NIH | Eunice Kennedy Shriver National Institute of Child Health and Human Development

DASH | Data and Specimen Hub

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DASH Quarterly eUpdate

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Implementing the NIH Policy for Data Management & Sharing

DASH and the Data Management and Sharing Policy

DASH is a key resource for many NICHD extramural and intramural researchers to comply with the new NIH Data Management and Sharing (DMS) Policy (DMS Policy), which went into effect on January 25, 2023. The final DMS Policy strongly encourages the use of established repositories such as DASH for sharing scientific data. DASH adheres to the desired characteristics for data sharing repositories described in Supplemental Information to the NIH Policy for Data Management and Sharing: Selecting a Repository for Data Resulting from NIH-Supported Research, including support for free and easy access, access controls for human participant data, curation and quality assurance, and security and integrity. DASH creates Digital Object Identifiers (DOIs) as unique persistent identifiers for tracking and citing all datasets shared through DASH.

Plan to Submit Your Data to DASH

All researchers funded by or seeking funding from NICHD for clinical research can share clinical data in DASH. Researchers seeking funding from another NIH Institute or Center in a research area relevant to the NICHD mission may also be able to share data through DASH. You may Contact SupportDASH@mail.nih.gov with a request to obtain a Letter of Approval for sharing your study data in DASH.

The new DASH Submission Resources page contains information to guide researchers developing Data Management and Sharing Plans as part of their grant applications or intramural clinical protocols. Researchers

planning to use DASH should include DASH submission-specific milestones and timelines in their DMS Plan and should consider those milestones when developing a DMS budget. Costs associated with biospecimen sharing should not be included in DMS budgets. DMS Plan milestones include:

- Researchers who plan to share data through DASH are required to submit an Institutional Certification to verify that study data are appropriate for sharing in DASH, **within the first year of grant award.**
- **By the second year of grant award**, investigators should submit a draft DASH Codebook, which is a templated data dictionary that captures information about datasets, variables, and coded values for all data submitted for a given study.
- As soon as the **data collection protocol is complete**, researchers should submit the final DASH Codebook to DASH.
- Investigators will share **data associated with a publication** through DASH no later than the first date of electronic publication and will share all study data by the end of the award performance period. Plan to submit data to DASH 4-6 months prior to expected publication release date for a given dataset.

NICHD Data Sharing - Presentations

On January 25th, 2023, Rebecca Rosen, Ph.D. presented on NICHD Data Sharing to the National Advisory Child Health and Human Development Council (NACHHD) during their One-Hundred and Eighty-First Meeting. Dr. Rosen discussed the NICHD Office of Data Science and Sharing, the NIH Policy for Data Management and Sharing, and Data Sharing Resources for NICHD Staff and Investigators.

Dr. Rosen's NICHD Data Sharing Presentation and additional meeting information can be found on the Current Council Meeting Webpage. The session recording is available on the NIH Videocast Website.

NICHD Office of Data Science and Sharing (ODSS) Web Resources

The NICHD Office of Data Science and Sharing (ODSS) is a trusted informational resource for NICHD staff and researchers on all NIH data sharing policies. The NICHD ODSS website contains a Data Management and Sharing Policy Resources section for the NICHD researcher community, including Tips for Writing a DMS Plan, Example DMS Plans, and links to data standards, data repository, and informed consent informational resources.

New NICHD Data Repository Finder Tool (Public)

NICHD ODSS has released the NICHD Data Repository Finder tool for researchers to find data repositories where they can share data as they develop and implement their NIH DMS Plans. The tool makes searchable key repository features to help researchers complete the Elements of their DMS Plans (e.g., metadata, controlled access support, submission requirements). It is currently in beta version and NICHD-relevant repositories will be added an ongoing basis.

NIH Resources and Guidance for the DMS Policy

NIH has launched a Scientific Data Sharing site resource. At this site, you and your investigators can stay up to date on public-facing NIH data sharing policy-related statements, resources (including the DMS Plan format page), news, and events, and look for training opportunities.

Public site contents include:

- **Example DMS Plans**
  - o NIH OER is collating example DMS Plans developed by NIH staff at multiple ICOs. Currently example DMS Plans are posted from NICHD, NIMH, and NHGRI.
- **Flyers and 1-pagers**
  - o Are you ready for NIH's DMS Policy? – *A printable 1-page PDF DMS Policy overview*
  - o The who, what, where, and when of the DMS Policy – *1-pager outlining when the policy goes into effect, what the policy expects, who needs to comply, and where data can be shared*

- NIH Data Sharing Policy Comparison – *Table outlining key differences between the 2003 Data Sharing Policy and the new Data Management and Sharing Policy*
- DMS Policy Postcard – *Printable postcard sized flyer for NIH staff to take to meetings/conferences. QR code links to NIH Scientific Data Sharing website*

Webinars and Trainings on Implementing the NIH Data Management and Sharing Policy

NIH is hosting several webinars to provide information and training on implementing the DMS Policy.

