

A National Strategic Plan for Chronic Disease Surveillance Modernization

Transforming data systems to promote thriving, connected communities



CONTENTS

Executive Summary.....	3
Background and Overview	5
Strategic Plan Structure	12
Strategic Plan Goals	13
Strategies and Objectives	16
Appendix	25

EXECUTIVE SUMMARY

The U.S. Centers for Disease Control and Prevention's (CDC) Data Modernization Initiative (DMI) is a multi-year, multi-billion-dollar effort to modernize the public health data infrastructure across federal and state, tribal, local, and territorial (STLT) public health agencies. This work, initially born out of the Data Elemental to Health campaign in 2019, has led to significant gains contributing to “better, faster, actionable insights for decision-making at all levels of public health,”¹ but massive challenges, gaps, and vulnerabilities remain regarding chronic disease surveillance. Chronic conditions and risk factors are not tracked and reported in the same way as infectious diseases, which benefit from state-mandated reporting requirements, infrastructure for nationally notifiable diseases, and commonly accepted standards for electronic case reporting (ECR) and electronic laboratory reporting (ELR). Although state laws mandate infectious disease case reporting, most states do not require reporting chronic disease information to public health agencies, which introduces challenging legal obstacles for data access and use. Few public health agencies have access to the breadth of clinical data available in electronic health record (EHR) systems or lack standard processes for using the data for chronic disease surveillance. These challenges make it difficult for current modernization investments to notably improve the chronic disease surveillance landscape. In addition, chronic disease programs experience significant delays between data collection, availability, and use through traditional surveillance systems and are constrained by the high cost of technology upgrades needed to address outdated and siloed systems. These challenges create a significant burden on an already strained chronic disease workforce confronted with limited resources to modernize. While navigating challenging funding environments, complex policies, and siloed infrastructure, STLT jurisdictions continue to innovate and search for opportunities to connect and optimize data to improve community health and reduce disparities. Opportunity exists to build on STLTs’ strengths and accelerate coordinated action towards a more modernized chronic disease landscape.

¹ U.S. Centers for Disease Control and Prevention. 2024. Data Modernization Initiative. Available at: <https://www.cdc.gov/data-modernization/php/about/dmi.html>. (Accessed June 24, 2024).



The CDC Public Health Data Strategy (PHDS)² builds on the DMI and outlines specific actions and accountability metrics in two-year increments to meet CDC’s public health data goals. While the PHDS’s four goals are highly relevant for all public health data, its current 2025-2026 priorities primarily focus on acute disease, and address few of the unique challenges and opportunities of chronic disease surveillance or offer specific milestones related to chronic diseases. In November 2023, CDC’s National Center for Chronic Disease Prevention and Health Promotion (NCCDHP) published a set of six federal chronic disease data modernization priorities³, building on the foundation of the broader DMI and PHDS. These areas inform specific goals, activities, and opportunities for federal chronic disease data modernization efforts. This strategic plan builds on NCCDHP’s priorities to articulate STLT chronic disease data modernization priorities and connects federal initiatives with public health agencies’ needs and aspirations for improving their chronic disease surveillance landscape.

Modernizing chronic disease surveillance is crucial to effectively use data to identify and reduce the burden of chronic diseases in all communities. Key benefits include improved management of chronic disease programs, streamlined data exchange, enhanced communication and coordination across federal and STLT partners and cross-sectoral partners, and reduced healthcare costs. It is critically important to recognize that STLT jurisdictions are at different starting points regarding capacity, resources, leadership buy-in, and other factors that influence the uptake and success of collective modernization efforts. For these reasons, STLT jurisdictions and partners, convened by the Council of State and Territorial Epidemiologists (CSTE) have engaged in a collaborative process to design this comprehensive, multi-year strategic plan for chronic disease surveillance data modernization, based on the specific needs and aspirations for chronic disease across all levels of public health.

2 U.S. Centers for Disease Control and Prevention Office of Public Health Data, Surveillance, and Technology. 2024. The Public Health Data Strategy. Available at <https://www.cdc.gov/public-health-data-strategy/php/index.html> (Accessed July 15, 2024).

3 Carney, Timothy Jay et al. 2023. Advancing Chronic Disease Practice Through the CDC Data Modernization Initiative. Available at https://www.cdc.gov/pcd/issues/2023/23_0120.htm (Accessed July 15, 2024).

BACKGROUND AND OVERVIEW

Chronic diseases including cancer, diabetes, and heart disease represent 8 out of the 10 top leading causes of death in the United States.⁴ It is currently estimated that by 2050, most individuals 50 years and older will have one or more chronic conditions, adding further strain to public health's capacity to monitor, manage, and prevent them. The chronic disease burden is disproportionately felt across communities and research indicates that these health disparities continue to increase.⁵ Accurate and timely data on chronic diseases and lifestyle risk factors such as smoking, diet, physical inactivity, and substance use are essential to developing and sustaining effective prevention strategies and identifying and addressing disparities in chronic disease outcomes. Monitoring chronic diseases can notably improve prevention and treatment approaches for infectious disease as well. Chronic diseases are linked to an increased risk of adverse outcomes from infectious diseases.⁶ During the COVID-19 pandemic, individuals with chronic diseases were at an increased risk of severe illness although public health and healthcare lacked the necessary data to identify this disparity in a timely way.⁷ Access to timelier chronic disease data could have helped with hospital capacity planning as well as vaccine prioritization conversations by understanding populations most at risk for adverse health outcomes from COVID. Better and faster data can also support people living with chronic disease

by helping to quickly direct resources and more effective health messaging. However, the current chronic disease surveillance data ecosystem presents major challenges to the timely and accurate assessment of population health.

Chronic disease data live among many different and disparate sectors, including public health, health care, insurance, social services, which presents challenges to STLT jurisdictions trying to access data. Often, risk and protective factors and social determinants of health (SDOH) are shared by more than one chronic disease, but many conditions are monitored separately in siloed and disconnected systems or use outdated software for capturing, analyzing, and reporting data. Chronic disease surveillance is further challenged by limitations in timeliness, increases in data collection and acquisition costs, decreases in funding, and inadequate staffing. Modernizing the chronic disease surveillance landscape requires creative and integrated approaches to address these challenges.

Modernizing chronic disease surveillance can improve public health's ability to implement data-driven, impactful interventions, effectively reducing major causes of morbidity and mortality in the U.S. Furthermore, modernizing chronic disease surveillance can enable federal agencies and STLT partners to more effectively access and use existing data sources, improving their ability analyze data for informed decision-making and resource allocation. Public health agencies could

4 U.S. Centers for Disease Control and Prevention, National Center for Health Statistics. 2024. Mortality in the United States, 2022. Available at <https://www.cdc.gov/nchs/data/databriefs/db492-tables.pdf#4> (Accessed July 19, 2024).

5 Caraballo, Cesar, et al. Temporal Trends in Racial and Ethnic Disparities in Multimorbidity Prevalence in the United States, 1999-2018. *The American Journal of Medicine*, vol. 135, no. 9, 2022, pp. 1083-1092.E14. Available at <https://doi.org/10.1016/j.amjmed.2022.04.010> (Accessed July 19, 2024).

6 Badawi, A., Drebot, M., & Ogden, N. H. (2019). Convergence of chronic and infectious diseases: a new direction in public health policy. *Canadian journal of public health = Revue canadienne de sante publique*, 110(4), 523-524. <https://doi.org/10.17269/s41997-019-00228-x> (Accessed October 24, 2024).

7 Hacker KA, Briss PA, Richardson L, Wright J, Petersen R. COVID-19 and Chronic Disease: The Impact Now and in the Future. *Prev Chronic Dis* 2021;18:210086. DOI: <http://dx.doi.org/10.5888/pcd18.210086> (Accessed October 24, 2024).and Chronic Disease: The Impact Now and in the Future. *Prev Chronic Dis* 2021;18:210086.



gain rapid access to actionable public health data that can effectively address health inequities and support populations with achieving positive health outcomes. By enabling more effective data access and analysis, modernization can empower public health agencies and partners to make informed decisions, ultimately leading to better health outcomes for all communities.

