NHS Lothian

THE UNIVERSITY of EDINBURGH

Anne Rowling
Regenerative Neurology Clinic

An evaluation of the United Kingdom Motor Neuron Disease Nurses and Allied Health Professionals (UK MND NAHP) workforce:

A Census

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Team Statement

L-R: Jessica Gill, Ethan Stoker, Judith Newton and Isaac Chau

We are excited to share the outcomes of the very first United Kingdom Motor Neuron Disease Nurses and Allied Health Professionals (UK MND NAHP) Workforce Census Report, which stems from our inaugural UK MND NAHP meeting on November 16th, 2023, spearheaded by Judith Newton.

This achievement has been a long time coming. Despite extensive research, we found no existing article evaluating this crucial area. Realising its significance, we took the initiative to conduct this survey. Through this brochure, we aim to present an accessible visual snapshot of our workforce, hoping to spark further discussions and engagement on this vital subject.

We extend a warm thank you to all the respondents whose input has shaped this report. Your contributions have provided invaluable insights that can benefit our wider community and the public.

Furthermore, we are grateful to the charitable organisations that made the UK MND NAHP meeting possible: The Alan Davidson Foundation, MND Association, My Name'5 Doddie Foundation, and MND Scotland. Your support has played a key role in advancing our collective efforts.

This report reflects the dedication and collaboration within our community. Let's build on this foundation to drive meaningful progress in our ongoing mission.

Isaac Chau, Research Nurse
Ethan Stoker, Research Nurse
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Judith Newton, MND Nurse Consultant

Fast Facts

Introduction

According to the National Institute for Health and Care Excellence (NICE), motor neuron disease (MND) assessment and management should be a coordinated, clinic-based, multidisciplinary team (MDT) approach. However, the wellbeing, work experiences, and the alignment with national frameworks and standards within the MND nurses and allied health professionals (NAHP) workforce are severely underreported and under-researched within the literature.

Therefore, **this report aimed to capture the UK MND NAHP workforce and their alignment with national frameworks and standards, and to assess their experiences working as a motor neuron disease (MND) healthcare professional (HCP).**

Methods

- A pragmatic research paradigm and a mixed methods approach was employed using a cross-sectional questionnaire survey to collect, compare, and interpret quantitative and qualitative data points.
- Data was gathered under the remit of an audit and service evaluation under NHS Lothian.
- Demographics data and work-related characteristics were collected.
- Job experience and wellbeing were collected using Likert Scales and open-ended questions which were analysed using Nvivo 14.
- The level of burnout was assessed using the validated tool, Burnout Assessment Tool (BAT).
- Compliance with national frameworks was based on the NICE Guidelines (2016) and the Scottish MND Advanced Clinical Nurse Specialist Pillars of Practice Competencies (2019).

Results

- 64 HCPs completed the questionnaire, with respondents from England (54.7%), Scotland (23%), and Wales and Northern Ireland (22.3%).
- Education level was mainly having a Bachelors (or equivalent) degree (40%), or a Masters (or equivalent) degree (31%), with the remaining respondents having a diploma-based qualification (29%).
- **The analysis revealed three key themes:**
  1. the importance of the MDT,
  2. the roles and the level of competencies,
  3. the benefits and challenges in providing direct care.

Discussion

- This report highlighted the importance of a collaborative MDT to support the needs of patients, their carers/family members and HCPs themselves.
- The workforce found the flexibility, autonomy, and variety within their role beneficial, where almost 80% of the respondents engaged in 8 of the 15 competencies. However, there is not a standardised competency framework for the clinical NAHP in the UK.
- The benefits of providing direct care were found to be associated with feeling valued by the patients, their carers/family members, and the core and extended MDT, and feeling satisfied about their work.
- The perceived challenges of providing direct care involved isolation, lack of direct funding, and a high caseload with complex needs and not enough time to provide quality care. This was associated with 14% and 12% being at risk of medium and high risk of burnout, respectively.

It is recommended that a national competency programme or a Masters level course in MND care should be developed to maintain the quality of care, and future research should aim to evaluate the entire workforce longitudinally, address organisational barriers, and explore burnout preventative strategies to maintain a resilient workforce.

Introduction

Background

Motor neuron disease (MND) is a group of neurodegenerative disorders that leads to premature death 2-4 years after diagnosis, often caused by respiratory failure due to the progressive degeneration of either or both upper or lower motor neurons (NICE, 2016).
It was imperative that a holistic representation of the workforce could be gathered to highlight areas of challenges and barriers that impact their adherence to national frameworks, as well as their experiences and wellbeing, and this could potentially inform policy change and guidance to increase support for the workforce.

MND assessment and management should include a coordinated, clinic-based, multidisciplinary team (MDT) approach
(NICE 2016)

Aim and Research Questions

Across the UK, several healthcare governing bodies conduct a census to understand the size of their workforce by various demographics such as job grading, number of working hours, and geographical spread. Therefore, the aim of this report was to capture the UK MND NAHP workforce and their alignment with national frameworks and standards, and to assess their experiences working as an MND HCP.

This was achieved by producing a census questionnaire that was distributed online and on paper during the UK MND NAHP meeting on November 16th, 2023, with more than 80 attendees across the UK including MND clinical nurse specialists, AHP, and MND research teams.

