AIRA AMERICAN IMMUNIZATION REGISTRY ASSOCIATION
Immunization Information Systems for a New Era

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Testimony of the American Immunization Registry Association National Committee on Vital and Health Statistics (NCVHS) Next Generation Vital Statistics: A hearing on current status, current issues and future possibilities

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The American Immunization Registry Association (AIRA) is a 501(c)(3) nonprofit membership organization that promotes the development and implementation of immunization information systems (IIS) as an important tool in preventing and controlling vaccine preventable diseases. Immunization Information Systems are operational in all 50 states, the District of Columbia, certain large cities and counties, the U.S. Territories and freely associated nations. Immunization information systems are confidential, population-based, computerized databases that record all immunization doses administered by participating providers to persons residing within a given geopolitical 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 provides aggregate data on vaccinations for use in surveillance and program operations, and in guiding public health action with the goals of improving vaccination rates and reducing vaccine-preventable disease.

AIRA is known for its leadership and guidance in using immunization information to address the ever-present challenge of vaccine preventable diseases. AIRA has a strong history of working with IIS and key stakeholders on a variety of technical, operational, and policy related items, including Vital Statistics.

Who are other users of Vital Statistics? What are these data needed for?

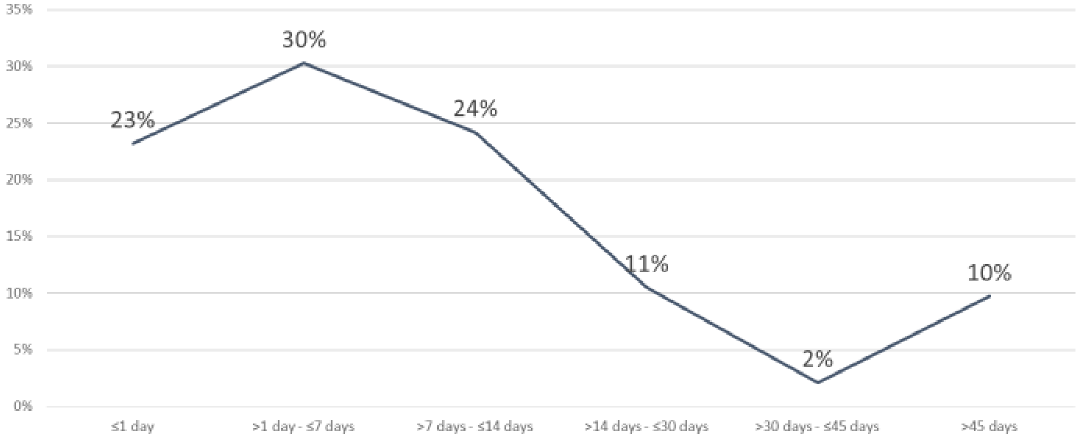
In most jurisdictions, IIS and Vital Records have a long-standing relationship. Vital Records is one of the first data exchange partners with IIS. Jurisdictions have established daily, weekly, or monthly data exchanges that may include birth data, death data, and adoption data.

The Immunization Information Systems Annual Report (IISAR) is an annual assessment conducted by CDC, National Center for Immunization and Respiratory Diseases (NCIRD), Immunization Information Systems (IIS) Support Branch, among the 64 immunization program awardees that receive funding under section 317b of the Public Health Service Act. Awardees include the 50 states, 5 cities, the District of Columbia (D.C.) and 8 Territories. Preliminary data for calendar year 2016, on the question of the number of patient records created in your IIS for children born and residing in your geopolitical area and born from January 1 through December 31, 2016 from Vital Records, out of 64 jurisdictions:

- 49 reported that they DID receive data from Vitals
- 14 reported that they did not receive data from Vital Statistics (Arkansas, Hawaii, Louisiana, Maryland, Mississippi, Nevada, South Carolina, American Samoa, Guam, Marshall Islands, Micronesia, Mariana Islands, Palau, and the Virgin Islands)
- 1 did not respond (New Hampshire – did not have an IIS at the time)

The IISAR captures data on the timeliness of data submission. The following table depicts the frequency of time between the birth of a child and the record being established in an IIS from Vital Statistics.

