

Ethical Considerations in Transforming the Public Health Informatics Infrastructure

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Public Health Ethics

- ▶ **Beneficence**
- ▶ **Nonmaleficence**
- ▶ **Respect for persons**
- ▶ **Justice**

APHA 2000, Kass 2001, Childress et. al. 2002, Roberts and Reich 2002

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Potential Benefits of Improved Information Infrastructure

- ▶ **Improvements in healthcare quality**
- ▶ **Enhance patient access to information and involvement in decisionmaking**
- ▶ **Improve access to care for underserved populations**

Hippocratic Oath

“And about whatever I may see or hear in treatment, or even without treatment, in the life of human beings -- things that should not ever be blurted out outside -- I will remain silent, holding such things to be unutterable.”

Translation by Heinrich Von Staden, "In a pure and holy way:" Personal and Professional Conduct in the Hippocratic Oath," *Journal of the History of Medicine and Allied Sciences* 51 (1996) 406-408.

Definitions

- ▶ **Privacy:** Individual's claim to limit access by others to some aspect of their personal life
- ▶ **Confidentiality:** Relationship of trust that protects informational privacy

Privacy Law

- ▶ **Whalen v Roe (S.Ct. 1977)**
 - ▶ “the orderly preservation of great quantities of information, much of which is personal in character and potentially embarrassing or harmful if disclosed.”
- ▶ **Tarasoff v Regents of the Univ of California (1976)**
 - ▶ **Limits on non-disclosure of information**

Consent for Information Use

- ▶ **Attentive to conditions under which information collected and consent obtained**
- ▶ **Future uses consistent with original purpose and consent?**

Fair Information Principles (HEW, 1973)

- ▶ 1. There must be no personal data record-keeping systems whose very existence is secret;
- ▶ 2. There must be a way for an individual to find out what information is in his or her file and how the information is being used;
- ▶ 3. There must be a way for an individual to correct information in his or her records;

Fair Information Principles (HEW, 1973)

- ▶ 4. Any organization creating, maintaining, using, or disseminating records of personally identifiable information must assure the reliability of the data for its intended use and must take precautions to prevent misuse; and
- ▶ 5. There must be a way for an individual to prevent personal information obtained for one purpose from being used for another purpose without his or her consent.