ROUND TABLE REPORT

Using Social Determinants of Health Data to Fight COVID-19 and Support Recovery Efforts

November 2020
The COVID-19 pandemic has shined a bright light on racial and ethnic health disparities in the United States. Data from the Centers for Disease Control and Prevention (CDC), including 14 states and 250 hospitals from March to July 2020, have quantified the problem: the age-adjusted rate of COVID-19 hospitalizations is about five times higher for American Indians and Alaska Natives, Blacks, and Latinos than for whites.

The identification of these health disparities – these populations with COVID hospitalization rates that are disproportionate to their representation in the overall population – must compel us to seek out root causes. These differences in health outcomes among different populations signal the existence of health inequities. Health inequities are defined as the lack of fairness or access to the same opportunities for attaining the highest level of health. How do social determinants of health (SDOH) fit into this context? Health inequities are driven by SDOH, which the U.S. Department of Health and Human Services' (HHS) Healthy People 2030 defines as the conditions in the environments in which people are born, live, learn, work and play that affect a wide range of health, functioning, and quality-of-life outcomes and risks. Therefore, communities across the nation, particularly racial and ethnic minority communities, urgently need data-driven interventions rooted in SDOH in order to fight COVID-19 health disparities.

Addressing SDOH that lead to health disparities is an overarching goal of Healthy People 2030, a national initiative led by the HHS Office of the Assistant Secretary for Health, Office of Disease Prevention and Health Promotion. Healthy People 2030, released in August 2020, presents science-based 10-year national objectives for improving the health of all Americans. Healthy People presents SDOHs as having five domains: (1) economic stability (e.g., employment and housing cost); (2) education access and quality (e.g., proficient reading skills); (3) health care access and quality (e.g., preventive health care access); (4) neighborhood and built environment (e.g., broadband internet access and indoor air quality); and (5) social and community context (e.g., incarceration rate and family and community support). When we are trying to improve health outcomes, we often think of interventions involving health care access and quality. However, a broader SDOH perspective can reveal multiple other areas that require interventions in order to optimally address a particular health inequity.

The HHS Centers for Disease Control and Prevention’s (CDC) Social Vulnerability Index (SVI) is an example of HHS’ efforts to promote the use of SDOH data. The SVI ranks each U.S. Census tract on 15 social factors (e.g., poverty, lack of vehicle access and crowded housing) and groups these factors into four related themes: socioeconomic status, household composition, race/ethnicity/language and housing/transportation. SVI data drove the location of COVID-19 Community Based Testing Sites.

These data also can help other officials identify communities that may need support in preparing for and recovering from natural or human-caused disasters. Insights from CDC’s SVI and similarly intentioned datasets can help guide targeted interventions for SDOH that address – or even better prevent – health disparities.
We can meet our collective desire for optimized health across the nation by working together to enhance the utilization of social determinants data. Racial and ethnic minority populations, low-income communities, our elderly, and other vulnerable populations are counting on us to turn around COVID-19 and other devastating health trends.

RADM Felicia Collins, MD, MPH, FAAP
Deputy Assistant Secretary for Minority Health
Director, HHS Office of Minority Health
The COVID-19 crisis has led to an explosion of data analysis and data-driven debate, perhaps more than any other event in recent history. Government agencies, nonprofits, and news organizations have collected public health and population data, published it widely, and conducted myriad analyses to help guide decision-making about the pandemic. While these models have been valuable, they do not fully reflect a critical factor: the impact of social and economic context on the likelihood of contracting COVID-19, the availability of testing, and access to care for the disease.

A growing body of evidence shows that the social determinants of health (SDOH) have a major influence on an individual’s health status — perhaps as much as, or even more than, the standard epidemiological measures that have been the basis of most COVID-19 models. The SDOH include a number of variables that have been shown to impact health profoundly, including income, education, environment, and access to food, housing, transportation, and healthcare. These factors can help researchers analyze the different risks COVID-19 poses to different communities, especially African American and Latino communities that already have poorer economic and health status. At the same time, these social factors also determine how efforts to mitigate COVID-19, for example by temporarily closing small businesses, may harm individuals and communities economically.

State health departments, healthcare companies, and academics are beginning to use SDOH data to predict COVID-19 risk in the populations they serve, at both a community and an individual level. However, organizations like these face a dual challenge: They need better data on the SDOH, and they need better data on the individuals who contract COVID-19 or who may be affected by the social consequences of mitigation.

To help meet these challenges, this report presents findings and recommendations from the Roundtable on Using SDOH Data to Fight COVID-19 and Support Recovery Efforts, held on August 13, 2020. The Roundtable was co-hosted by the nonprofit Center for Open Data Enterprise (CODE) and the Office of the Chief Technology Officer (CTO) in the U.S. Department of Health and Human Services (HHS). It was designed to identify rapid opportunities to use social factors to predict and address the impact of COVID-19 at a national, state, and local level.

As background for this Roundtable, CODE prepared a Briefing Paper that provided an in-depth summary of research on SDOH and COVID-19. CODE has previously explored the opportunities provided by SDOH data through a briefing paper, Roundtable, and Roundtable Report on Leveraging Data on the Social Determinants of Health all of which may provide additional useful context and information for readers of this paper. HHS and CODE also co-hosted a Webinar on the topic, which featured lightning talks that are summarized in call out boxes throughout this report. The Briefing Paper, a recording of the Webinar, and other resources are available to the public at the website sdoh4covid.crowdicity.com. We hope they will serve as important resources for policymakers, researchers, and healthcare practitioners now taking action to address the COVID-19 pandemic.
With the Briefing Paper and Webinar setting the stage, the Roundtable itself consisted of breakout sessions that enabled more than 70 participants to discuss challenges, opportunities, and solutions in small groups. The sessions covered four different themes: Addressing the impact on low-income and minority communities; Using data for health system resilience and recovery; Data-driven action at the state and local level; and Assessing and improving data resources for SDOH and COVID. Seven ideas emerged out of these discussion areas that, we believe, could accelerate the use of SDOH data in the fight against COVID-19 and are particularly ripe for further discussion and short-term development. We encourage readers of this report to use CODE’s engagement platform at SDOH4COVID.Crowdicity.com, where these High-Priority Recommendations are posted, to further develop them, collaborate with others, and take action to make them a reality.

### High-Priority Recommendations

1. Establish a public clearinghouse for SDOH data
2. Systematically assess and apply SDOH data from across federal agencies for use in and outside of government
3. Reassess privacy guidelines and data use agreements to expedite SDOH data sharing
4. Use SDOH data to better target local testing and contact tracing efforts
5. Improve and expand the use of the CDC’s Social Vulnerability Index (SVI)
6. Create a community of practice so that localities can share innovative policy ideas and learn from what is working
7. Develop an “Open Table” approach to connect individuals with social programs/services

The Roundtable also produced a number of ideas and recommendations in each of the following thematic areas that are further described in this report. These recommendations represent approaches and solutions that were discussed during the Roundtable and could help advance the state of SDOH data, fight the pandemic, or help planners prepare for future crises. In many cases, HHS and its partners are already implementing recommendations produced by the Roundtable; in others, the Roundtable’s recommendations reflect areas where participants saw opportunities to accelerate, amplify, and extend current efforts.

**Addressing the Impact on Low-Income and Minority Communities**

- Establish data-driven policies to relieve financial burdens for low-income and minority communities
- Use data on housing to reduce crowding and homelessness
- Improve collection of workforce data
- Increase publication frequency and expand access to Medicaid claims data
- Fund state and local governments for data-driven vaccine planning and distribution

**Using Data for Health System Resilience and Recovery**
- Measure displacement and impact on non-COVID patients who need hospital access
- Tackle the digital divide and rapidly improve telehealth services
- Define strategic metrics for disaster planning
- Build multi-sectoral coalitions that can improve data use
- Increase the number of variables available in granular data
- Relax rules to expedite sharing and integrate Medicare and Medicaid claims data
- Develop better models for interdependent SDOH factors
- Develop a set of HHS-approved Arc-GIS layers for more sophisticated modeling

**Data-driven Action at the State and Local Level**
- Create a national public database of COVID-19 cases/deaths/testing at the sub-Census tract level
- Make meaningful investments in effective contact tracing
- Support information sharing through storytelling and other best-practice communications approaches
- Create a core set of social need or social determinant indicators for data collection
- Harmonize state-level data collection systems

**Assessing and Improving Data Resources for SDOH and COVID**
- Build partnerships with local organizations to gather individual-level SDOH data
- Capitalize on the opportunities created by COVID-19 to address long-standing SDOH data challenges through pandemic-related legislation and other initiatives
- Improve COVID-19 case data and collection efforts
- Improve data definitions, documentation, and context
INTRODUCTION

The Roundtable on Using SDOH Data to Fight COVID-19 and Support Recovery Efforts was the fourth in a series of health data Roundtables conducted by CODE in partnership with the HHS Office of the Chief Technology Officer and funded by the Patient-Centered Outcomes Research Institute (PCORI). It built on the previous Roundtable on Leveraging Data on the Social Determinants of Health, held as part of the same series in October 2019, with a new focus on using SDOH to address the COVID-19 pandemic.³

At their core, SDOH data can be used to “create social and physical environments that promote good health for all,” as HHS’ Healthy People 2020 (the precursor to the recently released Healthy People 2030) describes them.⁴ Healthy People’s SDOH framework focuses on five key determinants: Economic Stability, Education, Social and Community Context, Health and Health Care, and Neighborhood and Built Environment.⁵

Image credit: Healthy People 2020

All of these determinants come into play in the fight against COVID-19. Using SDOH data to address COVID-19 can benefit the public in several ways. Epidemiologists and public health researchers can use the data to determine how social and environmental factors affect the spread and severity of the
disease, and assess the health and societal consequences of social interventions for pandemic control. State and local public health departments and healthcare administrators can use it to better plan for the use of hospital resources, or work to develop responsive economic and health models tailored to their communities. Policymakers will be able to use the data to better target interventions, such as through the identification of social characteristics that serve as risk or protective factors, and more effectively allocate limited resources to individuals and communities.

