Using Patient-Reported Outcomes to Drive Multiple Sclerosis Care Draft Measure Specifications for Field Testing	
Title:	Using Patient-Reported Outcomes to Drive Multiple Sclerosis Care
Description:	Percentage of persons with MS age 18 or older who, during the measurement period, complete an initial PRO assessment in association with a clinic encounter/visit , have a care plan developed based on the PRO responses and patient priorities, and complete at least one PRO follow-up assessment within the measurement period. (For field testing this will be reassessment within **6 months**)
Numerator:	All patients within the denominator who complete an initial PRO assessment using a qualified tool(s)* during a clinic encounter/visit AND have a care plan developed based on the PRO responses and patient prioritization AND complete at least one follow-up PRO assessment within 6 months. (For field testing the initial assessment should occur during the first six months of the trial period and follow-up reassessment would occur within **6 months**)
Denominator:	All MS patients age 18 and older who have a clinic encounter/visit, except those who are excluded.
Denominator and Numerator Exclusion criteria:	- Age < 18 at time of the first clinic encounter/visit during the field test - Non-English speaking and no translation of PROM available - Patient declines to complete the first or follow-up PROM - Patient does not complete the first or follow-up PROM even after 2 requests from provider - Patient is no longer receiving care from the practice/clinic - Patient encounter/visit was only for evaluation or second opinion
Measurement Period:	September 1, 2018 – August 31, 2019
Eligible Patient Population:	Patients with a confirmed diagnosis of MS (ICD-10, G35)
Eligible Providers:	Medical Doctors, Doctors of Osteopathy, and Nurse Practitioners specializing in neurology.
Measure Scoring:	Rate/Proportion
Interpretation of Score:	Higher score indicates better quality
Measure Type:	Process

*For field testing, the qualified tool is the MS-Specific Patient Reported Outcome Measure (PROM) provided in Appendix B.

MS-Specific PROM Implementation

The MS-specific PROM should be administered to all eligible patients at least twice during the measurement period ([September 1, 2018]-[August 31, 2019]), as documented in the patient's medical record. All eligible patients should have an *Initial Assessment* and *Follow-Up Assessment*, as defined below:

- **Initial Assessment**: the patient completes the MS-specific PROM at his/her first clinical encounter during the testing period. The patient may provide responses directly or an interviewer may ask the patient the questions and document the patient's responses. At least one question must have a valid response from the patient to be considered complete. The PROM should be administered up to 14 days before or at the time of the scheduled clinical visit. A care plan is developed by the provider and patient based on the patient's responses and priorities. The care plan must be documented in the patient's medical record. During field testing, collection of initial assessments will be limited to the first 6 months of the testing period.

- **Follow-Up Assessment**: the patient completes the MS-specific PROM within 6 months of his/her initial assessment. The PROM can be administered up to 14 days before or at the time of the scheduled clinical visit. Patients without a clinic visit should be contacted by the provider to request completion of the follow-up PROM. The patient may provide responses directly or an interviewer may ask the patient the questions and document the patient's responses. At least one question must have a valid response from the patient to be considered complete.

- **Note**: In order for a an assessment to be counted as "complete" the patient must respond to the seven core domain gateway questions along with the global QoL question (a total of 8 questions). Please see the MS-Specific PROM in Appendix B.

Administration: The MS-specific PROM should be administered to all eligible patients at least twice during the testing period. It may be administered on paper, via a computer-based data collection system, or by telephone interview. Interviewers may also assist patients who are unable to independently complete the PROM because of visual or upper extremity difficulties. Proxies may complete PROMs for patients who are unable to self-report because of cognitive deficits.

Scoring: The MS-specific PROM is intended to provide clinicians with item-level data (i.e., patient responses to individual questions). The ways in which clinicians access PROM results will vary depending on the data collection method and the site-specific clinical workflow. Acceptable methods include viewing paper-and-pencil copies, in an EHR, or in a separate data collection system.

