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PRIME New Team Member Onboarding

CDC + USDS Collaboration

Agenda

What we'll cover:

- Introduction to PRIME
- Part 1: Overview of Public Health
- Part 2: COVID-19 Case Data Flow
- Part 3: Types of Testing
- Part 4: CDC Structure

Not covering:

- Tech stacks, architecture, or other technical specifics
- This is not a deep dive on the individual PRIME projects

Introduction to PRIME

What is PRIME?

- PRIME is an acronym for **P**andemic-**R**eady **I**nteroperable **M**odernization **E**ffort
- PRIME is a multi-year collaboration between CDC and the U.S. Digital Service (USDS) to strengthen data quality and information technology systems in state and local health departments.

Mission Statement

To get better, faster, complete and accurate data to **state** and **local** public health departments so that they can take appropriate timely action.

Introduction to PRIME

PRIME Projects

1. ### SimpleReport
   A workflow tool that makes it easier for testing sites to manage and report test data to their health department

2. ### ReportStream
   Makes it easier to connect data senders to public health departments.

3. ### Public Health Data Infrastructure (PHDI)
   Exploring ways to improve data ingestion through better Data Storage, Tooling & Preparation, as well as the use of a common data model. Also exploring creating a ‘workbench’ with additional tools for data analysis

4. ### NBS Modernization
   Modernizing an existing tool for collecting, storing, and analyzing case data at public health departments

Quick history of PRIME

- **May/June 2020:** Discovery Sprint for Dr. Birx to understand challenges with collecting and reporting COVID-19 data
- **August 2020:** Kicked off collaboration with CDC to implement sprint recommendations
    - Found first STLT pilot partner (Pima County, AZ) willing to implement SimpleReport and ReportStream
- **December 2020:** First test results sent via SimpleReport/ReportStream
- **Mid-2021:** USDS starts does discovery sprints to evaluate opportunities for overall infrastructure improvement (not specific to COVID-19)—this led to the Public Health Data Infrastructure (PHDI) project.
- **Oct 2021:** Begins collaboration with NBS team on their modernization efforts

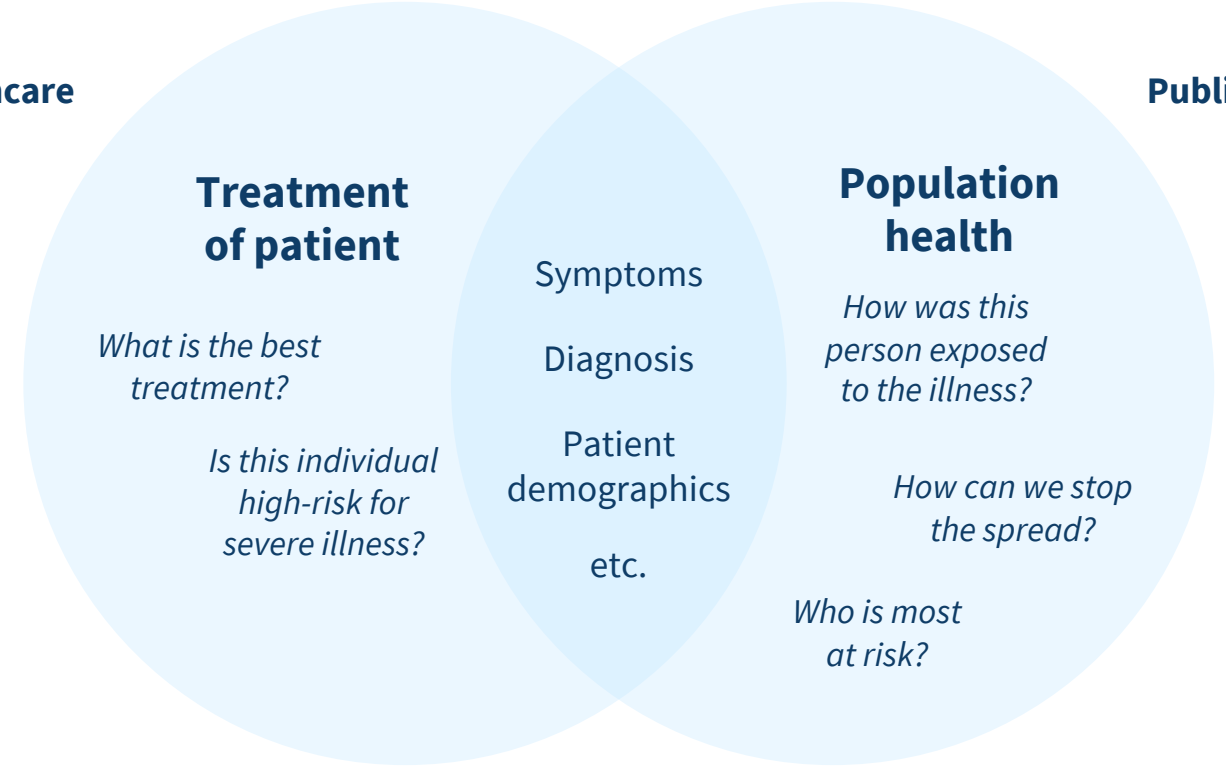
PRIME NEW TEAM MEMBER ONBOARDING

Part 1: Public Health Overview

Public Health Overview

Public health & Healthcare

They care about similar data, but are looking at it for different reasons



** Particularly in underserved, rural areas, public health departments often provide direct healthcare services

Public Health Overview

What is a public health department?

