





# Collaborative Body Meeting

Thursday, September 10, 2020  
12:00 P.M. – 1:30 P.M. ET

This meeting will be recorded for note-taking purposes only.

## Meeting Agenda

### Purpose:

The purpose of this meeting is to work toward a common vision for exchanging actionable information between health care and public health.

Time	Agenda Item
12:00 PM	Call to order and roll
12:05 PM	Agenda review, approval, and COI declarations
12:08 PM	Consent Agenda – No in-person meeting in January
12:10 PM	Background information on Use Case Project Statement Forms and evaluation
12:15 PM	NRC Workgroup Form presentation <ul style="list-style-type: none"> <li>• Discussion and Q&amp;A</li> <li>• Vote to approve workgroup moving forward</li> </ul>
12:45 PM	IZ Workgroup Form presentation and update <ul style="list-style-type: none"> <li>• Discussion and Q&amp;A</li> </ul>
1:00 PM	Discussion – capacity for workgroups moving forward
1:10 PM	eCR update
1:25 PM	Announcements
1:30 PM	Adjournment

## Conflict of Interest Declarations?

### Matters before the Collaborative Body today

#### 1. NRC Workgroup use case

#### Discussion item

- NRC Workgroup use case
- IZ Workgroup use case
- Capacity for workgroups moving forward

### Standing Rule III. Conflicts of Interests

Whenever a member (i.e., organization), member representative, officer, or a member's workgroup appointee has a financial or personal interest in any matter coming before the Collaborative Body or workgroup, the affected person shall

- a. fully disclose the nature of the interest and
- b. withdraw from discussion, lobbying, and voting on the matter.

Any transaction or vote involving a potential conflict of interest shall be approved only when a majority of disinterested members determine that it is in the best interest of the organization to do so.

The minutes of meetings at which such votes are taken shall record such disclosure, abstention and rationale for approval.

# Consent Agenda | September 2020

*John Lumpkin (Chair)*

# Collaborative Body Meeting Consent Agenda

## Protocol

1. Pre-meeting:
  - a. Chair places items that are believed to be non-controversial or routine
  - b. Items should be received with sufficient review time
2. Start of meeting:
  - a. Chair asks if any member wishes to move an item into regular discussion
  - b. All items left on the consent agenda are documented as approved by the governance body
  - c. Any item removed will be discussed during the meeting

## Sept 2020 Consent Agenda Items

1. January in-person meeting will be rescheduled as a virtual meeting

# Background information on Use Case Project Statement Forms and evaluation

*Vivian Singletary (Vice Chair)*

January 2020 in-person meeting

- Identified **4 uses cases for scoping** (IZ, NRC, C&R, SNF)
- Identified 1 use case to develop a **white paper** (API)

February – April 2020

- Scoping Methods Workgroup convened
- Use Case Project Statement Form was developed

May – July 2020

- Collaborative Body **approved charges** for each workgroup; **workgroup chairs appointed**
- Workgroups formed and began completing Project Statement Form
- Reps. of Executive Committee revised and finalized tool for assessment and feedback

August 2020

- 2 workgroups completed **draft Project Statement Form**
- **EC members** used tool for assessment and feedback to **review Project Statement Forms** for **IZ and NRC** workgroups

September 2020

- 2 workgroups present to Collaborative Body
- For any use case presented, the CB votes to **move forward as is**, **move forward with recommendations**, or **do not move forward**



# Scope

## Problem/Need

Define the relevant current problem or need

Describe the relevance to the DB mission and stakeholders

Define the intended patient and public health outcomes

## Clinical – Public Health Collaboration

Define use of modern information technologies

Describe stakeholder interests, benefits and value.

