

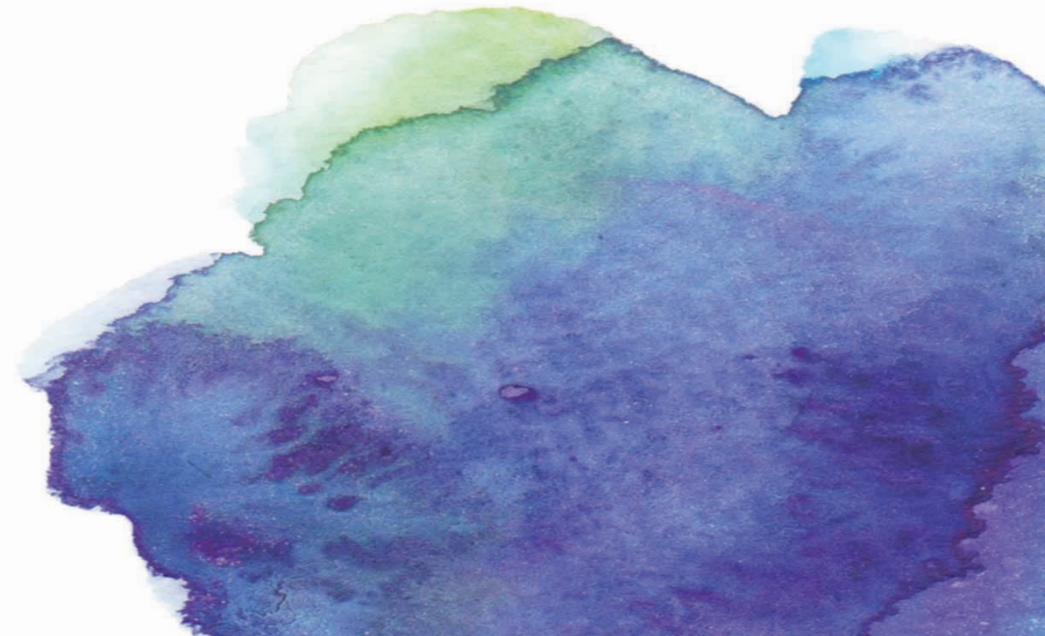
Questions about Policies and Procedures: What is needed for a Global Framework to Support Health Information Exchange

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Proposed Key Policy Areas for a Global Framework

- Governance
- General P&P
- Privacy, Security, Confidentiality
- Data Use Agreements
- Standards and Interoperability



Governance

- Data exchanges at an individual or aggregate level
- Data exchanges within country or between countries
- Data collection and storage
- Common governance or trust framework
 - Where does the governance framework apply
 - specific use cases
 - enterprise wide



P&P: General

- Patient identification
 - Unique identified and/or matched
 - Attributes needed for identification
 - Identification resolution



Privacy, Security, Confidentiality

- National laws regarding privacy and security for health data
- Underlying principles and cultural considerations
- Identification and authentication process to grant data access
- Patient consent
 - ownership or stewardship of the data
 - Individual consent process



Data Use Agreement

- Anticipated use and sharing of the data
 - List options and individual agreement
- Specified or limited use cases
- Participant obligations
 - Required to respond to queries/data requests
 - Process to report breaches or addressing issue resolution
- Data integrity and quality



Data Use Agreement

- Resolution dispute
- Liability for risk if harm
 - 'High risk' information sharing
- Auditing and reporting of audit
- Identity proofing and authentication



Standards and Interoperability

- Minimum common data set that should be collected
- Minimum set of interoperability standards requirements (terminology standards, content exchange standards)
- Guidance for implementation and use
 - Optional/mandatory



Resource

- <http://regenstriefins.wpengine.com/wp-content/uploads/2016/06/hieframework-version0-8clean-2-4.pdf>



