



### **Experience of Telehealth in People with Motor Neurone Disease using Non-Invasive Ventilation**

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## Implications for Rehabilitation

- Care for people with MND demands a flexible approach to accommodate the diversity of clinical needs and relentless physical deterioration
- Telehealth allows clinicians to provide person-centred care for everyone with MND through frequent monitoring
- Holistic and rehabilitative service facilitated by telehealth is generally acceptable and preferred to routine appointments among MND NIV patients
- Telehealth promotes time efficient engagement with professionals that leads to symptom awareness and interpretation, while benefiting physical and psychological well-being of MND NIV patients

# 1 Experience of Telehealth in People with Motor Neurone Disease using Non- 2 Invasive Ventilation

## 3 Abstract

4 **Introduction:** Evidence is emerging that telehealth provides timely and cost-effective support for  
5 individuals with motor neurone disease (MND). However, little is known about the subjective  
6 experience of using telehealth. This study was designed to examine the experiences of using  
7 telemonitoring in patients with MND on non-invasive ventilation (NIV).

8 **Methods:** Semi-structured interviews were conducted with seven patients (five males; mean  
9 age=63yrs; median illness duration=14m), who used a telemonitoring device for 24 weeks.  
10 Caregivers were present at five of the interviews; they supported communications and provided  
11 their feedback. Interviews were audio recorded and transcribed verbatim. Thematic analysis was  
12 conducted to find overarching themes.

13 **Results:** Five themes were identified: Benefits of Timely Intervention, Reducing the Unnecessary,  
14 Increased Self-Awareness, Taking Initiative, and Technical Challenges. Overall, timely interventions  
15 were observed as a result of regular monitoring, contributing to both physical and psychological  
16 well-being of the participants. The patient-caregiver dyads suggested that telemonitoring could  
17 reduce costs, save time and ameliorate hassles associated with attending hospital appointments.  
18 Participants articulated that telemonitoring enabled symptom awareness and interpretation; the  
19 device also enabled the participants to raise concerns and/or requests to the healthcare  
20 professionals via the messaging system. Participants confirmed that the telemonitoring device was  
21 easy to use, despite some technical issues.

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3 22 **Conclusions:** Telemonitoring was positively experienced. The findings suggest this approach is  
4  
5 23 empowering and effective in promoting patients' well-being, while potentially reducing unnecessary  
6  
7 24 clinical contact.  
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10  
11 25 Keywords: Telemonitoring; Telehealth; Qualitative study; Non-invasive ventilation; Motor neurone  
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13 26 disease; Amyotrophic lateral sclerosis  
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## 17 27 **Introduction**

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19  
20 28 The United Kingdom National Institute for Health and Care Excellence (NICE) [1] recommends  
21  
22 29 flexible approaches to the care of patients with motor neurone disease (MND) – also known as  
23  
24 30 amyotrophic lateral sclerosis (ALS) – according to their needs. MND is a fatal neurodegenerative  
25  
26 31 disease which primarily impacts on the motor systems. Appropriate symptom management,  
27  
28 32 particularly of respiratory challenges, is reflected in longer survival rates [2]. To this end, and to  
29  
30 33 improve quality of life for patients, the NICE guidelines prompt clinicians to consider: an individual's  
31  
32 34 capability to attend the clinic, the appropriate frequency for their assessments and arrangements for  
33  
34 35 prompt review when significant deterioration is declared. These recommendations reflect the  
35  
36 36 diversity in symptomatology and prognosis [3], the relentless deterioration, and rapid progression of  
37  
38 37 the condition towards the final stage [4]. The guideline also suggests the need for a new approach to  
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40 38 meet the challenging task of accommodating the diversity of clinical needs.  
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45 39 In view of the NICE guidelines, and the use of telehealth emerging as a promising platform for  
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47 40 clinicians to provide flexible approaches, we developed a telemonitoring system, using the Docobo<sup>Ltd</sup>  
48  
49 41 Careportal<sup>®</sup> device. The device allows clinicians to monitor their service users more frequently,  
50  
51 42 outside of the clinic, regarding their symptom changes, non-invasive ventilation (NIV) related issues,  
52  
53 43 nocturnal blood oxygen saturation levels, and patient-ventilator interaction data. Careportal<sup>®</sup> also  
54  
55 44 incorporates a messaging system for patient-clinician communications. The details of system and  
56  
57 45 intervention protocol are reported elsewhere [5].  
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3 46 There are a few studies that have examined telehealth systems in the care of MND. These include  
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5 47 videoconferencing [6], nurse-led weekly telephone call follow-up [7,8], and weekly telemonitoring of  
6  
7 48 NIV compliance [9,10]. Findings suggest that these telehealth systems are effective and provide an  
8  
9 49 approach for meeting the NICE recommendations to tailor care for each patient. Nevertheless, the  
10  
11 50 subjective experience of *using* telehealth must be explored to ensure that any changes to MND care  
12  
13 51 procedures are not made at the expense of patients. Little is known of the advantages and  
14  
15 52 disadvantages of telehealth for MND patients themselves. As far as we are aware, the only available  
16  
17 53 report of subjective accounts of using a telehealth service amongst people with MND is based on a  
18  
19 54 satisfaction questionnaire conducted via telephone [7]. There has been an attempt [11] to co-design  
20  
21 55 a MND telehealth service with MND patients and carers; however, at the consultation meetings  
22  
23 56 potential users of telehealth could only relate to aspirational benefits because at that time, none of  
24  
25 57 the MND patients or their carers had used Telehealth.