Define improved and protected health outcomes of patients and communities using interoperable systems

## Advance the Use Case

Define actions to minimize or mitigate barriers and risks

## Champions and Sponsors

Identify project lead and point of contact

Identify organizations and government agencies committed and interested in providing resources

## Workgroup Schedule – Extended (C&R and SNF)

Date	Event	Description
May CB Mtg	Charge approval	Review and approve of workgroup charge by Collaborative Body
June/July	Workgroup Formation	Finalize workgroup membership roster
June/July	Kick-off	Initiate work with orientation to key concepts and review of related in-person meeting products.
	Workgroup Mtgs	
October	Draft Project Statement	Provide draft project statement to Executive Committee
October 22nd	Executive Committee Mtg	Provide feedback on draft form
	Workgroup Mtg	Review Executive Committee feedback on draft statement and revise form for Collaborative Body submission
October 29 <sup>th</sup>	Final Project Statement	Provide final project statement to Collaborative Body
November 5 <sup>th</sup>	Collaborative Body Presentation	Discuss project with Collaborative Body; vote for possible approval

# Enhancing eCR Infrastructure for Newly Reportable and Non-reportable Conditions of Public Health Importance

*Priyanka Surio (ASTHO)*

*Lesliann Helmus (CDC)*

# Outline

- **Proposed Initiative**
- **Need**
- **Scope**
- **Information Flow**
- **Potential New Uses**
- **Relationship to Digital Bridge**
- **Potential Partners**
- **Workplan**
- **Key Issues and Risks**
- **Considerations for Collaborative Body**

## Proposed Initiative

This project builds on the current eCR implementation by adding decision support functionality that will expand its use.

By determining the event to which content is related and the appropriate recipient(s), the filtering and routing would facilitate use of eCR for the transmission of both reportable diseases and other information to public health.

It would also support use of the eCR infrastructure for transmitting patient level information, triggered by events, to additional types of legally authorized recipients.

## Identified Need

- Current electronic case reporting (eCR) implementation aggregates events for 60 minutes after an initial triggering event causing multiple reportable events to be included in one eCR transmission
- Some health departments have implemented filtering to provide the data to the appropriate programs within the agency, but central development of decision support functionality for this filtering workflow would provide a “build once, use multiple times for multiple conditions” solution

# Proposed Scope

- Using eCR infrastructure for newly reportable and non-reportable conditions of public health importance
- Defining the requirements for a centrally maintained decision support tool to filter reports from EHRs based on event, data type, and authorized recipient
  - Reporting of Parkinson's disease to Parkinson's disease registries
  - Reporting of attempted suicides and suicide completions to State Mental Health Authorities
  - Post marketing surveillance of adverse effects from COVID-19 vaccine

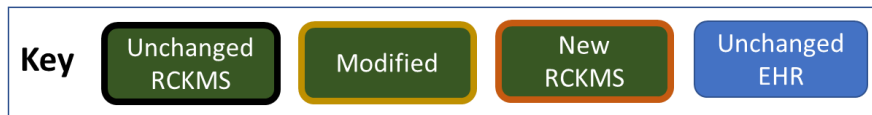
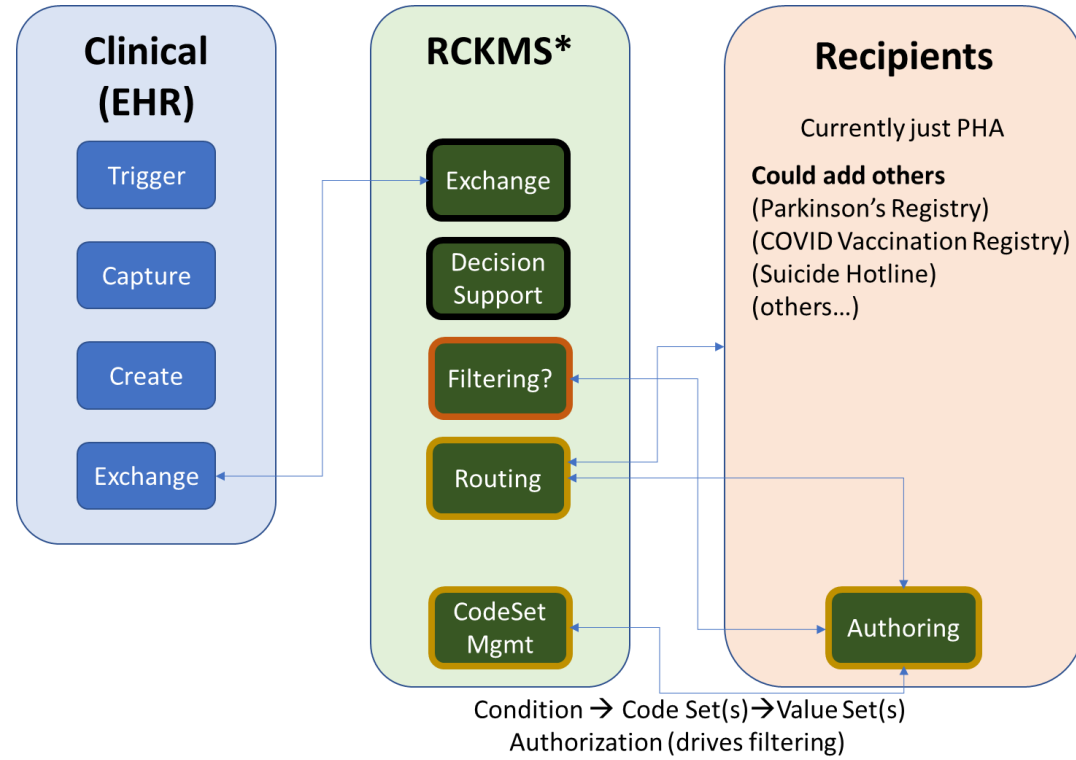
# Scenarios for CB to consider regarding scope

