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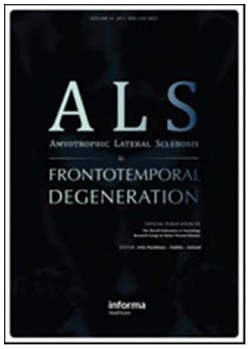

"Anything that makes life's journey better." Exploring the use of digital technology by people living with motor neurone disease

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"Anything that makes life's journey better." Exploring the use of digital technology by people living with motor neurone disease

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This project was conceived by EH and CJM. SF conducted the interviews. Both EH and SF conducted the analysis. All authors reviewed and interpreted the findings. All authors were involved in the preparation of the manuscript. SF was undertaking this project as part of a Master's degree in Clinical Neurology and had not met the participants prior to the day of the interview but attended their clinic appointment conducted by EH under the supervision of PJS.

EH is a National Institute for Health Research (NIHR) Doctoral Research Fellow working in an MND specialist clinic with experience conducting qualitative interviews within a mixed methods technology trial in MND. SF is an MSc Clinical Neurology student. PJS and CJM are consultant neurologists caring for patients with MND with experience of conducting clinical trials and qualitative studies.

The views and opinions expressed are those of the authors, and not necessarily those of the NHS, the NIHR or the Department of Health. EH, PJS and CJM are conducting trials of telehealth in MND. The Motor Neurone Disease Association helped publicised the online questionnaire but had no other involvement in this project.

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"Anything that makes life's journey better." Exploring the use of digital technology by people living with motor neurone disease using mixed methods

Abstract

Our aim was to explore the attitudes of those living with motor neurone disease towards digital technology.

Postal and online questionnaires surveyed 83 people with MND (pwMND) and 54 friends and family members (fMND). Five pwMND and five fMND underwent semi-structured interviews.

82% of pwMND and 87% of fMND use technology every day with iPads and laptops being the devices most commonly used. pwMND used technology to help them continue to participate in everyday activities such as socialising, entertainment and accessing the internet. The internet provided peer support and information about MND but information could be distressing or unreliable. Participants preferred information from professionals and official organisations. Participants were generally supportive of using of technology to access medical care.

Barriers to technology, such as lack of digital literacy skills and upper limb dysfunction, and potential solutions were identified. More challenging barriers included language and cognitive difficulties, and the fear of becoming dependent on technology. Addressing the barriers identified in this research could help pwMND access technology. However, as healthcare delivery becomes more reliant on digital technology, care should be taken to ensure those who are unable or unwilling to use technology continue to have their needs met in alternative ways.

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Introduction

Digital technology devices such as smart phones and tablet computers are now a prominent part of life. These everyday technologies, along with more specialist assistive equipment, offer ways to enhance the lives of people with disabilities, particularly those with motor neurone disease (MND). People with MND (pwMND) already use the internet to seek a diagnosis and to learn about the condition (1-3). Everyday devices can be adapted for disabilities, for example by using text-to-speech communication software or voice recognition. Specialist assistive technologies range from simple solutions such as adapted keyboards and switches to complex devices such environmental controls and brain-computer interfaces (4,5).

Digitalisation within healthcare is increasing, allowing patients to access medical records on-line, order medication or make appointments. Educational websites such as MyMND allow patients easy access to bespoke information (6). Technology can facilitate access to medical care; email, telephone and video calls (telemedicine) can be used for consultations and telehealth can be used to monitor the signs and symptoms of the disease (7). Given the growing evidence that specialist multidisciplinary care is associated with improved outcomes in MND (8-11) , technology that overcomes the barriers posed by the disease could be valuable in improving access to these services (7).

Technologies must be acceptable and accessible to pwMND and this study aimed to explore the use of, and attitudes towards digital technology in pwMND, their family members and friends.

Methods

We examined attitudes towards digital technology, focussing on everyday digital technologies (such as the internet, laptops and tablet computers) and everyday technologies that had been adapted for disabilities (such as communication software applications on tablet computers). We also explored attitudes towards digital "assistive technologies", i.e. those designed specifically for people with disabilities (such as environmental controls and switches).

We used a postal and an online questionnaire and, to explore the subject in more depth, we conducted semi-structured qualitative interviews. The research questions, questionnaires and interview topic guide were developed following a literature review. We also consulted with clinicians and the Sheffield Motor Neurone Disorders Research Advisory Group, a group of lay advisors including patients, carers and MND Association volunteers.

Questionnaire

We identified patients with all types of motor neurone disease (amyotrophic lateral sclerosis, primary lateral sclerosis and progressive muscular atrophy) who were cared for by the Sheffield Motor Neurone Disorders Care and Research Centre in June 2015 using a database search. We invited them to complete postal questionnaires which included information about their diagnosis, including

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disease duration and disability (i.e. whether the disease affects their limbs, bulbar function or breathing) (Appendix A). We asked patients to identify an unpaid carer (a family member or friend) who could also complete a questionnaire (Appendix B). We invited other pwMND in the UK, their friends and family members to participate. We used an online GoogleDocs questionnaire advertised using social media and the Motor Neurone Disease Association UK research newsletter (Appendix C).

Interviews

We invited by letter, patients with any type of motor neurone disease who were attending their routine MND clinic appointment to participate in semi-structured interviews. We also invited an accompanying friend or family member who cared for them to participate. We used convenience sampling to conduct one interview per clinic. Patients were excluded if they could not give consent, were too unwell to spend extra time in clinic, or who had already participated in qualitative research in the care centre. We collected basic demographic data and recorded their functional ability using the ALSFRS-R score (collected as part of usual care) (12). Disabilities in bulbar, upper and lower limbs were described as mild, (ALSFRS-R sub-score 9-11), moderate (6-8) or severe (<6).

SF conducted the interviews using a topic guide (Appendix D). SF was trained in qualitative interview technique by EH and attended interviews and read transcripts and qualitative literature. Interviews and reflexive notes were reviewed together by EH and SF, allowing further development of the interview schedule. Interviews were recorded and transcribed verbatim and data was organised using NVivo (13). Thematic analysis was used to interpret the data (14). Transcripts were read independently by SF and EH to familiarise themselves with the data and generate initial codes. Codes and themes were reviewed and refined together. The interviews were completed before the results of the questionnaire were available. However, following initial analysis , a process of methods triangulation compared the data sets to determine whether the findings from each data set were consistent (13). Where important themes, similarities and differences were identified, the datasets was reviewed looking for explanation for these findings. Results were then discussed with the wider research team and the qualitative data was reviewed, codes were further refined and EH recoded each interview and prepared the final manuscript.

Ethical approval was gained from the NRES Committee North West-Preston for the postal questionnaire and interviews. Written or witnessed consent was obtained. Ethical approval was not required for the anonymous online questionnaire but participants were directed to a website containing a participant information sheet and were required to confirm their understanding and willingness to participate.