Test Site Responsibilities

1. Use our qualified PROM to collect PRO-PM data on all eligible patients during the measurement period (at least 50 MS patients).
2. Work with NU to execute a contract and data use agreement and establish a secure data transfer protocol between site and Northwestern
   a. Identify who will send data to NU. Data may be sent by providers or other clinical staff, or authorized institutional representatives (e.g., IT staff within a health system)
   b. At NU, data may be shared with Dave Cella, Aaron Kaat, Cindy Nowinski, Anne Deutsch (consultant), the TBD analyst, Elijah Patten (study coordinator), and potentially informatics staff required to set up the transfer site.

3. Using the data model and codebook provided to them, send Northwestern the de-identified or masked data for the data elements summarized below.

    - Date of birth (masked) or age in years at time of first clinical encounter (CE), or for individuals age 90+ a statement to that effect
    - Dates (masked) for 1) initial assessment, 2) initial CE, 3) care plan (default date for this will be date of initial CE), 4) date of follow-up PRO assessment
    - PRO item responses for each assessment
    - Mode of PRO administration (paper-and-pencil; computer; interviewer)
    - PROM respondent: patient or proxy
    - Reason a PRO initial or re-assessment was not done – *Only for patients who did not receive a PRO assessment*
    - Indication that care plan was developed (Y/N checkbox)
    - Indication that person with MS was asked about priorities (Y/N)
    - Practice information (e.g. number of providers)
    - Clinical information (e.g. MS subtype; co-morbidities, treatment)
    - Other demographics (e.g. sex, race, ethnicity)
    - Unique identifier for each patient to provide linkage between data from initial and follow-up PRO assessments

4. For e-Measure evaluation, sites will provide information on
    a. data element availability in their EMR,
    b. source of data element and,
    c. how collection of the data elements fit into their clinical workflow.

5. Optional: To conduct a chart review for the purpose of auditing the care plan data element

Data Elements and Field Specifications
Use this section to build your data submission. The specifications contain detailed information regarding each column in the submission file, including column order, definitions, examples, and appropriate formatting.

Column	Field Name	Notes	Required	Format	Example
A	Clinic_ID	Identifier of clinic site	Yes	alphanumeric	NU-Neurology
B	Patient_ID	Sequentially-numbered identifier within a clinic site	Yes	numeric	1
C	DOB_shift	Shifted Date of Birth; January 1st of year of birth; patients should be no older than 90 years of age (i.e., 01/01/1929 is the earliest acceptable shifted DOB)	Yes	01/01/yyyy	01/01/1955
D	Patient_Gender	1=Male; 2=Female; 3=Other or Unknown	Yes	numeric	2
E	Assessment_Number	1=Baseline; 2=Follow-up	Yes	numeric	1
F	EncounterDate_shifted	Shifted date of baseline clinic visit or shifted date of follow-up PROM completion = Encounter date - [DOB - January 1st]. For example: a March 3rd DOB is 62 days (including the 3rd) from January 1st in a non-leap-year-of-birth. If a clinical encounter occurs on 10/10/2018, the date shifted encounter = 10/10/2018 - 62 days, which is 8/9/2018.	Yes	mm/dd/yyyy	8/9/2018
G	MOA	Mode of administration - 1=Electronic; 2=Paper; 3=Interview; 4=Telephone	Yes	numeric	3
H	Respondent	1=Self; 2=Proxy	Yes	numeric	1

