Case Service Design Year One Discovery

Case Service Design | September 2025

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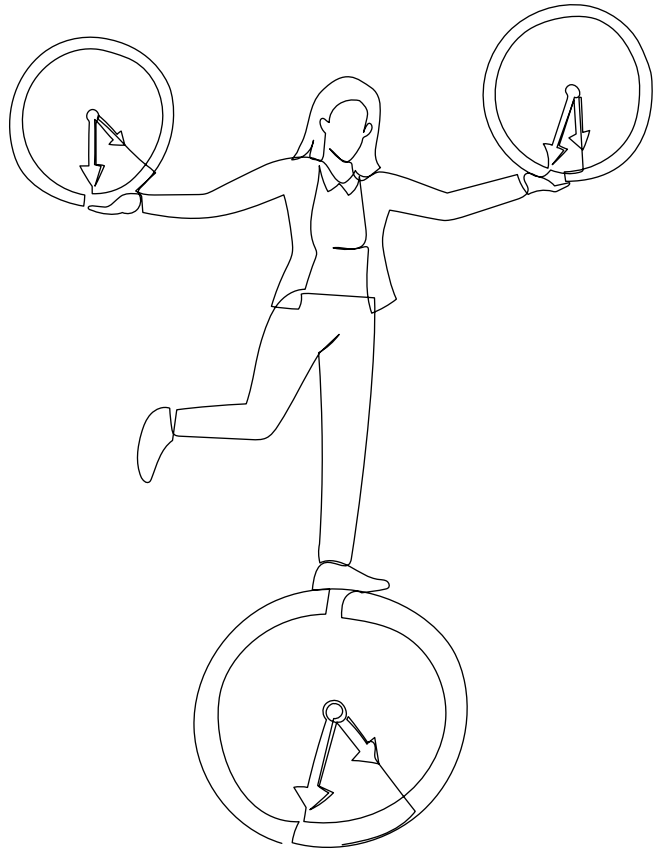


Overview

Year 1 Discovery

A summary of the CSD initiative in Year 1 captures the current state of public health, including archetypes that define the roles and responsibilities, a consolidated list of all the pain points we heard and moments that matter to address the pain points, and a wishlist inventory of potential solutions.

- Archetypes are definitions of types of workers across public health. Archetypes help us build alignment and understanding for the people whose problems we are solving.
- We've included an exhaustive list of pain points, moments that matter, and wishlist solutions to ensure we've captured everything we heard for inspiration and use moving forward.

How do we use these tools?

Standardizing how to talk about our problems creates efficiency in solving them. When we are solve problems together, we can:

- Reference moments that matter, jobs to be done and what must be trues in the future state story to provide context
- Use archetypes to understand variability across different jurisdictions and territories and build empathy for who we are solving problems
- Reference pain points so we know what Big Rocks we are chipping away at
- Reference the wishlist to inspire our solutions

As we use these tools together, we remove redundancy across public health and ensure that we are building a public health service that works for everyone.

About Case Service Design (CSD)

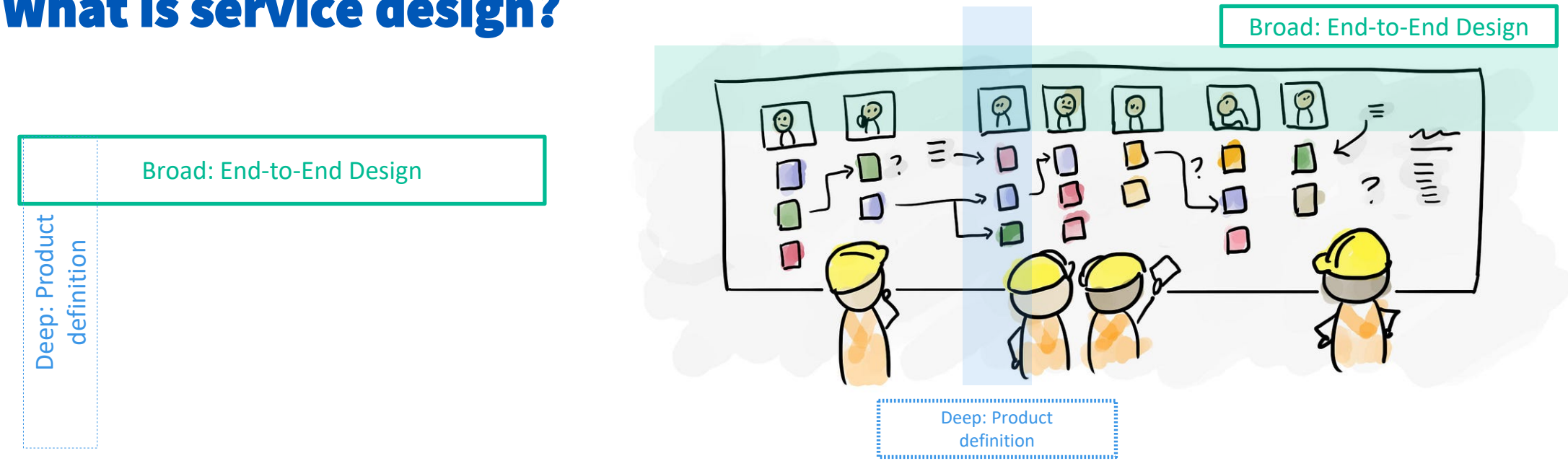
Case Service Design (CSD), a collaboration across public health to design and implement human-centered solutions for case data exchange among state, tribal, and local (STL) health departments, CDC, healthcare, and associated partners.

A multidisciplinary team of experts in public health, design, and technology is taking a holistic view of case data exchange across the entire public health ecosystem. The team is designing human-centered solutions for case data exchange comprehensively, from the point of care to public health action. This work will define the future state for case data exchange and inform the evolution of the Public Health Data Strategy, disease reporting and notification, core data, and 1CDP.

Note:

- *We collected qualitative data from a diverse sampling of STL and CDC programs. Data presented here reflect themes and patterns we identified from qualitative interviews with a diverse sampling of STL and CDC programs.*
- *Initial information collection did not include territories. It is likely they will share many of the same challenges. Our intent is to validate these findings with territories in the future.*

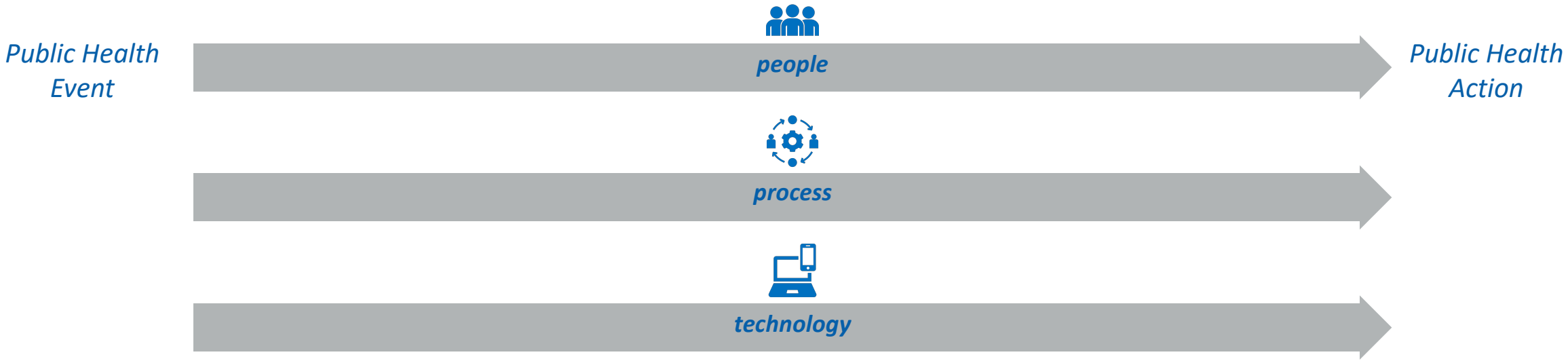
What is service design?



Service design helps organizations see end-to-end, surface-to-core perspectives so that they can strategically define solutions, streamline processes, eliminate unnecessary burden, and improve customer experience.

- Breaks siloed solutions by designing across multiple products and services
- Crafts more satisfying customer experiences by analyzing and reimagining the customer journey
- Orchestrates physical actions touchpoints with the behind the scenes processes and systems
- Provides direction for achieving strategic goals
- Ensures alignment on future state by using human-centered design methods

Service design connects people, processes, and technology



Holistic design

Solves systemic problems and connects siloes across state, tribal, local, territorial and CDC

Human-centered approach

Puts the public health workforce at the center of the design process

Data for public health action

Ensures easier access to the data you need when you need it

Designing the future state

Informs the evolution of the Public Health Data Strategy

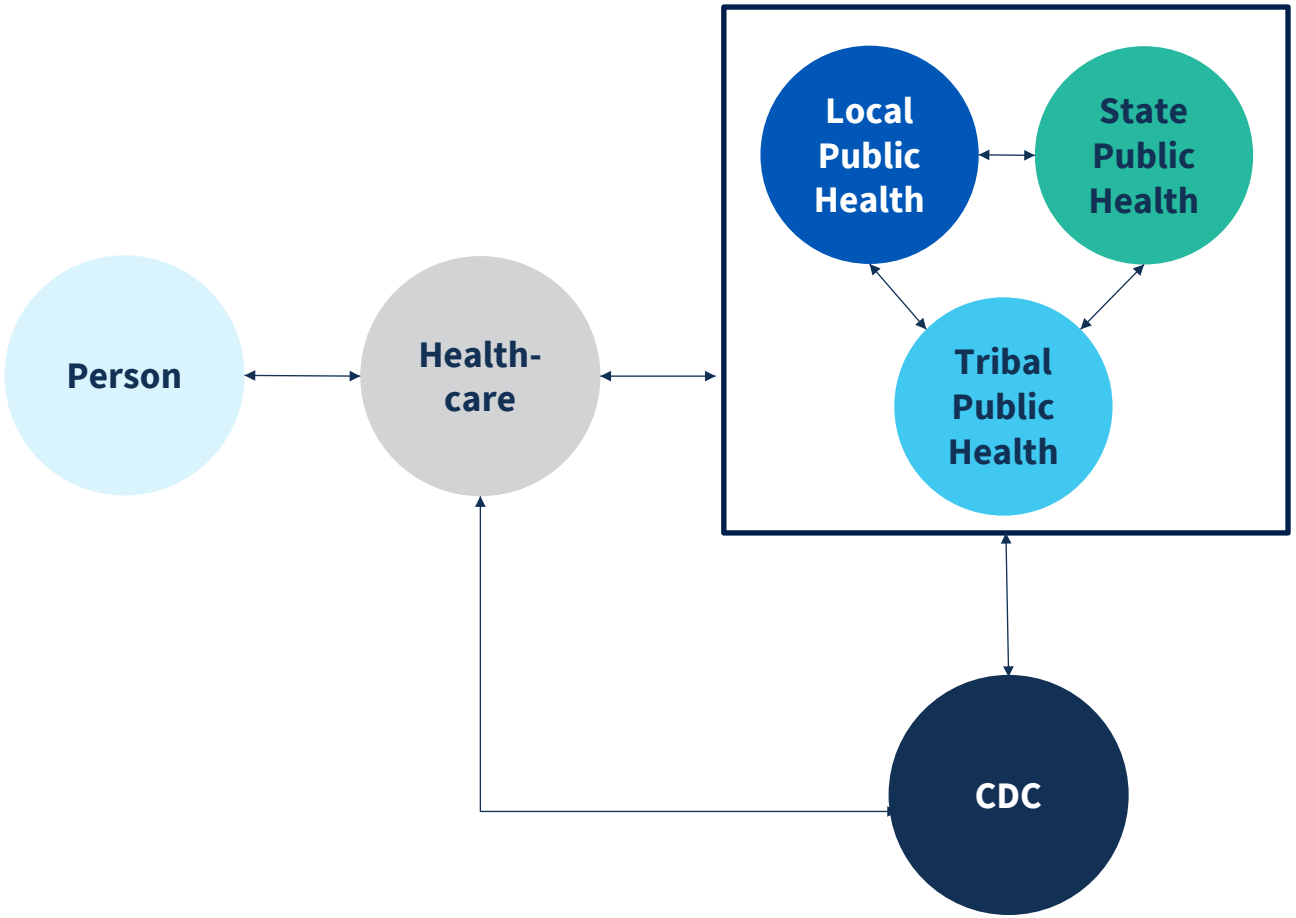
Health Department Context

Health department needs for data and technology infrastructure differ based on:

- State public health governance structure
- Responsibilities
- Resources

Collaboration bridges technical gaps along the data chain

- **Data chains represent the flow of information among people, healthcare, and public health entities.**
- **Effective public health action is possible when all parties along the data chain have clear roles and active participation.**
- **Deep collaboration prevents breaking the data chain and helps coordinate investments and responsibilities**
  - State health departments may provide many services for local health departments
  - Technologically under-resourced states can lean on CDC or collaborate with large local health departments and each other for infrastructure
  - Tribes with limited technology resources may collaborate with more well-resourced tribes, Tribal Epidemiology Centers, or nearby local
    or state public health

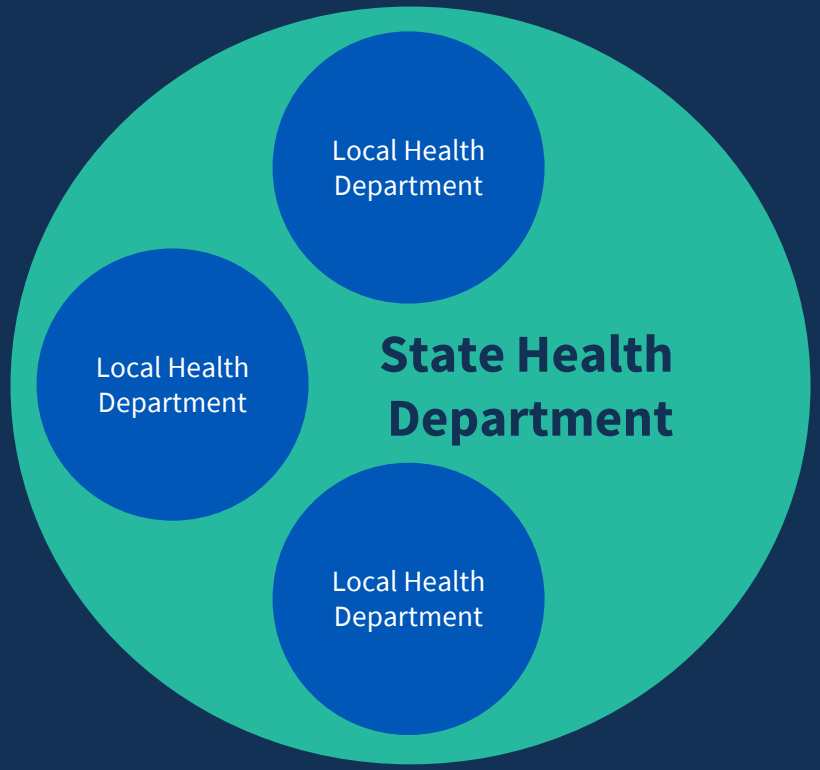


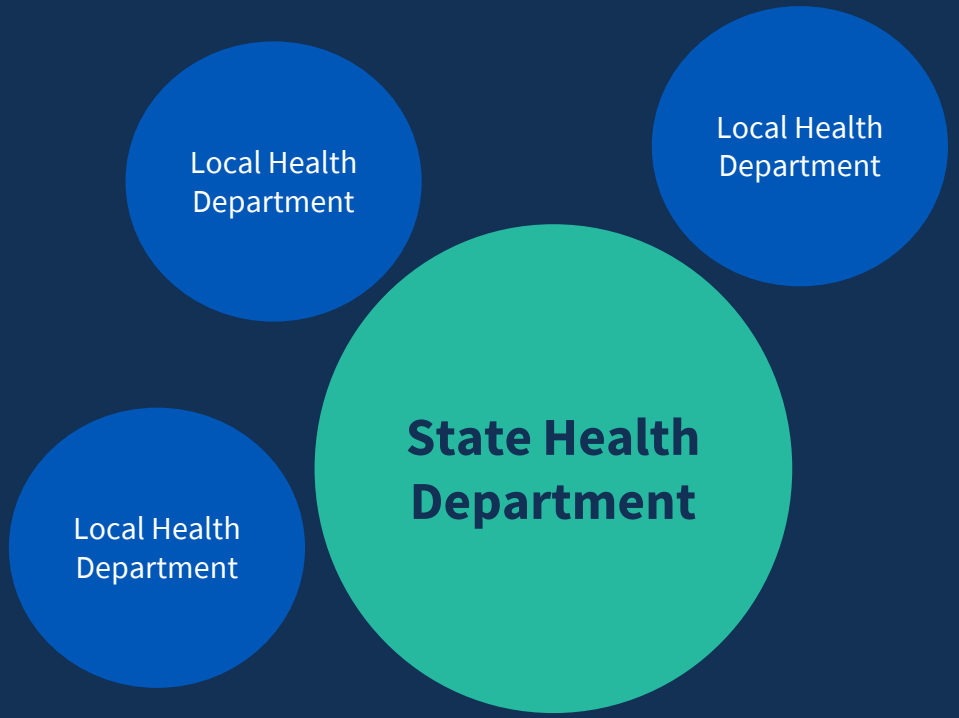
Public Health Governance and why it matters for data exchange