1. Reportable conditions within the Public Health purview
2. Additional reporting within the Public Health purview
3. Conditions to be reported to non-Public Health authorities

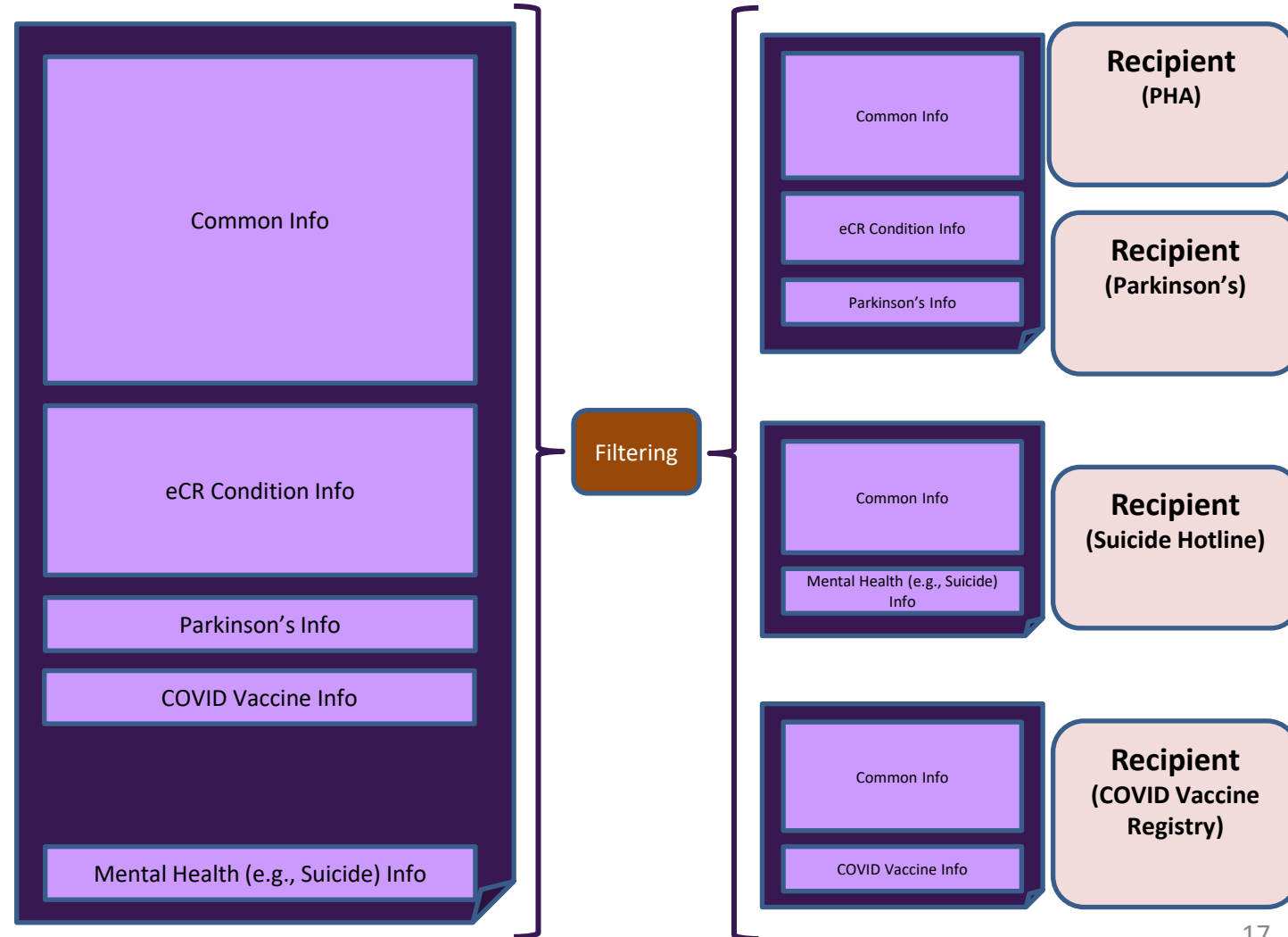


# Information Flow

Example only – not exhaustive



\* Reportable Conditions Knowledge Management System: Nationwide Decision Support Intermediary (DSI) tool



# Potential New Uses Enabled by Decision Support

- Submitting reportable chronic disease data to public health agencies (potential convergence with cancer eCR proposal)
- Facilitate legally mandated reporting of birth defects to public health
- Simultaneous transmission of data to CDC with patient identifier fields removed
- Reporting to disease registries for tracking
- Transmitting adverse events to the Food and Drug Administration (FDA) for monitoring the use of new drugs, vaccines or devices
- Transmitting data from encounters to clinical trials
- Reporting to mental health agencies or community resources for surveillance

# Value Proposition for Generic Infrastructure

- Addresses need for filtering content in eCR reports to public health
- Incorporates new capabilities by configuration rather than extensive new design, development, and deployment (rapid and cost-effective)
- Can expand beyond traditional public health reporting
- Expanded user base increases potential funders and introduces opportunity for hybrid funding model (philanthropic funding and commercial business models)
- Potentially creates a “capacity/scalability fund” to aid in future scaling of platform
- Aligns with ongoing data modernization initiatives

# Relationship to Digital Bridge

- Digital Bridge provides a forum to incorporate new partners and establish the needed trust relationships
- Digital Bridge offers access to resources to help explore legal issues related to authoring of requirements and validation of authority to receive data