Column	Field Name	Notes	Required	Format	Example
I	PROM_Timing	1=PROM completed during a clinical encounter; 2=PROM completed before clinical encounter (i.e. at home or community setting)	Yes	numeric	2
J	EHR_Int	Was the PROM integrated into the EHR data? (1=Yes; 2=No)	Yes	numeric	3
K	EHR_Ext	Was the PRO data (i.e. this file) extracted from an EHR or manually entered? (1=Extracted from EHR; 2=Entered manually)	Yes	numeric	2
L	Patient_Exclusions	0 = No exclusionary criteria; 1 = Age < 18 at time of initial assessment; 2 = Non-English speaking and no translation of PROM available; 3 = Patient declines to complete initial or follow-up PROM; 4 = Patient does not complete initial or follow-up PROM even after 2 requests from provider; 5 = Patient is no longer receiving care from the practice; 6 = Patient visit was only for evaluation or second opinion.	Yes	numeric	0
M	ContactAttempt1_shift	Shifted date of first active attempt by medical team to pursue PROM completion; required if patient declined after 2 contact attempts. Shifted date of contact attempts = Attempt date - [DOB - January 1st]. For example: a March 3rd DOB is 62 days (including the 3rd) from January 1st in a non-leap-year-of-birth. If a contact attempt occurs on 10/10/2018, the date shifted attempt = 10/10/2018 - 62 days, which is 8/9/2018.	No	mm/dd/yyyy	5/28/2018

Column	Field Name	Notes	Required	Format	Example
N	ContactAttempt2_shift	Shifted date of second active attempt by medical team to pursue PROM completion; required if patient declined after 2 contact attempts. Shifted date of contact attempts = Attempt date - [DOB - January 1st]. For example: a March 3rd DOB is 62 days (including the 3rd) from January 1st in a non-leap-year-of-birth. If a contact attempt occurs on 10/10/2018, the date shifted attempt = 10/10/2018 - 62 days, which is 8/9/2018.	No	mm/dd/yyyy	6/4/2018
O through BZ	PROM_Responses	Responses to all PROM items; Standard Vocabulary [For example: 5=Without any difficulty, 4=With a little difficulty, 3=With some difficulty, 2=With much difficulty, 1=Unable to do, -9=Skipped, -8=Refused]	Yes	numeric	4
CA	Careplan	Was a careplan developed based off of the PROM responses? [0=No plan developed; 1=Careplan developed]	Yes	numeric	1

Appendix A

PROM Rationale Outline

Project History and Stakeholder Involvement

Stakeholders, including clinicians, researchers, individuals with MS, and patient advocates, participated in this project from the beginning. A stakeholder panel was first assembled late in 2016 by the National Quality Forum (NQF) to discuss how to better create and incorporate patient-reported outcomes in the traditional care model of MS. The main recommendation that emerged from this session was the need for a performance measure paired with periodic PRO data and clinical intervention.

To implement this recommendation, NQF recruited three members from the expert panel (Drs. Cella, Deutsch and Kaat) to become developers of an MS-specific PRO measure (PROM) and a performance measure that assesses the use of an MS-specific PROM in clinical care. The remaining stakeholders have continued to contribute to the project by offering periodic input into the measure development. Specifically, in early 2018, the measure developer team convened the experts to discuss and receive feedback regarding draft versions of the PROM and performance measure. Clinician experts, in addition, have aided in the PRO item selection process by ranking items in terms of clinical actionability.

PRO Domain Selection and PROM Format

We reviewed commonly reported symptoms from the National Multiple Sclerosis Society (NMSS); PatientsLikeMe MS community survey (see the NQF report for more details); review of the literature on existing MS-specific PROMs; and multistakeholder input (including patients and clinicians). We identified 14 clinically relevant PRO domains. Given the heterogeneous nature of MS, both between and within individuals across time, we were pressed to balance comprehensive assessment and patient burden. We conceptualized a categorization system of "Core" and "Supplemental" domains in response to this challenge.

Our PROM (see table below) consists of seven domains which we consider "core," in that all patients are asked to complete these sections of the measure. All patients complete the six Core Domains plus a global HRQoL question. Each domain is assessed with up to four items (or questions). Assessment of Core Domains begins with a "gateway" item; the patient's response to the gateway item determines whether the patient is asked the remaining three items within that bank. Use of "gateway" questions and skip patterns are a useful way to reduce respondent burden, which increases the efficiency of the questionnaire by decreasing the number of questions that need responses. For example, if a respondent indicates s/he does not have pain, s/he can skip any follow-up questions asking about pain in terms of intensity of frequency. The use of gateway questions and skip patterns can also reduce errors, because a respondent who reports no pain is unable to provide a rating of the intensity of pain. This approach is

recommended in the literature for efficient questionnaire development. The use of gateway questions and skip patterns is used by the Centers for Medicare and Medicaid Services on the post-acute care assessment instruments. For example, the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI) uses this approach with several data elements, including C0100, C0600, GG0170H1, GG0170Q1, M0210.

