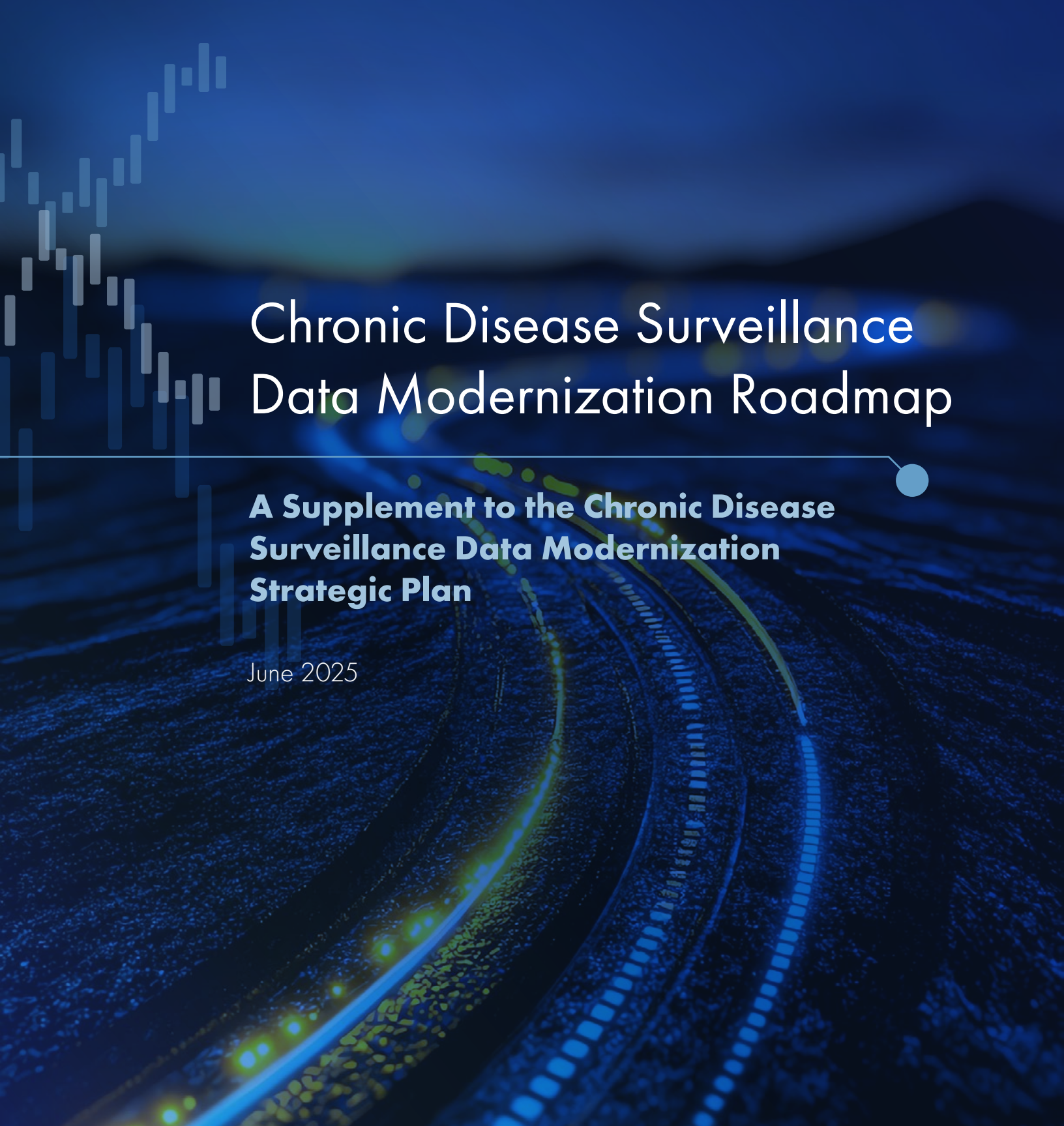




Chronic Disease Surveillance Data Modernization Roadmap

A Supplement to the Chronic Disease Surveillance Data Modernization Strategic Plan

June 2025



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CHRONIC DISEASE SURVEILLANCE DATA MODERNIZATION ROADMAP

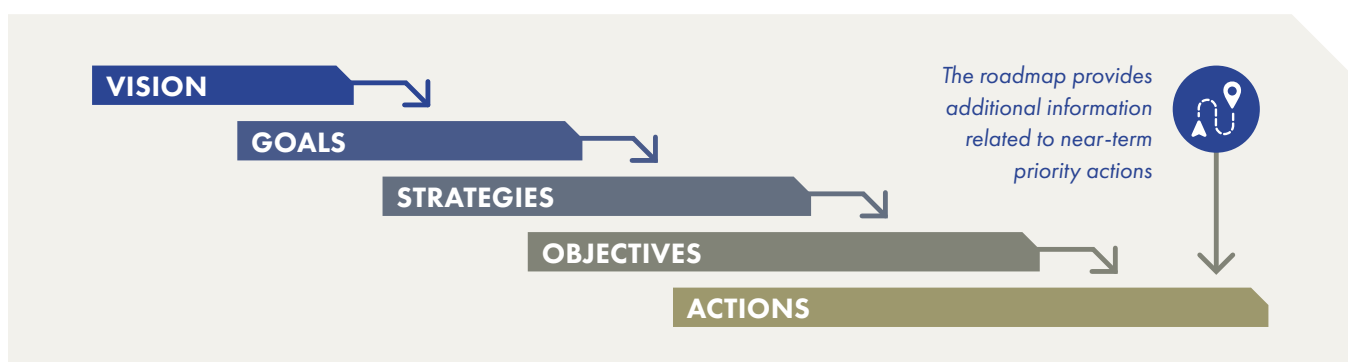
Overview and Introduction

The Chronic Disease Surveillance Data Modernization Roadmap (“roadmap”) is a supplement to the Chronic Disease Surveillance Data Modernization Strategic Plan (“strategic plan”). The strategic plan outlines an overarching vision for chronic disease surveillance in which “diverse partners can leverage a modernized information ecosystem to equitably transform chronic disease surveillance and promote thriving, connected communities.” Implementation of the strategic plan will advance chronic disease surveillance modernization at federal, state, Tribal, local, and territorial (STLT) public health jurisdictions by addressing known and emerging challenges, drawing on existing strengths, and capitalizing on opportunities for coordinating advancements across public health. For more information on chronic disease, chronic disease surveillance, the strategic plan development process, and the broader challenges and opportunities related to chronic disease surveillance modernization, see the strategic plan.

