

Neuro-QOL Adult Sociodemographic Form

On average, it takes 30 minutes to complete the Neuro-QOL survey

- 1 What is your telephone area code (where you currently live)? _____

- 2 What is your age? _____

- 3 What is your gender?
 - 1=Male
 - 2=Female

- 4 Are you of Spanish/Hispanic/Latino origin?
 - 0=No
 - 1=Yes

- 5 What is your racial or ethnic background? (Please mark all that apply)
 - 1=White
 - 2=Black or African-American
 - 3=American Indian/Alaska Native
 - 4=Asian
 - 5=Native Hawaiian/Other Pacific Islander

- 6 What is your current relationship status?
 - 1=Never Married
 - 2=Married
 - 3=Living with partner in committed relationship
 - 4=Separated
 - 5=Divorced
 - 6=Widowed

- 7 What is the highest grade in school that you completed?
 - 1=5th grade or less
 - 2= 6th grade
 - 3=7th grade
 - 4=8th grade
 - 5=Some high school
 - 6=High school grad/GED
 - 7=Some college/Technical degree/AA
 - 8=College degree (BA/BS)
 - 9=Advanced degree (MA, PhD, MD)

- 8 What is your current occupational status? (Please mark all that apply)
 - 1=Homemaker
 - 2=Unemployed
 - 3=Retired
 - 4=On disability
 - 5= On leave of absence
 - 6=Full-time employed
 - 7=Part-time employed
 - 8=Full-time student

- 9 What is your family household income (from all sources)?
 - 1=Less than \$20,000
 - 2=Between \$20,000 and \$49,999
 - 3=Between \$50,000 and \$99,999
 - 4=\$100,000 or more

- 10 What is your height? _____(feet) _____(inches)
- 11 What is your weight in pounds? _____
- 12 Mobility
1=I have no problems in walking about
2=I have some problems in walking about
3=I am confined to bed
- 13 Self-Care
1=I have no problems with self-care
2=I have some problems with washing or dressing myself
3=I am unable to wash or dress myself
- 14 Usual Activities (e.g. work, study, housework, family or leisure activities)
1=I have no problems with performing my usual activities
2=I have some problems with performing my usual activities
3=I am unable to perform my usual activities
- 15 Please indicate which statement below best describes your current activity level
0=I have normal activity, without symptoms
1=I have some symptoms, but do not require bed rest during the waking day
2=I require bed rest for less than 50% of the waking day
3=I require bed rest for more than 50% of the waking day
4=I am unable to get out of bed
- 16 Pain/Discomfort
1=I have no pain or discomfort
2=I have moderate pain or discomfort
3=I have extreme pain or discomfort
- 17 Anxiety/Depression
1=I am not anxious or depressed
2=I am moderately anxious or depressed
3=I am extremely anxious or depressed
- 18 In the past 30 days, have you used or taken medication for which a prescription is needed? Include only those products prescribed by a health professional such as a doctor or dentist.
0=No
1=Yes
2=Don't Know
- 19 How many different times did you stay in any hospital overnight or longer during the past 12 months? _____
- 20 During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities such as self-care, work, or recreation? _____

Neuro-QOL Adult Clinical Form

*****Note that each patient will not necessarily complete each of the following questions, but only those that apply*****

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|----|---|-------------------|
| 1 | Have you ever been told by a doctor or a health professional that you have high blood pressure (hypertension)? | 0 = No
1 = Yes |
| 2 | Are any of your current activities limited by your high blood pressure (hypertension)? | 0 = No
1 = Yes |
| 3 | Have you ever been told by a doctor or a health professional that you had chest pain (angina)? | 0 = No
1 = Yes |
| 4 | Are any of your current activities limited by your chest pain (angina)? | 0 = No
1 = Yes |
| 5 | Have you ever been told by a doctor or a health professional that you have hardening of the arteries (coronary artery disease)? | 0 = No
1 = Yes |
| 6 | Are any of your current activities limited by your hardening of the arteries (coronary artery disease)? | 0 = No
1 = Yes |
| 7 | Have you ever been told by a doctor or a health professional that you have heart failure or congestive heart failure? | 0 = No
1 = Yes |
| 8 | Are any of your current activities limited by your heart failure or congestive heart failure? | 0 = No
1 = Yes |
| 9 | Have you ever been told by a doctor or a health professional that you had a heart attack (myocardial infarction)? | 0 = No
1 = Yes |
| 10 | Are any of your current activities limited by your heart attack (myocardial infarction)? | 0 = No
1 = Yes |