Centralized: Some local health departments are part of the state health department – they are likely to depend on state funding and share resources with the state public health agency

Mixed: Some local health departments are governed by both state and local authorities

Decentralized: Some local health departments are part of local government – they are likely to have local funding, get local direction and share infrastructure with other agencies in their community





https://www.astho.org/globalassets/pdf/state-local-governance-classification-tree.pdf

Health Department (HD) Size, Complexity, and Responsibilities

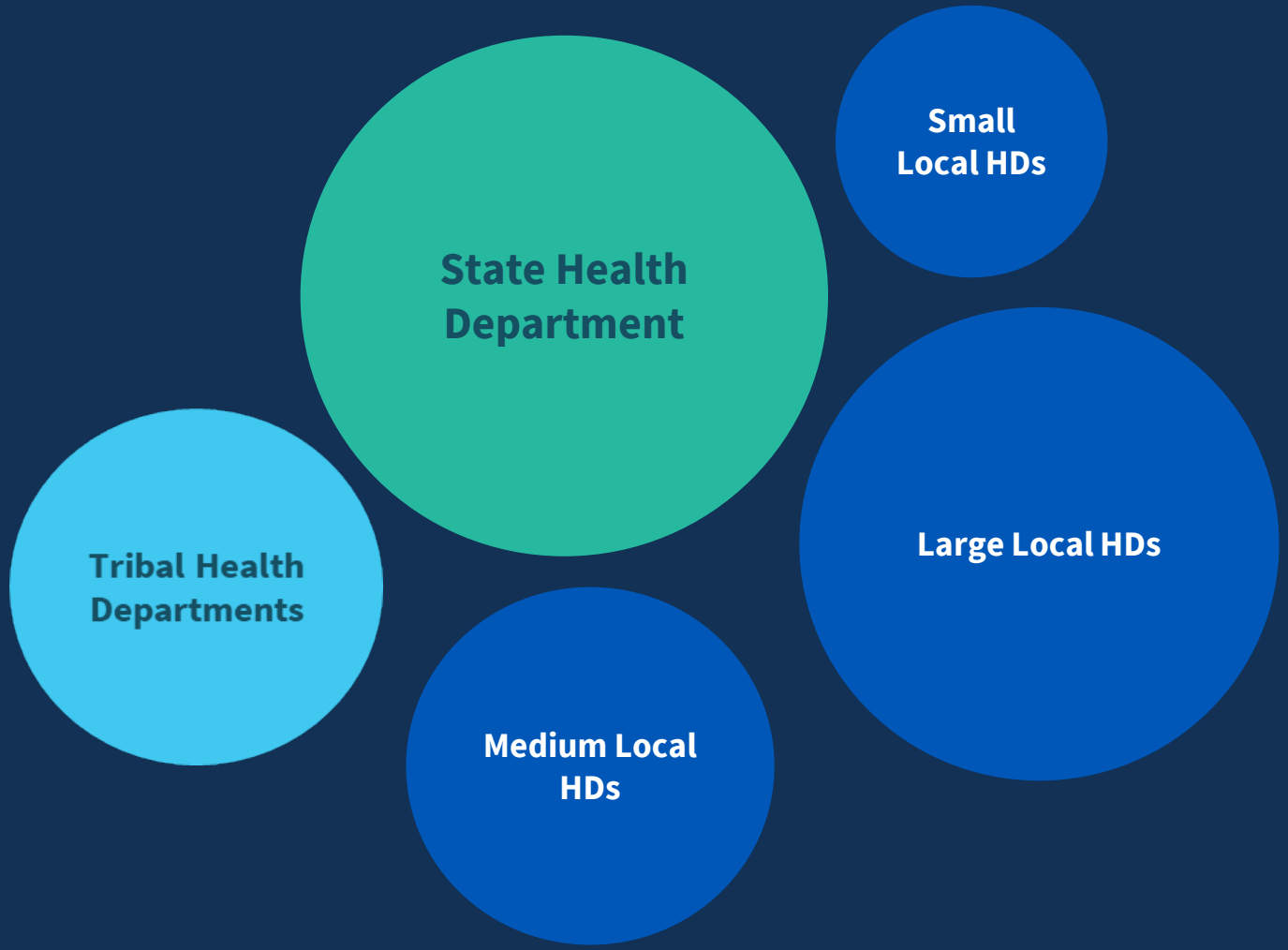
In many states, the state health department

- Is the largest public health agency
- Provides scientific and policy leadership
- Provides some statewide public health services
- Maintains infrastructure used by public health agencies throughout the state
- Receives funding from CDC for activities
- Runs the disease surveillance system and transmit statewide data to CDC

Compared to the state health department, some large local health departments may

- Have more funding
- Have more staff
- Provide more services
- Have better technology infrastructure
- Get funding directly

Tribal Health Departments provide important services to their communities, and have unique relationships with federal, state and local public health



https://www.naccho.org/uploads/downloadable-resources/Programs/Public-Health-Infrastructure/NACCHO_2019_Profile_final.pdf

Working Relationships

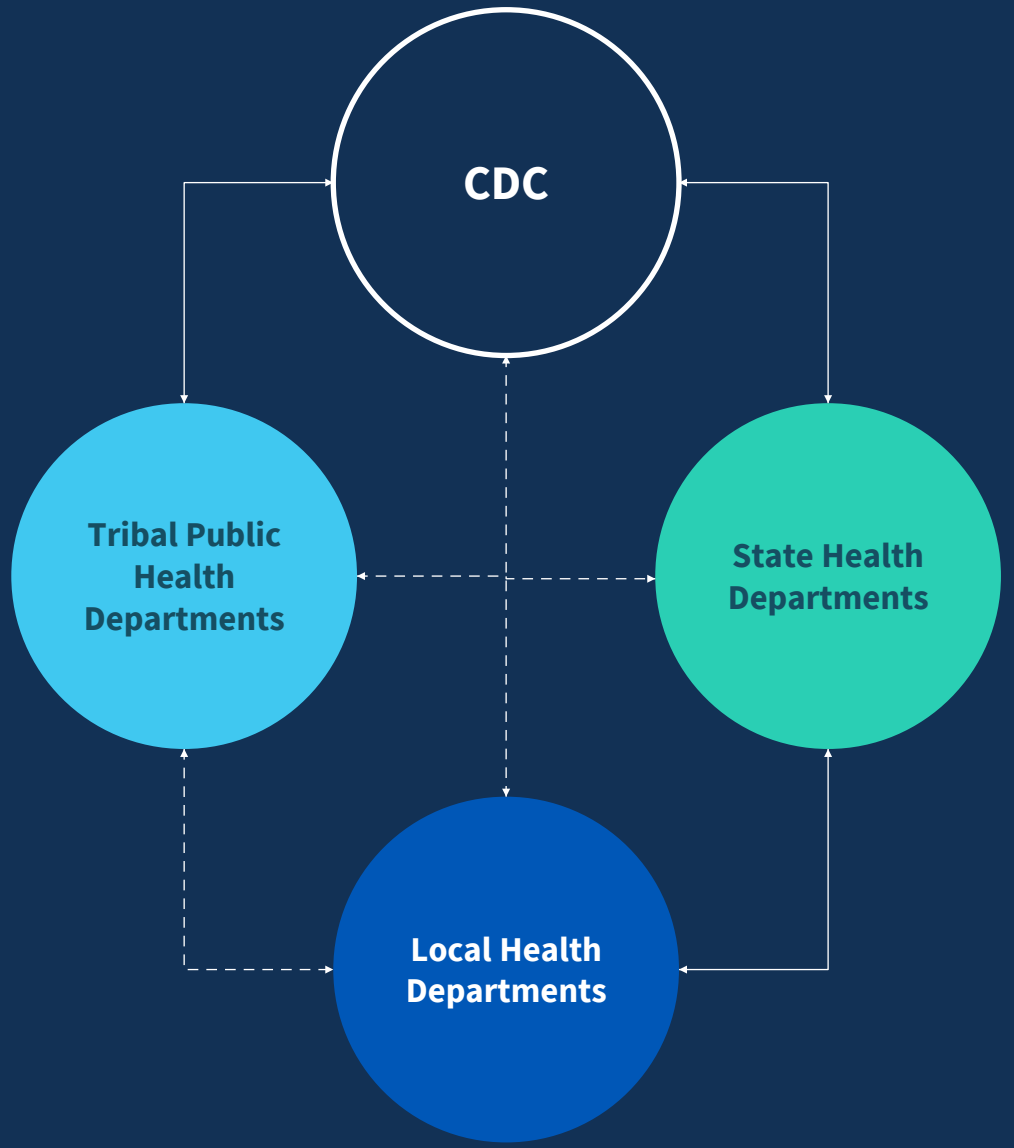
- CDC primarily works directly with state and tribal public health with technical assistance and funding
- There are often sound working relationships between tribal and state or local public health for coordination of efforts
- Local health departments have the closest relationships with their state but may also have working relationships with nearby local or tribal public health agencies or with CDC.

Relationships may be primarily defined by:

- Needing to share information
- Providing or receiving support, or
- Sharing resources

And they may be characterized as:

- Collaborative or transactional
- Ongoing or intermittent
- Closely integrated or not well coordinated



Health Department Staffing and Roles

How work is divided between local health departments and the state varies

- from state to state
- from local health department to local health department
- among tribal and non-tribal health departments.

The archetypes in the following section depict public health jobs that need to be done. They are not necessarily representative of any one person or health department.

- A large health department may have specialized roles to do one job
- In a small health department, one person might need to do many jobs
- Some jobs might only be done by the state health department or a large local health department

A note on the archetypes

Resources to staff these roles vary by health department and CDC program. In many cases, a single person may do the work of multiple archetypes. These archetypes are continually being updated as we to learn more about the workforce, either through our own discovery or through discovery from other teams or partner organizations.

The archetypes include:

- A description of the role, functions performed and responsibilities
- The archetype's mindset, the perspective and motivations
- Their needs, pain points and who they depend on

Public Health Archetypes

Archetypes articulate high-level jobs public health workers need to do. Each archetype consists of a series of patterns in mindset, needs and pain points that were identified through qualitative discovery.

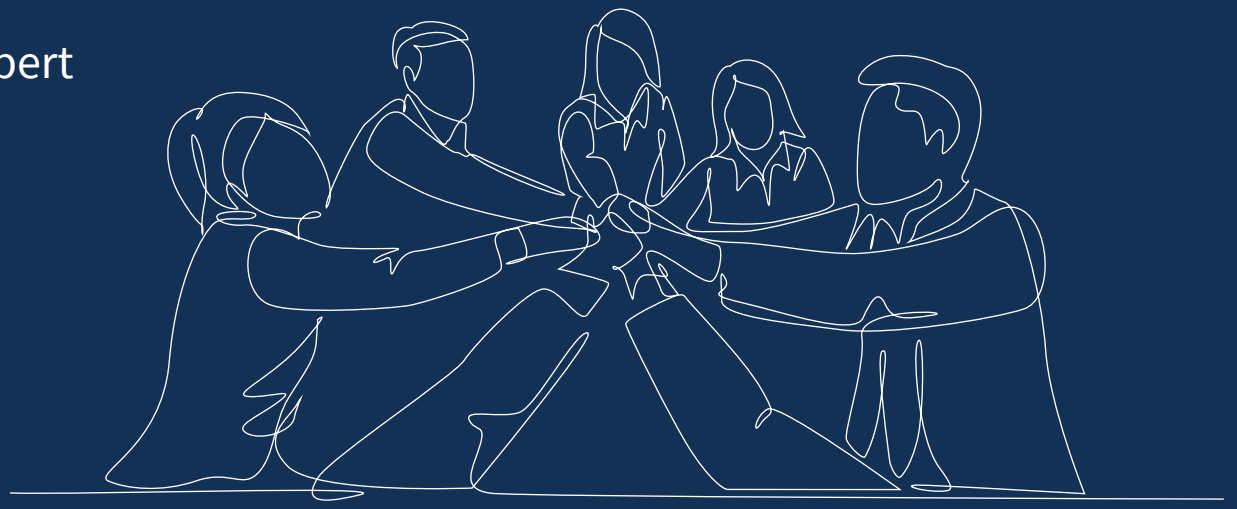
Health Department Archetypes include:

- Case Investigator
- Epidemiologist
- Informatician
- Data Visualization
- Health Educator
- Data Manager
- Systems Manager
- Reporting Processor
- Clinical Leader
- Organizational Leader
- IT Expert

CDC Program* *(work in progress)*
Archetypes include:

- Data Manager
- Informatician
- Data Analyst
- Technical Assistance Expert

** The case service design team focused more heavily on STLT verses CDC archetypes. CDC archetype list is meant to be added to as we implement solutions with CDC programs over time.*



