

**Specialised AAC services for people with MND:
evidence of the current position**

**APPENDIX: full results of the survey of speech and language therapists
(SLTs) conducted June 11th to July 6th 2015**

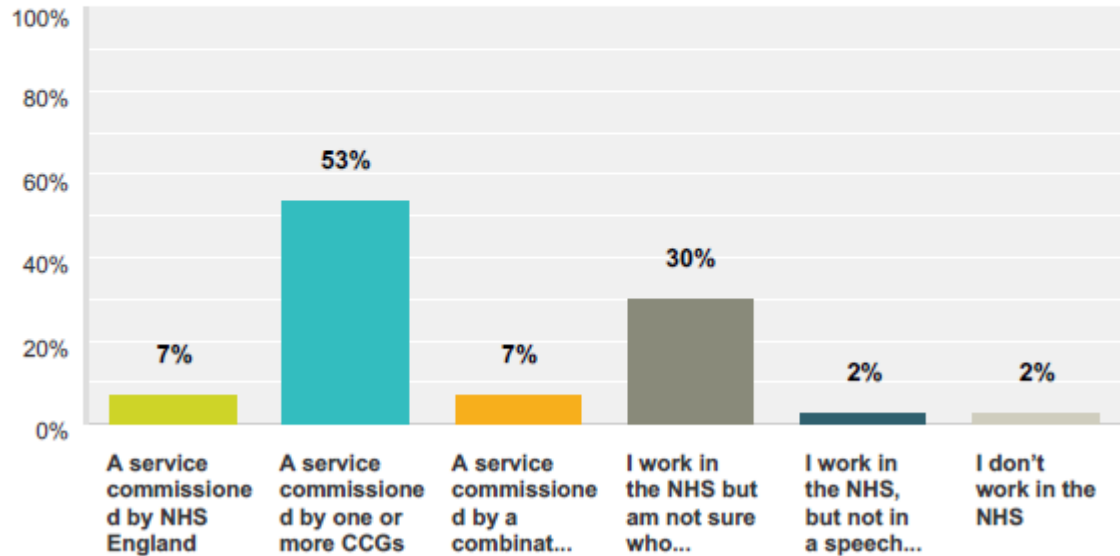
1. What organisation do you work for?

Of the 43 respondents, 34 named their employer. Respondents were told that the area they work in may be identified, but the services they work for would not. Accordingly, here we list the areas in which respondents work:

- Bedfordshire
- Birmingham
- Blackpool
- Bromley (Kent)
- Buckinghamshire
- Essex
- Herefordshire
- Hertfordshire
- Lincolnshire
- London
- Northamptonshire
- Shropshire
- Surrey
- Sussex
- Warwickshire
- York
- East Yorkshire.

Q2 Do you work for an organisation that is commissioned by NHS England, or a CCG, in respect of speech and language or AAC services?

Answered: 43 Skipped: 0

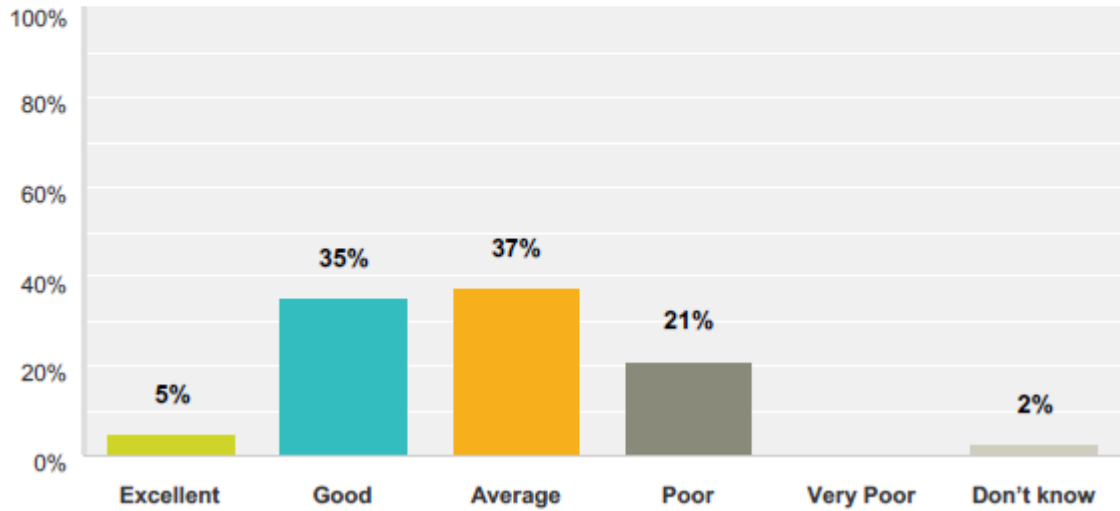


Answer Choices	Responses
A service commissioned by NHS England	7% 3
A service commissioned by one or more CCGs	53% 23
A service commissioned by a combination of NHS England and CCGs	7% 3
I work in the NHS but am not sure who commissions the service	30% 13
I work in the NHS, but not in a speech and language or AAC service	2% 1
I don't work in the NHS	2% 1
Total Respondents: 43	

It is clear that most respondents were SLTs in local services rather than the new hubs. The results also provide a further suggestion that commissioning can often be an opaque matter to those on the front line, with a substantial portion of respondents unsure who commissions the service they work in.

