Department of Health and Human Services
NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
March 31-April 1, 2021
MEETING SUMMARY – Held Virtually

***Note:** The transcript and slides for this meeting are posted on **ncvhs.hhs.gov**. See "Related Items" associated with the meeting agenda on the March-April 2021 "Meetings" page.*

Due to the COVID-19 pandemic, the National Committee on Vital and Health Statistics was convened virtually via Zoom on March 31 and April 1, 2021. The meeting was open to the public. Present:

Committee Members
Nick Coussoule, Chair
Tammy Feenstra Banks, MBA, FACMPE
Denise Chrysler, JD
James Cimino, MD
Nicholas Coussoule
Jamie Ferguson
Melissa M. Goldstein, JD
Richard Landen, MPH, MBA
Denise Love, BSN, MBA
Vickie Mays, PhD, MSPH
Jacki Monson, JD
Margaret Skurka, MS, RHIA, CCS, FAHIMA
Debra Strickland, MS
Valerie Watzlaf, PhD, MPH, RHIA, FAHIMA
Wu Xu, PhD

Executive Staff
Sharon Arnold, PhD, ASPE, Exec. Staff Director
Rebecca Hines, MHS, NCHS, Exec. Secretary/DFO
Kianna Morris, NCHS

Lead Staff
Lorraine Doo, MPH, CMS
Rachel Seeger, MA, MPA, OCR
Maya Bernstein, ASPE

NCVHS staff
Marietta Squire, NCHS
Geneva Cashaw, NCHS

Guest Presenters
Micky Tripathi, HHS/ONC
Evelyn Gallego, Gravity Project
Fin-Wah Fung, NIH/NLM
Daniel Jernigan, CDC
Expert Panel:
Elizabeth Pathak, PhD, MSPH, Women's Institute for Independent Social Enquiry
Seth Spielman, PhD, University of Colorado Boulder
David Van Riper, MA, University of Minnesota
Betty Bekemeier, PhD, MPH, RN, FAAN, University of Washington
Glen Mays, PhD, MPH, University of Colorado Anschutz Medical Campus
Michael Stoto, PhD, Harvard T.H. Chan School of Public Health
Ninez Ponce, MPP, PhD, UCLA Center for Health Policy and Research
Mark Cullen, MD, Stanford Center for Population Health Sciences (ret.)

In addition, 117 members of the public and other federal staff remotely attended the meeting on day 1, and 149 attended on day 2. A list of public attendees and their affiliations is appended to this meeting summary.

—DAY ONE—

Opening Remarks—Ms. Hines, Mr. Coussoule

Ms. Hines announced that Mr. Pasquale, Chair of the Subcommittee on Privacy, Confidentiality, and Security had resigned from NCVHS due to a new work opportunity. She and Mr. Coussoule welcomed Ms. Goldstein and Ms. Monson as the new co-chairs of the Subcommittee on Privacy, Confidentiality and Security, and Ms. Love as co-chair of the Subcommittee on Standards with Mr. Landen.

ASPE Update—Sharon Arnold, PhD

Dr. Arnold noted that Xavier Becerra had been confirmed as the new Secretary of HHS, and she acknowledged several other leadership appointments in the Department. President Biden has issued three executive orders to ensure an equitable, data-driven, unified, and effective response to the pandemic, and HHS has a number of initiatives and investments directed toward those goals. ASPE is also implementing components of the Cures Act and the Foundations for Evidence-Based Policymaking Act.

Members had questions and comments about uptake on the V-Safe reporting initiative; how NCVHS can support the Department's initiatives; and the timeframe for the protection of research data. On the second topic, Dr. Arnold said HHS would be greatly expanding the types of data it collects and making sure it can harmonize across data systems, and it would welcome the Committee's input on that effort. It will start by harmonizing data within and across HHS.

2021 Report to Congress-Nick Coussoule (Presentation)

NCVHS has a statutory requirement to submit a regular report to Congress on the implementation status of the administrative simplification and privacy protection provisions of HIPAA. A central focus is reporting on how well HIPAA implementation is working to achieve the goals of reducing cost and administrative burden, protecting information privacy and security, and supplying federal and state governments with information of sufficient quality to meet their obligations. Mr. Coussoule reviewed the authority and purpose for this NCVHS report, reminded members of the structure of the 2021 report (which addresses the reporting period 2019-2020), and updated them on its status. He then led members in a lengthy discussion of their prior edits, comments, and structure and content suggestions on the draft report as well as new editorial observations and solutions. This discussion continued briefly on day two of the meeting.

One focus on both days concerned the pros and cons of using the term "social determinants of health (SDOH)," which appears in several places in the report. On the one hand, it is the standard term used widely to refer to the social factors and essential human needs that have an impact on health; on the other hand, the term is a misnomer in that these factors influence but do not literally "determine" health; in addition, one member reported that some people find the term demeaning. After weighing these considerations, members agreed to use the term for the first set of reasons but to note its limitations. The Committee expects to release the 2021 Report to Congress in late Spring.

Subcommittee on Standards Update—Mr. Landen and Ms. Love Priorities and Alignment of Work (Presentation)

Mr. Landen reviewed the Subcommittee's charge and scope for the benefit of new members. In consultation with the industry and other stakeholders, it monitors and makes recommendations to the NCVHS Full Committee on health data standards. This includes implementation of the Administrative Simplification provisions of HIPAA, the Medicare Modernization Act, the Affordable Care Act, and associated areas of focus such as interoperability. The major focus of a four-year NCVHS initiative, through 2020, was development of the Predictability Roadmap, which recommended to the HHS Secretary ways to improve update and adoption of standards and support greater interoperability. In 2020, four Subcommittee members participated in ONC's Health Information Technology Advisory Committee (HITAC) Task Force on the Integration of Clinical and Administrative Data (ICAD). The previous Subcommittee co-chair also co-chaired the ICAD Task Force. NCVHS anticipates continued collaboration with ONC on next steps on that project ("ICAD2").

The ICAD Task Force's recommendations to ONC will inform the forthcoming NCVHS "Convergence 2.0" project (full name "Standardization of Information for Burden Reduction and Post-Pandemic America"). This project, which builds on the Predictability Roadmap as well as the ICAD report, will pursue new opportunities for standards, including the modernization of administrative and clinical data exchange standards and the integration of SDOH data into EHRs and HIPAA standards. (See slides for greater detail.) The Subcommittee will also continue its work around ICD-11 and on terminologies and vocabularies.

Mr. Landen then welcomed the new National Coordinator for Health Information Technology, Dr. Micky Tripathi.

Conversation with the National Coordinator for Health Information Technology —Micky Tripathi, PhD, MPP

Dr. Tripathi acknowledged the "critically important" part played by NCVHS with respect to health IT, and said he looked forward to deeper collaboration. He summarized ONC's current areas of focus, with COVID as a large priority. Related to that, it is working toward an operational definition of what they call "health equity by design." ONC also has been involved in developing the key principles for vaccine credentials (proof of vaccination), as part of an interagency team. Other activities include further work on the 21st Century Cures Act, including on the issue of information blocking. Dr. Tripathi said he has new appreciation for the importance of ONC's role in coordinating federal health IT activities, because a lot of work is underway. He congratulated NCVHS and HITAC on their great work on the ICAD report, noting that the important next step is to translate the "what" of the identified goals into the "how" of practical solutions.

