Better Conversations with Primary Progressive Aphasia (BCPPA): Developing and piloting a communication partner training intervention for people with primary progressive aphasia and their significant others.

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PhD Thesis

Supervised by Dr Suzanne Beeke and Professor Aimee Spector
I, Anna Louise Pridham Volkmer, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed……………………..
“Before we were married we were two separate individuals. When we were married we became a team. PPA pulled my wife away from me and out of our team. I needed to learn to change the way I communicate with her so I could stay in her team. Speech and language therapy helped me do that”

(anon CP).

I’d like to start these acknowledgements by thanking the people with PPA and their families and loved ones who’ve so generously shared their lives, experiences, opinions and ideas with me. I have met so many amazing people through my clinical work, the research, the PPA support group and the project steering group. Thank you to all those people with PPA who have contributed to the study, every single participant and all those potential participants too. You are the blood and soul of this work.

Without my primary supervisor, Associate Professor Suzanne Beeke this would not have been possible. She has believed in me from the first time I mentioned the idea. Without Suzanne I wouldn’t have secured the fellowship. I wouldn’t have developed my writing skills (my spelling and grammar have slightly improved but mainly my ability to talk science). Suzanne has always had time and patience for me. You are an inspiration. I hope one day I can be to someone else what you have been to me. And I hope we continue to work together as the Better Conversations team evolves! Thank you.
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Abstract

Primary progressive aphasia (PPA) is a language led dementia, often associated with Fronto-Temporal dementia or Alzheimer’s disease, presenting as insidious deterioration of language, initially with relative sparing of cognition. The effectiveness of communication partner training (CPT) for PPA is unknown, yet speech and language therapists (SLTs) report regular clinical use. This thesis developed and piloted a CPT for people with PPA and their communication partners (CPs), ‘Better Conversations with Primary Progressive Aphasia’ (BCPPA) following phases I and II of MRC guidelines for developing complex interventions.

Phase I included a UK survey of SLTs, a systematic review of PPA functional communication interventions, and development of the intervention manual, co-designed with a steering group and SLTs. Phase II comprised a single blind, randomised controlled pilot-feasibility study across 11 National Health Service sites in England and Wales.

Surveyed SLTs prioritised CPT over impairment-focused interventions. The systematic review identified key components of PPA functional communication interventions to be building on existing strategies, and practising with a CP. This informed development of the BCPPA manual alongside consensus work with SLTs to agree key intervention components, and steering group co-production of materials. The pilot-feasibility RCT recruited 18 people with PPA and their respective CPs (dyads). Participants and SLTs found BCPPA acceptable. Intervention fidelity was 87.2%. Preliminary intervention findings indicate 8 of 9
dyads achieved positive change in self-identified conversation goals. However, BCPPA was no more effective than no treatment on self-rated measures of quality of life, confidence in communication, impact of communication disorder, carer burden, and carer stress. Although the AIQ-21 was identified as a potentially suitably sensitive outcome measure, observation data on communication behaviours has not yet been analysed. The current sample size calculation is large and poses a potential difficulty in recruitment to a future full trial with the same design as the current pilot feasibility study. Data collection continues, and further analysis of as yet unexamined communication behaviour is underway. This work will provide additional information to make a better decision about the feasibility of a future large scale evaluation of BCPPA.
The number of people living with dementia is estimated at between 500,000 and 800,000 in the UK, and is set to triple by 2050. As a younger onset dementia, primary progressive aphasia (PPA), a language led dementia, has a disproportionate socioeconomic and human impact. There is some evidence for the effectiveness of interventions such as word relearning therapies for PPA. However, this type of daily practice does not meet the needs of people with PPA and their communication partners. Many speech and language therapists (SLTs) prefer communication partner training (CPT) over word relearning, despite there being little evidence demonstrating its effectiveness for PPA.

This study has developed, piloted and investigated the feasibility of the first CPT program designed by and for people with PPA and their communication partners; Better Conversations with PPA (BCPPA). The BCPPA program was co-produced with the project steering group who produced training modules and an intervention manual. This was done in line with guidance from the MRC on developing complex interventions and informed by a UK-wide survey of current speech and language therapy practice in PPA and a review of the research literature on functional communication focused interventions. BCPPA was tested in a randomised controlled pilot-feasibility study with 18 people with PPA and their communication partners across 11 NHS sites.

The findings of the pilot-feasibility study demonstrate that the BCPPA program is feasible to deliver in an NHS setting, and meets the needs of people with PPA and their communication partners. A questionnaire on the impact of
communication disability has been identified as a potentially suitably sensitive outcome measure. Trained local SLT collaborators achieved a high level of treatment fidelity. Overall these findings indicate that a future large scale evaluation study can be reliably delivered over multiple research sites. This research has the potential to inform future clinical practice. Preliminary findings suggest BCPPA enables people with PPA and their communication partners to implement positive strategies in conversation. The BCPPA program is hosted on the UCL eXtend short course portal. Ultimately, it will be made freely available to SLTs across the world.

Results of this work are published in the following peer reviewed journals:


to service provision across the UK. *Dementia, 0*(0) 1–15. Doi: 10.1177/1471301218797240

Social media outputs include blogs and podcasts at https://annavolkmersbigphdadventure.wordpress.com/ and https://www.dementiaresearcher.nihr.ac.uk/.
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Glossary

AIQ-21  
Aphasia Impact Questionnaire-21 (Swinburn et al., 2018;  
https://www.aiq-21.net/)

Applied CA  
Using conversation analysis to inform intervention  
development and delivery.

BCA  
Better Conversations with Aphasia

BCPPA  
Better Conversations with Primary Progressive Aphasia

CA  
Conversation Analysis; a rigorous method of analysing  
naturally occurring talk.

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

CCRSA  
Confidence in Communication Rating Scale for Aphasia  
(Babbitt, Heinemann, Semik, & Cherney, 2011)

CEN  
Clinical Excellence Network; a group of speech and language  
therapist with a common clinical interest who meet regularly  
for study days and peer support.

COM-B model  
The COM-B model (Michie, van Stralen, & West, 2011) is a  
thoretical model that accounts for an individual’s behaviour  
change as the product of three equally weighted components  
namely Capability, Opportunity and Motivation.
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<tr>
<td>Communication Aid</td>
<td>Communication aids assist people with communication difficulties to express themselves and may include both technology based solutions such as apps on computers, or low technology based solutions, such as drawing with a pen and paper.</td>
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<tr>
<td>CONSORT</td>
<td>Consolidated Standards of Reporting Trials</td>
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<td>CP(s)</td>
<td>Conversation partner(s)</td>
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<tr>
<td>CPT</td>
<td>Communication Partner Training; an intervention which aims to improve the communication behaviours of the conversation partners of, and people with communication difficulties.</td>
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<tr>
<td>DEMQOL</td>
<td>Dementia Quality of Life rating scale (Mulhern et al, 2013)</td>
</tr>
<tr>
<td>Formal assessment</td>
<td>An assessment undertaken using a published, and often psychometrically standardised tool.</td>
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<tr>
<td>Functional behavioural approach</td>
<td>An intervention that targets practical or behavioural strategies that an SLT has knowledge and experience of using</td>
</tr>
<tr>
<td>FCI</td>
<td>Functional Communication Intervention; An intervention focusing on functional communication; executing an activity and participating in life situations.</td>
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<tr>
<td>FTD</td>
<td>Fronto-temporal Dementia</td>
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Impairment focused intervention  An intervention that seeks to remediate, alleviate or improve symptoms

Informal assessment  An assessment undertaken without using a published or psychometrically standardised tool.

ITAX  Intervention Taxonomy (Schulz, Czaja, McKay, Ory, & Belle, 2012) used to analyse components of interventions documented in the research literature

IvPPA  logopenic variant Primary Progressive Aphasia

MRC  Medical Research Council

nfvPPA  non-fluent agrammatic variant Primary Progressive Aphasia

PPA  Primary Progressive Aphasia

PwPPA  Person with Primary Progressive Aphasia

PSS  Perceived Stress Scale (Cohen, Kamarck & Mermelsten, 1994)

RCSLT  Royal College of Speech and Language Therapists
Session
An episode of care, in speech and language therapy
this is commonly a 45-60 minute meeting between
the person and their SLT.

SLT
Speech and Language Therapist

SPIRIT
Standard Protocol Items: Recommendations for
Interventional Trials (Chan et al., 2013)

svPPA
semantic variant Primary Progressive Aphasia

TiDIER
Template for Intervention Description and Replication
(Hoffman et al, 2014)

Trouble indicating behaviours
Communication behaviours which indicate the
interlocutors in a conversation are not achieving
mutual understanding due to a conversational
breakdown such as a mishearing or misunderstanding
Chapter 1 Introduction

The number of people living with dementia worldwide continues to rise, estimated at around 46 million in 2015 and set to increase to around 131.5 million in 2050 (Prince et al., 2015). Primary Progressive Aphasia (PPA) is a language-led dementia associated with Fronto-Temporal Dementia (FTD) and Alzheimer’s disease (Marshall et al., 2018). Although relatively uncommon (estimated prevalence of three cases per 100,000 (Coyle-Gilchrist et al., 2016), PPA is often diagnosed in people in late middle age who are still working and have busy family and social lives (Croot, 2009; Dua, Nichols, & Setoya, 2012). All forms of PPA present as insidious deterioration of language skills, initially with relative sparing of other cognitive functions (Marshall et al., 2018).

There are reports of infrequent utilisation of SLT in Australia (Taylor et al., 2009) and Germany (Riedl et al., 2014) by people with PPA. These researchers speculate on the reasons for this, including a lack of awareness of the SLT role amongst referrers (Taylor et al., 2009) and a scarcity of SLTs who are experienced in the treatment of PPA (Riedl et al., 2014). The research literature on treatment approaches for people with PPA is a developing field. The majority of the research in this area has focused on impairment focused interventions that aim to maintain or improve the person’s ability to use words (Carthey-Goulart et al., 2013). Yet in clinical practice speech and language therapists (SLTs) are prioritising interventions that focus on improving communication between a person with PPA and their family (Kindell, Sage, & Cruice, 2015).

Many people with PPA disengage from naming therapies due to the frustration of practising individual words they will inevitably lose as the disease progresses (Croot, 2009). Additionally there is a need to engage family who are motivated to understand how they can best support their loved ones. Communication partner
training (CPT) has a growing evidence base in stroke related aphasia (Simmons-Mackie, Savage, & Worrall, 2014), demonstrating changes in the conversation skills of people with aphasia as well as communication partners (CP, Beeke et al., 2014; Best et al., 2016).

This study developed and piloted a CPT entitled Better Conversations with PPA (BCPPA). Work comprised phases I and II of the Medical Research Council guidelines on developing and researching complex interventions (Craig et al., 2008) and aimed to:

Phase 1:

- Assess the extent of UK-wide SLT engagement in assessment and management of PPA, determine the factors contributing to any shortfall and explore a gap in the research literature on current SLT practices with people with PPA.
- Identify the current functional communication interventions for people with PPA and their CPs, examine the effectiveness and identify the key components of these interventions.
- Define and refine a manual and an online training resource for SLTs delivering BCPPA to people with PPA and their CPs.

Phase II:

- Pilot the BCPPA program compared to a no speech and language therapy treatment control group over participating sites to establish for a main trial whether BCPPA can be delivered as intended in an NHS setting.

Specifically, the aim of piloting the BCPPA program was to establish:

- predicted patient recruitment and retention rates
- refined inclusion criteria
- the acceptability of randomisation
o an assessment of BCPPA treatment fidelity to determine necessary levels of SLT training
o the most appropriate primary outcome measure
o sample size calculation for a full trial, if warranted

Chapter 2 ‘Primary Progressive Aphasia’ describes the prevalence of PPA, and provides an overview of three PPA variants and their unique speech and language profiles. Speech and language provision is discussed, with reference to current research evidence for interventions in this area. Finally, this chapter reports on conversation in PPA and the available intervention approaches and highlights the gap in the research evidence that this study aims to address.

Chapter 3 presents the results of a UK-wide survey of SLTs to understand current clinical practice in the area of assessment and management of PPA, as well as any barriers to delivering these services. The implications for future research and clinical practice are discussed.

Chapter 4 describes a systematic review of the effects of functional communication interventions for people with PPA and their family caregivers. The key components of the interventions are examined and implications for future intervention studies are discussed, alongside the need for a set of core outcome measures.

Chapter 5 describes the six phases of BCPPA program development and manual drafting in preparation for the Phase II pilot-feasibility RCT. This includes co-production with a project steering group, alongside the input of SLTs, people with PPA and their families.
Chapter 6 reports on the protocol and results of the phase II pilot-feasibility RCT study of the BCPPA program. Recruitment and retention data, feedback on acceptability, treatment fidelity analysis and analysis of outcome measures are reported and discussed.

Chapter 7 draws the study results together. The findings are evaluated, study limitations are addressed, and directions for future research are presented.
Chapter 2 Primary Progressive Aphasia

Dementia is an umbrella term, describing a group of diseases that cause permanent and progressive damage to the cognitive function, behavior and brain (Public Health England, 2018). In 2018 there were estimated to be between 500,000 and 800,000 people living with a diagnosis of dementia in the UK (Alzheimer’s Research UK, 2018), and at least 16,730 of these were people with younger onset dementia (Public Health England, 2018). FTD is the leading cause of younger onset dementia in the UK (population prevalence rate of 11/100,000) with PPA syndromes accounting for around a third of cases (Coyle-Gilchrist et al., 2016). This conservative estimate means there are at least 2300 people currently living with PPA in the UK. Given that by 2050 the number of dementia cases worldwide is set to triple (Prince, Wimo, Guerchet, Ali, Wu, & Prina, 2015), the number of people living with PPA is similarly likely to rise. As a younger onset dementia, PPA is often diagnosed in people in their 50s-60s who are still employed, with dependent families and is therefore liable to have a disproportionate socioeconomic and human impact (Croot, 2009; Dua, Nichols, & Setoya, 2012).

PPA describes a heterogeneous group of language led dementias associated with atrophy of the fronto-temporal and temporo-parietal regions of the dominant hemisphere of the brain, responsible for processing and producing language (Bonner, Ash, & Grossman, 2010; Dickerson, 2011; Kertesz, Jesso, Harciarek, Blair, & McMonagle, 2010; Mesulam, 1982). The primary diagnostic feature for PPA, as agreed by international consensus, is a slowly worsening impairment of language impacting on daily living, on a background of relatively preserved
memory, visuospatial skills, reasoning, behaviour and executive and social skills (Gorno-Tempini et al., 2011; Mesulam, 1982).

2.1 Speech and Language in PPA

At present there are three internationally recognised PPA variants, each presenting with a distinct profile of language difficulties, neuroanatomy and underlying neuropathology (Gorno-Tempini et al., 2011; Marshall et al., 2018). Semantic variant PPA (svPPA/semantic dementia), predominantly associated with an underlying TDP43 (Type C) pathology, presents as a disorder of semantic memory, often manifesting initially as difficulties with single word comprehension, and naming, but affecting knowledge of tastes, smells, objects, people and sounds. On neuroimaging, individuals with svPPA present with increasing atrophy across the semantic memory network (Lambon-Ralph, Jefferies, Patterson, & Rogers, 2016) with a hallmark and often significant asymmetric, focal cerebral atrophy involving the left antero-inferior and mesial temporal lobe, including amygdala and anterior hippocampus spreading, over time, to involve more posterior temporal regions and homologous gyri in the contralateral temporal lobe as well as orbitofrontal cortex (Chan et al, 2001). People with svPPA produce increasingly less nuanced and empty verbal output as their semantic conceptual knowledge degrades. Initially these difficulties may be subtle as speech remains fluent, and an individual may use pronouns such as ‘they’ or ‘he’ in place of specific nouns, or use a less specific word, for example ‘animal’ instead of ‘Bulldog’ or ‘food’ instead of ‘cucumber’ (Heitkamp et al, 2016). SvPPA affects the ability to understand words, and as semantic knowledge deteriorates further, individuals may become increasingly unfamiliar with objects (Warrington, 1975). Reported or observed questioning about the meaning of a
word, such as “What is sellotape?” is characteristic. Importantly, this deficit is associated with semantic knowledge, not episodic memory, and by their repeated use in contextual settings frequently used words may be preserved in episodic memory (Cadório, Lousada, Martins, & Figueiredo, 2017).

A second variant, logopenic PPA (lvPPA) is predominantly associated with an underlying Alzheimer’s pathology (with underlying tau and amyloid-beta proteinopathies). It presents as a difficulty in retrieving word forms, resulting in problems with assembly and sequencing of phonological material. Brain imaging reveals wide variations between individuals with lvPPA, although atrophy tends to be observed around the areas involved in decoding speech sounds and activating lexical word forms (Spitsyna, Warren, Scott, Turkheimer, & Wise, 2006), namely the temporo-parietal junction of the left hemisphere, and in some individuals it will extend anteriorly into the hippocampi and surrounding anterior temporal lobe (Rohrer et al., 2010). A ‘tip-of-the-tongue’ hesitation is frequently reported in the initial stages, and, although not strictly non-fluent, people with lvPPA may present with word finding difficulties resulting in pauses and phonological errors (Wilson et al, 2010). Similar errors in reading aloud, associated with phonological encoding and assembly, are also evident (Piguet Leyton, Gleeson, Hoon, & Hodges, 2015). In the early stages of lvPPA repetition of sentences and digit strings of increasing length is impaired, distinguishing it from other variants, and is attributed to a disorder of working (phonological) memory (Giannini et al, 2017). Given that Alzheimer’s disease is the most common underlying pathology, people with lvPPA unsurprisingly often also present with additional symptoms including difficulties in memory, praxis and visual-spatial awareness (Marshall et al., 2018).
The final variant is non-fluent agrammatic PPA (nfvPPA), associated with multiple pathologies including an underlying Tau pathology, TDP-43 and Alzheimer’s proteins, this presents as a dysfluent apraxic speech disorder and/or an agrammatism (Josephs et al, 2012; Wilson et al, 2010). NfvPPA is associated with atrophy of the inferior frontal gyrus and insula cortex in the left hemisphere, with some extension in and around the superior temporal gyrus. These regions are fundamental for language output, motor speech programming and sentence processing (Rohrer et al., 2008). People who present with the apraxic component of nfvPPA will often demonstrate slow, effortful, groping speech, characterised by phoneme distortion and perseveration, which becomes more evident on multisyllabic words (Josephs et al, 2012). Apraxia may or may not co-occur in nfvPPA with agrammatism, presenting initially as errors in or omissions of grammatical forms such as function words or determiners, and may evolve to a telegraphic verbal output whereby brief noun and verb phrases are used with no grammatical markers (Wilson et al, 2010). A preserved semantic, lexical and graphemic system means that individuals with nfvPPA present with relative strengths in comprehension of spoken and written words, although difficulties with comprehension of grammar will also be evident when agrammatism is associated with the profile of impairments. People with nfvPPA usually present with some changes in executive function, and often with apathy and depression, the latter attributed to preserved insight. Many people with nfvPPA develop physical symptoms as the disease progresses such as limb apraxia or postural instability associated with underlying pathologies such as progressive supranuclear palsy or Parkinsonism (Graff-Radford, Duffy, Strand & Josephs, 2012).
Yet, according to some research, up to 40% of people with PPA do not fit these three canonical syndromes, and may instead present with a mixed or atypical PPA variant (Sajjadi, Patterson, Arnold, Watson, & Nestor, 2012). This is not dissimilar to stroke aphasia, where over a quarter of people with aphasia have been considered unclassifiable using the Boston Group classification system, and of those who were classified a mismatch between the observed syndrome and anticipated lesion was noted in more than 60% of people (Kasselimis, Simos, Peppas, Evdokimidis, & Potagas, 2017). A psycholinguistic deficit model has therefore been proposed as a more useful method of understanding an individual’s areas of difficulty and strength (Martin, Thomspson, & Worrall, 2008). Research using this approach has also demonstrated development of effective intervention approaches for aphasia (Kasselimis et al., 2017; Martin et al., 2008) such as CPT for people with aphasia and their CPs.

Using a syndrome based approach is useful for anticipating language, cognitive and physical symptoms and importantly identifying potential pharmaceutical options (e.g. memantine for lvPPA). Understanding an individual’s areas of strength and difficulty is, however, more valuable for developing appropriate and effective speech and language interventions, such as CPT, for people with PPA and their CPs. Additionally a strengths and difficulties based description is more meaningful to people and their families, who are anxious to understand what the diagnosis means for their conversations, relationships and quality of daily life.

Importantly however, individuals with PPA present with degraded rather than interrupted language networks. In contrast to traditional interventions for stroke aphasia, speech and language interventions for PPA need to take account of the fact that all individuals with PPA will continue to deteriorate, eventually developing
mutism or global aphasia (Rossor, Warrington, & Cipolotti, 1995). Global aphasia is defined as “a severe acquired impairment of communicative ability across all language modalities where often no single communicative modality is strikingly better than another. Visual nonverbal problem-solving abilities are often severely depressed as well and are usually compatible with language performance.” (Collins, 1986, p. 6).

2.2 Current speech and language provision

Given that speech and language are the primary areas of difficulty in PPA, it seems logical that SLTs should support this group of people. Rogers & Alarcon (1998) describe three key principles for management of people with PPA including planning interventions in anticipation of continued decline, working with CPs upon whom individuals will inevitably become dependent, and directing therapy at the level of disability since restitution is not ultimately possible given the deteriorating nature of the disease process. In contrast, a phased approach to treatment has been proposed by Hinshelwood & Henry (2016), whereby in the mild stage of the disease restorative therapies are employed, in the moderate stages Alternative and Augmentative Communication (AAC) and multimodal communication are prioritised, and in later stages there is a focus on environmental supports and CPT. More recently, Rogalski and colleagues, have advocated an overarching person-centered approach that “proactively informs the care plan through dynamic interactions with the clinician” (Rogalski et al. 2016, p.286) in order to maximize participation in daily life activities and maintain independence.

The Royal College of Speech and Language Therapists’ (RCSLT) position paper on dementia provides limited guidance on interventions for PPA (RCSLT., 2014)
referring to a systematic review of interventions by Carthey-Goulart et al (2013). Carthey-Goulart et al (2013) identified a total of 39 studies, published between 1995 and 2013, investigating interventions for a total of 67 people. Twenty-one of the 39 studies described interventions targeting only svPPA and 31 were impairment-based interventions\(^1\). The authors concluded they were unable to provide any guidance for clinical practice beyond a single recommendation that people with svPPA benefit from impairment focused word relearning interventions (aimed at lexical retrieval), based on 18 studies classified as being of adequate quality. The authors emphasized that due to the paucity and low quality of much work in this area, further research of sound methodological design is needed to support clinical recommendations (Carthey-Goulart et al., 2013).

Of the 39 studies identified by Carthey-Goulart et al (2013) only eight focused on functional communication interventions\(^2\), and three of these were deemed as lacking the methodological rigour required to reliably determine treatment effects. Despite the paucity of evidence, these are the types of interventions that SLTs favour in clinical practice with people with PPA (Volkmer, 2013), reporting that they borrow from the field of stroke aphasia (Rogalski et al., 2016) and dementia (Kindell et al., 2015). Importing evidence from other fields can be problematic however, given that many of the interventions for dementia have not been developed for people with language led symptoms and those for stroke related aphasia do not take account of the degenerative nature of PPA (Kindell, Sage, Wilkinson, & Keady, 2014; Morhardt et al., 2015; Volkmer et al., 2019).

\(^1\) defined as those that seek to remediate, alleviate or improve symptoms by the World Health Organization (WHO: 2001), and in this case predominantly word relearning.

\(^2\) these are studies that focus on environmental modifications, compensatory strategies or increasing levels of participation in communication activities as defined by the WHO (2001)
The effectiveness of word relearning interventions for PPA has been the focus of two recent systematic reviews (Cadório et al., 2017; Jokel, Graham, Rochon, & Leonard, 2014). Jokel et al (2015) examined 39 studies published between 1982 and 2013 in order to identify characteristics that defined candidacy for this type of intervention. Whilst unable to define the best candidates for word relearning interventions, they concluded their review with a list of 14 evidence-based factors that could facilitate word relearning interventions in different variants of PPA. This included the recommendation that people with nfvPPA benefit more from interventions focusing on phonology, whilst those with svPPA benefit more from those focused on semantics. Some factors identified by the authors have implications for functional communication interventions, for example involving the person in selecting personally relevant target items facilitates motivation, and leads to better outcomes. Jokel et al (2015) recommended that future research in this area report details on participants PPA variant, additional cognitive impairments, time since symptom onset and severity of impairment, as these may have some influence on candidacy for intervention.

Cadório et al's, (2017) review of the generalisation and maintenance of word relearning treatment gains confirmed that given the differing pathophysiology people with different PPA variants benefit from different approaches. Cadório et al (2017) examined 25 studies published between 2000 and 2016 that delivered semantic based word relearning interventions to 51 people with PPA. The authors concluded that maintenance depended on continued practice and PPA variant was less important. In comparison, generalisation was influenced by PPA variant and individuals with svPPA required more practice to generalise their learning, than those with lvPPA and nfvPPA. Cadorio et al (2017) attributed this to the
relative preservation of semantic knowledge in lvPPA and nfvPPA, which enabled
generalisation of cueing strategies for word retrieval to other items, in other tasks
and contexts. They hypothesised that in mild-moderate stage svPPA people were
able to embed new learning in episodic memory by intensive, contextualized
practice but as their condition progressed people with svPPA made more
generalisation errors, due to loss of conceptual knowledge. Cadorio et al’s (2017)
conclusions have implications for delivery of functional communication
interventions, suggesting that people with lvPPA and nfvPPA will also be able to
generalise functional communication interventions, whilst more practice, in a
contextualized setting at as early a time as possible will be important for people
with svPPA.

Croot's (2018) more recent research update reported on the techniques being
used to deliver word relearning interventions to different PPA variants. Croot
(2018) concluded that word relearning interventions that capitalise on residual
cognitive strengths are likely to be the most successful. For example people with
svPPA benefitted from using errorless learning techniques with cueing
hierarchies for word relearning, which take advantage of their procedural memory
skills (Jokel & Anderson, 2012). Although studies reviewed in this research
update also showed that long term maintenance is possible, Croot (2018)
emphasised that identifying the right candidates, who are motivated to participate
in ongoing commitment to practice may be difficult. It is not uncommon for
participants to deprioritise word relearning therapies in the presence of mood or
anxiety symptoms, or due to occupying obsessive behaviours and other life goals
(such as spending time with family) (Croot, Nickels, Laurence, & Manning, 2009;
Croot et al., 2019).
Specialist SLTs, who participated in a study to explore what interventions they choose when working with people with svPPA in clinical practice, reported that they de-prioritised word relearning interventions due to a need to deal with other “more pressing” issues (Kindell et al., 2015, p. 161). Kindell et al’s consensus group of six specialist SLTs was the first research to examine SLT practice in the UK. It highlighted that in practice, specialist SLTs use person centred care, which can be considered more in line with a strengths and difficulties based approach, than a syndrome focused approach, as it takes an individualised approach to identifying areas of need. The SLTs in Kindell’s study prioritise working with the people around a person with PPA, i.e. family and other care givers, in order to maximise the communication and life participation of those with the condition. This included providing individualised education and support to the person with PPA and their family members on meaningful strategies to support communication both immediately and over the long-term.

There is a relatively rigorous evidence base for communication training for the paid carers of people with dementia. Nguyen, Terry, Phan, Vickers & McInerney (2019) identified 17 studies in their systematic review, of which 12 were Randomised Controlled Trials (RCTs), with the strongest outcomes demonstrating improved carer communication skills and knowledge. This resulted in the National Institute for Health and Care Excellence guidelines for dementia (NICE; National Institute for Health and Care Excellence., 2018) making a recommendation that carers of people living with dementia be offered training to help them adapt their communication styles to improve interactions with the person living with dementia. The RCSLT dementia position paper RCSLT., 2014) advocates that, by providing support and recommending
communication strategies, SLTs facilitate the maintenance of interpersonal relationships. Given that people with memory-led dementias, such as Vascular and Alzheimer’s dementia, do not demonstrate the same issues in conversation breakdown as people with PPA (Taylor et al., 2014) the same CPT approaches may not be appropriate for people with PPA.

2.3 Conversation in PPA

While there are few studies of everyday language use in PPA, the research evidence in the dementia and stroke aphasia literature is much larger. Each will be addressed in turn.

Taylor-Rubin et al (2014) in a study of everyday conversations, hypothesised that different PPA variants would result in different types of trouble and repair. Trouble indicating behaviours can be interactive, requiring a response from the partner such as a request for specific information, “Where are you going?” or clarification, “Are you going to John’s house?”, or non-interactive, not requiring a response. Examples are a lack of uptake or continuation of a topic. Taylor-Rubin et al examined conversations between three people with PPA and their CPs, termed dyads, two of whom had nfvPPA and one who had lvPPA. The researchers concluded that there was no single observable difference between the dyads with lvPPA and nfvPPA, as each of them presented differently. However, in comparison with the literature on dementia and stroke aphasia, Taylor-Rubin et al (2014) found that the dyads in their study were more similar to those with stroke aphasia, showing a predominance of interactive trouble indicating behaviours over non-interactive trouble indicating behaviours.
Different CPs use different strategies to support conversations with the same partner (Kindell, Sage, Keady, & Wilkinson, 2013). In a study of a wife and son of a person with svPPA, Doug, who used a repeated practice of enactment, whereby he did not simply describe events but depicted or acted them out, through the use of speech, prosody, facial expression, and body movements, both partners reported using different approaches to managing the interaction. Kindell et al (2018) consequently examined the conversations of a second dyad with svPPA, Sarah and her husband, who presented very differently, demonstrated an almost total lack of interactional topics. These studies demonstrate differences between dyads may be associated with CP communicative behaviour as well as with that of people with PPA, and Kindell et al (2013) caution that generalising findings from conversations may mask individual issues.

A recent review of 50 research studies on conversation in dementia emphasised the breadth of this heterogenous group, with overlapping but also differing difficulties in conversation (Kindell, Keady, Sage, & Wilkinson, 2017). Memory difficulties were described as the cause of transactional issues (difficulties in conveying meaning), in the context of intact interactional skills, in dementias such as Vascular and Alzheimer’s disease. Whilst others, for example the behavioural variant of the FTDs, present with difficulties in executive skills and consequent planning of turn taking (Kindell et al., 2017).

Similarly, the stroke related aphasia literature also emphasises the differences in conversation behaviours between groups of fluent and non-fluent speakers, and mild versus more severely impaired speakers (Wilkinson, 2015). All aphasia types can result in long repair sequences due to attempts to deal with conversational breakdowns, and these are often much more extended when a
person is more severely impaired. These conversation difficulties ultimately lead to the common experience of loss of interactional competence (Kindell et al., 2017; Wilkinson, 2015).

People with stroke aphasia and dementia are however able to draw on a variety of retained strengths with a common purpose, namely to maintain interactional flow (Kindell et al., 2017; Perkins, Whitworth, & Lesser, 1998; Wilkinson, 2015). One common resource is gesture, and has been described as a strategy used by people with different types of stroke aphasia and dementia, to facilitate conversational interaction (Kindell et al., 2017; Wilkinson, 2015). CPs also facilitate conversational interaction through for example, collaborative repair behaviours in stroke aphasia (Beeke, 2013), but they also expose the difficulties and contribute to the experience of loss of interactional competence of people with both stroke aphasia and dementia (Kindell et al., 2017; Perkins et al., 1998; Wilkinson, 2015). The use of test-questions by a CP (whereby a CP asks a question despite knowing the answer), is common to both stroke aphasia and dementia conversations. It is often considered a behaviour that risks exposing the limitations of a person with a communication difficulty, resulting in a loss of face (Kindell et al., 2017; Wilkinson, 2015).

In the field of aphasia rehabilitation, a focus on communication strengths and limitations, and on the influence of a CP, has led to the development of CPT. Programs are designed to enhance conversational skill and confidence, employing activities that directly address conversation and “focus on changing behaviours within the context of genuine conversation” (Simmons-Mackie et al., 2014, p. 512). Two systematic reviews have identified 56 CPT programmes for people with stroke aphasia and their CPs (Simmons-Mackie, Raymer, Armstrong,
Holland, & Cherney, 2010; Simmons-Mackie, Raymer, & Cherney, 2016) that included two high quality class I trials, three class II studies and 52 class III case studies. The authors conclude with the recommendation that CPT be offered to CPs of people with chronic stroke aphasia of every severity level because it successfully changes the behaviour of CPs for the better, and it is ‘likely’ to result in greater participation in everyday interactions for people with stroke aphasia.

Similarly, a systematic review of CPT in dementia identified 12 trials training both professional caregivers and family caregivers in nursing homes and people’s own homes (Eggenberger, Heimerl, & Bennett, 2013). Studies used a variety of training methods including lectures, hands-on training, group discussions and role-play and found improvements in quality of life and wellbeing of people with dementia as well as increases in caregiver skills and competency (Eggenberger et al., 2013).

Given evidence for the benefits of CPT programmes in stroke aphasia and dementia, it seems logical that this approach should be considered in PPA, yet the research evidence remains sparse. One of the earlier longitudinal case studies (Murray, 1998) implemented an exploratory approach to intervention delivery with their participant with nfvPPA, prioritising CPT intervention after observing negative interaction behaviours used by the CP. It is difficult to attribute the reported improvements and maintenance of performance in Murray (1998)’s participants to the CPT however, due to the fact that the participant and his CP were concurrently participating in additional therapeutic activities. Wong, Anand, Chapman, Rackley, & Zientz (2009) reported on CPT that resulted in a reduction in frustration for both a person with svPPA and his wife. The authors noted a maintenance of communicative effectiveness, but this study lacked
methodological rigour given that participants attended group therapy alongside CPT.

In clinical practice SLTs report a preference for using CPT resources that come from the stroke aphasia literature according to a small non-representative survey of 23 SLTs working with people with PPA (Volkmer & Beeke, 2015). Respondents identified using tools such as Supporting Partners of People with Aphasia in Relationships and Conversation (SPPARC; Lock et al., 2001) and Better Conversations with Aphasia (BCA, Beeke, Sirman, Beckley, Maxim, Edwards, Swinburn, & Best, 2013). Both are designed to change the conversation skills of people with post-stroke aphasia as well as their CPs (Beckley et al., 2013; Beeke et al., 2014; Best et al., 2016).

2.4 Conclusion

People with PPA present with speech and language difficulties that impact upon daily conversations with their CPs. In addition, the behaviours of CPs may support or undermine communication with people with PPA. The majority of the research evidence on the effectiveness of interventions for PPA to date has been focused on word relearning interventions. In clinical practice, SLTs report a preference for using CPT, despite the paucity of research evidence in this area. CPT has been shown to be effective for stroke aphasia and in dementia. This PhD thesis aims to meet this identified need to examine the potential effectiveness of CPT for people with PPA and their CPs. Given that CPT has several interacting components, it is defined as a complex intervention by the MRC (Craig et al., 2008). The MRC provide guidance on overcoming practical and methodological difficulties and maximising rigour in the development, evaluation and implementation phases of research when developing complex
interventions. They describe four phases comprising I. Development, II. Feasibility/Piloting, III. Evaluation, and IV. Implementation. This thesis describes phase I and II work to develop a CPT programme, entitled BCPPA, and conduct an NHS based feasibility-pilot Randomised Controlled Trial study with BCPPA compared to no treatment.
Chapter 3 A survey of speech and language therapists working with people with PPA across the UK

These findings are published as:


The MRC complex interventions guidelines recommend that a systematic approach to developing new interventions should start with an evaluation of the best available evidence from a variety of sources (Craig et al., 2008). This chapter explains the context, methods, results and interpretation of a UK-wide survey of SLTs working with people with PPA and provides a key source of evidence to guide development of an intervention that may be realistically implemented in a clinical setting.

3.1 Context for a UK-wide survey of SLTs

Given that speech and language difficulties are at the core of PPA, a referral to speech and language therapy is warranted. Yet the authors of a German study highlight that people with PPA report being more isolated from speech and
language therapy services than from any other allied health discipline (Riedl, Last, Danek, & Diehl-Schmid, 2014). These authors suggest that this may be due to the rarity of the condition, resulting in relatively few people with PPA living within a speech and language therapy service’s catchment area. This in turn may mean the SLTs themselves have little experience of working with people with the condition. Yet researchers in the United States report an increase in referrals for both assessment and differential diagnosis of PPA variant, as well as for treatment (Henry & Grasso, 2018). Taylor et al (2009) surveyed 13 speech and language therapy services across the New South Wales state of Australia with the aim of establishing current speech and language therapy practice with people with PPA. The authors hypothesize that, in Australia, neurologists are most likely to refer to speech and language therapy as a result of knowledge of the treatment SLTs provide to people with non-progressive stroke related aphasia. Despite the dominance of word relearning interventions for PPA described in the research literature (Carthey-Goulart et al., 2013) SLTs can have a much broader role in supporting people with PPA (Marshall et al., 2018; Volkmer, 2013) but no-one yet has a UK-wide perspective on what is being delivered in clinical practice.

Given PPA’s degenerative nature, care pathways need to include different components than those for people with acute onset stroke aphasia. The European Pathways Association (2019, para. 9) defines a care pathway as “an explicit statement of the goals and key elements of care based on evidence, best practice and patient expectation”. Taylor et al., (2009) reported “no clear single management pathway” for speech and language therapy practice for PPA (Taylor et al., 2009, p. 12).
There is a need to establish a picture of current SLT referral patterns and care pathways in PPA and to identify research priorities and health policy recommendations in this area of care. This study aims to reveal the practices of UK SLTs in the areas of assessment and management of PPA, including outcome measurement, and determine the factors contributing to any barriers to access speech and language therapy.

3.2 Method
This survey conforms to the CHERRIES survey reporting checklist (Eysenbach, 2004) and Turk et al's (2018) extension to this. The Departmental Ethics Chair in Language and Cognition at University College London waived approval as the study met the criteria for service evaluation.

3.2.1 Survey development
Previous speech and language therapy surveys of clinical practice provided direction on development of survey sections and questions, specifically PPA in an Australian context (Taylor et al., 2009), stroke aphasia (Beckley, Best, & Beeke, 2017; Sirman, Beeke, & Cruice, 2017) and progressive dysarthria (Collis & Bloch, 2012). Literature on speech and language interventions for PPA (Carthey-Goulart, Graham, & Bak, 2011; Kindell et al., 2015; Volkmer, 2013) was consulted to guide category fields for questions related to assessment and intervention. Occupational and geographical domains were based on recognised socio-economic classifications (Office for National Statistics, 2010) and statistical regions (Office for National Statistics, 2009) within the UK. Questions were refined by the author with expert advice from the primary and secondary supervisors to ensure relevance, until a 37-item survey was agreed for initial piloting.
3.2.2 Pilot phase

A convenience sample of six practising SLTs piloted the survey to assess usability. To maintain the largest possible sample for the main study, the author invited SLTs based in the UK who do not work with people with PPA, and SLTs who see people with PPA but work in Australia (this was a convenience sample of SLTs known to the author). Pilot respondents recorded the time taken to complete the survey and provided written feedback on the format, category fields and wording of questions. Modifications in the light of this feedback included introduction of a number of ‘other’ or ‘none’ categories and provision of category examples in one question. Additionally, the survey format was modified to ensure respondents had to provide an answer before moving on, and a ‘back’ button was inserted so respondents could review their answers. After piloting, the number of questions in the final survey was unchanged. Questions were not randomised, and page numbers not displayed, instead a progress bar was provided.

