

# *Decision-making capacity in aphasia: SLT's contribution in England*

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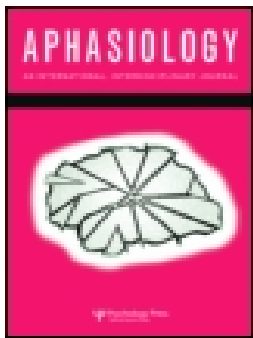
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# Decision-making capacity in aphasia: SLT's contribution in England

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## ABSTRACT

**Background:** Individuals' right to be involved with decisions regarding their health and social care is the cornerstone for modern patient-centred care. Decision-making is a complex process that involves multiple cognitive and linguistic abilities. These are often challenging for people with aphasia (PWA). The Mental Capacity Act (MCA) Code of Practice (2007) recommends that speech and language therapists (SLTs) support capacity assessments for individuals with communication problems, such as PWA. To date, little is known regarding SLTs' involvement in the UK for supporting decision-making and capacity assessment for PWA.

**Aims:** This research provides data to document when, how, and the extent to which SLTs are being used in capacity assessment for PWA in England. We also determined SLTs' training and resource needs in capacity assessments, and their role in inter-professional training.

**Methods & Procedures:** 56 SLTs working with PWA from a wide range of clinical settings in England were recruited; they completed a secure questionnaire using the online survey tool Survey Monkey. The questionnaire collected information in the following areas: knowledge and awareness of the MCA; current involvement of SLTs in capacity assessments and decision-making; inter-professional understanding of SLTs roles in capacity assessments; and training needs of SLTs.

**Outcomes & Results:** The SLTs who participated in this survey indicated that they were not regularly involved to support capacity assessment for PWA. Moreover, they also reported that other professionals on the care team did not fully recognise or utilise their skills in supporting capacity assessment for PWA. Moreover, SLTs were not solicited to train professionals regarding communication difficulties in aphasia and its impact on capacity assessments. SLTs wanted profession-specific training to fulfil the role of supporting PWA in capacity assessments more effectively and reliably.

**Conclusions:** Healthcare professionals have an ethical duty to ensure that judgements of capacity are unbiased and accurate. SLTs have an important contribution to make but their skills and knowledge are not fully recognised or utilised. These findings highlight an important need to raise the profile of SLTs' skills and expertise amongst professionals through education and/or inter-professional communications. This would enable SLTs to be regularly and effectively utilised in capacity assessments and decision-making for PWA.



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## Introduction

Modern health- and social care recognises the importance of patient-centred care. Central to this is the respect for the individual's right to be fully involved in decisions about their healthcare, a right that is protected by legislation for most Western countries. For example, in England, the NHS Constitution (2013) states that self-management, person-centred care, and shared decision-making are key deliverables as these contribute to health and well-being. A person with "mental capacity" is assumed to be able to make their own decisions with regard to their healthcare (e.g., medical procedures) and social needs (e.g., where and how they choose to live). However, decision-making is a complex process and involves multiple cognitive and linguistic abilities, including understanding information relevant to a decision, manipulating that information in a deliberative process, appreciating the consequences of making or not making a decision, and communicating a choice (Appelbaum & Grisso, 1988). When a person's ability to make decisions may be affected by neurological pathologies, a capacity assessment is carried out to determine his/her ability to make a particular decision. Because capacity assessment relies heavily on language skills, demonstrating capacity is often challenging or may be impossible for people with aphasia (PWA) (Carling-Rowl & Wahl, 2010; Pachet, Allan, & Erskine, 2012; Suleman & Hopper, 2016).

Research has shown that PWA may not be able to demonstrate their true decision-making abilities due to their language difficulties (Carling-Rowl & Wahl, 2010; Pachet et al., 2012; Suleman & Hopper, 2016). Aphasia can occur along with significant impairments in memory, attention, executive functioning, which further complicates the decision-making processes (Murray, 2012). The literature on capacity assessment in PWA highlights the need for involving speech and language therapists (SLTs) on a regular basis for capacity assessments (e.g., Suleman & Hopper, 2016). SLTs are trained to assess communication impairments in aphasia, to identify the remaining verbal and non-verbal abilities, and to identify methods of supporting communication to compensate or learn new ways of communicating. Specifically, they are skilled in adapting their style and means of communication to ensure PWA can comprehend information, understand a decision and its options, and facilitate the communication of that decision (Royal College of Speech-Language Therapist [RCSLT], 2014). Zuscak, Peisah, and Ferguson (2015) proposed that SLTs' expertise in communication places them ideally to champion and support the needs of PWA in capacity assessments.

Legislation in England and Wales (e.g., the Mental Capacity Act (MCA)) protects individuals 16 years and over who lack mental capacity as a result of brain injury due to disability or illness. Accordingly, a person lacks capacity if they are unable to understand information relevant to a decision, retain the information, use or weigh up the information, and/or communicate their decision (MCA, 2005). The MCA Code of practice recommends that SLTs' skills should be utilised to support those with communication difficulties, and guidance should be followed in assessments of capacity to inform decision-making in PWA.

SLTs' role in the capacity assessment of PWA has been documented in Canadian and Australian studies, but little is known regarding their involvement in the UK (Aldous, Tolmie, Worrall, & Ferguson, 2014; Carling-Rowl & Wahl, 2010; Suleman & Hopper, 2016). These studies have identified the following roles for SLTs in assessing capacity for decision-making in PWA. First, SLTs recognised and accepted their roles as assessors and advisors on communication strategies, and were aware of ethical and professional issues, but their scope was unclear in the assessment of decision-making capacity (Aldous et al., 2014).

