



**Speech and Language Therapy for Primary Progressive Aphasia across the UK: A survey of current practice.**

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**Full Title:**

Speech and Language Therapy for Primary Progressive Aphasia across the UK: A survey of current practice.

**Keywords:** Primary Progressive Aphasia; Speech and Language Therapy; Assessment; Treatment; Survey.

**Abstract:**

## Background

Primary progressive aphasia (PPA) describes a heterogeneous group of language led dementias. People with this type of dementia are increasingly being referred to speech and language therapy services. Yet there is a paucity of research evidence focusing on PPA interventions and little is known about speech and language therapy practice in terms of assessment and provision of intervention.

## Aim

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2  
3 To survey the practices of speech and language therapists in the areas of assessment and  
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5  
6 intervention for people with PPA.  
7

## 8 9 Methods & Procedures

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12 A 37-item, pilot-tested survey was distributed electronically through the Royal College of  
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15 Speech and Language Therapists (RCSLT), Clinical Excellence Networks (CENs), and social  
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18 media networks. Survey items included questions on care pathways, assessment and  
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21 intervention approaches, and future planning. Analysis was conducted using descriptive  
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24 statistics and thematic analysis.  
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## 26 27 Outcomes & Results

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30 One hundred and five SLTs completed the survey. Respondents reported more frequently  
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32  
33 using formal assessment tools designed for stroke related aphasia than for dementia. Informal  
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36 interviews were reportedly always used during assessment by almost 80% of respondents.  
37  
38  
39 Respondents were significantly more likely to use communication partner training than  
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41  
42 impairment focused interventions. Goal attainment was the most commonly used outcome  
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44  
45 measure. Respondents provided 88 goal examples which fell into six themes: 1.  
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47  
48 Communication Aid; 2. Conversation; 3. Functional Communication; 4. Impairment focused;  
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50  
51 5. Specific strategy; 6. Communication Partner. Additionally, respondents reported  
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53  
54 addressing areas such as future deterioration in communication and cognition, decision  
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56  
57 making and mental capacity, and driving. Ten (9.4%) respondents reported the existence of a  
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59  
60 care pathway for people with PPA within their service.

## Conclusions & Implications

This survey highlights the range of current PPA assessment and intervention practices in use by the respondents. Communication partner training is commonly used by the surveyed SLTs, despite the lack of research evidence examining its effectiveness for PPA. There is a need to develop evidence based, care pathways for people with PPA in order to advocate for further commissioning of clinical services.

### **Background:**

Dementia has been identified as the leading cause of death in England and Wales (Office of National Statistics 2015) and it is estimated that a third of people born in the United Kingdom (UK) in 2015 will go on to develop dementia (Lewis 2015). At present frontotemporal dementia (FTD) is the most common cause of younger onset dementia with UK population prevalence estimates of approximately 11/100,000 (Coyle-Gilchrist et al. 2016). Primary Progressive Aphasia (PPA) syndromes collectively account for around a third of these cases (Coyle-Gilchrist et al., 2016). This conservative estimate means there are at least 2300 people currently living with PPA in the UK.

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3 PPA describes a heterogeneous group of language led dementias, often associated with FTD  
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6 and Alzheimer's disease, which, in the initial stages, presents as an insidious deterioration in  
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8  
9 language skills, on a background of intact cognitive functions (Mesulam 1982). Currently there  
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11  
12 are three internationally recognised PPA syndromes, each presenting a distinct profile of  
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14  
15 language difficulties (Gorno-Tempini et al. 2011; Marshall et al. 2018). Semantic variant PPA  
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18 (svPPA, most often associated with an underlying FTD pathology, sometimes called semantic  
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21 dementia) results in difficulties in understanding word meanings. People with svPPA present  
22  
23  
24 with fluent, often empty speech and will have difficulty naming objects yet are able to use and  
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26  
27 understand grammar appropriately. Logopenic variant PPA (lvPPA, most often associated with  
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29  
30 an underlying Alzheimer's pathology) is identified by an individual's difficulties in expression.  
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32  
33 Although fluent, people with lvPPA present with difficulties accessing word forms and with  
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36 phonological assembly. Non-fluent agrammatic variant PPA (navPPA, most often associated  
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38  
39 with an underlying FTD pathology) presents as a dysfluent apraxic disorder and/or an  
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41  
42 agrammatism. People with navPPA demonstrate groping, effortful speech, and may use  
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45 increasingly less complex grammatical structures over time.

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51  
52 Given the centrality of communication difficulties experienced by people with PPA and their  
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55 families, a referral to speech and language therapy seems warranted. Yet people with PPA  
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57  
58 report being more isolated from speech and language therapy services than from any other  
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3 allied health discipline (Riedl et al. 2014). The authors of this German study suggest that this  
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5  
6 may be due to the rarity of the condition, resulting in relatively few people with PPA living  
7  
8  
9 within a speech and language therapy service's catchment area. This in turn may mean the  
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11  
12 SLTs themselves have little experience in working with people with the condition. However,  
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14  
15 in a companion paper to this one **reporting different aspects of the same survey**, Volkmer et al  
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17  
18 (2018) highlight a third of 105 UK SLTs working with people with PPA report an increase in  
19  
20  
21 referral numbers over recent years, mostly from neurologists. A total of 353 people with PPA  
22  
23  
24 were reported as seen over a 24-month period, averaging 3.27 per SLT respondent. In addition,  
25  
26  
27 more than three quarters of **Volkmer et al's (2018)the** respondents reported that there were  
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29  
30 people with PPA who were *not* able to access their services, most often due to a lack of  
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32  
33 awareness amongst referrers of the SLT's role, difficulties in diagnosis, and restrictive service  
34  
35  
36 criteria. Researchers in the United States also report an increase in referrals for both assessment  
37  
38  
39 and differential diagnosis of PPA variant, as well as for treatment (Henry & Grasso, 2018).  
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41  
42 Taylor et al (2009) hypothesize that, in Australia, neurologists are most likely to refer to speech  
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44  
45 and language therapy as a result of knowledge of the treatment SLTs provide to people with  
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47  
48 non-progressive stroke related aphasia.  
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55 Given its degenerative nature, care pathways for PPA need to include different components  
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57  
58 than those for people with acute onset non-progressive aphasia. The European Pathway  
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3 Association (2007) defines a care pathway as “an explicit statement of the goals and key  
4  
5 elements of care based on evidence, best practice and patient expectation”. Volkmer et al.  
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8  
9 (2018) highlight that more than 90% of SLT respondents across the UK who were wide  
10  
11  
12 survey of SLTs working with people with PPA reported there was no care pathway for PPA  
13  
14  
15 within their services (Volkmer et al., 2018). Taylor et al. (2009, p.12) reported “no clear  
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17  
18 single management pathway” for speech and language therapy practice for PPA in New  
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20  
21 South Wales, Australia.

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27 Previous attempts to outline key elements of care for PPA have come from studies carried out  
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29  
30 in the US. For example, Rogers & Alarcon (1998) describe three key principles for  
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32  
33 management of people with PPA including planning interventions in anticipation of  
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35  
36 continued decline, working with communication partners upon whom individuals will  
37  
38  
39 inevitably become dependent, and directing therapy at the level of disability since restitution  
40  
41  
42 is not ultimately possible given the deteriorating nature of the disease process. In contrast, a  
43  
44  
45 phased approach to treatment has been proposed by Hinshelwood & Henry (2016), whereby  
46  
47  
48 in the mild stage of the disease restorative therapies are employed, in the moderate stages  
49  
50  
51 AAC and multimodal communication are prioritised, and in later stages there is a focus on  
52  
53  
54 environmental supports and communication partner training (CPT). More recently, Rogalski  
55  
56  
57 and colleagues, have advocated an overarching person-centered approach that “proactively  
58  
59  
60 informs the care plan through dynamic interactions with the clinician” (Rogalski et al. 2016,

