

This is a repository copy of How healthcare professionals support cough and secretion management in amyotrophic lateral sclerosis (ALS): a UK national survey.

White Rose Research Online URL for this paper: <u>https://eprints.whiterose.ac.uk/228968/</u>

Version: Published Version

### Article:

Massey, C. orcid.org/0000-0003-2646-2724, Griffiths, A.W., McDermott, C. orcid.org/0000-0002-1269-9053 et al. (1 more author) (2025) How healthcare professionals support cough and secretion management in amyotrophic lateral sclerosis (ALS): a UK national survey. Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration. ISSN 2167-8421

https://doi.org/10.1080/21678421.2025.2522401

#### Reuse

This article is distributed under the terms of the Creative Commons Attribution (CC BY) licence. This licence allows you to distribute, remix, tweak, and build upon the work, even commercially, as long as you credit the authors for the original work. More information and the full terms of the licence here: https://creativecommons.org/licenses/

### Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.







**Amyotrophic Lateral Sclerosis and Frontotemporal** Degeneration

ISSN: 2167-8421 (Print) 2167-9223 (Online) Journal homepage: www.tandfonline.com/journals/iafd20

# How healthcare professionals support cough and secretion management in amyotrophic lateral sclerosis (ALS): a UK national survey

Charlotte Massey, Alys Wyn Griffiths, Christopher McDermott & Esther Hobson

To cite this article: Charlotte Massey, Alys Wyn Griffiths, Christopher McDermott & Esther Hobson (25 Jun 2025): How healthcare professionals support cough and secretion management in amyotrophic lateral sclerosis (ALS): a UK national survey, Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, DOI: 10.1080/21678421.2025.2522401

To link to this article: https://doi.org/10.1080/21678421.2025.2522401

© 2025 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



View supplementary material



Published online: 25 Jun 2025.



🖉 Submit your article to this journal 🗷

Article views: 227



View related articles 🗹

View Crossmark data 🗹

Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration, 2025; 0: 1-12



#### **RESEARCH ARTICLE**

## How healthcare professionals support cough and secretion management in amyotrophic lateral sclerosis (ALS): a UK national survey

# CHARLOTTE MASSEY<sup>1,2</sup> , ALYS WYN GRIFFITHS<sup>1</sup>, CHRISTOPHER MCDERMOTT<sup>1,2</sup> & ESTHER HOBSON<sup>1,2</sup>

<sup>1</sup>Sheffield Institute for Translational Neuroscience, University of Sheffield, Sheffield, UK and <sup>2</sup>Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

#### Abstract

*Objective*: To understand the practices of healthcare professionals supporting people with Amyotrophic Lateral Sclerosis (ALS) to manage cough and secretion issues. This includes utilization of and confidence in assessment and treatment techniques and barriers and enablers of care. *Methods*: An online cross-sectional survey was distributed to UK healthcare professionals involved in cough and/or secretion management care in people with ALS. *Results*: A total of 113 responses were analyzed, over half were from physiotherapists (52%). The majority (71%) of respondents reported a role managing saliva and secretions. Just under two thirds (60%) routinely assessed cough and almost all (89%) routinely assessed secretions. Healthcare professionals reported reduced confidence assessing secretions compared with cough and very few (5%) used validated secretion outcome measures. Participants reported lower confidence implementing all treatment strategies than recommending them. Multiple barriers to care were identified, including access to specialist care and equipment, education and skills training and a lack of evidence-based care guidelines. *Conclusion*: Cough and secretion management is complex and involves numerous professional groups. There is a need for clinical and educational interventions that address knowledge and skill gaps in managing cough and secretion issues, which will help increase healthcare professionals' confidence in assessing and treating these complex problems.

Keywords: Motor neuron disease, Amyotrophic Lateral Sclerosis, cough, secretion management, sialorrhoea, multidisciplinary care

#### Introduction

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive neurodegenerative condition characterized by the degeneration of both upper and lower motor neurons. Currently, there is no cure for ALS, and available interventions primarily aim to mitigate the progressive loss of motor, respiratory, and swallowing functions, and support quality of life. However, these interventions have only a limited impact on prolonging survival (1,2). The primary causes of respiratory dysfunction in ALS include the progressive decline in ventilatory capacity (2), the loss of ability to effectively clear secretions through coughing (3), and the increased risk of aspiration due to impaired swallowing (4). Up to 70% of individuals with ALS will experience problems with saliva and respiratory secretions (5). Cough and secretion issues significantly impact quality of life (6) and cause mortality and morbidity due to pneumonia (7).

