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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
May 9-10, 2019

Meeting Minutes

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The Board of Scientific Counselors (BSC) convened on May 9-10, 2019, 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.
Robert M. Hauser, Ph.D.
Mark Hayward, Ph.D.
Mary Ellen (Meg) Johantgen, Ph.D., R.N.
Helen G. Levy, Ph.D.
Kristen M. Olson, Ph.D. (present 5/10/19 only)
Andrey Peytchev, Ph.D.
Ninez A. Ponce, M.P.P., Ph.D. (by phone)
Robert Santos, M.A., Urban Institute
Gretchen Van Wye, Ph.D., M.A.

NCHS-CDC Staff

Jennifer Madans, Ph.D.
Gwendolyn Mustaf
Sayeedha Uddin, M.D., M.P.H., Designated Federal Officer, NCHS

General Audience

Bob Anderson, Division of Vital Statistics (DVS)
Cynthia Bush, Classification and Public Health Data Standards (CPHDSS)
Anjani Chandra, Division of Vital Statistics (DVS)
Jim Crower, Division of Analysis and Epidemiology (DAE)
Loraine Escobedo, Division of Vital Statistics (DVS)

Alica Frasier, RTI International
Cordell Golden, DAE
Kevin Heslin, DAE
Rebecca Hines, Office of Planning, Budget, and Legislation (OPBL)
Quinn Hirsch, Office of Management and Budget (OMB)/Office of Information and Regulatory Affairs (OIRA)
Sarah Lessen, Division of Health Interview Statistics (DHIS)
Xianfen Li, DAE
Don Malec, NCHS
Kendra McDow, NCHS
Michelle Oriaku, NCHS
Jennifer Parker, Ph.D., Division of Research and Methodology (DRM)
Jennifer Sayers, DAE
Margo Schwab, OMB
Angel Vahration, DHIS
Lisa Wagner, NCHS/OPBL
Jennifer Welham, ICF
Rashori Zandon, NCHS

List of Abbreviations

ASPE	Assistant Secretary for Planning and Evaluation
BSC	Board of Scientific Counselors
BTTB	Better than the Best
CDC	Centers for Disease Control and Prevention
CDO	Chief Data Officer
CIPSEA	Confidential Information Protection and Statistical Efficiency Act
CMS	Centers for Medicare & Medicaid Services
CPHDSS	Classification and Public Health Data Standards
DEA	Drug Enforcement Administration
DAE	Division of Analysis and Epidemiology
DHANES	Division of Health and Nutrition Examination Surveys
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
ESRD	End-Stage Renal Disease
FSRDC	Federal Statistical Research Data Centers
HCUP	Health Care Cost and Utilization Project
HP	Healthy People
HP2020	Healthy People 2020
HP2030	Healthy People 2030

HUD	Housing and Urban Development
ICD-10	International Classification of Diseases, 10th Revision
KHI	Key Health Indicators
ME/C	Medical examiners and coroners
NCHS	National Center for Health Statistics
NDI	National Death Index
NHANES	National Health and Nutrition Examination Survey
NHCS	National Hospital Care Survey
NHEFS	NHANES I Epidemiologic Follow-up Study
NHIS	National Health Interview Survey
NSDUH	National Survey on Drug Use and Health
NVSS	National Vital Statistics System
NVSS-M-O	NVSS restricted Mortality Data
OIRA	Office of Information and Regulatory Affairs
OMB	Office of Management and Budget
OPBL	Office of Planning, Budget, and Legislation
PCOR	Patient-Centered Outcomes Research
PCORI	Patient-Centered Outcomes Research Initiative
PCORTF	Patient-Centered Outcomes Research Trust Fund
PII	Personally identifiable information
RDC	Research Data Center
SAO	Statistical Agency Official
SSA	Social Security Administration
SSN	Social Security Numbers
TSM	Target-setting method
VA	Veterans Administration
WHO	World Health Organization

Action Steps

- BSC members will contact NCHS with any suggestions of potential candidates for DHANES director.
- BSC members will contact Dr. Arispe with any suggestions for the redesign of Health, US.
- The BSC will provide Dr. Miller with guidance on next steps for the evaluation study of opioid questions.
- NHIS will collect ideas for the bridge analyses and how to document the redesign.
- Future meeting dates for 2019-20: September 5-6, 2019; January 9-10, 2020; May 5-6, 2020; September 17-18, 2020.

Thursday, May 9, 2019

Presenters

Jennifer H. Madans, Ph.D., Acting Director, NCHS
Lisa Mirel, M.S., Chief Special Projects Branch, DAE

Irma Arispe, Ph.D., Director, DAE
David Huang, Ph.D., M.P.H., C.P.H., Chief, Health Promotion Statistics Branch, DAE
Kristen Miller, Ph.D., Director, Collaborating Center for Questionnaire Design and Evaluation
Research, DRM
Susan Queen, Ph.D., Director, Office of Planning, Budget & Legislation
Stephen J. Blumberg, Ph.D., Director, DHIS
Aaron Maitland, Ph.D., Chief, Survey Planning and Special Surveys Branch, DHIS
Sherry Glied, Ph.D., Chair, NHIS KHI Workgroup

Welcome, Introductions, and Call to Order

Linette T. Scott, M.D., M.P.H., Chair, BSC
Sayeedha Uddin, M.D., M.P.H., Designated Federal Officer, NCHS, BSC

Dr. Scott called the meeting to order. She asked BSC members to introduce themselves and state any conflicts of interest. None of the BSC members stated a conflict of interest.

NCHS Update

Jennifer H. Madans, Ph.D., Acting Director, NCHS

Dr. Madans introduced the new members of the BSC: Helen Levy; Andrey Peytchev; Kristen M. Olson (who will join the meeting on May 10); and John R. Lumpkin (who will join at the next meeting). She also recognized the members will be rotating off the BSC, thanked them for their service, and noted how much NCHS has valued their guidance: Timothy J. Beebe; Sherry A. Glied; and Mary Ellen Johantgen. She emphasized that former BSC members will always have a special place at NCHS and may be contacted by NCHS for help in the future.

Budget Update
Since FY2016, the NCHS budget has been stable at $160.4M, but the proposed FY2020 budget is $5.4M less than FY2019. Also, the $155M budget request for FY2020 is from the Evaluation Transfer Fund, which can be changed during the process of negotiations, resulting in a large cut.

Dr. Madans noted that the FY2020 House Appropriations Bill includes $100M for data improvements at CDC.

