NATIONAL CENTER FOR HEALTH STATISTICS

The National Center for Health Statistics (NCHS) is the nation's principal health statistics agency. Located in the Department of Health and Human Services (HHS) as part of the Centers for Disease Control and Prevention (CDC), NCHS's mission is to provide statistical information that informs the public and guides program and policy decisions to improve the nation's health. Created in 1960 through the joining of existing health and vital records collection systems, NCHS's current annual appropriation is approximately \$187 million, making it the fifth largest of the 13 principal federal statistical agencies by budget. NCHS's activities and topics are wide ranging, but in brief, the center:

- → Conducts and disseminates data needed to answer questions about health and healthcare in the United States;
- → Documents multiple aspects of the health status of the population and important subgroups;
- → Describes interactions with inpatient, outpatient, and long-term care components of the healthcare system;
- → Monitors trends in health status and healthcare delivery;
- → Provides data to monitor emerging health threats:
- → Identifies disparities in health by race or ethnicity, socioeconomic status, region, and other population characteristics;

- → Compiles and assesses the most thorough and reliable data regarding life expectancy and cause of death for the nation;
- → Provides nutrition monitoring information;
- → Monitors trends in maternal and infant health outcomes and family formation;
- → Provides data sources to support biomedical and health services research; and
- → Informs the development of public policies and programs and evaluates the impact of these policies and programs.

^{**}The following is based on publicly available information, information from former agency leadership, and select information from our questionnaire.

STRENGTH OF NCHS'S SUPPORT+

Autonomy: Mixed. No acute current threats, but NCHS lacks professional autonomy protections in statute. A chronic autonomy issue is NCHS's lack of brand autonomy.

Budget/staffing: Challenging. The NCHS budget has declined 15% in purchasing power since FY 2009, undermining the agency's ability to be innovative, maintain sustainable survey coverage and quality of data, and otherwise produce the most relevant and timely data. Its staffing is commensurate with its budget, but current staffing levels are insufficient to meet the growing need for data and the need to develop innovative data collection and analysis methods.

Parent agency: Mixed. CDC has provided NCHS with funds from the congressionally approved Data Modernization Initiative (DMI). CDC also supports NCHS IT needs. On the other hand, there is little public evidence of engagement of NCHS in department or CDC initiatives. Further, the median requested increase for NCHS's in the president's annual budget proposal is 0.4%, the lowest among the 13 principal federal statistical agencies and below inflation. CDC's respect for NCHS's professional autonomy has varied under different CDC leaders and is not protected in agency policy.

† See Supporting Materials F for an explanation of the support ratings.

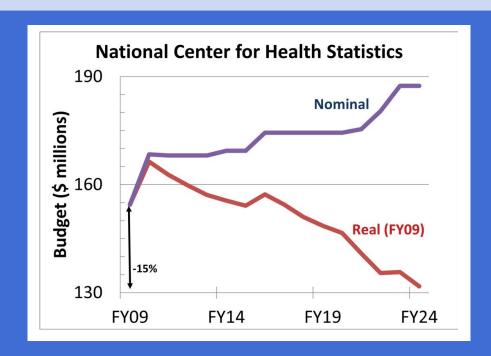
AGENCY FAST FACTS

- 1. Appropriations line item: \$187 million
- 2. NCHS receives funding from other agencies to augment critically needed information collected in NCHS's core platforms.
 - CDC has provided significant one-time funding to NCHS through the congressionally funded DMI, much of which was passed directly to states to modernize their vital records and statistics system.

Funding history, inflation adjusted

Budget inputs and

FY24 level



Appointment of head & layers down in the Department of Commerce org chart

Other

NCHS is one of eight principal federal statistical agencies for which the head is a career senior executive service appointee.

Three: The NCHS director reports to the assistant director of the Office of Public Health Data, Surveillance, and Technology, who reports to the CDC director, who reports to the Secretary of Health and Human Services.

- NCHS is authorized through the Public Health Service Act (Section 306).
- → The NCHS director is the statistical official for HHS.
- → NCHS collaborates with other members of the U.S. federal statistical system and with other countries and international organizations such as the United Nations and the Organisation for Economic Co-operation and Development (OECD) on data collection standards and quality improvement.
- → NCHS has a <u>history of contributions to American health and healthcare</u>, as highlighted in the callout below.

THE NATION'S DATA AT RISK | Meeting America's Information Needs for the 21st Century | Supporting Materials