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Results

Questionnaire participants

126 patients were invited. 49 patients (39% response rate) completed the patient postal questionnaire (Table 1) and 37 completed the friend/family postal questionnaire (Table 2). One patient questionnaire was excluded because no written consent was returned. 36 pwMND completed the online questionnaire. One online response was excluded because it was impossible to determine whether the patient had also completed a postal questionnaire. 19 family member/friends completed the online questionnaire. All friend and family members responses were combined and are referred to as "fMND". It was not possible to calculate a response rate for the online questionnaire.

Interview participants

Eight patients were approached for interviews. Two patients rescheduled their appointments and could not be interviewed. Five patients, all female, and five carers (all family members) were interviewed in six interviews, ranging from 16 to 37 minutes (Appendix E). One patient declined but his son was interviewed. Two patients had dysarthria and their carer helped them to communicate. One patient used communication aids but chose not to use them during the interview. The main themes identified were: the choice and value of technology to enable patients to continue with normal life; the role of the internet in providing information, the barriers to using technology and the role of technology in MND care. Further quotes supporting the findings are available in Appendix F.

Technology enabling a normal life

Most pwMND (82%) and fMND (87%) surveyed used at least one digital device every day. Participants used a range of technologies and adaptations (listed in Appendix ~~F~~G). iPads and laptops were the most frequently used everyday devices (Figure 1). Use of the internet, particularly for leisure was also common (Figure 2). Those interviewed were very positive about using everyday technology because they found technology enabled them to continue to lead as normal a life as possible.

> *"Anything that makes life's journey, when necessary, better: she will accept it." Husband 6*

Participants interviewed also valued technologies with which they were already familiar, could be used for multiple purposes (including leisure and assistance), and were easy to use. Internet services were described as particularly useful when MND made daily activities difficult. For example, for a patient with poor mobility, the ability to shop online independently was a *"life saver"*, (Son 3). Another found that email had helped avoid the social isolation associated with speech and language problems (Patient 6).

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Using the internet to access information and support

All those completing the online questionnaire and 60% of fMND in the postal questionnaire used the internet to seek information about MND. Fewer pwMND in the postal questionnaire sought information this way (40%). The most commonly visited website was the Motor Neurone Disease Association (UK) website and many revisited the site (Figure 3). Even in the postal questionnaire, 78% of pwMND had visited the site. Participants wanted to know more about all aspects of the disease (Figure 4) preferring information to be available on websites with written information, videos or emails (Figure 5). However, books and written leaflets remain popular, particularly amongst fMND and low users of technology. Of the pwMND who could remember, 79% thought that at diagnosis their MND care team had recommended looking on the internet although of these, only 30% were recommended a specific site. 21% recalled being advised not to look on the internet. The internet also provided a way of receiving support from other people living with MND: 77% of pwMND in the online questionnaire used the internet to talk to others with the condition although only 14% of those in the postal questionnaire did. fMND used this less commonly (online 42% and postal 11%).

Interview participants described turning to internet to learn how to cope with their condition, and to be prepared for the future. Researching alternative treatments offered hope and the feeling that they were doing something themselves to fight the disease.

> *"I would suggest that the family go on the internet and study the illness themselves. So that they can learn of how this disease works, how it affects: because they need to be prepared. The family needs to prepare themselves so that they can be strong for the MND sufferer." Patient 1*

Interview participants found the practical and emotional support available on the forums even more valuable because of the experiences they shared with fellow *"comrades"* living with the disease.

> *"The internet is a wonderful thing. I use it stay in touch with my fellow MND sufferers as we do support each other when one of us is feeling very scared. We'll all gather on the internet and just try and be a support, reassure them they'll get through this; we're all here for them. I'm learning so much more about the illness through other sufferers." Patient 1*

Not all the experiences of the internet were positive, particularly around the time of diagnosis when many participants who were interviewed naturally turned to the internet to seek information about the disease.

> *"It's natural, isn't it? There's something you don't know, you go online now don't you?" Husband 2*

Most had little knowledge of MND and, following the shock of the diagnosis, most of what participants could recall was negative: for example, the terminal

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nature of the disease, the lack of treatment and poor prognosis. Information on the internet reinforced these ideas.

> *"It was a shock, to be told you was going to die and especially, not having any awareness of the disease. … I was just told to go home, get my affairs in order, tell the family. That was it really." Patient 2*

> *"If you just Google 'MND'… you get all the gory bits first" Husband 2*

Many felt the information on the internet was unreliable or confusing and some stopped looking. Like those surveyed, most preferred to use official sites such as the Motor Neurone Disease Association explaining that they thought these sites were more reliable.

> *"There's as much misinformation as good information but you don't know which" Husband 4*

Two pwMND did not go online at all, explaining that they were fearful of facing the future and preferred instead to approach problems as they encountered them.

> *"I will never go online because I'm the kind of person that deals better with what I don't know-I can't worry about. I'm not going to change anything by reading all the bad things about it. I know what's going to happen. I'll deal with it when it comes." Patient 2*

Participants preferred to receive information from a professional because the information was felt to be more reliable, specific to their circumstances and was delivered with the correct detail and pace.

> *"Online has its place, but it all needs to be talked about." Husband 2*

Whilst pwMND could access reliable information from their health professionals, wider family members relied on the internet for information. This could be helpful when they wished to learn more about the disease than the pwMND. However, this could also cause tension, with three participants describing difficulties when their extended families had developed overly negative impressions of MND following research on the internet.

> *"My son went on the internet and frightened himself with the information that was on there. He thought I was immediately going to die*" Patient 4

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Barriers to using technology

Lack of experience or confidence using devices was a common barrier to using technology. Figure 6 describes the barriers identified in this study. The postal questionnaire identified 12 low users of technology: nine (19%) pwMND and three (9%) fMND used it less than once a month. They were older than the other participants (median 74.5 years, p<0.0001). Reasons given for not using technology were: having no need (four), not knowing how to use it (four), poor hand function (three), fear of breaking it (one), and having a bad experience of computers (one). However, nine of the twelve thought that they could use technology if they had the appropriate equipment and training. They all preferred written information, although some thought email (four) and books (three) would be helpful with none wishing to access information using the internet.

Three carers interviewed described their loved ones as not being *"technology people"* thinking that they lacked an innate ability to use devices. They thought they lacked confidence in problem solving and would rely on family members for help. One son thought his father was not interested in using technology because he had always been too busy to use it. Difficulties with cognition and language caused further problems that severely restricted one pwMND's use of technology (Patient 6): reading and concentration were difficult and she was unable to learn to use new devices such as a new mobile phone. Patient 6 found text-to-speech software too slow, instead relying on basic drawing software.

