Collaborative Body Meeting Summary

Meeting Information

Date:	April 1, 2021	**Location:**	Zoom; Meeting ID: 939 0518 7522
Time:	12:00 – 1:30 PM ET	**Note Taker:**	Neha Agrawal
Facilitator:	John Lumpkin	**Attendees:**	See attached

Agenda Item	Time (ET)
1. Call to order and roll call – John Lumpkin	12:00 pm
2. Agenda review, approval, and COI declarations – John Lumpkin	12:05 pm
3. ExeCC Use Case & Workgroup • Use case name – John Lumpkin • Co-Chairs – John Lumpkin • Overview of use case – Richard Hornaday & Joe Rogers • Scope, assumptions, technical workflow, LPR considerations – Richard Hornaday & Joe Rogers • Current membership – IPHI staff	12:10 pm
4. Expanding Collaborative Body • Outreach to new organizations – IPHI staff • Vote to approve new members - All	12:55 pm
6. eCR & eCR Now Update – John Loonsk	1:05 pm
7. Communications – IPHI staff	1:20 pm
8. Announcements and Next Steps – John Lumpkin	1:25 pm
9. Adjourn – John Lumpkin	1:30 pm

Decisions

The Collaborative Body approved the following organizations to join the Digital Bridge Collaborative Body: NAACCR, NCI, OCHIN, SHIEC, Sequoia Project, and American Cancer Society.

Meeting Summary

1. **Call to Order** – Quorum was met.
2. **Agenda Review and Approval and COI Declarations** *(John Lumpkin)*
    A. John Lumpkin, MD, MPH welcomed the Digital Bridge Collaborative Body to its April 2021 meeting. Dr. Lumpkin commented on the state of the country with respect to the COVID-19 vaccination rollout, noting the progress that has been made and attributing this progress to many of those on the call who worked on the mass vaccination campaign.
    B. There were no abstentions or changes to the agenda. There were no conflicts of interest declared.
3. **ExeCC Use Case & Workgroup**
    A. Use case name
        - At its February meeting, the Executive Committee voted to move forward with the naming convention recommended by David Jones at the January virtual meeting – ExeCC which stands for expanding eCR capacity and capability.
        - The below description of the ExeCC use case, a combination of the Cancer Registries (CR) and Newly Reportable Conditions use cases, has been included in IPHI's outreach e-mails to additional stakeholders.
            - The ExeCC (Expanding eCR's Capacity and Capability) Workgroup is focused on generic enhancements to the existing eCR infrastructure that would support additional reporting beyond nationally notifiable conditions. As the network of potential data exchange partners increases, additional centrally maintained decision support functionality is needed to ensure that report content is routed to the authorized recipient only. To utilize the existing eCR infrastructure, test cases must be based on clinical encounters and be easily identified using well defined clinical code sets. The workgroup's initial focus will be Cancer Registries. Implementing Cancer Registries in the enhanced architecture described above will allow Cancer Registries to reach real-time cancer case data exchange by establishing trigger-based electronic cancer case reporting, from EHRs to state- and territory-based central cancer registries.
        - Dr. Lumpkin acknowledged that Digital Bridge is trying to identify the use case's scope of work. It is a bit opaque currently and the goal for this call is to come up with a unified approach, or potentially an alternative solution to using CR as a tool to extend the eCR architecture in a way that both moves CR forward and paves the way for additional conditions.
    B. Co-Chairs
        - Richard Hornaday and Joe Rogers have agreed to serve as co-Chairs for the ExeCC use case workgroup. Richard Hornaday has been a Director of Healthcare Solutions Management at Allscripts for the past seven years. Richard was a workgroup member of the Newly Reportable Conditions workgroup. Joe Rogers has been a Team Lead of Informatics, Application Development, and Analytics at the CDC for the last 24 years. Joe Rogers presented the Cancer Registries use case concept to the Collaborative Body at its January 2020 in-person meeting.
    C. Overview of use case

- Richard reviewed the below agenda him and Joe Rogers presented on.
    - Current eICR and eCR process
        - ExeCC will be an evolution of the current eICR process
    - Assumptions & Limitations
        - Looking for consensus on assumptions and limitations
    - Decision Support Intermediary (DSI)
    - Legal, policy, and regulatory considerations
    - Characterizing the cancer surveillance landscape in context of EHR reporting
        - Legislation
        - Potential pilot sites
    - Tentative project timeline
        - There is a lot of uncertainty but hoping to achieve consensus on what minimally needs to be accomplished to determine the timeline.

