

Using Data to Advance Racial Equity in Healthcare



Using Data to Advance Racial Equity in Healthcare

Temilola Afolabi and Matt Rumsey

Center for Open Data Enterprise



2022

TABLE OF CONTENTS

Foreword 4

Executive Summary 6

Current State of Data for Racial Equity in Healthcare 8

 Federal requirements and actions on using data for racial equity 9

Racial Equity, Healthcare, and Data: Specific Topics 11

 The social determinants of health 12

 COVID-19 14

 Climate and environmental justice 16

 Emerging technologies 18

Cross-Cutting Themes in Using Data for Action on Healthcare Equity 20

 Community engagement and cultural sensitivity in designing and using
 data programs and technology 21

 Trust and data collection, use, privacy, and security 22

 Equitable data governance, data sovereignty, and data ownership 23

 Access to data and technology 23

 Data quality and gaps 24

 Data standards, interoperability, and sharing 25

 Technical capacity and resources 26

 Information and public health communication for data and technology 27

Recommendations for Leaders 28

Conclusion 30

Participating Organizations 31

Acknowledgments 36

About the Authors 37

Key Contact Information 38

Recent Reports from the IBM Center for The Business of Government 39

FOREWORD

On behalf of the IBM Center for The Business of Government, we are pleased to present this new report, *Using Data to Advance Racial Equity in Health Care*, by Temilola Afolabi and Matt Rumsey with the Center for Open Data Enterprise.

As the COVID-19 pandemic has evolved, multiple studies and reports have documented that Black Americans and other people of color are at higher risk of adverse health outcomes. Existing health disparities in the U.S. are heavily influenced by the conditions in which people are born, grow, live, work, and age, known as the social determinants of health (SDOH). Health outcomes can also be influenced by differential applications of emerging technology and differential effects of climate change.

Governments can use open data about the impact of the SDOH, technology, and climate change to manage health care programs and services in ways that drive more equitable outcomes for patients and their families. Moreover, better and more available data, combined with the use of emerging technologies, can help illuminate the problem and support new solutions to address health risk and access in a way that reduces the potential for bias.

In April 2022, the IBM Center for The Business of Government and the Center for Open Data Enterprise (CODE), with additional support from the health management company ZeOmega, collaborated to host a discussion of these and related issues via a *Roundtable on Open Data for Racial Equity in Healthcare*. The event included a public webinar followed by a highly engaged virtual discussion with dozens of experts. This report draws on the insights shared in that session, as well as additional research led by CODE, to refine findings and develop actionable recommendations for government leaders.

The Roundtable included a diverse range of perspectives. Plenary and breakout sessions brought together academic and research stakeholders, civil society representatives, government officials, health care experts, and other private and nonprofit leaders. The wide and deep interchange of views provided a rich base of information from which to draw conclusions, which addressed technical data issues as well as organizational and process change.



DANIEL J. CHENOK



MONIQUE OUTERBRIDGE



This report builds on recent work of the Center that has addressed how governments can emerge stronger given continuing impacts from the pandemic, including *Enabling a More Resilient and Shared Supply Chain Strategy for the Nation: Lessons Learned from Covid-19*; *Emerging Stronger and More Resilient: Responding to Covid-19 and Preparing for Future Shocks*; *Managing The Next Crisis: Twelve Principles For Dealing With Viral Uncertainty*; and *Covid-19 and Its Impact: Seven Essays on Reframing Government Management and Operations*.

We hope that this report provides helpful perspectives for government leaders and stakeholders in designing effective and equitable strategies and programs that promote better health outcomes for all Americans.

Daniel J. Chenok
Executive Director
IBM Center for The Business of Government
chenokd@us.ibm.com

Monique Outerbridge
Partner, US Federal Health
IBM Consulting
Monique.Outerbridge@ibm.com

EXECUTIVE SUMMARY

The COVID-19 pandemic along with the accelerating impacts of climate change have underscored the fact that Black, Indigenous, and People of Color (BIPOC) in America are at a higher risk of adverse health outcomes than their white counterparts.

The COVID-19 pandemic along with the accelerating impacts of climate change have underscored the fact that Black, Indigenous, and People of Color (BIPOC) in America are at a higher risk of adverse health outcomes than their white counterparts. While public health experts have been concerned about racial disparities in health for decades, this new awareness, and new government actions, provide an opportunity to address the issue more effectively and find data-driven solutions. President Biden's administration has made it a priority to use data to advance racial equity across a variety of domains, including health. His [Executive Order 13985](#), "Advancing Racial Equity and Support for Underserved Communities Through the Federal Government," created the Equitable Data Working Group and has led to individual Agency Equity Plans, including [new efforts](#) by the U.S. Department of Health and Human Services (HHS).

The Center for Open Data Enterprise (CODE) and the IBM Center for the Business of Government (IBM Center) have now partnered to explore how data related to health risk, healthcare access, and health outcomes can be leveraged to reduce these disparities and improve health equity in the United States. This paper builds on discussions at the *Roundtable on Open Data For Racial Equity in Healthcare* held by CODE and the IBM Center in April 2022 with support from population health management company ZeOmega. It describes ways that data can be applied to improve equity in healthcare and provides insights and recommendations for the Biden administration, the healthcare industry, community-based organizations (CBOs), and other leaders.

Opportunities and insights

The Roundtable began with a public Webinar (available in [video here](#) and as a [transcript here](#)), followed by a day of small-group discussions organized around four opportunity areas: the social determinants of health (SDOH), COVID-19, climate and environmental justice, and emerging technologies. While COVID-19 and the impact of climate and environmental injustice are unfortunate examples of health inequity, they also can provide insights that can improve equity during the next pandemic, climate-related disasters, or in healthcare overall. Meanwhile, the SDOH can help us understand where and why inequities exist and—more and more—take action to address them. Finally, emerging technologies can help health experts understand and implement the lessons from COVID, climate, and the SDOH.

While opportunities exist in each of these areas, the Roundtable also uncovered several themes that must be addressed to bring the power of data to bear on the existing inequities in American healthcare: trust and data collection, use, privacy, and security; equitable data governance, data sovereignty, and data ownership; access to data and technology; data quality and gaps; data standards, interoperability, and sharing; technical capacity and resources; and information and public health communication. Success also requires two important questions:

who is impacted by, and who benefits from, the use of data in healthcare? Ultimately, to increase equity, impacted communities have to benefit from the use of data collected from and about them.

Recommendations

Finally, this report presents a series of recommendations for leaders in the space:

- Supplement automated data collection (via satellite or other technology) with community-based data collection to ensure that data reflects the lived experience of communities it is about.
- Develop multi-stakeholder, community-led governance models for artificial intelligence and machine learning (AI/ML).
- Engage with organizations dedicated to improving quality and reducing bias in AI applications.
- Support development of a National Secure Data Service to ensure inclusion of health data.
- Promote approaches to data sovereignty that put control of data into the hands of those from whom it is collected.
- Continue efforts to expand access to broadband to all Americans.
- Inventory and update local, state, and federal regulations that may be restricting access to telehealth and other emerging health technologies.
- Expand access to geocoded data at the sub Census tract/ZIP code level.
- Explore opportunities to expand access to racially/ethnically disaggregated data.
- Invest in CBO data and technical capacity through grants and other financial support mechanisms.

Current State of Data for Racial Equity in Healthcare



Federal requirements and actions on using data for racial equity

The federal government has made leveraging data to advance racial equity and support underserved communities a priority during the Biden administration. Executive Order 13985, which established the Equitable Data Working Group, required agencies to conduct equity assessments and plan for more equitable practices in the future. This work has highlighted several themes that are particularly important for racial equity in healthcare, and that also emerged during the Roundtable: the need for high-quality, safely accessible, disaggregated data; the critical role of community engagement; and the interconnection between demographics, social factors, and outcomes.

Executive Order 13985 acknowledges that federal datasets are often not “disaggregated by race, ethnicity, gender, disability, income, veteran status, or other key demographic variables.” The Equitable Data Working Group is designed to address this gap by “identifying inadequacies in existing federal data collection programs, policies, and infrastructure . . . and . . . support agencies in implementing actions . . . that expand and refine the data available to the federal government to measure equity and capture the diversity of the American people.”

The Equitable Data Working Group released its first report, *A Vision for Equitable Data: Recommendations from the Equitable Data Working Group*, in April 2022. The report highlighted “priority uses for equitable data,” including using disaggregated data to better understand historically underserved groups and expanding access to disaggregated data among researchers and communities. It also recommended approaches that assess “compounded experiences and overlapping identities” because those interconnections are often tied to the need for specific programs or services.

