Health Systems Need to Transform Data Collection to Advance Health Equity

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At a medical conference in 1966, Dr. Martin Luther King poignantly stated that “of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in physical death.”1 More than 56 years later, America is confronting the most profound health injustices in modern history: the human toll of a pandemic, which unfairly and disproportionately impacts communities of color and other marginalized groups.

America’s inequitable health care system consistently neglects the needs of underserved communities, leaving them more susceptible to illness and infectious disease and without access to quality care.2 Today, the continuing pandemic has crystalized the inhumanity that results when equity is not intentionally woven throughout our national health care and public health services.

Increased Black maternal mortality rates, limited access and timeliness of care, and inadequate preventative health programs were magnified by COVID-19, revealing the depth of institutional racism and systemic health disparities driving adverse outcomes among minority communities.3–5 As we take stock of this legacy of neglect and its impact on too many American lives and families, what was once simply unacceptable should now be intolerable.

It is time for transformational change in our health care systems to advance long overdue health equity for millions of Americans who are regularly denied equal access to quality health care services. The challenge is that you cannot fix what you do not accurately measure. And today, standard data gathering practices among health systems and hospitals are not only siloed and disconnected, but they also rarely capture broader population level data—including vital race, gender, and social determinants of health (SDOH), like education and access to healthy food and stable housing—needed to address structural racism and the health disparities affecting well-being. The lack of data connectivity between America’s health care systems, community health providers, and public health departments has only served to widen America’s health equity gap.

There are 2 related issues that need to be solved to provide desired capacity. First, for the formal health care delivery system, the promised interconnectedness of meaningful use needs to be realized. Second, the myriad municipalities, territorialities, states, and other public health entities desperately need a public health “meaningful use program.” Meaningful use puts forward an agenda for semantic interoperability, or retention of the meaning of data, across different electronic health records. Much progress has been made in that regard, however, the data exchange capacity is lagging behind, though legal and regulatory prohibitions on blocking the flow of information and a trust framework for data exchange are now in place.

This allows new market entrants to monetize the successful flow of data, predicting that over time the benefits of a truly interconnected network will be realized. In contrast, a Robert Wood Johnson Foundation (RWJF) assessment conducted in 2016 determined that many health departments were using paper or obsolete technologies, such as original versions of Lotus Notes®, as their system of records. Many valuable lessons about what did and did not work were gained through the 2009 “meaningful use program” that could be applied to public health.

It is hard to imagine a more worthwhile investment in the public health infrastructure than the standards and technologies for interoperability among public health entities, those entities and health care providers, and the capacity to efficiently aggregate critical data nationally to better prepare for novel challenges such as pandemics, as well as the continuing challenges of health inequities.

The key to driving greater health justice is an equity-focused modernized interconnected data infrastructure that helps us detect, measure, and identify the tools to eliminate...
our nation’s persistent and growing health inequities. It is not enough for hospitals to know that communities of color have higher rates of colon cancer and heart disease. Health systems, public health agencies, and community partners need a shared data-driven understanding to set goals and measure progress addressing the issues that contribute to poor health outcomes.

The good news is that the expertise and technologies needed to revamp our health data infrastructure are widely available and, in some cases, already being successfully used to promote health equity. The more arduous task is galvanizing cross-sector support among the payer, health care provider, and public health sectors to embrace a shared mission to aggregate equity-centered data collection as a vital means to eliminate disparities and improve health care outcomes across America. As the entities that most immediately contend with the medical consequences of disparities, here are 3 key steps that health systems and hospitals can champion to lead the charge for long-overdue health data systems reform.

Setting Comprehensive and Unifying Standards for Data Collection

Current Office of Management and Budget (OMB) standards for race and ethnicity data required for federal programs, including Medicare and Medicaid, are archaic and inadequate. They do not reflect the complexities of our current national demographics, nor do they identify data needed for both individual care and community health, such as sexual orientation and gender identity. Similarly, collection of data regarding social determinants is currently optional. Given that 80% of factors contributing to population health outcomes in the United States are identified as SDOH, it is abundantly clear that America’s health systems are not uniformly using the critical data required to improve health and health equity.

Moreover, systems used by health care providers and public health agencies do not “talk to each other.” Forging a national consensus to set a new unifying standard for equity-centered data collection among government agencies, health care systems, hospitals, and the public health sector is urgently needed.

Health systems and hospitals must embark on the challenging yet critical work of embedding greater equity in their data collection practices. We applauded the National Committee for Quality Assurance (NCQA)’s new 2023 Health Effectiveness Data and Information Set quality measures for health plans, which recommend greater transparency and disaggregation of race and ethnicity data, and include revisions to “acknowledge and affirm” member gender identity. At the provider level, The Joint Commission requires compliance with new accreditation standards for hospitals and health care systems as of January 1, 2023.

These new standards call for evidence that institutional leadership is committed to rooting out health disparities by using data on health-related social factors to improve health care services and patient care outcomes. And for its part, the RWJF’s National Commission to Transform Public Health Data Systems offers a detailed roadmap and recommendations for comprehensive data systems reform, including centering health equity and well-being in narrative change; prioritizing equitable data governance and community engagement; and ensuring public health measurement addresses structural racism.

