**Measures for Life Course Research**

Life course epidemiology is defined as “the study of long-term biological, behavioral, and psychosocial processes that link adult health and disease risk to physical or social exposures acting during gestational, childhood, adolescence, and earlier or adult life or across generations.” (Shlomo & Kuh, 2014). A life course theoretical framework posits that exposures experienced across the life course interact to impact health outcomes, with this impact depending on the dose, duration, and timing of exposure (Hanson et al, 2020). Providing empirical support for this framework requires integration of datasets across the life span and standardization of the measures used to study key constructs. In this tool kit, we identify a set of constructs that are key to life course research and provide recommended measure (s) for each construct.

When possible, we chose measures that were included in the [PhenX Toolkit](https://www.phenxtoolkit.org/). The PhenX toolkit is a web-based catalog of recommended measurement protocols to include in studies of human participants. Specific measures were selected by expert working groups using the following criteria.

Measures should be:

1. Clearly defined
2. Well established
3. Broadly applicable and generally accepted
4. Low burden to participants and investigators
5. Broadly validated and demonstrated utility
6. Reproducible
7. Specific
8. Reliable
9. Standard measurement protocols exist
10. Crosscutting relevance for population groups as well as disease and conditions
11. Prior use in GWAS
12. Use in major reference study (e.g. NHANES)
13. Open-source software and nonproprietary instruments preferred
14. Brevity
15. Expectation of acceptance by the research community

PhnX Reference:

[Hamilton, et al.](http://www.ncbi.nlm.nih.gov/pubmed/21749974) (2011) The PhenX Toolkit: Get the Most From Your Measures. American Journal of Epidemiology, 174(3), 253-60.