Cough management in ALS can be described as the treatment of respiratory and bulbar impairments which impact cough strength and effectiveness. This includes airway clearance strategies, both proximal (cough augmentation) and peripheral (secretion mobilising) (8), and pharmacological support. Secretion management covers a breadth of treatments including treatment of oral sialorrhoea to treatment of viscous pulmonary secretions. Table 1 shows an overview of cough and secretion management techniques in ALS (9–14).

Correspondence: Charlotte Massey, Division of Neuroscience, 385a Glossop Road, Sheffield, S10 2HQ, UK. E-mail: c.massey@sheffield.ac.uk Supplemental data for this article can be accessed online at https://doi.org/10.1080/21678421.2025.2522401.

(Received 27 January 2025; revised 9 June 2025; accepted 15 June 2025)

ISSN 2167-8421 print/ISSN 2167-9223 online © 2025 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent. DOI: 10.1080/21678421.2025.2522401

#### 2 C. Massey et al.

Category	Sub-category	Technique
Airway clearance techniques	Proximal airway clearance techniques	Manually assisted cough
	(cough augmentation)	Lung volume recruitment techniques
		Mechanical Insufflation-Exsufflation (MI-E)
	Peripheral airway clearance (sputum	Manual techniques
	mobilisation)	High frequency chest wall oscillation (HFCWO)
Secretion management	Evaluation of swallowing and secretions	Symptom severity scores
		Video fluoroscopic assessment of swallowing
		Fiberoptic evaluation of swallow and secretions
	Pharmacotherapy	Anticholinergics
		Botulinum Toxin
		Radiotherapy

Table 1. Overview of cough and secretion management techniques in ALS (9-12).

Note: Table adapted and modified from McHenry et al. (2024) and Sheers, Andersen and Chatwin (2024).



Figure 1. The core ALS multidisciplinary team and their main roles in the UK. Adapted from MND Association community of practice (2023). ALS = Amyotrophic Lateral Sclerosis

There is limited evidence to guide clinicians on how to assess, provide and optimize cough and secretion management in ALS (13). Most existing guidelines rely on low quality evidence or expert consensus and give limited recommendations on how to assess secretions, saliva and cough to inform treatment (11,12,14). Multidisciplinary (MDT) care enhances both survival rates and quality of life in individuals with ALS (6,15,16). However, the challenges associated with delivering such care and facilitating complex decision-making in this context have been highlighted (17,18).

The setup of ALS multidisciplinary teams varies between and within countries depending on funding and national guidelines, although guidelines for care across countries are similar (11-14). In 2023 the UK Motor Neurone Association (MNDA) professionals' community of practice (19) identified the core members of the UK ALS multidisciplinary team and their main roles (Figure 1). There is limited information around how healthcare professionals support people living with ALS to manage cough and secretion issues. Our study aimed to explore the assessment and treatment techniques utilized by healthcare professionals, their confidence using them, and perceived barriers and enablers of care.

#### Materials and methods

#### Study design

A cross-sectional online survey was used to explore the clinical practices of UK healthcare professionals delivering cough and secretion management care to people with ALS. Reporting follows the CHERRIES checklist for reporting esurveys (20) (Supplementary data 1).

Survey design was informed by our recent literature review, using evidence-based concepts to design the questions and themes (21,22). The survey was piloted by seven healthcare professionals from three NHS Trusts. The survey was hosted on Qualtrics and utilized open and closed questions to gain insight into participants' self-reported skills and confidence in assessment and treatment techniques using the following scale which was adapted based on the principles of mastery and recent research on HCP confidence (23).

- Novice: Unaware of the process
- **Knows about:** Some awareness but managed by others
- Knows how: Can do but with support
- **Independent:** May get help with more difficult cases
- Master: Teaches/supervises others
- **Expert:** Leading national/international expert
- Not part of my job

Participants were also asked to self-report how often they completed assessment and treatment strategies within their daily roles using a likert scale ranging from "I frequently have to complete this" to "I would never have to complete this."

The survey used branching logic to ensure that participants only answered the questions relevant to their situation, based on their previous responses, therefore each question had different numbers of respondents. This is reported as (n=)in the text, tables and figures. All UK healthcare professionals who self-identified as being involved in cough and secretion management in ALS were eligible. Participants were recruited using social media, charity partners and special interest groups. The survey was open between August and October 2023. Participants provided informed consent before completing the survey. Participants were given reminders via Qualtrics after two weeks if the survey was started but remained unfinished. The study received ethical approval from University of Sheffield ethics panel (ref: 053871).

