Implementing eCR for Birth Defects Surveillance

Lessons learned and considerations

June 28, 2024

PHII PUBLIC HEALTH INFORMATICS INSTITUTE | THE TASK FORCE FOR GLOBAL HEALTH

Agenda

- Welcome and overview
- eCR overview
- Panel discussion
- Wrap-up

Funding disclaimer

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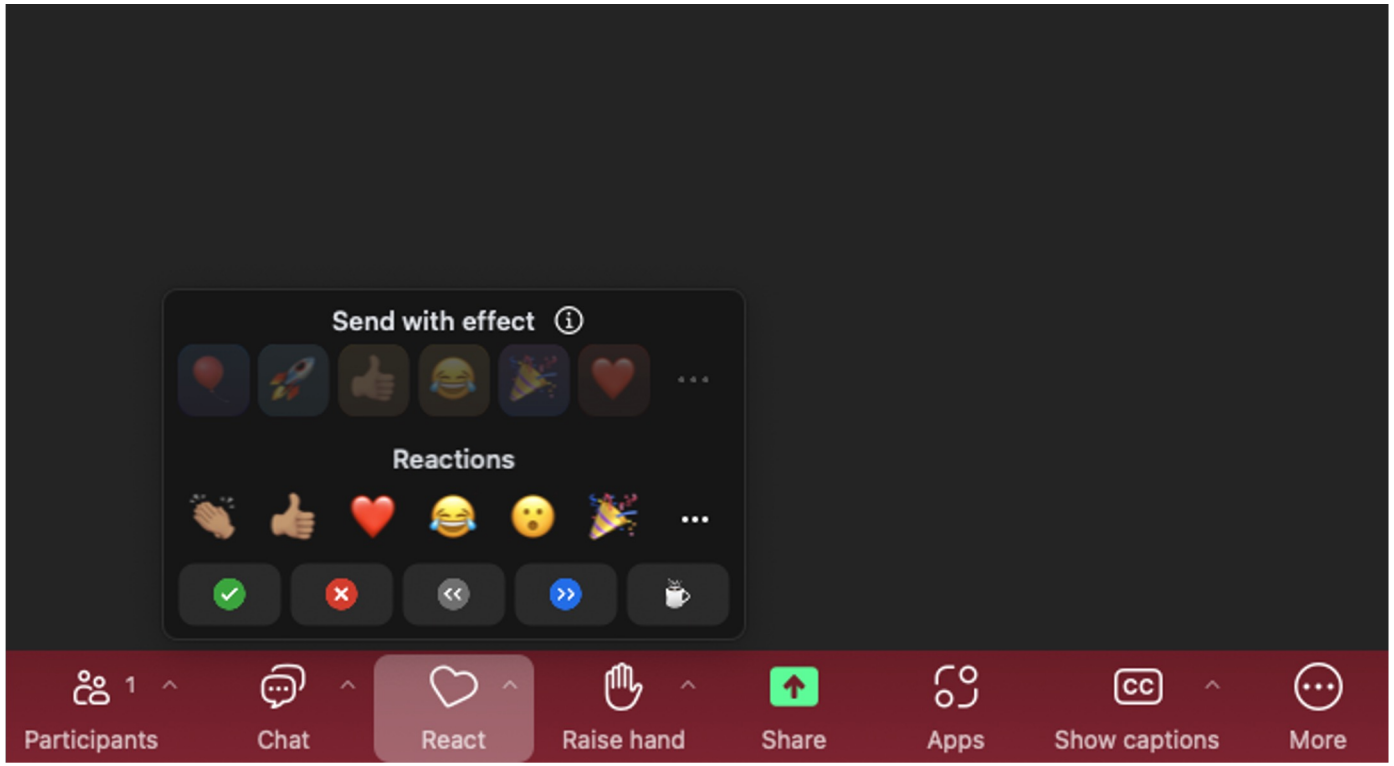
Many images from today's presentation have been downloaded from unsplash.com and freepik.com

Finding your way around Zoom

- Rename yourself to include your first and last name
- Type your questions into the chat or use reactions to communicate with presenters
- Show captions option



Webinar feedback

- Five short questions at the end of the zoom call
- Help us gauge the effectiveness of our webinar and provide additional resources to assist you

Laura Pabst, MPH
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

Electronic Case Reporting (eCR) Overview

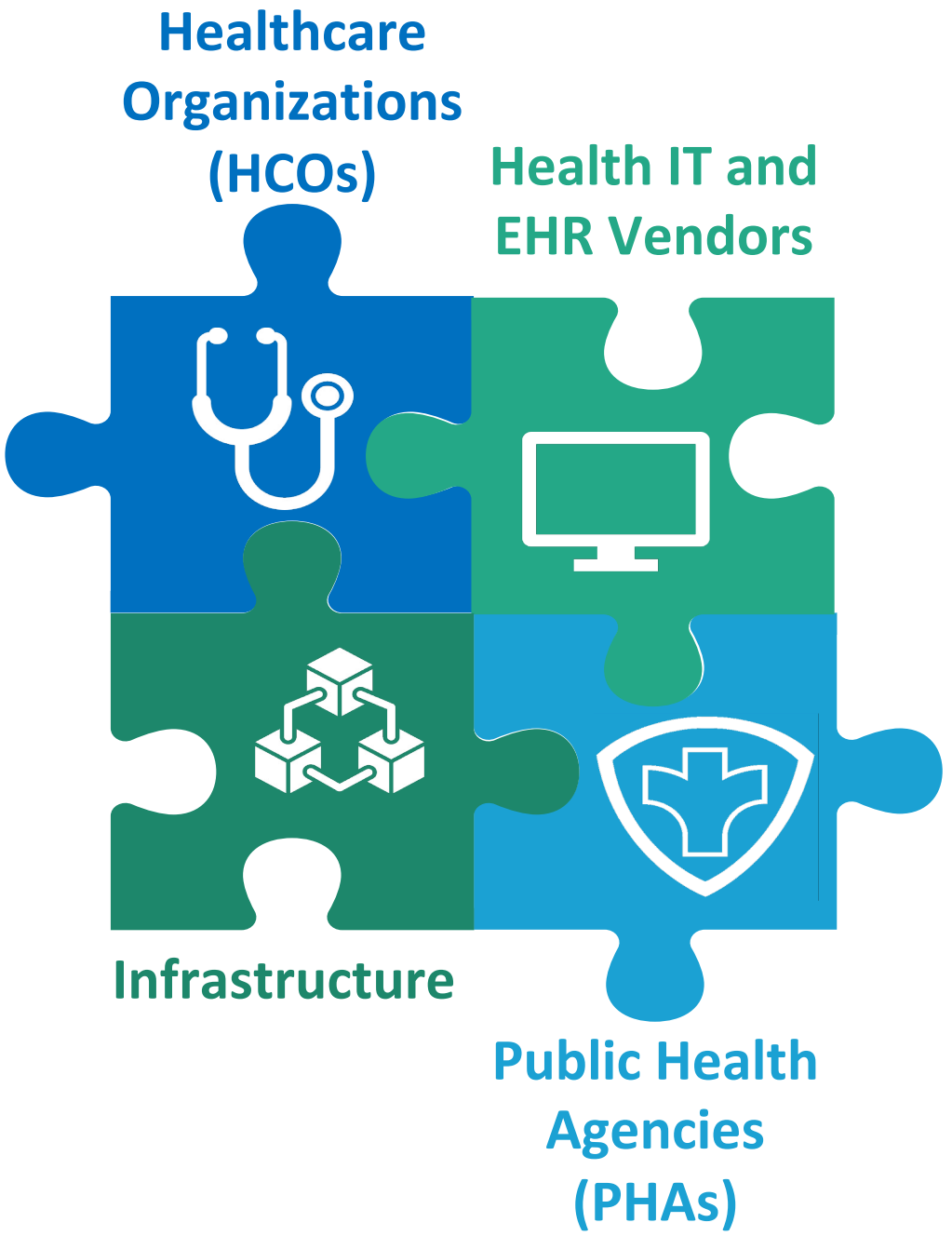
Melinda Thomas, MPH
CDC eCR Team, Public Health Agency (PHA) Support Lead