The newly announced Sync for Social Needs coalition is also a step in the right direction. This new initiative, launched at the 2022 White House Conference on Hunger, Nutrition, and Health, paves the way for leading health technology companies and health systems, including the Department of Veterans Affairs, to standardize the collection and sharing of critical patient data on social determinants, such as food insecurity.

Refinement of health systems’ current demographic and SDOH data standards can be used in conjunction with clinical and community outcomes data to identify racism and marginality and, in turn, to address the social conditions that consistently drive inequities among marginalized communities. These data related to social factors are similarly critical to public health and can be collected during patient encounters using standardized questions. However, public health systems’ effectiveness would also benefit from updated OMB guidance.

We invite health systems and hospitals to join the national commission in urging the White House, the U.S. Department of Health and Human Services, OMB, and Congress to establish an interagency data council, with responsibility for improving equity, racial justice, and social and public health data collection.

Connecting Provider and Public Health Data Technologies

The pandemic provided a stark reminder that health systems and services that maintain too narrow a focus on member health versus the health of the broader community results in tunnel vision and reduced quality of care. The computerization of hospitals, health systems, and physician offices was achieved over the past decade, largely due to federal policy that both supported implementation of electronic health records and required them for participation in federal programs such as Medicare and Medicaid. Unfortunately, no such support has previously existed for building the public health infrastructure. This is the moment to address 3 issues.

First, funding for public health programs must include greater allocations for the widespread adoption of interoperable public health information technology. Second, such technology must embrace revised social and demographic data as already described. Finally, public health information technology must be able to exchange critical information with health care providers.

Although the COVID-19 pandemic demonstrated the peril of not having a national public health data infrastructure (and further taxed already stressed hospitals and health systems by diverting caregivers to tasks such as counting masks and reporting cases), local examples of the adverse impacts of the lack of connectivity between public health and provider systems also exist. The “blue-ribbon panel” that investigated the Dallas hospital behind the delayed diagnosis of the Ebola virus found that a lack of awareness of the sociodemographics of the surrounding community was the root cause of the delay.

It is this simple: public health must inform health care and health care must inform public health. Without that
reciprocity, neither health nor care can be optimized, nor can disparities in communities or individual health outcomes be addressed. The administration’s “Sync for Social Needs” initiative mentioned earlier is an important effort to engage the informatics community, quality measurement and assessment organizations, and health care providers in actual use cases that introduce new standards for social determinants. The initial use case is related to food security and nutrition.

Build Trust in Data Collection and Governance

There is a widespread perception that collecting data on people’s race, ethnicity, and other SDOH is a threat to people’s privacy and could lead to greater discrimination in health care. Historically, health data have not been collected with sufficient community partnership and engagement to build trust. Currently, many state laws simply prevent health systems from asking members about their race, ethnicity, and language. In 2019, fewer than 25% of commercial health plans had race data for even half of their members.14

But the reality is that the lack of data collection on these critical identifiers has a direct and adverse impact on individual and community health. Building trust in data collection and how it is governed are essential to the widespread adoption of modern equity-centered data gathering practices across America’s health care systems and hospitals.

The public health sector must work together with health systems to institute data governance strategies that are developed in consensus with the communities they serve. These can include privacy checks such as tiered access and data deidentification, which would strengthen confidence in new heightened standards for data collection efforts. There also needs to be greater transparency in grassroots communications surrounding legitimate concerns about trust, privacy, confidentiality, and security.

Questions such as “how will my information be used?” and “will I receive any remuneration from medical breakthroughs associated with using my data?” should be addressed openly and honestly. This starts with sustained and deep conversations with communities whose health status has suffered because of the lack of actionable data to address and prevent health inequity.

Health systems must balance the collective public good with individual privacy concerns by advocating for secure and efficient linkages with race and origin data through the newly formed National Secure Data Service, which was authorized by Congress to improve data analytics in a “privacy-protected” environment.15 Fears of discrimination and invasion of privacy can also be addressed by implementing education initiatives centered on the value of data in improving individual and community health outcomes.

In addition, health systems should conduct workforce training on new and improved data collection practices, with a focus on building greater cultural awareness and advancing a systemwide cultural shift from explicit bias to conscious inclusion. Championing policies that ensure the autonomy and security of health systems data will be integral to building the trust needed for a comprehensive data systems overhaul.

Health equity in America can only be achieved through systematic changes, which are more achievable today than at any point since Dr. King highlighted health injustice in 1966. Not only have the nation’s most influential leaders in setting health care standards, including NCQA, OMB, the Joint Commission, and RWJF, publicly committed to advancing more equity-focused health data practices, but a broad national evidence-based movement has established the SDOH as critical factors in fostering healthier communities nationwide.

Martin Luther King also said that “the arc of the moral universe is long, but it bends toward justice.” That arc needs help, and Congress, the administration, public and private health systems, insurers, employers, community, and nongovernmental organizations—in short, every sector of society—has a critical role to play in building 21st century equity-centered health care and public health systems. With bold leadership, we must develop policy, deploy technology, and adopt the best practices that capture the complex demographics and social determinants driving our nation’s deepest structural inequities. Now is the time to implement transformational data systems reform to begin dismantling this legacy of neglect—and deliver on the long-overdue promise of health justice and equity for all.

Author Disclosure Statement

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References


