



HARNESSING DATA TO
ADVANCE HEALTH OUTCOMES
FOR ALL



Health IT Leadership Roundtable

DECEMBER 2021

Executive Summary

The health IT landscape has dramatically changed in recent years and especially in the wake of the COVID-19 pandemic, which has brought renewed attention to broad and longstanding challenges in the U.S. health care and public health systems.

As a result, there is an unprecedented opportunity for health care stakeholders to think boldly about their shared health IT goals. Stakeholders from across the health ecosystem have called for significant health IT changes and investments to improve health outcomes for all and to be better prepared for future pandemics.

In October 2021, a wide range of organizations representing clinicians, hospitals, payers, technology companies, and patient and consumer advocates came together to jointly host a **Health IT Leadership Roundtable** event on the *Vision for the Future of Health IT*.¹ Roundtable participants discussed how the health care community can harness data and health IT infrastructure to achieve its shared health outcomes and goals.

The Roundtable focused on two key goals: advancing health equity and modernizing our public health system. Speakers and participants discussed how foundational health IT policies – such as data access, data standardization, interoperability, and privacy and security – are needed to successfully advance these goals. Participants also spoke about the importance of community-engagement and cross-sector partnerships to build needed connection, establish trust, and expand opportunities for impact.

This White Paper summarizes many of the key conversations and perspectives raised during the Roundtable event, as well as recommendations for moving forward. The White Paper: (1) highlights how data can be used to identify disparities and to inform efforts to advance health equity; (2) describes the challenges faced by our public health system and the steps being taken to modernize and improve public health data and infrastructure; and (3) notes key takeaways of policies that will help to advance health IT.

HEALTH IT LEADERSHIP ROUNDTABLE HOST COMMITTEE

American Academy of Family Physicians | American College of Physicians | American Health Information Management Association | American Heart Association | American Hospital Association | American Medical Group Association | American Medical Informatics Association | Blue Cross Blue Shield Association | College of Healthcare Information Management Executives | Consumer Technology Association | Federation of American Hospitals | Medical Group Management Association | National Partnership for Women & Families | Premier

¹ More information about the event and previous Health IT Leadership Roundtable events can be found [here](#).

Key Takeaways and Recommendations:

Health Equity

- Enable the collection of standardized Race, Ethnicity, Language (REL) data across programs by supporting ongoing development and wide adoption of industry standards.
- Enable collection of standardized social needs data as appropriate by supporting ongoing development of industry standards.
- Ensure industry, government, and communities work together to develop and incentivize adoption of common industry standards.
- Develop industry standards/best practices to ensure privacy is protected and appropriate use of data.
- Partner with trusted entities, such as community-based organizations, to collaborate in screening and collection of information.
- Leverage REL and social needs data to inform where gaps exist, to help in directing resources and in ensuring additional assistance.

Public Health

- Appropriate and ensure sustained funding to support a robust public health infrastructure, which includes interoperable systems and workforce capacity.
- Increase data sharing between public health and health care organizations to support identification of public health threats and to help direct responses.
- Establish and maintain multisector collaboration between public, private, and nonprofit organizations to address vaccine hesitancy and to provide targeted outreach to communities.
- Leverage community-based organizations to help supplement public health and health care systems in their public health responses.

Introduction

COVID-19 emerged two years ago, spreading rapidly spread across the U.S. and the world, impacting lives and communities, and requiring wholesale coordination and rethinking of how we approach public health and health care.

The resulting COVID-19 pandemic exposed many longstanding shortcomings in our systems – uncovering disparities and inequities; highlighting the limitations of our public health system and its ability to generate a response at scale; and showcasing the difficulties in coordinating between public, private, and community-based organizations to improve health.

The pandemic also occurred as largescale changes to health care data and technology systems were already underway. Recent laws and regulations required new connections and interoperability, while the proliferation of value-based care drove coordination across entities and sectors. The compounding pressures of the pandemic led to rethinking of our health care and public health IT systems, requiring new data collections, reporting, connections, and partnership.

Additionally, the private sector has long played a leadership role in developing innovative and patient-focused solutions that improve health and outcomes. Physicians, hospitals, plans, health information exchanges, and technology organizations took initiative over the course of the pandemic to build partnerships, engage with communities, provide targeted care and outreach, and incorporate new technologies, data sets, and digital tools.

Data and technology are foundational elements of our health care and public health systems, and the rapid changes and progress made over the course of the last year would not be possible without the interrelated efforts made by policymakers, the private sector, and communities. As we seek to build on the progress made, we must continue to invest in and augment our data and technology systems, ensuring we have the right data, functionalities, connectivity, and partnerships to advance health outcomes for all.