The roadmap serves as a practical guide for stakeholders involved in chronic disease surveillance. It outlines specific actions developed through strategic planning, with each action aligned to a particular strategy and objective in the overall plan. The roadmap is not intended to be step-by-step guidance; rather, it aims to help partners identify which actions are most practical, feasible, and impactful to implement in alignment with the overall vision and goals of the strategic plan. The roadmap can also be used as a framework for evaluation and shared accountability, as the near-term priority actions include “What Success Looks Like” components that can be used as benchmarks to assess progress and sustain momentum. The roadmap should be routinely revisited (see “Sustainability Plan for Implementation”) to track progress on the strategic plan and to identify emerging priorities for collective action.

PROCESS FOR DEVELOPMENT

The Chronic Disease Surveillance Modernization Partners’ Network (Partners’ Network) comprised of over 50 members representing STLT jurisdictions, the Centers for Disease Control and Prevention (CDC), non-profit organizations, and academic research institutions, developed actions in the roadmap through the strategic planning process. CSTE, in collaboration with STLT volunteers, identified near-term priority actions that would be both feasible and most impactful within a year’s timeframe. CSTE further refined near-term priority actions through Roadmap Development Sessions and Focus Groups with STLT jurisdictions.¹ The near-term priority actions in the roadmap reflect those discussions and represent opportunities to focus modernization efforts.



¹ See Appendix 1 for more details.

Guiding Principles

The guiding principles articulated in the strategic plan also inform the roadmap to maximize usefulness, durability, and effectiveness as a foundation for chronic disease data modernization. The principles require that the strategic plan and roadmap:

- Be integrated into federal and STLT modernization efforts.
- Advance health equity.
- Enhance sustainability through shared goals, milestones, and successes.
- Inspire a culture change.
- Facilitate multi-directional communication and coordination to achieve core goals.
- Involve key partners, including public health agencies, healthcare providers, software companies, policy-makers, academia, and communities.

How to Use the Roadmap

The roadmap outlines the steps and considerations for selecting appropriate actions based on your organization's current capacity, needs, and goals for chronic disease surveillance modernization. STLT jurisdictions, federal partners, national associations, and cross-sectoral partners working in chronic disease surveillance can use this roadmap to inform their work planning.

- 1. Review the near-term priority actions to consider which would be most appropriate for your organization based on where you are now, and which actions seems most feasible and impactful.** Near-term priority actions are grouped by strategy and color-coded to show whether they are led by a collaborative workgroup—comprising multiple STLT jurisdictions, federal, and cross-sector partners, possibly hosted by a national organization—or implemented directly at the STLT level. Some actions can be implemented at both levels, such that STLTs can engage in the action in absence of a broader workgroup, though a workgroup could also take on the action to enable efficiency and standardization across jurisdictions. This color-coding is intended to support partners with identifying actions that are most relevant to their organization, whether coming from a STLT jurisdiction, a federal entity, a national association, or other cross-sectoral partner.
- 2. Review additional actions identified through the strategic planning process.** These are available to you in this document and will be available as an interactive dashboard in a forthcoming online toolkit from CSTE and the National Association of Chronic Disease Directors (NACDD). The toolkit will build upon the [strategic plan](#), roadmap, and existing data modernization landscape and support STLT partners with advancing chronic disease surveillance modernization. These actions are organized like the near-term priority actions, showing whether they would be implemented by the workgroup, STLT partners, or both. Reviewing these actions may spark ideas or you may identify actions that are more relevant for your organization at this time. Although the near-term priority actions were defined through Roadmap Development Sessions and Focus Groups with STLT representatives, they may not be reflective of your organization's capacities or near-term priorities.

If you choose some of these actions for your own work plan, you will want to further consider who else to engage for successful implementation, existing resources or materials that could be relevant, and potential outcomes (e.g., How will you know if you have made progress? How will you know when you have successfully completed the action?), as these components have not been defined for the additional actions.

3. **Once you have selected appropriate near-term priority actions and/or additional actions that are most applicable to your organization, consider developing a work plan.** Include timeframes, responsible parties, and other relevant details you will need to implement and complete the actions. See the toolkit for additional tools that may be helpful for implementation.

Sustainability Plan for Implementation

CSTE will revisit the roadmap on an annual basis to elevate and advance activities with funding opportunities and member buy-in, evaluate and share progress, and identify emerging priorities. To maintain transparency and accountability, CSTE will share completed milestones and activities, in progress projects, and priority opportunities for future work on the Chronic Disease Modernization Toolkit webpage.

Strategies and Objectives

Each **strategy** in the strategic plan outlines a specific pathway to achieving its goals. Strategies are interdisciplinary and require coordinated efforts for success. Each includes one or more **objectives** that highlight opportunities for action and progress. These are accompanied by near-term priority actions, additional actions identified through Roadmap Development Sessions and Focus Groups with STLT representatives (see Appendix 1), and relevant success stories.



Strategy 1: Leverage existing data processes, networks, and initiatives to advance chronic disease surveillance needs

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



Strategy 2: Update and develop new approaches to surveillance in response to the changing landscape of available data, information, and technology

OBJECTIVE 2.1: Improve traditional surveillance systems to provide timely and representative chronic disease insights.

