DMI
Data Modernization
INITIATIVE

Empowering public health with interoperable systems

Moderator

Tony Winters, Senior Informatics Analyst, Public Health Informatics Institute| May 26, 2022

Better data. Better decisions. Better health.

MENDS: Building a Distributed System for Chronic Disease Surveillance

Data Modernization Workshop 2022

May 26, 2022

NATIONAL ASSOCIATION OF CHRONIC DISEASE DIRECTORS
Promoting Health. Preventing Disease.

MENDS
MULTI-STATE EHR-BASED NETWORK FOR DISEASE SURVEILLANCE

Welcome

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Funding Acknowledgment

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official views of, nor an endorsement, by CDC/HHS, or the U.S. Government.

Overview

- **Background**
- **What is MENDS**
- **MENDS on FHIR®**

Background

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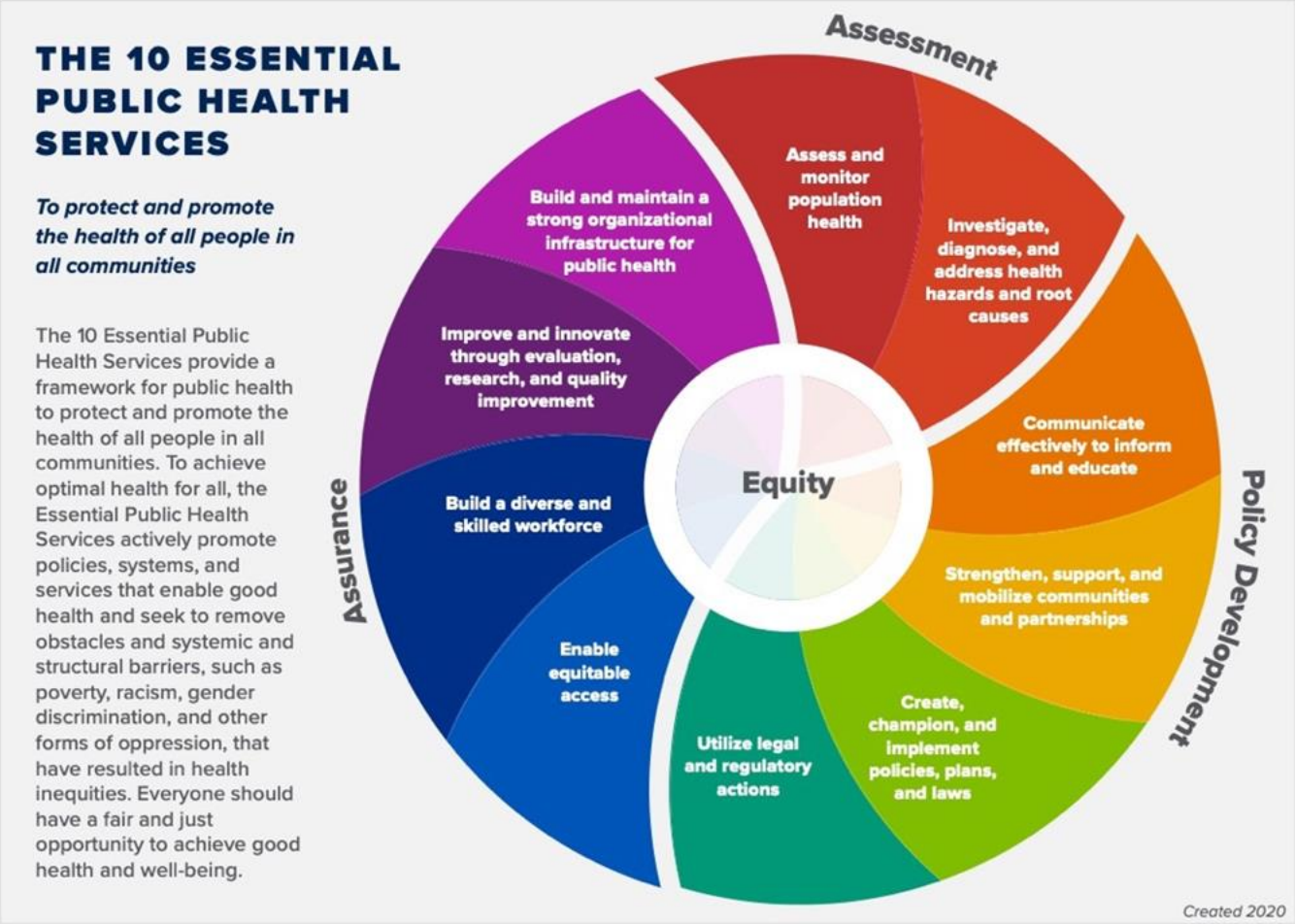
MULTI-STATE EHR-BASED NETWORK FOR DISEASE SURVEILLANCE

Background



Nationally Representative Surveys

- Limited in scope
- Self-reported
- Large lag time
- Declining response rates
- Reductions in funding

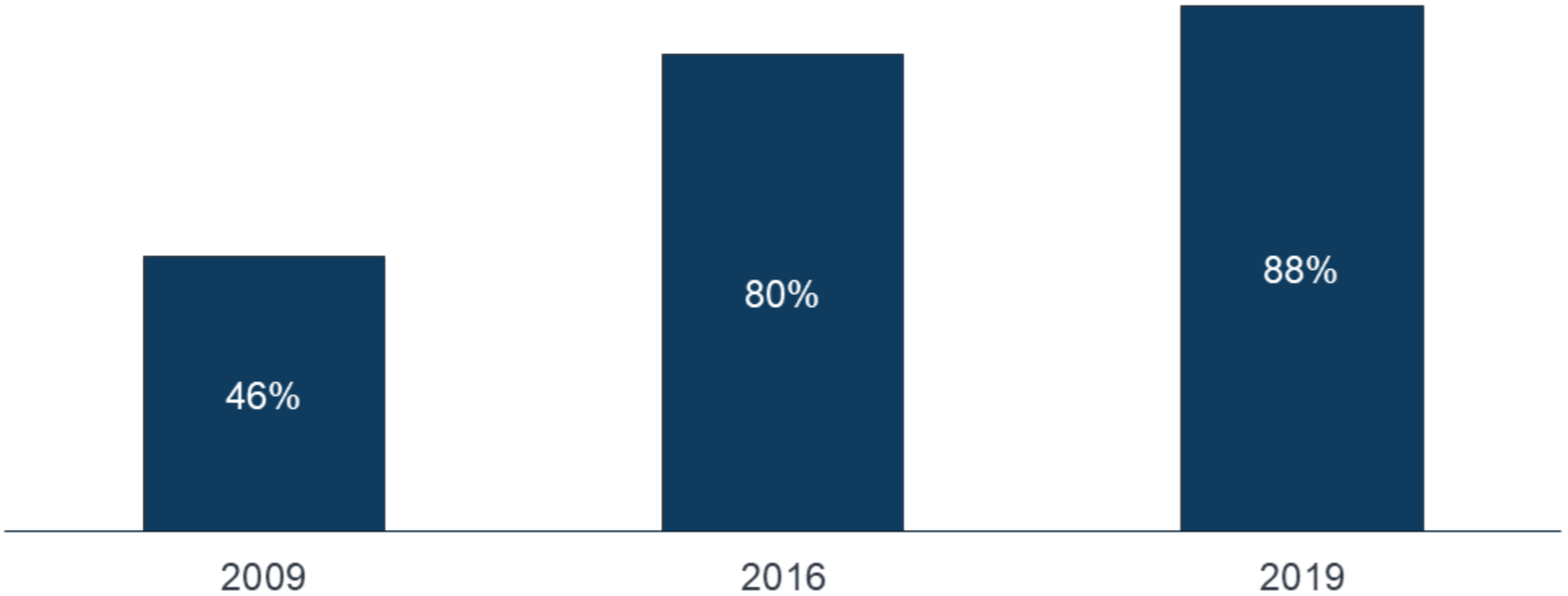
Large Administrative Datasets Managed by Public Heath

- Limited in scope
- Not timely
- Challenges in establishing DUAs
- Difficulty funding PH IT infrastructure

Figure 1

Majority Of The Public Now Says Their Physician Uses A Computer-Based Medical Record

Percent who say their doctor or other health provider usually enters their health information into a computer-based medical record:



SOURCE: KFF Health Tracking Polls. See toplines for full question wording and response options.

Published: Mar 18, 2019

Background

"Is there an opportunity for public health to use data for chronic disease surveillance that it does not own?"

- Limitations of existing surveillance
- Rise in health IT
- CDC's push towards data modernization
- Predecessor models: Macroscope, MDPHnet, CHORDS

"Yes"

Selecting a Pilot Model for EHR-based Surveillance

A model that embraced the following key principles:

1. Takes advantage of the breadth of clinical data available in EHRs (demographics, vital signs, laboratory tests, medications, and diagnoses)
2. Uses disease and condition algorithms that are transparent and clinically meaningful
3. Allows data owners to retain as much control and oversight of their data as needed to facilitate participation
4. Uses open-source resources
5. Is compatible with an array of EHR systems and emerging data exchange standards such as FHIR®

-> Massachusetts Department of Public Health's MDPHnet system

-> MDPHnet platforms: ESPnet, PopMedNet, RiskScape

Multi-state EHR-based Network for Disease Surveillance

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MENDS Project Goal

The goal of the MENDS pilot is to improve chronic disease surveillance and management through the use of electronic health records/health information systems.