What they do

Promote population health by directly providing services such as:

- screening for diseases and conditions
- disease prevention through education
- maintaining disease and immunization registries
- state laboratory services
- direct public health interventions
- much more

Who they are (Collectively referred to as "STLT" pronounced "stilt")

- **s**tate & **t**erritorial health departments
- **l**ocal health departments (generally county or city)
- **t**ribal health departments

Public Health Overview

Key players in public health

Public Health Officials

- executive and administrative leaders of public health
- play a key role in policy development
- must be versed in the relevant/current evidence, and provide expertise about health issues to the legislature and the governor.
- Can be a political appointees

Epidemiologists

(AKA "Epis" pronounced eh-pee)

- search for the cause of disease, asking questions like
  - Who is sick?
  - What are their symptoms?
  - When did they get sick?
  - Where could they have been exposed?
- study answers to those questions using statistical analysis to:
  - identify people who are at risk
  - determine how to control or stop the spread or prevent it from happening again.
- Most epidemiologists have a master's degree in public health (MPH) or a related field, and some have completed a doctoral degree in epidemiology or medicine.

Public health nurses

- Monitor health trends and identify health risk factors unique to specific communities
- Set local priorities for health-related interventions
- Advocate with local, state and federal authorities to improve access to health services for underserved communities
- Design and implement health education campaigns and disease prevention activities, such as immunizations and screenings
- Educate and provide direct health care services to vulnerable and at-risk populations

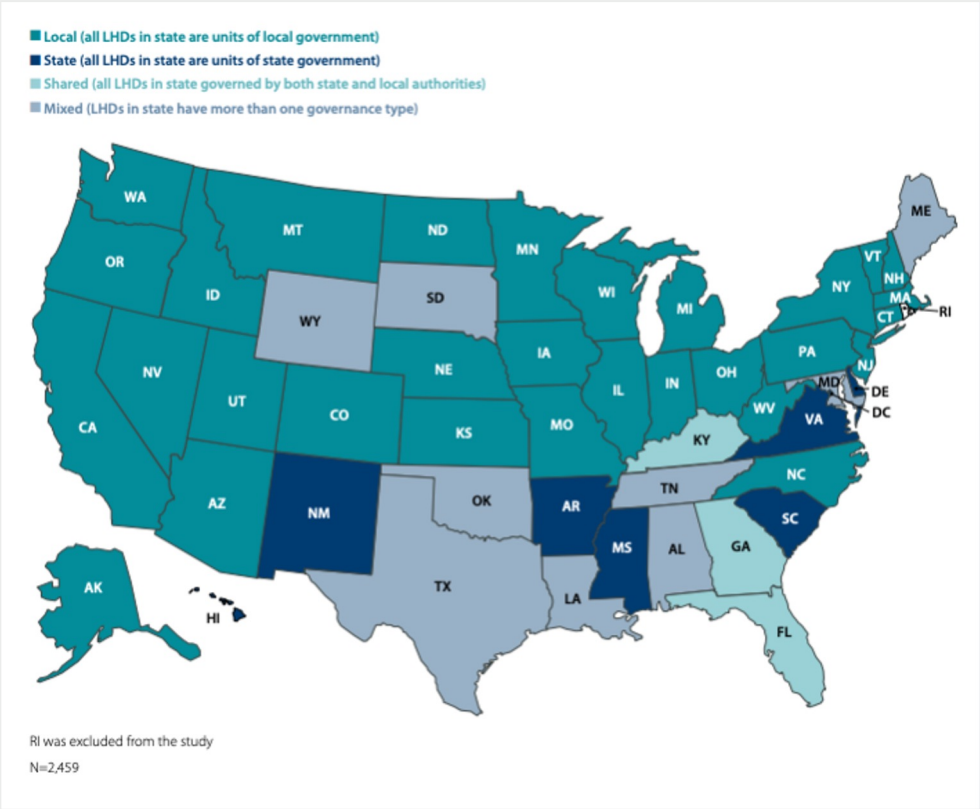
Contact Tracers

- notify contacts that they have been exposed to a disease
- contact tracers can be epidemiologists, public health nurses, or a separate team
- with COVID, many public health departments have hired separate teams just to do contact tracing in order to keep up with the large volume.

