The Office of the National Coordinator for
Health Information Technology

Consumer Access to Immunization Information

Project Summary

March, 2014

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Background and Objectives

Background

- Consumer access to Immunization Information is a priority initiative of the Office of the National Coordinator for Health Information Technology (ONC)

- The Centers for Disease Control and Prevention (CDC) and state immunization programs have also recognized the need for consensus around best practices for allowing consumer access to immunization information through state-run Immunization Information Systems (IIS)

- Consumer access to immunization information in state IIS has promise to significantly empower individuals to make more informed decisions regarding health care for themselves and family members

- The concept of consumer access to immunization registry information is not new; this ability is currently in place in multiple states

- Nearly twenty states use IIS applications based on the Wisconsin Immunization Registry (WIR) software application

Objectives

- Identify and document best practices for consumer access to immunization registries

- Facilitate collaboration amongst WIR solution users to contribute and benefit from the collective experiences of the WIR Consortium

- Provide a blueprint for a variety of WIR solution users to consider when establishing consumer access to their immunization registries
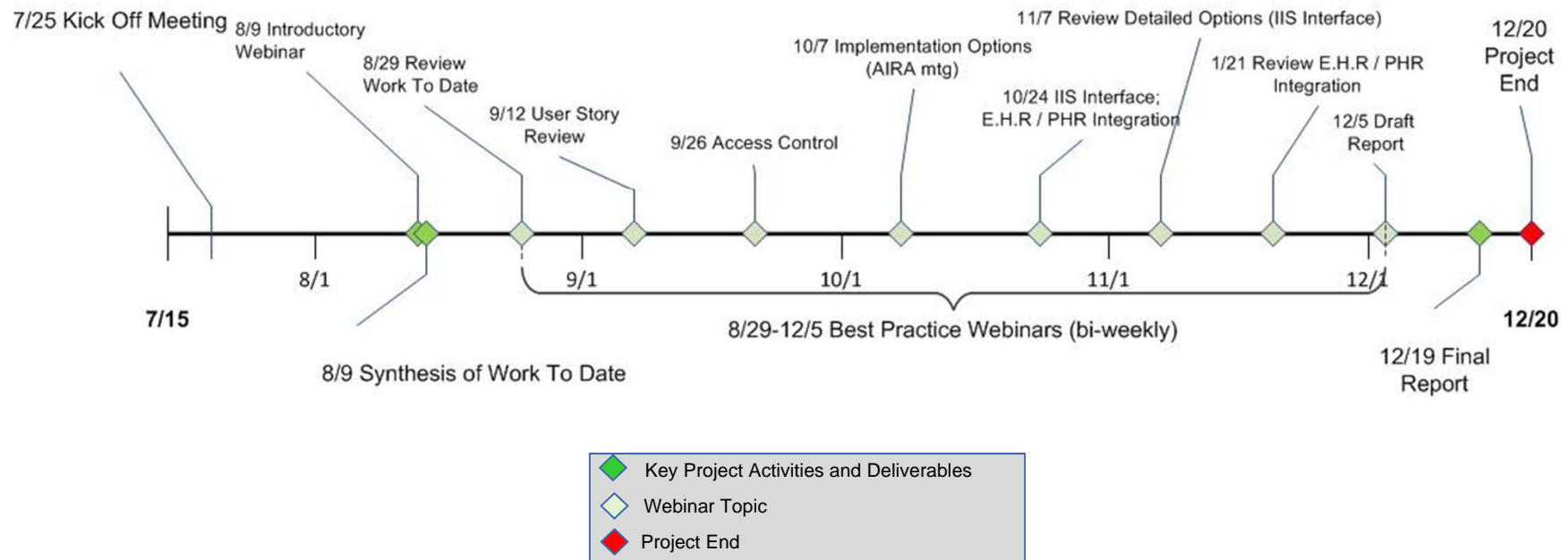
Project Scope and Approach

Project Scope

- The final deliverable will include Consumer Access Best Practices to Immunization Information recommendations and related documentation; the best practices discussion will be broad and explore a variety of options for consumer access to IIS

- System specifications and related design documents for specific systems including WIR or other statewide immunization information system, or any other health information are out of scope

Approach

- **An iterative, community, consensus - driven process** will be followed to establish a final best practices document

- **A collaborative and transparent approach** that can enable a wide variety of implementations is critical, given that there are a variety of IIS solutions, and each state or local IIS must follow their specific jurisdiction policies and technologies

- **A series of webinars** will serve as a collaborative space to share experiences and narrow-in on best practices

