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The Office of the National Coordinator for Health Information Technology

Consumer Access to Immunization Information System (IIS) Data: Final Management Report

December 19, 2013

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1. Background

For over twenty years, state and local jurisdictions have been collecting immunizations in a centralized database originally referred to as an Immunization Registries but more commonly referred to as Immunization Information Systems (IIS). The Centers for Disease Control and Prevention (CDC) defines IIS as, "confidential, population-based, computerized database that records all immunization doses administered by participating providers to persons residing within a given geopolitical area."[1] Individual/consumer access to immunization registry data has recently been identified as a priority initiative of the Office of the National Coordinator for Health Information Technology (ONC), the CDC, and many state immunization programs.

By enabling consumer access to immunization records, many stakeholders in the overall health system will be able to make better informed care decisions, and meet common daily needs. For example, parents will have the ability to obtain their child's immunization information to enroll in camp or school; they may also have a greater ability to see past vaccinations (potentially reducing duplicate procedures) as well as view and plan for upcoming forecasted vaccinations. Adult patients will have access to their records prior to international travel or prior to enrollment in college. Finally, providers and public immunization information system staff will have fewer patient and parent requests, potentially reducing the amount of time and effort finding and communicating this information for patients and parents.

To realize the full benefits of consumer access to immunization records at a national level, a complex set of policy and technical issues must be addressed at the state and local level. To assist in those efforts, a set of guidelines for jurisdictions has been developed, which builds on existing IIS consumer access approaches. Developing guidelines with nationwide implications is critical and must account for the programmatic and technical needs of a myriad of stakeholders.

2. Project Approach

Consumer access to immunization information 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, including Wisconsin, the origin of the Wisconsin Immunization Registry (WIR) solution. Given that there are a variety of IIS solutions, and each state or local IIS must follow their specific jurisdictional policies and technologies, providing guidance to enable consumer-based access required a collaborative approach. Such an approach allowed project participants to build on the existing efforts and studies that ONC and public health agencies have already undertaken. Also important is enabling a wide variety of implementation process and procedures, while fostering collaboration among a set of users with common infrastructure that can help collectively identify requirements and ideal solutions for consumer access.

[1] http://www.cdc.gov/vaccines/programs/iis/about.html

A critical element for identifying, documenting, confirming, and promoting the anticipated consumer access promising practices is soliciting, disseminating, and cataloging stakeholder input from IIS users and other key stakeholders that have expressed interest in IIS consumer access. The Deloitte team worked with ONC public health leadership to identify key stakeholders to develop a clear representation of IIS consumer access perspectives. Through this initiative, several state and territorial IIS representatives, the ONC, and the American Immunization Registry Association (AIRA) are investigating the opportunity for consumer access to their immunization registration data in support of Federal consumer health data initiatives. Figure 1 shows the jurisdictions that are represented as participants in this initiative.