All NCHS surveys are, to some extent, funded by outside sources (i.e., reimbursable funds), which could disappear. For example, the NSFG is supported by 83% reimbursable funds and 17% core funding.

Program updates
Division of Vital Statistics (DVS)
Every month, DVS releases predicted drug overdose death counts for the prior 12 months. To aid surveillance, these preliminary data are released before the data are complete. Overdose

rates from synthetic drugs (including Fentanyl) continues to increase. Unfortunately, the data lack the necessary specificity to track Fentanyl deaths separately.

In FY2018, DVS received a $2.6M grant from the Patient-Centered Outcomes Research Initiative (PCORI) and a $7.8M grant from the Opioid Response Coordinating Unit. In FY2019, DVS will receive a further $11.5M from the Opioid Response Coordinating Unit. The new opioid funding will be used to improve the mortality infrastructure of state vital statistics programs, expand state-level interoperability, upgrade IT infrastructure at NCHS, and support efforts to improve timely reporting of overdose deaths.

National Health Interview Survey (NHIS)
The redesigned NHIS has gone very well.

This morning, NCHS released a health insurance update based on the 2018 NHIS: the uninsured population increased from 29.3M in 2017 to 30.4M in 2018; and the percentage covered by a high-deductible plan increased from 44% to 46%.

Division of Health Care Statistics (DHCS)
DHCS has two top priorities: increasing participation of hospitals in the National Hospital Care Survey and developing the infrastructure by which EHR data are submitted to NCHS. Direct messaging for submission of EHR data is now operational. NCHS has certified 60 products for transmission of EHR data from vendors/hospitals to NCHS. DHCS has registered over 180,000 professionals/clinicians and 1,100 hospitals.

National Health and Nutrition Examination Survey (NHANES)
The Division of Health and Nutrition Examination Surveys (DHANES) director, Kathryn Porter, will retire on September 1st. NCHS is currently recruiting for a new director. BSC members will contact NCHS with any ideas of potential candidates.

NHANES recently solicited a contract to improve methods and response rates. NCHS has multiple nonresponse bias analysis projects in progress. Given that the contract for NHANES must be rebid, it is a good time to consider redesign. Planning for NHANES 2021-22 would normally be starting now, but NCHS is considering whether to conserve some budget and staff time for developmental work. Currently, NHANES is in the early stages of exploring the feasibility of a closer connection to the NHIS. One key concern is that the NHANES sample is highly clustered (only 15 locations within the US). If there is a change to the design of the NHANES, NCHS places a high priority on preserving the ability to estimate consistent trends.

This year NHANES is also piloting several new strategies: staggered incentives at different stages of screening; using social media advertisements to enhance participant engagement; and evaluating the feasibility and acceptability of infant (age < 2) blood collection.

A couple weeks ago, NHANES released data on dental fluorosis (i.e., alteration of the tooth enamel from early childhood exposure to dietary fluoride), which is assessed subjectively by a dentist in the Mobile Examination Center. NHANES generally prefers objective, quantitative, standardized measures. DHANES has long been concerned about the quality of these assessments. NHANES included a data quality report with this data release. Reliability statistics, based on comparisons of results from duplicate exams on the same individuals, indicate moderate to near perfect agreement, but there was variability over time. Current understanding of the biology argues that fluorosis is determined before the teeth emerge and should not change over one's lifespan. Yet, synthetic cohort analysis of NHANES data indicated prevalence of 9.5% in youth aged 6-9 in 2001-04 that increased to 46.9% among youth aged 16-19 in 2011-14 (i.e., representing the same birth cohort). This large, unexpected increase suggests data quality problems, and, DHANES has warned users about the data quality issues. DHANES stopped including fluorosis assessment in the survey after 2016 until a more precise method for measuring fluorosis is developed.

Division of Research & Methodology (DRM)
Peter Meyer retired as director of the Research Data Center (RDC), and Neil Russell became the new director in January. The NCHS RDC remote submission system was retired in April 2019; it is time to design a new one. In FY2020, the Census will implement a new cost model for access to the Federal Statistical Research Data Centers (FSRDCs), which will impose additional costs on NCHS.

The Collaborating Center for Questionnaire Design and Evaluation Research within the DRM is currently conducting evaluations of questions related to opioids, disability, selected questions for NHIS (e.g., adult health behavior & screening; children's health behavior), and other topics (e.g., gig employment).

Division Analysis and Epidemiology (DAE)
DAE is redesigning Health, US. The 2018 printed report was shorter than in the past (with detailed tables only available as an on-line supplement), allowing staff more time to focus on redesign activities. BSC members should contact Dr. Arispe with any ideas regarding Health, US. NCHS also released a spotlight infographic on racial and ethnic disparities in heart disease in April.

Healthy People
The Department of Health and Human Services received 1,732 public comments on the core objectives and 327 comments on developmental and research objectives for Healthy People 2030 (HP2030). After Department clearance the plan is to release the finalized data for HP 2020 and launch HP 2030 in early 2020.

NCHS Publications and Media Exposure
Since the last meeting, NCHS has released 26 new publications. Upcoming NCHS Data Briefs will focus on prescription drugs and dental care/coverage. Recent reports that received

considerable media attention included reports on dementia deaths and insurance rates and a study on Fentanyl.

Update on the Release of Linked Data Files

Lisa Mirel, M.S., Chief Data Linkage Methodology and Analysis Branch, Division of Analysis and Epidemiology (DAE)
Irma Arispe, Ph.D., Director, DAE

The NCHS Data Linkage Program aims to standardize the algorithms that link NCHS's health surveys with vital statistics and administrative records. As Ms. Mirel explained, DAE devotes a lot of effort to evaluating data quality and documenting the process for linking those data. Advantages of data linkage include: augmenting the information available (e.g., allowing for associations between survey data and vital statistics); providing detailed information that is difficult to collect via surveys (e.g., health care utilization); and reducing the cost burden of conducting longitudinal follow-up surveys.

There are two main types of NCHS Data Linkages: contextual data that uses geo-coded addresses of survey respondents linked to area data; and individual-level survey data linkage with administrative records (e.g., Medicare). Research using NCHS linked data has covered various substantive topics (e.g., health services utilization and costs, disability, mortality disparities by race/ethnicity). DAE also uses the linked data for methodological studies (e.g., validation of self-reports against administrative records).