> *"When [she] writes, even in there [note pad], it missed words out. The brain is working but the brain isn't actually interpreting it to say 'speak it properly' or even 'write it properly'. She knows what she wants to say and she knows what she wants to do, it doesn't always come in the right order." Husband 6*

Husband 6 was concerned what would happen if his wife could not use technology. She relied on it to avoid the social isolation associated with speech and language difficulties and they were unaware of any suitable alternatives.

Arm weakness was a common problem, but many pwMND adapted everyday technologies to overcome this with a preference expressed for devices that were light and not bulky. 33 (40%) of pwMND surveyed purchased additional equipment, mostly everyday technologies such as tablets and computers, but six pwMND had purchased specialist voice recognition or eye gaze software. (Appendix ~~F~~G) Cost and lack of awareness was particularly a barrier for unfamiliar and specialist technology. Four couples felt they didn't know enough about available specialist assistive technology and wanted more guidance from experts. Two pwMND wished that they had accessed specialist technology earlier in the disease in order to make the most of its benefits. Some experienced delays in receiving equipment or training and in one case, by the time equipment was available, the disease had progressed making the technology unusable.

> *"We should have known six months ago" Husband 2*
> *"...when I could still talk properly" Patient 2 [referring to voice banking]*

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Whilst technology was often recommended by health professionals and the MND Association, many learnt about adaptive and assistive technologies through word-of-mouth, internet research, the media or through personal recommendations on internet forums.

Everyday digital technologies, particularly those that pwMND were already using before the diagnosis were perceived to be part of normal life. However pwMND recognised that there would inevitably be a time when they would need to depend on more specialist assistive technology. There was more resistance to using this type of technology, even when they thought it would be valuable. Some pwMND had delayed thinking about, or accessing more specialist technology until they felt "*ready*" or until they really needed it. The need to rely on technology represented a significant milestone in the disease and fighting to remain independent helped maintain a positive outlook.

> *""If it takes about a year to persuade her to have them, and then when she has them then she really likes [it]... Once she stops going up and down the stairs, that's like a battle lost...." Son 3*

Using technology to access MND care

Only a minority of pwMND surveyed already used telephone (27%) and email (17%) to communicate with their specialist care team. Using everyday technology to communicate with the MND team was generally acceptable, particularly using email and telephone (Figure ~~8~~7). In the 12 low users of technology in the postal questionnaire, six supported telephone contact with their care team (answering "*Yes*" or "*Maybe*"). There was less support for using other technology; only one thinking email/computer contact was acceptable. There was less support for using technology as an alternative to clinic, and in the low users five thought telephone was, or "*maybe*" acceptable but only two supported email and one, video contact.

All the patients interviewed had telephoned the MND specialist nurse and one had used email. All reported positive experiences and thought technology could speed up communication. Whilst no pwMND had used telephone or video conferencing as an alternative to hospital appointments, one thought it could be useful as she became more unwell, as did a number of those who completed the questionnaire. Questionnaire participants were concerned about data security and the potential for loss of face-to-face contact if appointments were replaced.

> *"I would rather speak to people in person not machine" fMND postal survey*

The other concern raised was that communication would be difficult and that pwMND who are unable to speak or type quickly may be excluded from the consultation.

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Discussion

This study suggests that people living with MND have a positive attitude toward technology. The increasing availability of everyday technology which is familiar, accessible and affordable enables pwMND to continue to participate in many aspects of normal life. The variety and adaptable nature of technologies means there are likely to be solutions for the different and changing problems posed by MND. However, mirroring similar findings in an Australian survey, participants felt there needed to be a greater awareness amongst clinicians and pwMND about technology and that attention to timing of information and equipment provision was important (5).

This research has identified challenges that are not unique to MND. Whilst it is commonplace to turn to the internet for information about health and disease, information gained from health professionals remains more valued (15,16). Despite this, the value of the internet to many pwMND (helping them learn about their disease, promoting self-management and preparing them for the future) should be recognised and advising patients to avoid the internet may be counter productive (17). Instead, clinicians should signpost pwMND to reliable sources of information and help pwMND interpret their findings.

As medical services become more reliant on technology, addressing concerns raised in this research regarding accessibility, information security and the potential loss of human contact will be key to their success. If these barriers are not overcome, pwMND may lose access to medical services, increasing inequalities. Exposure to computers and training for those who are less likely to use technology (such as older adults and those with disabilities) improves attitudes towards technology (18-19) and internet and computer use in the over 65s in the UK is rapidly increasing from 6% in 2006 to 42% in 2014 (20).

Difficulties with cognition and language pose more challenging barriers to pwMND. The cost and limited function of specialist technologies can be prohibitive and even high-tech solutions may not meet pwMND's expectations (4,21). Reducing costs, improving awareness amongst patients and clinicians of solutions that meet their changing disabilities is important. Introducing new solutions sensitively, with hope and optimism (whilst managing expectations where technology is imperfect), may overcome some of the negative perceptions of technology use. At the same time, some people living with MND may remain unable or unwilling to use technology. As digital technology is becoming an increasing part of healthcare delivery, care should be taken to ensure that these patients continue to have their needs met in alternative ways.

This study involves a small sample from one care centre supplemented by a small number of online responses. As such the findings may not be representative of the wider MND population. There may be an over-representation of the views of younger people living with MND and those who already use technology. Given the median symptom duration was 41 months, our results may not reflect those with more rapidly progressive disease who may have different technology and information needs. Participants in the online

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survey were also more likely to have an upper limb disability. The reasons for this are unclear but they may experience more difficulties using technology and may have sought adaptations. Whilst spouses were the most common participants in the postal survey, more friends and wider family members completed the online survey. Our interview suggest that the wider family also has an influence on pwMND's use of technology and their attitudes warrant further investigation.

Despite these limitations the results are consistent with those in a smaller survey of pwMND in Australia (5). Furthermore, we have identified a rich range of the experiences and barriers to technology which were often shared by both high and low users of technology. The additional interviews identified more sensitive and potentially more challenging barriers specific to MND such as the fear of dependence on technology and impact of cognitive impairment. The experiences of pwMND less represented in this sample such as those without access to specialist MND services and those with cognitive and language difficulties would be worthy of future research.

Declaration of interests

The authors have no relevant declarations.