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28 58 Amongst other illness groups (e.g. diabetes and chronic heart failure), there are suggestions that  
29  
30 59 telemonitoring is supportive [12-19]. Patients generally found few problems using telemonitoring,  
31  
32 60 and whilst some difficulties were reported – with either the telemonitoring technology or internet  
33  
34 61 connectivity – these were minor [13,15,17]. Reports referred to a sense of reassurance and peace of  
35  
36 62 mind through using telemonitoring system, which were attributed to perceived continuous  
37  
38 63 monitoring and support by professionals [12,13, 18]. Also, telemonitoring has been linked with  
39  
40 64 increased knowledge of one's condition [12,18,19] and thereby facilitating patients to identify the  
41  
42 65 'norm' of their symptoms [12,19]. Although an increased awareness of symptoms may have a  
43  
44 66 negative effect on the minority of patients [14,18], self-awareness of health status through  
45  
46 67 telemonitoring was generally perceived to be positive and empowering to patients [12]. Hanley et al.  
47  
48 68 further reported that telehealth promoted healthy behaviour, although they acknowledged that this  
49  
50 69 may have been facilitated by participants' awareness of their data was being monitored [15].  
51  
52 70 Telemonitoring was seen to be a more convenient approach for patients, and the need for less  
53  
54 71 appointments with healthcare professionals was appreciated [15,18].

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3 72 Despite these positive findings of using a telehealth system, we cannot assuming subjective accounts  
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5 73 of the benefits of telemonitoring in other chronic conditions will generalise to the MND population;  
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7 74 there are clear differences in symptoms and prognoses of other conditions compared to MND. Thus,  
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9  
10 75 the current study was designed to explore subjective experiences of telehealth as facilitated by the  
11  
12 76 Careportal® device as a regular monitoring service amongst people with MND who were using NIV.  
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## 16 77 **Methods**

### 17 18 19 20 78 **Ethics**

21  
22 79 Ethical approval to conduct this study was obtained from United Kingdom National Health Service  
23  
24 80 (NHS) Research Ethics Service (Ref no. anonymous) and the Research and Development department  
25  
26  
27 81 of the study site.

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30 82 Potential participants were given an information sheet about the study and written consent was  
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32 83 obtained after participants had a chance to ask questions about the study and their role in it.  
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### 35 84 **Participants**

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38 85 Opportunity sampling was employed to recruit patients who had completed a 24-week trial of  
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40 86 telemonitoring using Careportal® [5]. 13 patients with MND on NIV were recruited for the 24-week  
41  
42 87 trial. Of the original 13, three patients died before the completion of the trial and an additional three  
43  
44 88 before interviews were conducted. The remaining seven patients agreed to be interviewed about  
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46  
47 89 their experience of care associated with telemonitoring. Table 1 shows demographics and illness  
48  
49 90 characteristics of the seven patients at the time of the trial. The median illness duration was 14  
50  
51 91 months and the median time on NIV was 12 months. The average time between the end of trial and  
52  
53 92 interview was 8 months.