Understanding Work Domains

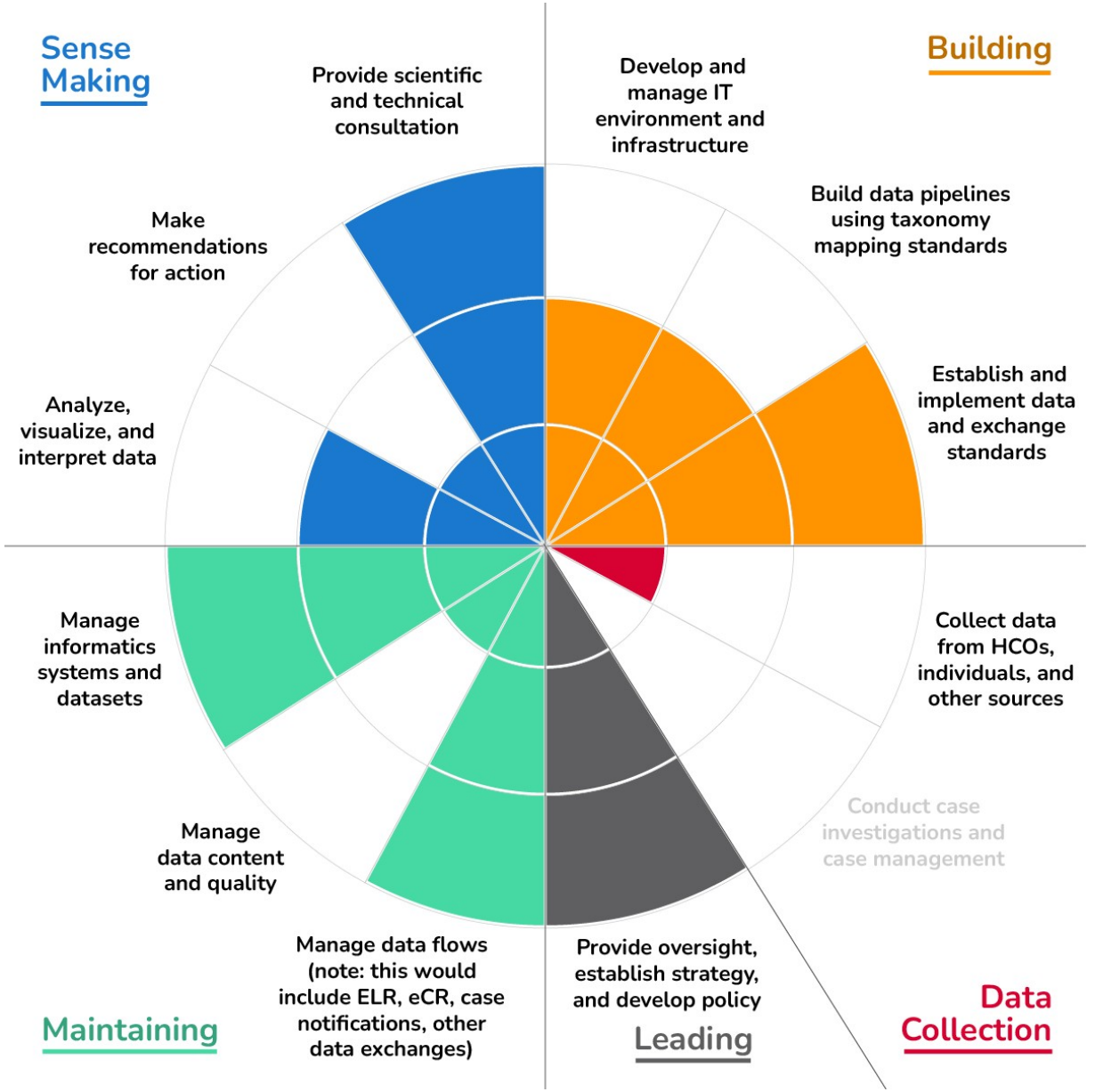
We identify 5 domains of broad work practices in STLT public health relevant to data exchange. The 5 domains are:

- Sense Making
- Building
- Maintaining
- Leadership
- Data Collection

Some roles spend the majority of their time specialized in 1 or 2 domains while also contributing as a collaborator for those specializing in other domains.

- Increased levels of a slice filled indicates more time dedicated to said task.

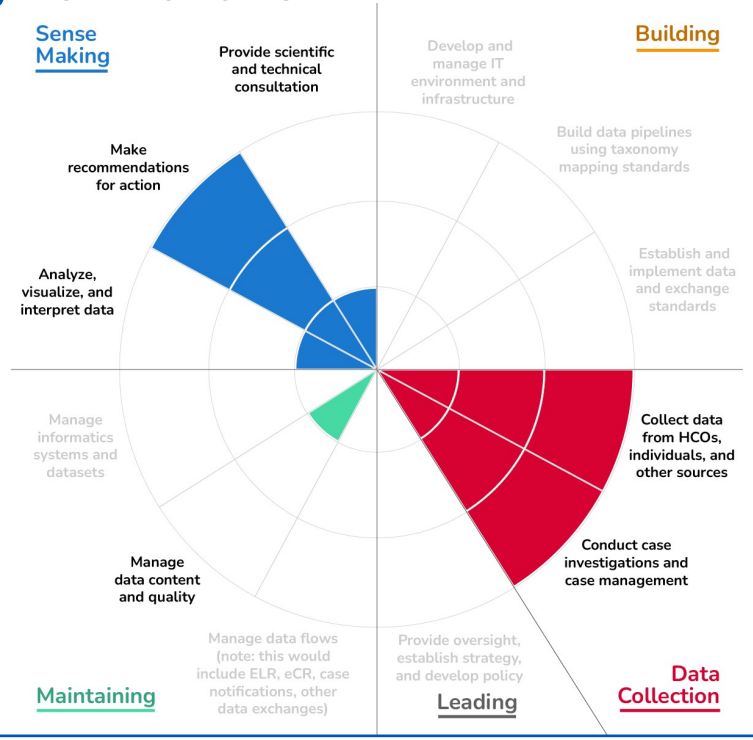
Let's take a look!



Case Investigator

I gather data from healthcare providers, labs, and individuals to investigate potential cases of illness. I prevent spread of disease through outreach and intervention and by collecting data needed for response.

My Work Domains



My Routine Activities

- I review what information is in the record and assess what information is needed to complete an investigation, as determined by disease. This includes medical info like clinical course and underlying conditions, behaviors, exposures, lists of contacts.
- I directly interact with cases to collect the information needed. I am resourceful in locating and communicating with clients and contacts who may be difficult to reach or reluctant to engage in conversation.
- I collaborate with others to classify the case as per case definition.
- I coordinate necessary public health actions to control disease.

My Needs

- Automation to reduce manual data entry between systems.
- Disease-specific knowledge.
- To track, confirm and verify contacts.
- Official disease control and prevention guidance from other experts.
- Agreed upon definitions for case ascertainment and classification
- Access to actionable healthcare data.
- Access to the state surveillance system.
- Patient and community cooperation.
- Coordination and collaboration with providers and community partners.
- Easy-to-use tools to capture the information that I collect.
- Established relationships with providers to get follow-up info or feedback to the provider about cases.

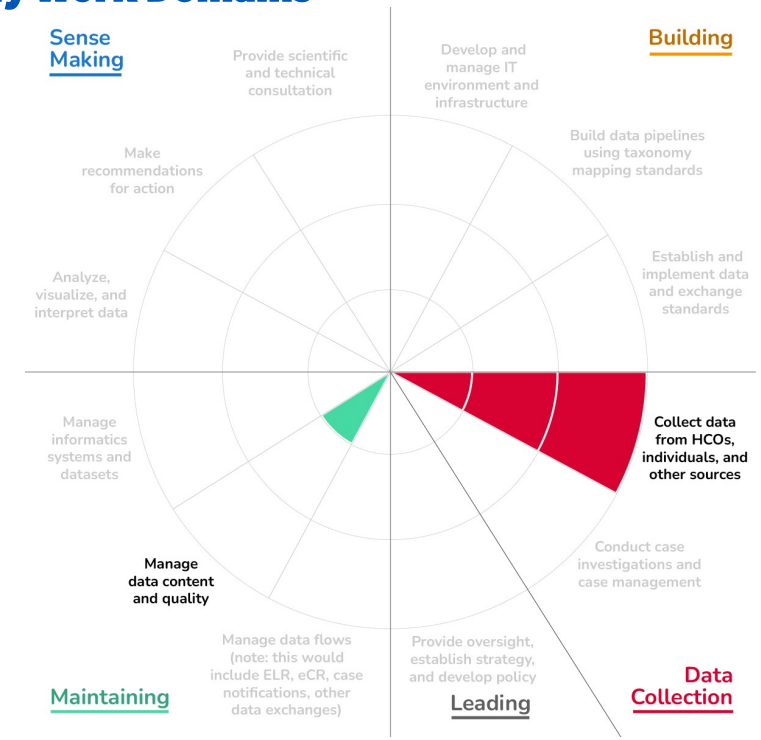
My Tools

- State / local disease surveillance system
- Data exchange intermediaries
- Telephone, fax machines, and emails to get data from tools my collaborators use but I may not have access to.
- Excel spreadsheets
- Data dashboards hosted by local or state PH department
- Case report form and interview guide
- eCR for gathering data from health providers
- Tools for contact tracing, like REDCAP

Case Report Processor

I do procedure-driven work that is focused on supporting case investigators and data managers. I never like to leave cases unprocessed. You will see people like me in jurisdictions with large populations or large case volumes.

My Work Domains



My Needs

- I need to access EHRs, public health data systems, and other data resources to find missing contact and health information on a suspect case.
- I need automated solutions (robotic process automation) for easier processing of high-volume case reports to leave more time for edge cases.
- I follow procedures, but they are only as good as the tools and databases I am provided. I cannot succeed if I cannot get the data, like if I cannot find the residential address of a case to confirm if it is within our jurisdiction and should be worked by our case investigator.

My Routine Activities

- I process incoming manual reports from providers and labs and make sure case investigators have all the information they need before interviewing the case.
- I process incoming calls from public about potential foodborne illness.
- I triage reports.
- I enter data in the disease surveillance system.
- I route suspect cases for investigation to the appropriate case investigator.
- I do the final close out of a case in the surveillance system when the investigation is completed.

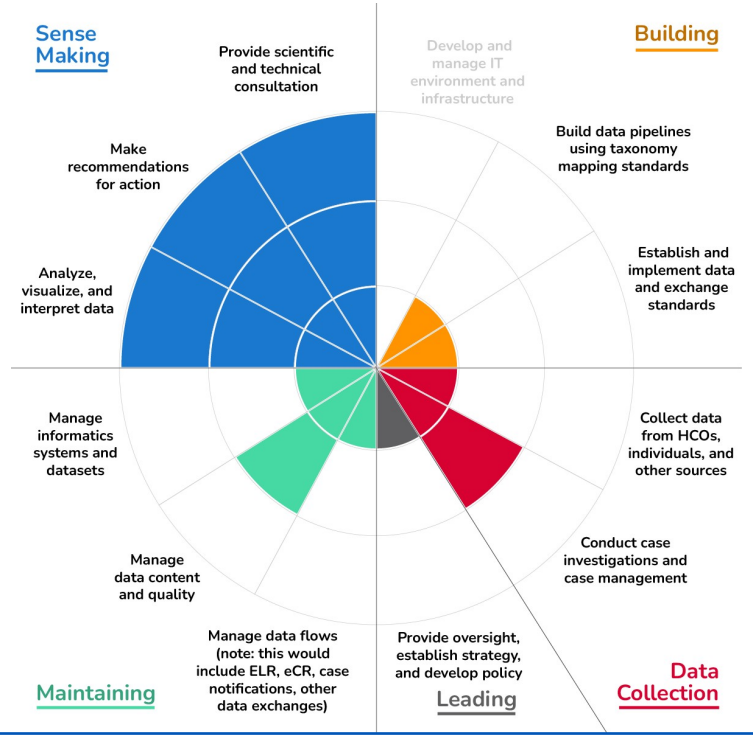
My Tools

- Disease surveillance system
- HIE portal
- Telephone, email, fax machine

Epidemiologist

I am the Swiss army knife of public health—my role can shift based on needs and situations. I do straight data analysis, and I am also an expert at translating and interpreting data and providing recommendations for public health investigation, intervention, and outbreak response.

My Work Domains



My Needs

- Specialized staff with skills to support case interviews and data collection, disease response, informatics, data management and communications.
- Systems that talk to each other for easier access to data - from healthcare, in my agency and across public health.
- Knowledgeable subject matter experts to turn to for uncommon diseases and illnesses.
- Time to focus on public health impact and important project work.
- More automation, including easier ingestion and integration of data into systems.
- To maintain relationships that foster trust around data, data sources, and data use.
- Consistent support and guidance from leadership to continuously improve my work.
- Good communication among health departments.

My Routine Activities

- I apply evidence-based interventions by managing and analyzing data and interpreting the results to describe factors that affect the health of a community.
- I lead surveillance and epidemiologic investigations.
- I apply epidemiological methods to evaluate and investigate health in the community.
- I use systems thinking to ensure our data flows and systems support our work.
- I provide a variety of partners with epidemiologic and surveillance data to inform and advise them on the development and improvement of policies, programs, services, and laws.

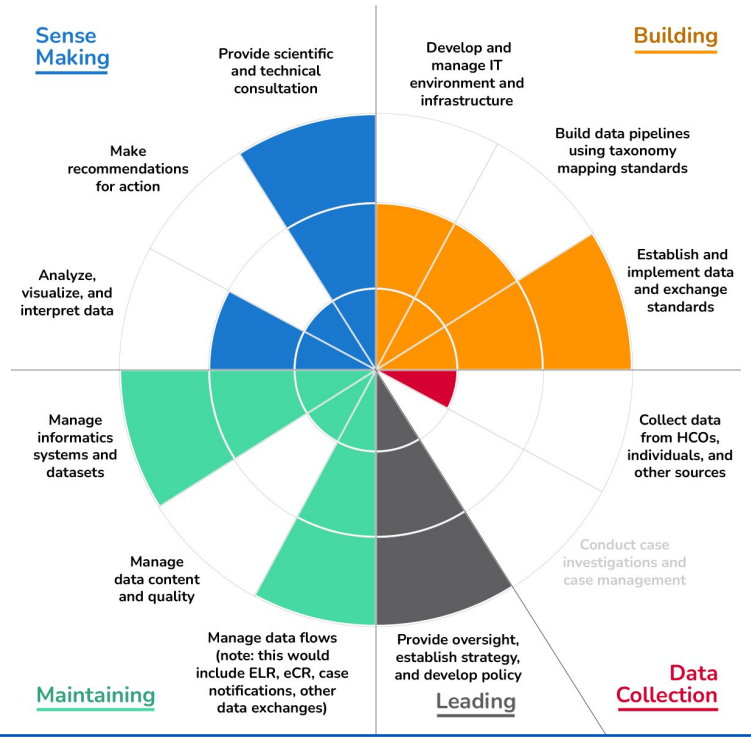
My Tools

- Disease surveillance system such as NBS, Maven, EpiTrax
- Data collection tools such as RedCap, Excel, pdfs
- Information channels such as telephone, email, fax machine
- For data software, tools like SAS, SPSS and R
- For data processing and management, tools like SQL
- For data visualization, tools like PowerBI and Tableau

Informatician aka Data Engineer

I use my expertise in health systems and data interoperability to define public health functions, data elements, data flow, and case definition. I manage data infrastructure and data flows. I help establish data and exchange standards, understand needs, and apply technology solutions to keep information flowing efficiently.

My Work Domains



My Needs

- To understand the facilities who submit data so I can meet them where they are and provide tailored support.
- More consistent data formats and tools to connect data between external sources and surveillance systems.
- Leverage to enforce adoption and adherence to consensus content and exchange standards.
- Data exchange intermediaries and broad acceptance of trust agreements and data use agreements to make data exchange less burdensome and to keep the data flowing.
- Good input from our system users so that I can make sure that our data and systems are meeting their needs.
- Secure data infrastructure so that we can be confident that data confidentiality and integrity are protected.

My Routine Activities

- I manage data exchange, data flows, data systems, and data warehouses across multiple disease programs.
- I work on solutions to pull data from a variety of sources into our surveillance system so that reporting processors, case investigators, and epidemiologists can put those data to work.
- I work on solutions to pull data out of our surveillance system to get it into the hands of partners who we share information with, like the CDC.
- I onboard and iterate improvements to ELR, eCR, and MMGs.