The history of NCHS data linkage began in the 1980s when NCHS linked the NHANES I Epidemiologic Follow-up Study (NHEFS) with death certificates obtained from states and Medicare records. Since then, NCHS has expanded linkages to include other NCHS surveys (e.g., NHIS) and other administration sources (e.g., Social Security Administration (SSA); End-Stage Renal Disease (ESRD); Housing and Urban Development (HUD)). Currently, DAE is discussion with the Veterans Administration (VA) to explore the potential for linkage to VA data.

Data from NCHS survey participants are currently linked with various other data sources (i.e., up to 30 years of follow-up for the NDI; up to 25 years of follow-up for Medicare/Medicaid; up to 15 years of follow-up for HUD; up to 20 years of follow-up for SSA). NCHS has disseminated numerous linked products, and results based on linked products have been published in many high-profile journals.

DAE is currently focused on improving linkage algorithms. In the past, DAE used deterministic matching based on personally identifiable information (PII). Given recent limitations in the collection of PII (e.g., only the last 4 digits of the social security number (SSN), exclusion of the individual's name), DAE staff are beginning to use more probabilistic techniques and machine learning. DAE has developed good matching algorithms even when a SSN is missing.

The linked mortality file is the only linked file available online as public-use microdata. To protect against disclosure that file is limited to adults, includes only selected causes of death, and some of the records are perturbed. However, data for all NCHS data linkages are available through the RDC. In addition, NCHS provides public-use feasibility files for Centers for Medicare & Medicaid Services (CMS) and SSA to help users determine potential sample size before they apply for access via the RDC.

DAE is updating the linked data more frequently (every 2-3 years) and developing a schedule for updates on a recurrent basis so that researchers can anticipate the availability for their research proposals. In conjunction with DHCS, DAE linked the National Hospital Care Survey (NHCS) data with NDI and CMS records as part of the Patient-Centered Outcomes Research Trust Fund (PCORTF) 2017 project. Additionally, DAE received PCORTF funding for 2019 to link NHCS with HUD and CMS data.

Dr. Arispe emphasized the need to balance opportunities (e.g., increased interest) with challenges (e.g., disclosure risk). The Foundations for Evidence-Based Policymaking Act of 2019 is likely to increase data use for policy making because it mandates that agencies proactively identify policy and evaluation questions and integrate them into their strategic plans. The act will also increase the number of statistical officials, increase access to CIPSEA (Confidential Information Protection and Statistical Efficiency Act) data, and expand the need to provide data to qualified users. When partnering with non-statistical agencies, NCHS needs to manage others' expectations about what is possible within the constraints of the law.

Providing more public-use files is one way of increasing data access, but NCHS must carefully assess disclosure risk. In some cases, the best approach may be to develop synthetic public-use micro data files that are still analytically useful and valid.

Discussion/Reaction by the Board
Discussion focused on efforts to protect confidentiality. One participant asked how linked datasets are screened prior to release. Ms. Mirel reiterated that most linked data are available only within the RDC, and applicants must complete a disclosure review process. For the public-use linked mortality file, the Data Linkage Program uses statistical matching to inform decisions about the degree of perturbation needed to protect confidentiality. Someone else asked whether DAE had considered producing synthetic administrative data. Ms. Mirel replied that they are currently exploring that possibility. Another participant asked if they used the same level of confidentiality protection for deceased individuals as for those still living. Yes; that is why they perturb the data in the public-use mortality microdata file.

Questions raised during the discussion centered on established guidance for de-identification, cost considerations, deciding which data will be linked, and how data sharing agreements are established.

One participant asked whether the 2005 statistical policy working paper that focused on data de-identification had been updated. The Federal Committee on Statistical Methodology is currently working on two major reports (i.e., an update to 2005 working paper and a report on evaluating the quality of blended data). Also, a new Committee on National Statistics panel related to transparency and reproducibility will start in May.

Cost considerations are important because NCHS must balance devoting more funds to expanding access versus collecting more data. NCHS welcomes advice from the BSC regarding how to balance these competing priorities. Using the linked data imposes a learning cost on new users; how can NCHS encourage more people to make that investment? Is it better to have more frequent updates or to link to more data sources? NCHS also needs help from the research community to understand what questions are of greatest interest. Someone asked if NCHS charges for the linked data: public-use files are free, but there are fees associated with use of the RDCs.

Regarding decisions about which data should be linked, someone asked if NCHS has any interest in linking (retroactively) to the (earlier) census files? There are no plans to link survey data with census data. Census data are linked to the NDI. Another participant asked how NCHS adjudicates potential requests for data linkage. Dr. Arispe explained that it has been opportunistic up to this point, but if this law [Foundations for Evidence-Based Policy Act of 2019] generates more interest in linked data, then DAE will need advice from the BSC about the criteria used to make those decisions. Dr. Madans noted that NCHS does not link to state-based data because of the complications

Someone suggested that NCHS share their process for establishing data sharing agreements. Others would find it helpful to know how NCHS obtains consent for linkage and negotiates different rules for each program to which data are linked.

Healthy People 2030 (HP2030) Target Setting--Tentative

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

Dr. Arispe began by overviewing the role of NCHS in Healthy People (HP). This 40-year partnership has benefited both parties. HP benefits from the statistical/methodological expertise and data curation provided by NCHS. NCHS benefits from increased exposure across the federal government and from opportunities to gain expertise across a variety of data systems, help harmonize measures, and obtain broader exposure to policy perspectives.

Today's presentation focuses on one aspect of that process: target setting. The inclusion of quantifiable targets is what distinguishes HP from other national monitoring efforts. These targets communicate policy expectations to the world and serve as markers for assessing progress. The targets are set by topic area work groups that comprise agency representatives and policy/subject matter experts. NCHS provides technical assistance on statistical matters and

promotes consistency in the target setting methods (TSMs), but does not to directly influence which targets are specified.

Dr. Huang explained how the TSMs have evolved over time. In the 1990s, objectives were predominately based on expert opinion. Over the subsequent decades, TSMs became more systematic and HP added an overarching goal of reducing health disparities. In the 2010s, they developed the Better than the Best (BTTB) TSM (i.e., a single target for population-based objectives that is one unit better than the rate of the best racial/ethnic group). HP2020 continued to use more systematic TSMs and reflected a desire for more realistic targets.

HP2030 aims for a more transparent, systematic approach that can be replicated at the state and local levels. Targets are intended to be challenging, yet achievable and should represent a statistically significant improvement from baseline. NCHS uses a flowchart to recommend which of four TSMs is preferred. The work group can deviate from those recommendations, but all targets must be justified. To facilitate transparency, HP2030 will share publicly those justifications. DAE is currently working on a publication (forthcoming in the next year or two) to document their process for target setting.

