

Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue

Conducted for the National Committee on Vital and Heath Statistics Subcommittee on Population Health

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This report was prepared under contract by R. Gibson Parrish, M.D.

NCVHS Membership and Lead Staff, Fall 2017

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Rebecca Hines, MHS, NCVHS Executive Secretary/DFO

Health Scientist National Center for Health Statistics, CDC, HHS

The National Committee on Vital and Health Statistics

(NCVHS) serves as the advisory committee to the Secretary of Health and Human Services (HHS) on health data, statistics, privacy, national health information policy, and the Health Insurance Portability and Accountability Act (HIPAA) (42U.S.C.242k[k]). The Committee also serves as a forum for interaction with interested private-sector groups on important health data issues. Its membership includes experts in health statistics, electronic interchange of healthcare information, privacy, confidentiality, and security of electronic information, population-based public health, purchasing or financing healthcare services, integrated computerized health information systems, health services research, consumer interests in health information, health data standards, epidemiology, and the provision of health services. Sixteen of the 18 members are appointed by the HHS Secretary to terms of four years each. Two additional members are selected by Congress. For more information, visit the NCVHS website: **www.ncvhs.hhs.gov.**

Updated February 2018 with formatting changes.

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Background and Purpose

The National Committee on Vital and Health Statistics (NCVHS) serves as the advisory committee to the Secretary of Health and Human Services on health data, statistics, privacy, standards, national health information policy, and the Health Insurance Portability and Accountability Act (HIPAA). In this capacity, it provides advice and assistance to the Department and serves as a forum for interaction with stakeholders on key issues related to population health, standards, privacy and confidentiality, and data access and use. Because the national vital statistics system (NVSS) plays a critical role in monitoring the health of the nation, conducting public health surveillance, understanding the effectiveness of the healthcare and health financing system, and supporting business and commerce, the NCVHS is exploring the state of the existing NVSS and identifying ways to improve the system. The goal of NCVHS' exploration is the answer to the following question:

"How do we transform today's vulnerable vital records data collection network into a network of state systems that produce accurate and timely information supporting a breadth of local, state and federal data needs?"

As part of this exploration, NCVHS held a "Hearing on Next Generation Vital Statistics" in Washington, D.C., on September 11–12, 2017. The hearing's objectives were to:

- (1) identify the essential elements of the vital statistics system;
- (2) assess the system's current status and risks to its viability; and
- (3) consider what actions are needed to protect and improve the system.

At the hearing, more than 25 agencies, organizations, and businesses testified about their use of, and reliance on, vital records and statistics for carrying out their day-to-day activities. Representatives of the NVSS at the Federal, state, and local level also testified about the current status of the NVSS and its ongoing challenges. The agenda, testimony, and a transcript of the hearing are available on the NCVHS website,¹ and a report summarizing the hearing is being prepared.

Following the hearing, members of NCVHS with the support of the National Center for Health Statistics (NCHS) determined that it would be useful to develop a companion report that would provide a summary of the uses and users of vital records and vital statistics and an analysis of the types and sources of revenue available to vital records jurisdictions in the United States

The purpose of this report is to present the uses, users, and sources of revenue for vital records and vital statistics. The information provided in this report contributes to the input being considered by the Committee as it identifies and considers recommendations for approaches that would address the many challenges facing the NVSS at this time.

¹ NCVHS. Agenda: Next Generation Vital Statistics: A Hearing on Current Status, Issues and Future Possibilities, Hubert H. Humphrey Building, Room 705A, Washington, DC; September 11-12, 2017. Available at https://www.ncvhs.hhs.gov/meeting-calendar/agenda-of-the-september-11-12-2017-subcommittee-onpopulation-health-next-generation-vital-statistics-hearing/

Terminology

Several terms are used to describe different aspects of the NVSS:

- (1) <u>Vital events</u> are the major life events for individuals and include fetal death, still birth, birth, marriage, divorce, and death. The focus of this report is on two vital events: birth and death.
- (2) <u>Vital registration</u> is the process of collecting, recording, and storing specific information on individual vital events. When this process is completed electronically, it is referred to as "electronic [vital event] registration"; examples include electronic birth registration and electronic death registration.
- (3) <u>Vital records</u> are the product of vital registration and consist of the completed paper or electronic forms that document vital events, such as birth certificates and death certificates. Vital records may be stored in either a paper or an electronic form.
- (4) <u>Vital registration system</u> consists of the various persons, agencies, equipment, forms, rules (standards), and processes that carry out vital registration. When this system completes vital registration electronically, it is referred to as an "electronic [vital event] registration system"; examples include electronic birth registration system (EBRS) and electronic death registration system (EDRS).
- (5) <u>Vital records office</u> (VRO) is the government agency or organization within a state, local, or territorial jurisdiction that is responsible for registering vital events, storing vital records, and issuing certified copies of vital records for legal and administrative purposes. In some jurisdictions, the VRO may be referred to as the "vital registration office" or the "vital statistics office."
- (6) <u>Vital statistics consists of quantitative data concerning vital events in a population, such as the number of births and the death rate. Vital statistics are derived from an analysis of vital records data.</u>

Approach

NCVHS contracted with R. Gibson Parrish, M.D., to prepare this report under the guidance of the NCVHS Subcommittee for Population Health, and Kate Brett, Lead Staff to the Population Health Subcommittee, and Rebecca Hines, NCVHS Executive Secretary, both with NCHS. Dr. Parrish prepared the report during October and November 2017.

To identify uses and users of vital records and vital statistics and the types and sources of revenue available to vital records offices in the United States, Dr. Parrish reviewed NCVHS Hearing-related materials, including the agenda, submitted testimony, and transcripts. Based on this review, he searched the Internet for agencies and organizations that produce, manage, support, or use vital records or vital statistics. The web sites identified in these searches are listed in association with the relevant table or tables in the findings section of this report and in this report's list of references. Dr. Parrish also interviewed or corresponded with the following individuals to gain additional information on the NVSS, and he appreciates the assistance that they provided:

- (1) Delton Atkinson, Director of the Division of Vital Statistics at the National Center for Health Statistics, Centers for Disease Control and Prevention
- (2) Kate Brett, Epidemiologist in the Division of Vital Statistics at the National Center for Health Statistics, Centers for Disease Control and Prevention
- (3) Bruce Cohen, National Committee on Vital and Health Statistics
- (4) Rebecca Hines, Health Scientist, National Center for Health Statistics, Centers for Disease Control and Prevention

- (5) Rich McCoy, Director of the Center for Health Statistics at the Vermont Department of Health, and President-Elect of the National Association of Public Health Statistics and Information Systems
- (6) Andrea Price, National Association of Public Health Statistics and Information Systems
- (7) Steven Schwartz, Registrar of the Bureau of Vital Statistics at the New York City Department of Health and Mental Hygiene
- (8) Anthony Stout, National Association of Public Health Statistics and Information Systems
- (9) Shawna Webster, Executive Director, National Association of Public Health Statistics and Information Systems

Findings

Overview of birth and death registration

Figures 1 and 2 provide overviews of the birth and death registration processes, respectively. Both figures show the process of gathering information about the vital event on the left, including the types of people and organizations involved in the process. The middle panels depict the roles of state government in registering the vital event and providing data about vital events to various state and national users. The right panels depict major national agencies and organizations that compile, use, and distribute birth and death records obtained from state vital records offices. The figures also depict payments made by various users of vital records to state or national organizations for the use of the records.²

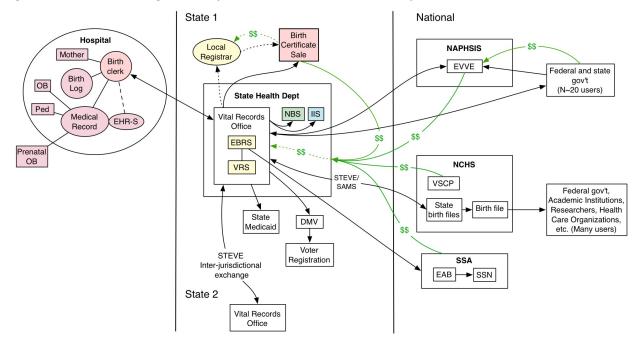


Figure 1. Current birth registration process for a state vital records jurisdiction

Legend for Figure 1:

------ Solid black and green lines denote typical processes and payments, respectively

---- Dashed black and green lines denote other, less common processes and payments, respectively

² Payments by users to providers of vital records or vital statistics data are shown by green lines with "\$\$".

DMV = Department of Motor Vehicles EAB = Enumeration at Birth EBRS = Electronic Birth Registration System EHR-S = Electronic Health Record System EVVE = Electronic Verification of Vital Events IIS = Immunization Information System NBS = Newborn Screening NCHS = National Center for Health Statistics OB = Obstetrician or comparable health care provider Ped = Pediatrician SAMS = Secure Access Management Services SHD = State Health Department SSA = Social Security Administration SSN = Social Security Number STEVE = State and Territorial Exchange of Vital Events System VRS = Vital Registration System VSCP = Vital Statistics Cooperative Program

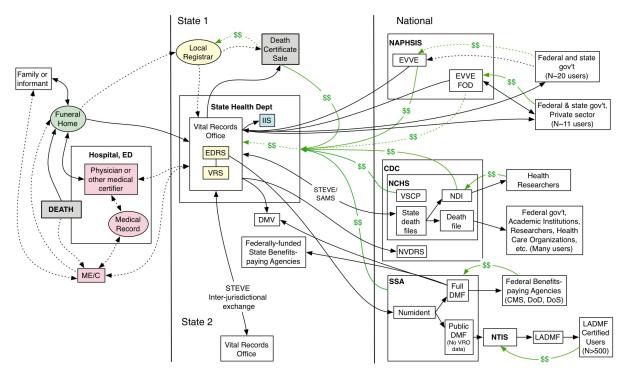


Figure 2. Current death registration process for a state vital records jurisdiction

Legend for Figure 2:

—— Solid black and green lines denote typical processes and payments, respectively

---- Dashed black and green lines denote other, less common processes and payments, respectively

CMS = Centers for Medicare and Medicaid Services	ME/C = Medical Examiner / Coroner
CR = Cancer Registry	NCHS = National Center for Health Statistics
DMF = Death Master File	NDI = National Death Index
DMV = Department of Motor Vehicles	NTIS = National Technical Information Service
DoD = U.S. Department of Defense	NVDRS = National Violent Death Reporting System
DoS = U.S. Department of State	SAMS = Secure Access Management Services
ED = Emergency Department	SHD = State Health Department
EDRS = Electronic Death Registration System	SSA = Social Security Administration
EHR-S = Electronic Health Record System	STEVE = State and Territorial Exchange of Vital Events System
EVVE = Electronic Verification of Vital Events	VRO = Vital Records Office
EVVE FOD = Electronic Verification of Vital Events Fact of Death	VRS = Vital Registration System
IIS = Immunization Information System	VSCP = Vital Statistics Cooperative Program
LADMF = Limited Access Death Master File	

Uses and users of identified birth and death records

Uses and users of <u>identified³</u> birth and death records are shown in Tables 1 and 2, respectively. These uses and users include individuals who use their birth certificate to establish their identity for various legal and administrative purposes; the Social Security Administration (SSA), which uses birth data to facilitate the issuance of Social Security Numbers (SSN) to persons born in the United States and death data to terminate the payment of benefits; and private organizations, which use death data to pay benefits and to prevent fraud.

³ "Identified records" refers to one or more of records, each of which contains information sufficient to identity the subject of the record, such as name, name of mother, and location and date of birth on a birth record.

These identified birth and death records are available through state and other vital records offices (VROs) to authorized individuals, who usually must pay a fee for copies or use of the records. Verification of birth and death records is also available to authorized users for all state and other vital records jurisdictions—except New York and Texas—through the Electronic Verification of Vital Events (EVVE) system, which is maintained by the National Association of Public Health Statistics and Information Systems (NAPHSIS). NAPHSIS also operates the Electronic Verification of Vital Events Fact of Death (EVVE FOD) system, which provides authorized users with the ability to discover if a death record exists for an individual. Currently, 42 states and jurisdictions participate in the EVVE FOD system. (See Appendix C and Table 5.)

The Social Security Administration purchases identified birth and death records from VROs to administer its benefits programs. These records form a part of the NUMIDENT electronic database, which contains SSA's records of Social Security Numbers (SSN) assigned to individuals since 1936. The SSA compiles its death information in the Death Master File (DMF), which is an extract of death information on NUMIDENT (see Appendix C). The DMF includes, if available, each deceased individual's SSN, first name, middle name, surname, date of birth, and date of death. The SSA provides access to the "full" DMF for a "reasonable cost" to Federal or state agencies that provide federally funded benefits to individuals. The SSA may also provide State driver's license agencies with access to its records to verify applicable information "pursuant to the Help America Vote Act of 2002." (See Appendix C and Table 5.)

A "public" version of the DMF contains death records extracted from the NUMIDENT database, but does <u>not</u> include death data received from the states. The "public" version of the DMF is available from the Department of Commerce's National Technical Information Service (NTIS) as the "Limited Access DMF," or "LADMF," to certified persons and organizations, who must have a legitimate fraud prevention interest, or have a legitimate business purpose pursuant to a law, governmental rule, regulation, or fiduciary duty. The NTIS charge fees for using the LADMF and to cover the costs associated with its certification program. (See Appendix C and Table 5.)

NCHS established and maintains the National Death Index (NDI), a centralized database of death record information on file in state vital statistics offices, as a resource to aid epidemiologists and other health and medical investigators with their mortality ascertainment activities. Researchers pay a fee for using the NDI and can request either a *routine* NDI search for those who do *not* need cause of death codes, or an NDI *Plus* search, which also provides cause of death codes. (See Appendix C and Table 5.)