PHII Implementing eCR for Birth Defects Surveillance:
Lessons Learned and Considerations Webinar
June 28, 2024

eCR and Its Partners

eCR is the **automated generation** and transmission of case reports from the electronic health record (EHR) to public health agencies for review and action

eCR is a **collaboration** among Association of Public Health Laboratories (**APHL**), Centers for Disease Control and Prevention (**CDC**), and Council of State and Territorial Epidemiologists (**CSTE**)



How Does eCR Work?

Patient is diagnosed with a reportable condition, such as measles

Healthcare provider enters patient's information into the electronic health record (EHR)

Data in the EHR automatically triggers a case report that is validated and sent to the appropriate public health agency(ies) if it meets reportability criteria

The public health agency receives the case report in real time and a response about reportability is sent back to the provider

After investigating and verifying the case, public health agency reaches out to patient for contact tracing, services, or other public health action

cdc.gov/eCR

CS339736-A 4/19/2023 11 AM

Public Health Agency eCR Benefits

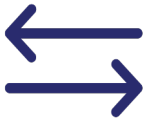
Provides critical clinical data from healthcare for better surveillance and response

Accelerates response

Efficiently monitors the spread of reportable diseases

Improves communication with healthcare

Provides more complete data



Enables bidirectional data exchange

Healthcare Provider eCR Benefits

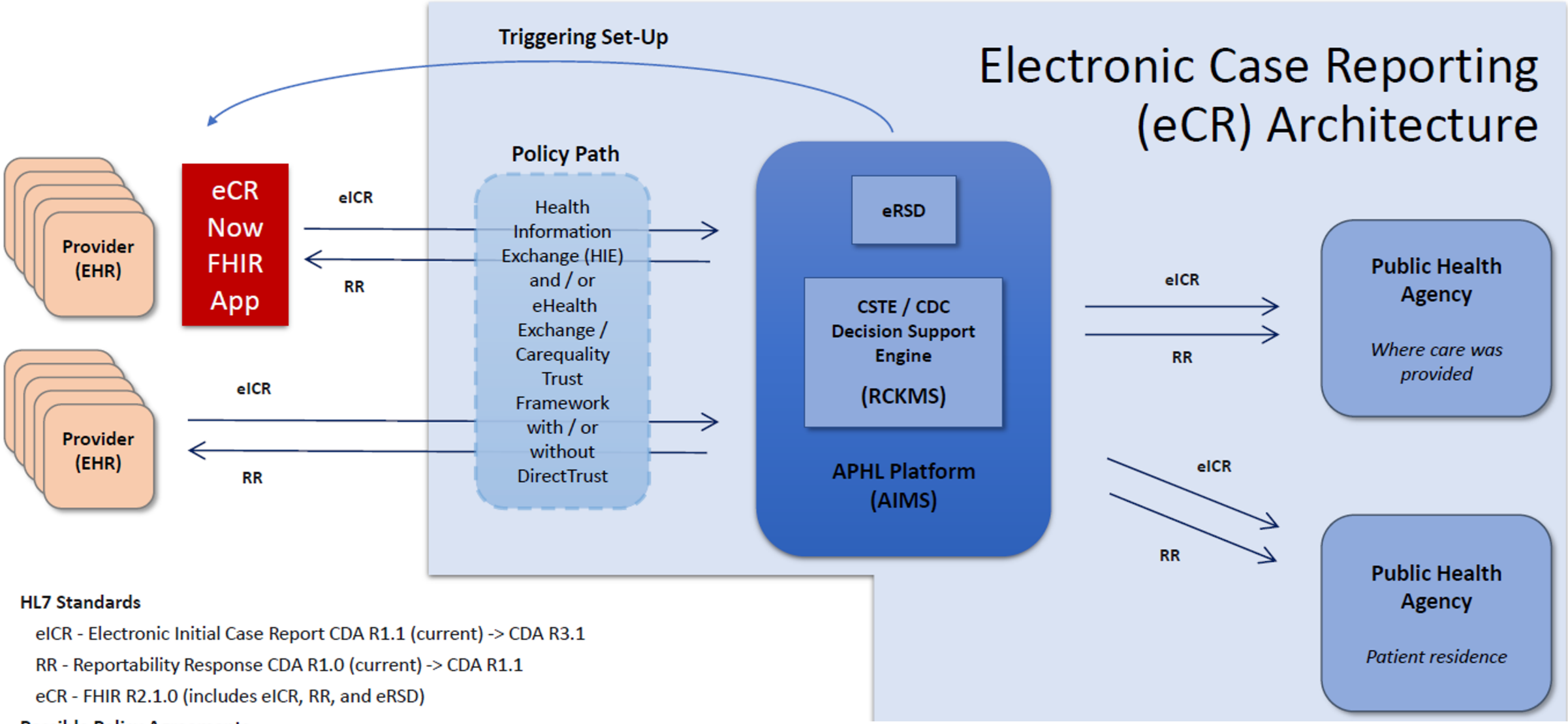
Reduces burden without disrupting the clinical workflow

