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**Board of Scientific Counselors**  
**National Center for Health Statistics**  
**Centers for Disease Control and Prevention**  
**[https://www.cdc.gov/nchs/about/bsc/bsc\\_meetings.htm](https://www.cdc.gov/nchs/about/bsc/bsc_meetings.htm)**  
October 24, 2022

**Meeting Summary**

The Board of Scientific Counselors (BSC) convened via Zoom on October 24, 2022. The virtual meeting was open to the public (via Zoom).

**Board Members Present**

John R. Lumpkin, M.D., M.P.H., Chair, BSC

Mollyann Brodie, Ph.D.

Kennon R. Copeland, Ph.D.

Tara Das, Ph.D., M.P.H.

Scott H. Holan, Ph.D.

V. Joseph Hotz, Ph.D.

Helen G. Levy, Ph.D.

Bradley A. Malin, Ph.D.

Sally C. Morton, Ph.D.

Lucila Ohno-Machado, M.D., Ph.D.

Kristen M. Olson, Ph.D.

Andy Peytchev, Ph.D.

Kelly Hoover Thompson, J.D.

David R. Williams, Ph.D., M.P.H.

**CDC/NCHS Panelists**

Brian Moyer, Ph.D., Director,  
National Center for Health  
Statistics (NCHS)

Rebecca Hines, M.H.S.,  
Designated Federal  
Official, NCHS, BSC

Farida Ahmad

Amy Branum  
Stephen Blumberg  
Carol DeFrances  
John Halter  
Travis Hoppe  
Meredith Massey  
Dagny Olivares

Kristen Olson  
Andy Peytchev  
Alan Simon  
Paul Sutton  
Anjel Vahrtanian  
Chia-Yih Wang  
Brian Ward

**Public Attendees**

Aya Abdelkader  
Joyce Abma  
Brian Adams  
Dzifa Adjaye-Gbewonyo  
Viviana Aguila  
Naman Ahluwalia  
Lara Akinbami  
Johanna Alfier  
Bren Ames

Robert Anderson  
Hallie Andrews  
Nicholas Ansai  
Yutaka Aoki  
Elizabeth Arias  
Irma Arispe  
Basilica Arockiaraj  
Jill Ashman  
Rihem Badwe

Brenda Baker  
Kai Baker Stringfield  
Andrés Berruti  
Jeanne Bertolli  
Peter Boersma  
Joseph Bohn  
Jonaki Bose  
Kate Brett  
Lisa Broitman

Cynthia (Cindy) Bush  
Christine Caffrey  
Christopher Cairns  
Christine Carr  
David Carranza  
Amy Cha  
Patrick Champion  
Anjani Chandra  
Don Cherry  
Jodi Cisewski  
Jay Clark  
Robin Cohen  
Steven Cohen  
Michelle Collins  
Victor Colocco  
Traci Cook  
Rebekah Corlew  
Jim Craver  
Nicole Cummings  
Anterio Cunningham  
James Dahlhamer-Tracy  
Darbro  
Barnali Das  
JD Davids  
Orlando Davy  
Michele Dillon  
Avay Dolberry  
Patricia Dunham  
Abigail Durak  
Susan Schneider  
Danielle Ely  
Patrick Forsyth  
Alicia Frasier  
Cheryl Fryar  
Matthew Garnett  
Carlye Gates  
Renee Gindi  
David Goldstein  
Yelena Gorina  
Heidi Guyer  
Gelila Haile  
Nancy Han  
Althelia Harris  
Yulei He  
Elizabeth Heitz  
Alston Hildreth  
Jacquie Hogan  
Robert Hood-Cree  
Isabelle Horon  
John Hough  
Rebecca Hu  
Marisol Iniguez  
Katherine Irimata  
Isabella Izquierdo  
Geoff Jackson  
Ahmed Jamal  
Matt Jans  
Adrienne Jones  
Jessly Joy  
WenYen Juan  
David Justice  
Ashley Kaiser  
Matt Karwowski  
Jessica Keralis  
Gina Kilpatrick  
J.M. King  
Brian Kit  
Richard Klein  
Ellen Kramarow  
Nataliya Kravets  
Melissa Kresin  
Deanna Kruszon-Moran  
Denys Lau  
Jessica Lendon  
Sarah Lessem  
Xianfen Li  
Laura Lindberg  
Anthony Lipphardt  
Michelle Liu  
Christine Lucas  
Jacqueline Lucas  
Justin Mezetur  
Sri Surya Maheedhara  
Aaron Maitland  
Crescent Martin  
Michael Martinez  
Gladys Martinez  
Rina Mascarenhas  
Nyrek Mason  
Juliana McAllister  
Susan McBroom  
Lisa McCorkell  
Jody McLean  
Grace Medley  
Justin Mezetur  
Donna Miller  
Kristen Miller  
Bibimasoumeh Mir Mousavi  
Yoshihisa Miyamoto  
Leyla Mohadjer  
Jennifer Moore  
Kiana Morris  
Michael Mussolini  
Gwen Mustaf  
Kelly Myrick  
Carolyn Neal  
Linda Neff  
Zakia Nelson  
Duong Nguyen  
Tina Norris  
Colleen Nugent  
Tatiana Nwankwo  
Adaeze O'Jiaku-Okorie  
Damon Ogburn  
Cynthia Ogden  
Sarah Osborne  
Jessie Parker  
Sue Pedrazzani  
Zachary Peters  
Donna Pickett  
John Pleis  
Deborah Porterfield  
Anthony Quintana  
Jennifer Rammon  
Elizabeth Rechtsteiner  
Maggie Ritsick  
Dorothy Roper  
Cheryl Rose  
Lauren Rossen  
Neil Russell  
Loredana Santo  
Neda Sarafrazi  
Sharon Saydah  
Jennifer Sayers  
Paul Scanlon  
Susan Schappert  
Jeannine Schiller  
Steven Schwartz  
Bobbie Shimizu  
Sandra Smith  
Merianne Spencer  
Marietta Squire  
Martha Starr  
Beth Stelson  
Bryan Stierman  
Renee Storandt  
Makram Talih  
Rashmi Tandon  
Chally Tate  
Danielle Taylor  
Ana Terry  
Alexander Tin  
Joy Ukaigwe

Elizabeth Unger	Antonia Warren	Jacqueline Wright
Allan Uribe	Valerie Watzlaf	Jianmin Xu
Maria Villarroel	Julie Weeks	Alana Yick
Rajesh Virkar	Steven White	Henry Yin
Thomas Walker	Sonja Williams	Benjamin Zablotsky
Meagan Walters	Jean Williams	Kevin Zhang
Edwina Wambogo	Amanda Wilmot	Chu Zhuang
Xun Wang	Michael Wolz	
Lindsay Ward-Gokhale	Ashley Woodall	
Margaret Warner	David Woodwell	
Meeting Tech	Damon Kane (RLA)	
Minutes	Amy Kiefer, Derek Johnson, Cooper Roache (RLA)	

### **List of Abbreviations**

ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
BSC	Board of Scientific Counselors
CASI	computer-assisted interviewing
CBHPS	Census Bureau's Household Pulse Survey
CCQDER	Collaborative Center for Questionnaire Design and Evaluation Research
CDC	Centers for Disease Control and Prevention
DHANES	Division of Health and Nutrition Examination Surveys
DHCS	Division of Health Care Statistics
DHIS	Division of Health Interview Statistics
DMI	Data Modernization Initiative
DVS	Division of Vital Statistics
ED	emergency department
EHR	electronic health record
FHIR	Fast Health Interoperability Resources
FQHC	Federally-Qualified Health Center
FY	fiscal year
HHS	Department of Health and Human Services
HL7	Health Level Seven
HRSA	Health Resources and Services Administration
ICD-10	International Classification of Diseases version 10 (international coding standard)
IG	implementation guide
IgG	Immunoglobulin G
NAMCS	National Ambulatory Medical Care Survey
NCHS	National Center for Health Statistics
NCVHS	National Committee for Vital and Health Statistics
NHANES	National Health and Nutrition Examination Survey
NHCS	National Health Care Survey
NHIS	National Health Interview Survey
NORC	National Opinion Research Center
NPALS	National Post-Acute and Long-term Care Study

NSA	North Star Architecture
NSDS	National Secure Data Service
NSFG	National Survey of Family Growth
NVSS	National Vital Statistics System
OIS	Office of Information Services
PASC	post-acute sequelae of SARS-CoV-2 infection
PCOR	Patient-Centered Outcomes Research (trust fund)
PII	personally identifiable information
PSU	primary sampling unit
RDC	Research Data Center
SARS-CoV-2	severe acute respiratory syndrome coronavirus 2
SDOH	social determinants of health
VA	Veterans Affairs

### **Action Steps**

The Board of Scientific Counselors (BSC) voted to approve recommendations based on language in the findings presented by the Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Survey regarding inclusion of measures of discrimination in the National Health Interview Survey (NHIS), National Survey of Family Growth (NSFG), and National Health and Nutrition Examination Survey (NHANES). The BSC will include this language in its letter to the NCHS Director.

