National Committee on Vital and Health Statistics (NCVHS)

Agenda


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

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Speakers/Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00 am</td>
<td>Welcome and introductions</td>
<td>Bruce Cohen, PhD &amp; Dave Ross, ScD: Hearing Co-Chairs</td>
</tr>
</tbody>
</table>

Page 1 Final Agenda (9/15/2017)
<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:55 am</td>
<td>Discussion and Public Comment</td>
<td></td>
</tr>
<tr>
<td>12:15 pm</td>
<td>Lunch</td>
<td></td>
</tr>
<tr>
<td>1:15 pm</td>
<td><strong>Panel 2. Current Status of Vital Records: Federal Perspective</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>FOCUS</strong>: Why do federal agencies need vital records? How are they managed? How and why are they shared?</td>
<td>Shawna A. Webster, CAE: NAPHSIS Richard H. McCoy: Vermont Dept. of Health and NAPHSIS</td>
</tr>
<tr>
<td></td>
<td>A) Federal Data Steward</td>
<td>Angela Shaw-Perkins: Medstar Washington Hospital Center</td>
</tr>
<tr>
<td></td>
<td>B) Federal Health Users</td>
<td>Susan Zannis: Southern NV Health District</td>
</tr>
<tr>
<td></td>
<td><strong>Committee Q &amp; A</strong></td>
<td>Robert C. Moore, IV, CFSP, CCO: Funeral director and NFDA</td>
</tr>
<tr>
<td></td>
<td><strong>Audience Input</strong></td>
<td>John Fudenberg, D-ABMDI: Clark Co. Office of the Coroner/Medical Examiner and IAC&amp;ME</td>
</tr>
<tr>
<td></td>
<td><strong>Linette Scott, MD, MPH: CA Dept. of Health Care Services (by phone)</strong></td>
<td>Kari Guida, MPH, MS: MN Dept. of Health</td>
</tr>
</tbody>
</table>

**FOCUS: Why do states collect vital records? How are they collected? How are they managed? How and why are they shared?**

- **A)** Introduction
- **B)** Births
- **15 minute break**
- **C)** Deaths
- **D)** State/Jurisdictional Health Information Technology and Information Technology: Committee Q & A

**Panel 2. Current Status of Vital Records: Federal Perspective**

- **FOCUS**: Why do federal agencies need vital records? How are they managed? How and why are they shared and used?
- **A)** Federal Data Steward
- **B)** Federal Health Users

