



# Strengthened Community Partnerships for More Holistic Approaches to Interoperability Project June 2022 Policy Listening Session

June 28, 2022

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## Glossary

### **21<sup>st</sup> Century Cures Act Final Rule**

On May 1, 2020, the Office of the National Coordinator for Health Information Technology published the 21st Century Cures Act Final Rule in the Federal Register. The Final Rule provides enforceable requirements in support of one focus of the 2016 21st Century Cures Act—the interoperability (i.e., ability to easily exchange data between different technology systems) of electronic health records. These requirements standardize the ways electronic health information (EHI) is exchanged, ensure certified technology supplies secure and affordable data access, and define information blocking (i.e., deliberate action to interfere with the access, exchange or use of EHI) and what reasonable practices are not likely to be considered interference.

<https://www.healthit.gov/curesrule/>

### **All-Payers Claims Databases (APCDs)**

Large state databases that include medical claims, pharmacy claims, dental claims, and eligibility and provider files collected from private and public payers. APCD data are reported directly by insurers to states, usually as part of a state mandate.

<https://www.ahrq.gov/data/apcd/index.html>

### **Application Programming Interface (API)**

A software interface or connection between two applications.

<https://digital.gov/2013/04/30/apis-in-government/>

### **Certified Health IT**

The Office of the National Coordinator (ONC) Health IT Certification Program provides assurance to purchasers and other users that a system meets the technological capability, functionality and security requirements adopted by the U.S. Department of Health & Human Services.

<https://www.healthit.gov/topic/certification-ehrs/certification-health-it>

### **Data Modernization Initiative (DMI)**

Launched in 2020, CDC's DMI is a multiyear, billion-plus dollar effort to modernize core data and surveillance infrastructure across the federal and state public health landscape.

<https://www.cdc.gov/surveillance/data-modernization/index.html>

### **Data Use Agreement (DUA)**

An executed agreement between a data provider and a data recipient that specifies the terms under which the data can be used.

[https://csrc.nist.gov/glossary/term/data\\_use\\_agreement](https://csrc.nist.gov/glossary/term/data_use_agreement)

### **Electronic Health Record (EHR)**

An electronic record of the administrative and clinical data associated with a patient's care.

<https://www.cms.gov/Medicare/E-Health/EHealthRecords>

### **Emergency Management Assistance Compact (EMAC)**

A mutual aid compact that serves as the base of emergency aid across the nation. EMAC helps during governor-declared states of emergency or disaster by allowing states to send personnel, equipment, and commodities to assist with response and recovery efforts in other states.

### **Fast Healthcare Interoperability Resources® (FHIR®)**

A Health Level Seven International® (HL7®) standard describing data formats and elements and an API for exchanging healthcare information.

<https://www.hl7.org/fhir/>

### **FHIR Bulk Data Access (Bulk FHIR)**

A FHIR-based API designed to exchange large analytical datasets, making it easier to access data on groups, cohorts and populations.

<https://www.cdc.gov/surveillance/pubs-resources/dmi-summary/overview-hl7.html>

### **Health Information Exchange (HIE)**

A system that allows healthcare professionals to appropriately access and securely share a patient's medical information electronically.

<https://www.healthit.gov/topic/health-it-and-health-information-exchange-basics/health-information-exchange>

### **Health Level Seven (HL7) International**

A standards-developing organization dedicated to describing standards for exchange of electronic health information.

<https://www.hl7.org/>

### **Prescription Drug Monitoring Program (PDMP)**

An electronic database that tracks controlled substance prescriptions in a state to provide health authorities timely information about prescribing and patient behaviors that contribute to the Opioid Overdose Epidemic, helping to facilitate a nimble and targeted response.

<https://www.cdc.gov/drugoverdose/pdmp/index.html>

### **Prescription Monitoring Program Gateway (PMP Gateway)**

A platform that makes accessing PDMP data easy for physicians and pharmacists by integrating the data directly in the clinical workflows of EHRs, pharmacy management systems and health information exchanges; the PMP Gateway increases utilization of the data, resulting in improved patient safety and greater compliance with state PDMP requirements.

