

FOR IMMEDIATE RELEASE
August 15, 2018

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COUNTING A DIVERSE NATION: ADVANCING HEALTH EQUITY THROUGH DISAGGREGATED RACIAL/ETHNIC DATA

OAKLAND, CA — How we measure America’s rapidly expanding diversity has critical implications for the health of the nation. Too often, the data used to drive policymaking, allocate resources, and combat health disparities is based on broad racial and ethnic categories that can render the unique needs, strengths, and life experiences of many communities invisible.

In *Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health*, released Wednesday, PolicyLink presents a multifaceted investigation that explores the leading issues and opportunities of racial/ethnic data disaggregation, and its implications for advancing health equity. The report, developed as part of an initiative commissioned by the Robert Wood Johnson Foundation (RWJF), taps the collaborative input of a multidisciplinary network of experts to provide a comprehensive assessment of data disaggregation practices today, and concrete recommendations for improving research methods and promoting government policies that would enhance and enable data disaggregation.

“America is strengthened by its remarkable array of races, ethnicities, cultures, and languages, but for us to fully benefit from that diversity, and foster healthy communities of opportunity for all, we must be able to document, measure, and appreciate the nuanced experiences of people of all backgrounds,” said Angela Glover Blackwell, Chief Executive Officer and Founder of PolicyLink. “That is why PolicyLink is honored to work with the Robert Wood Johnson Foundation to bring clarity to the issues, ideas, and best practices in data disaggregation through this report.”

The policies and practices that govern how we collect, protect, and employ population-level data have always had important implications for the U.S., but changing demographics, ongoing controversy over immigration, and questions surrounding the 2020 census have brought the far-reaching health, safety, and civil rights implications of data issues into sharper relief.

“Applying a more nuanced approach to disaggregating data has great consequences for our ability to advance health equity, and it also provides a window onto a broad range of important questions about the meaning of culture and identity in American society,” said Victor Rubin, Vice President for Research at PolicyLink, and lead author on the report. “We must thoughtfully improve the design, funding, and conduct of research using population-level data about race and ethnicity at a time of heightened concern over the safety and confidentiality of data and fears of its misuse.”

Though data on health behaviors and outcomes is often disaggregated by broad racial and ethnic categories, such as Black, Hispanic, Asian, White, or Native American, the diversity of the American population means that people’s actual experiences and opportunities for health are much more specific: for example, the health needs of a fifth-generation Chinese American may have little in common with a Hmong refugee from Laos, yet most data will include them in the same Asian American category. On the occasions when data has been more thoroughly disaggregated, it has often shown large differences in the prevalence of chronic diseases, access to care and insurance, and the economic and environmental factors that determine so many health outcomes.

“Aggregating data to those higher levels ignores the significant variation that exists within those broad categories and limits the field’s ability to target its resources where they are most needed,” said Tina Kauh, Senior Program Officer in the Research-Evaluation-Learning Unit at RWJF. “This report represents a crucial first step toward identifying solutions for improving ethnic/racial data disaggregation.”

Findings and recommendations in the report are grouped into two broad areas: methods for collecting and analyzing data about race and ethnicity at more detailed levels; and government policies and practices that can support data disaggregation. Key points within these discussions include:

- The implications of funding cuts within local, state, and national health and population survey budgets, including Federal spending limitations that could impact the 2020 census
- The need for data collection that considers factors beyond race and ethnicity, such as gender identity and skin tone, as well as the implications of migration, legal status, and cultural identity
- The unique challenges, safety concerns, and potential innovations surrounding the collection of data on undocumented individuals, refugees, and other immigrants
- The importance of ethical research practices that engage and empower marginalized communities, giving them ownership and leadership over how their data is collected and used

The report also lifts up advocacy efforts across the nation working to improve representation, including:

- Campaigns for representation at universities, including UCLA’s “Count Me In!” Campaign by Asian and Pacific Islander students and efforts to include a Middle Eastern/North African (MENA) designation at the University of Michigan
- Recent policy wins to enhance disaggregation, including California’s 2016 AHEAD Act, Rhode Island’s 2017 All Students Count Act, and Minnesota’s 2016 All Kids Count Act

In preparation of this report, PolicyLink convened a multidisciplinary set of academic researchers, policy analysts, community-based organizers, health practitioners, data scientists, managers of health surveillance surveys, government officials, funders, and other data users, fostering a collaborative process through which the report’s findings and recommendations were created.

“It is rare to be in fellowship with other data geeks and not have to prove that data disaggregation is important,” said Kathy Ko Chin, President and Chief Executive Officer of the Asian & Pacific Islander American Health Forum and participant in the project. “We’ve never been able to participate with such a wide array of organizations across the country [and] we hope that this kind of network can continue, across all racial and ethnic categories, to help us in our work.”

This network of experts will be an important ongoing resource for the advancement of racial/ethnic data disaggregation, providing expert opinion and community perspectives, making connections across issues, and bringing to bear members’ understanding of the nuances of practice, research, and policy change.

About PolicyLink

PolicyLink is a national research and action institute advancing racial and economic equity by Lifting Up What Works®. For more information, visit [PolicyLink.org](https://www.policylink.org)