Q3 How would you rate the level of communication support currently offered to the people with MND you work with?

Answered: 43 Skipped: 0

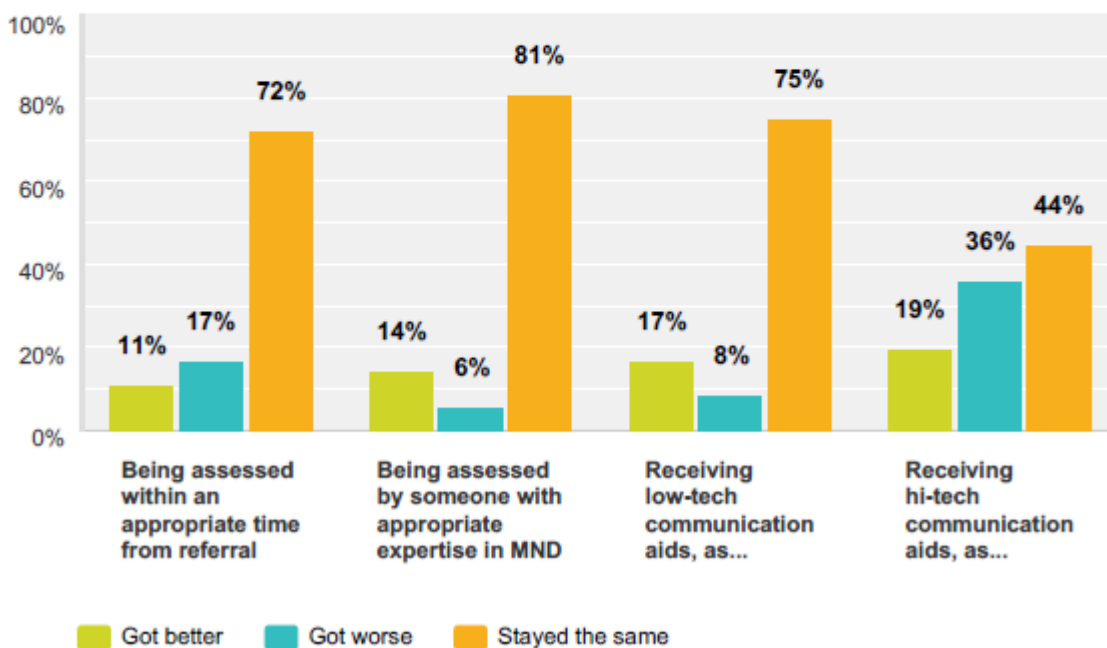


Answer Choices	Responses	Count
Excellent	5%	2
Good	35%	15
Average	37%	16
Poor	21%	9
Very Poor	0%	0
Don't know	2%	1
Total		43

This question was reproduced from the APPG report, and is discussed in section 2 of the main report.

Q4 Thinking about the period from APRIL 2013 to the end of OCTOBER 2014, in your view how did the following aspects of communication support change for the people with MND you work with?

