The Office of the National Coordinator for Health Information Technology

Summary of the Public Health Immunization Data and Consumer Access Pilot Projects

IMPROVING THE EFFICIENCY AND EFFECTIVENESS OF IMMUNIZATION INFORMATION SYSTEMS

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Introduction

The Office of the National Coordinator for Health Information Technology (ONC) is providing this final report to the Senate Committee on Appropriations in accordance with Senate Report 114-274, Departments of Labor, Health and Human Services (HHS), and Education, and Related Agencies Appropriations Bill, 2017. The Senate Report states:

> *"The Committee is aware of the Immunization Registry Data Exchange and the Consumer Access Immunization Registry pilot projects exploring ways to improve the efficiency and effectiveness of IIS. The Committee encourages ONC to continue these pilots and requests a report to the Committee from ONC no later than 180 days after enactment of this act with findings, results, and recommendations from the pilot studies. The Committee encourages ONC to partner with CDC and other relevant HHS partners to leverage knowledge and enhance education and information sharing opportunities between registry system administrators and related State and local personnel."*

ONC in partnership with the Centers for Disease Control and Prevention (CDC) and the National Vaccine Program Office (NVPO), began the pilots to gain additional information regarding implementation of IIS systems and consumer access to immunization records, and cross jurisdictional data exchange between public health agencies. Specifically, ONC contracted with Audacious Inquiry, LLC and JBS International Inc. to implement the pilots. The two contractors provided to ONC their findings, results and recommendations related to the pilot, which are included in this report. The report reflects work completed on the pilots between 2013 and 2017.

We are pleased to provide this report to you and we look forward to continuing to work with Congress on this important issue.

Overview of the Pilot Projects

Immunization information systems (IIS) are confidential, population-based, computerized databases that record all immunization doses administered by participating providers to persons residing within a given geographic area. At the point of clinical care, an IIS can provide consolidated immunization histories for use by a vaccination provider in determining appropriate client vaccinations. At the population level, an IIS can provide aggregate data on vaccinations for use in surveillance and program operations. In 2015, 54 percent of eligible professionals (EP) participating in Stage 2 of the Medicare EHR Incentive Program and 44 percent of professionals participating in modified stage 2 electronically reported immunizations to local registries.[1] These data help inform and guide public health activities designed to improve vaccination rates and reduce vaccine-preventable disease.

[1] Electronic Reporting to Immunization Information Services (IIS) by Stage of Meaningful Use

Two major challenges that IIS face are 1) enabling consumers to access this rich source of information and 2) sharing immunization information across jurisdictional IIS. Currently, it is difficult for consumers to have direct access to IIS data. As consumers seek care across jurisdictional boundaries or move from one state to another, their immunization histories do not follow them which results in the IIS and health care providers having incomplete data.

In order to address these two issues, ONC collaborated with the CDC and the NVPO on the following pilot projects:

- **Pilot One: Consumer Access to IIS**: This pilot project provided consumers online access to their records stored in a state IIS. The goal was to increase patient access to their information and to decrease provider burden by removing the need for providers to print immunization histories, forecast schedules and certificates on behalf of their patients. The primary use case focused on consumer's direct access to their child's immunization information for school or camp registration. However, for those IIS that collect adult immunizations, the pilot also supported access to immunization records for employment and travel requirements.
- **Pilot Two: Cross-Jurisdictional Exchange**: This pilot project addressed cross-jurisdictional exchange of immunization data, to support provider access to immunization records even when the patient moved out of the jurisdictional area. This helps decrease provider burden by ensuring that providers did not have to track down immunizations administered in other states manually. Instead, the provider has relevant, up-to-date information available to them in order to administer care.

Both projects focused on interoperability through the implementation and use of a standards-based approach. Specifically, the two projects followed the same Health Level Seven international (HL7) implementation guides adopted by HHS as part of the ONC Health IT Certification Program in its 2015 Edition[2] and 2014 Edition certification criteria to enable the query and response transactions with an IIS. This encouraged both IIS projects to follow the interoperability standards for IIS, which resulted in less variation in how the information presented across systems.

Key Findings

Program evaluation of the two pilot projects provide insight into continuing lessons learned. Key findings from the two pilot projects include:

- Analysis of and methods to improve data quality, as well as the use of multiple data points, improved patient match rates for consumer access to IIS.

[2] 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications, Final Rule, 80 Fed. Reg. 62601 (Oct 16, 2015).

