

Eunice Kennedy Shriver National Institute of Child Health and Human Development



## **DASH Quarterly Update**

December 2021

## NICHD's Decoding Maternal Morbidity Data Challenge – Winners Announced

The winners of NICHD's Decoding Maternal Morbidity Data Challenge were announced on December 7<sup>th</sup> in conjunction with the White House "day of action" on maternal health. Twelve prizes were awarded to seven winners who proposed innovative solutions to identify risk factors in first-time pregnancies.

The Decoding Maternal Morbidity Data Challenge prizes totaled \$400,000. Seven prizes of \$50,000 were awarded for innovation and five additional prizes of \$10,000 were awarded for addressing health disparities.

All the proposals analyzed participant data from NICHD's Nulliparous Pregnancy Outcomes Study: Monitoring Mothers-to-Be (nuMoM2b), a racially, ethnically and geographically diverse sample of people who were pregnant for the first time. nuMoM2b study has data on more than 10,000 pregnant women beginning in the sixth week of pregnancy and continuing through delivery. Learn more about the nuMoM2b study, available in the NICHD DASH.

"The winning teams developed methods to analyze the data, accurately flagging cases that were high-risk for complications." said NICHD's Maurice Davis, D.H.A., who managed the challenge, "These computational methods can now be used to analyze additional data from other pregnancies. These solutions have the potential to make a real difference and save lives." Read more in the NICHD 2021 Data Challenge Winners Announcement.

The team leads for each of the winning proposals are as follows (asterisks denote winners of both prize categories):

- Social Determinants of Health Phenotype Predicts Unplanned Cesarean Birth in the Path to • Maternal Morbidity Among Healthy Participants of the NuMoM2b Study Nicole Carlson, Ph.D.\*, Emory University, Atlanta
- Random Forests for Accurate Prediction of the Risk of Hypertensive Disorders of Pregnancy at • Term

Ali Ebrahim, Ph.D.\*, Delfina, San Francisco

- Structural Equation Model Identifies Causal Pathways Between Social Determinants of Maternal • Health, Biomarkers of Allostatic Load, and Hypertensive Disorders of Pregnancy Among U.S. Racial Groups Britnee Johnston\*, Johnston and Company, LLC, Salt Lake City
- The Relationship Between Marginalizing Behaviors and Postpartum Complications for Nulliparous Women Receiving an Undesired C-section Monica Keith, Ph.D.\*, University of Washington, Seattle
- A Fair Diagnosis Proposal of Maternal Morbidity with a Demonstrative Example in Predicting Stillbirths

Yaping Li, Feng Ya, LLC, Watkinsville, Georgia

- Tracking Changes in Health Metrics Between Visits to Model Adverse Pregnancy Outcomes
  Among Nulliparous Women
  Ainesh Pandey\*, IBM Data Science and AI Elite, San Francisco
- Columbia University and Hunter College, New York City
  On Predicting and Understanding Preeclampsia: A Machine Learning Approach
  Ansaf Salleb-Aouissi, Ph.D., Columbia University, New York City

#### **New Features in DASH Request Workspace**

In addition to accessing study data directly from the DASH Workspace, data requesters can add or remove members of their research team and download copies of the Data Use Agreement (DUA). Three new features have been added to the DASH Workspace to make it easier for requesters to renew their DUA, submit the Annual Data Use Report, and modify the Authorized Organizational Representative (AOR) or Signing Official for requests.

**Renew your DUA:** The DASH DUA is effective for a three-year term. For continued access to the data after this period, the Data Requester must renew their DUA prior to the expiration date. DASH system now automatically emails all requesters three months prior to their DUA expiration date. Requesters are directed to their DASH Workspace to complete an online Renewal Request Form and submit their renewal request. The DASH Data Access Committee then reviews the Renewal Request, and the Requester is notified by email of their approval decision.

**Submit your Annual Reports:** A Requester is required to submit a Data Use Report annually for each year that the DUA is effective. Now requesters can complete this report online, through the DASH Workspace. DASH will display the Annual Report option and email a notice to the Requester, one month prior to the due date of the report. The Annual Report asks for information about outcomes resulting from research using study data obtained through DASH. Outcomes may include publications, conference presentations, patents, and significant findings. With the new Annual Report feature in the DASH Workspace, requesters can quickly complete and submit their report in just a few minutes.

**Modify your AOR:** When the AOR or Signing Official changes at an institution for an existing DUA, data requesters can now notify DASH of this change through their DASH Workspace. This feature permits the updates to the AOR to be recorded in DASH so that future communications regarding DUA terminations and annual reports are directed to the correct point of contact.