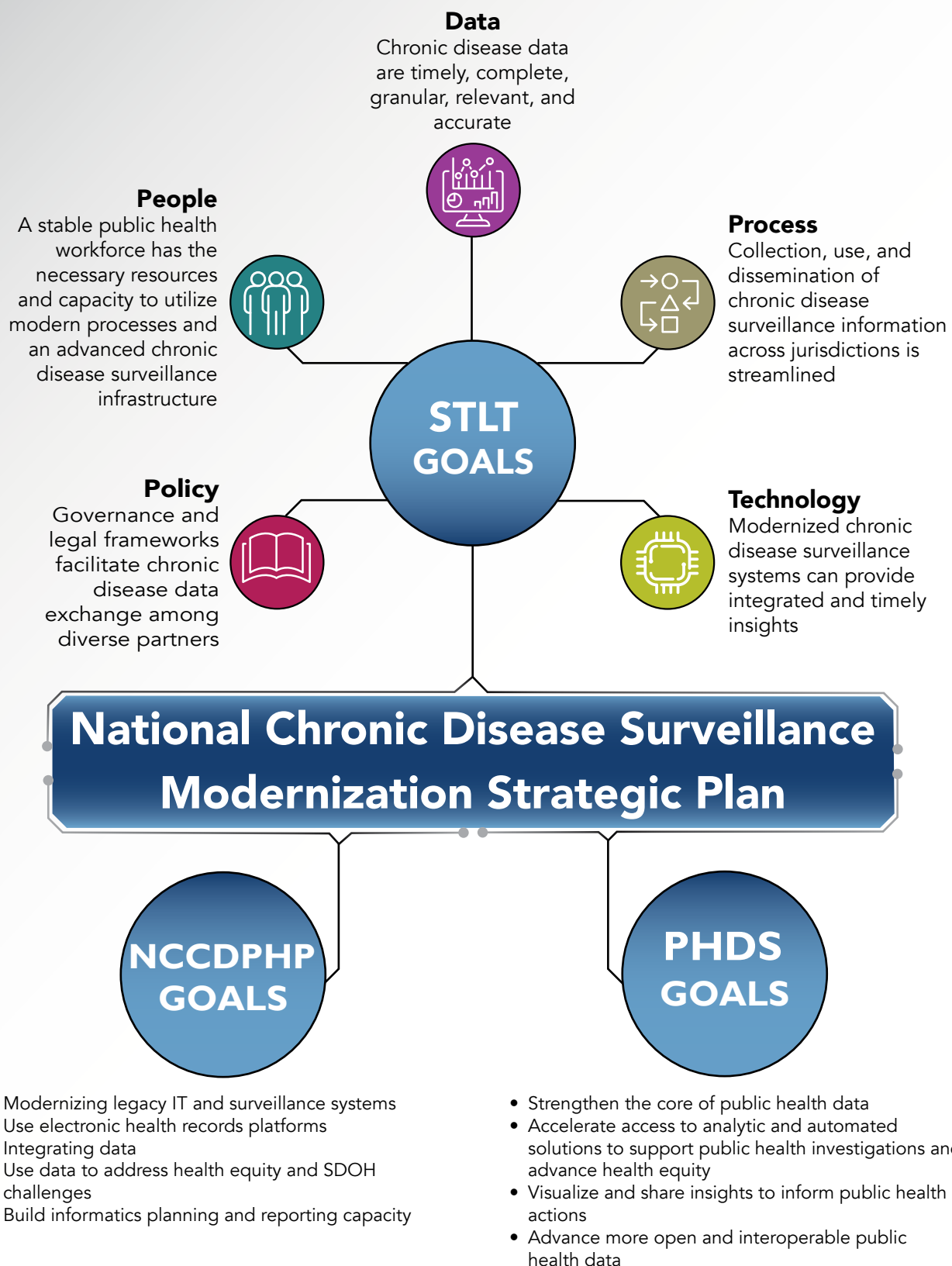
Strategic Plan Purpose

This comprehensive, multi-year strategic plan aims to advance chronic disease surveillance modernization at federal and STLT public health jurisdiction levels by addressing known and emerging challenges and drawing on existing federal and jurisdictional strengths and opportunities. It is designed to align with broader federal efforts around public health data modernization, including the PHDS and priorities described by the NCCPHP, as seen in Figure 1. The strategic plan addresses modernization needs across the chronic disease data ecosystem and is meant to guide planning and implementation efforts for STLT public health agencies. The plan focuses on establishing standardized and connected surveillance systems to monitor chronic disease burden and inform programmatic and policy initiatives. Although not

an explicit focus of this strategic plan, there is immense value in using programmatic data and qualitative insights to complement quantitative data metrics derived from these modernized systems.

Effective implementation will require staff in different roles taking on specific responsibilities and coordinating across disciplines. For example, the State Health Officer may use this plan to inform decisions around building strategic partnerships and identify opportunities to leverage various funding mechanisms to broaden data modernization application; department leadership can use it to inform chronic disease surveillance modernization priorities, pursue funding opportunities, and make funding allocation decisions, ensuring the sustainability of long-term objectives; information officers and information system vendors can use it to improve information system functionality and connectedness; and epidemiologists can determine what skills and training they may need to support modernization efforts on the horizon. Jurisdictions' starting points vary substantially, therefore the plan does not suggest a one-size-fits-all solution, but rather recognizes the need for flexibility to tailor to jurisdictional needs and capacity.