- Saves time by eliminating manual data entry and reporting
- Fulfills legal reporting requirements
- Streamlines jurisdiction reporting challenges
- Can be implemented for all reportable conditions
- Receives information back from public health associated with the reportable condition
- Fulfills the CMS Promoting Interoperability Program requirement for eCR

eCR Data Flow

Last updated: 08/17/2022

Electronic Case Reporting (eCR) Architecture



HL7 Standards

eICR - Electronic Initial Case Report CDA R1.1 (current) -> CDA R3.1

RR - Reportability Response CDA R1.0 (current) -> CDA R1.1

eCR - FHIR R2.1.0 (includes eICR, RR, and eRSD)

Possible Policy Agreements

eHealth Exchange, Carequality, APHL participation agreement

Terms

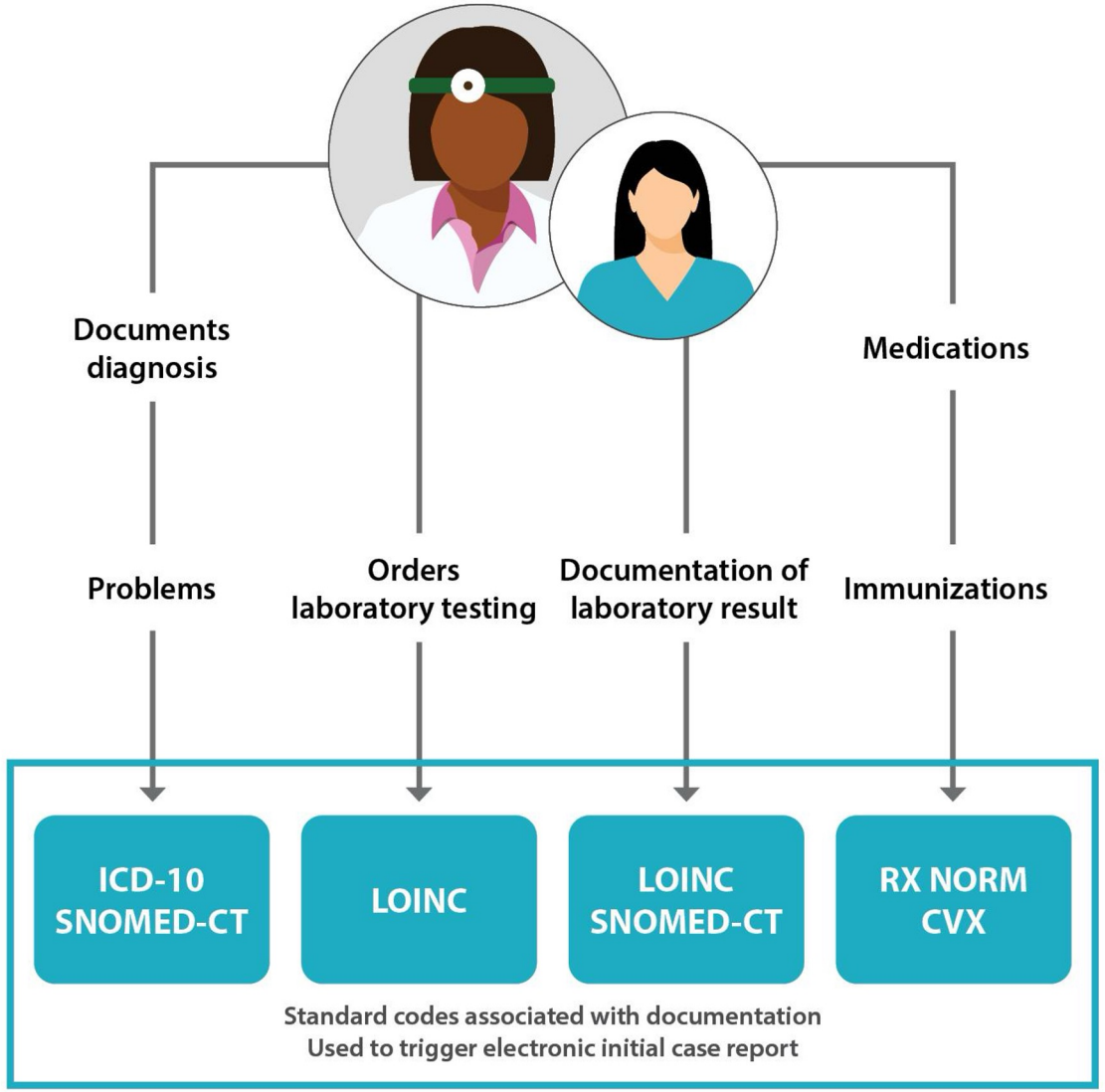
RCKMS - Reportable Condition Knowledge Management System

eRSD - Electronic Reporting and Surveillance Distribution System

Collaboration among Association of Public Health Laboratories (**APHL**), Centers for Disease Control and Prevention (**CDC**), and Council of State and Territorial Epidemiologists (**CSTE**)

Trigger Codes

- Consist of standard codes
- One nationwide set for all conditions, with a few exceptions
- Provided through the eRSD, along with additional triggering parameters, to EHR/HIT products



Electronic Initial Case Report (eICR)

- Includes CSTE-identified data elements necessary for public health to initiate a case investigation
- Uses HL7 CDA document or FHIR
- Currently implemented: the CDA eICR R1.1 Implementation Guide was published in January 2017
  - IG was updated based on implementation lessons learned and published CDA Release 3.1 in July 2022 and FHIR eCR IG Release 2.1

eICR Data Elements, Release 1.1

Patient	Patient	Provider	Facility	Encounter	Provenance

• **Identity**
  • Patient Id
  • Patient Name
  • Parent/ Guardian Name
• **Contact**
  • Patient or Parent/ Guardian Phone
  • Patient or Parent/ Guardian Email
• **Location**
  • Patient Address
	• **Demographics**
	  • Patient DOB
	  • Patient Administrative Sex
	  • Patient Birth Sex
	  • Patient Race
	  • Patient Ethnicity
	  • Patient Preferred Language
		• **Identity**
		  • Provider Id
		  • Provider Name
		• **Contact**
		  • Provider Phone
		  • Provider Fax
		  • Provider Email
		• **Location**
		  • Provider Office/Facility Name
		  • Provider Address
			• **Identity**
			  • Facility ID Number
			  • Facility Name
			  • Facility Type/ Hospital Unit
			• **Contact**
			  • Facility Phone
			  • Facility Fax
			• **Location**
			  • Facility Address
				• Encounter Type
				• Visit Date/Time (outpatient)
				• Admission Date/Time
				• Discharge Date/Time
					• **When**
					  • Date of Report
					  • Report Submission Date/Time
					• **Where**
					  • Sending application

eICR elements are aligned with the USCDI.

eICR Data Elements, Release 1.1 (Continued)

Clinical: Notes, Symptoms, & Diagnoses	Clinical: Lab	Clinical: Medication	Clinical: Risk Factors - Pregnancy	Clinical: Risk Factors -Other	Clinical: Other

• History of Present Illness
• Reason for Visit
• Symptom List
• Problem List
  • **Problem (Diagnosis) Trigger**
• Encounter Diagnoses
  • **Problem (Diagnosis) Trigger**
• Diagnosis Date
• Date of Onset
	• Lab Order Code (Ordered test)
	  • **Lab Order Code Trigger**
	• Placer Order Number
	• Lab Order Code (Resulted test)
	  • **Lab Order Code Trigger**
	• Lab Result
	  • **Lab Result Code Trigger**
	• Filler Order Number
		• Medications Administered (list)
		• Immunization Status (list)
			• Pregnancy Status	• Patient Occupation
				• Travel History Dates
				• Travel History Location
					• Death Date

eICR elements are aligned with the USCDI.

