THE CENTER FOR
OPEN DATA ENTERPRISE

Roundtable on Data Sharing Policies, Data-Driven Solutions, and the Opioid Crisis

Report and Recommendations

September 2018

EXECUTIVE SUMMARY

On July 13, 2018, the Office of the Chief Technology Officer (CTO) at the U.S. Department of Health and Human Services (HHS) and the nonprofit Center for Open Data Enterprise (CODE) co-hosted a Roundtable on Data Sharing Policies, Data-Driven Solutions, and the Opioid Crisis.

The Roundtable brought together over 70 experts from federal, state, and local government, the private sector, nonprofit organizations, and academia. The objective of the Roundtable was to "explore possibilities and limits of data sharing, and identify successes and proposed solutions for using data to address the opioid crisis."

Roundtable participants identified several current limitations to sharing and using data to address the opioid crisis:

- **Legal Barriers** include 42 CFR Part 2, which restricts essential data that practitioners and policymakers need to best treat patients with substance abuse issues, as well as widespread misunderstanding of the legal requirements for data sharing under HIPAA. The lack of standard Data Use Agreements (DUAs) inhibits data sharing between federal and state agencies.
- **Cultural Barriers** include the siloing of data between and within agencies, which limits the availability of data in addressing time-sensitive issues such as new trends and patterns in opioid overdoses. Additionally, the distribution of risk and reward leads to high risk-aversion because legal burdens are placed on the data-owner, not the agency requesting data.
- **Technical Barriers** include a lack of common data standards necessary for interoperability, as well as an inability to track and integrate individual patients' records across disparate datasets to improve treatment on a per-patient basis. More broadly, agencies do not have enough staff with the technical knowledge required to manage or share data effectively.

Roundtable participants proposed several solutions designed to address these legal, cultural, and technical barriers to sharing and using data to address the opioid crisis:

- Repeal 42 CFR Part 2 and protect substance abuse information under HIPAA requirements
- Educate stakeholders on the potential for data sharing under HIPAA
- Establish standard data usage agreements
- Update the Model Vital Statistics Law (MVSL)
- Adopt common data standards
- Provide controlled access to sensitive public health data
- Generate a unique patient identifier for health data

This report represents CODE's summary of Roundtable participants' discussions of these issues. The proposed solutions presented, which are designed to enable the sharing and application of data, are based on recommendations formulated in those discussions. They are not meant to represent a formal consensus of the group.

BACKGROUND

Data is a critical tool in fighting the deadly, nationwide opioid epidemic. Many government agencies, nonprofits, academic institutions, and private sector companies are using data to track opioid prescriptions, identify treatment opportunities, and understand risk factors that can predict opioid use. While there are significant opportunities to leverage data in the fight against the opioid crisis, there are also barriers to sharing and using this information. A background document with more detail, prepared for this Roundtable, is available here.

The U.S. Department of Health and Human Services (HHS) recognizes the opioid crisis as a major priority. HHS has also identified the potential of data-driven approaches and the need to scale these efforts rapidly to address the growing crisis.

In 2017, HHS declared a public health emergency and announced a 5-Point Strategy To Combat the Opioid Crisis. Building on these efforts, the HHS Office of the Chief Technology Officer (CTO) hosted an Opioid Code-a-Thon and Symposium in December 2017 "to promote and employ innovative ways to leverage technology and data to address the nationwide opioid epidemic." The Code-a-Thon brought together over 50 teams to develop data-driven tools and platforms, with three teams selected as winners from the prevention, treatment, and usage tracks of the competition.

This work has been part of a commitment by the HHS Office of the CTO to advance the goals of the ReImagine HHS effort to "Get Better Insights from Better Data". The Office of the CTO is leading a Department-wide effort to understand how HHS is using and sharing its own data to make more evidence-based policy decisions.

