of your NDI Application Form, feel free to call NDI staff at 301-458-4444 about any section of the form.
3. E-mail your **unsigned** NDI Application Form to ndi@cdc.gov. This initial draft submission does not need to be accompanied by a document showing that your study has been approved by an Institutional Review Board for the Protection of Human Subjects (IRB).
4. NDI staff will respond by e-mailing your assigned NDI number. Within about 1 week, NDI staff will let you know whether your draft application needs revisions before you submit your **final** application.
5. Express mail your final, signed NDI Application Form and a current IRB approval document to the National Center for Health Statistics (see address on website). E-mail the NDI staff at ndi@cdc.gov or call 301-458-4444 to confirm that we received your package or to ask questions at any time. Always include your assigned NDI number in your communication.
6. Your final application will be distributed to a 12-member panel for review and comment.
7. While your application is being reviewed, you can begin preparing your study subjects' records for submission on a CD. Carefully follow the specifications in Chapter 2 of the User's Guide. Note: We require that you password-protect your files using any self-decrypting software, such as PointSec, PGP, or WinZip. Call us if you need to make other arrangements for transmitting your data.
8. When your application is approved, an approval package will be sent via e-mail to the Principal Investigator or Project Director appearing on the application form. The package will include a blank NDI Transmittal Form(s) and

- a Worksheet for Calculating NDI Charges. (Contact NDI staff if you would like to be e-mailed the worksheet in Excel format.)
9. Send to NCHS, by overnight delivery, your CD containing a file(s) of study subjects' records. Include a separate NDI Transmittal Form for each file, a Worksheet for Calculating NDI Charges, and your check or purchase order. A check or purchase order must be received by NCHS before we will send you the NDI search results. Credit card payments that do not exceed \$1,500 can now be accepted—contact NDI staff to arrange for such payments. (Federal agencies must process a standard NDI interagency agreement in advance of their NDI searches. Checks or purchase orders are not acceptable from federal agencies, but credit card payments of \$1,500 or less can be accepted.) Once you have sent in your file(s), e-mail to NCHS your overnight-mail tracking number and the password to open your encrypted file(s) (we recommend you send it in separate e-mails).
 10. Within about 2 weeks after receiving your file(s), NDI staff will return, by overnight mail, a password-protected CD containing your NDI search results, your original CD, and an NDI Repeat Request Form for future searches for the same study. NCHS staff will e-mail to you the overnight-mail tracking number and the password to open your encrypted NDI files.
 11. Assess your results to identify the true matches using your own assessment criteria or the suggested NDI assessment criteria. (It is your responsibility to determine which, if any, of the possible NDI matches listed is actually the correct match.) You also have the option of purchasing death certificates on your own directly from state vital statistics offices—for all true matches, or just to adjudicate selected questionable matches.

If additional NDI searches are needed later for the same study or project, first mail to NCHS a signed NDI Repeat Request Form. (You will receive a new NDI Repeat Request Form each time you receive your NDI results, but you can also access a blank Repeat Request Form on the NDI website.) You should receive a letter or e-mail approving your repeat request within 2 weeks. You can then submit your new files for your next NDI search in the same manner as the first submission.

III: Early Release Pilot Program

[from: http://www.cdc.gov/nchs/data_access/ndi/ndi_early_release.htm, September 2014]

NDI Early Release Pilot Program

What is the NDI Early Release Program?

- Death records for a particular calendar year will be available for NDI Routine searches when approximately 90+% of the year's death records have been received and processed, but no later than 6 months after the end of the calendar year.
- Death records for a particular calendar year will be available for NDI Plus searches a couple months later.
- A website announcement will provide NDI users with a link to a table showing the estimated percentage of records available for each state as well as the total percentage for the nation. Based on the death records available, it will be

entirely up to the NDI user to decide whether to submit records of study subjects to be searched against the Early Release file or simply wait until NDI file is complete and closed for that calendar year. **NOTE: Early Release data is subject to additions and corrections.**

- Users who decide to have their records searched against an Early Release file must pay for the NDI search based on the number of subject records they submit. NOTE: ONCE THE FINAL FILE FOR THAT YEAR IS AVAILABLE THE USER WILL BE NOTIFIED THAT THEY HAVE **SIX MONTHS** TO SUBMIT THE SAME RECORDS FOR THEIR ONE FREE RERUN SEARCH (all parameters identical). For example: A user who gets an early release Routine NDI file search will only be able to get a free final Routine NDI search. A user who gets an early release NDI Plus search will get a free NDI Plus final search for the same file.

Why do we have an NDI Early Release Program?

Historically, before a particular calendar year of deaths can be made available for NDI searches, the National Center for Health Statistics must receive, process, and edit death records from ALL 50 state vital statistics offices plus New York City, Washington D.C., Puerto Rico and the U.S. Virgin Islands. This is a very time consuming process that often results in delays in the creation of the final NDI file for a particular year, typically 15 or more months after the end of that calendar year. Over the years NDI users and staff have expressed their frustrations with such delays. Consequently, the NDI is piloting a new effort to make preliminary NDI files available for earlier searches. This effort will be referred to as the EARLY RELEASE PROGRAM.

Procedures for Early Release matching

- All new users must go through the NDI application process. There is no exception for early release matching services. All repeat users must submit an NDI Repeat Request Form, just as they currently do.
- Upon receiving your letter of approval and the attached transmittal forms, you may submit your study subjects' records for whatever years of death are then available for NDI searches. There will be TWO different transmittal forms available. One for matching to an early release year(s) (it is conceivable there might be more than one available simultaneously), and the other for our normal matching process for complete years. You should use only the latter form UNLESS you decide you want to do an early release search. **EARLY RELEASE TRANSMITTAL forms are the only forms which will be accepted for early release searches. If multiple years are available for early release searches, you will need to submit a SEPARATE Early Release Transmittal Form and worksheet for each year you want.**
- Although you will need to complete a separate fee worksheet for the Early Release search, you may make only one payment for all the NDI searches you submit.

IV. NDI Early Release - Completion Status

[from http://www.cdc.gov/nchs/data_access/ndi/completion_status.htm, September 2014]

Jurisdiction/State	Percentage of Demographic Data for 2013
2013 NATIONAL PERCENTAGE	100
Alabama	100
Alaska	100
Arizona	100
Arkansas	100
California	100
Colorado	100
Connecticut	100
Delaware	100
District of Columbia	100
Florida	100
Georgia	99
Hawaii	100
Idaho	100
Illinois	100
Indiana	100
Iowa	100
Kansas	100
Kentucky	100
Louisiana	100
Maine	100
Maryland	100
Massachusetts	100
Michigan	100
Minnesota	100
Mississippi	100
Missouri	100
Montana	100
Nebraska	100
Nevada	100

Jurisdiction/State	Percentage of Demographic Data for 2013
New Hampshire	100
New Jersey	100
New Mexico	100
New York	100
New York City	100
North Carolina	100
North Dakota	100
Ohio	100
Oklahoma	100
Oregon	100
Pennsylvania	99
Rhode Island	100
South Carolina	100
South Dakota	100
Tennessee	100
Texas	100
Utah	100
Vermont	100
Virginia	100
Washington	100
West Virginia	100
Wisconsin	100
Wyoming	100
Puerto Rico	100
Virgin Islands	0

ATTACHMENT B—DEVELOPMENTS ON THE SSA DMF

I. SECTION 205R OF THE SOCIAL SECURITY ACT

Use of Death Certificates to Correct Program Information (paragraphs 1-7 of 9)

- (r)(1) The Commissioner of Social Security shall undertake to establish a program under which—
- (A) States (or political subdivisions thereof) voluntarily contract with the Commissioner of Social Security to furnish the Commissioner of Social Security periodically with information (in a form established by the Commissioner of Social Security in consultation with the States) concerning individuals with respect to whom death certificates (or equivalent documents maintained by the States or subdivisions) have been officially filed with them; and
 - (B) there will be (i) a comparison of such information on such individuals with information on such individuals in the records being used in the administration of this Act, (ii) validation of the results of such comparisons, and (iii) corrections in such records to accurately reflect the status of such individuals.
- (2) Each State (or political subdivision thereof) which furnishes the Commissioner of Social Security with information on records of deaths in the State or subdivision under this subsection may be paid by the Commissioner of Social Security from amounts available for administration of this Act the reasonable costs (established by the Commissioner of Social Security in consultations with the States) for transcribing and transmitting such information to the Commissioner of Social Security.
- (3) In the case of individuals with respect to whom federally funded benefits are provided by (or through) a Federal or State agency other than under this Act, the Commissioner of Social Security shall to the extent feasible provide such information through a cooperative arrangement with such agency, for ensuring proper payment of those benefits with respect to such individuals if—
- (A) under such arrangement the agency provides reimbursement to the Commissioner of Social Security for the reasonable cost of carrying out such arrangement, and
 - (B) such arrangement does not conflict with the duties of the Commissioner of Social Security under paragraph (1).
- (4) The Commissioner of Social Security may enter into similar agreements with States to provide information for their use in programs wholly funded by the States if the requirements of subparagraphs (A) and (B) of paragraph (3) are met.
- (5) The Commissioner of Social Security may use or provide for the use of such records as may be corrected under this section, subject to such safeguards as the Commissioner of Social Security determines are necessary or appropriate to protect the information from unauthorized use or disclosure, for statistical and research activities conducted by Federal and State agencies.
- (6) Information furnished to the Commissioner of Social Security under this subsection may not be used for any purpose other than the purpose described in this subsection and is exempt from disclosure under section 552 of title 5, United States Code, and from the requirements of section 552a of such title.
- (7) The Commissioner of Social Security shall include information on the status of the program established under this section and impediments to the effective implementation of the program in the 1984 report required under section 704 of this Act.