Use	User(s)	System	Records used	VRO Funding source
Individual or Family				
Establish identity for legal and administrative purposes	Individual or family	State and jurisdiction VROs	1	Sale of certificate
Obtain or renew U.S. Passport	Individual or family	State and jurisdiction VROs	1	Sale of certificate
Provide proof of citizenship or legal residency for employment	Individual person	State and jurisdiction VROs	1	Sale of certificate

Table 1. Uses of identified birth records and data sets

Verify identity for drivers license or identity card	Individual person	State and jurisdiction VROs	1	Sale of certificate
Verify age of child for sports league	Individual or family	State and jurisdiction VROs	1	Sale of certificate
Provide proof of country of birth for college admission	Individual person	State and jurisdiction VROs	1	Sale of certificate
Federal Government				
Verify and certify birth	SSA	EVVE*	1 to many	User fee
information	DoS/Diplomatic Security	EVVE*	1 to many	User fee
	OPM	EVVE*	1 to many	User fee
	Regional FBI Offices	EVVE*	1 to many	User fee
	DHS/USCIS	EVVE*	1 to many	User fee
Issue Social Security Number (SSN) to each newborn to prevent other parties from filing a request for a SSN in the name of the newborn	SSA	State and jurisdiction EBRS	All births	SSA contracts with State VROs
Obtain or renew U.S. Passport	DoS/Passport Services Fraud Prevention Offices	State and jurisdiction VROs	1 to many	Unknown†
		EVVE*	1 to many	User fee
Conduct evaluations of state Medicaid programs	CMS	State and jurisdiction VROs	1 to many	CMS contractor payments to VRO
Obtain birth certificate demographic and medical data for the National Vital Statistics System	NCHS	State and jurisdiction EBRS	All births	NCHS (VSCP)
State and Local Government				
Assist state and local government agencies in performing their official duties*	Secretary of State	EVVE*	Selected births	User fee
Enroll eligible children into Medicaid program	State Medicaid programs	State and jurisdiction VRO/EBRS	Selected births	Unknown†
		EVVE*		User fee
Verify identity for driver's license or identity card	DMV	State and jurisdiction VROs	Selected births	Unknown†
		EVVE*		User fee
Verify birth for voter	DMV	SSA birth file	Selected	None: Birth

registration			states and births	data obtained from SSA
Initialize entry in Immunization Information System (IIS)	State IIS	State and jurisdiction EBRS	All	Unknown†
Facilitate newborn screening for health disorders	Health care provider responsible for screening newborn	State and jurisdiction VRO/EBRS	All	Unknown†
Private (Non-Government) Or	ganizations			
Genealogical research	Individual person or	State and jurisdiction VROs	1 to many	Sale of certificate(s) or VR data
Verify age of child for sports league	Sport league	State and jurisdiction VROs	1 to many	Sale of certificate(s)
Use by media to verify identity or other information	Media organizations	State and jurisdiction VROs	1 to many	Sale of certificate(s) or VR data
Use of birth data for medical or other health research	Medical and other health researchers	State and jurisdiction VROs	1 to many	Sale of certificate(s) or VR data
Conduct background checks for government agencies, pension funds, or other organizations (Note: Some states can't provide certificates to these third parties.)	Company under contract to government agency or pension fund (e.g., Berwyn Group)	State and jurisdiction VROs	1 to many	Sale of certificate(s) or VR data
Determine property rights and place them in land records	Title search companies	State and jurisdiction VROs	1 to many	Sale of certificate(s) or VR data
Marketing products to parents of newborns. (Note: Some states can refuse these requests.)	Marketing companies	State and jurisdiction VROs	Many	Sale of certificate(s) or VR data

* For information on births occurring in states or jurisdictions not participating in EVVE, the user must contact the state or jurisdiction's VRO for information about birth records.

⁺ The author of this report was unable to find the information needed to fill in this cell in this table. The VRO source of funding may differ by jurisdiction.

Sources of information for Table 1:

- (1) NAPHSIS: About EVVE FOD. Available at https://www.naphsis.org/evve-fod; accessed on 4 Oct 2017.
- (2) Personal communication with Rich McCoy, Vermont State Registrar and Chief, Center for Health Statistics, 13 Oct 2017.
- (3) Presentations at NCVHS hearing, September 11-12, 2017, Washington, D.C., available at https://www.ncvhs.hhs.gov/meeting-calendar/agenda-of-the-september-11-12-2017subcommittee-on-population-health-next-generation-vital-statistics-hearing/; accessed on 4 Oct

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Table 2. Uses of identified death records and data sets

Use	User	System	Records used	VRO Funding source
Individual or Family				
Establish fact of death for legal and administrative purposes. Note: Death Certificate cannot be provided to funeral directors in all states.	Family of decedent	State and jurisdiction VROs	1	Purchase of certificate(s) by individual, family, or funeral director
Federal Government				
Assist federal government agencies in performing their	<i>Examples of users:</i> DHS	EVVE FOD†	1 to many	User fee
official duties (Federal	DoS	EVVE FOD ⁺	1 to many	User fee
Administrative Use)*	IRS	EVVE FOD [†]	1 to many	User fee
	NIOSH	EVVE FOD ⁺	1 to many	User fee
	U.S. Treasury	EVVE FOD ⁺	1 to many	User fee
	VA	EVVE FOD [†]	1 to many	User fee
Establish fact and cause of death to pay death benefit, or terminate payments under retirement or other	DoD/Defense Manpower Data Center	Full DMF	Active duty military deaths	None: DMF obtained from SSA
benefit programs	VA	Full DMF ⁺	Veteran deaths	
	Federal Retirement Thrift Investment Board	Full DMF†	Deaths of federal civilian and uniformed	
	OPM	Full DMF ⁺	services employees	
	HUD	Full DMF ⁺	Unknown++	
	USDA/FSA USDA/NRCS USDA/RMA	Full DMF†	Unknown††	
Establish fact of death to terminate, redirect, or otherwise modify Social Security payments or other benefits	SSA	State and jurisdiction EDRS	All deaths	SSA contracts with State VROs
Assist federal government agencies in paying death benefits, or terminating payments under disability, unemployment, workers' compensation, pension, retirement, or other benefit programs	DoL/OWCP	Unknown††	Deaths of certain civilian employees	Unknown††

Use	User	System	Records used	VRO Funding source
Establish fact of death to	CMS	Full DMF [†]	All deaths	None: DMF
terminate benefits	U.S. Railroad Retirement Board	Full DMF†	Deaths of railroad workers and their families	obtained from SSA
	Pension Benefit Guaranty Corporation	Full DMF†	Deaths of persons covered by PBGC	
Verify deaths of individuals to prevent tax fraud by use of identities of recently deceased individuals to claim tax refunds	IRS	Full DMF†	All deaths	None: DMF obtained from SSA
Identify and obtain information about deaths due to specific causes	CPSC	State and jurisdiction VROs	Selected deaths	Sale of certificates
Identify health study	CDC	NDI	All deaths	NDI user fees
subjects who have died	Census Bureau			
	CMS DoD NIH			
Identify health study subjects who have died, if researcher can't obtain records quickly enough through NDI, or research proposal is rejected by NDI, or researchers only need records from one or two states	NIH or other federal agency	State and jurisdiction VROs	Selected deaths	Sale of certificates
State and Local Government				
Assist state and local	Examples of users:			
government agencies in performing their official duties (State/local Administrative Use)*	ernment agencies in County EVVE FOD ⁺ 1 to r orming their official government es (State/local DMV	1 to many	User fees paid by state and local government	
	Secretary of State			agencies
	Social services See Appendix D	LADMF [†]	1 to many	None: NTIS User fees
Assist state and local government agencies in paying death benefits, or	State and local government pension plans	EVVE FOD†	All	User fees paid by state and local

Use	User	System	Records used	VRO Funding source
terminating payments under disability, unemployment, workers' compensation, pension, retirement, or other benefit programs (State/local Benefit Use)	Unemployment programs Workers' compensation program	- -		government agencies
Private (Non-Government) O	rganizations		EVVE FOD	
Assist financial institutions in verifying legitimacy and legal ownership of financial transactions, such as investments, loans and deposits.	Examples of users: Citigroup Equifax Fidelity Northern Trust	EVVE FOD†	1 to many	User fees paid by financial institutions
Assist healthcare organizations in determining whether patients survive care and in removing decedents from their files (Healthcare Administrative Use)	Examples of users: Ascension Health Tenet Healthcare Trinity Health	EVVE FOD†	1 to many	User fees paid by health care organizations
Determine property rights and enter them in land records	Title search companies	State and jurisdiction VROs	1 to many	Sale of certificate(s)
Establish fact and cause of death to pay benefit	Life insurance companies		1	None: Certificate obtained from decedent's family
Assist insurance companies in identifying insured individuals who have died,	Examples of users: MetLife State Farm	EVVE FOD ⁺	1 to many	User fee
providing warranted benefits to beneficiaries, and in complying with applicable state laws	See Appendix D	LADMF†	1 to many	None: User fees paid to NTIS
Establish fact of death to terminate payments or	Employer-based pension or	EVVE FOD†	Selected deaths	User fee
other benefits	retirement plans	LADMF ⁺	1 to many	None: User fees paid to NTIS
Obtain data on deaths for government agencies, pension funds, or other organizations (Note: Some states can't provide certificates to these third	Company under contract to government agency or pension fund (e.g., Berwyn Group)	State and jurisdiction VROs	1 to many	Sale of certificate(s) or VR data

Use	User	System	Records used	VRO Funding source
parties.)				
Identify health study subjects who have died	Academic institutions Medical centers	NDI	Selected deaths	NDI user fees
Identify health study subjects who have died, if researcher can't obtain records quickly enough through NDI, research proposal is rejected by NDI, or researchers only need records from one or two states	Private companies Health Researchers, Academic institutions	State and jurisdiction VROs	Selected deaths	Sale of certificate(s) or VR data
Use by media to verify death or find other information	Media organizations	State and jurisdiction VROs	1 to many	Sale of certificate(s) or VR data
Genealogical research	Individual person or organization	State and jurisdiction VROs	1 to many	Sale of certificate(s) or VR data

* Government agency administrative use excludes medical or health research uses, where such research is defined as a systematic study to gain information and understanding with the goal of finding ways to improve human health and/or is designed to develop or contribute to generalizable scientific knowledge. The National Death Index (NDI)—operated by the CDC's National Center for Health Statistics—provides fact of death information for medical and health research use. (See (1) NAPHSIS: About EVVE FOD, available at: https://www.naphsis.org/evve-fod; accessed 4 Oct 2017) and (2) CDC: NCHS: National Death Index, https://www.cdc.gov/nchs/ndi/index.htm; accessed on 9 Oct 2017.

 ⁺ For information on births occurring in states or jurisdictions not participating in Full DMF, EVVE, EVVE FOD, or LADMF, the user must contact the state or jurisdiction's VRO for information about birth records.
 ⁺ The author of this report was unable to find the information needed to fill in this cell in this table.

Sources of information for Table 2:

- (1) Email with Subject: Users of the 205(r) data: DMF Customers and Death Exchanges, from Tom Klouda, U.S. Senate, August 25, 2017 at 2:19:10 PM EDT.
- (2) NAPHSIS: About EVVE. Available at https://www.naphsis.org/evve; accessed on 4 Oct 2017.
- (3) National Technical Information Service: Limited Access Death Master File: List of persons certified to receive the Limited Access Death Master File, available at https://classic.ntis.gov/assets/pdf/DMFcertifiedList.docx; accessed on 9 Oct 2017.
- (4) Personal communication with Rich McCoy, Vermont State Registrar and Chief, Center for Health Statistics, 13 Oct 2017.
- (5) Presentations at NCVHS hearing, September 11-12, 2017, Washington, D.C., available at https://www.ncvhs.hhs.gov/meeting-calendar/agenda-of-the-september-11-12-2017subcommittee-on-population-health-next-generation-vital-statistics-hearing/; accessed on 4 Oct 2017.

Uses and users of de-identified natality (birth) and mortality (death) data sets

NCHS compiles the birth and death records from the 57 U.S. vital records jurisdictions into several deidentified vital statistics data sets, which are made available to various users, including researchers, policy makers, government agencies, academic institutions, private organizations, and the public (see Tables 3–5). NCHS disseminates public-use data files through interactive tables, online querying tools, and direct download through its FTP file server. The NCHS Research Data Center (RDC) allows access to restricted data and offers several modes of access on-site at the NCHS facility in Hyattsville, Maryland.⁴

Over the years, Federal confidentiality standards have changed for the public release of geographic and date data on national vital statistics data sets, which is reflected in the data items available in successive time periods. National birth, death, and fetal death public-use micro-data files prior to 1989 contain the county and exact dates (year, month, and day) of birth or death. For data years 1989 to 2004, micro-data files contain only geographic identifiers for counties and cities with a population of 100,000 or greater, and no exact dates. For birth, death, and fetal death files, the year, month, and day of week (e.g. Monday) are available. Beginning with the 2005 data year these data files contain individual-level vital event data at the national level only with no geographic identifiers. These files generally include most other items and detail from the vital record with the exception of exact dates.

Subject to certain limitations, data users may also access NCHS natality and mortality data using Internet programs to construct their own tabulations of births and deaths with geographic detail. These interactive systems allow users to build tables based on micro-data; however, only tabulated data are presented to the user. Interactive Web-based systems currently available are the CDC's WONDER (Wide-ranging ON-line Data for Epidemiological Research) and WISQARS (Web-based Injury Statistics Query and Reporting System).⁵

Customized NCHS natality and mortality data files are available under restricted conditions. Researchers may request customized files containing geographic details for all states and counties. These requests require a review by NAPHSIS. If the project proposal is denied because of issues related to data confidentiality, alternative access may be available through the NCHS RDC, which has specific procedures for controlled access to micro-data files. Researchers pay NCHS for the use of the RDC to support its maintenance.

State health statistics offices also may provide access to natality and mortality data files for their state for community health assessments, government research, private studies, and public inquiries. States provide differing levels of identifying details for these files. Some states also maintain Web-based data query systems, which provide interactive access to natality, mortality, and other state data.⁶

⁴ For more information, see (1) CDC: National Center for Health Statistics. Accessing Data from the National Center for Health Statistics, available at https://www.cdc.gov/nchs/data_access/index.htm; accessed 6 Nov 2017. (2) CDC: National Center for Health Statistics. Public-Use Data Files and Documentation, available at

https://www.cdc.gov/nchs/data_access/ftp_data.htm; accessed 6 Nov 2017. (3) CDC: National Center for Health Statistics. Resources for Researchers, available at https://www.cdc.gov/nchs/nchs_for_you/researchers.htm; accessed 6 Nov 2017.

⁵ WONDER is available at https://wonder.cdc.gov, and WISQARS is available at https://www.cdc.gov/injury/wisqars/index.html.

⁶ Information on uses and users of de-identified natality (birth) and mortality (death) data sets was provided by Kate Brett and Delton Atkinson, NCHS, 31 October 2017.

Use	User	VRO Funding source
Prepare natality statistics for the United States	NCHS	NCHS (VSCP)
Prepare natality statistics for state and local jurisdictions	 State and local offices of health statistics 	State or local budget
Develop health policy	 Federal, state, and local government agencies Academic institutions Non-governmental, health organizations 	None
Carry out health research	 Federal, state, and local government agencies Academic institutions Non-governmental, health organizations 	None
Conduct actuarial analyses for program planning and management	SSACMS	None
Prepare population estimates	Census Bureau	None

Table 3. Uses of de-identified natality (birth) data sets

Source of information for Table 3: Kate Brett and Delton Atkinson, NCHS, 31 Oct 2017.