#### **New Studies Available in DASH**

We are pleased to share the latest study additions in DASH, for a total of 189 studies in DASH. These studies cover 49 research topics, including Infant Care and Health, Infant Mortality, Pharmacology, Pediatric Injury, Child Health, and Traumatic Brain Injury. We encourage you to look through these new studies and see if the data might be of interest to you for your research. To learn more about a recently submitted study, select the title of a **Study Name** in the following list:

1. <u>Optimal Treatment for Women With a Persisting Pregnancy of Unknown Location (ACTorNOT)</u> from FIB

**Study Description:** This was a randomized controlled trial to compare three currently available management strategies for women with a persisting pregnancy of unknown location (PPUL), which made them at-risk for ectopic pregnancy. The study recruited hemodynamically stable women with a confirmed PPUL to be randomized to one of three strategies: 1) Uterine evacuation followed by methotrexate (MTX) for some (those that had evidence of a non-visualized ectopic pregnancy), 2) Empiric treatment with MTX for all, or 3) Expectant management. Randomization was 1:1:1 into these three arms. After randomization, they were followed and treated clinically, as was indicated by the progression of their condition. Primary outcome measures were the uneventful decline of hCG to 5 IU/mL.

#### 2. Inhaled Nitric Oxide Use in Pediatric Intensive Care (Nitric Oxide) from PTCIB

- **Study Description:** Acute lung injury (ALI) occurs in approximately 9 percent of mechanically ventilated children with 80 percent progressing to acute respiratory distress syndrome (ARDS). Inhaled nitric oxide (iNO) is an important therapy for neonates with persistent pulmonary hypertension, older children with pulmonary hypertension, and patients with congenital heart disease. It is hypothesized that iNO should benefit patients with ALI/ARDS by improving oxygenation. With this prospective observational trial, we found that clinician responsiveness to improved oxygenation was associated with less ventilator days. Algorithms to standardize ventilator management may improve signal to noise ratios in future trials enabling better assessment of the effect of inhaled nitric oxide on patient outcomes. Additionally, confining studies to more selective patient populations, such as those with right ventricular dysfunction, may be required.
- 3. CombinADO, a Combination Intervention Strategy to Improve Health Outcomes for Adolescents Living with HIV, Protocol #2: Understanding the Characteristics and Experiences of Adolescents Living with HIV in Nampula, Mozambique, a Mixed-methods Study (CombinADO Study #2) from MPIDB Study Description: The purpose of this study was to gather data to describe the demographic, biomedical, psychosocial, and behavioral characteristics of adolescents and young adults living with HIV (AYAHIV) in Nampula, Mozambique, to inform content of the multicomponent CombinADO intervention strategy, and to pilot measures for their social contextual relevance and comprehension by participants. A convenience sample of AYAHIV and a subset of their caregivers were recruited from three government health facilities in 2019 in Nampula, Mozambique. AYAHIV 15-19 years on antiretroviral therapy (ART), including females attending antenatal care, were eligible. A total of 212 AYAHIV (15-19 years) were enrolled. All participants completed a one-time quantitative survey that included questions related to sociodemographic characteristics, educational status, health history, sexual and reproductive health, and ART adherence. Routine HIV care data were extracted from medical charts.

#### 4. Pediatric ECMO and Cefepime (PEACE) from PTCIB

**Study Description:** In critically ill patients not receiving extracorporeal membrane oxygenation (ECMO), pharmacokinetic (PK) studies have demonstrated significant changes to drug exposure through interactions between the patient, pathology, and the drug. The ECMO system introduces additional variables, which are inherent to the circuit itself, as well as the systemic inflammation that results from use of an extracorporeal circuit. The amount of variability in drug disposition and pharmacokinetics with use of ECMO is largely unknown. The objective of this study was to gain preliminary data on the impact of ECMO on the pharmacokinetics of cefepime administered as standard of care to infants. A PK model was developed to evaluate cefepime disposition differences due to ECMO. This study found that cefepime clearance was reduced in pediatric patients treated with extracorporeal membrane oxygenation compared with previously reported values in children not receiving extracorporeal membrane oxygenation.

#### 5. Life After Pediatric Sepsis Evaluation (LAPSE) from PTCIB

**Study Description:** The purpose of this prospective observational study was to describe short and long-term outcomes among children surviving septic shock. LAPSE investigated the intensity and duration of sepsis-associated morbidity that persists following the acute septic event. LAPSE described the post sepsis illness trajectory through Health Related Quality of Life (HRQL) and subject functional status (FS). LAPSE examined organ dysfunction, as well as individual and environmental characteristics that influenced these outcomes. We hypothesized that variation of HRQL and FS would be seen following survival of severe sepsis, enabling development of composite outcome measures for future trials of pediatric sepsis. This study found that 11 percent of the children died within 3 months of their septic shock episode. Additionally, duration of stay, cumulative vasoactive-inotropic scores, duration of mechanical ventilation, and other factors were associated with adverse outcomes.