Second, although it is recognised by other professionals that SLTs have the professional skills to support decision-making in PWA, they were not consistently used in capacity assessments (Carling-Rowl & Wahl, 2010; Suleman & Hopper, 2016). Third, SLTs were most often used in assessment when there was conflict between the PWA and others, but not on a regular basis (Ferguson, Duffield, & Worrall, 2010). Fourth, even when SLTs were involved in capacity assessments, they were dissatisfied by the process and indicated that they would benefit from further training. Furthermore, SLTs indicated that concrete efforts are required to develop guidelines for practice, education, and case management, especially for newly qualified SLTs and students on clinical programmes (Aldous et al., 2014; Ferguson et al., 2010). An important consideration of these studies is that if SLTs are not regularly used in supporting capacity assessments, then it is unclear how multidisciplinary teams are ensuring proper capacity assessments for PWA. Importantly, there exists no report on how the SLTs are being used in supporting capacity assessment and decision-making in PWA in the UK. The present research fills this important gap in the literature by providing the current scenario in England.

In a UK study, Mackenzie, Lincoln, and Newby (2008) considered multidisciplinary teams' impressions of stroke patients' capacity to make decisions regarding discharge destination. They compared them to the results of formal capacity testing by a trained neuropsychologist and found that multidisciplinary teams' opinions did not relate with formal assessment. Staff presumed a lack of capacity if aphasia was present but this did not relate with a lack of capacity on testing, increasing the chances of misjudging the presence (or lack) of capacity. As expected, these "impressions" led to unsafe discharges, which did not reflect the PWAs' choice. Similarly, a Canadian study found that the process implemented to determine long-term care was inaccessible to PWA and competent individuals had been presumed to lack capacity due to communication barriers (Carling-Rowl, Black, McDonald, & Kagan, 2014). Crucially, these studies highlight that the presence of aphasia heightens the risk of presumption of incapacity, the need for staff to be trained in capacity assessment, and the unique skills of the SLT in assessing capacity.

The lack of training and resources has been identified as potential reasons for inappropriate capacity assessment, which leads to the exclusion of PWA from clinical and research studies, even by specialist staff, such as stroke research staff (Jayes & Palmer, 2014). Jayes and Palmer (2014) found that only 18% of 75 stroke research staff used accessible information when obtaining consent from PWA. Rowland and McDonald (2009) found that capacity assessors lacked the skills as effective communicators and were unable to modify the process to support communication, which led to incorrect conclusions about capacity for decision-making.

It has been shown that training improves capacity assessment skills and a growing awareness that unique skill sets possessed by SLTs could be tapped to advise and train others who support PWA in capacity assessments (Carling-Rowl et al., 2014). Several authors have recommended that SLTs can take leadership in providing information regarding aphasia and in training other professionals regarding communication strategies and environmental adaptation to enhance communication (Borthwick, 2012; Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010; Zuscak et al., 2015). Carling-Rowland and colleagues (2014) developed the Communication Aid to Capacity Evaluation (CACE), a communicatively accessible tool for healthcare professionals, to evaluate capacity of PWA. The authors used CACE to train social workers and found that the accessibility of the CACE

combined with communication training resulted in accurate determination of capacity for PWA. These reports highlight the need for training in capacity assessments for professionals so that PWA can fully participate in their care and decide their own future. However, it is unknown whether SLTs are involved in training other professionals in the UK.

Research findings advocate that SLTs should be a regular and integral part of capacity assessments for PWA and best outcome could be reached when professionals are trained on capacity assessments (Carling-Rowl et al., 2014; Suleman & Hopper, 2016). The encouraging aspect of this literature is that the challenges in capacity assessments with PWA have been identified and best practice recommendations for involving SLTs are available from Canadian and Australian studies. At present, there is a lack of studies in the UK to document when, how, and the extent to which SLTs are being involved in capacity assessment for PWA. Given that training, services, and clinical practices are often country specific, studies in Canada and Australia might not necessarily generalise to the UK setting. It is, therefore, important to determine the current state of practice in the UK to identifying the gaps in service delivery to ensure fair assessment for PWA. Moreover, the opportunity to identify training and resource needs for professionals involved in capacity assessment would ensure that they have appropriate skill set to effectively perform capacity assessments for PWA.

The overarching aim of the present study is to explore the current practices in England regarding the SLTs' involvement in supporting decision-making and capacity assessment for PWA. Using a survey method, SLTs working with PWA from a wide range of clinical settings completed a questionnaire, which was developed based on guidance from the existing literature (e.g., Ferguson et al., 2010; Suleman & Hopper, 2016). The questionnaire was designed to generate information in the areas of knowledge and awareness of the MCA amongst SLTs, their current involvement in capacity assessments and decision-making, their inter-professional understanding of their role in capacity assessments for aphasia, and their training needs. We aimed to determine the following:

- (1) Do SLTs have the knowledge and understanding of the MCA? Do they feel confident in undertaking capacity assessments for PWA?
- (2) What is the SLTs' involvement – how often, how regularly, when and what types of decisions – in capacity assessments for PWA?
- (3) What is the level of training of SLTs for conducting capacity assessments? What is the proportion of SLTs who provide inter-professional capacity training, and for which team members? Which members of the multidisciplinary teams are using SLTs to assist in capacity assessments for PWA?