80+
attendees across the UK

This report aimed to address the following research questions:

1. What is the size (by number) of the MND NAHP workforce in the UK?
2. What is the proportion of the UK MND services that comply with national frameworks and standards?
3. What are the experiences and wellbeing of the UK MND NAHP workforce, based on the Burnout Assessment Test (BAT-C and BAT-S)?
4. What are the themes that could be identified in relation to the NHS locality, demographics, and mental health and wellbeing among the UK MND NAHP workforce?

Therefore, this report hypothesises that:

1. The UK MND NAHP workforce is mainly made up of clinical and experienced HCPs
2. Alignment with national frameworks and standards is adhered by a high proportion of the workforce
3. There is a high proportion of burnout within the UK MND NAHP workforce based on the Burnout Assessment Tests (BAT-C and BAT-S) due to the terminal nature of MND

Methods

Ethical Considerations

This data was gathered under the remit of an audit and service evaluation under NHS Lothian. As the census did not gather patient identifiable information and had the main aim of assessing the standard of care, it was deemed that the aim and design of the census fit within the definition of an audit and service evaluation within NHS Lothian Quality Improvement guidelines. Approval was granted by NHS Lothian on 3rd November 2023.

Sampling Strategy

Participants were recruited through a convenience approach through an online/paper questionnaire. Participation was voluntary and the data was anonymised, collected, transcribed and stored on the Jisc Online Surveys platform before transferring to local secure servers where it will be held for a year. Study eligibility was based on participants self-reporting their occupation.

Data Collection

Demographics data and work-related characteristics were collected in the census and used to consistently measure the remaining quantitative variables. General compliance with national frameworks was assessed using the NICE guidelines (2016) and the Scottish MND advanced clinical nurse specialist pillars of practice competencies (2019). Satisfaction and the feeling of being valued was assessed using a 4-point Likert scale. Well-being was measured using the validated assessment tool, the **Burnout Assessment Tool- Core dimensions (BAT-C) and the Secondary dimensions (BAT-S)** developed by Schaufeli, De Witte, and Desart (2020).

Green — **No Burnout** where the score is **lower than 2.53**

Amber — **At-risk of Burnout** where the score is **higher than or equal to 2.54 and less than 2.96**

Red — **Most likely to Burnout** where the score is **higher than or equal to 2.96**

These questions, along with the questionnaire as a whole, were formulated through an expert panel to ensure the exploratory aims of the census were met and to make use of the unique opportunity.

Data Analysis

Quantitative analysis

For the quantitative analysis, the data was cleaned and any abnormalities identified were addressed before analysis. This included highlighting missing data points, along with coding specific answers, grouping demographic categories (for example job role), and equalising units for the continuous data sets. Missing data points were removed from the specific tests however the remaining data was used for the other points of analysis.

Data analysis was conducted in R. For the work experience and wellbeing analysis, only data from the clinical professionals was used in order to ensure the validity and relevance of the themes developed.

Qualitative analysis

For the qualitative analysis, a basic content analysis was employed, an inductive and descriptive qualitative approach that aims to develop a mid-range theory from text-based data (Drisko and Maschi, 2015). A conventional content analysis was used to answer the descriptive and exploratory aims of the research (Drisko and Maschi, 2015).

Data was analysed using NVivo 14, a data management and analysis software.

Results

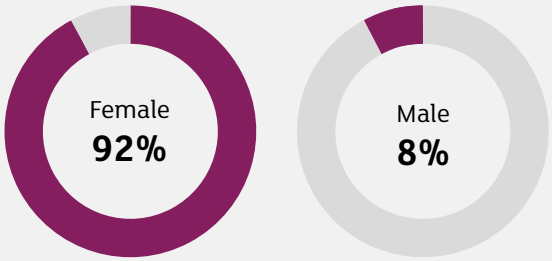
Descriptive Statistics

Figure 1 shows the general demographic distribution of the NAHP who completed the census. The 64 who completed the census questionnaire represented 75% of the eligible attendees at the nationwide meeting.

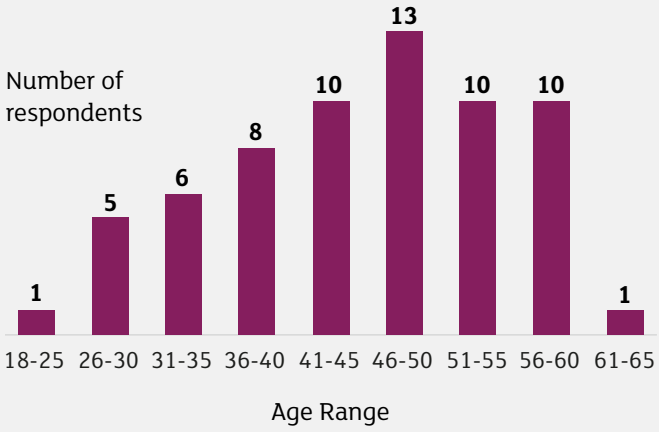
Figure 2 shows that the geographic location of the respondents was England (54.7%), Scotland (23%), and Wales and Northern Ireland (22.3%).

