

IMPROVING ACCESS TO SECONDARY DATA

National Institute of Child Health and Human Development

Regina Bures, PhD - Program Lead, DASH

Jennifer Weck, PhD - Program Lead, NICHD Biorepository



JESSIE SINGH
University of Michigan
Computer Science and Business

SECONDARY DATA PLATFORMS

- Allow for reuse of research data
- Researchers often use these for
 - Conducting secondary research
 - Testing out research questions
 - Building credibility
 - Training students

The screenshot shows the homepage of the NICHD Data and Specimen Hub (DASH). At the top, there is a navigation bar with the DASH logo, "Data and Specimen Hub", and links for "Explore Studies", "Explore Data", "Explore Biospecimens", and "Explore Data Collections". A yellow "Feedback" button is located on the left side of the header. The main content area features a large image of a baby's back and head. The title "Welcome to the Data and Specimen Hub" is displayed prominently. Below the title, a text block explains that DASH is a centralized resource for researchers to share and access de-identified data from studies funded by NICHD. It also serves as a portal for requesting biospecimens. A search bar with the placeholder "Search for studies..." and a magnifying glass icon is located below the title. The page is divided into four main sections: "New to DASH?", "Explore Studies", "Share Your Data", and "Have Questions?". Each section contains an icon and a brief description.

DASH Data and Specimen Hub

Explore Studies

Explore Data

Explore Biospecimens

Explore Data Collections

Feedback

Welcome to the Data and Specimen Hub

The NICHD Data and Specimen Hub (DASH) is a centralized resource that allows researchers to share and access de-identified data from studies funded by NICHD. DASH also serves as a portal for requesting biospecimens from selected DASH studies.

Studies ▾

Search for studies...

New to DASH?

New users are encouraged to visit our Tutorial

Explore Studies

Find and request studies of interest

Share Your Data

Learn about how to share your data

Have Questions?

Browse through the Frequently Asked Questions

GOALS

Provide a roadmap for

- Improving the searchability of studies
- Improving the interoperability of future datasets

INITIAL IMPRESSION OF PROBLEMS

- Much of data is restricted access
- Datasets may not be documented for standardized for reuse
- It can be difficult for researchers to tell if the data to answer their research question is available

HOW DO OTHER PLATFORMS DO IT?

- Emphasis on variable-level searchability
 - Requires interoperability
 - Setting standards earlier on
- Different types of data have different attributes
 - Survey metadata can be easier to interop
 - Genetic sequence data is more accessible
 - Clinical data is more diverse

RESULTS FROM USER RESEARCH

9 usability testing sessions with clinical researchers

Key Takeaways:

- Users struggled to find studies on the DASH website
- Users didn't fully understand the meaning of different website options
- Controlled access data required multiple approvals and caused users delays



Filters

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Topic

Study Type

NICHD Research Networks and Initiatives

Source Repository

Subjects by Sex

Subjects by Life Stage

Subjects by Ethnicity

Subjects by Race

Subjects by Location

74 Total Results

Results per page: 50 ▾ Sort By: Study Name ▾ Ascendin

A Phase II, Multicenter, Randomized, Double-Blind, Placebo-Controlled, Parallel Group Study to Determine the Pharmacodynamics of Sodium Nitroprusside During Prolonged Infusion in Pediatric Subjects (BPCA SNP2)

NICHD Division/Branch/Center: DER - Obstetric and Pediatric Pharmacology and Therapeutics Branch (OPPTB)



NICHD Research Networks and Initiatives: Best Pharmaceuticals for Children Act (BPCA)

Study Description: A Phase II, randomized, double-blind, withdrawal to placebo study examining the efficacy, safety, and tolerability of sodium nitroprusside (SNP) in pediatric subjects. Objectives were to determine the persistence of the effect of SNP on blood pressure during stable infusion regimens lasting at least 12 hours and to assess the potential for rebound hypertension during a 30 minute blinded phase following administration of SNP for at least 12 hours when infusion is temporarily discontinued.

Source Repository: DASH

[View Details](#)[Login to add to Cart](#)**A Pilot Study Using Cell Phone Interactions to Improve Medication Adherence in Adolescents Who Have Previously Failed Antiretroviral Therapy Due to Non-Adherence (ATN 078)**

NICHD Division/Branch/Center: DER - Maternal and Pediatric Infectious Disease Branch (MPIDB)

NICHD Research Networks and Initiatives: Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN)

Study Description: A randomized, behavioral trial examining whether HIV-infected youth ages 15 to 24 receiving cell phone support with study funded phone plans demonstrated improved ART adherence and viral control during the 24 week intervention and 24 week post-intervention periods, compared to controls. Participants were randomized to either the intervention or control group. Intervention group participants received Monday through Friday cell phone support from an Adherence Facilitator, including reminders, assessment of barriers to adherence, problem solving and referrals to services. Control group participants completed all on-study evaluations, except intervention exit interviews.