In a brief discussion period, NCVHS members expressed interest in the current thinking about "health equity by design" and about vaccine credentials. On the latter, he said one key principle is that the market is moving ahead, and the Department wants to encourage that. It is looking at different approaches.

Subcommittee Update, Continued—Mr. Landen

Mr. Landen turned to the proposed scope for the Subcommittee's Convergence 2.0 project, referring members to the March 22 scoping document. In the 25 years since HIPAA, industry business models, data flows, and technologies have changed; industry has stressed the need to modernize the standards process; there is new attention to the social determinants of health; and the rise of the internet and empowerment of patients have led to the bidirectional flow of their data. When the project was first envisioned some 18 months ago, conditions were different and the scope was narrower. As a result of the factors mentioned and others, the Subcommittee now plans to look at the data ecosystem rather than specific data systems, incorporating learnings from the Roadmap project and the ICAD Task Force process.

The project is slated to last for two years and will look at important use cases and standardization issues, in collaboration with multiple partners (see slides). Possible deliverables include the following:

1. A social determinants initiative to support the work already underway through the Gravity Project (see more on this below).
2. A public health data packet to support recommendations for a national floor (minimum) of public health data for reportable and surveillance data standards, with recommendations to State public health agencies—e.g., a floor or minimum that all states abide by.
3. Recommendations on alternative standards for HIPAA.

Mr. Landen said one hoped-for outcome is a future state in which the regulatory framework would allow both X12-type and API-type transactions, with a more industry-driven approach to standards updates.

- **Discussion**

The discussion within the Committee focused on how to carry out the Convergence 2.0 project. The first step over the first several months likely will be an environmental scan, with a convening of stakeholders for a listening session. The initial scan will enable a refinement of the scope. Mr. Coussoule noted that Committee members clearly support moving forward with the project. He explained to new members that the standard process for subcommittee projects is to present the initial idea and scope to the Full Committee to assess support and get input, then to keep non-subcommittee members apprised of progress and/or changes through briefings at subsequent Full Committee meetings. Scoping documents are posted on the website. Projects are also discussed at Executive Subcommittee meetings.

Gravity Project Update—Evelyn Gallego, EMI Advisors; Sara DeSilvey; and Bob Dieterle Gravity Project Update (Presentation)

Ms. Gallego is the program manager of the Gravity Project. She also acknowledged the other leaders of the project, including Dr. Sarah DeSilvey, the clinical informatics director, and Bob Dieterle, the technical director. The Social Interventions Research and Evaluation Network (SIREN) at UCSF plays a key role, and many entities sponsor the work. (See slides for all details.)

Although the business case and social impact of attending to SDOH are clear, clinical systems have not been able to consistently and effectively address social needs, for multiple reasons. The goal of the Gravity Project is to develop consensus-driven data standards for multiple social determinants of health domains to support the use and exchange of SDOH data, both within the health care sector and between it and other sectors including human services, education, and labor. The project was launched as a public collaborative in May 2019, and now has more than 1800 participants. Anyone can join. An initial target is to capture social determinants of health data in EHRs or health IT systems. There are two workstreams, terminology (SDOH health domains) and technical (FHIR), which function in parallel and intersect in the publication and use of value sets. The coding gaps were initially identified by health systems, but the project wants to support activities and interoperability across multiple systems. FHIR plays a critical role in this regard. Ms. Gallego showed the trajectories of the workstreams and where things stand now.

Dr. DeSilvey, a family nurse practitioner in rural Vermont, said she began the Gravity Project work to address the problems of social risk and social data sharing she encounters in her clinical work. She described the "intentional design" of Gravity's "transdisciplinary" collaborative structure, encompassing both clinical practice, informatics, and terminology experts. Every suggested data element is grounded in data; and there is also attention, through ongoing cross-checks, to practical usability. Data in the terminology workstream are organized into activities that will be built into SNOMED-CT and ICD-10-CM. The project was invited to present its multi-domain social risk ICD-10 submission to the ICD-10 Coordination and Maintenance Committee. The project considers the ecosystem in which it is building data, including hospitals, community-based organizations, and states, while working with federal partners. Patient-centered and provider goals are also considered.

The technical workstream accelerates adoption using nationally recognized standards. Mr. Dieterle said the project uses FHIR to define how it does interoperability in exchanging SDOH information. Gravity created an implementation guide in 2020, a framework guide that supports all the domains. It was balloted in the HL7 January cycle as a standard for trial use level 1, and that process is still under way. The project also is dealing with consent and aggregation for exchange and reporting. The underlying idea is that consent needs to be available between the patient and provider to release information from a HIPAA-controlled environment into a community-based one. Early on, the project assessed the risk to an individual of automation of a domain or group of domains. It is looking at creating smartphone applications to support community-based organizations that lack more advanced technology. See slides for further detail about this workstream. There will be a Connectathon in May 2021.

In conclusion, Ms. Gallego said the Gravity Project's success is measured by how the standards it is developing are integrated and used across multiple areas including policy, payment models, programs, and other standards. She showed some results in each area.

- **Discussion**

While praising the Gravity Project and its goals, members also had questions about how to keep it manageable in scale, sustainable, and accessible to communities and users with more modest resources. Ms. DeSilvey said the Project always considers "both simple and complex methods to achieve our goals," and she uses the assets and limitations of her own rural setting as a reference point. She added that piloting will be important for determining what is practical and doable. In response to another question, she said Gravity's standards can transition to ICD-11. Asked about validation and verification, she said the team had "great humility" in the work, and she acknowledged the challenges. The USDA food insecurity module is "the gold-standard tool," but outside that is "the Wild West." The Project works closely with partners on emerging tools, aiming to making them semantically clear to the end user and aligned with screening tools. Asked about sharing across domains in the policy arena, Ms. Gallego said the Project incorporates the viewpoints of many stakeholder groups and agencies. Asked about educational materials and help for users, she said the project needed to do a better job of getting educational materials out; it does have a website, and some of its partners are doing end-user education. Asked how NCVHS can help, she stressed the importance of finding entities that want to adopt the standards to help validate and implement them in the field.

Comparative Analysis of ICD-10-CM and ICD-11 for Morbidity Coding (ICD Update-Margaret Skurka (Presentation))

—Ms. Skurka and Dr. Kin-Wah Fung, NIH/National Library of Medicine Comparative Analysis of ICD-10-CM with ICD-11 for Morbidity Coding-Kin Wah Fung (Presentation)

Ms. Skurka briefly described ICD-11, noting that it is comprehensive and fully electronic. It will be adopted in the U.S. for coding underlying cause of death in 2022, but what is not known is if the U.S. can accept it for morbidity without a clinical modification (CM). It took years to develop the CM for ICD-10, and there were many delays in adopting ICD-10-CM. In late 2019, NCVHS sent the HHS Secretary three recommendations designed to achieve a smoother, simpler, and less burdensome implementation of ICD-11. The first recommendation was that HHS conduct research to evaluate different approaches to the transition to implementation for mortality and morbidity. With that as context, she introduced Dr. Fung.