Patients can elect to report on any Optional Domains that are of importance to them. Optional Domains do not include a gateway item. Across domains, patients can answer a minimum of 7 items and a maximum of 57 items on the MS-specific PROM. This approach is intended to minimize patient and provider burden while addressing key domains that are most important to patients with MS.

Source Measures

We relied on measurement systems with calibrated item banks to serve as our primary source measures. Using calibrated banks, scores can be generated for any subset of items. Specific items were chosen using psychometric information and clinician input on clinical relevance and actionability.

Of the existing calibrated measurement systems, we relied heavily on the Neuro-QoL system, given that it was developed for patients with neurological conditions and has been validated for use with MS. We also selected several PROMIS measures. PROMIS was developed for individuals with chronic conditions, and some measures (i.e., PROMIS MS Fatigue) have been specifically validated on individuals with MS.

A few domains were not addressed by either Neuro-QoL or PROMIS, in which case we looked to other measurement systems. We selected the Vision QOL Role Performance measure from the NIH Toolbox system. This IRT-calibrated measure was validated and normed in the general population.   For Bladder Function, we utilized the Bladder Management measure from SCI-QoL, another IRT-based measurement system closely related to Neuro-QoL. While developed for patients with spinal cord injuries, experts considered the items also appropriate for use in MS.

Of the available assessments relating to spasticity, we selected the Patient Reported Impact of Spasticity Measure (PRISM), which consists of 8 IRT-calibrated items. These items were developed using a combined spinal cord and MS sample.

Northwestern is the authorized distributor of all Neuro-QoL, PROMIS and NIH Toolbox measures. We have permission to use items from the other measurement systems.

Aside from the Core and Supplemental categorization, we also limit patient burden by skipping irrelevant items. Each Core domain begins with a "gateway" item. If a patient indicates no impairment on that item, the remaining items in the domain are not administered, and the patient advances to the next Core domain. If, however, a patient's response to the gateway item surpasses a certain threshold, they will receive the remaining three items for that domain.

Measure Contents

Core Domains	Minimum Number of Items	Maximum Number of Items	Source Measure
Mobility	1	4	Neuro-QoL Mobility
Cognitive function	1	4	Neuro-QoL Cognitive Function
Social function	1	4	Neuro-QoL Social Role Participation
Depression	1	4	PROMIS Depression
Pain	1	4	PROMIS Pain Interference
Fatigue	1	4	PROMIS MS Fatigue
Global HRQOL	1	1	PROMIS
Total:	7 items	25 items	
Optional Domains		**Number of Items**	**Source Measure**
Sleep		4	PROMIS Sleep Disturbance 8a
Sexual function		4	PROMIS Global Satisfaction
Bowel function		4	PROMIS Constipation and Incontinence SFs
Bladder function		4	SCI-QOL Bladder Management
Vision (sensory)		4	NIH Toolbox Vision QOL – Role performance
Stiffness/spasticity		4	Patient Reported Impact of Spasticity (PRISM)
Anxiety		4	PROMIS Anxiety
Upper extremity function		4	Neuro-QoL Upper Extremity Function
Total:		32 items	
All Domains	7 items	57 items	

Appendix B

PROM (paper-and-pencil version)

PAGE 1: MOBILITY

Please respond to these questions by marking one box per row.

---

1.   Are you able to go for a walk of at least 15 minutes?   PFA23

Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
☐	☐	☐	☐	☐
5	4	3	2	1

If "Without any difficulty" is selected, skip ahead to PAGE 2: FATIGUE

If any other response is selected, continue to the questions below.

