Perspective

Making Communities More Visible: Equity-Centered Data to Achieve Health Equity

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Policy Points:

- Despite decades of research exposing health disparities between populations and communities in the US, health equity goals remain largely unfulfilled. We argue these failures call for applying an equity lens in the way we approach data systems, from collection and analysis to interpretation and distribution. Hence, health equity requires data equity.
- There is notable federal interest in policy changes and federal investments to improve health equity. With this, we outline the opportunities to align these health equity goals with data equity by improving the way communities are engaged and how population data are collected, analyzed, interpreted, made accessible, and distributed.
- Policy priority areas for data equity include increasing the use of disaggregated data, increasing the use of currently underused federal data, building capacity for equity assessments, developing partnerships between government and community, and increasing data accountability to the public.

Keywords: community engagement, data disaggregation, health equity.

THE US CENTERS FOR DISEASE CONTROL AND PREVENTION regards "health equity" as a state when every person has the opportunity to "attain his or her full health potential" and no one is "disadvantaged from achieving their potential because of social position or other socially determined circumstances."[1] The COVID-19 pandemic exposed the disproportionate toll on historically marginalized and underresourced segments of the US population through systemic inequities in employment, education, housing, food security, and health care access. These segments of individuals and families were rendered invisible in policy decisions and public investments in health and health care because their assigned social categories—racialized and minoritized, socioeconomic, sexual orientation and gender identity, and differently abled—were already unfairly allocated limited resources.[2–5] Policy neglect for these "invisible" groups is also compounded, and at times misinformed, by differential investments by geographic location. Many of such investments are historically rooted in de facto segregation, redlining, and present-day gentrification.[6] The United States, as a historically inequitable nation, warrants reparative and restorative efforts in addressing the disproportional disadvantages faced by individuals, families, communities, and subsequently, populations. These structural exposures and the consequent experiences of marginalized populations are not documented in policy-setting data. A foundational step toward health equity is getting the measurement, interpretation, and use of structural and systemic bias in health data systems right, especially among populations who are "invisible" in the evidence platforms that inform policies.[5] Measurement and evaluation of systemic bias is a strong step toward achieving health equity, but the findings yielded by measuring and evaluating systemic biases must be paired with investments in infrastructure, protocols, and practice to build an equity-centered data ecosystem.In order to capture systemic bias, we must first ensure data are collected equitably. The collection of data by the federal government classified by racialized or ethnic group has a long and contentious history in the United States.[6] Variations in classification approaches in federal and state health statistics have substantial implications for measuring health status, access, and health care quality. Recent work suggests health disparities research has aided in preserving systems rooted in systemic racism.[7]

Although we have made strides in health disparities and health equity in the past 30 years, the defining goal of population health is to maintain and improve the health of the *entire* population and we have yet

to reduce inequalities between population groups.[8] Doing so requires making the transformative structural changes needed to tackle health disparities. Therefore, a closer look at our data is deeply needed in the conversation on health equity. Our first step is to improve the ways we collect data on racialized and ethnic groups, how we engage with such communities, how data are democratized, and how data can be used in the pathways to policy change.[9]

In this commentary, we focus on data equity in racialized and minoritized groups by commenting on the institutional commitments, notably community-partnered initiatives put forth as priorities by the Biden Administration in 2021.[10] We begin with definitions to frame our commentary. We acknowledge there may not be a consensus on these definitions and the ones we use may be more reproduced by established entities with blind spots in health equity. However, we engage these terms and this commentary to contribute to the momentum of change being led by federal entities in partnership with the communities for whom this change is most salient. Thus, for this reason, we have also chosen to make visible the names of racialized groups that are often made invisible by acronyms.

Definitions

Data Equity

Data equity is a process and a product. It is an essential element of achieving health equity. Throughout the process, marginalized communities help shape how data are collected, analyzed, interpreted, and distributed so that it is meaningful and can be easily accessed by and for their communities. Some examples of the product is what is in the "data dictionaries" of datasets, how coverage bias is reduced (i.e., was the data collected only in English or in several languages) in surveys, how sampling frames correct underrepresentation, how groups are tabulated and depicted in tabular data reports, and how missing data are handled—either dropped or imputed and how they are imputed. A key data equity process example is engagement of communities in all aspects of data collection and dissemination.

