

October 20, 2023

The Honorable Bill Cassidy
Ranking Member
Health, Education, Labor, and Pensions (HELP) Committee
United States Senate
Washington, DC 20510

Dear Senator Cassidy,

We appreciate the opportunity to comment in response to your September 26 call for input on the Centers for Disease Control and Prevention (CDC). We focus our comments on the National Center for Health Statistics (NCHS), which serves as the federal statistical agency for the Department of Health and Human Services (HHS) and is housed in the CDC under its recently formed Office of Public Health Data, Surveillance, and Technology. The NCHS director serves as the HHS statistical official, as directed by the Evidence Act of 2018. We urge you to take measures to empower NCHS so that it can better fulfill its HHS-wide and federal statistical agency mission to provide timely and objective statistics on our nation's health and healthcare.

A prominent lesson from the pandemic is the need to have more timely, frequent, and granular data on our nation's health and health care on an ongoing basis. NCHS has helped to meet that need through its data collection programs and partnership with other federal statistical and research agencies but much more is needed. With more resources and engagement, NCHS would not only be poised to play a key role in the CDC providing more timely, frequent, and granular data, but also to bring data resources together throughout HHS and other members of the federal statistical system.

We are heartened that the second category of questions in your request for information focused on "Making Data Work for Everyone." We address specific questions under that heading here:

2. *How does electronic health record (EHR) data currently factor into CDC's data modernization efforts? Are there instances in which partnerships with integrated health care organizations or EHR vendors could provide data directly to CDC to conduct sentinel surveillance and generate insights, rather than relying solely upon data collected through health departments?*

We believe NCHS is uniquely positioned to incorporate EHR data into statistics on American health and healthcare. Indeed, the Friends of NCHS has been urging funding for NCHS to do just that. See, for example, the [Friends of NCHS FY 25 priorities document](#). Pulling information from EHRs could help NCHS to provide more timely and granular health and health care information while also easing respondent burden but significant research is necessary because EHRs are not representative of the US population. NCHS scientists are especially experienced and qualified in addressing these challenges.

3. *How could more of CDC's datasets, methodology, and assumptions be shared quickly with outside researchers so that CDC's analyses and conclusions can be validated or clarified?*

NCHS is currently standing up a Rapid Survey System (RSS) to provide more timely data to policymakers and researchers. With additional investments, the RSS could be up and running more quickly. NCHS could also be supported to provide statistics at a more granular level, both geographically and demographically, to support community-level decision-making on public health challenges such as opioids, mental health, maternal health, and Covid-19.

5. *How can the data and analyses that CDC generates be more accessible to and useful for the American people?*

NCHS should be given the resources to provide more geographically and demographically granular data and then to make it readily accessible on their website. More granular data, for example, on the counties most impacted by opioid deaths and recent trends could help to direct resources and save lives. More timely, granular information on such issues as mental health and maternal health could also be lifesaving.

7. *What types of data collection support CDC's core mission, and what types of data collection or data elements are less necessary?*

Through the National Vital Statistics System (NVSS) and its three survey programs—the National Health Interview Survey, the National Health and Nutrition Examination Survey, and the family of provider surveys—NCHS provides authoritative data on the opioid crisis, cancer, obesity, suicide, maternal health, health insurance and much more. Yet NCHS has lost 20 percent in purchasing power since 2010, hampering its efforts to: modernize its surveys; more quickly diversify its data sources to include administrative data, Electronic Health Records, and private payer data; improve the scope of information provided through NVSS, and the speed at which it is provided; incorporate data linking capabilities to elucidate such information as social determinants of health; and otherwise take advantage of methodological, technological, and data science advances.

As the statistical agency for HHS, NCHS brings unique assets to the work of HHS and CDC. Because of the imperative that federal statistical agencies provide objective, reliable statistics that are broadly trusted by the public, the 13 principal statistical agencies have protections in place to collect and produce impartial information. NCHS also has privacy protections to ensure an individual's personal information is not disclosed while also providing cutting-edge access to such data in enclaves for researchers advancing scientific understanding. As required of statistical agencies, NCHS has extensive professional autonomy over many of its operations to facilitate public trust in its products by minimizing improper political influence or interference and perceptions thereof. NCHS scientists are also leading experts in measurement, data collection methods, record linkage, EHRs, incorporating diversified data sources, privacy protection, secure access, and other statistical and data science techniques benefitting from decades of experience in turning data into reliable, unbiased information.

8. *How can CDC, and the Department of Health and Human Services more broadly, further improve data governance and data sharing to minimize burden on reporters and improve the utility of collected data?*

Please see response to next question.