ROUNDTABLE OVERVIEW

On July 13, 2018, the HHS Office of the CTO and the nonprofit Center for Open Data Enterprise (CODE) co-hosted a Roundtable on Data Sharing Policies, Data-Driven Solutions, and the Opioid Crisis. The Roundtable was held at the HHS Hubert H. Humphrey Building in Washington, DC. The Roundtable brought together over 70 experts from federal, state, and local government, the private sector, nonprofit organizations, and academia to explore possibilities and limits of data sharing, and identify successes and proposed solutions for using data to address the opioid crisis

The Roundtable opened with remarks from Mona Siddiqui, the HHS Chief Data Officer, and Ed Simcox, the Chief Technology Officer. The event proceeded with presentatiations, lightning talks, and interactive breakout sessions. The day concluded with a presentation of highlights from the breakout sessions to the full group, who were joined by HHS leadership including Associate Deputy Secretary Charles Keckler.

The Roundtable was held under the Chatham House Rule, and participants were not asked to develop formal consensus but to share their own observations and suggestions. The full agenda for the Roundtable can be found here and the list of participating organizations can be found here.

LIMITS OF DATA SHARING

While there are significant opportunities to leverage data in the fight against the opioid crisis, there are legal, cultural, and technical barriers to sharing and using this information. Roundtable participants identified the following limitations:

LEGAL BARRIERS

Restrictions Under 42 CFR Part 2. Health practitioners and policymakers argue that the restrictions on data pertaining to drug abuse in Title 42 of the Code of Federal Regulations (CFR) Part 2 create a blind space in which policy and treatment decisions must be made in the dark. 42 CFR Part 2 requires that information on substance use be kept in separate electronic health records (EHR), and requires practitioners and pharmacists to request permission from each patient in order to enter data into the Prescription Drug Monitoring Program (PDMP), or to request information from the PDMP to ensure that individuals are not abusing the system to obtain opioids from multiple providers. Because the PDMP requires active consent from patients, its data are skewed toward including substance use information only from a small subset of patients willing to truthfully report their substance usage.

This legal barrier also makes it difficult or impossible for the professionals treating substance abusers to coordinate information essential to their care. For example, under 42 CFR Part 2, primary care physicians cannot access methadone data from opioid treatment programs or urine drug screening information for individual patients. During the Roundtable, CODE conducted a survey of all participants with regard to their familiarity with different limitations to data sharing. While a few participants indicated that they were not familiar with 42 CFR Part 2, the majority of participants were, and stated nearly unanimously that it poses a serious challenge to medical practitioners, policymakers, and non-governmental workers trying to combat the opioid crisis.

Furthermore, because 42 CFR Part 2 separates specific electronic health records pertaining to drug use from other health information, substance abuse is stigmatized. This makes it more difficult to help patients and reduces the likelihood that patients will be given the treatment and rehabilitation opportunities they need, because those patients that are most in need of help are the least likely to report their conditions. As a result, medical providers are unable to properly treat them.

Challenges in Interpreting HIPAA. Roundtable participants noted that the legal safeguards provided by The Health Insurance Portability and Accountability Act of 1996 (HIPAA) are widely misunderstood, particularly as they relate to data sharing and private patient information. While HIPAA does allow for the sharing of data, the ambiguity of its language often leads to diverging interpretations, with different agencies interpreting and applying HIPAA in different ways. As a result, less data is shared than the law actually allows.

HHS has already taken steps to address these misconceptions by publishing guidance on HIPAA and the opioid crisis for health care practitioners. However, Roundtable participants suggested that more resources are needed to address the interpretation of HIPAA. Several participants noted that government departments and agencies often lack adequate legal training on HIPAA and other statutes that impact data sharing and need information and guidance from HHS.

CULTURAL BARRIERS

Lack of Data Sharing Culture Across Government. Government agencies do not currently foster a culture that enables data sharing. Roundtable participants highlighted the fact that agencies often view their data as an asset to guard rather than to share, resulting in siloed data. They noted that many government agencies, which collect certain types of data for specific reasons, are concerned that their data might end up being used for unexpected ends, in ways that the agency might view as inappropriate. Because the current culture across government agencies does not promote data sharing, healthcare practitioners and researchers lack information about the content, quality, and structure of individual datasets. This hinders their ability to request data, since they are unable to pinpoint exactly how they would use it or which variables in particular they would analyze.

Building a Data-Driven Culture in West Virginia

From Analysis to Action

Per capita, the State of West Virginia has the largest number of opioid overdoses in the United States. One of the biggest challenges faced by the West Virginia Bureau for Public Health has been breaking down data silos in order to integrate and analyze information as part of a unified solution. To do so, West Virginia has worked to match facilities with data from the Department of Corrections, medical, and health organizations. This approach is providing access to critical information that can be used to generate risk profiles for opioid use, which the West Virginia Bureau for Public Health has used to identify and treat at-risk individuals and communities.