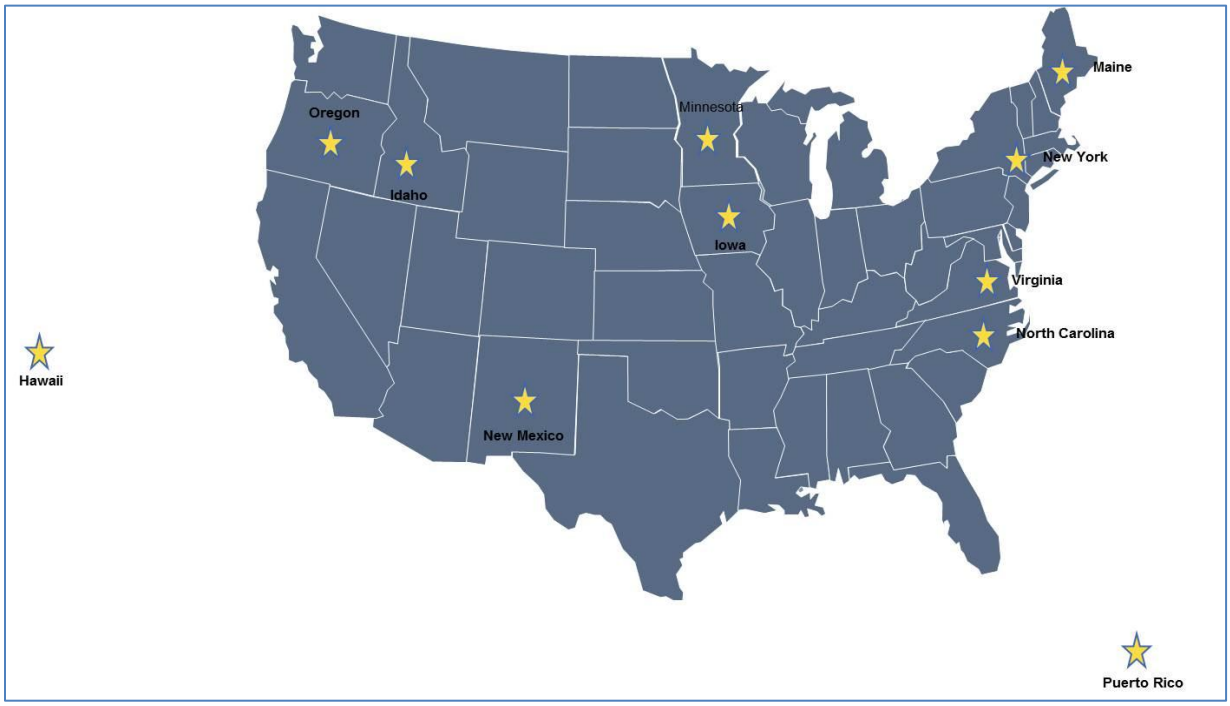

Figure 1 – Consumer Access to Immunization Information Participant Jurisdictions

Table 1 identifies the participants and their affiliation for the initiative.

Name	Organization/State
Rebecca Coyle	AIRA
Alison Chi	AIRA
James Wasa	Hawaii
Jennifer Baker	Idaho
Kim Tichy	Iowa
Bethany Kintigh	Iowa
John Callahan	Iowa
Tonya Philbrick	Maine
Emily Emerson	Minnesota
Priya Rajamani	Minnesota

Peggy Cooke	New Mexico
Amanda Dayton	North Carolina
Dina Hoeffer	New York
Michael Flynn	New York
Jim Daniel	ONC
Pamela Talley	ONC Fellow, Independent
Amanda Timmons	Oregon
Mary Beth Kurilo	Oregon/AIRA Board
Veronica Rodriguez	Puerto Rico
Juan Alicea Lopez	Puerto Rico
Greg Dennis	Virginia

Table 1 – Consumer Access to Immunization Information Participant Roster

2.1. Timeline

The *Best Practices for Consumer Access to Immunization Information Systems* project was initiated in July, 2013, and completed in December, 2013. This initiative introduced a community-based approach to establishing a set of promising practices and guidelines for consumer access to immunization registries. To do this effectively and efficiently, the team convened the participants to identify the current state and business requirements, discuss options for recommended practices, document consensus, and transfer knowledge to ONC and other key stakeholders.

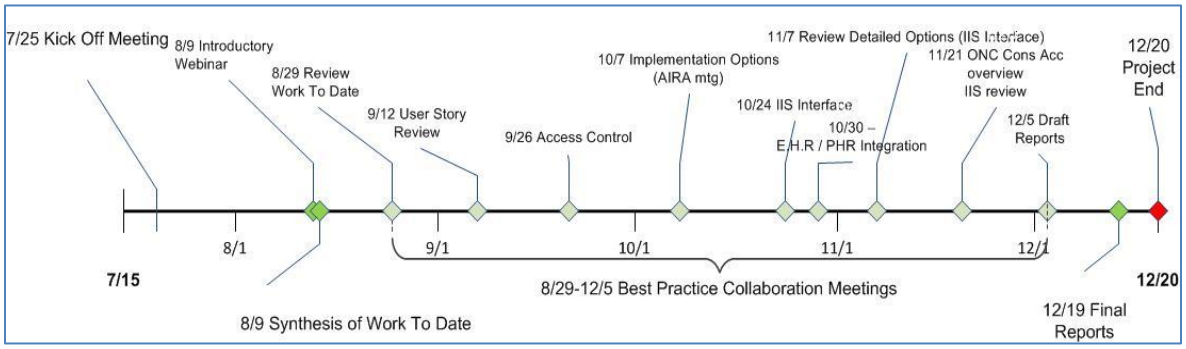

Figure 1 – Consumer Access to Immunization Information Project Timeline

A short description of the major project events and milestones listed in the project timelines are described below.