Public Health Overview

Governance types

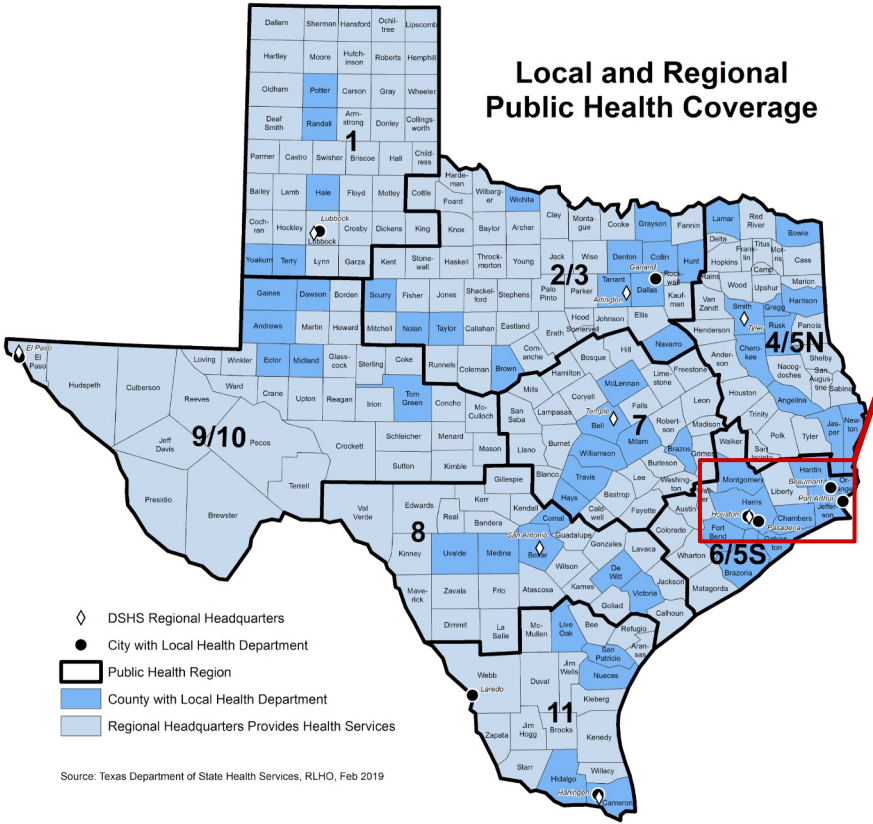
- **Local/Decentralized** — Local health departments are units led by local governments, which make most fiscal decisions. (AKA Home-rule states)
- **State/Centralized** — All local health departments are units of state government, which makes most fiscal decisions.
- **Shared** — All local health departments are governed by both state and local authorities.
- **Mixed** — Some local health departments are led by state government, and some are led by local government. No one arrangement predominates in the state.

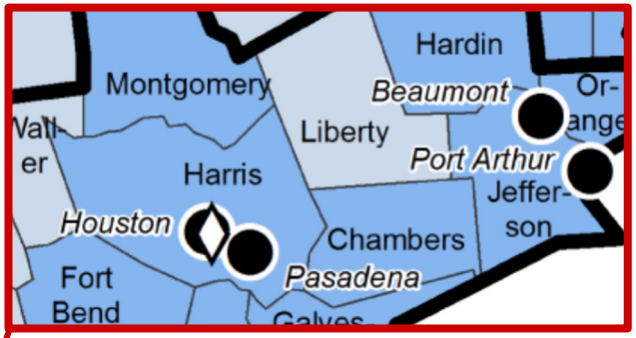


**From 2019 NAACHO National Profile Study | Source

Public Health Overview

Example: Texas



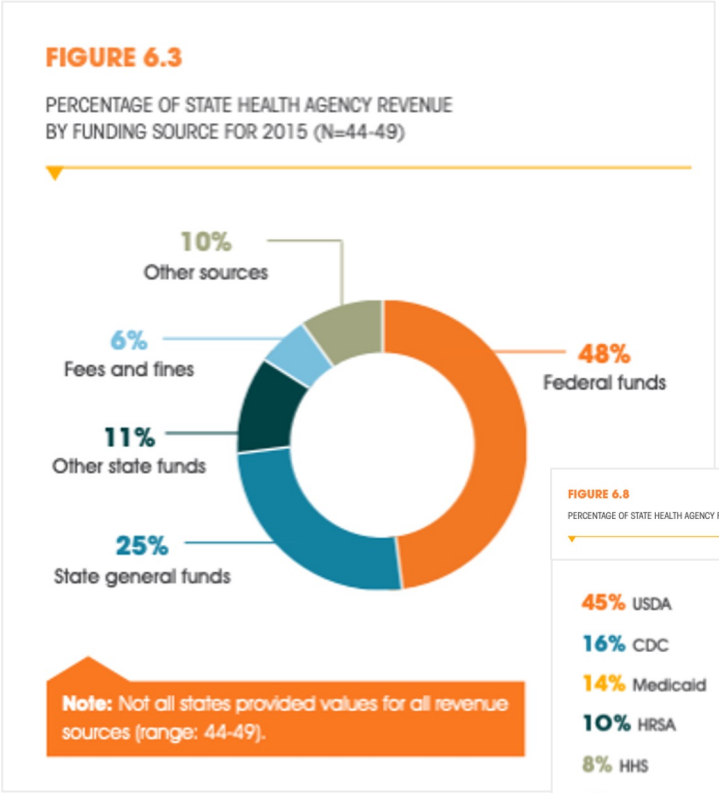


- **Houston** — City Health Department that receives direct funding from CDC and has authority over Houston city limits
- **Harris** — County that includes Houston. Harris has its own health department and has authority over all parts of Harris county *except* Houston.
- **Liberty**— County next to Harris that does not have a health department. Public health is run by the state of Texas.

Public Health Overview

How funding works

- Public health departments have been underfunded for decades
- Because of this, they haven't been able to invest in automation or technology
- ~50% of state public health funding comes from the federal government
- That funding is often tied to specific programs or diseases
- This has led to new systems being purchased or built to tackle specific diseases, rather than using the funds to expand or improve existing systems.