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|  |  | **Construct** | **Source** | **Type of measure** | **Description of measure** |
| --- | --- | --- | --- | --- | --- |
| All life stages | Environmental | Residential History | Parkinson’s Disease, Environment, and Genes Study (PEG Study)Selected by PhenX Demographics, Environmental Exposures, and Social Environments expert panel | Interviewer administered questionnaire; can be adapted to be self-administered | Captures information about every residence the respondent has lived in for 3 months or longerFor each address, participant reports:(1) Dates lived(2) Address: Street City, State, Zip code, Country (if not US) or landmark(3) Was this on a farm?(4) What was your water supply? Response options: city, private, filtered, bottled, other(5) Near fields or orchards?(6) Did you live close to the center or margin of town?These data can be linked to other databases to measure a variety of environmental exposures (e.g. air pollution, pesticide, etc.) across the life courseDetailed protocol for measure [here](https://www.phenxtoolkit.org/protocols/view/60301?origin=search) |
| All life stages | Socioeconomic | Neighborhood disadvantage | American Community Survey (ACS)Accessed from: University of Wisconsin, Center for Health Disparities Research:[The Neighborhood Atlas: Area Deprivation Index](https://www.neighborhoodatlas.medicine.wisc.edu/)  | Administrative data linked to individual residential history  | Census block group-level index calculated from 17 variables across 4 domains (1) Education(2) Income(3) Employment(4) Housing qualityExample paper with description of methodology to calculate ADI [here](https://pubmed.ncbi.nlm.nih.gov/25437404/) (Kind, 2014)Detailed protocol for using ACS estimate to measure Neighborhood Concentrated Disadvantage (PhenX Social Environments Working Group, Sampson et al 1997) [here](https://www.phenxtoolkit.org/protocols/view/211302?origin=search) |
| Intergenerational | Environmental | Birthplace of grandparents and parents | American Community Survey (ACS)Selected by PhenX Demographics expert panel | Self-administered questionnaire | 1 questionnaire item for each relativeWhere was [relative] born?(1) In the United States- Print name of state \_\_\_\_\_\_(2) Outside of the United States- Print name of U.S. Territory (e.g. Puerto Rico, U.S. Virgin Islands, Guam) or name of country \_\_\_\_\_\_\_\_(3) Don’t knowRepeat [relative] for mother’s mother (maternal grandmother), mother’s father (maternal grandfather), father’s mother (paternal grandmother), father’s father (paternal grandfather, biological mother, biological father |
| Intergenerational | Socioeconomic | Parental Education Status | National Longitudinal Study of Adolescent Health (Add Health)Selected by PhenX review panel on demographics, environmental exposures and social environments.  | Interviewer- administered or self-administered questionnaire | 2 questionnaire items:(1) This question is about the woman who functions as a mother in the respondent’s household; she could be the biological mother, stepmother, foster mother, or adoptive mother, or perhaps a grandmother or aunt. If there is no such woman, the question is skipped. How far in school did she go? (2) This question is about the man who functions as a father in the respondent’s household. If there is no such man, the question is skipped. How far in school did he go?Response options: (1) eight grade or less(2) more than eight grades, but did not graduate from high school(3) went to a business, trade, or vocational school instead of high school(4) high school graduate(5) completed a GED(6) went to a business, trade, or vocational school after high school(7) went to college, but did not graduate(8) graduated from a college or university(9) professional training beyond a four-year college or university(10) she never went to school(11) she went to school, but [respondent] doesn’t know what level(12) doesn’t know if she went to school(13) refused(14) skipped / not relevant(15) don’t knowSpecific protocol instructions [here](https://www.phenxtoolkit.org/protocols/view/210201?origin=search) |
| Intergenerational | Socioeconomic | Social Mobility | National Longitudinal Study of Adolescent Health (Add Health) | Computed from self-reported questionnaire responses | Computation: Step 1: Create occupational attainment variables for parents and respondents using the Nam-Power-Boyd ScaleStep 2: Create quintiles from occupational status scores for both parents and individual respondent (1 = the lowest status jobs, 5 = the highest status jobs)Step 3: Subtract parental scores from individual scoresMobility measure ranges from -4 to 4. For example:-4: four-steps downwards-1: one step downward0: immobile1: one step upwards4: four steps upwardsReference with detailed instructions [here](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8336836/) (Gugushvili, 2021) |
| Intergenerational | Health History | Family Health History | My Family Health Portrait (MFPH) Selected by PhenX Rare Genetic Conditions Working Group | Free internet-based data collection tool, endorsed by Centers for Disease Control and prevention (CDC) | Internet based tool that allows individuals to record their family health history regarding their close biological relatives. It assembles family health information and makes a “pedigree” or family tree that can be downloaded and provided to researchers or medical providersAccess My Family Health Portrait [here](https://www.cdc.gov/genomics/famhistory/knowing_not_enough.htm)Access detailed data collection protocol [here](https://www.phenxtoolkit.org/protocols/view/10401) |
| Infancy | Anthropometric | Birthweight and Gestational age | (1) Birth certificate or medical records(2) Self-report (if others not available); National Health and Nutrition Examination Survey (NHANES)  | (1) administrative, healthcare record(2) self-administered or interviewer administered questionnaire | Medical record abstraction from medical records ([Link to example protocol](https://www.phenxtoolkit.org/protocols/view/20201?origin=search), CDC NVSS 2005-2006)Administrative sources like birth records may not be available. Self-reported questionnaire items may be cost effective way to get the data, however may not be reliable in certain populations where recall bias is high (older adults) (more info [here](https://dapa-toolkit.mrc.ac.uk/anthropometry/subjective-methods/birth-weight))The NHANES survey uses the questionnaire items:(1) How much did you weight at birth? 1. If unknown, Did you weigh…
	1. More than 5 ½ pounds (2500g)
	2. Or less than 5 ½ pounds (2500g)
	3. Refused
	4. Don’t Know

More information on participant reported birth weight in NHANES [here](https://www.phenxtoolkit.org/protocols/view/20203)For gestational age, self-report of preterm vs term, rather estimation of gestational weeks at birth, can be more accurate. For example, “Were you born preterm? Preterm is defined as before 37 weeks gestation.” |
| Infancy | Environmental | Birthplace | National Health Interview Survey[Selected by PhenX review panel on demographics](https://www.phenxtoolkit.org/protocols/view/11201) | Self-administered questionnaire | (1) Were you born in the United States? 1. If no, what country were you born?
2. If no, about how long have you been in the United States? (years)

