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## **Supplementary Information 1. Survey pro-forma**

### **A survey of the nutritional management of people with Motor Neurone Disease in UK Health Services**

#### **Participant information sheet**

### **A survey of the nutritional management of people with Motor Neurone Disease in UK Health Services**

**Name of lead researcher:** Dr Vanessa Halliday, Senior Lecturer, University of Sheffield

We would like to invite you to take part in our research study, coordinated by a team at the University of Sheffield. Before you decide if you would like to take part, it is important that you understand why this research is being done and what it would involve for you. We would like to encourage you to read this information sheet in your own time and consider whether you would like to participate in the study. Thank you for reading this.

#### **What is the purpose of this project?**

This survey is part of the first work package in a programme of research to develop and test a complex intervention (HighCALs) to achieve a high calorie diet for people living with amyotrophic lateral sclerosis (ALS), also known as motor neurone disease (MND). The specific aim of this study is to investigate the role of healthcare professionals in the nutritional management of people with MND. We would also like to understand what their experiences and opinions are in relation to this aspect of care. The information gathered will inform the development of the HighCALs intervention that will be tested in a future project.

#### **Why have I been invited?**

You have been invited to participate in this study as a healthcare professional who may have a role in, or personal experience of, the nutritional needs and management of people with MND. The survey is open to any healthcare professionals who feel able to comment on this topic, including for example, doctors, nurses, dietitians, speech and language therapists, occupational therapists, physiotherapists and care coordinators.

### **What would my participation involve?**

If you decide to take part in the study, you will be asked to complete an online survey consisting of mostly multiple choice questions about your involvement with people with MND. Most of the questions will focus on the nutritional needs and management of this group of patients. The survey is expected to take approximately 15 to 20 minutes. If you are a dietitian, you will be asked a number of additional questions specifically about the nutritional assessment and treatment of patients with MND. We anticipate that these questions will take an additional 10 to 15 minutes to complete.

As part of the survey, you will also be given the opportunity to provide your email address so that the research team can contact you for further information about your response to a specific question in the survey around commissioning of services. Your email address will be collected and stored separately from your survey responses.

Please note that any information you enter will be stored and processed using services provided by Qualtrics. These services have been the subject of independent assessment to ensure compliance with applicable data security standards. Further information can be found on the Qualtrics website (<https://www.qualtrics.com/security-statement/>).

### **Do I have to take part?**

No. It is entirely up to you to decide whether or not to take part. You are free to end your

participation at any time before you complete the survey, without needing to give any reason. However, you will not be able to withdraw from the survey after you submit it.

### **What are the possible benefits and disadvantages of taking part?**

We hope that you will find the process beneficial as an opportunity to share your experiences in relation to the nutritional management of people with MND. There are no major disadvantages, other than the time taken to participate. Upon completion of the survey you will have the choice to be entered into a prize draw to win £200 in vouchers. If you wish to take part in the prize draw you will be asked for your email address. This will be collected and stored separately from your survey responses, and will only be kept for as long as is needed to manage the draw.

### **Use of my data**

In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is ‘a task in the public interest’.

The University of Sheffield is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Sheffield will keep identifiable information about you for 7 years after the study has finished, following this it will be destroyed. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting the HighCALs Programme Manager.

The research team will use your contact details to contact you about the research study, and to oversee the quality of the study. Individuals from the University of Sheffield and regulatory organisations may look at your research records to check the accuracy of the research study. The research team will pass these details to the University of Sheffield along with the information collected from you. The only people in the University of Sheffield who will have access to information that identifies you will be members of the research team or those auditing the data collection process.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is Anne Cutler and you can contact her at [dataprotection@sheffield.ac.uk](mailto:dataprotection@sheffield.ac.uk).

### **Who has reviewed this project?**

The study has been reviewed and approved by an independent NIHR scientific panel, the Health Research Authority (HRA) and the Research Ethics Committee at the School of Health and Related Research, University of Sheffield). If there is any aspect of the project, or your participation that you would like to discuss further, or feel you may need support with, please do not hesitate to get in touch with using the contact details listed below.

