Digital Bridge Collaborative Body
Annual Meeting 2021
January 21 & 22
Meeting Summary

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Meeting Information

Date:	January 21 & 22, 2021	**Location:**	Zoom; Meeting ID: Day 1: 942 0012 3795; Day 2: 943 8969 9939
Time:	1:00 – 5:00 PM ET (both days)	**Meeting Type:**	Virtual
Facilitator:	John Lumpkin	**Note Taker(s):**	Neha Agrawal & Samantha Lasky
Attendees:	See below		

Meeting Objectives

The meeting objectives of this two-day meeting were:

1. Obtain an update on and explore potential opportunities within public health data modernization and healthcare interoperability area.
2. Develop an action plan to move the Newly Reportable Conditions (NRC) and Cancer Registries (CR) use case forward over the next 12 months, by way of understanding the technical / infrastructure, legal, policy, regulatory, and implementation needs.
3. Discuss and approve version 1.0 of the Public Health API white paper, for publication and dissemination.

Materials

- NRC and CR Workgroup slides presented to CB in Fall 2020
- eCR use case charges from Technical/Infrastructure, Legal, Policy, & Regulatory, and Implementation Workgroups *(reference only, not a pre-read)*
- Public Health API White Paper
- List of questions for technical and legal/policy/regulatory breakout groups

Agenda - Thursday, January 21

Time (ET)	Agenda	Presenter/Lead Facilitator
1pm – 1:10pm (10 minutes)	Welcome, Logistics, and Meeting Overview and Goals	John Lumpkin, BCBSNC Laurie Call, IPHI
1:10-1:30 pm (20 mins)	eCR / eCR Now Update	Laura Conn, CDC CSELS
1:30-2:00 pm (30 minutes)	DB Brief History, Current State, and Where We Are Going	Vivian Singletary, PHII
2:00-2:40 pm (40 mins)	Public Health Data Modernization – John Lumpkin, Adi Gundlapalli, Bob Harmon, and Shan He ○ Public Health, represented by Adi Gundlapalli, CDC ○ Industry Partner, represented by Bob Harmon, Cerner ○ Healthcare, represented by Shan He, IMH	John Lumpkin, BCBSNC Adi Gundlapalli, CDC CSELS Bob Harmon, Cerner Shan He, Intermountain Healthcare

2:40-3:00 pm (20 mins)	BREAK	
3:00-3:30 pm (30 mins)	Level Setting and Combining CR with NRC into Single Use Case	1. John Lumpkin, BCBSNC 2. Comments from Collaborative Body
3:30-4:30 pm (1 hour)	Breakout Session A: Technical Infrastructure Breakout Group	Richard Hornaday, Allscripts
3:30-4:30 pm (1 hour)	Breakout Session B: Legal/Policy/Regulatory (LPR) Breakout Group	Walter Suarez, Kaiser Permanente
4:30-4:40 pm (10 mins)	BREAK	
4:40-5:00 pm (20 mins)	CONCLUDE DAY 1	John Lumpkin, BCBSNC

Agenda - Friday, January 22

Time (ET)	Agenda	Presenter/Lead Facilitator
1:00-1:10 pm (10 mins)	Welcome / Day 1 Reflection / Day 2 Overview	John Lumpkin, BCBSNC
1:10-1:30 pm (20 mins)	Technical Infrastructure Large Group Report Out from Day 1	Volunteer from Day 1 and feedback from Collaborative Body
1:30-1:50 pm (20 mins)	LPR Large Group Report Out from Day 1	Volunteer from Day 1 and feedback from Collaborative Body
1:50-2:00 pm (10 mins)	Breakout Group Instructions and Transition to Breakout Groups	
2:00-3:00 pm (1 hour)	Technical Infrastructure Breakout Group	Richard Hornaday, Allscripts
2:00-3:00 pm (1 hour)	LPR Breakout Group	Walter Suarez, Kaiser Permanente
3:00-3:20 pm (20 mins)	BREAK	
3:20-3:40 pm (20 mins)	Technical Infrastructure Large Group Report Out	Volunteer from group
3:40-4:00 pm (20 mins)	LPR Large Group Report Out	Volunteer from group
4:00-4:45 pm (45 mins)	Public Health API White Paper Update	Walter Suarez, Kaiser Permanente
4:45-5:00 pm (15 mins)	CONCLUDE DAY 2	John Lumpkin, BCBSNC

Decisions

1. The Collaborative Body approved the public health API white paper as version 1.0, with subsequent edits to be made including updates to the eCR section and updates to the building blocks figure.

Thursday, January 21, 2021 - Meeting Attendance

Sector	Organization	Attendee
Industry Partner	Allscripts	Richard Hornaday
Health Care	AMA	Andrea Garcia
Public Health	APHL	John Loonsk
Public Health	APHL	Michelle Meigs
Public Health	APHL	Scott Becker
Public Health	ASTHO	Mylynn Tufte
Public Health	ASTHO	Priyanka Surio
Non-member	ASTHO	Zeeshawn Chughtai
Insurance	BCBSNC	Veronica Alas
Insurance	BCBSNC	John Lumpkin
Public Health	CDC	Grace Mandel
Public Health	CDC	Laura Conn
Public Health	CDC	Adi Gundlapalli
Non-member	CDC	Lesliann Helmus
Non-member	CDC	David Jones
Non-member	CDC	Wendy Blumenthal
Sponsor	CDC Foundation	Bidisha Sinha
Sponsor	CDC Foundation	Brandon Talley
Sponsor	CDC Foundation	Judith Monroe
Industry Partner	Cerner	Bob Harmon
Industry Partner	Cerner	Kirsten Hagemann
Industry Partner	Cerner	Hans J. Buitendijk
Public Health	CSTE	Janet Hamilton
Public Health	CSTE	Kathy Turner
Public Health	CSTE	Becky Lampkins
Public Health	CSTE	Jeff Engel
Former Sponsor	de Beaumont Foundation	Christine Kudrav
Health Care	Deloitte	John Stinn
Health Care	Deloitte	Andy Wiesenthal
Industry Partner	eClinical Works	Tushar Malhotra
Industry Partner	Epic	Christopher Alban
Non-member	Epic	Nicky Quick
Health Care	HealthPartners	Richard Paskach
Health Care	HIMSS	Mari Greenberger
Health Care	Intermountain Healthcare	Sid Thornton
Health Care	Intermountain Healthcare	Shan He

Health Care	Kaiser Permanente	Walter Suarez
Health Care	Kaiser Permanente	Indu Ramachandran
Industry Partner	Meditech	Joe Wall
Public Health	NACCHO	Oscar Alleyne
Public Health	NACCHO	Art Davidson
Public Health	ONC	Rachel Abbey
Public Health	ONC	Dan Chaput
Non-member	Pew Charitable Trust	Ben Moscovitch
Non-member	Pew Charitable Trust	Molly Murray
Public Health	PHII	Vivian Singletary
Former Sponsor	RWJF	Hilary Heishman

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Health Care	Deloitte	Andy Wiesenthal
Industry Partner	Epic	Christopher Alban
Non-member	Epic	Nicky Quick
Non-member	Epic	John Stamm
Health Care	HealthPartners	Richard Paskach
Health Care	HIMSS	Eli Fleet
Health Care	Intermountain Healthcare	Sid Thornton
Health Care	Intermountain Healthcare	Shan He
Health Care	Kaiser Permanente	Walter Suarez

Health Care	Kaiser Permanente	Indu Ramachandran
Industry Partner	Meditech	Joe Wall
Public Health	NACCHO	Art Davidson
Public Health	NACCHO	Oscar Alleyne
Non-member	Pew Charitable Trust	Molly Murray

Meeting Notes

Thursday, January 21, 2021

1. **Call to Order**

Quorum was met.

2. **Welcome, Logistics, and Meeting Overview and Goals** *(John Lumpkin, BCBSNC and Laurie Call, IPHI)*

Laurie Call, IPHI staff, welcomed the group and requested that attendees introduce themselves in the chat by filling out their name, organization, sector, and answer to the ice-breaker question, "what do you see as Digital Bridge's value?" Meeting attendees let IPHI staff know which breakout session they would like to attend if they had not done so already.