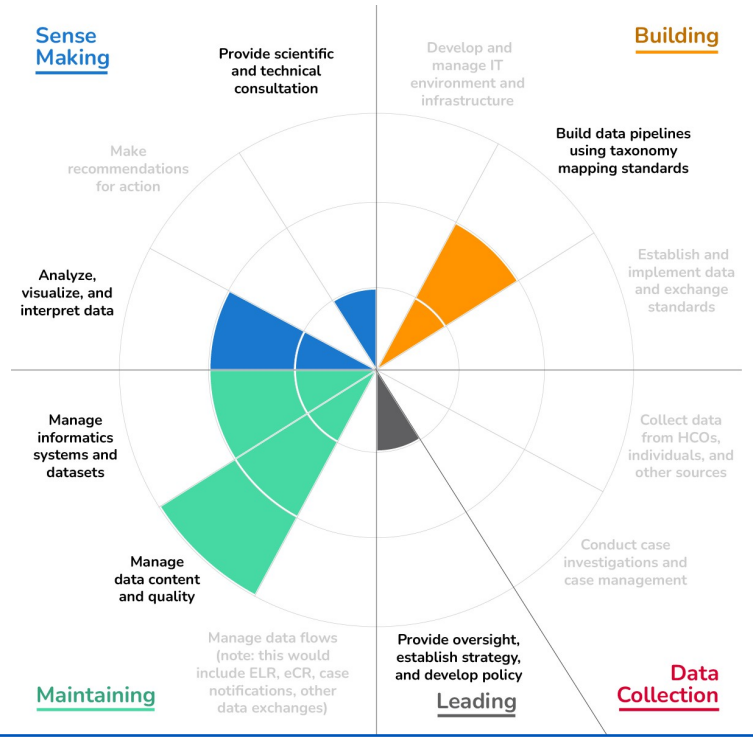
My Tools

- Integrative development environment and APIs
- Cloud services platforms such as AWS, Azure, and GCS
- Interoperability standards like HL7, FHIR, and OpenSSL
- Big data pipeline and management tools such as Snowflake, Redshift, and TensorFlow

Data Manager

QA and data management are key parts of what I do. I pull data to evaluate completeness and timeliness, and I develop strategies to find missing information, correct errors and improve timeliness. I also work with other health departments and CDC to reconcile data.

My Work Domains



My Needs

- A well-functioning surveillance system that supports our evolving needs.
- Automated, reliable data flows that provide high quality, timely data.
- Reliable use of data content and exchange standards so that less back-end work is needed for cleaning.
- Broad acceptance of trust agreements and data use agreements to make data sharing less burdensome.
- More time to focus on important projects and initiatives that support public health impact.
- IT trainers who can instruct new staff on how to enter data and use IT systems correctly.

My Routine Activities

- I conduct data management, data cleaning, and data quality improvement across one or more disease teams.
- I check to make sure all data elements are entered and that the ELR matches case definition.
- Weekly, I use automations to check investigation and case status, and fill in missing data like address and gender
- Annually, I make sure no duplicates show up in reports, make sure morbidity and mortality matches what we know about each condition, make sure we are tracking important cases and conditions.

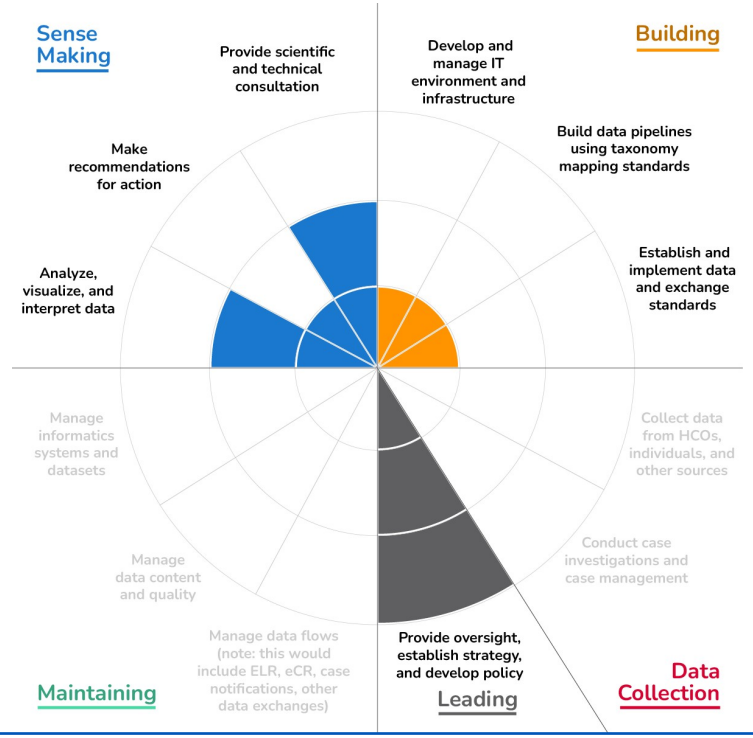
My Tools

- Disease surveillance system such as NBS, Maven, EpiTrax
- Automations
- De-duplication tools
- GIS and spatial analysis tools such as ESRI ArcGIS and GeoDa
- Data analysis software such as R, SQL, Python

Organizational Leader

I’m focused on agency strategy to ensure that we have a healthy community. I’m responsible for policy, workforce, governance, infrastructure, budget and grants. I’m invested in collaboration and in liaising with local, state and federal government, and with our community.

My Work Domains



My Needs

- Comprehensive, accurate and timely data so that we can be proactive, rather than reactive.
- Clear guidance on effective strategies for disease prevention and control, specially in emergency response situations, to support strategy and decision making.
- Strong collaborative and trusting relationships with health care providers and the public in our community, and among local, state, and federal public health.
- Effective strategies to hire, cultivate and maintain a skilled workforce, including modernized job classifications and pay scales, and partnerships for recruiting and upskilling talent.
- Sustained funding and a sound plan to modernize our information architecture with integrated and interoperable systems, a centralized data repository, frictionless data exchange, and strong data protections.

My Routine Activities

- I guide public health strategy using data, making sure that everything we do is as targeted and efficient as possible due to our limited resources. I ensure we develop dashboards that enable us to monitor trends in real-time.
- I develop strategy for data and information technology infrastructure. I make sure we have access to the data we need and have staff with the right competencies to analyze those data and set-up reports.
- I coordinate with partners on public health initiatives and data sharing.

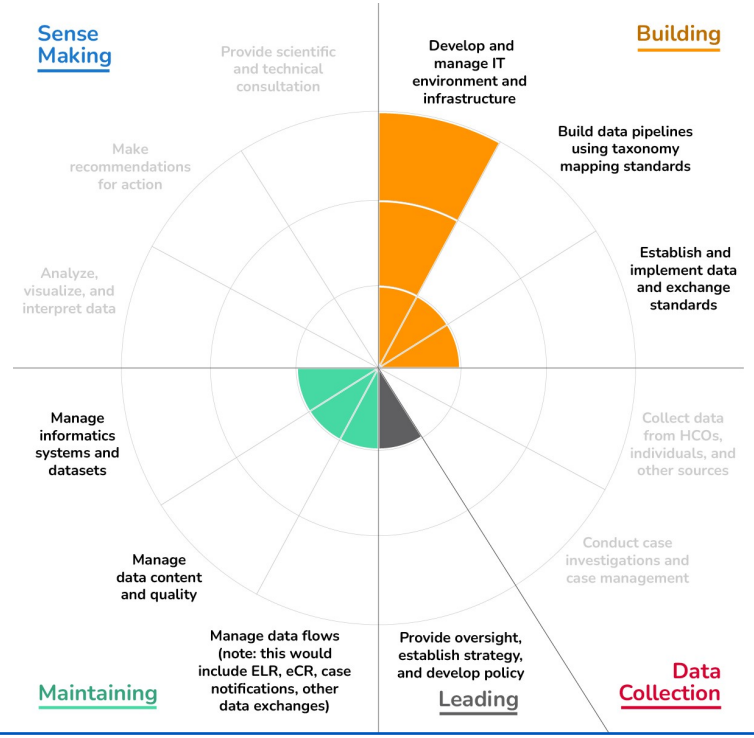
My Tools

- Real-time dashboards and reports

IT Expert

I work for a local/state IT agency and manage the technology infrastructure, not just for the public health agency, but for all the public agencies in the area. They rely on me to ensure that the infrastructure is reliable, secure and cost-effective. I might be a contractor.

My Work Domains



My Needs

- Thorough knowledge of my agency and agency partners, like CDC, for any agency-specific tools and applications.
- System modernization and more automation to improve reliability, security, and cost-effectiveness.
- Adoption of APIs for data exchange and AI for data processing.
- Tools to easily manage cloud services and network infrastructure.
- Access to public health subject matter experts on an ad hoc basis because I might not understand the nuances of public health data.
- Governance for contracting external IT services and hardware.

My Routine Activities

- I implement and manage interoperability between health systems and public health databases.
- I have knowledge of APIs and data exchange protocols.
- I provide guidance on risk assessment, information security best practices, and compliance with data governance and privacy regulations.
- I manage and maintain new and existing systems.
- I support the procurement process for new technologies.

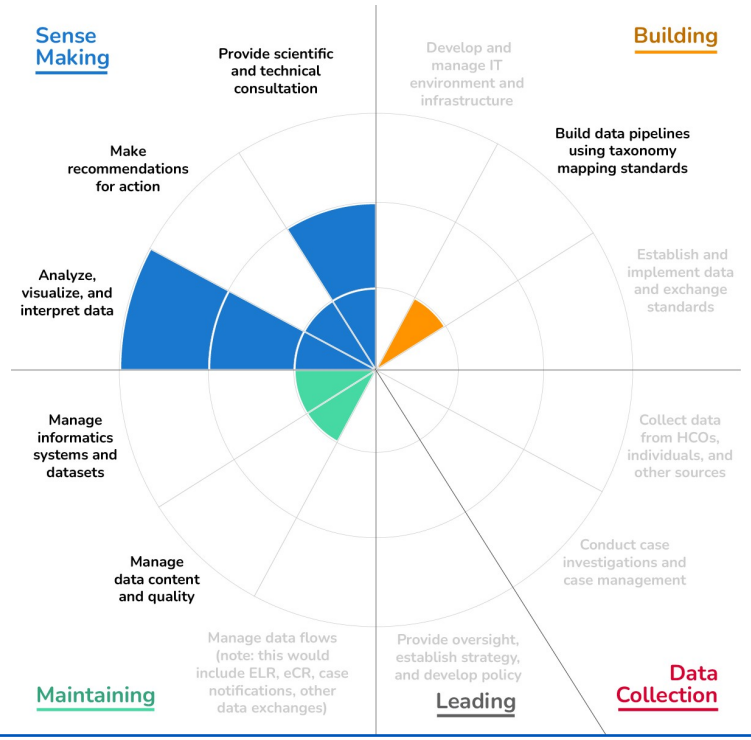
My Tools

- Integrative development environment and APIs
- Cloud services platforms such as AWS, Azure, and GCS
- Interoperability standards like HL7, FHIR, and OpenSSL
- Big data pipeline and management tools such as Snowflake, Redshift, and TensorFlow

Analysis & Visualization Specialist

I develop visualizations to help data tell its story. My graphics make information easy to understand and they highlight key messages on data dashboards and in reports. I also use data visualizations to identify data quality issues.

My Work Domains



My Needs

- Clean and timely data, with more consistent data formats and files.
- Access to local, regional, and national data sets
- Proactive collaboration across teams and between health departments.
- To be involved in projects from the start so I can understand goals and user needs.
- Data visualization standards and associated policies/best practices.
- Mechanism(s) for sharing data updates.
- Visualization tools to make my job easier

My Routine Activities

- I have strong data analysis and GIS skills and use graphics and dashboards to highlight key points in the data.
- Some of my visualizations help our team spot outbreaks or data quality issues, but I typically communicate internally.
- I rely on the investigators and epis to make sure I understand the story in the data, the audience, and the purpose.
- Once I develop a data presentation, I automate the data extraction, analysis and image generation so that updates can run on a schedule, and I just need to monitor and tweak.

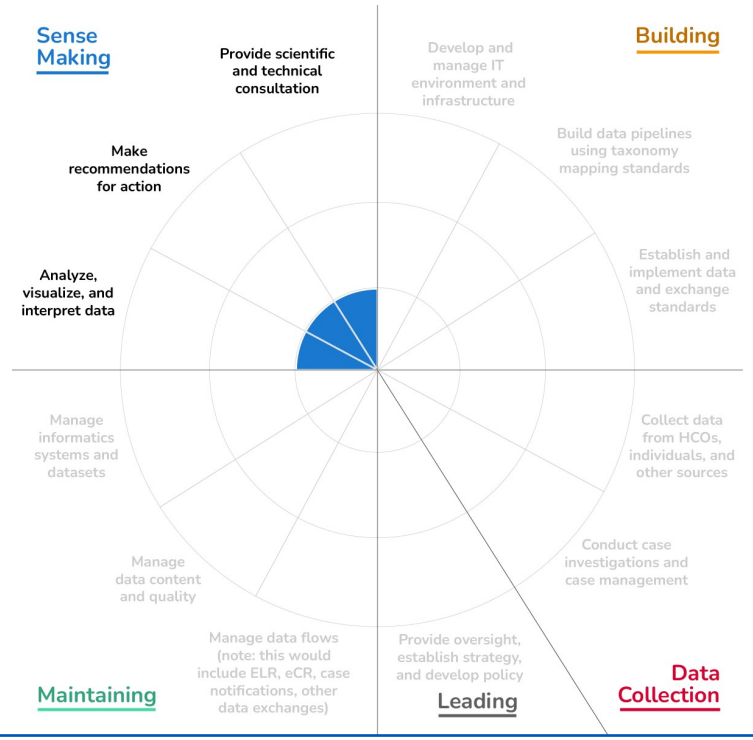
My Tools

- Data analysis tools like R, Python, SAS
- Data visualization tools like Rstudio, Tableau, PowerBI, ArcGIS, Looker
- Dashboards for story telling with data
- SQL queries for joining data sources

Health Educator

I manage communications for public health campaigns and plan community engagement in collaboration with public health. I love training and teaching others to increase awareness of public health and potential threats to the public. I also help track and support treatments and interventions.

My Work Domains



My Needs

- Collaboration and guidance from clinical staff and epidemiologists to shape the key messages.
- Sound, easy to understand data to prioritize efforts and to communicate the evidence for recommendations I make.

My Routine Activities

- I manage communications for public health campaigns.
- I plan community engagement.
- I collaborate with public health experts to identify the key messages and ensure that content is accurate and motivating
- Planned campaigns are always easier than emerging events.
- Managing the political sensitivities around issues is always on my mind.

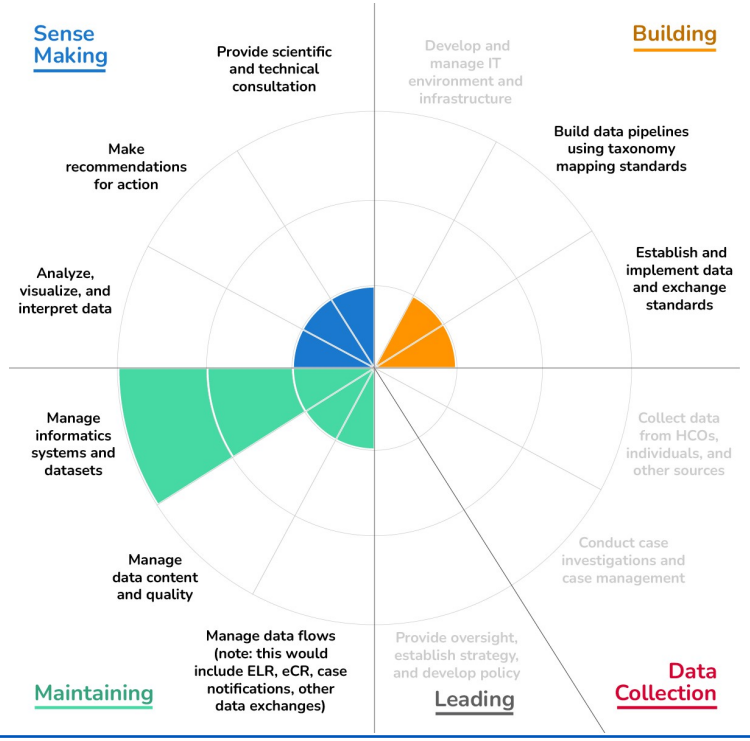
My Tools

- PowerPoint or graphics packages
- Real-time dashboards and reports
- Media (news papers, TV, radio)

Systems Manager

I am responsible for managing our integrated surveillance system, including enhancements and troubleshooting. I document business requirements, translate them into technical deliverables, and work with IT to implement technology solutions. I ensure that the system works for the users and that data flows smoothly through the system. I also work on coordinating activities like data intake, IT vendor contracting, and quality assurance and control.