Uneven Distribution of Risk and Reward. Roundtable participants noted that the uneven distribution of risk and reward with regard to sharing confidential information between and within agencies poses a barrier to data sharing. When sharing data, risk is shouldered almost entirely by the data-owner, while the reward accrues to the data-requester. This dysfunction is the result of of overlapping laws, ambiguous wording and concerns over accountability. As a result, many government agencies choose to minimize their risk by limiting data sharing activities. If a data-sharing project is well-received, the entrepreneurial nature of the data-requester will be applauded. On the other hand, if the project encounters serious legal pitfalls or data breaches, the original owner of the data will be criticized for reckless stewardship of data. This creates an endogenous cycle in which data become siloed within agencies. As several respondents noted, the practice of not sharing data has become, in many agencies, de-facto policy.

TECHNICAL BARRIERS

Lack of Common Data Standards. Federal and state government data do not adhere to universal standards or levels of analysis, which makes it difficult to merge data from disparate sources. For example, some data are structured at the state level, while other datasets are structured at the individual patient level. Across datasets, different terms are used to describe the same concept, or, vice-versa, different concepts are described by the same term. These confounding factors make merging datasets particularly difficult.

Participants pointed to the value of using a universal structure for data that would increase data interoperability. If possible, linking different kinds of data about individual patients through a unique anonymized personal identifier would allow for truly individualized patient care and data analysis. Using a personal identifier would also support a federated data model, allowing individual agencies to maintain control over their data while responding to centralized queries. This system would facilitate dataset generation for specific tasks while maintaining agency control over which data are shared.

Limited Resources and Staff Across All Levels of Government. As many participants noted, government agencies at the federal, state, and local levels often lack adequate resources and staff with the skills needed to undertake complex data collection, cleaning, standardization, and sharing. As a result, many agencies are left without a clear program of data stewardship, hindering their ability to share data. Data stewardship requires a dedicated team of individuals who are familiar with the ethical and technical challenges of collecting public health data, cleaning and managing data, and sharing the data with other organizations.

At several of the breakout discussion tables, Roundtable participants suggested establishing HHS agency-level 'data sharing officers', who would be responsible for ensuring that datasets are properly maintained and made available for integration with other HHS datasets. Participants recommended that this role would best be filled by dedicated personnel, although it could theoretically be combined with other duties. Either way, data sharing officers would be responsible for making requests and receiving data sharing requests to and from other HHS agencies, as well as ensuring that datasets are catalogued and maintained in accordance with HHS data standards (and common data standards, if implemented). Furthermore, the presence of dedicated personnel would help improve agency-level familiarity with data sharing under HIPAA, as well as improving the culture of data sharing and stewardship across HHS.

Collecting Timely Data to Save Lives
Wastewater Epidemiology

Biobot Analytics is a team of biologists, architects, chemists, and engineers developing cutting-edge technology to transform sewers into public health observatories. They are working to measure opioids and other drug metabolites in sewage to estimate consumption in cities in real time. The data collected through Biobot's Opioid Consumption Monitoring (OCM) program enables those working on harm reduction to assess opioid use in their communities, decide how to allocate resources, and evaluate interventions over time.

Access to Timely Data. A major challenge in addressing time-sensitive public health crises is having access to current, timely data. For example, to address a spike in opioid overdoses in a particular community, local authorities need immediate access to geospatial data on overdoses, the flow of drugs, and information about the surrounding regions most at risk from the ripple effects of opioid spikes. Unfortunately, such data is currently very difficult and, in some cases, impossible to access. Within HHS, data on opioid deaths and overdoses are often outdated. For example, the most recent data from the National Vital Statistics System are over eight months old at the time of this report.

Public health agencies may need to use new approaches to collect useful, timely data. For example, collecting data from sources external to patients, such as epidemiological data collected by Biobot Analytics in public wastewater, can provide real-time information about how opioids are being used at any given time. In the Washington, DC and Baltimore area, the High Intensity Drug Trafficking Areas (HIDTA) program developed a real-time ODMap that notifies first responders in affected and surrounding areas whenever an opioid overdose is reported. This allows emergency services to prepare for spikes in overdoses in their areas, saving the lives of substance users that overdose.