Finally, the report acknowledges that collaboration across agencies and with a “diverse community of external organizations” is key for building equitable data infrastructure. It also acknowledges that “providing tools that allow civil society . . . and community to use . . . federal data and chart government’s progress towards equitable outcomes is crucial for strengthening accountability and credibility with the American public.” All of these themes are relevant to equity in healthcare, as the Equitable Data Working Group acknowledges in the [release materials](#) for the report. There, they held up the “patchwork of data” on health and healthcare status as a barrier to understanding how and why care and outcomes differ across demographic groups.

More than 90 federal agencies have now released their “[equity action plans](#).” While these plans are not specifically oriented around data, many explore relevant issues and some present data driven best practices. For example, the Department of Education is [planning to create](#) an “Equity in Education” data dashboard that will provide access to relevant language and statistics, and may be expanded to include state and local data. This could serve as inspiration for other agencies, particularly HHS, which could combine data on the social determinants of health (SDOH) with information from Medicaid, Medicare, and other sources to explore health equity.

The HHS [equity action plan](#) is particularly relevant for leveraging data to improve racial equity in health. The plan outlines a path to “assess and change policies, programs, and processes . . . to concretely advance equity,” while also evolving HHS’ organizational culture. To do so, it embraces the core themes of data, community, and understanding the root causes and interconnections that lead to inequities.

This plan will enable HHS to build on existing, data-driven programs that address health equity. In the past year alone, HHS [launched or expanded](#) programs focused on health equity

across relevant topics like COVID-19, climate change, and social vulnerability. They established the Office of Climate Change and Health Equity (OCCHE) and [launched a dedicated Office of Environmental Justice](#) within it, developed a Minority Health Social Vulnerability Index, and established the COVID-19 health equity task force as part of an effort to increase engagement with individuals impacted by HHS policy. Additionally, efforts like [Healthy People 2030](#), which “sets data-driven national objectives to improve health and well-being over the next decade,” show the commitment by HHS to driving better health outcomes for all Americans using data-driven approaches.



Racial Equity, Healthcare, and Data: Specific Topics



The *Roundtable on Open Data for Racial Equity in Healthcare* was designed to fit within this context of a growing focus on using data to advance equity in the United States and to put a particular lens on issues related to data for equity in healthcare. It explored the topic through four timely, high-impact areas: social determinants of health (SDOH), COVID-19, climate and environmental justice, and emerging technologies.

The social determinants of health

The SDOH—defined as conditions in the places where people live, learn, work, and play—have many applications related to equity in healthcare and the impact of the COVID-19 pandemic. Health disparities in the U.S. are heavily influenced by the SDOH and data on them enables policymakers to understand health inequities and analyze healthcare disparities across communities. Factors like a poor neighborhood environment, substandard housing, limited access to healthy food, and other social determinants are closely intertwined with access to high-quality healthcare and overall health and well-being. The diagram below, which was first published in CODE’s [summary report](#) from its earlier Roundtable on Cross-Sectoral Collaboration on the Social Determinants of Health, illustrates the interconnected nature of the SDOH.



SDOH data are produced by the government, collected by the private sector, or aggregated and shared through third parties like research and civil society organizations. The rise of interest in the SDOH has been complemented by increasing access to this kind of data, which is being used to develop public health strategies, support health research, and target the delivery of social services.

Addressing the various aspects of the SDOH can help predict and improve overall health outcomes and well-being of individuals and communities, particularly those that are most at risk. The use of SDOH data has the ability to catalyze predictive analytics through improved location-based data about at-risk communities. This data can be collected directly from a patient in a clinical setting, and can be used in combination with an individual's electronic health records to better understand the possible risks they face. It can also be collected at the population level from a wide range of sources including federal, state, and local government agencies. Population-level SDOH data can be leveraged to develop an understanding of risks shared by groups of individuals in the same community or who share other characteristics.

While they apply to Americans of all races and ethnicities, SDOH data can be an especially important tool to understand and address issues of racial inequity in health. In particular, these data can help identify factors that interfere with healthcare access and show their relation to race. Access to healthcare is both an important determinant of health and a necessary means of addressing other SDOH factors in coordination with public services. The SDOH factors that impact healthcare access range from income and education, to public transportation and availability of healthcare facilities, which may disproportionately affect minority communities.

The federal government has embraced this understanding of the value of SDOH data, with a growing number of agencies highlighting the SDOH as central to policies and programs. For example, the SDOH have been identified as one of the main priority areas for [Healthy People 2030](#), which has an overarching goal to “create social, physical, and economic environments that promote attaining the full potential for health and well-being for all . . .” as well as a number of specific objectives related to SDOH. Healthy People's SDOH objectives were developed by a dedicated [Social Determinants of Health Workgroup](#).

The value of the SDOH has also been acknowledged as part of HHS' broader strategic focus. The Office of the Assistant Secretary for Planning and Evaluation (ASPE) [has developed](#) and shared multiple documents that explain why the SDOH are a departmental priority, describe HHS' strategic approach and specific actions to address them, and show how this strategy is based on data-driven, evidence-based learning. This strategy can be seen in recent actions by HHS. For example, the Centers for Medicare & Medicaid Services [has issued guidance](#) for states to address the SDOH to lower costs and improve outcomes for Medicaid and Children's Health Program (CHIP) recipients.

Despite the demonstrated value of SDOH data, there are [many gaps](#) in its availability and usability. Specific needs in this area include the need to better define and standardize SDOH data, including the use of open source assessment tools and improved data governance; to create a sustainable infrastructure for SDOH data, including the involvement of community-based organizations (CBOs); and to support local and state-based decision-makers using SDOH data.

Some of the key takeaways from the Roundtable discussion sessions on the SDOH include the suggestion that SDOH data use needs to go beyond identifying disparities, and shift towards directly addressing them. Furthermore, this data should be collected with the intention of understanding community needs, and an eye towards potential bias in data collection or use, privacy issues, and data ethics. Finally, SDOH data is still generally underused. Some of the data that does exist is underutilized, while other factors, such as social isolation, need to be more widely recognized as social determinants of health.

COVID-19

The COVID-19 pandemic has highlighted the high risk that BIPOC individuals have of adverse health outcomes, including much higher than average rates of severe COVID-19 infection and death. Official Centers for Disease Control and Prevention (CDC) [statistics](#) from early stages of the pandemic showed that Hispanic Americans are dying at four times the rate of their non-Hispanic white counterparts, while Black Americans were dying at similarly high rates. At the same time, there is little evidence suggesting there are underlying [genetic or biological factors](#) that make BIPOC individuals more likely to die of COVID than other demographic groups.

The risk of COVID may, however, be influenced by underlying health conditions that are more common in some demographic groups. For example, Black, Hispanic, American Indian and Asian American people are all at higher risk of developing [type 2 diabetes](#). Having certain conditions such as diabetes and [asthma](#), which is also highest among [Black Americans and Alaska Natives](#), increases the risk of severe illness from COVID-19.

Since the start of the pandemic, it has been challenging to track data on COVID-19 to understand these risks, determine how the virus spreads, and understand how different groups have been impacted by it. The COVID Tracking Project was launched to deal with the [complexity](#) of the data and data collection necessary and to fill [gaps](#) in federal data around COVID testing. Efforts by the media and volunteers, local, state, and federal government offices, and the private, nonprofit, and academic sectors eventually led to a [wealth of data](#) on the spread of COVID-19 and its impacts. Advances in data collection and infrastructure made during the pandemic could be institutionalized and expanded to help prepare for the next global public health challenge.

Research into disparate COVID-19 outcomes has focused increasingly on the impact of SDOH. A growing body of evidence shows that the SDOH have a major influence on an individual's health status—as much as, or even more than, the standard epidemiological measures that have been the basis of many COVID-19 models. These factors can provide insight into the differences in COVID-19 risk and outcomes between BIPOC and other communities.

An understanding of SDOH factors can [help explain and ultimately reduce](#) the high risk of COVID-19 that BIPOC communities have faced. Epidemiologists and public health researchers can use SDOH data to determine how social and environmental factors affect the spread and severity of the disease, while state and local public health departments can use SDOH data to design interventions and allocate the use of healthcare resources for COVID-19. There are many ways that different social determinants may impact the risk of COVID-19 infection and its severity in communities of color. Roundtable participants pointed out that social isolation, internet access, and vehicle ownership all play a role in COVID-19 risk, and BIPOC communities are historically more disenfranchised in many of these SDOH areas.