1  
2  
3 p.286) in order to maximize participation in daily life activities and maintain independence  
4  
5  
6 (see also Rogalski & Khayum, 2018).  
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12  
13 While such elements inform a PPA care pathway for speech and language therapy services,  
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15  
16 there remains a paucity of research evidence to underpin specific intervention approaches, and  
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18  
19 a lack of knowledge of best practice and client expectation. A 2013 systematic review of non-  
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21  
22 pharmacological interventions for PPA identified 39 studies investigating interventions for a  
23  
24  
25 total of 67 people (Carthery-Goulart et al. 2013). Twenty-one of these described interventions  
26  
27  
28 targeting solely svPPA and 31 of the 39 studies were impairment based interventions (word  
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30  
31 relearning). The effectiveness of restorative word retrieval therapies for PPA is the focus of  
32  
33 ~~t~~Two more recent systematic reviews ~~exist of the effectiveness of restorative word retrieval~~  
34  
35 ~~therapies for PPA~~ (Jokel et al. 2015; Cadório et al. 2017) and a research update (Croot, 2018).  
36  
37  
38  
39 A systematic review of the effects of functional communication focused interventions for  
40  
41  
42 people with PPA and their caregivers is currently in preparation by the authors.  
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50  
51 Despite the focus on impairment based interventions in the research evidence, limited literature  
52  
53  
54 on best practice indicates that functional communication focused interventions are considered  
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56  
57 a higher clinical priority (Volkmer 2013). Kindell et al (2015) conducted a study with six SLTs  
58  
59  
60 in England to ascertain consensus on the focus of speech and language therapy for svPPA



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2  
3 (referred to as semantic dementia). The top three therapeutic priorities were enabling better  
4  
5  
6 communication with family carers, supporting and educating the multidisciplinary team  
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8  
9 (MDT), and focusing on abilities and strengths (Kindell et al. 2015).  
10

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12  
13 This study aims to reveal the practices of UK SLTs in the areas of assessment and  
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15  
16 management of PPA, including outcome measurement. The literature suggests that SLTs  
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18  
19 have a wide ranging role in supporting people with PPA (Marshall et al. 2018; Volkmer  
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21  
22 2013) but no-one yet has a UK-wide perspective on this.  
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### 29 **Method:**

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33 This survey conforms to the CHERRIES survey reporting checklist (Eysenbach, 2004) and  
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35  
36 Turk et al's (2018) extension to this. The Departmental Ethics Chair in Language and  
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38  
39 Cognition at University College London waived approval as the study met the criteria for  
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42 service evaluation.  
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### 50 *Survey development*

51  
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54 Previous speech and language therapy surveys of clinical practice provided direction on  
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57 development of survey sections and questions, specifically PPA in an Australian context  
58  
59  
60 (Taylor et al. 2009), non-progressive aphasia (Beckley et al. 2017; Sirman et al. 2017) and

1  
2  
3 progressive dysarthria (Collis & Bloch 2012). Literature on speech and language interventions  
4  
5  
6 for PPA (Carthery-Goulart et al. 2011; Volkmer 2013; Kindell et al. 2015) was consulted to  
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8  
9 guide category fields for questions related to assessment and intervention. Occupational and  
10  
11  
12 geographical domains were based on recognised socio-economic classifications (Office for  
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14  
15 National Statistics 2010) and statistical regions (Office for National Statistics 2009) within the  
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17  
18 UK. Questions were refined by the first author (an SLT) with expert advice from co-authors to  
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20  
21 ensure relevance, until a 37-item survey was agreed for initial piloting.  
22  
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### 29 *Pilot phase*

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33 A convenience sample of six practising SLTs piloted the survey to assess usability. To maintain  
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35  
36 the largest possible sample for the main study, we invited SLTs based in the UK who do not  
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38  
39 work with people with PPA, and SLTs who see people with PPA but work in Australia (this  
40  
41  
42 was a convenience sample of SLTs known to the first author) . Pilot respondents recorded the  
43  
44  
45 time taken to complete the survey and provided written feedback on the format, category fields  
46  
47  
48 and wording of questions. Modifications in the light of this feedback included introduction of  
49  
50  
51 a number of ‘other’ or ‘none’ categories and provision of category examples in one question.  
52  
53  
54 Additionally, the survey format was modified to ensure respondents had to provide an answer  
55  
56  
57 before moving on, and a ‘back’ button was inserted so respondents could review their answers.  
58  
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3 After piloting, the number of questions in the final survey was unchanged. Questions were not  
4  
5  
6 randomised, and page numbers not displayed, instead a progress bar was provided.  
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9

10 The final survey comprised five sections: 1) Clinical background; 2) Number, type and source  
11  
12 of patients; 3) Time spent on management of people with PPA; 4) Specific assessment and  
13  
14 intervention approaches; 5) Outcome measures and planning for the future. There were closed  
15  
16 questions (for speed of completion) and open questions to elicit additional information  
17  
18  
19 (Schaeffer & Dykema 2011). The complete survey is presented in Appendix 1.  
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### 31 *Main survey*

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35 This survey was delivered online to facilitate dissemination across the UK. It was designed and  
36  
37 made openly available to respondents, for 8 weeks from the 4<sup>th</sup> February to the 7<sup>th</sup> April 2016,  
38  
39  
40 using Opinio 7.3 software. Once closed, no further responses were recorded. The initial page  
41  
42 of the online survey provided a statement making clear that by continuing, respondents were  
43  
44 giving consent to participate in the survey and that their responses would be stored  
45  
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48  
49 anonymously. No personal data was collected.  
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### 58 *Sample selection*

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3 In order to achieve a representative cohort of UK SLTs, the Royal College of Speech and  
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6 Language Therapists (RCSLT) was contacted to facilitate survey dissemination. A letter to the  
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8  
9 editor containing the survey link was published in the RCSLT practice magazine, 'The  
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11  
12 Bulletin', which is distributed to all 13,809 practising members. The survey link was also  
13  
14  
15 disseminated through an RCSLT electronic research newsletter and was emailed to 14 relevant  
16  
17  
18 Clinical Excellence Networks associated with the RCSLT for onward dissemination to  
19  
20  
21 members. Email and social media were also used to disseminate the link through the first and  
22  
23  
24 fourth authors' networks, including via Twitter and the first author's blog site. A reminder was  
25  
26  
27 sent via all these routes 2 weeks prior to closing the survey (see supplementary information for  
28  
29 dissemination details). **The email inviting SLTs to take part mentioned the development of an**  
30  
31  
32 **intervention but did not refer to CPT.**  
33  
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35

36 Participant inclusion criteria comprised SLTs a) practising in the UK (practising SLTs are  
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38  
39 employed in the UK National Health System from a band 5; entry level, to band 8; highly  
40  
41  
42 specialist, manager or consultant) and b) who had ever worked with a person with diagnosed  
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44  
45 or possible PPA. Respondents completed questions in section 1 of the survey on qualification,  
46  
47  
48 years of employment, and experience of working with people with PPA. If they did not meet  
49  
50  
51 the inclusion criteria at this point they exited the survey. Respondents who met the study  
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53  
54 criteria continued to section 2 of the survey.  
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### *Data analysis*

Following the elimination of duplicates (the last entry was used), completed surveys were extracted and analysed. Data were downloaded to IBM's Statistical Package for Social Science 23 software. Response rates were calculated in accordance with the CHERRIES definition (Eysenbach, 2004). Data on referral rates and patterns, and barriers to accessing speech and language therapy are reported in Volkmer et al (2018). This article reports on care pathways, assessment and intervention practices, outcome measurement, and future planning. A chi square test of independence was performed to examine the relation between intervention type and frequency of use. Remaining data were examined using frequency counts and contingency tables (Sauerbrei & Blettner 2009). For open ended questions or 'other' response categories, both descriptive statistics, such as coding and counting responses, and qualitative analysis was used. The latter included thematic analysis (Braun & Clarke 2006) of intervention goals supplied by respondents.

