The National Children’s Study Archive

INTRODUCTION

The National Children’s Study (NCS) Vanguard Data Archive and Access System (“NCS Archive”) was made available for public use earlier this year at https://ncsarchive.s-3.net.

The NCS Vanguard was a pilot for a planned cohort study of environmental influences on child health and development. Starting in 2009, recruitment strategies were tested in 43 counties across 31 states throughout the U.S. The study enrolled over 5,600 birth families and followed them through 2014. At protocol-specified study visits, questionnaires and interviews, neuropsychosocial and cognitive assessments, and physical examination data were collected, along with nearly 19,000 biological and 5,500 environmental primary samples from which a sample repository of over 250,000 items was created. That information and material is now available through the NCS Archive for approved research projects by qualified researchers. Data release will be complete in early 2017 and is available via requests for the desired role for each user.

The Research Request system allows researchers to submit novel study ideas that make use of existing NCS data and/or samples. Downloadable de-identified women, father, and child SAS and/or XML datasets are available for exploratory use.

The NCS Archive web portal includes the following features:

- Research Tools: Designed to promote and cultivate new ideas for study ideas that make use of existing NCS data and/or samples.
- Laboratory Data: Biological and environmental sample test data.
- Research Tools: Designed to promote and cultivate new ideas for exploratory use.
- WHAT’S THE THERE?
  - Reproductive and pregnancy history, medical conditions and history, health behavior, mental health, occupation, hobbies, environmental exposures, and social support.
- Neuro-psychosocial and Cognitive Assessments: Maternal mental health, infant sensory processing, child social and emotional development, and cognitive constructs such as language development, memory, and executive function, autism, and developmental delay, including:
  - K-BIT2
  - RSI
  - Major Life Events
  - Rothbart IQ
  - ASQ
  - M-CHAT
  - SWAN
- Physical Measures and Anthropometric Data: Weight, height, ulnar length, circumferences of the head, mid-upper arm, waist, and thigh, triceps and subscapular skinfold thickness, heart rate, blood pressure.
- Biospecimens: Include DNA, RNA, placentas, blood (from venipuncture, umbilical cord, and/or heel prick), meconium, vaginal swab, urine, saliva, hair, nails, breast milk.
- Environmental Samples: Include dust, air, and water. Study staff also performed observations of the internal and external structure of participant residences.

WHAT’S IT FOR?

The NCS Archive is a web portal application available to interested researchers, designed to facilitate and encourage continued research opportunities using NCS data. The web portal includes a request and tracking system, summaries of available data, data tracking, and management of access to the data.

The request and tracking system allows researchers to request and receive standard and custom datasets, using a web-based request, approval, and data delivery system. User accounts are established via requests for the desired role for each user.

The Research Request system allows researchers to submit novel study ideas that make use of existing NCS data and/or samples. downloadable de-identified women, father, and child SAS and/or XML datasets are available for exploratory use.

The NCS Archive web portal includes the following features:

- Research Tools: Designed to promote and cultivate new ideas for further exploration of existing NCS data.
- Data & Documentation: Users download de-identified datasets and dataset documentation, and documents related to the history, structure, and administration of the NCS. Additional datasets will be added over time.
- Research Request: Access data user training, submit data requests, manage requests.
- Sample Inventory: Listing of all stored sample materials.
- Laboratory Data: Biological and environmental sample test data.
- Help: Learn more about the NCS Archive, see responses to frequently asked questions, and submit requests for help.

HOW DOES IT WORK?

The NCS Archive has three components:

- NCS public webpages, a
- Registered Website, and a
- Secure Researcher Portal.

The public website provides basic Study Information. Users may register to obtain additional Study information, download available data files, and submit proposals to request access to more study data and stored materials.

WHAT DOES IT COST?

All requests are reviewed by a NICHD data access committee to determine that the proposed research use is scientifically and ethically appropriate and consistent with the informed consent. Criteria for sample request approval include sample availability and technical suitability with adequate funding, facilities, and expertise to perform the proposed research. Descriptions of approved proposals are viewable by all registered website users.

Once approved, the researcher is given access to a secure virtual workstation in the Researcher Portal. Archive support is provided to make available the requested data. NCS Archive staff can help bring in laboratory result data or extant data as needed. The researcher can work with NCS data in the secure environment using provided statistical software (SAS and R). When analysis is complete and prior to release of any information from the Researcher Portal, a data reviewer will help assure that any information to be transferred meets disclosure standards.

Step-by-Step

1. Go to the Registered Website at NCSarchive.s-3.net
2. Develop a Research Plan using the Archive tools:
   - Downloadable Operational Datasets
   - Protocol Browser (example below)
   - Variable Locator
   - Instrument and Dataset Inventory
   - Participant Explorer
   - Sample Explorer (example below)
3. Complete and submit a Data Request or Data and Sample Request form which includes:
   - Title of Research Plan
   - Requesting Investigator Information
   - Investigator’s Institution Information
   - Request Details—rationale, hypothesis, research aims
4. Complete the NCS Data User Training
5. Receive notification of approval or disapproval of the request at the email address specified in the request.

DATA EXPLORATION TOOL EXAMPLES

- NCS Protocol Browser
- NCS Sample Explorer
- NICHD website
- NCS Archive website
- NICHD General Email

Step-By-Step

TO CONTACT

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