Updates from HHS Opioid Code-a-Thon Winners

The HHS Office of the CTO hosted an Opioid Symposium and Code-a-Thon and in December 2017 "to promote and employ innovative ways to leverage technology and data to address the nationwide opioid epidemic." The Code-a-Thon brought together over 50 teams to develop data-driven tools and platforms, with three teams selected as winners from the prevention, treatment, and usage tracks.

The Roundtable on Data Sharing Policies, Data-Driven Solutions, and the Opioid Crisis featured brief presentations from each of the three winning teams of the HHS Opioid Code-a-Thon, including updates on their progress since December 2017.

- During the HHS Opioid Code-a-Thon, the **Visionist Inc.** team came up with a program called Take Back America, to assess the unmet need in five states for pharmacy-based take back programs where unused or unneeded opioids can be returned, taking a source of opioids out of circulation. Since December 2017, Visionist Inc. has continued to improve their tool, which uses government and academic data to help healthcare practitioners and the public locate drug take-back centers and help them meet the needs of local communities.

- The **Origami Innovations** team produced a model designed for real-time tracking of overdoses, allowing first responders and health authorities to be prepared for tracking events such as an outbreak of fentanyl overdoses in communities. This real time tracking would enable area hospitals and local health departments to allocate resources where they are most needed. Following the Code-a-Thon, **Telesphora** was formed in collaboration with Origami Innovations to continue this work, developing solutions that empower first responders, hospitals, and policymakers to more intelligently allocate resources to save lives.

- During the HHS Opioid Code-a-Thon, the Opioid Prescriber Awareness Tool (OPAT) team borrowed from military aviation to create an instrument panel providing clinicians with a visual representation of their opioid prescribing patterns compared with those of their peers. The tool also informs the referral process and provides easy access to contact information for multi-modal pain and addiction treatment options in the prescriber's area. Since December 2017, several members of the OPAT team founded **F3 Healthcare**. which is focused on making healthcare better, safer, and less expensive by turning data into actionable intelligence.

To learn more about **Visionist Inc.**, visit: https://www.visionistinc.com/

To learn more about **Origami Innovations and Telesphora**, visit: https://telesphora.com/

To learn more about **F3 Healthcare**, visit: http://prescribecompare.com/

PROPOSED SOLUTIONS

The following proposed solutions emerged from two structured breakout discussions that took place during the Roundtable. For each proposed solution, Roundtable participants outlined major objectives, stakeholders, and actionable next steps. The proposed solutions provide an initial framework for action on the part of the U.S. Department of Health and Human Services and other key stakeholders.

Repeal 42 CFR Part 2 and Protect Substance Abuse Information under HIPAA

Roundtable participants proposed repealing 42 CFR Part 2 to improve the treatment of patients who abuse opioids and other substances. While there have recently been calls to amend 42 CFR Part 2, participants in the Roundtable believed that the regulation can be completely repealed and that patients will still have adequate protections under HIPAA. Several pointed to a similar successful policy change around around the HIV/AIDS epidemic: While laws originally limited the sharing of patient information pertaining to HIV/AIDS, policy evolutions eventually folded this information into the protections afforded by HIPAA. Protecting HIV/AIDS data under HIPAA rather than through a separate law empowered practitioners to make more informed treatment decisions with better information. A similar strategy could be used with substance abuse data, empowering physicians and pharmacists to treat patients more effectively. Doing so would also empower academic researchers, non-profits, and select private-sector organizations to address the opioid crisis with more accessible data.

Objectives	Stakeholders	Actionable Next Steps
Develop strategy for new legal framework	HHS Office of the CTO and Office of the General Counsel	Convene a technical advisory panel to review 42 CFR Part 2.
	HHS Office of Civil Rights Substance Abuse and Mental Health Services Administration (SAMHSA)	Drawing from experiences with the HIV/AIDS model, develop a white paper that could establish the basis for repealing 42 CFR Part 2 and demonstrate how privacy protections could be folded into HIPAA.
Modernize legal framework	HHS Office of the CTO and Office of the General Counsel HHS Office of Civil Rights Substance Abuse and Mental Health Services Administration (SAMHSA)	Work with legislators to establish a bipartisan task force to address 42 CFR Part 2.