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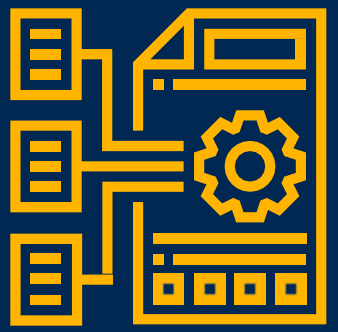
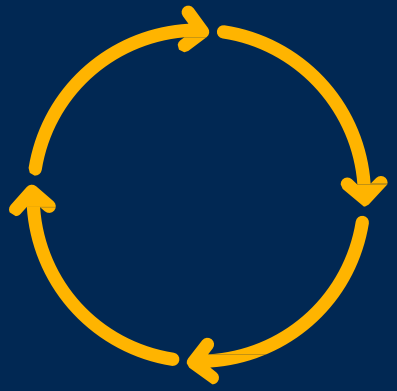
How MENDS Works

Concept 1: Health Systems



Concept 2: Integration by Data Aggregators



Concept 3: MENDS Data Processing

Concept 4: Data User Access

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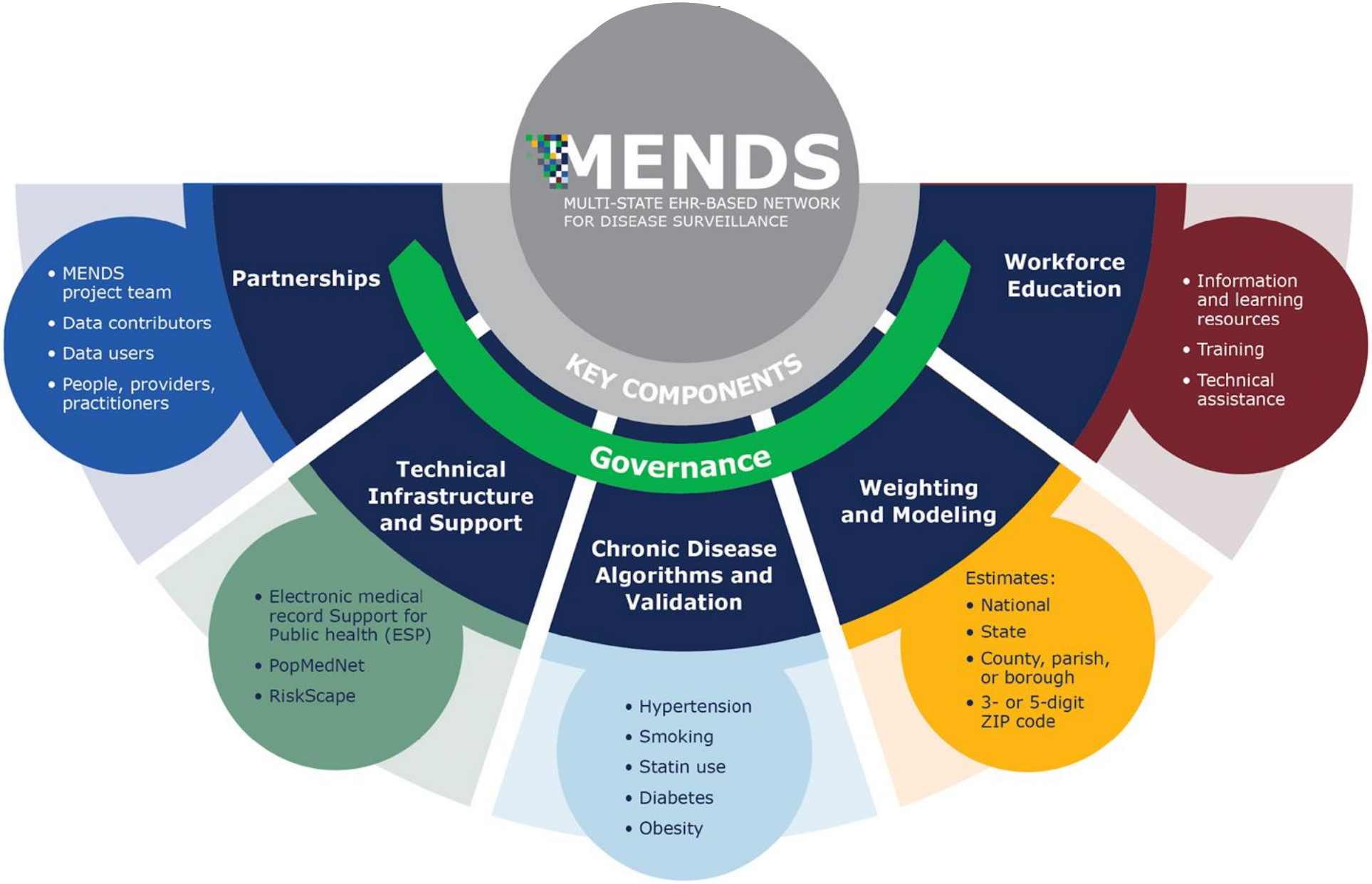
Key Components



MENDS Core National Project Team

NACDD Staff and Consultants – Direct CDC grantee that provides project oversight, establishes strategic direction, and serves as the Coordinating Center for the MENDS network

CDC - Epi and Surveillance Branch in the Division for Heart Disease and Stroke Prevention serves as both funder and a subject matter expert in surveillance, small area estimation, electronic case definitions, and data modernization

Commonwealth Informatics (CI) -Technical vendor that supports implementation of the software applications used in MENDS (installation, maintenance, updates)

Public Health Informatics Institute (PHII) - Supports building governance and information partnerships across the network

Harvard Medical School, Department of Population Medicine - Original developers of the ESP platform and MDPHnet, support algorithm development and validation efforts

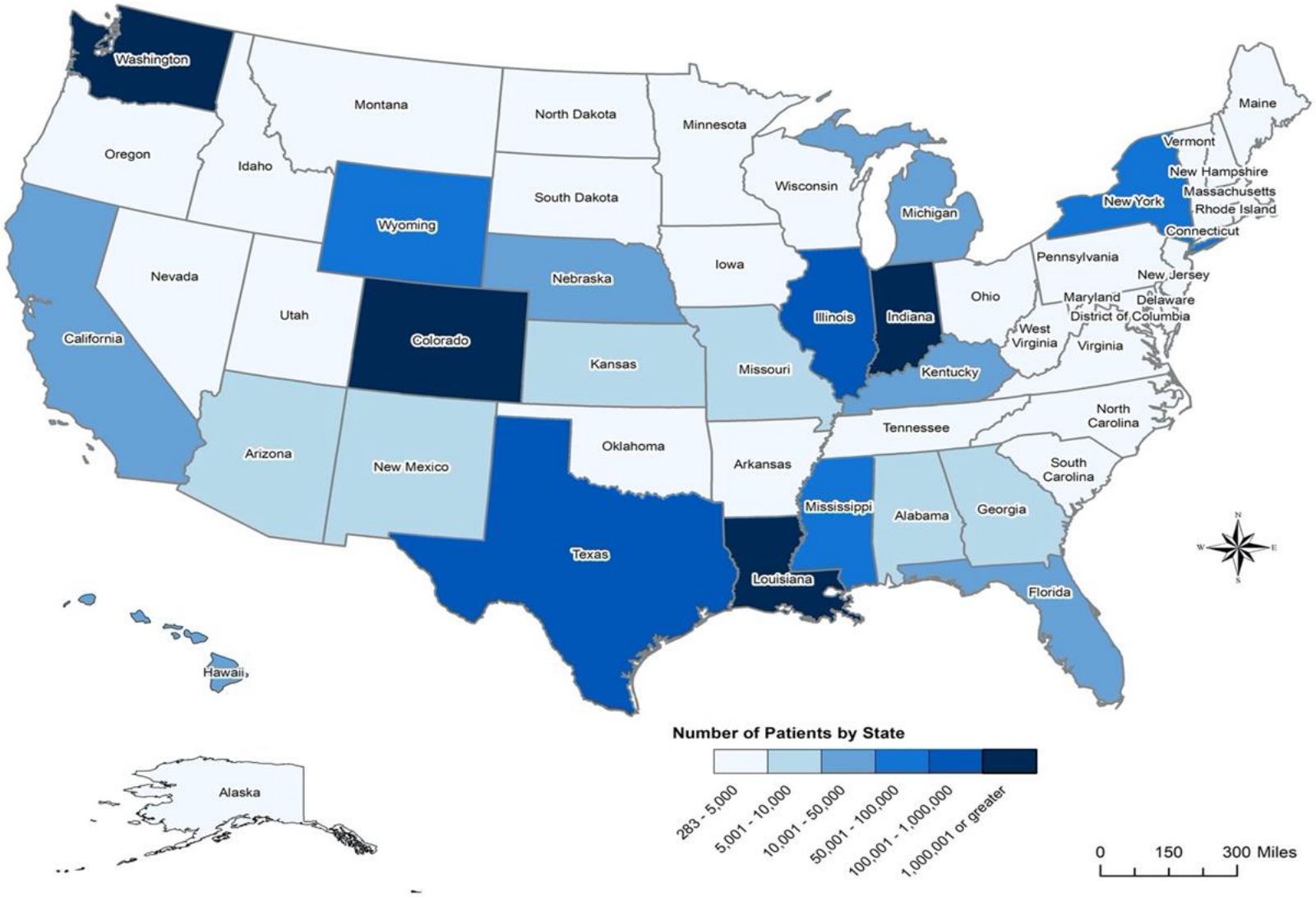
University of Massachusetts Lowell - Lead for developing weighting and modeling methods to generate prevalence estimates for varying geographic levels and subpopulations

MENDS Network

AllianceChicago	in partnership with	**Chicago Department of Public Health** **Cook County Department of Public Health**
OneHealthPort	in partnership with	**Washington State Department of Health**
REACHnet	in partnership with	**Louisiana Office of Public Health** **New Orleans Health Department** **Texas Department of State Health Services**
Regenstrief Institute	in partnership with	**Indiana Department of Health** **Marion County Public Health Department**
Health Data Compass	in partnership with	**University of Colorado Anschutz Medical Campus**

Coverage Map

Distribution of MENDS Patients by State



MENDS Applications

ESP Electronic medical record Support for Public Health

ESP Software puts data in standardized tables and runs disease detection algorithms nightly

