PhenX Highlights

PhenX Protocols Used in Major Research Studies

We know users are interested in finding PhenX protocols that are used in major research studies. We addressed that need by making it easy to see which protocols are being used by 8 major research studies including All of Us, ABCD, CONNECTS, ECHO, Gravity Project, PATH Study, NHANES and RECOVER. The filters are available on the Browse Protocols page and Advanced Search page. When looking at a specific protocol, users can see which study(ies) are using that protocol. When you use PhenX protocols that are being used by major research studies, it will facilitate data sharing with those studies.
New Sickle Cell Disease (SCD) Genitourinary Collection

The SCD Genitourinary collection was released on August 15, 2023. The Sickle Cell Disease (SCD) Genitourinary Working Group, Co-Chaired by Lillian Meacham, M.D. (Emory University School of Medicine) and Lydia Pecker, M.D. (Johns Hopkins School of Medicine), released 12 protocols in the PhenX Toolkit. The protocols address fertility, sexual function, contraception use, perimenopausal symptoms, pain associated with menstruation and quality of life. They are the newest addition to the Blood Sciences Research Collections, which are funded by the National Heart, Lung, and Blood Institute (NHLBI). Dr. Phil Tonkins is the NHLBI project scientist. The PhenX SCD Research and Scientific Panel, co-chaired by Dr. James Eckman of Emory University and Dr. John J. Strouse of Duke University, provides overarching guidance for the project.

PhenX in the Community

PhenX Presentations

Tabitha Hendershot presented “The PhenX Toolkit: Using standard protocols for research with human participants” at the Advancing Genomic Medicine Research (AGMR) Grantee meeting on February 29, 2024.

Wayne Huggins presented a poster “Leveraging Biomedical Standards and Related Resources to Increase the Interoperability of PhenX Protocols” at the NIH Data Repository & Knowledgebase (DRKB) Program PI Network meeting on February 28 and 29, 2024.

Tabitha Hendershot presented “The PhenX Toolkit: Using standard protocols for research with human participants” at the NHGRI Trainee Symposium on February 22, 2024.

American Society of Human Genetics Annual Meeting, November 1-5, 2023, in Washington D.C.

PhenX had a booth at the meeting to engage members of the scientific community.

David Williams presented a poster on November 2: The PhenX Toolkit: Recommended Measurement Protocols to Standardize Data Collection for COVID-19 Studies.
Jaleh Abedini led an educational workshop on November 3: The PhenX Toolkit: recommended protocols for study design.

NHLBI Annual Sickle Cell Disease Research meeting held August 14-16, 2023:

Dr. Wayne Huggins and Dr. Carol Hamilton gave a presentation on August 16: The PhenX Toolkit: a Resource for Sickle Cell Disease Research.

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**Featured:**

### Sickle Cell Disease Genitourinary Working Group

#### Lydia H. Pecker, MD, MHS

Dr. Lydia H. Pecker is an Assistant Professor of Medicine at Johns Hopkins University. She earned her Bachelors degree with honors in Africana Studies from Brown University and her MD from The University of Pennsylvania Medical School. She also holds a Masters in Health Sciences from the Johns Hopkins Bloomberg School of Public Health. Her NIH and foundation-funded research focuses on reproductive health in girls and women with SCD, particularly defining and mitigating infertility risks and management of high risk pregnancy pregnancy. She serves as an advisor to the CDC and is a member of the American Society of Hematology Maternal Health Committee, Foundation for Women and Girls with Blood Disorders’ Medical Advisory Committee, and a co-Founder of the Sickle Cell Reproductive Health Education Directive.

Dr. Pecker is the founding Director of the Young Adult Clinic at the Sickle Cell Center for Adults at Johns Hopkins, which aims to provide developmentally appropriate, expert care for young adults living with sickle cell disease.
Lillian Meacham, M.D. is a Professor of Pediatrics and a pediatric endocrinologist who serves as the program director for the Fertility Preservation and Reproductive Health Program for the Aflac Cancer and Blood Disorders Center at Children’s Healthcare of Atlanta. She leads a team that provides nearly 200 fertility consults/year to patients before gonadotoxic exposure for the purposes of infertility risk counseling and fertility preservation. She serves as the chair of the Best Practice Committee of the Pediatric Initiative Network of the Oncofertility Consortium. She serves as on the expert panel for the Ovarian and Testicular Taskforces for the COG Long-Term Follow-Up Guidelines. She has also participated in international collaborations to harmonize long term follow-up guidelines for cancer survivors in the areas of reproductive health. More recently she has become involved with reproductive health in patients with sickle cell disease (SCD) and has presented at the Foundation for Women & Girls with Blood Disorders in 2020, and at the 14th Annual SCD Research and Educational Symposium combined with the 43rd National SCD Scientific Meeting in 2020 and at ASH in 2022. In 2023, she presented on reproductive health outcomes in females with SCD at the Cure Sickle Executive Committee Retreat and at an NHLBI Workshop. She is currently leading the reproductive health aim for STELLAR (Sickle cell Transplant Evaluation of Long-Term and Late Effects Registry). She has over 30 years of experience treating endocrine disorders in hematology/oncology/HCT patients and has published more than 125 papers in the field.

Current PhenX Team Members

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Funding

PhenX has been funded by the National Human Genome Research Institute (NHGRI) since 2007. Current PhenX funding is as a Biomedical Knowledgebase (U24HG012556) with co-funding from the National Heart, Lung, and Blood Institute (NHLBI), the Office of the Director, Office of Behavioral and Social Sciences Research (OD/OBSSR), the National Institute of Neurological Disorders and Stroke (NINDS), and the National Institute on Minority Health and Health Disparities (NIMHD), and supplemental funding from the National Institute on Drug Abuse (NIDA). In addition, prior funding for PhenX has been provided by the National Institute of Mental Health (NIMH), the National Cancer Institute (NCI), and the Tobacco Regulatory Science Program (TRSP) of the National Institutes of Health (NIH).

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