New Data Elements in eICR Release 3.1

Patient	Clinical: Lab	Clinical: Medication	Clinical: Risk Factors - Pregnancy	Clinical: Risk Factors - Other	Clinical: Other
• Gender identity • Tribal Affiliation • Tribal Enrollment Status • Country of Nationality • Country of Residence	• Lab Result Status • Specimen Source • Specimen Type • Specimen Id • Specimen Collection Date	• Medications: Admission • Medications: Administered • Medications: Historical • Medications: Planned • Immunization Status • Vaccine Credential Patient Assertion	• Pregnancy Status • Pregnancy Status Determination Date and Method • Estimated Date of Delivery and Determination Method • Estimated Gestational Age of Pregnancy • Estimated Gestational Age Determination Date and Method • Last Menstrual Period • Pregnancy Outcome and Date • Postpartum Status	• Present/Usual Industry • Present/Usual Occupation • Current Job Title • Current Employer Name, Phone, Address • Occupational Exposure • Emergency Outbreak Information • Exposure/Contact Information • Travel History: Purpose and details • Homelessness Status • Disability Status	• Therapeutic Medication Response • Vital Signs • Chief Complaint • Past Medical History • Review of Systems • Procedure • Planned Procedure

Decision Support: The Reportable Conditions Knowledge Management System (RCKMS)

- Logic-based decision support service
- Sits on an intermediary services platform (AIMS)
- Consists of 3 parts
  - Authoring interface: Public health agencies enter their local reporting requirements
  - Knowledge repository
  - A decision support service that determines if a potential case is reportable or not, and to which jurisdiction(s)

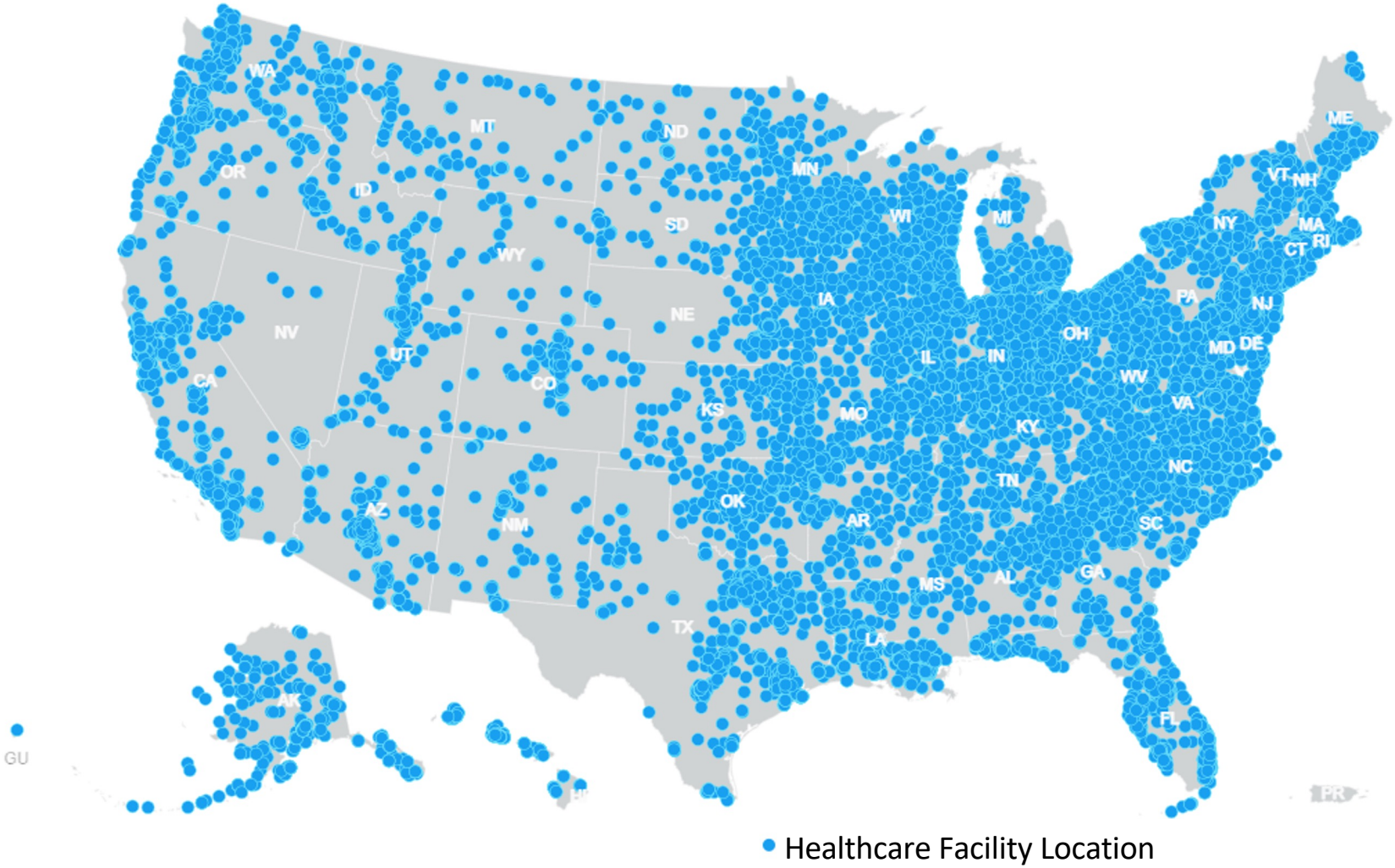
Reportability Response (RR)

Includes information from public health back to clinical care and confirms:

- Report of the condition
- Jurisdiction(s) receiving the report
- Optional additional relevant information

  (e.g., treatment guidelines or local context)
- Processing and provides feedback (i.e., errors)