### **Presenters**

John Lumpkin, M.D., M.P.H., Chair, BSC, NCHS  
 Rebecca Hines, M.H.S., Designated Federal Officer, BSC, NCHS  
 Brian Moyer, Ph.D., Director, NCHS  
 John Halter, J.D., Director, Office of Planning, Budget and Legislation, NCHS  
 Travis Hoppe, Ph.D., Associate Director of Data Science and Analytics, NCHS  
 Kristen Olson, Ph.D., Chair, Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Surveys  
 Amy Branum, Ph.D., Associate Director for Science, NCHS  
 Anjel Vahrtian Ph.D., M.P.H., Associate Director for Science, DHIS  
 Chia-Yih Wang, Ph.D., Team Lead, Planning Branch, DHANES  
 Meredith Massey, Ph.D., Senior Survey Methodologist, Collaborating Center for Questionnaire Design and Evaluation Research  
 Mortality Reporting, Farida Ahmad, M.P.H., Mortality Surveillance Lead, DVS  
 Carol DeFrances, Ph.D., Acting Director, Division of Healthcare Statistics, NCHS  
 Brian Ward, Ph.D., Chief, Ambulatory and Hospital Care Statistics Branch, Division of Healthcare Statistics, NCHS  
 Dagny Olivares, M.P.A., Associate Director for Communication, NCHS  
 Alan Simon, M.D., Director, DHANES  
 Stephen Blumberg, Ph.D., Director, DHIS  
 Paul Sutton, Ph.D., Deputy Director, DVS

## **Welcome and Call to Order**

John Lumpkin, M.D., M.P.H., Chair, BSC, NCHS  
Rebecca Hines, M.H.S., Designated Federal Officer, BSC, NCHS

Dr. Lumpkin opened the meeting by welcoming Board of Scientific Counselors (BSC) members, National Center for Health Statistics (NCHS) staff, and all other attendees.

Ms. Hines conducted roll call, asking members to introduce themselves and state conflicts of interest. Dr. Williams noted for awareness that he is involved in conducting discrimination research and developing measures of discrimination. None of the BSC members stated a conflict of interest.

## **NCHS Director's Update**

Brian Moyer, Ph.D., Director, NCHS  
John Halter, J.D., Director, Office of Planning, Budget and Legislation, NCHS  
Travis Hoppe, Ph.D., Associate Director of Data Science and Analytics, NCHS

### ***Board, Staffing, and NCHS Office Updates***

Dr. Moyer opened the meeting by thanking Drs. Olson and Levy for extending their time on the BSC and for their work with the Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Surveys. He asked BSC members to suggest new board candidates.

Dr. Moyer welcomed two new members of the NCHS leadership team, Mr. John Halter and Dr. Alan Simon. Mr. Halter is the new Director of the NCHS Office of Planning, Budget and Legislation. Dr. Simon is the new Director of the Division of Health and Nutrition Examination Survey (DHANES).

### ***CDC Moving Forward Initiative***

Dr. Moyer provided updates on the Centers for Disease Control and Prevention (CDC) Moving Forward Initiative. The goal of this effort is to modernize CDC structures, systems, and processes to enable CDC to consistently deliver public health information and guidance to the U.S. population in real time. CDC Director Dr. Walensky views this effort as a means for CDC to improve accountability, collaboration, communications, and timeliness, not only throughout its centers but also in its work with partners across the public health space. Through this effort, CDC aims to learn from the COVID-19 pandemic and other recent health emergencies to better prepare for ongoing and future health threats.

Dr. Walensky charged Dr. McCrae from the Health Resources and Services Administration (HRSA) to perform a programmatic and scientific review of CDC practices. Dr. McCrae recommended several actions to improve how CDC conducts scientific investigations and deploys guidance, in both emergency and non-emergency settings. The actions fall into five categories: (1) share scientific findings and data faster; (2) translate science into practical, easy-to-understand policy; (3) prioritize public health communications; (4) promote results-based partnerships; and (5) develop a diverse workforce prepared for future emergencies. Improvements under consideration as part of CDC Moving Forward Initiative will likely affect how NCHS works with other CDC centers and offices, as well as some of its cross-agency systems and processes.

During its May meeting, the BSC discussed the NCHS Data Modernization Initiative (DMI), which is focused on modernizing the flow of public health and surveillance data across CDC centers and to state, tribal, local, and territorial partners to improve data access, timeliness, and relevance. The CDC Moving Forward Initiative, by contrast, is focused on improving policy, public health preparedness, and response communications and the evolving workforce. Although different, the DMI and Initiative priorities are

complementary and, together, will enhance the ability of CDC and NCHS to respond to future public health threats.

### ***Evidence Act Implementation***

In 2018, Congress passed the Foundations for Evidence-based Policy Making Act (Evidence Act), whose purpose is to advance evidence building in the federal government by improving access to data and expanding evaluation capacity. It requires changes to the ways in which the federal government manages and uses the information it collects and emphasizes strong agency collaborations for strategic use of data. The act also establishes new legal expectations for data openness and accessibility. To support this effort, the act established an Advisory Committee on Data for Evidence Building within the Department of Commerce Office of the Under Secretary for Economic Affairs. The advisory committee was charged with providing recommendations to the Office of Management and Budget (OMB) on implementing the Evidence Act. As a statistical official of the U.S. Department of Health and Human Services (HHS), Dr. Moyer served on this advisory committee and was one of three federal statistical agency leaders invited to participate.

The primary task of the Advisory Committee on Data for Evidence Building was to review, analyze, and develop recommendations to promote the use of federal data, and potentially state and local data, for the purposes of evidence building and for determining the potential composition and function of a National Secure Data Service (NSDS). The NSDS is intended to function as a centralized coordinating unit for data sharing, linking, and protection across the federal statistical ecosystem and potentially the broader evidence-based ecosystem. It will partner with and enhance the existing evidence ecosystem, rather than supplant any existing components of that ecosystem.

Two weeks ago, the Advisory Committee on Data for Evidence Building released its second and final report, which is available on the U.S. Bureau of Economic Analysis website. This report offers several recommendations focused on the NSDS. It details the four core functions of NSDS: coordination, communication, data standardization, and research and development. The report proposes development of an organizational structure and governance for the NSDS, as well as a phased implementation, which would involve several use cases to pilot developmental work. One of these use cases is the National Vital Statistics System (NVSS) DMI.

The Creating Helpful Incentives to Produce Semiconductors (CHIPS) for America Act, which was signed into law in August 2022, includes funding for a demonstration NSDS. The National Science Foundation has been tasked with implementing this demonstration for 2 years and then preparing a report to Congress with recommendations for the future NSDS.

### ***NCHS Budget Update***

Over most of the past decade, NCHS's annual appropriation has remained stable, which has limited its ability to innovate. However, over the past 2 fiscal years (FYs), the dedicated budget line rose to its current level of \$180 million for FY22. House and Senate proposals for FY23 seek to appropriate \$190 million to NCHS. This amount does not include additional funding sources such as NCHS's portion of CDC's DMI funding. In previous FYs, this portion has ranged from \$50 to \$60 million per year.

With these additional funds, NCHS is working to enhance its modeling and analytics capacities, accelerate its survey and data analysis capabilities, and develop a new data query tool to integrate and streamline data access and improve data collection on race and ethnicity. NCHS and CDC are carefully reviewing the cost implications of inflation on the NCHS budget

NCHS plans to maintain the National Health Interview Survey (NHIS) baseline survey sample size established in FY23. NCHS will use additional resources to expand access to data, including public and restricted data. To maximize the efficiency of data collection across agencies and programs, NCHS plans to advance its equity analysis through data collection, such as collection of disaggregated data for Asian Americans, Native Hawaiians, and Pacific Islanders. NCHS also plans to evaluate electronic health records (EHRs) to better understand how to capture health equity variables, and to examine the misclassification of race and ethnicity in vital records to develop and implement methodologies that adjust for misclassification. NCHS will publish statistics, develop training materials, and conduct targeted outreach to data providers regarding proper classification.