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56 93 Five carers were also recruited to explore their experiences of using the Careportal®. An interview  
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58 94 with the other two carers was perceived unnecessary by the patients because they had little  
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3 95 involvement during the trial. Joint interviews were preferred by patients and their carers thus an  
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5 96 arrangement was made to interview them together.  
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8 97 [Table 1 about here]  
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## 10 11 98 **Data Collection**

12  
13  
14 99 Semi-structured interviews were conducted by a non-clinical researcher, who monitored the weekly  
15  
16 100 data input during the 24-week trial. Interview questions (Appendix 1) were developed by the  
17  
18 101 research team to explore subjective experiences of using Careportal® and to understand the impact,  
19  
20 102 if any, of having a telemonitoring service in the management of their MND illness situation. All  
21  
22 103 questions were addressed to both patients and their carers with one extra question only applicable  
23  
24 104 to the carers.  
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27  
28 105 All the interviews were conducted in participant's homes. During the interview, John and Margaret  
29  
30 106 used a communication device (i.e. iPad and an eye control computer), and three patients (i.e. John,  
31  
32 107 Margaret, Mary) required communication support from their carer. Carer's interpretations of  
33  
34 108 patient's comments were always checked with the patient. The length of interviews ranged between  
35  
36 109 30 minutes and 50 minutes with an average duration of 35 minutes. Interviews were audio recorded  
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38 110 and later transcribed verbatim.  
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## 41 42 43 111 **Data analysis**

44  
45 112 A qualitative study is explorative and researchers aim to understand subjective experiences of a  
46  
47 113 particular phenomenon by immersing themselves in the data and – through an iterative analysis  
48  
49 114 process – make sense of the narratives. As argued by Chamberlain, qualitative studies are interested  
50  
51 115 in what underlies the surface to answer 'how' and 'why' questions [22]. Thematic analysis [23] was  
52  
53 116 employed to answer 'how' telemonitoring service was perceived by the participants and 'why' it was  
54  
55 117 so. Codes were inductively generated from the transcripts and they were later examined to identify  
56  
57 118 the overarching themes, which were subsequently assessed to ensure that they reflected the data  
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3 119 set. Initial coding of the transcripts was assisted by software for qualitative analysis (NVivo11). The  
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5 120 analysis was conducted by the same non-clinical researcher who interviewed the participants. The  
6  
7 121 credibility of the analysis was examined by the research team; the findings were presented at a team  
8  
9 122 meeting, and a list of codes (Appendix 2) and all transcripts were shared with the team for a  
10  
11 123 credibility examination.  
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## 16 124 **Results**

17  
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19 125 Thematic analysis identified five themes: benefits of timely intervention, reducing the unnecessary,  
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21 126 increased self-awareness, taking initiative, and technical challenges. The following section expands  
22  
23 127 each theme using supportive quotes from the narrative accounts listed in brief sequential tables 2-6.  
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25 128 Each quote is cross referenced from the table into narrative of interpretation. Three full stops in  
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27 129 brackets indicate an omission of words.  
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### 31 130 **Benefits of timely intervention**

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34 131 Timely interventions were observed by six of the seven patients and all caregivers as a result of  
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36 132 regular monitoring of clinical information via Careportal®, contributing to both physical and  
37  
38 133 psychological well-being. Its benefits on physical well-being were observed when oximetry results  
39  
40 134 prompted interventions (1)a. Whilst participants James and Charlie did not perceive any gain from  
41  
42 135 Careportal® in terms of physical well-being at the time of trial, they still acknowledged potential  
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44 136 benefits for the future (1)b.  
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48

49 137 In addition to clinical benefits from using telemonitoring, a positive impact on psychological well-  
50  
51 138 being was reported. Participants appreciated their data being monitored by professionals who  
52  
53 139 would make timely actions if they saw any irregular signs: (1)c. The significance of these positive  
54  
55 140 impacts of Careportal® on psychological well-being was further highlighted by two participants who  
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57 141 had identified psychological well-being to be the key to coping with the condition (1)d.  
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3 142 Whilst the benefits of timely intervention were expressed as above, John and his professional home  
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5 143 carer did not perceive any benefits because of the good home care support he was receiving, as  
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7 144 argued by his carer (1)e. Because of multiple daily visits from carers John similarly agreed that there  
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9  
10 145 were no benefits of telemonitoring for him, however he suggested 99% of people were likely to  
11  
12 146 benefit: (1)f.

