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

MENDS
MULTI-STATE EHR-BASED NETWORK FOR DISEASE SURVEILLANCE

Enhancing Chronic Disease Surveillance Using Electronic Health Record Data Toolkit

Data Modernization and Opportunities for Chronic Disease Surveillance

The Centers for Disease Control and Prevention's (CDC) Data Modernization Initiative (DMI) "is a multi-year, multi-billion-dollar effort to modernize data across the federal and state public health landscape." DMI has five key priorities, with the ultimate goal "to get better, faster, actionable insights for decision-making at all levels of public health." Although the focus of this initiative to date has been the identification and prediction of epidemics, there are significant opportunities for strengthening and enhancing chronic disease surveillance across the United States (US) as well.

The Multi-State EHR-Based Network for Disease Surveillance (MENDS) is a CDC-funded pilot project that leverages timely electronic health record (EHR) data to enhance chronic disease surveillance. MENDS fosters information partnerships between healthcare organizations and public health departments. This toolkit was developed by the National Association of Chronic Disease Directors (NACDD) from its experience with the MENDS pilot project to aid state, tribal, local, and territorial health departments in data modernization efforts to enhance chronic disease surveillance.

In this Toolkit,

users will find tip sheets, use case examples, and additional resources they can use to learn about how EHR data can enhance chronic disease surveillance and how to develop information partnerships; understand data governance issues, identify or create new electronic phenotypes for chronic disease measures, and consider epidemiologic methods for population estimates.

Understanding and Using Clinical Data

To prepare the public health workforce for data modernization that includes EHR-based chronic disease surveillance, NACDD and the Public Health Informatics Institute (PHII) created a series of three web-based, on-demand courses. The courses provide practitioners with an understanding of clinical data, how to use it for chronic disease surveillance, and an introduction to the MENDS pilot project that are available on the NACDD Learning Center. In addition to the course tools, multiple resources are also available to aid practitioners in increasing their knowledge and skills in this area.

Training Resources: Courses and Modules

Understanding Clinical Data: A Data User Perspective (course)

- **Module:** The Origins and Nature of Digital Clinical Data
- **Module:** Management of Clinical Data by Healthcare Organizations
- **Module:** Clinical Data Aggregation — Bringing Data Together to Advance Health
- **Module:** Governance — Building and Sustaining Trust in an Information Partnership

Using Clinical Data: Transformation into Chronic Disease Surveillance Information (course)

- **Module:** Understanding the Strengths and Limitations of Clinical Data
- **Module:** Getting Beyond the Limitations — Optimizing Clinical Data for Chronic Disease Surveillance

Introduction to the Multi-state EHR-based Network for Disease Surveillance (MENDS) (course)

- **Module:** MENDS — A Novel Approach to Chronic Disease Surveillance
- **Module:** Using RiskScape — A Powerful Tool for Visualizing Chronic Disease Prevalence

Training Resources

Online courses and modules have been created for public health practitioners to learn how clinical data can be used in public health surveillance, and to inform development and evaluation of interventions and policies.
Go to: chronicdisease.org/course-catalog

Resources:

- Carney, TJ, Wiltz, JL, Davis, K, Briss, PA, & Hacker, K. Advancing Chronic Disease Practice Through the CDC Data Modernization Initiative. Prev Chronic Dis. 2023;20:E110.
- CDC Public Health Data Modernization Initiative: Harnessing the Power of Data to Save Lives
- CDC Public Health Surveillance and Data: Data Modernization Initiative
- Hohman KH, Martinez AK, Klompas M, et al. Leveraging electronic health record data for timely chronic disease surveillance: The Multi-State EHR-Based Network for Disease Surveillance. J Public Health Manag Pract. 2023;29(2):162–73.

Resources *(continued)*:

- Klompas M, Cocoros NM, Menchaca JT, et al. State and local chronic disease surveillance using electronic health record systems. Am J Public Health. 2017;107(9):1406–12.
- Kraus EM, Brand B, Hohman KH, Baker EL. New directions in public health surveillance: Using electronic health records to monitor chronic disease. J Public Health Manag Pract. 2022;28(2):203–6.
- MENDS Project Summary: Three-page summary document
- Webinar: Using Clinical Data for Chronic Disease Surveillance to Improve Population Health (2023)

Making the Value Case—Chronic Disease Use Cases

State, tribal, local, and territorial health departments use a variety of standard disease and risk factor surveillance systems to find the data needed for decision making. Enhancing those surveillance systems using EHR data can be valuable to programs and organizations that aim to characterize community characteristics and disease burden. Creating a compelling value case for using EHR data can help decision makers understand the benefits of this approach while also becoming aware of the process, timeline, and challenges. Developing an effective value case for internal partners may be somewhat different than for the external partners who will provide the data. MENDS has developed example use cases specific to chronic disease and related factors that programs can use as they develop their own EHR-based surveillance efforts.

