Article:
Musson, L.S. orcid.org/0000-0002-1246-2734, Baxter, S.K., Norman, P. orcid.org/0000-0002-5892-0470 et al. (7 more authors) (2022) Delivery of non-invasive ventilation to people living with motor neuron disease in the UK. ERJ Open Research, 9 (1). 00388. ISSN 2312-0541

https://doi.org/10.1183/23120541.00388-2022

ERJ open research
THE BEST IN OPEN ACCESS BASIC, TRANSLATIONAL & CLINICAL RESPIRATORY RESEARCH

Early View

Original research article

Delivery of non-invasive ventilation to people living with motor neuron disease in the UK

Lucy S. Musson, Susan K Baxter, Paul Norman, David O'Brien, Mark Elliott, Stephen Bianchi, Georgios Kaltsakas, Christopher J McDermott, Theocharis Stavroulakis, Esther V Hobson

Please cite this article as: Musson LS, Baxter SK, Norman P, *et al*. Delivery of non-invasive ventilation to people living with motor neuron disease in the UK. *ERJ Open Res* 2022; in press (https://doi.org/10.1183/23120541.00388-2022).

Delivery of non-invasive ventilation to people living with motor neuron disease in the UK

Lucy S. Musson[1], Susan K Baxter[2], Paul Norman[3], David O'Brien[4], Mark Elliott[5], Stephen Bianchi[6], Georgios Kaltsakas[7,8], Christopher J McDermott[1*], Theocharis Stavroulakis[1*], Esther V Hobson[1*]

[1]*Sheffield Institute for Translational Neuroscience, University of Sheffield, Sheffield, United Kingdom*
[2]*School of Health and Related Research, University of Sheffield, Sheffield, United Kingdom*
[3]*Department of Psychology, University of Sheffield, Sheffield, United Kingdom*
[4]*Medical School, University of Sheffield, Sheffield, United Kingdom*
[5]*Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom*
[6]*Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, United Kingdom*
[7]*Lane Fox Respiratory Service, Guy's and St Thomas' NHS Foundation Trust, London, United Kingdom*
[8]*Centre for Human and Applied Physiological Sciences (CHAPS), King's College London, London, United Kingdom*

*equal contribution

Corresponding author: Dr Esther Hobson, Sheffield Institute for Translational Neuroscience, University of Sheffield, Sheffield S10 2HQ, UK, e.hobson@sheffield.ac.uk

Take home message (256 character limit):
There is significant variation amongst UK healthcare professionals and services in the way non-invasive ventilation is delivered to people with motor neuron disease. Addressing weaknesses in all aspects of respiratory care could lead to improved outcomes.

Delivery of non-invasive ventilation to people living with motor neuron disease in the UK

Abstract

Objective

Non-invasive ventilation (NIV) improves survival and quality of life in motor neuron disease (MND), but many patients fail to receive effective ventilation. This study aimed to map the respiratory clinical care for MND patients at a service and individual healthcare professional (HCP) level to understand where attention may be needed to ensure all patients receive optimal care.

Methods

Two online surveys of HCPs working with MND patients in the UK were conducted. Survey 1 targeted HCPs providing specialist MND care. Survey 2 targeted HCPs working in respiratory/ventilation services and community teams. Data were analysed using descriptive and inferential statistics.

Results

Responses from 55 HCPs providing specialist MND care who worked at 21 MND care centres and networks and 13 Scotland Health Boards were analysed from Survey 1. Responses from 85 HCPs from respiratory/ventilation services and 73 HCPs from community teams, representing 97 services were analysed from Survey 2.

Significant differences in practice were identified at each stage of the respiratory care pathway as well as evidence of the need for improvement. This included when patients were referred to respiratory services, the time taken waiting to commence NIV, the availability of sufficient NIV equipment and provision of services, particularly out of hours.

Conclusion

We have highlighted significant disparity in MND respiratory care practices. Increased awareness of the factors that influence NIV success and the performance of individuals and services is important for optimal practice.

Introduction

Motor neuron disease (MND) is a progressive, neurological condition. Death usually occurs within 2-3 years of symptom onset and the most common cause of death is respiratory failure (1). The only intervention that substantially improves survival and sustains quality of life is non-invasive ventilation (NIV) (2). However, many patients have low adherence and even where adherence is good, ventilation is not effective in correcting hypoxia in many patients which is leading to poorer survival (3,4). The success of NIV depends on many factors throughout the respiratory care pathway; from diagnosis and preparing for NIV, initiation, monitoring and optimisation, and end-of-life care (4,5). Current guidelines provide recommendations, but they are fragmented and do not adequately cover all aspects of the pathway (6-12).

There is a need to better understand how NIV is delivered to people living with MND (plwMND). This study aimed to describe the current practices of individual healthcare professionals (HCPs) and services providing specialist MND care, respiratory/ventilation services and community services that support NIV delivery in the UK.

Material and methods

A multi-method design (13) was used involving two online cross-sectional surveys, sequentially, using Google Forms (14) and Qualtrics (15) (see supplementary materials). The questions for the surveys were informed by our earlier research (4,5) and existing clinical guidelines (in particular, the UK National Institute for Clinical Excellence 2019 NICE guidelines) (6-12) as we wanted to explore whether current recommendations are being met. Survey 2 was also informed by the findings of survey 1. The data were analysed using statistics with SPSS (16). Comparisons (e.g., between size of services) were performed using the Fisher's exact test. All comparisons were two-tailed and a p value of ≤ 0.05 indicated significance.

Survey 1

Survey 1 targeted HCPs providing specialist MND care in the UK (referred to as MND Service-HCPs). A purposive sample involving MND care centre coordinators as gatekeepers and snowballing techniques was used to recruit participants. This involved existing participants sharing the survey with other people. People were invited to complete the survey via email/telephone and the survey was open for one month in April 2018. Ethical approval was gained from the University of Sheffield (Ref. 018519).

Survey 2

Survey 2 targeted two groups: HCPs working in respiratory/ventilation services (staff who identified themselves as being involved in decision-making about the technical aspects of delivering NIV), referred to as Respiratory Service-HCPs, and HCPs working in community teams, referred to as Community-HCPs. Two clinical vignettes and a core set of questions applicable to all participants were used. A subset of questions relating to technical aspects of NIV delivery were given to Respiratory Service-HCPs.

A convenience sampling approach was used by inviting staff working in services identified in Survey 1 as delivering NIV care, staff identified on hospital websites, and through personal clinical contacts. The survey was also advertised on social media, through charity

networks/newsletters and using snowballing techniques and was open for nine weeks from January 2019. Approval was obtained from the Health Research Authority, UK (IRAS ID 254661).

Results

Figure 1 provides a flowchart of the surveys and the characteristics of participants. The 55 MND Service-HCPs in Survey 1 had an estimated total caseload of 4,547 patients. The 158 Survey 2 participants worked for 97 services which included 47 of the services (92%) identified in Survey 1 as providing NIV. Fifty-four services were specialist respiratory services. Responses describing services were excluded if there was variation between individuals replying from the same service. Services were categorised according to the number of plwMND using NIV as small (20), medium (20-50) and large (more than 50). Further data is included in the supplementary material.

[INSERT FIGURE 1]

Figure 1. Flowchart of data collection and participant characteristics.

HCPs, healthcare professionals

MND, motor neuron disease

NHS, National Health Service

Timing of involvement of respiratory/ventilation services (both surveys)

Over half of MND Service-HCPs (n=30, 55%) reported that referrals to respiratory/ventilation services occurred at the onset of respiratory signs/symptoms. Respiratory Service-HCPs reported that the most common time point of referral was when the patient developed signs, symptoms and/or respiratory function decline (n=33, 40%). Five Respiratory Service-HCPs (6%) reported that referrals most commonly occurred at the onset of respiratory failure. According to Respiratory Service-HCPs, 21 services (39%) received referrals at the time of MND diagnosis. Twenty-four Respiratory Service-HCPs (29%) reported that referral occurred late and of those who said the most common time point of referral was at diagnosis, nine (75%) thought this was at the right time. In 28 MND services (51%), respiratory specialists were available to see patients prior to the development of respiratory signs/symptoms. However, Respiratory Service-HCPs most commonly worked in a service that was separate to the MND clinic (n=52, 63%).

Respiratory function monitoring (Survey 2)

The majority of services (n=50, 98%) used more than one respiratory test with 41 services (80%) using five tests or more. One service (2%) reported using 12 different tests. The most commonly used respiratory test was forced vital capacity (FVC, 41 services 77%) (Figure 2). Polysomnography was used by 15 services (28%). Indications for polysomnography included if the patient was experiencing sleep apnoea, sleep-disturbance or bulbar dysfunction and when other tests are inconclusive. Despite the NICE guidelines recommending the use of nocturnal oximetry and/or a limited sleep study in uncertain cases, eight services (15%) used neither of these tests (6).

[INSERT FIGURE 2]

Figure 2. Respiratory function tests used by respiratory/ventilation services.

NIV, non-invasive ventilation

Respiratory Service-HCPs indicated the respiratory function threshold values which helped them decide whether to recommend NIV (Table 1). Staff tended to report similar thresholds whether patients had respiratory symptoms or not. For those without symptoms staff were using a higher FVC (median 70% predicted) than that stated in the NICE guidelines (less than 50% predicted) (6). There was variability in individual answers and when collated at service level. Respiratory Service-HCPs commented that testing could be inaccurate, and that (in line with clinical guidelines) decision-making relied on a global assessment of tests, symptoms and patient choice. In those with bulbar dysfunction, HCPs reported placing more significance on symptoms, polysomnography and other measures of ventilation (e.g., blood gases).

Table 1. Thresholds used by services to decide whether to recommend a trial of non-invasive ventilation for patients without bulbar dysfunction. The recommended thresholds from the NICE guidelines are also included for reference (6).

	With symptoms of respiratory insufficiency	Without symptoms of respiratory insufficiency
Respiratory function test	Median (Range) Mode [NICE value]	Median (Range) Mode [NICE value]
Forced vital capacity (%)	70 (50-100) 80[a] [80]	70 (40-80) 50[b] [50]
Vital capacity (%)	50 (40-80) 50 [80]	50 (40-80) 50 [50]
Sniff nasal inspiratory pressure (cmH20)	50 (4-65) 65[c] [40]	40 (4-65) 40[d] [65-Men/55-Women]
Maximum inspiratory pressure (cmH20)	60 (30-80) 50 [40]	40 (20-80) 40 [65-Men/55-Women]
Maximum expiratory pressure (cmH20)	60 (30-113) 60	60 (30-113) 30

[a]Two services excluded from the analysis due to variation in responses given by two respondents working at each service. [b]One service excluded from the analysis due to variation in responses given by two respondents working in the same service. [c]Two services excluded from the analysis due to variation in responses given by two respondents working at each service. [d]One service excluded from the analysis due to variation in responses given by two respondents working in the same service.

Discussions about NIV (both surveys)

The vast majority of Survey 2 participants (n=151, 97%) had a role in discussing the potential need for NIV. Discussions often start after diagnosis but before the onset of respiratory signs/symptoms or tests (n=73, 63%). Forty-three (38%) stated this was the most common time-point in their experience (Figure 3). When discussions occurred most commonly before the onset of respiratory signs/symptoms, 33 HCPs thought this was the right time (77%). However, when discussions occurred most commonly at the onset of respiratory failure, most HCPs (n=6, 86%) thought this was too late.

[INSERT FIGURE 3]

Figure 3. Most common timings of discussions about non-invasive ventilation reported by Survey 2 participants.

NIV, non-invasive ventilation

Respiratory Service-HCPs stated who would provide information to patients about NIV (Figure 4). The respiratory/ventilation services covered most topics but particularly technical aspects of using NIV. More than half of the MND services covered some aspects of the

benefits prior to referral. However, Respiratory Service-HCPs working at 36 services (69%) reported that the MND team did not talk about the impact of NIV on carers and Respiratory Service-HCPs working at 37 services (71%) reported that the MND team did not talk about options around withdrawal/end-of-life. Respiratory Service-HCPs in 13 services (25%) reported that options around withdrawal/end-of-life were not discussed in their service either. Respiratory Service-HCPs in four services (8%) said patients are often given limited (or no) information from the MND team.

[INSERT FIGURE 4]

Figure 4. Information perceived to be given by the motor neuron disease care team and respiratory/ventilation service to patients from the perspective of Respiratory Service-HCPs.

NIV, non-invasive ventilation
MND, motor neuron disease

Timing of initiation of NIV

NICE guidelines recommend patients with daytime hypercapnoea be seen within one week of referral (6). For urgent referrals, 31 Respiratory Service-HCPs (39%) reported that patients usually have to wait less than one week to see the respiratory team. Twenty-two (28%) said the wait was usually one week, 22 (28%) said the wait was usually two weeks, one (1%) said the wait was three weeks and three (4%) said four weeks. There was no significant association between size of the service and appointment waiting time for an urgent referral (Fisher's exact test, $p = 0.677$). For non-urgent referrals, four weeks was the modal time (32%) but 18 (24%) reported waits of five weeks or more with four (5%) reporting waits of 12 weeks. There was no significant association between size of the service and appointment waiting time for a routine referral (Fisher's exact test, $p = 0.250$). Thirty-two services (78%) had a waiting time of less than a week to commence NIV. Ten services were excluded from this analysis due to variation in responses from individuals working at the same service (two per service). Five services (12%) had a waiting time of two weeks, two services (5%) had a waiting time of one week and two (5%) had a waiting time of four weeks. There was no significant association between size of the service and waiting time to commence NIV (Fisher's exact test, $p = 0.212$).

Locations of initiating NIV (Survey 2)

The most common location available and used for initiating NIV was an outpatient setting with 38 services (79%) using this location. Initiation as a multiple-night admission was used in 31 services (65%), as a one-night admission in 19 services (40%) and as an inpatient day-case in 17 services (35%). Domiciliary initiation was offered in 31 services (65%). HCPs preferred initiating patients as an outpatient (n=33, 46%) followed by patient's homes (n=15, 21%). Nine services (19%) reported no funding for domiciliary initiation.

Equipment provision and funding (Survey 2)

Figure 5 shows the amount of equipment provided by services. In total, only 20 services were able to provide at least two NIV machines, one battery pack, two masks per year and a humidifier. Staff working in four services (15%) reported that no NIV machines were funded with one HCP reporting charity funding was required. All four services had less than 20 plwMND using NIV in their service. Eight services (32%) had no funding for battery packs. Only one of these services had more than 20 plwMND using NIV in their service. Three

services (12%) had no funding for masks and four (15%) had no funding for humidifiers. All of these services had less than 20 plwMND using NIV in their service.

[INSERT FIGURE 5]

Figure 5. Amount of equipment provided by respiratory/ventilation services: a) NIV machines, b) mask interfaces, c) battery packs, d) humidifiers.

NIV, non-invasive ventilation

[a*]Three services excluded from the analysis due to variation in responses given by two respondents working at each service. For example, one participant stated that the standard amount of NIV machines provided in their service was one and another participant working in the same service stated that their service provided two NIV machines as standard. [b*]Thirteen services excluded from the analysis due to variation in responses given by respondents working in the same service. [b**]Nine services excluded from the analysis due to variation in responses given by two respondents working at each service. [c*]Four services excluded from the analysis due to variation in responses given by two respondents working at each service. [c**]Four services excluded from the analysis due to variation in responses given by two respondents working at each service. [d*]Five services excluded from the analysis due to variation in responses given by two respondents working at each service. [d**]Four services excluded from the analysis due to variation in responses given by two respondents working at each service.'

Pressure-targeted settings were used by 44 services (96%). Volume assured pressure support was used by 23 services (50%) with inspiratory positive airway pressures (IPAP) of 12cm H2O and expiratory positive airway pressures (EPAP) of 4cm H2O being the most common choices for initiating NIV. The most common preferred choice for initiating both a patient with and without bulbar symptoms was pressure-targeted (n=54, 76% and n=58, 82% respectively).

A spontaneous-timed mode was available to use in 42 services (89%). Ten services (21%) used a spontaneous ventilation mode, 10 (21%) used a timed mode and 11 (23%) used other modes such as intermittent positive-pressure ventilation. The most common preferred ventilation mode was spontaneous-timed (n=51, 76%).