Advancing Health Equity through Health Data & Infrastructure

Background

Although systemic inequities have long existed in America, the COVID-19 pandemic and its disproportional impact on racial and ethnic minority groups has increased attention to and calls for improving health equity.²

Longstanding barriers and inequities have prevented many “from having fair opportunities for economic, physical and emotional health,” leading to disparate health outcomes.² The American Public Health Association defines health equity as when “everyone has the opportunity to attain their highest level of health.”³ The Robert Wood Johnson Foundation (RWJF) further elaborates, “this requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.”⁴ These factors, often referred to as social determinants of health, prevent many from being able to attain the highest level of health.

² CDC, “Health Equity Considerations and Racial and Ethnic Minority Groups.” Available [here](#)

³ APHA, “Health Equity.” Available [here](#).

⁴ Robert Wood Johnson Foundation, “What is Health Equity?” Available [here](#).

The COVID-19 pandemic highlighted in real time how such systemic factors and barriers drive disparate health outcomes. Over the course of the pandemic, Black, Hispanic, and American Indian individuals have had substantially higher rates of infection, hospitalization, and death, as compared with White individuals.^{1,2} Individuals in these groups are at increased risk for hospitalization and complications, because of a higher prevalence of chronic comorbidities including hypertension, obesity and diabetes.⁵ Additionally, people of color were simultaneously more likely to work in frontline positions that put them at increased risk for contracting COVID-19, and were more likely to rely on public transportation and to live in apartment buildings or other housing conditions with limited social distancing options.^{6,10}

While the lack of comprehensive and timely public health data has emerged as a widely discussed and lamented limitation in the U.S.' COVID-19 response, gaps in collecting, reporting, and aggregating standardized data related to race, ethnicity, and language (REL) and other demographic factors slowed our understanding of the depths of these disparities as they were occurring and stymied many initial efforts to respond.⁷

The lack of transparency and insight into unfolding and ongoing disparities in COVID-19 and beyond, and the resulting impact on many individuals and communities, has driven action across our health care and public health systems, and throughout government, to improve our health data and infrastructure systems to improve overall equity.

Steps to Advance Health Equity

The federal government has recently engaged in several strategies to improve its understanding of health inequities, to provide culturally appropriate resources and support, and to better align incentives to drive improved health outcomes for all – many of which rely on harnessing data and technological connections.

HHS and the Centers for Disease Control and Prevention (CDC) have issued grant funding and targeted culturally relevant outreach and education around testing and vaccines to underserved populations, including most recently \$140 million to expand community-based efforts to conduct local outreach and address barriers to vaccination in traditionally underserved communities.^{8,9} The Assistant Secretary for Planning and Evaluation (ASPE) has researched and issued several reports with recommendations on eliminating health disparities, including the potential creation of health equity measures in Medicare's value-based programs.^{10,11} The new CMS Innovation Center Strategy emphasizes that health equity will be at the center of new model development and notes that all new models will require participants to collect and report the demographic data of their beneficiaries and, as appropriate, data on social needs and social determinants of health.¹² Finally, the Office of the National Coordinator for Health IT (ONC) has announced its intent to pursue health equity by design in all programs and initiatives.¹³

⁵ JAMA Network "Racial and Ethnic Health Disparities Related to COVID-19." Available [here](#).

⁶ Kaiser Family Foundation, "Communities of Color at Higher Risk for Health and Economic Challenges due to COVID-19." Available [here](#).

⁷ Kaiser Family Foundation, "Advancing Health Equity Requires More and Better Data." Available [here](#)

⁸ CDC, "CDC Awards \$3 Billion to Expand COVID-19 Vaccine Programs." Available [here](#).

⁹ HHS, HRSA, "HHS Announces \$143.5 Million to Expand Community-Based Efforts to Address Barriers to COVID-19 Vaccination." Available [here](#).

¹⁰ HHS ASPE, "Health Disparities by Race and Ethnicity During the COVID-19 Pandemic: Current Evidence and Policy Approaches." Available [here](#).

¹¹ HHS ASPE, "Developing Health Equity Measures." Available [here](#)

¹² CMS Innovation Center, "Innovation Center Strategy Refresh." Available [here](#).

¹³ ONC, "ONC Health IT Framework for Advancing SDOH Data Use and Interoperability." Available [here](#).

