

Activity Booklet



# **Table of Contents**

Introduction	02
Strategic Agenda	03
Sentinel Surveillance	07
COVID-19 Seroprevalence	08
Advancing Health Equity	09
Collecting Better Data about People Experiencing Homelessness	10
Promoting Adoption of HL7® FHIR®	11
Promoting Use of Innovative Data Linkage Strategies	12
Standardizing Data Elements	13
Making Rapid Data Exchange a Reality	14
Improving Patient Care and Health Outcomes	15
Developing Technical and Architecture Solutions	16

## Introduction

The Public Health Informatics Office (PHIO), located within CDC's Center for Surveillance, Epidemiology, and Laboratory Services (CSELS), works to meet evolving data and informatics needs to protect Americans from health threats.



"PHIO welcomes the opportunity for collaboration to advance data informatics and surveillance by strengthening reporting, management, and innovation across CDC and the national public health data ecosystem."

- Adi V. Gundlapalli, MD, PhD, MS CSELS Chief Public Health Informatics Officer, PHIO Director, CSELS PHIO is an interdisciplinary office that collaborates across the agency and with private and governmental partners to provide innovative data, analytics, and technology solutions for public health action. PHIO provides leadership in data and informatics preparedness and response, partnership and advisory services to support data modernization, and informatics and technology innovation activities that benefit CDC and external partners.

PHIO is leading CSELS' efforts to develop solutions that modernize the way public health systems share data to better address emerging public health threats. This includes ensuring that the implementation of informatics and information technology solutions are interoperable and standards-based.

PHIO is also the hub of CDC's clinical informatics expertise and is growing the next generation of informaticians through several capacity development approaches, including fellowship opportunities, training, and mentoring.

This Activity Booklet offers examples of what PHIO does to support its mission of delivering strategic informatics leadership and advisement to advance the nation's evolving public health data needs. PHIO welcomes the opportunity for collaboration to advance data informatics and surveillance by strengthening reporting, management, and innovation across CDC and the national public health data ecosystem.

# STRATEGIC AGENDA

## 2022-2025

## Q VISION

A modern public health data ecosystem that is response-ready and leveraged to protect and improve health.

## **MISSION**

Deliver strategic informatics leadership and advisement to advance the nation's evolving public health data needs.

## **WALUES**

**PARTNERSHIP** 

We achieve goals together

INNOVATION

We deliver modern solutions

**LEADERSHIP** 

We aim for outcomes

### $\stackrel{ extstyle e$

#### Goal 1: Provide strategic public health informatics leadership

- 1.1 Build CDC's informatics workforce capacity through making available training opportunities.
- 1.2 Establish a data linkage strategy, including identifying guard rails, roles, funding needs, data governance, and security and privacy concerns, that can be evaluated and refined during pilot evaluations.
- 1.3 Co-lead CDC's Data Standards Management and Harmonization workgroup in collaboration with CDC's Office of the Chief Information Officer (OCIO) to increase the visibility of public health data standards, support cross-program surveillance standards management, and prioritize engagements with external partners on public health data standards.

## Goal 2: Foster collaboration and coordination to influence public health data modernization initiatives

- 2.1 Gain input from data providers and vendors conducting data linkage about the challenges and opportunities to expand work with public health agencies and jurisdictions.
- 2.2 Conduct an evaluation to identify best practices and barriers for applying data linkage strategies to improve future use in public health.
- 2.3 Pilot methods for linking individual healthcare data, public health data, and select federal agency data with other data sources for at least 2 public health conditions or diseases.
- 2.4 Facilitate collaboration across CDC to use data linkage strategies by engaging staff in data analysis and facilitating a data linkage Community of Practice.

## STRATEGIC AGENDA

## **□** GOALS AND OBJECTIVES

- 2.5 Facilitate public private collaborations working with HL7® FHIR® to rapidly design, test, and scale FHIR-based solutions for high priority public health use cases.
- 2.6 Inform data modernization initiative activities through leadership and advisement on foundational infrastructure, data standards and policies to accelerate interoperability, and partnerships.

# Goal 3: Inform the development of public health and health information technology (IT) policies and standards

- 3.1 Promote adoption of HL7® FHIR® standards by CDC programs with the provision of technical assistance by internal and external experts through trainings, presentations, and one-on-one advisement.
- 3.2 Assess data sources and standard practices for electronic healthcare data to identify opportunities to increase completeness of data to monitor health equity among a wide range of disproportionately affected populations.
- 3.3 Collaborate with other federal partners on USCDI data standards and quality measures to promote inclusion of public health data elements in electronic health records.
- 3.4 Identify barriers to utilizing data standards and develop tools to address identified barriers.