Dr. Huang closed by reviewing the timeline for HP. In September-December 2019, they will finalize the data from HP2020. In early 2020, they will close out HP2020 and launch HP2030. The HP2020 Final Review will be released in the fall of 2021.

Discussion/Reaction by the Board
The discussion focused on the nature of TSMs, efforts to document those TSMs, and the value of target setting.

In the 2010s, the nature of TSMs shifted from reducing health disparities to eliminating health disparities. The BTTB method is intended to help ensure improvement among all subgroups. One participant noted that it is possible to obtain independent views when soliciting expert opinion, whereas the shift to workgroups means that viewpoints are no longer independent. This person questioned whether NCHS has a means of assessing the reliability of the target setting process. Dr. Huang noted that in the past, there was no requirement that the targets be justified. A new requirement to provide these justifications for HP2030 will help to make to process more transparent. The questioner countered that transparency is not the same as reliability. Dr. Arispe explained that in an initiative of this size, it is not feasible to evaluate the reliability of the target setting process. Thus, they focus on making the process more explicit.

A participant expressed great appreciation for NCHS's efforts to document the TSMs. Another person appreciated that the objectives are quantitative, but noted that, for continuous measures, it would be useful to know more than simply whether or not the target was met, but by how much.

There was a lengthy discussion of the value of target setting. One person wondered if we are putting more effort into the target setting process than is warranted given how the objectives

are used. Other participants supported the value of the target setting process, pointing out that funding is often tied to reaching those targets. Another participant noted that including some difficult to attain goals can pique the interest of policy makers, but asked what is lost if the target is not met? A consequence of setting an unrealistic target is losing the respect of the public. Staff reiterated that NCHS does not try to influence which targets are chosen. Part of the reason for the BTTB method was to encourage ambitious targets. Someone else noted that there is a tendency to assume problems relate to national-level factors, but contributing factors often vary geographically, partly due to state-level policies. HP can help set federal priorities, but also serves a leadership role (i.e., encouraging states to endorse and promote these goals).

Evaluation Study of OPIOD Questions

Kristen Miller, Ph.D., Director, Collaborating Center for Questionnaire Design and Evaluation Research, DRM

At the June 2018 BSC meeting, Dr. Miller outlined the plans for this project; today she presents the results. She acknowledged that they are not sure what to do with these results and could use advice from the BSC to decide on the next steps. As part of the Opioid Comparative Cognitive Interviewing Study, they completed 140 interviews in English and are finishing up another 40 interviewers in Spanish. The sample represented locations across the country and was diverse with respect to opioid usage. A main goal of this study was to determine whether the questions are capturing the information as intended. For basic use, they compared two questions. The first (from the NHIS) included the term "opioid" and produced 13 errors (out of 140 interviews), whereas the second question (from the National Survey on Drug Use and Health, NSDUH) did not use the term "opioid" (but rather showed pictures of pain relievers with the names of those drugs) and yielded 8 errors (out of 140). For the NHIS question, false positives resulted because the respondent thought their medication was an opioid, whereas false negatives occurred because the respondent did not realize the medication was opioid, s/he had a limited view of what is included in the category of opioids, or s/he forgot about having taking an opioid months earlier. For the NSDUH question, false negatives resulted because the respondent did not know the name of their opioid, while false positive resulted because s/he misidentified their medication. Neither question dramatically outperformed the other, although the NHIS question generated more false negatives.

Questions about the misuse of opioids (from NSDUH), yielded 42 "yes" responses and 72 "no" responses, at least 13 of which represented false-negatives. They suspect there were additional false negatives and thus, have a serious concern about underestimation. Errors resulted primarily because respondents do not believe their behavior constitutes abuse/addiction (i.e., I am a responsible user). Based on the results, Dr. Miller proposed dividing the current question into two questions. The first would ask, "Did you ever take the medication more frequently or in higher doses than was prescribed?" The follow-up question would be, "Have you ever taken someone else's opioid medication, that is, pain relievers not prescribed to you by your doctor?"

Questions about opioid-related disorders were viewed by respondents as asking about addiction. Respondents had difficulty establishing causality (e.g., could not say whether the reason they are spending less time with family is because of opioid use). Dr. Miller concluded that these questions must be reconsidered and questioned whether it is feasible to obtain accurate reports to such questions in a population-based survey.

Dr. Miller argued that responses to the opioid questions are shaped by the respondents' understanding of themselves and depend on their social context (e.g., what they have heard about opioids and the epidemic; if they know anyone affected by the epidemic).

Dr. Miller closed by outlining their planned next steps: complete interviews in Spanish; continue analysis and report the results; begin cognitive interviewing work on revised questions; and evaluate validity of the questions. Her ultimate goal is to develop a standardized, validated set of opioid-related survey questions.

Discussion/Reaction by the Board
The discussion focused primarily on problems with these questions and suggestions for improving reporting. Participants were troubled by the findings regarding responses to the misuse and disorder questions. One person suggested that instead of asking about "abuse" or "misuse" at the start, it might be better to first ask about the respondents' pain and what they did to relieve it. Then, much later, the survey could ask whether or not those medications were prescribed by a doctor. Another participant suggested that mode of survey (i.e., self-administered vs. interview) might have an effect. Someone else reported that they have some experimental data regarding the effects of survey mode on responses to drug use questions and will share those results with Dr. Miller. Dr. Miller acknowledged that she does not know whether breaking apart the misuse question will improve accuracy; it is possible that respondents will still make rationalizations to avoid viewing their behavior as "misuse."

Update on Evidence Based Policy Making
Susan Queen, Ph.D., Director, Office of Planning, Budget & Legislation

The Evidence-Based Policymaking Commission report (released in September 2017) recommended strengthening federal evidence-building capacity, improving data access, and enhancing privacy protections. The Foundations for Evidence-Based Policymaking Act was signed into law on January 14, 2019.

Title I of this act requires that agencies develop evidence-building plans with respect to statistical activities. It also establishes agency evaluation officers, a statistical agency official, and an advisory committee that will make federal-level recommendations.

Title II dictates that data must be open by default and requires each agency to develop a comprehensive data inventory. Those inventories will become part of a Federal Data Catalogue,

which will serve as a single public interface. The catalogue does not require that all data be made publicly available, but it must include information about all data assets. The problem is that the act uses a very broad definition of data (i.e., any recorded information regardless of format).