#### **Annotation and Representation of Study Variables**

The annotation and representation of study variables in DASH will help users to explore dataset content by reviewing variable-level metadata (such as variable descriptions, units, and coded values) and associated statistics directly from the <u>Dataset Explorer</u>. On the Datasets Search Results page, select any dataset title to access the Dataset Overview page with variable-level information (if any). This feature is currently available for

datasets from eight studies in DASH. To view a listing of all datasets for a particular study, select the **Study Name** from the following list:

- Antenatal Late Preterm Steroids: A Randomized Placebo Controlled Trial (MFMU ALPS)
- <u>Mid-Trimester Endovaginal Sonography in Women at High Risk for Spontaneous Preterm</u> <u>Delivery (MFMU CRVUS)</u>
- Obstetrical Determinants of Neonatal Survival (MFMU ODNS)
- Screening for Risk Factors for Spontaneous Preterm Delivery (MFMU PREDS)
- Clinical Trial of Low-Dose Aspirin (60 mg) as a Preventive of Preeclampsia (MFMU LRA)
- <u>Clinical Trial of Low-Dose Aspirin to Prevent Preeclampsia in High-Risk Women (MFMU HRA)</u>
- <u>National Children's Study (NCS)</u>
- <u>Nulliparous Pregnancy Outcomes Study: Monitoring Mothers-to-be (nuMoM2b)</u>

## **Studies Offering Biospecimens in DASH**

Biospecimens are available for request through DASH from studies that span topics including HIV/AIDS, Child Health, Women's Health, Pregnancy, Preterm Labor and Birth, and Breastfeeding. Over 350,000 samples are available from 51 sample types for request through DASH. More biospecimen collections will be added in the future. Explore available samples, by selecting the **Study Name** in this list of studies offering biospecimens through DASH:

- 1. <u>National Children's Study (NCS)</u>: Biospecimens and environmental samples are available only for a limited time!
- 2. <u>Genomic and Proteomic Network for Preterm Birth Research Expression Profiling Study (GPN-PBR EP)</u>
- 3. Genomic and Proteomic Network for Preterm Birth Research GWAS Case Control Study (GPN-PBR CC)
- 4. Genomic and Proteomic Network for Preterm Birth Research Longitudinal Cohort Study (GPN-PBR LS)
- 5. <u>Prospective Study of Perinatal Transmission of HIV Infection and Developmental Outcome of Children</u> <u>Infected with HIV: Mothers and Infants Cohort Study (MICS)</u>
- 6. <u>A Prospective, Observational Study of HIV-Infected Pregnant Women and HIV-Exposed, Uninfected</u> Children at Clinical Sites in Latin American Countries (NISDI LILAC)
- 7. <u>A Prospective, Observational Study of HIV-Infected Pregnant Women and Their Infants at Clinical Sites</u> in Latin American and Caribbean Countries (NISDI Perinatal)
- 8. <u>A Prospective, Observational Study of HIV-Exposed and HIV-Infected Children at Clinical Sites in Latin</u> <u>American and Caribbean Countries (NISDI Pediatric)</u>
- 9. <u>NISDI Pediatric Latin American Countries Epidemiological Study: A Prospective, Observational Study</u> of HIV-infected Children at Clinical Sites in Latin American Countries (NISDI PLACES)

#### Top 20 Sample Types

- Blood (13,080)
- Cervicovaginal Fluid (5,785)
- Cord Blood (8,838)
- Cord Buffy Coat and RBC (3,796)
- Cord Dried Blood Spot (4,173)
- Cord Plasma (21,563)
- Cord Serum (922)

- Dried Blood Spot (3,812)
  - Environmental Samples (2,980: air filters, dust wipes, infant formula, vacuum dust, and water)
- Hair (802)
- Lymphocyte (18,614)
- Neonatal Saliva (1,380)

- PBMC (28,830)
- Placenta (2,397)
- Plasma (119,052)
- Saliva (6,248)
- Serum (53,613)
- Tissue (1,461)
- Urine (53,408)
- Vaginal Fluid (4,189)

#### **Noteworthy News**

**Publications Resulting from Data Reuse** 

Since the launch of DASH in August 2015, there have been 53 multicenter, peer-reviewed publications resulting from DASH data reuse, with an average time of 1.8 years to publish. <u>View a listing of Publications from DASH Data Reuse</u> to browse the outcomes of investigator's research.

#### 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 in DASH.

## **Relevant NICHD Funding Opportunities and Notices**

To learn more about a funding opportunity, select the **Name of the Funding Opportunity** in this list of funding opportunities:

NOT-HD-20-022 NOSI: Small Grants for Secondary Analyses of Existing Data Sets and Stored Biospecimens

PAR-20-064 Archiving and Documenting Child Health and Human Development Data Sets (R03 Clinical Trial Not Allowed)

# Final NIH Policy for Data Management and Sharing (effective January 25, 2023)

To learn more about a policy, select the **Policy Name** in this list of NIH Data Management and Sharing policies:

NOT-OD-21-013 Final NIH Policy for Data Management and Sharing

NOT-OD-21-014 Supplemental Information to the NIH Policy for Data Management and Sharing: Elements of an NIH Data Management and Sharing Plan

NOT-OD-21-015 <u>Supplemental Information to the NIH Policy for Data Management and Sharing: Allowable</u> <u>Costs for Data Management and Sharing</u>

NOT-OD-21-016 <u>Supplemental Information to the NIH Policy for Data Management and Sharing: Selecting a</u> <u>Repository for Data Resulting from NIH-Supported Research</u>

Other active FOAs issued by NICHD can be found on the <u>NICHD Grants and Contracts</u> page.

Questions? Please contact the DASH Administrator at <u>SupportDASH@mail.nih.gov.</u> To opt out of receiving the DASH Quarterly Update, please reply "unsubscribe" to this email.



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