NVAC Statement of Support Regarding Efforts to Better Implement IIS-to-IIS Data Exchange Across Jurisdictions

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National Vaccine Advisory Committee

In January 2015, a massive measles outbreak occurred after an infected individual visited an amusement park in California, resulting in more than 100 cases in individuals from 14 states and Mexico (as of February 6, 2015).[1] As the number of cases continued to rise and the geography of the outbreak widened, public health departments and health-care providers had to rapidly ascertain the immunization status of all potentially exposed and infected individuals.[2] Challenges may occur during outbreak response efforts if individuals have incomplete or inaccurate immunization records because they received immunizations from a number of different providers, live in border communities, or move often across state lines. To cope with such outbreaks, states need robust immunization information systems (IISs), and these systems should have the capability to exchange data with different jurisdictions to provide accurate immunization histories for individuals. This statement of support and recommendations from the National Vaccine Advisory Committee (NVAC) to the Assistant Secretary for Health highlights current efforts toward greater capabilities for cross-jurisdictional exchange of IIS data.

INFORMATION IMPROVES IMMUNIZATION PROGRAMS

Understanding the benefits and opportunities for cross-jurisdictional IIS data sharing

An IIS (also referred to as an immunization registry) is a confidential, computerized, population-based, public health information system that collects and consolidates vaccination data on individual children or adults served by participating providers within a defined geographic area.[3] An IIS can help consolidate individual patients' vaccination records from multiple providers to prevent over- or under-vaccination of those patients. It is also a vital public health tool for managing immunization programs.[4] Many immunization programs recognize that increased IIS interstate data exchange could potentially improve immunization record accuracy and lead to a reduction in missed opportunities or over-vaccination among those children and adults who move between jurisdictions.[5]

Interoperability between IISs can also lead to cost savings, especially during public health emergencies. For example, in the aftermath of Hurricane Katrina, connecting the Louisiana IIS to the Houston Harris County IIS allowed public health officials to recover more than 18,900 immunization records of individual patients, with an estimated cost savings of more than $3 million from potential vaccine and administration fees that would have been incurred

if these records had not been recovered and vaccines had to be readministered.[6] However, few jurisdictions currently exchange routine immunization information. According to recently published data, 36 IIS programs have the authority to transmit or allow access to immunization data across state borders, but only 11 are currently exchanging information directly with another IIS using batch files or bidirectional real-time exchange.[7]

States, territories, and some local jurisdictions maintain and operate their own IIS. Each jurisdiction has its own level of technical capability and its own legal authorities for sharing IIS data with other jurisdictions. All IISs should strive to meet a key set of necessary functions outlined in the U.S. Centers for Disease Control and Prevention (CDC)'s IIS Functional Standards, 2013–2017.[8] Building on the IIS Minimum Functional Standards adopted by NVAC in 2001,[9] the 2013–2017 Functional Standards include a set of core data elements (e.g., patient name, birth date, and vaccine lot number) that detail the patient and vaccine administration information necessary to accurately identify individuals and ensure immunization records are complete.[10] As NVAC previously noted, establishing core data elements ". . . will empower IIS[s] to capture information more uniformly and exchange it consistently with clinical systems and other IIS[s]."[11] Sharing of this information must comply with federal and state privacy, confidentiality, and consent laws. However, state laws and regulations can create challenges for data exchange.[7]

Many states recognize the value of IIS data exchange and want to engage in real-time bidirectional IIS interstate data exchange; however, many barriers, both technical and legal, need to be resolved. For example, while technical guidance is available to assist states with a standard for information transfer between systems,[12] a number of states must make technological upgrades to their current systems to conform to these requirements, which can take time and resources. In addition, substantial legal barriers exist, such as laws that prohibit IIS data transmission across borders in approximately 15 states. Another 15 states require a data use agreement to share data across jurisdictions,[7] which may necessitate additional resources to draft and implement. Furthermore, achieving full interoperability among each of the 64 CDC awardee immunization programs would result in more than 2,000 individual data use agreements (Personal communication, Rebecca Coyle, American Immunization Registry Association [AIRA], February 2015). This interoperability suggests the need for innovative solutions for shared services and governance, such as the U.S. Department of Health and Human Services (HHS)/Office of the National Coordinator for Health Information Technology (ONC)-sponsored Data Hub pilot project.[13] Finally, other states have additional legal barriers, including substantial restrictions on outbound data, stipulations on specific allowed users or sharing permissions, or special requirements for out-of-state providers.[7]

BREAKING DOWN BARRIERS TO CROSS-JURISDICTIONAL IIS DATA SHARING

Community efforts

To better identify these barriers, the Association of State and Territorial Health Officials (ASTHO) convened a meeting in August 2014 to explore solutions for both technical and legal interstate data exchange barriers. The meeting focused on barriers and potential solutions and included input from key stakeholders in five states. During the meeting, participants suggested developing a model or uniform law for states that lack authority to share data or where authority is too restrictive. Additionally, participants suggested developing a template for IIS interstate data-sharing agreements to establish data-sharing terms, gathering information to demonstrate the critical need for IIS interstate data sharing to help make this initiative a higher priority, and establishing resources to further advance public health in achieving IIS interstate data exchange. Participants also recommended the development of mutually agreed-upon business rules and algorithms to maintain consistency as more states share IIS data with other jurisdictions.[14]

As a result of this meeting, several stakeholders are addressing barriers to sharing. For example, ASTHO is developing a roadmap to help states move toward enhanced interstate data exchange (Personal communication, Kimberly Martin, ASTHO, February 2015), including collaborating with the Network for Public Health Law to develop a template legal agreement that could be used as a master agreement for states to join and/or a model to encourage states to use similar language to govern data exchange. Additional potential solutions include providing assistance to states interested in interstate data sharing and expanding current IIS interstate data-sharing exchange solutions (e.g., the aforementioned HHS/ONC Data Hub pilot project), identifying resources for shared services and governance, and quantifying the need for IIS interstate data exchange.[14]

AIRA is partnering with ASTHO to launch a Community of Practice[15] to address policy and technical strategies in support of interstate data exchange.[14] AIRA is also addressing IIS-to-IIS interfaces to coordinate the governance approach for joint development efforts

across the IIS community. Finally, AIRA and ASTHO are working with the ONC as part of the public health community platform[15] to develop pilot governance for the HHS/ONC Data Hub pilot project.[16] The public health community platform offers a technical solution that can, ideally, be leveraged throughout the IIS enterprise to support IIS-to-IIS data exchange.

Strong federal support has been critically important in providing guidance and resources on the technical, legal, and policy issues surrounding data exchange. In 2013, CDC's National Center for Immunization and Respiratory Diseases released an IIS Strategic Plan that included interoperability and data management as a priority, increased compliance with industry standards, and recommended support for collaborations with ONC and the National Vaccine Program Office on innovative solutions, such as the pilot Data Hub project.[17] ONC also recently released a draft Nationwide Interoperability Roadmap that includes provisions related to IIS data sharing by broadly identifying functional and business requirements for health information interoperability and actions for all stakeholders to work toward during the next 10 years.[18]

The nonfederal and federal efforts described herein are intended to establish and advance technology, legal, and policy solutions that can facilitate data exchange between IIS programs in different states. NVAC supports these efforts as necessary to achieve the ability of immunization providers (public and private) and public health departments across jurisdictions to accurately evaluate and meet the immunization needs of individuals.

PROPOSED NVAC RECOMMENDATIONS

NVAC makes the following recommendations in support of IIS-to-IIS data exchange:

1. NVAC recommends that the Assistant Secretary for Health (ASH) assist in promoting ongoing efforts to develop tools, standards, quality matrices, and common guidance documents (i.e., documents that are commonly used between states) to address the technical and legal barriers to cross-jurisdictional IIS data exchange. Leadership endorsement of these efforts will facilitate the adoption of a common framework for data exchange and will further support progress toward the interoperability and data management goals outlined in CDC's IIS Strategic Plan.

2. NVAC recommends that the ASH work closely with Regional Health Administrators and other federal and nonfederal partners to better quantify the needs for and specific barriers to IIS interstate data exchange at the regional and state levels. Doing so will help states and federal partners to provide the evidence needed to advocate to state and federal leaders and policy makers for political support and the appropriate allocation of resources.

3. NVAC recommends that the ASH actively engage HHS agencies and their partners to ensure that efforts continue to be harmonized across federal, regional, and state levels. Coordination across HHS entities will optimize the development of uniform policies and practices that support cross-jurisdictional IIS data exchange in a reliable and secure way.

4. NVAC requests that the National Vaccine Program Office continue to brief the Committee on the progress of these efforts, and other efforts related to IIS interstate data exchange, to ensure that policy barriers that can be addressed at the federal level are identified and given departmental consideration in a timely manner.

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