



The National Committee on Vital and Health Statistics
The Public Advisory Body to the Secretary of Health and Human Services

Privacy, Confidentiality and Security Sub-committee

**Privacy, Confidentiality and
Security Subcommittee meeting
June 11, 2014**



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Agenda

- 2:45 p.m. - Review and update on the PCS Subcommittee annual plan - *co-chairs*
- 2:50 p.m. - Review draft ***Community Data User Tool Kit*** - *Maureen Henry*
- 3:30 p.m. - Planning for a virtual Tool Kit reactor workshop on July 16 - *co-chairs*
- 3:40 p.m. - Briefing on data segmentation for privacy standards and technology - *Walter Suarez*
- 4:00 p.m. - Meeting takeaways and next steps - *co-chairs*
- 4:15 p.m. - Block adjournment



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Activity: Stewardship for Community Data Use	Target	Milestones*	Contract/staff resources
<p>1a. Report on Stewardship Best Practices for Community Use of Health Data</p> <ul style="list-style-type: none"> • Research • Workshop or other activity to advance best stewardship • Work products 	<p>Report to Committee in September 2014</p> <ul style="list-style-type: none"> • Q1 2014 • Q/2-3 2014 • Q3-4 2014 	<ul style="list-style-type: none"> • Finalize research questions and timeline • Review research work products • Design workshop plan • Conduct hearing • Outline report • Review report drafts 	<ul style="list-style-type: none"> • Contractor for research and report writing • Staff for hearing administration
<p>1b. Follow up on Public Health Privacy and Security Standards</p>	<p>Report in conjunction with standards letter(s)</p>	<ul style="list-style-type: none"> • Roll into 1a research • Determine needed follow up 	<ul style="list-style-type: none"> • Contractor for research and report writing • Staff for hearing administration



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Activity	Target	Milestones*	Contract/staff resources
2a.. HIPAA report to Congress – section on Privacy and Security	Final draft of section in April	<ul style="list-style-type: none">• Subcommittee call in November and December 2013.• In person Subcommittee meeting in February• Subcommittee call late March/April	M. Bernstein to draft working with T. Deutsch



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Activity	Target	Milestones*	Contract/staff resources
<p>3. Advice on privacy issues</p> <ul style="list-style-type: none"> a. Outstanding HIPAA related issues b. Emerging issue 	<p>Recommendations on HIPAA related issue as needed.</p> <p>Letter on Emerging issue for Committee review: February 2015</p> <ul style="list-style-type: none"> • Monitoring • Hearing on issue: Fall 2014 	<ul style="list-style-type: none"> • Select issues in June • Conduct issues research • Design hearing plan 	<ul style="list-style-type: none"> • Contractor or staff for research issue brief • Staff for hearing administration



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Community Data User Tool Kit

Project Objective

- Provide guidance for use of data to improve community health
 - Emphasis on privacy, confidentiality, and security
 - Not limited to privacy, confidentiality, and security



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What came before

- Joint Roundtable on Health Data Needs for Community-Driven Change (2013)
- Stewardship Framework Letter to HHS Secretary Sebelius (2012)
- The Community as a Learning System: Using Local Data to Improve Local Health (2011)



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Process

- Environmental scan
 - Review of past reports and recommendations
 - Interviews
- Culling/expansion process



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Charge

- Develop a Community Data User Toolkit



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Target Audience

- **Communities**
 - Local government
 - Non-profit organizations
 - Disease-specific groups
- **Others**



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Structure



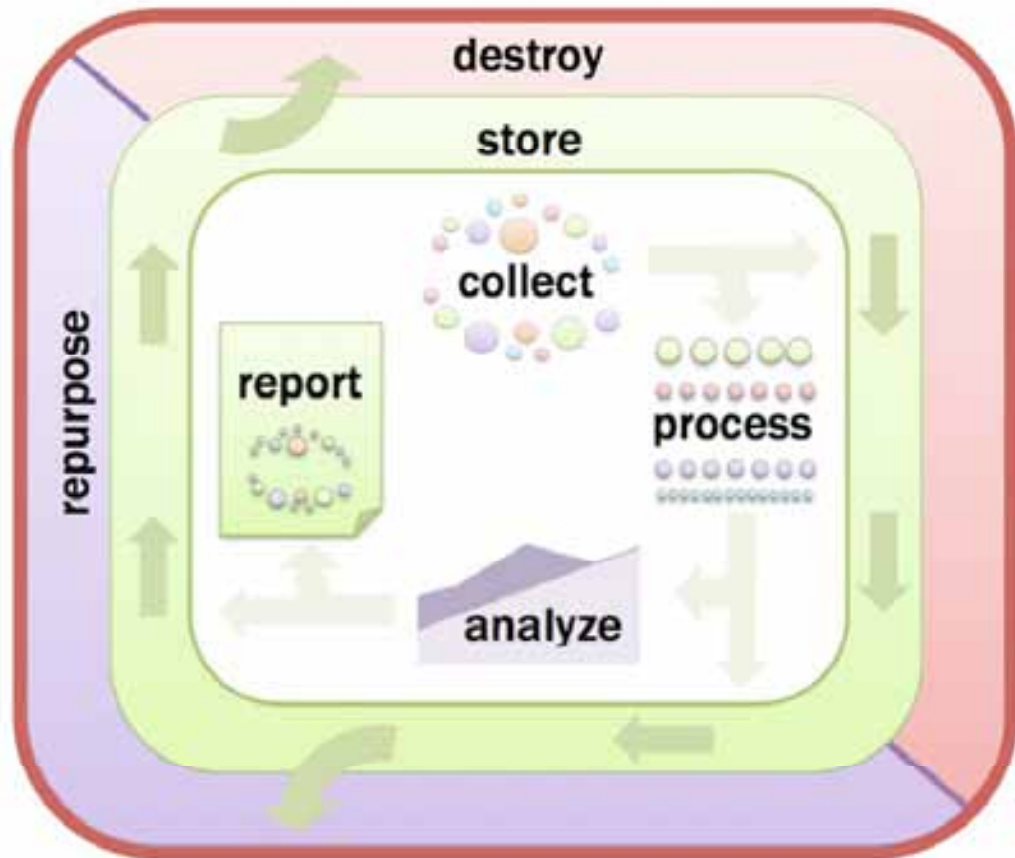


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Data Lifecycle





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Section Organization

- Brief explanation of topic
- Highlight an aspect of case study that illustrates main point
- Check-list



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Case Studies

- eMERGE Network
- Newborn Blood Spots
- University of Maine Refugee Health
- Indian Health Service
- Taking Neighborhood Health to Heart
- Havasupai Tribe Biological Samples
- Pine Study
- My Health Access



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- Regulatory and Legal Structures
 - HIPAA
 - Human subjects protections
- Data Use Agreements



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Templates

- Notice of privacy practices
- Data use agreement



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Community Data User Tool Kit
Virtual Toolkit Reactor Workshop

- July 16, 2014