

THE POWER OF TECHNOLOGY
TO TRANSFORM PATIENT
CARE

Health IT Priorities for 2021

Health IT
Leadership
Roundtable

May 2021

Executive Summary

The private sector has long played a leadership role in developing innovative and patient-focused solutions that enable individuals to access convenient, high-quality care, including through the use of technology and data.

The 2019 novel coronavirus (COVID-19) public health emergency (PHE) brought with it unprecedented challenges, requiring rapid innovation and collective responses to prevent infection, to ensure continued access to care, and to chart a pathway forward. The PHE propelled changes in the way health care is delivered and health data is exchanged, highlighting shortcomings in our public health infrastructure and response capabilities, and exposing deep, and longstanding health inequities.

With this in mind, in March 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** on *The Power of Technology to Transform Patient Care: Health IT Priorities for 2021*.¹ The Roundtable sought to provide an opportunity for a diverse set of patients, policymakers, and organizations to find common ground in exploring the impact of the COVID-19 pandemic on health IT and health care data policy and to discuss industry and policymaker priorities for 2021.

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) describes the role that health care and public health systems played in the pandemic response; (2) highlights the importance of collecting and reporting data on race, ethnicity, and social needs as part of a comprehensive effort to advance health equity; (3) notes the importance of ensuring health data privacy; and (4) provides recommendations to continue to advance health IT moving forward.

Key Recommendations

- Maintain Regulatory Flexibility for Virtual Care
- Provide Funding for and Prioritize Public Health Infrastructure Modernization
- Increase Electronic Case Reporting
- Incentivize Public Health Data Standardization Efforts
- Increase Collection of Race/Ethnicity Data Across Public Programs
- Encourage Cross Sector Data Sharing Collaborations and Standardization of Social Needs Data
- Enhance Health Data Privacy Protections and Strengthen Nondiscrimination Protections

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 Informatics Association | Blue Cross Blue Shield Association | College of Healthcare Information Management Executives | Consumer Technology Association | Federation of American Hospitals | National Partnership for Women & Families | Premier Healthcare Alliance

¹ See Appendix A for the agenda for the *Health IT Leadership Roundtable – The Power of Technology to Transform Patient Care: Health IT Priorities for 2021*. This is the third Health IT Leadership Roundtable convened by the Host Committee. For more information on previous Roundtable events and topics, see <https://sironastrategies.com/tag/health-it-leadership-roundtable/>

Introduction

The private sector has long played a leadership role in developing innovative and patient-focused solutions that enable patients to access convenient, high-quality care.

Physicians, hospitals, plans, and technology organizations have made significant advancements in expanding the scope and accessibility of electronic health data, ensuring interoperability, promoting and providing access to virtual care, and incorporating the use of new technologies, data sets, and digital tools to improve the convenience and quality of care delivered.

The COVID-19 pandemic has had an enormous impact on the health care system, accelerating and advancing technological investments and propelling the adoption of new practices in care delivery and cross-sector coordination. Health care entities rapidly expanded access to, and the delivery of, virtual care technologies and other tools to ensure that individuals could maintain their connection with health care providers. The novel challenges presented over the course of the past year have also led to new partnerships and initiatives across entities and sectors to deliver care in new ways and to exchange data more effectively.

The pandemic response and the growth in virtual care also heightened the importance of seamless, standardized data exchange. As virtual technologies such as telehealth expanded access to care, the importance of patients' and providers' ability to access and exchange records increased. To mitigate concerns regarding the declining rates of screenings, routine vaccinations, and other preventive care fell, health care entities used advanced analytics and performed outreach to ensure that critical preventive, chronic, and acute care continued to be provided.

The COVID-19 pandemic also laid bare the imbalance between, and disjointed nature of, our health care and public health systems. The myriad challenges faced by public health and health care officials in collecting, sharing, and reporting COVID-19 testing, vaccine distribution, and vaccine administration data have led to widespread calls for a 21st Century public health system that can better support public health data systems, as well as improved interoperability and data exchange with health care partners.

Moreover, as the pandemic has exposed health disparities both longstanding and new, public health and social determinants data is increasingly viewed as an essential component of efforts to better identify such disparities and to address gaps in care. Heightened awareness of long-standing data challenges and their impacts on health equity have escalated the urgency of strengthening data collection and sharing capabilities.

Finally, amidst the ongoing changes in care delivery and data exchange, new requirements are coming into effect that will make it easier for patients to access and share their health information. These important policies, however, are not linked to strengthened data privacy protections, raising concerns that health care data may not be sufficiently protected.