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Appendix G: A full list of digital technologies and adaptive solutions mentioned in the study

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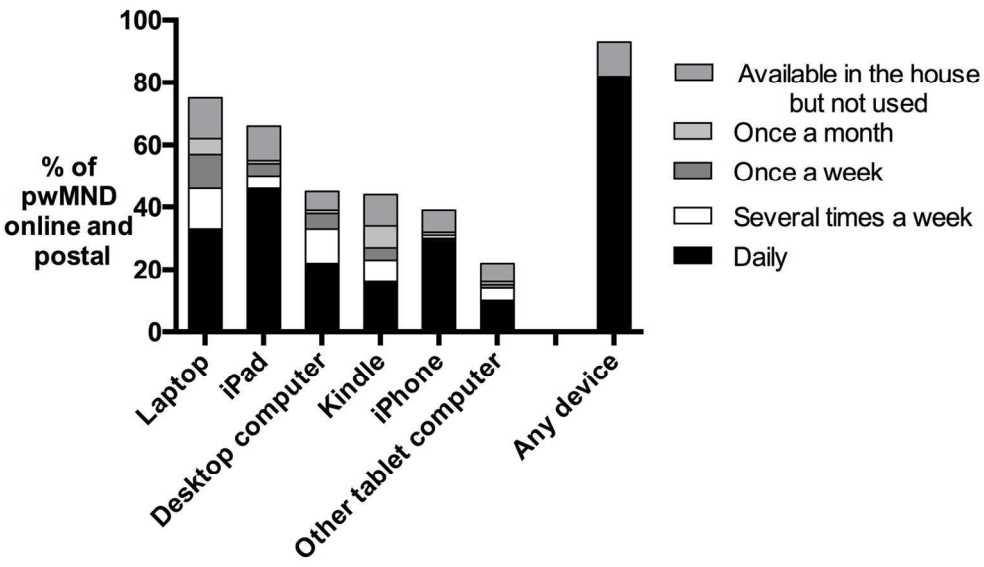

Figure 1: Frequency of use of everyday technology by pwMND (postal and online questionnaire combined).
Figure 1
147x86mm (300 x 300 DPI)

For Review Only

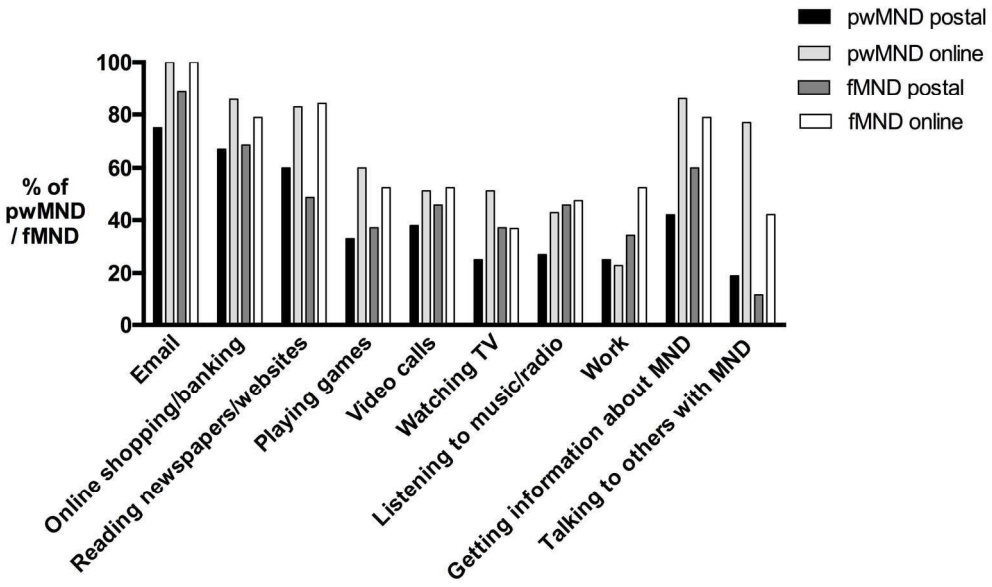

Figure 2: Uses of the internet by pwMND and fMND.
Figure 2
175x104mm (300 x 300 DPI)

For Review Only

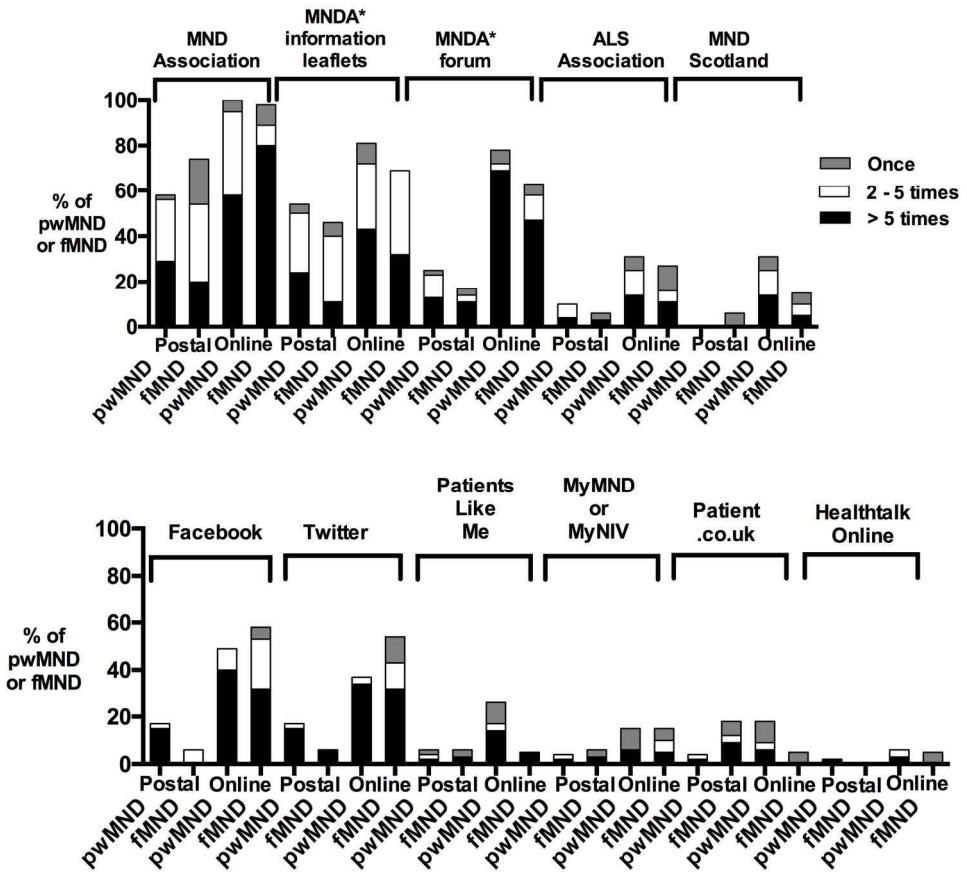

Figure 3 Frequency of visits to MND related websites by pwMND and fMND (*MNDA: Motor Neurone Disease Association)
Figure 3
166x151mm (300 x 300 DPI)