## Method

### *Participants*

Fifty-six self-selected SLTs working with PWA voluntarily participated in this study; 52% of the respondents were from north of England and 48% were from south of England. They came from a variety of settings, e.g., stroke units, community stroke teams, early supported discharge teams, and general acute and community care settings. Potential respondents were recruited via email to the members of the Royal College of Speech-Language Therapist

(RCSLT) aphasia- and dementia-clinical excellence networks, and contacts to SLT colleagues across England. Respondents were invited to take part in the study via an online questionnaire supported by an information sheet; proceeding to complete the questionnaire was taken as consent to participate. Ethical approval was obtained in advance from the University Research Ethics Committee.

### *Survey instrument, data collection, and analysis*

The online survey tool Survey Monkey was used to create an electronic questionnaire, which allowed secure, anonymous, and confidential data collection. The questionnaire provided in the [Appendix](#) collected information in the following areas: awareness and knowledge of the MCA, and confidence in performing capacity assessments (Q1–3); SLTs' involvement in capacity assessments for PWA, and inter-professionals' understanding of SLTs' skills to enhance capacity assessments in PWA (Q4–14); SLT involvement in training and supporting other team members for capacity assessments in PWA (Q15–16); and SLTs' current training status and future needs (Q17–23). Quantitative data were collected using multiple-choice responses and a five-point Likert rating scale (1 = no confidence, 5 = very confident) was used for question 3 to determine confidence level. Most questions allowed a choice of multiple responses, and some questions also allowed free text to add further information (e.g., Q22, gaps in knowledge and resources). No time restrictions were placed to complete the questionnaire and all respondents answered all questions. Prior to the data collection, two SLTs piloted the questionnaire to ensure ease of completion and to remove ambiguities in wording. These two SLTs did not participate in the main study. Minor adjustments were made to the final version of the questionnaire based on their feedback.

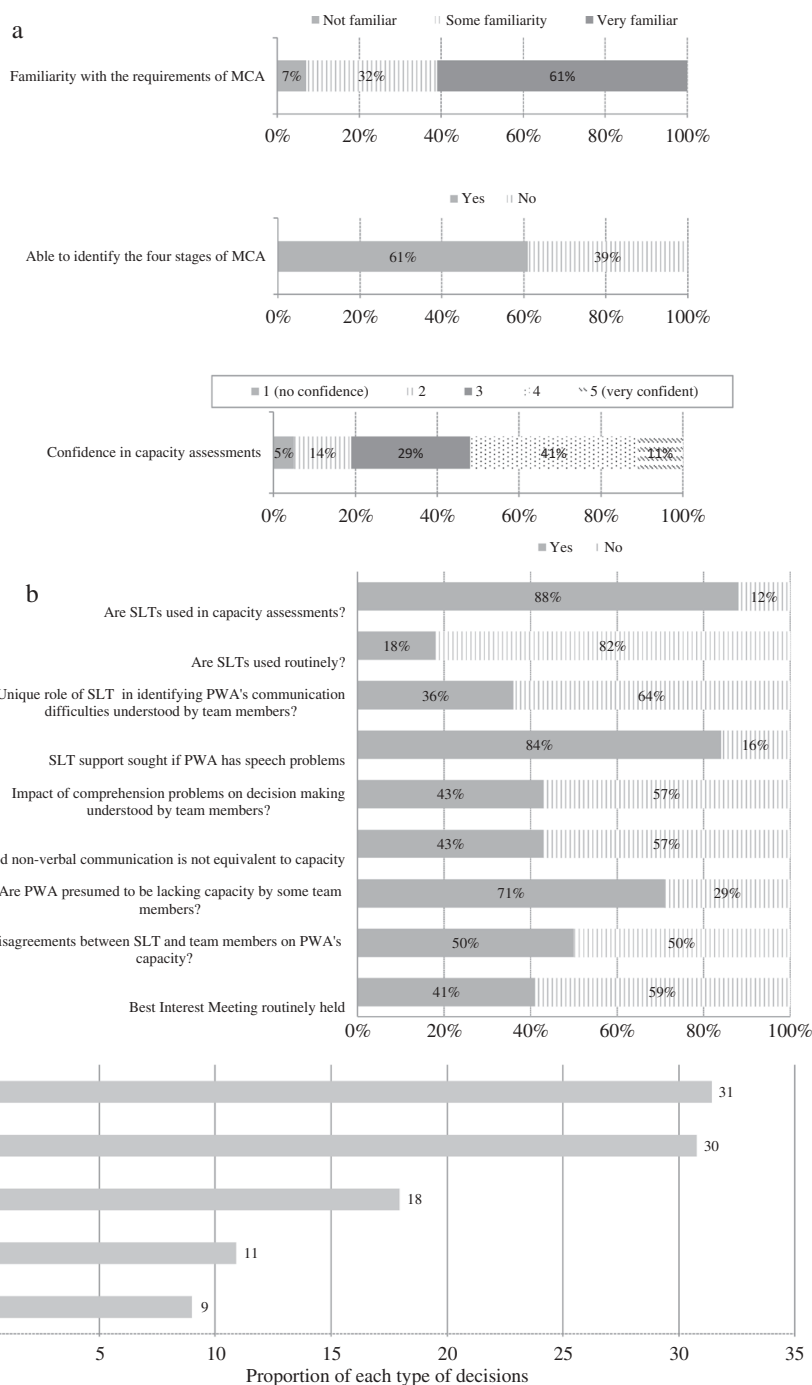
Quantitative responses were analysed in terms of raw data (actual number), cumulative counts, and percentages (proportion) of total responses. Findings are illustrated using response frequency, percentage tables, and bar charts. The qualitative data on resource and knowledge gaps from Q22 were organised in recurring themes in [Table 2](#) based on thematic analysis (Braun & Clark, 2006).

