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## Fostering Governance and Information Partnerships for Chronic Disease Surveillance: The Multi-State EHR-Based Network for Disease Surveillance

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## Abstract

**Context:** Electronic health records (EHRs) are an emerging chronic disease surveillance data source and facilitating this data sharing is complex.

**Program:** Using the experience of the Multi-State EHR-Based Network for Disease Surveillance (MENDS), this article describes implementation of a governance framework that aligns technical, statutory, and organizational requirements to facilitate EHR data sharing for chronic disease surveillance.

**Implementation:** MENDS governance was cocreated with data contributors and health departments representing Texas, New Orleans, Louisiana, Chicago, Washington, and Indiana through engagement from 2020 to 2022. MENDS convened a governance body, executed data-sharing agreements, and developed a master governance document to codify policies and procedures.

**Results:** The MENDS governance committee meets regularly to develop policies and procedures on data use and access, timeliness and quality, validation, representativeness, analytics, security, small cell suppression, software implementation and maintenance, and privacy. Resultant policies are codified in a master governance document.

**Discussion:** The MENDS governance approach resulted in a transparent governance framework that cultivates trust across the network. MENDS's experience highlights the time and resources needed by EHR-based public health surveillance networks to establish effective governance.

## Keywords

chronic disease; distributed network; governance; informatics

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Electronic health record (EHR) data, when standardized and aggregated from multiple health care systems, offer a powerful resource to enhance public health surveillance. According to data from the Centers for Disease Control and Prevention (CDC) and the Office of the National Coordinator for Health Information Technology, 89% of adults and 96% of children visit at least 1 health care provider annually, and more than 90% of providers use EHR systems. Because of this participation, EHR data can be used to create robust representative population samples for persons with access to health care.<sup>1,2</sup> However, current access to EHR data by departments of health (DOHs) is limited. Although many jurisdictions receive electronic laboratory data on infectious disease cases,<sup>3</sup> few DOHs have access to the breadth of clinical data available in EHR systems for chronic disease surveillance. Although state laws mandate infectious disease case reporting, most states do not require reporting chronic disease information to DOHs.<sup>4</sup> Without a legal mandate, reporting clinical data on chronic disease is voluntary and triggers different statutory requirements, bringing with it governance complexity.

In the context of sharing EHR data, governance is a set of behaviors, policies, and standards that enables participants to exchange health information in a safe, secure, trustworthy, and reliable manner.<sup>5–10</sup> In an information-sharing partnership between health care and DOHs, governance defines the requirements of data-contributing organizations within a framework that is responsive to the statutes that regulate data sharing and the needs of data users. In parallel, governance supports developing a community of trust.<sup>11–13</sup> Although governance for data sharing is a topic of great interest to DOHs,<sup>14</sup> the public health governance literature is limited and focuses mostly on governance requirements. Furthermore, because each governance implementation is unique, there is no prescribed governance approach, and published descriptions of public health governance implementation are limited.<sup>9,15</sup> A 2014 systematic review defined 20 technical, system, political, legal, and ethical barriers that hinder data sharing that can be resolved through governance and trust building.<sup>16</sup> One key recommendation stemming from the broader domain of health information exchange is the need for a governance body and layers therein to address organizational, network, and data governance issues.<sup>11</sup>

This article presents practical guidance for implementing governance for data sharing based on the experience of the Multi-State EHR-Based Network for Disease Surveillance (MENDS). Funded by the CDC, MENDS is a pilot project coordinated by the National Association of Chronic Disease Directors (NACDD)<sup>17</sup> to test feasibility, develop potential mechanisms, and demonstrate the value of using EHR data to estimate chronic disease risk and prevalence. The MENDS governance experience offers lessons learned that can inform other public health surveillance initiatives that require sharing clinical data.

## Methods

The Public Health Informatics Institute (PHII), a program of The Task Force for Global Health, was contracted by NACDD to convene a governance body, develop a governance approach, and implement the MENDS governance framework in partnership with partner sites and members of the MENDS project team. MENDS is guided by a project team from NACDD, PHII, CDC's Division for Heart Disease and Stroke Prevention, Commonwealth Informatics (MENDS IT vendor), Harvard University Department of Population Medicine, and University of Massachusetts Lowell (MENDS technical partner) (see Supplemental Digital Content Table 1, available at <http://links.lww.com/JPHMP/B228>).<sup>18</sup> The MENDS IT vendor assists data contributors in software implementation, and the MENDS technical partner conducts advanced analytic activities.

## Provenance and timing

The MENDS project team selected a distributed network design<sup>15,19–22</sup> and began recruiting data contributors in August 2018 (Figure 1). A distributed network consists of a series of interconnected data-contributing sites, which is an attractive model because data contributors retain control of how their data are used while sharing information with DOHs.<sup>23</sup> Distributed networks are promising for sharing clinical data with DOHs because they allow data to be voluntarily queried by or exchanged with authorized users without sensitive details (eg, identifiers) leaving the site.<sup>5,24,25</sup>

Recruitment required 2 years, partially because the approach was altered to better accommodate recruiting organizations that hold clinical data on behalf of multiple health systems. The revised approach increased efficiency and adjusted scale. During the recruitment phase, potential data contributors expressed a desire for a network-wide decision-making body and for codified policies and procedures to clarify the requirements for data contributors. Recruitment delays contributed to delays with initiating the governance process. Governance planning began in fall 2019.