Racial and socioeconomic disparities interconnect with the SDOH in a number of ways to impact COVID-19 risk. Broadly, the stress associated with racism can increase disparities in

[physical and mental health](#), increasing the likelihood of severe COVID infection. Lack of access to healthcare affects the ability to prevent severe illness and death from COVID-19, and racism can impact the quality of healthcare. For example, communities of color are more likely to encounter barriers to getting healthcare through lack of health insurance or sick leave. BIPOC individuals, particularly Hispanic Americans, may also lack insurance. Poor healthcare can also contribute to underlying health conditions, such as obesity, hypertension, and chronic kidney disease, that increase the risk of serious COVID infection. Working conditions also contribute to a greater risk of infection. Many people of color work in essential jobs that cannot be done from home, require personal interaction, and come with limited sick time—even if they offer healthcare benefits. For example, [nearly 25 percent](#) of employed Hispanic and Black Americans work in service industries, compared with just 16 percent of non-Hispanic white workers.

Americans who are Black or Hispanic, immigrants, or have low-incomes are more likely to rely on [public transportation](#) to get to these jobs. Research indicates that public transportation [may have served](#) as a major source of coronavirus transmission during the early days of the COVID-19 pandemic. While wealthier individuals can avoid high risk settings like public transportation by driving or working from home, those in the service sector and other lower paying occupations don't have the same flexibility, further increasing their risk.

Crowded living conditions and unstable housing also contribute to greater infectious disease transmission, and can hinder the ability to adhere to prevention strategies. Asian, Hispanic, and Black Americans are more likely to live in [multigenerational](#) and crowded homes than white Americans.

In a recent turn of events, new studies are showing that the COVID death rate has declined for Black, Latino, and Asian Americans, and is actually now lower than the death rate for white Americans. This dramatic reversal is primarily due to a rapid increase in vaccination rates among Black and Latino Americans since 2021. As of May 2022, vaccination rates for both of these populations were slightly higher than those of white Americans. Researchers are attributing this increase in vaccination rates to intense, bottom-up outreach efforts by medical workers, community organizers, and others. While this may turn out to be a public health success story, the underlying factors that increased COVID risk for Black and Latino Americans still remain—and the total COVID death rate for Black and Latino Americans remains the highest among races, due to early disparities being so large.

A [recent report](#) raised concerns that Black Americans may also be more likely to face the negative impacts of Long COVID. [Long COVID](#), a term for post-COVID-19 conditions, can include a wide range of ongoing health problems, which can last weeks, months, or even years. Although post-COVID conditions are found more often in people who had severe COVID-19 illness, anyone who has been infected with the virus can experience them, and a recent CDC study [suggests that](#) more than one out of every five people infected with COVID could develop Long COVID.

The [symptoms](#) of Long COVID can include respiratory and heart symptoms, like heart palpitations, neurological symptoms, including paresthesia and brain fog, digestive symptoms, such as stomach pain, and other general symptoms, including fatigue, joint pain, and changes in menstrual cycles. The National Institutes of Health (NIH) has developed a well-funded [research program](#) to study and prevent Long COVID, even though funding for immediate COVID prevention and treatment has been stalled. Black Americans may specifically face barriers accessing Long COVID trials and research studies, treatment programs, and patient registries.

At this stage of the pandemic, researchers and public health officials are continuing to address the urgent needs of vulnerable populations, while simultaneously ramping up research on the disease and possible treatments. Roundtable participants identified a number of themes that can impact their success. They noted the lack of trust in government and the healthcare system in many BIPOC communities for various reasons, including the prior handling of pandemics like H1N1 and SARS, and the historical mistreatment of minority and indigenous communities by the healthcare system. Participants discussed the need for increased general and COVID health literacy among both healthcare professionals and the public, particularly in underserved communities. Better education on vaccines and how COVID affects the body could improve outcomes while increasing trust.

Roundtable participants also pointed out the lessons learned from the pandemic that can help improve data systems in the future. COVID-19 has demonstrated an overarching need for stronger data systems as well as the value of certain new technologies. Technologies like text messaging, telehealth, and apps for contact tracing have been widely leveraged during the pandemic and should continue to be used in the future.

Climate and environmental justice

The growing national focus on environmental justice is adding new urgency to addressing environmental and climate impacts on health. [Multiple studies](#) have documented how communities of color are disproportionately impacted by air and water pollution, including lead in the water supply, and other negative environmental consequences of the built environment. For example, industrial plants and concentrated animal feeding operations (CAFOs) are more likely to be located in [communities of color](#).

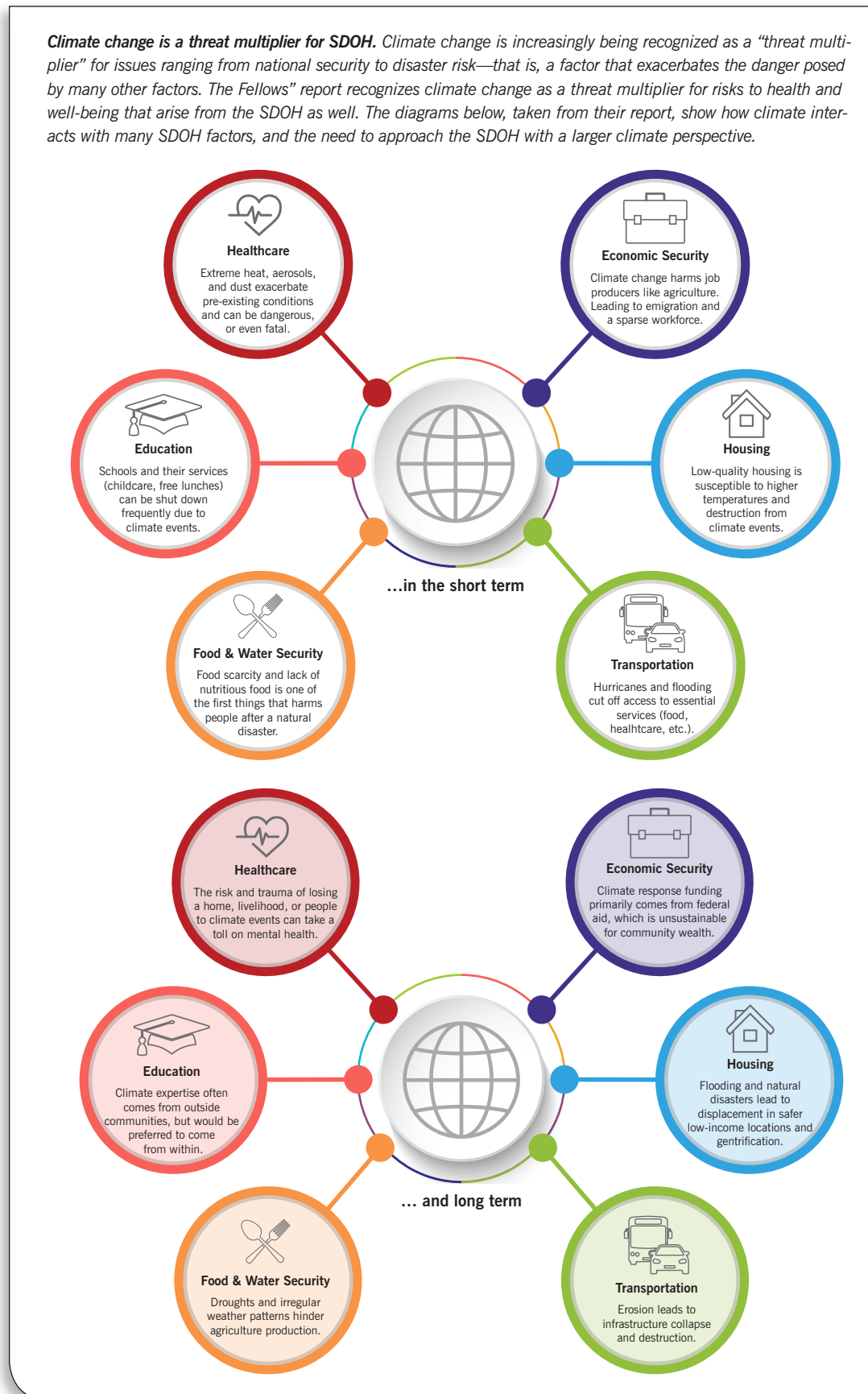
Recent efforts to advance environmental justice have drawn attention to the connection between race and the risk of environmental hazards. Recently, the Council on Environmental Quality released the [Climate and Environmental Justice Screening Tool](#) (CEJST) as a tool to help direct funds to disadvantaged areas under the Justice 40 program. The CEJST did not include race as a factor, and was criticized on that basis. However, [an independent analysis](#) showed that the results of the tool would have been similar if race had been included, showing that race is highly correlated with other factors related to environmental risk.

