

Friends of NCHS Fiscal Year 2022 Recommendation for the National Center for Health Statistics

March 29, 2021

The Friends of NCHS is a coalition of public health associations, patient organizations, scientific societies, and research institutions who rely on the information produced by the National Center for Health Statistics (NCHS) within the Centers for Disease Control and Prevention (CDC). In order to support NCHS's continued work to monitor the health of the American people and to allow the agency to make much-needed investments in the next generation of its surveys and products, the Friends of NCHS recommend an appropriation of at least \$200 million for the agency in fiscal year (FY) 2022. Our recommendation reflects an increase to NCHS's base budget of \$25 million from its FY 2021 appropriation. This funding will enhance NCHS's ability to continue to provide timely, unbiased, and accurate data on Americans' health during a period of increased public health concern due to the COVID-19 pandemic.

The COVID-19 pandemic highlighted the troubling limitations of the Nation's statistical system. While NCHS was successful in providing critical information to monitor the impacts of the pandemic, the need for major investments to expand on the scope, timeliness, quality and useability of information was glaringly apparent. Investments are needed to improve the timeliness, scope and quality of data on vital events, health care access and utilization and on population health and in how the information collected is provided to a range of users. Deficiencies in obtaining information on health care utilization both for COVID and non-COVID related care and in how the pandemic affected other aspects of the health of the population confounded the response. Investing in the agency now will allow NCHS to use its expertise to become a nimble twenty-first century statistical agency and reaffirm NCHS's status as the world's gold-standard producer of health statistics. With additional funding, NCHS will:

- Collect the information needed to monitor health and health care and make it available when it is
 needed. NCHS will build on its strong data collection systems by adopting new data collection
 methodologies and targeting new data sources that will expand the range of information available along
 with more timely data release.
 - O NCHS will take advantage of web-based data collection as it has with its RANDS initiative and will expand the timeliness of the collection of bio measures including from blood and urine. Had such investments been made it would have been possible to quickly monitor the impact of COVID-19 on the population and providers and to determine the quality of data produced by methods know to have biases.
 - NCHS will develop partnerships with electronic health record vendors, intermediaries, and health care data providers to standardize and make available critical data items so that NCHS can monitor health care at the national, state and local level in a timely manner and be able to monitor quickly unexpected health outcomes.
 - Data collections will be restructured so that it will be possible to add modules to respond to emerging data needs. In the short run, modules addressing the changing impact of COVID-19 will be added to NHIS and NHANES such as the assessment of the health problems of COVID survivors. Including bio measures in the NHIS, as noted above, has the promise of providing critical information in a timely fashion.
 - NCHS will work with registration jurisdictions to improve quality and timeliness of vital statistics through the modernization of electronic birth and death registration systems and medical

- examiner/coroner case management systems and assuring interconnectedness with electronic health records. There is a need for standardizing and rationalizing the collection of vital registration data at the county and state level, improving the training around vital registration data, and ensuring that critical demographic information is systematically collected.
- O NCHS will expand the use of machine learning and artificial intelligence to improve efficiency of data collection and processing. These technologies could allow NCHS to automate the coding of deaths of high public health interest such as drug overdose deaths, emerging infectious diseases, deaths due to natural disasters, and infant and maternal deaths, which are currently coded manually.
- o NCHS will advance the linkage and integration of data reporting systems at the data provider level to increase collection and processing efficiency, reduce burden on local data providers, and enable faster analysis and release of statistics.
- Significantly expand the Data Linkage Program of NCHS across HHS and other government data holdings. NCHS has over the years shown the benefit in linking it survey and vital registration data with CMS, SSA and HUD data holdings but has lacked the requisite support to really make a difference. COVID-19 has shown that we need to bring data together in new ways to better measure the impact of disease on disadvantaged populations. NCHS will make its data linkage program at least equivalent to its other data systems activities and will continually link to data systems throughout HHS and government and to present its findings for policy makers in a timely manner and provide these linked files in a secure environment for researchers.
- Make data more easily accessible for policy formation, program monitoring and research. NCHS will restructure its data access platform so that information can be found easily and presented in a way that will address pressing questions about the range of health and health care concerns.
 - O NCHS will expand the availability of information for geographic areas while protecting confidentiality. For some data systems this will require sample expansion so that generalizable estimates can be made for subnational areas. For some systems additional location information will need to be obtained. For all systems, data access mechanism will need to be developed that provide needed information at the geographic level desired while protecting the confidentiality of the data providers.
 - O NCHS, along with CDC, is in the process of moving to a cloud infrastructure, however NCHS will require additional security for personal identifying information (PII) and electronic health records (EHR). For external users, this could also take the form of a Virtual Research Data Center many researchers do not live close enough to a brick-and-mortar RDC and COVID has severely restricted access to physical buildings.
- In addition to improvements in data collection and dissemination, produce data analyses that are more policy relevant. In response to the need for information to inform COVID-19 policy, NCHS modeled granular data to produce more robust demographic and geographic analyses. An expansion of work in this area will allow for the more rapid sharing of key findings. The results of these models will only be of use if they are developed in a transparent way with appropriate attention to model limitations. A robust research program is needed to support these efforts.

Even under a tightly constrained budget, NCHS has pioneered innovative new techniques to get the most value out of every taxpayer dollar. Over the past several years, NCHS has closed the gap between data collection and publication for leading causes of death, resumed official estimates of maternal mortality after over a decade, implemented literal text analysis to identify the drugs most frequently involved in overdose deaths, executed a redesign of the Health Interview Survey to reduce the burden on respondents, and contributed to the design and implementation of the Household Pulse Survey during the pandemic. These achievements only serve to highlight how far additional investment in NCHS would go towards helping the agency rise to the challenges it faces.

We thank you again for your continued support of NCHS's essential data and statistics and encourage to you make sustained investments in how we measure our nation's health. We urge you to support a funding level of at least \$200 million for NCHS in FY 2022.

Friends of NCHS

Academic Pediatric Association

Academy of Nutrition and Dietetics

AcademyHealth

Advocates for Better Children's Diets

American Academy of Pediatrics

American Anthropological Association

American Association for Clinical Chemistry

American Association of Colleges of Nursing

American Association on Health and Disability

American Heart Association

American Pediatric Society

American Society for Nutrition

American Statistical Association

Association of Medical School Pediatric Department Chairs

Association of Public Data Users (APDU)

Association of Schools and Programs of Public Health

Consortium of Social Science Associations

Council of Professional Associations on Federal Statistics (COPAFS)

Healthy Teen Network

Inter-university Consortium for Political and Social Research

Lakeshore Foundation

March of Dimes

NAPHSIS

National Safety Council

Pediatric Policy Council

Population Association of America

Power to Decide

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Society for Maternal-Fetal Medicine

Society for Pediatric Research