Data Sharing Policies and Protocols Notes from the Indiana HIE

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My Background and Biases

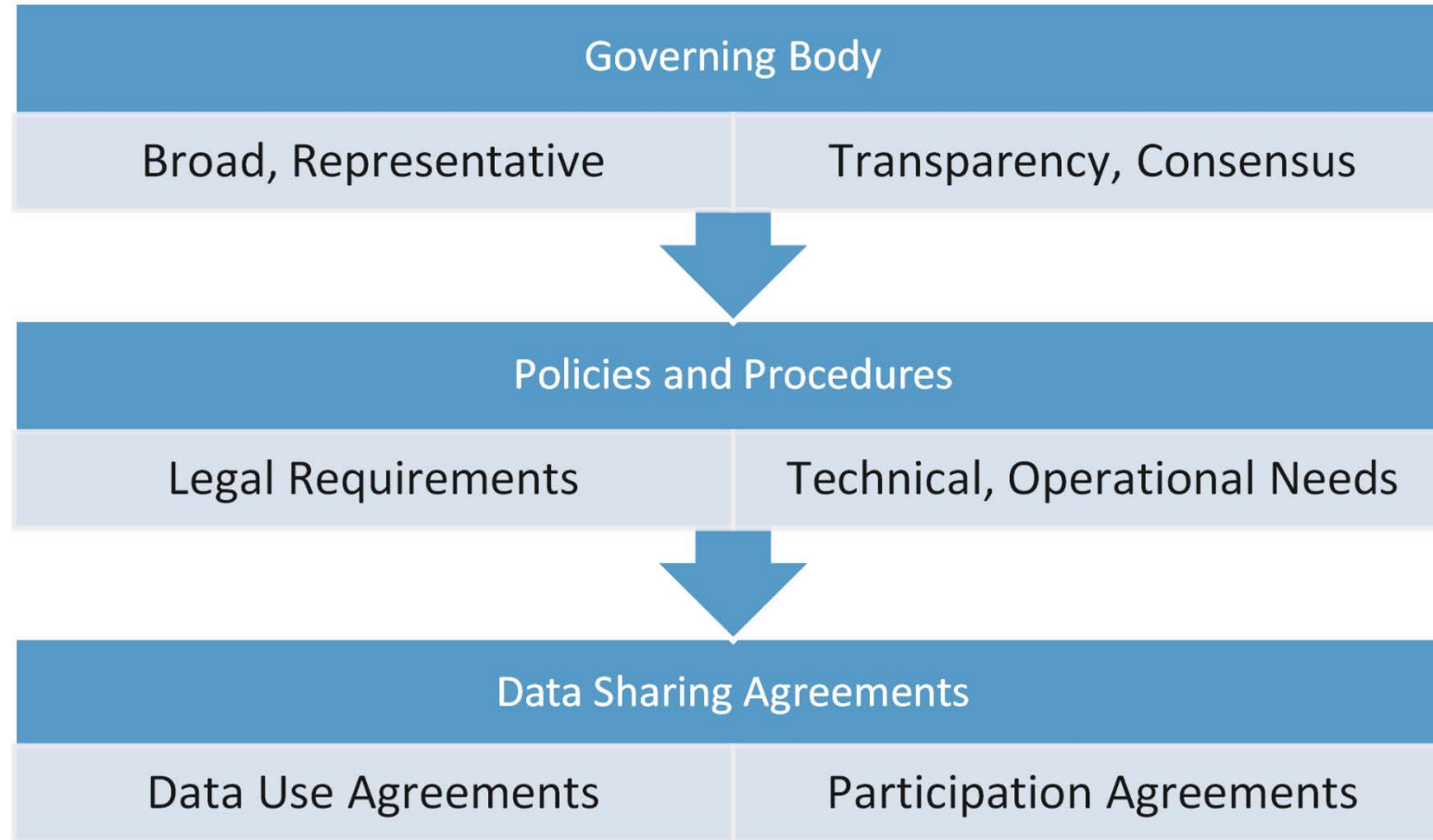
- I have worked with LOINC and the Indiana HIE for more than 10 years
- I have served as an HIE developer, project manager, and now researcher
- I wrote a book on HIE as there were none, and it includes a chapter on Governance plus Privacy/Security



A Fabric of Trust



A Framework for Governance



From Kelley KW, Feldman SS, Gravely SD. Engaging and Sustaining Stakeholders: Towards Governance.

In Dixon BE (Ed) *Health Information Exchange:*

Navigating and Managing a Network of Health Information Systems. Academic Press, 2016.



Policies and Procedures

- Policies establish the “rules of the road” for the network of PHS partners
- Procedures describe how work is done
 - Technical operations
 - Processes for getting requests approved
 - Accounts for privacy and security measures (when data are captured, managed)



Purpose of Use and Users

- Permitted purposes of use
 - What is the scope of the network?
- Permitted users
 - Who can access the network (under what circumstances)?
 - What are the roles of these users?
- Examples
 - Epidemiologist vs. Physician
 - Health minister vs. Community health worker



Procedures for Use

- How will the use of the network be monitoring and audited?
 - Who will be responsible?
 - How will audit logs be created? Backed up?
- How will users and user roles be defined?
 - Universal health care worker identifiers?
 - Standard codes for user roles?



Documenting Policies and Procedures

- Governance Charter
 - What are the operating rules of the governance group?
- Participation Agreement
 - Partners agree to share data for specific use cases
- Data Use Agreement
 - If I give you data, what can you do with them?



Privacy & Security: A Balancing Act



Electronic Triggers for Security

- Patient admitted to hospital
 - Access to clinical team for 72 hours
- Patient has scheduled appointment with GP
 - Access to clinical team for 6 months
- Patient has notifiable disease
 - Access to nurse epidemiologists / DIS for 3 months



Open Challenges and Questions

- National versus local versus cultural laws
- Should individuals opt-in or opt-out of HIE?
- How do we best engage stakeholders?
- What have you done to build a fabric of trust?



Questions?

Discussion



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