Figure 1: General Demographic

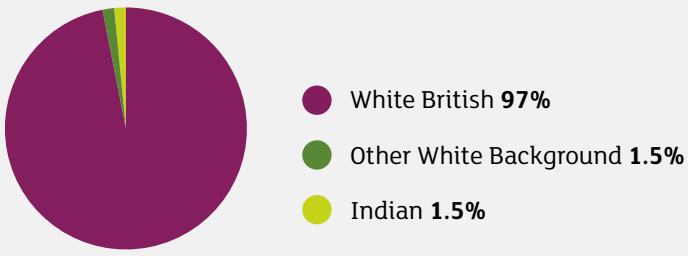
(a) Sex Distribution

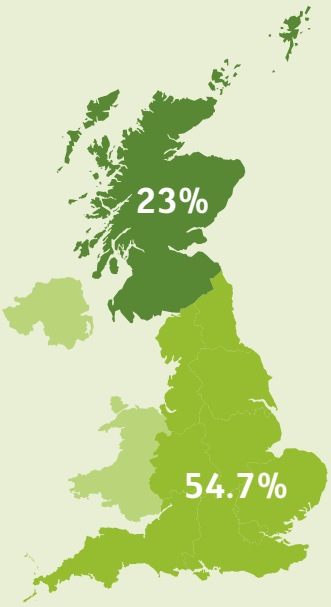


(b) Age Range



(c) Ethnicity Distribution





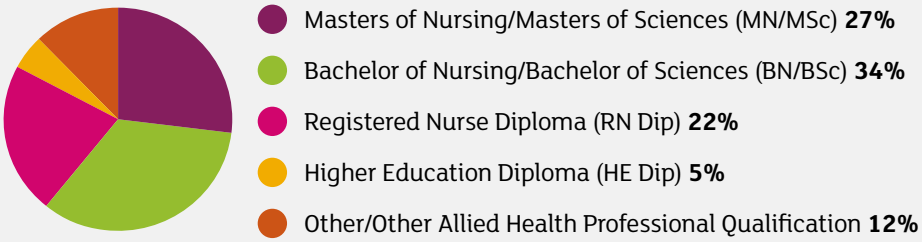
75%
of attendees completed the census

92%
of respondents were female

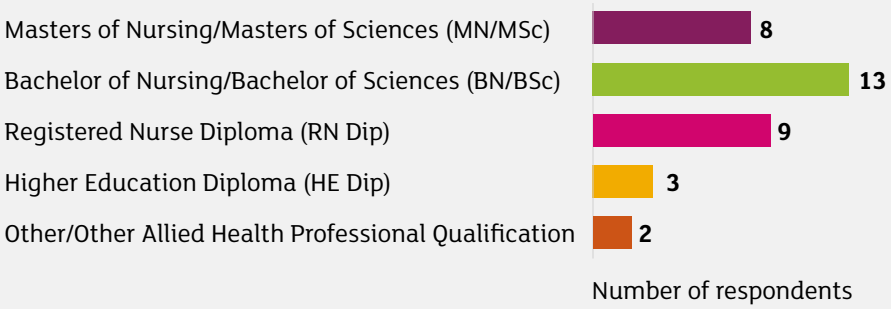
97%
of respondents were white British

Figure 2: Qualification Demographics

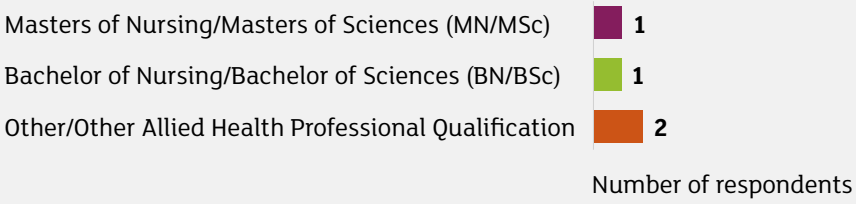
(a) Qualifications in total



(b) Qualification by Clinical Nurses (MND and non-MND specific)



(c) Qualifications by AHP



74.4%
of respondents were a Band 7

54.7%
of respondents work full-time

50%
of respondents were Clinical Nurse Specialists (MND)

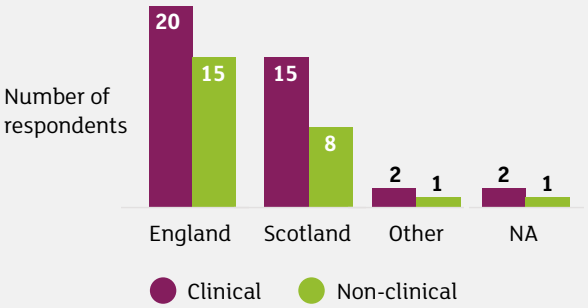
40%
of respondents had a Bachelors degree (or equivalent)

31%
of respondents had a Masters degree (or equivalent)

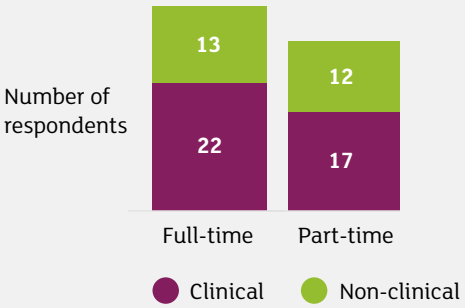
29%
of respondents had a Diploma-based qualification