#### Analysis

Demographic data were collected to allow comparisons between different professional groups and specialities. Descriptive statistics were conducted using IBM SPSS statistics (v28.0.0.0). Subgroup analysis of the largest three professional groups was performed: physiotherapists, speech and language therapists and nurses. Cross tabulations were used to identify differences between professional groups and specialities. For analysis of confidence, independent, master and expert were grouped together to show those healthcare professionals who were able to complete this task independently on a day-to-day basis with no support. A Spearman correlation coefficient was used to assess correlations between confidence levels and frequency of task completion as the data were not normally distributed. Thematic analysis was used to analyze responses to open text questions (24). A Mann-Whitney U test was completed to determine any differences in confidence between specialists (defined as participants who work in a specialists ALS or respiratory center) and non-specialists.

#### Results

The survey received 123 responses. After removal of non-completions 113 responses were analyzed.

#### Participant characteristics

Over half (52%) of the 113 respondents to the survey were physiotherapists, with speech and language therapists (31%) the second largest group. The majority (74%) of participants completing the survey had over 5 years' experience working with people with ALS. See Table 2 for a full overview. There was a spread of roles in cough and secretion management, with the majority (71%) stating that they had a role in assessment of saliva (Figure 2).

#### Current practice

**Cough assessment.** Sixty percent of participants assessed cough as part of their routine assessment, using the following assessment techniques; report of chest infection history (96%), patient report of cough effectiveness (91%) and audible assessment (88%), and peak cough flow (72%) (Figure 3). Cough assessment was mostly led by respiratory or ALS/Neuromuscular specialist physiotherapists (Figure 4). Eighty-eight percent of physiotherapists routinely assessed cough compared to 44% of other healthcare professionals.

**Secretion assessment.** Most participants (89%) routinely assessed secretions and of these, all participants reported using patient reporting of secretions in their assessment. Similar to cough assessment, observation (92%) and history of chest infections (87%) were the most frequently reported forms of assessment (Figure 3). Very few participants used any patient reported outcomes in their assessment (25–27). Secretion assessment was led by a range of professionals (Figure 4).

# Healthcare professional confidence in assessment and treatment strategies

Assessment (n = 75 respondents). For those who reported that performing a peak cough flow (PCF) was part of their job (79%), more than half

#### 4 C. Massey et al.

#### Table 2. Participant demographics.

Characteristic		Total N (%)	PT N (%)	SLT N (%)	Nurse N (%)
Profession $(n=113)$	Physiotherapist (PT)	59 (52)			
	Speech and Language therapist (SLT)	35 (31)			
	Nurse	9 (8)			
	MND coordinator	1 (1)			
	Neurologist	1 (1)			
	Other	8 (7)			
Years working with people with ALS $(n=95)$	Less than a year	4 (4)	1 (2)	1 (3)	2 (25)
	1–2 years	6 (6)	2 (4)	3 (12)	0 (0)
	3–4 years	15 (16)	9 (16)	3 (12)	2 (25)
	5–10 years	33 (35)	19 (38)	10 (39)	2 (25)
	11–15 years	16 (17)	10 (19)	3 (11)	0 (0)
	16 years +	21 (22)	11 (21)	6 (23)	2 (25)
Specialty $(n = 110)$	Respiratory	40 (36)	32 (54)	2 (6)	3 (32)
	Neuromuscular (NMD)	13 (12)	9 (16)	4 (12)	0 (0)
	ALS	16 (14)	5 (8)	4 (12)	4 (44)
	Long term conditions	14 (12)	4 (7)	9 (27)	1 (12)
	Palliative care	5 (4)	0 (0)	1 (3)	1 (12)
	Generalist	8 (7)	5 (8)	3 (9)	0 (0)
	Other	14 (13)	4 (7)	10 (31)	0 (0)
Main place of work $(n = 96)$	Specialist ALS care center	15 (16)	4 (7)	4 (15)	4 (50)
	Specialist respiratory center	24 (25)	17 (32)	3 (12)	2 (25)
	General Hospital – Respiratory	12 (12)	12 (24)	0 (0)	0 (0)
	General Hospital – Neuro	3 (3)	3 (6)	0 (0)	0 (0)
	General Hospital – Generalist	17 (18)	5 (9)	11 (42)	1 (12.5)
	Community – Neurology specialist	8 (8)	3 (6)	5 (18)	0 (0)
	Community – Generalist	4 (4)	3 (6)	1 (4)	0 (0)
	Hospice	12 (13)	5 (9)	2 (9)	1 (12.5)
	Other	1 (1)	1 (1)	0 (0)	0 (0)
Number of people with ALS	0	4 (4)	4 (8)	0 (0)	0 (0)
within service currently $(n = 95)$	1-9	31 (33)	18 (34)	10 (38)	2 (25)
······································	10-49	29 (31)	13 (24)	12 (46)	1(12.5)
	50-99	11 (12)	7 (13)	1 (4)	2 (25)
	100+	20 (20)	10 (21)	3 (12)	3 (37.5)

Abbreviations: MND = Motor Neuron Disease, NMD = Neuromuscular disease, PT = physiotherapist, SLT = Speech and language therapist.

