All official NCHS BSC documents are posted on the BSC website:
https://www.cdc.gov/nchs/about/bsc/bsc_meetings.htm

Department of Health and Human Services (HHS)

Board of Scientific Counselors
National Center for Health Statistics
Centers for Disease Control and Prevention
February 10, 2022

Meeting Summary

The Board of Scientific Counselors (BSC) convened via Zoom on February 10, 2022. The virtual meeting was open to the public (via Zoom).

<u>Board Members Present</u>

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., M.L.I.S.
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.
Andrey Peytchev, Ph.D.
C. Matthew Snipp, Ph.D.
Kelly Hoover Thompson, J.D.
David R. Williams, Ph.D., M.P.H.

<u>CDC/NCHS Panelists</u>

Brian Moyer, Ph.D., Director, National Center for Health Statistics (NCHS)	Farida Ahmad	Geoff Jackson
	Irma Arispe	Jen Layden
	Stephen Blumberg	Kristen Miller
Rebecca Hines, M.H.S, Designated Federal Officer, NCHS, BSC	Amy Branum	Gwen Mustaf
	Anjani Chandra	Jennifer Parker
	James Craver	Ryne Paulose

<u>Other Attendees</u>

Joyce Abma	Yutaka Aoki	Jonaki Bose
Brian Adams	Jill Ashman	Debra Brody
Nikki Adams	Rihem Badwe	Lisa Broitman
Dzifa Adjaye-Gbewonyo	Coretta Bailey	Amy Brown
Johanna Alfier	Brenda Baker	Sherry Brown-Scoggins
Lara Akinbami	Kai Baker Stringfield	Carol DeFrances
Hallie Andrews	Bryan Bassig	Amy Cha
Nicholas Ansai	Negasi Beyene	Jay Clark

Robin Cohen	Denys Lau	Cheryl Rose
Traci Cook	Florence Lee	Jinan Saaddine
Lauren Creamer	Jessica Lendon	Jennifer Saadine
Krista Crider	Sarah Lessem	Jennifer Sayers
Anterio Cunningham	Taylor Lewis	Paul Scanlon
James Dahlhamer	Jordan Lin	Susan Schappert
Kim Daniels	Anthony Lipphardt	Jeannine Schiller
Barnali Das	Jacqueline Lucas	Paul Schroeder
Danielle Davis	Ann MacFayden	Steven Schwartz
Orlando Davy	Aaron Maitland	Salah Shaikh
Patricia Dunham	Crescent Martin	Ilana Siegal
Steven Fink	Michael Martinez	Catherine Simile
Anika Foster	Gladys Martinez	Sandra Smith
Cheryl Franco	Meredith Massey	Zachary Smith
Sheila Franco	Juliana McAllister	Merianne Spencer
Cheryl Fryar	Susan McBroom	Renee Storandt
Adena Galinsky	Brian McGough	Guillermo Suchicital
Matthew Garnett	Grace Medley	Paul Sutton
Renee Gindi	Justin Mezetin	Rashmi Tandon
Jessica Graber	Donna Miller	Chally Tate
Lello Guluma	Lisa Meril	Danielle Taylor
Leda Gurley	Leyla Mohadjer	Ana Terry
Heidi Guyer	Mary Moien	Amanda Titus
Nancy Han	Jennifer Moore	Allan Uribe
Mahogany Hanks	Kiana Morris	Anjel Vahratian
Althelia Harris	Kelly Myrick	Van Van Parsons
Yulei He	Zakia Nelson	Maria Villarroel
Qiming He	Duong Nguyen	Lisa Wagner
Andrew Herrin	Tina Morris	Edwina Wambogo
Kevin Heslin	Colleen Nugent	Antonia Warren
Travis Hoppe	Tatiana Nwnakwo	Donielle White
Isabelle Horon	Dagny Olivares	Diana Wilkerson
John Hough	Jennifer Parker	Deniece Wilkins
Rebecca Hu	Zachary Peters	Jean Williams
Marisol Iniguez	Emilia Peytcheva	Amanda Wilmot
Katherine Irimata	Kellina Phan	Ashley Woodall
Christine Jones	Donna Pickett	David Woodwell
WenYen Juan	Steve Pierson	Jianmin Xu
David Justice	Nancy Potischman	Jiaquan Xu
Ashley Kaiser	Paul Pulliam	Jing Xu
Gina Kilpatrick	Anthony Quintana	Yeats Ye
Christine Kim	Catherine Rappole	Sahar Zangeneh
Susan Kinsey	Daniela Relf	Carla Zelaya
Ellen Kramarow	Minsun Riddles	Keith Zevallos
Jeff Lancashire	Dorothy Roper	Guangyu Zhang

Presentation Tech	Mike Kavounis (RLA)
Minutes	Christina Huffman (RLA)

List of Abbreviations

API	application programming interface
BSC	Board of Scientific Counselors
CCQDER	Collaborative Center for Questionnaire Design and Evaluation Research
CDC	Centers for Disease Control and Prevention
CSELS	Center for Surveillance, Epidemiology, and Laboratory Services
DHCS	Division of Health Care Statistics
DHIS	Division of Health Interview Statistics
DMI	Data Modernization Initiative
DOS	Department of State
DRM	Division of Research and Methodology
eCR	electronic case reporting
ED	emergency department
EHR	electronic health record
FY	fiscal year
HEHR	healthcare electronic health records
HHS	Department of Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act of 1996
MEC	mobile exam center
MHI	mental health issue
NAMCS	National Ambulatory Medical Care Survey
NCHS	National Center for Health Statistics
NCVHS	National Committee for Vital and Health Statistics
NDI	National Death Index
NHANES	National Health and Nutrition Examination Survey
NHCS	National Hospital Care Survey
NHIS	National Health Interview Survey
NLP	natural language processing
NPALS	National Post-Acute and Long-term Care Study
NSFG	National Survey of Family Growth
NSLTCP	National Study of Long-Term Care Providers
NVSS	National Vital Statistics System
OMB	Office of Management and Budget
PHSPMDP	Population Health Survey Planning, Methodology and Data Presentation Workgroup
SDOH	social determinants of health
SOGI	sexual orientation and gender identity
STLT	state, tribal, local, and territorial
SUD	substance use disorder
VSRR	Vital Statistics Rapid Release
WONDER	Wide-ranging Online Data for Epidemiologic Research system

Action Steps

- The BSC voted unanimously to approve the creation of a Workgroup to study discrimination measures in NCHS surveys.
- The following BSC members volunteered to participate in this Workgroup: Drs. Levy, Olson, Peytchev, Snipp, and Williams with Dr. Holan volunteering later in the meeting.
- Dr. Blumberg will follow up with the BSC members that volunteered to join this Workgroup to schedule an initial organizational meeting.