The rapid changes and progress made over the course of the last year would not be possible without the interrelated efforts made by policymakers and the private sector. Health IT policy helped to lay a foundation for our response to COVID-19, but the past year has shown there is more progress to be made. In considering health IT policy priorities for 2021 and beyond, it is important to take into account the ongoing evolution of technology and data in advancing patient care; the need to enhance and connect public health infrastructure with health care infrastructure; the role that race and ethnicity and social needs data play in ensuring equitable health outcomes; and the importance of a patient-centered approach to ensuring privacy and access. Below, we explore each of these topics in more detail and discuss lessons learned and opportunities to continue to advance the value of health IT moving forward.

Improving Health Care & Public Health Data and Technology Infrastructure

Health care organizations across the U.S. have invested in health care technologies and data infrastructure to provide for a 21st Century health care system. Providers, health systems, and payers have offered telehealth and other virtual care tools to expand access to convenient care, built out electronic health information systems and pursued advanced data analytics, and offered portals for individuals to access their health information. These longstanding investments served as a foundation for the health care system's initial COVID-19 response, as health care organizations rapidly sought new ways to maintain access to care and to coordinate across different types of entities and sectors.

However, the past year has also served to highlight the challenges that remain, including the gaps between our health care and public health infrastructure in terms of their respective readiness and capacity to respond to public health crises.

Expanding Access to and Continuity of Care through Technology

Use of virtual care tools, such as telehealth and remote monitoring was steadily growing by employers, plans, providers, and individuals prior to the pandemic, but increased rapidly in the wake of stay-at-home orders and social distancing practices.²

A participant in the first Health IT Leadership Roundtable (Roundtable) panel described the initial challenges that providers and payers faced in providing ongoing care and to support patients, especially for those with chronic needs. Given social distancing, many patients opted to defer in-person care, including screenings, checkups, immunizations, and other preventive or chronic care that is routinely performed. As a result, providers and payers had little insight into potential health issues that may be occurring, or that may emerge down the road, for individual patients and with respect to broader population health.

To address this challenge, payers and providers rapidly adopted telehealth and other virtual care tools to maintain connections with patients, and federal and state governments moved to eliminate coverage and reimbursement barriers. A CDC report found that even in the early stages of the pandemic, the first quarter of 2020, the number of telehealth visits increased by 50 percent compared to the same period in 2019.³ FAIR Health, which tracks commercial insurance claims, has consistently reported substantially higher rates of telehealth claims in 2020 as compared to 2019. For example, the number of telehealth claims were almost 3000 percent higher in December 2020 than a year prior.⁴ Studies have also indicated that individuals are generally satisfied with telehealth and virtual care, with 80 percent of respondents in one study indicating that they are likely to have another virtual visit.⁵

² American Medical Association (AMA), "AMA Digital Health Research: Physicians' motivations and requirements for adopting digital health – Adoption and attitudinal shifts from 2016 to 2019." Available here: <https://bit.ly/3ul9bOb>

³ CDC, MMWR, "Trends in the Use of telehealth During the Emergence of the COVID-19 Pandemic – United States, January – March 2020." Available here: <https://bit.ly/3rBUPqE>

⁴ FAIR Health, "Monthly Telehealth Regional Tracker, Dec. 2020." Available here: <https://bit.ly/3cxLdJt>

⁵ Deloitte Center for Health Solutions, "Are consumers already living in the future of health?" Available here: <https://bit.ly/3m86E6V>

Additionally, companies have developed new types of diagnostic tools, such as genetic tests or blood tests, and communications platforms for individuals to use at home. According to a study, between 30 and 50 percent of individuals are comfortable using at-home diagnostics, particularly for diagnosing infections.⁶

Although social distancing necessitated the expansion of at-home diagnostics and other virtual care tools, such options have been widely known to expand access and are convenient, and, given the rapid expansion during COVID-19 and subsequent acceptance, are likely to continue to be used over the long term.

Public and private payers have also indicated interest in maintaining access to virtual care tools as they can help bridge geographic and other gaps in access to care.⁷ For example, although rarely covered prior to the pandemic, recent policies that allowed payment for audio-only telehealth services helped to connect individuals in areas with limited broadband availability to care.⁸

Building a Foundation of Health Care Technology & Data

Health systems, hospitals, and providers have also invested heavily in electronic health record systems and information technology over the past decade, spurred by the Health Information Technology for Economic and Clinical Health (HITECH) Act.⁹ Nearly 100 percent of hospitals and 86 percent of providers now leverage electronic health record systems to capture and exchange health information.^{10,11} These systems improve care coordination and allow for the use of tools such as clinical decision support or advanced analytics by integrating patient information from multiple sources.

