Immunization Information System (IIS) Interjurisdictional Data Sharing: Addressing Technical and Legal Barriers

December 9, 2015
How to Use Webex

- **Audio**: If you can hear us through your computer, you do not need to use your phone. Just adjust your computer speakers as needed.

- **Support**: If you need technical assistance, call Webex Technical Support at 1-866-863-3904.

- **Submitting Questions**: All participants are muted. Type a question into the Q & A panel for our panelists to answer. Submit your questions at any time during webinar.

- **Recording**: This webinar is being recorded. If you arrive late, miss details or would like to share it, we will send you a link to this recording after the session has ended.
Moderator

Terry Dwelle, State Health Officer, North Dakota Department of Health

- M.D., St. Louis University School of Medicine
- M.P.H.T.M., Tulane University
- CPH

- Research interests/areas of expertise:
  - Pediatrics
  - Development of community-based health care program in East Africa
  - Community-based health care disease management
Presenter

**Molly Howell**, Immunization Program Manager and Assistant Director Division of Disease Control, North Dakota Department of Health

- M.P.H., University of Massachusetts
- Certificate in Public Health Core Concepts, University of Minnesota

Research interests/areas of expertise:
- Immunization
- Infectious Disease Surveillance
- Association of Immunization Managers Member

IIS Interjurisdictional Data Sharing
Presenter

**Denise Chrysler**, Director, Network for Public Health Law’s Mid-States Region

- Member, Ingham County (Michigan) Board of Health
- Previously, Public Health Legal Director and Privacy Officer, Michigan Department of Community Health
- J.D., University of Michigan Law School

- Research interests/areas of expertise:
  - Legal issues related to data collection, use, sharing and protection
  - Public health statutory and regulatory authority
  - Bed bugs
  - Newborn screening samples and research
Presenter

Robert Swanson, Director, Division of Immunization, Michigan Department of Community Health

- M.P.H., University of Michigan
- Research interests/areas of expertise:
  - Immunization Registry
  - VFC Program
  - School and child care reporting
Presenter

**Mary Beth Kurilo,** Policy and Planning Director, American Immunization Registry Association (AIRA)

- M.P.H., M.S.W., University of Washington

- Research interests/areas of expertise:
  - Immunization Programs, Immunization Information Systems
  - Prevention Work and Health Information Systems on impacting health care delivery and outcomes
NEED FOR INTERSTATE DATA EXCHANGE

MOLLY HOWELL, MPH
IMMUNIZATION PROGRAM MANAGER
ASSISTANT DIRECTOR, DISEASE CONTROL
WHAT IS AN IIS?

- 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 geopolitical area. (CDC)
  - 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.
IIS INTERSTATE DATA EXCHANGE

- States, territories, and some local jurisdictions maintain their own IIS.
  - There is not a national IIS in the United States.
  - IIS contain different fields and have different functionality.
- Many states recognize the need for IIS data to be shared between states, as people often move.
- Additionally, people often receive healthcare, including immunizations, across borders.
  - For example, many western Minnesota residents receive health care in North Dakota.
- A relatively few number of states currently exchange data between IIS.
NORTH DAKOTA POPULATION CHANGES

- North Dakota’s 2014 census estimate showed a 9.9% change in population from the 2010 census (U.S. average change was 3.3%)
  - Since the 2010 census count, North Dakota has seen a large influx of people in the western area of the state due to the oil boom in that area.
- According to the April 2012 US Census news release, North Dakota had:
  - One of the top 50 fastest growing metro areas from 2010 – 2011
    - Bismarck, ND which is the state’s capitol and 2nd largest city
  - Three of the nation’s fastest growing micro areas between April 1, 2010 – July 1, 2011
  - One of the 10 fastest growing counties between 2000 – 2010
    - Williams County (where Williston is located) was ranked # 3
North Dakota health care providers and local public health units reported spending countless hours trying to obtain out-of-state immunization records for children.

- Schools reported similar issues.

Providers and the Department of Health had varying degrees of success gaining access to out-of-state immunization information systems (IIS) or records.