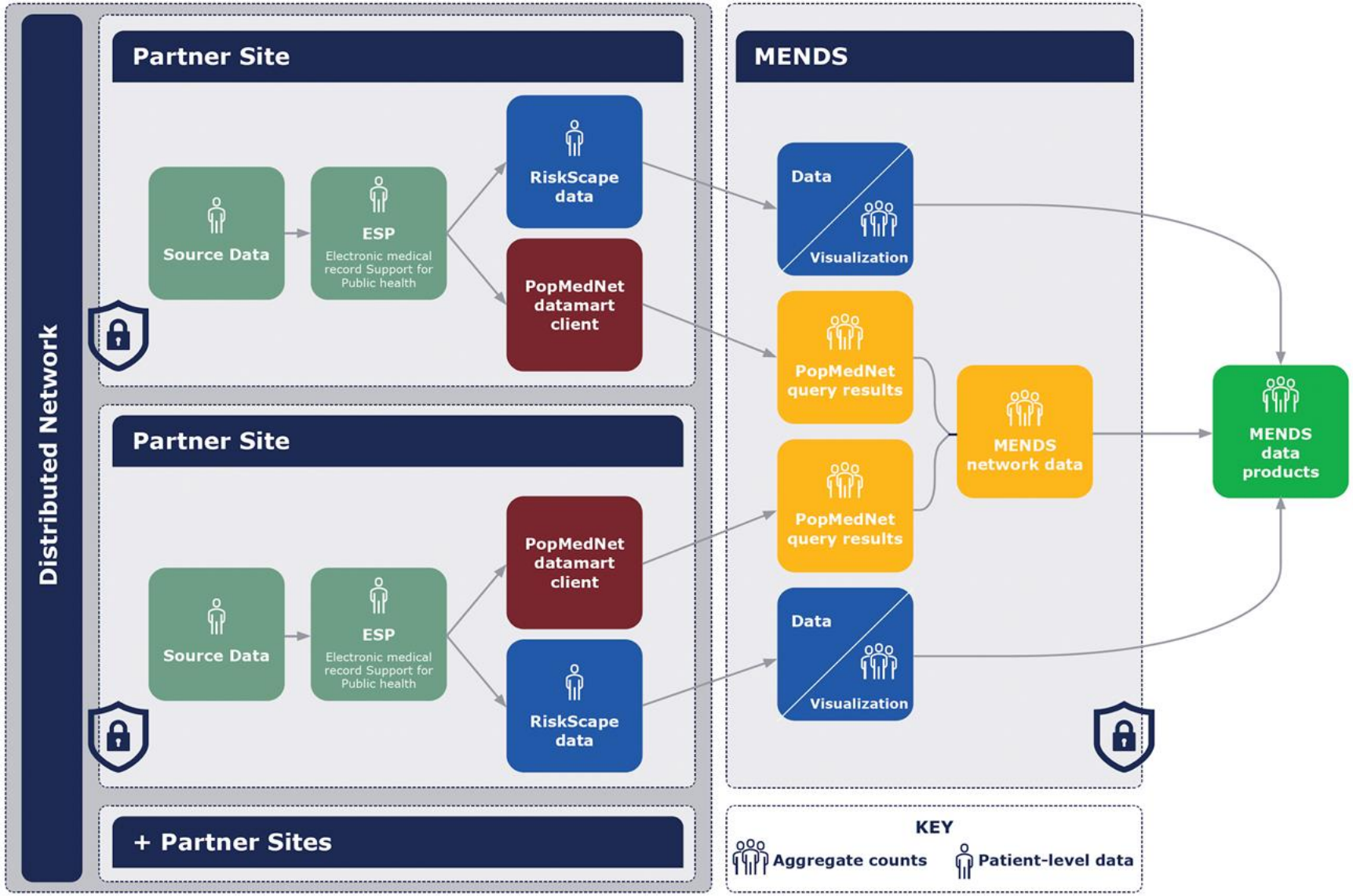
PopMedNet

PopMedNet accepts custom queries and distributes them to data partners. Data partners must approve all queries.

RiskScape

RiskScape is an interactive, web-based data visualization platform with pre-programmed and custom analyses.

Overview of MENDS Set-up



MENDS ESP Data Model

Patient
Patient ID
Medical Record #
State
ZIP code (full)
ZIP code (5-digit)
Country
Date of Birth
Date of Death
Gender
Race
Ethnicity

Encounter
Patient ID
Encounter Date
Encounter Type
Pregnant
Expected Date of Delivery
Temperature
Weight
Height
BP Systolic
BP Diastolic
BMI
Diagnosis Codes
Hospital Admit Date
Hospital Discharge Date
Provider ID
Primary Payer

Prescription Orders
Patient ID
Order Date
Prescription Name
Code
Directions
Dose
Frequency
Quantity
Refills
Route
Start Date
End Date
Quantity Type
Provider ID

Lab Test Results
Patient ID
Ordering Date
Native Code
Native Name
Result Date
Collection Date
Status
Abnormal Flag
Numeric Result
Character Result
Specimen ID
Specimen Source
Provider ID

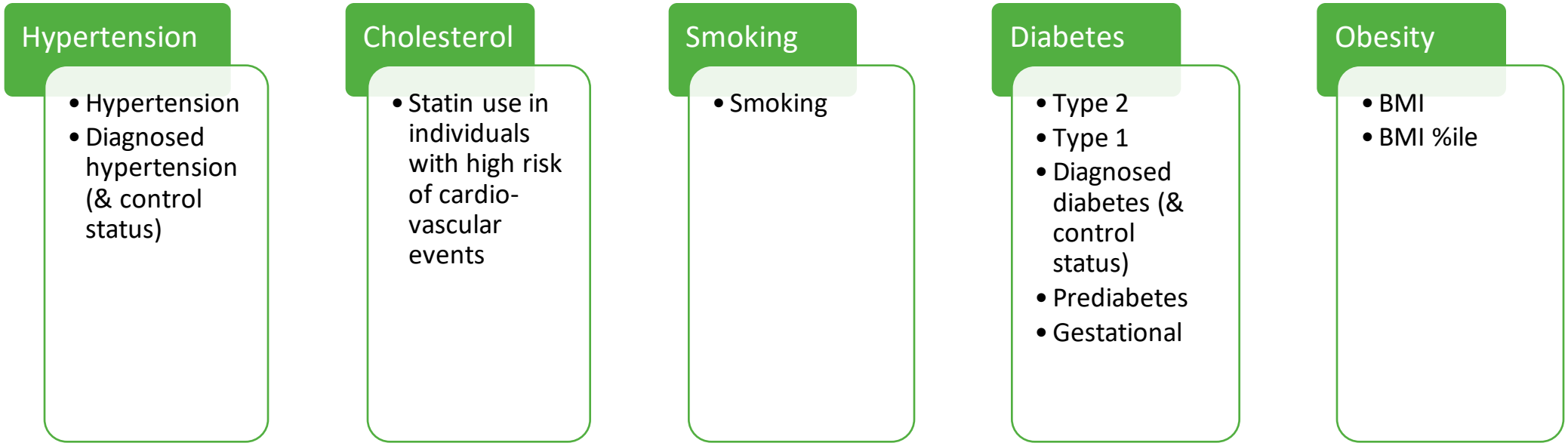
Social History
Patient ID
Date
Tobacco Use
Alcohol Use
Provider ID

Immunization
Patient ID
Immunization ID
Immunization Name
Immunization Date
Dose
Manufacturer
Lot Number
Provider ID

Health Events Framework
Patient ID
Name of Derived Event
Source
Date of Event
Provider ID

Takes advantage of the breadth of clinical data available in EHRs (demographics, vital signs, laboratory tests, prescriptions, and diagnoses)

MENDS Priority Chronic Disease Conditions



The figure shows the relationship between risk factors and specific indicators. The figure also represents the order of validation partner sites will follow, from left to right, as well as the order of validation within a risk factor, from top to bottom.

MENDS Indicator Case Documentation

Indicator(s)	Algorithm documentation link
Hypertension	• https://espnet.atlassian.net/wiki/spaces/EP/pages/93585410/ESP+Algorithms?preview=/93585410/888143873/ESP%20Case%20Definition%20Hypertension_with_diagnosed_controlled%201.4%20DRAFT.pdf
Cholesterol/Statin-use	• With shift to statin use, ESP Case Detection Algorithm documentation is underdevelopment/not yet posted, but is based off CMS eCQM 347- https://ecqi.healthit.gov/ecqm/ep/2020/cms347v3
Smoking	• https://espnet.atlassian.net/wiki/spaces/EP/pages/93585410/ESP+Algorithms?preview=/93585410/568000543/ESP%20Smoking%20Case%20Definition%2020130827.docx
Diabetes	• https://espnet.atlassian.net/wiki/spaces/EP/pages/93585410/ESP+Algorithms?preview=/93585410/93749296/ESP%20Case%20Definition%20Diabetes%20v1.2%202014-5-29.pdf • https://espnet.atlassian.net/wiki/spaces/EP/pages/93585410/ESP+Algorithms?preview=/93585410/93650966/ESP%20Case%20Definition%20Pre-diabetes%20v1.2%202011-09-01.pdf • https://espnet.atlassian.net/wiki/spaces/EP/pages/93585410/ESP+Algorithms?preview=/93585410/2459107414/ESP%20Case%20Definition%20Gestational%20Diabetes%20v2.3%2020210423_clean.pdf
Obesity	• https://espnet.atlassian.net/wiki/spaces/EP/pages/93585410/ESP+Algorithms?preview=/93585410/93650966/ESP%20Case%20Definition%20Pre-diabetes%20v1.2%202011-09-01.pdf

Validation

1. **Testing the ESP installation**
   ESP Data ETL Testing Guide and Report (expected counts, data completeness)
2. **Characterizing the data**
   Partner site reviews data characterization workbooks (vitals ranges, % excluded)
3. **Indicator algorithm validation**
   Partner site completes patient level review of cases (# based on indicator)
   Indicator passes 90% confirmed threshold
4. **External indicator algorithm validation**
   If appropriate external data is available

Data Available to Data Users

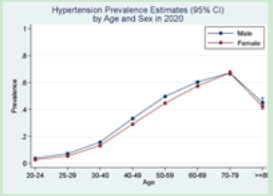
RiskScape

RiskScape is an interactive, web-based data visualization platform with pre-programmed and custom analyses.

PopMedNet

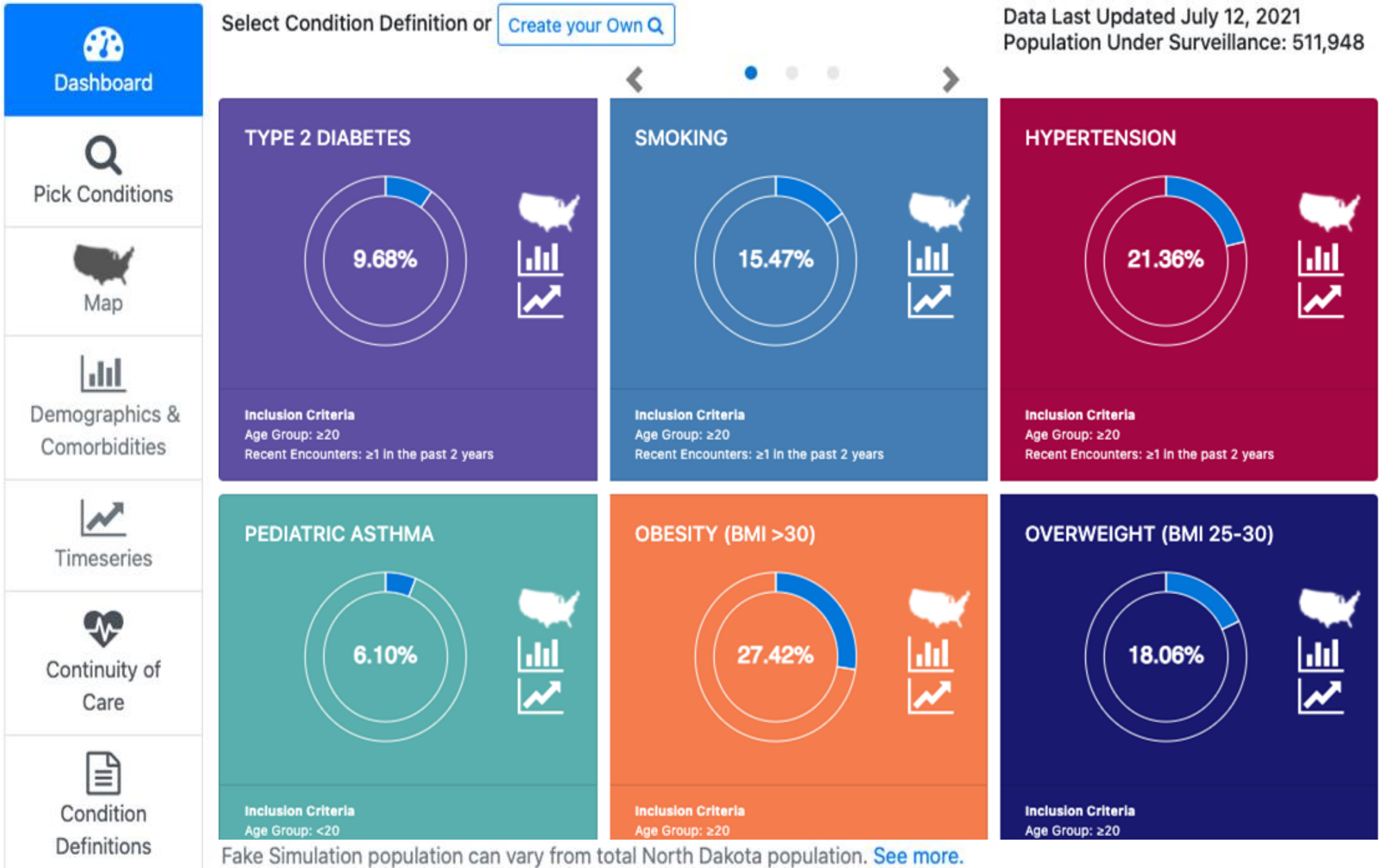
PopMedNet accepts custom queries and distributes them to data partners. Data partners must approve all queries.