### Network membership

Five partner sites (“sites”) across the United States contribute data to MENDS (Figure 2). Partner sites are dyads of data contributor and data user organizations.<sup>17,18</sup> MENDS data contributors—AllianceChicago, Louisiana Public Health Institute/REACHnet, OneHealthPort, University of Colorado Anschutz Medical Campus and Health Data Compass, and Trustees of Indiana University and Regenstrief Institute—are health information organizations that aggregate EHR data from multiple health care organizations, typically to provide operational services, reporting, research, or other analytics. MENDS membership requires data contributors to implement the MENDS technical architecture. This process includes installing software, creating and populating a database based on MENDS’ common data model, and validating clinical data.

MENDS defined 2 types of data use (1) partner site data use between a data contributor and data user, and (2) network data use across multiple partner sites via the MENDS Coordinating Center (NACDD). For example, partner site data reflect the geographic catchment of the data contributor and may be a county prevalence estimate, whereas network data reflect the reach of multiple or all data contributors, such as a national prevalence estimate. MENDS data use occurs through the RiskScape visualization tool, the PopMedNet query tool, and data products using data accessed from RiskScape and PopMedNet. Within a partner site, data contributors typically use MENDS software to look at their own data, choose at least 1 data user organization (usually DOHs), set processes for partner site data access, and provide that/those data user organization(s) with authorized access to RiskScape and PopMedNet.

### Network and partner-site governance

MENDS selected a 2-tiered governance framework composed of 1 multifunctional network governance committee and locally managed governance activities within each partner site.

For the governance committee, each data contributor and data user from every partner site is required to self-identify 1 primary voting member and 1 alternate voting member (Figure 3). This 2-member structure balances the perspectives of the data contributors and data users. Governance committee meetings are open to other attendees but only members may vote. Materials are distributed to members for review prior to governance committee meetings to facilitate rich discussion. Voting is verbal and occurs only when a quorum of members is present based on Roberts’ Rules of Order.<sup>18</sup> Motions require a simple majority to pass; however, motions about data use or changes to governance processes require a unanimous

vote. Individuals from the MENDS project team attend in a nonvoting ex officio role. If a partner site departs MENDS, its governance committee membership is terminated.

Within a partner site, governance is driven by the requirements of the data contributor organization and the relationship with data users. The project team meets regularly with each data contributor to track implementation of the MENDS technical infrastructure, oversee data quality and validation, and support data use and access to MENDS' software.

During partner site implementation, local governance issues often emerged. For example, patient-level data are shared with a technical partner to generate modeled estimates, but a state statute applicable to one of the partner sites prohibits patient-level data sharing without additional approvals and agreements. To prevent agreement-related delays, an alternate process was developed to extract aggregate counts for modeling. At another partner site, the data contributor's agreement with participating health care systems lacked language-permitting use of data for public health surveillance and required use case-specific approvals for every data release. After evaluating potential solutions, the data contributor elected to amend its participant agreement to incorporate public health surveillance as an approved use, thereby removing the need for recurring approvals.

### Agreements

MENDS requires data contributors to share limited data sets as defined by the Health Insurance Portability and Accountability Act (HIPAA) or other local statutes or agreements.<sup>26</sup> Business associate agreements and data-sharing agreements (DSAs) were executed to define the parameters for data sharing and permitted uses. Business associate agreements and/or DSAs were executed between each data contributor and the following entities to facilitate sharing (1) NACDD; (2) Commonwealth Informatics, a technology vendor responsible for implementation and maintenance activities; and (3) the University of Massachusetts Lowell, a technical partner that provides advanced analytic services.

Additional DSAs were executed within some partner sites as part of data contributors granting access to the MENDS visualization and query tool for DOHs. Other data contributors had existing arrangements for sharing data with data users, so a DSA was unnecessary.

### Governance policies and procedures

The primary products of the governance committee are policies and procedures. Once developed, discussed with the governance committee, and approved, they are added to the MENDS master governance document.<sup>27</sup> The document, along with the governance committee description and meeting materials, is stored and managed using a secure online collaboration space to provide easy access for members and promote transparency.

The master governance document addresses many topics (Table), including how sections of HIPAA apply to MENDS. The project team drafts governance content with input from partner sites, which is then reviewed, modified as needed, and approved by the governance committee. The initial version of the master governance document was approved in October 2020. Version 2, added software governance content, was approved in June 2021.

## Results

The governance committee was charged with laying the foundation for long-term, broadly representative MENDS network governance. In August 2020, the inaugural governance committee meeting was convened (Figure 1). Virtual meetings were held monthly to establish policies and procedures and to approve governance documents. Meeting cadence evolved with the network's needs to bimonthly meetings (January 2022) and then quarterly meetings (July 2022) and will continue meeting as long as data are being shared through the MENDS network. Initially, meetings were not recorded to promote candid dialogue. However, as trust increased among the members, the governance committee approved the use of recordings to help members reference missed meeting discussions.