A Racialized Group

A racialized group is a collection of individuals that have been grouped together by external entities, such as the Office of Management and Budget (OMB), based on observable and often phenotypical characteristics (i.e., skin color, country of origin, language). In the United States, individuals are racialized (assigned a race or ethnicity) under the current OMB construct of ethnicity as "Hispanic or Latino or Not Hispanic or Latino" and race as "American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or other Pacific Islander, and White." All groups except those racialized as non-Hispanic White are minoritized. We acknowledge that the current OMB minimum guidance on collection of race and ethnicity categories hides identities within the non-Hispanic White categories, such as peoples from Middle East and North Africa, who are also minoritized.[11–13] In this manuscript, to acknowledge the social construction of both race and ethnicity, we use the term "racialized" when referring to racial and ethnic categorization. Racialization is a historic process of assigning individuals to social groups (i.e., races) based on phenotypical characteristics, and discrimination is the process of differentially providing access to those social groups. Although the terms like racialization are less common in health policy research, this term and its inextricable link to discrimination are better known in the fields of psychology and sociology. Because of racialization and discrimination, it is most apt to use the term "racialized group" to acknowledge the role of systems in labeling individuals. To simply refer to these groups as race/ethnicity or racial groups might ignore racialization and might allow the conflation of race with ancestry and genetics.

Health Disparities

The health disparity measurement is comparative—often the comparison of socially disadvantaged communities or populations with a "most advantaged group"—and the focus is on differences in health outcomes, not on the processes or societal conditions that produced the disadvantage. Health disparity measurements by racialized race and ethnicity groups are limited by the quality of the data in its error of omissions and missingness or lack of specificity of populations they purport to represent.

Social Determinants of Health

Social determinants of health, as defined by the World Health Organization Commission on Social Determinants of Health, are the circumstances of people's lives and their access to health care, schools and education; their conditions of work and leisure; their homes, communities, towns, and cities; and their chances of leading a flourishing life. The World Health Organization also identifies the structural determinants of these conditions as the distribution of power, income, goods, and services.

Community

Community has been defined as " any configuration of individuals, families, and groups whose values, characteristics, interests, geography, or social relations unite them in some way."[14] Although communities are often circumscribed by geography or historic experiences of trauma (e.g., genocide, slavery, indentured servitude), smaller communities may be geographically dispersed and place-based initiatives may overlook their health and wellbeing.

The Biden Administration's Racial Equity Policies

When President Biden signed an executive order in January 2021 on advancing racial equity and supporting underserved communities, it was largely seen by many health equity researchers as a much-awaited opportunity to translate research into action and take lessons from research into policy.[15–19] This order was part of a whole government equity agenda in which federal agencies were asked to determine whether their programs and policies perpetuate systemic barriers that hold back marginalized communities. With this momentum, we are poised to begin to make bold policy changes to improve health equity. However, we must pay close attention to the data, metrics, and tools that have built the research base from which many new policy changes will be proposed. There is also an opportunity to improve upon the data systems and methods used to identify health disparities with the goal of improving health equity.

To address the goal of improving equitable data practices, the Executive Order in 2021 initiated the formation of the Equitable Data Working Group.[20] This group, cochaired by representatives from the Office of Science and Technology Policy and the OMB, worked with other federal government representatives, advocates, academics, and community leaders. In April of 2022, the Equitable Data Working Group published a report based on its work, bringing forth a set of recommendations to advance a "long-term vision for equity, data, and policymaking."[21] Key recommendations and tasks from the Equitable Data Working Group are shown in Table 1. Priority areas include increasing the use of disaggregated data, increasing the use of currently underused federal data, building capacity for equity assessments, developing partnership across levels of government and community, and increasing accountability to the public. Under these priority areas, the Equitable Data Working Group identified specific recommendations and described proposed tasks or tasks already underway. Most of the tasks identified to achieve the recommended actions under the priorities are those proposed in the President Biden's Fiscal Year 2023 budget. Table 1 outlines the priority areas, and we comment on the progress needed to achieve health equity below.