<https://apprisshealth.com/solutions/pmp-gateway/>

### **Ryan White Comprehensive AIDS Resources Emergency Act (Ryan White CARE Act)**

An act of the U.S. Congress that made federal funding available through contingency grants to states for low-income, uninsured and under-insured people to be treated for HIV.

### **Substitutable Medical Applications, Reusable Technologies on FHIR (SMART on FHIR)**

A FHIR-based API used to integrate EHRs with applications.

<https://smarthealthit.org/>

### **The Office of the National Coordinator for Health Information Technology (ONC)**

A division of the Office of the Secretary, within the U.S. Department of Health and Human Services, dedicated to health information technology and the promotion of standards-based health information exchange.

<https://www.healthit.gov/>

### **Trusted Exchange Framework and Common Agreement (TEFCA)**

An agreement that will establish a floor of universal interoperability across the country; TEFCA will establish the infrastructure model and the governing approach for users in different networks to securely share basic clinical information with each other—all under commonly agreed-to expectations and rules and regardless of which network they happen to be in.

<https://www.healthit.gov/topic/interoperability/trusted-exchange-framework-and-common-agreement>

### **U.S. Core Data for Interoperability (USCDI)**

A standardized set of data elements and classes used for health information exchange.

<https://www.healthit.gov/isa/united-states-core-data-interoperability-uscdi>

## Executive Summary

The CDC Foundation is partnering with public health, healthcare and other interested parties to define, prioritize and test ways that public health can leverage new data standards outlined in the 21st Century Cures Act to access well-processed, up-to-date information on cohorts and populations more efficiently. Access to these data can drive decision-making, inform the public more quickly and with greater precision, and build a transformational nationwide approach to public health informatics.

Through the Strengthened Community Partnerships for More Holistic Approaches to Interoperability Project (CDC Foundation Interoperability Project), the CDC Foundation is conducting a series of listening sessions to identify policy, operational and technical considerations to facilitate public health participation in a federated data system via the SMART/Health Level Seven International (HL7®) Fast Healthcare Interoperability Resources (FHIR®) Bulk Data Access (Bulk FHIR). On June 28, 2022, the CDC Foundation convened legal experts who advise state, tribal, local and territorial (STLT) partners on data sharing matters for a moderated listening session. The meeting objective was to gain insights into policy and legal challenges to exchanging public health data and improving interoperability. Experts were asked to share individual experiences within their respective jurisdictions in adopting new standards and other data modernization efforts. Specific topics included: (1) key policy or legal issues that either challenge or facilitate public health data exchange; (2) current trends, practices and experiences of individual public health entities; and (3) major lessons learned, useful resources or noteworthy successes.

Observations across eleven themes emerged from the discussion of these subjects. The first six themes summarize potential policy and legal challenges related to public health data exchange that the participants have observed. The remaining five themes describe possible options participants discussed to facilitate more effective data exchange across jurisdictions.

Challenges that have been observed by one or more participants:

1. Many current privacy and reporting laws differ widely from state to state and region to region, creating potential challenges to reach consensus on the parameters of data sharing, particularly across jurisdictions.
2. Many existing state and local laws and policies that pertain to privacy and reporting may need to be updated to contemplate the current or future state of data collection and sharing.
3. HIPAA can be misinterpreted as preventing data sharing, rather than outlining permissible data sharing, which can create barriers to public health's efforts to advance data modernization and interoperability.
4. It appears that patients' understandings of consent to share their data may be changing, but laws may not be keeping pace.
5. Tribal nations sometimes encounter barriers when they attempt to access health data that they have the authority to obtain.
6. With the COVID-19 public health emergency moving from the pandemic to endemic phase, there could be hesitancy to retain the temporary data sharing provisions enacted during the state of emergency.

