



National Committee on Vital and Health Statistics (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

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

Using a multi-stakeholder presentation and generative discussion approach, this hearing will:

- Identify the essential elements of the vital statistics 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.

Monday, September 11, 2017

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| 9:00 am | Welcome and introductions | Bruce Cohen, PhD & Dave Ross, ScD: Hearing Co-Chairs |
| 9:15 am | Overview – Importance and Need for Vital Records: Local, State, Federal, International Committee Q & A | Tara Das, PhD, MPH, MLIS: Texas Dept. of Health Services Valérie Gaston, MA: Statistics Canada, Health Statistics |
| 10:15 am | Panel 1. Current Status for Vital Records: State and Local Data Producers | |

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| | <p>FOCUS: Why do states collect vital records? How are they collected? How are they managed? How and why are they shared?</p> <p>A) Introduction</p> <p>B) Births</p> <p>15 minute break</p> <p>C) Deaths</p> <p>D) State/Jurisdictional Health Information Technology and Information Technology:</p> <p>Committee Q & A</p> <p>Audience Input</p> | <p>Shawna A. Webster, CAE: NAPHSIS Richard H. McCoy: Vermont Dept. of Health and NAPHSIS</p> <p>Angela Shaw-Perkins: Medstar Washington Hospital Center Susan Zannis: Southern NV Health District</p> <p>Robert C. Moore, IV, CFSP, CCO: Funeral director and NFDA John Fudenberg, D-ABMDI: Clark Co. Office of the Coroner/Medical Examiner and IAC&ME</p> <p>Kari Guida, MPH, MS: MN Dept. of Health Linette Scott, MD, MPH: CA Dept. of Health Care Services (<i>by phone</i>)</p> |
| 11:55 am | Discussion and Public Comment | |
| 12:15 pm | Lunch | |
| 1:15 pm | <p>Panel 2. Current Status of Vital Records: Federal Perspective</p> <p>FOCUS: Why do federal agencies need vital records? How are they managed? How and why are they shared and used?</p> <p>A) Federal Data Steward</p> <p>B) Federal Health Users</p> | <p>Delton Atkinson, MPH, MPH, PMP: NCHS, CDC</p> <p>Karen Matsuoka, PhD: CMCS, CMS Cathy Carter: OIT, CMS William Riley, PhD: OBSSR, NIH Ursula Bauer, PhD, MPH: NCCDPHP, CDC Michael D. Kogan, PhD: MCHB, HRSA</p> |

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| | <p>Committee Q&A</p> <p>C) Other Federal Users</p> <p>Committee Q & A</p> <p>Audience Input</p> | <p>Stephen C. Goss, ASA, MAAA: Social Security Administration Corryne Carter, MPA: Dept. of State Carolyn Clancy, MD: Dept. of Veterans Affairs Aaron Firoved, PhD: Dept. of Homeland Security</p> |
| 3:15 pm | Break | |
| 3:30 pm | <p>Panel 3. Current Status for Vital Records: Other Users of Vital Statistics Data</p> <p>FOCUS: Who are other users of vital statistics? What are these data needed for?</p> <p>A) State users</p> <p>B) Researchers</p> <p>Committee Q & A</p> <p>C) Commercial users:</p> <p>Committee Q & A</p> <p>Audience Input</p> | <p>Rebecca Coyle, MEd: AIRA Michael D. Warren, MD, MPH, FAAP: TN Dept. of Health and AMCHP</p> <p>Mohsen Naghavi, MD, PhD: Univ. of Washington Rebecca B. Russell, MSPH: March of Dimes</p> <p>Susan McDonald: Pension Benefits information, LLC Edward Hall, JD: Verus Financial, LLC Steven M. Emmert, JD: LexisNexis Risk Solutions</p> |
| 5:15 pm | Discussion and Public Comment | |
| 5:45 pm | Adjourn | |