Table 4. Uses of de-identified mortality data sets (death and linked birth-infant death)

		VRO Funding
Use	User	source
Prepare mortality statistics for the United States	NCHS	NCHS (VSCP)
Prepare mortality statistics for state and local jurisdictions	 State and local offices of health statistics 	State or local budget
Develop health policy	 Federal, state, and local government agencies Academic institutions Non-governmental, health organizations 	None
Carry out health research	 Federal, state, and local government agencies Academic institutions Non-governmental, health organizations 	None
Conduct actuarial analyses for insurance, pension, and other benefit programs	 SSA CMS Insurance Companies Private and Government Pension Funds 	None
Prepare population estimates	Census Bureau	None

Source of information for Table 4: Kate Brett and Delton Atkinson, NCHS, 31 Oct 2017.

Table 5. Selected data sets and information systems based on vital records that provide data about vital events

System*	Responsible agency or organization	Description	Type of vital records data to which access is provided	Authorized users
<i>Birth Data</i> Birth file	CDC, NCHS	Provides record level birth data derived from state and jurisdiction birth certificates submitted to NCHS through the Vital Statistics Cooperative	Identified records ⁺ with demographic, geographic, and medical information for births ⁺ ⁺	Researchers who submit and receive approval for a research proposal outlining the need for "sensitive" records
		Program (VSCP)	De-identified records for statistical reporting and analysis	Members of the public who are willing to agree to not use data to identify any individuals or to link data with individually identifiable data from other NCHS or non- NCHS datasets.
CDC WONDER	CDC	Provides users with the ability to quickly query and analyze birth and death data sets from the National Vital Statistics System	De-identified demographic, geographic, and medical information for births††	Members of the public who are willing to agree to not use data to identify any individuals
Web- based data query systems (WDQS)	State or local governments who maintain these systems	Provide users with the ability to query and conduct statistical analyses of birth, death, and other state or local data	De-identified demographic, geographic location, and medical information about births and deaths for analysis	Members of the public. Some WDQS may ask users to agree to not use data to identify any individuals.
EVVE	NAPHSIS	Provides users with the ability to quickly, reliably, and securely verify birth or death data with or without a paper certificate	None is provided to user. The system simply confirms or denies that there is a match of the individual in the request with a birth or death record.	State and federal government agencies
Death Data				
Multiple Cause of Death Data File	CDC, NCHS	Provides record level death data derived from state and jurisdiction birth certificates submitted to NCHS through the Vital	Identified records ⁺ with demographic, geographic, place, and complete cause information	Researchers who submit and receive approval for a research proposal outlining the need for "sensitive" records

System*	Responsible agency or organization	Description	Type of vital records data to which access is provided	Authorized users
		Statistics Cooperative Program (VSCP)	for death De-identified records for statistical reporting and analysis	Members of the public who are willing to agree to not use data to identify any individuals or to link data with individually identifiable data from other NCHS or non- NCHS datasets.
Linked birth- infant death file: period data	CDC, NCHS	Provides data on all infant deaths occurring in a given year (e.g., 2015) linked to their corresponding birth certificates, whether the birth occurred in the given year (e.g., 2015) or the previous year (e.g., 2014). The denominator file for the data set is the given year's natality file, that is, all births occurring in the	Identified records [†] with demographic, geographic, and medical information about the birth and death of infants who die De-identified records for statistical reporting and analysis	Researchers who submit and receive approval for a research proposal outlining the need for "sensitive" records Members of the public who are willing to agree to not use data to identify any individuals or to link data with individually identifiable
		given year (e.g., 2015).	-	data from other NCHS or non- NCHS datasets.
CDC WONDER	CDC	Provides users with the ability to quickly query and analyze birth and death data sets from the National Vital Statistics System	De-identified demographic, geographic location, place, and cause information for deaths	Members of the public who are willing to agree to not use data to identify any individuals
WISQARS	CDC	Provides fatal and nonfatal injury, violent death, and cost of injury data from a variety of trusted sources, including the NVSS.	De-identified demographic, geographic, and cause information for injury-related deaths	Members of the public who are willing to agree to not use data to identify any individuals
Full DMF	SSA	Provides authorized user with access to all records of deaths reported to the SSA from 1936 to the present, including records reported to SSA by state and jurisdiction VROs through EDRS.	Name, social security account number, date of birth, and date of death of deceased individuals maintained by the Commissioner of Social Security	Federal benefits agencies, such as CMS, VA, OPM, and Federal Retirement Thrift Investment Board. See Table 7.
LADMF	SSA through NTIS	Provides certified users access to records of	Name, social security account	Individuals and organization who have successfully

System*	Responsible agency or organization	Description	Type of vital records data to which access is provided	Authorized users
		deaths reported to the SSA from 1936 to the present for (1) preventing identity fraud, (2) verifying death, and (3) identifying decedents in order to provide benefits to their beneficiaries. LADMF does not include protected state and jurisdiction vital records data.	number, date of birth, and date of death of deceased individuals maintained by the Commissioner of Social Security	completed the NTIS certification process. See Appendix D for a list of certified users.
EVVE	NAPHSIS	Provides users with the ability to quickly, reliably, and securely verify birth or death data with or without a paper certificate	None is provided to user. The system simply confirms or denies that there is a match of the individual in the request with a birth or death record.	State and federal government agencies
EVVE FOD	NAPHSIS	Provides users with the ability to quickly, reliably, and securely discover if a death record exists	Fact, place, and date of death, with other optional fields returned depending upon the jurisdiction	 (1) federal benefits agencies, (2) federal administrative agencies, (3) state or local government benefits agencies, (4) state or local government administrative agencies, (5) non- governmental employers providing pension or retirement plans for their employees, (6) insurance companies, (7) companies "in the process of managing [their] assets," and (8) institutions that deal with financial transactions, such as banks
NDI	CDC, NCHS	Assists investigators in determining whether persons in their research studies have died, and, if so, provides the names of the states in which those deaths occurred, the dates of death, and the corresponding death certificate numbers	Fact of death, jurisdiction, and death certificate number for identified deaths and, optionally, cause of death	Epidemiologists and other health and medical investigators for use in medical and health research

* State birth and death files usually can't be released under state statutes.

⁺ Restricted data sets for research, including those with geographically identified data, are available through the NCHS Research Data Center (RDC). See https://www.cdc.gov/rdc/index.htm (access on 23 Oct 2017) for more information on the NCHS RDC.

++ Birth data includes demographic and medical information about the newborn and the mother.

Sources of information for Table 5:

- (1) CDC: CDC WONDER, available https://wonder.cdc.gov, accessed on 23 Oct 2017.
- (2) CDC: NCHS: Data User Agreement, available at https://www.cdc.gov/nchs/data_access/restrictions.htm, accessed on 23 Oct 2017.
- (3) CDC: Welcome to WISQARS, available at https://www.cdc.gov/injury/wisqars/index.html, accessed on 23 Oct 2017.
- (4) EVVE & EVVE FOD: email communication with NAPHSIS staff Anthony Stout on 16 Oct 2017.
- (5) NCHS: FastStats: Births and Natality, available at https://www.cdc.gov/nchs/fastats/births.htm, accessed on 23 Oct 2017.
- (6) NCHS: FastStats: Deaths and Mortality, available at https://www.cdc.gov/nchs/fastats/deaths.htm, accessed on 23 Oct 2017.
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- (9) NCHS: Vital Statistics Data Available Online, available at https://www.cdc.gov/nchs/data_access/vitalstatsonline.htm, accessed on 23 Oct 2017.
- (10) NTIS: Limited Access Death Master File (https://classic.ntis.gov/products/ssa-dmf/#; accessed on 4 Oct 2017).
- (11) Social Security: Requesting The Full Death Master File (DMF), available at https://www.ssa.gov/dataexchange/request_dmf.html; accessed on 17 October 2017.

Sources of revenue for vital records offices

Vital records offices potentially receive revenue from several sources, including state and local government appropriations; sale of birth and death certificates to individuals, families, and organizations; the NCHS' Vital Statistics Cooperative Program (VSCP); National Death Index use fees; SSA payments for birth and death data and records; payments from the NAPHSIS EVVE and EVVE FOD services; and payments from the Consumer Product Safety Commission for death certificates with specific causes of death (Table 6).

The ability of VROs to receive and use revenue from these sources varies by jurisdiction and by source. In some jurisdictions, virtually all revenue from the sale of birth and death certificates and vital records data goes into the jurisdiction's general fund, or to the agency that houses the VRO, such as the health department. The VROs in other jurisdictions are able to keep revenue from all sources to fund their operation, or to keep revenue from at least some sources.

Based on interviews for this report, there appears to be no complete listing by jurisdiction of the way in which vital records offices are funded, or how revenue from the sale of certificates and from NAPHSIS, NCHS, and SSA use of vital records data is handled administratively. There also appears to be no centralized compilation of the budgets and other financial information for the 57 U.S. vital registration jurisdictions, using standardized definitions and accounting methods.

Table 6. Sources of revenue for state and jurisdiction vital records offices (VRO)

- 1. Appropriations from state, local, or territorial government for VRO
- 2. Revenue from sale of birth and death certificates to individuals and families
 - a. # certificates issued x cost per certificate (see Appendix F for cost and availability of certificates by state or jurisdiction)
- 3. Revenue from sale of individual birth and death certificates to private organizations
 - a. # certificates issued x cost per certificate
- 4. Revenue from preparation of new birth certificates by the VRO for adoptions and changes in paternity information
 - a. # certificates prepared x cost per certificate
 - b. # certificates changed x cost per certificate
- 5. Revenue from amendments (e.g., name change) to birth certificates by the VRO
 - a. # certificates amended x cost per certificate
- 6. Revenue from state, local, or territorial government agency(ies) for providing access to birth or death records to carry out agency's mission (e.g., DMV, Medicaid, Injury Prevention)
- 7. Contracts with VROs under the NCHS Vital Statistics Cooperative Program (VSCP)
 - a. NAPHSIS and NCHS negotiate the content and revenue for records that will be exchanged, and then NCHS pays states directly via contracts for their records.
 - b. **Total amount of VSCP for most recent year: \$21,148,548.** (Note: The total amount of the VSCP contract with state VROs has been constant for the past 5 years.)
 - c. The annual VSCP allocation to each jurisdiction is specified in the VSCP contract. Each jurisdiction receives at least \$50,000. All VSCP funds go to states or jurisdictions, but not all VROs are able to use these funds. In some jurisdictions, the funds go the jurisdiction's general fund, rather than to the jurisdiction's VRO.
- 8. Special projects funding of VROs through the NCHS VSCP
 - a. Project specific funding is awarded to states and territories on a competitive basis.
 - b. Total amount of VSCP Special Project Funding awarded to jurisdictions for the 5-year period, 2013–2017 was \$10,962,969. All 57 vital registration jurisdictions received at least some funding during this period, with median funding for jurisdictions of \$178,095 and a range of \$6,000 to \$689,037. See Appendix G.
- 9. Revenue from National Death Index
 - a. NDI total revenue in dollars and amount paid to jurisdictions for past 3 years:

Federal fiscal year	Total NDI revenue (\$)	NDI revenue paid to jurisdictions (\$)
2015	4,137,314	1,687,286
2016	4,305,463	1,685,269
2017	6,170,434	2,763,711

- b. NDI revenue varies by year depending on the number and size of the requests from researchers
- c. Allocation formula for each state or jurisdiction is based on the number of death records matched by each state or jurisdiction: see description at https://www.cdc.gov/nchs/data/ndi/ndi_user_fees_worksheet.pdf.

10. Contract between VROs and SSA for electronic birth and death records to support SSA mission

- a. SSA pays state, local, and territorial governments for birth and death records.
- b. Allocation formula for each state and jurisdiction: # records provided x payment per record

c. Current SSA payment: \$3.67 per birth record, and the following payments for death records, based on when SSA receives each record:

	Payment per
Timeframe for SSA receipt of death record	record
SSA receives EDR* within 6 business days of death	\$3.16
SSA receives EDR within 7–30 business days of death	\$1.83
SSA receives EDR or other death record within 31–120 business days of death	\$0.91
SSA receives EDR or other death record beyond 120 business days of death	\$0.01

* EDR = Electronic Death Record

- d. State registrars are proposing an increase in the SSA payment from \$3.16 to \$4.88 per EDR received within 6 business days of death.
- e. Based on current payment formulas listed above, birth and death data for 2015 from NCHS, ^{7,8} and the assumption that SSA received an EDR within 6 business days for <u>all</u> 2015 deaths, the estimated total SSA payments to VROs for 2015 would be the following:
 - (1) Birth records: \$3.67 per record x 3,978,497 births ≅ \$14,601,084
 - (2) Death records: \$3.16 per record x 2,712,630 deaths ≅ \$8,571,911
- 11. Revenue from NAPHSIS EVVE service
 - a. EVVE queries currently produce revenues of about \$1.2 million per year.
 - b. NAPHSIS reimburses each state or jurisdiction from revenues it receives from EVVE users.
 - c. Allocation formula for each state or jurisdiction: (# births and deaths matched x cost per match) + (# certifications issued x cost per certification)
- 12. Revenue from NAPHSIS EVVE FOD service
 - a. NAPHSIS reimburses each state or jurisdiction from revenues it receives from EVVE FOD users after NAPHSIS expenses for developing and managing EVVE FOD have been deducted.
 - b. Allocation formula for each state or jurisdiction: (EVVE FOD revenue NAPHSIS expenses) x % total deaths occurring in the jurisdiction x participation amount for all jurisdictions.
- 13. Revenue from Consumer Product Safety Commission's purchase of death certificates with cause of death codes for which there is a high probability that consumer products are involved.
- 14. Revenue from the private sector (e.g., Ancestry.com) for use of records as a resource (only available in a few states)

Notes:

(1) Depending on the state or jurisdiction, revenue from the sale of certificates or other VRO registration services may go to support the VRO directly, or it may go into the general fund of the health department or the state government. In some states, revenue from the sale of

⁷ Martin JA, Hamilton BE, Osterman MJK, et al. Births: Final data for 2015. National vital statistics report; vol 66, no 1. Hyattsville, MD: National Center for Health Statistics. 2017.