Educate Stakeholders on the Potential for Data Sharing under HIPAA

Roundtable participants noted that many government agencies do not interpret and implement data sharing under HIPAA in the same way. This fosters high levels of risk aversion, hindering HHS from sharing data within and across its agencies. As a result, data is often siloed and unaccessible to those practitioners and researchers that need it. This problem could be addressed by clear communication from HHS as well as a training regimen designed to standardize how HHS agencies and state agencies share data under HIPAA.

HHS has already provided initial guidance on how practitioners can share data under HIPAA to respond to the opioid crisis. However, Roundtable participants suggested the need for additional resources that could be developed by HHS to help assuage concerns about HIPAA and promote the sharing of essential health data. For example, by providing a workshop to discuss data sharing under HIPAA as well as providing access to online tools and resources that easily explain when data can and cannot be shared, HHS could greatly improve the understanding of data sharing practices that are allowed under HIPAA.

Objectives	Stakeholders	Actionable Next Steps
Disseminate HIPAA data sharing rules	HHS Office of the CTO, Office of Civil Rights, and Office of the General Counsel	Draft clear, comprehensive,HHS-wide guidelines for each HHS agency to follow in implementing data sharing under HIPAA.
	HHS Office of the CTO, HHS agencies and offices	Hold a workshop including representatives of all HHS agencies and offices to provide training on data sharing under HIPAA and the new HHS-wide guidelines. The HHS Office of the CTO should determine which individuals best represent each agency, based on responsibilities for data within those agencies.
	HHS Office of the CTO State Departments of Health and Human Services	Develop online resources to communicate HHS-wide policies to other federal, state, and local government agencies, healthcare practitioners, and the general public.

Establish Standard Data Usage Agreement

The development of standardized Data Usage Agreements (DUAs) would greatly reduce the amount of time and effort required to successfully share data between and within agencies. Universal DUA templates that can be tailored to each specific request could begin within HHS and become a model for data sharing within the Federal Government. Standardized data usage agreements (DUAs) will allow federal and state agencies to quickly and easily arrange for inter-agency data sharing required to comprehensively address the opioid epidemic and other public health emergencies. Standard DUAs, in conjunction with specialized data sharing officers at each HHS agency, could significantly improve the ability of HHS to respond quickly to time-sensitive opioid-related developments.

Objectives	Stakeholders	Actionable Next Steps
Facilitate and standardize data sharing between and within agencies	HHS Office of the CTO and HHS agency representatives	Establish a working group of the Chief Technology Officer, Chief Data Officer, and representatives from each agency of the U.S. Department of Health and Human Services.
		Within one year of its creation, the working group will review existing DUAs and identify the requirements for one or more standard DUA templates
	HHS Office of the General Counsel	Develop DUA templates to be tested within and between HHS agencies
	HHS Office of the CTO	Designate an individual within each agency to coordinate data sharing efforts.

Update the Model Vital Statistics Law (MVSL)

Roundtable participants noted the potential benefit of modernizing the Model Vital Statistics Law (MVSL), which establishes a standard for all vital statistics, including birth and death certificates, in the United States. The MVSL was Initially passed in 1907 and most recently revised in 1992, and requires the standardization of vital statistics across different states and the Federal Government. Modernizing the MVSL will help to ensure that there is an automated procedure for updating vital record systems. The Model Vital Statistics Law has not been updated in 20 years and it does not adequately address automation of data entry and linkage or guidance on when and how data should be shared.

In 2011, a Draft Model Law was proposed with the intention of improving data security and confidentiality surrounding national vital statistics, including birth and death records. The draft law would also make the entire data entry process more uniform, standardizing records and facilitating interoperability of vital statistics records, and would transition away from the use of paper records toward a more complete digital platform, leading to more easily accessible data. The Draft Model Law was developed by the Model Law Revision Work Group, made up of members of the Centers for Disease Control and Prevention (CDC) and state health departments. The revision has not yet been passed into law, and is being championed by National Association for Public Health Statistics (NAPHSIS), a non-profit organization focused on vital and public health statistics.