9. *Do you see any opportunities to improve CDC's public health data modernization initiative and related efforts to implement public health data standards?*

Despite NCHS's strengths and invaluable role in informing health and health care decisions, the CDC and HHS have not engaged NCHS to the extent we believe would most benefit the Department and the country. The administration's total requested funding increase for NCHS—an agency that has lost 20 percent in purchasing power since FY10—over three years, for example, was \$4 million: \$0 for FY22; \$1.5 million for FY23, and \$2.1 million for FY24. At the early stages of the pandemic, the National Academies of Sciences, Engineering and Medicine (NASEM) at the request of Congress provided a report of recommendations to improve morbidity and mortality reporting during national disasters including pandemics. In that report, no agency was mentioned more than NCHS as critical to improving data responsiveness and quality. Yet NCHS was minimally engaged in this and the previous administrations' responses to the pandemic and received relatively modest one-time funding through COVID-19 emergency supplementals and funding for the Data Modernization Initiative, the majority of which was passed through NCHS to local and state entities.

NCHS also suffers from a lack of name recognition, which has had numerous deleterious effects. Trust in a federal statistical agency is paramount if it is to fulfill its mission to produce objective and timely statistics. An agency must be trusted by respondents to provide information through its surveys. An agency must also be trusted for its products to be regarded as impartial. Without NCHS name recognition, NCHS must rely on that of CDC, whose public image ebbs and flows. Finally, a lack of Congressional awareness of NCHS' mission and capabilities has been detrimental to the agency's success in the annual appropriations process.

NCHS' relatively low name recognition can be attributed to two factors: (i) the CDC branding on the NCHS website and products; and (ii) NCHS being two layers below the CDC director and three below the HHS secretary. NCHS name recognition, as well as its budget, could be contrasted with that of the Bureau of Labor Statistics (BLS) whose home agency, the Department of Labor, has a total annual budget a fraction of that of HHS. The BLS reports directly to the Secretary of Labor and its budget is more than three times that of NCHS.

We believe the work of CDC and HHS to enhance the health and well-being of all Americans would greatly benefit from stronger incorporation of NCHS' capabilities and expertise into its evidence-based policymaking through, for example, its pandemic response, preparations for the next public health crisis, and the Evidence Act-mandated learning agenda. NCHS must be fully integrated into DMI and receive sufficient DMI funding to guarantee the advancement of a modern and fully interoperable public health data system that includes more than just vital statistics.

We also urge NCHS to be provided with full control in statute over its professional and statistical operations, including budget, contracting and cooperative agreements, hiring and staffing levels, publishing, data collection and analysis, and agency branding of its reports and website. Trust in and agility of a statistical agency is bolstered by that agency having full control over its professional and statistical operations. These changes can and should be made while maintaining NCHS' accountability to Congress, the administration, NCHS data users, and taxpayers.

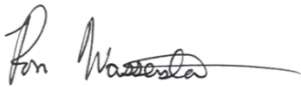
The control over professional and statistical operations for which we advocate—referred to as “professional autonomy” in the federal statistical community—are guided by Office of Management and Budget (OMB) directives, the Evidence Act of 2018, and principles from NASEM and the United Nations. A March 2023 paper published in the American Statistical Association (ASA) journal, *Statistics and Public Policy*, reviews and documents this guidance: [What Protects the Autonomy of the Federal Statistical Agencies? An Assessment of the Procedures in Place that Protect the Independence and Objectivity of Official Statistics](#). The authors, which include former leaders of the federal statistical agencies and a former Chief Statistician of the US, found a “surprising lack of statutory protections for many agencies” for professional autonomy and urged specific, statutory autonomy protections that address each of six measures of autonomy for all 13 principal federal statistical agencies. One of those agencies lacking autonomy protections was NCHS.

We also urge consideration of the optimal placement of NCHS in the HHS organizational chart, given our concerns about the disappointing lack of engagement of NCHS in meeting HHS data needs which, in part, can be attributed to its placement three layers below the HHS secretary. In contrast, the positions for Chief Data Officer and Evaluation Officer created in the Evidence Act, are positioned within HHS and have been provided budgets to carry out their Evidence-Act responsibilities. NCHS should also be authorized at a higher funding level so that it is better positioned to both provide objective and timely statistics on our nation’s health and health care and fulfill its Evidence-Act duties.

We refer you to the report [Safeguarding Vital and Health Statistics](#), a 2007 document that unfortunately continues to remain all too relevant 16 years later. Prepared for the Population Association of America Committee on Population Statistics, the document examines NCHS’s fiscal, operational, and organizational challenges and possible solutions.

Thank you for your consideration. We would welcome the opportunity to further discuss with you the critical role that NCHS can and should play both in the work of CDC and HHS. Please do not hesitate to contact Steve Pierson, Director of Science Policy for the American Statistical Association (spierson@amstat.org) for questions or to arrange a discussion.

Sincerely,



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