## Approach

The epidemiology-environment work group first identified broad categories of exposure relevant to Huntington’s disease (HD). After selecting key categories, instruments were identified for each. The preference was to select existing instruments that were validated, those with prior use in HD studies, and, as appropriate, those used in other disease or general components of the NINDS CDE.

## Organization and classification of instruments

The elements are arranged by broad category with the case report forms (CRF), followed by the template and data dictionary. The dictionary provides the variable name and coding for permissible values for each variable.

Most instruments are designed to be administered by an interviewer, although some may also be completed by self- report, and others such as the dietary questionnaires are designed to be self report instruments. Study case report forms should capture information on how the information was obtained (e.g. self report, informant, etc.). Evidence may change, but at the current time the Subgroup has not classified any of the recommendations as core. All of the elements are classified as supplemental and provide detailed information regarding the exposure and may be appropriate for etiological studies, either case control or prospective. Users may consider selecting only the instrument case report forms for the exposure categories of interest. However, since most of the instruments have been validated as presented it is not recommended that questions be selected individually from an instrument.

## Overview of instruments

Many instruments were used in prior HD trials, including PHAROS and Track-HD. A number of others have been taken from the Parkinson’s Disease Common Data Elements, and are based on the PD Risk Factor Questionnaire (PD-RFQ). This was a questionnaire developed by an epidemiology working group sponsored by the Collaborative Centers for Parkinson’s Disease Epidemiology Research. It has been validated and is now available in eleven languages. Case report forms from the RFQ are included for occupation, physical activity and sleep, residential history, toxicants, history of smoking, home pesticide use, work pesticide use, height and weight (available with pictographs of body habitus or text), medications such as Non-steroidal anti-inflammatory agents (NSAIDS) and calcium channel blockers (CCB).

The Nurse’s Health Study (NHS) behavior assessment is a self administered assessment of smoking, physical activity, and other behaviors. The dietary assessment is a food frequency questionnaire consisting of a list of foods and questions regarding the frequency of use of each food on the list. These instruments have been extensively used and validated in large epidemiological studies. Both are copyrighted and permission for use should be obtained.

Some questions came from the Phenx tool kit.

The older version of the NIH Dietary History Questionnaire was used successfully in PHAROS. The Diet History Questionnaire (DHQ) is a food frequency questionnaire that consists of 124 food items and includes both portion size and dietary supplement questions. Cognitive research findings were used in the design of the instrument so that it would be easy to use. It takes about one hour to complete. The DHQ and accompanying instructions and analytic software are available at [Diet History Questionnaire (DHQ)](http://riskfactor.cancer.gov/DHQ/).

Two instruments for head injury are included. The Ohio State University traumatic brain injury (OSU TBI) instrument is also recommended in the PD-CDE’s. A second instrument covering a broad range of trauma including head injury was developed for use in a NINDS-supported study of dystonia. Questions regarding history of illicit drug use are derived from the Drug History Questionnaire and the PhenX toolkit questionnaire. The PhenX toolkit consists of a list of high priority consensus measures for phenotypes and exposures for use in large scale genomic research studies.

The mini-environmental risk factor questionnaire (MERQ) is from the Parkinson’s Disease Data and Organizing Center (PD-DOC). It contains questions regarding use of medications linked to PD occurrence or progression such as NSAIDs, statins, and hormone replacement therapy. The potential roles of these therapies have not been extensively assessed in HD, but the committee felt it reasonable to consider assessment as they may have general effects on neuron integrity. This instrument is copyrighted.

Questions regarding enriching activities are measured with the Lifetime Cognitive Activity Assessment. These instruments have been used extensively in Alzheimer’s disease and aging research, and the Cognitive Activities Survey was used in PHAROS.

Table of Environmental Data Elements

| Category | Instrument name | Validation | Classification | Admin time |
| --- | --- | --- | --- | --- |
| Occupation | RFQ | yes | Supplemental | 5-18 minutes |
| Physical activity | RFQ | yes | Supplemental | 9-13 minutes |
| Residential history | RFQ | yes | Supplemental | 4-8 minutes |
| Toxicants | RFQ | yes | Supplemental | 3-8 minutes |
| Smoking | RFQ | yes | Supplemental | 1-4 minutes |
| Pesticides home use | RFQ | yes | Supplemental | 3-8 minutes |
| Pesticides work use | RFQ | yes | Supplemental | 3-8 minutes |
| Body habitus | RFQ | yes | Supplemental | 1-2 minutes |
| Medications (optional) | RFQ | yes | Supplemental | 1-5 minutes |
| Medications | PD DOC MERQ | Intentionally left blank | Supplemental | 1-5 minutes |
| Early life exposures | Intentionally left blank | no | Supplemental | 3-5 minutes |
| Head injury | OSU TBI | Intentionally left blank | Supplemental | Intentionally left blank |
| Diet | NHS - FFQ | yes | Supplemental | Intentionally left blank |
| Smoking and other behaviors | NHS - behavior assessment | yes | Supplemental | Intentionally left blank |
| Non-prescribed meds | Drug history questionnaire/phenX | Intentionally left blank | Supplemental | Intentionally left blank |
| Diet | NIH Diet History Questionnaire | yes | Supplemental | 1 hour |
| Enrichment | Cognitive Activities Survey | Intentionally left blank | Supplemental | Intentionally left blank |