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16 147 [Table 2 about here]

### 20 148 **Reducing the Unnecessary**

21  
22  
23 149 Given the accessibility of timely intervention via telemonitoring, participants were keen to utilise the  
24  
25 150 device to reduce the current hospital appointments unless it was necessary. Five patients suggested  
26  
27 151 Careportal® follow-ups to be more cost and time effective, besides reducing the hassles of attending  
28  
29 152 the clinic – often described as brief with little benefit. In particular, James and Charlie, did not  
30  
31 153 perceive any need for them to attend the clinics when little change in their physical well-being over  
32  
33 154 time (2)a,b. Similarly, potential positive impact on health economics was noted by two participants.  
34  
35 155 (2)c.

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40 156 For those more physically impaired by the condition, reduced hospital appointments were perceived  
41  
42 157 to be beneficial as these were stressful experiences. Similar to time/cost effectiveness, these views  
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44 158 were in the context of perceiving little benefit of face-to-face consultations. (2)d. Face-to-face  
45  
46 159 consultation, however, was not completely dismissed. Mary and Logan were keen to regularly  
47  
48 160 attend hospital because of the perceived advantage of direct contact with a consultant. (2)e.  
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50  
51 161 Nevertheless, the benefits may depend on the usefulness of hospital clinics considering Mary also  
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53 162 suggested reducing appointments elsewhere in her interview.

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58 163 [Table 3 about here]

## 164 **Increased self-awareness**

165 Participants were supportive of the regular monitoring of symptoms required by telemonitoring.

166 Patients reported that this was a feature of having MND – appreciating that there are symptoms to  
167 experience and cope with. Their acceptance of telemonitoring then appeared to be a consequence  
168 of patients’ general understanding of fluctuations in their physical well-being (3)a.

169 Telemonitoring further enabled symptom awareness and interpretation for four patients. For one  
170 patient, this was through voluntarily taking extra readings of pulse oximetry: (3)b. For Logan, it was  
171 through answering symptom related questions (3)c. Yet for another patient, having a follow-up  
172 conversation with the physiotherapist increased the symptom awareness. Furthermore, it was  
173 pointed out by two relatives that regularly monitoring symptoms led patients to be less biased and  
174 to become objective about their condition: (3)d

175 As illustrated above, being accurate about their symptoms and coming to understand more about  
176 their physical well-being as a part of the process of reporting through the Careportal® was perceived  
177 to be beneficial, and this was also voiced by Mary herself and Charlie. These accounts and the  
178 following quote suggest that telemonitoring can promote an active engagement with self-care (3)e.

179 [Table 4 about here]

## 180 **Taking Initiative**

181 Five of the seven patients were positive about their experiences from using the message system on  
182 the Careportal® because it allowed them to get in touch with the healthcare providers when they  
183 needed support (4)a. As illustrated, patients were able to register their concerns as the need arose,  
184 with the assurance of future contact from the healthcare providers. And, even though the answers  
185 may not be instant, this gave the patient ‘peace of mind’. The concerns that led to engaging with the

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3 186 professionals were in relation to symptoms, general information, and equipment needs. This service  
4  
5 187 format based around their needs was a sharp contrast to current communication with hospitals  
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7  
8 188 which was described as a one-way communication or communications with a long wait at best: (4)b.  
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11  
12 189 Although the benefit of having the contact point was observed, this was not shared by William or  
13  
14 190 John. Whilst William perceived the potential benefits, he had problems with sending messages (as  
15  
16 191 shown below) therefore he never used the Careportal® to initiate contact. John did not perceive the  
17  
18 192 benefits of having Careportal® as a contact point because he already had a good contact system set  
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20  
21 193 up as suggested by his carer: (4)c.  
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25 194 [Table 5 about here]  
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## 28 29 195 **Technical challenges**