Answered: 36 Skipped: 7

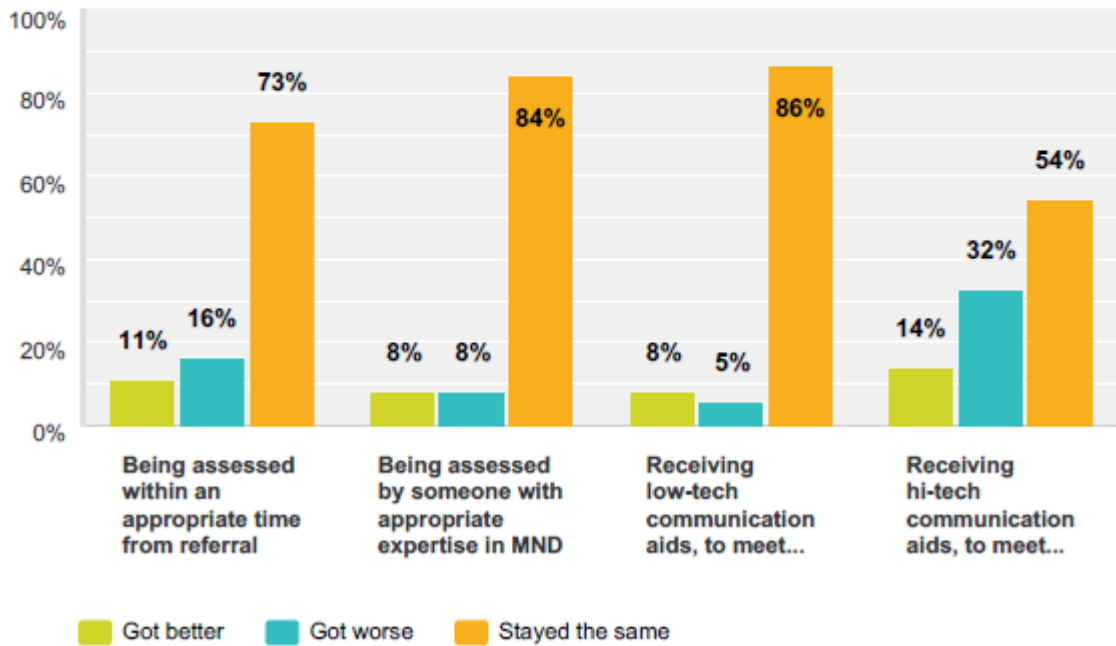


	Got better	Got worse	Stayed the same	Total
Being assessed within an appropriate time from referral	11% 4	17% 6	72% 26	36
Being assessed by someone with appropriate expertise in MND	14% 5	6% 2	81% 29	36
Receiving low-tech communication aids, as identified in an assessment, in a timely way	17% 6	8% 3	75% 27	36
Receiving hi-tech communication aids, as identified in an assessment, in a timely way	19% 7	36% 13	44% 16	36

The small sample size makes it difficult to draw detailed conclusions from the exact figures presented here, although the contrast between the responses in respect of hi-tech aids and the other items is striking, and appears to reinforce the APPG report's conclusion that problems occurred in this area during this period.

Q5 Thinking about the period from NOVEMBER 2014 to now, in your view how did the following aspects of communication support change for the people with MND you work with?

Answered: 37 Skipped: 6

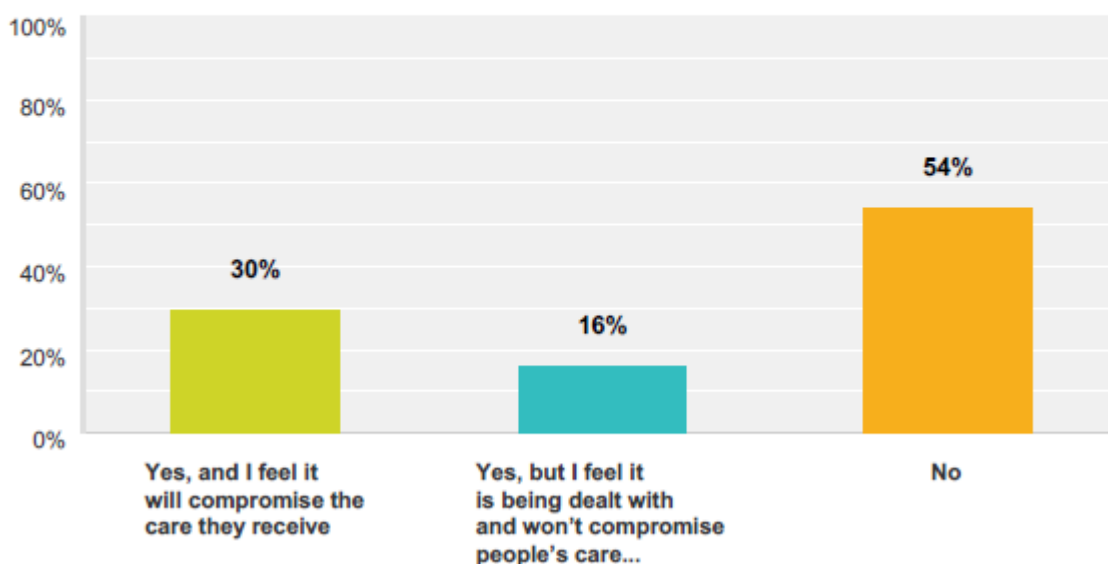


	Got better	Got worse	Stayed the same	Total
Being assessed within an appropriate time from referral	11% 4	16% 6	73% 27	37
Being assessed by someone with appropriate expertise in MND	8% 3	8% 3	84% 31	37
Receiving low-tech communication aids, to meet needs identified in an assessment, in a timely way	8% 3	5% 2	86% 32	37
Receiving hi-tech communication aids, to meet needs identified in an assessment, in a timely way	14% 5	32% 12	54% 20	37

The results of this question are discussed in section 2 of the main report. As with question 4, perhaps the clearest available conclusion is that the picture in respect of hi-tech aids continues to be worse than for other aspects of AAC, and possibly even that a deterioration in services has continued in some areas.

Q6 Are you aware of a backlog of people with MND waiting for assessment in your area?

Answered: 37 Skipped: 6



Answer Choices	Responses	
Yes, and I feel it will compromise the care they receive	30%	11
Yes, but I feel it is being dealt with and won't compromise people's care significantly	16%	6
No	54%	20
Total		37

Superficially, this appears a reasonably positive response: while the free text responses and other sources of evidence discussed in the report indicate clearly that substantial backlogs exist in some hubs, many respondents felt there was no backlog. However, analysis of individual response shows that respondents from the same area often gave differing perspectives on this issue: this suggests that the extent to which backlogs pose a threat to the care of a given person with MND may depend on the skill of their SLT in navigating the system, and that knowledge and expertise are too variable in this respect. This is supported by the answers to later questions.

Respondents who indicates they were not aware of a backlog were from:

- Bedfordshire
- Birmingham
- Bromley
- Essex
- Hertfordshire
- Lincolnshire
- London
- Northamptonshire
- Warwickshire
- York

Respondents who felt that although there was a backlog it was not affecting patient care were from:

- Blackpool
- Bedfordshire
- Essex
- Herefordshire
- Hertfordshire
- London
- Shropshire.

