



**National Committee On Vital And Health
Statistics
Ad Hoc Workgroup for Secondary Uses of
Health Data**

**Testimony on Perspectives on Uses of Health Data
Public Health/Statewide Planning**

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AUGUST 1, 2007



Secondary Uses for and by Public Health

- Formerly Data Products Manager for hospital discharge data collected by the Washington State Department of Health (WA DOH)
- Disseminated data for secondary uses in both the public and private sector
- Public sector uses: epidemiology, program management and evaluation, grant writing, rate rebasing, mandated reporting, research, planning, mapping, indicators and measurements, outcomes
- Private sector uses: planning, marketing, research



Dissemination Practices in WA

- WA DOH disseminates hospital discharge data for secondary uses, with the goal to release unless explicitly prohibited by law
- Have a legally mandated public data set equal to a HIPAA limited data set
- Often respond to requests by creating customized data sets using minimum necessary
- Trust developed through working in partnership on issues related to the data, demonstrating appropriate protections, ongoing communication and transparency in actions



Data Collection in WA

- WA DOH has mandated collection authority for hospital discharge data and a mandated stewardship and dissemination role
- The same or similar information is also collected by other entities, such as the state Hospital Association and Medicaid program
- Relationships based on mandated reporting or reporting for reimbursement, which do not always facilitate trust. Additional efforts must be made to build trust



Public Participation

- Health care consumers are generally not knowledgeable about all the secondary uses of their health information
- WA DOH did create consumer information using the hospital discharge data and made copies available to providers to hand out
- Consumers invited to participate in public meetings on changes to or proposed expansions of data collection activities



State Confidentiality and Privacy Protections

- Confidential information requires IRB approval if for research or a data sharing agreement if for other authorized uses
- No redisclosure of confidential data is allowed by the recipient without explicit approval from WA DOH; no further research uses without IRB approval
- Customized responses to data requests for both public and confidential data are made using minimum necessary criteria



Quality vs. Research

- Usage of the terms “quality” and “research” is not standard; the terms can mean different things to different users
- In practice, areas of overlap are usually handled under the stricter standards and treated as research
- Differentiate quality and research primarily on who benefits: if the organization, it is quality; if the public or the general health field, it is research



Secondary Uses under HIE

- Needs for new data sources or availability are increasing
- Longitudinal data and linkage across disparate existing health data sets open a whole new window for progress in understanding health factors
- HIE could facilitate these connections and simplify the effort needed to bring data together



Secondary Use Issues under HIE

- Many health data uses are secondary, as information pulled direct from the source requires more cost and effort to use. Even providers request
 - Data stewards such as state data organizations and hospital associations provide a service in cleaning, subsetting, and aggregating the data to make it more useful to users
 - HIE must factor in this process to facilitate the creation and dissemination of usable data



Barriers to Secondary Uses

- Legal privacy, confidentiality, and reporting requirements are narrow and scattered, and may conflict or contradict
- Privacy and confidentiality requirements are often undefined or poorly defined and lack specifics
- Privacy and confidentiality are often assumed rather than assured in health agencies and programs
- Health professionals adhere to professional ethics and often lack knowledge of state laws



To Facilitate Secondary Uses

- Balance strong privacy protections while providing for access for legitimate uses
- Consolidate, synchronize, and simplify confidentiality and privacy requirements
- Standardize definitions of “confidentiality” and “privacy” and specify what actions or behaviors are required
- Provide guidance and assistance to bridge the gap between the letter of the law and operational practices to help implementation of good privacy protections



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