National Committee on Vital and Health Statistics (NCVHS)

Tentative 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.

Tentative Agenda

Monday, September 11, 2017

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Speakers</th>
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<tr>
<td>9:00 am</td>
<td>Welcome and introductions</td>
<td>Bruce Cohen, PhD &amp; Dave Ross, ScD: Hearing Co-Chairs</td>
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<tr>
<td>9:15 am</td>
<td><strong>Overview – Importance and Need for Vital Records: Local, State, Federal, International</strong> Committee Q &amp; A</td>
<td>Tara Das, PhD, MPH, MLIS: Texas Dept. of Health Services; Valérie Gaston, MA: Statistics Canada, Health Statistics</td>
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<tr>
<td>11:55 am</td>
<td>Discussion and Public Comment</td>
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<td>12:15 pm</td>
<td>Lunch</td>
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<td>1:15 pm</td>
<td>Panel 2. Current Status of Vital Records: Federal Perspective</td>
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<td><strong>FOCUS</strong>: Why do federal agencies need vital records? How are they managed? How and why are they shared and used?</td>
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<td>A) Federal Data Steward</td>
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<td>B) Federal Health Users</td>
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<td></td>
<td><strong>Committee Q&amp;A</strong></td>
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Shawna A. Webster, CAE: NAPHSIS
Richard H. McCoy: Vermont Dept. of Health and NAPHSIS

Angela Shaw: Medstar Washington Hospital Center
Susan Zannis: Southern NV Health District

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

Kari Guida, MPH, MS: MN Dept. of Health
Linette Scott, MD, MPH: CA Dept. of Health Care Services *(by phone)*

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
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<thead>
<tr>
<th>Time</th>
<th>Event Description</th>
<th>Participants</th>
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<tbody>
<tr>
<td>3:15 pm</td>
<td>Break</td>
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<tr>
<td>3:30 pm</td>
<td><strong>Panel 3. Current Status for Vital Records: Other Users of Vital Statistics Data</strong></td>
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<td><strong>FOCUS:</strong> Who are other users of vital statistics? What are these data needed for?</td>
<td>A) State users</td>
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<td>B) Researchers</td>
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<td>C) Commercial users:</td>
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<td><strong>Committee Q &amp; A</strong></td>
<td>Rebecca Coyle, MSEd: AIRA</td>
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<td>Michael D. Warren, MD, MPH, FAAP: TN Dept. of Health and AMCHP</td>
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<td>Janet J. Hamilton, MPH: FL Dept. of Health and CSTE</td>
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<td><strong>Committee Q &amp; A</strong></td>
<td>Mohsen Naghavi, MD, PhD: Univ. of Washington</td>
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<td>Rebecca B. Russell, MSPH: March of Dimes</td>
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<td><strong>Audience Input</strong></td>
<td>Susan McDonald: Pension Benefits information, LLC</td>
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<td>Edward Hall, JD: Verus Financial, LLC</td>
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<td>Steven M. Emmert, JD: LexisNexis Risk Solutions</td>
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<td>5:15 pm</td>
<td><strong>Discussion and Public Comment</strong></td>
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<td>5:45 pm</td>
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**Tuesday, September 12, 2017**
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<tr>
<th>Time</th>
<th>Session</th>
<th>Chairpersons</th>
<th>Panelists</th>
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<tr>
<td>8:30 am</td>
<td><strong>Reconvene &amp; Welcome</strong></td>
<td>Dave Ross, ScD and Bruce Cohen, PhD: Hearing Co-Chairs</td>
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<td><strong>Framing the Day:</strong></td>
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<td>• Current challenges &amp; barriers regarding the vital statistics system</td>
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<td>• Potential consequences if current challenges are not addressed</td>
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<td>• Opportunities available to leverage technology and new innovation to support the vital statistics system</td>
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<td>8:45 am</td>
<td><strong>Panel 4. Challenges and Opportunities: Federal Level</strong></td>
<td>Delton Atkinson, MPH, MPH, PMP: NCHS, CDC Eric Hughes, PhD: MITRE Corp. (under contract w/NCHS) Caitlin Cross-Barnet, PhD: CMMI, CMS Lekisha Daniel-Robinson, MSPH: CMCS, CMS Ursula Bauer, PhD: NCCDPHP, CDC William Riley, PhD: OBSSR, NIH Stephen C. Goss, MS: SSA Benjamin Bolender, PhD: Census Bureau, Dept. of Commerce Corryne Carter, MPA: Bureau of Consular Affairs, Dept. of State</td>
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<td><strong>FOCUS:</strong> What are the current challenges and issues for federal users, and how might they be addressed?</td>
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<td>10:15 am</td>
<td><strong>Break</strong></td>
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<td>10:30 am</td>
<td><strong>Panel 5. Challenges and Opportunities: State and Local Levels</strong></td>
<td>Elizabeth W. (Lou) Saadi, PhD: KS Dept. of Health &amp; Environment and NAPHSIS Terra J. Abrams, MBA, BPM: DC Dept. of Health Mary Ann Sens, MD, PhD: Grand Forks County Coroner’s Office, Univ. of ND and NAME Gregory G. Davis, MD, MSPH: Jefferson County AL Medical Examiner’s Office and Univ. of AL at Birmingham Mary Beth Kurilo, MPH, MSW: ARIA Amy Zimmerman, MPH: RI Exec. Office</td>
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<td><strong>FOCUS:</strong> What are the current challenges and issues for State and local users, and how might they be addressed?</td>
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<td>Time</td>
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<td>12:10 pm</td>
<td>Discussion and Public Comment</td>
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<td>Lunch</td>
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<td><strong>Panel 6. Future Directions</strong></td>
<td>John R. Lumpkin, MD, MPH: RWJF</td>
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<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>Kalvin Yu, MD: Southern CA Kaiser Permanente</td>
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<td>Chesley M. Richards, MD, MPH, FACP: OPHSS, CDC</td>
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<td>3:00 pm</td>
<td>Discussion and Public Comment</td>
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<td>3:25 pm</td>
<td>Instructions for Audience Input and Break</td>
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<td>3:45 pm</td>
<td>Audience Input</td>
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<td>4:00 pm</td>
<td><strong>Moving Forward: An Integrated Vision – Discussion</strong></td>
<td>R. Gibson Parrish, II, MD, Facilitator</td>
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<td><strong>Focus</strong>: Identify key issues and key themes. Formulate framework to synthesize testimony.</td>
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<td>4:45 pm</td>
<td>Wrap-Up</td>
<td>Dave Ross, ScD and Bruce Cohen, PhD</td>
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<td>5:00 pm</td>
<td>Adjourn</td>
<td>Dave Ross, ScD and Bruce Cohen, PhD</td>
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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 statistics system 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?
   5. How are the data used and by whom?

