Technology use in MND

Thank you for your interest in this study. Please read through the information below before deciding whether you wish to take part. If you would like further information you can look at a detailed patient information leaflet at http://sitran.dept.shef.ac.uk/clinical-studies/telemedicine/survey/.

We are looking to involve as many people as possible who have experience of living with motor neurone disease (MND), both patients and their family and friends. We would like to hear from those who do not use any technology as well as those who do.

You are eligible to take part if you are 18 years or over, live in the UK, have any form of motor neurone disease (including primary muscular atrophy and primary lateral sclerosis) diagnosed by a doctor or you are a friend or family member of someone with MND.

If you attend the Sheffield MND clinic you may have received an invitation to complete the survey. You can complete this survey but please remember to return the completed consent form.

In order to collect the information the surveys need to completed by the 1st of July 2015.

It is up to you to decide whether or not to take part. You can skip a question if you would prefer not answer it although a few answers are required to make sure we ask you the right questions. All the answers are anonymous and will only be accessible by the Sheffield MND research team.

* Required

1. **Before you answer the survey we'd be grateful if you would confirm the following....** *
   Check all that apply.

   ☐ I am 18 years or over and I either have MND or are a friend or family member of someone with MND

2. *
   Check all that apply.

   ☐ I have read the study information and understand that this study is entirely voluntary

3. *
   Check all that apply.

   ☐ I wish to take part in this study.

About you

4. **How old are you?**

   .....

5. **Are you?**
   Mark only one oval.

   ◯ Male
   ◯ Female

6. **Can you tell us the first half of your postcode? e.g. S6 or NG12**

.....

7. **Are you...** *
Mark only one oval.

- Someone with MND *Skip to question 11.*
- A partner or spouse of someone with MND *Skip to question 8.*
- Another family member of someone with MND *Skip to question 8.*
- A friend of someone with MND *Skip to question 8.*

8. **Has the person you know who has MND received an invitation from the Sheffield MND team to complete this survey?** *
Patients from the Shefifeld MND care centre may have received a letter in the post invitation them and you to take part.
Mark only one oval.

- Yes *Skip to question 9.*
- No *Skip to question 9.*

Skip to question 9.

Using technology

9. **Which of these do you use?**
Mark only one oval per row.

	Daily	Several times a week	Once a week or less	Once a month or less	Available in the house but I don't use them	Not available in the house
Desktop computer						
Laptop						
iPad						
iPad mini						
Assistive technology e.g. remote control switches						
Kindle						
Other tablet computer						
Lightwriter						
iPhone						
Other smart phone						

10. **If you use other technologies you can describe them here.**

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Skip to question 33.

About your MND

11. **When did the symptoms of MND start? (e.g. June 2013)**

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12. **Which areas of your body does MND affect?**
Check all that apply.

- [ ] My arms
- [ ] My legs
- [ ] My speech or swallow muscles
- [ ] My breathing

13. **Do you have...**
Mark only one oval.

- ( ) A feeding tube
- ( ) A breathing machine
- ( ) Neither

14. **Do you attend a MND hospital clinic?**
Mark only one oval.

- ( ) I currently attend a clinic
- ( ) I used to attend a clinic but I don't anymore
- ( ) I've never attended a specialist clinic

15. **If you have attended an MND hospital clinic, can you tell us which one?**

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16. **Have you received an invitation from the Sheffield MND team to complete this survey?** *
Patients from the Sheffield MND care centre may have received a letter in the post.
Mark only one oval.

- ( ) Yes
- ( ) No *Skip to question 17.*

Skip to question 17.

17. **Which of these do you use?**
Mark only one oval per row.

	Daily	Several times a week	Once a week or less	Once a month or less	Available in the house but I don't use them	Not available in the house
Desktop computer						
Laptop						
iPad						
iPad mini						
Kindle						
Other tablet computer						
Lightwriter						
iPhone						
Other smart phone						
Assistive technologies e.g. remote control switches						

18. **If you use any other technologies you can describe them here.**

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Untitled Page

19. **Do you have any of these problems using a computer or a telephone?**
Check all that apply.

- [ ] Hand problems
- [ ] Vision problems
- [ ] No problems
- [ ] Other: .....

20. **Do you use any of these adaptions to your technology?**
Check all that apply.

- [ ] A stylus pen (e.g. on a tablet computer)
- [ ] Adapted mouse
- [ ] I don't use any devices
- [ ] Eye gaze
- [ ] Finger switches
- [ ] Head / body switches
- [ ] Speech recognition
- [ ] Someone uses it for me
- [ ] Other: .....

21. **Do you have a computer, tablet, laptop or smart phone at home?** *
This question helps us ask you the right questions on the next page of the survey.
Mark only one oval.

- ( ) Yes
- ( ) No *Skip to question 33.*

22. **Do you have the internet at home?**
Check all that apply.

- [ ] Broadband
- [ ] 3G or 4G mobile internet
- [ ] None: I don't want/need the internet
- [ ] None: I can't get internet in my house
- [ ] Other: .....

23. **Is your internet fast enough to watch a short video?**
You could try this video of the ice bucket challenge as an example: www.youtube.com/watch?v=zlRaSpVtvCk (It will open in a new window, you won't lose your answers)
Mark only one oval.

- ( ) Yes
- ( ) No
- ( ) Don't know
- ( ) I don't have the internet

24. **If you have a computer or laptop, do you remember which year you bought it?**
This doesn't include tablet computers or iPads.
Don't worry if you can't remember.