2.1.1. Synthesis of work to-date

A clear picture of the status and scope of IIS consumer access work to date was needed to efficiently assess options in order to create a set of consumer access guidelines for immunization registries utilizing the WIR solution. To help develop the work to date, the team reviewed efforts in the areas of access control, legal/policy, and technical approaches. This work included a review of the minutes from the September 2012 ONC Consumer Access meeting. The team built upon a previously completed study by HLN Consulting, LLC conducted

for the state of Minnesota.[2] The resulting product in this phase was a *Synthesis of Work to-Date***,** delivered on August 9, 2013, establishing the current state of past and in-progress consumer access efforts and providing a foundation to develop a roadmap for future IIS consumer access efforts.

2.1.2. Collaborative Analysis and Discussion

To facilitate requirements discussion, analysis, and potential recommendation selection, a series of one hour bi-weekly webinars were utilized to facilitate group working sessions and serve as a collaborative space to share experiences and narrow in on promising practices. Nine virtual meetings and one face-to-face meeting were utilized to facilitate collaboration among initiative stakeholders, specifically identifying the contributions and benefits from the collective experiences of the participants. Discussions were broad in nature and explored a variety of options for consumer access to IIS. Table 2 identifies the dates and key topics covered in each meeting.

Webinar Date	Activities
8/9/13	• Kickoff
8/29/13	• Review Synthesis of Work to Date • Frame Requirements and Options
9/12/13	• Results of participant survey • User stories and work flow review • Determine if any additional options should be described
9/26/13	• Discuss access control strategies for selected options • Review MU Stage 2 V/D/T requirements • Discuss principles for option selection
10/7/13 – Face-to-Face Meeting at AIRA Conference	• Confirm requirements and guiding principles • Discuss and narrow down set of options for both WIR and non-WIR states
10/24/13	• Continue to discuss options based on agreements made at Face-to-Face Meeting
10/30/13	• Discuss approach of interfacing with EHR and PHR systems
11/7/13	• Review detailed options (not dependent on WIR)
11/21/13	• Review detailed options (dependent on WIR) • Include review of current WIR implementations (WI, NE) and prospective strategies, if any

12/5/13	• Review draft final reports
	  ○ Management Report
	  ○ Consumer Access to Immunization Information System

[2] http://www.health.state.mn.us/e-health/consumeraccessdata.pdf

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

Table 2 – Consumer Access to Immunization Information Key Meetings

A project wiki[3] was also used to post background materials, webinar slides, webinar recordings, and meeting minutes from the engagement. This wiki will remain available as a source of materials and findings for future consumer access projects.

2.1.3. Supplemental Surveys

During this project, the consulting team also surveyed the participating stakeholders on several key functions that influence the types of consumer access solutions. The first survey helped document different IIS approaches for submitting data to registries; each state's ability to provide direct consumer access, the laws surrounding such legislation, and method for doing so; and any collective desires on the ideal method for providing such access in the future, as well as any concerns the stakeholders may have in implementing consumer access within their IIS environments.

The second survey helped to clarify the priorities of an interim vs. long term solution recommendation. This survey also explored access control requirements, as well as the content and channels for data to be communicated to patients, parents, and other stakeholders in implementing consumer access solutions.

Please refer to Appendices A and B for the survey forms used in this project.

2.1.4. Promising Practices Documentation

In the course of the project, it became clear that two deliverables documenting the recommendations of the group were required. The *Consumer Access to Immunization Information System (IIS) Data: A Guide for Consumer Access via an IIS Portal* report documents promising practices and will focus on solutions focused on how current IIS's can be accessed directly by a patient portal.

The *Consumer Access to Immunization Information System (IIS) Data: A Guide for EHR and PHR System Vendors* report discusses guidelines for how consumer access interfaces can be designed to allow for integration with Electronic Health Record and Personal Health Record Systems.

To finalize all deliverables, the team used a two-week review period for stakeholders to provide feedback. In this period, the team used a webinar to proactively solicit communal feedback, and also established other communication channels (e.g., email, phone contact) for stakeholders that may have schedule conflicts, but who were still interested in providing

[3] https://support.hln.com/oncwiki/index.php/Welcome

feedback. All feedback was captured in a MS Excel based comment log, and each comment resolution was tracked.

2.1.5. Project Close / Knowledge Transfer

To close the engagement, the Deloitte team created an archive of all final deliverables, including:

- Final Project Management Plan
- Synthesis of Work To Date
- Webinar slides and other public facing communication materials used during the project
- Final *Consumer Access to IIS Best Practice* Documents and Comment Log

These documents are posted to the project wiki.