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32 196 Although participants expressed general ease of using the telehealth device, a few technical issues  
33  
34 197 were reported. Whilst most challenges were perceived as minor, or they were quickly solved by the  
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36 198 Careportal® provider, four participants expressed frustration with the messaging system – in  
37  
38 199 particular on-screen keyboard. This was used to draft messages to their health providers.  
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41 200 Participants said the keys were too small, as well as the touch panel having insufficient sensitivity  
42  
43 201 and the time allowance for formulating a message was also insufficient. In particular, the on-screen  
44  
45 202 keyboard issues discouraged William from using the message system: (5)a.  
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47  
48 203 Other challenges were oximetry transmission (n=4), device fault (n=2), and mobile signal loss (n=1).  
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51 204 [Table 6 about here]  
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## 205 Discussion

206 Interviews with seven MND patients who had used a weekly telemonitoring service via Careportal®  
207 strongly suggest that they accepted telehealth as a suitable support for them, and that it may  
208 provide new benefits to MND healthcare provision. Regular assessments of physical well-being via  
209 Careportal® were considered not only beneficial to symptom management, but also to psychological  
210 well-being because of the perceived continuity of support by medical staff. Using telehealth to  
211 potentially reduce unnecessary cost, time and hassles of attending hospital appointments were  
212 identified as an important benefit. The telehealth approach led participants to better understand  
213 their condition and enabled them to actively seek support for their needs.

214 An investigation into the usefulness of telehealth in the care of people with MND has been slow  
215 compared to its development in other illnesses. To our knowledge, this was the first qualitative  
216 study to explore the experience of using remote monitoring for ventilated people with MND. The  
217 current study explored 'why' participants in the nurse-led telephone follow-up may have been  
218 satisfied with telehealth [7]. The findings of our study reflect the positive evaluations of people with  
219 other chronic conditions such as diabetes and chronic heart failure reported in previous qualitative  
220 works examining the subjective experience of telemonitoring. In line with these studies  
221 [12,13,18,19,24], patients suggested that monitoring their symptoms increased their knowledge of  
222 their symptoms – and this helped some individuals to establish their 'norm' [12,19]. In addition, as  
223 increased knowledge of one's own health status has been found to encourage some patients to  
224 engage with behavioural health management including treatment adjustment [12,15,24], we  
225 similarly found proactive symptom management. In our study, the utilisation of the Careportal®  
226 device increased self-awareness of well-being amongst participants which promoted an active  
227 engagement with self-care. The positive impact of telemonitoring on psychological well-being  
228 observed in the present study has been also supported by previous studies, reporting telemonitoring  
229 gives patients a sense of reassurance [12,13,16,18,25]. Due to positive experiences and also benefits

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3 230 of regular monitoring leading to timely interventions, our participants preferred telemonitoring to  
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5 231 hospital appointments if they perceived hospital visits to create more burdens than benefits. This  
6  
7 232 favourable response to a possible reduction of clinic appointment echoes the patients' acceptability  
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9 233 of telehealth in the care of MND by a recent study, which reported on the development of a  
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11 234 telehealth system [11]. Similar to previous report [12,14,16,17,19], technical challenges of  
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13 235 telemonitoring were generally perceived as a hassle, but did not detract from the benefits.  
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17 236 The current study also provides a novel account of an individual for whom there was no perceived  
18  
19 237 benefit of telemonitoring. Previously, an ambivalent attitude towards the benefits of telemonitoring  
20  
21 238 was expressed mainly by professional carers [26], and therefore this study adds to the current  
22  
23 239 understanding on potential patients to whom telehealth may provide little benefit. One study  
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25 240 reports professionals' view that telemonitoring is more beneficial for those with advanced condition  
26  
27 241 with chronic heart failure than for those with stable symptoms [13]. In MND, initiation of NIV seems  
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29 242 to be a good indication for introducing telemonitoring given the main cause of death is pulmonary  
30  
31 243 complications [27,28]. Interestingly the current work notes that telemonitoring may not be  
32  
33 244 perceived necessary for those with frequent daily visits from professional caregivers; though it  
34  
35 245 should be noted the patient may not grasp the value of the technical data monitored and how that  
36  
37 246 might be used to optimise care delivery such as ventilator settings.  
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### 43 **Limitations of the current study**