Visibility in Data: Disaggregated Data

Most population-based health surveys are mandated to minimally collect data by racialized groups per the 1997 OMB Statistical Policy Directive 15. OMB's racialized categories provide a minimum set of categories. The OMB minimum categories for racialized groups are as follows: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. The OMB minimum categories for ethnicity are as follows: Hispanic or Latino and Not Hispanic or Latino. OMB encourages additional granularity where it is supported by sample size and as long as the additional detail can be aggregated back to the minimum standard set of racialized categories. The Affordable Care Act section 4302 provides more granular federal standards as well as measures of gender (often biologized as *sex*), English language proficiency, and disability status that aligns with the granularity of collection in the American Community Survey.[22] The federal Department of Health and Human Services 2011 guidance specified a collection of seven groups racialized as Asian (Asian Indian,

Table 1. Key Recommendations From the Equitable Data Working Group, Formed Pursuant to Executive Order 13985, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government, January 2021

Priority Area	Selected Recommendations	Selected Tasks Identified for Fiscal Year 2023
Disaggregated data	Revise OMB Statistical Policy Directive 15	OMB to examine racialized group categories, consider including categories that are not represented within the current minimum policy, e.g., Middle Eastern and North African, groups of Asian American, Native Hawaiian, and Pacific Islanders
	Produce disaggregated statistical estimates	Potential funding for National Center for Health Statistics to increase sample size of National Health Interview Survey to allow disaggregated estimates among racialized groups, sexual orientation, and gender identity; funding for Census Bureau to develop sampling frameworks for marginalized communities, improvements in record linkage and imputation methods, and feasibility studies on producing estimates for smaller population groups
	Establish best practices for gender identity, sexual orientation, disability, and rural location	Potential funding for research on how to add questions on gender identity and sexual orientation to the Census Bureau's American Community Survey

Continued

Table 1. (Continued)

Priority Area	Selected Recommendations	Selected Tasks Identified for Fiscal Year 2023
Underused data	Expand protected access to data	Potential funding for the Census Bureau to help social safety nets and business assistance programs obtain demographic characteristics of their participants while maintaining privacy
Capacity for equity assessment	Invest in human capital	Potential agency funding for staff to build statistical, data science, and evaluation capacity to conduct equity assessment
Partnerships across government and research communities	Increase federal-state-local data sharing	Develop federal collaborations with state, local, territorial, and tribal governments, as well as HBCUs
Accountability to the public	Increase transparency about serving underserved populations	Potential funding for federal engagement with underrepresented and underserved communities
	Build user-friendly data access tools	Potential funding for the Census Bureau to develop data equity tools and for National Center for Health Statistics to improve visualization and presentation tools

Abbreviation: HBCU, historically Black college and university; OMB, Office of Management and Budget.

Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asian) four groups racialized as Native Hawaiian or Other Pacific Islander (Native Hawaiian, Guamanian or Chamorro, Samoan, and Other Pacific Islander) and four groups racialized as Latino/Hispanic (Mexican/Mexican American/Chicano, Puerto Rican, Cuban, Another Hispanic, Latino or

Spanish origin).[23] The 2015 Census National Content Test provided preliminary evidence in favor of a separate category racialized as Middle Eastern/North African, but this was not implemented in the 2020 Census.[24]

The action item to revise the OMB 1997 standards are a first step. In our work of providing technical assistance in the "how" of data disaggregation, we found that many data producers and custodians were unclear whether the OMB standards were a "guidance" or a mandate. There is also no explicit incentive or penalty to examine compliance. Regardless of whether it is a guidance or a mandate, disclosure risk mitigation is a staple of statistical agencies in protecting human participants. Thus, it is believed that presenting more "disaggregated" data reduces sample size and increases identifiability in datasets. The balance between reporting more granular racialized group categories with data disclosure concerns requires creating new ways for data producers to increase data access.