A growing body of evidence shows that the SDOH have a major influence on an individual’s health status — perhaps as much as, or even more than, the standard epidemiological measures that have been the basis of most COVID-19 models. These social factors can contribute to our understanding of the different risks COVID-19 or its mitigation pose to different communities, especially African American and Latino communities that already face poorer economic and health outcomes.

State health departments, healthcare companies, and academics are beginning to use SDOH data to predict COVID-19 risk in the populations they serve, at both a community and an individual level. But what kinds of SDOH data are most needed and where do they come from? The addition of SDOH data to existing predictive analytic tools can provide a more holistic picture of location-based risk in vulnerable communities. This data can be collected directly from a patient in a clinical setting or from other surveys, such as housing or economic indicators, and can be used in combination with an individual’s EHR - with appropriate privacy protections - and other information about individual and community based risk factors to better understand the possible risks they face. SDOH data can be collected at the individual, local, and 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. Unfortunately, there are many gaps in the availability of SDOH data as well as COVID-19 data-specific health outcome data relevant to at-risk populations.

Ultimately, more consistent, timely, representative, and comprehensive data will be needed in the fight against COVID-19: Both data on the social determinants of health and data on the individuals who contract COVID-19 or who may be affected by the social consequences of mitigation efforts. The Roundtable on Using SDOH Data to Fight COVID-19 and Support Recovery Efforts explored the challenges making it harder to find and use this data as well as solutions that can help develop, unlock, and leverage it in the fight against COVID-19 and ongoing recovery efforts.
ADDRESSING THE IMPACT ON LOW-INCOME AND MINORITY COMMUNITIES

The disparate impact of COVID-19 on minority and low-income communities shows how profoundly social and economic factors are shaping this pandemic. But while we know that the SDOH impact vulnerable groups' risk, we don't know which factors are responsible, how important those factors are, or how to address them to combat COVID-19. Roundtable discussions on this theme explored how to use SDOH and clinical data to understand risk patterns and develop social and medical interventions to improve health and the healthcare system response in these communities.

Table: Identified challenges and solutions

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<td>Other challenges</td>
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Challenges

Roundtable participants noted that there are many relevant challenges associated with mitigating the impact of COVID-19 on low-income and minority communities. The most important include:

**Historic and pervasive discrimination resulting in poor investment in communities.** Low-income and minority communities experience higher rates of poverty and homelessness and lower levels of education due to historic disenfranchisement. This is especially consequential during COVID-19, where the factors of one's day-to-day life play major roles in how people are affected by the disease. These vulnerable communities include greater numbers of essential workers who have lower quality, less accessible, and less affordable, healthcare. Combined with higher rates of pre-existing conditions and comorbidities, their risk of severe COVID-19 infection is higher than that of the general population.
Precarious employment status/lack of employment. Employment status impacts communities of color in several ways: First, individuals in these communities are more likely to be “essential workers” with limited or poor health insurance coverage, low wages, and few additional benefits. Many “essential workers” are unable to socially distance at work or work from home and do not receive benefits like paid sick leave that would allow them to safely isolate in case of exposure to COVID-19. In addition, when these workers become unemployed they may lose job-related insurance and also have a harder time meeting key social needs - the immediate need to help people at risk for homelessness, food insecurity, social isolation, or other factors that can impact overall health outcomes and COVID-19 risk.

Disparate quality of healthcare. Low-income and minority communities often struggle to access high-quality healthcare. Low-income and minority patients are more likely to access care at public or safety net providers with fewer resources and higher staffing ratios, as well as to encounter barriers when they seek care (e.g., transportation, cost, or language barriers). These communities may lack trust in the health system, making them less likely to seek care when sick. The lack of trust may also be a major hurdle to the adoption of a new vaccine once one is made available and promoted by the government.

High housing density. Low-income individuals often share housing with other members of their families or live in close proximity to other families in spaces like public housing, making it more difficult for them to safely isolate in case of exposure to COVID-19. They may also lack adequate outdoor space (whether public space like parks or private space like a backyard) to safely socially distance.

In Action

Building a National Infrastructure for Mitigating the Impact of COVID-19 within Racial and Ethnic Minority Communities. The U.S. Department of Health and Human Services (HHS) Office of Minority Health (OMH) has partnered with the Morehouse School of Medicine to launch its National Infrastructure for Mitigating the Impact of COVID-19 within Racial and Ethnic Minority Communities (NIMIC). This $40 million initiative to fight COVID-19 will lead to a strategic network of national, state, territorial, tribal and local organizations delivering COVID-19-related information to racial and ethnic minority, rural and other socially vulnerable communities hard hit by the pandemic.

The initiative builds on the work of the National COVID-19 Resiliency Network (NCRN) and plans to roll out a series of digital tools that work closely with community-based organizations around the country. A National Community Coalition Board will provide community-tested strategies that prepare culturally diverse and language-friendly media outreach materials to target communities. It will also strengthen efforts to link communities to COVID-19 testing, healthcare and social services, and to best share and implement effective response, recovery and resilience strategies. The project started with work to roll out the initial action plan for the NCRN which will build consensus, create data hubs, and define the pre-COVID implementation landscape for COVID.
Solutions

Establish data-driven policies to relieve financial burdens for low-income and minority communities. COVID-19 has created severe financial stress across the U.S., and even more so in low-income and minority communities. Policies could be put in place to ease these financial burdens, and the outcomes of those policies could be measured. For example, collecting data on COVID-19 rates in workplaces with paid sick leave may highlight how this benefit could be expanded to other workplaces. Roundtable participants suggested mandating paid sick leave for workers and implementing other policies to reduce current and emerging poverty and economic hardship. Policies that connect unemployed or underemployed groups to social services are also essential for these communities.

Improve collection of workforce data. A key factor in one's likelihood of contracting COVID-19 is employment status and employee benefits, or lack thereof. Certain jobs - many of which are deemed “essential” during the pandemic - and workplace policies place workers at an increased risk of contracting COVID-19. Such data on individuals in low-income communities can help identify who has a job-related risk of COVID-19 positivity and severe infection. Important factors to consider are employment status, essential worker status, employer health insurance, availability of sick leave, and more. These factors can each have an impact on individuals' risk of COVID-19 infection.

Increase publication frequency and expand access to Medicaid claims data. Roundtable participants identified a need to increase the frequency with which Medicaid claims data is published and expand access to that data. Medicaid claims data can be used to identify at-risk populations and understand the prevalence of comorbidities. For example, a county health official can use claims data to see Medicaid recipients in their county and what kinds of procedures have been carried out among that population, allowing them to better understand their potential for increased COVID-19 risk. Policymakers - including those at CMS - should consider ways to provide more access to Medicaid claims data to researchers and others with appropriate protections for individual privacy.

Use data on housing to reduce crowding and homelessness. Low-income and minority communities are more likely than the rest of the U.S. population to live in multigenerational or multi-family households. This reality, in addition to high rates of homelessness, makes it harder to follow COVID-19 mitigation measures including social distancing and quarantining for these communities. To address this issue, Roundtable participants suggested making empty hotel and dorm rooms available for the homeless and others in extenuating circumstances. HUD and Census data should be utilized to identify areas with high rates of homelessness and poverty to develop these interventions.

In the early days of the pandemic it was reported that multiple jurisdictions were renting hotel rooms - and even entire hotels - to house COVID-19 patients and first responders in need of housing close to hospitals. Others rented empty hotel rooms to help residents experiencing homelessness to self-isolate after a COVID-19 diagnosis or while awaiting test results. These sorts of programs could be continued in the wake of the COVID-19 pandemic to help those experiencing homelessness secure temporary housing while they deal with economic and other reverberations from the crisis.
Fund state and local governments for data-driven vaccine planning and distribution. The lack of trust between minority communities and the U.S. health system is a persistent barrier to the delivery of adequate healthcare to these populations. Collecting data on healthcare utilization patterns and the languages spoken in different communities could help improve outreach and the work of community-based organizations (CBOs) in targeting demographic groups for vaccine uptake. In addition to a general distrust of healthcare institutions, minority communities may be skeptical about the development and use of vaccines due to historical negative experiences with medical research, including unlawful experimentation and mistreatment (e.g. the Tuskegee Syphilis Study). The federal government can allocate funds to states and localities to support community resources and community-based organizations for vaccine planning to help overcome this trust barrier. This will be critical when vaccines for COVID-19 are ready for public use, and will be essential for widespread uptake. States and localities can leverage community members who already hold the trust of their communities to help increase others' trust in the health system and, ultimately, vaccine uptake.
USING DATA FOR HEALTH SYSTEM RESILIENCE AND RECOVERY

The COVID-19 pandemic has stretched the capabilities of the U.S. healthcare and public health systems and revealed large gaps in both data collection and healthcare delivery. This shock to the system has sparked urgent conversations about the need to improve health system resilience.