Possible options to facilitate data exchange, as identified by one or more participants:

7. Involving attorneys early and often in the planning and discussion of contracts and data use agreements has potential to better align consideration of policy implications with the project goals. Addressing them in tandem may prevent loss of momentum or delays in implementation of the technology.
8. Engaging with vendors and contractors can, on occasion, create additional challenges (e.g., issues with exchanging data with a private entity, hesitancy for vendors to share data with each other). Be prepared to address these potential challenges.
9. Policies or laws at the federal level could be beneficial to standardize and facilitate data sharing across and among jurisdictions given the variety in state and local requirements.
10. Navigating data use agreements and fiduciary responsibilities can be time-consuming, but it is critically important work.
11. Look to key success stories that exemplify data modernization at their best and share lessons learned with other jurisdictions and agencies.

Legal experts working with STLT partners possess valuable insights into policy and legal challenges surrounding public health data sharing. Data modernization efforts require time, cooperation and legal engagement, from initial discussions through project completion. There may be challenges, but there are also historical examples of success that may provide lessons learned for current and future efforts. Building on the gains in flexibility made during the COVID-19 public health emergency, while also retaining the highest standards in data protection and integrity, is possible—with strong partnerships, ongoing engagement across jurisdictions and an openness to innovation.

## Project Summary

Through the Strengthened Community Partnerships for More Holistic Approaches to Interoperability Project (CDC Foundation Interoperability Project), the CDC Foundation is conducting a series of listening sessions to identify policy, operational and technical considerations to facilitate public health participation in a federated data system via the SMART/Health Level Seven International (HL7) Fast Healthcare Interoperability Resources (FHIR) Bulk Data Access (Bulk FHIR). Understanding these considerations is an essential step in understanding Bulk FHIR's potential to improve access to richer, more standardized population health data that is of value to public health.

## Purpose and Objectives

On June 28, 2022, the CDC Foundation convened legal experts who advise STLT partners on data sharing matters for a moderated listening session. The meeting objective was to gain insights into policy and legal challenges to exchanging public health data and improving interoperability. Experts were asked to share experiences within their respective STLTs in adopting new standards and other data modernization efforts. Engaging legal experts in this listening session provided an opportunity to learn about policy and legal considerations that facilitate, challenge or otherwise affect data modernization efforts.

## Opening Remarks

### Welcome

Brandon Tally, MPH

Vice President for Non-Infectious Disease Programs

CDC Foundation

As an independent 501(c)(3), the CDC Foundation unleashes the power of collaboration among the Centers for Disease Control and Prevention (CDC), philanthropic organizations, the private sector and individuals to promote public health. CDC Foundation recognizes the impact data modernization is having and will continue to have on the future of public health and is honored to support the field both as a strategic implementing partner and through its unique convening power.

With funding from and in partnership with CDC, the CDC Foundation's Interoperability Project is engaging public health, healthcare and other interested parties to uncover key insights related to the adoption of new standards and data modernization efforts by STLT organizations and agencies as outlined in the 21st Century Cures Act. While healthcare is currently working to meet regulatory requirements that support new and emerging healthcare technologies, public health is simultaneously seeking to leverage the resulting opportunities to provide access to timely, reliable and actionable information that can guide decision making and evaluate the impact of public health prevention and response activities.

Legal experts who advise STLT partners on data sharing have a crucial vantage point. Their collective wisdom and experience with existing data systems will help inform considerations



related to interoperability. Much progress has been made on this front, yet important factors remain to be considered. This listening session offers an opportunity to better understand the range, richness and variety of experiences around policy and legal matters that arise within this effort to exchange public health data and improve interoperability.

## Listening Session

During the moderated listening session, participants discussed the following questions, with additional insights prompted by the conversation.

