

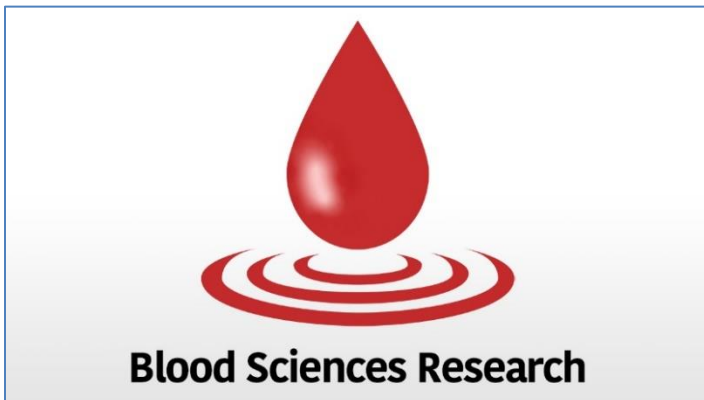


PhenX Newsletter

Issue 38. October 2024

PhenX Highlights

New Sickle Cell Disease (SCD) Pregnancy Collection



The [Sickle Cell Disease \(SCD\) Pregnancy Working Group](#), Co-Chaired by A. Kinga Malinowski, M.D., MSc, FRCS (University of Toronto and Mount Sinai) and Deva Sharma, M.D., MS (Vanderbilt University Medical Center), recommended [8 protocols](#) in the PhenX Toolkit. The SCD Pregnancy collection was released on August 6th, 2024. The protocols address maternal and fetal

health, hydroxyurea use and adherence, thrombosis and transfusion management. These protocols 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 (Emory University) and Dr. John J. Strouse (Duke University), provides overarching guidance for the project.

Tobacco Regulatory Research (TRR) Collection Update

The PhenX TRR Collection was recently reviewed and updated by the [TRR Content Expert Panel](#) (CEP) led by Dr. Meghan Rabbitt Morean (Yale School of Medicine) and Dr. Cassandra A. Stanton, PhD (Westat). TRR protocols utilizing earlier waves of the Population Assessment of Tobacco and Health (PATH Study) were updated to the PATH Study wave 7 (2022). In addition, the CEP reviewed and updated non-PATH Study protocols, as needed, to account for changes in the tobacco products people

use and other changes in the field. This timely effort was initiated to support TCORS investigators launching new projects under a recent award.

PhenX in the Community

American Society of Human Genetics (ASHG) Conference

The PhenX Toolkit team is attending the

[American Society of Human Genetics](#)

[\(ASHG\)](#) annual meeting at the Denver, Colorado Convention Center.



We will be at Booth 1102 during exhibit

hall hours November 6-8 to answer questions and demonstrate how to use the PhenX Toolkit. Please stop by and say hello!

Marian Sullivan is presenting poster #4132W “The PhenX Toolkit: New Protocols for Sickle Cell Disease Pregnancy, Medical Cannabis, Polysubstance Use and Recovery, and Updated Protocols for Tobacco Regulatory Research” on Wednesday, November 6 from 2:30pm – 4:30pm.

Upcoming PhenX Workshop Series

PhenX is excited to announce a series of monthly workshops that introduce the PhenX Toolkit and highlight useful features. Join us for the inaugural session on November 14 where we will cover the guiding principles of the PhenX Toolkit, including consensus building and community engagement. The first workshop provides a comprehensive roadmap of the Toolkit’s features, demonstrating how they support studies involving human participants and align with the NIH’s increased focus on data management and sharing.

Thursday, Nov. 14 3-4pm EST | Zoom

Workshop 1: What is the PhenX Toolkit and why use standard measurement protocols?

[Register Now!](#)

Recent PhenX Project Publications

Ives, C. L., et al. [The PhenX Toolkit: Recommended Measurement Protocols for Social Determinants of Health Research](#). *Current Protocols*. March 2024.