Figure 3: Employment Demographics

(a) Country of Work by Clinical and Non-clinical HCP



(b) Clinical vs Non-clinical and Full-time vs Part-time HCP



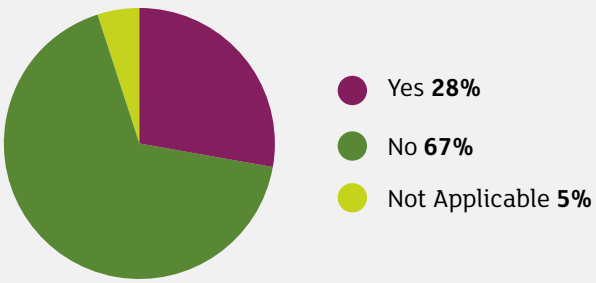
(c) Job Title

4	32	3	10	15
AAHPs	Clinical Nurse Specialists (MND)	Clinical Nurse Specialists (non-MND specific)	Clinical Research Nurses	MND Care Service Coordinators

(d) Time of work per week

	Hours Worked (hours)	Worked in MND care (months)	Number of Patients (n)	Time in Current Post (weeks)
Mean	31.81	112.5	94.87	343.4
Min	15	3	1	3
Max	37.50	360	380	1144
Standard Deviation	7.256	89.01	94.30	286.8
Median	37.50	84	45	260

(e) Vacancies in Core MDT (Clinical workers only)



Theme One: The Multidisciplinary Team

The first theme to be developed from the data is the importance of the MDT.

This was a prominent and recurring theme within the open text box questions, where many respondents discussed the importance of the MDT to meet the needs of patients, their families, and the HCPs themselves.

> **"Having a core MDT is essential as we have 'on hand' expert advice and information for patients, families and other health care professionals."**
> (Respondent 118421608)

> **"MDT working is fantastic – swift access to support, excellent peer support. Collaborating with regional teams and our community teams such as DNs (District Nurses), care agencies etc."**
> (Respondent 118972185)

These positive responses can be correlated with Figure 4(b) where out of the **respondents who were clinical professionals, a vast majority reported working with various members of the 'core MDT'** as detailed in the NICE guidelines (2016), with **particularly high rates seen with those who work with neurologists, other specialist nurses, and dieticians**.

There was **a plethora of responses that identified vacancies as a limitation and issue that affected patient care and produced a "knock-on" effect**, as highlighted by this respondent:

> **"We as a team run short staffed which has a knock-on effect."**
> (Respondent 118442902)

Furthermore, many respondents identified how **issues in accessing the extended services caused delays and hardships for the people with MND and their carers while also producing a negative effect on the staff themselves**.

> **"Access to other consultant specialities i.e. ENT or maxillofacial."**
> (Respondent 118420947)

> **"No psychology and limited access to counselling services."**
> (Respondent 118713457)

80%+
of clinical professionals reported relationships with respiratory services, gastroenterology, wheelchair services, & assistive technology services

30%
of clinical professionals reported vacancies within the core MDT

Theme Two: Roles and Responsibilities

The second theme developed from the data refers to the relevant competencies and conceptualisations of the MND NAHP workforce.

As seen in **Figure 4(a)**, the clinical professionals were associated with a range of competencies as detailed in the Pillars of Practice Competency Framework (2019) for the Scottish MND nurses. This can form links with some of the qualitative codes and sub-themes on the perceived **benefits of the flexibility, autonomy, and variety seen within the clinical care**. **Respondents felt that they had the freedom to manage their own time**, in terms of providing care and developing competencies in a challenging and evolving work environment.

"Flexibility of being able to manage own time and prioritise, in particularly assigning sufficient time to meet patient needs at clinic appointments or home visits."
(Respondent 118709878)

"Varied, enjoy the mixture of job roles challenging, learn new things all the time."
(Respondent 118455679)

"Joining the dots as one family described my role to ensure patient centred coordinated care."
(Respondent 118420738)

However, this flexibility and variability in competencies was not always positive. From the qualitative themes, it was recognised how the **often-nebulous definitions of what the MND service is** and what the related health professionals provide caused conflict when it did not align with what the patients and their families and carers expected from the service.

