What is the PhenX Toolkit?

The PhenX Toolkit is an online catalog of recommended, standard measures and is available for use at no cost at https://www.phenxtoolkit.org.

The purpose of the PhenX Toolkit is to:

- Provide recommended, standard measures of phenotypes and exposures for use in biomedical research
- Facilitate acceptance and use of standard PhenX measures
- Promote collaboration and facilitate cross-study analyses

Researchers visit the Toolkit to:

- Select and incorporate standard measures into ongoing studies
- Consider PhenX measures when planning new studies
- Review and select high-quality, recommended, standard measures in order to expand a study beyond the primary research focus
- Review and select PhenX measures that relate to researchers’ primary research focus

PhenX Toolkit features:

- The Smart Query Tool provides two search options: a Smart Search based on keywords (and synonyms) and a Text Search that searches all text
- Browse options: Domains, Measures, Collections, Supplemental Information, and hierarchical tree view
- Register your study to find other researchers using the same measures and to explore opportunities for cross-study analysis
- Standards included: cancer Data Standards Registry and Repository (caDSR) Common Data Elements (CDEs) and Logical Observation Identifiers Names and Codes (LOINC)
- Registered Users have access to additional features and functionality, e.g., saving more than one “My Toolkit”
- Quick Start and Tutorial resources help new users become familiar with the Toolkit
- Annotation Tool in Toolkit Resources: Annotate the PhenX protocols that you use to assess rare genetic diseases and conditions
- REDCap Instrument Zip files for PhenX protocols can be uploaded directly to REDCap

For each PhenX measure, the following information is provided:

- Brief description of the measure
- Rationale for selecting the measure for inclusion in the Toolkit
- Detailed protocol(s) for collecting the measure
- Information about the personnel, training, and equipment needed to collect the measure
- Any special requirements
- Essential and related measures
- References

PhenX Research Domains

- Alcohol, Tobacco, and Other Substances
- Anthropometrics
- Cancer
- Cardiovascular
- Demographics
- Diabetes
- Environmental Exposures
- Gastrointestinal
- Infectious Diseases and Immunity
- Neurology
- Nutrition and Dietary Supplements
- Obesity
- Ocular
- Oral Health
- Physical Activity and Physical Fitness
- Psychiatric
- Psychosocial
- Rare Genetic Conditions
- Reproductive Health
- Respiratory
- Skin, Bone, Muscle, and Joint
- Social Environments
- Speech and Hearing

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Dr. Carol M. Hamilton is the RTI International Principal Investigator, and Dr. Erin M. Ramos is the NHGRI Project Scientist.

More information is available at the project web portal: https://www.phenx.org

Related projects, links, and additional resources can be found at https://www.phenxtoolkit.org
Instrument Zip Files

To enable web-based data collection, PhenX protocols are available as "Instrument Zip" files from REDCap External Libraries in the PhenX Toolkit. PhenX protocols can be downloaded from PhenX “My Toolkit” and be uploaded directly into REDCap using the “Upload” option under “Online Designer.”

PhenX Register Your Study

The PhenX Register Your Study feature makes it possible for Toolkit Registered Users to see what PhenX measures other investigators are using. After you register and log in, you can register your study by filling out a short form with the following information:

- Name of funded study
- Selected PhenX protocols
- Principal investigator
- Primary contact name
- Primary contact email
- Number of participants
- Funding source
- Primary research focus

This will only take you a few minutes and will foster collaboration and cross-study analysis.

If you need assistance, please email contact@phenxtoolkit.org, and we will be happy to help you Register Your Study.

Annotate PhenX Measures

PhenX developed a web-based Annotation Tool to collect information about the use of PhenX measures to assess rare genetic diseases and conditions.

If you would like to enhance the PhenX measures by providing information about rare genetic conditions or other diseases, please use the Annotation Tool under the “Resource” navigation bar. There are five steps to using the Annotation Tool:

1. Select a condition
2. Select a PhenX measure by browsing or searching
3. Provide a publication citation
4. Add comments
5. Hit the “Submit” button

By annotating PhenX measures, you will help the biomedical community use PhenX measures to assess rare genetic conditions and promote use of common measures.

PhenX Supplements

Several National Institutes of Health institutes and programs have contributed supplemental funding to add depth to the Toolkit in specific areas of research.

- PhenX Measures for Sickle Cell Disease Research funded by the National Heart, Lung, and Blood Institute (NHLBI).
- PhenX Measures for Tobacco Regulatory Research funded by the Food and Drug Administration (FDA) and the Tobacco Regulatory Science Program (TRSP).
- PhenX Measures for Mental Health Research funded by the National Institute of Mental Health (NIMH).
- PhenX Measures for Substance Abuse and Addiction Research funded by the National Institute on Drug Abuse (NIDA).

Expert Review Panels

Expert Review Panels (ERPs) are being formed to review and update measures in the PhenX Toolkit. For each domain being reviewed, the ERP includes one former Working Group member and one external reviewer. The PhenX Steering Committee reviews all ERP recommendations.

Each ERP is responsible for:

- Assessing the scope of the domain
- Recommending changes to the Toolkit, such as adding new measures and updating, replacing, or retiring measures and/or protocols
- Conducting email outreach to the scientific community to gather input about existing measures and new measures