COVID-19 is one of several external challenges to the capacity of the U.S. health system, which also include antimicrobial resistance, individual financial burdens, extreme climate events, and ongoing disease epidemics (both nationally and internationally) that have and will continue to require the system and its stakeholders to react and adapt. Improved resilience would represent the ability of the U.S. and global health systems to foresee, measure, plan for, quickly adapt and respond to, and recover from challenges such as COVID-19. For the purposes of this report, “Health System Resilience” is defined (conceptually) as the degree of change or harmful threats that a health system can endure while maintaining nominal functionality.8 For example, the United States Agency for International Development aims to promote health system resilience in international settings by being able to distribute commodities to areas in need, redeploy human and financial resources for vulnerable populations, and work across government sectors to engage community leaders and other key stakeholders.9

The HHS Office of the Assistant Secretary for Health recently circulated a Request for Information to better understand how key stakeholders define resilience through “their use of data, analytic approaches, and proven indicators.”10 With HHS’ guidance, discussions on this theme were tailored to include a focus on how to use SDOH and clinical data to manage healthcare capacity before, during, and after surges of COVID-19 cases.

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**Challenges**

**Timeliness and granularity of data.** Publicly available data helps tell a broad story about a region’s susceptibility to COVID-19 but may not provide enough detail or real-time value to inform responses to emerging social needs. Health systems and community-based organizations often need immediate assessments of social needs for efficient and effective operations. However, SDOH data is not always collected or updated in real time and may not be systematically collected by a single entity. Moreover, in many cases the available datasets may only capture a small fraction of patients. Many healthcare systems with population health divisions, such as New York City’s Mount Sinai Health System, have opted to purchase commercial datasets, like Transunion credit risk reports, instead of relying on public or open data.

**Inconsistent healthcare access.** Patients choose when and where to access medical services for a variety of reasons. They may avoid primary care and instead rely on emergency departments due to a lack of insurance or they may avoid the healthcare system altogether because of a lack of trust. Many healthcare systems face challenges corresponding with patients and understanding why they avoid medical settings. This lack of information can reduce levels of care and ultimately harm vulnerable populations.

**Supply chain inefficiencies caused by data gaps and integration challenges.** The United States faced a substantial disruption in its supply chains as producers and distributors faced challenges in providing essential goods like cleaning products, medical equipment, and basic consumer goods. For example, the food distribution system is an important part of the necessary infrastructure to ensure the ongoing health of communities. During the pandemic, some crops rotted in fields while others were unavailable in stores and Americans turned to food banks in increasing numbers. In dense urban areas like New York City, many CBOs faced challenges in addressing food security and opted to collaborate with venture
groups and other NGOs to avoid overwhelming pantry demand. Better supply chain data integration could make it easier for government officials to see major gaps in key consumer goods. In the case of food distribution, better data can make it easier to connect excess food supply to those who needed it most, instead those resources went to waste. Data and nontraditional partnerships can also provide value where food relief has to be delivered directly to individual clients rather than distributed via a central pantry to avoid the spread of COVID.

**Low CBO technical capacity.** The October 2019 Roundtable on Leveraging Data to Address the Social Determinants of Health, co-hosted by CODE and the HHS Office of the CTO, found that many CBOs lack the technical capacity to collect large amounts of data that can be shared and integrated into existing medical frameworks. While some larger organizations like regional food banks have advanced systems of data intake, smaller distribution centers or organizations with deep ties to their community may lack this technical capacity or gather data through paper forms. This data can help measure social needs during times of crisis and can inform health systems that look to provide support to vulnerable populations.

**Uncoordinated state-level data collection systems.** There are approximately 60 separate state-level data systems that collect varying kinds of data at different frequencies from health care facilities and local public health departments for situational awareness, incident management, and to inform data reports provided to the federal government. Some of these systems are custom-made while others are off-the-shelf incident management data systems. They are funded in part by the Assistant Secretary for Preparedness and Response (ASPR) and the CDC’s Public Health Emergency Preparedness Program. Many federal departments and agencies hoping to aggregate and analyze state- and sub-state level data will find it difficult to access or combine these data, while state agencies often gather data piecemeal from local hospitals and clinics for reporting purposes. Changing data reporting requirements from the federal government and unclear guidance about mandated reporting have compounded this issue.

**In Action**

**KYSTATS Connecting Longitudinal Data to the Fight Against COVID-19.** KYSTATS houses Kentucky’s longitudinal data system and labor information office. The data system is one of the most robust in the nation. Their current research agenda is focused on equity as a priority in education, workforce, and social services and has aligned well with COVID-19 response. KYSTATS has worked with Kentucky’s Cabinet for Health and Family Services to integrate their data and look at SDOH information relating to education and workforce along with data on SNAP, TANF, Medicaid, and other benefits. KYStats has done reporting to link data across systems and is using data to plan for pandemic recovery. For example, information about long standing equity issues and barriers can inform leaders about who has been impacted by COVID-19 related job loss and issues like transportation or childcare that may be standing in the way of getting them back to work. Additionally, the pandemic is likely to spark discussions around policy changes. The KYSTATS data system is set up to identify who will be impacted by proposed policy changes and how they will be affected.
Solutions

Measure displacement and impact on non-COVID patients who need hospital access. There is growing evidence that patients who need specialized care will have to be accounted for during crises that impact health systems. Roundtable participants from HHS pointed out that county health departments should have an understanding of this patient population and have a response plan to ensure they are able to meet their needs during COVID-19 and future health crises. HHS should enable county health departments and local officials to understand their vulnerable patient populations and provide localized datasets that identify populations with high healthcare system utilization.

Tackle the digital divide and rapidly improve telehealth services. Broadband and strong wifi connectivity are necessary to launch effective telehealth programs and deliver services and training. Telehealth has not only provided additional capacity for clinics that can no longer see people in person but has also enabled healthcare professionals to train new volunteer workers remotely, walking them through basic safety and health protocols. However, CBOs and other local groups often have limited digital and analytic capabilities. HHS should work with partners at the FCC and other relevant agencies to compile data about local wifi connectivity and identify gaps in broadband access, both for households and health care institutions. HHS could also provide training or funding to CBOs to improve wifi connectivity, expand technical bandwidth, provide services or counseling remotely, and share information they gather on the ground.

Define strategic metrics for disaster planning. Public health officials plan for a variety of disasters, including infectious diseases, natural disasters, and mass casualty incidents, which all require different sets of metrics to measure response. In the case of COVID-19, HHS should clearly identify the high-value metrics needed to track government response to this disease, such as access to PPE or ICU bed capacity, and also be able to track and share those metrics with key stakeholders. HHS should first conduct a landscape analysis of both current datasets it collects and strategic high-value datasets as part of an initial discovery phase involving the disaster planning divisions of HHS. HHS could also release a data framework that includes recommended local data collection for counties seeking to understand their planning capacity.

Build multi-sectoral coalitions that can improve data use. Data sharing across healthcare systems and CBOs can lead to an improved understanding of social needs. To respond to the spread of COVID-19 in New York City, for example, healthcare systems, CBOs, and public officials leveraged the value of Quick Multisectoral Coalitions with their NYC COVID-19 Rapid response Coalition Playbook which helped coordinate resources, secure a contracting vehicle to obtain resources, and ensured collaboration rather than competition between healthcare systems. HHS and other officials could provide guidelines for these coalitions to improve data collection, use, and sharing, either through existing data sharing mechanisms or new portals.

Increase the number of variables available in granular data. Much of the data that is provided through Electronic Health Records (EHRs) may not include important demographic information or other variables that are helpful for policymakers and medical professionals to target at-risk patients. Congress or the
HHS ONC could set new minimum requirements for data to be collected by medical systems, including race and other demographic data, which would enable practitioners to immediately identify high-risk patients and patient groups. These practitioners could then communicate patient needs to CBOs or refer patients to more tailored community services to help mitigate the impact of COVID-19 or other emerging threats on individuals and on health system resilience. This would respect privacy rules around data sharing while ensuring these patients are receiving a more holistic response to meeting basic health. HHS could also convene insurers and other private organizations who have projects dedicated to making use of SDOH data to explore these issues.

**Relax Rules to Expedite Sharing and integrate Medicare and Medicaid Claims Data.** Multiple Roundtable participants noted that the element of timeliness is key in order to respond rapidly and effectively during emergencies. Additionally, participants noted that for certain diseases like COVID-19, it’s useful to access both Medicare and Medicaid EHRs to understand comorbidities and other risk factors. These documents could be used to build customized risk profiles and prioritize patients that either will be at risk of contracting COVID-19 or who may still need urgent medical care and be displaced by COVID-19. However, these data may not provide up to date snapshots of vulnerable groups and can be difficult to access. The Centers for Medicare & Medicaid Services (CMS) could provide more timely, accessible data by improving its existing mechanisms for sharing individual-level Medicare data with qualified researchers. Improving those mechanisms could ensure expanded access to key Medicare data and facilitate merging with Medicaid data. Additionally, Medicare could publish its data more frequently to ensure that it better presents current risk profiles of populations.

**Develop better models for interdependent SDOH factors.** While many disaster planners have used models that leverage areas of food insecurity or housing shortages, some of these models were not developed in conjunction with one another, creating major challenges in understanding the full impact on communities. For example, supply chain issues at the onset of the pandemic that may have been tied to increased demand, new stresses on the transportation system, short term job losses tied to quarantine requirements, or other factors. Modelers should consider how to develop more sophisticated models that can provide an understanding of how non-clinical interventions may cause a change in one SDOH variable that may impact another SDOH variable. For example, while food insecurity was immediately flagged as a major need for many populations at the beginning of the pandemic, few anticipated how COVID-19 might also impact transportation and the distribution of food. These models can also be appropriately weighted to respond to different issues in rural and urban settings, or from one neighborhood to another. A new approach to modeling may help during recovery and in future crises where resilience is needed.

**Develop a set of HHS-approved ArcGIS layers for modeling.** HHS and its partners can potentially develop a set of layers in ArcGIS - a geographic information system used to create maps and compile, share, and analyze geographic data - that can show different SDOH factors or other medical risk factors on digital maps. These can then either be layered on existing models or maps that display risk, or be used to improve models.
Introduce an enterprise emergency planning system at the federal level. The multitude of state data collection systems for disasters has inhibited the federal government's ability to properly respond to large-scale pandemics like COVID-19. HHS and its federal partners should build on the key metrics for disaster planning and improve situational awareness through a harmonized system of data ingestion and visualization. This system could either build on or model the DHS's Medical and Public Health Information Sharing Environment (MPHISE) system for rapid implementation and improved federal understanding of the spread of the pandemic.
DATA-DRIVEN ACTION AT THE STATE AND LOCAL LEVEL

State health departments are developing models to predict COVID-19 risk in the populations they serve, at both a community and an individual level. There is a growing need to rapidly enable state and local governments to expand their data collection efforts and coordinate these projects to provide more accessible data for widespread analysis. Discussions on this theme aimed to identify actions that government, academia, the private sector, healthcare providers, and civil society can take to accelerate understanding and action related to SDOH and COVID-19 at the state and local level.

Table: Identified challenges and solutions

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<thead>
<tr>
<th>Challenges</th>
<th>Solutions</th>
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<td>Lack of investment in state and local infrastructure</td>
<td>▪ Make meaningful investments in effective contact tracing</td>
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<td>▪ Support information sharing through storytelling and other best-practice communication approaches</td>
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<tr>
<td>Absence of a national, interoperable health data sharing system</td>
<td>▪ Create a core set of social need or social determinant indicators for data collection</td>
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<td>▪ Harmonize state-level data collection systems</td>
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Challenges

Lack of investment in state and local infrastructure. Lack of adequate data infrastructure came up throughout the Roundtable as a major challenge area. It is easy to overlook the need for quality data infrastructure in normal times, but the pandemic has highlighted the inadequacy of current systems. For example, some state and local systems still rely on paper processes, and even when their data is digitized, it is generally not interoperable across levels of government. Funding and centralization guidance could come from the federal government, but the impacts must be spread across state and local systems and even down to CBOs and other community groups.

Absence of a national, interoperable health data sharing system. On a similar note, there is no common core data standard or otherwise interoperable health data sharing system. For example, while healthcare
organizations have increasingly embraced EHRs, they have not reached the same level of adoption among CBOs and other organizations that could drive true interoperability. The lack of a standard unique patient ID is another barrier to interoperability. Health Information Exchanges (HIE) may provide a useful model by allowing health care professionals and patients to access and securely share patient medical information electronically.

Incomplete or inconsistent data across cities and counties. It is difficult to get an accurate and comprehensive view of where COVID-19 is affecting communities due to lack of data sharing between cities and counties, especially in low-income areas where data collection is a challenge. For example, poorer rural communities may have inadequate data collection systems that do not report accurate caseloads to county health officials.

In Action

Data Matters, Stories Convince: Indiana’s approach to integrating data into the fight against COVID-19. The State of Indiana took a novel approach to integrating key data sources, including its HIE, into its efforts to fight COVID-19. With Indiana’s health outcomes ranking at 41 out of 50 states, the state developed its Office of Healthy Opportunities in an attempt to better understand how their members lived, worked, and played. Indiana’s Family and Social Services Administration offered a Social Risk Assessment which asked ten key questions to understand unmet social needs at the end of any SNAP, TANF, and Medicaid application. Indiana has developed a Health and Wellbeing Atlas with demographics, geographies, and overall ranking of high priority needs. This revealed that food was one of the largest unmet needs allowing for better coordination of services and food delivery around the state. The state also rolled out a 211 tool including quality information that can layer over quantitative information. It provided Indiana with the who, what, and where of social needs during the COVID-19 pandemic, and helped the office shift to a data-driven culture that informs strategy and tactics.

Solutions

Create a national public database of COVID-19 cases/deaths/testing at the sub-Census tract level. Hyper-local information is essential to making local policy decisions and is also a powerful tool for individuals making choices in their daily lives to keep themselves safe. Available platforms, presented at higher levels of aggregation, do not sufficiently inform actions at the community and neighborhood level, including decisions about reopening schools. A national public database of COVID-19 cases, deaths, and test positivity rates at the sub-Census tract level would help mitigate these issues. This lack of access to hyper-local data is not limited to COVID-19. More granular data on the SDOH would also be very useful.13

Make meaningful investments in effective contact tracing. In order to collect valid information, contact tracers must be trusted by the communities from which they collect data. When possible, contact tracers
should share a cultural background with communities they work in and speak the languages that those communities speak. Contact tracers also need to be paid more than minimum wage to support this valuable stream of work and the livelihoods for those engaging in it.

**Support information sharing through storytelling and other best-practice communication approaches.** The arrival of the COVID-19 pandemic has been accompanied by a steady stream of new public health messages, but more must be done to ensure that everyone who needs this information receives and comprehends it. This can be facilitated by working with the media - specifically non-English language media - to share qualitative data and stories that illustrate key messages. It is important that risk communication is conducted via channels and in ways that resonate with different communities and messages regarding prevention, risk mitigation, and testing will be most effective when tailored to each community. This can help build trust with communities that are at high risk for COVID-19 and also less likely to engage with the government or the healthcare system.

**Create a core set of social need or social determinant indicators for data collection.** State and local data would be improved by having a core set of social determinant or social need measures that could be collected in the clinical or public health environment and made available for analysis. At this time, it is left to the discretion of the interested party (local/state health authority, CBO, clinician, insurance companies, etc.) to determine what information is useful. That lack of consistency results in incomplete data for analysis at the population level and inconsistent data across levels of government.

**Harmonize state-level data collection systems.** With about 60 different reporting systems used by different states, it can be difficult to gather information at the state level in a useful way. Roundtable participants flagged the need for federal incentives to encourage states to improve their data systems. HHS could provide funding or other support to harmonize those systems or issue specific guidance for future pandemics and crises that mandate required data that must be reported in a uniform manner.
ASSESSING AND IMPROVING DATA RESOURCES FOR SDOH AND COVID DATA

The explosion of data that has resulted from COVID-19 provides an unprecedented opportunity to both improve existing models and fill major gaps in data collection to provide needed information for policymakers, civil society, researchers, and the medical community. Some of these gaps include challenges associated with data interoperability, file formatting, and structure due to the variety of legacy systems at play across the federal, state, and local levels. There is also a lack of standards for data sharing and definitions, lending to the difficulty of aggregating and assessing these data sources together. At the Roundtable, several participants identified immediate actions that could address shortcomings in data collection and sharing to fight the pandemic.

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<td>▪ Improve data definitions, documentation, context, and interoperability</td>
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Challenges

Privacy and trust concerns are in conflict with the fluid exchange of information. Existing privacy rules – including the Health Insurance Portability and Accountability Act (HIPAA), the set of federal regulations that governs health data privacy, and other federal, state, and local laws and regulations - may unduly hinder data collection and sharing. Additionally, individuals may be hesitant to share personal data or data about their community, regardless of privacy rules. This may include a reticence to share sensitive health issues or not feeling comfortable with government authorities monitoring their movements or
actions. This may result in existing data collection processes producing incomplete data. For example, if data on social and personal factors is collected only in clinical settings, patients may be less willing to share information - particularly if they are dealing with providers that they have not built trusting relationships with. Community groups may be better able to collect data in a trusted setting, but often lack the technological know-how or infrastructure to do so.

**It is necessary but difficult to integrate rapidly-changing public health data with long-term SDOH indicators.** Public health data collection during the COVID-19 pandemic is more dynamic than SDOH data collection, making it more complicated to collect, but at the same time vital to understanding how the situation is evolving. It needs to be used together with more static SDOH data to determine how medical and social needs are evolving during the crisis. While SDOH data can help policymakers and practitioners gain a baseline understanding of social needs, public health data collected during the pandemic can help identify changing needs for rapid response.

**There is a lack of consistent quality in COVID-19 case data.** There are a number of gaps and inconsistencies in COVID-19 case data and required reporting. There is wide variation among state and local data collection efforts. Some have incomplete information on disease severity and treatment, such as hospitalization status and ICU admission, while others don’t collect important patient characteristics, including underlying health conditions, age, race, gender, and ethnicity.

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**In Action**

**COVID-19 Reporting as a Use Case for electronic Case Reporting (eCR).** Digital Bridge was started to answer a question. How do we get accurate and timely epidemiological data, including SDOH data? That question has become even more important during the coronavirus pandemic. Traditionally, reporting is low for common or widely spread diseases. It is time consuming for clinicians and often relies on antiquated processes. To this end Digital Bridge brought together public health officials, healthcare organizations, and EHR vendors to facilitate data sharing between the public health and healthcare systems with the goal of improving the health of the nation. The effort designed and implemented an electronic case reporting system for the more than 90 nationally notifiable conditions. The mechanism enables EHRs to automatically generate reports when a condition is identified and aligns with reporting requirements across jurisdictions.

A pilot completed last year resulted in quicker and more complete reporting. Following the success of the pilot, the CDC took over the project to pursue nationwide adoption. Currently, 50 states, DC, and 8 large local jurisdictions have put reporting requirements into eCR infrastructure. At the beginning of the coronavirus pandemic, the system was quickly updated to add COVID-19 as a condition. Now, more than 3,000 facilities have implemented the system for COVID-19 reporting, resulting in 1.3 million reports to date. These reports are shared more quickly than other sources and include critical demographic data, allowing for a more robust understanding of who the epidemic is impacting and where it is hitting hardest. This new data is also timely and complete enough to understand the current state of pandemic and to enable rapid contact tracing.
**Solutions**

**Build partnerships with local organizations to gather individual SDOH data.** Questionnaires and interviews are an important source of SDOH data, but issues of trust may keep individuals from answering honestly when in a clinical setting. Researchers could build partnerships for data collection with churches, soup kitchens, CBOs, and other entities that have already built trust within the community. Colorado’s Be Heard Mile High program is one possible model. This kind of approach is especially critical as people maintain connections with their local communities, but are less likely to go to their doctors’ offices for clinical care during the pandemic.

**Capitalize on the opportunities created by COVID-19 to address long-standing SDOH data challenges through pandemic-related legislation and other initiatives.** COVID-19 has heightened general awareness of the significance of SDOH and is opening up new funding as various response legislation is passed. This can present opportunities to insert components to address long-standing challenges, such as the interoperability of SDOH data across sectors and levels of government; the need for unique patient identifiers; standardization of SDOH data elements; and the lack of electronic records (analogous to EHRs) in community-based and social service organizations. These and other long standing challenges are explored in greater detail in the report from CODE’s 2019 *Roundtable on Leveraging Data on the Social Determinants of Health*. As one example of progress that could be made, HHS, particularly the CDC, could partner with OCHIN - a nonprofit healthcare innovation center that works to promote quality, affordable healthcare for all - to advance ongoing work to integrate social service record locators into EHRs, which will eventually allow for that data to be combined with claims data.

**Improve COVID-19 case data and collection efforts.** Nationally, the CDC has collected data on COVID-19 cases as an initial basis for tracking and analyzing the spread of COVID-19, but there are still gaps and inconsistencies in this data and required reporting. These include missing or incomplete information on disease severity and treatment, such as hospitalization status and ICU admission, as well as an absence of important patient characteristics, including underlying health conditions, age, race, gender, and ethnicity. To mitigate these disparities, the CDC and other entities should focus their efforts on collecting data at small area geographic levels to get a more comprehensive view of areas being affected. For example, the Agency for Healthcare Research and Quality is developing a consolidated set of national standardized databases on valid and reliable SDOH factors at the small-area and other geographic levels, building on existing databases developed by federal agencies including HRSA, the CDC, ASPE, and the NIH. They should also compile a record of best practices from those who are leading COVID-19 case data collection.

**Improve data definitions, documentation, context, and interoperability.** Local policymakers and health officials often receive large amounts of data from varying sources, including the federal government. For example, Medicare and Medicaid claims data is a valuable source of data about the health needs of the elderly and the poor but may not be the most up to date data to measure risk in certain populations. The suppliers of federal data should provide clear information about the limitations and advantages of using different datasets, with robust metadata, definitions, and any clear shortcomings. This will enable local policymakers to create more accurate models and forecasts for potential risks in their counties. In addition, the federal government should implement interoperability and standards to better facilitate data sharing between states and other parties.
Specific Data Needs and Sources

Roundtable participants shared a number of data types and sources that would be valuable in the fight against COVID-19 and current recovery efforts. This section provides an overview of some of these specific data types, their importance, and sample sources. Some of these desired data types do not have, or are still developing, concrete sources of data. It is important to note that although the datasets listed important, this is not a comprehensive list of data types and sources needed to combat the pandemic and its effects.

Housing data (housing insecurity, homelessness, urban housing units)
Racial and ethnic minorities are more likely to live in densely populated areas, and to experience homelessness. Collection efforts for housing data should be significantly ramped up in order to mitigate disparities in the most severely affected neighborhoods and better predict COVID-19 impact.

A June survey from Pew found that 3% of Americans have moved since the pandemic. 6% have a new person or people in their house in the same time frame.\textsuperscript{15} Government data on household density and stability would be highly valuable. More granular housing and neighborhood data may also exist in the private sector.

Sources:
Average number of people per household — U.S. Census Bureau
Home Value Index — Zillow
Small area fair market rental rates — U.S. Department of Housing and Urban Development (HUD)

Transportation and infrastructure data
Having data on access to and mode of transportation is essential for mitigating the effects of COVID-19. Those who rely on public transportation and use it to commute to work face higher risks of exposure to the virus. Also, those who don’t have access to reliable transportation will have greater difficulty receiving proper healthcare for COVID-19 or other conditions during the pandemic.

The distribution of a vaccine and other key materials is also vital during a pandemic. Transportation and infrastructure data will enable planners and policymakers to effectively distribute the vaccine to those populations most in need.

Sources:
Household car count — Heller School for Social Policy and Management at Brandeis University
Transit Score — Walk Score
Planning and Performance Transportation Data — mySidewalk
Employment/workforce
The U.S. has faced record levels of unemployment, a major factor in how people are being affected by the pandemic. The economic stress of unemployment can increase an individual's overall risk of illness, due to factors like the loss of one's insurance through a previous employer, and inability to afford quality healthcare. Although basic employment status data is being collected, there needs to be a push for better collection of data on paid sick leave, employee insurance, and essential worker status.

Sources:
Unemployment rates by area, Average weekly wages — U.S. Bureau of Labor Statistics
Employment status and sector of employment by state, — U.S. Census Bureau, Household Pulse Survey (HPS)
Occupation — U.S. Census Bureau

Racial, ethnic, and language data
Data collection on language is sparse, but essential if the medical community wants to administer better care. Many Americans who don’t speak English as their first language can be deterred from seeking care and getting tested for COVID-19 when they face difficulties understanding English or lack information available in their own languages. Data on race and ethnicity is also not collected in a standard manner and is missing from many key datasets dealing with COVID-19. Data standards should be developed according to guidelines from the White House Office of Management and Budget (OMB) for the collection of race and ethnicity data, and should be a mandatory field in COVID-19 case data.

Sources:
Race and ethnicity — U.S. Census Bureau
Language spoken at home — U.S. Census Bureau

Internet access
Internet access affects whether individuals are able to access important information regarding COVID-19, including testing facility locations, proximity to health care, and any updates on the state of the pandemic, as well as their ability to utilize telemedicine. Vulnerable communities have lower rates of internet access, and in turn, are bearing more of the consequences of the pandemic.

Sources:
Computer and Internet Use — U.S. Census Bureau
Broadband access — FCC Broadband Map

County and urban density and hospital bed occupancy
Government data on household density and stability, and urban density at a granular geographic level would be of extreme value. Hospital resource use including hospital and ICU bed capacity, and invasive ventilator availability is also vital information to have. This data can help predict hotspots for the pandemic. Proximity and population density are key. Sources of this sort of data may include the U.S. Census and the U.S. Department of Housing and Urban Development.
Food insecurity data
The number of people facing food insecurity in the U.S. is rising due to the pandemic, particularly in already vulnerable communities. Improved data collection efforts for food insecurity, SNAP/WIC enrollment, and food access are needed to combat this issue.

The New York Times reported that nearly 1 in 8 households doesn’t have enough food to eat during the ongoing pandemic. Food insecurity data is an important piece of understanding this landscape and responding in kind. This data could be aggregated by regional food banks or other community organizations.

Sources:
- Low food access — U.S. Department of Agriculture (USDA), ERS, Food Access Research Atlas
- Food insecurity by county and congressional level — Feeding America, Map the Meal Gap
- Obesity — CDC, Robert Wood Johnson Foundation, 500 Cities

Air quality
Air pollution has been linked to more severe cases and higher mortality rates for COVID-19, making air quality a critical factor to analyze during the pandemic. Studies have concluded that increased long-term exposure to air pollution have resulted in larger increases in COVID death rates, and low income and minority communities are more likely to experience poor air quality.

Sources:
- Air quality — U.S. Environmental Protection Agency, AirNow API

Up to date Medicaid claims data and health status
Medicaid claims data helps identify at risk populations and understand what comorbidities might exist among poor and at-risk communities. Data on individuals' health status is also critical to identifying and assessing at-risk populations. With this data, people like county health officials can identify their Medicaid populations with a snapshot of what procedures and conditions they have, and use this information to allocate greater resources, care, and recovery support efforts.

Sources:
- Quarterly Medicaid enrollment — Centers for Medicare and Medicaid Services, Medicaid.gov
- Health status (fair or poor health) — CDC, Behavioral Risk Factor Surveillance System (BRFSS)

COVID-19 tests, cases, and deaths
Geographically granular testing and case data is essential in managing all aspects of this pandemic. This data serves as the foundation for most COVID-19 forecasting models, which predict future case surges and demand for emergency room services, hospital beds, ventilator equipment, and other forms of care. Without adequate testing data, forecasters are forced to rely on flawed data and their own assumptions.
Health insurance status

Most workers receive health insurance through their jobs, but due to increasing rates of unemployment, many people are losing their coverage. In addition, even those who have insurance may have difficulty meeting their deductibles, covering their copays, or accessing quality health care. Better data on individuals’ insurance status would support efforts to reduce healthcare disparities and improve access to high-quality healthcare. Measures should be taken to collect data on individuals’ insurance status in order to mitigate disparities.

Health care coverage by state, Metropolitan/Micropolitan Statistical Areas (MMSAs) — CDC, Behavioral Risk Factor Surveillance System (BRFSS)
Current health insurance status by state, 15 MMSAs — U.S. Census Bureau, Household Pulse Survey

Cross-Cutting Data Collections and Aggregations

In addition to sources of data that provide information on specific factors, other sources provide information on multiple types of data. This section highlights some that roundtable participants prioritized.

Databases or sources
FEMA’S Analysis and Planning Tool: is a free GIS web map that allows federal, state, local, tribal and territorial emergency managers and other community leaders to examine the interplay of census data, infrastructure locations, and hazards, including real-time weather forecasts, historic disasters and projected hazard risk. This map could be modified to incorporate new layers that model COVID-19 risk factors or social determinants of health that could improve how officials respond.

U.S. Census Bureau
The Census Bureau’s mission is to serve as the leading source of quality data about the nation’s people and economy. Part of the Department’s Economics and Statistics Administration, the Bureau collects data on:

- Population & Housing Census—every 10 years
- Economic Census—every 5 years
- Census of Governments—every 5 years
- American Community Survey—annually
- Surveys—both Demographic & Economic
- Economic Indicators—each is released on a specific schedule
The 500 Cities Project: Local data for better health partnership

500 Cities seeks to provide chronic disease indicators at the census tract level. This is a valuable resource due to the abundance of granular surveillance data it houses, as there is a shortage of such data from other sources. One of the few shortcomings of the 500 Cities Project is the timeliness of the data. Data from the most recent 2018 release includes only 2015-16 model-based small area estimates.

CDC’s Social Vulnerability Index (SVI)
The SVI is a well-established, concrete metric that can be overlaid with COVID-19 data for new insights and applications. The SVI provides data on 15 SDOH factors at the census tract level, grouped in 4 themes: socioeconomic status, household composition, race/ethnicity/language, and housing/transportation. There is a separate score for each theme as well as overall SVI score.

Surgo Foundation Community Vulnerability Index (CCVI)
The CCVI builds off CDC’s Social Vulnerability Index (SVI), a validated metric to help policymakers and public health officials respond to disasters, including disease outbreaks. It incorporates the SVI’s sociodemographic variables, along with risk factors specific to COVID-19 and variables measuring the capacity of public health systems.
The many solutions proposed through this Roundtable can lead to progress in the use of SDOH data and other approaches to fight COVID-19. The approaches described earlier in this report cover a range of options for further discussion and long-term action. In addition, CODE has identified seven recommendations that we believe can be quickly developed to accelerate the use of SDOH data in the fight against COVID-19. We encourage readers of this report to use CODE’s engagement platform at SDOH4COVID.Crowdincity.com, where these High-Priority Recommendations are posted, to further develop them, collaborate with others, and take action to make them a reality.

1. Establish a public clearinghouse for SDOH data

SDOH data pertinent to vulnerable communities is spread across many different platforms and lacks standardization. A number of federal, state, and private entities are collecting different types of data on SDOH already. Additionally, many companies provide data on individual SDOH factors like walkability scores and housing prices. A clearinghouse of publicly available data collected from all of these existing sources could be leveraged to target interventions to mitigate health risks in low-income and minority communities. It would immediately make SDOH data more accessible to large numbers of people and organizations, and over time would encourage more data sharing between states, healthcare entities, and public health agencies. A public clearinghouse for SDOH data would also help enable the other recommendations in this section.

**Next Steps:** Identify and convene stakeholders to develop a collaborative approach to building a public clearinghouse for SDOH data.

**Impact:** A public clearinghouse for SDOH data would facilitate better data sharing between states, healthcare entities, and public health agencies, making it easier to use SDOH data in the fight against COVID-19 and for other purposes, while providing opportunities for further data standardization and coordination.

**Who can take action:** Healthcare institutions, private foundations, nonprofit organizations, academic organizations, HHS and other federal agencies like the AHRQ.

2. Systematically assess and apply SDOH data from across federal agencies for use in and outside of government

A wide range of stakeholders would benefit from a deeper understanding of available sources of SDOH data across the federal government. Efforts are already underway to inventory and assess federal data sources that can be made available at a granular enough level to be relevant to individuals and communities.19 By focusing on data with particular relevance to the COVID-19 pandemic, this work could be expanded, accelerating current efforts to improve the use of SDOH data overall. This effort
could serve as a basis for a longer-term goal of identifying core social needs and SDOH indicators. While HHS is well positioned to move this work forward, most government-collected SDOH data is already published as open data, making it possible for nongovernmental actors to help assess and aggregate federal SDOH data as well.

**Next step:** Continue ongoing efforts to inventory federal SDOH data sources with a focus on relevance to COVID-19. Coordinate and consult with data stakeholders to understand what may be missing from current assessments.

**Impact:** A systematic understanding of federal SDOH data will make it easier to apply to a range of use cases including assessing risks, identifying locations for public testing sites, and directing resources to the hardest hit communities.

**Who can take action:** Federal agencies, including HHS, the U.S. Census Bureau, OMB, the General Services Administration and other agencies with data on housing, food insecurity, income, employment, transportation, and other SDOH factors. Healthcare institutions (eg. the Kaiser Family Foundation, which has done significant work on the SDOH), healthcare providers, healthcare analytics companies, nonprofit research organizations.

3. **Reassess privacy guidelines and data use agreements to expedite SDOH data sharing**

Multiple Roundtable participants noted that timely data is essential to respond rapidly and effectively during emergencies, including to understand changes in the prevalence and severity of COVID-19 infection. While much of the data collected by researchers or government agencies can be made publicly available, some data carries the risk of revealing sensitive information about individuals. Much though not all health data falls under privacy rules including HIPAA, the set of federal regulations that governs health data privacy, and other federal, state, and local laws and regulations. Privacy guidelines are equally important for SDOH data, especially since combining SDOH data with medical data may increase the risk of personal identification. However, if privacy rules are too strict - or are interpreted too conservatively - researchers may be unable to share and analyze SDOH and COVID-19 data in ways that are essential in responding to the pandemic.

HHS can lead the way to clarify and, where necessary, revise privacy guidelines that now make it difficult to share data that is essential to fighting the pandemic. This would align with American attitudes, which a recent survey shows support improved health data sharing.20 As a first step, HHS could clarify the kinds of data sharing that are already allowed under HIPAA, which may be broader than many healthcare providers realize. Developing standard Data Use Agreements would help federal agencies exchange data with each other, with state and local governments, and with the private sector. The HHS Office of Civil Rights has already 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. Further short-term or long-term changes to HIPAA or its implementation specifically focused on SDOH
data sharing could be considered. Roundtable participants suggested a next step could be a follow-up Roundtable, including both HHS and key stakeholders, to assess what changes are needed and develop innovative approaches.

**Next Steps:** Conduct an analysis of privacy risks and restrictions under current laws, regulations, guidelines, as well as data use agreements for sharing sensitive data, to identify possible adjustments that would make it easier to share and analyze this data while maintaining individual privacy. Engage medical practitioners, community groups, and government organizations to determine what changes would be acceptable.

**Impact:** SDOH data could be combined with clinical data more effectively to address COVID-19 risk on a highly localized and individual level - including building customized risk profiles to prioritize patients at risk of contracting severe cases of COVID-19.

**Who can take action:** HHS, including legal and privacy experts. Nonprofit or academic research institutions. Private-sector healthcare companies, ranging from health plans and institutions to companies specializing in SDOH data.

### 4. Use SDOH data to better target local testing and contact tracing efforts

SDOH data can be used to help local governments understand which populations may be most at risk of contracting COVID-19 and target resources appropriately. SDOH data can also be used to understand impacted populations and plan culturally appropriate contact tracing. Public testing sites can be located based on analysis of the relation between testing facilities and COVID-19 burden as well as data from sources like the CDC’s Social Vulnerability Index (SVI), which can shed light on where communities may need additional testing capacity due to lack of insurance coverage, high unemployment rates, systemic inequities, and other factors.

Some cities and programs are already using this approach. For example, the Washington, D.C. government has used SDOH data to proactively identify potential hotspots and open testing sites in areas that most need testing capacity. The D.C. Office of Health Equity has analyzed factors like life expectancy, food insecurity, car ownership, and crime across 51 D.C. statistical neighborhoods by borrowing data and analysis from numerous offices in the federal government. In a few cities and regions, the Resilient American Communities (RAC) initiative is providing toolkits and resources to enable communities to improve contact tracing efforts and testing for vulnerable populations. The RAC draws upon data from those local communities and also enables community groups to provide local insight into neighborhoods where public health officials should focus their efforts. These efforts could be scaled to achieve more widespread impact.

**Next steps:** Identify examples and develop guidelines that could be used by local officials to apply SDOH data to help them locate public testing sites. Encourage increased information sharing between local
health departments, CDC, healthcare providers, commercial testing companies, and other stakeholders involved in testing with a focus on integrating existing sources of SDOH data with data on testing sites and availability. Provide technical assistance to localities to facilitate their implementation of the new guidelines.

**Impact:** Will give local planners more insight into testing capacity and need across geographies and make it easier for federal agencies to direct resources in more targeted ways. May also help build touch points with communities that have traditionally distrusted the government and medical system by ensuring that they have access to testing and are included in contact tracing efforts.

**Who can take action:** Offices within HHS, for example the CDC or the Office of the National Coordinator. Commercial data companies (eg. digital map providers). Local governments. Nonprofit and industry organizations.

5. **Improve and expand the use of the CDC’s Social Vulnerability Index (SVI)**

The SVI is a well-established, concrete metric that combines different types of SDOH data to help local officials identify communities that may need support in preparing for and recovering from natural or human-caused disasters. The CDC is already working with the HHS OMH to expand the SVI to include additional information regarding racial and ethnic minority populations. The CDC and its stakeholders can work to publicize the SVI and expand its use, while also gathering stakeholder input and developing recommendations to improve timeliness, granularity, or other factors that would add to its value. For example, Roundtable participants noted the need to include age-adjusted data, on a per capita basis, with information on race and ethnicity following standards established by OMB.

**Next Steps:** Develop a program for stakeholder input and identify opportunities to improve SVI data. Develop a program to promote the SVI and build its user community.

**Impact:** As the COVID-19 pandemic continues, and in the event of future disasters, a more robust and widely used SVI will make it easier to identify and direct aid to communities most in need of support. User-driven improvements to the SVI would make it even more valuable for local planning and response efforts by private health systems, local health departments, community-based organizations, and social services organizations. An expanded SVI could feed into an SDOH data clearinghouse, which would include a larger set of data, allowing for deeper analysis of SDOH across varying predictive areas.

**Who can take action:** Federal agencies like the CDC and the U.S. Census Bureau. Local officials in public health, emergency response, disaster planning, and other relevant domains. SVI users, including nonprofits and academics, who can suggest ways to strengthen the SVI and amplify its value.
6. **Create a community of practice so that localities can share innovative policy ideas and learn from what is working**

The Roundtable briefing paper, webinar, and breakout sessions highlighted many examples of states and localities using SDOH data in innovative ways to respond to COVID-19. An online platform, communications programs, or live convenings could enable local leaders to exchange ideas and learn from each other. While such an effort could be led by HHS, foundations, or other national organizations, it should be developed collaboratively with local departments of health to ensure that their concerns and interests are understood and met.

**Next Steps:** Identify one or more government agencies or organizations that can lead this community of practice. Engage local health departments to identify key components of a community of practice or information sharing mechanism.

**Impact:** Will increase the spread of best practices in the fight against COVID-19 and build relationships between key stakeholders. Could eventually help build partnerships with local organizations to gather individual-level SDOH data, better connect communities with aid, and more.

**Who can take action:** Convening organization(s) such as HHS or major foundations. State and local departments of health, CBOs and other local nonprofit groups, individuals, hospitals and other healthcare institutions.

7. **Develop an “Open Table” approach to connect individuals with social programs/services**

While the structural social determinants of health are important in understanding and treating COVID-19, it is urgent to address individuals' social needs. Roundtable participants suggested developing apps or other tools to connect people with social services as their needs are identified. Research on public health trends and on SDOH, collected through both population studies and individual questionnaires, can help identify at-risk individuals and prioritize their needs for social services. There may be opportunities to explore public-private partnerships with companies that already work to connect individuals with social service providers and fill other needs.

**Next Steps:** Integrate “matching” programs for social services with clinical care at several levels, from individual practitioners to health plans and healthcare providers.

**Impact:** Reduce COVID-19 risk for individuals and communities by addressing social needs that increase disease risk.

**Who can take action:** Health plans and healthcare providers with access to information on their patients’ social needs. Private companies, such as UniteUs and Aunt Bertha, that have developed apps to connect individuals with social services. Community-based organizations.
CONCLUSION

The COVID-19 pandemic is the most significant and immediate national and global health crisis in more than a generation. It has also exposed the ways in which social factors impact health and well-being. The data that we collect about these social factors can play a powerful role in our response to the COVID-19 pandemic and future crises.

The Roundtable uncovered a wide range of potential solutions and related datasets that can be leveraged as we continue to fight against COVID-19. Some can be developed in a short time frame with limited resources while others may take months or years to be fully realized. In both cases, it is imperative that we start to ask the right questions, build productive partnerships, and take action to mitigate the ongoing damage done by COVID-19 as we look towards the future.
ABOUT THIS REPORT

The Center for Open Data Enterprise (CODE) is an independent nonprofit organization based in Washington, D.C. CODE’s mission is to maximize the value of open and shared data for the public good, by working with government agencies, businesses, nonprofits, and researchers who are both data providers and data users. Since it was founded in January 2015, CODE has held more than two dozen Roundtables and Workshops with the White House and federal agencies focusing on topics including medical research and health care, energy and the environment, and federal data strategy. CODE has also developed informational materials and recommendations to promote the use of government data and public-private collaboration around data sharing and application. In addition to working with government agencies in the U.S. and internationally, CODE partners with private sector companies, foundations, and other nonprofit organizations to achieve its mission. More information about CODE is available at www.odenterprise.org.

This report was written by Matt Rumsey, CODE’s Research and Communications Manager, and Temilola Afolabi, CODE’s Research Associate, with support from CODE Roundtables Program Manager Paul Kuhne. The report is produced by the Center for Open Data Enterprise and represents CODE’s independent synthesis of input from the Roundtable on Using SDOH Data to Fight COVID-19 and Support Recovery Efforts. It is not a U.S. government report. Information and opinions in this report do not necessarily reflect the opinions of the U.S. Department of Health and Human Services, or any other component of the federal government. Federal Advisory Committee Act rules were not applicable to the Roundtable, which was an invitation-only event designed to elicit individual views and suggestions from experts in the field. This report is not meant to represent a consensus of Roundtable participants, but reflects CODE’s analysis of individual participants’ input and other research done before and after the Roundtable.
Participating Organizations

RESEARCHERS & ACADEMIA

Beeck Center for Social Impact and Innovation was launched in 2014 at the Georgetown University to provide students with new ways to impact society, in a cross disciplinary, hands-on experiential way.

Center for Digital Health Innovation at UCSF CDHI envisions and realizes new technologies, developed at UCSF and beyond, and evaluates them in clinical settings. Their areas of expertise include data science, product management, software development, EHR integration, project management, and digital health policy.

The Johns Hopkins Bloomberg School of Public Health has advanced research, education and practice to create solutions to public health problems around the world since 1916. The Bloomberg School works to keep millions around the world safe from illness and injury by pioneering new research, deploying knowledge in the field and educating tomorrow’s public health leaders.

The Meharry-Vanderbilt Alliance develops and supports collaborative initiatives. It has provided opportunities for collaboration between Meharry Medical College and Vanderbilt University Medical Center, and for collaboration with projects in the community.

Morehouse School of Medicine trains physicians, biomedical scientists and public health practitioners to improve the health and well-being of people of color and the underserved urban and rural populations in Georgia and the nation.

The National Patient Advocate Foundation (NPAF), the advocacy affiliate of the Patient Advocate Foundation, represents the patient voice by articulating the powerful stories of individuals and the collective needs of the community. We are dedicated to improving health care access, quality and affordability through policies, programs and practices that optimize the experience and outcomes for patients and caregivers.

New York University Langone School of Medicine strives to enroll a diverse group of academically talented students with the personal attributes, endeavors, and accomplishments to succeed as future leaders and scholars of medicine. Their ultimate goal is to enroll a student body with a collective desire to improve the health of all segments of our society through outstanding patient care, research, and education.

UC Berkeley Division of Computing, Data Science, and Society launched in July 2019 to leverage Berkeley’s preeminence in research and excellence across disciplines to propel data science discovery, education, and impact.
The University of Albany Center for Technology and Government focuses on the combined social and technical aspects of information use across organizational boundaries, looking at how knowledge and information are shared in multi-organizational collaborations to solve pressing public problems or deliver quality public services.

The University California, San Diego is one of the world's leading public research universities, located in beautiful La Jolla, California.

University of North Carolina Chapel Hill is the first public research university in Chapel Hill, North Carolina and its School of Medicine aligns research and education with outstanding patient care, and to transform clinical medicine into patient-centered care.

University of Wisconsin-Madison is a public research university in Madison, Wisconsin. Founded when Wisconsin achieved statehood in 1848, UW–Madison is the official state university of Wisconsin, and the flagship campus of the University of Wisconsin System.

**FEDERAL GOVERNMENT**

The U.S. Department of Health and Human Services (HHS) 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, human error or deliberate attack, CDC fights disease and supports communities and citizens to do the same.

The Centers for Medicare and Medicaid Services (CMS) administers the Medicare program and works in partnership with state governments to administer Medicaid, the Children’s Health Insurance Program (CHIP), and health insurance portability standards, among other responsibilities.

The Health Resources and Services Administration (HRSA) is the primary federal agency for improving health care to people who are geographically isolated, economically or medically vulnerable.

The National Institutes of Health (NIH) 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 the Assistant Secretary for Health (OASH) 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.

The Office of the Assistant Secretary for Preparedness and Response (ASPR) leads the nation's medical and public health preparedness for, response to, and recovery from disasters and public
health emergencies. ASPR collaborates with hospitals, healthcare coalitions, biotech firms, community members, state, local, tribal, and territorial governments, and other partners across the country to improve readiness and response capabilities.

The Office of the National Coordinator for Health Information Technology (ONC) is at the forefront of the administration’s health IT efforts and is a resource to the entire health system to support the adoption of health information technology and the promotion of nationwide health information exchange to improve health care.

The U.S. Department of Housing and Urban Development administers programs that provide housing and community development assistance. The Department also works to ensure fair and equal housing opportunity for all.

The 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.

STATE & LOCAL GOVERNMENT

The District of Columbia Health Department promotes health, wellness and equity, across the District, and protects the safety of residents, visitors and those doing business in our nation’s Capital. Their responsibilities include identifying health risks; educating the public; preventing and controlling diseases, injuries and exposure to environmental hazards; promoting effective community collaborations; and optimizing equitable access to community resources.

The Indiana Family and Social Services Administration’s mission is to compassionately serve our diverse community of Hoosiers by dismantling long-standing, persistent inequity through deliberate human services system improvement.

The Washington Division of Labor and Industries is comprised of 51 attorneys and 55 professional staff in Olympia and Seattle. There is someone handling L&I litigation at every Attorney General’s Office location, but the Labor and Industries Division has primary responsibility for assigning cases and providing advice to the Department.

PHYSICIANS AND PROVIDERS

America’s Essential Hospitals is an industry trade association representing 325 members. It supports its members through advocacy, policy development, research, and education. It operates research and quality activities through the Essential Hospitals Institute. The Institute supports hospitals in providing high-quality, equitable, and affordable care to communities.

Datavant’s provides solutions to help institutions protect, match and share health data. Their mission is to connect the world’s health data to improve patient outcomes, and help their customers protect patient privacy and connect to the nation’s largest ecosystem of real-world data.

Mount Sinai Health System is an integrated healthcare delivery system with seven hospitals, one medical school, and more than 300 locations. It is also one of the oldest and largest teaching hospitals in the US.
PRIVATE SECTOR

**Digital Bridge** works to open up new opportunities to impoverished people in local and global communities who have been left behind in technology. By working with local nonprofits to provide technical service and computer lab donations, they’ve implemented over 20 computer labs spanning across three continents.

**HMS** delivers healthcare technology, analytics and engagement solutions to help reduce costs, improve health outcomes and enhance consumer experience.

**OptumLabs** brings together a community of partners dedicated to improving patient care by sharing information assets, technologies, knowledge tools & expertise.

**Posterity Capital Group’s** mission is to generate above-market, risk-adjusted returns by investing in companies that improve health or healthcare. The Group invests in companies with a proven model that are seeking capital and healthcare expertise to support business growth and scale, acquisitions, or recapitalization.

**Socially Determined** is a health care technology and analytics company focused on measuring the impact of the Social Determinants of Health (SDOH). The company's purpose-built analytic platform, SocialScape®, quantifies and visualizes risk exposure and impact using the nation's largest curated repository of SDOH and social risk intelligence.

**ZeOmega’s** mission is to deliver proven population health management software solutions that enable our clients to enhance the value of healthcare and bend the cost curve. We deliver integrated informatics and business process management solutions so actionable information can be delivered in real-time, at the right time, and to all stakeholders in the care management continuum.

INSURANCE PAYERS

**Humana** is a for-profit American health insurance company based in Louisville, Kentucky. As of 2014 Humana had over 13 million members in the U.S., reported a 2013 revenue of $41.3 billion, and had 41,600 employees.

CIVIL SOCIETY

**AcademyHealth** is a nonpartisan, nonprofit professional organization dedicated to advancing the fields of health services research and health policy. AcademyHealth acts as an objective broker of information, bringing together stakeholders to address the current and future needs of an evolving health system, inform health policy and practice, and translate evidence into action.

**ACT | The App Association** represents more than 5,000 app companies and information technology firms across the mobile economy. ACT advocates for an environment that inspires and rewards innovation, while providing the necessary resources to help its members leverage their intellectual assets to raise capital and create jobs.

**The Center for African American Health** offers African American and Black Metro Denver communities culturally responsive resources that support them in overcoming the root causes of health problems so
they can maximize their individual and family health.

**The COVID Tracking Project** is a volunteer organization launched from The Atlantic and dedicated to collecting and publishing the data required to understand the COVID-19 outbreak in the United States.

Data Coalition advocates for responsible policies to make government data high-quality, accessible and usable. As a membership-based trade association, the Data Coalition advocates for responsible policies to make government data high-quality, accessible, and usable.

**Data.org** is a platform for partnerships to build the field of data science for social impact. We envision a world that uses the power of data science to tackle society’s greatest challenges. The organization 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.

**Health Equity Solutions (HES)** is an organization focused on achieving health equity in Connecticut. HES ensures that all people have access to optimal health despite their race, ethnicity, culture, or socioeconomic status.

**HealthBegins** emerged as a national leader in the Upstream Movement, helping healthcare and community partners across the country through communications, network building, and hundreds of trainings on Upstream Quality Improvement — their signature braiding of social medicine and quality improvement approaches.

**Healthcare Association of New York State (HANYS)** works to ensure every New Yorker has access to affordable, high-quality care. HANYS advances the health of individuals and communities by providing leadership, representation and service to not-for-profit and public hospitals, nursing homes and other healthcare organizations throughout New York state.

**The National Alliance to impact the Social Determinants of Health (NASDOH)** is a group of stakeholders working to systematically and pragmatically build a common understanding of the importance of addressing social needs as part of an overall approach to health improvement.

**OCHIN** is one of the largest health information and innovation networks, serving over 500 organizations and 10,000 clinicians across the U.S. with the technology, research, and expertise to improve healthcare delivery and integration.

**Resolve to Save Lives** helps governments and civil society implement scalable, proven strategies and is an initiative of the global public health organization Vital Strategies. They are determined to prevent millions of deaths from cardiovascular disease and epidemics, with a focus on accelerating action through speed, simplicity, and scale in low- and middle-income countries.

**Trust for America’s Health** is a non-profit, non-partisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority. It reports on and recommends evidence-based programs and policies that make prevention and health equity foundational to health and community systems.
## Roundtable Agenda

**Webinar on Using SDOH Data to Fight COVID-19 and Support Recovery Efforts**

**12:00 - 1:00 p.m. | Wednesday, August 12, 2020**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker(s)</th>
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<tbody>
<tr>
<td>12:00</td>
<td>Welcome and Opening Remarks</td>
<td>Sanjay Koyani, ReImagine HHS Data Insights Initiative Executive Director U.S. Department of Health and Human Services (HHS)</td>
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<tr>
<td>12:10</td>
<td>Special Remarks</td>
<td>Rear Admiral Felicia Collins, M.D., M.P.H., FAAP, Director of the Office of Minority Health, HHS</td>
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<tr>
<td>12:20</td>
<td>Q&amp;A with RADM Dr. Felicia Collins</td>
<td>Sanjay Koyani, ReImagine HHS Data Insights Initiative Executive Director, HHS</td>
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<td>12:25</td>
<td>SDOH Data Findings from Center for Open Data Enterprise (CODE)</td>
<td>Joel Gurin, President, CODE</td>
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<td>12:30</td>
<td>Lightning Talk 1: Deploying SDOH Data to fight COVID-19 at the State Level</td>
<td>Jennifer Sullivan, Secretary, Indiana Family and Social Services Administration</td>
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<td>12:35</td>
<td>Lightning Talk 2: COVID-19 Reporting as a Use Case for eCR</td>
<td>John Lumpkin, Chair, Digital Bridge</td>
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<tr>
<td>12:40</td>
<td>Lightning Talk 3: Uniting Data to Support Kentucky’s COVID-19 Response</td>
<td>Jessica Cunningham, Executive Director, KYSTATS</td>
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<td>12:45</td>
<td>Lightning Talk 4: National Infrastructure for Mitigating the Impact of COVID-19 within Racial and Ethnic Minority Communities</td>
<td>Dominic Mack, Director of National Center for Primary Care, Morehouse School of Medicine</td>
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<td>12:50</td>
<td>Questions and Answers Period</td>
<td>Joel Gurin, President, CODE</td>
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<tr>
<td>12:55</td>
<td>Closing Remarks and Adjourn for Roundtable Orientation</td>
<td>Sanjay Koyani, ReImagine HHS Data Insights Initiative Executive Director, HHS</td>
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<td>1:00</td>
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References


2. For more, see: https://healthdatasharing.org/social-determinants-of-health/


4. For more on Healthy People 2030, visit https://health.gov/healthypeople