(59%) reported their confidence as independent, master or expert (Figure 5). Overall confidence in performing subjective assessments (history, audible assessment and impact of bulbar impairment on assessment) was higher than performing objective measures (PCF and spirometry). Very few (<10%) rated themselves as a novice in any assessments relating to cough assessment. Most of these participants (80%) rated themselves as independent (44%), master (24%) or expert (12%) in using observation of saliva and secretions in their assessment. However, use of patient reported outcome measures showed much less confidence with around 50% of participants rating themselves as a novice for CSS-MNS (52%), CNS-BFS (49%) and OSS (49%).

Data were analyzed for the three largest professional groups – physiotherapists, speech therapists and nurses (Table 3). Physiotherapists and speech therapists rated themselves as confident (i.e. independent, master, or expert) to take a history of cough and secretions (98% and 76% respectively) and assess the impact of bulbar function on cough assessment (73% and 76%). Only a minority of nurses (11%) reported confidence assessing the impact of bulbar impairment on cough. Almost all physiotherapists (90%) rated themselves as confident to assess PCF, compared to only 5% of speech therapists and no nurses. All professions reported being less confident completing patient reported outcomes of saliva and secretions. Speech therapists reported more confidence performing these than physiotherapists.

**Recommending treatment strategies (n = 76 respondents).** Participants showed more confidence recommending cough strategies than secretion management strategies. Where it was part of their role, most participants (>65%) rated themselves as independent, master or expert when recommending most cough treatment strategies except Lung volume recruitment (LVR) (51%). Participants felt much less confident recommending Botox (39%) or reflux advice (39%).



#### Main roles caring for people with ALS (n=96)

Figure 2. Healthcare professional's main roles caring for people with ALS. Roles were selected from a closed list of options and participants were able to choose more than one option. NIV = noninvasive ventilation. N=96 shows the number of participants who answered this question.



Figure 3. Utilization of cough and secretion assessment techniques. Branching question following question asking if they performed cough and secretion assessment therefore there are different n numbers. MIP/MEP = Maximal inspiratory pressure/maximal expiratory pressure, ALSFRS-R = Revised Amyotrophic Lateral Sclerosis Functional Rating Scale. N= shows the number of participants who answered this question.



Figure 4. Professionals who lead cough and secretion assessment. PT = physiotherapist, MND = Motor Neuron Disease, NMD = Neuromuscular Disease, SLT = Speech and language therapist, GP = General Practitioner. N = shows the number of participants who answered this question.

**Implementing treatment strategies (n = 76 respondents).** Participants felt less confident implementing treatment strategies than recommending them and there was greater confidence implementing cough management strategies. Secretion management strategies showed much less confidence to implement.

#### Relationship between healthcare professional confidence and frequency of performance

Assessment (n = 74 respondents). Eight assessment techniques showed a significant correlation between healthcare professionals' confidence and how frequently they performed this task (figure 6 and supplementary data 3). Three techniques showed non-significant correlations; these were all specific skills that required additional training to perform: peak cough flow, spirometry and nasendoscopy. When this data were analyzed by the two largest professional groups, different patterns emerged. In the physiotherapy group there were significant correlations between confidence and frequency for all cough assessments except spirometry; however, in the speech therapy group only taking a history (p = 0.046) and impact of bulbar function on cough (p = 0.004) showed a significant correlation between confidence and frequency of task performance. In the physiotherapy group only observation of secretions showed a significant correlation (p = 0.006) whereas the speech therapy

group showed significant correlations for use of saliva validated outcome measures.

**Treatment** (n = 74 respondents). Only three treatment strategies showed significant correlation between confidence and how frequently the task was performed (supplementary data 3); these were advice on posture and positioning (p < 0.001), suction (p = 0.011) and swallowing advice (p = 0.045). Again, there were differences when physiotherapists and speech therapists were analyzed separately. There were no significant correlations for treatment techniques in the speech therapy group except for swallowing advice which showed a negative correlation of -1. In the physiotherapy group there were significant correlations for posture and positioning (p = 0.008),breath stacking (p = 0.048), Lung volume recruitment (p = 0.005), cough assist (p = 0.017) and suction (p = 0.006). There were no significant differences between confidence of specialists (n=22) and non-specialists (n=40) except for provision of cough assists (p = 0.046) (Supplementary data 6).

# Barriers and enablers to effective cough and secretion management

Participants were asked free text questions to identify barriers and enablers to effective care (Table 4 and Supplementary data 7).