My Work Domains



My Needs

- Skilled informatics workforce and adequate staffing.
- Clear expectations for ISS functionality, so that I know what will be needed to interoperate with the national public health ecosystem and can build toward it.
- More automation, including APIs and AI for data processing.
- Support from IT and streamlined IT contracting processes to modernize the system. Sometimes when there is a centralized state IT agency, we have difficulty getting things done.

My Routine Activities

- I'm likely to be an informatician, epidemiologist or IT person.
- I understand the case surveillance process that the system needs to support.
- I make system updates and do day-to-day troubleshooting to keep the system running optimally and keep data flowing.
- I gather user requirements for enhancements , write contacts to get changes made or purchase new tools, coordinate with the IT team people doing the work, and train users in the new features.

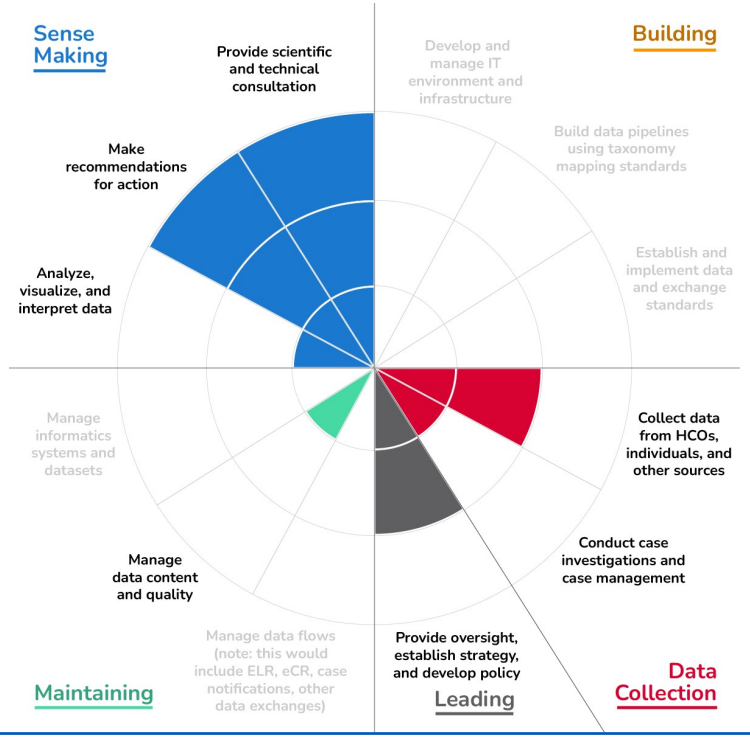
My Tools

- Integrated Surveillance System (ISS)
- Community of Practice with ISS managers in other states
- Resources and tools that the ISS interoperates with (e.g., agency's integrated data repository, master person index, GIS files, integration engine)
- Automated processes to exchange data with healthcare and labs (e.g., eCR, ELR) and with other public health agencies (e.g., CDC and neighboring jurisdictions)

Clinical Leader

My job is to coordinate our health department's clinical activities. This includes providing medical guidance, and staff management and development, especially for our clinics. I also handle coordination of state reporting, clinical resources, and education.

My Work Domains



My Needs

- More financial and human resources so my team can get the work done.
- The opportunity to provide input into system modernization efforts and into the interfaces between healthcare and public health systems.
- Good data to understand emerging health issues in the community to that I can prioritize efforts.
- Data systems that support our workflow and that are reliable, so that my team can work efficiently.

My Routine Activities

- I may be a nurse, epidemiologist or administrator by training.
- I ensure the scientific and clinical integrity of our work and the development of our scientific and clinical staff.
- I coordinate across programs to ensure that they work together to support the agency's priorities.
- I keep staff focused on our public health priorities so that we effectively manage the routine activities that keep people healthy and the crises that need immediate attention and a lot of resources.

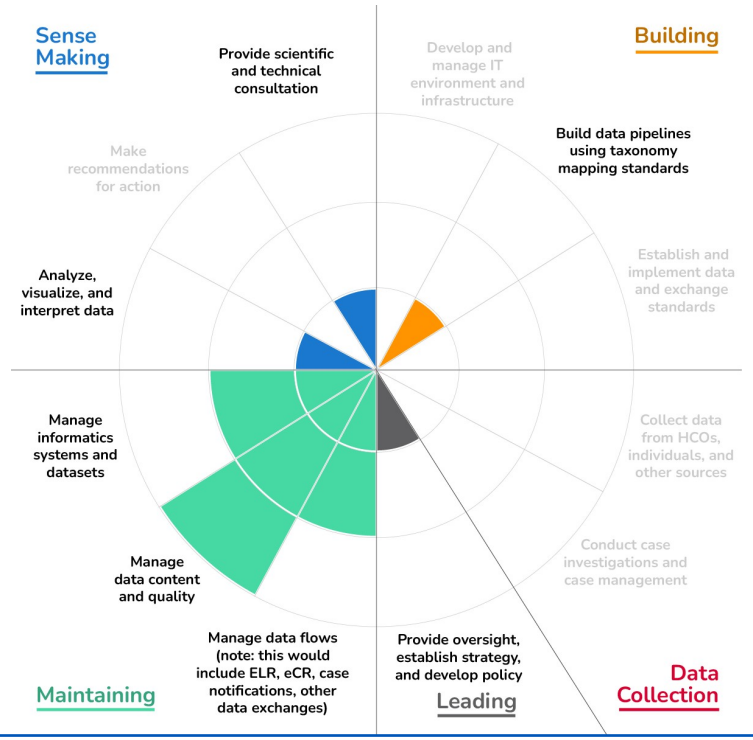
My Tools

- Real-time dashboards and reports
- Integrated Surveillance System (ISS)
- Immunization registry
- Health department EHR
- Clinical and epidemiologic guidance (e.g., from CDC, pediatric Red Book, Control of Disease in Man, ACIP recommendations)

CDC Program Data Manager

Data quality assurance and management are key parts of what I do. I evaluate data completeness and timeliness. I develop strategies to find missing information, collaborate and follow-up to correct errors, and improve timeliness. I also work with jurisdictions to reconcile data.

My Work Domains



My Routine Activities

- I am responsible for data management and data quality for surveillance data.
- I work with the states and territories on a day-to-day basis to resolve data quality issues.
- I support publishing of surveillance reports.
- I aggregate current and historical data or data from multiple data streams when needed for analysis.
- I help states with data transformation and quality when changing transmission methods or data systems.

My Needs

- Clear expectations for data submitters and open collaboration to resolve data problems.
- A data pipeline I can trust.
- Automated algorithms that facilitate checking the data.
- Informatics support to implement transformations, resolve processing problems, and integrate data sources.
- Tools on 1CDP that jurisdictions can use to enter or upload data for any CDC program.

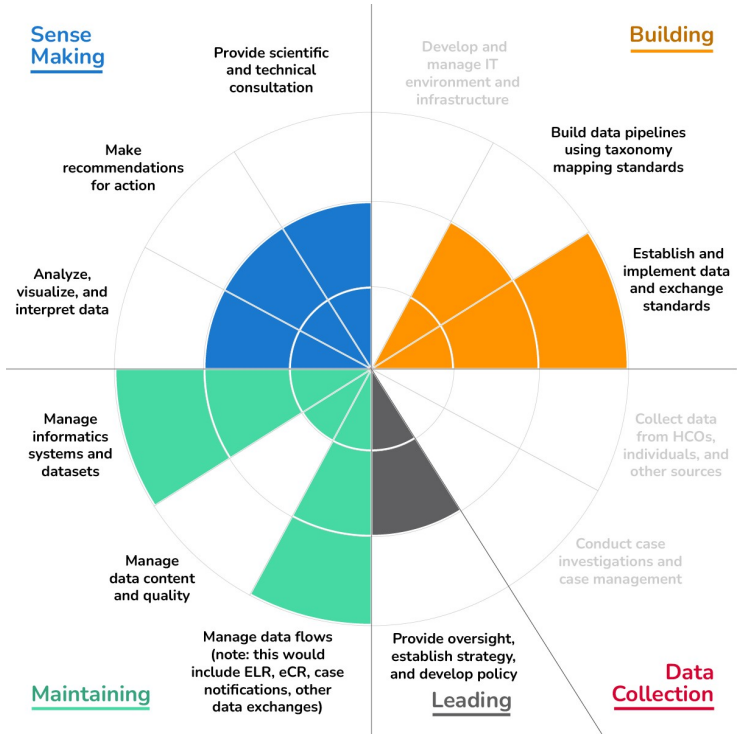
My Tools

- Specifications for data content and format
- Statistical analysis tools
- A solution to validate content and format of incoming data
- A way to make sure that data at CDC matches data at the jurisdiction

CDC Program Informatician

I use my expertise in health systems and data interoperability to manage data infrastructure and data flows. I help establish data and exchange standards, understand needs, and apply technology solutions to keep information flowing efficiently.

My Work Domains



My Needs

- Input into upstream planning and decision making.
- Control over the full pipeline so that we can identify and implement solutions as soon as we detect a problem.
- Good monitoring tools for the data pipeline.
- Streamlined onboarding process for jurisdictions to send in HL7.
- Good, up-to-date documentation on data and processes.

My Routine Activities

- I automate, improve and maintain data pipelines.
- I improve data processes to make them as easy and as accurate as possible.
- I support jurisdiction onboarding to HL7 MMGs.
- I build data dashboards and help others build them.

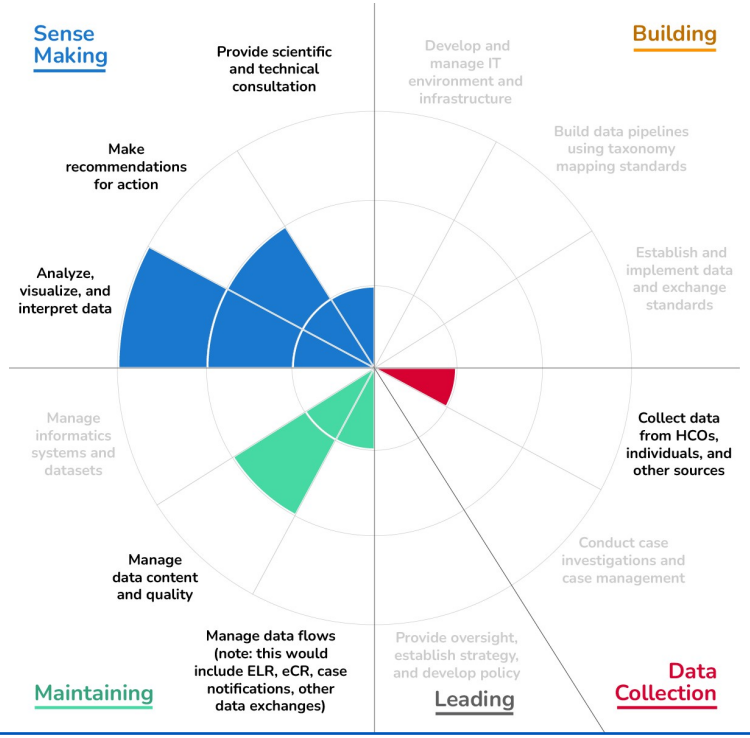
My Tools

- Specifications for data content and format
- Solutions for direct entry or upload by jurisdictions
- A solution to validate content and format of incoming data
- A way to make sure that data at CDC matches data at the jurisdiction
- A solution to integrate data from different sources
- Statistical analysis tools to help set up data checking and quality tools for other users

CDC Program Data Analyst

I transform complex health data into actionable insights that inform national health decisions. I track disease spread and evaluate intervention effectiveness. I ensure my analyses address real-world public health challenges. I create reports, dashboards, and briefings that translate complex findings into accessible information for policymakers and the public.

My Work Domains



My Routine Activities

- I run routine data analysis and statistics for surveillance.
- I do data analysis and create visualizations that focus on specific problems, either by request or by need.
- I solve epidemiology problems around gaps in data.
- I interpret findings for reports and publications.
- I build data dashboards and help others build them.

My Needs

- Flexible processes so that I can get the data I need when I need it (ex. more ability to change what the jurisdictions send).
- Easy to get timely, analysis-ready datasets.
- Need good decisions about what data is needed and how it should be interpreted/used.
- Need to resolve issues about ownership of the data which limit what CDC can publish (e.g., more granularity, county level data).
- Move everyone away from NETSS transmission to modern methods so that we don't lose valuable data.

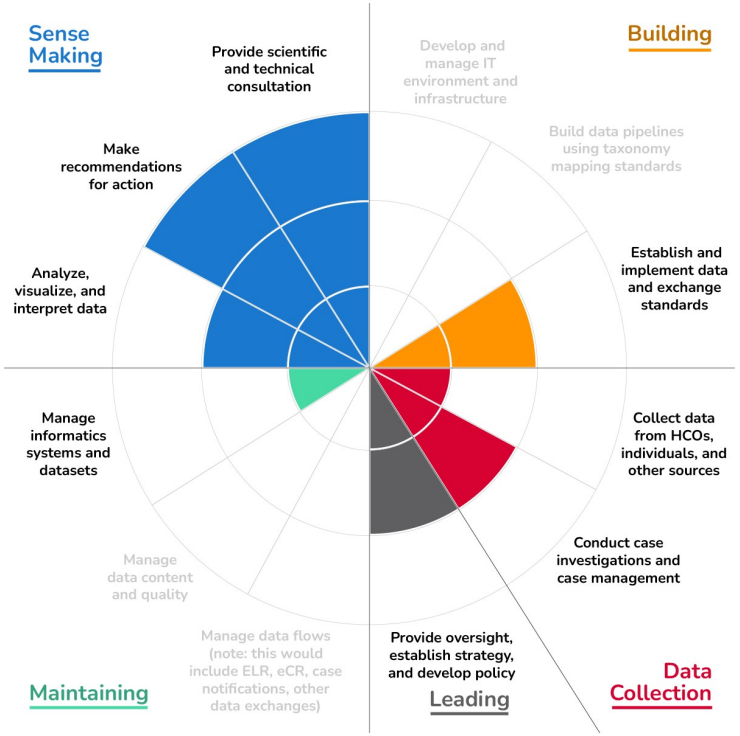
My Tools

- Specifications for data content and format
- Solutions for direct entry or upload by jurisdictions
- A solution to validate content and format of incoming data
- A way to make sure that data at CDC matches data at the jurisdiction
- A solution to integrate data from different sources

CDC Program Technical Assistance Expert

I am an expert problem-solver and eager to share what I know to help others meet their objectives. I use my highly specialized expertise to work with a jurisdiction or program to understand their problem and needs. I help them develop tailored solutions by drawing on my knowledge and skills, and on a broad network of resources.

My Work Domains



My Needs

- Good working relationships and to be trusted by whomever I help.
- Access to guidance and the expertise of others.
- Skills to interpret data and the gaps in data.
- Detailed data, like disease-specific data, above and beyond routine data for prevention and control analysis.

My Routine Activities

- I assist jurisdictions with investigation and control and data issues.
- I produce guidance to drive prevention and control.
- I provide input about how data elements should be interpreted, used, or improved, including gaps in data.
- I might go out into the field to provide hands-on assistance.