- **Research** into emerging techniques and strategies for consumer engagement will be on-going

- **Engagement of selected external stakeholders** to help identify best practice and gauge the impact of consumer access on their activities

- A **community conducted document review** will drive different iterations of the best practices document; feedback will be collected in a comment log; the Support Team will work with group members to resolve comments

- **A finalized best-practices document** will be presented to ONC, and CDC IISB Leadership for review and sign-off

Project Timeline

7/25 Kick Off Meeting
8/9 Introductory Webinar
8/29 Review Work To Date
9/12 User Story Review
9/26 Access Control
10/7 Implementation Options (AIRA mtg)
11/7 Review Detailed Options (IIS Interface)
10/24 IIS Interface; E.H.R / PHR Integration
1/21 Review E.H.R / PHR Integration
12/5 Draft Report
12/20 Project End

7/15
8/1
9/1
10/1
11/1
12/1
12/20

8/9 Synthesis of Work To Date
8/29-12/5 Best Practice Webinars (bi-weekly)
12/19 Final Report

Legend:
- Key Project Activities and Deliverables
- Webinar Topic
- Project End

Project co-sponsored by MN Department of Health and ONC

Synthesis of Work-To-Date

- Executive Summary

- Introduction and Background

  - Scoping the Issue

  - Federal Perspective

- Requirements and Limitations

- Current Consumer Access to IIS

- Models for IIS Consumer Access

- Authentication and Authorization for Consumer

- Conclusions and Recommendations

- Appendix A: Sources

- Appendix B: Glossary of Terms

Core Requirements

1. Support Federal Consumer health data access initiative.
2. Query access is provided for a patient's record.
3. Query returns one and only one target record.
4. Query response does not return demographic data that was not originally supplied in the query parameters.
5. Only authorized users can see data for a particular patient.
6. If the solution requires authentication, then single-factor authentication is sufficient for this project.
7. User can view consolidated, de-duplicated immunization history.
8. User can generate or download a report with vaccine history suitable for school, camp, or child care admission.

Snapshot of Three States Interviewed

	Nebraska	Wisconsin	Indiana
Registry Name	**NESIIS (WIR implementation)**	**WIR**	**CHIRP**
Consumer Access	• Started on 2010 • Via State portal. Separate web application against production IZ database	• Started in 2005 when Governor announced Kids First • Same web portal as provider link • More restrictive search then providers	• Access via MyVax Indiana • Patients need URL and PIN from provider or help desk
State Laws	• Wrote original statutes but they need updating	• None on public access	• State law says individual has the right to see their record.
Search Criteria/ Identifiers	• SSN used as unique identifier but not mandatory. • Also need name DOB	• First released with SSN or Medicaid ID Recently added MRN. Very popular search • Also need name, DOB	• PIN required. • Also need name and DOB
What you see	• Print official record • No SSN, physician's name or location of IZ displayed. • Access to proof of age by children • Schools have separate access	• Print official record • Provides history and forecast info. • No location for shots or providers • Provide only PHI that was already provided	• Print official record • No SSN, physician's name or location of IZ given.
Functionality	• Print only	• Print only	• Print, possibly more

Recommendations from Preliminary Work

- Outreach to the community must be done to determine if this functionality is desired or demanded.

- The EHR market is not yet sophisticated in terms of patient access, but the implementation of MU Stage 2's "view/download/transmit" measure may quickly change this.

- State and public health agency technical, legal, and information security staff involvement is key in the decision process.

- If no unique identifiers easily known to the outside community (SSN, Medicaid ID, etc.) consumer access cannot be provided without some level of technical or administrative effort.

- Identity proofing for consumer access are a red herring: The tough part is not user authentication but rather user *authorization*, *i.e.,* establishing the user's relationship to the patient.

Recommendations from Preliminary Work
(continued)

- Expanding the use of the existing WIR software web client needs to be carefully considered against the cost to implement changes, to support a new type of end-user, and the potential merits of other options.

- The creation of a mobile application is the most forward thinking, but support for printing from these devices needs to be carefully considered.

- Access via query from electronic health record (EHR) and/or personal health record (PHR) systems require the least modification, but require close cooperation with the vendors and sites.

- Pursuit of a Blue Button+ strategy is the most forward-thinking of all the options.

