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Department of Health and Human Services

Board of Scientific Counselors
National Center for Health Statistics
Centers for Disease Control and Prevention
December 4, 2018

Meeting Minutes

The Board of Scientific Counselors (BSC) convened on December 4, 2018, at the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC), 3311 Toledo Road, Hyattsville, MD. The meeting was open to the public.

Board Members Present

Linette T. Scott, M.D., M.P.H., Chair, BSC
Timothy J. Beebe, Ph.D. (by phone)
Prashila Dullabh, M.D.
Darrell J. Gaskin, Ph.D.
Sherry A. Glied, Ph.D. (by phone)
Robert M. Hauser, Ph.D. (by phone)
Mark Hayward, Ph.D.
Mary Ellen (Meg) Johantgen, Ph.D., R.N.
Robert Phillips, M.D., M.S.P.H., National Committee on Vital and Health Statistics (NCVHS) Liaison
Ninez A. Ponce, M.P.P., Ph.D.
Robert Santos, M.A., Urban Institute
Margo Schwab, Ph.D., Alternate Ex Officio Member, Office of Management and Budget (OMB)
Gretchen Van Wye, Ph.D., M.A.

NCHS-CDC Staff

Charles J. Rothwell, M.B.A., M.S.
Rebecca Hines, M.H.S. (by phone)
Jennifer Madans, Ph.D.
Gwendolyn Mustaf
Chesley Richards, M.D., M.P.H., FACP
Sayeedha Uddin, M.D., M.P.H., Designated Federal Official, NCHS

General Audience

Chris Bishop, ICF, International Inc.
Verita Buie, Office of Planning, Budget, and Legislation (OPBL)
Amy Branum, OCD
Stephen Blumberg, Division of Health Interview Statistics (DHIS)
Alicia Frasier, RTI International
Chad Heilig, Center for Surveillance, Epidemiology, and Laboratory Services (CSELS)
Debbie Jackson, Classification and Public Health Data Standards (CPHDSS)

Mary Moien, Division of Health Care Statistics (DHCS)
Peter Meyer, Chief Research Data Center, Division of Research and Methodology (DRM)
Hanyu Ni, Division of Vital Statistics (DVS)
Kathy O'Connor, DHCS
Jennifer Parker, Ph.D., DRM
Jeannine Schiller, DHIS
Steven Schwartz, DVS
Merianne Spencer, Office of Analysis and Epidemiology (OAE)
Suresh Srinivasan, DHIS
Harrison Quick, NCHS
Angel Vahration, DHIS
Julie Weeks, OAE
Jennifer Welham, ICF
Jianmin Xu, DHCS
Kevin Zhang, ICF

List of Abbreviations

BSC	Board of Scientific Counselors
CDA	Clinical Document Architecture
CDC	Centers for Disease Control and Prevention
CHIS	California Health Interview Survey
CMS	Centers for Medicare & Medicaid Services
COD	Cause of Death
CPHDSS	Classification and Public Health Data Standards
CSELS	Center for Surveillance, Epidemiology, and Laboratory Services
DHCS	Division of Health Care Statistics
DHIS	Division of Health Interview Statistics
DRM	Division of Research and Methodology
DVS	Division of Vital Statistics
EHR	Electronic health records
ER	Early Release
FHIR	Fast Healthcare Interoperability Resources
HHS	Health and Human Services
HP2020	Healthy People 2020
HP2030	Healthy People 2030
ICD-10-CM	International Classification of Diseases, 10th Revision, Clinical Modification
IG	Implementation Guide (a.k.a., HL7 CDA IG)
LTC	Long-Term Care
LTSS	Long-Term Services and Supports
NAMCS	National Ambulatory Medical Care Survey
NAS	Neonatal Abstinence Syndrome
NCHS	National Center for Health Statistics
NCVHS	National Committee on Vital and Health Statistics
NDI	National Death Index

NHAMCS	National Hospital Ambulatory Medical Care Survey
NHANES	National Health and Nutrition Examination Survey
NHCS	National Hospital Care Survey
NHDS	National Hospital Discharge Survey
NHIS	National Health Interview Survey
NORC	National Opinion Research Center
NPALS	National Post-Acute And Long-term care Study
NSLTCP	National Study of Long-Term Care Providers
OAE	Office of Analysis and Epidemiology
ODPHP	Office of Disease Prevention and Health Promotion
OMB	Office of Management and Budget
OPBL	Office of Planning, Budget, and Legislation
PCOR	Patient-Centered Outcomes Research
PCORTF	Patient-Centered Outcomes Research Trust Fund
RDC	Research Data Center
SNOMED	Systematized Nomenclature of Medicine

Action Steps

- The BSC voted unanimously to form a NHIS Key Health Indicators workgroup with Dr. Ponce, Dr. Hayward, and Mr. Santos volunteering to serve on the workgroup.
- Other BSC members wishing to participate in the new NHIS Key Health Indicators workgroup should notify Dr. Scott of their interest.
- NCHS would welcome suggestions from the BSC of ways to evaluate data quality of the redesigned NHIS.
- Members of the public including the BSC, can share their comments regarding the set of core objectives for HP2030 at HealthyPeople.gov.
- BSC members should notify NCHS of any concerns or comments they might have.
- After Mr. Rothwell retires at the end of 2018, NCHS will appoint a new acting director.
- The next BSC (virtual) meeting will take place January 22, 2019 via WebEx.
- Future meeting dates for the remainder of 2019: May 9-10 and September 5-6.