For Peer Review Only

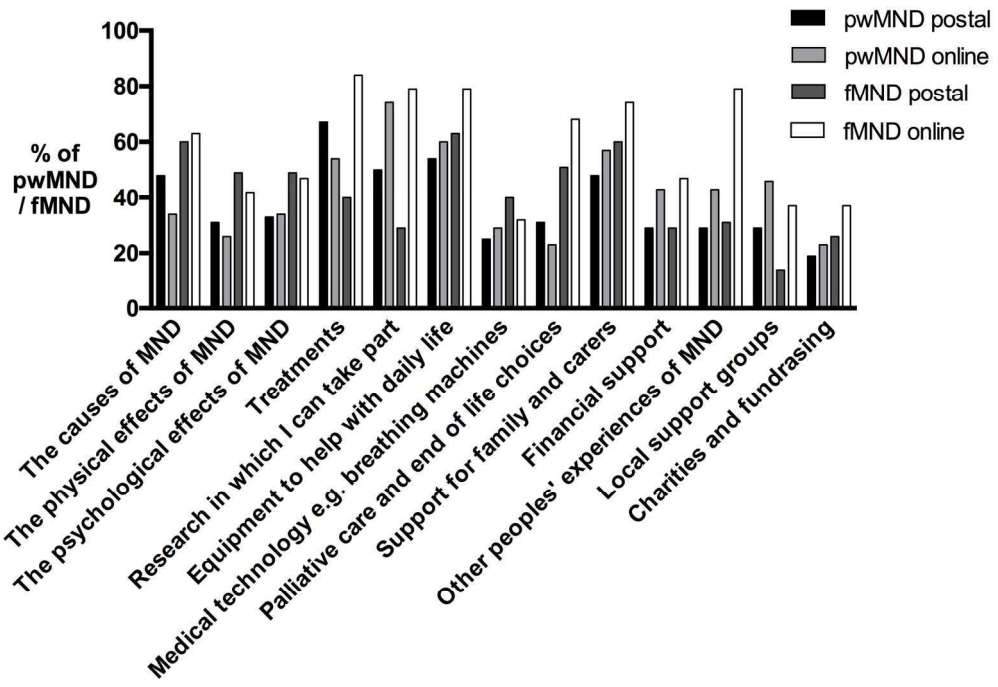

Figure 4: PwMND's and fMND's preferred topics of information about MND.
Figure 4
165x114mm (300 x 300 DPI)

View Only

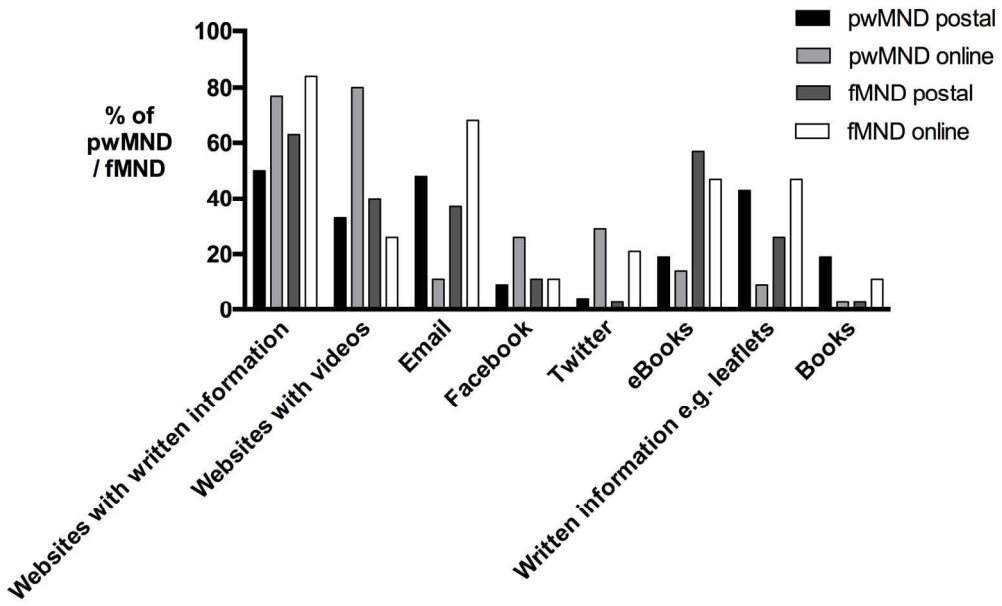

Figure 5: PwMND's and fMND's preferred methods of receiving information about MND.
Figure 5
164x101mm (300 x 300 DPI)

For Review Only

Figure 6: Barriers to technology use identified in this study.
Figure 6
282x301mm (300 x 300 DPI)

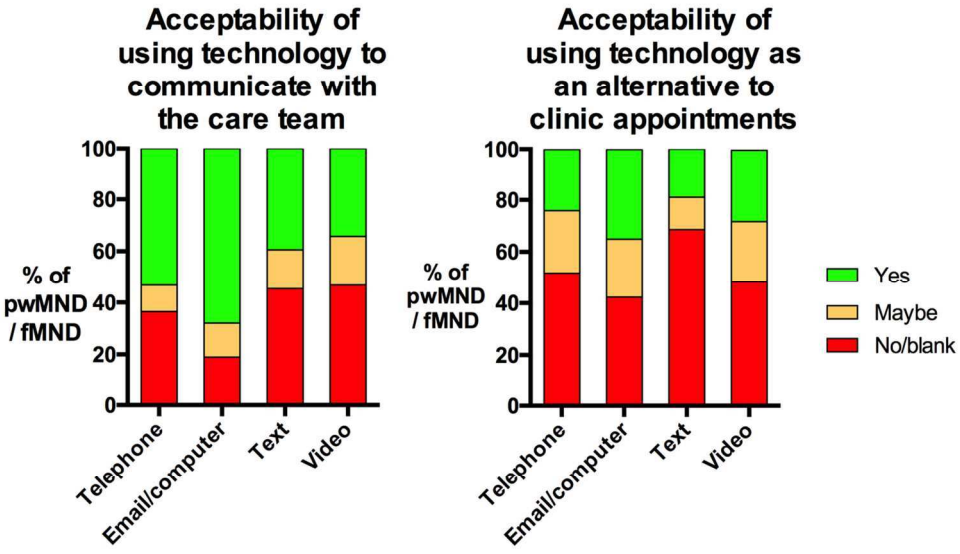

Figure 7: Acceptability of using technology to communicate with their MND team and as an alternative to MND clinic appointments (online and postal survey results are combined).
Figure 7
121x70mm (300 x 300 DPI)

For Review Only

Table 1: Characteristics of pwMND (questionnaire)

