



**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**

**Subcommittee meeting**  
**February 20, 2014**



**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**

## Agenda

1. Privacy section of HIPAA Report to Congress (20min)
2. Stewardship progress report: environmental scan on community health data stewardship practices (20min)
3. Subcommittee work plan for balance of 2014 (10min)
4. Review of Tiger Team recommendations on accounting for disclosures -10 min



**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**

1. Privacy section of HIPAA Report to Congress –  
Second Draft - Privacy Section

Committee discussion



**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**

## 2. Stewardship Progress Report: Environmental Scan

- Identify new and emerging health data privacy events and concerns
- Privacy protection for health information when communities use data to advance health
- Revisit next steps raised in hearings, letters, and reports



**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**

Stewardship Letter 12/5/12:  
Elements of a framework to guide  
community health data stewardship

- Openness, transparency, and choice
- Purpose specification
- Community engagement and participation
- Data integrity and security
- Accountability
- Protecting de-identified data
- Risks of enhanced data sets
- Avoid stigma and discrimination

NCVHS Letter to Secretary Sebelius,  
December 5, 2012



**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**

## Recommendation to Secretary

- Support the development of dynamic guidance resources that compile **best practices that experts, communities, and other** data users are learning about stewardship

NCVHS Letter to Secretary Sebelius,  
December 5, 2012



**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**

**Recommendation to Secretary:  
Dynamic guidance resources**

- How-to examples and case studies about de-identified data
- Risks of disclosure and data reporting, e.g. data aggregation, small groups
- Data use agreements and their enforcement
- Methods and best practices for openness and transparency
- Community engagement, closing the loop with communities

NCVHS Letter to Secretary Sebelius,  
December 5, 2012



**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**

## Environmental Scan: De-Identification

- Safe harbor for de-identification under HIPAA, some state public health law
- De-id and aggregation are primary means of privacy protection when communities use health data (ES)
- E.g.: Community Commons, Chicago Health Atlas

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets





**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**

## De-Identification: Risks

- De-identification may never protect privacy (AMIA report) especially when data is combined with other public data
- At community level, de-identified data may not be supported by DUAs prohibiting re-id attempts