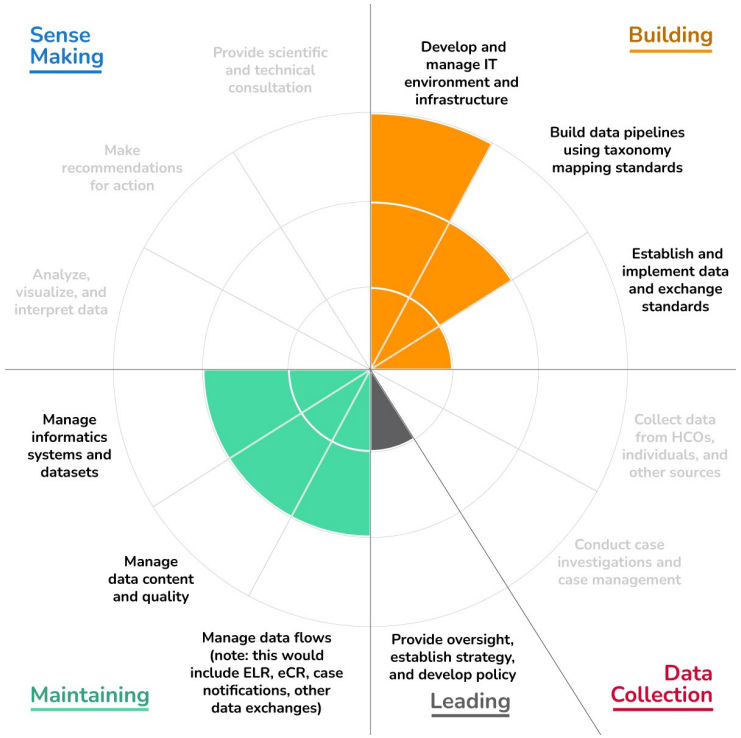
My Tools

- Specifications for data content and format
- Solutions for direct entry or upload by jurisdictions
- A solution to validate content and format of incoming data
- A way to make sure that data at CDC matches data at the jurisdiction
- A solution to integrate data from different sources

CDC IT Manager

I manage the technology infrastructure within CDC. Programs and jurisdictions rely on me to ensure that the infrastructure is reliable, secure and cost-effective.

My Work Domains



My Needs

- Thorough knowledge of CDC programs and jurisdictional partners for any disease-specific tools and applications.
- System modernization and more automation to improve reliability, security, and cost-effectiveness.
- Adoption of APIs for data exchange and AI for data processing.
- Tools to easily manage cloud services and network infrastructure.
- Access to public health subject matter experts on an ad hoc basis because I might not understand the nuances of public health data.
- Governance for contracting external IT services and hardware.

My Routine Activities

- I implement and manage interoperability between CDC and data exchange partners and among databases within CDC.
- I have knowledge of APIs and data exchange protocols.
- I provide guidance on risk assessment, information security best practices, and compliance with data governance and privacy regulations.
- I manage and maintain new and existing systems.
- I support the procurement process for new technologies.

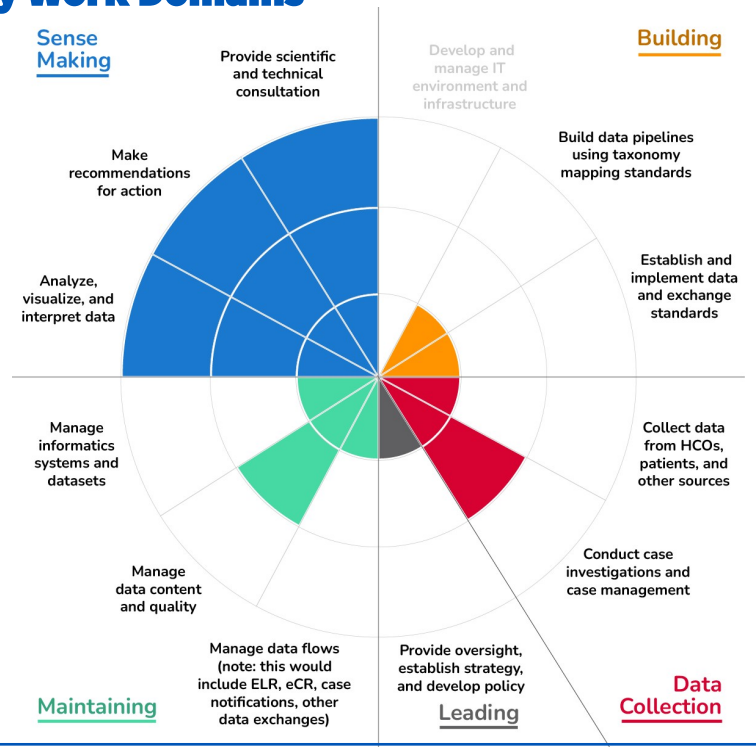
My Tools

- Integrative development environment and APIs
- Cloud services platforms such as AWS, Azure, and GCS
- Interoperability standards like HL7, FHIR, and OpenSSL
- Big data pipeline and management tools such as Snowflake, Redshift, and TensorFlow

CDC Program Epidemiologist

I am the Swiss army knife of public health—my role can shift based on needs and situations. I do straight data analysis, and I am also an expert at translating and interpreting data and providing recommendations for public health investigation, intervention, and outbreak response.

My Work Domains



My Routine Activities

- I manage and analyze data, interpreting the results to understand disease progression, risk factors and control strategies.
- I apply epidemiological methods to evaluate and investigate health in the community.
- I use systems thinking to ensure our data flows and systems support our work.
- I provide a variety of partners with epidemiologic and surveillance data to inform and advise them on the development and improvement of policies, programs, services, and laws.
- I coordinate with centralized bodies (e.g., CSTE workgroups) in developing definition standards.

My Needs

- Specialized staff with skills to support case interviews and data collection, disease response, informatics, data management and communications.
- Systems that talk to each other for easier access to data - from healthcare, in my agency and across public health.
- Knowledgeable subject matter experts to turn to for uncommon diseases and illnesses.
- Time to focus on public health impact and important project work.
- More automation, including easier ingestion and integration of data into systems.
- To maintain relationships that foster trust around data, data sources, and data use.
- Consistent support and guidance from leadership to continuously improve my work.
- Good communication among health departments.

My Tools

- Integrated data repositories that bring together epidemiologic, clinical, environmental and social data
- Data collection tools such as RedCap, Excel, pdfs
- Targeted studies to collect in-depth data beyond routine surveillance
- Information channels such as telephone, email, fax machine
- For data software, tools like SAS, SPSS and R
- For data processing and management, tools like SQL
- For data visualization, tools like PowerBI and Tableau

Big rocks, pain points, and key insights

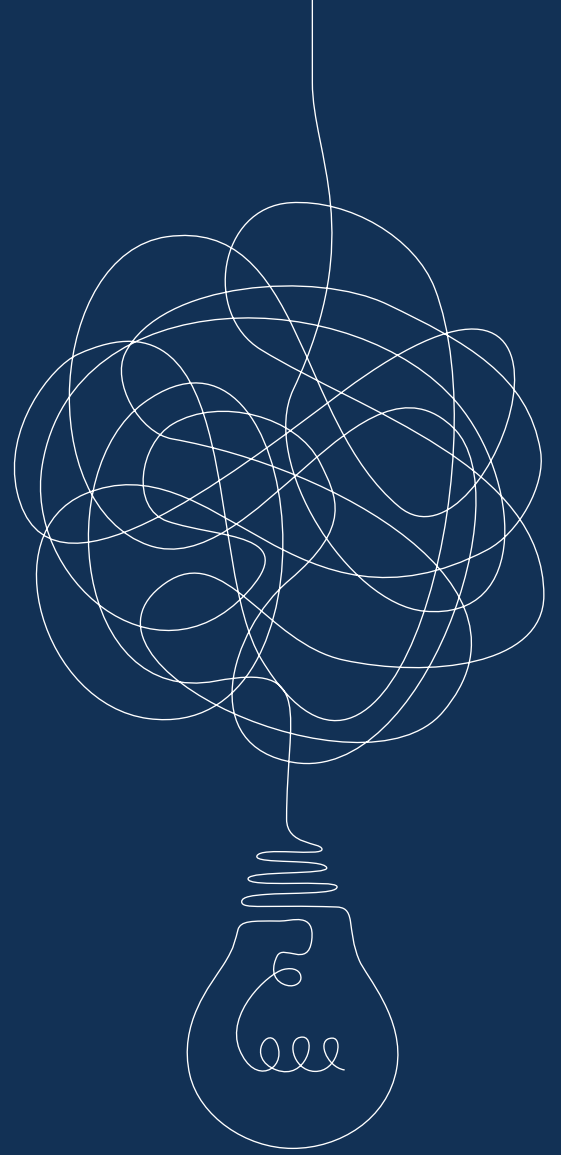
A note on big rocks

Under a summary slide for each big rock, information is provided on specific paint points that Summit participants experience. These slides indicate what aspects of the current state cause the pain point and often include a direct quote from a participant.

Big rocks, pain points, and key insights (2)

During the summit, the CSD team shared stories that represented recurring problems the team heard from both jurisdictions and CDC programs. Participants at each table read the story given to them and each person shared their own related experiences. This built a deeper understanding of each other's perspectives and validated pain points in the current state.

The pain points that each table identified were brought together to identify common themes across stories, diseases, and jurisdictions. They were grouped as "big rocks" -- prioritized systemic challenges we must solve to succeed. We can break them into pebbles to organize work and keep efforts focused.



Big Rocks [systemic challenges]

Manual processes

There are **too many inefficient, manual processes in the exchange of public health data** that delay action, introduce errors, and create painful experiences for public health and healthcare workforce.

Siloed systems + processes

Siloed systems block access to data, force redundant work, and strain the workforce putting accurate and timely public health action and community trust at risk.

Access to data

Public health **workers lack efficient or consistent access to critical data** creating additional manual work, gaps in [actionable] knowledge, and less effective and delayed public health action.

Sustainable workforce

The **lack of defined staff skills, boom and bust categorical funding, and poorly defined roles** that don't match people's actual tasks impede the ability of public health agencies to hire, retain, and train adequate and effective staffing.

Collaboration + orchestration

Lack of strategic planning, timeliness and transparency in decision making, and changing priorities have resulted in suboptimal data modernization efforts that have further eroded efficacy across an already strained PH ecosystem.

Standardization

The **lack of consistent and aligned governance** makes it challenging to promote the development, adoption **and implementation of interoperability standards** across the public health and healthcare ecosystem.

Manual processes: Pain points overview

There are **too many inefficient, manual processes in the exchange of public health data** that delay action, introduce errors, and create painful experiences for public health and healthcare workforce.

1. The **eCR data is difficult to unpack and use for jursidictions**. It is often both overwhelming and incomplete.
2. Public health workers often resort to **burdensome manual processes** to enter, extract, transform, format and transmit data between health departments and to CDC.
3. Because notifiable condition **message mapping guides (MMGs) are not available for all conditions** and because **onboarding is slow**, health departments must enter case data into multiple systems and transmit it through multiple routes.
4. **Manual data entry slows access to data**, which delays public health action.

Current pain point

The eCR data is difficult to unpack and use for jurisdictions. It is often both overwhelming and incomplete.

Key insight

When jurisdictions can easily access the data they need from eCRs, they will be more confident in discontinuing paper reporting. Investing in usability is critical to get the full value of eCR.

Participant quotes

> *A big issue is eCR because those electronic reports should replace paper faxed reports. But what I've heard from locals is that what's in the paper case report isn't in the eCR. You can't get that information into the eCR. [Anonymous SME] says this best—not all data needed for a case report lives in the eCR."*

> *The eCR doesn't tell us anything that the fax doesn't tell us. And it's such a long table, they just end up doing a CTRL+F to find what they want because there's just so much in there that's extraneous. I mean, sometimes it's an entire medical history."*

What we heard about the current state

- Incomplete electronic data means that paper reporting is still happening. Jurisdictions are receiving duplicative reporting via eCR and fax while the completeness and quality of eCR is verified during eCR onboarding.
- There is a constant need for health departments to monitor and fix eCR problems and changes to data feed.
- Health departments often have to acquire or build tools to process the data and populate the surveillance system; this presents an additional burden.
- Health departments receiving PDFs for eCR data makes it difficult to process and sift through to find needed case data.
- Reading eCR is labor intensive and information from the paper reports is often missing from the eCR.
- Even if the jurisdiction's eCR program is ready to onboard you may have to wait in line for two-plus years for the facility to onboard with them.
- I need help quickly parsing through electronic case reporting (eCR) records to find the information I need.

Manual processes

Current pain point

Public health workers often resort to burdensome, manual processes to enter, extract, transform, format and transmit data between health departments and to CDC.

Manual processes (2)

Key insight

Technical solutions must be coupled with sound, collaborative data governance to ensure that the data exchanged is meaningful and useful.

Key insight

Only through good data governance will public health be able to establish consensus on data standards and reduce inconsistent and shifting expectations for content and format. This is necessary to allow automation to reduce customized, high-burden data exchanges among public health agencies.

Participant quote

The reliance on spreadsheets and manual data reconciliation processes is a major blocker that could potentially be automated."

The nurses at the local level are always complaining about having to manually enter data into the ISS. We wish there was a way to scan a form or file."

What we heard about the current state

- Manually creating CSVs is a waste of time and should be automated.
- Process could have been batched or based on a trigger and automated.
- There are opportunities for integration and automation to increase overall efficiencies for case surveillance workflows.
- There is a need and desire for automated tools to reduce reliance on manual processes like spreadsheet reconciliation.
- Reliance on spreadsheets and manual data handling leads to redundancies and inefficiencies. This was identified as a major issue affecting workflows.
- Lack of integration and insufficient data coordination between local, state, and federal systems complicates data reporting and surveillance efforts, taxes the workforce, and leads to inefficiencies.
- Related data sits in separate systems (NNDSS, SLDSS, NORS).
- I need CDC to consolidate and coordinate requests for data on a case so that my team isn't burdened with duplicative work.

Current pain point

Because message mapping guides (MMGs) are not available for all conditions and because onboarding is slow, health departments must enter case data into multiple systems and transmit it through multiple routes.

Key insight

It needs to be easier for jurisdictions to send case data to CDC. Standards for what to send and how to send it make it easier for everyone, but the current processes for MMG creation and implementation don't work.

- CDC needs a more efficient way to specify what disease-specific data is needed and how it should be formatted.
- Jurisdictions need ISS that are flexible enough to incorporate new data requirements.
- Streamlined approval processes are needed to allow jurisdictions to quickly begin sending in the new formats.

Participant quote

[There is] duplicative data entry due to unlinked or different systems, [like] having to input the same data in local, state, and fed systems."

What we heard about the current state

- Manual efforts are required to send data to CDC while sate health departments wait for CDC to be able to receive new MMGs.
- It is difficult to work on MMGs when system modernization needs to be done.
- Even if you want to build out a new MMG state health departments still have to wait.
- Lack of a standard structure leads to mapping challenges.
- There are too many MMGs with too many tabs and jurisdiction surveillance systems are slow to adopt MMGs.
- Manual process are needed for locals to meet state requirements that are driven by MMGs.
- Double entry is needed when local health departments need to submit case data to the state surveillance system and enter data into the CDC surveillance system.
- Consolidating programs and automating processes would reduce manual workload and improve efficiency.
- Multiple steps / systems are needed to meet data collection and submission requirements.
- Questions are not consistent between case report forms, ISS and CDC submission specifications.
- Manual reporting to CDC is burdensome.
- Manual uploads to SAMS are burdensome.
- CDC needs to be able to accept data in multiple formats.

Manual processes (3)

Current pain point

Manual data entry slows access to data, which delays public health action.

