NCVHS 2008
Reflections and Questions for Discussion

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Overview

- Where have we been?
- Where should we be going?
- How should we organize ourselves to get there?

Where have we been?

NCVHS 1949 to 2008

NCVHS Charter: Areas of Focus
Inside and Outside HHS

- Data needs assessment, emerging data issues
- Data collection strategies:
  - multipurpose, integrated, shared, "multiple uses of data collected once"
- Data standards, terminology, classifications
- Information network design, interoperability
- Privacy and Security
- HIPAA implementation

Selected NCVHS History

Year	Focus	Data sources	Impact
1949	Mortality Morbidity Reportable disease	Raw statistics	Increased national awareness
1980s	Care delivery site data sets: Hospital Ambulatory Long Term Care	ICD codes	Improved understanding of Disease Disparities (minorities, indigent, mental health disability, LTC, race and ethnicity)
1996	HIPAA Privacy Security	Electronic transaction standards	• Increased opportunity for aggregation of claims data • Better understanding of disease management, resource utilization
2002	NHII/NHIN E Prescribing	Clinical, lab, medication data	• Potential to define/assess longitudinal episodes of care • Person-centric focus

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NCVHS "Recent" History

- 1986 developed "Characteristics for Assessing Emerging Issues"

- Work moved away from technical to conceptual and consultative toward:
  - Analyzing problems
  - Reviewing research
  - Talking with experts and those affected by the issues
  - Recommending an approach
  - Urging further study

- Functions
  - Draw attention to issues
  - Provide a forum for legitimizing and reinforcing new ideas
  - Facilitating dialogue

NCVHS Production

Year	Privacy	Std & Sec*	Populations	NHII	Quality	Other	SUM
1997	3		1				4
1998	3	6	2	1	1		13
1999	1	2	2				5
2000	1	3	1				5
2001	2	4	4	1			11
2002	4	3		1			8
2003	1	8	4	1	1		15
2004	7	5	2	1	1		16
2005		3	1	1			5
2006	1	5		2			8
2007	3	4	1			Uses of data	9
2008					1		1
	26	43	18	8	4	1	100

* Includes HIPAA reports to Congress

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Where should we be going?

Shaping Statistics for 21st C Core Values

- Maintaining confidentiality

- Maximizing the scientific integrity of all aspects of health statistics, while acknowledging the specific ways in which the political, cultural, and business contexts may affect data collection, analysis and interpretation

- Optimizing the enterprise's accountability to its users to ensure the availability of the information that is needed for improving the nation's health

- Ensuring the enterprises accountability to its data suppliers to minimize their burden and to provide them with timely feedback

Shaping Statistics for 21st C
Guiding Principles

- Enterprise-wide planning and coordination…
- Broad collaboration…
- Rigorous policies and procedures for protecting privacy…
- Flexibility to identify emerging health issues
- Use of data standards to facilitate sharing and comparability…
- Sufficient detail at different levels of aggregation to support decision making
- Integrated, streamlined data collection for multiple purposes
- Timely production of valid and reliable health statistics
- Appropriate access to and ease of use of health statistics
- Continuous evaluation of the completeness, accuracy and timeliness of health statistics and of the ability of the health statistics enterprise to support their production

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Balancing the Portfolio

- Ongoing oversight

- Collaboration

- Emerging issues

- Visioning the future

Changing Landscape

- EHR development and adoption
- NHIN interoperability
- AHIC move to the private sector
- Quality agenda
  - Public reporting, P4P
  - Research vs. quality
- Legislation
  - E.g. Wired for Health Care Quality Act S1693
- Populations strategy to ensure that processes and data enhance its success
- Key drivers of standards
  - HITSP, CCHIT, CMS
- Data
  - Stewardship
  - Quality
  - In support of future needs