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25. **Do you know what brand or type of computer or laptop it is?**
e.g. Sony laptop, apple macbook pro

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26. **Do you know what operating system it uses?**
E.g. OS 10.1 or Windows XP (don't worry if you don't know how to find this)

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27. **Did you buy any technology as a result of you having MND?**
Mark only one oval.

- Yes *After the last question in this section, skip to question 33.*
- No (you can move on to the next page) *After the last question in this section, skip to question 33.*

28. **What technology did you buy?**
e.g. an iPad mini, lightwriter

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29. **What do you use it for?**
e.g. communication speech aid, emails etc.

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30. **Were you given any technology from a charity or health professional (e.g. the MND Association or speech therapist)?**
Mark only one oval.

- Yes *After the last question in this section, skip to question 33.*
- No (you can move on to the next page) *After the last question in this section, skip to question 33.*

31. **What technology did you receive?**
e.g. an iPad, lightwriter

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32. **What do you use it for?**
e.g. communication speech aid, emails etc.

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Skip to question 33.

33. **How often do you use any form of technology (e.g. computer, internet, tablet computer)?..** *
This helps us ask you the right questions on the next page of the survey.
Mark only one oval.

- ( ) Once a month or more *Skip to question 37.*
- ( ) Less than once a month

This page is for people who use technology less than once a month

34. **Can you tell us why you don't often use technology?**
Check all that apply.

- [ ] I don't need it
- [ ] I don't know how to use it
- [ ] I'm worried I might break something
- [ ] I can't afford to buy a computer
- [ ] I feel too ill
- [ ] My hand function isn't good enough
- [ ] My reading isn't good enough
- [ ] My vision isn't good enough
- [ ] Other: .....

35. **If you had the correct equipment to overcome any disability you have, how confident are you using a basic computer?**
Check all that apply.

- [ ] I could use it with little or no help
- [ ] I'd need some training but could probably manage
- [ ] I don't think I could use one without help
- [ ] I wouldn't be interested in learning
- [ ] Other: _____

36. **Is there someone living with you who could help you use a computer?**
Mark only one oval.

- ( ) Yes
- ( ) Yes

Skip to question 40.

37. **If you use the internet or a tablet computer, which of these do you use?**
You can tick as many as you like
Check all that apply.

- [ ] Email
- [ ] Skype/Facetime/making video calls
- [ ] Reading newspapers or websites
- [ ] Online shopping or banking
- [ ] Playing games
- [ ] Watching TV
- [ ] Listening to music or the radio
- [ ] Work
- [ ] Getting information about MND
- [ ] Talking to other people with MND e.g. on forums/twitter
- [ ] I don't use the internet
- [ ] Other: _____

38. **Have you ever used any of these websites to find out about MND?**

Mark only one oval per row.

	Never	Once	Two to five times	More than five times
MND Association				
MND Association information leaflets				
MND Assocation forum				
MND Scotland				
ALS Association				
MyMND or MyNIV				
Patient.co.uk				
Healthtalkonline.org				
Facebook sites				
Twitter				
PatientsLikeMe.com				

39. **Do you look at any other websites related to MND?**

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40. **What information regarding MND would you like to know more about?**

You can tick as many as you like

Check all that apply.

- [ ] The causes of MND
- [ ] The physical effects of MND
- [ ] The psychological effects of MND
- [ ] Treatments
- [ ] Research in which I can take part
- [ ] Equipment to help with daily life
- [ ] Medical treatments such as breathing machines
- [ ] Palliative care and end of life choices
- [ ] Other peoples' experiences of MND
- [ ] Financial support
- [ ] Support for family and carers
- [ ] Local support groups
- [ ] Charities or fundraising
- [ ] Other: .....

41. **How would you prefer to receive information? Please chose your favourite THREE**
Check all that apply.

- [ ] Internet websites containing written information
- [ ] Internet websites containing videos
- [ ] Twitter
- [ ] Facebook
- [ ] ebooks or pamphlets I can download e.g. onto a Kindle
- [ ] Email
- [ ] Written information e.g. leaflets
- [ ] Books
- [ ] Other: .....

42. **Did your MND care team tell you about information available on the internet?**
Mark only one oval.

- ( ) They recommended looking at the internet
- ( ) They recommended not looking at the internet
- ( ) They recommended a specific site
- ( ) Other: .....

43. **If they recommended a particular site, which was it?**

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44. **Has your MND doctor ever used one of these methods to talk to you at home?**
Check all that apply.

- [ ] Telephone calls
- [ ] Email/computer
- [ ] Text messaging
- [ ] Video conferencing
- [ ] None of these

45. **If you had the correct equipment and training, do you think any of these would be acceptable ways to talk to your MND care team?**

Mark only one oval per row.

	Yes	Maybe	No
Telephone calls			
Email/computer questions			
Text messaging			
Video calls			

46. **If you had the correct equipment and training, do you think any of these wold be acceptable ways to use INSTEAD OF a hospital appointment?**

Mark only one oval per row.

	Yes	Maybe	No
Telephone calls			
Email/computer questions			
Text messaging			
Video calls			

47. **Do you have any concerns about using these methods to talk to your care team?**

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48. **Do you have any other comments to tell the research team?**

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Thank you! Please press the submit button to send your answers.

You’re finished. Thank you! Your involvement in research is important to improve the lives of people living with MND.

Results will be published here: http://sitran.dept.shef.ac.uk later in the year.

Don't forget: If you received a questionnaire in the post from Sheffield, please fill in the front page of the booklet and return it in the free post envelope.