## **Results**

[Figure 1](#) presents data on SLTs awareness and knowledge of MCA, their confidence in undertaking capacity assessments, and their involvement – how often, how regularly, when and what types of decisions – in capacity assessments for PWA. [Figure 1\(a\)](#) shows that the majority, 93% ( $n = 52$ ), of the SLTs had some familiarity with the MCA, and 61% ( $n = 34$ ), could identify the four stages of the MCA, which was taken as a test for the knowledge of MCA. In terms of confidence, 81% ( $n = 45$ ) of the respondents rated themselves as 3 or above (1 = no confidence, 5 = very confident) for carrying out capacity assessments for PWA.

[Figure 1\(b\)](#) presents the data relating to the role and utilisation of SLT in capacity assessments for PWA. A high number, 88% ( $n = 49$ ), of the SLTs had been involved in capacity assessments for PWA, but only 18% ( $n = 7$ ) were involved routinely. The unique skill set available to SLTs for identifying PWAs' communication difficulties was not well understood by members of the multidisciplinary teams, as only 36% ( $n = 20$ ) of the respondents reported that their role in enhancing and supporting communication was recognised by their team members. The vast majority, 84% ( $n = 47$ ), reported that SLT's help was sought when PWA





**Figure 1.** Data from the questionnaire on (a) awareness of MCA, and SLTs' confidence in undertaking capacity assessments (upper panel); (b) role and utilisation of SLTs in capacity assessment for PWA (middle panel); and (c) types of decisions (and proportion) in which SLTs' expertise were sought (lower panel).

**Table 1.** SLTs' capacity assessment training and their role in inter-professional training.

	<b>Yes</b>	<b>No</b>		
SLTs received training on capacity assessment	84% (47)	16% (9)		
Provider of the training	<b>Organisation's mandatory requirement</b>	<b>SLT-specific training</b>		
	85% (49)	15% (7)		
Length of training	<b>1–2 h</b>	<b>Half day</b>	<b>&gt; Half day</b>	
	53% (25)	41% (19)	6% (3)	
Recency of training	<b>No training</b>	<b>Within the last year</b>	<b>Within the last 3 years</b>	<b>&gt; 3 years ago</b>
	16% (9)	39% (22)	43% (24)	2% (1)
Preferred delivery method of training	<b>Face-to-face</b>	<b>Online</b>	<b>No preference</b>	
	77% (43)	11% (6)	12% (7)	
Are there knowledge gaps?	<b>Yes</b>	<b>No</b>		
	68% (38)	32% (18)		
SLTs provided training to other team members	38% (21)	62% (35)		
Service received additional funding for supporting capacity training	0% (0)	100% (56)		

evidenced a speech problem, but 57% ( $n = 32$ ) of the respondents reported that their team members did not appreciate the impact of comprehension impairments on decision-making abilities for PWA. Similar proportion of team members did not understand that good non-verbal communication does not necessarily equal capacity/comprehension. A large percentage of SLTs, 71% ( $n = 40$ ), reported that their team members presumed PWA to be lacking capacity, and 50% ( $n = 28$ ) of the time there were disagreements between SLTs and team members on judging PWA's capacity. Best Interest Meetings were held only 41% ( $n = 23$ ) of time. Figure 1(c) illustrates that the SLTs were involved in capacity assessments in a wide range of decisions including medical decisions (e.g., PEG insertion, life-sustaining treatment), social decisions (e.g., discharge destinations), as well as financial and legal decisions.

Table 1 shows the amount of capacity assessment training for SLTs and their role in inter-professional training. The majority of SLTs, 84% ( $n = 47$ ), had received some training on capacity assessment, mostly through their organisation's mandatory requirement. Training had been frequently in the form of a 1–2 h or a half-day session, and there was a big range when the training was received, with most participants having received training within the last three years. In terms of training preference, most SLTs, 77% ( $n = 43$ ), preferred face-to-face training, as opposed to other methods (e.g., online, self-directed learning). A large percentage of SLTs, 68% ( $n = 38$ ), reported gaps in knowledge and resources in capacity assessments in the areas of understanding and interpreting the Act, training needs, inter-professional understanding, confidence in performing capacity assessments, and resource need to conduct proper capacity assessments. Table 2 provides examples of the qualitative responses with regard to these gaps. Of the 56 respondents from different services, 10 respondents reported that they had requested additional funds for training in capacity assessments, but none of these services received additional funding for capacity training. Only 38% ( $n = 21$ ) of SLTs provided training to other team members regarding supported communication to assist capacity assessment for PWA.