Figure 1. Alignment with Federal Data Modernization Priorities



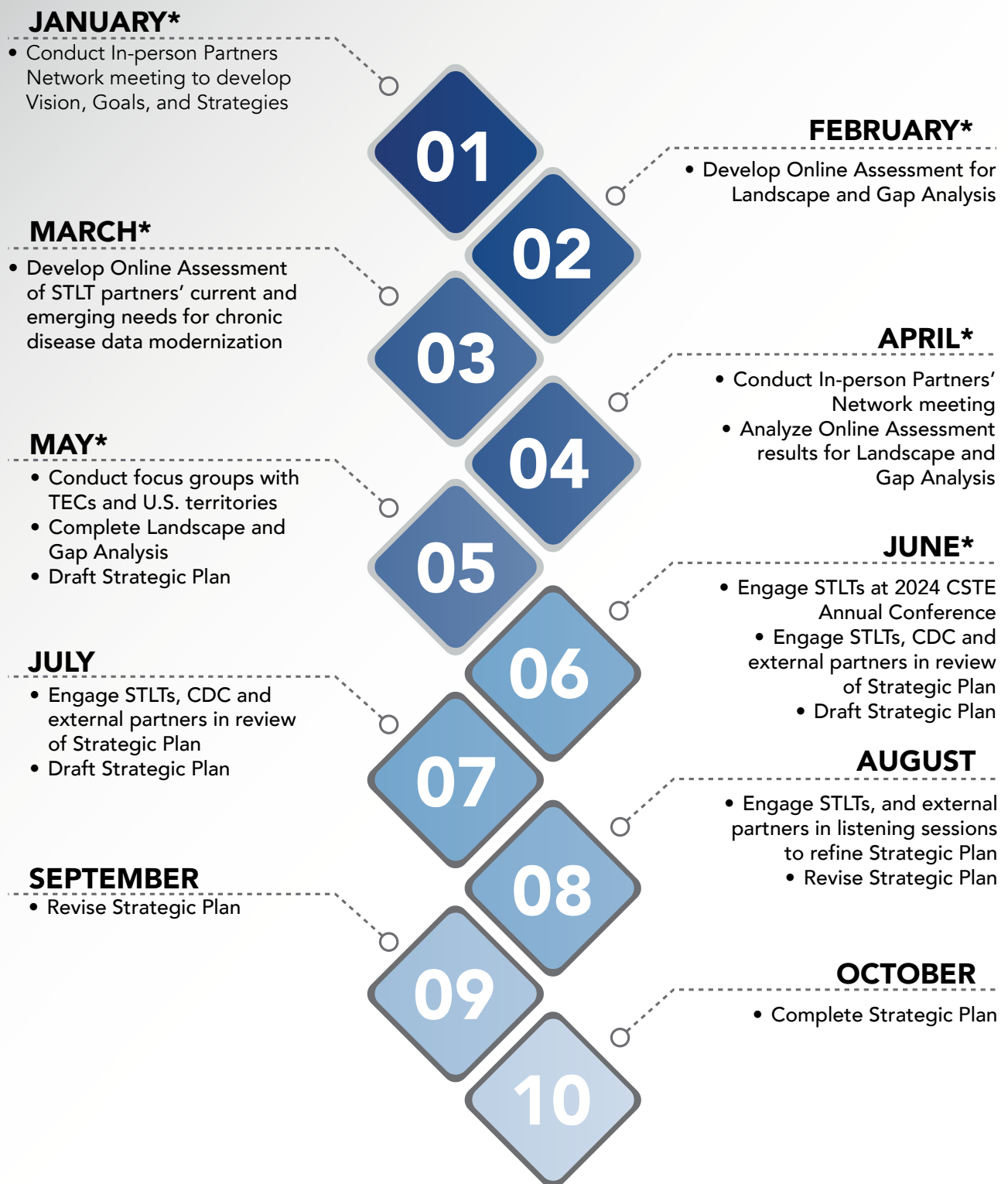


Strategic Plan Development Process

Development of this strategic plan began in late 2023 when CSTE convened several key partner organizations and STLT chronic disease epidemiologists into a national Chronic Disease and Health Promotion Surveillance Modernization Partners' Network (Partners' Network). The Partners' Network is a multidisciplinary group of experts representing STLT applied chronic disease epidemiologists and program directors, public health organizations, policymakers, healthcare organizations, community partners, and government organizations. The jurisdictional participants primarily represented state and local public health agencies with a background in chronic disease, informatics, and data modernization.

The Partners' Network identified specific challenges around modernizing the chronic disease surveillance data landscape, as well as potential solutions. After completing this initial inventory, information was categorized into five groups adopted from CDC's DMI: data, people, process, technology, and policy. During subsequent months, the Partners' Network met regularly—in person and virtually—to refine these ideas into goals, strategies, and objectives that comprised the initial strategic plan. See Figure 2 for a summarized activity timeline.

Figure 2. Strategic Plan Process and Timeline.



* Monthly virtual Partners' Network Meetings to develop and refine components of the Strategic Plan.

* Landscape and Gap Analysis research

The strategic plan was also informed by a landscape and gaps analysis conducted between January and May 2024, which consisted of a literature scan and online assessment. The literature scan focused on a subset of scientific and grey literature identified by the Partners' Network (e.g., materials from websites, surveys, and meetings). The online assessment supplemented the literature scan to gather partner insights around current and emerging needs for chronic disease data modernization. Nearly 250 federal, STLT, nonprofit, and private sector public health partners completed the online assessment between March to April 2024. Notably, there were only 4 responses from tribal and territorial partners. To address this gap, two focus groups were conducted in May 2024 with Tribal Epidemiology Centers (TEC) and U.S. territories to better understand the strengths and challenges tribes and territories face with chronic disease surveillance modernization. The TEC focus group included six participants from four organizations, the Alaska Native Tribal Health Consortium, the Great Plains Tribal Epidemiology Center, the Great Lakes Inter-Tribal Epidemiology Center, and the Rocky Mountain Tribal Leaders Council Epidemiology Center. The U.S. territories focus group included three participants from Guam and the U.S. Virgin Islands. The strategic plan also incorporated feedback received from representatives of the Commonwealth of the Northern Mariana Islands. An important limitation to note is that the strategic plan was developed based on the input of many, but not all, STLT jurisdictions. CSTE continues to conduct outreach, connect with more members, and strives to integrate broader feedback and voices into their work to equitably advance chronic disease surveillance modernization.

Vision Statement

With feedback from STLT jurisdictions, the Partners Network crafted the following five-year vision statement for the multi-year strategic plan:

VISION

Diverse partners can leverage a modernized information ecosystem to equitably transform chronic disease surveillance and promote thriving, connected communities.

The chronic disease surveillance landscape encompasses partners across several levels and disciplines including, but not limited to, federal agencies, STLT public health agencies, healthcare providers, EHR vendors, social services, policymakers, academia, and community members. Engaging diverse partners will strengthen public health's capacity to transform the surveillance landscape. Furthermore, it's essential to acknowledge that partners are entering the chronic disease data modernization space with varying levels of resources and capacity. Providing flexible and adaptable levels of support will enhance the equitable transformation across the information ecosystem. An equitable ecosystem also highlights the need to involve communities in defining their own data priorities based on what they need to thrive. Ultimately, these modernization efforts will allow public health agencies and partners to improve their understanding of chronic disease trends and disparities, advance health equity, and reduce the burden of chronic diseases.



Guiding Principles

The guiding principles articulate qualities that apply throughout the strategic plan to maximize its usefulness, durability, and effectiveness as a foundation for chronic disease data modernization. The principles require that the plan:

- **Integrates into federal and STLT modernization efforts.** Components of chronic disease data modernization should align with, leverage, and build upon existing infrastructure or planned upgrades at federal agencies. At the same time, infrastructure planning at the national level needs to engage STLT chronic disease programs to thoughtfully integrate chronic disease needs from the design outset. As data modernization rapidly evolves across the public health ecosystem, it is similarly critical for existing STLT-led data modernization projects to encompass the needs of chronic disease and other public health domains (e.g., environmental public health, maternal and child health, injury, substance use, mental health, and others).
- **Advances health equity.** Promoting equitable data system transformation demands equitable resource allocation and support to engage with and implement modernization opportunities. As systems improve, it is simultaneously critical to ensure that the data collected and used is granular and meaningful to identify and reduce chronic disease disparities and achieve health equity. Equity needs to be operationalized throughout the modernization process as well as throughout the chronic disease data lifecycle.
- **Enhances sustainability through shared goals, milestones, and successes.** Common success metrics facilitate infrastructure development, workforce investments, and governance structures to achieve long-term success. Developing clear and impactful chronic disease modernization milestones can align partners and potentially stabilize future funding allocations.
- **Inspires a culture change.** Engaging in data modernization requires that all programs and jurisdictions feel seen and prioritized. This strategic plan highlights the importance of inspiring a culture change so that chronic disease modernization needs are understood, valued and prioritized across STLT and federal public health agencies.
- **Facilitates multidirectional communication and coordination to achieve core goals.** The strategic plan should (1) inform STLT efforts to enhance chronic disease surveillance data for use in their jurisdictions; (2) inform STLT and national programming and funding priorities; and (3) inform CDC's priorities and understanding of what STLTs need to achieve chronic disease surveillance modernization.
- **Involves key partners,** including public health agencies, healthcare providers, software companies, policymakers, academia, and communities to ensure data modernization efforts meet their needs and fosters collaboration. Engaging partners early and often can help align goals, streamline implementation, and promote equitable outcomes.

STRATEGIC PLAN STRUCTURE

The plan structure depicts the hierarchy of elements in the strategic plan, anchored by the overarching vision. The structure includes a series of goals underlying the vision, with associated strategies and objectives to achieve each goal. The actions described under each objective are further prioritized and defined in the Strategic Plan Roadmap to identify metrics of success and necessary collaborations to support implementation. The roadmap will be published in summer 2025.

Figure 3. Strategic Plan Components and Structure



STRATEGIC PLAN GOALS

The Partners' Network organized essential components for modernizing chronic disease surveillance into five categories—People, Data, Process, Technology, and Policy—adapted from the CDC's Data Modernization Initiative. They set goals within each of these categories for the desired future state, addressing identified challenges, aspirations, and opportunities for improvement. The goals summarized below illustrate essential characteristics of a modernized chronic disease surveillance landscape within the scope of the five-year vision statement.



PEOPLE

A stable public health workforce has the necessary resources and capacity to utilize modern processes and technologies.

