

ELECTRONIC CASE REPORTING ROADMAP

For Tribes and Tribal Epidemiology Centers

NIHR | NATIONAL INDIAN
HEALTH BOARD



Record

Medical Information

	Nationality	ID Card/Passport
	Address	
	Telephone	e-mail
	Occupation	
	Office Address	
	Contact Person	

Photo

Gender

Date of Birth

Marital

Telephone

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ABOUT NIHB



The National Indian Health Board (NIHB) represents Tribal governments—both those that operate their own health care delivery systems through contracting and compacting, and those receiving health care directly from the Indian Health Service (IHS).

Established by the Tribes to advocate as the united voice of federally recognized American Indian and Alaska Native (AI/AN) Tribes, NIHB seeks to reinforce Tribal sovereignty, strengthen Tribal health systems, secure resources, and build capacity to achieve the highest level of health and well-being for our People. NIHB continually presents the Tribal perspective while monitoring federal legislation, and opening opportunities to network with other national health care organizations to engage their support on Indian health care issues. The only organization of its kind; dedicated to strengthening healthcare for all AI/ANs.

Located in Washington DC on Capitol Hill, NIHB, a 501(c)(3) non-profit organization with Federal Tax ID number 23-7226316, provides a variety of services to tribes, Area Health Boards, Tribal organizations, federal agencies, and private foundations.



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- Great Plains Tribal Epidemiology Center
- Salt River Pima Maricopa Indian Community
- Tule River Health Center
- Turtle Mountain Band of Chippewa Indians

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GLOSSARY

NAME	ACRONYM
Association of Public Health Laboratories	APHL
Association of Public Health Laboratories Informatics Messaging Services	AIMS
Centers for Disease Control and Prevention	CDC
Council of State and Territorial Epidemiologists	CSTE
Decision Support Service	DSS
Electronic Case Reporting	eCR
Electronic Health Records	EHR
Electronic Initial Case Report	eICR
Electronic Lab Reporting	ELR
Health Insurance Portability and Accountability Act	HIPAA
Indian Health Service	IHS
National Indian Health Board	NIHB
Reportable Conditions Knowledge Management System	RCKMS
Reportability Response	RR
Tribal Epidemiology Center	TEC

UNDERSTANDING ELECTRONIC CASE REPORTING (ECR)

OVERVIEW: NIHB'S TRIBAL DATA SOVEREIGNTY PROJECT FOR ECR

In support of NIHB's mission, NIHB advocates for and leads efforts to strengthen Tribal sovereignty in healthcare and public health initiatives. Tribes, as sovereign nations, have the right and responsibility to provide health services to their citizens. As our public health systems modernize in the wake of the COVID-19 pandemic, the key role of data in public health systems has become more apparent.

NIHB has been a leader in efforts to increase data sovereignty- a principle of Tribal sovereignty which supports Tribes having control over their own data. NIHB has supported this through advocacy, policy, education of lawmakers and legal professionals, research on data sharing barriers, technical assistance, and funding to Tribes.

One of NIHB's pilot projects to increase access has been the electronic case reporting (eCR) for disease surveillance project. In partnership with the Centers for Disease Control and Prevention, (CDC) NIHB launched several initiatives to explore how Tribes might use eCR to improve data access, apply data to real-time public health decisions, and increase Tribal data sovereignty. NIHB has supported the following efforts to improve Tribal interest in and usage of eCR for surveillance data:

- Pilot project: Providing direct funding and technical assistance to Tribes and TECs to implement eCR connections to receive public health data.
- Hosting federal listening sessions on eCR and data modernization.
- Providing trainings on eCR, data modernization, and data sovereignty at conferences including the National Tribal Health Conference, Public Health Law Conference, and Tribal Public Health Data Modernization Learning Community.
- Publishing resources on eCR.
- Working with national partners to increase understanding and support for Tribal data sovereignty.
- Learning more about eCR implementation through key informant interviews.
- Developing the Tribal eCR Roadmap.

Pilot Project for eCR Implementation

In September of 2022, NIHB onboarded the Pilot Cohort of Tribal Public Health Authorities with the goal of connecting two Tribes to the Association of Public Health Laboratories (APHL) Informatics Messaging Services (AIMS) to receive public health data on reportable conditions through eCR. The Salt River Pima Maricopa Indian Community (SRPMIC) and the Turtle Mountain Band of Chippewa Indians (TMBCI) joined as pilot implementation sites, with the goal of receiving Tribal member data on reportable conditions directly, in real time. Both sites planned to use this data to take action on conditions of concern to their Tribe such as COVID-19 and other communicable disease outbreaks. Both Tribes were ultimately successful in connecting to the AIMS platform for eCR and receiving electronic initial case reports (eICRs).

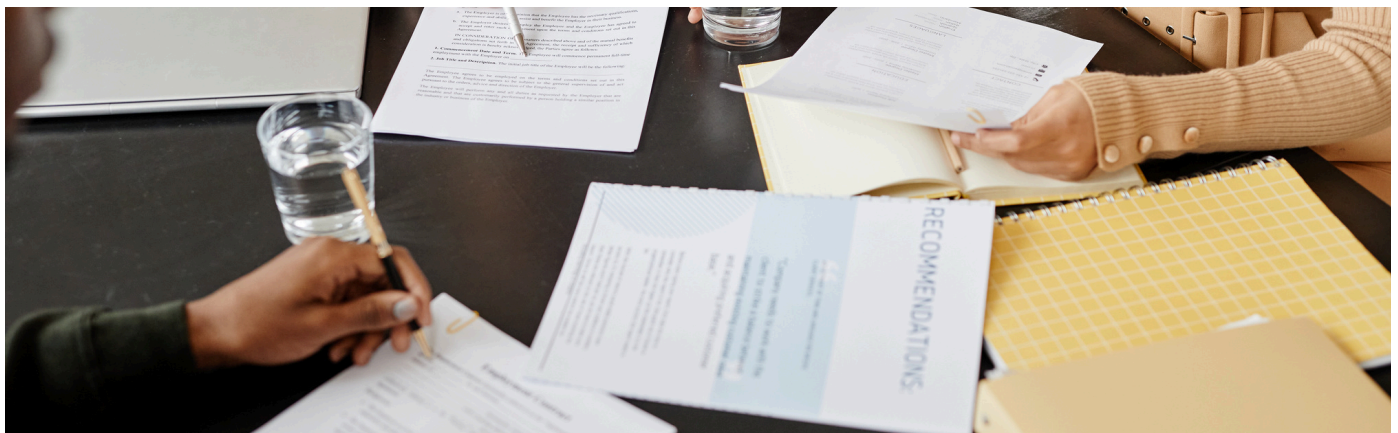
In 2023, NIHB onboarded two additional pilot implementation sites- the Great Plains Tribal Epidemiology Center (GPTEC) as the first Tribal Epidemiology Center (TEC) to attempt an eCR connection through AIMS, and the Tule River Indian Health Center (TRIHC), a Tribal health center granted public health authority by the Tule River Tribe. As of the time of this report, TRIHC had connected to the AIMS platform for eCR and received eICRs and the GPTEC was in the process of continuing to pursue a final connection.

As the first four Tribal-serving organizations to pursue eCR for public health data, these four public health authorities led the way for Tribes and TECs. Their work towards connecting to eCR is the primary driver of this Roadmap. The challenges they faced differed significantly from their state and local counterparts as, like many other systems, the eCR AIMS platform was primarily designed with state and local public health systems in mind. The lessons they learned are an excellent starting point for any Tribal Public Health Authority looking to connect to eCR in the future.



About this eCR Roadmap

Goal: Tribal public health authorities will receive the data they need to protect and promote the health of Tribal citizens in real time while exercising their sovereignty. The Electronic Case Reporting Roadmap for Tribes and Tribal Epidemiology Centers (eCR Roadmap) is a project undertaken by NIHB with support from the Centers for Disease Control and Prevention (CDC) to create a step-by-step guiding document for Tribes and TECs interested in directly connecting to the AIMS platform for eCR for the purposes of receiving data on reportable conditions in real time. The goal of this Roadmap is to make eCR connections more accessible for Tribes and TECs by outlining clear steps to achieving a connection. This Roadmap will also outline challenges Tribes and TECs may face in connecting to eCR and shares resources and best practices for overcoming these challenges. Finally, this Roadmap will provide resources and language for Tribes and TECs to advocate for their own legal right to access public health data.



Who Will Benefit from the eCR Roadmap?

The eCR Roadmap is specifically intended for Tribal public health authorities (Tribes/ the entity designated by the Tribe as the public health authority and TECs) interested in learning more about eCR and the process of directly connecting to the AIMS platform in order to receive public health data.

BACKGROUND: INTRODUCTION TO ECR FOR PUBLIC HEALTH SURVEILLANCE

Data Flow for Reportable and Notifiable Conditions

Case surveillance is a core function of public health authorities and requires the sharing of data on reportable and notifiable conditions. These conditions are generally diseases that cause public health concern due to their impact on the health of the community, such as by causing disease outbreaks.

Cases of notifiable and reportable conditions are sent to appropriate public health authorities using a variety of data-transfer processes. This allows public health authorities to identify and act upon conditions that might pose a threat to the people in a jurisdiction, including communicable, foodborne, and waterborne diseases (i.e. COVID-19, sexually transmitted infections, salmonella), and noninfectious diseases of public health concern, such as those spread through environmental contamination (i.e. lead, certain cancers) [i].

The designation of a disease as a reportable condition is mandated by individual state, territorial, and Tribal laws, policies, codes, and ordinances [ii]. These states, territories, and Tribes are considered public health authorities, and have the jurisdictional authority to determine which conditions, under which circumstances must be reported, by whom, and the timeline this reporting must take place. Reporting is generally required of laboratories and healthcare professionals, while the timeline and information required may differ based on the condition and the severity of the expected public health impact. Jurisdictions receiving these reports assess the threat a case poses and can act to prevent the spread of this disease through a variety of methods, including but not limited to:

- Case investigations to determine cause of disease spread
- Contact tracing to stop person-to-person spread
- Working with food handlers or restaurants to stop an outbreak of foodborne disease
- Providing prophylaxis to those exposed to a pathogen
- Providing community vaccinations to those exposed or at risk

- Conducting educational campaigns
- In severe cases, imposing isolation or quarantine measures to prevent disease spread

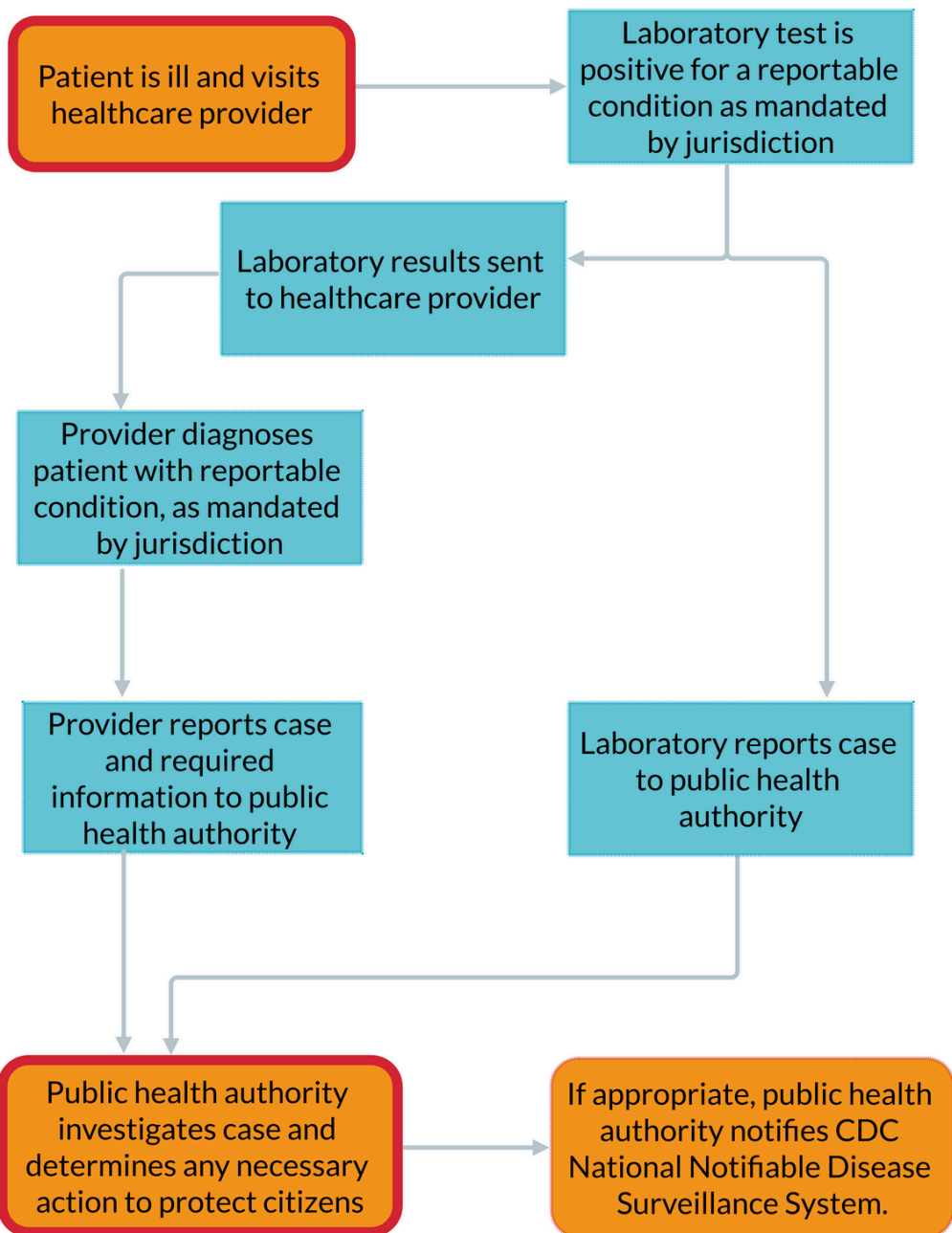
For approximately 120 Nationally Notifiable Diseases selected by CDC in partnership with the Council of State and Territorial Epidemiologists (CSTE), CDC collects de-identified data on cases. This data is voluntarily submitted by states, territories, and other health departments that opt into this system [i]. CDC’s authority to collect this information depends on the laws of the jurisdictions reporting the data, and outside certain federal

mandates, CDC generally does not have the authority to require reporting independently.[iii]

CDC does also require reporting from jurisdictions in certain scenarios, including but not limited to, jurisdictions that receive federal funding through certain CDC agreements. Reporting requirements may vary depending on the specific project or funding mechanism.

****Note that some conditions are reportable on suspicion without an actual diagnosis or confirmed lab results.***

FIGURE 1: GENERAL DIAGNOSIS AND REPORTING PROCESS FOR REPORTABLE/NOTIFIABLE DISEASES[IV]



Historically, states have been the de facto holder of public health data. Tribes, despite having the same sovereign powers as states to require reporting on their citizens, have not been able to access data directly in most cases, and have needed to rely on data-sharing agreements with states. The availability of data has depended on the relationship between state and Tribe, state laws that may limit data sharing, and Tribal access to data reporting systems. Despite having the same rights and responsibilities as states to mandate disease reporting, Tribes have been left out of national surveillance systems and have been limited in their ability to set up their own disease surveillance systems. For example, while Tribes are public health authorities, they have not been included in many prior models of data reporting flow, likely due to their historically minimal role in disease surveillance (**Figure 2**). Furthermore, Tribes may choose to enlist the help of a Tribal Epidemiology Center (TEC), a regional organization that has been granted public health authority for the purposes of receiving Health Insurance Portability and Accountability Act (HIPAA) protected data to assist a Tribe in epidemiological and other public health activities. TECs have not been included in historical models for data flow (**Figure 2**).