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45 248 No interview was conducted with patients who had declined to be part of the Telehealth trial that  
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47 249 preceded this research [5]. Given that one of the factors affecting the uptake of telehealth is  
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49 250 people's motivation [29], perspectives of such individuals would be useful to scope if telehealth was  
50  
51 251 to be translated into a formal service approach. Also, we have not sought interviews with the  
52  
53 252 healthcare providers to explore their experiences of utilising the telemonitoring to provide care for  
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55 253 ventilated patients with MND. Previous studies on telehealth in MND reported time and cost  
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57 254 effectiveness of telehealth [7-10], yet studies in other chronic conditions found difficulties of  
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3 255 information sharing amongst professionals [13,14,23,26,30] which was potentially time consuming.  
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5 256 Given the importance of multidisciplinary teams in delivering care in MND, the aspect of  
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7 257 communication difficulties, and other potential problems, of using telehealth amongst the  
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10 258 professionals needs to be defined. Although we attempted to capture the experience of lay carers in  
11  
12 259 our study, only joint interviews were conducted at the request of both patients and caregivers.  
13  
14 260 Nevertheless, it is reflected that carers of people with MND experience great burdens due to the  
15  
16 261 illness [31], and thus a separate interview may have provided an environment for open discussion.  
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19 262 Further examinations of carers' experience of using telehealth in the care of MND NIV patients  
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21 263 would be crucial especially in situations where patients become completely dependent on carers.  
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## 24 264 **Conclusions**

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27 265 The findings of this study suggest that telemonitoring via Careportal® may facilitate delivery of NICE  
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29 266 recommendations relating to the care for people with MND. It is anticipated that this would extend  
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31 267 to similar systems with appropriate procedures. In particular, amongst the non-invasively ventilated  
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33 268 patients we studied here, telemonitoring did not compromise patients' experience of healthcare  
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35 269 services, and for six of our seven participants it was enhanced. Telehealth enables clinicians to  
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38 270 remotely monitor patients, thus no travel is required, thereby providing an alternative to support  
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40 271 those who cannot attend the clinic. It may be argued, therefore, that regular assessment through  
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42 272 telemonitoring may reduce clinical appointments while promoting tailored care fitting the  
43  
44 273 individual's needs. The increased awareness of symptoms through telemonitoring is further aided by  
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46  
47 274 the messaging system, which functions as a contact point to appropriately notify clinicians of the  
48  
49 275 issues and the need for further assessment. This is particularly beneficial when a patient experiences  
50  
51 276 a significant change in symptoms. It was only here where full appreciation of motor challenges for  
52  
53 277 this patient population is needed to ensure there are no barriers with being able to send a message.  
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56 278 Effective interactions made through telehealth are anticipated to also contribute to efficiency  
57  
58 279 savings if, this became a general approach. This fits well with the NHS Quality, Innovation,  
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3 280 Productivity and Prevention (QIPP) approach which is designed to improve the quality of care, while  
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5 281 making efficiency savings to reinvest into the system [32].  
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8 282 The finding of positive experiences of using telemonitoring reported here is encouraging as it  
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10 283 suggests that telemonitoring, using a device such as Careportal®, would allow an effective tailored  
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12 284 approach while enhancing the experience of patients and their caregivers. The results advocate  
13  
14 285 further investigation, ideally with a controlled trial, and separate caregiver interviews, to assess the  
15  
16 286 overall impact of telehealth on care in MND patients, particularly those in the advanced stage on  
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18 287 NIV. We are now designing a study to test the feasibility of telemonitoring for the routine care of NIV  
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20 288 MND patients in collaboration with a local Clinical Commissioning Group (CCG) which provides  
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22 289 telehealth to other illness groups [5].  
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For Peer Review

Table 1: Demographics and illness characteristics of patients at the time of trial

Patient (pseudonym)	age	Illness duration	NIV duration (month)	Onset type	ALSFERS-R Baseline	ALSFERS-R Post-trial	Carer	Living arrangement
Charlie	62	11y 10m	18	Limb	21	21	Spouse	with a spouse and child(ren)
James	58	5y 7m	34	Limb	37	31	-	with a partner
John	49	13y 7m	36	Limb	6	6	Professional home carer	alone
Logan	66	14m	12	Respiratory	37	28	Spouse	with a spouse and child(ren)
Margaret	68	8m	0	Limb	25	15	Daughter	alone
Mary	68	14m	10	Limb	22	21	Spouse	with a spouse
William	71	7m	4	Limb	34	33	-	with a child(ren)