Congressional members and committees have also expressed significant interest in tackling inequities. For example, Congress is considering several provisions around health equity in the Build Back Better package, including provisions to address maternal health disparities through data collection, quality metrics, and digital tools.¹⁴ Additionally, the House Ways & Means Committee has pledged to use health equity as a lens to evaluate all its policymaking. The Committee has undertaken several steps over the last few years to advance health equity, including the launch of the bipartisan Rural and Underserved Communities Task Force; a request for information from stakeholders on the barriers the Committee should be considering and a subsequent report; and a Committee Report and Framework called “Something Must Change, Inequities in Policy and Society” and a legislative framework aimed at addressing economic and health inequities.^{15,16,17,18} Finally, the recently launched Congressional Social Determinants of Health Caucus is in the process of reviewing responses to its request for information on legislative solutions to address social determinants of health.¹⁹

Stakeholders outside of government have also been active. For example, groups such as the American Academy of Family Physicians, American Hospital Association, Blue Cross Blue Shield Association, Families USA, and others have released guidance and materials on steps to improve care provided to all, better collect standardized REL and other data, and to help patients and consumers overcome barriers to accessing care.^{20,21,22,23} Finally, RWJF established an independent National Commission to Transform Public Health Data Systems to reimagine the public health infrastructure to advance health equity.²⁴

Key Ongoing Challenges and Needed Steps

Despite ongoing efforts and new initiatives, foundational gaps remain. One of the key initial barriers that stakeholders have identified is that there is limited use of uniform, commonly used standards and minimal requirements for collecting and reporting REL and social needs data. Aggregated, standardized REL and social needs data is key to understanding the scope and extent to which certain populations face disparate outcomes and informing targeted and effective responses.

Although the Office of Management and Budget and the CDC have both established data standards for the collection and reporting of REL data, there are few requirements for the use of such standards or for

¹⁴ White House, “Build Back Better Framework”, Available [here](#).

¹⁵ House Ways & Means Committee, “Rural and Underserved Communities Health Task Force Request for Information.” Available [here](#).

¹⁶ House Ways & Means Committee, “Left Out: Barriers to Health Equity for Rural and Underserved Communities.” Available [here](#).

¹⁷ House Ways & Means Committee, “Something Must Change: Inequities in U.S. Policy and Society.” Available [here](#).

¹⁸ House Ways & Means Committee, “A Bold Vision for a Legislative Pathway Toward Health and Economic Equity.”

¹⁹ Congressional Social Determinants of Health Caucus. Available [here](#).

²⁰ American Academy of Family Physicians, “Health Equity Curricular Toolkit.” Available [here](#).

²¹ American Hospital Association, “Race, Ethnicity, Language Data Collection Best Practices.” Available [here](#).

²² Blue Cross Blue Shield Association, “National Health Equity Strategy.” Available [here](#).

²³ Families USA, “Making progress Toward Health Equity: Opportunities for State Policymakers to Reduce Health Inequities Through Payment and Delivery System Reform.” Available [here](#).

²⁴ Robert Wood Johnson Foundation, “Better Data for Better Health.” Available [here](#).

reporting of REL data.^{25,26} In practice, many organizations have adopted modified standards, or collect additional information beyond the OMB or CDC standards. Some organizations have advocated for more specificity and granularity beyond the broad categorizations established by OMB and CDC, and for the collection of other types of information, such as sexual orientation and gender identity (SOGI) data.²⁷

Similarly, although many organizations and clinicians screen individuals for social needs using a range of commonly available screening tools, collected social needs data is often not standardized nor uniformly entered into systems of record.

Lack of uniformity in collecting and reporting this information makes it difficult to aggregate data and draw inferences across different populations, organizations and state and government agencies.

To address these concerns, health care organizations, communities, and the federal government should work together to create common industry standards and collection methods. Common industry standards will help to enable improved collection and exchange of data.

In the area of industry standards, the HL7 Gravity Project has led consensus-based efforts to create common social needs data standards and has encouraged the federal government and key industry stakeholders to adopt such standards.²⁸

Federal and state governments can play a role in incentivizing stakeholders to collect standardized REL or social needs data and should also develop and provide appropriate educational and technical assistance resources.