Services had a variety of mask interfaces available, including nasal pillows (n=48, 100%), total face masks (n=47, 98%), nasal masks (n=47, 98%), oronasal masks (n=46, 96%) and mouthpieces (n=34, 71%). For patients with and without bulbar symptoms, the most common choice of mask for initiation was an oronasal mask (both n=31, 44%) followed by a nasal mask (n=26, 37% and n=21, 30% respectively). Mask selection depended on patient choice, disability and mask fit.

Early initiation and follow-up (both surveys)

The daily target for using NIV recommended by Respiratory Service-HCPs ranged from 4-12 hours with the most common being four hours (n=14, 35%). The most common preferred target representing optimal adherence for patients with and without bulbar impairment was using NIV all night (n=39, 51% and n=44, 57% respectively), although HCPs often wrote that targets were individualised. Sixteen Respiratory Service-HCPs (20%) stated that they recommend patients try to increase their usage of NIV. Strategies to achieve this included encouraging patients to use NIV during the day to begin with before moving to night-time use.

Following initiation, the median number of weeks to the first respiratory follow-up was two and a half weeks (IQR 1-4), to the second follow-up was eight weeks (IQR 4-12) and to the

third follow-up was 12 weeks (IQR 6-24). The median time for routine follow-ups after the patient is established on NIV was every 12 weeks (IQR 12-12). Community-HCPs were asked to state how often they saw patients using NIV which ranged from 1-24 weeks.

Once established on NIV, most MND Service-HCPs monitored the patient for symptoms of respiratory insufficiency (n=52, 95%) and NIV comfort (n=47, 85%). Respiratory services represented in Survey 2 reported ways in which they monitored effective adherence and ventilation. Sixteen (21%) services used patient-reporting alone to monitor adherence but others used machine downloads (n=51, 66%) and/or telemonitoring (n=25, 33%). Thirteen services (18%) used patient-reported symptoms alone to monitor ventilation. Others used a combination of symptoms and objective measures: oxygen/CO2 measurements (n=49, 69%), machine downloads (n=44, 62%), telemonitoring (n=23, 32%) and polysomnography (n=9, 13%).

In-hours telephone support was available in 81 services (84%) and email support was available in 55 services (57%). Sixty-three percent of services (n=57) could be contacted by patients during out-of-hours times (outside of Monday-Friday 9am-5pm). Funding was a barrier to out-of-hours support, but staff also identified that those answering calls out-of-hours were not always adequately trained to address problems.

Modifications to NIV therapy to improve adherence/effectiveness of NIV (Survey 2)
Participants reported that the pressure levels used were dependent on weight, comfort, tolerance, efficacy and bulbar function. Individual patient adaptations included higher EPAP and longer breath length for patients with bulbar dysfunction. A shorter rise time was reported to reduce airway collapse.

Figure 6 shows what troubleshooting steps services used to overcome mask leaks. The most common step taken was optimising mask fitting (n=58, 94%). To overcome upper airway obstructive events, the most common step taken was increasing the EPAP, which was used by 46 services (77%). Ventilator setting changes were triggered by patient discomfort, poor adherence/compliance, inadequate ventilation/asynchronies and respiratory decline.

[INSERT FIGURE 6]
Figure 6. Steps taken by services to overcome mask leaks.

End-of-life care (Survey 2)
Survey 2 participants reported the most common time of discussion about end-of-life respiratory care is when the patient asks to discuss end-of-life care (n=97, 69%) and when there is increased dependency on the ventilator (n=91, 65%). Only eight HCPs (6%) reported the most common time being when a patient is initiated on NIV. Fifty participants (37%) thought discussions occurred late. This was particularly the case for those who said discussions occur most commonly when there is increased dependency on the ventilator (n=16, 70%). Participants commented that discussions should be patient-centred and occur early as part of a process to allow patients the time to plan. One person thought planning end-of-life too early could impact on the success of NIV.

Services used a variety of supportive measures when discussions about the withdrawal of NIV began including discussing palliative care (n=67, 97%) and offering reassurance (n=65, 94%). Sixty-nine participants (72%) thought patients were referred to palliative care services at the right time, but 20 (21%) thought referral was late.

Discussion

Despite NIV being the most effective treatment for MND (2), our research demonstrates variation in clinical practice in the UK. We have identified sites and individuals who have the skills, equipment and staff to deliver best practice in at least some areas of the respiratory pathway. However, this is not yet available to all patients at all sites. Variation occurs due to individual preference and service limitations and specific evidence-based quality standards to guide practice remains limited. Published guidance (6,8,9) particularly lacks detail about the technical aspects of how NIV is initiated and optimised and how patients are followed up. This might explain why this aspect of service was so variable. We have made some recommendations based on the best available current evidence (4-12), along with evidence of good local practice and our consultations with experts, that could be considered to help services evaluate and improve their care.

While the evidence for optimal timing of NIV is limited (17), early focus on respiratory function enables time for patients/carers to be optimised physically and practically (18). Patients need to understand the trajectory of their disease and their options in order to make the "right decision" at the "right time" (19). Moreover, there may be a survival benefit for early NIV initiation (20). Our research found evidence of good practice with many services preparing patients for respiratory failure shortly after diagnosis (6). However, as reported elsewhere (21,22), HCPs in our study reported that discussions about respiratory function and referrals to respiratory/ventilation services were often taking place at the onset of respiratory failure. It was reported in some services that patients were often given limited (or no) information from the MND team about respiratory failure/NIV. It is important to recognise that this is what was perceived to be happening by Respiratory Service-HCPs and therefore, not necessarily a true reflection of information provision by the MND team.

Early diagnosis of respiratory dysfunction may prevent the need for urgent/late initiation of NIV which is associated with reduced compliance and survival (18,23). Despite NICE guidelines recommending patients are seen within one week of an urgent referral to respiratory/ventilation services (6), nearly two thirds of Respiratory Service-HCPs reported that patients usually wait more than a week and some reported waiting times of up to three months for routine referrals. Services need to be staffed and flexible to respond to the need for rapid NIV initiation and avoid delays. For example, considering using outpatient initiation which has been associated with more rapid initiation and reduced early mortality in patients awaiting an inpatient bed (24).

As outlined in published guidance, regular assessment of respiratory function beginning at, or soon after, diagnosis and using robust measures that are interpreted in combination with symptoms will identify respiratory dysfunction earlier (6-9). All but one UK service used a combination of respiratory tests to direct clinical decision-making. Despite FVC poorly correlating with respiratory symptoms (25), it is still the most commonly used test. The average respiratory testing thresholds for considering NIV was higher than that recommended by the guidelines reflecting the growing recognition that early initiation of NIV may improve outcomes. However, many staff were using very low thresholds to trigger NIV initiation which may allow insufficient time for preparation and optimisation of NIV (6). The more predictive sniff nasal inspiratory pressure was only used by 53% of services (26), although 72% were using blood gases which are more sensitive (27). In a recent Italian study, after plwMND were initiated on NIV their bicarbonate levels were a predictor of their adherence and tolerance to NIV as well as death (28). When bicarbonate levels were above 29 mmol/L

patients' survival was significantly shortened (28). We should be mindful that additional/more complex tests may be helpful in difficult cases but may delay diagnosis/initiation of NIV.

Following initiation, evidence suggests that many patients do not reach adequate usage or effective ventilation (3) which is associated with reduced survival (29). Contrary to guidance (6-9), our findings indicate that monitoring was often infrequent and many relied on subjective measures alone. Telemonitoring provides a solution to receive feedback in real time, but this requires staffing and expertise (30,31). Sufficient equipment is needed to optimise patients; however, only 20 services were able to provide a core level of equipment and out-of-hours support was often limited.

We found that multiple specialists need to be involved to ensure that each component of the pathway is effective in order to optimally deliver NIV (6-10). This may explain why patients who attend a specialist multidisciplinary centre have improved survival compared to patients attending a non-specialist centre (32). This coordinated assessment and decision-making process may reduce decision-making delays and facilitate sharing of good practice.

Strengths and limitations

Our findings reflect the current practice of most services delivering NIV in the UK, although there was some variation in responses given by HCPs working in the same service. Therefore, analysis at the service-level was based on responses where there was no variation or used the majority response. The study was also self-reported and at times HCPs reported what they thought services did, which may not necessarily reflect reality. Similarly, the respondents had a wide range of experience and backgrounds reflecting the usual staff make-up within these services which may explain some of the variation in responses.

To our knowledge there has been no comparable nationwide service evaluation in the UK or other countries. Therefore, it is important to acknowledge that service variation may be even greater in countries without a publicly-funded health service and in low-socioeconomic countries due to the complexity of delivering NIV and the cost/access to equipment.

Our surveys were carried out prior to the COVID-19 pandemic. However, we recognise that services will have changed due to the pandemic. Factors such as redeployment of staff and equipment, disruption in the multidisciplinary team and difficulties seeing patients face-to-face have impacted upon services (33). Some respiratory function tests have been identified as aerosol generating procedures and therefore difficult to conduct. PlwMND have faced longer waiting times for testing/appointments and the provision of treatments have been disrupted (33-35). The pandemic may pose opportunities to improve services through more experience of remote monitoring, multidisciplinary working becoming more accessible, and more staff having been exposed to using NIV and therefore, gaining expertise.

Our study focused on respiratory assessment and delivery of NIV though from our earlier work, we recognise that a holistic approach to respiratory care should include optimisation of cough, secretions and psychosocial matters as well as they can influence NIV success (4,5). Our educational website (www.niv4mnd.co.uk) contains further information on ancillary respiratory care but there is even less evidence in these areas to guide practice and we recommend that this is a key priority to explore in future research using a similar approach to that adopted in this study.

Conclusion

There is considerable variation in the quality of the NIV service available to patients with MND in the UK. Key issues include delays in the pathway, lack of equipment and variation in staff expertise and behaviour. Good practice appears achievable but is not universally available for every patient. There needs to be increased awareness of the areas of the need for improvement in each service at every stage of the respiratory care pathway. Staff training, improved funding and service reconfiguration may be needed to deliver this.

Acknowledgements

The authors are grateful to everyone who completed the surveys, the organisations that advertised them and those who piloted them.

Conflict of interest

The authors have nothing to disclose.

Support statement

The study was funded by a National Institute for Health Research (NIHR) programme grant for Research for Patient Benefit (PB-PG-1216-20041). CJM is supported by the NIHR Biomedical Research Centre Sheffield and is an NIHR Research Professor. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

References

1. Rafiq MK, Proctor AR, McDermott CJ, et al. Respiratory management of motor neurone disease: a review of current practice and new developments. *Pract Neurol.* 2012;12:166-76.
2. Bourke SC. Tomlinson M, Williams TL, et al. Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial. *Lancet Neurol.* 2006;5(2):140-47.
3. McDermott CJ, Bradburn MJ, Maguire C, et al. DiPALS: Diaphragm Pacing in patients with Amyotrophic Lateral Sclerosis - a randomised controlled trial. *Health Technol Assess.* 2016;20(45):1-186.
4. Baxter SK, Johnson M, Clowes M, et al. Optimizing the noninvasive ventilation pathway for patients with amyotrophic lateral sclerosis/motor neuron disease: a systematic review. *Amyotroph Lateral Scler Frontotemporal Degener.* 2019;20(7-8):461-72.
5. O'Brien D, Stavroulakis T, Baxter S, et al. The optimisation of noninvasive ventilation in amyotrophic lateral sclerosis: a systematic review. *Eur Respir J.* 2019;54(3):1900261.
6. National Institute for Health and Care Excellence. MND: assessment and management [NG42] July 2019:1-44.
7. Motor Neurone Disease Association. Managing respiratory symptoms in motor neurone disease. September 2017:1-16.
8. EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis. EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)--revised report of an EFNS task force *Eur J Neurol.* 2012;19(3):360-75.
9. Miller RG, Jackson CE, Kasarskis EJ, et al. Practice parameter update: the care of the patient with amyotrophic lateral sclerosis: drug, nutritional, and respiratory therapies (an evidence-based review): report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology* 2009;73:1218-26.

10. Davidson AC, Banham S, Elliott M, et al. BTS/ICS guideline for the ventilatory management of acute hypercapnic respiratory failure in adults. *Thorax.* April 2016;71(suppl 2):ii1-ii35.
11. Fairbairn S. All Wales guidelines for acute non-invasive ventilation (NIV). NHS Wales. N.d:1-19.
12. Faull C. Withdrawal of ventilation at the request of a patient with motor neurone disease: guidance for professionals. Association for Palliative Medicine of Great Britain and Ireland. 2015:1-67.
13. Schoonenboom J, Johnson RB. How to construct a mixed methods research design. *Kolner Z Soz Sozpsychol.* 2017;69(Suppl2):101-31.
14. Google forms. Google Inc [Online software]. 2022; UK. Available at: https://docs.google.com/forms.
15. Qualtrics. Qualtrics (September 2018) [Online software]. 2018; Provo, UT. Available at https://www.qualtrics.com
16. IBM Corp. IBM SPSS Statistics for Windows (Version 25.0). 2017: Armonk, NY.
17. Andersen PM, Borasio GD, Dengler R, et al. Good practice in the management of amyotrophic lateral sclerosis: Clinical guidelines. An evidence-based review with good practice points. EALSC Working Group. *Amyotroph Lateral Scler Frontotemporal Degener* 2007;84:195-213.
18. Baxter SK, Baird WO, Thompson S, et al. The initiation of non-invasive ventilation for patients with motor neuron disease: patient and carer perceptions of obstacles and outcomes. *Amyotroph Lateral Scler Frontotemporal Degener.* 2013;14:105-10.
19. Martin NH, Lawrence V, Murray J, et al. Decision making about gastrostomy and noninvasive ventilation in amyotrophic lateral sclerosis. *Qual Health Res.* 2016;26(10):1366-81.
20. Lechtzin N, Scott Y, Busse AM, et al. Early use of non-invasive ventilation prolongs survival in subjects with ALS. *Amyotroph Lateral Scler Frontotemporal Degener*. 2007;8(3):185-8.
21. Georges M, Golmard JL, Llontop C, et al. Initiation of non-invasive ventilation in amyotrophic lateral sclerosis and clinical practice guidelines: Single-centre, retrospective, descriptive study in a national reference centre. *Amyotroph Lateral Scler Frontotemporal Degener.* 2017;18:46-52.
22. Chio A, Silani V, Italian ALS Study Group. Amyotrophic lateral sclerosis care in Italy: a nationwide study in neurological centers. *J Neurol Sci.* 2001;191:145-50.
23. Pinto AC, de Carvalho M, Evangelista T, Lopes A et al. Nocturnal pulse oximetry: A new approach to establish the appropriate time for non-invasive ventilation in ALS patients. *Amyotroph Lateral Scler Frontotemporal Degener.* 2003;4(1):31-5.
24. Sheers N, Berlowitz DJ, Rautela L, et al. Improved survival with an ambulatory model of non-invasive ventilation implementation in motor neuron disease. *Amyotroph Lateral Scler Frontotemproal Degener.* 2014;15(3-4):180–84.
25. Jackson CE, Rosenfeld J, Moore DH, et al. A preliminary evaluation of a prospective study of pulmonary function studies and symptoms of hypoventilation in ALS/MND patients. *J Neurol Sci.* 2001;191(1-2):75-78.
26. Polkey MI, Lyall RA, Yang K, et al. Respiratory Muscle Strength as a Predictive Biomarker for Survival in Amyotrophic Lateral Sclerosis. *Am J Respir Crit Care Med.* 2017;195(1):86-95.

27. Manera U, Torrieri MC, Moglia C, et al. The role of arterial blood gas analysis (ABG) in amyotrophic lateral sclerosis respiratory monitoring. *J Neurol Neurosurg Psychiatry.* 2020;91(9):999-1000.
28. Manera U, Torrieri MC, Moglia C, et al. Arterial blood gas analysis: base excess and carbonate are predictive of noninvasive ventilation adaptation and survival in amyotrophic lateral sclerosis. *Amyotroph Lateral Scler Frontotemporal Degener.* 2021;22:33-39.
29. Kleopa KA, Sherman M, Neal B, et al. Bipap improves survival and rate of pulmonary function decline in patients with ALS. *J Neurol Sci.* 1999;164(1):82-88.
30. Hobson EV, Baird WO, Bradburn M, et al. Using telehealth in motor neuron disease to increase access to specialist multidisciplinary care: a UK-based pilot and feasibility study. *BMJ Open.* 2019;9:e028525.
31. Hobson E, Baird W, Bradburn M, et al. Process evaluation and exploration of telehealth in motor neuron disease in a UK specialist centre. *BMJ Open.* 2019;e028526.
32. Rooney J, Byrne S, Heverin M, et al. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg & Psychiatry.* 2015;86(5):496-501.
33. Musson LS, Collins A, Opie-Martin O, et al. Impact of the Covid-19 pandemic on amyotrophic lateral sclerosis care in the UK. *Amyotroph Lateral Scler Frontotemporal Degener.* 2022;22:1-9.
34. Glasmacher SA, Larraz J, Mehta AR, et al. The immediate impact of the COVID-19 pandemic on motor neuron disease services and mortality in Scotland. *J Neurol.* 2020;(0123456789):1–3.
35. Andrews JA, Berry JD, Baloh RH, et al. Amyotrophic lateral sclerosis care and research in the United States during the COVID-19 pandemic: Challenges and opportunities. *Muscle Nerve.* 2020;62(2):182–186.

