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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 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 (DMS) Policy Resources section for the NICHD researchers developing and implementing their DMS Plans, including [Tips for Writing a DMS Plan](#), Example DMS Plans, the [NICHD Data Repository Finder](#) to help researchers find data repositories where they can share data, and links to data standards, data repository, and informed consent informational resources.

NIH Resources and Guidance for the DMS Policy

NIH continues to update their [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, FAQs, resources (including the DMS Plan format page), news, and events, and look for training opportunities.

Additionally, researchers can use the following NIH-wide resources to identify data repositories for sharing their data:

- **NIH Repositories for Sharing Scientific Data**: https://sharing.nih.gov/data-management-and-sharing-policy/sharing-scientific-data/repositories-for-sharing-scientific-data
- **Genomic Data Repositories**: https://sharing.nih.gov/genomic-data-sharing-policy/submitting-genomic-data/where-to-submit-genomic-data
- **National Library of Medicine repository resources**:
  - https://www.nnlm.gov/finder
  - https://www.nlm.nih.gov/NIHbmic/domain_specific_repositories.html

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.

- **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: NICHD Research Highlight

The NIH Office of Data Science Strategy hosted a seminar series to highlight exemplars of data sharing and reuse. This month featured Nara Sobriera, M.D., Ph.D., a Gabriella Miller Kids First investigator at Johns Hopkins University and Johns Hopkins Medicine presented on PhenoDB, a phenotypic and genotypic data-sharing tool. In her introduction of Dr. Sobriera, Valerie Cotton, B.Sc., deputy director of the NICHD Office of Data Science and Sharing (ODSS), highlighted the importance of data sharing in federally funded research and described how ODSS is leveraging lessons learned from Kids First and other efforts to build the NICHD data ecosystem and advance data science. Dr. Sobriera also presented a poster about her work with Kids First during a special session of the NICHD advisory council's June meeting prior to the seminar. Recordings of past seminars are available on the Seminar Web page.

The next seminar will be held on July 14, 2023 at 12:00 PM EST by Dr. Elizabeth DuPre who will present "Open Science Enables New Neuroscience: A call for community-driven methods development". Webinar Registration.

DASH Updates

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.

Recently Updated Study

- Turner Syndrome: Genotype and Phenotype (TS)

  Study Description: Turner syndrome (TS) is a sporadic disorder affecting ~ 1/2500 live female births, caused by the absence of all or significant parts of one sex-chromosome. Developmental consequences include severe short stature, ovarian failure and distinctive cognitive and behavioral traits, sometimes with renal and cardiovascular defects. Adults with TS have excessive rates of osteoporosis, hypertension and diabetes mellitus, and high rates of morbidity and mortality. This study aims to correlate TS phenotypes and genotypes, to identify X-chromosome genes and epigenetic mechanisms causing the different features of TS. For TS subjects with a 45X genotype, the parental origin of the single normal X-chromosome will be traced. X chromosomal structural defects will be analyzed in relation to data from the Human Genome Project. The elucidation of genetic mechanisms in TS will help improve the diagnosis and treatment of girls and women with this disorder and further our understanding of gene dosage effects in general.

  Updates: Additional datasets are now available for the Turner Syndrome study. Users can now request access for "Bone Density" and "Pelvic Ultrasound" datasets associated with this study.

  Release Date: April 7, 2019

  Update Date: May 12, 2023

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 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 93 peer-reviewed publications resulting from DASH data reuse, with an average time of 1.5 years to publish. We encourage you to look through these publications on the [Publications from DASH Data Reuse](#) page.

Recent Publications:

- [Diagnosis of fetal growth restriction in a cohort of small-for-gestational-age neonates at term: neonatal and maternal outcomes](#)
  Authors: Beth L Pineles, Hector Mendez-Figueroa, Suneet P Chauhan
  Publication Date: September 1, 2022
  DASH Study: [Consortium on Safe Labor (CSL)](#)
- [Relationships Among Sleep, Physical Activity, and Weight Status in Children and Adolescents](#)
  Authors: Agnes Bucko
  Publication Date: July 1, 2022
  DASH Study: [Next Generation Health Study (NEXT)](#)
- [Geographic and demographic variability in serum PFAS concentrations for pregnant women in the United States](#)
  Authors: Nicole M. DeLuca, Kent Thomas, Ashley Mullikin, Rachel Slover, Lindsay W. Stanek, Andrew N. Pilant, Elaine A. Cohen Hubal
  Publication Date: January 25, 2023
  DASH Study: [National Children's Study (NCS)](#)

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:

- PAR-22-261 Archiving and Documenting Child Health and Human Development Data Sets (R03 Clinical Trial Not Allowed)
- PAR-21-229 Screening and Functional Validation of Human Birth Defects Genomic Variants (R01 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)
- PAR-23-075 Small Research Grants for Analyses of Gabriella Miller Kids First Pediatric Research Data (R03 Clinical Trial Not Allowed)

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:

- PAR-23-132 NIDCR Small Research Grants for Analyses of Existing Genomics Data (R03 Clinical Trial Not Allowed)
- PAR-23-133 NIDCR Research Grants for Analyses of Existing Genomics Data (R01 Clinical Trial Not Allowed)
- 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
- 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-LM-23-001 Notice of Special Interest (NOSI): Computational and Statistical Methods to Enhance Discovery from Health Data
- 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)
- RFA-AG-24-009 Alzheimer's Disease (AD) and AD-Related Dementias (ADRD) Real-World Data Platform (U54 Clinical Trial Optional)

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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