⁸ Xu JQ, Murphy SL, Kochanek KD, Arias E. Mortality in the United States, 2015. NCHS data brief, no 267. Hyattsville, MD: National Center for Health Statistics. 2016.

certificates may go to local issuing offices or agents (e.g., Vermont).

(2) Revenue from sales may be carried over to future years in some states (e.g., NH), but in other states the revenues must be spent by the VRO before the end of the fiscal year, or be lost.

Sources of information for Table 6:

- (1) Hnatov M, U.S. Consumer Product Safety Commission. Electrocutions associated with consumer products: 2009, Appendix B. Bethesda, MD: U.S. Consumer Product Safety Commission, November 2012. Available at: https://www.cpsc.gov/s3fs-public/2009electrocutions.pdf; accessed 6 Nov 2017.
- (2) NAPHSIS: About EVVE. Available at https://www.naphsis.org/evve; accessed on 4 Oct 2017.
- (3) Personal communication with Delton Atkinson, Director, Division of Vital Statistics, NCHS, CDC, 24 Oct 2017.
- (4) Personal communication with Rich McCoy, Vermont State Registrar and Chief, Center for Health Statistics, 13 Oct 2017.
- (5) Personal communication with Shawna Webster, Executive Director, NAPHSIS, 5 Oct 2017.
- (6) Presentations at NCVHS hearing, September 11-12, 2017, Washington, D.C., available at https://www.ncvhs.hhs.gov/meeting-calendar/agenda-of-the-september-11-12-2017-subcommittee-onpopulation-health-next-generation-vital-statistics-hearing/; accessed on 4 Oct 2017.
- (7) Rothwell CJ (CDC/NCHS), SSA Death Master File & NCHS National Death Index: How do they relate? [Slide Presentation], available at https://www.cdc.gov/nchs/data/bsc/rothwell.pdf; accessed on 9 Oct 2017.
- (8) U.S. Consumer Product Safety Commission: Guide to Public Information: Death Certificate File, available at https://www.cpsc.gov/Newsroom/FOIA/Guide-to-Public-Information; accessed 6 Nov 2017.

Conclusions

This report summarizes the uses, users, systems, and sources of revenue for vital records and vital statistics in the United States. Vital records and vital statistics are critical for many legal, administrative, financial, policy, health research, and public and private benefit program needs. In spite of their importance, relatively little is known about the actual functioning, funding, and long-term stability and viability of the vital records offices and vital statistics programs—both individually and as a whole—that collect, manage, archive, and make available vital records and statistics and constitute the national vital records and statistics, but relatively few of them appear to directly fund the vital records and statistics system. To better understand this system and to aid in undertaking future improvements of it, the author of this report recommends a systematic effort to obtain the following information for each state and jurisdiction:

- (1) <u>Costs</u> for running VROs. Information should be systematically collected using a standardized approach, including standardized definitions and expense categories.
- (2) <u>Revenues</u> from sale of birth and death certificates for each state/jurisdiction
- (3) <u>Agencies/programs</u> that receive and have authority to spend revenues generated by vital certificate sales
- (4) <u>Distribution</u> of (a) funds from VSCP contracts, (b) sale of birth and death data to SSA, and (c) revenue from other federal agencies
- (5) <u>Distribution of revenues</u> from the use of birth and death data by state agencies
- (6) <u>Laws and statutes</u> that control/limit the ability of VROs to distribute/sell <u>identified</u> birth and death data to federal and state government agencies and to private parties and organizations
- (7) <u>Satisfaction</u> of users of vital records and vital statistics with VRO services, including the timeliness and cost of obtaining vital records; and user suggestions for improving the current system to better meet their needs

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- (1) Atkinson D, Director, Division of Vital Statistics, NCHS, CDC, 24 Oct 2017 [Personal communication].
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- (4) CDC: National Center for Health Statistics. Accessing Data from the National Center for Health Statistics, available at https://www.cdc.gov/nchs/data_access/index.htm; accessed 6 Nov 2017.
- (5) CDC: National Center for Health Statistics. Public-Use Data Files and Documentation, available at https://www.cdc.gov/nchs/data_access/ftp_data.htm; accessed 6 Nov 2017.
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Appendices

Appendix A. Abbreviations and acronyms used in report

CDC: Centers for Disease Control and Prevention CMS: Centers for Medicare and Medicaid Services **CPSC: Consumer Products Safety Commission** DHS: United States Department of Homeland Security DMF: Death Master File **DMV: Department of Motor Vehicles** DoD: United States Department of Defense **DoL: United States Department of Labor** DoS: United States Department of State EBRS: Electronic Birth Registration System EDRS: Electronic Death Registration System **EVVE: Electronic Verification of Vital Events** EVVE FOD: Electronic Verification of Vital Events Fact of Death FBI: Federal Bureau of Investigation FSA: United States Department of Agriculture's Farm Service Agency **IIS: Immunization Information Systems IRS: Internal Revenue Service** LADMF: Limited Access Death Master File NAPHSIS: National Association of Public Health Statistics and Information Systems NCHS: National Center for Health Statistics NDI: National Death Index NRCS: United States Department of Agriculture's Natural Resources Conservation Service **OPM: United States Office of Personnel Management** OWCP: United States Department of Labor's Office of Workers' Compensation Programs RMA: United States Department of Agriculture's Risk Management Agency SSA: Social Security Administration STEVE: State and Territorial Exchange of Vital Events system USDA: United States Department of Agriculture USCIS: United States Department of Homeland Security's United States Citizenship and Immigration Services VA: U.S. Department of Veterans Affairs VRO: Vital Records Office VSCP: Vital Statistics Cooperative Program

Appendix B. Brief descriptions of selected uses and users listed in tables and figures

Citizenship and Immigration Services. The U.S. Citizenship and Immigration Services (USCIS), which is located within the U.S. Department of Homeland Security, is the government agency that oversees lawful immigration to the United States. The USCIS has 19,000 government employees and contractors working at 223 offices across the world. USCIS administers the program that verifies that an individual may legally work in the United States by comparing information from an employee's Form I-9 with other government records. USCIS is funded primarily by immigration and naturalization benefit fees charged to applicants and petitioners. Source: U.S. Department of Homeland Security: Citizenship and Immigration Services, available at https://www.state.gov/m/ds/rls/274294.htm, accessed on 23 Oct 2017.

Defense Manpower Data Center. Since 1974, the DMDC has evolved into a world leader in Department of Defense (DoD) identity management, serving uniformed service members and their families across the globe. Among its many roles, DMDC is:

- The leader in joint information sharing and support on DoD human resource issues
- The central source for identifying, authenticating, authorizing, and providing information on personnel during and after their affiliation with DoD
- The one, central access point for information and assistance on DoD entitlements, benefits, and medical readiness for uniformed service members, veterans, and their families.

Source: U.S. Department of Defense: Defense Manpower Data Center, available at https://www.dmdc.osd.mil/appj/dwp/index.jsp, accessed on 23 Oct 2017.

Diplomatic Security. The Diplomatic Security Service (DSS) is the law enforcement and security arm of the U.S. Department of State. It bears the core responsibility for providing a safe environment for the conduct of U.S. foreign policy. DSS may use birth certificates and birth data to identify adoption fraud, which may rely on document fraud, including fraudulent U.S. passports and visas. Sources: (1) U.S. Department of State: Bureau of Diplomatic Security, available at https://www.state.gov/m/ds/, accessed on 23 Oct 2017; (2) U.S. Department of State: Diplomacy and Law Enforcement Unite to Dismantle Major International Adoption Fraud Scheme, by Angela French, DSS Public Affairs, available at https://www.state.gov/m/ds/rls/274294.htm, accessed on 23 Oct 2017.

Federal Workers' Compensation. The Department of Labor's Office of Workers' Compensation Programs (OWCP) administers four major disability compensation programs, which provide to federal workers (or their dependents) who are injured at work or acquire an occupational disease the following benefits: (1) Wage replacement benefits, (2) Medical treatment, (3) Vocational rehabilitation, and (4) Other benefits. The following compensation programs cover other specific groups: (1) Energy Employees Occupational Illness Compensation Program, (2) Federal Employees' Compensation Program, (3) Longshore and Harbor Workers' Compensation Program, and (4) Black Lung Benefits Program. These entities serve the specific employee groups who are covered under the relevant statutes and regulations by mitigating the financial burden resulting from workplace injury. Source: United States Department of Labor: Workers' Compensation, available at https://www.dol.gov/general/topic/workcomp; accessed on 4 Oct 2017.

Federal Retirement Thrift Investment Board. The Federal Retirement Thrift Investment Board administers the Thrift Savings Plan (TSP), a tax-deferred defined contribution plan similar to private sector 401(k) plans, which provides Federal employees and members of the uniformed services the

opportunity to save for additional retirement security. Source: Federal Retirement Thrift Investment Board: Home, available at https://www.frtib.gov; accessed on 9 Oct 2017.

Immunization Information Systems (IIS). Previously known as immunization registries, these are statebased programs that maintain "confidential, population-based, computerized databases that record all immunization doses administered by participating providers to persons residing within a given geopolitical area." The IIS in most states works with the state VRO to establish new immunization records for children born and residing in the state. See NCVHS hearing testimony from the American Immunization Registry Association (AIRA). See also AIRA at http://www.immregistries.org, accessed on 30 Sep 2017; and CDC: Immunization Information Systems, available at https://www.cdc.gov/vaccines/programs/iis/index.html, accessed on 30 Sep 2017.

Newborn screening. State-based programs that screen newborns for a number of genetic, endocrine, and metabolic disorders; critical congenital heart defects; and hearing loss. Source: (1) CDC: Newborn Screening Portal, available at https://www.cdc.gov/newbornscreening/, accessed on 30 Sep 2017; and (2) individual state newborn screening program websites, available at http://www.savebabies.org/screening.html, accessed on 30 Sep 2017.

Office of Workers' Compensation Programs. The U.S. Department of Labor's Office of Workers' Compensation Programs administers four major disability compensation programs which provide wage replacement benefits, medical treatment, vocational rehabilitation and other benefits to certain workers or their dependents who experience work-related injury or occupational disease:

- Energy Employees Occupational Illness Compensation program,
- Federal Employees' Compensation Program,
- Longshore and Harbor Workers' Compensation Program, and
- Coal Mine Workers' Compensation Program.

Source: United States Department of Labor: Office of Workers' Compensation Programs (OWCP), available at https://www.dol.gov/owcp/owcpabot.htm, accessed on 23 Oct 2017.

Passport Services. The Department of State's Passport Services Directorate issues U.S. passports to traveling Americans. It protects the integrity of the U.S. passport as proof of U.S. citizenship at home and around the world. Applicants for a U.S. Passport must provide proof of U.S. citizenship, consisting of a previous U.S. passport, <u>certified</u> birth certificate, or other documentation acceptable to Passport Services. Source: U.S. Department of State, Bureau of Consular Affairs: U.S. Passports & International Travel, available at https://travel.state.gov/content/passports/en/passports.html, accessed on 23 Oct 2017.

Pension Benefit Guaranty Corporation. PBGC guarantees the "basic benefits" that people earn before their pension plan's termination date (or the date their employer's bankruptcy proceeding began, if applicable) up to legal limits set by Congress. PBGC pays benefits:

- If a sponsoring company seeking to reorganize in bankruptcy proves that it cannot remain in business and continue funding the pension plan
- If a plan runs out of money to pay benefits due
- If a sponsoring company files for liquidation (as opposed to reorganization)

Source and additional information is available at Pension Benefit Guaranty Corporation: A U.S. Government Agency, https://www.pbgc.gov; accessed on 9 Oct 2017.

U.S. Railroad Retirement Board. The Railroad Retirement Board (RRB) is an independent agency in the

executive branch of the Federal Government. The RRB's primary function is to administer comprehensive retirement-survivor and unemployment-sickness benefit programs for the nation's railroad workers and their families, under the Railroad Retirement and Railroad Unemployment Insurance Acts. As part of the retirement program, the RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and railroad workers' Medicare coverage. Source and additional information is available at U.S. Railroad Retirement Board: Menu: Agency Overview, https://www.rrb.gov; accessed on 9 Oct 2017.

Appendix C. Descriptions of selected information systems based on vital records that provide data about vital events to various users

Death Master File (DMF)

The Social Security Administration (SSA) collects death information to administer its programs. Death reports come from many sources, including family members, funeral homes, financial institutions, postal authorities, states and other federal agencies, but the death reports collected by SSA are NOT a comprehensive record of all deaths in the United States.

The SSA compiles its death information in the Death Master File (DMF), which is an extract of death information on NUMIDENT, the electronic database that contains SSA's records of Social Security Numbers (SSN) assigned to individuals since 1936. The DMF includes, if available, each deceased individual's SSN, first name, middle name, surname, date of birth, and date of death. SSA currently prepares two versions of the DMF:

(1) The <u>full</u> DMF contains all death records extracted from the SSA NUMIDENT database, including death data received from states, and is shared only with certain federal and state agencies pursuant to section 205(r) of the Social Security Act.⁹

⁹ Section (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."
- Section (r)(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."
- Section 205(r)(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) <u>under such arrangement the agency provides reimbursement to the Commissioner of Social Security for the reasonable cost of carrying out such arrangement</u>, and (B) such arrangement does not conflict with the duties of the Commissioner of Social Security under paragraph (1)." [Emphasis added.]
- Section 205(r)(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.
- Section 205(r)(8)(A): The Commissioner of Social Security shall, upon the request of the official responsible for a State driver's license agency pursuant to the Help America Vote Act of 2002— (i) enter into an agreement with such official for the purpose of verifying applicable information, so long as the requirements of subparagraphs (A) and (B) of paragraph (3) are met; and ... (ii) include in such agreement safeguards to assure the maintenance of the confidentiality of any applicable information disclosed and procedures to permit such agency to use the applicable information for the purpose of maintaining its records.

Source: Social Security: Compilation of the Social Security Laws: Evidence, Procedure, and Certification for Payment: Sec. 205. [42 U.S.C. 405], available at https://www.ssa.gov/OP_Home/ssact/title02/0205.htm; accessed

(2) The <u>public</u> DMF contains death records extracted from the SSA NUMIDENT database, but does <u>not</u> include death data received from the states. SSA provides this version to the Department of Commerce's National Technical Information Service, a clearinghouse for government information, which sells it to the public (other agencies and private organizations such as banks and credit companies) as the Limited Access Death Master File (LADMF).¹⁰

The LADMF has three principal uses: (1) prevent identity fraud, (2) verify death, and (3) identify decedents in order to provide benefits to their beneficiaries, which are described in more detail below.