Additionally, it is important to consider the role of health and digital literacy; patients and consumers should understand what their data is being used for and how to interpret it. The government can

Race, Ethnicity, and Language Data Collection during COVID-19

Many stakeholders raised concerns early in the COVID-19 pandemic about the virus's disproportionate impact on minority populations and called for the federal government to increase requirements for the collection of race, ethnicity, and language data and to make such data publicly available.^{i,ii,iii}

In June of 2020, HHS began requiring laboratories to report REL data to the federal government to better understand how COVID-19 was impacting different racial and ethnic communities. The Trump Administration also announced a series of efforts to improve the understanding of COVID-19's impact on minorities.^{iv, v, vi}

Yet, despite these actions, as of October 5, 2021, race and ethnicity data was only known for roughly 60 percent of the over 34 million COVID-19 cases.^{vii} The same issues have persisted with vaccine rollout, where REL data collection continues to be limited, despite being required. During the first month of the U.S.' vaccine rollout, race and ethnicity data were missing for 48 percent of people, even though collection was required.^{vii}

ⁱ Senator Warren, "Senator Warren Introducing Bicameral Legislation to Require Federal Government to Collect and Report Coronavirus Demographic Data – Including Race and Ethnicity." Available [here](#)

ⁱⁱ AAMC, "AAMC Calls for Enhanced COVID-19 Data Collection on Health Disparities." Available [here](#)

ⁱⁱⁱ AMA, "Top Physician Orgs Urge COVID-19 Mortality Data by Race, Ethnicity." Available [here](#)

^{iv} HHS, "HHS Announces New Laboratory Data Reporting Guidance for COVID-19 Testing." Available [here](#).

^{vi} HHS, COVID-19 Pandemic Response, Laboratory Data Reporting: CARES Act Section 18115." Available [here](#).

^{vi} HHS, "HHS Initiatives to Address the Disparate Impact of COVID-19 on African Americans and Other Racial and Ethnic Minorities." Available [here](#).

^{vii} CDC, "COVID Data Tracker" Available [here](#)

^{vii} Health Affairs, "Centering Equity in the Design and Use of Health Information Systems: Patterning with Communities on Race, Ethnicity, and Language Data." Available [here](#)

²⁵ CMS Office of Minority Health, "Explanation of Data Standards for Race, Ethnicity, Sex, Primary Language, and Disability." Available [here](#).

²⁶ CDC, "Race and Ethnicity Code Set, Version 1.0." Available [here](#).

²⁷ AAFP, "Collecting Racial, Ethnic, Sexual Orientation, and Gender Identity Data in Surveys." Available [here](#)

²⁸ The Gravity Project, Available [here](#).

play a role in raising awareness of the importance of collecting data and on educating stakeholders and patients and consumers as to why the data is being collected and how it will be used.⁷

It can be challenging to build the trust necessary to collect data from individuals regarding their race and ethnicity, or the presence of housing or food access needs. Partnering with trusted community voices and organizations in the development and dissemination of educational materials and adapting to the needs of the community can help to build trust and sustained connections.

At the same time, it's important to ensure there are sufficient guardrails and protections around sharing and use of sensitive data, especially given a history of misuse.²⁹ Although data has the potential to help us track and understand inequities and better target needs, it also has the potential to exacerbate disparities. As one example, the House Ways & Means Committee Democratic staff issued a report in October 2021 examining the use of race data in clinical algorithms and finding that, unless addressed, the current methods and assumptions underlying many algorithms can further perpetuate existing disparities.³⁰ Health care organizations should work alongside the federal government to develop industry standards and best practices to ensure the appropriate use of data.

Modernizing and Advancing Public Health

Background

The COVID-19 pandemic placed enormous strain on our health care and public health systems, exposing long-standing disparities and inequities, and straining fragmented systems that often struggled to respond effectively and efficiently. As we emerge from a post-pandemic world, one of the lessons learned has been the need for a health and public health data system that is capable of data collection at-scale and real-time information sharing between public health agencies, health care clinicians, and the federal government to respond effectively and equitably against emerging threats.

Investment in our health care and public health systems have largely been separate and unequal, making coordination between the two difficult. Public health funding has also largely supported disparate aspects of community health, owing to the public health system's siloed nature. While COVID-19 relief funding has provided significant amounts of funding to the CDC and jurisdictional public health programs – and President Biden's fiscal year 2022 budget request³¹ includes the largest boost in funding in nearly 20 years – decades of underfunding left the public health system struggling to effectively respond to the scope of the COVID-19 pandemic.

Chronic underinvestment has impacted the scale of the public health workforce and public health agencies' ability to invest in state-of-the-art systems and technology that are capable of exchanging data in real-time with health care organizations, communities, and other government agencies. The limited use of public health data standards hindered efforts to aggregate and report data, for state and federal governments to identify trends and disparities, and to respond efficiently.

Additionally, due to data sharing limitations, it has often been difficult for plans, clinicians, or community partners to know whether individuals have been vaccinated, or to access critical information at the point of care, adding to the complexity of public health outreach initiatives.

²⁹ Health Affairs, "Centering Equity in The Design and Use Of Health Information Systems: Partnering With Communities On Race, Ethnicity, And Language Data." Available [here](#).