Presenters

Brian Moyer, Ph.D., Director, NCHS
John Lumpkin, M.D., M.P.H., Chair, BSC, NCHS
Jen Layden, M.D., Ph.D., Acting Associate Deputy Director for Public Health Science and Surveillance, NCHS
Jim Craver, M.A.A., Acting Deputy Director for Management and Operations, NCHS
Ryne Paulose, Ph.D., Acting Director, Division of Health and Nutrition Examination Survey, NCHS
Stephen Blumberg, Ph.D., Director, Division of Health Interview Statistics
Amy Branum, Ph.D., Associate Director for Science, NCHS
Kristen Miller, Ph.D., Collaborative Center for Questionnaire Design and Evaluation Research (CCQDER), NCHS
Jennifer Parker, Ph.D., Director, Division of Research and Methodology
Andy Peytchev, Ph.D., BSC Member and Chair, Population Health Survey Planning, Methodology and Data Presentation (PHSPMDP) Workgroup
Geoff Jackson, Hospital Care Team Leader, Division of Health Care Statistics, NCHS
Anjani Chandra, Ph.D., NSFG Team Lead & Principal Investigator, Division of Vital Statistics
Farida Ahmad, M.P.H., Mortality Surveillance Lead, Division of Vital Statistics

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 providing an overview of the history of the NCHS BSC. Prior to the passage of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the National Committee on Vital and Health Statistics (NCVHS) was the main federal advisory committee to NCHS and its programs. HIPAA added to NCVHS's responsibilities, which led NCHS to determine the need for an advisory body focused on critical issues regarding health care statistics, surveys, and data analyses. The BSC charter was enshrined in 2001, and the first BSC was appointed in 2003.

Ms. Hines conducted roll call, asking members to introduce themselves and state conflicts of interest. None of the BSC members stated a conflict of interest. Dr. Peytchev did note that he is a fellow at RTI, which supports the National Survey on Family Growth (NSFG) and as such will recuse himself from the NSFG agenda topic.

Dr. Lumpkin welcomed the five new BSC members who each provided brief background in response to Dr. Lumpkin's prompt to share their background and expertise pertinent to the BSC.

NCHS Leadership Update

Jen Layden, M.D., Ph.D., Acting Associate Deputy Director for Public Health Science and Surveillance, NCHS
Brian Moyer, Ph.D., Director, NCHS

Jim Craver, M.A.A., Acting Deputy Director for Management and Operations, NCHS

Centers for Disease Control and Prevention (CDC) and NCHS Data Modernization Initiatives
In December 2021, the CDC released its Data Modernization Initiative (DMI) strategic implementation plan to modernize and integrate public health data systems and incorporate lessons learned from recent public health emergencies such as the COVID-19 pandemic and the opioid crisis. CDC's DMI strategic plan has five key priorities:

1. Build the right foundation: strengthen and unify critical infrastructure for a response-ready public health ecosystem
2. Accelerate data into action to improve decision-making and protect health
3. Develop a state-of-the-art workforce
4. Support and extend partnerships
5. Manage change and governance to support new ways of thinking and working

NCHS plays a key role in implementing CDC's DMI strategy and is particularly focused on the first two priorities: (1) building foundations, including cloud architecture and shared enterprise resources; and (2) accelerating data into action, including greater interoperability and visualizations for public health policy decisions.

NCHS is also focusing on response readiness platforms that can respond to both emerging needs such as new pandemics as well as longer-term issues such as health inequities and climate change. To better plan for future public needs, NCHS held a stakeholder meeting in January 2022 with more than 200 representatives from different CDC programs and offices to identify key "North Star" data modernization objectives. This meeting stressed collaboration with other federal agencies and state, tribal, local, and territorial (STLT) partners. Further, NCHS partners with the United States Digital Service (USDS) to improve data collection from vital records, lab data, and other core data sources.

NCHS also recognizes the need to coordinate modernization efforts across different groups and agencies. NCHS is actively involving epidemiological, data science, laboratory, military detection, and bioinformatics experts into data modernization efforts. NCHS also established a consortium with STLT partners to coordinate data collection efforts and is collaborating with the U.S. Department of Veterans Affairs to potentially share and integrate health data systems. Finally, in January 2022, representatives from 17 states participated in an NCHS-hosted Mini-Connectathon to conduct interoperability testing between NCHS and all 57 National Vital Statistics System (NVSS) jurisdictions.

NCHS's DMI activities are focused on promoting greater data accessibility and interoperability as well as ensuring compliance with the Foundations for Evidence-Based Policymaking Act of 2018. To promote data interoperability and actionable data, NCHS has identified five data modernization priorities:

1. Electronic health records (EHRs): developing partnerships with EHR providers for enhanced analyses, including analyzing emergency department (ED) data from 118 hospitals
2. Healthcare Electronic Health Records (HEHR) Cloud Migration: migrating HEHR systems to cloud-based infrastructures that can be leveraged by NCHS, CDC, and agency partners
3. Microdata access: standardizing NCHS data and metadata analyses to improve reporting, visualization, and advanced analytics
4. Model-based early estimates: statistical methods for analyzing and visualizations, producing faster, more granular data for health statistics
5. NVSS modernization: enhancing data interoperability, including an application programming interface (API) for data exchange with local jurisdictions

Health Equity and Social Determinants of Health
In accordance with the Biden administration's focus on health equity and social determinants of health (SDOH), NCHS is engaged with agencies across the Department of Health and Human Services (HHS) to define key SDOH, access the relevant data, and identify gaps in knowledge to inform development of an HHS SDOH Action Plan that will address systematic and environmental SDOH as well as connect to Healthy People 2030. To support this joint effort, a CDC Task Force has formed subcommittees that will focus on policy and law, data and surveillance (on which NCHS representative are chairs), evaluation and evidence building, partnerships and collaboration, community engagement, and infrastructure and capacity.

