# Cancer Measures for PhenX Toolkit

Co-chairs of this Working Group were Dr. Christine B. Ambrosone of Roswell Park Cancer Institute and Dr. Neil Caporaso of the National Cancer Institute.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Description of Measurement Protocol</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Cancer Screenings</td>
<td>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.</td>
</tr>
<tr>
<td>2 Cancer Treatments</td>
<td>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.</td>
</tr>
<tr>
<td>3 Cancer: Personal and Family History</td>
<td>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.</td>
</tr>
<tr>
<td>4 Cumulative Lifetime Alcohol Exposure</td>
<td>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.</td>
</tr>
<tr>
<td>5 Cumulative Lifetime Physical Activity</td>
<td>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.</td>
</tr>
<tr>
<td>6 Exogenous Female Hormone Use</td>
<td>Female respondents self-report the use of estrogen and progesterone, including the duration and dose.</td>
</tr>
<tr>
<td>7 Medications (Current and Past Use of Pain Relievers, Statins, and Steroids)</td>
<td>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.</td>
</tr>
<tr>
<td>8 Ovulation History</td>
<td>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.</td>
</tr>
<tr>
<td>9 Passive Smoke Exposure</td>
<td>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.</td>
</tr>
<tr>
<td>10 Personal Perception and Knowledge of Smoking-related Cancer Risk</td>
<td>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.</td>
</tr>
<tr>
<td>11 Pre-existing Conditions Associated with Cancer</td>
<td>Self-administered questions ask respondents to indicate the year of diagnosis for clinician-diagnosed illnesses.</td>
</tr>
<tr>
<td>12 Smoking Quit Attempts</td>
<td>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.</td>
</tr>
</tbody>
</table>

Complete measurement protocols are available at [https://www.phenxtoolkit.org](https://www.phenxtoolkit.org).
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
- Link 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); 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
- Data Dictionaries compatible with submission to the database of Genotypes and Phenotypes (dbGaP) and Custom Data Collection Worksheets can be downloaded
- 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
- 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
- Pregnancy
- Psychiatric
- Psychosocial
- Rare Genetic Conditions
- Reproductive Health
- Respiratory
- Skin, Bone, Muscle and Joint
- Social Environments
- Speech and Hearing

PhenX supplements:

Several National Institutes of Health (NIH) 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 (NHBLI).

PhenX Measures for Tobacco Regulatory Research were supported by NIH and the Food and Drug Administration’s Center for Tobacco Products (CTP).

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).

1 Funding for the Social Environments domain provided by the Office of Behavioral and Social Sciences Research (OBSSR).