- **Understanding the New NIH DMS Policy – Webinar Series**

  The NIH Office of Science Policy (OSP) and the Office of Extramural Research (OER) hosted a two-part webinar series focused on the new NIH DMS Policy which went into effect on January 25, 2023. The first webinar in this series titled: "*Understanding the New NIH Data Management and Sharing Policy*" covered DMS Policy expectations, the applicability of the policy, how to prepare a Data Management and Sharing Plan, and considerations for sharing data responsibly. The second webinar titled: "*Diving Deeper into the NIH Data Management and Sharing Policy*" expanded upon the information presented in the first webinar and dove deeper into topics including privacy protections for data from human participants and justifiable limitations on sharing data.

  The Resource Slide Deck and Webinar Recording from both parts of the DMS Policy Webinar series are available on the NIH Scientific Data Sharing website.

- **Data Curation Network – Event Series**

  The NIH Office of Data Science Strategy (ODSS), in partnership with NLM, organized an event series led by the Data Curation Network (DCN). To prepare for the implementation of the NIH DMS Policy, researchers will need to gain new skills in managing and sharing their data. This event series provided new approaches, methods, and best practices from representatives of the Data Curation Network on management, curation, and sharing to promote transparency, reproducibility, and reuse of research data. Videos of the first session, "Introduction to Data Curation & Services for Researchers" and the second session, "Towards Authenticity: Critical Appraisal of Data Management Plans", are available on the Data Curation Series Webpage.

- **GREI Collaborative Webinar Series on Data Sharing in Generalist Repositories**

  Access resources from a series of presentations and panel discussions by generalist repositories to learn about available repository resources and best practices for sharing NIH-funded research. Presented by the members of the NIH Generalist Repository Ecosystem Initiative (GREI): Dryad, Dataverse, Figshare, Mendeley Data, Open Science Framework, and Vivli. Webinar Site.

- **Data Sharing Presentations from 2023 NIH Grants Conference Available**

  The 2022-2023 conference season is over, but the opportunity to learn from it isn't. Explore the recordings, slide sets, and transcripts. If you have questions, check out the FAQs and other resources on the NIH Grants & Funding site.

  Genomic Data Sharing, Other Sharing Policies, and Open Q&A: Video, PowerPoint, Transcript

  The NIH Final Policy for Data Management and Sharing is in Effect: Planning for Success!: Video, PowerPoint, Transcript

NIH Data Sharing and Reuse Seminar Series

The NIH Office of Data Science Strategy hosted a seminar series to highlight exemplars of data sharing and reuse. The monthly series highlighted researchers who took existing data and found clever ways to reuse the data or generate new findings. A different NIH institute or center (IC) also share its data science activities each month. Recordings of past seminars are available on the Seminar Web page.

The next seminar will be held on April 24, 2023 at 12:00 PM EST by Dr. Valerie Schneider who will present "The NIH Comparative Genomics Resource (CGR): A new ecosystem facilitating reliable comparative genomics". Webinar Registration.

DASH Updates

New Studies Available in DASH

There are 207 studies archived in DASH covering 54 research topics including Pregnancy, Infant Care and Health, Infant Mortality, Pharmacology, Pediatric Injury, Child Health, and Traumatic Brain Injury.

- [Prospective Cohort Study of HIV and Zika in Infants and Pregnancy (HIV ZIP)](#)

  Study Description: The aims of this two-phase study of pregnant women and their infants were to compare the incidence of ZIKV infection among pregnant women with and without HIV infection and to determine the risk of adverse maternal and child outcomes associated with ZIKV/HIV co-infection at clinical sites in Brazil, Puerto Rico, and the continental United States. Phase I was designed to enroll pregnant women/infant pairs who were infected with HIV only, infected with ZIKV only, infected with HIV and ZIKV, and not infected with either HIV or ZIKV. A key goal was to assess the feasibility of enrolling 200 women/infant pairs within a year, with a target of 150 WLHIV, 50 HIV-uninfected women, and a minimum of 20 who were co-infected with HIV/ ZIKV. If the feasibility of Phase I proved successful, Phase II would enroll additional pregnant women/infant pairs to the same four groups, and follow the women and the infants for one year after birth. Primary outcome measures noted HIV suppression at the time of delivery in HIV-infected alone versus HIV/ZIKV co-infected pregnant women, cumulative incidence of ZIKV infection during pregnancy among women with and without HIV infection, incidence of adverse pregnancy outcomes in each cohort and incidence of vertical transmission of HIV and/or ZIKV in women infected with HIV or ZIKV alone versus HIV/ZIKV Co-infection. Observed major congenital malformations were as follows: anhydramnios, cerebral ventriculomegaly, clubfoot, down syndrome, hydrops, hypospadias, patient ductus arteriosus, polydactyly, Potter syndrome, short stature, and syndactyly.

