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VIEWPOINT

Completing a National Birth Cohort in the United States

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Not only is life expectancy in the United States shorter than in other high-income nations, but the US population also ranks comparatively worse across 9 key health areas: (1) infant mortality and low birth weight; (2) injuries and homicides; (3) adolescent pregnancy and sexually transmitted infections; (4) human immunodeficiency virus and AIDS; (5) drug-related deaths; (6) obesity and diabetes; (7) heart disease; (8) chronic lung disease; and (9) disability.¹ Unfortunately, policy makers and the health community lack a complete explanation for the US health disadvantage. Researchers know that persistent racial, ethnic, socioeconomic, and geographic disparities in health are part of the explanation, but they do not fully understand them or know how best to address them.² Especially in a country as increasingly diverse as the United States and during a time when the social environment is rapidly changing as a result of digital technologies, it is crucial to fully understand how factors, such as geographic location and family, social, economic, physical, nutritional, and community environments, produce disparate health outcomes.

In the late 1990s, scientists and researchers throughout the United States highlighted the need for information that ultimately would lead to improvements in the health, development, and well-being of children. This led to the creation of the National Children's Study (NCS) through the National Children's Health Act of 2000. The NCS was designed as a birth cohort study to follow up a nationally representative birth cohort of 100 000 children until the age of 21 years. The NCS was to be a definitive study of children's health. However, in the wake of criticisms of the study's management in the National Research Council/Institute of Medicine report³ and the assessment by a National Institutes of Health (NIH) advisory committee to the director that the plans for the study were not feasible,⁴ the study was cancelled in December 2014.

To identify whether a US longitudinal birth cohort study is still needed and, if so, to suggest methods for its design and implementation, 2 expert meetings were convened in 2016 by the National Academies of Sciences, Engineering, and Medicine, with funding from the Robert Wood Johnson Foundation. In these meetings, a group of 16 experts from academia, philanthropy, industry, and government discussed current NIH initiatives to understand children's health and development, the weaknesses of the NCS, and the questions of whether a national birth cohort study is still needed and feasible. The experts also considered whether the studies that are now planned by the NIH in lieu of the NCS are capable of providing comprehensive explanations for the relatively poor health of the US population. A synthesis of the group's discussions and conclusions

was published on May 31 as part of the National Academy of Medicine *Perspectives* series (<http://nam.edu/LifelongHealth>).^{5,6}

The series' articles contend that a nationally representative birth cohort study—beginning in the prenatal stage and following up children into adulthood—is not only feasible but remains crucial to building effective US health policy. Although selective cohort or cross-sectional studies are certainly less expensive to implement, they cannot provide the more comprehensive understanding of the effects of the family, social, economic, physical, nutritional, and community environments on health that is needed. These kinds of studies are limited in that they only examine populations in specific locations that do not represent the diversity of the United States, focus on a small number of factors, or involve a limited period of human development. Therefore, they will not allow for an understanding of the full complement of environmental and social factors that interact to affect health over the life course.

To remedy some of these issues, the NIH has begun a new effort, the Environmental Influences on Child Health Outcomes (ECHO) Study. The ECHO Study is proposed to be a collection of existing cohort studies. By merging existing cohorts, the ECHO Study will have increased statistical power to detect associations between the environment and health when compared with a single cohort. However, given that the ECHO cohorts were not designed to be merged, they cannot provide data that generalize to the full range of diverse population subgroups and geographic locations in the United States. In contrast, studies based on a national probability sampling frame can support the kinds of generalizable statistical inferences that are crucial for understanding how children grow into healthy adults and live up to their full developmental potential across all of the variations in social, physical, nutritional, and chemical exposures. They also provide a much stronger basis for health policy formulation than results from studies that do not represent diversity across the United States.

The research community has learned much about the conduct of birth cohort studies from a decade of planning for the NCS, from the approximately 6000 NCS Vanguard Study families who participated, and from other birth cohort studies in the United States and abroad. It will be feasible, efficient, and cost-effective to conduct a new national birth cohort study from the prenatal period to adulthood if researchers adhere to the following principles:

- A hospital/birth center-based sampling frame and recruitment of pregnant participants through sampled settings that represent clinicians across the nation.

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- A sample size of between 30 000 and 50 000 pregnant women, which would reduce the cost of a national birth cohort study substantially.
- Reliance on technologies and extant data sources that can decrease the costs and burdens associated with monitoring health, behavior, and diverse aspects of the environment.
- Proper management of data so that reports, data, and study findings can be released quickly to the public and relevant stakeholders.

The National Academy of Medicine's *Perspectives* series^{5,6} provides a compelling case for moving forward with plans for a new national birth cohort study that improves and builds on the work of the NCS. It is important to note that planning a study of this magnitude requires a breadth of expertise and ample time for design. The time to start this effort is now, before the lessons learned from the NCS have been forgotten. This will allow designers to make well-informed decisions about measures to be included, balancing the scientific importance of the measures with their logistical feasibility, costs, and respondent burden. Designers should engage stakeholders early in the implementation phase to develop community

commitment to support recruitment, and they should plan to release results and make data accessible as quickly as possible to demonstrate the benefits of the research to funders, other stakeholders, and society at large.

There is a need to ameliorate health disparities because they threaten future US prosperity. Carefully collected data can provide the foundation for an action agenda to improve the nation's health. Such data are most useful when obtained through a nationally representative longitudinal birth cohort study that reveals how social, physical, chemical, and nutritional influences interact to shape health and development across the life course. Such data will provide the information that policy makers, families, and individuals need to reduce risks and promote health; this knowledge, in turn, will guide interventions capable of fostering optimal development and reversing health disparities. Finally, proactive and transparent sharing of such data and their implications is crucial to inform the public and promote support for children's health and development, as well as to foster political will to invest in policies that will positively affect how children in the United States grow, live, and prosper.

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