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|----|--|---|
| 11 | Have you ever been told by a doctor or a health professional that you had a stroke or transient ischemic attack (TIA)? | 0 = No
1 = Yes |
| 12 | Are any of your current activities limited by your stroke or transient ischemic attack (TIA)? | 0 = No
1 = Yes |
| 13 | How many years ago did you have your stroke or transient ischemic attack (TIA)? | _____ |
| 14 | Compare your overall stroke-related symptoms now with what you experienced one year ago. Are they better, worse or about the same? | 1=Better
2=Worse
3=About the Same |
| 15 | Have you ever been told by a doctor or a health professional that you have migraines or severe headaches? | 0 = No
1 = Yes |
| 16 | Are any of your current activities limited by your migraines or severe headaches? | 0 = No
1 = Yes |
| 17 | Have you ever been told by a doctor or a health professional that you have diabetes or high blood sugar or sugar in your urine? | 0 = No
1 = Yes |
| 18 | Are any of your current activities limited by your diabetes or high blood sugar or sugar in your urine? | 0 = No
1 = Yes |
| 19 | How many years have you had diabetes? | _____ |
| 20 | Has your diabetes caused a problem for any of the following parts of your body: eyes, kidneys or feet? | 0=No
1=Yes
2=Not Sure |
| 21 | Have you ever been hospitalized because of your diabetes? | 0=No
1=Yes
2=Not Sure |
| 22 | Have you ever been told by a doctor or a health professional that you have cancer (other than non-melanoma skin cancer)? | 0 = No
1 = Yes |

- 23 Are any of your current activities limited by your cancer (other than non-melanoma skin cancer)?
- 0 = No
1 = Yes
- 24 Please select your "primary" cancer diagnosis from the list below (usually where the cancer started)
- 1=Bone/muscle (e.g. Sarcomas)
2=Brain
3=Breast
4=Melanoma
5=Esophagus or Stomach
6=Gynecologic (e.g. Cervical, Ovarian, Uterine)
7=Head/Neck
8=Hodgkin's Lymphoma
9=Leukemia
10=Liver
11=Lung
12=Colon or Rectum
13 =Multiple Myeloma
14=Non-Hodgkin's Lymphoma
15=Non Melanoma Skin
16=Pancreas
17=Prostate
18=Urologic(e.g. Bladder, Kidney, Testis)
19=Unknown or Other
- 25 Have you had a recurrence of your cancer (i.e., has your cancer come back)?
- 0=No
1=Yes
2=Not Sure
- 26 Has your cancer spread to any lymph nodes?
- 0=No
1=Yes
2=Not Sure
- 27 Has your cancer spread to another part of your body (other than to any lymph nodes)?
- 0=No
1=Yes
2=Not Sure
- 28 Do you currently have any numbness, tingling, or pain in your hands or feet?
- 0=No
1=Yes
- 29 Have you ever been told by a doctor or a health professional that you have depression?
- 0 = No
1 = Yes
- 30 Are any of your current activities limited by your depression?
- 0 = No
1 = Yes

