and regional levels in LMICs. We also need broadly distributed sites for manufacturing products to meet global needs and regulatory systems that are prepared to provide emergency approval of new products and ensure their rational allocation by prioritizing distribution to regions where products can be most effective in stopping progression of a pandemic.[5]

Finally, in an era of nearly limitless digital potential, we can harness the tools of the information age to share essential data for detecting new pathogens, accelerating product development, and enhancing pandemic response efforts. Countries should work together to break down barriers to data sharing while taking steps to protect privacy and prevent misuse.

An audio interview with Dr. Elias is available at NEJM.org

The annual cost of making these investments would be billions of dollars. The GPMB has reported that adequate investment in preparedness would require an average of $5 per person worldwide each year. In comparison, economists estimate that the world has already spent more than $11 trillion fighting Covid-19 and that the pandemic will exact another $10 trillion in lost future earnings. The NAM will continue to play an important role in these debates. Recently, for example, the National Academies of Sciences, Engineering, and Medicine published a consensus study report, *Framework for Equitable Allocation of Covid-19 Vaccine.*

We believe it's time for world leaders to heed warning signs, abandon half-measures, and commit to the global system we need to respond to the ever-present danger of emerging infectious diseases. We simply cannot afford the alternative.

The series editors are Victor J. Dzau, M.D., Harvey V. Fineberg, M.D., Ph.D., Kenneth I. Shine, M.D., Samuel O. Thier, M.D., Debra Malina, Ph.D., and Stephen Morrissey, Ph.D.

Disclosure forms provided by the authors are available at NEJM.org.

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This article was published on March 27, 2021, at NEJM.org.

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DOI: 10.1056/NEJMp2034517
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Ensuring That LGBTQI+ People Count — Collecting Data on Sexual Orientation, Gender Identity, and Intersex Status

Kellan E. Baker, Ph.D., M.P.H., Carl G. Streed, Jr., M.D., M.P.H., and Laura E. Durso, Ph.D.

Most national surveys in the United States, including the decennial census, do not collect demographic data on sexual orientation, gender identity, or intersex status. As a result, despite improvements in the social and legal standing of lesbian, gay, bisexual, transgender, queer, intersex, and other sexual and gender-diverse (LGBTQI+) populations, many simple facts about these communities remain elusive. As outlined in a comprehensive new report on LGBTQI+ populations from the National Academies of Sciences, Engineering, and Medicine, the data that do exist point to epidemics of depression, substance use, HIV infection, violence, homelessness, and other adverse outcomes driven by the discrimination and social and economic marginalization that many LGBTQI+ people continue to experience.[1] For every gap in health and well-being whose contours we have mapped, the widespread lack of comprehensive data collection means that many more disparities — and the policy and programmatic interventions that might address them — remain unknown.

Data are fundamentally political: decisions about which data are collected and which are overlooked both reflect and shape policy and program priorities. At

the same time, however, data are also simply the stuff of everyday life. Sexual orientation, gender identity, and intersex status are core components of identity that shape a person's daily contact with the world through families and relationships, jobs and health care, and growing up and growing older. By not asking questions about these characteristics, our health care and public health systems are forgoing critical information necessary for designing and implementing effective strategies not just for closing disparities affecting specific populations but also for providing person-centered care and services to the U.S. population as a whole.

According to the National Academies report, there are several types of data-collection activities that should routinely include measures of sexual orientation, gender identity, and intersex status. These are population surveys, such as the National Health Interview Survey and the American Community Survey; clinical trials and other research activities; public health surveillance and other administrative data systems; and electronic health records (EHRs). The report calls on the federal government to develop standards to guide the collection of these data throughout the activities of federal agencies. It also calls on private entities, including hospitals and clinics, to collect these data in a consistent and structured manner.

The means of collecting these data are already well documented. At the national level, the Federal Committee on Statistical Methodology, an interagency committee dedicated to improving the quality of federal statistics, has released several reports assessing existing data-collection practices and discussing key implementation issues. The Sexual and Gender Minority Research Office at the National Institutes of Health (NIH), which cosponsored the National Academies report, maintains a comprehensive website devoted to methods and measurement in sexual and gender minority health research and has helped ensure that the NIH PhenX Toolkit for biomedical research includes standardized measures for sexual orientation, gender identity, and intersex status. Federal regulations already require certified EHR systems to have the capacity to collect, store, and retrieve structured data on sexual orientation and gender identity, and in October 2020 the Government Accountability Office recommended that the Veterans Health Administration similarly collect sexual orientation and gender identity in its EHR system.

