

Key Focus Areas for Data Disaggregation to Advance a Culture of Health

These themes and topics emerged from collective discussion across the convenings as key focus areas. The themes were repeatedly brought up as issues, challenges, needs, and opportunities for data disaggregation. Below each theme, the topics elaborate details related to action in research, policy, and advocacy.

Increasing the *visibility of populations* can better our understanding of health disparities among racial and ethnic categories, beyond broad comparisons of major groups, such as White and Black.

- **Data collection on small and hard-to-reach populations** is a chronic challenge for surveys due to logistical, financial, and outreach constraints. The disproportionately low response rates of certain populations limit their representativeness and exacerbate their vulnerabilities and disconnectedness.
- **Multiple definitions of “Indian”** in law and practice complicate and challenge how federal dollars are allocated and distributed. Each federal agency uses their own definitions in funding formulas, from self-identification to formal tribal affiliation. Any solution must honor the sovereign authority of tribes to confer tribal membership.
- **States are beginning to enact laws and policies that improve disaggregation of data about their populations**, with health and education outcomes for the Asian American, Native Hawaiian and Pacific Islander population being the most common focus of these efforts.

There are growing concerns over *fear* of government oversight, *discrimination* of public programs, and *safety* of respondents in data collection, building upon data security challenges for respondent privacy.

- **The current political environment** increases the sense of fear within marginalized communities, specifically the Middle Eastern and North African population and the immigrant population (regardless of documentation status), about data being used for immigration or other law enforcement. When outlets for xenophobia and discrimination are amplified, vulnerable communities retreat from public life. Their access and usage of vital services, including health care, as well as their responses to surveys, will likely decrease.
- **Data security and confidentiality** continue to be an imperative to protect the privacy and safety of communities. Although there is research and advocacy demand for the cross-tabulation of data sets, there are risks of data security breaches, detrimental use of data, and targeting of communities.

Multiple definitions of race and ethnicity, including growth of the multiracial population, are evolving and complicating our understanding of how race and ethnicity affects health.

- **Measuring the multiracial population** is challenging when surveys rely solely on self-reported identity and there is no standardized way to measure this fast-growing population.
- **Misclassification is unavoidable as long as surveys use self-reported data on race/ethnicity and the provision of care uses ‘other-report.’** This misclassification leads to disproportionately inaccurate counts and tracking of the multiracial population and the American Indian and Alaska Native population. These inaccuracies exist throughout data collection, statistical analysis, and reporting, challenging our understanding of multiracial health.
- **Measuring skin tone** illuminates that within-group skin tone variation is associated with greater health disparities than White-Black disparities. When asked in context with other biological markers, there are “near zero missing report data.” Most salient with the Black and

African American population, measuring skin tone may also evolve legal interpretations of discrimination and civil rights beyond race and ethnicity alone.

- **Elements of personal identity other than race, notably sexual orientation and gender identity**, are inextricably interconnected with race and ethnicity with respect to the incidence of, and responses to, health inequities.

Beyond racial and ethnic identity, *immigrants and migrants* have unique characteristics and experiences that affect their health in the U.S. in both positive and negative ways.

- **Accurately measuring acculturation**, which encompasses immigrant integration and assimilation, is essential for a comprehensive understanding of the particular migration experiences of different groups. There are unique protective and resilient factors of being an immigrant that contribute to the immigrant health paradox. At the same time, there are factors like acculturative stress that underscore the dangers of romanticizing immigrant resiliency.
- **Documentation and citizenship** are important to analyze for understanding the nation's demographic trends, economy, and social safety net. Estimation of the undocumented population is extremely difficult and often relies on proxy variables, such as non-U.S.-born and without a green card, but some large-scale surveys have developed effective methods.
- **Internal migration**, both historical and recent, is a critically important factor in upward and downward mobility related to health disparities. For example, the rural to urban migration of Black and African Americans, the cyclical migration on and off tribal lands of urban American Indian/Alaska Natives, and the secondary resettlement of immigrants and migrants all varies access to health care and opportunity. Internal migration has clear implications for health, but many health data systems do not track this information.

Community ownership and efforts to advance data disaggregation facilitate health equity goals and achievements in ways that are respectful of cultural sensitivity, place-based contexts, and people.