- Every state had a different immunization data sharing policy/procedure.
- One state could not share anything.

North Dakota Department of Health unable to assess immunization coverage rates due to lack of historical immunizations for new North Dakotans being in the NDIIS.
The Infectious Disease Policy Committee (IDPC) identified IIS interstate data sharing as a top priority for 2013/2014 and again in 2014/2015.

Recognized there was a special need to develop solutions to address the temporary workforce issue in North Dakota.

Determined that a meeting among state stakeholders may spark new ideas for how to achieve IIS interstate data sharing and overcome barriers.
ASTHO-IIS INTERSTATE DATA EXCHANGE MEETING

Key State Stakeholder Participants:
- State health official/senior deputy
- Immunization program manager
- IIS manager
- Health IT coordinator
- Legal counsel

Other Stakeholder Participants:
- HHS/ONC
- HHS/NVPO
- CDC
- AIRA

August 26 and 27 in Minneapolis, MN
MEETING OBJECTIVES

- Engage key stakeholders from five states in a discussion about barriers and potential solutions regarding IIS data sharing.
- Identify and develop resources to be used by states and other stakeholders seeking to have IIS interstate data sharing.
- Propose next steps to further enhance IIS interstate data sharing efforts.
LEGAL

Barriers

- Laws may strictly prohibit data sharing
- Laws may require a data sharing agreement
- If out-of-state providers want to directly query the IIS, they may be required to establish a user agreement with each provider/clinic

Solutions

- Change the law to include providers from other states, not just those licensed in the state
- Draft a template interstate data sharing agreement or memorandum of understanding
- Develop standard statute language, uniform law, or another integrated approach
**TECHNICAL**

**Barriers**

- States must make technological upgrades to their current system, which can take time and resources
- Lack of consistent business processes for an entire network of interstate data exchange
- State-to-state differences in IIS

**Solutions**

- Create mutually agreed upon standards and core measures, as well as, uniform business requirements and architecture
- Resources are needed for:
  - Additional staff at health departments on both the programmatic and technical side
  - Vendors to move interoperability forward
  - Health information exchanges (HIEs)
Barriers

- Devoting time, money, and resources to establishing the connection and agreeing to procedures
- Ability to prioritize this initiative

Solutions

- Gathering more information to determine how often people move between jurisdictions may help to elevate this initiative to a higher priority
POTENTIAL NEXT STEPS

- Develop a template memorandum of understanding
- Provide technical assistance to states interested in interstate data sharing and expand current IIS interstate data exchange solutions (e.g., the HHS/ONC pilot)
- Identify resources for shared services and governance
- Quantify the need for IIS interstate data exchange and produce information for state health officials
Addressing Legal Barriers to IIS Data Sharing

Denise Chrysler, JD
Director, Mid-States Region
Network for Public Health Law
University of Michigan School of Public Health

Webinar, December 9, 2015
Law governs every aspect of data

Collection   Use
Sharing      Protection

Law friend or foe?
- How does law help us to do our job?
- How is law a barrier?
Resources: Interjurisdictional exchange IIS data

» Memorandum: Legal Issues Related to Cross-jurisdictional Sharing of State Immunization Information System Data

» Public Health Interjurisdictional Immunization Information System Memorandum of Understanding Template

» URL: http://www.astho.org/Public-Policy/Public-Health-Law/Resources/Partnership-for-Public-Health-Law/
Legal memorandum cross-jurisdictional exchange IIS data

» Assists public health to determine its legal authority to exchange IIS information with other jurisdictions

» Provides practical guidance to resolve legal issues and create data sharing agreements

» Identifies approaches to facilitate nationwide exchange
Determining exchange authority

1. **Establish facts**
   -- Data
   -- Participants
   -- Flow

2. **Identify law**

3. **Apply law**

4. **Establish & document terms for sharing**
General barriers to exchange

» State law applies – variation among states
» General vs. specific authority to exchange data
» Scope of sharing: prerequisites, conditions & limits
» Within a state – applicability of multiple laws, need to harmonize

» Variety and changing systems, manner of exchange, technological capability

-- Growing complexity, multiple points of data transfer, HIE laws
Facilitating exchange among IIS

“[T]he task to achieve full interoperability between each of the 64 CDC awardee immunization programs would require more than 2,000 individual data use agreements, requiring innovative solutions for shared services and governance, such as the HHS-sponsored federal Data Hub pilot project.”

-- NVAC Statement of Support Regarding Efforts to Better Implement IIS to IIS Data Exchange Across Jurisdictions, adopted 10 February 2015, quoting Jim Daniel, ONC
National solutions to facilitate exchange?

» National IIS
- 1993: Congress rejected national IIS provisions in Child Immunization Act
- 1999: NVAC report outlines policy directions and major steps needed to establish nationwide network of community/state population-based registries

» Model or uniform state law
- 2005: Model Interstate Immunization Information Sharing Statute

» Master data sharing agreement (e.g. vital records; cancer registries)

» Piecemeal exchange among groups of states
Specific barriers to exchange among five states convened by ASTHO

- One state: no authority to disclose information to other jurisdictions
- Limits on scope of authority to disclose information to other IIS
- Restrictions on data elements that can be shared
- Limits on use and disclosure of information by receiving state
- Sending IIS’ responsibility for information once sent
- Deleting data when right to opt-out exercised in sending state (applicability to information previously sent)
Data sharing agreement or memorandum of understanding to exchange IIS information

- Some laws require agreement
- Necessary, even if not explicitly required
- Sets out legal authority, terms for sharing, provides for monitoring and accountability for compliance with terms
- IIS memorandum provides components to consider for DSA (Appendix C)
MOU template provisions

» Parties – original and additional
» Purpose
» Communications outside MOU; emergency powers
» Definitions
» Data to be provided (elements, frequency, method of exchange)
» Incorporation, use and disclosure of data
» Privacy and security safeguards
» HIPAA – exchange among “public health authorities”
» Period of MOU
» Termination
» Warranties – best efforts, no guarantees
» Contract boilerplate (e.g. authority, entire agreement, severability, limitation on liability, no third party beneficiaries, governing law, etc.)
Appendix A: Identifies IIS core data elements and any additional data elements that each party is able to provide and receive from other parties

Appendix B: Each party identifies frequency and methods of exchange and transport

Appendix C: Each sending party identifies any limitations on maintenance, use or disclosure of data based on the sending party’s law or policies
And now for execution and implementation!

...stay tuned

Denise Chrysler
dchrysler@networkforphl.org
Practical Implementation of the MOU

Bob Swanson, MPH

Director, Division of Immunization
# What Michigan Looks Like

<table>
<thead>
<tr>
<th>Number of People</th>
<th>STATE</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>8,726,106</td>
<td>Michigan</td>
<td>US</td>
</tr>
<tr>
<td>30,893</td>
<td>Ohio</td>
<td>US</td>
</tr>
<tr>
<td>26,194</td>
<td>Florida</td>
<td>US</td>
</tr>
<tr>
<td>19,794</td>
<td>Wisconsin</td>
<td>US</td>
</tr>
<tr>
<td>19,697</td>
<td>Indiana</td>
<td>US</td>
</tr>
<tr>
<td>19,361</td>
<td>Texas</td>
<td>US</td>
</tr>
<tr>
<td>17,417</td>
<td>Illinois</td>
<td>US</td>
</tr>
<tr>
<td>12,218</td>
<td>California</td>
<td>US</td>
</tr>
<tr>
<td>10,144</td>
<td>Georgia</td>
<td>US</td>
</tr>
<tr>
<td>8,775</td>
<td>North Carolina</td>
<td>US</td>
</tr>
<tr>
<td>8,589</td>
<td>Tennessee</td>
<td>US</td>
</tr>
<tr>
<td>7,980</td>
<td>Arizona</td>
<td>US</td>
</tr>
<tr>
<td>6,968</td>
<td>New York</td>
<td>US</td>
</tr>
<tr>
<td>6,005</td>
<td>Virginia</td>
<td>US</td>
</tr>
<tr>
<td>5,331</td>
<td>Pennsylvania</td>
<td>US</td>
</tr>
<tr>
<td>4,700</td>
<td>Kentucky</td>
<td>US</td>
</tr>
<tr>
<td>4,637</td>
<td>Colorado</td>
<td>US</td>
</tr>
<tr>
<td>4,429</td>
<td>Minnesota</td>
<td>US</td>
</tr>
<tr>
<td>4,237</td>
<td>Missouri</td>
<td>US</td>
</tr>
<tr>
<td>4,044</td>
<td>South Carolina</td>
<td>US</td>
</tr>
<tr>
<td>3,699</td>
<td>Washington</td>
<td>US</td>
</tr>
<tr>
<td>3,668</td>
<td>Alabama</td>
<td>US</td>
</tr>
<tr>
<td>3,130</td>
<td>New Jersey</td>
<td>US</td>
</tr>
<tr>
<td>3,058</td>
<td>Maryland</td>
<td>US</td>
</tr>
<tr>
<td>2,421</td>
<td>Ontario</td>
<td>notUS</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of People</th>
<th>STATE</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>2,409</td>
<td>Iowa</td>
<td>US</td>
</tr>
<tr>
<td>2,384</td>
<td>Massachusetts</td>
<td>US</td>
</tr>
<tr>
<td>2,339</td>
<td>Nevada</td>
<td>US</td>
</tr>
<tr>
<td>1,986</td>
<td>Arkansas</td>
<td>US</td>
</tr>
<tr>
<td>1,837</td>
<td>Connecticut</td>
<td>US</td>
</tr>
<tr>
<td>1,836</td>
<td>Louisiana</td>
<td>US</td>
</tr>
<tr>
<td>1,810</td>
<td>Oklahoma</td>
<td>US</td>
</tr>
<tr>
<td>1,801</td>
<td>Kansas</td>
<td>US</td>
</tr>
<tr>
<td>1,745</td>
<td>Mississippi</td>
<td>US</td>
</tr>
<tr>
<td>1,671</td>
<td>Utah</td>
<td>US</td>
</tr>
<tr>
<td>1,543</td>
<td>Oregon</td>
<td>US</td>
</tr>
<tr>
<td>1,058</td>
<td>Nebraska</td>
<td>US</td>
</tr>
<tr>
<td>1,015</td>
<td>New Mexico</td>
<td>US</td>
</tr>
<tr>
<td>934</td>
<td>West Virginia</td>
<td>US</td>
</tr>
<tr>
<td>916</td>
<td>Idaho</td>
<td>US</td>
</tr>
<tr>
<td>874</td>
<td>Alaska</td>
<td>US</td>
</tr>
<tr>
<td>802</td>
<td>Montana</td>
<td>US</td>
</tr>
<tr>
<td>773</td>
<td>Wyoming</td>
<td>US</td>
</tr>
<tr>
<td>717</td>
<td>South Dakota</td>
<td>US</td>
</tr>
<tr>
<td>631</td>
<td>North Dakota</td>
<td>US</td>
</tr>
<tr>
<td>592</td>
<td>New Hampshire</td>
<td>US</td>
</tr>
<tr>
<td>590</td>
<td>Maine</td>
<td>US</td>
</tr>
<tr>
<td>503</td>
<td>Hawaii</td>
<td>US</td>
</tr>
<tr>
<td>365</td>
<td>District of Columbia</td>
<td>US</td>
</tr>
<tr>
<td>358</td>
<td>Delaware</td>
<td>US</td>
</tr>
<tr>
<td>294</td>
<td>Vermont</td>
<td>US</td>
</tr>
<tr>
<td>253</td>
<td>Rhode Island</td>
<td>US</td>
</tr>
<tr>
<td>172</td>
<td>Puerto Rico</td>
<td>US</td>
</tr>
<tr>
<td>52</td>
<td>Virgin Isl</td>
<td>US</td>
</tr>
<tr>
<td>35</td>
<td>Guam</td>
<td>notUS</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of People</th>
<th>STATE</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>British Columbia</td>
<td>notUS</td>
</tr>
<tr>
<td>17</td>
<td>Quebec</td>
<td>notUS</td>
</tr>
<tr>
<td>15</td>
<td>Alberta</td>
<td>notUS</td>
</tr>
<tr>
<td>6</td>
<td>Manitoba</td>
<td>notUS</td>
</tr>
<tr>
<td>4</td>
<td>Nunavut</td>
<td>notUS</td>
</tr>
<tr>
<td>3</td>
<td>Northwest Territories</td>
<td>notUS</td>
</tr>
<tr>
<td>3</td>
<td>Saskatchewan</td>
<td>notUS</td>
</tr>
<tr>
<td>2</td>
<td>New Brunswick</td>
<td>notUS</td>
</tr>
<tr>
<td>1</td>
<td>Newfoundland</td>
<td>notUS</td>
</tr>
<tr>
<td></td>
<td>Nova Scotia</td>
<td>notUS</td>
</tr>
</tbody>
</table>
Challenges of MOU

- Getting the right people to sign the MOU
- Standardizing the data to be shared
- Working with the right people
  - Business
  - Technical
- Routinizing the sharing of data
  - Daily, weekly, monthly
Phases to implementation of IIS 
Interstate Data Sharing

- Phase 1: Sharing data using a flat file upload.
  - Standardize the flat file format
  - Upload data to the other state for all addresses in the system that belong to the other state
    - Requires a separate upload to each state participating
    - Manual work, not fully automated
    - Requires work to retrieve the data and upload the data on the receiving side
  - Standardize the frequency of this upload
Phases to implementation of IIS Interstate Data Sharing

- **Phase 2:** Requesting data from another state when the person presents
  - Request the individual record electronically using a standard HL7 message
  - Need to know what state to request the data from
  - IIS’s are not set up to query at this point
  - How to direct the message to the appropriate IIS
    - ONC data hub being developed
Phase 3: Pushing Immunization data to another state

- If an address is updated in the IIS with an address from another state, data should be pushed to the new state.
- This would be an unsolicited push of data to another IIS
- Again use of the data hub to facilitate the data transfer to the other state
IIS Interjurisdictional Data Sharing: Addressing Technical and Legal Barriers

MARY BETH KURILO, MPH, MSW
PLANNING AND POLICY DIRECTOR, AMERICAN IMMUNIZATION REGISTRY ASSOCIATION
DECEMBER 9TH, 2015, 1PM ET
AIYA’s Interest in IIS Interjurisdictional Exchange

Our members continue to advocate for increased cross-border data sharing, in recognition of our mobile population.

Stronger standards adoption is facilitating both EHR-IIS and IIS-IIS data exchange.

The IIS community is increasingly being asked to function as a nationwide network, rather than a collection of independent jurisdictions.

It’s a complicated process...
Intersecting Components

- Laws and Regulations
- Data Use Agreements
- Memoranda of Understanding

- Message Transport
- Message Content
- Testing
- Implementation

- Priority Trading Partners
- Impact on Imm. Program Goals (more complete data, etc.)

- Use Cases for Manual vs. Automated Query/Exchange
- Access for IIS Staff, End Users, etc.
Policy

AIRA is continuing to partner with ASTHO to support the current multi-state effort regarding a uniform Memorandum of Understanding (MOU)

- Major barriers cited: Competing priorities, delays with legal approval and signature, evaluating potential exceptions
- Growing recognition of need for formal IIS Interjurisdictional Administration:
  - Early thinking pointed to the Public Health Community Platform as an entity to serve as administrator and technical vehicle, however, this is not a current or immediate option

Goal: Have original five states (Colorado, Michigan, Minnesota, North Dakota and Idaho) + sixth early adopter state (Wisconsin) complete signing on to a common MOU
Policy

Interest is growing among additional states who want to explore signing on to the multi-state MOU as well

- These states are encouraged to develop exchanges using the same MOU Template/Model

Other point-to-point efforts continue to progress, most with separate and/or pre-existing policy agreements – Examples include:

- Minnesota – Wisconsin
- Minnesota – North Dakota
- Oregon – Washington
- New York State – New York City
Technical: Standards Support

INTEROPERABILITY TESTING
PROJECT UNDER THE
ASSESSMENT INITIATIVE

Supporting alignment with HL7 2.5.1, release 1.5 guide, including consistent ACK messaging, VXU and VXQ formatting

Supporting alignment with IIS Transport Standard for SOAP/Web Services and CDC WSDL

JOINT DEVELOPMENT AND IMPLEMENTATION INITIATIVE, PROJECT FOCUS

Continuing monthly user groups for WIR and Awardee-Developed systems (and available for support to STC and Envision users)

Exploring centralized address cleansing and geocoding service that will support cleaner EHR-IIS and IIS-IIS exchanges
Technical: ONC Hub Pilot Project

AIRA is supportive of ONC’s work to use a centralized hub for transporting interjurisdictional messages:

- Early partners: Oregon and Washington
- Recent partners: Maryland, West Virginia, DC

The project uses a combination of triggers to exchange data through a central router hosted by the Association of Public Health Labs (APHL):

- 1) New record directly entered by provider into current IIS; update sent to partner jurisdiction’s IIS (Automated Trigger)
- 2) Current IIS queries partner jurisdiction’s IIS triggered by the patient’s address (Automated Trigger)
- 3) Provider queries patient’s former IIS (partner jurisdiction) and then enters a new patient record directly into the IIS (Manual Trigger)
Policy/Technical: ONC Hub Project

Participation in the project typically requires two policy documents:
- Signed Data Use Agreement (DUA) between the IIS/Jurisdiction and APHL
- Signed MOU/DUA between participating IIS/Jurisdiction
  - Note: Even if these aren’t believed to be needed at the outset of the project, they are often required by legal representatives before the data feed can go live

Current and potential states are encouraged to use the MOU template and method between IIS when moving forward with their exchanges
AIRA and ASTHO are invested in supporting these initial six states as they move forward with operationalizing the exchanges to the full extent possible.
Programmatic/Operational

AIRA will continue to support our members with technical assistance and guidance toward implementation through the Community of Practice and through direct requests for assistance. However, AIRA needs input on its potential role as “Administrator”

Models exist - National Association for Public Health Statistics and Information Systems (NAPHSIS) and North American Association of Central Cancer Registries (NAACCR) - but questions remain:

◦ What can we learn from the current pilots (Multi-state MOU, Hub and point-to-point exchanges) to help us understand the best approach?
◦ How much of a priority is interjurisdictional exchange, in light of current competing priorities?
◦ How can AIRA best provide visibility to the status of exchanges and their exceptions?
AIRA will host a session to gather input and information on IIS prioritization and focus on interjurisdictional exchange.
Summary Next Steps

Expand the ASTHO/AIRA Community of Practice on Interjurisdictional Exchange
  ◦ Continue to support the multi-state MOU pilot through to signatures and to implementation where possible
  ◦ Provide a venue for troubleshooting policy, technical, operational and programmatic issues as they arise for any interested states

Partner with ONC to gather lessons learned through the Hub pilot projects

Explore AIRA’s increasing role as an Administrator
  ◦ Host an event at the AIRA IIS National Meeting in Seattle in April, 2016 to gather input
  ◦ Leverage NAPHSIS and NAACCR lessons as Administrators in their communities
Questions? Discussion?

For More Information:
Mary Beth Kurilo, MPH, MSW
AIRA Policy and Planning Director
mbkurilo@immregistries.org
202-552-0197

www.immregistries.org

THANK YOU!
Q&A

Please type your questions in the Q&A panel.
Thank you for attending

Please join us for this upcoming webinar:

**Practical Realities of Managed Care**
Thursday, January 21 — 1pm (ET)

More information: networkforphl.org/webinars