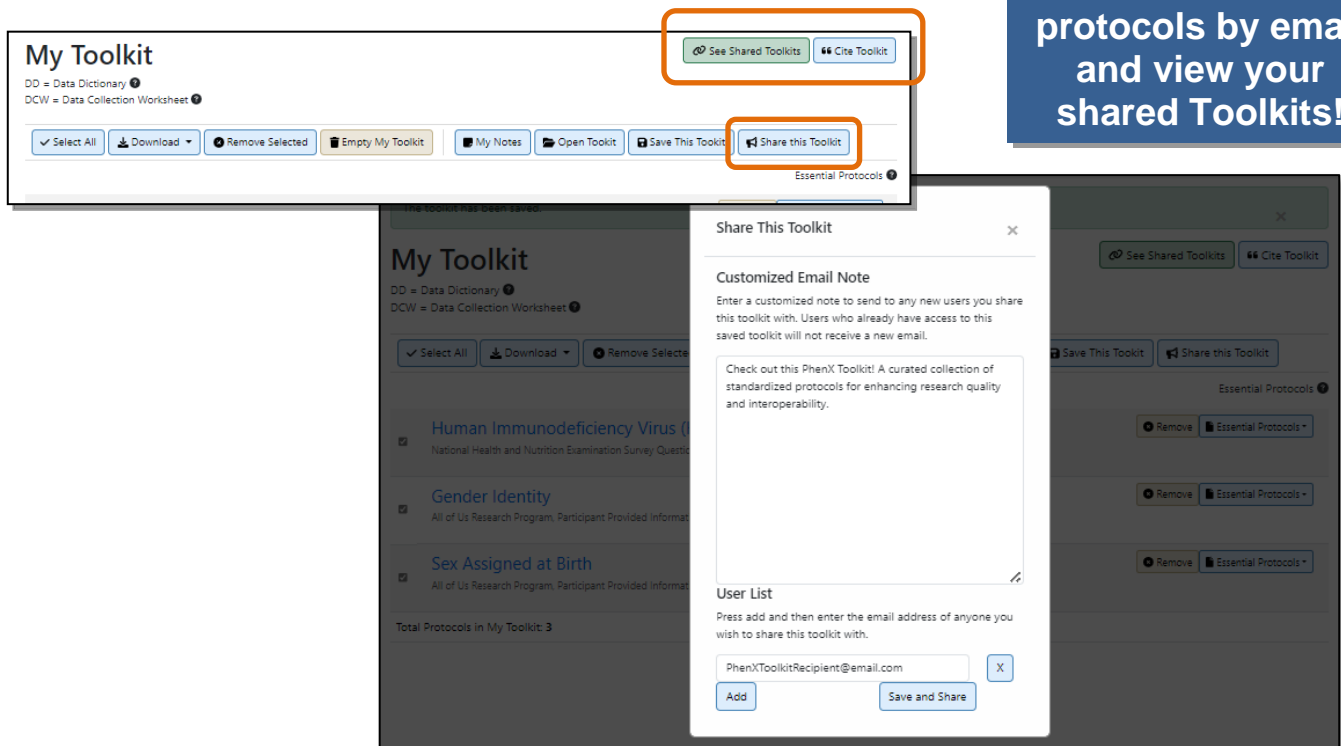
Explore the PhenX Toolkit

New Feature: Share My Toolkit

To help investigators and other researchers share protocols in the PhenX Toolkit, registered users can now share self-curated Toolkits by email! This feature simplifies the process of collaborating with colleagues by allowing you to share specific protocols directly from the Toolkit. For instance, if you are compiling protocols to My Toolkit for a new data collection form, you can easily share your Toolkit with your study coordinator. The email can be personalized, and the recipient will receive instructions on how to create a PhenX Toolkit account if they do not already have one. The recipient must have a PhenX Toolkit user account to view the shared Toolkit; we will provide the recipient instructions on how to create