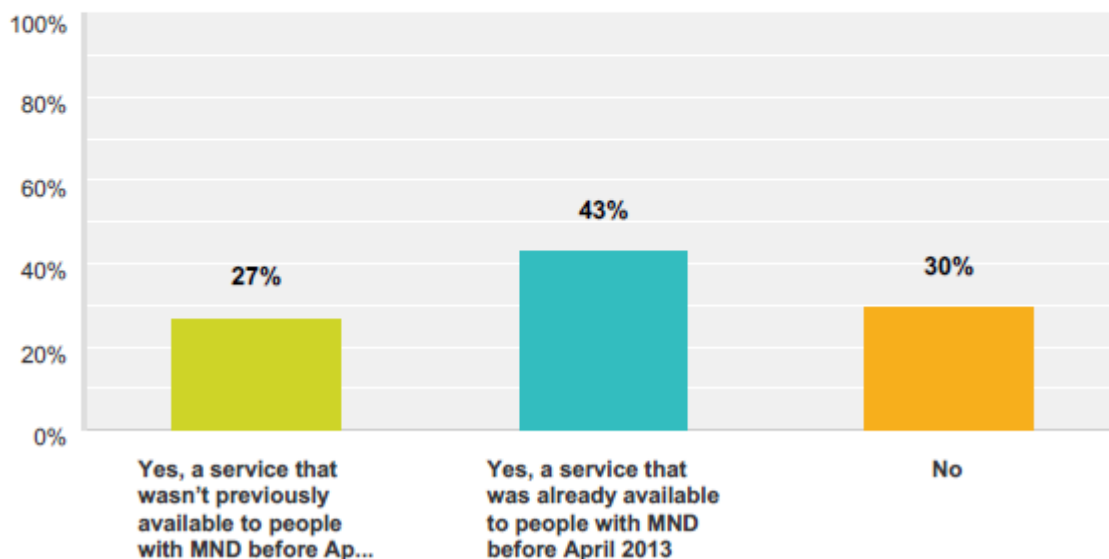
Respondents who felt the backlog was harming patient care were from:

- Birmingham
- Blackpool
- Hertfordshire
- London
- Surrey
- East Yorkshire.

Numerous areas appear in two or more sets of responses, which strongly suggests that these results tell us more about perceptions on the part of SLTs than specifically about the status of individual services. These perceptions are of course vitally important, however, as people with MND will rely on these professionals to guide them through the system.

Q7 Are you aware of a specialist NHS AAC service in your area for people with MND? This can include the organisation you work for, if applicable.

Answered: 37 Skipped: 6

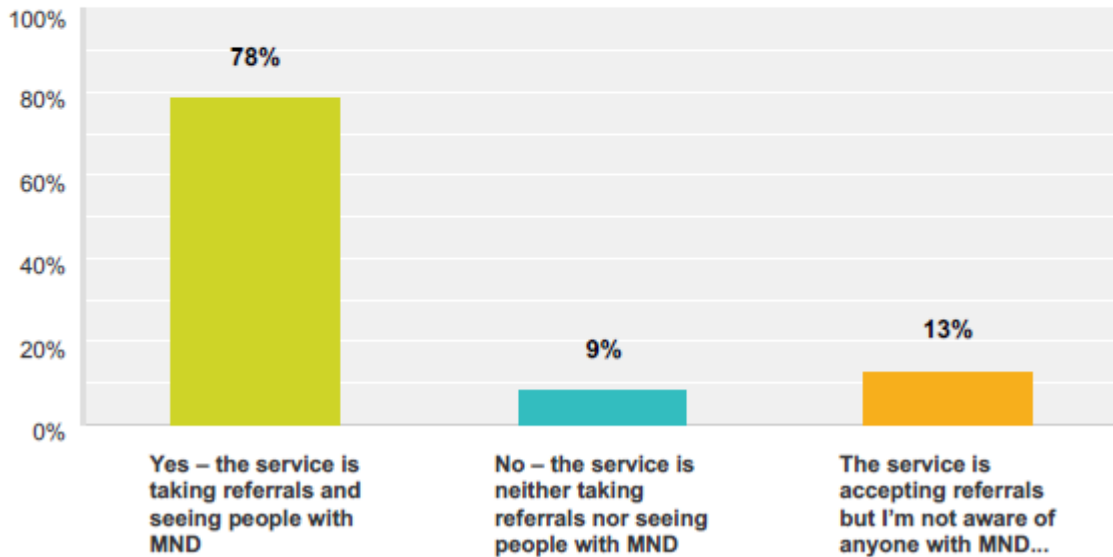


Answer Choices	Responses	
Yes, a service that wasn't previously available to people with MND before April 2013	27%	10
Yes, a service that was already available to people with MND before April 2013	43%	16
No	30%	11
Total		37

The respondents who answered 'no' were mainly in areas to be served by the East of England hub when it is established, or the Barnsley hub once it has expanded the population it covers (specifically they were from Bedfordshire, Essex, Hertfordshire, London, York and East Yorkshire). However, this does suggest confusion about how to get patients in these areas to specialised services in the interim, as it is not strictly correct to say that no service is available – other hubs should be seeing patients from these areas, and in some cases are already doing so.

