
digital bridge

digital bridge

Collaborative Body Meeting

Thursday, November 5, 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 review the Cancer Registries Reporting (C&R) use case, re-review the Newly Reportable Conditions (NRC) use case, vote on moving one or both use cases forward, review the Skilled Nursing Facilities (SNF) work to date, and finalize the process for approving the Public Health API white paper.

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 – New Collaborative Body members
12:10 PM	Cancer Registries Reporting Workgroup Use Case Project Statement Form presentation
12:40 PM	Review of Newly Reportable Conditions using eCR Infrastructure Workgroup Use Case Project Statement Form
12:50 PM	Vote to move forward with one or both use cases
12:55 PM	Discuss implications of select use case(s)
1:05 PM	Skilled Nursing Facilities Use Case presentation on work to date
1:15 PM	Application Programming Interface White Paper
1:25 PM	Announcements and Next Steps
1:30 PM	Adjournment

Conflict of Interest Declarations?

Matters before the Collaborative Body today

1. C&R Workgroup use case
2. NRC Workgroup use case

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 | November 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

November 2020 Consent Agenda Items

1. ASTHO - J.T. Lane primary representative
   a. JT serves as the Chief Population Health & Innovation Officer at ASTHO.
2. APHL - John Loonsk primary representative
   a. Dr. Loonsk is with ONC and a consultant to APHL.
3. BCBSNC - Veronica Alas alternate representative
   a. Veronica serves as a Leader, Data & Analytics Consulting Solutions at BCBSNC.
4. CDC Foundation - Bidisha Sinha alternate representative
   a. Bidisha is a Senior Program Officer at CDCF.

Cancer Registry Use Case

David Jones (CDC), Kirsten Hagemann (Cerner), Greg Shemancik (MITRE/CodeX), and Brandon Talley (CDC Foundation)

Use Case Need

- *Major challenges face the cancer surveillance community.*
- *24 months: The time it takes to make cancer surveillance data available to the public.*
- *Where we can add value:*
  - *Breakdown data silos and reduce reliance on manual entry.*
  - *Balance data requirements to help streamline information exchange between EHRs and central cancer registries*
- *Goal: Reduce the 24 months to near real-time cancer data exchange*

Use Case Description

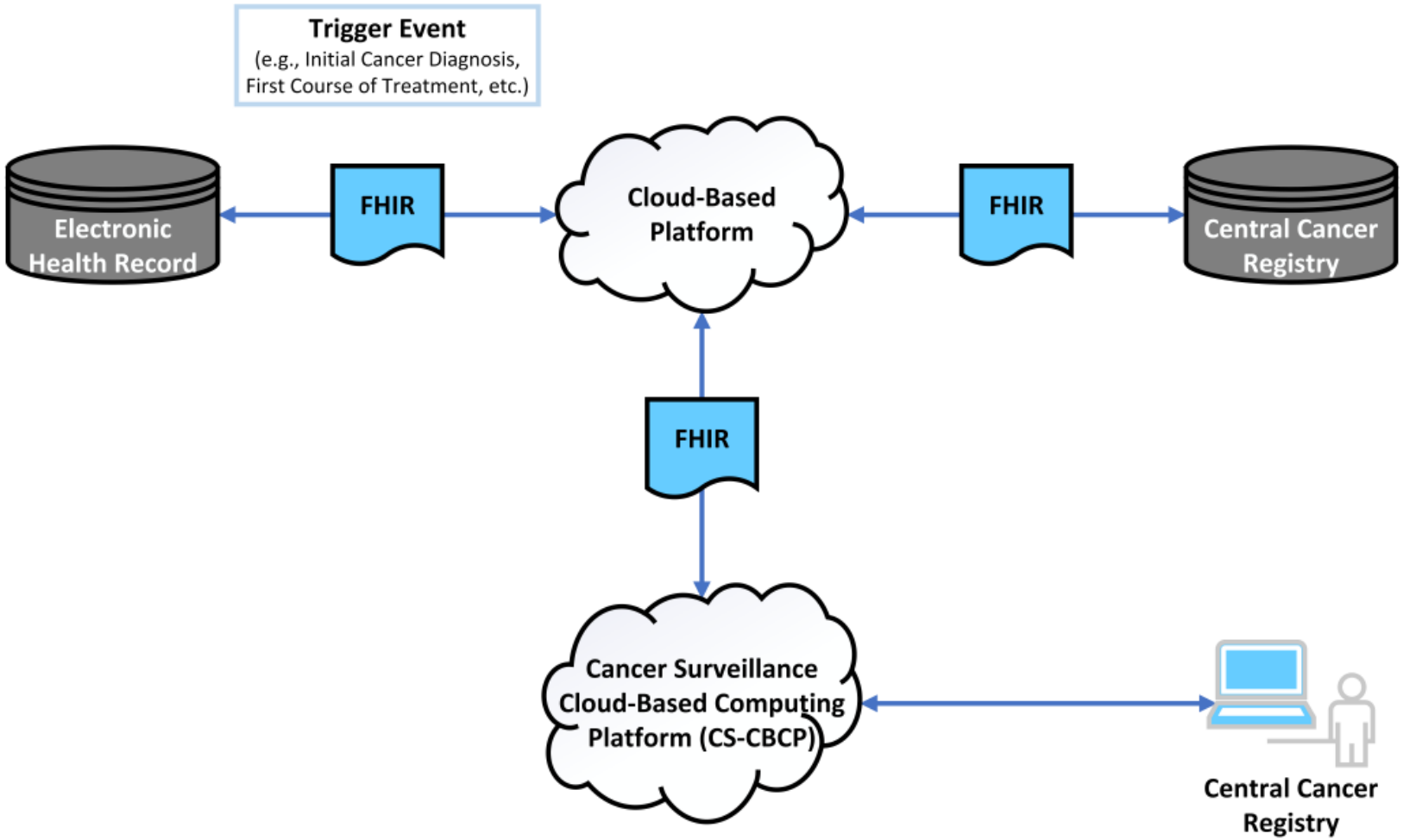
Purpose: Leverage and expand existing Digital Bridge and stakeholders' capacity and infrastructure for cancer registry reporting in near real-time.