an a

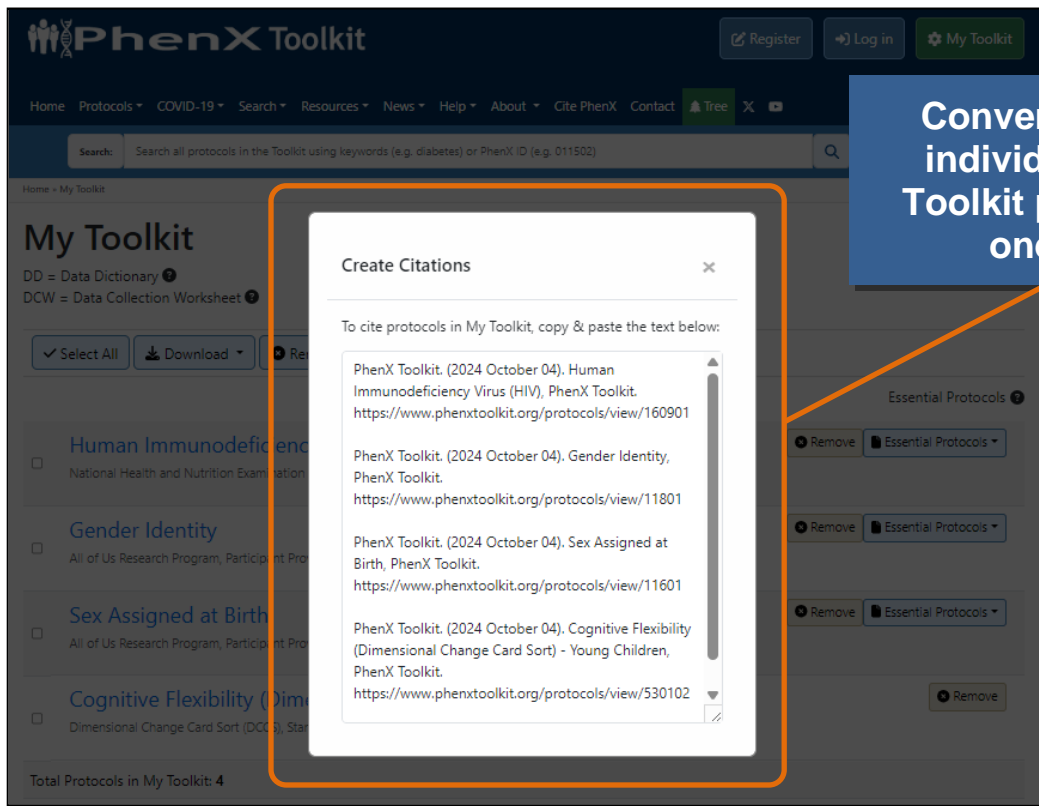
Share selected protocols by email and view your shared Toolkits!



New Feature: Create Citations for PhenX Protocols

With the new Cite My Toolkit feature, you can generate citations for each protocol you use. This feature allows you to easily cite PhenX Toolkit protocols in your publications, ensuring proper attribution and

enhancing the credibility of your research. Simply select the protocols from your Toolkit that you want to cite, and the Toolkit will generate a citation for each protocol you include in your references.



The screenshot shows the PhenX Toolkit website interface. A 'Create Citations' dialog box is open, displaying a list of protocols selected in the user's toolkit. Each protocol entry includes the protocol name, the date (2024 October 04), and a URL. The protocols listed are: Human Immunodeficiency Virus (HIV), Gender Identity, Sex Assigned at Birth, and Cognitive Flexibility (Dimensional Change Card Sort). A blue callout box with white text points to the dialog box, stating: 'Conveniently cite individual PhenX Toolkit protocols in one click!'

Featured:

Sickle Cell Disease Pregnancy Working Group

. A. Kinga Malinowski, M.D., MSc, FRCS



Dr. Malinowski completed her fellowship in Maternal-Fetal Medicine at Mount Sinai Hospital, Toronto. Since joining the Maternal-Fetal Medicine Division at Mount Sinai Hospital in 2011, her clinical activity has focused on haematologic conditions affecting pregnancy. She is Co-Director of the Hematology in Pregnancy Program. Dr. Malinowski also holds the position of Clinician Investigator at Mount Sinai Hospital and the Lunenfeld-Tanenbaum Research Institute, with a cross-appointment at the rank of Associate

Professor at the University of Toronto. Thematically, her research interests parallel her clinical focus, with an emphasis on haematologic disorders in pregnancy, particularly as it relates to studies addressing the impact of Sickle Cell Disease on pregnancy outcomes.