Tuesday, December 4, 2018

Presenters

Charles J. Rothwell, M.B.A., M.S., Director of NCHS
Stephen J. Blumberg, Ph.D., Director, Division of Health Interview Statistics
Aaron Maitland, Ph.D., Chief, Survey Planning and Special Surveys Branch, Division of Health Interview Statistics
Carol DeFrances, Ph.D., Chief, Ambulatory and Hospital Care Statistics Branch, Division of Health Care Statistics
Peter Meyer, M.A., M.P.H., Chief Research Data Center, Division of Research and Methodology
Lauren Harris-Kojetin, Ph.D., Chief, Long Term Care Statistics Branch, Division of Health Care Statistics
Ninez Ponce, M.P.P., Ph.D., Professor, Department of Health Policy and Management, UCLA Fielding School of Public Health, Principal Investigator, California Health Interview Survey, BSC Board member
Gretchen Van Wye, Ph.D., M.A., PCORTF Drug Workgroup Chair, BSC Member

David Huang, Ph.D., M.P.H., C.P.H., Chief, Health Promotion Statistics Branch, Office of Analysis and
    Epidemiology
Irma Arispe, Ph.D., Director, Office of Analysis and Epidemiology
Anne Driscoll, Ph.D., Reproductive Statistics Branch, Division of Vital Statistics

Welcome, Introductions, and Call to Order

Linette T. Scott, M.D., M.P.H., Chair, BSC

Dr. Scott called the meeting to order. She asked Board members to introduce themselves and state any conflicts of interest.

NCHS Update

Charles J. Rothwell, Director NCHS

Mr. Rothwell reported that the NCHS enacted budget for FY2019 was $160.4M, which is the same as the level in FY2018. He is pleased that NCHS has begun rehiring and will be continuing to fill vacancies.

He then described the new Federal Data Strategy, which is related to the Evidence-Based Policy Commission report. The administration is developing the Federal Data Strategy to increase coordination within and across departments with respect to data use and governance. They are currently working to define the principles and practices. A Year 1 action plan is planned for release in April 2019. A key issue is how NCHS can harness existing data that might inform NCHS' other activities. Mr. Rothwell hopes that this approach will help NCHS take advantage of innovations from the private sector without creating breaches of data confidentiality. NCHS remains committed to upholding ethical standards with respect to data protection. An investment in learning will also be crucial. NCHS needs to bring in staff with fresh ideas about making data more accessible and incorporating new data sources.

Program updates
Last week, NCHS released the final report on mortality for 2017 as well as two other related reports. One of those reports showed age-adjusted drug overdose rates by opioid category: mortality rates from synthetic opioids continued to increase rapidly through 2017. NCHS has already published overall drug overdose rates through April 2018; the rates may be leveling off. The other report showed continued increase in suicide rates.

The full dress rehearsal of the redesigned NHIS went into the field in October. In the next session, Dr. Blumberg will provide more details about how it has been received.

NHANES is still struggling with response rates. NCHS is continuing to evaluate redesign options for the future. A current priority for NHANES is to fill job vacancies; NHANES was particularly affected by the freeze on hiring.

Within the DHCS, they are continuing to explore potential uses for Electronic Health Records (EHR). As data linkage becomes increasingly important, NCHS is striving to identify the problems inherent with data linkage and to determine how to link data in a safe environment that avoids inadvertent disclosure. Nonetheless, NCHS should not waste resources linking data that do not need to be linked. Therefore, it is important to begin by defining the questions we are trying to answer. Furthermore, as NCHS builds these rich data resources, we must develop strategies to encourage people to use the data.

In the future, measuring long-term care will be important at NCHS. One of the challenges is that long-term care is provided at a variety of institutions—some of which are regulated and others less regulated—as well as within the home.

NCHS Publications and Media Exposure

From July 2018 to November 2018, NCHS issued 59 publications. For example, a Data Brief on fast food consumption received a lot of press. Mr. Rothwell pointed out that many of the NCHS Data Briefs are based on information we would not have without data from the NHANES examinations. Although the reports on health insurance coverage (based on NHIS) do not currently attract much interest, Mr. Rothwell believes they will be of great interest in the next two years. A new report featuring small-area life expectancy estimates has gotten a lot of attention not only in the national media, but also in small town newspapers across the US. The Robert Wood Johnson Foundation encouraged and provided the funding and support for this report. Three consecutive years of a decline in overall US life expectancy at birth also made big headlines.

Mr. Rothwell closed by reminding the BSC that he will retire in three weeks.

Discussion

Discussion focused on the possibilities and challenges related to integrating and sharing data and on NCHS' efforts to foster a learning culture.

Efforts to integrate and share data present both opportunities and challenges. Mr. Rothwell noted that a Data Hub operated by the CDC helps make data publicly available, including non-governmental data that have been purchased from the private sector. Sharing such resources between agencies offers many benefits. One person stressed the importance of the partnership between data and technology. Another person cautioned that given budget constraints, NCHS must make difficult choices about where they devote their resources. Furthermore, there is tension between maintaining data quality and efforts to integrate data from different sources (i.e., data collected for one purpose may not be suitable for more general purposes). Data users can play an important role by demanding that data providers provide complete documentation that enables users to evaluate data quality.   Many data sources fail in that respect.

There was also discussion about efforts to foster a learning culture at NCHS. Someone asked whether the focus was more internal or whether NCHS solicits input from consumers and advocacy groups to help ensure the relevance and value of the data. Mr. Rothwell explained that their focus is more internal, although NCHS has a mentoring program that operates across multiple statistical agencies. He also noted that junior staff are playing a bigger role at NCHS than in the past. Whereas senior staff made key presentations in the past, now many of these presentations are delivered by junior staff who understand that NCHS must evolve, taking into account the new sources (e.g., social media) and means (e.g., mobile devices) by which people obtain information.

NHIS Redesign Bridge Sample Updates & Workgroup Request for Key Indicators Selection and Dissemination

Stephen Blumberg, Ph.D., Director, DHIS
Aaron Maitland, Ph.D., Chief, Survey Planning and Special Surveys Branch, DHIS

After years of planning, Dr. Blumberg reported that they launched the full-scale dress rehearsal of the redesigned 2019 NHIS in October. The new survey went into the field alongside the 2018 NHIS questionnaire, thus forming a bridge sample that will allow NCHS to make comparisons between the old and new instruments. Early results (as of early November) indicate that the redesign achieved the goals of reducing interview length and arresting response rate decline.

He then turned the presentation over to Dr. Maitland to provide a more detailed review of the activities related to the NHIS redesign during the period from June through November 2018.