Recent regulations from the Centers for Medicare & Medicaid Services (CMS) and the Office of the National Coordinator for Health IT (ONC), which stem from the 21st Century Cures Act, will help to increase connections between health data systems, enabling greater access to, exchange, and use of electronic health information across EHRs and health care organizations and providing individuals with easier access to their health care information.^{12,13}

Additionally, standards development organizations such as Health Level Seven International (HL7) have worked to improve the standardization of health care data elements, allowing for more streamlined, seamless exchange of health care information across entities and systems. The final CMS and ONC rules require certain health care entities to exchange, at a minimum, the standardized set of health data classes

⁶ Deloitte Center for Health Solutions, “Are consumers already living in the future of health?” Available here:

<https://bit.ly/3m86E6V>

⁷ Seema Verma, Health Affairs, “Early Impact of CMS Expansion of Medicare Telehealth During COVID-19.” Available here:

<https://bit.ly/3rP6pPG>

⁸ HHS, “Billing for telehealth during COVID-19.” Available here: <https://bit.ly/3m8C3pM>

⁹ Centers for Medicare & Medicaid Services (CMS), “Promoting Interoperability: Data and Program Reports.” Available here:

<https://go.cms.gov/2PMaE16>

¹⁰ HHS Office of the National Coordinator for Health IT (ONC), “Adoption of Electronic Health Record Systems among U.S. Non-Federal Acute Care Hospitals: 2008-2015.” Available here: <https://bit.ly/3cwPWLn>

¹¹ Centers for Disease Control and Prevention (CDC), “Percentage of office-based physicians using any electronic health record (EHR)/electronic medical record (EMR) system and physicians that have a certified EHR/EMR system, by U.S. state: national Electronic Health Records Survey, 2017.” Available here: <https://bit.ly/2PCTWB4>

¹² Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access for Medicare Advantage Organization and Medicaid Managed Care Plans, State Medicaid Agencies, CHIP Agencies, and CHIP Managed Care Entities, Issuers of Qualified Health Plans on the Federally-Facilitated Exchange, and Health Care Providers. Available here: <https://bit.ly/2Od6UFg>

¹³ 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program. Available here: <https://bit.ly/3sL79X1>

and data elements outlined in the U.S. Core Data for Interoperability (USCDI),¹⁴ and ONC is continuing to solicit public comment and recommendations in its efforts to expand upon the standardized data elements in the USCDI moving forward.¹⁵

Health Care and Public Health Infrastructure in the COVID-19 Response

The growth and investment in health care data and technologies helped to lay the foundation for part of our nation's COVID-19 response. Previous investments in the exchange and use of health data, in virtual tools, and advanced analytics helped health care entities respond quickly to the varying demands of the pandemic. However, the past year has also laid bare the limitations of the public health system's data and technology infrastructure and its connections with the health care system. The most prevalent issue raised throughout the Health IT Leadership Roundtable discussion were the challenges that governments and health care organizations faced in accessing, reporting, and sharing public health data during the pandemic. These limitations served to hamstring the U.S.'s early understanding of the spread of the virus and challenged response efforts.

Public health agencies, which are generally charged with predicting, preventing, and tracking disease outbreaks, were primarily responsible for tracking and responding to COVID-19. However, as a September 2019 report from the Council of State and Territorial Epidemiologists and the de Beaumont Foundation noted, chronic underinvestment in public health infrastructure laid a weak foundation for its ability to respond quickly and effectively to a public health crisis.¹⁶ Just six months after the report was published, the realities of the chronic underinvestment were made clear. Public health agencies across the country struggled to collect and rapidly report comprehensive COVID-19 data to federal systems, and to exchange data with health care partners.