#### Confidence performing assessment (n=75)



Confidence recommending treatment strategies (n=76)

Confidence implementing treatment strategies (n=76)



Figure 5. Pyramid plots showing self-reported confidence performing assessment, recommending treatment and implementing treatment strategies. Results presented are from those participants who stated that this task was part of their job, therefore n numbers are different for each task. CSS-MND = Clinical saliva scale MND, CNS-BFS = Center for Neurological Study-Bulbar function scale, ALSFRS-R = Revised Amyotrophic Lateral Sclerosis Functional Rating Scale, OSS = Oral secretion scale, ACBT = active cycle of breathing technique, LVR = Lung volume recruitment. N = shows the number of participants who answered this question.

#### 8 C. Massey et al.

Table 3. Confidence performing cough and secretion assessments by profession.

	Physiotherapist $(n = 41)$		Speech therapist $(n=21)$		Nurse $(n = 6)$	
	N (%) independent, master or expert	N (%) not part of my job	N (%) independent, master and expert	N (%) not part of my job	N (%) independent, master and expert	N ( <b>%</b> ) not part of my job
Peak cough flow	37 (90)	1 (2)	1 (5)	12 (57)	0 (0)	2 (22)
Spirometry	20 (51)	7 (18)	1 (5)	14 (67)	2 (22)	2 (22)
Taking a history	40 (98)	0 (0)	16 (76)	0 (0)	4 (44)	0 (0)
Audible assessment of cough	37 (93)	0 (0)	12 (57)	1 (5)	2 (22)	1 (11)
Impact of bulbar assessment on cough	30 (73)	1 (2)	16 (76)	0 (0)	1 (11)	1 (11)
Observation of saliva and secretions	34 (83)	1 (2)	18 (86)	0 (0)	4 (44)	0 (0)
Nasendoscope assessment	0 (0)	22 (54)	8 (38)	6 (27)	0 (0)	3 (33)
CSS-MND	3 (7)	6 (15)	5 (25)	0 (0)	1 (11)	1 (11)
CNS-BFS	1 (2)	6 (15)	4 (19)	0 (0)	0 (0)	1 (11)
ALSFRS	7 (17)	5 (12)	4 (19)	0 (0)	1 (11)	2 (22)
OSS	1 (2)	6 (15)	5 (24)	0 (0)	0 (0)	1 (11)

Abbreviations: CSS-MND = Clinical saliva scale MND, CNS-BFS = Center for Neurological Study-Bulbar function scale, ALSFRS-R = Revised Amyotrophic Lateral Sclerosis Functional Rating Scale, OSS = Oral secretion scale.



Figure 6. Frequency assessment and treatment tasks were performed for all participants. PCF = peak cough flow, CSS-MND = Clinical saliva scale MND, CNS-BFS = Center for Neurological Study-Bulbar function scale, ALSFRS-R = Revised Amyotrophic Lateral Sclerosis Functional Rating Scale, OSS = Oral secretion scale, ACBT = active cycle of breathing technique, LVR = Lung volume recruitment, MI-E = Mechanical insufflation-exsufflation. N = shows the number of participants who answered this question.

Barriers included limited access to specialist MDT care and staff with specialist knowledge and skills, both in hospital and at home.

Lack of a broad skill set among those frequently assessing, and lack of access to specialist clinics (Physiotherapist 27)

Many also noted issues with access to equipment and pharmaceutical support, which included specialist prescribing knowledge and access to drugs. Challenges included the commissioning to provide and follow up equipment, as well as training for patients and caregivers. The complexity of ALS, especially the interaction between bulbar issues and cough problems, was emphasized. A lack of research and evidencebased care guidelines was a recurring concern, with participants stressing the need for more research to improve care practices.

Key enablers to effective care included access to multidisciplinary teams, timely assessments, and staff with a solid knowledge base supported by education. Many responses highlighted the importance of having the right professional available at the right time and emphasized a "*team approach*" with good communication and strong working relationships.

B	arriers	Enablers		
Theme	Subtheme	Theme	Sub theme	
Resources	Local resources Funding	Timely assessment and intervention	Reviews of treatment efficacy Access to specialist services	
	Caregivers	Carer involvement	Education and upskilling of carers	
	Access to specialist care		Carers provide support for day-to-day interventions	
	Access to equipment	Joined up working	Community and acute services working together	
Evidence based research	Lack of evidence-based guidelines		Using an interdisciplinary approach	
Knowledge base and skills	Management of bulbar issues Thick versus thin secretions	Education, knowledge and skills	Access to specialist knowledge Access to education to increase knowledge and develop skills	
	Pharyngeal vs chest secretions		Time for healthcare professionals to attend education and develop new skills	
Multidisciplinary work and	Expectations of care			
communication	Overlapping assessments by different professionals			
	Communications between different institutions and professionals			
	Understanding each other's roles			

Table 4. Barriers and enablers to care.