Evidence suggests that information on sexual orientation and gender identity is not considered particularly sensitive by survey respondents or by patients in health care settings. A study exploring collection of these data in the emergency department, for instance, found a striking contrast between negative expectations and reality: whereas 80% of clinicians believed that patients would refuse to disclose their sexual orientation, only 10% of patients reported that they would choose not to answer a question about their sexual orientation.[2] Similarly, in a study conducted among racially diverse patient populations in both urban and rural federally qualified health centers, more than 80% of respondents agreed that data about sexual orientation and gender identity are important in health care settings and indicated that they would answer these questions if asked.[3]

Concerns that collection of these data will expose LGBTQI+ people to discrimination are rooted in the long history of mistreatment of LGBTQI+ people by the health care system, including harassment and physical abuse, malign neglect, and harmful practices such as conversion therapy and medically unnecessary surgeries on the bodies of intersex children who are too young to consent.[1,4] Not collecting these data, however, makes discrimination and mistreatment harder to address: without tracking the experiences of patients by sexual orientation, gender identity, and intersex status, it is impossible to identify and rectify patterns of poorer access, treatment, and outcomes for LGBTQI+ people. Standardized and consistent measurement over time is also essential enough to permit robust intersectional analyses of the needs of groups that face mistreatment and disparities across multiple axes of identity, such as LGBTQI+ people with disabilities, Two Spirit Indigenous people, and LGBTQI+ Black and other people of color.

The Office of Management and Budget (OMB) has the authority to promulgate flexible standards to guide collection of demographic data throughout the federal statistical system. As the National Academies report notes, an OMB standard for data collection on sexual orientation, gender identity, and intersex status would give federal agencies guidance on collecting these data in a scientifically sound manner while permitting flexibility to ensure that measures are tailored appro-

priately for different populations, settings, and domains. For instance, in health care settings, all three components of sexual orientation — attraction, behavior, and identity — may be important to measure, whereas sexual orientation identity alone (self-identification as heterosexual, gay or lesbian, or bisexual) might be appropriate in settings such as employment. Explicit federal guidance on gathering these data would also assist states and other entities seeking to expand their own data-collection efforts for purposes such as understanding and addressing the experiences of LGBTQI+ populations during the coronavirus pandemic.

Under the Obama administration, the Departments of Justice, Housing and Urban Development, and Health and Human Services, as well as the Environmental Protection Agency, requested that federal surveys such as the American Community Survey routinely ask questions about sexual orientation and gender identity to improve efforts to protect and serve LGBTQI+ populations. The Trump administration, however, blocked advances in data collection at every turn.[5] With a new presidential administration, as well as the Supreme Court's landmark decision in *Bostock v. Clayton County* clarifying that sex nondiscrimination laws cover sexual orientation and gender identity, the time has come to prioritize a government-wide effort to track and address systemic inequalities by implementing standards for the routine collection of data on sexual orientation, gender identity, and intersex status. Gathering these data throughout the health care and public health systems — as well as across domains such as employment, housing, education, and criminal justice — is essential to identifying the drivers of disparities and promoting the health and well-being of LGBTQI+ people in all areas of their lives.

Disclosure forms provided by the authors are available at NEJM.org.

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This article was published on March 27, 2021, at NEJM.org.

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DOI: 10.1056/NEJMp2032447
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HISTORY OF MEDICINE

"To Mitigate the Afflictions of the Human Race" — The Legacy of Dr. Rebecca Crumpler

Perri Klass, M.D.

For physicians in the 19th century, caring for sick infants and children still meant presiding at inevitable death after inevitable death. The organized public health struggle against infant mortality had not yet taken shape in 1883, when Dr. Rebecca Crumpler published *A Book of Medical Discourses*, yet she believed that many tragic outcomes were preventable. "People do not wish to feel that death ensues through neglect on their part," Crumpler writes, so they "speak of consumption, cholera infantum, and diphtheria, etc., as if sent by God to destroy our infants." But in her view, "there is no doubt that thousands of little ones annually die at our very doors, from diseases which could have been prevented, or cut short by timely aid."[1]

Ahead of her time in many ways, Rebecca Davis Lee Crumpler was the first Black woman