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Supplementary Information 2. Complete data set of survey responses from dietitians to the survey

Nutritional screening

Question	n (%)
Does routine nutritional screening occur for people with ALS? (N=129)	
Yes	54 (42)
No	25 (19)
Unsure	46 (36)
Not relevant to my role	4 (3)
Is a screening tool used? (N=54)	
Yes	36 (67)
No	12 (22)
Unsure	6 (11)
Which screening tool is used? (N=36)	
MUST	30 (83)
SGA	0 (0)
Locally developed screening tool	5 (14)
Other	1 (3)
Who performs screening? (N=54)	
Neurologist	11 (20)
ALS nurse	28 (52)
Nurse	31 (57)
Doctor	11 (20)
Healthcare support worker	12 (22)
Dietitian	29 (54)
Other	10 (19)
Unsure	1 (2)
Where is the nutritional screening taking place? (n=54)	
At specialist ALS clinic	24 (44)
Hospital ward	27 (50)
Home visit	27 (50)
General out-patient clinic	9 (17)

Attendance at GP surgery	8 (15)
At specialist neurology clinic	8 (15)
Other	9 (17)
Unsure	54 (100)
When does nutritional screening take place? (N=54)	
At diagnosis	28 (52)
At every follow up appointment at ALS clinic	22 (41)
In-patient admission	28 (52)
When there are indications that nutrition may be a concern	30 (56)
Ad-hoc	9 (7)
Other	8 (15)
Unsure	4 (7)
Is screening recorded in a standard way? (N=124)	
Yes, in electronic form	39 (32)
Yes, in paper form	32 (26)
No	37 (30)
Other	16 (13)
How successful do you feel the healthcare team is at identifying nutritional issues in people with ALS? (N=130)	
Unsuccessful	4 (3)
Slightly successful	12 (9)
Moderately successful	56 (43)
Very successful	53 (4)
Extremely successful	5 (4)

Dietetic referral

Question	n (%)
What factors would initiate a referral to a dietitian? (N=129)	
All people with ALS are referred	34 (26)
Low BMI	86 (67)
Bulbar symptoms	66 (51)
Recurrent chest infections due to aspiration	49 (38)

Deteriorating respiratory function	32 (25)
Deteriorating ALSFRS score	4 (3)
Patient/carer reporting extended mealtimes	49 (38)
Patient/carer reporting poor dietary intake	101 (78)
Patient/carer reporting weight loss	105 (81)
Patient/carer reporting problems with swallowing	72 (56)
Unsafe swallow assessment by SLT	110 (85)
As a result of using a nutrition screening tool	81 (62)
Weight loss	108 (84)
How easy is it to refer to a dietitian (N=130):	
Very easy	66 (51)
Easy	39 (30)
Neither easy or difficult	19 (15)
Difficult	5 (4)
Very difficult	1 (1)
Which healthcare professionals normally provide referrals into your service? (N=130)	
Doctor	118 (91)
Nurse	111 (85)
OT	37 (29)
Physiotherapist	41 (32)
Psychologist	9 (7)
SLT	115 (89)
Other (other RD; care home; healthcare assistants; ALS care coordinator)	24 (19)
When are people with ALS first referred to dietetic service? (N=129)	
Pre MND diagnosis	2 (2)
At the time of ALS diagnosis	25 (19)
When nutritional problems identified in ALS clinic	57 (44)
When nutritional problems identified by non-ALS professionals	19 (15)
At the time of enteral feeding initiation	15 (12)
Unsure	4 (3)
Other (e.g. for pre-gastrostomy discussion; during in-patient stay;	7 (5)
In your experience, are people with ALS referred for dietetic advice	

(N=129):	
Too early	1 (1)
About the right time	64 (50)
Too late	57 (44)
Unsure	7 (5)