Climate hazards may have an especially dangerous impact on communities of color. A recent [CODE Roundtable](#), co-hosted with the National Oceanic and Atmospheric Administration (NOAA), studied the use of data to assess climate risk in vulnerable communities. NOAA is now increasing its efforts to help [address climate risk on a community level](#), focusing on extreme heat, drought, wildfires, flood, and coastal risks.

Beyond these immediate impacts, climate change is a threat multiplier that can worsen the impact of a wide range of social determinants of health. The diagram below, reprinted in a [CODE report](#) on the social determinants of health, shows an HHS analysis of near-term and long-term impacts of climate change on the SDOH.

Figure 1: Climate Change as a Threat Multiplier for the SDOH

Climate change is a threat multiplier for SDOH. Climate change is increasingly being recognized as a “threat multiplier” for issues ranging from national security to disaster risk—that is, a factor that exacerbates the danger posed by many other factors. The Fellows’ report recognizes climate change as a threat multiplier for risks to health and well-being that arise from the SDOH as well. The diagrams below, taken from their report, show how climate interacts with many SDOH factors, and the need to approach the SDOH with a larger climate perspective.



Roundtable participants described climate as an *inequity multiplier*, meaning those already suffering from negative SDOH and poor environmental infrastructure conditions face more severe effects of climate change, with hazards further exacerbating negative health conditions. Understanding these factors requires community engagement and highly localized data that reflects a community's lived experience. Higher-level climate scorecards and social vulnerability indices can be useful for city and state officials, but may not be granular enough to be useful at a community level. In addition, climate and environmental data needs to be disaggregated by race and ethnicity to show a full picture of climate impacts.

Better standards for climate and environmental data collection are also needed at local levels. Data on different environmental factors and hazards tend to be siloed, making it difficult to get a comprehensive view of the interrelationship of different factors and their compounded effects. Standardization can make the data more interoperable and lead to greater insights for action.

Emerging technologies

The Roundtable explored the appropriate use of emerging technologies to help improve service and reduce bias in healthcare. It covered two issues that may particularly impact communities of color: disparities in access to technology, and potential bias in data and data analysis.

Emerging technologies have the potential to overcome bias and help ensure more equitable medical treatment. For example, connected heart monitors that transmit signals for computer analysis can detect problems and trigger necessary interventions based on the data, regardless of a patient's race. At the same time, there is a growing awareness of the need to address the digital divide in healthcare, including gaps in digital literacy, access to health technologies, and broadband access in communities of color around the country.

The impact of technology access on health is starting to become evident, with some recent research showing a high correlation between [poor broadband access](#) and COVID risk. Broadband is a critical gateway to health information, healthcare services, and telemedicine, and [research](#) has shown differences in broadband access by race and ethnicity. A [2015 study](#) showed that 83 percent of Asians and 81 percent of white Americans had home-internet access, compared to 72 percent of American Indian/Alaska Natives, 70 percent of Hispanics, and 68 percent of Black Americans. The disparities may be related to the racial wealth gap: In this study, less than half of households with annual family incomes less than \$20,000 had home-internet access. A [more recent analysis](#) of the digital divide by Census tract has shown a similar relationship between internet access and race.

New artificial intelligence applications in health can also have [either](#) positive or negative effects, depending on how they are developed and applied. These applications may draw on and analyze data in biased ways that disadvantage minorities, an issue that the Agency for Healthcare Research and Quality (AHRQ) has investigated. Their [systematic review](#) suggested a set of actions and steps that healthcare providers should take to reduce the bias and improve the effectiveness of healthcare algorithms.

The issue of [algorithmic bias](#) has become a concern as AI and machine learning are increasingly being incorporated into healthcare decision tools for better healthcare delivery, including clinical guideline development, clinical decision support programs in electronic health records, and healthcare operational systems. Algorithms are defined as mathematical formulas and models that combine different variables or factors to inform a calculation or an estimate, often for risk. In healthcare specifically, algorithms are being leveraged to support healthcare screening, risk prediction for medical events, diagnosis, prognosis, treatment planning, and allocation of resources.

Race and ethnicity are increasingly being used as input variables in healthcare algorithms and influence both clinical decision-making and patient outcomes. These factors are included in algorithms to increase diagnostic or predictive accuracy. However, some researchers have argued that including race and ethnicity in this way can be misleading, since they are largely **social constructs** rather than biological factors. Including race and ethnicity in healthcare algorithms can lead to **unknown or unwanted** effects and even exacerbate or perpetuate health and healthcare disparities.

In recent years, several studies have shown that healthcare algorithms can lead to BIPOC patients **receiving less high-quality care** than white patients. One study, for example, found that algorithms used previous healthcare spending to determine future risk and need for additional care, which is misleading because Black people tend to spend **less on healthcare**. Some insurance companies misuse personal information such as **race and income** in risk-prediction algorithms to raise premiums in ways that may disadvantage people of color.

As the table below from the AHRQ shows, biases can be introduced at any step in the algorithm development-to-implementation process, including the conception of the algorithm, the applied training data, or the team used to review the algorithmic outputs.

Table 1: Examples of biases that can be introduced during machine learning and conventional statistical model development

Feature	Description
Data Selection and Management	<ol style="list-style-type: none"> 1. Biases in study inclusion criteria, e.g., using eGFR to select study participants 2. Study data collection biases (including misclassification of race/ethnicity) 3. Lack of representation / selection in the dataset 4. Missing data 5. Biases in imputed data 6. Biases in learning and training data 7. Collapsing race variables 8. Lack of reporting for methodological approach 9. Insufficient sample size 10. Labeling bias
Model Training/ Development	<ol style="list-style-type: none"> 1. Overfitting 2. Lack of reporting for methodological approach 3. Interpretation bias 4. Correlation bias
Validation/ Evaluation	<ol style="list-style-type: none"> 1. Training-validation data skew 2. Lack of external validation 3. Lack of performance assessments, such as calibration and discrimination 4. Lack of reporting for methodological approach

Source: <https://effectivehealthcare.ahrq.gov/products/racial-disparities-health-healthcare/protocol>.

A number of approaches are now being explored to reduce the risk of algorithmic bias. These include adopting a more collaborative, patient-centered approach; developing specific processes for evaluating and addressing bias; developing a regulatory framework for algorithmic transparency and accountability; and applying ethical principles for AI, such as those **developed by IBM**.

While technologies are important tools, it is essential to understand the specific need and purpose before investing in developing new tech. Issues of bias, inclusion, quality, and accountability all need to be addressed during the design phase of any new technology rather than after the fact.

Cross-Cutting Themes in Using Data for Action on Healthcare Equity



In addition to the issue-specific insights described above, discussions at the Roundtable touched on a number of cross-cutting themes related to the use of data for action on racial equity in healthcare. They emphasized that data and technologies have to be used as tools for action, not just to understand where problems exist, and impacted communities have to drive strategies for action. The following principles can help ensure that data and technologies are properly leveraged to take action in support of communities that have historically suffered from health inequities.

Community engagement and cultural sensitivity in designing and using data programs and technology

Community engagement and cultural sensitivity are critical in designing and executing data programs and new technologies. Community engagement is vital to implementing principles of trust, data quality, governance, data and technology use, communications, and more.

Roundtable discussions highlighted the need to build trust with communities in order to collect and manage data appropriately, particularly with regard to potentially sensitive, individual-level SDOH issues. A best practice is not to begin asking for data until trust has been built by working with trusted community members and community-based organizations (CBOs).

Without community engagement and the accompanying trust that it engenders, data quality will suffer. For example, parents may not share information about lead pipes or paint in their homes if they fear it could lead to their children being taken out of the home, despite the fact that sharing that information through appropriate channels could help them remediate the issue, protecting their children's health.

In the context of climate change, data collected via satellites or other automated means may not represent the lived experience of communities, making it less useful for achieving positive health outcomes. Similarly, data that is only collected in the immediate aftermath of a disaster will provide a limited understanding of potential problems, particularly around health conditions that may take years to develop.

Building trustworthy, high quality data through community engagement is particularly relevant for the governance of emerging technologies like AI that can have significant impact, but also have clear risks with respect to bias, equity, and inclusion. Roundtable participants focused on the importance of community input into AI models, arguing for multi-stakeholder engagement to ensure the use cases for AI are well considered and that benefits confer to communities.

Community engagement in the design and development of data and other technology products is also needed to ensure those products are also put to use for community benefit. In the case of COVID-19, Roundtable participants pointed out that community partnerships improved vaccine uptake by, for example, offering shots through trusted CBOs or bringing mobile vaccine clinics to construction sites.