- Project supports Digital Bridge intent to ease burden and costs of information exchange between health care and public health through unified, standards-based approaches.

# Potential Partners

Partners	Details
CSTE (RCKMS, RCTC, entity management)	Committed
CDC (tell us what is needed)	Committed
APHL (AIMS platform)	Interested. Need to confirm commitment.
ASTHO	Interested. Need to confirm commitment.
Data submitters/receivers – Mental Health, Neurologic Surveillance, Public Health	Recruitment effort needed: CA Parkinson’s Registry, Michael J. Fox Foundation, Utah, Nebraska if project is accepted by Digital Bridge Collaborative Body
EHRA	Need to submit formal request if project is accepted by Digital Bridge Collaborative Body

Project initiation may be delayed while resources are focused on COVID-19 response

# Workplan

- **Phase 1 – Planning Phase – 9 months**
  - Documentation of requirements
  - Estimate of resources and costs for development of filtering decision support
  - Description of the types of data exchanges best served by enhanced eCR functionality
  - Proposed governance strategy to address authoring of requirements and validation of authority to receive data
  - Estimate ongoing operations resources and costs
  - Recommendations regarding suitability of models
  - Materials to communicate the value proposition

# Workplan

- **Decision on whether to proceed**
- **Phase 2 – Implementation Phase – 9 months**
  - Decision support and authoring functionality needed for content filtering and routing developed and implemented
  - Processes to manage authoring and access validation developed/implemented
- **Phase 3 – Pilot Phase – 9 months**
  - Successful data exchange in pilot for least one new data exchange scenario using the new decision support/authoring functionality

Project initiation may be delayed while resources are focused on COVID-19 response

## Key Issues and Risks

1. Reportable conditions within the Public Health purview
  - Narrow scope hinders development of generic/extensible solution
  - Misses opportunity to address a larger data exchange need
  - Narrow set of potential funders
2. Additional reporting within the Public Health purview
  - Narrow scope hinders development of generic/extensible solution
  - Misses opportunity to address a larger data exchange need
3. Conditions to be reported to non-Public Health authorities
  - Need funding or commercial model to justify investment for generic infrastructure
  - Filtering needs will drive additional complexity to the authoring capabilities
  - Privacy issues from potential uses introduces challenges
  - Assuring legal authority to receive data introduces challenges
  - Managing larger number of transactions and more complexity introduces costs



# Discussion with Collaborative Body

# Considerations for Collaborative Body

- ***What is the appropriate scope?***

1. Reportable conditions within the Public Health purview
2. Additional reporting within the Public Health purview
3. Conditions to be reported to non-Public Health authorities

Examples proposed for use in developing requirements

- Reporting of Parkinson's disease to Parkinson's disease registries
- Reporting of attempted suicides and suicide completions to State Mental Health Authorities
- Post marketing surveillance of adverse effects from COVID-19 vaccine

- ***Is proposal feasible, given the demands of the COVID response?***
- ***Is it worth building out?***
- ***Is funding likely to be available?***

Action:  
**Vote to Move Forward NRC Workgroup  
Use Case**

- 1. Move forward as is;*
- 2. Move forward with recommendations; or*
- 3. Do not move forward*

# Immunization Registries Workgroup

*Malini DeSilva (HealthPartners)*

*Dan Chaput (ONC)*

## Workgroup Charge – Statement of Purpose

- The purpose of this Digital Bridge Project Statement Workgroup (IZ Workgroup) is to investigate, deliberate, and recommend collaborative work that advances information exchange capabilities for clinical immunization practices (e.g., alerting clinicians to vaccines due for pediatric patients) in alignment with the Digital Bridge mission.

### *Taken from the January 2020 in-person meeting:*

- Immunizations – Enabling bidirectional data sharing to alert pediatricians to which immunizations a child has not yet had. In particular, enabling cross-state data sharing. Exploring this project further would include investigating the vaccine registries' data completeness. This project could also include data sharing for adult immunizations.

Date	Purpose of Meeting	Decisions Made during Meeting
July 13 <sup>th</sup> – Meeting	Initial meeting – overview of charge, purpose of work, and next steps	Stakeholders to present on current work in immunizations landscape
July 20 <sup>th</sup> – Meeting	Presentations on current landscape	Gain level setting information on FHIR and discuss alignment with HIMSS work and DB
July 27 <sup>th</sup> – Meeting	Presentation on FHIR, HIMSS discussion, and review form	Obtain summaries of existing work (IIP, IZ Gateway, etc.) and begin draft of form
August 4 <sup>th</sup> – Meeting	Review direction of potential use case	Presentation on multi-jurisdictional query and IZ Gateway share component. Discuss gaps and goals of potential support activities
August 10 <sup>th</sup> – Meeting	Presentation on multi-jurisdictional query and IZ Gateway and discussion of alignment with existing work	
August 17 <sup>th</sup> – Meeting	Final review of form, attempt to reach consensus of direction of workgroup	Submitted V1 of Use Case Project Statement Form to Executive Committee on August 18 <sup>th</sup>
August 24 <sup>th</sup> – Meeting	Reviewed feedback from Executive Committee and discussion about defining the specific project proposal	Recognized capacity for collaboration with IIP, IZ Gateway teams is limited and will be unable to participate during this time; Draft formal letter to EC about decision to pause scoping of this workgroup
August 31 <sup>st</sup>	IZ Workgroup submitted formal letter to Executive Committee	Pause further discussions about Digital Bridge’s involvement related to IZ Gateway activities for the next 11–12 months

## ***Use Case statement (brief)***

**The Digital Bridge Immunization Registries Workgroup proposes the following use case pending above conversation with IZ Gateway leadership:**

