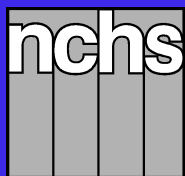


Confidentiality Programs and Practices at the National Center for Health Statistics

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BTS Confidentiality Seminar Series
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National Center for Health Statistics

- Public Health Service Act – July, 1956
- Origins:
 - National Office of Vital Statistics (Census)
 - National Health Survey (Public Health Service)

NCHS - Mission

- Surveys and special studies on the Nation's health
- Study of methods and survey techniques and data dissemination

NCHS – Data Collections Systems

- Population Based surveys
 - Health Interview Survey
 - Clinical Examination
 - Family Formation
- Records Based data collection
 - Vital Statistics
 - Hospital, Nursing home, M.D.

Data Collected I

- Self perceived health status
- Health condition
- Disability
- Health Insurance
- Use of health care facilities
- Birth weight
- Cause of death

Data Collected II

- Coroner's reports
- Cause of fetal death
- Other cause: suicide, hiv
- Drug & alcohol use
- Sexual experiences
- Sexually transmitted disease
- Income

Data Collected III

- Date of birth, gender
- Occupation
- Race
- Geographic area (county, state)
- Rare events conditions

Overview

- Organization
- NCHS Confidentiality Statute
- “Training”- Initial Orientation/Continuing
- Security – physical/electronic
- Exit procedures
- Protocol review

Overview (cont.)

- Data handling – program practices, physical inspections
- Data file tracking
- Preparation of public use files
- Research Data Center

Staff

- Confidentiality Officer (Hlth Stat. -15)
- Program Analyst - 12
- Program Analyst - 11

Organization

- NCHS Director
- Associate Director, Office of Planning, Budget & Legislation
- Confidentiality Officer
- Division Directors

The Law

- Privacy Act
- Public Health Service Act
Section 308(d)
- FOIA
Personal and medical files:
Exemption 3 – specifically exempted by statute
Exemption 6 – clearly unwarranted
invasions of privacy

Public Health Service Act

- Section 308(c): NCHS shall disseminate its statistics on as wide a basis as is practicable
- Section 308(d): *Identifiable* data not used for any other: (1) purpose or (2) party than that *consented* to by respondent

Informed Consent and Confidentiality

full exposure to the facts the respondent needs to make an intelligent decision concerning the provision of personal information to NCHS.

Types of Consent

- Two Types:
 - passive: providing data = consent
 - active: signing form = consent
- Assurance of confidentiality
 - household/clinic/establishment
 - telephone

Identifiability

- information which can be used to establish individual or establishment identity,
 - **directly** - name, address or unique identifying number
 - **indirectly** - matching data about a persons/establishment with other data containing names, addresses, etc.

Re-identification by Matching

“De-identification”

Identified file	Name abcdefghijkl
Identifier deleted	abcdefghijkl

“Re-identification”

Public use file	abcdefghijkl
External file	abcdefghijklmno Name

Recent Legal Developments

- 2001: NCHS Confidentiality Statute upheld by U.S. Appeals Court
 - Akzo-Nobel v. United States
- E-Government Act of 2002
 - Title V (CIPSEA) Confidentiality Information Protection and Statistical Efficiency Act

CIPSEA

- Fines and Penalties for unauthorized disclosure of confidential information collected under a pledge of confidentiality for statistical purposes
 - \$250,000
 - Felony

Staff Training-Orientation

- Video

- Law and violations
- staff obligations
- confidentiality
- identifiability
- data release policy
- acceptable practices
- non-acceptable practices

Staff Training-Orientation

- Personal contact
- Non-disclosure affidavit
- Orientation Package
- NCHS Staff Manual on Confidentiality

Staff Training – Continuing awareness

- Re-signing of pledge
- Posters (Do's & Don'ts)
- Confidentiality policy reminders
- Confidentiality “quiz”
- Special Presentations

Security

- Physical inspection of program areas (“walk-throughs”) – periodic
- Secure Building
- Electronic security
- Employee exit procedures

Review of Data Collection Protocols I

- Assurance of Confidentiality
 - Authority
 - Voluntary
 - Statistical use
 - Effect on respondent
 - Statement of data sharing, linking

Review of Data Collection Protocols II

- SSN, Medicare no. questions, data linking, consent for provider data
- Plans for data sharing
- Status of research participant – other agencies, contractors, collaborators
- Document consistency
- Re-contact statement

Working with the Programs

- Questionnaire design
- Data requests
- FOIA requests
- Confidentiality brochures and web statements on data handling and safeguards
- Interagency confidentiality agreements, mou's, psc's, contracts

Data Tracking I

- Internal
 - Program to program
 - Limited access
 - Duration of use
 - Program responsible

Data Tracking II

- Special case and external use (written agreements with beta testers and collaborators):
 - Minimum necessary
 - Clear responsibility/accountability
 - Time limitations
 - Tracking data base
 - Return/destruction

NCHS Disclosure Review Board

- Review of all micro data files intended for public use
- Organization
- Procedures: survey description, file documentation, disclosure potential checklist

Assessment of Disclosure Risk

- Survey timing, link to other surveys
- Geography
- Items with unusual risk: direct identifiers, income, race and ethnicity, occupation, health conditions, verbatim text, contextual variables
- Matches with known files
- Existing/added distortion

NCHS Research Data Center

- On-site, remote access
- NCHS staff supervision.
- Dedicated & specially modified hardware
 - no floppy drive, no connection to outside networks.
- All merges performed by NCHS staff.
- Restriction on material brought into RDC.
- Restrictions on material taken from RDC

Thank You

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