Dr. Fung said that NLM collaborated with NCHS and CDC on the research into whether ICD-11 can fully support morbidity classification in the U.S. without a clinical modification. He described the research methods, which used Medicare and other claims data to look at 943 frequently-used ICD-10 codes. The codes were recoded by two terminologists, and the results were compared and evaluated. (Refer to the transcript and slides for details.)

Dr. Fung explained that ICD-11 allows for post coordination, which makes it possible to add more detail to a given entity and/or to combine or cluster codes to represent a new meaning, thereby adding different types of information to different elements. This can only be used to make a code more specific. The study defined three levels of representation: 1) ICD-11 can fully represent the ICD-10-CM code meaning without post-coordination; 2) full representation with post-coordination; and 3) partial representation. It found that among the 943 codes, 23.5 percent are in category 1, 8.6 percent in category 2, and 67.9 percent in category 3. The distribution of codes is highly variable among the chapters; when that is taken into account, 53 percent of usage can be fully represented without post-coordination (i.e., category 1). The study also found 75 percent inter-rater agreement in ICD-11 coding. Every ICD-10 code that could not achieve full representation was reviewed to see why that was the case; Dr. Fung outlined several reasons. The failure analysis showed that a few changes in ICD-11 could make a big difference in the coverage and level of representation. The study also reviewed the coding guidances of ICD-10-CM and ICD-11, which are important in understanding the full meaning of the code. Most of the guidance conflicts found in the study are potential rather than actual. Indexes are another possible source of conflict that was studied in a focused review.

Dr. Fung concluded by sharing some personal thoughts, representing only himself. Regarding the overarching study question, in his view the transition from 10-CM to ICD-11 “may not be more disruptive than the transition from 9-CM to 10-CM”; and the disruption can be reduced by using post-coordination (with some caveats that he outlined). The advantages of using ICD-11 for morbidity coding include avoiding the costs of creating and maintaining a clinical modification, avoiding potential divergence from the international core, and being able to make use of the foundation component of ICD-11—its logical underpinning—to align it, for example, with SNOMED-CT. He outlined several alternatives if ICD-11 cannot totally replace ICD-10-CM, including only modifying some chapters and/or deriving an ICD-11-CM as a linearization of ICD-11 using the same logical underpinning.

In a brief discussion period, Dr. Fung said in response to a question that ICD-11 embraces the desiderata for controlled medical terminologies. He noted that ICD-11 is still in its early days, just in its second or third iteration. Ms. Love noted that Dr. Fung’s presentation aligns with the NCVHS recommendations in its November 2019 letter to the Secretary. The Subcommittee on Standards will be taking these learnings and mapping out next steps with respect to ICD-11.

Semantic Harmonization and Classifications—Jamie Ferguson, Subcommittee on Standards

Mr. Ferguson observed that to improve and increase the validity and usefulness of health statistics, the U.S. needs a more broadly harmonized and converged set of semantic standards that can operate across clinical, administrative, social services, and public health use cases. The pandemic has exposed the need for convergence that goes beyond the regulatory authorities for EHRs and HIPAA and encompasses not only ONC and CMS but also CDC, AHRQ, and NIH, among others. At present there is unsustainable variation in the reportable conditions and health resources data being collected. States and counties need resources they could adopt to improve the quality and utility of their health data. This would require nationally standardized cross-maps among multiple existing terminology standards in which the same concept is now expressed in different ways in different places. ICD-11 cannot be implemented without such standard mappings. This framing extends the scope of semantic harmonization beyond what the recent ICAD report recommended, to include other types of data including on public health reportable conditions, social factors data, and sexual orientation and gender identity. Mr. Ferguson invited Committee discussion.

The Full Committee discussion affirmed that these concepts and goals fit squarely in the Standards Subcommittee's forthcoming project on Standardization of Information for Burden Reduction and Post-Pandemic America (Convergence 2.0), described previously by Mr. Landen. Mr. Ferguson reiterated that the project would create a set of resources available to states and counties, and provide better standardized cross-maps for multiple use cases and scenarios. Mr. Landen noted that this also ties to ICD-11 and the Gravity Project, both described earlier. The framework NIST is building, related to an ANSI report on data standardization for artificial intelligence, was also mentioned. In its thought leadership role, NCVHS is looking at data flows as part of an ecosystem, building for tomorrow. He welcomed these concepts as part of the Convergence 2.0 project. Mr. Coussoule called attention to relevant NCVHS work and recommendations on terminologies and vocabularies in the recent past. He and others agreed that given the Committee's bandwidth constraints, it will be important to identify priorities for this initiative.

Public Comment

Katherine Isbell of LexiCode expressed appreciation for Dr. Fung's presentation and, as a coding educator, predicted that coders would be "just fine" learning a new system.

David Wilderman of the Defense Health Agency asked about anticipated rulemaking on attachments; Ms. Doo (Lead Staff to the Subcommittee on Standards) advised him to keep an eye on the *Federal Registry*.

The meeting then recessed until the following day.

—DAY TWO—

Subcommittee on Privacy, Confidentiality & Security—Co-Chairs Monson and Goldstein (Project Scoping: Improving Security in Healthcare (Presentation))

The Subcommittee co-chairs presented an overview of its proposed project "Improving Security in Health Care" and then invited discussion by the Full Committee. The Subcommittee chose to focus on this issue because of the many challenges in safeguarding individually identifiable information that have grown increasingly complex in recent years. New technology and increasing interoperability create many opportunities but also heighten security risks, exacerbated by poor security practices. Data from the HHS Office for Civil Rights document the many large breaches over the past five years. In view of these developments, the Subcommittee has designed a project to examine solutions for improving the security posture of the health care industry at federal, state, local, and tribal organization levels. Project goals are to identify and describe the changing security landscape, to lay out integrative models for how best to secure individually identifiable information while enabling appropriate uses, and to formulate recommendations and prepare a report for the Secretary. Ms. Monson outlined the four phases of the project as envisioned, ending in the third quarter of 2022. Ms. Goldstein thanked the Subcommittee's lead staff, Rachel Seeger, for her assistance and subject matter expertise in developing the presentation.

The co-chairs asked for feedback on the project outlines, and discussion followed. Regarding the challenging scope of the project, Ms. Monson said the Subcommittee plans to invite the experts in the initial environmental scan to help define and tighten the focus. Noting the rapidity with which technology threats and solutions are changing, Mr. Ferguson urged a focus on policy and governance rather than on specific threats. Ms. Seeger said the plan is to "keep it technology neutral." Ms. Chrysler noted the opportunity to enhance other NCVHS work, for example regarding the deficits in data collection related to race and the public concerns about sharing information with the government. Several members urged that the scope of work encompass public health. Members discussed the potential partners who will be invited to the table. Asked to comment on the plans, Dr. Arnold affirmed that the Committee has excellent expertise to complement the work of federal government in this area.

Ms. Monson then presented the scoping document for the project, which members endorsed. They noted the relevance of the Committee's previous "Beyond HIPAA" work and of the September 2020 NCVHS hearing on the data privacy challenges around COVID. On the latter, Ms. Monson said the Subcommittee planned to create a list of recommendations on this for the Secretary, which Dr. Arnold welcomed. In a show of hands, all NCVHS members expressed support for the Subcommittee's plans for this project.

