The National Children’s Study Archive


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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.i-3.net. The NCS Vanguard was a pilot for a planned cohort study of environmentally 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 included families and followed them through 2011. At protocol-specified study visits, questionnaires and interviews, neuropsychosocial and cognitive assessments, and physical examinations were collected, along with nearly 19,000 biological and 5,500 environmental primary samples from which a sample repository of over 250,000 primary samples were generated. This information is now available through the NCS Archive for approved research projects by qualified investigators. The initial release consists of study data from 2009-2010. Additional data and sample availability will follow in subsequent releases later this year. The purpose of the Vanguard Study was to test procedures for use in the larger study, and due to its pilot nature, identical evaluations were not conducted on all participants.

Study Locations by Size and Recruitment

Study Recruitment

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 NCS Archive 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. Downloadable de-identified women, father, and child SAV and csv 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.
- Help: Learn more about the NCS Archive, see responses to frequently asked questions, and submit requests for help.

WHAT’S THERE?

- Questionnaire Data: Reproductive and pregnancy history, medical conditions and history, health behaviors, mental health, occupation, hobbies, environmental exposures, and social support.
- Neuro-psychosocial and Cognitive Assessments: Assess maternal mental health, infant sensory processing, child social and emotional development, and cognitive constructs such as language development, memory, and executive function, autism and executive development. Examples include:
  - E-BITZ
  - BSI
  - Major Life Events
  - Robinson IQB
  - ASQ
  - ACHAT
  - SWAN
- Physical Measures and Anthropometric Data: Weight, height, subscapular, circumferences of the head, mid-upper arm, waist, and thigh, triceps and subscapular skinfold thickness, heart rate, blood pressure.
- Biopsocles: Include placenta, 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.

HOW DOES IT WORK?

The NCS Archive has three components:

- NCS webpages on the NICHHD public website,
- A Researcher Portal,
- 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.

All requests are reviewed by a NICHD data access committee to determine if 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.

WHAT DOES IT COST?

There is no cost to researchers to use the NCS Archive and data. Handling and shipping costs may apply for biological or environmental sample requests.

STEP-BY-STEP

1. To Register and Request NCS Vanguard Data:
   - Go to NCS Archive (https://ncsarchive.i-3.net)
   - Create an account
   - Complete your profile
   - Accept the data use agreement
2. Develop a Research Plan using the Archive tools:
   - Downloadable Operational Datasets
   - Protocol Browser (below)
   - Variable Locator (below)
   - Instrument and Dataset Inventory
   - Participant Explorer
   - Sample Explorer
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. Privacy protection and data security (20 mins)
6. Receive notification of approval or disapproval of the request at the email address specified in the request

DATA EXPLORATION TOOL EXAMPLES

Table: Study Participants by Size and Recruitment

What’s It For?

What’s There?

How Does It Work?

What Does It Cost?

Step-by-Step