- Delton Atkinson, MPH, MPH, PMP: NCHS, CDC
- 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
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>3:15 pm</td>
<td>Break</td>
</tr>
</tbody>
</table>
| 3:30 pm  | **Panel 3. Current Status for Vital Records: Other Users of Vital Statistics Data**  
            **FOCUS:** Who are other users of vital statistics? What are these data needed for?  
            A) State users  
            B) Researchers  
            C) Commercial users:).
| 5:15 pm  | Discussion and Public Comment                                        |
| 5:45 pm  | Adjourn                                                               |
**Tuesday, September 12, 2017**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Presenters</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30 am</td>
<td>Reconvene &amp; Welcome</td>
<td>Framing the Day:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Current challenges &amp; barriers regarding the vital statistics system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Potential consequences if current challenges are not addressed</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Opportunities available to leverage technology and new innovation to support the vital statistics system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dave Ross, ScD and Bruce Cohen, PhD: Hearing Co-Chairs</td>
</tr>
<tr>
<td>8:45 am</td>
<td>Panel 4. Challenges and Opportunities: Federal Level</td>
<td>FOCUS: What are the current challenges and issues for federal users, and how might they be addressed?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Committee Q &amp; A</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Audience Input</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delton Atkinson, MPH, MPH, PMP: NCHS, CDC</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Eric Hughes, PhD: MITRE Corp. (under contract w/NCHS)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Caitlin Cross-Barnet, PhD: CMMI, CMS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lekisha Daniel-Robinson, MSPH: CMCS, CMS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Ursula Bauer, PhD: NCCDPHP, CDC</td>
</tr>
<tr>
<td></td>
<td></td>
<td>William Riley, PhD: OBSSR, NIH</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Karen P. Glenn, FSA, EA, MAAA and K. Mark Bye, ASA: Social Security Administration</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Benjamin Bolender, PhD: Census Bureau, Dept. of Commerce</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Corryne Carter, MPA: Bureau of Consular Affairs, Dept. of State</td>
</tr>
<tr>
<td>10:15 am</td>
<td>Break</td>
<td></td>
</tr>
<tr>
<td>10:30 am</td>
<td>Panel 5. Challenges and Opportunities: State and Local Levels</td>
<td>FOCUS: What are the current challenges and issues for State and local users, and how might they be addressed?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Elizabeth W. (Lou) Saadi, PhD: KS Dept. of Health &amp; Environment and NAPHSIS</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Terra J. Abrams, MBA, BPM: DC Dept. of Health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mary Ann Sens, MD, PhD: Grand Forks County Coroner’s Office, Univ. of ND and NAME</td>
</tr>
<tr>
<td>Time</td>
<td>Event Description</td>
<td>Speakers</td>
</tr>
<tr>
<td>-------</td>
<td>--------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>12:10 pm</td>
<td>Discussion and Public Comment</td>
<td></td>
</tr>
<tr>
<td>12:30 pm</td>
<td>Lunch</td>
<td></td>
</tr>
<tr>
<td>1:30 pm</td>
<td>Panel 6. Future Directions</td>
<td>John R. Lumpkin, MD, MPH: RWJF, Kalvin Yu, MD: Southern CA Kaiser Permanente, Chesley M. Richards, MD, MPH, FACP: OPHSS, CDC</td>
</tr>
<tr>
<td></td>
<td><strong>FOCUS:</strong> In light of evolving technology and practice, what are the opportunities to reinforce and strengthen the national vital statistics system?</td>
<td></td>
</tr>
<tr>
<td>3:00 pm</td>
<td>Discussion and Public Comment</td>
<td></td>
</tr>
<tr>
<td>3:25 pm</td>
<td>Instructions for Audience Input and Break</td>
<td></td>
</tr>
<tr>
<td>3:45 pm</td>
<td>Audience Input</td>
<td></td>
</tr>
<tr>
<td>4:00 pm</td>
<td>Moving Forward: An Integrated Vision – Discussion</td>
<td>R. Gibson Parrish, II, MD, Facilitator</td>
</tr>
<tr>
<td></td>
<td><strong>Focus:</strong> Identify key issues and key themes. Formulate framework to synthesize testimony.</td>
<td></td>
</tr>
<tr>
<td>4:45 pm</td>
<td>Wrap-Up</td>
<td>Dave Ross, ScD and Bruce Cohen, PhD</td>
</tr>
<tr>
<td>5:00 pm</td>
<td>Adjourn</td>
<td>Dave Ross, ScD and Bruce Cohen, PhD</td>
</tr>
</tbody>
</table>
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 vital 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
List of Testifiers

Opening Session

Tara Das, PhD, MPH, MLIS  Valérie Gaston, MA
State Registrar and Director, Vital Statistics  Chief, Vital Statistics
Texas Department of State Health Services  Health Statistics Division
1100 W. 49th Street  Statistics Canada
Austin, TX 78756  150 Tunney’s Pasture Way


A) Overall

Shawna Webster, CAE  Richard H. McCoy
Executive Director, National Association for Public  President-Elect, NAPHSIS
Health Statistics and Information Systems (NAPHSIS)  Director, Center for Health Statistics
962 Wayne Avenue, Suite 701  Chief, Public Health Statistics
Silver Spring, MD 20910  Vermont Department of Health

B) Births

Susan Zannis  Angela Shaw-Perkins
Vital Statistics Supervisor  Birth/Death Registrar
Southern Nevada Health District  MedStar Washington Hospital Center
PO Box 3902  110 Irving Street NW
Las Vegas, NV 89127  Suite 2A-39

C) Deaths

Robert C. Moore, IV, CFSP, CCO  John Fudenberg, D-ABMDI
Past President, National Funeral Directors Association  Former President/Secretary, International
Funeral Director  Association of Coroners & Medical Examiners
1591 Alps Rd  Coroner, Clark County Office of the
Wayne, NJ 07470  Coroner/Medical Examiner

Las Vegas, NV 89106  1704 Pinto Lane
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


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, MSEd  
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 Medicaid 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

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

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

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

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

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

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

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

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

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

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

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

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

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