Cultural sensitivity is also key. For example, limited language options can make it more difficult for individuals to access information and care. One Roundtable participant highlighted their organization's work to translate materials into Spanish, add a Spanish option to their phone system, and hire more Spanish-speaking patient coordinators as an important step to support the health of Spanish-speaking populations. This sort of expanded access is vital for immigrant and other non-English speaking communities.

Capacity building may be needed at the community level to empower communities to understand their own health issues and how to address them. Increased community capacity can also have benefits for data quality and use at higher levels, as many small, mission-oriented CBOs may not have the capacity to report quality data back to the government.



Case Study: Data.org’s Rising Equitable Community Data Ecosystems (RECoDE) Project

The RECoDE project sought to center and engage directly with community voices in a conversation around how to ensure that data ecosystems are accountable to communities. Specifically, the project recognized that data systems around housing, health, education, and employment were largely based in discriminatory assumptions. The RECoDE project represents an attempt to “better understand how to undo antiquated and dangerous data systems” and build ecosystems to replace them that provide communities with “power over where, when, and how their data is used.”

RECoDE’s report, which was based on engagement with nearly 500 individuals representing communities across the country, highlights [five recommendations](#) for building these equitable community data ecosystems:

- Trust starts with the community
- Co-create, don’t dictate
- Design with intention
- Build capacity
- Reset the rules

Trust and data collection, use, privacy, and security

Researchers and public health officials can build trust around data by embracing community engagement, designing data programs with the unique needs of different cultures in mind, and an awareness of historical inequities that can lead to community distrust. It is also important to collect only necessary data, ensure that it is used for the benefit of underserved communities, and establish clarity around questions of consent, security, and privacy.

Participants highlighted thoughtful and transparent data collection and use as a key part of trust building. Data can be used to harm as well as help, and it is important to be clear about the reasons data is being collected and how it will be shared. Data privacy and data sovereignty, described below, can help build trust by giving communities control over information about them.



Case Study: National Secure Data Service

There are several [models](#) for secure data sharing that work to preserve privacy. Particularly relevant to data sharing for health equity at the federal level may be efforts to build a [National Secure Data Service](#). Stemming from a [recommendation](#) by the U.S. Commission on Evidence-Based Policymaking, such a service could increase coordination and use of federal data for policymaking and potentially [improve](#) privacy at the same time. Roundtable participants highlighted the potential of a National Secure Data Service to provide a place to safely link sensitive health data.

Equitable data governance, data sovereignty, and data ownership

Roundtable discussions raised important questions around data and technology governance—including ownership and how to build flexible data systems and encourage sharing and use while protecting and empowering communities. Specifically, robust governance can help build trust, improve data quality, and ensure community benefit. Embracing multi-stakeholder approaches, increasing transparency around decision making, sorting out issues around data ownership, and embracing data sovereignty to ensure that underserved communities have control over how their health data is accessed and used.

Multi-stakeholder, transparent, and accountable governance structures are particularly necessary when dealing with emerging technologies or controversial uses of data. For example, participants suggested building an objective entity that could examine AI applications and algorithms for potential bias. Such an organization could provide context and analysis around potential limitations of AI applications and potentially provide a trusted “stamp of approval” for AI uses that were shown to improve outcomes and increase equity.

Data sovereignty—emerging Indigenous data sovereignty approaches in particular—is a valuable way to give control of data to patients and communities, while encouraging sharing and data use for good. Traditional approaches to data sovereignty subject data to the laws of the nation in which it is *stored*. Recently, Indigenous data sovereignty has developed as a way to give control over data to the people in nations from which it is *collected*. These approaches can be used to protect community privacy while also encouraging data sharing between private entities who collect data from individuals or groups.



Case Study: United States Indigenous Data Sovereignty Network (USIDSN)

Traditional conceptions of “data sovereignty” subject data to the laws of the nation in which it is stored. [Indigenous Data Sovereignty](#), on the other hand, places data under the control of the laws of the nation from which it is collected. The [USIDSN](#) works to ensure that data collected from Indigenous nations and peoples in the US “are utilized to advance Indigenous aspirations for collective and individual well-being.” The USIDSN brings together advocates at all levels and promotes the [CARE Principles for Indigenous Data Governance](#), which build off the [FAIR](#) (Findable, Accessible, Interoperable, Reusable) principles in a way that considers people and purpose. The CARE Principles are:

- Collective benefit
- Responsibility
- Authority to control
- Ethics

Access to data and technology

Access to data and technology is a key part of achieving racial equity in healthcare. Access can directly connect individuals to care and improve their health outcomes, and can also help communities manage public health emergencies. Barriers to access can take many forms, including geographic isolation, lack of technology literacy, and lack of data sharing.

The pandemic has underscored the value of technology in health, particularly in the use of telehealth services that have enabled patients to access care during a time of forced social isolation. One analysis [found that](#), during the COVID-19 pandemic, telehealth claims peaked at 78 times higher than pre-pandemic levels and stabilized at 39 times higher into 2021. Other technologies like SMS and location-based services used during the pandemic also show the value of technology access for health.

Government policies can help expand both the availability of technology and its use. Early in the pandemic, the HHS Office of Civil Rights (OCR) issued guidance related to COVID-19 and HIPAA in a number of areas, including rapidly amending regulations governing telehealth to address healthcare needs during the pandemic. Specifically, the OCR decided to waive potential penalties for [HIPAA violations](#) against healthcare providers that serve patients through everyday communications technologies. The Roundtable highlighted opportunities to improve access to and affordability of vital technology. More recently, the Biden administration has shared the details of a plan to make internet access [more affordable](#) for millions of Americans.



Case Study: Correlation Between COVID-19 Death Rates and Internet Access

Just as technology can improve health outcomes, a lack of technology can be a factor in health inequities. For example, recent research [has found](#) a connection between COVID-19 mortality rates and Internet access. A March 2022 [article in JAMA Network Open](#) explored how COVID-19 mortality is impacted by structural factors and how that can help explain inequities in outcomes across different ethnic groups. Overall, the study found “an association between different SDOH measures and COVID-19 mortality that varied across racial and ethnic groups and community types.”

Tellingly, the study found a correlation between [limited internet access](#) and death due to COVID-19. This was true across community types and demographic groups, with rural and urban populations as well as different racial and ethnic groups impacted. While it is unclear exactly what drives this connection, the researchers behind the study believe it is likely tied to the degree of access to high-quality information. Individuals without internet access may rely more on their friends and family for information, leading to vaccine hesitancy or a misunderstanding of important public health messages.

Data quality and gaps

Roundtable participants identified a number of data quality issues as well as some specific data gaps that can lead to poor outcomes or hold back efforts to improve health equity. These include data silos, inconsistent and incomplete data collection, underdeveloped metadata, data that lacks necessary timeliness or granularity, and a lack of racially disaggregated data.

Data silos were discussed in multiple sessions, including with respect to SDOH and climate hazards, as limiting the overall usefulness of data for health equity. For example, participants highlighted climate as an “inequity multiplier” that leads to worse effects for those already suffering negative health impacts tied to various SDOH factors. Siloed data limits our ability to understand and address these compound effects.

Similarly, inconsistent levels of data quality across EHR systems, as well as underdeveloped metadata was cited as a hindrance to data use. Participants noted that EHR data hold significant promise when it comes to understanding health outcomes and inequities, but lack of consistency could instead lead to poor decision making.

To be truly useful for efforts to improve health equity, Roundtable participants pointed out that data needs to be both timely enough to enable quick decision making and granular enough to shed light on inequities at the community and even individual level. While ZIP Code and Census tract level data is often used as a proxy variable for SDOH characteristics, even data at that level may be too geographically broad to provide an accurate understanding of equity. ZIP+4 and geocoding data can provide a better understanding of individual and community

needs. Data from government sources can also be combined with citizen generated data and other community-based data sources to improve its utility.

Finally, participants noted that without racially disaggregated data, progress in understanding and improving inequities in healthcare will be extremely limited. Disaggregated data can ensure that the experience of impacted communities is represented and understood. Without it, data can lead to misleading conclusions and even end up increasing disparities. The Equitable Data Working Group, formed by President Biden's Executive Order 13985, released a [report](#) emphasizing the need for interoperable and sufficiently disaggregated data to identify inadequacies and increase available data for measuring equity and representing the diversity of the U.S.



Case Study: The California Health Interview Survey (CHIS)

The CHIS is America's [largest state health survey](#). Used by policymakers, researchers, the media, and other stakeholders, it provides credible, comprehensive data on the health of Californians generally as well as data that specifically covers the state's racial and ethnic groups. Roundtable participants highlighted CHIS as a best practice for health data collection, particularly when it comes to developing disaggregated data. CHIS releases a range of data to the public and also provides restricted access to more [sensitive data](#) through the CHIS Data Access Center.