1. Please highlight one policy or legal issue that you would prioritize as either a challenge or facilitator to improving public health data exchange and why?
2. What other key policy or legal considerations should public health entities be aware of when implementing interoperable health IT solutions or exchanging public health data generally?
3. We would like to understand current trends, practices and experiences of public health entities implementing data modernization initiatives and adopting new standards. Can you share what you are seeing either within your organization or within organizations you collaborate with?
4. Do you know of any particularly successful efforts in STLT organizations to implement public health data modernization initiatives?
5. In your experience, are there any lessons learned or surprise findings while implementing interoperable health IT solutions that you would like to share with us, or that other organizations could benefit from knowing about?
6. How useful have you found centralized systems (i.e., platforms serving as intermediaries) for electronic lab and electronic case reporting? Examples include the one provided by APHL and eHealth exchange. What are the benefits? Any key considerations or challenges?
7. We would like to understand your experience with data use agreements (DUAs). For instance, what situations have warranted their development? Restrictions, benefits or challenges of DUAs or master DUAs? Thoughts on the Trusted Exchange Framework and Common Agreement (TEFCA)?
8. Does the term “data interoperability” resonate with public health audiences? What are the top three things that public health audiences should know when it comes to the policy and legal considerations around data interoperability?
9. From a legal and policy perspective, are health systems ready to engage in data modernization efforts?

Captured below is a summary of high-level themes, additional participant comments and key takeaways from the discussion.

## Theme and Key Takeaways

### Challenges that have been observed by one or more participants:

**Theme 1. Many current privacy and reporting laws differ widely from state to state and region to region, creating potential challenges to reach consensus on the parameters of data sharing, particularly across jurisdictions.**

Participants noted that health privacy laws in the U.S. vary widely across municipalities, states, territories and federal entities—creating a web of privacy laws to navigate. This variability makes data sharing difficult, especially across jurisdictional lines and levels.

Additional participant comments:

- Privacy laws across jurisdictions are not in harmony. Some laws are very specific, while others are general. Some are specific to certain types of data, while others are not. Navigating this variation can pose a constant challenge.
- In circumstances where information has been successfully de-identified, sharing that data can still be difficult at the state and federal levels. This is due to numerous confidentiality laws, privacy laws and policies surrounding medical records.
- Tensions are possible between policies at the local level and state requirements. It works well when teams at the local and state levels partner to navigate the complexity of data sharing between each level, while ensuring that community trust and data independence/autonomy remain in place.

### Key Takeaways

Data modernization efforts will need to contend with the wide variation in health privacy laws across regions and jurisdictions. The number and diversity of these laws can slow or obstruct successful data sharing efforts, especially if different entities understand their operations as operating independently. Understanding and acknowledging the jurisdictional approach can help when navigating privacy considerations.

**Theme 2: Many existing state and local laws and policies that pertain to privacy and reporting may need to be updated to contemplate the current or future state of data collection and sharing.**

Participants noted that, generally, existing laws and policies outlining when and how health data can be shared pre-date current data-sharing needs and capacities. Many relevant laws have not been updated, resulting in outdated laws that govern modern data-sharing. While the U.S. health system works to continue to meet new interoperability requirements, in many instances, state and local laws have not yet been updated to reflect recent technological advances, emerging standards and related changes.

Additional participant comments:

- Laws currently governing health data were drafted prior to the level of electronic data sharing that exists today. These laws did not contemplate the need for data sharing in the ways that information technology has made possible today and in the future.
- Similarly, the risk assessments built into these older laws do not reflect how data is currently shared. Supporting today's health IT and data sharing systems is a complex endeavor, often requiring multiple public health agencies, healthcare institutions and

vendors. Older risk assessment models are not always equipped to take these multiple dynamics into account.

- Many laws need to be updated to better reflect current and future data-sharing needs and the kind of work being done right now around data modernization in public health to address those needs.

### Key Takeaways

Health information laws often trail behind the data needed and the mechanisms available for data exchange. Updating laws and policies to incorporate existing needs and technologies would help enable the legal system to better support public health data exchange.