When MENDS recruited partner sites, the master governance document was essential because it captures partner-site requirements by defining, in detail, what, how, when, and with whom data can be shared and how resulting data can be used. Initial recruitment highlighted that some data contributors had limited experience sharing data for public health surveillance, which manifested as differing perspectives on the legal requirements and risks of MENDS participation. For some, the recruitment process has included familiarizing legal counsel with HIPAA's public health provisions.

Each data contributor has taken a different approach to engaging data users in the governance committee. For instance, 1 partner site rotates its voting authority among multiple DOHs. In contrast, other sites have selected 1 DOH as its data user with the intent of expanding to other DOHs in the future.

Members and alternates consistently attended governance committee meetings. Quorum was always met, and most votes were unanimous. In rare cases when consensus is not evident, decisions and votes are postponed until the committee reaches consensus. For example, a data security requirement discussion revealed variation in data contributors' technical infrastructures, which led to different perspectives. The topic was tabled, and a decision was made at the next meeting to require each data contributor to develop a data security plan that appropriately addressed the needs of its own technical environment.

During the development of MENDS governance, many questions surfaced related to the different types of data within MENDS. Before data types were well defined, early conversations about MENDS data were generally unproductive. Thus, MENDS data use guidelines were developed within the MENDS governance document to define the 6 distinct MENDS data types (eg, source data and MENDS network data).<sup>27</sup> For each MENDS data type, the appropriate level of access and security was defined (Figure 4).<sup>27</sup> Moreover, procedures had to be developed for any task that needed to be completed uniformly across partner sites because the MENDS network was new. Once developed, procedures for query distribution, data quality and curation, indicator validation, de-identification review of data products, and partner-site review of data products were tested and refined, when necessary, to improve efficiency.

A recurring challenge was matching governance processes and decisions to the tempo of ongoing technical implementation activities. Because MENDS technical and governance

implementations occurred in parallel, many unanticipated policy and procedural gaps surfaced that required rapid governance solutions. For instance, when the first partner site finished populating its database, it became evident that the governance committee needed to develop a robust data validation procedure. However, the resulting time required to create and vet a validation procedure exceeded expectations and delayed implementation. When issues like this occur, the project team (1) discusses the issue with the governance committee; (2) proposes potential solutions; (3) records the governance committee's decision or holds a vote; and then (4) integrates the policy changes or updates into the master governance document.

The governance committee has identified the following strategies for building trust within the MENDS governance framework to advance data-sharing efforts at a national network level:

### **Establish a single unified governance body**

Establishing a single, multifunctional governance body fosters transparency among partner sites by balancing perspectives between data contributors and data users and allowing both perspectives to have equal voice and vote. Through consistent meetings, governance committee members can build strong rapport with one another and solidify relationships. Operating a single governance body avoids delays incurred by creating subcommittees and the risk that they would generate controversial or problematic recommendations for the full governance committee. From questions and comments raised in the governance committee, members gain a working knowledge of the variations in data system architecture, technology, and regulatory concerns, and become aware of all aspects of network governance that might have otherwise resided in subcommittees. Notably, this approach favors partner sites engaged from the project outset; partner sites joining MENDS later in the implementation missed the formative governance development work.

### **Ensure transparency**

Timely, frequent, and transparent communications are critical in addressing governance challenges. Occasionally, the project team unintentionally provided inaccurate statements to the governance committee based on assumptions. In these situations, transparent communication with the governance committee is required to correct previous statements or clarify misrepresentations. Taking responsibility for missteps and their impacts demonstrates the project team's commitment to accountability and establishes a model for partner sites to openly share their own missteps or challenges.

### **Build flexibility into policy**

MENDS employs a continuum of flexibility to accommodate the variation across partner sites when developing policy, which mostly results from technical differences between data contributors. For a given governance topic, the level of flexibility is assessed in 3 categories: (1) no flexibility—requires an exacting policy and standard procedure with no deviation by all partner sites, (2) moderate flexibility—requires consistent outputs/outcomes across partner sites but not specificity on procedure, and (3) high flexibility—requires no uniformity, and responsibility can be delegated to the partner site. The rationale for

allowing flexibility in policy is compelling and avoids the risk that overly prescriptive policies in areas where uniformity is not required could create infeasibility or extreme inconvenience possibly jeopardizing participation and partner-site support. An example of a no flexibility policy is MENDS' cell suppression policy for small populations. MENDS set a nonnegotiable threshold for cell suppression at counts less than 11, in line with Centers for Medicare & Medicaid Services (CMS) Medicare policy.<sup>28</sup> Examples of moderate flexibility are server capacity and software installation. Instead of codifying the *how* of servers and software installation procedures, the policy focuses on the *what* of the required outcome, stating "partner sites shall provide and maintain an adequate technical environment for MENDS to function and install the MENDS software," without further specification. A high flexibility example where a requirement is entirely delegated to the data contributor is relationship management with health systems. This governance approach establishes network-wide standards while also offering partner-sites flexibility to meet requirements through the most practical and appropriate means for their setting.