Laurie welcomed HIMSS, the newest organizational member to join the Digital Bridge Collaborative Body. HIMSS will a voting member of the Collaborative Body and will represent the Healthcare sector. The Primary Representative is Mari Greenberger, MPPA, Senior Director of Informatics. Alternative Representatives are Christel Anderson, Vice President of Informatics, Eli Fleet, Director of Federal Affairs, and Jessie Bird, CAE, Manager of Strategic Relations.

Laurie reviewed meeting logistics, for example, the meeting will be recorded for note-taking purposes, all unidentified names or phone numbers must identify themselves or may be disconnected for security reasons, attendees can mute and unmute themselves but should remained muted if there is any background noise, participants should use video camera if available/able, and input comments or questions into the Zoom chat box. Laurie then handed it over to John Lumpkin, MD MPH, Blue Cross Blue Shield of North Carolina (BCBSNC), and Digital Bridge Chair.

Dr. Lumpkin provided the Digital Bridge context for this annual meeting, specifically that it is an important checkpoint and milestone for the initiative; members can spend some time together and move forward Digital Bridge's agenda. Dr. Lumpkin also set the context of the meeting within the landscape of national and world events. First, this is the beginning of a new (Biden) administration. With that comes new appointments, and the new director of CDC (Rochelle P. Walensky, MD, MPH began her post as the 19th Director of the CDC) has highlighted the importance of policy development based on scientific evidence. Digital Bridge is appreciative for its partnership with the CDC. Dr. Lumpkin also had as part of his Zoom background the Lincoln Memorial reflecting pool adorned with 400 lights from earlier in the week. Each light represented 1000 people who have died from COVID-19. It is important to keep COVID-19 in mind during this meeting. There has been much accomplishment with eCR as it has been significant in getting the country to monitor and identify how the pandemic is progressing. At the same time, the pandemic has presented a challenge in Digital Bridge member bandwidth and carrying out programming. When the Digital Bridge had its 2020 annual meeting it scoped four use cases and a white paper. However, with the onset and duration of the pandemic, bandwidth of Digital Bridge members has been re-focused to pandemic-relief efforts from healthcare, public health, and industry vantage points. To that end, the focus of Digital Bridge now is moving the combined Cancer Registries (CR) and Newly Reportable Conditions (NRC) use cases forward and sharing and refining the public health API white paper. The 1918 pandemic left an indelible mark on those who survived it and this pandemic will have the same effect on our society.

Dr. Lumpkin reviewed the day's agenda, the crux of which is to develop a workplan around the technical infrastructure and legal/policy/regulatory (LPR) requirements to move the CR/NRC use case forward. The day 1 agenda begins with an update on eCR and eCR Now, which resides with the CDC, CSTE, and APHL. There will be an overview of the Digital Bridge history and accomplishments, its current state, and future goals. Next there will be a panel discussion with members of Digital Bridge, to

discuss key issues around public health data modernization and healthcare interoperability. Before dividing into breakout groups, Dr. Lumpkin will level set on the single use case that is focused on CR within the NRC enhanced and general infrastructure. The group will divide into breakout groups focusing on either the technical aspects or LPR aspects of the use case, and build upon our experience from developing and implementing eCR. The group will re-convene for a brief conclusion and preview of day 2, before adjourning for the day.

The meeting objectives are:

- Obtain an update on and explore potential opportunities within public health data modernization and healthcare interoperability area.
- Develop an action plan to move the Newly Reportable Conditions (NRC) and Cancer Registries (CR) use case forward over the next 12 months, by way of understanding the technical / infrastructure, legal, policy, regulatory, and implementation needs.
- Discuss and approve version 1.0 of the Public Health API white paper, for publication and dissemination.

3. **eCR / eCR Now Update** *(Laura Conn, CDC CSELS and John Loonsk, APHL)*

Laura Conn, MPH, eCR Lead, Health Scientist, CSELS, CDC and John Loonsk, MD, eCR Lead, APHL provided an update. See here for the eCR January 2021 update. Member discussion and question/answer session ensued. A member asked about eCR Now – Element 3, the Nationwide eCR trust framework for eHealth Exchange, Carequality, and CommonWell Health Alliance members specifically if CDC, CSTE, and APHL have run into challenges from public health agencies around joining the trust framework since not all of them are leveraging syndromic surveillance. The presenters answered that the public health agency does not need to be a member for this to function, and most of them are not. The setup of the policy architecture is that APHL is the one that needs to be a member and APHL makes a public health disclosure to the appropriate public health agency after processing in RCKMS. By virtue of APHL's agreement with eHealth Exchange, Carequality, and CommonWell Health Alliance a link of trust is established and goes from the provider to those links, to APHL, and then a public health disclosure is made to the public health agency. Another member asked about the state public health agency's ability to consume the eCR reports and automatically integrate the reports into their electronic disease surveillance systems. The presenters noted that this is an area of work that is needed. There is currently a lot of variance with jurisdictions; some are using them readily and putting them into surveillance systems, for example Utah worked with them early on with Intermountain Healthcare and provided feedback that they were seeing case reports before lab reports. Other jurisdictions are relying heavily on the human readable, HTML. APHL has a strong technical assistance component and has been working with states on a one-on-one basis. For example, APHL has been making calls to state and utilizing a mapper tool, which was developed by APHL and assists with eICR consumption into surveillance system. There is an evaluation effort underway with the state of Florida and preliminary analysis shows that their eCR race and ethnicity data is over 90 percent complete compared with 40-50 percent complete in the lab and manual reports. CDC has a data use agreement with the Florida Department of Health so can get more definitive data and share more broadly when appropriate. This builds off the earlier evaluation plan Digital Bridge worked on.

4. **Digital Bridge History, Current State, and Where We Are Going** *(Vivian Singletary, PHII)*

Vivian Singletary, MBA, JM, Public Health Informatics Institute, and Digital Bridge Vice Chair provided the group with an overview of the origins of Digital Bridge, what the initiative has achieved to date, and where it is going. "A Journey of A Thousand Miles Begins With One Step" ~Lao Tzu. Digital Bridge formed in 2016 and began with an inaugural meeting in June 2016 in Chicago, IL. Healthcare, public health, and industry partners decided that there needs to be a better way to exchange data between healthcare and public health. A governing body was formed comprised of leaders from these three entities. Digital Bridge was initially funded by the Robert Wood Johnson Foundation, operated by PHII and Kahuina Consulting, and

Chaired by Dr. Lumpkin. Digital Bridge's first use case was electronic case reporting (eCR) and in 2016 the group created high-level objectives and a structure to support this use case. In 2017, Digital Bridge continued its journey of designing eCR leveraging existing data standards. Digital Bridge formed workgroups to support eCR, for example the Technical / Infrastructure workgroup, which developed functional requirements and the technical infrastructure, created initial sustainability and communications plans, shared preliminary legal recommendations, and selected eCR implementation sites. Vivian gave thanks to supporting stakeholders such as RWJF, de Beaumont Foundation, CDC, Cerner, Allscripts, Meditech, and Epic as progress on work would not have been successful without their belief in this endeavor. In 2018 Digital Bridge coordinated getting legal forms and agreements in place for implementation at initial pilot sites. eCR launched its first implementation site in late 2018. Digital Bridge also established additional workgroups to support eCR and held its second in-person governance body meeting. In 2019 the Digital Bridge progressed with additional success; eCR was implemented at several sites and demonstrated that implementation in varying conditions was and is possible. Digital Bridge began evaluations of initial implementation sites and developed recommendations to scale eCR nationally. In Fall 2019 eCR was fully transitioned to CDC, APHL, and CSTE. In January 2020, the Digital Bridge held its annual meeting in Atlanta, GA. The Collaborative Body decided to incubate four new use cases and a white paper topic:

1. Newly Reportable Conditions using eCR Infrastructure
2. Cancer Registries
3. Immunization Registries
4. National Health care Safety Network Reporting of Healthcare Acquired Infections Reporting by Skilled Nursing Facilities
5. Public Health Application Programming Interfaces white paper

However, weeks after the 2020 annual meeting the COVID-19 pandemic hit and reinforced the understanding and journey that began in 2016 to promote the bi-directionality of data exchange between healthcare and public health. Although met with the pandemic, the Collaborative Body continued its work and accomplished the following:

<u>February – April 2020</u>

- Collaborative Body formed Digital Bridge Charter and Bylaws
- Scoping Methods Workgroup developed a Use Case Project Statement Form for use case workgroups to complete
- Dr. Lumpkin re-elected as Digital Bridge Chair

<u>May – July 2020</u>

- Vivian Singletary, MBA, JM elected as Digital Bridge Vice Chair
- Executive Committee formed
- IPHI assumed role of Secretariat of Digital Bridge program
- Use Case Workgroup Chairs and Members appointed
- Executive Committee finalized a Use Case Assessment and Feedback tool to evaluate proposed use cases for moving forward

<u>August – November 2020</u>

- With input from the Executive Committee, the Collaborative Body reviewed all four uses cases at its September and November meetings and made the decision to move forward with CR and NRC.
- The Public Health API white paper went to public comment through the end of 2020.

In terms of the way forward, Digital Bridge has more to do and more steps to take in its journey. The Collaborative Body made the decision to move forward with the CR and NRC use cases and the public health API white paper. Much thanks and appreciation to Digital Bridge members and workgroup members who have stayed engaged in this visionary work. There will be other pandemics that touch our lives and loved ones in the future. As the group continues its work of Digital Bridge to help organizations and the country in exchanging critical information between public health and healthcare, know that the work the group is doing is vital and much needed to support the nation's health.

After the presentation concluded, a Collaborative Body member asked about the future state of the Immunization Registries (IZ) use case and the Skilled Nursing Facilities (SNF) use case. With the pandemic there is reduced bandwidth of the voluntary Digital Bridge workforce to address all four use cases. The CDC, in collaboration with the Department of Health & Human Services Office of the Chief Technology Officer, sponsored and executed the Immunization (IZ) Gateway project which has been a focus of national efforts towards interstate immunization information system data sharing. The IZ use case meets bi-monthly to obtain updates on the IZ Gateway project and other related endeavors. If there is supporting work or gaps to fill that Digital Bridge has the capacity to take on, it will address this later. Once Digital Bridge members have signed up for workgroups to support the NRC and CR use cases, the SNF workgroup will revise its end-state deliverable and potentially broaden the original scope, which was to examine and potentially pursue a solution to advance SNF surveillance and quality measurement. That workgroup will gauge if CB members have the capacity to work on the revised proposal. Another Collaborative Body wanted to recognize the public health community platform initiative from 2014-2016, staffed by ASTHO, which laid the groundwork of the AIMS platform and eCR as an important use case opportunity. This was funded by the CDC and then handed over to Digital Bridge. It is also part of the history that is posted on the eCR Now website.

5. **Public Health Data Modernization Panel** *(John Lumpkin, BCBSNC, Adi Gundlapalli, CDC CSELS, Bob Harmon, Cerner, and Shan He, Intermountain Healthcare)*

Adi V. Gundlapalli, MD, PhD, MS, CDC CSELS provided an update on public health data modernization, reinforcing the need to accelerate data modernization efforts and changing the culture around data and innovation. Dr. Gundlapalli's presentation included the opportunities for prevention and response, CDC's data modernization priorities, and priority focus areas – vital records, syndromic surveillance, electronic case reporting, reportable conditions, and electronic laboratory data exchange. See here for the full presentation.

Bob Harmon, MD, Cerner thanked Dr. Gundlapalli for his presentation and emphasized that CDC has strong support for its data modernization efforts and pandemic response leadership. Dr. Harmon represents the industry partner perspective. Cerner recommendations were submitted to the CDC after ongoing virtual meetings; recommendations included connecting the surveillance systems to one platform, complete with modern standards, requirements, and interoperability. In the process this would remove silos, help with provider burden, and enable real-time analysis that would ultimately assist with policy making. Cerner has been working with the eCR Now team, including APHL, for some time to use the FHIR-app approach to adopt eCR. Cerner expects that the FHIR-app approach will be generally available by March 1. Several Cerner clients are eager to adopt it and other industry partners are in route to implementing the CDA and FHIR-app approach as well. One of the reasons for the delay at Cerner is the increased complexity on the front-end with the FHIR app, but once it is up and running it will be quick for clients to adopt. Cerner has held multiple virtual forums with its clients on a variety of topics to provide guidance on operating within the context of the pandemic. Many EHR tools have been produced, including alerts, order sets, care pathways, patient communication guidelines, and quick visits. A needed area going forward is mass vaccination capabilities. All along the way Cerner has been utilizing CDC guidelines. A growth area has been telehealth solutions, digital self-service, and reporting. Many of these solutions have been adopted by the Department of Defense. Dr. Harmon concluded by emphasizing that with the new leadership in the White House and CDC there is a renewed opportunity to pursue expanded data modernization as well as pandemic control.

Shan He, PhD, Intermountain Healthcare (IMH) thanked Dr. Harmon and shared a slide depicting existing public health interoperability projects/efforts at IMH. Data sharing goes from IMH to several public health agencies including the Utah Department of Health, Utah Public health Laboratory (also called state lab), and CDC's National Healthcare Safety Network (NHSN). Dr. He reviewed the number of initiatives underway related to interoperability including:

- eCR and electronic lab reporting.

  - IMH implemented the eCR solution with Cerner's EHR, which went live end of 2018.
  - Recently re-designed electronic lab reporting solution to send real-time lab reporting to the state.
- Diagnostic Newborn Hearing Test Reporting.
  - Is an early hearing intervention program and accomplished this five or six years ago.
  - Before this project, had to manually pull reports of newborns that failed hearing tests. Designed automated solution using CDA standards and have been sending records to public health agency.
- Immunization Integration.
  - Utah has an Immunization registry called Utah Statewide Immunization Information System (USIIS).
  - Working on integration based on Cerner EHR to query the forecast, query the immunization history, and submit immunization records to the state. Enabled functionality to receive data on patients who received immunizations outside of IMH.
- Syndromic surveillance.
  - Based on Cerner syndromic surveillance that Dr. Harmon discussed.
- Newborn screening.
  - Goal of project is to send electronic orders to state labs and integrate newborn screening results into EHR. This is an ongoing project.
  - Enable specimen tracking so that they system can catch if a specimen is delayed.
- Death Data Integration.
  - Receiving death data from the state; working with state to get the cause of death in addition to end result of death.
- Birth Data Integration
  - Currently a manual effort to report birth data to the state.
  - Looking to make this a two-way, automated communication, between healthcare and public health.

Dr. Lumpkin posed the first question - **to what extent do you see the work of Digital Bridge helping the public health system meet 21st Century challenges?** Dr. Harmon noted the reference to "The Future of the Public's Health in the 21st Century" report that the Institute of Medicine Committee on Assuring the Health of the Public in the 21st Century put forth several years ago. This famous report highlighted the inadequacies of public health in America due to underfunding. Dr. Harmon noted that COVID-19 has highlighted these inadequacies. Digital Bridge is trying to modernize and centralize its approach with national platforms, standards, and requirements so all states and territories can participate in a coordinated fashion. With COVID-19 this needs to happen fast. Dr. He commented that from the healthcare perspective there have always been competing priorities with technical needs, the public health infrastructure, and clinical needs. Digital Bridge can help obtain more resources into this area and increase the number of people recognizing this as a priority. Dr. Gundlapalli prefaced his comments stating that this was his own viewpoint and not that of the CDC. Where we want to be may always be elusive. Could not have predicted what a leap was needed to respond to the pandemic. We should be in a continuous cycle of improvement, combining a leapfrog approach and an incremental approach. In addition, cannot and should not answer the challenges with the same questions asked around that challenge. The bigger question is should every system be individualized to its own needs and designs or should all systems be integrated into some sort of cloud-based system.