Healthcare Facilities Live with eCR



Healthcare Facility Location

As of June 21, 2024

>38,000

Facilities are live with eCR

Almost 40%

have implemented All Conditions trigger code set

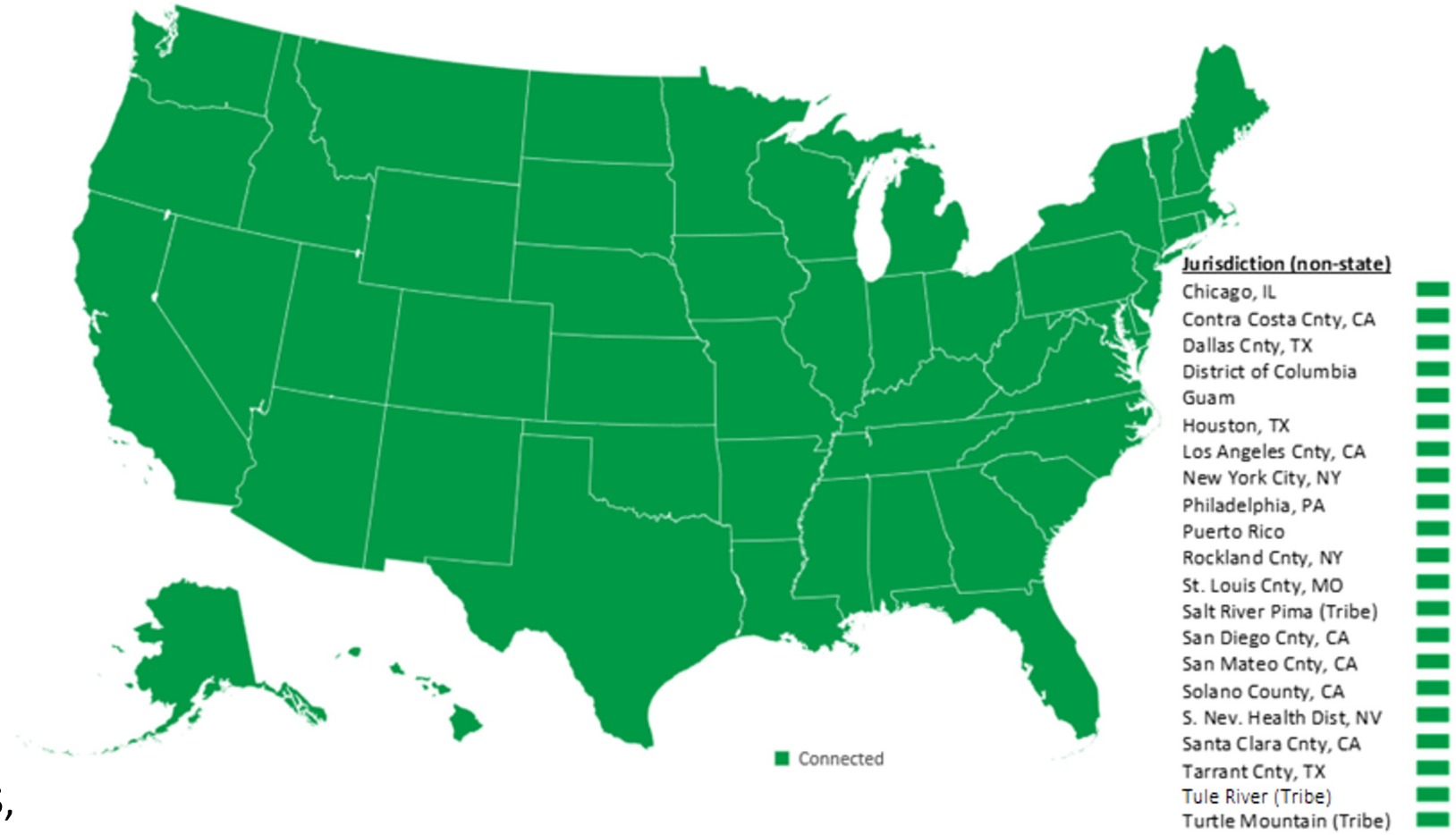
PHAs Connected for eCR

71 jurisdictions currently connected:

All 50 states, Washington D.C., Puerto Rico, Guam, 15 local jurisdictions, and 3 Tribal jurisdictions

Additional jurisdictions working to connect:

American Samoa, 2 additional local jurisdictions, 1 Tribal Epi Center



As of June 21, 2024

Birth Defects and Infant Disorders in RCKMS

Thirteen (13) Current Conditions

Anencephaly	Cleft Lip Alone	Cleft Lip with Cleft Palate	Cleft Palate Alone
Congenital cytomegalovirus (cCMV) Infection and Disease*	Down Syndrome	Gastroschisis	Infant Hearing Loss
Limb Reduction	Neonatal Abstinence Syndrome*	Phenylketonuria	Primary Congenital Hypothyroidism
Spina Bifida			

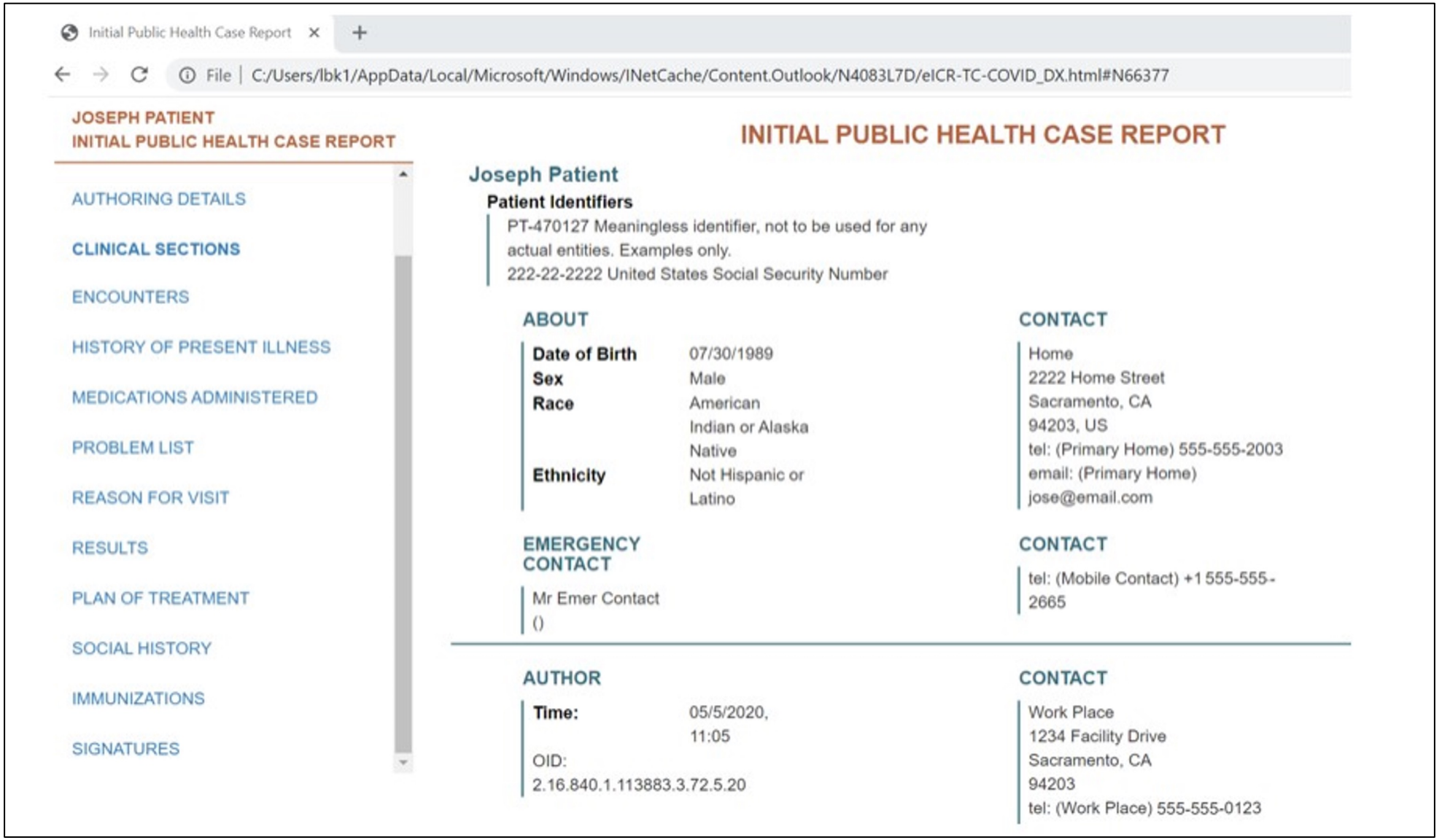
*Two (2) conditions currently have the option for Diagnosis/Active Problem Timeboxing

