|  |
| --- |
| **Epilepsy Screener** |
| **Protocol Id** | 130401 |
| **Description of Protocol** | The following protocol is a nine-item interviewer-administered questionnaire to screen for the presence of epilepsy. |
| **Specific Instructions** | None |
| **Protocol Text** | 1. Did anyone ever tell you that you had a seizure or convulsion caused by a high fever when you were a child?         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t know2. [Other than the seizure[s] you had because of a high fever] Have you ever had, or has anyone ever told you that you had, a seizure disorder or epilepsy?\*         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t knowIf the respondent answers "Yes" to question 2, the protocol is complete. Ask the following questions only if the subject said "NO" to epilepsy or a seizure disorder in question 2.3. [Other than the seizure[s] you had because of a high fever] Have you ever had, or has anyone ever told you that you had, any of the following...\*3a. A seizure, convulsion, fit or spell under any circumstances?         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t know3b. Uncontrolled movements of part or all of your body such as twitching, jerking, shaking or going limp?         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t know3c. An unexplained change in your mental state or level of awareness; or an episode of "spacing out" that you could not control?         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t know3d. Did anyone ever tell you that when you were a small child, you would daydream or stare into space more than other children?         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t know3e. Have you ever noticed any unusual body movements or feelings when exposed to strobe lights, video games, flickering lights, or sun glare?         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t know3f. Shortly after waking up, either in the morning or after a nap, have you ever noticed uncontrollable jerking or clumsiness, such as dropping things or things suddenly "flying" from your hands?         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t know3g. Have you ever had any other type of repeated unusual spells?         [ ] Yes         [ ] No         [ ] Possible         [ ] Don’t know\*Phrase "Other than the seizure[s] you had because of a high fever" added only if subject responded "yes" or "possible" to question 1. |
| **Selection Rationale** | This screener was vetted against similar protocols and selected because it is a validated, brief instrument that is low burden for investigators and respondents. |
| **Source** | Ottman R, Barker-Cummings C, Leibson CL, Vasoli VM, Hauser WA, Buchhalter JR; (2010). Validation of a brief screening instrument for the ascertainment of epilepsy. Epilepsia, 51(2):191-1977. |
| **Language** | English |
| **Participant** | Adult, aged 18 or older |
| **Personnel and Training Required** | The interviewer must be trained to conduct personal interviews with individuals from the general population. The interviewer must be trained and found to be competent (i.e., tested by an expert) at the completion of personal interviews. The interviewer should be trained to prompt respondents further if a "don't know" response is provided. |
| **Equipment Needs** | Either a pencil and paper or computer-assisted instrument may be used. If a computer-assisted instrument is used, computer software may be necessary to develop the instrument. The interviewer will require a laptop computer/handheld computer to administer a computer-assisted questionnaire. |
| **Standards** |

|  |  |  |  |
| --- | --- | --- | --- |
| **Standard** | **Name** | **ID** | **Source** |
| Common Data Element (CDE) | Person Epilepsy Assessment Description Text | 3076113 | [CDE Browser](https://cdebrowser.nci.nih.gov/CDEBrowser/search?elementDetails=9&FirstTimer=0&PageId=ElementDetailsGroup&publicId=3076113&version=1.0) |
| Logical Observation Identifiers Names and Codes (LOINC) | Epilepsy screener proto | 62763-8 | [LOINC](http://s.details.loinc.org/LOINC/62763-8.html?sections=Web) |

 |
| **General References** | Aminoff MJ, Greenberg DA, & Simon RP (2005). *Clinical Neurology* (6th ed.). Lange: McGraw-Hill Medical. pp.¿241-5.Levinsohn, PM. (2007). The autism-epilepsy connection. Epilepsia, 48 Supplement 9:33-35Pliplys S, Dunn, DW, Caplan, R. (2007). 10-year research update review: psychiatric problems in children with epilepsy. Journal of the American Academy of Child Adolescent Psychiatry 46(11): 1389-1402.Meisler, MH, Kearney, JA (2005). Sodium channel mutations in epilepsy and other neurological disorders. Journal of Clinical Investigation. 115(8): 2010-2017. |
| **Protocol Type** | Interviewer-administered questionnaire |
| **Derived Variables** | None |
| **Requirements** |

|  |  |
| --- | --- |
| **Requirement Category** | **Required** |
| Average time of greater than 15 minutes in an unaffected individualAverage time of greater than 15 minutes in an unaffected individual | No |
| Major equipmentThis measure requires a specialized measurement device that may not be readily available in every setting where genome wide association studies are being conducted. Examples of specialized equipment are DEXA, Echocardiography, and Spirometry | No |
| Specialized requirements for biospecimen collectionThis protocol requires that blood, urine, etc. be collected from the study participants. | No |
| Specialized trainingThis measure requires staff training in the protocol methodology and/or in the conduct of the data analysis. | No |

 |