Weighted & Modeled



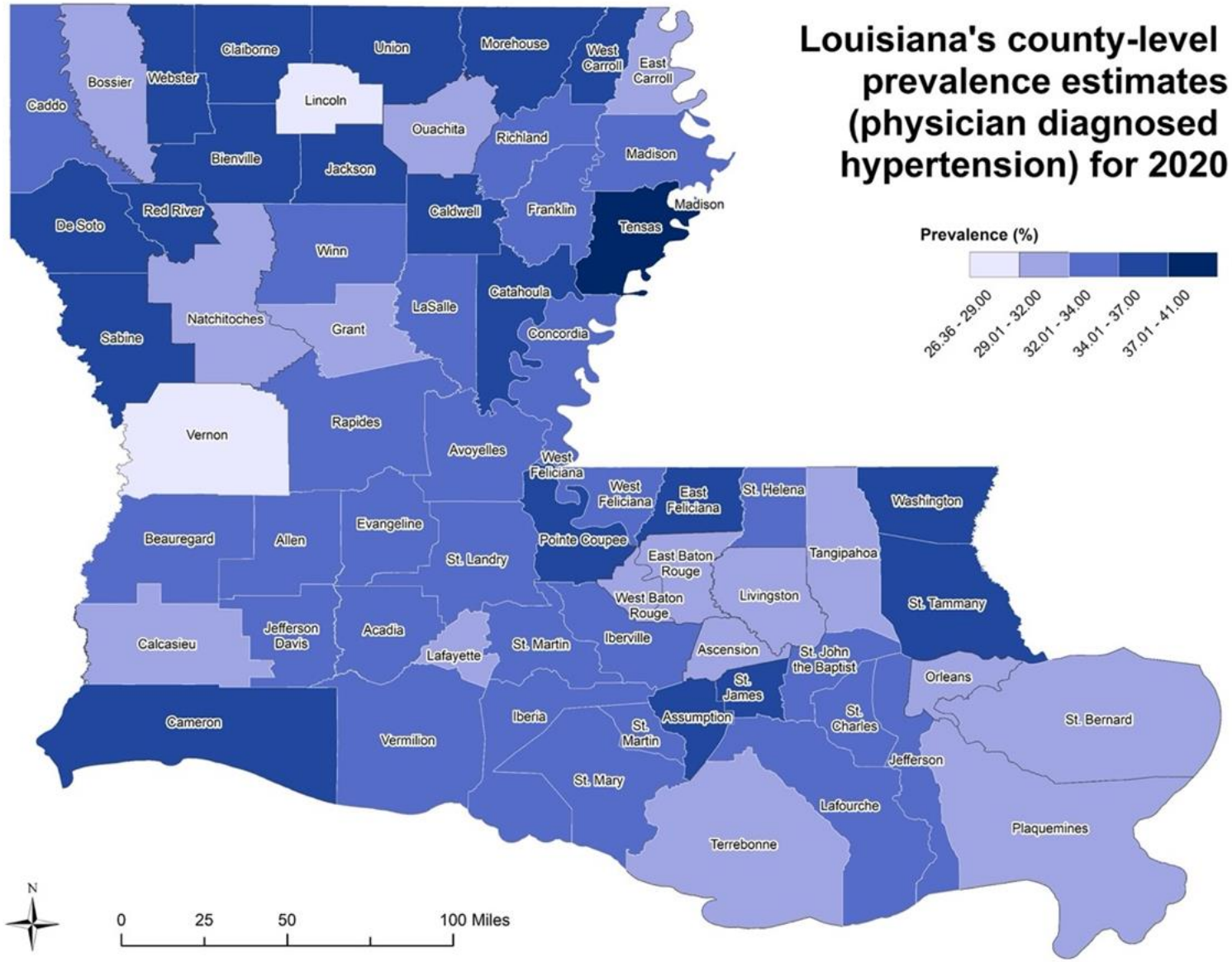
Weighted prevalence estimates and model-based estimates for small geographic regions and populations that are under-represented in MENDS data.

RiskScape


Dashboard
Pick Conditions
Map
Demographics & Comorbidities
Timeseries
Continuity of Care
Condition Definitions
Select Condition Definition or
Create your Own
Data Last Updated July 12, 2021
Population Under Surveillance: 511,948
TYPE 2 DIABETES
9.68%
Inclusion Criteria
Age Group: ≥20
Recent Encounters: ≥1 in the past 2 years
SMOKING
15.47%
Inclusion Criteria
Age Group: ≥20
Recent Encounters: ≥1 in the past 2 years
HYPERTENSION
21.36%
Inclusion Criteria
Age Group: ≥20
Recent Encounters: ≥1 in the past 2 years
PEDIATRIC ASTHMA
6.10%
Inclusion Criteria
Age Group: <20
OBESITY (BMI >30)
27.42%
Inclusion Criteria
Age Group: ≥20
OVERWEIGHT (BMI 25-30)
18.06%
Inclusion Criteria
Age Group: ≥20
Fake Simulation population can vary from total North Dakota population. See more.

W&M prototype

Model-based County-level Hypertension Prevalence Estimates (2020)



MENDS Learning Resources

- **Audiences**
  - Chronic disease staff in state and local health departments
    - Don’t need to be a MENDS Partner Site
- **Format**
  - Online, on-demand e-learning
  - Courses comprised of 10-15 minute modules
  - Learners can pick and choose modules based on their needs.
  - Embedded knowledge check questions to help cement learning
  - Available through NACDD website
  - No cost
- **Scope**
  - Foundational learning for working with clinical data for surveillance

MENDS Learning Courses

I. Introduction to MENDS

1. MENDS: A Novel Approach to Chronic Disease Surveillance

1. Using RiskScape: A Powerful Tool for Visualizing Chronic Disease Prevalence

Resources:
- Using PopMedNet: Finding Answers to new Questions
- Using ESP: Understanding Data Transformation
- Understanding Weighted and Modeled Data Within MENDS
- Understanding the Indicator Validation Process within MENDS

II. Understanding Clinical Data: A Data User Perspective

1. The Origins and Nature of Digital Clinical Data

1. Management of Clinical Data by Healthcare Organizations

3. Health Data Aggregators: Bringing Data Together to Add Value

4. Governance: Building and Sustaining Trust in an Information Partnership

III. Using Clinical Data: Transformation into Chronic Disease Surveillance Information

1. Understanding the Strengths and Limitations of Clinical Data for Surveillance and Other Population Health Purposes

1. Getting Beyond the Limitations - Optimizing Clinical Data for Chronic Disease Surveillance

Learnings

- Rethinking the Partner Site Recruitment Approach
- Instituting a Discovery Process
- Strengthening a New Type of Information Partnership to Share Data for Public Health
- Fostering Governance Flexibility to Meet Partner Site Needs Beyond the Network
- Aligning a Phased Algorithm Validation Effort to Capacity
- Building Workforce Development and Training for Public Health Data Users
- Piloting Gains to Efficiency Through Fast Healthcare Interoperability Resources FHIR® Standards

MENDS on FHIR®

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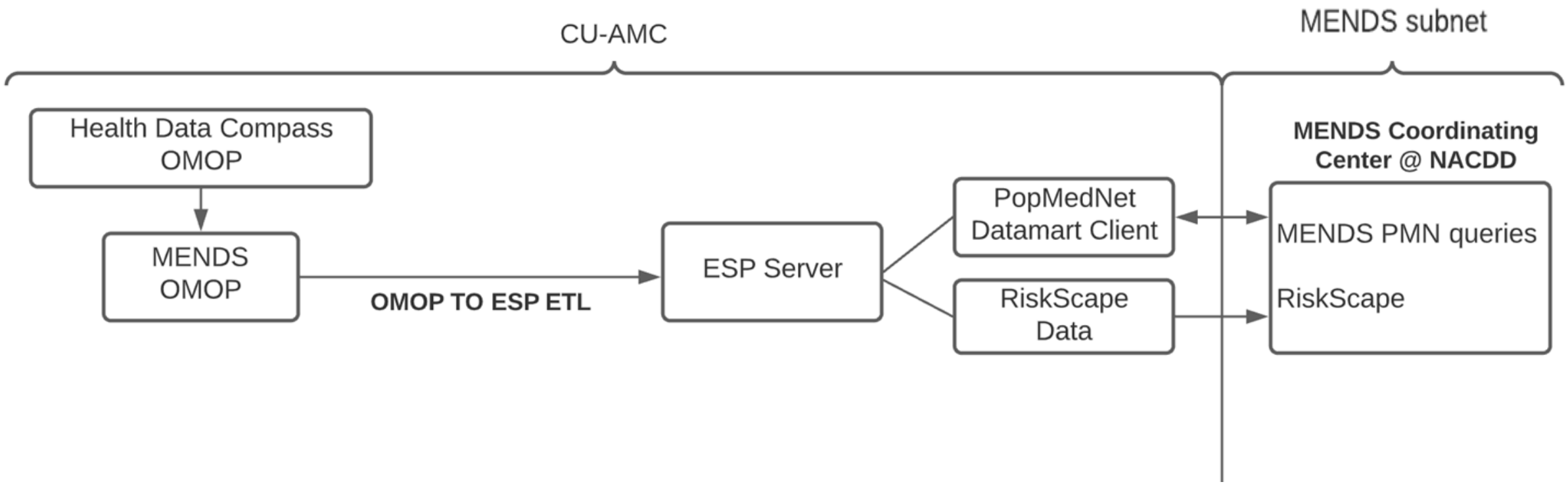
FOR DISEASE SURVEILLANCE