Q8 In your reply to the previous question, you said you know of a specialist AAC service for people with MND in your area. Are people with MND currently being seen by this service?

Answered: 23 Skipped: 20



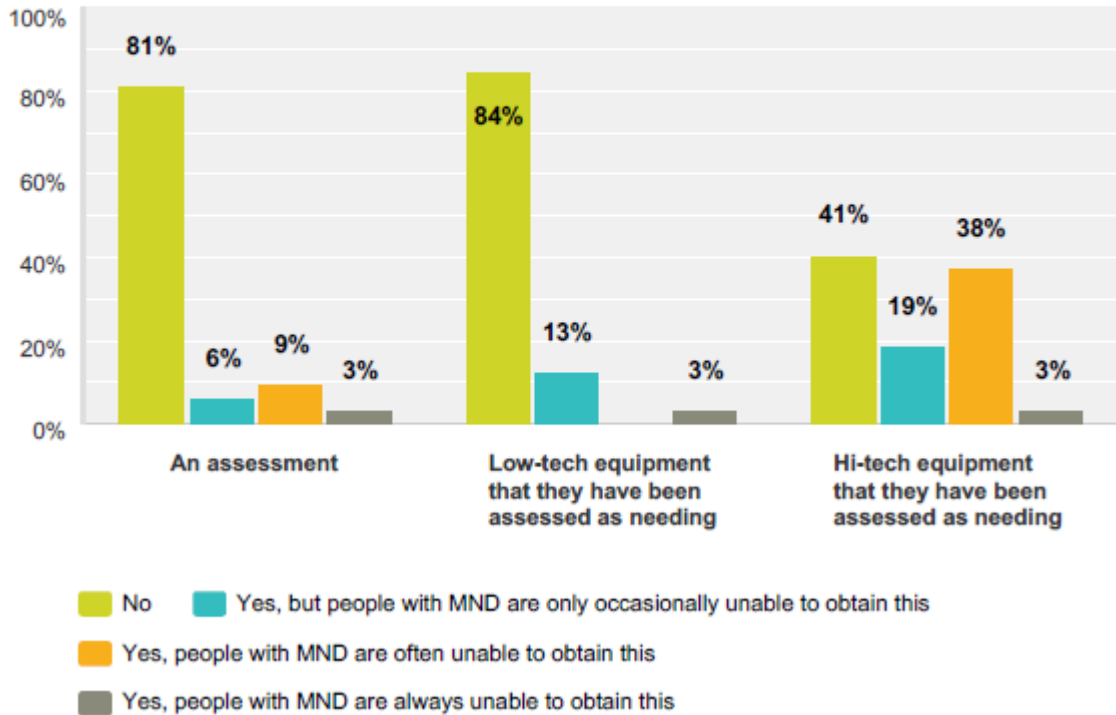
Answer Choices	Responses
Yes – the service is taking referrals and seeing people with MND	78% 18
No – the service is neither taking referrals nor seeing people with MND	9% 2
The service is accepting referrals but I'm not aware of anyone with MND having been seen by it yet	13% 3
Total	23

The respondents who indicated the service is not yet taking referrals were from Lincolnshire (consistent with the hub’s report on the Communication Matters website that it is not currently taking referrals) and Northamptonshire.

There is no readily apparent pattern among those who indicated they were unaware of the service having seen anyone with MND yet; this may be a matter of personal experience on the part of the SLTs involved rather than any indication of a problem.

Q9 Since the start of March 2015, has any person with MND that you work with been unable to secure any of the following?