  Release Date: November 29, 2022

Studies Offering Biospecimens in DASH

Over 350,000 biospecimens and 51 sample types from nine studies are available for request through DASH. These collections span research topics including HIV/AIDS, Infant and Child Health, Women's Health, Pregnancy, Preterm Labor and Birth, and Breastfeeding. Additional biospecimen collections will also be added in the future. To explore available samples in DASH, select the **Study Name** in the following list of studies offering biospecimens:

- [National Children's Study (NCS) biospecimens and environmental samples:](#)
- [Genomic and Proteomic Network for Preterm Birth Research Expression Profiling Study (GPN-PBR EP) biospecimens](#)
- [Genomic and Proteomic Network for Preterm Birth Research GWAS Case Control Study (GPN-PBR CC) biospecimens](#)
- [Genomic and Proteomic Network for Preterm Birth Research Longitudinal Cohort Study (GPN-PBR LS) biospecimens](#)
- [Prospective Study of Perinatal Transmission of HIV Infection and Developmental Outcome of Children Infected with HIV: Mothers and Infants Cohort Study (MICS) biospecimens](#)
- [A Prospective, Observational Study of HIV-Infected Pregnant Women and HIV-Exposed, Uninfected Children at Clinical Sites in Latin American Countries (NISDI LILAC) biospecimens](#)
- [A Prospective, Observational Study of HIV-Infected Pregnant Women and Their Infants at Clinical Sites in Latin American and Caribbean Countries (NISDI Perinatal) biospecimens](#)
- [A Prospective, Observational Study of HIV-Exposed and HIV-Infected Children at Clinical Sites in Latin American and Caribbean Countries (NISDI Pediatric) biospecimens](#)
- [NISDI Pediatric Latin American Countries Epidemiological Study: A Prospective, Observational Study of HIV-infected Children at Clinical Sites in Latin American Countries (NISDI PLACES) biospecimens](#)

Additional Specimens Available: The Reproductive Medicine Network (RMN) has serum, semen and/or DNA biospecimens available for request. If you are interested in obtaining biospecimens from these studies, please refer to the RMN Biospecimen Sharing Policy under the list of Descriptive Documents on the study pages:

- [Pregnancy in Polycystic Ovary Syndrome II: A 25 Week Double-Blind Randomized Trial of Clomiphene Citrate and Letrozole for the Treatment of Infertility in Women with Polycystic Ovary Syndrome (PPCOS II)](#) - serum
- [Assessment of Multiple Intrauterine Gestations from Ovarian Stimulation (AMIGOS)](#) - serum, semen, and DNA
- [Males, Antioxidants, and Infertility Trial (MOXI)](#) - serum, semen, and DNA

Publications Resulting from Data Reuse

Since the launch of DASH in August 2015, there have been 89 peer-reviewed publications resulting from DASH data reuse, with an average time of 1.6 years to publish. We encourage you to look through these publications on the [Publications from DASH Data Reuse](#) page.

Recent Publications:

- [Associations between evening shift work, irregular sleep timing, and gestational diabetes in the Nulliparous Pregnancy Outcomes Study: Monitoring Mothers-to-be (nuMoM2b)](#)
  Authors: Danielle Wallace, Kathryn Reid, William Grobman, Francesca Facco, Robert Silver, Grace Pien, Judette Louis, Phyllis Zee, Susan Redline, Tamar Sofer
  DASH Study: [Nulliparous Pregnancy Outcomes Study: Monitoring Mothers-to-be (nuMoM2b)](#) (from PPB)
- [Improving the external validity of Antenatal Late Preterm Steroids trial findings](#)
  Authors: Jennifer A. Hutcheon, Jessica Liauw
  DASH Study: [Antenatal Late Preterm Steroids: A Randomized Placebo Controlled Trial (MFMU ALPS)](#) (from PPB)

DASH Data/Biospecimen Use Acknowledgments

As a reminder, NICHD requires all investigators who access research data and biospecimens from NICHD DASH to acknowledge the contributing investigator(s) who conducted the original study, the funding organization(s) that supported the original study, and NICHD DASH in all resulting oral or written presentations, disclosures, or publications of the analyses. Specific guidance for acknowledgement text is provided during the data and/or biospecimen request process.