Title III repeals and re-codifies what we know as CIPSEA. New elements include a definition of what constitutes "evidence" and the presumption of data accessibility (i.e., data requested for evidence-building must be provided unless prohibited by statute). In addition, statistical agencies will be required to make comprehensive risk assessments explaining why particular data are, or are not, public.

Title IV (General Provisions) stipulates that no new funding will be provided to meet the requirements of this act; agencies must use existing budget and employees. On April 24, 2019, the acting director of OMB issued a memo that represents the first step in implementing this act.

Discussion/Reaction by the Board
There was brief discussion of the implications of this act for NCHS. One participant noted that although the Commission was not allowed to recommend additional funding, many commissioners felt the work could not be accomplished without more money. This act will require that NCHS think more carefully about how data are made available. For example, will NCHS need to create public versions of confidential data sources in order to meet the requirements?

NHIS Redesign Update

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

Dr. Blumberg reviewed the reasons for redesigning the NHIS (i.e., need to reconsider content because last major redesign was in 1997; concerns about increasing respondent burden and declining response rates). Between 2006 and 2017, the average length of the NHIS interview grew from about 60 to 90 minutes, but NHIS staff noticed that response rates appeared to be somewhat higher in years when the interview was a little shorter. The main goals of the redesign were to improve the relevance of covered health topics, harmonize overlapping content with other federal health surveys, reduce respondent burden, and eliminate redundancies. The redesign reduced interview length by rotating content. NHIS also eliminated the family module (i.e., information collected for all family members); now NHIS randomly selects one adult and one child from each household.

Dr. Maitland outlined the progress made since September 2018. Data collection with the redesigned instrument began in January 2019. In addition to reducing both mean and median interview length to less than 60 minutes, the redesign has resulted in fewer refusals,

particularly those mentioning time constraints; subjective perceptions of burden have improved; and sample adult response rates have increased. In April 2019, they began experimenting with a redesigned advance letter; those results will be reported at the next BSC meeting.

Next steps include continuing analysis of the bridge samples (i.e., differences in estimates from old vs. the new design) and documenting the process of redesigning NHIS and its impact. Dr. Maitland noted that they welcome ideas from BSC members for the bridge analyses and how to document the redesign.

Dr. Blumberg highlighted other redesign activities such as implementing new technologies to manage data and metadata. They are also working to identify recodes and composite variable to be added to the data file. Historically, NHIS data files have not included many recodes, but instead left it to the data analyst to decide how to use the raw data. In response to user complaints about the burden of merging together multiple files, NHIS is trying to reduce number of data files. NHIS staff are also evaluating disclosure risk and tradeoffs to decide how much detail can be included on public-use files. They are building a data visualization system for summary health statistics, to replace the 126 page PDF tables produced currently. Finally, they are redesigning the early release (ER) reports and working on nonresponse bias analyses.

Discussion/Reaction by the Board
The discussion focused on several themes: efforts to ease use of NHIS and encourage user engagement in improvements, plans for non-response bias analysis, and consequences of the redesign.

One person applauded the efforts to ease data use, noting that it may reduce misuse. Several people endorsed making the bridge data (i.e., old versus new) available as a public-use file, which may encourage users to help with analyzing and enhancing comparability.

Another person asked whether NHIS is planning to do non-response bias analyses like those presented at earlier meetings for NHANES. Dr. Blumberg confirmed that they plan to assess many of those same research questions, but they also have a contract to ICF to do a more in-depth non-response analysis that will incorporate machine learning. NCHS just received the first deliverable this week; the BSC can expect to hear more about the results at the August meeting, which will also be shared publicly.

With respect to the impact of the redesign, one person noted that current response rates for the redesigned NHIS are comparable with 2012-13 response rates and wondered whether we should expect response rates to continue further decline? Dr. Blumberg suspects that response rates will continue to decline, but hopes they will not have to cut another 40% of content in 5 years in order to raise response rates. One participant questioned the implications of dropping the family module. Specifically, using historical data, would NHIS obtain the same estimate of health insurance coverage if they used weighted data for sample adults only? Yes, NHIS staff have tested that and will continue to test such reliability.

NHIS Redesign Key Health Indicators (KHI) Workgroup Report

Sherry Glied, Ph.D., Chair, NHIS KHI Workgroup

The purpose of the key health indicators (KHI), which are released as part of the ER program, is to allow more timely tracking of trends. Because of the NHIS redesign, the KHI had to be reconsidered because some of the previous indicators were eliminated or became rotating content. The main goal of the workgroup was to prioritize indicators. Dr. Glied reiterated that all NHIS data get released; the question is what information will be released early? The workgroup considered various criteria for selecting indicators: sensitivity to policy, timeliness, consistency over time, reliability, representativeness of the issue, parsimony, and seasonal variation.

Selection of Indicators: Dr. Glied highlighted indicators that were selected by five or more workgroup participants (e.g., cigarette smoking; see p. 3 of the associated summary for the complete list). She also listed additional indicators that were selected by fewer than five participants (see pp. 3-4 of associated summary). They purposefully tried to avoid questions pertaining to prevalence (i.e., "ever…") because prevalence is not likely to change much from one quarter to the next.

Potential Covariates: The workgroup concluded that the following covariates should be included: education, age, sex, race and Hispanic origin, metropolitan statistical area status, and nativity/citizenship status.

Periodicity: The consensus of the workgroup was that periodicity should be determined based on sample size and which estimates are deemed most "meaningful." For example, because of sample size concerns, it might be better to provide semi-annual estimates for subgroups. They also recommended providing quarterly national estimates (rather than cumulative estimates for the entire year as they currently do).

Type of Statistics to be Included: The workgroup recommends providing unadjusted six-month estimates for the public health dashboard, but annual NHIS results should use seasonally adjusted estimates. When available, separate estimates should be provided for adults and children.

Process for Making Future Changes: The workgroup advocates that NCHS: 1) use the web interface to solicit user suggestions; 2) analyze metrics from the website (i.e., which indicators are people using most?); 3) regularly assess the usefulness of the KHI ER report for CDC policy priorities; and 4) add review of ER indicators as a regular agenda item for future BSC meetings**.**

Discussion/Reaction by the Board
The discussion focused on questions related to specific indicators and the BSC voted on whether to forward the findings of the workgroup as recommendations to NCHS.