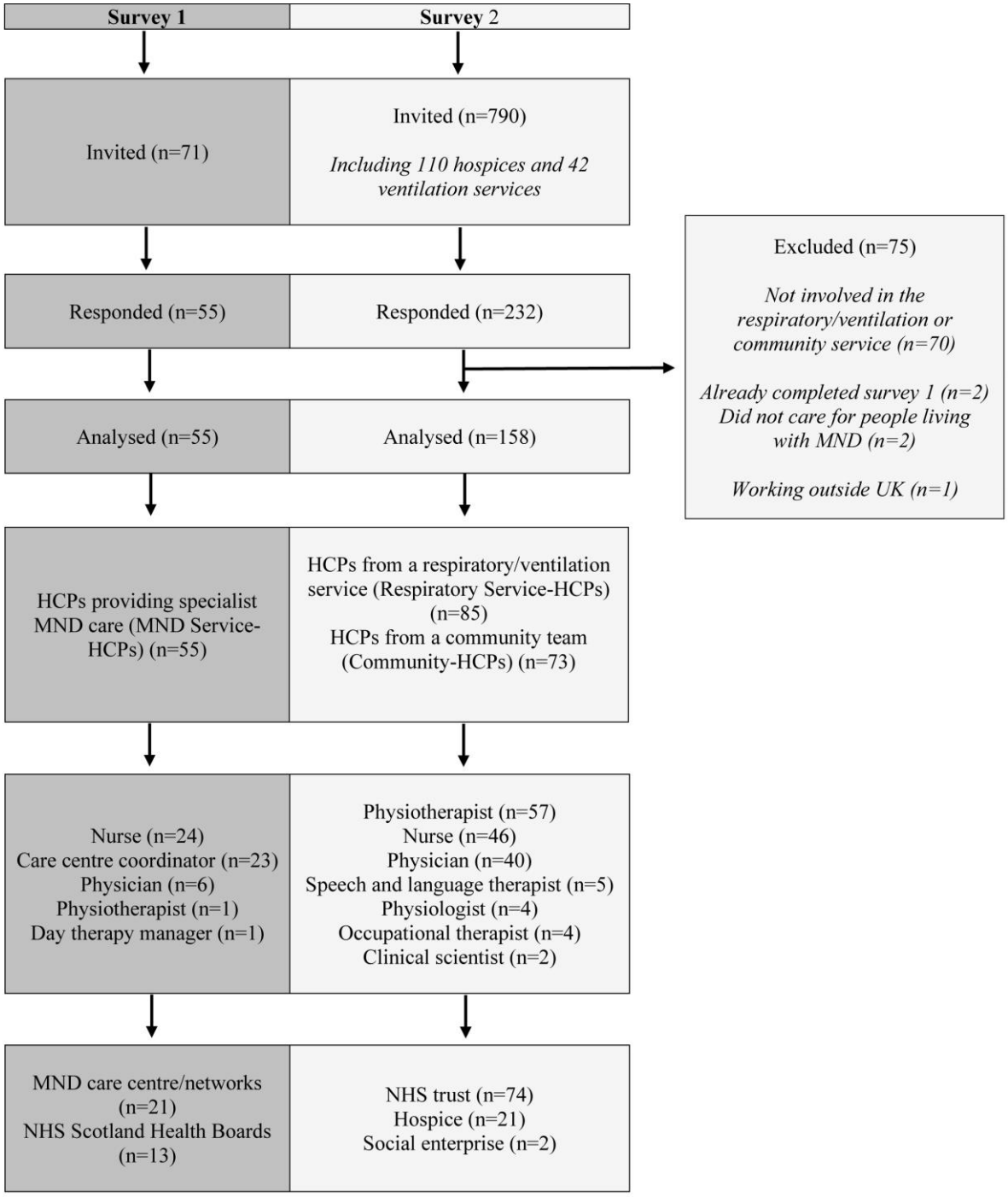
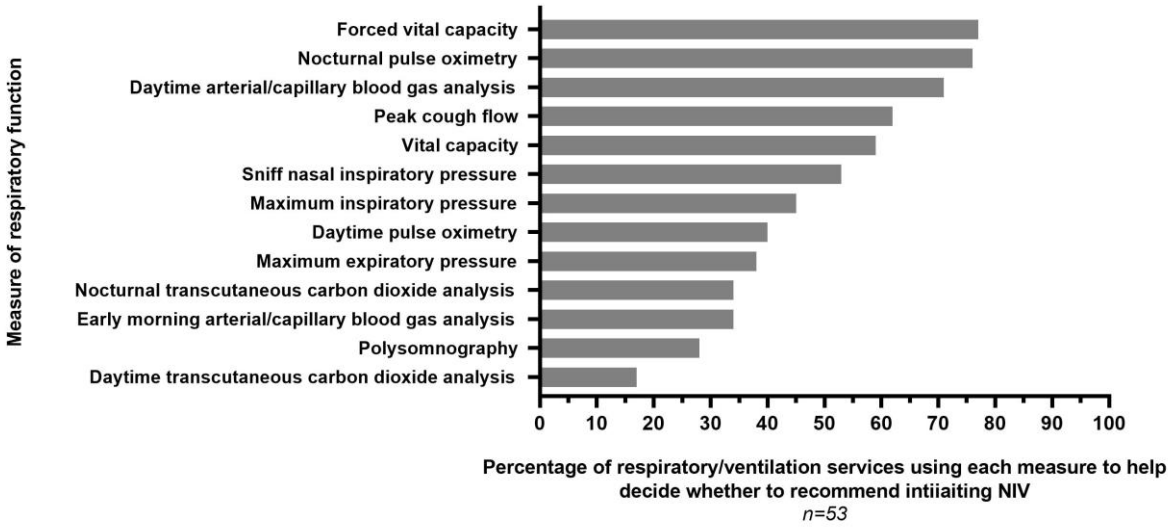
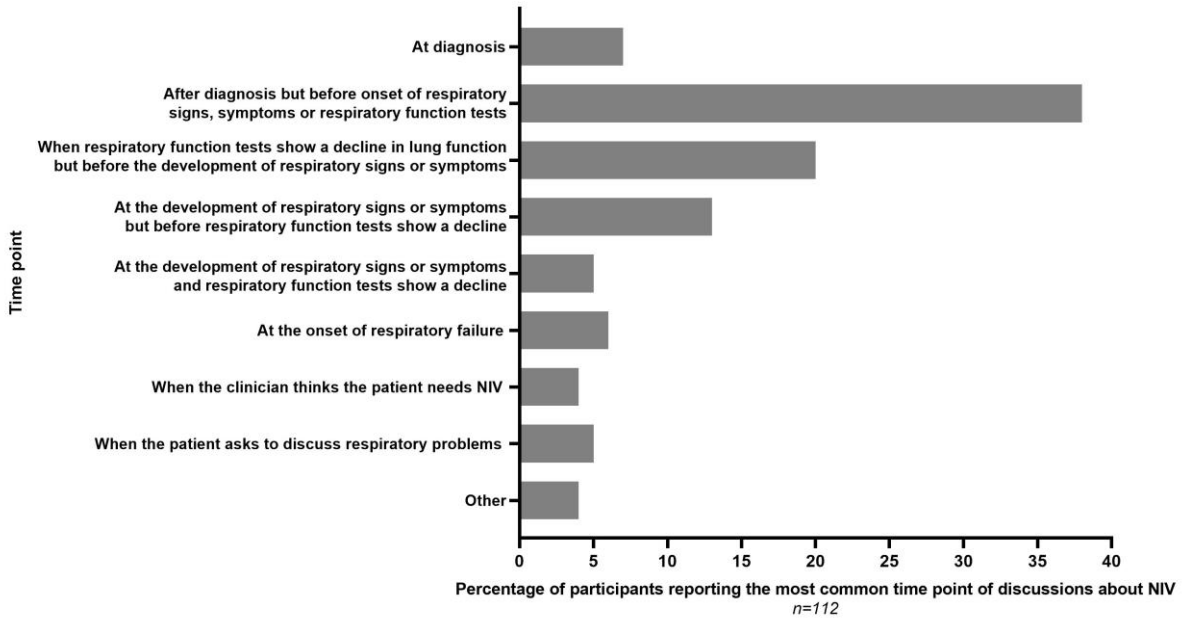
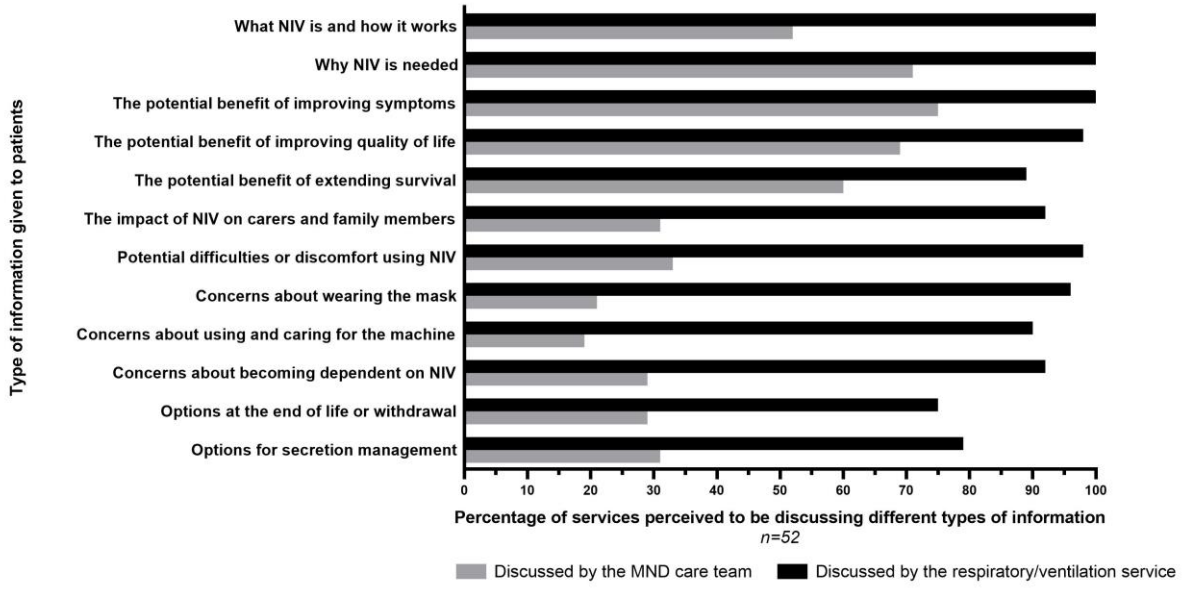


Figure 1. Flowchart of data collection and participant characteristics.
HCPs, healthcare professionals
MND, motor neuron disease
NHS, National Health Service


Measure of respiratory function
Forced vital capacity
Nocturnal pulse oximetry
Daytime arterial/capillary blood gas analysis
Peak cough flow
Vital capacity
Sniff nasal inspiratory pressure
Maximum inspiratory pressure
Daytime pulse oximetry
Maximum expiratory pressure
Nocturnal transcutaneous carbon dioxide analysis
Early morning arterial/capillary blood gas analysis
Polysomnography
Daytime transcutaneous carbon dioxide analysis
0
10
20
30
40
50
60
70
80
90
100
Percentage of respiratory/ventilation services using each measure to help decide whether to recommend intiiaiting NIV
n=53


Time point
At diagnosis
After diagnosis but before onset of respiratory signs, symptoms or respiratory function tests
When respiratory function tests show a decline in lung function but before the development of respiratory signs or symptoms
At the development of respiratory signs or symptoms but before respiratory function tests show a decline
At the development of respiratory signs or symptoms and respiratory function tests show a decline
At the onset of respiratory failure
When the clinician thinks the patient needs NIV
When the patient asks to discuss respiratory problems
Other
0
5
10
15
20
25
30
35
40
Percentage of participants reporting the most common time point of discussions about NIV
n=112


Type of information given to patients
What NIV is and how it works
Why NIV is needed
The potential benefit of improving symptoms
The potential benefit of improving quality of life
The potential benefit of extending survival
The impact of NIV on carers and family members
Potential difficulties or discomfort using NIV
Concerns about wearing the mask
Concerns about using and caring for the machine
Concerns about becoming dependent on NIV
Options at the end of life or withdrawal
Options for secretion management
0
10
20
30
40
50
60
70
80
90
100
Percentage of services perceived to be discussing different types of information
n=52
Discussed by the MND care team
Discussed by the respiratory/ventilation service

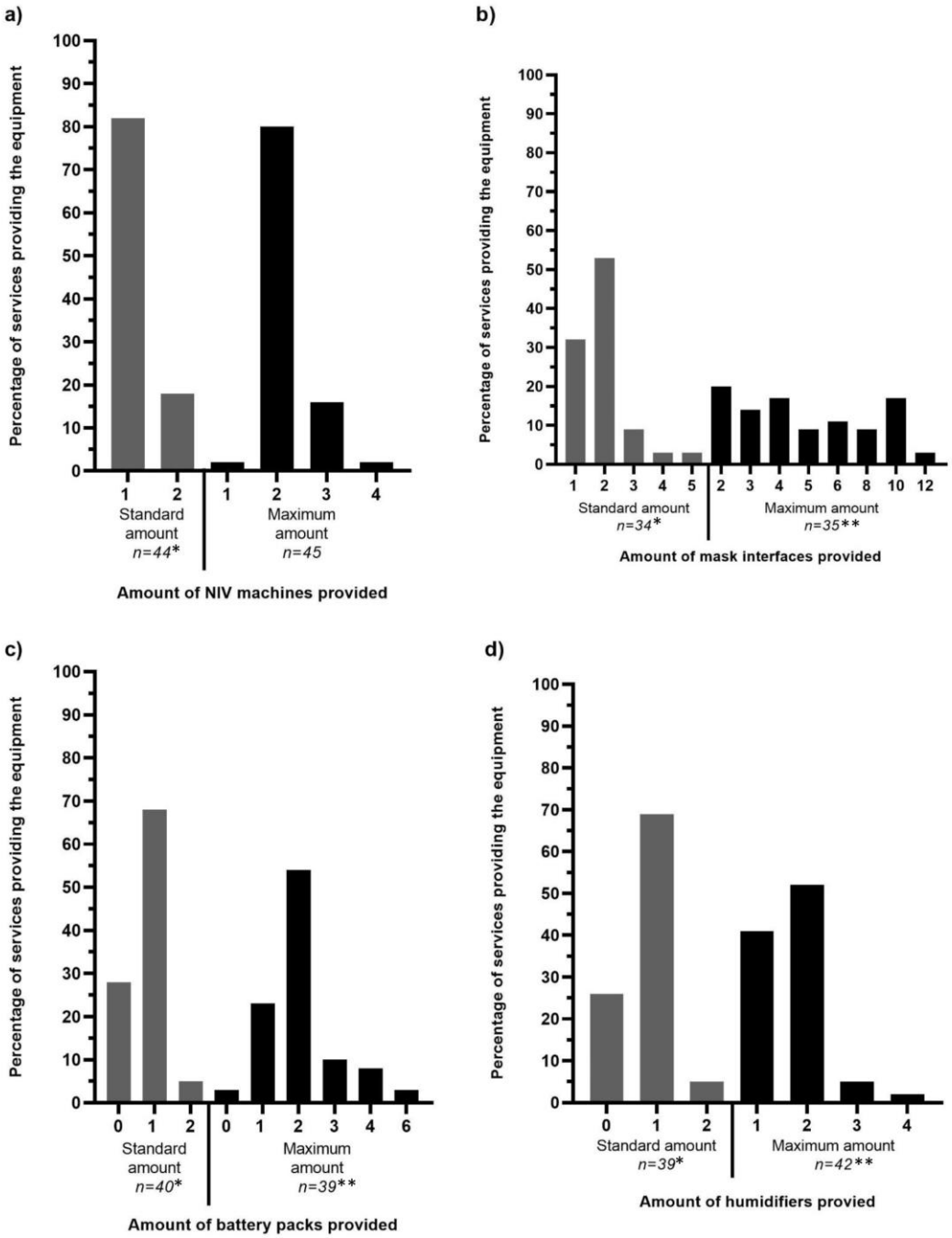
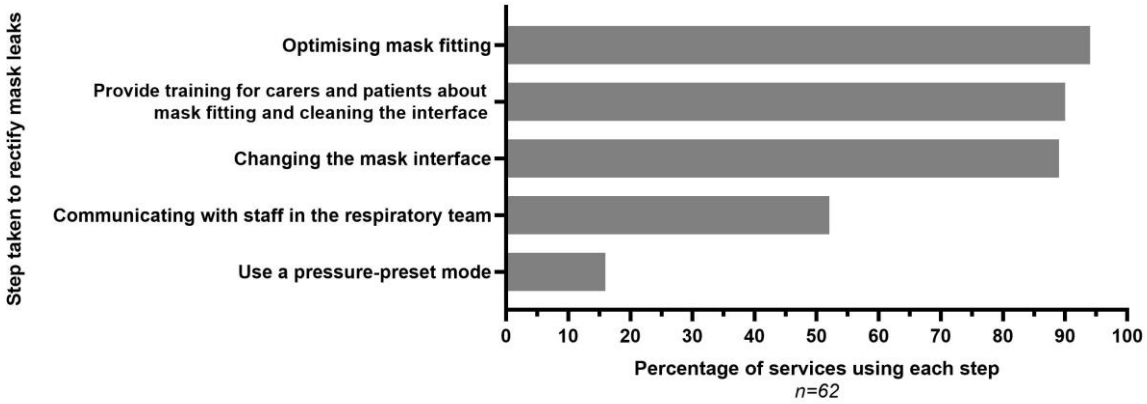


Figure 5. Amount of equipment provided by respiratory/ventilation services: a) NIV machines, b) mask interfaces, c) battery packs, d) humidifiers.