³⁰ House Ways & Means Committee, "Clinical Decision Support Tools and The (Mis)Use Of Race." Available [here](#).

³¹ White House, "President's Budget." Available [here](#).

Despite these limitations, public health and health care organizations and systems have shown remarkable agility and innovation over the course of the pandemic, working to overcome obstacles and continuously improve their response.

Actions to Improve Public Health Data and Infrastructure

Federal Efforts

The federal government has placed responding to COVID-19 and improving our public health systems as a top priority. For instance, in one of his first acts upon entering office, President Biden signed an Executive Order on Ensuring a Data-Driven Response³² instructing federal agencies to improve public health data collection and reporting processes.

As part of HHS' response to the Executive Order, the Office of the National Coordinator for Health Information Technology (ONC) Health Information Technology Advisory Committee (HITAC) stood up a Public Health Data Systems Task Force to identify and prioritize policy and technical gaps associated with effectiveness, interoperability, and connectivity of information systems relevant to public health.

The Task Force issued a set of recommendations to inform future ONC work, and which recommended ONC work collaboratively across CDC, CMS, OCR, FDA and other agencies. ONC is in the process of reviewing the recommendations, and in the meantime, it has engaged in cross-agency coordination with the CDC on efforts related to standardization of data elements,³³ interoperability and trusted exchange,³⁴ and promoting a Fast Healthcare Interoperability Resources (FHIR) roadmap for public health.³⁵

The federal government is engaged in other initiatives to improve health data and infrastructure including CDC's recently announced Center for Forecasting and Outbreak Analytics,³⁶ which will bring together public health data, disease modeling, data scientists, and private and public health practitioners.

HITAC Public Health Data Systems Task Force

The HITAC Public Health Data Systems Task Force issued a final reportⁱ with 52 recommendations in total, including:

- **22** recommendations related to public health data systems infrastructure, syndromic surveillance, laboratory reporting, case reporting, immunizations, situational awareness data, and standards development and adoption.
- **16** recommendations related to needed policy underlying the development of 21st century public health data systems and funding mechanisms by which these systems can be achieved.
- **6** cross-cutting recommendations that apply across the spectrum of public health data systems to facilitate a range of key activities.
- **6** recommendations for improving engagement between public health authorities, healthcare organizations and practitioners, individuals, and governing bodies at the federal, state, and local levels.
- **2** recommendations, as well as through guidance within the other sections, this report identifies data systems, data uses, and strategic approaches necessary to address historically under-resourced needs, eliminate health disparities, and advance health equity in the U.S.

ⁱHITAC Recommendations Available [here](#).

³² White House, "Executive Order on Ensuring a Data-Driven Response to COVID-19 and Future High-Consequence Public Health Threats." Available [here](#).

³³ ONC, "Thinking Outside the Box: The USCDI+ Initiative." Available [here](#).

³⁴ ONC, "Trusted Exchange Framework and Common Agreement." Available [here](#).

³⁵ ONC, "Fast Healthcare Interoperability Resources (FHIR)." Available [here](#).

³⁶ CDC, "CDC Stands Up New Disease Forecasting Center." Available [here](#).

Finally, the Coronavirus Aid, Relief, and Economic Security (CARES) Act³⁷ and the American Rescue Plan Act³⁸ provided CDC with \$1 billion for public health data modernization, including the CDC Data Modernization Initiative (DMI). CDC's DMI³⁹ brings together state, tribal, local, and territorial public health jurisdictions and private and public sector partners to create modern, interoperable and real-time public health data and surveillance systems. CDC aims to promote seamless reporting of clinical and laboratory data to public health, ensure interoperability among core public health surveillance systems, and support cross-cutting upgrades, such as migration to the cloud and access to new data sources.

Referring to the CDC's Data Modernization Initiative in her keynote remarks during the Health IT Leadership Roundtable, Catherine Oakar, Special Assistant to the President for Public Health and Disparities noted: *"It will move us from a siloed and brittle public health data system to a more connected, resilient, adaptable, and sustainable early response system."*

Meanwhile, members of Congress have also held several hearings^{40,41} focused on public health infrastructure and data, issued staff reports^{42,43,44,45,46} with recommendations, and have advocated for passage of legislation that would improve and bolster the public health system.

For example, Representative Doris Matsui (D-CA) and Senator Richard Blumenthal (D-CT) introduced the bicameral *Public Health Funding Prevents Pandemics Act*⁴⁷ to restore full funding to the Prevention and Public Health Fund (PPHF), which is the first and only federal mandatory public health funding stream. The PPHF supports vital public health programs, including those involved in responding to the COVID-19 pandemic like the Epidemiology and Lab Capacity program. Despite the original intent to build up reserves through the fund, it has instead been repeatedly depleted for other uses, limiting its ability to be leveraged in cases of a public health emergency.