Specific protocol [here](https://www.phenxtoolkit.org/protocols/view/11201) |
| Childhood | Psychosocial | Adverse Childhood Experiences (ACEs) | Behavioral Risk Factor Surveillance System (BRFSS) ACE Data | Interviewer administered or self-administered qustionnaire  | 11-item QuestionnaireParticipant reports whether they experienced each event by age of 18 * ACES included: living with someone with mental illness (1 item), living with someone with substance use problems (2 items), criminal behavior (1 Item), parental divorce (1 item), physical abuse (2 items), emotional abuse (1 item), sexual abuse (3 items)
* Response options: yes, no, don’t know / not sure, refused
* Access measure: [2020 BRFSS Questionnaire (cdc.gov)](https://www.cdc.gov/brfss/questionnaires/pdf-ques/2020-BRFSS-Questionnaire-508.pdf)
 |
| Childhood | Psychosocial | Childhood Maltreatment | Childhood Trauma Questionnaire – Short formSelected by PhenX working groups | Interviewer administered or self-administered questionnaire | 28-item questionnaireWhen I was growing up….Items organized under five domains:(1) Physical abuse (e.g. people in my family hit me so hard that it left me with bruises or marks)(2) Sexual abuse (e.g. Someone tried to make me do sexual things or watch sexual things)(3) Emotional abuse (e.g. people in my family said hurtful or insulting things to me)(4) Physical neglect (e.g. I had to wear dirty clothes)(5) Emotional neglect (e.g. I thought my parents wished I had never been born)Response options: never, rarely true, sometimes true, often true, very often trueSpecific protocol [here](https://www.phenxtoolkit.org/protocols/view/210101?origin=search) |
| Childhood | Environmental | Residential Instability / displacement | The National Longitudinal Study of Adolescent to Adult Health  | Self-administered questionnaire  | 3-items(1) Before your 18th birthday, about how much total time did you spend in jail or detention? (2) Have you ever been homeless for a week or longer – that is, you slept in a place where people weren’t meant to sleep, or slept in a homeless shelter, or didn’t have a regular residence in which to sleep?(3) Have you ever stayed in a homeless shelter?Access Add Health codebook [here](https://addhealth.cpc.unc.edu/documentation/codebook-explorer/#/) |
| Childhood | Socioeconomic | Perceived childhood socioeconomic status | Health and Retirement Survey (HRS) Life History Questionnaire, Section A: Childhood Family and Health | Self-administered questionnaire  | 3-items(1) Now think about your family when you were growing up, from birth to age 16. Would you say your family during that time was pretty well off financially, about average, or poor?(1 = pretty well off financially, 3 = about average, 5 = poor, 6 = it varied, 8 = don’t know, 9 = refuse)(2) While you were growing up, before age 16, did financial difficulties ever cause you or your family to move to a different place? (1 = Yes, 5 = No, 8 = don’t know, 9 = refuse)(3) Before age 16, was there a time when you or your family received help from relatives because of financial difficulties? (1 = yes, 5 = no, 8 = don’t know, 9 = refused)Access HRS codebook [here](https://hrs.isr.umich.edu/sites/default/files/meta/xyear/childfamhealth/codebook/aggchldfh2016a_r.htm) |
| Childhood | Health history | Perceived childhood health status | Health and Retirement Survey (HRS) Life History Questionnaire, Section A: Childhood Family and Health | Self-administered questionnaire | 1 item(1) Consider your health while you were growing up, before you were 16 years old. Would you say that your health during that time was excellent, very good, good, fair, or poor?  (1 = excellent, 2 = very good, 3 = good, 4 = fair, 5 = poor, 8 = don’t know, 9 = refuse)Access HRS codebook [here](https://hrs.isr.umich.edu/sites/default/files/meta/xyear/childfamhealth/codebook/aggchldfh2016a_r.htm) |
| Adolescence | Reproductive | Prepubertal Development - Female | Black Women’s Health Study (BWHS)Selected by PhenX Reproductive Health Working Group | Self-administered questionnaire | 2 items(1) How old were you when your menstrual periods began? Response options: 9 or less, 10, 11, 12, 13, 14, 15, 16, 17 or more, never had periods(2) At about what age did you reach your full height? Response options: before age 13, between 13 and 17 years of age, after age 17, don’t knowAccess protocol [here](https://www.phenxtoolkit.org/protocols/view/100601) |
| Adolescence | Reproductive | Prepubertal development - Male | Study for Future Families and National Longitudinal Survey of YouthSelected by PhenX Reproductive Health Working Group | Self-administered questionnaire | 5 itemsThink about when the following events happened to you. Was this earlier than most of your friends, around the same time, or later? (1) Your voice changed. (2) Your penis started increasing in size. (3) Your testicles started increasing in size(4) You developed pubic hair(5) How old were you when you entered puberty (that is, when these changes began)? Access protocol [here](https://www.phenxtoolkit.org/protocols/view/100602) |
| Adult | Psychosocial | Trauma and stressful events across the life course  | Life stressor Checklist - Revised  | Interviewer-administered or Self-administered questionnaire | Life Stressor Checklist - Revised ([Wolfe](https://www.ptsd.va.gov/professional/assessment/documents/LSC-R.pdf) et al 1997)30-item questionnaire Prologue: now we are going to ask you some questions about events in your life that are frightening, or stressful to most people. Please think back over your **whole life** when you answer these questions. Some of these questions may be about upsetting events that you don’t usually talk about. Your answers are important, but **you do not have to answer any questions that you do not want to.**Example item: Have you ever been in a serious disaster (for example, an earthquake, hurricane, large fire, explosion)? If yes, * A. How old were you when this happened?
* B. At the time of the event did you believe that you or someone else could be killed or seriously harmed?
* C. At the time of the event did you experience feelings of intense helplessness, fear, or, or horror?
* D. How much has this affected your life in the past year? (1 = not at all to 5 = extremely