We agree with the appropriation of potential funding for the National Center for Health Statistics to increase the sample size of the National Health Interview Survey to allow disaggregated estimates by and across marginalized communities like the racialized, sexual orientation, and gender identity groups. We also endorse funding for the Census Bureau to develop sampling frameworks for marginalized communities to improve record linkage and imputation methods and feasibility studies on producing estimates for smaller population groups. However, a necessary element in better serving marginalized communities is engaging with these communities in the redesign of sampling, data collection, and generation of useful data products. For example, the National Center for Health Statistics could release 5-year National Health Interview Survey public-use files that would facilitate public access to data for smaller racialized, sexual orientation, and gender identity groups. In some cases, incorporating probability-based samples for very small groups is cost prohibitive, so special samples may be considered, as was done in the 2014 National Health Interview Survey for the Native Hawaiian and Pacific Islander community,[25] and in the 2022 California Health Interview Survey to obtain special samples for the Native Hawaiian and Pacific Islander, sexual orientation, and gender identity populations.[26]

Data disaggregation policies, as a way toward data visibility, must include guidance on racialized coding and tabulation in datasets. For populations racialized as American Indian and Alaska Native, there are sampling and methodological challenges abound in identifying

and quantifying the health status, health behaviors, and utilization and access to health care of this diverse population across the United States.[27,28] In a study for the US Office of the Assistant Secretary for Planning and Evaluation, researchers found significant variation in the measurement of groups racialized as American Indian and Alaska Native across population surveys in the United States.[29] Across all nine surveys evaluated, the single-race group "non-Hispanic" was the one category found in most public-use datasets, yet only a minority of those who identify as American Indian and Alaska Native are racialized as not Latino/Hispanic. Those who identify as American Indian and Alaska Native in combination with another racialized group are often recoded into a multiracial category that does not allow users to identify them as American Indian and Alaska Native. Thus, disaggregation of multiracial American Indian and Alaska Native groups from the overall multiracial category would increase insights for populations racialized as American Indian and Alaska Native. The separation from the broader multiracial categories would also benefit populations racialized as Native Hawaiian and Pacific Islander. American Indian and Alaska Native and Native Hawaiian and Pacific Islander are the two smallest racialized groups in the United States and have the largest segment of multiracial individuals.[30]

The 2020 Census found the group that experienced the largest increase over time was the multiracial population. In 2010, there were approximately 9 million people who reported being multiracial, and in 2020, it grew to nearly 34 million people, which is a 276% increase. How datasets currently handle categorizing respondents who report multiple racialized groups differs, with most placing them in a catch-all category of "multiracial" and some others placing them in a category based on what racialized group they "most" identify with. It is known that self-identification as "multiple race" is vulnerable to the modern fluidity of the social constructions of racial identity.[31–34] In survey data collection, this may be influenced by specific contexts or situations at the time of interview,[35] the respondent's developmental stage of life, the context in which the question is asked, and perceived benefit or loss of identifying one way versus another.[36]

Only a few large-population surveys in which respondents who report more than one racialized group were asked whether they "most" identify with one group: the Behavioral Risk Factor Surveillance System, the National Health Interview Survey up to 2019, and the California Health

Interview Survey. In the Behavioral Risk Factor Surveillance System, respondents who report more than one racialized group are asked which of the reported groups they "most" identify with.[29] This report is coded as the respondent's preferred racialized group. In the National Health Interview Survey, for each household member who is reported by the respondent as identifying with more than one racialized group, the respondent is asked which of the reported groups the household member considers to be their primary.[29] In the California Health Interview Survey, the respondent who chooses more than one racialized group is first asked whether they primarily identify with one group, and if "yes," which one. These follow-up questions help data producers establish tabulation rules that are more precise in depicting the racialized group experience. Depicting the health needs of multiracial people is more complex than a better measurement of group membership. A national survey on being multiracial in America found that "the way in which people describe their own racialized background doesn't always match the way they believe others see them."[37] A recent study compiled evidence that racial identity invalidation impacts the mental health of multiracial people.[38] Increasingly, the addition of "street race" or how one is perceived has been proposed to be included in racialized group measurement, though this approach should be interrogated further.[39]