- While physician-facilitated engagement supported consumer access, marketing outlets specifically intended for the targeted consumer audience were most effective and helped reduce burden.
- In-store registration for consumer access was challenging for pharmacists who often have limited resources to devote to the registration process.
- Expanded evaluation efforts focusing on non-self-reported consumer metrics were necessary to better understand consumer behavior.
- Early identification of the right jurisdiction and vendor resources to install digital certificates and implement the technical requirements was crucial to success rates.
- Privacy and data sharing was a challenge when one jurisdiction did not have an established data sharing agreement with the other jurisdiction.
- Engagement from various levels of participant leadership enabled the committed and successful exchange environment needed to carry out legal and technical implementation requirements.

Pilot One: Consumer Access to IIS

BACKGROUND

In many instances, patients obtain their immunization records by calling or visiting a provider practice or state or local health department. This process is often time-consuming and burdensome for providers, patients, and state/local health department officials. This is particularly true during kindergarten or back-to-school season when providers receive a high volume of immunization records requests.

In 2017, almost 3 in 10 consumers were offered access to their online medical record and viewed their record at least once within the past year. Of these individuals, 55 percent reported that their online medical record included immunization or vaccination history.[3] However, most providers are only able to provide patients with access to records for immunizations given at their own practice. For consumers who visit multiple practices or who have moved, this presents the additional burden of consolidating immunization records from disparate sources. Lastly, consumers often lack access to their immunization forecasting schedule, making it difficult to keep track of upcoming or past-due immunizations.

In order to explore methods to overcome the aforementioned challenges, in 2013, the ONC launched the Consumer Engagement for IIS Project. This pilot aims to alleviate the issues of the traditional methods for obtaining immunization records by providing patients and their families with a convenient way to access immunization histories and forecasting schedules online. ONC contracted with Audacious Inquiry, LLC (Ai) to provide project management support and coordination of the development, expansion, and evaluation of the Consumer Engagement for IIS project. Ai engaged sub-contractors to

[3] Patel V & Johnson C. (April 2018). Individuals' use of online medical records and technology for health needs. ONC Data Brief, no.40. Office of the National Coordinator for Health Information Technology: Washington DC.

support project implementation. Representatives from ONC, CDC, NVPO, Ai and their sub-contractors formed a project team to provide project guidance and oversight.

The Consumer Engagement for IIS Project piloted a web-based immunization portal called MyIR.net™ (MyIR), a product of Scientific Technologies Corporation (STC), in Alaska[4], Arizona, Louisiana, Washington, and West Virginia. MyIR allows consumers to access official immunization records and forecasting schedules from each state's IIS. State IIS consolidate records for all immunizations administered for a specific individual within a state and generate a single record for an individual. MyIR interoperates with any state IIS or any other system that complies with HL7 bidirectional query-and-response specifications, which is the same standard adopted in ONC's 2015 Edition certification criteria[5].

CONSUMER ACCESS TO IIS SUMMARY

The primary goal of the Consumer Engagement for IIS Project is to encourage consumer access to immunization records and forecasting schedules to empower informed decision-making.

During the first two years of the project, MyIR registration required patients to visit their provider to complete the identity proofing process and confirm the patient's identity. In the third year of the project, the project team implemented online authentication to allow consumers to complete the registration and identity proofing process autonomously. This process required consumers to match their demographic information with data within their state IIS, using a valid phone number or current address. MyIR sends an activation code immediately to the consumer by text message, autodial or mailed to their physical address.

Along with the implementation of the MyIR tool in pilot states, the project team implemented marketing and evaluation activities. In prior years, marketing specifically targeted healthcare providers to increase their participation in the project. This was based on the assumption that the provider would assist patients with the enrollment and spread the word regarding the availability of MyIR for online immunization record access. However, the project team found that enrolling patients in MyIR took significant time for providers. As the project evolved, the focus shifted from recruiting providers to directly marketing to consumers with a specific emphasis on caregivers of school-aged children.

The project team implemented various marketing approaches including the distribution of printed materials, such as flat panel cards and posters, engaging health groups including non-profits and school nurse associations, and promoting MyIR through digital ad campaigns in two pilot markets (Seattle-Tacoma, Washington, and Baton Rouge, Louisiana).

Key modifications identified by the project team included: 1) transitioning from provider-initiated registration to consumer-initiated online authentication as few registrants completed the process of visiting their provider for purposes of identity proofing, and 2) using targeted marketing outlets to reach

[4] At the end of the second pilot year, Alaska opted to withdraw from the pilot program, citing significant staffing limitations.

