

# NCVHS Hearing: Public Health Data Standards

Public Health and Emergency Response Workgroup

HL7

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# HL7

- Thank you
- HL7 is committed to providing an open, collegial, and constructive vehicle to advance interoperability in healthcare.
- HL7 recognizes the special needs of public health and PHER is the home to serve those needs.

# PHER

- PHER has been one of the most prolific workgroups within HL7 in recent years.
- PHER also acts as the voice for public health domain perspective on many of the standards developed by other workgroups that either impact or are impacted by public health.

# State of Standards

- Areas of strength
  - Vital Records
  - Immunization
  - Lab Reporting
  - Case Reporting
  - Newborn Screening

# State of Standards

- Areas of
  - The impressive record has been achieved based on a small number of public health contributors.
  - Your own Michelle Williamson is the role model for public health contributors.
  - Shepherded several individual standards for Vital Records.
  - Engages and represents a broad consortium of public health stakeholders who cannot be at the table in person
  - Strategically coordinated to maximize the potential impact from the fewest standards.

# State of Standards

- Challenges
  - Only a fraction of the important data exchanges between providers and public health have standards in place.
  - We need more hands.
  - We need more minds.

# State of Standards

- Threats
  - Standards will be deficient if they are developed without the insights and input of those who need to use them.
  - Deficient standards are not just a waste they can be a liability.
  - They can be disruptive.
  - They can be a barrier to new standards.

# State of Standards

- Standards with a capital S
  - Standards are not just documents or specifications
  - They are the product of open, transparent, and consensus based efforts.
  - They are living and evolving.
  - They require longitudinal management, publication, and curation.
  - They need an SDO.



# Incentives

- Why standards?
  - Cost
  - Quality
  - Quantity
  - Timeliness

# Barriers

- For public health
  - Awareness –importantly at grassroots levels
  - Converting from program level up
  - Standards knowledgeable technical staff
  - Cultural shift from controlled silos to sharing
- For providers
  - Waiting on public health
  - Costs to enable public health specific technology

# Out of scope

- As an SDO we believe the following questions posed by this committee are ones we are not qualified to comment on:
  - State of information exchanges
  - Implementation challenges
  - Security standards that should be used

# Privacy and Security

- Separation of concerns
  - Content standards – what is being exchanged.
  - Security standards – how do you ensure what is exchanged is from the correct party, has not been tampered or viewed by anyone else, and is safe when it gets there.
  - Privacy standards – how do you determine who should be allowed to see what data on whom?

# Privacy and Security

- Separation of concerns
  - As an SDO we attempt to provide standards for each of these and in general attempt to make them “modular” so an implementation can choose the right content, send it with the security (regardless of content), and convey the information necessary to implement disclosure policies to honor privacy needs.

# Privacy and Security

- Separation of concerns
  - Power comes from not “embedding” security in content.
  - Flexibility produced also facilitates reuse encouraging adoption, compliance, and reducing costs.

# Standards Needed

- Vocabulary standards
  - There are few areas where the public health silos are more problematic.
  - We need strong public health contribution to enable our vocabularies to provide the nuanced messaging that is needed.
  - We need public health to adopt and be consistent across domains and agencies once vocabularies are established.
  - If they are deficient, refine them don't ignore them.

# Standards Needed

- Content standards
  - As noted earlier a few areas have a rich suite of standards but we believe there is a need for a much broader representation of public health.
  - Increased use of modular standards to encode public health data in “normal” healthcare content standards (especially CDA documents).



# Standards Needed

- Privacy standards
  - Under current law public health enjoys a special consideration related to privacy.
  - A systematic evaluation of existing privacy standards and how (if at all) those need to be modified for:
    - When the party accessing the data is public health so those disclosing it have a clear mechanism for those special policies.
    - When the party disclosing the data is public health to allow data held in public health to enrich the care of the patients.

# Standards Needed

- Data Query
  - Standards that allow public health to query provider resources for data that are not normally transmitted but may be required “on the fly”.
  - Standards that allow provider to query public health resources for data that are not normally published but may be required “on the fly”.
  - These are clearly intimately related to the privacy standards but are distinct from them.

# Standards Needed

- Protocols
  - Systematic examination of the standards for clinical decision support to identify what if any modifications are required to allow jurisdiction specific public health protocols to be used by provider systems.

# Standards Needed

- Case Level From Public Health
  - Most of the focus for public health standards has focused on the flow of data from providers to public health.
  - As an active participant in healthcare, public health will sometimes be the holder or custodian of data on individual cases that can benefit the care of that patient.
  - Standards for transmission of case level data from public health will become increasingly important.

# Summary

- Standards are an investment and their potential is limited by the level of involvement in their development.
- Standards that aren't used are worse than none at all. Public health has to adopt first.
- Public health is a big universe. You have a few stars but there is a long way to go.
- SDOs are your friends. Use them.