Figure 2(a) presents data on SLTs' involvement in training other professionals to support capacity assessment in PWA and indicates that SLTs mostly trained occupational therapists,

**Table 2.** Areas of knowledge gaps identified and resources needed by SLTs for capacity assessments in PWA.

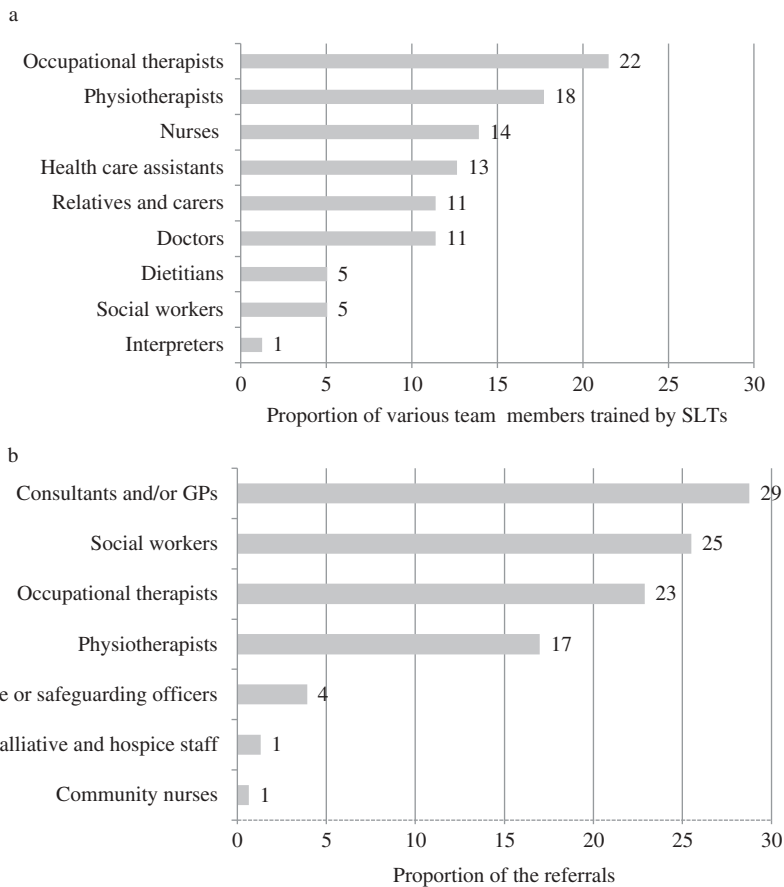
Areas of gaps	Examples of respondents comments
The Act (7)	<p>"We need advice on what to do if the MCA is not being followed and examples of this. The training we have received and the act itself doesn't explain this well enough."</p> <p>"There is a problem with assessing capacity those cases that are borderline as these are always the trickiest. The process is very clear for patients who clearly don't have capacity but it is harder to feel confident in exactly what is required of each step when someone is more borderline, or for example where they do not want to engage in discussions about the risks – e.g. if they are in denial or are indecisive on different days (which sometimes feels a reasonable and normal reaction rather than a sign that someone lacks capacity)."</p>
Training (9)	<p>"Training isn't updated often enough. It's normally the consultants view or someone with a role that is 'better understood' who's decision is taken as final. There is a lack of respect for SLTs in some places I've worked in and our insight into communication can be ignored because some professions aren't aware of our expertise. Training and educating professionals is necessary."</p> <p>"MCA training needs to be a part of all trust inductions. The last 3 trusts haven't had that."</p> <p>"Joint training with other MDT<sup>2</sup> and the individual roles of each profession in assessments."</p>
Inter-professional understanding (7)	<p>"The gaps are in the knowledge of other professionals in understanding how SLTs can help support aphasics in particular as well as our expertise in aiding other conditions."</p> <p>"The wider MDT<sup>2</sup>s have a lack of understanding of the role of SLTs and when to consult them."</p> <p>"More training to other professionals is needed from SLTs. We can explain conditions such as aphasia e.g.: 'no doesn't always explicitly mean no. There is complexity to conditions that some people see past."</p>
Confidence (6)	<p>"There is a lack of confidence, I have witnessed in my team, as such an important decision often feels like it comes down to an SLT's assessment, and therefore so crucial that it is done properly."</p> <p>"Confidence in carrying out assessment. Not everyone has been trained yet we are expected to carry out these decisions."</p> <p>"There is a general lack of confidence due to inexperience and lack of specific training to SLTs and MDT."</p>
Resources (5)	<p>"Profession specific resources would really help ... There is a lack of this at our hospital which means alternative needs are relied on, this is not always the most effective."</p> <p>"We need to regularly update our knowledge re mental capacity. In particular, published resources would be useful to support capacity assessments."</p>

Number in the parenthesis represents the number of participants who commented on this theme.  
MCA = Mental Capacity Act; MDT = Multidisciplinary Team.

physiotherapists, nurses, along with healthcare assistants, doctors, and even relatives and carers. [Figure 2\(b\)](#) shows the proportion of various referral sources for capacity assessments for PWA; consultants, social workers, occupational therapists, and physiotherapists were the professionals who made the most referrals to SLTs for supporting PWA in capacity assessments. Unfortunately, social workers who were amongst the professionals who sought SLT support in capacity assessments did not receive much training from SLTs (see [Figure 2\(a\)](#)). Although care for PWA involves a host of other professionals, e.g., nurses and dieticians, these results highlight that not all professionals are using the support of SLTs needed for their PWA clients.

**Discussion**

This research was set out to explore the current practices in England regarding SLTs' involvement in supporting decision-making and capacity assessment for PWA. SLTs working with



**Figure 2.** Proportion of team members trained by SLTs to support capacity assessment in PWA (upper panel, a), and proportion of referrals from various team members who sought SLTs' support for capacity assessments in PWA (lower panel, b).