A trained workforce, representative of the communities served, is essential to conducting both chronic disease surveillance and data modernization efforts. Many STLT jurisdictions are understaffed in both areas due to burnout, limited and unpredictable funding, non-competitive salaries, and time spent on tasks that could be automated such as data cleaning and linking data across systems. Building workforce capacity is a critical foundation to implement other modernization strategies. The current chronic disease landscape also lacks leadership awareness, buy-in, and support at multiple levels within public health organizations and across sectors. Developing comprehensive training programs for chronic disease epidemiologists and informaticians as well as creating interdisciplinary fellowship programs can bolster existing capacity. Investing in a skilled STLT workforce is necessary to achieve all chronic disease surveillance modernization goals.



DATA

Data are timely, complete, granular, relevant, and accurate.

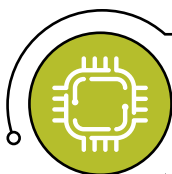
Chronic disease data often lack the specificity to address community-specific needs due to limited geographic representativeness, limited or inaccurate demographic information, and dominant-culture relevance. Subsequently, it can be difficult to access and use data to accurately monitor chronic disease trends, identify disparities, and to plan and implement targeted prevention interventions. Inclusion of key social, cultural, and environmental variables (i.e. social class, gender, race, ethnicity, disability, language, and others) will enhance the ability to monitor chronic disease trends across communities and direct resources and programming where it is most needed.



PROCESS

Collection, use, and dissemination of chronic disease information is streamlined across jurisdictions.

Current siloed processes across the chronic disease data landscape make it challenging to establish effective workflows to gather, link, analyze, and share data to support surveillance activities. The effectiveness of critical chronic disease interventions is significantly hindered by lags in data collection and processing, inconsistent data quality, and lack of protocols for access and use of data sources. There are opportunities to advance chronic disease surveillance processes across the data lifecycle to ensure jurisdictions are adequately resourced to receive, analyze, and communicate chronic disease data, in collaboration with their partners and communities, for meaningful public health action.



TECHNOLOGY

Modernized systems can provide integrated and timely insights.

Current data systems are outdated, fragmented, and siloed, creating roadblocks for timely, standardized, and representative data for public health actions. Upgrading and integrating technology and systems is a key component of modernization. Investments in technology are costly and resource intensive to implement and sustain, therefore they must be done efficiently, and with awareness of jurisdictions' starting points and ongoing modernization efforts. As systems are upgraded, harmonized, and integrated with one another, they can more readily exchange data and drive action with timelier analytic insights.



POLICY

Policy, governance, and legal frameworks facilitate data exchange among diverse partners.

To reduce the burden of chronic diseases, it will be critical to improve data sharing practices and recognition of public health data as a public good. There is a significant gap in governance, legal frameworks, and data standards for healthcare and social services or other relevant systems to share chronic disease information with public health agencies, communities, and tribal health authorities. Furthermore, data exchange policies and practices are highly variable across jurisdictions and result in inconsistent or inequitable data sharing between state, local, and tribal public health agencies. Jurisdictions must evaluate their data sharing practices and implement changes to ensure data is readily accessible and usable by local, tribal, territorial, and community partners. Developing policies and infrastructure to support chronic disease data collection and appropriate access will require standards and guidelines and must acknowledge the role and importance of data sovereignty.

STRATEGIES AND OBJECTIVES

The following strategies provide specific pathways for achieving the overall strategic plan goals. Each strategy contains more granular objectives to identify opportunities for action and progress. The strategies cut across the five categories—Data, Process, Technology, Policy, and People—to acknowledge the coordinated approach needed to achieve success. As noted by many STLT partners, building partnerships both within public health agencies—for example, between chronic disease programs and information technology departments—and

across sectors—including public health, health care, and social services—is a critical early step for all modernization efforts. The articulated actions provide tangible opportunities for STLT jurisdictions, federal agencies, and partner organizations to advance each strategy. The Strategic Plan Roadmap will further prioritize actions that are feasible for STLT jurisdictions to engage with in the near-term and provide additional details around metrics of success and collaboration opportunities.

Strategy 1: Leverage Existing Data Processes, Networks, and Initiatives to Advance Chronic Disease Surveillance Needs

There is significant momentum around data modernization priorities across public health, though at varying degrees from federal, state, territorial, local, and tribal-level jurisdictions. Multiple processes and networks exist and should be leveraged for addressing chronic disease surveillance needs. With greater awareness of national-level efforts and benefits to STLT public health agencies and their chronic disease partners, more jurisdictions can take advantage of efforts underway and launch or continue their own modernization efforts with greater efficiency and less redundancy.



Objective and Actions

Objective 1.1 - Ensure chronic disease surveillance is integrated into new and emerging programs, initiatives, and policies.

Action

- | | |
|------|--|
| 1.1a | Identify and elevate the significance of chronic disease use cases that can be used in efforts to plan, pilot, and implement data modernization opportunities. |
| 1.1b | Conduct pilot projects to test chronic disease use cases using existing and newer data transmission pathways, including electronic case reporting (eCR), syndromic surveillance, or Multi-state Electronic Health Record (EHR) -based Network for Disease Surveillance, or "MENDS"). Successes from pilot projects can be used to inform use cases for emerging opportunities such as the Trusted Exchange Framework and Common Agreement (TEFCA). |
| 1.1c | Work to align with US Core Data for Interoperability (USCDI) ⁸ and USCDI ⁹ + to ensure comprehensive integration of chronic disease data elements and set the stage for interoperable health information exchange. |
| 1.1d | Develop a plan to integrate data from diverse local, tribal, and territorial health systems (e.g., Resource and Patient Management System ¹⁰) with other chronic disease reporting systems. |
| 1.1e | Maintain awareness of and engagement with the chronic disease community, including partners at ASTHO, NACCHO, NACDD, PHII, CSTE, and others, around emerging initiatives relevant to data exchange and surveillance through integrated partnerships and shared learning spaces. |
| 1.1f | Incorporate chronic disease collaboration and reporting metrics into data modernization work funded by federal grants and Cooperative Agreements to ensure that the DMI priorities can advance both infectious and non-infectious disease work. |

8 U.S. Department of Health and Human Services. 2024. United States Core Data for Interoperability (USCDI).

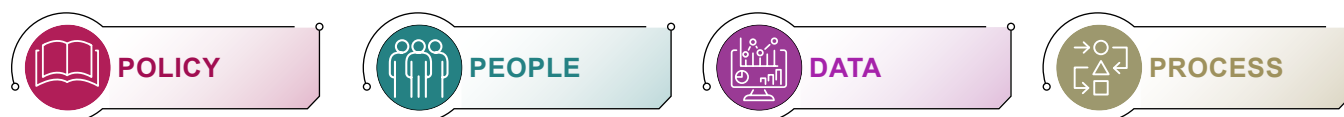
Available at <https://www.healthit.gov/isp/united-states-core-data-interoperability-uscdi> (Accessed July 15, 2024).

9 U.S. Department of Health and Human Services. 2024. USCDI+. Available at <https://www.healthit.gov/topic/interoperability/uscdi-plus> (Accessed July 15, 2024).

10 Indian Health Services. Resource and Patient Management Systems (RPMS). Available at <https://www.ihs.gov/rpms/> (Accessed July 15, 2024).

Strategy 2: Update and Develop New Approaches to Surveillance in Response to the Changing Landscape of Available Data, Information, and Technology

Evaluation of both traditional, population-based surveillance systems and data generated from healthcare entities is critical to determine what already exists and can be improved and what additional assets are needed to create a more modernized surveillance system. The ideal end-state is near real-time surveillance data, enhanced data linkages, and increased geographic granularity for more robust analysis across diseases and conditions.



Objective and Actions

Objective 2.1 - Improve traditional surveillance systems to provide timely and representative chronic disease insights.