### **Theme 3: HIPAA can be misinterpreted as preventing data sharing, rather than outlining permissible data sharing, which can create barriers to public health's efforts to advance data modernization and interoperability.**

Several participants commented that, since the 1996 enactment of HIPAA, many health officials and health lawyers have misinterpreted this federal law as prohibiting the sharing of health data. HIPAA outlines when and how data can be shared; it does not prohibit sharing altogether. Participants indicated that education and awareness are needed to change this cultural conversation around HIPAA.

Additional participant comments:

- An awareness campaign could help counter the widespread assumption that health data cannot be shared. Without such educational efforts, common misunderstandings of HIPAA could continue to impede data sharing and modernization efforts within public health.
- There are laws beyond HIPAA that also govern health data sharing, but HIPAA is the one law the public knows the most and around which the most assumptions are possible.

### Key Takeaways

Data modernization efforts would do well to include an educational campaign to change the public's—and public health's—perceptions of HIPAA. The law itself is not a barrier to modernization efforts; misunderstandings and narrow interpretations of this law are the primary challenges.

### **Theme 4: It appears that patients' understandings of consent to share their data may be changing, but laws may not be keeping pace.**

How and when patients provide consent to share their personal health data is often a cumbersome process. Consent is required at multiple steps because patient data can be used for multiple purposes (e.g., patient care and public health reporting). Participants discussed consent models and simplifying them to make it easier for patients who wish to share data to do so. A national effort led by Stewards of Change Institute and other partners is underway to create a consent utility too.

Additional participant comments:

- Patients today are often more willing to share data than current policies and practices assume.

- Consent needs to be streamlined, especially for members of the public who have expressed willingness to have their health data shared. Models that empower the patient to share data with whomever they choose, as well as opt-out models, can facilitate patient choice.
- When developing consent structures, planners need to account for the immense volume of health data currently being generated and what implications that has on consent.
- An important question remains: What are the privacy expectations for health data in other countries? Can those expectations and the policies governing them inform the U.S. approach to consent and privacy?

### Key Takeaways

Reassessing the consent process is key to improving data sharing. Given the current volume of health information available, patient consent at each step of the process can become impractical and burdensome. A cultural shift regarding privacy expectations around health information may already be underway.

### **Theme 5: Tribal nations sometimes encounter barriers when they attempt to access health data that they have the authority to obtain.**

Some participants observed that tribal nations, as sovereign nations, have the right to receive health data on their tribal members, yet they often face barriers when attempting to access this information. Federal, state and local officials are not always well-versed in their legal obligations to share these data with tribes.

Additional participant comments:

- The Government Accountability Office (GAO) recently released a report, "[Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access](#)" (March 2022), which found that tribal epidemiology centers across the U.S. are experiencing challenges accessing health data collected on tribal members.
- There can be confusion among some state and local officials about the effect HIPAA has on data sharing between tribes and state and local agencies. Tribes are public health authorities and can collect or receive data based on that authority.

### Key Takeaways

Removing barriers that tribes confront when trying to access health data on their tribal members could facilitate a more equitable approach to data modernization and interoperability. Educating local and state health officials on the legal basis and authority for sharing these data with tribes and tribal epidemiology centers could help address this challenge.

### **Theme 6: With the COVID-19 public health emergency moving from the pandemic to endemic phase, there could be hesitancy to retain the temporary data sharing provisions enacted during the state of emergency.**

During the initial stages of the COVID-19 public health emergency, emergency provisions were put in place for the greater good. This lessened barriers to accessing public health data and allowed health systems to respond more swiftly to the national crisis. A few participants commented that now that this emergency state is shifting, some jurisdictions and government agencies are becoming more restrained about sharing health data.

Additional participant comments:

- There can be hesitancy to share data with public health agencies if the entity generating and sharing the data is not certain that its information can be protected by the receiving agency.
- Having clearer and more concise laws and policies that outline how, when and why health data is shared for public health purposes could instill greater confidence in data modernization.
- During the COVID-19 public health emergency, providers and health systems used telemedicine in ways that benefited both patients and providers. Finding methods to maintain this level of flexibility would support public health and medicine across various health areas moving forward. For example, among the emergency provisions created, the permitted use of apps (e.g., FaceTime) for teleconferencing provided significant support for many local health departments with limited resources to invest in a telemedicine platform.