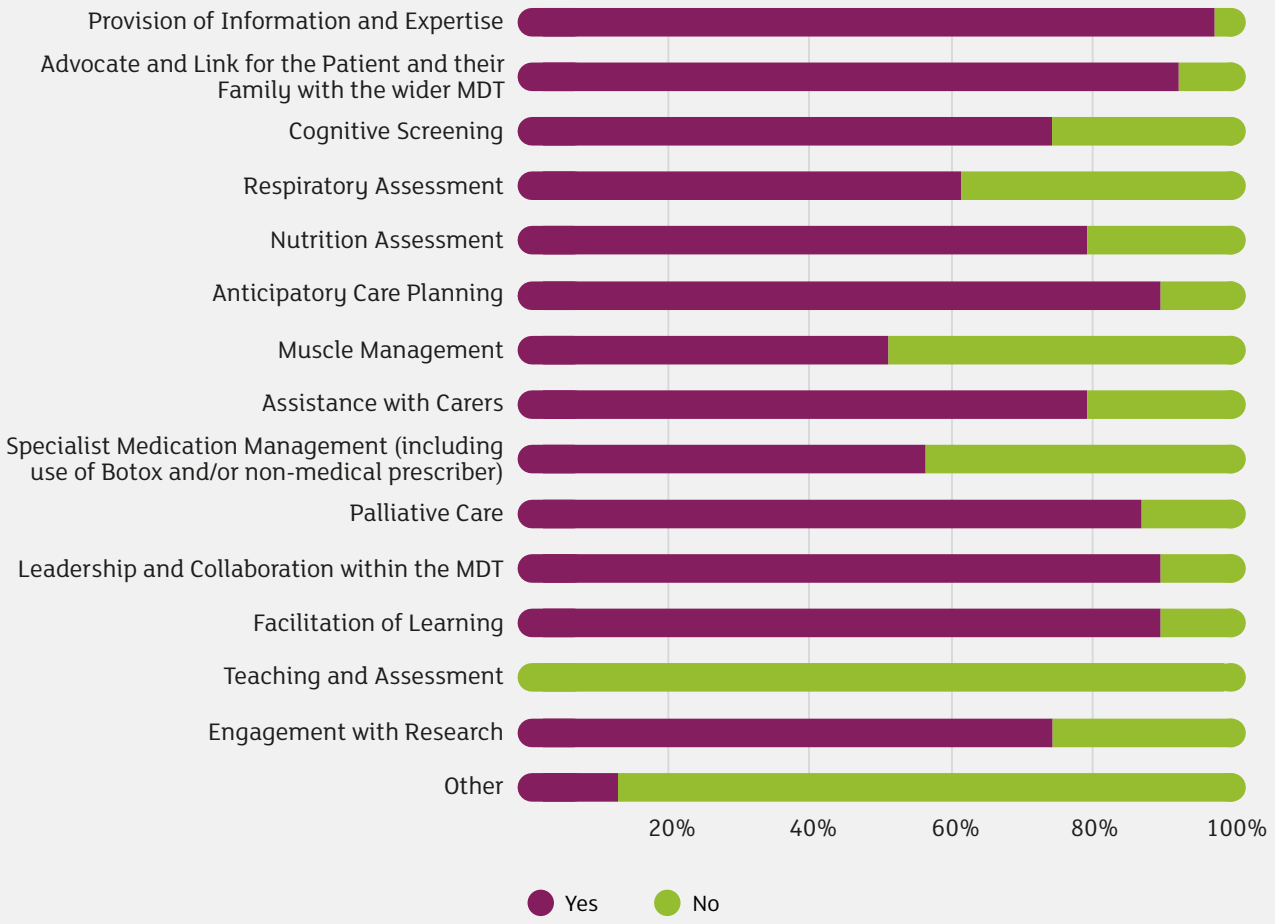
This was then expanded to the rest of the MDT, who, as they may not specialise in MND care, were sometimes **not aware of the full complexity of the condition or what the service does**.

"We are not here 24/7 and we are not an emergency service – expectations of patients, families and colleagues are often exceptionally high. Colleagues (outside the MDT) often have high and unrealistic expectations of the support we can and should provide."
(Respondent 118972185)

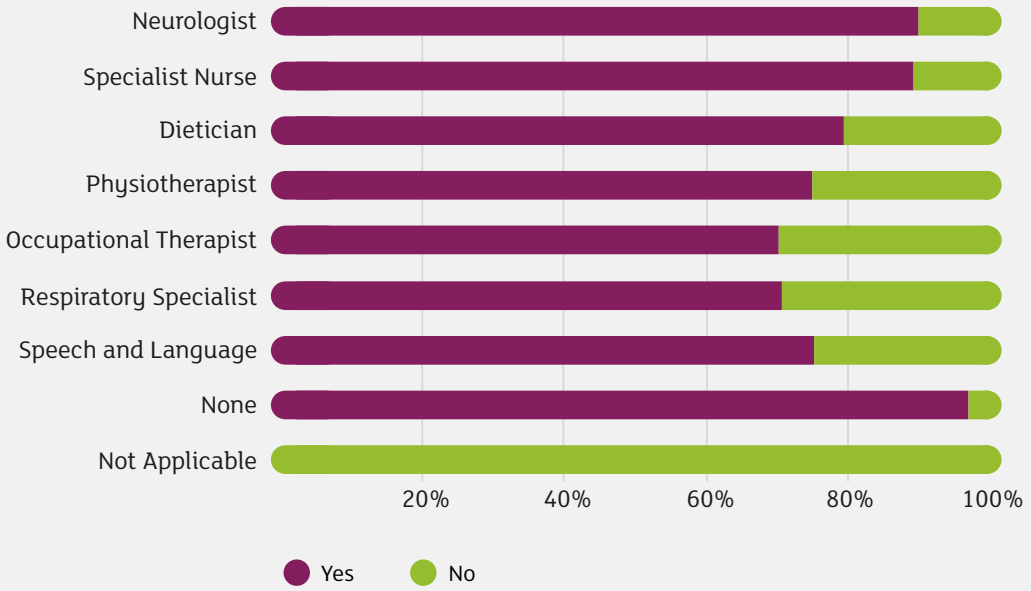
97%
of clinical professionals engage in the provision of information and expertise