Model for IIS Consumer Access
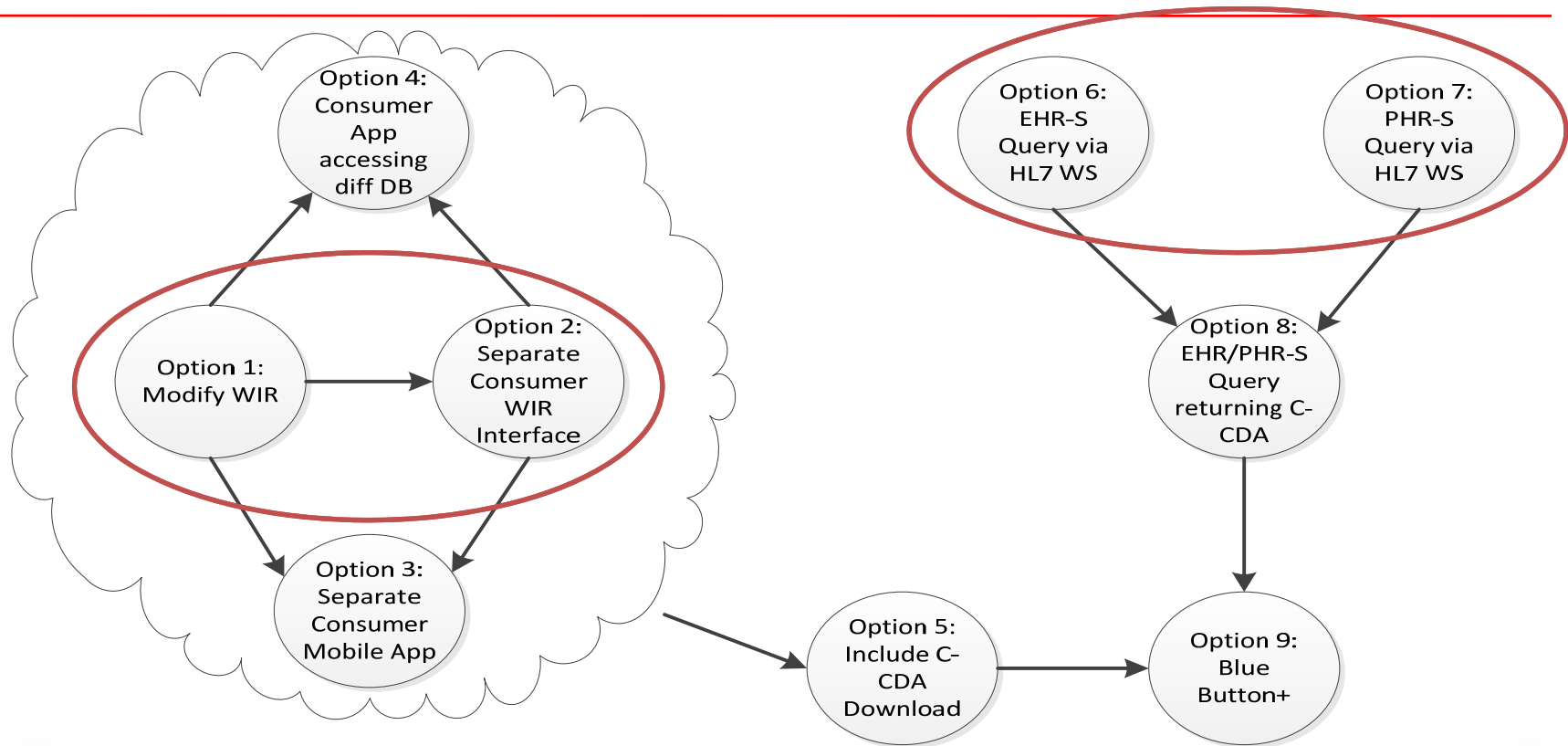
Principals for Option Selection

- **Meet Requirements**: Recommended options should meet all the core requirements and as many of the other requirements as possible.

- **High leverage**: Recommended options should leverage existing (and planned) IIS and non-IIS activities wherever possible.

- **Consistency with National Standards:** Recommended options should be consistent with national standards and directions both within and outside of the IIS community. It is recognized than some elements of the national scene may not yet be certain.

- **Recognize Diversity:** We need to recognize the diversity in both IIS implementation and state and local laws/regulations. There is no "one size fits all" solution so multiple recommended strategies are expected. On the other hand, too many options will degrade our focus and distract progress.

- **Feasibility:** Recommended options should be feasible for deployment within one year of project commencement.

- **Cost**: Recommended options should be cost effective especially since it may be an interim solution. Cost should include total cost of ownership, including ongoing maintenance, and transition to longer term solutions.

- **Incremental Steps:** We should recognize that it will likely take incremental steps to move us in the direction we want to go. But there may be a tension between short-term and long-term strategies.