Questions were raised regarding selected indicators. First, someone asked about the selection of disability rather than self-reported health status. Dr. Glied noted that the workgroup felt disability to be a better measure of health than self-reported health. Someone else noted that although self-reported health status may be a good predictor of survival at the end of life, it changes very little over time at the population level; functional limitations is a better indicator of changes over time in health. Second, a participant expressed concerns about cigarettes and electronic cigarettes as indicators because the official estimates of prevalence are based on the tobacco surveys; we should avoid creating competing estimates. Workgroup members felt that was a detail that NCHS should sort out and reiterated that NCHS is not obliged to accept the recommendations of the BSC. Third, some concerns were raised regarding the mental health questions. The workgroup recognized that that there were tradeoffs because some items are from the rotating core and other questions may be less sensitive to change over time. Someone noted that mental health disorders are most common among the population not covered by the survey (e.g., institutionalized, homeless); is that a concern? Dr. Glied countered that the selected questions cover general disorders experienced by a large segment of the population rather than rare mental health disorders.

Dr. Scott thanked the workgroup and their efficiency in completing the task in only one meeting. This is an important first step, but the issue will need to be revisited once data from the redesign become available. In December 2019, NHIS plans to release the first national estimates from the redesigned survey.

Actions
Dr. Scott moved that the BSC forward the summary to NCHS and express their support for the workgroup's findings and action items. The BSC voted unanimously in support.

The meeting adjourned for the day at 5:00 p.m.

Friday, May 10, 2019

Presenters
Bob Anderson, Ph.D., Chief, Mortality Statistics Branch, DVS
Kate Brett, Ph.D., DVS
Carol DeFrances, Ph.D., Chief, Ambulatory and Hospital Care Statistics Branch, DHCS

Call to Order
Linette T. Scott, M.D., M.P.H., Chair, BSC

Dr. Scott opened day two of the meeting and welcomed new member, Dr. Olson. She asked all BSC member to re-introduce themselves and restate their conflicts of interest.

Maternal Mortality Data Update

Bob Anderson, Ph.D., Chief, Mortality Statistics Branch, DVS

Dr. Madans introduced the topic by noting that final mortality data are usually released at the end of November each year. Thus, NCHS must start planning now for the release of the 2018 mortality data.

Dr. Anderson reviewed the Vital Statistics Cooperative Program, which comprises a federal-state contractual arrangement with 50 states, New York City, the District of Columbia, and five US territories. States collect the data and then provide those data to NCHS.

Measurement of Maternal Mortality in the U.S.
NCHS follows the World Health Organization (WHO) definition of maternal death (i.e., the death of woman while pregnant or within 42 days of termination of pregnancy from any cause related to or aggravated by pregnancy, which includes both direct and indirect maternal conditions, but does not include deaths from incidental causes). The definition of late maternal death is essentially the same, but includes deaths occurring 43 days to one year after the end of pregnancy. All these deaths are coded to chapter XV (conditions related to Pregnancy, Childbirth and the Puerperium, i.e. O-codes) of the International Classification of Diseases, 10th Revision (ICD-10). Another common definition used by CDC in the Division of Reproductive Health's Pregnancy Mortality Surveillance System (PMSS) is pregnancy-related death which combines maternal and late maternal deaths.

Research has shown that the National Vital Statistics System (NVSS) has long underreported maternal mortality. To improve reporting, some states introduced a pregnancy checkbox on the death certificate, but the format was not standard across states. The 2003 revision of the US Standard Death Certificate added a pregnancy checkbox in the hopes of solving the underreporting problem. Only five jurisdictions had a pregnancy checkbox that was consistent with the standard in 2003. It was 2017 before 49 states had implemented the new standard certificate; California's pregnancy checkbox still does not conform.

Current coding rules require that the cause of death be assigned to an appropriate ICD-10 O-code from Chapter XV (conditions related to Pregnancy, Childbirth and the Puerperium) if there is any indication of pregnancy. This indication can be a cause of death specific to pregnancy, i.e., a pregnancy-related term in the COD fields, or solely a response in the pregnancy checkbox item indicating that the woman was pregnant at death or within the past year. The WHO definition stipulates that deaths from incidental causes should be excluded, but WHO does not define which causes are "incidental" except for injury-related causes. Coders are not qualified to make a judgement about whether the death is incidental, especially given the limited information reported on death certificates, so all deaths from medical conditions are assigned an O-code if pregnancy is indicated. This practice of assigning all medical conditions a maternal code has another unintended consequence of blocking the selection of an external cause as the underlying cause when there are medical terms listed among the multiple causes of death. Additionally, not all medical conditions have specific codes within the O chapter. So assignment of causes of death to maternal condition codes often results in a loss of information because an

underlying cause of death that otherwise would have been assigned to a specific code in a different ICD-10 chapter may be coded to a less specific O-code (e.g., O26.8, O99.8). In sum, the unintended consequences of the current coding procedure itself are: sometimes the selected underlying cause does not reflect the disease process or actual underlying cause; some deaths from causes that might be incidental are incorrectly coded as maternal; many specific conditions are coded to ill-defined O-codes and some deaths due to external causes were coded as maternal (NCHS has recently addressed this issue).

Research has also revealed various errors resulting from incorrect use of the pregnancy checkbox (i.e., some maternal deaths are missed, while other non-maternal deaths are misclassified as maternal). It is not clear why the errors occur; it could simply represent random error in selecting the appropriate pregnancy status category. The Division of Reproductive Health at CDC is currently conducting a study of the error patterns, which NCHS hopes will be published this summer so DVS can use it to develop a new coding algorithm. Research has shown that most of the errors where a non-maternal death was misclassified as maternal were noted among deaths of older women (age > 40). This could simply reflect the fact that most deaths occur at older ages. If the selection of the wrong pregnancy status category was random, about 70% of the errors would occur above age 40. The net result is that maternal deaths are currently being overestimated by about 15%, although the magnitude of over-reporting probably varies by state (e.g., a recent study by the Texas Department of Health suggested that maternal mortality was overreported by 50%).

Proposed Changes to Address Errors from Incorrect Use of the Pregnancy Checkbox Item and Consequences of Current Maternal Death Coding Rules
Trends in maternal mortality (based on current coding rules) suggest that rates more than doubled between 1999 and 2017; NCHS believes this increase is mostly a statistical artifact resulting from incremental implementation of the standard pregnancy checkbox. Because of concerns about the accuracy of the estimates, NCHS stopped publishing these data after 2007.