II. SECTION 203 OF THE BIPARTISAN BUDGET ACT OF 2013— RESTRICTION ON ACCESS TO THE DEATH MASTER FILE

(a) IN GENERAL.—The Secretary of Commerce shall not disclose to any person information contained on the Death Master File with respect to any deceased individual at any time during the 3-calendar-year period beginning on the date of the individual's death, unless such person is certified under the program established under subsection (b).

(b) CERTIFICATION PROGRAM.—

(1) IN GENERAL.—The Secretary of Commerce shall establish a program—

(A) to certify persons who are eligible to access the information described in subsection (a) contained on the Death Master File, and (B) to perform periodic and unscheduled audits of certified persons to determine the compliance by such certified persons with the requirements of the program.

(2) CERTIFICATION.—A person shall not be certified under the program established under paragraph

(1) unless such person certifies that access to the information described in subsection (a) is appropriate because such person—

(A) has—

(i) a legitimate fraud prevention interest, or

(ii) a legitimate business purpose pursuant to a law, governmental rule, regulation, or fiduciary duty, and (B) has systems, facilities, and procedures in place to safeguard such information, and experience in maintaining the confidentiality, security, and appropriate use of such information, pursuant to requirements similar to the requirements of section 6103(p)(4) of the Internal Revenue Code of 1986, and

(C) agrees to satisfy the requirements of such section 6103(p)(4) as if such section applied to such person.

(3) FEES.—

(A) IN GENERAL.—The Secretary of Commerce shall establish under section 9701 of title 31, United States Code, a program for the charge of fees sufficient to cover (but not to exceed) all costs associated with evaluating applications for certification and auditing, inspecting, and monitoring certified persons under the program. Any fees so collected shall be deposited and credited as offsetting collections to the accounts from which such costs are paid.

(B) REPORT.—The Secretary of Commerce shall report on an annual basis to the Committee on Finance of the Senate and the Committee on Ways and Means of the House of Representatives on the total fees collected during the preceding year and the cost of administering the certification program under this subsection for such year.

(c) IMPOSITION OF PENALTY.—

(1) IN GENERAL.—Any person who is certified under the program established under subsection (b), who receives information described in subsection (a), and who during the period of time described in subsection (a)—

(A) discloses such information to any person other than a person who meets the requirements of subparagraphs

(A), (B), and (C) of subsection (b)(2),

(B) discloses such information to any person who uses the information for any purpose not listed under subsection

(b)(2)(A) or who further discloses the information to a person who does not meet such requirements, or (C) uses any such information for any purpose not listed under subsection (b)(2)(A), and any person to whom such information is disclosed who further discloses or uses such information as described in the preceding subparagraphs, shall pay a penalty of \$1,000 for each such disclosure or use.

(2) LIMITATION ON PENALTY.—

(A) IN GENERAL.—The total amount of the penalty imposed under this subsection on any person for any calendar year shall not exceed \$250,000.

(B) EXCEPTION FOR WILLFUL VIOLATIONS.—Subparagraph (A) shall not apply in the case of violations under paragraph (1) that the Secretary of Commerce determines to be willful or intentional violations.

(d) DEATH MASTER FILE.—For purposes of this section, the term “Death Master File” means information on the name, social security account number, date of birth, and date of death of deceased individuals maintained by the Commissioner of Social Security, other than information that was provided to such Commissioner under section 205(r) of the Social Security Act (42 U.S.C. 405(r)).

(e) EXEMPTION FROM FREEDOM OF INFORMATION ACT REQUIREMENT WITH RESPECT TO CERTAIN RECORDS OF DECEASED INDIVIDUALS.—

(1) IN GENERAL.—No Federal agency shall be compelled to disclose the information described in subsection (a) to any person who is not certified under the program established under subsection (b).

(2) TREATMENT OF INFORMATION.—For purposes of section 552 of title 5, United States Code, this section shall be considered a statute described in subsection (b)(3) of such section 552.

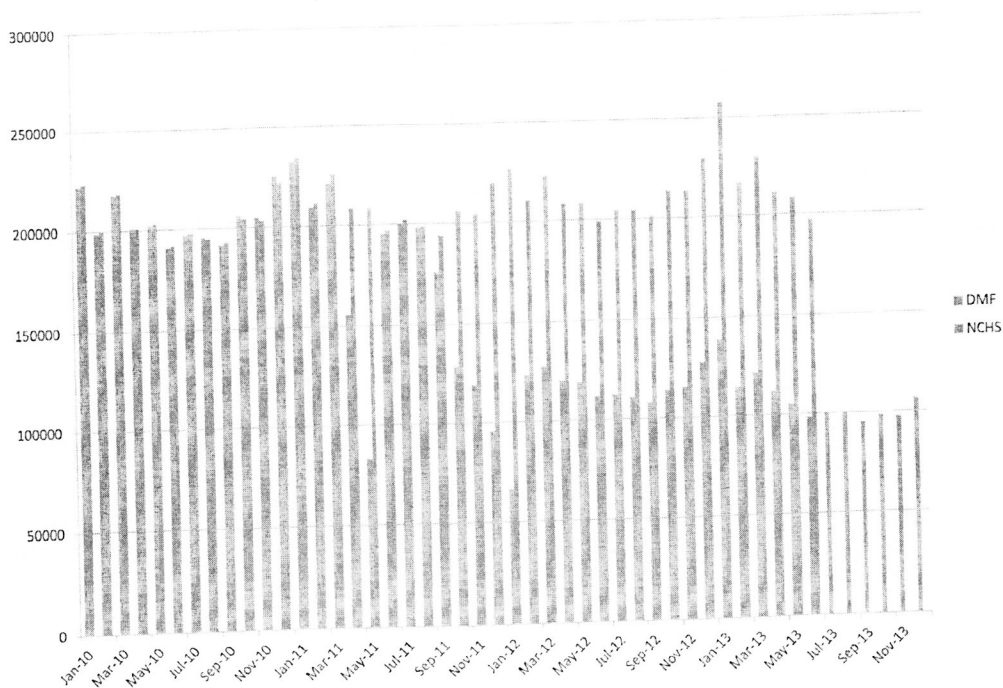
(f) EFFECTIVE DATE.—

(1) IN GENERAL.—Except as provided in paragraph (2), this section shall take effect on the date that is 90 days after the date of the enactment of this Act.

(2) FOIA EXEMPTION.—Subsection (e) shall take effect on the date of the enactment of this Act.

III. COVERAGE OF DEATH RECORDS IN THE SSA DMF AND NCHS NDI, BY MONTH, JANUARY 2010 – NOVEMBER 2013 [from David Weir, University of Michigan]

Monthly US Deaths, DMF and NCHS



ATTACHMENT C—CMS PROVISION OF DEATH RECORDS

I. Relevant Files from the Centers for Medicare and Medicaid Services (CMS)

[from: <http://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/IdentifiableDataFiles/NameandAddressFileandVitalStatusFile.html>, September 2014]

Name and Address File and Vital Status File

The Names and Addresses File and the Vital Status File are subsets of the data elements in the Enrollment Database (EDB). The particular information in each file is tailored to the request and is used to support health care researchers. Both files are created as needed by specific request from the EDB using one of the following two methods:

- a. A numeric search using a list of Health Insurance Claim (HIC) numbers or Social Security Numbers (SSNs)
- b. A demographic sampling

Each file contains fixed-length records, usually arranged sequentially. Fields in the record are in display format. There are no binary or Comp-3 fields.