In sum, data visibility efforts are a major part of data equity and achieving health equity. "Invisible" populations, especially smaller groups, face the risk of imprecise survey estimates stemming from decisions in classification, tabulation, weighting, and public-use data access. The cost of imprecision in health estimates for racialized and minoritized groups that have been disadvantaged by policy neglect, blunt programmatics, and public investment efforts to address health inequities. However, these efforts cannot exist without the contributions of marginalized groups to assist with the development of appropriate identification and measurement of their communities and its impact on health inequities the United States.

Underused Data

The Equitable Data Working Group proposes to address "underused data" through "potential funding for the Census Bureau to help social safety nets and business assistance programs obtain demographic

characteristics of their participants while maintaining privacy." Although this priority seems to benefit programs, we apply this priority domain to populations, in which data are indeed collected but unseen in public-facing files and platforms.

Researchers have had a key role to play in pushing efforts forward in analyzing "underused" data. Recently, the National Institutes of Health Notice of Special Interests have focused research on marginalized populations in which there are limited insights on improving health.[40] Without population-based data infrastructure, these studies may be constrained by scale and lack of prior studies. Thus, potential funding for the Census Bureau to help researchers that are partnered with the communities they aim to generate insight from in getting access to restricted data should be considered in this priority area. Access to restricted data levies time and material transaction costs. These costs lead to lesser production of new knowledge on smaller populations and privileges data insights on groups with readily available public-use data. Encouraging use of data should, therefore, also be directed to researchers in addition to social safety nets and business assistance programs, with a greater proportion going to communities themselves.

Capacity for Equity Assessment

The field of health policy research has largely evolved from being a magnifying glass of disparities to one that recognizes the need to improve health equity. Fundamental to this has been the recognition of the role racism plays in driving inequities and reorienting ourselves to dismantling the structures that systematically disenfranchise racialized and minoritized communities.[41–45]

Developing Metrics on Racism

With the categorizations of racialized groups being the by-products of racism, it is imperative that we include in our scope metrics of racism that capture the process by which racism is directed.[44] Largely, academic communities within sociology, as well as the psychological and social sciences, have led the discourse on racism and how to capture its prevalence and impact on historically marginalized communities.[46–50] Such efforts have spilled over into public health and medicine, which have only in

the last 20 years recognized racial discrimination as a key contributor to health disparities.[51,52] Because of racialized US labor markets and the current housing crisis, many racialized and minoritized communities were disproportionately exposed to severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2; the virus that causes COVID-19).[53–55] The US government, via its underfunded public health and health care infrastructure,[56] aided in the disproportionate access to testing, treatment, and vaccination of racialized and minoritized communities.[57–60] The continued disproportionate policing of racialized and minoritized communities throughout the COVID-19 pandemic[61] and the public killings of members of said communities by the police and citizens empowered by racist ideologies put on display the ways racism is housed and reinforced by a structural system (i.e., structural racism).[44] Hence, the actions of such a system and its impact on racialized and minoritized communities are necessary to capture over time.[62]

There is a repertoire of metrics developed by sociologists, psychologists, statisticians, and epidemiologists from racialized and minoritized communities.[3,63–70] Additionally, there are efforts by scholars like Dr. Rachel Hardeman at the University of Minnesota to develop a portal that houses metrics of racism that scientists, policymakers, and community members alike can use, but the government should be involved in this work. It is not through minimal efforts like funding request for proposals that still encourage racist practices in which highly funded, predominately White research units are awarded thanks to an abundance of resources to swiftly respond to these announcements. The US government can mandate that every data-gathering entity (National Institutes of Health, Census, Department of Defense, etc.) implement metrics of racism that capture multidimensional, multilevel, and life-course racism. Additionally, the government can mandate that each institution measure racism within their institutions (i.e., institutional or organizational racism) and evaluate and report changes over time to the public.[4,71,72] Measuring and capturing racism is a great start toward assessing equity, as it is interlocked with and reinforces other forms of structured biases like sexism, transphobia, xenophobia, immigrant blame and exclusions, and language and accent bias.[45,73–76]