### Key Takeaways

During the COVID-19 public health emergency, the easing of certain privacy requirements demonstrated how swiftly and efficiently data can be shared for circumstances important to public health and providing healthcare, while maintaining an essential level of privacy. Easier access to telemedicine supported health departments and allowed patients greater access to providers. Finding ways to retain those gains made during the state of emergency remains important. A cultural shift among lawmakers and members of the public about the value of data sharing with public health may facilitate retaining such flexibilities.

### Possible options to facilitate data exchange, as identified by one or more participants:

**Theme 7. Involving attorneys early and often in the planning and discussion of contracts and data use agreements has potential to better align consideration of policy implications with the project goals. Addressing them in tandem may prevent loss of momentum or delays in implementation of the technology.**

Participants observed that contracting language around health data privacy is a complex challenge that requires legal expertise from the beginning. When each jurisdiction's laws are slightly different, creating an agreement between jurisdictions becomes difficult. Attorney leadership and engagement are key to success.

Additional participant comments:

- Boilerplate provisions that have nothing to do with the data sharing activity itself can be a barrier to successful data use agreements, especially multi-jurisdictional contracts, and vendor contracts. For example, indemnification provisions, clauses that transfer risk between contracting parties, often lead to unexecuted contracts.
- Some type of immunity or protection from liability, similar to that provided by the [Public Readiness and Emergency Preparedness Act](#), could alleviate the stress placed on the data-sharing agency and reduce the need for indemnification and other boilerplate provisions.

- Attorneys should comprise a key part of the sender and receiver teams when a new data sharing project is being considered. Their involvement from the outset can help teams to identify and resolve potential legal issues during the planning and implementation phases of the project.

### Key Takeaways

Waiting to bring an attorney into the conversation can cost valuable time, especially if a project inadvertently takes a direction that is not legally advisable. Prioritizing bringing legal expertise into the contracting process from the start of a technical project, including initial discussions, is essential to maintain momentum. To that end, jurisdictions can enable attorneys to engage directly with other attorneys, especially when constructing multi-jurisdictional agreements. Finding ways to alleviate liability concerns for agencies engaged in these agreements may mitigate the delays caused by boilerplate provisions.

**Theme 8. Engaging with vendors and contractors can, on occasion, create additional challenges (e.g., issues with exchanging data with a private entity, hesitancy for vendors to share data with each other). Be prepared to address these potential challenges.**

Vendors and contractors are key partners in data exchange and need to be included in solutions. Participants noted, however, that barriers to innovation can arise if these intermediaries take a one-size-fits-all approach to their platforms or lack the flexibility to allow some agencies to share more information and others less. For example, a vendor system may not be able to accommodate a state-specific data restriction policy, leaving that state unable to use the system at all. In addition, some vendors have not always been open to sharing data with one another, though the 21st Century Cures Act's [Information Blocking Rule](#) will help alleviate this issue. Finding solutions often takes time, but this is essential to innovative data exchange.

Additional participant comments:

- When vendors and contractors become involved in public health projects, complications in data sharing can reduce innovation and discourage new data sharing efforts. When vendors and contractors are positioned in the middle, states and other entities are forced to exchange data with a private entity, not with CDC or other government agencies; this insertion of intermediaries can be limiting from a legal perspective.
- Vendors sometimes struggle to create platforms that can accommodate both states with more flexible data sharing laws and states with less flexible laws. The result can be a one-size-fits-all product that does not meet states' needs well.
- Technology vendors often have business interests involved in keeping data and not sharing it with other vendors. This competitive element can hamper collaboration, especially since many IT platforms are controlled by private entities.
- Using one federal vendor to implement a federal standard could promote collaboration among jurisdictions by reducing vendor reluctance to share data. This model would be accessible to agencies and states and include language (legislative or otherwise) accelerating use of a federal standard.