Tuesday, September 12, 2017

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| 8:30 am | <p>Reconvene & Welcome</p> <p>Framing the Day:</p> <ul style="list-style-type: none"> • Current challenges & barriers regarding the vital statistics system • Potential consequences if current challenges are not addressed • Opportunities available to leverage technology and new innovation to support the vital statistics system | <p>Dave Ross, ScD and Bruce Cohen, PhD: Hearing Co-Chairs</p> |
| 8:45 am | <p>Panel 4. Challenges and Opportunities: Federal Level</p> <p>FOCUS: What are the current challenges and issues for federal users, and how might they be addressed?</p> <p>Committee Q & A</p> <p>Audience Input</p> | <p>Delton Atkinson, MPH, MPH, PMP: NCHS, CDC</p> <p>Eric Hughes, PhD: MITRE Corp. (under contract w/NCHS)</p> <p>Caitlin Cross-Barnet, PhD: CMMI, CMS</p> <p>Lekisha Daniel-Robinson, MSPH: CMCS, CMS</p> <p>Ursula Bauer, PhD: NCCDPHP, CDC</p> <p>William Riley, PhD: OBSSR, NIH</p> <p>Karen P. Glenn, FSA, EA, MAAA and K. Mark Bye, ASA: Social Security Administration</p> <p>Benjamin Bolender, PhD: Census Bureau, Dept. of Commerce</p> <p>Corryne Carter, MPA: Bureau of Consular Affairs, Dept. of State</p> |
| 10:15 am | Break | |
| 10:30 am | <p>Panel 5. Challenges and Opportunities: State and Local Levels</p> <p>FOCUS: What are the current challenges and issues for State and local users, and how might they be addressed?</p> | <p>Elizabeth W. (Lou) Saadi, PhD: KS Dept. of Health & Environment and NAPHSIS</p> <p>Terra J. Abrams, MBA, BPM: DC Dept. of Health</p> <p>Mary Ann Sens, MD, PhD: Grand Forks County Coroner’s Office, Univ. of ND and NAME</p> |

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| | <p>Committee Q & A</p> <p>Audience Input</p> | <p>Gregory G. Davis, MD, MSPH: Jefferson County AL Medical Examiner’s Office and Univ. of AL at Birmingham</p> <p>Mary Beth Kurilo, MPH, MSW: ARIA</p> <p>Amy Zimmerman, MPH: RI Exec. Office of Health & Human Services</p> <p>Michael Hogarth, MD, FACP, FACMI: UC San Diego Health</p> <p>Janet J. Hamilton, MPH: FL Dept. of Health and CSTE</p> |
| 12:10 pm | Discussion and Public Comment | |
| 12:30 pm | Lunch | |
| 1:30 pm | <p>Panel 6. Future Directions</p> <p>FOCUS: In light of evolving technology and practice, what are the opportunities to reinforce and strengthen the national vital statistics system?</p> <p>Committee Q & A</p> <p>Audience Input</p> | <p>John R. Lumpkin, MD, MPH: RWJF</p> <p>Kalvin Yu, MD: Southern CA Kaiser Permanente</p> <p>Chesley M. Richards, MD, MPH, FACP: OPHSS, CDC</p> |
| 3:00 pm | Discussion and Public Comment | |
| 3:25 pm | Instructions for Audience Input and Break | |
| 3:45 pm | Audience Input | |
| 4:00 pm | <p>Moving Forward: An Integrated Vision – Discussion</p> <p>Focus: Identify key issues and key themes. Formulate framework to synthesize testimony.</p> | R. Gibson Parrish, II, MD, Facilitator |
| 4:45 pm | Wrap-Up | Dave Ross, ScD and Bruce Cohen, PhD |
| 5:00 pm | Adjourn | Dave Ross, ScD and Bruce Cohen, PhD |

QUESTIONS FOR DAY 1, PANEL 1

A) NAPHSIS and State Vital Health Registrar

1. Explain where your role fits into the overall vital statistics system process. What is the workflow of that process at a high level?
2. What are the legal underpinnings of the current system?
3. How is the system financed? How does the financing approach impact your ability to participate in broader electronic data exchange?
4. How are the data used and by whom?