Other events covered: serious accident, incarceration, adoption, divorce or separation, financial problems, serious physical or mental illness, abuse, neglect, abortion or miscarriage, child taken away, child with disability, caretaking burden, death in the family, robbed/mugged/physically attacked, etc.)Access full questionnaire here |
| Adult | Psychosocial | Exposure to violence and displacement from home | Health and Retirement Survey (HRS); Life History Survey | Self-administered questionnaire | 7 items(1) were you ever in a jail, prison, or a detention center for more than 3 days?(2) were you ever a long-term inpatient in a hospital for 1 month?(3) did you ever live in a combat zone?(4) did you ever live on a military base or in military housing?(5) were you ever homeless for 1 month or more?(6) were you ever a long-term patient for 1 month or more in a clinic for mental, emotional, or substance abuse problem?(7) were you ever displaced from your home for more than 3 days because of a natural disaster? (e.g. earthquake, tornado, floo(Access full questionnaire [here](https://hrsdata.isr.umich.edu/sites/default/files/documentation/questionnaires/HRSLifeHistorySurvey2017_Fall.pdf?_ga=2.49269295.802691082.1666973961-292257114.1666973961) |
| Adult | Anthropometric | Weight gain or loss | Study of Women’s Health Across the Nation (SWAN) Baseline Dataset | Self-administered questionnaire | 2-items(1) Up until now, about how many times have you gained 10 or more pounds (besides during pregnancy) since you were 18 years old? (1 = never, 2 = 1-5 times, 3 = 6-10 times, 4 = more than 10 times)(2) Up until now, about how many times have you lost 10 or more pounds (besides during pregnancy) since you were 18 years old? (1 = never, 2 = 1-5 times, 3 = 6-10 times, 4 = more than 10 times)Access full questionnaire [here](https://www.icpsr.umich.edu/web/ICPSR/series/00253/variables?start=50&SERIESQ=253&EXTERNAL_FLAG=1&ARCHIVE=ICPSR&sort=score%20desc%2CVARLABEL_SORT%20asc&rows=50&q=pregnancy) |
| Adult | Medical history | Lifetime medical history | American Health Information Management Association – My Personal Health Record (myPHR)Selected by PhenX working groups | Self-administered or proxy-administered questionnaire | 1 itemCheck presence of any medical condition. If present, indicate age of onset in years. 1. Acquired immunodeficiency syndrome (AIDs) or HIV Positive
2. Arthritis
3. Asthma
4. Bronchitis
5. Cancer
6. Chlamydia
7. Diabetes
8. Dizziness
9. Emphysema
10. Epilepsy
11. Eye problem
12. Fainting
13. Frequent or severe headaches
14. Glaucoma
15. Gonorrhea
16. Hearing impairment
17. Heart condition
18. Hemodialysis
19. Herpes
20. High blood cholesterol
21. High blood pressure
22. Hypoglycemia
23. Jaundice
24. Kidney disease
25. Low blood pressure
26. Mental retardation / intellectual disability
27. Pain or pressure in chest
28. Palpitations
29. Periods of unconsciousness
30. Rheumatic fever
31. Rheumatism
32. Seizures
33. Shortness of breath
34. Stomach liver or intestinal problems
35. Syphilis
36. Tuberculosis
37. Tumor
38. Thyroid problems
39. Urinary tract infection
40. Other

Access protocol [here](https://www.phenxtoolkit.org/protocols/view/161301?origin=search) |
| Adult | Reproductive | Reproductive history – Male | The Longitudinal Investigation of Fertility and the Environment Study (LIFE)Included in PhenX toolkit | Self-administered questionnaire | 7-item questionnaire1. Have you ever fathered a pregnancy, regardless of outcome? (if no, skip rest of questions)
2. How many?
3. How old were you when you fathered this pregnancy? (years)
4. Was his a planned pregnancy? (e.g. you and you partner had intended to get pregnant)
	1. If yes, how many months did it take for your partner to achieve pregnancy?
5. Was this a multiple pregnancy? (e.g. twins, triplets, etc.)?
	1. If yes, specify number of fetuses
6. What was the outcome of this pregnancy? (NOTE: if multiple birth, repeat question for each fetus. Response options: Live birth, miscarriage, stillbirth, abortion, ectopic/tubal, molar pregnancy
7. Date of birth or loss