The Office of Planning, Budget, and Legislation in conjunction with senior leadership is beginning budget preparation for FY24. Mr. Halter closed by thanking the BSC members for their efforts and requesting their input on the proposed uses of NCHS's increased resources.

### ***NCHS New Reports and Data***

Dr. Moyer highlighted several high-visibility reports, datasets, and estimate highlights recently released by NCHS.

- **Reports:** [Provisional Numbers and Rates of Suicide by Month and Demographic Characteristics, United States, 2021](#) and [Cause-of-Death Data From the Fetal Death File, 2018-2020](#)
- **Datasets:** [Telemedicine Use Among Adults: United States, 2021](#) and [COVID-19 Mortality Among Adults Aged 65 Years and Over: United States, 2020](#)
- **Estimate highlights:** [COVID-19 Death Rates in Urban and Rural Areas: United States, 2020](#); [Quarterly Provisional Estimates for Selected Causes of Death: Q1 2019 – Q1 2022](#); and [COVID-19 Mortality by Usual Occupation and Industry: 46 States and New York City, United States, 2020](#)

Dr. Moyer thanked NCHS staff for their contributions to these publications and for their commitment to the NCHS mission.

### ***DMI Strategic Roadmap***

The recently released DMI roadmap details NCHS's phased approach to data modernization. During the past 2 years, as part of Phase 1, NCHS has focused on laying the groundwork for meeting the ultimate goal of developing scalable response systems that have a positive impact on public health. Phase 1 included forming the DMI consortium to engage with external stakeholders, establishing foundational cloud capabilities, designing North Star Architecture (NSA), and developing measures of success. NSA will guide the development of technology for internal and external users in the public health ecosystem, including flexible, standardized, and replicable user tools.

DMI is currently transitioning from Phase 1 to Phase 2. During this time, NCHS will focus on the future of NSA. NCHS will adopt key enterprise decisions and begin to demonstrate DMI's impact with specific use cases, one of which will be NVSS data modernization. Phase 2 sets the stage for Phases 3 and 4, during which NCHS will scale these efforts, release new processes and data across the broader agency and public health ecosystem, and continuously iterate on and improve existing processes.

Two specific DMI activities involve data linkage and NCHS metadata. The DMI investment in data linkage draws on various data science tools, such as machine learning to expand linkages and enhance NCHS's methods and algorithms. NCHS's DMI has performed a record number of data linkages across a variety of survey and administrative datasets, covering topics such as health behaviors and conditions, socioeconomic status, and mortality. The enhanced algorithms recently enabled the first-ever linkage of NCHS survey data with Veterans Affairs (VA) data. The linkage expands the research potential of NCHS

surveys to include aspects of veterans' health. Similar linkages with other datasets will enable NCHS to analyze health outcomes and social determinants of health (SDOH) without incurring additional costs for data collection.

#### ***NCHS Metadata Updates***

Several metadata projects within NCHS focus on data findability and accessibility and on ensuring that data leaving NCHS's systems are well-documented and discoverable. Data discoverability is important not only for data available on the NCHS website, but also when the data are federated with other systems. The datasets available on data.CDC.gov are machine readable and can be accessed as a JavaScript Object Notation (JSON). A system called Socratic manages the datasets and includes metadata such as the publisher, program codes, the frequency with which the codes are updated, descriptions, abstracts, and data tags. CDC and NCHS metadata stewards recently removed 820 inconsistencies within the datasets, which will be checked monthly for inconsistencies. NCHS is also working with CDC on additional metadata projects involving variable- and column-level metadata.

Now that NCHS has metadata stewards, it is assembling a catalog of restricted datasets. The catalog is available on the Research Data Center (RDC) website. This effort aligns with a section of the Evidence Act that requires development of a standard application process for requests for specific federal datasets. Snapshots of 17 restricted-access NCHS datasets are now available on data.CDC.gov, and the full datasets can be accessed via the RDC or NCHS's upcoming virtual data enclave access.

An NCHS pilot program is creating dataset-level tags focused on the SDOH, using *Healthy People 2030* as a starting framework. Once a consistent set of tags is developed, they will be used to create catalogs of SDOH topics. Users will be able to click on the tags on data.CDC.gov to view how the tagged datasets are organized and how to access them.

The CDC Chief Data Officer is establishing a new office, the Enterprise Data Office, to help guide metadata efforts and to build the Enterprise Data Catalog, which is an internal catalog to help CDC users to find and reuse datasets.

#### ***Discussion/Reaction by the Board***

Dr. Lumpkin asked how data linkages and metadata will account for imputed data, particularly for data on race and ethnicity. Dr. Hoppe replied that NCHS is working to address tagging of imputed and synthetic data and communication of these data and their potential pitfalls to the public. This work is part of the larger effort to develop variable-level metadata and to ensure that their tags remain consistent across users. The linkage group is also using NHIS data, which is considered the gold standard for race and ethnicity data, to assess the quality of SDOH and health equity data across multiple data sources.

#### **Workgroup Update: Using NCHS Surveys to Measure Respondents' Perceptions of Discrimination**

Kristen Olson, Ph.D., Chair, Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Surveys

During its February 2022 meeting, the BSC voted to formally establish a workgroup to consider whether NCHS can feasibly and practically add measures of discrimination to the NHIS, the National Survey of Family Growth (NSFG), and National Health and Nutrition Examination Survey (NHANES). Structural and interpersonal racism are known to substantially affect health and wellbeing. Discrimination is a form of racism that can cause psychosocial stress and contribute to health disparities across ethnic and racial subgroups.

### ***BSC Questions Posed to the Workgroup***

The NCHS Division of Health Interview Statistics (DHIS) proposed, and the BSC adopted, several questions to help facilitate the discussions of the Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Surveys. These questions fall into two categories, Feasibility and Practicality and Methodology.

#### **Feasibility and Practicality**

1. Given the limited space available on NHIS, NSFG, and NHANES, does the BSC consider this an achievable goal for NCHS?
2. If so, what are the most important contributions NCHS can make by including measures of discrimination on NHIS, NSFG, and/or NHANES?
3. How best can NHIS, NSFG, and NHANES data collection contribute to research and/or surveillance efforts related to racism and discrimination?
4. Should NCHS survey have a focus on discrimination in health care settings or consider experiences of discrimination more generally?
5. Given similarities and differences in the purposes and core content of NHIS, NSFG, and NHANES, should discrimination content (if any) be similar or different across NCHS surveys?

#### **Methodology**

6. Should the surveys measure the perceived reason (attribution) for discrimination? If so, is a one- or two-stage approach recommended for measuring discrimination on NCHS surveys?
7. If attribution is assessed, would it be beneficial to include “mark all that apply” options?
8. Would it be beneficial to adopt an intersectional approach to measuring discrimination? If yes, what would be the best way to accomplish this based on the number and nature of questions/response options recommended?
9. What would be the most appropriate scale to use for a face-to-face interviewer administered survey like NHIS? Does the recommendation change if self-response is an option, as can be done using computer-assisted self-interviewing (CASI) within NHANES and NSFG?
10. What is the most appropriate reference/recall period for cross-sectional surveys such as NHIS, NHANES, and NSFG?
11. Are there other aspects of discrimination measures that should be taken into consideration when being included on NCHS surveys (e.g., how to best handle comprehension, skipping/don’t know)?
12. Is additional developmental research needed? For example, would using open-ended question follow-ups and/or cognitive interviewing be beneficial to ascertain how respondents comprehend discrimination and unfair treatment?

#### ***Review and Panel Process***

The Workgroup identified several guiding concepts to frame its discussion of these questions:

- Discrimination is an important psychosocial stressor that contributes to health disparities. Many aspects of discrimination, racism, and ruminative or anticipatory stress in response to racism can contribute to health disparities.
- Surveys may vary in the amount of “real estate” (e.g., time, minutes, questions) available to devote to measures of discrimination.
- NCHS will evaluate questions under consideration using standard testing and evaluation methodologies to inform the design and administration of any items that may be used.

The Workgroup reviewed existing literature on discrimination measures and convened six meetings, including two panel discussions with subject matter experts and CDC stakeholders: Margaret Hicken, M.P.H. Ph.D., University of Michigan; Tené Lewis, Ph.D., Emory University; Gilbert Gee, Ph.D.,

University of California, Los Angeles; LCDR Rashid Njai, Ph.D., Minority Health and Health Equity Science Team, CDC; and Tina Norris, Ph.D., DHIS, NCHS. Throughout this process, the Workgroup iteratively drafted a memo to track its discussions and inform its final Findings Report.