### Key Takeaways

Data modernization and interoperability depend not just on public health's involvement, but also on the engagement of numerous private vendors and contractors supporting the work. Vendor and contractor engagement, while vital to project success, can complicate data sharing and the

laws surrounding it. The 21st Century Cures Act also is anticipated to offer relief on information blocking issues.

**Theme 9: Policies or laws at the federal level could be beneficial to standardize and facilitate data sharing across and among jurisdictions given the variety in state and local requirements.**

Participants discussed that a unified or more cohesive approach to data sharing may be difficult to implement at the state level given the variety in laws and policies across jurisdictions. Several stated that a federal law or policy could be one potential way to facilitate information sharing and streamline processes. This could enable STLT partners to communicate more effectively about health privacy and data sharing, come together around shared goals and reduce hesitancy about data exchange. One participant offered the Ryan White CARE Act as an example of federal law that provides uniform standards used by states.

Additional participant comments:

- State policies tend to create a piecemeal effect for data sharing efforts, making it difficult to work collaboratively.
- Federal laws that create a universal sharing of critical health information (e.g., vaccine information) could be a gateway to more effective data sharing.
- Alternatively, a national effort could be based on governors' authority.

**Key Takeaways**

A federal law could help facilitate easier data sharing and collaboration between jurisdictions. The Ryan White CARE Act is an example of a federal policy that sets uniform notification standards that states have used successfully to improve public health. While federal legislation may be impactful toward minimizing or eliminating the challenges arising from the variety of state and local data sharing laws and policies, considering public attitudes about such a strategic effort could help maintain the public's trust.

**Theme 10: Navigating data use agreements and fiduciary responsibilities can be time-consuming, but it is critically important work.**

Public health agencies often take time to navigate data sharing agreements, in part because they have a strong fiduciary duty to protect that data from misuse and must err on the side of caution. Data use agreements, while intended to protect patients and their health information, can become unmanageable and often discourage cooperation. In multi-agency agreements involving vendors, it is important to determine who is responsible for data security.

Additional participant comments:

- Public health organizations have a fiduciary duty to protect patients and their data. These agencies understand that if a data leak occurs, they may be held liable. This reality often contributes to the length of time it takes agencies to move forward with data sharing and can make them prone to caution when data sharing opportunities arise.
- Because negotiating data use agreements may take significant time, the data can be outdated by the time the agreement is executed.
- One possible solution is a master data use agreement that covers a range of activities, with task orders developed beneath those umbrella agreements for each specific exchange of data. These task orders can be processed more quickly.



- Data use agreements are not always necessary—for example, they may not be needed between local and state public health entities.
- Determining who bears final responsibility for data security on a given project becomes more complicated when platforms are controlled by private entities, which often seek limited responsibility.

### Key Takeaways

Determining who accepts final responsibility for data security and privacy when sharing data remains a challenge for public health and may cause delays. Concerns about reducing risk and the effort to ensure data stays safe across an entire platform or data environment frequently leads public health entities to avoid sharing data, simply because of the costs of a potential breach. Exploring methods to reduce this risk, minimize delays and encourage participation is key, as is the identification of solutions that go beyond traditional data use agreements.

### **Theme 11: Look to key success stories that exemplify data modernization at its best and share lessons learned with other jurisdictions and agencies.**

Participants noted that, while identifying barriers to data sharing is important, sharing success stories is equally valuable. Several listening session participants described projects that are making progress toward data sharing and interoperability. These projects are possible models for broader efforts.