NIV, non-invasive ventilation

[a*]Three services excluded from the analysis due to variation in responses given by two respondents working at each service. For example, one participant stated that the standard amount of NIV machines provided in their service was one and another participant working in the same service stated that their service provided two NIV machines as standard. [b*]Thirteen services excluded from the analysis due to variation in responses given by respondents working in the same service. [b**]Nine services excluded from the analysis due to variation in responses given by two respondents working at each service. [c*]Four services excluded from the analysis due to variation in responses given by two respondents working at each service. [c**]Four services excluded from the analysis due to variation in responses given by two respondents working at each service. [d*]Five services excluded from the analysis due to variation in responses given by two respondents working at each service. [d**]Four services excluded from the analysis due to variation in responses given by two respondents working at each service.


Step taken to rectify mask leaks
Optimising mask fitting
Provide training for carers and patients about mask fitting and cleaning the interface
Changing the mask interface
Communicating with staff in the respiratory team
Use a pressure-preset mode
0
10
20
30
40
50
60
70
80
90
100
Percentage of services using each step
n=62

Supplementary data/further findings from Survey 1 and Survey 2

Data from Survey 1 (1)

Involvement of the MND service in earlier NIV decision-making

Participants were asked what their MND centre's usual role was relating to a variety of aspects of care regarding NIV initiation once a patient had been referred for NIV. Different aspects of care relating to earlier NIV management were grouped into three categories:

- NIV equipment (ventilator choice, interface choice, ventilator set-up and trial, heated humidification)
- NIV usage (patient education, setting adherence targets)
- Secretion management (medical secretion management and cough management)

The relative decision-making involvement of the MND service in these combined aspects of care related to earlier NIV management is illustrated below in Figure 1, which demonstrates less involvement in decisions related to NIV equipment and NIV usage, and more involvement with regards secretion management.

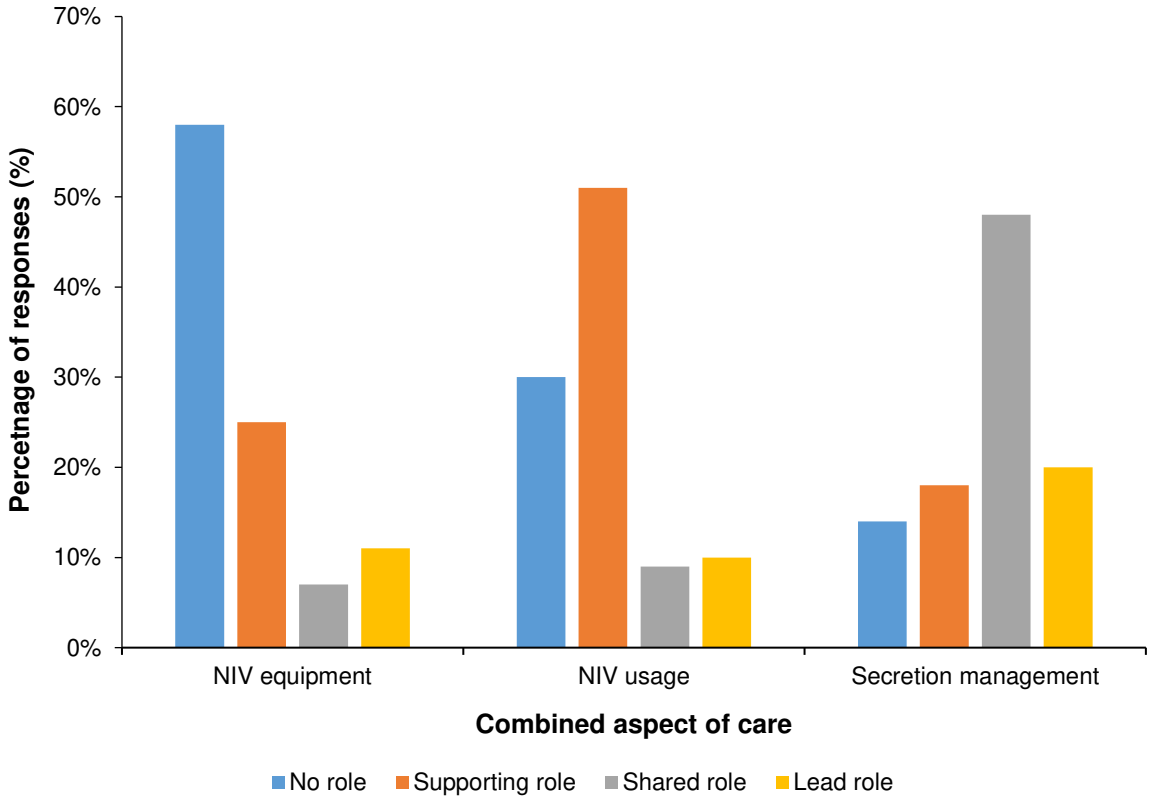


Figure 1. Involvement of MND services in earlier NIV management (n=55)

Involvement of the MND service in later NIV decision-making

Participants were asked what their MND centre's usual role was relating to a variety of aspects of care regarding ongoing NIV care once a patient had been established on NIV. Different aspects of care relating to earlier NIV management were grouped into four categories:

- NIV equipment (ventilator setting changes, interface changes, heated humidification)

- NIV usage (patient education, monitoring adherence, identifying causes for poor adherence, resolving poor adherence, nasal steroids for congestion, treatment for mask-related pressure sores)
- NIV quality (monitoring ventilation, identifying causes for ineffective ventilation, resolving ineffective ventilation)
- Secretion management (medical secretion management and cough management)

The relative decision-making involvement of the MND service in these combined aspects of care related to later NIV management is illustrated in Figure 2, which demonstrates less involvement in decisions related to NIV equipment, more involvement in decisions related to NIV usage and NIV quality, and greatest involvement with regards secretion management.

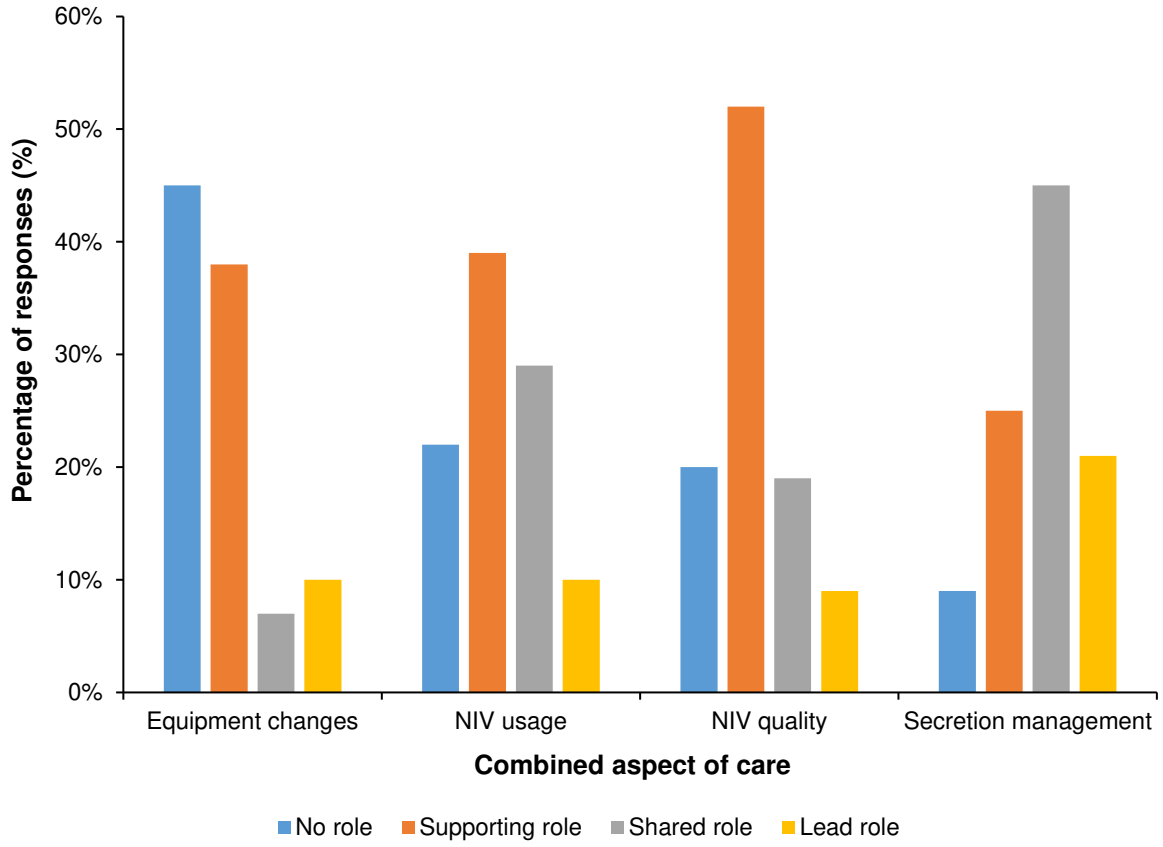


Figure 2. Involvement of the MND service in later NIV decision-making (n=55)

Measuring NIV effectiveness

Participants in Survey 1 were asked what the usual availability for a range of measures was to assess NIV effectiveness at their MND centre. The analysis explored whether it was provided by their MND service, the NIV service or if the availability weas unknown. Symptoms were monitored at every centre, either by the MND services (n=52, 95%) or by the NIV service (n=3, 5%). The least commonly-used measures by MND and NIV services were: polysomnography, diurnal and nocturnal capnography, device-recorded data and blood gases (early morning and daytime arterial, and capillary gases). This is illustrated in Figure 3.

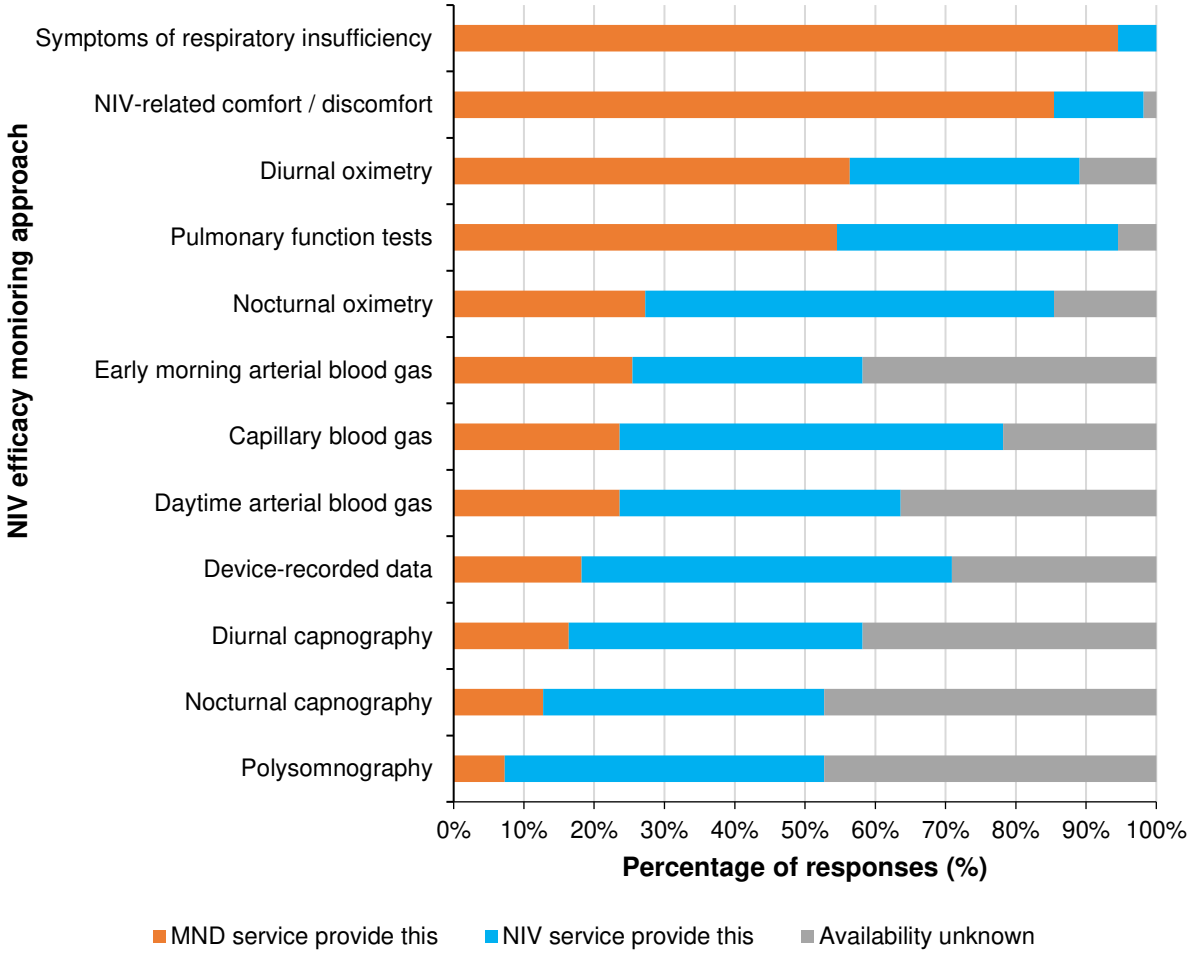


Figure *Error! No text of specified style in document.*. Measures used to monitor effective ventilation (n=55)

Data from Survey 2

Support prior to initiating NIV

In Survey 2, professionals from eight services (8%) said they did not provide any support when a patient is offered a trial of NIV. Eighty-nine services (92%) provided some support when a patient is offered a trial of NIV. The most common supportive measure offered to patients when they are recommended a trial of NIV was having discussions with the patient, family members and carers (n=74, 84%) (see Figure 4). This included trusts, social enterprises and hospices. Two services (2%) which were both NHS trusts, provided group workshops with other patient(s) starting NIV and fourteen services (16%) offered meetings with other patients using NIV. Twenty-four services (27%) provided additional support including personalised information, email and telephone support, home visits, reassurance and patient/carer training. Thirty-three services (37%) provided support by referring patients to other healthcare professionals.