PWA completed a questionnaire which elicited information to identify SLTs' knowledge and awareness of MCA, their current involvement in capacity assessments, inter-professional understanding of SLTs roles in capacity assessments for aphasia, and their training and resource needs.

The majority, 88%, of the SLTs has been used in capacity assessments for PWA, which is very encouraging. On the other hand, only 18% reported routine involvement as a part of their professional roles. This concurs with the situation from Canadian and Australian studies (Aldous et al., 2014; Carling-Rowl & Wahl, 2010; Suleman & Hopper, 2016). Ninety-three per cent of the SLTs had some familiarity with requirements of the MCA, 81% of them felt confident in carrying out capacity assessments for PWA. This indicates that despite SLTs' confidence in performing capacity assessments they were not involved regularly in capacity assessments for PWA. This limited routine involvement of SLTs in capacity assessments is problematic as the MCA's Code of Practice (2007) stipulates that individuals with brain injury should be supported adequately to make informed decision about their choices and recommends the use of SLTs to support capacity assessments.

It is possible that the limited routine involvement of SLTs in capacity assessments reflects the lack of appreciation by other team members of the skill sets that SLTs possess in understanding and interpreting communication difficulties of PWA (Carling-Rowl & Wahl, 2010; Suleman & Hopper, 2016). This possibility is evidenced by SLTs' responses, which showed that only 36% of them believed that other team members understood their role in identifying PWA communication difficulties and their contribution in capacity assessments. This highlights that the team members were unaware of SLTs' role in facilitating active and full engagement for PWA in the decision-making process. This potentially results in under-utilisation of SLTs in capacity assessments. Moreover, the team members were not fully aware of the significance of PWA's expressive and receptive language problems and the consequences of these problems on decision-making and capacity assessments. The respondents reported that their team members sought SLTs' help 84% of the time when PWA had expressive problems but only 43% of the time when the difficulty was in comprehension. Importantly, SLTs reported that their team members did not fully appreciate the importance of comprehension problems on decision-making on PWA (Kaga, 1998; Knight, Worrall, & Rose, 2006).

The largest proportion of referrals to SLTs came from consultants, social workers, occupational therapists, and physiotherapists. However, PWA's care regularly involves larger teams, including nurses, caregivers, healthcare assistants, and dieticians. Thompson and Mckeever (2014) highlight that nurses' communication was not suitable to support PWA's communication challenges, which impacted their rights to make decisions. The authors suggested that training in communication strategies for the nurses would benefit the process of decision-making involving PWA. The lack of referrals from these professions suggests a scope for inter-professional education and awareness rising of the capacity assessment role of SLTs.

The results show that 71% of the respondents' team members presumed a lack of capacity for PWA, and 50% of the time there were disagreements between the SLT and team members on the PWA's capacity. This resonates with the findings from other international studies on presumed lack of capacity for PWA and disagreements on capacity judgements amongst team members (Mackenzie et al., 2008; Savage, 2006; Stein & Brady Wagner, 2006). In the absence of support from SLTs in capacity assessments with PWA, professionals in England may be incorrectly presuming the presence or lack of capacity.

Importantly, SLTs were used in both medical and non-medical decision for PWA. This highlights that their role could be utilised in different settings and for different types of decisions. In an Australian study, Ferguson et al. (2010) found that SLTs took on the role of assessor, advocate, leader, negotiator, educator, interpreter, consultant, and decisions included legal matters about finance, accommodation, consent, and discharge. Ferguson et al. highlight that SLTs, however, had limited resources, experience, and training in these roles.

Improving the outcome of capacity assessment for PWA would require education and information regarding the impact of language difficulties on decision-making and capacity assessments for care professionals as well as for SLTs. Several studies suggest that training on communication strategies for communication partners has beneficial impact on the overall outcome of care of PWA (Hersh, Godecke, Armstrong, Ciccone, & Bernhardt, 2016; Simmons-Mackie et al., 2010; Togher, McDonald, Code, & Grant, 2004).

The analysis of training needs in the present study revealed that 84% of the SLT had received *some* training on capacity assessments. This is encouraging but many SLTs (77%) wanted updated profession-specific, preferably face-to-face training along with other professionals in their multidisciplinary teams. This could be gleaned from the comments in under “Training” in Table 2. It is important to note that 68% felt that there were resource and knowledge gaps in their training. These gaps relate to difficulties in tackling non-adherence to the guidance, a lack of confidence due to limited experience, a lack of recognition of the SLTs’ skills by other professionals, and a need for resources which can be used to support assessment. Our results revealed that none of the services received any additional funding to support capacity assessments. Unfortunately, SLT skills and expertise were not tapped optimally to train other professionals in understanding of aphasia and its impact on capacity and decision-making, as well as in capacity assessments. In a Canadian study, Suleman and Hopper (2016) concluded that SLTs were not used consistently despite having appropriate skills.

This is the first study documenting the SLTs’ involvement in supporting capacity assessment and decision-making in PWA in England. The results confirm and extend findings from international studies from Canada and Australia on similar issues (Carling-Rowl & Wahl, 2010; Suleman & Hopper, 2016). These findings also raise several questions that have to be addressed in future research. A larger group of respondents with a range of years of experience and grade level across the UK will increase generalisability of the findings to the population of SLTs across England. We also need to identify who are currently performing capacity assessments in aphasia and for which type of decisions, and determine which means and tools (e.g., verbal or non-verbal) are used by clinicians to facilitate capacity assessments. This would enable us to develop specific resources, materials, and training for professionals involved in supporting capacity assessments for PWA.