	Online (n=35)	Postal (n=48)	p value
Age - years, mean (range)	59 (30-80)	66 (45-86)	**p=0.001**
Gender - female (%)	15 (43%)	20 (42%)	p=1
Time since symptom onset - months, median (range)	41 (11-410)	41 (11-234)	p=0.46
Upper limb disability	36 (75%)	21 (43%)	**p=0.003**
Lower limb disability	36 (79%)	32 (66%)	p=0.2
Bulbar disability	30 (63%)	36 (74%)	p=0.3
Respiratory disability	18 (38%)	14 (29%)	p=0.48
Using non-invasive ventilation	14 (29%)	16 (34%)	p=0.6
Using gastrostomy	5 (10%)	7 (14%)	p=0.7

For Peer Review Only

Table 2: Characteristics of friends and family members (questionnaire)

	Online (n=19)	Postal (n=35)	p value
Age – years, mean (range)	47 (27-67)	61 (23-87)	**p=0.0004**
Gender – female (%)	11 (58%)	28 (80%)	p=0.11
Family member	2 (11%)	9 (26%)	
Friend	8 (42%)	1 (2%)	**p=0.001***
Partner/spouse	9 (47%)	25 (71%)	

*Calculated using a 3x2 contingency table using Chi-squared comparing the types of fMND in the online and postal questionnaire.

For Peer Review Only

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: .....

Exploring technology use by those living with motor neurone disease. STH 18885 Participant ID ____
Patient survey 13/04/15 V1

Exploring technology use by those living with motor neurone disease. STH 18885 Participant ID ____
Patient survey 13/04/15 V1

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 ☐

Exploring technology use by those living with motor neurone disease. STH 18885 Participant ID ____
Patient survey 13/04/15 V1

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	☐	☐	☐	☐	☐	☐
b. Laptop	☐	☐	☐	☐	☐	☐
c. iPad	☐	☐	☐	☐	☐	☐
d. Kindle	☐	☐	☐	☐	☐	☐
e. Other tablet computer	☐	☐	☐	☐	☐	☐
f iPhone	☐	☐	☐	☐	☐	☐
g. Other smart phone	☐	☐	☐	☐	☐	☐
h. Other (please describe) _____	☐	☐	☐	☐	☐	☐

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 adaptions 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 ☐

URL: http://mc.manuscriptcentral.com/als Email: gerd.halvorsen@informa.com

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=zlRaSpVtvCk

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 ☐
I don't know how to use them ☐
I'm worried I might break something ☐
I can't afford to buy a computer ☐
I'm too ill ☐
My hand function isn't good enough ☐
My reading isn't good enough ☐
My vision isn't good enough ☐
Other _____ ☐

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 ☐
I'd need some training but could probably manage ☐
I don't think I could use one without help ☐
Other *(please describe)* _____ ☐

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

Yes ☐
No ☐

****

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

- Email ☐
- Skype/making calls ☐
- Facebook/twitter ☐
- Reading newspapers or other 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 ☐
- Other _____ ☐
- I don't use the internet ☐

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	☐	☐	☐	☐
b. MND Association information leaflets	☐	☐	☐	☐
c. MND Association forum	☐	☐	☐	☐
d. MND Scotland	☐	☐	☐	☐
e. ALS Association	☐	☐	☐	☐
f. PatientsLikeMe	☐	☐	☐	☐
g. MyMND or MyNIV	☐	☐	☐	☐
h. Patient.co.uk	☐	☐	☐	☐
i. Healthtalkonline.org	☐	☐	☐	☐
j. Facebook sites	☐	☐	☐	☐
k. Twitter	☐	☐	☐	☐
l. Other (please describe) _____	☐	☐	☐	☐

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

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

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

Please choose your top three

- ☐ Internet websites with written information
- ☐ Internet websites with videos
- ☐ Twitter
- ☐ Facebook
- ☐ eBooks I can download e.g. for a Kindle or tablet
- ☐ Email
- ☐ Written information e.g. leaflets
- ☐ Books
- ☐ I don't want any more information

Other (please describe) _____

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

- ☐ They recommended looking on the internet
- ☐ They recommended not looking on the internet
- ☐ They recommended a specific site

Which site(s) did they recommend? _____

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

Telephone calls ☐
Email/computer ☐
Text messaging ☐
Video calls e.g. Skype ☐
None of these ☐

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	☐	☐	☐
Email/computer	☐	☐	☐
Text	☐	☐	☐
Video calls e.g. Skype or via your TV	☐	☐	☐

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	☐	☐	☐
Email/computer	☐	☐	☐
Text	☐	☐	☐
Video calls e.g. Skype or via your TV	☐	☐	☐

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 **********

Exploring technology use by those living with motor neurone disease. STH 18885 Participant ID ____
Patient survey 13/04/15 V1

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

Exploring technology use by those living with motor neurone disease.

THIS SURVEY IS FOR FAMILY MEMBERS OR FRIENDS

- 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 to 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 confirm I am 18 years old or over and am a friend or family member of someone with MND.

- **I agree to take part in this study**

Signature: ……

Print Name: ..... Date:.....

Address: ……

Exploring technology use by those living with motor neurone disease. STH 18885 Participant ID ____
Carer survey 13/4/15 V1

Exploring technology use by those living with motor neurone disease. STH 18885 Participant ID ____
Carer survey 13/4/15 V1

Please try and answer all the questions 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 10-15 minutes but please take as long as you wish.

1. How old are you? ☐☐ years

2. Are you… Male ☐ Female ☐

3. What is your postcode? ☐☐☐☐ [redacted]

(*just give us the first 3 or 4 letters or numbers e.g. S6 or NG14..)*

4. Are you.?

A partner of someone with MND ☐
A family member of someone with MND ☐
A friend of someone with MND ☐

5. 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	☐	☐	☐	☐	☐	☐
b. Laptop	☐	☐	☐	☐	☐	☐
c. iPad	☐	☐	☐	☐	☐	☐
d. Kindle	☐	☐	☐	☐	☐	☐
e. Other tablet computer	☐	☐	☐	☐	☐	☐
f iPhone	☐	☐	☐	☐	☐	☐
g. Other smart phone	☐	☐	☐	☐	☐	☐
h. Other (please describe) _____	☐	☐	☐	☐	☐	☐

****

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.