Augmenting Place-Based With
Population-Based Measures for Smaller
Populations

In the Department of Health and Human Services' Health Equity Plan, the department's work on the Minority Social Vulnerability Index is highlighted as a past accomplishment in the agency's work on health equity.[77] This index is a type of equity data tool used to help identify areas of need and allocate resources more equitably to marginalized communities that disproportionately lack access to services including health care, education, safe housing, and other structural and social determinants of health. Developed in 2011, the Social Vulnerability Index was developed by the Centers for Disease Control and Prevention to help government officials identify communities likely in need of support during public health emergencies.[78] The original Social Vulnerability Index incorporated 15 social factors based on Census data including socioeconomic status, language, disability, type of housing, and lack of vehicle. In 2021, the Department of Health and Human Services' Office of Minority Health partnered with Centers for Disease Control and Prevention to produce the Minority Health Social Vulnerability Index, which is an extension of the original.[79] It expanded the social factors included in the original with additional factors and expanded to include statistics for the five racialized and minoritized groups defined by the 1997 OMB Directive 15 and the top five languages spoken by populations with limited English proficient at the county level. The development of the Minority Health Social Vulnerability Index that directly factors in racialized groups, language, and other sociodemographic variables is a notable advance of the tool. But, even if the index does factor in these variables, it may not be able to identify small communities or those that are geographically dispersed.

Therefore, the use of place-based indices must be augmented by population data. For example, populations racialized as Native Hawaiian and Other Pacific Islander suffered the highest case and death rates of COVID-19 in several states.[80] However, place-based multidimensional indices such as the Healthy Places Index in California that triaged rescue and recovery resources in fighting the pandemic overlooked these populations.[81] To better identify Native Hawaiian and Other Pacific Islander needs, place-based indices should have included a broader range of relevant metrics such as proportion of limited English

proficiency or language spoken at home and the proportion of multigenerational/multifamily households. Place-based indices should always be considered alongside population metrics on racism, as described above, and other metrics relevant to the condition or population of interest.

Partnerships Across Government and Research Communities

We endorse the priority of partnerships across government and research communities, especially in building the pipeline of statisticians and researchers from marginalized populations. From a data equity perspective, partnerships require connections to establish and activate shared timely data in the service of preventing and intervening on health inequities. The COVID-19 pandemic revealed the difficulty of timely data exchange with inconsistent reporting of racialized group incidence and mortality rates.[82] A study by the National Committee for Quality Assurance and Grantmakers in Health found inconsistent requirements across federal programs for submission of racialized group data and limited flexibility in collecting granular categories.[23] They give the example of various levels of reporting for populations racialized as Native Hawaiian and Other Pacific Islander; the Women, Infants, and Children Program reports Native Hawaiian and Other Pacific Islander as one racialized population, consistent with the OMB 15 Directive. The Uniform Data System used by Federally Qualified Health Centers disaggregates Native Hawaiian from Other Pacific Islander. Medicaid's Transformed Medicaid Statistical Information System includes more detailed categories for Native Hawaiian and Other Pacific Islander consistent with standards published in 2011 by the Department of Health and Human Services. The National Committee for Quality Assurance and Grantmakers in Health suggests the need for allowing systems to collect the most granular data—in this case, as done in the Medicaid dataset—and allow rollup or aggregation for disparities comparison or harmony with the other datasets when small sample sizes do not allow for reporting of the disaggregated categories. Thus, these intergovernmental partnerships across government, with innovations learned from local and tribal agencies and researchers trusted by marginalized communities, are an important step.