## Summary and conclusions

In this study, we surveyed SLTs’ involvement in supporting decision-making and capacity assessment for PWA. We investigated when, how, and the extent to which SLTs are being involved in capacity assessment for PWA. The results revealed that SLTs were not used routinely to support capacity assessment; other professionals on the care team did not fully recognise or utilise the skills of the SLTs in supporting decision-making and capacity assessment for PWA; and SLTs were not solicited to train professionals regarding communication difficulties in aphasia and its impact on capacity assessments. SLTs also felt that PWA are not appropriately assessed or supported by others to make decisions. These findings highlight an important need to raise the profile of SLTs’ skills and expertise amongst professionals through education and/or inter-professional communications to enable them to be regularly and effectively utilised in capacity assessments and decision-making for PWA.

Raising awareness could be achieved through organisations involved in supporting professionals, such as RCSLT. Initiating campaign regarding the role of SLTs in decision-making for professionals working with PWA would enhance inter-professional appreciation and empower SLTs. Training SLTs on decision-making and capacity assessment should be an integral part of curriculum in SLT programmes, which would result in better prepared clinicians. In addition, regular and updated training for SLTs would increase their confidence in performing these assessments and their skills and expertise could be utilised to train

other members of the care team. Failure to provide unbiased and accurate judgements of capacity for PWA would be unethical for individuals in health- and social care, and risks that legislative recommendation not being followed for PWA.

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## References

- Aldous, K., Tolmie, R., Worrall, L., & Ferguson, A. (2014). Speech-language pathologists' contribution to the assessment of decision-making capacity in aphasia: A survey of common practices. *International Journal of Speech-Language Pathology*, 16, 231–241. doi:10.3109/17549507.2013.871751
- Appelbaum, P. S., & Grisso, T. (1988). Assessing patients' capacities to consent to treatment. *New England Journal of Medicine*, 319, 1635–1638. doi:10.1056/NEJM19881223192504
- Borthwick, S. (2012). Communication impairment in patients following stroke. *Nursing Standard*, 26, 35–41. doi:10.7748/ns2012.01.26.19.35.c8879
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. doi:10.1191/1478088706qp063oa
- Carling-Rowl, A., Black, S., McDonald, L., & Kagan, A. (2014). Increasing access to fair capacity evaluation for discharge-destination making for people with aphasia: A randomized control trial. *Aphasiology*, 28, 750–765. doi:10.1080/02687038.2014.895975
- Carling-Rowl, A., & Wahl, J. (2010). The evaluation of capacity to make admission decisions: Is it a fair process for individuals with communication barriers? *Medical Law International*, 10, 171–190. doi:10.1177/096853321001000301
- Department for Constitutional Affairs. (2007). *Mental capacity act code of practice*. London, UK: The Stationary Office.
- Ferguson, A., Duffield, G., & Worrall, L. (2010). Legal decision making by people with aphasia: Critical incidents for speech pathologists. *International Journal of Language & Communication Disorders*, 45, 244–258. doi:10.3109/13682820902936714
- Hersh, D., Godecke, E., Armstrong, E., Ciccone, N., & Bernhardt, J. (2016). "Ward talk": Nurses' interaction with people with and without aphasia in the very early period poststroke. *Aphasiology*, 30, 609–628. doi:10.1080/02687038.2014.933520
- Jayes, M. J., & Palmer, R. L. (2014). Stroke research staff's experiences of seeking consent from people with communication difficulties: Results of a national online survey. *Topics in Stroke Rehabilitation*, 21, 443–451. doi:10.1310/tsr2105-443
- Kaga, A. C. (1998). Supported conversation for adults with aphasia: Methods resources for training conversation partners. *Aphasiology*, 12, 947–964. doi:10.1080/02687039808249575
- Knight, K., Worrall, L., & Rose, T. (2006). The provision of health information to stroke patients within an acute hospital setting: What actually happens how do patients feel about it? *Topics in Stroke Rehabilitation*, 13, 78–97. doi:10.1310/FC6M-P7L0-W3XD-4WAE