Figure 4. Nutritional assessment

Question	n (%)
When are patients routinely weighed:	
Patients are not weighed	0 (0)
Ad hoc	34 (26)
When there are indications that nutrition may be a concern	54 (42)
At diagnosis	41 (32)
In-patient admission	51 (39)
At 3 monthly hospital follow-up appointments	32 (25)
At 6 monthly hospital follow-up appointments	13 (10)
At annual hospital follow-up appointments	11 (9)
At each GP clinic visit	3 (2.3)
Unsure	37 (29)
Other	23 (18)
What weighing scales available to weigh people with ALS? (N=130)	
Hoist scales	58 (45)
Step on scales	102 (79)
Wheelchair scales	85 (65)
We don't have equipment	1 (1)
Unsure	14 (11)
Other	21 (16)
How often do people with ALS have nutritional issues at diagnosis?:	
Always	7 (5)
Most of the time	43 (33)
About half the time	35 (27)
Sometimes	44 (34)

Never	0 (0)
When first seen a person with ALS is usually (N=129):	
Nutritionally stable	3 (2.3)
Nutritionally stable but starting to experience nutritional problems (e.g. weight loss or reduced food intake)	51 (40)
Experiencing a non-significant (e.g. less than 10% weight loss in 6 months) reduction in weight	17 (13)
Experiencing significant reduction in weight (>10% weight loss in previous 6 months)	30 (23)
Making a decision to have gastrostomy placed	28 (22)
What measures do you use to determine the nutritional status of patients? (N=130)	
Body weight	119 (92)
BMI	119 (92)
MUAMC	40 (31)
TSF	2 (2)
BIA	1 (1)
% weight loss from pre-morbid weight	86 (66)
% weight loss from diagnosis weight	63 (49)
% weight loss previous 3-6 months	106 (82)
SGA	30 (23)
Other (e.g. blood biochemistry; exercise capacity; clinical presentation; hand grip dynamometry; MUST; subjective assessment)	13 (10)
How do you usually calculate the ideal body weight (IBW) of people with ALS? (N=128):	
BMI	50 (39)
Pre-morbid weight	1 (1)
I don't usually calculate IBW	75 (59)
Hamwi equation	0 (0)
Other (e.g. combination of factors; specific BMI)	2 (2)
How do dietitians assess the nutritional intake of people with ALS? (N=128)	
Diet history	114 (89)

24 hour recall	6 (5)
3 day diet diary	3 (2)
7 day diet diary	3 (2)
Other (e.g. mixture of methods)	2 (2)
How is nutritional content of people with ALS diets estimated? (N=128):	
Using my knowledge of nutritional content of foods	127 (99)
McCance and Widdowsons The composition of foods	11 (9)
Dietary analysis software	11 (9)
Web-based dietary analysis package	7 (6)
Other (e.g. using hospital meal nutritional content; search engine; PENG clinical handbook)	10 (8)
Are people with ALS asked to self-monitor nutritional intake? (N=128):	
Yes	97 (76)
No	31 (24)
How energy requirements are calculated? (N=128)	
Indirect calorimetry	0 (0)
Resting Metabolic Rate predictive equation	1 (1)
Haris Benedict	3 (2)
Schofield	9 (7)
Ireton-Jones	0 (0)
Mifflin-St Jeor	0 (0)
Owen	0 (0)
Rosenbaum	0 (0)
Wang	0 (0)
Henry	106 (83)
Kasarkis	0 (0)
I don't usually calculate energy requirements	4 (3)
Other (including Oxford 2005 and ESPEN 2018; 30kcal/kg; ESPEN guidelines 2017 (ventilated non - ventilated patients, weight maintenance / gain) and use clinical judgement, best practice approach as every case is individual, patient centred approach.	5 (4)
Are stress factors added to estimated energy requirement due to ALS diagnosis? (N=128)	

Yes, in every case	27 (21)
Yes, in some cases	59 (46)
Never	36 (28)
Unsure	6 (5)
What percentage stress factor added for diagnosis of ALS? (N=86)	
<5%	3 (4)
6-10%	39 (45)
11-15%	10 (12)
16-20%	21 (24)
21-25%	7 (8)
26-30%	2 (2)
>30%	4 (5)
What is the rationale for adding a stress factor? (N=85)	
Hypermetabolic effect of ALS	68 (80)
On NIV	35 (41)
Metabolic effect associated with being in respiratory failure	47 (55)
Other (e.g. combination of reasons; infection; weight loss)	7 (8)
How protein requirement calculated? (N=128)	
Dietary reference value	1 (0)
PENG guideline	120 (94)
g/kg body weight	6 (5)
Other (no answer)	1 (1)
How is fluid requirement calculated?	Majority use PENG guideline: 30-35ml/kg
Approximately how long does an initial consultation with a new patient with ALS last? (N=127)	
0-20 minutes	0 (0)
20-30 minutes	9 (7)
30-40 minutes	29 (23)
40-50 minutes	20 (16)

50-60 minutes	47 (37)
More than 60 minutes	22 (17)

Estimation of total nutrient intake

What nutrient values do you estimate the intake of and how frequently? (n (%))				
	Never	Occasionally	At most reviews	At every review
Energy (N=127)	0 (0)	6 (5)	45 (35)	76 (60)
Protein (N=128)	1 (1)	6 (5)	48 (38)	73 (57)
Fat (N=117)	49 (42)	43 (37)	20 (17)	5 (4)
Carbohydrate (N=119)	45 (38)	48 (40)	21 (18)	5 (4)
Vitamins (N=121)	25 (22)	45 (37)	38 (31)	13 (11)
Minerals (N=121)	27 (22)	44 (36)	38 (31)	12 (10)
Fluid (N=126)	0 (0)	4 (3)	45 (36)	77 (61)
Fibre (N=124)	8 (7)	42 (34)	50 (40)	24 (19)

Figure 6. Nutritional intervention

Question	n (%)
How successful is the healthcare team at implementing nutritional management plans to address nutritional issues in people with ALS? (N=130)	
Unsuccessful	3 (2)
Slightly successful	16 (12)
Moderately successful	63 (49)

Very successful	46 (35)
Extremely successful	2 (2)
How effective do you believe the food first approach is for people with ALS? (N=130)	
Not very effective	3 (2)
Slightly effective	27 (21)
Moderately effective	72 (55)
Very effective	27 (21)
Extremely effective	1 (1)
How often do you recommend oral nutritional supplements at your first contact with people with ALS? (N=128)	
Never	2 (2)
Rarely	9 (7)
Sometimes	65 (51)
Often	41 (32)
Almost always	11 (9)

Recommendation of oral nutritional supplements

	How likely would you recommend the following? (n (%))				
	Very unlikely	Unlikely	Neither likely nor unlikely	Likely	Very likely
Ready to drink milk based supplements (N=125)	0 (0)	2 (2)	14 (11)	67 (54)	42 (34)
Juice based supplement (N=123)	8 (7)	21 (17)	41 (33)	46 (37)	7 (6)
Powdered supplements reconstituted with milk (N=123)	9 (7)	14 (11)	24 (20)	51 (42)	25 (20)

Modular liquid calorie dense supplements (N=122)	11 (9)	32 (26)	34 (28)	37 (30)	8 (7)
Modular powdered supplements (N=122)	26 (21)	32 (26)	34 (28)	37 (30)	8 (7)

Weight goal setting.

BMI (kg/m ²)	Weight goal dietitians would set for people with ALS (n (%))		
	Weight loss	Weight maintenance	Weight gain
<18.5 (N=130)	0 (0)	12 (9)	115 (91)
18.5-25 (N=130)	0 (0)	92 (72)	35 (28)
25-30 (N=130)	2 (2)	125 (98)	0 (0)
>30 (N=127)	27 (21)	100 (79)	(0)

Nutritional monitoring

Question	n (%)
How successful do you believe the healthcare team is at monitoring the nutritional management of people with ALS? (N=129)	
Unsuccessful	6 (5)
Slightly successful	23 (18)
Moderately successful	66 (51)
Very successful	33 (26)
Extremely successful	1 (1)
How often does dietitian weigh people with ALS? (N=126)	
At least once a month	38 (30)
Every 2 months	20 (16)
Every 3 months	32 (25)
Less than every months	36 (29)
Is frequency of weighing people with ALS enough? (N=128)	
Yes	53 (41)
No	55 (43)

Unsure	20 (16)
Do dietitians ask for people with ALS to self-monitor their weight? (N=128)	
Yes	113 (88)
No	15 (12)
How often do dietitians feel people with ALS should be weighed? (N=129)	
Weekly	19 (15)
1-4 weekly	50 (39)
Monthly	52 (40)
2 monthly	3 (2)
3 monthly	4 (3)
>3 monthly	1 (1)
Approximately, how often do you routinely follow-up / monitor your ALS patients that are receiving oral nutritional advice? (N=128)	
Once a week	13 (10)
Every 2 weeks	1 (1)
Every month	27 (21)
Every 2-3 months	55 (43)
Every 4-5 months	0 (0)
Every 5-6 months	2 (2)
Every 6-12 months	1 (1)
Annually or less often	0 (0)
I do not usually provide routine follow up	17 (13)
Approximately, how often do you routinely follow-up / monitor your ALS patients that are receiving artificial nutrition support? (N=128)	
Once a week	17 (13)
Every 2 weeks	2 (2)
Every 4 weeks	17 (13)
Every 5-8 weeks	24 (19)
Every 2 to 3 months	36 (28)
Every 4-5 months	3 (2)
Every 6 months	9 (7)
Annually or less often	0 (0)
I do not usually provide routine follow up	20 (16)

Approximately how long does a follow-up consultation with a patient with ALS last (N=128)?	
Less than 10 minutes	0 (0)
10-20 minutes	9 (7)
20-30 minutes	35 (28)
30-40 minutes	43 (34)
40-50 minutes	15 (12)
50-60 minutes	22 (17)
More than 60 minutes	3 (2)
Where does nutritional monitoring of people with ALS take place? (N=128)	
NHS Hospital in-patient service	41 (32)
NHS hospital out-patient specialist ALS clinic	25 (20)
NHS hospital out-patient neurology clinic	10 (8)
NHS hospital out-patient general clinic	0 (0)
Community general practice (GP) clinic	16 (13)
Patients home	97 (76)
Palliative care centre/hospice	30 (23)
Private hospital in-patient service	0 (0)
Private hospital out-patient service	0 (0)
Other (care homes; health centres; telephone; community dietetic clinic; nutrition support clinic)	13 (10)
How are people with ALS that are unable to attend clinic monitored? (N=126)	
Home visits	101 (80)
Phone review	73 (58)
They are not monitored	3 (2)
Unsure	5 (4)
Other (e-mail; by others; on-line)	13 (10)
Are people with ALS that are unable to attend clinic able to be weighed? (N=127)	
Yes	79 (62)
No	14 (11)
Unsure	34 (27)

In your locality, are patients who are unable to stand on weighing scales able to be weighed? (N=127)	
Yes	104 (82)
No	14 (11)
Unsure	9 (7)
What dietetic goals do you set in the nutritional management of people with ALS receiving oral nutrition support? (N=128)	
Achieve and maintain ideal body weight (IBW)	49 (38)
Achieve pre-morbid weight	10 (8)
Achieve pre-diagnosis weight	7 (6)
Maintain current weight regardless of premorbid weight or IBW	72 (56)
Gain weight regardless of current weight	4 (3)
Meet nutritional requirements	95 (74)
I do not set dietetic goals	2 (2)
Other (focus on QOL; goals depend on stage of disease; depends on what is achievable for patient; focus on functional outcomes; realistic goal setting; patient centred goal setting; slow rate of weight loss)	25 (19)
How effective do you believe that your monitoring is, of the outcome of nutritional interventions commenced, for people with ALS? (n=127)	
Not at all effective	2 (2)
Slightly effective	12 (9)
Moderately effective	57 (45)
Very effective	55 (43)
Extremely effective	1 (1)