Why FHIR

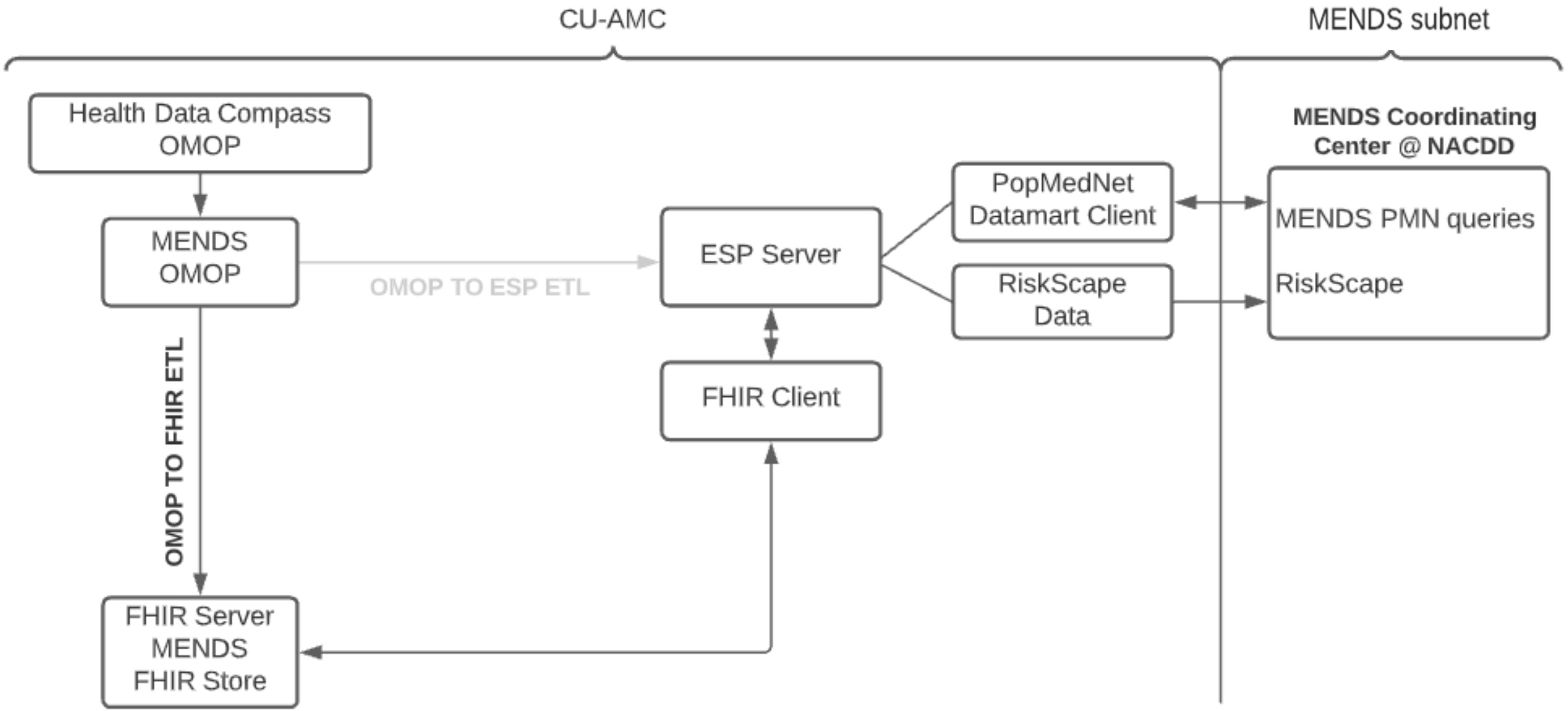
Moving toward the Fast Healthcare Interoperability Resources (FHIR) standard

- FHIR is a standard describing data formats and elements and an API for exchanging EHR data
- Created by HL7 a health-care standards organization
- Onboarded a new partner site in 2021 to test FHIR
- FHIR bulk data API would serve the purpose of custom ETL script used today

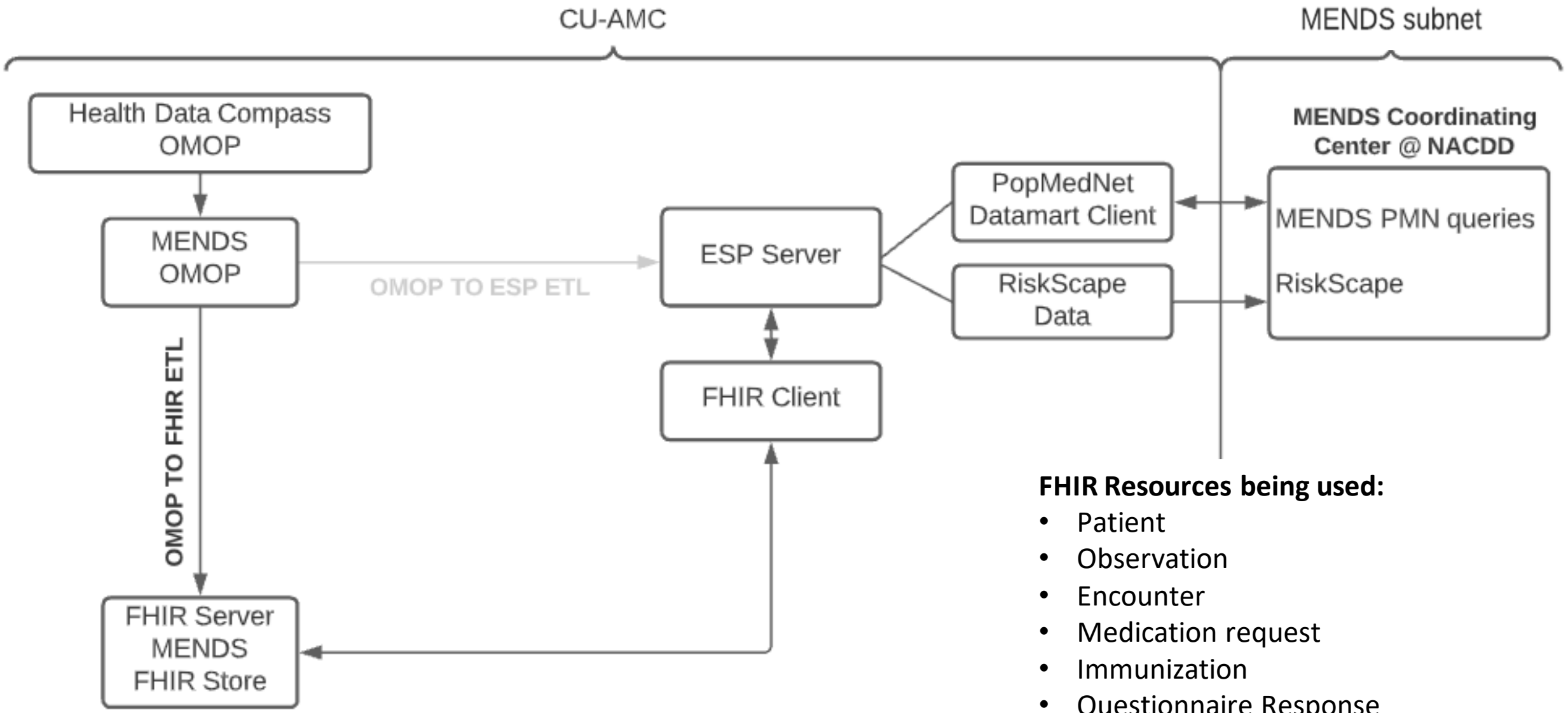
Standard Implementation



FHIR Implementation



FHIR Implementation



FHIR Resources being used:

- Patient
- Observation
- Encounter
- Medication request
- Immunization
- Questionnaire Response

Looking ahead

- Learning from OMOP-FHIR pilot
- By end of the year, producing national state, county, city hypertension estimates
- Continuing to engage the MENDS Governance Committee
- Re-engaging public health users
- Disseminating education/training tools that support use of EHR-based data for surveillance

GOAL: Leveraging data routinely stored in EHRs to generate timely prevalence estimates of chronic disease measures at national and local levels for public health surveillance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MULTI-STATE EHR-BASED NETWORK
FOR DISEASE SURVEILLANCE


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National Association for Public Health Statistics and Information Systems

MAY 26, 2022

NAPHSIS

Protecting Personal Identity
Promoting Public Health

STEVE 2.0

NAPHSIS Mission & Vision

OUR MISSION

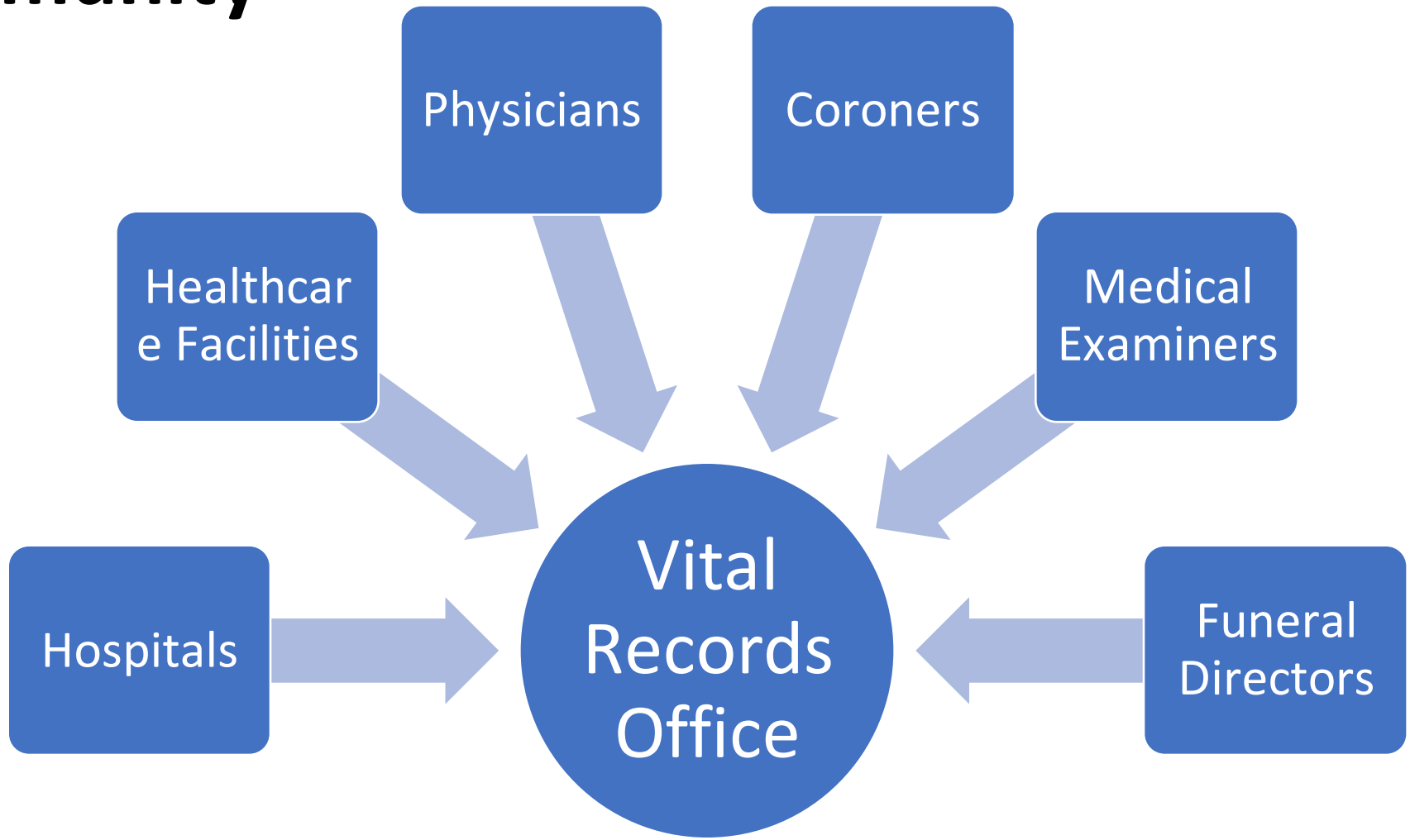
- To serve the vital records community by providing national leadership to advance public health and protect individual identity.