- Mackenzie, A., Lincoln, B., & Newby, J. (2008). Capacity to make a decision about discharge destination after stroke: A pilot study. *Clinical Rehabilitation*, 22, 1116–1126. doi:10.1177/0269215508096175
- Mental Capacity Act. (2005). Retrieved from [www.legislation.gov.uk/ukpga/2005/9/contents](http://www.legislation.gov.uk/ukpga/2005/9/contents)
- Murray, L. (2012). Attention and other cognitive deficits in aphasia: Presence and relation to language and communication measures. *American Journal of Speech-Language Pathology*, 21, 551–564. doi:10.1044/1058-0360(2012/11-0067)
- NHS England. (2013). NHS outcomes framework – 5 domains resources. Retrieved February 21, 2016, from <https://www.engl.nhs.uk/resources/resources-for-ccgs/out-frwrk/>
- Pachet, A., Allan, L., & Erskine, L. (2012). Assessment of fluctuating decision-making capacity in individuals with communication barriers: A case study. *Topics in Stroke Rehabilitation*, 19, 75–85. doi:10.1310/tsr1901-75
- Rowland, A., & McDonald, L. (2009). Evaluation of social work communication skills to allow people with aphasia to be part of the decision making process in healthcare. *Social Work Education*, 28, 124–144. doi:10.1080/02615470802029965
- Royal College of Speech and Language Therapists. (2014). Submission from the RCSLT to the department of health. *Social Serviced Public Safety and the Department of Justice's Consultation on proposals for the Draft Mental Capacity Bill*. Northern Ireland. Retrieved from <http://tinyurl.com/zb3522k>
- Savage, T. A. (2006). Ethical issues in research with patients who have experienced stroke. *Topics in Stroke Rehabilitation*, 13, 1–10. doi:10.1310/tsr1304-1
- Simmons-Mackie, N., Raymer, A., Armstrong, E., Holland, A., & Cherney, R. (2010). Communication partner training in aphasia: A systematic review. *Archives Of Physical Medicine Rehabilitation*, 91, 1814–1837. doi:10.1016/j.apmr.2010.08.026
- Stein, J., & Brady Wagner, L. C. (2006). Is informed consent a “yes or no” response? Enhancing the shared decision-making process for persons with aphasia. *Topics in Stroke Rehabilitation*, 13, 42–46. doi:10.1310/tsr1304-42
- Suleman, S., & Hopper, T. (2016). Decision making capacity in aphasia: Speech-language pathologists' perspectives. *Aphasiology*, 30, 1–15. doi:10.1080/02687038.2015.1065468
- Thompson, J., & McKeever, M. (2014). Improving support for patients with aphasia. *Nursing Times*, 110, 18–20.
- Togher, L., McDonald, S., Code, C., & Grant, S. (2004). Training communication partners of people with traumatic brain injury: A randomized controlled trial. *Aphasiology*, 18, 313–335. doi:10.1080/02687030344000535
- Zuscak, S., Peisah, C., & Ferguson, A. (2015). A collaborative approach to supporting communication in assessment of decision making capacity. *Disability Rehabilitation*, 38, 1–6. doi:10.3109/09638288.2015.1092176

## Appendix

### Questionnaire to determine SLTs' contribution in supporting decision-making and capacity assessment in aphasia.

- (1) How familiar are you with requirements of the Mental Capacity Assessment (MCA)?
  - Not at all familiar
  - Some familiarity
  - Very familiar
- (2) MCA assessment is often referred to as a four-stage process. Can you identify the four stages?
  - Yes (Please indicate the four stages).....
  - No
- (3) How confident do you feel in assisting/carrying out capacity assessments?

1= no confidence ←————→ 5 = very confident  
 1                      2                      3                      4                      5



- (4) Are SLTs involved in assessing capacity/supporting decision-making in PWA in your work setting?
  - Yes
  - No
- (5) Are SLTs used as a matter of routine to support PWA during capacity assessments or is advice sought occasionally as an ad hoc basis?
  - Yes (routinely)
  - No (ad hoc)
- (6) What types of decisions have SLTs been asked to support?
  - Life-sustaining treatment
  - PEG insertion
  - Discharge destination
  - Financial decisions
  - Legal decisions (e.g., changes to a will)

Please add.....

- (7) Is the unique role/skill of the SLT in identifying levels of comprehension/expression abilities of the PWA understood and used appropriately by others across your team to support capacity assessments to consent?
  - Yes
  - No
- (8) Is SLT support more likely to be sought if PWA has a significant speech (output) problem?
  - Yes
  - No
- (9) Are problems with comprehension and the potential effect on decision-making well recognised by others in your team?
  - Yes
  - No
- (10) Do others in your team understand that good non-verbal communication does not necessarily equal capacity/comprehension?
  - Yes
  - No
- (11) Are PWA, in your experience, presumed by others in your team to lack capacity?
  - Yes
  - No
- (12) Have there been disagreements between SLT and others in the team regarding whether an individual has or lacks capacity?
  - Yes
  - No
- (13) Are Best Interest Meetings used routinely with PWA to make decisions (in the absence of attempts to facilitate independent decision-making and the presumption of incapacity)?
  - Yes
  - No
- (14) Which professionals in your experience have sought the support of SLT when working with PWA and carrying out capacity assessments?
  - Doctors
  - Nurse

- Healthcare assistants
  - Physiotherapist
  - Occupational therapist
  - Dietician
  - Social worker
  - Others (please state).....
- (15) Have you provided any training to others in your team regarding supported communication to assist them to capacity assessments with PWA?
- Yes
  - No
- (16) If you have provided training, who have you trained?
- Doctors
  - Nurses
  - Healthcare assistants
  - Physiotherapists
  - Occupational therapists
  - Dieticians
  - Social workers
  - Relatives/carers
  - Others (please state).....
- (17) Have you received training on the MCA and the assessment of capacity?
- Yes
  - No
- (18) Was this training:
- Part of your organisation's mandatory training for all staff
  - SLT-specific training
  - Other (please state).....
- (19) What was the length of the training you received?
- 1–2 h
  - Half day
  - More than half day
- (20) MCA and capacity assessment training is meant to be regularly updated like other mandatory training. When did you last receive training?
- No training
  - Within the last year
  - Within the last 3 years
  - More than 3 years ago
- (21) If you feel you would benefit from further training, what delivery method would you prefer?
- Face-to-face training course
  - Online modules
  - Other (please state).....
- (22) Are there any particular knowledge gaps that you feel need addressing (please state)?
- Yes
  - No
  - Please state which areas: .....
- (23) Has your service received any additional funding for sessions/posts as a result of the MCA and the acknowledgement of the SLT's role in supporting capacity assessments?
- Yes
  - No
- Please state if you had requested for funding: .....