Answered: 32 Skipped: 11

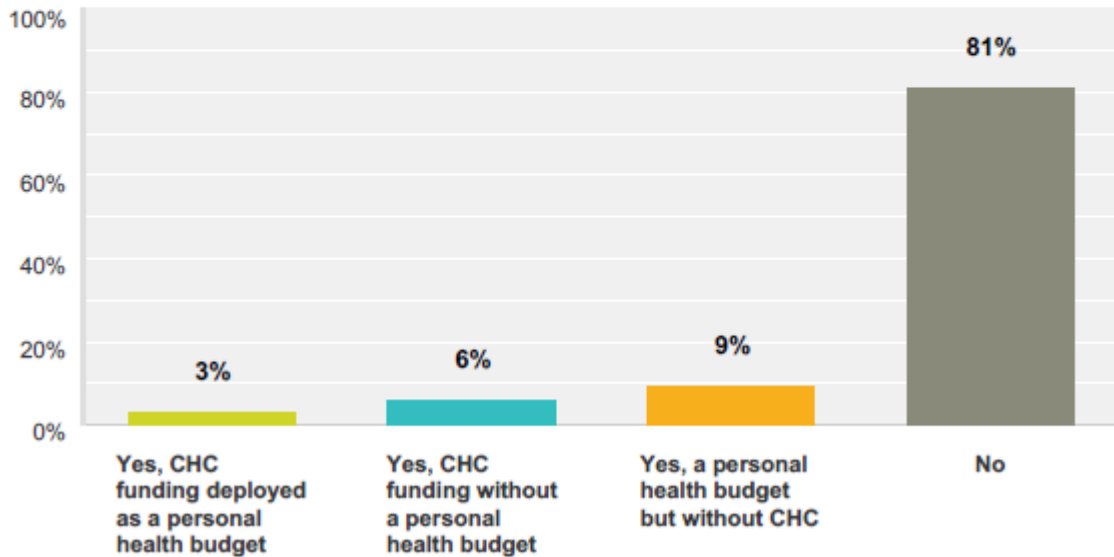


	No	Yes, but people with MND are only occasionally unable to obtain this	Yes, people with MND are often unable to obtain this	Yes, people with MND are always unable to obtain this	Total
An assessment	81% 26	6% 2	9% 3	3% 1	32
Low-tech equipment that they have been assessed as needing	84% 27	13% 4	0% 0	3% 1	32
Hi-tech equipment that they have been assessed as needing	41% 13	19% 6	38% 12	3% 1	32

As with questions 4 and 5, it is probably not feasible to draw detailed conclusions from this data, although the results in respect of hi-tech aids again contrast notably with those for assessments and low-tech aids, supporting the conclusion that specialised services still have some way to go in delivering for people with MND.

Q10 Are you aware of any cases of a person with MND using NHS Continuing Healthcare (CHC) funding, and/or a personal health budget, to obtain AAC?

Answered: 32 Skipped: 11

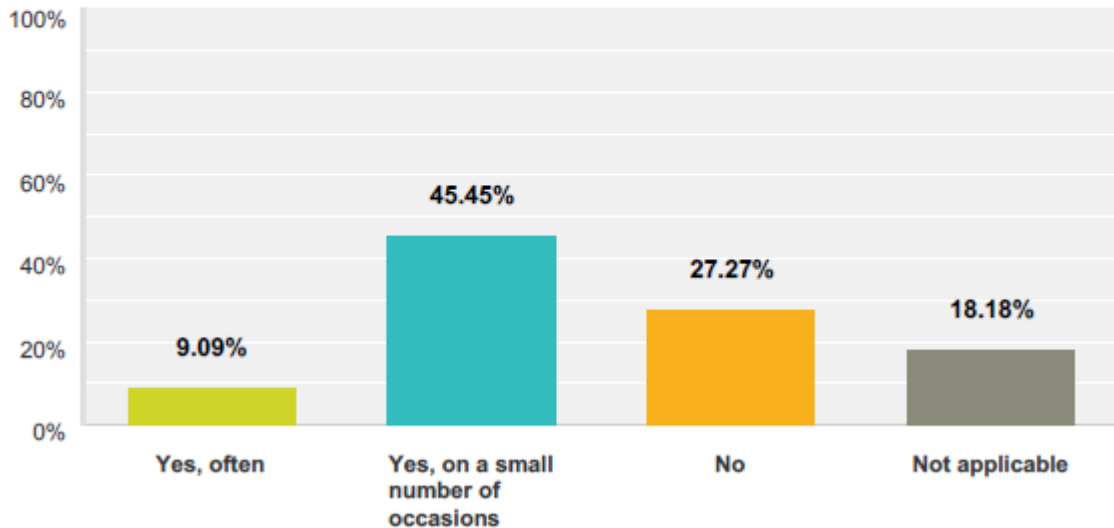


Answer Choices	Responses	
Yes, CHC funding deployed as a personal health budget	3%	1
Yes, CHC funding without a personal health budget	6%	2
Yes, a personal health budget but without CHC	9%	3
No	81%	26
Total		32

Overall, CHC and personal budgets appear not to be common ways of accessing AAC.

Q11 Since the start of March 2015, have you had to approach organisations outside the NHS to secure funding for a hi-tech communications aid?

Answered: 33 Skipped: 10

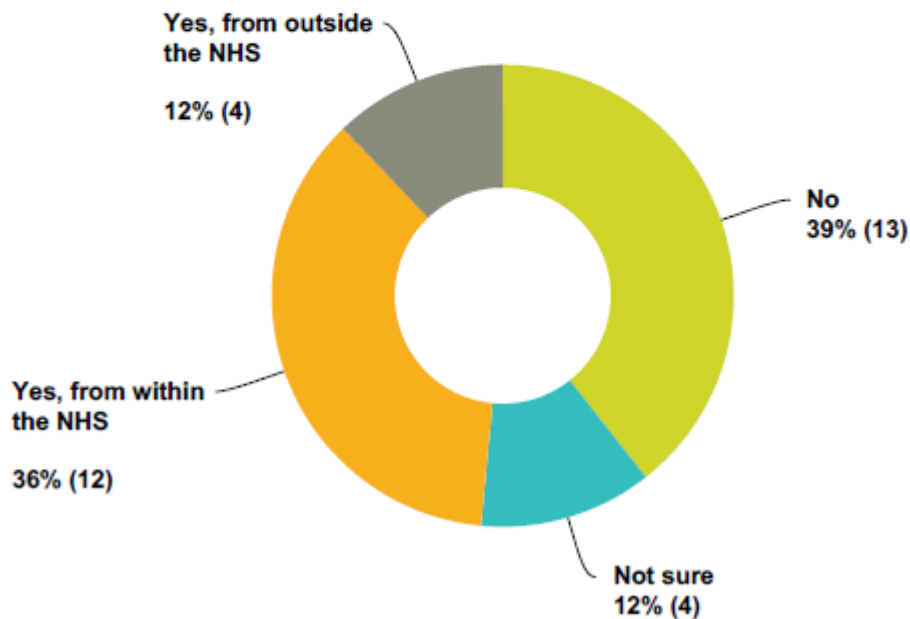


Answer Choices	Responses
Yes, often	9.09% 3
Yes, on a small number of occasions	45.45% 15
No	27.27% 9
Not applicable	18.18% 6
Total	33

Many SLT respondents indicated that recourse to charitable support is still sometimes necessary in order to ensure that people with MND receive the services they need. This appears consistent with the data presented in the main report on MND Association support grants.