Figure 4: Clinical Scoring

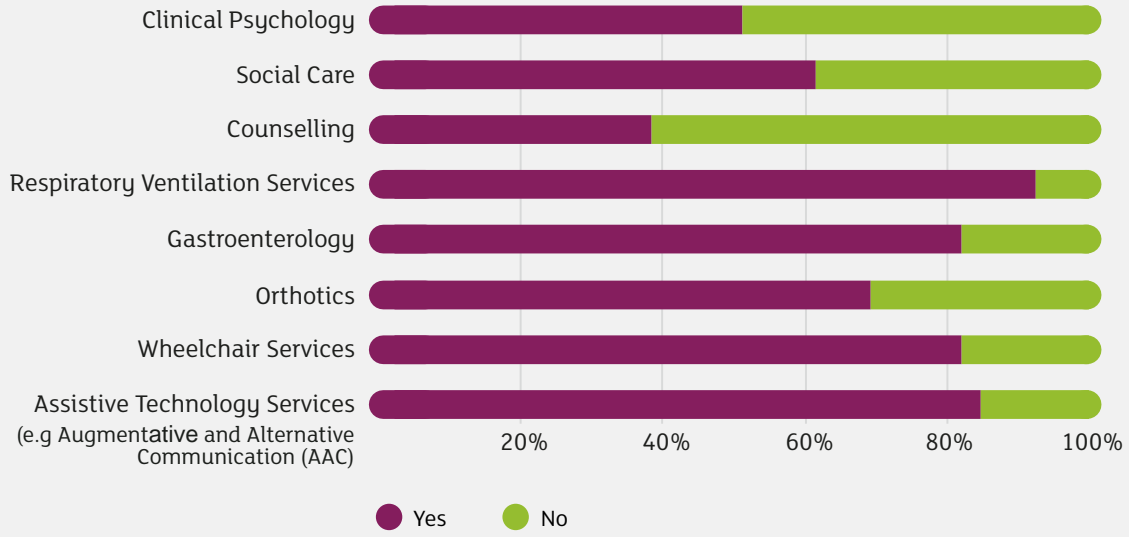
(a) Competencies of MND care based on the NICE guidelines (2016) and NHS MND Advanced Clinical Nurse Specialist Pillars of Practice (2019)



(b) HCP/Specialty Involvement in Core MDT

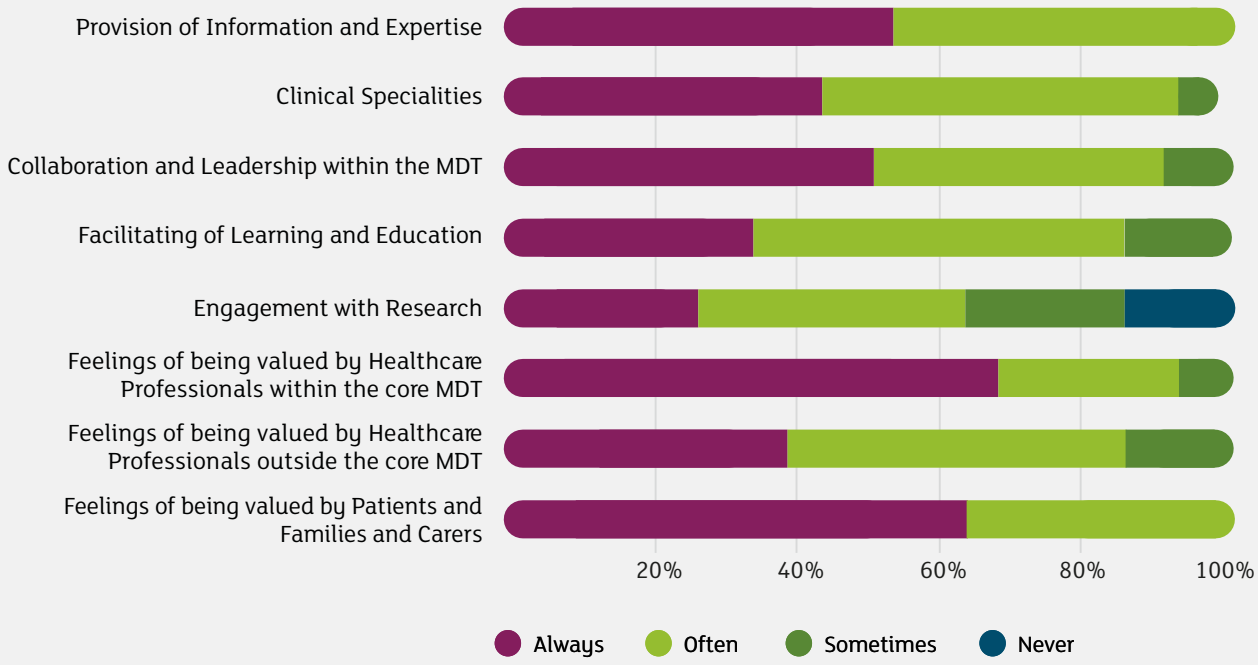


(c) Established Relationship with NHS Services



Note. Responses are from 39 respondents who work in a clinical setting based on the (a) engagement with aspect of care, (b) speciality involved in the core MDT, (c) established relationship with NHS services.

Figure 5: Clinical Satisfaction Scores



Note. Responses are from the 39 respondents who work in a clinical setting. One respondent did not answer the 'Clinical Specialities' question.

Theme Three: Benefits and Challenges in Providing Direct Care

The final theme developed from the data is the overall perceived benefits and challenges in providing care to people with MND.

The most prominent aspect of the data collected was the benefits of direct care and engagement with the patients and their carers/family members. As seen in **Figure 5**, 100% of participants felt often or always valued by patients and their families which was further discussed in the qualitative data where respondents expressed gratitude for the individuals they look after alongside their families and carers and highlighted this as a key benefit in their current post.