(1) By methodically running financial, credit, payment and other applications against the LADMF, the financial community, insurance companies, security firms and state and local governments are better able to <u>identify and prevent identity fraud</u>.

(2) The LADMF is important for <u>death verification</u>. Medical researchers, hospitals, oncology programs all need to track former patients and study subjects. Investigative firms use the data to verify the death of persons, in the course of their investigations.

(3) "Pension funds, insurance organizations, Federal, State and Local governments and others responsible for payments to recipients/retirees all need to know if they might be sending checks to deceased persons. Individuals may search for loved ones, or work toward growing their family trees. Professional and amateur genealogists can search for missing links." See Social Security Death Master File (www.ssdmf.com/; accessed on 4 Oct 2017). "The Death Master File is an important tool which can be used by pension funds, insurance organizations, Federal, State and Local governments and others responsible for verifying deceased person(s) in support of fulfillment of benefits to their beneficiaries."

As described above, the LADMF is available from the National Technical Information Service (NTIS). A user may access an online search application, or download and maintain a raw data version of the file. The online service is updated weekly, and the weekly and monthly updates are offered electronically via https to reduce handling and production time. NTIS established a certification program for those seeking access to the LADMF pursuant to Section 203 of the Bipartisan Budget Act of 2013 (Pub. L.113-67);¹¹ the

on 9 Oct 2017.

¹⁰ The public DMF, which was created in 1980 in response to a 1978 FOIA lawsuit, originally contained over 89 million records of deaths reported to SSA since 1936. In 2002, the SSA public DMF began disclosing state electronic death records. In 2010–2011, SSA examined its disclosure of "protected" state death records, and determined that Section 205(r) of the Social Security Act prohibits SSA from disclosing the state death records that SSA receives through its contracts with the states, except in limited circumstances. As of November 1, 2011, SSA decided to withdraw protected state death records from the public DMF data made available to NTIS for online search and download products. The public DMF continued to contain non-state records, but the number of death records in the public DMF was reduced by approximately 4.2 million, and SSA now adds about 1 million fewer records annually to the DMF. The public DMF, which is distributed by NTIS as the LADMF, currently contains over 86 million records. A user may access an online search application, or download and maintain a raw data version of the file. The online service is updated weekly, and the weekly and monthly updates are offered electronically via https to reduce handling and production time.

¹¹ Section 203 of the Bipartisan Budget Act of 2013, Public Law 113-67 (Act), passed into law on December 26, 2013 prohibits the Secretary of Commerce from disclosing DMF information during the three-calendar- year period following an individual's death (referred to as the "Limited Access DMF," or "LADMF"), unless the person requesting the information has been certified to access that information pursuant to certain criteria in a program that the Secretary establishes. The Act further requires the Secretary to establish a fee-based program to certify Persons for access to LADMF. In addition, it provides for penalties for Persons who receive or distribute LADMF without being certified or otherwise satisfying the requirements of the Act. The Secretary delegated the authority to carry out Section 203 to the Director of NTIS. The final rule for the certification program became effective

program limits access to LADMF information to those persons certified under the program.¹² Certified persons, also called Subscribers, must have a legitimate fraud prevention interest, or have a legitimate business purpose pursuant to a law, governmental rule, regulation, or fiduciary duty in order to be certified under the program. Section 203 requires that NTIS charge fees sufficient to cover the costs associated with the certification program. Information on the cost of using the DMF is available from NTIS at NTIS: Limited Access Death Master File Available Through Value-Added Online Products (https://classic.ntis.gov/products/ssa-online/). A list of current certified users can be found in Appendix D and here: https://classic.ntis.gov/assets/pdf/DMFcertifiedList.docx.

Table 7. Death Master File death records exchanges conducted under Section 205(r) of the Social	
Security Act, as of 25 August 2017	

Benefit-Paying Agencies	Version	Frequency
Centers for Medicare and Medicaid Services	Public+State	Weekly updates
Dept. of Agriculture—Farm Service Agency, Natural Resources Conservation Service, Risk Management Agency	Public+State	Weekly updates & 1 full file in FY 16
Dept. of Defense—Defense Manpower Data Center	Public+State	Monthly updates
Dept. of Housing and Urban Development	Public+State	Weekly & 1 full file in June 2017
Dept. of Veterans Affairs	Public+State	Weekly updates & 1 full file annually
Federal Retirement Thrift Investment Board	Public+State	Monthly updates
Internal Revenue Service	Public+State	Weekly updates & 1 full file annually
Office of Personnel Management	Public+State	Weekly updates & 1 full file annually
Pension Benefit Guaranty Corporation	Public+State	Weekly updates & 1 full file annually
Railroad Retirement Board	Public+State	Monthly updates
Non-Benefit-Paying Agencies		
Government Accountability Office	Public+State	Monthly updates
National Technical Information Service	Public	Monthly & weekly updates & 1 full file quarterly

November 28, 2016.

¹² Executive departments or agencies of the United States Government are not considered "Persons!" for the purposes of this rule; and Executive departments or agencies do not have to complete the Certification Form as set forth in the rule, and can access Limited Access DMF under a subscription or license agreement with NTIS, describing the purpose(s) for which Limited Access DMF is collected, used, maintained and shared. Those working on behalf of and authorized by Executive departments or agencies may access the Limited Access DMF from their sponsoring Executive department or agency, which will be responsible for ensuring that such access is solely for the authorized purposes described by the agency. Unauthorized secondary use of Limited Access DMF by Executive department or agency wishes those working on its behalf to access the Limited Access DMF directly from NTIS, then those working on behalf of that Executive department or agency are required to complete and submit the Certification Form as set forth in the rule and enter into a subscription agreement with NTIS in order to directly access the Limited Access DMF.

Source for information in Table 7: Email with Subject: Users of the 205(r) data: DMF Customers and Death Exchanges, from Tom Klouda, U.S. Senate, August 25, 2017 at 2:19:10 PM EDT.

Sources of information about the Death Master File:

- (1) Department of Commerce, National Technical Information Service, Certification Program for Access to the Death Master File. Federal Register, June 1, 2016, Volume 81, Number 105, pages 34882-34895; available at https://www.gpo.gov/fdsys/pkg/FR-2016-06-01/html/2016-12479.htm.)
- (2) Department of Commerce, National Technical Information Service. List of persons certified to receive the Limited Access Death Master File as of June 1, 2017, available at https://classic.ntis.gov/assets/pdf/DMFcertifiedList.docx; accessed on 4 Oct 2017.
- (3) NAPHSIS: About EVVE FOD, available at https://www.naphsis.org/evve; accessed on 4 Oct 2017.
- (4) NTIS: Limited Access Death Master File (https://classic.ntis.gov/products/ssa-dmf/#; accessed on 4 Oct 2017).
- (5) NTIS: Limited Access Death Master File Available Through Value-Added Online Products, available at https://classic.ntis.gov/products/ssa-online/; accessed on 4 Oct 2017.
- (6) Rothwell CJ (CDC/NCHS), SSA Death Master File & NCHS National Death Index: How do they relate? [Slide Presentation], available at https://www.cdc.gov/nchs/data/bsc/rothwell.pdf; accessed on 9 Oct 2017.
- (7) Social Security Death Master File, available at www.ssdmf.com/; accessed on 4 Oct 2017.
- (8) Social Security: Compilation of the Social Security Laws: Evidence, Procedure, and Certification for Payment: Sec. 205. [42 U.S.C. 405], available at
- https://www.ssa.gov/OP_Home/ssact/title02/0205.htm; accessed on 9 Oct 2017. (9) Social Security: Requesting The Full Death Master File (DMF), available at
- https://www.ssa.gov/dataexchange/request_dmf.html; accessed on 17 October 2017. (10)U.S. Department of Commerce: National Technical Information Service. Important Notice:
- Change in Public Death Master File Records. Available at https://classic.ntis.gov/assets/pdf/import-change-dmf.pdf; accessed on 4 Oct 2017.

Electronic Verification of Vital Events (EVVE)

The <u>E</u>lectronic <u>V</u>erification of <u>V</u>ital <u>E</u>vents, which became operational in 2002 and is operated by NAPHSIS, provides customers with the ability to quickly, reliably, and securely <u>verify birth or death data</u> <u>with or without a paper certificate</u>. State agencies (e.g., DMV, Secretary of State, Medicaid, and Army National Guard) and federal agencies (e.g., SSA, OPM, and Dept of State) actively utilize EVVE to improve business operations and customer service, and to protect against fraudulent activities. Currently, EVVE has about 20 customers, including the following:

- Social Security Administration
- Office of Personnel Management
- Department of Motor Vehicles
- Medicaid Offices
- Department of Homeland Security USCIS
- Department of State Passport Services Fraud Prevention Offices
- Department of State Diplomatic Security
- Army National Guard
- Regional FBI Offices
- Secretary of State Offices

EVVE currently has access to over 250 million birth and death records from state and jurisdiction owned

vital record databases nationwide. (Currently, all states except New York and Texas fully participate in EVVE birth and death verification. All territories participate in EVVE birth verification, but only Puerto Rico participates in EVVE death verification, as the other territories do not currently have electronic death registration.)

Electronic inquiries from authorized users—inquiries that are usually derived from information about a person from a vital record, form, or other document that the user wishes to verify—are sent to the participating state(s) and jurisdiction(s) specified in the query.¹³ The EVVE response to a query notifies the user that the person of interest either matches or does not match an EVVE vital record. If the query matches a record, the user has the choice of obtaining official certification of the record from the relevant state or jurisdiction's vital records office. See Figure 3 below. Most EVVE queries (>97%) are for birth verifications; death verifications, which make up less than 3% of EVVE queries, are more commonly done through EVVE FOD, which is described below.

Figure 3. Steps in the Electronic Verification of Vital Events system for verifying birth and death information



Source: NAPHSIS: About EVVE. Available at https://www.naphsis.org/evve; accessed on 4 Oct 2017.

EVVE users are charged for queries based on the type of query. A <u>verification</u> query is done when the user has a certificate is in-hand, and the query requires data from that certificate. A \$0.55 basic query fee is charged; and if a match is obtained, a \$1.35 jurisdiction fee is charged as well. A <u>certification</u> query is done when the user does not have a certificate; this type of query provides an Electronic Birth Certificate or an Electronic Death Certificate. As such, the jurisdiction fee is the same as the cost for a paper certificate from that jurisdiction; and there is an additional EVVE system fee, which is 18% of the jurisdiction fee in addition to the \$0.55 basic query fee.

EVVE queries currently produce revenues of about \$1.2 million per year. Approximately 80% of the basic query fee goes to the state with the vital record for the person of interest to the user; the remainder of the basic query fee goes to NAPHSIS to support the operation of EVVE.

Source of information about EVVE:

- (1) Email communication with NAPHSIS staff Anthony Stout on 16 Oct 2017.
- (2) NAPHSIS: About EVVE. Available at https://www.naphsis.org/evve; accessed on 4 Oct 2017;

¹³ As part of a future EVVE update, if the user does not know the jurisdiction for the vital event, EVVE will have the ability to "broadcast" the query to all participating EVVE states and jurisdictions.

Electronic Verification of Vital Events Fact of Death (EVVE FOD)

EVVE FOD, which became operational in March 2017 and is owned and operated by NAPHSIS and managed by LexisNexis VitalChek, provides customers with the ability to quickly, reliably, and securely discover if a death record exists. EVVE FOD provides an alternative to the Security Administration's (SSA) Death Master File (DMF) for authorized users to obtain information on the fact of death. (To be authorized, a user must be from one of the 8 following organizational categories: (1) federal benefits agencies, (2) federal administrative agencies, (3) state or local government benefits agencies, (4) state or local government administrative agencies, (5) non-governmental employers providing pension or retirement plans for their employees, (6) insurance companies, (7) companies "in the process of managing [their] assets," and (8) institutions that deal with financial transactions, such as banks. Currently, EVVE FOD has about 11 users.) Currently, 42 vital registration jurisdictions are fully participating in the EVVE FOD system by providing access to authorized categories of users to current, accurate, and complete records of deaths that occur in their jurisdictions. (See Figure 4 for a map showing fully participating states and jurisdictions. *Note that access to death records in these participating states and jurisdictions may vary by the category of user. For example, access for federal agencies providing benefits may differ from the access provided to insurance companies.*)

The EVVE FOD user can submit a single query or a group of queries, usually through the EVVE FOD web page. User queries are sent to all participating states and jurisdictions—based on the user's business category—to be matched against death records from state and jurisdiction owned vital record databases. (Schedule A of the Regulatory Settlement Agreements between state insurance departments and insurance companies specifies the criteria used by EVVE FOD for matching. The criteria include exact Social Security Number (SSN) matches and "fuzzy" matches based on first and last name, date of birth, and SSN.) Once the query has been completed, any matches found will return the date of death as well as the place of death. Depending on where—i.e., the state or jurisdiction—the event occurred, more or less detailed information may be returned.

EVVE FOD users are charged based on (1) the type of user: private (full price), federal government (30% discount), or state or local government (60% discount); and (2) the number of queries submitted per month.¹⁴ NAPHSIS used funds from its "investment reserves" to develop the EVVE FOD product, and revenues from EVVE FOD queries will go to NAPHSIS until development costs have been covered. At that point, net revenue after expenses will be split 50-50 between NAPHSIS and the jurisdictions. How much a jurisdiction participates, its proportionate number of occurrence deaths, and the ability of other jurisdictions to participate will determine the jurisdiction's portion of the net revenues.

Sources of information about EVVE FOD:

- (1) Email communication with NAPHSIS staff Anthony Stout on 16 Oct 2017, 15 Nov 2017, and 16 Nov 2017.
- (2) NAPHSIS: About EVVE FOD. Available at https://www.naphsis.org/evve-fod; accessed on 4 Oct 2017.

¹⁴ The pricing structure for EVVE FOD is available at NAPHSIS: About EVVE FOD: EVVE FOD Questions? Available at https://www.naphsis.org/evve-fod; accessed on 6 Oct 2017.