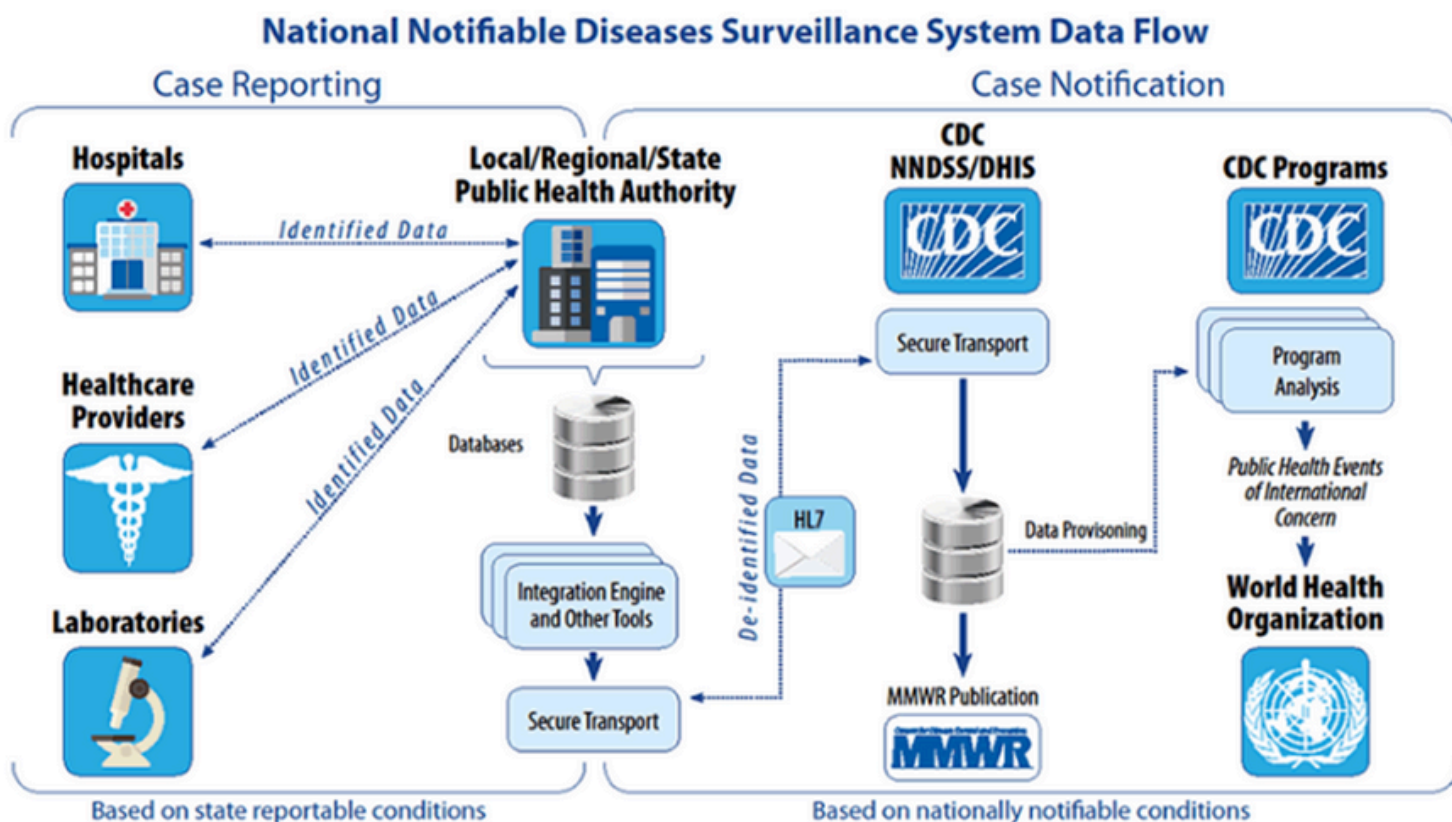
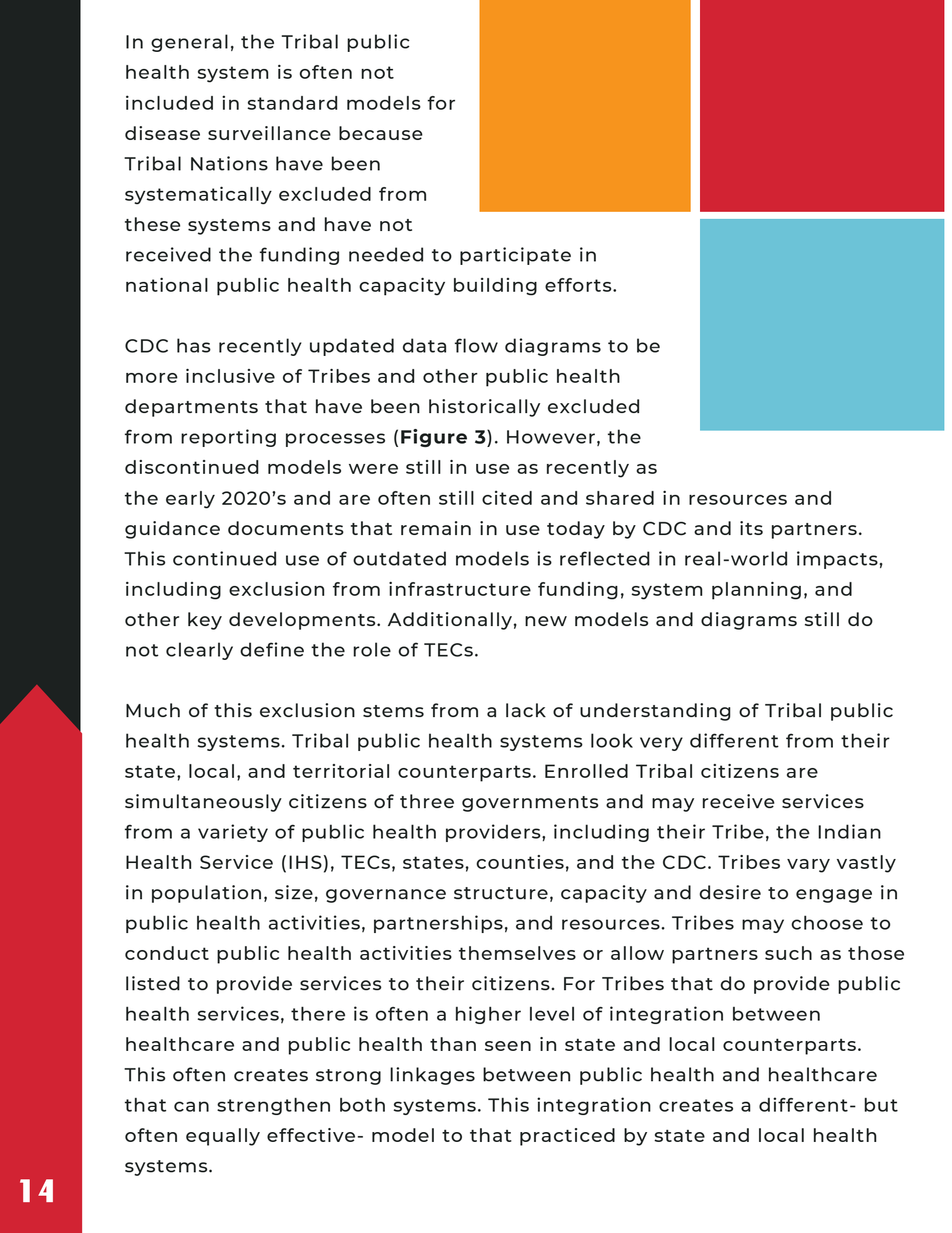


FIGURE 2: NATIONAL NOTIFIABLE DISEASES SURVEILLANCE SYSTEM DATA FLOW (DISCONTINUED VERSION)[V]

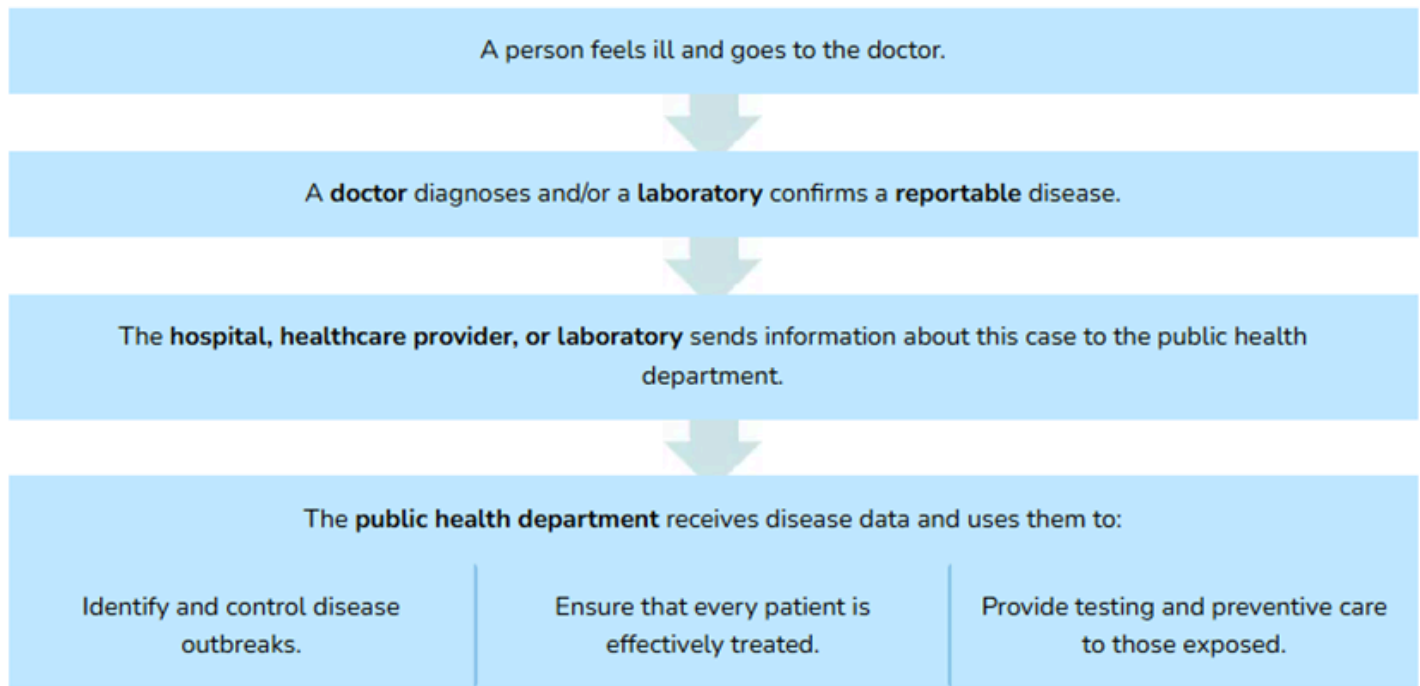


In general, the Tribal public health system is often not included in standard models for disease surveillance because Tribal Nations have been systematically excluded from these systems and have not received the funding needed to participate in national public health capacity building efforts.

CDC has recently updated data flow diagrams to be more inclusive of Tribes and other public health departments that have been historically excluded from reporting processes (**Figure 3**). However, the discontinued models were still in use as recently as the early 2020's and are often still cited and shared in resources and guidance documents that remain in use today by CDC and its partners. This continued use of outdated models is reflected in real-world impacts, including exclusion from infrastructure funding, system planning, and other key developments. Additionally, new models and diagrams still do not clearly define the role of TECs.

Much of this exclusion stems from a lack of understanding of Tribal public health systems. Tribal public health systems look very different from their state, local, and territorial counterparts. Enrolled Tribal citizens are simultaneously citizens of three governments and may receive services from a variety of public health providers, including their Tribe, the Indian Health Service (IHS), TECs, states, counties, and the CDC. Tribes vary vastly in population, size, governance structure, capacity and desire to engage in public health activities, partnerships, and resources. Tribes may choose to conduct public health activities themselves or allow partners such as those listed to provide services to their citizens. For Tribes that do provide public health services, there is often a higher level of integration between healthcare and public health than seen in state and local counterparts. This often creates strong linkages between public health and healthcare that can strengthen both systems. This integration creates a different- but often equally effective- model to that practiced by state and local health systems.

Case Reporting



Case Notification

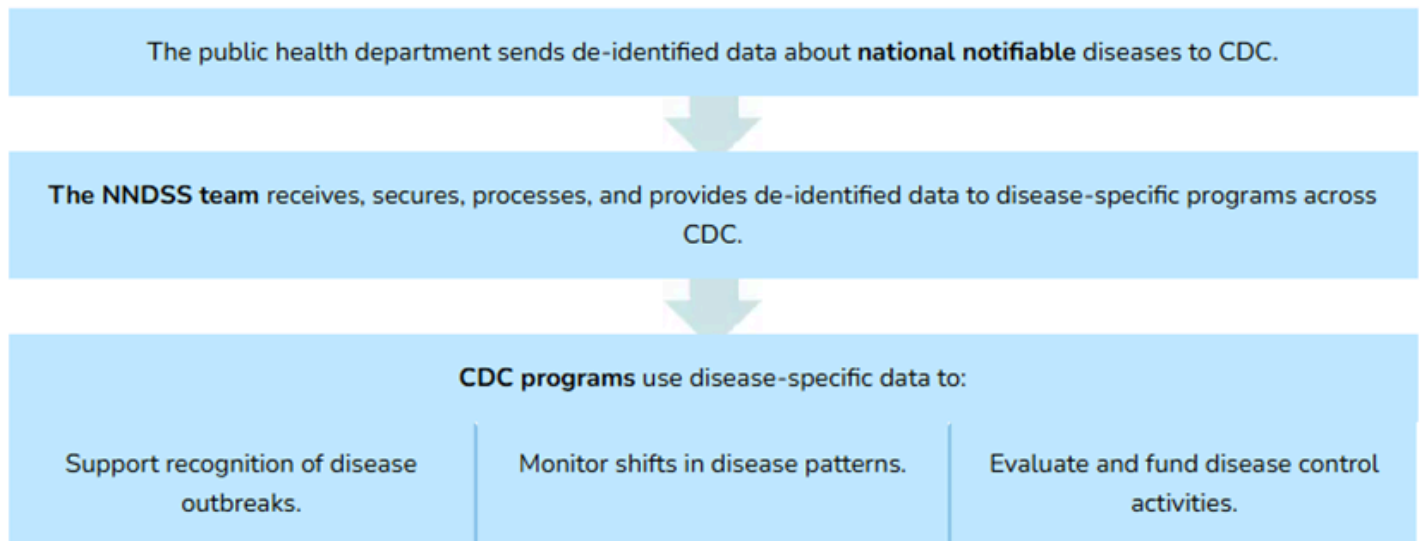
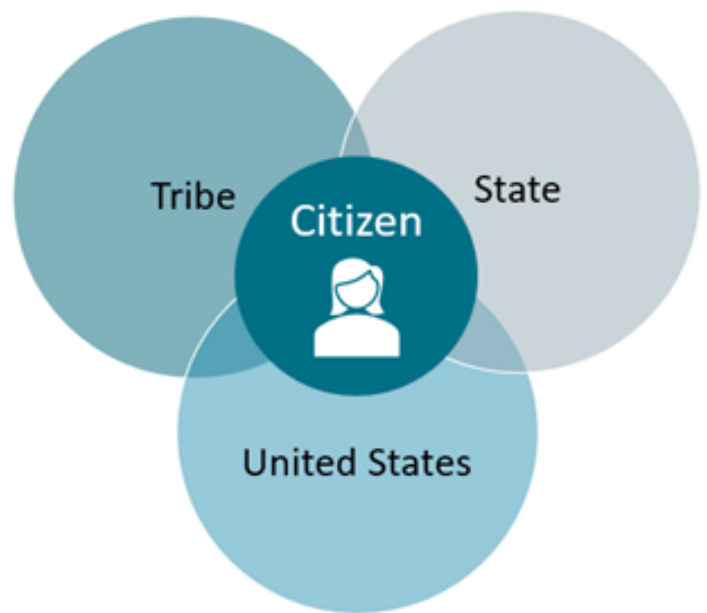


FIGURE 3: UPDATED NATIONAL NOTIFIABLE DISEASES SURVEILLANCE SYSTEM DATA FLOW[VI]

Furthermore, the United States federal government as a whole has a Trust Responsibility to Tribal Nations, and it is the responsibility of the federal government to provide health services to Tribal citizens while honoring Tribal sovereignty.

Despite these challenges fitting into the “standard” health department model, Federal Indian Law is clear that Tribes are jurisdictional public health authorities (**see Supplement I: Understanding Tribal Public Health Authority**). As such, and despite these challenges, many Tribes have chosen to exercise their rights to require reporting from providers, engage in case investigations, and take measures to prevent infections within their jurisdiction (**see Appendix II: Tribal Laws Pertaining to Disease Surveillance and Response**). To meet these challenges and improve Tribal access to their data, electronic case reporting (eCR) is one proposed and promising solution to ensuring Tribal data sovereignty.



What is eCR?



Historically, case reports and lab reports for reportable diseases were sent from healthcare providers and laboratories to public health authorities using patchwork and disconnected systems. The actual processes for reporting varied by jurisdiction and

relied heavily on healthcare provider and laboratory awareness of and compliance with jurisdictional reporting requirements. Methods of transmission could include electronic reporting systems, secure web portals, fax, secure email, phone, and mail communication depending on a jurisdiction’s requirements and information technology capacity. Public health agencies often received incomplete information, and needed to follow up with the provider, delaying data sharing. Additionally, the provider did not receive real-time feedback on a patient, reducing their ability to be a strong partner in preventing disease, and the public health agency was required to manually enter data, limiting the time health staff could spend on responding to a health concern [vii].

This siloed and disjointed system of case reporting often led to inconsistencies in surveillance capabilities across jurisdictions and could cause delays in receiving vital information on emerging public health threats. Ultimately the COVID-19 pandemic demonstrated the inability of the public health system to rapidly detect and respond to threats to community health and sparked needed nationwide efforts to invest in data modernization for public health systems. In particular, COVID-19 highlighted the exclusion of Tribes from the larger public health system. American Indians and Alaska Natives were disproportionately impacted by COVID-19, and Tribes and TECs faced significant struggles accessing the necessary data to combat the pandemic through existing surveillance infrastructure. eCR is one of the key initiatives proposed to modernize public health data surveillance systems and improve equity for Tribal public health infrastructure.

eCR is the automated, real-time exchange of disease case report information between healthcare providers' electronic health records (EHRs) and public health agencies. eCR is a tool that public health authorities can use, according to their needs, interests, and policies to receive immediate data on reportable diseases and possible outbreaks. eCR securely transfers patient and clinical information from healthcare providers to public health for disease tracking, case management, and contact tracing.

How Does eCR Work?

eCR securely transfers data from EHRs to public health agencies. When patients are diagnosed with a reportable condition, this triggers the automatic creation of a report within a healthcare provider's EHR. This report is sent automatically, and in real-time to the public health agency or agencies to which it is reportable through a secure connection. This connection is facilitated by a centralized platform that allows communication between healthcare and public health systems.

Jurisdiction is determined by ZIP code- both that of the healthcare center where a patient is seen, and the residence address of the patient. Any time a report is triggered, a reportability response is sent back to the provider stating whether or not the case was found reportable and if it was, for what conditions and to what public health agency or agencies. The public health agencies to which the case was reported also receive a copy of the reportability response. The public health agency can then transfer the data to their own data storage and disease surveillance systems and proceed with any actions necessary to address the case. Public health agencies can pre-set condition-specific information to be sent back to healthcare providers in the reportability response, such as providing a link to a webpage containing information associated with the case report.

eCR eliminates the burden of healthcare providers having to manually report cases while enabling them to send out more detailed and complete information. It is important to note that the data reported through eCR is the “minimum necessary” needed for public health action, as determined by the Council of State and Territorial Epidemiologists (CSTE). Because eCR is automatic, it does not rely on individual provider knowledge on various jurisdictional requirements. eCR also strengthens the partnership between healthcare and public health, as providers are notified in real time if a patient's condition is reportable and can assist in outbreak prevention measures [viii].

eCR implementation is a joint effort between the Association of Public Health Laboratories (APHL), CSTE, and the CDC. There are two main platforms that enable eCR for public health agencies nationwide. More information on these platforms is described in the following section.



How Does eCR Work?