NIV: non-invasive ventilation, ALSFRS-R: revised amyotrophic lateral sclerosis functional rating scale [20,21]

Table 2: Quotes for 'Benefits of timely intervention'

Quote	
(1) a	You know that was very good. Because the oximetry, when it worked, it was very good because [physio] could be on the work: "Well, we need to alter these settings [on NIV]". You had that once, didn't you? [Mary's husband]
(1) b	I don't see myself as being that ill. But I can really understand needing it or using it if you are in the worse situation sort of thing. You could have poor breathing because of a disease – MND – or whatever. I could see it being really useful then. [James]
(1) c	It was probably just making me feel a little bit safer because I knew when you... get all the answers, as soon as you've seen something not regular, you'd ring me up. [Logan]
(1) d	Once it starts to deteriorate more it would be even more... you know, more vital to have it [Careportal®] then. Because if you are okay up here, your well-being is going to be better. You know, [if] you are thinking more; if you are worrying about everything then it's going to be worse for you. [Charlie]
(1) e	Because he [John] has those carers coming in like five times a day, six times a day – I don't know. Six times a day? [John indicates six] It is [six]. You know morning and then the mid-morning like now and there's lunch call and then it's mid-afternoon, then it's tea call, then it's mid-evening call, and then put to bed call. So, he's always got somebody in here anyway and we should all notice if anything happens to him. [John's home carer]
(1) f	It [Careportal®] would be handy for 99% of people. [John]

Table 3: Quotes for 'Reducing the unnecessary'

Quote	
(2) a	I go to [hospital 1] every six months with [neurologist] and that [it] lasts for between 30 seconds and 2 minutes. He goes, 'How are you? Yeah, yeah. Okay. See you then.' And the same [physician] I've probably seen – is it every 6 months? Or 12 months? I think it's 6 months I see [physician] or one of his people. Same sort of thing – I walk in and 'How are you?' 'Yeah, fine off you go.' If it stops you doing that it would be brilliant. There is no need. [James]
(2) b	It'll save a lot of money as well as you know because I won't need to keep going to hospital when I don't need to go. [Charlie]
(2) c	It's – I'm taking their [clinicians] time up, taking car parking space up – it's just... Careportal® is the way to go for me [James].
(2) d	<p><b>Margaret:</b> [on iPad]: Doctor doesn't say much.</p> <p><b>Daughter:</b> [Laughs] I know I know what she is referring to. I know. You see, when we go to the neurology clinic ... Like I say, it's a big thing to get my mum washed, dressed, in a wheelchair to the hospital and you sort of go in and 'How are you?' 'Alright' 'Okay then I will see you.' It's literally that short that appointment. There's no - there's no benefit to her do you know? It's a big thing for my mum to go there do you know what I mean? It's like, 'Why?' [Laughs] You know so in that respect yeah because it... there is no point in going to that appointment do you know what I mean because you get absolutely nothing – not a thing.</p>
(2) e	I would like to see the doctors now and again just for peace of mind. [...] They tell you exactly what you should be doing or what you are doing wrong and even if there's a slight deterioration you know they tell you. [Logan]

Table 4: Quotes for 'Increased self-awareness'

Quote
(3) a Basically, I'm monitoring every day in my head anyway. I know when I'm having a good day and when I'm having a bad day. [Logan]
(3) b But sometimes you can feel ... and you think, 'I'll check that'. Then you know yourself when you are not quite up to scratch then it [oximetry reading] will just confirm it – that's about it. [Charlie]
(3) c When you get questions on about 'Have you had phlegm?' and 'What colour the phlegm is?' and all that - it probably makes you think about that side of it because without pressing them buttons, I wouldn't even think about that. [Logan]
(3) d I think it is very easy for people to just get locked into what they are experiencing, and you can look at it in a more negative ways, whereas the Careportal® was asking questions and you think, 'Oh... I answered similar earlier in the week', you know, 'Things are ok.' It's not, 'Oh no, I feel a lot worse', or whatever. Or, 'I'm having more and more phlegm' – I think it was just making us both aware of what was happening. And it was fairly consistent. [Mary's husband]
(3) e <b>Patient:</b> I think you've got to be honest with your answers. <b>Interviewer:</b> So, if you were not completing the Careportal®, you might just ignore symptoms? <b>Patient:</b> There was – 'Have you had phlegm?' Maybe you had a little bit [but] you put 'No'. So, not helping yourself.