Financial incentives may also help advance data equity actions. In California, for example, state policy requires its health insurance marketplace (Covered California) plans to meet at least 80% completeness of data for all enrollees and to meet standards for racialized group and language data collection, with financial penalties when thresholds are not met.[83] Better collection of racialized group data and data sharing is at the core of California's state Medicaid program (Medi-Cal). This includes California Advancing and Innovating Medi-Cal, which aims to transform Medi-Cal by making it more equitable across the state and integrates the program with social services.[84]

Accountability to the Public: Leading with Community

A community-centered approach to health equity will help identify potential blind spots and invalid identity measures that could lead to tensions and mistrust. Communities have told us that although disaggregation is beneficial and critical to health equity, there is also concern about misuse of data, data security, missing data, misclassification, and lack of trust in who uses these data and why.[11]

We argue here that all federally sponsored or led actions must start with marginalized communities. Community involvement, partnership, and trust building is key to an equity-centered approach.[85] The preferences of marginalized communities outweigh those of entities that develop and manage data. Thus, such entities, including federal and nonfederal, must reckon with the reality that there is no one-size-fits-all approach to making communities visible in data. For a solid foundation, there must be visibility of marginalized communities throughout the pipeline of data equity that is from the data collection or capture to data use to how data are used and by whom.

Limited racialized group disaggregation reporting in health data hinders the opportunity to create outreach and interventions and inform policy investments in communities made "invisible" in the data. Among "invisible" communities, those racialized as Native Hawaiians and Other Pacific Islanders were among the hardest hit by COVID-19 in the United States Community leaders, reporters, and social media were the first to alert the public of the spread in their communities across the United States. However, it was not until mortality data

were accessed and highlighted by community-based researchers did the truth of the disproportionate impact of COVID-19 gain wider recognition and legitimacy among policymakers.[86] In some cases, mortality data were never published in public-use files or publicly available reports with the degree of disaggregation needed to expose the disproportionate impact on communities racialized as Native Hawaiians and Other Pacific Islanders, thus keeping them "invisible" from notice. A coalition of community leaders and researchers known as the National Pacific Islander COVID-19 Response Team was formed to fill the urgent need for data infrastructure for these communities. This led to the formation of the Native Hawaiians and Other Pacific Islander COVID-19 Data Policy Lab in March 2020, made up of a team of graduate students and working professionals, the majority of whom identify as Native Hawaiians and Other Pacific Islanders. The Native Hawaiians and Other Pacific Islander COVID-19 Data Policy Lab responded to community guidance to generate data products and launch an online data dashboard, revealing COVID-19 impacts on populations racialized as Native Hawaiians and Other Pacific Islanders across the United States.[81,87] This platform allowed communities to identify places of need and became a source for data for advocacy for more resources to help communities in which people racialized as Native Hawaiians and Other Pacific Islanders were disproportionately impacted.[88] For example, for the Marshallese community in Arkansas, outreach included enhanced case management of chronic conditions through remote patient-monitoring paired with telemedicine.[89]

Concrete solutions in the right direction include funding for federal engagement with marginalized communities to build user-friendly data access tools, including funding for the Census Bureau to develop data equity tools and for National Center for Health Statistics to improve visualization and presentation tools. Various nongovernmental efforts on COVID-19 dashboards[80,90] rolled out data that scraped from local health departments and that visually displayed and quickly conveyed the narrative of inequities, sometimes obscured by hard-to-grasp data tables. Alongside these local- and community-based innovations, federal engagement with marginalized communities could improve the democratization of data, an essential component of data equity.

Trustworthiness

Trust in how data are being used is critical to participation of communities in the data collection process. Racial profiling, misuse of data, and reporting data to authorities are among a number of concerns marginalized groups have about data sharing with federal agencies.[91] Lack of trust may also come from exclusion and misrepresentation, an example of which includes persons racialized as Asian Americans who have faced racist stereotypes of the model minority, the perpetual foreigner, or the healthy immigrant.[92] Recent hate incidents targeted to communities racialized as Asian during the pandemic have exacerbated fear in these communities and come off the heels of anti-immigrant rhetoric that was amplified during the previous administration.[91,93,94] Building trust with communities requires context, and how questions are asked requires a community-engaged process.[95]