Beginning with data for 2018, DVS proposes the following changes in the coding procedure for maternal deaths: 1) in checkbox-only cases, only the underlying cause will reflect an O-code making it straightforward for analysts to identify checkbox-only cases; 2) further restricting the application of the checkbox by lowering the upper limit of the age range from 54 to 40 or 44 (pending results from the study by the Division of Reproductive Health before deciding). The age restriction will affect only the checkbox-only cases; if an obstetric condition is mentioned elsewhere on the death certificate, it will be coded as maternal death regardless of the age of the women; and 3) adding an extra digit that will indicate which code would have been assigned as the underlying cause of death if there had not been a checkbox.

DVS is currently preparing a report on the effect of the pregnancy checkbox on the 2015-16 data. When they release the final 2018 mortality data—with maternal deaths coded according to the new methodology—DVS will also publish a report explaining the new methodology.

DVS is also working with the Council of State and Territorial Epidemiologists, which formed a workgroup on maternal mortality. The goal is to publish a reference guide for certifying deaths associated with pregnancy, similar to the reference guides for drug overdoses and disaster-related deaths.

Dr. Anderson acknowledged that the proposed changes are only a short-term solution. In the long-term, efforts are needed to investigate all deaths to women of reproductive age (e.g., linkages to birth and fetal death records to verify pregnancy; review of medical records to determine whether pregnancy was a factor in the woman's death). It would be better to have experts making those determinations rather than relying on the coder to deduce whether a cause was incidental. The biggest challenge is that information from such investigations must be reported in a timely fashion if it is to be reflected in the national statistics.

With the 2018 data release, DVS will resume publication of the national maternal mortality rate both with and without the information from the pregnancy status checkbox using the new coding rules for maternal deaths noted earlier. The organization of the multiple cause of death fields will be modified to maximize the flexibility for analysis in dealing with checkbox-only cases. Recoding has been completed for 2015-16, and they plan to recode data for 2003-14 and 2017 in the same manner. Their goals are to increase the availability of trend data and to evaluate the addition of the checkbox.

Discussion/Reaction by the Board
Issues raised during the discussion included questions about the checkbox, methods for improving estimates, and the comparability of estimates across countries and subgroups.

Regarding the pregnancy checkbox, results using data from the National Hospital Care Survey linked with death records to compare information from the death certificate against hospital records suggested that there were more false positives (i.e., non-maternal death coded as maternal death) than false negatives. Recoding maternal deaths as if there were no checkbox will provide a consistent trendline, but maternal deaths will be underreported. A question was asked regarding how the presence of the checkbox influences other information that is reported on the death certificate. Dr. Anderson acknowledged that it is probably not completely independent. Kentucky experimented with a checkbox for diabetes and found that it reduced the number of deaths coded to diabetes as the underlying cause because certifiers thought if they checked the box, then they did not need to record it in the cause of death section.

Discussion ensued regarding possible ways of correcting the data such as linking to EHR, Medicare, Medicaid, and/or Health Care Cost and Utilization Project (HCUP) data. While any solutions must be timely, these options present opportunities for improving data quality. Some states investigate maternal deaths, but the results do not get recorded on the death certificate. DVS is trying to establish collaborations with those states so the data can be corrected. A participant asked how much of a delay there is in receiving determinations from maternal

review committees. Most committees take years to resolve these cases; it cannot be a viable solution unless it becomes a lot more efficient. Currently, the system for electronically entering death certificate data only helps correct spelling, but it may be possible to adapt that system to query the certifier to ensure s/he really meant to choose a positive pregnancy status response to the pregnancy checkbox. This option might have the most immediate impact. In theory, an entirely separate system could be created to track maternal mortality, but it would be very expensive. It is cheaper and more efficient to do it via the vital statistics system. Other participants noted that DVS is currently focusing on corrections on the measurement side, but they could make post-hoc adjustments (e.g., using modeling). Dr. Anderson pointed to the problem of transparency; if DVS were to use a complex model, it becomes difficult for others to determine what DVS did and to be able to reproduce the data. There are approximately 700 maternal deaths a year; thus, it represents a small but important number. With the 2018 data release, DVS will include a separate report on maternal mortality to highlight the quality profile of the available data. Unfortunately, the coding process is so complicated that it will be difficult to communicate it to the public. If we want to include maternal mortality with the final 2018 death data, NCHS must make decisions now. The BSC agreed with the approach outlined by Dr. Anderson, but cautioned that the documentation should clearly explain what adjustments were made.

Finally, someone asked about the comparability of US maternal mortality rates with those reported in other countries and between subgroups. Dr. Anderson explained that European countries follow the WHO definition and use the same coding rules as the US, but most do not have a pregnancy checkbox. They do use linkages to check for pregnancy, but these countries generally have fewer deaths and smaller, centralized systems. He does not believe coding varies by population subgroups, but differences in age composition and state-level coding variation could affect subgroup disparities.

Wrap-up by Dr. Madans

Dr. Madans expressed her regrets that she must leave the meeting early. She thanked all the BSC members, including those leaving and those joining the board.

PCORTF Projects Update: Coding Drugs From Mortality Literal Text Fields

Kate Brett, Ph.D., Division of Vital Statistics

Dr. Brett reviewed the formal recommendations from the BSC focused on coding drugs from literal text on the death certificate and presented NCHS's response to those recommendations. The first recommendation was to create a supplement that maps to the ICD-10 coding scheme to capture more diverse kinds of information. DVS hopes to map to various systems (including ICD-10) currently being used in drug research. DVS aims to develop a standardized classification scheme for its own use as well as linkages to other schemes.

Secondly, the workgroup concluded that researchers want as much detail as possible, but the information should be useful and pertinent to the cause of death. Researchers also want to

know where on the death certificate it comes from. DVS aims to maintain detail, but will ensure it includes only drugs associated with death. In addition, DVS will link those drugs to the location on the death certificate.

Third, the workgroup recommended that the system is quickly adaptable. DVS plans to update the drug coding system regularly using curated source materials (e.g., National Library of Medicine, Department of Justice). Furthermore, they aim to use continuous training of machine learning to identify new drugs.

The fourth recommendation was that the NCHS list of drugs should be anchored in some standardized reference system. DVS will use data from RxNorm for pharmaceutically manufactured drugs and the Department of Justice on seized scheduled illicitly manufactured drugs.

The final recommendation is that users need to know how to ask questions about the data to ensure their analyses are appropriate and reasonable. DVS is not sure how to accomplish that goal and will bring this issue to the next workgroup meeting for further discussion. For example, how should DVS document the data? Is there a need for webinars or other training opportunities?

