



National Committee on Vital and Health Statistics

Advising the Secretary of Health and Human Services
on health information policy since 1949.

Next Generation Vital Statistics: Current Status, Issues and Future Possibilities

NCVHS Full Committee Meeting

January 9, 2018

Challenge



- Vital statistics and related administrative data play an **essential role in protecting a broad range of needs:**
 - Establishment of fact of birth and death
 - Public health surveillance, e.g., opioid epidemic
 - Population health
 - Health care, business, commercial use
 - National security
- Stakeholders at state and national level concerned the vital statistics system is **at risk** as a result of serious structural and resource challenges

Opportunities



Opportunities:

- Timely reporting
- Reduce redundancy
- Close data gaps
- Increase appropriate use
- Improve identity establishment

Vision:

A sustainable, secure and robust U.S. vital records infrastructure that meets the nation's need for timely and accurate information.

Guiding 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?



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Population Health Subcommittee Activity

September 2017

Next Generation Vital Statistics Hearing



- Sought input from main stakeholders
 - States and Territories
 - Vital Records Offices
 - Experts at HHS, other Federal Departments e.g., State Dept, Homeland Security
 - Healthcare Providers
 - Coroners, Medical Examiners, Funeral Directors
 - Organizations that rely on vital administrative and statistics data
 - Researchers
- Clearly defined the challenges
- Began to identify potential approaches to address them

Since September Hearing



- Identified gaps in information during hearing
- Commissioned Report:
 - “Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue”
- Drafted Hearing Summary
- **In Progress:**
 - Identifying Potential Approaches to achieve the vision



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

Commissioned Report to NCVHS

Purpose of Report



- During 2017 NCVHS hearing on Next Generation Vital Statistics, several questions were raised by several different speakers:
 - What are the uses of vital records and vital statistics
 - Who are the users of vital records and vital statistics
 - What types and sources of revenue available to vital records jurisdictions
- In responses to these issues, NCVHS contracted with R. Gibson Parrish, M.D. to address these issues. His analytic approach was:
 - To review NCVHS Hearing-related material
 - Based on this review, research internet sites of identified organization
 - Interview or correspond with selected informants

Examples of Uses & Users of Identified Birth Records



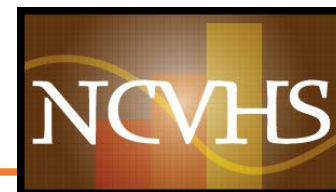
Use	User
<i>Establish identify for legal and administrative purposes</i>	
Obtain SSN at birth	<ul style="list-style-type: none">• SSA
Obtain or renew U.S. Passport or obtain driver's license	<ul style="list-style-type: none">• Individual• Dept of State• State registry of Motor Vehicles
Provide proof of citizenship or legal residency for employment	<ul style="list-style-type: none">• DHS• OPM
<i>Programmatic, research, and other uses</i>	
Facilitate newborn screening for health disorders	<ul style="list-style-type: none">• State health department
Enrollment of eligible children into Medicaid program	<ul style="list-style-type: none">• State Medicaid program

Examples of Uses & Users of Identified Death Records



Use	User
<i>Establish identify for legal and administrative purposes</i>	
Verify deaths of individuals to prevent tax fraud	<ul style="list-style-type: none">• IRS
Pay death benefit or terminate payments under Federal retirement or other benefit programs	<ul style="list-style-type: none">• SSA, CMS, DoD, DHS, DoL, DoS, OPM, Treasury, VA
Determine property rights and enter them in land records	<ul style="list-style-type: none">• Local governments
<i>Programmatic, research, and other uses</i>	
Identify and obtain information about deaths due to specific causes	<ul style="list-style-type: none">• CPSC
Identify health study subjects who have died	<ul style="list-style-type: none">• CDC, Census, CMS, DoD, NIH, Academic Institutions, Medical Centers, Private Companies