Two Strategies Emerged

- Access Through an IIS Portal

  Deloitte. H1N Consulting

  Consumer Access to Immunization
  Information System (IIS) Data:
  A Guide for Consumer Access via an IIS Portal

  December 19, 2013

- Access Through EHR/PHR Systems

  Deloitte. H1N Consulting

  Consumer Access to Immunization
  Information System (IIS) Data:
  A Guide for EHR and PHR System Vendors

  December 19, 2013
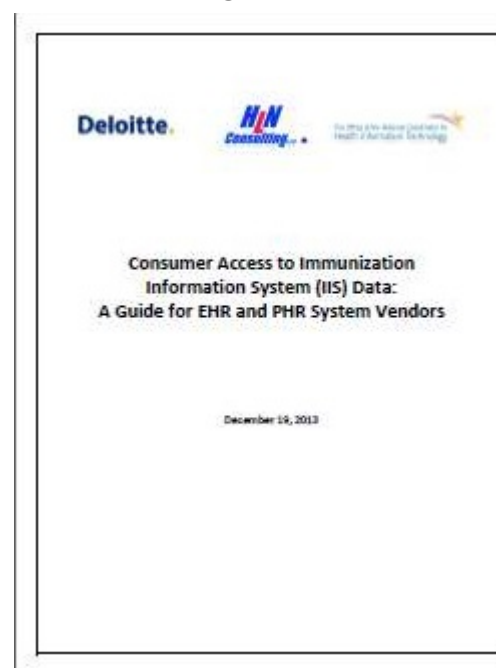
Project deliverables posted at:
http://www.health.state.mn.us/e-health/patientengage.html

Strategy 1: Access Through IIS Portal

Option 1A Person of Record

- Query with "what is know" criteria
- Flash notice that email will be sent to Person of Record
- If email exist, send PDF to Person of Record
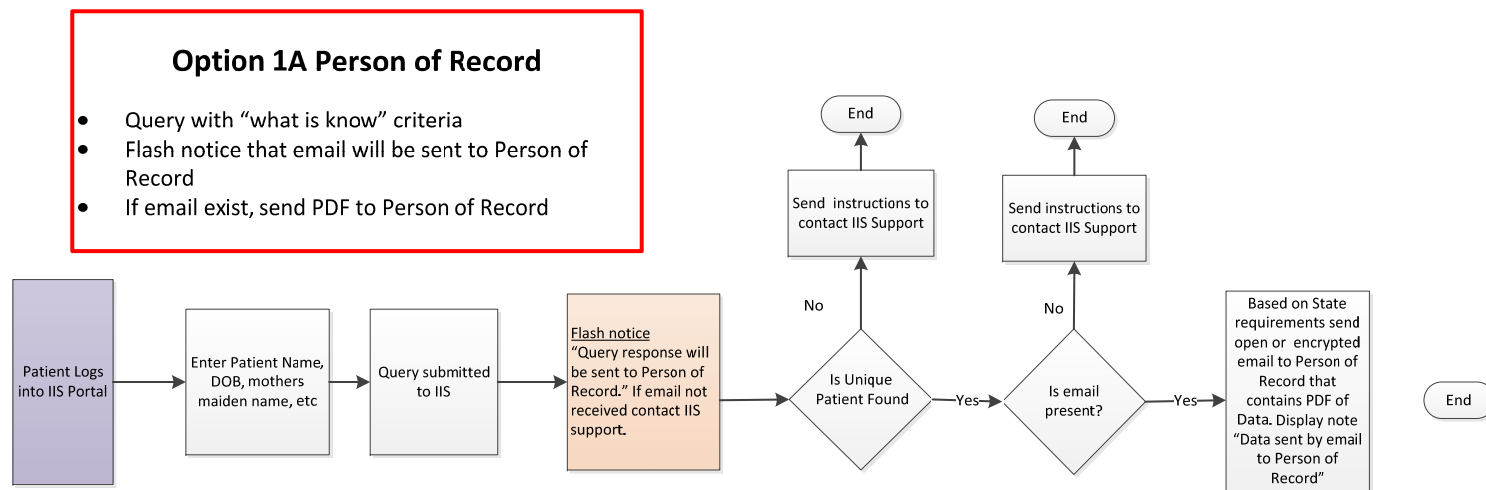
- Allows individual states to determine the search criteria for the query. Queries can be made based on "what you know" or based with a PIN number assigned by the provider or by the IIS.
- Takes advantage of an HL7 query against the IIS which is readily accessible by IIS systems.
- Allows for a real-time or delayed query response based on the state's capability of running real-time or batch QBPs.
- Allows the states to determine if the query response is sent to the person making the query or directed to a "person of record" already identified in the IIS.
- Promotes best practice by requiring unique searches for each person in the IIS.
- Allows States to filter adolescent sexual health data if required by state or local law.
- Allows States to provide a selection of report options that may or may not include personally-identifiable health information such as address, phone or location of immunization.
- Allows for incorporation of Blue Button and/or Blue Button+ capabilities (though these options were deemed out of scope by the work group).