- | | | |
|----|--|---|
| 31 | Have you received treatment from a mental health specialist (for example a psychiatrist, psychologist, social worker, or other therapist) for your depression? | 0=No
1=Yes |
| 32 | To what extent does your depression interfere with your relationships with family or friends? | 0=Not at all
1=A little bit
2=Somewhat
3= Quite a bit
4=Very much |
| 33 | To what extent does your depression interfere with maintaining your responsibilities at work or at home? | 0=Not at all
1=A little bit
2=Somewhat
3= Quite a bit
4=Very much |
| 34 | Have you ever been told by a doctor or a health professional that you have anxiety? | 0 = No
1 = Yes |
| 35 | Are any of your current activities limited by your anxiety? | 0 = No
1 = Yes |
| 36 | Have you received treatment from a mental health specialist (for example a psychiatrist, psychologist, social worker, or other therapist) for your anxiety? | 0=No
1=Yes |
| 37 | To what extent does your anxiety interfere with your relationships with family or friends? | 0=Not at all
1=A little bit
2=Somewhat
3= Quite a bit
4=Very much |
| 38 | To what extent does your anxiety interfere with maintaining your responsibilities at work or at home? | 0=Not at all
1=A little bit
2=Somewhat
3= Quite a bit
4=Very much |

- 39 Have you ever been told by a doctor or a health professional that you have an alcohol or drug problem? 0 = No
1 = Yes
- 40 Are any of your current activities limited by your alcohol or drug problem? 0 = No
1 = Yes
- 41 Have you received treatment from a mental health specialist (for example a psychiatrist, psychologist, social worker, or other therapist) for your alcohol or drug problem? 0=No
1=Yes
- 42 To what extent does your alcohol or drug problem interfere with your relationships with family and friends? 0=Not at all
1=A little bit
2=Somewhat
3= Quite a bit
4=Very much
- 43 To what extent does your alcohol or drug problem interfere with maintaining your responsibilities at work or at home? 0=Not at all
1=A little bit
2=Somewhat
3= Quite a bit
4=Very much
- 44 Have you ever been told by a doctor or a health professional that you have a sleep disorder? 0 = No
1 = Yes
- 45 Are any of your current activities limited by your sleep disorder? 0 = No
1 = Yes
- 46 What type of sleep disorder was diagnosed? (Please mark all that apply) 1=Insomnia
2=Narcolepsy
3=Obstructive sleep apnea
4=Idiopathic hypersomnia
5=Restless Legs Syndrome
6=Sleep terrors
7=Periodic limb movement disorder
8=Sleepwalking
9=Delayed sleep phase syndrome
10=Nightmares
11=Advanced sleep phase syndrome
12=REM sleep behavior disorder
13=Shift work sleep disorder

- 47 Has your sleep disorder been treated?
0=No
1=Yes
2=Not Sure
- 48 What type of treatment did you receive? (Please mark all that apply)
1=Medication
2=CPAP, Bilevel pressure
3=Oral appliance
4=Behavioral
5=Over-the-counter or non-prescription treatment
6=Other
- 49 Did the treatment help you?
0=Not at all
1=A little bit
2=Somewhat
3= Quite a bit
4=Very much
- 50 Have you ever been told by a doctor or a health professional that you have HIV or AIDS?
0 = No
1 = Yes
- 51 Are any of your current activities limited by your HIV or AIDS?
0 = No
1 = Yes
- 52 Have you ever been told by a doctor or a health professional that you have a spinal cord injury?
0 = No
1 = Yes
- 53 Are any of your current activities limited by your spinal cord injury?
0 = No
1 = Yes
- 54 How long ago was your spinal cord injury?
1=Less than two years ago
2=Between two and five years ago
3=Between six and ten years ago
4=Between 11 and 20 years ago
5=More than 20 years ago
- 55 At what level is your spinal cord injury?
1=Lumbar
2=Thoracic
3=Cervical

- 56 Is your spinal cord injury complete or incomplete?
1=Complete
2=Incomplete
- 57 Have you ever been told by a doctor or a health professional that you have Multiple Sclerosis (MS)?
0 = No
1 = Yes
- 58 Are any of your current activities limited by your Multiple Sclerosis (MS)?
0 = No
1 = Yes
- 59 How long ago was your MS diagnosed?
1=Less than two years ago
2=Between two and five years ago
3=Between six and ten years ago
4=Between 11 and 20 years ago
5=More than 20 years ago
- 60 Compare your overall symptoms now with what you experienced one year ago. Is your MS better, worse or about the same?
1=Better
2=Worse
3=About the Same
- 61 Are you taking disease-modifying drugs for your MS such as Avonex, Betaseron, Copaxone or Rebif?
0=No
1=Yes
- 62 Have you ever been told by a doctor or a health professional that you had Parkinson's Disease?
0 = No
1 = Yes
- 63 Are any of your current activities limited by your Parkinson's Disease?
0 = No
1 = Yes
- 64 How long ago was your Parkinson's disease diagnosed?
1=Less than two years ago
2=Between two and five years ago
3=Between six and ten years ago
4=Between 11 and 20 years ago
5=More than 20 years ago
- 65 Compare your overall symptoms now with what you experienced one year ago. Is your Parkinson's disease better, worse or about the same?
1=Better
2=Worse
3=About the Same