Uses & Users of De-identified Natality Data Sets



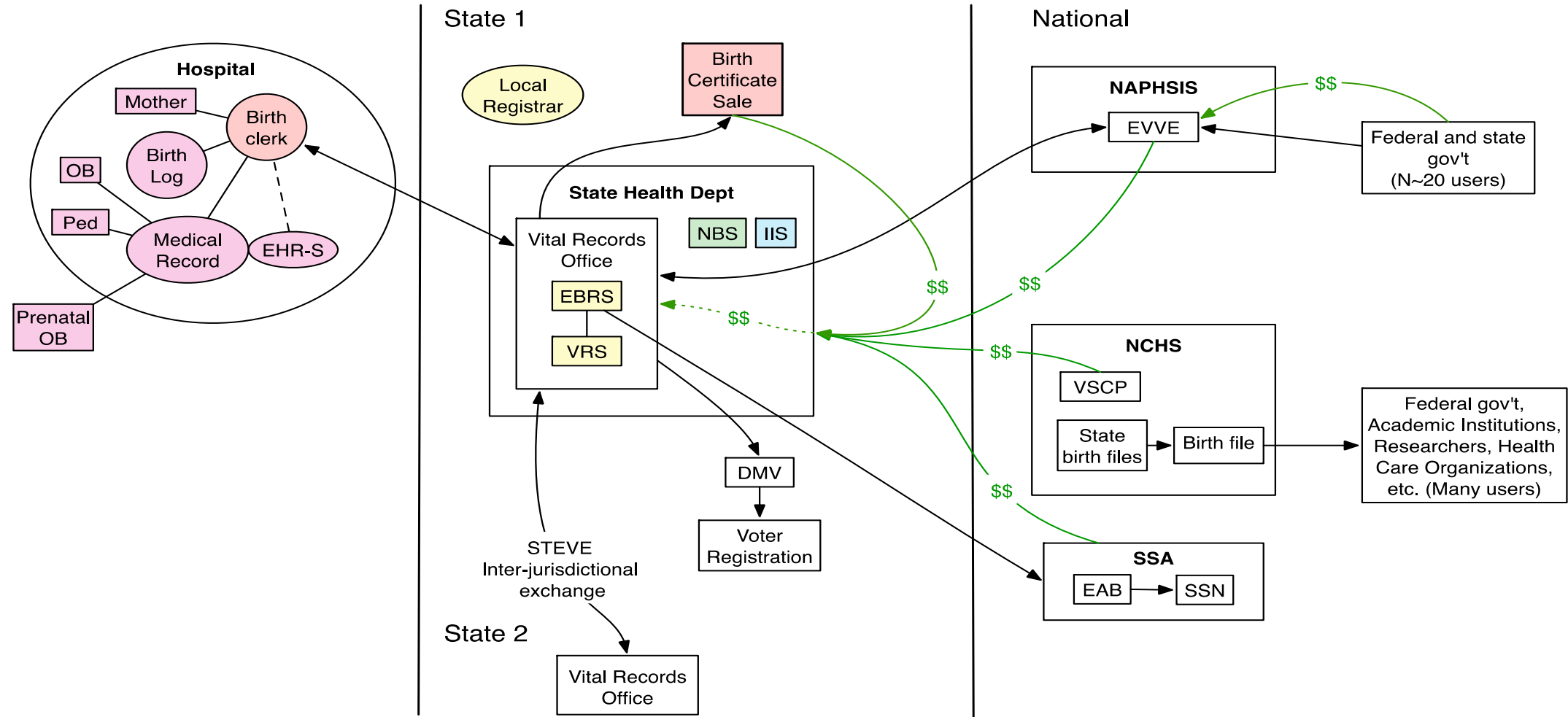
Use	User
Prepare natality statistics for the United States	<ul style="list-style-type: none">• NCHS
Prepare natality statistics for state and local jurisdictions	<ul style="list-style-type: none">• State and local offices of health statistics
Develop health policy	<ul style="list-style-type: none">• Federal, state, and local government agencies• Academic institutions• Non-governmental, health organizations
Carry out health research	<ul style="list-style-type: none">• Federal, state, and local government agencies• Academic institutions• Non-governmental, health organizations
Conduct actuarial analyses for program planning and management	<ul style="list-style-type: none">• SSA• CMS
Prepare population estimates	<ul style="list-style-type: none">• Census Bureau