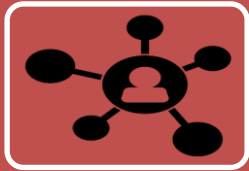
- **Ensure provider-initiated multi-jurisdictional data exchange (submission and query/response) can be successfully operationalized by providers (including EHRs) by:**
  - **Supporting the CDC IZ Gateway, by serving as a convening body to assist in the coordination and advancement/implementation of public-private immunization data exchange efforts, in particular, efforts to exchange data across multiple jurisdictions in order to increase utilization of IZ Gateway.**
  - **Supporting existing collaborative efforts to advance IIS-EHR exchange**
  - **Supporting provider and EHR implementers of IZ Gateway submission and queries by recommending standardized onboarding to ensure best practices are followed and allow for ease of integration into clinical work flows.**
  - **Continue to identify gaps left unaddressed by IZ Gateway in order to support use and uptake of multi-jurisdictional Immunization data exchange.**

# IZ Gateway Portfolio Overview

- The Immunization (IZ) Gateway is a portfolio of components which share a **common IT infrastructure**.
- The IZ Gateway aims to rapidly onboard IIS to support **state readiness for COVID-19 vaccine response** through data exchange, both among IIS and between IIS and federal providers/mass vaccination reporting and consumer access tools.
- The IZ Gateway aims to increase the availability and volume of **complete and accurate** immunization data stored within IIS and available to providers and consumers regardless of their jurisdictional boundaries.



# IZ Gateway Portfolio of Projects



## Connect

National Provider Organizations to Multiple IIS



## Share

Cross-jurisdictional IIS to IIS



## Analytics

Provider de-identified snapshot of COVID-19 vaccinations



## Access

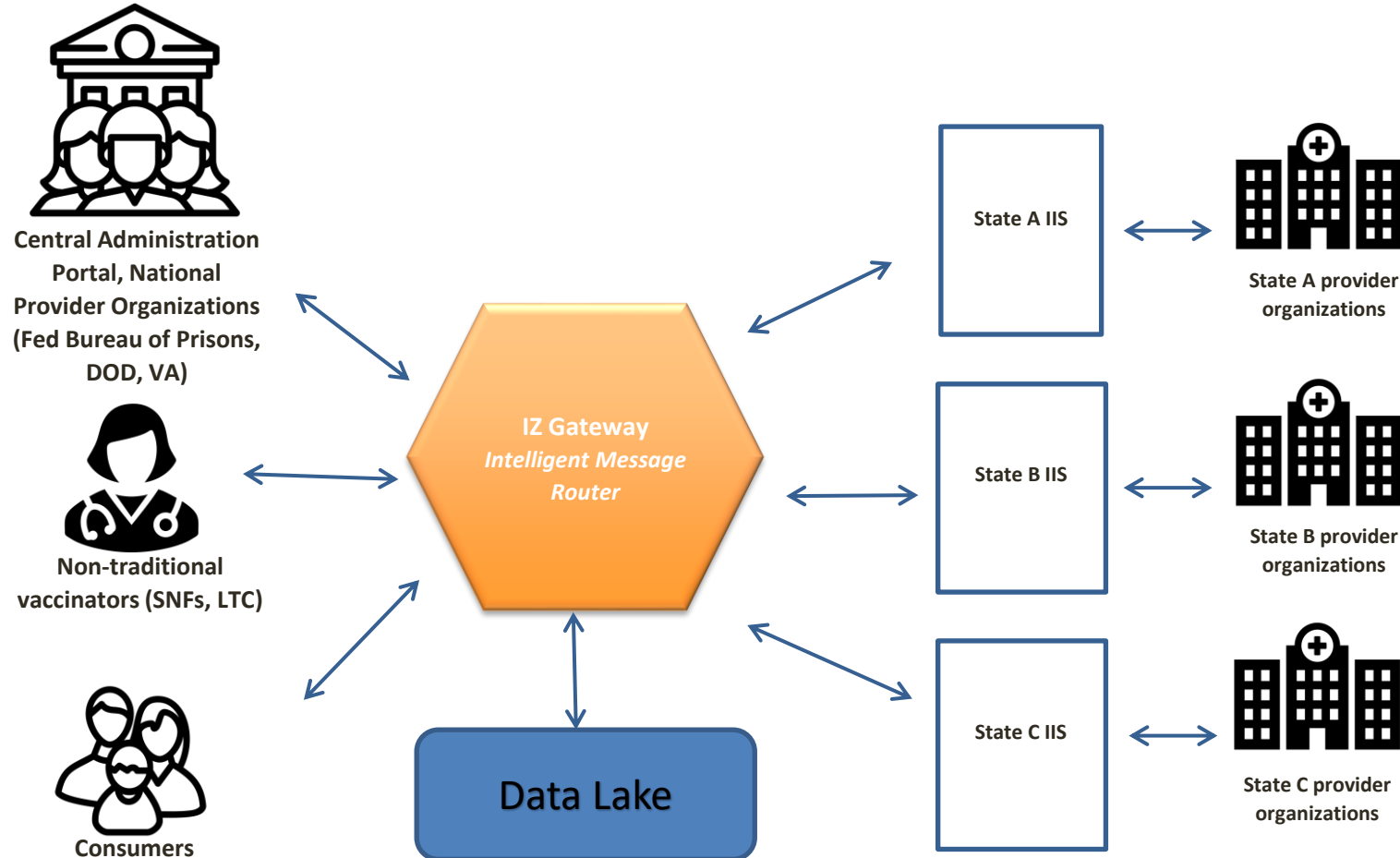
Consumer Access to IIS through Digital Tools



## Provider-initiated Multi-Jurisdictional Data Exchange

Query multiple jurisdictions to receive consolidated immunization data

The **IZ Gateway** is a **centralized technical infrastructure** that supports bidirectional exchange of immunization data.



# IZ Gateway & COVID-19 Vaccine Readiness

The IZ Gateway Team will provide technical and financial support to IIS programs and vendors to improve COVID-19 vaccine response readiness, including:

- Developing requirements and expectations to ensure successful onboarding and sustainable data exchange.
- Fixing existing bugs or basic issues/functionality that limit accurate and timely immunization data exchange through the IZ Gateway.
- Enabling functionality in support of data exchange through the IZ Gateway between IIS and national providers (Connect) and among IIS (Share).

# Discussion and Q&A

# Discussion – Capacity for workgroups moving forward

*John Lumpkin (Chair)*

# Announcements and Next Steps

# Announcements

## Communications Announcements:

- External/internal communications feedback form
- External newsletter – 2 weeks post-CB mtg
- Next internal newsletter ~ 9/20/20

## Workgroup Announcement:

- SNF and C&R workgroups presenting in November 5<sup>th</sup> CB meeting

## **NOTICE: Upcoming Meeting**

Collaborative Body: Thursday, November 5, 2020 12:00PM – 1:30PM ET

## **Action Items**

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# What agreements are needed to proceed?

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Should we explore clinical registries that collect information on conditions (both reportable and non-reportable to public health)?

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Is there a potential to align with other DB workgroups like the Cancer Registries workgroup? (e.g., should we explore using cancer registries as an example to pilot in the expanded eCR infrastructure?)

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Discuss conditions where public health has authority for reporting/sending vs. when we get outside of public health authority? (e.g., behavioral health and suicide)

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Discuss the assumption that we would use the RCKMS infrastructure and trigger codes. Will CDC and CSTE be in position to expand trigger codes?

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Is AIMS willing to support and/or host upon central development of a decision support functionality for the filtering workflow?

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What are privacy implications to consider and how does Digital Bridge wish to address those?

# Information Flow

- EHR system uses trigger codes from RCTC to initiate eCR
  - eCR may contain information on more than one event
- RCKMS determines public health jurisdictions should receive eCR
- RCKMS sends eCR to appropriate public health jurisdiction(s)
- Additional decision support functionality determines which events or content should be delivered to recipients based on their legal authority to receive it

RCTC = Reportable Condition Trigger Codes

RCKMS = Reportable Conditions Knowledge Management System

# Inputs to Data Flow

- Existing trigger codes and additional triggers for new uses
- Health data from EHRs in eCR based on trigger events
- RCKMS and RCTC authoring capabilities for
  - Conditions to be triggered
  - Rules for routing
- New decision support tool authoring filtering records on content