B) Births

1. Explain where your role fits into the overall vital statistics system process. What is the workflow of that process at a high level?
2. How does data sharing and transmission work?
3. How are data protected?
4. How are privacy and confidentiality issues addressed?
5. How are the data used and by whom?

C) Deaths

1. Explain where your role fits into the overall vitals data process. What is the workflow of that process at a high level?
2. How does data sharing and transmission work?
3. How are data protected?
4. How are privacy and confidentiality issues addressed?
5. How are the data used and by whom?

D) State/Jurisdictional IT Lead

1. Explain where your role fits into the overall vitals data process. What is the workflow of that process?
2. How does data sharing and transmission work?
3. How are data protected?
4. How are privacy and confidentiality issues addressed?

QUESTIONS FOR DAY 1, PANEL 2

1. How are vital statistics used by your agency?
2. How important of a role do they play?
3. What are the quality concerns regarding the data?
4. How are the data obtained/managed/shared/protected?
5. How do you verify or confirm the authenticity of birth and death certificates?

QUESTIONS FOR DAY 1, PANEL 3

1. What do you use the data for? Why are they important?
2. What is the current "experience" with vital records?
3. How does data sharing, transmission and protection work?

QUESTIONS FOR DAY 2, PANEL 4

1. From the vantage point of your agency, what are the challenges & barriers you are encountering in your use of vital records and statistics?
2. From your agency's perspective, what kinds of solutions do you believe would be helpful?
3. What would be some possible consequences if current challenges are not addressed?

QUESTIONS FOR DAY 2, PANEL 5

1. From the vantage point of your organization, what are the challenges & barriers you encounter in your using, accessing, or producing vital records and statistics?
2. From your organization's perspective, what kinds of solutions do you believe would be helpful?
3. What would be some possible consequences if current challenges are not addressed?

QUESTIONS FOR DAY 2, PANEL 6

1. What opportunities are available to leverage technology/new innovation to support the vital statistics system?
2. How would these opportunities improve the vital statistics system, e.g. data quality and timeliness?
3. What issues and challenges need to be addressed? What are options for approaches?

NCVHS
Next Generation Vital Statistics: A Hearing on Current Status,
Issues and Future Possibilities
List of Testifiers

Opening Session

Tara Das, PhD, MPH, MLIS
State Registrar and Director, Vital Statistics
Texas Department of State Health Services
1100 W. 49th Street
Austin, TX 78756

Valérie Gaston, MA
Chief, Vital Statistics
Health Statistics Division
Statistics Canada
150 Tunney's Pasture Way
Ottawa, Ontario, CA K1A016

Panel 1. Current Status for Vital Records: State and Local Data Producers

A) Overall

Shawna Webster, CAE
Executive Director, National Association for Public
Health Statistics and Information Systems (NAPHSIS)
962 Wayne Avenue, Suite 701
Silver Spring, MD 20910

Richard H. McCoy
President-Elect, NAPHSIS
Director, Center for Health Statistics
Chief, Public Health Statistics
Vermont Department of Health
108 Cherry Street
Burlington, VT 05402

B) Births

Susan Zannis
Vital Statistics Supervisor
Southern Nevada Health District
PO Box 3902
Las Vegas, NV 89127

Angela Shaw-Perkins
Birth/Death Registrar
MedStar Washington Hospital Center
110 Irving Street NW
Suite 2A-39
Washington DC, 20010

C) Deaths

Robert C. Moore, IV, CFSP, CCO
Past President, National Funeral Directors Association
Funeral Director
1591 Alps Rd
Wayne, NJ 07470

John Fudenberg, D-ABMDI
Former President/Secretary, International
Association of Coroners & Medical Examiners
Coroner, Clark County Office of the
Coroner/Medical Examiner
1704 Pinto Lane
Las Vegas, NV 89106

