Data Democratization for Health Equity: A Public Health of Consequence, August 2023

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See also Jamal et al., p. 852, and Liu et al., p. 883.

The increasing speed of availability, volume, and complexity of data accessible to public health professionals are paralleled by rapid developments in software programs and applications with cutting-edge computational abilities to manage data. Ideally, the product of these advancements will have powerful potential for affecting population health. For example, from a surveillance perspective, using multisectoral data would provide timely information on population health status and improve our knowledge and understanding of how health inequities are shaped by social, economic, and political forces.[1]

From public health and health policy perspectives, these data would guide where, when, and how to apply policies and practices that would narrow health inequities. It is clear that early in the COVID-19 pandemic the lack of timely, accurate, and accessible data limited public health's ability to determine what local action would avert substantial COVID-19–related morbidity and mortality. As the COVID-19 pandemic evolved, the proliferating data dashboards—at federal, state, and local levels—for providing various types and layers of data on the physical, economic, social, and environmental conditions as drivers of COVID-19 became a mainstay.

Data dashboards are no longer confined to COVID-19: one can find them on opioid overdose[2] and HIV (https://ahead.hiv.gov), as just two examples. Yet, across these domains, challenges associated with developing, managing, and maintaining data dashboards persist and may undermine efforts that can ensure the true democratization of data.

DATA DEMOCRATIZATION

Understanding which agencies manage data collection systems, how they determine what data are collected, and whether, how, and to whom they make data accessible all play salient and significant roles in how data are used. At the same time, the people—and this means everyone—that we collect data from need to have clear assurances that their information will be used to improve their health and well-being, that it will be protected, and that it will be used with their interests at the forefront. In this issue of *AJPH*, we consider some of these key concerns with an eye to how the democratization of public health data can become a community asset in our march toward health justice and health equity.

DATA COLLECTION PRACTICES FOR EQUITY

Collection of data from minoritized and marginalized people involves ascertaining meaningful information with the goal of positively transforming the type and quality of clinical health care services, health promotion and prevention services, and socioeconomic resources that people want, need, and should receive. Increasingly, efforts are being made to collect information on the social determinants of health in clinical settings as well as in federal, state, and local data systems. These efforts, particularly with regard to collecting sexual orientation and gender identity (SOGI) data, highlight how thoughtful and careful data collection practices are necessary to enable sensitive but necessary data collection.

Following a Health Resources and Services Administration mandate that all federally qualified health centers collect SOGI data,[3] a 2016 review of SOGI collection at these centers revealed that 77.1%[4] of health center clients had no SOGI information in their electronic health records. Fast-forward, and in this issue of *AJPH*, Liu et al. (p. 883) report that sexual orientation was not collected on 29.1% of patients and gender identity on 24.0%. Importantly, as Liu et al. note, federally qualified health centers located in the Southern United States, which are more likely to be the usual source of health care for low-income and Black patients, were more likely to do better at collecting complete SOGI data. The authors attribute these gains in SOGI data collection—across all jurisdictions—to provider and clinical staff training efforts. This success does not rest on getting buy-in from clinical staff alone.

The foundation for these successes is honoring the specific and diverse communities served by federally qualified health centers and heeding their feedback on how to reduce provider and staff stigma and discrimination, ensure privacy of information, respect local norms, and translate SOGI data into information and practice that translates into health equity and health justice for LGBTQ+ (lesbian, gay, bisexual, transgender, and queer or questioning) patients. Moving forward, these practices will need to be flexible and consider how to incorporate and honor the diverse cultural backgrounds, languages, and evolving SOGI terminology that are specific to a given region or group. This will require striking a balance between uniformity of methodology and responsiveness to local communities.

DATA ACCESS FOR DATA EQUITY

As with efforts to enhance methods for collecting SOGI data, efforts to collect disaggregated data on Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPIs) have gained momentum over the past decade. The challenges to the logistics of sampling and oversampling across disaggregated AANHPI groups persists, but a more pressing concern is the barrier to accessing these data. Although federal laws and policies governing the privacy and security of public health data are meant to protect the confidentiality of survey participants, these same policies can be significant barriers to gaining access to these data to identify and understand health inequities.

In this issue, Jamal et al. (p. 852) present an overview of federal disaggregated AANHPI data sets; yet, because of concerns regarding security and confidentiality, full and easy access to these data is restricted. Although protecting data is necessary, a lack of accessibility to disaggregated data undermines the ability to understand health inequities in and across AANHPI groups—groups that include vastly diverse linguistic, cultural, religious, and economic domains. The data use restrictions enumerated by Jamal et al. are not negligible and often involve significant costs and other logistical burdens that can prevent use. Once again, the call for striking a balance between protecting confidentiality and enabling data use is warranted. One way to manage data that may provide a pathway for greater data sharing is using the FAIR (Findable, Accessible, Interoperable, Reusable) guiding principles (https://www.go-fair.org/fair-principles). Indeed, such a framework could prove useful to achieving data equity and could become a pathway toward achieving health equity.

CONCLUSIONS

As we continue to compile meaningful data for public-facing dashboards, these dashboards' ability to be in tune with and meet the needs of communities and stakeholders relies on accurate and complete data collection of key social determinants of health and unrestricted access to the underlying data for the communities that they seek to profile.

Let us bear in mind that our goal is not to collect data for the sake of collecting data. Rather, we collect data to transform it into information, which grants us better knowledge and knowledge that provides guidance for evidence-based public health practices. Moreover, to achieve data equity, we need to be engaged with the communities from which these data arise to make sense of the data by understanding the context and human landscape they represent.

A public health of consequence rests on data equity, which encompasses the continuum from data collection to data access—if we are committed to seeing where health inequalities and injustices are present to end them. AJPH

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CONFLICTS OF INTEREST

The author has no conflicts of interest to disclose.

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