Data standards, interoperability, and sharing

Many Roundtable participants raised the need for increased standardization and interoperability as a path towards breaking down silos and enabling better data exchange. Increased standardization and interoperability can help encourage consistent data collection over time as well as reporting and sharing. Standards may need to evolve over time to account for new knowledge and emerging health issues.

There is a clear need to bring standardization to the local and state levels to encourage more consistent reporting. Varying data collection techniques and standards across the country make it difficult to report data up from the local level. This in turn makes it more difficult to get a picture of health equity across the country or to set and track targets for progress.

Standardization can be helpful at the point of data collection, as well as when aggregating or sharing information. Standardization at the survey question level, along with specific definitions and standards around race and racism, ethnicity, and [health equity](#) itself, will improve data quality. For example, participants urged the development of standard, culturally competent survey questions to provide more consistent, high quality data on health equity issues.



Case Study: The Gravity Project

The [Gravity Project](#) is a collaborative effort developing data standards to improve sharing and use of information on the SDOH. Their standards allow individual-level SDOH information to be shared in digital platforms and used by healthcare organizations, providers, and caregivers.



Case Study: The Gravity Project (continued)

The Gravity Project started with standards around food, housing, and transportation, which are already included in studies of SDOH factors, and has expanded to look at new factors from there. The Gravity Project's work has also helped expand access to granular data through [PLACES](#), which builds on the 500 Cities Project launched by the CDC, the Robert Wood Johnson Foundation, and the CDC foundation. PLACES provides small area estimates (SAE) on 29 chronic disease measures for a variety of hyperlocal geographies, across the entire United States.

Technical capacity and resources

Financial and other resources are necessary to build sustainable, interoperable data infrastructure in support of health equity. Just as important, resources and technical capacity-building efforts need to flow to communities to ensure that they can make use of available data and technology to understand and advocate for their own health and well-being.

Communities that have traditionally faced the burden of health inequities may benefit from investments in community-level capacity building as well as training and skill development around data use. CBOs are particularly high-priority targets for investment due to their mission-driven approach, their value as data producers, and the trust that community members place in them.



Case Study: Cities of Opportunity

The [Cities of Opportunity](#) (CoO) initiative, which ran from January 2021 through December 2021, was created by the National League of Cities with support from the Robert Wood Johnson Foundation to build on the role of city leaders to address SDOH and increase equity and opportunity for all residents. The CoO helped cities strengthen their capacity for systems and policy change so all residents have the opportunities for healthy, fulfilling lives. The program engaged and evaluated 56 cities around the United States.

The CoO provided hands-on assistance, tools, and peer learning to cities to deepen awareness of systemic change and the city's role to plan, implement and sustain health and equity initiatives. It also had specific focus on sustainability, diversified funding, program/policy alignment, data capacity, partnerships and civic engagement.

The CoO offered value through peer learning and engagement with other cities; the provision of space for customized technical assistance; facilitation and coaching to consider issues and design solutions; connecting to field experts to expand knowledge and more. The CoO helped:

- Charlotte, North Carolina, infuse equity into its new comprehensive plan through community engagement.
- Napa, California, expand its healthcare partner network as part of a plan for health and equity.
- Duluth, Minnesota, develop scoring criteria for federal funds distribution that prioritized equitable opportunities.
- Grand Rapids, Michigan, collaborate on a regional data hub centered on health equity and the SDOH with multisector partners. Information and public health communication for data and technology

Information and public health communication for data and technology

Without adequate information sharing and public health communication, no amount of data or novel technology will lead to greater racial equity in the American healthcare system. Misinformation and disinformation are everywhere, particularly around high-impact topics like climate change and COVID. The issues at play are complicated and the data-driven approaches to solving them can be difficult to explain.

Public health communications and targeted education campaigns can promote health literacy across demographic groups, create health-literate institutions, and ensure access to information where people consume and trust it. Reaching people where they are most receptive to information—whether in a trusted and safe community setting or via their smartphones—is important to help ensure the success of these campaigns.

CBOs and other trusted community institutions can be an effective conduit for public health information. For example, barber shops and other community partners helped advance knowledge about and trust for vaccination during the H1N1 pandemic in 2009.

It is also important for healthcare institutions to understand how their stakeholders prefer to communicate. For example, Kaiser is working to understand the best ways to communicate with their various clients, and to respect individual preferences for communication by phone call, text, or other means.



Case Study: California's Proposed Office of Community Partnerships and Strategic Communications (OCPSC)

Building on lessons learned during the COVID-19 pandemic, Gavin Newsom, the governor of California, has [proposed](#) an Office of Community Partnerships and Strategic Communications in his latest budget proposal, which will be finalized in mid-2022.

If funded, the office would “manage priority public education and community engagement efforts” while supporting CBOs. The governor’s budget request recognizes the key role that CBOs played in reaching marginalized communities during the pandemic. If funded, the new office would work with state departments to develop community outreach and public awareness campaigns, connect CBOs to grant funding, and help communities share insights and feedback with stakeholders in state government and elsewhere.

RECOMMENDATIONS FOR LEADERS

The following recommendations emerged from discussions at the Roundtable as well as additional research. They are intended for federal, state, and local leaders including policymakers and public health officials. They may also be applicable to CBOs and other nonprofit organizations as well as for-profit companies, academics, and other stakeholders.

- 1. Supplement automated data collection (via satellite or other technology) with community-based data collection to ensure that data reflects the lived experience of communities it is about.** Current data collection methods provide an incomplete picture of the lived experiences of communities. For example, readings collected from temperature-reading technology placed on roofs will be a few degrees cooler or warmer than what is felt on the street, and air pollution data from a single source will not reflect extreme [block-by-block](#) differences connected to race and socioeconomic factors. Government data sources like these need to be analyzed alongside community-based [data sources](#) in order to get the most accurate information on a community.
- 2. Develop multi-stakeholder, community-led governance models for AI/ML.** Issues like biases and existing disparities are important considerations when developing algorithms for artificial intelligence and machine learning models. Multi-stakeholder and community input is essential when developing such technology, so that the most relevant use cases of other models are well considered, and that communities realize the benefits.
- 3. Engage with organizations dedicated to improving quality and reducing bias in AI applications.** Although artificial intelligence technology and machine learning algorithms have the potential to greatly improve the health data landscape, a number of technical issues must be considered before and while developing and using such technology. Engaging relevant organizations, multi-stakeholder experts, and community leaders focused on AI applications and ethics will help curb the effects of implicit and algorithmic biases, among other issues.
- 4. Support development of a National Secure Data Service to ensure inclusion of health data.** The [National Secure Data Service Act](#), first introduced in the House of Representatives in 2021, will advance responsible data sharing in government by creating a service that rapidly addresses policy questions and reduces unintended burdens for data sharing, while [aligning](#) with design principles and concepts presented in recommendations from data and privacy experts. Including health data in the service could provide a safe space to link sensitive health data held by different government agencies.
- 5. Promote approaches to data sovereignty that put control of data into the hands of those from whom it is collected.** By embracing multi-stakeholder approaches, increasing transparency around decision making, and sorting out issues around data ownership, embracing the concepts of Indigenous data sovereignty will help to ensure that underserved communities have control over how their data is accessed and used. This is especially necessary when dealing with emerging technologies or controversial uses of data.
- 6. Continue efforts to expand access to broadband to all Americans.** Broadband internet access is a critical gateway to health information, healthcare services, and telemedicine, and [research](#) has shown differences in broadband access by race and ethnicity as well as a correlation between [access](#) and COVID-19 death rates. The Biden administration is moving on policies that would make the internet [more affordable](#) for millions of Americans. These efforts should be continued and expanded.

