MEMORANDUM

To: The Honorable Sam Johnson, Chairman
Kim Hildred, Staff Director
Subcommittee on Social Security, Committee on Ways & Means
U.S. House of Representatives

From: Patricia W. Potrzebowski, Ph.D., Executive Director
National Association for Public Health Statistics and Information Systems

Date: April 4, 2012

Subject: Responses to Questions from Hearing on Social Security Death Master File

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Attached please find responses to questions for the record from the National Association for Public Health Statistics and Information Systems (NAPHSIS). NAPHSIS greatly appreciates the opportunity to contribute to this important dialogue.

If you have additional questions, please do not hesitate to contact our Washington representative, Emily Holubowich at eholubowich@dc-crd.com and 202.484.1100.

National Association for Public Health Statistics and Information Systems
Responses to Questions from Hearing on Social Security Death Master File

Subcommittee on Social Security, Committee on Ways & Means, U.S. House of Representatives

1. **You have indicated in your testimony that under our Constitution, States have the responsibility and the rights to manage vital statistics, which of course includes death records. If a system of accreditation is developed for sharing data amongs certified users, what should be the role of state death data and what considerations should be given to state sovereignty over this data? What suggestions would you have for making sure the states retain control of vital statistics both legally and in regards to personal privacy of their citizens?**

   Any system of accreditation that is developed for sharing state death record data among certified users would need to preserve the authority of each State for permitting access to the vital statistics data they provide to this system. That is, each state should have responsibility for and control over who accesses their own state provided death records. That consideration should be paramount, that is, it should override any other considerations.

   The easiest way to do this is to exclude all state provided death records, as is currently being done with the public DMF, but other alternatives are possible. The EVVE system allows each State to approve each data user. That means, for example, that State X, an open record state, can permit access to its death data by any certified requestor, but that State Y, which permits fact-of-death data to be provided only for government agency use, can limit access only to certified users that are government agencies. State Z, may permit access not only to governmen agencies, but also to organizations that can demonstrate a direct and tangible interest in the record (e.g. a credit card or life insurance company). This type of system would make sure that the states retain control of vital statistics both legally and in regards to personal privacy of their citizens.

   What level of reimbursement to the States should users pay?

   It is difficult to say exactly what level of reimbursement to the States users should pay for access to state death records, because different States set different fees. Many state vital records offices are funded solely through fees collected primarily from the sale of certified copies of birth and death records. In other states, the fees collected are used to offset state appropriated funds to support the vital records operation. This fee based revenue must cover <u>all</u> of the costs of collecting and processing the information that is contained in vital records, including the purchase and maintenance of computer systems; staff to operate data collection and quality control systems; staff to educate and work with the data providers (i.e., physicians, funeral directors, hospital and other health care facility staff, coroners, etc.) to ensure that vital records are complete, accurate, and submitted on a timely basis; staff to provide services to the public and other data requestors, including correction and amendment of records and issuance of certified copies, analyses and preparation of statistical reports and special requests for data; and other related costs.

   To protect state vital records offices from losing essential revenue, it is recommended that each user of state death data pay a fee to the state vital records office for each access to the death data. This fee would cover the loss of revenue that states incur and is consistent with the State position that they are providing a license to use the data for a specified purpose.

The current EVVE pricing model includes a monthly maintenance fee and a transaction fee for each query, as well as a fee when a match occurs. The match fees differ if the request is a verification (i.e., the user already has a birth or death certificate for the person being queried) or a certification (i.e., the person querying does not have a birth or death certificate for the person being queried). Match fees are set by the individual states. NAPHSIS would be happy to work with the States to evaluate and consider revisions to the current EVVE pricing model based on new uses of EVVE.

