

Vital Data Release: Why states say “no”

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September 14, 2006



U.S. Vital Registration System

- State function designed for two purposes
 - Civil registration
 - Collection of public health data
- New risks
 - Identity theft
 - National security
 - Technology



Birth Certificate System

- Proof of U.S. citizenship
- Birth certificates are breeder documents
 - Social Security cards
 - Driver's licenses
 - Passports
 - Little League enrollment



Vital Registration in the U.S.- 1

- There are 57 Vital Registration jurisdictions in the United States
- 50 States
- 5 territories
- District of Columbia
- New York City
- NAPHSIS represents all the jurisdictions



Vital Registration in the U.S.- 2

- States have their own laws, regulations, rules, policies and procedures on data release
- States may have open or restricted access to birth and death certificates
- Confidential medical reports of birth and death have greater protections



Vital Registration in the U.S.- 3

- National security legislation will tighten access to vital records and vital data
 - Intelligence Reform and Terrorism Prevention Act
 - Real ID Act



Vital Data are Special

- Inclusion in database is
 - Mandatory (data gathered without consent)
 - Universal
- Birth and death data are attractive targets
 - Full identifying information (SSN, maiden name)
 - Sensitive data (pregnancy history)
- Risks if people refuse to provide data



The Challenge- 1

- Balancing
 - Public health benefits
 - Research opportunities
 - Personal privacy threats
 - Identity theft risks
 - National security
 - State laws



The Challenge- 2

- Risks created by technology
 - Mainframe v. PCs
 - Proliferation of databases
 - Opportunities for matching
 - Ease of copying and sharing data



The Challenge- 3

- Enforcement and penalties are weak
 - Size and nature of penalties?
 - Who is responsible?
 - Graduate student? Faculty member? Academic department? School? University? Federal agency?
 - Who enforces?
 - Who prosecutes?



The Goal

- Maximize the use of vital statistics data for public health purposes, while protecting confidentiality and complying with state laws and regulations