**From 2016 ASTHO National Profile Study | Source

Part 1: Public Health Overview

Summary

- **It’s complicated.**
- The problems faced by public health departments are long-standing and complex
- We need to work closely with our STLT partners to understand their specific needs
- We also need to keep an eye on the big picture so we can build tools that can help solve common problems that exist across many locations

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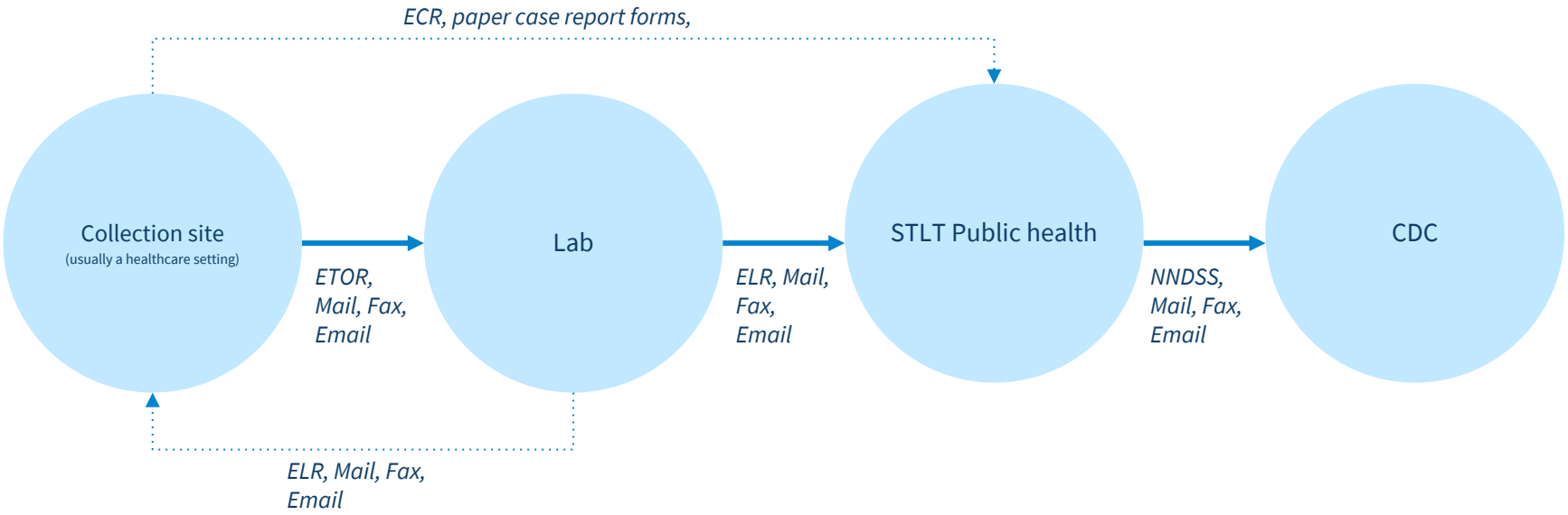
Part 2: COVID-19 Case Data Flow

 = manual process that could be fully or partially automated

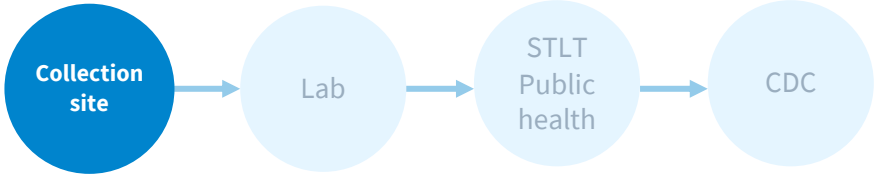
Public Health Case Data Flow

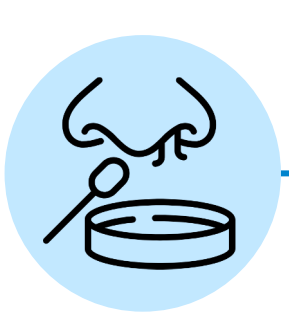
Overview



Public Health Case Data Flow

Collection Sites





Sample Collection

- Collection can happen in a **traditional healthcare setting** such as a hospital or urgent care
- Or it can happen in a **non-traditional setting** such as a drive-thru site, a school, or place of employment
- Testing in non-traditional settings has grown a lot for COVID

Data Collection

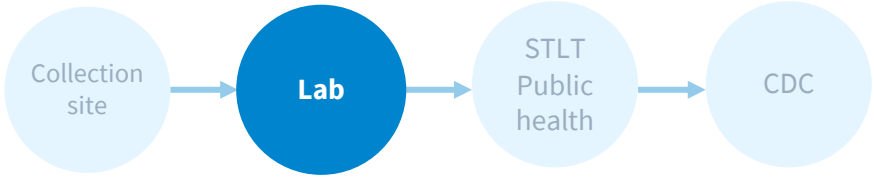
- In healthcare settings, data collection will happen in their **EHR/EMR** (Electronic Health/Medical Record) and/or on **paper**.
- In non-healthcare settings, data is often collected on **paper**.
- Data collected includes name and contact info, demographics, symptom info, etc.