CDC Data Modernization Initiative—Dan Jernigan, MD, MPH, CDC (Public Health Data + IT Modernization at CDC (Presentation))

Dr. Jernigan is Acting Deputy Director for Public Health Science and Surveillance at CDC. His primary focus is to lead CDC's data modernization initiative (DMI) and advise the CDC Director. He briefed the Committee on the plans for the initiative, the current status, and accomplishments to date. (Refer to the transcript and slides for details.)

The DMI is a national effort to create modern, integrated in real-time public health data and surveillance to protect the nation from health threats. While it is largely driven by infectious diseases, it is not pathogen-specific. COVID-19 highlighted the extent to which things in public health information systems were "not working the way they should." The initiative has involved getting engagement, putting together a plan and implementation capabilities, and ultimately acquiring the resources to enable CDC to move forward (appropriations to CDC total $600 million in 2020 and 2021 plus increased funding for states). A series of pilot projects have enabled everyone at CDC to see how they can participate in a more integrated approach; and the benefits extend to public health partners at state, tribal, local, and territorial (STLC) health departments and other parts of government.

The five main areas in which improvement is sought are syndromic surveillance, electronic case reporting, notifiable diseases, electronic laboratory reporting, and vital records. The priorities include ways to collect data and make them available to STLC partners and other stakeholders as well as to CDC and government; building a stronger public health workforce; and ongoing data modernization and innovation. CDC seeks to increase the amount of engagement with all public health partners, and a driving factor in the planning is to ensure that implementation is sustainable. Dr. Jernigan showed a diagram of the public health ecosystem and outlined the vision for better-coordinated and seamless data exchange with attention to data providers, CDC operations, and interoperability. The approaches aim to be program-agnostic. He then described three themes, or "buckets of work," and the objectives and accomplishments in each area. The themes are 1) data-sharing across the public health ecosystem; 2) CDC systems and service enhancements for ongoing data modernization; and 3) new standards and approaches for public health reporting.

One effort, Pandemic-Ready Interoperability Modernization Effort (PRIME), has the goal of getting better, faster, complete, and accurate data to state and local public health departments so they can take appropriate and timely action. It is a collaboration between CDC and the U.S. Digital Service and was started last year with a focus on the capture of lab data and hospitalizations.

- **Discussion**

NCVHS members talked with Dr. Jernigan about these topics: how states can leverage the CDC's modernization initiative to modernize their own systems; the importance of not neglecting vital records in state-level modernization; how to deal with variations in state law; CDC's priorities regarding improving the collection of data on race and ethnicity (e.g., in state immunization registries); potential uses of all-payer claims databases to inform gaps in information; mechanisms for appropriate release of robust public health data to third-party trusted validators; and the need for better standardization of data definitions (e.g., sexual orientation and gender identity). Ms. Hines invited Dr. Jernigan to call on NCVHS if the Committee can assist with any aspect of the CDC's data modernization work.

EXPERT PANEL SESSION

COVID-19: Capacity, Gaps and Quality in Collection of Race/Ethnicity Data —Moderated by Dr. Vickie Mays and Denise Love

Note: *The transcript and slides for this session are posted on https://ncvhs.hhs.gov/meetings/full-committee-meeting-7/ on the March-April 2021 "Meetings" page.*

Welcome and Introduction—Dr. Mays and Ms. Love

Dr. Mays began by thanking Dr. Arnold and other ASPE leaders for raising the issues to be addressed in this panel. 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 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 are a part of reporting requirements. This raised issues about the method of collection and 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 all call for national attention and leadership.

As noted by Herman (2021) and Krieger and her team (2021) and others approximately one month into the rollout 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.

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 the kind of health inequities seen in the COVID-19 pandemic. 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.

Ms. Love reviewed the agenda for this special session; Dr. Mays then named and thanked the presenters and welcomed the first one.

PANEL A: Data Collection and Inputs

Measuring Disparities in COVID-19 in Children and Teens: The Problem of Missing Race and Ethnicity Data (Presentation)

—Elizabeth Pathak, PhD, MSPH

Director, The COVKID Project and President, Women's Institute for Independent Social Enquiry, (WiiSE)

Dr. Pathak indicated that although her program focuses on missing race and ethnicity data on COVID-19 for kids, the problems addressed are true for people of all ages. Five types of surveillance data are needed to understand the epidemiology of COVID-19 in kids: testing and case data for the incidence of disease, hospitalization and intensive care admissions data for disease severity, and death certificate data for disease fatality. All five sources are needed to understand race and ethnicity disparities. Dr. Pathak outlined the problems of missing race and ethnicity data in these sources. Race and ethnicity data are missing for 45 percent of the cases in the CDC case file, and the situation is much worse for hospitalization data. She showed slides on the availability and lack of race and ethnicity data for each of the five types of data.

The COVKID Project assembled its best estimate of the total number of COVID cases, using a combination of COVKID estimates and the CDC case file. This increased the total count by 160,000, to over 800,000 kids. Its purpose was to go back and impute race and ethnicity for the 45 percent of kids for whom that information was missing. The estimate was at the aggregate level, state by state; COVKID does not recommend imputation at the individual case level. Its method is to assume the same racial and ethnic distribution of the missing cases as in the non-missing ones. Dr. Pathak showed the results for children aged 0 to 9 years. The point of the effort is to understand the impact of the missing data on incidence rates; the increase in rates is greatest for Hispanics. CDC does not perform any race/ethnicity imputation in its case file; the missing cases are simply excluded. Regarding hospitalization, Dr. Pathak said that because the Virtual Pediatric Systems (VSP) registry is voluntary, it represents an undercount of the number of kids admitted to intensive care with COVID-19. On death data, she recommended visiting the COVKID disparities dashboard.

Summarizing the priorities that come from the analysis, she observed that race/ethnicity data without age stratification is of limited utility. The paucity of such data needs to be systematically investigated and then actively intervened upon, because it is an ongoing problem. Priorities for states include expanding state dashboard reporting for kids and improving comparability among states. Detailed mandatory hospital reporting is needed for all COVID-19 hospitalizations of kids, along with emergency department visit registries.

Finally, Dr. Pathak cited the information being produced by the state of Florida as an example of what is possible. Dr. Jason Salemi of the University of Florida publishes a daily dashboard of more than 75 metrics, maps, and charts; however, it lacks the race and ethnicity of the cases.

Uncertainty in Demographic and Socioeconomic Data, the Use of Differential Privacy for Disclosure Control, and its Potential Impact on Age and Race/ethnicity Count (Presentation)

—Seth Spielman, PhD
Chief Data Strategy and Analytics Officer, Associate Professor of Geography, University of Colorado Boulder; Faculty Associate, Institute of Behavioral Science
—David Van Riper, MA
Director, Spatial Analysis, Institute for Social Research and Data Innovation, Minnesota Population Center, University of Minnesota

Dr. Spielman and Mr. Van Riper discussed national sources of race and ethnicity data from the U.S. Census Bureau. These data inform denominators in calculating rates. The two primary sources of race and ethnicity data are the American Community Survey (ACS) and the Decennial Census. The presenters emphasized that both sources involve some uncertainty—the ACS because it consists of estimates based on a sample that could be different on a different day, and the Census because of the “obfuscation” introduced into the data to protect privacy. The Census Bureau adopted a new approach to privacy protection in 2020, injecting noise directly into the data that affects the ability to understand small populations.

