



# PhenX Newsletter

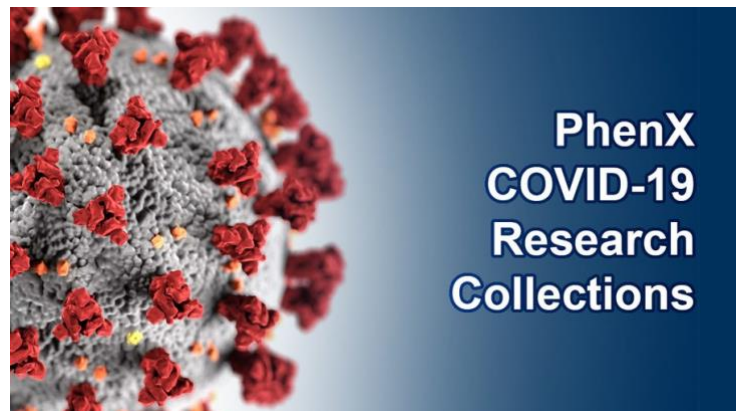
Issue 36, June 2023

## PhenX Highlights

### Long COVID Protocols Added to COVID-19 Research Collections

The [Long COVID Specialty Collection](#) was added to the PhenX Toolkit on March 17, 2023.

The Long COVID Specialty Collection includes 23 protocols recommended for use by the PhenX Steering Committee. They were selected from the PhenX COVID-19 Protocol Library. The PhenX Steering Committee also selected COVID-19 vaccination protocols, which were added to the COVID-19 History, Treatment and Outcomes Specialty Collection.



Other [COVID-19 Specialty Collections](#) include Behaviors and Risks; Ethnicity, Race and Demographics; Information Resources; Psychosocial and Mental Health; and Socioeconomic. The [Social Determinants of Health Core Collection](#) is recommended for COVID-19 research, and more broadly for all Toolkit users.

Funding to establish recommended collections of measurement protocols for COVID-19 research was provided by the Office of Behavioral and Social Sciences Research (OBSSR), the National Human Genome Research Institute (NHGRI), the National Institute on Drug Abuse (NIDA), the National Institute on Minority Health and Health Disparities (NIMHD), and the National Cancer Institute (NCI).

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### New SCD Psychosocial and Social Determinants of Health Collection



The [Sickle Cell Disease \(SCD\) Psychosocial and Social Determinants of Health Working Group](#), chaired by Dr. Lori Crosby of University of Cincinnati (featured below), recently released [15 protocols](#) in the PhenX Toolkit. These protocols address SCD transition readiness, stigma, responses to stress, trust in medical care and research, prolonged grief, resilience, health-related stigma and self-management. 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.

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## New Protocols in the Social Determinants of Health Collection

The PhenX [Social Determinants of Health Expansion \(SDoH-X\) Working Group](#) selected 11 protocols for the SDoH Individual Specialty Collection and 4 protocols for the Structural Specialty Collection. Released in the Toolkit on

December 14, 2022, these protocols focus on additional high priority areas that build on existing content in the [SDoH collections](#), including healthcare communications, internet access and family history of incarceration. The SDoH-X Working Group was co-chaired by Dr. Keith Norris of the University of California, Los Angeles, and Dr. Myles Cockburn of the University of Southern California. The PhenX SDoH Collections were funded by the National Institute on Minority Health and Health Disparities (NIMHD). Dr. Nancy Jones and Dr. Vanessa Marshall are the NIMHD project scientists.



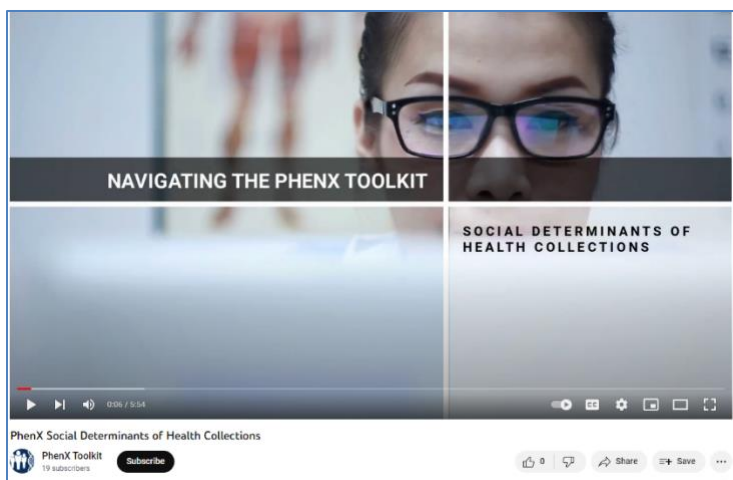
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## New Bone and Joint Domain