*(ES suggests providers' privacy sometimes trumps individuals')*

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets

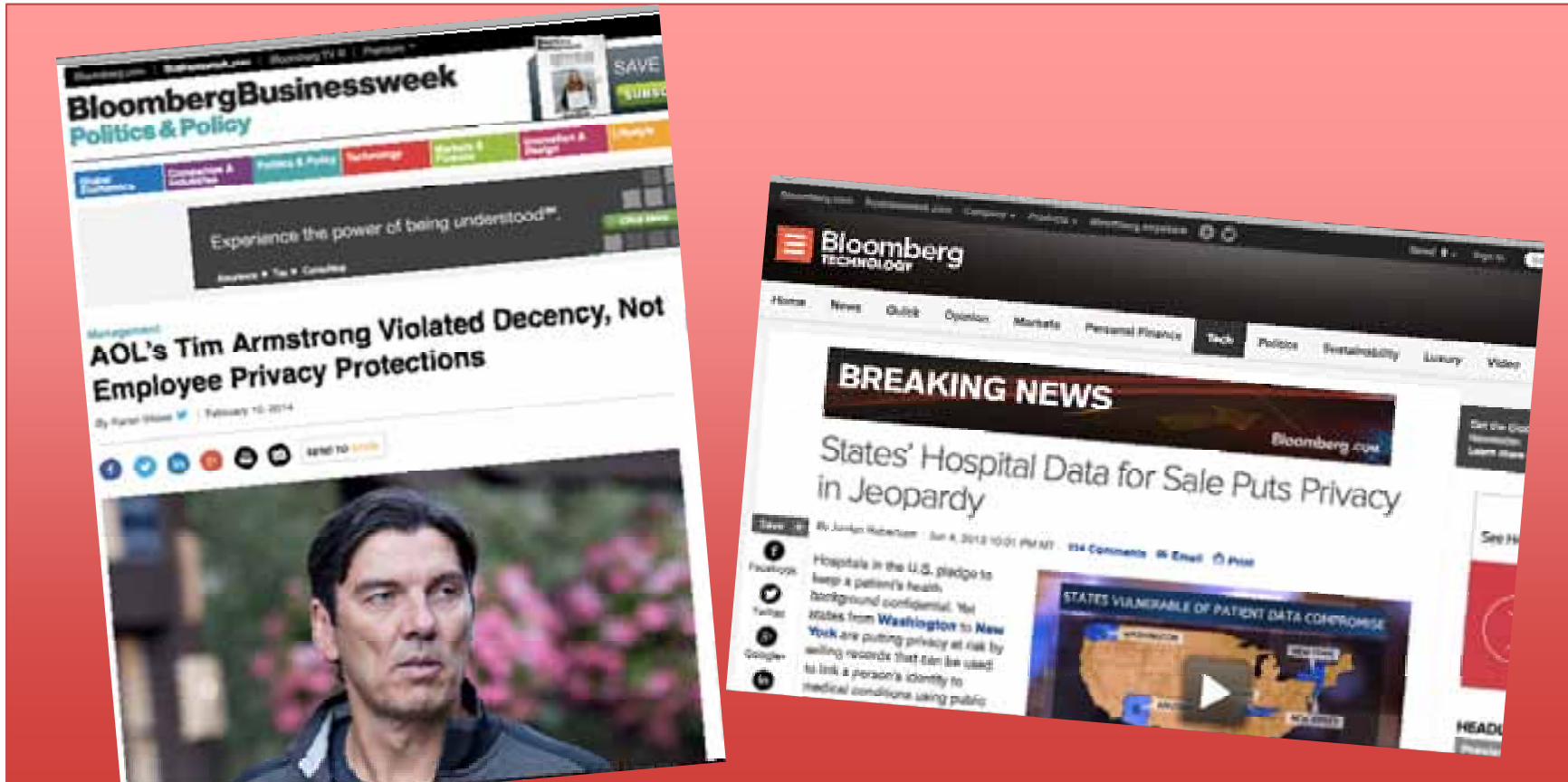


# The National Committee on Vital and Health Statistics

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

## Privacy, Confidentiality and Security Sub-committee

### De-identification: Risks



data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## How-to examples and case studies about de-identified data

### Recommendations:

- Provide plain-language information, examples
  - HIPAA
  - CDC
  - state health department laws and regs
  - other de-identification approaches

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## How-to examples and case studies about de-identified data (cont'd)

### Recommendations (cont'd)

- Highlight risks of re-identification
- Explain use of DUAs to prevent users from attempting to re-identify individuals

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## Data Aggregation

- Broader aggregation lowers risk of violating individual privacy or confidentiality
- Permits wider dissemination and use of health data
- Less subject to misuse or improper statistical analysis than sharing de-identified raw data

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## Data Aggregation Risks

- Individuals may be identified, especially when small cell-counts (AOL?)
- Inconsistent guidelines about what level of aggregation is necessary, appropriate (ES)
- May lessen value of data set

*(ES found examples where aggregation diluted the message; small group dynamics were lost in less granular analysis)*

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## How-to examples and case studies about aggregated data

### Recommendations

- Provide plain-language information about a range of guidelines for aggregation
  - cell counts
  - CDC guidelines
  - state health department guidelines

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## How-to examples and case studies about aggregated data

### Recommendations (cont'd)

- Highlight risks of re-identification
- Suggest use of DUAs to prevent data users from attempting to re-identify individuals from aggregated data sets (although this may be less effective than with de-identified data)

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets





**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**

## How-to examples and case studies about aggregated data

- **Community Commons**
  - geo-map aggregated data that could risk confidentiality or privacy
  - provide print copies to community-level users
  - but not make it available electronically

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## How-to examples and case studies about aggregated data

- King County, Washington
  - provided rank ordered census tract data
  - did not report data that could risk privacy/confidentiality, especially when small numbers involved

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## Data Use Agreements

- DUAs place limits on shared health data
  - Purpose
  - Use
- Effective backstop to re-identification
- Can allow safe sharing of granular data for very targeted uses

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## Data Use Agreements: Challenges

- Enforcing may be difficult and costly
- Too often (perhaps rarely) no monitoring or follow-up after data is shared
- No standardized language



**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**

## DUAs: How-to examples and case studies

- **Recommendations:**
  - Collect examples that can be shared with communities using health data
  - Summarize necessary elements of DUAs

data integrity and security

protecting de-identified data

accountability

risks of enhanced data sets



**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**

## Community Engagement

- Engaging communities in advance of data collection or when data is repurposed
  - Avoids adverse outcomes downstream (Havasupai settlement, destruction of blood spots in Texas)
  - Can improve quality of data collected
  - Can improve access to study participants (e.g. patients like me)
  - Can improve study design

openness, transparency & choice

avoid stigma and discrimination

accountability

community engagement & participation

purpose specification



**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**

## Community Engagement

- Study results relevant within a community can improve health for individuals within the community
- *Community participation appears to reduce concerns about individual privacy, confidentiality, and small-group stigmatization (ES)*

openness, transparency & choice

avoid stigma and discrimination

accountability

community engagement & participation

purpose specification



**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**

## Community Engagement: Challenges

- Many communities lack an obvious governance structure
- Creating a governance structure can be challenging, time-consuming, and costly

openness, transparency & choice

avoid stigma and discrimination

accountability

community engagement & participation

purpose specification





# 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

### Community Engagement: Challenges



openness, transparency & choice

avoid stigma and discrimination

accountability

community engagement & participation

purpose specification



**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**

## Positive Examples of Community Engagement

- Small, ethnic communities find it “more important to understand the true needs and to be asked about the issues than to not be asked at all.”
- Though communities may be quite small, “privacy has not been an immense issue. We've done our best to keep data anonymous, when possible, and confidential.”

openness, transparency & choice

avoid stigma and discrimination

accountability

community engagement & participation

purpose specification



**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**

## Positive Examples of Community Engagement (cont'd)

“individuals have been identified as cancer survivors, however this has been viewed as an asset as most have taken this opportunity (when they are comfortable to do so) to educate others and promote awareness about the risks of cancer. We haven't had many, if any I can recall, instances where privacy was lost and people's wishes were not honored.”

openness, transparency & choice

avoid stigma and discrimination

accountability

community engagement & participation

purpose specification



**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**

## Community Engagement: Recommendations

- Find and describe effective models
  - Denver
  - Genetic Alliance
  - Community Commons
  - other?

openness, transparency & choice

avoid stigma and discrimination

accountability

community engagement & participation

purpose specification



# 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

### New and Emerging Privacy Concerns



Press attention to NSA **surveillance** creating public fears about public health surveillance





**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**

## New and Emerging Concerns

- Difficulty getting access to data at all levels  
*(Past frameworks have not addressed an affirmative duty to share when appropriate)*
  - Emerged in interviews as a more urgent problem than privacy protection
  - HIPAA characterized as an excuse for not sharing
  - Cost of obtaining data from private sources is a barrier to public health



**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**

## New and Emerging Concerns

- Difficulty getting access to data at all levels (cont.)
  - “Integration and sharing of health data that currently reside in silos are necessary for the optimal use of the data”



**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**

## New and Emerging Concerns

- Data is more than what is in an individual's medical record
  - Can be environmental, e.g. food desert
  - Non-medical sources increasingly a privacy concern where no protections
  - credit card data
  - social media
  - FICO medication adherence score

(Senate Commerce Committee Hearing, December 2013)





**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**

## New and Emerging Concerns

- This type of data is relevant to public health, but public health agencies can't afford it
- Tension between academic/IRB norms and what works with communities
  - E.g. members of an immigrant community wanted the family to answer a survey collectively
  - IRB was concerned about privacy among family members



**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**

## New and Emerging Concerns

- Tension between academic/IRB norms and what works with communities (cont)
  - “The community asked, ‘What if a study found something negative about our community? We would not want to publish that.’ Yet as academics, we are committed, and even have institutional policies, regarding suppressing the results of research.”



**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**

## Environmental scan: Brief summary

When considering community level use of health data, privacy protections/protocols seem to be unchanged since 2011/2012/2013 hearings



**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**

## Proposal for Next Steps

- Synthesize findings and recommendations from past NCVHS letters/reports
- Identify examples of communities that are effectively using health data at the community level
- Identify sample criteria for aggregation & de-identification that could serve as a resource for communities using health data



**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**

## Proposal for Next Steps (continued)

- Identify elements that should be addressed in DUAs
- Provide sample DUAs
- Other???



**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**

## Recommendations about de-identification: Subcommittee discussion of next steps

- Provide plain-language information, examples
  - HIPAA
  - CDC
  - state health department laws and regs
  - other de-identification approaches
- Highlight risks of re-identification
- Explain use of DUAs to prevent re-id



**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**

## Recommendations about data aggregation: Subcommittee discussion of next steps

- **Community Commons**
  - geo-map aggregated data that could risk confidentiality or privacy
  - provide print copies to community-level users
  - but not make it available electronically



**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**

## Recommendations about data aggregation: Subcommittee discussion of next steps

- King County, WA
  - provided rank ordered census tract data
  - did not give numbers that could put privacy, confidentiality at risk, especially when small numbers involved
  - Collect examples





**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**

## Recommendations about DUAs: Subcommittee discussion of next steps

- Collect examples of DUAs that can be shared with communities using health data
- Summarize elements necessary in DUAs



**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**

## Recommendations on community engagement: Subcommittee discussion of next steps

- Find and describe effective models
  - Denver
  - Genetic Alliance
  - Community Commons
  - other?



**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**

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



**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**

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



**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**

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



**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**

## 4. Accounting for Disclosures

### Recommendations of HIT Policy Committee

- Due to the uncertainties and complexities involved in implementing the HITECH requirements to account for disclosures for TPO made through an EHR, approach implementation in a step-wise or staged fashion, pursuing an initial pathway that is workable from both a policy and technology perspective.
- Focus on the patients' rights to a report of disclosures *outside* the entity or organized health care arrangement and the patients' rights to an investigation of inappropriate accesses *inside*