[5] 2015 Edition Health Information Technology (Health IT) Certification Criteria, 2015 Edition Base Electronic Health Record (EHR) Definition, and ONC Health IT Certification Program Modifications, Final Rule, 80 Fed. Reg. 62601 (Oct 16, 2015).

consumers that are more likely to have a need to access their children's immunization records for purposes of school or camp registration.

PROGRAM EVALUATION

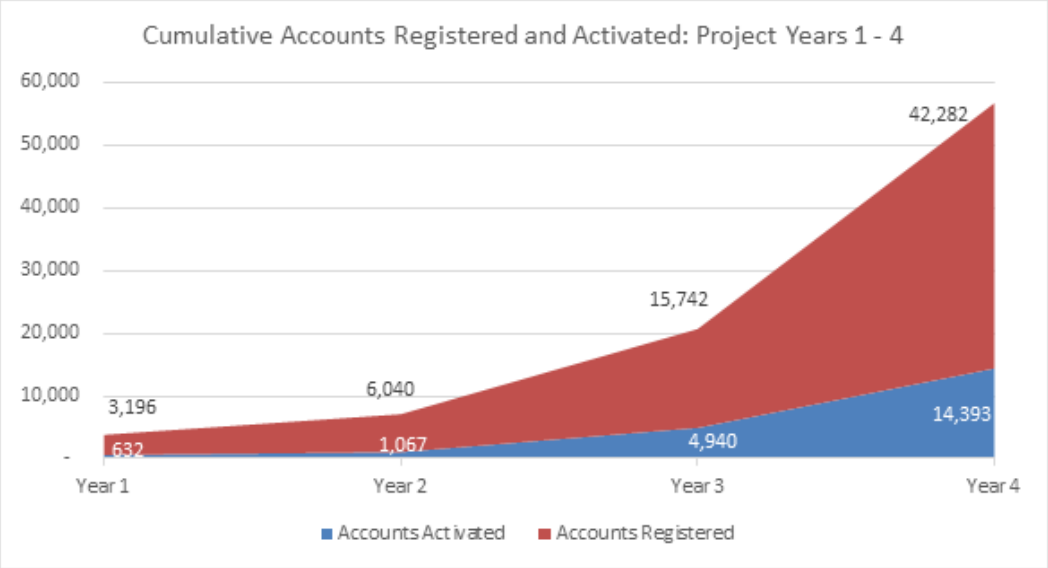
Over the four years of the pilot, the project's evaluation strategy evolved based on lessons learned. Evaluation activities included the analysis of weekly registration and activation metrics, consumer surveys fielded in each pilot state, key informant interviews with pilot participants, and a comparison of web analytics for the MyIR webpages.

MyIR Registration and Activation Analytics at a Glance

As of July 2017, there are 42,282 registered, and 14,393 activated accounts providing consumers with access to their immunization records across all participating states (see Figure 1). Activated accounts are those in which the consumer has registered for a MyIR account and completed identity proofing authentication to successfully access their immunization record. When comparing registration and activation metrics across all four years of the project, there is a drastic increase between years three and four in both registration and activation (see Figures 1 and 2). After three years of project activities, there were 15,742 registered accounts and 4,940 activated accounts. However, between project years three and four, there was a 169 percent increase in registered accounts and a 191 percent increase in activated accounts.

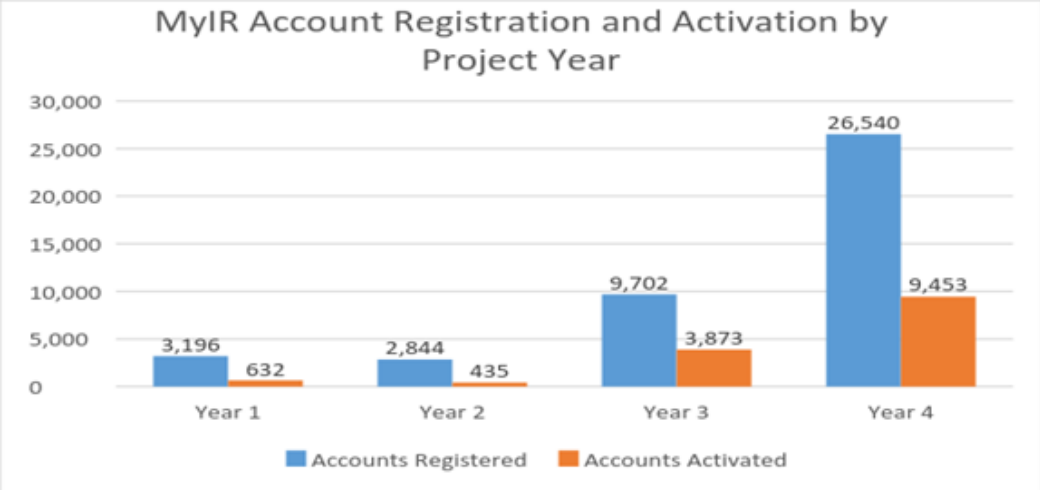
There are multiple activities that contributed to the increase in engagement with MyIR. For example, between September 2015 and May 2016, the online authentication registration process tripled the number of registered and activated accounts than had occurred during the three prior project years. The online authentication process allows consumers to complete registration and activation entirely online without having to visit their providers or pharmacist's office for identity proofing. In addition, marketing efforts were expanded to include pilot ad campaigns in two metropolitan markets.

Figure 1: Cumulative Accounts Registered and Activated: Project Years 1-4



Source: Audacious Inquiry and STC

Figure 2: MyIR Account Registration and Activation by Project Year



Source: Audacious Inquiry and STC

When the barrier of a visit was removed, MyIR registration and activation increased. However, match rates still proved to be a challenge. Data quality and system issues encumbered the online authentication process. For example, in some cases phone numbers or addresses may not be up to date in the IIS, which prevented consumers from successful online registration. As of July 2017, the overall success rate for all MyIR registration methods was 36 percent, a four percent improvement over the prior year (see Table 1).

Table 1: Registration and Activation Counts by Registration Workflow from September 29, 2016 – July 7, 2017

	Total Registered Accounts	Total Fully Activated Accounts
Provider-Assisted Authentication	901	201
Activation Success Rate	-	*22%*
Online Authentication	24,427	8,238
Activation Success Rate	-	*34%*
WA State Assisted	1,212	1,014
Activation Success Rate	-	*84%*
Total (All Registration Methods)	26,540	9,453
Overall Activation Success Rate	-	*36%*

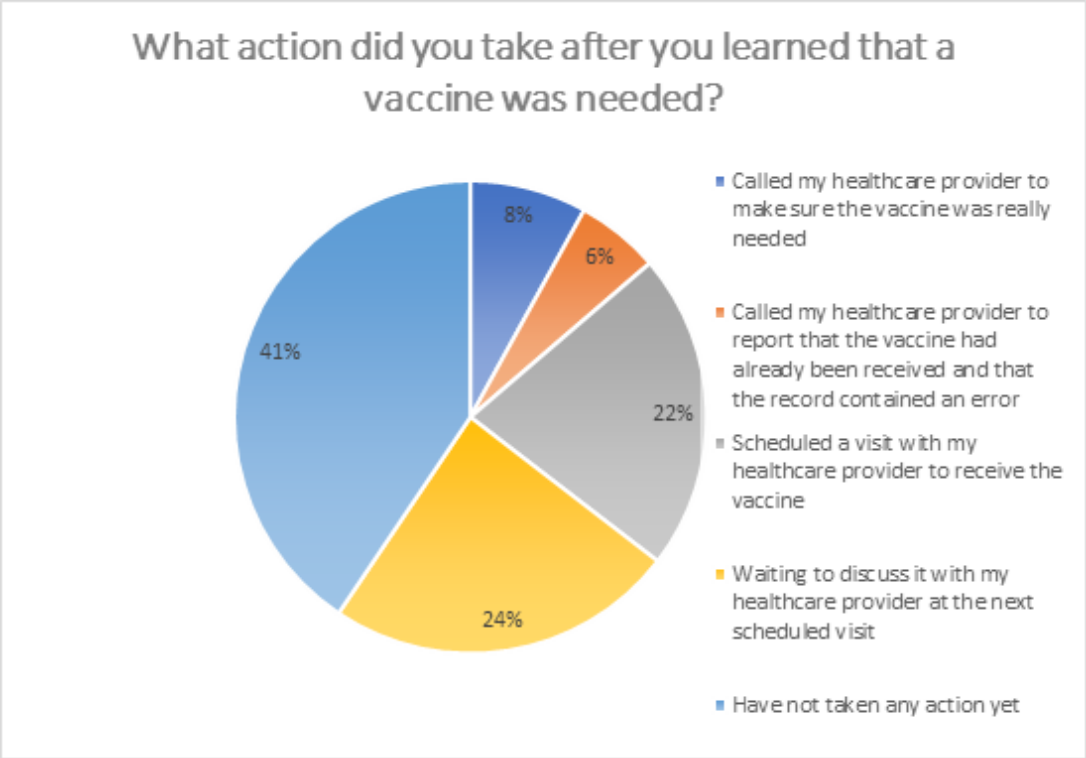
Source: Audacious Inquiry and STC

Consumer Access Analytics at a Glance

Enabling consumer access to immunization records empowers patients to manage their healthcare better. Consumer surveys were disseminated to individuals that registered for MyIR. Each year between the months of March and June, Ai electronically disseminated the consumer surveys. Ai selected these months to understand the impact of the pilot ad campaign on consumer registration. In the fourth year of the project, 21,234 consumers in four pilot states received the survey. Of those surveyed, 1,266 (6%) individuals completed some or all of the survey. Since the majority of the individuals that registered for and or used MyIR reside in Washington State, the majority of respondents were from Washington (76%).

Of the survey respondents that registered for MyIR during the fourth year of the project and were able to access their immunization records, 35 percent (n=315) indicated that they had an overdue vaccination. Because of this knowledge, 36 percent of respondents took action by calling and/or visiting their provider (See Figure 3: Note, 8 percent, 6 percent, and 22 percent; percent=36, n=62). Consumer access to immunization records has increased steadily over the four years of the project. However, as technology improves and more consumers rely on electronic data exchange, it will be necessary to evolve project activities to keep up with consumer expectations for website usability. As such, in year five of the project, the project team will further streamline the registration process by improving website functionality and on-screen guidance.

Figure 3: Survey Question Summary: What action did you take after you learned that a vaccine was needed?



Source: Audacious Inquiry and STC (n=175 individuals that accessed their immunization record and learned a vaccine was needed)

KEY FINDINGS AND RESULTS

Analysis of and Methods to Improve Data Quality, as well as the Use of Multiple Data Points, Improved Patient Match Rates for Consumer Access to IIS.