Table 5: Quotes for 'Taking initiative'

Quote
(4) a If you've got a problem, no matter what time it is, you can type it in. Okay, there is no-one to be there until the next day, but you type in what your problem is at that time and you know at some point someone will get back to you. [James]
(4) b We don't really have a great deal of communication. The only thing you have is they send you out an appointment and you go to your appointment and you come away until next one and that's pretty much all the communication that you have. [Margaret's daughter]
(4) c Very rare, isn't it that you [John] need to speak to anybody, is there really? And if you do, you'll send an email to somebody, won't you? You know, he'll... that's how he'll contact people - by an email. [John's home carer]

Table 6: Quotes for 'Technical challenges'

Quote
(5) a The keyboard is that frustrating I just couldn't be bothered trying to get it to work because it wouldn't. [William]

For Peer Review

### Interview schedule for semi-structured interviews

Both patient and caregiver:

1. What was it like to use the Careportal?
  - Positive
  - Negative
2. Was the Careportal useful at that time it was offered to you/patient? (Ask participants to expand their response.)
3. Were there any problems resulted from using the Careportal? If so what were they?
4. Please tell us any bad points about using this device. (if not already covered in Q1)
5. Did you have any contacts from clinicians due to the answers you provided on the device? How useful was the follow up action?
6. How did you find this way of working with you in comparison to the normal way of treatment you receive?
  - before Careportal
  - after Careportal
7. Was there any time you wanted to get in touch with us using Careportal, but you didn't? If so, what stopped you?
8. Do you think using this device in MND service routinely would be useful and if so why/how?
9. How did you feel about monitoring your own/patient's symptoms of MND? (positive/negative)
10. How did you find the handling of the device?
11. How can we improve technical aspects of Careportal?

Additional question for caregiver (after the first question):

12. What impact did the Careportal have on you as opposed to its impact on [Patient]?

## Appendix 2: Qualitative codes

Theme	Supreme code	Code	Source (no. of participants): name
<b>Benefits of timely Intervention</b>	Effectiveness of telemonitoring	Real time information	6: James, Charlie, Mary, Logan, William, Margaret
	Physiological well-being	Effective interactions	5: James, Charlie, Mary, William, Margaret
	Psychological well-being	Enjoy using Careportal®	2: Charlie, Mary
		Feeling Valued	1: Mary
		Good feeling	1: William
		Peace of mind/sense of security	5: Charlie, James, Mary, Logan, Margaret
		Significance of psychological well-being	2: Charlie, Mary
	No perceived benefits	No perceived medical benefits	3: James, Charlie, John
Already having a good support system		1: John	
<b>Reducing the Unnecessary</b>	No perceived benefits of outpatient appointment		5: James, Charlie, John, William, Margaret
	Savings	Health economics	2: James, William
		Hassles of hospital visits	3: Mary, William, Margaret
		Less financial burdens	1: Charlie
Value of face-to-face consultation		4: James, Charlie, Mary, Logan	
<b>Increased Self-awareness</b>	Increased Self-awareness	Self-monitoring	4: Charlie, James, Mary, Logan, Margaret
		Careportal® as educational	2: Charlie, Logan
	Further promoting self-care		2: Charlie, Mary
<b>Taking initiative</b>	Active role in the care	Message to get in touch	5: James, Charlie, Mary, Logan, Margaret
		Careportal® as a backup	5: James, Charlie, Mary, Logan, Margaret
	Contact with hospital	Asking questions via messaging system	3: Charlie, Mary, Margaret
		Contact to get accessories	2: Charlie, Logan
		Personal contact through Careportal®	2: Mary, Logan

		Traditional one-way communication with hospital	4: Charlie, Mary, John, Margaret
<b>Technical Challenges</b>	Easiness	Easiness of Careportal®	5: James, Charlie, John, Logan, Margaret
	Technical issues	Messaging system	4: James, Mary, Logan, William
		Entry time	3: Charlie, Mary, William
		Faulty machine	2: Logan, Margaret
		Oximetry related	5: James, Mary, John, William, Margaret
		Signals	1: Charlie

For Peer Review