# Supporting Statement B for

## Quality of Life Outcomes in Neurological Disorders (NINDS)

**Project Officer:**  Claudia S. Moy, PhD

**IC:** National Institute of Neurological Disorders and Stroke (NINDS)

**Address:**   Neuroscience Center, room 2214

6001 Executive Blvd., MSC 9520

Bethesda, MD  20892-9520

Voice: 301/496-2789

Fax: 301-480-1080

Email: moyc@ninds.nih.gov

**LIST OF ATTACHMENTS**

**Attachment 1 –** Expert Neurology Professionals Consulted

**Attachment 2 –** Public comment on federal register

**Attachment 3 –** Panel Testing Company Invitation to Participate

**Attachment 4 –** Panel Testing Company Privacy Policy

**Attachment 5 –** ENH IRB Report

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**Quality of Life Outcomes in Neurological Disorders (NINDS)**

Part B: Collection of Information Employing Statistical Methods

### B.1.  Respondent Universe and Sampling Methods

Respondents will be recruited via an Internet survey company from their 1 million member online panels. A maximum of 6000 adults (4000 English-speaking and 2000 Spanish speaking) and 3000 children (2000 English-speaking and 1000 Spanish-speaking) stratified by age, gender and race will be recruited for Wave 1. The primary purpose of this survey is to collect sufficient data to perform item calibrations. Since IRT item parameter estimations require that each trait be adequately covered along its entire range, we will purposively sample English-speaking respondents at the floor level for each trait to ensure that all categories of all items are answered by some proportion of the sample.  Gender and race stratification will be used in order to enable analyses of differential item functioning on these two variables.

Item banks are grouped into 6 forms and each respondent will be randomly assigned to one form. As shown in Tables B.1-1 and B.1-2, adult testing consists of 4 forms (form A-D) with 4000 English speaking and 2000 Spanish speaking respondents,  while there are 2 forms for pediatric respondents (2000 English-speaking and 1000 Spanish-speaking).

**Table B.1-1. Phase II, Wave 1 - Adult Enrollment**

| Banks | Estimated Items Per Bank | Form | English | Spanish | Total Per Form |
|---|---|---|---|---|---|
| Social Role Performance | 49 | A | 1,000 | 500 | **1,500** |
| Social Role Satisfaction | 51 | | | | |
| Assistive Devices Screen | 13 | B | 1,000 | 500 | **1,500** |
| Physical Function Screen | 1 | | | | |
| Mobility/Ambulation | 37 | | | | |
| Upper Extremity/ADLs | 44 | | | | |
| Depression | 31 | C | 1,000 | 500 | **1,500** |
| Fear/Anxiety | 28 | | | | |
| Positive Psychological Function | 27 | | | | |
| Perceived Cognitive Function | 45 | D | 1,000 | 500 | **1,500** |
| Applied Cognitive Function | 44 | | | | |
| **Total Adult Enrollment** | | | **4,000** | **2,000** | **6,000** |

**Table B.1-2 - Phase II, Wave 1 - Pediatric Enrollment**

| Banks | Estimated Items Per Bank | Form | English | Spanish | Total Per Form |
|---|---|---|---|---|---|
| Emotional Distress | 46 | E | 1,000 | 500 | **1,500** |
| Social Function | 38 | | | | |
| Physical Function Screen | 1 | F | 1,000 | 500 | **1,500** |
| Physical Function Walking Aids | 11 | | | | |
| Physical Function Wheel Chair | 21 | | | | |
| Upper Extremity Function | 41 | | | | |
| Mobility/Lower Extremity Function | 39 | | | | |
| **Total Pediatric Enrollment** | | | **2,000** | **1,000** | **3,000** |

B.2.  Procedures for the Collection of Information

The respondents for this internet survey will be selected from a panel of over one million respondents, using the company's sample matching methodology.  The first step in the process is to extract all active

and available panelists that meet the screening criteria (e.g., demographic) into a pool. After randomly sorting this pool, an algorithm is used to iteratively sample panelists who meet selection criteria (e.g., age, gender, race/ethnicity, language, and presence or absence of self-identified neurological condition) in their order of priority until a sample of panelists balanced to the target criteria has been identified. Once potential respondents are selected into a balanced sample, they are emailed an invitation with a unique URL. This provides access to the questionnaire. Once the desired number of respondents meeting specified criteria is achieved (e.g., gender, age), the survey for that quota is closed.

**Panel Recruitment**

Panelists have been recruited by a variety of methods, such as e-random digit dialing, invitations via web newsletters, and Internet poll-based recruitment where panelists have opted to participate in a survey advertised on the World Wide Web. The topics of these surveys vary greatly – from politics to polls on popular entertainment.

All of the panelists have provided their e-mail so that they may receive survey invitations to participate in surveys run by our collaborator. The invitation for this survey is included as Attachment 3.

**B.3.  Methods to Maximize Response Rates and Deal with Nonresponse**

The online panel testing company that we plan to use has reported a base response rate of 30-60%, depending on the sample being surveyed. This response rate should be sufficient to recruit the sample needed for the study, given that the panel we are recruiting from is large and diverse. Since we are not seeking a sample representative of the general US population, aggressive measures to increase this rate (e.g., sending more than two invitations to take the survey) will not be used.

**B.4.  Test of Procedures or Methods to be Undertaken**

All of the proposed methods have been implemented in other similar projects, such as the PROMIS

project that is being conducted by the same organization, thus no pre-testing of the proposed procedures is

to be undertaken.

**B.5.  Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data**

| Last | First | Credentials | Institution | Phone Number |
|------|-------|-------------|-------------|--------------|
| Vollets-Zacarias | Betsy | PhD | IPSOS | 920-465-1799 |
| Gershon | Richard | PhD | ENH | 224-364-7311 |
| Lai | Jin Shei | PhD | ENH | 224-364-7312 |
| Choi | Seung | PhD | ENH | 224-364-7317 |
| Bass | Michael | MS | ENH | 224-364-7362 |
| Bode | Rita | PhD | RIC | 312-238-0713 |