

The National Committee on Vital and Health Statistics

*The Public Advisory Body to the Secretary of Health
and Human Services*

Draft Letter:

A Stewardship Framework for the Use of Community Health Data

Privacy, Confidentiality and Security Subcommittee:

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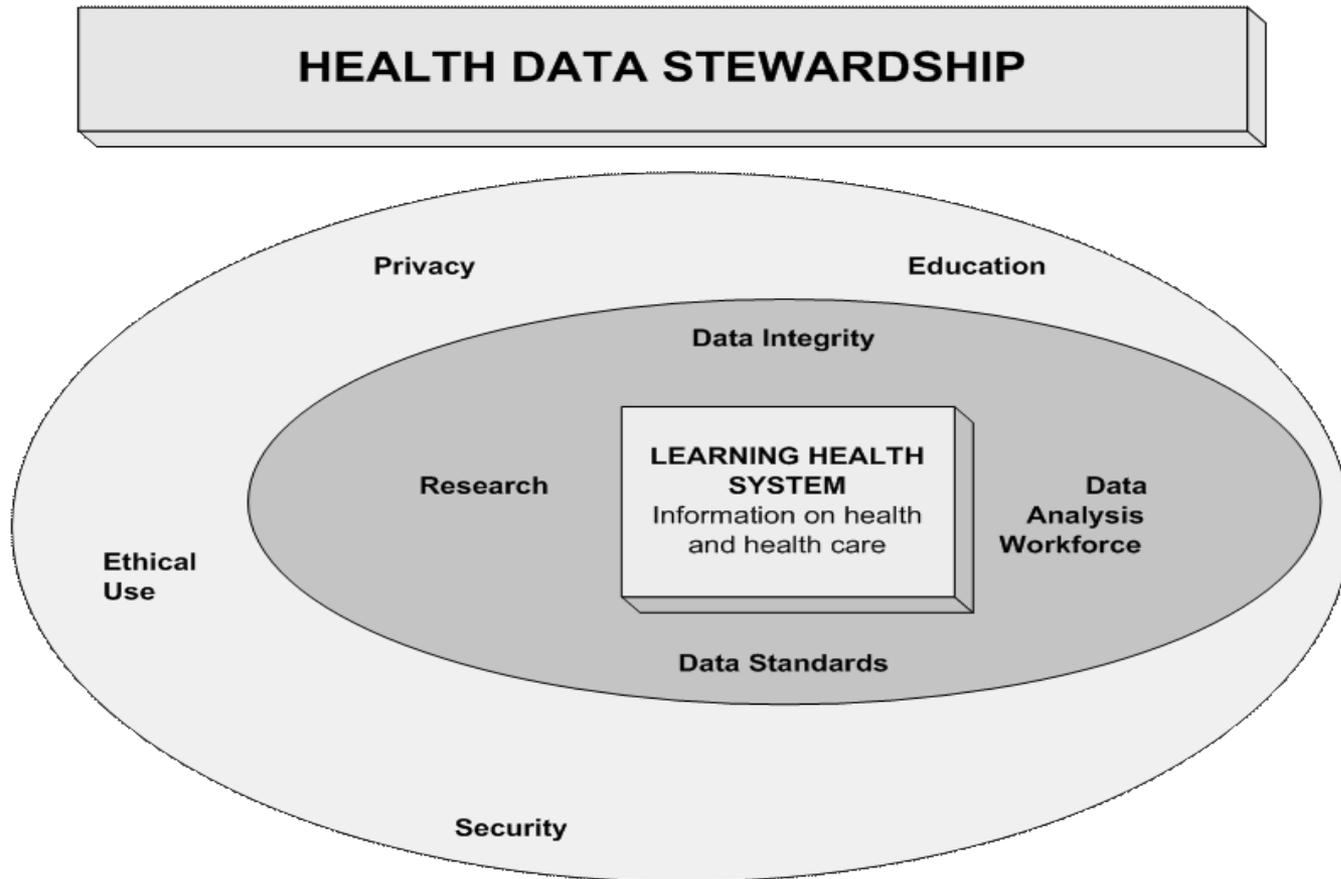
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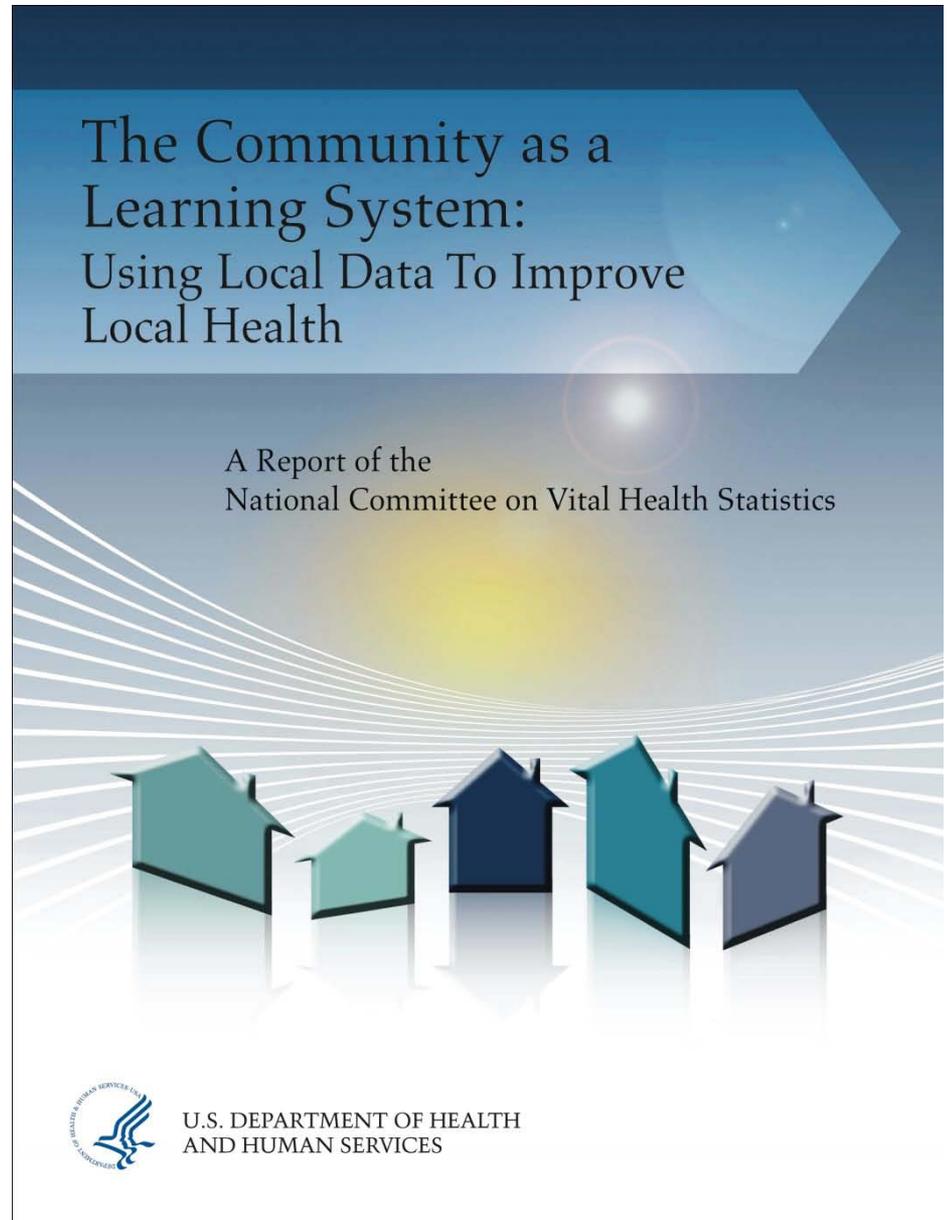
Health Data Stewardship