OBJECTIVE 2.2: Leverage non-traditional data to enrich traditional data sources.



Strategy 3: Build a skilled, multidisciplinary workforce to increase informatics and chronic disease competencies

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

OBJECTIVE 3.2: Promote continuous learning opportunities to sustain and enhance workforce competencies.



Strategy 4: Evaluate policy landscape to identify gaps and opportunities relevant for equitable chronic disease surveillance modernization

OBJECTIVE 4.1: Conduct a focused policy landscape analysis of data governance policies and legal frameworks.

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



Strategy 5: Build partnerships and identify opportunities to align and promote chronic disease modernization goals

OBJECTIVE 5.1: Build bridges and articulate common values with healthcare partners.

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



Strategy 6: Develop resources to increase uptake of data modernization activities

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

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

Near-term priority actions are STLT-identified, high priority activities based on feasibility and potential impact. For each near-term priority action, the roadmap provides context for getting started, potential collaborators, and potential successes and outcomes from pursuing the action.

Additional actions are important to advance chronic disease modernization but may not be feasible or essential within the next year. The suite of additional actions merits closer review and discussion by STLT jurisdictions to further refine outcomes, potential collaborators, and contextual considerations for implementation.

Success stories from CSTE members showcase progress in chronic disease surveillance across jurisdictions. They highlight challenges related to data modernization, the solutions implemented, and how jurisdictions plan to build on these achievements.

Near-term priority actions and additional actions are color-coded to indicate the entity most likely to lead the effort. It is important to note that STLTs are meant to be involved in each action, including actions led by workgroups.

- WORKGROUP

Actions that can be advanced via collaboration between one or more associations and/or CDC and STLT jurisdictions.
- STLT

Actions that can be advanced at the STLT jurisdiction level and are not dependent on collaboration with an association and/or CDC.
- BOTH

Actions that can be advanced by STLT jurisdictions on their own or in complement to workgroup-led efforts.



Strategy 1. Leverage existing data processes, networks, and initiatives to advance chronic disease surveillance needs

OBJECTIVE 1.1: *Ensure chronic disease surveillance is integrated into new and emerging programs, initiatives, and policies.*

Near-Term Priority Actions

ID	Lead	Action
1.1.A	WORKGROUP	Develop chronic disease case definitions for public health usage of administrative data for chronic disease surveillance. Building on the work of CSTE, NACDD, and CDC, a workgroup of STLT epidemiologists, informaticians, and healthcare partners can develop case definitions for chronic conditions. Case definitions should consider the relevant data sources available to jurisdictions and the minimum data elements needed to conduct routine surveillance. CDC-funded phenotype research, Multi-state Electronic Health Record-based Network for Disease Surveillance (MENDS²) case definitions, and United States Core Data for Interoperability (USCDI) standards should inform these case definitions. The workgroup should consider how data ownership, data sharing, and geographic scale would impact case definitions. By developing the case definitions, STLTs will be able to leverage electronic healthcare information (EHI) to advance their chronic disease surveillance efforts. What Success Looks Like: STLTs have a standardized surveillance infrastructure that supports chronic disease surveillance using administrative data and provides consistent and comparable estimates across jurisdictions.

² For more on MENDS, see [About MENDS - National Association of Chronic Disease Directors](#)

ID	Lead	Action
1.1.B	BOTH	Host a series of listening sessions between informaticians and epidemiologists on chronic disease surveillance to foster collaboration and enhance the effectiveness of data modernization initiatives. These sessions should occur within health departments, hosted by data modernization leads for the jurisdiction, and across health departments if hosted by CDC, CSTE, or other national and STLT organizations. When possible, sessions should include health information exchange (HIE) partners who can help bridge the gap between fields, and infectious disease staff who can share best practices from infectious disease surveillance data modernization that can be adapted to chronic disease. For each listening session, leads should clearly define the agenda, objectives, and key topics of discussion (e.g., strategies for leveraging Data Modernization Initiative (DMI) funding, technological needs, and workforce capacity). Leads can then formulate actionable plans to address the technical requirements necessary to support these initiatives and determine how to build out the necessary infrastructure and tools. These conversations will be crucial in laying the groundwork for coordinated collaboration and ensuring that all parties have aligned goals and expectations. Sessions should address different resource disparities, particularly those among Tribal and territorial jurisdictions, that impact data modernization efforts. What Success Looks Like: Sessions result in actionable data modernization plans for STLT health departments, based on lessons and successes from infectious disease; STLTs strengthen relationships and ability to collaborate among informaticians, epidemiologists, and other involved staff.

Additional Actions

ID	Lead	Action
1.1.C	WORKGROUP	Conduct pilot projects to test chronic disease use cases using existing and emerging data transmission pathways, including electronic case reporting (eCR), syndromic 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 ³).
1.1.D	WORKGROUP	Work to align with USCDI and USCDI+ to ensure comprehensive integration of chronic disease data elements and set the stage for interoperable health information exchange.
1.1.E	WORKGROUP	Develop a plan to integrate data from existing, diverse local, Tribal, and territorial health systems with other chronic disease reporting systems. Integrating Tribal data will specifically require jurisdictions to work with the current Resource and Patient Management System (RPMS).
1.1.F	BOTH	Actively engage with the chronic disease community, including partners at the Association of State and Territorial Health Officials (ASTHO), National Association of County and City Health Officials (NACCHO), NACDD, Public Health Informatics Institute (PHII), CSTE, and others, including those involved in healthcare administration. Leverage these integrated partnerships and shared learning spaces to inform decision-making and collaboration for exchanging data and conducting surveillance.
1.1.G	WORKGROUP	Incorporate chronic disease collaboration and reporting metrics into data modernization work funded by the Epidemiology and Laboratory Capacity for Prevention and Control of Emerging Infectious Diseases (ELC) Cooperative Agreement and Public Health Infrastructure Grant (PHIG), or other federal grants to ensure that DMI priorities can advance both infectious and non-infectious disease work.

