



# PhenX Toolkit

consensus measures for Phenotypes and eXposures

<https://www.phenxtoolkit.org>

## Cancer Measures for PhenX Toolkit

	Measure	Description of Measurement Protocol
1	Cancer Screenings	Self-administered questions ask about different cancer screening tests a respondent may have had in the past 3 years. The protocol includes the following screenings: mammogram, pap smear, pelvic examination, Prostate-Specific Antigen (PSA) test, colonoscopy, ultrasound of the ovaries, barium enema, chest x-ray, sigmoidoscopy, and digital rectal examination.
2	Cancer Treatments	Questions for respondents who have had cancer. Detailed follow-up questions asking about the type of cancer treatment, including surgery, chemotherapy, radiation, and hormone therapy.
3	Cancer: Personal and Family History	Assesses if the respondent and his or her biological parents, siblings, and children have had cancer. This protocol also obtains information about vital status, age, type of cancer, age at first diagnosis, and any additional cancer diagnoses.
4	Cumulative Lifetime Alcohol Exposure	Interviewer-administered questions ask about drinking alcohol at least once a week for 6 months or more. This question is asked for different age ranges, reflecting alcohol consumption during different periods of life.
5	Cumulative Lifetime Physical Activity	Assesses strenuous and moderate physical activities and exercise at various stages of life. Respondents are asked to estimate the average amount of time each week and the average number of months each year that they spend doing strenuous and moderate exercise.
6	Exogenous Female Hormone Use	Female respondents self-report the use of estrogen and progesterone, including the duration and dose.
7	Medications (Current and Past Use of Pain Relievers, Statins, and Steroids)	Assesses current and past use of prescription and over-the-counter (OTC) medications. Protocol obtains information about pain-relieving medications, statins, steroids, and inhaled bronchodilators.
8	Ovulation History	Self-administered questions asking about menstruation and pregnancy history. Female respondents are asked about age at first menstruation, onset and cause of menopause, and pregnancy history and outcomes.
9	Passive Smoke Exposure	Assesses exposure to environmental tobacco smoke (ETS) during childhood and in adulthood at home, at work, and in social settings. The duration of ETS exposure is collected in hours per day and years for each setting. In addition, there is a question about current ETS exposure.
10	Personal Perception and Knowledge of Smoking-related Cancer Risk	Questions ask current and former smokers how often they worry about lung cancer and ask them to assess their perception of being diagnosed with lung cancer.
11	Pre-existing Conditions Associated with Cancer	Self-administered questions ask respondents to indicate the year of diagnosis for clinician-diagnosed illnesses.
12	Smoking Quit Attempts	Self-administered questions ask current and former smokers about their intention to quit smoking, details of past attempts to quit, and whether a healthcare professional advised the respondent to quit smoking.

**NOTE:** Complete protocols and links to common data elements are available through the PhenX Survey at <https://www.phenxtoolkit.org>.

## What Is PhenX?

PhenX is a collaborative, consensus project between RTI International, the National Human Genome Research Institute (NHGRI) of the National Institutes of Health, and the larger research community. The objective of PhenX is to recommend measures with specified measurement protocols that have a high priority for inclusion in genome-wide association studies (GWAS). The consistent use of some measurement protocols across studies will facilitate cross-study comparisons. High-priority measures are, therefore, those measures that are broadly relevant to multiple health outcomes or assessments of health outcomes, although the measures are not focused on differential diagnosis.

## Research Domains

The PhenX Steering Committee (SC) chose 21 research domains. A research domain is a field of research with a unifying theme and easily enumerated quantitative and qualitative measures. Working Groups (WGs) of experts in a specific domain were constituted, and they:

- Evaluated the scope of the domain and the broad elements of that scope, and then
- Recommended potential high-priority measures with specific measurement protocols.

These measures were vetted with the larger research community, and final recommendations from the WGs were reviewed by the SC. The primary goal of the project is to collect these recommendations in a Toolkit that will enable scientists to select measures and implement those measures in studies.

For more information on the PhenX project, please visit the project's website at <https://www.phenx.org/>.

Research Area (Domain)	Status	WG Chair(s)	SC Liaison
Alcohol, Tobacco and Other Substances	In Toolkit	Deborah S Hasin	Erin M Ramos
Anthropometrics	In Toolkit	Michele Forman	Michelle Williams
Cancer	In Toolkit	Neil Caporaso and Christine B Ambrosone	Margaret R Spitz
Cardiovascular	In Toolkit	Thomas A Pearson	William R Harlan
Demographics	In Toolkit	Myles Cockburn	Peter Kraft
Diabetes	In Toolkit	Craig L Hanis	William R Harlan
Environmental Exposures	In Toolkit	Lynn R Goldman	Diane Wagener
Gastrointestinal	In Toolkit	David Whitcomb	William R Harlan
Infectious Diseases and Immunity	In Toolkit	Richard Kaslow	Jonathan Haines
Neurology	In Toolkit	Jeffery M Vance	Lindsay A Farrer
Nutrition and Dietary Supplements	In Toolkit	Patrick J Stover	Jose M Ordovas
Ocular	In Toolkit	Janey L Wiggs	Jonathan Haines
Oral Health	In Toolkit	James Beck and Bryan Michalowicz	Mary L Marazita
Physical Activity and Physical Fitness	In Toolkit	Bill Haskell and Rick Troiano	Jose M Ordovas
Psychiatric	In Toolkit	Jordan Smoller and Kenneth Kendler	Carlos N Pato
Psychosocial	In Toolkit	Bernice Pescosolido	Carlos N Pato
Reproductive Health	In Toolkit	Carol Hogue	Michelle Williams
Respiratory	In Toolkit	Edwin K Silverman	Terri H Beaty
Skin, Bone, Muscle and Joint	In Toolkit	Douglas P Kiel	Lindsay A Farrer
Social Environments	In Toolkit	Barbara Entwisle	Peter Kraft
Speech and Hearing	In Toolkit	Cynthia Morton and Mabel Rice	Mary L Marazita