The final survey comprised five sections: 1) Clinical background; 2) Number, type and source of patients; 3) Time spent on management of people with PPA; 4) Specific assessment and intervention approaches; 5) Outcome measures and planning for the future. There were closed questions (for speed of completion) and open questions to elicit additional information (Schaeffer & Dykema, 2011). The complete survey is presented in Appendix 3.1.

3.2.3 Main survey

This survey was delivered online to facilitate dissemination across the UK. It was made available to respondents for 8 weeks from the 4th February to the 7th April 2016, using Opinio 7.3 software. Once closed, no further responses were
recorded. The initial page of the online survey provided a statement making clear that by continuing, respondents were giving consent to participate in the survey and that their responses would be stored anonymously. No personal data was collected.

### 3.2.4 Sample selection

In order to achieve a representative cohort of UK SLTs, the RCSLT was contacted to facilitate survey dissemination. A letter to the editor containing the survey link was published in the RCSLT practice magazine, ‘The Bulletin’, which is distributed to all 13,809 practising members. The survey link was also disseminated through an RCSLT electronic research newsletter and was emailed to 14 relevant Clinical Excellence Networks (CENs)\(^3\) associated with the RCSLT for onward dissemination to members. Email and social media were also used to disseminate the link through author’s and the primary supervisor’s networks, including via Twitter and the author’s blog site. A reminder was sent via all these routes 2 weeks prior to closing the survey (see appendix 3.2 for dissemination details). The email inviting SLTs to take part mentioned the development of an intervention but did not refer to CPT so as not to bias the respondents.

Participant inclusion criteria comprised SLTs a) practising in the UK\(^4\) and b) who had ever worked with a person with diagnosed or possible PPA. Respondents completed questions in section 1 of the survey on qualification, years of employment, and experience of working with people with PPA. If they did not

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\(^3\) Clinical Excellence Networks are groups of SLTs with a common clinical specialism who come together for study days and meetings, to share practice and research.

\(^4\) Practising SLTs are employed in the UK National Health System from a band 5; entry level, to band 8; highly specialist, manager or consultant
meet the inclusion criteria at this point they exited the survey. Respondents who met the study criteria continued to section 2 of the survey.

3.2.5 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). Descriptive statistics were used to analyse characteristics of respondents, and referral patterns. In view of the small sample sizes across geographical regions, data were grouped into north England (Yorkshire and the Humber, North East, North West, East Midlands and West-Midlands) and south England (London, South East, South West and East) for further analysis using Mann-Whitney non-parametric statistics to compare referral numbers. 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.

3.3 Results

3.3.1 Demographics of 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 survey because they had insufficient experience with PPA.
The remaining 105 had experience of working with people with PPA and submitted complete surveys, resulting in a completion rate of 106:105. There are no available data on numbers of UK SLTs providing services for PPA, therefore it is not possible to calculate the percentage response rate. Respondents were from a range of grade bands between 5 and 8, and worked across several professional locations, i.e. primary care, acute health, and mental health⁵. Table 3-1 summarises respondent characteristics. Just over one third were employed at band 7 (n=39, 37.1%) and just under one third at band 6 level (n=33, 31.4%). More than half had over 10 years’ experience (n=57, 54.3%). Just under half were based in primary care (n=48, 45.7%), with 28 in acute health (26.7%) and 15 in mental health care (14.3%). There is no national data on proportions of SLTs employed in primary care, acute health and mental health, yet this sample appears representative as services to mental health are known, within the profession, to be fewer. On comparing respondent rates across UK regions (Office for National Statistics 2009) the highest number of respondents were from Scotland (n=18, 17.1%) and fewest respondents came from the North West of England (n=2, 1.9%).

⁵ (Practising SLTs are employed in the UK National Health Service from a band 5; entry level, to band 8; highly specialist, manager or consultant)
Table 3-1: Characteristics of SLT survey respondents

<table>
<thead>
<tr>
<th>Years post qualification</th>
<th>Current banding</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Newly qualified</td>
</tr>
<tr>
<td>1-2</td>
<td>12.4% (13)</td>
</tr>
<tr>
<td>3-4</td>
<td>6.7% (7)</td>
</tr>
<tr>
<td>4-10</td>
<td>26.7% (28)</td>
</tr>
<tr>
<td>10+</td>
<td>54.3% (57)</td>
</tr>
<tr>
<td></td>
<td>Band 5</td>
</tr>
<tr>
<td>12.4% (13)</td>
<td></td>
</tr>
<tr>
<td>6.7% (7)</td>
<td></td>
</tr>
<tr>
<td>26.7% (28)</td>
<td></td>
</tr>
<tr>
<td>54.3% (57)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Band 6</td>
</tr>
<tr>
<td>12.4% (13)</td>
<td></td>
</tr>
<tr>
<td>6.7% (7)</td>
<td></td>
</tr>
<tr>
<td>26.7% (28)</td>
<td></td>
</tr>
<tr>
<td>54.3% (57)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Band 7</td>
</tr>
<tr>
<td>12.4% (13)</td>
<td></td>
</tr>
<tr>
<td>6.7% (7)</td>
<td></td>
</tr>
<tr>
<td>26.7% (28)</td>
<td></td>
</tr>
<tr>
<td>54.3% (57)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Band 8</td>
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<tr>
<td>12.4% (13)</td>
<td></td>
</tr>
<tr>
<td>6.7% (7)</td>
<td></td>
</tr>
<tr>
<td>26.7% (28)</td>
<td></td>
</tr>
<tr>
<td>54.3% (57)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
<tr>
<td>12.4% (13)</td>
<td></td>
</tr>
<tr>
<td>6.7% (7)</td>
<td></td>
</tr>
<tr>
<td>26.7% (28)</td>
<td></td>
</tr>
<tr>
<td>54.3% (57)</td>
<td></td>
</tr>
</tbody>
</table>

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

3.3.2 Referral patterns

Respondents were asked to reflect on the patients with PPA they had seen over the previous 24 months. Collectively, respondents reported seeing a total of 353 patients over this period. On average 3.27 people with PPA were seen per respondent, with a range of 0-17 (see Figure 3:1). Geographical variation was observed (see Figure 3:2) with most patients seen per respondent in the South East (5.6) and least in Northern Ireland (1.6) and Wales (1.5). There was no significant difference in the number of patients across the North (mean = 3 patients) and the South of England (mean = 3 patients) (U=535.5, z=-0.045, NS).
Figure 3-1: Distribution of people with PPA seen by SLTs over the last 24 months

Figure 3-2: Average number of PPA patients on SLT caseloads across the UK
Respondents reported seeing patients with PPA across multiple settings within the same service. Most often this was in community (n=75; 45.5%) or outpatient settings (n=54; 32.7%), whilst a smaller number were seen in memory clinics (n=13; 7.9%) or in acute medical settings (n=12; 7.3%).

There were significant differences between geographical region for people seen in outpatient settings ($\chi(1) = 23.114$, $p = 0.017$) with more than 75% of respondents in Scotland (n=14), Wales and the North East reporting that they saw patients in this setting, whilst none of the respondents in the East (of England) and West Midlands reported this. No other significant differences in setting were observed across geographical regions.

3.3.3 Characteristics of patients referred to SLT

Almost two thirds (n=65; 61.9%) of respondents reported seeing patients with PPA aged between 60 to 70 years, and just under half (n=47; 44.8%) reported seeing people aged between 50 and 60 years. Most respondents reported patients were from an English speaking background (n= 92; 87.6%). Of those who reported seeing patients from non-English (n=13; 12.4%) or multilingual (n=16; 15.2%) backgrounds, respondents were generally concentrated in London and the South of England. The following languages were listed: Flemish, French, Greek, Irish, Swedish, Turkish and Welsh. Around two thirds (n=65; 61.9%) of respondents reported seeing patients from high managerial occupations, and just over half (n= 53; 50.5%) reported patients with intermediate occupations (Office for National Statistics examples include supervisory, clerical & junior managerial,
administrative, and professional occupations). A similar number of respondents (n=56; 53.3%) reported patients with manual occupations.

3.3.4 Access to speech and language therapy services

Table 3-2 summarise the details of how patients access SLT services. Respondents reported that they receive a large number of their referrals from neurologists (n=52; 22.5%). Almost all respondents reported receiving referrals regarding concerns about word finding difficulties (n=101; 96%). Around one third (n=37; 32.2%) reported patients were ‘always’ or ‘often’ informed they had PPA or FTD. When asked to select a category reflecting when the majority of their patients were referred, almost half of respondents (n=49; 46.7%) reported this was within 2-3 years of symptom onset. A further 40% (n=42) of respondents reported this was within 1 year of symptom onset.
Table 3-2: Access to SLT services

<table>
<thead>
<tr>
<th>Access to SLT services (% response; multiple responses allowed)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Source of referrals</strong></td>
</tr>
<tr>
<td>Neurologists</td>
</tr>
<tr>
<td>General Practitioners</td>
</tr>
<tr>
<td>Psychiatrists</td>
</tr>
<tr>
<td>Geriatricians</td>
</tr>
<tr>
<td><strong>Referral reason</strong></td>
</tr>
<tr>
<td>Word finding difficulties</td>
</tr>
<tr>
<td>Swallowing difficulties</td>
</tr>
<tr>
<td>Slurred speech</td>
</tr>
<tr>
<td><strong>Time since symptom onset</strong></td>
</tr>
<tr>
<td>Within 2-3 years</td>
</tr>
<tr>
<td>Within 1 year</td>
</tr>
<tr>
<td><strong>Respondents whose patients had always/often been informed of their diagnosis as:</strong></td>
</tr>
<tr>
<td>Dementia</td>
</tr>
<tr>
<td>PPA or FTD</td>
</tr>
<tr>
<td>svPPA</td>
</tr>
<tr>
<td>IvPPA</td>
</tr>
<tr>
<td>nfvPPA</td>
</tr>
<tr>
<td><strong>Barriers to accessing SLT services</strong></td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Service Criteria</td>
</tr>
<tr>
<td>Geographical location</td>
</tr>
<tr>
<td>Offered but declined</td>
</tr>
<tr>
<td>Language barrier</td>
</tr>
</tbody>
</table>

When asked to indicate whether they felt people with PPA may not have accessed speech and language therapy services, more than three quarters (n=82; 78.1%) of respondents agreed. The most common barriers to access were identified firstly as ‘other’ (n=51; 41.8%) and secondly as service criteria (n= 32; 26.2%). An analysis of the text responses under the ‘other’ category revealed two major issues: lack of awareness of the SLT’s role amongst referrers (69.2%), and difficulties in diagnosis (30.8%). Respondents working in third sector organisations reported geographical location as a significant barrier for their patients (H(4) = 13.156, p<0.01). There were no other significant associations.
found between the type of healthcare service that respondents worked in and barriers to accessing speech and language therapy.

3.3.5 Care pathways

The majority of respondents (n=95; 90.5%) reported there was no care pathway for people with PPA within their service. All respondents who reported the existence of a PPA care pathway (n=10, 9.5%) were asked to describe it. One respondent listed an onward referral process to another speech and language therapy service. Two respondents described their service’s care pathway as comprising only assessment and advice. One respondent provided a detailed seven stage care pathway delivered over six sessions, where following assessment at stage 1, the remaining stages focused on a range of interventions including:

“Rehearsal and integration of appropriate strategies into communication, through modelling, rehearsing and home tasks which incorporate significant communication partners. Provision of information regarding appropriate high-tech communication aids”.

This respondent was the only one who referenced the intervention research literature. The other six respondents provided an overview of their service’s care pathways by giving some examples of intervention mode (individual, dyadic & group) or activities offered. Only one of the 10 respondents reporting a local PPA care pathway described dysphagia assessment and management (see Figure 3:3 for a list of key components).
Although seven respondents stated that assessment was part of the care pathway, only one of the 10 respondents described being involved in the diagnosis of PPA. When describing the assessment stage of the care pathway, one respondent provided detailed information, including tools used:

"Assessment of impairment and activity/participation. This will include an aphasia and communication strengths and weaknesses profile, with specific consideration of spontaneous strategy use by the client. It will also include identification of the client’s significant communication partners and their roles. (Assessments: dynamic testing with Boston Naming Test (BNT); PALPA subtests; CAT subtests)."

Seven of the 10 respondents stated that intervention was a part of their care pathway, with two explaining that this was based on the “individual’s profile”. Three respondents mentioned impairment focused interventions, with one of the three respondents describing the provision of:

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

Another respondent added the caveat that:

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

Education and “explanation of the condition” was mentioned by three respondents as part of the intervention stage of their service’s care pathway.
Three respondents described provision of group therapy (one of whom specified a couples group), and six respondents described involvement of a carer.

Functional communication focused intervention options were described by four respondents, with one commenting:

“Training in supportive conversational partner strategies offered (not formal training package, but tailored to individual). Low-tech AAC & communication passports/life story work”.

Finally, six of the 10 respondents with a care pathway described ongoing or future input such as onward referral to other services, signposting to support groups, and review or maintenance sessions within the speech and language therapy service.

Figure 3-3: Components of care pathways described by 10 respondents
3.3.6 Assessment and management activities

All respondents were asked how many sessions they devoted to assessment and management activities. Respondents were given the following definitions:

Assessment includes assessment of language and communication, contributing to diagnosis of PPA, assessment of dysphagia and mental capacity assessment.

Management includes case/care review meetings, joint sessions with other disciplines, education for person with PPA, family education, staff education, impairment-focused language intervention, functional communication focused interventions, combined language/communication focused intervention, group therapy with people with PPA, management of dysphagia.

Figure 3:4 summarises the average number of speech and language therapy sessions respondents reportedly spent on assessment and management activities. On average, respondents spent 2.2 sessions on communication assessment, but only 1.2 sessions on diagnosis, 0.8 sessions on dysphagia assessment and 0.5 sessions on mental capacity assessment. Results show that respondents spent more time on functional communication focused interventions than on any other activity, with an average of 4.9 sessions. This contrasts with 2.8 sessions for impairment focused intervention, 2.8 sessions for combined language and communication intervention, 2 sessions on family education, 2 sessions on education for the person with PPA, and 1.5 sessions on group therapy. When asked how much time they would ideally like to spend on functional communication interventions, the average response was 7.8 sessions,
nearly three sessions more than the average number reported as available. The smallest amount of time was spent on joint sessions with other disciplines, on average 0.5 sessions.

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 3-4: Average number of sessions spent on assessment and management activities by SLT respondents working with people with PPA across the UK

3.3.6.1 Assessment Tools

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

3.3.6.2 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 3.6 presents the reported frequency of use of intervention approaches. The least used intervention approach, impairment directed intervention 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 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 (comprising both naming and speech 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 they used, respondents reported 12 options. The most commonly identified were communication books and wallet cards, 

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6 The International Classification of Functioning, Disability and Health (ICF, WHO 2001) describes impairment based interventions as those that seek to remediate, alleviate or improve. Activity and participation based interventions focus on functional communication, engagement in executing an activity and participating in a life situation.
mentioned by 14 respondents, whilst life story work and total communication strategies were each suggested by three respondents.
Figure 3-6: Frequency of reported use of intervention approaches with people with PPA over the last 24 months.
3.3.7 Measuring outcomes

When asked which outcome measures they used to document progress in therapy, respondents were able to choose multiple options from a list of six. Goal setting was reported as the most commonly used measure (n=57, 53.8%), followed by self-rating scales completed by the person with PPA or their CP (n=53, 50%), language assessment (n=51, 48.1%), Therapy Outcome Measures (TOMS; Enderby et al. 2013) (n=37, 34.9%), rating scales completed by the SLT (n=21, 19.8%) and video-recording of conversation (n=8, 7.6%) (the exact aspect of the recording that provided an outcome measure is not known, since respondents were not asked to provide further information). Respondents were asked for examples of other outcome measures they used and provided nine further tools. Audio recording, and the East Kent Outcome Measure (EKOS; Murphy & Logan 2009) were each identified by two respondents, whilst the remaining seven measures: Aphasia Impact Questionnaire-21 (AIQ-21, Swinburn, 2013), client feedback, carer feedback, informal naming assessment, Communication Outcomes after Stroke (COAST; Long, Hesketh, Paszek, Booth, & Bowen, 2008), Cognitive Linguistic Quick Test (CLQT; Helm-Estabrooks, 2001) and Visual Analogue Self-Esteem Scale (VASES; Brumfitt & Sheeran, 1999), were identified by only one respondent each. Respondents were asked to provide examples of the types of goals set and provided 88 in total. Six separate main themes arose from analysis of these goals: 1. Communication aid; 2. Conversation; 3. Functional communication; 4. Impairment focused; 5. Practising a strategy; 6. Communication partner.

Each goal was assigned to one theme (see Figure 3-7). Of the 101 goals, 43 % (n=44) fell into theme 2. Conversation, or 3. Functional communication. All
conversation goals (n=15) centred on using specific strategies, such as gesture or drawing, in conversations. Fourteen of the twenty-nine functional communication goals related to completing specific functional communication activities with family and friends, such as ordering a meal or coffee. Twenty six percent (n=26) of goals focused on using a communication aid in specific situations (theme 1), such as a tablet device, wallet card or a communication book. Only 9% (n=9) of goals fell into theme 4. Impairment focused, which comprised those associated with word relearning and naming, such as learning a certain number of words in a certain time frame. Fourteen percent (n=14) of goals fell into theme 5. Practising a strategy, such as learning to use circumlocution effectively. Finally, 8% (n=8) of goals targeted a CP (theme 6) and focused on using a specific strategy to support or enable their partner with PPA in conversations.
Figure 3-7: Example goals given by respondents, organised by theme
3.3.8 Future planning and onward referral

Respondents were asked whether they addressed cognitive changes and deterioration in communication, legal issues including assessment of capacity, driving, family care supports, or family finance supports in planning for the future with people with PPA (see Table 3-3). Almost all respondents (n=91, 85.9%) reported that they explicitly addressed both cognitive changes and deterioration in communication. When asked to give other examples of future planning, respondents identified the following additional issues: educating children; supporting other staff; housing; signposting carers to organisations for social and emotional support; advance care planning. Respondents reported the most commonly used third sector organisations for onward referral to be the Alzheimer’s Society and the Rare Dementia PPA Support Group. Local stroke aphasia and memory groups, dementia cafes and other dementia groups were listed, as well as a variety of organisations such as Befriending, Age UK, Age Northern Ireland, Alzheimer’s Scotland, Motor Neurone Disease Scotland, Young People with Dementia Groups, and Admiral Nursing.
Table 3-3: Future planning and onward referral

<table>
<thead>
<tr>
<th>Areas that SLTs explicitly address in future planning</th>
<th>% response (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>cognitive changes and deterioration in communication</td>
<td>85.9% (n=91)</td>
</tr>
<tr>
<td>planning for legal, financial, health and social care issues including assessments of capacity</td>
<td>44.3% (n=47)</td>
</tr>
<tr>
<td>family care supports such as respite</td>
<td>38.7% (n=41)</td>
</tr>
<tr>
<td>driving</td>
<td>18.9% (n=20)</td>
</tr>
<tr>
<td>family, financial supports such as benefits</td>
<td>15.1% (n=16)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Most commonly used third sector organisations for onward referral</th>
<th>% response (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Disease Society</td>
<td>51.9% (n=55)</td>
</tr>
<tr>
<td>Rare Dementia PPA support group</td>
<td>28.4% (n=30)</td>
</tr>
<tr>
<td>Stroke Association</td>
<td>15.1% (n=16)</td>
</tr>
<tr>
<td>Connect</td>
<td>13.2% (n=14)</td>
</tr>
<tr>
<td>Dyscover</td>
<td>3.8% (n=4)</td>
</tr>
</tbody>
</table>

### 3.4 Discussion

The role of SLTs in PPA is an emerging area of practice across the UK and the findings from this survey suggest there are major inequities in access and referral to speech and language therapy for people with PPA. However, respondents report seeing a total of 353 patients in the last 2 years which, given prevalence...
numbers for the condition outlined in Chapter 2, represents a significant shortfall in terms of overall proportion of PPA cases being seen by SLT. There is poor representation in terms of characteristics of the wider UK adult population; respondents describe their patients as largely from higher socioeconomic backgrounds and predominantly English-speaking. Clearly only a minority of people with PPA living in the UK have access to SLT, with key barriers being socioeconomic status and linguistic background. In addition, respondents identified further barriers as delays in diagnosis and restrictive criteria resulting in people being ineligible for services.

SLT respondents reported that the majority of their patients with PPA were between 60-70 years of age. This is consistent with a recent UK study (Coyle-Gilchrist et al., 2016) and a systematic review (Hogan et al., 2016). Both studies hypothesise that it becomes harder to differentiate PPA from other dementia types in people over 70 years of age. Further, (Hall, Shapira, Gallagher, & Denny, 2013.) report that it is not uncommon for younger people with PPA who present with intact cognition to be given a psychiatric diagnosis, such as anxiety or personality disorder, in the early stages of the disease. This may partially explain why many respondents in this survey report their patients are only referred 2-3 years after diagnosis. Broader difficulties in PPA diagnosis may account for reports from respondents that diagnostic delays can be a barrier to people accessing SLT, and the concerning report that nearly half of people who are referred do not know their diagnosis.

The finding that many SLTs perceive service criteria to be a barrier to accessing intervention may reflect the division between services for older people (above 65 years) and those who are younger. Many NHS SLT services for older people with
progressive conditions such as dementia are only commissioned to provide input around management of swallowing disorders. This means people with PPA above 65 years of age, who meet these service criteria but need communication support, may only be able to access input for swallowing. In contrast neuro-rehabilitation services for people under 65 that do provide support for communication, often exclude people with progressive conditions. This means people with PPA below the age of 65 who would benefit from communication therapy are excluded because they have a progressive condition and thus do not meet these service criteria.

The finding that the majority of people with PPA seen by SLTs are predominantly English-speaking is not entirely surprising in light of the England and Wales national census data (Office for National Statistics, 2011) which highlights that 92.3% of people report English as their first language. It is noteworthy that people with PPA from multilingual or non-English backgrounds were reported in this survey to speak only Western-European languages such as Swedish and Flemish. Although this survey targeted respondents in Greater London, people from Asian and Afro-Caribbean multilingual communities were not reflected in the data. London is the most ethnically diverse area in England and Wales with at least 7% of the population identifying as African, 6.6% as Indian and 4.2% as Caribbean (Office for National Statistics, 2011). One explanation for this finding may lie in cultural factors around health and illness. Mukadam, Cooper, Basit, & Livingston (2011) highlight that people from minority ethnic communities are less likely to access health services due to the “stigma of mental illness and negative experience of psychiatric services” (Mukadam et al., 2011, p. 1075).
In this study the reported socio-economic distribution of people with PPA referred to SLT was predominantly high managerial. This does not reflect that of the general population, close to 50% of whom are employed in manual occupations in comparison to under 30% in high managerial professions (Office for National Statistics, 2010). Given that research has indicated increased occupational attainment reduces the risk of dementia (Wang, MacDonald, Dekhtyar, & Fratiglioni, 2017) this survey suggests a significant number of people of intermediate and manual occupational backgrounds may be failing to access SLT, or indeed any services for PPA. Previous research has shown that people with higher levels of education are more likely to seek out support and interventions (Ploeg et al., 2009), and this issue may offer an explanation for the current findings.

This survey also highlights the lack of care pathways for people with PPA; only 10 of 105 respondents reported the existence of one in their area. Importantly respondents reported a range of assessment and intervention practices that extend beyond those with a developed evidence base for PPA. Additionally, these prioritise communication training, suggesting that the needs of people living with PPA and their families are not being met by a focus on impairment alone.

Care pathways have a positive impact on the way care is organised (Seys et al., 2017). At present, there are no national care pathways for people with PPA or FTD, and only a small number of respondents reported having PPA care pathways within their services. A defining characteristic of a care pathway is identification of the required healthcare resources (European Pathways Association., 2019). Of the pathways that were described by respondents, only seven of the 10 included both assessment and intervention, and only one
respondent outlined a detailed pathway linked to the current research evidence. Without this kind of care pathway in place, SLTs may find it difficult to commission and thus deliver best practice care for people with PPA.

Despite there being a number of dementia specific formal assessment tools available, the most popular assessments that respondents reported on were informal interviews, functional observation, and a stroke aphasia language battery (the CAT, Swinburn, Porter, Howard 2004). Henry & Grasso (2018) observe that standard aphasia batteries developed for use with stroke aphasia are better able to characterize the language profile of an individual with PPA, and to distinguish between PPA variants, in order to plan interventions, whilst assessments of dementia are generally designed to assess changes in cognition rather than language. Notably Henry & Grasso (2018) point out that a number of tools to assess language in PPA and support intervention planning are only available in journal articles or by contacting university departments in the US and Australia. SLTs working in clinical settings in the UK are often unable to access such articles, unless their employer subscribes to the relevant journal, which may account for these respondents’ overwhelming preference for informal assessment tools. This may also indicate that SLTs are unsure of what formal assessment tools are best to use with this client group. Alternatively, it may illustrate the need for assessment tools designed specifically for people with PPA that support both diagnostic profiling and intervention planning.

3.4.1 Current practices and interventions

Both when selecting intervention approaches for people with PPA and when listing goals for therapy, survey respondents report a clear preference for interventions focusing on conversation or communication with family, friends and
carers. This emphasis on enabling better communication between the person with PPA and their family aligns with the results of a consensus study with SLTs, identifying priorities for clinical care with svPPA, by Kindell et al. (2015). The authors describe this as “carer-focused person centred” dementia care. Rogalski & Khayum (2018) highlight one of the core elements of a person-centered approach to PPA to be working with a patient in order to facilitate their participation in everyday activities. Communicating with family and friends is a critical everyday activity. As yet, there are no methodologically rigorous effectiveness studies that report on the use of CPT with people with PPA and their families (Taylor-Rubin et al., 2017). There is a worrying mismatch between an evidence base that supports word relearning, and clinical practice that favours functional approaches to support communication, which highlights the urgent need for further research. Studies must examine the effectiveness of interventions that SLTs perceive to be clinically relevant for people with PPA, beginning with CPT.

The average number of sessions reported by respondents to be available for impairment focused interventions (2.8), is significantly less than the number of sessions reported to be effective in a recent review of impairment focused interventions for PPA (Cadório et al., 2017). This review examined evidence from studies delivering interventions over a range of between 5 and 96 therapy sessions. Despite there being little indication of the ‘optimal’ dose, longer interventions resulted in better outcomes for svPPA (Cadório et al., 2017). It is possible that these SLT respondents deprioritise impairment focused interventions knowing they are unable to deliver them at the intensity reported in the research literature. The disparity between recommended and clinically
delivered dosage is a known issue in stroke aphasia interventions (Doogan, Dignam, Copland, & Leff, 2018). Developing a CPT programme that is deliverable within the time frame available is likely to be key to implementation and SLT respondents in this study report having an average of four sessions available for functional communication interventions, providing a guide for future programme development.

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 may account for some of the diversity seen in this survey concerning the amount of therapy that is reportedly available; 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 respondents may need to prioritise broader issues such as future planning, thus reducing the time available for speech and language interventions. Consideration should be given to these commissioning issues in the development of a new intervention, to ensure availability of information and resources, and to increase an SLT’s capacity to prioritise speech and language interventions.

### 3.4.2 Survey limitations

It is difficult to assess how many SLTs across the UK received this survey. The RCSLT estimates that 2,000 of its registered members work with adults but there is no data on client groups, which could include, amongst others, head and neck cancer, voice, stroke, and mental health. This figure also excludes SLTs not registered with the RCSLT (this is not obligatory for employment in the NHS),
who may be working in private or third sector organisations. In addition, respondents may have been a self-selecting sample based on clinical interest and confidence. The group are likely to include respondents based in specialist services for people with PPA and this may have skewed the data. Yet, with a sample size of 105, representing all geographical regions of the UK, the number of respondents compares favourably to other surveys of speech and language therapy practice, with numbers ranging from 13 to 147 (Taylor et al. 2009; Collis & Bloch 2012; Beckley et al. 2017; Miller & Bloch 2017; Sirman et al. 2017).

One of the major limitations of the survey was that no information was collected on the proportion of people with PPA on a respondent’s caseload in relation to those with other conditions. Comparison between services for PPA and other types of dementia is thus not possible, nor is it possible to reflect on whether it is only referral numbers for PPA that are increasing, or whether general referrals to SLT are rising too.

A further limitation includes access to the survey software, with some SLT respondents reporting that this was blocked by local IT services. This may have prevented some SLTs from responding.

3.5 Conclusion

This chapter has highlighted key barriers to accessing SLT services in the UK including a lack of awareness of the SLT role amongst potential referrers, service criteria that exclude people with PPA, geography and delays in diagnosis. This study has also 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. Importantly,
this survey demonstrates that SLTs working with people with PPA are using a range of assessment tools and intervention practices. The preference for using CPT over other interventions, despite the lack of research evidence examining its effectiveness for PPA, emphasises that this should be a research priority for the profession.
Chapter 4 A systematic review of the effects of functional communication interventions for people with primary progressive aphasia and their family caregivers

The findings are published as:


Identifying the relevant and existing evidence base prior to developing a new complex intervention should be a priority. The MRC complex intervention guidelines specifically recommend carrying out a systematic review (Craig et al., 2008). This chapter describes a systematic review of the existing research evidence on functional communication interventions for people with PPA and their family caregivers, utilising a systematic analysis method to identify the key intervention components.

4.1 Context for a systematic review of functional communication interventions in PPA

The International Classification of Functioning, Disability and Health (World Health Organization, 2001) classifies all non-pharmacological interventions into three domains: impairment, activity and participation. It describes impairment based interventions as those that seek to remediate, alleviate or improve symptoms. This includes interventions targeting the relearning of words and
sentences, reading and writing or restoration of oral movements. Activity and participation based interventions focus on functional communication; executing an activity and participating in life situations. This includes environmental modifications (e.g. working with families and caregivers), compensatory strategies or aids, and activities focused on engagement in an everyday task or situation. For the purposes of this study interventions are described as either impairment focused or functional communication interventions (FCIs) (the latter encompassing both activity and participation domains).

Carthery-Goulart et al’s (2013) review of non-pharmacological treatments for people with PPA is the only review to date that has included both impairment and FCIs. The authors identified a total of 39 studies, of which 31 were impairment focused interventions and eight FCIs. They reported a lack of FCI studies of adequate quality to make any practice recommendations in this area. This review did not provide detail on the key components of interventions that would allow for replication by a researcher or clinician, instead focusing on study quality.

A movement towards detailed reporting of interventions resulted in the publication of the Consolidated Standards of Reporting Trials (CONSORT) statement 2010 (Eldridge, Chan, et al., 2016). SPIRIT (Standard Protocol Items: Recommendations for Interventional Trials) (Chan et al., 2013) built on this, highlighting the need for interventions in a trial to be named and described. The Template for Intervention Description and Replication (TIDieR, Hoffmann et al., 2014) is the standard reporting tool for all intervention study designs, including trials. Despite this, the TIDieR has been found to contain inadequate information when examining complex speech and language interventions such as CPT (Cruice, Blom Johansson, Isaksen, & Horton, 2018; O’Rourke, Power,
O’Halloran, & Rietdijk, 2018). O’Rourke and colleagues recommend the Intervention Taxonomy (ITAX, Schulz, Czaja, McKay, Ory, & Belle, 2012) as it encompasses both intervention characteristics, content and goals. O’Rourke et al (2018) adapted the ITAX and demonstrated its utility in providing a detailed analysis and comparison of complex speech and language therapy intervention components to inform future intervention development.

In summary, there has been no review to date examining the key components of FCIs for people with PPA and their caregivers, and the adapted ITAX provides a tool to effectively report on complex interventions such as CPTs, a form of FCI. This systematic review employs the adapted ITAX (see appendix 4.1) in order to answer the following research questions: 1. What are the current FCIs for people with PPA and their caregivers? 2. What is the effectiveness of these interventions? 3. What are the key intervention components?

4.2 Methods

The systematic review protocol was registered with PROSPERO on 1st March 2018 and updated on 13th February 2019 (registration number: CRD42018089126). The protocol follows the PRISMA-P and PRISMA E&E (Liberati et al., 2009) transparent reporting of systematic reviews recommendations (see PRISMA checklist in Appendix 4.1).

4.2.1 Data sources

A systematic search was undertaken across the following databases: PubMed, MEDLINE, CINAHL, OVID-EMBASE, PsycINFO, Web of Science, SPEECHBITE, LILACS and trial databases (Access Clinical Trials, Clinical trials.gov, ISRCTN Registry, Access EU Clinical Trials Register and Access the
International Clinical Trials Registry Platform). A search of the grey literature was also undertaken using Google Scholar. Searches were implemented with controlled vocabulary, supplemented with free-text searching of keywords and titles. Database specific conventions such as mapping and use of multiple search fields and filters were customised for individual databases. English language filters were applied to all search results. Search terms included:

(Primary progressive aphasia OR semantic dementia OR non-fluent progressive aphasia OR logopenic aphasia OR progressive language OR language variant FTD) AND (intervention OR therapy OR rehabilitation OR training OR treatment OR speech pathology OR support OR aids) OR (carer OR family OR caregiver OR conversation partner) AND (primary progressive aphasia OR semantic dementia OR non-fluent progressive aphasia OR logopenic aphasia OR progressive language OR language variant FTD) AND (education OR intervention OR therapy OR rehabilitation OR training OR treatment OR speech AND pathology OR support OR aids). The reference lists of all identified reports and articles were searched for additional studies. The search was conducted in September 2018.

4.2.2 Inclusion criteria

1) All study designs containing empirical data on interventions: randomised controlled trials (RCTs), controlled studies, case controlled studies, observational studies and qualitative studies using any recognisable qualitative methodology. 2) Adults who meet the international diagnostic criteria for PPA (Gorno-Tempini et al., 2011) or carers/family members of people with this diagnosis. 3) FCIs, defined as interventions that meet the International Classification of Functioning, Disability and Health (World Health Organization, 2001) for an activity /
participation based intervention. 4) Indexed, published, peer reviewed literature written in English from 1998 to 2018.

4.2.3 Exclusion criteria

1) Participants presenting with a co-occurring history of stroke, brain lesions, major head trauma or a major psychiatric diagnosis. 2) Studies focused on impairment based interventions as defined by the ICF, WHO (2001). 3) Studies examining the effectiveness of pharmacological interventions.

4.2.4 Study selection

The author independently inspected citations from the searches against the study criteria and identified relevant abstracts. Given the topic did not require difficult judgments, in line with PRISMA-P, a UCL PhD student familiar with adult communication disorders research re-inspected a random sample of 10% of these abstracts to ensure reliability of selection. The author then obtained and inspected full reports of all the citations that met the inclusion criteria and the same fellow PhD student re-inspected a random sample of 10% of these to ensure reliability of selection. Disagreements between reviewers were resolved by contacting study authors to provide clarification and through further discussion between reviewers to achieve consensus. Reasons for excluding studies from the review were recorded. Neither reviewer was blinded to the journal titles, study authors, or author institutions.

4.2.5 Data extraction

The author independently extracted and tabulated data from each included article; the primary supervisor independently extracted and tabulated data from a random sample of 20% (n=4) of these articles to ensure reliability of data.
extraction. The author and the primary supervisor initially inspected each article to identify key components of the interventions using the 11 question ITAX adaptation data sheet (O’Rourke et al, 2018). As per the ITAX adaptation (O’Rourke et al., 2018), the theoretical underpinning for development of the intervention programmes was captured using the descriptive terms from Simmons-Mackie et al (2014), encapsulate the philosophical, theoretical and practical roots for CPTs as: 1) conversation analysis (CA), a rigorous method of analysing naturally occurring talk that is used to inform interventions through a focus on topic maintenance, repair and turn construction (such as Lock et al, 2001; Beeke, Sirman, et al, 2013); 2) the social model, focused on participation in life situations and often described as a life participation approach (such as Kagan, 1998); 3) functional-behavioural approaches, targeting practical or behavioural strategies that an SLT has knowledge and experience of using (such as Simmons Mackie, Kearns & Potechin 2005); 4) relationship orientated approaches, explicitly drawing on counselling literature (such as Sorin-Peters, 2004). Finally, the ITAX adaptation domains of treatment content strategies (how the intervention is delivered) and mechanism of action (how it works) were extracted. Judgements on these two domains were achieved by reading the full text of the article and judging which ITAX-listed strategies and actions were most aligned with the described intervention.

Where the author and the primary supervisor were unsure of specific terminology the authors of the ITAX adaptation were contacted to provide clarification. The author and the primary supervisor discussed and resolved any discrepancies for the four articles. Data on all study outcomes were extracted and tabulated by the author. The intention was to subject the data to further scrutiny and statistical analysis, if appropriate. However, the heterogeneity of outcome measures, and
the lack of appropriate and comparable statistical methods did not allow for this.

### 4.2.6 Risk of bias

The risk of bias of each study was assessed by the author using the tool developed by Dugmore, Orrell, & Spector (2015) to examine qualitative studies of psychosocial interventions for dementia. 53% of studies in this review were qualitative and, given the need for a uniform procedure applied across studies, it seemed logical to use a tool tailored to these, enabling a smoother comparison. The scale comprises 12 criteria including relevance, and design of the study (see Table 4-2). Studies are assigned a score out of 12. Scores below 8 are considered poor quality and scores of 9 or above considered good quality.

