

Building Governance: Leading Governance Practices to Support Effective Data Sharing

Public health is actively moving toward modernizing systems and processes with the goal of enabling faster and more responsive decision-making and intervention. Infectious diseases, such as COVID-19, call for health departments' ability to respond rapidly to emerging health threats. Similarly, chronic disease surveillance, disaster preparedness and response, and environmental health surveillance programs can benefit from these types of data modernization efforts. Trusted and safe data sharing among public health agencies and partners are critical to achieve goals for timely public health action.

Data governance, defined here as the **people, policies, and procedures that support how data are used and protected**,¹ enables effective data sharing. It sets the ground rules and expectations for all involved partners on what, how, when, where, and by whom data are shared. Health departments have existing structures in place to govern routine internal and external data sharing. However, many are looking for additional guidance and resources to enable larger, sustained data-sharing initiatives, particularly with new data partners. Shown below are examples of large-scale data-sharing initiatives with varying governance approaches that could be used to inform other public health data-sharing initiatives.

[Trusted Exchange Framework and Common Agreement \(TEFCA\)](#) establishes a shared set of principles, terminology, and conditions to facilitate the creation of a Common Agreement that promotes the nationwide exchange of electronic health information across various qualified health information networks.

[Multi-State EHR-Based Network for Disease Surveillance \(MENDS\)](#) is a distributed network funded by the Centers for Disease Control and Prevention (CDC) and led by the National Association of Chronic Disease Directors that uses electronic health record (EHR) data to produce timely prevalence estimates of chronic disease measures at both national and local levels.

[Clinical and Community Data Initiative \(CODI\)](#) is a CDC-funded and led project that connects individuals, processes, and information technology within clinical and community organizations to build trust, establish shared goals, and link data.

[National Patient-Centered Clinical Research \(PCORnet\)](#), funded by the Patient-Centered Outcomes Research Institute, is a network of networks that provides access to patient-centered clinical data for comparative effectiveness research.

¹ Adapted from *Finding a Way Forward*, AISP, p. 14, retrieved:
<https://aisp.upenn.edu/resource-article/finding-a-way-forward-how-to-create-a-strong-legal-framework-for-data-integration>

The adage **“data is shared at the speed of trust”** exemplifies the need to engage partners in a deliberate governance-building process that fosters trust and promotes transparency. **There is no perfect way to develop governance**—governance reflects the organizations sharing the data, the people requesting access to the data, and the type of data being shared. The group initiating the data sharing will have many decisions to make: the scope of what is being governed (e.g., internal data sharing within an organization versus external data sharing across a distributed network); the structure of the governing body (e.g., steering committee with subcommittees versus two-tiered governing body); the role of the governing body (e.g., decision-making authority versus advisory role); representation in the governing body (e.g., all partners are equally represented versus select members represent the interests of groups within the network); and many other aspects of governance.

There are some broad considerations that health departments should consider as they explore and develop partnerships that enable data-sharing for public health impact. Shown below are leading practices, tips, and considerations principally informed by the MENDS and CODI experiences in building governance.^{2,3} They offer a starting point; however, health departments should first reference the experiences and documentation of existing data-sharing networks within and external to their own department to inform their efforts in building governance.

Leading Practice	Tips and Considerations
<p>Co-create governance</p>	<ul style="list-style-type: none"> • Consider principles of equity in all aspects of governance (e.g., representativeness of data and membership of governing body). • Allow parties to develop a sense of ownership through active participation and contribution in developing governance. • Build consensus for a shared vision. The vision and purpose of an initiative shape its governance. • Clarify the scope of data sharing because it will dictate governance. Individuals at different points in the data lifecycle may not have the same scope in mind, and the lack of a clearly defined scope can lead to confusion and frustration. The scope may be updated over time, as needed, through a deliberative process with parties, but early agreement on the initial scope moves governance forward. • Communicate clearly and frequently. Creating governance and the infrastructure to support it will take time, resources, and patience. Keeping members apprised of changes in timelines, risks, and delays as they come up helps maintain engagement and trust.

² https://journals.lww.com/jphmp/fulltext/2024/03000/fostering_governance_and_information_partnerships.15.aspx

³ <https://phii.org/module-4/governance-model>



Leading Practice	Tips and Considerations
<p>Establish a unified governance body with regular cadence and communication</p>	<ul style="list-style-type: none"> • Establish a multi-functional governance body with diverse perspectives to balance individual viewpoints because it supports well-informed decision-making. • If possible, coordinate administrative tasks using an external group outside the formal governing body to assist with the day-to-day operation of the governance body. Support for planning and facilitating meetings, developing and maintaining governance documentation, and performing data analysis and modeling and other tasks frees up the governing body members to focus on the group’s vision alignment, strategy, and growth. • Create a consistent, predictable meeting cadence that allows members to build strong rapport with one another and solidify trust and partnerships. The frequency of meetings can be adjusted as necessary, but more frequent meetings are often necessary during the initiating phase. Consistent meetings and related communications maintain partner engagement in all aspects of governance (e.g., data system architecture, technology, regulatory/policy adherence). • Develop a shared language and understanding of governance. A common language is developed through agreements (e.g., data sharing and business agreement) and agreed-upon governance (e.g., governance documents). Detailed, well-documented policies and procedures establish clear expectations for participant engagement. • Facilitate an understanding of the types and volume of data to be governed because there may be conflicting federal, state, and local policies that may affect the technical infrastructure needed to extract, transform, and/or process the data.



