

Health Privacy and the Public's Right to Know

A Guide for Public Deliberation

Compiled and Written by Craig S. Paterson

Revised November 4, 2003

Understanding the Problem:

Health information is powerful—it can save lives, but it can also be abused to cause great harm to people and communities.

Approaches for Forum Deliberation:

✓ **OPEN 'Essential' Health Information for Effective Preventive Medicine**

- Health information can save lives—trust the scientific method that is the basis for all modern medical breakthroughs!
- Responsible use of 'essential' health information can save lives and prevent suffering through carefully focused testing and research—'essential' data must be gathered quickly and processed effectively by appropriate medical personnel without interference or public panic.
- Who: Health care professionals, Center for Disease Control, World Health Organization, medical research labs, health care entrepreneurs, etc.
- But... this information must be used responsibly, relevant to preventive medical intervention, coordinated by health care professionals and protected carefully by all parties.
- Questions:
 - What kinds of information are 'essential' to save lives in preventing the spread of a contagious disease?
 - Who are the professionals we depend on to collect, process and protect this 'essential' information?
 - How can this 'essential' information be handled without public panic?
 - How do we make sure this system of 'essential' information isn't abused, making the public more vulnerable to disease or discrimination?

✓ **PROTECT Health Information from Inappropriate Uses in Economic or Social Injustices**

- Health information can be abused—safeguard the public from well-intended, but unfairly damaging public disclosure of personal information.
- Open access to even the most basic personal health information can unfairly threaten the lives and livelihoods of individuals and families, because health information has no 'shelf-life' and the opportunities for abuse are vast.

- Who: Insurance companies, employers, government agencies, school officials, health vigilantes, landlords, etc.
- Because... health information can make people vulnerable to insurance abuses, job elimination, isolation, quarantine, prejudice, violence, housing discrimination, so safeguards like HIPAA must be strengthened and universally applied to protect people from inappropriate uses. But... these safeguards may make 'essential' information more difficult to gather for timely and effective intervention in a potential crisis.
- Questions:
 - What kinds of abuses have inspired laws like HIPAA to protect innocent people from discrimination, exclusion from health benefits and potential violence in the event of health information disclosure?
 - What are the most likely groups and agencies to unfairly use the health information that might be disclosed at the time of a crisis?
 - How can sensitive medical information be handled to protect people from future discrimination?
 - How can we make sure 'protection' isn't used to hide dangerous medical conditions that could threaten public health?

✓ **COORDINATE the Uses of Health Information for Effective Diagnosis and Control of Disease**

- Health information must be coordinated among agencies and professional groups—prepare for crises by sharing information policies and limits before they're needed.
- Timely use of accurate health information can control epidemics and limit the spread of all contagious diseases by alerting the health care professionals, governmental agencies and the public in local communities and around the world.
- Who: Public health agencies, local governments, the news media, school officials, Center for Disease Control, World Health Organization, non-governmental organizations, etc.
- But... this information must be accurate, relevant to a risk situation, coordinated by health professionals and proportional to the level of threat to the public.
- Questions:
 - What kinds of coordination would be most helpful in preparing the community for a health crisis?
 - What agencies or groups would need to be included to inspire confidence in the community?
 - How can different agencies and groups coordinate their efforts without jeopardizing their uniquely objective view of the crisis?
 - How do we make sure that 'coordination' doesn't lead to coercion or control by governmental agencies?