³ For more on TEFCA, see [TEFCA | HealthIT.gov](#).

SUCCESS STORIES

Washington State Department of Health: Leveraging GitHub in Chronic Disease Surveillance Workflows and Production

As data projects become more complex and involve multiple contributors, epidemiologists look for ways to work more efficiently to quickly make sense of data. Epidemiologists at the Washington State Department of Health (WADOH) have begun using GitHub, a web platform that allows users to create, store, manage, and share their code. This centralized and secure platform enabled chronic disease epidemiologists to streamline their traditional workflows and production processes. Once staff were upskilled and repositories were set up, they found that using GitHub not only strengthened collaboration between internal analytical teams but gave them more time to focus on high-priority work like data analysis and communicating insights to drive better public health decisions. WADOH plans to expand their use of GitHub and other data tools to continue modernizing their data processes.

Guam Department of Public Health and Social Services: Modernizing Data Collection to Combat Rising Diabetes Rates

The U.S. territory of Guam hosts numerous public health screening fairs each year, organized by a wide range of partners including government, private, non-governmental, and faith-based organizations. To improve the consistency and quality of data collected at these events, the Guam Diabetes Control Coalition (GDCC), a multi-sectoral group, has been working to standardize health screening data for non-communicable diseases. With support from the NACDD, Guam has begun modernizing its data and surveillance systems. This effort was piloted during the Diabetes Alert Day Health Fair on March 23, 2025, where participants used iPad kiosks to record health metrics and demographic information. This streamlined approach enabled faster data analysis and helped identify high-risk individuals more efficiently. The urgency of these efforts is underscored by a sharp rise in diabetes prevalence in Guam—from 11.7% in 2019 to 21.6% in 2022—as well as smoking rates that remain significantly above the U.S. average. Looking ahead, the GDCC is drafting standard operating procedures for lending iPads to community groups, ensuring broader access to these vital health screening tools.

SUCCESS STORY

Washington State Department of Health: Building on the MENDS Pilot Project

Washington State joined the MENDS project, piloting electronic health record (EHR)-based surveillance to produce more actionable chronic disease estimates. Implementing MENDS in Washington required collaboration among various national, state, and local partners including epidemiologists, data scientists, and health informaticians; healthcare providers and administrators; Health IT developers and consultants; and chronic disease program subject matter experts. The MENDS system in Washington currently contains data on approximately 873,000 Medicaid managed care clients collected from provider submissions to the Medicaid Clinical Data Repository. These clients make up one-fifth of Washington's statewide population. As a result, WADOH epidemiologists have gained access to aggregate chronic disease prevalence rates for this large cohort of Medicaid managed care clients. Participating in the MENDS pilot has helped enhance decision-making, advance workforce skills, strengthen collaborative networks, and increase awareness. Building on the success of the MENDS pilot, the significant gains achieved, and the growing interest from partners, WADOH has secured the necessary resources to launch a new EHR-based chronic disease surveillance pilot project with a large healthcare system that provides services at dozens of locations across Washington State.



Strategy 2. Update and develop new approaches to surveillance in response to the changing landscape of available data, information, and technology

OBJECTIVE 2.1: *Improve traditional surveillance systems to provide timely and representative chronic disease insights.*

Near-Term Priority Actions

ID	Lead	Action
2.1.A	WORKGROUP	Develop an evaluation framework for existing surveillance systems and EHI, to identify strengths, challenges, overlap, and unique information. A CSTE member-led workgroup can collaborate with CDC data modernization teams and healthcare representatives to identify surveillance systems and data sources with potential to address chronic conditions. The workgroup should be informed by programmatic expertise and community input to capture the value of each data system. The framework should include steps for STLs to assess data quality, understand how data sources can complement one another, and provide considerations for linking data. What Success Looks Like: Jurisdictions have a clear understanding of the strengths and weaknesses of their current systems and recognize specific areas where improvements can be made to enhance traditional systems or supplement with information from novel data sources.

ID	Lead	Action
2.1.B	BOTH	Develop a tool for STLs to determine the resources needed for managing existing or implementing emerging surveillance systems from workforce, technology, and financial perspectives. The tool, built on the work of existing assessment tools, should be piloted by workgroups led by CSTE that include surveillance epidemiologists and managers, chronic disease leaders, and data modernization directors. The tool should involve a pilot process with a sample of jurisdictions and pilot testing results should be rolled up and reported in summary form, along with the tool for jurisdictions to use. With this tool, STLs should gain concrete information about resources needed to prioritize funding for their chronic disease surveillance modernization efforts. Suggested resources for developing the tool, include: Office of Public Health Data, Surveillance, and Technology (OPHDST) needs and capacity assessments; NACDD chronic disease capacity assessment; PHII health departments' body of work on informatics; surveys of current surveillance teams, data modernization directors, and Information Technology (IT) staff on their experiences and perspectives; and jurisdictional level assessment toolkits. The tool can also include guidance or resources for STLs to educate IT staff on what updates, systems, and technology are needed to pursue data modernization efforts for chronic disease surveillance. What Success Looks Like: Jurisdictions can make data informed decisions about the resources needed for data modernization workforce, technology, and funding.

OBJECTIVE 2.2: *Leverage non-traditional data to enrich traditional data sources.*

Near-Term Priority Action

ID	Lead	Action
2.2.A	WORKGROUP	Create an Electronic Health Record (EHR) validation plan for chronic disease surveillance. The CDC, in collaboration with infectious disease or other data receivers and interoperability points of contact, are important partners to include because they have funded phenotype research that can inform the plan. A validation plan (1) identifies opportunities to augment surveillance using innovative and timelier data sources (i.e., EHR, All-Payer Claims Databases (APCDs), HIE, etc.) and (2) helps to increase buy-in from leadership on new ways of monitoring data and trends, complementing and improving current systems and processes. What Success Looks Like: An EHR validation plan is made available and enhances jurisdictions' ability to use EHR data for chronic disease surveillance.