Use of Literal Text in Death Certificate Data

Bob Anderson, Ph.D., Chief, Mortality Statistics Branch, DVS

The original text is reported by the cause of death certifier on the death certificate in Part I, Part II, and the "describe how injury occurred" box. Dr. Anderson noted that DVS has used the literal text to check suspected coding errors and to better understand cause of death determination.

NCHS began collecting literal text from all states in 2003, but did not begin using this information to review potential coding errors until 2005. In 2007, NCHS decided to release the literal text to federal agencies under a data use agreement and to others through the RDC. Unfortunately, in 2010 they discovered the existence of some personal identifiers in the literal text field and consequently, and restricted data access to in-house staff until that issue could be resolved.

Currently, DVS is planning to use literal text not only to identify specific drugs but also emerging diseases (e.g., new flu variants). They want to make the literal text available to researchers and have nearly completed a redaction effort to remove personal identifiers from the 2016 literal text. As soon as the data are ready, DVS will make them available in the RDC. Then, they will repeat the process for additional data years. DVS hopes to finish redaction of the 2010-17 literal text data by end of 2019.

Discussion/Reaction by the Board

Discussion focused on the prevalence of personal identifiers, the benefits of having NCHS do this work, and the pros and cons of releasing the data publicly.

One participant asked about the prevalence of personal identifiers in these fields. Dr. Anderson explained that the prevalence is low (1 in 10,000) and often entails mention of the decedent's name (e.g., Mr. Smith) or a doctor's name. Despite low prevalence, DVS felt they must address it.

Other discussion related to potential benefits of this project. One person noted that literal text can be used to improve coding; if some external researcher does the work rather than NCHS, then others may not have the opportunity to use it. Someone else asked if this work might encourage certifiers to provide more detailed information in the descriptive fields? Yes, Dr. Anderson expects a feedback effect. There are many questions DVS cannot answer without the literal text.

There was also mention of both pros and cons of releasing the data. One person noted that the literal text will be very valuable to researchers. Furthermore, after the raw data are released, DVS may get feedback from users that could help with quality improvement as well as to monitor the use of literal text information. One potential downside of releasing the data is the risk that users might recode the data in different ways that results in variation in estimates. Dr. Anderson acknowledged that they will have to watch for that problem. There are already some problems with people using different aggregations of the ICD-10 coded data and interpreting those aggregations incorrectly.

PCORTF Projects Update: Enhancing ID of Opioid-involved Health Outcomes Using Linked Hospital Care and Mortality Data

Carol DeFrances, Ph.D., Chief, Ambulatory and Hospital Care Statistics Branch, DHCS

The project was to inform efforts to improve opioid-involved health outcomes by developing enhanced methods that make use of structured and unstructured data from NHCS, the NDI, and the NVSS restricted mortality data (NVSS-M-O) to identify specific opioids. There are four project tasks, but this presentation focuses on the first (now completed) and the second (in progress) tasks.

The first task was to link the 2014 NHCS data with the 2014-15 NDI and NVSS-M-DO (which identifies specific drugs involved in drug overdoses). That file has been created and will soon go into the RDC. These data will allow researchers to determine what happens after a hospitalization and to identify which hospitalizations may have preceded death.

The second task is to develop a methodology to identity opioid-involved encounters. First, DHCS needed a better, more inclusive definition of opioids. DHCS is also including co-occurring

use of stimulants, both prescribed and illicit. They will focus on acute opioid overdose. Opioid-involved hospital encounters will be limited to mentions of opioids used prior to arrival at the hospital. DHCS is developing algorithms to deal with both structured (code-based) and unstructured data (e.g., clinical notes fields). For unstructured data, they will adapt the Drugs Mentioned with Involvement (DMI) program for use with hospital data and employ natural language processing (NLP).

The NLP plan starts with creating a comprehensive list of all opioids and selected stimulants. Then, DHCS will perform initial queries to identify drug mentions, confirm true cases, and annotate the data. The annotated data will be used to train the program to distinguish between true cases and false positives. Some benefits of the NLP approach are that it can efficiently capture relevant data despite misspellings, abbreviations, and colloquialisms; queries can be made more flexible by adding/modifying rules; the computer can be taught to discover new terms and patterns in the data; and it can examine the context surrounding key terms to help eliminate false positives. Some of the challenges include the need to reformat the text data; difficulties installing of Python; and the fact that some hospitals do not indicate when an opioid was used, making it impossible to determine if use occurred pre-hospitalization.

The next steps are to parse out the clinical notes so the DMI program can identify opioid involved encounters; finalize the NLP development plan; harmonize the three methods (coded algorithm, DMI program, and NLP); adapt the algorithms to other substances of interest; merge the datasets and disseminate them; and test a beta version on the hospital report web portal, which they hope will encourage hospital participation. They plan to work with the BSC workgroup on dissemination.

Dr. DeFrances closed by mentioning a new PCORTF-funded project for FY19, which builds on the methods developed in FY18 and includes a validation study of those algorithms.

Discussion/Reaction by the Board
The discussion centered on issues related to the compilation of drug lists, data quality control, terminology, and dissemination.

One Board member asked what sources are used to identify illicit drugs and whether the list represents full coverage. DHCS uses the Drug Enforcement Administration (DEA) list, which includes street names, as well as lists from every other agency that has a list. DHCS believes their list to be exhaustive.

Another BSC member else asked how check data quality is checked. For the FY18 project, data quality control is built into the annotation process. Questionable cases are flagged, and subject matter experts judge whether it is a true case or not and explain why. For the 2019 project, DHCS will be doing a formal validation.

Several participants expressed some concern that unfamiliar terminology and methods with which they have no direct experience (e.g., NLP) make it difficult for them to communicate

about this work. Someone else noted that would be helpful if DHCS could provide concrete examples. Dr. DeFrances noted that they will post to their website the reports they produce that provide examples of this work.

For dissemination, it is important to recognize that there are different kinds of data users. A Board member asked whether DHCS will disseminate the data via a web interface (e.g., Google Trends) that makes it easy for users interested only in descriptive analysis. Dr. DeFrances agreed that it is important to provide more visualizations of the data. DHCS must determine the best way to distribute the data.

Final Wrap-up

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

Dr. Scott expressed her appreciation for everyone's feedback on the presentations and thanked the workgroup on Key Health Indicators, whose work is now complete. We will hear more about the other workgroup at the next BSC meeting.

Public Comment

There was no public comment.

The meeting was adjourned at 11:50 am.

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

_____/s/_____   _____9/5/2019_____
Linette T. Scott, M.D., M.P.H.   DATE
Chair, BSC