D) State/Jurisdictional Health Information Technology and Information Technology

Kari Guida, MPH, MS
Senior Health Informatician
Office of Health Information Technology
Minnesota Department of Health
PO Box 64882
St. Paul, MN 55164-0882

Linette Scott, MD, MPH
Chief Medical Information Officer
Deputy Director, Information Management
Office
California Department of Health Care Services
1501 Capitol Avenue
Sacramento, CA 95814

Panel 2. Current Status of Vital Records: Federal Perspective

A) Federal Data Steward

Delton Atkinson, MPH, MPH, PMP, FAC-P/PM
Director, Division of Vital Statistics
National Center for Health Statistics
Centers for Disease Control and Prevention
Catawba Building, Suite 200, Room 2022
3210 East NC 54
Durham, NC 27709

B) Federal Health Users

Cathy Carter
Director, Enterprise Systems Solutions Group
Office of Information Technology
Centers for Medicare and Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Karen Matsuoka, PhD
Director, Division of Quality & Health Outcome
Child and Adults Health Programs Group
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

William Riley, PhD
NIH Associate Director, Behavioral and Social
Sciences Research
Director, Office of Behavioral and Social Sciences
Network
National Institutes of Health
31 Center Drive
Building 31, Room B1C19
Bethesda, MD 20892

Ursula Bauer, PhD, MPH
Director, National Center for Chronic Disease
Prevention and Health Promotion
Centers for Disease Control and Prevention
Chamblee Building 101, Room 8243
4770 Buford Highway
Atlanta, GA 30341

Michel D. Kogan, PhD
Director, Office of Epidemiology and Research
Maternal and Child Health Bureau
Health Resources and Services Administration
500 Fishers Lane, Room 18N128
Rockville, MD 20857

C) Other Federal Users

Stephen C. Goss, ASA, MAAA
Chief Actuary, Office of the Chief Actuary
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235

Corryne Carter, MPA
Program Analyst, Special Projects & Data Share
Division
Passport Services, Office of Integrity & Internal
Controls
Bureau of Consular Affairs
US Department of State
600 19th Street, NW
Washington, DC 20036

Carolyn Clancy, MD
Deputy Undersecretary for Health for Organizational
Excellence
Veterans Health Administration
US Department of Veterans Affairs
810 Vermont Avenue, NW
Washington, DC 20420

Arron M. Firoved, PhD
Director, National Biosurveillance Integration
Center
Office of Health Affairs
Department of Homeland Security
Washington, DC 20528

Panel 3: Current Status for Vital Records: Other Users of Vital Statistics Data

A) State Users

Rebecca Coyle, MEd
Executive Director, American Immunization Registry
Association
1155 F Street, NW, Suite 1050
Washington, DC 20004

Michael D. Warren, MD, MPH, FAAP
President, Association of Maternal & Child
Health Programs
Deputy Commissioner for Population Health
Tennessee Department of Health
Andrew Johnson Tower, 5th Floor
710 James Robertson Parkway
Nashville, TN 37243

B) Researchers

Mohsen Naghavi, MD, PhD
Professor of Global Health
Institute of Health Metrics and Evaluation (HME)
University of Washington
2301 5th Avenue, Suite 600
Seattle, WA 98121

Rebecca B. Russell, MSPH
Director, Perinatal Data Center
March of Dimes Foundation
1275 Mamaroneck Avenue
White Plain, Y 10605

C) Commercial Users

Susan McDonald
President
Pension Benefit Information, LLC
711 Grand Ave, Suite 210
San Rafael, CA 94901

Edward Hall, JD
Associate General Counsel, Chief
Compliance Officer and Managing Director
Verus Financial, LLC
500 Chase Parkway
Waterbury, CT 06708

Steven M. Emmert, JD
Senior Director for Government & Industry Affairs
RELX Group and LexisNexis
1150 Eighteenth Street, NW
Washington, D.C. 20036