Additional Actions

ID	Lead	Action
2.2.B	BOTH	Review methodologies for surveys and other traditional surveillance data sources and identify opportunities to increase participation, representativeness, accuracy, and completeness. Federal partners could consider different approaches to chronic disease data collection that is locally tailored for community needs.
2.2.C	BOTH	Determine where critical lag times occur for collecting, processing, and reporting population health survey data and identify potential mitigation strategies by working together with entities involved in each stage, including CDC, contractors, and others.
2.2.D	BOTH	Determine the geographic granularity and protected health information needed for optimal chronic disease surveillance, including identifying health inequities.

ID	Lead	Action
2.2.E	BOTH	Explore opportunities to leverage advanced analytics, machine learning, and artificial intelligence (AI) to detect and predict patterns, and support public health decision-making.
2.2.F	BOTH	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.

SUCCESS STORIES

Washington State Department of Health: Enhancing Spatial Analysis in Chronic Disease Surveillance Through a Low-Cost, User-Friendly Approach

Public health interventions and resource allocations depend on the understanding of geographic distributions and impacts of chronic disease outcomes at the sub-county level. In Washington State, chronic disease and Geographic Information System (GIS) epidemiologists have partnered together to expand spatial analysis capabilities to properly identify areas disproportionately affected by chronic disease. By integrating the use of several tools (e.g., FleXScan, SaTScan, and GeoDa) in GIS workflows, epidemiologists are able to create maps with more accurate representations of chronic disease impact, improve decision-making to apply equity-focused public health strategies, and strengthen analytical partnerships. Epidemiologists will be leveraging these new spatial analysis tools to further examine sub-county chronic disease surveillance data from CDC PLACES, All-Payer Claims Databases, and Vital Statistics.

Dallas County Health & Human Services: Enhanced Surveillance to Address Pediatric Asthma

Asthma is a major health issue among children in Dallas County, Texas, with notable disparities affecting low-income and minority children. These children face higher exposure to environmental triggers and poor housing conditions, which increase both the prevalence and severity of asthma. Recent Community Health Needs Assessments (CHNAs) have identified asthma as a key driver of pediatric morbidity and mortality in the area. In response, Dallas County Health & Human Services (DCHHS) staff explored various strategies to improve asthma outcomes, including enhanced asthma surveillance and monitoring. This effort led to the creation of the Pediatric Asthma Surveillance System (PASS), developed by DCHHS in collaboration with Parkland Health and the Parkland Center for Clinical Innovation. The PASS tool includes two key components: (1) a vulnerability index that assesses pediatric asthma risk based on clinical, environmental, and social factors, and (2) an AI-driven, interactive dashboard for community use. This dashboard highlights high-risk areas for poor asthma outcomes at the zip-code and census-tract levels using color-coded maps and impact scores. PASS was launched as a Power BI-based tool on the DCHHS website, featuring visualizations of risk predictors, community demographic profiles, and variable-specific impact scores. Building on the success of PASS, DCHHS plans to expand this approach to monitor other chronic diseases such as diabetes and hypertension. The broader goal is to strengthen the public health infrastructure in Dallas County by addressing the rising burden of chronic diseases, fostering cross-system collaboration, and improving overall population health outcomes.



Strategy 3. Build a skilled, multidisciplinary workforce to increase informatics and chronic disease competencies

OBJECTIVE 3.1: *Enhance chronic disease informatics capacity through integrated training opportunities and engagement with data modernization staff.*

Near-Term Priority Action

ID	Lead	Action
3.1.A	STLT	Support the professional development of current staff by promoting existing training opportunities with relevance to chronic disease data modernization. STLTs can take advantage of existing fellowships and training programs by partnering with infectious disease programs and informatics teams within their jurisdiction to develop opportunities that support multiple systems, including chronic disease. A national association, CDC, or other entity with a national view of data modernization efforts should support STLTs in this action by creating a resource list of existing training programs of interest for chronic disease public health staff, as described in Action 6.1.A.⁴ Training programs may include CDC's Public Health Informatics Fellowship Program (PHIFP), Epidemic Intelligence Service (EIS) officers, CSTE's Applied Epidemiology Fellowship (AEF), the Applied Public Health Informatics Fellowship (APHIF), or CSTE's Data Science Team Training program (DSTT). What Success Looks Like: More STLTs can apply for and complete training and fellowship opportunities, increasing jurisdiction-level capacity for chronic disease surveillance modernization.

Additional Actions

ID	Lead	Action
3.1.B	STLT	Assess current skill levels and training needs for epidemiologists, informatics, and data science staff. STLTs should leverage capacity-specific frameworks described in Action 6.2.A to justify staff skills assessments to address training needs. ⁵
3.1.C	STLT	Promote and incentivize sharing technical expertise across public health programs to leverage existing informatics and data modernization staff for chronic disease modernization efforts.
3.1.D	WORKGROUP	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. Trainings should include specialized modules for informatics staff to understand the workflows and needs of chronic disease programs, including technical and standards solutions.
3.1.E	STLT	Explore opportunities to expand the programmatic workforce through braided funding streams. Expand or use existing funding for informatics fellows to support chronic disease data modernization efforts across STLTs.

⁴ Action 6.1.A - Develop a "collaboration and learning" navigation toolkit to provide engagement opportunities, tools, templates, success stories, implementation guides, and pilot opportunities.

⁵ Action 6.2.A - Develop a set of tailored frameworks that STLTs can utilize based on results from their self-assessment of current capacity and needs for chronic disease surveillance modernization.

