



**Final Agenda**  
**National Committee on Vital and Health Statistics**  
**Virtual Meeting, March 31-April 1, 2021**  
Info to connect: <https://ncvhs.hhs.gov/meetings-meeting/>

**Wednesday, March 31**

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| <b>10:30 a.m.</b> | <b>Call to Order/Roll Call</b>   | Rebecca Hines<br>Executive Secretary/<br>Designated Federal Officer  |
| <b>10:35 a.m.</b> | <b>Welcome Remarks/Agenda Review</b>   | Nick Coussoule, Chair  |
| <b>10:45 a.m.</b> | <b>ASPE Update</b>   | Sharon Arnold, <i>ASPE</i>   |
| <b>11:15 a.m.</b> | <b>NCVHS 2021 Report to Congress</b>   | Nick Coussoule & Committee   |
| <b>12:30 p.m.</b> | <b>Break</b>   |  |
| <b>1:15 p.m.</b>  | <b>Subcommittee on Standards</b> <ul style="list-style-type: none"><li>• Priorities and alignment of work</li></ul>  | Rich Landen & Denise Love<br>Co-chairs, Subcommittee on Standards<br><br>Micky Tripathi<br>National Coordinator for Health IT<br>ONC |
| <b>2:00 p.m.</b>  | <b>Subcommittee on Standards Update</b> <ul style="list-style-type: none"><li>• Discussion on proposed project “Standardization of Information for Burden Reduction and Post-Pandemic America”</li></ul> | Rich Landen & Denise Love<br>Co-chairs, Subcommittee on Standards  |
| <b>3:00 p.m.</b>  | <b>Break</b>   |  |
| <b>3:15 p.m.</b>  | <b>Gravity Project Update</b> <ul style="list-style-type: none"><li>• Consensus-driven standards for Social Determinants of Health using FHIR</li></ul>  | Evelyn Gallego<br>Chief Executive Officer<br>EMI Advisors  |
| <b>4:15 p.m.</b>  | <b>Comparative Analysis of ICD-10-CM with ICD-11 for Morbidity Coding</b>  | Margaret Skurka, NCVHS member<br><br>Kin-Wah Fung<br>Scientist, NIH/NLM  |
| <b>5:00 p.m.</b>  | <b>Standards Discussion: Semantic Harmonization &amp; Classifications</b>  | Jamie Ferguson<br>Subcommittee on Standards  |
| <b>5:30 p.m.</b>  | <b>Public Comment</b>  | Rebecca Hines<br>Executive Secretary/DFO   |
| <b>5:45 p.m.</b>  | <b>Adjourn</b>   | Nick Coussoule, Chair  |

## Thursday, April 1

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|-------------------|---|--|
| <b>10:00 a.m.</b> | <b>Call to Order/Roll Call</b>  | Rebecca Hines<br>Executive Secretary/DFO   |
| <b>10:05 a.m.</b> | <b>Welcome Remarks/Agenda Review</b>  | Nick Coussoule, Chair  |
| <b>10:15 a.m.</b> | <b>Subcommittee on Privacy, Confidentiality and Security</b> <ul style="list-style-type: none"><li>• Discussion on proposed project “Improving Security in Healthcare”</li></ul>  | Melissa Goldstein & Jacki Monson<br>Co-chairs, Subcommittee on Privacy, Confidentiality and Security |
| <b>11:30 a.m.</b> | <b>CDC Data Modernization Initiative</b>  | Daniel B. Jernigan<br>Deputy Director for Public Health Science and Surveillance (Acting)<br>CDC     |
| <b>12:15 p.m.</b> | <b>Break</b>  |  |
| <b>1:00 pm</b>    | <b>Covid-19: Capacity, Gaps &amp; Quality in Collection of Race/Ethnicity Data – Expert Panel Session:</b> <ul style="list-style-type: none"><li>A. Data Collection &amp; Inputs</li><li>B. Research Innovations in Methods &amp; Solutions</li><li>C. Discussion</li></ul> | Vickie Mays & Denise Love<br>Panel moderators<br><br>Invited experts                                 |
| <b>3:45 p.m.</b>  | <b>Break</b>  |  |
| <b>4:00 p.m.</b>  | <b>2020 NCVHS Workplan</b>  | Chair and Full Committee   |
| <b>4:45 p.m.</b>  | <b>Public Comment</b>   | Rebecca Hines<br>Executive Secretary/DFO   |
| <b>4:55 p.m.</b>  | <b>Closing Remarks &amp; Adjourn</b>  | Nick Coussoule, Chair  |

## Upcoming NCVHS Meetings

- Full Committee Meeting, September 9-10, 2021

April 1, 2021

## NCVHS Expert Panel Session

Thursday April 1, 1:00-3:30 pm

### Covid-19: Capacity, Gaps & Quality in Collection of Race/Ethnicity Data

**Moderated by Dr. Vickie Mays and Denise Love**

The Covid-19 pandemic exposed a number of data gaps in the ability to respond quickly and efficiently in determining the impact in racial/ethnic minority populations. Early in the Covid-19 epidemic researchers, advocates and states called out the lack of data identifying race/ethnicity in cases, hospitalization and deaths despite the fact that such data is a part of reporting requirements. This raised issues about the method of collection, the lack of reporting of race/ethnicity in health data, electronic health records, and mortality records. Concerns about standards of incompleteness of health records and a lack of enforcement for completion in a timely manner, lack of data quality due to incompleteness, and inability to link records in order to fill in missing data call for national attention and leadership.