****

6. 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 ☐
I don't know how to use them ☐
I'm worried I might break something ☐
I can't afford to buy a computer ☐
I'm too ill ☐
My hand function isn't good enough ☐
My reading isn't good enough ☐
My vision isn't good enough ☐
Other _____ ☐

7. If you had the correct equipment, how confident are you using a basic computer?

I know how to use one with no/little help ☐
I'd need a some training but could probably manage ☐
I don't think I could use one without help ☐
Other (please describe) _____ ☐

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

Yes ☐
No ☐

****

9. If you use the internet, which of these do you use? *(you can tick as many as you like)*

Email ☐
Skype/making calls ☐
Facebook/twitter ☐
Reading newspapers or other 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 ☐
Other _____ ☐
I don't use the internet ☐

10. 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	☐	☐	☐	☐
b. MND Association information leaflets	☐	☐	☐	☐
c. MND Association forum	☐	☐	☐	☐
d. MND Scotland	☐	☐	☐	☐
e. ALS Association	☐	☐	☐	☐
f. Patientslikeme	☐	☐	☐	☐
g. MyMND or MyNIV	☐	☐	☐	☐
h. Patient.co.uk	☐	☐	☐	☐
i. Healthtalkonline.org	☐	☐	☐	☐
j. Facebook sites	☐	☐	☐	☐
k. Twitter	☐	☐	☐	☐
l. Other (please describe) _____	☐	☐	☐	☐

11. What information would you like to know more about?

a. The causes of MND	☐
b. The physical effects of MND	☐
c. The psychological effects of MND	☐
d. Treatments	☐
e. Research in which I can take part	☐
f Equipment to help with daily life	☐
g. Medical treatments such as breathing machines	☐
h. Palliative care and end of life choices	☐
i. Other peoples' experience of MND	☐
j. Financial support	☐
k. Family and carer support	☐
l. Local groups or talking to other people with MND	☐
m. Charities and fundraising	☐
n. Other *(please describe)* _____	☐

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

Please choose your top three

- ☐ Internet websites with written information
- ☐ Internet websites with videos
- ☐ Twitter
- ☐ eBooks I can download e.g. for a Kindle or tablet
- ☐ Email
- ☐ Written information e.g. leaflets
- ☐ Books
- ☐ I don't want any more information

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

- ☐ They recommended looking on the internet
- ☐ They recommended not looking on the internet
- ☐ They recommended a specific site

Which site(s) did they recommend? _____

13. Has the MND doctor caring for your friend/relative ever used any of these methods to talk to either of you at home?

- Telephone calls ☐
- Email/computer ☐
- Text ☐
- Video calls e.g. Skype ☐
- None of these ☐

14. 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	☐	☐	☐
Email/computer	☐	☐	☐
Text	☐	☐	☐
Video calls e.g. Skype or via your TV	☐	☐	☐

15. 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	☐	☐	☐
Email/computer	☐	☐	☐
Text	☐	☐	☐
Video calls e.g. Skype or via your TV	☐	☐	☐

16. 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 later in the year, or get more information by calling 0114 22 22260 or email e.hobson@sheffield.ac.uk

Exploring technology use by those living with motor neurone disease. STH 18885 Participant ID ____
Carer survey 13/4/15 V1

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

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.**

.....

.....

.....

.....

.....

Skip to question 33.

About your MND

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

.....

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?**

.....

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.**

.....

.....

.....

.....

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.

.....

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

.....

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)

.....

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

.....

.....

.....

.....

.....

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

.....

.....

.....

.....

.....

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

.....

.....

.....

.....

.....

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

.....

.....

.....

.....

.....

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?**

.....

.....

.....

.....

.....

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?**

.....

.....

.....

.....

.....

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?**

.....

.....

.....

.....

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

.....

.....

.....

.....

.....

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.

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Appendix D: Interview topic guide

The topic guide was developed by EH and SF. The topic guide was shaped by a literature review, consultation with the Sheffield MND Research Advisory Group which includes patients, carers and volunteers and consultation with MND clinicians. Early interviews influenced the development of the topic guide.

***

Introductions, aims of the interview, ground rules established and consent reconfirmed.

Information seeking and needs at diagnosis

1. So if we go back to the start, can you tell me about the day you were diagnosed with MND?
2. When you were first diagnosed with MND, how did you receive information about MND?
3. Were you happy with the amount of information that you received on that day?
4. Could there have been more or little information discussed on that particular day?
5. MND Association?
6. How did that make you feel?
7. Were you told how to access information about MND from the MND Care Team?
8. What are your views on that?
9. Do you think you need different information now you have lived with MND for some time?
10. Can you think of a time when you needed to know the answer to a question? What happened?
11. What information would you tell someone who has just been diagnosed with MND? What about their family or those who care for them?

Attitudes towards the internet and other devices

12. Do you have access to the Internet at home? If yes- Do you use the internet?
13. How do you use the Internet?
14. Are there any certain devices/technologies that help you use the Internet easier?
15. Do you find any difficulties in using technology? If yes- what are the difficulties (expand?) Can you explain a little further please?
16. What technology did you have before your diagnosis of MND?
17. Have you bought any technology since the diagnosis? If yes, what?
18. Have you ever used email or telephone to speak to your doctor or your MND care team?
19. Do you think that is something you might want to consider in the near future?
20. Can you tell me about your experience (good/bad) when you have used email/telephone to contact the doctor/MND care team?

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21. Are there any devices/technologies that you don't have (or not have access to) that you think would help your day-to-day living with MND?
22. How would these technologies improve living with MND?
23. Are there any barriers for which you are not able to have these devices/technologies (e.g. money)?

Conclusion, reconfirm consent.

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Appendix E: Descriptions of the participants in the qualitative interviews

Interview	Patient	Gender Age	Disease duration	Disability severity	ALS FRS-R	Technology use	Family member	Age	Technology use
1	Patient 1	F 40s	ALS 13 years	Bulbar: mild UL: moderate LL: mild	38	Daily	No carer present	-	-
2	Patient 2	F 40s	ALS 4 years	Bulbar: mild UL: severe LL: moderate	28	Daily	Husband 2	40s	Daily
3	Patient 3	F 70s	ALS 11 years	Bulbar: mild UL: severe LL: severe	33	Daily	Son 3	50s	Daily
4	Patient 4	F 50s	ALS 10 months	Bulbar: mild UL: mild LL: mild	40	Daily	Husband 4	50s	Daily
5		-	-	-	-	-	Son 5	30s	Daily
6	Patient 6	F 70s	ALS 4 months	Bulbar: mild UL: mild LL: mild Other impairments: cognition, language	40	Less than once a week	Husband 6	70s	Daily

M: male, F: female, UL: upper limb, LL: lower limb

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Appendix F: Supporting quotes from interviews and questionnaires

Technology enabling a normal life

"It's going to a stage where he's going worse now but at the moment we can still manage." Son 5

"I'm amazed at the technology that there is out there. Have we mastered it all ourselves at this moment in time?-No. Are we going looking for it at this moment in time?-No. Will we go look for it in the future?-Maybe" Husband 6

"iPad mini: using it for documents instead of paper or needing heavier laptop taking notes as can't use pens etc" Patient online questionnaire