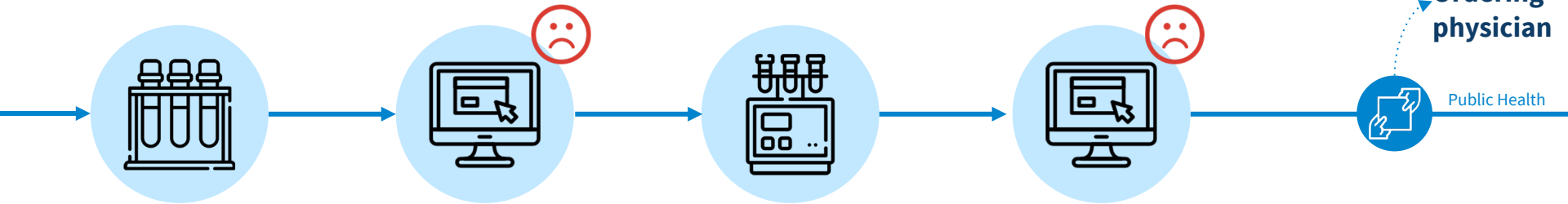
Sending

- Sample and data are packaged and sent to a lab

Public Health Case Data Flow

Labs





Samples Received

- Bring samples and paper lab orders in
- Scan barcodes to link everything into their Lab Information Management Systems **(LIMS)**

Manual Data Entry

- Manual data entry of information on paper lab orders

Samples Analyzed

- Samples are placed in machines to be analyzed for virus
- This takes up to 7–8 hours

Result Entered in LIMS

- Some machines can automatically interface with LIMS
- Machines without those interfaces require a person to manually enter results into the LIMS

Results Reported

- Results are reported either digitally using eLR (Electronic Lab Reporting)
- Or manually, either by emailing a CSV, via fax, phone call, or physical mail

Public Health Case Data Flow

Public Health Department

Collection site → Lab → **STLT Public health** → CDC

Disease Surveillance System

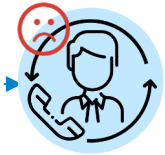
- Lab reports are submitted to the public health departments.
- If submitted by ELR, it should be automatic
- If sent via fax or CSV then manual work will be required to get the data into the surveillance system.

Case Investigation

- Manual 30–45 minute phone call to fill in case report details and gather contacts

Contact Tracing

- Contact tracers call contacts to notify them of their exposure and get them to quarantine



Daily Monitoring

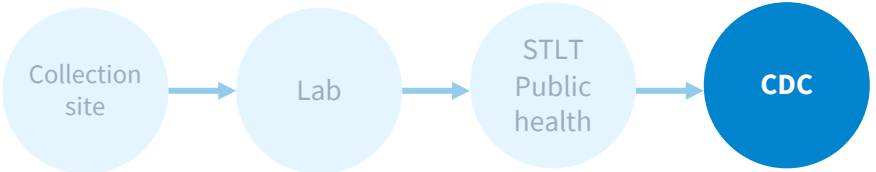
- The Public Health Dept follows up daily to see whether the person becomes sick

Monitoring

- For COVID, short (1–2 minute) daily phone call to track symptom progression

Public Health Case Data Flow

CDC



Public Health Departments

- 3 ways they can report
- Data reported to the federal government is always de-identified

NNDSS

- CDC-created protocol to report directly from disease surveillance systems (NBS has this built in)

-OR-

CSV Upload ☹

- DCIPHER has a front-end UI that allows you to upload a CSV

Labs

- ELR messages routed through AIMS can get sent to the CDC via CELR

CELR

- CDC product that sits on top of AIMS.
- Receives identified data and de-identifies it

DCIPHER

- CDC Palantir instance
- Used for emergency response (right now COVID)

COVID-19 Case Data Flow

Cross-Jurisdiction Routing

- Sometimes people get tests in a different jurisdiction than where they live, and the results end up in the wrong public health department.
- Contacts on a case often live in a different jurisdiction than where the case is being investigated
- Public Health systems across state lines are rarely interoperable, and this problem sometimes exists between jurisdictions within the same state

Photo from 2020 discovery sprint.