Access protocol [here](https://www.phenxtoolkit.org/protocols/view/101302?origin=search) |
| Adult | Reproductive  | Timing of first period - female | Women’s Health Initiative Clinical Trial and Observational Study: Form 31 (  | Self-administered questionnaire | 2 items (1) How old were you when you had your first menstrual period (menses)?(2) During most of your life, were your periods regular; that is, did they occur about once a month? (Do not include any time when you were pregnant or taking birth control pills)Access full questionnaire [here](https://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/document.cgi?study_id=phs000200.v2.p1&phd=1916) |
| Adult | Reproductive | Timing of menopause - female | Women’s Health Initiative Clinical Trial and Observational Study: Form 31  | Self-administered questionnaire | 4 items(1) How old were you when you last had regular menstrual bleeding (a period)?(2) Between the time you had your first period and your last period, did you ever go without any periods for at least one year?(3) How old were you when you last had any menstrual bleeding?(4) Have you ever had menopausal symptoms, such as hot flashes or night sweats? (how old?)Access full questionnaire [here](https://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/document.cgi?study_id=phs000200.v2.p1&phd=1916) |
| Adult | Reproductive  | Pregnancy history / Length of reproductive period - female | Women’s Health Initiative Clinical Trial and Observational Study: Form 31  | Self-administered questionnaire | 6 items(1) Have you ever been pregnant? (including live births, stillbirths, miscarriages, tubal (ectopics), and abortions)(2) How many times have you been pregnant?(3) Did you ever have a pregnancy that lasted at least 6 months?(4) How many pregnancies lasting at least 6 months did you have?(5) How old were you at the end of the first of these pregnancies?(6) How old were you at the end of the last of these pregnancies?Access full questionnaire [here](https://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/document.cgi?study_id=phs000200.v2.p1&phd=1916) |
| Adult | Reproductive | Fertility - female | Women’s Health Initiative Clinical Trial and Observational Study: Form 31  | Self-administered questionnaire  | 4 items(1) Have you ever tried to become pregnant for more than 1 year without becoming pregnant?(2) If yes, did you visit a doctor or clinic because you didn’t get pregnant?(3) If yes, was a reason found for why you did not become pregnant?(4) If yes, what was the reason you did not become pregnant? (Mark: problem with your hormones or ovulation, problem with your tubes or uterus, endometriosis, other problem, don’t know, problem in your partner)Access full questionnaire [here](https://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/document.cgi?study_id=phs000200.v2.p1&phd=1916) |
| Adult | Reproductive | Gravidity and Parity - female | Women’s Health Initiative Clinical Trial and Observational Study: Form 31  | Self-administered questionnaire  | 4 items(1) How many live births did you have?(2) How many stillbirths (from a pregnancy lasting 6 months or more) did you have?(3) How many spontaneous miscarriages did you have?(4) How many tubal (ectopic) pregnancies did you have?Access full questionnaire [here](https://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/document.cgi?study_id=phs000200.v2.p1&phd=1916) |
| Adult | Reproductive | Pregnancy complications - female | Hispanic Community Health Study / Study of Latinos: Pregnancy Complications History Form | Self-administered questionnaire  | For each pregnancy: (1) What was the date of this birth [ or when did this pregnancy end’?(2) Did you have high blood pressure or hypertension during this pregnancy? (if yes: did you have high blood pressure or hypertension before this pregnancy [ and at a time when you weren’t pregnant](3) Did you have preeclampsia or toxemia during this pregnancy?(4) Did you have eclampsia or a seizure during this pregnancy?(5) Did you have diabetes or high blood sugar during this pregnancy? (if yes: did you take medication for your blood sugar during this pregnancy?; did you have diabetes before this pregnancy? [ and at a time when you weren’t pregnant?](6) Was this birth by c-section or vaginal delivery?(7) What was the weight of the baby?(8) How many months or weeks had you been pregnant when [the baby was born / the babies were born / the pregnancy ended]?Access full questionnaire [here](https://sites.cscc.unc.edu/hchs/system/files/forms/PCE-Pregnancy%20Complications%20Hx-9-5-2014.pdf) |

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