Thirteen (13) Forthcoming Conditions - Available Summer/Fall 2024, RCKMS Content Release 12**

Coarctation of the Aorta	Double Outlet Right Ventricle (DORV)	Transposition of the Great Arteries (TGA)	Ebstein Anomaly
Hypoplastic Left Heart Syndrome (HLHS)	Interrupted Aortic Arch	Pulmonary Valve Atresia and Stenosis	Single Ventricle
Tetralogy of Fallot (TOF)	Total Anomalous Pulmonary Venous Connection (TAPVC)	Tricuspid Valve Atresia and Stenosis	Truncus Arteriosus (Common Truncus)
Atrioventricular septal defect (Endocardial cushion defect)			

**RCKMS Content Release 12 will give all Birth Defects and Infant Disorders conditions the option for Diagnosis/Active Problem Timeboxing

Using HTML Electronic Initial Case Reports (eICRs)



Using HTML Reportability Responses (RRs)

Patient	Patient, Joseph
Patient ID(s)	PT-470127 2.16.840.1.113883.19.5 222-22-2222 2.16.840.1.113883.4.1
Contact info	Home: 2222 Home Street Sacramento, CA 94203, US
Date of Birth	July 30, 1989
Sex	Male
Race	American Indian or Alaska Native
Ethnicity	Not Hispanic or Latino
Primary Information Recipient:	SanDiego, Carmen
Contact info	Home: 1234 Provider Street Sacramento, CA 94203, US
eICR Identifier:	38e6a983-38ad-484f-a7d2-b294cdbe5435

Subject:

Public Health Reporting Communication: one or more conditions are reportable, or may be reportable, to public health.

Summary:

Your organization electronically submitted an initial case report to determine if reporting to public health is needed for a patient.

"Disease caused by severe acute respiratory syndrome coronavirus 2 (disorder)" is reportable to "California Department of Public Health". The initial case report was sent to "California Department of Public Health". Additional information may be required for this report.

"Disease caused by severe acute respiratory syndrome coronavirus 2 (disorder)" for "California Department of Public Health"

Reporting is required immediately. Reporting to this Public Health Agency is based on "Both patient home address and provider facility address"

> CDC COVID-19 webpage (Information only)

> Local Health Department Contact Information (Information only)

Opportunities for PHA Program Areas

- Learn more about eCR
- Collaborate with your PHA's eCR team
  - Assess if eCR will meet program's needs
  - Discuss setting up RCKMS Authoring
    - Consider roles
    - Wait until after Summer RCKMS Content Release
  - Think through internal data flow, processes, and storage and use of data
    - Resources, technical solutions, policy/governance considerations
    - Engage with other key agency partners as needed (e.g., IT, Informatics)
- Connect with other PHA Birth Defects Surveillance Programs

eCR Resources

- CDC eCR webpage: Electronic Case Reporting (eCR) | CDC
  - Public list of EHR/Health IT Vendors in General Availability: Getting Started with eCR | CDC
- Reportable Conditions Knowledge Management System (RCKMS): https://www.rckms.org/about-rckms/
  - Conditions available: https://www.rckms.org/conditions-available-in-rckms/
  - RCKMS Training Modules: https://www.rckms.org/rckms-training-modules/
  - Authoring Support Associates: https://www.rckms.org/rckms-authoring-support-team/
  - Timeboxing: https://www.rckms.org/rckms-timeboxing/
- APHL eCR Information for PHAs: https://ecr.aimsplatform.org/public-health-agencies/
  - eCR Data Needs spreadsheet v14: https://ecr.aimsplatform.org/cms/resources/eicrdataneedsv1412-2023.xlsx

Questions?

Email us at ecr@cdc.gov

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

Panel discussion

Birth defects programs: California, Minnesota and Texas

California Department of PublicHealth

Valorie Eckert

Valorie Eckert is a Research Scientist Supervisor and Chief of the California Birth Defects Monitoring Program. Her role is overall guidance and oversight of California's eCR birth defects surveillance effort.

Olga Barer

As a Registry Data Systems Manager, Olga Barer oversees data management processes for the California Birth Defects Monitoring Program, including data collection, review, and linkage effort for California Birth Defects Registry and work with the Research Scientists to provide reports and data runs. She is a technical lead on the eCR integration project.

Sam Roodbar

Sam Roodbar serves as the lead analyst on the eCR implementation project for CBDMP. His role involves development of evaluation plans to thoroughly examine incoming eCRs to ensure receipt of complete, accurate and timely reports.

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Anna Lintelmann

Anna Lintelmann has been the informatics lead for the Children and Youth with Special Health Needs section at the Minnesota Department of Health for six years. She began working with eCRs during the COVID-19 pandemic response and is a part of MDH's eCR Team. She has a Master of Public Health degree in Epidemiology and previously worked in clinical research.