The data contain personal identifiers and other material covered by the Privacy Act, and therefore, require authorization for use.

Beneficiary data are demographic. The Names and Addresses File contains name and address, state, sex, race, date of birth, date of death, etc. There is no last date of service or other non-demographic data in the files. The Centers for Medicare & Medicaid Services (CMS) will only agree to release the name and address file for the purpose of contacting beneficiaries for research. Additionally, CMS will not release the Name & Address File directly to the researcher. In other words, researchers would define their sample, but will no longer be able to contact beneficiaries prior to the beneficiary giving consent to participate. A CMS hired contractor will mail out descriptive information to the beneficiary about the study. In comparison, the Vital Status File contains the same demographic data with the exception of the beneficiary name and address. The Vital Status File is released directly to the researcher.

All Requests for identifiable data must be developed and reviewed with the assistance of the Research Data Assistance Center (ResDAC), who may be contacted at www.resdac.org or at resdac@umn.edu.

Once your data request has been reviewed by ResDAC, the final request can be sent to CMS as directed by ResDAC.

II. Correspondence between C. Citro and CMS re Above Files

C. Citro recently queried the CMS Research Data Assistance Center (ResDAC) for more information about the above files as follows:

Dear CMS Research Data Assistance Center—I'm hoping that you can give me some information about the following. For a project CNSTAT is doing for the National Institute on Aging, I'm interested in finding out more about the CMS Name and Address and Vital Status File. The issue has to do with access

to death records for NIA-funded researchers who are running longitudinal studies of the elderly--they need the information to determine whether one of their sample cases may have died since the previous interview and also to formulate research studies for the sample cases' families. Previously, many researchers used SSA death record data provided through the National Technical Information Service, but legal changes have made that source no longer viable. I understand from David Weir, who is the PI for the Health and Retirement Study, that his study receives Medicare records and the vital status file from CMS, which he links to the HRS survey data in a secure environment. Might you be able to tell me more about your death record file—where you get your information, whether the file covers deaths at all ages or just for people 65 and over, how frequently you update your file, whether you charge for access, etc.? Any help you can give me in understanding your set-up for access to this file would be much appreciated.

In reply, ResDAC sent Citro the following information:

The CMS Vital Status file is considered a research identifiable (RIF) data file <<http://www.resdac.org/cms-data/request/research-identifiable-files>> and would require a CMS Data Use Agreement (DUA) to be in place for each specific study that is using the information. If researchers only require death information, the name and address would not be released. The name and address are typically only released for the purpose of contacting beneficiaries for surveys, study participation, etc.

The date of death information found within the CMS Vitals Statistics file is sourced from data found in CMS's Chronic Conditions Warehouse (CCW). The CCW date of death information is in turn sourced from CMS's Medicare Enrollment Database (EDB).

Death information found within the Medicare EDB is an amalgamation of death information reported to CMS from a number of sources. The main sources CMS uses to develop its death information are:

- * Medicare claims data from the Medicare Common Working File (CWF)
- * Online date of death edits submitted by family members
- * Benefit information used to administer the Medicare program collected from the Railroad Retirement Board (RRB) and SSA

The vital status is only for Medicare beneficiaries; it would not include non-Medicare beneficiaries. When the file is pulled for researchers, the information is typically current as of a few months prior. As I mentioned above, researchers would need to have a DUA in place for the file and they'd only be able to request the file for the cohort of beneficiaries applicable to their study rather than the entire file. The cost would depend on the size of the cohort, but the vital status starts at \$1,000 for a cohort of up to 1 million beneficiaries.

**ATTACHMENT D—
NAPHSIS'S ELECTRONIC INITIATIVES RELEVANT TO DEATH RECORDS**

I. NAPHSIS Testimony to Congress, February 2, 2012

Statement for the Record
submitted by
Patricia W. Potrzebowski, Ph.D.
on behalf of
National Association for Public Health Statistics and
Information Systems
for
U.S. House of Representatives
Committee on Ways and Means
Subcommittee on Social Security
February 2, 2012

Mr. Chairman and Members of the Subcommittee—

The National Association for Public Health Statistics and Information Systems (NAPHSIS) welcomes the opportunity to provide the House Committee on Ways and Means, Subcommittee on Social Security this written statement for the record on vital records and specifically, the reporting and electronic verification of deaths. Established in 1933, NAPHSIS is a non-profit membership organization representing the 57 vital records jurisdictions that collect, process, and issue vital records in the United States, including the 50 states, New York City, the District of Columbia and the five territories. NAPHSIS coordinates and enhances the activities of the vital records jurisdictions by developing standards, promoting consistent policies, working with federal partners, and providing technical assistance.

Vital Records Serve Important Civil Registration Function

Vital records are permanent legal records of life events, including live births, deaths, fetal deaths, marriages, and divorces. Their history in the United States dates back to the first American settlers in the mid-1600s, and in England as early as 1538.¹⁰ More than 8 million vital events were recorded in the United State in 2009.¹¹

Many organizations and millions of Americans use these records—or certified copies of them—for myriad legal, health, personal, and other purposes.

- Birth certificates provide proof of birth, age, parentage, birthplace, and citizenship, and are used extensively for employment purposes, school entrance, voter registration, and obtaining federal and state benefits (e.g., Social Security). Birth certificates are the cornerstone for proving identity, and as breeder documents are thus used to obtain other official identification documents, such as driver licenses, Social Security cards, and passports.

¹⁰ *U.S. Vital Statistics System: Major Activities and Developments, 1950 – 1995*. Centers for Disease Control and Prevention, National Center for Health Statistics. Feb 1997. Available online at: <http://www.cdc.gov/nchs/data/misc/usvss.pdf>.

¹¹ National Center for Health Statistics, Centers for Disease Control and Prevention. Available online at <http://www.cdc.gov/nchs/data/databriefs/db16.htm> and http://www.cdc.gov/nchs/data/nvsr/nvsr58/nvsr58_25.pdf.

- Death certificates provide proof of date of death, date and place of internment, cause and manner of death, and are used to obtain insurance benefits and cease direct benefit payments, transfer property, and generally settle estates.

Data providers—for example, hospitals for birth information and funeral homes, physicians, and coroners for death information—submit birth and death data to the vital records jurisdictions so that the vital event can be reviewed, edited, processed and officially registered. The jurisdictions are then responsible for maintaining registries of such vital events and for issuing certified copies of birth and death records.

The federal government does not maintain a national database that contains all of this information. Consistent with the constitutional framework set forth by our founding fathers in 1785, states were assigned certain powers. The 57 vital records jurisdictions, not the federal government, have legal authority for the registration of these records, which are thus governed under state laws. The laws governing what information may be shared, with whom, and under what circumstances varies by jurisdiction. In most jurisdictions, access to death records is restricted to family members for personal or property rights, to government agencies in pursuit of their official duties, or for research purposes. In other jurisdictions, release of death record information may be subject to less restrictive limitations; and in a few states identifiable information from death certificates is publicly available.

In an example of effective federalism, the vital records jurisdictions provide the federal government with data collected through birth and death records to compile national health statistics, facilitate secure Social Security number (SSN) issuance to newborns through the Enumeration at Birth (EAB) Program, and report individuals' deaths.^{12, 13} For example, the National Center for Health Statistics obtains de-identified vital events data from the jurisdictions to compile national data on births, deaths, marriages, divorces, and fetal deaths. These data are used to monitor leading causes of death and our nation's overall health status, develop programs to improve public health, and evaluate the effectiveness of those interventions. In addition, the jurisdictions provide SSA with fact of death information—including the decedent's name, date of birth, date of death, and SSN as filed with the jurisdiction—for use in the administration of the programs established under the Social Security Act to reduce erroneous payments to deceased persons receiving Social Security benefits.

Electronic Systems Enhance Death Reporting Accuracy, Timeliness, and Security

A death certificate contains both demographic (personal) information and medical (cause of death) information about the decedent. Over the last century in the United States, death certificate completion has mostly been the responsibility of funeral directors, with physicians, medical examiners, and coroners providing cause and manner of death information. Once the demographic data and medical data are complete, the death certificate is then filed with the vital records office. In some states, the death certificate is filed at the local vital records office, and then sent to the state office; in other states the death certificate is filed directly with the state office. The data are then reported to state and federal entities for public health and administrative purposes.

¹² The National Center for Health Statistics, Centers for Disease Control and Prevention, Department of Health and Human Services purchases data from the vital records jurisdictions through the Vital Statistics Cooperative Program to produce national vital statistics and for research purposes as part of the National Death Index.

¹³ The EAB program allows parents to complete applications for SSNs for their newborns as part of the hospital birth registration process. About 96 percent of SSNs for infants are assigned through the EAB process.

Manual certificate preparation, including the personal delivery of records to physicians for signature, extensive and costly travel by funeral director staff to file certificates, and labor-intensive processing of paper records locally and at the state vital records offices, all contribute to slowing registration and delaying the availability of death data.

Furthermore, even though each state has laws requiring the registration of death records within a specific time period, a significant number of certificates are not appropriately filed, may contain incorrect or inconsistent entries, or are not finalized until many weeks after the death occurred. In addition, incomplete death certificates and coroner cases may take weeks or even months to resolve. These late-filed and/or partially completed death certificates are not generally acceptable for use by family members, nor do they meet federal administrative needs or satisfy the information demands of local, state and federal agencies.

In January 1997, the report, *Toward an Electronic Death Registration System in the United States: Report of the Steering Committee to Reengineer the Death Registration Process* was prepared by a task force of representatives from federal agencies—the National Center for Health Statistics and SSA—as well as NAPHSIS and other professional organizations representing funeral directors, physicians, medical examiners, coroners, hospitals, and medical records professionals. The Committee examined in detail the feasibility of developing electronic death registration in the United States. The conclusion of the report was that the introduction of automated registration processes in the states is a viable means to resolve several historical and continuing problems in the process of death registration.

The advent of technology has facilitated the automation of death registration and reporting, which is the key to addressing these long-standing issues related to accuracy, security, and timeliness of data. To date, 37 vital records jurisdictions have implemented electronic death registration systems (EDRS) to better meet the public health and administrative death information needs (see Appendix 1). For states using an EDRS, death reporting is:

- More Accurate and Complete. An EDRS ensures that all required fields are completed before the death certificate is filed using built-in, real-time edits and crosschecks on the data entered. For example, it can ensure that the individual recording the data does not inadvertently indicate that a two-year old decedent has a college education. For purposes of SSA, an EDRS incorporates a real-time check of the decedent's SSN against the SSA data files to ensure accuracy of the SSN recorded before the death certificate is registered and filed.¹⁴
- More Timely. An EDRS allows different death data providers, e.g. the funeral director and physician, to complete the death record concurrently from their computers. It eliminates the need for a paper death certificate to be hand-delivered by funeral home staff to the physician's office for completion. Automatic reminders and workflow prompts are built into an EDRS so a physician is notified via e-mail when a death certificate is awaiting completion. Once the electronic death record is complete, state vital records offices may submit fact-of-death records to SSA daily (Monday-Friday).
- More Secure. An EDRS requires a distinct username and password for each death data provider to access the death records. An EDRS also has built-in audit trails to monitor the users' activity.

While vital records jurisdictions have made great strides in implementing EDRS, there is still much to be done. In some of the 37 vital records jurisdictions that have implemented EDRS, not all physicians or funeral directors submit death records electronically. Implementation of the EDRS in the vital records

¹⁴Among the 37 vital records jurisdictions with EDRS, three have not integrated the capability to verify SSN into their EDRS: Illinois, Maine, and Wyoming.

office is just one piece of the puzzle. To be effective, all data providers—funeral homes, hospitals, physician offices, nursing homes, hospices, coroners and medical examiners —also must use the system. These users must then adjust their workflow processes and make themselves available for training. From start to finish, the full rollout of an EDRS may take years and a significant financial commitment on the part of the state and local health departments and the death data providers themselves. The lack of adequate resources—both financial and human capital—are the biggest barriers to more widespread EDRS adoption. This is particularly true for death data providers who do not report a significant number of deaths each year, and therefore do not see the value of the required investments.

Between 2001 and 2006, SSA provided funding to many vital records jurisdictions to help support their EDRS implementation efforts. Based on a late-2008 survey of the vital records jurisdiction, NAPHSIS estimates that \$20 million is needed to complete EDRS implementation in all 57 vital records jurisdictions and to increase use of EDRS among death data providers. Some additional funding may be required on an annual basis to facilitate death data provider training.

Preventing Fraud, Identity Theft through Electronic Verification of Vital Events (EVVE)

Because vital records are essential legal documents linked to identity, and because criminals need new identities, vital records are sought out and used to commit fraud, identity theft, and even terrorist activities.^{15, 16, 17} It is therefore essential that birth and death records be protected, and that federal and state agencies have the ability to verify the source data contained therein. In addition, the ability to quickly catch and stop the fraudulent use of Social Security and other public benefits would reduce wasteful spending, and restore public trust in government.

Recognizing the need to verify benefit eligibility in a timely and secure fashion, SSA awarded NAPHSIS a grant in 2001 to develop and implement the Electronic Verification of Vital Events (EVVE) system. EVVE is an online system that verifies birth and death certificate information. It provides authorized users at participating agencies with a single interface to quickly, reliably, and securely validate birth and death information at any vital records jurisdiction in the country, circumventing the need for a national database of such information. In so doing, *no additional personal information is divulged* to the person verifying information—EVVE simply relays a message that there was, or was not a match, with the birth and death records maintained by the state, city, or territory. In addition, EVVE has the capability to flag individuals who are deceased, eliminating a key loophole whereby thieves use a valid birth certificate of a deceased individual to create a new identity.

Today, SSA uses EVVE to verify proof of age and place of birth as a program policy requirement before issuing Social Security benefits. EVVE is used by other federal and state agencies to verify or certify identification and authenticity of birth certificates:

- Passport Fraud Prevention Managers began using the EVVE system in March 2009 for birth certificate verifications. In their first six weeks of use, there were two instances where the Fraud Prevention Managers used the EVVE system to electronically verify the birth certificates, and EVVE returned a ‘no match.’ Upon further follow up with the vital records offices that ‘issued’ the birth

¹⁵The 9/11 Commission Report, Final Report of the National Commission on Terrorist Attacks upon the United States, July 2004, p. 390.

¹⁶Department of Health and Human Services, Office of Inspector General, *Birth Certificate Fraud*, Sept. 2009 (OEI-07-99-00570).

¹⁷Government Accountability Office, *Department of State: Undercover Tests Reveal Significant Vulnerabilities in State's Passport Issuance Process*, Mar. 2009 (GAO-09-447) and *State Department: Undercover Tests Show Passport Issuance Process Remains Vulnerable to Fraud*, July 2010 (GAO-10-922T)

certificates it was determined that indeed the birth certificates presented with those passport applications were fraudulent. Based on these and other successes, NAPHSIS is working with the Department of State to integrate EVVE into the standard passport adjudication process.

- The Office of Personnel Management (OPM) is responsible for processing federal employment applications and at times security clearances. To reduce the administrative burden of applicants submitting certified birth certificates, OPM uses EVVE to electronically certify an individual's citizenship in lieu of obtaining a paper copy of the birth certificate. OPM conducted a pilot in parallel with their manual voucher process of requesting certification information from the vital records jurisdictions. The match rate for those same queries was 84 percent in both manual and EVVE mode. In addition, the response time was just 10 seconds using EVVE compared to 42 days using the manual process.
- The Deficit Reduction Act of 2005 requires the verification of citizenship and identity for enrollment in Medicaid through a birth certificate or other official document. The South Dakota Medicaid Office was the first to use EVVE for this purpose in 2007, followed by Medicaid Offices in Mississippi, Minnesota, and Washington, as well as the Mississippi Health District Offices. Since then, several other states have inquired about using EVVE for determining Medicaid eligibility.
- In response to the 9/11 Commission's recommendations for secure identification documents, Congress enacted the REAL ID Act in May 2005, requiring that driver's license applicants present their birth certificates to the Department of Motor Vehicles (DMV) to validate U.S. citizenship and date of birth, and that DMVs verify the authenticity of those birth certificates using EVVE. Three state DMVs—North Dakota, South Dakota, and Iowa—used EVVE in this capacity as part of a federally-funding pilot program through the Department of Homeland Security.

These users are enthusiastic about the EVVE system, citing its ability to:

- Provide protection against the potential use of birth certificates for fraudulent activities.
- Improve customer service by facilitating rapid access to accurate and verifiable vital record data in real-time.
- Safeguard the confidentiality of birth and death data.
- Offer a secure mechanism for communication between agencies and vital records offices via the Internet.
- Easily integrate with current legacy systems that the federal or state agencies may already be using, and for serving as a user-friendly interface for agencies that seek a stand-alone query system.

In April 2011, the Office of the National Coordinator for Health Information Technology, HIT Policy Committee Enrollment Workgroup Committee recommended the use of EVVE as a potential tool to facilitate enrollment in federal and state health and human services programs, such as offerings by new health insurance exchanges established through the Affordable Care Act.

As of February 1, 2012, EVVE is currently installed in 36 vital records jurisdictions (see Appendix 1). NAPHSIS is working to install EVVE in the remaining 21 jurisdictions, with 11 jurisdictions currently in progress. NAPHSIS has also procured a data analysis and quality control tool that all jurisdictions can

utilize to analyze their EVVE database for anomalies, inconsistencies, accuracy, and completeness. This tool and the analysis of EVVE data has been completed in 30 jurisdictions, as of February 1, 2012.¹⁸

Despite EVVE's security, speed, and ease of use, the system is only as good as the underlying data infrastructure upon which it relies. Digitizing paper-based birth and death records, then cleaning and linking those records, will provide for secure, reliable, real-time identity verification using EVVE. For example, there are cases where an individual has assumed a false identity by obtaining a birth certificate of a person who has died. Therefore, it is important that all jurisdictions' death and birth records be linked to flag individuals who are deceased and identify fraudulent birth documentation.

The vital records jurisdictions' efforts to digitize, clean, and link vital records have been hindered by state budget shortfalls. In short, the jurisdictions need the federal government's help to complete building a secure data infrastructure. Specifically, resources are needed to help vital records jurisdictions digitize their birth records back to 1945, to clean these data to support electronic queries, and link birth and death records.

NAPHSIS appreciates the opportunity to submit this statement for the record and looks forward to working with the Subcommittee.

Appendix 1: Status of Electronic Death Registration System (EDRS) and Electronic Verification of Vital Events (EVVE) System, by Vital Records Jurisdiction*

Jurisdiction	EDRS**	EVVE***
Alabama	✓	✓
Alaska		
American Samoa		
Arizona	✓	✓
Arkansas	✓	✓
California	✓	✓
Colorado		✓
Connecticut	✓	✓
Delaware	✓	✓
District of Columbia	✓	✓
Florida	✓	
Georgia	✓	✓
Guam		✓
Hawaii	✓	✓
Idaho	✓	
Illinois	✓	
Indiana	✓	✓
Iowa		✓
Kansas	✓	✓
Kentucky	✓	✓
Louisiana		✓
Maine	✓	

¹⁸ Potential EVVE users interested in obtaining additional information about applying to become an approved EVVE user for either verification or certification of vital events should contact Rose Trasatti Heim via email at rtrasatti@naphsis.org.

Maryland		✓
Massachusetts		
Michigan	✓	✓
Minnesota	✓	✓
Mississippi		✓
Missouri	✓	✓
Montana	✓	✓
Nebraska	✓	✓
Nevada	✓	
New Hampshire	✓	
New Jersey	✓	✓
New Mexico	✓	
New York City	✓	✓
New York State		
North Carolina		
North Dakota	✓	✓

Jurisdiction	EDRS	EVVE
Northern Marianas		✓
Ohio	✓	✓
Oklahoma	✓	✓
Oregon	✓	✓
Pennsylvania		✓
Puerto Rico		
Rhode Island		✓
South Carolina	✓	
South Dakota	✓	✓
Tennessee		
Texas	✓	
Utah	✓	✓
Vermont	✓	✓
Virgin Islands		
Virginia		
Washington	✓	
West Virginia		✓
Wisconsin		
Wyoming	✓	
Total	37	36

*Implementation status as of February 1, 2012.

**This column indicates in which jurisdictions the vital records office has adopted an EDRS. It does not indicate total penetrance of EDRS among death data providers in that jurisdiction. The implementation of EDRS is in progress in three vital records jurisdictions, including Louisiana, Mississippi, and Wisconsin. Ten jurisdictions are in the planning stages, including Alaska, Colorado, Iowa, Maryland, Massachusetts, New York State, North Carolina, Pennsylvania, Tennessee, and Virginia.

*** As of February 1, 2012, the implementation of EVVE is also in progress in 11 vital records jurisdictions, including Alaska, Florida, Massachusetts, Nevada, New Mexico, North Carolina, South Carolina, Tennessee, U.S. Virgin Islands, Virginia, and Wyoming.

II. More Information About EDRS

[from: <http://www.naphsis.org/Pages/ElectronicDeathRegistrationSystemsProject.aspx>,
September 2014]

The committee examined in detail the feasibility of developing electronic death registration in the United States. The conclusion of the report was that the introduction of automated registration processes in the States is a viable means to resolve several historical and continuing problems in the process of death registration.

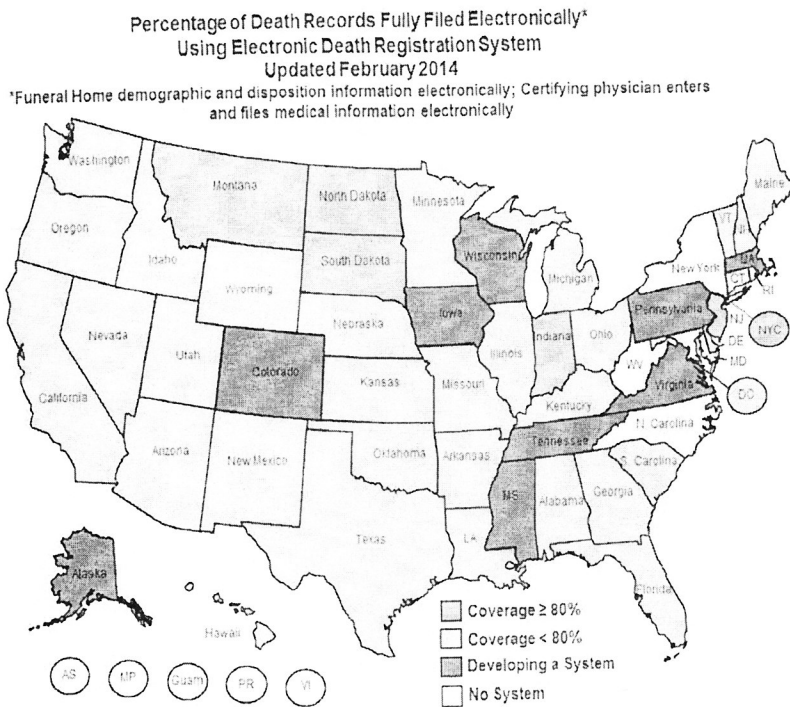
Death certificates are used in the United States for administrative and public health purposes. For nearly a century the States have managed centralized vital records agencies to collect, process, and archive death certificates. Death records are universally recognized as the primary source of death information, but registration processes remain labor intensive, employ disparate and limited automated procedures, and require several professionals at different locations to complete each of the more than 2.3 million death certificates registered each year.

Since the origination of civil vital records registration in the United States, death certificate completion has mostly remained the provenance of funeral directors, with physicians and frequently medical examiners and coroners providing cause and manner of death information. Manual certificate preparation, including the personal delivery of records to physicians for signature, extensive and costly travel by funeral director staff to file certificates, and labor-intensive processing of paper records locally and at state Vital Records offices, all contribute to slowing registration and delay the availability of death data.

Furthermore, even though each state has laws requiring the registration of death records within a specific time period, a significant number of certificates are not appropriately filed, may contain incorrect or inconsistent entries, or are not finalized until many weeks after the death occurred. In addition, incomplete death certificates and coroner cases may take weeks or even months to resolve. These late-filed, partially completed or inaccurate death certificates are not acceptable for use by family members, nor do they meet federal administrative needs or satisfy the information demands of local, state and federal agencies. In fact, they can adversely affect mortality statistics which are routinely produced by state and federal agencies. Automating death registration processes is the key to addressing these long-standing issues.

The States and federal agencies understand the shortcomings of death registration methods currently practiced in the United States. Now that recent advances in computer and network access technology allow for the practical and efficient development and implementation of automated systems to register death information, several registration areas have independently pioneered electronic death registration methods. These different approaches will serve as the basis for developing standardized EDR attributes, methods, and processes in order that the

States may successfully implement electronic death registration to satisfy administrative and statistical death information needs.



* As of September 2014, Georgia, Iowa, Louisiana, Minnesota, Texas, Utah, and Vermont are above 80 percent coverage; Arizona and California are also above 80 percent if fax attestation counts as completely electronic.