ID	Lead	Action
3.1.F	STLT	Engage schools of public health and community partners to incorporate data modernization and informatics into Master of Public Health (MPH) criteria and competencies. 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 could provide opportunities across public health domains to ensure data modernization supports all diseases and conditions.

OBJECTIVE 3.2: *Promote continuous learning opportunities to sustain and enhance workforce competencies.*

ID	Lead	Action
3.2.A	WORKGROUP	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.
3.2.B	BOTH	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.
3.2.C	BOTH	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

OBJECTIVE 4.1: *Conduct a focused policy landscape analysis of data governance policies and legal frameworks.*

Near-Term Priority Action

ID	Lead	Action
4.1.A	BOTH	Engage with Tribal health authorities to understand Tribal data needs, data sharing concerns, opportunities, and legal or governance considerations related to this strategy. Tribal sovereignty should be prioritized at the forefront of all data modernization work agreements. It is the collective responsibility for all federal, state, and local public health organizations to prioritize Tribal engagement in their data modernization efforts. Partner associations can further advocate for and support these engagements. Discussions at the national level should cover methods to analyze race in ways that are meaningful for tribes and develop strategies to better capture Tribal enrollment. This action should take place within listening sessions described in Action 1.1.B.⁶

⁶ Action 1.1.B - Host a series of listening sessions between informaticians and epidemiologists working on chronic disease surveillance to foster collaboration and enhance the effectiveness of data modernization initiatives.

ID	Lead	Action
		What Success Looks Like: Tribal partners report improved relationships with the health agencies and can access the data they need in a timely and coordinated way.

Additional Actions

ID	Lead	Action
4.1.B	WORKGROUP	Conduct policy landscape analysis of data governance policies and legal frameworks relevant to chronic disease data sharing.
4.1.C	BOTH	Identify existing models used to share identified, de-identified, and aggregate chronic disease data.

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

Near-Term Priority Action

ID	Lead	Action
4.2.A	WORKGROUP	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. Existing efforts through CDC’s data sharing agreements and the Implementation Centers’ legal resources should collaborate with STLT representatives to generate resources, share guidance, and alleviate legal challenges to facilitate data exchange. The guidance should consider data ownership and geographic scale and should support standardization and improved interoperability between datasets. The guidance should address linkage considerations—such as data suppression, rate stability, and any state- or dataset-specific suppression rules—when planning for data sharing and use. What Success Looks Like: STLTs feel confident engaging in data sharing conversations with internal and external partners to improve their access to chronic disease information.

Additional Action

ID	Lead	Action
4.2.B	WORKGROUP	Ensure chronic disease-related data needs are incorporated and met in the CDC-led national core data use agreement (DUA) which includes common provisions and data source-specific addenda for STLT sharing to CDC.

SUCCESS STORY

Association of State and Territorial Health Officials: Establishing Public Health Data Sharing Agreements with Tribal-serving Organizations

With PHIG funding, the Alaska Division of Public Health (DPH) and the Alaska Native Tribal Health Consortium (ANTHC) established a practical legal framework for data sharing between their organizations. The framework includes an umbrella agreement (data use agreement) that other jurisdictions can adapt to improve data sharing with more Tribal-serving organizations.

Historically, the Alaska Native Epidemiology Center (ANEC) within ANTHC experienced numerous barriers when requesting DPH data to support their public health surveillance, education, and intervention efforts among Alaskan Natives and Native Americans in Alaska. Despite DPH leadership's desire to disclose more public health data to ANTHC, their efforts to do so were often hindered by the lack of a formal data disclosure policy; without one, there were no consistent or recognized standards for evaluating data requests from ANTHC and no process for handling them swiftly, consistently, and effectively. To address these challenges, DPH sought and received funding from ASTHO to hire a legal consultant to help develop a legal framework to support long-term data sharing between DPH and ANTHC.

The legal consultant collaborated with DPH, ANTHC, and ANEC to understand their goals for data sharing and existing barriers. Additionally, the consultant reviewed existing data sharing agreements between DPH and ANTHC, evaluated DPH's legal authority to disclose health data, and ANTHC's legal authority to have such health data, including protected health information.

Following the research process and negotiations between DPH and ANTHC, a suite of documents was produced to streamline data sharing. An umbrella agreement was established to ensure that DPH could share data with ANTHC for public health purposes. A data disclosure appendix was also developed to inform data sharing for specific data systems. Lastly, a data request form was created to support DPH staff with processing ANTHC's data requests. Throughout this process, DPH and ANTHC strengthened their partnership, and staff gained a clearer understanding of their data sharing policies, which greatly reduced the time and resources needed for DPH's legal staff to process ANTHC's data requests. For more details on this process, refer to the ASTHO article, "[Tribal Data Sharing Lessons from Alaska](#)".



Strategy 5. Build partnerships and identify opportunities to align and promote chronic disease modernization goals

OBJECTIVE 5.1: *Build bridges and articulate common values with healthcare partners.*

Near-Term Priority Actions

ID	Lead	Action
5.1.A	WORKGROUP	Develop materials for STLT-led workshops and training sessions to inform partners about the role of data modernization in chronic disease prevention and control. CSTE would develop the content for the workshops and training sessions for STLTs to implement with stakeholders in their respective jurisdictions. These workshops and training sessions should further support collaboration between STLTs and healthcare providers and payors to support chronic disease surveillance modernization. STLTs should better understand how healthcare providers and payors gather patient data, and healthcare providers should learn how sharing their data supports broader chronic disease prevention and control efforts. What Success Looks Like: Chronic disease directors are better connected with healthcare partners and feel confident articulating the value of chronic disease data for public health work.
5.1.B	BOTH	Begin legal discussions to identify opportunities to increase chronic disease data sharing and integration efforts. Associations, such as NACCHO, ASTHO, NACDD, and CSTE can host forums for STLTs to engage with one another and share best practices and lessons learned to improve data sharing and integration. To support STLTs in these conversations, a national association or other organization, such as the Network for Public Health Law, should develop a standard process or template that STLTs should use to assess their own legal environment. Since there are various legal requirements and barriers that impact data sharing, STLTs need adequate resources to engage in conversations that would facilitate data exchange across jurisdictions and between healthcare and public health partners. What Success Looks Like: STLTs gain a clearer understanding of their own legal environments and those of other jurisdictions regarding data sharing, including key barriers and potential solutions.