Early intervention with joint assessment by physio and SLT... We triaged every MND patient with full respiratory review, followed by physio, SLT, and dietetic input. This approach worked incredibly well (Speech therapist 10)

Timely intervention and access to ongoing education for healthcare professionals were consistently highlighted, with an emphasis on improving knowledge through skill-sharing forums to enhance care.

#### Discussion

This survey explored delivery of cough and secretion care for people with ALS. It demonstrates the challenges faced by healthcare professionals managing cough and secretion issues and has highlighted barriers and enablers to care, areas for improvement, and identified the need for further research. This study captures the number of different healthcare professional groups, working within a range of specialities, involved in cough and secretion management in ALS.

#### Assessment

Physiotherapists were most likely to report that they led cough assessment, but no single professional takes the lead on secretion assessment. This may be due to lower confidence in secretion assessment techniques identified in this survey or because secretion management requires a multidisciplinary approach. Subjective techniques such as taking a history and observation were associated with greater confidence levels than objective assessments, such as peak cough flow. It could be hypothesized that these soft skills are transferable between numerous different disease groups whereas specific cough and secretion outcome measures may require disease specific competencies.

#### Treatment

Amongst all professional groups there was less confidence implementing treatment strategies than recommending them. This would suggest that healthcare professionals have the knowledge of treatment techniques but may lack the clinical skills to be able to implement treatment strategies (5,28) which has been highlighted as one of the main barriers to delivering effective ALS MDT care (29). A clear example of this within the survey is Botulinum Toxin (Botox), with 40% reporting confidence to independently recommend and only 8% reporting confidence to independently administer it. To prevent this having a negative impact on care, the appropriate organizational resources to support communication of this need and access to it in a timely way is important. The complex interplay of swallow, cough, respiratory care and nutritional support means that each member of the MDT contributes discrete knowledge to support collective decision making around secretion management treatment options (18) highlighted by the qualitative responses of participants. However, this approach needs clear lines of communication, understanding of each other's roles and the knowledge and skills to be able to implement appropriate treatment options and without this shared understanding of the goal, effective and timely management may be hindered. There were no differences between the frequency and confidence of specialists and non-specialists performing assessment and/or treatment tasks which was surprising. This could have been due to how we defined a specialist as a professional who worked within a specialist ALS or respiratory service.

#### Multidisciplinary/interdisciplinary working

The value of multidisciplinary or interdisciplinary care was consistently highlighted and the analysis of this survey poses numerous questions around role, responsibilities and upskilling. Although the results show divided roles, with physiotherapists tending to focus on cough and speech therapists focusing on secretion and saliva management, it could be argued that both skill sets are needed to provide effective care. This is being implemented in specialist clinics, where speech therapists and physiotherapists sit together (30,31) and was highlighted by several respondents. These interdisciplinary care models appear to work well when staff are co-located within the same team, site or institution but are more challenging when professionals are spread geographically, highlighting the need for technology to support collaborative working (32). How to support these care models and staff upskilling to improve cough and secretion management care are questions that remain unanswered and require further research.

#### Validated secretion outcome measures

Participants reported a lack of confidence and use of secretion rating scales. Around 50% rated themselves as novices for all secretion rating scales with very few rating themselves as confident to independently implement these. The reasons for this are unclear in the survey data and further qualitative research will be undertaken to explore this. It has been previously reported that approximately half of people with ALS with secretion issues, despite treatment, are still experiencing symptoms which impact their quality of life (28). How treatments are monitored in routine clinical practice without the use of validated secretion rating scales should be explored further. Validated outcome measures to support effective communication about secretion severity between team members are important for improving secretion management in this patient group, supporting interdisciplinary collaboration. They can also be used to measure the effectiveness of secretion management interventions.

#### Barriers to care

The survey identified several barriers to the management of cough and secretion issues. The complexity of care networks which span acute, primary and palliative care being delivered across numerous organizations and settings was highlighted as a key barrier to effective care delivery. The lack of robust evidence and clinical guidelines was acknowledged as a barrier to effective care. Participants reported using non-evidence-based local guidance meaning that care is not consistent throughout the healthcare system, making it harder to work together toward a common treatment goal. The rapid multisystem deterioration (e.g. bulbar, respiratory, trunk, and limbs), and how these systems are interlinked, makes managing cough and secretion issues particularly challenging. Respondents noted that availability of specialist education, advice and support was one of the biggest enablers to care, reflecting much of the literature describing the challenges of managing complex health conditions such as ALS (29,33,34). The survey results highlight a need for education to address knowledge and skill gaps in managing cough and secretion issues, which will help increase healthcare professionals' confidence in assessing and treating these complex problems.