A participant in the first panel of the Roundtable described his organization's experience in trying to connect and report data across different states. He noted that his organization has 190 hospitals in 19 states, which meant coordinating among 19 state public health agency systems to ensure compliance with 19 different sets of reporting requirements. He noted that not only did the reporting requirements across states differ, but the data standards required to report on each measure also varied across states, which creates considerable complexity and burden for health systems and other health care entities. As a point of contrast, he noted that the federal reporting system, TeleTracking, was built to serve as a singular interface for hospitals to report COVID-19 case data to the

State of Public Health Infrastructure

"Despite the availability of new technologies to facilitate timely data exchange, public health departments struggle to take advantage of these advancements and continue to rely on sluggish, manual processes like paper records, phone calls, spreadsheets, and faxes requiring manual data entry. These outcomes do not result from a lack of data or the limitations of today's technology; rather, these poor outcomes are due to inadequate resources. Public health has been unable to access existing data or implement advanced technologies necessary to improve the timeliness of public health surveillance."

¹⁴ ONC, "Cures Act Final Rule: United States Core Data for Interoperability." Available here: <https://bit.ly/3dqjHwP>

¹⁵ ONC, "United States Core Data for Interoperability: Draft Version 2 (January 2021)." Available here: <https://bit.ly/39vqNit>

¹⁶ Council for State and Territorial Epidemiologists, de Beaumont Foundation, "Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway." Available here: <https://bit.ly/3w7GjKR>

federal government.¹⁷ According to TeleTracking, as of October 2020, it was receiving information from 95 percent of hospitals daily.¹⁸

Another panelist added that there has been a huge volume of data generated throughout the PHE related to COVID-19 lab reports and diagnoses – but there is varied and often limited ability for labs, providers and others health care entities to electronically report case data to public health agencies or registries.

Investing in Public Health Infrastructure

U.S. Representative Scott Peters (D-CA) noted that COVID-19 has exposed weaknesses in our data systems, including inconsistent data and reporting requirements. This has led to missing data on race, which has masked the disproportionate impact that COVID-19 has had on communities of color. The gaps persist because our current public health IT makes it difficult to rapidly assemble data from several different public health entities. The systems are not always compatible, and the data is not always standardized. Rep. Peters introduced the bipartisan Health STATISTICS Act (H.R. 831) to help address these issues, which would direct CDC to adopt public health technical and reporting standards and establishes a technical working group to make ongoing recommendations to establish these standards, among other provisions. He urged that we should use this crisis to streamline ad hoc data sharing agreements, to remove data siloes, and fix the patchwork of data systems responsible for reporting vital statistics.

Rather than reporting via burdensome paper-based methods, hospitals, nursing homes, laboratories, pharmacies physician practices, and other sites of care need to be able to seamlessly connect, report, and exchange standardized electronic information with public health registries and immunization systems. Public health organizations have urged increased funding to improve and expand electronic case reporting (eCR), which automatically generates an electronic submission of reportable diseases and conditions from an EHR to public health agencies. eCR, public health organizations argue, “dramatically improves disease/condition reporting and reduces physician burden in fulfilling their legal responsibility to report, which leads to early implementation of public health interventions and limits further spread of infectious agents.”¹⁹

Additionally, unlike the health care system, which has been pushed to adopt standardized data elements with robust implementation guides that help to ensure consistency in use, public health systems have not yet undergone a similar national data standardization process. This has led to challenges with consistent data capture and reporting, leading to concerns about data quality and completeness.

The public health crisis created new opportunities for partnership and investment to build on and improve our health care infrastructure, however, the pandemic also demonstrated the need for additional investment and prioritization to build up public health infrastructure so that it may sit on equal and integrated footing and to better prepare for the next pandemic.

¹⁷ CDC, “CDC Director Dr. Robert R. Redfield and HHS Chief Information Officer Jose Arrieta Remarks on HHS Protect.” Available here: <https://bit.ly/3uex21J>

¹⁸ Healthcare IT News, “HHS Renews Contract with TeleTracking, Despite Lingering Questions.” Available here: <https://bit.ly/31Aznl9v>

¹⁹ APHA, ASTHO, CSTE, HIMSS, NACCHO, NAPHIS Letter to Congress re: Letter to Key Appropriators in Support of Data Modernization. Available here: <https://bit.ly/3ubNfog>

Advancing Health Equity through Health IT

Of particular concern throughout the pandemic has been the disproportionate impact that COVID-19 has had on communities of color.^{20,21} Disparities in health outcomes are a longstanding issue in the U.S. but have come to the forefront of public discourse over the past year, prompting reevaluations of our health care and public health data collection methods and our collective approaches to ensuring equitable access to care.