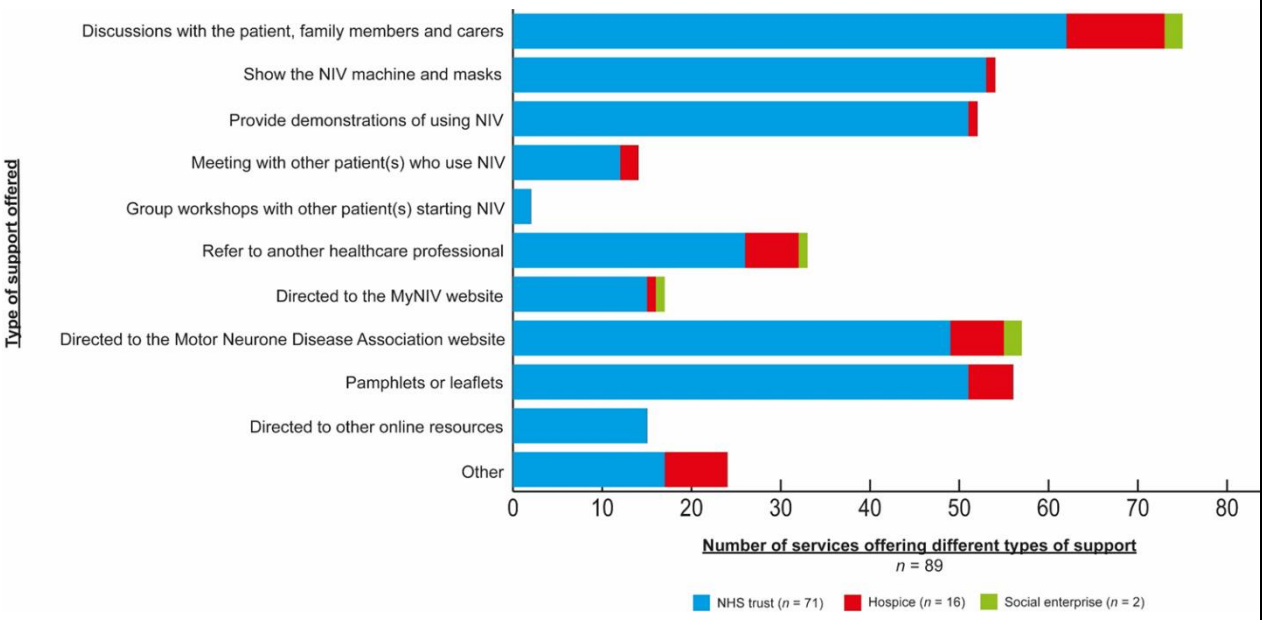


Figure 4. Supportive measures offered by services in Survey 2 when a patient is offered a trial of NIV.

The most common points of referral were the respiratory and/or sleep team (n=17, 52%), physiotherapy (n=8, 24%) and the community team (n=8, 24%) (see Figure 5).

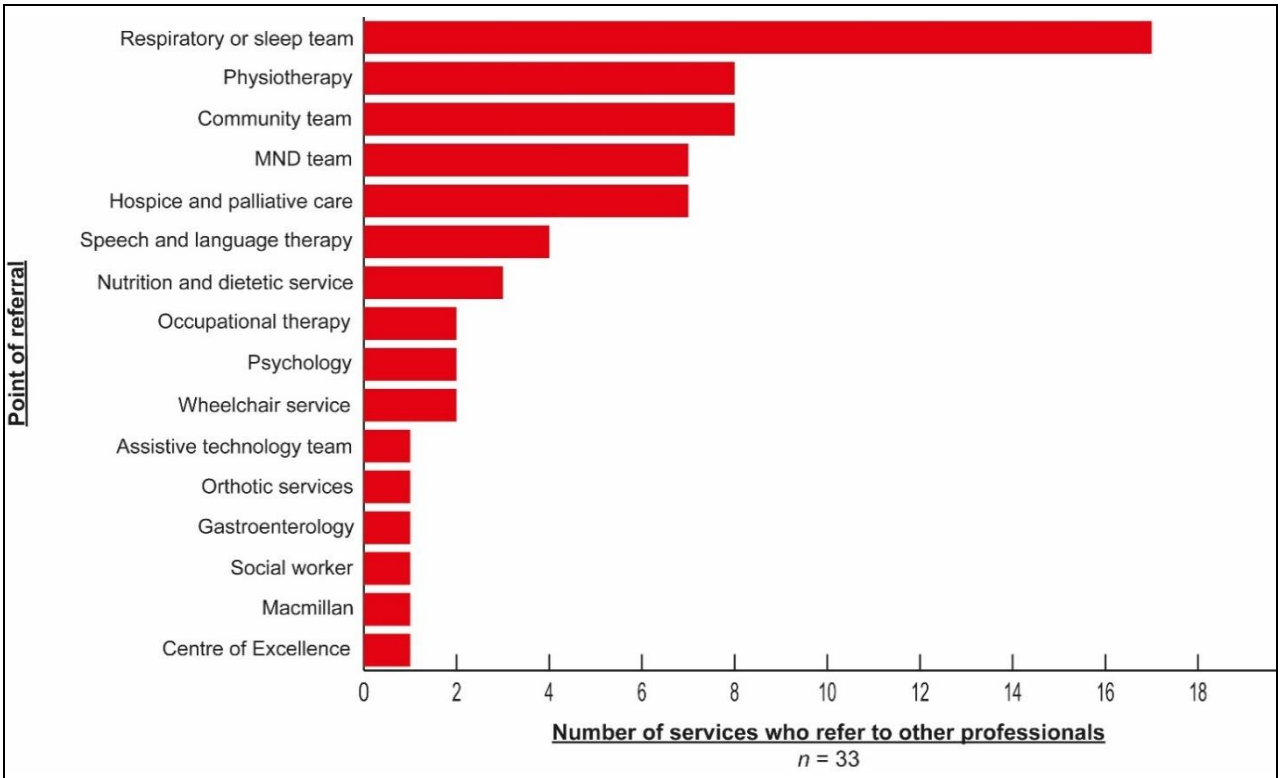


Figure 5. Where services refer patients to when they are offered a trial of NIV.

Assessing the effectiveness of the ventilation

Services in Survey 2 used a variety of measures to assess the effectiveness of the ventilation (Figure 6). The most commonly used measure to assess the effectiveness of the ventilation at the end of the initiation phase and at regular follow-up was self-reported symptoms (n=63, 89% and n=62, 87% respectively). The most common oxygen/CO_2 measurement used was daytime blood gas analysis (n=46, 85%).

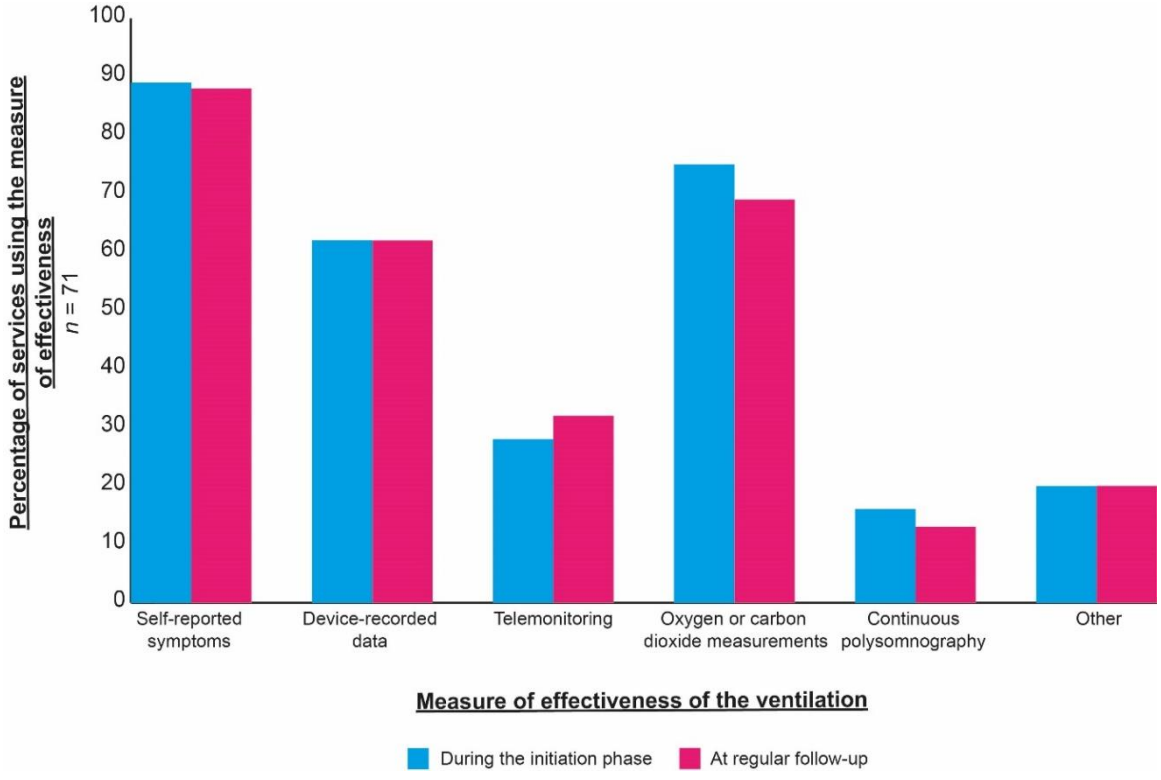


Figure 6. Measures used by services to assess the effectiveness of the ventilation.

Troubleshooting options

Participants were asked to state whether their service had a range of troubleshooting options available. The most common options available were a heated humidifier (56, 58%), having a joint appointment (54, 56%), nasal plasters (48, 50%), and mouthpieces (42, 43%). Forty-one services (42%) provided an inpatient assessment and 36 (37%) had psychological interventions available. Twelve services (12%) did not provide any of the above. Participants working in 22 services (23%) specified that they had other options available, including dressings/liners, equipment such as electric beds, home visits, nebulisers, upper airway assessment, carer training and liaising with, or referring to, other teams.

Troubleshooting to overcome upper airway obstructive events

Eighty-six out of 95 participants (91%) stated that they had a role in rectifying upper airway obstructive events. Fifty-two percent (n=49) had a lead role. Participants took a range of steps to rectify upper airway obstructive events (see Figure 6). The most common step taken was increasing the expiratory positive airway pressure, which was used by 46 services (77%). Fourteen services (23%) used 'other' steps including nasendoscopy, laryngoscopy, muscle relaxants and providing positional advice.

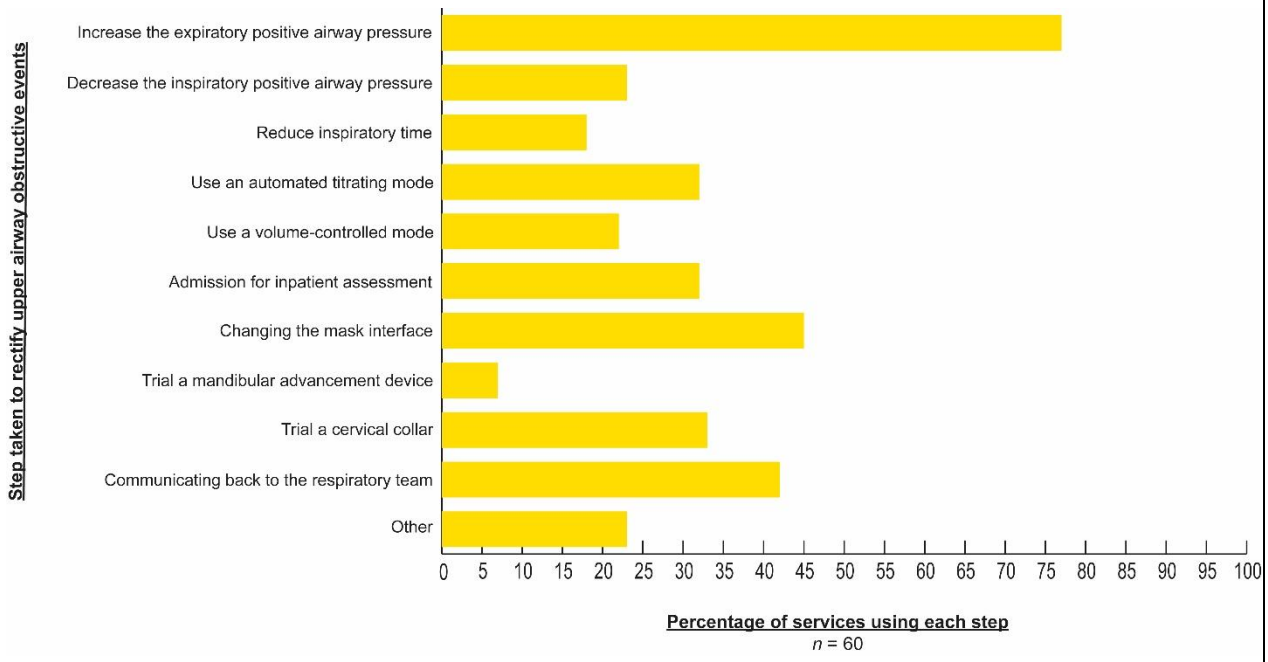


Figure 6. Steps taken by services in Survey 2 to rectify upper airway obstructive events.

Troubleshooting to rectify patient-ventilator asynchronies

Eighty-six out of 96 participants (90%) stated they had a role in rectifying patient-ventilator asynchronies. Fifty-three percent (n=51) had a lead role. A range of steps to rectify patient-ventilator asynchronies were identified from the free-text responses. An important step appeared to be monitoring, reviewing and adjusting the ventilator settings. This included altering the pressures (e.g., increasing the EPAP), adjusting the rise time, inspiratory time and back up rate and altering the inspiratory/expiratory trigger sensitivities. It was also important to identify the cause of the asynchrony (e.g., mask leak) so admitting patients was seen as helpful for assessing this. Telemonitoring was also seen as helpful for tracking changes. Reviewing the mask fit and adjusting or changing the interface was seen as helpful for rectifying asynchronies. Other steps taken included changing the mode (e.g., to a pressure-controlled or timed mode), changing the type of ventilator, carrying out a nasendoscopy, using sedation, coaching patients about breathing on NIV, liaising with and referring to other healthcare professionals (e.g., the specialist respiratory team) and having discussions with patients.

Tracheostomy ventilation

Sixty-nine percent of NIV services (n=34) had no patients with MND using tracheostomy ventilation in their service. The range was 0-12.

Support during the withdrawal of NIV

Sixty-one percent of participants (n=95) stated that they provide support for patients, family members and carers when discussions about withdrawal begin. Fifty-six (36%) said they do not provide support but refer patients to another service. The most common point of referral by participants who said they did not provide support but did refer patients to another service was hospice and palliative care (n=37, 66%) (see Figure 7).

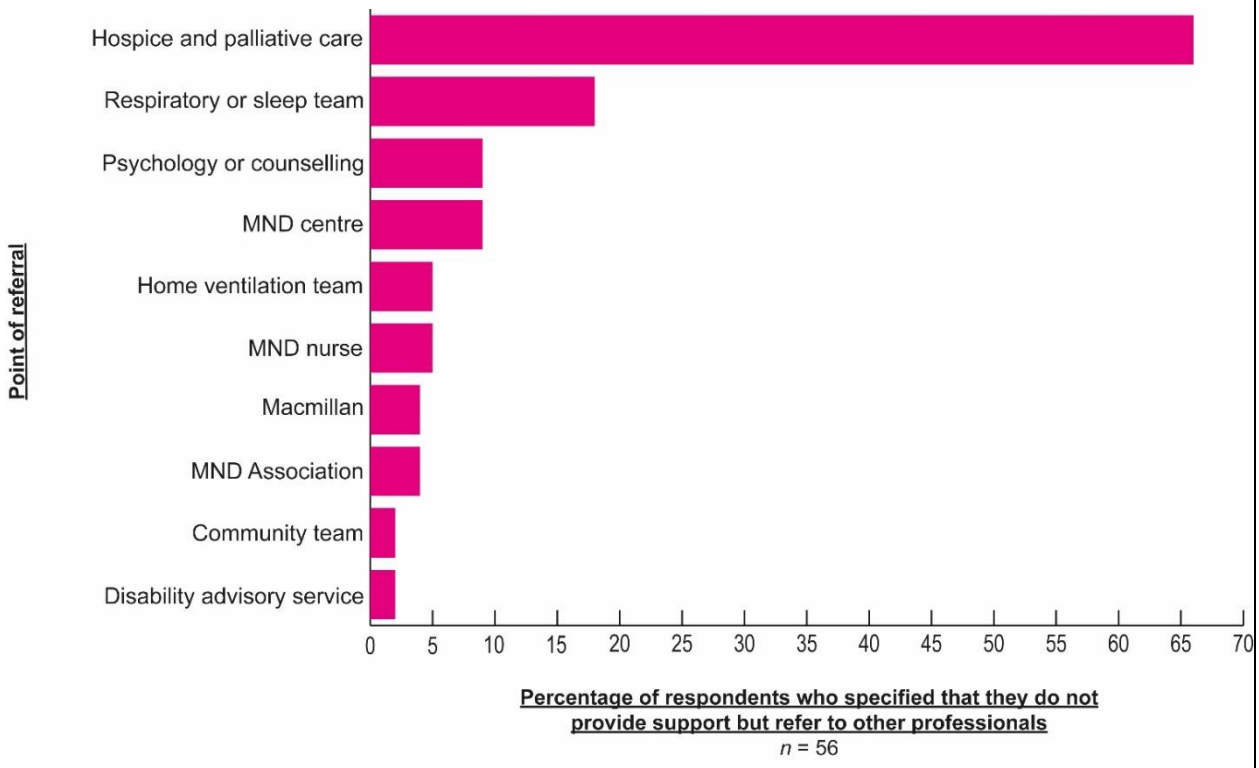


Figure 7. Point of referral from participants in Survey 2 who specified that they do not provide support at withdrawal of NIV but do refer patients to another service.