OUR VISION

- A healthier and more secure world through vital records

STEVE 2.0

Vital Records: Products of a Varied Data Provider Community



STEVE 2.0

Who is STEVE?

- State and Territorial Exchange of Vital Events
- Interoperable vital statistics data exchange platform developed in mid-2010s.
- Uses the Inter-Jurisdictional Exchange (IJE) data format among 54 U.S. Vital Records Offices (VROs).
- Facilitates data sharing with CDC for public health purposes:
  - National Center for Health Statistics (NCHS) under Vital Statistics Cooperative Program
  - National Violent Death Reporting System (NVDRS)
  - Division of Reproductive Health (DRH)
    - Pregnancy Mortality Surveillance System (PMSS) and Maternal Mortality Review Information Application (MMRIA)
    - Pregnancy Risk Assessment Monitoring System (PRAMS)
  - National Syndromic Surveillance Program (NSSP)

STEVE 2.0

CDC Division of Reproductive Health (DRH) – STEVE Project

STEVE 2.0

Overview

- Purpose
  - Share data in a timelier manner with CDC DRH
  - Replace the existing PMSS process and the PRAMS annual file for grantee states with direct connection via STEVE
- Pilot Year (fall 2019) - 6 jurisdictions
  - Established DSA and STEVE mailbox for maternal mortality program
  - Jurisdictions began sharing birth, fetal death and death data
- Year 2 (fall 2020) -12 jurisdictions
  - Added 6 more jurisdictions and PRAMS mailbox
  - began sharing data on same frequency as sending to NCHS

STEVE 2.0

National Syndromic Surveillance Program (NSSP) – STEVE Project

STEVE 2.0

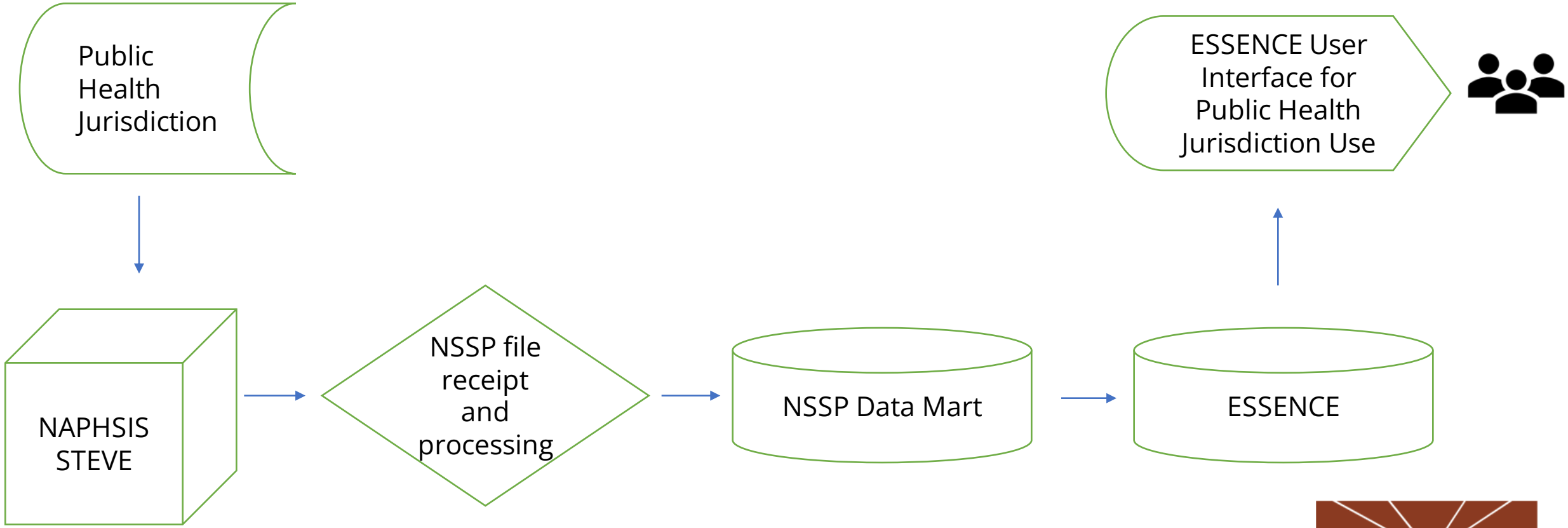
NSSP Project Overview

- National Mailbox Development
  - Single access point for CDC staff
  - Drop down menu selection for jurisdictions (opt-in)

- External API connects data to ESSENCE

STEVE 2.0

Fields of Significance to Public Health Surveillance: *Data Process*



STEVE 2.0

Project Accomplishments

- 17+ Participating Sites
  - 6 sending production data to NSSP weekly: CO, GA, KS, KY, MN, OR
  - 11 in onboarding (test files, DUAs, interest expressed): IA, IN, MA, MI, NH, NYC, NJ, TN, VA, WA, WI
- External API functionality (2021).

STEVE 2.0

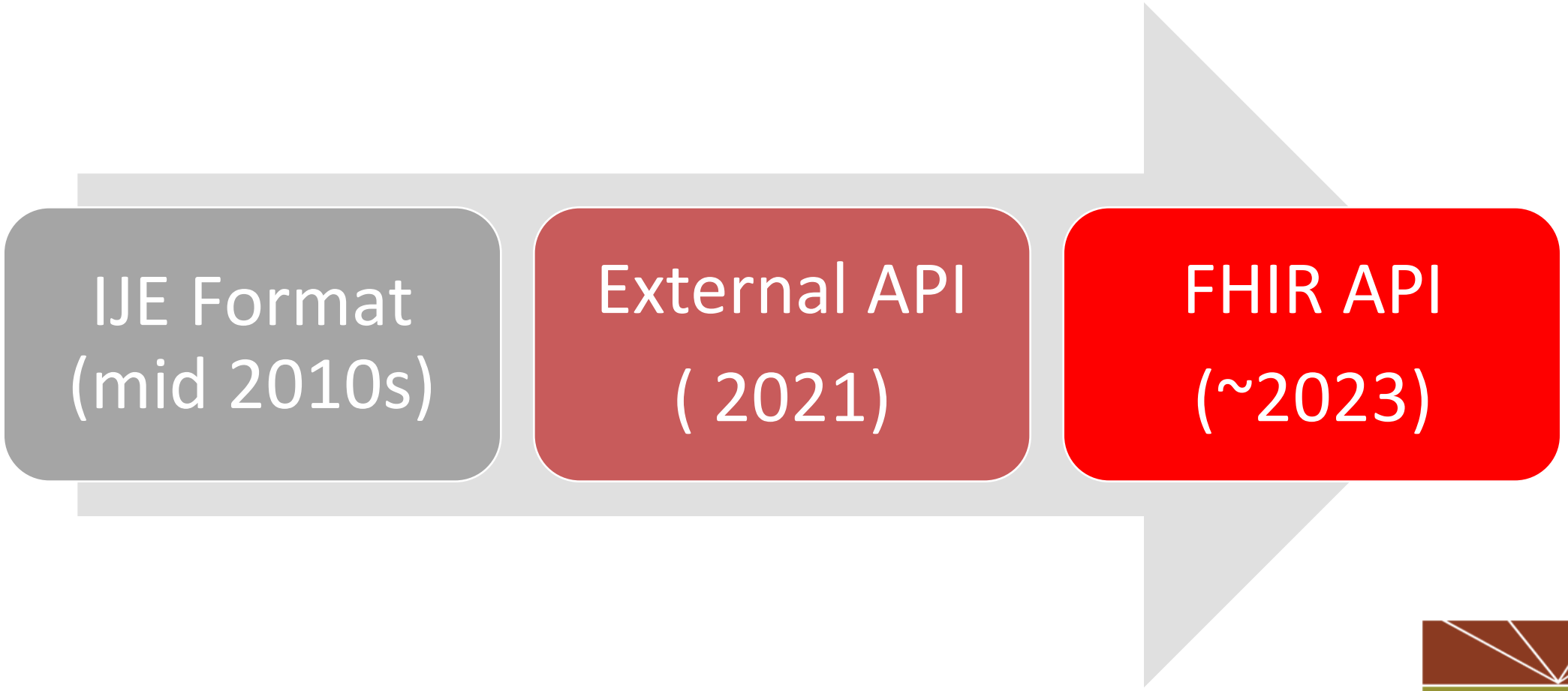
NVSS Modernization FHIR API – STEVE Project

STEVE on FHIR

- National Vital Statistics System Modernization Task Order
  - Adds a FHIR-enabled API to STEVE
  - VRDR (mortality) now, BFDR (natality & fetal death) later
- Timed with ELC funding for each jurisdiction to achieve FHIR capabilities in Electronic Death Registration System
- STEVE will connect with jurisdictions and CDC to provide record-level processing, replacing the current batch processing method.