### ***Workgroup Findings and Recommendations***

Dr. Olson presented the key findings related to feasibility and practicality:

- The inclusion of discrimination measures is an achievable goal for NCHS.
- No nationally representative benchmark study collected on a regular time frame containing self-reported discrimination measures and their association with health is currently available.
- States and localities need a national benchmark.
- Inclusion of measures of discrimination will allow for evaluating associations with a broad array of health outcomes.
- Regular data collection of discrimination measures on important subgroups will allow for detecting signals of change in reports.
- Expansion of novel measures beyond discrimination to those reflecting anticipatory stress and vigilance during social interactions may also be useful.
- Global experiences and within health care context are likely to be important.
- Needed are measures of experiences of discrimination across multiple domains, including but not limited to health care settings.
- It would be valuable to have a small core set of identical questions asked on all surveys.
- How many items depends on (1) which constructs (e.g., discrimination, heightened vigilance), (2) how many items are needed to measure the breadth of these constructs, and (3) survey real estate.

Dr. Olson emphasized that leveraging novel measures beyond discrimination can help to uncover mechanisms underlying the impact of discrimination on health, such as vigilance and anticipatory stress. In particular, the subject matter experts stressed that vigilance must be studied alongside discrimination, not in place of it.

Dr. Olson then presented the key findings related to methodology:

- Collecting information about experiences of discrimination even without attribution to the “main reason” for the discrimination is valuable.
- If the “main reason” for experiencing discrimination is assessed, then allowing respondents to identify multiple reasons is important. It may be worth evaluating existing scales through cognitive testing or other qualitative work to identify whether items reflect experiences of individuals with varying social identities.
- More experimental work is needed to evaluate effect of mode—especially face-to-face vs. ACASI—on discrimination measures. Prior work suggests race-of-interviewer effects on racial discrimination questions.
- Some scales do not have an explicit reference period. Evidence suggests that respondents may forget distant experiences of discrimination, suggesting a more recent reference period may be more useful.

### ***Discussion/Reaction by the Board***

Dr. Brodie asked whether measures of anticipatory stress and vigilance are sufficiently well developed and studied for NCHS to adopt them into surveys. Dr. Olson responded that these measures, although less common, have been used for the same length of time as other measures of discrimination. She added that the Workgroup believed that attempting to assess the mechanisms by which discrimination affects health was important. Moreover, the Workgroup recognized the need for cognitive testing and question

evaluation before administration of any measure, and this process may illuminate better methods for assessing these constructs.

Dr. Brodie also inquired about Dr. William's statement during opening remarks that he has a conflict of interest on the topic. Dr. Brodie noted that because this is an area he has been working in, she would like to hear his opinions on this particular area of work, indicating that his experience will be important to the conversation. Ms. Hines clarified that Dr. Williams does not have a financial conflict of interest, and has provided information to Workgroup members drawing on his expertise as they finalized the Workgroup's findings. Dr. Williams noted that research shows that vigilance and anticipatory stress have adverse physiological consequences and can lead individuals to attempt to avoid stressors.

### ***Proposed Language for BSC Consideration***

Following discussion, Dr. Olson provided the Workgroup's draft language for BSC consideration and potential inclusion in a letter to the NCHS Director:

1. The Board accepts the findings from the report from the NCHS BSC Workgroup to Consider and Assess Measures of Discrimination for Use in NCHS Surveys.
2. The Board recommends that NCHS include measures of discrimination in the NHIS, NHANES, and NSFG, based on question evaluation and testing, amount of time available in each survey, and review of the literature.
3. The Board recommends that NCHS include measures of heightened vigilance in the NHIS, NHANES, and NSFG, based on question evaluation and testing, amount of time available in each survey, and review of the literature.

Dr. Olson moved to vote to accept the proposed language, and Dr. Levy seconded this motion. Dr. Brodie, Dr. Copeland, Ms. Das, Dr. Holan, Dr. Levy, Dr. Lumpkin, Dr. Malin, Dr. Ohno-Machado, Dr. Peytchev, Ms. Thompson, and Dr. Williams voted to accept the proposed language, which exceeded the threshold of nine votes needed to approve the motion.

### **Panel on Long COVID Tracking at NCHS**

#### ***Introduction***

Amy Branum, Ph.D., Associate Director for Science, NCHS

Long COVID has many names, including long-haul COVID, post-acute COVID-19, post-acute sequelae of SARS-CoV-2 infection (PASC), long-term effects of COVID, and chronic COVID. Long COVID encompasses any health problems experienced after infection with SARS-CoV-2. Affected individuals can present with a wide range of health-related symptoms that may persist for weeks, months, or longer. Researchers have variously defined long COVID as symptoms persisting for 3 months, or more recently, for 4 weeks after infection. Anyone infected with SARS-CoV-2 may develop long COVID. People with severe acute infections may be at higher risk for long COVID, but people whose initial symptoms are mild can also develop long COVID. Doctors and scientists are still learning about long COVID, which may have a large and ongoing impact on the U.S. population.

Currently, no widely accepted objective diagnostic tests or biomarkers are available for diagnosing long COVID. Given the lack of clinical and diagnostic criteria, NCHS will need to determine how best to measure long COVID using existing data collection systems.

#### ***Long COVID Content in the National Health Interview Survey and the Household Pulse Survey***

Anjel Vahrtanian, Ph.D., M.P.H., Associate Director for Science, DHIS

### *National Health Interview Survey*

NHIS is an address-based household survey designed to monitor the health of the nation through the collection of a broad range of health topics. The annual sample size includes more than 27,000 adults and 9,000 children. In January 2022, two questions were added to the adult and the child interviews to inquire about COVID infection history:

- Do you or your child have any symptoms lasting three months or longer that you did not have prior to having coronavirus or COVID-19?
- If yes, do you or your child have symptoms now?

These questions allow for estimation of the percentage of children and adults who currently have, and who have ever had, long COVID. The 2023 NHIS will continue to ask these questions as well as a third question to assess activity limitations: do these long-term symptoms affect your ability to carry out day-to-day activities, compared with the time before you had COVID-19? Answer options will be yes, a lot; yes, a little; and not at all. Long COVID estimates based on the 2022 NHIS data will be available in 2023.

### *Census Bureau's Household Pulse Survey*

Census Bureau's Household Pulse Survey (CBHPS) was launched on April 23, 2020, to monitor how the COVID-19 pandemic is affecting households across the country from a social and economic perspective. The survey only captures data from adults and is conducted online. The health content on this survey has evolved since its launch; the NHIS questions on long COVID were added on June 1, 2022, and the NHIS question on activity limitations on September 14, 2022. Four datasets are currently available on past and current long COVID estimates from June through September 2022, as well as one dataset on activity limitations. The Census Bureau releases estimates every month, and the October 2022 estimates will be made public on Wednesday, October 26, 2022.

Data for Week 49 of the survey were collected from September 14 to 26, 2022. The response rate was 4.7 percent, with an unweighted sample of 50,258 adults. These data yielded estimates on the percentage of adults currently or ever suffering from long COVID, and the percentage of those with any or significant activity limitations from long COVID. These estimates can be reviewed in the context of all adults in the United States or only adults who have had COVID-19. NCHS receives data from the Census Bureau on the Friday prior to the public release on Wednesday. This timing enables NCHS to review the new estimates and update data visualizations before posting the data to the NCHS dashboard.

For Week 49, NCHS estimates that 48.2 percent of all U.S. adults have ever had COVID-19. Of all U.S. adults, 14.2 percent have had long COVID, and 7.2 percent currently have long COVID; 5.9 percent have had long COVID that affects their day-to-day activities at least a little, and 1.8 percent have had long COVID that affects these activities a lot. Among adults who have had COVID-19, 29.6 percent have had long COVID, and 15 percent currently have long COVID. Among adults who currently have long COVID, 81.4 percent report at least a small impact on their day-to-day activities, and 25.1 percent report a large impact. These estimates can be reviewed in the context of age, sex, sexual orientation, gender identity, race, and Hispanic origin. Additional information is available on the NCHS website, including information on symptoms of anxiety and depression. The Census Bureau's website also contains information on the CBHPS, data tables, and additional data visualizations.