## **Results**

### *Demographics of SLT respondents*

There were 179 unique survey visitors of which 106 agreed to participate by starting to complete the survey, resulting in a participation rate of 179:106. **One participant exited the**

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2  
3 survey because they had insufficient experience with PPA. The remaining Of these, 105 had

4  
5  
6 experience of working with people with PPA and submitted complete surveys, resulting in a  
7  
8 completion rate of 106:105. There is no available data on numbers of UK SLTs providing  
9  
10 services for PPA, therefore it is not possible to calculate the percentage response rate.  
11

12  
13  
14 Respondents were from a range of grade bands between 5 and 8, and worked across several  
15  
16 professional locations, i.e. primary care, acute health and mental health. Table 1 summarises  
17  
18 respondent characteristics. Just over a third were employed at band 7 (37.1%, n=39) and just  
19  
20 under a third at band 6 level (31.4%, n=33). More than half had over 10 years' experience  
21  
22 (54.3%, n=57). Just under half were based in primary care (45.7%, n=48), with 28 in acute  
23  
24 health (26.7%) and 15 in mental health care (14.3%). There is no national data on proportions  
25  
26 of SLTs employed in primary care, acute health and mental health, yet this sample appears  
27  
28 representative as services to mental health are known, within the profession, to be ~~less~~.  
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38 On comparing respondent rates across UK regions (Office for National Statistics 2009) the  
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40 highest number of respondents were from Scotland (17.1%, n=18) and fewest respondents  
41  
42 came from the North West of England (1.9%, n=2).  
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50  
51 INSERT TABLE 1: Characteristics of SLT survey respondents  
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53  
54 *Care Pathways*  
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3 All respondents who reported having a care pathway for people with PPA (9.4%, n=10) were  
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5  
6 asked to describe this pathway (see Figure 1 for key components). One respondent listed an  
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8  
9 onward referral process to another SLT service. Two respondents described their service's care  
10  
11  
12 pathway as comprising only assessment and advice. One respondent provided a detailed seven  
13  
14  
15 stage care pathway delivered over six sessions, where following assessment at stage 1, the  
16  
17  
18 remaining stages focused on a range of interventions including "Rehearsal and integration of  
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21 appropriate strategies into communication, through modelling, rehearsing and home tasks  
22  
23  
24 which incorporate significant communication partners. Provision of information regarding  
25  
26  
27 appropriate high-tech communication aids". This respondent was the only one who referenced  
28  
29  
30 the intervention research literature. The other six respondents provided an overview of their  
31  
32  
33 service's care pathways by giving some examples of intervention mode (individual, dyadic &  
34  
35  
36 group) or activities that may be offered. Only one of the 10 respondents reporting a local PPA  
37  
38  
39 care pathway described dysphagia assessment and management.

40  
41  
42 Of the 10, only one respondent described being involved in the diagnosis of PPA, although  
43  
44  
45 seven respondents stated that assessment was part of the care pathway. When describing the  
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47  
48 assessment stage of the care pathway, one respondent provided detailed information including  
49  
50  
51 tools used:

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54  
55 "Assessment of impairment and activity/participation. This will include an aphasia and  
56  
57  
58 communication strengths and weaknesses profile, with specific consideration of  
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3 spontaneous strategy use by the client. It will also include identification of the client's  
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5  
6 significant communication partners and their roles. (Assessments: dynamic testing with  
7  
8  
9 Boston Naming Test (BNT); PALPA subtests; CAT subtests).”

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11  
12  
13 Seven of the 10 respondents with a care pathway stated that intervention was a part of it, with  
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15  
16 two explaining that this was based on the “individual's profile”. Three respondents mentioned  
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18  
19 impairment focused interventions, with one of the three respondents describing the provision  
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21  
22 of:

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25  
26 “Impairment based neuro-protective therapy drilling of functional words (written  
27  
28  
29 and/or spoken as appropriate) through modelling in session and in home- tasks. Control  
30  
31  
32 items to be used to aid evaluation of this input.”

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35  
36 Another respondent added the caveat that:

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40 “A package of impairment-based therapy may be offered and provided if the client is  
41  
42  
43 keen, has support and responds well”.

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47  
48 Education and “explanation of the condition” was mentioned by three respondents as part of  
49  
50  
51 the intervention stage of their service's care pathway. Three respondents described provision  
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53  
54 of group therapy (one of whom specified a couples group), and six respondents described  
55  
56  
57 involvement of a carer.



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3 Functional communication focused intervention options were described by four respondents,  
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6 with one commenting:  
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10 “Training in supportive conversational partner strategies offered (not formal training  
11  
12 package, but tailored to individual). Low-tech AAC & communication passports/life  
13  
14 story work”.  
15  
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20 Finally, six of the 10 respondents with a care pathway described ongoing or future input such  
21  
22 as onward referral to other services, signposting to support groups, and review or maintenance  
23  
24 sessions within the speech and language therapy service.  
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29

30 INSERT FIGURE 1. Components of care pathways described by SLT respondents  
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35 All respondents were asked how many sessions they devoted to assessment and management  
36  
37 activities. Respondents were given the following definitions: Assessment includes assessment  
38  
39 of language and communication, contributing to diagnosis of PPA, assessment of dysphagia  
40  
41 and mental capacity assessment; Management includes case/care review meetings, joint  
42  
43 sessions with other disciplines, education for person with PPA, family education, staff  
44  
45 education, impairment-focused language intervention, functional communication focused  
46  
47 interventions, combined language/communication focused intervention, group therapy with  
48  
49 people with PPA, management of dysphagia. Figure 2 summarises the average number of SLT  
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51 sessions respondents reportedly spent on assessment and management activities. On average,  
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3 respondents spent 2.2 sessions on communication assessment, but only 1.2 sessions on  
4  
5 diagnosis, 0.8 sessions on dysphagia assessment and 0.5 sessions on mental capacity  
6  
7 assessment. Results show that respondents spent more time on functional communication  
8  
9 focused interventions than on any other activity, with an average of 4.9 sessions. This contrasts  
10  
11 with 2.8 sessions for impairment focused intervention, 2.8 sessions for combined language &  
12  
13 communication intervention, 2 sessions on family education, 2 sessions on education for the  
14  
15 person with PPA, and 1.5 sessions on group therapy. The smallest amount of time was spent  
16  
17 on joint sessions with other disciplines, on average 0.5 sessions.  
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28 INSERT FIGURE 2. Average number of sessions spent on assessment and management  
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30 activities by SLT respondents working with people with PPA across the UK  
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### 39 *Assessment Tools*

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44 Respondents were asked to rate on a 5-point scale (never, occasionally, sometimes, often,  
45  
46 always) the frequency with which they used a selection of 10 listed assessment tools over the  
47  
48 last 24 months. Figure 3 presents the reported frequency of use of assessment tools. The least  
49  
50 used tool, Mini Mental State Exam (MMSE; Creavin et al. 2016), was rated as never used by  
51  
52 83% (n=87) of respondents and always used by 1.9% (n=2) of respondents. Comparatively the  
53  
54 most used tool, informal interview, was rated as never used by 4.7% (n=5) respondents and  
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2  
3 always used by 78.1% (n=82) of respondents. The second most commonly used tool, informal  
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6 functional assessment was rated as never used by 6.67% (n=7) of respondents and always used  
7  
8  
9 by 65.7% (n=69) of respondents. The third most commonly used tool, informal impairment  
10  
11  
12 based communication screen, was rated as never used by 15.2% (n=16) and always used by  
13  
14  
15 38.1% (n=40). The most commonly used formal published assessment was identified as the  
16  
17 Comprehensive Aphasia Test (CAT; (Swinburn, Porter and Howard, 2004), always or often  
18  
19 used by 44% of (n=46) respondents and never used by 30.5% (n=32) of respondents. When  
20  
21 asked to state other assessments they used, respondents identified 28 further formal tools. The  
22  
23 most commonly named were the Mount Wilga High Level Language Test (Christie, Clark, &  
24  
25 Mortensen 1986) (mentioned by 6 respondents), the Montreal Cognitive Assessment (MOCA;  
26  
27 Freitas et al. 2012) (5 respondents), the Butt Non Verbal Reasoning Test (Butt & Bucks, 2017)  
28  
29 (3 respondents) and the Controlled Oral Word Association Test (COWAT, Patterson 2011) (3  
30  
31 respondents). Of the remaining 24 stated tools, four were suggested by two respondents each,  
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33 and the remainder by one respondent each.  
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45 INSERT FIGURE 3: Frequency of reported use of assessment tools with people with PPA over  
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47 the last 24 months.

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52 INSERT FIGURE 4: Frequency of reported use of intervention approaches with people with  
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54 PPA over the last 24 months  
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### *Intervention approaches*

Respondents were asked to rate on a 5-point scale the frequency (never, occasionally, sometimes, often, always) with which they had used seven listed intervention approaches over the last 24 months. Figure 4 presents the reported frequency of use of intervention approaches.