Objectives: Collaborate with the necessary stakeholders to establish a plan, develop a solution, and implement the solution and infrastructure to accomplish the goal of near real-time cancer case data exchange in an appropriate, committed pilot site(s).

Relationship to Digital Bridge:

- *Leverages Digital Bridge as facilitator and coordinator of partners in service to the stated objective*
- *Expands on previous work of Digital Bridge by bringing FHIR to a new public health domain: cancer surveillance*

Use Case Technical Details



Use Case Stakeholders

Stakeholder Type	Specific agencies, entities, programs, etc.
Health Care Delivery and Diagnostics	Healthcare providers (oncologists, primary care providers, and other specialists), hospitals, hospital cancer registries, healthcare networks, academic medical center researchers
Industry Partners	EHR system developers and other registry involved health IT vendors, private research registries with an oncology focus, professional societies in medicine/oncology specifically
Government	CDC NPCR and National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) Program
State- and Territory-based Organizations	Jurisdiction-based central cancer registries and public health agencies
Other state/national Organizations	American Cancer Society, CDC Foundation, APHL, CSTE, and NAACCR

Use Case Potential Funders

- In-kind contributions
- Local foundations associated with pilot sites
- Partners and philanthropic organizations with interest in cancer surveillance, data modernization, or both.

What agreements are needed to proceed?

- Jurisdictions
- Partners
- Data sharing
- Pilot sites

Timeline and success metrics

- 24 months from requirement scoping to pilot implementation.
- During that period, various workgroups will need to consider not only requirements but also the technical architecture, implementation plan, legal issues, evaluation of success, and transition to sustainability.
- At a minimum, success metrics could include:
  - # of hospital-based EHRs in a pilot implementation site leveraging this project's trigger-based FHIR strategy for reporting cancer case data to a pilot implementation site's central cancer registry
  - # of physician-based EHRs in a pilot implementation site leveraging this project's trigger-based FHIR strategy for reporting cancer case data to a pilot implementation site's central cancer registry
  - Time to report cancer incidence data to the jurisdiction-based central cancer registry (date reported to jurisdiction-based central cancer registry minus date of diagnosis)
  - Time to report cancer incidence data to NPCR (date reported to NPCR minus date of cancer diagnosis)
  - Rate ratio and standard error for defining health equity at the county level in mortality outcomes for different types of cancers

Key Issues and Risks

Risk/issue Type	Description
Implementation	There may be misunderstanding that this project seeks to replace existing hospital cancer registry reporting with direct connectivity to the EHR for trigger-based reporting to central cancer registries.
Policy	Each central cancer registry is subject to the state/local regulations for cancer reporting. This presents challenges to scaling nationally when looking at standardization of cancer case reporting.
Technical	Each type of cancer can require different data elements be captured in the EHR, including both structured and unstructured data that the EHR developers should be able to capture or parse from text.
Privacy	Privacy and consent policies are a significant challenge especially when examining patient data portability when providers query for patient data.
Legal	Different jurisdictions may have differing data sharing agreement forms. Preparing a Business Associate Agreement from healthcare provider to this exchange mechanism could entail legal finesse.