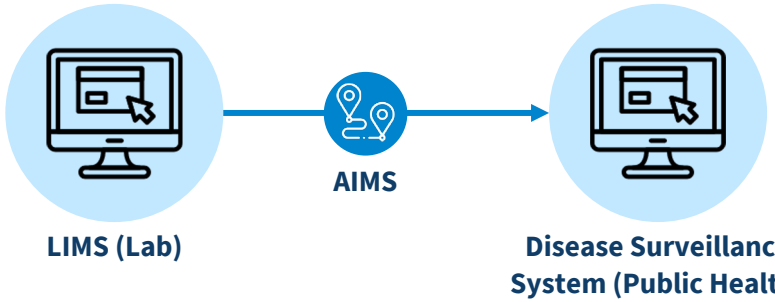
COVID-19 Case Data Flow

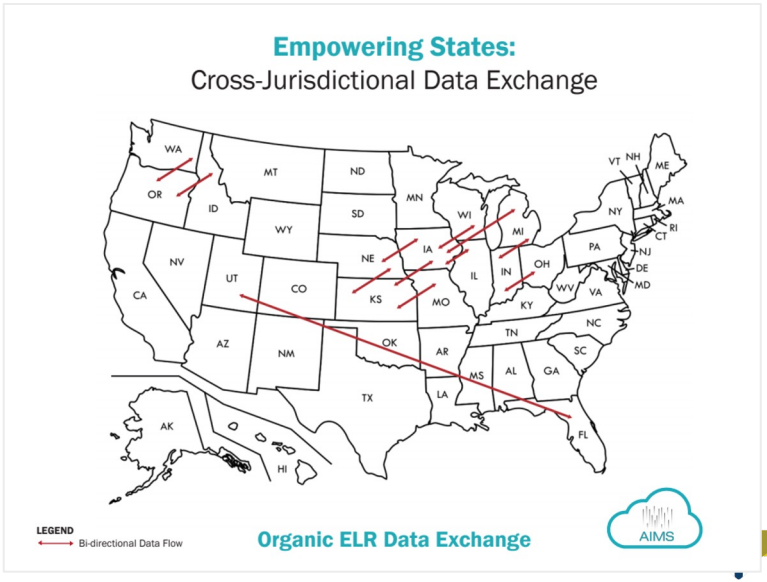
Cross-Jurisdiction Routing

AIMS Platform

AIMS is a routing platform. Labs can route their Electronic Lab Reporting (ELR) messages through AIMS and it will direct them to the correct jurisdiction, including across state lines if that state has also signed up for AIMS.

- AIMS makes it easier to route their lab results to the appropriate public health department.
- Built by APHL (Association of Public Health Laboratories) — a non-governmental industry group





Part 2: COVID-19 Case Data Flow

Summary

- Lack of data automation calls for manual processes
- Manual processes can increase errors, affect data quality, and slow down reporting speed
- At the scale of thousands of tests a day, that adds up to a big burden on public health departments
- Many labs that are using electronic lab reporting can’t afford to route their ELR messages through AIMS

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Part 3: Types of Testing

Types of Testing

PCR vs. Antigen vs. Serology

PCR/Molecular	Antigen	Serology (Antibody)
PCR tests look for pieces of SARS-CoV-2, the virus that causes COVID-19, in the nose, throat, or other areas in the respiratory tract to determine if the person has an **active infection**. These are typically thought to be more accurate than Antigen tests	Antigen tests look for pieces of proteins that make up the SARS- CoV-2 virus to determine if the person has an **active infection**. These are thought to be less accurate than PCR but they are typically cheaper and faster	Serology looks for antibodies against SARS-CoV-2 in the blood to determine if there was a **past infection**.

Types of Testing

Point of Care Tests (AKA Rapid Tests)

Point of care tests can return results in around 15 minutes. This means that instead of sending a sample to a lab for analysis and waiting days to get results, you can get results while you wait.

Most POC tests are antigen tests. However the Abbott ID Now machine is a rapid PCR test.

Some of these machines have been on the market long before COVID, and have historically been used to test for things like strep throat and the flu. Others are new and have been developed specifically to test for COVID.

Types of Testing

Problems with Point of Care Tests

1

Some POC test devices offer limited or no digital connections, meaning it can be difficult to automate reporting from these machines. They also only test one sample at a time.

2

They're springing in places such as schools and places of employment, that have no EHR or LIMS, and have never had to report to public health before.

That means there are probably a lot of tests that are **not getting reported at all**.

Types of Testing

At-home tests

New at-home tests pose unique challenges in capturing and sending data because they eliminate clinicians and labs from the equation and rely on either the patient or the device to do the reporting—something that has never been done.

The New York Times

New At-Home Covid Test Gets Green Light From F.D.A.

Unlike similar at-home tests, Ellume's does not require a prescription.

2 weeks ago

Part 3: Types of Testing

Summary

- There are a number of testing types that differ in pricing, accuracy, and availability
- Point-of-care tests offer little or no digital connection from testing entity to public health
- No way to enforce those reporting entities to who are required to submit data
- At-home tests are now available, but they eliminate the lab and clinician – patient must self-report