During September 2016, the project team conducted a data quality analysis to better understand the matching difficulties between demographic data provided by consumers and data in the IIS. To conduct the analysis, the project team collected a random sample in three pilot states of thirty consumers that were unable to match. The project team compared registration data to IIS data to determine why consumer matches were failing. Match rates for each data element varied by pilot state, but phone numbers and addresses proved to be the most frequently mismatched fields. As a result, the project team decided to allow consumers to add more than one phone number while completing their registration. In addition, they added language prompting consumers to try an old address in the event that they are unable to match. Finally, during the data analysis, the team found that trailing spaces before or after characters and numbers were being included in the match comparison and thus decided to truncate each field to remove the spaces. Because of these changes, the overall online authentication match rate improved from 28 percent in year three to 32 percent in year four.

While Physician-Facilitated Engagement Supported Consumer Access, Marketing Outlets Specifically Intended for the Targeted Consumer Audience were Most Effective and Help Reduce Burden.

During the 2017 pilot ad campaigns in the Seattle, WA and Baton Rouge, LA metro areas, various marketing outlets were engaged to increase consumer awareness of MyIR. While citywide online news sites had the largest viewership, they were not very effective in driving consumer registration. Advertisements placed on large media sites such as *The Seattle Times* and *The Advocate* of Baton Rouge resulted in increased MyIR page viewership. However, registration rates remained low in comparison to page views for these sites. Conversely, blogs targeting caregivers of school aged children (such as Baton Rouge Parents and Seattle's Child) had fewer views of the MyIR page, but a more significant conversion rate of views to actual registrations.

In Store Registration was Challenging for Pharmacists Who Often Have Limited Resources to Devote to the Registration Process.

The MyIR Pharmacy Pilot implemented in the 2017 project year aimed to provide consumers an alternate location to complete their MyIR registration. However, there were many challenges to making the pilot successful. First, the MyIR Pharmacy Pilot was implemented in one district in one state. As a result, marketing efforts were limited to in-store advertising to avoid consumers visiting other pharmacies to attempt the registration. In addition, there were competing priorities for pharmacists, which limited time available to spend on MyIR registrations. For example, one state experienced a major influenza outbreak during the pilot, which influenced their ability to spend time on the registrations. In examining ways to improve the MyIR Pharmacy Pilot implementation, these challenges will be difficult to overcome.

Expanded Evaluation Efforts Focusing on Non-self-reported Consumer Metrics were Necessary to Better Understand Consumer Behavior.

In past years, the project team primarily relied upon self-reported measures from consumers to determine how they heard about MyIR. The project team compiled these metrics from the MyIR registration page as well as consumer surveys. During the fourth project year, the project team leveraged web analytics to determine how consumers were reaching the MyIR websites.

The majority of consumers organically visited the MyIR website by searching for vaccination records using a search engine or by typing the URL into their browser, despite the purposeful marketing efforts. Between September 29, 2016 and July 7, 2017, there were 87,305 total sessions on the MyIR website for all states. A session is the period of time a user is actively engaged with a website. Of these sessions, 63,999 were unique users, or first-time users. Over a quarter of visitors to MyIR (28%) directly accessed MyIR by typing the URL into their web browser and another 6% searched for MyIR using the Google search engine, likely as a result of a specific need to obtain a family member's immunization certificate. Twenty-four percent of visitors to MyIR.net were linked through the Washington Department of Health's web page. The Arizona Department of Health web page and the Louisiana Department of Health's webpages accounted for seven percent and five percent of visits respectively. Therefore, it is possible that consumers found out about MyIR through advertising efforts and then search for the tool. While search analytics do not provide the entire picture, the analytics did provide a more complete view of consumer behavior and interaction with the MyIR website.

Consumer Access Technologies May Need to Evolve to Keep Up with Consumer Expectations for Accessing Health Data.

Multiple consumers referenced challenges using the MyIR website and understanding the registration process. Moving forward, it may be necessary to improve the user experience interacting with the MyIR

website through the development of on-screen instructions and a more streamlined registration process. In addition, as consumers rely more on technology in everyday life, it may be necessary to keep up with consumer expectations for how technology should work. For example, MyIR registration provides consumers access to their immunization records and by registering for MyIR, consumers generate another username and password tailored for one specific use case. Based on consumer feedback, in the future it may be beneficial to integrate immunization records access with additional health tools and services in order to streamline records access for consumers.

Year Five Project Activities

The project team identified the following activities to enhance the Consumer Engagement for IIS project during the fifth year of its implementation in 2018.

Evaluate Alternate Approaches to Consumer Engagement.

In the 2018 project year, the project team will work to integrate the Consumer Engagement for IIS Project with immunization record efforts already in motion by health information exchange (HIE) organizations and personal health records (PHRs). As consumers increasingly rely on technology to access their health records, it may be necessary to simplify and streamline the methods by which consumers access their immunization records in a unified space. The project team will engage partners that are attempting to unify healthcare record access in a simple way for consumers. This registration workflow will enable consumers to have one login to access the majority of their health records.

Enable Access to Official State Records.

While gaining access to immunization records is necessary to stay informed and on schedule with vaccinations, the majority of consumers only access records when it is—for example—necessary for school, camp, work, or travel. Therefore, when piloting alternate consumer access methods such as through a PHR, it may be necessary to enable printing of an official state recognized immunization record through the online tool. As future efforts are made to streamline access to health records, it may be necessary to ensure the state recognizes such printed immunization records as an official health record for the respective state. As such, the project team will work to replicate systems where the generation of official state immunization records have occurred already.

Enhance Current Evaluation Strategies.

The project team has worked to enhance evaluation methods to measure project activities based on lessons learned through the program evaluation that occurs at the conclusion of each project year. In 2018, the project team will work with stakeholders to ensure workflows are appropriately evaluated for project success with the intended goal of increasing consumer's access to their vaccination records as new project activities (e.g., as integration with PHRs and health information exchange organizations) are implemented.

Pilot Two: Cross-Jurisdictional Exchange and IIS

Background

On average, a person in the United States moves residences 11 times over their lifetime.[6] This provides a challenge for consumers to keep track of their immunization records. Because IIS are state-based systems, if a consumer were to live in 11 different states, they would need to collect their immunization records from each state IIS. This pilot addresses this reality and identifies best practices for states to easily share consumer immunization data across jurisdictional boundaries.

The Public Health Immunization Data Exchange (PHIZ) Project launched in Fall 2013 to build an immunization data exchange hub (PHIZ Hub) for cross jurisdictional exchange of immunization data between jurisdictions' IIS. This enables a state IIS to exchange immunization information with another state's IIS to improve visibility of shared patient immunization records within and outside a provider's jurisdiction. ONC contracted with JBS International, Inc. (JBS) to build the data hub and onboard participating state IIS. Representatives from CDC, NVPO, ONC, JBS, sub-contractors, and participating states created a project team to share progress, identify challenges and provide guidance to the PHIZ Project.

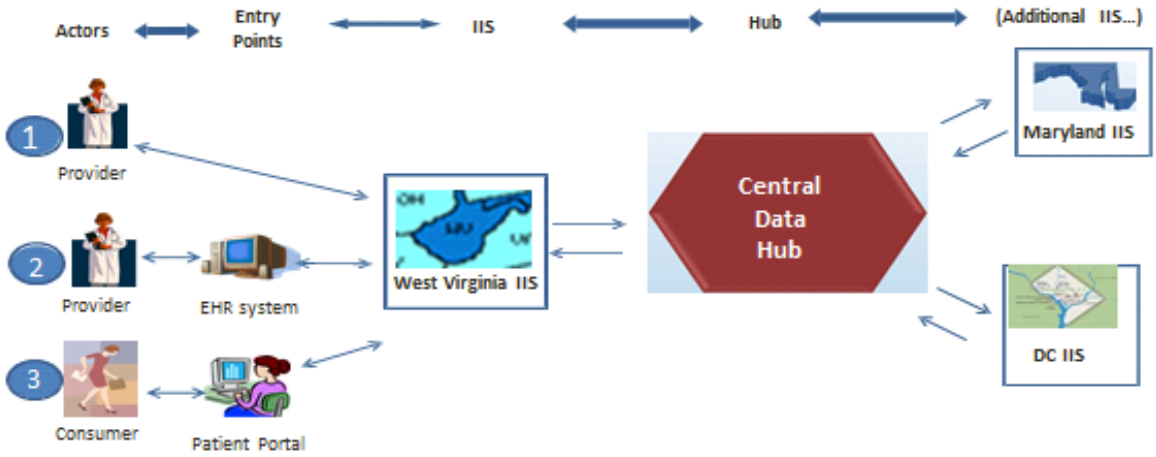
Now in its fourth year, ONC's PHIZ Project has enabled cross-jurisdictional exchange of immunization data for nine jurisdictions spanning the Northwest, Mid-Atlantic, and southern United States.[7] These jurisdictions are in various stages of connecting to or have already connected to a data hub (see Table 1). The data hub enables IIS to send queries and updates to other jurisdictions, and to respond to queries from other jurisdictions through a central infrastructure. Such data exchange enables better capture of immunization events and for immunization data to follow patients as they move across jurisdictional/state boundaries. This allows providers to access the full immunization record of patients across the boundaries of participating jurisdictions, enabling better care and helping to avoid repeat and unneeded immunization services that inconvenience individuals, raise health care costs, and expose people to unnecessary health risks.

POINTS OF ENTRY TO CROSS JURISDICTIONAL EXCHANGE HUB

[6] U.S. Census Bureau. *Calculating Migration Expectancy Using ACS Data*.

[7] Delaware, District of Columbia (D.C.), Maryland, Mississippi, Oregon, Washington, West Virginia, and the City of Philadelphia.

Figure 4: IIS Point of Entry



ONC and the PHIZ support team have worked with multiple entities over the course of the pilot project including technology vendors, government and private sector partners, and IIS stakeholders to advance the PHIZ initiative. The PHIZ pilot project has completed four phases in which: 1) the data hub was built and deployed; 2) public key infrastructure (PKI)-based security was established; 3) systems have been security tested, documentation created, business requirements and rules identified; and 4) nine jurisdictions brought onboard. Table 1 below shows Pilot updates at a glance, as of the end of the 2017 project year.

Table 1: PHIZ Project Pilot Update at a Glance (September 30, 2017)

Pilot Site	Partners	Data Sharing Agreement	Data Use Agreement	Digital Cert. Status	IIS Upgrade Status	User Acceptance Testing (UAT)	Production Readiness
Delaware (DE)	Philly	Signed	Signed	Installed	Complete	In Progress	Not Started
City of Philadelphia (Philly)	DE	Signed	Signed	Installed	Complete	In Progress	Not Started
Maryland (MD)	DC, WV, DE, Philly	In progress	Signed	Installed	Complete	In Progress	Not Started

Pilot Site	Partners	Data Sharing Agreement	Data Use Agreement	Digital Cert. Status	IIS Upgrade Status	User Acceptance Testing (UAT)	Production Readiness
Mississippi (MS)	LA	In Progress	Signed	In Progress	In Progress	Not Started	Not Started
Louisiana (LA)	MS	Signed	Signed	In Progress	In Progress	Not Started	Not Started
District of Columbia (DC)	MD, WV	On Hold	On Hold	On Hold	Complete	Complete	On Hold
West Virginia (WV)	MD, DC	In progress	Signed	Installed	Complete	Not Started	Not Started
Oregon (OR)	WA	Signed	Signed	Installed	Complete	Complete	Not Started
Washington (WA)	OR	Signed	Signed	On Hold	Complete	On Hold	On Hold

In fiscal year 2017, no new pilot jurisdictions joined. The State of Michigan did show a strong interest in participating and attended the onboarding discussion and subsequently decided that the Michigan Health Information Network (MiHIN) will participate in fiscal year 2018 and start working on their IIS upgrade and related activities. The newly added jurisdictions from fiscal year 2016—Delaware, Louisiana, Maryland, Mississippi, and the City of Philadelphia—successfully completed their IIS updates and testing within their testing environments. The IIS vendors—Envision Technology Partners (Envision), Scientific Technologies Corporation (STC) and DXC Technology Corporation (DXC) (formerly Hewlett Packard Enterprise (HPE)) supported the new states.

Due to participants being in various stages of their project lifecycle, it was not always possible for a participating jurisdiction to perform end-to-end testing as they would need to do in a real-world scenario. A separate PHIZ IIS test environment needed to be available for participants to run queries and perform end-to-end system testing using PHIZ hub. JBS worked with STC to build such an environment, and STC successfully built and deployed a PHIZ testing environment for all participating jurisdictions in fiscal year 2017. This enabled states, like Maryland, to be able to perform end-to-end system testing using the PHIZ IIS test environment.

The project team conducted additional outreach with two interested health information exchange organizations[8] and two interested partner states[9] piloting the Association of State and Territorial Health

[8] Michigan Health Information Network (MiHIN) and Delaware Health Information Network (DHIN)

[9] Minnesota and North Dakota

Officials (ASTHO) Memorandum of Understanding (MOU) template developed by The Network for Public Health Law for inter-jurisdictional exchange of immunization data. The MOU provided a model for some states to develop and pilot a formal agreement to share immunization data across jurisdictions which alleviated some burden of designing a new agreement for the purposes of the pilot. Envision, as the states' IIS vendor, also fielded inquiries from Kansas, Missouri, and Oklahoma regarding participation in the project.

Key Findings and Results

Early Identification of the Right Jurisdiction and Vendor Resources to Install Digital Certificates and Implement the Technical Requirements was Crucial to Success: The introduction of public key infrastructure (PKI)-based security required the installation of digital certificates. In addition, due to the distribution of IT responsibilities in large jurisdictions, delays occurred in simple jurisdictional specific technical workflow tasks. Finally, in some instances, the maintenance of the IIS is through a centralized state IT authority, which also makes it difficult to prioritize simple requests and often requires support from the team who overseas their system. Therefore, early identification of the right jurisdiction and vendor resources to install the certificate and implement the technical requirements was crucial to successfully implementing technical requirements.

Privacy and Data sharing are a Challenge when One Jurisdiction Does Not Have an Established Data Sharing Agreement with the Other Jurisdiction: Having data sharing agreements in place became increasingly important as pilots built their systems and prepared to begin data exchange. Without data sharing agreements in place, pilot participants that used personal health information in their test environment experience challenges. The participants could not use this data for integration testing or end-to-end testing with other participants because of the presence of real patient data. Additionally, there were situations where a jurisdiction was unable to establish a testing environment that is free of production data (data with real patient information). Some participants, like Maryland, leveraged the American Immunization Registry Association (AIRA) and ASTHO inter-jurisdictional MOU to establish a multistate data sharing agreement which alleviated some burden of designing a new agreement for the purposes of the pilot.

Engagement from Various Levels of Participant Leadership Enabled the Committed and Successful Exchange Environment Needed to Carry out Legal and Technical Implementation Requirements: The PHIZ project team were most successful when they were able to engage with all the involved pilot resources, as needed, to provide technical assistance throughout implementation. This included working with vendor resources, such as technical or security experts, which proved challenging for engagement as some vendors may have competing priorities and may not be able to support the pilot's need within their timeline. Ensuring the right technical and policy subject matter experts were involved was important for the success of the pilots.

Engagement from various levels of participant leadership enabled the project environment to carry out the legal and technical implementation requirements. This leadership engagement was important for participants, especially for those that did not have an integrated technical and management team.

Next Steps

In 2018, ONC is guiding the implementation of the fifth year of the two immunization pilot projects. The consumer access to IIS pilot will focus on leveraging some of the existing technologies (e.g., personal health records and health information exchange organizations) to continue to increase consumer access to immunization records. The cross jurisdictional IIS pilot will build on lessons learned and expand the number of state pilots participating in the PHIZ data hub to exchange immunization records across jurisdictional boundaries. ONC, in partnership with CDC and NVPO, will continue to document the findings, results, and recommendations of the pilot projects to share with the larger immunization registry and consumer communities.