2. **I assume that your group, that represents all the vital statistic bureaus throughtout the US., is not a part of this interagency working group. Yet, you have clearly shown us that under our system of federalism, states have the responsibility for managing their vital statistics records. What should this group keep in mind as they consider options and what recommendations would you have for this interagency group?**

NAPHSIS is not part of the interagency working group. NAPHSIS would be pleased to participate on or meet with the working group to provide information and to answer questions. NAPHSIS recommends that the interagency working group keep the following key points in mind as they consider options and recommendations for use of state death data:

(1) Assure that State Provided Death Records are Not Released to the Public

The interagency working group should understand that access to identifiable death records differs based on state statutes. In a few states this information is public information, while in most states access to identifiable death record data is limited to family members or others with a direct and tangible interest, government agencies, or for medical research purposes. Some states prohibit commercial use of vital records data. It should be noted that this is different from the Federal Privacy Act, under which a person who is deceased is no longer afforded the right to privacy. Because state statutes differ, it is critical that state death records continue to be excluded from public release by SSA or any other government agency, without the prior approval of the appropriate state vital records office.

(2) Prevent State Loss of Essential Operating Revenue

Many state vital records offices are funded solely through fees collected primarily from the sale of certified copies of birth and death records. In other states, the fees collected are used to offset state appropriated funds to support the vital records operation. This fee based revenue must cover <u>all</u> of the costs of collecting and processing the information that is contained in vital records, including the purchase and maintenance of computer systems; staff to operate data collection and quality control systems; staff to educate and work with the data providers (i.e., physicians, funeral directors, hospital and other health care facility staff, coroners, etc.) to ensure that vital records are complete, accurate, and submitted on a timely basis; staff to provide services to the public and other data requestors, including correction and amendment of records and issuance of certified copies, analyses and preparation of statistical reports and special requests for data; and other related costs.

To protect state vital records offices from losing essential revenue, it is recommended that the interagency workgroup require that each proposed new government user of state death data pay a surcharge to the state vital records office for each new use. This surcharge would not increase SSA's costs, but would be passed through to the other government agency users of the state data. This

surcharge for the state vital records offices would cover the loss of revenue that states would incur by the expanded use of state death data for government agency use. This is consistent with the State position that they are providing a license to use the data for a specified purpose.

(3) Prohibit Re-Release of State Data

Again, consistent with the States providing a license to use their data for a specific purpose, the state vital records offices recommend that any provision of vital records data to a government agency after payment of the negotiated surcharge (license fee) must not be permitted to be re-released for the same use to any other organization/entity, either public or private (e.g., local or state government partners or any other grantees) without prior state vital records office approval. Nor can a government agency use the state death data provided for an additional use not specified in the initial request. Prohibiting such re-release will protect state vital records offices from the loss of essential revenue and help assure that the data are used only for allowable and approved purposes under state law.

(4) Limit Use to Administrative, Non-Research Purposes

The National Death Index (NDI) was established in 1979 by the National Center for Health Statistics (NCHS) in the Centers for Disease Control and Prevention (CDC) for use by medical or health researchers to determine if study subjects have died anywhere within the United States without the researcher having to contact each state vital records office. State vital records offices provide their death record information to the NDI, including cause of death information (NDI Plus). When researchers use the NDI Plus, they pay a surcharge to NCHS that is then shared with state vital records offices. The state vital records offices are concerned about loss of existing revenue if their death data is permitted to be used for research purposes. They therefore recommend that no state death data be permitted to be used for research uses and that government agency use be limited to administrative uses only.

(5) Delay Public Release to Allow Time for Birth/Death Matching by States

The Intelligence Reform and Terrorism Prevention Act of 2004 requires state vital records offices to match birth and death records once a death has occurred, and to mark the birth record "deceased." This is critical for protecting against identity theft, but it cannot happen instantaneously, particularly when a person dies in a different state than s/he was born. It takes some time for the death record to be transmitted to the state of birth and for the birth record to be marked as deceased. Not all states are currently participating in the electronic State and Territorial Exchange of Vital Events (STEVE) system, so in nearly half the states, this is still a manual process. In order to protect publicly provided death records from being used for identity theft, the state vital records offices recommend that a time lag of 60 days after the date of death be considered for any public release of death records. This time will allow state vital records offices to match the death record with the decedent's birth record and to mark the birth record "deceased," thus preventing the birth record's use for identity theft.

3. **With 57 different vital record jurisdictions managing death data, I am sure there are many variations. Can you describe for us in general the policy States use to govern data?**

Access to identifiable death records differs based on state statutes. In a few states, this information is public information, while in most states access to identifiable death record data is limited to family members or others with a direct and tangible interest, government agencies, or for medical research purposes. Some states prohibit all commercial use of vital records data.

In most states there is a charge for providing death information (similar to a license to use the information) and generally—with the exception of a family member or their legal representative who must submit an application for a certified copy of the death record—a requestor must also sign a data use agreement. The data use agreement specifies the data provided, the purpose for which the data are requested, prohibits re-release, and requires the requestor to agree to a number of conditions to protect the confidentiality and security of the information provided.

4. **Do States allow access to their data? If so, to whom and for what purposes and are certain data elements redacted or restricted?**

   A few states allow public access to their vital statistics death data. In some states the access is restricted at the state level but is concidered to be public information at the local government level (e.g., town clerk or local registrar).

   All states permit family members or next of kin to apply for and purchase a certified copy of the death record. Most states permit government agencies to obtain selected data elements, but only those needed for the specific government agency use. Many states permit medical or health researchers to obtain selected data elements, but only those data needed for the research. For medical/health research or for government agency use, many states restrict access only to certain needed data elements. In some states, the cause and manner of death are restricted or redacted for almost all purposes, unless specifically authorized.

5. **Do some States sell data to other government or private buyers?**

   Yes, some states "sell" data to government agencies, but this is more accurately characterized as a "license" for the government agency to use the data for a specific purpose. Some open record states may sell data to private buyers, generally on a record by record basis, although it is possible that a few states sell entire data files.

6. **You spoke about a system, similar to a computer hub-like system, that takes electronic queries from government agencies to confirm birth and death information from the records of the other states. You called this the Electronic Verification of Vital Events. Tell us exactly how this works, if it might open some day to commerical users and if this system might be the solution for certain types of data authentication problems.**

   Many Federal and State agencies rely on birth certificates for proof of age, proof of citizenship, identification for employment purposes, to issue benefits or other documents (e.g. driver's licenses, Social Security cards, and passports) and to assist in determining eligibility for public programs or benefits. NAPHSIS has developed and implemented the Electronic Verification of Vital Events (EVVE) system, which provides the capability to quickly, reliably, and securely validate birth and death information. Via a single interface, authorized Federal and State agency users can generate an electronic query to any participating vital records jurisdiction throughout the country to verify the contents of a paper birth certificate or to request an electronic certification (in lieu of the paper

birth certificate), irrespective of the place or date of issuance. An electronic response from the participating vital records jurisdiction either verifies or denies the match with official state or jurisdiction records.

EVVE also provides an indication to the requestor if the birth record matched via EVVE has been marked deceased. The EVVE system is also capable of supporting the electronic verification and/or electronic certification of death records. The EVVE system supports real-time queries as well as batch queries. If the state of birth or death is not known, a broadcast system is available for electronic certification requests.

The EVVE system works by accepting a query from an approved agency user. That query is sent to the EVVE hub, which will then forward the query to the vital records office where the birth or death occurred. There is a piece of EVVE that is installed in each vital record jurisdiction infrastructure that accepts the query and checks the data entered as part of the query against its birth or death database. The results of the query are sent back to the EVVE hub, and then forwarded onto the originating requestor. Queries and their responses are sent over the internet, in an encrypted standard XML messaging schema, so confidential data is secure and protected. The EVVE system has also been certified and accredited by an independent organization to be compliant with the NIST 800-53 moderate level security standards.

The following Federal and State agencies have used the EVVE system: Department of Motor Vehicle Agencies, Medicaid Offices, Social Security Administration, Office of Personnel Management, District Health Offices, Army National Guard, and Department of State Fraud Prevention Offices.

While the EVVE system is currently limited to government agencies, it is possible that it may in future become available for commercial users, and would then be the solution for certain types of data authentication. The reason this approach would work is that with the EVVE system, each vital records office has the capability to approve or disapprove each requested user of EVVE for their own state's data.

NAPHSIS is currently developing possible solutions that would establish alternatives to assist authorized public and private sector entities to access state fact-of-death data for legitimate needs where state laws permit.

7. **The future of good statistic management seems to lie in more use of electronic death record systems. As more States send electronic death records (EDRs) to Social Security, there should be fewer erroneous reports of living persons put on their death roles, correct?**

Each State/jurisdiction submits to SSA death data for each death record filed in their State/jurisdiction. The development of an EDR system will improve the timeliness of receiving death data, along with its completeness and accuracy, especially if the EDR system has incorporated the process of verifying the decedent's SSN. If the EDR system incorporates a verification check of the SSN, the results of that verification are submitted to SSA with the death record.

Generally state death records are very accurate and complete, and only rarely do errors occur. However, if SSA continues to use sources other than EDRs from state health departments for reporting of deaths, and if the EDRs from those states do not override reports from other sources,

erroneous reports of the deaths of living persons could still exist in SSA death files.

8. **You mentioned that Social Security once helped underwrite funding for electronic death registration systems in the various States, but that funding has ended. You also stated that $20 million could insure these electronic systems in all States and jurisdictions. That capability would not only be good for Social Security but the other nine federal agenices that share Social Security's database for benefit management. Describe in more detail what the funding would support.**

   Additional funding would be used to support the development and implementation of electronic death registration (EDR) systems in those States/jurisdictions that do not currently have an EDR system. The additional funding would also be used to support the rollout of the EDR system to the death data providers, in those states/jurisdictions that need to develop their EDR system, and those states/jurisdictions that have already developed their EDR system but need to bring additional death data providers on-line so that the death records can be completed and filed electronically. With an EDR system, there are many death data providers that need access to the EDR system and training on how to use the EDR system. In most states and jurisdictions, this includes funeral directors, funeral home clerks, medical examiner and coroner offices, hospitals, physicians, nursing homes, and other entities that may certify the cause of death. Also, state and local registrars need to be on-line with the EDR system. So this funding will be used for development, implementation, and rollout of EDR systems in the states/jurisdictions.

   Would the development of EDRs eventually bring down the cost of accessing death data while increasing its security and if so, explain further these posiitive factors?

   The development of an EDR system will improve the timeliness of receiving death data, along with its completeness and accuracy. Edit checks on the data are incorporated into an EDR system to ensure that data quality is maintained. For example, an EDRS will prompt the user if the user indicates that a two year old decedent has a college education so they can review the data they have entered. An EDR system can also be integrated with the on-line verification of SSN (OVS) system to perform a real-time verification of the decedent's SSN.

   An EDR system will increase the security of death data, along with timeliness and quality, but NAPHSIS does not envision an EDR system bringing down the costs of accessing death data. EDR systems are costly to develop, implement, rollout, and maintain. There are additional IT costs associated with an EDR system that you would not have in the 'paper' manual registration environment. In other words, the costs are not decreased, but are shifted.

9. **If a third party such as your organization is able to provide the information to entities using vital statistics for legitimate and lawful reasons, is there a way to have data that is searchable and compatible with the entities that need this information?**

   We are not aware of any serious technical barriers to having data that are searchable and compatible with the entities that need identifiable fact-of-death death information for legitimate and lawful reasons. Rather the critical issue is related to the differing State statutes and regulations that govern access. That is why the EVVE system, which allows each State to decide on a case by case basis which users would be permitted to access their State's death data is a feasible alternative for some users.