Sook Ja Cho

Sook Ja Cho is Principal Epidemiologist working for the Birth Defects Monitoring and Analysis Unit at the Minnesota Department of Health (MDH). She has also served as Principal Investigator for federal grants (non-research) since she joined the MDH in 2013.She earned her master's degree in public Heath from the Seoul National University in South Korea and her doctorate (in public health) from the University of Minnesota.

TEXAS Health and Human Services | Texas Department of State Health Services

Rachel Allred

Rachel Allred holds a PhD in behavioral neuroscience from the University of Texas at Austin. She received her MPH in epidemiology from the University of Texas Health Science Center at Houston. Dr. Allred is the olds the position of Epidemiology Team Lead at the Texas Department of State Health Services Birth Defects Epidemiology and Surveillance Branch.

Hye Na Jeon

Hye Na Jeon holds a BS in Public Health from the University of Texas at Austin. Mrs. Hye Na started working at the Texas Department of State Health Services Birth Defects Epidemiology and Surveillance Branch in 2021 as a Project Specialist/Grant Coordinator and is now the Birth Defects Branch Interoperability Project Manager.

Asha Phillips

Asha Phillips holds a BS in Business Administration from Tennessee Technological University in Cookeville, Tennessee. She completed her MBA with a specialization in Management Information Systems from the University of Texas at El Paso. Asha is an Application Support Specialist at the Texas Department of State Health Services for the Birth Defects Epidemiology and Surveillance Branch in support of the application registry.

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eCR Lessons learned summary

Tony K. Winters, DrPH,MSPH
Public Health Informatics Institute


Questions?

Post-call survey

Don’t forget to give us your feedback in the post call survey!


THANK YOU

Appendix

eCR Terminology

- Electronic Case Reporting (**eCR**)
- Electronic Initial Case Report (**eICR**)
  - HL7® Clinical Document Architecture (**CDA**®) format
  - HL7 Fast Healthcare Interoperability Resources (**FHIR**®) format
- Reportability Response (**RR**)
- APHL Informatics Messaging Services (**AIMS**) platform
- Electronic Reporting and Surveillance Distribution (**eRSD**)
  - Reportable Conditions Trigger Codes (**RCTC**) (‘triggers’)
- Reportable Conditions Knowledge Management System (**RCKMS**)
  - Reporting Criteria and Reporting Specifications (‘authored rules’)

eCR By The Numbers

Healthcare Facilities

>38,000 facilities are in production for eCR

2,705 (37%) hospitals are using eCR

513 (38%) Critical Access Hospitals are using eCR

1,779 (13%) Federally Qualified Health Center service sites (including look-alike sites) are using eCR

20,666 (12%) ambulatory facilities staffed by MIPS providers are using eCR

as of June 21, 2024

eCR By The Numbers

Public Health Agencies

50 states, D.C., Puerto Rico, Guam, **15** local jurisdictions, and **3** Tribal jurisdiction are now receiving electronic initial case reports from AIMS

38 PHAs are processing the eICR into a production surveillance system

6 PHAs are processing the eICR into a test environment

as of June 21, 2024

High-level Focus Areas for PHA eCR Implementation

Establish, maintain, and monitor **connection to AIMS/RCKMS** intermediary

Expand and refine conditions authored in RCKMS that are reportable in your jurisdiction*

Collaborate with Healthcare Organizations to onboard additional facilities to improve data quality, and implement all condition triggers (the full eRSD)

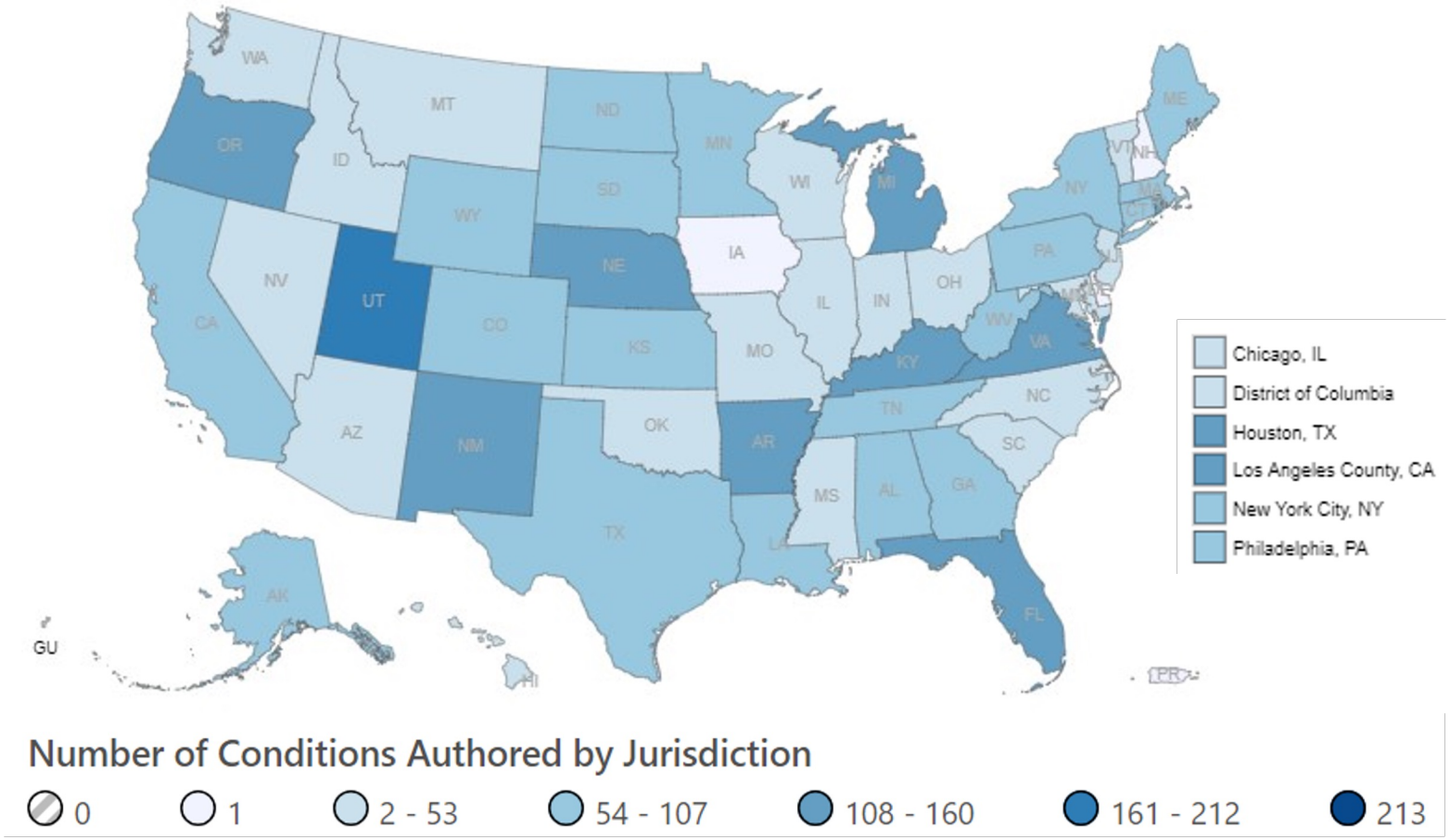
Increase use and access of eCR data by case investigators and epidemiologists, including **processing into disease surveillance system(s)***