---

2.   Are you able to run errands and shop?   PFA53

Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
☐	☐	☐	☐	☐
5	4	3	2	1

3.   Are you able to get in and out of a car?   PFA56

Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
☐	☐	☐	☐	☐
5	4	3	2	1

4.   Are you able to get out of bed into a chair?   PFA45

Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
☐	☐	☐	☐	☐
5	4	3	2	1

Continue to PAGE 2: FATIGUE

PAGE 2: FATIGUE

Please respond to these questions by marking one box per row.

In the past 7 days…

5. **How often did you have trouble finishing things because of your fatigue?** | FATIMP16 |

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

If "Never" is selected, skip ahead to PAGE 3: PAIN

If any other response is selected, continue to the questions below.

---

6. **How often did you feel tired even when you had not done anything?** | FATEXP6 |

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

7. **How often did you have to push yourself to get things done because of your fatigue?** | FATIMP3 |

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

8. **How often did you find yourself getting tired easily?** | FATIMP48 |

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

Continue to PAGE 3: PAIN

PAGE 3: PAIN

Please respond to these questions by marking one box per row.

In the past 7 days…

9. How much did pain interfere with your day to day activities? | PAININ9

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

If "Not at all" is selected, skip ahead to PAGE 4: COGNITION

If any other response is selected, continue to the questions below.

10. How much did pain interfere with the things you usually do for fun? | PAININ12

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

11. How much did pain interfere with your enjoyment of life? | PAININ3

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

12. How much did pain interfere with work around the home? | PAININ22

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

Continue to PAGE 4: COGNITION

PAGE 4: COGNITION

Please respond to these questions by marking one box per row.

In the past 7 days…

13. I had trouble concentrating. NQCOG80

Never	Rarely (once)	Sometimes (2-3 times)	Often (once a day)	Very often (several times a day)
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

If "Never" is selected, skip ahead to PAGE 5: MOOD

If any other response is selected, continue to the questions below.

14. I had to read something several times to understand it. NQCOG64

Never	Rarely (once)	Sometimes (2-3 times)	Often (once a day)	Very often (several times a day)
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

15. I had to work really hard to pay attention or I would make a mistake. NQCOG77

Never	Rarely (once)	Sometimes (2-3 times)	Often (once a day)	Very often (several times a day)
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

16. How much DIFFICULTY do you currently have planning for and keeping appointments that are not part of your weekly routine (e.g., a therapy or doctor appointment, or a social gathering with friends and family)? NQCOG24

None	A little	Somewhat	A lot	Cannot Do
☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

Continue to PAGE 5: MOOD

PAGE 5: MOOD

Please respond to these questions by marking one box per row.

In the past 7 days…

17. I felt depressed. | EDDEP29 |

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

If "Never" is selected, skip ahead to PAGE 6: BLADDER FUNCTION

If any other response is selected, continue to the questions below.

18. I felt that I had nothing to look forward to. | EDDEP05 |

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

19. I felt hopeless. | EDDEP41 |

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

20. I felt unhappy. | EDDEP36 |

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

Continue to PAGE 6: BLADDER FUNCTION

PAGE 6: BLADDER FUNCTION

Please respond to these questions by marking one box per row.

In the past 7 days…

21. I had bladder accidents.

SCIBF7

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

If "Never" is selected, skip ahead to PAGE 7: SOCIAL FUNCTION

If any other response is selected, continue to the questions below.

22. I worried that I would have a bladder accident.

SCIBF2

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

23. Bladder accidents have disrupted my daily activities.

SCIBF6

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

24. Bladder accidents limited my independence.

SCIBF4

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

Continue to PAGE 7: SOCIAL FUNCTION

PAGE 7: SOCIAL FUNCTION

Please respond to these questions by marking one box per row.

In the past 7 days…

25. I am able to participate in leisure activities.   `NQPRF26`

Always	Often	Sometimes	Rarely	Never
☐	☐	☐	☐	☐
5	4	3	2	1

If "Always" is selected, skip ahead to PAGE 8: QUALITY OF LIFE

If any other response is selected, continue to the questions below.