Referral to palliative care services was seen as important for enabling early planning and establishing a good rapport with patients. The majority of services (n=69, 91%) referred patients with MND on NIV to palliative care at the withdrawal stage of the respiratory patient care pathway. There was a significant association between service and referral to palliative care services. Those that included representation from specialist ventilation services (n=36, 97%) were more likely to refer than services which included representation from community teams (n=22, 79%) (Fisher's exact test, $p = 0.030$).

References

1. O'Brien D. Enhancing the efficacy of non-invasive ventilation for patients with motor neurone disease: A systematic review and multicentre survey [BMedSci thesis]. University of Sheffield. 2018.

Survey 1

Enhancing the efficacy of non-invasive ventilation for patients with motor neurone disease: a survey of MND care providers

We are aiming to identify the best ways to optimise non-invasive ventilation (NIV) for patients with MND and monitor its effectiveness over time. We would be very grateful if you could answer a few questions regarding the usual delivery of NIV for a typical patient with MND at your centre. This research has received support from the MNDA and ethical approval from the University of Sheffield. The questionnaire will take around 10 -15 minutes to complete. Your contribution will inform further research and help to broaden our understanding of how to optimise NIV for people with MND.

***Required**

The University Of Sheffield.

SITraN
Sheffield Institute for Translational Neuroscience

Section 1: MND service

1. **Name of respondent** *

2. **Email address** *

3. **Job title (e.g. care centre coordinator)** *

4. **Centre name/location** *

5. **Estimated number of NEW patients seen each month with MND at your centre** *

6. **Estimated total number of patients with MND under follow-up care at your centre** *

Section 2: NIV services

At the end of this section you will be afforded the opportunity to elaborate on or clarify any of the answers you provide

1. For the main NIV service you refer to:

---

a) Name of the service/centre (e.g. hospital and department) *

b) Name of consultant(s)/lead clinician(s) referred to for NIV

c) Contact details for the above lead clinician(s), if known (i.e. phone number and/or email)

d) Name and job title of supporting healthcare professional(s) for MND patients on NIV (e.g. Joe Bloggs - respiratory physiologist/ physiotherapist/ specialist nurse)

e) Contact details for the above supporting healthcare professional(s) if known (i.e. phone number and/or email)

f) At what point does your centre MOST COMMONLY refer patients to NIV services? *

Mark only one oval.

- At diagnosis of MND
- After diagnosis of MND but prior to development of respiratory signs/symptoms (including respiratory function tests)
- At the development of respiratory signs/symptoms (including respiratory function tests)
- At the onset of respiratory failure
- When the patient broaches the issue of respiratory problems/NIV
- When patient requires gastrostomy
- Other: _____

g) Please clarify or elaborate upon any of the answers provided to the above questions as necessary

_____

_____

_____

_____

_____

h) If the above questions are not suited to your model of care, please briefly explain the structure of your NIV services

_____

_____

_____

_____

_____

2. For any other services your centre refers its MND patients to for NIV

You may have one main service but we are trying to capture details of any additional services who provide NIV to your patients with MND and in what circumstances (e.g. for patients who live further afield)

a) Name of the service/centre(s)

b) In what circumstances would your centre refer patients here? (e.g. for patients that live in a specific area, please give details)

c) Provide any other relevant details about these services here

3. Referral data

If exact numbers are not available, please give your best estimate

a) How many NIV referrals did your centre make in the last MONTH for patients with MND? *

b) How many tracheostomy referrals did your centre make in the last YEAR for patients with MND? *

c) Please indicate if these referral figures are exact or estimated * Mark only one oval.

Exact

Estimated

4. Involvement of respiratory staff at your MND centre

In this question, we'll be asking you about the respiratory NIV service itself but we'd like to know how the MND service works with the respiratory team. We appreciate that every centre has a different model so there is space to describe your model below if it doesn't fit into our description

a) Are any of the following respiratory healthcare professionals funded as part of your core MND MDT service? *

If you refer patients to a separate department, tick 'None'

Tick all that apply.

- [ ] Respiratory consultant
- [ ] Respiratory nurse
- [ ] Respiratory physiotherapist
- [ ] Respiratory physiologist
- [ ] None
- [ ] Other: _____

b) Please describe their involvement (e.g. attend MND MDT clinics, run separate respiratory clinics)

_____

_____

_____

c) Within your MND service (e.g. when the patient comes to the MND clinic), is anyone from the respiratory team involved in patient care BEFORE the development of respiratory signs or symptoms? *

Mark only one oval.

- ◯ Yes, they are available to provide respiratory monitoring
- ◯ Yes, they are available for patient information / counselling
- ◯ No, patients do not meet the respiratory team until they are referred
- ◯ Other: _____

d) Provide any other relevant details about the involvement of respiratory staff in the care of your MND patients on NIV

e) If the above questions are not suited to your model of care, please briefly explain the involvement of respiratory staff in your centre

6. ## 5. NIV guidelines/pathways

a) Does your centre use any pathways or guidelines for the delivery of NIV services to your patients with MND? (e.g. national/local/manufacturer's guidelines) *

Mark only one oval.

- **Yes**
- **No, but I am aware of some in existence**
- **No, and I am not aware of any in existence**

b) If you answered "Yes" or "No, but I am aware of some in existence", could you please provide details

Section 3: NIV delivery

At the end of this section you will be afforded the opportunity to clarify or elaborate upon any of the answers you provide to the following questions

1. Once a typical patient has been referred for NIV, what is the USUAL role of the MND care centre/clinic staff in the following (regarding NIV initiation):

Definitions

- **Lead role: Your centre takes on the lead decision-making role regarding this aspect of care**

- **Shared role: Your centre shares the decision-making role regarding this aspect of care with another service (e.g. the NIV service patients are referred to)**

- **Supporting role: Your centre has a supporting role (e.g. providing encouragement) regarding this aspect of care, while another service takes on the lead decision-making role**

- No role: Your centre has no role in this aspect of care/refers onto another service

a) Initial choice of ventilator type, mode and settings * **Mark only one oval.**

Lead role

Shared role

Supporting role

No role

b) Initial choice of mask interface * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

c) Technical set-up of ventilator and mask, and initiation of ventilation trial * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

d) Patient/carer education on the optimal use of NIV *

If providing encouragement only, tick "supporting role"

Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

e) Setting of NIV adherence targets (e.g. >4 hours nightly use) * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

f) Optimising medical secretion management prior to NIV initiation (to facilitate NIV use) *

Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

g) Optimising cough management prior to NIV initiation (to facilitate NIV use) * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

h) Prescribing heated humidification for NIV * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

i) Please clarify or elaborate upon any of the answers you have provided to the above questions in this section as necessary

j) If the above questions are not suited to your model of care, please briefly explain the role of your centre in NIV initiation

2. Once a typical patient is established on NIV, what is the USUAL role of the MND clinic staff in the following (regarding ongoing NIV care):

Definitions

- **Lead role: Your centre takes on the lead decision-making role regarding this aspect of care**

- **Shared role: Your centre shares the decision-making role regarding this aspect of care with another service (e.g. the NIV service patients are referred to)**

- **Supporting role: Your centre has a supporting role (e.g. providing encouragement) regarding this aspect of care, while another service takes on the lead decision-making role**

- **No role: Your centre has no role in this aspect of care/refers onto another service**

a) Changes to NIV machine settings * Mark only one oval.

- **Lead role**
- **Shared role**
- **Supporting role**
- **No role**

b) Changes to mask interfaces *

If adjustments of straps or headgear only, tick "supporting role"

Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

c) Patient/carer education on the continued optimal use of NIV *

If providing encouragement only, tick "supporting role"

Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

d) Optimising medical secretion management while on NIV (to facilitate NIV use) *

Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

e) Optimising cough management while on NIV (to facilitate NIV use) * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

f) Monitoring NIV use and adherence to set targets (e.g. >4 hours nightly) * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

g) Identifying reasons for poor adherence to prescribed NIV * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

h) Implementing solutions to causes of poor adherence * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

i) Assessing the effectiveness of NIV *

If you question the patient but refer to the respiratory team for detailed assessment of effectiveness tick “supporting role"

Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

j) Identifying reasons for ineffective ventilation (e.g. mask leak, airway obstruction, poor mask fitting or inadequate ventilator settings) * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

k) Implementing solutions to causes of ineffective ventilation * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

l) Prescribing heated humidification * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

m) Prescribing nasal steroids for congestion * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

n) Treating mask sores with dressings * Mark only one oval.

- Lead role
- Shared role
- Supporting role
- No role

o) Please clarify or elaborate upon any of the answers you have provided to the above questions in this section as necessary

p) If the above questions are not suited to your model of care, please briefly explain the role of your centre in NIV follow-up care

3. Once a typical patient is established on NIV, what is the USUAL availability of the following measures of NIV effectiveness at your MND centre:

At the end of this section you will be afforded the opportunity to clarify or elaborate upon any of the answers you provide to the following questions

a) Symptoms of respiratory insufficiency (e.g. morning headaches, unrefreshing sleep, breathing difficulties, weak cough) *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

b) NIV related comfort/discomfort *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

c) Pulmonary function tests (e.g. FVC, MIP, SNIP) *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

d) Daytime pulse oximetry *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

e) Overnight pulse oximetry *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

f) Daytime transcutaneous CO2 measurement (e.g. TOSCA) *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

g) Overnight transcutaneous CO2 measurement *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

h) Capillary blood gases (e.g. earlobe sample) *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

i) Early morning arterial blood gas sample *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

j) Daytime arterial blood gas sample *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

k) Formal sleep studies (e.g. polysomnography) *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

l) Device-recorded data (e.g. mask leak, compliance, tidal volumes) - accessed via smartcard/other *

For patients established on NIV

Mark only one oval.

- Monitored at all MND clinic appointments
- Monitored at some MND clinic appointments
- Unavailable at MND clinics but provided by the MND centre (e.g. as an inpatient)
- Unavailable at MND clinics but can be requested from the NIV service
- MND clinic have no involvement but I am aware that the NIV service provide this
- Not known if this is available from NIV services

n) Does your MND centre use any other measures to determine NIV effectiveness (provide details)

o) Please clarify or elaborate upon any of the answers provided to the above questions as necessary

p) If the above questions are not suited to your model of care, please briefly explain the role of your centre in monitoring the effectiveness of NIV

4. Psychological support for patients on NIV

a) Do you have access to any psychological support to help people use NIV? * **Mark only one oval.**

- Yes (funded within the core MND service)
- Yes (referred to an external service)
- No
- Other:

b) If yes, please briefly outline this

Section 4

You're nearly there... Just a couple more questions!

1. Would you be happy for us to get in touch in the future to communicate our findings or for further research? *

Mark only one oval.

- Yes
- No

2. Would you be interested in learning more about how to optimise NIV in patients with MND? *

Mark only one oval.

- Yes
- No

3. If so, what format would be most appropriate to you? (tick all that apply) * Tick all that apply.

- [ ] Website
- [ ] Mobile app
- [ ] e-Learning
- [ ] Masterclass
- [ ] Journal article
- [ ] Pamphlet
- [ ] Other: _____

4. Would you be happy for us to contact you for clarification on any of the answers provided above? *

Mark only one oval.

- ◯ Yes
- ◯ No

5. Could you provide details of any other services/centres near you that you are aware of that provide specialist care to MND patients similar to that of an MND care centre (e.g. LOROS Hospice, Leicester)

For instance, they may have an MND specialist nurse or dedicated MND clinic, but lack official MND care centre status

_____

_____

_____

_____

_____

Thanks very much, you have finished! Your answers will be invaluable in our efforts to improve NIV for people with MND. Click SUBMIT below!

If you have any additional comments or concerns please drop us a line:

David O'Brien - dobrien2@sheffield.ac.uk

Dr Esther Hobson - e.hobson@sheffield.ac.uk

Dr Haris Stavroulakis - t.stavroulakis@sheffield.ac.uk

Professor Chris McDermott - c.j.mcdermott@sheffield.ac.uk

Sheffield Institute for Translational Neuroscience - 0114 222 2230

Please provide any comments on the design, delivery or content of this questionnaire so that we may address any areas for improvement (then click SUBMIT below)

By completing and returning this questionnaire I agree to take part in this survey

O'Brien DJ, Hobson EV, Stavroulakis T, Bianchi SM, Baxter SK, Elliott MW, Norman P, McDermott CJ. Enhancing the efficacy of non-invasive ventilation for patients with motor neurone disease: a survey of MND care providers

The University Of Sheffield.

SITraN
Sheffield Institute for Translational Neuroscience

Participant information

Enhancing the efficacy of non-invasive ventilation (NIV) for patients with motor neurone disease (MND): exploring the services that provide and deliver NIV to people with MND.

This section provides a summary of the participant information. For more details, please see [LINK FOR PARTICIPANT INFORMATION SHEET].

Aim
The aim of this survey is to explore the role and clinical practices of professionals who help patients with MND use NIV to see how practice varies and identify areas of good practice. This study will use these findings to develop resources to help improve the way in which NIV is delivered.

How long will the survey take?
We expect the survey to take approximately 15-35 minutes. This depends on the amount of detail you wish to provide. You are not required to answer all of the questions. If you choose to leave the survey, you can pick up where you left off at a later date by clicking on the link but the survey must be submitted prior to the deadline (insert date).

How will my information be used?
You can choose to complete the survey anonymously but can choose to leave your details at the end for further research. No one will be identifiable in any of the reports. Your data will remain on Qualtrics for 1 month. This has been the subject of independent assessment to ensure compliance with applicable data security standards. Your data will then be stored securely by the University of Sheffield. Medical School M: drive. Only members of the research team will have access to the information.

Recruitment
We want to collect the experiences of as many people as possible. **If you have any colleagues who work with people with MND using NIV, please forward the following link to them:**

[INSERT LINK]

Further information
If you have any other questions please contact:

Lucy Musson (Research assistant) - l.musson@sheffield.ac.uk
Dr Esther Hobson (Chief investigator) - e.hobson@sheffield.ac.uk

Consent form

Below are several statements. Before being directed to the survey, we ask that you read each statement:

I confirm that I understand what participation will involve.

I understand that my participation is voluntary.

I understand that my information will be stored and processed using services provided by Qualtrics.

I understand that my responses in the survey will be kept confidential and I give permission for the research team to have access to my responses.

I understand that some of my quotes may be used in publication but that neither I nor my place of work will be identifiable in the report(s).

I understand how my data will be used in the study.

Please can you confirm that you have read and understood each statement and that you consent to take part in the study by clicking "I agree to take part in this study" below.

- ○ I agree to take part in this study

Your role

Please can you select the statement which best describes your role:

- ○ I am involved in a respiratory or ventilation service/team (e.g. deciding to start NIV, setting up NIV such as deciding on equipment and/or monitoring and adjusting NIV such as changing the settings etc.)
- ○ I am involved in the community MND team and visit patients with MND at their home
- ○ I am **NOT** involved in any of the above

Are you a healthcare professional working in the United Kingdom?