Field Testing of the Redesigned Questionnaire (June 2018)
In June, field testing of the redesigned questionnaire was conducted with 315 respondents across two different locations, chosen specifically to test the Spanish language as well as the English version of the instrument. The purpose of field testing was to allow staff to observe the interviews and evaluate how the questions performed, to obtain feedback on the instrument from interviewers, and to gain a realistic estimate of the redesigned interview length. The timing of this field testing was planned to allow enough time to make necessary changes before October. Based on the field testing, they made over 200 changes, most of which were minor modifications to improve the flow of the interview. This stage of testing verified that the mean and median length of the redesigned interview were well under the 60-minute target.

Centralized Interviewer Training (September 2018)
In September, NHIS staff conducted centralized interviewer training with approximately 600 interviewers. The goals of this training were to raise interviewer morale, help interviewers with recruiting strategies to improve response rates, and obtain additional ideas from interviewers to address respondent concerns that inhibit survey participation. NHIS staff made a concerted effort to make the training interactive and engaging for interviewers. For example, instead of the usual methodological walkthrough of the entire survey, they instead selected particularly challenging sections of the instrument and staged dramatic enactments of interviewer-respondent interactions. To facilitate dialogue, they allowed ample time to address questions that the interviewers asked or submitted in writing via notecards. They also included a separate 1.5 hour training for Spanish-speaking interviewers.

Bridge Sample (October 2018)
In October, NHIS staff proceeded with the dress rehearsal and full-scale systems test. They used a split sample design: the redesigned instrument was administered to a random half of the sample with the current 2018 instrument administered to the remaining half. This "bridge sample" allows staff to make direct comparisons between the new versus old instruments in terms of response rates, contact attempts, and respondent burden. Later, they will be also compare substantive results for key health variables.

The preliminary month 1 (October) results indicate that response rates among sample adults were higher for the redesigned (59%) instrument compared with the old (54%) instrument, while response rates among sample children were similar (60% vs. 61%, respectively). [Note: The household response rates are not comparable because the redesign eliminated the family interview.] The mean and median length of the redesigned interview were both under one hour, making it the shortest NHIS interview since 2009.

To assess respondent burden, NHIS introduced additional subjective measures at the end of instrument. In response to the question "How burdensome was this survey for you?", the proportion of respondents reporting it was "not at all burdensome" was higher for the redesigned instrument (63%) compared with the old instrument (54%). Similarly, the proportion reporting it was "very easy" to answer the questions was higher for the redesigned instrument (77% vs. 68% for the old instrument). Given that various mental health questions were added to the redesigned instrument, NCHS was concerned that the questionnaire might be perceived by the respondent as more sensitive. Nonetheless, these early results demonstrated positive results: the percentage reporting that the questions were "not at all sensitive" was higher for the redesign (51%) compared with the old instrument (45%).

Future Plans
In terms of next steps, the redesigned questionnaire will go into full production in January 2019. They have contracted with the research firm ICF to conduct nonresponse bias analyses. ICF will use techniques like machine learning and propensity models to identify predictors of response as well as multilevel models to measure neighborhood, community, and interviewer effects. Finally, ICF will test and evaluate different non-response weighting methods.

NHIS is also working on content development for 2020. They are considering including questions regarding sleep, child injury, child screen time, and child physical activity. They will also add sponsored adult content for lung cancer screening, physical activity, and the built environment.

Redesign of the Early Release Program and Proposed Workgroup for Key Health Indicators
Dr. Blumberg reviewed some of the consequences of the redesign for the Early Release (ER) program. In particular, two key health indicators are no longer included in the NHIS (i.e., HIV testing, personal care needs), while others are now rotating content that are not asked every year (i.e., leisure time physical activity, alcohol consumption, serious psychological distress). Thus, NHIS must reconsider which indicators should be included in the ER report. They are also considering which demographic subgroups should be included (e.g., add education, income, and/or region?), which types of estimates should be presented (e.g., crude vs. age- and/or sex-adjusted?), and the periodicity of ER products (i.e., continue as quarterly reports or transition to semi-annual reporting?). Currently, they report cumulative quarters (i.e., third quarter report includes the first nine months of the year), but they are considering whether they should instead report independent quarters.

To address these questions, NCHS requests that the BSC form a Key Health Indicators Workgroup (see outline that was circulated with the meeting materials for more details regarding the purpose and objectives of this workgroup). The workgroup will involve one meeting in February 2019 with follow-up as needed by e-mail or teleconference. The objectives of the workgroup will focus on: 1) indicator selection, 2) covariate selection, 3) types of estimates to be included, and 4) periodicity of the product. The findings of the workgroup will be presented to the BSC at the May meeting.

Discussion/Reaction by the Board
Topics covered during the discussion centered on the proposed workgroup, interviewer training, methods for gauging data quality, and the incentive system.

In the discussion of the proposed Key Health Indicators workgroup, the BSC was reminded that two members of BSC are needed to serve on the workgroup. The workgroup will also include other subject matter experts. As discussed at the last meeting, BSC has already formed another workgroup (PCORTF),

which Dr. Van Wye is chairing. The new proposed workgroup would be time-limited (i.e., only one main meeting). The BSC voted on whether or not to convene the proposed workgroup; BSC support was unanimous. Dr. Ponce, Dr. Santos, and Dr. Hayward volunteered to serve on this new workgroup. Any other BSC member who decides later that s/he would like to participate would be welcomed. Dr. Uddin will serve as the NCHS point of contact for this workgroup with assistance from Jeannine Schiller (survey staff).

BSC members expressed positive feedback regarding the interviewer training. Although it was time-consuming, expensive, and challenging to incorporate all the feedback from 600 interviewers, Dr. Blumberg stressed how valuable the training was to the success of the redesigned NHIS and thanked Adena Galinsky for her role in coordinating it. One person particularly valued the fact that they included special training for interviews conducted in Spanish.   Someone asked whether the survey is fielded in Asian languages as well. Dr. Blumberg explained that the instrument is translated only into Spanish, but they have interpreters that can assist with on-the-fly translation of the survey. The questioner cautioned the importance of ensuring that informed consent is well conveyed in such cases.