D. Cancer surveillance community

- National Program of Cancer Registries (NPCR) at the CDC funds ~50 different programs. SEER covers the entire United States. Central cancer registries are population-based and differ from cancer registries at Commission on Cancer (CoC) facilities.
- The following organizations are involved in the development of standard codes for cancer:
    - The World Health Organization (WHO) developed the International Classification of Diseases for Oncology (ICD-0 manual) and the International Statistical Classification of Diseases and Related Health Problems (ICD-10, 11). These two manuals help identify cancer cases.
    - The American Joint Committee on Cancer (AJCC) developed standard codes for topography (bodies of cancer), morphology (cell type of cancer, e.g., melanoma, leukemia), and extent of tumor spread.
- The following organizations shape standards for facility and population-based registries:
    - The National Program of Cancer Registries (NPCR), administered by the Centers for Disease Control and Prevention, develops standards/best practices on cancer registry operations and data accuracy (i.e. data completeness, timeliness, and quality).
    - The Commission on Cancer of the American College of Surgeons (CoC) requires their certified hospitals to have registries in cancer management.
    - The SEER develops procedures for central registry monitoring of data quality.
- Although all standard-setting agencies (CDC, NCI, and CoC) run training programs, the National Cancer Registrars Association (NCRA) develops training programs specifically for certified tumor registrars (CTRs), who are specially trained to abstract and code cancer cases. Currently there are CTRs trained in looking at medical records and abstracting data elements, using their subject matter expertise. Can take one hour to an hour-and-a-half to build a cancer report via this method.
- The North American Association of Central Cancer Registries (NAACCR) promotes the development of common standards shared by central and facility registries. NAACCR is

an umbrella organization for all the cancer surveillance / cancer registry community and help put together standards.

E. Current reporting process
   - Initially either a pathology or imaging report is sent to clinician and subsequently the central cancer registry can receive up to 10 reports on each tumor case. There is a process of linking and consolidating reports. Once per year these cancer registries send reports to SEER and CDC (data de-identified and is tumor-based, i.e. one record = one tumor).
   - Often treatment can take months following the diagnosis, and enough time (~6 months) is needed before these data are abstracted.

F. Triggers and defining what is reportable
   - CoC is where most of the data are abstracted. Those working in a CoC facility spend a lot of time coding those cases.
   - Joe's team is working with RCKMS and have provided them with value sets. Most of those value sets are almost complete.

G. Payload
   - Preliminary mapping of cancer reporting with Electronic Initial Case Report (eICR) has been completed. Have taken what is in the eICR and mapped it.
   - Significant overlap for the patient, provider, laboratory results, medication, and procedure information.
   - Significant gaps:
     - eICR does not include cancer-specific data elements, such as tumor site, histology, behavior, laterality, grade, and stage.
     - eICR includes data elements not collected by cancer registries, such as immunization status, travel information, guardian, and pregnancy status.
   - The to-be state for the ExeCC use case can work within this payload and allow for registries to receive select data they want.

H. Legislation on cancer surveillance
   - For a central cancer registry to receive funding, they must have a state law in place that requires those facilities to report. NAACCR has developed a searchable database on state laws and regulations by each state registry: CaRI Database Search (naaccr-cina.org).
   - Focus of reporting to central cancer registries is what is reportable to PHA as well
   - Some states explicitly list what data elements are required to be reported.

I. Potential test sites
   - California: How to Report - California Cancer Registry (ccrcal.org)
     - They have already agreed to be a test site.
   - South Carolina, North Carolina, Michigan.
   - Current cancer registries that are actively participating in Meaningful Use and/or Making EHR Data More Available for Research and Public Health (MedMorph) project.

J. Timeline
   - Phase 1 Timeline
     - Requirements Gathering (~3 months)
       - For generic infrastructure, including that of Cancer Registries.

    - Map requirements to phases.
    - Initial assessments of legal/policy repercussions.
    - Dependencies include collaboration with developers, understanding repercussions on the RCKMS systems, and securing additional funding.
- Development
    - Dependencies include an understanding of eCR baseline, and funding considerations, as development projections impacted by funding.
    - Pilot prep and engaging sites within 2021.
- Implementation Assumptions