Dr. Spielman showed a series of illustrative graphs showing the margin of error associated with ACS estimates related to the Hispanic population in various types of census tracts. They show that there is a lot of uncertainty for the Hispanic population at the neighborhood level, though the degree of uncertainty varies depending on the size of the Hispanic population in different areas. He also showed data for other reported racial and ethnic categories and said that data and estimates on subsets of racial and ethnic populations such as age-groups are even more uncertain. There are methods to refine estimates from ACS data, but despite these fixes there are problems with getting denominator data on racial and ethnic groups.

Mr. Van Riper then described the new disclosure avoidance method being implemented for the 2020 Census in place of the swapping technique used in 2010. The new “noise infusion” method perturbs most of the counts to protect privacy. The noise in the statistical distributions is controlled by policy decisions by the data producers, which can be made public. The Census Bureau can spend from a “privacy loss budget” to make some statistics more accurate; it has been focusing this spending on states, counties, and tracts. In addition to geography, the Bureau has to decide which statistics and queries to make more accurate. Mr. Van Riper showed slides of a few illustrative results.

The presenters’ conclusions *(from the slide)*: From ACS and Decennial Census, one can expect good city-level rates/population estimates. But within-city or county, these factors are harder to understand. Geographic and demographic resolution matter. Units with larger counts will be more accurate, and demographic groups with larger counts will be more accurate. It is possible to process publicly released data to improve estimates, particularly for ACS data. Decennial data have more uncertainty.

Data, capacity-building, and training needs to address rural health inequities (Presentation)
—Betty Bekemeier, PhD, MPH, RN, FAAN
Professor, Kirby & Ellery Cramer Endowed Professor; Director, Northwest Center for Public Health Practice; Affiliate faculty, University of Washington 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

Dr. Bekemeier offered a local and especially rural public health perspective on the needs of the public health practice system, particularly from the vantage point of local public health departments, which have pivotal positions in improving population health, promoting health equity, and reducing disparities. These local leaders are expected to use and contribute to the evidence base for public health, and are the ones to which communities look for information and support around community decision-making.

During the 2008 economic crisis, Dr. Bekemeier’s group did a study of how local budget decisions were being made. They found that needed data were not available; the decision-makers talked about the small role data played in their decisions and their desire for greater access to data. This situation “has not changed much since then.” Both public health administrative data and community data around public health status are critical to addressing health equity. Public health agencies cannot compare themselves against others because no standard of comparison exists, and data are not comparable. This applies to the COVID pandemic, which has exacerbated disparities.

The SHARE-NW project focused on rural health departments in four northwest states and the availability of data for health equity. They found that public health leaders were overwhelmed by data volume, questioned its trustworthiness, and lacked data on underserved groups, among other findings. The Public Health Activities and Services Tracking (PHAST) team developed a model to represent what public health practitioners need and the factors for integrating standardized administrative data into public health systems. Practitioners need access to relevant and usable data and the ability to make better use of existing data to design effective strategies for community health improvement. Dr. Bekemeier outlined the implications for researchers in generating and analyzing the data and improving access for evidence-based practice. The low-hanging fruit, she said, is capacity-building and training. She added that improving data for more equitable resource allocation requires data standardization, which should be mandated, with incentives. She concluded that the field needs to find a solution to the practice of suppressing small numbers of data so that variations by race and ethnicity can be addressed.

Race, Ethnicity and the Validity of Cause of Death Assignment for COVID-19 in the U.S. (Presentation**)**
—Andrew Stokes, PhD
Assistant Professor, Global Health, Department of Sociology, Boston University School of Public Health

Dr. Stokes said his team looked at small-area patterns of excess mortality in the U.S. across counties and found that the racial and ethnic disparities in COVID mortality are significantly underestimated in official NCHS tallies. Using its own methods and tools, they found much larger disparities for Latinx, non-Hispanic Black, and Native American individuals. This means that the full extent of the mortality crisis in the U.S. and its differential impact on different groups is being underestimated. His presentation covered the different types of excess death estimators, what is known about racial disparities, and the study findings to be published in *PLOS Medicine* and other journals. He also discussed the reasons for the underreporting of race and ethnic disparities and future directions for research.

“Excess deaths” are defined as the difference between the observed number of deaths in a specific time period and the expected number in the same period. During the pandemic, a significant number of these have been assigned to COVID-19 but an additional number were not so assigned. There are clear patterns of misclassification of deaths and misattribution of deaths to other causes. It is estimated that 20 to 22 percent of all excess deaths were (mistakenly) not assigned to COVID. Some deaths were due to interruptions in health care services; some stem from the broad social and economic consequences of the pandemic.

Dr. Stokes stressed the need to explore the kind of mechanisms that explain why these deaths are ending up in other categories to fully understand the causes of excess mortality. Small-area data are needed to do so, and the absence of these data has made it difficult to look at the social structural factors and other mechanisms and patterns related to excess mortality. His team hopes to contribute to this conversation. He cited some of what is known about inequities in the official tallies, which reveal problematic differences for Hispanic/Latinx, non-Hispanic Black, non-Hispanic American Indian or Alaska Native, and non-Hispanic Native Hawaiian or other Pacific Islander individuals. He described his team’s work on the mechanisms of underreporting. One major finding was that the percent of excess deaths not assigned to COVID-19 is significantly higher in areas with more non-Hispanic Black residents and fewer non-Hispanic white residents. When hidden or uncounted deaths are factored in, stark patterns emerge, with higher disparities between Black and white communities.

He concluded by commenting on the possible reasons for the underreporting, which include differential access to testing and health care; higher prevalence of comorbidities due to racial inequities; bias in death investigation systems; interpersonal bias; and a greater incidence of home deaths. All of these factors represent pathways through which structural racism within health systems could affect the extent of underreporting of COVID-19 deaths.

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? (Presentation)

—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

Dr. Mays observed that everyone is struggling now with the question of what is the best equity metric to use. The over-emphasis on preexisting health conditions among racial/ethnic minorities has made some people feel they were being blamed for being infected with COVID-19. Working with the UCLA Center for Neighborhood Knowledge, she and her colleagues looked at what factors make people vulnerable and put them at risk. The team developed medical vulnerability indicators based on four factors: pre-existing health conditions, barriers to accessing services, built-environment risk, and social vulnerability. She outlined the contributors in each area, identified based on the available scientific literature. The study adapted the CDC Social Vulnerability Index to zip code tabulation areas. Using these variables, the team mapped Los Angeles County to show the different levels of vulnerability for exposure and infection to COVID in different areas. In addition, they analyzed the ethno-racial distribution of risk for each medical vulnerability factor. Dr. Mays concluded that this analysis and the mapping tools provide a way to target where to roll out resources.

Collection and Use of Race/Ethnic Data through Cross-sector Data Sharing Networks Presentation

—Glen Mays PhD, MPH

Professor and Chair, Health Systems, Management and Policy, University of Colorado Anschutz Medical Campus

Dr. Mays focused on community networks—networks of community-based organizations (CBOs) working together—as a potential solution for collecting better data on race and ethnicity and using that information to reduce local health risks. He shared data that illuminate the importance of these networks and coalitions and their relationships, and discussed the implications for better data on race and ethnicity to empower the networks to protect their communities. Collective action is needed because no single organization can do all that is needed in public health, medical care, and social services.

CDC launched the Health Security Index was launched in 2012 to measure the strength of protection capabilities, with funding from the Robert Wood Johnson Foundation. The Index measures these domains: surveillance, community planning and engagement, incident management, health care delivery, countermeasure management, and environmental and occupational health. The Index has been produced since 2013, revealing national trends over time in each domain and marked geographical variations in health security across the U.S. (See slides.)

The community planning and engagement domain of the Health Security Index is the strongest predictor of improved COVID-19 outcomes; places that score higher in this domain generally have lower rates of death from COVID. Cross-sector community collaboration is one of its major components. Dr. (Glen) Mays's program has several measures of community network strength, using the National Longitudinal Survey of Public Health Systems. The network metrics are the strongest individual predictors of COVID mortality across the U.S. Significantly, however, these multi-sector community networks are limited in what they can do by the data limitations discussed in the present session. The networks rely heavily on small area estimates of race and ethnicity from the ACS, which as noted have high margins of error; and they use administrative data sources that also are imperfect. They are trying to use other data sources, and some emerging ones show promise in filling into the gaps. He concluded that further efforts are needed to find solutions, including to the problem of the lack of standardization.

A National Framework to Improve Mortality, Morbidity, and Disparities Data for COVID-19 and Other Large-Scale Disasters (Presentation)

—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

Dr. Stoto described work he did with a committee of the National Academy of Sciences, Engineering, and Medicine (NASEM) that was formed in response to difficulties in estimating the number of people impacted by Hurricane Maria. It completed its work just as COVID-19 hit, and much of its analysis and findings apply to COVID as well. His presentation focused on the kind of data public health officials need to make decisions and the problems and challenges with these data, including uncounted deaths. Data anomalies are significant because policy makers are using the data to make decisions (e.g., the "tiers" in California). Both numerators and denominators change over time in complex ways that don't have to do with the epidemiology of COVID, and it is hard to know what is really going on.

He outlined some of the reasons for the problems with case surveillance data, including that only a fraction of infections are reported and there are differences between the tests in different states. There are similar issues with reported deaths, and more severe ones with the data on race and ethnicity. For example, the CDC's data on race and ethnicity disparities are based on data from only 16 states and big cities, covering only 30 percent of the U.S. population; this leads to very biased samples.

The NASEM report offers a number of recommendations to address these issues. It recommends that CDC standardize case definitions, measurement processes, metric definitions, and measurement time periods. It outlines ways to build a system that can perform better in future emergencies. For the near term, during the pandemic, the report suggests three statistical estimation methods to complement counts: excess mortality methods, syndromic surveillance, and surveys based on representative samples. Having a constant reference population is very important; this is often missing in current metric systems. Dr. Stoto concluded that research is needed to develop the best methods and standardize the approaches. The federal government has an opportunity to develop a framework that can be put in place after or at the outset of a public health emergency to track the impacts.

The Implications for COVID-19 Vaccine Equity in Not Disaggregating Data in Native Hawaiian and Pacific Islanders (Presentation)

—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

Dr. Ponce has been tracking data equity in COVID-19 with respect to the invisibility of the Filipinx/a/o population and more broadly Native Hawaiians and Pacific Islanders (NHPIs), a category of government statistics per the 1997 OMB Directive 15. Both Asians and NHPIs are underrepresented in a California equity metric, the Healthy Places Index, which is used to determine vaccine allocation and other public policies. She cited the definition of data equity: Data are collected, analyzed, interpreted, and distributed such that marginalized communities (i.e., those with low literacy, limited English proficiency, and no broadband access) have access to and can use these data. This, she said, is a global imperative. OMB Directive 15 encourages further detail, especially if it is needed to represent diversity of local populations.

She showed an illustrative July 2020 *New York Times* report on racial and ethnic impacts of COVID-19 data containing no data on Asians and NHPIs, and juxtaposed it with a graph showing NHPI case rates for the same month rising at the same rate as Hispanics and more steeply than other racial and ethnic groups. Because public health systems do not disaggregate Asian categories, the U.S. is most aware of the impact of COVID on Filipinos in relation to the death of Filipino nurses: 31.5 percent of RN deaths are Filipinos. As shown in a dashboard developed by the UCLA Center for Health Policy, only about 20 states have data on the NHPI population. Eighteen states have used an equity metric for vaccine allocation. Only the Social Vulnerability Index includes data on minority status and language; the other indexes miss these aspects of vulnerability. Communities of color are underrepresented in California's Healthy Places Index.

In conclusion, Dr. Ponce suggested that place-based equity algorithms be enhanced and augmented to include domains that include English proficiency, linguistic isolation, and language spoken at home. (See slide for complete list.)

The Contribution of Linked Private-sector Data to the Understanding of Gender, Race/ethnic and SES Disparities in COVID (Presentation)

—Mark Cullen, MD

Founding Director, Stanford Center for Population Health Sciences (retired)

Dr. Cullen cited the need for granular and accurate data, including accurate reporting of race and ethnicity. This is needed for public transparency, for day-to-day clinical medicine and public health practice, and for research. His remarks focused on the third of these.

He described the COVID-19 Research Database (RDB), designed to accelerate the amount of real-world data that researchers can freely access to better understand and mitigate the effects of the COVID-19 pandemic. In March 2020, some 30 commercial entities in the health care system (now 35) got together to form a loose consortium to pool their data in a safe way and develop a method for linking the data in appropriate ways so they are rapidly available to the research community. There is an emphasis on data quality, and although the reporting on race and ethnicity is less than perfect, it is more complete than in comparable publicly available databases. The data are refreshed every week. The partners developed a scientific review and administrative oversight process using technology to secure data privacy. Dr. Cullen showed a series of slides on the processes and their management. The RDB contains at least partial information on about 90 percent of the insured and documented U.S. population (though the data "do not cover complete populations virtually anywhere"). The datasets are linked to datasets containing social information. (See the slides for details.)

After one year, 2200 groups including public agencies have registered for the dataset; 150 have made active research proposals; and 400 researchers are working on the platform. It is all completely free.

- **Committee Discussion**

Several members observed that the panelists' presentations were both fascinating and alarming. Some asked questions about specific methodologies. Dr. Mays noted the importance of thinking about the implications of the Census issues, given that all NCHS datasets are based on Census data. She also pointed to concerns about for-profits and others using the data in the COVID-19 RDB. The need for more resources and more standardization was a recurrent theme of the discussion. Dr. Ponce noted that a mandate, an incentive, and guidelines on how to do it are needed to achieve system change. Ms. Skurka raised the issue of possible mis-classification of the underlying cause of death as a factor in undercounts of COVID deaths.

Ms. Hines read a comment from audience member Ruth Wangerin about the limitations of comparing COVID statistics derived from testing. She wrote that the test positivity rate is being interpreted as a measure of prevalence in the community, but this is not comparable from one community to another because it depends on the thoroughness of testing coverage. Dr. Ponce agreed with this point.

***(Note:** Other comments received from audience members but not discussed due to time constraints are attached to these minutes.)*

Ms. Banks commented on the desirability of harmonizing across the multiple sectors collecting and contributing data on race and ethnicity (e.g., education, real estate). Ms. Love proposed that centralizing data collection within health care is a good place to start. Dr. Xu noted that CMS could provide incentives to providers and payers to get better data. Dr. Glen Mays commented on the "chain of custody" as health information is exchanged and the risk of the information getting lost; this is one way race and ethnicity data get lost.

Finally, Mr. Coussoule thanked the panelists and the panel moderators and organizers.

NCVHS 2021 Workplan Review and Discussion

Mr. Coussoule noted that a decision had not yet been made about whether the Committee's September 2021 meeting would be virtual or in person. A special virtual Full Committee meeting will be convened to review and approve the 2021 Report to Congress. Members then discussed the Committee's work plan, including the scopes of work and means of conducting forthcoming subcommittee projects (as described earlier in the meeting).

They also agreed to create a small, cross-cutting NCVHS group to recommend next steps on ICD-11, based on the NLM research reported previously. Volunteers: Ms. Skurka, Ms. Banks, Dr. Xu, Mr. Ferguson, Dr. Cimino. They will work with Ms. Donna Pickett of NCHS.

Members also agreed to create a document pulling together what was learned from the panel on race and ethnicity data gaps and COVID-19 and highlighting priorities. Dr. Arnold said such a summary would be useful to the Department. Volunteers: Ms. Banks, Ms. Strickland, Ms. Chrysler, Ms. Love.

Public Comment

Pini Herman described the trouble her Los Angeles organization (name indiscernible) had been having getting comparable data to evaluate the effectiveness of arranging vaccinations in impacted communities and comparing them to data from the local health department.

Final Comments and Adjournment—Mr. Coussoule

Mr. Coussoule thanked NCVHS members, staff, and technical partners for their contributions to this successful meeting. Ms. Hines

Mr. Coussoule then adjourned the meeting.

I hereby certify that, to the best of my knowledge, the foregoing summary of minutes is accurate and complete.

/s/	July 7, 2021
Chair	Date

APPENDICES

1. Public attendance list
2. Written public comments

NCVHS Meeting of the Full Committee

Public Attendees

March 31 – April 1, 2021

First Name	Last Name	Organization
Nelson	Adekoya	
Oluwarantimi	Adetunji	HHS
Farida	Ahmad	CDC
Robin	Albany	
Juan	Albertorio	National Center for Health Statistics (NCHS)
Josephine	Alford	CDC/NCHS
Latasha	Allen	
Johnnie	Allen	Ohio Department of Health
Liz	Amos	National Library of Medicine
Lauren	Anderson	HHS/OS/ASPE
Damon	Arnold	HCSC BCBSIL
Vivian	Auld	NIH/NLM
Victoria	Aysola	HHS/ASPE
Prince	Baawuah	CMS
Maria	Baron	New Jersey Department of Health
Chrystel	Barron	Cleveland Clinic
Micah	Bass	Centers for Disease Control and Prevention
Jeannie	Baumann	Bloomberg Law
Brooke	Beaulieu	CSTE
Trnidad	Beleche	HHS
Mitcell	Berge	
Mike	Berry	HHS/ONC
Meryl	Bloomrosen	Premier healthcare alliance
Amy	Blum	CDC/NCHS
Sue	Bowman	American Health Information Management Association
Juliet	Bui	
Lorraine	Burton	HRSA
Laina	Bush	HHS/ASPE
Christen	Byler	BLS
Laura	Caldwell	GDIT
Patricia	Canessa	Chicago Hispanic Health Coalition
Becky	Captioner	Captions
Amanda	Cash	HHS/ASPE
Man-Huei	Chang	CDC
William	Chang	McKesson
Avena	Cheng	
Joya	Chowdhury	HHS
Catina	Conner	CDC
Beth	Connor	CMS
Traci	Cook	NCHS/OPBL
Krycia	Cowling	HHS

Jessica	Czulewicz	CMS
Brittney	Daniel	California Community Foundation
Susan	Dardine	Genesis Rehabilitation Services
Mike	Denison	Change Healthcare Operations LLC
Sarah	Desilvey	UVM
Maria	Diacogiannis	CMS
Kim	Diehl-Boyd	CoverMyMeds
Bob	Dieterle	Enablecare
Carmen	DiFelice	Independence Blue Cross
Michele	Dillon	Rose Li Associates
Scott	Douglas	HHS/OS/ASPE
Matthew	Downey	WEDI
Dawn	Duchek	Trizetto Provider Solutions
Cynthia	Dunn	Health Department
Adrienne	Durham	Indiana Department of Health
Morgan	Earp	
Daniel	Elchert	Senate Health, Education, Labor and Pensions
Scott	Erickson	Urban Indian Health Institute
Michele	Farry	City of Northampton
Steven	Fink	
Charles	Fleming	George Washington University
Rachel	Foerster	Rachel Foerster & Associates Ltd
Robin	Free	Palmetto GBA
Rebecca	Garcia	Premise Health
Christine	Gerhardt	CMS/OBRHI/NSG
Robin	Ghertner	HHS
Aida L	Giachello	Northwestern University
Kathy	Giannangelo	
Debra	Gilliam	CASET Associates, Ltd.
Renee	Gindi	CDC/NCHS
Natalie	Gonzales	CDC
Alix	Goss	Imprado
Christopher	Gracon	
Mary	Greene	CMS/Office of Burden Reduction and Health Informatics
Shay	Greene	Palmetto GBA
Kirk	Greenway	IHS
Violanda	Grigorescu	HHS/ASPE
Rebecca	Haffajee	HHS/ASPE
Katherine	Heck	UCSF
Pini	Herman	One LA -IAF
Laura	Hoffman	AMA
Jhamirah	Howard	HHS
David	Huang	HHS/CDC/NCHS
Mildred	Hunter	US Dept of Health & Human Services, Region 5

Katherine	Irimata	NCHS
Katherine	Isbell	LexiCode
Olga	Joos	CDC Foundation
Daniel	Kalwa	CMS
Susan	Kanaan	Susan Baird Kanaan
Bhavana	Kapoor	
Sarah	Keller	ITCMI
Dan	Kim	
Nate	Kim	HHS/ASPE
Katherine	Knapp	VHA
Gail	Kocher	BCBSA
Lisa	Lang	HHS/ASPE
Euny	Lee	HHS
Celine	Lefebvre	AMA
Amy	Lightstone	LA County Department of Public Health
Michelle	Liu	CDC/NCHS
Tiffany	Lopes	UCLA Center for Health Policy Research
Nancy	Lopez	University of New Mexico
Ana Carolina	Loyola Briceno	HRSA/BPHC/OQI
Marilyn	Luke	AHIP
Iti	Madan	
Alan	Mai	
Stella	Mandl	CMS
Octavio	Martinez	Hogg Foundation for Mental Health
William	Marton	HHS/OS/ASPE
Rena	McClain	CMS
Shannon	McConnell-Lamptey	NCHS
Nicholas	McGraw	National Library of Medicine
Patrick	McLaughlin	National Library of Medicine
Malikah	McNeal	CDC
Deidre	McPhillips	CNN
Erica	Meade	HHS/ASPE
Leo	Meister	CMS
Janelle	Menard	WiiSE
Ryan	Mintz	HHS
Cindy	Monarch	BCBS Michigan
Devaiah	Muccatira	North Dakota Department of Health
Jovita	Murillo	Charles Drew University
Kelly	Myrick	NCHS
Jean	Narcisi	American Dental Association
Josephine	Nguyen	White House Fellow
Jim	Nowicki	Palantir
Jon	Oliver	
Dauda	Onawola	Novometrix Research Incorporation

Elena	Ong	AA
Michelle	Panneton	CDC Foundation
Elise	Pechter	Occupational Health Surveillance Program, Mass Dept Public Health
Steve	Pegula	HHS/HRSA
Dr. Vernita	Perkins	
Kellina	Phan	NHCS
Luping	Qu	CMS
Susan	Queen	HHS/ASPE
Naveen	Raja	UCLA Health
Deneen	Ratchford	CMS
Molly	Reese	American Medical Association
Leo	Rennie	American Psychological Association
Greg	Richardson	Rose Li Associates
Lauren	Riplinger	AHIMA
Kaitlin	Roach	HHS
Howard	Rodenberg	Baptist Health, Jacksonville, Florida
Michael	Rodriguez	UCLA
D	Roper	NCHS
Tara	Rose	Optum
Ken	Rosenberg	
Lauren	Rossen	CDC/NCHS
Charles	Rothwell	NCHS (retired)
Suzy	Roy	SNOMED International
Jason	Salemi	University of South Florida College of Public Health
Tom	Scholomiti	consultant
Bobbie	Shimizu	CDC/NCHS
Carla	Shoff	Centers for Medicare & Medicaid Services
Beth	Sieloff	Inter-Tribal Council of Michigan
kathy	sites	Availity
Elizabeth	Smith	Zotec Partners, Inc
Celena	Snoddy	National Institutes of Health
John	Snyder	U.S. National Library of Medicine, National Institutes of Health
Ben	Sommers	
Aurora	Soto	United ISD-Lyndon B. Johnson High School
Nancy	Spector	NUCC
Anagha	Sridhara	Office of the Surgeon General
John	Stamm	Epic
Scott	Stare	CMS OMH
Bill	Stead	Vanderbilt University
Charles	Stellar	WEDI
Wafa	Tarazi	HHS
Robert	Tennant	WEDI
Herman	Thurman	CDC/NCHS/CPHDSS

Paul	Tindall	AASTEC
Rosali	Topper	HHS/CMS
Alexandra	Turner	CMS
Gina	Turrini	
Julienne	Vaillancourt	FDA/CBER
Judy	Van Alstyne	HRSA
Tracey	Veal	Los Angeles Public Health
Lisa	Wagner	HHS/CDC/NCHS
Pat	Waller	Cambia Health Solutions
Meagan	Walters	HHS/CDC/NCHS
Ruth	Wangerin	Lehman College
Sara	Wei	
Margaret	Weiker	NCPDP
Minh	Wendt	Office of Minority Health - HHS
Gloria	Wheatcroft	CMS
Michelle	White	US Consumer Product Safety Commission
Kristin	Whitehair	Krames Patient Education Solutions
Meredith	Whitmire	National Association of Nutrition and Aging Services Programs
Hannah	Wichern	Inter-Tribal Council of Michigan
David	Wilderman	Defense Health Agency - Contract Support
Kim	Williamson	Rose Li Associates
Doreena	Wong	Asian Resources, Inc
Chantal	Worzala	Alazro Consulting
Caroline	Young	GWU
Rachael	Zuckerman	HHS/ASPE

Written Public Comments sent in Zoom

NCVHS Meeting – Day 2 (April 1, 2021)

Nancy Lopez
Is there any research on the rates of Covid infection/death/vaccine access for people of Hispanic orign by their racial status/street race/socially assigned race and intersectional social locaiton educational attainment, gender, age? Thank you! Nancy

D Roper
Continuing to SDOH with explainations will create the opportunity to collect the general public's position with the use of SDOH or moving away from the use of SDOH. An opportunity to get an environmental scan on the use of SDOH from a broader scope of individuals.

Doreena Wong
As an community-based organization (CBOS) working in collaboration with many others to reach and educate vulnerable and at risk communities on the grond, I appreciate Dr, Ninez Ponce's presentation about the need for disaggregated race and ethnicity data, as well as the importance of including additional social determinants of health, such as language, immirgration status, per capita income, etc. (as recommended by Dr. Ponce) to the Healthy Places Index. Her recommendations to improve the identification for targeting vaccinations to disproportionately impacted communities using equity tools such as HPI and working with CBOS like ours to reach those populations, are critical to ensure an equitable distribution of vaccines to those most at need. Thank you for allowing public comments for this meeting. Doreena Wong, Policy Director, Asian Resources, Inc, dwong@asianresources.org.

Pini Herman
There is heightened awareness of inequities but the inequities are essentially divorced from meaningful census tract level (5-8K persons) geographies by lack of geocoding on all levels of government, federal state and local.

Pini Herman
Are there plans to geocode to the census tract level at the PRIME hub level so that the data can be usable at the 5-8K person community level? This is important for achieving Covid vaccination equity.

Nancy Lopez
Has anyone seen and intersectional analysis of Covid deaths/vaccines by social location (Race, Gender, Educational Attainment, age). This may help underscore the need to make the invisible visible.

Is there any research on the rates of Covid infection/death/vaccine access for people of Hispanic orign by their racial status/street race/socially assigned race and intersectional social locaiton educational attainment, gender, age? Thank you!

Ruth Wangerin
I rarely hear anyone explain the limitations of comparing statistics about COVID that are derived from testing for infection. Rarely are differences in testing coverage from one neighborhood (or race/ethnicity, or age) to another reported, yet "cases" and "percent positives" in these different groups are compared as if they're comparable. Unless the population of a zip code, for example, are being regularly and randomly tested, and across all age groups, how can we interpret statistics like number of

cases, or cases/100,000, or percent positivity in the population in that zip code? Clearly, the USA never got the ideal surveillance system going, yet even professionals talk about the statistics as if they are "real." In some populations, people are rarely tested, even if sick. In other populations, people are frequently tested just to make sure they're not infected. These differences in testing are related to race, ethnicity, and especially socio-economic status.

The test positivity rate is being interpreted as a measure of prevalence in the community, but it's not comparable from one community to another because it depends on rate and thoroughness of testing coverage. Thank you.

Elena Ong
Could you also post info the denominator: e.g., census timeline and decision-making? thank you. Interesting question about UNDERLYING CAUSES OF DEATH - expressed as ICD-11, what about SOCIAL DETERMINANTS OF DEATH?