A question was raised about whether NCHS has ways of gauging data quality beyond the response rate. Staff explained that with only one month of preliminary data, they have not yet delved into the issue of data quality. They acknowledged that it is difficult to evaluate data quality and would welcome any suggestions from the BSC. Someone asked whether they do cognitive interviewing. Yes, they do selective cognitive interviewing, but not for every question because of limited time. Another person asked whether they validate the health insurance questions against administrative records. Dr. Blumberg noted that the interviewer asks to see the respondent's insurance card. He agreed that linkages to administrative records would reveal more about the quality of these data and remains open to that possibility.

Finally, someone questioned whether the incentives used in NHIS have changed. Dr. Blumberg explained that NHIS does not offer incentives. NHIS has tested incentives in the past, but found they did not increase participation or improve data quality. The only benefit they found was that monetary incentives increased the proportion of respondents who completed the survey rather than a partial interview. After the NHIS redesign is fully implemented, they may re-assess the question of incentives. NHIS may also be able to learn from the work that NHANES is doing on this issue. Someone else commented that evaluation across government programs suggests that, in general, incentives are not very effective.

Utilizing EHR Data in NCHS Data Systems

Carol DeFrances, Ph.D., Chief, Ambulatory and Hospital Care Statistics Branch, DHCS
Peter Meyer, M.A., M.P.H., Chief Research Data Center, DRM

Dr. DeFrances began by reviewing the family of National Health Care Surveys administered by DHCS. The long-term care surveys will be covered by Dr. Harris-Kojetin during the next session. The other branch of this survey family covers ambulatory and hospital care: the National Ambulatory Medical Care Survey (NAMCS), which surveys office-based physicians and community health centers; the National Hospital Ambulatory Medical Care Survey (NHAMCS), which samples emergency department visits, outpatient department visits, and ambulatory surgery locations; and the National Hospital Care Survey (NHCS), which is the newest survey and incorporated the National Hospital Discharge Survey (NHDS, last fielded in 2010) that collected in-patient information. Eventually, DHCS plans to integrate NHAMCS into

the NHCS. The NHCS and the NAMCS are the surveys for which they are moving towards Electronic Health Record (EHR) data collection.

Why EHR Data Collection?

The benefits of incorporating EHR data include lowering the burden of collection; increased clinical detail and depth; greater volume of data; and better data security. As part of the move towards EHR data collection, DHCS conducted pilot studies, developed a standard for data submission (i.e., HL7 Clinical Document Architecture (CDA) Implementation Guide (IG)), and pursued incentives such as Meaningful Use credit (now called Promoting Interoperability) through the CMS EHR Incentive Programs. Beginning January 1, 2019, providers will be required to submit data using the HL7 CDA IG. DHCS has also developed a new on-line registration portal that debuted in September 2018. Providers and hospitals are no longer being registered manually; instead, they can register on-line.

Many EHR vendors are already offering a variety of IG products. NCHS is actively working with others (i.e., eClinicalWorks, MediTech) on interface development. NCHS has encountered some issues with Epic, who serves thousands of physicians and hundreds of hospitals. With the help of Mr. Rothwell and Dr. Richards they are working on developing an interface with Epic for tentative release in November 2019. DHCS is also preparing for Connectathon in January 2019, which will allow EHR vendors to test and certify their interface to promoting interoperability criteria for public health reporting.

Data Release

In 2016 and 2017, NAMCS collected both abstracted and EHR data, which they are working to integrate. In January 2019, NCHS plans to publicly release the 2016 NAMCS abstracted data, with release of the combined abstracted and EHR data in the NCHS Research Data Center (RDC) at a later date. Release of the 2017 data will follow, hopefully by the third or fourth quarter of 2019. There is a lot of integration work that must be done to reconcile the abstracted data with the EHR data. For example, the EHR data includes 73 unique combinations for race, whereas the abstracted data allow only six race codes.

The 2016 NHCS data collection encompassed 44.9M unique encounters from 158 hospitals; EHR data were provided for 4.3M of those encounters. DHCS has encountered some difficulty determining whether the encounter occurred in the emergency or outpatient department, extracting a diagnosis code, and converting Systematized Nomenclature of Medicine (SNOMED) codes to the International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM) codes.

PCOR Projects

The FY17 Patient Centered Outcomes Research Trust Fund (PCORTF) Linkage Project has the goal of linking the hospital care data with the National Death Index (NDI) and with the Centers for Medicare & Medicaid Services (CMS) data. They have already released the 2014 Hospital Care file, which links claims with the 2014-15 NDI. Later this month, they plan to release the 2016 Hospital Care file, which will include EHR data as well as claims and will be linked to the 2016-17 NDI. The 2014 Hospital Care file linked to CMS data will also be released at the end of this month.

Dr. DeFrances provided an example of new information obtained by these linkages. From the 2014 data, they identified 39,000 opioid-involved emergency department visits, which they were able to link with individual patients, and then link to the NDI. Consequently, they can determine not only the percentage who died at the hospital (which was already known from the hospital care data), but also the percentage who died within 30 days, 31-90 days, and >90 days post-discharge. Furthermore, they have

cause of death from the NDI and can determine the reason for hospitalization by referring back to the hospital data.

The NCHS FY18 PCORTF Opioid Project is still in the initial stages. It aims to develop and apply text-mining strategies to identify specific opioids in written and coded data from hospital encounters and drug overdose deaths. The final product will be a web-based portal that will allow them to report back to participating hospitals with clinical information about opioid cases and aggregate (hospital-specific) 30, 60, and 90-day post-acute mortality outcomes. DHCS believes that the promise of reporting information back to hospitals is creating an incentive for participation.

For the future, their plans include updating the registration portal with enhancements; continuing to recruit hospitals for the 2018 Hospital Care Survey; working with EHR vendors to build, test and implement the HL7 CDA IG; and exploring options for storing and processing large volumes of data.

Challenges
Dr. DeFrances then turned the presentation over to Mr. Meyer, who highlighted some of the challenges NCHS faces as they seek to incorporate EHR data. NCHS needs to understand new methods that move beyond traditional statistics. Thus, they need data scientists who are well-versed in these new methods. Unfortunately, it is difficult for NCHS to hire data scientists with the necessary skills given the high demand for them. An alternative is to develop them in-house. Ideally, NCHS would hire a whole cohort of autodidacts who could learn and work together, but the federal hiring system is not conducive to hiring cohorts of people at the same time.