26. I am able to socialize with friends.   `NQPRF08`

Always	Often	Sometimes	Rarely	Never
☐	☐	☐	☐	☐
5	4	3	2	1

27. I can keep up with my family responsibilities.   `NQPRF01`

Always	Often	Sometimes	Rarely	Never
☐	☐	☐	☐	☐
5	4	3	2	1

28. I can keep up with my work responsibilities (include work at home).   `NQPRF34`

Always	Often	Sometimes	Rarely	Never
☐	☐	☐	☐	☐
5	4	3	2	1

Continue to PAGE 8: QUALITY OF LIFE

PAGE 8: QUALITY OF LIFE

Please respond to these questions by marking one box per row.

29. In general, would you say your quality of life is:				**Global02**
Excellent	Very good	Good	Fair	Poor
☐	☐	☐	☐	☐
5	4	3	2	1

Continue to PAGE 9: ADDITIONAL CONCERNS

PAGE 9: ADDITIONAL CONCERNS

Would you like to tell your doctor about any of the following areas (for all selected areas, please follow the page prompts to provide further information)?

30. Your sleep:

☐ Yes, I would like my doctor to know more *(if selected, please complete page 10)*

☐ No, I would not like my doctor to know more

31. Your problems with using your hands and arms:

☐ Yes, I would like my doctor to know more *(if selected, please complete page 11)*

☐ No, I would not like my doctor to know more

32. Your spasticity (problems with muscle control):

☐ Yes, I would like my doctor to know more *(if selected, please complete page 12)*

☐ No, I would not like my doctor to know more

33. Your anxiety or worry:

☐ Yes, I would like my doctor to know more *(if selected, please complete page 13)*

☐ No, I would not like my doctor to know more

34. Your sexual function:

☐ Yes, I would like my doctor to know more *(if selected, please complete page 14)*

☐ No, I would not like my doctor to know more

35. Your bowel function:

☐ Yes, I would like my doctor to know more *(if selected, please complete page 15)*
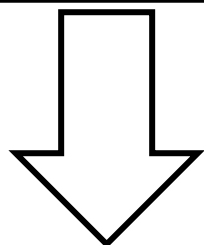
☐ No, I would not like my doctor to know more

36. Your vision:

☐ Yes, I would like my doctor to know more *(if selected, please complete page 16)*

☐ No, I would not like my doctor to know more

If "Yes" to any of the above, continue to and complete the appropriate section(s)

If "No" to all of the above, you have completed the questionnaire.

PAGE 10: SLEEP

Please respond to these questions by marking one box per row.

In the past 7 days…

37. I had trouble sleeping.

Sleep90

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

38. I had difficulty falling asleep.

Sleep44

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

39. I had trouble staying asleep.

Sleep87

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

40. My sleep was restless.

Sleep108

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

PAGE 11: HAND AND ARM FUNCTION

Please respond to these questions by marking one box per row.

41. Are you able to write with a pen or pencil?   `PFA43`

Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
☐	☐	☐	☐	☐
5	4	3	2	1

42. Are you able to make a phone call using a touch tone key-pad?   `NQUEX44`

Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
☐	☐	☐	☐	☐
5	4	3	2	1

43. Are you able to pick up coins from a table top?   `PFB21`

Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
☐	☐	☐	☐	☐
5	4	3	2	1

44. Are you able to turn a key in a lock?   `PFA40`

Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
☐	☐	☐	☐	☐
5	4	3	2	1

PAGE 12: SPASTICITY

Please respond to these questions by marking one box per row.