NICHD Funding Opportunities and Notices

All active Funding Opportunity Announcements issued by NICHD can be found on the [NICHD Grants and Contracts](#) page. To learn more about a funding opportunity, select the **Name of the Funding Opportunity** in the following list:

- NOT-HD-20-022 [Small Grants for Secondary Analyses of Existing Data Sets and Stored Biospecimens](#) (R03 Clinical Trial Not Allowed)
- PAR-22-261 [Archiving and Documenting Child Health and Human Development Data Sets (R03 Clinical Trial Not Allowed)](#)
- PAR-20-126 [NICHD Resource Program Grants in Bioinformatics (P41 Clinical Trial Not Allowed)](#)
- PAR-21-229 [Screening and Functional Validation of Human Birth Defects Genomic Variants (R01 Clinical Trial Not Allowed)](#)
- RFA-HD-24-006 [Using Archived Data and Specimen Collections to Advance Maternal and Pediatric HIV/AIDS Research (R21 - Clinical Trial Not Allowed)](#)

- PAR-23-037 [Multisite Clinical Research: Leveraging Network Infrastructure to Advance Research for Women, Children, Pregnant and Lactating Individuals, and Persons with Disabilities (U01 Clinical Trial Optional)](#)

NICHD – Relevant Funding Opportunities and Notices

Additional active Funding Opportunity Announcements relevant to NICHD are included below. To learn more about a funding opportunity, select the **Name of the Funding Opportunity** in the following list:

- RFA-DA-24-008 [Leveraging Big Data Science to Elucidate the Mechanisms of HIV Activity and Interaction with Substance Use Disorder (R01 Clinical Trials Not Allowed)](#)

- NOT-RM-23-005 [Notice of Special Interest (NOSI): Research supplements to promote workforce diversity and enhance utility and use of Common Fund datasets](#)

- NOT-LM-23-002 [Notice to Extend the Expiration Date for PAR-20-304 "Computational Approaches to Curation at Scale for Biomedical Research Assets (R01 Clinical Trial Not Allowed)"](#)

- RFA-DA-24-027 [Education Activities for Responsible Analyses of Complex, Large-Scale Data (R25-Clinical Trial Not Allowed)](#)

- PAR-23-089 [Data Harmonization, Curation and Secondary Analysis of Existing Clinical Datasets (R61/R33 Clinical Trial Not Allowed)](#)

- NOT-OD-23-068 [Notice of Special Interest (NOSI): Revision Applications to add a Curation and Informatics Component to existing Animal and Biological Material Resource Centers (P40) (Clinical Trials Not Allowed)](#)

- NOT-NS-23-042 [Notice of Special Interest (NOSI) for Administrative Supplements: Harmonization and Joint Analysis of Human Brain Single-Cell Datasets](#)

- NOT-LM-23-001 [Notice of Special Interest (NOSI): Computational and Statistical Methods to Enhance Discovery from Health Data](#)

- RFA-ES-23-002 [Accelerating Data and Metadata Standards in the Environmental Health Sciences (R24 Clinical Trial Not Allowed)](#)

- PAR-22-261 [Archiving and Documenting Child Health and Human Development Data Sets (R03 Clinical Trial Not Allowed)](#)

- NOT-CA-23-026 [Notice to Correct and Clarify Eligibility Requirements in PAR-21-306, NCI Research Specialist (Clinical Scientist) Award (R50 Clinical Trial Not Allowed)](#)

- NOT-GM-23-015 [Notice of Special Interest (NOSI): Optimization of Data Storage and Utilization for the Sequence Read Archive (SRA)](#)

- NOT-PM-23-002 [Notice of Future Research Opportunity Announcement for the All of Us Center for Linkage and Acquisition of Data](#)

- NOT-OD-23-009 [International Collaborations: Policies, Processes, & Partnerships NIH Virtual Event on November 9, 2022](#)

Previous issues of the DASH Quarterly eUpdate are available on the [NICHD ODSS Website](#) in the NICHD Data and Specimen Hub (DASH) section.

Questions? Please contact the DASH Administrator at [SupportDASH@mail.nih.gov.](#)

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