Q12 Have you received any communication or training on how the new system is intended to operate in respect of specialised AAC, following the reforms?

Answered: 33 Skipped: 10

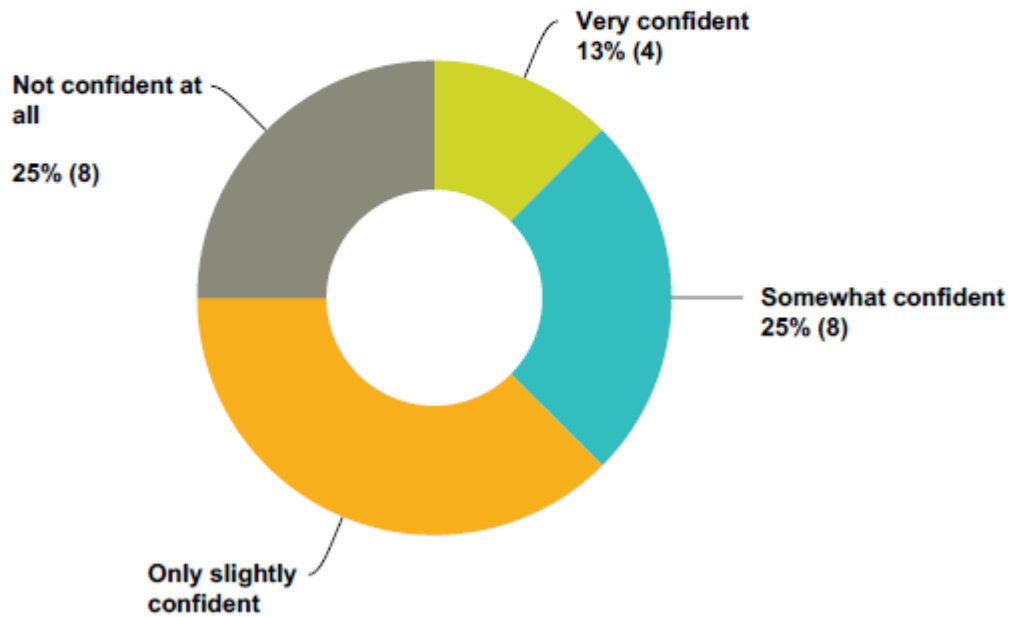


Answer Choices	Responses	
No	39%	13
Not sure	12%	4
Yes, from within the NHS	36%	12
Yes, from outside the NHS	12%	4
Total		33

This question and the ones that follow were intended to explore the extent to which SLTs understand the new system and feel confident in navigating it to ensure that it provides the best possible support to their patients. Overall they suggest that there is more to do in ensuring this, and the substantial proportion of respondents who have received no training indicates that more work is needed. The main report outlines how numerous hubs report that they are planning training programmes.

Q13 How confident are you that you understand how the system for getting specialised AAC for people with MND is supposed to operate?

Answered: 32 Skipped: 11

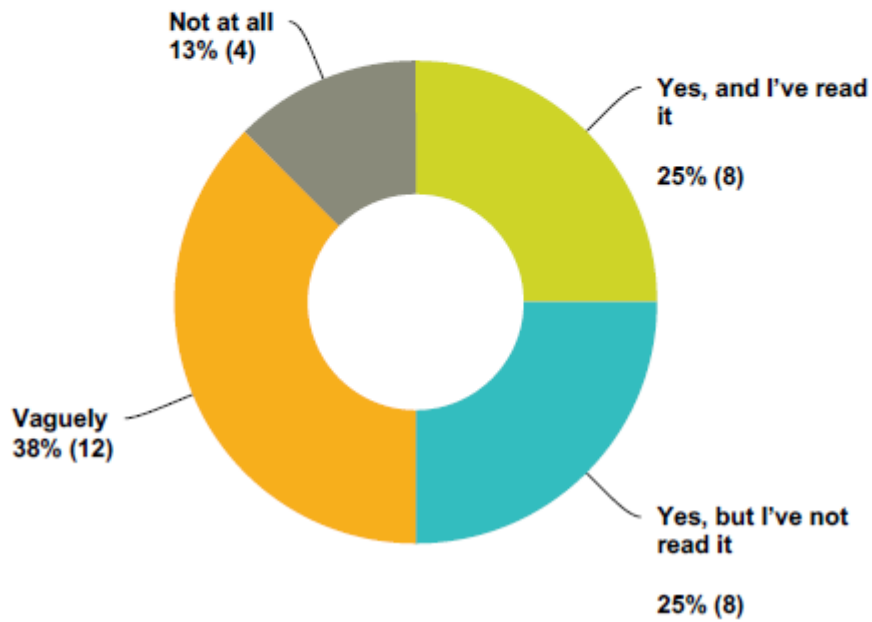


Answer Choices	Responses	
Very confident	13%	4
Somewhat confident	25%	8
Only slightly confident	38%	12
Not confident at all	25%	8
Total		32

These responses show a considerable variation in the extent to which SLTs feel confident in navigating the new system.