NCHS has talked with many groups (e.g., NCI, Dell) that are willing to build a platform for NCHS, but a new platform would require ongoing maintenance. NCHS would rather use an existing platform. They have found a promising solution: Oak Ridge National Laboratory, which is a federally-funded research data center under the Department of Energy. Oak Ridge already has a health data institute and a lot of experience working with NCHS-like data. They have no laws with respect to data ownership and would be collaborators rather than a vendor. Oak Ridge already has 80 data scientists and ample processing capacity. They also understand the problem of confidentiality and other issues that future technology will raise (e.g., differential privacy, the problem of producing a synthetic dataset that is workable for all outcomes, the challenges of a query system and remote execution). Mr. Meyer hopes that they will have an agreement with Oak Ridge in place by next year.

Discussion/Reaction by the Board
The discussion centered on issues related to hiring Data Scientists, fostering partnerships with providers and EHR vendors, and the future growth potential of this work.

With respect to hiring, one problem is that job classifications are not always written in the modern language and terminology that will attract the people NCHS needs. One person shared a story about two Ph.D. candidates that were having trouble finding a position and thus, attended a Data Science boot camp, which enabled them to obtain work as Data Scientists. Perhaps NCHS could use a similar strategy to hire Data Scientists at a government-level wage.

In terms of fostering partnerships, NCHS is actively building a network to decrease burden across the system. They are emphasizing interoperability and interconnectivity. Someone asked whether they had considered adopting the new Fast Healthcare Interoperability Resources (FHIR)-based standards in place

of the Clinical Document Architecture (CDA). Dr. DeFrances replied that there was a debate about whether to use FHIR or CDA when they developed the IG; they decided to use CDA. She noted that their current priority is getting data for their surveys; if they keep changing the IG, she fears they will never get the data. In some cases, providers are inappropriately using HIPAA to refuse data sharing. They need to change the culture to ensure data is exchanged whenever it is appropriate.

There was also discussion of the potential for growth based on this work. NCHS has already demonstrated that it can be done. If they had the necessary resources, it could transform NCHS into a real-time data provider covering every health care provider in the country. It would allow bi-directional communication that would create value for providers.   It could provide not only national estimates, but also estimates at a detailed local level. Although a lot of information could be obtained solely via EHR, some data will still require sampling. If NCHS had a platform that could cover the entire population (and 100% of hospitals), the main barrier would be cost. NCHS could become the broker of a huge, standardized database, but it would require infrastructure far beyond current capacity in terms of people, machines, and processing power. That is the advantage of collaboration with Oak Ridge, which has this technical infrastructure capabilities.

National Study of Long-Term Care Providers (NSLTCP)

Lauren Harris-Kojetin, Ph.D., Chief, Long Term Care Statistics Branch, Division of Health Care Statistics

Dr. Harris-Kojetin reviewed the context and goals of the National Study of Long-Term Care Providers (NSLTCP), which was launched in 2012 to replace the historical surveys related to long-term care (LTC). As noted earlier by Dr. DeFrances, it is part of the family of National Health Care Surveys. The NSLTCP monitors trends in paid, regulated LTC services across five sectors. Unique features compared with the historical surveys are that it allows state-level estimates, permits comparisons of multiple LTC sectors within a one- to three-year period, and produces public-use files (beginning with the 2018 wave). Topics covered in the NSLTCP include antecedents (e.g., characteristics of the patients such as prevalence of diabetes and co-morbidities), structural factors (e.g., characteristics of the organization such as size and payer mix), variables related to process (e.g., medication and pain management), and outcomes (e.g., emergency department or hospital visit). In 2016, the NSLTCP captured 65,500 paid, regulated LTC providers serving more than 8.3M people in the US.

She highlighted some of the many products and uses made of the NSLTCP data. Since 2013, they have published a vast array of products (e.g., QuickStats, Data Briefs, National Health Statistics Reports, Series 3 Reports, journal articles, stand-alone web tables) that have resulted in more than 113,000 downloads and page views. They have made presentations at dozens of conferences. Many other government agencies and non-profits also use data from the NSLTCP.

Combining Multiple Data Sources
NSLTCP combines data from multiple sources. Data for three sectors (i.e., hospices, nursing homes, and home health care agencies) come from administrative records: claims, assessment, and regulatory data from CMS. The other two sectors (i.e., residential care communities & adult day service centers) are not federally regulated and thus, administrative data are not available. For these two sectors, they fund primary data collection. To be more cost-effective, they use multi-mode methods rather than the in-person interviews used in the past. To reduce respondent burden while maximizing content, they rotate modules between waves. They also alternate the survey design between an aggregate approach (i.e., 2012, 2014, 2016, & planned 2020 waves; sample size approximately 17,000; mail-in and web protocol

followed by telephone follow-up for nonresponse; aggregate-level data at both state and national levels; no public-use files) and an individual approach (i.e., 2018 & planned 2022 waves; sample size approximately 4,000; telephone interviews; individual-level data but only at the national level; includes public-use files).

Future Plans
In the future, NCHS plans to 1) add more post-acute sectors (i.e., LTC hospitals, inpatient rehabilitation facilities), 2) change the name of the survey from NSLTCP to NPALS (National Post-Acute And Long-term care Study), 3) add qualitative interviews with some adult day service centers and residential care communities to examine alignment between questionnaire items and record keeping practices, and 4) convene an expert stakeholder workgroup in 2019 or 2020. The name change will officially be linked with the 2020 survey wave; DHCS is beginning to announce the change in public venues as the opportunity arises starting now. The new name purposefully eliminates the word "providers", which is misleading since the study also includes information about services users. NSLTCP plans to maintain their core mission of collecting primary data on adult day and residential care, while building potential partnerships with other entities to add one-time questions or periodic supplements on a specific sector or topic.