### 4.3 Results

#### 4.3.1 Search results and characteristics

A PRISMA diagram of the search results is presented in Figure 4:1. Database searches identified 12,309 records, and searches of grey literature identified an additional 174. Following removal of duplicates, 10,201 records remained. As a result of screening (including an independent check of 10% of records with an initial inter-rater agreement rate of 97%, prior to discussion and final agreement), a further 10,097 records were excluded. After full text eligibility checking of the remaining 104 articles by the author, and independent examination of 10% of these by a fellow PhD student (with an inter-rater agreement rate of 82% prior to discussion and final agreement), 85 further studies were excluded, leaving 19 studies for review. Table 4-1 presents an overview of the study design and participant characteristics for the 19 studies comprising 11 case studies, one case series, one pilot intervention trial, five intervention trials (no control) and one controlled intervention trial.
<table>
<thead>
<tr>
<th>Study</th>
<th>Participant diagnosis</th>
<th>Participant age/gender</th>
<th>Study design</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Murray, 1998)</td>
<td>nfvPPA</td>
<td>F 64 years at start of study</td>
<td>Case study - Class III</td>
</tr>
<tr>
<td>(Rogers &amp; Alarcon, 1998)</td>
<td>nfvPPA</td>
<td>M 69 years at start of study</td>
<td>Case study - Class III</td>
</tr>
</tbody>
</table>
| (Cress & King, 1999) | nfvPPA  
PAP (variant not reported) | F 59 years at start of study  
M 60 years at start of study | Case series; 2 participants - Class III |
| (Pattee, Von Berg, & Ghezzi, 2006) | PPA with Apraxia of speech | F 57 years | Case study - Class III |
| (Cartwright & Elliott, 2009) | PPA- variant not reported | Four participants 3F:1M aged 59,62,65,66 years | Intervention trial; 4 participants – Class II |
| (Wong et al., 2009) | svPPA | M 61 years old | Case study – Class III |
| (Fried-Oken, Rowland, & Gibbons, 2010) | nfvPPA | 3M:4F aged 71-78 years | Intervention trial; 7 participants – Class II |
| (Bier et al., 2011) | svPPA | F 68 years old | Case study – Class III |
| (Gibbons, Oken, & Fried-Oken, 2012) | Aphasia & word deafness with bvFTD | M 57 years of age | Case study – Class III |
| (Bier, Paquette, & Macoir, 2018) | svPPA | M 56 years of age | Case study – Class III |
| (Bier et al., 2015) | svPPA | M 55 years of age | Case study – Class III |
| (Goral-Polrola et al., 2016) | nfvPPA | F 73 years of age | Case study – Class III |
| (Rogalski et al., 2016) | PPA, Variant not reported | 13M:18F aged 56-83 years | Pilot intervention trial; 34 participants – Class III |
| (Morhardt, O’Hara, Zachrich, Wieneke, & Rogalski, 2017) | PPA, Variant not reported | Pilot phase: 4M:2F, aged 53-80 years  
Full trial: People with PPA 5M:4F aged 55-82 years  
CPs 2M:6:F | Pilot intervention trial; six participants) followed by intervention trial; 17 participants (9 people with PPA and 8 CPs) – Class III |
<table>
<thead>
<tr>
<th>Study</th>
<th>Group 1</th>
<th>Group 2</th>
<th>Study Design</th>
<th>Evidence Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Jokel et al., 2017)</td>
<td>Treatment group: 3 nfvPPA &amp; 2 lvPPA</td>
<td>Treatment group: 3M:2F aged 71-80 years (spouses aged 58-85). Control group: 4M:1F aged 64-73 (CPs aged 59-75)</td>
<td>Unrandomised controlled trial; five people with PPA and their CPs in each group – Class II</td>
<td></td>
</tr>
<tr>
<td>(Kindell et al., 2018)</td>
<td>svPPA</td>
<td>F 64 years of age</td>
<td>Case study – Class III</td>
<td></td>
</tr>
<tr>
<td>(Mooney, Beale, &amp; Fried-Oken, 2018)</td>
<td>PPA, Variant not reported</td>
<td>Treatment group: 3M:2F aged 63-73 years (6 CPs aged 49-76)</td>
<td>Intervention trial; five people with PPA and their CPs – Class II</td>
<td></td>
</tr>
<tr>
<td>(Mooney, Bedrick, Noethe, Spaulding, &amp; Fried-Oken, 2018)</td>
<td>3- nfvPPA 2 svPPA 1 lvPPA</td>
<td>3M:3F aged 62-80 years</td>
<td>Crossover study; 6 participants. (alternating interventions experimental trial) – Class II</td>
<td></td>
</tr>
<tr>
<td>(Kim, Figeys, Hubbard, &amp; Wilson, 2018)</td>
<td>lvPPA</td>
<td>F 62 years of age (spouse = 68 years of age)</td>
<td>Case study; dyad – Class III</td>
<td></td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td>nfvPPA: 20</td>
<td>Male: 46</td>
<td>Case studies: 11</td>
<td></td>
</tr>
<tr>
<td></td>
<td>lvPPA: 6</td>
<td>Female: 47</td>
<td>Case series design: 1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>svPPA: 7</td>
<td>Age range from 53 years to 83 years (unable to report average data due to incomplete reporting in original studies)</td>
<td>Pilot intervention trial: 1</td>
<td></td>
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<tr>
<td></td>
<td>unspecified PPA: 56</td>
<td></td>
<td>Intervention trials: 5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other: 2</td>
<td></td>
<td>Controlled intervention trials: 1</td>
<td></td>
</tr>
</tbody>
</table>

**Total no. of participants across all studies:** 91

nfvPPA=nonfluent aggrammatic variant primary progressive aphasia; lvPPA=logopenic variant primary progressive aphasia; svPPA=semantic variant primary progressive aphasia; bvFTD=behavioural variant fronto-temporal dementia; CP=communication partner; M=male; F=female. Cicerone et al. (2000), p.1598 define class II level evidence as "prospective, nonrandomized cohort studies; retrospective, nonrandomized case-control studies; or clinical series with well-designed controls that permitted between-subject comparisons of treatment conditions, such as multiple baseline across subjects" and class III level evidence as "Clinical series without concurrent controls, or studies with results from 1 or more single cases that used appropriate single-subject methods".
### 4.3.2 Risk of bias of included studies

Table 4-2 reveals study performance on the Dugmore et al (2015) risk of bias rating scale. All 19 studies provided a clear research question (item 2), yet none used 'member checking', i.e. using respondents to validate research findings (item 11). The lowest scoring study was also the oldest (Rogers & Alarcon, 1998) and the two scoring highest were the more recent (Jokel et al., 2017; Mooney, Bedrick, Noethe, Spaulding, & Fried-Oken, 2018). Six of the 19 studies scored less than 8 and are thus considered of poor quality (Fried-Oken, Rowland, & Gibbons, 2010; Gibbons, Oken, & Fried-Oken, 2012; Goral-Polrola et al., 2016;
Kindell et al., 2018; Rogers & Alarcon, 1998; Wong et al., 2009) Six studies scored exactly 8 (Bier, Brambati, et al., 2015; Cress & King, 1999; Kim et al., 2018; Morhardt, O'Hara, Zachrich, Wieneke, & Rogalski, 2017; Murray, 1998; Pattee, Von Berg, & Ghezzi, 2006). Finally, seven studies scored 9 or above and can be considered good quality (Bier, Macoir, Joubert, Bottari, Chayer, Pigot, Giroux, & SemAssist, 2011; Bier et al., 2018; Jokel et al., 2017; Mooney, Beale, et al., 2018; Mooney, Bedrick, et al., 2018; Rogalski et al., 2016).
Table 4-2: Risk of bias of included studies

<table>
<thead>
<tr>
<th>Adapted from (Mays &amp; Pope, 2000)</th>
<th>(1) Worth or relevance</th>
<th>(2) Clarity of research question</th>
<th>(3) Appropriateness of the design to the question</th>
<th>(4) Context</th>
<th>(5) Sampling</th>
<th>(6) Data collection and analysis systematic</th>
<th>(7) ‘Audit trail’</th>
<th>(8) Disconfirming cases</th>
<th>(9) Analytical criteria</th>
<th>(10) Findings triangulated</th>
<th>(11) Member checking</th>
<th>(12) Reflexivity of the account</th>
<th>Total score out of 12:</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Murray, 1998)</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>8</td>
</tr>
<tr>
<td>(Rogers &amp; Alarcon, 1998)</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>3</td>
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<tr>
<td>(Cress &amp; King, 1999)</td>
<td>Y</td>
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<td>N</td>
<td>Y</td>
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<td>Y</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>8</td>
</tr>
<tr>
<td>(Pattee, Von Berg, &amp; Ghezzi, 2006)</td>
<td>Y</td>
<td>Y</td>
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<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
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<tr>
<td>(Wong et al., 2009)</td>
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<td>Y</td>
<td>Y</td>
<td>N</td>
<td>N</td>
<td>N</td>
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<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>5</td>
</tr>
<tr>
<td>(Cartwright &amp; Elliott, 2009)</td>
<td>Y</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<td>N</td>
<td>N</td>
<td>10</td>
</tr>
<tr>
<td>(Fried-Oken et al., 2010)</td>
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<td>Y</td>
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<td></td>
</tr>
<tr>
<td>(Mooney, Beale, et al., 2018)</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<td>Y</td>
<td>N</td>
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<td>10</td>
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<tr>
<td>(Mooney, Bedrick, et al., 2018)</td>
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<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<td>Y</td>
<td>N</td>
<td>Y</td>
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<tr>
<td>No. or articles that fulfil this criteria of total 19 articles</td>
<td>18</td>
<td>19</td>
<td>17</td>
<td>15</td>
<td>14</td>
<td>16</td>
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<td>9</td>
<td>12</td>
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</tr>
</tbody>
</table>

Quality Rating Scale adapted from (Mays and Pope, 2000) by (Dugmore et al., 2015). NB: < 8/12: poor quality, > 8/12: good quality
4.3.3 Intervention programmes

4.3.3.1 Delivery of Intervention Programmes

The delivery characteristics of the FCIs are summarised in Table 4-3. Eighteen interventions were delivered face to face and one study was delivered via video conferencing. Fifteen interventions were delivered in either a dyadic or a group situation, involving CPs. Of the 11 studies that reported on the interventionists' characteristics, 10 were delivered by an individual with disciplinary or professional expertise and the other provided specific training to the interventionist. Concerning sensitivity to participant characteristics, 17 studies reported using visual supplements or augmentative communication devices.
Table 4-3: Delivery characteristics of FCIs for PPA using the ITAS adaptation (O’Rourke et al., 2018)

<table>
<thead>
<tr>
<th>Mode</th>
<th>Method of contact</th>
<th>Materials</th>
<th>Location</th>
<th>Duration</th>
<th>Scripting</th>
<th>Interventionist</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Murray, 1998)</td>
<td>individual, dyadic and group treatment</td>
<td>face to face</td>
<td>Videotapes, drawing materials and assistive devices</td>
<td>Research facility</td>
<td>Period 1. 24 sessions (1 hr 2 x p/wk for 12 weeks). Period 2. 41 hours dyad, 10 hours group therapy over 12 months).</td>
<td>Goals and exercises/tasks of each session are specified.</td>
</tr>
<tr>
<td>(Rogers &amp; Alarcon, 1998)</td>
<td>individual and dyadic</td>
<td>face to face</td>
<td>Videotapes, Assistive devices</td>
<td>Research facility (University Clinic)</td>
<td>Not reported</td>
<td>General guidelines provided</td>
</tr>
<tr>
<td>(Cress &amp; King, 1999)</td>
<td>individually and dyadic and group</td>
<td>face to face</td>
<td>Manuals/ workbooks, Assistive devices</td>
<td>Research facility (plus in the community)</td>
<td>Two case studies- MC: One off session CE: 4 years advice, 1 month intervention (3-4 hour individual sessions p/week, 4-6 hours of training with/for family)</td>
<td>General guidelines provided</td>
</tr>
<tr>
<td>(Pattee et al., 2006.)</td>
<td>individually</td>
<td>face to face</td>
<td>Assistive devices, Information sheets/checklists</td>
<td>Not reported</td>
<td>8 sessions over 9 weeks</td>
<td>Goals and exercises/tasks of each session are specified.</td>
</tr>
<tr>
<td>Study (Ref.)</td>
<td>Setting</td>
<td>Treatment Type</td>
<td>Settings</td>
<td>Materials</td>
<td>Setting Location</td>
<td>Sessions</td>
</tr>
<tr>
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</tr>
<tr>
<td>Cartwright &amp; Elliott (2009)</td>
<td>Hospital</td>
<td>Group</td>
<td>Face to face</td>
<td>Pamphlets, Videotapes, Assistive devices</td>
<td>8 sessions, 90 minutes each, over 8 weeks (1 x weekly)</td>
<td>Specific language is provided, with room for elaboration</td>
</tr>
<tr>
<td>Wong et al. (2009)</td>
<td>Research facility (University Clinic)</td>
<td>Individual and group</td>
<td>Face to face</td>
<td>CDs/DVDs, Assistive Devices, Workbooks and props of participants choosing</td>
<td>Not reported</td>
<td>Goals/tasks specified but no further scripting</td>
</tr>
<tr>
<td>Fried-Oken et al. (2010)</td>
<td>Research facility (University Clinic)</td>
<td>Dyadic</td>
<td>Face to face</td>
<td>Assistive devices</td>
<td>6 sessions</td>
<td>Goals/tasks specified but no further scripting</td>
</tr>
<tr>
<td>Bier et al. (2011)</td>
<td>Participants home</td>
<td>Individually</td>
<td>Face to face</td>
<td>Assistive devices, Manuals/ workbooks.</td>
<td>11 sessions, fortnightly where possible re participants schedule, over 5-month period</td>
<td>Specific language is provided, with room for elaboration</td>
</tr>
<tr>
<td>Gibbons et al. (2012)</td>
<td>Not reported</td>
<td>Individually, and dyadic</td>
<td>Face to face</td>
<td>Assistive devices</td>
<td>Not reported</td>
<td>Goals/tasks specified but no further scripting</td>
</tr>
<tr>
<td>Study</td>
<td>Intervention Format</td>
<td>Mode</td>
<td>Assistive Devices</td>
<td>Setting</td>
<td>Sessions</td>
<td>Specific Language</td>
</tr>
<tr>
<td>-------------------------------</td>
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</tr>
<tr>
<td>(Bier, Paquette, et al., 2015)</td>
<td>Individually</td>
<td>Face to face</td>
<td>Assistive devices (smartphone)</td>
<td>Participants home</td>
<td>7 sessions, 1.5 hours, 1x weekly</td>
<td>Specific language provided with elaboration allowed / not allowed</td>
</tr>
<tr>
<td>(Bier, Brambati, et al., 2015)</td>
<td>Individually</td>
<td>Face to face</td>
<td>Assistive devices (smartphone)</td>
<td>Research facility</td>
<td>5 intervention sessions</td>
<td>Specific language provided with elaboration allowed / not allowed</td>
</tr>
<tr>
<td>(Goral-Polrola et al., 2016)</td>
<td>Individually and group</td>
<td>Face to face</td>
<td>Assistive devices</td>
<td>Nursing home</td>
<td>20 sessions</td>
<td>General guidelines provided</td>
</tr>
<tr>
<td>(Rogalski et al., 2016)</td>
<td>Internet and video instruction, individually and dyadic</td>
<td>Telephone contact with computer (Video conferencing)</td>
<td>Internet, videotapes</td>
<td>Participants home</td>
<td>8 sessions, 1-hour</td>
<td>Goals/tasks specified but no further scripting</td>
</tr>
<tr>
<td>(Morhardt et al., 2017)</td>
<td>Group</td>
<td>Face to face</td>
<td>PowerPoint presentations, materials for activities</td>
<td>Not reported</td>
<td>Pilot: 5 x 90-minute bimonthly sessions Formal Intervention: 10 sessions, twice p/month over 5 months</td>
<td>Goals of each exercises/tasks of each session are specified but no further scripting</td>
</tr>
<tr>
<td>(Jokel et al., 2017)</td>
<td>Lectures, group treatment</td>
<td>Face to face</td>
<td>Information sheets, pamphlets, live demonstration,</td>
<td>Not reported</td>
<td>10 sessions, 2 hours each, once weekly</td>
<td>Goals/tasks specified but no further scripting</td>
</tr>
<tr>
<td>Study Source</td>
<td>Treatment Type</td>
<td>Delivery</td>
<td>Materials</td>
<td>Duration</td>
<td>Guidelines Provided</td>
<td>Additional Information</td>
</tr>
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</tr>
<tr>
<td>(Kindell et al., 2018)</td>
<td>Individual and group</td>
<td>Face to face and group</td>
<td>CDs/DVDs</td>
<td>2 intervention sessions, 40 minutes</td>
<td>General guidelines provided</td>
<td>Not reported</td>
</tr>
<tr>
<td>(Mooney, Beale, et al., 2018)</td>
<td>Group lectures</td>
<td>Face to face</td>
<td>Information sheets/checklists, Pamphlets, Assistive devices, Live demonstrations</td>
<td>Research facility (University Clinic)</td>
<td>12 sessions, 1 hour per session, held twice weekly for 6 weeks</td>
<td>Goals and exercises/tasks of each session are specified but no further scripting</td>
</tr>
<tr>
<td>(Mooney, Bedrick, et al., 2018)</td>
<td>Individually and dyadic</td>
<td>Face to face</td>
<td>Assistive devices</td>
<td>Participants home</td>
<td>6-7 sessions, 3 months</td>
<td>Goals/tasks specified but no further scripting</td>
</tr>
<tr>
<td>(Kim et al., 2018)</td>
<td>Group</td>
<td>Face to face and group</td>
<td>Live demonstrations</td>
<td>One weekend annually in September</td>
<td>Goals/tasks specified but no further scripting</td>
<td>Required disciplinary/professional expertise for interventionists</td>
</tr>
</tbody>
</table>

CP: Communication Partner
There was variability across interventions on the ITAX adaptation items including intervention materials, intervention delivery location, intervention schedule, provided scripts, and intervention adaptability. All 19 studies listed materials, and 11 reported using multiple types of materials. Most commonly reported intervention materials were: assistive devices (14 studies), additional items such as videotape (4), information sheets/checklists (4), manuals/workbooks (3), pamphlets (3), live demonstrations (3), CDs/DVDs (2), PowerPoint presentations (2), the internet (1), drawing materials (1), props of participants’ choice (1) and materials for activities (1). Of the 15 studies that reported on intervention delivery location, seven were delivered in a research facility, five at participants’ homes, and four at other locations including hospitals, nursing homes, in the local community, and at a “rustic location” (Kim et al., 2018, p. 272). Of the 13 studies that reported on intervention schedule, this ranged from a single session (length not specified) (Cress & King, 1999) to a package of 41 hours of dyadic intervention, 10 hours of group intervention and 24 hours of individual intervention with a person with PPA (75 hours in total) (Murray, 1998). All 19 studies used a script to guide the interventionist, of these 11 studies described goals or tasks (a subset of these five provided goals or tasks for each individual session), four studies provided specific language with elaboration allowed, and four studies provided general guidelines. Of the 13 studies that reported on intervention adaptability, 12 reported adapting the content or target of the intervention, two reported also adapting the mode e.g. from individual to dyadic, and one reported adapting the number and schedule of sessions. Multiple reasons were cited for recommended adaptations, including participant preference, clinical judgment, spontaneous request, assessment, and participant progress at baseline, intake or at set intervals. Only one of the studies (Rogalski et al., 2016) reported on
treatment implementation, asking participants to report on their adherence to the programme.

4.3.3.2 Content of intervention programmes

Of the 19 studies, 12 were identified as having one theoretical approach underpinning them, and seven were underpinned by more than one theory. Of the 12 studies underpinned by one approach, six used a functional-behavioural approach (which targets practical or behavioural strategies such as turning off background noise), five a social model approach (focused on participation in life situations) and one a CA approach (underpinned by rigorous analysis of naturally occurring conversations and focused on turn construction, repair and topic). Of the seven studies underpinned by more than one approach, three combined functional behavioural and social model theories, two combined CA and social model theories, and one combined relationship orientated and social model theories. Finally, one study combined functional behavioural and social model theories in stage 1 and then CA and social model theories in stage 2. All interventions had different goals related to functional communication.

In terms of treatment content strategy, all 19 studies used skill building techniques (i.e. building on areas of current strength) and provision of instruction. Of these, 15 also used problem solving techniques. An assessment strategy was used the least, in only seven interventions. The most common mechanism of action was behavioural skills (i.e. practical actions undertaken with participants to learn and practise the skills and content being taught, such as practising having a conversation), noted in 18 studies, with evaluation the least common mechanism of action, in four studies.
4.3.4 Outcome measures and intervention effects

In total, the 19 studies listed 42 different outcome measures (see Table 4-4 for details, and the reported significance of results). Only two studies deployed the same outcome measure, the smartphone function measure. Developed by Bier, Brambati, et al (2015) and used also by Bier, Paquette, et al (2015), this measure scores the number of steps a participant successfully navigates during the use of a function on a smartphone e.g. video recording. A wide variety of outcome measures were used including: formal language tests such as the Boston Naming Test (BNT; Kaplan, Goodglass, & Weintraub, 1983); measurements of discrete behaviours such as use of a communication aid; social validity judgements such as transactional communication success judged by a naïve listener; qualitative methods such as semi structured interviews and questionnaires; CA; rating scales such as the Communication Confidence Rating Scale in Aphasia (CCRSA; Babbitt, Heinemann, Semik, & Cherney, 2011). Of the 42 measures, significance data is reported for 19 measures from across eight different studies. Of these 19 measures, 17 revealed a statistically significant improvement across eight different studies. Two measures across two of these same eight studies also reported a statistically significant deterioration.
Table 4-4: Outcome measures and reported significance

<table>
<thead>
<tr>
<th>Category</th>
<th>Outcome measure</th>
<th>Significance (for experimental group)</th>
</tr>
</thead>
<tbody>
<tr>
<td>formal language tests</td>
<td>x Daily Mishaps Test (Helm-Estabrooks, &amp; Albert, 1991)</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td>Communication Activities in Daily Living (CADL, ( Holland, 1980))</td>
<td></td>
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<tr>
<td>measurements of discrete behaviours</td>
<td>x American speech-language Hearing Association Functional Assessment of</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td>Communication Skills for Adults (AHSA FACS, Frattali, Thompson, Holland, Wohl, &amp;</td>
<td></td>
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<tr>
<td></td>
<td>Ferketic, 1995)</td>
<td></td>
</tr>
<tr>
<td>social validity judgements</td>
<td>x qualititative analysis of pre and post intervention conversation samples</td>
<td>NR</td>
</tr>
<tr>
<td>interviews and questionnaires</td>
<td>x The four-point communicative rating scale developed by (Davis &amp; Wilcox, 1981)</td>
<td>NR</td>
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<tr>
<td></td>
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<td></td>
</tr>
<tr>
<td>conversations analysis</td>
<td>x</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>rating scales</td>
<td>x</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>x Boston Naming Test (BNT; Kaplan et al., 1983)</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td>x Reading Commands subtest Western aphasia battery (WAB, Kertesz, 2006)</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td>x Written subtest of the Minnesota test for differential diagnosis of Aphasia (MTDDA,</td>
<td>NR</td>
</tr>
<tr>
<td></td>
<td>x Controlled Oral Word Association Test (COWAT, Patterson, 2011)</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Measures Used</td>
<td></td>
</tr>
<tr>
<td>-------</td>
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<td></td>
</tr>
<tr>
<td>Social validity judgements</td>
<td>Content Unit Identification using the Cookie theft picture from the Boston Diagnostic Aphasia Examination (BDAE; Goodglass, Kaplan, &amp; Barresi, 2000)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Interviews and questionnaires</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Conversation analysis</td>
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<tr>
<td></td>
<td>Rating scales</td>
<td></td>
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<tr>
<td>Other</td>
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<td></td>
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<tr>
<td>Interviews and questionnaires</td>
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</table>

**Note:** NR indicates not reported.
<table>
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<tr>
<th></th>
<th>x</th>
<th>Discourse comprehension</th>
<th>Concrete</th>
<th>Opinion</th>
<th>Inferential</th>
<th>+</th>
<th>+</th>
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<tr>
<td>social validity</td>
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<tr>
<td>judgements</td>
<td>Production of story information units</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>+</td>
</tr>
<tr>
<td>conversations</td>
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<td></td>
<td></td>
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<td>analysis</td>
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<td>rating scales</td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>x</td>
<td>Transactional success</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>NR</td>
</tr>
</tbody>
</table>

(Wong et al., 2009)

| formal language tests  | x                                      | Communication Effectiveness- rated by the therapist | NR |
| measurements of        |                                        |                                                        |    |
| discrete behaviours    |                                        |                                                        |    |
| social validity        | x                                      |                                                        |    |
| judgements             | Production of story information units  |                                                        |    |
| conversations          |                                        |                                                        |    |
| analysis               |                                        |                                                        |    |
| rating scales          |                                        |                                                        |    |
| Other                  |                                        |                                                        |    |

(Fried-Oken et al., 2010)

<p>| formal language tests  | x                                      | Weighted conversation scores | + |
| measurements of        |                                        |                            |    |
| discrete behaviours    |                                        |                            |    |
| social validity        | x                                      |                            |    |
| judgements             |                                                        |                            |    |
| conversations          |                                        |                            |    |
| analysis               |                                        |                            |    |
| rating scales          |                                        |                            |    |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Other</th>
<th>Measured Constructs</th>
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</thead>
</table>
| (Bier et al., 2011)          | formal language tests      | Instrumental Activities of Daily Living Profile (IADL, Bottari, Dassa, Rainville, & Dutil, 2010)  
<p>|                              | x                          | +                                                                                   |
|                              | social validity judgements | +                                                                                   |
|                              | interviews and questionnaires |                                                     |
|                              | conversation analysis     |                                                     |
|                              | rating scales             |                                                     |
|                              | Other                      | Generation of semantic attributes                                                     |
| (Gibbons et al., 2012)       | formal language tests      | Communication board use                                                              |
|                              | x                          | +                                                                                   |
|                              | Functional communication test     |                                                                                  |
|                              | social validity judgements | NR                                                                                  |
|                              | interviews and questionnaires |                                                     |
|                              | conversation analysis     |                                                     |
|                              | rating scales             |                                                     |
|                              | Other                      |                                                     |
| (Bier, Brambati, et al., 2015)| formal language tests    | Smartphone function measures                                                        |
|                              | x                          | +                                                                                   |
|                              | Daily integration of functions |                                                     |
|                              | social validity judgements | +                                                                                   |</p>
<table>
<thead>
<tr>
<th>Study</th>
<th>Methods</th>
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<tbody>
<tr>
<td>(Bier, Paquette, et al., 2015)</td>
<td>interviews and questionnaires, conversation analysis, rating scales, Other x Semantic knowledge about Functions +</td>
</tr>
<tr>
<td></td>
<td>formal language tests, measurements of discrete behaviours x Smartphone function measures +</td>
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<tr>
<td></td>
<td>social validity judgements, interviews and questionnaires, conversation analysis, rating scales</td>
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<tr>
<td></td>
<td>Other x Personalised semantic measure -</td>
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<tr>
<td>(Goral-Polrola et al., 2016)</td>
<td>formal language tests, measurements of discrete behaviours x Use of communication aid</td>
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<tr>
<td></td>
<td>Participation in functional tasks NR</td>
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<tr>
<td></td>
<td>social validity judgements, interviews and questionnaires, conversation analysis, rating scales</td>
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<tr>
<td></td>
<td>Other</td>
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<tr>
<td>(Rogalski et al., 2016)</td>
<td>formal language tests, measurements of discrete behaviours</td>
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NR: Not reported
<table>
<thead>
<tr>
<th>Method</th>
<th>Description</th>
<th>Notes</th>
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<tbody>
<tr>
<td>Clinician rated participants</td>
<td>Ongoing compliance</td>
<td>NR</td>
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<tr>
<td>Semi structured interviews</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication Confidence Rating Scale</td>
<td>Communication Confidence Rating Scale for Aphasia (CCRSA; Babbitt et al., 2011).</td>
<td>+</td>
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<tr>
<td>American Speech–Language–Hearing Association functional communication measures (ASHA-FCM; (American Speech Hearing Association, 2009))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Observational field notes</td>
<td></td>
<td>NR</td>
</tr>
<tr>
<td>Transcription of group sessions</td>
<td></td>
<td>NR</td>
</tr>
<tr>
<td>Use of communication strategies</td>
<td>Use of communication strategies as rated from video recorded interactions with CP</td>
<td>NR</td>
</tr>
<tr>
<td>Spousal Questionnaire</td>
<td></td>
<td>+</td>
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<tr>
<td>Study</td>
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<tr>
<td></td>
<td><strong>Conversation analysis</strong></td>
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<td></td>
<td>- rating scales</td>
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<tr>
<td></td>
<td>- <strong>Quality of Communication Life Scale (QCLS, Paul et al., 2004)</strong></td>
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<td></td>
<td><strong>Other</strong></td>
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<tr>
<td>(Kindell et al., 2018)</td>
<td><strong>Formal language tests</strong></td>
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<td></td>
<td>- measurements of discrete behaviours</td>
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<td></td>
<td><strong>Social validity judgements</strong></td>
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<td></td>
<td><strong>Conversation analysis</strong></td>
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<td></td>
<td>- <strong>Qualitative Analysis using conversation analysis</strong></td>
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<td><strong>Other</strong></td>
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<tr>
<td>(Mooney, Beale, et al., 2018)</td>
<td><strong>Formal language tests</strong></td>
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<td></td>
<td>- measurements of discrete behaviours</td>
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<td><strong>Social validity judgements</strong></td>
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<td></td>
<td><strong>Interviews and questionnaires</strong></td>
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<td></td>
<td>- <strong>Mode of communication survey</strong></td>
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<td>- <strong>CP evaluation of mode of communication</strong></td>
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<td>(Mooney, Bedrick, et al., 2018)</td>
<td><strong>Formal language tests</strong></td>
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<td></td>
<td>- measurements of discrete behaviours</td>
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<td></td>
<td>- <strong>Mastery of tablet operations</strong></td>
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<td></td>
<td>- <strong>Story retell using no technology, photo and only and GoChat app</strong></td>
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<td><strong>NR</strong></td>
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<tr>
<td>Method</td>
<td>Kim et al., 2018</td>
<td>Notes</td>
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<tr>
<td>Social validity judgements</td>
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<td>x User feedback</td>
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<td>Interviews and questionnaires</td>
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<td>Conversation analysis</td>
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<td>Rating scales</td>
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<td>Other</td>
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<tr>
<td>Formal language tests</td>
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<td>Measurements of discrete behaviours</td>
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<td>Social validity judgements</td>
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<td>Conversation analysis</td>
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<td>Rating scales</td>
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<tr>
<td>Other</td>
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</tbody>
</table>

+, positive effect for experimental group; −, negative effect for experimental group; NR, not reported;
4.4 Discussion

The aim of this systematic review was to identify FCIs for people with PPA and their caregivers described in the research literature between 1998 and 2018, examine their effectiveness and establish the key components of these interventions. Nineteen studies met the inclusion criteria for this review, demonstrating an increase in the number of published articles since Carthery-Goulart et al’s (2013) review 5 years ago, which identified only eight FCI studies. The quality of the 19 studies identified was better than those identified by Carthery-Goulart et al (2013), who reported on five case studies, one case series, one intervention trial (no control) and one intervention trial with a control group. This review included five intervention trials (no control) and one controlled intervention trial, as well as one pilot intervention trial. Five studies in this review can be classified as class II level evidence and meet the criteria leading to recommendations on practice guidelines (Cicerone et al., 2000).

4.4.1 Key components of FCI interventions

Fifteen of the 19 studies include CPs in the intervention, either delivering dyadic or group interventions. This has parallels with the results of the UK wide survey, described in Chapter 3, which found that SLTs report prioritising CP training in clinical practice. One of the most common theoretical underpinnings for intervention development in these studies was identified as a functional-behavioural approach, which draws on the knowledge and experience of the interventionist to provide practical strategies to modify communication behaviour. In addition, Rogalski et al (2016) and Kim et al (2018) explicitly state they used research evidence from stroke aphasia to guide the development of their interventions. CP training is an established intervention for stroke aphasia (Cruice
et al., 2018; Simmons-Mackie et al., 2016) and it appears that its carry-over into PPA interventions is motivated by opportunities for the person with PPA and the CP to practise strategies in a relevant context, i.e. together.

All but one study was underpinned by the interventionist using skill building techniques (i.e. building on areas of current strength) to change communication behaviours, indicating that this is a key component for FCIs for PPA. This result can be interpreted in the light of knowledge from the stroke aphasia literature, where researchers have found that building on existing communication skills rather than introducing new strategies may be a more effective method of compensating for communication difficulties (Simmons-Mackie & Damico, 1997). These authors emphasise that the goal of therapy must be to develop automatic, efficient communication strategy use that does not place a cognitive burden on an individual. Skill-building techniques are hypothesised to minimise cognitive burden for people with stroke aphasia, who can struggle to change behaviour in response to a communication breakdown because of impaired cognitive flexibility (Chiou & Kennedy, 2009). Thus, it seems logical that people with PPA may similarly benefit from a skill building approach.

It is difficult to draw any conclusions on key components such as optimal location and dosage for FCIs for PPA as there was little consistency across interventions. The large variation in dosage and location could be explained by considering how PPA variant may affect response to intervention. A review of generalisation of treatment gains for impairment focused interventions (predominantly single word relearning) by Cadório et al (2017) reported that people with svPPA have more difficulties maintaining and generalising personally relevant words learnt in therapy, requiring large amounts of practice delivered in as natural an
environment as possible. In contrast, Cadório et al (2017) report that individuals with nfvPPA and lvPPA are better able to generalise following fewer sessions, delivered in any setting, as they do not have item specific impairments. Of the 91 participants included in the studies in this review, 62% were not diagnosed with a specific PPA variant. This may be attributed to a lack of reporting, but adds to the difficulty of drawing conclusions on optimal location and dosage for FCIs for PPA.

4.4.2 Future considerations for FCI studies

Due to heterogeneity of interventions and outcomes, meta-analysis was not possible. Complex interventions can result in a range of possible outcomes (Craig et al., 2008) which is reflected in the use of 42 different measures, across the 19 studies included in this review, measuring constructs that ranged from language to functional performance and confidence in communicating. Future studies have an obligation to use rigorous research methods, and, ideally, a core set of outcome measures. While using multiple measures can more consistently capture unanticipated gains if samples are adequate (Craig et al., 2008), the choice of at least some core measures, such as those focused on confidence and quality of life, to allow for cross-study comparison, is a priority.

The study may be limited by the inclusion of research articles describing participants diagnosed with all three PPA variants, resulting in a heterogeneous participant group who have different communication strengths and areas of difficulty, and thus different therapeutic needs. In fact, many of the studies included pre-date the publication of an article where the classification of PPA and its variants was internationally recognised and agreed upon (Gorno-Tempini et al., 2011). This may have affected the nomenclature used in earlier studies but
excluding them would significantly reduce the number of available articles. Even the studies published after 2011 did not select participants based on PPA variant. Consistent reporting of scores from standardised language measures, alongside details of PPA variant if available, will provide data that can allow readers to make judgement based on an individual’s diagnosis. PPA is a rare disorder, thus there is a real need to cooperate across centres and internationally, with agreed uniform terminology and collaboration for intervention trials. This will be particularly important if speech and language therapy is to take its place as an adjunct to disease modifying therapies in due course.

It is also vital that future studies consistently report key intervention components. When compared to tools such as the TIDieR, the ITAX adaptation is superior, enabling comparison of both key intervention components, such as dosage, in addition to the content, mechanism of action, and goals of intervention (O’Rourke et al., 2018). Tools such as the ITAX adaptation will permit the investigation of links between core intervention components and outcomes in the longer term. Examining treatment response to FCIs across PPA variants may highlight different outcomes.

4.5 Conclusion
This systematic review of the literature highlights that, just as in stroke aphasia, building on existing strategies and practising these with a CP, are key components of FCIs for people with PPA. This provides guidance for the development of a new CPT intervention for people with PPA and their CPs, which will be the focus of the next chapter. Additional components, such as the optimal dosage, require further research. In order to fully appraise the effectiveness of FCIs future studies need to ensure comprehensive reporting of interventions,
using tools such as the adapted ITAX (O’Rourke et al, 2018) for guidance, as well as documenting PPA variant and using common outcome measures in order to aid comparison across studies. This provides helpful guidance for reporting of the pilot-feasibility study in Chapter 6 of this thesis.
Chapter 5 Development of the Better Conversations with PPA Intervention

This chapter describes the underlying theory and proposed mechanisms of change for the BCPPA program, a 4-session, manualised, CPT intervention to help people with PPA and their CPs identify and practice strategies to reduce barriers and increase facilitators in conversations. The aim of the intervention development phase was to define and refine a manual and an online learning resource hosted on UCLeXtend for SLTs. New primary research informed the co-production of the manual and online learning resource.

5.1 Method

Intervention development was based on stages one and two of the Medical Research Council (MRC) Guidance for complex interventions (Craig et al., 2008). This comprised six stages including examination of existing literature, consultation and co-production work, development of an initial draft, consensus work with SLTs, focus groups with people with PPA and their families in order to further refine the BCPPA intervention and manual in preparation for the pilot-feasibility RCT study (see figure 5.1 for an overview of the framework of development stages of the BCPPA intervention and manual drafting). Further public involvement (PI) work undertaken to finalise outstanding training modules identified as not essential to the delivery of this RCT will not be discussed here. All stages described were led by the author, an experienced SLT.
Examination of existing literature (stage 1)
- Bio-psychosocial model of Dementia
- Applied Conversation Analysis
- Behaviour change theory
- Self-management and self-efficacy

First draft of the BCPPA manual (stage 3)

Consultation and co-production work (stage 2)
- Co-production of intervention materials with BCPPA steering group.
- The steering group met a total of 12 times throughout the development process.

Consensus work (Nominal Group Technique) with SLTs (stage 4)
- 36 SLT participants recruited from the Dementia and Mental Health Clinical Excellence Network.
- Provided survey feedback on usability and used NGT method to identify 8 most important components of the BCPPA intervention.

Second draft of the BCPPA manual (stage 6)

Focus groups with people with PPA and their families (stage 5)
- Eight participants attended two focus group meetings.
- Participants discussed "How can speech and language therapists support people with PPA to live well and maintain relationships?"

Phase II Pilot-Feasibility RCT Study

Further PPI work to finalise remaining BCPPA modules

Future launch of BCPPA as part of UCLeXtend Website

Figure 5-1: Framework of development stages of the BCPPA intervention and manual drafting, based on the MRC guideline for development of complex interventions
5.1.1 Ethics

Consultation and co-production work (Stage 2): Ethical approval is not required when involving people in the planning or design of research for example when they are members of a research steering or advisory group (Health Research Authority., 2019).

Consensus work (Nominal Group Technique) with SLTs (Stage 4): The UCL Research Ethics Committee confirmed the NGT consensus work (Stage 4) with SLT participants to be service evaluation. Participants were informed that all responses would be anonymous and at the start of the event they signed consent forms.

Focus groups with people with PPA and their families (Stage 5): Camden and Kings Cross Research Ethics Committee (IRAS ID: 202353, Rec Ref: 17/LO/0357) approved the focus group study with people with PPA and their families. Informed consent was obtained by the author following the current guidance from the Mental Capacity Act (Department of Health, 2005) and RCSLT regarding gaining consent from people with communication difficulties. A caregiver (a friend or relative) was asked to witness the informed consent process whenever possible.

Participant information sheets, consultee information sheets, consent forms and consultee declaration forms (see appendices 5.1, 5.2, 5.3 & 5.4) were designed to be accessible to support the process of gaining informed consent. These were designed using a resource for researchers in communication disability “Engaging people who have aphasia” (Pearl, 2014) and modified with advice from the project steering group. Throughout the interactions with potential participants the author
used best-practice communication strategies: speaking slowly and clearly; repeating information where necessary; asking open as opposed to closed questions (Mental Capacity Act Code of Practice, Department for Constitutional Affairs., 2007, Chapter 3).

Transcriptions of the focus group data were anonymised during transcription via the allocation to each participant of a unique research number, used at all times. All names, places and personal information were pseudonymised.