The least used intervention approach, impairment directed interventions for speech production, was rated as never used by 69.5% (n=73) of respondents. No respondents indicated they always used this approach but it was often used by 8.6% (n=9) of respondents. Comparatively the most used intervention, communication training for families and carers, was rated as never used by 1.9% (n=2) and always or often used by 84.8% (n=81) of respondents. The second most commonly used intervention, functional communication focused interventions, was rated as never used by 17.1% (n=18) and always or often used by 42.9% (n=45) of respondents and sometimes used by 28.6% (n=30) of respondents. Communication training for staff was rated as never used by 37.1% (n=39) respondents, always used by 20% (n=21), and sometimes used by 29.5% (31). Impairment directed interventions were rated as never used by 30.5% (n=32), always or often used by 20% (n=21), and sometimes used by 31.4% (n=33). A chi square test of independence was performed to examine the relation between intervention type (communication training/impairment focused) and frequency of use (always/never). The relation between these variables was significant,  $X^2 (2, N=215) = 71.6442, p=0.00$ , demonstrating that communication training is significantly more likely to be rated as always used than impairment focused intervention. When asked to state other intervention approaches

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3 they used, respondents reported 12 options. The most commonly identified were  
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6 communication books and wallet cards, mentioned by 14 respondents, whilst life story work  
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9 and total communication strategies were each suggested by three respondents.  
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### 11 12 13 14 15 16 *Measuring outcomes*

- 17  
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19 • When asked which outcome measures they used to document progress in therapy  
20  
21 respondents were able to choose multiple options from a list of six options. Goal setting  
22  
23 was reported as the most commonly used measure (53.8%, n=57), followed by self-  
24  
25 rating scales completed by the person with PPA or their communication partner (50%,  
26  
27 n=53), language assessment (48.1%, n=51), Therapy Outcome Measures (TOMS;  
28  
29 Enderby et al. 2013) (34.9%, n=37), rating scales completed by the SLT (19.8%, n=21)  
30  
31 and video-recording of conversation (7.6%, n=8) (the exact aspect of the recording that  
32  
33 provided an outcome measure is not known, since we did not ask respondents to provide  
34  
35 further information). Respondents were asked for examples of other outcome measures  
36  
37 they used and provided nine further tools. Audio recording, and the East Kent Outcome  
38  
39 Measure (EKOS; Murphy & Logan 2009) were each identified by two respondents,  
40  
41 whilst the remaining seven even measures: Aphasia Impact Questionnaire-21 (Swinburn  
42  
43 2013), client feedback, ~~or~~ carer feedback, informal naming assessment,  
44  
45 Communication Outcomes after Stroke (Long et al. 2008), Cognitive Linguistic Quick  
46  
47 Test (Helm-Estabrooks 2001) and Visual Analogue Self-Esteem Scale (Brumfitt &  
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3 Sheeran 1999), were identified by only one respondent each. Respondents were asked  
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5  
6 to provide examples of the types of goals set and provided 88 in total. Six main separate  
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8  
9 main themes arose from analysis of these goals: 1. Communication Aid; 2.  
10  
11  
12 Conversation; 3. Functional communication; 4. Impairment focused; 5. Specific  
13  
14  
15 Practising a strategy; 6. Communication Partner. Figure 5 provides examples of the  
16  
17  
18 goals listed by respondents. Each goal was assigned to one theme. Of the 88 goals, 50%  
19  
20  
21 (n=44) fell into themes 2. Conversation or 3. Functional communication. Conversation  
22  
23  
24 goals centred around using specific strategies, such as gesture or drawing, in  
25  
26  
27 conversations. Fourteen of the functional communication goals related to completing  
28  
29  
30 specific functional communication activities with family and friends, such as ordering  
31  
32  
33 a meal or coffee. Thirty percent (n=29) of goals focused on using a communication aid  
34  
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36 (theme 1), such as tablet devices and wallet cards or communication books in a specific  
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39 situation. Only 10% (n=9) of goals fell into theme 4. Impairment focused, which  
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41  
42 comprised those associated with word relearning and naming, such as learning a certain  
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45 number of words in a certain time frame. Sixteen percent (n=14) of goals fell into theme  
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48 5. Practising a strategy, such as learning to use circumlocution effectively when  
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51 experiencing a word finding difficulty. Finally, 9% (n=8) of goals targeted a  
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54 communication partner and focused on using a specific strategy to support or enable  
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57 their partner with PPA in conversations.  
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3 INSERT Figure 5. Example goals given by respondents organised by theme  
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### 10 *Future planning and onward referral*

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14 Respondents were asked whether they addressed cognitive changes and deterioration in  
15  
16 communication, legal issues including assessment of capacity, driving, family care supports,  
17  
18 or family finance supports in planning for the future with people with PPA (see Table 24).  
19  
20 Almost all respondents (85.9%, n=91) reported that they explicitly addressed both cognitive  
21  
22 changes and deterioration in communication. When asked to give other examples of what they  
23  
24 addressed when planning for the future, respondents identified the following additional issues:  
25  
26 educating children; supporting other staff; housing; signposting carers to organisations for  
27  
28 social and emotional support; advance care planning. Respondents reported the most  
29  
30 commonly used third sector organisations for onward referral to be the Alzheimer's Society  
31  
32 (51.9%, n=55) and the Rare Dementia PPA Support Group (28.35%, n=30). Local aphasia and  
33  
34 memory groups, dementia cafes and other dementia groups were listed, as well as a variety of  
35  
36 organisations such as Befriending, Age UK, Age Northern Ireland, Alzheimer's Scotland,  
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38 Motor Neurone Disease Scotland, Young People with Dementia Groups, and Admiral Nursing.  
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52 INSERT: Table 2: Future planning and onward referral  
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## 58 **Discussion**

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3 The role of SLTs in PPA is an emerging area of practice across the UK. This survey highlights  
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5  
6 the range of current assessment and intervention practices of SLT **respondents** working with  
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8  
9 people with PPA. Importantly these results demonstrate that the range of interventions used by  
10  
11  
12 **respondent** SLTs extend beyond those with a developed evidence base for PPA. **The surveyed**  
13  
14  
15 **SLTss** report that they prioritise communication training for families, suggesting that the needs  
16  
17  
18 of people living with PPA and their families are not being met by a focus on impairment alone.  
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25 Care pathways have a positive impact on the way care is organised (Seys et al. 2017). At  
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28 present, there are no national care pathways for people with PPA or FTD, and only a small  
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31 number of respondents reported having PPA care pathways within their services. A defining  
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34 characteristic of a care pathway is identification of the required healthcare resources (The  
35  
36  
37 European Pathways Association, 2007). Of the pathways that were described by respondents,  
38  
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40 only seven of the 10 included both assessment and intervention, and only one respondent  
41  
42  
43 outlined a **detailed multi-stage care pathway** linked to the current research evidence. Without  
44  
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46 this kind of care pathway in place, SLTs may find it difficult to commission and thus deliver  
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48  
49 best practice care for people with PPA.  
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55 Despite there being a number of dementia specific formal assessment tools available, the most  
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58 popular assessments **that respondents** reported on were informal interviews, functional  
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1  
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3 observation, and a stroke aphasia language battery (the CAT, Swinburn, Porter, Howard 2004).  
4  
5  
6 Henry & Grasso (2018) observe that standard aphasia batteries developed for use with stroke  
7  
8 related aphasia are better able to characterize the language profile of an individual with PPA,  
9  
10 and to distinguish between PPA variants, in order to plan interventions, whilst assessments of  
11  
12 dementia are generally designed to assess changes in cognition rather than language. Notably  
13  
14 Henry & Grasso (2018) point out that a number of tools to assess language in PPA and support  
15  
16 intervention planning are only available in journal articles or by contacting university  
17  
18 departments in the US and Australia. SLTs working in clinical settings in the UK are often  
19  
20 unable to access peer reviewed articles, unless their employer subscribes to the relevant journal,  
21  
22 which may account for these respondents' overwhelming preference for informal assessment  
23  
24 tools. This may indicate that SLTs are unsure of what formal assessment are best to use with  
25  
26 this client group. Alternatively, this may illustrate the need for more available assessment tools  
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28 designed for people with PPA that support both diagnostic profiling and intervention planning.  
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45 The average number of sessions available for impairment focused interventions (2.8), reported  
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47 by respondents, is significantly less than the number of sessions reported to be effective in a  
48  
49 recent review of impairment-based interventions for PPA (Cadório et al. 2017). This review  
50  
51 examined evidence from studies delivering interventions over a range of between 5 and 96  
52  
53 therapy sessions. Despite there being little indication of the 'optimal' dose, longer interventions  
54  
55 did result in better outcomes in people with svPPA (Cadório et al. 2017). It is possible that  
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3 these SLT respondents deprioritise impairment-based interventions knowing they are unable  
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5  
6 to deliver them at the intensity reported in the research literature. In-contrastdeed, 80% of SLT  
7  
8  
9 respondents identified that they would never or only occasionally use impairment focused  
10  
11 interventions for speech production, and 48.6% would never or only occasionally use  
12  
13 impairment focused interventions for naming. The disparity between recommended and  
14  
15  
16 clinically delivered dosages is also a known issue in stroke aphasia interventions (Doogan et  
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19 al. 2018).  
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Clinical commissioning of healthcare in England is based on evidence produced in scientific research as well as local data, expertise and experiences (Swan et al. 2017). This approach to commissioning may account for some of the diversity in the amount of therapy that is reportedly available from SLT respondents to this survey; some services may be commissioned on expertise to which other commissioning groups do not have access. If occupational therapy or social care services for PPA are not commissioned, then an SLT may be the only health professional involved in a person's care. Consequently, these SLT respondents may prioritise broader issues such as future planning, thus reducing the time available for speech and language interventions.