### ***Long COVID Questions in NHANES***

*Chia-Yih Wang, Ph.D., Team Lead, Planning Branch, DHANES*

The NHANES 2021-2022 aims to examine 5,000 people of all ages per year that comprise an annually, nationally representative sample. Each annual sample is collected from 15 primary sampling units

(PSUs). This cycle did not oversample by race, ethnicity, or income. Individuals under age 19 or over age 60 have higher probabilities of selection than other individuals. Data collection began in August 2021 and will finish in August 2023.

NHANES 2021-2022 collects detailed information on COVID-19 infection, testing, and vaccinations. It also asks about symptom severity, overnight hospital stays, weakened immune systems, and household member infections. In 2022, NHANES added questions regarding the long COVID (post-COVID conditions), and the use of prescription medications to treat or prevent COVID-19. NHANES also has laboratory data on spike protein and nucleocapsid antibodies, to distinguish between infection-based and vaccination-based immunity. NHANES has received approval for quantitative testing for immunoglobulin G (IgG) antibodies on the specimens collected.

The NHANES' long COVID questions were adapted from existing surveys, including NHIS, CBHPS, CDC's Behavioral Risk Factor Surveillance System (BRFSS), the Red Cross COVID-19 survey, the Porter Novelli Summer Styles Survey, and UK's Office for National Statistics' COVID-19 Infection Survey. The NHANES team has worked closely with CDC's Division of Viral Disease and National Center for Immunization and Respiratory Diseases, and the DHANES Clinician Advisory Group to design long COVID questions. Last month, the questions were approved and implemented. NHANES' plan is to collect data from all 15 PSUs in the 2022 data collection cycle. These questions are asked to participants who report having had COVID-19, having tested positive for COVID-19, or who having been tested and are still awaiting their results. These questions address post-COVID conditions and symptoms that were experienced by the participant 4 weeks or later after the initial infection. People reporting long COVID symptoms are asked about their three most bothersome symptoms, day-to-day activity limitations, current presence of symptoms, and symptom duration.

Dr. Wang then requested input from the BSC on which research questions to prioritize once the NHANES 2021-2022 data are available and whether NHANES should consider adding other measures on long COVID. Dr. Wang shared preliminary unweighted 2021 NHANES data. Data were collected from 5,557 individuals, of which 1,479 previously had COVID-19. COVID-19 infections were reported by 88 children under age 4, 165 children ages 5-11 years, 175 adolescents ages 12-17 years, 722 individuals ages 18-59 years, and 329 individuals age 60 and older. The numbers for people testing positive for COVID-19 are slightly lower than reported infections, presumably because not everyone was tested. The reverse also occurred, with some individuals who tested positive reported never having had COVID-19.

#### ***Collaborating Center for Questionnaire Design and Evaluation Research Question Testing***

Meredith Massey, Ph.D., Senior Survey Methodologist, Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER)

CCQDER has tested survey questions related to COVID-19 and long COVID as part of a larger testing project, which involved 50 in-person interviews conducted in Los Angeles during October 2022. The questions related to COVID-19 infection were as follows:

1. Have you ever had or likely had Coronavirus or COVID-19?
2. Have you ever been tested for Coronavirus or COVID-19?
3. Has a test found that you or your spouse had Coronavirus or COVID-19?
4. How would you describe your coronavirus symptoms when they were at their worst? Would you say you had no symptoms, mild symptoms, moderate symptoms, or severe symptoms?

Of those interviewed, 17 reported having had COVID-19, 30 reported not having COVID-19, and 3 refused to answer. Not all people reporting having had COVID-19 received a positive test for the virus; some assumed they had COVID-19 based upon symptoms. Individuals who reported they had not had COVID-19 included individuals who did not believe that COVID-19 is a real disease and people who

believed they received a false positive test. Those who refused to answer included individuals who were unsure whether they had asymptomatic COVID-19 and those who do not believe in the COVID-19 pandemic.

The 17 interviewees who reported having had COVID-19 were additionally asked a set of long COVID-related questions, either from NHIS, NHANES, or UK's Office for National Statistics (ONS). A subset of interviewees was asked the following question from NHIS: Did you have any symptoms lasting 3 months or longer that you did not have prior to having coronavirus or COVID-19? Eight interviewees responded that they did not have any new long-lasting symptoms after COVID-19 infection, including one individual whose sense of taste did not fully return to normal until 3 months post infection, but began to recover after 1 month. Several other individuals reported having symptoms that lasted 1-2 months.

Another subset of the 17 interviewees who reported having COVID-19 was asked the following NHANES long COVID question: Did you or your spouse experience any new, recurring, or ongoing symptoms after being infected with COVID-19 or suspecting to have been infected with COVID-19? These symptoms can sometimes appear after recovering from the initial infection. Two interviewees responded affirmatively, and 4 responded that they did not have any new or ongoing symptoms. Interviewees seemed to have considered loss of taste or smell in answering this question. They were then asked the following two NHANES follow-up questions:

1. Among all of the post-COVID symptoms that you experienced, which ones bothered you the most? List up to three different symptoms. What are the (first, second, and third) symptoms that bothered you the most?
2. Do you still experience any of these symptoms now?

To the first question, one interviewee reported “severe body aches,” apparently conflating acute COVID symptoms with post-COVID symptoms. To the second question, one interviewee reported not feeling post-COVID symptoms, and another was unsure whether their taste had returned to normal or not.

A third subset of interviewees who reported having COVID-19 was asked ONS’s long COVID question: Would you describe yourself as having “long COVID,” that is, you are still experiencing symptoms more than 3 months after you first had COVID-19, that are not explained by something else? All 6 interviewees replied “no.” Several had not heard the term “long COVID” before, and others thought mainly of loss of taste and smell.

Dr. Massey emphasized that life circumstances, beliefs about COVID-19 and other illnesses, symptoms, and personal knowledge of people who had become very ill or died of COVID-19 influenced responses to these questions. CCQDER is planning to conduct additional virtual interviews this fall and winter to further understand how respondents address the long COVID questions. She requested feedback from BSC regarding what aspects to focus upon during these upcoming interviews.

### ***Mortality Reporting***

Farida Ahmad, M.P.H., Mortality Surveillance Lead, DVS

The Division of Vital Statistics (DVS) defines long COVID as the long-term symptoms experienced after recovery from an acute infection with SARS-CoV-2. Only limited information about long COVID mortality exists. No estimates of the number of long COVID deaths in the United States are currently available. The lack of data stems from evolving diagnostic guidelines, a lack of a simple diagnostic test for long COVID, changes in terminology, no cause-of-death code for long COVID in the United States, and a lack of standardized guidance for listing long COVID as “cause of death” on death certificates.

NVSS captures death certificate data according to the *International Classification of Diseases, Tenth Revision* (ICD-10). ICD-10 code U09.9 is used for coding and reporting post-COVID conditions linked with preceding acute COVID-19. The World Health Organization adopted this code in September 2020, but NVSS has not yet adopted it for mortality coding in the United States. Implementing the new ICD-10 codes requires developing coding guidelines and training for manual coders, developing coding logic for automated coding systems, and updating downstream data systems to recognize the new coding. Before NVSS can adopt a new code, it must understand the text terms being written on death certificates and how often those terms are used.

DVS researchers conducted exploratory analyses using NVSS literal text data from death certificates. First, they made a list of key terms for identifying death certificates of interest, including long COVID, long-haul COVID, post-COVID, post-COVID syndrome, PASC, post-acute sequelae of COVID-19, and post-acute sequelae SARS-CoV-2 infection. They only analyzed deaths with COVID-19 as a contributing or underlying cause (i.e., coded of U07.1). They also restricted analyses to deaths occurring prior to June 30, 2022. Lastly, to compute crude and age-adjusted rates, they used the 12-month period from July 2021 to June 2022. DVS is planning to summarize and publish the findings in a Vital Statistics Rapid Release Report. It may also update the analyses with more recent data and refine key terms. Ms. Ahmad requested that BSC provide feedback on additional considerations for certification guidance to promote consistent and accurate reporting of long COVID on death certificates. She also requested BSC feedback on the implementation of ICD-10 code U09.9.

#### Discussion/Reaction by the Board

##### *Assessing Long COVID*

Dr. Levy asked whether the discussion regarding the implementation of the U09.9 code was used to help design long COVID survey questions. Dr. Wang noted that NHIS finalized its long COVID questions in late 2021, before that discussion. Since then, NHIS has considered changing the question timeframe from symptoms lasting 3 months or longer, but thus far has decided against any changes.