K. Collaborative Body discussion

- Joe's team is working on a reportability list comprised of value sets that would unify entities reporting on cancer cases.
- To clarify, case finding does not require a complete list of all data elements. Cancer cases in a catchment area can be sent to the central cancer registry (CCR) via a cloud-computing platform, and CCR can then send case information back to provider to identify and complete remaining data elements. Trigger report does not need to include everything; as mentioned above it takes about six months to populate the longitudinal record. The important thing is we use EHRs to identify cases to report to CCRs; the term is "case finding."
- A member asked about filtering on the eICR based on reportable diseases that are explicitly laid out in state laws. Public health agencies (PHAs) often receive an entire medical record of an individual. Has there been an evaluation on if a filtering tool is based on some kind of risk placed on PHAs receiving swath of information? PHAs have broad power to receive healthcare data they need.
- A member made the following comments:
    - The basis of eCR currently is that PHAs receive reports they are eligible to receive per HIPAA and state laws. DSI functionality ensures that only reports legally authorized will be send to recipient / PHA.
    - There is no content filtering within DSI right now due to several technical and policy reasons. It is a huge endeavor to implement this concept of filtering and more investigation is needed.
    - Cancer reporting needs more information than what is currently in the eICR. That information is not always codes, but could be as an example information around tumor location, etc. HL-7 is not needed for a prototype. First look at the payload; filtering activity could be potentially avoided.
- A member recommended making better use of the bi-directional system that we do not always leverage. eICR acts as case finder and may not be complete initially until provider inputs additional information, as Joe discussed above.
- Clarification that case finding and follow-back (PHA goes back to provider for additional data elements) has been going on for ~25 years. Developing a cloud computing platform where recipient sends an abstract to providers office for office to complete.
- In demonstrations of eCR done at HIMSS and elsewhere, the first step was report, second was reportability response, and then third was a URL initiated from the reportability response which allowed for supplemental information to be reported directly to the PHA. A lot of work has been done on that model. A lot of progress in network query domain that should be investigated as well. The authorities in which public health investigation occurs (third step) are different than authorities for public health reporting.

- A member asked what percent of cancer cases are not reported to CCRs. CDC looks at data completeness via applying an algorithm to data submission; to publish on a catchment area data completeness should be at least 90 percent. Over 1/3 of programs are at 100 percent completeness.
- Process of case finding is very labor intensive so having a more efficient process for case finding will be useful.
- A member noted the following:
    - What extent can a filtering tool be applied to a FHIR app such as eCR Now, whether it is filtering or parsing out of different components of eICR?
    - We are not seeing reporting as being a complete report. Often there are follow-up activities that need to occur like contract tracing or other public health actions.
    - CCRs are a public health function; do not follow the exact format as notifiable conditions to PHAs, but is a variant of that.
- A member clarified that classic reporting is when public health recipients identify the payload that meets their needs. eCR represents a harmonization of 99 different conditions that can be reported via eICR. It is possible for an app like eCR Now to create a different output, i.e. filtering, however not all EHRs use that app and many have native implementations. Requirements to add or remove data elements is on the onus of EHRs. The industry is split on using the app versus EHRs.

4. **Expanding Collaborative Body**
    A. Below is the list of additional organizations to add to the Collaborative Body:
        - North American Association of Central Cancer Registries (NAACCR) (held interest call and they expressed interest in joining)
        - National Cancer Institute (NCI)
        - OCHIN (held interest call and they expressed interest in joining)
        - Strategic Health Information Exchange Collaborative (SHIEC) (held interest call and they expressed interest in joining)
        - Sequoia Project (held interest call and they expressed interest in joining)
        - American Cancer Society

    B. Collaborative Body discussion
        - A member recommended that going forward the Collaborative Body votes to approve new members and then circle back with the organization extending an invite and hold an interest/orientation call.
        - A member agreed with Dr. Lumpkin's recommendation to do a block vote on all organizations, unless members want to remove single entities to discuss their qualifications and contributions.
        - A member recommended doing future outreach to healthcare delivery systems, to maintain that perspective.

The Collaborative Body approved the following organizations to join the Digital Bridge Collaborative Body: NAACCR, NCI, OCHIN, SHIEC, Sequoia Project, and American Cancer Society. Motion by Walter Suarez; seconded by Vivian Singletary; verbal vote taken, all "ayes," no "nays" or abstentions.

5. **eCR & eCR Now Update**
    A. See here for slide presentation.

6. **Announcements and Next Steps** *(John Lumpkin)*
    A. Public Health API White Paper will be put forth for a second public comment period.

B. Ms. Agrawal solicited article ideas for upcoming external and internal newsletters. For example, announcements of relevant meetings that are upcoming and articles on work that ties to Digital Bridge's mission.
C. Next Collaborative Body Meeting: Thursday, July 8, 2021 12pm to 1:30pm ET.

7. **Adjourned.** *(John Lumpkin)*