- 7. Inventory and update local, state, and federal regulations that may be restricting access to telehealth and other emerging health technologies.** The pandemic underscored the value of technology in health, and led to expanded use of telehealth services that enabled patients to access care during a time of forced social isolation. However, Roundtable participants pointed out several examples of existing regulations at various levels of government that still make it difficult for individuals to access telehealth services or other technologies. Policymakers at all levels should inventory and update regulations to ensure these technologies can be used appropriately, learning from efforts early on in the pandemic, like those by the HHS Office of Civil Rights (OCR), which issued guidance related to COVID-19 and HIPAA in a number of areas, including rapidly amending regulations governing telehealth.
- 8. Expand access to geocoded data at the sub Census tract/ZIP code level.** To be truly useful for efforts to improve health equity, data needs to be both timely enough to enable quick decision making and granular enough to shed light on inequities at the community and even individual level. Data at the ZIP Code and Census tract level may be too geographically broad to provide an accurate understanding of equity. ZIP+4 and geocoding data can provide a better understanding of individual and community needs. A variety of work is underway in this area, including in academia at [Harvard](#) and the [University of California San Francisco](#). Continued work in this area can include expanding access to this more granular data where appropriate.
- 9. Explore opportunities to expand access to racially/ethnically disaggregated data.** Data disaggregated by race, ethnicity, gender or other key demographic variables is necessary to better understand long standing health inequities and challenges faced by historically underserved groups. However, such data is often not available or is difficult to access, especially at the federal level. Data stewards should explore ways to develop more disaggregated data and expand access to disaggregated data among researchers and communities who would benefit from it most. They should also explore ways to overcome legal or regulatory barriers that may currently make it more difficult to collect, develop, and share disaggregated data. For example, recent efforts to develop tools to screen for environmental risks have [been complicated](#) by legal and other concerns about using race as a factor.
- 10. Invest in CBO data and technical capacity through grants and other financial support mechanisms.** Communities that have traditionally faced the burden of health inequities may benefit from investments in community-level capacity building as well as training and skill development around data use. Community level capacity building can empower communities to understand their own health issues and how to address them and support small CBOs to achieve their missions and report better data. Examples like Cities of Opportunity and the RECoDE project, highlighted earlier in this paper, can provide inspiration for leaders looking to support capacity building in communities.

CONCLUSION

The *Roundtable on Open Data for Racial Equity in Healthcare* and associated research raised two important questions around data use that need to be answered to make the American healthcare system more equitable for BIPOC communities: Who is impacted by, and who benefits from, the use of data in healthcare?

This paper has explored these questions in the context of the SDOH, COVID-19, climate and environmental justice, and emerging technologies. The recommendations are designed to support progress towards useful answers. Investments in capacity building, broadband access, and improved data privacy, security, and control can enable historically underserved populations to exert more influence over the systems that traditionally have not worked for them.

At the same time, data can be improved and disaggregated to better represent lived experiences. Empowered communities can then ensure that this granular, high-quality data, as well as new and existing technologies, are used to benefit their own health and well-being. By empowering historically underserved communities and ensuring that data is used to benefit them, we can bring more equity to the American healthcare system.

PARTICIPATING ORGANIZATIONS

The following organizations participated in the *Roundtable on Open Data for Racial Equity in Healthcare*. Discussions at the Roundtable provided the core inputs for the recommendations and other insights presented in this paper.

Academia

Duke's Margolis Center for Health Policy's leading capabilities including interdisciplinary academic research and capacity for education and engagement, to inform policymaking and implementation for better health and healthcare.

Harvard Medical School is committed to convening and nurturing a diverse community of individuals dedicated to promoting excellence and leadership in medicine and science through education, research, clinical care, and service.

Mailman School of Public Health is the public health graduate school of Columbia University. Located on the Columbia University Medical Center campus in the Washington Heights neighborhood of Manhattan in New York City.

North Carolina State University is a public land-grant research university in Raleigh, North Carolina. Founded in 1887 and part of the University of North Carolina system, it is the largest university in the Carolinas

The University of California, Berkeley is a public land-grant research university in Berkeley, California. Established in 1868 as the University of California, it is the state's first land-grant university and the first campus of the University of California system.

The University California San Diego (UCSD) is one of the world's leading public research universities, located in La Jolla, California. The University has a Center for Community Health that works to promote optimal health in all populations through interventions that target chronic disease and obesity prevention.

Civil society

Academy Health is a nonpartisan, nonprofit professional organization dedicated to advancing the fields of health services research and health policy.

ACT | The App Association represents more than 5,000 app makers and connected device companies in the mobile economy, a \$1.7 trillion ecosystem. Organization members leverage the connectivity of smart devices to create innovative solutions that make people's lives better.

Catalyst Miami's mission is to identify and collectively solve issues adversely affecting low-wealth communities throughout Miami-Dade County. The organization's vision is a just and equitable society in which all communities thrive.

Civitas Networks for Health is a mission- and member-driven organization dedicated to using health information exchange, health data, and multi-stakeholder, cross-sector approaches to improve health.

Corporation for Supportive Housing is a national leader in supportive housing, focusing on person-centered growth, recovery and success that contributes to the health and wellbeing of the entire community.

Data Foundation is a nonprofit think tank based in Washington, D.C. that seeks to improve government and society by using data to inform public policymaking.

Data.org is a platform for partnerships to build the field of data science for social impact. Data.org works with organizations from all over the world to increase the use of data science in order to improve the lives of millions of people.

KB Stack Consulting is an independent consultant helping government and nonprofit organizations develop creative strategies for using data, evidence, and innovation to improve the impact of government social programs.

Minnesota Community Measurement delivers data to healthcare payer and provider members to illustrate performance on quality and cost measures. Members use these data to understand gaps and inform improvement efforts. These data include comparisons to statewide results and to peers in the market.

National League of Cities is an organization comprised of city, town, and village leaders that are focused on improving the quality of life for their current and future constituents.

National Minority Quality Forum is a research and educational organization dedicated to ensuring that high-risk racial and ethnic populations and communities receive optimal healthcare. This nonprofit, nonpartisan organization integrates data and expertise in support of initiatives to eliminate health disparities.

The National Patient Advocate Foundation is dedicated to advancing person-centered care for everyone facing a serious illness. The Foundation advocates for accessible, high quality, affordable health care.

The Patient Advocate Foundation provides patient services, eliminating obstacles in access to quality healthcare. The Foundation believes in empowering patients with the skills to navigate their healthcare and advocate for their prescribed care.

Federal government

U.S. Department of Health and Human Services is a cabinet-level department of the U.S. federal government with the goal of protecting the health of all Americans and providing essential human services.

The Centers for Disease Control and Prevention Center (CDC) works to protect America from health, safety and security threats, both foreign and in the U.S. Whether diseases start at home or abroad, are chronic or acute, curable or preventable, due to human error or deliberate attack, CDC fights disease and supports communities and citizens to do the same.

The Centers for Medicare & Medicaid Services Innovation Center develops and tests new healthcare payment and service delivery models to improve patient care, lower costs, and better align payment systems to promote patient-centered practices.

The Assistant Secretary for Planning and Evaluation is the principal advisor to the Secretary of the U.S. Department of Health and Human Services on policy development, and is responsi-

ble for major activities in policy coordination, legislation development, strategic planning, policy research, evaluation, and economic analysis.

The National Institutes of Health seeks fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

The Office of Minority Health within the Centers for Medicare and Medicaid Services offers a comprehensive source of information on eliminating health disparities and improving the health of all minority populations, people with disabilities, members of the lesbian, gay, bisexual, and transgender community, individuals with limited English proficiency, and rural populations.

The Office of the Assistant Secretary for Health oversees the Department's key public health offices and programs, a number of Presidential and Secretarial advisory committees, 10 regional health offices across the nation, and the Office of the Surgeon General and the U.S. Public Health Service Commissioned Corps.

HHS emPOWER Program is a mission-critical partnership between the Office of the Assistant Secretary for Preparedness and Response (ASPR) and the Centers for Medicare and Medicaid Services (CMS).

The Office of the National Coordinator for Health Information Technology (ONC) works to improve the health and well-being of individuals and communities through the use of technology and health information that is accessible when and where it matters most.

U.S. Department of Veterans Affairs seeks to provide veterans the world-class benefits and services they have earned—and to do so by adhering to the highest standards of compassion, commitment, excellence, professionalism, integrity, accountability, and stewardship.

The White House Office of Management and Budget oversees the implementation of the President's vision across the Executive Branch. OMB carries out its mission through five main functions across executive departments and agencies: Budget development and execution; management; coordination and review of all significant regulations; clearance and coordination of legislative and other materials; and clearance of Presidential Executive Orders and memoranda.

State and local government

The District of Columbia Department of Health's mission is to promote and protect the health, safety, and quality of life of residents, visitors, and those doing business in Washington, D.C.

Maryland Health and Health Disparities' mission is to address the social determinants of health and eliminate health disparities by leveraging the Department's resources, providing health equity consultation, impacting external communications, guiding policy decisions and influencing strategic direction on behalf of the Secretary of Health.

Maryland Primary Care is a one-stop clinic for all those patients who need effective primary and urgent care. It's a full-service medical care clinic which offers an array of services including urgent care, immunization, vaccination, blood tests, and travel consulting.