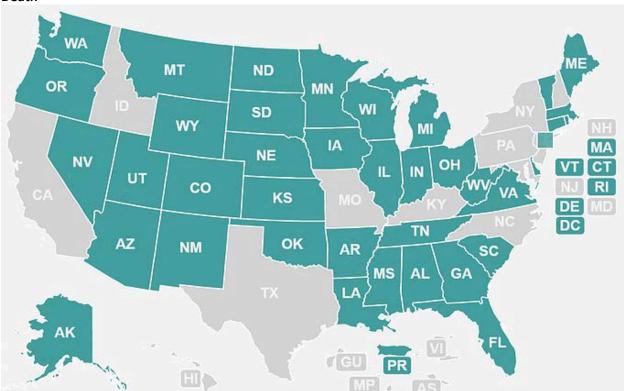


Figure 4. States and jurisdictions fully participating in the Electronic Verification of Vital Events Fact of Death

Participating jurisdictions are shown in green and include New York City. Although not shown on the map, Maryland also participates in EVVE FOD, raising the number of participating jurisdictions to 42. Note that access to death records in these participating states and jurisdictions may vary by the type of user. For example, access for federal agencies providing benefits may differ from the access provided to insurance companies.

Sources:

(1) NAPHSIS: About EVVE FOD: FOD Use Maps. Available at: https://www.naphsis.org/evve-fod, accessed on 6 Oct 2017

(2) email communication with NAPHSIS staff Anthony Stout on 15 Nov 2017.

National Death Index (NDI)

"The 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 2015** 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."

The NDI Retrieval Program is used to search the NDI file to determine whether a particular NDI death record qualifies as a possible record match with a particular user record. To qualify as a possible record match, both records must satisfy at least one of seven conditions or matching criteria, and the specified data items must agree on both records. Chapter 4 of the NDI User Guide provides a complete list of the matching criteria. To facilitate matching, NDI users are encouraged to submit as many of the following data items as possible for each study subject: first and last name, middle initial, father's surname, social security number, month, day, and year of birth, race, sex, marital status, state of residence, and state of birth.

Researchers can request either a *routine* NDI search for those who do *not* need cause of death codes, or an NDI *Plus* search, which also provides cause of death codes. The cost for using the NDI consist of (1) a service charge (\$350 for initial submission and \$100 for each subsequent submission); (2) a cost per subject with unknown vital status x the number of years searched (\$0.21 per subject per year for NDI *Plus* or \$0.15 per subject per year for NDI *Routine*); and (3) a fixed cost for each subject known to be deceased (\$5.00 when researcher has no death certificate or \$2.50 when researcher has death certificate).¹⁵

Source of information above and additional information on the NDI are available at CDC: NCHS: National Death Index, https://www.cdc.gov/nchs/ndi/index.htm; accessed on 9 Oct 2017.

State and Territorial Exchange of Vital Events system (STEVE)

NAPHSIS began planning the <u>S</u>tate and <u>T</u>erritorial <u>E</u>xchange of <u>V</u>ital <u>E</u>vents system (STEVE) in spring 2006 with conversations about the potential for an information exchange system and how it could be funded. A meeting to gather functional requirements was held October 31–November 1, 2006. STEVE became operational in fall 2008 and allowed vital records jurisdictions to electronically complete the following transactions:

- (1) sending statistical data to the National Center for Health Statistics for inclusion in the National Vital Statistics System,
- (2) sending vital records that pertain to residents in other jurisdictions so the home state's reports include these important data,
- (3) sending death information to the jurisdiction of birth so that birth certificates can be flagged as 'deceased,' an important step in preventing fraud and identity theft, and
- (4) providing data to authorized data partners for use in authorized public health and administrative purposes, such as newborn hearing screening, cancer registries, the National Violent Death Registration System, and voter registration.¹⁶

The administrative foundation for the exchange among jurisdictions and authorized data partners is a legal agreement called the Interjurisdictional Exchange of Vital Records (IJE) Agreement, which establishes what data a state or jurisdiction will share and will not share. The IJE Agreement allows a

¹⁵ Costs were effective as of October 1, 2004. Additional information on NDI user fees is available at https://www.cdc.gov/nchs/data/ndi/ndi_user_fees_worksheet.pdf; accessed 9 Oct 2017.

¹⁶ The list of authorized data partners is included in the Interjurisdictional Exchange of Vital Records (IJE) Agreement.

jurisdiction to share any of the following six IJE layouts with any other resident jurisdiction and NCHS:

- (1) natality
- (2) mortality
- (3) mortality roster
- (4) fetal death
- (5) birth-infant death
- (6) induced termination of pregnancy

STEVE is the mechanism by which the IJE Agreement is operationalized. STEVE was a software application that was installed in every vital records jurisdiction, most often on a server within the domain of what became a centralized information technology (IT) department. The software encrypted and sent data to NCHS, other jurisdictions, and the authorized data partners mentioned above. Specifically, required data for IJE layouts were extracted from a jurisdiction's electronic birth, infant death, and death registration systems and then transferred into STEVE. STEVE then distributed the first section of each layout to NCHS¹⁷; next, it parsed the remaining data according to the rules of the IJE Agreement and distributed appropriate data to other jurisdictions and data partners. Upon arrival at the recipient's electronic mailbox, data files were decrypted by STEVE and could be opened in Excel format.

By 2015, STEVE had been updated several times, and several versions were in use across the country. Several STEVE software components had reached "end-of-life" status, and IT departments were concerned about the security risks that STEVE presented to their networks and were reluctant to continue to host STEVE.¹⁸ In 2015, the NAPHSIS Board decided that an entire STEVE "rebuild" would be necessary, and in September 2015, NAPHSIS held a functional requirements meeting to draft specifications for STEVE 2.0.

NAPHSIS and its members released STEVE 2.0 in late 2016 to provide greater functionality, flexibility, and security than the original STEVE software (STEVE 1.0). Development of STEVE 2.0 cost about \$550,000, and annual support and maintenance costs are expected to cost about \$150,000. Each vital registration jurisdiction contributed \$5,000 to help pay for the development of STEVE 2.0 in 2016; the annual STEVE 2.0 support and maintenance fee for 2017 for each jurisdiction is \$3,500.

STEVE 2.0 performs the same functions as STEVE 1.0 and uses the same IJE layouts. In contrast to STEVE 1.0, STEVE 2.0 uses a "web-based user interface with a cloud-based infrastructure hosted on the Association of Public Health Laboratories' (APHL) APHL Informatics Messaging Services (AIMS) platform to provide states and territories with bi-directional core messaging capabilities." STEVE 2.0 can be operated in manual mode from workstations within the vital records office rather than on a server within the IT department. Jurisdictions can automate sending and receiving data through STEVE 2.0, which must be coordinated with the jurisdiction's IT department to assure the security of the data and the continued operation of the STEVE 2.0 service.

¹⁷ The information from the first section of each layout that is sent to NCHS—as well as to other jurisdictions—is the central component of the Vital Statistics Cooperative Program contract NCHS holds with each jurisdiction.
¹⁸ Many jurisdictions had to apply for exceptions to IT security requirements to keep STEVE in operation. While its software was outmoded, NAPHSIS felt that there was little to no danger of a breach because of the way the software was designed and the components it used. On the other hand, the STEVE software could became unstable if even one jurisdiction had technical trouble, which was usually related to changes made to server environments by state or jurisdiction IT departments and to the frequent need to update security certificates to allow PHINMS to run.

Between late December 2016 and late September 2017, STEVE 2.0 relayed over 66 million messages. Its only significant outages have been the result of reliance on the aging PHINMS system, not due to its own infrastructure. Security certificates are upgraded in one location, thereby relieving jurisdictions of this task, which was one of the limiting factors of STEVE 1.0. In addition, STEVE 2.0 has a modular design, which allows upgrades and enhancements with little or no downtime. Because STEVE 2.0 resides on the AIMS platform, it is able to handle HL7 and other messaging protocols and take advantage of a variety of technical methods for automation.

information systems based on		•				
	Full DMF	LADMF	EVVE	EVVE FOD	NDI	STEVE
Data item						
Name, First	х	х	х	х	Х	NA
Name, Last	х	х	х	х	Х	NA
DOB	х	х	х		х	NA
DOD	х	х	х	х	х	NA
Sex			х	х	х	NA
SSN	х	х			х	NA
Birth Certificate #			х			NA
Death Certificate #			х	х	х	NA
Jurisdiction of birth			Х			NA
Jurisdiction of death			х	х	х	NA
Cause of death					х	NA
Coverage						
Number of participating U.S.	57	0	55*	42†	57	57
vital registration jurisdictions						
% U.S. birth records	NA	NA	~87%	NA	NA	NA
% U.S. death records	>98%**	~60%++	~90%	>65%	100%	NA
Years covered	1936-	1936–	1800s-	1800s-	1979-	NA
	2017	2017	2017‡	2017‡	2016	

Table 8. Data items, vital registration jurisdictions, and years of data accessible through six
information systems based on vital records that provide data about vital events to various users

NA = Not applicable

* EVVE does not currently include births and deaths from New York State and Texas.

† Number of participating jurisdictions varies by the intended use of the data.

** The author was unable to confirm this estimate of % U.S. death records with SSA. The estimate applies to deaths that occurred after ~2000 and is based on the assumption that virtually all deaths are currently reported to SSA through either jurisdiction-based EDRS, jurisdiction-based data files containing data needed by SSA for the DMF, or copies of death certificates submitted to SSA by jurisdictions unable to send electronic data files.

++ The author was unable to confirm this estimate of % U.S. death records with SSA. The estimate applies to deaths that occurred after ~2011 and is based on the assumption that SSA does <u>not</u> receive data from non-VRO sources for about the 40% of deaths that occur each year in the United States.
+ The first year for which vital events data are available varies by jurisdiction.

Sources of information for Appendix C:

(1) CDC: NCHS: National Death Index, https://www.cdc.gov/nchs/ndi/index.htm; accessed on 9 Oct 2017.

- (2) Department of Commerce, National Technical Information Service, Certification Program for Access to the Death Master File. Federal Register, June 1, 2016, Volume 81, Number 105, pages 34882-34895; available at https://www.gpo.gov/fdsys/pkg/FR-2016-06-01/html/2016-12479.htm.)
- (3) Department of Commerce, National Technical Information Service. List of persons certified to receive the Limited Access Death Master File as of June 1, 2017, available at https://classic.ntis.gov/assets/pdf/DMFcertifiedList.docx; accessed on 4 Oct 2017.
- (4) Email communication with NAPHSIS staff Andrea Price and Bill Bolton on 13 Oct 2017.
- (5) Email communication with NAPHSIS staff Anthony Stout on 16 Oct 2017.
- (6) Email communications with NAPHSIS Executive Director Shawna Webster on 12–13 Dec 2017.
- (7) NAPHSIS: About EVVE FOD, available at https://www.naphsis.org/evve; accessed on 4 Oct 2017.
- (8) NAPHSIS: About EVVE FOD: FOD Use Maps. Available at: https://www.naphsis.org/evve-fod; accessed on 6 Oct 2017
- (9) NAPHSIS: About EVVE. Available at https://www.naphsis.org/evve; accessed on 4 Oct 2017; email communication with NAPHSIS staff Anthony Stout on 16 Oct 2017.
- (10)NAPHSIS: Information systems for vital records stewardship: STEVE: available at https://www.naphsis.org/systems, accessed on 6 Oct 2017;
- (11)NAPHSIS: STEVE 2.0: available at https://www.steve2.org, accessed on 6 Oct 2017;
- (12)NTIS: Limited Access Death Master File (https://classic.ntis.gov/products/ssa-dmf/#; accessed on 4 Oct 2017).
- (13)NTIS: Limited Access Death Master File Available Through Value-Added Online Products, available at https://classic.ntis.gov/products/ssa-online/; accessed on 4 Oct 2017.
- (14)Rothwell CJ (CDC/NCHS), SSA Death Master File & NCHS National Death Index: How do they relate? [Slide Presentation], available at https://www.cdc.gov/nchs/data/bsc/rothwell.pdf; accessed on 9 Oct 2017.
- (15)Social Security Death Master File, available at www.ssdmf.com/; accessed on 4 Oct 2017.

(16)Social Security: Compilation of the Social Security Laws: Evidence, Procedure, and Certification for Payment: Sec. 205. [42 U.S.C. 405], available at

https://www.ssa.gov/OP_Home/ssact/title02/0205.htm; accessed on 9 Oct 2017.

(17)Social Security: Requesting The Full Death Master File (DMF), available at https://www.ssa.gov/dataexchange/request_dmf.html; accessed on 17 October 2017.

(18)U.S. Department of Commerce: National Technical Information Service. Important Notice: Change in Public Death Master File Records. Available at https://classic.ntis.gov/assets/pdf/import-change-dmf.pdf; accessed on 4 Oct 2017.

(19)UberOps, NAPHSIS. STEVE v2.0 High Level Design: available at https://www.steve2.org/#/resources, accessed on 6 Oct 2017; and

Appendix D. List of persons certified to receive the Limited Access Death Master File as of June 1, 2017

Source: National Technical Information Service: Limited Access Death Master File: List of persons certified to receive the Limited Access Death Master File, available at https://classic.ntis.gov/assets/pdf/DMFcertifiedList.docx; accessed on 9 Oct 2017.