The purpose of this expert panel session is to learn about the ways in which current practices and gaps in data collection, input, sharing, linkages and analytic methods could be improved to address health inequities. The lack of race/ethnicity data also impedes future capacity to identify outcomes in research, treatment and appropriate evidence-based interventions at the sub-population level.

As noted by Herman (2021) and Krieger and her team (2021) and others approximately one month into the roll-out of the Covid-19 vaccination, the CDC Feb 2 MMWR report indicated that of all persons vaccinated for when data was reported, 48.1% were missing data on race/ethnicity. As they note, this stands in stark contrast to the 0.1% and 3% missing data respectively on age and sex. While in some instances there are methods that can be employed to fix such data in a pandemic/disaster emergency response, this adds weeks to having good quality data from which to make decisions, deploy resources or intervene. This lack of complete quality data to determine how racial/ethnic populations fare during Covid-19 in real time leads to inequity.

#### **PANEL A: Data Collection & Inputs**

- ***Measuring Racial/Ethnic Disparities in COVID-19 in Children and Teens: The Problem of Missing Race and Ethnicity Data***  
**Elizabeth Pathak, PhD, MSPH**  
Director, The COVKID Project  
President, Women's Institute for Independent Social Enquiry, (WiiSE)
- ***Uncertainty in Demographic and Socioeconomic Data. The Use of Differential Privacy for Disclosure Control, and its Potential Impact on Age and Race/ethnicity Count***  
**Seth Spielman, PhD**  
Chief Data Strategy and Analytics Officer  
Associate Professor of Geography, University of Colorado Boulder  
Faculty Associate, Institute of Behavioral Science  
**and David Van Riper, MA**  
Director, Spatial Analysis, Institute for Social Research and Data Innovation, Minnesota Population Center, University of Minnesota
- ***What Public Health Practice says about Data Gaps for Advancing Rural Health Equity***  
**Betty Bekemeier, PhD, MPH, RN, FAAN**  
Professor, Kirby & Ellery Cramer Endowed Professor  
Director, Northwest Center for Public Health Practice  
Affiliate faculty, UW Center for Studies in Demography and Ecology

PI, Public Health Activities and Services Tracking (PHAST) Study  
Adjunct Professor, UW School of Public Health, Department of Health Services

- ***Race, Ethnicity and the Validity of Cause of Death Assignment for COVID-19 in the U.S.***  
**Andrew C. Stokes, PhD**  
Boston University School of Public Health

## **PANEL B: Research Innovations in Methods & Solutions**

- ***A Predictive Equity Metric for the Distribution of Testing and Vaccination Resources Based on Vulnerability to COVID-19: Race and Ethnicity Plus What?***  
**Vickie Mays, PhD, MSPH**  
Distinguished Professor of Psychology, College of Letters and Sciences  
Distinguished Professor of Health Policy & Management, Fielding School of Public Health  
Director, UCLA BRITE Center for Science, Research & Policy Special Advisor to the Chancellor
- ***Collection and Use of Race/Ethnic Data through Cross-sector Networks: Implications for COVID-19 Response***  
**Glen Mays PhD, MPH**  
Professor and Chair, Health Systems, Management and Policy  
University of Colorado Anschutz Medical Campus
- ***A National Framework to Improve Mortality, Morbidity, and Disparities Data for COVID-19 and Other Large-Scale Disasters***  
**Michael Stoto, PhD**  
Professor of Health Systems Administration and Population Health, Georgetown University  
Adjunct Professor of Biostatistics & Senior Preparedness Fellow  
Harvard T.H. Chan School of Public Health
- ***The Implications for Covid-19 Vaccine Equity in not Disaggregating Data in Asian and Native Hawaiian and Pacific Islanders Communities***  
**Ninez Ponce, MPP, PhD**  
Director, UCLA Center for Health Policy and Research  
Principal Investigator, California Health Interview Survey  
Professor, Health Policy and Management  
UCLA Fielding School of Public Health
- ***The Contribution of Linked Private-sector Data to the Understanding of Gender, Race/ethnic and SES Disparities in COVID***  
**Mark Cullen, MD**  
Founding Director, Stanford Center for Population Health Sciences (retired)

## **PANEL C: Discussion**

- **All Panelists & NCVHS members**