Collection and Reporting of Race/Ethnicity Data

Gaps in the collection of race and ethnicity data due to varying reporting requirements across state and local jurisdictions led to an incomplete picture of how the virus was impacting certain populations and communities.²² In response, HHS has taken steps to require laboratories and other entities to include demographic data, like race, ethnicity, age and sex when reporting data on COVID-19 tests.^{23,24} However, as of March 31, race/ethnicity data was available for only 54 percent of all COVID-19 cases, and for 75 percent of deaths.²⁵

The U.S. Government Accountability Office (GAO) has recommended that HHS take steps to ensure the complete reporting of race and ethnicity information for recipients of COVID-19 vaccinations,²⁶ and the White House COVID-19 Health Equity Task Force, created through President Biden's January 21 Executive Order, is drafting recommendations to improve federal data collection to help address COVID-19 health inequities.²⁷ Meanwhile, members of Congress have called for improved collection of race and ethnicity data and have introduced legislation to require the reporting of COVID-19 testing, treatment, outcomes, fatalities, and vaccination data by race, ethnicity, age, sex, county, primary language, socioeconomic status, and disability status.²⁸ These recommendations should be applied across the health care system to improve detection of health disparities and ensure they are addressed.

'Health Equity by Design'

In his keynote remarks for the Roundtable, National Coordinator Micky Tripathi noted that the Administration is prioritizing health equity, or as he described it, 'health equity by design.' With this approach, ONC is working to ensure that it is building in equity considerations for their work from the outset, rather than trying to backfill when disparities or other consequences are later realized. This includes thinking through how to apply a health equity lens for policy, for purposes of standards development, or in considering the potential promise and pitfalls of AI, among other priorities.

²⁰ CDC, "COVID-19 Racial and Ethnic Health Disparities." Available here: <https://bit.ly/3cN9oUx>

²¹ HHS Assistant Secretary for Planning and Evaluation, "Health Disparities by Race and Ethnicity During the COVID-19 Pandemic: Current Evidence and Policy Approaches." Available here: <https://bit.ly/3dArZIS>

²² National Academy for State Health Policy (NASHP), "How States Collect, Report, and Act on COVID-19 Race and Ethnicity Data." Available here: <https://bit.ly/3wbMP3v>

²³ HHS, "HHS Announces New Laboratory Data Reporting Guidance for COVID-19 Testing." Available here: <https://bit.ly/31Atcnx>

²⁴ HHS, "COVID-19 Pandemic Response, Laboratory Data Reporting: CARES Act Section 18115." Available here: <https://bit.ly/2PngBS8>

²⁵ CDC, "COVID-19 Data Tracker." Available here: <https://bit.ly/3rFx9SD>

²⁶ U.S. Government Accountability Office (GAO), "COVID-19: Sustained Federal Action is Crucial as Pandemic Enters its Second Year." Available here: <https://bit.ly/3ueAOYW>

²⁷ White House, "Executive Order on Ensuring an Equitable Pandemic Response and Recovery." Available here: <https://bit.ly/3rC8s9r>

²⁸ Rep. Ayanna Pressley, Sen. Warren "Pressley, Warren, Bass, Lee, Kelly Reintroduce Bicameral Bill to Mandate Federal Government Collect and Report Coronavirus Demographic Data – Including Race and Ethnicity." Available here: <https://bit.ly/3fs3M3D> and here: <https://bit.ly/3miSFex>

Collection of Social Needs Data and Cross-Sector Coordination

The COVID-19 pandemic has shown not only the gaps in our health and public health systems and data infrastructure, but also in how such systems share data and coordinate with social services agencies and organizations.

Many individuals face negative social risk factors, such as a shortage of stable or affordable housing, food insecurity, lack of transportation options, and other underlying resource inequities that impact their health and wellbeing.²⁹ These social risk factors may make it difficult for individuals to safely social distance or to maintain their health while social distancing. Better understanding the scope of such risk factors faced by individuals, in addition to information on race and ethnicity as described earlier, will improve efforts to identify and address health inequities both now and moving forward.

The private sector, in addition to the federal government, has increasingly recognized the value of capturing and understanding the non-clinical factors that drive health care outcomes, such as information related to a patient's housing, nutrition, or transportation needs.³⁰ Social needs data is increasingly being collected through screening tools,³¹ helping providers to better understand and address patients' health and social needs. Collection of such data can be used to drive social care referrals and to inform a more holistic care plan for patients, but also may be used in aggregate to identify health disparities and to improve community health.^{32,33}