Andrew Wiesenthal, MD, Deloitte, applauded the panelists on all the good work within each sector they represent. Deloitte works in multiple jurisdictions around the country. What they are seeing now in terms of gaps is a result of investment and funding gaps, as well as the federated nature of public health which is a matter of policy. California and Texas have the same problem as the federal level. Cannot dictate to the local health jurisdiction what health system they are going to use. Recommendation that a collaboration such as Digital Bridge to propose a standard data model and have local jurisdictions add to it as appropriate, for specific local health purposes. Janet Hamilton, MPH, CSTE commented that another consideration is the current laws and rules; can have identifiable information at the state and local level, but the federal level

does not include this. The way data are shared between federal and state changed immediately with the pandemic and states were surprised by that. Digital Bridge could think through intermediaries so states are comfortable with what sharing data should look like. Dr. Lumpkin agreed with Dr. Wiesenthal's comments raises a question on the basis for the formation of Digital Bridge. In addition to Digital Bridge convening public health, healthcare, and industry partners, a key component is convening public health stakeholders to define requirements. A critical change from the past has been taking a standards-based approach. Back in the day data systems were provided to us from the federal level, were disparate, and required manual data entry. As we implement the CR/NRC use case, should think about Digital Bridge as a forum to address these issues that have been discussed. John Loonsk, MD, APHL noted that in the research community there has been a lot of movement to using a FHIR-data standard since it has been adopted within clinical settings. Lesliann Helmus, MS, CHTS-CP, CDC, noted that the National Electronic Disease Surveillance System (NEDSS) Base System (NBS) is currently used in 23 states. NEDSS NBS is a CDC-developed integrated information system that helps local, state, and territorial public health departments manage reportable disease data and send notifiable disease data to CDC. Richard Hornaday, Allscripts emphasized the importance of a unified structure. Once a unified structure is in place, people can tailor the system to their preferences at their own cost.

6. **Level Setting and Combining CR with NRC into Single Use Case** *(John Lumpkin, BCBSNC and comments from Collaborative Body)*

The remainder of the afternoon to focus on the combined NRC and CR use case. Dr. Lumpkin briefly described the context for this use case, namely that it is the result of about a year's work on the project statement forms, and deliberation by the Collaborative Body. CR and NRC started off separately and each use case workgroup developed timelines, its scope of work, and presented a detailed presentation to the Executive Committee and Collaborative Body. After the Collaborative Body met in Fall 2020 and voted to move both use cases forward, there was a recommendation that the workgroups meet to determine where there is overlap and how to move forward in a coordinated way. Out of this came the recommendation that the pilot use case to target for using the enhanced genericized eCR infrastructure will be Cancer Registries, and these will be the focus of Digital Bridge over the next several months. Later can look at other "use cases" such as Parkinson's Disease. To move forward, will rely on the experiences from eCR, which had a few workgroups including technical infrastructure (dissolved later into implementation) and LPR workgroups. Technical and LPR cannot work in isolation so an overarching workgroup can serve as the coordinating function and engage in activities such as stakeholder outreach. The goal for today is to think through what we can leverage from eCR's corresponding workgroup and where there may be gaps. In addition, what additional stakeholder should be invited to the Collaborative Body, potential funding sources, and an initial development of tasks for the workgroup. One differentiation of Cancer Registries is the longitudinal nature of a cancer record, for example the diagnosis, treatment, how effective treatment is, and outcomes within a single record. Have had conversations with CDC and the division of non-infectious diseases is very interested in Cancer Registries. Lastly, as the group works through the technical architecture should think about how rapidly the infrastructure can be used for Parkinson's and other diseases. Dr. Lumpkin opened the discussion to the Collaborative Body.

A member recommended re-naming the project to better capture the revised intent. The term "newly" referred to a new use of the existing eCR infrastructure and building it out to support other conditions. There was group consensus to re-name this use case and that will be a task of the breakout groups.

Walter Suarez, MD, MPH, Kaiser Permanente, provided a brief overview of the LPR breakout group. The main purpose of this workgroup will be to advise, identify, and define the best available legal framework to achieve the implementation of Cancer Registries within NRC generic infrastructure, and recommending alternative technical approaches to make implementation more feasible from legal and regulatory perspectives. Between today and tomorrow the breakout group will look at commonalities and differences across jurisdictions from an LPR lens and solutions to potential legal challenges the technical

workgroup may encounter. Richard Hornaday, Allscripts, provided a brief overview of the Technical breakout group. Purpose of today is to identify what the gaps are amongst the existing eCR infrastructure, to meet the end goal of supporting recipients beyond the existing Public Health Agency bases such as Cancer Registries within an enhanced nationwide eCR infrastructure. Specifically, will look at an overview of the current proposal for handling other scenarios, additional technical and data requirements, additional stakeholders and outreach plans, scheduling and logistics, funding opportunities and challenges, and implementation considerations. Need to create a user environment e.g., for authoring) that is customized to the needs of the user and ensure the user is not getting data elements s/he does not need.

7. **Breakout Session A: Technical Infrastructure Breakout Group** *(Richard Hornaday, Allscripts)*

Overview and Purpose of Technical Infrastructure
Purpose of today is to look at the current eCR infrastructure, the future state of the infrastructure which would include the filtering tool and additional required functionality, discuss data and requirements needed to get to the future state, additional stakeholders to invite to Digital Bridge to support this use case, and an outreach plan. The initial goal of this use case is to implement Cancer Registries within NRC enhanced infrastructure.

Agenda for both days:

- Overview of the current proposal for handling other scenarios
- Discussion: Additional technical and data requirements
- Discussion: Additional stakeholders and outreach plans
- Discussion: Schedule and logistics
- Discussion: Funding opportunities & challenges
- Discussion: Implementation considerations

Key Discussion Points

Current eCR Infrastructure

- Clinical (EHR):
    - No overt action by clinical staff, as this happens on the backend. That means no need to train clinicians
    - Simple triggering (no “AND” or “IF” conditions)
    - This vertical includes trigger, capture, create, and exchange
- Nationwide Decision Support Intermediary:
    - AIMS and RCKMS platforms, as both address these capabilities
    - No storage of eICR messages (process & forward only)
    - Current functions include exchange, decision support, routing, and code set management.
    - Will have to look at complexity and HIPAA-related issues if eICR messages are stored.
- Public Health (recipient)
    - eICR(s), ELR(s), and other sources are linked together.
    - Currently public health agencies are the sole recipients
- Condition → Code Set(s)→Value Set(s)

Future state of Infrastructure

- Decision Support Intermediary:
    - No Storage of eICR messages (process & forward only)

    - Current functions include exchange, decision support, routing, and code set management. With the enhanced infrastructure, it will also include "filtering" and access control enhancements such as Authorization/Roles to provide usable control of these enhancements
    - CDC already has plans for updating Reportable Conditions Trigger Codes (RCTC) for all reportable conditions
- Recipients
    - Could add others outside the existing Public Health Agency recipients, with initial focus on Cancer Registries
    - 70-75% of hospitals have their own cancer registries. Reporting from EHRs to cancer registries in this use case to exclude these hospital registries (i.e. focus of this use case not looking to replace hospital registries).
- Legal consideration that if information is automated from EHR, hospitals still need to report. This use case does not replace this requirement.
- Policy concern – just because we have eICR does not mean pipeline from lab reporting should be turned off.
- This is a generic infrastructure – so goal is to accommodate many scenarios in the future.

Example of additional capabilities

- See slide 45 here for the example.
- Robust additional information you get from common data elements.
- The filtering tool decides what information (triggered data elements) gets routed where. Recipient should not get superfluous information.
- Core set of information in each eICR and then added modules for each triggered data element.
- Filtering would not be applied to core set of information as everyone gets that. It is the modules on a per-trigger basis that are set up as adjunct – that is where filtering comes in. eICR with multiple triggered components is where filtering applies. There are some data elements that cancer registries normally do not get but would have use for.
- RCKMS authoring currently has the capability of where data should get routed to, based on authoring rules. This may be sufficient for this enhanced use case, but further enhancements may be needed (open requirements item)
- Need to architect this in such a way that is usable and user-friendly. Include in design considerations.
- A precedent is being set for the cancer registries to leverage AIMS existing connections with the PHAs for electronic pathology reporting rather than establish direct connections to the cancer registries. At this point in time only one registry, CA cancer registry, has a direct connection to AIMS.