The National Committee on Vital and Health Statistics



- Published, November 2011
- Joint Project of the Population Health and Privacy, Confidentiality and Security Subcommittees



Building Trust

- Educating community members and leaders about data use and benefits
- Involving community members in decisions about data use and more
- Trust-building among organizations and agencies that are data sources
- Governance fosters a sense of ownership and control

“...further efforts and leadership are needed to define a privacy and security framework to guide the innovative uses of local data emerging in communities across the country.”

The Community as a Learning System for Health, NCVHS, December 2011, p. 19

Trust and the Community: Hearings on April 17-18, 2012

- Privacy is not an individual issue only, it's societal and family
- Chain of trust involving the whole process from collaboration through use of data
- Participatory Governance and special obligations of data stewards to the community
- Spectrum of consent

“Trust is our Most Important Resource....and Trustworthy practices require attention to relationships and accountability.”

Kelly Edwards, PhD, Department of Bioethics and Humanities University of Washington School of Medicine

Drafting the Stewardship Framework Letter

1. Surveyed major existing frameworks
2. Identified gaps in these frameworks as they apply to community data uses—areas that are simply not addressed in existing frameworks (although they are present in privacy/trust discussions)
3. Draft letter discussed at September 2012 NCVHS meeting
4. Revisions reflect suggestions and questions raised in September.