Challenges
There are challenges at all stages of the survey protocol: screening for eligibility, completion of the provider questionnaire by web or mail, and completion of a follow-up telephone interview providing information about two sampled current residents/participants. Among 4000 sampled cases, only 60% of adult day service centers and 50% of residential care communities completed the eligibility screening. Among those screened and eligible, only 40% of adult day centers and 20% of residential care communities completed both the provider and the service user questionnaires as of late November; data collection continues through February 2019.

The possibility of data linkage represents another challenge. NSLTCP surveyed directors at HIPAA-covered establishments, but found that, at best, only 7% would be willing to provide the personal identifying information necessary for data linkage. Thus, data linkage for the NSLTCP does not seem promising.

Assessing Use of and Demand for Long-Term Services and Supports in the California Health Interview Survey (CHIS)

Ninez Ponce, M.P.P., Ph.D., Professor, Department of Health Policy and Management, UCLA Fielding School of Public Health, Principal Investigator, CHIS, BSC Board member

Dr. Ponce outlined the limitations regarding data on long-term services and supports (LTSS) in California. The state lacks the population-level data necessary to assess needs, the level of use, and possible gaps in services. Many programs do not uniformly collect and report the data. The available data are fragmented, and there is limited capacity for sharing data.

To help fill this void, the California Health Interview Survey (CHIS) is planning a new follow-on survey to assess LTSS. The CHIS is the largest annual population-based state health survey in the U.S., covering approximately 20,000 households per year. The follow-on survey is planned for the 2019-20 & 2023-24 cycles. It will include about 2,000 respondents per cycle, who will be administered 50-80 questions

expected to require 15 minutes to complete. In 2021, they will also conduct qualitative interviews with about 100 respondents.

CHIS LTSS Workgroup
To guide this project, they have convened a CHIS LTSS Workgroup, which includes a diverse set of stakeholders. The objectives of the workgroup include reviewing and selecting the screening questions that will determine eligibility for the follow-on module; identifying major content areas; reviewing existing CHIS indicators that might be used to link data with national LTSS data; reviewing other surveys to identify questions for possible inclusion; and revising or developing new survey questions as needed.

Screening Questions
They hope that the screening questions can be completed in less than one minute. These questions will be translated into Spanish, Chinese (Cantonese and Mandarin), Vietnamese, Tagalog, and Korean. They will also include proxy interviews.

Follow-On Survey Domains
The follow-on survey domains will center on the following research questions: What is the need for LTSS? What are the consequences of unmet need? Who has access to the services and what types of services are available? What are consumers' perceptions of the quality of services? How satisfied are consumers with those services?

Timeline
With respect to the timeline for implementation, pre-testing for the CHIS 2019-20 will conclude in January 2019, with pilot testing in March 2019 followed by data collection during April 2019 through December 2020. For the LTSS Follow-On Survey 2019-20, pre- and pilot testing will begin in March 2019, with data collection planned for May 2019 through January 2021.

Dr. Ponce closed by explaining that the LTSS Follow-On Survey was spurred by advocates within the LTSS community of providers and consumers as well as by a one-time expenditure of approximately $3M from the state legislature to assess LTSS needs in California.

Discussion/Reaction by the Board
Issues raised during the discussion included the possibility of collaborating with CMS, advantages and disadvantages of the NSLTCP data collection system, and the need to adapt to future changes in LTC.

One person asked whether NSLTCP was in communication with CMS, which is starting to produce a Medicaid scorecard that includes indicators related to LTSS. Dr. Harris-Kojetin replied that they have found it difficult to establish a collaborative relationship with CMS because the agency is so big that they must make and maintain contacts with people in many different offices. She acknowledged that they may need to revisit their efforts to foster collaboration with CMS.

There was discussion of advantages and disadvantages of the NSLTCP model for data collection. The NSLTCP is a good example of supplementing existing administrative data with primary data collection to create a blended product. It is the least expensive data collection within NCHS, yet there are many challenges because of data quality issues within the existing systems. Someone asked if they had considered transitioning the NSLTCP to an annual or continuous survey (rather than biennial), which would provide greater opportunity for experimentation. Dr. Harris-Kojetin noted that they had

originally planned to make it an annual survey, but have found that the current model works very well. They have well-established routines for the different stages of the survey. She also pointed out that they have embedded experiments within the survey that have led to helpful improvements.

The remaining discussion focused on the need to adapt to future changes in the field of LTC. Currently, there is a focus on aging in place. The surveys provide information about paid LTC services, but the survey does not capture home care provided by family members. A better understanding of caregiver burden and the range of community support being deployed would help us design better policies. Also, given that state policies are very dynamic, one advisor cautioned that rotating modules in the NSLTCP may miss important changes from one year to the next.

Patient Centered Outcomes Research Trust Fund Drug Workgroup Update

Gretchen Van Wye, Ph.D., M.A., PCORTF Drug Workgroup Chair, BSC Member

Dr. Van Wye reported on the progress of the workgroup that was convened since the last BSC meeting. They held their second meeting on November 29th, attended by BSC members Dr. Van Wye and Dr. Scott as well as external experts. The problem this workgroup is attempting to solve is that data entered on the death certificate as literal text are not as useful to researchers as they could be. The main goal of this workgroup is to develop a tool to transform literal text into usable information. Although this project focuses on drugs as a case study, such a tool is expected to have a broader application.

She highlighted several key themes they heard from the experts at this meeting. First, researchers generally want as much data at the greatest level of detail possible. However, it is important to recognize that there are many different types of data users: some have limited processing skills, while others are highly skilled at data manipulation. Furthermore, they want only the information that is relevant to the cause of death (i.e., part of the casual chain), not all the extraneous details about events that may have occurred in the process.

Second, the system needs to be flexible because drugs are constantly changing, making them hard to track. The system will need to be updated regularly, and those updates must be well-documented and transparent to users.

Third, the drugs listed on the death certificate need to be anchored to meaningful codes. Currently, there is no coding schema for illicit drugs.
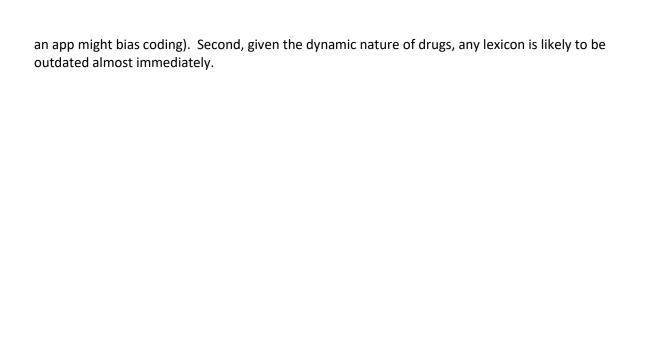
Fourth, in the current context of Big Data, it is important that users know how to ask good research questions. Otherwise, there is a high risk of data mining.

Finally, whatever tool is developed will inevitably be incomplete and imperfect, and it needs to be stable yet flexible.

A summary from their meeting will be presented at the January teleconference of the BSC.

Discussion
One person questioned whether the lexicon that might be developed by this project could be used to create a useful app for providers and medical examiners and become part of the electronic death registration system. There were two main concerns raised with respect to that idea. First, NCHS needs to be careful not to create a situation that will influence coding practice by providers (e.g., use of such

an app might bias coding). Second, given the dynamic nature of drugs, any lexicon is likely to be outdated almost immediately.

Developing Healthy People 2030: Challenges in Prioritization

David Huang, Ph.D., M.P.H., C.P.H., Chief, Health Promotion Statistics Branch, OAE
Irma Arispe, Ph.D., Director, OAE

Dr. Huang explained that the aim of the Healthy People Initiative is to provide a strategic framework for a national prevention agenda that specifies measurable objectives and allows tracking of data-driven outcomes. Healthy People was first launched in 1979. It comes out every 10 years with targets to be achieved by the end of the decade.   Over the years, it has expanded substantially in scope from 15 topic areas with 226 objectives for Healthy People 1990 to 42 topic areas with more than 1300 objectives for Healthy People 2020 (HP2020).

The initiative is federally-led by Health and Human Services (HHS) and the Office of Disease Prevention and Health Promotion (ODPHP), but stakeholder driven with NCHS as a key advisor. A federal interagency work group involving almost 30 HHS agencies as well as other offices outside of HHS acts as the steering committee. In addition, there are 42 topic area workgroups composed of subject matter experts. Finally, there is further involvement at the national, state, community, and individual levels.

The Role of NCHS in the Healthy People Initiative
NCHS serves as the statistical advisor, providing an analyst for each of the 42 topic area workgroups. NCHS also conducts research and develops methods for measuring the overarching goals, helps create analytic and graphical products, maintains a comprehensive database for all the objectives, and provides expertise and technical assistance to national, state, and local health monitoring efforts. Furthermore, NCHS hosts monthly webinars on leading health indicators and publishes the mid-course and final reviews for Healthy People.

NCHS as a Change Agent in the HP2030 Development Process
Dr. Arispe took over the presentation to review NCHS's role as a change agent in the HP2030 Development Process. NCHS absorbs all the costs associated with their work on Healthy People but cannot make decisions regarding content. In May 2016, the NCHS director (Mr. Rothwell) sent a memo to the HHS secretary voicing the need for a more parsimonious and conceptually coherent set of objectives. In this memo, Mr. Rothwell recommended that HP2030 be reduced to 10-15 topic areas with 150-200 objectives as outlined by a 2007 National Opinion Research Center (NORC) study commissioned during planning for HP2020. This articulation of NCHS' perspective, along with feedback from stakeholders, yielded a commitment to reduce the number of objectives.

One problem with the development process is that although there are objective selection criteria, they have not been operationalized and thus, have been ineffective for the purpose of excluding objectives. Although NCHS had proposed that HHS set a fixed limit on the total number of objectives, HHS did not want to impose that constraint, but rather preferred a consensus-based approach. Therefore, NCHS proposed several alternative approaches: 1) eliminate programmatically detailed, multi-part objectives; 2) use a leading health indicators approach that collapses multi-part objectives and limits the number of objectives per topic; 3) implement a scoring exercise to synthesize the evidence and develop priority recommendations; and 4) prioritize based on data source quality. Ultimately, elements of each of these approaches were used to reduce the number of objectives.

Other stakeholders were also interested in a more parsimonious set of objectives and thus, helped further that goal. Indeed, the process encouraged competition between topic areas by revealing which

areas had been most successful in generating a parsimonious list. By consistent implementation of the objective selection criteria, NCHS was able to vote down particular objectives. In the end, approximately 1200 objectives were reduced to 355 core objectives that are more focused, based on better data quality, and more conceptually coherent. This slate of objectives was released on HealthyPeople.gov for public comment on December 3, 2018.

HP2030 Development Process
Dr. Arispe turned the presentation back over to Dr. Huang, who reviewed the HP2030 Development Process. This process involves three components: the Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives; the Federal Interagency Workgroup and Topic Area Workgroups; and public engagement.

Development of Healthy People is split into two pre-launch phases. Phase one consists of framework development (i.e., vision, mission, overarching goals), which began in 2016 and has recently been completed. Phase two, which is currently in progress and expected to be completed in 2019, comprises development of the core objectives. The Federal Interagency Workgroup approved five criteria for selecting the core objectives. The first two criteria deal with data availability (i.e., must be measurable by 2019) and quality (i.e., baseline data no older than 2015 and two additional data points during the HP2030 decade). Other criteria stipulate that the objectives are nationally important and evidence-based (i.e., there are effective interventions to achieve the objectives). While not a strict requirement, the final criterion gives special consideration to objectives that address health equity and disparities.

They expect to launch HP2030 in the first quarter 2020, at which time they will close out HP2020.   Final review for HP2020 is scheduled to be released in 2021.

Discussion
Topics covered during the discussion focused on the number and coverage of the objectives.

With respect to the number of objectives, some attendees were happy that the list had been reduced from more than 1300 to a more manageable number. Yet, one person noted that 355 is still a lot of objectives and expressed concern that retaining so many objectives diminishes the importance of each. Someone else acknowledged the benefits of reducing the number of objectives, but wondered what might have been lost in the streamlining process. Another person pointed out that despite the simpler list of core objectives, there are still many sub-objectives that merit attention. Someone else noted that no one evaluates their programs or makes budget decisions based on Healthy People objectives, but this refocusing effort may make the objectives more useful in that respect. Dr. Arispe explained that a key problem is that more people want to add objectives than to eliminate any objectives. By participating in the public comment process, BSC members (and the rest of the public) can play an important role in helping balance the objectives. Public comment may lead to some objectives being changed, added, or eliminated.

Regarding the coverage of the objectives, someone pointed out that most of the indicators seem to be person-based, yet many public health problems must be addressed at the environmental/structural level. Dr. Arispe replied that the list includes a variety of objectives at many different levels including a public health infrastructure topic area. In particular, there are many structural-based objectives in cases where the objectives are heavily affected by state policies (e.g., tobacco). Someone else questioned the distribution of objectives, noting that some important areas (e.g., social determinants of health and

mental health) have a smaller number of objectives. This person argued that not all objectives are equality important: some are more influential and may affect other objectives. One person asked whether all the selection criteria were given the same weight? No. Dr. Huang explained that they tried to create a scoring mechanism, but they were not successful. Given the large number of topic areas (42), many objectives could be cross-classified across multiple topics. Thus, the distribution may be deceptive. Most people focus only on the topic area of interest to them; very few look across the full spectrum of topics. Thus, it is difficult to achieve balance. NCHS has been considering how to repackage the objectives to reflect cross-classifications.

Evaluation of Birth Outcomes Associated with Drug Use

Anne Driscoll, Ph.D., Reproductive Statistics Branch, DVS

Dr. Driscoll reviewed the overall goals of the PCOR-funded project, which aims to strengthen the mortality data infrastructure to enhance researchers' ability to investigate opioid-related deaths. One part of this project focuses on opioid-related, adverse pregnancy outcomes including drug-related infant deaths and Neonatal Abstinence Syndrome (NAS). The remainder of the presentation focused on NAS.

NAS results from postnatal drug withdrawal that occurs primarily among opioid-exposed infants, typically within 72 hours after the birth. The key question under consideration is whether NAS should be reported on the birth certificate at the national level. As rates of opioid use disorder have risen rapidly, incidence of NAS has also increased. Currently, NAS is a reportable condition in only seven states, and there is no national reporting system. The DVS has been collaborating with the Birth Data Quality Workgroup to review the potential for collecting NAS on the birth certificate.

In pursuit of this effort, DVS has also been collaborating with three states (CT, NJ, WV) that have been reporting NAS on the birth certificate since 2016 and one other state (NH) that began collecting similar information in mid-2018 ("Was the infant monitored for signs of opioid withdrawal or neonatal abstinence syndrome?"). All four of these states have overdose mortality rates that are higher than US average. Data on NAS from the three states reporting NAS since 2016 indicate that rates of NAS remained stable between 2016 and 2017, mothers aged 25-29 exhibited the highest rates of NAS (e.g., 6.8% in WV in 2017), and rates were higher among non-Hispanic whites than among non-Hispanic blacks or Hispanics. Compared with all births, NAS diagnosed cases were more likely to be paid for by Medicaid and more likely to be admitted to the neonatal intensive care unit.

In October 2018, the Birth Data Quality Workgroup surveyed states to identify potential impediments to collecting NAS on the birth certificate; 39 states and one territory responded. Two states (CA & WA) reported that state law would prohibit collecting NAS on the birth certificate, while five other states were unsure whether or not the law would allow it. The remaining 32 states reported no known prohibitions that would preclude reporting, but expressed other concerns. Many states questioned whether NAS could be diagnosed within the timeframe for filing birth certificates. Some worried about reporting a potentially negative maternal behavior because the information might be used against the mother and because it could compromise data quality and completeness. Several states expressed concern about the lack of specificity of the NAS definition (i.e., which can vary across hospitals). Additional concerns pertained to the cost of training and changes to electronic systems and the questionable value of reporting NAS in states where opioid abuse is low.

Their planned next steps include linking hospital discharge data with birth certificate data in the three NAS reporting states to verify accuracy and completeness and to evaluate whether the NAS diagnosis occurred within the birth certificate reporting time frame. Next week, the Council of State and Territorial Epidemiologists is meeting to develop a standard NAS definition. DVS representatives will attend that meeting.

Discussion
Questions raised during the discussion centered on overdose-related infant/maternal deaths and whether it might be possible to examine prevalence of NAS at a lower geographic level than the state.

In response to a question about overdose-related infant and/or maternal deaths, Dr. Driscoll explained that a separate sub-project is examining cause of death data for infant and fetal deaths to identify those linked with opioid use.

Someone else noted that data regarding the prevalence of NAS at the sub-state level might allow them to identify the greatest mismatch between the prevalence and the healthcare workforce needed to address it. Dr. Driscoll explained that the county level is the smallest geographic unit they could identify with birth certificate data. Someone else noted that individual states are also working to address within-state geographic disparities.

BSC Wrap-up

Linette T. Scott, M.D., M.P.H.
Charles J. Rothwell, M.B.A., M.S.

Dr. Scott noted that the BSC will hear the report from the PCOR Workgroup at the January meeting. She thanked Mark Hayward, Ninez Ponce, and Robert Santos for volunteering to serve on the new NHIS Key Indicator Workgroup.   She reminded the BSC that the HP2030 core objectives have now been released for public comment and encouraged the BSC to respond and share their thoughts. Finally, she concluded by thanking Mr. Rothwell for his fine leadership of the NCHS.

Mr. Rothwell stressed the important role of the BSC in providing guidance to NCHS. Whenever a BSC member has a concern, it is important to let NCHS know about it. It is very helpful to NCHS to hear the perspectives from people with a wide range of experiences.   He expressed his pleasure at working with NCHS and with everyone on the BSC. After he retires at the end of 2018, NCHS will appoint an acting director. Mr. Rothwell hopes that they will soon have a new director.

Discussion
The Discussion highlighted the important role that Mr. Rothwell has played in leading the BSC to make actionable decisions.

Public Comment

There was no public comment.

The meeting was adjourned at 4:50 p.m.

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

_____/s/_____   _____3/6/19_____
Linette T. Scott, M.D., M.P.H.   DATE
Chair, BSC