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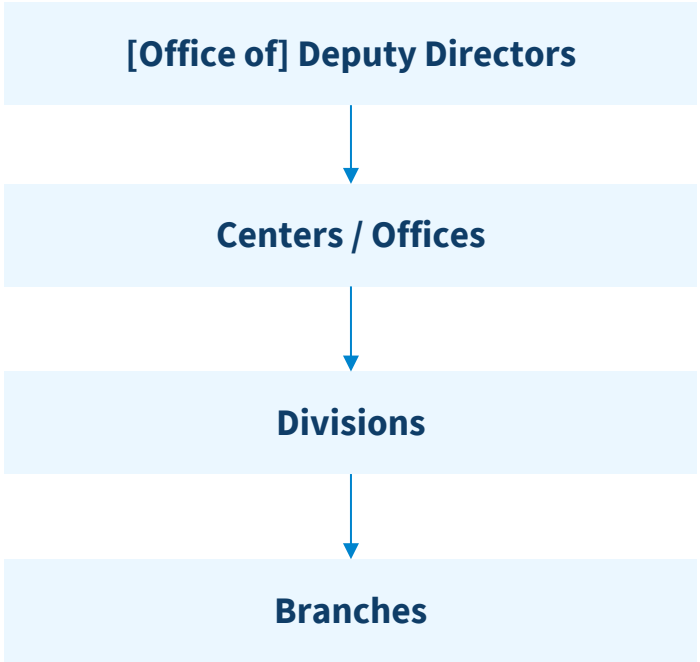
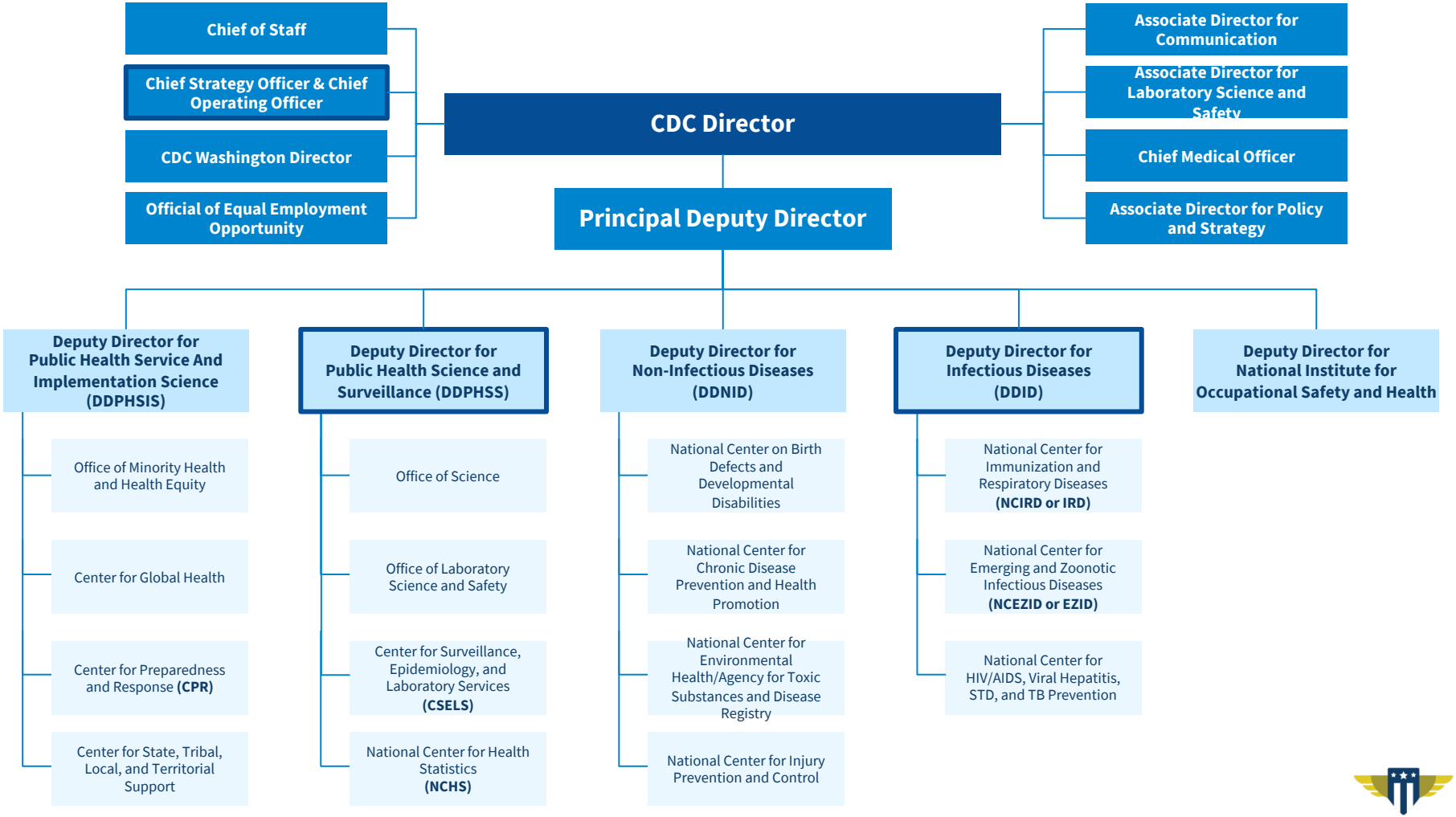
Part 4: CDC Structure