Q14 Are you aware of the existence of the service specification for specialised AAC, which sets out the service that NHS England is required to commission?

Answered: 32 Skipped: 11

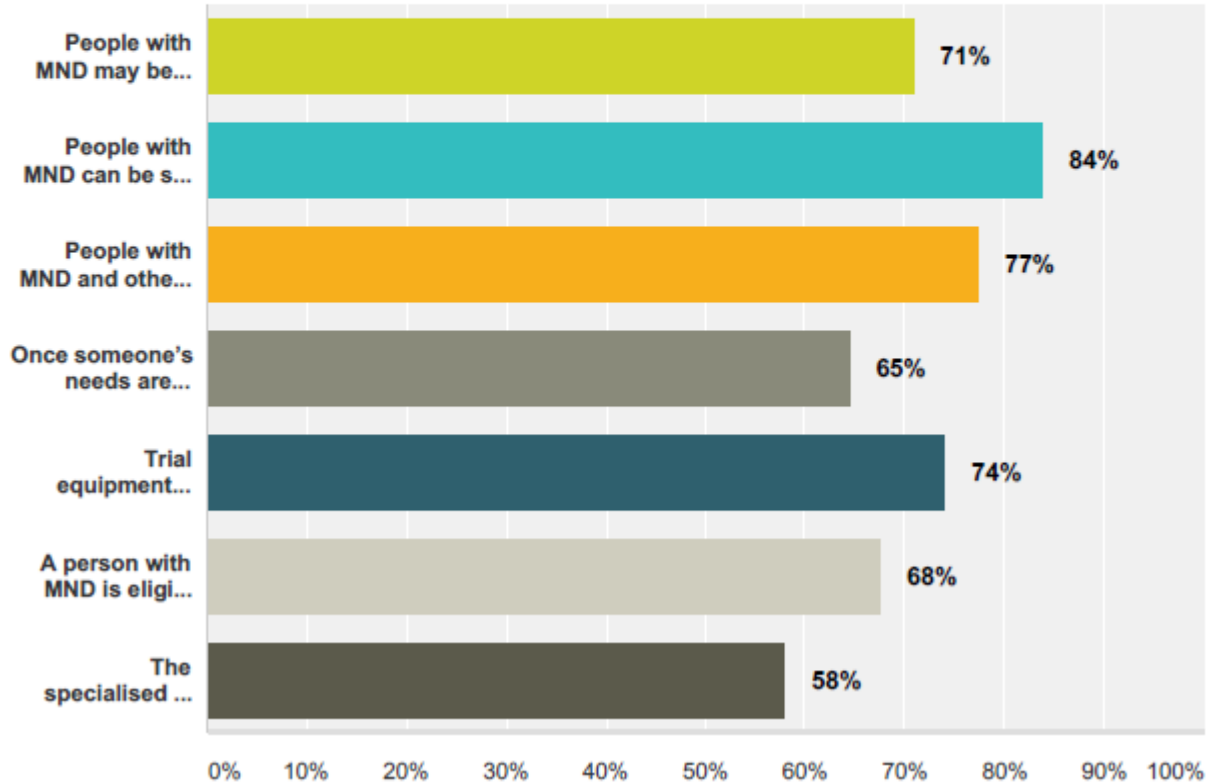


Answer Choices	Responses	
Yes, and I've read it	25%	8
Yes, but I've not read it	25%	8
Vaguely	38%	12
Not at all	13%	4
Total		32

Perhaps unsurprisingly, there is substantial variation in awareness of the service specification. Provided that other training materials and guidance are available, and accurate, it need not be essential for SLTs to read the spec.

Q15 Which of the following is, to the best of your knowledge, a feature of the service specification for specialised AAC? Select as many as you think apply.

Answered: 31 Skipped: 12



Answer Choices	Responses
People with MND may be referred in anticipation of future need arising, before it has done so	71% 22
People with MND can be seen in their own home instead of having to travel to a centre	84% 26
People with MND and other rapidly progressive conditions can and should be fast-tracked	77% 24
Once someone's needs are assessed to be specialised, NHS England pays for their assessment and treatment, not the local CCG	65% 20
Trial equipment should be provided to people with MND when appropriate	74% 23
A person with MND is eligible for specialised AAC once their communication need is severe or complex, but they may be seen by local SLT services before then	68% 21
The specialised AAC service will provide facilities for customising and modernising equipment	58% 18
Total Respondents: 31	

All of the items listed in this question are summaries of items in the specification, so the results show a reasonable level of awareness of all the listed aspects, though there is variation within this. NHS England should aim to raise awareness from this level.

At the end of the survey, respondents were told that all of these items are features of the spec, and presented with them again for reference.