STEVE 2.0

STEVE Interoperability Maturity



STEVE 2.0

OVERVIEW

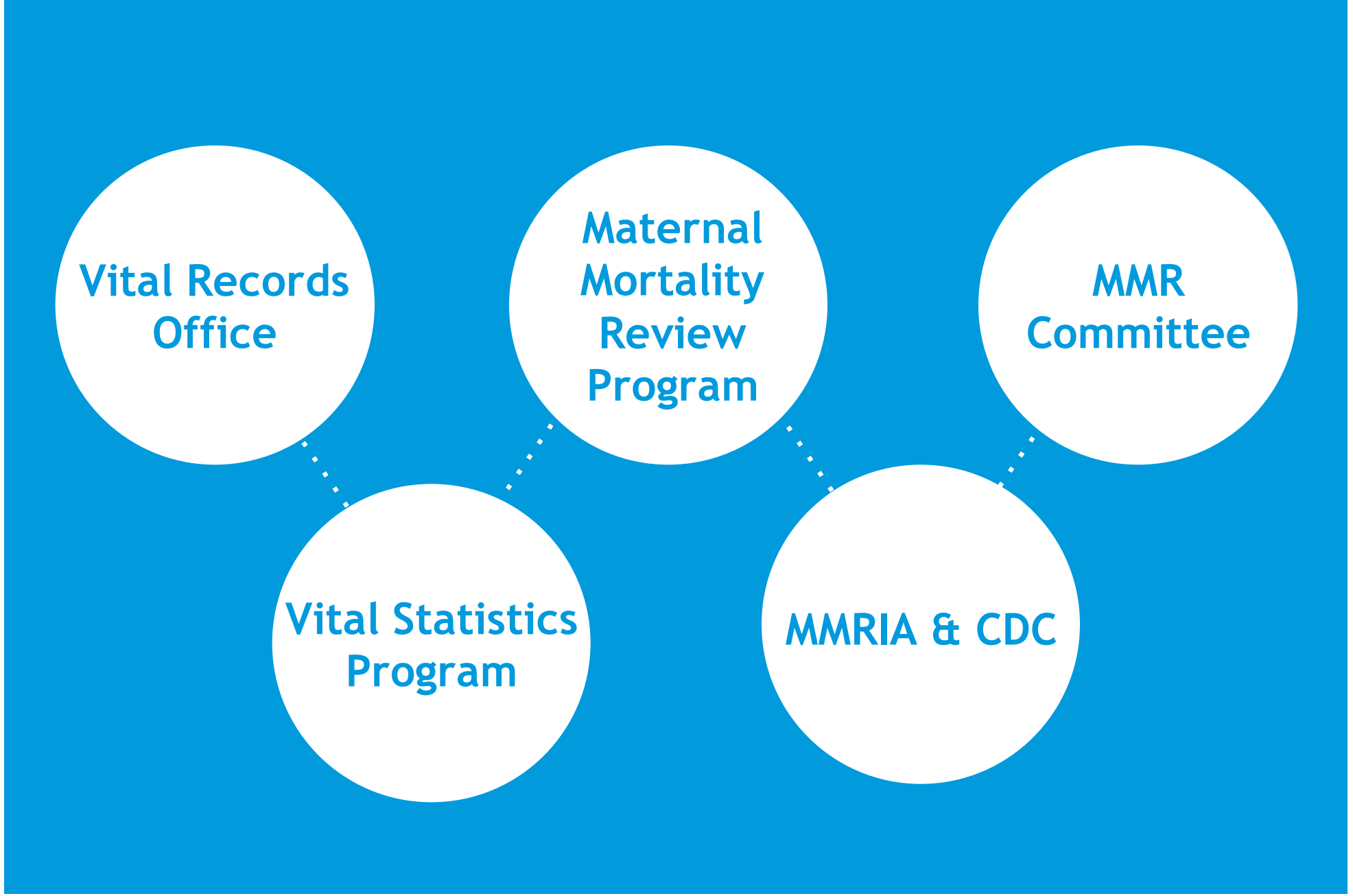
Prior state

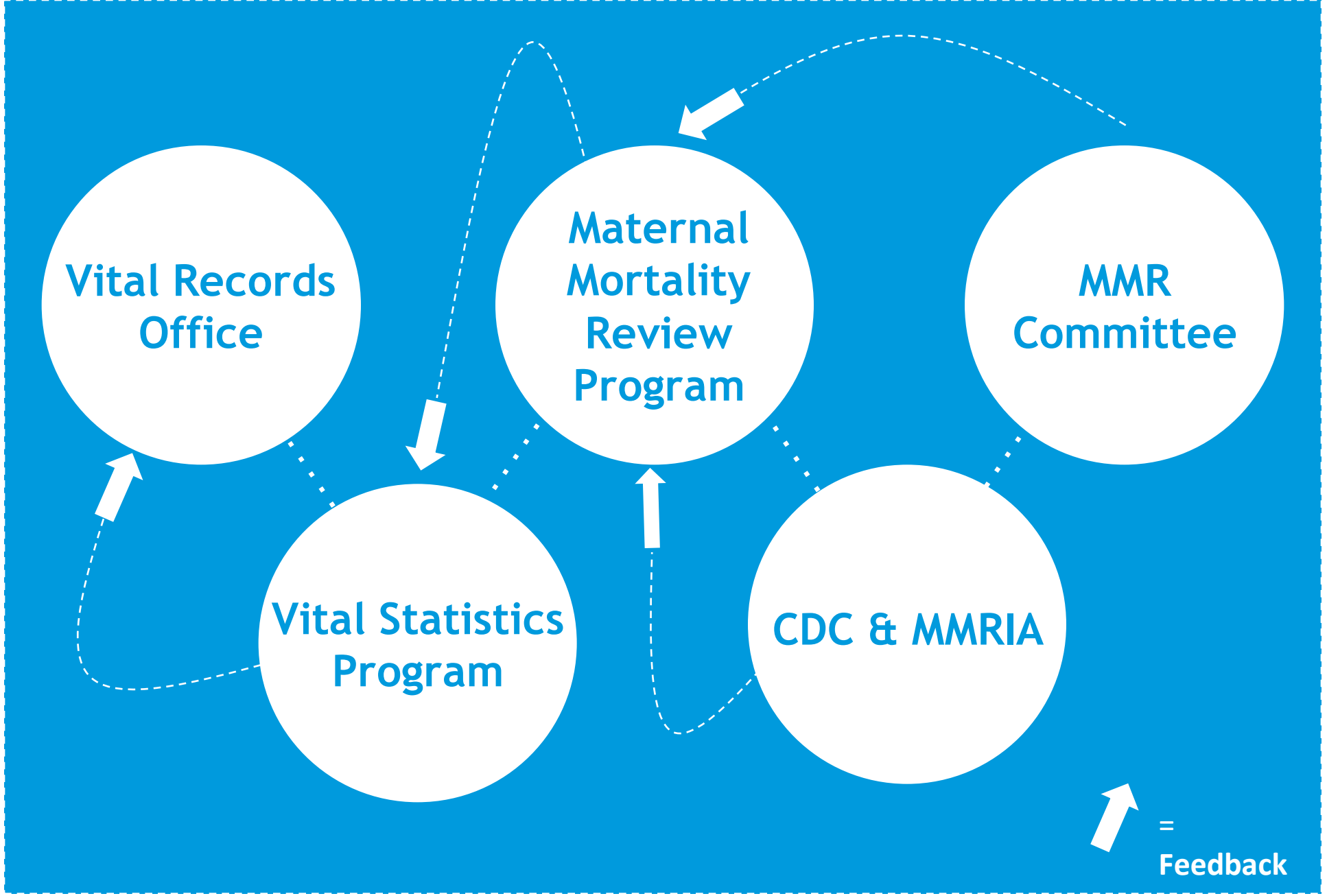
Current state

Improvements

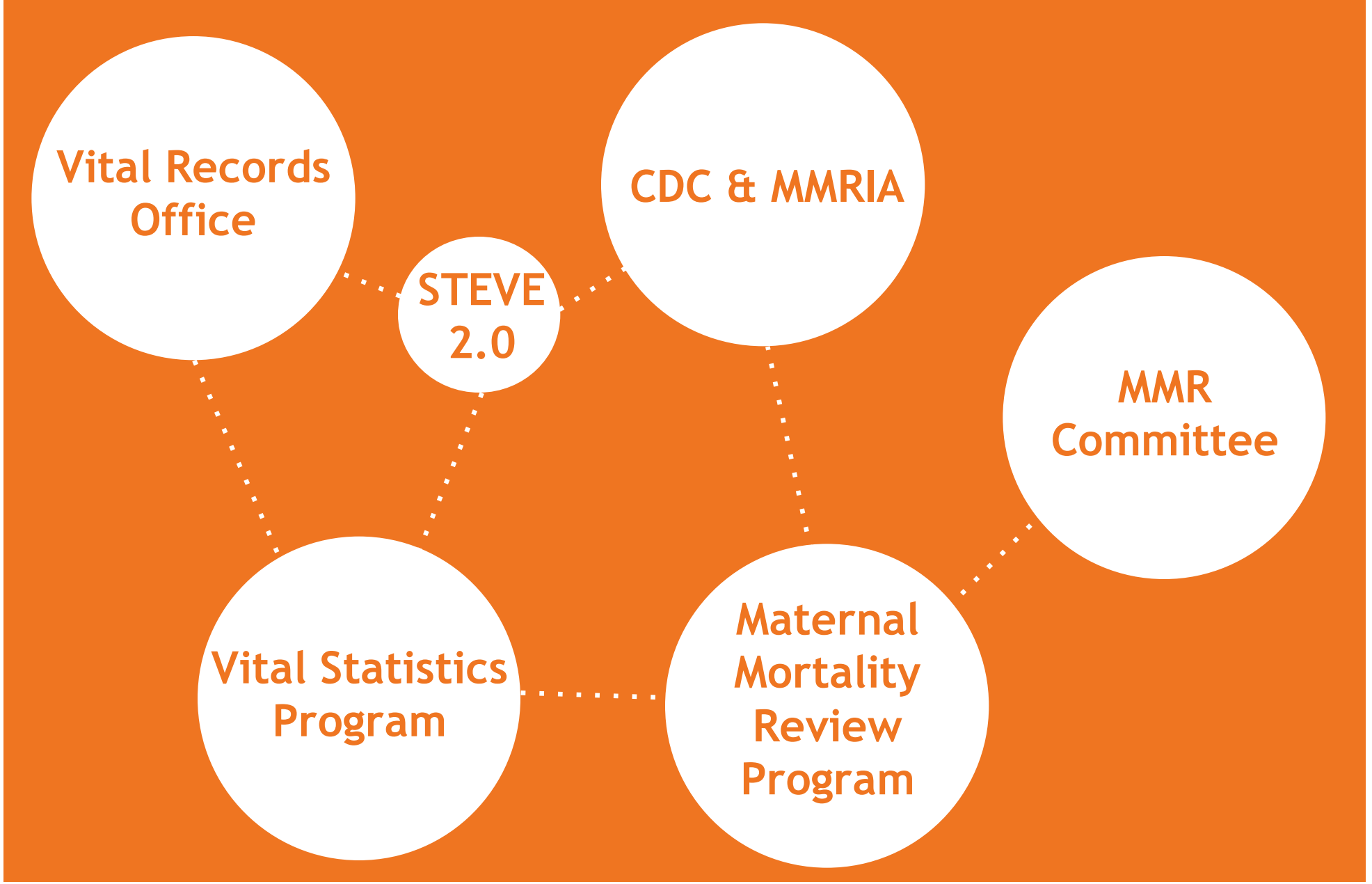
Future opportunities

PRIOR STATE


Vital Records Office
Maternal Mortality Review Program
MMR Committee
Vital Statistics Program
MMRIA & CDC


Vital Records Office
Maternal Mortality Review Program
MMR Committee
Vital Statistics Program
CDC & MMRIA
=
Feedback