Additional Actions

ID	Lead	Action
5.1.C	WORKGROUP	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.
5.1.D	BOTH	Begin discussions around Health Insurance Portability and Accountability Act (HIPAA) regulations to expand public health use cases to allow STLTs to be more permissive with geographic variables without revealing personal health information (PHI).
5.1.E	BOTH	Identify mechanisms to collect healthcare data from EHRs and make it more easily available to chronic disease programs.

ID	Lead	Action
5.1.F	BOTH	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.*

ID	Lead	Action
5.2.A	BOTH	Build relationships and communities of practice among public health agency leadership, data modernization staff, chronic disease epidemiologists, and programmatic staff to increase collaboration and peer learning.

SUCCESS STORIES

Great Lakes Inter-Tribal Epidemiology Center: Coordinating Data Use Agreements with Service Area States

Chronic disease surveillance for Tribes depends on access to critical data from Tribal members. With over 70% of American Indians/Alaska Natives (AI/AN) living in urban areas, their health data is often housed by non-Tribal health authorities. However, under the 2010 Affordable Care Act, Tribal Epidemiology Centers (TECs) were formally recognized as public health authorities and granted access to data held by the U.S. Department of Health and Human Services (HHS). The Great Lakes Inter-Tribal Epidemiology Center (GLITEC) coordinated with two service area states (Michigan and Wisconsin) to establish DUAs that would allow them access to Tribal member data. The process involved building strong relationships with state-level Tribal liaisons to coordinate with stakeholders who needed to be involved in preparing the DUA. Stakeholders included Tribal leadership, Tribal health directors, state health officials, TEC directors, data stewards, and lawyers who collaborated for over a year to complete the DUA. GLITEC plans to use their DUA with the Michigan Department of Health & Human Services and Wisconsin Department of Health Services to create a health data dashboard that local Tribes can access via a secure link. Additionally, the process for establishing this DUA could serve as a framework for creating additional DUAs between TECs and other jurisdictions.

Utah Department of Health & Human Services: Healthcare Providers Pilot Project

The Utah Department of Health & Human Services (DHHS) established a chronic disease workgroup to collaborate with healthcare providers (i.e., federally qualified health centers) to pilot projects to improve clinical data collection and exchange between the healthcare sector and public health. This work has allowed Utah DHHS to pilot data collection on five chronic disease use cases: diabetes, hypertension, Alzheimer's disease and other related dementias, arthritis, and asthma. This work highlighted how clinical data can be used to support chronic disease program decision making as well as identifying areas of need to make this clinical data collection sustainable and useful.



Strategy 6. Develop resources to increase uptake of data modernization activities

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

Near-Term Priority Actions

ID	Lead	Action
6.1.A	WORKGROUP	Develop a “collaboration and learning” navigation toolkit to provide engagement opportunities, tools, templates, success stories, implementation guides, and pilot opportunities. A chronic disease subcommittee within CSTE or another special forum for data modernization should develop the toolkit. The toolkit should include input from diverse perspectives, including those from partners in healthcare and data stewards. The toolkit should provide a standardized, stepwise process for data modernization implementation that lowers the barriers to implementation for jurisdictions. Development of the toolkit should include sustainability planning to ensure that it is actively maintained over time, as related to Action 6.1.B.⁷ The toolkit should promote knowledge sharing across all levels of chronic disease management and support STLs with increasing informatics and chronic disease expertise among staff as related to Action 3.1.B.⁸ Resources on data modernization from existing public health organizations (e.g., CSTE, CDC, and PHIL), the business sector, and other sectors should be adapted to inform the development of the toolkit. What Success Looks Like: Chronic disease epidemiologists and program staff have an increased knowledge of data modernization activities and opportunities to leverage those activities to support their work.
6.1.B	WORKGROUP	Establish or leverage an existing community of practice to maintain and update the toolkit (developed in Action 6.1.A), identify emerging needs, and increase awareness of the resource among all STLs and partners.⁹ Given CSTE’s role in bridging chronic disease and data modernization experts, the organization should take the lead in facilitating a community of practice composed of STL members. The NACDD or the Data Modernization Learning Community should also support ongoing maintenance and promote the toolkit. The community of practice should work in alignment with surveillance priorities that other organizations are pursuing (e.g., NACDD and Chronic Disease in Rural America) to ensure that the toolkit reduces redundancies and supports STLs with increasing their knowledge and implementation of data modernization activities across jurisdictions. The community of practice should be comprised of diverse membership of STLs and partners, reflecting the data ecosystem envisioned through this work. Over time, the community of practice will promote the toolkit among their partners and jurisdictional staff and ensure that it aligns with STLs’ needs. The community of practice should track the toolkit’s dissemination jurisdictional examples of the toolkit being used for chronic disease modernization activities.

⁷ Action 6.1.B - Establish or leverage an existing community of practice to maintain and update the toolkit (developed in Action 6.1.A), identify emerging needs, and increase awareness of the resource among all STLs and partners.

⁸ Action 3.1.B - Assess current skill levels and training needs for epidemiologists, informatics, and data science staff.

⁹ Action 6.1.A - Develop a “collaboration and learning” navigation toolkit to provide engagement opportunities, tools, templates, success stories, implementation guides, and pilot opportunities.