3. Project Results: Synthesis of Work to Date

3.1. National Perspective

The goal of providing access to consumers to enhance their health care engagement is a priority of the ONC. The ONC is looking at many different strategies to address consumer access to health care data. While the original release of Health Insurance Portability and Accountability Act (HIPAA) in 1996 guaranteed the right of access to personal health care information, access to this data still presents many technological challenges and consumer demand is marginal. The Centers for Medicare & Medicaid Services (CMS) EHR Incentive Program's Meaningful Use (MU) encourages enhanced patient engagement and consumer access. The ONC has recently posted a web page seeking the public's input on Federal Consumer e-Health Strategies. This page details the ONC's "3 A's" of consumer engagement: **A**ccess, **A**ction, and **A**ttitude.[4] It states that when patients have the ability to review and update their health record, they become active participants in their health care. A recently conducted Deloitte survey stated that 60% of people interviewed would consider changing their health care provider if they could access their health care records.[5]

One of the solutions to provide consumer access to health records is the Blue Button Initiative. The Blue Button Initiative was launched in 2010 for the Veterans Administration from the MyHealtheVet portal.[6] The application was developed to allow Veterans to easily access and download their medical data for their own use or to share it with other medical providers. The guideline for the data in Blue Button was that it had to be both human and computer readable. Blue Button was branded and the icon represents a mechanism to view and/or download personal health data in a wider variety of settings. Its use continues to grow and this year reports its one-millionth user. The 2011 campaign by the U.S. Department of Veterans Affairs

[4] http://content.healthaffairs.org/content/32/2/376.abstract
[5] ONC's Strategy for Engaging Consumers - 2012 Consumer Health IT Summit
[6] http://www.va.gov/bluebutton/

(VA) encouraged widespread use of this technology and encouraged vendors and developers to create applications to enhance the use of these data. Health care providers and organizations are encouraged to use this technology on their web page to promote easy access to data.[7]

In 2013 ONC released Blue Button+ (BB+) which extended the original Blue Button Initiative.[8] This initiative provides for digital access to health information. Specifications and use cases have been developed through the Standards and Interoperability (S&I) Framework process. The BB+ initiative encourages the use of structure data and intentionally allows the marketplace to determine how and what types of tools should be developed.

The CMS EHR Incentive Programs provide another backdrop for consumer access to immunization data.[9] Established in 2010, the incentive programs encourage eligible professionals and hospitals to implement health information technology. The primary focus of this program is the implementation of electronic health record systems and their "meaningful use" (MU). This multi-year program will roll out in several phases, or "stages." A critical component of the programs is a set of public health objectives related to reporting, with corresponding measures and standards, which eligible professionals and hospitals will be expected to support if the public health agencies in their jurisdictions are capable of exchanging data electronically. Immunization reporting, established as a “menu set,” or optional, measure in Stage 1 of the program, was elevated to a “core set” item in Stage 2 which begins in 2014.

The Stage 2 Eligible Professional (EP) MU Core Measure 7 outlines the Patient Electronic Access. The objective states that the provider must “provide patients the ability to view online, download and transmit their health information within four business days of the information being available to the EP.”[10] It further defines the meaning of access, view, and transmission as stated below.

“View/Download/Transmit” represents a new, more formal requirement for patients to access their own health data ostensibly through the provider’s EHR system. Blue Button/Blue Button+ may become one strategy for providing this access. As IIS contemplate strategies for providing data access directly to consumers, these initiatives may provide strong points of leverage in accomplishing this goal.

National IIS policy originates with the National Center for Immunization and Respiratory Diseases (NCIRD), a branch of the CDC. As stated above, the CDC echoed the sentiments of several states HLN interviewed that the demand for direct access to immunization records does not appear to be coming directly from the consumer at this time. The demand for this service is coming from the top: the Secretary of Health and Human Services and the National Coordinator for Health Information Technology at ONC, as a function of their consumer empowerment

[7] http://bluebuttondata.org/
[8] http://bluebuttonplus.org/
[9] http://healthit.hhs.gov/portal/server.pt?open=512&objID=2996&mode=2
[10] http://www.gpo.gov/fdsys/pkg/FR-2012-09-04/pdf/2012-21050.pdf#12

initiative. This initiative is part of a large Federal initiative related to consumer access to data that transcends health care.[11]

3.2. State Perspectives

From February to August, 2013, the State of Minnesota contracted with HLN Consulting, LLC, to develop a snapshot of the current state of immunization information system consumer access approaches[12]. To gather an understanding of how states were providing access to IIS data, interviews were held with states providing consumer access through their IIS software, with the following conclusions:

- States that have provided consumer access have done so with little up-front cost and little to no impact on current IIS operations or system performance.
- State and public health agency technical, legal, and information security staff members should be fairly involved in IIS operations and decision-making so any move toward providing consumer access will require the scrutiny of these offices. This may limit IIS' ability to move forward quickly or easily.
- If there are no unique identifiers (i.e., Social Security Number (SSN), Medicaid ID, Medical Record Number (MRN)) in the IIS known easily to the outside community, consumer access cannot be provided without some level of effort, technical or administrative.
- User identity proofing issues for consumer access are somewhat of a red herring: The tough part is not independent user authentication but rather user authorization (i.e., establishing the user's relationship to the patient). This is difficult to do in an IIS alone without corroborating that relationship with data in the IIS or validating that independently with another source (e.g., the provider).

Participant surveys also provided key insights and general themes which helped the analysis of potential solutions. These include:

- Near universal support for Health Level 7 data submission – 11 of 13 (85%) participating states supported HL7 reporting to their registries
- All participants supported multiple means for file transfer to and from their IIS
- Participants indicated strong, though not universal support, for web services (6 of 13, 46%), and limited support for Direct (2 of 13, 15%)
- Bi-directional information exchange between the IIS and authorized stakeholders is in place in most participating IIS environments (8 of 12 responses, 67%).
- Wide support for various identifiers available to query in the stakeholder IIS's, including name (100%), patient DOB (100%), Medical Record Number (58%)
- Limited support for SSN (33%) and other identifiers

[11] http://www.data.gov/
[12] http://www.health.state.mn.us/e-health/consumeraccessdata.pdf

- While there were few legal impediments identified across the stakeholders (83% of the respondents said there were not any legal impediments), only a small number (9%) of participating states were providing consumer access to immunization information
- Costs, security, and prioritization were cited as factors that may impede the implementation of this functionality

3.3. Electronic Health Record / Personal Health Record Perspectives

Several leading EHR and PHR vendors were invited to participate in interviews to gauge the interest of their clients to provide direct consumer access to immunization and general health data. They were also asked to discuss how they were addressing the issue of view/download/transmit. The precondition for this meeting was that specific vendor information would not be shared.

The team reached out to eight EHR vendors and one PHR vendor. Five EHR vendors initially responded but only three were willing to be interviewed; the PHR vendor also agreed. The general consensus of the EHR vendors interviewed is that direct consumer access was not a top priority of their clients. Two of the vendors were currently working on immunization query but this was provider based access rather than consumer based access. The third vendor was actively providing immunization information via a patient portal. When asked about MU Stage 2 requirements for view/download/transmit, they all had this on their horizon but did not have a specific timeline for development or implementation.

All three EHRs stated that the providers wanted to authorize patients to use their portal. They believed they had a strong provider-patient relationship that they wanted to nurture. One EHR required in-person portal registration while the other two EHRs allowed patients to register for the portal electronically, but this had to be approved by the provider or the staff. Proxy or guardian accounts were permitted. The only additional insight offered by the PHR vendor was interest in being able to consolidate data from *across* IIS projects as PHRs tend to have patient-centric and not practice-centric perspectives.

Currently the EHRs are planning to provide a history and one is developing a forecast into their EHR system. Official and or parent reports were under development for one EHR vendor. The others were considering printing the C-CDA when available.

4. Project Results: Consumer Access to Immunization Data Promising Practices

4.1. Documented Requirements

Based on the research and discussion conducted by the Project the following core requirements were identified:

1. **Support for Federal consumer health data access initiative** as referred to above. This is an evolving set of initiatives and may or may not imply specific strategies.
2. **Query access is provided for a patient's record.** While this may sound obvious, it is at the core of what this project is intended to address.
3. **Query returns one, and only one, target record.** When providers access an IIS, they can typically enter search criteria that may yield multiple potential patients' records. For consumers, however, they must know enough about a unique record to establish a single match in response to a query.
4. **Query response does not return demographic data that was not originally supplied in the query parameters.** The project is very sensitive to the need to provide immunization data but little else back to a consumer that might prove to be a violation of patient privacy.
5. **Only authorized users can see data for a particular patient.** User relationship to patient is either established reliably before the query or user knows enough data about the patient to substantiate the relationship with the patient.
6. **If the solution requires authentication then single-factor authentication is sufficient for this project.** ONC indicates that two-factor authentication is recommended, and perhaps required, for access to patient records, but this may not be practical in this scenario.
7. **User can view consolidated, de-duplicated immunization history** (at a minimum, series, vaccine, and date), indicator of validity for each dose, and, potentially, **a forecast of doses due** (and overdue if algorithm provides this distinction). This view of the data may be simpler than what a provider sees currently through their IIS, or through their local EHR system, but is sufficient for a patient.
8. **User can generate or download a report with vaccine history suitable for school, camp, or child care admission.** This is a key requirement, and is often the reason why parents and adult students want access to this data in the first place.

These items were viewed by the project as *minimum,* or core requirements; additional requirements may be imposed by particular jurisdictions.

4.2. Issues to Consider

There are a number of important issues and choices that need to be considered in order for a solution to be effective in a given settings:

	Issue/Key Question	Suggested Guidance
Technical	EHR/PHR systems and IIS must support HL7 query/response. Some IIS implementations differ across the country.	Encourage use of CDC WSDL[13] for more consistent implementations.
	IIS may experience performance issues as volume of queries increases.	Work closely with IIS partners to understand constraints and capacity of IIS

[13] Web Services Definition Language – See http://www.cdc.gov/vaccines/programs/iis/interop-proj/ehr.html#technical

	Issue/Key Question	Suggested Guidance
		system.
Privacy and Security	Some patients may not have routine access to a primary care provider and thus might not have access to the data (public health agencies may need to provide access).	Encourage use of untethered PHRs for these patients, or consider using public health agencies (local or state) and surrogate medical homes.
	Potential exposure of personally-identifiable health information in electronic form in patients hands may be increased as immunization data may be combined with more sensitive health information.	Educate patients about information privacy and security and the risks that come from even possessing unencrypted copies of electronic health information.
	Jurisdictional law may prevent patient access to IIS data.	Work with public health agencies to change legislation to allow this access.
	Access by untethered PHRs to IIS data requires extension of trust domain to PHR systems which may require new or different data sharing agreements and use of legal services.	This may be a particularly difficult issue for some IIS projects, as untethered PHRs have no provider organization to intermediate and to hold accountable for data queries. Over time, security models will evolve that include this type of access control. In the meantime, legal counsel may need to be consulted to determine how to craft an appropriate data sharing agreement.
Functional	States that have “official” parent reports need to consider whether vendors can generate these according to specifications provided by the jurisdiction.	EHR systems may have to be modified to include these specific report formats in their patient portals. Untethered PHR systems should have less trouble meeting these requirements.
	PHR systems vary in the data about immunization events that are displayed, and IIS project differ in the data they would *like* PHR systems to display.	See below for suggested best practice for immunization data display. Generally speaking, it is best for PHR systems to display immunizations in a longitudinal record rather than an encounter-based record. Some patients might also find it useful to identify the source of each immunization, though some IIS may be concerned about the potential to share this information inappropriately (*e.g.,* with a non-custodial parent).

	Issue/Key Question	Suggested Guidance
	If the tethered PHR does not query the IIS for records (alternative/lower work flow above), the patient risks seeing an incomplete immunization history and potentially an inaccurate forecast.	There is a tradeoff between the risk of an incomplete record and the potential for error and duplication without clinical review of immunizations received by an EHR system in response to an IIS query. The concern is somewhat mitigated by a strong patient medical home where most/all of the immunizations are likely administered by the provider and captured locally in the EHR system. This is a greater concern with patients who have no consistent medical home, have moved locations, or who receive immunizations in pharmacy locations.
	If a tethered PHR queries the IIS for records but does not provide clinical review, or if an untethered PHR has no clinical review of immunizations received, there is the potential for duplicate and/or near-duplicate immunizations to be stored especially if the immunization history is received from multiple sources. This can lead to a confusing display for the patient and potentially to an inaccurate forecast.	Untethered PHR systems should consider using best practices for de-duplicating immunizations and presenting a cleaner, filtered display for the patient.[14] Display of duplicate immunizations is less risky to the patient than potentially missing some immunizations altogether, and a good immunization forecast system will ignore duplicate immunizations in its evaluation of immunization history.[15]
	PHR does not show a forecast of immunizations due.	The absence of a forecast still satisfies an important need for the patient: provision of an immunization history for school, camp, or child care admission. However, absence of a forecast represents an important missed opportunity to inform a patient about immunizations due or overdue.