- NCHS modernized the process for reporting mortality data, which has reduced the gap in time from the event to data release to 10 days and facilitates such products as the following:
 - Weekly Pneumonia and Influenza (P&I) Mortality Surveillance reports
 - Monthly Provisional Drug Overdose Deaths
 - Quarterly Provisional Estimates for Selected Causes of Death
 - Annual final mortality data for all states released in under a year
- → NCHS enhanced coordination and cooperation of the 57 jurisdictions and local offices (who provide vital records data through disparate IT systems) and the use of machine learning to accurately code almost 90% of all mortality records and provide coded data back to states overnight.
- NCHS documented the decline in life expectancy and comparisons with countries and accurately monitored the extent of Covid-19 deaths throughout the epidemic using excess mortality measures. NCHS also documented the decline in U.S. fertility rates and has produced the first nationwide data sets and studies regarding the impact and prevalence of Long Covid.
- → NCHS initiated the Rapid Survey System to collect data on emerging public health topics, attitudes, and behaviors to meet decision-makers' needs for time-sensitive data while maintaining data quality.
- NCHS established the Coordinating Office for Medical Examiners and Coroners to improve tracking of mortality trends, such as opioid overdoses and maternal infant mortality, through more engagement and support of medical examiners and coroners.
- NCHS continued to expand the NCHS Data Linkage Program to link NCHS survey data to administrative files from Medicaid, Medicare, Department of Housing and Urban Development (HUD), and Department of Veterans Affairs (VA) to provide data resources to researchers and programs that can be used to evaluate the impact of their programs on those they serve. NCHS's long-standing linkage of survey data to mortality files allows the investigation of the longer-term impacts of health and health-related characteristics.
- → From 2020 to 2022, NCHS doubled its document downloads and website visits to 1.7 million and 41 million, respectively, through such new topic-specific web resources as COVID-19 Death Data and Resources, NVSS—Maternal Mortality, and Mortality Data.
- → HHS-wide activities:
 - Published Health US using data from NCHS and across HHS both as the annual report of the HHS Secretary to Congress and an online report where data are updated as available. Information is provided on trends in four areas: health status and determinants, healthcare utilization, healthcare resources, and health expenditures and payers.
 - Healthy People 2030: NCHS continues to be responsible for monitoring the nation's progress toward <u>Healthy People</u> targets using data from more than 80 different data sources to continually update national progress for HHS programs and activities.

Recent successes

→ NCHS has designed its data systems to provide the core data collection infrastructure platforms used throughout HHS. NCHS partners with a wide range of federal agencies who make broad use of its data, and its partners can efficiently obtain targeted information by providing funding to add questions or modules or expand sample size to the infrastructure collections.

→ CDC directs DMI funds to NCHS, which it has used to address critical needs, especially in the vital statistics program.

Agency strengths

- NCHS has an active outside group of stakeholders advocating for NCHS's budget to Congress, HHS, CDC, and the Office of Management and Budget (OMB).
- → Peer-reviewed manuscripts authored by NCHS staff are routinely cited in the academic work on public health and related fields. As of summer 2023, there were more than 2.300 citations of NCHS work from 2020.
- NCHS recognizes its staff annually through the NCHS Director's Awards Ceremony and includes the Excellence in Innovation Award to "recognize an NCHS Employee or Group Who Develops a New, Innovative Approach to Survey Design, Methods, Products, or Services."

Agency threats/ vulnerabilities

- NCHS's relatively low profile in CDC/HHS does not reflect the importance of its data as critical measures of U.S. health status and, more broadly, puts it at risk of further losing purchasing power and thereby becoming unable to meet the Evidence Act requirement to produce relevant and timely data.
- → NCHS's reliance on other agencies for funding to implement its data collection programs puts those surveys at risk of major cuts should other agencies withdraw or pare back support. The National Health and Nutrition Examination Survey (NHANES), National Health Interview Survey (NHIS), National Survey of Family Growth (NSFG), and National Health Care Surveys are particularly reliant on funding from other agencies for core operations and therefore for NCHS's unique products.
- Response rates for NHANES and the NHIS have both declined, as has been the case for surveys throughout the federal statistical system. NCHS needs funding to develop methods to assess the impact of lower response rates and to develop ways to increase response or mitigate the effects.

Agency Challenges

NCHS gets little support in the annual presidential budget request process. CDC's median requested increase since 2001 for NCHS is 0.4%, the lowest by a factor of 10 for the 9 non-cyclical agency budgets determined in the appropriations process. (See this Google sheet, sixth tab, Pierson et al. 2024.)

- → Similarly, while CDC uses and references NCHS data often, we find little public evidence of NCHS being engaged in department- or CDC-wide initiatives. This administration has requested only a net \$3.5 million increase for the agency over its four budget requests. However, if enacted, would fail to sustain the agency's purchasing power. In its FY 2023 request specifically, released two years into the pandemic and supporting a "Data-Driven Response to COVID-19," the administration only requested a \$1.4 million (0.8%) increase for NCHS. The next year, after the White House released its report, U.S. Playbook to Address Social Determinants of Health, which called on Congress to provide NCHS additional funding to "collect, analyze, integrate, link, and disseminate data related to social determinants of health," the president's FY 2024 request was only \$2.1 million (1.1%) over FY 2023. Further, the Department of Health & Human Services' FY 2023-2026 Evidence-Building Plan does not engage NCHS expertise despite the stated requirement to include "potential data, tools, methods and analytic approaches to be used to answer priority questions."
- NCHS's low profile is also reflected in the CDC's creation of its Center for Forecasting and Outbreak Analytics, the name for which includes two functions squarely in the expertise of a federal statistical agency. While NCHS's scope may have had to be expanded somewhat to include all of the desired capabilities, CDC opted for a new center rather than engaging NCHS and its expertise. More broadly, Senator Mitt Romney's 2022 proposal for a Center for Public Health Data, with a stated mission to "improve access to impartial and objective public health data in real time and bolster our infectious disease intelligence and preparedness" also has a similar mission as that of NCHS—illustrating that NCHS is not being recognized for its expertise and contributions or being supported to meet critical policy needs: "NCHS collects, analyzes, and disseminates timely, relevant, and accurate health data and statistics. Our products and services inform the public and guide program and policy decisions to improve our nation's health."