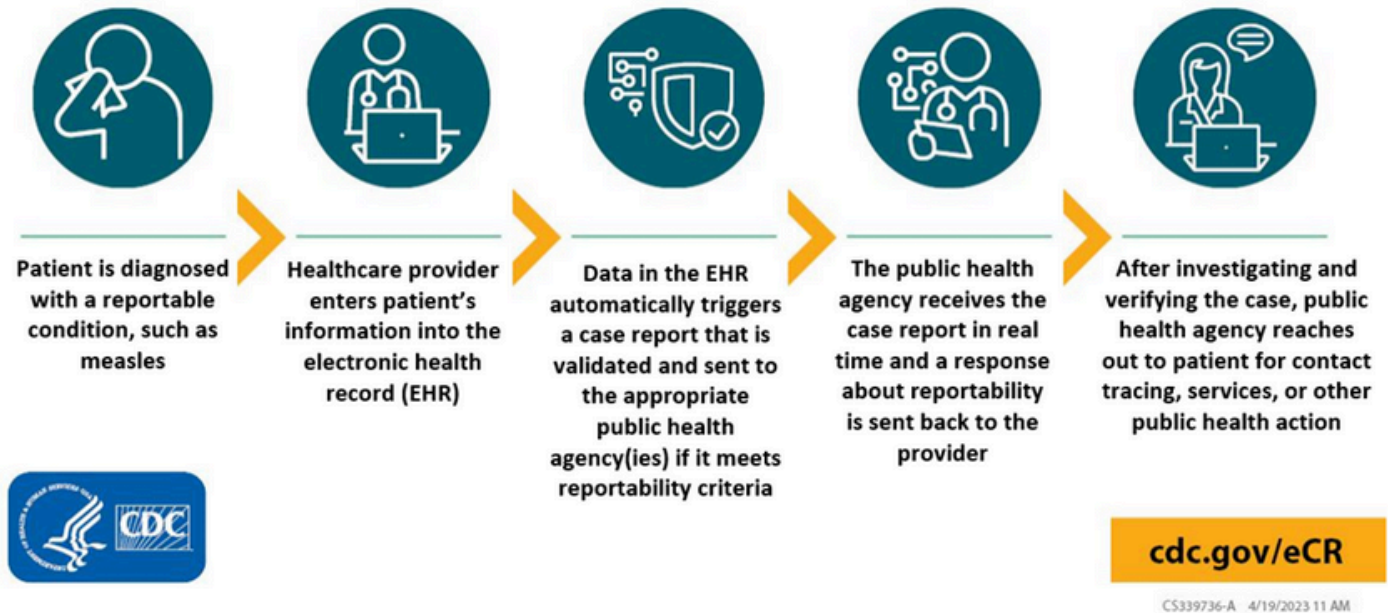


FIGURE 4: CDC GRAPHIC DEMONSTRATING BASIC FLOW OF DATA THROUGH ECR [IX]

APHL Informatics Messaging Services Platform

APHL hosts and manages the APHL Informatics Messaging Services (AIMS) platform. AIMS is:

“...a secure, cloud-based platform that accelerates the implementation of health messaging by providing shared services to aid in the visualization, interoperability, security and hosting of electronic data [x].”

AIMS is a centralized platform where messages are routed, and information is exchanged. AIMS supports a number of data exchanges including the eCR platform used between healthcare providers and public health authorities in the United States. AIMS allows for interoperability across different data transport protocols.



For eCR, both the healthcare provider and public health agency have a connection to the AIMS platform. When a condition triggers a report in the healthcare provider’s EHR, an electronic initial case report (eICR) is sent to the AIMS platform. If it meets the reporting requirements of a jurisdiction, it will be transferred to the public health agency through a secure connection, while a Reportability Response (RR) will be transferred both back to the provider and the public health agencies to which the case is reportable through AIMS (**Figure 5**). A decision support engine- the Reportable Conditions Knowledge Management System (RCKMS)- is hosted on and interfaces with AIMS and determines if a case meets the reporting requirements for a specific jurisdiction and generates the RR.

Reportable Conditions Knowledge Management System

RCKMS is a system hosted and managed by CSTE. RCKMS is:

“...an authoritative, real-time portal to improve disease surveillance. RCKMS stores comprehensive information on public health reporting requirements and acts as a decision support service (DSS) to determine if a potential case is reportable and to which jurisdiction(s) [xi].”

Public health agencies connect to RCKMS to “author” or input the reporting criteria as decided by their jurisdiction. As public health



authorities, each jurisdiction has the right to determine what qualifies as a “case” within their jurisdiction. Typically, existing laws and other legal requirements in a jurisdiction determine what cases are reportable. RCKMS does include templates and “default” reporting criteria for diseases. Within the framework of existing laws and legal case reporting requirements, public health authorities must determine, through the RCKMS platform, the jurisdictional criteria they will use to determine if a case is reportable to them.

Once authored, reporting criteria are stored in a database called the knowledge repository and deployed to the DSS. Since RCKMS is hosted centrally on the AIMS platform, when an eICR is sent to AIMS, the RCKMS DSS evaluates if the eICR meets reportability requirements by calling upon the knowledge repository (**Figure 5**) [ix].

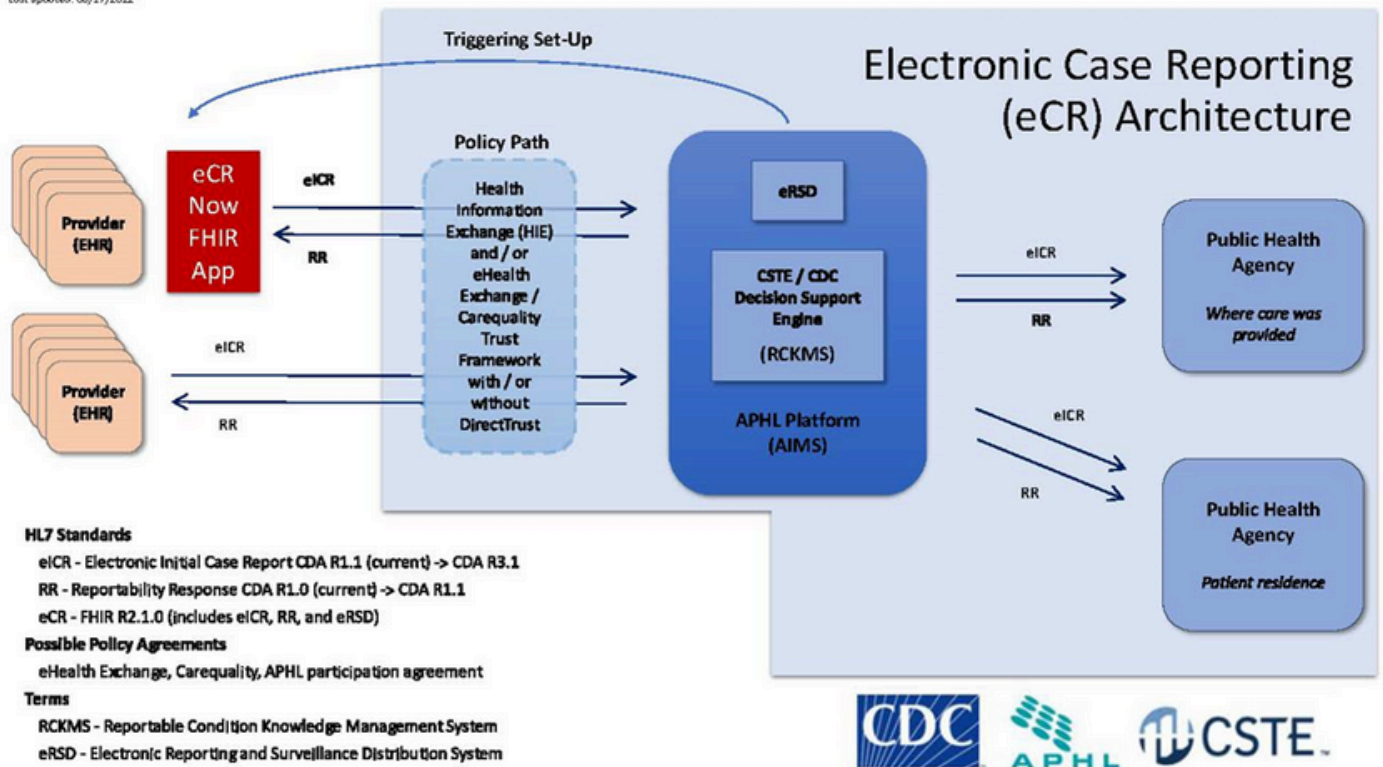


FIGURE 5: CDC GRAPHIC DEMONSTRATING FLOW OF DATA THROUGH AIMS PLATFORM FOR ECR

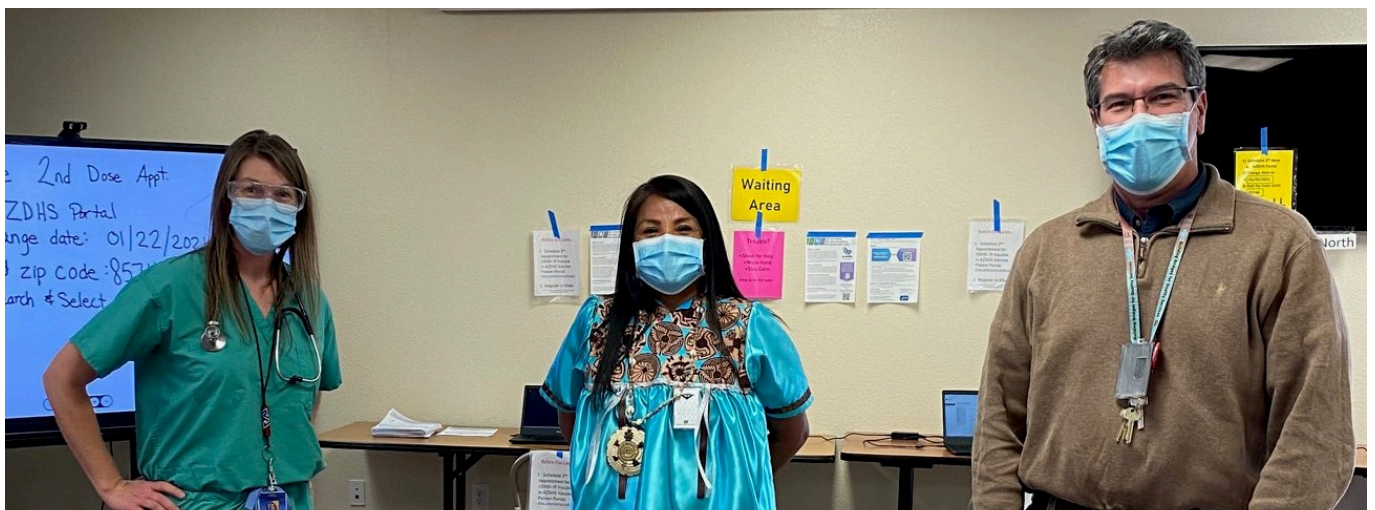
Role of the Healthcare EHR System

An EHR system that is correctly set up to report to an eCR platform is a necessary component of successful case reporting. Trigger codes are set up directly within an EHR and are necessary to generate and transmit an eICR to the AIMS platform. EHR implementers subscribe to get notifications of updates to the trigger code parameters. Based on the specific reporting requirements of a condition, triggers can include orders for certain laboratory tests, diagnosed or suspected diagnoses, lab results received by a provider, or when certain medications are prescribed [xii].

The successful public health applications of eCR depend on EHR systems to trigger, create and send eCR documents, and receive reportability responses or to integrate with the eCR Now FHIR app [i] for products that don't have inherent eCR capabilities. A list of EHRs that are ready for healthcare organization onboarding to eCR can be found at <https://www.cdc.gov/ecr/php/getting-started/index.html>.

Healthcare organizations utilizing EHR systems with eCR capabilities or the FHIR app will need to enable eCR and connect to AIMS. This is a key step for Tribal healthcare facilities, as public health authorities only receive eICRs from healthcare facilities currently connected to eCR.

For Tribes and TECs, this is something to consider when determining if eCR is right for your organization. Tribes should determine which healthcare systems are most likely to see patients who are within the Tribal jurisdiction. As jurisdiction is determined by ZIP code (where care is provided and where a patient resides) Tribes should consider both clinics on Tribal land, and healthcare clinics that frequently see patients who reside on Tribal land. If these healthcare organizations are not eCR enabled, Tribes may want to 1) work with or encourage the clinic(s) to onboard to eCR if the EHR system is compatible, or 2) provide the clinic(s) alternate methods of reporting data (fax, secure message, phone, etc.) as a temporary measure to ensure data is not missed. Tribes should also note that the IHS Resource and Patient Management System (RPMS) is not currently compatible with eCR. IHS is currently in the process of modernizing its EHR system.[xiv] Tribal clinics using RPMS will need to use alternative reporting methods to the Tribe.



Why Should Tribes and TECs Connect to eCR?

eCR Empowers Tribes

Historical methods of disease surveillance have been particularly challenging for Tribes and TECs and have contributed to the large inequities in data access. Traditional methods rely on provider knowledge of reporting requirements for their jurisdictions and the jurisdiction of their patients. Combined with the fact that many Tribes have not had publicly available jurisdictional reporting requirements, healthcare providers tend to report to local and state public health agencies. As such, states are the default recipients and managers of public health surveillance data. Tribes and TECs often have had to create direct agreements with states in order to access disease surveillance data. These agreements depend on the will of the state in question, and the relationship between state and Tribe or TEC.

Tribes and TECs have had similar challenges with accessing their data from federal sources. While the federal government may hold some data of interest to Tribes, a 2022 Government Accountability Office (GAO) report found federal agencies have withheld data from TECs [xv].

eCR offers a real opportunity to overcome these barriers. Because eCR is automatically routed via ZIP code to all relevant public health authorities simultaneously, this eliminates the status quo of states being the holders of Tribal data and the subsequent delays- and complete blocking- of Tribal access to jurisdictional data. Therefore, eCR can potentially be an important tool towards achieving data sovereignty [xvi]. Ultimately, eCR can give Tribes and TECs the tools needed to take charge of their public health systems and make decisions for the health of their people.

As Stephanie Jay, Turtle Mountain Band of Chippewa Public Health stated,

"Electronic case reporting will greatly improve the communication between healthcare providers and our Tribal public health department, and the real-time data will provide a timely response to potential outbreaks that can improve health equity. Access to Tribal member health data is crucial for public health's efforts to respond to detection of disease, surveillance, investigation, and response [xvii]."

eCR Will Continue Improving for Tribal and TEC Use

Tribes and TECs should consider that eCR will not eliminate all challenges. There are several remaining limitations that Tribes and TECs should consider when onboarding to eCR.

- Not all health care provider EHRs are reporting to eCR, including Tribal healthcare providers using systems that have not onboarded or that are not compatible with eCR (such as RPMS).
- ZIP codes do not always match with Tribal lands and determining which ZIP codes will be sufficient/ appropriate is challenging.
- Tribal citizens may live outside of Tribal lands, and the usage of ZIP codes will not allow Tribes to collect all cases of a disease in Tribal citizens.

Because of these challenges, eCR is not currently a perfect solution to data challenges, and Tribes and TECs would still benefit from developing data sharing agreements with state and local governments in tandem with eCR. However, it is expected that over time, improvements to eCR will address these challenges.

Regarding EHR reporting and compatibility with eCR, more and more health clinics are onboarding to eCR. Additionally, IHS's data modernization initiative creates the opportunity for Tribes that choose not to implement their own private EHR system to connect in the future.

In regard to ZIP code limitations, CDC, CSTE, APHL, NIHB, and Tribal organizations and leaders across the country are in conversations about how to improve routing of data. Proposals have included adding Tribal enrollment as an EHR data field (this is slated to be a required standard by the end of 2025), using better methods of geographic mapping that reflect the true barriers of jurisdictions, or increasing the number of ZIP codes Tribes and/or TECs receive data from and allowing these Tribal public health authorities to compare data received against enrollment records and delete non-Tribal data securely. These discussions remain ongoing, and a final solution has not been proposed.

Despite these challenges, eCR provides immediate benefits in getting Tribes and TECs data they may not have otherwise received. Additionally, by gaining access to eCR over the next few years, Tribes will be ready to receive more complete data as healthcare reporting and routing procedures catch up to the public health innovations.

eCR vs. ELR

eCR is specifically used to describe case reports that transfer between healthcare EHRs and public health agencies. This encompasses hospital systems, health clinics, and other healthcare providers. However, laboratories are also often required to report conditions of public health concern. This can be done through electronic laboratory reporting (ELR), the immediate transfer of data between laboratories and public health authorities. eCR is not meant to replace ELR, but rather to supplement this. While ELR may provide early or supplemental notification of a case, public health authorities have always needed to receive information from healthcare providers to be able to ascertain risk and contact the patient. eCR is one of multiple tools that can be used to receive more complete and timely public health data.



MAPPING THE ECR IMPLEMENTATION PROCESS

eCR Roadmap for Tribes and TECs: Mapping the Overall eCR Process

Pre-Implementation

eCR Implementation Steps

Contemplating eCR Implementation

*

*

Planning for eCR Implementation

1

Public Health Authority Designation

Initiate eCR with CDC

2

3

Establish SFTP/S3 Connection to AIMS

4

Develop Reportable Conditions Rules and Guidelines

5

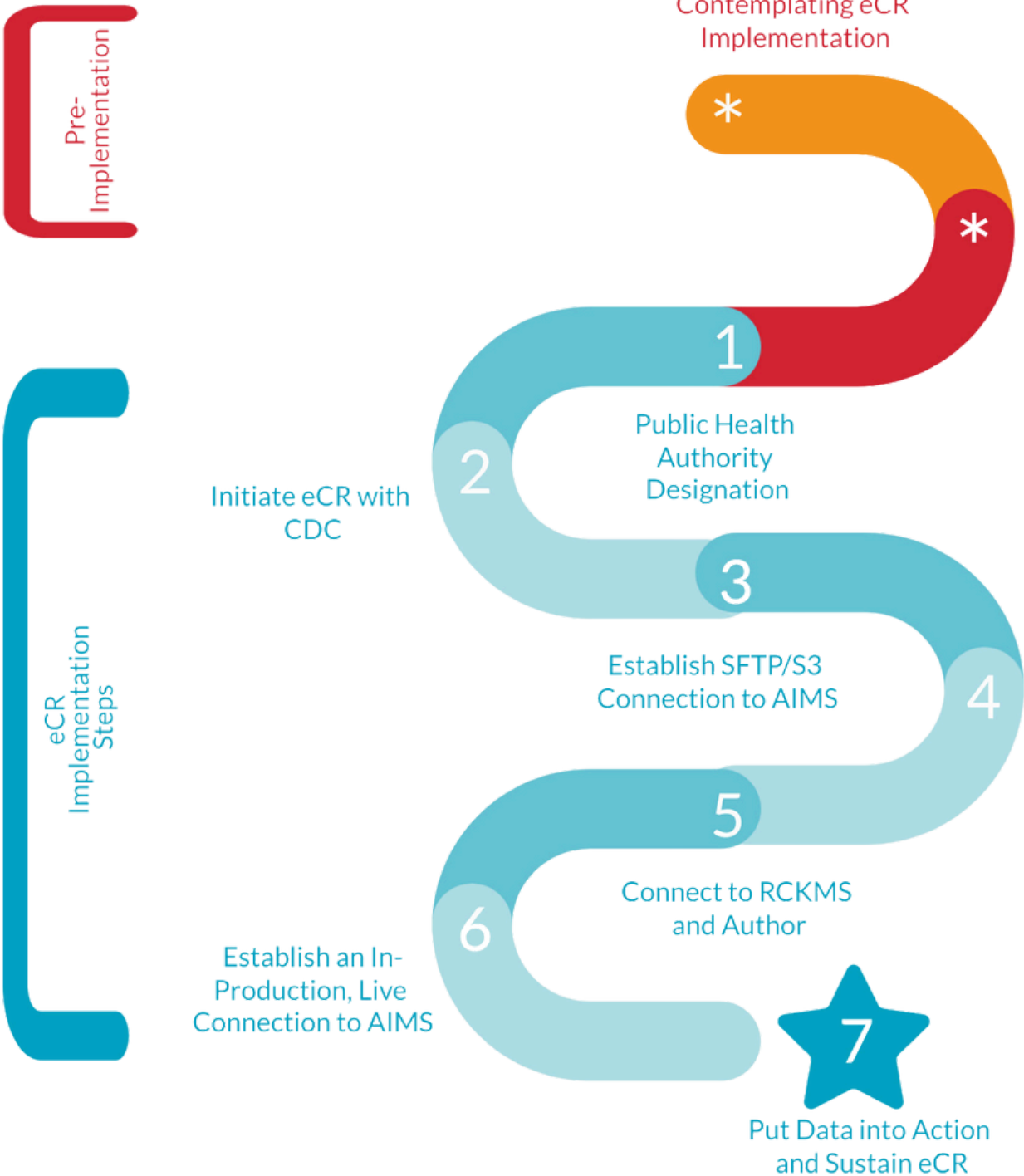
Connect to RCKMS and Author

Establish an In-Production, Live Connection to AIMS

6

7

Put Data into Action and Sustain eCR



CONTEMPLATING ECR IMPLEMENTATION

First and foremost, to implement eCR, Tribes and TECs, like other public health authorities, have to carefully contemplate and make determinations regarding their readiness and capacity to initiate, launch and maintain eCR.