Leading Practice	Tips and Considerations
Leverage legal support early	<ul style="list-style-type: none"> • Consult with legal representatives early in the process of establishing governance. Share the value case to build trust and create buy-in and support for the project. Legislation and legal policies governing health-related data can serve to promote or hinder data sharing, so engaging your organization’s legal staff will help to identify facilitating factors and potential risks sooner. • Uncover areas of opportunity to leverage time and resources. Your legal staff may be aware of existing data-sharing and business associate agreements that can be used to update or develop new agreements. • Maintain momentum by addressing legal needs early. Developing and executing legal agreements can take several months, depending on the complexity of the agreement, the number of entities involved in the agreement, availability of staff and resources, and other factors.
Ensure transparency	<ul style="list-style-type: none"> • Conduct timely, frequent, and transparent communications to address governance challenges. Open communication maintains trust and helps to sustain initiatives through times of uncertainty or conflict. • Be open about and take responsibility when mistakes occur. Owning and collaboratively resolving the missteps engenders a culture of accountability and responsiveness. • Maintain connection to the why behind the work. To earn credibility with members, adhere to established governance obligations and continually seek ways to add value to the partnership.
Build flexibility into policy	<ul style="list-style-type: none"> • Develop policy collaboratively and consider the impact on members. Allowing for flexibility avoids the pitfall of producing overly prescriptive policies in areas where homogeneity is not necessary. Inflexibility could result in some members enduring difficulty or extreme inconvenience in adhering to some policies, which could jeopardize participation and member support.



Leading Practice	Tips and Considerations
<p>Build flexibility into policy (cont.)</p>	<ul style="list-style-type: none"> • Reduce barriers to entry and participation in data sharing by creating policies that meet members where they are. Provide resources and ample time for all partners to fully understand the technical and non-technical components of the governance structure. Partners from research institutions and academic centers often have extensive experience with data sharing, but that is not necessarily true of all partners. • Establish criteria for the levels of flexibility needed. Some policies and procedures will require little to no flexibility (e.g., policies governing data security or adherence to superseding federal or state legislation); however, whenever possible, govern the what, not the how. Levels of flexibility possible within policy and procedures are as follows: <ul style="list-style-type: none"> ◦ No flexibility—Requires a precise policy and procedure with no deviation allowed by any partner. <i>Example:</i> Data suppression policy ◦ Moderate flexibility—Requires consistent outputs/ outcomes (the what) across partners but not specificity on procedure (the how). <i>Example:</i> Hardware and software selection ◦ High flexibility—Requires no uniformity, and responsibility can be delegated to the partner. <i>Example:</i> When and through what channels data products are shared within the organization • Consider the ethical use of the data. Decisions regarding flexibility and data sharing in general should be rooted in the value case for data sharing. The first question when entering into a data sharing project is whether the data should be shared.
<p>Grow strategically</p>	<ul style="list-style-type: none"> • Accept change as a natural part of governance. A strategic approach to governance and network growth helps maintain alignment with the initiative's vision and purpose. • Foster the momentum created in the collaborative process by routinely maintaining and updating governance. Regularly update governance documents, vision, and/or scope collaboratively with partners. The needs of partners and organizational conditions can change, and governance should change—as agreed to by the members—to accommodate these shifts.



Effective data sharing requires a deliberative and collaborative governance-building process that is representative of the needs and capabilities of partners. The MENDS resource [Getting to “Yes!”: Building Support for Using Clinical Data to Enhance Chronic Disease Surveillance](#) offers insights into laying the groundwork for creating value and use case(s) for using clinical data for chronic disease surveillance. It also raises questions to guide the development of a governance policy. Below, find more resources to build governance for effective data sharing.

Resources

- **Centering Racial Equity Throughout Data Integration Toolkit:**
<https://aisp.upenn.edu/centering-equity>
- **CODI Toolbox:**
<https://phii.org/module-4/governance-model>
- **Data Encyclopedia from Vermont Department of Health:**
https://www.healthvermont.gov/sites/default/files/documents/pdf/HS_Data_Encyclopedia.pdf
- **Data Sharing Guidebook from North Carolina Department of Health and Human Services:**
<https://www.ncdhhs.gov/ncdhhs-data-sharing-guidebook/open>
- **Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration:**
https://aisp.upenn.edu/wp-content/uploads/2022/06/AISP_Finding-A-Way-Forward_Final_6.16.2022_.pdf
- **Fostering Governance and Information Partnerships for Chronic Disease Surveillance: The Multi-State EHR-Based Network for Disease Surveillance:**
https://journals.lww.com/jphmp/fulltext/2024/03000/fostering_governance_and_information_partnerships.15.aspx
- **MENDS Governance Principles, Policies, and Processes:**
<https://chronicdisease.org/cphl/technical-assistance-hub/mends/project-resources/#flipbook-mends-governance-document-2/1>
- **Network for Public Health Law Technical Assistance:**
<https://www.networkforphl.org/request-assistance>
- **New Directions in Public Health Surveillance: Using Electronic Health Records to Monitor Chronic Disease:**
https://journals.lww.com/jphmp/Fulltext/2022/03000/New_Directions_in_Public_Health_Surveillance_.16.aspx
- **Public Health Informatics Institute Data Governance for Public Health e-Learning Tool:**
<https://rise.articulate.com/share/YFvntDOHKU8yOrXeVH59lJH7zZUfMkx5#>
- **Sustaining Research Networks: The Twenty-Year Experience of the HMO Research Network:**
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4371441>

For more information, contact: mends@chronicdisease.org

The “Improving Chronic Disease Surveillance and Management Through the Use of Electronic Health Records/Health Information Systems” project is supported by the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,800,000 with 100 percent funded by CDC/HHS. Disclaimer: The contents are those of the authors and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