Standard [protocols for Bone and Joint research](#) were released in the PhenX Toolkit on October 21, 2022. The [Bone and Joint Working Group](#) was co-chaired by Dr. David Felson of Boston Medical Center and Dr. Gayle Lester of the National Institute of Arthritis and Musculoskeletal Skin Diseases (featured below). The Bone and Joint domain contains 15 protocols, including those to assess gout flare, psoriatic arthritis, and knee pain.

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# Explore the PhenX Toolkit



## SDoH Collection Video Tutorial

A new video tutorial, [“PhenX Social Determinants of Health Collections,”](#) helps users explore the Social Determinants of Health Collections and learn about protocols in the Core, Individual, and Structural Collections.

Check out the [PhenX YouTube channel](#) for other tutorials.

## Top PhenX Domains and Protocols

### \*Top 5 Protocols:

1. [Current Employment Status](#)
2. [Annual Family Income](#)
3. [Educational Attainment - Individual](#)
4. [Ethnicity and Race](#)
5. [Current Age](#)

### Top 5 Domains:

1. [Tobacco Regulatory Research](#)
2. [Mental Health Research](#)
3. [Substance Abuse and Addiction](#)
4. [Demographics](#)
5. [Sickle Cell Disease](#)

\* Rankings are based on downloads to “My Toolkit” from January 1 to March 31, 2023. See PhenX Toolkit [Use Statistics](#) for additional data.

## NIH Funding Opportunities Mentioning PhenX

To date, PhenX has been mentioned in 621 Funding Opportunity Announcements (FOAs) and 29 Notices. Recent announcements include:

- Applicants for RADx-@UP Dissemination and Implementation Research on COVID-19 Testing Interventions among Underserved and Vulnerable Populations ([RFA-OD-23-051](#)) are strongly encouraged to leverage relevant measures in PhenX Social Determinants of Health (SDOH) Collection for data elements not covered by RADx-UP CDEs.
- Applicants for the Heal Initiative: Interdisciplinary Team Science to Uncover the Mechanisms of Pain Relief by Medical Devices ([RFA-NS-23-028](#)) are encouraged to use data standards including the PhenX Toolkit.

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# PhenX in the Community

## PhenX Presentations

**Carol M. Hamilton** of RTI presented the “PhenX Toolkit” at the Environmental Health Language Collaborative 2023 Workshop, Sharing Your Environmental Health Sciences (EHS) Data: Metadata, Standards, and Tools on February 1, 2023.

**Dr. Stephanie Guarino** of Nemours Children's Hospital presented “Expansion of Content in the PhenX Toolkit for Sickle Cell Disease Pain,” a poster at the American Society of Hematology Meeting on December 12, 2022.

**Dr. Lori Crosby** of the University of Cincinnati presented “A new PhenX Collection: Sickle Cell Disease Psychosocial and Social Determinants of Health Protocols Collection,” a poster at the American Society of Hematology Meeting on December 11, 2022.

**Michelle Engle** of RTI presented “Using the PhenX Toolkit to Design Studies Optimized for Data Sharing,” a workshop at American Society of Human Genetics (ASHG) annual meeting on October 28, 2022.

**David Williams** of RTI presented “Using the PhenX COVID-19 Collection and Variable Compare Tool,” a poster for ASHG on October 26, 2022.

**Michelle Krzyzanowski** of RTI presented “PhenX Presents Bone and Joint updates and expansion of Social Determinants of Health,” a poster for ASHG on October 26, 2022.

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## PhenX Publications

Bierut, L.J., et al. [Smoking cessation, harm reduction, and biomarkers protocols in the PhenX Toolkit: Tools for standardized data collection.](#) *Addiction Neuroscience*. March 2023.