In 2018, when the Trump Administration proposed an expansion of the public programs considered in determining immigrants likely to be deemed a "public charge," marginalized communities were the first to sound the alarm regarding the potential harm this rule change would bring to immigrant communities. Community groups and health centers noted potential trouble when they began to see a decline in the use of health services by immigrants in response to early news about a potential change in the rules about how use of public programs might impact immigration status.[96–101] In California, groups such as Asian Health Services serving racialized and minoritized communities approached trusted academic partners at the Universities of California at Los Angeles and Berkeley to provide estimates of the impact of the proposed rules.[102] Additionally, organizations and coalitions within marginalized communities are central to dissemination efforts, and research was used for education and advocacy.[103] Through this example and others, we see that input from marginalized communities is key to identifying who is being impacted early on by a policy or a change. This input is key to developing a population frame for further research or intervention. Therefore, there is no action toward data equity that the Biden Administration or other entities can take that should be done with substantial involvement from marginalized communities.

Moving Health Equity Research Forward

It has been nearly 40 years since the 1985 Secretary of Health and Human Services' Margaret M. Heckler's landmark report on Black and Minority Health, which brought to light the appalling degree to which health outcomes vary by racialized group.[51] For the most part, researchers, community advocates, and policymakers seem to agree that health and many of the structural and social determinants of health have hardly improved for marginalized communities.[104,105]

The health policy research field has only recently begun to shift from being largely a real-world laboratory in which populations are seen as a medium from which to gather observations to one that seeks to build action by applying findings to the context of achieving equity. One key element in translating health research into policy and action is the ability to gather meaningful socioeconomic and environmental impact data, capturing the nuanced experiences of individuals that impact health, which should include how structural racism has impacted an individual's health over time or their social network or support systems.[106] In their commentary published in this issue of the journal, Alberti and Pierce argue for the "collection of intervenable social factor data, useful at hyper-local levels yet standardized across communities."[107] Such localized data requires community centeredness from data design to dissemination. This means communities are involved in identifying needs, how they are to be seen, and how data are to be used. This type of data collection not only honors the community but offers the ability to conduct better evaluations of policies and programs to be able to identify intended and unintended effects. This impetus for hyper-localized, community-centered data needs to be conducted with provisions for the protection of privacy but not at a cost to data access and data equity.

The high financial costs to obtain data pose a major barrier to access.[27] The price tags attached to obtaining access to datasets prevent the utilization of data, as only privileged, highly resourced institutions can afford such fees. There are already financial roadblocks that dictate who can obtain access to the educational paths that give way to careers in data development, management, and custodianship. These educational disparities influence other resource disparities in which marginalized communities do not own the data that came from their communities and then lack access to the resources to develop sustainable

data infrastructures. Communities have the right to the data collected on them. For instance, tribal nations racialized as American Indian and Alaska Native have the right to collection, ownership, and use of data on their people, known as Indigenous data sovereignty, which has been articulated in the United Nations Declaration of the Rights of Indigenous Peoples.[108] This right is fundamental to what we maintain is leading with the community, being trustworthy, and holding trust. In a review of reporting categories for populations racialized as American Indian and Alaska Native, authors noted the need for alignment of data systems to meet the needs of tribes while considering "(1) tribal nations have limited resources to invest in data systems, and (2) the federal government has an obligation to support the collection of accurate and meaningful tribal data as part of the federal trust responsibility."[27] Ultimately, the collection of any community data should be done to identify and respond to health concerns in the community. Therefore, it is the responsibility of the federal government to accurately collect data and provide guidance on identifying and responding to the needs of populations. Furthermore, it is the responsibility of this federal government to provide access to such data, especially given systemic barriers.

As the US population becomes more diverse with inequitable distribution of resources and agency to effect change, these overarching health equity principles must be operationalized at all federal agency levels and local governments nationwide with marginalized communities at the center of all the conversations and actions. Data equity involves concrete steps to create a more inclusive knowledge pathway, and we hope that in 2 years, these concrete steps will be institutionalized to better inform health policy to uplift marginalized communities.

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