

BARRIERS TO REHABILITATIVE CARE SURVEY

University of North Carolina at Chapel Hill

Research Information Sheet

IRB Study #: 20-2420

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The purpose of this research study is to understand accessibility to rehabilitation care from the patient and clinician perspective. You are being asked to take part in a research study because you are either a physical therapist providing care or a current/former patient that received care.

Being in a research study is completely voluntary. You can choose not to be in this research study. You can also say yes now and change your mind later. Deciding not to be in the research study, now or later, will not affect your ability to receive medical care at UNC.

If you agree to take part in this research, you will be asked to complete a survey. Your participation in this study will take about 15-20 minutes. We expect that 50 people will take part in this research study.

You can choose not to answer any question you do not wish to answer. You can also choose to stop taking the survey at any time. You must be at least 18 years old to participate. If you are younger than 18 years old, please stop now.

The possible risks to you in taking part in this research are:

- Breach of confidentiality

This study does not provide any potential benefits to participants.

To protect your identity as a research subject, no identifiable information will be collected.

If you have any questions about this research, please contact the Investigator named at the top of this form by calling 919-966-8404 or emailing CassidyLab@unc.edu. If you have questions or concerns about your rights as a research subject, you may contact the UNC Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

Who **should** fill out this survey: Adults 18 years or older with a diagnosis of MS, ALS, or PD, who live and receive medical care in North Carolina.

You can also complete this survey by scanning the QR code at the top or by going online to this URL: <https://bit.ly/3imUS54>.

Who is filling out this form? Self Caregiver Other

Part A. General Background Information

1. Have you been diagnosed with MS, ALS, or PD? MS ALS PD
2. How old are you? 18-24 25-34 35-44 45-54 55-64 65 or older
3. How long ago were you diagnosed with MS, ALS, or PD? Less than 1 year 1-5 years
 6-10 years 11-15 years 16-20 years More than 20 years
4. With what race do you identify? Select all that apply: Black or African-American
 American Indian or Alaska Native Asian Native Hawaiian or Pacific Islander
 White Other: _____ I prefer not to disclose.
5. Are you of Hispanic, Latinx, or Spanish origin? Yes No I prefer not to disclose.
6. With what gender do you identify? Woman Man Non-binary
 Transgender Other: _____ I prefer not to disclose

Part B. General Household Information *(Please answer the following questions, as best you can, thinking about your health status and access to care before the COVID-19 pandemic prior to March 2020.)*

1. In what NC county do you live? _____
2. In what type of community do you live? Rural Suburban Urban
3. In approximately what size town or city do you live? Fewer than 50,000 residents
 50,000-250,000 residents More than 250,000 residents
4. What is your annual household income? Less than \$10,000 \$10,000-19,999
 \$20,000-29,999 \$30,000-39,999 \$40,000-49,999 \$50,000 or greater
5. Choose the highest degree or level of education you have completed.
 Some primary education High School/GED Some college
 Vocational/technical training Associate's degree Bachelor's degree
 Master's degree Professional/Doctoral degree
6. Including yourself, how many people live in your household (not including independent roommates or paid health aides)? 1 2 3 4 5 or more

Part C. Access to health care and physical therapy *(Please answer the following questions, as best you can, thinking about your health status and access to care before the COVID-19 pandemic prior to March 2020.)*

1. What type of insurance do you have? Select all that apply:
 Medicare or Medicare Advantage Medicaid TRICARE or VA Health Care
 Private insurance through your own or spouse/domestic partner's employer
 Private insurance through Healthcare.gov I do not have any insurance.

2. Have you attended physical therapy before to address any aspect of your diagnosis?
 Yes No
 If No, have you attempted to access PT and been unable to do so for any reason?
 Yes No
3. Whether or not you have attended physical therapy, what barriers to care most affect you?
Select all that apply: Lack of transportation Lack of available time
 Distance between home and clinic/hospital Overall cost/Insurance/Co-pay
 Difficulty due to my diagnosis Other: _____ None of these
4. How far do you have to travel for your physical therapy services?
 Fewer than 30 minutes 30-59 minutes 1-2 hours More than 2 hours
5. How do you typically get to a physical therapy appointment?
 Walk Drive Bus or other public transportation
 Taxi/Uber/Lyft or other hired service Other: _____
6. How do you currently get around your *home*?
 Walk Non-motorized wheelchair Motorized wheelchair
7. How do you currently get around your *community*?
 Walk Non-motorized wheelchair Motorized wheelchair Not applicable (N/A)

Part D. Satisfaction with and utilization of PT care related to your diagnosis of MS, ALS, or PD

(Please answer the following questions, as best you can, thinking about your health status and access to care before the COVID-19 pandemic prior to March 2020.)

1. How satisfied are you with your current or most recent physical therapy experience?
 (0 = Not at all satisfied, 10 = very satisfied)
 0 1 2 3 4 5 6 7 8 9 10 Not applicable (N/A)
2. How knowledgeable do you feel your physical therapist is about your diagnosis of MS, ALS, or PD? (0 = Not at all knowledgeable, 10 = Very knowledgeable)
 0 1 2 3 4 5 6 7 8 9 10 Not applicable (N/A)
3. Do you utilize or participate in any community/outside resources, such as support groups, for your specific diagnosis?
 Yes No I am unaware of any of these resources in my area.
4. For how long have you attended PT *specifically* for your diagnosis of MS, ALS, or PD, whether you have attended continuously or on-and-off as needed?
 Less than 1 year 1-3 years More than 3 years
 I have not received physical therapy care for my diagnosis.

5. During your current or most recent episode of PT care, about how often do/did you attend PT appointments?
- More than once a week Once a week More than once a month
 Once a month 1-2 times a year Not applicable (N/A)
6. During your current or most recent episode of PT care, about how often do/did you miss or cancel your PT appointment(s) due to any of the barriers previously listed (lack of transportation, lack of available time, cost, etc.)?
- Twice a week Once a week Twice a month Once a month
 Less than once a month Never

Part E. Other questions

1. Since the beginning of the COVID-19 pandemic in North Carolina in March 2020, have you received PT care?
- Yes, in person Yes, via teletherapy No
2. Overall, how has the COVID-19 pandemic affected your PT care since March 2020?
- It has not affected my access to PT.
 I have attended PT in person or via teletherapy more often.
 I have attended PT in person or via teletherapy less often.
 I have discontinued PT due to the COVID-19 pandemic.
3. What other providers have you seen directly related to your diagnosis of MS, ALS, or PD, (in-person and/or teletherapy)? Select all that apply:
- Primary Care Provider (Physician, Nurse Practitioner, Physician Assistant)
 Neurologist or Neurosurgeon Orthopedic surgeon or specialist
 Physical Medicine & Rehabilitation Occupational Therapist
 Speech-Language Pathologist Pharmacist Social Worker
 Other: _____ None of these
4. Is there anything else you would like us to know about how you access PT or any difficulties you have experienced?

End of Questions. **Thank you for taking the time to complete this survey.**