Similarly, several Senate Democrats, including Senate HELP Committee Chair Patty Murray (D-WA) and 19 of her colleagues re-introduced the *Public Health Infrastructure Saves Lives Act*,⁴⁸ which would provide \$4.5 billion in sustained, predictable funding to support state, territorial, local and tribal health department capabilities and investments at the CDC.

³⁷ Coronavirus Aid, Relief, and Economic Security (CARES) Act. Available [here](#).

³⁸ American Rescue Plan Act. Available [here](#).

³⁹ CDC, "Public Health Data Modernization Initiative."

⁴⁰ House Select Subcommittee on the Coronavirus Crisis, "Hybrid Hearing On "Upgrading Public Health Infrastructure: The Need To Protect, Rebuild, And Strengthen State And Local Public Health Departments." Available [here](#).

⁴¹ Senate HELP Committee, "The Path Forward: Building on Lessons Learned from the COVID-19 Pandemic." Available [here](#).

⁴² Senate HELP Committee, Ranking Member Burr, "Modernizing CDC: Ensuring a Strategic Approach and Improving Accountability." Available [here](#).

⁴³ Senate HELP Committee, Ranking Member Burr, "Reforming and Strengthening ASPR: Ensuring Specialized Capabilities, Sufficient Capacity, and Specific Authorities to Meet 21st Century Public Health Threat." Available [here](#).

⁴⁴ Senate HELP Committee, Ranking Member Burr, "Preparing for Future Public Health Threats: Improving and Sustaining Foundational Public Health Capabilities in Response to COVID-19." Available [here](#).

⁴⁵ Senate HELP Committee, Ranking Member Burr, "Strengthening FDA's Regulatory Readiness: Implementing Lessons Learned from the COVID-19 Pandemic." Available [here](#).

⁴⁶ Senate HELP Committee, Ranking Member Burr, "Strengthening the Safety and Security of Laboratories." Available [here](#).

⁴⁷ Public Health Funding Prevents Pandemics Act. Available [here](#).

⁴⁸ Public Health Infrastructure Saves Lives Act. Available [here](#).

“As we continue our efforts to end the ongoing COVID-19 crisis and rebuild stronger and fairer, it’s critical we end the cycle of crisis and complacency when it comes to funding for public health,” Senate HELP Committee Chair Murray said. *“And the better funded and prepared our public health system is before a crisis, the more lives it will be able to save during one.”*

Public/Private Partnerships and Collaborations

The private sector has been crucial to supporting federal, state, and local governments in their public health response to COVID-19, especially with respect to leveraging data collection and exchange to improve monitoring and surveillance, to better target communications and outreach, and to identify and mitigate gaps and disparities.

*“In Colorado, we’ve had a longstanding partnership with our Public Health Department... serving as the conduit between the investments being made in the private sector and doing our best to make sure that that information is **bidirectional in nature**, meaning it not only provides support to public health departments and their necessary reporting requirements, but also makes sure we have data in the hands of providers taking care of the population,”* said Morgan Honea, Executive Vice President of Contexture and Chief Executive Officer for the Consortium for State and Regional Interoperability, during the Roundtable.

Coordination among public, private and community stakeholders can help to ensure that outreach and resources are targeted to high-need areas. Many states have partnered with clinicians through state health information exchanges (HIEs) and health care consortia to augment state immunization data with data contained in electronic health records (EHRs) and insurance claims. For example, Maryland’s HIE, CRISP, is working with the Department of Health to match data from the state immunization information system with Medicare and Medicaid claims and prior hospitalizations from an all-payer claims database. Combining these data has allowed the state to leverage more accurate and complete race and ethnicity data to promote equity and engage higher-risk populations.⁴⁹

Other cross-sector partnerships have been successful in utilizing data to target high-risk populations for COVID-19 vaccines. In early March 2021, the White House, America’s Health Insurance Plans (AHIP) and Blue Cross Blue Shield Association (BCBSA) announced the Vaccine Community Connectors pilot initiative, which aimed to vaccinate two million people over the age of 65 in the most vulnerable communities across the country. Participating health insurance plans used their data and analytic expertise to identify populations at higher risk of poor outcomes in areas with inequitable vaccination rates and contact them to answer their questions, facilitate vaccine registration and appointment scheduling, and coordinate services to overcome barriers that may stand between them and getting vaccinated, such as transportation. More than 50 payers have joined AHIP and BCBSA in the vaccine initiative, which has expanded to include Medicaid members and other underserved communities. The program surpassed its two-million-person goal in under 100 days.⁵⁰

⁴⁹ Duke Margolis Center for Health Policy, “Building Public-Private Partnerships to Support Efficient and Equitable COVID-19 Vaccine Distribution, Access, and Uptake.” Available [here](#).