Panel 4: Challenges, Barriers and Potential Solutions: Federal Level

Delton Atkinson, MPH, PMP
(See contact information in Panel 2. A)

Eric Hughes, PhD
Chief Architect, Analytic Solutions
MITRE Corp.
202 Burlington Rd.
Bedford, MA 01730

Caitlin Cross-Barnet, PhD
Research Analyst
Center for Medicare and Medicaid Innovation
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Lakeisha Daniel-Robinson, MSPH
Coordinator, Maternal and Infant Health
Center for Medicare and CHIP Services
Centers for Medicare and Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Ursula Bauer, PhD
(See contact information in Panel 2. B)

William Riley, PhD
(See contact information in Panel 2.B)

Karen P. Glenn, FSA, EA, MAAA
Deputy Chief Actuary, Office of the Chief Actuary
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235

K. Mark Bye, ASA
Actuary, Office of the Chief Actuary
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235

Benjamin Bolender, PhD
Assistant Division Chief,
Population Estimates & Population
Census Bureau
U.S Department of Commerce
4600 Silver Hill Rd.
Suitland, MD 20746

Corryne Carter, MPA
(See contact information in Panel 2.C)

Panel 5: Challenges, Barriers and Potential Solutions: Local Level

Elizabeth W. Saadi, PhD
President, NAPHSIS
State Registrar and Director, Public Health Informatics
Kansas Department of Health and Environment
Curtis State Office Building
1000 SW Jackson
Topeka, KA 66612

Mary Ann Sens, MD, PhD
Grand Forks County Coroner
Past President, National Association of Medical Examiners
Professor and Chair, Pathology Department
School of Medicine & Health Sciences
University of North Dakota Forensic Pathology Practice
Center
1451 44th Avenue South Unit G
Grand Forks, ND 58201

Amy Zimmerman, MPH
HIT Coordinator, Rhode Island Executive Offices of Health
and Human Services
Rhode Island Department of Health
3 Capitol Hill
Providence, RI 02908

Michael Hogarth, MD, FACP, FACMI
Clinical Research Information Officer
Physician Diplomate, Division of PI, California Death
Registration System (CA-EDRS)
Biomedical Informatics
Department of Internal Medicine
University of California San Diego Health
9500 Gilman Drive
La Jolla, CA 92093

Terra J. Abrams, MBA, BPM
State Registrar, Vital Records Division
Center for Policy, Planning and Evaluation
District of Columbia Department of Health
899 North Capitol Street NE, 1st Floor
Washington, DC 20002

Gregory G. Davis, MD, MSPH
Chief Coroner/Medical Examiner, Jefferson
County, Alabama
Professor and Director, Forensic Division
Department of Pathology
University of Alabama at Birmingham
619 19th Street
Birmingham, AL 35210

Mary Beth Kurilo, MPH, MSW
Director, Policy and Planning
American Immunization Registry Association
1155 F Street NW, Suite 1050
Washington, DC 20004

Janet J. Hamilton, MPH
President, Council of State and Territorial
Epidemiologist
Surveillance and Surveillance Systems
Administrator
Bureau of Epidemiology
Florida Department of Health
4052 Bald Cypress Way
Tallahassee FL, 32399

Panel 6: e-Health and its Relation to e-Vitals

John Lumpkin, MD, MPH
Senior Vice President – Program
Robert Wood Johnson Foundation
50 College Road East
Princeton, NJ 08540

Kalvin Yu, MD
Chief Integration Officer
Physician Lead, Community Benefits &
Public Health
Kaiser Permanente Southern California
393 E. Walnut St, 3SW, 33R10
Pasadena, CA, 91188

Chesley Richards, MD, MPH, FACP
Deputy Director, Public Health Scientific Services
Director, Office of Public Health Scientific Services
Centers for Disease Control and Prevention
2500 Century Center Parkway, Room 5202
Atlanta, GA 30334

Moving Forward: An Integrated Vision

R. Gibson Parrish, MD
Independent Consultant
481 Sligo Road
Yarmouth, ME 04096