Next Steps

Next Steps

- Collaborative Body decision
- Establishing needed workgroups to focus on requirements and other key areas
- Identify workgroup members
- Develop workgroup charges

Discussion with Collaborative Body

Questions for Collaborative Body

- What new Digital Bridge members might help this use case succeed?
- How might we identify resource gaps and ways to fill them?

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

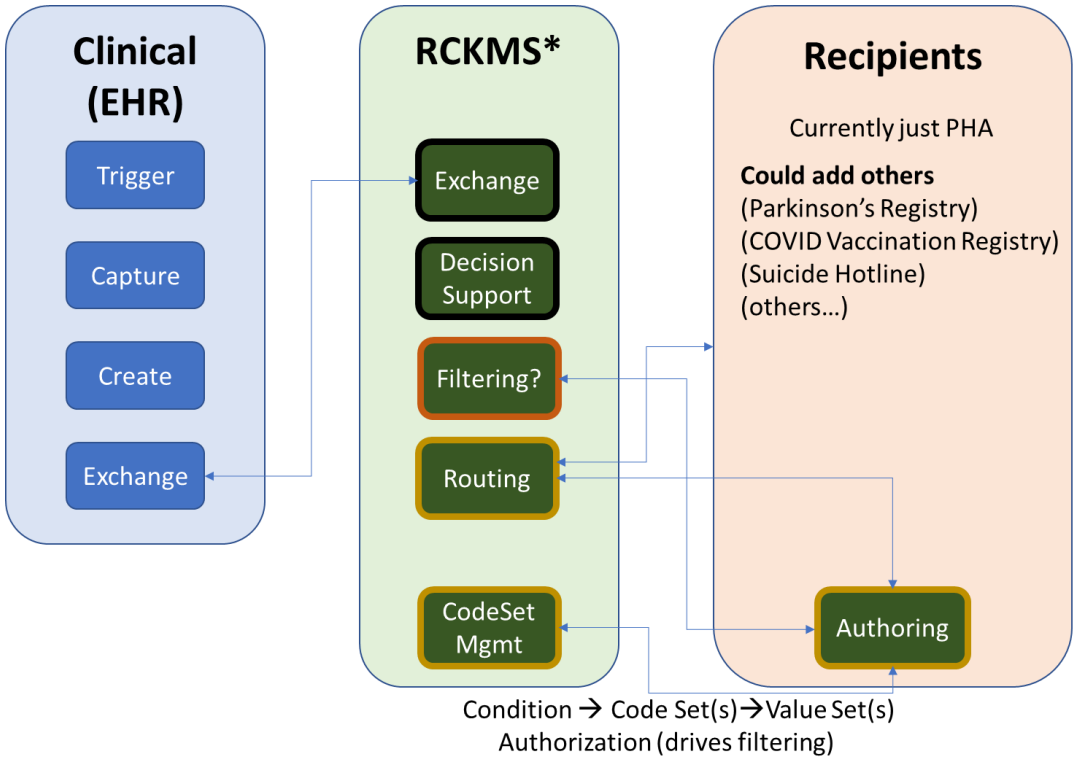
Proposed Scope

- 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

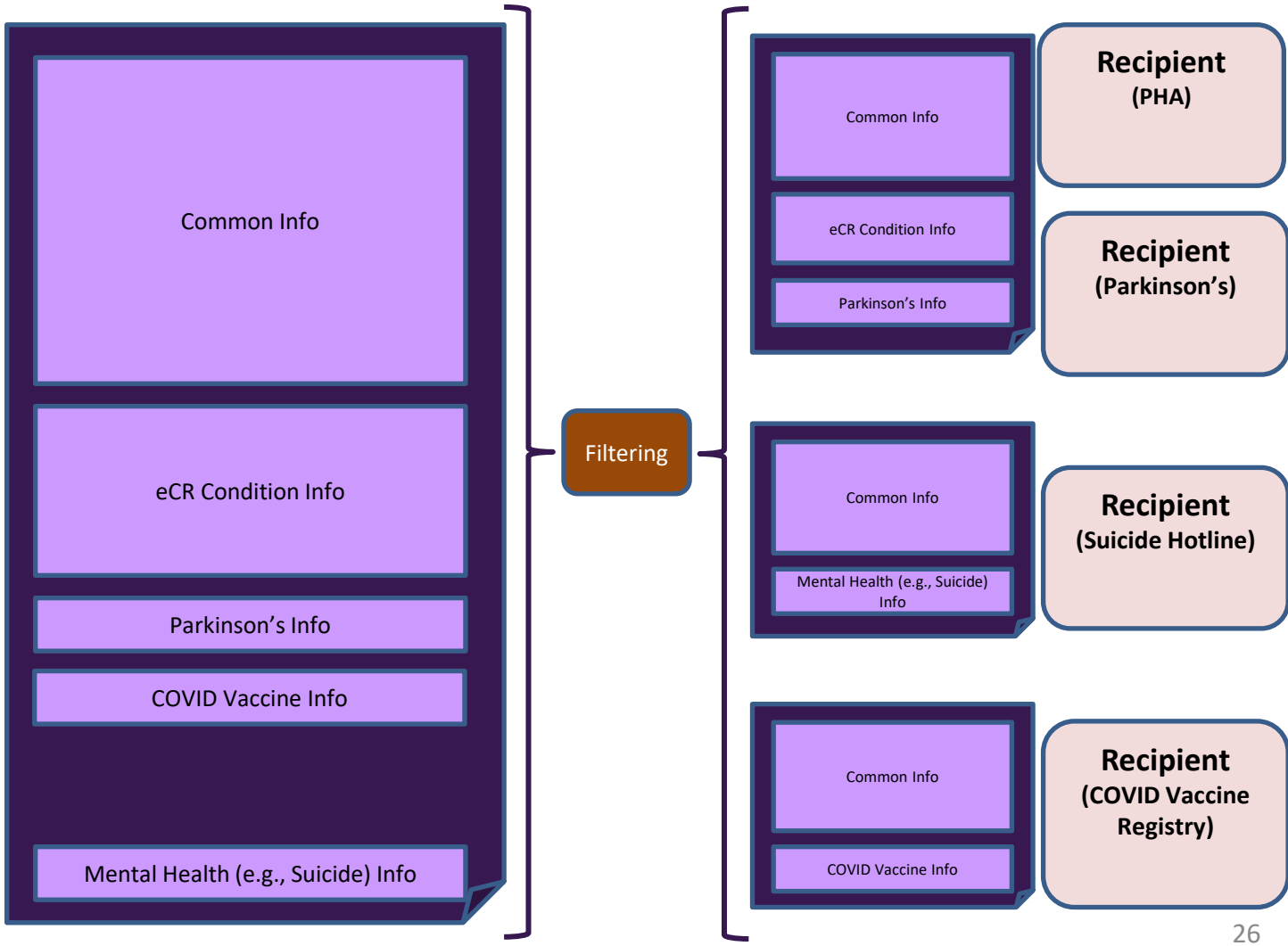
1. Reportable conditions within the Public Health purview
2. Additional reporting within the Public Health purview
3. Conditions to be reported to non-Public Health authorities

Information Flow



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

Example only – not exhaustive



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

Vote to Move Use Case(s) Forward

Implications of Selected Use Case

Considerations to move forward with use case

- Who else should be part of the Collaborative Body or workgroup?
- Funding and/or sponsorship considerations?
- Timeframe for completion of work.

Skilled Nursing Facilities Reporting Workgroup

Grace Mandel (CDC)
Jeneita Bell (CDC)

Use Case Need

1. Public Health Agencies, CDC NHSN, CMS, and healthcare organizations all need better information about healthcare acquired infections (HAIs) that originated in other institutions (or were present on admission to a new healthcare facility.
2. The data collection should return information to the skilled nursing facility or other type of healthcare facility that makes the report for quality improvement.
3. The data collection should not add burden.
4. This type of connection will support research and public health prevention.

Use Case Description

The Collaborative Cody requested answers to the below questions through this workgroup:

1. Data Requirements

2. Identify how data will be used by various stakeholders.

3. Engagement and collaboration from industry partners, particularly those who are have market share in the skilled nursing facility market.