### **Further information**

We would be very happy to keep you informed about how the project progresses and the conclusions that are reached – you can contact us using the details below. For further information about the research study, please contact the HighCALs Programme Manager, using the details

below:

Daniel Beever

Telephone: 0114 2220820

Email: [high.cals@sheffield.ac.uk](mailto:high.cals@sheffield.ac.uk)

Webpage: <https://www.sheffield.ac.uk/scharr/highcals>

This document can be downloaded in an extended version from the following link and saved if you would like it for future reference: [\[Link to participant information sheet\]](#) Thank you for taking the time to read this document, if you are happy to continue please click the arrow below!

## Consent form

Before participating in the survey we ask that you confirm you have read each statement below by clicking on it.

I confirm that I have read and understood the participant information and I am eligible to participate in the study. (1)

I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my responses including the use of any quotes that I provide in the survey. (2)

I understand how my data will be used in the study. (3)

By clicking “I agree” below you are indicating that you have read and understood this consent form and agree to take part in this research study. (4)

I agree. (5)

## Demographic information

**What is your profession?**

Dietitian (1)

Doctor (2)

Nurse (3)

Occupational Therapist (4)

Psychologist (5)

Physiotherapist (6)

Speech and Language Therapist (7)

Other (8)

Q19 If Other, please specify: \_\_\_\_\_

**What year did you qualify?** \_\_\_\_\_

**What is your current job title?** \_\_\_\_\_

**How many years have you been in your current post?**

▼ 1 (1) ... 50 (50)

**What is the name of the organisation that you work for? If you work in a hospital please give the name of the NHS Trust that you work for. For example, Sheffield Teaching Hospitals NHS Foundation Trust.**

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**Do you work:**

Full Time (1)

Part Time (2)

**Do you specialise in a particular area of practice?**

Yes (1)



No (2)

**If Yes, what is your specialist area?** \_\_\_\_\_

**Your involvement with people that have MND**

**Do you currently provide care to people with motor neurone disease?**

Yes (1)

No, but I have in the past (2)

No (3)

**Where is/was that care delivered? (tick all that apply)**

NHS Hospital in patient service (1)

NHS Hospital outpatient specialist MND clinic (2)

NHS Hospital outpatient neurology clinic (3)

NHS Hospital outpatient general clinic (4)

Community General Practice (GP) clinic (5)

Patient's home (6)

Palliative care centre / hospice (7)

Private Hospital in patient service (8)

Private Hospital outpatient service (9)

Other (10)

**If Other, please specify:** \_\_\_\_\_

**How many year's experience do you have working with people with MND?**

▼ 1 (1) ... 50 (50)

**Approximately, what percentage of your total caseload at present are patients with MND?**

0-20% (1)

21-40% (2)

41-60% (3)

61-80% (4)

81-100% (5)

**Does supporting people with MND take up:**

None of your time (1)

Very little of your time (2)

Some of your time (3)

The majority of your time (4)

All of your time (5)

**Approximately, how many new patients with MND do you personally see in a year?**

(1)

11-25 (2)

26-50 (3)

51-75 (4)

76-100 (5)

101-150 (6)

>150 (7)

**Approximately, what is the total number of patients with MND that contribute to your caseload?**

(1)

11-25 (2)

26-50 (3)

51-75 (4)

76-100 (5)

101-150 (6)

>150 (7)

**Do you know how the service that you provide to patients with MND is funded?**

Yes (1)

No (2)

Unsure (3)

**If yes, please tell us how:**

---

**To what extent do you agree with the following statement: "There is sufficient funding for MND patients in your locality"?**

- Strongly disagree (1)
- Disagree (2)
- Somewhat disagree (3)
- Neither agree nor disagree (4)
- Somewhat agree (5)
- Agree (6)
- Strongly agree (7)

**MND multidisciplinary team working**

**Do you consider yourself to work as part of a MND multidisciplinary team (MDT)?**

- Yes (1)
- No (2)
- Unsure (3)

**How do you interact with the MND MDT? (tick all that apply)**

- Attendance at regular MDT meetings (1)
- Regular attendance at MDT specialist clinics (2)
- Correspondence by email or letter when required (3)

Verbal communication when required (4)

Other (5)

If Other, please specify: \_\_\_\_\_

**Is there a MDT that provides care to patients with MND in your organisation?**

Yes (1)

No (2)

Unsure (3)