However, unlike information on an individual's health care needs, social needs data is often not integrated into EHRs and exchanged in a meaningful way, limiting providers' ability to take steps to address them on an individual and community level.³⁴ Part of the issue has been a lack of standardization of social determinants data elements. The Gravity Project, a consensus-driven national public collaborative and HL7 International FHIR Accelerator organization initiated by SIREN with funding from the Robert Wood Johnson Foundation, convenes "broad stakeholder groups in identifying and harmonizing social risk factor data for interoperable electronic health information exchange."^{35,36} It is developing individual-level data standards to represent the capture and exchange of social determinants of health information in health and human services electronic systems. In December 2020 it recommended that ONC include standardized social determinants data elements in forthcoming versions of the USCDI.³⁷

Integrating social needs data into electronic health records can also help to drive improved cross-sector collaboration between health and social services providers. A participant in the second Roundtable panel spoke about the importance of integrating care provided on the clinical side with that provided on the community side. She noted that Health Information Exchanges (HIEs) can be a powerful tool to connect health care providers with community-based organizations to share referrals and for bidirectional data

²⁹ CDC, "COVID-19 Racial and Ethnic Health Disparities." Available here: <https://bit.ly/3cN9oUx>

³⁰ ONC, "Social Determinants of Health." Available here: <https://bit.ly/3wfbkYl>

³¹ SIREN, "Social Needs Screening Tool Comparison Table." Available here: <https://bit.ly/31D8xiP>

³² CDC, "Sources for Data on Social Determinants of Health." Available here: <https://bit.ly/3wfvvul>

³³ ONC, "Social Determinants of Health." Available here: <https://bit.ly/3wfbkYl>

³⁴ Health Affairs, "Integrating Social and Medical Data to Improve Population Health: Opportunities and Barriers." Available here: <https://bit.ly/3sOqBCo>

³⁵ Gravity Project. Available here: <https://bit.ly/3dImDul>

³⁶ Gravity Project, "New HL7 FHIR Accelerator Project Aims to Improve Interoperability of Social Determinants of Health Data." Available here: <https://bit.ly/3eIqGSt>

³⁷ Gravity Project, Letter to ONC re: "The Gravity Project's Submission to Include Social Determinants of Health in the U.S. Core Data for Interoperability, Version 2, for Better Care and Better Health Nationwide." Available here: <https://bit.ly/3ucPgRA>

sharing. Such an approach – if broadly adopted – could allow both health and social services providers to have a fuller picture of patient needs. HIEs, community information exchanges,³⁸ and other efforts to improve coordination of health and social services information have proliferated recently, driven by private sector investment, state and regional coordinated efforts, and federal strategic planning.³⁹

Maintaining Patient Access and Trust

Alongside efforts to expand interoperability, improve access to health information, accelerate data exchange, and coordinate across sectors, policymakers and stakeholders have engaged in robust conversations regarding health data privacy and security. If individuals do not trust providers, plans, or technology companies to appropriately protect their health data, they will be less willing to engage with the health care system.

Participants throughout the Roundtable discussion spoke about the balance in ensuring individual access to, and the exchange of, data; maintaining privacy and security protections; and offering portals or other digital tools that are seamless, meet patients' needs, and do not increase burden on providers.

Ensuring Data Privacy

The recent ONC and CMS patient access, interoperability, and information blocking regulations are poised to greatly expand access, exchange and use of electronic health information. The rules seek to provide individuals with new avenues and opportunities to access and aggregate their health information. New requirements for the development and implementation of Application Programming Interfaces (APIs) will allow individuals to use applications (apps) and other tools to easily access their health information for their own purposes. Additionally, the new proposed rules to modernize HIPAA regulations from the HHS Office for Civil Rights seek to improve individual access to health care information, including through a new pathway for personal health applications.⁴⁰

However, current HIPAA Privacy Rule protections often do not extend to apps. HIPAA only protects the privacy of data held by covered entities; once that data leaves the protection of the covered entity, HIPAA no longer applies. In its proposed rule, OCR does not propose to apply new protections to personal health applications, noting that because “a personal health application is not acting on behalf of, or at the direction of a covered entity,” it is not subject to the HIPAA rules and obligations. Additionally, there are no specific requirements for apps to provide easy to understand notice to individuals. Stakeholders have raised concerns that individuals who request access to their data through an app may not be aware that their health information is no longer being protected and that they may lose the ability to know how their data is being used and who is using it.⁴¹

³⁸ The National Center for Complex Health & Social Needs, “Community Information Exchange toolkit: Collaboration and cross-sector data sharing to create healthier communities.” Available here: <https://bit.ly/3urNgoi>

