

Modification to the NCHS Data Release Policy

-A Response to the States-

NCHS Board of Scientific Counselors, September 16, 2005



SAFER • HEALTHIER • PEOPLE™

**Centers for Disease Control and Prevention
National Center for Health Statistics**



Current Data Release Policy

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

Current Data Release Policy, cont.

- **Special requests for unit record data for smaller geographic units and/or exact dates are reviewed on individual basis:**
 - **For Federal agencies, signed data user agreement required**
 - **For non-Federal requests, researchers are referred to NCHS' Research Data Center**

Other access to vital statistics data – NOT unit record data

- **Aggregated data by county, e.g., the Compressed Mortality File (CMS)**
- **Aggregated birth and death data in CDC' WONDER, other data access systems**

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

So why is current policy under review?

- **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**

Revised policy provides 4 types of electronic (CD) data releases:

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

Individual-level public-use data file

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

Aggregated Public Use Death File

- CDC's interactive web-system WONDER extracts data from NCHS's Compressed Mortality File (CMF), including death files since 1979;
- WONDER provides aggregate counts/rates for all counties, but suppresses cells ≤ 5 for single-year data and county population $< 100,000$;
- WONDER Variables: age in categories, race (white, black, other), sex, underlying cause of death (all causes according to ICD in effect for a given year);
- Propose release of aggregated (CMF) file on CD-ROM for counties $\geq 100,000$;
- Other future options: change 10-year age intervals to 5 year intervals; add race and Hispanic detail.

Aggregated Public-Use Birth File

- **Available now on CDC's interactive internet system WONDER, using individual-level natality files;**
- **WONDER provides aggregate data for counties \geq 100,000 population;**
- **Categorized variables: mother's age and education; birthweight, gestation, month prenatal care began; Other variables: mother's race and Hispanic origin, sex of child, and plurality;**
- **Propose release of aggregated birth file on CD-ROM for counties \geq 100,000;**
- **Future options: Add all counties in WONDER with small cell suppression. Add mother's marital status, number of prenatal visits, adequacy of prenatal care index, live birth order (to 6+), and cesarean delivery.**

Aggregated Public-Use Linked Birth/Infant Death File

- **Available now on CDC's interactive internet system WONDER, using period files for 1995-1998;**
- **WONDER provides aggregate data for counties \geq 250,000 population;**
- **Categorized variables: mother's age and education; birthweight, gestation, month prenatal care began, child's age at death; Other variables: mother's race and Hispanic origin, marital status; live birth order (to 6+);**
- **Propose release of aggregated linked birth/infant death file on CD-ROM for counties \geq 250,000;**
- **Future option: Add all counties in WONDER with suppression of small cells. Add number of prenatal visits, adequacy of prenatal care index, and cesarean delivery.**

Custom individual-level files for Federal agencies

- **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.**

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.**

NCHS Research Data Center

- **Researchers whose requests for individual-level 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 stand-alone computer at NCHS that controls confidentiality; output is inspected and no confidential data leave NCHS premises.**

NCHS Research Data Center

- **Limitations**
 - **Not flexible for exploratory “what if” analysis and testing of multiple hypotheses**
 - **No opportunity for data linkage including related data sets or contextual data analysis**

Where are we in negotiations for a modified NCHS Data Release Policy?

NAPHSIS' Response to Proposed Modification of NCHS Data Release Policy for Vital Statistics

- **Some jurisdictions have requested further limitations:**
 - **Authority to restrict certain variables, at the state level, from the *National* Public Use File as well as from the compressed/aggregated files**
 - **Exclude day of week**
- **These restrictions compromise utility and value of the *National* Public Use File and the compressed files**

New but Related Topic:

Data Release Issues for NEW Items on Birth and Death Certificates

- **NCHS is collecting data on NEW items from the revised birth and death certificates from states/jurisdictions which have implemented the revisions**

NEW and IMPROVED DATA ELEMENTS for Births

Maternal Risk Factors

- Hypertension
 - Prepregnancy
 - Gestational
 - Eclampsia
- Fertility therapy
 - Drugs, artificial insemination, intrauterine insemination
 - Assisted reproductive technology
- Infections during pregnancy
 - STDs (gonorrhea, syphilis, chlamydia)
 - Hepatitis B; hepatitis C
- Previous preterm birth

NEW and IMPROVED DATA ELEMENTS for Births, cont.

- Use of WIC food during this pregnancy
- Principal source of payment for the delivery
- Cigarette smoking before and during pregnancy, captures levels of smoking
- Pre-pregnancy weight, weight at delivery and height = Body Mass Index and weight gain
- Method of delivery includes fetal presentation and trial of labor prior to cesarean delivery
- Congenital anomalies

NEW DATA ELEMENTS for Deaths

- Decedent's marital status distinguishes "Married" from "Married, but separated"
- Place of death includes hospice facility
- If female, pregnancy status at time of death that will help identify maternal and pregnancy-related deaths
- If transportation injury, decedent's role with respect to vehicles
- Did tobacco use contribute to death?
- Separate instructions for funeral director and person completing medical portion

NAPHSIS' Position on NEW Data Items

- **NAPHSIS' resolution authorizes jurisdictions to share *NEW* data items with NCHS, but the new data items cannot be included in any Public Use File or in NCHS reports**
- **NAPHSIS wants NCHS to pay for the additional data items and/or to increase \$\$ support for the entire data set**

**Current status of negotiations
between NCHS and NAPHSIS over
NCHS' Data Release Policy:**

“Still talking”