⁵⁰ BlueCross BlueShield, “Health Insurance Providers Help Vaccinate More Than 2 Million Seniors Against COVID-19 in Underserved Communities.” Available [here](#).

To support community-based efforts, Data Across Sectors for Health (DASH), funded by RWJF, is building local capacity for multi-sector data-sharing, specifically the capacity, the movement and the evidence base to inform equity and lifting up disadvantaged and underserved communities.⁵¹ DASH is focusing on bringing communities and states together on data sharing collaboratives to advance community data sharing and data integration efforts. DASH's latest partnership will grant awardees funding to support local or state governments – in collaboration with community partnerships – to advance the use of COVID-19 relief funds to support data-sharing and data-integration efforts that aim to improve health, equity, and well-being in local communities.⁵²

As highlighted throughout the Roundtable, Congress and the Biden Administration, as well as the private sector, should utilize the lessons learned during the pandemic and build upon partnership opportunities to set up the ideal public health system of the future.

Key Ongoing Challenges and Needed Steps

The COVID-19 pandemic made evident many of the shortcomings of our nation's public health system and highlighted the need for an enhanced, interoperable infrastructure that can seamlessly coordinate with other sectors. Pre-existing weaknesses in the accurate collection and timely sharing of standardized data between federal, state, and local public health departments and across public health and health care systems and organizations hampered insights and limited our ability to fight the spread of COVID-19. Furthermore, persistent funding gaps at the federal, state and local levels, and siloed approaches to funding, may have contributed vastly to our inability to track, prepare for and respond to COVID-19.

While federal, state, and local governments, and the private sector have already made significant strides in bolstering the public health system for the future, additional investments and improvements in health data and data infrastructure are needed to ensure a seamless, interconnected and interoperable system.

Successful public-private partnerships, as well as partnerships with community-based organizations, can reach their full potential and drive improved health for all when they are equipped with faster and more informed data insights that can be shared across sectors. Data infrastructure must be sufficient to support all aspects of public health including surveillance and reporting, clinical outcomes, social determinants of health, and connectivity between health care clinicians and social needs supports. Together, public health data insights and subsequent responses may be more connected, sustainable and more equitably distributed across our nation.

⁵¹ Data Across Sectors for Health. Available [here](#).

⁵² Data Across Sectors for Health, "Learning and Action in Policy and Partnerships (LAPP)." Available [here](#).

Key Takeaways and Recommendations

Advancing Health Equity Through Health Data and Infrastructure

- *Enable the collection of standardized race, ethnicity, and language (REL) data across programs by supporting ongoing development and wide adoption of uniform industry standards.* Industry standards will enable organizations and programs to improve the collection of race and ethnicity data, and stratify data by race, ethnicity, and other demographics where feasible in reports. Federal incentives and funding can help to support greater adoption.
- *Enable the collection of standardized social needs data as appropriate by supporting ongoing development of industry standards.* Uniform, industry standards will also enable organizations to collect and report standardized social needs data where possible and appropriate, and organizations should take steps to connect patients and consumers with identified social needs with available resources. Federal incentives and funding can help to support screening and collection of data.
- *Ensure industry, government, and communities work together to develop and incentivize adoption of common industry standards.* The federal government should partner with industry and communities to develop and incent the adoption of common data standards for collection and exchange of REL and other demographic and social needs data.
- *Develop industry standards/best practices to ensure privacy is protected and appropriate use of data.* Health care organizations and governments should define appropriate uses for REL and other demographic data, such as social needs data, and ensure that patients and consumers understand what their information is being used for.
- *Partner with trusted entities, such as community-based organizations, to collaborate in screening and collection of information.* Where possible, organizations should partner with local, trusted community members and organizations to help communicate the intent and importance of collecting REL and other demographic and social needs data and to maintain trust.
- *Leverage REL and social needs data to inform where gaps exist, to help in directing resources and in ensuring additional assistance.* Public, private, and community-based entities should ensure that collected data on race, ethnicity, language, or social needs can be aggregated and used to identify disparities, target interventions, and close gaps.