Agency challenges

- → NCHS has lost 21% in purchasing power since FY 2010, inhibiting its ability to provide relevant and timely data, including more granular data.
 - Funding mechanisms that were designed to provide funding to augment collections beyond the core components to provide targeted data for partners have had to be used for core support to maintain the integrity of the collections.
 - NCHS's limited budget has prevented the agency from addressing the coverage, timeliness, and granularity of its National Health Care Surveys, thereby limiting the utility of these surveys for monitoring healthcare and health outcomes, particularly for emerging problems such as mortality due to drug overdose, Covid-19, and pneumonia. For example, the latest available emergency department visit data are for 2021. The lack of granularity prevents NCHS from measuring differentials in treatment and outcomes for high-risk groups or by geographic location or characteristics such as level of urbanization. The surveys have also not been sufficiently supported in utilizing electronic records and being able to match records across sectors to better understand use of services and the quality and effectiveness of those services.
 - NCHS's loss of purchasing power also means NHANES may only be able to
 produce biannual reports at the national level. Data are likely not to be granular
 enough to identify many high-risk groups. Compounding the impact of the lack
 of funding is the inability to explore new ways to collect the data to allow for
 larger sample size and quicker reporting.

Agency challenges

- The DMI funds have helped NCHS address critical needs, especially in the vital statistics system, but NCHS still lacks sufficient support for producing new, innovative data products, in addition to needed expansion of its three major survey programs.
- → NCHS data are frequently not attributed to NCHS, only to CDC, undermining name recognition of NCHS, which is critical to it being a trusted statistical agency and beneficial in the Congressional appropriations process.

Agency opportunities

- → With the pandemic helping to raise attention to the demand for and importance of more granular, timely, and frequent health statistics, NCHS together with HHS, CDC, and its stakeholders have a unique opportunity to draw attention to its budget needs.
- → With its statutory privacy protections to ensure an individual's personal information is not disclosed and its deep expertise in such areas as measurement, data collection methods, record linkage, electronic health records (EHRs), and incorporating diversified data sources, NCHS is poised to play a leading role in HHS initiatives to understand social determinants of health and inform policy and initiatives.
- The Friends of NCHS have identified <u>how additional funds could be invested for immediate effect</u>.

Agency-specific recommendations

In addition to the all-agency recommendations in the body of the report, we recommend that:

- CDC should allow NCHS to use its name and logo prominently on its website, products, and outreach to facilitate greater public awareness and trust of NCHS.
- → HHS and CDC should engage NCHS in department- and CDC-wide initiatives.
- → CDC should engage with Congress along with NCHS to provide NCHS the resources to better fulfill its requirement to provide relevant and timely data.

Further reading

- 1. State of the Nation's Health Data Infrastructure: Experts Weigh in Two Years into Pandemic. (2020). Amstat News.
- 2. A Framework for Assessing Mortality and Morbidity After Large-Scale Disasters. (2020). Washington, DC: The National Academies Press. https://doi.org/10.17226/25863.

A HISTORY OF CONTRIBUTIONS TO AMERICAN HEALTH AND HEALTHCARE

NCHS's data collections cover the full range of topics related to health and healthcare. Below are some examples of how NCHS has contributed to knowledge on health and healthcare in America.

- → Health disparities: NCHS data have long documented disparities in a wide range of health indicators based on race, gender, region and urbanization level, and income, including life expectancy, infant mortality, a variety of risk factors, health status, health insurance coverage, access to care, and use of healthcare services.
- Nutrition, growth charts, and environmental effects: NCHS data are used to recommend and evaluate food fortification decisions, develop and revise the Dietary Guidelines for Americans, and help set recommended intake levels for vitamins, minerals, and other nutrients. The pediatric growth charts used by pediatricians and parents to monitor children's growth are based on NCHS data. NCHS data were used to document the impact of removing lead from gasoline, in addition to ongoing childhood lead poisoning prevention efforts throughout the country.
- → Physical activity and tobacco: NCHS data are used to examine physical activity levels and compliance with national guidelines. NCHS has chronicled cigarette smoking levels for adults since 1964, the year the first Surgeon General's report on smoking was released. In 1964, more than 40% of U.S. adults smoked cigarettes; currently fewer than 14% smoke.
- → Health insurance: NCHS data are used to document the impact and coverage of Medicaid, Medicare, and the Affordable Care Act.
- → Significant changes in causes of death: NCHS documented increases in opioid deaths, Covid-19 deaths, deaths due to firearms and motor vehicles, and changes in leading causes of death.

The extensive topics included in the NCHS portfolio enable comparison of the health of the U.S. population to populations in other countries.