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

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

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?
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