Additional technical and data requirements

1. Trigger codes to drive complete report of clinical information
    - Goal: no modifications to existing RCTC structure (e.g., no additional code sets beyond those currently supported)
2. Decision support tool
    - Filtering to provide tailored information to each recipient (role)
    - Routing the filtered data to the appropriate recipients
    - Identify and mange gaps / other needed capabilities
3. Content of common data elements
4. Updates to authoring tools
    - New requirements, or evolution of existing RCKMS authoring capabilities?
    - Optimizing usability to manage additional complexity

- One potential gap – need for longitudinal record. Address at recipient level since correlation needs likely differ by each recipient/user needs. If this is a requirement on DSI, this would require storage & correlation in DSI – potential HIPAA and policy issues.

- Have initial trigger codes. Do not want to modify existing RCTC structure. Changing value sets is fine, but not changing the structure.
- Need to accommodate both passive intermediaries and active intermediaries.
- RCKMS is doing a piece of this, but AIMS platform does end-to-end processing. Specifically, AIMS (not just RCKMS) is integral even to the FHIR-based implementation.
- A related potential gap was identified: Does the solution require AIMS/RCKMS as the DSI, or could our solution support other DSIs? It was noted that if other DSIs were supported, this likely would require EHRs to fork a common eICR to multiple destinations.
- Is there additional information that some recipients may need that is not in the CDA? Specifically, in the Common aspects of the eICR?
- Existing RCKMS authoring process does not need to always pick and choose value sets; it often operates at a higher abstraction level.
- Common data elements – common clinical data set (CCDS) is part of eICR. There is a robust process for making changes within HL7.
- Common clinical data set (CCDS) is shifting to become part of USCDI (US Core Data for Interoperability).
- CSTE has already made a RCTC available for all notifiable conditions. They are extending to reportable conditions (that are not notifiable) now.
- It was noted that some Cancer Registries get very robust information already from some Hospital and University systems and thus may have reduced need for information in an eICR. Need to determine whether these scenarios would need DSI to suppress eICR to those recipients or if they would want to get them anyway to correlate to their existing robust source.
    - As a related item, it was noted that when eICR delivery exists, it would be a goal that sources (Hospitals/Universities) do not cancel/suspend these robust sources – at least until there can be analysis and agreement that there is total redundancy. This is more of a policy issue than a technical issue.

Additional Stakeholders and Outreach Plan

- NAACCR
    - David Jones has reached out to NAACCR.
- Individual state cancer registries. Cancer registries located at universities would be interested in this use case.
    - Universities – Kirsten noted she may have some contacts.
- Dave Jones and Wendy Blumenthal at CDC can provide some proposed state registry contacts.

8. **Breakout Session B: Legal/Policy/Regulatory (LPR) Breakout Group** *(Walter Suarez, Kaiser Permanente)*

Overview and Purpose of LPR

Advise, identify, and define the best available legal framework to achieve the implementation of Cancer Registries within NRC generic infrastructure, and recommending alternative technical approaches to make implementation more feasible from legal and regulatory perspectives.

Key Discussion Points

Commonalities in Reporting

- There are different level of reporting requirements for cancer cases in all jurisdictions. Some jurisdictions participate in an additional set of requirements (types of cancer, case definitions, data required) for cancer, but all of them follow a base national standard for cancer reporting that is generally legally mandated.
- Who holds the cancer registry differs by state – could be state health department or university system or others.

    - Others delegate their authority to another entity like a hospital association to carry out the registry function.
    - There is usually either a contractual relationship or an actual public health law that delegates the registry to be managed by a specific entity outside from the state agency.
        - Those are both mechanisms by which, under HIPAA, public health authority delegation can occur. The commonality in those is that they have delegated public health authorities regardless of where it resides.
    - Dr. Suarez recommended that the workgroup create a matrix/table of the basic reporting characteristics in all 50 states.
- The main entities required to report include healthcare providers, hospitals, and laboratories. It is not standard across all jurisdictions.
    - Kathy Turner, CSTE identified the state reportable conditions assessment by CSTE.

Differences in Reporting

- Timeliness: There is an initial report followed by ongoing reports for updates to the status.
    - Some states have different report requirements along the course of illness that are required to be reported, can range from 16 business days to 180 days to 2 years. The timeliness is more about *what* is reportable, with regards to requirements of reporting, not only initial diagnosis, but other spots across course of illness require various reporting timelines.
        - Time from the clinical event to report.
        - Longitudinal reporting across illness when additional data needs reported (follow-up, supplements). From longitudinal reporting, if there is an active problem in the problem list, it can trigger and support additional reporting. If the problem, cancer diagnosis, was recorded in the clinical problem list – the next encounter would "re-trigger" an updated report.
- Triggers in cancer: Cancer program at CDC working on this and those exist in clinical care and sponsor the sending of a report to the platform. Need to have a cancer registry specialist advise.
- Rules for reporting: The rules applied on a rules-engine platform would determine what is reportable and to whom. This is the current model used in our eCase Reporting Digital Bridge approach and seems to fit well for the cancer reporting model as well. The cancer program has been working on cancer specific trigger codes for the triggering part and there are different rules for the state reporting part that can be brought to bear for the rule portion.
    - If you have a sequela from the diagnosis or advance from your stage, they want to know that, but they don't want to keep getting a new reports on changed if this is a person already reported.
    - Need to determine in rules if they exist on the platform or within an EHR what needs to be reported. That would vary from state to state as not all states are doing that sort of follow-up.
- Important to consider State reporting laws (ID and ND rules as example).
- There are some national standards and some state differences.
    - Prominent difference is this is a chronic disease and most reportable are acute (not all). Ongoing data about a single patient longitudinally are expected for cancer.
- How does data get reported? HL7 standards?
    - There are national standards in place for reporting cancer
    - The question is, to what extent are they being used? Is there a FIHR based resource to support cancer-based registry reporting?
        - ONC in its Interoperability Standards Advisory has identified the standards available to report electronically cancer cases to registries. See https://www.healthit.gov/isa/reporting-cancer-cases-public-health-agencies. They include:

        - HL7 CDA Release 2 (IG for Reporting to Public Health Cancer Registries)
        - NAACCR Standard for Cancer Registries, Volume V, Pathology Laboratory Electronic Reporting, and
        - IHE Quality, Research and Public Health Technical Framework Structure Data Capture.
    - Separately there are the Coding and Terminology standards used in connection to the reporting standards, including ICD-10, SNOMED, LOINC
    - An HL7 FHIR Resource and Implementation Guide is also on the works
    - With NAACCR, cancer has a specification for CDA reporting. They do not have a FIHR specification but are developing one as part of the MedMorph project. There are activities ongoing in that space. MedMorph comes from making EHR data more available for research in public health and has generous funding. For the patient centered outcomes research program. 3 use cases pursuing Hep C, Cancer, and health care surveys. John is the co-chair of the technical expert panel for MedMorph. What should be specified on the MedMorph line is that working to developing a FIHR standard for cancer reporting vs. the CDA one that is the NAACCR one. The CDA one is required in the ONC regs for certified EHR.
    - Under the former CMS Meaningful Use program, one of the optional public health reporting metrics was the reporting of cancer cases to registries using the ONC designated standard (HL7 CDA). As of 2019, under the CMS change of the main Meaningful Use program to the Promoting Interoperability program, all Eligible Professionals (physicians, clinicians) must use a certified EHR and report cancer cases to registries using cancer reporting standards in order to this reporting as one of the measures for incentive payment
    - Some states reference the standards for cancer registry in their regulations.
    - Certified EHRs must use certain standards for cancer reporting as well.
    - Cancers to be reported are as listed in Administrative Rule Chapter 33-06-01, Conditions Designated as Reportable.
    - https://ndcancer.org/index.html
    - NAACCR Data Standards https://www.naaccr.org/data-standards-data-dictionary/
- There are laws that also define **how** cancer cases should be reporting. (EHR can be connected to HIE, other point to point reporting) That can be like eCR, where the HIEs have role in some states.