Source Repository: DASH

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Source Repository: DASH

[View Details](#)[Login to add to Cart](#)**A Pilot Study to Identify Undiagnosed Asymptomatic HIV Infections in Adolescent and Young Adult Women (ATN 067)**

NICHD Division/Branch/Center: DER - Maternal and Pediatric Infectious Disease Branch (MPIDB)

NICHD Research Networks and Initiatives: Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN)

Study Description: A cross-sectional pilot study that enrolled sexually experienced Hispanic, Latino and African American adolescent and young adult women to serve as index recruiters, who in turn recruited members of their female friendship network to undergo HIV screening. Participants were stratified into three groups based on self-reported HIV infection status. The feasibility and acceptability of identifying and recruiting young women who self-disclose their HIV status to serve as index recruiters were examined. Factors facilitating and hindering recruitment of friendship network members to undergo HIV screening, friendship network members undergoing HIV screening, and HIV negative and HIV status unknown index recruiters undergoing HIV screening were also examined.

Source Repository: DASH

[View Details](#)[Login to add to Cart](#)**ATN 116 Structural Enhancements to the SMILE Program / ATN 128 PEACOC: A Multi-Agency (ATN-NIH-CDC-HRSA) Collaboration (ATN 116_128)**

NICHD Division/Branch/Center: DER - Maternal and Pediatric Infectious Disease Branch (MPIDB)

NICHD Research Networks and Initiatives: Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN)

Study Description: ATN 116 utilized existing Connect to Protect (C2P) coalition infrastructure to address structural barriers hindering the ability of HIV-infected youth to link to care and remain engaged in care, continuing efforts outlined in ATN 095 and ATN 105. Enhanced strategic planning activities assisted coalitions in identifying structural changes to address Linkage-to-Care (LTC), Engagement-in-Care (EIC), and/or Retention-in-Care (RIC) outcomes for newly diagnosed HIV+ youth. ATN 128 extended ATN 116, pairing four Ryan White Part D (RWD) sites with five Adolescent Medicine Trials Units. LTC Coordinators at the paired sites received intensive training in motivational interviewing focused on improving acceptance of LTC services and increasing adherence to HIV-related medical visits. RWD site personnel also joined C2P activities intended to address structural barriers to HIV care. As ATN 128 is a continuation of ATN 116, the files should be analyzed together.

Source Repository: DASH

[View Details](#)[Login to add to Cart](#)**Adolescent Master Protocol, PH200 (AMP)**

NICHD Division/Branch/Center: DER - Maternal and Pediatric Infectious Disease Branch (MPIDB)

NICHD Research Networks and Initiatives: Pediatric HIV/AIDS Cohort Study (PHACS)

Study Description: The PHACS AMP study is designed to define the impact of HIV infection and antiretroviral therapy on pre-adolescents and adolescents with perinatal HIV infection. Domains investigated include growth and sexual maturation; metabolic risk factors for cardiovascular disease; cardiac function; bone health; neurologic, neurodevelopment, language, hearing, and behavioral function; and adolescent gynecology and HPV infection. Biospecimens are available.

Source Repository: DASH

[View Details](#)[Login to add to Cart](#)**Adolescent Safer Sex Social Network Intervention (ATN 032)**

NICHD Division/Branch/Center: DER - Maternal and Pediatric Infectious Disease Branch (MPIDB)

NICHD Research Networks and Initiatives: Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN)

Study Description: A Phase II non-randomized, experimental design evaluation the feasibility, acceptability, and preliminary effectiveness of a small-group peer-network behavioral intervention among adolescent males and females and their friend/kin networks. Index friends/recruited members of their social network

Studies ▾

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Consortium on Safe Labor (CSL)

NICHD Division/Branch/Center: DIPHR - Division of Intramural Population Health Research

NICHD Research Networks and Initiatives: Other Initiatives

Study Description: Collected detailed information from electronic medical records for 228,438 deliveries in 19 U.S. hospitals. Primary objectives were to explore the underlying causes of the high cesarean rate in the U.S. population, describe contemporary **labor** progression at the national level, and determine when is the more appropriate time to perform a cesarean delivery in women with **labor** protraction and arrest. NOTE: Data requesters should refer to the "CSL Read Me" PDF describing data caveats.

Source Repository: DASH

[View Details](#)[Login to add to Cart](#)**Screening for Risk Factors for Spontaneous Preterm Delivery (MFMU PREDS)**

NICHD Division/Branch/Center: DER - Pregnancy and Perinatology Branch (PPB)

NICHD Research Networks and Initiatives: Maternal-Fetal Medicine Units (MFMU) Network

Study Description: A prospective, observational study of women with singleton pregnancies to identify and evaluate tests which could define a group of patients with at least a twofold increase in risk of spontaneous preterm delivery. Primary outcome was delivery from 23 to 34 weeks gestation following spontaneous preterm **labor** or premature rupture of membranes.

Source Repository: DASH

[View Details](#)[Login to add to Cart](#)**Genomic and Proteomic Network for Preterm Birth Research GWAS Case Control Study (GPN-PBR CC)**

NICHD Division/Branch/Center: DER - Pregnancy and Perinatology Branch (PPB)

RECOMMENDATIONS

Immediate

- Pushing changes to search results ordering
- Simplifying entry-level interface

Medium Term

- Integrating user research into planning decisions
- Integrating interoperability standards
- Investigating new customer areas

THANK YOU

Special thank you to everyone who made my summer experience amazing, including:

- My supervisors **Regina Bures** and **Jen Weck** for endless support and help
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- My mentor **Aaron Snow** for lending his experience & perspective
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