Uses & Users of De-identified Mortality Data Sets

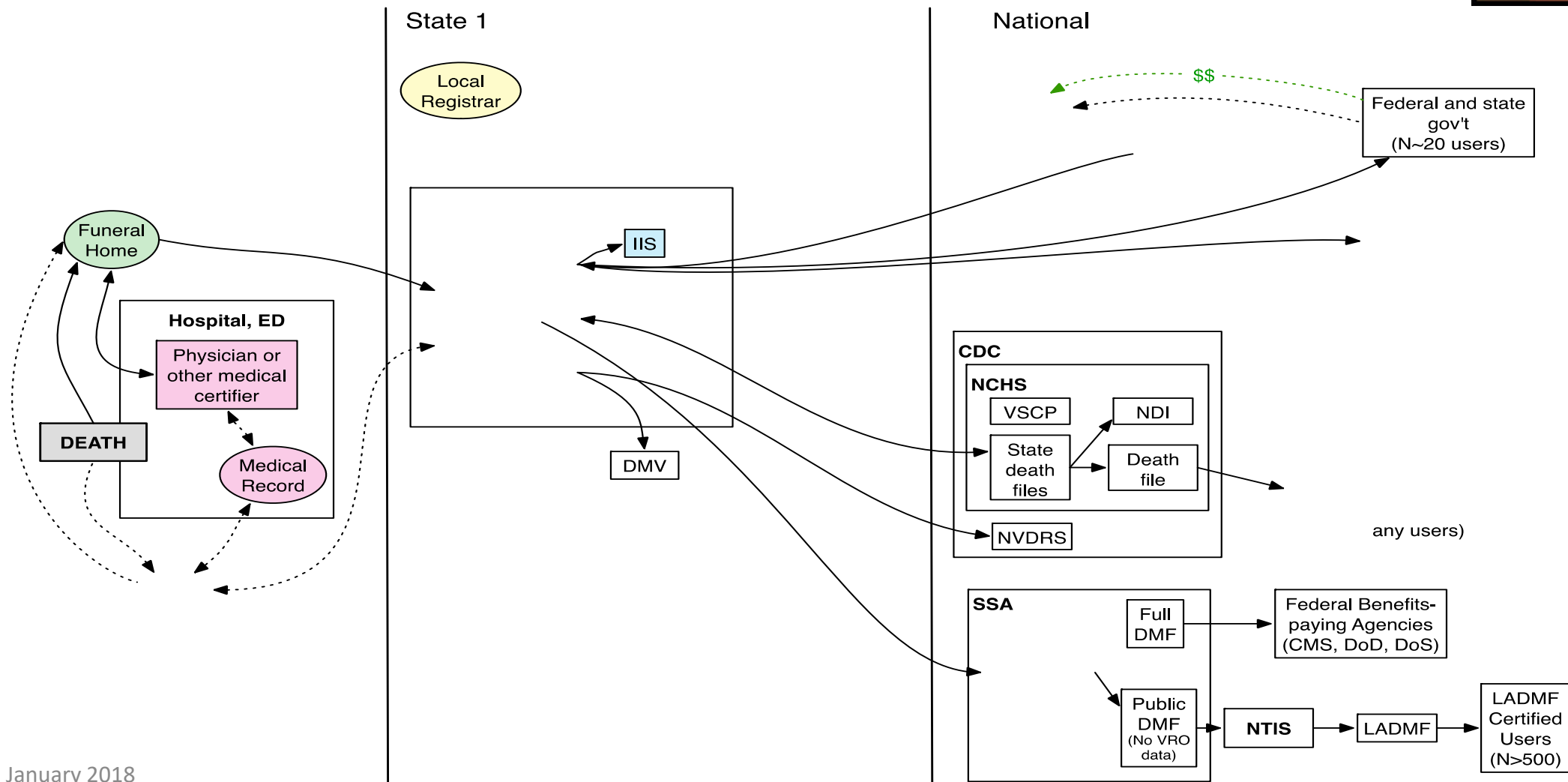


Use	User
Prepare mortality statistics for the United States	<ul style="list-style-type: none">• NCHS
Prepare mortality statistics for state and local jurisdictions	<ul style="list-style-type: none">• State and local offices of health statistics
Develop health policy	<ul style="list-style-type: none">• Federal, state, and local government agencies• Academic institutions• Non-governmental, health organizations
Carry out health research	<ul style="list-style-type: none">• Federal, state, and local government agencies• Academic institutions• Non-governmental, health organizations
Conduct actuarial analyses for insurance, pension, and other benefit programs	<ul style="list-style-type: none">• SSA• CMS• Insurance Companies• Private and Government Pension Funds
Prepare population estimates	<ul style="list-style-type: none">• Census Bureau

Birth Registration System Overview



Death Registration System Overview



Sources of Revenue for Vital Records Offices



Source*	Amount
Appropriations from state, local, or territorial government for VRO	??
Revenue from sale of birth and death certificates	??
Contracts with VROs under the NCHS Vital Statistics Cooperative Program (VSCP)	\$21.1 M
Special projects funding of VROs through the NCHS VSCP	\$2.2 M
Revenue from National Death Index	\$2.8 M
Contract between VROs and SSA for electronic birth and death records to support SSA programs	Birth ~ \$14 M Death ~ \$8 M
Revenue from NAPHSIS EVVE and EVVE FOD services	\$1.2 M
Revenue from Consumer Product Safety Commission's purchase of death certificates	??
Revenue from the private sector (e.g., Ancestry.com) for use of records as a resource (only available in a few states)	??

* *The ability of VROs to receive and use revenue from these sources varies by jurisdiction and by source.*



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Update on September 2017 Hearing Summary

Hearing Vision and Objectives



Vision: a sustainable, secure and robust U.S. vital records infrastructure that meets the nation's need for timely and accurate information.

Guiding 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?

Objectives: Use a multi-stakeholder presentation and generative discussion approach:

- Identify the essential elements of the vital registration system – the components and as a whole,
- Assess its current status and risks to its viability, and
- Consider what actions are needed both to protect and improve the system.

Proposed Hearing Summary Report Structure



- Introduction
- Key concepts and components (e.g., vital records, NDI, DMF)
- Stakeholder perspectives and concerns (the panels)
 - Data producers
 - Data users
- Data uses
- Major areas of challenge
- Crosscutting themes and findings

Process for Hearing Summary Completion



December	<ul style="list-style-type: none">• Draft reviewed by Pop Health planning group
Early January	<ul style="list-style-type: none">• Subcommittee staff reviewing hearing transcript• Will add detail to the draft report<ul style="list-style-type: none">• To ensure hearing participant input to the Committee is clearly presented
Mid-January	<ul style="list-style-type: none">• Fourth draft completed• Planning group reviews and comments
February	<ul style="list-style-type: none">• Penultimate draft completed• Send to Full Committee & hearing participants• All given 10 days to review and send feedback• Feedback reviewed by Population Health Subcommittee & incorporated
Early March	<ul style="list-style-type: none">• Final report ready for formatting and posting to Web



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Potential Approaches