**What are the reasons that you do not work as part of the MDT?**

Not a requirement of my job (1)

Not enough time (2)

Funding of my post does not allow for this (3)

Other (4)

**How effective do you believe communication is between MDT health care professionals that are caring for people with MND with regards their nutritional management?**

Not at all effective (1)

Slightly effective (2)

Moderately effective (3)

Very effective (4)

Extremely effective (5)

**How well coordinated do you feel the approach to the nutritional management of people with MND is in your locality?**

Uncoordinated (1)

Slightly well-coordinated (2)

Moderately well-coordinated (3)

Very well coordinated (4)

Extremely well coordinate (5)

### **Nutrition knowledge and skills**

**How do you rate your level of knowledge of nutritional issues in MND?**

Very poor (1)

Poor (2)

Fair (3)

Good (4)

Excellent (5)

**How satisfied are you with your level of knowledge of nutritional issues in MND?**

Not at all satisfied (1)

Slightly satisfied (2)

Moderately satisfied (3)

Very satisfied (4)

Extremely satisfied (5)

**Have you ever provided nutritional advice to MND patients or their carers?**

Yes (1)

No (2)

**What was this advice about? (tick all that apply)**

Healthy eating (1)

Weight reduction (2)

High protein diet (3)

High energy (calorie) diet (4)

Texture modification (e.g. soft or pureed diet) (5)



- Thickened fluids (6)
- Dysphagia management (e.g. swallowing techniques) (7)
- Vitamin or minerals supplements (8)
- Recommendation of sip feeds or energy supplements e.g. Fortisip or Calogen (9)
- Hydration advice (10)
- Nasogastric tube placement (11)
- Nasogastric feeding (12)
- Pre-gastrostomy tube decision support (13)
- Gastrostomy feeding (14)
- Gastrostomy tube complication advice e.g., broken tube parts, blocked tube, split tube (15)
- Gastrostomy feeding related complication advice e.g. gastrointestinal disturbance (16)
- Parenteral feeding (17)
- Palliative care symptom control (18)
- Withdrawal of artificial nutritional support (19)

Other (20)

If Other, please specify: \_\_\_\_\_

**Do you base your nutritional advice on set guidelines or standards?**

Yes (1)

No (2)

Unsure (3)

**Which guidelines or standards do you use? (tick all that apply)**

Locally developed NHS Trust guidelines (1)

Parenteral & Enteral Nutrition Group (PENG) (2)

British Association for Parenteral and Enteral Nutrition (BAPEN) (3)

National Institute for Health and Care Excellence (NICE) (4)

British Society of Gastroenterology (BSG) (5)

National Nurses Nutrition Group (NNNG) (6)

European Society for Enteral and Parenteral Nutrition (ESPEN) (7)

Motor Neurone Disease Association (MNDA) (8)

American Academy of Neurology (AAN) (9)

European Federation of Neurological Societies (EFNS) (10)

I don't refer to any guidelines (11)

Locally developed guidelines (12)

Other (13)

If Other, please specify: \_\_\_\_\_

**What other sources of information e.g. patient information, dietary information, research literature, inform your nutritional management of patients with MND? (tick all that apply)**

British Dietetic Association (BDA) (1)

Parenteral & Enteral Nutrition Group (PENG) (2)

British Association for Parenteral and Enteral Nutrition (BAPEN) (3)

Motor Neurone Disease Association (MNDA) (4)

Other official MND/ALS organisations (5)

Colleagues within the MDT (6)

Other colleagues... (7)

Research publications (e.g. journals etc.) (8)

- Nutritional conferences, meetings etc. (9)
- Neurological conferences, meetings etc. (10)
- Own research findings/audit (11)
- Local study days (12)
- Other (13)

If Other, please specify: \_\_\_\_\_

**Is there any additional support or training that you would like related to the nutritional management of people living with MND?**

\_\_\_\_\_

#### **Nutrition and dietetic services**

**In your organisation, what factors would initiate a referral to a dietitian for a patient with MND? (tick all that apply)**

- All patients with MND are referred to a dietitian around the time of diagnosis (7)
- As a result of using a nutrition screening tool (8)
- Low BMI (9)
- Patient/carer reported weight loss (10)
- Patient/carer reported poor dietary intake (11)

