

# Crafting Inter- Jurisdictional Data Exchange Agreements



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*on behalf of the*  
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# Topics for Discussion

- Why create data exchange agreements?
- What should you be aware of when crafting an agreement?
- What are typical provisions of an agreement?
- Where to go for additional information?

# Why data exchange agreements?

- Health information is increasingly digitized, and increasingly flowing across jurisdictional boundaries.
- Laws governing data uses/disclosure vary by jurisdiction.
- Privacy and security practices are under increased scrutiny.
- Your interests are served by having clear, shared understandings between parties

# Purpose of the document

- To provide practical guidance to health departments entering into inter-jurisdictional information exchange.
- To help prepare staff for conversation with their attorneys and privacy officers.
- Created by the Joint Public Health Informatics Taskforce  
([www.jphit.org](http://www.jphit.org))

*JPHIT is ten public health membership associations committed to improving public health practice and population health through informatics.*

# General Considerations

- Begin by clearly articulating what information you need to exchange and for what public health purpose(s).
- Ask around for other examples (see also [www.jphit.org](http://www.jphit.org)).
- Plan ahead—these agreements can take time!
- Write in clear, concrete, unambiguous terms

# General Considerations

- Write as if none of the current individuals will be involved in implementation.
  - Don't make any assumptions or leave anything out because "it's understood."
- Focus on building trust.
  - Remember: information exchange proceeds at the speed of trust.
- The agreement will need to reflect any differences in the laws of each jurisdiction.
  - Any major differences will have to be negotiated by the attorneys.

# General Considerations

- *Work with your attorney early and often!*
- It takes time, and can be frustrating, *but it's the smart and right thing to do.*

# Privacy, Confidentiality, Security

- ▶ *Privacy* refers to rights of an individual to control how information about them is collected, used, and disclosed.
- ▶ *Confidentiality* refers to the obligations of individuals or groups who receive or use information to respect the privacy interests of individuals.
- ▶ *Security* refers to technologic, physical, or administrative safeguards or tools designed to protect data from unwarranted access or disclosure



# Typical Provisions

- Parties to the Agreement
  - Legal names of the entities that will sign the agreement.
- Definitions
  - Reduces ambiguity; helps ensure parties have same understandings
- Purpose of the Agreement
  - What public health goal, and how data exchange helps achieve that goal.

# Typical Provisions

- Responsibilities of the Parties
  - Ensure everyone knows what they are getting into!
- Authority to Exchange
  - Make sure you can disclose (and receive) the data
  - Cite the statute

# Typical Provisions

- Data to be Exchanged
  - Be specific about the data elements
  - Include any vocabulary or format (and even transport) standards
  - Be clear whether protected health information under HIPAA

# Typical Provisions

- Allowable Uses
  - Based on the laws of all involved jurisdictions
  - Be especially clear in this provision
  - Any use not specified would generally be a violation of the agreement
- Privacy Protections
  - Works hand-in-glove with Allowable Uses provision
  - Cite relevant statutes
  - Protections persists after agreement terminates

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# Typical Provisions

- Data ownership
  - Who “owns” the data when it’s being exchanged?  
Does it matter?
- Timing of Exchange
  - Set the schedule
  - Will ad hoc queries be acceptable?

# Typical Provisions

- Amendments / Addendums
  - What is the formal process? How to be flexible without being *too* flexible?
- Rescinding / Termination
  - What happens to the data?

# Reflection questions

- ▶ Have I clearly and concretely defined why the data needs to be exchanged, what public health goal is being supported?
- ▶ Have I identified the relevant laws, policies and rules for my jurisdiction?
- ▶ Do I know how the laws and policies of my trading partners differ from my jurisdiction's?
- ▶ Have I had at least an initial conversation with counsel?



# Sample agreements

- ▶ Inter–Jurisdictional Exchange Agreement for Vital Events, 2014–2018
- ▶ NAACCR Inter–Registry Resident Data Exchange Agreement
- ▶ New York State IIS Data Sharing Agreement
- ▶ Inter–State Data Sharing Agreement between the State of Oregon and the State of Washington
- ▶ [www.jphit.org/resources](http://www.jphit.org/resources)

# Where else to go to for help

- ▶ Your agency's legal counsel, first and last
- ▶ Your professional association (ISDS, ASTHO, NACCHO, CSTE, etc.)
- ▶ Neighboring jurisdictions
- ▶ National Birth Defects Prevention Network  
(  
[http://www.nbdpn.org/  
interstate\\_data\\_exchange\\_and\\_h.php](http://www.nbdpn.org/interstate_data_exchange_and_h.php))

# Other resources from JPHIT

## ▶ *Future Information Capabilities for Public Health Agencies*

- Primers on seven topics of interest:
  - Consumer engagement
  - Big data
  - Information Architecture
  - Interoperability: Transport
  - Interoperability: Semantics
  - Clinical Decision Support
  - Re-Visiting Public Health Registries
- Available for download from [www.jphit.org/resources](http://www.jphit.org/resources)

# Q & A



The logo for the International Society for Disease Surveillance (ISDS). It features the letters 'iSDS' in a bold, dark blue, sans-serif font. A small green square is positioned above the 'i'.

INTERNATIONAL SOCIETY  
FOR DISEASE SURVEILLANCE

*THANK YOU!*

The logo for the Joint Public Health Informatics Taskforce (jPHIT). It features the letters 'jPHIT' in a bold, blue, sans-serif font. Below this, the words 'Joint Public Health' and 'Informatics Taskforce' are stacked in a smaller, blue, sans-serif font. A horizontal line is positioned above the 'PHIT' part of the logo.