Leveraging Current eCR Capabilities

- Leverage current eCR:
    - AIMS network used by APHL
    - RCKMS resources
    - HL7 eICR and Reportability Response Standards
    - eCR Now for COVID-19
- As noted above, a similar approach to what eCR uses (triggers, RCKMS, decision support intermediary, etc) can be applied to cancer reporting, directing the right case report to the right registry.
- Central cancer registries at the state level or other levels. Databases that could benefit from a national set of standards and national decision-support intermediary for what EHR data feed is reportable and where it should go.
- The implication of being a public health authority is that a public health disclosure can be made to them and that is critical in the policy architecture. The public health disclosure can be utilized for transmission from a platform to a registry. The other components of the policy architecture in place involved the networks and their policy frameworks that allow APHL to act on behalf of the clinical care organization to make those disclosures.

    - The agreement with E-Health Exchange, Care Quality, and CommonWealth participation in care quality enable all those that are connected to them.
    - Could also apply to a cancer registry – need specific use cases for reporting.
    - Three step process:
        - the triggering in clinical care;
        - the business associate like-authorities under HIPAA, that enable the PH platform at APHL to indeed support a decision support engine and;
        - decision support engine that ensures that the accurate and only the reports that need to go do go through a public health disclosure through a public health authority that's operating them.
- This is all leveraging the entire development of the legal framework for eCase reporting using APHL AIMS and decision-support intermediary.
    - Could consider using the same types of network components and legal agreements for solution with cancer registry reporting.
- There is a need for something like the RCKMS and trigger codes for cancer to leverage the above process to work for the initial report.

9. **Conclude Day 1** (John Lumpkin, BCBSNC)

Dr. Lumpkin concluded Day 1 with a preview of Day 2's agenda and a reminder that each breakout group from the day should have anointed someone to provide a report-out to the large group on Day 2. IPHI staff conducted a meeting effectiveness poll comprised of three statements:

- The discussion was open, with the sharing of diverse ideas and perspectives.
- I said or contributed what I thought was important to achieving our objectives for this meeting.
- The group was effective in meeting its objectives during this meeting.

A total 30 participants responded to the poll on Day 1. IPHI staff also asked for feedback in the chat log on what worked today and what could be improved for tomorrow.

Friday, January 22, 2021

10. **Welcome / Day 1 Reflection / Day 2 Overview** *(John Lumpkin, BCBSNC and Neha Agrawal, IPHI)*

Neha Agrawal, IPHI, welcomed everyone to Day 2 of the Digital Bridge annual meeting. She shared a word cloud from the previous day of what attendees see as the value of Digital Bridge, as noted in the chatbox. Highlights included collaboration across sectors, idea incubation, and advancing interoperability and communication of data. She reviewed the outstanding tasks for the LPR breakout group and TI breakout group, noted below. Dr. Lumpkin reviewed the agenda for Day 2 and reminded the group to e-mail IPHI with the breakout group they would like to attend, if they have not done so already.

Outstanding tasks for LPR

- What additional work need to be done to identify a best available legal framework to achieve CR/NRCs, and what need to be in place within such legal framework to move to implementation (review of timeline and tollgates to move to pilots/implementation) *20 minutes*
- What other stakeholders should be invited to the Collaborative Body to support LPR for CR, NRC? *5 mins*
- Discussion of funding sources. *10 mins*
- Identification of workgroup tasks and a draft workplan *15 mins*
- Next steps – *10 mins*

Outstanding tasks for TI

- Timeline
- Funding opportunities
- Identification of workgroups tasks and a draft workplan

11. **Technical Infrastructure Large Group Report Out from Day 1** *(Richard Hornaday, Allscripts with feedback from Collaborative Body)*

Richard provided a recap of what the Technical/Infrastructure breakout group discussed on Day 1 (see notes above for full discussion). Accomplishments included:

1. The group level-set on how eCR works and the current state of eCR in terms of how it handles other scenarios.
2. Spent most of the time on 1) technical and data requirements and 2) additional stakeholders and outreach plans.

The group also had homework for Day 2: Is there additional information that some recipients may need that is not in the Common aspects of the eICR? During Day 2 breakout, the group will discuss scheduling and logistics, funding opportunities and challenges, implementation considerations, and the development of a workplan. The group also came up with a proposed name for the use case: ExeCC (Expanding eCR Capacity and Capability).

Next, the Collaborative Body engaged in discussion. Janet Hamilton, CSTE, clarified that on the RCKMS function, CSTE has expanded beyond notifiable conditions. There is the list of nationally notifiable conditions that are supported, and those that are reportable in at least one jurisdiction. Any states have a list of reportable conditions specific to that state. Janet clarified that the filtering concept is still there. Jeff Engel, CSTE, asked among CAP and their coding structure for surgical pathological specimens – is there a 1:1 correlation with ICD-10? Andy Wiesenthal, Deloitte, responded that he was on the SNOMED Board for 10 years. There may not be a 1:1 correlation between SNOMED and ICD-10. There is a nationally standard map between SNOMED and ICD-10 that is maintained by the National Library of Medicine. There is a slow migration to SNOMED. As healthcare moves away from FFS, they will want to use SNOMED rather than ICD because it helps with analytics. David Jones, CDC, commented that the CDA documents they receive for cancer reporting and the pathology labs are the diagnoses currently in ICD-10. His team is starting to investigate SNOMED as well. Bob Harmon, Cerner, asked if there are ASTHO affiliates with chronic disease? ASTHO representatives responded that ASTHO has been active with disease-specific projects. Art Davidson, NACCHO, proposed engaging a hospital Tumor Board member to better understand case reporting and follow-up. John Lumpkin recommended involving the American Cancer Society.

12. **LPR Large Group Report Out from Day 1** *(Walter Suarez, Kaiser Permanente with feedback from Collaborative Body)*

Key Points can be reviewed in the breakout room notes above.

Richard Hornaday: We consider this a generic infrastructure, right now we are simplifying and saying our first scenario is something that has a public health authority. When we had initial discussions about this, one of the real challenges was what was going to be the policy and legal requirements if the people who want to use this infrastructure are not a delegated public health authority.

Walter Suarez: When we talk about a contracted entity acting on behalf of a state authority, there are contractual relationships that provide the ability for the contracted entity to collect the data on behalf of the states. The entity submitting would have the ability to disclose the data to that entity without patient consent because it is covered under the HIPAA public health authority required reporting exception. There are, in some cases, volunteer tumor registries in which entities participate. In those cases, the entity voluntarily collecting the data (serving as a repository) has to become a business associate of the HIPAA covered entity (provider) that is submitting the data to it. Those same agreements would

allow for a process like the one we have in Digital Bridge for eCR to be used in the reporting to cancer registries. There is enough legal coverage to support the ability to exchange data through a DB-like approach. There will be a need to have legal agreement.

John Lumpkin: There are many hospitals that have a registry – a quality improvement tool. We would not want to create a mechanism that would solely look at the public health use of central cancer registries, but ideally would be useful, not only in public health, but in healthcare thinking through some of their data collection for QI aspects of managing and following cancer. This would then create the functionality that could be translated to other diseases like Parkinson's and Diabetes.

Richard: We know that Parkinson's is part of the public health infrastructure in the state of California, but that is not the case in every state. While it might work for one state, it might not for others. Would need something that would work across all the states and make sure we are not violating one state's rules because they do not do things exactly the way the other states do it.

Walter: I think those situations can be covered through agreements. That is what the use of the standard legal documents to allow this to be done by HIE's and others; even if there is no state law that requires it. Those are some of the elements we are going to be into when we move forward. And out legal documentation work done for the eCR before will help in developing a legal framework for cancer registry reporting via the Digital Bridge route.