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3 When selecting intervention approaches for people with PPA, 84.8% of survey respondents  
4  
5  
6 reported that they always or often choose communication partner training (CPT) for family and  
7  
8  
9 carers. ~~In contrast, 80% identified that they would never or only occasionally use impairment~~  
10  
11 ~~focused interventions for speech production, and 48.6% would never or only occasionally use~~  
12  
13 ~~impairment focused interventions for naming.~~ Similarly, 37 of 88 goals listed by survey  
14  
15 respondents focused either on conversation or communication with family and friends, or on  
16  
17 engaging in functional activities with family and friends. This emphasis on enabling better  
18  
19 communication between the person with PPA and their family carer aligns with the consensus  
20  
21 results of Kindell et al (2015), which the authors describe as “carer-focused person centred”  
22  
23 dementia care. Rogalski and Khayum (2018) explain that the core elements of a person-  
24  
25 centered approach to PPA include working with a client in order to facilitate their participation  
26  
27 in everyday activities. Communicating with family and friends is a crucial everyday activity.  
28  
29 As yet, there is no research demonstrating the effectiveness of this approach for people with  
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31 PPA and their families (Taylor-Rubin et al. 2017).  
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### 49 *Implications*

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51 This survey suggests that as a profession we need to investigate the potential to develop a care  
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53 pathway for PPA in our services, then to shape this pathway to bring together scientific research,  
54  
55 best practice and service user priorities in order to influence health commissioning. This study  
56  
57 presents national data that SLTs can use in support of this aim. **Given how many SLTs in this**  
58  
59  
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2  
3 **survey report using essential** communication training ~~is~~ for people with PPA and their families,  
4  
5  
6 demonstrating its effectiveness is also of high priority for the speech and language research  
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9 community. This evidence will in turn support future endeavours to influence a national care  
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12 pathway for PPA, which will require rigorous evidence ~~from the highest levels of evidence~~ to  
13  
14  
15 inform recommendations.

### 21 *Limitations*

22  
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24  
25 It is difficult to assess how many SLTs across the UK received this survey. The RCSLT  
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28 estimates that 2,000 of its registered members work with adults but there is no data on client  
29  
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31 groups, which could include, amongst others, head and neck cancer, voice, stroke, and mental  
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34 health. This figure also excludes SLTs not registered with RCSLT (this is not obligatory for  
35  
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37 employment in the NHS), who may be working in private or third sector organisations. Yet,  
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40 with a sample size of 105, representing all geographical regions of the UK, the number of  
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42  
43 respondents to this survey compares favourably to other surveys of speech and language  
44  
45  
46 therapy practice, with respondent numbers ranging between 13 and 147 (Taylor et al. 2009;  
47  
48  
49 Collis & Bloch 2012; Beckley et al. 2017; Miller & Bloch 2017; Sirman et al. 2017). A further  
50  
51  
52 limitation includes access to the survey software, with some SLT respondents reporting that  
53  
54  
55 this was blocked by local IT services. This may have prevented some SLTs from responding.  
56  
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## Conclusion

This survey has highlighted a range of assessment tools and intervention practices used by SLT respondents working with people with PPA. The SLT respondents in this study preference for using the use of CPT over other interventions, despite the lack of research evidence examining its effectiveness for PPA. This approach appears to complement other aspects of a potential care pathway for PPA, such as managing cognitive and communication deterioration, and issues related to future decision making., emphasises that this should be a research priority for the profession. Importantly this study has highlighted the need for evidence based care pathways to guide SLTs working in this emerging area of practice. Care pathways can enable SLTs to advocate for commissioning of appropriately resourced services.

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50 Table 1: Characteristics of SLT survey respondents  
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Years post qualification		Current banding	
1-2	12.4% (13)	Newly qualified	5.7% (6)
3-4	6.7% (7)	Band 5	6.7% (7)
4-10	26.7% (28)	Band 6	31.4% (33)
10+	54.3% (57)	Band 7	37.1% (39)
		Band 8	11.4% (12)

		Other	7.6% (8)
Healthcare service		Geographical region	
Acute Health care	26.7% (28)	East	7.6% (8)
Mental Health care	14.3% (15)	East Midlands	4.8% (5)
Primary Care	45.7% (48)	Northern Ireland	9.5% (10)
Charity/Third sector	3.8% (4)	London	13.3% (14)
Independent/Private	0	North East	3.8% (4)
Other	9.5% (10)	North West	1.9% (2)
		Scotland	17.1% (18)
		South East	15.2% (16)
		South West	10.5% (11)
		Wales	5.7% (6)
		West Midlands	4.8% (5)
		Yorkshire and the Humber	5.7% (6)

Table 2: Future planning and onward referral

Future planning and onward referral (% response; multiple responses allowed)	
Areas that SLTs explicitly address in future planning	

cognitive changes and deterioration in communication	85.9% (n=91)
planning for legal, financial, health and social care issues including assessments of capacity	44.3% (n=47)
family care supports such as respite	38.7% (n=41)
driving	18.9% (n=20)
family, financial supports such as benefits	15.1% (n=16)
Most commonly used third sector organisations for onward referral	
Alzheimer's Disease Society	51.9% (n=55)
Rare Dementia PPA support group	28.4% (n=30)
Stroke Association	15.1% (n=16)
Connect	13.2% (n=14)
Dyscover	3.8% (n=4)