#### Strengths and limitations

There were a high number of physiotherapist participants, possibly due to physiotherapists' involvement in managing cough and secretion issues in ALS, or the lead researcher's background as a physiotherapist. This may have influenced recruitment through social media. Few medical professio-Most nals participated. participants were experienced, with over half having more than five vears of experience with ALS, indicating that less experienced healthcare professionals' perspectives may have been underrepresented. This may have impacted data around confidence and reduced generalizability. As with any survey methodology, all answers are self-reported, and participants may document what they think their practice should be rather than what it actually is. This study presents data from the UK, but these recommendations have applicability internationally, in a wide range of healthcare services. Further research should conduct similar surveys to establish consistency and areas of divergence.

#### Conclusion

Numerous barriers and challenges exist in cough and secretion management in ALS. Healthcare professionals report low confidence in both assessing and treating secretion and saliva management using validated tools and access to specialist care and associated specialist equipment remains variable. Healthcare professionals emphasized the importance of education, skill acquisition and greater research into this area to support practice. Therefore, clinical training needs to focus on educational clinical tools to improve knowledge and skill acquisition and interdisciplinary working. Future research needs to evaluate the use of such interventions within clinical practice to develop and implement best practice models.

#### Acknowledgement

The authors would like to acknowledge all the participants who piloted and completed the survey.

#### **Declaration of interest**

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

#### Funding

This study was funded as part of "Better Outcomes for patients living with Motor Neuron disease" Research Professorship by the National Institute for Health and Care Research (Award ID: NIHR301648) awarded to Professor McDermott. The views expressed in this publication are those of the authors and not necessarily those of the NIHR, NHS, or the UK Department of Health and Social Care.

#### ORCID

Charlotte Massey D http://orcid.org/0000-0003-2646-2724 Christopher McDermott D http://orcid.org/0000-0002-1269-9053

### Data availability statement

The participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data is not available.

#### References

1. Georgoulopoulou E, Fini N, Vinceti M, Monelli M, Vacondio P, Bianconi G, et al. The impact of clinical factors, riluzole and therapeutic interventions on ALS survival: a population based study in Modena, Italy. Amyotroph Lateral Scler Frontotemporal Degener. 2013; 14:338–45.

- Bourke SC, Tomlinson M, Williams TL, Bullock RE, Shaw PJ, Gibson GJ, 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;5:140–7.
- Sancho J, Bures E, de La Asunción S, Servera E. Effect of high-frequency oscillations on cough peak flows generated by mechanical in-exsufflation in medically stable subjects with amyotrophic lateral sclerosis. Respir Care. 2016;61: 1051–8.
- 4. Bach J. Air stacking for cough assistance. Muscle Nerve. 2004;30:680–1; author reply 681.
- Pearson I, Glasmacher SA, Newton J, Beswick E, Mehta AR, Davenport R, et al. The Prevalence and management of saliva problems in motor neuron disease: a 4-Year analysis of the scottish motor neuron disease register. Neurodegener Dis. 2020;20:147–52.
- Hobson EV, McDermott CJ. Supportive and symptomatic management of amyotrophic lateral sclerosis. Nat Rev Neurol. 2016;12:526–38.
- Sancho J, Martínez D, Bures E, Díaz JL, Ponz A, Servera E, et al. Bulbar impairment score and survival of stable amyotrophic lateral sclerosis patients after noninvasive ventilation initiation. ERJ Open Res. 2018;4:00159-2017.
- Chatwin M, Toussaint M, Gonçalves MR, Sheers N, Mellies U, Gonzales-Bermejo J, et al. Airway clearance techniques in neuromuscular disorders: a state of the art review. Respir Med. 2018;136:98–110.
- McHenry KL. Airway clearance strategies and secretion management in amyotrophic lateral sclerosis. Respir Care. 2024;69:227–37.
- Sheers NL, Andersen T, Chatwin M. Airway clearance in neuromuscular disease. Sleep Med Clin. 2024;19:485–96.
- Khan A, Frazer-Green L, Amin R, Wolfe L, Faulkner G, Casey K, et al. Respiratory management of patients with neuromuscular weakness. CHEST J. 2023;164:394–413.
- Shoesmith C, Abrahao A, Benstead T, Chum M, Dupre N, Izenberg A, et al. Canadian best practice recommendations for the management of amyotrophic lateral sclerosis. CMAJ. 2020;16; 192: E1453–68.
- 13. Van Damme P, Al-Chalabi A, Andersen PM, Chiò A, Couratier P, De Carvalho M, et al. European Academy of Neurology (EAN) guideline on the management of amyotrophic lateral sclerosis in collaboration with European Reference Network for Neuromuscular Diseases (ERNEURO-NMD). Eur J Neurol. 2024;31:e16264.
- NICE. Overview | Motor neurone disease: assessment and management | Guidance | NICE 2016.https://www.nice. org.uk/guidance/ng42. Accessed January 1, 2025.
- Van den Berg JP, Kalmijn S, Lindeman E, Veldink JH, de Visser M, Van der Graaff MM, et al. Multidisciplinary ALS care improves quality of life in patients with ALS. Neurology. 2005;65:1264–7.
- Rooney J, Byrne S, Heverin M, Tobin K, Dick A, Donaghy C, 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;86:496–501.
- 17. White S, O'Cathain A, Halliday V, Bradburn M, McDermott CJ. Supporting people with Motor Neuron Disease (MND) to make decisions about gastrostomy feeding tube placement: a survey of UK healthcare professionals' practice and beliefs. Amyotroph Lateral Scler Frontotemporal Degener. 2024;25:290–8.
- Berlowitz DJ, Mathers S, Hutchinson K, Hogden A, Carey KA, Graco M, et al. The complexity of multidisciplinary respiratory care in amyotrophic lateral sclerosis. Breathe (Sheff). 2023;19:220269.