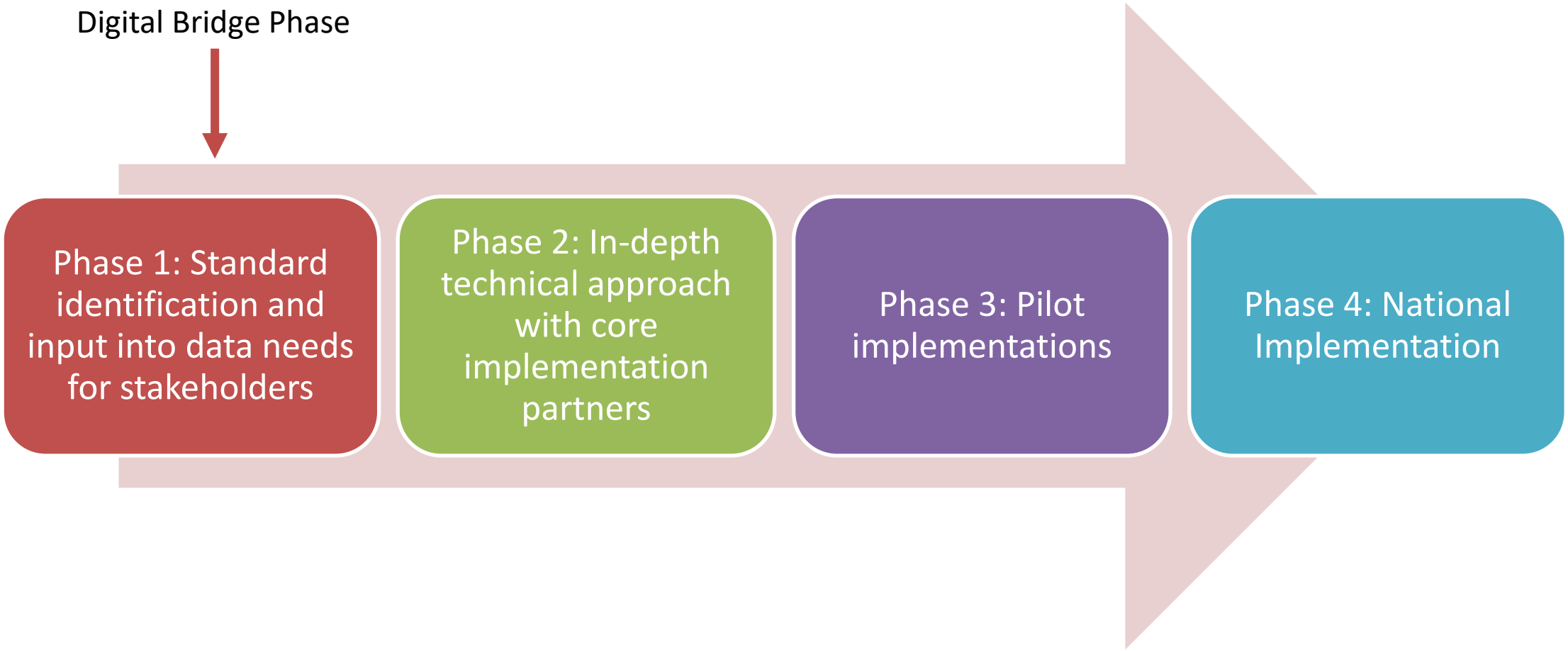
Proposed Scope

- In Scope:
  - Discussion of data requirements and standards
  - Discussion of triggering approaches
  - Discussion of EHR capabilities to support this project
  - Input on the way standards and eCR infrastructure can support the identification of healthcare acquired infections that are present on admission to healthcare facilities
- Out of scope:
  - Digital Bridge cannot advise CDC, CMS or other government entities on whether there should be a quality measure or any policy or regulatory guidance related to HAIs or SNFs.
  - Legal or policy frameworks for data flowing (too mature for this phase of development).
  - Operational responsibilities for implementing the project.

Workplan

Project Deliverables	Target Date
Convene a workgroup	Week 0
Compare standards for HAI, the eICR, and the RR	Week 3
Identify data elements needed to address healthcare acquired infections	Week 6
Analysis of approaches to data for healthcare acquired infections including data needed by public health and data needed by the nursing homes	Week 10
Discussion of how reportability response would be used and by whom (e.g., healthcare organization, SNF)?	Week 14
A proposal of data elements to ensure that the goals of the end users (in both healthcare settings and government settings) could receive appropriate information to take action. Engagement by Digital Bridge partners in leveraging existing infrastructure to improve surveillance of healthcare acquired infections that are present on admission to healthcare facilities.	Week 16

Phased Project Approach



Discussion with Collaborative Body

Questions for Collaborative Body

- What other **vendors**, **industry partners**, and **collaborators** should **participate** in this use case [and in Digital Bridge].
  - Can we get **input** from the largest **vendors** in **nursing home** and **long-term** care facility EHR market?
- How can we best **leverage electronic health records** (EHRs) for both **healthcare** and **public health**?

- Is proposal **feasible**, given the demands of the COVID response?

SNF Next Steps

Public Health API White Paper update

Walter Suarez (Kaiser Permanente)

Announcements and Next Steps

Announcements

- January virtual meeting
- Election for Executive Committee At-Large position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