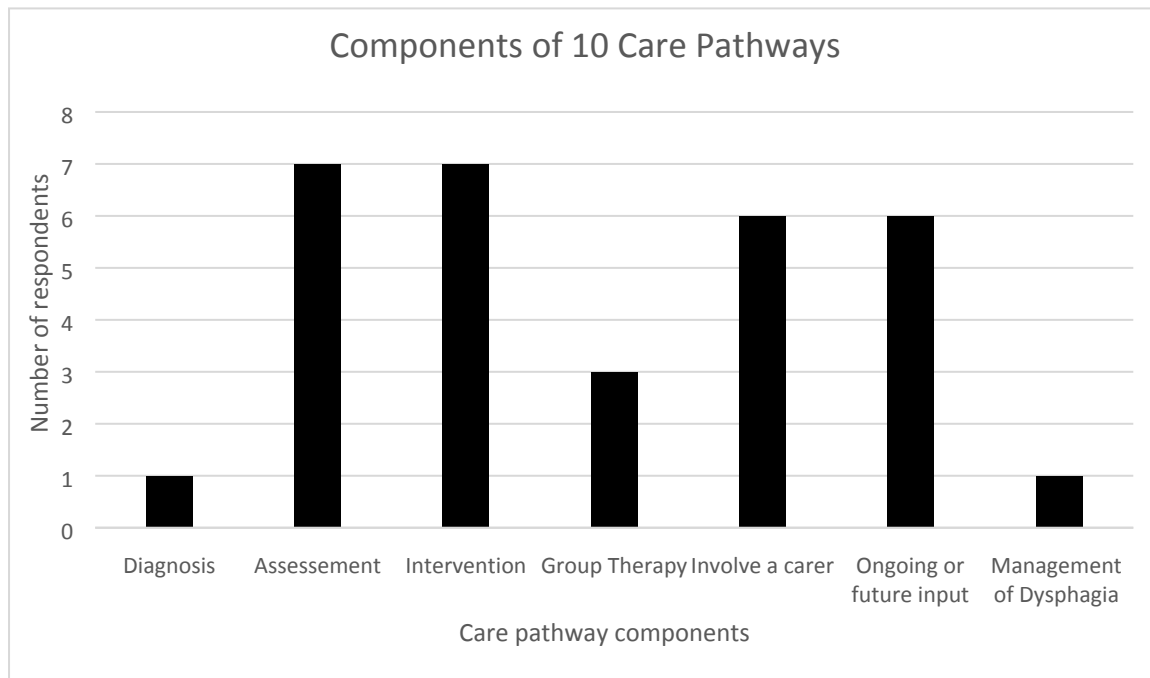
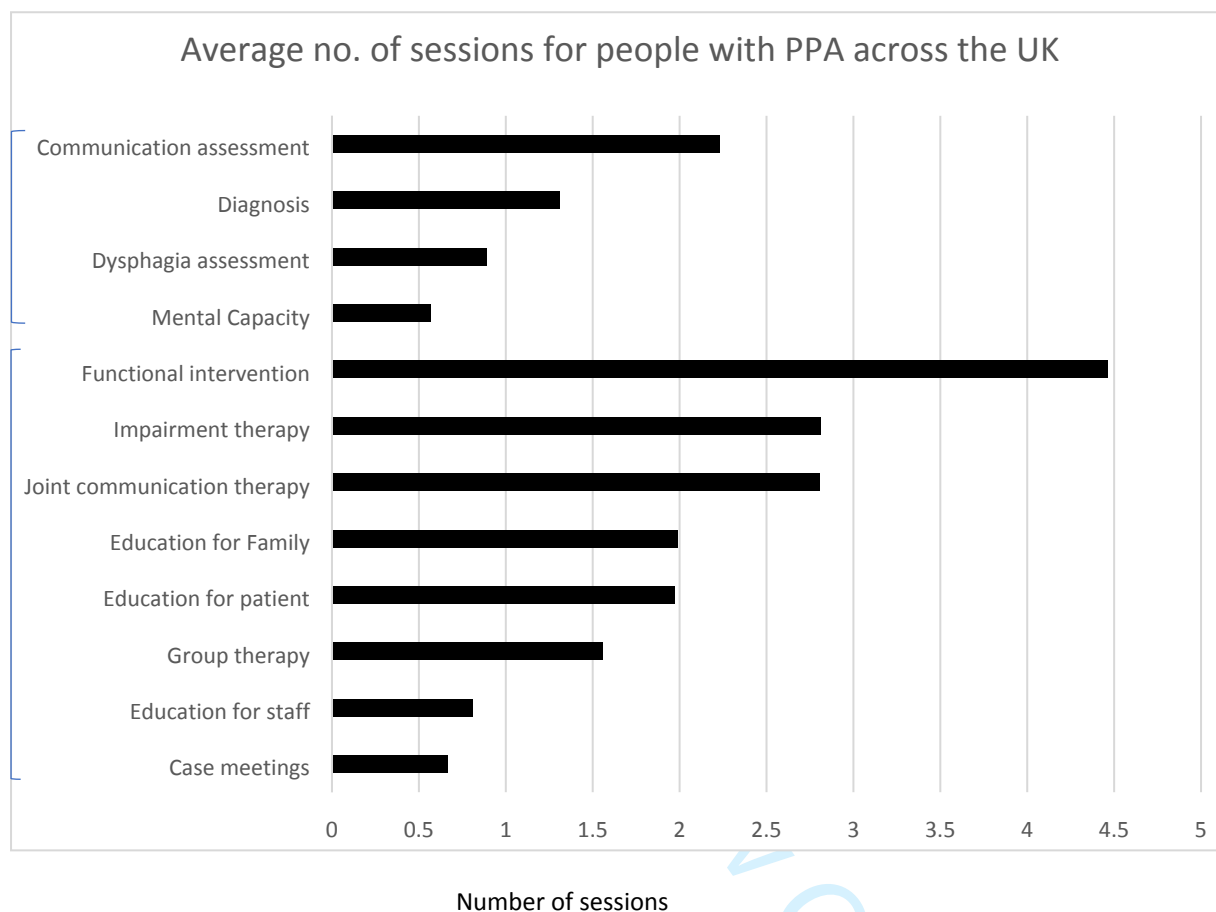


Figure 1. Components of care pathways described by SLT respondents



Assessment activities were defined as: assessment of language and communication, contributing to diagnosis of PPA, dysphagia assessment, mental capacity assessment. Management activities were defined as: functional communication focused interventions, impairment-focused language intervention, combined language/communication focused intervention, family education, education for person with PPA, group therapy with people with PPA, staff education, case/care review meetings.

FIGURE 2. Average number of sessions spent on assessment and management activities by SLT respondents working with people with PPA across the UK

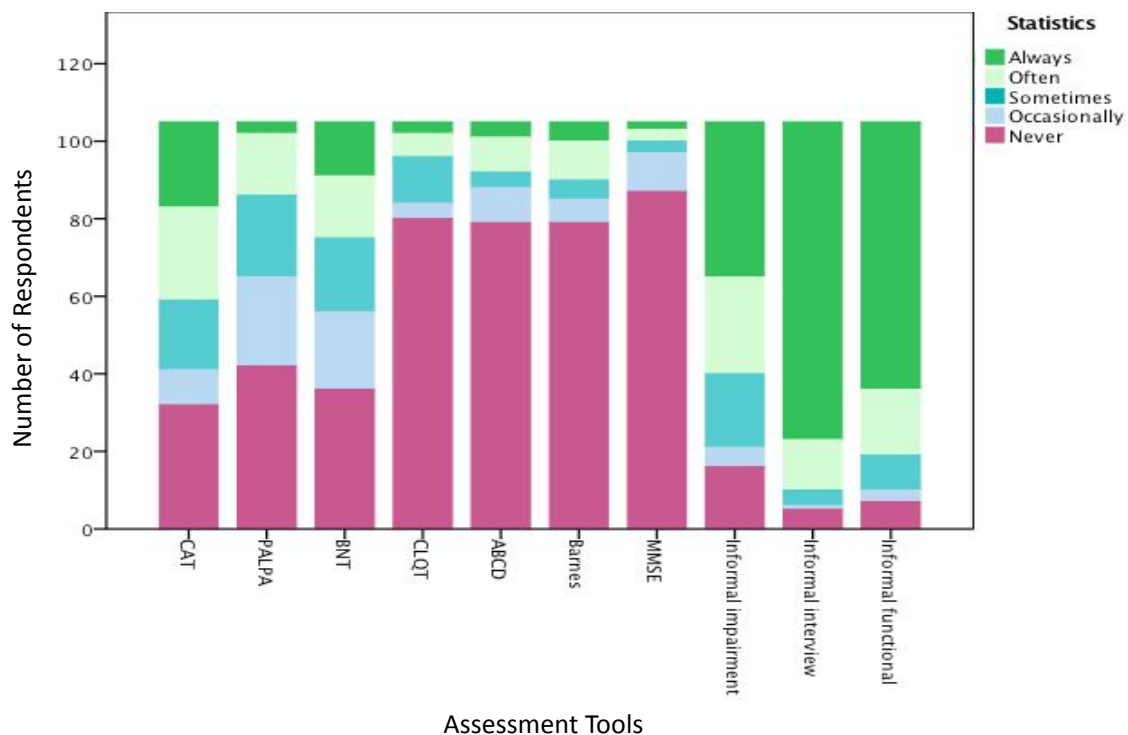


FIGURE 3: Frequency of reported use of assessment tools with people with PPA over the last 24 months.

