

Exploring technology use by those living with motor neurone disease.

THIS SURVEY IS FOR PATIENTS

- Please complete **all** of this form and then go on to fill in the attached survey.
- If you wish to complete the survey online go to
<http://sitran.dept.shef.ac.uk/clinical-studies/telemedicine/survey/>
- You will also need to fill in all of the first page of this booklet and return it in the freepost envelope.
- Please return the freepost envelope by the **1st July 2015**.
- *Thanks for helping us with our research.*

CONSENT FORM:

- I confirm that I have read and understood the "Patient and family member information leaflet" version 1 and have had enough time and opportunity discuss the study and ask any questions in order to come to my decision.
- I understand that my participation is voluntary but after I return the completed survey the information I give would be retained for analysis.
- **I agree to take part in this study**

Patient:

Signature:

Print Name: Date:.....

Address:

If you are unable to sign your name you can ask a friend or family member to sign to confirm that they have witnessed that you agree to take part in the study.

I have witnessed this person consent to take part in this study.

Signature of the witness..... Date:.....

Name of the witness:

Relationship to patient:

Name of the patient:

Address of the patient:

Please complete each page although you are welcome to skip a question if you don't wish to answer it. There is a space in the last sheet to write comments. We expect this to take about 5-10 minutes but please take as long as you wish. You can ask someone to help you complete the questions and you don't need to complete it all in one go.

1. How old are you? years

2. Are you... Male ☐ Female ☐

3. What is your postcode?

(just give us the first half of your postcode e.g. S6 or NG15.)

5. When did you first notice symptoms of MND? Month Year

6. Does MND affect...

Your arms ☐
Your legs ☐
Your speech or swallow muscles ☐
Your breathing ☐

7. Do you use...

A feeding tube ☐
A breathing machine ☐
Neither ☐

8. Do you attend another hospital clinic for your MND, other than Sheffield?

Yes ☐

Please tell us where this is _____

No ☐

9. Which of these do you use?

	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 my house
a. Desktop computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Laptop	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. iPad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Kindle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Other tablet computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. iPhone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Other smart phone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Other (please describe) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. Do you have any these problems using a computer or telephone?

- Hand problems ☐
- Vision problems ☐
- Other ☐
- (please describe) _____
- No problems ☐
- I don't use any devices ☐

11. Do you use any of these adaptations to use your devices?

- A stylus pen on a tablet computer ☐
- Adapted mouse ☐
- Eye gaze ☐
- Finger switches / buttons ☐
- Head / body switches ☐
- Speech recognition ☐
- Someone uses it for me ☐
- Other ☐
- (please describe) _____
- None needed ☐
- I don't use any devices ☐

12. Do you have the internet at home?

Broadband ☐

3G or 4G internet (on a phone or dongle) ☐

Another form of internet (*please describe*) ☐

None: I don't want/need internet ☐

None: I can't get internet in my house ☐

13. Is your internet fast enough to watch a short video? (e.g. Youtube or iPlayer)

You could try this as an example: www.youtube.com/watch?v=zIRaSpVtvCk

Yes ☐

No ☐

Don't know ☐

I don't have internet ☐

14. If you have a computer or laptop, do you remember approximately?

(don't worry if you don't know this)

Which year you bought it?

Type of computer _____

e.g. Sony viao laptop, apple macbook pro

Operating system _____

(e.g. OX 10.1, Windows XP, Windows 7)

I don't have a computer ☐

14. Did you buy any technology as a result of you having MND?

Type of technology: *e.g. iPad/lightwriter* _____

What you use it for? *e.g. emails, speech* _____

14. Did you receive any of your technology from a charity or healthcare professional (e.g. speech therapist)?

Type of technology: _____

What you use it for: _____

This page is for people who use technology LESS THAN once a month. If you use technology more than once a month you can skip to the next page.