### **Cocreate governance**

Perhaps the most critical lesson learned in developing a governance framework for a distributed network is achieving the right balance between what is preestablished by the project team and what is cocreated with the member organizations. Although MENDS did some early planning for governance, most of the governance framework was cocreated with the partner sites. An overly scripted framework would have lacked the aforementioned flexibility (the *what* vs the *how*) now considered essential to network operations. Cocreation also allowed data contributors and data users to feel a shared sense of ownership of the architecture they built.

### **Discussion**

MENDS has successfully established relationships and a governance framework to foster long-term data-sharing partnerships. Although partner sites naturally wanted to collaborate to improve chronic disease surveillance, operationalizing EHR data sharing depended on meeting HIPAA data-sharing guidelines and the requirements of data contributors' structural, security, and legal parameters. Through regular governance committee meetings, supported with legal agreements and robust governing documents, MENDS defined clear and transparent policies and procedures detailing how clinical data would be shared and used for chronic disease surveillance. Cocreated with partner sites, the 2-tiered governance framework is a flexible design that has helped address challenging governance issues throughout implementation. The MENDS experience highlights how governance is foundational to data sharing because it builds trust among data contributors and users while aligning them with a common vision of sharing clinical data for chronic disease surveillance.

Establishing MENDS governance took substantial time and resources and required significant support to bring appropriate content to the governance body for review and to facilitate decision making. The project team needed 6 months to plan before convening the governance committee, followed by a year of monthly meetings to develop and codify the necessary policies and procedures for MENDS to begin sharing data. The initial MENDS

work plan and complementary budget did not include time to establish governance or staff resources to facilitate governance, resulting in reorganization and timeline setbacks. Two years of steady governance activities have resulted in a strong foundation, preparing MENDS to build and execute a sustainability strategy for the network, potentially including new funding sources, new partner sites, and new functionality. Essentially, the process of developing governance infrastructure must be resourced to succeed.

Early on, the necessary and often complex topic of establishing a decision-making authority structure had to be addressed. Funders can possess an outsized influence on decision making; however, this arrangement assumes that funders are responsible for funding the project in perpetuity. In informatics projects, data contributors provide the data and the underlying IT infrastructure, which frequently reflects a larger cumulative investment than any funder-provided project resources. Furthermore, HIPAA requires health care systems and their business associates to apply necessary safeguards to protect health information, so data contributors are generally well informed and highly engaged in decision making concerning clinical data sharing because they carry the legal risk for project participation. Ultimately, investments from both sides are substantial and essential to project's success. MENDS addressed this tension by translating funder expectations into required network functions and participation requirements. Within those requirements, MENDS delegated decision-making authority to the governance committee. Although funder representatives consistently engaged in MENDS governance as ex officio members, they did not dominate network decision making. This decision-making model encourages sustainability because it accommodates future shifts in funders and diversified funding.

The MENDS experience is relevant to current federal efforts to develop national data networks for clinical and public health uses, known as the Trusted Exchange Framework and Common Agreement (TEFCA).<sup>29</sup> Essentially, MENDS is a network of networks model in which data contributors act as local networks that interconnect in support of chronic disease surveillance. Prior federal policies, such as the Health Information Technology for Economic and Clinical Health (HITECH) Act,<sup>30</sup> invested significantly in the development of enterprise systems deployed within health systems and local data-sharing networks.<sup>31</sup> Moving forward, efforts at the local level will presumably continue in concert with efforts at the national level to connect each node together to form a national fabric of data sharing. The governance for the national network is only just emerging; therefore, it remains unclear at this time whether national network governance will largely replace local network governance or whether the national model will serve more as a global connector. Either way, the MENDS model of architecting a governance bridge between local and national data aggregation and exchange efforts illustrates a path forward for health care and public health to work collaboratively for mutual benefit in the evolving health information marketplace. To promote MENDS sustainability, it will be important for the governance committee and project team to align with emerging national health information exchange standards such as TEFCA to inform the next iteration of governance policy and procedures.

Data aggregators have an important role in the future of public health's use of clinical data. For health care organizations enthusiastic about leveraging their data for innovative population health purposes, data aggregator-supported participation in projects such as

MENDS adds value. MENDS demonstrates the complex environment in which data contributors operate as data stewards, bound by legal agreements executed with their data owners (eg, health care providers). As TEFCA adoption progresses, having a common network agreement could benefit efforts such as MENDS if the national framework incorporates public health surveillance. Moreover, a national, common agreement could help more data owners connect to data aggregators without ad hoc approval processes from state and/or local public health authorities. Although not well defined, such an agreement should be a goal for efforts such as TEFCA to enable broad public health use of HER data to support health and well-being of populations.