NCHS activities to address SDOH include (1) developing measures and analytical tools to understand the effects of SDOH; (2) expanding SDOH data through data linkage and use of alternative data sources; (3) developing new *International Classification of Diseases*, Tenth Revision, Clinical Modification (ICD-10-CM) codes for social determinants such as caregiving, food insecurity, and housing and transportation; and (4) expanding analysis and dissemination of SDOH data visualization and tools. These activities are built into NCHS's data modernization initiatives and 2022-2025 strategic plan.

Program Updates and New Initiatives
NCHS provisional mortality data are now available in CDC's Wide-ranging Online Data for Epidemiologic Research (WONDER) platform, which is an online public health information system. This update enables researchers and policymakers to access more timely and detailed information.

NCHS has established the Medical Examiners and Coroners Office to serve as an information hub for medical examiners, coroners, and other federal and jurisdictional partners. This office will promote quality and consistency in death investigation and cause-of-death information; promote collection, automation, and distribution of medicolegal death investigation data; facilitate information sharing within the medicolegal death investigation community; and coordinate public health surveillance efforts among CDC and its partners.

NCHS is also leading efforts to better measure health outcomes among minorities. Recognizing racism as a public health threat, NCHS has proposed formation of a new BSC workgroup to consider and assess measures of discrimination for use in NCHS surveys. NCHS is also exploring methods to incorporate gender identity into surveys, including the National Health Interview Survey, in response to a Presidential Executive Order to prevent and combat discrimination based on gender identity.

Finally, NCHS is onboarding CDC researchers to its virtual data enclave, which will expand access to its restricted data. NCHS will start to test its first projects in February 2022.

NCHS Strategic Plan—Fiscal Years 2022-2025
Dr. Moyer thanked BSC members for their inputs into the 2022-2025 NCHS Strategic plan, which is available on the NCHS website. These inputs focused on integrating health equity measures, expanding and improving existing programs, and developing the NCHS workforce. An operational plan will include logic models, action planning tools, and a performance scorecard.

Recent Data Releases and Reports
NCHS is actively collecting many types of data on the COVID-19 pandemic beyond mortality data. NCHS partnered with the U.S. Census Bureau to collect data on anxiety, depression, access to care, and telemedicine usage. NCHS recently released data from its National Post-Acute and Long-term Care Study (NPALS) on COVID-19 cases, hospitalizations, and deaths among residential care community residents by U.S. Census region. The National Ambulatory Medical Care Survey continually collects data on

experiences of office-based physicians during the COVID-19 pandemic, including shortages of personal protective equipment (PPE).

NCHS released multiple reports in December 2021 and January 2022 that covered mortality data, maternal and infant characteristics and outcomes among women with confirmed or presumed COVID-19 during pregnancy, drug overdose death data, and stressful life events among children by disability status. Upcoming reports for February 2022 will cover updated birth data, marriage and divorce rates by state, and demographic variation in health insurance coverage.

NCHS Budget Update
Federal agencies are currently operating under a continuing resolution for fiscal year (FY) 2022, and NCHS actively monitors the Congressional budget process to determine the impact of potential funding scenarios on NCHS programs. Appropriated funds constitute the majority of NCHS's funding, but NCHS also receives funding from collaborators, survey sponsors, and other special funding. BSC will update the NCHS budget information and forecasts upon release of the Biden administration's FY 2023 budget.

Discussion/Reaction by the Board
Dr. Snipp asked how NCHS distinguishes between the social and structural conditions that affect SDOH. Dr. Moyer replied that structural conditions refer to institutional and structural constructs (e.g., laws, government program policies), while social conditions refer to factors such as implicit bias and socioeconomic status. As part of its efforts to examine SDOH, NCHS is collaborating with the U.S. Census Bureau and economic agencies (e.g., Bureau of Economic Analysis) to further elucidate factors that influence health disparities.

Dr. Lumpkin noted that the CDC Center for Surveillance, Epidemiology, and Laboratory Services (CSELS) successfully gained quick access to EHR data to develop the Electronic Case Reporting (eCR) Now system, and NCHS could use similar approaches to access additional data on overdoses and substance use disorders. Mr. Craver commented that NCHS regularly collaborates with CSELS and the CDC Deputy Director for Public Health Science and Surveillance to develop methods to access EHR data. NCHS is also working with the CDC Office of the Chief Information Officer to create an enterprise architecture for receiving EHR data. Access to EHR data is subject to a robust governance process to ensure compliance with the HIPAA and other confidentiality requirements.

Dr. Lumpkin also asked how researchers examining SDOH harmonize and link data from different sources (e.g., surveys, public health data). Dr. Moyer agreed that harmonizing data from disparate sources can present challenges, and NCHS is actively pursuing methods to measure data quality and linkages. Dr. Arispe added that CDC is working with other HHS agencies and health equity groups to analyze gaps in SDOH data linkage; results from this gap analysis should be available by the next BSC meeting.

Understanding National Health and Nutrition Examination Survey Response Rates During Data Collection in a Pandemic

Ryne Paulose, Ph.D., Acting Director, Division of Health and Nutrition Examination Survey, NCHS

The National Health and Nutrition Examination Survey (NHANES) provides key information on health and dietary habits of U.S. households, and these data help guide public health actions and policies. NHANES collects data using three stages: (1) initial screening to determine eligibility; (2) in-home interview, in which participants are asked demographic, socioeconomic, and dietary and health-related questions; and (3) mobile exam center (MEC) examination, including physical exam, specialized tests, biospecimen collection, and dietary assessment.

NHANES uses a multi-stage probability sampling design that aims to examine approximately 5,000 persons per year. NHANES also uses varying sample designs between years to oversample certain subgroups. However, in 2021, NHANES did not oversample for racial and ethnic minorities or income groups, in order to decrease the number of household contacts and increase the efficiency of screening. Rather, NHANES over-sampled persons based on age only.