Key insight

Investing in electronic data transfer and automation will reduce the pain of manual data entry and processing. These investments can increase the accuracy of data and accelerate access to information needed for action.

Participant quotes

For [my state], the biggest issue is getting information to us at the local level, not us getting info to CDC. The system is too antiquated."

The nurses at the local level are always complaining about having to manually put enter data into the ISS. We wish there was a way to scan a form or file."

What we heard about the current state

- Manual and duplicative processes—including data collection, entry, cleaning, and transmission—are hurting public health efforts; the entire process is very manual.
- Manual data transmission is time consuming, and STLT epis are forced to be data managers instead of using data.
- There is no outbreak-level entity within the database to reduce manual copying of data.
- Copy and paste and manual uploads are often needed to move data between systems or agencies
- Information is needed for local action; Data requested in case report forms don't address local needs.
- NETSS manual upload is time consuming.
- Creating / updating an MMG is time-consuming for CDC teams.
- Local health departments lack technical capacity to generate files.
- We've seen 6-week data entry backlogs.
- Why can't NETSS just be a simple CSV?

Manual processes (4)

Siloed systems + processes: Pain points overview

Siloed systems block access to data, force redundant work, and strain the workforce putting accurate and timely public health action and community trust at risk.

1. Public health data and systems are **not well integrated or interoperable** and are fraught with redundancies.
2. **Modernization is un-orchestrated** across jurisdictions; the need to accommodate outdated approaches slows modernization and wastes resources.
3. Public health **agencies need similar tools**—like reporting tools or a way to link ELR and eCR—but for the most part resort to building or procuring their own.

Current pain point

Public health data and systems are not well integrated or interoperable and are fraught with redundancies.

Key insight

Well-defined, consensus standards would allow interoperability among systems and among public health agencies (PHAs) and would give PHAs the flexibility to use the systems they choose.

These standards, in conjunction with a unified reporting strategy, would reduce the number of systems needed to exchange data and streamline how data is reported.

Participant quote

"I need systems and tools that help me integrate information because public health action requires pulling together data from multiple sources for analysis and interpretation."

What we heard about the current state

- Lack of integration and insufficient data coordination between local, state, and federal systems complicates data reporting and surveillance efforts, taxes the workforce, and leads to inefficiencies.
- There are too many fragmented reporting methods currently in use.
- There is a lack of interoperable systems; siloed systems don't talk or integrate (yet).
- A new investigation specific data system is needed for response.
- New data collection and submission systems are created by CDC as workarounds because integrating into current systems takes too much time and coordination.
- There is no link between epidemiology and environmental data.
- Additional effort is required when local systems have to be translated to match state and CDC systems.
- There are difficulties sharing data across vendors; systems can't adopt use cases developed for another system.
- Epidemiologists lose visibility on trends when data is decentralized.
- System development is often delayed due to poor communication between public health and the vendor and insufficient user acceptance testing. Delays and failure to deliver what was promised result in a lack of trust.
- Jurisdictions and CDC run multiple instances of REDCap. Sometimes this makes sense, but they take more effort to maintain and make it harder to integrate the data.
- Data shared in multiple formats creates more manual reconciliation work.
- Duplicate systems for reporting increase redundancies and potential for errors.

Siloed systems + processes

Current pain point

Modernization is un-orchestrated across jurisdictions; the need to accommodate outdated approaches slows modernization and wastes resources.

Key insight

To enable technical interoperability at scale, STLT and CDC need to ensure that all health departments meet minimum capability requirements. We can't continue to require that modern solutions be backward-compatible with outdated technology. It will require a unified vision and roadmap for data modernization, supported by technical and financial assistance to bring under-resourced jurisdictions to a level where they can participate in an integrated public health ecosystem.

Participant quote

"I need the ability to update surveillance systems quickly and with little disruption to current workflows."

What we heard about the current state

- Public health lacks a unified vision and roadmap for case data modernization so everyone knows how to plan and invest.
- CDC should consistently communicate modernization plans and proactively seek feedback so that they can feel confident in the decisions being made.
- Even if you are working in modernized systems, silos can still occur.
- Our STLT health department wants to get more data through eCR but is waiting on facilities to be ready to send eCR.
- Old surveillance systems are very time consuming to maintain and use.
- Using an agile approach might help accomplish modernization goals.
- Multiple systems could be transitioned to a single new system.
- Need an approach that starts with a minimum viable product.
- Multiple systems are at different phases / uses.
- Epidemiologist wanted to move away from manual process but had to wait on something to be developed. They had no ability to move it forward.
- Data sharing that happens over the phone is an indicator that systems aren't integrated and communicating.
- It isn't enough to focus on data collection only.
- Projects are frequently in competition for priority and resources.
- "Dumbing down" data to the lowest common denominator leads to a loss of valuable information.
- The cost of modern surveillance systems is high, and they take a long time to implement.

Siloed systems + processes

Current pain point

Public health agencies need similar tools—like reporting tools or a way to link ELR and eCR—but for the most part resort to building or procuring their own.

Key insight

CDC can accelerate modernization and make efficient use of resources by identifying where tools can be built once and used by many jurisdictions. CDC should make solutions accessible both by building tools and by supporting and promoting those developed by STLTs.

Participant quote

"If only the ELR, EHR, EMR, eCRs and ISS were all somehow integrated and connected; communicating necessary and vital information to the PHA."

What we heard about the current state

- State health departments need a tool to link ELR and eCR within our surveillance system.
- A new reports tool is needed.
- When there's an error in the MVPS Portal, the data submitter at the state has to figure out whose error it is and where it needs to be fixed.
- Each STLT is developing their own process to automate the sending of NETSS data. This could create even more silos.
- I need help quickly parsing through electronic case reporting (eCR) records so I can find and view the information I need.

Siloed systems + processes

Access to data: Pain points overview

Public health **workers lack efficient or consistent access to critical data** creating additional manual work, gaps in [actionable] knowledge, and less effective and delayed public health action.

1. Access to data is not enough – it must be **high quality and easily available to be useful.**
2. **Existing infrastructure to access data** doesn't meet the demands of today's public health needs.
3. Getting access to data is a challenge because **people don't trust others to understand the data and to protect confidentiality,** and because there are so many hoops to go through to get authorization.
4. Even when access is granted, **finding data across isolated systems is burdensome** and slows time to action.
5. Often **tribal sovereignty** and tribal public health's need for timely, accurate and useful data is not well understood or acknowledged.

Current pain point

Access to data is not enough – it must be high quality and easily available to be useful.

Key insight

Efforts to develop data infrastructure, acquire data, and provide access need to be coupled with development and enforcement of data content, format and quality standards to ensure usability and value.

Participant quote

I need access to health care records to reduce the amount of phone calls and emails needed to track down case data."

What we heard about the current state

- Even if medical records are accessible, the quality of the data is not always reliable.
- Lack of access to access to quality clinical data may lead to an increase in manual processes (ex. a phone call to the doctor interrupts the doctor)
- Data migration challenges raise data quality concerns.
- Data dumping provides data, but it may not be useable or helpful.
- Incomplete electronic data means that paper reporting is still happening.
- Incomplete data is going from local to state health departments.
- Tribal and state public health need to better route cases and assignments to jurisdictions because zip codes are not reliable for finding individuals.
- If STLT public health doesn't have good case surveillance, we can't do good contact tracing and stop disease spread.
- Without data, all the technology in the world won't matter.
- Data quality varies by jurisdiction depending on entry method. Lack of standardization and filtering down to the common denominator hurt data quality.
- Data validation is automated, ongoing, and applied.

Current pain point

Existing infrastructure to access data doesn't meet the demands of today's public health needs.

Key insight

Modern strategies that enable access to secure, reliable and flexible data are needed to ensure timely information sharing and support decision making.

Participant quote

I need access to secure technical infrastructure such as internet, email, secure transfer file protocol (SFTP), application programming interfaces (APIs), and the cloud so that I can send, receive, and use case data efficiently and confidently."

What we heard about the current state

- Loading data through SAMS requires additional overhead to do the manual loads and maintain user access.
- There are barriers in the connections between departments that keep us from being able to see or access the data.
- LHDs don't always have needed access to data systems.
- I need to have transparency with and access to my data across local, state and federal levels.
- Without data, all the technology in the world won't matter.
- Tribal and state public health should move beyond zip codes for case routing and assignment to jurisdictions because they are not reliable for finding individuals.
- CDC needs to be able to consume data in multiple formats.

Current pain point

Getting access to data is a challenge because people don't trust others to understand the data and to protect confidentiality, and because there are so many hoops to go through to get authorization.

Key insight

Clear expectations for data use and protection, and re-usable data agreements could ease data access and provide a more complete picture of health and risks in the community.

Key Insight

A collaborative governance process to establish expectations for data protections and data sharing could help establish the foundation of trust needed for more fluid sharing of data.

Participant quote

"It's beneficial when agencies can just go in and look for what they want without having to submit a request. If you submit a request and it's not exactly what you needed, you have to go submit another one. That's a lot of back and forth."

What we heard about the current state

- State, local, and tribal public health encounter challenging relationships that dictate their access to data.
- Getting data out of federal facilities (CDC, VA, DOD, IHS, etc.) is really hard.
- It is challenging to obtain information because of gatekeeping that prevents access.
- Some entities (like the VA) require a bunch of forms before granting access to data.
- Program-specific or narrowly-scoped DUAs limit effective data sharing.
- Knowing applicable data sharing policies at each level of government can be overwhelming.
- Some local and tribal health departments have no access to their own data.
- Each set of state lawyers has a different level of risk tolerance.
- Need trusted neutral party to govern data sharing.
- Public health needs to know that data being exchanged is handled responsibly and is being used for meaningful public health action.

Access to data

Current pain point

Even when access is granted, finding data across isolated systems is burdensome and slows time to action.

Key insight

People need to easily find, integrate and use data from multiple sources. Standards-based data that are linked and are maintained in integrated repositories provides the opportunity to generate insights and improve situational awareness.

Participant quote

I need systems and tools that help me integrate information because public health action requires pulling together data from multiple sources for analysis and interpretation."

What we heard about the current state

- Epidemiologists and analysts need data sets that are formatted and ready for analysis.
- Once granted access, there is a lot to sift through in multiple different systems.
- I need to have transparency with and access to my data across local, state and federal levels.
- Case investigators need help quickly parsing through electronic case reporting (eCR) records so I can find & view the information I need.
- Without data, all the tech in the world won't matter.
- Lack of interoperability makes it difficult for local and state health departments to exchange data.
- Need a state health data utility, where all data is in one place and people with different authorities have different access permissions. A utility needs to be funded, sustained, surged. Putting it in one place reduces the need to move data around.

Access to data

Current pain point

Often tribal sovereignty and tribal public health's need for timely, accurate and useful data is not well understood or acknowledged.

Key insight

Because of the important role that tribal public health plays in protecting the health of their communities, tribal input should be sought in the development of strategies to address data content, data flows, data infrastructure and data sharing.

Participant quote

"We want to identify the health issues of the community, but there are a lot of data access bottlenecks in our way."

What we heard about the current state

- Sometimes tribal sovereignty is not recognized by federal, state or local public health.
- Overall, there is a lack of understanding of tribal public health authorities' rights to access data.
- There is a lack of understanding of the role, or even existence, of tribal public health agencies.
- Data sharing agreements, both US Government-to-Tribal Nation and State-to-Tribal Nation, need to be implemented.
- It is important that all levels of public health consult with tribes before decisions are made.
- Tribes need to have the authority to decide what data is shared or published.
- There is great variation in tribal public health agency roles, scope of responsibility, and resources, but more and more are achieving PHAB certification.
- Identifying tribe-specific data can be difficult, especially when GIS boundary files don't match tribal borders, when AI/AN racial information is incomplete, and when data sets don't include tribal affiliation.
- Local and state laws, or varying interpretation of law or policy, may obstruct data sharing between non-tribal and tribal public health agencies.

Sustainable workforce: Pain points overview

The **lack of defined staff skills, boom and bust categorical funding, and poorly defined roles** that don't match people's actual tasks impede the ability of public health agencies to hire, retain, and train adequate and effective staffing.

1. **Lack of training, education, and support** makes it difficult to maintain a sustainable work practice.
2. At every level of public health, there is more work than there are capabilities or resources for, resulting in **staff burnout and turnover.**
3. **Funding and contract constraints** can stop progress/modernization in its tracks.

Current pain point

Lack of training, education, and support makes it difficult to maintain a sustainable work practice.

Key insight

Attracting and retaining a technologically savvy workforce requires investment in training and career advancement that evolves with the state of public health.

Participant quote

"With data modernization, depending on the age of your workforce, that can be a real challenge to learn and implement."

"It is very time consuming to build and execute MMGs. You need a knowledgeable staff for designing them, testing them, etc.."

What we heard about the current state

- Continuing education to healthcare from public health.
- Cross-training can help personal development and organizational resiliency.
- Some of the surveillance case definitions are challenging; training on them would help.
- Staff with HL7 and XML knowledge are still needed to implement eCR and near-term modernization.
- Staff is needed to build and maintain systems.
- The biggest challenges are building out MMGs and having knowledgeable staff to do it.

Sustainable workforce

Current pain point

At every level of public health, there is more work than there are capabilities or resources for, resulting in staff burnout and turnover.

Key insight

Reduced commitment to adequate staffing at all levels of public health increases inefficiencies and attrition and which means less public health work gets done, putting the public at greater risk.

Participant quote

I need administrative and operations staff and processes in place to run my health department efficiently."

What we heard about the current state

- Hiring processes at STLTs and CDC are cumbersome.
- There is not enough staff to both modernize and continue the data flow – both are being done poorly, and people are being stretched thin.
- Some state priorities, like eCR, are not yet useful to the staff at local public health.
- Insufficient resources at CDC to onboard MMGs hold-up jurisdiction progress.
- Onboarding with CDC programs can have a long wait time and can take over 2 months.
- Jurisdictions don't have staff to validate whether eCR data is as good as paper reports.
- We're seeing employee turnover due to the work burden. Turnover oftentimes means starting a process over.
- Low-volume, under resourced labs and facilities struggle with keeping up with modernization.
- Overburdened staff (especially at the local level), don't have enough staff or time to manage all activities.
- Many workers are overburdened because of low staffing numbers and restricted resources.
- Staff are stretched thin in outbreaks and still need to do other work.

Sustainable workforce

Current pain point

Funding and contract constraints can stop progress / modernization in its tracks.

Key insight

Consistent and effective modernization require maintaining deep expertise and institutional knowledge that staff can only acquire over time. When the workforce is dependent on grant and contract funding there is a revolving door of staff that leads to a repeated delays and technology pivots.

Participant quote

During COVID, we found a [salesforce-based contact tracing] system that we loved, a system that felt like stepping into the future. Then they saw the price tag, and they took it away. We all got a taste of what it felt like to have the best of the best."

What we heard about the current state

- Federal funding should acknowledge that some aspects of technology costs are the same regardless of size or population.
- Many health depts are dependent on funding to onboard eCR in their systems even though requirements are cumbersome and vary and eCR doesn't provide value. However, loss of funding would mean having to stop other, important public health work.
- Procuring contracts takes too long.
- Relational knowledge lost is difficult to replace.

Sustainable workforce

Collaboration + orchestration: Pain points overview

Lack of strategic planning, timeliness and transparency in decision making, and changing priorities have resulted in suboptimal data modernization efforts that have further eroded efficacy across an already strained PH ecosystem.