John Loonsk: There is a difference between something that is required by state law and something that is not in terms of how it is implemented from how it relates to a public health agency and the agreements with eHealth Exchange and CareQuality. The policy infrastructure is very different for something that is legally reportable and something that is not.

Richard: AIMS could not manage individual point-to-point BAAs with all participants. We needed to find an aggregation function. Just because it is possible, it might be not sufficient from a practical perspective. Something to keep in mind as we keep going into the discussions.

Walter: The expectation is not that APHL would sign a BA with every provider that is going to be submitting data to a voluntary effort not mandated by state. If there is an entity that already has those agreements in a state, APHL could enter into a BA with that organization that would cover all of the entities that would report to that organization. There will be ways to address this as we move forward.

13. **Breakout Session A: Technical Infrastructure Breakout Group** *(Richard Hornaday, Allscripts)*

<u>Additional Data and Technical Requirements (con't from Day 1)</u>

- Additional data elements outside of existing eCR infrastructure.
- Supplemental data that are condition-specific. Separate standard that may not be part of eICR. For cancer this could be staging, therapies, etc. Is there anything absolutely essential that is not in there and how do we handle that?
- Challenging items in getting clinical terminology from eICR (because typically these come from labs) from the following:
    - Histology
    - Laterality
    - Primary site
    - Behavior
    - Grade
    - Stage
- One guiding principle for the eICR data elements was, what's the minimum amount of data a PHA needs to receive to

begin case investigation and follow up activities with the person, so, I agree that if the purpose of sending data to a registry differs from that - we will find new data elements to include in a standard or addendum to the eICR.

- To reiterate, this does not replace reporting of hospital registries to local jurisdiction.
- MedMorph project is looking at m-codes.
- Looking at how to get synoptic data utilizing FHIR and utilizing m-code extensions.
- What information is needed in the eICR and what can be in the follow-up? Also gets at idea of supplemental report beyond the eICR report. Shouldn't be in parallel given longitudinal nature of cancer case.
- Note that eCR not is necessarily based solely on a one-time trigger; it may aggregate across an encounter to include multiple triggered items. Some of these aggregated triggered items may be reportable in one jurisdiction and not reportable in another.

<u>Additional stakeholders to engage</u>

- NAACCR (North American Association of Central Cancer Registries)
- Invite individual cancer registries as well as NAACCR.
- Cancer registries located at universities would be interested in this use case

Universities

- There are some states that are linking cancer data with birth defects (from a registry for example). However, this is not cancer-related.
- American Cancer Society.
- College of American Pathologists (CAP) or someone at SNOMED. CAP and ACS are members of the federation.
- American Society of Clinical Oncology (ASCO).
- American College of Surgeons (CoC – accredits hospitals based on cancer registries).
- Potentially invite MITRE to Collaborative Body, in addition to workgroup participation that we have currently. MITRE taking mcode capability and building on that to do FHIR reporting called CodeX. Would feed data to external registries like bone marrow registries, among others.
- NCI – National Cancer Institute. NCI uses SEER standard. NCI more research-focused. NCI funds several state cancer registry projects.

Draft Workplan

Deliverable	Timeframe

Phase 1:
• First task is to engage CSTE and APHL so they are aware
• Requirements Gathering Workgroup
  ○ Architectural and Functional Enhancements
  ○ Environment Scan (Review Existing Standards and Existing Workgroups (e.g., MedMorph, CodeX, mCODE, etc.))
  ○ Healthcare Provider Stakeholder Engagement and Feedback Sessions
	6-8 Months

Phase 2: Development and System Integration Testing • Dependent on CSTE and APHL and funding • Before implementing with pilot sites, some level of testing needed	?
Phase 3: Pilot Sites (min 1 university and 1 state) • California Cancer Registry • New York Cancer Registry • University-based registry (look at Kentucky or Georgia) • Dana Farber (i.e. Harvard) or MD Anderson • University of Utah • IntermountainHealth • Requirement = site has worked with eCR	3-4 months for each pilot site
Phase 4: Implementation	?

- Goal is to meet bi-weekly.
- Have check-points with LPR group.
- Hard to commit due to funding cycles.
- Dependencies – meeting with LPR group, example set of trigger codes specific to Cancer. RCKMS team helping with this. CSTE and APHL funding.
- Tollgate – obtain clinical terminology for trigger codes and then get into authoring tools.
- Expectation of where things could change.
- Risks – pilot site may have other priorities related to COVID-19. To mitigate – having a few contacts and people working on this for backup.
- Cerner was Utah site in initial eCR pilot activities.
- Epic was Texas site in initial eCR pilot activities.
- Some states where cancer registry is farmed to University.
- Select one that is outsourced to University and one that is outsourced to public health agency.
- Engage pilot sites early.

14. **Breakout Session B: LPR Breakout Group** *(Walter Suarez, Kaiser Permanente)*

Key Discussion Points – Day 2

Additional Work for Legal Framework – Additional Resources and Groups to Bring

- Resources – Existing Public Health Reporting Agreements:
    - Help to gather some of NAACR's (North American Association of Central Cancer Registries) legal agreements that help them implement registries.
        - Larger agenda about non-profit organizations themselves and its members.
    - Work done by the Sequoia Project and DURSA (Data Use and Reciprocity Agreement)
    - Digital Bridge already worked on legal agreements that support the use of the APHL AIMS network for reporting.
    - Art Davidson (NACCHO) is involved in CODI initiative funded by PCORI with MITRE – may be able to use some of this work.
- National Cancer Registrar's Association list of different types of cancer registries that exist - https://www.ncra-usa.org/About/State-Associations
    - Professional organization with professionals who work in the registries.
    - Wendy Blumenthal and David Jones (CDC) have close associations and partnerships with NAACR and different state cancer registries. Monthly call with CSTE and their state's in their registries. CDC has strong connections with these groups.
- PPRL has gained traction at CDC
    - MITRE has developed report that CDC is using for the response, a swell. PPRL is a commodity = purchase it from vendors
- Statements to address:
    - Legal frameworks exist to support this use case for cancer registry reporting and addressing variability between states can be handled through RCKMS.
    - There are important nuances, some reporting voluntary/some mandatory in PH law, that need to be taken into consideration.
    - Need to address privacy protected record linkage across registries (look at MITRE report on PPRL)

Potential Starting Points

- When the registries are in the state, they are allowed and mandated to receive personally identifiable information. The key is identifying how they are going to link this to other data sets within the state, other Cancer registries in other states, and follow individuals.
    - CDC has struggled to get an overall national picture that could combine the data sets from individual registries and see them. They need a unique identifier but cannot currently link across states because it is de-identifiable.
    - Working to set up a national mechanism where near real time pathologists and healthcare providers could upload into a cloud-based system.
    - Engagement has fallen off due to COVID-19 response.
    - Met several months agree to help them negotiate. Spent time on technical but did not get into legal frameworks. Build on that and use the wisdom of this group to get it going rather than identify what those are.
- Idea to start with pediatrics because individuals frequently must cross state lines for care. There will be strong advocates to get started.
    - Addresses the key problem of creating linkages across state lines.