The MENDS governance approach has at least 3 limitations. The team's governance approach was strongly influenced by the network's distributed design and may not be easily translated for use in data-sharing efforts with alternative structures. Furthermore, the governance issues tied to MENDS policies and processes reflect partner-site priorities and are not exhaustive. More governance issues are expected to emerge with MENDS that will cause the governance infrastructure to grow and evolve such that existing MENDS governance documentation may not contain policy or process solutions to new governance concern(s). Finally, other stakeholders may find the MENDS governance approach more layered or complicated than needed for their project, especially data-sharing efforts with fewer technical components, smaller observed population, and smaller geographic scale. However, lessons learned from MENDS, especially strategies for building trust, have widespread applicability.

## Conclusion

MENDS governance activities have forged a novel information partnership among health care systems, aggregators of clinical data, and public health. Although MENDS is still in the pilot phase and focused on chronic disease, it could be scaled up or expanded to support public health surveillance on myriad health topics (eg, social determinants of health). The cocreation of governance with partner sites, instead of unilaterally instituted policies and procedures, nurtured relationships, cultivated knowledge, and culminated in the creation of a flexible structure that can be expanded to include other public health surveillance targets. The MENDS pilot bears witness to the adage that health information exchange proceeds at the speed of trust. MENDS, as a governance example, highlights both the challenges and the enduring value created when public health and health care organizations share data to advance population health.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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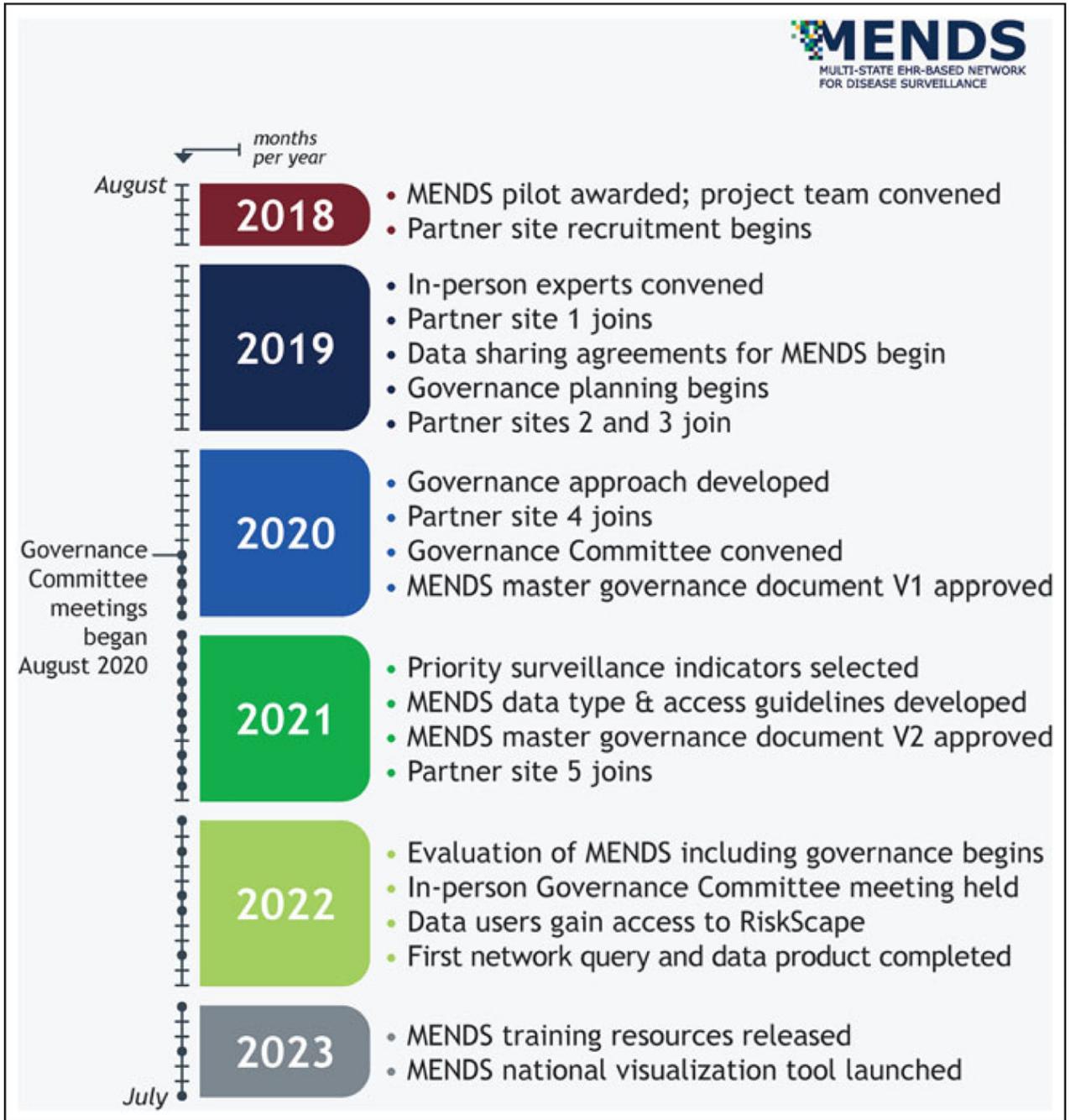
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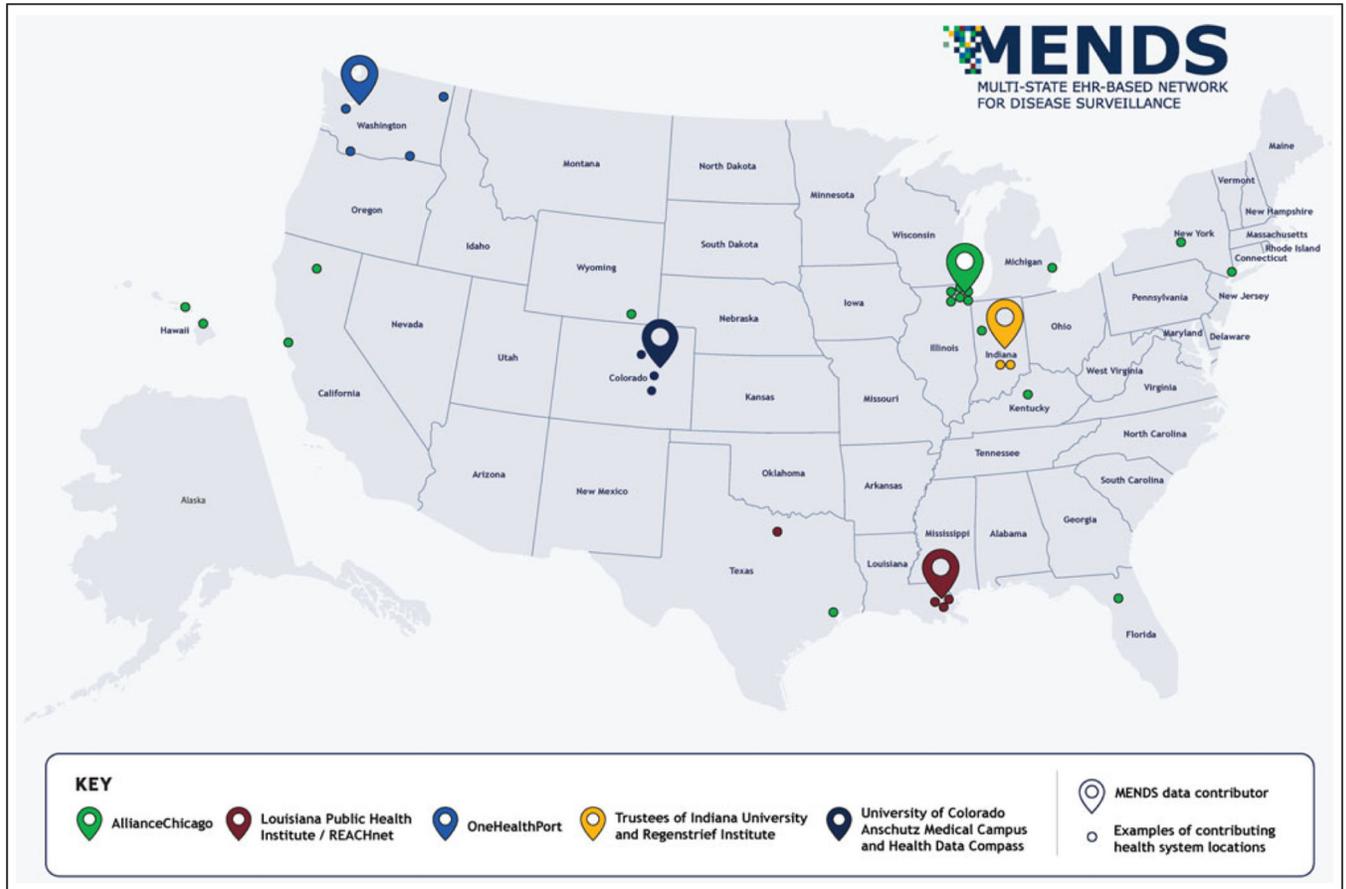