Prepare for **expanded eCR data formats** – eICR CDA R3.1 & RR CDA R1.1, and/or eCR FHIR 2.1

* Associated with a 2024/2025 Public Health Data Strategy milestone

Authoring in RCKMS – Published to Production

All Connected ELC-funded PHAs

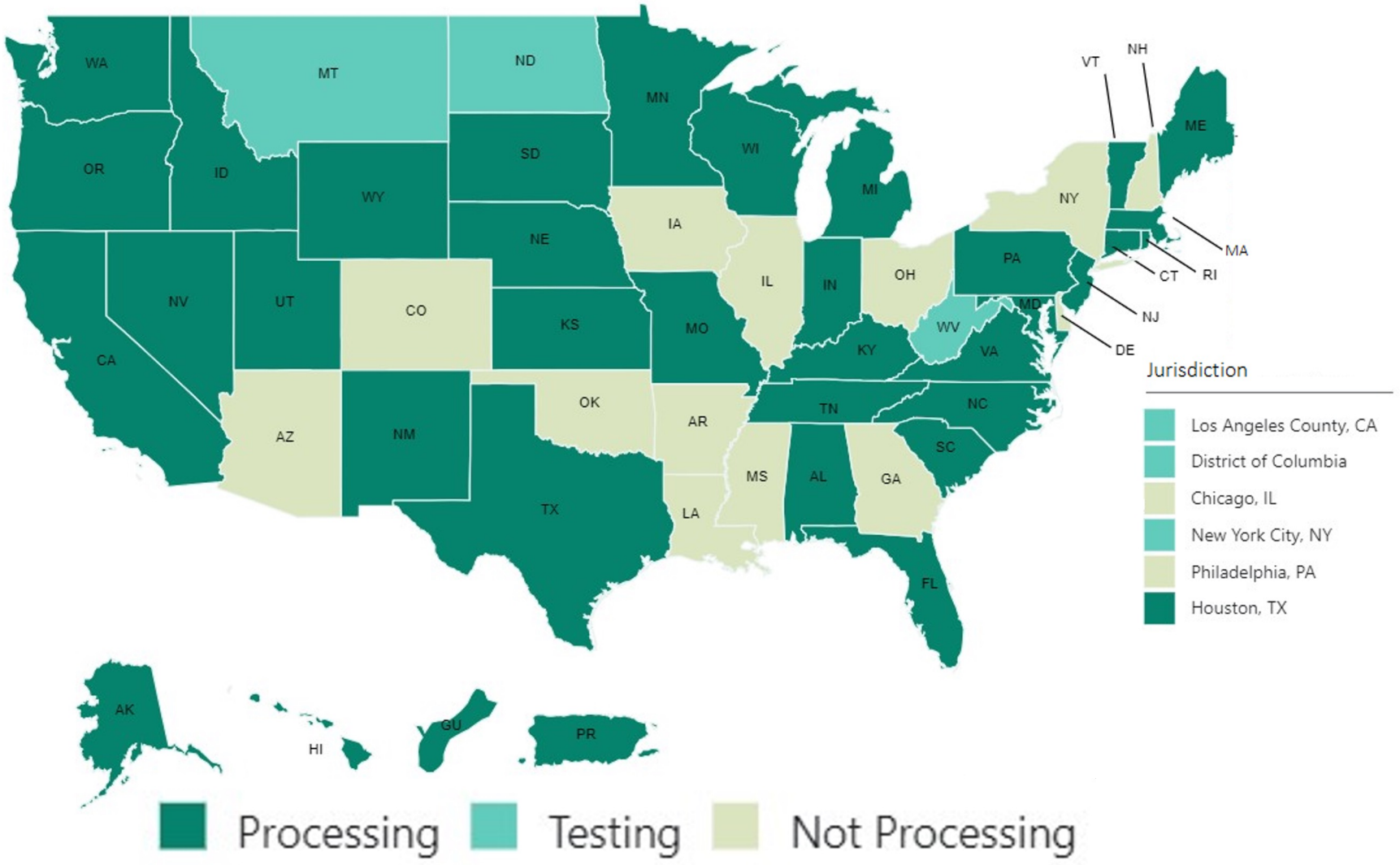


- An average of 63 conditions are authored by each PHA*
- Out of 213 conditions available in RCKMS, an average of 106 conditions are reportable for each PHA*
- **48**% (n=28) of PHAs* have at least 75% of their reportable conditions authored.
  - 4 additional PHAs have at least 70%.

*ELC-funded PHAs connected for eCR (n=58)

As of May 31, 2024

PHA Processing of eICRs



- 35 States, Puerto Rico, Guam, and 1 local PHA are processing eICRs into a production surveillance system.
- 3 States, D.C., and 2 local PHAs are processing eICRs in test environments.

As of June 21, 2024

*64 ELC-funded PHAs

PHAs Successes and Lessons Learned with eCR

- **Reducing** provider **underreporting**
- **Better** PHA **awareness** through improved timeliness and receipt
- Testing and validation processes to **ensure data quality**
- Successfully **onboarding** many **healthcare organizations (HCOs)** to production
- **Better capacity for eCR/eICR** capture and reporting in surveillance systems

- Taking advantage of **resources and support from the eCR team**:
  - APHL Technical Resolution (TR) and Direct Support (DS)
  - CDC Onboarding and PHA Support
  - CSTE/RCKMS Authoring Support
  - Soft Go-Live (SGL) data for HCO testing and validation (opt-in)
  - SGL Monitoring Reports and Production Monitoring Reports
  - Monthly HCO Implementation Onboarding Reports

PHA Challenges and Opportunities with eCR

- **Data quality** issues from different factors: flexibility of standard, variability of EHR/HIT products, inconsistencies in clinical workflow
- Public health practitioners unfamiliar with rawer **electronic clinical data**
- Public health agency **infrastructure and systems** require upgrades and/or additional upstream tools/resources to process eICRs and RRs
    - **Processing** data-dense CDA into actionable components for case investigators
- **Transitioning** from an ELR mindset to an eCR mindset, especially for eCR healthcare organization onboarding and validation