IMRPROVED STATE


Vital Records Office
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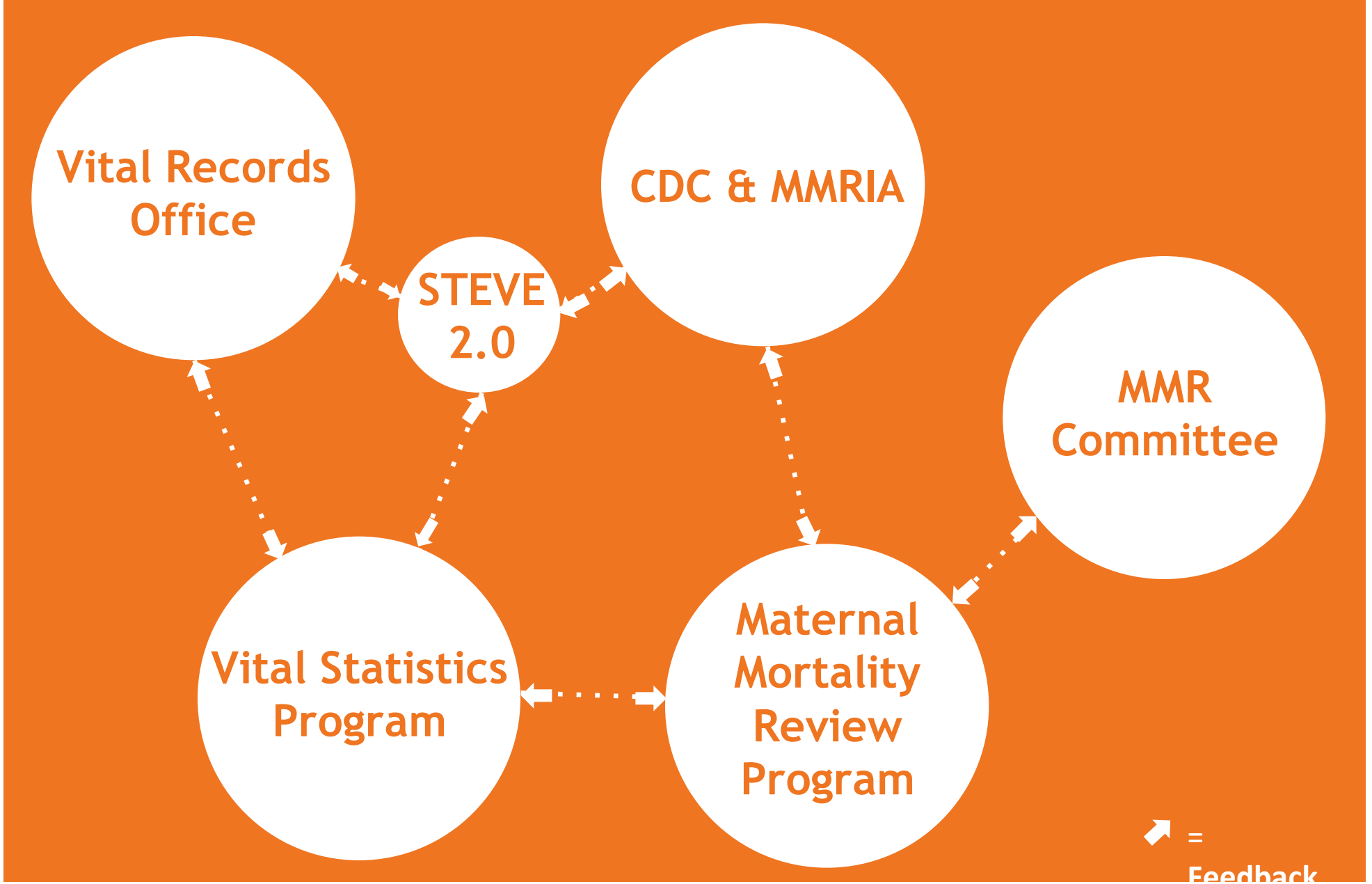
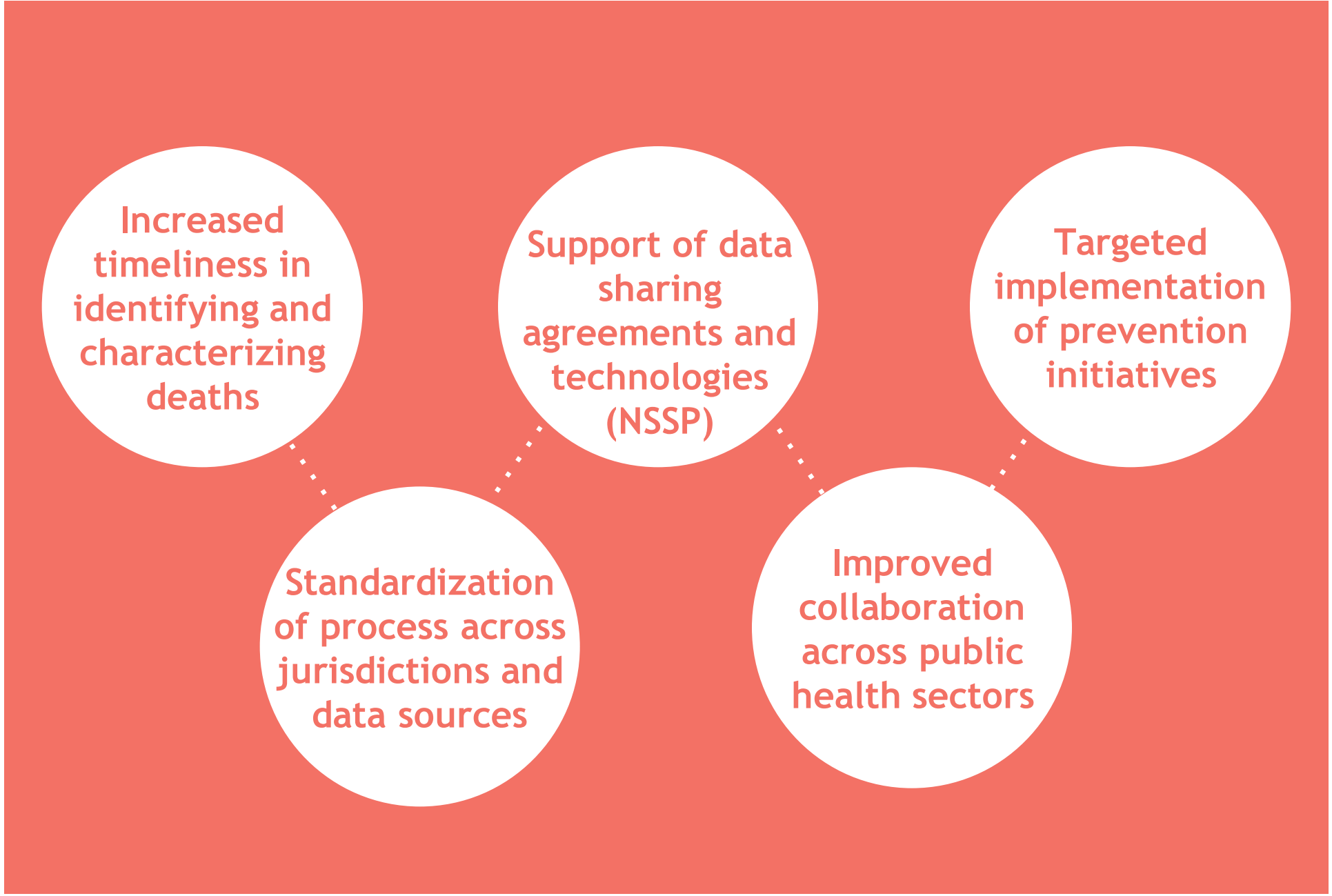

Vital Records Office
STEVE 2.0
CDC & MMRIA
MMR Committee
Vital Statistics Program
Maternal Mortality Review Program
= Feedback

IMPROVEMENTS


More timely data submission to MMR
More timely feedback on data quality
More timely MMRC review
More timely application of findings

4 FUTURE OPPORTUNITIES


Increased timeliness in identifying and characterizing deaths
Support of data sharing agreements and technologies (NSSP)
Targeted implementation of prevention initiatives
Standardization of process across jurisdictions and data sources
Improved collaboration across public health sectors

Thank you!

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Manager, Vital Statistics Program
Colorado Center for Health & Environmental Data
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STEVE 2.0

Interoperability Models in an Integrated Child Health Information System

2022 Data Modernization Workshop
Thursday Campfires Session
May 26, 2022

Agenda

- Background: Immunization Registries, Integrated Child Health Information Systems, and KIDSNET
- Integrated Child Health Information System interoperability models
- DMI Considerations from the Integrated Child Health Information System Experience

Background: Immunization Registries and Integrated Child Health Information Systems

- Immunization information systems (IIS)
  - confidential, population-based systems
  - collect and consolidate immunization data in a given jurisdiction
  - provide actionable information for clinical and public health decision making. (Source: CDC)
- Integrated Child Health Information System
  - similar to IIS, but scope is child health data more broadly
  - with a focus on the provision of timely and appropriate preventive health services and follow up

Background: KIDSNET

Statewide integrated child health information system and immunization registry (RICAIR) operated by the Rhode Island Department of Health (RIDOH) since 1997.

- Immunization
- Newborn Screening
  - Vital Records / Newborn Developmental Risk
  - Critical Congenital Heart Disease (CCHD)
  - Blood Spot Screening
  - Hearing Screening (EHDI)
- Lead Screening
- Women, Infants, Children (WIC), Early Intervention (EI), Family Visiting, Cedar Family Centers, Head Start, Child Outreach, Asthma
- Birth Defects Reporting
- Newborn Diagnostic Referrals and Reporting

Integrated Child Health Information System interoperability models

- Shared data & infrastructure:
  - Demographics
  - Consent
  - Data Quality
  - Data Standards
  - Interfaces
  - Security, Access Control and User Management
  - Data Sharing Agreements

Integrated Child Health Information System interoperability models

- Program data – different levels of participation:
  - **Host the entire program**
    - *Example: EHDI*
  - **Aggregator/hub**
    - *Examples: Immunization, CCHD*
  - **Data Repository**
    - *Examples: WIC, EI*
  - **Hybrid**
    - *Examples: Home Visiting, Child Outreach*

DMI Considerations from the Integrated Child Health Information System Experience

- Shared demographics and consent well-suited for population-based registries
- Rising tide lifts all boats: Data quality, interfaces & services, FHIR

- Different levels of data & interoperability standards across programs
- Transaction-oriented system vs. query-oriented system
- Data quality challenges across interoperability models

Thank you!

For More Information or Questions…

Mike Berry
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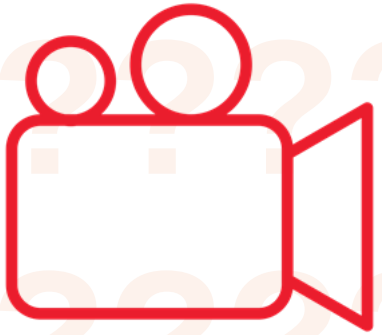
Questions and answer

Post in the chat

Raise your hand



Turn on your video

Next Steps

- Post additional questions on Circle - link provided in the chat
- Common grounds networking break 1:40-1:55 PM EST
- Next session 1:55 PM EST
  - *Workshop reflections*

Thank you.

DMI

Better data. Better decisions. Better health.