Modernizing and Advancing Public Health

- *Appropriate and ensure sustained funding to support a robust public health infrastructure, which includes interoperable systems and workforce capacity.* Congress should provide and maintain sufficient funding for public health systems' improvement, operations, and maintenance.
- *Increase data sharing between public health and health care organizations to support identification of public health threats and to help direct responses.* The federal government should support the development of common standards that can be used to improve data exchange between public health and health care organizations, while maintaining appropriate privacy protections.
- *Establish and maintain multisector collaboration between public, private, and nonprofit organizations to address vaccine hesitancy and to provide targeted outreach to communities.* Partnerships between government, the private sector, and community organizations can help to better identify gaps, target resources, and build trust as part of health care and public health initiatives.
- *Leverage community-based organizations to help supplement public health and health care systems in their public health responses.* Community-based organizations, with their local roots and trusted partners, should be a critical component of any health care or public health response.

APPENDIX

Health IT Leadership Roundtable October 2021 Agenda

Time	Agenda
9:00 a.m.	Welcome & Housekeeping
9:05 a.m.	Opening Remarks
9:15 a.m.	<p>Executive Roundtable: Harnessing Health Data to Advance Health Outcomes</p> <p><u>Moderator:</u></p> <p>Rachel Roubein, National Health Care Reporter, Washington Post</p> <p><u>Participants:</u></p> <ul style="list-style-type: none"> - Ramsey Alwin, President & Chief Executive Officer, National Council on Aging - Shawn Martin, Executive Vice President & Chief Executive Officer, American Academy of Family Physicians - Sean Robbins, Executive Vice President of External Affairs, Blue Cross Blue Shield Association
9:50 a.m.	<p>Perspectives from Congress on Data & Health Equity</p> <ul style="list-style-type: none"> - Rachel Dolin, PhD, Professional Staff Member, House Ways & Means Committee, Health Subcommittee - Sara Berkemeier-Bell, Policy Advisor, Senator Dan Sullivan of Alaska
10:10 a.m.	<p>Panel #1: Advancing Health Equity through Health Data & Infrastructure</p> <p>The goal of this panel is to explore how to advance health equity by design. Panelists will discuss how improved collection, standardization, exchange, and reporting of data can support efforts to better identify and address health inequities. Panelists will discuss the current challenges health care organizations and governments face in comprehensively collecting and reporting data on race, ethnicity, and social determinants, highlight the role of public-private partnerships in driving consensus-based standards, and identify policy solutions. Panelists will also discuss how health care infrastructure can best support patients’ overall needs, through increased access to care and information, care coordination, and privacy protections.</p> <p><u>Moderator:</u></p> <p>Dr. Lucienne Ide, Chief Executive Officer, Rimidi; Co-Chair of the Health Equity and Access Leadership Coalition (HEAL)</p> <p><u>Panelists:</u></p> <ul style="list-style-type: none"> - Dr. Maria Caban Alizondo, Director, Health Information Management Services, UCLA Health System - Eliot Fishman, PhD, Senior Director, Health Policy, Families USA

Time	Agenda
	<ul style="list-style-type: none"> - Joy Lewis, Senior Vice President, Health Equity Strategies & Executive Director, Institute for Diversity and Health Equity, American Hospital Association - Dr. Lisa Schaffner, Vice President of Care Analytics, Highmark
10:50 a.m.	<p>Administration Keynote</p> <p>Catherine Oakar, Special Assistant to the President for Public Health and Disparities, Executive Office of the President</p>
11:10 a.m.	<p>Panel #2: Modernizing and Advancing Public Health</p> <p>The goal of this panel is to explore current efforts to modernize and intentionally rebuild our public health systems in the aftermath of COVID-19. Panelists will discuss key tenets that federal and state governments should consider when designing and building new public health infrastructure. Panelists also will share best practices in data standardization, data exchange, and reporting, and highlight the importance of connecting the public health and health care systems to ensure coordination across the spectrum of health.</p> <p><u>Moderator:</u></p> <p>Molly Murray, Senior Manager, Health Information Technology, Pew Charitable Trusts</p> <p><u>Panelists:</u></p> <ul style="list-style-type: none"> - Amanda Cavanagh, Senior Program Manager, Center for Health Information Sharing and Innovation, Illinois Public Health Institute; Data Across Sectors for Health - Ashok Chennuru, Chief Data and Analytics Officer, Anthem - Dr. Annie Fine, Chief Science and Surveillance Officer, Senior Advisor to Data Modernization Initiative, Council of State and Territorial Epidemiologists - Morgan Honea, Executive Vice President, Contexture; Chief Executive Officer, Consortium for State and Regional Interoperability
11:50 a.m.	Closing Remarks
12:00 p.m.	Adjourn