- **Community-Based Participatory Research** can incorporate community members and organizations into data collection and research projects, ensuring that research outcomes are in alignment with community needs, voices, and context.
- **Effective access to most large databases** is extremely limited outside of academia and certain government agencies, making it challenging and inaccessible for community-led efforts to use empirical evidence in their advocacy.
- **Community ownership of data** places value on the perspectives of those most affected by health disparities to own, create, and use data in ways that have greater accountability and transparency. This approach also questions the interpretation of statistics that perpetuate false stereotypes and frameworks focused only on identifying disparities, not assets and strengths, of communities.

There are numerous *data access, methodological, and research challenges* that can and should be overcome for researchers and practitioners to grow our common understanding of health inequities.

- **Limited funding and capacity** constrain many state and local health surveys and community organizations from maintaining high-quality and longitudinal data sets that can be analyzed to address health disparities, especially for small population subgroups.
- **Some “roll up” of small populations of particular ethnicities to be included in larger population groups** is inevitable in certain circumstances in order to maintain statistical

reliability and protect the identities of members of small subgroups. This process needs further guidance to maintain the integrity of small subgroups at varying levels of reporting.

- **Indigenous data sovereignty** asserts the authority of tribal governments to own, create, and use data in alignment with their values and needs. This legal sovereignty is based upon *trust responsibility* and the government-to-government relationship with the US. It places central value on the perspectives of indigenous communities, and it counters the *deficient indigene* narrative that perpetuates false stereotypes and disregard for Native culture.
- **Training the next generation of researchers and transforming the fields of demography and population health** will require increased funding, institutionalized systems reform, and a critical analysis to integrate lenses for race and ethnicity, data disaggregation, and health equity.

The *federal government* is critically responsible for many significant policies, data sets, and programs that the field of health equity relies upon to improve the health of those living in the U.S.

- **As grounded in the U.S. Constitution**, counting all the people in the U.S. supports our democracy. More granular data better represents our nation, acknowledges the increasing diversity, and allows for more fair and efficient distribution of resources and services.
- **The U.S. Census Bureau is facing extreme budget limitations** in preparation for the 2020 Census, which will compromise its quality, including its intended innovations in measuring race and ethnicity. A constrained Census would limit our understanding of our nation for the next ten years. Already, there have been cuts to outreach efforts and end-to-end testing.
- **A wealth of federal data is unused** due to legislation that mandates its collection, but not its analysis or dissemination. There can and should be more streamlined collection, analysis, and dissemination that boost the impact of high-quality data.
- **The Office of Management and Budget's** Federal Interagency Working Group for Research on Race and Ethnicity is updating the 1997 *Standards for Data Collection on Race and Ethnicity*, the gold standard for surveying race and ethnicity self-identification and mandatory minimums for subgroup reporting. Recommendations of the Working Group, which embody a strong set of innovations to better account for race and ethnicity in many respects, will come before OMB in late 2017.
- **The Department of Health and Human Services** is one example of an agency going beyond OMB requirements and building the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (National CLAS Standards).

To increase our efficacy in achieving health equity, we need to improve our *making the case* for data disaggregation among researchers, practitioners, lawmakers, business, advocacy, and philanthropy.

- **Understanding the health outcomes of racial and ethnic subgroups** grows our shared understanding of the nation's increasing diversity. Otherwise, we risk overgeneralizing what we know about race and health, masking important health disparities and missing opportunities to develop culturally competent strategies. Data that captures further granularity and within-group differences can better support evidence-based policies that determine the allocation of resources.
- **Opposition to data disaggregation** is often, but not always, linked to ideological opposition to racial preferences and racial consciousness in government spending and programming, and the argument that certain groups would have an unfair advantage over others, particularly in

health, education, and employment. Concerns about diluting the overall size of racial groups can also contribute to skepticism about disaggregation or multiple racial categories.

- **Big Data and the private sector** are facing increasing opportunities to engage with the social determinants of health. These businesses have the capacity to track and distribute data regarding their customers that contribute to a Culture of Health. For example, the Redfin Data Center tracks the housing market and ESRI distributes geocoded data for spatial analysis.

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