Action

- 2.1a Develop an evaluation toolkit for existing surveillance systems and electronic health information (EHI)¹¹, to identify strengths, challenges, overlap, and unique information. The evaluation tool should consider programmatic expertise and community input around data needs and assets.
- 2.1b Review methodologies for surveys and other traditional surveillance data sources and identify opportunities to increase participation, representativeness, accuracy, and completeness. Federal partners should “consider alternative methods to support locally tailored adult chronic disease data collection in the USAPI (e.g., regular funding for the PIHOA NCD Hybrid Survey).”¹²
- 2.1c Determine where critical lag times occur for processing and reporting population health survey data and identify potential mitigation strategies.
- 2.1d Determine the geographic granularity and protected health information needed for optimal chronic disease surveillance, including identifying health inequities.
- 2.1e Integrate chronic disease data infrastructure considerations into federal and partner data modernization maturity assessments to evaluate jurisdictions’ current data capabilities. The assessment should quantify the workforce, technology, and financial resources needed for managing and updating existing surveillance systems and implementing emerging technologies.

11 U.S. Department of Health and Human Services, The Office of the National Coordinator for Health Information Technology. 2021. Understanding Electronic Health Information (EHI). Available at https://www.healthit.gov/sites/default/files/page2/2021-12/Understanding_EHI.pdf (Accessed July 15, 2024).

12 Recommendation from: Addressing Island Participation in Six Priority Federal Public Health Datasets: Report Addendum. Available at <https://www.astho.org/topic/report/including-island-areas-in-federal-public-health-datasets/> (Accessed October 24, 2024).

Objective 2.2 - Leverage non-traditional data to enrich traditional data sources.

Action

- 2.2a Develop resources for STLTs to validate EHR data for chronic disease surveillance. Resources should include a validation tool and guidance for using EHR data to complement traditional surveillance data.
- 2.2b Explore opportunities for leveraging advanced analytics, machine learning, and artificial intelligence to detect and predict patterns, and support public health decision-making.
- 2.2c Improve data granularity and opportunities to increase health equity by developing new or refining existing data collection and analytic methodologies, including sampling, modeling, and weighting for non-traditional datasets, data for small regions and populations, and tribal areas.
- 2.2d Identify opportunities to augment surveillance using innovative and timelier data sources (i.e. EHR, All-Payer Claims Databases, etc.), including data provided by health care entities and communities.

Strategy 3: Build a Skilled, Multidisciplinary Workforce to Increase Informatics and Chronic Disease Competencies

Developing, supporting, and enhancing a well-trained workforce is essential for building and sustaining a modernized chronic disease surveillance ecosystem. This strategy recognizes the need to bolster the existing chronic disease workforce and leverage opportunities to recruit and upskill staff experienced in informatics and data science. This is particularly important for STLT jurisdictions already capacity constrained for basic surveillance activities. Solutions to some of these needs already exist and others will require development of targeted curricula and hiring approaches for multidisciplinary capacity building.



Objective and Actions

Objective 3.1 – Enhance chronic disease informatics capacity through integrated training opportunities and engagement with data modernization staff.

Action

- 3.1a Assess current skill levels and training needs for epidemiologists, informatics, and data science staff. Identify specific areas where additional training is required to integrate modern data standards, technologies, and methods and develop a plan to upskill staff where appropriate.
- 3.1b Identify existing training programs with relevance to chronic disease data modernization that STLT jurisdictions can leverage including CDC's Public Health Informatics Fellowship Program (PHIFP) and Epidemiologic Intelligence Service (EIS) officers or CSTE's Applied Epidemiology Fellowship (AEF) or the Applied Public Health Informatics Fellowship (APHIF).
- 3.1c Promote and incentivize sharing technical expertise across public health programs to leverage existing informatics and data modernization staff for chronic disease modernization efforts.
- 3.1d Develop and provide new training modules or programs to address current workforce gaps. This may include comprehensive training programs for chronic disease epidemiologists, focusing on clinical languages, data standards, innovative methodologies, and the use of modern informatics tools. Training should also cover specialized modules for informatics staff to understand the workflows and needs of chronic disease programs, including technical and standards solutions.
- 3.1e Explore opportunities to expand the programmatic workforce through braided funded streams. Expand or use existing funding for informatics fellows to support chronic disease data modernization efforts across STLTs.
- 3.1f Engage schools of public health and community partners to incorporate data modernization and informatics into MPH criteria. Develop training opportunities for students and community members, including non-MPH undergraduates in data or computer science, to participate in data modernization efforts through internships, practicums, and other educational programs. Training opportunities should provide opportunities across public health domains to ensure data modernization supports all diseases and conditions.

Objective and Actions

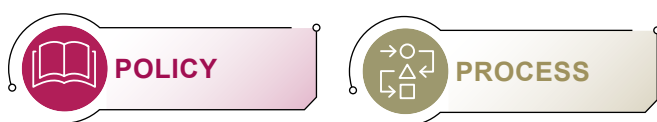
Objective 3.2 – Promote continuous learning opportunities to sustain and enhance workforce competencies.

Action

- 3.2a Support current staff with data modernization training programs, such as CSTE's Data Science Team Training program. Identify opportunities for staff to participate in data modernization conferences and join professional associations with relevance to chronic disease surveillance and data modernization.
- 3.2b Provide regular training sessions, workshops, and seminars for STLTs and other public health professionals to stay updated on the latest advancements in chronic disease surveillance and informatics.
- 3.2c Partner with academic institutions, professional organizations, and other experts to deliver high-quality training programs and resources on new and emerging topics with relevance to data modernization for chronic disease.
- 3.2d Establish a continuous learning environment that encourages professional development and interdisciplinary collaboration among chronic disease, infectious disease, and informatics staff.

Strategy 4: Evaluate Policy Landscape to Identify Gaps and Opportunities Relevant for Equitable Chronic Disease Surveillance Modernization

Policies and legal framework are critical levers to facilitate data exchange between partners and across systems. Although laws and policies are often in place to ensure compliance with data privacy regulations and to protect sensitive health information, they can impair access to and utility of public health data. Data access policies often apply to a specific disease or data source, which creates a confusing morass of rules that leave authorities reluctant to share data. Addressing gaps or deficiencies in the policy and legal frameworks governing chronic disease data sharing should improve data flow while continuing to adhere to data privacy protection standards. Ultimately, this strategy will help ensure that chronic disease data are equitably shared, accessed, and used to inform interventions to improve the public's health.



Objective and Actions

Objective 4.1 - Conduct a focused policy landscape analysis of data governance policies and legal frameworks.

Action

- 4.1a Conduct policy landscape analysis of data governance policies and legal frameworks relevant to chronic disease data sharing.
- 4.1b Identify existing models used to share identified, de-identified, and aggregate chronic disease data.
- 4.1c Engage with tribal health authorities to understand unique tribal data needs, data sharing concerns, opportunities, and legal or governance considerations related to this strategy.

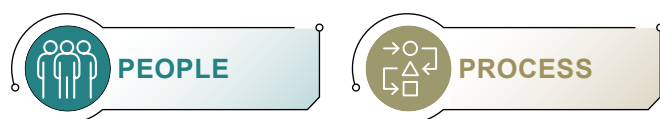
Objective 4.2 – Develop model policies and guidance for data sharing and governance based on initial landscape analysis (Objective 4.1)

Action

- 4.2a Develop consistent national policy talking points for chronic disease data modernization and need for timely access to data.
- 4.2b Leverage model laws to develop data sharing guidance grounded in available policy and legal frameworks that can be used to increase sharing while adhering to highest standards of privacy and security requirements. Include linkage considerations, such as data suppression and rate stability, when thinking about data sharing and use.
- 4.2c Ensure chronic disease-related data needs are incorporated and met in the CDC-led national core DUA which includes common provisions and data source-specific addenda for STLT sharing to CDC.

Strategy 5: Build Partnerships and Identify Opportunities to Align and Promote Chronic Disease Modernization Goals

Chronic disease modernization will require new and strengthened partnerships across healthcare and social services in addition to within public health agencies. Partners must meet and communicate regularly to share use cases, case studies, data sharing needs, challenges, and opportunities to collaborate around shared objectives. This is particularly important at leadership levels and across public health agencies and healthcare organizations. Partners should also ensure that data are shared back with the communities they represent, ensuring that the information collected is broadly communicated and used to improve community health and wellbeing.



Objective and Actions

Objective 5.1 - Build bridges and articulate common values with healthcare partners.