> **"Being able to support patients, their families, carers at a very difficult and challenging time of their life."**
> (Respondent 118923353)

> **"Working with such a lovely cohort of people at such a difficult time in their lives."**
> (Respondent 118709722)

> **"I feel like I'm part of a much wider team to make a difference in MND."**
> (Respondent 118736747)

> **"If I can do one thing to make a difference in my patients life than I have done my job."**
> (Respondent 118713352)

This is seen in the quantitative data (see **Figure 5**) where respondents felt largely satisfied in most areas of their job. This includes **100% of respondents feeling always or often satisfied in the provision of information and expertise, 98% of respondents feeling always or often satisfied in their clinical specialities, 93% of respondents feeling always or often satisfied in the provision of collaboration and leadership within the MDT, and 88% of respondents feeling always or often satisfied in the facilitation of learning and education**.

The largely positive responses from the respondents were further seen in the analysis of the BAT-C scores. It was identified how **82% of respondents were at a low risk of burnout** across the various sub-sections (see **Figure6(a)**). However, when breaking down the total score into the individual sub-sections, it can be identified how there exist issues that correspond with the qualitative sub-themes describing the negatives of providing direct care.

Green — **82% of respondents were at low risk of burnout**

For example, when assessing the exhaustion sub-section of the BAT-C, it can be seen how **14% of respondents were identified as a medium risk of burnout** and **12% of participants were identified as high risk of burnout**.

Amber — **14% of respondents were at medium risk of burnout**

100%
of respondents
feeling always or often satisfied in the provision of information and expertise

95%
of respondents
felt always or often valued by the 'core MDT'

When linking with the qualitative data, comments on isolation, rurality, and issues with lack of time and high demand (such as with the high caseload numbers, which were shown to vary in **Figure 6(a)**) were all associated with feelings of exhaustion and not being able to provide the care they wanted to be able to provide.

"Very time limited, currently not enough time to provide a gold standard service."
(Respondent 118709818)

Expanding on from this, when assessing the emotional impairment and cognitive impairment sub-sections of the BAT-C, the results indicate how **24% and 21% were at a medium-high risk of burnout** respectively.

Red **24% and 21% were at medium-high risk of burnout**

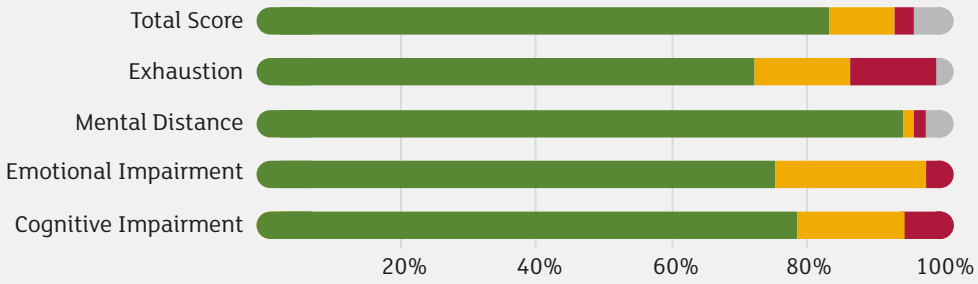
"The financial burden of MND/care and support/adaptions on people living in England. Availability of social care packages. Numerous electronic record systems across the wider MDT across trusts/ social care systems which are not viewable unless you are employed within the applicable trust."
(Respondent 118910045)

Finally, it was also discussed by respondents, how the **nature of the work can be challenging** as the patient group is complex and often has a variety of care needs at varying intensities. This created challenges and restrictions to the care provided to people with MND that was often exacerbated by the organisational factors and increased demand.

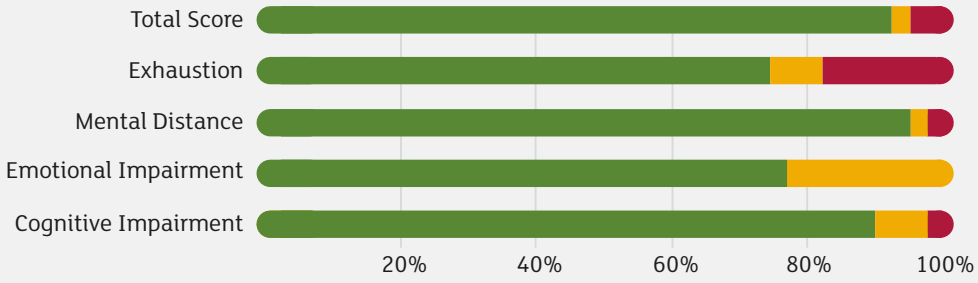
"Conflicting priorities so unable to focus all the services/patient needs."
(Respondent 118758297)

Figure 6: Burnout Assessment Test

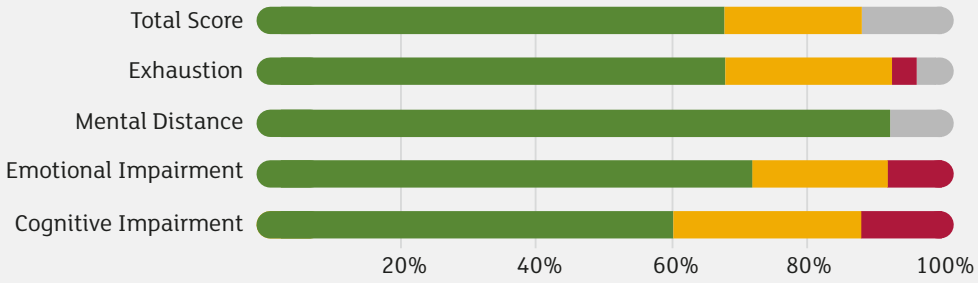
(a) Burnout Assessment Tool-Core (BAT-C) Total Scores