Is a Direct eCR Connection Right for Your Tribe or TEC?

Considerations for Direct eCR Connection through AIMS for Tribes and Tribal Epidemiology Centers



Purpose in Connecting to eCR



Capacity to Connect to eCR



Capacity to Use eCR Data



Alternatives to Direct eCR

Tribes vary considerably in their capacity and interest in carrying out public health activities. Some Tribes may rely on partnerships to carry out public health services such as disease surveillance, including but not limited to state and local public health organizations and TECs. Others may carry out public health surveillance activities themselves or in consortium with other Tribes.

TECs also vary widely in their capacity and interest in supporting disease surveillance.

As TECs serve Tribes in their Area, each TEC will need to work with Tribes in their region to determine the best method of support. Some options for TECs could include 1) connecting to eCR to provide surveillance services to Tribes in their Area, 2) connecting to eCR in order to create a central data repository for Tribes and then sending data to each individual Tribe, or 3) not connecting to eCR, but providing technical assistance to Tribes on conducting surveillance. The services requested might differ Tribe-by-Tribe or may be agreed upon by all Tribes within a TEC's service Area.

Tribal public health authorities choosing to implement eCR through the AIMS platform should generally consider 1) their purpose in connecting to eCR, 2) their capacity to connect to eCR, 3) their capacity to use the data they receive for public health activities, and 4) the alternatives to a direct connection to the AIMS platform for eCR.

Purpose in Connecting to eCR: Tribes may benefit from eCR if they already are engaged in public health surveillance activities and wish to increase their capacity to conduct surveillance for one or more health conditions independently. Alternately Tribes may benefit from eCR if they do not currently conduct surveillance but are interested in starting to take over these functions. TECs may benefit from eCR if they have been asked to assist Tribes in collecting and/or using public health surveillance data, particularly if they or the Tribes they serve struggle to get access to this data through other mechanisms. TECs may also benefit from this data if they, in partnership with Tribes, have specific diseases that they are interested in monitoring across various Tribes in their region.

Capacity to Connect to eCR: Considerations for Tribes and TECs include their ability to secure funding, their IT systems capabilities, legal support in navigating the initial connection, the expected number of cases that will be reported in their jurisdiction, and the size of the data storage system needed.

Capacity to Use Data: Considerations for Tribes and TECs includes staffing, IT and infrastructure capacity to act on public health data, laws, policies, and ordinance related to disease prevention, surveillance, and control, and leadership support for public health activities.

Alternatives to Direct AIMS Connection for eCR: Tribes and TECs may consider alternatives to a direct connection to AIMS for eCR. Some Tribes may choose to have partners such as state and local health organizations engage in surveillance activities and may choose not to receive the data themselves. For Tribes or TECs that conduct or wish to conduct their own surveillance, some may have data sharing agreements with state and/or local public health organizations or be considering such agreements. These agreements can include access to state and/or local eCR data, or even access to state and/or local surveillance systems. For some Tribes and TECs, this access may be sufficient for receiving real-time data, and they may decide that a direct AIMS connection for eCR is not necessary for receiving public health data.

Others may decide that, despite data sharing agreements or access to state/local eCR data, they may still wish to directly receive their own data. Finally, some Tribe and TECs may face more difficulty in receiving data from state or local public health organizations and may need to directly connect to eCR to ensure that they have access to their own data.

PAUSE!



There is more than one way to receive eCR data! Consider what works best for your Tribal public health authority.

Assessing Your Organization's Capacity for eCR

Tribes and TECs may wish to formally assess their readiness for creating a direct eCR connection through AIMS prior to pursuing an implementation project.

Readiness Assessments are an important, systematic tool for determining if your Tribe or TEC has the infrastructure, including support, knowledge, and buy in to engage in a new initiative. Currently, there are no known readiness assessment frameworks specifically for the purposes of eCR implementation/data modernization.

The Community Readiness Model (CRM) created by Colorado State University researchers in the 1990s [xviii], has been previously adapted and used successfully by Tribes to determine their readiness for public health accreditation and to engage in capacity building efforts [xvi]. It is worth considering that an adaptation of the CRM for Tribes, and TECs planning to implement eCR, can provide a useful and systematic way of determining the Tribal/TEC readiness to begin the eCR implementation process. The CRM is particularly useful for Tribal public health authorities, as it focuses on the underlying factors that can lead to success and promotes a high level of community ownership in each public health initiative. See **Appendix IV: eCR Implementation Readiness Model** for more information on adapting the CRM.

Regardless of the strategy employed to determine readiness for eCR implementation and broader data modernization initiatives, careful consideration to assess institutional status and capacity in the following areas will be necessary, in preparation for the subsequent planning phase (**Figure 6, Pg 30**):

- Support from Tribal Governing Bodies (including Tribal councils, executive leadership, and/or health organization leadership)

- Sustainable funding source(s)
- Sufficient staffing or capacity to create necessary positions
- Information technology (IT) infrastructure and resources
- Legal support to assist in considerations related to designating public health authority, navigating jurisdictional overlap between Tribal public health authorities and other jurisdictions, and understanding Indian Law pertaining to data sharing and public health authority
- Partnerships, including those at the state, local and Tribal/TEC-level
- Capacity, and processes in place for using data for public health action



PLANNING FOR ECR IMPLEMENTATION

As a Tribe, TEC or Tribal public health organization moves from contemplating and making determinations regarding their readiness and capacity to initiate, launch and maintain eCR, they can begin the process of planning for eCR implementation. Tribal public health organizations should have several plans in place prior to formally onboarding to eCR. These plans will assist in strengthening the organization's capacity for success in the eCR onboarding process by addressing the underlying factors discussed in the Contemplating eCR Implementation section of the eCR Roadmap (**Figure 6**).



FIGURE 6: UNDERLYING FACTORS TO ADDRESS WHEN PLANNING FOR ECR IMPLEMENTATION

Support from Tribal Governing Bodies

Tribal public health authorities connecting to eCR may have to complete certain requirements to receive case reports. For Tribes, this may include ensuring that the entity receiving data is clearly defined as being the designated public health authority by the Tribe's governing body (i.e. designating the Tribal public health department or health center as a public health authority through a Tribal resolution). For TECs, this may involve having the approval of Tribes for whom they will be receiving identifiable information. For both Tribes and TECs, there should be appropriate laws, codes, ordinances, or policies indicating which conditions are reportable for healthcare providers in their jurisdiction xix. Additionally, Tribal public health authorities will need the governing body to support sustainable funding for costs associated with eCR implementation and disease surveillance.

Tribal public health authorities should create a plan to assess Tribal leaders' priorities, educate Tribal leaders on eCR and disease surveillance, and ensure there is the buy-in necessary to receive the necessary resolutions early in the process of pursuing an eCR connection.

Tribes may also want to clearly outline which public health authorities make which decisions regarding disease surveillance. For example, a Tribe may require that the Tribal council makes all decisions regarding disease reportability. Alternatively, the Tribal council may grant the power to pass ordinances regarding reportability to the governing body of the entity connected to eCR (i.e. the health board governing a Tribal public health department).

Sustainable Funding and Budget

eCR implementation requires that Tribes and TECs identify a funding source prior to engaging in a connection. Programs looking to connect should expect higher upfront costs associated with implementing a new system, and ongoing costs associated with maintaining an eCR connection. There are ongoing costs to conducting surveillance, so Tribal public health authorities may want to consider how to create a sustainable source of revenue for the program, including the use of internal funding sources.

Common costs for eCR implementation and maintenance may include:

- Staff or consultant salaries
- Training costs
- Meeting costs
- IT equipment
- Conference and travel fees

Grant Funding Opportunities

For Tribal public health authorities without internal sources of funding for eCR, grants remain one of the most available opportunities for public health organizations- including Tribes and TECs- to engage in modernization efforts for eCR. Tribes considering connecting to eCR may wish to apply for grants to support these efforts if they do not have the internal revenue to cover the costs. The following information identifies several organizations that may offer funding through grants:

National Indian Health Board: NIHB, through a cooperative agreement with the CDC, has previously offered funding specific to eCR implementation, as well as general public health infrastructure funding. NIHB expects to continue to offer annual funding for eCR through 2029, pending continued funding from CDC. Sign up for our newsletters below to receive updates about any future funding. NIHB shares funding announcements from our partners, NIHB funded opportunities, and more.

Sign Up to Learn About Upcoming Funding Opportunities for DMI

NIHB regularly sends out grants and resources on data modernization through our newsletters and listservs:



[NIHB DMI Learning
Community Listserv](#)



[NIHB Newsletters](#)

Centers for Disease Control and Prevention: The CDC Data Modernization Initiative (CDC DMI), Epidemiology and Laboratory Capacity for Prevention and Control of Emerging Infectious Diseases (ELC) Cooperative Agreement, and Public Health Infrastructure Improvement Grant (PHIG) have supported significant data modernization investment in public health authorities across the United States. Unfortunately, Tribes have not participated in or been left out of many of these opportunities. CDC is working with NIHB and Tribal partners to increase the availability of their funding. At present, the CDC-RFA-TO-23-0001: Strengthening Public Health Systems and Services in Indian Country for Tribes and TECs serves as a primary source of CDC DMI funding for Tribes and TECs. As CDC continues to prioritize data modernization, Tribes and TECs should consider future opportunities to fund their eCR projects, and other DMI needs. Learn more at: <https://www.cdc.gov/surveillance/data-modernization/index.html>.

Indian Health Service (IHS): While IHS focuses on healthcare services, the organization does engage in some public health activities and has published prior funding opportunities for public health infrastructure. Learn more at: <https://www.ihs.gov/dgm/funding/>.

National Network for Public Health Institutes (NNPHI): NNPHI has announced that, in partnership with the Association for State and Territorial Health Officials (ASTHO) and the Public Health Accreditation Board (PHAB), they will subaward approximately \$23 million dollars for Tribal public health authorities to support activities related to data modernization, including eCR. This work will be supported by the newly established Tribal Data Modernization Implementation Center. Learn more at: <https://nnphi.org/focus-areas-service/public-health-infrastructure-grant-phig/>.

Tribal Epidemiology Centers: TECs may offer subawards and other financial support to Tribes related to a variety of capacity building efforts for public health. Learn more at: <https://tribalepicenters.org/12-tecs/>.

State health departments: Diseases do not recognize jurisdictional boundaries, and some states may offer funding to Tribal partners with bordering jurisdictions. Tribes can work with their individual state partner(s) to identify funding sources. While states have no jurisdiction within Tribal lands, states have received significantly more resources compared to their Tribal counterparts, and many understand the benefit of working together to strengthen surveillance in both jurisdictions.

Staffing

Building a strong public health workforce remains a challenge in Indian Country in the face of underfunding, instability of funds, and challenges in staff recruitment and retention due, in part, to the remoteness and limited resources of many Tribal Nations. Having a strong workforce is key to ensuring the success of eCR.

Key positions for eCR implementation and maintenance may include:

- Project support staff, which includes project directors, project managers, project coordinators, etc.
- Epidemiologists, data analysts and/or health informatics staff
- IT staff or consultants
- Legal counsel
- Operations staff, which includes those working in finance, human resources, and grants management.

Staffing Support Opportunities

A number of national organizations have programs dedicated to improving staffing capacity for public health authorities across the nation, including Tribes and TECs.

CDC Foundation: The CDC Foundation has previously supported two rounds of the Workforce Acceleration Initiative- an effort to provide expert staff to strengthen data systems in public health agencies across the country. CDC Foundation is interested in supporting Tribal health systems. Learn more at <https://www.cdcfoundation.org/workforceacceleration>.

Centers for Disease Control and Prevention: CDC hosts several programs to place public health professionals as field assignees to various public health organizations, including the Public Health Associate Program (PHAP). Tribal health departments have successfully hosted CDC fellows through several programs. Learn more at <https://www.cdc.gov/fellowships/php/host-sites/index.html>.

Information Technology (IT) Infrastructure and Resources

To ensure the necessary IT infrastructure and resources are in place for the launching and maintenance of eCR, Tribes and TECs should assess current capabilities and plan to acquire the following infrastructure:

- General hardware and equipment, i.e., computers, laptops, internal and/or external servers
- Data storage and security solutions
- Capability to establish and support the SFTP or S3 connection required for eCR
- Data management and analysis software



Legal Support

Acquiring and maintaining legal counsel and support throughout the eCR implementation process is essential to ensure that the legal stipulations and ramifications related to Tribal public health authority, and the secure exchange, storage and use of public health data are clearly outlined, understood and translated into sound institutional practices. Tribal public health authorities have noted that legal and policy barriers have been significant in delaying data access, and that Tribes and TECs face unique challenges to conducting surveillance and accessing data that are not faced by or well understood by their state and local counterparts.

Partnerships

Creating partnerships is a key component of eCR implementation. It is crucial for Tribal public health authorities that are in the process of implementing eCR to foster partnerships with the reporting healthcare organizations in their jurisdiction to effectively coordinate the necessary processes for effective data exchange. It can also be beneficial, and sometimes critical, for Tribal public health authorities implementing eCR to formalize partnerships with other public health institutions including TECs, AIHBs, and state and local health departments in their region to ensure adequate data sharing and coordination of public health processes and disease prevention activities.

Healthcare Organizations: Healthcare organizations are a required partner for successful eCR implementation, and surveillance in general. Healthcare organizations collect the data Tribal public health authorities need to successfully monitor and detect diseases of concern. To receive complete data through eCR, the healthcare organizations within your jurisdiction and organizations outside your jurisdiction that regularly see patients living within your jurisdiction must be onboarded to eCR. If they are not onboarded, they should report through alternative manual methods.

Tribal Data Modernization Implementation Center: Beginning September 2024, the Public Health Infrastructure Grant (PHIG) national partners expect to establish an implementation center with the purpose of serving Tribal public health authorities in pursuing data modernization projects, including eCR. The Tribal Implementation Center will be established with the goal of providing culturally appropriate technical assistance for data modernization projects. Learn more at:

<https://www.phinfrastructure.org/implementation-centers/>



Data-Use Plan

Tribes and TECs will need to consider the ways in which they will use the data received through eCR for the purposes of public health action.

Actionable ways in which eCR data can be used include:

- Public health data sharing between public health and healthcare institutions
- Public health data sharing across jurisdictions
- Disease surveillance and outbreak detection
- Direct field investigations for disease interventions, and treatment purposes

Having clearly established goals for the data a Tribal public health authority will receive through eCR is an important pre-condition to beginning to implement an eCR connection. This data-use plan will ultimately guide Tribes and TECs through decision making on what data they need to receive and assist them in creating messaging on why eCR is important for their organization.

Specific Considerations for TECs:

What else do TECs need to consider when planning for eCR implementation?

When planning for eCR implementation, TECs, as lawfully designated Tribal public health authorities for the purposes of receiving public health data, will need to exercise putting this authority into practice by establishing formalized data agreements with the Tribes within the region they serve, if none exist, and updating and enforcing those that do. TECs are regional institutions, spanning, not only multiple Tribes and reservations, but also multiple localities and states. For this reason, when implementing eCR, TECs need to be extra vigilant in fostering the necessary relationships and partnerships with the various entities in their region, including state and local health departments. These formalized partnerships will help in optimizing public health information and data sharing, and improve regional coordination of public health surveillance, and disease control and prevention activities.