#### Project examples:

- Along with other partners, Stewards of Change Institute is creating a consent-to-share patient consent utility tool to facilitate individuals' ability to consent to share their information. Bronx Regional Health Information Organization (RHIO) is on the workgroup team.
- An innovative project undertaken by Rush University Medical Center and the Chicago Department of Public Health created a data hub for COVID-19 information. This hub receives data from different electronic medical record systems across the city and pulls data directly from those records into the hub.
- CDC's Immunization Gateway (IZ Gateway) offers another example of how data sharing efforts can advance on a national scale. The IZ Gateway provides a central repository where immunization data is funneled and shared across jurisdictions.
- Georgetown University's Blackbox project has demonstrated successful interoperability practices for securely sharing HIV data.
- The general assembly of South Carolina has created a data warehouse with the Office of Revenue and Fiscal Affairs (RFA), providing a strong example of data sharing at the state level. RFA de-identifies health data, matches it with data coming from other state agencies, and then shares that de-identified information with researchers and others for improved health outcomes, if there are no conflicts with existing privacy laws. The budget proviso includes a list of all state agencies authorized to share data in this way with RFA.
- The state of Ohio is currently migrating its data onto a common platform that will make all data accessible in one place. Although siloed within that shared platform, this comprehensive data will become increasingly sharable and exchangeable. Projects emerging from this new resource (e.g., opiate response work) will be better equipped to consider the whole person, from employment status to child welfare to education and mental health services, rather than looking only at a single health issue, event or contact.



- The Emergency Management Assistance Compact (EMAC) is another successful example of how an interstate compact can facilitate the sharing of data.

## Conclusion

Legal experts who advise STLT partners on data sharing possess critical insights into policy and legal challenges to the successful exchange of public health data. As participants in the listening session noted, data modernization efforts must overcome barriers both in policy and culture for progress to be made. Building on the gains in flexibility made during the COVID-19 public health emergency and leveraging requirements in the 21<sup>st</sup> Century Cures Act, while retaining the highest standards in data protection and integrity, is an ongoing challenge that will require time, cooperation and continued communication in the months ahead.

Key takeaways from the listening session included the following:

- It is important to acknowledge that the wide variation in health privacy laws across jurisdictions can slow or hinder successful data sharing efforts, especially if different entities understand their operations as operating independently. Solutions will take time and may require forming strong multi-jurisdictional partnerships.
- Because health information laws often lag behind the data needed and mechanisms available for data exchange, updating these laws, where reasonable and feasible, could support data sharing.
- Data modernization projects need an educational and technical component. Changing the public's—and public health's—perceptions of HIPAA is important.
- Data sharing is expected to become more efficient if and when the consent process can be streamlined. Given the current volume of health information available, providing consent at each step of the process can be impractical for many patients.
- Removing barriers confronted by tribes when trying to access health data on their own tribal members can lead to more equitable data modernization and interoperability efforts.
- The easing of certain privacy requirements during the COVID-19 public health emergency demonstrated how data can be shared more efficiently. Finding ways to retain certain key gains made during the public health emergency remains important.
- Prioritize bringing legal expertise into the data sharing contracting process from the start and in initial discussions of a project. Enable attorneys to work directly with other attorneys, especially when constructing multi-jurisdictional agreements.
- Data modernization and interoperability depend not just on public health's involvement, but also on the engagement of numerous private vendors and contractors supporting the work. The 21st Century Cures Act should offer some relief by limiting the impact of vendors' possible hesitancy to share data with each other.
- A federal law could help minimize the effect of a sometimes-conflicting array of state, local, and territorial laws and policies on domestic data sharing. Public attitudes toward such a federal standard would be important to consider.
- Who accepts final responsibility for data security and privacy remains a perennial challenge and can contribute to possible delays in data sharing and an overall cautionary outlook. Finding ways to reduce this risk, minimize delays and encourage participation will help advance data sharing—including identifying solutions that go beyond traditional data use agreements.

Finally, while identifying barriers to data sharing remains necessary and important, sharing success stories is equally useful. The projects that listening session participants described offer useful examples and lessons learned, marking substantial progress toward data sharing and interoperability for the improvement of public health. These successes could serve as models for other data sharing efforts moving forward.

## Appendix A: Presenters, Participants and Observers

### Presenters

#### Welcome and Closing Remarks

Brandon Talley, MPH  
Vice President for Non-Infectious Disease Programs  
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### Participants

#### Michigan

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### Observers

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