### Implications for Policy & Practice

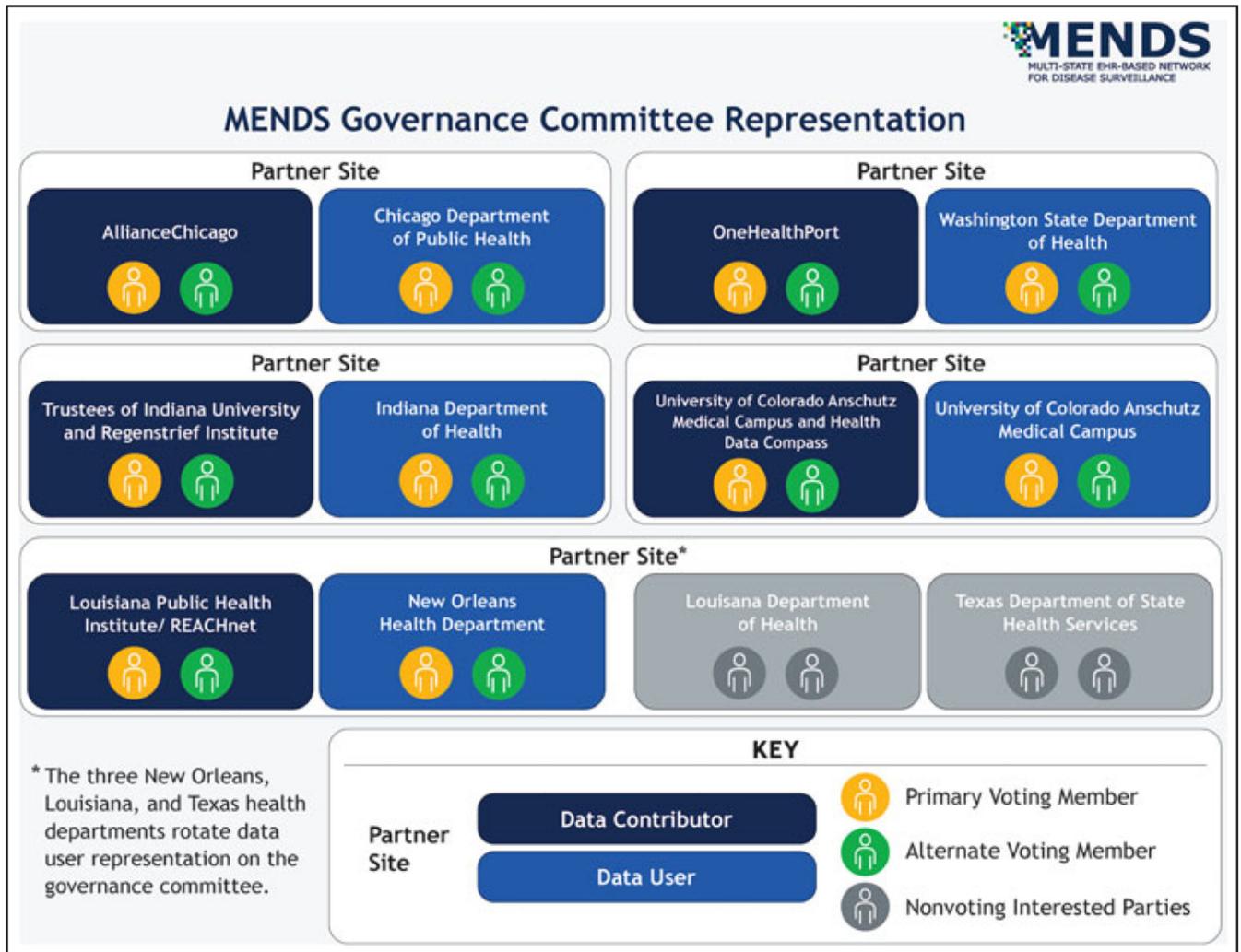
- An intentional governance approach that builds trust between data contributors and public health is critical when sharing data.
- Organizations that aggregate data on behalf of multiple health systems are valuable data-sharing partners because they offer data with greater population coverage that has already been harmonized and normalized across health systems. However, building a network with health data aggregators adds governance complexity, and, therefore, health departments have to be aware of established ways of working (eg, relationships, policies, procedures, and agreements).
- The cocreation of governance with partners nurtures relationships, cultivates knowledge, and can result in a flexible structure that can be expanded to meet emerging public health needs.
- The MENDS governance process illustrates challenges, lessons learned, and the enduring value created when public health and health care organizations share data for chronic disease surveillance efforts to advance population health.