- ○ Yes
- ○ No

Demographics

What is your role?

- ○ Doctor
- ○ Physiotherapist
- ○ Occupational therapist
- ○ Nurse
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

What is your band/grade (e.g. 8, consultant)?
[FREE TEXT RESPONSE]

What is your speciality?

- ○ Respiratory
- ○ Neurology
- ○ MND
- ○ Palliative care
- ○ Community
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

How many years have you been working with patients with MND?
(If less than 1 year, please select 0)
[DROP DOWN 1-50]

What is the name and location of the service you work in?
[FREE TEXT RESPONSE]

How many referrals for NIV in MND did your service have over the last YEAR?
[FREE TEXT RESPONSE]

How many patients with MND are currently using NIV in your service?
[FREE TEXT RESPONSE]

How many people with MND who are using NIV are currently on your community caseload?
[FREE TEXT RESPONSE]

Are these figures exact or estimated?

- ○ Exact
- ○ Estimated

Where do you usually see patients?

- ○ In the MND clinic
- ○ Separately from the MND clinic (e.g. in a separate respiratory service)
- ○ Both

Timings

Prior to referral

Are you involved in MND patient care BEFORE the patient develops respiratory signs or symptoms?

- ○ Yes
- ○ No

From your experience of being involved in MND patient care, at what time do discussions about NIV with patients begin?

(Please select all that apply)

- ○ At diagnosis.
- ○ After diagnosis but **before** onset of respiratory signs, symptoms or respiratory function tests.
- ○ When respiratory function tests show a decline in lung function but **before** the development of respiratory signs or symptoms.

- ○ At the development of respiratory signs or symptoms but **before** respiratory function tests show a decline.
- ○ At the development of respiratory signs or symptoms **and** respiratory function tests show a decline.
- ○ At the onset of respiratory failure.
- ○ When the clinician thinks the patient needs NIV.
- ○ When the patient asks to discuss respiratory problems.
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

From your experience of being involved in MND patient care, at what time do discussions about NIV with patients <u>MOST COMMONLY</u> begin?

- ○ At diagnosis.
- ○ After diagnosis but **before** onset of respiratory signs, symptoms or respiratory function tests.
- ○ When respiratory function tests show a decline in lung function but **before** the development of respiratory signs or symptoms.
- ○ At the development of respiratory signs or symptoms but **before** respiratory function tests show a decline.
- ○ At the development of respiratory signs or symptoms **and** respiratory function tests show a decline.
- ○ At the onset of respiratory failure.
- ○ When the clinician thinks the patient needs NIV.
- ○ When the patient asks to discuss respiratory problems.
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

In your opinion, do you think discussions about NIV typically begin...?

Very early	Early	At the right time	Late	Very late
○	○	○	○	○

Please explain why you have chosen that answer:
[FREE TEXT RESPONSE]

At referral

When are patients with MND referred to your service?

(Please select all that apply)

- ○ At diagnosis.
- ○ After diagnosis but **before** onset of respiratory signs, symptoms or respiratory function tests.
- ○ When respiratory function tests show a decline in lung function but **before** the development of respiratory signs or symptoms.
- ○ At the development of respiratory signs or symptoms but **before** respiratory function tests show a decline.
- ○ At the development of respiratory signs or symptoms **and** respiratory function tests show a decline.
- ○ At the onset of respiratory failure.
- ○ When the clinician thinks the patient needs NIV.
- ○ When the patient asks to discuss respiratory problems.
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

When are patients with MND MOST COMMONLY referred to your service?

- ○ At diagnosis.
- ○ After diagnosis but **before** onset of respiratory signs, symptoms or respiratory function tests.
- ○ When respiratory function tests show a decline in lung function but **before** the development of respiratory signs or symptoms.
- ○ At the development of respiratory signs or symptoms but **before** respiratory function tests show a decline.
- ○ At the development of respiratory signs or symptoms **and** respiratory function tests show a decline.
- ○ At the onset of respiratory failure.
- ○ When the clinician thinks the patient needs NIV.
- ○ When the patient asks to discuss respiratory problems.
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

In your opinion, are patients referred...?

Very early	Early	At the right time	Late	Very late
○	○	○	○	○

Please explain why you have chosen that answer:
[FREE TEXT RESPONSE]

How long does a patient usually have to wait for an appointment with the respiratory team after an <u>URGENT</u> assessment or NIV referral has been made?
[DROP DOWN]

How long does a patient usually have to wait for an appointment with the respiratory team after a <u>ROUTINE</u> assessment or NIV referral has been made?
[DROP DOWN]

From your experience, are there any reasons for delaying referral of patients to your service?

- ○ Yes
- ○ No
- ○ Unsure

What reasons are there for delaying referral of patients to your service?
(Please consider patient, carer and service factors)
[FREE TEXT RESPONSE]

<u>Initiation of NIV</u>

How long does it usually take to initiate NIV after a decision has been made to start NIV?
[DROP DOWN]

Do you think this time frame is...?

Very short	Short	About right	Long	Very long
○	○	○	○	○

Please explain why you have chosen that answer, including any enablers or barriers which result in fast or delayed initiation of NIV:
(Please consider patient, carer and service factors)
[FREE TEXT BOX]

Monitoring

When and where do you typically see patients after the initiation of NIV?

	When	Where		
	Number of weeks	Patient's home	Clinic	In-patient
First follow-up	[FREE TEXT]	○	○	○
Second follow-up	[FREE TEXT]	○	○	○
Third follow-up	[FREE TEXT]	○	○	○

When and where do you typically see patients for routine follow-ups after they are established on NIV (e.g. every 6 weeks)?

	When	Where		
	Every how many weeks	Patient's home	Clinic	In-patient
Regular follow-up	[FREE TEXT]	○	○	○

How often do you typically see patients with MND who are using NIV (e.g. every 6 weeks)?
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

Before starting NIV

Please use the following definitions when answering the questions:

Lead role: *Your service takes on the lead role and does this by directly providing the support and care (e.g. setting up equipment, initiating medication prescriptions or monitoring effectiveness).*

Shared role: *Your service shares this role with another service and is involved in the decision-making and giving advice to patients and carers.*

Supporting role: *Your service has a supporting role (e.g. by communicating back to the other teams involved in MND care) but does not get involved in any management decisions.*

No role: *Your service has no role in this aspect of delivering NIV.*

Identifying signs and symptoms

What is your usual role in identifying signs and symptoms of respiratory insufficiency and/or the need for respiratory support (e.g. NIV)?

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

Use of respiratory function tests

On referral, which tests do you carry out to help decide whether to recommend initiating NIV for patients with MND?

(Please select all that apply)

- ○ Peak cough flow
- ○ Maximum inspiratory pressure (MIP)
- ○ Maximum expiratory pressure (MEP)
- ○ Sniff nasal inspiratory pressure (SNIP)
- ○ Vital capacity (VC)
- ○ Forced vital capacity (FVC)
- ○ Daytime pulse oximetry
- ○ Night time pulse oximetry
- ○ Daytime transcutaneous carbon dioxide analysis
- ○ Night time transcutaneous carbon dioxide analysis
- ○ Early morning arterial/capillary blood gas analysis
- ○ Daytime arterial/capillary blood gas analysis
- ○ Polysomnography (sleep study)
- ○ Other (please specify below)
- ○ **N/A** – This is not part of my role

If "other", please specify below:
[FREE TEXT RESPONSE]

Which patients would undergo a polysomnography?
[FREE TEXT RESPONSE]

What threshold value do you typically use for deciding to recommend a trial of NIV for patients WITHOUT bulbar dysfunction?
(You will have the option to provide additional details below)

	With symptoms of respiratory insufficiency	**Without** symptoms of respiratory insufficiency
Maximum inspiratory pressure (cmH20)	[FREE TEXT]	[FREE TEXT]
Maximum expiratory pressure (cmH20)	[FREE TEXT]	[FREE TEXT]
Sniff nasal inspiratory pressure (cmH20)	[FREE TEXT]	[FREE TEXT]

What percentage of predicted threshold value do you typically use for deciding to recommend a trial of NIV for patients <u>WITHOUT</u> bulbar dysfunction?
(You will have the option to provide additional details below)

	With symptoms of respiratory insufficiency	**Without** symptoms of respiratory insufficiency
Vital capacity (%)	[FREE TEXT]	[FREE TEXT]
Forced vital capacity (%)	[FREE TEXT]	[FREE TEXT]

If you wish to provide additional details about the values used, please use the space below:
[FREE TEXT RESPONSE]

<u>Considerations when testing respiratory function</u>

When using respiratory function tests, are there any added considerations for those patients <u>WITH</u> bulbar dysfunction?

- ○ Yes
- ○ No
- ○ Unsure

If "yes", what are the extra considerations for those patients <u>WITH</u> bulbar dysfunction?
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

<u>Discussions with the patient</u>

What is your usual role in discussing the potential need for NIV with patients, carers and family members?

- ○ Lead role
- ○ Shared role
- ○ Supporting role

- ○ No role

What information are patients typically given by the MND care team <u>BEFORE</u> they are referred to your service?
(Please select all that apply)

- ○ What NIV is and how it works
- ○ Why NIV is needed
- ○ The potential benefit of improving symptoms of respiratory failure
- ○ The potential benefit of improving quality of life
- ○ The potential benefit of extending survival
- ○ The impact of NIV on carers and family members
- ○ Potential difficulties or discomfort using NIV
- ○ Concerns about wearing the mask
- ○ Concerns about using and caring for the machine
- ○ Concerns about becoming dependent on NIV
- ○ Options at the end of life or withdrawal
- ○ Options for secretion management
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

What do you discuss with patients when recommending a trial of NIV?
(Please select all that apply)

- ○ What NIV is and how it works
- ○ Why NIV is needed
- ○ The potential benefit of improving symptoms of respiratory failure
- ○ The potential benefit of improving quality of life
- ○ The potential benefit of extending survival
- ○ The impact of NIV on carers and family members
- ○ Potential difficulties or discomfort using NIV
- ○ Concerns about wearing the mask
- ○ Concerns about using and caring for the machine
- ○ Concerns about becoming dependent on NIV
- ○ Options at the end of life or withdrawal
- ○ Options for secretion management
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

Support during NIV initiation

Once the patient has been offered a trial of NIV, which of the following do you offer? *(Please select all that apply)*

- ○ Discussions with the patient, family members and carers
- ○ Show the NIV machine and masks
- ○ Provide demonstrations of using NIV
- ○ Meeting with other patient(s) who use NIV
- ○ Group workshops with other patient(s) starting NIV
- ○ Refer to another healthcare professional
- ○ Directed to the MyNIV website
- ○ Directed to the Motor Neurone Disease Association website
- ○ Pamphlets or leaflets
- ○ Directed to other online resources
- ○ Other (please specify below)
- ○ **N/A** - This is not part of my role

If you refer to another healthcare professional, please specify who you refer to:
[FREE TEXT RESPONSE]

If "other", please specify below:
[FREE TEXT RESPONSE]

Does your service or team provide any of the following so patients can contact you if they need help or advice about their NIV? *(Please select all that apply)*

- ○ Telephone
- ○ Email
- ○ None of the above
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

Can patients contact your service or during out-of-hours (outside of Monday-Friday 9am-5pm)?

- ○ Yes
- ○ No

Additional comments:
[FREE TEXT RESPONSE]

Communication

How often do you communicate with healthcare professionals in the MND care team about a patient's care?

- ○ After every patient visit
- ○ After a patient visit if there are particular issues
- ○ Only at multidisciplinary team meetings
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

Who do you primarily communicate with?

- ○ Respiratory team
- ○ Patient's general practitioner
- ○ MND clinic team
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

How do you communicate with other healthcare professionals in the MND care team about a patient's care? *(Please select all that apply)*

- ○ Letter
- ○ Pro forma
- ○ Meeting
- ○ Email
- ○ Telephone
- ○ Electronic patient record
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

How satisfied are you with the communication between your service and other healthcare professionals in the MND care team?

Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
○	○	○	○	○

Please explain why you have chosen that answer:
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

Set up at initiation

Are you involved in initiating patients with MND on NIV?

- ○ Yes
- ○ No

Equipment

We would like to know about the equipment your service provides.

Can you please tell us how many of the following are funded in your service, how many you provide as a standard to each patient and how many you provide as a maximum to an individual patient? *(You will have the option to explain your choices below)*

	Standard amount given to one patient	Maximum given to one patient	Total number funded in your service
NIV machine	[ENTER NUMBER]	[ENTER NUMBER]	[ENTER NUMBER]
Battery pack	[ENTER NUMBER]	[ENTER NUMBER]	[ENTER NUMBER]
Mask interface	[ENTER NUMBER]	[ENTER NUMBER]	[ENTER NUMBER]
Humidifier	[ENTER NUMBER]	[ENTER NUMBER]	[ENTER NUMBER]

If you have any additional comments about the amount of equipment that is provided, please use the space below:
[FREE TEXT RESPONSE]

Which options of mask interfaces does your service provide?
(Please select all that apply)

- ○ Total face mask
- ○ Oronasal mask
- ○ Nasal mask

- ○ Nasal pillow
- ○ Mouth piece

Please explain how the mask interface is chosen:
[FREE TEXT RESPONSE]

Please consider the following scenarios:

Patient A: A 65-year-old male with weakness in both legs and arms but NO problems with his speech, swallow or saliva.

Patient B: A 65-year-old male with no weakness in his limbs but poor speech and swallow and problems with drooling and thick chest secretions.

Which mask interface would be your preferred choice for initiating Patient A and Patient B on?

	Total face mask	Oronasal mask	Nasal mask	Nasal pillow	Mouth piece
Patient A	○	○	○	○	○
Patient B	○	○	○	○	○

Please give details of the reason(s) for your choices:

Patient A (no bulbar impairment) – [FREE TEXT RESPONSE]

Patient B (has bulbar impairment) – [FREE TEXT RESPONSE]

Modes of ventilation

Please consider the following scenarios:

Patient A: A 65-year-old male with weakness in both legs and arms but NO problems with his speech, swallow or saliva.

Patient B: A 65-year-old male with no weakness in his limbs but poor speech and swallow and problems with drooling and thick chest secretions.

Which of the following modes of ventilation is your preferred choice and the one that you would choose to initiate Patient A and Patient B on?

	Pressure-targeted	Volume-targeted	Volume Assured Pressure Support (e.g AVAPS, iVAPS etc)	Other (please specify below)
Your preferred choice	○	○	○	○
Initiating Patient A	○	○	○	○
Initiating Patient B	○	○	○	○

If "other", please specify below:
[FREE TEXT RESPONSE]

If applicable, please provide details of the pre-defined pressure levels, tidal volumes, pressure ranges etc. which you would use to initiate Patient A and Patient B on:

Patient A (no bulbar impairment) – [FREE TEXT RESPONSE]

Patient B (has bulbar impairment) – [FREE TEXT RESPONSE]

What percentage of patients with MND in your service are initiated on NIV using each of the following modes?
(Please ensure that the total value is 100%)

Pressure-targeted	[ENTER NUMBER]
Volume-targeted	[ENTER NUMBER]
Volume Assured Pressure Support (e.g. AVAPS, iVAPS etc.)	[ENTER NUMBER]
Other (please specify below)	[ENTER NUMBER]
Total -	[ENTER NUMBER]

If "other", please specify below:
[FREE TEXT RESPONSE]

Which of the following modes of ventilation is your preferred choice and the one you would choose to initiate Patient A and Patient B on?

	Spontaneous	Timed	Spontaneous-timed	Other (please specify below)
Your preferred choice	○	○	○	○
Choice for initiating Patient A	○	○	○	○
Choice for initiating Patient B	○	○	○	○

If "other", please specify below:
[FREE TEXT RESPONSE]

What percentage of patients with MND in your service are initiated on NIV using each of the following modes?
(Please ensure that the total value is 100%)

Spontaneous	[ENTER NUMBER]
Timed	[ENTER NUMBER]
Spontaneous-timed	[ENTER NUMBER]

Other (please specify below) [ENTER NUMBER]

Total - [ENTER NUMBER]

If "other", please specify below:
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

Location

What locations are used for the initiation of NIV in your service?
(Please select all that apply)

	Inpatient day case	One-night admission	Multiple night admission	Outpatient	Patient's home
Funded in your service	○	○	○	○	○
Used but not funded	○	○	○	○	○

What percentage of patients with MND in your service are initiated on NIV in each of the following locations...?
(Please ensure that the total value is 100%)

Inpatient day case [ENTER NUMBER]
One-night admission [ENTER NUMBER]
Multiple night admission [ENTER NUMBER]
Outpatient [ENTER NUMBER]
Patient's home [ENTER NUMBER]

Total - [ENTER NUMBER]

What location is your preferred choice for the initiation of NIV?