Krzyzanowski, M.C, et al. [The PhenX Toolkit: Measurement Protocols for Assessment of Social Determinants of Health.](#) *American Journal of Preventive Medicine*. March 17, 2023.

Nekhlyudov, L., et al. [The PhenX Toolkit: standard measurement resources for cancer outcomes and survivorship research.](#) *Journal of the National Cancer Institute*, January 20, 2023

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# Featured:

ABOUT

## Sickle Cell Disease: Psychosocial and Social Determinants of Health Chair



### **Lori Crosby, PsyD**

Dr. Crosby is a professor of pediatrics at Cincinnati Children's Hospital Medical Center (CCHMC) and the University of Cincinnati (UC) College of Medicine. She directs the UC/CCHMC Community Engagement Core and is co-director for faculty diversity, equity, and inclusion for CCHMC. She is a clinical psychologist and researcher who specializes in treating adolescents and young adults with conditions such as chronic pain and sickle cell disease (SCD) and conducts clinical and translational research focused on helping individuals living with SCD manage their disease. She conducts research to learn the best ways for the medical team, patients and families to work together to improve care, particularly for youth transitioning to adult healthcare. She serves as a member of the National Academies of Sciences workgroup that produced "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action" report.

## Bone and Joint Working Group Co-chairs

### ABOUT



### **Gayle Lester, PhD**

Dr. Lester is the Director of Extramural Research at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). Prior to this appointment in 2018, she managed the NIAMS portfolio on Clinical Osteoarthritis and Diagnostic Imaging and worked with the Foundation for the National Institutes of Health (NIH) and other NIH institutes to develop the Osteoarthritis Initiative, a longitudinal cohort study focused on knee osteoarthritis and the discovery of biomarkers. She also initiated NIAMS efforts related to bone quality and biomarker discovery for osteoporosis and serves as the Project Director for Collaborative Initiative on Bone Strength, a public private partnership focused on discovery of possible surrogates for bone fracture.

### **David Felson, MD, MPH**

Dr. Felson is a rheumatologist at Boston Medical Center (BMC) and a professor of Epidemiology at Boston University Chobanian & Avedisian School of Medicine and Boston University School of Public Health. Dr. Felson is also the Director of Training and Education for the Boston University Clinical Translational Science Institute. A renowned clinician and scientist, Dr. Felson specializes in rheumatic diseases, arthritis, and osteoarthritis. He has received numerous prestigious national and international awards, including the Kunkel Young Investigator Award and the Clinical Research Award from the American College of Rheumatology.



# Current PhenX Team Members

[MORE](#)

## 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

**Deborah Maiese, MPA**  
Consensus Coordinator

**Shannon Bell, PhD**

**Patricia Ceger, MS**

**Bethany Cook, MS**

**Lisa Cox, MS**

**Steve Edwards, PhD**

**Michelle Engle, PhD**

**Lisa Gehtland, MD**

**Lauren Gridley, MS**

**Ginnie Hench, PhD**

**Cataia Ives, MS**

**Iris Glaze**

**Michelle Krzyzanowski, PhD**

**Thien Lam, MA**

**Meisha Mandal, PhD**

**Mark Nelms, PhD**

**Helen Pan, PhD**

**Mike Phillips, MS**

**Ying Qin, MS**

**Tanya Reeve, MS**

**Jennifer Schoden, MA**

**Marian Sullivan, MPH**

**Grace Swank, MS**

**Pat West**

**David Williams, Meng**

**Xin Wu, PhD**

## National Human Genome Research Institute

**Jyoti Dayal, MS**

PhenX Project Scientist

**Erin Ramos, PhD, MPH**

Deputy Director, Division of Genomic Medicine

**Stephanie Calluori**

Scientific Program Analyst

## PhenX Project Scientists, Co-funding

**Nancy Jones, PhD, MA**

National Institute on Minority Health and Health Disparities

**Phil Tonkins, Jr., DrPH.**

National Heart, Lung, and Blood Institute



## 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). In addition, prior funding for PhenX has been provided by the National Institute on Drug Abuse (NIDA), 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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