Deva Sharma, M.D., MS

Dr. Deva Sharma is an Assistant Professor of Hematology-Oncology & Transfusion Medicine at Vanderbilt University Medical Center. Her clinical and research interests are focused on the study of reproductive-health related morbidity in women with sickle cell disease. She is a previous recipient of awards from the Foundation for Women and Girls with Blood Disorders, Thrombosis and Hemostasis Societies of North America (THSNA) and Celgene, to study the epidemiology of acute vaso-occlusive pain associated with menstruation in women with sickle cell disease. She serves as co-chair of NLHBI Sickle Cell Disease Pregnancy Working Group, former co-chair for Research and Publications Subcommittee for the Foundation for Women and Girls with Blood Disorders, co-chair of an International Delphi Panel on Pregnancy Management in Sickle Cell Disease, and co-chair of the American Society of Hematology Maternal Health Working Group. In her current faculty appointment at Vanderbilt University Medical Center, she serves as Medical Director of the Vanderbilt Apheresis Clinic, Medical Co-Director of the Nashville VA Blood Bank, Medical Co-Director of the Nashville VA Stem Cell Processing Lab, and Medical Director of the Alvin C. York VA Blood Bank.



Tobacco Regulatory Research (TRR) Content Expert Panel

. Megan Rabbitt Morean, Ph.D.



Dr. Morean's research focuses on factors that promote the initiation, maintenance, and cessation of commonly used substances (e.g., nicotine, alcohol, cannabis) across the lifespan; developing psychometrically-sound measures to improve the quality of substance-related research; and survey-based research methodology. She has expertise in adolescent and adult ENDS use, nicotine dependence, smoking cessation, building complex online surveys, and using online

sampling methods.

Cassandra A. Stanton, Ph.D.

Cassandra Stanton, PhD, is an associate vice president of Behavioral Health and Health Policy at Westat. With over 30 years of continuous NIH support, Dr. Stanton is an expert in health equity and tobacco prevention, control, and regulatory science. Dr. Stanton has served in scientific leadership for over 10 years of the Centers for Coordination of Analytics, Science, Enhancement, and



Logistics (CASEL) in Tobacco Regulatory Science (TRS) funded by the FDA Center for Tobacco Products (FDA CTP) and National Institute of Health (NIH). She also collaborates with federal agencies and academic partners to disseminate findings from the Population Assessment of Tobacco and Health (PATH) Study. Dr. Stanton is an established principal investigator and co-investigator of multiple NIH funded tobacco cessation clinical trials and studies that focused on populations such as people living with HIV, older adults undergoing cancer screening, urban and rural communities, youth and young adults, and families in underserved neighborhoods.

Current PhenX Team Members

RTI International

Carol M. Hamilton, PhD

Principal Investigator

Tabitha Hendershot

Co-Investigator

Wayne Huggins, PhD

Co-Investigator

Cindy Changar, PMP

Project Manager

Jaleh Abedini, MS

Assistant Project Manager

Patricia Ceger, MS

Bethany Cook, MS

Lisa Cox, MS

Elizabeth Fallon

Iris Glaze

Lauren Gridley, MS

Christine Hill, MPA

Cataia Ives, MS

Kritika Kolla

Michelle Krzyzanowski, PhD

Meisha Mandal, PhD

Mark Nelms, PhD

Helen Pan, PhD

Tanya Reeve, MS

Marian Sullivan, MPH

David Williams, Meng

Xin Wu, PhD

National Human Genome Research Institute

Jyoti Dayal, MS

PhenX Project Scientist

Alauna Rupert

PhenX Project Analyst

Erin Ramos, PhD, MPH

Deputy Director, Division of Genomic Medicine

PhenX Project Scientists, Co-funding and Supplemental Funding

Phil Tonkins, Jr., DrPH.

National Heart, Lung, and Blood Institute

Tamara Haegerich, PhD

National Institute on Drug Abuse

Vanessa Marshall, PhD

National Institute on Minority Health and Health Disparities

Kay Wanke, PhD, MPH

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