- ○ Inpatient day case
- ○ One-night admission
- ○ Multiple night admission
- ○ Outpatient
- ○ Patient's home

Please explain how the location for initiating NIV is decided:
[FREE TEXT RESPONSE]

Are there any barriers preventing you from using your preferred location?
(e.g. patient and carer barriers and/or service barriers)

- ○ Yes
- ○ No
- ○ Unsure

What are the barriers which prevent you from using your preferred location?
(If applicable, please include both patient and carer barriers as well as service barriers)
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

Ongoing monitoring and optimisation

Please use the following definitions when answering the questions:

Lead role: *Your service takes on the lead role and does this by directly providing the support and care (e.g. setting up equipment, initiating medication prescriptions or monitoring effectiveness).*

Shared role: *Your service shares this role with another service and is involved in the decision-making and giving advice to patients and carers.*

Supporting role: *Your service has a supporting role (e.g. by communicating back to the other teams involved in MND care) but does not get involved in any management decisions.*

No role: *Your service has no role in this aspect of delivering NIV.*

Are you involved in monitoring patients on NIV?
(e.g. checking patient usage and identifying problems causing poor adherence and/or ineffective ventilation such as mask leaks etc.)

- ○ Yes
- ○ No

Are you involved in optimising NIV?
(e.g. rectifying issues causing poor adherence and/or ineffective ventilation such as adjusting mask straps or machine settings etc.)

- ○ Yes
- ○ No

Adherence targets

What is your usual role in setting adherence (number of hours used) targets?

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

How many hours per day (of using NIV) do you recommend patients aim for at the end of initiation?
[DROP DOWN 1-24]

Please consider the following scenarios:

Patient A: A 65-year-old male with weakness in both legs and arms but no problems with his speech, swallow or saliva.

Patient B: A 65-year-old male with no weakness in his limbs but poor speech and swallow and problems with drooling and thick chest secretions.

Which of the following adherence targets would you be your first preference and second preference for checking adherence to NIV for Patient A (no bulbar impairment)?

	Using NIV for more than 1 hour per day	Using NIV for more than 4 hours per day	Using NIV for more than 4 hours per night	Using NIV all night	Other (please specify below)
First preference	○	○	○	○	○
Second preference	○	○	○	○	○

If "other", please specify below:
[FREE TEXT RESPONSE]

Which of the following adherence targets would you be your first preference and second preference for checking adherence to NIV for Patient B (has bulbar impairment)?

	Using NIV for more than 1 hour per day	Using NIV for more than 4 hours per day	Using NIV for more than 4 hours per night	Using NIV all night	Other (please specify below)
First preference	○	○	○	○	○
Second preference	○	○	○	○	○

If "other", please specify below:
[FREE TEXT RESPONSE]

Do you have a regime you recommend patients try to increase their use (e.g. 1 hour in the first week, 2 hours in the second week)?

- ○ Yes
- ○ No

Please provide details of the regime you recommend:
[FREE TEXT RESPONSE]

Monitoring adherence

What is your usual role in monitoring NIV use and adherence to set targets?

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

How do you measure adherence?
(Please select all that apply)

- ○ Self-reported adherence
- ○ Diary
- ○ Tele-monitoring
- ○ Downloads from the NIV machine
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

From your experience, what factors promote good adherence to NIV?
(Please consider patient, carer and service factors)
[FREE TEXT RESPONSE]

From your experience, what reasons have you have identified for low adherence to NIV?
(Please consider patient, carer and service factors)
[FREE TEXT RESPONSE]

Improving adherence

What is your usual role in implementing solutions to improve adherence to NIV?

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

What solutions do you implement for poor adherence to NIV and in what circumstances are they used?
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

Monitoring effectiveness

What is your usual role in monitoring the effectiveness of NIV (how well the ventilation is working)?

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

What do you use to assess the effectiveness of the ventilation at the end of the initiation phase and at regular follow-ups? *(Please select all that apply)*

	Initiation phase	Regular follow-up
Self-reported symptoms (e.g. questionnaires or talking to patients)	○	○
Device recorded data (downloads from the machine)	○	○
Tele-monitoring	○	○
Oxygen and/or CO2 measurements	○	○
Continuous polysomnography (sleep study)	○	○
Other (please specify below)	○	○

If "other", please specify below:
[FREE TEXT RESPONSE]

If you use oxygen or CO2 measurements, which of the following do you use?

- ○ Daytime blood gas analysis
- ○ Night time blood gas analysis
- ○ Daytime pulse oximetry
- ○ Night time pulse oximetry
- ○ Daytime transcutaneous carbon dioxide monitoring
- ○ Night time transcutaneous carbon dioxide monitoring

From your experience, what factors promote effective ventilation?
[FREE TEXT RESPONSE]

From your experience, what factors act as barriers to effective ventilation?
[FREE TEXT RESPONSE]

Improving effectiveness

What is your usual role in implementing solutions for ineffective ventilation (ventilation that is not working well)?
(e.g. adjusting mask straps, pressure settings etc.)

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

What is your usual role in rectifying mask leaks?

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

What steps do you take to rectify mask leaks? *(Please select all that apply)*

- ○ Optimising mask fitting
- ○ Change the mask interface
- ○ Use a pressure-preset mode
- ○ Change other machine settings (please specify below)
- ○ Provide training for carers and patients about mask fitting and cleaning the interface
- ○ Communicating back to the respiratory team
- ○ Other (please specify below)

If "change other machine settings", please describe what you would change below:
[FREE TEXT RESPONSE]

If "other", please specify below:
[FREE TEXT RESPONSE]

What is your usual role in rectifying upper airway obstructive events?

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

What steps do you take to rectify upper airway obstructive events?
(Please select all that apply)

- ○ Increase expiratory positive airway pressure (EPAP)
- ○ Decrease inspiratory positive airway pressure (IPAP)
- ○ Reduce inspiratory time
- ○ Use an automated titrating mode
- ○ Use a volume-controlled mode
- ○ Admission for inpatient assessment
- ○ Change the mask interface
- ○ Trial a mandibular advancement device
- ○ Trial a cervical collar
- ○ Communicating back to the respiratory team
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

What is your usual role in rectifying patient-ventilator asynchronies?

- ○ Lead role
- ○ Shared role
- ○ Supporting role
- ○ No role

Please explain what you do to rectify patient-ventilator asynchronies?
[FREE TEXT RESPONSE]

What other solutions (which you have not already covered) do you implement for ineffective ventilation and in what circumstances are they used?
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

<u>Trouble-shooting</u>

Which of the following options do you have available for troubleshooting and improving adherence and/or effectiveness? *(Please select all that apply)*

- ○ Mouth piece
- ○ Nasal plasters
- ○ Psychological interventions
- ○ Inpatient assessment
- ○ Joint appointment with another HCP e.g. speech and language therapist
- ○ Heated humidifier
- ○ None of the above

- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

In what circumstances would the settings of the NIV machine be changed and how is this decided?
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

Withdrawal of NIV

Please use the following definitions when answering the questions:

Lead role: *Your service takes on the lead role and does this by directly providing the support and care (e.g. setting up equipment, initiating medication prescriptions or monitoring effectiveness).*

Shared role: *Your service shares this role with another service and is involved in the decision-making and giving advice to patients and carers.*

Supporting role: *Your service has a supporting role (e.g. by communicating back to the other teams involved in MND care) but does not get involved in any management decisions.*

No role: *Your service has no role in this aspect of delivering NIV.*

Use of invasive ventilation

How many patients with MND are currently using a tracheostomy in your service?
[FREE TEXT RESPONSE]

Is this figure exact or estimated?

- ○ Exact
- ○ Estimated

Discussing end of life care

What is your usual role in discussing end of life respiratory care with the patient and carer?

- ○ Lead role
- ○ Shared role

- ○ Supporting role
- ○ No role

At what time do discussions about end of life respiratory care typically begin?

(Please select all that apply)

- ○ At diagnosis.
- ○ After diagnosis but **before** onset of respiratory signs, symptoms or respiratory function tests.
- ○ When respiratory function tests show a decline in lung function but **before** the development of respiratory signs or symptoms.
- ○ At the development of respiratory signs or symptoms but **before** respiratory function tests show a decline.
- ○ At the development of respiratory signs or symptoms **and** respiratory function tests show a decline.
- ○ At the onset of respiratory failure.
- ○ When a patient is referred for NIV.
- ○ When a patient accepts or declines NIV.
- ○ When a patient is initiated on NIV.
- ○ When there is increased dependency on the ventilator.
- ○ When the patient asks to discuss end of life care.
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

When do discussions about end of life respiratory care <u>MOST COMMONLY</u> begin?

- ○ At diagnosis.
- ○ After diagnosis but **before** onset of respiratory signs, symptoms or respiratory function tests.
- ○ When respiratory function tests show a decline in lung function but **before** the development of respiratory signs or symptoms.
- ○ At the development of respiratory signs or symptoms but **before** respiratory function tests show a decline.
- ○ At the development of respiratory signs or symptoms **and** respiratory function tests show a decline.
- ○ At the onset of respiratory failure.
- ○ When a patient is referred for NIV.
- ○ When a patient accepts or declines NIV.

- ○ When a patient is initiated on NIV.
- ○ When there is increased dependency on the ventilator.
- ○ When the patient asks to discuss end of life care.
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

In your opinion, do you think discussion about end of life respiratory care typically begins...?

Very early	Early	At the right time	Late	Very late
○	○	○	○	○

Please explain why you have chosen that answer:
[FREE TEXT RESPONSE]

Have you ever been involved with a patient who was thinking of withdrawing or has withdrawn from NIV?

- ○ Yes
- ○ No

<u>Patient and carer support</u>

Do you provide any information, counselling, or any other support for patients, family members and carers when discussions about the withdrawal of NIV begin?

- ○ Yes
- ○ No, but we refer patients to another service
- ○ No, and we do not refer patients to another service

If you refer to another service, please specify who you refer the patient and carer to below:
[FREE TEXT RESPONSE]

Which of the following types of support do you typically provide for patents and carers when discussions about the withdrawal of NIV begin?

(Please select all that apply)

- ○ Discussions with the patient, family members and carers
- ○ Offer reassurance to patients, family members and carers
- ○ Refer to palliative care services
- ○ Directed to the MyNIV website
- ○ Directed to the Motor Neurone Disease Association website

- ○ Pamphlets or leaflets
- ○ Directed to other online resources
- ○ Other (please specify below)
- ○ **N/A** - This is not part of my role

If "other", please specify below:
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

Decision to withdraw NIV

Have you experienced any problems and/or barriers to withdrawing NIV?
- ○ Yes
- ○ No
- ○ Unsure

What are the barriers to withdrawing NIV?
[FREE TEXT RESPONSE]

In your experience, are there any enablers to withdrawing NIV?
- ○ Yes
- ○ No
- ○ Unsure

What are the enablers to withdrawing NIV?
[FREE TEXT RESPONSE]

Do you refer patients with MND on NIV to palliative care services?
- ○ Yes
- ○ No

In your opinion, do you think patients are referred to palliative services...?

Very early	Early	At the right time	Late	Very late
○	○	○	○	○

Please explain why you have chosen that answer:
[FREE TEXT RESPONSE]

Additional comments:
[FREE TEXT RESPONSE]

NIV guidelines and pathways

Do you follow any guidelines, information sheets, pathways or protocols for recommending, delivering and supporting NIV use and withdrawing NIV in patients with MND? *(This includes those for starting NIV, monitoring NIV and stopping NIV)*

- ○ Yes
- ○ No

Please can you provide details of those you follow below:
[FREE TEXT RESPONSE]

Support for staff

Have you completed any specific training or courses relating to MND and/or NIV? *(e.g. a degree in respiratory care, training on delivering NIV as part of your role etc.)*

- ○ Yes
- ○ No

Please give details of the training and/or course(s) you have completed:
(Please state whether or not the training or course was part of your standard role at work)
[FREE TEXT RESPONSE]

Confidence before starting and when initiating NIV

How confident are you…?

	Extremely confident	Very confident	Moderately confident	Slightly confident	Not at all confident	**N/A** - This is not part of my role
Identifying signs and symptoms of respiratory insufficiency	○	○	○	○	○	○
Talking to patients and carers about the potential need for NIV	○	○	○	○	○	○
Deciding to recommend a trial of NIV	○	○	○	○	○	○

	Extremely confident	Very confident	Moderately confident	Slightly confident	Not at all confident	**N/A** - This is not part of my role
Talking about what using NIV will involve	○	○	○	○	○	○

Providing support or training to patients and carers starting NIV	○	○	○	○	○	○
Setting up NIV (e.g. deciding on equipment, settings etc.)	○	○	○	○	○	○

Confidence during the monitoring and withdrawal of NIV

How confident are you…?

	Extremely confident	Very confident	Moderately confident	Slightly confident	Not at all confident	**N/A** - This is not part of my role
Monitoring for problems with adherence	○	○	○	○	○	○
Monitoring for problems or barriers preventing the effectiveness of NIV	○	○	○	○	○	○
Implementing solutions to poor adherence	○	○	○	○	○	○
Implementing solutions for ineffective ventilation	○	○	○	○	○	○
Monitoring and adjusting NIV mode and settings for optimising effectiveness	○	○	○	○	○	○

	Extremely confident	Very confident	Moderately confident	Slightly confident	Not at all confident	**N/A** - This is not part of my role
Talking about problems causing poor adherence and/or ineffective ventilation	○	○	○	○	○	○
Talking about the patient's progression	○	○	○	○	○	○
Talking about the withdrawal of NIV	○	○	○	○	○	○
Planning for withdrawal of NIV (e.g. date, time, location etc.)	○	○	○	○	○	○
Conducting the withdrawal of NIV	○	○	○	○	○	○

Learning

Would you be interested in learning more about NIV in MND?

- ○ Yes
- ○ No

Which topics would you like to know more about?

- ○ Identifying respiratory insufficiency and/or discussing NIV with patients
- ○ Setting up NIV
- ○ Monitoring and optimisation of NIV
- ○ Withdrawal of NIV

What formats for learning would you prefer?
(Please select all that apply)

- ○ Website
- ○ Mobile app
- ○ E-learning
- ○ Masterclass
- ○ Journal article
- ○ Pamphlet
- ○ Other (please specify below)

If "other", please specify below:
[FREE TEXT RESPONSE]

How long would you devote to learning?

- ○ 30 minutes
- ○ 1 hour
- ○ ½ a day
- ○ A full day (9am-5pm)
- ○ More than one day
- ○ Other (please specify below)

If other, please specify below:
[FREE TEXT RESPONSE]

Just a couple more questions…

We understand that not everyone's role or practice fits into our survey. If you have any comments about this please make them below:
[FREE TEXT RESPONSE]

I would be happy for you to contact me if you identify an area of good practice in my answers which you would like to find out more about or to clarify something important?

- ○ Yes
- ○ No

I would be interested in hearing about the future phases of the project?

- ○ Yes
- ○ No

I would be interested in being invited to take part in a questionnaire about cough augmentation in MND?

- ○ Yes
- ○ No

Because you have selected "Yes" to one of the above questions, do you give us permission to collect your contact details and store them with your responses?

(Your identity will not be identifiable in any of the reports)

- ○ Yes
- ○ No

Please provide your contact details below:

Name – [FREE TEXT RESPONSE]

Email – [FREE TEXT RESPONSE]

Would you like to enter the prize draw for the chance to win one of two £50 prizes?

(You will be redirected to a separate page in order to enter your contact details)

- ○ Yes
- ○ No

In order to enter the prize draw, please can you provide us with your contact details below:

(Please note that unless you have specified that you are happy for us to contact you in the future, then the contact details you enter here will NOT be stored with your responses)

Name – [FREE TEXT RESPONSE]
Email – [FREE TEXT RESPONSE]

If you are happy to submit your responses, please click on the button <u>BELOW.</u>

(You will not be able to go back and change any of your responses once your responses are submitted).