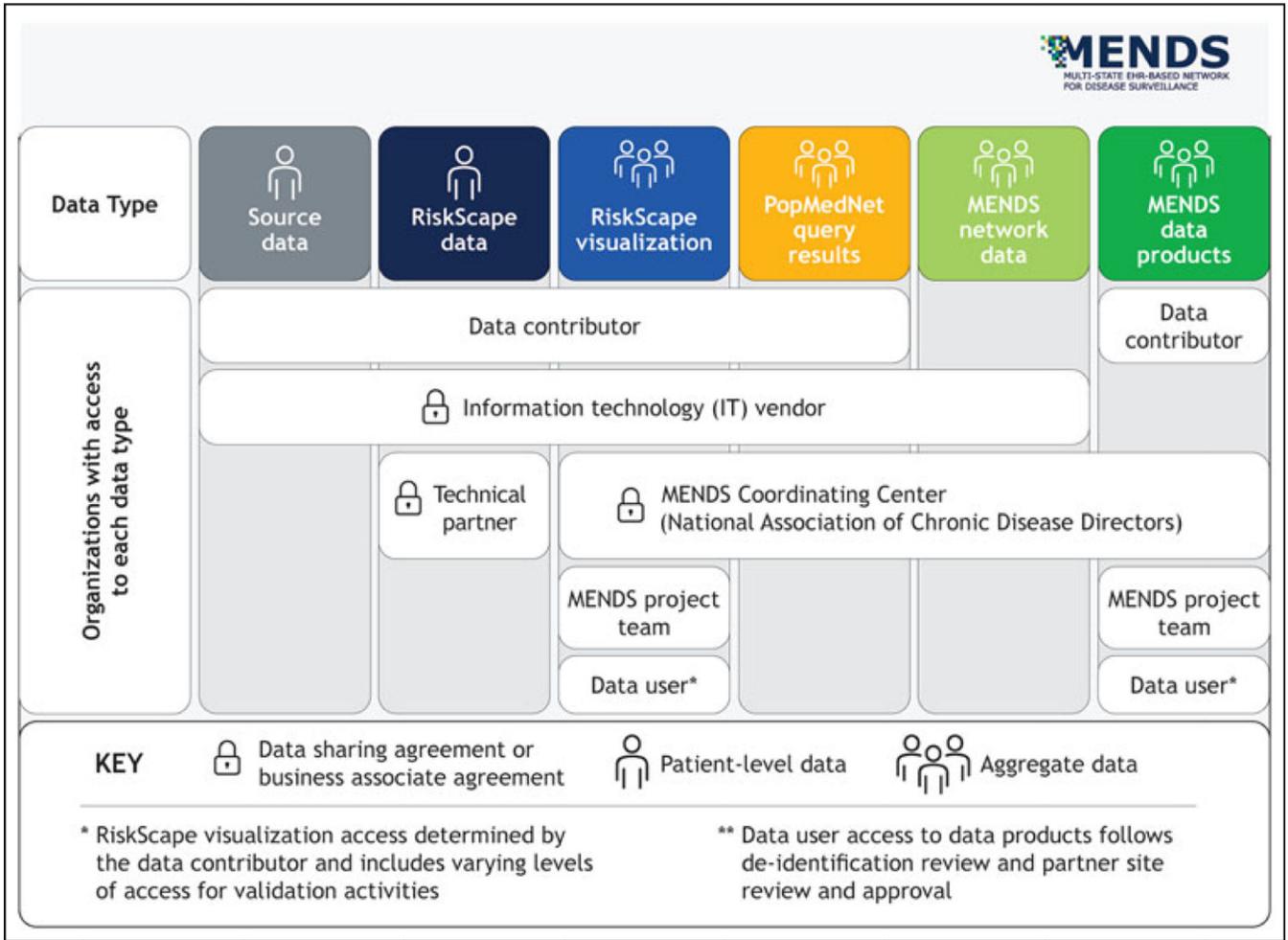
**FIGURE 1.**  
Timeline of MENDS Implementation and Governance Milestones  
Abbreviation: MENDS, Multi-State EHR-Based Network for Disease Surveillance.



**FIGURE 2.** Map of MENDS Data Contributors and Health System Partners<sup>a</sup>  
<sup>a</sup>Visual representation of health systems and examples and does not necessarily represent the exact location of all health care entities contributing data to MENDS.



**FIGURE 3.** Composition of MENDS Governance Committee  
 Abbreviation: MENDS, Multi-State EHR-Based Network for Disease Surveillance.



**FIGURE 4.**  
 MENDS Data Type and Access  
 Abbreviation: MENDS, Multi-State EHR-Based Network for Disease Surveillance.

**TABLE**

**MENDS Master Governance Document Topics and Resulting Goals**

<b>Governance Topic</b>	<b>Topic-Specific Goal</b>
<i>Section 1: Data governance</i>	
Data Use	Ensure that local, state, and national public health surveillance information produced by MENDS can be used by project stakeholders.
Data Timeliness	Ensure that MENDS surveillance can be conducted on data that are as near-real time as possible.
Data Quality and Validation	Ensure that MENDS generates the highest quality surveillance information.
Data Suppression and Privacy	Protect the identity of data partners and the privacy of individuals whose data are contributed to MENDS.
Representativeness	Generate surveillance information that prioritizes representativeness of the underlying population based on all available sociodemographic and geographic data.
Advanced Analytics	Maximize the proper use of MENDS data for local and national surveillance, planning, and evaluation by applying statistical tools and complementary data.
Reproducibility and Acceptability	Ensure that surveillance estimates meet acceptable standards and best practices of data quality and presentation.
<i>Section 2: Software governance</i>	
Software Installation and Training	Achieve complete installation, testing, and training of Electronic Medical Record Support for Public Health and PopMedNet across all MENDS partner sites.
Source Data and MENDS Common Data Model	Build and populate a datamart based on the MENDS common data model specification using source data at each data contributor.
Electronic Medical Record Support for Public Health	Use Electronic Medical Record Support for Public Health to analyze clinical data to identify conditions of interest.
PopMedNet	Maintain PopMedNet connectivity within the partner site (between the data contributor and data user) and at the network level (between the data contributor and the data coordinating center).
PopMedNet Queries	Use PopMedNet queries to generate chronic disease surveillance information within MENDS partner sites and across the network.
RiskScape	Use RiskScape to visualize surveillance information within MENDS partner sites.
Security	Ensure the security of data and software at each MENDS partner site and the larger MENDS network.
Software Maintenance and Enhancement	Ensure that MENDS software is proactively maintained to preserve continuity of network functionality.

Abbreviations: MENDS, Multi-State EHR-Based Network for Disease Surveillance.