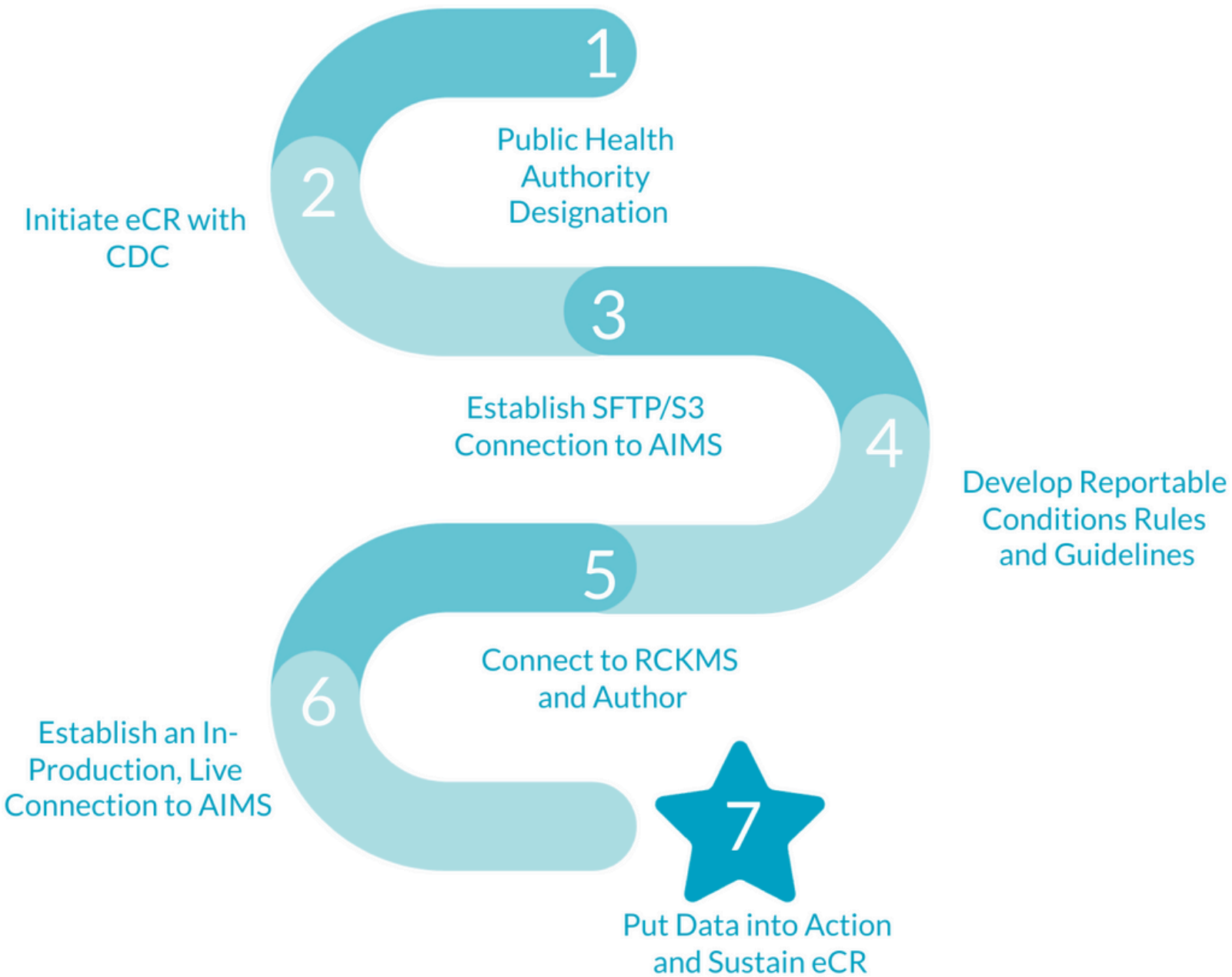
STEP-BY-STEP GUIDE FOR IMPLEMENTING A DIRECT CONNECTION TO ECR

The following steps can be used as a guide for jurisdictions who are planning on or are in the process of implementing a direct connection to the AIMS platform for eCR to send and receive public health data. The steps outlined are a representation of the most common sequence of activities that a Tribal public health authority would need to carry out to establish an eCR connection and begin sending and receiving the pertinent data for public health purposes. In practice, some of these steps can happen concurrently or in tandem with other steps, or even in varying order when implementing eCR. The steps are to be used as a guide, outlining the crucial steps and considerations necessary to securely establish and maintain eCR. Please note that, in this section, Tribal public health authorities refer to Tribes and the entities designated by Tribes to serve as public health authorities, and TECs. If a section refers specifically to Tribes or TECs, it will be clearly stated as such.



Detailed information on how the Tribal eCR Implementation Pilot Cohort connected, and their challenges, successes, and lessons learned can be found in **Appendix I: Key Informant Interviews with eCR Tribal Implementers.**

eCR Implementation Steps



Step 1: Public Health Authority Designation

In order for a Tribal entity to be set up to implement eCR, they would need to determine their public health authority designation. Tribes, by law, are inherently designated as Tribal public health authorities, and have the right to send and receive data for health care as well as public health purposes. For a detailed definition on public health authority as it relates to Tribes, refer to **Supplement I: Understanding Tribal Public Health Authority** within this document. It is important to note that Tribal public health authority is inherent and separate from existing state and local public health authorities in and around the Tribal boundaries. Tribal councils or Tribal health boards representing specific Tribes can also designate a health care organization or a public health department within their jurisdiction, as the public health authority to send and receive public health data and carry out disease prevention and control activities on the Tribe's behalf.

As a Tribe's governing body will generally assign public health authority to a Tribal entity such as a Tribal public health department, formal determination of public health authority may be established through a formal resolution process. This resolution should clearly approve and designate Tribal public health authority to a specified entity on behalf of the Tribe. In some cases, this formal process of public health authority designation can take several months and up to a year or more, depending on the Tribal jurisdiction (Please refer to **Appendix I: Key Informant Interviews with eCR Tribal Implementers** for further details and examples).

TECs are designated by Congress as public health authorities for the purposes of protected health information and are tasked with carrying out public health and disease control activities to support, and in consultation with Tribes. See the **Tribal Epidemiology Center Public Health Authority: Legal Basis** section in **Supplement I** of this document for further information on TECs and public health authority. In summary, TECs are "designated public health authorities" and, as a result, if the Tribe(s) in question deem it fit, TECs are lawfully able to send and receive data for health care and public health purposes. There may, however, be requirements for TECs to attest that they have the approval to receive data from their partnering Tribes.

Once Tribal public health authority is confirmed and necessary documentation/ attestations are in place, Tribes, or their designees and TECs can begin the process of implementing eCR in their jurisdiction, carrying out next steps in securing the appropriate and necessary connections to the public health data sources, determining their reportable conditions/cases, and establishing specific criteria on jurisdictional boundaries/ZIP codes that would render cases reportable to the Tribe or TEC.



Step 2: Connect with CDC's eCR Coordination Team to Initiate the eCR Implementation Process

After determining and ensuring Tribal public health authority status is in place, the process of eCR implementation can begin. To initiate the eCR implementation process, Tribes and TECs will communicate with the eCR coordination team at CDC to inform them of their intention to connect to eCR via email at ecr@cdc.gov. Once an email is sent to the CDC eCR team, CDC will communicate with the Tribe or TEC and inform them of the next steps required to prepare, set up and connect to eCR. The CDC eCR team will direct the Tribal staff to the required training, and facilitate connecting with the APHL AIMS platform and the CSTE RCKMS support staff charged with providing the necessary technical support and assistance to Tribal public health authorities seeking to establish and maintain eCR connectivity (**Step 3** and **Step 4** offer further details on the process of connecting to the AIMS and RCKMS platforms necessary for eCR).

Tribal public health authorities will need to designate the specific staff within their organization who will be granted secure access to the AIMS platform. This will usually include IT, informatics, epidemiological and/or management staff. Careful consideration should be made regarding which staff will gain and manage access to AIMS and the eCR data received through the platform.

Step 3: Establish an SFTP/S3 Connection to the AIMS Platform

An SFTP connection is a secure protocol that uses encryption to transfer sensitive data securely between two systems. Similarly, S3 is a secure and scalable web-based connection protocol serviced through Amazon Web Services (AWS). For successful eCR implementation, an SFTP or an S3 connection is necessary to connect and receive eCR data securely from pertinent health care organizations. Tribal jurisdictions implementing eCR will need to establish one of these connection types to receive and store eCR data securely and effectively.

Once established, the SFTP/S3 connection would need to be used to connect with the AIMS platform, the designated nationwide platform used for public health data exchange for eCR purposes. Tribal public health authorities must establish a secure connection to AIMS, with the assistance and coordination of their IT departments as well as APHL designated staff.



Step 4: Develop a Systematic Framework of Rules and Guidelines for Reportable Conditions to Govern the Exchange of eCR Data

While access and connection to AIMS is being established, and before connecting to RCKMS (find more details on RCKMS in **Step 5**), it is essential for Tribal public health authorities to systematically develop, outline, and make public detailed rules and guidelines that healthcare organizations sending eCRs. These guidelines should also include processes for providers who are not connected to AIMS or are using manual reporting mechanisms. The healthcare providers will use this Framework to adhere to jurisdictional reporting requirements as determined by the public health authorities.

In developing a systematic framework of rules and guidelines for case reporting and the exchange of eCR data, it will be necessary to:

- Determine what reportable conditions the Tribal public health authority will require. Considerations for selecting these include interest in the disease, the capacity of the Tribal public health authority to follow up with these conditions, and the capacity of the surveillance and disease intervention systems and mechanisms that are in place to enable this work. Tribal public health authorities can choose from conditions currently available in RCKMS for reporting with eCR; this list is regularly updated at <https://www.rckms.org/conditions-available-in-rckms/>.
- Establish or update Tribal rules (laws, ordinances, and codes) for reportable conditions specific to the jurisdiction of the Tribal public health authority. This should include guidance on what the jurisdiction considers “reportable” and what is considered a “case”.
- Determine what the Tribal public health authority will do with the eCR data on reportable conditions once received, and ensure legal mechanisms (laws, ordinances, and codes) and appropriate policies are in place to take this action. It may be necessary to receive internal legal counsel and engage with the legal representatives of the eCR coordinating institutions (APHL and CSTE) during the development of rules and guidelines/laws and codes for reportable conditions.
- Determine the geographical area (as currently defined by ZIP code) that will be designated as reportable to the Tribal public health authority. This may include shared geographical boundaries with local and/or state jurisdictions. It may be necessary to receive internal legal counsel and engage with legal representatives of the eCR coordinating institutions (APHL and CSTE) during the development of rules (laws and codes) for reportable conditions and in the designation of geographical criteria to use for jurisdictional reporting.
- Consider the proportion and capacity of healthcare providers/organizations in the public health authority’s jurisdiction that are already connected to or that could potentially connect to eCR.
- Develop a mechanism to ensure partnership and transparency between the Tribal public health authority and the healthcare providers/organizations from which they are receiving eCR data.
- Determine what partnerships and formal agreements need to be established with external entities to potentially assist with surveillance and disease intervention activities.

Any rules and guidelines for reportable conditions developed by the Tribal public health authority receiving eCR data should be clearly outlined and shared in such a way that the entities reporting can readily access and refer to them, to ensure transmission of data within the required parameters. In some cases, this may be in the form of a published list of the Tribal public health authority's reportable conditions posted on a public-facing website or document-sharing platform.

Many of the steps outlined above will be further outlined in **Step 5**, which involves operationalizing these decisions in RCKMS.

Specific Considerations for TECs:

What else do TECs need to consider when developing rules and guidelines for reportable conditions for eCR purposes?

As noted previously, TECs are regional institutions, spanning, not only multiple Tribes and reservations, but also multiple localities and states.

Because of this, when developing rules and guidelines for reportable conditions under eCR, TECs will need to take into consideration the laws and codes in place for reportable conditions for all the states in their region. Weighing out the similarities and differences among the states in what conditions are reportable is key. TECs will need to use this assessment to guide their own reportable conditions, which, in practice, would likely be a composite of the reportable conditions from each state in their region.

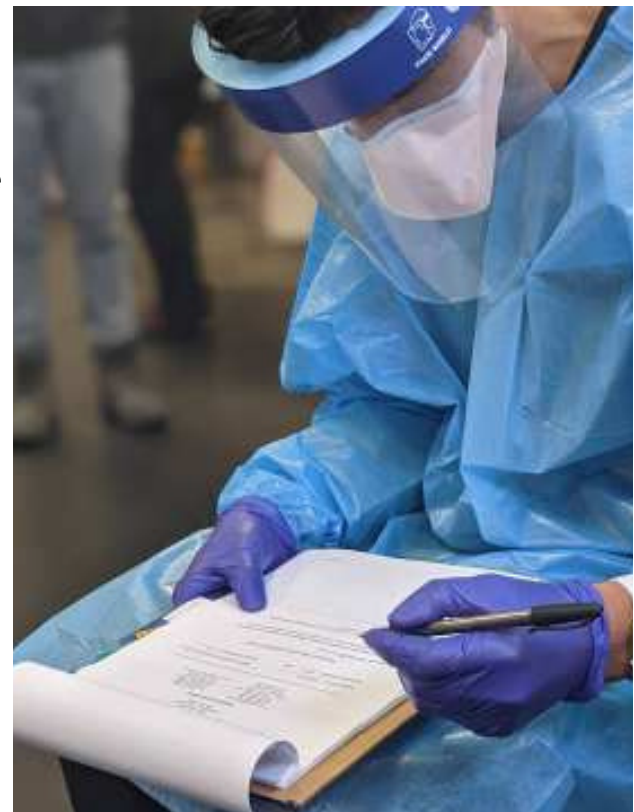
For Tribal jurisdictions, reportable criteria triggered by ZIP code can prove problematic, because Tribal boundaries do not neatly align with the conventional boundaries set by ZIP codes. For TECs specifically, this issue is complicated further by the regionally-defined, jurisdictional nature of TECs, which stretches across multiple states. TECs may need to seek legal counsel in carving out their jurisdictional criteria for eCR purposes, coordinate with APHL and the CSTE staff who administer RCKMS, and take into careful consideration, the pros and cons of casting a wide net or narrowing down the qualifying geographical criteria for the purposes of reporting under the eCR guidelines and infrastructure that they create.

Step 5: Connect to RCKMS and Author Reportable Conditions and Geographical Criteria

In addition to the SFTP/S3 connection to AIMS, Tribal public health authorities need to establish an RCKMS account, which is housed within the AIMS platform. Administered by CSTE, RCKMS is a tool developed to enhance surveillance by providing comprehensive information to clinicians, labs, and public health authorities about the “who, what, where, when, and how” of case reporting, and to deliver this information from healthcare providers to state, local, and Tribal public health entities, for eCR purposes [xviii]. RCKMS consists of three components: the Authoring Interface, the Knowledge Repository, and the Decision Support Service (DSS). Through all three of these components, public health authorities are able to input, edit, and manage case reporting criteria for their jurisdiction. The DSS, specifically, is linked to the electronic health record (EHRs) of the healthcare organizations reporting cases to public health authorities.

RCKMS is where Tribal public health authorities will make the Framework of Guidelines developed in Step 4 actionable for eCR. RCKMS allows jurisdictions to carve out the reportable conditions and geographical criteria to be used to trigger and initiate the eCR process from start to finish. For an overview of RCKMS please refer to the Background: Introduction to eCR for Public Health Surveillance section of this report [xviii].

In order to gain access to and use RCKMS for eCR implementation, Tribal public health authorities would need to do the following:



Step 5a. Connect with CSTE's RCKMS Team to Begin the Process of Authoring in RCKMS

Tribal public health authorities will need to connect with the RCKMS Team at CSTE to begin authoring in RCKMS. Authoring in RCKMS is the process by which public health agencies input, edit, and manage their jurisdictional reporting criteria, as developed in **Step 4** for eCR. The Authoring Interface in RCKMS is pre-populated with default reporting criteria defined by CSTE. Tribal public health authorities implementing eCR will use the RCKMS Authoring Interface to input the case reporting criteria and specifications relevant to their jurisdiction. CSTE will provide Tribal public health authorities with the training necessary to gain access and author in RCKMS. Tribal public health authorities will also need to designate specific staff who will be granted secure access and authoring capabilities in RCKMS.

Step 5b: Determine Jurisdictional/ZIP Code Criteria for Reporting in RCKMS

Tribal public health authorities need to determine their jurisdictional boundaries, as defined by ZIP codes. These ZIP codes will be used to route case reports to the appropriate jurisdiction(s). The jurisdictional boundaries and ZIP codes will depend on what the Tribal public health authority considers the geographical area minimally necessary for receiving data for effective public health and disease control activities. For some Tribes, the jurisdictions and associated ZIP codes being used to determine the cases they receive through eCR may coincide with the area within their Tribal land boundaries, while for others, this may include the area within and adjacent to their Tribal boundaries.

Once the ZIP code criteria for eCR have been determined, this will be input into RCKMS. RCKMS will use these criteria to dictate what geographical areas and conditions will result in the delivery of eCR to the Tribal public health authority. ZIP codes are a pre-requisite of connecting to RCKMS and authoring for conditions in the next step.

Specific Considerations for TECs:

What else do TECs need to consider when connecting to RCKMS and authoring their reportable conditions and geographical/ZIP code criteria?

For TECs, determining the minimum necessary ZIP codes to define their jurisdiction is more complex. TECs that are designated to receive eCR data on behalf of Tribal partners may need data for only specific Tribes, may need data for all Tribes in their region, or may potentially determine the need to cast a wider net and include larger areas that go well beyond the Tribal boundaries. For TECs deciding to directly connect to eCR, legal counsel will be a key requirement when working with APHL, CSTE, and CDC to determine the appropriate jurisdiction. The appropriate jurisdictional boundaries will likely differ TEC by TEC based on existing relationships and data sharing agreements with their Tribal partners and their determination, in consultation with the Tribes of what constitutes the “minimum necessary” required to conduct their Tribal public health responsibilities. TECs should work closely with their Tribal partners to ensure that they have the necessary permission to access Tribal data.

Step 5c: Determine Criteria for Reportable Cases/Conditions in RCKMS

Tribal entities implementing eCR must determine the reportable conditions/cases that they will receive through this process. In order to do so, Tribal public health authorities need to assess and develop protocol for which reportable conditions and cases will be received through the secure eCR connection. What conditions and what criteria are used for case reporting will be dependent on the specific Tribal jurisdiction and what they deem necessary and suitable to carry out their public health authority and disease control activities. For instance, a Tribe or TEC may have limited staff as well as data storage and management capacity, so they may opt to only connect with eCR for two conditions, while a Tribe or TEC with much greater capacity may select several hundred reportable conditions under eCR. Please refer to **Step 4** for further details on this process. It is important to note, that the conditions reported to a Tribal public health authority are also directly dependent on which healthcare providers are connected to AIMS and eCR-capable, and on the conditions their EHRs are configured to trigger on for reporting through eCR.

Step 6: Establish an In-Production, Live Connection in AIMS to Receive eCRs

Once a Tribal public health authority has completed setup and testing of the SFTP/S3 connection to AIMS, and an active account in RCKMS has been created, jurisdictional boundaries selected, and reportable conditions authored, the Tribal public health authority can proceed from the test connection to the live, in-production connection to AIMS. Once connected to the AIMS production environment, the Tribal public health authority can begin receiving real-time reports from healthcare providers participating in eCR within their specified jurisdiction.