In the first five stands of 2021, the in-home interview response rate was 55.8 percent, which is similar to response rates in 2019 and early 2020. During 2021, participants could request phone interviews, and approximately 67 percent of interviews were conducted by phone. NHANES also offered a $25 interview incentive in 2021, and the combination of phone interviews and the incentive likely contributed to consistent interview response rates.

However, in 2021, only 70.5 percent of interviewed respondents were later examined at a MEC, a decrease from approximately 90 percent in 2019 and early 2020. In 2021, 27.9 percent of MEC examinations were rescheduled compared to 18.7 percent in 2019 and early 2020. In 2021, 12 percent of interviewed participants refused to schedule an appointment at a MEC, and 20 percent of participants either canceled or did not attend their MEC appointment. In contrast, in 2019 and early 2020, 3 percent did not schedule an appointment and 8 percent either canceled or did not attend.

Examination response rates did not vary between socioeconomic groups and were only slightly lower in younger participants (notably ages 0-5). Similarly, prior COVID-19 infection did not affect examination response rates. However, 76 percent of vaccinated individuals attended their MEC appointment, compared to 65 percent of unvaccinated individuals, and areas with higher vaccination rates also had higher MEC examination response rates. In contrast, COVID-19 case rates were negatively correlated with examination response rates.

NHANES is implementing multiple approaches to increase MEC participation. The MEC incentive was increased to $125, and participants have additional options for receiving transportation incentives. A MEC clinician contacts participants who miss examinations or are reluctant to schedule an appointment to discuss their concerns, and NHANES is identifying "study ambassadors," that is, previous study participants who can encourage reluctant participants to schedule and attend their examinations. NHANES will also conduct a survey of MEC nonrespondents to better understand their reasons for declining and will overbook MEC appointment slots for participants who are more likely to cancel or not attend their MEC appointment.

These results indicate that participants in similar surveys are likely to be interviewed by phone but less likely to visit a MEC, particularly in regions with high COVID-19 case rates. Reduced in-person examination rates are due to multiple factors, including reluctance to schedule appointments and increased appointment rescheduling, cancelations, and no-shows. Patterns of nonresponse are not random but vary by vaccination status and COVID-19 case rates.

Discussion/Reaction by the Board
Dr. Paulose asked BSC members to suggest additional interventions that could be implemented in real time to address examination nonresponse. Dr. Copeland contemplated whether certain portions of the examination could be performed at the respondent's residence, and suggested that NHANES adapt the survey design to prioritize subgroups that may drive nonresponse bias or offer a greater incentive to such groups. Dr. Paulose noted that NHANES is exploring the extent to which in-home examinations would necessitate significant changes to exam procedures and protocols. Similarly, NHANES is considering changes to the incentive structure, which are subject to Office of Management and Budget (OMB) approval.

Dr. Peytchev commented that greater incentives may not significantly improve response and examination rates. He suggested analyzing patterns of interview responses of examination nonrespondents to build models that predict examination nonresponse. He also suggested additional weighting methods to account for examination nonresponse, including whether reluctance is due to COVID-19 concerns or other factors.

Dr. Olson agreed with Dr. Peytchev and recommended examining whether variation between interviewer attitudes and concerns over COVID-19 may contribute to higher examination nonresponse rates. Study reluctance may be due to household structural factors such as childcare, which may compress times available for in-person examinations. Concerns about COVID-19 safety protocols within MEC trailers, including airflow, may also contribute to examination reluctance.

Dr. Malin noted that examination response rates may vary between geographic regions, similar to vaccination rates. He recommended that NHANES examine geographic variation and plan future sampling strategies based on regional variation in response rates. Dr. Lumpkin agreed and noted that the increasingly polarized views on vaccination and the CDC within U.S. society likely affect examination response rates.

Dr. Williams asked whether the decision to not oversample for racial and ethnic minorities has affected population coverage and the reliability of estimates. Dr. Paulose replied that NHANES made this decision to reduce the number of screened households by about 50%, which would reduce the number of interviewer household contacts and protect the safety of NHANES field staff during the pandemic NHANES does plan to resume oversampling of minority populations by 2024. Dr. Williams also suggested providing a portion of the examination incentive when scheduling the examination appointment, because this may encourage further participation.

Measuring Perceived Discrimination in NCHS Surveys

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

CDC recognizes racism as a "serious threat to the public's health" that can affect many factors that in turn affect health, including housing, education, occupation, and other SDOH. As Director of the CDC, Dr. Walensky has stated a renewed commitment to address racism as an obstacle to health equity. As part of that commitment, NCHS will incorporate measures of discrimination into its surveys, including NHANES, the National Survey of Family Growth (NSFG), and the National Health Interview Survey (NHIS), to enable data users to track the prevalence of discrimination and the relationships between discrimination and key health indicators in nationally representative samples. Previous survey pilot studies, as well as the NHIS-Teen, have included questions regarding discrimination during childhood based on race/ethnicity as well as sexual orientation and gender identify (SOGI). Many measures of discrimination are currently available, including the Intersectional Discrimination Index and the Everyday Discrimination Scale.

The Division of Health Interview Statistics (DHIS) proposes creation of a new BSC workgroup to consider and assess measures of discrimination for use in NCHS surveys. This new workgroup will advise on the feasibility and practicality of including discrimination measures in NCHS surveys and the selection of effective survey questions and discrimination measures.

Questions related to the feasibility and practicality of discrimination measures include the following:
- Given the limited space available in many health surveys (e.g., NHANES, NSFG, NHIS), does BSC consider the inclusion of additional discrimination measures to be a priority?
- How can NCHS best contribute to discrimination research and surveillance?

- Should NCHS surveys focus on discrimination in health care settings or measure overall discrimination?
- Should discrimination measures be consistent across NCHS surveys, or should these measures be tailored to each survey's focus?

Similarly, questions related to selecting effective discrimination measures include the following:

- What is the minimum number of survey items needed to gauge discrimination?
- Should NCHS assess the perceived reason for discrimination? If so, how?
- Is discrimination best assessed using in-person surveys or computer-assisted self-interviewing?
- Does NCHS need to conduct additional developmental research on measuring and evaluating discrimination measures?