- Think about a way to getting a case reported to the right jurisdiction. The first element for providers to report to the correct registry.
    1. Provider report to registry
    2. Aggregation across cancer registries
    3. Get data to CDC

Stakeholders to Invite:

- National Cancer Institute
- CDC
- North American Association of Central Cancer Registries
- National Cancer Registrar Association
- State Cancer Registries
    - Should engage some of the states that are engaging in some of this work)
    - Include central registries at the state level (some states have multiple registries, some academic, and some are sub-populations of states)
- American Cancer Society
- Could get specific funder if we focus on a type of cancer
    - Group of Children's hospitals that contribute to a centralized data set that is shared through a data system
    - Cerner and Epic may have info compiled info from their pediatric clients
- American College of Surgeons (Accreditation for Cancer Hospitals)
- SNOMED and LOINC, RxNORM, NLM – Jim Case, Stan Huff from Intermountain
- Pathology Labs – Regency Institute (for identification)
- National organizations likely have attorneys

Funding Sources

- Work with CDC Foundation and National Cancer Institute to identify potential funding sources
- AHRQC
- Family Foundations – like the case for Parkinson's (through ACS)

Identification of Tasks

Task	Timeline	Resources Needed	Who?
Clarify defining the use case and problem the use case is solving.			In collaborations with TI workgroup
Work closely with CDC Cancer Registries Team to identify existing work, gaps, and where DB can help			CDC Cancer Registry Team
Develop WG Charge and full workplan, including meeting schedule			
Gather legal framework information that exists to support this			
Compile difference in			

regulatory reporting (examples)			
Copy of PPRL report from MITRE/CDC			Working with CDC Cancer registry
Talk to TI workgroup and CDCF about funding opportunities and strategies			TI workgroup and CDCF
Reach out to various orgs we identified to get them involved			

15. **Technical Infrastructure Large Group Report Out** *(Richard Hornaday, Allscripts)*

Key points can be reviewed in the breakout notes above.

Art Davidson asked if the use case is sufficiently defined to begin requirements gathering. There were a few other suggested uses that are not in line with the eCR we have right now. Want to make sure we are not omitting a piece that would help design the solution. Richard commented that verbally yes, it is defined enough to start the technical requirements activities. One of the first items is looking at existing eCR infrastructure and gaps to accomplish this use case. Want to make this a generic infrastructure to allow for additional scenarios and conditions in the future.

16. **LPR Large Group Report Out** *(Walter Suarez, Kaiser Permanente)*

Key Points can be reviewed in the breakout notes above.

Richard Hornaday: Highlighted the value proposition question. This might highlight a need for an additional workgroup – marketing/value proposition to identify who would really want to use this. Would need to put specific focus on that to communicate to the users the reason why they should be doing this as well as the value proposition to any funders.

Walter Suarez: Talked about what might be some of the risks/fears/concerns of what this approach could create. Examples of folks thinking this might take away the jobs as well as changes in workflows and processes. It would be important to have a value proposition to address those concerns with the value it provides.

Mylynn Tufte: Had discussion to flesh out the use cases to make sure we have the value proposition clear. There is probably more in the value proposition that was outlined in the original proposal that wasn't highlighted here.

Richard: It is going to be important to have that first scenario to drive the activities. The real value proposition is going to be across multiple activities. Two tasks: what is the value proposition for the primary requirement for cancer registries? but, also for other folks, as well. There are other organizations that are going to get value out of this functionality.

John Lumpkin: It's going to be important for us to think about how we apportion them between the workgroup, which is the combined workgroup now. Some of these tasks would be appropriately dealt with and then get handed down to the sub-workgroups. Need to have discussion to flesh out those organizations and are focused in on those tasks and are coordinated by the NRC/CR workgroup.

Laurie Call: Clarification on intention to have an overarching group from representatives from NRC/CR with two sub-

workgroups focused on 1) technical infrastructure, and 2) legal, policy, regulatory.

John Lumpkin: We will have to have that discussion with the Executive Committee with recommendations to the full Collaborative Body. There are critical tasks that need to be done in both avenues with overarching activities related to clarifying and refining the use case. A number of issues related to reaching out to stakeholders. I don't think we want the two groups doing separate outreach. That all brings it up to a level of coordination around the NRC and CR that is at a level between the overarching look of what DB is doing – the Executive Committee and technical infrastructure and legal and regulatory groups.

John: As we move into the next phase, we have gotten some important workplans. The next step is to populate these structures. We will send out a sign-up sheet for the overarching (ExeCC) workgroup and the two sub-workgroups (LPR and TI). We will have the discussion in the ExeCC workgroup about recommendations for the timing of putting together the marketing/value proposition activities and identifying when we reach certain tollgates.

17. **Public Health API White Paper Update** *(Walter Suarez, Kaiser Permanente)*

Walter Suarez, Kaiser Permanente, Public Health API White Paper Workgroup Chair, thanked workgroup members for their contributions in writing sections of the white paper and providing feedback at meetings, over the last six months. Walter also thanked those who provided public comments including Noam Arzt, an active member of the public health IT / immunization space and Thomson Kuhn, an active member of HL-7 and someone who has significant knowledge applying API to various fields including public health. By way of background, at its January 2020 annual meeting, Digital Bridge chartered a workgroup to develop a white paper that aims to serve as a reference for public health professionals as they look to develop and implement their organization's public health API strategy. The white paper includes an introductory overview of APIs in general and as they apply to public health, a summary of recent health policy developments related to API, basic technical and API concepts and building blocks, public health use cases, policy and privacy issues, strategies and steps needed to implement a public health API strategy, and a listing of tools and resources available to support implementation of an API strategy. The paper is intended primarily for public health professionals in local, state, and federal agencies, industry groups, and professional associations, and targets groups implementing or developing API Infrastructure capabilities. It is not intended to serve as a roadmap for implementation of an API platform or program. The Collaborative Body reviewed version 1.0 of the white paper, and once approved, the paper will be disseminated more broadly within the industry for review and feedback. The second iteration of the document, which will incorporate public comments, will be version 2.0.

After providing this background information, Walter walked through the document. The white paper begins with the value and importance of APIs. Section two highlights policy developments and includes links to relevant laws. Section two also includes the most significant benefits from implementing a public health API. Section 3 outlines the building blocks of an API concept, which includes users, infrastructure in the center, and API services. Following this meeting, the workgroup will add to the "API Services" section of the paper, before moving it to public comment. Section 4 goes into use cases, and includes several connections to the current pandemic. Section 5 delves into policy and privacy considerations, including federal and local laws that affect API. Section 6 outlines strategies and steps to implement an API. Section 7 aggregates tools, resources, and references. Note that none of these resources came from industry vendors. Section 8 is the conclusion and next steps. Next steps include the call for a public health API community that can serve as a forum for professionals to collaborate. The second recommendation is to develop a generic API infrastructure/framework for public health. A complementary document to this one would describe and formalize this generic framework. The third recommendation is to obtain more feedback from the community.

Digital Bridge members and meeting attendees offered their congratulations on the completion of version 1.0 of the paper. A member recommended that public health should not deviate from healthcare clinical APIs, which is FHIR. There are concerns

currently from public health agencies on making changes to workflow that works well already, for example lab results reporting. Another member added that healthcare has extended itself to public health in some ways, for example addressing social determinants of health, and those organizations do not use FHIR as the underlying channel for communicating. There is an open referral API that allows for bridging health into the community. A member asked how APIs work with other systems. For example, syndromic surveillance and how APIs are used in the existing infrastructure. The workgroup plans to discuss FHIR more in the complementary document to accompany the white paper and is hoping to receive more feedback from healthcare per version 1.0 of the paper. In addition, the next iteration of the paper will include more information about how APIs operate within existing systems. Lastly, Walter will work with CDC to obtain updates to the eCR section. Next steps are to incorporate subsequent revisions to develop a version 2.0 of the paper.

The Collaborative Body approved the public health API white paper as version 1.0, with subsequent edits to be made including updates to the eCR section and updates to the building blocks figure. Motion made by Bob Harmon; seconded by Vivian Singletary; verbal vote taken, all "ayes," no "nays" or abstentions.

18. **Conclude Day 2** *(John Lumpkin, BCBSNC)*

John concluded the two-day meeting. He reminded the group that we have fleshed out the work on the CR as a use case under NRC; still have some work on the exact architecture but see that the initial work will be around technical and LPR considerations for the for the ExeCC *(working title)* use case. Next steps will be to circulate a sign-up sheet for the workgroup, assign leadership, and invite relevant stakeholders to Digital Bridge and this use case workgroup. Subsequent workgroups, such as implementation, evaluation, and sustainability, will be convened later. John thanked the group for spending two afternoons on the work of Digital Bridge. The work will have a significant impact on surveillance of cancer, amongst other conditions. IPHI launched a meeting effectiveness poll via Zoom prior to the conclusion of the meeting.