Over the past week…

45. My abnormal muscle control or involuntary muscle movement bothered me a lot. `PRISM1`

Never true for me	Rarely true for me	Sometimes true for me	Often true for me	Very often true for me
☐	☐	☐	☐	☐
0	1	2	3	4

46. My abnormal muscle control or involuntary muscle movement made transfers hard for me or my caregiver. `PRISM6`

Never true for me	Rarely true for me	Sometimes true for me	Often true for me	Very often true for me
☐	☐	☐	☐	☐
0	1	2	3	4

47. My abnormal muscle control or involuntary muscle movement made me feel frustrated. `PRISM4`

Never true for me	Rarely true for me	Sometimes true for me	Often true for me	Very often true for me
☐	☐	☐	☐	☐
0	1	2	3	4

48. My abnormal muscle control or involuntary muscle movement interrupt my sleep. `PRISM8`

Never true for me	Rarely true for me	Sometimes true for me	Often true for me	Very often true for me
☐	☐	☐	☐	☐
0	1	2	3	4

PAGE 13: ANXIETY OR WORRY

Please respond to these questions by marking one box per row.

In the past 7 days…

49. I felt anxious.

EDANX05

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

50. I felt tense.

EDANX54

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

51. I felt like I needed help for my anxiety.

EDANX07

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

52. I found it hard to focus on anything other than my anxiety.

EDANX40

Never	Rarely	Sometimes	Often	Always
☐	☐	☐	☐	☐
1	2	3	4	5

PAGE 14: SEXUAL FUNCTION

Please respond to these questions by marking one box per row.

In the past 30 days…

53. How satisfied have you been with your sex life? | SFSAT101

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

54. When you have had sexual activity, how much have you enjoyed it? | SFSAT105

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

55. How much pleasure has your sex life given you? | SFSAT102

None	A little bit	Somewhat	Quite a bit	A lot
☐	☐	☐	☐	☐
1	2	3	4	5

56. How satisfied have you been with your sexual relationship with a partner? | SFSAT104

Not at all	A little bit	Somewhat	Quite a bit	Very much
☐	☐	☐	☐	☐
1	2	3	4	5

PAGE 15: BOWEL FUNCTION

Please respond to these questions by marking one box per row.

In the past 7 days…

57. How often did you have bowel incontinence—that is, have an accident because you could not make it to the bathroom in time?

| GISX45 |

No days	1 day	2-3 days	4-5 days	6-7 days
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

58. How often did you soil or dirty your underwear before getting to a bathroom?

| GISX46 |

No days	1 day	2-3 days	4-5 days	6-7 days
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

59. How often after a bowel movement did you feel unfinished—that is, that you had not passed all your stool?

| GISX72 |

Never	Rarely	Sometimes	Often	Always
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

60. How often did you leak stool or soil your underwear?

| GISX47 |

No days	1 day	2-3 days	4-5 days	6-7 days
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

PAGE 16: VISION

Please respond to these questions by marking one box per row.

Please remember that all the questions ask about your vision while wearing any glasses or contact lenses that you usually use. Answer the questions thinking of your vision as it is when corrected by any glasses or contact lenses that you usually use.

61. Because of your eyesight, how limited are you in doing your daily activities? `49VS`

Not limited at all	A little bit limited	Somewhat limited	A lot limited	Unable to do because of eyesight	Unable or limited in daily work because of another reason
☐	☐	☐	☐	☐	☐
1	2	3	4	5	6

62. Because of your eyesight, how much are you limited in how long you can work or do other activities? `52VS`

Not limited at all	A little bit limited	Somewhat limited	A lot limited	Unable to do because of eyesight	Unable or limited in daily work because of another reason
☐	☐	☐	☐	☐	☐
1	2	3	4	5	6

63. Because of your eyesight, how limited are you in doing your daily work whether inside or outside the house? `50VS`

Not limited at all	A little bit limited	Somewhat limited	A lot limited	Unable to do because of eyesight	Unable or limited in daily work because of another reason
☐	☐	☐	☐	☐	☐
1	2	3	4	5	6

64. Because of your eyesight, how much less do you accomplish than you would like? `51VS`

Do not accomplish less at all	Accomplish a little bit less	Accomplish somewhat less	Accomplish a lot less
☐	☐	☐	☐
1	2	3	4