Chart 1.
Percent of children born in 2016 with a record in an IIS established from vital records and the time since birth and the establishment of a record in an IIS (timeliness)



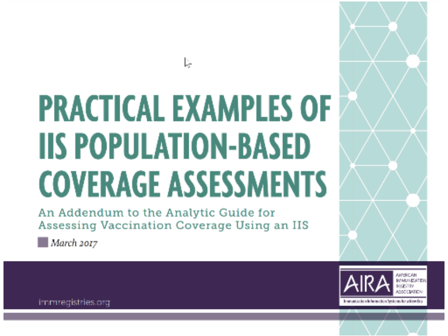
The IIS utilizes data for the following purposes:

- Populating the IIS with demographic birth data
- Managing the denominator by removing deceased individuals
- Managing identity with name changes
- Managing adoptions

Populating the IIS with birth data allows the IIS to be a truly population-based system. Most children born in a hospital receive a birth dose of Hepatitis B vaccine shortly after birth. Ideally, both the birth information and the birth dose of Hepatitis B vaccine are recorded by Vital Records and transmitted to the IIS. Additional information that might be collected on the birth certificate include the Hepatitis B surface antigen status of each mother and whether or not Hepatitis B immune globulin was administered. Both sets of data are very useful to public health, but may not be collected, or if collected, they may not be transmitted to the IIS. Babies born to Hepatitis B surface antigen (HBsAg) positive mothers need both a birth does of Hepatitis B and immune globulin shortly after birth. In addition, they require follow up to ensure completion of the Hepatitis B vaccine series to help prevent chronic Hepatitis B infection. Public Health rely on the IIS to record all doses of vaccines administered, including Hepatitis B vaccine, and often utilize the IIS for case management including patient reminders for vaccines needed.

To ensure the denominator is consistent with the population, death data is needed. However, death data is less likely to be included in original data exchange agreements and often requires years of additional discussion to update the data sharing agreement, memorandum of understanding or other data exchange protocol.

A practical example of a strong relationship between IIS and a Vital Records program is found in Minnesota. Minnesota started hearing anecdotal rumors in 2009 of vaccine hesitancy in the Somali population due to autism concerns. A measles outbreak in 2011 prompted Minnesota to look at the available data to help understand the situation. Minnesota's IIS is populated by vital records data and as a result, can be used to determine population-based coverage. Minnesota used vital statistics data to identify Somali children. Children were identified as Somali if the mother or father's country of birth was Somalia on the birth certificate or if the child's race/ethnicity was indicated as Somali. These birth certificate records were matched to records in the IIS using the birth certificate number. Analysis determined that Somali children had lower rates of MMR and Varicella coverage by 24 months compared to non-Somali children in Minnesota. As a result of this information the immunization program was able to develop outreach materials. Please note that this pocket of need was identified prior to the 2017 measles outbreak in Minnesota. More information about the analysis can be found on the AIRA website in the Practical Examples of IIS Population-Based Coverage Assessments.



PRACTICAL EXAMPLES OF IIS POPULATION-BASED COVERAGE ASSESSMENTS

An Addendum to the Analytic Guide for Assessing Vaccination Coverage Using an IIS

March 2017

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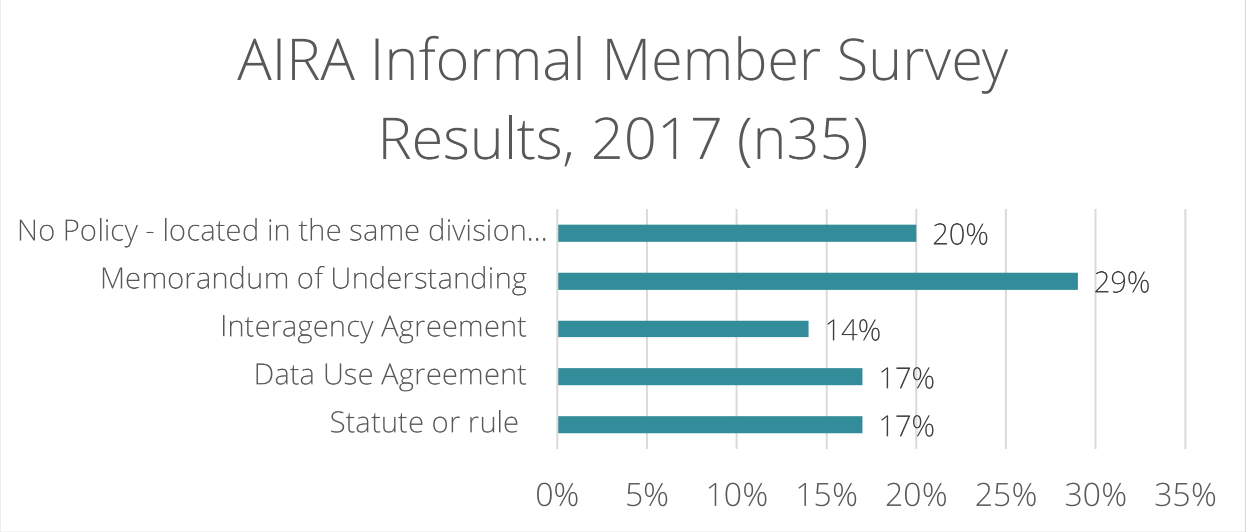
How does data sharing, transmission and protection work?

Data sharing occurs through each jurisdiction negotiating its agreement between the IIS and Vital Records. This is accomplished through a memorandum of understanding, interagency agreements, data use agreements, or through statute or rule. In preparation for this hearing, AIRA conducted an informal survey of IIS jurisdictions and had a total of 35 jurisdictions respond to the survey. The following question was asked; W*hat policy is in place to support data exchange with Vital Records?* The following chart depicts the responses to the survey.



What are the current challenges & barriers regarding the Vital Statistics system?

While IIS values the relationship it has with Vital Records, there are challenges that present opportunities for improved relationships and efficiencies.

The relationship between IIS and Vital Records is long-standing and very solid in the vast majority of jurisdictions. There is, of course, always room for improvement, but it is important to underscore that the foundation between these two essential public health programs is strong.

The majority of information presented below was sourced through the AIRA member survey noted above.

Challenges

Policy

Perhaps the most challenging area for this exchange is in the realm of policy.

Not only do statutes and laws vary across jurisdictions, but the policy tools used to implement the statute or law vary as well. These tools could include data use agreements, memoranda of understanding (MOUs), interagency agreements, or other policy vehicles that define the terms and responsibilities of data exchange.

For example, in some jurisdictions, following an adoption, immunization information may be required to be deleted/removed as a safeguard to privacy. However, this also eliminates the valuable consolidated record that has been built. A uniform policy approach might allow both confidentiality and clinical needs to be met.

Variations in Data Received

An additional challenge is in the variety of specific data received when comparing jurisdictions. Most IIS receive birth demographic data, while only 50% receive birth dose and/or adoption data, and only two-thirds receive death data, so completeness across the IIS network of systems varies substantially. Similarly, completeness within a jurisdiction can vary if jurisdictions are relying on individuals to “opt in” to data sharing. It is also important to recognize that some IIS (14 IIS in 2016) don’t currently receive any Vital Statistics data.

Timeliness

The timing of data submission varies broadly as noted above in chart 1. Increasingly, hospitals and health systems are set up for real-time or near-real-time data exchange with IIS, which means that an Electronic Health Record (or EHR) report of a newborn or of that newborn’s shots may make it to the IIS before the Vital records report. This isn't necessarily problematic, but to the extent that we consider the Vital Statistics data to be the "gold standard" report, we would want these data to reach the IIS first to populate that demographic record with the most accurate data. When consolidating data, the merging and deduplication algorithms function at their strongest when populated with complete, accurate data at the point the record is established.

Data received monthly or quarterly does not meet the IIS community's measure of 90% of data being received within 14 days of administration.

Funding

Funding is a significant challenge across Public Health, and there are a few areas where it directly impacts the Vital records/IIS interfaces:

1) There is no dedicated funding source that funds the exchange of data between these two public health programs. It is prioritized across systems, but a direct funding stream that supports a base level of exchange does not exist.
2) Vendors for Vital Statistics systems and IIS may be operating with limited visibility to the others exchange needs. As a result, requirements may not be articulated or documented clearly.
3) Finally, routine development work in either system may delay or break working interfaces, and resources may be needed to research the problem and reinstate the interface.

It is interesting to note that in the member survey several IIS program staff called out the need for funding not for their own programs, but for Vital Record programs.

Data Quality

Currently, there is a lack of uniform standards for the capture and submission of vital records data for IIS. This affects the quality of data coming in to the IIS. Some examples of where this can negatively impact data quality include:

- Inability to track the necessary data elements for Hepatitis B and HBIG or failing to capture these data.
- In some jurisdictions, the Hepatitis B dose is reported as a yes/no, and lacks any of the information needed (date of administration, manufacturer, lot number, etc.) to record an administered dose in the IIS.
- Placeholder information like “Baby Smith” or “Twin A” can create false merges.

Finally, many data exchange processes themselves are heavily manual or outdated, using flat file or SFTP exchanges when more current data exchange message content and format standards could be leveraged that support data quality more fully.

Data Sensitivity

And a final challenge, before solutions are presented, is in regard to the sensitivity of vital records data, and the need to be thoughtful and careful in our approaches to data exchange and data use. In the IIS world, we recognize the need for rigorous confidentiality and privacy. It is critical we protect the sensitivity of adoption records, and that we track the records of deceased clients to avoid any inappropriate outreach following a death. Close collaboration between IIS and Vital Records is key to ensuring the sensitivity of data is never overlooked.

What are potential solutions to these challenges?

Development of Standards

In terms of proposed solutions, the single solution that would move both IIS and Vital Records forward the most swiftly involves the development of standards, particularly regarding the message format and transport of Vital Records data to an IIS. Ideally, a common transport method could help with prompt reporting and data exchange. Likewise, a common messaging format, such as HL7, could improve quality and consistency.

Additionally, the capture of common data elements across all jurisdictions, including birth dose Hepatitis B and HBIG would prove valuable for public health.

And finally, the suggestion has been made to consider drawing data from electronic health records to feed into both the IIS and the Vital Records birth data. We recognize that this would take substantial exploration and potentially development time, but it may be worth considering to improve the quality and reduce the burden of reporting.

Automation and Uniform Exchange

A second potential solution involves the automation of data exchange between Vital Statistics and IIS. An investment in automated interfaces for all IIS and Vital Record programs would:

- Limit human error
- Decrease resources needed to sustain interactions
- Increase quality
- Increase timeliness of exchange

There are also opportunities to explore synergy in the exchange of data across jurisdictional lines. Both Vital Records and IIS have demonstrated needs for interjurisdictional exchange, and there may be opportunities to leverage the same pathways and policy approaches.

Cross Training

Opportunities exist to improve accurate data capture, transfer, import, and use through training and knowledge transfer across Vital Record and IIS programs. This should extend to birth centers and hospitals where the data are being collected, since this is the origination of the data and where good data quality begins. For cross training and knowledge transfer to be sustained, it is essential for the leadership at the jurisdictional and national level to be engaged in order to prioritize these efforts.

Increase Dedicated Funding

Finally, increases in dedicated funds for Vital Record systems could potentially support the work outlined above around data quality, automation, standardization, and cross training. In addition, it could be used to modernize and enhance some of the aging systems that are in use across the country. It is also recognized that identifying new sources of funds is not without significant challenges.

Possible Consequences of Remaining with the Status Quo

What happens if we do nothing, and continue with the status quo? Most jurisdictions have a good working relationship with their Vital Record partners, and those agreements that are being individually negotiated and operationalized would likely continue. The relationships themselves will remain strong. However, the current state of jurisdictional variation and ad hoc processes will continue. These manual processes will consume more resources than necessary, and will adversely affect data quality timeliness, completeness and accuracy. Ultimately, we will fall short of our full potential for leveraging Vital Statistics data within the IIS.

In closing, to reinforce three key themes heard repeatedly from our community:

1) The relationship between the Immunization/IIS Community and Vital Records is strong and foundational across Public Health Programs.
2) However, opportunities exist for standardization, automation and modernization.
3) Lastly, working together to leverage investment across our nation-wide networks would save resources, improve data quality, and bring benefits to the populations we serve.

Thank you, for the opportunity to share our experiences with Vital Statistics and outline potential solutions. For additional questions or information related to IIS that arise from this testimony, please contact Rebecca Coyle, Executive Director at CoyleR@immregistries.org or Mary Beth Kurilo at MBKurilo@immregistries.org.