One potential benefit of an updated law is that it will facilitate the linkage of death records with data on opioid overdoses. Another is that it will greatly improve interoperability between health records systems at the state and local level.

Objectives	Stakeholders	Actionable Next Steps
Update Vital Statistics Laws	National Center for Health Statistics (NCHS) Members of Model Law Revision Work Group	CDC/NCHS to modify the proposed 2011 revision to update it to 2018 standards, in consultation with members of the Model Law Revision Work Group.
	National Association for Public Health Statistics (NAPHSIS)	NAPHSIS to champion need to revise MVSL for consideration in Congress.

Adopt Common Data Standards

Participants emphasized the importance of adopting common data standards. Common data standards enable policymakers and researchers to merge data from disparate sources, empowering them to develop solutions to time-sensitive public health crises. Participants pointed to successes like the National Information Exchange Model (NIEM) and the Common Data Model (CDM) developed through the Patient-Centered Outcomes Research Institute's PCORnet effort. These examples provide real-world guidance for how to design and implement common data standards.

Implementing Community-Driven Data Standards

National Information Exchange Model

Roundtable participants commonly referred to the **National Information Exchange Model (NIEM)** as a successful model of community-driven data standards. Originally developed by the U.S. Departments of Justice, Homeland Security, and Health and Human Services, NIEM "connects communities of people who share a common need to exchange information in order to advance their mission." When an organization buys into NIEM it agrees to use a "data-dictionary of agreed-upon terms, definitions, relationships and formats—independent of how information is stored in individual systems." This information exchange model helps to produce data that is higher quality, machine-readable, interoperable, and real-time.

The Federal Government also has recent experience developing and implementing government-wide data standards. The DATA Act (Digital Accountability and Transparency Act) of 2014 established common standards for federal spending data, known as the DATA Act Information Model Schema (DAIMS). Implementation of the DATA Act and the DAIMS has made federal spending data more accessible, searchable, and reliable.

Within the context of health and the opioid crisis, participants suggested starting with developing common data standards for Prescription Drug Monitoring Program (PDMP) data, which includes rich information about substance abuse but is not easily shared between states. The development of common data standards for PDMP data could serve as a proof-of-concept for future work to improve standards across the board.

Objectives	Stakeholders	Actionable Next Steps
Develop common data standards	HHS Office of the CTO	Establish a panel convened by the HHS Office of the CTO to evaluate the viability and value of a common set of data standards for PDMP data
	State Government Agencies Academic Institutions	Develop a beta common data standard and begin to implement it in HHS
		Use an iterative process that enables the panel to gather input and revise standards over time.
Codify common data standards for wider use	HHS Office of the CTO	Finalize and implement first version of common data standards across all HHS datasets

Provide Controlled Access to Sensitive Public Health Data

Participants recommended that HHS Office of the CTO could establish a working group to facilitate controlled access to sensitive public health data and encourage data sharing between government, clinical, and academic organizations. Access would be contingent upon a credentialing system for organizations committed to working to solve the opioid crisis. By providing access to sensitive data, the government could help incubate and accelerate data-driven solutions to the opioid crisis. Controlled access by way of credentialing - making sensitive data available to qualified researchers under controlled conditions - could function much like the system currently used with Human Subjects Research at Institutional Review Boards at universities across the United States. The credentialing process would include training on privacy, HIPAA, and related issues.

There is precedent for this approach to controlled data access in the Federal Government. The National Institutes of Health (NIH) currently oversees the Model of Infectious Disease Agent Study (MIDAS) program, which provides data access to credentialed universities to encourage collaborative and dynamic responses to outbreaks of infectious diseases. Additionally, SAMHSA has already taken steps toward this approach by issuing SAMHSA-4162-20, which states that certain data may be shared to qualified and credentialed researchers.