- MNDA community of practice document. https://www. mndassociation.org/sites/default/files/2022-11/Infographic% 20MDT.pdf. Accessed November 11, 2024.
- 20. Eysenbach G. Improving the quality of web surveys: the checklist for reporting results of internet e-surveys (CHERRIES). J Med Internet Res. 2004;6:e34.
- Kelley K. Good practice in the conduct and reporting of survey research. Int J Qual Health Care. 2003;15:261–6.
- 22. Artino AR, La Rochelle JS, Dezee KJ, Gehlbach H. Developing questionnaires for educational research: AMEE Guide No. 87. Med Teach. 2014;36:463–74.
- Penlington C, Pornsukjantra P, Chazot P, Cole F, Denneny D. Confidence of practitioners to support selfmanagement of pain: a multidisciplinary survey. Br J Pain. 2024;18:148–54.
- 24. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77–101.
- Smith RA, Macklin EA, Myers KJ, Pattee GL, Goslin KL, Meekins GD, et al. Assessment of bulbar function in amyotrophic lateral sclerosis: validation of a self-report scale (Center for Neurologic Study Bulbar Function Scale). Eur J Neurol. 2018;25:907–e66.
- Cazzolli PA, Brooks BR, Nakayama Y, Lewarski JS, McKim DA, Holt SL, et al. The oral secretion scale and prognostic factors for survival in subjects with amyotrophic lateral sclerosis. Respir Care. 2020;65:1063–76.
- McGeachan AJ, Hobson EV, Al-Chalabi A, Stephenson J, Chandran S, Crawley F, et al. A multicentre evaluation of oropharyngeal secretion management practices in amyotrophic lateral sclerosis. Amyotroph Lateral Scler Frontotemporal Degener. 2017;18:1–9.

- Hobson EV, McGeachan A, Al-Chalabi A, Chandran S, Crawley F, Dick D, et al. Management of sialorrhoea in motor neuron disease: a survey of current UK practice. Amyotroph Lateral Scler Frontotemporal Degener. 2013; 14:521–7.
- 29. Hutchinson K, Schutz A, Hogden A, Carr S, Reynolds M, Goodwin N, et al. Enablers and barriers to delivering a motor neurone disease multidisciplinary clinic in regional New South Wales, Australia. Int J Integr Care. 2023;23: 529.
- Allen J, Massey C. Cough and secretion management for people living with neuromuscular conditions: an interdisciplinary approach. UCLH Connect Journal. 2023. https://www.uclh.nhs.uk/download\_file/13225/630. Accessed October 10, 2024.
- Boggiano S, Holme S, Wallace S. Patterns of laryngeal changes on clinical application of mechanical insufflationexsufflation seen with transnasal laryngoscopy for patients with varied neurological conditions and bulbar impairment. EMJ Neurol. 2024; 12(1):99–108.
- Knox L, McDermott C, Hobson E. Telehealth in longterm neurological conditions: the potential, the challenges and the key recommendations. J Med Eng Technol. 2022; 46:506–17.
- Hogden A, Labra J, Power E. Enabling decision-making: what assists people with motor neurone disease when they consider gastrostomy insertion? Disabil Rehabil. 2025;47: 2535–42.
- Rahn AC, Solari A, Beckerman H, Nicholas R, Wilkie D, Heesen C, et al. "I will respect the autonomy of my patient." Int J MS Care. 2020;22:285–93.