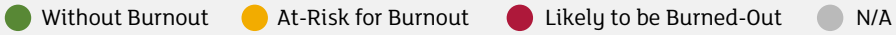


(b) Burnout Assessment Tool-Core (BAT-C) by Clinical HCP

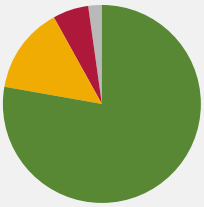


(c) Burnout Assessment Tool-Core (BAT-C) by Non-clinical HCP



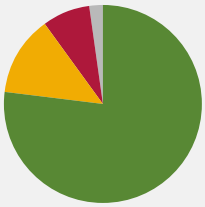


(d) Burnout Assessment Test-Secondary (BAT-S) Total Scores



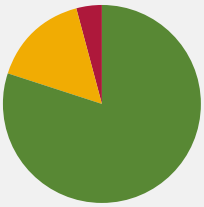
- Without Burnout **78%**
- At-Risk for Burnout **14%**
- Likely to be Burned-Out **6%**
- N/A **2%**

(e) Burnout Assessment Test-Secondary (BAT-S) by Clinical HCP



- Without Burnout **77%**
- At-Risk for Burnout **13%**
- Likely to be Burned-Out **8%**
- N/A **2%**

(f) Burnout Assessment Test-Secondary (BAT-S) by Non-Clinical HCP



- Without Burnout **80%**
- At-Risk for Burnout **16%**
- Likely to be Burned-Out **4%**

Note. The clinical cut-off scores are grouped into three categories:

1. "Without Burnout" – Green, the score is lower than 2.58,
2. "At-Risk for Burnout" – Amber, the score is higher than or equal to 2.59 and less than 3.02,
3. "Likely to be Burned-Out" – Red, the score is higher or equal to 3.02. A red score indicates that the specificity is greater than or equal to 0.90 that corresponds to a maximum misclassification of 10%.

Implications and Recommendations

The findings from this report have implications for policy, practice, and research in MND care. The discrepancies between the workforce and the adherence to national guidelines, vacancies within the MDT, and challenges in competencies should prompt targeted action to allocate additional resources and reduce these gaps.

The authors recommend that a national competency programme or a Masters level course in MND care should be developed in cooperation with leaders of the workforce, policymakers, and charities to ensure standardisation of the training and competencies required to provide effective MND care across the UK. This can enhance the adherence to national guidelines and address the workforce shortage and challenges in providing direct care. Furthermore, this report has identified that burnout and job satisfaction are crucial determinants to the well-being of HCP.

Future research should develop a strategy to evaluate the entire workforce longitudinally to have a better understanding how the time of experience affects HCP wellbeing, and to generalise the findings. Additionally, there is a need to explore the organisational barriers and burnout preventative strategies to maintain a resilient and effective workforce.

Strengths and Limitations

This report had five strengths:

Firstly, as this was the first census that evaluated the UK MND NAHP workforce, the employment of a mixed-methods approach allowed for greater depth and a holistic insight into the workforce.

Secondly, it provided a comprehensive assessment which covered areas such as the changing dynamics of the MDT, the understanding of roles and responsibilities, and the perceived benefits and challenges of providing MND care.

Thirdly, the descriptive analysis was performed by two of the authors to reinforce the robustness and validity of the study.

Fourthly, this study was carried out with approval from NHS Lothian, and the respondents were anonymised to ensure confidentiality.

Fifthly, this study utilised the Burnout Assessment Tool- Core dimensions (BAT-C) and -Secondary dimensions (BAT-S), which is a validated assessment tool that measures the risk of burnout among the workforce.

There were several weaknesses in this study that needs to be addressed. As this was a single meeting, the level of transferability of the data will be low. For the same reason, and also due to the small sample size (n= 64), the conclusions drawn from this report may not be generalised to the entire workforce.

Additionally, the use of qualitative data has a potential for response bias. There were some respondents who recently started their post (e.g. 3 months) and this would affect their burnout and job satisfaction levels and overall scores compared to those who have worked for longer.

Conclusion

This report was able to provide novel and valuable insights into the UK MND NAHP workforce by evaluating aspects of their roles, competencies, experiences, and wellbeing.

By using a mixed-methods approach, the study was able to answer the intended research questions and highlighted **three important themes**:

1. the importance of a collaborative MDT to support the needs of patients, their carers/family members, and HCPs themselves,
2. the roles and competencies of the workforce,
3. the benefits and challenges of providing direct care.

The challenges that this report identified included vacancies within the MDT, limited access to services, and organisational barriers that impacted the delivery of care.

Despite these challenges, the majority of the workforce feels strongly satisfied with their jobs and feels valued by the MDT and their patients and carers/family members. Furthermore, the workforce mostly adheres to national guidelines on MND care.

However, it is imperative that future research should aim to maintain consistency and quality of care through a standardised competency or training programme, address organisational barriers, and target interventions to support the workforce to enhance their wellbeing and resilience.

Overall, the results have contributed to the understanding of the NAHPs who work in MND care, serves as a starting point for further research and prompts policy changes to improve the care delivery to people with MND and their carers/family members.

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