ID	Lead	Action
		What Success Looks Like: The toolkit provides relevant and timely information that reflects existing priorities and opportunities. STLTs have an increased familiarity with data modernization principles and engage in more robust conversations to implement modernization opportunities.

Additional Actions

ID	Lead	Action
6.1.C	BOTH	Identify or create shared tools and resources such as downloadable code snippets, templates, visualizations, and best practices, that can be used by all STLT jurisdictions to improve their chronic disease surveillance capabilities. Since local jurisdictions typically need to use multiple data sources for surveillance, they would also benefit from having an implementation guide to understand what data sources to use, how to use them, and what information is provided by data sources on different populations.
6.1.D	WORKGROUP	Develop guidance for connecting data systems that define shared systems and data sources in the chronic disease surveillance landscape. Include details on how existing data systems are used by STLTs and points of contact for support.
6.1.E	BOTH	Increase awareness of and leverage resources at the federal level, when available, to support modernization efforts at state, Tribal, local, and territorial jurisdictions.

OBJECTIVE 6.2: *Develop guidance and other materials for STLT staff to begin their data modernization efforts.*

ID	Lead	Action
6.2.A	WORKGROUP	Develop a set of tailored frameworks that STLTs can utilize based on results from their self-assessment of current capacity and needs for chronic disease surveillance modernization, refer to the assessment in Action 2.1.B. ¹⁰ These capacity-specific frameworks will guide STLTs in prioritizing activities, making informed decisions, and building capacity for chronic disease surveillance modernization. Leverage existing information from NACCHO's informatics capacity surveys when designing the frameworks.
6.2.B	WORKGROUP	Develop consistent national policy talking points and fact sheets for jurisdictions and federal partners to raise awareness and advocate for chronic disease data modernization and timely access to data. Materials should be tailored to specific audiences with varying levels of technical understanding (e.g., data stewards, healthcare partners, public health agency leadership, Information Technology staff). They should include consistent messaging and highlight information such as the data-to-action path, a graphic workflow for collecting and exchanging data across STLTs and other health data stewards, and qualitative or quantitative data on how these efforts contribute to data security, accessibility, public health, and healthcare across the nation.

¹⁰ Action 2.1.B - Develop a tool for STLTs to determine the resources needed for managing and implementing existing and emerging surveillance systems from workforce, technology, and financial perspectives.

APPENDIX 1. ROADMAP DEVELOPMENT PROCESS



Overview

Development of the national strategic plan for chronic disease surveillance data modernization began in late 2023 when CSTE convened several partner organizations and STLT jurisdictions into the Partners' Network. The Partners' Network represented a multidisciplinary group of experts including applied chronic disease epidemiologists, program directors, public health organizations, policymakers, healthcare organizations, community partners, and government agencies. STLT jurisdictions in the Partners' Network primarily represent 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 an initial inventory, opportunities were categorized into five groups adopted from the CDC Data Modernization Initiative: Data, People, Process, Technology, and Policy. During subsequent months, the Partners' Network regularly met –in person and virtually– to refine ideas into the vision, goals, strategies, and objectives that comprised the strategic plan. These elements then informed the development of actions for each objective. Actions were further prioritized and defined by CSTE and STLT jurisdictions for the roadmap to include metrics of success and necessary activities to support implementation.

Roadmap Development Sessions

In October 2024, CSTE-led three Roadmap Development Sessions during which STLT jurisdictions and other partners refined elements of the roadmap. During Session 1, "Prioritizing Actions", participants discussed the capabilities and perspectives represented by the roadmap; identified attainable, one-year actions for STLT jurisdictions across strategies; and evaluated gaps across actions. In Session 2, "Metrics of Success", participants identified quantifiable metrics of success for Near-term Priority Actions and described existing tools or resources to support implementation of the actions. Lastly, Session 3, "Defining Collaboration", focused on describing the necessary collaborations for implementation and ways to meaningfully engage STLT jurisdictions in implementation of the roadmap. Session 3 also helped to improve specificity of actions by assigning responsibility and highlighting how STLT jurisdictions could be involved in implementation.

Roadmap Focus Groups

As part of CSTE's effort to develop the roadmap, Ross Strategic facilitated 12 focus groups with STLT jurisdictions in between January and March 2025. STLT jurisdictions were contacted to participate in focus groups based on their participation in the Partners' Network, response to the 2024 chronic disease surveillance modernization survey where respondents were asked if they would like to participate in future efforts related to the strategic plan, and participation in CSTE Roadmap Development Sessions conducted in August and September 2024.

The table below provides an overview of the focus groups and the strategies they discussed. Focus groups were conducted across state, territorial, local, and Tribal jurisdiction levels and included two to four staff from each agency who worked in various departments (e.g., informatics, epidemiology, and evaluation). Each focus group primarily discussed one of the six Strategies in the roadmap along with relevant Near-term Priority Actions and Additional Actions.

Strategy Covered in Focus Group	Agency
1	Local San Antonio Metro Health (Texas)
1	Tribal Great Plains Tribal Epidemiology Center
2	Local Public Health - Seattle & King County (Washington)
2	State Utah Department of Health and Human Services
3	State Vermont Department of Health
4	State Montana Department of Public Health and Human Services
4	Local East Shore District Health Department (Connecticut)
5	Local Fairfax County Health Department (Virginia)
5	Tribal Great Lakes Inter-Tribal Epidemiology Center
6	State Kansas Department of Health and Environment
6	Local Snohomish County Health Department (Washington)
1, 3, 4, 6	Territories and Freely Associated States Commonwealth Healthcare Corporation (Northern Mariana Islands), Guam Department of Public Health and Social Services

After completing the focus groups, Ross Strategic developed a synthesis document that summarized feedback received from focus group participants related to Strategies, Near-term Priority Actions, and Additional Actions. The synthesis document was organized by Strategy, with tables detailing original action language, comments received from focus groups, and proposed revisions for input from CSTE.