Arizona Department of Transportation-MVD Abacus Settlements, LLC Access2care LLC Acxiom Corporation **ADP Screening & Selection Svcs** ADP Screening and Selection Scvs AETNA Inc. (Aetna Medicaid Administrators) AIS Recovery Solutions LLC Albany-Schoharie-Schenectady-Saratoga Boces dba Capital **Region Boces** Alegent Health Creighton Saint Joseph Managed Care Services Alliance One International Inc. Alphacare of New York Altru Health System American Express American Family Archives & Chronicles Dba Obituarydata.Com American Fidelity Life Ins. Co American Health and Life **Insurance Company** American Heritage Federal Credit Union American Research Bureau American Underwriters Life Insurance Amerigroup AMGI Multispecialty Group D/B/A Esse Health Anchor Computer Inc. Ann Arbor VA Healthcare System (Sub is under Ann Arbor VA Medical Center) Anselmo Lindberg Oliver LLC Anthem, Inc. Aperture Credentialing LLC

Apollo Education Group Inc. Appriss Inc. AR DFA Individual Income Tax Section Arizona Health Care Cost Containment System (AHCCCS) Asset Protection Unit Inc. **Associated Press** Aurora Health Care Automation Research Inc. Avera Health Avesis Incorporated & **Subsidiaries** BAE Systems, Inc. Bank Compensation Consulting Bank of America Mortgage Data Technology Group **Baylor Heart and Vascular** Institute BCBSM, Inc., D/B/A Blue Cross and Blue Shield of Minnesota Becklin Research Inc. **Bellmore-Merrick Central High** School District Benefit Allocation Systems Inc. Benefit Plan Manager Benevis. LLC Beth Israel Deaconess Medical Center Blue Cross & Blue Shield of Montana Blue Cross & Blue Shield of Texas Blue Shield of California Bluebonnet Life Insurance Co. Board of Trustees of Leland Stanford Junior University, On Behalf of Its School of Medicine Boetger & Associates Inc. & Northwest Savings Bank **Boone County Fire Protection**

District Borgess Health **Boston Medical Center** Healthnet Plan Boston Mutual Life Insurance Company **Boston Scientific Boston University** Brigham & Women's Hospital Copdgene Study Brightpoint Brown & Brown of Pennsylvania, LP **BWW Law Group LLC** California Insurance Guarantee Association (CAIGA) California State Controller's office Division of Audits **Cambia Health Solutions** Capital Forensics Inc. Careington International Corporation Caris MPI, Inc. **Carpenters Combined Funds** Inc. Catalist, LLC Catholic Life Insurance **Catholic Relief Services CBIZ Benefits & Insurance** Services, Inc. **CDYNE** Corporation Central Research Inc. Central States Health and Life Co. of Omaha Central States Indemnity Co of Omaha and CSI Life Central Texas Community Health Centers DBA Communitycare Chan Healthcare, A Subsidiary of Crowe Horwath LLP

Charlotte-Mecklenburg Hospital Authority AKA Carolinas Healthcare System Chatham County Government Children's Hospital of Philadelphia **Chronic Disease Research** Group (CDRG) CIGNA (LINA) (PA) CIGNA Health & Life Insurance Co. On Behalf of Self and **Subsidiaries** City of Bristol City of Buffalo City of Hoboken City of Niagara Falls, NY City of Rochester City of Sanibel **Clarity Services Inc.** Clinical Reference Laboratory, Inc. Colorado Department of Revenue Columbia University Columbia Valley Community Health Columbian Mutual Life **Insurance Company** Comerica Bank Commonwealth of Massachusetts, Office of State Auditor Commonwealth of Pa, Insurance Dept., Bureau of Special Funds, Workers' Comp Security Fund, Auto Cat Fund Community Care Network of VA **Comprehensive Health** Management - WellCare Computer Services, Inc. **Concordia Plan Services Confluence Health** Consol Energy Inc. - CNX Land LLC Cookeville Regional Medical Center **Coordinated Care Corporation** dba Managed Health Services

Corelogic Solutions, LLC **Cornerstone Education Loan** Services CreDENTIALS Services Inc. dba Verifpoint/Credentialing Solutions Credit Shop Inc. Cross Country Computer Corp **Crump Life Insurance Services** D Greene & Company Data Center Inc. (DCI) Datalab USA Dataline Inc. DCM Services LLC DCS Information Systems **Dearborn National Life** Insurance Company of New York Delta Dental of Puerto Rico, Inc. Department of Community Services & Development (HEAP) Dillard's Inc. **Discover Bank** Discover Products, Inc. **DISH Network, LLC** Doyle & Foutty, PC DST Systems, Inc. Duke Cardiovascular Magnetic **Resonance Center Duke Patient Revenue** Management Organization Early Warning Services LLC East Syracuse Minoa Central School District Echo, Inc. EECS LLC **Electronic Medical Office** Logistics (EMOL) Emblem Health **Employment Screening Services** Inc. Equitable Life & Casualty Insurance Company **Essen Medical Associates PC** Essentia Health Estate Information Services, LLC **Everyone Counts Inc. Evolution Consulting LLC**

Examone Experian Health Inc. Experian Marketing Services Express Scripts Holding Company Extend Health Inc., Willis **Towers Watson** Fair Isaac Corporation Fannie Mae Farm Bureau Life Insurance Company of Missouri **Fast Data Services** Federation of State Medical Boards FHC of Puerto Rico Inc. **Fiduciary Trust Company** International Financial Industry Regulatory Authority Inc. (FINRA) **First American Financial** Corporation First County Bank **Flagstar Bank** Flatiron Health Inc. Florida Department of Corrections Florida Department of Highway Safety and Motor Vehicles Florida Department of State Florida Hospital Orlando Foresters Life Insurance and Annuity Company Franchise Tax Board Franciscan Health System Freeman Physician Hospital Organization - FPHO - Freeman Health System Fresenius Medical Care, North America Fuzion Analytics Inc. Gabriel Roeder Smith & Company Garretson Resolution Group Geisel School of Medicine at Dartmouth College, Dartmouth-Hitchcock Medical Center **Geisinger Clinic** General Board of Pensions

General Information Services Inc. **Genworth Financial** Georgia Department of Revenue **GMG Health Systems** Associates, Pa dba, Gonzaba Medical Group Golden Gate Bridge, Highway & **Transportation District** Gorra Childrens Trust Great Lakes Educational Loan Services **Guardian Research Network** Inc. **Guidestone Financial Resources** Gundersen Lutheran Admin Svcs. Inc. Hannis T. Bourgeois, LLP Hart Software, Inc. Harvard University Institute for Quantitative Social Science Hattiesburg Clinic, PA Hawaii Medical Service Administration (Hmsa) Headco Industries. Inc. Health Network Solutions Inc. Health One Alliance Health Plan of The Upper Ohio Valley Inc. Healthcore Inc. Healthfirst Management Services, LLC Healthmarkets Inc. Healthpartners Inc. Healthplex **Heart Imaging Technologies** LLC, A Delaware Corporation Hennepin County Medical Center Heritage Pension Advisors LLC Heritage Provider Network Hewlett Packard Enterprise (OH) Hewlett Packard Enterprise (WI) **Highlands Wellmont Health** Network HME Recovery, LLC

HMS Inc. - Health Management Systems Inc. HS1 Medical Management Inc. HubHealth of South Mississippi, Inc. Humana Inc. **Huntington Hospital** HygenicsData LLC Icahn School of Medicine at Mount Sinai ID Analytics, LLC Idaho Transportation Department, Division of Motor Vehicles Idology Inc. Illinois Dept of Healthcare & Family Services Office of Inspector General Illinois Office of The Auditor General Imc Salud - First Medical Health Plan Inc. Impac Medical Systems, an Elekta Company Impact Makers Inc. Indecs Corporation Infutor Data Solutions LLC Inogen, Inc. Inova Health System Inspira Institute for Fair Elections **Integrated Solutions Health** Network Intellicorp Records Inc. Interactive Data LLC Interlife America Inc. International Union, UAW Invenio, LLC Ivision International of Puerto Rico Inc. Jackson Clinic, PA John Hancock Life Insurance Company USA (John Hancock Mutual Life Ins. Co) John Hopkins Hospital Johns Hopkins Bloomberg School of Public Health JP Morgan Chase

Kansas Department of Revenue Kansas Department of Revenue - State of Kansas Karmadata. Inc. Keck Medicine of USC Kelmar Associates Keyport Investors, LLC **Kinnect Services** L2 Inc. Labor-Management Healthcare Fund Lake Huron PHO Layline Energy, LLC Formerly Known as Layline Petroleum, LLC Leadership Institute LeadsOnline LLC Legacy Health Lexis Nexis Risk Data Retrieval Services LLC Life Assurance Fund Operating Company Life Status 360, LLC Lifeplans, Inc. Loews Corporation Louisiana Department of Revenue LTC Partners Lutheran Church-Missouri Synod Foundation (LCMS Foundation) M&A Profilers, Inc. dba Colley Investigations M2s, Inc. Maine Revenue Services Mary's Center Massachusetts Department of Revenue Massachusetts Department of Unemployment Assistance Massachusetts Mutual Life Insurance Company, C.M. Life Insurance Company, MML Bay State Life Insurance Company, And MML Investors Services LLC MassDOT Registry of Motor Vehicles Maximus Health Services, Inc.

McDermott Will & Emery LLP **McKesson Specialty Health** MDeverywhere Inc. Medica Health Plans **Medical Provider Resources** Medimore, Inc. Medtronic PLC Medversant Technologies LLC Melissa Data Corporation Memorial Health Services/Memorial Health Care System Memorialcare Health System Menno Haven Inc. Mercy Mercy Medical Center - Des Moines Mercy of Iowa City Regional **Physician Hospital Organization** (PHO) **Methodist Health Partners** Metlife Metro Plus Health Plan **Metrocare Physicians** Metropolitan Health Plan Mhmr of Tarrant County Mib Solutions Inc. Michael Moecker & Assocciates Michigan (Mi) Department of HIth & Human Services Michigan Department of State **Microbilt Corporation** Midwest Employers Casualty Company Milliman Inc. Minnesota Department of **Human Services** Mission Hospital, Inc. Mississippi Department of Revenue (Ms Dept of Revenue) Missouri Secretary of State **Modesto Irrigation District** Mohela **Molina Medicaid Solutions** Monroe 2-Orleans BOCES Montefiore Information Technology **Multicare Health System**

Multiplan Inc. Multiple Injury Trust Fund Muscogee (Creek) National Citizenship office National Benefit Life National Council of The State Boards of Nursing (NCSBN) National Jewish Health National Medtrans Network Naveos LLC Navigant Consulting Inc. Navion Healthcare Solutions, LLC NCAN Services, Inc. Nebraska Health Partners Neighborhood Health Plan of Rhode Island Nelnet Service, LLC Nelnet Servicing, LLC Network Solutions IPA New Jersey Division of Taxation New Mexico Taxation And **Revenue Department** New York City Department of Housing Preservation And Development (HPD NYC) New York Methodist Hospital New York State Catholic Health Plan Inc. (D/B/A Fidelis Care) New York State Office of The State Comptroller - Office of **Unclaimed Funds** New York State Office of The State Comptroller, New York State and Local Retirement System New York State Teachers' **Retirement System** New York-Presbyterian Hospital NJ Division of Family Development, Dept. of Human Services NJ Motor Vehicle Commission North Carolina Department of Information Technology North Mississippi Health Link, Inc. Northeast Escrow Services LLC

Northshore University Healthsystem Nova Management Services Inc. NY State Dept. of Tax & Finance (New York State Department of Taxation and Finance) NYS Gaming Commission Office of The Chief Financial officer, Office of Tax & Revenue (Washington, DC) Office of The Texas Secretary of State Ohio Department of Taxation **Ohio Public Employees Retirement System** Ohio State University Wexner Medical Center **Oklahoma Tax Commission Olmsted Medical Center** Onco Inc. One Source Technology dba Asurint **OPENonline**, LLC Optum Optuminsight, Inc. (KS) Optumrx OSI Vision, LLC Ozark National Life Insurance Company Painters Union Pension Fund Palladian Health LLC Partners Healthcare System Inc. Peacehealth CVO Pediatric Associates Saltzman, Tanis, Pittel, Levin Penn Medicine Pennsylvania Higher Education Assistance Agency (PHEAA) Pension Benefit Information Inc. Phin Solutions Inc. Pinnacle Care Inc. Plainedge UFSD PNT Data Corp Pointright Inc. Pointserv Technologies, LLC Polish National Alliance of The U.S. of North America

Political Data Inc. Pondera Solutions, Inc. Port Authority of New York (NY) & New Jersey (NJ) **PRA Receivables Management** LLC **Preston Ventures LLC** Pricewaterhousecoopers Primerica Life Insurance Company **Primewest Health PrIncipal Financial Group** Probate Recovery Systems LLC **Professional Credential** Verification Service Inc. (PCVS) **Progressive Data Services Providence Health and Services** Prudential **PSC-CUNY Welfare Fund** P-Solve, LLC Public Health - Seattle & King County **Q** Capital Strategies LLC Quantum3 Group LLC R L Polk & Co Rapidcourt LLC Regenstrief Institute, Inc. **Regional Justice Information** Service **Reliance Standard Life** Insurance Company Ri Executive office of Health & Human Services **Riversource Life Insurance** Company and Riversource Life Insurance Co. of New York Rush University Medical Center Rutgers, The State University of New Jersey, office of Enterprise **Risk Management** Saint Francis Health System Saint Joseph Mercy Health System (sub under St Joseph Mercy Hospital) Sallie Mae Bank Sandhills Center for MH/DD/SAS Santa Barbara Tax Products

Group Savannah College of Art and Design Schoedinger Funeral Service Scion Dental Screen Actors Guild Producers Pension Plan - SAG Pension Health Plan Scripps Health SE2, LLC Seattle Children's Hospital, **Medical Staff Services** Securecare Inc. Securian Financial Group Inc. Security Mutual Life Insurance Company of New York Security Software Solutions Select Medical Sensient Technologies Corporation Sentara Healthcare Sentinel Security Life Insurance Service Corporation International (SCI) Seton Insurance Services Sharp Healthcare Signature Bank Simpson Thacher & Bartlett, LLP Skagit County Public Hospital, District 1 Slome Capital Corp South Carolina PEBA South Carolina State Election Commission Southeastrans Southern Financial Life Insurance Co Southwest Medical IPA Alliance SSDC Services St Barnabas Hospital St Jude Medical, Inc. Stanislaus County District Attorney's office State Bar of Texas State Compensation Insurance Fund State Farm Life Insurance Companies

State of Delaware, Division of Revenue State of Illinois Department of Revenue State of Michigan, Department of Treasury, Discovery & Tax Enforcement State of Rhode Island **Department of Human Services** State of Tennessee HCFA **Bureau of TENNCARE** Stern & Eisenberg PC Stony Brook University Hospital Stony Brook University of School Medicine Streamline Verify Subsequent Injury Fund Sumo Group Inc. SUNY College of Optometry/University Eye Center SUNY Upstate University Hospital Surety Life & Casualty Insurance Company Sutherland Healthcare Solutions, Inc. Sutter Health Sutter Shared Services Swedish Health Services **Technosoft Corporation Tenet Healthcare Corporation** Tennessee Department of Correction **Texas Vascular Associates** The Advisory Board Company The Berwyn Group Inc. The Bessemer Group, Inc. The Brooklyn Hospital Center The Everett Clinic The Guthrie Clinic The Ministers and Missionaries Benefit Board (MMBB) The Polyclinic The Verification Group **Thomson Reuters** TINCheck, LLC Toolcase LLC

Tougaloo College Transamerica Life Insurance **Company and Its Affiliates** Transunion LLC **Transunion Risk and Alternative** Data Solutions, Inc. **Trico Products Corporation** Triple-S Salud, Inc. **Triplus Services Inc.** Truven Health Analytics, An IBM Company Typhoon Data, LC **UAB** Transplant Informatics UAMS - MIRT (Board of Trustees of The University of Arkansas Acting for and on Behalf of The University of Arkansas For Medical Sciences) UC San Diego Health Udren Law offices, Pc **UMC** Physicians **UMWA Health & Retirement** Funds **UNCAS & Company** Universal Life Insurance Company Universal Patient Key Inc. University (Univ) of Wisconsin (WI) School of Medicine University Clinical Health University Health Shreveport University Health System University of California San Francisco (UCSF) Interstitial Lung Disease Program University of Chicago University of Iowa Clinical Staff office University of Kansas Hospital University of Kansas Medical **Center - Greater Plains Collaborative Clinical Data Research Network** University of Maryland Baltimore, Department of Anesthesiology