³⁹ HHS Administration for Community Living, “Strategi Framework for Action: State Opportunities to Integrate Services and Improve Outcomes for Older Adults and People with Disabilities.” Available here: <https://bit.ly/3cQQmwa>

⁴⁰ HHS Office for Civil Rights, “Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement.” Available here: <https://bit.ly/3mlJvhy>

⁴¹ Modern Healthcare, “Interoperability rule exposes gaps in protecting privacy.” Available here: <https://bit.ly/31DbG1O>

Applying the Golden Rule to Health Data Privacy

In keynote remarks, Sen. Cassidy (R-LA) spoke about the dual importance of using technology to enhance and improve care while also ensuring privacy. He discussed the pitfalls of our data privacy system, in that data collected from apps or from online searches may be sold and used in new ways to derive insights about our consumer and patient behavior. Some of this might be helpful, such as information that a provider may learn from a patient's smartwatch about their physical activity, but access and use of some data may be harmful if not appropriately authorized and protected. He noted that the current limitations put in place by HIPAA can provide certain protections, and there is a lot of data being used to drive innovation in the health care digital and IT markets that is not protected by HIPAA. Sen. Cassidy noted that the COVID-19 pandemic has led to a reckoning of these issues, as virtual care and digital health has taken off. He argued that we are obligated to ensure that there is trust and that our sensitive information will be protected and that Congress should pass comprehensive federal privacy legislation.

Similar concerns have been raised in the context of the COVID-19 pandemic, as testing data is increasingly being shared for contact tracing and other public health efforts, and as private businesses and governments consider whether to employ COVID-19 vaccine passports or other credentials.⁴²

Creating Patient-Centered Care

Participants in the second panel of the Roundtable noted the importance of ensuring that approaches to data and infrastructure are patient-centric, arguing that they should be intuitive, seamless, and should leverage standards and technologies that support the individual's experience.

One example raised in both the first and second panels is vaccine access. The diffuse and decentralized way in which the federal government has implemented its vaccination strategy has meant that vaccines are being allocated across many different sites of care, including pharmacies, providers, hospitals, nursing homes, and other federal partners. Some states and localities have created centralized call centers and leveraged APIs to integrate all the available vaccine appointments into one place, which makes it easier for individuals to understand their options and to access appointments. However, in many places, there is not one centralized place where an individual can go or access to sign up for a vaccine, which has led to a complex, and often inequitable, distribution process. Even primary care physicians, plans, and other entities do not necessarily have access to timely information to help guide individuals nor to understand which individuals have received a vaccine and which have not. While the current approach may allow for more rapid and geographically dispersed administration of the vaccine, it also creates a difficult process for individuals to navigate, limiting trust in the system.

⁴² CNBC, "Vaccine passports could prove to be privacy minefield for regulators." Available here: <https://cnb.cx/3cJlKgp>

Key Takeaways & Recommendations

Improving Health Care & Public Health Data and Technology Infrastructure

- *Maintain Regulatory Flexibility for Virtual Care* – The health care system took steps over the course of the last year to invest in and advance access to virtual care tools, such as telehealth. Federal and state-based policymakers aided in these efforts by providing regulatory flexibility for coverage, payment, and enforcement discretion. Policymakers should continue to provide ongoing flexibility through the remainder of the public health emergency and assess whether certain policies should be made permanent.
- *Provide Funding for and Prioritize Public Health Infrastructure Modernization* –
 - o Public Health Funding - Congress appropriated funding through several of the COVID-19 relief packages to CDC for public health data and infrastructure modernization. This funding is being used to modernize CDC's data systems and for state and local jurisdictions to upgrade their systems and to expand capacity. Congress should evaluate whether additional funding is needed in the short term and should provide an ongoing and dedicated source of funding for public health infrastructure maintenance.
 - o Connecting Public Health and Health Care Infrastructure - The Administration should structure future funding opportunities to ensure a cross-sector approach to strengthening public health and health care systems rather than a continued siloed approach to data sharing.
- *Enhance Seamless Public Health Data Exchange*
 - o Increase Electronic Case Reporting – Public health organizations have urged increased funding to improve and expand electronic case reporting (eCR), which automatically generates an electronic submission of reportable diseases and conditions from an EHR to public health agencies.
 - o Incentivize Public Health Data Standardization Efforts – Encourage the implementation and use of standardized public health data classes and elements to facilitate more streamlined exchange of public health data.