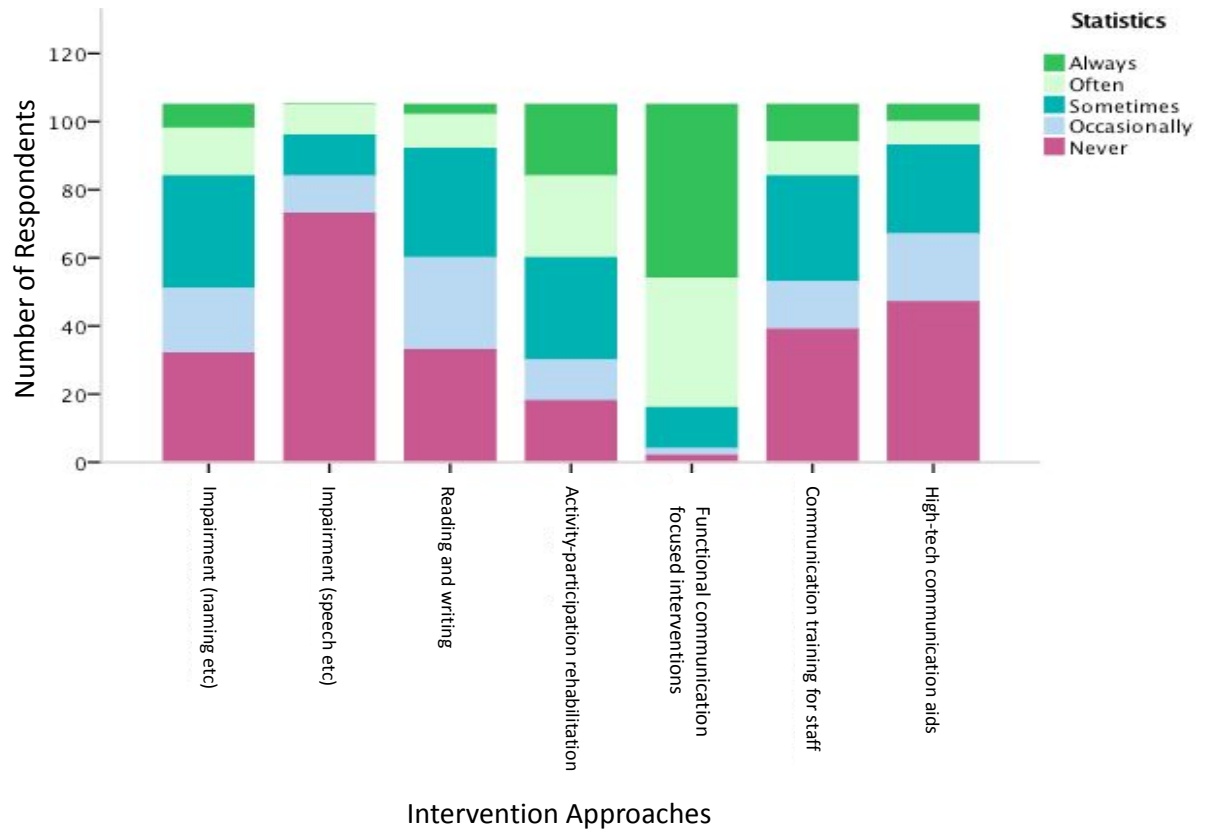


FIGURE 4: Frequency of reported use of intervention approaches with people with PPA over the last 24 months

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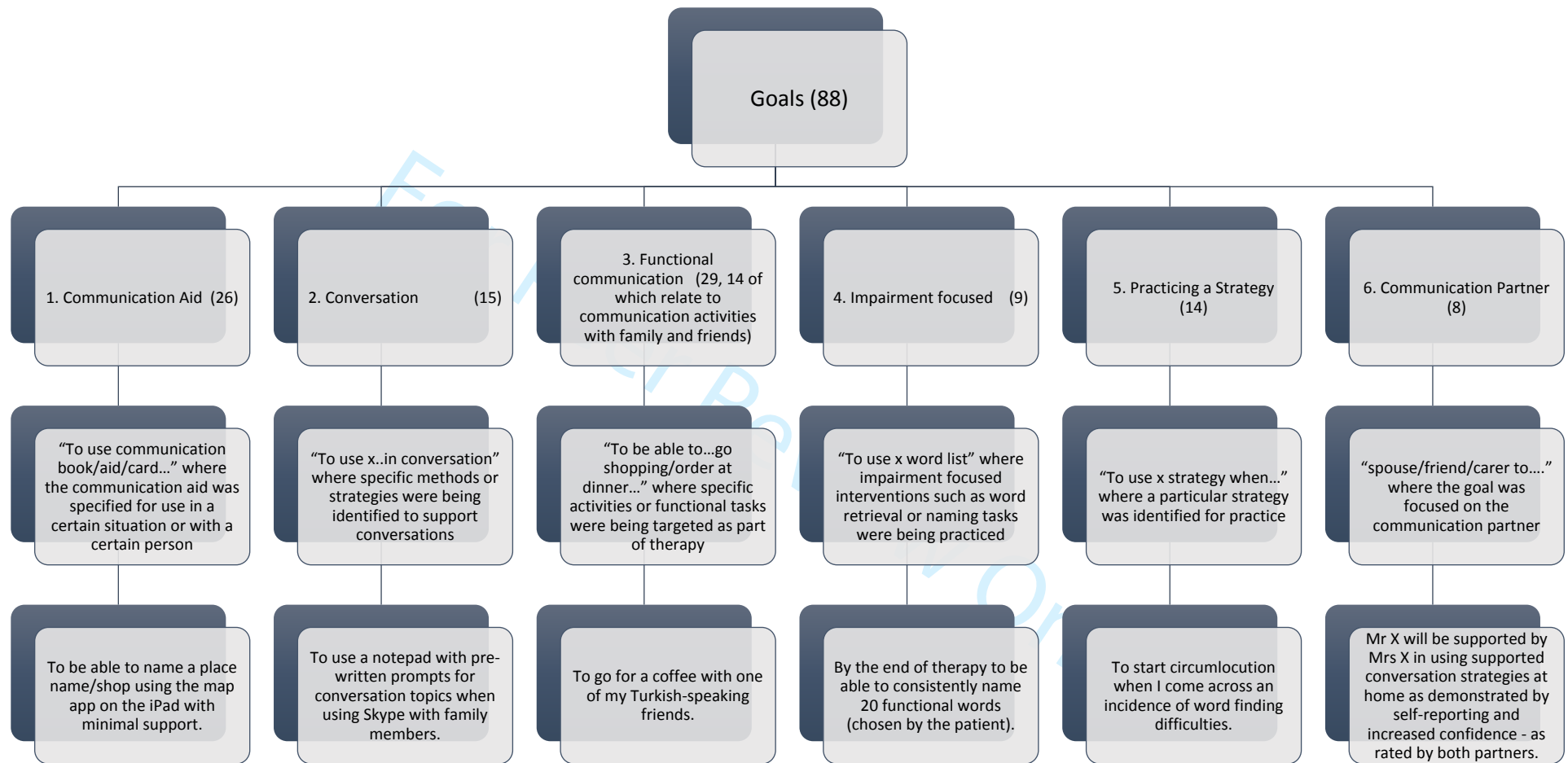


Figure 5: Example goals given by respondents organised by theme

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### Supplementary Material 1

#### Dissemination of survey via emails used the following information:

I would be most grateful if you could disseminate the survey below to as many speech and language therapists to whom this may be relevant.

#### **Calling all Speech and Language Therapists (SLTs) who see people with Progressive Aphasia:**

PPA (a type of dementia) is a progressive language impairment. It is often diagnosed when people are in their 50s and 60s. Speech and language therapy services provided to this group are variable and anecdotally therapists report using many different approaches in managing this group.

Last summer I was awarded an NIHR Doctoral Research Fellowship to complete a PhD at UCL, supervised by Dr Suzanne Beeke and Dr Aimee Spector. My research will focus on refining and piloting an intervention for people with primary progressive aphasia (PPA).

The first stage of my research is to conduct a survey of current speech and language therapy practices across the UK. If you work with adults with neurological conditions and have seen someone with PPA in the last 24 months please complete my survey. The link is:

<https://opinio.ucl.ac.uk/s?s=42060>

I am currently only planning to keep the survey open for the next couple of months so please do distribute and respond if you are able.

You can follow the project on twitter @volkmer\_anna or <https://annavolkmersbigphdadventure.wordpress.com>.

Or email me at: [a.volkmer.15@ucl.ac.uk](mailto:a.volkmer.15@ucl.ac.uk)

Many thanks in advance.

Anna

## APPENDIX 1: Survey Questions

**Section 1: Your clinical background**

1. My job title is (open box)
2. How many years post-qualification are you? Please select one option.
  - Newly Qualified
  - 1-2
  - 3-4
  - 4-10
  - 10+
3. What is your current banding? Please select one option.
  - Newly Qualified Band 5
  - Band 5
  - Band 6
  - Band 7
  - Band 8
  - Other, please specify.
4. What healthcare service is your position funded by? Please tick one box:
  - Acute Health Care
  - Mental Health Care
  - Primary Care
  - Charity / Third sector
  - Independent / Private
  - Other, please specify
5. Which of these categories most closely represents where you work geographically?
  - Please tick one box:
  - South west
  - South East
  - London
  - East

- 1  
2  
3 West Midlands  
4  
5 East Midlands  
6  
7 Yorkshire and The Humber  
8  
9 North West  
10  
11 North East  
12  
13 Ireland  
14  
15 Wales  
16  
17 Scotland  
18  
19 Outside the UK

20 6. Have you EVER seen a patient with confirmed or queried PPA?