Dr. Peytchev noted that women report higher rates of long COVID, even though men on average appear to have longer viral persistence. The apparent sex difference in rates of long COVID might therefore reflect measurement artifacts and differences in willingness to report symptoms rather than true differences in rates of long COVID. Given the high prevalence of COVID-19 infections and long COVID among people who have had COVID-19, Dr. Peytchev proposed adding additional survey questions on long COVID, including those that provide a more granular assessment of specific symptoms and behaviors. Dr. Branum agreed, and suggested that RANDS might provide a good venue for additional testing.

##### *Measuring Additional Aspects of Long COVID*

Dr. Peytchev proposed adding questions regarding long COVID's impact on worker productivity. BLS may be interested in such data.

Dr. Copeland suggested adding survey questions that assess how people with long COVID are seeking or accessing care, which is a challenging endeavor currently. Dr. Peytchev agreed. Drs. Copeland and Brodie emphasized the importance of collecting new diagnoses and health issues occurring after COVID-19 infection, because not all new health problems fall under the shifting rubric of long COVID. Dr. Brodie proposed asking about post-COVID experiences and then classifying individuals as having long COVID based on their experiences, as opposed to asking about long COVID directly. Dr. Olson agreed and noted it might also be valuable to ask individuals which symptoms they or their doctors attribute to long COVID. Dr. Olson also proposed asking about symptom duration using an event history approach.

### *Assessing Long COVID on Death Certificates*

One possible additional analysis of value would examine death certificates with long COVID literal text but not the U07.1 code, because how death certificates are coded in these cases is not clear. However, most death certificates mentioning COVID in the literal text will have a U07.1 code. Ms. Das recommended developing a new guidance document as soon as NVSS has results from the preliminary analysis. She also recommended updating the general guidance on certifying deaths due to COVID-19 that released in April 2020, rather than publishing a new guidance. Providing one guidance for acute and long COVID would help doctors, nurses, and physician assistants, who certify most COVID-19 death certificates.

### **Upcoming Changes to the National Hospital Ambulatory Medical Care Survey (NHAMCS) and Update on National Ambulatory Medical Care Survey (NAMCS)**

Carol DeFrances, Ph.D., Acting Director, Division of Health Care Statistics

Brian Ward, Ph.D., Chief, Ambulatory and Hospital Care Statistics Branch, Division of Health Care Statistics

#### *The National Health Care Surveys*

The National Health Care Surveys (NHCS) are a family of nationally representative surveys that examine health care across a wide spectrum, including ambulatory, in-hospital, outpatient, and long-term care. These surveys are establishment surveys, not household-based surveys, and survey participation is voluntary. Their unit of analysis is the patient visit or health care encounter. Hence, these surveys provide estimates related to the variety of encounters with providers, not estimates of the entire population. Historically, patient-level data used by the survey have been abstracted from medical or administrative data. This group of surveys also includes health care provider surveys that aim to understand the provider's experiences.

Currently, the Division of Health Care Statistics (DHCS) conducts five active National Health Care Surveys: two physician surveys (i.e., NAMCS and the National Electronic Health Records Survey [NEHRS]), two hospital surveys (i.e., NHAMCS and the National Hospital Care Survey), and the National Post-Acute in Long-term Care Study (NPALS). NPALS covers seven health care sectors. For five of these sectors, DHCS purchases data from the Centers for Medicare & Medicaid Services. In the other two sectors, Adult Day Service Centers and Residential Care Communities, DHCS conducts original data collection. For the 2022 NPALS, DHCS is exploring whether data can be extracted from commercial EHR platforms for these two sectors. In addition, DHCS is working with the Assistant Secretary for Planning and Evaluation (ASPE) to design a pilot study of direct care workers, including personal care aides, nursing assistants, and home health aides.

Over the past several decades, many changes have occurred in the health care system. The scope and the settings have tremendously expanded, particularly in the ambulatory sector. During the COVID-19 pandemic, the use of telemedicine, telehealth, and e-health services has increased. EHR adoption has also created opportunities for sharing and accessing additional clinical information. However, these opportunities also present challenges regarding the transfer and processing of EHR-based information and ensuring data security.

#### **NHAMCS**

NHAMCS has been conducted since 1992 and involves the collection of data on the utilization and provision of ambulatory care services in hospital emergency departments (EDs), outpatient departments, and ambulatory surgery locations. Since 2018, NHAMCS has collected only ED data. Annually, NHAMCS collects data from about 400 hospitals, which are generally short-stay hospitals. NHAMCS excludes federal, institutional, military, and VA hospitals. To participate in the survey, hospitals must

have six staffed in-patient beds and the EDs must be available to operate 24 hours a day. Data are collected in-person via questionnaire and computer-assisted manual extraction of about 100 sampled ED records. NHAMCS collects data on patient demographics, insurance status, residential zip code, and medical conditions. NHAMCS also collects data on health care encounters, including reason for the visit, diagnosis, procedures, medications, immunizations, injuries, triage, and disposition. These data are available as restricted use and public use files and web tables, and via the NHAMCS Online Dashboard. Data collection has grown increasingly challenging, because of decreasing response rates, increased security and legal concerns, increased competition with other reporting systems, and the pandemic-related challenges regarding in-person data collection. Thus, NHAMCS data collection will cease after the 2022 cycle.

Beginning in 2023, the National Hospital Care Survey (NHCS) will provide national estimates on ED visits and will be the sole source of hospital data collected by DHCS. NHCS is transitioning to using EHR data. Its sample consists of 6080 non-federal, non-institutional hospitals that have six or more staffed in-patient beds. To date, NHCS has recruited a little over 200 such hospitals. NHCS leverages in-patient and ED data for a calendar year and collects personal identifiable information (PII) to examine repeat ED visits and hospitalizations, as well as to enable data linking with external data sources. NHCS is working with staff at DRM and NORC to develop nationally representative weights for the 2020 NHCS data. Three years of overlap between NHAMCS and NHCS data are planned, which will allow for comparison of ED estimates.

### **NAMCS**

NAMCS is designed to obtain objective, reliable information about the provision and use of ambulatory care services in the United States. NAMCS visit data provide the only national estimate for office-based physician care. The NAMCS sample includes physicians classified by the American Medical Association and the American Osteopathic Association who are not federally employed and do not work in anesthesiology, radiology, or pathology. An induction interview is conducted in-person to collect data at the physician level. On-site medical record abstraction is then used to sample visit data. Visit data includes patient demographics, insurance status, residential zip code, past medical conditions, and smoking history. Data also includes encounter-related information: reason for visit, diagnosis, procedures and services performed or ordered, medication and immunizations, labs, and testing, and provider type. The most recent sample size of the survey is 3,000 physicians. NAMCS only collected physician-level data in early 2020 and throughout 2021.

NAMCS public use data files are available through 2018. Physician-level data for 2020 are available through RDC. DHCS plans to release the 2019 NAMCS data by year end 2022. The NAMCS physician interviews conducted in 2020 and 2021 include questions on physician experiences during the COVID-19 pandemic. DHCS used these data to generate preliminary estimates regarding these experiences, which are available through an online dashboard and can be stratified by various physician characteristics.

NAMCS has faced many of the same challenges as NHAMCS, including falling response rates, rising costs incurred during data collection, lack of PII collected during 2020 and 2021 for data linkages, increased competition through other reporting requirements for hospitals, and difficulty collecting in-person data due to the COVID-19 pandemic. In addition, many individual physicians' offices are being incorporated into large health care systems.

In 2023, NAMCS will pilot a self-administered web- and mail-based physician survey, with the U.S. Census Bureau serving as the data collection entity. The survey will include timely topics such as telemedicine, knowledge of opioid guidance, and culturally and linguistically appropriate services. Because an increasingly diverse number and types of clinicians are delivering ambulatory care, the pilot will include not only 5,000 physicians but also 5,000 PAs. No visit data will be collected. NAMCS is

considering expanding the size of future samples to include additional advanced practice providers. NAMCS will release public and restricted use files of the pilot data through RDC.

DHCS is working with RTI International to determine the feasibility of developing a nationally representative sample of provider groups. DHCS is also exploring the use of EHR submissions to collect information on visits with providers throughout the year. DHCS plans to pilot its Fast Health Interoperability Resources (FHIR) Health Level Seven (HL7) content implementation guide (IG) with two ambulatory provider groups, one hospital and one Federally-Qualified Health Center (FQHC). This IG is aligned with the United States Core Data for Interoperability (USCDI) standard and uses the technical infrastructure of the HL7 MedMorph Reference Architecture IG, most notably the MedMorph application, which is also used in other CDC efforts.

