

Consent form

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Project title: Stakeholder engagement to inform the design of a comparative effectiveness study of treatment options for walking difficulties in multiple sclerosis
Principal investigator: Prue Plummer, PT, PhD

People living with multiple sclerosis are invited to participate in this online survey.

The purpose of this study is to identify how people living with multiple sclerosis (MS) determine whether they have benefited meaningfully from rehabilitation for walking impairments. We also wish to gain insight into how individuals with MS make decisions about their treatment options.

This is a research project being conducted by Prue Plummer, PhD, PT, a clinical researcher and Associate Professor at the University of North Carolina at Chapel Hill.

Completion of this survey should take approximately 15 minutes.

Your participation is completely voluntary. You may decline to take part or exit the survey at any time. You are also free to decline to answer any particular question, if you wish.

There are no foreseeable risks involved in participating in this study. You will not directly benefit from participating in this study.

Your survey answers will be submitted via the Qualtrics Survey Tool at the University of North Carolina at Chapel Hill. Only the researchers will have access to the responses and all data are stored in a password-protected electronic format. No identifying information will be collected, including your name, email address, or IP address. Therefore, your responses will be anonymous, unless you choose to disclose any potentially identifiable information in your open-responses to the researchers.

If you have any questions about the study, you may contact Prue Plummer via telephone at 919-843-8658 or via email at prue@med.unc.edu.

This study has been approved the IRB at the University of North Carolina at Chapel Hill (IRB #17-0055).

If you have questions or concerns about your rights as a research participant you may contact, anonymously if you wish, the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu

ELECTRONIC CONSENT: Please select your choice below.

Clicking on the "agree" button below indicates that:

- You have read the above information
- You voluntarily agree to participate
- You are at least 21 years of age
- You have been diagnosed with MS or you are responding on behalf of someone who has multiple sclerosis
- You have not already participated in a focus group or interview for this study

If you do not wish to participate in the research study, please decline participation by clicking on the "disagree" button.

- Agree
- Disagree

Walking is an important part of how we get around and do things in our daily life, and it is one of the most commonly affected aspects of function for people with MS.

What are some of the difficulties that you experience as a result of your MS that limit your walking or your ability to move around your home and in the community?

(Select all that apply, or insert your own responses)

- I fall or lose my balance
- I am afraid of falling
- I need someone with me when I walk

- I walk very slowly / I can't walk as fast as I need to
- I drag my foot on the ground when I walk
- My knees buckle or lock
- I don't have proper feeling in my legs or feet, or I have tingling
- I get very fatigued with walking
- I have spasticity that limits my walking
- I experience pain when I walk
- I experience dizziness when I walk
- I have double vision (or other visual problems) that limit my walking
- I have jerky movements (ataxia)
- I can't do other things while I walk (e.g., talk to a friend)
- Walking takes up so much energy
- I have trouble remembering directions or where I am going
- I am not comfortable walking in public
- I have difficulty with stairs
- I have difficulty with escalators
- I have difficulty with changes in surfaces (e.g., carpet to tile, grass to cement)
- Other:
- Other:

Think back to the last time you went to physical therapy for problems related to your walking or balance. What did you hope to achieve from physical therapy?

(Select all that apply)

- Increase my walking speed or ability to walk faster when needed
- Improve the way I walk (e.g., smoothness, quality)
- Improve my balance (not fall or feel unsteady when standing or walking)
- Improve my strength
- Walk without my assistive device (cane, walker, etc.)
- Not drag my foot
- Be able to walk further or for longer duration without needing a rest
- Be able to walk with less attention
- Get a new home exercise program
- Other (please specify):

Did you communicate your goals for physical therapy with your physical therapist?

- Yes
- No
- Not sure

What did you think was the most effective part of your physical therapy?

What did you think was the least effective part of your physical therapy?

Do you believe that your physical therapist was appropriately qualified (or had sufficient experience) to help you with your MS-related movement and balance problems?

- Definitely yes
- Probably yes
- Might or might not
- Probably not
- Definitely not

Overall, were you satisfied with your physical therapy?

- Yes
- No

How do you assess if the physical therapy treatment you have received has been effective?
(*Select all that apply and add additional responses as necessary*)

- I didn't get any worse during the therapy period
- I can walk faster
- I am not as wobbly or unsteady when I walk

- I don't rely on others to help me as much
- I feel like I can do more (can do things longer)
- I have less fatigue
- I have a general feeling of improved wellness
- I don't feel as tired
- I don't need my assistive device as much as I used to
- I am more confident in my abilities
- Other specific example:
- Other specific example:

Rank the following in order of importance to you:
(1 = most important, 7 = least important)

I want to walk faster

I want to walk more smoothly

I want to walk without an assistive device (e.g., cane, walker)

I want to be able to walk longer distances

I want to be able to talk or do other things while walking

I don't want to fall

Something else is more important (please specify):

What is most important to you when choosing a treatment option? (rank in order, 1 = most important)

How much I think it will help me

Having the "right" therapist

How much it will cost

How easy it is to do

That I can do it at home (instead of a hospital or clinic)

Have you ever taken or are you currently taking dalfampridine (Ampyra) for your walking difficulties?

- Yes, and I am still taking it
- Yes, but I stopped taking it
- Never tried it
- Not sure

For what reasons did you stop taking Ampyra? Select only one response that most accurately applies.

- I didn't feel like it was helping me (my choice to stop)
- My doctor recommended that I stop taking it
- I experienced unpleasant side effects
- It was too expensive / my insurance would not cover it
- Other (please specify):

Demographics

The following information is being gathered to aid in description of the participant sample.

Please indicate your gender.

- Male
- Female
- Prefer not to disclose

Age:

- 21-24 years
- 25-34 years

- 35-44 years
- 45-54 years
- 55-64 years
- 65-74 years
- 75 years or older

Type of MS:

- Relapsing-remitting MS
- Secondary progressive MS
- Primary progressive MS
- Clinically isolated syndrome
- Radiologically isolated syndrome
- Not sure

Year of diagnosis (give approximate year if unsure):

Last time I had physical therapy:

- I am currently receiving physical therapy
- In the last 3 months, but not currently
- 3-6 months ago
- 6-12 months ago
- More than 12 months ago
- Never

Do you own a mobility aid or assistive device for walking (e.g., scooter, cane, walker)?

- Yes
- No

How often do you use your mobility aid or assistive device?

- Always
- Most of the time
- About half the time
- Sometimes
- Never

Optional: If you do not always use your assistive device, provide reasons why you choose not to use it at times.

Powered by Qualtrics