Step 7: Put Data Into Action and Sustain eCR

Data Storage and Analysis

Developing a detailed data analysis plan prior to implementing eCR and revisiting and updating the plan continually as needed is essential. Furthermore, once a Tribal public health authority begins receiving eCR data, it is paramount to assess organizational capacity, prepare for a potentially higher volume of eCR data files, and to devise plans to mitigate the resulting system slowdowns is paramount, such as managing high volumes of data through batching and scheduled archiving of files on a monthly basis, or increasing in-house data storage capacity.

Use of eCR Data for Public Health Action

It is important for Tribal public health authorities receiving eCR data to develop comprehensive plans to analyze and effectively utilize the eCR data received for disease control and prevention activities, contact tracing, disease quantification, community engagement, and the development of new and improved community/public health interventions. In doing so, careful consideration should be given to the Tribal public health authority's organizational capacity, level of funding, IT systems and infrastructure, disease patterns, and public health priorities.

Communicating with Healthcare Providers/ Organizations

It is important for Tribal public health authorities receiving eCR data to develop comprehensive plans to analyze and effectively utilize the eCR data received for disease control and prevention activities, contact tracing, disease quantification, community engagement, and the development of new and improved community/public health interventions. In doing so, careful consideration should be given to the Tribal public health authority's organizational capacity, level of funding, IT systems and infrastructure, disease patterns, and public health priorities.

Partnerships and Collaboration

Successful eCR implementation necessitates clear, consistent, and persistent communication with stakeholders, including educating personnel at various levels within the organization throughout the implementation process. Partnerships with state and local public health entities can prove very useful for Tribes and TECs in coordinating and optimizing the eCR implementation process and data modernization efforts for all public health players in a given geographical area, through formalized data sharing, exchange of best practices and lessons learned, and minimizing the duplication of effort for more efficient and effective public health action.



LESSONS LEARNED IN IMPLEMENTING ECR

NAVIGATING THROUGH THE CHALLENGES OF SETTING UP ECR

As Tribal public health authorities have pursued eCR connection, they have faced a number of challenges and roadblocks along the way. Tribes and TECs have tackled these challenges head on and explored possible solutions. As more Tribal public health authorities pursue these challenges, the lessons learned from the Tribal eCR Implementation Pilot Cohort may help them better navigate the specific barriers faced specifically by those working in Indian Country. Detailed information on the lessons learned by the Tribal eCR Implementation Pilot Cohort can be found in **Appendix I: Key Informant Interviews with eCR Tribal Implementers.**

Legal and Institutional Challenges in the Interpretation and Designation of Tribal Public Health Authority

The process of designating Tribal public health authority for eCR, whether it is an arm within the Tribe, a Tribal healthcare organization, a Tribal health department, or another Tribally-designated entity, will be unique to each situation and the specific Tribal policies and procedures that are in place. In some cases, the process of designating Tribal public health authority can be laborious and lengthy and can pose various legal and institutional challenges. When seeking Tribal public health authority designation, careful consideration needs to be made to educate and inform Tribal leadership and the key staff involved in eCR implementation, on why its designation is important for not just eCR, but for advancing public health in Indian Country as a whole.

Beyond internal needs to educate Tribal leadership, Tribal public health authorities may face a lack of understanding of Tribal data sovereignty and Tribal and TEC legal status of public health authorities. This lack of understanding at the state, local, or national level can create barriers to data access and funding for eCR and other surveillance efforts.

Supplement I: Understanding Tribal Public Health Authority and the resources in **Appendix III: Resources for Learning More** can provide Tribal public health authorities with the language to advocate and educate. NIHB and CDC can provide technical assistance to Tribes facing challenges. Finally, ensuring legal counsel is available prior to pursuing eCR can build Tribal capacity to navigate these legal challenges and communicate about Tribal public health authorities' legal rights to access public health data.

Challenges in Outlining the Tribal/TEC Jurisdiction for eCR Purposes

eCR relies on ZIP codes for data routing in RCKMS/AIMS. Because Tribal jurisdictions do not align neatly with conventional geographical ZIP codes and US state and local boundaries, this poses significant challenges when outlining a Tribal public health authority's jurisdictional/geographical boundaries for eCR purposes. Tribes and TECs will need to consult with their legal representatives in concert with the legal counsel of the eCR-implementing agencies, specifically APHL, as well as CSTE and CDC if necessary to determine how to proceed. Generally, as with state and local public health authorities, Tribes are able to access data in overlapping jurisdictions when appropriate processes are in place to ensure the secure deletion of non-Tribal data. **Tribes should not be denied access to their jurisdictional data due to shared ZIP codes.**

In addition, when outlining their reportable jurisdiction criteria, Tribes and TECs should carefully consider their Tribal boundaries, and regional jurisdiction, as well as the neighboring localities and counties housing large proportions of their Tribal citizens. Healthcare providers may need to report to multiple jurisdictions, and this can lead to confusion when each jurisdiction has different reporting requirements. Additionally, data for Tribal citizens that do not live and did not receive services within the Tribal jurisdiction may be reported to a state or local public health authority. Once these factors are taken into consideration, along with the associated legal stipulations, Tribal public health authorities should weigh these out against their institutional capacity and public health priorities to inform the best path forward. In some cases, formal partnerships and data sharing agreements with state and local public health authorities with adjacent and/or overlapping jurisdictions in AIMS may be necessary or beneficial to achieving the comprehensive public health data required for optimal Tribal public health action.

AI/AN Race and Ethnicity Misclassification Challenges in Disease Reporting

Racial misclassification of American Indian/Alaska Native persons (AI/AN) continues to be a challenge nationally when collecting, analyzing and reporting data for public health purposes. AI/AN race and ethnicity is often misclassified or underreported in public health data. This is a continued challenge that Tribal public health authorities must navigate. One solution is for Tribal public health authorities to link eCR data received to existing IHS patient registries (where possible/ depending on service population) or Tribal enrollment records to ascertain actual AI/AN racial status for persons included in data received through case reporting, including eCR.

Limited Funding

Tribal public health authorities face significant challenges in the funding sources available to them. Federal funding for Tribes and TECs to participate in national public health capacity building efforts has been historically limited. This has often led to challenges for Tribes and TECs in attaining the adequate staffing and infrastructure needed for public health purposes. Tribes and TECs need to continuously seek funding mechanisms to support and sustain their public health programs. Please refer to the **Sustainable Funding and Budget** section of this document for a list of resources on funding opportunities available to Tribes, TECs and other Tribal organizations.

Sustainability

Directly related to limitations in funding sources, the issue of sustainability of eCR, and maintaining the infrastructure and support necessary for continued public health action, remains a continued challenge. Tribes and TECs will need to practice due diligence in applying for and securing continued funding for programmatic, infrastructure and staffing support to continue eCR and other data modernization work, and to advance public health capacity in Indian Country, as a whole.

SUCCESSSES OF ECR IMPLEMENTATION

The experience of eCR implementation among these early adopters of eCR in Indian Country under this grant, has the capacity to inform the process of eCR implementation and data modernization for other Tribes and TECs in Indian Country.

Promoting Partnerships and Collaboration

The process of Tribes/TECs implementing eCR provides numerous opportunities for formalized partnerships between Tribal public health authorities and state and local public health entities. These partnerships are crucial for the coordination and optimization of public health activities including disease prevention, control, surveillance, intervention activities across all jurisdictions that share geographical boundaries. These partnerships can take the form of formalized data sharing agreements, exchange of best practices and lessons learned, and deduplication of efforts for more efficient and effective public health action.

It is also important to note that the process of eCR implementation provides an opportunity for increased collaboration between various entities within a Tribe or TEC. More specifically, eCR implementation can foster collaboration between Tribal Councils and Tribal Health Boards; between Tribes and the specific TEC in their region; and between Tribes, TECs and the Tribal health centers in their area.

Strengthening of IT and Public Health Infrastructure

The process of eCR implementation for any public health authority, by nature, is an exercise in data modernization that strengthens IT and institutional infrastructure to better respond to public health problems. Tribal public health authorities can benefit from the improvements in IT and public health infrastructure that goes in hand with the implementation of eCR and broader data modernization initiatives.

Promoting Tribal Understanding of the Important Role of Public Health, eCR and Data Modernization Efforts

The process of eCR implementation presents some key opportunities to promote Tribal understanding of the important role of Tribal public health authority, and, in turn, public health, eCR and data modernization for Tribal disease control and prevention activities, and the promotion of mechanisms to better the health of Tribal communities.

Promoting Tribal Data Sovereignty

The process of implementing eCR allows Tribal public health authorities greater access to Tribal public health data, which enhances Tribal ownership of the data they need for effective public health action on Tribal lands that benefits Tribal citizens, as well as residents of theirs and nearby jurisdictions. Any mechanisms that promote Tribal data sovereignty, such as eCR, by nature also promote overall Tribal sovereignty, allowing Tribes to put their inherent sovereign authority into practice.



SUPPLEMENTS

SUPPLEMENT I: UNDERSTANDING TRIBAL PUBLIC HEALTH AUTHORITY

What is Public Health Authority?

Public health authority is a broad term that applies to governmental public health agencies. The term refers to a sovereign government's rights and responsibilities to engage in activities that protect and promote the health of citizens of their jurisdiction.[i] In terms of data sharing, Public Health Authorities have certain rights and responsibilities related to the gathering, sharing, analysis, and use of public health data, including protected health information.

The Health Insurance Portability and Accountability Act (HIPAA) is an important federal law that governs data sharing of protected health information. Under HIPAA, public health authorities are recognized as unique entities that have the need for protected health information to carry out their mission to protect public health. The HIPAA Privacy Rule defines Public health authorities under 45 CFR 164.512(b):

"...an agency or authority of the United States government, a State, a territory, a political subdivision of a State or territory, or Indian Tribe that is responsible for public health matters as part of its official mandate, as well as a person or entity acting under a grant of authority from, or under a contract with, a public health agency".

Examples of activities that a public health authority might conduct that require protected health information include:

- General disease surveillance
 - Purpose: Determine health risks, disparities, and opportunities for improved health within a communities
 - Example: Cancer statistics within a community
- Disease case reporting
 - Purpose: Notification of potential infectious disease outbreaks, environmental contaminants, etc.
 - Example: Laboratory confirmed positive cases for COVID-19

- Disease investigation information
 - Purpose: Investigate outbreaks of disease and intervene in risks to public health and safety of the community
 - Example: Information on where a patient ate prior to becoming sick; information on medication provided by healthcare provider
- Vital statistics
 - Purpose: Have accurate birth and death information
 - Example: Birth and death records

As outlined in 45 CFR 164.512(b), HIPAA covered entities are permitted to disclose protected health information to public health authorities. Public health authorities make the determination for the minimum necessary information needed to carry out public health activities. Public health authorities generally set standard rules and/or regulations to address the specific practices related to reporting data. For case reporting, this includes which diseases are reportable, under which circumstances they are reportable, the timeline for reporting, and the method for reporting. These requirements may differ across public health authorities, and covered entities will follow the reporting requirements for their jurisdiction.

Tribal Public Health Authority: Legal Basis

Tribal public health authority stems from Tribal Nations' status as sovereign nations. This status has been affirmed by the U.S. Supreme Court, the U.S. Constitution, and hundreds of Indian treaties and federal statutes.

The United States Government recognizes Tribal sovereignty: the legal principle that Tribes retain all inherent sovereignty that the federal government has not encroached upon.



It is the obligation of the federal government to protect tribal self-governance, lands, assets, resources, and treaty rights, and to carry out the directions of federal statutes and court cases.

Congress is the only party that can divest Tribes of their authority to engage in public health activities; however, Congress has taken no actions to limit Tribes' rights to engage in these activities as part of their sovereign status [i]. Therefore, Tribes fully maintain their inherent public health authority.

Tribal Consortia, Health Organizations, and Other Entities as Granted Public Health Authorities

As sovereign nations, Tribes have the right to develop their own systems of governance. This means that Tribes have the option to form a variety of governing bodies, including but not limited to elected Tribal councils, Tribal chiefs or chairpersons, executive officers, presidents, etc. Some Tribes may have more than one governing body. Tribal health organizations are often governed by additional entities to the Tribal governing body, including health boards, boards of directors, executive directors, etc.

Tribes also have the option to form inter-Tribal consortia, a partnership between more than one Tribe or Tribal organization. These consortia can be granted governance by each individual Tribe and can subsequently be granted public health authority on behalf of the member-Tribes. Similarly, Tribes may create health organizations to serve their people, either within the Tribe or as a separate entity. These health centers often offer integrated healthcare and public health services and may functionally serve as health departments for Tribes. Tribes can choose to grant their health systems public health authority to perform governmental public health functions on behalf of the Tribe.

Tribal Epidemiology Center Public Health Authority: Legal Basis

The twelve Tribal Epidemiology Centers (TECs) are designated by federal law as public health authorities for the purposes of the HIPAA.

The Indian Health Care Improvement Act (IHCIA) states that the Secretary of Health and Human Services “shall grant to each epidemiology center . . . access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary [iii].”

While TECs do not have the same broad, inherent public health authority as sovereign Tribal Nations, this federal statute grants TECs authority to carry out specified public health activities and to be considered public health authorities for the purposes of accessing protected health information covered by HIPAA. IHCIA states that when carrying out these activities, TECs must work at the request of and in consultation with Tribes. Tribes may also choose to grant TECs additional authority to carry out other public health activities on the Tribes' behalf [iv].

A March 2022 Government Accountability Office (GAO) report re-affirms that TECs are defined as public health authorities by federal law and are intended to perform core epidemiological functions with and at the request of Tribes, Tribal organizations, and Urban Indian organizations [xv].



Tribal and Tribal Epidemiology Center Public Health Authority in Practice

Based on the March 2022 GAO report investigation, TECs face significant barriers in accessing data, including infectious disease data that is necessary for public health decision-making. Despite being legally designated Public Health Authorities, TECs have had to wait months or even years for access to essential public health data. Even during the pandemic, receipt of vital COVID-19 data was delayed by up to 7 months – hindering effective emergency response efforts. Because TECs provide Tribes with data to support Tribal decision-making, delays or limitations in TECs' access to data may limit the ability of Tribes to make informed decisions about how to address their communities' health needs and reduce the health disparities faced by their communities [xiii].

FIGURE 7: INHERENT VS. DESIGNATED PUBLIC HEALTH AUTHORITIES



APPENDICES

APPENDIX I: KEY INFORMANT INTERVIEWS WITH ECR TRIBAL IMPLEMENTERS

Overview and Purpose

In an effort to better understand the electronic case reporting (eCR) implementation process, interviews were conducted with staff from three Tribes (Tule River Tribe of California, Salt River Pima-Maricopa Indian Community, Turtle Mountain Band of Chippewa Indians) and one Tribal epidemiology center (Great Plains Tribal Epidemiology Center) who have implemented or are in the process of implementing eCR.

Methods

Staff were chosen to participate in interviews based on their direct experience of being involved in the implementation of eCR, either through being the project lead, technical support, or other support staff. Interviews were conducted via Zoom by NIHB Program Evaluator, Karen Alexander (PhD) and Project Coordinator Sophie Sembajwe (MSPH). All participants signed Consent to Participate and Content Release forms prior to being interviewed. Each interview included 2-3 Tribal staff and lasted approximately one hour. Interviews were held on 6/27/24, 7/2/24, and 7/9/24.

Each interview began with introductions from facilitators, who then explained the interview process (Interview Protocol). Participants' questions about the process were answered prior to conducting the interviews. In keeping with cultural values of reciprocity and respect, follow-up contact was discussed to make sure that all information reported is accurate and congruent with the meaning that participants intended to impart. The interview questions we asked reflect our desire to understand how Tribes/Tribal organizations navigated the process of eCR implementation, including their challenges, successes, and lessons learned. Eight questions were asked during the interviews (See **Interview Questions** in the following section). Participants took turns answering questions, conveying their knowledge and experience based on their role in the project. After answering all questions, participants were thanked for their participation, and the interview concluded.

Each interview was audio recorded and transcribed using the Zoom transcription feature. An AI summary was also provided by Zoom.

Each interview transcript was then analyzed independently by first organizing and categorizing data by interview question. Attention was given to quotable material along with any themes that surfaced during interviews. The AI summaries were useful in providing a general overview of data collected during interviews which were reviewed along with the interview transcripts. Results are reported in a summary format broken down into the following sections/topic areas: Importance of eCR Implementation for Tribes, Steps of eCR Implementation, Public Health Authority Designation, Partnerships, Additional Steps to eCR Implementation, Establishing and Testing Connections, Best Practices for Implementation, Challenges and Successes, Lessons Learned, and Utilizing eCR Data.

Providing an aggregate summary protects the individual identity of Tribes. Since there were some notable differences in the eCR implementation process for Tribal epidemiology centers, their results will be reported separately. Please refer to the TEC Spotlight.

Interview Questions

Question 1. Please tell me what your official role is at your organization and what your responsibilities have been related to eCR implementation.

Question 2. Tell me about the process your Tribe followed to implement eCR. What steps did you take, and what was the order of these steps?

Question 3. Tell me about the challenges your Tribe encountered, and what solutions were most helpful.

Question 4. Tell me about the successes your Tribe had with eCR implementation.

Question 5. What are the greatest lessons you learned by going through the process of eCR implementation?

Question 6. How did you/ do you plan to use the data received through eCR, and how will this impact your jurisdiction?

Question 7. Is there anything else you would like to share with us?

Summary of Key Informant Interviews on Tribal eCR Implementation

This summary covers the experiences of Tribes in completing the eCR implementation process and is broken down into the following sections: Importance of eCR Implementation for Tribes, Steps to eCR Implementation, Public Health Authority Designation, Partnerships, Additional Steps to eCR Implementation, Establishing and Testing Connections, Best Practices for Implementation, Challenges and Successes, Lessons Learned, and Utilizing eCR Data. Themes that emerged during the interviews were the importance of education, partnerships, communication, and sustainability and are covered in the main sections of the summary.

Importance of eCR Implementation for Tribes

Participants from one Tribe expressed that the need for up-to-date information was made apparent during the COVID pandemic. There were questions about the number of cases of COVID in Tribal communities. It was quickly discovered that the exact count was not available. Although it was possible to get data for people who used Tribal health services, there was no data for those who were tested for COVID off the reservation, if they did not list the Tribe as their provider. One participant said, “From this experience, I realized how important it was to have a system like eCR, where we would have a definitive answer to the question of how many people had COVID.” It was apparent that other diseases like Syphilis, HIV, or Tuberculosis could also be tracked with the eCR. These realizations, and the need to have greater ownership of Tribal public health data to take appropriate action were the reasons why some applied for eCR implementation funding.

Steps for eCR Implementation

Although each Tribe had followed a similar sequence of steps for successful implementation of eCR, each had a path that was somewhat different from the others due to circumstances specific to their situation. Each Tribe had to establish public health authority designation, initiate the eCR implementation process, establish a connection to the AIMS platform, determine rules for reportable conditions and ZIP code/geographical criteria, connect to the RCKMS platform (determine ZIP codes), test the connection, and establish a live connection to AIMS to receive eCR data. Some of these steps were straightforward and accomplished relatively easily while there were challenges they faced with some steps.

One of these that took time and presented some obstacles to overcome was in the establishing of Tribal public health authority.

Public Health Authority Designation

This step is a requirement of eCR implementation and was sometimes difficult to obtain. The process for all Tribes included bringing a resolution before Tribal Council to approve the designated Tribal entity (whether it be a Tribal public health department or Tribal health organization) selected to carry out the public health activities including eCR implementation on behalf of the Tribe(s). Having this official designation in place gave Tribes the authority to implement and enforce reportable conditions so they could then receive eCR data. One of the designated Tribal health organizations was previously designated as a public health authority, but when the federal public health emergency declaration ended in May 2023, the Tribe rescinded their public health authority designation. The project was stalled until the Tribe reinstated the designation in November 2023. Besides the extended time it took to get public health authority status, this same Tribal public health authority reported issues with their State Department of Health which happened simultaneously to their seeking public health authority status and added to the challenges they experienced. Another Tribe stated that it took around 6 months to complete the process to gain public health authority status, but having this designation is “one of the greatest outcomes of this project.” Others agree that having a Tribal entity with officially designated public health authority status is beneficial to the Tribes. Understanding the meaning and importance of having Public Health Status was cited by some as one of the areas that people gained knowledge about during the project.

Partnerships

One project team discussed the importance of partnerships and having support and technical assistance in eCR implementation. Both NIHB and CDC staff assisted with all aspects of the project, and “were very patient with us, and the delays, and they were so understanding and supported us along the way.” All project teams expressed appreciation of the assistance and one person said, “we felt like we had allies.” CDC staff were helpful in connecting project teams with those who had expertise in all aspects of eCR implementation. One of these ways was to connect the Tribes with the RCKMS team.

One project team stated the following in relation to building partnerships on the technical side: “One important piece of the whole process was finding and establishing or developing a connection or partnership” with an entity in the Tribe that had the technology and infrastructure to manage this kind of project. The project team found that the Tribe’s college was a good fit due to their well-established infrastructure, which was helpful to the process. For this Tribe, a staff member (IT Contractor) assisted with the technical aspects of the project such as establishing a connection to RCKMS and worked with a program analyst at RCKMS who was very helpful. This IT contractor found that the system is actually “intuitive and user friendly.”

Additional Steps for eCR Implementation

Some additional steps required in the eCR implementation process include registering and authoring in RCKMS, which include defining ZIP codes, and reportable conditions criteria, were highlighted in the interviews.

Registration in RCKMS was straightforward for one Tribe due to only having one ZIP code. For another Tribe, choosing ZIP codes was “a relatively simple process” due to having a GIS department within the Tribal community who assisted with this step. For this Tribe, there were four ZIP codes published with about 75% of the Tribal community residing in one ZIP code. For another team, choosing ZIP codes was relatively easy due to there being 5 major ZIP codes associated with the Tribe. As we will highlight in the TEC Spotlight, the process of ZIP code designation for the TEC staff (who also participated in the interviews) posed a huge and ongoing challenge.

Project teams then had to contact their liaison at RCKMS to obtain access to author and publish the list of conditions to use. Next, the project teams authored all of their reportable conditions in RCKMS. When it came to choosing conditions to author, one participant said, “we started out wanting it all” but quickly found out that it needed to be narrowed to align with their state to avoid confusion. In most cases, the list of reportable conditions for the Tribal jurisdiction was posted to an official public-facing website for jurisdictional health care organizations and other stakeholders to reference.

Establishing and Testing Connections

Establishing and testing connections was a relatively easy process for Tribes. For one Tribe’s project team, testing the connection was accomplished easily during one or two virtual meetings with their contact at APHL, their IT

department, and their Project Director. The IT Contractor worked directly with APHL to establish and test the connection. The connection was then tested successfully a second time. All project teams had IT staff or contractors who assisted with the technical IT aspects of the project such as establishing and testing their connections to AIMS.

One Tribe's IT Consultants worked closely with AIMS support to establish a secure connection. This was done through a secure server at the Tribal college, which then transferred the data to a secure server at the Tribe's Public Health Department. Testing the connection to the AIMS system took a few days to make sure that the information was getting across. The IT Consultants worked with the Project Director while AIMS successfully sent a test file and then turned on the system.

Best Practices for eCR Implementation

When project teams were asked about best practices, the topic areas they reported on most frequently were the following: education and training, public health authority designation, and communication.

Education is essential to eCR implementation due to the nature of the project and the high level of knowledge acquisition required prior to implementing the project. All project teams began the process by first learning about eCR implementation. Staff reported that the onboarding/eCR 101 training presentation provided by CDC was very helpful, especially the diagram explaining the process. One participant stated, "there's a huge learning component to this" and "not everyone is going to ever be able to really understand all the complexities of it," but there are people with the technical skills "to figure that out." A participant stated that it is important to share knowledge about eCR implementation with others, so "people can understand and see the value in it." In addition, participants found it important to educate everyone about the benefits of eCR, such as being able to access data that was not available to Tribes during COVID. Sharing the benefits of eCR for the Tribe and emphasizing its importance one interview participant discussed how they convinced the leadership of the Tribe to support the project, by pointing out that "we're going to be able to find out how many cases are in the community."

It was stated by many participants that everyone involved who has been and will be involved in eCR implementation needs training and education on the various topics related to eCR such as, steps required to implement eCR,

public health authority, and HIPAA. There are certain topics that are important to understand, “especially the difference between public health authority and healthcare, and how the data authorities are different,” one person stated. Another mentioned that “there’s a lot of confusion over how HIPAA applies to this, so learning about that is really important.” The Tribes all expressed gratitude to CDC and NIHB for training received on all these topics. In addition, the program analyst at RCKMS assisted with teaching project teams how to publish in the RCKMS system, which participants found beneficial.

A crucial topic area related to best practices was the process of acquiring Tribal public health authority designation to implement eCR on behalf of the Tribe. Participants discussed the variations in the processes they followed to attain public health authority designation. Participants continued to express appreciation to NIHB in the public health authority designation process. One participant specifically stated that NIHB staff “really helped us with the letter that was sent out on our behalf” and this assisted in educating their state on public health authority. The letter paved the way to better understanding and “lowered any boundaries or barriers to receiving data” and decreased “any pushback” that may have otherwise been received.

The importance of partnerships and communication was reported by many participants. Having partnerships “was absolutely critical” to the successful implementation of the project. NIHB and CDC offered assistance in many ways, and having partnerships with states, and other Tribal departments was very important as well. One Tribe noted that partnering with an agency who provided “cyber security related services” was crucial to their project, as it helped with “securing the data back and forth” and provided protection of their data. For many, the project required partnerships with many stakeholders, and effective and continued channels of communication proved vital. As one participant noted, “I had to communicate with a lot of stakeholders to get a lot of teams on the same page.” This also included reporting to their Tribal council to keep them updated on the project, “about what we’re doing” and “how this is going to help us to be better at what we do” as a Tribal public health agency. One participant stated the following: “I think communication would be considered a best practice” as it is important to understanding “exactly what you’re looking for, and where you want to go.” Another participant added, “Because of staff turnover, it was necessary to be persistent in communicating to “keep everyone continuously informed on where we were on the project.”

To help other Tribes with the eCR implementation process, one participant offered advised others who are in the process of implementing eCR to “start small” and continued by emphasizing that even if the Tribe has interest in following diseases of more public health importance than the ones they are currently able to follow, the collection of this data through eCR can be planned for in the future. Another person talked about wanting to collect data on many diseases but knew that the focus had to be mainly on COVID because it needed to align more closely with their state’s reporting system. Other reportable conditions can be added to the system in the future.

Challenges and Successes

A challenge for some project teams was finding the right people to partner with because it took so many people to make the project a success, “because there’s no one person that was able to do this, it was a whole team effort,” one interviewee reported. Once the right partnerships were formed it was “through those connections, through those champions that we were able to make it a priority” and this was “how we got it across the finish line,” they continued. Another participant added that partnering with the right people is important because there are people with a variety of skills or experience. There are some people who “don’t speak technical language” and others have those skills. Someone might say “try it this way or go to this person and do it that way.” Although it was a challenge at times to create the right partnerships, participants emphasized that this added to the success of the projects.

Another challenge people experienced was in dealing with different vantage points and perspectives of Tribal staff and leadership, as well as managing the fact that some staff had a considerable lack of technical knowledge related to eCR implementation at the onset of the project. One participant called it “the lack of industry knowledge” because some staff come from a background from public health, while others have IT backgrounds.

One participant mentioned that it can seem like “you’re speaking a lot of different languages.” It took time for people to gain the knowledge needed to move forward, and this was accomplished through education and many meetings and conversations. It was challenging, but eventually everyone had “common knowledge and common communication.” Everyone helped each other to “get up to speed” and learn about the others’ areas of expertise. Through teamwork and communication, the projects were a success.

One participant reported, “the biggest success is the achievement and accomplishment of implementing the project” adding “we receive data on a daily basis, and that’s what we set out to do.” Another participant agreed, saying “that is the accomplishment, the fact that we can now say we're connected, that we're getting the data now.”

Many stated that attaining designation as a public health authority is a great accomplishment, “We’re glad we have it now. We can say that we have it, and not just for this project, but for future projects.” Having public health authority designation is also about ownership of data and is an “investment in the future” for Tribes, because “we don’t have to ask permission to receive this data” and “we don’t have to rely on any other entities.” Another added, “this is why it’s important for us to keep our data within the Tribal boundaries, and that it’s not being hosted by other people, and for us to have more control of that data.”

Funding was mentioned by some participants as a concern for sustaining the eCR project in the long term. Some project teams had initial funding that has since ended, so they are in the process of looking at options for sustainability of eCR projects beyond the initial phase of implementation. Some of the teams are applying for grants for support because, “we’re really spread thin as far as trying to make sure we can sustain the connection and use the data.” One project team is considering the possibility of collaborating with a TEC to lessen the cost burden on their Tribe.

Another challenge encountered by some project teams was in securing the support of Tribal leadership. As is typical of Tribes, there is a chain of leadership that has to be followed and takes time. One participant discussed how explaining the benefits and value of the project through communication and providing education, led to their Tribal Council’s approval and support of the project. Helping leadership to “understand how important it is” was how one team approached this challenge and was successful.

One team plans to use the success of eCR implementation as a step towards building stronger relationships and to expand collaborative work and partnerships between the Health Center and Tribal government with the goal of “strengthening relationships, strengthening the knowledge, strengthening the information between all of us as an organization.”

Lessons Learned

Project teams found the process of eCR implementation to be a learning experience, from acquiring knowledge on the ins and outs of eCR, to learning and educating others on how eCR implementation can benefit Tribes and public health. Participants reported that just being a part of the project was a great learning experience, and one person said, “every step of the way I've learned something, or I've learned more, or I've learned about things that I didn't even know about. The whole thing for me was just a learning experience in itself.” Another participant stated, “Being able to do all these things and making sure this data is protected has definitely been a learning process for us.”

A lesson learned by one participant is the importance of information and education, and this individual would like “to educate [others] about public health and inform the community about what public health can do.” They went on to say, “I see eCR as a fundamental part of public health and of Tribal public health departments, especially for the future.” Another stated, “I think this could be really foundational to a lot of Tribal public health departments getting data that they likely did not have access to before.” Another participant, reflecting on what they learned during the process, and the importance of the project, said, “I think this is really important, especially for Tribes that don't have access to any disease control system. I think it could be a real game changer especially for tribes that are maybe a little bit smaller.”

Utilizing eCR Data

There was discussion about how Tribes are currently using data (receiving, storing, analyzing, etc.) and plans for data use in the future. Some project teams reported not currently having a surveillance system in place and using a secure folder to receive and store data. For one Tribe in particular, the eCR data received in various readable formats was being entered manually into an Excel spreadsheet for tracking and analyzed with a statistical software program.

Another project team reported that “to implement eCR, you do not need a surveillance system, however it is good to have one.” This Tribe does not have one and receives the cases in the form of data packets that are delivered directly to a secure network folder. This folder is updated every day with new data. The format of the data is XML and in an HTML format.

In the case of this Tribe, it is then up to the Project Director to analyze and report on the data. It was made clear during the interviews that having this kind of system adds to a Tribe's capacity for public health action, which will be helpful in the future. According to one Tribe that has a grant that allows them to partner with the county, they can "work more strategically with the county" as well as the Tribe on "disease intervention and tracing services." Another project team recently completed a community health assessment and although "it would have been stronger if we had this data" from eCR previously, there are plans to use eCR data to track progress on their community health improvement plan in the future.

In conclusion, all three Tribes report positive outcomes from participating in eCR implementation projects. In some cases, there were delays and challenges to overcome, but in the end all staff associated with the project had positive experiences and expressed gratitude for all the assistance they received from various stakeholders such as those in other agencies and Tribal departments, as well as project partners at NIHB and CDC. Many cited education and partnerships as being most important to the project, especially learning about eCR and public health authority designation. Sharing knowledge and relying on each other's expertise, along with keeping the lines of communication open seemed to be the most important components to the eCR implementation process to many of them.

Spotlight on a TEC's Experience Implementing eCR: Successes, Challenges, and Lessons Learned

One TEC received CDC funding through NIHB to undergo the processes and procedures necessary to implement eCR for the governing Tribes that they represent. Through this grant funding, the TEC staff spearheading the eCR project, with guidance and technical assistance from NIHB and CDC staff, were able to initiate a connection to the AIMS platform and develop a detailed framework of case reporting criteria that encompass the prevailing reporting rules of all the states overlapping the TEC's jurisdiction. The TEC staff also developed geographical criteria to be input in RCKMS, to guide the qualifying geographical boundaries and ZIP codes that would render a case reportable to the TEC. Moreover, the CDC eCR funding, along with funds from IHS, supported the TEC staff dedicated to enhancing the IT infrastructure and capacity, in preparation for the receipt of eCR data. The TEC was able to launch new cloud service solutions in the form of an Azure Blob Storage data lake with an SFTP application programming interface.

Having this infrastructure in place enabled the TEC to launch a test connection to the AIMS platform. As of the closing of this grant, the TEC has the capacity for an in-production connection to AIMS to receive real-time eCR data.

It is important to note that, even though the TEC developed and compiled the specific case reporting criteria of reportable conditions and the geographic/ZIP code guidelines that will govern which case reports they receive through AIMS, they have experienced significant legal roadblocks in gaining the required access to RCKMS in order to do so. The TEC and APHL have had to work through jurisdictional questions regarding the zip codes, the regional geographic nature of the TEC, which overlaps several states, as well as the relationship between the TEC and its constituent Tribes. As a result of this work, the TEC and APHL have reached agreement in principle and expect that the TEC will begin receiving data soon.

One monumental success the TEC achieved, in tandem with their efforts to work toward a direct connection to eCR through AIMS, was establishing an alternate pathway to real-time eCR data through a formal partnership with one of the states in their region. At the time of this report, the TEC and the state were able to execute a historical data transfer of reportable conditions as well as establish the first ever real-time, continuous delta feed of reportable conditions from a state to a Tribal entity.

APPENDIX II: TRIBAL LAWS PERTAINING TO DISEASE SURVEILLANCE AND RESPONSE

The following is a non-exhaustive list of Tribal laws, codes, policies, ordinances, and regulations related to the surveillance, detection, control, and prevention of diseases of public health concern (communicable diseases, infectious diseases, vaccine-preventable diseases, non-infectious diseases of public health concern, etc.).

- Makah Communicable Disease Code: <https://makah.com/wp-content/uploads/2021/11/Title-14-Communicable-Disease-Code.pdf>
- Salt River-Pima Maricopa Indian Community Communicable Disease Reporting Ordinance: <https://www.srpmic-nsn.gov/government/hhs/ph/>
- Tribal Government of the Menominee Indian Tribe of WI Article XII Communicable Diseases: <https://ecode360.com/12094531>
- Tule River Indian Health Center list of ordinances and codes related to Public Health Authority, Communicable Diseases, Isolation, and Quarantine: <https://www.trihci.org/covid-19/public-health-authority-orders/>
- Turtle Mountain Band of Chippewa Indians
 - Tribal Code Title 52: Public Health: <https://law.tmchippewa.com/us/nsn/tmchippewa/council/code/52>
 - TMBCI Mandatory Reportable Conditions: <https://www.tmbcimasterhealth.com/wp-content/uploads/2024/02/TMBCI-Reportable-Conditions.pdf>
- Yakama Nation Communicable Disease Code: <https://www.yakama.com/wp-content/uploads/2021/10/Title-XX-Yakama-Nation-Communicable-Disease-Code.pdf>
- Yurok Tribe Tribal Code Chapter 11.10, Public Health: https://yurok.Tribal.codes/YTC/11.10_ArtIII

An additional selection of Tribal codes related to infectious disease can be found in the CDC Public Health Law Brief, Menu of Selected Tribal Laws Related to Infectious Disease Control at <https://www.cdc.gov/phlp/docs/Tribalidlaws-brief.pdf>.

Note: These codes are meant to serve as a resource for Tribes and Tribal Epidemiology Centers looking to implement similar legal principles in their governing documents. This list is, in no way, meant to represent the full list of Tribes that exercise their sovereignty through laws related to public health data, nor does inclusion on this list mean that a code is currently active and enforceable- Tribes may rescind, update, or replace the following codes as needed and decided upon by their governing body.

APPENDIX III: RESOURCES FOR LEARNING MORE

The following resources provide additional information and guidance to assist Tribal public health authorities in connecting to eCR.

eCR Implementation

APHL eCR AIMS Platform Website

A website with detailed information on onboarding to the AIMS platform for eCR, including guidance for public health agencies on readiness, using RCKMS, and other topics of interest.