# Goal 4: Ensure implementation of informatics solutions are interoperable and standards-based

- 4.1 Pilot and evaluate strategy to increase reliable and efficient data exchange for electronic health records.
- 4.2 Build and test public health information technology and architecture solutions.
- 4.3 Disseminate strategies to improve the accessibility and efficient use of clinical guidelines by healthcare providers.
- 4.4 Identify and promote to the health information technology community standardized data related to health equity and social determinants of heath.

## Goal 5: Lead public health data and informatics preparedness and response

- 5.1 Establish federal collaboration and other strategies to strengthen data exchange related to emerging pathogens.
- 5.2 Partner with external laboratories to broaden understanding for the evolving burden of COVID-19 to inform state and national action and policy.
- 5.3 Provide leadership on data access, analytic strategies, and information technology infrastructure to strengthen CDC's data-driven preparedness and response public health action.

#### Goal 6: Lead IT and data governance

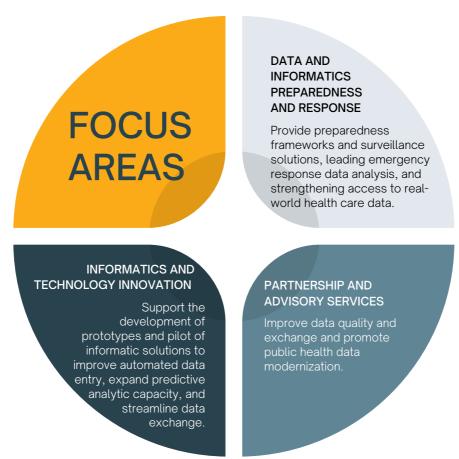
- 6.1 Implement strategies to increase efficiency of CSELS' IT and data governance review processes.
- 6.2 Complete all IT and data systems semi-annual reviews as required by regulation.
- 6.3 Conduct annual reviews of CSELS' IT and data investment portfolio.

## STRATEGIC AGENDA

The Public Health Informatics Office (PHIO) provides leadership in three overarching focus areas - data and informatics preparedness and response, partnership and advisory services, and informatics and technology innovation. PHIO collaborates with interdisciplinary internal and external partners to provide innovative data, analytics, and technology solutions for public health action.

Examples of collaborative partnerships include:

- Private sector professionals to provide innovative solutions that streamline data exchange.
- Technical experts to solve real-world data challenges with electronic health records.
- State, tribal, local, and territorial public health agencies to address their informatics needs.
- Programs across CDC and other federal agencies to modernize data systems and processes.



PHIO also leads IT and data governance through the CSELS Information and Data Resources Oversight Committee (CIDROC). CIDROC works with CDC's Information Technology and Data Governance (ITDG) to optimize deployment and use of information and data resources across CSELS by directing and supporting consistency, accountability, and transparency.

The work of PHIO is designed to meet evolving data and informatics needs to protect and improve health. Strengthening the public health infrastructure and its workforce are critical to achieve this. PHIO is building a stronger workforce by mentoring and training the next generation of informaticians through fellowship opportunities to address the nation's public health data challenges and make a lasting impact on sustainable systems.



Here are examples of what PHIO does to support its mission.

## Sentinel Surveillance

Bio-Khoj: Coordinated Sentinel Surveillance and Discovery for Emerging Human Pathogens

Ongoing detection and surveillance for emerging and reemerging pathogens are central to public health outbreak preparedness. However, many infections do not have a microbiological diagnosis even after extensive testing. Coordinated surveillance and detection of emerging pathogens by the Centers for Disease Control and Prevention (CDC) and commercial and other clinical laboratories are often lacking. Increased collaboration and streamlined specimen and associated data exchange and linkage processes are needed to strengthen coordinated public health action.





#### Bio-Khoj

Khoj is Hindi for detection and discovery. This project is supported by CDC's Center for Preparedness and Response. The project will establish a leadership and strategy framework to strengthen ongoing detection of emerging, reemerging, and underdiagnosed human pathogens using sequencing. Project activities will also strengthen proactive surveillance networks, identify and establish bio-informatics resources to support rapid pathogen identification, and inform a model for a coordinated national approach.



## **Project Activities**

- Conduct a landscape analysis of existing research and surveillance programs in healthcare settings.
- Develop approaches to increase information sharing and collaboration.
- Pilot receipt and analysis of specimens by CDC from external laboratory partners.
- Examine the feasibility of accessing CDC Biorepository to set up control panels.
- Establish an interagency steering committee.



### Partner Engagement

Experts in advanced pathogen diagnosis and discovery methods, bioinformatics, public health informatics, and emergency preparedness will be engaged to strengthen collaboration between CDC, other federal agencies, and external independent clinical laboratories.

Information on current activities is requested as well as suggestions on ways to improve coordination of specimen and data exchange.

# COVID-19 Seroprevalence

Researchers need to understand the true number of infections to properly allocate resources and provide life-saving interventions during the COVID-19 pandemic. Traditional case-based surveillance can underestimate these numbers.

The Multistate Assessment of SARS-CoV-2 Seroprevalence (MASS) is a nationwide study that is expanding what we know about the true number of COVID-19 infections.

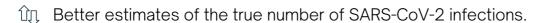
Seroprevalence is the percentage of individuals in a population who have antibodies to an infectious agent.

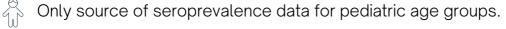
## What We Know Now

- Understanding the number of infections that are actually reported as cases provides important context to case surveillance data and impacts public health action.
- Case-based surveillance underestimated the number of children infected with SARS CoV-2 more than among all other age groups, according to a study in JAMA Open Forum.
- MASS provided key data on the percentage of children ages 5-11 that had no detectable SARS-CoV-2 antibodies, an important aspect for the approval of a vaccine for this age group.
- Beyond seroprevalence, MASS surveys will help researchers monitor waning immunity on the individual level after infection, vaccination, or booster doses.



## Benefits





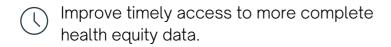
Infection estimates by jurisdiction and geographic region.

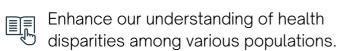
Critical data to inform state and national decisions and policymaking.

# **Advancing Health Equity**

The COVID-19 pandemic demonstrated the need for having established data sources that can be accessed quickly to monitor trends in health conditions among disproportionately affected populations. The Public Health Informatics Office, in collaboration with partners, is working to understand and address the root causes of data challenges to improve health equity for people with disabilities, people with a substance use disorder, and people experiencing homelessness.

Addressing Identified Challenges





Allow practitioners to understand the scope of the problem and where to apply appropriate interventions.



## **Taking Action**



Improve surveillance
data by
understanding gaps
and best practices
for reporting in
traditional case
surveillance systems.



Develop strategies to increase visibility and priority for disproportionately affected populations by leveraging electronic health records and using informatics standards.



Develop resources and technical assistance to assist jurisdictions to enhance collection of data related to health equity and social determinants of health.

# Collecting Better Data about People Experiencing Homelessness

People experiencing homelessness face a disproportionate burden of a wide range of health concerns. Understanding the immunization status of this population can help communities create effective public health strategies to improve rates of immunizations and overall health. Improving the exchange of data between Homeless Management Information Systems (HMIS) and Immunization Information Systems (IIS) can guide the implementation of evidence-based interventions and communications, improve health equity, and inform tailored services.

# Homeless Management Information System

This data system is managed by local organizing bodies for homeless services. HMIS includes data that are important to better understand the challenges and needs of people experiencing homelessness, including: length of shelter stays, demographics, disability and veteran status, and health indicators.

# Immunization Information Systems

These systems consolidate immunization information available at the state or city level. IIS provides records to patients, authorized healthcare providers, and public health officials. The information can be used to guide patient care, improve vaccination rates, and ultimately reduce vaccine-preventable disease.

## Strategic Activities

HMIS and IIS have unique data that if linked could improve health surveillance and public health action. This project is identifying innovative ways to address current interoperability challenges by:



Conducting a landscape analysis of best practices and lessons learned from past and ongoing efforts to link HMIS with other information systems.



Partnering with 2 jurisdictions to increase the interoperability of HMIS and IIS.



Providing a model for better data exchange between homelessness and public health systems to improve public health decision making and action.

# Promoting Adoption of HL7°FHIR°

The Public Health Informatics Office leads many HL7® FHIR® collaborative initiatives to promote the adoption of HL7® FHIR® standards across the agency, directly helping educate FHIR® implementers and advancing our nation's infrastructure for public health data collection and research.

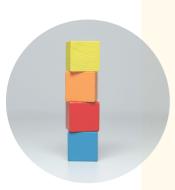


#### FHIR® Community of Practice

- Raises awareness of related initiatives across federal, state, and local public health communities.
- Showcases projects that have successfully implemented HL7® FHIR® standards.
- Includes more than 250 members, ranging from health IT staff to developers.
- Works to increase adoption of HL7® FHIR® standards at CDC with more than 50 projects across CDC are using HL7® FHIR®.

#### Public Health FHIR® Implementation Collaborative

- Provides a community forum for public health practitioners to learn and use FHIR®.
- Focuses on state, tribal, local, and territorial (STLT) collaboration and addressing new, priority data exchange needs with an initial focus on exchange within public health.
- Partners on challenges that are most relevant to current needs that has led to widespread adoption through community building.



### FHIR® Technical Advisory Services

- Allows FHIR® practitioners to partner with knowledge seekers who can educate them on existing building blocks and common approaches.
- Offers services to CDC programs, such as Office Hours, Ask a Question, Project Reviews, and Workshops.
- Promotes standardized implementation approaches of FHIR® across public health and uses common FHIR® building blocks and resources to
- develop sustainable data exchange.

#### Helios FHIR® Accelerator

- Promotes rapid, nationwide adoption of high priority public health use cases with an initial focus on exchange with health care.
- Provides a forum for multi-disciplinary dialogue and collaboration and builds consensus around industry goals, priorities, and approaches.
- Focuses on scalability, providing Helios members help to demonstrate the utility of FHIR® and ensure public health needs are at the forefront as FHIR®-based implementations evolve.
- Brings a wide variety of viewpoints and roles in the collection, exchange, and use of public health data.

# Promoting Use of Innovative Data Linkage Strategies

The Public Health Informatics Office leads the examination of Privacy Preserving Record Linkage (PPRL) as an innovative strategy to link data. PPRL is an approach to linking individuals' health records in and across data systems while protecting personally identifiable information (PII), such as name, address, and social security number. PPRL builds trust in data and promotes evidenced-based solutions to protect public health.

#### What PPRL Can Do

- De-duplicate data for public health notification.
- Build longitudinal records to evaluate interventions.
- Inform public health insights and action through research.

#### **How PPRL Works**

Following are example key steps in the PPRL process. Neither CDC nor the linkage agent can view the PII or re-identify individuals at any point in the process.

Data provider installs a PPRL engine behind the firewall of its information system

PPRL engine converts PII into unique codes tokens

Data provider sends tokens to trusted third-party linkage agent Linkage agent uses tokens to create PPRL IDs and sends to CDC

CDC uses PPRL IDs to link individuals' data across place and time

PPRL facilitates sharing privacy-protected data and helps accelerate data into action, providing benefits to data providers as well as to CDC and the wider public health community.

## Values

#### To Data Providers

- More complete and accurate data to inform organizational planning
- Increased collaboration with other data providers
- Reduced data submission burden

#### To CDC and Public Health Community

- Improved allocation of federal resources for local public health
- Better data for evidenced-based recommendations
- Improved identification of public health issues and priorities

To learn more about PPRL, email PHIOTeam@cdc.gov.

# **Standardizing Data Elements**

Healthcare and public health action are more efficient when providers can use and exchange commonly formatted (standardized) data. The Office of National Coordinator for Health Information Technology (ONC) publishes the United States Core Data for Interoperability (USCDI) to support data exchange (interoperability) within health IT and meet the interoperability goals of the 21st Century Cures Act.



## Addressing Data Standardization

- Organizations such as ONC encourage engagement and coordination, allowing partners to provide input on baseline data elements (e.g., USCDI).
- CDC's Public Health Informatics Office (PHIO) takes part in the continuous expansion of standard data elements by partnering with external partners interested in identifying public health priority data elements and informing CDC's recommendations for future USCDI versions.
- PHIO facilitates CDC's Data Standards Management and Harmonization Work Group (DSMH) in coordinating input for the USCDI+ program to help refine ONC provided use cases and identify specific data elements.
- Standardization of data elements is combined with other standards to allow for easier data exchange (e.g., Health Level 7 Fast Healthcare Interoperability Resources).



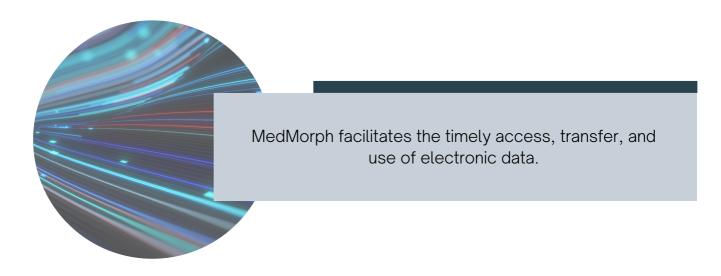
## Benefits

- Helps address data gaps and inconsistencies across the health care continuum.
- Improves data quality, making data analysis more efficient.
- Captures accurate data that are accessed, exchanged, and used to make better health decisions are made for healthcare.
- Informs strategies that address health inequities that public health can utilize to better understand disparities.
- Lessens work performed by public health to access and exchange data.

# Making Rapid Data Exchange a Reality

Public health professionals and researchers need quick access to data to address public health threats. Without rapid access to data, health professionals face obstacles developing the strategies needed to eliminate disease and improve public health.

The Making Electronic Data More Available for Research and Public Health (MedMorph) project addresses this challenge. MedMorph is one example of streamlining data exchange to create a reliable, adaptable, and efficient way to collect various types of high-quality data for public health and research scenarios (use cases).



## **Benefits**



Acts as a blueprint for use case scenarios and outlines how to use best practices and the Fast Healthcare Interoperability Resources (FHIR®) standard to be more efficient in data exchange efforts.



Expands to data sources beyond electronic health records (e.g., lab systems, immunization registries) and for additional uses (e.g., measure reporting, health care surveys) for both disease-based and non-disease areas.



Reduces the burden for those sending and receiving data by providing a common, standards-based approach, saving programs and partners time, effort, and cost.



Tests and improves reference architecture implementation guide for multiple use cases to assess real-world impact and broad applicability.

# **Improving Patient Care and Health Outcomes**



Clinical guidelines help practitioners and patients make decisions about health care based on the latest evidence. The traditional long narrative format can make understanding and adherence difficult. The Adapting Clinical Guidelines for the Digital Age (ACG) initiative may improve patient care and health outcomes by ensuring accessible evidence-based guidance and consistent guideline translation.

In today's hyperconnected world, delivering swift, accurate information to patients and providers saves lives. The ACG methods, standards, and tools aim to reduce the time it takes to disseminate and apply new or evolving clinical guidance to patient care. CDC programs are applying standards like Fast Healthcare Interoperability Resources (FHIR®) and the ACG's integrated process to improve the use of clinical guidance in practice.

## Benefits



## Faster application

Scientific information can take more than a decade to apply to patient care. Developing both narrative and computable guidance concurrently helps provide information in a more actionable format.



#### Streamlined dissemination and translation

Streamlining the way all guidance is released and translated eliminates unnecessary redundancy, confusion, and misinterpretations, ensuring patients receive accurate advice or care.



#### Stronger patient connections

Clinicians are expected to stay current on new guidance. By removing the challenge of trying to review, interpret, and retain new guidance, clinicians can focus more on patient care.



#### Holistic approach

A human-centered way to use ACG across health topics and during all situations (emergency and nonemergency).

Developing Technical and Architecture Solutions

The Public Health Informatics Office (PHIO) advises CDC programs and external partners on information technology strategies that foster cutting-edge capabilities to advance public health. PHIO stands committed to provide the best technical advisement across all technology domains. It brings subject matter expertise and competencies that fill the technical gap and contribute to solving next generation problems.



## Advancing Technical Capabilities

PHIO offers expertise in informatics, technical, and architecture domains through services that include, but are not limited to:

Scientific Consulting

**External Partner Collaboration** 

System Integration

Architecture Expertise

Work Scoping

Architecture Governance

**Guidelines and Best Practices** 

Cutting Edge Innovation

System Development Guidance

PHIO promotes technical capabilities and best practices to improve public health. The examples below illustrate where PHIO is shaping, informing, and helping implement responsive and sustainable systems designed to address both current and emerging public health challenges.











# Contact Us

Public Health Informatics Office PHIOTeam@cdc.gov

Center for Surveillance, Epidemiology, and Laboratory Services CSELS@cdc.gov