Action

- 5.1a Establish a governance structure for chronic disease partners to convene and articulate the benefits of chronic disease data exchange, identify priority use cases for public health surveillance, and develop solutions that maximize the utility of data exchange while minimizing the burden for providers and healthcare staff.
- 5.1b Conduct workshops and training sessions to inform healthcare providers and payors about the role of public health in chronic disease prevention and control.
- 5.1c Begin discussions around HIPAA regulations to identify opportunities to be more permissive with geographic variables to support public health use cases.
- 5.1d Identify mechanisms to collect healthcare data from EHRs and make it more easily available to chronic disease programs.
- 5.1e Establish regular meetings and communication channels between public health and healthcare organizations and payors to discuss data-sharing needs, challenges, and opportunities.

Objective 5.2 – Articulate chronic disease modernization needs and priorities across public health domains and elevate to agency leadership.

Action

- 5.2a Build relationships and communities of practice between public health agency leadership, data modernization staff, and chronic disease epidemiologists and programmatic staff to increase collaboration and peer learning.

Strategy 6: Develop Resources to Support Integration of Data Modernization Activities into Chronic Disease Surveillance

Chronic disease data modernization is complex and it requires a shared understanding of its value among multiple actors and disciplines and a high degree of information sharing and coordination around key activities. Many STLTs and national partners have already generated useful guidance for implementing new processes, building partnerships, and integrating systems, and others are just getting started. Facilitating access and use of these resources can empower chronic disease programs to assess their current capacity, determine what resources they need, and share their own best practices to enhance scalability to other jurisdictions. This is especially important for jurisdictions who may have lower capacity and fewer resources to begin modernization efforts, as they can learn from peer experts and more efficiently identify priorities and solutions.



Objective and Actions

Objective 6.1 – Improve access to new and existing chronic disease data resources, including analytic tools, learning communities and repositories, to scale modernization efforts.

Action

- 6.1a Create navigation tools for chronic disease partners to better access and use data modernization activities, forums, tools, templates, success stories, implementation guides, and pilot opportunities.
- 6.1b Establish or leverage existing communities of practice for strengthening chronic disease data modernization. Communities of practice should encourage bidirectional information exchange to increase chronic disease's awareness and knowledge of data modernization opportunities and to increase the presence of chronic disease priorities within data modernization conversations.
- 6.1c Identify or create shared tools and resources such as code snippets, visualizations, and best practices, that can be used by all STLT jurisdictions to improve their chronic disease surveillance capabilities.
- 6.1d Develop a toolkit for connecting data systems that define shared systems and data sources in the chronic disease surveillance landscape. .
- 6.1e Increase awareness of and leverage resources at the federal level to support modernization efforts at state, territorial, local, and tribal jurisdictions.

Objective 6.2 – Develop guidance and other materials for STLT staff to begin their data modernization efforts.

Action

- 6.2a Develop a set of capacity-specific frameworks that STLTs can utilize based on their self-assessment of their current capacity and needs for chronic disease surveillance modernization..
- 6.2b Develop talking points and fact sheets for jurisdictions and federal partners to use for raising awareness and making the case for chronic disease modernization to specific audiences (e.g., data stewards; healthcare partners; public health agency leadership; IT staff).
- 6.2c Develop supplemental, role-specific one-pagers of how to engage in chronic disease modernization efforts for staff in variety of roles at public health agencies.



APPENDIX

Organizations in the CSTE Chronic Disease Surveillance Modernization Partners' Network

CSTE convened partners in the Chronic Disease Surveillance Modernization Partners' Network (Partners' Network) and 53 members attended and actively engaged in Partners' Network meetings. The table below provides a list of agencies and organizations represented in the Partners' Network. Members were associated with STLT jurisdictions, CDC, non-profit organizations, and academic research institutions.

- | | | |
|---|---|--|
| • Alabama Department of Health | • DC Health | • Public Health Informatics Institute |
| • Altarum | • Great Plains Tribal Leaders Health Board | • Tennessee Department of Health |
| • Alaska Native Tribal Health Consortium | • Indiana University/Regenstrief Institute | • University of Texas Health Science Center at San Antonio |
| • Association of Public Health Laboratories | • Louisville Metro Department of Public Health and Wellness | • Utah Department of Health of Health & Human Services |
| • Association of State and Territorial Health Officials | • Marion County Public Health Department | • Virginia Department of Health |
| • CDC National Center for Chronic Disease Prevention and Health Promotion | • National Association of County and City Health Officials | • Washington State Department of Health |
| • CDC Office of Public Health Data, Surveillance, and Technology | • National Association of Chronic Disease Directors | • Wisconsin Department of Health Services |
| • CDC Foundation | • North Dakota Health & Human Services | |
| • Council of State and Territorial Epidemiologists | • Office of the National Coordinator for Health IT | |

Focus Groups with Territorial and Tribal Partners

In May 2024, focus groups with public health agency staff from the following Tribal Epidemiology Centers (TEC) and Territorial jurisdictions were conducted to understand their strengths and challenges related to chronic disease surveillance modernization. Participants in the Tribal Partners focus group shared how a unique strength of the Indian Health Service (IHS) is the health data on American Indian and Alaska Native (AI/AN) populations that are agnostic to insurance providers and healthcare providers. Participants also raised challenges with various agencies claiming data ownership and restricting access to public health data; ideally, these data would be recognized as a communal resource to protect people's health.

To achieve chronic disease surveillance modernization, participants suggested that it will be critical to integrate equity in every step of the work, revise existing data systems, or create new systems, to address biases, and explicitly name the diverse partners who should be at the table, including TECs.

Participants in the focus group with Territorial Partners raised challenges related to limited funding, minimal workforce capacity, cultural and language barriers, and limitations with procurement and data sharing. A major strength across territories is the presence of strong, interconnected communities, which expedite information sharing and help build community support for the implementation of public health initiatives. Participants suggested specific actions for 1) building data collection and storage infrastructure; 2) supporting territorial partners with developing and implementing policies for data-sharing; and 3) improving interoperability and workforce capacity. Participants expressed the importance of engaging territorial partners so they can share their unique perspectives and continue learning from each other about chronic disease surveillance modernization. A full list of focus group representation is provided in the table below.

Focus Group with Tribal Partners	Focus Group with Territorial Partners
Alaska Native Tribal Health Consortium	Guam
Great Lakes Inter Tribal Epidemiology Center*	U.S. Virgin Islands
Great Plains Tribal Epidemiology Center*	Commonwealth of the Northern Mariana Islands+
Rocky Mountain Tribal Epidemiology Center	

* More than one representative participated in focus groups.
+ Provided feedback after the focus group.

Good Health and Wellness in Indian Country (GHWIC) and Data Modernization Workgroup

In June 2024, CSTE conducted two discussion sessions for the draft strategic plan (Version 1) with GHWIC members and the Data Modernization Workgroup. GHWIC members raised the importance of addressing tribal sovereignty and the public health authority of Tribes and TECs. Tribes continue to struggle with data access (e.g., cancer registry data, mortality data, hospital discharge data, and Urban Health Clinic data), yet they should have the public health authority for data access. Additionally, data suppression significantly hinders tribes from using chronic disease data and this may be an opportunity to adopt new data analysis methods. Since the Strategic Plan includes goals related to capacity building, it will be critical to build capacity from within tribal communities and among tribal youth. Lastly, members emphasized that qualitative data and stories are essential data for tribal communities. Members of the Data Modernization Workgroup noted how the draft plan was missing the link between building a modernized surveillance system and public health actions that would result from more timely and better data. The Workgroup also raised that data sharing and reportability solutions have costs and this ties to the need to engage early and often with diverse partners to ensure data modernization solutions are holistic and feasible for various types of agencies.

Feedback Summary for Strategic Plan (Version 3)

“Background and Overview”

We appreciate the inclusion of lifestyle risk factors as a key contributor to chronic disease and an important component of surveillance.

Consider adding reference to estimate with chronic conditions in 2050

Consider mentioning something about the more recent implications of the changing health needs and demands from a large aging baby boom generation (by 2030, within next 5 years, all will be at least age 65).

Lot of great information on benefits of modernizing chronic disease surveillance systems in different contexts. For ease of consumption, consider providing list or table of benefits by type/specificity (some overarching, some more nuanced) and whom they apply.

When talking about limitations of current chronic disease data ecosystem, maybe call out more specific examples to better differentiate from infections/communicable disease data modernization. For example, provide text box with list of chronic disease related limitations (such as heavy reliance on self-report survey data to monitor trends in prevalence) so reader can readily see differences and why we are calling the unique needs of chronic disease in data modernization efforts.

It read very smoothly. No changes suggested.

Phrase “adverse outcomes due to infectious disease” trips me up, perhaps change “due to” to something else?

Given we were always learning something new about COVID (and who was most at risk), the connection between chronic disease surveillance and hospital capacity planning/vaccine prioritization is not clear to me. Also, given the prevalence of most chronic diseases doesn’t usually vary drastically (like from 20% to 40% of the population from 1 year to the next), the timeliness argument doesn’t make as much sense to me here. Since I see it as more of a data use issue rather than a lack of data issue, I think this argument needs to be rephrased or expounded on more to make it stronger because otherwise I find it off putting to have a justification/illustration of importance that to me is a reach right off the bat because it implies there aren’t any better/more clear reasons for the importance of chronic disease surveillance.

Perhaps change the and between “one another,” and “use outdated software” to an “or” or an “and/or” as the primary source of chronic disease surveillance are the surveys which actually measure a lot of the risk/protective factors (including SDOH) & multiple chronic diseases.



“Purpose”

In this list of examples of use of this plan, consider adding: CIOs [and information system vendors] can use it in strategic planning of improved information systems and functionality;

We like the flexibility of being able to tailor the Plan to jurisdictional needs/capacity.

Maybe provide a bit more context around why plan focuses heavily on “surveillance data and sources” but also acknowledges there are other important data sources used to inform decision-making, resource allocation, policy/program planning for chronic disease that can also benefit from data modernization (e.g., programmatic data, evaluation data, quality improvement data, qualitative data, stories of lived experiences, etc). Would be helpful to at least mention and provide some understanding on how they impact or fit into this plan as well.

It may not hurt to re-define the abbreviation PHDS since it wasn’t used in the background and overview at all, just the summary

Do you have a plan for drawing leadership attention to chronic disease surveillance? are they really a viable target audience?

“Development Process”

I would like more information about who was invited to join the Partners’ Network and what, if any, reason those participants were included

Who in these jurisdictions was the online assessment sent to? how many of each group participated?

What led to the participation of those TECs and not others?

“Vision”

We appreciate the acknowledgement that diverse partners and community members need to be engaged and that different partners will have different resources and need different support.

Appears that “equitable transformation” is defined in a few importantly distinct ways, that I don’t think the wording in vision statement readily captures. Throughout the plan I see it mentioned as 1) the equity in levels of support to address differences in resources and capacity to implement data modernization, 2) inclusion of diverse partners in modernization processes, 3) prioritizing community engagement to define needs and gather input. Feels like it needs distinct language for these different components called out at various times throughout the document under the “equitably transform” umbrella.



“Vision”

Vision statement wording suggestion that felt like it was missing some of the what and the who: ...equitably transform (and improve) chronic disease surveillance (to provide actionable data that supports activities) to reduce burden of chronic disease (in all communities).

It's fine. I like the paragraph describing exactly what is meant by the phrasing. It makes the vision statement more meaningful to me.

“Guiding Principles”

Do we want to focus on only federal-level mod efforts (in bold)? I feel it should be generic or call out Federal and STLT level mod efforts.

In this list of key partners, consider adding “software companies”.

We thought these were very well crafted and already align (or can easily be woven into) our Department's principles.

Advance Health Equity - See similar comments under vision feedback. Again, be a bit clearer in distinctly talking about equity in implementation vs equity in benefits of data modernization. Seems like a big term being used repeatedly in different context throughout and is a bit confusing (at least for me). Maybe bullets or callouts would help.

Success stories - Really like this being called out throughout and looking forward to toolkits with examples that will be incredibly useful.

General: clarify if the guiding principles were guides for the development of the plan or are for using the plan

“Structure”

Like the simplicity and how it goes all the way down to “action” which sometimes is a missing crucial piece in plans.

Nice to have a figure

“Goals”

It states, “The jurisdictional variability in data authorities also makes it difficult to establish a federal surveillance system.” Is the overarching goal to have a federal surveillance system? This statement seems to come out of left field and assumes that STLTs are looking for a federal surveillance system. I would have thought we would be accessing national level data using modern capabilities, such as TEFCA, to populate STLT surveillance systems to allow for the level of specificity and nuance needed to monitor and serve specific communities.

Add “link” (linking data is essential to chr. dis. surv. and is certainly one of the biggest challenges): Current processes across the chronic disease data landscape make it challenging to gather, link, analyze, and share data to

Replace “management” (a vague term) with “appropriate access” (more specific to this point): Developing policies and infrastructure to support chronic disease data collection and appropriate access will require

Add “non-competitive salaries”, surely one of the biggest workforce challenges regarding recruiting for the PH IT/technical workforce:

Jurisdictions must evaluate their data sharing practices and implement changes to ensure data are readily accessible and usable by local, tribal, territorial, and community partners. (add local, territorial, and community)

These goals feel too broad to know what actions will really be able to move the current state enough to achieve them. We understand that the roadmap will have more details, but just looking at these goals as someone working in chronic disease surveillance on a day-to-day basis, they feel impossible. It would help to see more short-term goals that could be stepping stones to the ultimate vision.

Appreciate adaptation of components from the CDC DM initiative. Makes it easy to relate to broader efforts.

When speaking about inclusion of key variables, think about replacing “for race, ethnicity, and other demographic data” to more inclusive and caring language such as “Inclusion of key variables for social and cultural identity and environments (e.g., social class, gender, race, ethnicity, disability, language, and others).

Current (insert>siloes) process across the chronic disease landscape make it challenging to (insert>establish effective workflows) to gather, analyze....

Circle back to goal of providing timely insight by adding to end of sentence...exchange data and drive action with analytics (insert>and more insight).



“Goals”

Maybe instead of saying the limitations make it difficult (which I feel implies that the current chronic disease surveillance data are invalid) use a different word or phrase that more clearly denotes that these things could be made easier/are harder than the need to be right now. “These limitations increase the difficulty of accessing and using data to accurately...”

There is a lot more to demographics and SDOH than race/ethnicity. I recommend adding at least one other specific example, such as disability status, or gender identity.

Without keeping the goal of improving integration in mind when updating technology, upgrading systems will not necessarily improve interoperability. I think something should be added here about collaboration between programs/with other surveillance (ie infectious disease) etc.

This line has the beginning of a sentence that to me implies jurisdictional variability is an issue. However, the final sentence of this goal (213) seems to contradict this. I think this part of the goal needs to be clarified or rephrased so that it reads as less contradictory because data sovereignty is going to involve jurisdictional variability.

“To utilize modern processes and an advanced chronic disease surveillance infrastructure” trips me up as I was initially confused that the sentence meant that the people could use the infrastructure. Simply removing the “an” before “advanced” might help with that

Cont.: I really feel like this goal contains a lot of the most important reasons the current “system” is the way it is. I think this goal needs to come earlier (maybe even before the data goal) in the section.

“Strategy Overview”

Simply well written highlighting key information for ease of understanding.

As this section highlights the critical importance of the people/partnerships as the foundation for pretty much everything else, I think it shows that the people goal really should be higher. Also, Strategy 5 should really be the first strategy since it is the one that talks about getting leadership buy in and forming partnerships.



“Strategy 1”

General comment: this is a good/important strategy. These horizontal relationships (rather than trying to start with going through the formal hierarchy) are critical when chronic disease is playing catch-up and for learning about what is already happening. Especially without existing buy-in/support/direction from leadership. I also hope that by getting buy-in and support from people outside chronic disease, that eventually trying to get leadership buy-in will be easier/we'll be starting from a stronger position as a diverse team rather than a single program pursuing more resources etc.

“Strategy 2”

With regards to Objective 2.1 regarding conducting a maturity assessment. STLT agencies are being asked to perform many assessments at this time. CDC is currently designing a maturity model for data modernization, and it would be good to tie into this to limit the number of assessments.

2.2a Wording a bit confusing. Not sure what plan for validation of EHR surveillance means in this context? Seemed more like a plan for utilization, but could be I'm not understanding this action well as worded.

2.2d Consider providing examples of non-traditional data sources in parenthesis (EHR, APCD, etc.) for reader that are unique to chronic disease surveillance.

Increased geographic granularity is mentioned in objective 2.1b, but I think it would strengthen the argument if it was also stated explicitly in the introduction paragraph.

I think objective 2.1 could maybe include something about engaging with the programs/people currently operating these systems. Unfortunately, so far, my experience with department leadership is that they have a tendency towards making top down decisions without engaging (or with very limited engagement) of experts and people actually doing the work. My concern is that a person or program outside of the traditional surveillance systems may take it upon themselves to do these things without sufficient input.

“Strategy 3”

We'd love to see more federal funding to support informatics and IT staff at STLTs. Training the existing workforce is great, but epidemiologists are not informaticians, or database administrators. Professional development won't change that.

Important strategy



“Strategy 3”

Add “methods” in 3.1a and 3.1c (we need to modernize how we do things, like using machine learning and new approaches to link data):

3.1a Assess current skill levels and training needs for epidemiologists, informatics, and data science staff. Identify specific areas where additional training is required to support integration of modern data standards, methods, technologies, and interdisciplinary collaboration, and develop a plan to upskill staff where appropriate.

3.1c Develop and provide new training modules or programs to address current workforce gaps. This may include comprehensive training programs for chronic disease epidemiologists, focusing on clinical languages, data standards, and the use of modern informatics tools, methods, or specialized training modules for informatics staff to understand the workflows and needs of chronic disease programs, including technical and standards solutions.

In Objective 3.1e, there is the mention of engaging schools of public health to incorporate data modernization and informatics into MPH criteria. I agree that is important and that needs to stay, but I also think there needs to be a strengthening of chronic disease education in those programs as well. Infectious disease professionals far outstrip chronic disease professionals coming out of these programs. If there is a way to make chronic disease more appealing in MPH education, then we should definitely do it. Otherwise, this section of public health will continue to be chronically understaffed.

“Strategy 4”

Add a sentence (“Data access ... at all.”) about complex variation in policies, and add the work “inconsistencies” to what should be addressed: Impair access to and utility of public health data. Data access policies often by disease or data source, creating a confusing morass of rules that leave authorities reluctant to share data at all. Work to address gaps, inconsistencies, or deficiencies in the policy and legal frameworks

Inset, item 4.1b: To be more specific about what model we need, change “used to share” to “that enable valuable, timely sharing of”: 4.1b Identify existing models that enable valuable, timely sharing of identified, de-identified, and aggregate chronic disease data.

4.2c I like that data suppression and rate stability are mentioned as considerations for data sharing & use.

“Strategy 5”

This doesn’t seem related to partnerships with healthcare. I would move it to a separate objective devoted to getting leadership buy-in.



“Strategy 5”

Looking at strategy 5 again, I'm not sure why healthcare is specifically highlighted with its own strategy. I think we need partnerships with IT, informatics, infectious disease (since they are usually ahead of us in surveillance modernization), healthcare systems, and communities. Broaden strategy 5 and make partnerships with healthcare one objective of several, because otherwise it seems as though the main/only route for modernization is through getting access to healthcare data (which is only a piece). In my current position, to work towards chronic disease surveillance modernization, I need partnerships within my department and buy-in from leadership before I can move to trying to communicate with healthcare partners.

I agree that partnerships with the healthcare sector is important for chronic disease surveillance, but I also think the social service sector should be included in this strategy as well. Partnerships with that sector will allow for more collection of SDOH data, much of which is related to chronic disease.

Governance seems so critical to modernized chronic disease surv solutions. should we add a action under 5.1 around establishing a governance group/structure for partners (payors, providers, etc...)?

“Strategy 6”

Objective 6.2 feels duplicative of activities already going on. I do not feel it is in chronic diseases best interest to spend time cataloging data modernization resources. CSTE and PHII both have repositories for data modernization, so I would encourage this to be more about leveraging existing partners who are working in this space to improve their catalogs and CoP to meet your needs. With regards to this statement “Establish a community of practice to maintain and update the repository, identify emerging needs, and increase awareness of the resource among all STLTs and partners.” Are you saying establish a CoP for data modernization or for chronic disease specifically. There seemed to already be an objective to establish a CoP for chronic disease so I am assuming this one is for data modernization. There are already far too many groups supporting data modernization as well as many places where folks are trying to build repositories to store this information. Best to work with them to improve what is already out there then build yet another one.

In the spirit of integrating with current data modernization efforts, consider adding as 6.1e or 6.2d: Identify the overlap in tools and functionality needed for data modernization in both infectious and chronic disease, to leverage advancements from the modernization of infectious disease information systems.

Objective 6.3b. Develop talking points and fact sheets for jurisdictions and federal partners to use for raising awareness and making the case for chronic disease modernization to specific audiences (e.g., data stewards; healthcare partners; public health agency leadership; IT staff).

(Add “and federal partners”)

“Strategy 6”

Action items under this objective were confusing. Some areas appear redundant and overlap with objectives 6.2 and 6.3 actions. May be wording that makes it hard for me to understand and unable to immediately see difference from other objectives. Not clear that the action items are focused on technical/analytic aspects of data modernization, if that is what this objective is about.

Central repository seems to be more of an objective than a strategy, but I love the idea of it

“Additional Comments”

The overview, goals and strategies are well put together and showcases the need for chronic disease data. However, there is a gap in how the strategies, objectives and actions will be funded. None of the activities can be implemented without a plan of action for adequate funding. States and local public health agencies are unable to fund large projects and staff development. Budgets have been cut substantially. While many agencies are using the PHIG funding to move DMI forward, without a long-term plan these goals will only be goals. When state and local public health agencies are asked by the CDC to provide performance measure data on healthcare metrics, the funding ask from healthcare systems is too large and the projects are not feasible.

Thank you for the opportunity to review this strategic plan.

I really like the addition of success stories under each strategy. Provides something tangible that is very helpful.

in the spirit of integrating with current efforts (rather than belittling them), change FROM: While the PHDS is highly relevant for all public health data, it does not address the unique challenges and opportunities of chronic disease surveillance needs and priorities or offer specific milestones related to chronic diseases, nor does it specifically address the needs and priorities of STLT jurisdictions.

TO: While the PHDS's four goals are highly relevant for all public health data, it's 2024-2025 milestones primarily focus on acute disease, and address few of the unique challenges and opportunities of chronic disease surveillance needs and priorities or offer specific milestones related

31 to chronic diseases.

(I think the original sentence there is argumentative. It is easy to argue that the PHDS goals address chr. dis. needs, so saying that the PHDS does not address them is likely to be seen as an overstatement. And STLT jurisdiction needs and priorities vary a lot, so whether the PHDS addresses STLT jurisdiction needs and priorities varies by STLT.)

This looks great! A few others from my jurisdiction reviewed and didn't have any feedback and said it covered what they wanted to see in the plan.

Overall, this is looking fantastic! Really provides some useful information and guidance on where we are going. The time, effort, thoughtfulness, and passion to pull this together and continually gather feedback to make it a valuable plan for so many is very much appreciated.



“Additional Comments”

Overall, this seems very high level and it's hard to see how the actions will be implemented. Is there a way to put more emphasis on the action items and provide links to examples of how states are doing this? Success stories are some of the most useful information; it would help to expand on these with more details and/or links.

We also appreciate that this provides a non-CDC resource (for variety) to have in our toolbox.

Thank you to all for the time and effort in drafting this!

I noticed that all of the success stories are state based. Given that one of the arguments is that chronic disease data needs more granularity, it might be helpful to include a success story (if one can be found) from a local jurisdiction.

It's been really great to be able to participate in this process and learn about data modernization.