1. **Communication siloes hinder work,** alignment, and case surveillance between systems and between groups within a system.
2. **Processes take too long**. Locals need solutions now.
3. **Lack of coordinated vision across public health hinders** action and alignment of CDC, state, tribal, local and territorial modernization roadmaps.
4. **Unclear roles, standards, and governance processes** complicate reporting, surveillance, and collaboration.
5. Experiencing a lack of control from **unfunded mandates, timeline delays, and a lack of resources** makes public health work more difficult.
6. **There are missed opportunities for relationship and trust building** between public health and hospitals, local, state, tribes, Tribal Epidemiology Centers (TECs), counties, and federal entities and facilities.
7. **Slow and disjointed vendor and contract procurement and management** create more discrepancies between local and state public health departments.

Current pain point

Processes take too long. STLTs need solutions now.

Collaboration + orchestration

Key insight

Enabling regular collaboration and convening across levels and disciplines of public health will accelerate solutions for the most critical problems.

Participant quote

Just having the state epis more available to us [at the local-level] in general would be a big improvement."

What we heard about the current state

- Like the children's game "telephone," siloes mean that communicating across public health gets distorted.
- There is a lack of communication between hospital system and state or city public health systems.
- Needs at the local level and at CDC don't align.
- There were communication gaps between informatics, epidemiologists, and public health officials, particularly in data sharing and interpretation.
- There are several untracked and siloed communications between HDs.
- There is a need for better communication channels between informatics, epidemiologists, and other stakeholders (IT, leadership) to ensure data is effectively shared and utilized.
- It can be difficult to identify all interested parties when there is an emergency.
- There is lack of communication between public health SME's and IT engineers.
- Emphasis is needed to enhance communication channels between various stakeholders to ensure better coordination and data sharing.
- Better collaboration and orchestration between IT contractors and public health entities is critical.
- Tribal consultation doesn't occur often enough, so decisions are made without input on tribal public health needs.
- The wide variety of structures and interested parties in the state, local, and tribal health departments and tribal epidemiology centers make coordination complicated.
- Better communication with hospital infectious control is needed.
- Changes that appear to create resource savings at one public health level may add burden at other levels of public health.
- Having an epidemiologist at the state health department who is focused on tribal needs can support tribes who don't have a PH department.

Current pain point

Processes take too long. STLTs need solutions now.

Key insight

Building consensus, implementing solutions, and changing processes at one level of public health should not negatively affect the work of other levels, like local PHAs that need to respond urgently.

Participant quote

"Collaboration takes a long time, and [it] still might not be realistic for all jurisdictions."

What we heard about the current state

- Message Mapping Guide development, pre-onboarding and onboarding take too long.
- CDC creates things they can't implement in a timely way.
- Lots of factors can cause delays in implementation timelines (e.g., data collection forms change during a system implementation).
- Waiting for new surveillance systems delays progress on other things, like implementing MMGs.
- There seems to be a lack of urgency in solving problems that impact day-to-day work.
- Sometimes it takes greater than 6 months to develop consensus.
- The whole process of consensus building takes a lot of time and effort.

Collaboration + orchestration (2)

Current pain point

Unclear roles, standards, and governance processes complicate reporting, surveillance, and collaboration.

Key insight

Reporting and surveillance will not improve through technology enhancements alone. We must also rework legacy processes, governance and standards for national surveillance so that they support more flexible and actionable data exchange for all conditions that pose a threat to the public's health and safety.

Participant quote

"There is a need for a single system, centralized system access, and/or standardized data across systems to ensure seamless integration."

What we heard about the current state

- HDs and CDC don't have a solution to exchange data while waiting for lengthy transition in MMG strategy.
- There is a lot of taking but not a lot of giving of information across public health agencies.
- Need better governance to prevent battles with leadership over who can access systems/data.
- The lack of integration between local, state, and federal systems complicates data reporting and surveillance efforts.
- Public health needs different data strategies for different public health outcomes.
- Data are not available during MMG onboarding, so we need to come up with alternative ways to get the data.

Collaboration + orchestration (3)

Current pain point

Experiencing a lack of control from unfunded mandates, timeline delays, and a lack of resources makes public health work more difficult.

Key insight

CDC strategies and resources, including implementation centers, must support jurisdiction progress and help them align with the national vision for the public health data ecosystem.

Participant quote

> *Taking 6 months to develop and 2 years to implement is awful."*

> *I have to continue conducting investigations while managing teams and while working on the IT project."*

What we heard about the current state

- Need time to implement improvements.
- There are lots of requirements pushed down from CDC without funding to implement
- Some states do most infectious disease work through grants but funding may only cover a fraction of the need
- Challenges with vendors are real, including negotiating, managing, scoping work, and keeping them accountable.
- Procuring contracting takes too long.
- There are issues with building a system that doesn't meet needs and is disruptive to established workflows.
- Workers are stretched too thin. There is a lack of resources.
- There are many teams and programs involved to test or create a solution
- Local public health has low incentives to take on extra steps and efforts
- Mandates put demands on states to do more work with little support.
- Difficult to work on MMGs when system modernization needs to be done

Collaboration + orchestration (4)

Current pain point

There are missed opportunities for relationship and trust building between public health and hospitals, local, state, tribes, TECs, counties, and federal entities and facilities.

Key insight

Earning and maintaining trust is essential. Even neglecting a single relationship along the data chain can risk the quality and speed of public health action.

Participant quote

Data sharing is complex and sensitive; data sharing agreements are challenging to negotiate and often aren't stable."

CDC could help by advocating within the public health community for better case-level data sharing, with governance that supports tribal data sovereignty, and with funding for end-to-end solutions."

What we heard about the current state

- Where there is low trust between public health and hospitals, between local and state, and in other relationships this inhibits data sharing.
- Communication/maintaining relationships takes time and effort.
- Relationships with healthcare facilities have to be good to get the information we need.
- Sometimes personal connections and knowing the right channels gets the job done, but means getting information is fragile.
- Relationship, processes and the ways that people work together across federal, state, local, and tribal public health is complex and delicate.
- Often trust and transparency are low.
- There continue to be missed opportunities for relationship building and engagement.

Collaboration + orchestration (5)

Current pain point

Lack of coordinated vision across public health hinders action and alignment of CDC, state, tribal, local and territorial modernization roadmaps.

Collaboration + orchestration (6)

Key insight

CDC must facilitate development and orchestrate the execution of a national vision. Without alignment on and articulation of data strategies, the public health ecosystem risks continued fragmentation.

Key insight

Though the Public Health Data Strategy provides initial steps, continuing to mature the PHDS to include actionable, shared goals across all levels of public health will accelerate progress.

Participant quote

"What happens when leadership at the state level decides to go in a different direction?"

What we heard about the current state

- There are too many cooks in the kitchen.
- Too often, leadership pulls out the rug, changes direction, or changes their opinion.
- Conflicting priorities, slow changes, and poor communication affect our ability to get things done.
- Top-down communications from the CDC are not always clear. STLT health departments don't always know what needs to be fixed.
- Need better communication about what data CDC needs and how CDC uses it.
- It isn't clear what "approved by CDC" means, especially for eCR implementation.
- Outdated, inflexible policies or laws penalize both good and bad actors, e.g., for data access.
- There are just too many nationally notifiable diseases; we need to narrow the list.
- State leadership changes, so priorities change.
- I and other data modernization leads need a common vision and strategy to work towards so that I understand my purpose and feel empowered to make an impact.

Current pain point

Slow and disjointed vendor and contract procurement and management create more discrepancies between local and state public health departments.

Key insight

A clear vision and standards for system capabilities from CDC will make it easier to write contracts that hold vendors accountable.

Participant quote

"Currently we have an old system. [We're] getting a new system, but [it] doesn't have all the functionalities that we need."

What we heard about the current state

- Standardization on contract language and technology needs for states would make procurement more efficient and modernization across PH more consistent.
- Vendors are not producing/performing as they promised.
- Need to clarify with vendors what's "in scope" under contract vs. what is needed for public health.
- Delays and changes at the state for vendor procurement make progress stumble.
- Barriers of moving to new systems from current proprietary products present a challenge.
- How can we alleviate the protracted procurement processes and timelines, complicated by federal budget period and jurisdictional requirements. It takes more than a year to write and compete an RFP.
- Procured contracts should not just be the cheapest but also the best solution for public health.
- State and local public health looks to the CDC to support standards for systems' capabilities.
- It takes a long time to establish a contract.

Collaboration + orchestration (7)

Standardization: Pain points overview

The **lack of consistent and aligned governance** makes it challenging to promote the development, adoption **and implementation of interoperability standards** across the public health and healthcare ecosystem.

1. **Lack of integration between case surveillance workflows** delays public health actions.
2. **Creating and implementing standards is time-consuming.** When we create unnecessary standards, we risk flexibility to meet changing needs.
3. **Low adoption of standards and low consistency of following policies** hamper interoperability and disrupt public health work.

Current pain point

Lack of integration between case surveillance workflows delays public health actions.

Key insight

CDC, in partnership with STLTs, needs to rethink how we collect, use, and share case data to align on strategies that will maximize efficiency, inspire insights, and improve time to action.

Participant quote

"We need to develop a unified reporting system to replace the multiple, fragmented systems currently in use."

What we heard about the current state

- Healthcare and public health informaticians and enterprise administrators need clear standards that make it easier for health care to report case data and for public health to use it.
- Having too many nationally notifiable diseases are diluting what goes into each MMG.
- Lack of integration between case surveillance workflows delays public health actions, contributes to data quality issues, and results in both double data entry and increases in cases.
- Sending data is an issue when systems don't talk easily to each other.
- The limitations of NETSS and the proliferation of REDCap is a result of not having a good solution to get the data we need quickly.
- There is desire for a state health data utility where all data are in one place and people have different authorities and permissions to gain access. A utility needs to be funded, sustained, surged. Not moving data around but putting it all in one place.

Current pain point

Creating and implementing standards is time-consuming. When we create unnecessary standards, we risk flexibility to meet changing needs.

Key insight

Public health needs standards to help us align, but they shouldn't create more burden than value.

Participant quote

"I need consistent message mapping standards so that I can send data to CDC quickly and efficiently during routine and emergency response surveillance."

What we heard about the current state

- Interview questions can vary by state or CDC program, causing confusion and difficulty interpreting across datasets.
- Some states investigate some things in more detail than others.
- Public health needs standards that won't lock us into old ways of doing things; they need to be adaptable enough to evolve as need change
- MMGs are inflexible. Once they become a standard, they are hard to update.
- Newer MMGs don't do well in balancing precision with the need to move quickly.
- Inflexible and disease-specific MMGs don't keep up with surveillance needs.
- There are so many MMGs to onboard, multiplying the time and effort burden in onboarding.
- There are too many differences in surveillance systems.

Standardization (2)

Current pain point

Low adoption of standards and low consistency of following policies hamper interoperability and disrupt public health work.

Key insight

Collaboration in standards development for content and systems and support for their implementation are critical for timely adoption.

Participant quote

"Any time there is a change in the data, there is a lot of rebuilding that goes into the process. A whole new code can take time."

What we heard about the current state

- Each CDC program creates its own suite of data standards.
- Frequent and poorly communicated changes to the data schema are disruptive.
- Public health informaticians need disease surveillance systems to adopt shared standards so that data exchange between public health agencies is easier, faster, and more sustainable.
- Implementing a change in data structure and source is too time consuming.
- Updating the data requests and updating the systems are not the same thing. Durable solutions are needed.
- Will need enhanced training and resources for public health workers on using new standardized systems or tools.
- Adopting a standard can take too long when the work doesn't take a break to make room for 6 months to finalize an MMG.

Explanation of Terms

Explanations of Terms 1 of 5

- **1CDP viewer** – An interface provided by 1CDP that provides role-based access to view data held by CDC.
- **Actionable Data** – Information that is sufficiently timely, relevant, and accurate to allow public health agencies to prioritize, plan, and execute activities to improve the health of the community.
- **All parties** – in this context it is all individuals and organizations expected and authorized to use the data. This is likely to include STLT staff and CDC program and response staff, and there might be roles for other federal agencies, healthcare providers, or others.
- **Analytic-ready data** – Data that has been cleaned, transformed, and linked and is in a format that is optimized for analysis (rather than for transactions or for storage). For some users, the data may need to be aggregated or have other data suppression applied for confidentiality.
- **Appropriate data** – Data authorized for access by data sharing agreements and user role. It may be limited based on a variety of factors such as disease condition, jurisdiction, data elements, intended use, or level of data aggregation/suppression.
- **Case data** – Information on the case of a disease or condition that includes clinical information from health care, relevant laboratory finings, and information gathered through the public health case investigation on risk factors, potential exposures, control measures initiated, and other information not available from the clinical record..

Explanations of Terms 2 of 5

- **Core DUA** – A data use agreement between CDC and public health jurisdictions intended to simplify and streamline data sharing. It includes
  1) common provisions that outline CDC responsibilities and procedures that apply across data sets, and 2) data-specific addenda that address data source-specific and jurisdiction-specific requirements
- **Data exchange protocols** – Processes and agreements as to when and how data will be exchanged between parties.
- **Data Governance –** The policies and processes an organization uses to manage and secure their data
- **Data integrity checks** – Automated checks to ensure that data processing does not introduce errors into the data.
- **Data suppression criteria** – Statistical strategies to minimize the risk that the data could be used to, or appear to, provide information on any individual.
- **De-Identification** – Removal of data elements that could identify an individual before information is released. HIPAA provides rigorous de-identification standards while NNDSS allows inclusion of some epidemiologically important data elements that would not be permitted under the HIPAA standard
- **Disease management** – Actions recommended by public health to mitigate against the spread of disease or of severe illness in the affected infected.

Explanations of Terms 3 of 5

- **Emergent conditions** – Disease conditions that are rapidly emerging as health concerns for human populations in the US.
- **Health exchange** – A Health Information Exchange (HIE). By presenting access to multiple facilities' EHRs, it can provide an efficient interface for PH staff to query EHRs for additional data on a case. Often there is a single HIE for the state, but there may be multiple within a state and not all health care facilities currently participate in an HIE.
- **Healthcare** – Organizations, facilities, and clinicians that provide direct health care to patients.
- **Interoperability** – The ability of software systems to work together and exchange information to achieve a purpose. The includes the ability to communicate through compatible formats and protocols and the ability to exchange information and interpret it accurately.
- **Interoperability standards (Health IT)** – The content and exchange standards that allow fluid data exchange and semantic interoperability for healthcare data.
- **Interoperability and transmission standards** – Standards that define data content, format, and how it is to be sent. Adherence to these standards will allow public health to fluidly exchange data that can be understood and interpreted by the user. Current standards need to be expanded, updated, and refined to achieve this.

Explanations of Terms 4 of 5

- **Necessary data elements needed to initiate case investigations** – A basic set of data elements needed by the public health agency to initiate a case investigation. They include disease condition, contact information, basic demographics, basic diagnostic and symptom information.
- **Observability of data** – The ability of jurisdictions that submit data to CDC to see where it is in processing and how it is being used and interpreted by CDC.
- **Public health guidance** – Recommendations issued by public health agencies for treatment, isolation, prophylaxis, and other measures to manage conditions of public health concern.
- **Public health reporting** – Legally required submission of data by healthcare (and other designated reporters) to public health agencies on individuals diagnosed with or suspected of having specified conditions.
- **Raw data** – Data as provided by the source.
- **Ready to use data** – Data that has been cleaned, transformed, and linked and is in a format that is optimized for analysis (rather than for transactions or for storage). For some users, the data may need to be aggregated or have other data suppression applied for confidentiality.
- **Single partner workspace** – One workspace that is available to all relevant users.

Explanations of Terms 5 of 5

- **Standard analytic products** – A specified set of data analysis tools that are centrally managed and supported and are available to all users.
- **Transparency of data** – The ability of jurisdictions that submit data to CDC to see any transformations or changes made in processing and how it is being used and interpreted by CDC.
- **Urgent conditions** – Disease conditions that have a serious health impact and potential for spread that require rapid action to control their spread.

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