The Workgroup will consist of at least two BSC members, one of whom will serve as Workgroup Chair, and nongovernmental expert consultants. It will meet two to three times before the May 2022 BSC meeting, during which its members will present its findings.

Discussion/Reaction by the Board

Dr. Brodie expressed support for the establishment of this Workgroup, noting that its efforts could be helpful across the health care field. Dr. Morton seconded the support, adding that the Workgroup's definition of discrimination will be important to guiding its efforts. Dr. Blumberg confirmed that the Workgroup would focus on interpersonal discrimination and the perceptions from individuals regarding whether they have felt discrimination. Dr. Holan also expressed support for this Workgroup and emphasized that the statistical approach to incorporating these measures will be important topic of discussion.

Dr. Snipp made a motion to approve the establishment of a new Workgroup to consider and assess measures of discrimination for use in NCHS surveys, and this motion was seconded. BSC members unanimously voted to approve this motion. The following BSC members volunteered to participate in the Workgroup: Drs. Levy, Olson, Peytchev, Snipp, and Williams.

Update on SOGI Question Design and Testing

Amy Branum, Ph.D., Associate Director for Science, Acting Deputy Director for Programs, NCHS
Kristen Miller, Ph.D., Collaborative Center for Questionnaire Design and Evaluation Research, NCHS

Many federal health and behavior surveys collect information on sexual orientation, but few also collect information on gender identity, creating a gap in knowledge around health outcomes among transgender and gender nonbinary populations. NCHS is engaged in multiple activities centered on harmonizing, or at least investigating, how the survey questions used to collect gender identify data align with proposed interoperability standards in EHR data collection. Gender identity data collection is a key component of NCHS's contributions to the CDC CORE (Cultivate, Optimize, Reinforce, and Enhance) health equity goals. This work includes testing gender identity questions among a sample of adults in the 2022 NHIS and adding gender identity questions to NHANES.

The NCHS Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) conducts question evaluation and development studies for NCHS, CDC, and other HHS surveys. CCQDER's activities center on question development and evaluation to ensure that surveys are reliable; methodological research to refine question evaluation methods and better understand the question response process and survey response error; and development of technology products to improve

qualitative data collection and analysis and to increase the accessibility and transparency of question evaluation studies.

CCQDER's primary method of evaluation is cognitive interviewing, with the goals of conducting interviews to "look for problems" (cognitive testing), identifying the constructs captured by individual questions by identifying the specific phenomena that account for respondent's answers (validity study), and determining whether constructs are consistently captured across salient respondent groups (comparability study).

Through its mixed-method Research and Development Survey (with RAND), CCQDER can quantify the findings from cognitive interviewing studies. This approach combines cognitive interviewing, web panel survey data, and embedded construct and error probes to estimate survey error within demographic groups. Results from RANDS enable CCDQER to test different versions of questions using experimental design.

Many federal agencies and external partners are collaborating to coordinate collection of gender identity data. Although empirical data are lacking on the performance of gender identity–related survey questions, the following questions have currently become standard on many surveys, including the U.S. Census Household Pulse Survey:

1. Sex: "What sex were you assigned at birth, on your original birth certificate?"
2. Gender: "How do you describe yourself?"
3. Confirm: "Just to confirm, you were assigned [response to Question 1] at birth and now you describe yourself as [response to Question 2]. Is that correct?"

The third confirmatory question is designed to address potential respondent confusion.

The Census uses two response patterns to define gender minorities: respondents who answer "Transgender" for Question 2 and respondents with different answers for Questions 1 and 2. Respondents who answer "No" to the confirmatory Question 3 are considered false positives and are not included in gender minority estimates. Organizations using this approach have found unusually high false-positive rates (22% in the Census survey and up to 50% among Spanish speakers in a Pew survey). In addition, 1.16 percent of respondents to the Census survey who indicated that their gender was "none of the above" were disregarded in calculations of gender minorities. In addition to these false positives—which can undermine researchers' ability to accurately characterize the gender minority population—the standard survey question may also generate false negatives from respondents who do not wish to disclose their gender identity because of privacy concerns. Dr. Miller noted that these challenges must be addressed for the field to achieve its goal of capturing as much of the complexity and range of sexual orientation and gender identity as possible.

CCQDER is currently working on multiple efforts to improve question design and thus address these challenges. These efforts include cognitive interviewing studies to define the constructs measured by standard survey questions, to explore differences in how various groups define and interpret gender identity (including differences between adults and teenagers and between gender minorities and non-minorities), and to gauge when proxy responses (e.g., from a person such as a parent or physician) are appropriate.

CCQDER is also currently conducting multiple RAND studies to further examine factors that affect responses to gender identity questions, including the order of the questions and specific assigned sex and gender categories. CCQDER has also conducted a study for the Department of State (DOS) to define the "X" gender marker on US passports and is developing studies to examine gender identity among DOS

staff, which would enable DOS to examine and mitigate potential discrimination on the basis of gender identity. Dr. Miller noted that respondents' understanding of how data will be used can be as important a factor in survey administration as question design; if respondents understand that data are anonymous, for example, then false negatives due to privacy concerns can be mitigated.

Discussion/Reaction by the Board
Dr. Copeland postulated that some of the "none of the above" responses may be due to respondents falsely answering in order to alter survey data. Dr. Miller agreed, noting that CCQDER is evaluating methods to reduce the occurrence of purposefully false responses.

Dr. Bradley asked whether CCQDER is accounting for changing definitions of *sexuality*, in addition to sex and gender. Dr. Miller noted that current efforts to survey for gender identity are based on extensive previous research on sexual identity questions and experimental design. She noted recent changes in sexual identity reporting, including fewer respondents identifying as lesbian and more respondents identifying as other SOGI minorities.

Dr. Bradley asked why CCQDER included a write-in option for gender identity in its RAND survey, noting the wide variability of responses to such questions. He noted that previous studies on social media have identified a wide array of gender identification terms, including "gender fluid" and "asexual," and he expressed concern that the diversity of terms may hamper effective analyses. Dr. Miller noted that she does not generally recommend inclusion of write-in options in surveys; instead, CCQDER has employed the option to identify potential missing categories. CCQDER is employing an artificial intelligence technique to better categorize and group nonbinary gender identities.