University of Massachusetts Medical School University of Michigan Health System University of Mississippi Medical Center University of North Carolina At Chapel Hill, Collaborative Studies Coordinating Center University of Pittsburgh University of Texas Southwestern Medical Center University of Vermont Health Network (Credentialing & Enrollment Department) University of Vermont Medical Center University of Virginia University of Washington School of Medicine (UW SOM) office of Medical Staff Appointments University Physicians' Association Inc. University Physicians Network LLC **Unum Group** UPCR LLC UPMC Usable Life Insurance Company UTG Inc. UW Medicine Valley Medical Center Valence Health VCU Health System Venio LLC Dba Keane Verafin Inc. Verato, Inc. Verisk Analytics, Inc. Verisys Corporation Verizon Communications Verus Financial LLC Virginia Department of Elections Virtua Visa Inc., including Its Wholly

Owned Subsidiary Advanced Resolution Services, Inc. (Visa Inc.) Visions Federal Credit Union Vital Decisions, LLC Wake Forest Baptist Medical Center Walla Walla Clinic Washington (WA) State Social and Health Services Washington State Board for Volunteer Firefighers And **Reserve officers** Washington State Department of Labor and Industries Wayne State University Physician Group WEA Insurance Corporation Welland Company Wellplace, MI West Virginia Clinical and Translational Science Institute (WVCTSI) West Virginia United Insurance Services, Inc./Health Partners Network. Inc. Westchester Management Services Organization, LLC Western Psychological and **Counseling Services Pc** Western Union Westmed Practice Partners Westside Family Healthcare Inc. Wheaton Franciscan Healthcare-Iowa, Inc. D/B/A Covenant Centralized **Credentials Verification** Organization WI Insurance Security Fund Will Notification LLC Willis-Knighton Health System Wisconsin Department of Revenue Xerox State & Local Solutions Inc. Zebu Compliance Solutions

Appendix E. Cost estimate for Vital Records Systems in the United States

(1) <u>Estimated population of 10 states in 2013</u>: 65,143,263 (10 states are AL, FL, IL, KS, OK, MD, MI, ND, OR, and VT)
 (Source: https://www.census.gov/data/tables/2016/demo/popest/state-total.html)

 (2) <u>Estimated population of New York City in 2013</u>: 8,405,837
 (Source: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=PEP_2014_PEPANN RES&prodType=table)

(3) <u>Total estimated population of for 10 states and NYC in 2013</u>: 65,143,263 + 8,405,837 = 73,549,100

(4) Estimated cost of Vital Records System for 10 states and NYC in 2013: 2 x \$16,624,274 = \$33,248,548 (Estimate is based on assumptions that these 10 states and NYC are representative of the United States as a whole, and that SSA payments for Enumeration at birth (EAB) to these 11 jurisdictions, i.e., \$3,324,855, is 20% of the cost for their birth systems and that the cost of their death systems is the same as the cost for birth systems.)*

(5) <u>Estimated population of United States in 2013</u>: 316,204,908 (Source: https://www.census.gov/data/tables/2016/demo/popest/state-total.html)

(6) <u>Proportion of U.S. population in 10 states and NYC in 2013</u>: 73,549,100/316,204,908 = 0.232599489

(7) <u>Estimated cost of Vital Records Systems for United States in 2013</u>: \$33,248,548/0.232599489 = \$142,943,341.

(8) Estimated cost per capita for Vital Records Systems for United States in 2013: \$33,248,548/73,549,100 = \$0.452059209.

*Estimate based on information gathered by Jennifer Woodward, Manager of the Oregon Center for Health Statistics, and NAPHSIS in 2013 as background for cost estimates for vital records.

Appendix F. Availability and cost of birth, death, and fetal death certificates and number of births, deaths, and fetal deaths registered, by vital registration jurisdiction, United States, 2016.

				Cost of ce	rtificates				
	Availability	y of certificates	В	irth	D	eath	Numbe	er of events,	2016
									Fetal
Jurisdiction	Birth	Death	First	Additional	First	Additional	Births	Deaths	Deaths
Alabama	Closed	Closed	\$15.00	\$6.00	\$15.00	\$6.00	57,647	51,431	500
Alaska	Closed	Closed	\$30.00	\$25.00	\$30.00	\$25.00	11,095	4,355	74
American Samoa	Closed	Closed	\$5.00	\$5.00	\$5.00	\$5.00	1,077	281	12
Arizona	Closed	Closed	\$20.00	\$20.00	\$20.00	\$20.00	85,573	57,215	527
Arkansas	Closed	Closed	\$12.00	\$12.00	\$10.00	\$8.00	36,913	31,028	207
California	Open*	Open	\$25.00	\$25.00	\$21.00	\$21.00	489,976	263,201	2,400
Colorado	Closed	Closed	\$17.75	\$10.00	\$20.00	\$13.00	67,183	38,151	396
Connecticut	Closed	Open	\$30.00	\$15.00	\$20.00	\$20.00	37,467	30,641	172
Delaware	Closed	Closed	\$25.00	\$25.00	\$25.00	\$25.00	11,415	8,980	72
District of Columbia	Closed	Closed	\$23.00	\$23.00	\$18.00	\$18.00	14,847	6,055	157
Florida	Closed	Closed*	\$14.00	\$14.00	\$5.00	\$4.00	225,260	199,964	1,627
Georgia	Closed	Open	\$25.00	\$5.00	\$25.00	\$5.00	130,961	81,783	8,304
Guam	Closed	Closed	\$5.00	\$5.00	\$5.00	\$5.00	3,433	1,021	35
Hawaii	Closed	Closed	\$10.00	\$4.00	\$10.00	\$4.00	18,057	11,041	814
Idaho	Closed	Closed	\$16.00	\$16.00	\$16.00	\$16.00	22,179	13,297	128
Illinois	Closed	Closed	\$10.00	\$2.00	\$19.00	\$4.00	150,789	104,092	944
Indiana	Closed	Open*	\$10.00	\$4.00	\$8.00	\$4.00	83,983	64,051	569
lowa	Open	Open	\$20.00	\$20.00	\$20.00	\$20.00	39,094	29,318	174
Kansas	Closed	Closed	\$15.00	\$15.00	\$15.00	\$15.00	39,317	25,489	195
Kentucky	Open	Open	\$10.00	\$10.00	\$6.00	\$6.00	53,062	47,606	345
Louisiana	Closed	Closed	\$15.00	\$15.00	\$7.00	\$7.00	63,277	44,411	368
Maine	Closed	Closed*	\$15.00	\$6.00	\$15.00	\$6.00	12,477	14,069	55
Maryland	Closed	Closed	\$10.00	\$10.00	\$10.00	\$12.00	73,544	47,235	526
Massachusetts	Open*	Open	\$20.00	\$20.00	\$20.00	\$20.00	71,935	57,861	372
Michigan	Closed	Open	\$34.00	\$16.00	\$34.00	\$16.00	112,340	98,840	623
Minnesota	Closed	Open	\$26.00	\$19.00	\$13.00	\$6.00	69,831	43,134	460
Mississippi	Closed	Closed	\$15.00	\$5.00	\$15.00	\$5.00	57,139	31,016	410
Missouri	Closed	Closed*	\$15.00	\$15.00	\$13.00	\$10.00	75,864	61,888	456
Montana	Open*	Open	\$12.00	\$5.00	\$15.00	\$8.00	12,280	9,941	55
Nebraska	Closed		\$17.00	\$17.00	\$16.00	\$16.00	27,101	16,400	138
Nevada	Open*	Closed	\$20.00	\$20.00	\$20.00	\$20.00	35,915	24,692	230
New Hampshire	Closed	Closed	\$15.00	\$10.00	\$15.00	\$10.00	12,350	11,909	56
New Jersey	Closed	Closed	\$25.00	\$2.00	\$25.00	\$2.00	100,379	72,082	667
New Mexico	Closed	Closed	\$10.00	\$10.00	\$5.00	\$5.00	23,322	177,632	98
New York City	Closed	Closed	\$15.00	\$15.00	\$15.00	\$15.00	120,367	54,280	12,068
New York State	Closed	Closed	\$30.00	\$15.00	\$30.00	\$15.00	114,494	98,766	5,172
North Carolina	Open	Open	\$24.00	\$15.00	\$24.00	\$15.00	122,780	91,349	933
North Dakota	Closed	· ·	\$7.00	\$4.00	\$5.00	\$2.00	13,035	6,806	76
Northern Marianas	Closed	Closed	\$20.00	\$20.00	\$15.00	\$15.00	1,217	222	11
Ohio	Open	Open	\$21.50	\$21.50	\$21.50	\$21.50	138,570	119,618	893
Oklahoma	Closed*	Closed*	\$15.00	\$15.00	\$15.00	\$15.00	51,319	38,170	308
Oregon	Closed	Closed	\$25.00	\$20.00	\$25.00	\$20.00	45,533	35,799	186
Pennsylvania	Closed	Closed	\$20.00	\$20.00	\$9.00	\$9.00	138,637	134,523	1,257
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				Cost of ce	rtificates				
Availability of certificates		Birth		Death		Number of events, 2016			
	-								Fetal
Jurisdiction	Birth	Death	First	Additional	First	Additional	Births	Deaths	Deaths
Puerto Rico	Closed	Closed	\$5.00	\$10.00	\$10.00	\$10.00	28,326	29,626	419
Rhode Island	Closed	Closed	\$20.00	\$15.00	\$20.00	\$15.00	11,430	10,023	697
South Carolina	Closed	Closed	\$12.00	\$3.00	\$12.00	\$3.00	53,810	47,123	466
South Dakota	Closed	Closed*	\$15.00	\$15.00	\$15.00	\$15.00	12,910	7,945	88
Tennessee	Open*		\$15.00	\$15.00	\$15.00	\$15.00	86,540	71,507	631
Texas	Open	Closed*	\$22.00	\$22.00	\$20.00	\$3.00	406,945	194,845	2,263
Utah	Closed	Closed*	\$20.00	\$8.00	\$18.00	\$8.00	52,121	18,499	472
Vermont	Open	Open	\$10.00	\$10.00	\$10.00	\$10.00	5,567	5,787	24
Virgin Islands	Closed	Closed	\$12.00	\$12.00	\$12.00	\$12.00	1,197	651	32
Virginia	Closed	Closed	\$12.00	\$12.00	\$12.00	\$12.00	101,216	65,580	4,654
Washington	Open*	Open	\$20.00	\$20.00	\$20.00	\$20.00	90,301	54,767	562
West Virginia	Closed	Closed	\$12.00	\$12.00	\$12.00	\$12.00	19,887	21,990	98
Wisconsin	Closed	Open	\$20.00	\$3.00	\$20.00	\$3.00	66,239	51,650	324
Wyoming	Closed	Closed	\$13.00	\$13.00	\$10.00	\$10.00	6,710	4,347	32
Total							4,016,233	2,943,983	53,832
Minimum			\$5.00	\$2.00	\$5.00	\$2.00	1,077	222	11
Median			\$15.00	\$15.00	\$15.00	\$11.00	51,720	36,975	370
Maximum			\$34.00	\$25.00	\$34.00	\$25.00	489,976	263,201	12,068

* The availability of the birth or death certificate is restricted to individuals with a direct relationship to the individual named on the certificate, or there are other requirements that must be met to obtain a copy of a certificate. These restrictions and requirements may vary by jurisdiction.

Sources of information in Appendix F:

- (1) Emails from Andrea Price, NAPHSIS, on 17 and 18 October 2017.
- (2) Extract of NAPHSIS database on jurisdictions, provided by Andrea Price, NAPHSIS on 17 October 2017.
- (3) Numbers of events for 2016 are from the NAPHSIS database on jurisdictions; these numbers are derived from NCHS/NVSS reports for natality and mortality events received through the Vital Statistics Cooperative Program.

Appendix G. NCHS Vital Statistics Cooperative Program funding awarded for special projects, by vital registration jurisdiction, United States, 2013–2017.

Jurisdiction	Total Special Project Funding Awarded in 2013-2017
Alabama	\$8,500.00
Alaska	\$6,000.00
American Samoa	\$6,000.00
Arizona	\$8,500.00
Arkansas	\$426,350.00
California	\$644,810.57
Colorado	\$8,000.00
Connecticut	\$8,500.00
Delaware	\$6,000.00
District of Columbia	\$416,915.20
Florida	\$484,696.90
Georgia	\$218,500.00
Guam	\$6,000.00
Hawaii	\$473,700.00
Idaho	\$255,818.00
Illinois	\$9,000.00
Indiana	\$438,500.00
lowa	\$689,037.00
Kansas	\$152,563.00
Kentucky	\$8,000.00
Louisiana	\$214,713.00
Maine	\$155,999.84
Maryland Massachusetts	\$178,095.00
	\$369,614.00 \$214,719.00
Michigan Minnesota	\$214,719.00
Mississippi	\$8,500.00
Missouri	\$218,500.00
Montana	\$6,000.00
Nebraska	\$217,000.00
Nevada	\$342,828.44
New Hampshire	\$436,000.00
New Jersey	\$258,500.00
New Mexico	\$562,500.00
New York City	\$588,879.00
New York State	\$218,099.00
North Carolina	\$228,500.00
North Dakota	\$6,000.00
Northern Marianas	\$6,000.00
Ohio	\$8,500.00
Oklahoma	\$187,649.00
Oregon	\$212,851.00
Pennsylvania	\$219,000.00
Puerto Rico	\$6,000.00
Rhode Island	\$6,000.00

Jurisdiction	Total Special Project Funding Awarded in 2013-2017
South Carolina	\$8,500.00
South Dakota	\$8,000.00
Tennessee	\$8,000.00
Texas	\$8,500.00
Utah	\$326,417.71
Vermont	\$135,920.00
Virgin Islands	\$6,000.00
Virginia	\$218,500.00
Washington	\$614,925.00
West Virginia	\$100,806.00
Wisconsin	\$8,000.00
Wyoming	\$155,562.34
Total	\$10,962,969.00
Minimum	\$6,000.00
Median	\$178,095.00
Maximum	\$689,037.00

Source of information in Appendix G: VSCP Summary of 2013-2017 VSCP Special Project Funding, provided by Delton Atkinson, NCHS, on 27 Oct 2017.