# Outputs from Data Flow

- Workflow:
  - eCR messages
  - Reportability responses
  - Additional data exchanges supported by new decision support functionality
- Administrative: RCTC and RCKMS updates

# Technical Standards and Interoperability

- Electronic Case Reporting HL7 standards
- Documentation of public health disease reporting requirements in the centralized RCKMS
- Repository of reportability triggers is maintained in the RCTCs
- These standards are based on:
  - HL7 CDA, FHIR, ICD-10, SNOMED, LOINC, RxNorm and CVX codes

# Anticipated Users

- Public Health – chronic disease, behavioral health, drug regulatory and environmental health programs, disease registries, national associations
- Clinical Users – minimize burden on clinicians while facilitating transmission of clinical information for required or voluntary reporting
- EHRs – eliminates the need for EHR systems/vendors to develop and maintain functionality to support clinician reporting

# Anticipated Users

- Data Recipients – disease registries, clinical research trials, adverse effects monitoring organizations will benefit from the eCR Trigger Capture Create Exchange method
- Data Aggregators/Evaluators – manage content distribution/access
- Facilitators of the Process – Digital Bridge participating organizations and their partners



# Stakeholders

- **Health Care Delivery and Diagnostics**
  - Any healthcare entity that has deployed an EHR (healthcare systems, facilities, clinical trial data managers, HIEs, eHealth Exchange)
- **Industry Partners**
  - EHR vendors, health care systems, eHealth Exchange, and legal/trust frameworks
  - Public health associations managing the infrastructure currently used in eCR
    - Council of State and Territorial Epidemiologists (CSTE)
    - Association of Public Health Laboratories (APHL)
  - Public health associations advocating for improved data exchange with public health
    - Association of State and Territorial Public Health Officers (ASTHO)
    - National Association for Public Health Statistics and Information Systems (NAPHSIS)
    - American Immunization Registry Association (AIRA)

# Stakeholders

- **Government**
  - Local, state, or federal government agencies with authority to collect clinical information (FDA, NIH)
- **Community-based Organizations (CBOs)**
  - Health service, HIV/AIDS, wrap-around service organizations
  - Disease-focused associations
  - Members of the general public

# Key Issues and Risks

- **Implementation Risk**
  - Use Case Barrier – inability to establish funding or a commercial model, inability to demonstrate value to healthcare providers/data recipients, competing demands on partners/stakeholders (due to COVID-19 response)
  - Mitigation Strategy – advocate for generic infrastructure vs specific point-solution funding, good communication strategy, delay initiation until COVID-19 demands diminish
  - DB Role – facilitators for business case development and technical/legal framework, provide forum for sharing vision and opportunity with healthcare partners, offer realistic assessment or resource commitment

# Key Issues and Risks

- **Policy Risk**

- Use Case Barrier – competing priorities among healthcare delivery systems/EHR industry partners, lack of a policy mandate placing use case on the national HIT priority list, behavioral health data privacy policies
- Mitigation Strategy – explain public health urgency, marketing eCR infrastructure expansion
- DB Role – strategic communication and advocacy

- **Technical Risk**

- Use Case Barrier – filtering capabilities are new and complicated
- Mitigation Strategy – involve proper stakeholders in the requirements definition, technical assistance from eCR contractors
- DB Role – facilitation; engage right stakeholders

# Key Issues and Risks

- **Privacy Risk**
  - Use Case Barrier – new HIPAA, behavioral health, and other privacy concerns (mental health reporting)
  - Mitigation Strategy – assistance from legal experts
  - DB Role – facilitation; funding of legal experts
- **Legal Risk**
  - Use Case Barrier – need to determine authority of CSTE and APHL to act as intermediaries
  - Mitigation Strategy – assistance from legal experts
  - DB Role – facilitation; funding of legal experts

# Key Issues and Risks

- **Other Risk(s)**
  - Use Case Barrier – need for a culture change to ensure buy-in
  - Mitigation Strategy – engaging all stakeholders (including 5 DB public health leaders/funders) to be part of the solution
  - DB Role – strategic communication and advocacy, transition from pilots to scale-up, responsibilities assumed with DB’s involvement vs the decision support intermediary and organization in charge of the filtering workflow