NATIONAL ASSOCIATION OF CHRONIC DISEASE DIRECTORS
Promoting Health. Preventing Disease.

MENDS
MULTI-STATE EHR-BASED NETWORK FOR DISEASE SURVEILLANCE

Getting to YES!

Building Support for Using Clinical Data to Enhance Chronic Disease Surveillance

Public health departments are increasingly interested in expanding their chronic disease surveillance portfolio to include clinical data. Clinical data may allow them to access community-level data more quickly and frequently than using traditional population surveys such as the Behavioral Risk Factor Surveillance System.

Clinical data from electronic health records (EHRs): (1) are more timely and contain greater clinical and medical detail; (2) contain structured and standardized information; (3) contain geographically granular attributes; and (4) are longitudinal in nature—making them an attractive data source. These data offer more objective detail on many chronic conditions and can allow repeated individual-level measures to evaluate change over time.

Despite this compelling value case, implementing the use of clinical data to enhance chronic disease surveillance can be challenging. This document describes some potential challenges health departments might encounter in the domains of partnership development, data access, technical capacity, and data use. In addition, it offers guiding questions that health departments can explore with their partners to facilitate sharing clinical data.

Considerations

Preparing to use clinical data for surveillance calls for health departments to carefully consider and respond to several possible issues, preferably by incorporating potential solutions into a detailed implementation plan. Transforming clinical data for surveillance is akin to building a new surveillance system and rarely succeeds without an intentional planning process.

A secondary planning consideration is building consensus across various health department perspectives. Health department decision-makers need to agree that they can use clinical data effectively in existing or planned efforts and assure themselves that the clinical data would provide actionable insights and value to inform public health decisions.

In addition, health departments will need to make the value case to external partners, such as data-contributing organizations. It may be necessary to articulate public health roles and responsibilities, how public health surveillance data are collected and used, and ways clinical data can complement traditional surveillance data and advance public health's mission.

RESOURCES

Health departments can leverage a number of relevant NACDD resources to make the value case, such as "Transforming Clinical Data for Hypertension Surveillance: A Use Case of the Multi-State EHR-Based Network for Disease Surveillance (MENDS)" and other MENDS pilot project resources.

Finally, health departments must be willing to commit the needed time and resources to make using clinical data for chronic disease surveillance a reality. To prepare, it is important to consider the questions data-contributing organizations and other technical experts will need to answer for themselves: (1) Do we want to do this? (2) Can we do this? (3) How will we do this?

Health departments will also need to consider the governance structures within and across organizations that can support this type of data-sharing and sustained information partnership. Moreover, partners in other areas of the health department may already be experienced in implementing similar initiatives and able to share internal knowledge. Intentional planning is part of getting to "YES!"

When considering each domain below, a discussion of the associated key questions can serve as a first action step toward using clinical data to enhance chronic disease surveillance.

Potential Challenges by Domain	Key Questions to Address
Partnership Development Healthcare organizations (e.g., health information exchanges (HIEs), health systems, and clinics) are not legally required to share clinical data about chronic disease in most jurisdictions; such data sharing is voluntary. This often necessitates formation of a trusted information-sharing partnership between health departments and healthcare organizations, built around a compelling value case for both entities. Such partnerships take time to formalize and require dedicated resources to maintain or grow.	• Which and how many healthcare organizations will share clinical data with our health department? • Are other areas of our health department doing this type of work or partnering with any healthcare organizations to whom we could reach out? • Who are the primary points of contact at the data-contributing organizations? Who will be the primary points of contact at our health department? • Does the data-contributing organization itself desire access to the EHR-based surveillance information? • How often will we meet with data-contributing partners about this work? • Who at our health department is responsible for managing the relationship with each data-contributing partner? • How will collaborative decisions about data use (i.e., governance) be made? • How will we monitor the activities and results of our partnership? • Do the healthcare partners have goals that could also be accomplished with data-sharing partnerships?

Potential Challenges by Domain	Key Questions to Address
Data Access Healthcare organizations extract data using manual and/or automated processes. Developing and implementing these processes, including navigating the administrative processes and approvals, takes time and effort. Healthcare providers are bound by law to keep health information secure by limiting access to clinical data to authorized users and defined uses. Data security considerations trigger additional requirements for recipient health departments.	• Have data analytic experts looked at the data or performed analytics, and, if so, for what purpose? What questions are being asked based on that review of data? • What are the desired elements, criteria, and format for the shared dataset? • Does the clinical dataset have identifiers or protected health information? If so, how will that be handled? • How and how often will the clinical data be transmitted to our health department? • Who at the data contributor is responsible for extracting the clinical dataset? • Who at our health department is responsible for retrieving the clinical dataset? • How will the clinical dataset be stored at our health department, and how will access be managed? • Who are the legal experts to involve across parties (e.g., health department; health system and/or clinic; HIE, etc.)?
Technical Capacity Clinical data for chronic disease is significant in volume compared with infectious disease. Transforming volumes of clinical data from an EHR format into surveillance information often requires robust technical capacity. Clinical data must be cleaned, curated, and validated before they can be used for surveillance. A technical design responsive to the complexity of chronic disease data is needed to define, in detail, the necessary tools, resources, and processes to achieve the needed data transformation.	• What are the technical functions required to receive and process clinical data and generate surveillance data? • What are the existing technical infrastructure and capacity of our health department and its collaborators? How does the technical infrastructure/capacity need to be expanded to meet these functions? • How will the clinical dataset(s) be transformed into surveillance information? • What case definition will be used for each surveillance indicator and how will the complexity of case definitions be handled? • What data standards or parameters will be used for data transmission and transformation? • How will data quality in the clinical dataset be addressed? • What standards can be leveraged within this infrastructure?

Potential Challenges by Domain	Key Questions to Address
Data Use Because clinical data can inform so many health topics, health departments can struggle with where to start. Prioritizing an initial use case (e.g., hypertension prevalence) provides needed clarity about the end user, uses, and required clinical dataset. Compared with traditional public health data sources, clinical data are harder to use—requiring training and experience that take staff time to cultivate.	• What is the priority use case, and what surveillance indicators will be calculated? • What are the limitations of the data and how will partners consider and communicate the limitations? • What are the needed clinical data attributes for the surveillance indicators? • How can this surveillance information add value to and inform the actions of the chronic disease program? • How will surveillance estimates and the underlying clinical data be validated? • What governance infrastructure will support decision-making about current and future data use? • How will new use cases be identified, and how will partners be engaged in this process? • How will we disseminate surveillance information to partners, and what kinds of questions can we anticipate receiving based on this information?

Answers to the questions above can be the foundation of an implementation plan for a clinical data-based chronic disease surveillance system.

Yet these suggested questions are only a starting point; they are not an exhaustive list. In fact, answering these questions will undoubtedly raise more questions to consider. In addition, there is no one right answer for all health departments.

Instead, there are practical, feasible responses that work with each health department's infrastructure, resources, and partnership ecosystem. Success with using clinical data for chronic disease surveillance can result in additional chronic disease use cases and implementation learnings, implying the answers to these questions will change and evolve.

This initial planning exercise and the formalization of an implementation plan could mature into a data governance infrastructure that allows collaborative decision-making with partners across the discussed domains to advance chronic disease surveillance.

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