Dr. Ohno-Machado noted that an individual's gender identity may differ from how others perceive that person's gender, and suggested that examination of these differences is crucial for understanding gender identity. Dr. Miller agreed that more research is needed on this difference and suggested that this general relationship between self and other perceptions are part of the theoretical underpinning of CCQDER's survey work.

Workgroup Update: Assessing the Use of Commercial Web-based Survey Panels by NCHS

Jennifer Parker, Ph.D., Director, Division of Research and Methodology
Andy Peytchev, Ph.D., Chair, Population Health Survey Planning, Methodology and Data Presentation Workgroup

Since January 2021, the NCHS Division of Research and Methodology has made significant progress in integrating online surveys into NHIS. As part of this effort, the Division of Research and Methodology (DRM) established the Population Health Survey Planning, Methodology and Data Presentation (PHSPMDP) Workgroup in July 2021 to assess the use of web-based panel survey data for NCHS. DRM presented background and preliminary results from this assessment during the October 2021 BSC meeting.

NCHS tasked the Workgroup with exploring two key questions: (1) Given current scientific knowledge, under what conditions would you recommend the use of online panel surveys for emerging or supplemental topics? (2) What additional research and evaluation is needed to increase confidence in the fitness-for-use of estimates from online survey panels for these purposes? NCHS also suggested that the Workgroup consider multiple approaches, including supplementing online panel data with other survey modes, adding questions to regular NCHS surveys to link results with online panels, improving statistical approaches for integrating online panel data, and communicating data quality from online surveys.

To respond to this statement of task, the Workgroup decided to focus on incorporating external web-based panels rather than NCHS developing its own web-based panels. Web-based panels will be used to examine emerging topics (e.g., telemedicine usage during the COVID-19 pandemic) to supplement content already captured by existing NCHS surveys. NCHS will retain control over survey content and collected data, and these data will be disseminated through the NCHS Experimental Estimates program.

The Workgroup is developing a rapid survey program, which will enable NCHS to rapidly measure and analyze high-priority and emerging health topics. DHIS will run this rapid survey program, in collaboration with DRM, and will conduct quarterly surveys with approximately 4,000 completes per round. DHIS and DRM will use commercial web-based surveys and will select specific questions based on NCHS and CDC priorities. DRM will calibrate weighting of survey data to align with other NCHS and CDC surveys to enable improved data harmonization.

On January 6, 2022, the PHSPMDP Workgroup met with multiple external survey panel providers, including the Pew Research Center, the Gallup Organization, Ipsos, and the National Opinion Research Center (NORC), to review multiple topics, including recruitment methods, panel design, data collection modes, questions that exhibit bias when examined in probability-based models, and strategies for sample retirement and refreshment. The Workgroup also met with representatives from the U.S. Census Bureau and conducted a second survey panel for government agency users. The Workgroup gathered much information from these efforts, for example,

- Web-based survey data collection should focus on estimating parameters that require timely identification rather than those that can be reported using more standard cross-sectional household surveys.
- Web-based survey panels should avoid estimates that are related to the data collection methods (e.g., technology use) and willingness to participate (e.g., volunteering, voting).
- Sampling should ensure that survey results are representative, not only of demographics, but also of specific subgroups (e.g., different income groups within a race or ethnic group).
- DHIS and DRM should conduct pilot studies prior to large-scale household studies to examine the efficacy and comparability of these web-based surveys.
- Additional research should explore whether web-based panels can be augmented with other samples or administrative data to address under-coverage and nonresponse issues.
- Panel surveys should be augmented with other probability-based data sources to ensure data linkages.

Finally, feedback suggested that the Workgroup could conduct an evaluation study using a short omnibus survey with NCHS-relevant measures in multiple panels. At least one panel would be augmented with different survey outreach methods or incentives (e.g., pre-paid cell phone cards for low-income participants) to examine how these augmentations affect survey responsiveness and data comparability. A panel that uses address-based survey mail and web surveys can be compared with traditional NHIS procedures to determine whether these alternative methods enhance responsiveness or alter results. This survey could also examine different data adjustment and statistical analysis methods. Finally, periodic conduct of this survey will ensure that the survey structure functions over time.

Discussion/Reaction by the Board
Dr. Olson noted that self-administered surveys (e.g., web- or mail-based) may produce different responses than surveys administered by an interviewer, particularly responses to sensitive questions. Dr. Olson also suggested explicitly stating that the Workgroup's goal is to start with probability-based sample panels but that these panel structures may change over time due to nonresponse and sample refreshment. Dr. Peytchev agreed, and shared his plan to present additional results and findings from these studies during the next BSC meeting.

Enhancing Identification of Opioid-Involved Hospitalizations with Clinical Data and Notes from Electronic Health Records

Geoff Jackson, Hospital Care Team Leader, Division of Health Care Statistics, NCHS

The Division of Health Care Statistics (DHCS) collects health care information across a wide range of care environments, including EDs, ambulatory surgery locations, inpatient departments, physician offices, and long-term care facilities. Data from these environments are routinely collected by multiple surveys, including the National Ambulatory Medical Care Survey (NAMCS), NPALS, National Study of Long-Term Care Providers (NSLTCP), and National Hospital Care Survey (NHCS).

NHCS is one of the core studies used by NCHS, CDC, and other public health agencies to quantify hospital utilization. NHCS is a sample of 608 noninstitutional, nonfederal hospitals with six or more staffed inpatient beds that provide data on all hospitalizations and ED visits. NHCS includes patient personally identifiable information, enabling researchers to track patient outcomes and link patient data with outside data sources. Data sources include uniform billing (UB)-04 administrative claims and EHRs, which provide a wide array of data such as patient age and sex, encounter dates, diagnoses and procedures, lab tests and results, medications, vital signs, and clinical notes.

To examine outcomes from opioid-involved hospitalizations, DHCS linked NHCS data and patient data with the National Death Index (NDI). NCHS data provide patient demographics, diagnoses, services received, and discharge status, while NDI data provide date and cause of death. This linkage enables DHCS researchers to examine in-hospital and post-acute mortality and cause of death for in-hospital deaths. It also provides data on morality within one year after hospital discharge. If a patient died from an overdose following hospital discharge, then researchers can examine the types of care received by that patient or whether they were hospitalized for other health reasons.

DHCS launched the Enhanced Opioid Identification Project to improve the identification of opioid-related hospitalizations and ED visits, which requires analysis of disparate data sources, including condition codes, diagnosis codes, and coded information in death certifications. This project used natural language processing (NLP) analyses and machine learning to develop the Enhanced Opioid Identification Algorithm, which queries unstructured mentions of opioid involvement from these data sources to identify opioid-related cases and then relates these data to mortality information from the NDI. The NLP algorithm searches records for specific opioids (e.g., fentanyl, oxycodone), drugs involved in treating opioid dependency and overdoses (e.g., naloxone), and common text in clinician notes that indicate opioid dependency and/or treatment.

DHCS researchers used this approach to analyze 2016 NHCS data and identified 1,370,827 opioid-involved hospitalizations in the inpatient and ED settings, including 21,603 opioid-involved overdose encounters in both settings. Among overdoses within a year of hospital discharge in the 2014 NHCS, heroin was identified on the death certificate for 45.7 percent, fentanyl was mentioned on the death certificate for 19.7 percent, and other opioids (e.g., oxycodone, morphine, hydrocodone) accounted for smaller percentages. The researchers also examined the number of patients with co-occurring substance use disorders (SUDs) (e.g., alcohol, cocaine) or mental health issues (MHIs; e.g., depression, anxiety, suicidal ideation). Of the 1,370,827 opioid-involved hospitalized patients, 399,632 (29 percent) had only a co-occurring SUD, 100,102 (7 percent) had at least MHI only, and 159,491 (12 percent) had both a co-occurring SUD and at least one MHI.

DHCS also conducted a validation study to further improve the Enhanced Opioid Identification Algorithm. It collaborated with a data collection contractor, which sampled 100 encounters from nine different hospitals (i.e., 900 encounters total), and the algorithm previously identified 865 of these

encounters as opioid-involved. Medical clinicians from the data collection contractor then reviewed these hospital records to validate opioid involvement. Medical clinicians identified evidence of opioid involvement in 92.8 percent of the 865 records identified by the algorithm.

DHCS recently published reports on demonstration projects for opioid-involved hospitalizations using NHCS data and plans to soon release more detailed reports on the identification of comorbid SUDs and MHIs and the validation study. DHCS will also provide the Python code for the Enhanced Opioid Identification Algorithm in GitHub for other NCHS researchers who are interested in linking EHR data with other public health information.

Discussion/Reaction by the Board
DHCS used an NLP approach because much of the opioid and treatment data were open-ended text data. These data were not weighted because the number of participating hospitals in 2016 was insufficient for reliable estimates, and results are presented as an unweighted descriptive analysis. The use of NLP is crucial for these analyses because diagnostic and billing codes often do not capture opioid involvement, and reliance on these codes alone likely underestimates the prevalence of opioid-involved hospitalizations. Other CDC surveillance systems, such as CSELS, have incorporated text data and NLP for similar reasons.

Linking EHR data, particularly text data, with NDI data increases the risk of false positives and false negatives. DHCS addressed this issue by matching up social security numbers when possible and by employing a probabilistic approach. With this approach, analyses that linked hospital and NDI data had low Type I and Type II error rates. Dr. Bradley recommended that DHCS include an error bound in future analyses to further control for potential errors.

Dr. Peytchev asked whether top coding (i.e., coding the most serious or pressing issue) may obscure other comorbid conditions. For example, the record for a patient with both cocaine and alcohol use disorders may list only the cocaine disorder. Mr. Jackson confirmed this possibility but added that DHCS is limited to what clinicians record in patient records. DHCS is working to further refine the NLP algorithm to capture additional comorbid factors to mitigate this issue.

NCHS Program Updates

New Suppression Standards for Rates
Jennifer Parker, Ph.D., Director, Division of Research and Methodology

In 2017, NCHS released the Data Presentation Standards for Proportions, which included (1) criteria based on a minimum sample size and both absolute and relative width of an exact confidence interval and (2) estimated proportions with few degrees of freedom or with suppressed complementary proportions that will be evaluated individually. The release of this report led to more estimates presented compared to prior criteria.

Following the success of the 2017 report, NCHS formed the Data Presentation Standards for rates Workgroup in 2018 with the following goals: identify current practices for data suppression of rates and counts, review and examine statistical principles (particularly properties of intervals calculated for rates and counts), and create and evaluate presentation standards for rates and counts. This Workgroup presented its provisional guidance regarding vital rates and counts to the BSC in January 2020: rates with non-constant numerators and constant denominators from vital statistics include national and state death rates, birth and fertility rates, age-adjusted death rates, and rates for subpopulations. Another part of this guidance related to a future strategy to identify and compare current presentation guidelines, methods of interval estimation, and relative standard errors.

This Workgroup focused on evaluating estimates from the National Vital Statistics System (NVSS), the NCHS population health surveys, and National Health Care Surveys using distributional assumptions, age-adjusted death rates, and simulations. The Workgroup identified the following presentation criteria: minimum sample size and effective sample size (when applicable) of 10 in the numerator (rates and counts) and in the denominator (rates only), maximum relative width of confidence interval (160 percent or lower), and minimum degrees of freedom (more than 8 degrees of freedom will be flagged). In reviewing estimates, the Workgroup identified methods to deploy when denominators are assumed constant or non-constant. For NVSS, when the denominator is constant, the standard will be to calculate the gamma interval and perform Fay-Feuer adjustments for age-adjusted vital rates. When the denominator is non-constant, the standard will be to calculate the Students t-test for the logarithm for the rates with variance estimated using methods supplied by the data source. Parameters for age-adjusted intervals will be weighted combinations of age-specific estimates.

The Workgroup has developed its findings into the Data Presentation Standard for Rates and Counts report, which has been reviewed by NCHS Associate Directors of Science (ADS) and mathematical statisticians. Next steps for the Workgroup include consolidating comments, preparing for official NCHS clearance, and presenting the report to NCHS.

National Survey of Family Growth Update: Resuming Data Collection with a New Multimode Design
Anjani Chandra, Ph.D., National Survey of Family Growth Team Lead and Principal Investigator, Division of Vital Statistics

NCHS began conducting the NSFG in 1973 with the goal to address Section 306 of the Public Health Service Act, which stipulates that NCHS will collect statistics on family formation, growth, and dissolution to help explain variations in birth rates using intermediate determinants of fertility; assess factors that affect timing and consequences of sexual activity and pregnancy; describe relationships and families; measure receipt of family planning and other medical services; and monitor the risk of HIV and sexually transmitted infections in general household populations. Each survey data release from 1973 to 2017-2019 provides a nationally representative, cross-sectional snapshot of the U.S. household reproductive-age population. NSFG has been updated many times over the years, for example, the inclusion of never-married women in 1982, transition of continuous fieldwork design in 2006, and expansion of age range from 15-44 to 15-49 years old in 2015. The 10-year contract with University of Michigan ended in 2020. The last set of public-use files supported by University of Michigan efforts was related during October 2020 and all restricted files were made available through the Research Data Center. Since those releases, a data brief was released in October 2020 and the NSFG Key Statistics webpage was updated November 2021; additional statistics were published in 2021, but most analyses were delayed due to staffing constraints.

The NSFG team awarded a new 10-year contract to RTI during September 2020 and has recently resumed data collection in January 2022, using a new multi-mode design. The NSFG team are collaborating with RTI on the following activities: establishing sample design and quarterly sample areas, developing interviewer training materials, training contractor staff and hire interviewers, enacting an IT system that meets CDC security requirements, modifying the contract to move web survey to Year 1 of data collection, and obtaining clearances for OMB and the Ethics Review Board (ERB). The primary work of the NSFG team over the past 18 months has been to develop instruments, including a web screener to manage multiple survey tasks accomplished in face-to-face modalities and an electronic life history calendar. As part of this work, the team produced programmer-ready full questionnaire specifications for both in-person and web modes, and performed extensive testing in both survey modes and in English and Spanish.

For NSFG data collection 2022-2029, the NSFG team aims to build upon the successes of the continuous face-to-face survey design used during 2006-2019 and to interview one person aged 15-49 in each sample household. The current multi-mode design organizes fieldwork into four 16-week quarters per year, compared to four 12-week quarters in the prior design. Each quarter contains three main phases: Phase 1 (weeks 1-4) is web-based and involves a $2 incentive for screening and $40 for the interview; Phase 2 (weeks 5-12) includes web-based interviews and involves the same incentives as Phase 1; and Phase 3 (weeks 13-16) is a combination of web-based and face-to-face interviews focused on up to 50 percent of a subsample of nonrespondents from Phases 1 and 2 and includes a $5 incentive for screening, $40 for the main interview, and $40 following the interview. At the end of quarters 1 and 2, the NSFG team will also conduct Phase 4, which involves a nonresponse follow-up via mail. At the time of this meeting the NSFG team planned to conduct a design comparison study to evaluate the n2022, but this study is likely to be postponed to 2023. The team is also considering additional updates to the design, including developing mailed paper-based screening to augment the web screening tool, conducting telephone prompting calls to complete the web survey, and testing the accelerated delivery of Phase 3's higher incentives.

Provisional Mortality Data on WONDER
Farida Ahmad, M.P.H., Mortality Surveillance Lead, Division of Vital Statistics

The Vital Statistics Rapid Release (VSRR) Program provides timely access to provisional mortality data to government agencies, researchers, and the public. These provisional mortality data are non-final, preliminary estimates based on the current flow of death certificate data to the NVSS. DMI efforts have helped improve data quality and timeliness of this program. Since 2011, the proportion of U.S. mortality records received within 10 days of the date of death per year has increased steadily, from 10.6 percent in 2011 to 66.8 in 2020; the goal of the VSRR Program aims to increase this proportion to 80 percent in upcoming years. Because of these steady increases in timely data, the VSRR Program has been able to expand its report offerings, including the following:

- 2015: Quarterly Provisional Estimates, State, and National Provisional Counts
- 2016: Vital Statistics Rapid Release Report on Timeliness, FluView, Interactive Switches to Using NCHS Death Data
- 2017: Provisional Monthly Drug Overdose Death Report
- 2020: COVID-19 Surveillance and Release of Daily Counts, Expanded Quarterly Provisional Estimates
- 2021: Provisional County-Level Drug Overdose Death Counts, Early Model-Based Provisional Estimates, Provisional Data Released on Wide-Ranging Online Data for Epidemiologic Research (WONDER)

WONDER is an accessible, menu-driven system that produces tables as output. It provides access to a wide array of public health information originated by CDC. It also offers the following features: customization of queries by time period, geography, place of death, demographics, and cause of death; visualization of results through charts; the ability to share and save queries; easy exportation of results into text files; and APIs for web pages or widgets. Provisional data on WONDER were first released in December 2021. These data are updated monthly during the first week of the month. Due to delays in death certificate completion, data for injury-related deaths (including drug overdoses or suicides) are released after an approximate 6-month delay.

Recent updates to WONDER's features include enabling queries focused on jurisdiction of occurrence and by the *Morbidity and Mortality Weekly Report* (MMWR) week in which the death occurred. Future improvements for WONDER include developing weekly updates for provisional data (instead of monthly), linking additional years of final data (1999-2007), and adding exclusion criteria for cause of death searches.

BSC Wrap-up and Future Plans

Drs. Lumpkin and Moyer thanked attendees and speakers for their participation in today's meeting, as well as emphasized their appreciation for NCHS in developing the Discrimination Workgroup and for those attendees that volunteered to participate in this Workgroup.

Dr. Moyer encouraged participants to suggest topics for future BSC meetings. Dr. Moyer also emphasized the importance of ongoing evidence-based policymaking efforts across the federal government and suggested these efforts be discussion topic during a future BSC meeting.

Public Comment

Public participants were also invited to submit emails in lieu of comments at the meeting itself. BSC did not receive any public comments, so the public comment period was closed.

The meeting was adjourned at 4:35 p.m. ET.

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

        /s/   April 28, 2022

_____   _____

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