

July 31, 2023

Mandy Cohen, MD, MPH Director Centers of Disease Control and Prevention 1600 Clifton Road NE Atlanta, GA 30333

Dear Director Cohen,

On behalf of the Friends of the National Center for Health Statistics (NCHS), congratulations on your new post as Director of the Centers for Disease Control and Prevention (CDC). Thank you for accepting the important responsibility to lead our nation's premier agency devoted to protecting our public health.

The Friends of NCHS is a voluntary coalition of 180 organizations and individuals that support NCHS and advocate for sufficient resources for the Center. We look forward to working with you in your new role, and urge you to improve the integration of NCHS, as the principal statistical agency for the entire Department of Health and Human Services (HHS), into CDC, HHS, the broader public health spectrum, and the federal statistical system.

The COVID-19 pandemic demonstrated clearly that we need more timely, frequent, and granular data on our nation's health and health care on an ongoing basis. NCHS has helped meet that need through its data collection programs and partnerships with other federal statistical and research agencies, but much more is needed. With more resources and engagement, NCHS is poised to lead essential efforts for CDC and HHS to provide this critical timely, frequent, and granular data.

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 vital statistics, the opioid crisis, cancer, obesity, suicide, health care utilization and insurance, and much more. Despite its essential role, NCHS has lost 18 percent in purchasing power since Fiscal Year 2010. This has severely restricted its efforts in multiple areas including: modernization of its surveys; rapid diversification of its data sources to include administrative data, EHRs, and private data; expansion in the scope of information provided through NVSS, and the speed at which it is provided; advancement of data linking capabilities to elucidate such information as social determinants; and ability to take advantage of methodological, technological, and data science advances.

As the principal health statistics agency for HHS, NCHS brings unique assets to the department's work. 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 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, diverse 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.

NCHS plays a critical role in the Data Modernization Initiative (DMI) as well. As such, 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, but goes beyond, vital statistics.

As the Friends of NCHS continue to advocate for sufficient resources for NCHS, we encourage you to prioritize the role of the center at CDC and do everything you can to elevate its work. To that end, I enclose the recommendations and priorities of Friends of NCHS for FY25. We would welcome the opportunity to further discuss with you the critical role that NCHS can and should play in CDC's and HHS' work.

Thank you for your consideration of these important issues. Please do not hesitate to contact Friends of NCHS Chair Steve Pierson at <a href="mailto:spierson@amstat.org">spierson@amstat.org</a> or Vice Chair Meghan Riley at <a href="mailto:mriley@dc-crd.com">mriley@dc-crd.com</a> if our coalition can be a resource to you.

Sincerely,

Steve Pierson

Chair, Friends of NCHS

CC: Nirav Shah, Principal Deputy Director, CDC; Jeff Reczek, Director, CDC Washington Office

Enclosure: Friends of NCHS FY25 Priorities



## Invest in the future of US health statistics:

The case for funding the National Center for Health Statistics (NCHS) at \$220 million in FY25

## NCHS' Two Overarching Drivers for Innovation and Investment

## 1. Data-user demand for

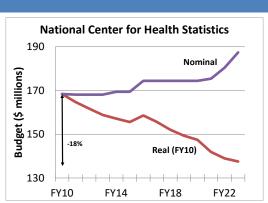
- a. More real-time data to inform core indicators of health and healthcare and be prepared for the next public health crisis;
- b. More granular data on key population subgroups including those defined by age, gender, race and ethnicity, socioeconomic status, disability, and geographic area;
- c. Data on health and healthcare equity especially in regard to the immediate and long-term consequences of the COVID pandemic; and
- d. Expanded information on social determinants of health and healthcare, including economic stability, healthcare quality/access, education, community context, and physical environment.

## 2. NCHS challenges/threats

- a. Existing programs will become outdated in terms of topics covered, methodology, and technology due to a <u>19% loss of purchasing power since FY10</u>. This has reduced the scope of NCHS data collections and made significant methodological and *technology* improvements impossible when they are most needed.
- b. Declining response rates require additional investment in data collection *methods and new technologies* that not only improve response but *also* allow for the determination and correction of non-response bias. Investments are needed to support research in a variety of areas to improve data quality, granularity, and timeliness.
- c. To capitalize on the Data Modernization Initiative (DMI) investments in NCHS' vital statistics program, continued investment is necessary to expand reporting on maternal health, high risk births, and fetal deaths, improve cause of death ascertainment and expand NCHS' support of DMI-funded state vital records systems modernization and other state data modernizations efforts.

THE CHALLENGE: NCHS must fulfill demand for new data products that are more real-time, higher frequency, and more granular while maintaining its current data products.

NCHS data have long been the gold standard for measuring health status and changes in health outcomes for the most vulnerable and identifying emerging health issues for the nation. To remain so and to meet evolving data needs, NCHS' statistical systems need to be overhauled over the next several years. NCHS' challenge is to continue to provide data products while the necessary wholesale changes take place. Without funds to innovate in a significant way, NCHS is left to innovate around the edges to try to maintain quality.



The Friends of NCHS recommend a minimum of \$220 million in FY25. The \$33 million increase over the FY23 level, which partially restores NCHS to its FY10 level when adjusted for inflation, could be used in the following ways:

- 1. Expand the content, granularity, and timeliness of data products: More granular and timely data products are needed including those that identify key social determinants of health and health disparities. With additional resources, NCHS could increase sample sizes in the agency's signature surveys, including the National Health Interview Survey and Health and Nutrition Examination Survey, to produce stable subgroup estimates. Funding is also needed to support the new NCHS Rapid Surveys System, which will collect data on emerging public health topics, attitudes, and behaviors to meet decision makers' need for time-sensitive data while maintaining data quality. New staff would also be necessary to develop and implement the range of data products that NCHS will be able to release on a more rapid basis. An increased investment of \$11 million is requested for data collection, research, and staffing.
- 2. Saving lives through better understanding of deaths: Increased investment is required to support a fully modernized vital statistics system capable of tracking critical mortality trends, such as opioid overdoses, and maternal infant mortality. Production of timely mortality data depends on the thousands of medical examiners and coroners who report on unnatural and unexpected deaths. The recently created Coordinating Office of Medical Examiners and Coroners gives NCHS the opportunity to increase the quality of the information provided by these all-too-often under-resourced offices. An increased investment of \$7 million, will support these offices, improve vital records sharing with jurisdictions and advance the timeliness of data through research, staffing and systems development.
- **3. Electronic Health Records:** Data collections based on existing Electronic Health Records (EHRs) provide a great resource to better understand care provided by the US healthcare system at the national, state, and local level, but investments are needed to harness this resource through more real time interpretability. An increased investment of **\$11 million** is recommended to support EHR purchasing, staffing, research, and cloud migration.
- 4. Expand data linkage and modeling: The usefulness of data obtained through surveys and from administrative systems is substantially increased when linked, especially when examining the impact of social determinants of health. The growing need for information on the drivers of health differences across the U.S. population also call for more investment in modeling. Expansion of NCHS' linkage program and Investment in modeling would support the use of predictive analytics and produce estimates of health differences at smaller geographic areas, thereby helping CDC and HHS to target resources more effectively and efficiently. An increased investment of \$4 million is recommended to support research, staffing and privacy protection.

How the 4 components of the \$220 million recommendation meet NCHS needs and challenges

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Electronic health records	✓	<b>√</b>	✓				✓		
Data linkage & modeling	✓	✓	✓	✓	✓	✓	✓		
Expanded content, granularity, & timeliness fo data products	✓	✓	✓	✓	✓	✓			
More rapid, relevant vital statistics	✓		✓		✓	✓			