Objectives	Stakeholders	Actionable Next Steps
Develop the foundation for the controlled access program	HHS Office of the CTO	HHS Office of the CTO can convene current MIDAS partners to discuss the utility of an opioid-focused MIDAS-like working group.
	Current MIDAS Partners Centers for Disease Control and Prevention (CDC) National Center for Health Statistics (NCHS) National Institutes of Health (NIH)	The HHS Office of the CTO can specify the terms and conditions for a working group to develop a controlled access approach to opioid data, including how to respond to new and existing trends of the opioid crisis.
		Using the MIDAS program as a model, convene a controlled-access data working group. Determine which data would be required, and prioritize datasets for controlled access.
Begin granting access to sensitive opioid data	HHS Office of the General Counsel and Office of the CTO	Develop a credentialing system that would allow governmental and non-governmental organizations to apply for controlled access to sensitive government data. Begin with existing MIDAS members.
	HHS Office of the CTO	Implement the first version of the controlled access program for credentialed members of academia, private business, Federal Government, state governments, and non-governmental organizations.

Generate a Unique Patient Identifier for Health Data

Generating a unique identifier for each patient would greatly improve provision of healthcare as well as the development of policy and research pertaining to public health crises. Implementing such an identifier would provide practitioners with the best possible information when making decisions about treatment, prescription, and follow-up. Policymakers would be able to track and identify risk factors at the individual or regional level across time, space, and health intervention, providing them with unprecedented power to generate policies to reduce risks of overdose, ensure timely follow-up, and save lives. For example, if policymakers observed that individuals that attended specific medical or therapy clinics fared significantly better than their peers, policies could be developed to replicate the successes of those clinics at a larger scale.

HIPAA currently provides guidance for the creation of unique identifiers for health plans (HPID), employers (EID), and providers (NPI). These could serve as guidance for the development of a unique patient identifier. In 2012, the U.S. Department of Health and Human Services authored a white paper on unique health identifier for individuals, in which it proposed a legally mandated unique identifier for individual patients in the United States.

Objectives	Stakeholders	Actionable Next Steps
Beta-test the unique identifier	HHS Office of the CTO	Develop working model of unique identifier
	HHS Office of the CTO, SAMHSA, CDC, CMS	Merge unique identifier into multiple datasets and make datasets available to HHS Agencies
		Report findings of implementing unique identifier and propose iterative improvements
	HHS Office of the CTO, SAMHSA, CDC, CMS Academic Institutions State and Local Governments	Integrate iterative improvements and release data to credentialed academic institutions and state and local governments
Release unique identifier	HHS Office of the CTO	Finalize unique identifier and merge onto existing datasets available to HHS

CONCLUSION

The opioid epidemic is continuing to grow in scale and importance in the United States. Data is a critical tool in solving this deadly epidemic. Government agencies, academic institutions, nonprofit organizations, and private organizations are currently limited by a series of legal, cultural, and technical barriers to data sharing that hinder their ability to develop solutions to save lives.

The Roundtable on Data Sharing Policies, Data-Driven Solutions, and the Opioid Crisis convened dozens of experts to explore the possibilities and limits of data sharing, and identify successes and proposed solutions for using data to address the opioid crisis. One outcome of the Roundtable was to increase the participants' understanding of the issues and help foster new approaches. According to a survey conducted by CODE at the end of the Roundtable, participants indicated a substantial improvement in their familiarity with the limitations and possibilities of data-sharing, particularly with regard to developing data-driven policies and solutions to the opioid crisis. In addition to improving familiarity with the issues, the Roundtable helped to develop a common understanding across multiple HHS agencies, state and local governments, and non-governmental organizations.

While much of the day's discussions focused on sharing experiences and learned lessons, Roundtable participants also worked to propose actionable next steps that can be taken by HHS and other key stakeholders to better enable data-driven solutions to the opioid crisis. There is now an opportunity to implement these proposed next steps and transform how data is used and shared across the healthcare system.

ABOUT THE CENTER FOR OPEN DATA ENTERPRISE | The Center for Open Data Enterprise (CODE) is a 501(c)3 nonprofit organization based in Washington, DC. Its mission is to maximize the value of open government data as a public resource for economic growth, social good, and scientific research. Over the past several years, CODE has worked with the White House and numerous federal agencies to help them improve how they collect, publish, and apply data to better meet the needs of data users. For more information, please visit OpenDataEnterprise.org.

We welcome feedback on this report. Please send comments and inquiries to Jacob Lewis, Research Fellow, at jacob@odenterprise.org.

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PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community. PCORI funded the development of a distributed data network and common data model designed to address modern challenges to sharing health data for clinical research. For more information, visit PCORnet: The Patient-Centered Clinical Research Network.

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