21  
22 Yes/No  
23

24 [If no please finish the survey now and enter submit]  
25

26 7. Which setting have you seen patients with PPA in? Please tick all those that apply.  
27

- 28 Acute Medical  
29  
30 Inpatient Rehabilitation Unit  
31  
32 Outpatients  
33  
34 Community- domiciliary, ESD  
35  
36 Memory Clinic  
37  
38 Other, please specify  
39  
40

41 ***Section 2: Number of patients, types of patients and where from?***  
42

43 8. Please estimate how many patients with PPA you have had on your caseload over  
44 the last 24 months? (please indicate a specific number)  
45

46  
47  
48 9. Please estimate the age range of the patients referred:  
49

- 50 < 50 years of age  
51  
52 50-60 years of age  
53  
54 60-70 years of age  
55  
56 >70 years of age  
57  
58

59 10. Please estimate what percentage came from the following backgrounds?  
60

1  
2  
3 English speaking background only

4  
5 Non-English speaking background

6  
7 Bi / Multi-lingual background

8  
9 If you saw individuals who spoke languages other than English, please list below the  
10 languages used:

11  
12  
13  
14 11. Of the patients referred to you with PPA what were their current or previous  
15 professions:

16  
17 (Please estimate what percentage were from the following professional areas)

18  
19 Higher managerial, administrative & professional occupations

20  
21 Intermediate occupations (such as supervisory, clerical & junior managerial,  
22 administrative, professional occupations)

23  
24 Routine and manual occupations (such as skilled, semi-skilled & unskilled  
25 manual occupations)

26  
27 Never worked or long-term unemployed

28  
29  
30  
31  
32 12. Do you feel there are people with PPA who haven't accessed the services you  
33 provide?

34  
35 Yes/No

36  
37 If yes what are some of the barriers (please tick all that apply):

38  
39 Geographical location

40  
41 Language barrier

42  
43 Offered by decline

44  
45 Service criteria

46  
47 Other: (please explain)

48  
49  
50  
51 13. Compared to previous years do you feel the number of patients with PPA on your  
52 caseload has (please tick one box):

53  
54 Increased

55  
56 Decreased

57  
58 Stayed the same

59  
60 If increased or decreased, please explain why you think this has happened:

1  
2  
3  
4  
5 14. Which professionals mainly refer people with PPA to the speech and language  
6 therapy service where you work? (tick all that apply)  
7

8 Psychiatrists

9 Neurologists

10 Geriatricians

11 GPs

12 Psychologists

13 Other Speech and Language Therapists

14 Other:

15 15 What were the symptoms that prompted the referral to your service?

16 (Please estimate the percentage of referrals for each item)

17 Word finding difficulties

18 Slurred speech

19 Volume of speech

20 Swallowing difficulties

21 Other:

22  
23  
24 16. Prior to their referral to you, were the patients and their family members made  
25 aware of their diagnosis of PPA?

26 Always/mostly/sometimes/occasionally/never

27  
28  
29 17. If the patient/family members were NOT made aware of the diagnosis, what other  
30 terms / labels were used by the doctor to describe the condition, if any? (open box)

31  
32 18. If the patient/family member have been made aware, which of these terms was  
33 used?

34 Primary progressive aphasia

35 Logopenic PPA

36 Semantic PPA

37 Non-fluent PPA

38 Semantic dementia

1  
2  
3 Frontotemporal dementia

4  
5 Other:

6  
7  
8  
9 19. Were they informed that this was a type of dementia?

10 Always/mostly/sometimes/occasionally/never

11  
12  
13  
14 20. What difficulties if any do patients report in getting a diagnosis of PPA? (open  
15 box?)

16  
17  
18  
19 21. When are the majority of these patients being referred to you? (please tick one  
20 box)

21  
22 Within a year of symptom onset (around diagnosis)

23  
24 2-3 years post onset (mid-way through the disease process when language  
25 symptoms are still the primary issue)

26  
27 4+ years post onset (later stage of the disease when cognitive symptoms have  
28 emerged)

29  
30 Unknown

31  
32  
33  
34 22. Do you have an established care pathway for people with PPA?

35 Yes/no

36  
37 Please describe:

38  
39  
40  
41  
42 ***Section 3: Time spent on management of this patient group***

43  
44 23. Does your service stipulate how long an individual's intervention can last when  
45 they have a diagnosis of PPA? For example intermediate care often has a six-week  
46 intervention limit

47  
48 Yes - Please tick the approximate number of sessions (please tick one)

49 1-2 sessions

50 2-3 sessions

51 4-6 sessions

52 6+ sessions

53  
54 Other, please specify



1  
2  
3  
4  
5 No – How many sessions on average would you estimate you spend with an  
6 individual from this patient group  
7

8 Please tick the approximate number of sessions (please tick one)  
9

10 1-2 sessions  
11

12 2-3 sessions  
13

14 4-6 sessions  
15

16 6+ sessions  
17

18 Other, please specify  
19  
20

21  
22 24. Please estimate how many sessions you spend on the following when working  
23 with patients with PPA and / or their families  
24

25 Direct assessment of language and communication  
26

27 Assessment of dysphagia  
28

29 Contributing to diagnosis of PPA  
30

31 Impairment-directed language intervention  
32

33 Functional interventions to support communication  
34

35 Management of dysphagia  
36

37 Education/information for patient  
38

39 Education/information for family  
40

41 Education/information for staff  
42

43 Joint language / communication focused intervention with patient and  
44 family/friend/other  
45

46 Mental Capacity assessment  
47

48 Case/care review meetings  
49

50 Joint sessions with other disciplines  
51

52 Group therapy  
53  
54

55 25. If you are providing functional interventions to support communication, in what  
56 setting would these ideally occur in your opinion? (tick one)  
57

58 Inpatient  
59

60 Outpatient

Domiciliary

26. Ideally how much time would you like to spend with someone with PPA on functional interventions to support communication?

Enter number of sessions:

***Section 4: Specific assessment and intervention approaches***

27. When working with people with PPA how often do you use each of the following assessments/tools?

Always/ often/sometimes/occasionally/never

Comprehensive Aphasia Test (CAT) - Swinburn, Porter & Howard (2004)

Psycholinguistic Assessment of Language Processing in Aphasia (PALPA) – Kay, Lesser & Coltheart (1992)

Boston Naming Test

Cognitive Linguistic Quick Test (CLQT) - Helm-Estabrooks (2001)

Arizona Battery for Communication Disorders (ABCD) - Bayles & Tomoeda (1993)

Barnes Language Assessment – Designed by Psychiatry of Old Age SIG members.

Mini Mental State Examination (MMSE)

Informal impairment based communication test/screen

Informal interview with person / family on personal history / conversation style / personality etc

Informal assessment or observation of communication in functional activities

If you use any other assessment tools give name/authors (if appropriate), and a brief description of purpose

28. When working with people with PPA how often do you use the following intervention options?

Always/ often/sometimes/occasionally/never

Impairment-directed interventions including naming, semantic attributes, lexical retrieval, object use, phonological skills,

Impairment-directed interventions for speech production (apraxia of speech)

1  
2  
3 Work on reading and writing

4  
5 Activity participation rehabilitation e.g. working on communication activities  
6 for a cooking task or TV watching Functional communication e.g. practising  
7 the use of multi-modal strategies such as gesture, drawing, writing

8  
9 Communication training for families /carers

10  
11 Communication training for staff

12  
13 High tech communication aid provision and training- e.g. making an informed  
14 choice about app/device and training the client to use it, developing a  
15 communication book / word book or diary system etc

16  
17 Introducing the person and their family to social and support networks

18  
19 If you use any other interventions please describe

20  
21  
22  
23 ***Section 5: Outcome measures and planning for the future***

24  
25 29. Do you use any of the following as an outcome measure for patients with PPA:

26  
27 Goal setting

28  
29 TOMS (ref)

30  
31 Language assessments e.g. naming, picture description

32  
33 Self-rating scales

34  
35 Speech and language therapist rating scale

36  
37 Video-recording of communication

38  
39 Other. Please specify

40  
41 30. Please provide one example of a goal that you have set with a patient with PPA.  
42 Open question:

43  
44 31. Do you explicitly address any of the following in planning for the future with  
45 patients with PPA? Tick all that apply:

46  
47 Cognitive changes and deterioration in communication

48  
49 Legal, financial, health and social care issues, including assessment of  
50 capacity.

51  
52 Driving

53  
54 Family care supports such as respite

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56 Family financial supports such as benefits

57  
58 Other. Please specify:  
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32. Do you refer patients and their families to any of the following charity or third sector organisations? Tick all that apply:

- PPA support group
- Alzheimer’s Society
- Dyscover
- Stroke Association
- Connect
- Other – please specify

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