15. Could you tell us why you use technology less than once a month? (you can tick as many as you like)

- | | |
|-------------------------------------|--------------------------|
| I don't need it | <input type="checkbox"/> |
| I don't know how to use them | <input type="checkbox"/> |
| I'm worried I might break something | <input type="checkbox"/> |
| I can't afford to buy a computer | <input type="checkbox"/> |
| I'm too ill | <input type="checkbox"/> |
| My hand function isn't good enough | <input type="checkbox"/> |
| My reading isn't good enough | <input type="checkbox"/> |
| My vision isn't good enough | <input type="checkbox"/> |
| Other _____ | <input type="checkbox"/> |

16. If you had the correct equipment to overcome your disability, how confident are you using a basic computer?

- | | |
|--|--------------------------|
| I know how to use one with no/little help | <input type="checkbox"/> |
| I'd need some training but could probably manage | <input type="checkbox"/> |
| I don't think I could use one without help | <input type="checkbox"/> |
| Other (please describe) _____ | <input type="checkbox"/> |

17. Is there someone else living with you who does use a computer, tablet or smart phone?

- | | |
|-----|--------------------------|
| Yes | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

18. If you use the internet or tablet computer, which of these do you use? (you can tick as many as you like)

Email	<input type="checkbox"/>
Skype/making calls	<input type="checkbox"/>
Facebook/twitter	<input type="checkbox"/>
Reading newspapers or other websites	<input type="checkbox"/>
Online shopping or banking	<input type="checkbox"/>
Playing games	<input type="checkbox"/>
Watching TV	<input type="checkbox"/>
Listening to music or the radio	<input type="checkbox"/>
Work	<input type="checkbox"/>
Getting information about MND	<input type="checkbox"/>
Talking to other people with MND e.g. on forums	<input type="checkbox"/>
Other _____	<input type="checkbox"/>
I don't use the internet	<input type="checkbox"/>

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

	Never	Once	Two to five times	More than five times
a. MND Association	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. MND Association information leaflets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. MND Association forum	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. MND Scotland	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. ALS Association	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. PatientsLikeMe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. MyMND or MyNIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Patient.co.uk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Healthtalkonline.org	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Facebook sites	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Twitter	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Other (please describe) _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

a. The causes of MND	<input type="checkbox"/>
b. The physical effects of MND	<input type="checkbox"/>
c. The psychological effects of MND	<input type="checkbox"/>
d. Treatments	<input type="checkbox"/>
e. Research in which I can take part	<input type="checkbox"/>
f. Equipment to help with daily life	<input type="checkbox"/>
g. Medical treatments such as breathing machines	<input type="checkbox"/>
h. Palliative care and end of life choices	<input type="checkbox"/>
i. Other peoples' experiences of MND	<input type="checkbox"/>
j. Financial support	<input type="checkbox"/>
k. Support for family and carers	<input type="checkbox"/>
l. Local support groups	<input type="checkbox"/>
m. Charities and fundraising	<input type="checkbox"/>
n. Other (<i>please describe</i>) _____	<input type="checkbox"/>

21. How would you prefer to receive information about MND?

Internet websites with written information	<input type="checkbox"/>	Please choose your top three
Internet websites with videos	<input type="checkbox"/>	
Twitter	<input type="checkbox"/>	
Facebook	<input type="checkbox"/>	
eBooks I can download e.g. for a Kindle or tablet	<input type="checkbox"/>	
Email	<input type="checkbox"/>	
Written information e.g. leaflets	<input type="checkbox"/>	
Books	<input type="checkbox"/>	
I don't want any more information	<input type="checkbox"/>	
Other (<i>please describe</i>) _____		

22. Did your MND care team tell you about information available on the internet?

They recommended looking on the internet	<input type="checkbox"/>
They recommended not looking on the internet	<input type="checkbox"/>
They recommended a specific site	<input type="checkbox"/>

Which site(s) did they recommend? _____ 8

23. Has your MND doctor ever used any of these methods to talk to you at home?

Telephone calls	<input type="checkbox"/>
Email/computer	<input type="checkbox"/>
Text messaging	<input type="checkbox"/>
Video calls e.g. Skype	<input type="checkbox"/>
None of these	<input type="checkbox"/>

24. 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?

	Yes	Maybe	No
Telephone calls	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Email/computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Text	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Video calls e.g. Skype or via your TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25. If you had the correct equipment and training do you think any of these would be acceptable to you to use INSTEAD OF a hospital appointment?

	Yes	Maybe	No
Telephone calls	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Email/computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Text	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Video calls e.g. Skype or via your TV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26. If you answered maybe or definitely no, what might concern you about these options?
 You can carry on on the next page.

You're finished. Thank you! Your involvement in research is important to improve the lives of people living with MND. Please check to make sure you have answered every page and return the survey in the freepost envelope as soon as possible and before the **1st of July**.

You can read the results of this research on the Sheffield Institute for Translational Neurosciences website <http://sitran.dept.shef.ac.uk/> later in the year, or get more information by calling ***** or email *****

If you wish to make any more comments, please do so here.