In addition to its provider component, NAMCS collects EHR data regarding the provision and use of ambulatory medical care services at U.S. health centers. A facility questionnaire collects information for statistical weighting. The sample consists of FQHCs and FQHC look-alikes, as classified by HRSA. The 2021 sample consisted of 50 centers. In 2022, DHCS added an additional 50 centers, and plans to add 50 more centers in 2023 for a total sample of 150 centers. DHCS will initially release these data as restricted use files. Assuming there are no challenges or issues, DHCS plans to create public use files.

DHCS is preparing to collect ambulatory visit data for provider groups and FQHCs. In addition, DHCS will soon recruit two large provider groups (50+ individuals) and an individual FQHC for the FHIR pilot. DHCS offers a \$10,000 set-up fee for activating the IG on centers' EHR systems. Funding for the set-up comes in part from the CDC DMI, which will also support the development of an interactive dashboard.

For the first time, NAMCS will collect PII from EHR records, enabling data linkage. The Patient-Centered Outcomes Research (PCOR) trust fund is supporting the exploration of 2021 data linkages, with a special focus on maternal health outcomes. DHSC plans to link 2021 NAMCS data to U.S. Housing and Urban Development data and the National Death Index. DHCS has applied for additional funding from the PCOR trust fund to link 2023 NAMCS data with Medicaid data.

DHCS requests that the BSC suggest any additional data sources that could supplement the provider and health center data that DHCS collects, as well as provide recommendations of FQHCs and large provider groups of 50 or more physicians that may participate in the FHIR IG pilot.

#### *Discussion/Reaction by the Board*

Dr. Lumpkin suggested engaging with community health organizations. DHCS has OCHIN to learn more about the data OCHIN collects, and to determine whether it could collect data from OCHIN.

The health care system is evolving in many directions, which presents many data collection challenges and opportunities. Venture capital trends are starting to affect ownership of physician practices, but NAMCS is not currently designed to assess the impact of venture capital on physician practices. Increasing vertical integration presents additional data collection challenges. For example, Walgreens is starting to integrate health insurance, pharmacies, and provision of primary care. Classifying the settings in which physicians practice has also become more complicated in recent years, because many physicians now work in more than one setting.

#### **NCHS Website Modernization**

Dagny Olivares, M.P.A., Associate Director for Communication, NCHS

## ***Project Overview***

The NCHS website is the nation's premier digital access point for the congressionally mandated health statistics collected by CDC. Policy makers, public health officials, and researchers rely on these statistics to help them understand, characterize, support, address, and communicate about the nation's health. Currently, the NCHS website struggles to meet the needs of its audiences and make critical statistical data readily accessible to the general public. Current challenges for the website include disconnected information, obsolete data formats, and difficulties in facilitating data discovery and navigation. To address these issues and modernize the website, NCHS received DMI funding for a 2-year project to be conducted by the Office of Information Services (OIS) leveraging contract services provided through the Geospatial Research, Analysis, and Services Program within the Agency for Toxic Substances and Disease Registry. The project aims to

- develop digital and data-driven formats,
- improve navigation and organization,
- tailor the website for all user types and proficiencies,
- deliver relevant statistics from multiple sources on a wide range of topics,
- ensure clear communication using plain language and appealing content,
- increase visibility of tools and resources for data collection and research, and
- identify scalable platforms for data storage and transfer.

## ***First-Year Website Assessments***

In the first year, OIS completed an analysis of the current state of the website and environmental assessment. The work included a review of content, user experience, structure, functionality, and search engine optimization (SEO). OIS also reviewed all website survey results and metrics, held conversations with senior staff and contacts for key NCHS and CDC activities, and assessed other agencies' data statistics websites. From the survey review, the website scored well on grammar, mechanics, and headlines, and poorly on readability and word/image comparison. However, OIS found wide variations in user experiences, as well as inconsistent metadata, SEO practices, structure, and writing styles. In addition, users found that the relevance and meaning of website data was unclear, the design was not based on user needs and behaviors, and digital best practices were inconsistent.

Internal interviews and focus groups found that the website needed content driven by diverse user requirements, increased data visualization, and a consensus on topics and content to help users sort and find current information. The internal environmental assessment analyzed related CDC websites (e.g., CDC COVID website), based on structure, design, data presentation, content, and functionality, for comparison to the NCHS website. Other websites use metrics to inform continuous progress and display consistent branding and user-driven organization, but struggle with displaying large datasets.

Unfortunately, external applications to capture metrics require more resources than are available for the project. However, the current infrastructure and shared services can address many needs for NCHS. The external environmental assessment analyzed 12 websites from statistical agencies that are external to CDC, such as the Bureau of Economic Analysis, scoring them on several criteria. Interviews with the agencies that received the top three scores revealed that their audiences changed and had new needs, new staff positions were necessary for key roles, and the user experience should be monitored to drive improvement.

OIS drew conclusions on several strengths and gaps from the overall analysis of these assessments. The strengths of the current NCHS website included high functionality, public availability of datasets, reduced cost of existing shared web, data, and visualization services, and appropriate systems management. The gaps identified for the website included content misalignment with expanding audiences, unclear information, unintuitive user experience, and inconsistent quality control. OIS also identified opportunities for improvement including enhancing readability, developing intuitive site organization,

leveraging prebuilt data visualizations, addressing new user personas, implementing SEO best practices, presenting information through a health equity lens, and developing workflow dashboards.

### ***Second-Year Goals***

Based on findings from the assessments, OIS's contracted experts recommended website changes and priorities, which comprise the foundation for developing a unified NCHS website during the second year of the project. Through August 2023, the project aims to overhaul the website, develop a comprehensive content strategy, improve user experience, develop an NCHS digital style guide, establish website management, and implement digital first and communication principles. The website overhaul will change information architecture, navigation, and taxonomy to aid users in finding relevant content. The content strategy will focus on the planning, creation, and delivery of content, including text, images, and media, in order to develop meaningful, cohesive, and sustainable content. The project will also provide the foundation for establishing an NCHS Digital Communications Strategist role, who will oversee the content strategy development, implementation, and maintenance of the website, as well as collaborate with programs and provide digital guidance.

Improving the user experience will include redesigning the homepage and landing pages, and will prioritize clarity over complexity. The planned NCHS digital style guide will include center-wide branding guidance and best practices, as well as guidelines for the use of visuals and graphics and clear communication principles to follow the Plain Writing Act of 2010. The project will establish website management processes and implement digital first principles that leverage off-the-shelf functionality of CDC's web content management to transition data into digital formats. Work will continue on the website after DMI funding has concluded, though at a slower pace, and the project scope will not affect information architecture within applications run by CDC programs. Additional recommendations from OIS's contracted experts, which may be implemented in the future, include the following:

- Develop and document communication standards and a framework for data visualization.
- Increase the use of data.cdc.gov to host and catalogue datasets.
- Leverage shared services for efficiency and cost effectiveness.
- Institute digital KPIs and the ongoing metrics analysis rhythm.
- Modernize and optimize FastStats.
- Develop an SEO plan.
- Create an NCHS website help section.
- Produce a series of short videos to assist with finding and using data.
- Integrate the NCHS blog into the main website.
- Use social media strategically and systematically.

### ***Discussion/Reaction by the Board***

Ms. Olivares stated that although the project will also consider high school and college students as potential users, it has largely focused on the recently expanded user base that includes reporters and policy makers. As the website expands its reach to a broader user base, the project will consider how to appropriately engage new users through improving design, best practices, navigation, and information architecture. Ms. Olivares also stated that OIS aims to reassess the website every 3 to 5 years. In addition to website reassessments, continual quality control checks and metrics tracking will alleviate the burden of reassessment and help continuously evolve the website.

Dr. Lumpkin emphasized the importance of how success should be defined for the NCHS website. Because users typically do not voice when they are satisfied with a website, Dr. Malin suggested defining success based on the number of user complaints. Dr. Olson also suggested tracking whether users found website information using the internal search engine or an external search engine such as Google.

Ms. Olivares responded that the federal government is limited in how it can track users' digital footprints because of privacy requirements. However, the first-year assessment found that Google and other search engines are driving a large portion of traffic into the website. The project aims to improve the metadata and tagging of NCHS web content so that the internal search engine can better help users find relevant information, as well as navigate to related pages after a successful search.