Link: <https://ecr.aimsplatform.org/general/>

CDC eCR Website

Website geared at sharing information about eCR, including general background information, getting started, and success stories. Also includes contact information for CDC staff working on eCR.

Link: <https://www.cdc.gov/ecr/php/index.html>

CDC Data Modernization Initiative

Provides information on CDC's data modernization initiative at large.

Link: <https://www.cdc.gov/surveillance/data-modernization/index.html>

Getting Started with eCR

A short guide by CDC for healthcare organizations, EHR vendors, and public health agencies in connecting to the AIMS platform for eCR.

Link: <https://www.cdc.gov/ecr/php/getting-started/index.html>

NIHB eCR Website

NIHB's website providing information on eCR for Tribes, including information on upcoming funding opportunities and the Tribal DMI Learning Community

Link: https://www.nihb.org/public_health/eCR.php

RCKMS Authoring Tool User Guide Version 2.0

Detailed guidance on authoring in RCKMS.

Link: https://rckms-prod-authoring.aimsplatform.com/assets/2020%20RCKMS%20User%20Guide_Final.pdf

Case Reporting and Selecting Reportable Conditions:eCR Implementation

CDC National Notifiable Diseases Surveillance System

Website providing information on case reporting, including background on case surveillance and resources in conducting surveillance.

Link: <https://www.cdc.gov/nndss/index.html>

CSTE Surveillance Informatics Website

CSTE website with resources on surveillance and informatics, including information on electronic laboratory and disease reporting, as well as RCKMS.

Link: <https://www.cste.org/page/surveillance-informatics>

Specific Reportable Conditions Currently Available for eCR Authoring:

This list of conditions is available on the RCKMS website.

Link: <https://www.rckms.org/wp-content/uploads/2024/08/Conditions-available-in-RCKMS-August-2024.pdf>

Understanding Tribal Public Health Authority and Data Sovereignty

Barriers and Opportunities for Tribal Access to Public Health Data to Advance Health Equity

A peer reviewed article by NIHB discussing the legal basis for Tribal data access, and how eCR can advance equity and data sovereignty.

Link: <https://www.cambridge.org/core/journals/journal-of-law-medicine-and-ethics/article/barriers-and-opportunities-for-tribal-access-to-public-health-data-to-advance-health-equity/8FED7AAAFE2A8AF9F112756601002CDE>

CSTE's Tribal Epidemiology Toolkit (Recently updated in 2024)

A toolkit developed and updated by CSTE in collaboration with the Great Plains Tribal Leaders Health Board with the core aim of “improving data quality and data sharing in Indian Country.”

Link: <https://tribal.cste.org/>

TECs Designated as Public Health Authorities under HIPAA

Guidance from the Public Health Law center under the Office for State, Tribal, Local, and Territorial Support at CDC on how to understand the role of TECs and their designation as public health authorities.

Link: <https://www.cdc.gov/phlp/docs/tec-issuebrief.pdf>

APPENDIX IV: ECR IMPLEMENTATION READINESS MODEL

Assessing readiness can be a tool for Tribal public health authorities to determine the likelihood of success in connecting to eCR successfully and can help Tribes and TECs determine how to build their capacity to ensure readiness in the future.

The Community Readiness Model (CRM) is a model that has been used by Tribes in their efforts to achieve public health accreditation and engage in performance and system improvement for public health. The model is particularly appropriate for Tribes as it relies on local level resources and expertise, promoting community ownership. The model shifts focus from milestones to the underlying processes that are necessary for success.

The original CRM contains six basic dimensions that could potentially be adapted from the standard community-based framework to one tailored specifically to eCR implementation and data modernization, more broadly.

Table 1 displays the traditional framework of the CRM and the analogous components that could be used in a modified eCR implementation readiness model.

Community Readiness Model	Proposed eCR Implementation Readiness Model
<p>A: Community Efforts - To what extent are there activities, efforts, programs or policies in the community?</p>	<p>A: eCR Implementation Efforts – To what extent are there activities, efforts, programs, and policies that address or leverage the plan for eCR implementation/data modernization?</p>
<p>B: Community Knowledge of the Efforts - To what extent do community members know about local efforts and their effectiveness, and are the efforts accessible to all segments of the community?</p>	<p>B: Knowledge of eCR Implementation – To what extent do Tribal health department/Tribe organization/TEC or Tribal staff know about eCR implementation and related efforts, progress, and effectiveness?</p>

<p>C: Community Climate - What is the prevailing attitude of the community toward the issue? Is it one of helplessness or one of responsibility and empowerment</p>	<p>C: Climate – What is the prevailing attitude of the Tribal health department/Tribe organization/TEC or Tribal staff toward eCR implementation/data modernization? Is it one of helplessness or one of responsibility and empowerment?</p>
<p>D: Leadership - To what extent are appointed leaders and influential community members supportive of the issue?</p>	<p>D: Leadership – To what extent are appointed and/or elected leaders and influential community/Tribal members aware and supportive of eCR implementation/data modernization?</p>
<p>E: Community Knowledge of the Issue - How much does the community know about the issue?</p>	<p>E: Community Knowledge about eCR Implementation - To what extent do community members know about eCR implementation/data modernization activities, the purpose and courses of action, and how it may impact the community?</p>
<p>F: Resources - To what extent are local resources –people, time, money, space, etc. – available to support efforts?</p>	<p>F: Resources Related to eCR Implementation/Data Modernization - To what extent are local resources – staff, time, money, space, storage, etc. – available to support eCR implementation/data modernization?</p>

TABLE 1: ADAPTED COMMUNITY READINESS MODEL FOR ECR

Ultimately, The Tribe/TEC can use the adapted set of questions, as outlined in column 2 of Table 1, to systematically determine their level of readiness for eCR implementation (**Figure 8**).

Levels of Community Readiness

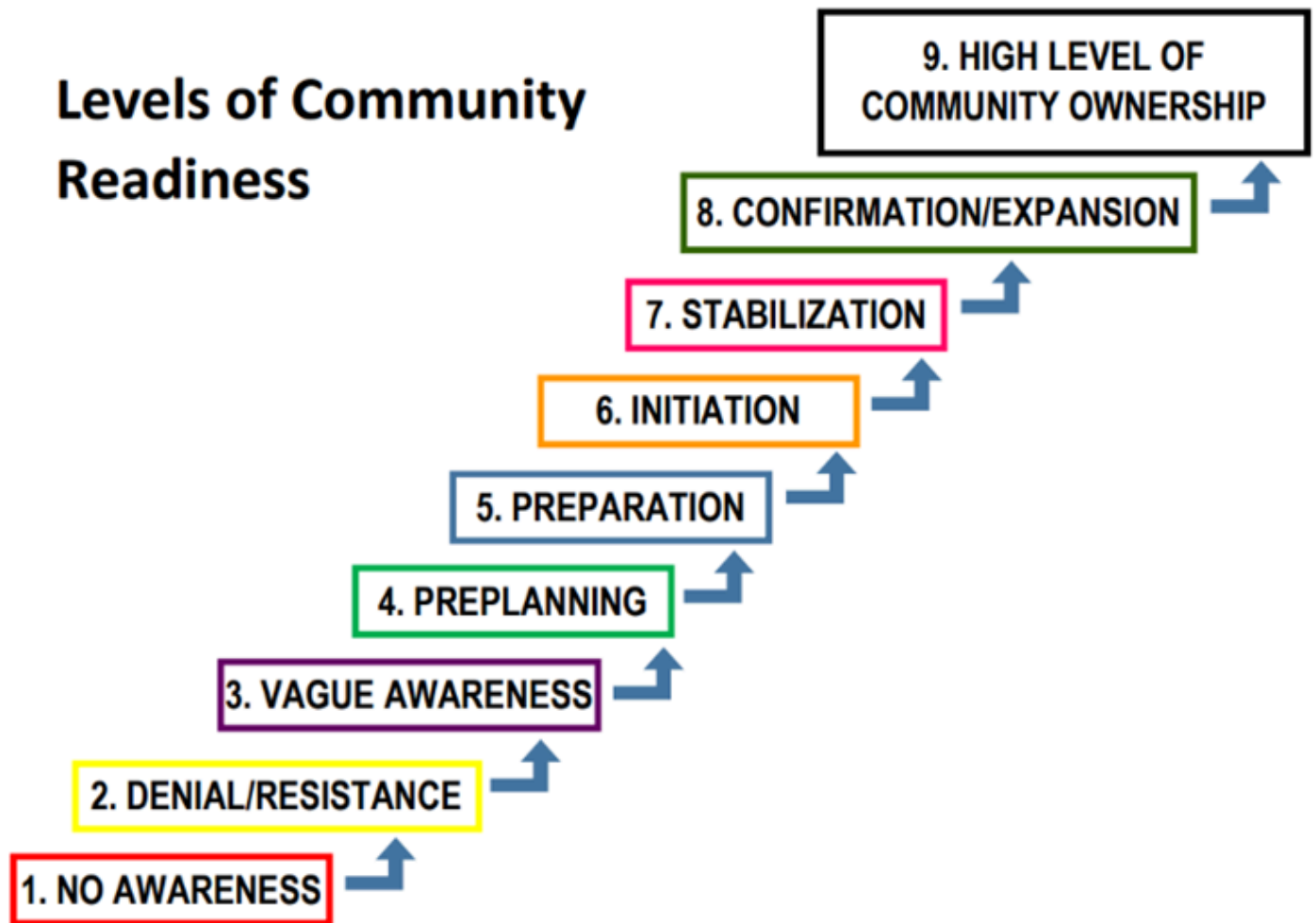


FIGURE 8: STAGES OF READINESS (1)
(1) CHICKASAW ACCREDITATION CASE STUDY

The Community Tool Box has a detailed guide for conducting a readiness assessment, including a list of generalized questions that can be used in scoring, and guidance for identifying your stage of readiness. Visit <https://ctb.ku.edu/en/table-of-contents/overview/models-for-community-health-and-development/community-readiness/main> for more information on the CRM model.

APPENDIX V: SAMPLE WORKPLAN FOR ECR IMPLEMENTATION

In partnership with the CDC, NIHB developed the following workplan as a template for developing an eCR implementation workplan (**Table 2: Sample eCR Implementation Workplan for Tribes and TECs**). This workplan has been adapted based on feedback from the Pilot Cohort of Tribal Public Health Authorities. This workplan is a template, and will need to be adapted to the specific needs of each Tribal public health authority. This workplan assumes that, for Tribal implementers, documentation is already in place clearly establishing the Tribal entity pursuing a connection as a public health authority, as designated by a Tribe's governing body.



Table 2: Sample eCR Implementation Workplan for Tribes and TECs

Goal: To increase Tribal knowledge around and begin the implementation process of electronic case reporting (eCR) directly to Tribal Public Health Authorities.				
Objective 1: PREPARE: Assess current processes and identify needs and gaps to successfully transition to an eCR surveillance system				
Activity	Person(s) Responsible	Deadline	Deliverable(s) / Outputs	Progress Notes (Leave blank – to be used during project implementation)
Activity 1.1: Conduct a review or scan of current case reporting processes and systems; and compare to existing processes and systems used by Public Health Authorities currently receiving eCR. Gaps and needs to transition to a surveillance system will be identified.			Completed review/scan	
Objective 2: CONNECT: Establish the systems and processes needed to receive eCR data directly to the Tribal Public Health Authority by connecting to the Association of Public Health Laboratories (APHL) Informatics Messaging Services (AIMS).				
Activity	Person(s) Responsible	Deadline	Deliverable(s) / Outputs	Progress Notes
Activity 2.1: Contact the Association of Public Health Laboratories Informatics Messaging			Documented communication channel established	

Services (AIMS) and establish a communication channel.				
Activity 2.2: Create a Secure File Transfer Protocol (SFTP) or Simple Storage Service (S3) endpoint.			Endpoint established	
Activity 2.3: Attend training(s) and/or webinar(s) to educate program staff around the use of the AIMS systems.			Training/webinar attended, agenda, and notes	
Activity 2.4: Send AIMS team a list of ZIP codes that identify the Tribal jurisdiction.			Tribal jurisdictional ZIP codes sent to APHL	
Activity 2.5: Test and implement an SFTP or S3 connection to AIMS to receive electronic initial case reports (eICRs).			Successful testing of SFTP or S3 connection	
Objective 3: AUTHOR: Establish a set of criteria, or rules, that will be used by AIMS to send the designated eCRs of Tribal citizens directly to the Tribal Public Health Authority.				
Activity	Person(s) Responsible	Deadline	Deliverable(s) / Outputs	Progress Notes
Activity 3.1: Establish the reportable conditions the Tribal Public Health Authority plans to receive through eCR.			Reportable conditions established	
Activity 3.2: Publish the Tribal Public Health Authority's list of reportable conditions publicly and communicate reporting			Reportable condition list posted publicly	

requirements to healthcare providers within your jurisdiction.				
Activity 3.2: Establish Reportable Conditions Knowledge Management System (RCKMS) authors.			Authors established	
Activity 3.3: Meet with the Council of State and Territorial Epidemiologists (CSTE) and request authoring access.			Documented meeting with CSTE, agenda, and notes	
Activity 3.4: Establish case criteria to be received by the Tribal Public Health Authority.			Case criteria established	
Activity 3.5: Publish rules for your condition(s) to production in RCKMS.			Conditions published	
Activity 3.6: Develop a workflow process or plan around updating case criteria or establishing additional reportable conditions.			One (1) workflow process or plan developed	
Objective 4: COORDINATION and PARTNERSHIP: Establish the necessary internal processes to ensure timely and successful project implementation.				
Activity	Person(s) Responsible	Deadline	Deliverable(s) / Outputs	Progress Notes
Activity 4.1 Collaborate with in-jurisdiction healthcare organizations to educate about sending electronic initial case reports.			Collaboration notes	

REFERENCES

- i. Centers for Disease Control and Prevention. (2024, August 12). National Notifiable Diseases Surveillance System (NNDSS). Retrieved 10/31/2024 from <https://www.cdc.gov/nndss/about/>.
- ii. Office for State, Tribal, Local, and Territorial Support, CDC. (N.D.) Menu of Selected Tribal Laws Related to Infectious Disease Control. Retrieved 10/31/2024 from <https://www.cdc.gov/php/docs/Tribalidlaws-brief.pdf>.
- iii. Centers for Disease Control and Prevention. (2023, May 17). Public Health and Data Authority. Retrieved 10/31/2024 from <https://www.cdc.gov/surveillance/policy-standards/data-authority.html>. Graphic adapted from <https://www.cdc.gov/nndss/docs/NNDSS-Infographic-508.pdf>
- iv. Centers for Disease Control and Prevention. (N.D.). Stories: Surveillance and Data In Action. Retrieved 10/31/2024 from <https://www.cdc.gov/surveillance/news/blogs-and-stories.html>.
- v. National Notifiable Diseases Surveillance System, CDC. (2024, January 31). How We Conduct Case Surveillance. Retrieved 10/31/2024 from <https://www.cdc.gov/nndss/what-is-case-surveillance/conducting.html#:~:text=The%20process%20begins%20with%20data,track%20outbreaks%20and%20disease%20spread>.
- vi. Centers for Disease Control and Prevention. (2021, December 1). The Difference Between eCR and Traditional Case Reporting (video). Retrieved 10/31/2024 from <https://youtu.be/qnh4L98H7z0>.
- vii. Centers for Disease Control and Prevention. (2024, September 9). What is eCR. Retrieved 10/31/2024 from <https://www.cdc.gov/ecr/php/about/index.html>. Source: [cdc.gov/ecr](https://www.cdc.gov/ecr).
- viii. Association of Public Health Laboratories (N.D.). AIMS Platform. Retrieved 10/31/2024 from https://www.aphl.org/programs/informatics/pages/aims_platform.aspx.
- ix. Council for State and Territorial Health Officials. (N.D.) About RCKMS. Retrieved 10/31/2024 from <https://www.rckms.org/about-rckms/>.
- x. eCR AIMS Platform. (N.D.). EHR Implementers. Retrieved 10/31/2024 from <https://ecr.aimsplatform.org/ehr-implementers/triggering/>.
- xi. eCR AIMS Platform. (N.D.). eCR General Information. Retrieved 10/31/2024 from <https://ecr.aimsplatform.org/general/ecr-now-fhir-app>.

- xii. Indian Health Service (N.D.) IHS Health IT Modernization Program. Retrieved 10/31/2024 from <https://www.ihs.gov/hit/>.
- xiii. United States Government Accountability Office. (2022, March). Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access. GAO. Retrieved 2/23/2023 from <https://www.gao.gov/assets/gao-22-104698.pdf>.
- xiv. Field C, Price S, Locklear AC. Barriers and Opportunities for Tribal Access to Public Health Data to Advance Health Equity. *Journal of Law, Medicine & Ethics*. 2024;52(S1):39-42. doi:10.1017/jme.2024.45. Retrieved 10/31/2024 from <https://www.cambridge.org/core/journals/journal-of-law-medicine-and-ethics/article/barriers-and-opportunities-for-tribal-access-to-public-health-data-to-advance-health-equity/8FED7AAAFE2A8AF9F112756601002CDE>
- xv. Centers for Disease Control and Prevention. (2023, December 11). Two Tribal Public Health Agencies to Receive eCR Data. Retrieved 10/31/2024 from <https://www.cdc.gov/ecr/php/stories/two-Tribal-public-health-agencies-to-receive-ecr-data.html>.
- xvi. Tribal Public Health Accreditation Readiness Case Study: Chickasaw Nation, August 2018.
- xvii. Centers for Disease Control and Prevention. (2024, October 16). Getting started with eCR. Retrieved 10/31/2024 from <https://www.cdc.gov/ecr/php/getting-started/index.html>.
- xviii. RCKMS Authoring Tool User Guide. (2020). Version 2.0. Retrieved 10/31/2024 from https://rckms-prod-authoring.aimsplatform.com/assets/2020%20RCKMS%20User%20Guide_Final.pdf.
- xix. Hoss, A. (2021, January 12). Tribes are Public Health Authorities: Protecting Tribal Sovereignty in Times of Public Health Crisis. Available on SSRN. DOI: <https://dx.doi.org/10.2139/ssrn.3759311>.
- xx. Hoss, A. (2015, April 16). Tribal Epidemiology Centers Designated as Public Health Authorities Under the Health Insurance Portability and Accountability Act. Public Health Law; Centers for Disease Control and Prevention. Retrieved 1/31/2023 from <https://www.cdc.gov/phlp/docs/tec-issuebrief.pdf>.

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