THE NATIONAL CHILDREN'S STUDY

HEALTH GROWTH ENVIRONMENT

The National Children's Study

August 24, 2011

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Executive Summary

- To achieve public health goals described in the Children's Health Act, prompt access to NCS data must be clearly established for all members of the research community.
- The NCS design will present challenges to the protection of participant data collected under a commitment of confidentiality.
- Data access mechanisms are established, but need expansion to achieve study goals.

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NCS Has Committed to Public Data Access

NIH Data Sharing Policy (02/26/2003)

http://grants1.nih.gov/grants/policy/data_sharing/index.htm

- Final data collected through NIH grant, cooperative agreement or contract of $500,000 direct costs or more per year since 2003 must be made available to the research public.
- "If data from large epidemiologic or longitudinal studies are collected over several discrete time periods or waves, data should be released in waves as data become available or main findings from waves of the data are published."

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NCS Disclosure Risk Management Requirements

- The NCS informed consent commits to participant confidentiality and provides the justification for disclosure risk management
- The Privacy Act of 1974, Public Health Service Act (308 d), the E-Government Act of 2001, and the NIH certificate of confidentiality form the framework of NCS confidentiality policy
- Other best practices – established by law or recognized professional practice for studies of similar disclosure risk – guide NCS policy and procedures

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NCS Data: Unique Sources of Risk

- Disclosure risk increases when
  - Geographic sample areas are known
  - Sample selection criteria are based on public information (e.g., year of birth)
  - Data are from multiple reporters
  - Data collection is longitudinal
  - The number of investigators is large (e.g., information management)
- Confidentiality risk is cumulative
- Disclosure risk reduction plans are living documents
  - Affected by changes in the environment
  - Affected by changes in data file
  - Affected by other technological changes

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Available NCS Access Mechanisms

- Access mechanisms are available that offer various levels of confidentiality protection and user access (from less to more)
  - FISMA-compliant file encryption and transfer *(all SCs)*
  - Data use agreements *(about 45 to date, about 73 amendments)*
  - Remote access systems (users can access confidential data but cannot see it) *(not in place at NCS)*
  - Data centers *(37+3 SCs)*
- Within each mechanism, confidential data should be made available on a need to know basis for everyone

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