Healthcare organizations

Anthem Blue Cross Blue Shield is an independent licensee of the Blue Cross and Blue Shield Association. Anthem is dedicated to delivering better care to our members, providing greater value to our customers and helping improve the health of our communities.

Circulo Health develops innovative approaches to primary health care, insurance plans, and independent living facilities.

HealthBegins is a national mission-driven consulting and technology firm dedicated to improving care and the social and structural drivers of health equity.

Humana is a for-profit American health insurance company based in Louisville, Kentucky, that works to improve healthcare and make it more accessible.

ProMedica is a mission-based, not-for-profit health and well-being organization headquartered in Toledo, Ohio. The organization offers acute and ambulatory care, an insurance company with a dental plan, and post-acute and academic business lines.

ZeOmega delivers integrated, whole-person health management for more than 30 million people, with utilization management, case management, disease management, population health, and analytics capabilities across its Jiva platform.

Private sector

BrightHive is an impact-driven data technology company using data trusts to transform the way social services providers, government agencies, and funders share data, make decisions, and affect the outcomes of beneficiaries.

Epic was founded in 1979 and develops software to help people get well, help people stay well, and help future generations be healthier. More than 250 million patients have a current electronic record in Epic.

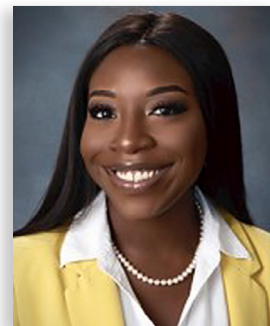
ACKNOWLEDGMENTS

Special thanks to Dan Chenok, Monique Outerbridge, and Ruth Gordon from IBM as well as Joel Gurin, Paul Kuhne, and Sophie Hu from the Center for Open Data Enterprise for their help conceptualizing, planning, and executing the Roundtable. Additional thanks to Emeobong “Eme” Martin and Dr. Malcom Glover, for their expert facilitation at the Roundtable, and to Victoria Felt, Jesus Hernandez, and Mark Taylor for taking notes.

CODE also thanks ZeOmega for providing additional support for this project. ZeOmega was founded in 2001 to empower health plans and other risk-bearing organizations with 17 industry-leading technologies for delivering integrated, whole-person health management. ZeOmega supports more than 30 million lives with utilization management, case management, disease management, population health, and analytics capabilities across its Jiva platform.

ABOUT THE AUTHORS

Temilola Afolabi is a research associate at the Center for Open Data Enterprise (CODE). In this role, Temi is responsible for leading research efforts on how open data can be applied for various social good efforts, writing reports with actionable recommendations for the federal government, and supporting Roundtable logistics and stakeholder engagement. She also co-leads CODE's Open Data for Racial Equity program, where she works to identify ways to advance racial equity in fair housing, criminal justice, environmental justice, healthcare, and the workforce using open data. Temi received her Bachelor's degree at the University of Maryland College Park, where she studied International Government and Politics, with a Minor certificate in International Development and Conflict Management.



TEMILOLA AFOLABI

Matt Rumsey is the research and communications manager at CODE. He has experience in open government data as an advocate, policy analyst, and researcher. Prior to joining CODE, Matt worked as an independent researcher with organizations including the Data Foundation, CODE, and the Sunlight Foundation. He conducted research and wrote policy and briefing papers on topics including DATA Act implementation, grants data standardization, legal entity identification, the interaction between open data and privacy, and open research data. He got his start in open data at the Sunlight Foundation, where he worked on federal policy initiatives. He advocated for passage and effective implementation of the DATA Act, conducted research and advocacy around executive branch open data efforts, and helped to conceptualize and draft what would become the OPEN Government Data Act. Matt has a B.A. in history from American University in Washington, D.C.



MATT RUMSEY



KEY CONTACT INFORMATION

Temilola Afolabi

Center for Open Data Enterprise
Washington, D.C.

Email: Temilola@odenterprise.org

Matt Rumsey

Center for Open Data Enterprise
Washington, D.C.

Email: Matthew@odenterprise.org

RECENT REPORTS FROM THE IBM CENTER FOR THE BUSINESS OF GOVERNMENT

For a full listing of our publications, visit www.businessofgovernment.org



Agility

Agile Government: The Role of Public Affairs Education by Angela Evans

Adopting Agile in State and Local Governments by Sukumar Ganapati

The Road to Agile GOVERNMENT: Driving Change to Achieve Success by G. Edward DeSeve

Transforming How Government Operates: Four Methods of Change by Andrew B. Whitford

Agile Problem Solving in Government: A Case Study of The Opportunity Project by Joel Gurin, Katarina Rebello



Digital

Collaborative Networks: The Next Frontier in Data Driven Management by Julia Carboni, Co-Authors

Artificial Intelligence in the Public Sector: A Maturity Model by Kevin C. Desouza

Aligning Open Data, Open Source, and Hybrid Cloud Adoption in Government by Matt Rumsey, Joel Gurin

Innovation and Emerging Technologies in Government: Keys to Success by Dr. Alan R. Shark

Risk Management in the AI Era: Navigating the Opportunities and Challenges of AI Tools in the Public Sector by Justin B. Bullock, Matthew M. Young



Effectiveness

Three Reforms to Improve Defense Resource Management by John Whitley

Managing The Next Crisis: Twelve Principles For Dealing With Viral Uncertainty by Katherine Barrett and Richard Greene, Donald F. Kettl

Other Transactions Authorities: After 60 Years, Hitting Their Stride or Hitting The Wall? by Stan Soloway, Jason Knudson, Vincent Wroble

Guidance on Regulatory Guidance: What the Government Needs to Know and Do to Engage the Public by Susan Webb Yackee

Federal Grants Management: Improving Outcomes by Shelley H. Metzenbaum

COVID-19 and its Impact: Seven Essays on Reframing Government Management and Operations by Richard C. Feiock, Gurdeep Gill, Laura Goddeeris, Zachary S. Huitink, Robert Handfield, Dr. Rodney Scott, Sherri Greenberg, Eleanor Merton, Maya McKenzie, Tad McGalliard



Insight

Optimizing Analytics for Policymaking and Governance by Dr. Jennifer Bachner

Enabling a More Resilient and Shared Supply Chain Strategy for the Nation: Lessons Learned from COVID-19 by Robert Handfield

The Key to Modern Governmental Supply Chain Practice: Analytical Technology Innovation by David Preston, Daniel Chen, Morgan Swink

Delivering on the Vision of Multi-Domain Command and Control by Dr. David Bray

Using Technology and Analytics to Enhance Stakeholder Engagement in Environmental Decision-Making by Jenna Yeagert

Improving Outcomes in Government through Data and Intelligent Automation by The IBM Center for The Business of Government, Partnership for Public Service



People

The Age of Remote Work: How COVID-19 Transformed Organizations in Real Time by David C. Wyld

Reskilling the Workforce with Technology-Oriented Training by Stacie Petter, Laurie Giddens

Sustaining a Distant Vision: NASA, Mars, and Relay Leadership by JW. Henry Lambright

Distance Work Arrangements: The Workplace of the Future Is Now by John Kamensky, Emily G. Craig, Michaela Drust, Dr. Sheri I. Fields, Lawrence Tobin



Risk

Government transformation in tumultuous times by Institute for Business Value

Emerge Stronger and More Resilient: Responding to COVID-19 and Preparing for Future Shocks by Mike Stone, Tim Paydos

Emerging Technology for Response and Recovery: An International Dialogue by Kevin C. Desouza

The Rise of the Sustainable Enterprise by Wayne S. Balta, Jacob Dencik, Daniel C. Esty, Scott Fulton

Managing Cybersecurity Risk in Government by Anupam Kumar, James Haddow, Rajni Goel

About the IBM Center for The Business of Government

Through research stipends and events, the IBM Center for The Business of Government stimulates research and facilitates discussion of new approaches to improving the effectiveness of government at the federal, state, local, and international levels.

About IBM Consulting

With consultants and professional staff in more than 160 countries globally, IBM Consulting is the world's largest consulting services organization. IBM Consulting provides clients with business process and industry expertise, a deep understanding of technology solutions that address specific industry issues, and the ability to design, build, and run those solutions in a way that delivers bottom-line value. To learn more visit ibm.com.

For more information:

Daniel J. Chenok

Executive Director

IBM Center for The Business of Government

600 14th Street NW
Second Floor
Washington, D.C. 20005
(202) 551-9342

website: www.businessofgovernment.org
e-mail: businessofgovernment@us.ibm.com

Stay connected with the IBM Center on:



or, send us your name and e-mail to receive our newsletters.



IBM Center for
The Business of Government