- 66 Have you ever been told by a doctor or a health professional that you had epilepsy?
0 = No
1 = Yes
- 67 Are any of your current activities limited by your epilepsy?
0 = No
1 = Yes
- 68 How long ago was your epilepsy diagnosed?
1=Less than two years ago
2=Between two and five years ago
3=Between six and ten years ago
4=Between 11 and 20 years ago
5=More than 20 years ago
- 69 Compare your overall symptoms now with what you experienced one year ago. Is your epilepsy better, worse or about the same?
1=Better
2=Worse
3=About the Same
- 70 Have you ever been told by a doctor or a health professional that you had Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease?
0 = No
1 = Yes
- 71 Are any of your current activities limited by your Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's disease?
0 = No
1 = Yes
- 72 How long ago was your ALS diagnosed?
1=Less than 1 year ago
2=Between 1 -- 2 years ago
3=Between 3 -- 5 years ago
4=Between 6 -- 10 years ago
5=More than 10 years ago
- 73 Compare your overall symptoms now with what you experienced one year ago. Is your ALS better, worse or about the same?
1=Better
2=Worse
3=About the Same
- 74 Do you have children under 20?
0 = No
1 = Yes
- 75 Have you ever been told by a doctor or a health professional that your child had epilepsy?
0 = No
1 = Yes

- 76 Are any of your child's current activities limited by epilepsy?
0 = No
1 = Yes
- 77 How long ago was your child's epilepsy diagnosed?
1=Less than two years ago
2=Between two and five years ago
3=Between six and ten years ago
4=Between 11 and 20 years ago
5=More than 20 years ago
- 78 Compare your child's overall symptoms now with what he/she experienced one year ago. Is your child's epilepsy better, worse or about the same?
1=Better
2=Worse
3=About the Same
- 79 Have you ever been told by a doctor or a health professional that your child had muscular dystrophy?
0 = No
1 = Yes
- 80 Are any of your child's current activities limited by muscular dystrophy?
0 = No
1 = Yes
- 81 How long ago was your child's muscular dystrophy diagnosed?
1=Less than two years ago
2=Between two and five years ago
3=Between six and ten years ago
4=Between 11 and 20 years ago
5=More than 20 years ago
- 82 Compare your child's overall symptoms now with what he/she experienced one year ago. Is your child's muscular dystrophy better, worse or about the same?
1=Better
2=Worse
3=About the Same

Neuro-QOL Sociodemographic Form (PEDIATRIC VERSION)

- 1 What is your telephone area code (where you currently live) _____
- 2 How old are you? _____
- 3 What is your gender?
1=Male
2=Female
- 4 Are you of Spanish/Hispanic/Latino origin?
0=No
1=Yes
- 5 What is your racial or ethnic background? (Please mark all that apply)
1=White
2=Black or African-American
3=American Indian/Alaska Native
4=Asian
5=Native Hawaiian/Other Pacific Islander
- 6 Are you attending school now (including home school)?
If yes, what grade are you in? _____
If no, what is the highest grade in school that you completed? _____
- 7 What is your current occupational status? (Please mark all that apply)
1=Full-time employed
2=Part-time employed
3=Full-time student
4=Part-time student
5=none of above
- 8 What is your height? _____(feet) _____(inches)
- 9 What is your weight in pounds? _____
- 10 How many different times did you stay in any hospital overnight or longer during the past 12 months?