Advancing Health Equity through Health IT

- *Increase Collection of Race/Ethnicity Data Across Public Programs* – Public programs should be required to collect race and ethnicity data, and publicly report health data stratified by race/ethnicity, at a minimum, for all individual-level data collection and reporting. The federal government should also provide guidance to state and local officials and ensure that all data collected is done so in a standardized way.
- *Encourage Cross Sector Data Sharing Collaborations* – Public policymaking should encourage the development and enhancement of current cross-sector data sharing efforts. HHS should also take steps to further the standardization and interoperability of social needs data.

Maintaining Patient Access and Trust

- *Enhance Privacy Protections* – HHS should require third party applications (including personal health applications) to provide individuals with a clear, concise notification about their privacy practices. HHS should also provide robust outreach and education to individuals and should take steps to strengthen privacy and non-discrimination protections for health and health-related data.

APPENDIX – Health IT Leadership Roundtable: March 11, 2021 Agenda

| Time | Agenda |
|------------|---|
| 9:00 a.m. | Welcome & Housekeeping |
| 9:05 a.m. | Opening Remarks <i>Justine Handelman, Senior Vice President, Office of Policy and Representation, Blue Cross Blue Shield Association</i> |
| 9:30 a.m. | Congressional Keynote <i>Senator Cassidy (R-LA), Member of the Senate Finance Committee and Senate HELP Committee, U.S. Senate</i> |
| 9:45 a.m. | Video Intro to Biden Administration Health IT Priorities |
| 9:50 a.m. | The Power of Technology to Transform Patient Care <i>Micky Tripathi, National Coordinator for Health IT, Office of the National Coordinator, U.S. Department of Health and Human Services</i> |
| 10:20 a.m. | <p>Panel #1: Data, Infrastructure, and Fostering Emerging Technology</p> <p>The goal of this panel is to explore recent advances, as well as ongoing challenges, in health care data sharing and technology, using the COVID-10 vaccine administration effort as an example of our system’s current opportunities and limitations. Panelists will discuss the ongoing work around data standardization and data quality; advances and challenges in interoperability, data exchange, and information blocking; and the role of public/private partnerships in emerging technology platforms to enhance innovation. The panel will also discuss new opportunities and issues that have come to the forefront, including the importance of incorporating social determinants and public health data and systems to better improve health and to understand and address health disparities.</p> <p><u>Moderator:</u> <i>Sophia Tripoli, Director, Health Care Innovation, Families USA</i></p> <p><u>Panelists:</u></p> <ul style="list-style-type: none"> • <i>Dr. Jim Jirjis, Chief Information Officer, HCA Healthcare</i> • <i>Linda Hyde, Coding Systems Expert, EMI Advisors/Gravity Project</i> • <i>James Daniel, Lead, State and Local Public Health, Amazon Web Services; former Director of Public Health Innovation, U.S. Department of Health and Human Services Office of the Chief Technology Officer</i> • <i>Joe Bastante, Chief Technology Officer, BCBS-NC</i> |
| 10:55 a.m. | <p>Panel #2: Patient Access and Trust</p> <p>This goal is this panel is to reflect on the comments made during the earlier panel from the patient perspective. This panel will highlight the importance of and challenges inherent in patient access to health information, as well as commentary on recent privacy reform efforts, including ensuring strong privacy and security protections for</p> |

Health IT Leadership Roundtable: The Power of Technology to Transform Patient Care

| Time | Agenda |
|-----------------------|---|
| | <p>HIPAA and non-HIPAA covered data, maintaining patient trust, the value of virtual care and use of digital health tools, and the rules of the road for linking health data with public health and social determinants data.</p> <p><u>Moderator:</u> <i>Lina Walker, Vice President, Health Security, AARP</i></p> <p><u>Panelists:</u></p> <ul style="list-style-type: none"> • <i>Dr. Darilyn V. Moyer, Executive Vice President and Chief Executive Officer, American College of Physicians</i> • <i>Dr. S. Mark McNeill, Trillium Family Medicine, Asheville, North Carolina</i> • <i>Leigh Ann Eagle, Director, Health and Wellness Program, Maintaining Active Citizens, Inc., an Area Agency on Aging</i> • <i>Laurant Rotival, SVP Strategic Technology Solutions; Chief Information Officer; Cambia Health Solutions</i> |
| <p>11:30 a.m.</p> | <p>Closing Keynote <i>Sinsi Hernández-Cancio, Vice President for Health Justice, National Partnership for Women & Families</i></p> |
| <p>12:00</p> | <p>Adjourn</p> |