III. Description of STEVE

[from: <http://www.naphsis.org/Pages/AnOverviewoftheSTEVESystem.aspx>, September 2014]

The State and Territorial Exchange of Vital Events (STEVE) System is an innovative messaging application developed by NAPHISIS for the electronic exchange of vital event data between jurisdictions. It provides automated support for the Interjurisdictional Exchange of Vital Records (IJE). STEVE replaces the current, less secure practice of exchanging paper copies, line lists and printed computer abstracts which most states use today for record exchange. STEVE replaces the Secure Data Network (SDN) as the conduit for state reporting of statistical data to the National Center for Health Statistics (NCHS). STEVE is currently installed in 45 of the 57 vital records jurisdictions, with plans to install the remaining 12 jurisdictions in early 2014. Participation in STEVE is open to all U.S. vital records jurisdictions, Canadian provinces and to the National Center for Health Statistics (NCHS). Additional trading partners may join the community in the future, as approved by the IJE Committee.

**ATTACHMENT E—
EXAMPLES OF RESEARCH NEEDS FOR DEATH RECORDS
AND OBSERVATIONS ON EXISTING SOURCES**
[submissions lightly edited by C. Citro; identified by organization]

National Cancer Institute (NCI)

- Need for death information, including cause of death, is essential to follow-up patients in clinical trials, study participants in observational studies and prevention trials, and follow persons with cancer from cancer registries.
- Both our large extramural portfolio of grantees and our intramural scientists need these resources.
- We need death information for many purposes: identification of adverse events and deaths in trials, surveillance of cancer outcomes in the population and etiologic studies in human populations, and, especially, ways to monitor people in clinical trials after trial completion.
- We have studies with very large numbers of study participants and our cancer registries, plus those supported by CDC, cover all cancer patients in the U.S. who all need to be followed for death outcomes.
- The current NDI system is inadequate due to lack of timeliness, although data from NDI are of high quality. Also, application processes and general processes for obtaining these data from NDI are costly and inconvenient. Lack of timeliness is a big problem with respect to adverse events in trials, which need to be detected immediately.
- Improvements needed include improved timeliness and efficient and inexpensive processes to obtain death data. It would be good to allow real time linkage with NDI instead of discrete annual applications and linkages, patterning on some of the Genomic Data Sharing best practices that allow for automation of processes, vetting of researchers, and various patient protections.

National Cancer Institute and former extramural health services research

I would emphasize the need to improve the cause of death information. This is a tough thing to do, but I hope they are constantly thinking about ways to improve this. Regarding timeliness, this is the major problem from an extramural perspective. Here is what they say on their site:

1. Download the National Death Index (NDI) Application Form. Allow approximately 2 to 3 months for your application to be reviewed and approved.

The application is 22 pages long. It is not horribly complicated, but it does have a fair amount of jargon. The request can be submitted via email with signatures coming later, which is good. I found the supplemental confidentiality agreement instructions confusing, and it looks like they require signatures from everyone participating in the study, not just those with data access. That seems unnecessary and adds to the difficulty and time involved on the investigator side. I didn't read it carefully, but it looked like confidentiality and data disposition were dealt with in two different places, undoubtedly creating confusion.

My suggestion is to go to an Electronic Research Administration (eRA) Commons-like system (of the NIH), whereby people can enter all of this information on line and then give others access to it. There could be a submission for initial review option to replace the email. The PI would be able to grant access to the information to the people who need to sign it, so it would be available for their review. The PI

would gather all those signatures and load a final pdf, then hit submit final. I think this would ease the burden on applicants some, assuming the system worked properly.

Another thing that would shorten the application would be to exempt federally funded projects from providing extensive information about their project. An abstract and Notice of Grant Award (NOGA) from NIH would give NDI a description of the study and document peer review and IRB approval (grants do not go out without it!).

Taking 2 to 3 months to review and approve an application is a problem. Do they really need a 12-member panel to review and comment on all these (particularly if peer review has occurred)? Maybe when it first became available and people were not used to using it?

The web page does not comment on how long it takes to get data back. The last time I did this, a few years ago, it was 8 or 9 months from beginning the application process to getting the data. At least half that time was on the NDI side. This basically means a year of grant money was burned waiting for death data. We had primary data collection to do, but in a secondary data analysis study this delay pretty much guarantees people will be a year behind and carrying over money and asking for a no cost extension.

Having said that, the data and the documentation were fantastic to have! It was well worth the heartache.

National Heart, Lung, and Blood Institute (NHLBI)

Staff provided a number of examples of uses of death records from the public DMF, including studies that evaluated the accuracy and completeness of the data, and stated that research would not have been possible without the frequent, low-cost, easy-to-work with updates of the public DMF that had been available from NTIS.

- Frobert, O., Lagerqvist, B., Olivecrona, G.K., Omerovic, E. (and 18 other authors). (2013). Thrombus aspiration during ST-segment elevation myocardial infarction. *New England Journal of Medicine* 369(17, October 24):1587-1597—research conducted with a first class, accessible death registry in Sweden.
- Lauer, M.S., and D'Agostino, R.B. (2013). The randomized registry trial—The next disruptive technology in clinical research? *New England Journal of Medicine* 369(17, October 24)—comments on the registry study in Frobert et al. as a type of randomized trial that avoids the costs and other problems of traditional clinical trials.
- Blackstone, E.H. (2012). Demise of a vital resource. Editorial. *The Journal of Thoracic and Cardiovascular Surgery* 143(1):37-38—documents the value of the public DMF and laments the loss of its usefulness for biomedical research due to the deletion of state death records in 2011.
- Frolkis, J.P., Pothier, C.E., Blackstone, E.H., and Lauer, M.S. (2009), Frequent ventricular ectopy after exercise, *New England Journal of Medicine* 348(9, February):781-90—lead *NEJM* article using public DMF.
- Nishimi, E.O., Cole, C.R., Blackstone, E.H., Pashkow, F.J., and Lauer, M.S. (2000). Heart rate recovery and treadmill exercise score as predictors of mortality in patients referred for exercise ECG. *JAMA* 284(11, September):1392-1398—assesses quality of public DMF favorably as against the NDI (p. 1393, 3rd column).

- Cole, C.R., Blackstone, E.H., Pashkow, F.J., Snader, C.E., and Lauer, M.S. (1999). Heart-rate recovery immediately after exercise as a predictor of mortality. *New England Journal of Medicine* 341(18):1351-1357—ready access to public DMF gave this researcher a start before receiving NIH funding and before coming to NHLBI.
- Lauer, M.S., Blackstone, E.H., Young, J.B., and Topol, E.J. (1999). Viewpoint—Cause of death in clinical research—time for a reassessment? *Journal of the American College of Cardiology* 34(3):618-620—supports use of mortality from all causes as an unbiased outcome variable instead of individual causes of death for which the data are problematic.
- Lloyd-Jones, D.M., Martin, D.O., Larson, M.G., and Levy, D. (1998). Accuracy of death certificates for coding coronary heart disease as the cause of death. *Annals of Internal Medicine* 129(12, December 2015):1020-1026—estimates upward bias in coronary heart disease as cause of death on death certificates.

**National Institute of Environmental Health Sciences (NIEHS)—
NIEHS Sisters Study and NIH Agricultural Health Study**

It is important to be able to obtain causes of death for participants in studies that cover broad geographic areas, in addition to the need for high quality data and timely data. For the Ag Health Study, which draws its population in two states, they can go to state vital statistics for complete coverage or near complete coverage of the cohort, and they can potentially get these data sooner than through NDI. For cohorts such as the Sister Study which recruited across the US and Puerto Rico, this national resource is invaluable and all we have.

We are using (or plan to use) NDI for passive follow up of Sister participants who have been lost to follow-up or who explicitly agreed to passive follow-up only; to obtain causes of death when a death is reported to us; and to confirm breast cancer when a participant or next of kin reports the diagnosis to us but does not provide access to medical records.

International Epidemiology Institute

Our group has extensively used both Social Security Administration (SSA) and National Death Index (NDI) files to ascertain vital status and cause of death in a number of cohort studies (e.g. the Southern Community Cohort Study, following 90,000 adults and shedding light on reasons for higher rates of cancer among African-Americans). Some comments about these two resources follow:

1. It would be incredibly useful to researchers if somehow the SSA Service to Epidemiologic Research and the NDI could combine, or at least coordinate, efforts so that in addition to fact and cause of death, NDI could also provide a confirmation of alive status (only SSA does this now). Then researchers would only need to apply and submit their cohorts to one system to obtain complete vital status information.
2. Accuracy
 - o Demographic Information: It appears that the data recorded in the NDI for Name, SSN, DOB, etc., are not cleaned after being recorded. Hence, they may be subject to typos or other errors. It

- would be useful if NDI data could be cleaned before being released. This could be facilitated by electronic linkages of NDI and SSA files to detect and resolve discrepancies (e.g., same SSN but different names or dates of birth) between the databases.
- o Underlying Cause of Death coding has always been questioned (e.g., vs. a medical record review by experts), but entries on the death certificates are what they are, and we are not aware of any systematic problems in the way the NCHS algorithms choose the UCOD.
3. Completeness
 - o Foreign Deaths: Incorporation of foreign deaths of U.S. citizens (e.g., during war or while traveling) would be very helpful for some studies.
 - o Domestic Deaths: NDI ascertainment of deaths is very high, but we have uncovered instances of deaths reported by SSA that are not included in NDI (and vice versa). Implementing routine linkage of SSA files and NDI files before the annual release of NDI data should help raise NDI ascertainment to an even higher percentage of deaths.
 4. Timeliness – NDI lag time seems variable, with an increase in the lag this year compared with last year (2012 is still not finalized). NDI recently began an “Early Release” program to try to get researchers data sooner; this is partially helpful, but the process adds work since it requires two submissions (once early and once when the file is finalized). Better would be more timely returns from the states to NDI.
 5. Data items provided – There are some data fields from the death certificate that are not provided in an NDI linkage that might be useful to researchers, like place of death, manner of death, whether an autopsy was performed, etc.
 6. Deaths pre-1979 – It would not be possible to create a complete register of deaths prior to 1979, but many states do have electronic mortality data prior to 1979 available. The data are not always complete (e.g., missing SSN, etc.), and contributing causes of death are not always available, but a compilation of existing pre-1979 state mortality data into a publicly available file would greatly reduce the number of death certificates researchers have to request for retrospective cohort studies tracking occupational or other groups identified in the 1970s and earlier.
 7. Cost – We understand that agreements between NDI and the states appear to drive the price for NDI linkages, but discounts for federally-funded researchers conducting approved research would be helpful.

Westat

(contractor to NIH/NCI for the Prostate, Lung, Colorectal, and Ovarian Cancer Screening prevention trial, with an observational component)

Major benefits of the NDI

The NDI offers an important and unique benefit to researchers: the primary cause of death code and the contributing cause of death codes. Linking these data to study subjects makes it possible to associate risk factors with subject mortality and morbidity. Careful selection of the codes improves the accuracy of causes of death and standardizes coding. The selection process takes time. Only if better automated, a difficult objective, would the timeliness of the NDI approach that of the DMF.

The NDI application, IRB review, and approval process work much faster and more efficiently when compared to requests for state mortality files or death certificates.

Deficiencies in the NDI

While timing of the releases of new mortality cases by the NDI has improved during the last several years, complete and more timely mortality data would help speed up mortality studies and improve the timeliness of subject vital status in longitudinal studies. Faster releases of mortality data would especially help studies that update vital status of a cohort annually.

The NDI does not support disease incidence studies. It does not include the date of diagnosis of the diseases coded as primary or underlying causes of death. For example, cancers reported as causes of death in the NDI cannot be integrated easily with cancer registry records. Neither does the NDI classify diseases as primary or secondary (e.g., metastatic). The NDI is a mortality registry and does not have the same purposes as a cancer or other disease registry. Nonetheless, the task of collecting disease incidence data falls largely to the states, and a resident of one state may have an incident disease reported in another state. The NDI has a national scope for reporting locations and causes of death, but not for incident diseases associated with deaths. Many states, aided by CDC/NPCR, make an effort to reconcile cancer causes of death in the NDI to cancer registry cases, but not all states link surviving patients to the NDI on an annual basis.

Though far simpler and general than applications and approval processes required for access to state death certificates, the IRB requires an application and approval for each search. Researchers have no on-line access or direct access to personal identifiers. Linkage remains an 11 step process.

NDI search methods combine rules and a variant of probabilistic linkage. Search results typically include a substantial number of false matches. Researchers have to review returns but do not receive values of personal identifiers in the NDI to compare with study identifiers. Classifier and probabilistic scores rank potential matches, but not in the same order. The NDI could improve the sensitivity and specificity of linkage by integrating state mortality data with SSA “presumed alive” and DMF data, and with vendor vital status and “observed at address” dates.

The emerging National Vital Status Statistics (NVSS) registry promises more timely and accurate vital status data, but could be years away from reaching that goal. A third of the states and territories did not have the requisite data collection system operating in 2013, and other states and territories have not implementing it fully. A fully operational NVSS could be years away. The NDI Early Release Pilot looks more promising in the near future—95% mortality ascertainment within 6 months would take researchers back to the pre-2011 DMF (see graph provided by David Weir in Attachment B above). The cost and application delay of an early NDI (no cause of death) search will be much greater than the cost and update delay of a DMF search by subscribers to the DMF updates.

Death ascertainment based on CMS data will have severe limitations. In most instances, relatively few studies will have the alternative ID (HIC numbers) for subjects, and some may not have SSNs required for linkage to CMS data. Only subjects receiving benefits under Medicare or Medicaid will link to study records. Subject consent requirements will further limit the value of CMS vital status.

Progressively stricter limits on researcher access to mortality data and increasing data costs have impaired mortality studies. The initiatives proposed for the NVSS and by the NDI and CMS may bring data access back up to earlier levels, but entail greater costs and delays.

Solutions to the problem of greater restrictions of access to existing data by health researchers has to include outreach to federal and state legislators and streamlining of approval processes. Risks of

exposures of confidential and private information by health researchers have been minimal, and the benefits of having timely and accurate data available to researchers have been substantial.

Other Comments from Westat

Longitudinal studies of large cohorts with periodic mailings or other subject contact (follow-up mail or phone surveys, newsletters, advisories) need mortality ascertainment to avoid upsetting families by attempting to contact deceased persons, to monitor survival, and to reduce costs of distributing printed materials or of phone calls.

Katzmarzyk (2009) linked subjects to the Canadian Mortality Database (CMDB). It contains all recorded deaths in Canada since 1950 and is regularly updated. The USA has nothing equivalent.

State cancer registries in the U.S. have in the past used the SSA DMF to improve linkage to state mortality data and the NDI. Registries update the vital status of patients in the registry, find patient deaths that occur out of state, estimate survival rates, and check for unreported cancer cases. Mortality data withheld since November 2011 reduces the accuracy of cancer mortality statistics that states publish. (See *LINKING NATIONAL PROGRAM OF CANCER REGISTRIES (NPCR) DATA WITH NATIONAL DEATH INDEX (NDI) DATA Maine Cancer Registry (MCR) User's Guide Version 2.0.*)

Many health researchers used the SSA DMF as an early and inexpensive step in tracing study subjects lost to follow up. SSA DMF search results combined with vendors' vital status indicators gave researchers acceptably accurate and more timely all-cause mortality outcomes for studies of the risk of obesity, smoking, and many other important risk factors. The NIH-AARP study relied on linkages with the DMF to provide information about who in the cohort has died. The Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial used the DMF to help monitor adverse events that result in death. Figure 1 shows the shortfall in DMF and LexisNexis death reports that resulted from data withheld from the DMF beginning in 2011.

The Congressionally-mandated Camp Lejeune Mortality Study by ASTDR (with linkage and other technical support from Westat) ascertained mortality in a cohort of some 550,000 Marines and family members who may have been exposed to toxic chemicals. The methodology for the study looked back retrospectively over a twenty-year time span and combined search results from an SSA "presumed alive" search, an SSA DMF search, a LexisNexis vital status and address history search for a substantial number of subjects that the SSA search could not match, and an NDI Plus search. A 2011 report, *Mortality Study of Former Marines, Dependents and Employees Potentially Exposed to Contaminated Drinking Water at USMC Base Camp Lejeune: Camp Lejeune Mortality Study (CLMS)*, includes detailed descriptions of mortality ascertainment methods and processes.

SSA DMF search results increased substantially the statistical power of the important 2006 Adams *et al.* all-causes mortality and obesity paper. The NIH-AARP study team and collaborators have continued to investigate mortality risk factors, and have published about 25 additional papers based on mortality data:

Adams KF, Leitzmann MF, Ballard-Barbash R, Albanes D, Harris TB, Hollenbeck A, Kipnis V, Body Mass and Weight Change in Adults in Relation to Mortality Risk. *Am J Epidemiol.* 2014;179(2):135-44.

Adams KF, Schatzkin A, Harris TB, Kipnis V, Mouw T, Ballard-Barbash R, Hollenbeck A, Leitzmann MF. Overweight, obesity, and mortality in a large prospective cohort of persons 50 to 71 years old. *N Engl J Med* 2006; 355(8):763-78.

- Arem H, Park Y, Pelsler C, Ballard-Barbash R, Irwin ML, Hollenbeck A, Gierach GL, Brinton LA, Pfeiffer RM, Matthews CE. Prediagnosis body mass index, physical activity, and mortality in endometrial cancer patients. *J Natl Cancer Inst.* 2013;105:342-9.
- Behrens G, Fischer B, Kohler S, Park Y, Hollenbeck AR, Leitzmann MF. Healthy lifestyle behaviors and decreased risk of mortality in a large prospective study of U.S. women and men. *Eur J Epidemiol.* 2013; 28(5): 361-72.
- Berrington de Gonzalez A, Hartge P, Cerhan JR, Flint AJ, Hannan L, MacInnis RJ, Moore SC, Tobias GS, Anton-Culver H, Freeman LB, Beeson WL, Clipp SL, English DR, Folsom AR, Freedman DM, Giles G, Hakansson N, Henderson KD, Hoffman-Bolton J, Hoppin JA, Koenig KL, Lee IM, Linet MS, Park Y, Pocobelli G, Schatzkin A, Sesso HD, Weiderpass E, Willcox BJ, Wolk A, Zeleniuch-Jacquotte A, Willett WC, Thun MJ. Body-mass index and mortality among 1.46 million white adults. *New England Journal of Medicine.* 2010;363:2211-9.
- Cerhan JR, Moore SC, Jacobs EJ, Kitahara CM, Rosenberg PS, Adami H, Ebbert JO, English DR, Gapstur SM, Giles GG, Horn-Ross PL, Park Y, Patel A, Robein K, Weiderpass E, Willett WC, Wolk A, Zeleniuch-Jacquotte A, Hartge P, Bernstein L, de Gonzalez AB. Waist Circumference and Mortality in 650,000 Adults. *Mayo Clin Proc.* 2014;89(3):335-45.
- Eisenberg ML, Park Y, Hollenbeck AR, Lipshultz LI, Schatzkin A, Pletcher MJ. Fatherhood and the risk of cardiovascular mortality in the NIH-AARP Diet and Health Study. *Hum Reprod.* 2011;26:3479-85.
- Kant AK, Leitzmann MF, Park Y, Hollenbeck A, Schatzkin A. Patterns of Recommended Dietary Behaviors Predict Subsequent Risk of Mortality in a Large Cohort of Men and Women in the United States. *J Nutr* 2009;139:1374-80.
- Koster A, Leitzmann MF, Schatzkin A, Mouw T, Adams KF, van Eijk JIM, Hollenbeck A, Harris TB. Waist circumference and mortality. *Am J Epidemiol* 2008 Jun 15;167(12):1465-75.
- Leitzmann MF, Moore SC, Koster A, Harris TB, Park Y, Hollenbeck A, Schatzkin A. Waist Circumference as Compared with Body-Mass Index in Predicting Mortality from Specific Causes. *PLoS One.* 2011;6:e18582.
- Leitzmann MF, Park Y, Blair A, Ballard-Barbash R, Mouw T, Hollenbeck AR, Schatzkin A. Physical activity recommendations and decreased risk of mortality. *Arch Intern Med.* 2007; 167:2453-60.
- Li WQ, Park Y, McGlynn KA, Hollenbeck AR, Taylor PR, Goldstein AM, Freedman ND. Index-based dietary patterns and risk of incident hepatocellular carcinoma and mortality from chronic liver disease in a prospective study. *Hepatology.* 2014;60(2):588-97.
- Major JM, Doubeni CA, Freedman ND, Park Y, Lian M, Hollenbeck AR, Schatzkin A, Graubard BI, Sinha R. Neighborhood Socioeconomic Deprivation and Mortality: NIH-AARP Diet and Health Study. *PLoS One.* 2010 Nov;5(11): e15538.
- Matthews CE, George SM, Moore SC, et al. Amount of time spent in sedentary behaviors and cause-specific mortality in US adults. *Am J Clin Nutr.* 2012;95:437-45.
- Moore SC, Peters TM, Ahn J, Park Y, Schatzkin A, Albanes D, Ballard-Barbash R, Hollenbeck A, Leitzmann MF. Physical activity in relation to total, advanced, and fatal prostate cancer. *Cancer Epi Biomarker Prev* 2008 17(9):2458-66.
- Park Y, Hartge P, Moore SC, Kitahara CM, Hollenbeck AR, Berrington de Gonzalez A. Body Mass Index and Mortality in Non-Hispanic Black Adults in the NIH-AARP Diet and Health Study. *PLoS One.* 2012;7:e50091.
- Park Y, Subar AF, Hollenbeck A, Schatzkin A. Dietary Fiber Intake and Mortality in the NIH-AARP Diet and Health Study. *Arch Intern Med.* 2011;171:1061-8.
- Park Y, Wang S, Kitahara CM, Moore SC, de Gonzalez AB, Bernstein L, Chang ET, Flint AJ, Freedman DM, Gaziano JM, Hoover RN, Linet MS, Purdue M, Robien K, Schairer C, Sesso HD, White E, Willcox BJ, Thun MJ, Hartge P, Willett WC. Body Mass Index and Risk of Death in Asian Americans. *Am J Public Health.* 2014;104(3):520-5.
- Persson EC, Schwartz LM, Park Y, Trabert B, Hollenbeck AR, Graubard BI, Freedman ND, McGlynn KA. Alcohol consumption, folate intake, hepatocellular carcinoma, and liver disease mortality. *Cancer Epidemiol Biomarkers Prev.* 2013;22:415-21.

- Reedy J, Krebs-Smith SM, Miller PE, Liese AD, Kahle LL, Park Y, Subar AF. Higher diet quality is associated with decreased risk of all-cause, cardiovascular disease, and cancer mortality among older adults. *J Nutr*. 2014;144(6):881-9.
- Sinha R, Cross AJ, Graubard BI, Leitzmann MF, Schatzkin A. Meat intake and mortality: a prospective study of over half a million people. *Arch Intern Med*. 2009;169:562-71.
- Tasevska N, Park Y, Jiao L, Hollenbeck A, Subar AF, Potischman N. Sugars and risk of mortality in the NIH AARP Diet and Health Study. *Am J Clin Nutr*. 2014;99(5):1077-88.
- Teras LR, Kitahara CM, Birmann BM, Hartge PA, Wang SS, Robien K, Patel AV, Adami HO, Weiderpass E, Giles GG, Singh PN, Alavanja M, Beane Freeman LE, Bernstein L, Buring JE, Colditz GA, Fraser GE, Gapstur SM, Gaziano JM, Giovannucci E, Hofmann JN, Linet MS, Neta G, Park Y, Peters U, Rosenberg PS, Schairer C, Sesso HD, Stampfer MJ, Visvanathan K, White E, Wolk A, Zeleniuch-Jacquotte A, de González AB, Purdue MP. Body Size and Multiple Myeloma Mortality: a pooled analysis of 20 prospective studies. *Br J Haematol*. 2014;166(5):667-76.
- Thun MJ, Carter BD, Feskanich D, Freedman ND, Prentice R, Lopez AD, Hartge P, Gapstur SM. 50-year trends in smoking-related mortality in the United States. *N Engl J Med*. 2013;368:351-64.
- Wright ME, Chang S-C, Schatzkin A, Albanes D, Kipnis V, Mouw T, Hurwitz P, Hollenbeck A, Leitzmann MF. Prospective study of adiposity and weight change in relation to prostate cancer incidence and mortality. *Cancer* 2007;109:675-84.

Until ~2011, the DMF included about 96 percent of the mortality cases in the NDI, with a two quarter lag instead of a two year lag (and the DMF included about 2% of mortality cases that did not show up in the NDI). Withholding of about 35 percent of mortality cases has greatly reduced the accuracy of timely mortality studies, and the impact of that development has spilled over into other sources of mortality data such as the SSA "presumed alive" search and commercial vendors. More recently, vendors distributing updates to the SSA DMF and to other data are now requiring researchers to sign data use agreements that include "permitted uses" clauses that limit access to SSA and other mortality records to law enforcement, homeland security, credit bureaus, financial institutions, pension funds, and similar organizations. The clauses in effect exclude researchers not conducting research authorized by law.

Suggestions are to combine data from the SSA DMF, SSA "Presumed Alive" database (which draws on IRS payroll data), state mortality files, and commercial databases to ascertain deaths at a level and a lag suitable for timely research. Improve linkage methods by reconciling reports of death across multiple data sources. Avoid compiling mortality reports into a single data source until person identity issues have been resolved. The Census Bureau has assembled data on vital status that could, if allowed, be used for quality control purposes. Multiple sources improve the completeness of mortality data and lead to exposes of classification errors.