D) State/Jurisdictional IT Lead
   1. Explain where your role fits into the overall vital statistics system 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?
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


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  
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Angela Shaw  
Birth/Death Registrar  
MedStar Washington Hospital Center  
110 Irving Street NW  
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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


A) Federal Data Steward

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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

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Office of Information Technology
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Baltimore, MD 21244

Karen Matsuoka, PhD
Director, Division of Quality and 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
C) Other Federal Users

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

Corryne Carter, MPA  
Program Analyst, Special Projects and Data Share Division  
Passport Services, Office of Integrity and 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

Ira Katz, MD, PhD  
Deputy Chief, Patient Care Services  
Office for Mental Health  
Veterans Health Administration  
US Department of Veterans Affairs  
810 Vermont Avenue  
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
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

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

Dennis Becker  
Vice President Content  
Corporation Markers and Identity Management Solutions  
LexisNexis Risk Solutions  
1000 Alderman Dr.  
Alpharetta, GA 30005

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

Ursula Bauer, PhD  
(See contact information in Panel 2. B)  
William Riley, PhD  
(See contact information in Panel 2.B)
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
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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
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Director, Policy and Planning
American Immunization Registry Association
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Washington, DC 20004

Amy Zimmerman, MPH
HIT Coordinator, Rhode Island Executive Offices of Health and Human Services
Rhode Island Department of Health
3 Capitol Hill
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Director, Policy and Planning
American Immunization Registry Association
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Washington, DC 20004

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

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

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

Terra J. Abrams, MBA, BPM
State Registrar, Vital Records Division
Center for Policy, Planning and Evaluation
District of Columbia Department of Health
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Washington, DC 20002

Elizabeth W. Saadi, PhD
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State Registrar and Director, Public Health Informatics
Kansas Department of Health and Environment
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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

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

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

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
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