Strategy 2: Access Through EHR/PHR

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┌──────────────┐     ┌──────────────┐     ┌──────────────┐     ┌──────────────┐                      ┌──────────────┐
│ Patient logs │     │ PHR/EHR/HIE  │     │ IIS receives │     │ PHR/EHR/HIE  │                      │ Patient is   │
│ into         │────▶│ queries IIS  │────▶│ query and    │────▶│ stores       │                      │ able to view,│
│ PHR/EHR/HIE  │     │ for patient  │     │ responds with│     │ immunization │                      │ download, and│
│ portal       │     │ records      │     │ immunization │     │ history and  │                      │ transmit a   │
│ following    │     └──────────────┘     │ history and  │     │ forecast for │                      │ C-CDA File   │
│ portal       │                          │ forecast via │     │ the patient  │                      └──────────────┘
│ authentication│                         │ HL7 v2 msg   │     └──────────────┘
│ requirements │                          └──────────────┘          ┌──────────────┐                 ┌──────────────┐
└──────────────┘                                                    │ Patient views│                 │ Patient      │
        │                                                           │ longitudinal │────────────────▶│ downloads    │
        │              Alternate flow                               │ immunization │                 │ immunization │
        └──────────────without additional query──────────────────▶ │ history and  │                 │ record as PDF│
                                                                    │ forecast     │                 └──────────────┘
                                                                    └──────────────┘
                                                                                                      ┌──────────────┐
                                                                                                      │ Patient views│
                                                                                                      │ or downloads │
                                                                                                      │ standard     │
                                                                                                      │ immunization │
                                                                                                      │ report(s)    │
                                                                                                      └──────────────┘
```

- Allows authoritative immunization data in IIS to be accessed by authorized systems.
- IIS can accommodate the interoperability requirements described below with little or no additional effort.
- Leverages current national interoperability standards, including likely MU Stage 3 requirements.
- Relies on querying systems which have preexisting relationship with the patient to provide patient access control.
- Consistent with MU requirements for View/Download/Transmit of patient records which is required of EHR systems.
- Encourages query of IIS and incorporation of more complete records into EHR systems.
- Provides easy to fulfill "carrot" for patients to use provider-based portals for records access
- Can easily be expanded to incorporate PHR-S Query simultaneously; can co-exist with untethered PHR access
- In some implementations, this may allow for the potential for patients to consolidate patient records from multiple sources.

Next Steps: Strategy 1

- Consistent with MyIR pilot currently being funded by ONC
- Some jurisdictions might not want to use hosted deployment option (perhaps they want to retain control, or they want to maintain their own branding, or they don't like the pricing model)

Proposal: Approach WIR project states, and other states through AIRA, and determine if any are interested in a joint development project to create new front end portal for consumer access that leverages their HL7 query/response capabilities

- Best to create portal using agile (rapid) development methodology
- Portal would be generic enough to work with any compliant IIS with a template-driven look and feel that could be customized (within limits) for different projects

Next Steps: Strategy 2

- EHR system vendors continue to be very busy and not looking for distractions in the short run. At best we can engage them on a future PH-EHR Vendors Collaboration Initiative call

- A number of PHR vendors are very interested in working with schools to improve the IIS-Parent-School data sharing through PHR products that query IIS on behalf of parents and pass immunization data on to school systems

Proposal: Conduct one or more pilots to develop IIS-PHR-School interoperability that leverages IIS HL7 query/response capabilities. Funding could go to PHR vendor, school, or both

  - Would enable existing PHR systems to query IIS by adding HL7 capabilities
  - PHR systems would form partnership with school district, convert data to necessary school system format
  - Parent gains access to data *and* authorizes data transfer to schools

Next Steps: Strategies 1 & 2

- Some IIS projects lag in their ability to implement standards-based bi-directional HL7 query/response capability

Proposal: Provide funding and technical assistance to IIS to speed their implementation of standards-based bi-directional HL7 query/response capability

  - In some cases it is migrating providers to AIRA/CDC-standard WSDL
  - In some cases it maybe direct funding to an IIS project to continue work they are doing or to engage their existing vendor to complete the work

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