Tools:

- Hypertension Prevalence Use Case
- Asthma Prevalence Use Case

Resources:

- PHII Making the Value Case
- Carney, TJ, Wiltz, JL, Davis, K, Briss, PA, & Hacker, K. Advancing Chronic Disease Practice Through the CDC Data Modernization Initiative. Prev Chronic Dis. 2023;20:E110.
- Hohman KH, Martinez AK, Klompas M, et al. Leveraging electronic health record data for timely chronic disease surveillance: The Multi-State EHR-Based Network for Disease Surveillance. J Public Health Manag Pract. 2023;29(2):162–73.

Potential Use Cases for EHR-Based Data

To Improve the Health of the Population

Monitor Trends

Inform Policy

Plan Programs

Evaluate Outcomes

Planning and Partnerships

"Public health is an information business." (Kraus JPHMP 2022) State, tribal, local, and territorial health departments need to be able to make evidence-informed decisions leading to effective action, and access to timely, accurate, and granular information is critical to achieving that goal. Public health has a number of surveillance systems that inform chronic disease practice, but as data modernization efforts take hold, health departments will need to reach out and build new partnerships to compete in an informatics world. This effort will involve developing the appropriate informatics organizational infrastructure and workforce capacity, as well as identifying new partners that have relevant data. Although there are no "one size fits all" models to create an "informatics-savvy health department," there are many different key questions and challenges to consider in the planning stages.

Tools:

- Getting to Yes: Building Support for Using Clinical Data to Enhance Chronic Disease Surveillance

Resources:

- Kraus EM, Brand B, Hohman KH, Baker EL. New directions in public health surveillance: Using electronic health records to monitor chronic disease. J Public Health Manag Pract. 2022;28(2):203–6.

Governance

Data governance addresses the people, policies, and procedures that support how data are used and protected. Developing a strong data process enables effective data sharing and sets the policies and procedures for all involved partners. Many state, tribal, local, and territorial health departments already have structures in place that govern internal and external data sharing, but additional guidance may be required when developing partnerships and data sharing with external clinical partners or creating larger-scale data sharing initiatives. The actual structure and function of governance will depend on the organizations sharing data, the people involved, and the data that are being shared. Although it is unlikely that any two organizations will approach this in exactly the same way, there are some general considerations that can help build effective governance for enhancing chronic disease surveillance with EHR data.

Tools:

- Building Governance: Leading Governance Practices to Support Effective Data Sharing

Resources:

- Kraus, EM, Saintus, L, Martinez, AK, et al. Fostering governance and information partnerships for chronic disease surveillance: The Multi-State EHR-Based Network for Disease Surveillance. J Public Health Manag Pract. 2024;30(2):244–54.
- PHII Data Governance for Public Health e-learning resource

Developing EHR-Based Electronic Phenotypes for Chronic Disease Indicators

Advancing chronic disease surveillance efforts will increasingly require leveraging new data sources, including EHRs. Using EHR data to create electronic phenotypes of relevant chronic disease measures will help public health agencies address key public health surveillance gaps and better characterize population-level disease burden. A systematic process to identify or develop chronic disease electronic phenotypes will lead to more relevant and useful chronic disease measures to monitor and improve population health.

Tools:

- Developing Electronic Health Record-Based Electronic Phenotypes for Chronic Disease Indicators
- Algorithm Development Worksheet

Resources:

Hohman, KH, Zambarano, B, Klompas, M, Wall, HK, Kraus, EM, Carton, TW, & Jackson, SL. Development of a hypertension electronic phenotype for chronic disease surveillance in electronic health records: Key analytic decisions and their impacts. Prev Chronic Dis. 2023;20:230026.

Validation, Weighting, and Modeling

EHR data are collected primarily for billing and patient-level documentation and not for population-based surveillance. Therefore, issues of data quality and missingness can introduce analytic challenges. In addition, EHR data will provide information about a healthcare-seeking population and may not represent the population to which health departments want to generalize. Health departments that look to enhance their chronic disease surveillance efforts with EHR data should consider the need for appropriate validation, weighting, and modeling methods.

Resources:

Hohman KH, Klompas M, Zambarano B, Wall HK, Jackson SL, Kraus EM. Validation of Multi-State EHR-Based Network for Disease Surveillance (MENDS) data and implications for improving data quality and representativeness. Prev Chronic Dis. 2024; 21:230409.

Connect with MENDS

We hope that this brief toolkit encourages your organization to get involved with EHR-based chronic disease surveillance through a data-contributing partnership or use of MENDS tools and resources.

For questions, contact: mends@chronicdisease.org
To access additional information and resources, chronicdisease.org/mendsinfo

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