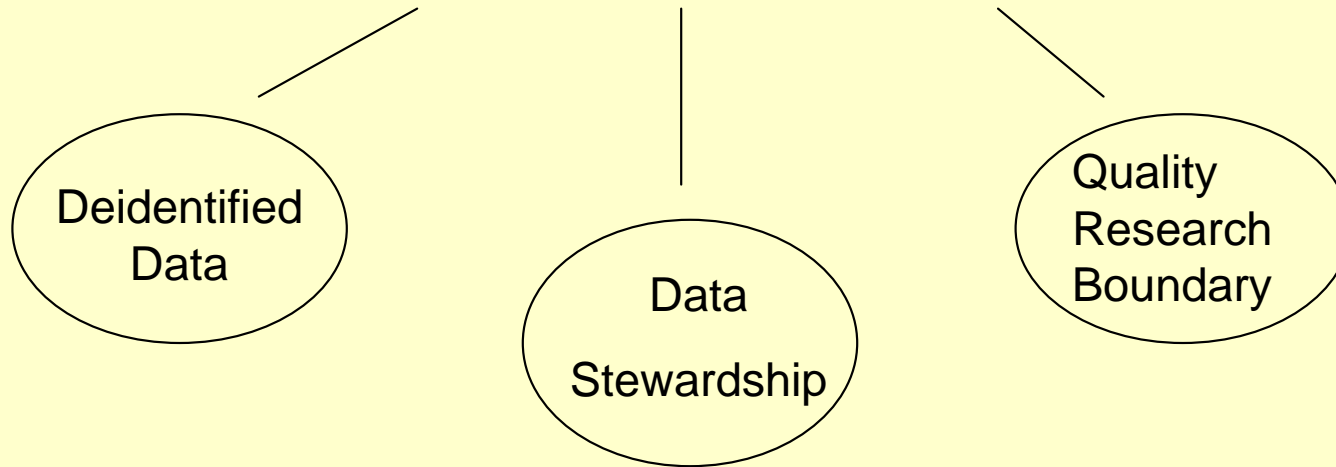# How should we organize ourselves to get there?

Configuration

Now				
Privacy	NHII	Standards & Security	Populations	*Quality WG*
		Ad hoc		
	NHIN		*Uses of data*	
Future				
Most issues need representation from all areas (privacy, standards, quality, etc.) as opposed to being addressed by a single committee				
Some areas (e.g. Standards) will have ongoing issues.				

Ad Hoc Workgroup Model

- Benefits
  - Participant expertise alignment insuring fundamental knowledge base
  - Opportunity for different committee members to work together
  - Active working partnership with staff
  - Broad perspectives incorporated from other members serving as reviewers.

- Challenges
  - Timelines
  - Workload
  - Generation of new topics spawned by original topic

How do we manage topics that emerge from an ad hoc committee?

Uses of Health Data Report

Deidentified Data

Data Stewardship

Quality Research Boundary

How do we balance and manage requests for NCVHS service?

- How do we make a difference by staying at the right level of consideration?

- Multiple sources of requests
  - **NCVHS:**   *2001 NHII*   *Eliminating Health Disparities*
  - **Congress:** *HIPAA*   *E Rx*
  - **ONC:**   *NHIN*   *Uses of data*
  - **NCHS:**   *21st Century Vision*
  - **AHRQ:**   *Composite quality and safety measures*

- Topic selections
  - *Reactive vs. proactive?*
  - *Broaden topics beyond HIPAA and NHIN?*
  - *Insuring availability of necessary data to support health care reform*

NCVHS Structure

- Reconsider role of standing committees?

- Rename or reorganize standing committees and workgroups?
  - *e.g. relocate Security? refocus Quality to Data Usage? **NHII reinvigorate***

- Reconfigure around ad hoc work groups?

- Designated cross-committee representation for each subject vs. ad hoc self-selection?

Member Participation

- What are the expectations?
  - Alignment with expertise vs. cross fertilization
  - Attendance and participation
    - Full Committee
    - Sub committees
  - Distribution of work within a committee
    - Staff
    - Members
    - Consultants

- How to cultivate leadership to preserve continuity?
  - Succession plan
  - Committee vice chairs *(recommended but not implemented)*
  - Education of new members

Writers/Consultants/Staff

- Who writes the letter/report?
  - Content
  - Editorial polish

- Balancing discussion between staff and members

- Consistent look/feel to documents and website

Other Issues?