Ms. Hines highlighted the importance of having workshop attendees participate in user testing and provide feedback on specific website modernization activities in 2023. Attendees can contact Ms. Hines about their interest in user testing, feedback on website modernization, and feedback on current usage of the website.

### **Public Comment**

Michael Waltz commented on the website upgrade. He noted that navigating a website is similar to navigating a city, and that when routes through a city change, older residents can become lost.

### **NCHS Round Robin Updates**

#### ***NHANES Update***

Alan E. Simon, MD, Director, Division of Health and Nutrition Examination Surveys

##### *Current Challenges at NHANES*

Dr. Simon noted that recent challenges have emerged in the health care survey field, such as the devaluation of random sampling and a shift toward alternative data collections (e.g., insurance data, large convenience cohorts); these practices raise questions about the utility of data collected using these methods. Recent public health crises have emphasized the need to generate informative and actionable data at a pace that is useful for public policy changes. These challenges present opportunities for DHANES not only to optimize current data collection and analysis practices, such as improving response rates and utilizing new data analysis software for large datasets, but also to build more robust studies through the inclusion of longitudinal components and utilization of wearables.

These challenges and opportunities are of particular importance because the current NHANES cycle is scheduled to end during August 2023, providing an ideal time to implement changes to data collection methodology and to identify new areas of interest. However, given the significant amount of data already generated through previous iterations of NHANES, DHANES is facilitating use of these data, specifically x-ray film from NHANES I through NHANES III, by digitizing the x-ray film.

##### *Additional Work by NHANES*

The body mass index for-age growth chart is a reference chart for health care providers to assess growth in children aged 2-20 years. To enable better characterization at the extreme ends of the chart and create more consistency in clinical trials, particularly obesity studies, NHANES is adding additional percentiles. These additional percentiles will not produce any modifications to body mass indices under the 95th percentile. Further information will be released in a report on December 15, 2022.

Additionally, NHANES will participate in a workshop convened by the National Academies of Sciences, Engineering, and Medicine, focusing on returning individual genomic results from population-based surveys. As genomic information is increasingly collected from participants, the expectation that this information will be communicated back to the participants increases. Producing guidelines and policies in this area has been challenging for not only DHANES, but also the National Institutes of Health. This workshop will aid in developing practices regarding returning genetic data to the participants.

### ***Discussion/Reaction from the Board***

Dr. Malin questioned the anticipated cost and timeline for digitizing the x-ray film and emphasized that this other organization have declined to complete such a cost- and labor-intensive process. Dr. Simon responded that he could not recall the exact costs but that DHANES had received funding from the DMI to support this effort. Further, the timeline is unclear because it depends upon the speed of physically accessing numerous boxes whose organizational structure is unclear. Dr. Holan then inquired whether x-ray film would be selected for this process based on image quality. Dr. Simon noted that each image was scrutinized by radiologists at the time of storage, so the quality should be acceptable. However, limitations to the quality of the image captured remains, which has led to the selected resolution of 300 dots per inch.

### **Rapid Surveys Update**

Stephen Blumberg, Ph.D., Director, Division of Health Interview Statistics

#### *Overview of the Rapid Surveys Program*

The Rapid Surveys program (whose name might change) is a new data system built collaboratively between DHIS and DRM. The program was designed for NCHS as a mechanism to provide CDC partners with data on emerging and priority health topics that are fit for decision making. Practically, it is a data system that prioritizes speed and relevancy while maintaining accuracy. The system utilizes data from commercial online panels to produce health estimates, which underscores the need to validate the system in terms of data transparency and fitness for use. This scrutiny echoes the CDC's Moving Forward Initiative, which aims to position the CDC to better anticipate and respond to public health threats, with the goals of providing data faster and enhancing evidence-based public health responses.

In September 2022, contracts were awarded to two data-collection companies—Ipsos Public Affairs and NORC at the University of Chicago—that utilize probability-based online survey panels. These panels will be the source of data for the Rapid Surveys program, the Rapid Surveys program will assess whether utilizing two panels provides better data than an individual panel. The specific research topics will be solicited from CDC and other HHS programs, and data will be collected quarterly, with at least 6,000 surveys per quarter in the first year and 4,000 per quarter thereafter. A third contract was awarded to a survey support company, RTI International, which will assist in coding, data file preparation, and dissemination of results, among other tasks. The vision of the Rapid Surveys program in this context is to provide timely releases of information (no more than 6 months from data collection) with regular transparent evaluations and production of public use and restricted-access data files. The Rapid Surveys program is expected to soft-launch in mid-2023, with full implementation in 2024.

#### *Recommendations and Conditions for Use of the Rapid Surveys Program*

At the request of program staff, the BSC recommended the following uses of the Rapid Surveys program:

- Consider online panels for timely estimates for new, emerging, or supplemental topics.
- Consider online panels for generating estimates of change over time.
- Avoid estimates related to the data collection methods or willingness to participate.
- Avoid subgroup/subdomain estimates.
- Consider online panels for gathering information on the performance of new or altered survey questions while retaining inference to the general population, to inform decisions about new content or changes to the household population surveys.

The BSC also identified areas warranting research:

- Conduct research on augmenting a panel with other samples or administrative data to address under-coverage and nonresponse

- Conduct an evaluation study to better inform the suitability of an online panel for particular types of estimates, the limitations of the panel approach, any needed changes to the design, and any improvements to the weighting and estimation
- Evaluate different post-survey weighting adjustment methods
- Design auxiliary variables to aid weighting adjustments, rather than only rely on measures that are currently available
- Periodically evaluate online panel methodology
- Research how to communicate data quality for web panel data relative to established NCHS survey data

Program staff have taken several steps in response to these suggestions. First, the Rapid Surveys program has requested, and subsequently funded, proposals from Ipsos and NORC on methods to address coverage and non-response. In addition, each company will perform an evaluation study of its panels to determine suitability and areas of improvement; these studies will incorporate post-survey evaluation methods. Questions were added to the NHIS in July that probe civic duty, engagement, and access to health information so that these data may be provided to the data-collection companies for use in post-survey weighting adjustments. Finally, discussions are ongoing to establish steps to effectively communicate data quality.

### **NVSS Update**

Paul Sutton, Ph.D., Deputy Director Division of Vital Statistics

As a testament to its commitment to produce actionable data, NVSS has produced more than 24 products and reports since the last BSC meeting. In addition, it has released the final 2021 birth data and the final 2020 period-linked infant death file, and expects to release the 2021 final mortality data in December 2022.

In the past year, several NVSS programs have become fully active and experienced much success. The CDC Wonder platform, which provides provisional mortality data has undergone more than 400,000 queries, and NVSS hopes to provide provisional birth data on this platform soon. MedCoder, the system that is used to convert text on death certificates to ICD-10 codes, has transitioned to a fully active status, with 86 percent of records being correctly auto coded. This result compares favorably to the correct auto-coding of 70 percent of records via the legacy coding system. Finally, the Collaborating Office for Medical Examiners and Coroners, which works to bring together valuable resources from across CDC to support the work in the medical examiner and coroner community, now has a formal web presence.

One area of emphasis for NVSS has been the development and formalization of the Vital Statistics Modernization Community of Practice, which was launched in 2020. This virtual forum was designed for sharing ideas, technical tools, resources, and promising practices to optimize birth and death data. Although reported experiences are positive, measuring the effectiveness of this tool is difficult. One potential measurement approach is NCHS-hosted testing events, which test ongoing modernization activities. These events occur quarterly, and the number of participating groups has consistently increased over the past year.

### **BSC Wrap-up and Future Plans**

Drs. Lumpkin and Moyer thanked attendees and speakers for their participation in today's meeting and emphasized their appreciation for BSC participation in various workgroups, including in the workgroup that examined the inclusion of discrimination measures in NCHS surveys. Dr. Lumpkin noted the need for ongoing conversations regarding long COVID.

Dr. Moyer reiterated that the CDC Moving Forward Initiative is progressing rapidly; that he may contact BSC members to request their thoughts on aspects related to this initiative. He encouraged members to provide suggest candidates for BSC membership. He closed by again thanking Drs. Olson and Levy for their service to the board.

The meeting was adjourned.

To the best of my knowledge, the foregoing summary of minutes is accurate and complete.

/s/

February 16, 2023

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John R. Lumpkin, M.D., M.P.H.  
Chair, BSC

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DATE