[14] See *MIROW Best Practice Guidelines Chapter 2: Vaccine Level Deduplication in Immunization Information Systems,"* American Immunization Registry Association (AIRA), 2006. <http://www.immregistries.org/resources/AIRA-BP_guide_Vaccine_DeDup_120706.pdf>

[15] For an example see http://www.hln.com/ice

4.3. Guiding Principles of Solution

The project team considered direct access to IIS and EHR/PHR access solutions could be as potential strategies promoting consumer access to immunization information. The following principles were used by the project in selecting options and should be upheld to the degree possible within any solution that is deployed:

- **Meet Requirements**: Recommended options should meet all the core requirements and as many of the other requirements as possible (see section 2 above).
- **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 that 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 investigated if the state has the resources to feasibly implement the solution 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.

4.4. Consensus Practice Recommendations

In the *Synthesis-of-Work-to-Date* document, the consulting team identified nine options for providing consumer access to immunization information. During the course of the project, the project stakeholders agreed that practice recommendations should focus on near-term immunization information system modifications, as well as long-term efforts to provide access through Electronic Health Record and Personal Health Record systems.

4.4.1. IIS Portal Recommendations

Three solution practices focused on IIS adaptations were identified, including:

- Modifying IIS software to provide a new web-based user interface for consumer access. This new interface accesses the same underlying database as the IIS provider client. Users can be authorized by IIS staff, primary care provider, or no one at all (user must

substantiate relationship with patient through knowledge of patient demographic details). Users should be able to view a record and download a PDF of the record at minimum.
- Creating a new, separate, stand-alone web-based interface for consumer access.

The details for each of these recommendations are described in the *Consumer Access to Immunization Information System (IIS) Data: A Guide for Consumer Access via an IIS Portal* report.

4.4.2. EHR/PHR Portal Recommendations

Two solution practices focused on Electronic Health Record and Personal Health Record interfaces were identified:

- Allow EHR systems to query IIS for patient records and forecast via HL7 v2 messages. Encourage patient access through interfaces provided by provider organizations.
- Allow authorized PHR systems or HIE to query IIS for patient records and forecast via HL7 v2 messages. Patient access is provided through PHR account. IIS relies on PHR to authenticate and authorize users.

The details for these recommendations are described in the *Consumer Access to Immunization Information System (IIS) Data: A Guide for EHR and PHR System Vendors*

5. Conclusions and Recommendations

As the project concludes, the Deloitte team offers the following conclusions and recommendations:

- The collaborative process yielded priorities and recommendations that enhanced existing solutions and provided greater detail to potential long term solutions than previously documented.
- The collaborative approach required a modest pace and multiple modes of communication to allow for appropriate stakeholder participation.
- There is a focus on longer term solutions independent of WIR or other specific IIS products.
- Access control practices and implementation will require examination of jurisdiction laws, policies, and risk tolerances in design and implementation. User identity proofing issues for consumer access are somewhat of a red herring: The tough part is not independent user authentication but rather user *authorization* (i.e., establishing the user's relationship to the patient). This is difficult to do in an IIS alone without corroborating that relationship with data in the IIS or validating that independently with another source (e.g., the provider).
- In terms of the implementation options identified in the report, it may be challenging for a public health agency to expand the use of the WIR software web client for consumer access.

- Creation of a mobile app is probably the most forward-thinking in terms of consumer access and emerging technology usage patterns, though the difficulty in printing a formatted report from a mobile device may be a real barrier.
- Permitted access via query from electronic health record (EHR) and/or personal health record (PHR) systems require the least modification to operations and software, but require close cooperation with the vendors and sites. Pursuit of a Blue Button+ strategy is the most forward-thinking of all the options.

6. Appendix A – IIS Survey 1 Form

State: Type your State (one survey per State)

Name: Type your name

Email: Type you email address

Date: Today's Date

Instructions

Each State should complete one survey. The completed survey should be returned to Natalie Jorgenson at njorgenson@deloitte.com by noon ***Tuesday August 20, 2013***. If you have any questions, please contact Natalie Jorgenson directly.

1) _____ **How are data currently submitted to your Registry? (Select all that apply.)**

   a. Manual Entry
   b. Batch Flat File
   c. HL7 Message
   d. Other (please explain)

2) _____ **What file transport is supported by your Registry?**

   a. Web Services
   b. HTTP Post
   c. PHINMS
   d. Direct
   e. SFTP
   f. Other (please explain)_____

3) _____ **Is submission to your State IIS required? If yes, please indicate any are age restrictions.**

   a. YES; Age Restrictions:_____
   b. NO

4) _____ **Does your Registry Support Bi-Directional Access? (i.e., query/response via web services)**

   a. YES
   b. NO

5) _____ **What kinds of Identifiers are used for Searches?**

_____

a. Name
b. DOB
c. SSN
d. Medicaid ID #
e. Medical Record Number
f. Other. Briefly explain:_____

6) _____ **Is there an Official IIS Record (or parent/school/camp report) used by your State?**

a. YES. Is it required? _____
b. NO

7) _____ **Is Direct Consumer Access to IIS data available in your State?**

a. YES (Please proceed to question 8)
b. NO (Please proceed to question 10)

8) _____ **If Consumer Access is available, how is access provided?**

a. Web access
b. Access through Provider Portal
c. Other. Briefly explain:_____

9) _____ **If Consumer Access is available, how is authentication of the patient/guardian achieved?**

a. By Provider Only
b. Challenge Questions
c. Other. Briefly explain:_____

10) _____ **Are there laws or statutes in your State restricting Consumer Access to IIS data?**

a. YES : _____
b. NO

11) _____ **Is there currently Consumer Access to any health data provided by your State public health agency?**

a. YES. Briefly explain: _____
b. NO

12) _____ **Briefly explain any thoughts, expectations, or concerns about Consumer Access.**

a. Comments: _____

13) _____ **Additional comments?**

Please include any additional comments:

_____
_____
_____
_____
_____
a. _____

7. Appendix B – IIS Survey 2 Form

IIS Registry Survey

Name: Type your name

State: Type your State

Date: Today's Date

Instructions

There seems to be confusion on whether we should pursue both a **short term solution:** direct IIS access model with provider-intermediated access control for patients and/or a **long term solution:** reliance on patient access control through EHR-tethered patient portals or untethered PHRs.

In order to better prepare for upcoming webinars below are a list of questions specifically about the short term solution for your review. Please take a few minutes to review and complete. ***Return by COB Tuesday October 29th.***

The webinar this Wednesday October 30th will focus on the long term solution and if time permits a discussion about the results of this survey.

Thank you for your assistance.

1) _____ **Which method of providing access for patients do we need to support?**

   a. Short term solution : Direct access to the IIS for consumers
   b. Long term solution: Access through the EHR system
   c. Both

2) _____ **For patient authentication which method(s) do we need to support?**

   a. One which relies on what a patient (or the patient's guardian) knows to query the IIS each time for records
   b. One which relies on providers to verify a patient's identity and provide them with a unique PIN or username/password which is then used to access the IIS directly.
   c. Both
   d. Something else. Please explain:

3) **If you selected 2a above, how would you address IIS systems that do not have enough demographic fields to support a unique search?**

   Provider you thoughts here:

4) _____ **If you selected 2b above, should an authorized guardian receive separate credentials for each authorized patient to be accessed or be able to select from a list of *authorized* patients to access records?**

a. Separate credentials for each authorized patient

b. One set of credentials and the ability to select from a list of authorized patients

5) _____ **Should the results of a request for records by a patient or guardian only be routed to the authorized contact already registered in the IIS rather than present a list on the screen to the individual who queried the IIS?**

a. YES

b. NO

6) _____ **If a query did not *return* any demographics *beyond those provided by the patient* during the query itself, is there an issue with access by non-custodial parents who would still see the basic query parameters?**

a. YES

b. NO

7) _____ **Should the team address access control issues for adolescent patients given state regulation surrounding parent access to adolescent sexual health data? This will likely be an add-on solution.**

a. YES

b. NO

5) _____ **Assuming we wish to show the patient data on the screen after a query, what information what would want to display?**

Some options include: screen display of immunization history and forecast including or excluding location of immunization and patients address; printable version of screen display; official printable State report; etc.

Provide your thoughts here: