NCHS Update

National Committee on Vital and Health Statistics February 23, 2006





Centers for Disease Control and Prevention National Center for Health Statistics



Two Topics

- Data Release and Confidentiality Issues for Vital Statistics
- Board of Scientific Counselors Review of Mortality Vital Statistics

Data Release and Confidentiality Issues for Vital Statistics

Data Release and Confidentiality Issues for Vital Statistics

Review of Current Policy

Data Release and Confidentiality

 No known breach of confidentiality to date under NCHS' current data release policy –

however,

- Jurisdictions asked NCHS to review the current policy because of concerns that the NCHS policy is at variance with either
 - State laws and/or
 - State regulations and/or
 - State practices

Current Policy for Data Release NCHS Vital Statistics

- Public Use File includes individual record data with all variables, with these restrictions:
 - No exact dates provided; instead:
 - -Age of parents/decedent
 - -Month and year of event
 - Geography limited to counties and cities of 100,000+ population
- No restrictions on access to Public Use File; available to anyone

Current Data Release Policy, cont.

- Special Requests: For custom data sets, including unit records with smaller geographic units and/or exact dates, are reviewed on individual basis:
 - For Federal agencies, a signed data user agreement is required
 - For non-Federal requests, researchers are referred to NCHS' <u>Research Data</u> <u>Center</u>

NCHS Research Data Center

- Researchers whose requests for individuallevel files are not approved, or who request exact dates, may use facilities of NCHS's Research Data Center (RDC);
- RDC allows access for a fee to detailed data in a secure environment with standalone computer at NCHS that controls confidentiality; output is inspected and no confidential data leave NCHS premises.

Other Access to Vital Statistics Data – NOT Unit Record Data

- Pre-aggregated data for all counties, the Compressed Mortality File (CMS), available on CD-ROM for each year since 1979;
- Aggregated birth and death data available in WONDER, CDC's interactive internet web site, and in other Federal data access systems.

Issue

- Jurisdictions asked NCHS to review the current policy because of concerns that the NCHS policy is at variance with either
 - State laws and/or
 - State regulations and/or
 - State practices

NCHS Proposal: 4 Types of Releases

- Aggregated public-use data file, such as Compressed Mortality File on CDC's WONDER internet system
- Individual-level NATIONAL public-use data file with no geographic detail (no State, county, or city identifiers) or exact dates
- Customized individual-level file for Federal agencies with approved research proposals
- Customized individual-level file for non-Federal researchers with approved research proposals

Proposed: Aggregated Public-Use Birth and Death files: WONDER

- CDC's interactive web-system WONDER extracts data from NCHS's Compressed Mortality File (CMF), including death files since 1979
- WONDER provides aggregate death counts/rates for all counties, but suppresses cells <=5 for single-year data and county population < 100,000
- Aggregated birth data available now on WONDER, using individual-level natality files
- WONDER provides aggregate birth data for counties >= 100,000 population

Proposed: New Public-use Data File (PUF)

- Continues to include individual-level data
- Include all items and detail in the current PUF except for geography
 - National file only—no State, county, or city identifiers
- Available for births, deaths, fetal deaths, linked birth/infant death

Proposed: Custom Individual-level Files for Non-federal Researchers

- Researcher provides proposal and signed Data User Agreement
- Proposal review by NCHS committee, including NAPHSIS representative with veto power
- Customized individual-level file for specific project—may include all State, county, and city codes, as needed and approved, but not exact dates
- Return files to NCHS within one year unless renewal is requested and approved

Custom Individual-level Files for Federal Agencies

- Federal agency provides proposal and signed Data User Agreement
- Proposal review by NCHS committee, including NAPHSIS representative with veto power
- Customized individual-level file for specific project—may include exact dates and/or all State, county, and city codes, as needed and approved
- Return files to NCHS within one year unless renewal is requested and approved

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NAPHSIS Proposal

- Some jurisdictions have requested further limitations, for example:
 - Authority to restrict certain variables at the state level from the National PUF as well as from the compressed/aggregated files;
 - Exclude day of week
- NAPHSIS requests retroactive application of the policy to all public use data files
- Utility and value of the National PUF and the compressed files are under evaluation

Process Underway

- NAPHSIS' Statistics Committee is asking all individual jurisdictions for copies of laws, policies, regulations, and practices regarding data release and data re-release by Federal agencies
- NAPHSIS and NCHS will review documents to determine data release limitations and to develop mutually acceptable data rerelease policy

NCHS Board of Scientific Counselors

Program Reviews

Mortality Statistics Branch Review

- Reviewed by a seven member outside panel
- Reported to the BSC January 26-27
- BSC will prepare recommendations to NCHS
- NCHS reviewing report of panel

Overarching Recommendations of Review Panel

- Improve data input quality and process
- Improve data access and dissemination
- Develop a specific analytic/research plan
- Strengthen collaborative efforts with other Federal agencies, states, and academic/research institutions

Overarching Recommendations, cont.

- Work with NAPHSIS and States to address issues of confidentially, privacy and data release
- Appoint an ongoing working group to assist in strategic analytic plan development
- Take a 5-10 year perspective for implementation

Reproductive Statistics Branch Review

- Beginning immediately
- Same process of outside Panel reporting to BSC
- Anticipated report to BSC in September