CDC Structure

Organization Structure

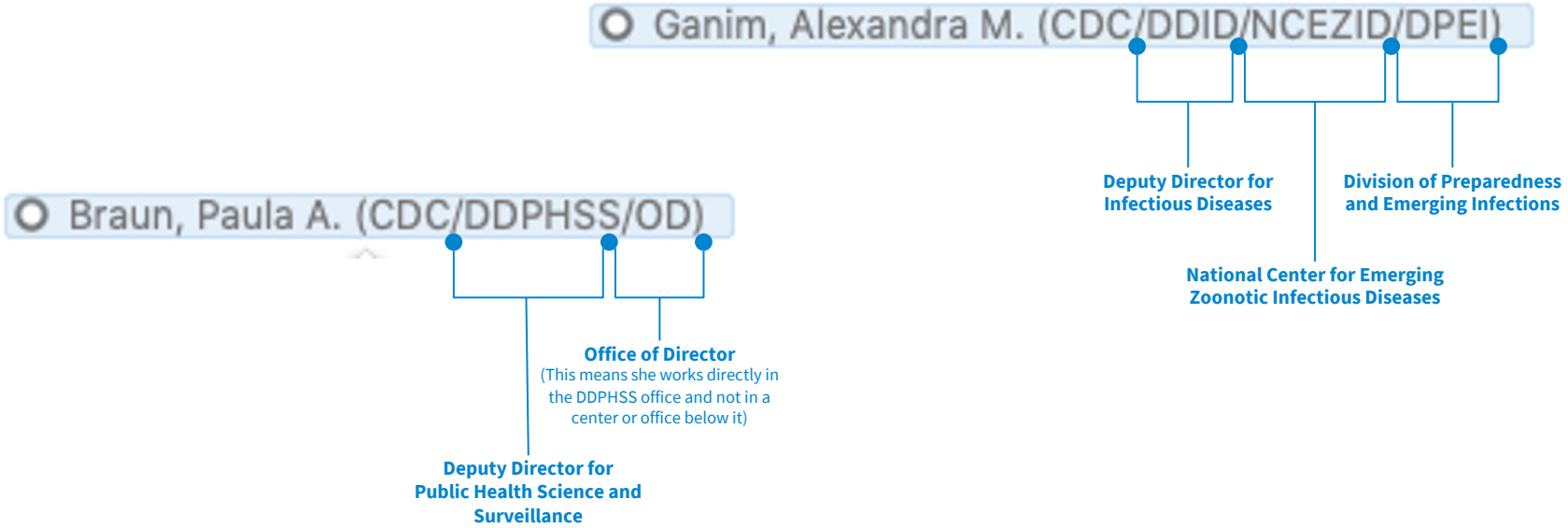



Chief of Staff
Chief Strategy Officer & Chief Operating Officer
CDC Washington Director
Official of Equal Employment Opportunity
CDC Director
Principal Deputy Director
Associate Director for Communication
Associate Director for Laboratory Science and Safety
Chief Medical Officer
Associate Director for Policy and Strategy
Deputy Director for Public Health Service And Implementation Science (DDPHSIS)
Office of Minority Health and Health Equity
Center for Global Health
Center for Preparedness and Response (CPR)
Center for State, Tribal, Local, and Territorial Support
Deputy Director for Public Health Science and Surveillance (DDPHSS)
Office of Science
Office of Laboratory Science and Safety
Center for Surveillance, Epidemiology, and Laboratory Services (CSELS)
National Center for Health Statistics (NCHS)
Deputy Director for Non-Infectious Diseases (DDNID)
National Center on Birth Defects and Developmental Disabilities
National Center for Chronic Disease Prevention and Health Promotion
National Center for Environmental Health/Agency for Toxic Substances and Disease Registry
National Center for Injury Prevention and Control
Deputy Director for Infectious Diseases (DDID)
National Center for Immunization and Respiratory Diseases (NCIRD or IRD)
National Center for Emerging and Zoonotic Infectious Diseases (NCEZID or EZID)
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention
Deputy Director for National Institute for Occupational Safety and Health

CDC Structure

How to decipher an email signature

You can see where a person sits within the CDC org. chart based on their email



CDC Structure

The role of different government agencies in public health

There are many more agencies involved in public health through funding and other activities, but these are the ones you should be familiar with for our purposes.

Health & Human Services (HHS)

- Parent agency
- Creates reporting requirements

National Institutes of Health (NIH)

- Medical research agency — making important discoveries that improve health and save lives.
- Working on COVID vaccine research

Centers for Disease Control and Prevention (CDC)

- Top federal public health agency in the country
- Science and research
- Provide on-the-ground support where needed
- Provides funding to state/local public health
- Develop resources like NBS for use by states/locals

Centers for Medicare & Medicaid Services (CMS)

- Provides a lot of funding to local public health via Medicaid
- Can create regulations as a condition of receiving payments, which is a powerful tool

Food & Drug Administration (FDA)

- Regulates drugs and medical devices
- Has power to set requirements on testing devices

Health Resources & Services Administration (HRSA)

- Improves access to health care services for people who are uninsured, isolated or medically vulnerable
- Reimburses health care providers for testing and treatment of COVID for uninsured people

Indian Health Service (IHS)

- Provides direct medical and public health services to members of federally-recognized Native American Tribes and Alaska Native people

Part 4: CDC Structure

Summary

- Within CDC, there are many deputy directors, centers and offices, divisions and branches that support and touch the work we do on PRIME
- There are many more agencies outside of CDC involved in public health (CMS, FDA, HRSA, IHS, NIH, etc.)
- Health & Human Services (HHS) is our parent agency that creates reporting requirements

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Resources

Resources

Mentioned resources and links:

SimpleReport (SR): https://www.simplereport.gov/

ReportStream (RS): https://reportstream.cdc.gov/

Public Health Data Infrastructure (PHDI)

NBS Modernization: https://www.cdc.gov/nbs/overview/index.html

2016 ASTHO National Profile Study: https://www.astho.org/globalassets/pdf/profile/profile-stph-vol-4.pdf

National Notifiable Diseases Surveillance System (NNDSS): https://www.cdc.gov/nndss/index.html

National Electronic Disease Surveillance System (NEDSS): https://www.cdc.gov/nndss/about/nedss.html

APHL Informatics Messaging Services (AIMS): https://www.aphl.org/programs/informatics/pages/aims_platform.aspx

Data Collation and Integration for Public Health Event Response (DCIPHER)

U.S. Department of Health & Human Services (HHS): https://www.hhs.gov/

Centers for Disease Control and Prevention (CDC): https://www.cdc.gov/

Centers for Medicare & Medicaid Services (CMS): https://www.cms.gov/

Food and Drug Administration (FDA): https://www.fda.gov/

Health Resources & Services Administration (HRSA): https://www.hrsa.gov/

Indian Health Service (HIS): https://www.hrsa.gov/

National Institutes of Health (NIH): https://www.nih.gov/