"Dragon software; I use for emails, surveys and on occasion when my hands are tired I use the commands to move the mouse cursor around the screen on my PC." Patient online questionnaire

"I purchased an iPad primarily to read books but also I understand other software can be used on this to assist with communications at a later date. I had hoped that the included voice activated software would have been better as I would like software that could actually open the book I'm reading and actually turn the pages for me." Patient online questionnaire

Using the internet to access information and support

"We knew nothing of the condition, and obviously we wanted to research it." Patient 2

"I think from the doctor's point of view we weren't really given that much information at all. It was likelihood is two to three years and that's about it. We did have some questions about whether it'd be a steady progression or this kind of stuff. I remember there were no pamphlets to take home or anything but you know 'you got MND what are you going to do next?' or anything like that. Most of the stuff we found out I suppose we found out either on the internet or [an MND specialist]" Son 3

"I don't know anyone who's got it. I'm always on the internet: I like doing a lot of research and stuff but it's something that's never crossed my mind. We wasn't given any direct information from the doctor who gave us the results. … I just went on the internet, typed it in all the forum that came up, from there it started, figuring out what people suffer. Husband 6

"On the day I was diagnosed, I just had a piece of paper like a 24 hour helpline and something from the hospital and then [MND specialist nurse's] number to call and [consultant's] name and number for her secretary." Patient 4

"We kind had a good look at the herbal side of things, you do take some between 10 and 15 herbal pills a day. Whether they're working or whether she's just stubborn, we're not quite sure." Son 3

" Every now and again there's a question what somebody puts up. You don't know the answer but all of a sudden there's somebody else knows the answer and "Oh, that's an idea", and obviously that information is shared between the people going through it." Husband 2

"I do always have to have an arm rest. I had to buy and have fitted an arm rest in my car umm to rest my arms because they do get tired." Patient 1

"I went for a laptop as well because it's larger. I find the smaller devices, I find that they're too close, I tend to press something I don't want to press and so a laptop and the largest I can get. Umm, I find it easier to use." Patient 1

"I generally use my iPad and bought the laptop to enable me to use a head mouse, it was bought on the recommendation of Assistive Technology department as it has more uses than an iPad" Patient online questionnaire

"A: But we only found this out because we're, we're friends with another couple that has this,….

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H: Who's doing it…
A: the husband has it and he's doing it and everything that we've sorted out recently is because they've gone: 'Haven't you got this?' 'Haven't you got that?' 'Why aren't you doing this?' [referring to voice banking]" Husband 2

"I won't…there's lots of things written on the net. I'm not a doctor: my interpretation can be way off beam. Leave it to the professionals. … I don't want to be looking up MND… A [doctor] has said to us: "No two patients with ALS are the same"." Husband 6

"It's almost like the MND Association are telling the worst because it's stories that gets some money in for the Association, which is good in one way but actually it's not helped my brother or my mum." Patient 4

"[The information] was either very technical or not enough information… a lot of it was contradictory" Son 3

"*If I read something, it will worry me and it will go round in my head, it'll keep me awake. I don't need to, if it isn't going to do anything beneficial, I don't need to read about it and worry myself. I would rather just deal with the disease as it goes along and keep positive attitude." Patient 2*

"I don't want to be delving into technology on Google, I'll listen to the technology that we're getting from the MND Association and I'll listen to the technology that we're getting from the professionals but not 'tell me about MND' on Google." Husband 6

"I would only recommend certain sites, like MNDA…they will tell you the facts. Just make sure if you go to the correct place." Patient 1

"I wouldn't advise anyone to go online… not initially… Not until they have actually spoke to [an ALS specialist], to try and understand the condition a little more because … the guidelines are that you will die within 2 years or what of the diagnosis. And that's not necessarily the case. Online has its place but it all needs to be talked [about], [you] still need to meet people like the doctors, the nurses here who deal with it day to day and not just what somebody's just 'writ' once." Husband 2

"I would ring [ALS nurse] and she would answer any questions. So I didn't really feel I needed the internet." Patient 1

"*We came away really positively and everybody else was saying "oooh you've got that" but I said but there's hope"* Patient 4

"If [the doctor] had given us too much, I think that it would have frightened … I couldn't have coped with it." Husband 4

"Instantly, somebody who's diagnosed with motor neurone would have a one point of contact, who'd know where to find the information, might not know it but would find the information out so they could help." Husband 2

"I had never heard of MND before but sadly my mum had heard of it. So it hit her before it hit me." Patient 1

"If we'd be able to control what they got to hear from us, rather than going on the internet and frightening themselves… it was quite difficult really… they had probably too much information rather than not enough…"
"That's what's difficult you know, it's everybody else." Patient and Husband 4

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Using technology to access ALS care

"There's a good triangulation and the best of it is that they do communicate with each other so whatever [MND doctor] writes up today, [hospice] will get a copy and also our doctor gets a copy so if you like, the triangle and the loop is constantly being topped up. Technology plays its wonderful part in that because it isn't the snail mail anymore you know, its email, its all sorts of different things so they are talking to each other." Husband 6

"It would make better use of resources and it saves those suffers from having to travel when it is virtually impossible to leave there home" Patient online

"Being in the late stages of Mnd it would be an advantage to use computers Internet FaceTime etc rather than being dragged to a busy hospital for an appointment." Patient online questionnaire

"I'm looked after in Sheffield. I like to go over to see them. I much prefer a face to face session with them." Patient postal questionnaire

"I feel that more can be gained from a face-to-face meeting as communication is more than just using a voice." Patient online questionnaire

"Given that the vast majority of people with MND loose their ability to speak, having an effective spontaneous conversation using a communication device whilst under time pressure e.g. on a video call, is not really possible." Patient postal survey

Barriers to technology use

"She's not a major gizmo technology person" Husband 6

"He's never really been interested. He's worked all his life and he's been work, home, work, home, rest, go back to work … it's never really bothered him really" Son 5

"[My wife] can't read for any length of time because of concentration. I ended up reading a lot of the stuff to her… Because you've slowed down you feel you're too slow when you're using it. It's one of the problems … your coordination [and] you slow down." Husband 6

"It would be nice to somebody could show you or tell you without having the obligation to sell it to you. They'll tell you what you want to hear to buy it not necessarily whether if it's any good for you" Husband 4

"We should have known six months ago" Husband 2
"…when I could still talk properly" Patient 2 [referring to voice banking]

"Getting used to using technology as never used a computer before. I am going to need technology based help as my speech is getting worse, using a tablet is helping me lose my fear of not being able to use computerised aids." Patient online questionnaire

"I used Dragon voice activated software, I'm actually using it to complete this survey except for mouse clicks as I can still left click a mouse with my right hand and the software to use the mouse is very slow." Patient online questionnaire

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259x256mm (300 x 300 DPI)