Bulbar symptoms (12)

Unsafe swallow assessment by SALT (13)

Deteriorating respiratory function (14)

Deteriorating ALSFRS score (15)

Recurrent chest infections due to aspiration (16)

Patient/carer reported problems with swallowing e.g. coughing and choking (17)

Patient/carer reported extended mealtimes (18)

Weight loss (19)

**What BMI would trigger action?**

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**What % weight loss over what time period would trigger action?**

---

**In your organisation, how easy is it to refer a patient with MND to a dietitian?**

Very difficult (1)

Difficult (2)

Neither easy nor difficult (3)

Easy (4)

Very easy (5)

Please explain your answer:

---

**Other than dietitians, which other members of the healthcare team provide nutritional advice to patients living with MND in your area? (tick all that apply)**

Neurologist (1)

Nurse specialist in MND (2)

Nurse (other) (3)

Psychologist (4)

Respiratory physiologist (5)

Occupational therapist (6)

Palliative care specialist (7)

Physiotherapist (8)

Social worker (9)

Speech & language therapist (10)

Other (11)

If Other, please specify: \_\_\_\_\_

### **Nutritional screening**

**Nutritional screening is usually undertaken by doctors and nurses to identify patients that are at risk of malnutrition. In your organisation, following a diagnosis of MND, are nutritional issues routinely screened for?**

Yes (1)

No (2)

Unsure (3)

**Is a screening tool used?**

Yes (1)

No (2)

Unsure (3)

**Which nutrition screening tool is used?**

Malnutrition Universal Screening Tool (MUST) (1)

Subjective Global Assessment (SGA) (2)

Locally developed screening tool (3)

Other (4)

If Other, please specify:

---

**How are nutritional issues identified? (tick all that apply)**

Non-routine questioning by MDT (1)

Patient has to raise issues (2)

On completion of ALSFRS-r (3)

Nutritional issues are not usually identified (4)

Unsure (5)

Other (6)

If Other, please specify:

---

**Who conducts this screening? (tick all that apply)**

Neurologist (1)

Doctor (2)

MND Nurse (3)



Nurse (4)

Healthcare support worker (5)

Dietitian (6)

Unsure (7)

Other (8)

If Other, please specify: \_\_\_\_\_

**Where is this screening conducted? (tick all that apply)**

At specialist MND clinic (1)

At specialist neurology clinic (2)

General outpatient clinic (3)

Attendance at GP surgery (4)

Hospital ward (5)

Home visit (6)

Unsure (7)

Other (8)

If Other, please specify: \_\_\_\_\_

**When is this screening conducted? (tick all that apply)**

At diagnosis (1)

At every follow-up appointment at MND clinic (2)

Inpatient admission (3)

When there are indications that nutrition may be a concern (4)

Adhoc (5)

At each GP clinic visit (6)

Unsure (7)

Other (8)

If Other, please specify: \_\_\_\_\_

**Do you use blood tests as part of nutrition screening?**

Yes (1)

No (2)

Unsure (3)

Which ones?

---

**In your organisation is this screening recorded in a standardised way? (tick all that apply)**

Yes, in paper form (1)

Yes, in electronic form (2)

No (3)

Other (4)

If Other, please specify:

---

**Other than routine nutritional screening, are patients with MND at risk of malnutrition identified in other ways?**

Yes (1)

No (2)

Unsure (3)

**In which way? (tick all that apply)**

Patient/carer reported weight loss (1)

Patient/carer reported poor dietary intake (2)

Bulbar symptoms (3)

Low BMI (4)

Unsafe swallow assessment by SALT (5)

Recurrent chest infections due to aspiration (6)

Patient/carer reported problems with swallowing e.g. coughing or choking (7)

Patient/carer reported extended mealtimes (8)

Weight loss (9)

Other (10)

If Other, please specify: \_\_\_\_\_

**What BMI would trigger action?**

\_\_\_\_\_

**What % weight loss over what time period would trigger action?**

\_\_\_\_\_

**In your organisation, are patients with MND routinely weighed? (tick all that apply)**

At diagnosis (1)

At hospital follow up appointments e.g. every 3 months (2)

At hospital follow up appointments e.g every 6 months (3)

At hospital follow up appointments e.g. annually (4)

Inpatient admission (5)

When there are indications that nutrition may be a concern (6)

Adhoc (7)

At each GP clinic visit (8)

Patients are not weighed (9)

Unsure (10)

Other (11)

If Other, please specify: \_\_\_\_\_

**What equipment is available for weighing patients with MND?**

Step on scales (1)

Hoist Scales (2)

Wheelchair scales (3)

We don't have equipment available (4)

Unsure (5)

Other (6)

If Other, please specify: \_\_\_\_\_

**In your organisation, when do patients with MND receive a complete nutritional assessment?**

- At diagnosis (1)
- They do not routinely receive a complete nutritional assessment (2)
- Only when a nutritional issue is identified and they are referred to the dietitian (3)
- Unsure (4)
- Other (5)

If Other, please specify: \_\_\_\_\_

### **Nutritional management**

**In your opinion:**

**How often do people have nutritional issues (e.g. swallowing problems, weight loss, reduced food intake) that are related to the effects of MND, at the time of diagnosis?**

- Never (1)
- Sometimes (2)

About half the time (3)

Most of the time (4)

Always (5)

**How successful do you believe the healthcare team is at identifying nutritional issues in people with MND?**

Unsuccessful (1)

Slightly successful (2)

Moderately successful (3)

Very successful (4)

Extremely successful (5)

**How successful do you believe the healthcare team is at implementing nutritional management plans to address nutritional issues in people with MND?**

Unsuccessful (1)

Slightly successful (2)



Moderately successful (3)

Very successful (4)

Extremely successful (5)

**How effective do you believe the food first approach (high calorie, high protein and food fortification dietary advice) is in meeting the nutritional requirements of people recently diagnosed with MND?**

Not very effective (1)

Slightly effective (2)

Moderately effective (3)

Very effective (4)

Extremely effective (5)

**How successful do you believe the healthcare team is at monitoring the nutritional management of people with MND?**

Unsuccessful (1)

Slightly successful (2)

Moderately successful (3)

Very successful (4)

Extremely successful (5)

**How important do you believe it is to support the nutritional needs of people living with MND?**

Not at all important (1)

Slightly important (2)

Moderately important (3)

Very important (4)

Extremely important (5)

**What level of priority do you give to managing the nutritional needs of people with MND?**

Very low priority (1)

Low priority (2)

Medium priority (3)

High priority (4)

Very high priority (5)

**What level of priority do you believe people with MND give to the nutritional management of their condition?**

Very low priority (1)

Low priority (2)

Medium priority (3)

High priority (4)

Very high priority (5)

**What level of priority do you believe that carers of people with MND give to the nutritional management of the condition**

Very low priority (1)

Low priority (2)

Medium priority (3)

High priority (4)

Very high priority (5)

**In your experience, what are the barriers to people with MND meeting their nutritional requirements orally?**

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Almost always (5)
Loss of appetite (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatigue (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Swallowing problems e.g. choking or coughing (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sore mouth (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Poor lip seal  
(5)

Impaired  
respiratory  
function (6)

Unable to go  
shopping (7)

Unable to  
prepare food  
(8)

Motor  
impairment  
resulting in an  
inability to feed  
themselves (9)

Eating no  
longer a social  
activity (10)

Posture not  
conducive with  
eating (11)

Feeding aids,  
such as adapted  
cutlery,  
unavailable  
(12)

Nobody  
available to  
assist with  
feeding (13)

Reluctance to  
accept help  
with feeding  
(14)

Reluctance to  
deviate from a  
'healthy diet'

(15)

Not accepting  
of diagnosis or  
symptoms (16)

Low mood  
(e.g. anxiety,  
depression)

(17)

Cognitive  
impairment

(18)

Lack of  
motivation (19)

Does not  
consider poor  
intake a  
problem (20)

Is happy with

weight loss

(21)

Time taken to

finish meals

(22)

Gastrointestinal

symptoms e.g.

constipation or

bloating (23)

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other:

---

**In your experience, what are the factors (i.e. enablers) that help people with MND to meet their nutritional requirements?**

---

**In your experience, what are the barriers to you, as a healthcare professional, in providing nutritional support/management to people living with MND?**

---

### **Commissioning and funding of MND services**

**Do you have experience of commissioning nutritional services for patients with MND?**



Yes (1)

No (2)

**At what stage? (tick all that apply)**

Assessing needs (1)

Reviewing service provisions (2)

Deciding priorities (3)

Designing services (4)

Shaping structure of supply (5)

Planning capacity and managing demand (6)

Supporting patient choice (7)

Managing performance (8)

Seeking public and patient views (9)

**To what extent do you agree with the following statement: "there is sufficient funding for the nutritional management of patients with MND in your locality"?**

- Strongly disagree (1)
- Somewhat disagree (2)
- Neither agree nor disagree (3)
- Somewhat agree (4)
- Strongly agree (5)

**Have you ever been involved in writing a business case for the commissioning of services to support the nutritional management of patients living with MND?**

- Yes (1)
- No (2)
- Unsure (3)

**Please provide your email address at the end of the survey if you would be happy to share the details.**

---

**What level of priority do you believe is given to commissioning services that support the nutritional management of patients living with MND?**

Very low priority (1)

Low priority (2)

Medium priority (3)

High priority (4)

Very high priority (5)

**If you have any additional comments or experiences that you would like to share about the structure and commissioning of nutrition and dietetic services for people living with MND please include these here:**

---

**Since you indicated that you are a dietitian, we have a brief set of additional questions for you. Are you happy to proceed?**

Yes (1)

No (2)

#### **Additional questions for dietitians**

**What groups of patients do you see? (tick all that apply)**

- MND patients only (1)
- Neurology mixed caseload (2)
- Care of the elderly (3)
- Oncology (4)
- Renal (5)
- Cystic fibrosis (6)
- General nutrition support (7)
- Haematology (8)
- ENT (9)
- Gastroenterology (10)
- Diabetes (11)
- Weight management (12)
- Paediatrics (13)

Other (14)

**Where do you see MND patients for the first consultation? (tick all that apply)**

Inpatient hospital ward (following admission for investigation into symptoms) (1)

Inpatient hospital ward (after diagnosis of MND) (2)

Inpatient hospital ward (following admission for gastrostomy insertion – before procedure) (3)

Inpatient hospital ward (following admission for gastrostomy insertion – after procedure) (4)

General outpatient clinic (5)

MND outpatient clinic (follow-up routine visit after diagnosis) (6)

GP surgery (7)

Patients home (before diagnosis, after diagnosis, before gastrostomy, after gastrostomy) (8)

Hospice (9)

Other (10)

If Other, please specify: \_\_\_\_\_

**In your experience when are patients with MND first referred to the dietetic service?**

- Pre-MND diagnosis (1)
- At the time of MND diagnosis (2)
- When nutritional problems identified in MND clinic (3)
- When nutritional problems identified by non-MND professionals (4)
- At the time of enteral feeding initiation (5)
- Unsure (6)
- Other (7)

If Other, please specify: \_\_\_\_\_

**In your experience, are patients with MND referred for dietetic advice:**

- Too early (1)
- About the right time (2)

Too late (3)

Unsure (4)

**When you first see a patient with MND are they usually:**

Nutritionally stable (1)

Nutritionally stable but starting to experience nutritional problems (e.g. weight loss or reduced food intake) (2)

Experiencing a non-significant (e.g. less than 10% weight loss in 6 months) reduction in weight (3)

Experiencing significant reduction in weight (>10% weight loss in previous 6 months) (4)

Making a decision to have gastrostomy placed (5)

**What measures do you use to determine the nutritional status of patients? (tick all that apply)**

Body weight (1)

Body mass index (BMI) (2)

% of weight loss from premorbid weight (3)

% of weight loss from diagnosis weight (4)

% of weight loss of previous 3-6 months (5)

Triceps skinfold thickness (TSF) (6)

Mid upper arm muscle circumference (MUAMC) (7)

Bioelectrical impedance analysis (BIA) (8)

Dual-energy X-ray absorptiometry (DEXA) (9)

Magnetic resonance imaging (MRI) (10)

Computerized tomographic (CT) scanning (11)

Ultrasound (12)

Subjective global assessment (13)

Other (14)

If Other, please specify: \_\_\_\_\_



**How often do you weigh patients?**

- At least once every month (1)
- Every 2 months (2)
- Every 3 months (3)
- Less than every 3 months (4)

**Do you believe that this is frequent enough?**

- Yes (1)
- No (2)
- Unsure (3)

**Do you ever ask patients to self-monitor their weight?**

- Yes (1)
- No (2)

**How often do you feel people with MND should be weighed to identify nutritional problems? Every:**

Week (1)

1-4 weeks (2)

Month (3)

2 months (4)

3 months (5)

> 3 months (6)

**How do you rate the nutritional support people with MND receive in your area?**

Very poor (1)

Poor (2)

Fair (3)

Good (4)

Excellent (5)

**How do you usually calculate the ideal body weight (IBW) of patients with MND?**

- Body mass index (BMI) (1)
- Hamwi equation (2)
- Pre-morbid weight (3)
- I don't usually calculate IBW (4)
- Other (5)

If Other, please specify: \_\_\_\_\_

**How do you usually assess the nutritional intake of patients with MND?**

- 24-hour recall (1)
- Diet history (of meal patterns, typical portion sizes and snacks consumed) (2)
- 3-day food diary (3)
- 7-day food diary (4)
- I don't usually assess nutritional intake (5)
- Other (6)

If Other, please specify: \_\_\_\_\_

**What nutrient values do you estimate the intake of and how frequently**

	Never (1)	Occasionally (2)	At most reviews (3)	At every review (4)
Energy (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Protein (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fat (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Carbohydrate (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Vitamins (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Minerals (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fluid (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Fibre (8)

**How do estimate the nutritional content of patients' oral intake? (tick all that apply)**

Estimate using my knowledge of the nutritional content of foods (1)

McCance and Widdowson's The composition of foods (2)

Dietary analysis computer software package (please state which one) (3)

Web-based dietary analysis package (4)

Unsure (5)

Other (6)

If Other, please specify: \_\_\_\_\_

**Do you ever ask people with MND to self-monitor their nutritional intake?**

Yes (1)

No (2)

**How do you usually calculate the energy requirements of patients with MND?**

- Indirect calorimetry (1)
- Resting Metabolic Rate (RMR predictive equations) (2)
- Harris-Benedict (1919) equation (3)
- Schofield (1985) equation (4)
- Ireton-Jones (2002) equation (5)
- Mifflin-St Jeor (1990) equation (6)
- Owen (1986, 1987) equation (7)
- Rosenbaum (1996) equation (8)
- Wang (2000) equation (9)
- Henry (2005) equation (10)
- Kasarskis (2014) equation (11)
- I don't usually estimate energy requirements (13)
- Other (12)

If Other, please specify: \_\_\_\_\_

**Do you add additional calories (stress factor) to the estimated energy requirement due to having a diagnosis of MND?**

Yes, in every case (1)

Yes, in some cases (2)

Never (3)

Unsure (4)

**What percentage?**

(1)

6-10% (2)

11-15% (3)

16-20% (4)

21-25% (5)

26-30% (6)

>30% (7)

**At what stage of their illness?**

---

**What is your rationale for adding a stress factor? (tick all that apply)**

Hypermetabolic effect of disease (1)

Patient on non-invasive ventilation (2)

Metabolic effect associated with patient being in respiratory failure (3)

Other (4)

If Other, please specify: \_\_\_\_\_

**If a patient had the following BMI (kg/m<sup>2</sup>) would you aim be for weight loss, weight maintenance or weight gain?**

	Weight loss (1)	Weight maintenance (2)	Weight gain (3)
BMI < 18.5 (kg/m <sup>2</sup> ) (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



BMI 18.5-25 (kg/m<sup>2</sup>)

(2)

BMI 25-30 (kg/m<sup>2</sup>)

(3)

BMI > 30 (kg/m<sup>2</sup>) (4)

**How do you calculate protein requirements?**

Parenteral & Enteral Nutrition Group (PENG) guidelines (1)

Dietary reference value (1991) (2)

Other (3)

If Other, please specify: \_\_\_\_\_

**How do you estimate hydration (fluid) requirements for patients with MND?**

\_\_\_\_\_

**Approximately how long does an initial consultation with a new patient with MND last?**

Less than 10 minutes (1)

10 to 20 minutes (2)

20 to 30 minutes (3)

30 to 40 minutes (4)

40 to 50 minutes (5)

50 to 60 minutes (6)

More than 60 minutes (7)

**How often do you recommend oral nutritional supplements at your first contact with people with MND?**

Never (1)

Rarely (2)

Sometimes (3)

Often (4)

Almost always (5)

**How likely would you recommend the following?**

	Very unlikely (1)	Unlikely (2)	Neither likely nor unlikely (3)	Likely (4)	Very likely (5)
Ready to drink milk based supplements (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Juice based supplement (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Powdered supplements reconstituted with milk (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Modular liquid calorie dense supplements	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(4)

Modular

powdered  
supplements

(5)

**Please describe any other types of supplement that you advise patients with MND to take:**

---

**Approximately, how often do you routinely follow-up / monitor your MND patients that are receiving oral nutritional advice?**

- Once a week or more (1)
- Every two weeks (Fortnightly) (2)
- Every month (3)
- Every 2 to 3 months (4)

- Every 3 to 4 months (5)
- Every 4 to 5 months (6)
- Every 5 to 6 months (7)
- Every 6 to 12 months (8)
- Annually or less often (9)
- I do not usually provide routine follow-up (10)

**Approximately, how often do you routinely follow-up / monitor your MND patients that are receiving artificial nutrition support?**

- Once a week or more (1)
- Every two weeks (Fortnightly) (2)
- Every 4 weeks (Monthly) (3)
- Every 5 to 8 weeks (4)
- Every 2 to 3 months (5)
- Every 4 to 5 months (6)

- Every 6 months (7)
- Annually or less (8)
- I do not usually provide routine follow-up (9)

**Approximately how long does a follow-up consultation with a patient with MND last?**

- Less than 10 minutes (1)
- 10 to 20 minutes (2)
- 20 to 30 minutes (3)
- 30 to 40 minutes (4)
- 40 to 50 minutes (5)
- 50 to 60 minutes (6)
- More than 60 minutes (7)

**Where does nutritional monitoring of patients with MND take place? (tick all that apply)**

- NHS Hospital in patient service (1)

NHS Hospital out patient specialist MND clinic (2)

NHS Hospital out patient neurology clinic (3)

NHS Hospital out patient general clinic (4)

Community General Practice (GP) clinic (5)

Patient's home (6)

Palliative care centre / hospice (7)

Private Hospital in patient service (8)

Private Hospital out patient service (9)

Other (10)

If Other, please specify: \_\_\_\_\_

**How are patients with MND that are unable to attend clinic monitored? (tick all that apply)**

Home visits (1)

Phone review (2)

They are not monitored (3)

Unsure (4)

Other (5)

If Other, please specify: \_\_\_\_\_

**Are patients that are unable to attend clinic able to be weighed?**

Yes (1)

No (2)

Unsure (3)

Please specify how: \_\_\_\_\_

**In your locality, are patients who are unable to stand on weighing scales able to be weighed?**

Yes (1)

No (2)



Unsure (3)

**Please specify how:**

---

**What dietetic goals do you set in the nutritional management of patients with MND receiving oral nutrition support?**

Achieve and maintain ideal body weight (IBW) (1)

Achieve premorbid weight (2)

Achieve pre-diagnosis weight (3)

Maintain current weight regardless of premorbid weight or IBW (4)

Gain weight regardless of current weight (5)

Meet nutritional requirements (6)

I do not set dietetic goals (7)

Other (8)

If Other, please specify: \_\_\_\_\_

**How often do you feedback to the MND MDT about your involvement and recommendations to people with MND?**

- Never (1)
- Rarely (2)
- Sometimes (3)
- Often (4)
- Almost always (5)

**How effective do you believe that your monitoring is, of the outcome of nutritional interventions commenced, for people with MND?**

- Not at all effective (1)
- Slightly effective (2)
- Moderately effective (3)
- Very effective (4)
- Extremely effective (5)

**If you have any additional comments or experiences that you would like to share about the structure and commissioning of nutrition and dietetic services for people living with MND please include these here:**

### **Prize draw**

If you would like to enter the prize draw for the chance to win £200, please provide your email address:

If you have been involved in writing a business case for the commissioning of services to support the nutritional management of people living with MND and you are happy to share your experiences, please provide your email address so that we can get in touch: