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

Identifier deleted

“Re-identification”

Public use file

External file
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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