5.1.2 Recruitment

Consultation and co-production work (Stage 2): An opportunistic sample of people with PPA and their families, specialist SLTs and neuropsychologists were invited to the project steering group. They were known to the author through her clinical work and her links with the PPA branch of the Rare Dementias Support Group based at UCL. The author emailed people who were known to her through clinical work, and asked the facilitator of the support group to forward an invitation email to individuals in the support group, inviting them to participate. Participants who replied expressing an interest attended the meetings, and were reimbursed for their travel. People with PPA and their families were additionally paid an honorarium.

Consensus work (Nominal Group Technique) with SLTs (Stage 4): SLTs were recruited to participate in the NGT consensus study through the RCSLT Dementia and Mental Health Clinical Excellence Network (CEN), of which the author was on the committee. Their twice annual study day event was advertised in the RCSLT Clinical Practice magazine (Bulletin) and via emails circulated to
CEN members 2 months prior to the study day taking place on Tuesday 16th May 2017 (see advertisement in appendix 5.5).

*Focus groups with people with PPA and their families (Stage 5):* People with PPA and their families who attend the PPA branch of the Rare Dementias Support Group based at UCL were invited to participate in one of two focus group meetings held at an accessible venue on the UCL campus (see advert in appendix 5.6). The aim was to recruit eight people to each focus groups, totalling 18 participants. Potential participants who responded to the advert were contacted by the author by phone for information to judge if they met the inclusion and exclusion criteria in Table 5-1.

**Table 5-1: Stage 5 Focus group inclusion and exclusion criteria**

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>(a) Diagnosis or possible diagnosis of PPA/Relative with a diagnosis or possible diagnosis</th>
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<tbody>
<tr>
<td></td>
<td>(b) Some ability to communicate and understand communication in order to participate in a focus group discussion</td>
</tr>
<tr>
<td></td>
<td>(d) Able to see and hear well enough to participate in a focus group</td>
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<td></td>
<td>(e) English as their language of daily use</td>
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<table>
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<tr>
<th>Exclusion Criteria</th>
<th>(a) History of brain lesions or major head trauma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(b) Major physical illness or disability which could impact on participation</td>
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</table>

Potential participants were invited to express their preferred group format for the focus group discussions; participants with PPA only, families only, or a mixed group. This type of purposive sampling strategy is good practice, allowing
participants to choose the most comfortable setting where they may be able to comment as freely as possible (Barbour, 2008). All participants chose to attend a mixed group. Given that people with PPA frequently experience fatigue and difficulties in sustained activity, the length and frequency of planned comfort breaks for each focus group session were adjusted to meet the needs of the individual group members.

5.1.3 Examination of existing literature (Stage 1)

Existing models of dementia, principles of applied conversation analysis (conversation analytic methods applied to intervention development and delivery, Wilkinson, 2014), behaviour change theory and frameworks for chronic disease self-management were examined. This informed the preliminary contents and focus of the intervention.

5.1.4 Consultation and co-production work (Stage 2)

Four people with PPA and their spouses, two expert SLTs and a neuropsychologist were invited to take part in twelve formal BCPPA PI steering group meetings. These focused on identifying what distinct training modules would be required for the BCPPA training resource, to be hosted on the UCLeXtend website, and co-producing modules and materials for the BCPPA intervention (see appendix 5.7 for an overview of each meeting). Steering group members were informed of the topic for discussion in advance of the meetings and invited to contribute in advance, during or after meetings using verbal, written or visual means e.g. bringing photos, drawing pictures or re-assembling draft materials. Video conferencing allowed people to participate in meetings when they were unable to attend physically, telephone calls and individual pre-steering
group meetings provided opportunities for those who found communicating in the group settings difficult to reflect on and contribute to ideas with scaffolding from the group facilitator (the author). Additionally, as part of the PI process less formal telephone conversations and teleconferences were held with three further people with PPA and their family members.

5.1.5 First draft of the manual (Stage 3)

A draft of the BCPPA manual was developed based on stages one and two of the framework (Figure 5-1). The author created the online materials using PowerPoint software, with assistance from SLT researchers and PhD students who were paid for their time. In order to upload these to the UCLeXtend website an online software called Articulate was used to adapt the PowerPoint slides to an appropriate format.

5.1.6 Consensus work (Nominal Group Technique) with SLTs (Stage 4)

Draft one of the manual was made available to a group of SLTs, who were attending a CEN day, to ensure the BCPPA intervention reflected a consensus view of the most important components to include in a CPT intervention for people with PPA and their families. SLTs were encouraged to review the resource and try it out with their clients. Given that many of the SLTs participating in the CEN day had pre-existing relationships that could bias discussions, a Nominal Group Technique (NGT) method was chosen to promote independent unbiased idea exploration, providing opportunities to weight ideas equally, yet allowing for clarification and discussion (Delbecq, Van de Ven & Gustafson, 1975).

Six weeks prior to attending the CEN day SLTs were sent an email inviting them to access the first draft of the BCPPA manual online in order to familiarise
themselves with it and to gather immediate feedback on usability of the manual. Participants were invited to anonymously complete a 12-item survey (appendix 5.8), hosted online via the Google Forms platform. Survey questions were developed by the author in consultation with the steering group. Reminder emails were circulated 4, 2 and 1 week prior to the event.

The NGT meeting itself comprised a two stage ranking process commencing with a 90 minute session on the afternoon of the CEN day (stage one), and follow-up via email (stage two). The session was led by the author, with the primary supervisor to co-facilitate. They agreed the session plan and central question for discussion in advance (see appendix 5.9), in line with Delbecq et al (1975) guidelines for conducting NGT meetings.

In the second stage results of the NGT meeting were circulated via email to all participants, providing information on the scores and mean rank for each of the items. As per guidance from Delbecq, et al's (1975) items describing the same ideas from the two groups were merged, following discussion and agreement between the author and primary supervisor. Participants were asked to reply via email identifying and ranking their top eight items from this list (by placing a number from 1-8 to reflect which is most important - 8 and least important - 1). As per Delbecq, et al's (1975) NGT guidelines, scores were tallied and mean ranking calculated to identify the top eight rankings overall.

5.1.7 Focus groups with people with PPA and their families (Stage 5)

Two focus groups were planned to provide people with PPA and their families the choice of attending a group with partners or a group without partners. All participants expressed no desire to attend a group with or without a partner,
prioritising convenience of date of meetings, thus groups were mixed to meet this need. Groups comprised between three and eight participants, allowing group members the opportunity to contribute (Barrett & Kirk, 2000). Discussion was guided by the question of how SLTs can support people with PPA to live well and maintain relationships. The focus groups were jointly facilitated by the author, alongside a volunteer student SLT from UCL. A topic guide was co-produced with the BCPPA steering group and attendees of the PPA branch of the Rare Dementia Support Group at UCL (see appendix 5.10).

Focus group discussions were video recorded and transcribed by UCL student SLTs (using the transcription guide from McLellan, MacQueen, & Neidig, 2003). Once the author was familiar with the transcripts (phase 1), the remaining five phases of thematic analysis were applied (Braun & Clarke, 2006). Initial codes were generated by systematically coding interesting features (phase 2), collating these into potential themes (phase 3) and reviewing them in relation to the coded extracts (phase 4). Potential themes were refined to generate definitions and names (phase 5). These named themes were inspected to identify and report any additional key elements (phase 6). In addition, to improve reliability of analysis, four researchers (primary supervisor and three other UCL researchers with experience of thematic analysis) independently extracted data from a randomly selected section of transcript. The researchers met as a group with the author to discuss the two transcripts and reach an agreement on the coding of themes arising from the data.

5.1.8 Second draft of manual (Stage 6)

A second draft of the BCPPA manual was developed based on stage 4 and 5 of the framework (Figure 5-1).
5.2 Results

5.2.1 Examination of existing literature (Stage 1)

As outlined in Figure 5-1 stage 1 of the intervention development process involved an examination of existing literature comprising the bio-psychosocial model of dementia, applied CA, behaviour change theory and self-management and self-efficacy theory.

5.2.1.1 Bio-psychosocial model of dementia

The bio-psychosocial model (Spector & Orrell, 2010) proposes that in both the biological and psychosocial domain there are factors other than the organic causes of dementia that influence the nature and speed of deterioration in daily functioning. These include some that are fixed (such as education and age) and cannot be changed, and tractable factors (such as coping mechanisms, the environment, and conversation), which may be amenable to change. Some tractable factors may be protective, resulting in better day to day function, whilst others may increase the risk of worsening day to day functioning. The difference between a person’s potential and actual functioning can be considered the excess disability (Spector & Orrell, 2010) and may be reduced by interventions that target factors affecting this gap. The BCPPA intervention seeks to take account of fixed factors whilst targeting tractable factors, by harnessing and enhancing protective factors such as use of gesture to enable the person with PPA to take or hold a turn. Also targeting change in those that have a negative impact, such as use of test questions by the CP that result in a loss of competence for the person with PPA, in order to improve a person’s actual functioning in conversation.

PPA variant is a fixed biological factor that BCPPA needs to account for, and
different variants are associated with different language and cognitive profiles (Marshall et al., 2018). This means that people with svPPA who commonly present with a loss of conceptual knowledge, are likely to have difficulties in generalising new knowledge whilst people with nfvPPA are less likely to experience this difficulty as they (initially) present with intact conceptual knowledge (Cadório et al., 2017). The BCPPA intervention manual takes this into account by providing opportunities for optional practice tasks, both during and outside of intervention sessions to support generalisation of learnt strategies.

Given that BCPPA is a form of CPT, the environment, specifically the CP, which is highlighted as a tractable psychosocial factor in the bio-psychosocial model, must be taken into account. The way in which a CP interacts with the person with PPA can result in a conversation breakdown, or can facilitate its continuation (Kindell et al., 2013). This experience may in turn discourage or encourage both the person with PPA or their CP. The BCPPA intervention directs the CP to identify the strategies they use that enable and facilitate conversation, as well as reduce their use of behaviours that act as barriers to participation in conversation, with the aim of building confidence.

Coping strategies and adaptive mechanisms are psychosocial tractable factors that are also amenable to change and can be both effective and ineffective according to Bahro, Silber and Sunderland (1995). The use of multiple questions, requests for repetition or test questions by a CP, who feels this provides a helpful practice opportunity but may result in the person with PPA feeling incompetent (Kindell et al., 2017), may be accounted for as an ineffective adaptive mechanism. Similarly the use of gesture, eye pointing, enactment (whole body gesture and pantomime) or circumlocution, when a person with PPA is having
difficulties retrieving the spoken word but wishes to continue a conversation (Kindell et al., 2013), could be described as an effective coping strategy. BCPPA aims to address this by supporting a person with PPA to reflect on the impact of effective mechanisms on conversation (potential function) with the impact of ineffective mechanisms on conversation (actual function), and then practice the use of effective mechanisms to achieve their potential function.

5.2.1.2 Applied Conversation Analysis

In order to understand which strategies and adaptive mechanisms are effective or ineffective BCPPA is informed by principles from applied Conversation Analysis (CA). CA is an approach to the study of human social interaction which assumes a fine-grained order underpinning all interaction and seeks to identify structures that underlie this through the analysis of spontaneous, natural occurring talk (Sidnell & Stivers, 2012). CA research has covered a breadth of interactions from those among children, to court room and healthcare settings (Sidnell & Stivers, 2012). There has also been a focus on examining atypical interactions in the CA research, such as between people with cognitive impairment or stroke aphasia and their CPs (Sidnell & Stivers, 2012).

CA considers conversation to be a dynamic flow of language and interaction between interlocutors (Kindell et al., 2017) and collates evidence about a speaker’s intention based on the response of their interlocutor in the conversation (Beeke, 2013). In a sequence of turns, each participant’s turn builds on the turn that went before it, and creates context for any turn that follows, thus contributing to the process of achieving mutual understanding (Beeke, 2013). Trouble and repair in conversation, where participants orientate themselves to something
within the interaction as troublesome or problematic such as a misunderstanding, overlapping speech or an overextended pause, and attempt to fix it, can be useful to examine in communication disorder. Repair may be initiated or completed by the self (the speaker of the trouble source) or by the other (the recipient of the trouble source). In everyday conversation there is an overwhelming preference for self-initiated, self-repair (Beeke, 2013). Repair mechanisms in communication disorders differ from typical interactions. In PPA they are not dissimilar to those in post stroke aphasia, and include an increased trajectory of repair over long sequences (Taylor et al., 2014).

CA studies in stroke aphasia have shown that many aphasic interactional behaviours arise from a desire to maintain conversational interaction and competence, rather than as a direct result of the language disorder (Beeke, 2013). Consequently, Wilkinson (2014) describes the development of a number of CA informed stroke aphasia intervention studies and clinical resources such as SPPARC (Lock et al., 2001) and BCA (Beeke Sirman, Beckley, Maxim, Edwards, Swinburn & Best, 2013). See Chapter 2 for a review of these studies. These CA informed interventions have in common the collection and analysis of video recordings of natural conversations between the person with aphasia and their CP, as a foundation for planning and targeting therapy (Wilkinson, 2014). The SLT (who typically delivers such an intervention) spends time analysing the video to identify behaviours resulting in trouble in conversation, barriers, and how both members of the dyad successfully resolve or circumlocute troubles to maintain interaction, facilitators. The process of identifying what to target in therapy focuses on what the dyad themselves orientate to as problematic, in order to ensure a meaningful outcome, often aided by eliciting their views after
playing them brief clips from their own recordings (Wilkinson, 2014). The aim is to increase the awareness of the impact of the behaviours in one of both members of the dyad, and agree a focus for therapy. Early work by the author of this thesis provides a number of examples such as identifying that when the CP gives the person with PPA more time to finish their turn, this is helpful in enabling the person to feel listened to, whilst interjecting when they have not finished may make them feel the opposite. Similarly, if a person with PPA does not participate in conversation, the CP may feel the person with PPA is no longer interested in talking to them, whilst use of gesture, nodding and minimal turns to convey engagement may demonstrate participation (Volkmer & Beeke, 2015). Once the focus of therapy is agreed, a process of practice, through role play and reflection, is usually employed (Wilkinson, 2014).

The BCPPA intervention is informed by this CA-underpinned approach to CPT. It makes use of video recordings of a person with PPA and their CP in everyday conversation. These are recorded by the dyad prior to participating in the intervention. The SLT uses the principles of applied CA to support clients to identify the behaviours themselves that act as facilitators or barriers in the conversation samples. The dyad are then guided to select communication strategies for practice during the intervention, and to target specific barriers they wish to eradicate. This approach ensures that the BCPPA intervention being delivered is grounded in the conversational experiences of the people with PPA and their CPs (Kindell et al., 2018).
5.2.1.3 Behaviour change theory

Recognising conversational barrier behaviours in video recordings of oneself and setting a goal to cease these or adopt facilitative strategies instead does not guarantee that a change in behaviour will occur (Beckley et al., 2013). Behaviour change theory, specifically the COM-B model (Michie, van Stralen, & West, 2011) accounts for an individual’s behaviour change as the product of three equally weighted components namely Capability, Opportunity and Motivation. According to Johnson, Best, Beckley, Maxim and Beeke’s (2017) exploration of behaviour change in a CPT, Capability includes the knowledge (awareness) and skills to carry out a behaviour such as increased awareness through watching video samples of a conversation, setting specific goals to increase the use of a facilitator, and increasing the ease of using a behaviour through practice. Opportunity encompasses the environmental elements that help or hinder a person from engaging in this behaviour such as practicing in the relevant environment. Motivation includes the brain processes that direct a behaviour including the strengthened belief in that behaviour, re-evaluating the purpose of that behaviour and a changed perception of success (Johnson et al., 2017).

The COM-B model can be used to identify the essential change processes of an intervention and the core procedures that serve them (Johnson, 2015). Johnson et al., (2017) examined video recordings of CPT being delivered to people with stroke aphasia and their CPs and used the COM-B model (Michie et al, 2011) to identify how these influenced successful behaviour change. The findings highlight seven core mechanisms underpinning conversational behaviour change, specifically the processes to motivate change and those that embed changes. These mechanisms include: 1) Change in conversation support for people with
aphasia’s strategies, whereby the CP prompts their partner to use gesture for example; 2. Increased awareness of own behaviour, such as watching video recordings to facilitate reflection of the impact of behaviours on others; 3. Replacing barriers with facilitators, such as replacing test questions with clarification questions; 4. Increased ease at implementing strategies through home based practice tasks between intervention sessions for example; 5. Changed expectation of behaviour’s impact, such as trialling strategies to demonstrate success; 6. Changed priorities for conversation, by, for example, discussion on the purpose of conversation i.e. eliciting accurate verbal communication versus interaction through any mode of communication; 7. Changed perception of success in conversation, for example by recognising success, which in turn boosts confidence. The BCPPA intervention incorporates the core mechanisms identified by Johnson et al. (2017) as essential to behaviour change in a CPT.

5.2.1.4 Self-management and self-efficacy

Increasingly, self-management is being used by healthcare providers working with people with chronic conditions (Turner, Anderson, Wallace, & Bourne, 2015). Self-management approaches support people to keep wellness in the psychological foreground. Central to this approach is the client as an active participant whose current status, just as hypothesised by the bio-psychosocial model, is not only influenced by diagnosis but by psychological responses and experiences. This means interventions should address the medical symptoms, but also the ability to self-manage daily activities and the emotional journey. Furthermore, self-management approaches are driven by what a client identifies...
as the area of meaningful change through joint goal setting and motivational interviewing (Yorkston, Baylor, & Britton, 2017).

Taking action to accomplish a plan is more likely to succeed if a person has the confidence or self-efficacy to achieve it (Lorig & Holman, 2003). According to Lorig & Holman (2003) self-efficacy is a mechanism that directs behaviour change, for if one feels in control of a behaviour it becomes easier to make the change in this behaviour. Yorkston et al (2017) highlight five core self-management skills and four key self-efficacy mechanisms that should be incorporated into SLT interventions with people with progressive communication difficulties and which have been considered in the development of the BCPPA intervention.

According to Yorkston et al (2017) self-management skills are:

1. Owning problem-solving skills: In BCPPA the SLT works as a facilitator, guiding the person with PPA and their CP to identify problems in their conversations, analysing video clips of their own conversations, and how they will address these, by setting their own meaningful goals for therapy.
2. Decision-Making: The person must have a good understanding of their condition and what to expect as it progresses. The BCPPA intervention provides opportunities to discuss how the progression of PPA will lead to continued changes in conversations.
3. Resources: Arguably a CP is one of the most useful resources for a person with PPA in conversation, thus including them in the BCPPA intervention should maximise the utility of this resource.
4. Relationships with healthcare providers: The BCPPA intervention includes the provision of information on future contact with SLT and support services.

5. Taking action: A large component of BCPPA includes practicing strategies, both within the therapy sessions and outside of therapy as part of home based tasks.

Yorkston et al's (2017) self-efficacy mechanisms are:

1. Performance mastery: BCPPA provides the opportunity for people with PPA and their CPs to practice strategies throughout the intervention period, strengthening their belief in their own ability to use these strategies.

2. Finding models: Including examples of experiences of other people with PPA and their CPs in the intervention materials provides models for people participating in the intervention.

3. Reinterpreting symptoms: By focusing on conversation as a dynamic flow of communication between two people, a person with PPA and their CP are re-orientated to understand that there may be multiple contributing factors impacting on their conversations.

4. Social persuasion: Involving both a person with PPA and their CP throughout the intervention enables mutual persuasion.

5.2.2 Consultation and co-production work with the steering group (Stage 2)

Work to develop the BCPPA intervention materials and training modules was informed by feedback from people with PPA who had previously received CPT, research undertaken by the author and research on the BCA for people with
stroke related aphasia (Beeke et al, 2013). First the BCPPA steering group were consulted on the training materials that SLTs will need. Seven subjects were identified, forming distinct training modules within the BCPPA program (see Table 5-2). Consequently, the author and steering group identified a timeline for development of modules required for the Phase II RCT Feasibility Pilot Study versus those only needed for the future launch of the online BCPPA program.

Secondly, results of a quality improvement project funded by Guys and St Thomas’ Charity were reviewed by the steering group (Volkmer & Beeke, 2015). This included suggestions that had been collected from people with PPA and their CPs who had received CPT using the BCA program (Beeke, 2013). This informed the decision by the steering group to develop a topic list for the Module 3: How to make a video, to support participants when making video recordings of conversations.

Next data collected in the UK wide survey of SLTs described in Chapter 3, and from the systematic review of functional communication interventions for PPA described in Chapter 4 was presented to the steering group. This data informed the decision to condense the components of the BCA intervention into four 1-hour sessions and provide more information on PPA in Module 5: The BCPPA therapy.

Suggestions from previous SLTs who were consulted on barriers to using BCA with people with stroke aphasia in clinical practice (Beckley et al., 2017) were discussed during the steering group meetings. Consequently the decision was made to create video samples, made by volunteers from the steering group, to provide examples of how to make a video, set up the optimal environment and select suitable clips to show clients in Module 3: How to make a video and Module
4: What to target in therapy.

Finally, formatting of all content was evaluated by the steering group to ensure information in the draft manual was presented in an accessible way for people with PPA and their CPs, including type of language used, formatting, and layout. This included decisions on the types of images used and the use of page borders on all handouts in Module 5: The BCPPA therapy.
<table>
<thead>
<tr>
<th>BCPPA training modules</th>
<th>Learning objectives for module</th>
<th>Co-produced module components</th>
<th>Development timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Module 1: What is PPA?</td>
<td>To explain what PPA is according to: People with PPA and their relatives who have worked on this module SLTs working in the area The research literature in this area</td>
<td>Co-produced with steering group. References selected by steering group.</td>
<td>Prior to launch of online BCPPA program</td>
</tr>
<tr>
<td>Module 2: What is conversation training?</td>
<td>To explain what conversation training is, based on interviews with: SLTs working in the area; People with PPA and their relatives who have worked on this module.</td>
<td>Co-produced with steering group Video clips planned, filmed and selected by steering group</td>
<td>Prior to launch of online BCPPA program</td>
</tr>
<tr>
<td>Module 3: How to make a video</td>
<td>• To have an appropriate tool available to gain consent for the purpose of videoing of a couple in conversation with one another to be used in the conversation training intervention, BCPPA. • To be aware of the MCA (2005) and how this will impact on consent. • For SLTs to be supported to make and store videos of conversation between a client and their conversation partner for the purpose of the BCPPA intervention. • To be able to set up an optimal environment for the purposes of making a video for the BCPPA intervention.</td>
<td>Co-produced work with the steering group included: a topic sheet to support participants in identifying what to discuss during video recording, example consent forms, video samples and formatting of module.</td>
<td>Prior to Phase II RCT Feasibility Pilot Study</td>
</tr>
<tr>
<td>Module 4: What to target in therapy</td>
<td>To understand the three stages of the goal setting process: 1) Identification of facilitators and barriers from pre-therapy videos 2) Selection of suitable video clips of appropriate length and focus to show clients, and 3) Negotiation of goals with a person with PPA and their conversation partner</td>
<td>Co-produced work with people with PPA included: video samples and formatting of module.</td>
<td>Prior to Phase II RCT Feasibility Pilot Study</td>
</tr>
<tr>
<td>Module 5: BCPPA therapy</td>
<td>To deliver the four BCPPA therapy sessions, supporting people with PPA and their conversation partners to:</td>
<td>Co-produced work with steering group included: Therapy handouts</td>
<td>Prior to Phase II RCT Feasibility Pilot Study</td>
</tr>
<tr>
<td>Module 6: Measuring it</td>
<td>To consider what options there are for measuring outcomes for BCPPA; To think about the pros and cons of different outcome measures; To consider how to use outcome measures in clinical practice.</td>
<td>Co-produced with SLTs working with people with PPA (local collaborators who participated in the Phase II RCT Feasibility Study)</td>
<td>Prior to launch of online BCPPA program</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Module 7: Useful Resources</td>
<td>To learn about some activities people with PPA enjoy; To find out about some useful websites and resources; To have thought about what has been useful in your therapy.</td>
<td>Co-produced with steering group Online resources selected by steering group</td>
<td>Prior to launch of online BCPPA program</td>
</tr>
</tbody>
</table>
5.2.3 First draft of BCPPA manual (Stage 3)

Based on an examination of existing literature (see Section 5.2.1) and consultation and co-production work (see Section 5.2.2) the first draft of the BCPPA manual and training program was developed. The BCPPA training program modules addressed the learning objectives through included activities and information to support SLTs to engage with and critically reflect on information provided to support their learning. Table 5-3 provides an overview of the content of each of the three modules. Module 5: the BCPPA therapy, hosted the BCPPA manual materials.

The BCPPA manual comprised session plans and handouts to accompany the session and home based tasks. Table 5-4 provides an overview of the aims, tasks and materials for each of the four BCPPA intervention sessions. The session plans outlined how to provide the person with PPA and their CP (referred to as a dyad) with information and education on conversation (what it is and how it works) in the first session. In session two the session plans explained how to support the dyad to reflect on a video sample of their own conversation to identify behaviours that facilitate or are a barrier to communication. Consequently the process of supported goal setting was explained, using Goal Attainment Scaling (Turner-Stokes, 2009), to identify target communication strategies which are then practised during activities, role play and homework tasks over sessions three and four. Finally, session plan four provided information on supporting the dyad to plan for future communication changes. Given the importance of tailoring interventions to the needs of the individual, identified during the examination of existing literature (stage 1), the session plans identified key components of the intervention versus optional, tailored components. Video-recorded conversation
samples, made by the person with PPA and their CP prior to receiving the intervention as per guidance from training Module 3: How to make a video, were used to provide clips for video feedback during sessions.

The first draft of the manual was uploaded to a dedicated BCPPA area on the UCLeXtend website. Despite not being publicly accessible, the manual was made available via a bespoke URL shared with SLTs participating in the stage 4 Consensus Work (Nominal Group technique), who could download session plans, handouts and homebased worksheets for review.
<table>
<thead>
<tr>
<th>Module</th>
<th>Overview of content</th>
</tr>
</thead>
</table>
| Module 3: How to make a video | Discussion of barriers to using consent forms  
Activity for user to identify local policy re consent  
Practical task to evaluate the accessibility of a consent form  
Provision of an example consent form  
Basic overview of key aspects of the MCA (2005) and the MCA Code of Practice (2007)  
Tips on creating accessible information and practical exercise to create a consent form  
Overview of functional capacity assessment from the MCA (2005) and case study of how to gain consent  
Common barriers to making videos in clinical practice  
Practical task to overcome barriers  
Tips on making a good quality video- using video samples  
Practical tasks on what to consider when making a good video- using video samples  
Tips and ideas to choose the topic of conversation for video recording |

**Summary: How to make a video**

The following diagram summarises the key steps that have discussed in this module.

**Part 1: Develop a tool to gain consent for video recording clients and their conversation partners for conversation therapy.**

**Part 2: Make and store a video of a client and their conversation partner in your work environment.**

**Part 3: Set up the optimal environment for the purposes of making a video for the BCPPA intervention.**
Module 4: What to target in therapy

**Summary:** What to target in therapy

1. Video-record 1-2 conversations of the person with aphasia and their partner.
2. Watch the videos and identify the facilitators and barriers.
3. Identify which facilitators and barriers to work on in therapy.
4. Select the best examples.
5. Preparing to show video clips.
6. Ready for agreeing goals.

An overview of what facilitators and barriers are
Examples of facilitators and barriers in conversations between a person with PPA and their partners
Video examples of PwPPA and their CPs and the barriers and facilitators that may arise and practical exercise to identify these
Tips on how to link barriers and facilitators to what to work on in therapy
Practical tasks on selecting and presenting the video clips to show PwPPA and their families
Things to consider when setting a goal
Practical tasks using example goals from therapists who have shared real goals that they set for people in therapy

Module 5: BCPPA therapy

**Summary of BCPPA therapy.**

The following diagram summarises the four sessions in BCPPA.

**Session 1:** What is conversation? Introduce the therapy and conversation
**Session 2:** Goal setting.
**Session 3:** Practice the strategies identified during the goal setting session
**Session 4:** Problem solving and planning for future changes in communication

Prompt / reminder to look at Modules 3 & 4
Sessions 1: provision of aims, sessions plan, therapy handouts and home-based tasks for PwPPA and CP
Session 2: provision of aims, session plan, therapy handouts and home-based tasks for PwPPA and CP.
Session 3: provision of aims, session plan, therapy handouts and home-based tasks for PwPPA and CP.
Session 4: provision of aims, session plan, therapy handouts and home-based tasks for PwPPA and CP.
<table>
<thead>
<tr>
<th>Session</th>
<th>Aims</th>
<th>Tasks</th>
<th>Materials</th>
<th>Theory/Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is Conversation?</td>
<td>Discuss aims of therapy Discuss and explore what conversation is and how it can go wrong Initial viewing of their own video</td>
<td>Give an overview of therapy Explanation of how conversation works Initial discussions and exploration of how PPA affects conversations Initial viewing of a video Home based task in preparation for next session</td>
<td>Session plan 1: What is Conversation? Handout 1: How does conversation work and what can go wrong? Homebased task 1: Your conversation troubles and repairs</td>
<td>Applied CA, Behaviour Change Theory Co-production of handouts</td>
</tr>
<tr>
<td>2. Goal Setting</td>
<td>Identify barriers and facilitators in their own conversation Set goals for therapy based on this discussion</td>
<td>View video of their own conversation Identify areas of strength and areas where there are problems in the conversation Identifying goals to target in therapy Home based task in preparation for next session</td>
<td>Session plan 2: Goal Setting Handout 2: Goal setting Handout 3: Strategies for the person with PPA Homebased task 1: A chance to practice some strategies</td>
<td>Bio-psychosocial model of dementia, Behaviour Change Theory, Applied CA Co-production of handouts</td>
</tr>
<tr>
<td>3. Practice</td>
<td>Practice conversation using the strategies identified during goal setting Problem solve any issues that have arisen in using identified strategies in conversations outside of therapy sessions</td>
<td>Role play or record the couple in the session practicing strategy use Identify when and where they will use these strategies at home and if not why not. Home based task in preparation for next session</td>
<td>Session plan 3: Practice Topic List Prompt Sheet Homebased task 1: A chance to practice some strategies Homebased task 2: Joining forces: Conversation strategy practice for both of you</td>
<td>Behaviour Change Theory, Self-management and self-efficacy Co-production of handout</td>
</tr>
<tr>
<td>4. Problem solving and planning for the future</td>
<td>Consider planning for future changes in communication Practice conversation using the strategies identified during goal setting</td>
<td>Role play or record the couple in the session practicing strategy use Review goals set in session 2 Discuss and plan for future changes in communication</td>
<td>Session plan 4: Problem solving and planning for the future Handout 4: Information for the future</td>
<td>Self-management and self-efficacy</td>
</tr>
</tbody>
</table>
5.2.4 Consensus work (Nominal Group Technique) with SLTs (Stage 4)

5.2.4.1 Demographics and characteristics of SLT participants

Thirty seven SLTs attended the CEN day. One attendee declined to participate in the NGT meeting, thus 36 SLTs took part. Of these, 17 had completed the pre-NGT meeting survey, 22 had viewed the first draft of the BCPPA manual and training program prior to attending as requested, and two had been able to use the BCPPA manual with a client with PPA. Table 5-5 presents demographics of the SLT participants and familiarity with the BCPPA manual and training program. Following the meeting, 20 participants completed the final NGT ranking task by email.

Table 5-5: Demographics of SLTs who participated in the NGT meeting and their familiarity with the BCPPA program

<table>
<thead>
<tr>
<th>SLT participants (n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (m:f)</td>
</tr>
<tr>
<td>2:34</td>
</tr>
<tr>
<td>Years practicing as an SLT (mean and range)</td>
</tr>
<tr>
<td>12.5 (0-21)</td>
</tr>
<tr>
<td>Number of clients with PPA seen in clinical career (mean and range)</td>
</tr>
<tr>
<td>9 (0-20)</td>
</tr>
<tr>
<td>BCPPA modules viewed online prior to meeting:</td>
</tr>
<tr>
<td>None but knows of BCA</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>Module 3 How to make a video</td>
</tr>
<tr>
<td>Module 4 What to target in therapy</td>
</tr>
<tr>
<td>Module 5 BCPPA therapy</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>11</td>
</tr>
<tr>
<td>22</td>
</tr>
<tr>
<td>21</td>
</tr>
<tr>
<td>22</td>
</tr>
</tbody>
</table>


5.2.4.2 Pre-NGT meeting survey

When asked what surprised them when they first accessed the online BCPPA program, five of 17 respondents commented on the level of detail as being surprising. Five respondents described the program as clear, easy to use and accessible, one person highlighted the comprehensive and detailed step by step
guidance. Four respondents stated that they were unsurprised by the BCPPA program, given their familiarity with the BCA program on which BCPPA is based. Two respondents reported surprise that it provided advice on how to make a video recording of conversation. Of the remaining questions which asked respondents to provide feedback on the BCPPA program, 17 replied to questions on the positives and negatives of each modules and what was most useful and deliverable. Sixteen provided feedback on formatting, 14 on additions or changes. Eleven provided suggestions and comments and 10 respondents identified the least useful aspects of the program. Four themes arose from this data: 1. General usefulness; 2. Specific ‘helpful’ tasks or sections; 3. Access issues ‘I had trouble with’; 4. ‘Could you add’; 5. ‘Not a fan’. These themes are illustrated with quotes in Figure 5:2.
Theme 1: General usefulness

Respondents made positive comments about the usefulness of the modules and intervention.

"Really easy to follow and would make using it easy and quick to prepare"

Theme 2: Specific 'helpful' tasks or sections

Respondents selected specific examples or particular elements they found useful.

"aphasia friedly consent form in really useful"

Theme 3: Access issues 'I had trouble with'

Respondents identified parts of the program they had difficulties using.

"the purple boxes didn't work"

Theme 4: 'Could you add'

Respondents made suggestions for things to add or change.

"page numbers would be handy"

Theme 5: 'Not a fan'

Respondents described things they did not find useful.

"It is not always possible to be prescriptive with conversation therapy"

Figure 5-2: Themes identified from survey responses in Stage 4 consensus work.
1. General usefulness

This theme captures the positive comments made about the usefulness of the BCPPA manual and training program. One respondent emphasised that in Module 3: How to make a video, it was “useful to highlight barriers that clinicians [SLTs] face to acknowledge and problem solve these”. Module 4: What to target in therapy, was praised for the “Comprehensive guidelines on what to target in therapy”. The step by step approach was felt to be an overarching strength of the entire program and particularly Module 5: BCPPA therapy, with its session plans. One respondent explained that the session plans in Module 5 were “Really easy to follow and would make using it easy and quick to prepare”.

2. Specific ‘helpful’ tasks or sections

Four respondents reported the aphasia friendly consent forms for video recording to be particularly useful. Three others emphasised that they found the examples of real-life therapy goals useful, one respondent explained that this was particularly useful “to know that I’m targeting similar aspects in my therapy with dyads with PPA”. Ten participants identified the session plans and handouts as useful. The video examples in Module 3, How to make a video, and Module 4, what to target in therapy, (see Table 5-3) were also identified as helpful.

3. Access issues ‘I had trouble with’

Respondents reported difficulties with the usability of some aspects of the modules, such as downloading documents in Module 5: BCPPA therapy. A number of respondents reported functional elements of the program as problematic for example “I had difficulties navigating from one page to the next
as the arrows were not always there”, “the slides moved too quickly” (the slides were put on a timer to move along automatically, if not done manually, after 10 seconds) and “the screen didn’t seem to fit the window”.

4. ‘Could you add’

This theme captures the suggestions made by respondents to improve the BCPPA manual and training program. One respondent suggested that “page numbers would be handy as personally I flick back and forth a lot”. Another respondent made a specific suggestion to expand the session plans to include “a few more examples of ways to practise the specific strategies”. When asked if respondents had suggestions for additional content for the modules and the intervention materials, five respondents identified more video examples, specifically of the intervention being delivered, as a priority. Additional suggestions included requests for examples of how to support people with PPA to be more independent, advice for clients on what to expect (with videos from people with PPA talking about living with PPA) and an overview of what PPA is, as well as information on services and resources to signpost clients to.

5. ‘Not a fan’

The final theme captured what respondents did not find useful in the BCPPA program. There were comments that much of the content was “common sense” and that the modules included “more content than needed, as most clinicians should know this information”. Module 3: How to make a video, was described as “very long”. One respondent expressed concerns that in Module 4: What to target in therapy, there was no guidance on what to work on when the clients did not
agree with the SLT “It is often hard to identify which barriers to work on, especially if the therapist feels there is a particular barrier present but the people with PPA or their partner does not want to work on this in therapy”.

Another respondent stated “I am not a big fan of the images” (these were sourced from Pearl, 2014). Additionally others raised concerns that the people they work with do not always have CPs available, and that the therapy is too prescriptive.

5.2.4.3 Nominal Group Technique:
As a result of two iterations of consensus work focused on the question “What components of the draft BCPPA therapy sessions are important for people with PPA and their conversation partners?” eight components were identified, and ranked in order of importance, see Table 5-6. (Appendix 5.11 provides the data from the first stage of the NGT rankings). The group identified the most important component to be a focus on people’s strengths, with these to be targeted in addition to areas of potential breakdown. This component included identifying facilitators and barriers to conversation through the use of video feedback. The second most important component was a tailored and person centred approach, including components such as goal setting, strategies, conversational topic, and practice opportunities. Getting a message across rather than focusing on a perfect interaction was ranked third.
Table 5-6: Final eight ranked components identified as important for the BCPPA program, from two stage NGT consensus work

<table>
<thead>
<tr>
<th></th>
<th>Use of video feedback to identify facilitators versus barriers in conversation when focusing on people’s strengths as well as areas of potential breakdown</th>
</tr>
</thead>
</table>
| 2 | Tailored and person centred:  
- goals,  
- conversational topics,  
- strategies  
- practice opportunities |
| 3 | Emphasising a focus on getting message across rather than a perfect interaction |
| 4 | Focusing individual attention on non-verbal communication strategies such as body language, gesture, facial expression and other methods of total communication. |
| 5 | Recognising and building on current communication strengths. |
| 6 | Working with both the person with PPA and the CP together. |
| 7 | Providing opportunities to practice strategies and get feedback from the SLT. |
| 8 | Providing an opportunity to discuss their communication difficulties |

5.2.4.4 Decisions made as a result of consensus work with SLTs:

The following decisions were made to further refine the BCPPA manual and training program (Table 5.8 describes how these were addressed in the second draft of the BCPPA manual -Stage 6):

- Provide more practice activities in the intervention materials.
- Provide more information on resources and other services
- Include more video examples of conversation breakdown between people with PPA and their CPs.
- Record and include video examples of the intervention being delivered.
- Include testimonies from people with PPA in Module 1: What is PPA? and Module 2: What is CPT?
- Address access and formatting issues within the website such as size of images, ensure all links are operational etc.
5.2.5 Focus groups with people with PPA and their families (Stage 5)

5.2.5.1 Demographics of participants

Thirteen participants, six people with PPA and seven family members, responded to the advertisement for focus group participants and were eligible for the study. Of these, all agreed to participate but one couple withdrew from the study the day before their focus group was held (the second focus group), due to a conflicting commitment. The remaining 11 participants attended two focus groups (group 1: seven participants; group 2: four participants). Participants represented all three PPA variants, as well as atypical mixed variants. Demographic information is outlined in Table 5-7.

Table 5-7: Demographic information for focus group participants

<table>
<thead>
<tr>
<th>Focus Group 1:</th>
<th>Person with PPA (PwPPA) and communication partner (CP)</th>
<th>PPA variant</th>
<th>Time since symptom onset</th>
<th>Time since diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PwPPA (m) + CP (f)</td>
<td>lvPPA</td>
<td>4 years, 3 years (9 years)</td>
<td>2 years (4 years)</td>
</tr>
<tr>
<td></td>
<td>PwPPA (f) + CP (m)</td>
<td>Mixed</td>
<td>5 years</td>
<td>4 years</td>
</tr>
<tr>
<td></td>
<td>CP (f)</td>
<td>nfvPPA</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>PwPPA (f) + CP (m)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Focus Group 2:</td>
<td>PwPPA (m)</td>
<td>lvPPA</td>
<td>4 years, 5 years (8 years)</td>
<td>1 year (5 years)</td>
</tr>
<tr>
<td></td>
<td>PwPPA (f) + CP (m)</td>
<td>svPPA</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>CP (m)</td>
<td>(Mixed)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PwPPA: person with primary progressive aphasia, CP: communication partner, lvPPA: logopenic variant primary progressive aphasia, svPPA: semantic variant primary progressive aphasia, nfvPPA: non-fluent agrammatic variant primary progressive aphasia

5.2.5.2 Themes arising from the focus group:

Three overarching themes emerged from the focus groups: 1) Timing of intervention, 2) SLTs’ understanding of types of dementia, and 3) Knowing what helps (see Figure 5:3). Theme 3 encompassed five further subthemes: ‘No one size fits all’, ‘I’ve discovered that’, ‘who’s targeted’, ‘therapy approaches’ and ‘toolkit’. These themes will be discussed in relation to illustrative units of data.
Figure 5-3: Themes and subthemes arising from focus groups with people with PPA and their CPs
1. **Timing of intervention**

This theme encompasses participants’ opinions on when they should have received input from SLTs, as compared to their experience of receiving input. Overwhelmingly participants felt SLT should have happened earlier than it did:

> Intervention needs to be relatively early in the cycle.”

(Participant F202, CP)

Many participants felt the intervention they did receive was too late:

> It was almost too little too late.  

(Participant F204, CP)

> I thought, my goodness, if we’d have had that, three or four years ago.

(Participant F202, CP)

It was felt that early intervention could have maintained language:

> If you can get in there with some tools that you specialise in that you think might be more valuable and they might be able to hold on to that for longer.

(Participant F204, CP)
Early intervention was also felt to reduce unnecessary distress:

Would probably save a lot of money and angst and … mental health problems and you know all the stress and stuff that’s goes alongside.

(Participant F106, CP)

The participants did emphasise that intervention should continue beyond the early stage:

I suggest 6 monthly check-ups. (Participant F106, CP)

In view of how the situation can change in PPA, ongoing intervention was identified as important:

And the situation now, 2 years on is completely different to how it was then anyway so anything that was useful then probably isn’t really very useful now. (Participant F106, CP)

Despite the emphasis on early intervention, one participant suggested that there was a period when speech and language therapy input wasn’t needed:

In the first 12 months there wouldn’t have been any point because she would have said well I know that’s a … that’s a cow, I know that’s an apple,
or whatever it might be but I would say after about 12 months might be the
time to start.  
(Participant F204, CP)

Two participants reported difficulties in accessing speech and language therapy
services altogether:

We’ve never been offered any of that.  
(Participant F103, CP)

I’ve tried. I’ve asked three times… no.  
(Participant F201, PwPPA)

2. **SLTs’ understanding of types of dementia**

Participants who had accessed speech and language therapy services reported
that SLTs often lacked an understanding of the different types of dementia,
particularly in regard to PPA:

I don’t know whether this SLT really understood what semantic dementia
was.  
(Participant F204, CP)

The level of ignorance about, PPA, amongst the speech and language
sorority, or fraternity, or whatever you call them and, as so often can
happen, if someone’s got their professional hat on, they won’t
acknowledge what they don’t know.  
(Participant F102, CP)
The lack of understanding was considered a barrier to receiving intervention and participants described this experience as demoralising:

The minute you say… right this is a case of dementia now there’s nothing in their toolkit at all… they’re just flummoxed.  (Participant F204, CP)

They just said, oh there’s nothing we can do for you. You know, you’ve got dementia, it’s getting worse. Bye. That was it. Very demoralising.

( Participant F103, CP)

However participants did emphasise that other professionals were equally uninformed about PPA:

Some GPs haven’t even heard of it and some local services have never dealt with it before.  (Participant F103, CP)

3. **Knowing what helps**

Knowing what helps was the broadest theme encapsulating the participant’s opinions and experiences of what helps and what could help communication. Five subthemes arose within this theme. ‘No one size fits all’ was a sub-theme that arose out of participants describing their experiences of being offered therapy that was not tailored to their needs:
They’re not like…just one size fits all they’re completely different.

(Participant F204, CP)

Many of the attendees had been living with their symptoms for years before they had been diagnosed or seen by an SLT, and had explored what worked themselves. The sub-theme ‘I’ve discovered that’ captures these successes:

I’ve discovered that when she says ‘everything’s bad’ it means she doesn’t like it.

(Participant F204, CP)

One participant explained how he learnt to work out his wife’s preferences despite her having an unreliable yes and no:

Faced with a problem you think to yourself what the answer is, ask yes no questions… but of course if you do that then… you’re struggling to interpret the answer you’re getting so you really need to get an answer 2 or 3 times consistently and then you’re pretty sure you’ve got it then.

(Participant F202, CP)

Another participant complimented his wife’s use of a notebook to write things down to communicate her message:
She took a lot of initiative in these things. She’s very resourceful.

(Participant F102, CP)

A recurring subtheme ‘Who’s targeted’ highlighted that CPs also need support:

A training course that carers could go on to just teach them some basic principles of how to communicate with someone who’s having difficulties would be so helpful.

(Participant F103, CP)

Participants understood this would not mean they could be trained as an SLT, just that there might be ways for carers to support their loved ones more effectively in a conversation. This quote is lengthy, but provides an illuminating example:

If there’d be some sort of basic training programme for carers, because, I appreciate it takes years to become skilled in your discipline, but basic skills of communication would be enormously helpful. To take an example, my dad. I don’t want to criticise him because he did so much for mum. But he has this annoying habit of asking her test questions. So if I phone up, and we’re on FaceTime so I can see them both. Even if mum can’t speak we can exchange glances, and he’ll do something like this. He’ll go what were we doing today? What did you have for your dinner? Now, she knows
what she did and she knows what she had for her dinner, and I just go, dad, uh, huh, and then I end up pulling a face at mum and poking my tongue out and doing this, or something, anything, to just, distract him from that, and to try and make her laugh to cheer her up. That's an example of something where...he obviously means well, and he's trying to draw out something from her, but it's not, it's not functional communication. It's just putting pressure on her, completely pointlessly as far as I'm concerned. So, some sort of training course that carers could go on that would just teach them some basic principles of how to communicate with someone who's having difficulties, and how to make it functional. And if you did it you could do it in quite large groups in fact. (Participant F103, CP)

Some participants felt involving other family was useful but highlighted that there is a limited budget for the SLT to work with others:

Do you think the speech therapist could help with children, friends and partners? (Participant FF201, facilitator)

I just don't think there's any economy for that. (Participant F104, PwPPA)

Another participant felt that by participating in the session, this may not be helpful for the SLT, and he didn't want to interfere in therapy tasks:
We’ve had two speech therapists actually. The first one, I was involved in the first two meetings. And then I asked whether they wanted me to be involved, or not, and they suggested perhaps not, because in the sense that, you might look to me to give a word, and I would give the word, and that may not be what the speech and language therapist wants to happen.

(Participant F105, CP)

Focus group participants made a number of suggestions for ‘Therapy approaches’ that were captured in subtheme four. Examples of this included providing people with options to choose from in therapy:

If we had an outline maybe just a list of ten points of what SLTs do that they can bring to the table on this then it would be [helpful] because crikey I didn’t know they did that.  
(Participant F204, CP)

Or a flow chart of ideas:

It’s really difficult to think about stuff by yourself. So, if you could have a clear, sort of, flow chart, of things, strategies you could try, that you could pin on the fridge, and you can go back to. As a carer, I think, that would be enormously helpful.  
(Participant F103, CP)
If they have difficulties with X, Y and Z try the notepad, or a flow chart.

(Participant F103, CP)

They felt that SLTs were vital to providing ideas such as technology and smart tablet apps:

If you don’t see a speech therapist then you don’t get these ideas (pointing to spouses smart tablet).

(Participant F102, CP)

They also identified that SLTs could provide specific exercises for word finding:

If the speech and language therapist could teach some sort of breathing technique perhaps to calm you, you know, when you’re searching for that word and a, perhaps a simple phrase that you could utter to say hang on a minute, I’m trying to get this word.

(Participant F104, CP)

And SLTs could support maintenance through therapy techniques, as well as providing suggestions for alternative communication:

I think… that the idea of maintenance… I don’t know that there’s much at a really deep level can be done but if there are techniques … where you
can hang onto things longer and perhaps sort out some key words and by practicing those lengthen the period of time which they’re available and usable. (Participant F202, CP)

Whether there’s a way of using noises not words but noises and sort of... trying to sort of say well this noise… means yes and that noise, you know… but substituting” “maybe something pictorial” “Or gestures I mean you… you’re using gestures a lot... you’re using gestures a lot and it is helpful I mean… it helps me… (Participant F202, CP)

The final subtheme reflects a recurrent idea the groups explored for a ‘toolkit’ to support SLTs to deliver services to people with PPA:

It would be great if you can come up with a package that could be taught to local services. (Participant F103, CP)

Participants suggested “some kind of living resource” or method of sharing knowledge:

Say a speech and language therapists going out to see someone with PNFA [progressive non-fluent aphasia is another term used for nfvPPA] and they can sort of you know send a round robin or send an email out to their colleagues in the area or maybe in the country like I’m going to see
somebody with PNFA I haven’t seen anybody with PNFA before any tips or hints someone comes back says well yeah I’ve got two… clients like that um… these are the sort of things which would be a real help so a sort of central repository I mean. (Participant F204, CP)

Participants also made specific suggestions, such as a care pathway to guide clinical practice:

Be great is if speech and language, is if you could classify people’s, um, difficulties, into, sort of clear, or, broadly, broad categories, un then for each category, you had a kind of strategic pathway they could be put on. So first of all, if they are, say they are early stage PPA.

( Participant F103, CP)

5.2.5.3 Decisions made as a result of focus groups with people with PPA and their families

The following decisions were made to further refine the BCPPA manual and training program (Table 5-8 describes how these were addressed in the second draft of the BCPPA manual -Stage 6):

- Provide more options on strategies and practice tasks in the intervention
- Provide a summary sheet including suggestions for future changes on one handout at the end of the intervention.
- Provide more information on how PPA impacts on communication
• Provide information for SLTs on what PPA is and what other SLTs are doing in routine clinical practice

5.2.6 Second draft of BCPPA manual (Stage 6)

Refinements that arose from stages 4 and 5 of the intervention development, included modifications and additions to content and delivery of the BCPPA manual and training program, and access and formatting within the website. These are presented in Table 5-8, alongside actions taken to address these. The addition of video recordings, demonstrating the delivery of the intervention had ethical implications, requiring a submission for a minor amendment to HRA ethical approval to video record a dyad receiving the intervention. Having received ethical approval for this amendment in July 2017, a dyad were recruited through an email advert to members of the PPA branch of the UCL Rare Dementia Support Group. After consenting to participate in the project, the dyad made four pre-intervention video recordings of their conversations, and received BCPPA therapy from the author. All four sessions were video recorded. The researcher then identified a selection of short video clips that illustrated key components of the intervention such as the process of supporting dyads to identify barriers and facilitators in their conversation sample, goal setting and discussion on future planning. The dyad viewed these clips prior to giving final consent for their upload to the online BCPPA program.

The remaining decisions outlined in Table 5-8, such as providing more options on strategies and practice activities, were presented to the project steering group where work to co-produce new handouts in preparation for the phase II randomised controlled pilot-feasibility study was prioritised. Access and
formatting issues, such as increasing size of window and improvement of wayfinding within the website, were amended by the author with assistance from PhD students and SLT researchers assisting in the development of the BCPPA manual and intervention.

The refined BCPPA program was consequently made available to participating local SLT collaborators on UCLeXtend as part of their training in preparation for delivering the intervention for the randomised controlled pilot-feasibility study. Further to this the project steering group made plans to continue working to co-produce the remaining modules in line with the project timeline (Table 5-2), in anticipation of a future launch to make the BCPPA program publicly available.

Table 5-8: Refinements for BCPPA manual and intervention

<table>
<thead>
<tr>
<th>Decisions made</th>
<th>Examples of refinements made</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide more options on strategies and practice activities in the intervention materials.</td>
<td>Addition of Homebased task 2: Strategies to help turntaking and expansion of session plan 3 to include a list of 11 optional additional strategy practice ideas based on ideas collated from SLTs, people with PPA and their families and a review of manuals for stroke related aphasia communication partner training manuals.</td>
</tr>
<tr>
<td>Provide more information on resources and other services.</td>
<td>Expansion of session plan 4 to include a list of resources and other services for SLTs making recommendations for the future.</td>
</tr>
<tr>
<td>Develop video examples of the intervention being delivered.</td>
<td>Addition of video recordings of conversation breakdown and intervention being delivered inserted to Module 5: The BCPPA therapy. These included: Session 1:</td>
</tr>
<tr>
<td>Include more testimonies from people with PPA in Module 1: What is PPA and Module 2: What is communication partner training?</td>
<td>Use of quotes to illustrate experience of communication facilitators and barriers in Module 4: What to target in therapy.</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Provide a summary sheet including suggestions for future changes on one handout at the end of the intervention.</td>
<td>Addition of summary handout for session 4: Handout 6: Your strategies</td>
</tr>
</tbody>
</table>
5.3 Discussion

The BCPPA manual and training program were developed according to the framework described in the MRC guidelines for development of complex interventions (Craig et al., 2008). The intervention content is underpinned by the biopsychosocial model of dementia, applied conversation analysis theory, behaviour change theory, and self-management and self-efficacy literature. Consultation and co-production work with the project steering group provided the first draft of the BCPPA manual and training program. Consensus work using a Nominal Group Technique with practising SLTs, and focus groups with people with PPA and their families identified areas for further refinement. These included additions to the manual, and modifications to improve access to and use of the materials on the website.

SLTs have described seeing people with PPA in their clinics who report feeling incompetent in conversations, whilst their CPs feel helpless to support them in these situations (Taylor et al., 2014). Addressing this by exploring meaningful strategies to maintain conversation via CPT involving both the person with PPA and their CP, has been recommended by expert SLTs (Kindell et al., 2015). The UK-wide survey reported in Chapter 3, demonstrated that SLTs working in PPA prioritise CPT over other intervention approaches, using tools from their experience of working with people with stroke aphasia. The BCPPA manual and training program address the gap in the SLTs’ toolkit, as described by participants in the focus groups in this chapter, of interventions for people with PPA, and provides an evidence based, manualised training resource designed for, and by, people with PPA and their CPs.
5.3.1 Strengths and Limitations

Drawing on the best available evidence and appropriate theory to develop the BCPPA manual, in accordance with MRC guidance, should increase the likelihood that components of the intervention result in behaviour change. Extensive use of theory has been associated with larger effect sizes in a review of online behaviour change interventions (Webb, Joseph, Yardley, & Michie, 2010). This work has involved new research with those targeted by the intervention as well as those delivering it. However, there are some methods limitations. NGT does not allow for anonymisation in the same way that other consensus methods such as Delphi methods do, and can thus bias the responses of the participants. Given the large participant numbers however, NGT provided a method of recruiting participants and incorporating mathematical voting techniques to aggregate group judgements (Delbecq et al, 1975). Making the intervention manual available for scrutiny of its plausibility for clinical practice has allowed for prioritisation of key components in anticipation of the phase II randomised controlled feasibility-pilot study.

Despite being a useful method for eliciting participant’s genuine and honest opinions, focus groups can also be challenging communication environments (Wilkinson, 1998). As an experienced SLT, the facilitator and the skilled student SLT co-facilitators role was to enable participants to contribute to discussion. Given this steering group was established a number of years prior to the recently published practice standards for PI it is likely that the methods employed may have limited the effectiveness of the co-produced work (Staniszewska, Denegri, Matthews, & Minogue, 2018). Some identified limitations of these types of groups have included the criticism that consulting with only a small number of individuals
(there were only three couples with PPA in the group) may have limited value. PPA, is however, a relatively rare condition and therefore people were approached to reflect the known diversity within the group, additionally new members were sought when others withdrew due to the disease progression and the author sought to gather perspectives of other people and their families through individual telephone contact.

A manualised approach enables standardised delivery of the intervention for a future trial. Given that Chapter 3 reports SLTs in clinical practice may have limited experience of working with people with PPA this helps to maximise ease of delivery for future implementation. However, a manualised intervention may limit possibility of tailoring an intervention for example not using video recording of the dyad in therapy or, delivering the intervention to a person accompanied by two CPs. Person centred components have been identified as important in Chapter 4 on functional communication interventions for people with PPA, and have been highlighted as important for behaviour change (Johnson et al., 2017; Yorkston et al., 2017). The development of this intervention did take behaviour change theory into account and embedded the core processes and mechanisms that had been identified in previous CPT research as essential components. These were clearly signposted in the manual and distinguished from the non-essential components that were amendable to tailoring. Furthermore, expecting four 1-hour therapy sessions to result in a change may seem ambitious. However, this decision was made as this was average number of sessions that SLTs in Chapter 3 reported having available to deliver functional communication interventions, and thus developing an intervention that met this requirement increases the chance of implementation. This serves to underline the importance of testing the
intervention procedures in an NHS setting, identifying an optimal outcome measure, determining a sample size and estimating recruitment requirements in a feasibility-pilot study prior to a full-scale evaluation of effectiveness.

5.4 Conclusion

The BCPPA manual and training program were developed according to the MRC guidelines for development of complex interventions (Craig et al., 2008). The six stage process undertaken to develop the intervention included a review of existing literature, consultation and co-production with the project steering group to develop an initial draft. Consensus work undertaken with SLTs and focus groups with people with PPA and their families identified further refinements. The BCPPA manual was then finalised in preparation for the phase II NHS based randomised controlled pilot-feasibility study, which will be presented in the next chapter.
Chapter 6 A randomised controlled pilot-feasibility study of the
Better Conversations with PPA communication partner
training program for people with PPA and their CPs.

The protocol for this study is published:


**Trial registration:**

Retrospectively registered 28/02/2018 ISRCTN10148247

https://doi.org/10.1186/ISRCTN10148247

The evidence base for CPT in PPA is limited, yet front-line SLTs favour this over word relearning interventions with a stronger evidence base. We presently lack evidence to guide effective CPT interventions in PPA. In response, the author undertook a research study to develop and pilot a communication skills training program for people with PPA and their CPs. In terms of the MRC guidance on development and evaluation of complex interventions, this chapter describes a Phase II randomised controlled pilot-feasibility study of the BCPPA program. The UK wide survey of SLTs described in Chapter 3 demonstrates that there is no standard speech and language treatment for people with PPA, thus it is not
possible to have a usual care comparison group for the study. Instead a no speech and language therapy treatment control group has been used. The trial conforms to the CONSORT (Consolidated Standards of Reporting Trials) guidelines (Eldridge, Chan, et al., 2016), and the SPIRIT (Standard Protocol Items: Recommendations for Intervventional Trials) statement (Chan et al., 2013).

Aim

The primary aim of this study was to pilot the BCPPA program compared to a no speech and language therapy treatment control group over participating sites to establish for a main trial whether BCPPA can be delivered as intended in an NHS setting. Specifically, the aim of piloting the BCPPA program was to establish:

1. predicted patient recruitment and retention rates
2. refined inclusion criteria
3. the acceptability of randomisation
4. an assessment of BCPPA treatment fidelity to determine necessary levels of SLT training
5. the most appropriate primary outcome measure
6. sample size calculation

6.1 Methods

6.1.1 Design

This was a single blind, randomised controlled pilot-feasibility study with BCPPA intervention program versus no speech and language therapy treatment, employing a randomisation ratio of 1:1. Participants were involved for a total of 6 weeks: pre-intervention measures (week 1); intervention/control (weeks 2-5);
post-intervention measures (week 6). This research study was granted ethical approval by London-Camden and Kings Cross Research Ethics Committee (reference: 17/LO/0357, received 26th April 2017).

6.1.2 Setting

The 11 participating NHS sites were located across England and Wales. Table 6-1 provides an overview of the characteristics of the participating sites. Local collaborators (SLTs) at these sites recruited participants, obtained consent, completed pre-intervention measures and delivered the BCPPA intervention.

Table 6.1: Characteristics of sites participating in the BCPPA pilot-feasibility RCT

<table>
<thead>
<tr>
<th>Characteristics of sites</th>
<th>Number of sites (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type of healthcare service:</td>
<td></td>
</tr>
<tr>
<td>General hospital and community health service</td>
<td>3</td>
</tr>
<tr>
<td>Specialist neurology hospital</td>
<td>1</td>
</tr>
<tr>
<td>Community health service</td>
<td>2</td>
</tr>
<tr>
<td>Mental health service</td>
<td>4</td>
</tr>
<tr>
<td>Mental and physical health service</td>
<td>1</td>
</tr>
<tr>
<td>Area serviced by the healthcare service:</td>
<td>1</td>
</tr>
<tr>
<td>National centre</td>
<td>5</td>
</tr>
<tr>
<td>Urban</td>
<td>5</td>
</tr>
<tr>
<td>Regional</td>
<td>5</td>
</tr>
<tr>
<td>Number of local SLT collaborators trained at each site:</td>
<td>3</td>
</tr>
<tr>
<td>1 SLT trained</td>
<td>1</td>
</tr>
<tr>
<td>2 SLTs trained</td>
<td>4</td>
</tr>
<tr>
<td>3 SLTs trained</td>
<td>1</td>
</tr>
<tr>
<td>4 SLTs trained</td>
<td>2</td>
</tr>
<tr>
<td>5 SLTs trained</td>
<td>2</td>
</tr>
<tr>
<td>Setting where patients with PPA are seen:</td>
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</tr>
<tr>
<td>Outpatient</td>
<td>5</td>
</tr>
<tr>
<td>Community</td>
<td>4</td>
</tr>
<tr>
<td>Both outpatient and community</td>
<td>4</td>
</tr>
</tbody>
</table>
6.1.3 Eligibility criteria

The study included adults (>18 years) with a diagnosis or potential diagnosis of PPA (in view of the difficult and often protracted diagnostic process). See Table 6-1 for inclusion and exclusion criteria.

Table 6-1: Participant inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>(a) Diagnosis or possible diagnosis of PPA (in line with international consensus criteria, Gorno-Tempini et al., 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(b) Some ability to communicate and understand communication in order to participate in the BCPPA program;</td>
</tr>
<tr>
<td></td>
<td>(c) Able to see and hear well enough to participate in the BCPPA program</td>
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<tr>
<td></td>
<td>(d) Functionally able to engage in the BCPPA program (i.e. able to maintain some concentration and remain in a 60-90 minute session, minimal challenging behaviour that would be unlikely to cause disruption)</td>
</tr>
<tr>
<td></td>
<td>(e) English as their language of daily use;</td>
</tr>
<tr>
<td></td>
<td>(f) Conversation partner (CP) available to and who consents to participating in the project.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exclusion Criteria</th>
<th>(a) History of brain lesions (tumour/stroke) or major head trauma;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(b) Major physical illness or disability which could impact on participation;</td>
</tr>
<tr>
<td></td>
<td>(c) Major psychiatric diagnosis;</td>
</tr>
<tr>
<td></td>
<td>(d) Prominent behavioural disturbance;</td>
</tr>
<tr>
<td></td>
<td>(e) Prominent episodic memory, visual memory or visuoperceptual impairments.</td>
</tr>
</tbody>
</table>

6.1.4 Identification and recruitment of participants

Local collaborators were asked to identify people referred to their service with a diagnosis or potential diagnosis of PPA who met the inclusion criteria, and to invite them to participate. People who met the inclusion criteria were not under any obligation to take part in this research and this was made clear from the outset. Potential participants and their CPs were provided with information sheets.
(see appendix 6.1 and 6.2) before informed consent was obtained at least 48 hours later (see Figure 6-1 for consent flowchart). Participant information sheets and consent forms were designed to be dementia friendly and modified with advice from the study’s steering group of people with PPA and their carers (see consent form and consultee declaration form in appendix 6.3 and 6.4 respectively). Local collaborators completed a log to record the number of people referred to their service with a diagnosis or potential diagnosis of PPA (see appendix 6.5) who did not meet the inclusion criteria. They also recorded the number of people who were eligible, but who declined to participate in the study and their reasons why, if provided. This information was used to supplement recruitment and retention data.
The study aimed to recruit people with mild to moderate stages of PPA, and therefore, were generally competent to give informed consent to participate, provided that appropriate care was taken to explain the research and sufficient
time was allowed for them to reach a decision. Due to the brief nature of the involvement in the study (6 weeks) it was not anticipated that decision-making capacity would change over this time, however this was monitored by the local collaborator who obtained consent following the Mental Capacity Act (MCA, 2005), RCSLT guidelines, and Good Clinical Practice Standards. The local collaborators were specialist SLTs with considerable experience of supporting individuals with communication and cognitive impairment, and they completed annual mandatory training on the MCA and issues related to obtaining consent. If a local collaborator had any doubts regarding the capacity of a person with PPA to provide informed consent, advice was sought from the author, or an appropriate professional involved in their care, e.g. the GP, as is standard practice.

6.1.5 Randomisation
Randomisation was conducted by a member of the team not involved in data collection or intervention delivery, to ensure blindness, using a random number generator and stratified by site using blocks of four to balance across the BCPPA intervention and no speech and language therapy treatment control groups within each site. Block sizes were not disclosed to local collaborators. Local collaborators were informed of participant group allocation by telephone by the author after pre-assessment had been completed.

6.1.6 Blinding
Post-intervention measures were administered by pairs of junior researchers (student SLTs at UCL) after undergoing training (see 6.1.11), but crucially blinded to group allocation. Participants and CPs were asked not to reveal their group allocation to the junior researchers during the post-intervention assessment.
session. They were reminded of this prior to their appointment, by letter or phone, and verbally at the start of the session. If the junior researchers became unblinded during the reassessment process, this was documented and the reasons recorded.

6.1.7 Sample size justification
As there were no data available to estimate the sample size, the recruitment of participants was dealt with pragmatically. Based on discussion with clinicians at the primary research site, it was originally estimated that it would be possible to recruit 42 participants over an 18-month period at three research sites in England. Recruitment was reviewed at 2-month intervals during the study and the strategy amended as necessary. Recruitment was slower than anticipated and complicated by changes in staffing and service delivery models with the local speech and language therapy departments. As a result further research sites were identified and added to the study, resulting in a final total of 11 research sites across England and Wales. Additionally the recruitment period for the study was extended. Based on slower than anticipated recruitment and time limitations in relation to collation of data, a sample size of 20 was identified for the purpose of the thesis.

6.1.8 Pre- and post-intervention measures
Participants dyads completed pre-intervention language, communication and quality of life measures with the local collaborator in week 1 of the study. All measures were repeated after intervention at week 6 by pairs of junior researchers. Additionally participant dyads randomised to the BCPPA intervention arm of the study completed Goal Attainment Scaling (GAS; Turner-Stokes, 2009) during the intervention itself. Participant dyads wrote goals with
support from the local collaborator during session 2 (see Chapter 2, Table 3-1) and weighted the goals according to their importance and likelihood of being achieved. All goals were given a baseline rating of -1 and at the end of therapy the goals were reviewed and an outcome score given by the participant dyads in agreement with the local collaborator. Table 6-3 summarises the schedule of pre- and post-intervention measures.

Table 6-2: Schedule of pre-and post-intervention measures

<table>
<thead>
<tr>
<th>Week</th>
<th>Consent session</th>
<th>Pre-intervention Assessment (1 week)</th>
<th>Treatment/Control (4 weeks)</th>
<th>Post-intervention Assessment (1 week)</th>
<th>Final data collection</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2 3 4 5</td>
<td>6</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>Conversation</td>
<td>1a 2i 3i</td>
<td>4a</td>
<td></td>
<td>5a</td>
<td>6i 7i 8i</td>
</tr>
</tbody>
</table>

Conversation video recording: a – assessor present but not in room; i – independent home recording

In order to objectively rate PPA variant and severity, language measures were included. Data on various outcome measures were collected to assess appropriate outcome measures to be used in a large-scale trial. Communication measures provided objective data, examining change in presence of conversation behaviours in a video recorded conversation sample. Given the aim of the BCPPA program to reduce the impact of PPA communication difficulties as well as improve quality of life, a range of quality of life measures were identified from the stroke aphasia and dementia literature. These were all validated and widely used in clinical practice. (Table 6-2 provides a description of the outcome measures)

---

7 Importance is rated as 3 = very, 2 = moderately, 1= a little, similarly likelihood is rated as 3 = very, 2 = moderately, 1= a little
8 Outcomes were rated on a basis that 0 = achieved goal as expected, -1 = less than expected, -2 = much less than expected, +1 = more than expected, +2 = much more than expected
In a protocol based on that used in the CPT evaluation study of Best et al (2016) four 10-minute baseline conversation samples were video recorded (the communication measure). The first (sample 1a) was recorded in week 1 with the assessor present but not in the same room. At this session participants were trained to independently use an iPad to video record two further conversation samples independently at home (2i and 3i). The final baseline recording (4a) was made in week 1 at the pre-intervention assessment session. Four post-intervention conversation samples were recorded, one in week 6 (5a, assessor present but not in the room) and three independently recorded at home in week 7 (samples 6i, 7i and 8i). A conversation topic list was provided to support this process should the dyad require it. Conversation samples were not analysed for this thesis.

Table 6-3: List of outcome measures

<table>
<thead>
<tr>
<th>Language measures:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><em>PwPPA</em></td>
<td>Comprehensive Aphasia Test (Swinburn, Porter, Howard, 2004)</td>
</tr>
<tr>
<td></td>
<td>This language battery provides a profile of performance across all modalities of language production and comprehension. This is a standardised formal assessment scored by the expert SLT assessor, providing a score for each item and subtest, as well as composite scores across subsections including comprehension of spoken and written language, repetition, expression, writing and reading aloud. Higher scores represent a better outcome. Chosen because it is the most commonly used language assessment used by SLTs as identified in the chapter 3 UK-wide survey.</td>
</tr>
<tr>
<td>Communication measure:</td>
<td></td>
</tr>
<tr>
<td><em>PwPPA and CP</em></td>
<td>Video recordings of conversation samples</td>
</tr>
<tr>
<td></td>
<td>This informal measure adapted from the Aphasia Conversation Measure (Best et al., 2016) identifies barriers and facilitators to conversation between the person with PPA and their CP and assesses changes in conversation behaviours after intervention. A decrease in barriers and an increase in facilitators represents a better outcome.</td>
</tr>
<tr>
<td>Quality of Life measures:</td>
<td></td>
</tr>
<tr>
<td><em>PwPPA</em></td>
<td>Dementia Quality of Life Measure (Mulhern et al., 2013)</td>
</tr>
<tr>
<td></td>
<td>This 29-item questionnaire is designed to ask people with dementia to rate their quality of life across the three main domains of feelings, memory and everyday life using a rating scale from 1-4. Higher</td>
</tr>
</tbody>
</table>
scores represent a better outcome. This was chosen as it has been previously used as an outcome measure for a complex intervention in dementia.

<table>
<thead>
<tr>
<th>PwPPA</th>
<th>Communication Confidence Rating Scale for Aphasia (Babbitt et al., 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>This is a ten-item questionnaire of communication confidence that uses a self-rating scale from 0-10 designed for people with aphasia. Higher scores represent a better outcome. This was chosen as it has been previously used as an outcome measure for a pilot intervention study for PPA (Rogalski et al., 2016).</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PwPPA</th>
<th>The Aphasia Impact Questionnaire (Swinburn, 2013)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A tool designed to measure the impact of living with aphasia across three domains of communication, participation and emotional well-being. The participant rates their response to 19 questions on a scale from 0-4 represented pictorially in an accessible format. Lower scores represent a better outcome. This was chosen as it measures similar concepts to the CCRSA but was co-developed by people with aphasia in the UK.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CP</th>
<th>Perceived Stress Scale (Cohen, Kamarck, &amp; Mermelstein, 1983)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>This is a ten-item self-report questionnaire for measuring the respondent's perception of stress. CPs rate their answers on a scale of 0-4. Lower scores represent a better outcome. This was chosen due to its superior psychometric properties</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CP</th>
<th>Zarit burden interview (Zarit, Orr, 1985)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>This is a 22-item caregiver self-report questionnaire for measuring personal and care strain. CPs rate their answers on a scale of 0-4. Lower scores represent a better outcome. This was chosen as it was specifically designed to measure burden of carers for dementia.</td>
</tr>
</tbody>
</table>

6.1.9 Description of the intervention

6.1.9.1 BCPPA program

BCPPA provides a protocol for SLTs to deliver a four-session communication training program for people with PPA and their CPs. Participant dyads’ pre-intervention video-recorded conversation samples were used to provide clips for video feedback during intervention sessions. The manual was made available to local collaborators online. The development of the intervention is described in detail in Chapter 5, an overview of the four sessions and their aims in presented in Table 5-3.
6.1.9.2 No speech and language therapy treatment

Given the results of the UK-wide survey presented in Chapter 3 of this thesis that highlight there is no standard speech and language treatment for people with PPA, a no treatment control group was selected. In fact, this survey highlighted the difficulties for many people with PPA in the UK in accessing speech and language therapy, thus a no treatment control group is not dissimilar to usual care. Word relearning seems an obvious alternative control, given the amount of research evidence in this area (see chapter 4). However, as Cadorio et al (2017) highlight, people with different PPA syndromes require different word relearning interventions, thus this approach would lack homogeneity as a control condition in the BCPPA pilot-feasibility study. An alternative more homogenous social control would be challenging, as it is difficult to disentangle the active ingredients of CPT from an attention control group, e.g. activities to promote social interaction. The use of a no treatment control is in line with other RCTs for people with dementia (CST, Spector et al, 2003) and stroke aphasia trials (Brady et al, 2016).

Those participants assigned to a no speech and language therapy treatment condition received usual healthcare provision (anticipated to include neurology, GP reviews, and allied health input such as physiotherapy). However, speech and language therapy intervention was excluded for the duration of their participation in the study. The period of no speech and language therapy treatment was 6 weeks (4 weeks when the treatment group received BCPPA, and 2 weeks when both groups completed pre- and post- intervention assessments). As there is no critical period for treatment delivery for people with PPA, after 6 weeks the participants allocated to the no speech and language
therapy treatment group resumed all aspects of local speech and language therapy provision without further interruption.

6.1.10 Assessment of acceptability of the intervention

In order to ensure the treatment was acceptable to people with PPA, their CPs and local collaborators, they were each asked to provide feedback. Accessible feedback forms (see appendix 6.6) were given to participants with PPA and their CPs at every intervention session, to be completed jointly by the dyad and returned anonymously in pre-stamped addressed envelopes directly to the author. Feedback forms comprised 13 questions, including closed questions (multiple choice and ratings) for speed of response and open questions to elicit additional information. Local collaborators were also asked to include feedback on acceptability as part of a fidelity questionnaire, completed after every intervention session (see Section 6.1.12 for details).

6.1.11 Training of local collaborators

Local collaborators were trained to deliver the BCPPA program by the author and were given access to the online BCPPA manual and training resource as well as being provided with a training package including all required materials. Junior researchers received the same training package so they were able to complete post-intervention assessments (see Section 6.1.8). Table 6-4 presents an overview of training content.
Table 6-4: Overview of training of local collaborators delivered over 2 days, in 4.5 hour sessions.

### Training goals

For local collaborators to be able to:

- Identify potential participants who meet the study inclusion criteria
- Consent participants to the study
- Deliver the BCPPA program
- Complete pre-intervention measures
- Complete fidelity measures
- Access the support and advice of the author throughout the study

### Pre-training work

- Pre-training local collaborators were given access to the online BCPPA manual and training resource and sent reading materials from the Study Training Pack. Pre-training work required local collaborators to review:
  - Study inclusion and exclusion criteria,
  - Diagnostic criteria for PPA (Gorno-Tempini et al., 2011),
  - Online BCPPA Module 3, How to make a video,
  - Online BCPPA Module 4, What to target in therapy,
  - Online BCPPA Module 5, BCPPA therapy.

### Day 1. (4.5 hours)

- Review study procedures
- Discuss inclusion/exclusion criteria with vignettes to problem solve
- Discuss consent procedures and flow chart with accompanying case study
- Discuss purpose and process of video recording conversation samples as an outcome measure and to support intervention
- Practice video recording of conversation samples
- Observe sample video recordings and identify barriers and facilitators to conversation with a view to planning intervention

### Day 2. (4.5 hours)

- Discuss and practice completing formal outcome measures
- Discuss therapy sessions and practice completing notes boxes on session plans e.g. writing down what video clips they would show in session 1 and 2, circling the choice of activities for session 3 and what further information they would provide in session 4.
- Complete a role play task from the BCPPA intervention session plans to introduce the discussion on what conversation is.
- Observe and discuss BCPPA training video recordings demonstrating delivery of intervention, including goal setting and dealing with emotional therapeutic interactions
- Discuss fidelity measures (video recordings, local collaborator fidelity questionnaire and participant feedback questionnaire)
- Provide researcher contact information for ongoing support

Some pragmatic decisions were made about necessary variations to timing of training delivery, for example the furthest site received the training in two 4 hour sessions delivered over one day.
6.1.12 Assessment of treatment fidelity

Fidelity of treatment delivery refers to the extent to which the treatment was delivered as intended, and is important to help understand whether a planned intervention is effective (Borrelli, 2011). In order to allow for investigation of treatment fidelity, all local collaborators were asked to video or audio record themselves delivering BCPPA intervention sessions with all participant dyads. Local collaborators were given support and feedback from the author during delivery of the intervention either by telephone, email or video conferencing to ensure knowledge and skills from training were maintained. This included the author remotely viewing video recordings of their first BCPPA intervention session and providing feedback.

Although fidelity data is sparse for speech and language intervention trials, processes such as those deployed in our study have been shown to achieve an average 80%-100% fidelity (Heilemann, Best, Johnson, Beckley, Edwards, Maxim, and Beeke, 2014; Holland, Watkins, Boaden, & Lightbody, 2018; Whitworth et al., 2015). Thus, we selected 80% as the minimum target for fidelity.

In line with recommendations for measuring treatment fidelity (Walton, Spector, Williamson, Tombor, & Michie, 2019), a random sample of 20% of these session recordings were chosen for analysis, using a random list generator. This sample comprised data from eight intervention sessions, i.e. the complete set of four BCPPA intervention sessions delivered by two different SLTs to two different participants. Using methods for developing measures of fidelity for complex interventions (Walton et al., 2019) data were analysed using a fidelity checklist and a coding manual. These were developed from the BCPPA intervention manual by two UCL student SLTs as part of their masters dissertations,
supervised by the author, her primary supervisor and a UCL colleague with expertise in treatment fidelity. These same students acted as independent raters, double coding 100% of the sample. Any coding discrepancies were discussed and raters came to an agreement in order to ensure reliability.

Local collaborators were also asked to reflect on their own fidelity to the intervention manual by completing a questionnaire after each session (see appendix 6.7). This included closed questions on session length, tasks completed and ratings of participant interest and enjoyment, with additional open questions to elicit further details. These were to be completed and returned anonymously in pre-stamped addressed envelopes directly to the first author.

6.1.13 Data management

Participant dyads were given a unique number which was used to store all information on diagnosis, medical and social history and on all paperwork including assessment score sheets and in the names of all video files, and in all subsequent analysis documents and publications. At each NHS site the local collaborator stored a list of the participant names and their unique numbers (required to conduct the remote randomisation procedure) in a locked cabinet. Each list only contained the names of participants based at the relevant site.

Participant dyads consented to be video recorded in conversation for the purposes of outcome measurement, and to provide clips for video feedback during intervention sessions. Only the author, her supervisors and the junior researchers had access to the video data set. Where conversation data were transcribed for evaluation, they were anonymised through the use of pseudonyms for all named people and places. Participants’ faces are fully visible in these video
recordings as facial expression forms a significant part of natural human communication, the focus of this intervention. As a result, while confidentiality could be guaranteed in the use of footage for presentations, the preservation of anonymity was not possible. Judicious selection of recordings minimised this risk (e.g. footage where personal details were discussed was not used and names were blanked out of the audio stream). Participants and their CPs were asked whether they were willing to accept the possibility of being recognised by consenting to use of their video data for presentations. If not they could choose to opt out of use of their data in this way whilst remaining part of the study.

6.1.14 Data analysis

Criteria to proceed to a full trial were identified in advance of the study as:

- patients and local collaborators report generally positive views about the acceptability of randomisation, and of the intervention, as determined by evaluation of feedback forms;
- a suitable sensitive outcome measure is determined, and sample size estimated;
- local collaborator intervention fidelity rate is at least 80%.

Descriptive statistics were used to report recruitment, attendance, and attrition data including reasons for dropout. Participant dyad feedback and fidelity data was reported using descriptive statistics and narrative data.

Outcome measure data were entered into a database and analysed using the Statistical Package for the Social Sciences version 25 (IBM, 2011) and the G*Power 3.1 software (Faul, Erdfelder, Buchner, & Lang, 2009). The guide to using GAS provided guidance on calculating the baseline and attainment score.
(Turner-Stokes, 2009). Data from GAS scores were entered into an excel spreadsheet, the weighting was calculated by multiplying the importance rating by the difficulty rating. The extent to which each dyad’s goals were attained was calculated using a standardised formula: GAS score = \[
\frac{50 + 10 \sum (w_i x_i)}{0.7 \sum w_i^2 0.3 (\sum w_i)^2}^{1/2},
\]
where \(w_i\) = weight assigned to the goal and \(x_i\) = the attained score for the goal. In this study, all goals were assigned a baseline of -1 and both a baseline and attainment GAS score calculated using the above formula.

A minimally clinically important difference (MCID) is defined as the smallest change between two scores that is subjectively meaningful to patients (Peto, 2001). It was not possible to use the MCID to inform the exploration of the most suitably sensitive outcome measure as a MCID has not previously been established for any of the measures used in this study. Consequently a sample size calculation was conducted. To inform a sample size calculation the mean pre and post intervention scores, and a mean change score, 95% confidence intervals (CI) and standard deviations were calculated for each measure. The mean change scores and standard deviations were entered into G*Power software and an effect size calculated, this then informed a two tailed sample size calculation for each measure.

It is not considered appropriate to report effectiveness calculations for pilot-feasibility studies as these are considered underpowered and unrepresentative (Eldridge, Lancaster, et al., 2016). However for the purposes of this thesis participant outcomes data will be explored, acknowledging the limitation of a small and heterogeneous sample. Data were analysed using ANCOVAs, where assumptions of the general linear model were violated a viable non-parametric
equivalent was sought, but none were available. ANCOVAs compared BCPPA versus no-speech and language therapy group performance on each measure post-intervention, incorporating baseline score on the relevant measure as covariate.

6.2 Results

The data reported here were collected over a 23-month period from November 2017 to September 2019.

6.2.1 Screening, recruitment and retention

Of the 11 research sites participating in the study, four had to pause their involvement in the study on one occasion, one site had to pause involvement on two occasions and eventually discontinued participation as a research site. Of the 31 SLTs trained as local collaborators eight left their positions or were unable to continue as local collaborators.

Fifty nine people were screened for potential inclusion in the study from 11 sites between November 2017 and September 2019. Of the 59 potential participants 23 were excluded as they did not meet the inclusion criteria, 11 declined to participate in the study, despite being eligible, and five were excluded for other reasons (see Figure 6-2). Of the 20 participant dyads who were deemed eligible and consented to participate in the study, two withdrew from the study immediately after the pre-assessment process reporting that it was too difficult. These 20 participant dyads were recruited from seven research sites. Eighteen participant dyads were randomised and completed the study. Junior researchers who completed the post-intervention assessment with all 18 participant dyads remained blinded to randomisation for 15 of these assessments. On two
occasions the participant dyads revealed their allocation prior to assessment and there was one occasion where participant dyads informed the junior researchers of their allocation at the completion of the assessment.

Figure 6-2: Participant flow through study
6.2.2 Acceptability of randomisation

6.2.2.1 Acceptability to participant dyads

All participant dyads who were randomised to the BCPPA intervention group completed and returned anonymised feedback forms following each intervention session (see Appendix 6.6).

6.2.2.1.1 Explanations, format, delivery and expectations of the intervention

Participant dyads rated the explanation, format and delivery of all sessions between three and five out of five, although ratings increased as therapy progressed, with session 1 scoring an average of 4.5 compared to an average of 4.7 for session 4 (see Figure 6-3). Similarly, the participant dyads’ expectations of intervention changed over time. At the start only four of the nine dyads reported that session 1 was what they had expected, but by session 4 all dyads reported the session met their expectations. Only one suggestion was made of an addition to the intervention: “to be told how to find alternative words when stuck”.
In summary, dyads across all four sessions rated 92% the intervention as useful. Sessions 3 and 4 were unanimously considered useful by all dyads, session 1 considered useful by 78%, and session two by 89% of dyads. One CP felt the introductory session to be “juvenile” and another felt their partner with PPA had not understood it. Two dyads commented specifically on the utility of watching the video clips of themselves and the handouts. Video-feedback was considered useful throughout the intervention by 69% of dyads. One respondent explained that “When we speak we don’t realise how we talk - the slowness, the actions we do. Watching the video made us realise this”. Technical issues with the volume of the videos was reported as problematic by one dyad, and another reported that the person with PPA did not wish to see herself on video.
Seventy-five percent of dyads reported that the homework tasks were useful. One explained that “it gave us a chance to discuss things together and relate to the problems we are facing together - to put our views down on paper - it’s given us more ways and ideas to get around some of the problems”. However another reported: “my wife’s lack of interest and her general apathy mean it is difficult to engage fully with the homework task”.

6.2.2.1.2 Reported improvements as a result of the intervention

Dyads were asked whether each session improved their (i) knowledge and understanding of PPA, and their (ii) communication skills. By session 4, 56% of participant dyads rated both domains as improved, and only 11% rated no improvement in either (see Figure 6-4).

Figure 6-4: Participant dyad’s ratings of whether BCPPA interventions sessions improved their (i) knowledge and understanding of PPA, and their (ii) communication skills
Participant dyads were asked whether therapy was helpful, and if they had made any changes in their communication since starting therapy. After session 1 56% reported it was helpful and 44% that they had made communication changes. By the end of therapy 89% reported that therapy was helpful and 100% that they had made changes (see Figure 6:5).

![Bar chart showing participant dyad's ratings of whether BCPPA intervention sessions were helpful and whether they had made any change in their communication](image)

**Figure 6-5:** Participant dyad's ratings of whether BCPPA intervention sessions were helpful and whether they had made any change in their communication

**6.2.2.2 Acceptability to local SLT collaborators**

For each of the nine dyads randomised to the BCPPA arm the local collaborator who delivered the intervention completed a fidelity questionnaire (see appendix 6.7). Table 6-5 summarises data on aims met, session length, setting, and confidence.
Table 6-5: Local collaborators responses to fidelity questionnaire items on aims met, session length, setting and confidence.

<table>
<thead>
<tr>
<th>Number of aims met</th>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
<th>Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean length of session in minutes (range)</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>58 (40-70)</td>
<td>60 (60)</td>
<td>61 (55-65)</td>
<td>62 (60-75)</td>
<td></td>
</tr>
<tr>
<td>Setting delivered</td>
<td>Very confident: 1</td>
<td>Confident: 6</td>
<td>Very confident: 1</td>
<td>Very confident: 1</td>
</tr>
<tr>
<td>7= at their home</td>
<td>Confident: 6</td>
<td>Confident: 6</td>
<td>Confident: 6</td>
<td>Confident: 7</td>
</tr>
<tr>
<td>2 = hospital outpatients</td>
<td>Somewhat confident: 3</td>
<td>Somewhat confident: 2</td>
<td>Somewhat confident: 2</td>
<td>Somewhat confident: 1</td>
</tr>
</tbody>
</table>

SLTs were asked to rate how interesting and enjoyable the dyad found the sessions on a 5-point scale (a little, quite a bit, quite a lot, very much and extremely). Ratings increased as the intervention progressed, with SLTs rating 55% of dyads as finding session 1 ‘very much’ or ‘extremely’ interesting, and 22% of dyads as having enjoyed it ‘very much’ or ‘extremely’ (see Figure 6-6). By session 4, 89% of dyads were rated by SLTs on the top two points of both the interest and enjoyment scales ('very much' or 'extremely').
Figure 6-6: Local SLT ratings of dyad’s interest and enjoyment of the BCPPA intervention sessions.

SLTs were invited to make comments on the dyads enjoyment and interest during the intervention. One SLT reported that a CP found the discussion and handouts a bit infantile in session 1. Another explained that it was difficult to move discussion from the person with PPA to the CP in session 2. One dyad reportedly “really enjoyed the practice tasks” in session 3, and another SLT felt that the conversations between the dyad started to feel more natural at this point. Following session 4 two SLTs reported it had been difficult for a CP to discuss future deterioration.

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9 Session 3 and 4 of the BCPPA program includes practice tasks that can be selected from a list of 11 options, where participants are asked to use the strategies they are working on during, for example discussion of a newspaper article or describing a picture.
SLTs were also invited to make general comments. One reported a preference for delivering the intervention in a different order than prescribed in the session plans, namely presenting more of the video feedback before giving the information on how conversation works. Another two commented on technical difficulties experienced when showing video clips. Three commented on session two requiring more preparation time than the previous session. Following the fourth session two SLTs suggested the dyads they worked with could have benefitted from more practice. In comparison another reported the dyad they worked with could have had one less session.

Summary

Dyads rated explanation, format and delivery of the intervention highly. They rated the intervention as generally useful and after the last session all dyads rated that they had made a change as a consequence of the intervention. The majority of local collaborators reported feeling confident in delivering the intervention. They reported an increase in the interest and enjoyment of the dyads they were working with.

6.2.3 BCPPA treatment fidelity

Treatment fidelity was 87.2% for the standardised components of the BCPPA intervention. For tailored components it was 63.8%. Average fidelity scores for each of the four sessions, following rater discussion and agreement are presented in Table 6-6. Inter-rater reliability across the eight observed sessions was 90.74% (range=80.95%-100%) prior to discussion and agreement between raters. On examination of tailored components, some of the same components were delivered, such as reviewing homework tasks, and some of the same
components were not delivered, such as asking participant dyads to recall one or two things from the previous session. This fidelity rating work was completed by two UCL student SLTs, and will be published following the completion of this study.

Table 6-6: Treatment fidelity per session, across standardised and tailored components of the BCPPA program

<table>
<thead>
<tr>
<th></th>
<th>Standardised components (average score and % fidelity)</th>
<th>Tailored components (average score and % fidelity)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1</td>
<td>16.5</td>
<td>91.67%</td>
</tr>
<tr>
<td>Session 2</td>
<td>20</td>
<td>76.92%</td>
</tr>
<tr>
<td>Session 3</td>
<td>15</td>
<td>93.75%</td>
</tr>
<tr>
<td>Session 4</td>
<td>19</td>
<td>86.36%</td>
</tr>
<tr>
<td>Total percentage adherence:</td>
<td></td>
<td>87.2%</td>
</tr>
</tbody>
</table>

This table represents data from two randomly selected dyads examined in the analysis. Maximum possible scores for standardised components were session 1 = 18, session 2 = 26, session 3 = 16, session 4 = 22, for tailored components were session 1 = 14, session 2 = 16, session 3 = 30, session 4 = 20.

6.2.4 Demographic and clinical characteristics of participant dyads at randomisation

The characteristics and demographic information of the participants with PPA and their CPs is presented in Table 6-7. All participants with PPA and their CPs spoke English as their language of daily use. The intervention group comprised four men and five women with PPA who had an average age of 72.1 years (range 57-85 years). Seven of the CPs were spouses, and two were adult children, with an average age of 64.6 years (ranging from 34-80 years).
The no treatment control group comprised four men and five women with PPA who had an average age of 71.3 years (ranging from 63-85 years). Eight of the CPs were spouses and one was a close friend, with an average age of 71.6 years (ranging from 69-85 years).

Seven of 18 the participants with PPA presented with a PPA diagnosis, with no specific variant specified. Examination of pre-intervention language test data (see Section 6.1.8) was used to inform differential diagnosis of PPA variant in line with the Gorno-Tempini et al's. (2011) internationally agreed diagnostic criteria. Four of the seven participants were given a new diagnosis, the remaining three presented with symptoms consistent with mixed PPA. Of the four given new diagnoses three of these were given a diagnosis of lvPPA on the basis of no signs of apraxia, but difficulties in digit span, sentence repetition and word retrieval in the presence of relatively spared comprehension of single words. One participant was given a diagnosis of nfvPPA due to the presence of apraxia and agrammatism with relatively intact comprehension.
<table>
<thead>
<tr>
<th></th>
<th>BCPPA</th>
<th>CP (BCPPA)</th>
<th>No treatment</th>
<th>CP (No treatment)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (years)</strong></td>
<td>72.1</td>
<td>64.6</td>
<td>71.3</td>
<td>71.6</td>
</tr>
<tr>
<td><strong>Age (range)</strong></td>
<td>57-85</td>
<td>34-80</td>
<td>63-85</td>
<td>69-85</td>
</tr>
<tr>
<td><strong>Gender (m:f)</strong></td>
<td>4:5</td>
<td>4:5</td>
<td>4:5</td>
<td>4:5</td>
</tr>
<tr>
<td><strong>nfvPPA (n)</strong></td>
<td>4</td>
<td>-</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td><strong>lvPPA (n)</strong></td>
<td>3</td>
<td>-</td>
<td>5</td>
<td>-</td>
</tr>
<tr>
<td><strong>svPPA (n)</strong></td>
<td>0</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td><strong>Mixed PPA (n)</strong></td>
<td>2</td>
<td>-</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td><strong>Time since symptom onset</strong></td>
<td>37.3 (27-67)</td>
<td>-</td>
<td>46.9 (20-84)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td>18.1 (5-36)</td>
<td>-</td>
<td>20.4 (8-72)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>Tertiary: 4</td>
<td>Tertiary: 2</td>
<td>Tertiary: 2</td>
<td>Tertiary: 2</td>
</tr>
<tr>
<td><strong>Occupational status</strong></td>
<td>Retired: 8</td>
<td>Retired: 2</td>
<td>Retired: 9</td>
<td>Retired:3</td>
</tr>
<tr>
<td>(recorded prior or current occupation)</td>
<td>Working: 1</td>
<td>Working: 3</td>
<td>(3=manual, 9=manual)</td>
<td>Working: 2</td>
</tr>
<tr>
<td></td>
<td>(1=manual)</td>
<td>(2=manual)</td>
<td>(5=intermediate/high managerial)</td>
<td>(2=manual)</td>
</tr>
<tr>
<td></td>
<td>8=intermediate/high managerial)</td>
<td>Not known: 5</td>
<td>Not known: 1</td>
<td>Not known: 4</td>
</tr>
<tr>
<td><strong>Comprehensive Aphasia Test mean and range scores on:</strong></td>
<td>53 (19-64)</td>
<td>46.6 (21-62)</td>
<td>47.4 (5-71)</td>
<td>49 (25-71)</td>
</tr>
<tr>
<td>Comprehension of spoken language (max score 66)</td>
<td>35.3 (0-48)</td>
<td>23 (0-48)</td>
<td>26.2 (3-50)</td>
<td>23.1(1-50)</td>
</tr>
<tr>
<td>Repetition (max score 74)</td>
<td>28.2 (0-8)</td>
<td>22 (0-48)</td>
<td>26.1 (0-8)</td>
<td>22.1(0-48)</td>
</tr>
<tr>
<td>Naming objects (max score 48)</td>
<td>28.2 (0-8)</td>
<td>22 (0-48)</td>
<td>26.1 (0-8)</td>
<td>22.1(0-48)</td>
</tr>
<tr>
<td>Picture description</td>
<td>28.2 (0-8)</td>
<td>22 (0-48)</td>
<td>26.1 (0-8)</td>
<td>22.1(0-48)</td>
</tr>
</tbody>
</table>

BCPPA= Better Conversations with Primary Progressive Aphasia, CP= Communication Partner, m=male, f=female, nfvPPA= nonfluent agrammatic variant Primary Progressive Aphasia, lvPPA= logopenic variant Primary Progressive Aphasia, svPPA= semantic variant Primary Progressive Aphasia
All nine dyads with PPA randomised to the BCPPA treatment group were included in the analysis. The DEMQOL and CCRSA data from one participant randomised to the no treatment control group was excluded due to significant fatigue during post-intervention assessment, resulting in scores at floor. This was not consistent with performance on baseline, nor with other measures during the post-intervention assessment session.

6.2.5 Assessment of outcome measures for a full-scale trial

Feedback from the local collaborators and junior researchers indicated a preference for the AIQ-21 measure over other measures. They reported it was the most meaningful and practicable measure to complete with the participants as it linked closely to the purpose of the intervention, to reduce the impact of PPA on a person’s conversation, and the images made it accessible. This was the only measure done with people with PPA where data from all participants could be included, emphasising its accessibility. Importantly, the AIQ-21 has been demonstrated to have statistically significant concurrent validity and good internal consistency, and the prototype has been demonstrated as sensitive to detecting change in people with stroke aphasia following a community intervention (Swinburn et al., 2019). Thus the AIQ-21 presents a logical choice for an outcome measure.

The pre- and post-intervention scores, and the change scores from the five outcome measures are shown in Table 6-8, and Figure 6-7, Figure 6-8, Figure 6-9, Figure 6-10 and Figure 6-11, respectively. The AIQ-21 results demonstrate a mean change score in the intended direction of -3.33 (95% CI -4.26, -2.41) for the BCPPA intervention group, indicating a reduction in the impact of PPA. The mean change score of 2.78 (95% CI -2.11, 7.45) for the no treatment control
group indicates an increase in the impact of aphasia. On closer examination of
the AIQ-21 mean scores (see Figure 6-7) it is apparent there is a large disparity
between the BCPPA and the control group mean scores initially, such that the
post-intervention score may be attributed to a regression to the mean (the
phenomenon of scores being extreme on first measurement, and closer to the
mean on second measurement) rather than the impact of the intervention.

Results from the DEMQOL, demonstrate a mean change score in the intended
direction, from pre to post intervention of 3.11 (95% CI -3.19, 9.42) in the
BCPPA intervention group, and 6.5 (95% CI -1.27, 14.27) in the no treatment
control group. This indicates both groups experienced an improvement in
quality of life. The CCRSA results demonstrate a mean change score in the
intended direction of 3.44 (95% CI -5.31, 12.2) for the BCPPA intervention
group and 12.75 (95% CI 5.04, 20.46) for the no treatment control group. This
indicates both groups experienced an improvement in communication
confidence.

The PSS results demonstrate a mean change score in the intended direction of
-0.89 (95% CI -2.44, 0.66) for the BCPPA intervention group and -3.33 (95% CI
-6.27,-0.39) for the no treatment group. Indicating both groups experienced a
reduction in perceived stress. The Zarit Burden Scale results demonstrate a
mean change score in the intended direction of -4.78 (95% CI -9.78, 0.23) for
the BCPPA intervention group and -5.22 (95% CI -10.27,-0.17) for the no
treatment control group. Indicating both groups experienced a reduction in carer
burden.
Table 6-8: Pre, post and change scores on outcome measures for the BCPPA intervention group and the no treatment control group

<table>
<thead>
<tr>
<th>Rater</th>
<th>Measure</th>
<th>BCPPA group (n=9)</th>
<th>No treatment (control) group (n=8 for DEMQOL &amp; CCRSA, n=9 for all other measures)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Pre</td>
<td>Post</td>
</tr>
<tr>
<td>PwPPA</td>
<td>Aphasia Impact Questionnaire 21 (AIQ-21, Swinburn, 2013)</td>
<td>19.78</td>
<td>16.56</td>
</tr>
<tr>
<td></td>
<td>Dementia Quality of Life Measure (DEMQOL, Mulhern et al., 2013)</td>
<td>87.89</td>
<td>92.38</td>
</tr>
<tr>
<td></td>
<td>Communication Confidence Rating Scale for Aphasia (CCRSA; Babbitt et al., 2011)</td>
<td>59.67</td>
<td>63.11</td>
</tr>
<tr>
<td>CP</td>
<td>Perceived Stress Scale (PSS, Cohen et al., 1983)</td>
<td>13.66</td>
<td>12.78</td>
</tr>
<tr>
<td></td>
<td>Zarit Burden Scale (Zarit et al., 1985)</td>
<td>27.33</td>
<td>22.56</td>
</tr>
</tbody>
</table>

PwPPA= person with Primary Progressive Aphasia, CP= Communication Partner, BCPPA= Better Conversations with Primary Progressive Aphasia; SD= Standard Deviation.
Figure 6-7: Pre-and post-intervention AIQ-21 mean scores for the BCPPA intervention group compared to the no treatment control group.

Figure 6-8: Pre- and Post-intervention DEMQOL mean scores for the BCPPA intervention group compared to the no treatment control group.
Figure 6-9: Pre- and post-intervention CCRSA mean scores for the BCPPA intervention group compared to the no treatment control group

Figure 6-10: Pre- and post-intervention Perceived Stress Scale mean scores for the BCPPA intervention group compared to the no treatment control group
Goal Attainment Scores (GAS) set and rated by participant dyads in the BCPPA intervention group indicate that of the 30 goals set, 20 achieved more than expected, seven were achieved, two much more than expected and one not achieved (see Table 6-9). The mean baseline score was 36.77 and the post intervention mean attainment score was 59.13, resulting in a mean change score of 22.36 (95% CI 16.75, 27.95).
<table>
<thead>
<tr>
<th>Dyad</th>
<th>Goals agreed by dyad and local collaborator</th>
<th>Achievement of goals</th>
<th>Baseline Score</th>
<th>Attainment Score</th>
<th>Change Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.01</td>
<td>To elaborate more (PwPPA)</td>
<td>A+</td>
<td>35.78</td>
<td>64.22*</td>
<td>28.44</td>
</tr>
<tr>
<td></td>
<td>To wait or avoid finishing PwPPA’s sentences (CP)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To ask more questions (PwPPA)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To ask more open questions (CP)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.01</td>
<td>To use gestures when encountering word finding difficulties (PwPPA)</td>
<td>A</td>
<td>35.81</td>
<td>58.9</td>
<td>23.09</td>
</tr>
<tr>
<td></td>
<td>To ask less test questions (CP)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To give additional information around a person’s identity when unable to generate name (PwPPA)</td>
<td>A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To waiting before offering prompts to help (CP)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.02</td>
<td>To use prompt card when needed to help facilitate conversations (PwPPA)</td>
<td>A+</td>
<td>38.76</td>
<td>63.3*</td>
<td>24.54</td>
</tr>
<tr>
<td></td>
<td>To let PwPPA lead conversations (CP)</td>
<td>A++</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.03</td>
<td>To pause when PwPPA gets stuck on a word and give a bit more time (CP)</td>
<td>A+</td>
<td>36.78</td>
<td>67.6*</td>
<td>30.82</td>
</tr>
<tr>
<td></td>
<td>To use eye gaze to point, when stuck on a word, to indicate word/topic (PwPPA)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To use hands for gesture/mime to support talking (to prompt self &amp; indicate to others) (PwPPA)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.01</td>
<td>To choose the topic (PwPPA)</td>
<td>A+</td>
<td>35.38</td>
<td>63.2*</td>
<td>27.82</td>
</tr>
<tr>
<td></td>
<td>To describe or use gesture if I can’t think of the word (PwPPA)</td>
<td>A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To ask single questions rather than either or questions (CP)</td>
<td>A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To use shorter sentences (CP)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To ask questions to prompt PwPPA to choose a topic (CP)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.04</td>
<td>To prompt / use open ended questions to encourage expanded responses (CP)</td>
<td>A</td>
<td>37.64</td>
<td>43.1</td>
<td>5.46</td>
</tr>
<tr>
<td></td>
<td>To use a key word then comment based on this, to try and expand responses (to avoid always saying yes / no or agreeing) (PwPPA)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To use a gesture / signal when it’s the end of turn – difficult to know if finished OR if needing time to generate next response (PwPPA)</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Code</td>
<td>Task</td>
<td>Achievement</td>
<td>Mean</td>
<td>SD</td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>----------------------------------------------------------------------</td>
<td>-------------</td>
<td>--------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>6.01</td>
<td>To use more meaningful gesture in conversation (PwPPA)</td>
<td>A+</td>
<td>36.31</td>
<td>6.01</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To use more writing and drawing in conversation (PwPPA)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To use more key words and automatic phrases in conversation (PwPPA)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.01</td>
<td>To use non-verbal communication / gesture to indicate understanding (PwPPA)</td>
<td>A+</td>
<td>36.31</td>
<td>63.7*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To feel less frustrated in conversations (PwPPA and CP)</td>
<td>A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To have strategies for managing negotiations in conversation (PwPPA and CP)</td>
<td>A+</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.03</td>
<td>To use intonation more to indicate agreement/disagreement, opinion, feelings and mood (PwPPA)</td>
<td>A+</td>
<td>38.2</td>
<td>27.39</td>
<td></td>
</tr>
<tr>
<td></td>
<td>To use eye gaze to point to support shared attention (PwPPA)</td>
<td>A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>To use props/objects to support conversations (PwPPA and CP)</td>
<td>A</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total mean: 36.77  59.13  22.36 (SD: 8.57)

CP= Communication partner, PwPPA= Person with Primary Progressive Aphasia, NA= Not Achieved, A=Achieved as expected, A+=Achieved more than expected, A++ Achieved much more than expected, *=more than 1 SD from the published t-score mean (Turner-Stokes, 2009)
6.2.5.1 Data to inform the sample size calculation

Having calculated an effect size of 0.86 for the AIQ-21 measure, at 95% power and using \( \alpha = 0.05 \), a sample size of 74 would be required. This was however a small randomised controlled pilot-feasibility study and the effect size could therefore be inflated. Based on a more conservative effect size calculation of 0.5, at 95% power and using \( \alpha = 0.05 \), a sample size of 210 would be required.

6.2.5.2 Effectiveness

Levene’s Test for Equality of Variance was not significant for four of the five comparisons, \( p > .05 \), indicating equal variances could be assumed between groups at follow-up for the AIQ-21, DEMQOL, CCRSA and the PSS. For the Zarit this was significant, \( F(1,16)=5.43, p=.03 \), indicating unequal variances between groups at follow up. Given there was an equal number of datasets in the two groups, it was decided to proceed with the ANCOVA analysis regardless. Scores did not differ significantly between groups at baseline for any outcome measures \((p>.05)\). There were no significant differences between groups on any measures (Table 6-10).

Table 6-10: Analysis of effectiveness results

<table>
<thead>
<tr>
<th>Rater</th>
<th>Measure</th>
<th>ANCOVA</th>
</tr>
</thead>
</table>
| PwPPA   | Aphasia Impact Questionnaire - 21 (AIQ-21, Swinburn, 2013)              | \( F(1, 15) = .095, p = .762, \)  
|         |                                                                         | partial \( \eta^2 = .006. \) |
|         | Dementia Quality of Life Measures (DEMQOL; Mulhern et al., 2013))      | \( F(1, 14) = .915, p = .355, \)  
|         |                                                                         | partial \( \eta^2 = .061. \) |
|         | Communication Confidence Rating Scale for Aphasia (CCRSA, Babbitt et al., 2011) | \( F(1, 14) =2.76, p = .119, \)  
|         |                                                                         | partial \( \eta^2 = .165. \) |
| CP      | Perceived Stress Scale (PSS, Cohen et al., 1983)                       | \( F(1, 15) =3.428, p = .084, \)  
|         |                                                                         | partial \( \eta^2 = .186. \) |
|         | Zarit Burden Scale (Zarit et al, 1985)                                 | \( F(1, 15) =1.435, p = .249, \)  
|         |                                                                         | partial \( \eta^2 = .087. \) |
6.2.6 Safety

There were no adverse events or serious adverse events reported in the pilot-feasibility RCT.

6.3 Discussion

The primary aim of this study was to pilot the BCPPA program compared to a no speech and language therapy treatment control group over participating sites to establish for a main trial whether BCPPA can be delivered as intended in an NHS setting. This discussion will address the results of this randomised controlled pilot-feasibility study in line with the specific aims outlined in the introduction of this chapter to 1. predict patient recruitment and retention rate, 2. refine inclusion criteria, 3. establish the acceptability of randomisation, 4. assess treatment fidelity to determine necessary levels of SLT training, 5. identify the most appropriate primary outcome measure and 6. establish a sample size calculation.

6.3.1 Recruitment, eligibility and declining to participate (aim 1 and 2)

Based on referral rates to the first three research sites in the three years preceding the study, it was originally planned that 42 participants would be recruited from these three centres over 18 months. In the first few months of the study opening one of the original sites paused recruitment, and the remaining reported a reduced capacity, both due to reductions in staffing and changes in service structure resulting in slower recruitment of participants than expected. Given the author was independently managing the trial as part of a small PhD study a decision was made to reduce the target recruitment to 20 participants. Further sites were recruited through clinical networks known to the author, yet staffing issues continued to plague the study. This is not dissimilar to other recent NHS based trials of speech and language interventions who also report slower
recruitment than anticipated in NHS based RCTs (Bowen et al., 2012; Sackley et al., 2018). Time constraints on busy clinicians has been reported as a common barrier to recruiting participants (Ross et al., 1999). Given that local SLT collaborators had increased clinical demands on their time due to reported staffing shortages and service restructuring, it is likely to have been challenging to spend time recruiting, consenting, assessing and delivering intervention to people with PPA for this study.

The main reason that individuals with PPA did not participate in the study was not meeting the inclusion criteria, often due to prominent behavioural or memory disturbance associated with disease severity. On examination of the demographic data of participants with PPA at randomisation, it is noticeable that the average time post symptom onset was approximately 3.5 years. This indicates that people are referred to speech and language therapy when disease progression renders them less able to benefit from the breadth of interventions on offer. The two participants who withdrew following pre-intervention assessment cited reasons associated with disease progression. This chimes with findings from the development stage of this study (Chapter 5), where people with PPA and their families advocated much earlier referral to speech and language therapy. Difficulties in diagnosis including misdiagnosis as psychiatric illness (Hall et al., 2013) and other dementia variants (Coyle-Gilchrist et al., 2016), are likely to make early speech and language therapy referral difficult. Further, the lack of a national care pathway for PPA and FTD may contribute to the delay in referral, given that health professionals may not be aware of the SLT’s role in PPA without this as highlighted in Chapter 3.
Local collaborators reported that participants who declined participation in the study had been recently diagnosed and reported not wishing to burden a CP, expressing a preference for impairment focused interventions. Other participants who did wish to participate were also unable to identify an available CP. This finding emphasises the importance of giving individuals the opportunity to participate, rather than constraining the inclusion criteria further. Choosing not to participate in research due to a preference for alternative interventions is not particular to people with PPA, having been described as common to other RCTs (Ross et al., 1999). The BCPPA intervention will not meet the needs of all people with PPA, as is the case for word relearning interventions (Croot, 2009). This underlines the importance of a person centred approach for people with PPA (Rogalski & Khayum, 2018) where interventions are offered and chosen based on an individual’s current needs as highlighted in Chapter 4. The results of this randomised controlled pilot-feasibility study suggest such an approach should also consider the presence of an available CP. Trialling novel delivery methods such as video conferencing, such as those described by Rogalski et al. (2016) or single sessions could improve accessibility for CPs who are unable to attend speech and language therapy sessions. Alternatively inviting people to participate in group therapy activities could provide access to new CPs for more socially isolated individuals (Mooney, Beale, et al., 2018).

6.3.2 Acceptability (aim 3)

Given that no participants withdrew from the study following randomisation, randomisation was considered acceptable. Participant dyads and local SLT collaborators reported generally positive views about acceptability of the intervention, as determined by evaluation of feedback forms. It is notable that
dyads’ ratings of the sessions increased as the sessions progressed, and the local collaborators’ estimation of participant dyads’ interest and enjoyment increased after the first session. The less positive views at the beginning of intervention appear to reflect its unexpected nature; approximately half reported the intervention was not what they expected initially, despite having received the information sheets. Given the lack of awareness of the breadth of speech and language interventions amongst referrers highlighted in Chapter 3 the referring health professional may have contributed to these expectations. Additionally, some participants will have previously had impairment focused interventions and may have been expecting more that. Anecdotally, clients and SLTs may understand conversation to be different things, indeed Sirman et al (2017) found that SLTs working with people with stroke aphasia find it difficult to describe CPT.

6.3.3 Treatment fidelity (aim 4)

The BCPPA manualised session plans, handouts and homebased tasks specify the standardised and tailored elements of the intervention. The high fidelity rate confirms that the two 4.5 hour training sessions (see Section 6.1.11) delivered were adequate for the local SLT collaborators across outpatient and community settings to adhere to the manuals provided. Analysis of tailored components that were or were not delivered will provided key information to further tailor the manuals. Analysis of the local SLT collaborators’ fidelity questionnaires indicates that the manualised BCPPA intervention can be delivered within four sessions of approximately 1 hour each. Despite being a relatively small dosage, SLTs across the UK report having an average of only four available sessions to deliver functional communication interventions to people with PPA as reported in Chapter 3 of this thesis. The results of this randomised controlled pilot-feasibility
study indicate it is feasible to deliver and adhere to the BCPPA intervention manual in four sessions in an NHS setting. This is important for the implementation of the BCPPA intervention and allows for accurate analysis of effectiveness.

6.3.4 Primary outcome measure and sample size calculation (aims 5 and 6)

Given the aim of the intervention was to reduce the impact of the person’s PPA on their lives, the AIQ-21 presents the most suitably sensitive outcome measure. It is a highly appropriate choice with its questions about communication, participation, well-being and emotional state. Importantly, the AIQ-21 was the only measure showing a trend in a direction favouring the intervention. The DEMQOL, the CCRSA, the PSS and the Zarit Burden Scale demonstrated a change in the intended direction in both groups, with greater change seen in the no treatment group. Given that these measures capture concepts related to quality of life, rather than change in communication behaviours (the focus of the intervention), these findings may reflect issues unrelated to the intervention and thus present a limitation in the measures. Alternatively, it may be that participating in the intervention increased carer stress or burden.

It is, however, considered a general rule of thumb that a pilot study must recruit at least 30 participants in order to accurately inform a future full trial (Lancaster, Dodd, & Williamson, 2004). A sample of 30 participants would provide more reliable data to inform the identification of a suitably sensitive outcome measure and a relevant sample size estimate for a future full trial. Additionally a larger sample size will provide more data to examine the disparity between the baseline AIQ-21 scores and may serve to clarify whether results are a result of regression
to the mean rather than the impact of the intervention. For this reason, recruitment remains ongoing.

In order to recruit an adequate sample size for a full trial it will be important to provide resources, such as dedicated research staff who can recruit, consent, assess and deliver the intervention to reduce the pressure on local SLT collaborators. Considering the current UK prevalence estimates for PPA, described in chapter 2, of approximately 2300 people, this randomised controlled pilot-feasibility study has only captured a potential pool of 2.6% and recruited less than 1% of these. A future full trial would be aiming to recruit closer to 9%. Given the difficulties in recruitment this may not be feasible. Although, focusing on key national centres and considering the addition of non-NHS recruitment sites such the PPA branch of the UCL rare dementia support group, where information can be disseminated directly to potential participants, will be useful for any future evaluation study.

6.3.5 Implications for future research
This study has presented preliminary effectiveness data for 18 participant dyads across the two groups, and there is no evidence that the BCPPA intervention was more effective than no treatment. Importantly BCPPA does achieve meaningful change in participant dyads’ conversations according to the evaluation of self-identified goals. It may be that the current sample size is too small, and a Type II error cannot be dismissed. However it may also indicate that the measures are not sensitive to changes resulting from the intervention. Undertaking qualitative interviews with participant dyads in the study will provide valuable information on what changes are most important to them, and further inform the selection of the primary outcome measure for a future full trial. These interviews will provide an
opportunity to collate further information of whether the dosage was felt to be adequate, and whether dyads with different PPA variants benefitted differently from the intervention.

Only one person with svPPA has been recruited to the BCPPA pilot-feasibility study to date, likely due to the common occurrence of behavioural difficulties in this variant that may prohibit their inclusion in the study (Marshall et al., 2018). Future research should collate diagnostic data on PPA variant of excluded participants to inform candidacy for future CPT studies. Given the small sample size analysis of response to the intervention across PPA variants was not feasible in this study but should be prioritised in future adequately powered CPT trials. Analysis of each participant dyads’ eight 10 minute video recorded conversation samples (four baselines and four post-intervention) has not been undertaken as part of this study for logistical reasons. Currently this comprises 144 samples. Following transcription, communication behaviours can be coded in pre- and post-intervention conversation samples. Once coded these can be quantified and a comparison made in the frequency of behaviours pre- and post-intervention. This method of analysis has been used in the stroke aphasia literature to demonstrate changes in behaviour following CPT (Best et al., 2016).

### 6.3.6 Limitations

Given the small and heterogeneous sample these results must be interpreted with caution. Recruitment will continue until December 2021 with a view to reaching a sample of 30 participants for the purposes of publication. Ethical approval has been given for this amendment to the research protocol.
Other study limitations include the inability to blind participants to group allocation, a common barrier in behavioural studies. Those allocated to the control group did not receive any speech and language therapy intervention for 4 weeks as there is no standard speech and language intervention for PPA. Similarly, it was not possible to blind local collaborators delivering the intervention. For this reason, post-intervention assessment was completed by pairs of student SLTs blinded to group allocation.

Despite the intervention being deliverable within four sessions, many participating local SLT collaborators were unable to offer these on a weekly basis. Thus on occasion the author became aware that the intervention sessions were delivered with anticipated or unanticipated interruptions due to Christmas, holidays, illness and weather limitations. However, systematic data on the intensity and range of intervention delivery were not collected. As this is relevant to dosage, it would be beneficial to consider in future trials (Baker, 2012).

The inclusion criteria for this study resulted in significant heterogeneity across participants in terms of language profile and communication difficulties. This makes it difficult to compare participants' to one another, thus a range of outcome measures were piloted across language, communication and quality of life to identify the most sensitive across all participants. The large number of measures may have contributed to anxiety experienced by the two participants who chose to withdraw from the study following pre-intervention assessment. This emphasises the importance of selecting fewer, suitably sensitive measures for a future full trial.
The current study was dependent on a single baseline and a single post-intervention measure. Multiple baselines would have enabled analysis of baseline scores to differentiate between regression to the mean and genuine change after intervention. Multiple post-intervention measures would provide information on maintenance of treatment effects following intervention. It is ambitious to expect a 4 week intervention to result in immediate gain, and there is some evidence from the chronic disease literature that treatment effects following self-management interventions may be more observable in the period following an intervention, as participants establish proficiency in using in daily life what they have learnt (Luszczynska & Schwarzer, 2005).

6.4 Conclusions

There is little evidence of the impact of CPT programmes for people with PPA and their CPs, yet there are reports of widespread clinical use by UK SLTs. The results of this randomised controlled pilot-feasibility study within the NHS have demonstrated that the BCPPA program is both acceptable and feasible compared to 4 weeks of no speech and language therapy treatment. Although the AIQ-21 was identified as a potentially suitably sensitive outcome measure, observation data on communication behaviours has not yet been analysed. Data collection continues, and further analysis of, as yet, unexamined communication behaviour remains underway. This will provide more reliable information to guide the feasibility of a future large scale evaluation of BCPPA.
Chapter 7 Discussion and future directions

This thesis has piloted and investigated the feasibility of the BCPPA CPT program for people with PPA and their CPs. The aims of the investigation were to define and refine a manual and an online training resource for SLTs delivering BCPPA, and to pilot the BCPPA program to establish for a main trial whether BCPPA can be delivered as intended in an NHS setting, and is acceptable to participants and to SLTs. Underpinning this work, a UK-wide SLT survey reporting on current practices in the assessment and management of PPA was presented in Chapter 3. Chapter 4 described a systematic review of current functional communication interventions for people with PPA and their CPs, examining the effectiveness and identifying the key components of these interventions. The six stages of intervention development and refinement were reported on in Chapter 5. The randomised controlled pilot-feasibility study comparing the BCPPA program to a no speech and language therapy treatment control group was presented in Chapter 6. The work reported in this thesis is in line with phases I and II of the MRC complex intervention development guidelines (Craig et al., 2008).

The current chapter will evaluate the key findings from this intervention study and the implications for clinical practice and future research. The main study findings are discussed in Section 7.1. The CPT approach to PPA is addressed in Section 7.2, and Section 7.3 discusses the progressive nature of PPA and the issue of access to speech and language therapy. Section 7.4 explores the issue of measuring outcomes of CPT for PPA and 7.5 makes recommendations for a future full RCT, and for wider research. A summary of limitations and final conclusions are presented in Sections 7.6 and 7.7 respectively.
7.1 Main study findings

The UK-wide survey captured responses from 105 SLTs working with people with PPA across England, Wales, Scotland and Northern Ireland. The survey builds on research with expert SLTs working in PPA by Kindell et al (2015), to provide a detailed benchmark of current speech and language therapy practice across the UK. A range of assessment and intervention approaches are reportedly used in clinical practice with people with PPA, extending beyond those with a developed evidence base. Specifically SLTs report a strong preference for CPT over more evidence based impairment focused interventions. Respondents report borrowing resources from the stroke aphasia literature to deliver CPT for PPA. This survey brings to light a worrying gap between current clinical practice and the PPA research evidence. In parallel with surveys conducted in Australia (Taylor et al., 2009) and Germany (Riedl et al., 2014), a lack of awareness of the SLTs role amongst referrers, and restrictive service criteria were identified as barriers to accessing to speech and language therapy for this client group. This often results in people with PPA falling through the cracks because they are too young and able for standard dementia services and fail to qualify for stroke aphasia services due to their dementia diagnosis.

Nineteen studies met the inclusion criteria for the systematic review of functional communication interventions reported in Chapter 4, demonstrating an increase in the number and rigour of articles published since Carthy-Goulart et al’s (2013) review which identified only eight studies of limited quality. Due to the heterogeneity of outcomes across studies considered for this thesis, a meta-analysis was not possible. However, using the ITAX amendment developed by O’Rourke et al (2018), this systematic review highlights that, just as in stroke
aphasia, key components of functional communication interventions for people with PPA are building on existing strategies, and practising these with a CP. As Simmons-Mackie & Damico (1997) showed for stroke aphasia building on existing communication skills rather than introducing new strategies can be a more effective approach to compensating for communication difficulties. This appears to apply also to PPA.

Development of the BCPPA program involved a six-stage approach firstly exploring the research literature on the theoretical underpinnings for the intervention, the biopsychosocial model of dementia, applied conversation analysis, behaviour change theory, self-management and self-efficacy. Qualitative research with SLTs and people with PPA and their CPs further informed the refinement of the final 4-session, manualised, CPT intervention. Importantly, session plans, handouts and home-based tasks were co-produced with the project steering group to ensure they met the needs of people with PPA and their CPs. An online learning resource was developed alongside this to support local SLT collaborators delivering the BCPPA intervention for the stage II randomised controlled pilot-feasibility study. The NIHR INVOLVE guidance (2018) emphasises that co-production is vital to ensuring a real understanding of people’s experiences is at the heart of the research. The co-production of BCPPA resulted in a program that met the needs of the people with PPA and their CPs who participated in the pilot-feasibility study.

A randomised controlled pilot-feasibility RCT was conducted across 11 NHS sites in England and Wales. Despite slower than anticipated recruitment, 59 potential participants were identified, of which 18 consented, and were randomised to either 4 weeks of the BCPPA program or four weeks of no speech and language
therapy treatment. All 18 participants completed pre-and post- intervention measures of language, communication and quality of life. Results demonstrated that a future full trial is acceptable, given the positive views of participants and local SLT collaborators. It is also feasible, with SLT collaborators having exceeded the target fidelity criterion of 80% following a training course comprising two 4.5 hour sessions, and as-and-when ongoing support, and with data leading to the identification of a potentially suitable primary outcome measure (the AIQ-21). Preliminary results do not demonstrate that the BCPPA program is any more effective than a similar period of no speech and language therapy treatment, however given the small sample size results must be interpreted with caution at this stage. Data collection remains underway, aiming for a sample size of 30 participants to allow for further assessment of feasibility and future publication of this randomised controlled pilot-feasibility study.

7.2 CPT approach to PPA

Despite the predominance of word relearning interventions in the research literature for people with PPA, Rogers & Alarcon (1998) and Hinshelwood et al (2016) have previously advocated CPT as an important treatment approach for this group. And investigations of the impact of PPA on conversations confirm this; we know that strategies adopted by a person with PPA and their CP can result in conversation breakdown, or can be facilitative (Kindell et al., 2013; Taylor et al., 2014). It appears that UK SLTs agree with this position, with Chapter 3 survey results showing CPT approaches are prioritised above word relearning interventions in the clinical field of speech and language therapy for PPA. While a few individual case studies of CPT for PPA exist in the published literature, with
Murray (1998) and Wong et al. (2009) reporting promising results, these studies lack rigour, both in the study design and reporting of the intervention.

BCPPA is the first manualised CPT intervention for PPA grounded in the bio-psychosocial model of dementia, applied CA, behaviour change theory, and self-management and self-efficacy theory. The bio-psychosocial model of dementia theorises that a person’s day to day functioning is influenced by multiple factors, some of which (the tractable factors) can be influenced by interventions (Spector & Orrell, 2010). BCPPA explicitly sets out to target some of these factors, namely the coping strategies and adaptive mechanisms used in conversations by both the person with PPA and their CP.

The collection and analysis of video recordings of natural conversations between a person with post-stroke aphasia and their CP, for use in video-feedback, is a foundation of CA influenced interventions (Wilkinson, 2014). BCPPA is similarly informed by video recorded conversations between people with PPA and their CP, made prior to the intervention. This ensures that BCPPA is grounded in an individual dyad’s needs, a theme identified by people with PPA and their families to be important to delivering interventions to support conversations in Chapter 5. Brief clips from video recordings are presented to the dyad, who are supported to reflect on the facilitators and barriers in these conversations using handouts co-produced by the project steering group. The dyad are then supported to set goals on facilitators they would like to practice and barriers they wish to decrease in the remaining sessions. Focusing on and refining strategies individuals are already using is one of the two key components of functional communication interventions for PPA as outlined in the Chapter 3 systematic review. Practice has been identified as an important mechanism to support the opportunity for
behaviour change in conversations where one person has stroke aphasia (Johnson et al., 2017). BCPPA embeds multiple opportunities for practice through the provision of a list of options co-produced with the project steering group, such as discussing a newspaper article, or describing a picture.

CPT is a therapy approach that requires participants to do a lot of cognitive work to reflect on and problem solve difficulties arising in a conversation and then use a strategy at an appropriate point in a conversation. These are tasks that might prove challenging to someone with a diagnosis of PPA. This has also been considered in the stroke aphasia research, given the limited but growing understanding of the underlying cognitive impairments of many people with this type of aphasia (Beckley et al., 2013). The concrete nature of the BCPPA program is designed to be helpful in participating in the metacognitive components of the intervention, for example the staged nature of the therapy sessions whereby the dyad first watch videos to identify areas of breakdown before then going on to discuss how to solve these. Additionally, the use of practice as an opportunity to problem solve and receive online feedback in a situation approximating a real life conversation is considerably more likely to enable a person to use alternative strategies in conversation (Beckley et al., 2013).

At the end of BCPPA a dyad are supported to re-visit and re-rate the goals they set using a well-regarded rehabilitation tool, Goal Attainment Scaling (GAS, Turner-Stokes, 2009). Johnson et al’s work on CPT for stroke aphasia also highlights goal setting as an important mechanism for behaviour change providing an individual with the capability and motivation to change. Results of the BCPPA pilot-feasibility study reveal all participants’ goals, excepting one,
were achieved. So although preliminary results show no change on formal outcome measures, participants in the study were able to achieve their self-identified conversation behaviour changes after BCPPA.

In summary, this evaluation of CPT for PPA has shown that the approach holds promise as a means to improve self-identified meaningful communication behaviours between people with PPA and their CPs. The next section discusses the challenge to CPT posed by the progressive nature of PPA and its diagnosis.

7.3 The progressive nature of PPA and its diagnosis

Research evidence from post stroke aphasia has often been used to guide the development of functional interventions for people with PPA (Rogalski et al, 2016; Kim et al, 2018). However, post-stroke interventions are not equipped to deal with the progressive nature of PPA (Kindell et al., 2017). Strategies taught may not continue to be useful, and the ability of the person with PPA to engage with strategy use may alter. In response to this issue a focus on planning for future changes in communication is a key element of the final session of the BCPPA intervention. Handouts, co-produced with the project steering group, prepare the dyad to consider future communication changes and anticipate strategies to support communication into the future.

Some of these difficulties in engaging in BCPPA may be negated by earlier opportunities for speech and language therapy to enable people to plan for future changes (Hinshelwood et al., 2016). Early intervention has been identified as a factor in maintenance of therapeutic gains in some interventions studies (Croot, 2018). Earlier referral to speech and language therapy has been advocated by people with PPA and their families in the focus groups carried out for this study.
(Chapter 5). However the results of the UK-wide survey of SLTs (Chapter 3) and the recruitment data from the randomised controlled pilot-feasibility study (Chapter 6) highlight that people with PPA who are referred to speech and language therapy, are often referred too late to benefit from a range of speech and language therapy interventions. This may be attributed to difficulties in diagnosis, with individuals often diagnosed late in the disease journey, or misdiagnosed with psychiatric issues or another form of dementia (Coyle-Gilchrist et al., 2016; Hall et al., 2013). Additionally a number of people may not fit a PPA variant, or may present with an atypical PPA variant (Sajjadi et al., 2012). Perhaps due to the problem in accurate diagnosis of PPA, many intervention studies do not report on PPA variant. Yet people with different PPA variants have been shown to benefit differently from word relearning interventions (Cadório et al, 2017). Future research on functional communication interventions for PPA may benefit from routinely reporting on participants’ language skills using standardised language scores that reflect the range of strengths and difficulties in individual participants, alongside PPA variant, and allow for comparison across studies. There is an urgent need to develop care pathways to make the broader health care community aware of the breadth of the SLT role, and improve access to speech and language therapy interventions. Improvement in both study design and the rigour of reporting on research evidence in this area will contribute to this process.

7.4 Challenge of measuring outcomes of CPT for PPA

The purpose of BCPPA is to reduce the impact of PPA on the lives of the person and their CP. Saldert, Jensen, Blom Johansson, & Simmons-Mackie (2018) highlight the challenge in CPT of aligning the objective of the intervention with the
projected outcome. They report that despite the main objective of CPT being more closely aligned with distal purposes of reducing the impact of a communication disorder in terms of how a participant feels, intervention effects are usually more likely to be demonstrated in proximal outcomes such as changes in interactional behaviours. This may explain why measures in the pilot-feasibility study, which all examine distal concepts such as impact (AIQ-21), quality of life (DEMQOL), confidence (CCRSA) and carer stress and burden (PSS and the Zarit burden scale) have not demonstrated a significant change.

Changes in frequency of specific interactional behaviours are outcomes that may be observed by an independent rater in a video recording and have been used by Best et al (2016) to demonstrate changes in behaviours following CPT with a person with stroke aphasia and their CP. Preliminary work has been undertaken by an MSc student to examine the video recordings of two dyads with PPA randomised to the BCPPA arm of the pilot-feasibility study. Results of this work showed there was a significant reduction in the number of word finding pauses of one participant with PPA following the intervention (Tryfonidis, 2018). Importantly in the treatment fidelity literature observing and identifying the frequency of interactional behaviours in this way may also be considered a component of monitoring a participants’ adherence to an intervention (Walton et al., 2019). This is referred to as enactment, described as the process of putting plans into practice in daily life, whilst receipt is a participant’s ability to understand and perform the skills. Together these describe how a participant has engaged in the intervention (Borrelli, 2011). Investigation of enactment for the whole dataset in the pilot-feasibility study is ongoing via MSc student projects currently underway.
Qualitative interviews with participants in the BCPPA pilot-feasibility study are also planned to gather data on what changes are most important to people with PPA. Given that BCPPA was co-produced to meet the needs of people with PPA and their CPs, establishing the most meaningful measure to examine this will provide valuable guidance.

7.5 Future research

The research reported in this thesis has demonstrated that a co-produced CPT intervention delivered over 4-sessions within the NHS is acceptable and feasible for a future full trial. Whilst the study has broadened knowledge of current clinical practice amongst SLTs working with PPA, and has provided a more detailed understanding of the common components of functional communication interventions for PPA, it has also raised further research questions. Firstly, whether a care pathway for can PPA improve access to speech and language therapy. As evidenced in this thesis, people with PPA are currently experiencing difficulties in accessing speech and language therapy and establishing a national care pathway would provide guidance to referrers on the role of the SLT and when this may be of benefit. Implementation of such a care pathway would require ongoing research and review to ensure its effectiveness.

As the research evidence in this relatively new area of practice continues to develop, establishing a set of core outcome measures will be of benefit to maximise opportunities for comparison across studies. Using consensus methods with expert researchers in the field to identify and agree these measures will be a priority. This should take account of the opinions of people with PPA and their CPs on the most meaningful measure for recipients of functional communication interventions. Interviews planned with BCPPA participants, as
outlined in Section 7.4, will provide data on those measures considered most meaningful and relevant to CPT. This will inform a future phase III full trial of BCPPA to establish whether the BCPPA intervention is effective for people with PPA.

Given the research evidence indicating people with different PPA variants benefit differently from impairment focused word relearning interventions (Cadório et al., 2017) it seems logical that the same may be expected from functional communication interventions such as CPT. Further data collection, with a larger number of participants, including more participants with svPPA will provide more guidance on this question. Cadório et al (2017) also illustrate that as language and cognition degrade, people with PPA do not benefit as much from impairment focused interventions. Given the BCPPA program works with both people with PPA and their CPs, there may be some rationale to suggest that functional communication interventions still benefit dyads late into the disease process. The question of candidacy for CPT interventions based on diagnostic variant and time post onset of symptoms will provide useful information to guide the delivery of speech and language therapy to people with PPA.

Criteria to proceed to a full trial, set in advance of the randomised controlled pilot-feasibility study, have been met (see Section 6.1.14) thus warranting a future full trial examining the effectiveness of BCPPA compared to no speech and language therapy treatment. Realistically, the sample size estimate for a future full trial may not be feasible, given the difficulties in recruitment to the pilot-feasibility study. Recruitment to this study remains ongoing to allow the sample size calculation to be updated based on larger numbers, and will inform decision making on the feasibility of future recruitment. Any future study will undoubtedly need to be
hosted across multiple NHS and non-NHS sites to enable adequate recruitment, and supported by a funded trial manager, and trained SLTs employed as research assistants to recruit participants and deliver the intervention. Alternatively if the sample size proves unfeasible following final calculations, there may be some benefit in a future study not following the same format, but instead considering a case series or waiting list design. A case series would have benefits of requiring fewer participants, with each participant acting as their own control, thus requiring less time and resources. A waiting list design would provide an untreated comparison group, who would consequently receive the intervention, over time boosting the numbers in the intervention group.

7.6 Limitations

Overall the results of the BCPPA pilot-feasibility study are promising, but given the small and heterogeneous sample they must be interpreted with caution. Recruitment will continue until December 2021 with a view to reaching a robust sample of 30 participants for the purposes of analysis. The slower than anticipated recruitment has been a limitation in this study, as well as the fact that only one participant with svPPA has been recruited to the study. Should a future full trial proceed, it seems logical that the provision of additional resources to support it will be necessary. Additionally, identifying recruitment sites where participants may be identified earlier in their disease trajectory may increase the chance of recruiting individuals with svPPA.

To date it has only been possible to examine the measures that captured the more distal concepts of quality of life, impact, confidence, and carer burden and stress. Conversation data, which would provide a proximal measure of change, was collected but there was not adequate time to examine it. Analysis of this data
will provide a better understanding of the most suitably sensitive outcome measure, when considered alongside patient and carer reported outcomes. This work is ongoing.

Despite the intervention being deliverable within four sessions, many participating local SLT collaborators were unable to offer these on a weekly basis. Thus on occasion the author became aware that the intervention sessions were delivered with anticipated or unanticipated interruptions due to Christmas, holidays, illness and weather. However, systematic data on the intensity and range of intervention delivery was not collected. As this is relevant to dosage, it would be beneficial to consider in future trials (Baker, 2012). A four session block was identified as the average length of therapy by SLT respondents in the UK-wide survey (chapter 3). Should an increase in dosage result in a more effective intervention, this may support the commissioning of more sessions for clinical speech and language therapy services. Qualitative interviews with current BCPPA participants and their CPs will also provide an opportunity to collate further information on the length of time they felt they needed to practice and consolidate strategy use.

7.7 Conclusion

This thesis contributes to the field by producing new co-produced evidence-based CPT resources for PPA and an evaluation of these in an NHS setting alongside no speech and language therapy intervention for a group of people with PPA and their CPs. The co-production of the BCPPA program incorporated results of a UK-wide survey and systematic review of the research on functional communication interventions for PPA, creating a 4-session manualised intervention that meets the identified needs of people with PPA and their CPs. The randomised controlled pilot-feasibility study undertaken across 11 NHS sites
has demonstrated that the BCPPA intervention is acceptable to both people with PPA and their CPs, and to SLTs delivering the intervention. Although the AIQ-21 was identified as a potentially suitably sensitive outcome measure, observation data on communication behaviours has not yet been analysed. The current sample size calculation is large and poses a potential difficulty in recruitment to a future full trial with the same design as the current pilot feasibility study. Data collection continues, and further analysis of as yet unexamined communication behaviour is underway. This work will provide additional information to make a better decision about the feasibility of a future large scale evaluation of BCPPA.
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Appendices

3.1. Complete survey questions for UK-wide survey of SLTs
3.2. Dissemination details for recruitment of SLT respondents to UK-wide survey of SLTs
4.1. ITAX adaptation data sheet (O’Rourke et al, 2018)
4.2. PRISMA checklist for systematic review of Functional Communication Interventions for PPA
5.1. Participant Information Sheets for focus groups with people with PPA and CPs
5.2. Consultee Information Sheets for focus groups with people with PPA and CPs
5.3. Consent forms for focus groups with people with PPA and CPs
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5.5. CEN study day advertisement
5.6. Focus group advertisement
5.7. Overview of all BCPPA steering group meetings
5.8. Survey questions disseminated to SLTs prior to CEN study day
5.9. NGT session plan
5.10. Topic guide for focus groups
5.11. Data from first stage of NGT rankings with SLTs
6.1. Pilot-feasibility study Participant Information Sheets
6.2. Pilot-feasibility study Carer Information Sheets
6.3. Pilot-feasibility participant consent forms
6.4. Pilot-feasibility consultee declaration forms
6.5. Log for patients with PPA not recruited for the BCPPA study
6.6. Pilot-feasibility study feedback forms for participants randomised to receive the BCPPA intervention
6.7. Pilot-feasibility study SLT fidelity questionnaire
Appendix 3.1 Complete survey questions for UK-wide survey of SLTs

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
   - West Midlands
   - East Midlands
Yorkshire and The Humber
North West
North East
Ireland
Wales
Scotland
Outside the UK

6. Have you EVER seen a patient with confirmed or queried PPA?
   Yes/No
   [If no please finish the survey now and enter submit]

7. Which setting have you seen patients with PPA in? Please tick all those that apply.
   Acute Medical
   Inpatient Rehabilitation Unit
   Outpatients
   Community- domiciliary, ESD
   Memory Clinic
   Other, please specify

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

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

9. Please estimate the age range of the patients referred:
   < 50 years of age
   50-60 years of age
   60-70 years of age
   >70 years of age

10. Please estimate what percentage came from the following backgrounds?
    English speaking background only
    Non-English speaking background
    Bi / Multi-lingual background
If you saw individuals who spoke languages other than English, please list below the languages used:

11. Of the patients referred to you with PPA what were their current or previous professions:
(Please estimate what percentage were from the following professional areas)
Higher managerial, administrative & professional occupations
Intermediate occupations (such as supervisory, clerical & junior managerial, administrative, professional occupations)
Routine and manual occupations (such as skilled, semi-skilled & unskilled manual occupations)
Never worked or long-term unemployed

12. Do you feel there are people with PPA who haven’t accessed the services you provide?
Yes/No
If yes what are some of the barriers (please tick all that apply):
Geographical location
Language barrier
Offered by decline
Service criteria
Other: (please explain)

13. Compared to previous years do you feel the number of patients with PPA on your caseload has (please tick one box):
Increased
Decreased
Stayed the same
If increased or decreased, please explain why you think this has happened:

14. Which professionals mainly refer people with PPA to the speech and language therapy service where you work? (tick all that apply)
Psychiatrists
Neurologists
Geriatricians
GPs
Psychologists
Other Speech and Language Therapists
Other:

15 What were the symptoms that prompted the referral to your service? (Please estimate the percentage of referrals for each item)
   Word finding difficulties
   Slurred speech
   Volume of speech
   Swallowing difficulties
   Other:

16. Prior to their referral to you, were the patients and their family members made aware of their diagnosis of PPA?
   Always/mostly/sometimes/occasionally/never

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

18. If the patient/family member have been made aware, which of these terms was used?
   Primary progressive aphasia
   Logopenic PPA
   Semantic PPA
   Non-fluent PPA
   Semantic dementia
   Frontotemporal dementia
   Other:

19. Were they informed that this was a type of dementia?
   Always/mostly/sometimes/occasionally/never
20. What difficulties if any do patients report in getting a diagnosis of PPA? (open box?)

21. When are the majority of these patients being referred to you? (please tick one box)
   - Within a year of symptom onset (around diagnosis)
   - 2-3 years post onset (mid-way through the disease process when language symptoms are still the primary issue)
   - 4+ years post onset (later stage of the disease when cognitive symptoms have emerged)
   - Unknown

22. Do you have an established care pathway for people with PPA?
   Yes/no
   Please describe:

Section 3: Time spent on management of this patient group

23. Does your service stipulate how long an individual’s intervention can last when they have a diagnosis of PPA? For example intermediate care often has a six-week intervention limit
   Yes - Please tick the approximate number of sessions (please tick one)
      - 1-2 sessions
      - 2-3 sessions
      - 4-6 sessions
      - 6+ sessions
      - Other, please specify

   No – How many sessions on average would you estimate you spend with an individual from this patient group
   Please tick the approximate number of sessions (please tick one)
      - 1-2 sessions
      - 2-3 sessions
      - 4-6 sessions
      - 6+ sessions
      - Other, please specify

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

- Direct assessment of language and communication
- Assessment of dysphagia
- Contributing to diagnosis of PPA
- Impairment-directed language intervention
- Functional interventions to support communication
- Management of dysphagia
- Education/information for patient
- Education/information for family
- Education/information for staff
- Joint language/communication focused intervention with patient and family/friend/other
- Mental Capacity assessment
- Case/care review meetings
- Joint sessions with other disciplines
- Group therapy

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

- Inpatient
- 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 sue 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)

- Work on reading and writing

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

- Communication training for families /carers

- Communication training for staff

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

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Introducing the person and their family to social and support networks

If you use any other interventions please describe

Section 5: Outcome measures and planning for the future

29. Do you use any of the following as an outcome measure for patients with PPA:
   - Goal setting
   - TOMS (ref)
   - Language assessments e.g. naming, picture description
   - Self-rating scales
   - Speech and language therapist rating scale
   - Video-recording of communication

Other. Please specify

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

31. Do you explicitly address any of the following in planning for the future with patients with PPA? Tick all that apply:
   - Cognitive changes and deterioration in communication
   - Legal, financial, health and social care issues, including assessment of capacity.
   - Driving
   - Family care supports such as respite
   - Family financial supports such as benefits
   - Other. Please specify:

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
Appendix 3.2. Dissemination details for recruitment of SLT respondents to UK-wide survey of SLTs

**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

Many thanks in advance.

Anna
## Appendix 4.1 ITAX adaptation data sheet (O'Rourke et al, 2018).

Data sheet for delivery characteristics (adapted from ITAX delivery characteristics taxonomy)

<table>
<thead>
<tr>
<th>Brief name</th>
<th>Why describe any rationale, the core goal of the intervention (if item 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Method</td>
<td>Method of contact between intervention and participant (if item 6)</td>
</tr>
<tr>
<td>Materials</td>
<td>Materials used in delivery of intervention (if item 3 and 4)</td>
</tr>
<tr>
<td>Location</td>
<td>Where intervention is delivered (if item 7)</td>
</tr>
<tr>
<td>Schedule</td>
<td>Duration and intensity of intervention (if item 5)</td>
</tr>
<tr>
<td>Scoring</td>
<td>Level of detail of guiding integration between the intervention and participant (if item 8)</td>
</tr>
<tr>
<td>Sensibility</td>
<td>Sensitivity to participant characteristics (if item 9)</td>
</tr>
<tr>
<td>Interpersonal characteristics</td>
<td>Qualifications and training, concordance with participant characteristics (if item 10)</td>
</tr>
<tr>
<td>Adaptability</td>
<td>Extent to which intervention can be modified (if item 11)</td>
</tr>
<tr>
<td>Treatment implementation</td>
<td>Documentation of interventionist compliance to intended treatment and modifications (delivery)</td>
</tr>
<tr>
<td></td>
<td>Extent to which processes are implemented by participants and/or professionals (delivery)</td>
</tr>
<tr>
<td></td>
<td>Extent to which knowledge and skills acquired during treatment are applied in real-world settings outside of treatment</td>
</tr>
</tbody>
</table>

### Interventions
- Group
  - No. of people in group: ___
  - Dyadic
  - Individual

### Method of delivery
- Face to face
  - Telephone interview
  - Videoconference
  - Web-based instruction
  - Other: (if item 12)

### Overall duration of intervention
- Minimum guidelines: ___
- Maximum guidelines: ___
- Goals of each session are specified: ___
- Goals and exercises/tasks of each session are specified: ___
- Specific language is provided: ___
- Specific language is provided, with room for elaboration: ___
- Session is provided for humans to speak: ___
- Intervention is delivered by machine: ___
- Intervention materials and delivery in language universal by participant: ___
- Materials written for specific readers or health literacy level: ___
- Visual supplements: ___
- Augmentative communication devices for hearing impaired: ___
- Augmentative communication devices for vision impaired: ___
- Augmentative communication devices for cognition impaired: ___
- Required disciplinary/professional expertise for interventions: ___
- Training/certification requirements: ___
- Tee and quantity of training provided: ___
- Frequency tests passed: ___
- Neuropsychological/gender matching of interventionists to participants: ___
- Intervention staff recruited from participant community: ___
- Intervention staff knowledgeable of cultural views and values of participants: ___

### Distribution of contact time
- Number of sessions: ___
- Number of scheduled sessions: ___
- Number of unscheduled sessions: ___
- Number of time slots: ___
- Number of time slots per week: ___
- Number of time slots per month: ___

### Notes
- Number of contact days: ___
- Number of contact hours: ___
- Number of contact minutes: ___
- Number of contact seconds: ___
- Number of contact sessions: ___
- Number of contact sessions per week: ___
- Number of contact sessions per month: ___
- Number of contact sessions per year: ___

### Adaptable
- Extent to which intervention can be modified (what, on what basis, when?): ___
- Extent to which processes are implemented by participant and/or professionals (delivery): ___
- Extent to which knowledge and skills acquired during treatment are applied in real-world settings outside of treatment: ___

### Treatment implementation
- Documentation of interventionist compliance to intended treatment and modifications (delivery): ___
- Extent to which processes are implemented by participant and/or professionals (delivery): ___
- Extent to which knowledge and skills acquired during treatment are applied in real-world settings outside of treatment: ___

### Notes
- Extent to which intervention was delivered as planned: ___
- Extent to which intervention was delivered as intended: ___
- Extent to which processes were implemented by participant and/or professionals (delivery): ___
- Extent to which knowledge and skills acquired during treatment are applied in real-world settings outside of treatment: ___
Data sheet for program content (adapted from ITAX ‘Content and goals of intervention’ table)

<table>
<thead>
<tr>
<th>Treatment Content Strategies</th>
<th>Mechanisms of Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>(i.e. what does the clinician do)</td>
<td>(i.e. what is the expected change in the participant?)</td>
</tr>
<tr>
<td>Information included in this section was categorised as either:</td>
<td>Information included in this section was categorised as either:</td>
</tr>
<tr>
<td>• Provision of information</td>
<td>• Knowledge</td>
</tr>
<tr>
<td>• Provision of feedback</td>
<td>• Behavioural skills</td>
</tr>
<tr>
<td>• Behavioural incentives/reinforcements</td>
<td>• Motivation</td>
</tr>
<tr>
<td>• Skill building techniques</td>
<td>• Self-efficacy</td>
</tr>
<tr>
<td>• Problem-solving techniques</td>
<td>• Social support</td>
</tr>
<tr>
<td>• Facilitation of social support</td>
<td>• Social engagement</td>
</tr>
<tr>
<td>• Assessment</td>
<td>• Evaluation</td>
</tr>
<tr>
<td>• Tracking of program</td>
<td></td>
</tr>
<tr>
<td>• Provision of instructions</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 4.2. PRISMA checklist for systematic review of Functional Communication Interventions for PPA

<table>
<thead>
<tr>
<th>Section/topic</th>
<th>#</th>
<th>Checklist item</th>
<th>Reported on page #</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TITLE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Title</td>
<td>1</td>
<td>Identify the report as a systematic review, meta-analysis, or both.</td>
<td>1</td>
</tr>
<tr>
<td><strong>ABSTRACT</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structured summary</td>
<td>2</td>
<td>Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.</td>
<td>2</td>
</tr>
<tr>
<td><strong>INTRODUCTION</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rationale</td>
<td>3</td>
<td>Describe the rationale for the review in the context of what is already known.</td>
<td>3-6</td>
</tr>
<tr>
<td>Objectives</td>
<td>4</td>
<td>Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICO).</td>
<td>6</td>
</tr>
<tr>
<td><strong>METHODS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protocol and registration</td>
<td>5</td>
<td>Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.</td>
<td>6</td>
</tr>
<tr>
<td>Eligibility criteria</td>
<td>6</td>
<td>Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.</td>
<td>7-8</td>
</tr>
<tr>
<td>Information sources</td>
<td>7</td>
<td>Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.</td>
<td>7</td>
</tr>
<tr>
<td>Search</td>
<td>8</td>
<td>Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.</td>
<td>7</td>
</tr>
<tr>
<td>Study selection</td>
<td>9</td>
<td>State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).</td>
<td>7-8</td>
</tr>
<tr>
<td>Data collection process</td>
<td>10</td>
<td>Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.</td>
<td>8-10</td>
</tr>
<tr>
<td>Data items</td>
<td>11</td>
<td>List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.</td>
<td>8-10</td>
</tr>
<tr>
<td>Risk of bias in individual studies</td>
<td>12</td>
<td>Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.</td>
<td>10</td>
</tr>
<tr>
<td>Summary measures</td>
<td>13</td>
<td>State the principal summary measures (e.g., risk ratio, difference in means).</td>
<td>10</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>14</td>
<td>Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I²) for each meta-analysis.</td>
<td>8-10</td>
</tr>
<tr>
<td>Section/topic</td>
<td>#</td>
<td>Checklist item</td>
<td>Reported on page #</td>
</tr>
<tr>
<td>--------------------------</td>
<td>----</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>15</td>
<td>Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).</td>
<td>10</td>
</tr>
<tr>
<td>Additional analyses</td>
<td>16</td>
<td>Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.</td>
<td>8-10</td>
</tr>
<tr>
<td>RESULTS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study selection</td>
<td>17</td>
<td>Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.</td>
<td>10-11</td>
</tr>
<tr>
<td>Study characteristics</td>
<td>18</td>
<td>For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.</td>
<td>11</td>
</tr>
<tr>
<td>Risk of bias within studies</td>
<td>19</td>
<td>Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).</td>
<td>11</td>
</tr>
<tr>
<td>Results of individual studies</td>
<td>20</td>
<td>For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.</td>
<td>14-15</td>
</tr>
<tr>
<td>Synthesis of results</td>
<td>21</td>
<td>Present results of each meta-analysis done, including confidence intervals and measures of consistency.</td>
<td>N/A</td>
</tr>
<tr>
<td>Risk of bias across studies</td>
<td>22</td>
<td>Present results of any assessment of risk of bias across studies (see Item 15).</td>
<td>11</td>
</tr>
<tr>
<td>Additional analysis</td>
<td>23</td>
<td>Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).</td>
<td>12-14</td>
</tr>
<tr>
<td>DISCUSSION</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Summary of evidence</td>
<td>24</td>
<td>Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).</td>
<td>15-19</td>
</tr>
<tr>
<td>Limitations</td>
<td>25</td>
<td>Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).</td>
<td>17</td>
</tr>
<tr>
<td>Conclusions</td>
<td>26</td>
<td>Provide a general interpretation of the results in the context of other evidence, and implications for future research.</td>
<td>19</td>
</tr>
<tr>
<td>FUNDING</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td>27</td>
<td>Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.</td>
<td>21</td>
</tr>
</tbody>
</table>

Appendix 5.1. Participant Information Sheets for focus groups with people with PPA and CPs

Participant Information Sheet

Better Conversations with Primary Progressive Aphasia (BCPPA)

Focus Group

Who is doing the research?

The research is being done from University College London.

The main researcher on this project is: Anna Volkmer

You can contact her on

National Institute for Health Research

The National Institute for Health Research is paying for this research

Before you accept it is important to understand:

- Who is doing the research?
- Why is the research being done?
- What will it involve?
- You can choose if you do or do not want to do the research.
- You can talk about this with family and friends.
- You can ask questions at any time.
**Why is the research being done?**

Speech and language therapists provide therapy for people with primary progressive aphasia.

But we don't know enough about it.
The research will help us learn more.

We are asking people like you (who have primary progressive aphasia or have someone in your family with primary progressive aphasia) what they want.

We want to know:

What do you want?

What do you NOT want?

---

**What will it involve?**

You will be invited to one meeting.
You can choose which group you meet with:

1. People with primary progressive aphasia and their families/carers.
2. People with primary progressive aphasia only.
3. Families/carers only.

The meeting will be 2 hours long.

The meeting will be held at University College London.

We will ask your opinions on speech and language therapy.
There will be refreshments available at the group.

There will be a 20 minute rest break in the middle of the meeting.

We will pay for your travel costs.

We will collect information about you, your contact details and when you or your family member were diagnosed with PPA. We will also ask about your hearing and vision.

We will make a video of the group so we do not miss anything.

The information will be stored in a locked filing cabinet at UCL for 10 years.

During the study the videos will be stored in a locked computer hard drive.

**Other questions?**

- You can choose if you want to do the research or not.

- You can talk about this with family and friends.

- You can stop being in the research at any time.

- If you stop you do not have to give a reason...and you or your family member will still get your normal care.

- If you stop your data will still be included in the study.

- We will let your doctor know that you are taking part (if you give permission).

- If you tell us that you or someone else are at risk of harm we will need to speak to other people about this to keep everyone safe.
The videos will be stored in the Human Communication Audio Visual Archive (CAVA) at UCL Library for either

a) **As long as the library exists.** If you agree your videos will be used for future research. Future researchers will sign a contract to respect your confidentiality, rights and dignity and use the videos responsibly.

b) **For one year after the study ends,** when they will be destroyed.

You can choose how long the videos are kept.

Other researchers and students might look at the videos to do more research.

They will be able to see your faces.

They will keep the videos and the information about you safe.

---

**What might be difficult about taking part?**

- **Some people find talking about PPA helps them. You may find it doesn’t help you.**

- You may find it tiring.

- You may find it upsetting.

- It will take 2 hours of your time.
What might be good about taking part?

You may enjoy taking part.

You may find it interesting.

The results may help people in the future.

If you need to make a complaint or you think you were harmed please contact:

1. The main researcher, Anna Vekiczer,

2. The project leader, Suzanne Beeke
If you are still unhappy, make a formal complaint by writing to the NHS Trust that is looking after you. Tell them the project number is ________________.

You can also contact the Patient Advice and Liaison Service (PALS) in your local hospital trust. You can find your local PALS service by asking any local health provider or by looking on the NHS Choices website.

The University has insurance.
Appendix 5.2. Consultee Information Sheet for focus groups with people with PPA and their CPs

Consultee Information Sheet
Student Study
Better Conversations with Primary Progressive Aphasia (BCPPA)
Focus Group

This project has been approved by the Health Research Authority, reference number:

Introduction

We feel your relative/friend is unable to decide for him/herself whether to participate in this research.

To help decide if he/she should join the study, we’d like to ask your opinion whether or not they would want to be involved. We’d ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will also ask you to read and sign the consultee declaration form. We’ll then give you a copy to keep.

We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/friend.

Before you accept it is important to understand:

- **Who** is doing the research?
- **Why** is the research being done?
- **What** will it involve?
- **You can choose** if you do or do not want to do the research.
- **You can talk about this with family and friends.**
- **You can ask questions** at any time.
Who is doing the research?

The research is being done from University College London.

The main researcher on this project is: Anna Vollmer

You can contact her on

National Institute for Health Research

The National Institute for Health Research is paying for this research

Why is the research being done?

Speech and language therapists provide therapy for people with primary progressive aphasia.

But we don’t know enough about it.

The research will help us learn more.

We are asking people like your friend/relative who has primary progressive aphasia or has someone in your family with primary progressive aphasia what they want.

We want to know:

What do you want?

What do you NOT want?
What will it involve?

You relative/friend will be invited to one meeting. They can choose which group they meet with:

1. People with primary progressive aphasia and their families/carers.
2. People with primary progressive aphasia only.
3. Families/carers only.

The meeting will be 2 hours long.

The meeting will be held at University College London.

We will ask your relative’s opinions on speech and language therapy.

There will be refreshments available at the group.

There will be a 20 minute rest break in the middle of the meeting.

We will pay for travel costs.

We will collect information about your friend/relative, their contact details and when they were diagnosed with PPA. We will also ask about hearing and vision.

We will make a video of the group so we do not miss anything.

The information will be stored in a locked filing cabinet at UCL for 10 years.

During the study the videos will be stored in a locked computer hard drive.
Other questions?

You can choose if you want your friend/relative to do the research or not.

You can talk about this with family and friends.

You can withdraw your friend/relative from the research at any time.

If you withdraw them you do not have to give a reason... and your friend/relative will still get their normal care.

If you withdraw them their data will still be included in the study.

We will let your friend/relative’s doctor know that they are taking part (if you give permission).

If your friend/relative tell us that they or someone else are at risk of harm we will need to speak to other people about this to keep everyone safe.

The videos will be stored in the Human Communication Audio Visual Archive (CAVA) at UCL Library for either

a) As long as the Library exists. If you agree the videos will be used for future research. Future researchers will sign a contract to respect your friend/relative’s confidentiality, rights and dignity and use the videos responsibly.

b) For one year after the study ends, when they will be destroyed.

You can choose how long the videos are kept.

Other researchers and students might look at the videos to do more research.

They will be able to see your friend/relative’s face.

They will keep the videos and the information about your friend/relative safe.
What might be difficult about taking part?

- Some people find talking about their PPA helps them. Your friend/relative may find it doesn’t help them.
- Your friend/relative may find it tiring.
- Your friend/relative may find it upsetting.
- It will take 2 hours of your friend/relative’s time.

What might be good about taking part?

- Your friend/relative may enjoy taking part.
- Your friend/relative may find it interesting.
- The results may help people in the future.
If you need to make a complaint or you think your friend/relative were harmed please contact:

1. The main researcher, Anna Volkmer,

2. The project leader,

If you are still unhappy, make a formal complaint by writing to the NHS Trust that is looking after you. Tell them the project number is

You can also contact the Patient Advice and Liaison Service (PALS) in your local hospital trust. You can find your local PALS service by asking any local health provider or by looking on the NHS Choices website.

The University has insurance.
Appendix 5.3. Consent forms for focus groups with people with PPA and CPs

Consent Form
Better Conversations with Primary Progressive Aphasia (BCPPA)
Student Study

Focus Groups

This project has been approved by the Health Research... reference number.

I understand:

1. The main researcher on this project is:
   Anna Volkmer

2. You can contact her on

3. I have read the information about the research.

4. I have had the chance to ask questions about the research.

5. I am happy with the answers to my questions.

6. My name and contact details will not be shared with anyone outside the research team.
7. I understand that the researcher will make a video recording of the group.

8. I understand that the videos and the information will be stored safely at UCL.

9. The information will be in a locked filing cabinet at UCL for 10 years. During the study the videos will be stored in a locked computer hard drive.

10. I understand that I can stop being in the research at any time.

11. If I stop I do not have to give a reason and I will still get my normal care.

12. If I stop my data will still be included in the study.

13. I understand other researchers and students might look at the videos to do more research.

14. I understand that I will get information about the results of the study.

15. I understand that the researcher may present the research and use quotes at conferences or in teaching.

16. I understand that results of the study will be published.

17. I know I will not be identified by my real name.
18. I understand that I can choose how long the videos will be stored in the Human Communication Audio Visual Archive (CAVA) at UCL Library for:

a) As long as the Library exists, for future research. I know that future researchers will sign a contract to respect my confidentiality, rights and dignity and use the videos responsibly.

b) For one year after the study, when they will be destroyed.

I agree to take part in the research.

Name:______________________________

Signed:______________________________
Appendix 5.4. Consultee declaration form for focus groups with people with PPA and their CPs

1. The main researcher on this project is: Anna Vollmer

2. You can contact her on

3. I have been consulted about ˈs participation in this Study.

4. I have read the information about the research.

5. I have had the chance to ask questions about the research.

6. I am happy with the answers to my questions.

7. ˈs name and contact details will not be shared with anyone outside the research team.
8. I understand that the researcher will make a video recording of the group.

9. I understand that the videos and the information will be stored safely at UCL.

10. The information will be in a locked filing cabinet at UCL for 10 years. During the study, the videos will be stored in a locked computer hard drive.

11. I understand that ___________’s participation is voluntary and I can withdraw him/her from the research at any time.

12. If he/she does stop, I do not have to give a reason...and he/she will still get their normal care.

13. If he/she does stop, his/her data will still be included in the study.

14. I understand other researchers and students might look at the videos to do more research.

15. I understand that I will get information about the results of the study.

16. I understand that the researcher may present the research and use quotes at conferences or in teaching.

17. I understand that results of the study will be published.

18. I know __________ will not be identified by his/her real name.
19. I understand that I can **choose how long**
the videos will be stored in the Human
Communication Audio Visual Archive (CAVA)
at UCL Library for:

   a) **As long as the Library exists, for future**
      research. I know that future
      researchers will sign a contract to
      respect ......... confidentiality, rights
      and dignity and use the videos
      responsibly.

   b) **For one year after the study, when**
      they will be destroyed.

20. In my opinion ................. would have
    no objection to taking part in the study.

Please sign and date:

Name of Consultee          Date          Signature

Relationship to Participant: ____________________________

Researcher               Date          Signature

Researcher               Date          Signature
Appendix 5.5. CEN study day advertisement

Dear all,

I am very excited to be writing to give you the first sneak peak at the Better Conversations with Primary Progressive Aphasia program (BCPPA).

Many of you provided me with your contact details following the Dementia and Mental Health in Older Adults CEN study day in November 2016, others have signed up for the forthcoming study in May 2017. Either way I am excited to be able to invite you to participate in evaluating the resource. We are still developing the website and at this stage I am inviting you all to have a look at the first modules within the resource (3 modules). If you have a chance to use them with a patient, even just one handout or a homebased task or one session that would be wonderful. Equally if not please still have a look at the resource and tell me what you think.

You may need to register on the website if you have not previously used Better Conversations- but this is all free. Please do go ahead and do this. If you already have an account you should be able to sign in as usually. Please let me know if you have any problems. (NB: on some devices you may need to scroll to the left side of the screen to login).

The aim of this exercise is for you to critique the BCPPA program and its usability so I can continue to refine the program prior to piloting it in September 2017. All your comments are useful.

Once you have had a look please have a go at filling out the anonymous feedback form on this link:

https://docs.google.com/forms/d/e/1FAIpQLSflFh52pHVOtu8zkTMjPoYVDQ9vT3hR02z2Iy26TNJdoNUg/viewform?usp=sf_link

I will then use the results of the feedback to guide a consensus discussion in the forthcoming study day on 16th May. Even if you are not able to or planning to attend the study day please do complete the feedback as it will still be invaluable.

Many thanks

Anna
Appendix 5.6. Focus group advertisement for PPA support group newsletter

Better Conversations with Primary Progressive Aphasia (BCPPA)

Tell us about what you would like from speech and language therapy.

We are conducting research to find out what people with PPA and their friends and relatives find most useful when working with speech and language therapists.

Anna Volkmer, a PhD student at UCL is conducting research on this over the next few months. She will be holding groups, providing free refreshments and paying for travel costs. Anna will be hosting three groups, one for people with PPA, one for carers and one for people with PPA and their carers who would like to come together.

Please contact Anna on a.volkmer.15@ucl.ac.uk or [telephone number] if you are interested in hearing some more about this research
## Appendix 5.7. Overview of BCPPA steering group meetings

<table>
<thead>
<tr>
<th>Meeting date</th>
<th>Agenda</th>
<th>Key points from discussion</th>
</tr>
</thead>
</table>
| **March 2016** | - Introduction to the BCPPA steering group  
- Review and refinement of Participant Information Sheets and Consent forms | Group members provided guidance on layout and images used on Participant Information Sheets and Consent forms and suggested both CPs and PwPPA use the same forms where possible, given the accessible format is accessible for both. |
<p>| <strong>July 2016</strong> | - Plan development of first draft of BCPPA intervention and training modules | Wrote and agreed list of 7 key modules |
| <strong>November 2016</strong> | - Write a conference poster to showcase role of BCPPA steering group | Wrote and agreed layout, content and took photos for inclusion in poster. Anna presented poster at the National NIHR conference 2016. |
| <strong>March 2017</strong> | - Develop topic list for BCPPA therapy- to support PwPPA and CPs when making video recordings of conversations before, during and after therapy | Members collated topics from their conversations in the week prior to the meeting, shared these in the meeting and refined list to identify key topics for topic list. |
| <strong>July 2017</strong> | - Review and re-write the BCPPA therapy session 1 handouts on what conversation is and how it goes wrong in PPA with guidance from feedback from SLTs in NGT and the focus group data. Also to plan new handout for session 4- to summarise sessions. | Re-wrote BCPPA therapy session 1 handouts completely, adjusted layout and re-formatted image use on handouts on what is conversation and how it goes wrong in PPA. Wrote handouts for BCPPA therapy session 4. |</p>
<table>
<thead>
<tr>
<th>Month</th>
<th>Action</th>
<th>Notes</th>
</tr>
</thead>
</table>
| November 2017 | - Write work plan for forthcoming 6 meetings.  
- Commence work on new module 1, What is PPA? | Workplan written and agreed. Group members shared their experiences and definitions of What PPA is, and we drafted handouts for inclusion in module 1, What is PPA? |
| March 2018   | - Finalise Module 1, What is PPA?  
- Start work on Module 2, What is conversation training? | Finalised layout and editing handouts for inclusion in module 1. Commenced discussions on Module 2, What is conversation training? - agreed that this module might be best communicated with video testimonials from people with PPA, CPs and SLTs |
| July 2018    | - Finalise Module 2, What is conversation training? | Shared questions that would provide a guide for video content – and produced videos with members of the steering group. |
| November 2018 | - Finalise Module 2, What is conversation training?  
- Write Module 7, Useful Resources | Reviewed video clips for Module 2, what is conversation training and agreed additions to layout and formatting. Group members collated lists prior to attending the session on leisure activities they do, and how they modify these to continue doing them. |
| March 2019   | - Review of modules 1, 2 & 7  
- Planning for how the group will stay in touch | Collated final edits for module formatting, particularly use of images in module 7, Useful Resources. Discussed options for keeping in touch, Anna to liaise separately with individuals to agree future plan |
| July 2019    | - Thank you celebration lunch.  
- Planning ideas for dissemination | Identified the main groups we think should know about the project and where we should spread the word e.g. journals, conferences, blogs, through charities and practice magazines |
Appendix 5.8. Survey instructions and questions disseminated to SLTs prior to CEN study day

The BCPPA program is in the process of being developed and tested. In order to keep refining we need your expert critique. We want this to be a useful program with things that will help in clinical practice. Please do be as honest as possible – this is what is most useful.

Your answers WILL be anonymous!!!

1. What was surprising to you when you first accessed BCPPA?
2. List one positive and one negative aspect of Module 3: How to make a video?
3. List one positive and one negative aspect of Module 4: What to target in therapy?
4. List one positive and one negative aspect of Module 5: BCPPA therapy
5. Is there anything you would delete, add or change?
6. Have we missed anything important?
7. Are any materials less useful?
8. What do you feel is most useful in the entire BCPPA program so far?
9. Is the format usable (i.e. the separate modules, with session plans, sessions handouts and home based tasks as downloadable documents) - what would you change?
10. Is the program deliverable for people with PPA- if not why not?
11. We will be developing some other modules to support these- is there anything we should include?
12. Any other comments:
Appendix 5.9. Session plan for Nominal Group Technique with SLTs

1. Introduction:
   Facilitators introduce themselves to the group.
   AV provides a brief summary of the BCPPA program content and processes for the meeting.

2. Attendees separate into two groups, each seated in a semi-circle

3. Research question to be presented:
   What components of the draft BCPPA therapy sessions are important for people with PPA and their conversation partners?

4. Facilitators hand out sheets for 10 minutes of silent work. Participants asked to write down:
   a) demographic information (gender, years of experience, number of people with PPA seen in their career),
   b) Ideas to answer research question.

5. Participants to be asked to share ideas in turn within their group. Facilitator records each idea on a flip chart until all ideas are listed. Ideas are recorded verbatim. Each idea will be given a number.

6. Once recorded each idea will be revisited in turn and the following question asked “Does anyone have any questions about this point and what it means?” A maximum of 3 minutes will be spent clarifying each point. Participants to be prompted that this time is for clarification only, not to provide opinions.

7. Facilitators to hand out eight cards to each participant and ask them to spend 10 minutes in silence choosing the 8 most important items from the flip chart and writing one on each card. Once finished participants o be asked to spend another 10 minutes in silence ranking their choice of eight items from 1-8 (8 being the most important and 1 being the least important).

8. Once completed participants place their anonymous rankings in envelopes and return them to the facilitator.

9. Finish:

All attendees to be thanked for their participation. All attendees to be informed that the results from the two groups would be collated and circulated for final ranking via email.
Appendix 5.10. Topic guide for focus groups with people with PPA and their families

This topic guide has been designed, reviewed and reformulated with advice from the project steering group and service users through the PPA branch of the Rare Dementia Support Group at UCL.

Duration of focus groups including refreshments: 2 hours

1. Introduction of group facilitators, final check that consent paperwork has been completed.
2. Introduction to research topic (use title), reminder re confidentiality and respecting others opinions and plan for today.
3. (start video) Invite group members to introduce themselves:
   “First of all I would like to invite you all to introduce yourselves to the group by telling us your name and how PPA affects your life, perhaps X could start us off?”.
   (30 minutes)

1. Question to guide discussion:
   “How can speech and language therapists support people with PPA to live well and maintain relationships?”

   Prompts:
   What do you no longer talk about? and What would you like to talk about?
   What interventions/resources have you had that have been useful / successful?
   (45 minutes)

6. Close and thank you, advise group on how data will be used and when they will receive a summary of the focus group findings.
(10 minutes)
**Better Conversations with PPA**

Results of the Nominal Group Technique discussion at the Dementia and Mental Health CEN meeting on Tuesday 16th May. The following list provides an overview of the ranked items (some of the items have been merged between the groups as they were so similar. So you can see below a list of ALL the rankings for these and their mean rank. I have listed them in no particular order.

**PLEASE COULD YOU READ AND CHOOSE YOUR TOP 8** from this new list (now you can see all the points from both groups). If could then rank your top 8 in the new column- placing a number from 1-8 to reflect which is most important (8), and least important (1) and all those in between (2,3,4,5,6,7).

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Tally</th>
<th>Mean rank</th>
<th>NEW RANKING</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Focusing on people's strength and working on them as well as areas of potential breakdown. Identifying good versus bad (barriers) communication skills –use of video biofeedback.</td>
<td>8, 6, 8, 7, 4, 4, 8, 4, 5, 8, 7, 6, 6, 8, 2, 7, 7, 8, 4, 5, 8, 1, 3, 5, 7, 6, 1, 6</td>
<td>159 mean = 6</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Person centred and customizable for it to be personal. Individualised: - give PwPPA and carers opportunity to select goals, - Conversational topics, - making it real, - Toolkit to help choose their own strategies</td>
<td>7, 8, 4, 6, 3, 6, 8, 5, 8, 8, 6, 4, 6, 5, 5, 3, 6, 5, 5, 8, 8, 2, 8, 7, 8</td>
<td>157 mean= 6</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Emphasis on communication rather than just speech. Going through areas that may be supportive such as body language, gesture, facial expression, total communication so they’ll feel supported</td>
<td>7, 2, 7, 3, 7, 3, 7, 1, 7, 7, 3, 3, 4, 5, 7</td>
<td>73 mean=5</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Functionality of therapy for individuals involved</td>
<td>6, 7, 3</td>
<td>16 mean = 5</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>A focus on getting message across rather than a perfect interaction</td>
<td>6, 8, 6, 7, 8, 8, 8, 8, 7, 2</td>
<td>68 mean= 7</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Opportunities to practise strategies and get feedback from clinician – better chance of generalising</td>
<td>4, 7, 5, 7, 1, 5, 6, 6, 1, 5, 5, 5, 4, 4</td>
<td>69 mean= 5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>because it’s more of a situation</td>
<td>5, 4, 8, 5, 6, 8, 6, 8, 8, 1</td>
<td>65 mean = 6</td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>--------------------------------------------------------------------------------------------------</td>
<td>------------------------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Carers views of what is successful interaction- better appreciation. Important to understand role of communication partner and how they can help (to understand what it is to carry the conversational load is key to being successful – A normal conversation)</td>
<td>5, 8, 7, 1, 8, 3, 6, 6, 1, 7, 7</td>
<td>59 mean=5</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Recognising and building on current communication strengths</td>
<td>6, 6</td>
<td>12 mean=6</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>How it affect the Conversation Partner- they should be referred together</td>
<td>8, 5, 5, 1</td>
<td>24 Mean=5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The opportunity to reflect on their communication and their impairment re. education but at the start of the program.</td>
<td>8, 5, 5, 1</td>
<td>(4.8)</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Having education without all the jargon</td>
<td>3, 3, 6, 6, 4, 4</td>
<td>34 mean=5</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>Having education without all the jargon</td>
<td>3, 7, 8, 4, 6, 1, 8,4</td>
<td>41 mean=5</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Being told there is something we can do for PPA- that is best practice</td>
<td>3, 7, 8, 4, 6, 1, 8,4</td>
<td>(5.1)</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 6.1. Pilot-feasibility study Participant Information Sheets

Who is doing the research?

The research is being done
from University College
London.

The main researcher on this
project is: Anna Vollmer

You can contact her on

National Institute for
Health Research

The National Institute for
Health Research is paying for
this research

Before you accept it is important to understand:

- Who is doing the research?
- Why is the research being done?
- What will it involve?
- You can choose if you do or do not want to do the research.
- You can talk about this with family and friends.
- You can ask questions at any time.

Page 1 of 2 BCOPPA Pilot Study PIS, IRAS Project ID: 201353, version 2.0 (06/4/2017).
**Why is the research being done?**

Speech and language therapists provide therapy for people with primary progressive aphasia.

But we don’t know enough about it.

The research will help us learn more.

We are developing a therapy treatment called Better Conversations with Primary Progressive Aphasia.

The researcher will look at the results.

We want to know if it works.

**What will it involve?**

We want 42 pairs to take part.

We want to compare Better Conversations with Primary Progressive Aphasia with no treatment.

Half the people will have the Better Conversations with Primary Progressive Aphasia treatment for 4 weeks.

Half the people will have no treatment for 4 weeks.

If you agree to take part you will be randomly assigned to either:

1) Better Conversations with Primary Progressive Aphasia

OR

2) No treatment.
What will I have to do?

Week 1

- Some tests

Weeks 2-5

- Group A
  - 4 sessions of BCPA

- Group B
  - no treatment

Week 6

- Repeat the tests

The tests:

Your speech and language therapist will test your talking, reading and writing. She will ask you how you feel about talking and the impact that PPA has on your life.

You will be video recorded 4 times having a conversation with your family member. The speech and language therapist will make 2 videos, you will make 2 videos at home. We will train you to use the video camera or iPad.

GROUP A: Better Conversations with PPA therapy treatment:

You will watch the videos with the speech and language therapist.

The speech and language therapist will help you see the good strategies, and things that are not working well.

You and your family member will practice how to make conversation easier.

GROUP B: No treatment:

You will have no speech and language therapy for 4 weeks. You will get all your other NHS care as normal.

Repeating the tests:

You will do the tests of talking, reading and writing again.

You will make 4 more videos of you talking with your family member.

Other questions?

We will collect information about you, your contact details and when you were diagnosed with PPA. We will also ask you what other languages you speak, your previous occupation and other medical conditions you might have.

The information we collect will be stored in a locked filing cabinet at UCL for 10 years.

During the study the videos will be stored in a locked computer hard drive.

After the 6 weeks of tests and treatment is finished you can go back to your normal speech and language therapy.
Other questions?

You can choose if you want to do the research or not.

You can talk about this with family and friends.

You can stop being in the research at any time.

If you stop you do not have to give a reason... and you will still get your normal care.

If you stop your data will still be included in the study.

We will let your doctor know that you are taking part (if you give permission).

If you tell us that you or someone else are at risk of harm we will need to speak to other people about this to keep everyone safe.

The videos will be stored in the Human Communication Audio Visual Archive (CAVA) at UCL Library for either:

a) As long as the library exists. If you agree your videos will be used for future research.

Future researchers will sign a contract to respect your confidentiality, rights and dignity and use the videos responsibly.

b) For one year after the study ends, when they will be destroyed.

You can choose how long the videos are kept.

Other researchers and students might look at the videos to do more research.

They will be able to see your faces.

They will keep the videos and the information about you safe.
**What might be difficult about taking part?**

- You may find it won't help you.
- You may find it tiring.
- You may find it upsetting.
- It will take 6 weeks of your time.

**What might be good about taking part?**

- You may find it helps you.
- Other people have found it:
  - makes conversations easier
  - improves things with their family members
  - makes them feel more confident
- You may enjoy taking part.
- You may find it interesting.
- The results may help people in the future.
If you need to make a complaint or you think you were harmed please contact:

1. The main researcher,
   Anna Volkmer,

2. The project leader,
   Suzanne Beeke

Email s.beeke@ucl.ac.uk

If you are still unhappy, make a formal complaint by writing to the NHS Trust that is looking after you. Tell them the project number is

..........................

You can also contact the Patient Advice and Liaison Service (PALS) in your local hospital trust. You can find your local PALS service by asking any local health provider or by looking on the NHS Choices website.

The University has insurance.
Appendix 6.2. Pilot-feasibility study Carer Information Sheets

Who is doing the research?

The research is being done from University College London.

The main researcher on this project is Anna Volkmer

You can contact her on

Who is doing the research?

The National Institute for Health Research is paying for this research.

Before you accept it is important to understand:

- Who is doing the research?
- Why is the research being done?
- What will it involve?
- You can choose if you do or do not want to do the research.
- You can talk about this with family and friends.
- You can ask questions at any time.

This project has been approved by the Health Research Authority. REC reference number: 17/L00357

Page 1 of 12 BCIPPA Pilot Study PIS, IRAS Project ID: 202353, version 2.0 (06/4/2017)
Why is the research being done?

Speech and language therapists provide therapy for people with primary progressive aphasia.

But we don’t know enough about it.

The research will help us learn more.

We are developing a therapy treatment called Better Conversations with Primary Progressive Aphasia.

The researcher will look at the results.

We want to know if it works.

What will it involve?

We want 42 pairs to take part.

We want to compare Better Conversations with Primary Progressive Aphasia with no treatment.

Half the people will have the Better Conversations with Primary Progressive Aphasia treatment for 4 weeks.

Half the people will have no treatment for 4 weeks.

If you agree to take part you will be randomly assigned to either:

1) Better Conversations with Primary Progressive Aphasia

OR

2) No treatment.
What will I have to do?

**Week 1**
- Some tests

**Weeks 2-5**
- Group A
  - 4 sessions of BCPA
- Group B
  - No treatment

**Week 6**
- Repeat the tests

**The tests:**
Your speech and language therapist will test your family member’s talking, reading and writing. She will ask you how you both feel about talking and the impact that PPA has on your life.

You will be **video recorded 4 times** having a conversation with your family member. The speech and language therapist will make 2 videos, you will make 2 videos at home. We will train you to use the video camera or iPad.

**GROUP A: Better Conversations with PPA therapy treatment:**
You will **watch the videos** with the speech and language therapist. The speech and language therapist will help you see the good strategies, and things that are not working well. You and your family member will **practice** how to make conversation easier.

**GROUP B: No treatment:**
You and your family member will have **no speech and language therapy** for 4 weeks. You will get all your other NHS care as normal.

**Repeating the tests:**
Your family member will do the tests of talking, reading and writing again.
You will make **4 more videos** of you talking with your family member.

---

**Other questions?**

We will collect information about you, your **contact details**, and when you were diagnosed with PPA. We will also ask both of you what other languages you speak, your previous occupation and other medical conditions you might have.

The information we collect will be stored in a locked filing cabinet at UG, for 10 years.

During the study the videos will be stored in a locked computer hard drive.

After the 6 weeks of tests and treatment is finished you can go back to your normal speech and language therapy.
Other questions?

You can choose if you want to do the research or not.

You can talk about this with family and friends.

You can stop being in the research at any time.

If you stop you do not have to give a reason, and you and your family member will still get your normal care.

If you stop your data will still be included in the study.

We will let your family member’s doctor know that you are taking part (if you give permission).

If you tell us that you or someone else are at risk of harm we will need to speak to other people about this to keep everyone safe.

The videos will be stored in the Human Communication Audio Visual Archive (CAVA) at UCL Library for either

a) As long as the library exists. If you agree your videos will be used for future research. Future researchers will sign a contract to respect your confidentiality, rights and dignity and use the videos responsibly.

b) For one year after the study ends, when they will be destroyed.

You can choose how long the videos are kept.

Other researchers and students might look at the videos to do more research.

They will be able to see your faces. They will keep the videos and the information about you safe.
What might be difficult about taking part?

You may find it won't help you.

You may find it tiring.

You may find it upsetting.

It will take 6 weeks of your time.

What might be good about taking part?

You may find it helps you.

Other people have found it:
- makes conversations easier
- improves things with their family members
- makes them feel more confident

You may enjoy taking part.

You may find it interesting.

The results may help people in the future.
If you need to make a complaint or you think you were harmed please contact:

1. The main researcher,
   Anna Volkmer,
   - - -

Or

2. The project leader,
   Suzanne Beke

Email s.beke@guf.kc.uk

If you are still unhappy, make a formal complaint by writing to the NHS Trust that is looking after you. Tell them the project number is

______________

You can also contact the Patient Advice and Liaison Service (PALS) in your local hospital trust. You can find your local PALS service by asking any local health provider or by looking on the NHS Choices website.

The University has insurance.
Appendix 6.3. Pilot-feasibility participant consent forms

Consent Form
Better Conversations with Primary Progressive Aphasia (BCPPA) Student Study

Pilot Study

This project has been approved by the Health Research Authority. REC reference number: 17/LO/0307

I understand:

1. The main researcher on this project is: Anna Volkmer

2. You can contact her on

3. I have read the information about the research.

4. I have had the chance to ask questions about the research.

5. I am happy with the answers to my questions.

6. My name and contact details will not be shared with anyone outside the research team.
7. I understand that the researcher will make a video recording of me and my family member.

8. I understand that the videos and the information will be stored safely at UCL.

9. The information will be in a locked filing cabinet at UCL for 10 years. During the study the videos will be stored in a locked computer hard drive.

10. I understand that I can stop being in the research at any time.

11. If I stop I do not have to give a reason....and my family member and I will still get our normal care.

12. If I stop my data will still be included in the study.

13. I understand other researchers and students might look at the videos to do more research.

14. I understand that I will get information about the results of the study.

15. I understand that results of the study will be published.

16. I know I will not be identified by my real name.
17. I understand that I can choose how long the videos will be stored in the Human Communication Audio Visual Archive (CAVA) at UCL Library for:

a) As long as the Library exists, for future research. I know that future researchers will sign a contract to respect my confidentiality, rights and dignity and use the videos responsibly.

b) For one year after the study, when they will be destroyed.

18. I understand that the researcher may show videos of me at conferences or in teaching.

19. I understand that people might recognise me.

20. I understand that anyone who sees these videos will be health professionals, or students studying to be health professionals.

a) I agree that the researcher can use videos of me at conferences or in teaching

b) I do not want videos of me used at conferences or in teaching

I agree to take part in the research.

Name: ..........................................

Signed: ........................................

Research Use: Allocation center for the person

Page 6 of 6 BCOPPA Pilot Study Consent Form, IRAS Project ID: 20283, version 1.0 (10/1/2017).
Appendix 6.4. Pilot-feasibility study consultee declaration form

Consultee Declaration Form
Better Conversations with Primary Progressive Aphasia (BCPPA) Study

Pilot Study

I understand:

1. The main researcher on this project is: Anna Volkmer

2. You can contact her on...

3. I........................ have been consulted about .................’s participation in this Study.

4. I have read the information about the research.

5. I have had the chance to ask questions about the research.

6. I am happy with the answers to my questions.

7. ............’s name and contact details will not be shared with anyone outside the research team.
8. I understand that the researcher will make a video recording of him/her with a family member.

9. I understand that the videos and the information will be stored safely at UCL.

10. The information will be in a locked filing cabinet at UCL for 10 years. During the study the videos will be stored in a locked computer hard drive.

11. I understand that __________’s participation is voluntary and I can withdraw him/her from the research at any time.

12. If he/she does stop I do not have to give a reason… and he/she will still get their normal care.

13. If he/she does stop his/her data will still be included in the study.

14. I understand other researchers and students might look at the videos to do more research.

15. I understand that I will get information about the results of the study.

16. I understand that results of the study will be published.

17. I know __________ will not be identified by his/her real name.
18. I understand that I can choose how long the videos will be stored in the Human Communication Audio Visual Archive (CAVA) at UCL Library for:

a) As long as the Library exists, for future research. I know that future researchers will sign a contract to respect my confidentiality, rights and dignity and use the videos responsibly.

b) For one year after the study, when they will be destroyed.

19. I understand that the researcher may show videos of __________ at conferences or in teaching.

20. I understand that people might recognise _________ him/her.

21. I understand that anyone who sees these videos will be health professionals or students studying to be health professionals.

   a) I agree that the researcher can use videos of __________ at conferences or in teaching.

   b) I do not want videos of __________ used at conferences or in teaching.

22. In my opinion _______________ would have __________ no objection to taking part in the study.
Appendix 6.5. Log for patients with PPA not recruited for the BCPPA study

As part of the BCPPA project we are also collecting on the total numbers of people with PPA or suspected PPA being referred to each service. This will provide information on recruitment data for a future full trial.

If a participant who has PPA or suspected PPA is on your caseload and is **NOT participating in the pilot study** please enter their details below.

Please email this document to me on a monthly basis.

<table>
<thead>
<tr>
<th>Date of referral (month/year)</th>
<th>Gender and age</th>
<th>Please complete the following</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td>Is the person eligible for the study? No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>If no, please indicate relevant exclusion criteria</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(a) Have a history of brain lesions or major head trauma;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(b) Have major physical illness or disability which could impact on participation;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(c) Present with a major psychiatric diagnosis;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(d) Present with prominent behavioural disturbance;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(e) Present with prominent episodic memory, visual memory or visuoperceptual impairments.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(f) Eligible but declined to participate y/n</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(g) other</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>Is the person eligible for the study? y/n</td>
</tr>
<tr>
<td></td>
<td></td>
<td>If no, please indicate relevant exclusion criteria</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(a) Have a history of brain lesions or major head trauma;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(b) Have major physical illness or disability which could impact on participation;</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>(c) Present with a major psychiatric diagnosis;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d) Present with prominent behavioural disturbance;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e) Present with prominent episodic memory, visual memory or visuoperceptual impairments.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(f) Eligible but declined to participate y/n</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(g) other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 6.6. Pilot-feasibility study feedback forms for participants randomised to receive the BCPPA intervention

Pilot Study: Feedback Form

Better Conversations with Primary Progressive Aphasia (BCPPA)

This questionnaire has been designed for you to complete together after every therapy session. Please complete your homework first.

Your views are very important to us as they will help to develop the therapy programme for others in the future.

Your answers will be used anonymously. Your comments will be stored safely and securely as outlined in the consent forms.

Thank you for your time.

Please rate how the session was explained to you.
(e.g. enough detail given, well explained?)

1 2 3 4 5

Poorly Explained very well explained

Why?
2. How would you rate the **format** of the session?

   1. **e.g. order of discussions**
   2. **time spent on each section**

<table>
<thead>
<tr>
<th>Poor Format</th>
<th>great format</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

3. How would you rate the therapist’s **delivery** of the session?

<table>
<thead>
<tr>
<th>Poor delivery</th>
<th>great delivery</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

   Why?
4. Were any parts of this week’s session particularly useful for you?
   
   Yes / No (delete as appropriate)

5. Were any parts of this week’s session not useful for you?

   Yes / No (delete as appropriate)

What? Why?
6. Did you find watching the videos of yourselves useful, as part of the session?

Yes / No (delete as appropriate)

Why?

7. Did you find the homework task useful?

Yes/No (delete as appropriate)

Why?
8. Was the session what you expected?

Yes / No (delete as appropriate)

Why?

9. Do you think anything else should have been included in the session?

10. So far, is the therapy helping?

Yes / No (delete as appropriate)

Why?
11. Do you think the session helped you with your: (please circle)

Knowledge and understanding of PPA

Communication skills

If so, how?

12. Have you made any changes to your communication since the start of therapy?

Yes / No (delete as appropriate)

Example:

..................................................................................................................  
..................................................................................................................
..................................................................................................................
................................................................................................................
13. Did anything affect your response to therapy this week?

- e.g. medication changes
- illness
- stress
- any other therapy e.g. psychology appointment
- Anything else:

Thank you for taking the time to complete this questionnaire.

Please return to the researchers in the stamped addressed envelope enclosed.
Appendix 6.7. Fidelity questionnaire for SLT collaborators BCPPA pilot-feasibility study

**During BCPPA therapy for every dyad**

Thank you for participating in the BCPPA training- we really appreciate your role in the research project. To continue to improve the research work please could you answer the following questions.

<table>
<thead>
<tr>
<th>Complete after delivering Session 1:</th>
</tr>
</thead>
<tbody>
<tr>
<td>How confident did you feel about delivering BCPPA therapy session 1 [What is conversation?]?</td>
</tr>
<tr>
<td>very confident</td>
</tr>
<tr>
<td>1A. Did you discuss the aims of therapy with the dyad?</td>
</tr>
<tr>
<td>1B. Did you explore with the dyad what conversation is and how it can go wrong?</td>
</tr>
<tr>
<td>1C. Did you show the dyad a video of their own conversation?</td>
</tr>
</tbody>
</table>

If the answer to any of these questions about session 1 was NO, please comment:

2. Did the dyad show interest in this session?

<table>
<thead>
<tr>
<th>extremely interested</th>
<th>very much interested</th>
<th>quite a lot interested</th>
<th>a little interested</th>
<th>not at all interested</th>
</tr>
</thead>
</table>

Any comments:

3. Did the dyad show enjoyment in this session?

<table>
<thead>
<tr>
<th>extremely enjoyed</th>
<th>very much enjoyed</th>
<th>quite a lot enjoyed</th>
<th>a little enjoyed</th>
<th>not at all enjoyed</th>
</tr>
</thead>
</table>

Any comments:

4. How long was the session (please explain any reason for it being more or less than 60 minutes)?

5. Where was the session delivered?

<table>
<thead>
<tr>
<th>At home</th>
<th>In outpatient setting</th>
</tr>
</thead>
</table>

Do you have any other comments about delivering the session with this dyad?
Complete after delivering Session 2:

1. How confident did you feel about delivering BCPPA therapy session 2 [Goal setting]?
   very confident confident somewhat confident not at all confident

2B. Did you facilitate the dyad to identify barriers and facilitators in their own conversations? YES/NO

2B. Did you facilitate goal setting for therapy based on this discussion? YES/NO

If the answer to any of these questions about session 2 was NO, please comment:

2. Did the dyad show interest in this session?
   extremely very much quite a lot a little not at all

Any comments:

3. Did the dyad show enjoyment in this session?
   extremely very much quite a lot a little not at all

Any comments:

4. How long was the session (please explain any reason for it being more or less than 60 minutes)?

5. Where was the session delivered?
   At home In outpatient setting

6. Do you have any other comments about delivering the session with this dyad?
Complete after delivering Session 3:

1. How confident did you feel about delivering BCPPA therapy session 3 [Practice]?

   very confident  confident  somewhat confident  not at all confident

3A. Did the dyad practice conversation using the strategies identified during goal setting? YES / NO

3B. Did you problem solve any issues that arose for the dyad when using their strategies in conversations outside of therapy sessions? YES / NO

   If the answer to any of these questions about session 3 was NO, please comment:

2. Did the dyad show interest in this session?

   extremely  very much  quite a lot  a little  not at all

   Any comments:

3. Did the dyad show enjoyment in this session?

   extremely  very much  quite a lot  a little  not at all

   Any comments:

4. How long was the session (please explain any reason for it being more or less than 60 minutes)?

5. Where was the session delivered?

   At home    In outpatient setting

6. Do you have any other comments about delivering the session with this dyad?

Complete after delivering Session 4:

1. How confident did you feel about delivering BCPPA therapy session 4 [Problem solving and planning for the future]?
### Session 4 Questions

4A. Did the dyad practice conversation using the strategies identified during goal setting? **YES/NO**

4B. Did you facilitate a discussion with the dyad on planning for future changes in communication? **YES/NO**

If the answer to any of these questions about session 4 was NO, please comment:

2. Did the dyad show interest in this session?

   extremely very much quite a lot a little not at all

   Any comments:

3. Did the dyad show enjoyment in this session?

   extremely very much quite a lot a little not at all

   Any comments:

4. How long was the session (please explain any reason for it being more or less than 60 minutes)?

5. Where was the session delivered?

   At home In outpatient setting

6. Do you have any other comments about delivering the session with this dyad?

---

Please put your completed questionnaire in the stamped, addressed envelope provided to maintain confidentiality. Return the envelope to Dr Suzanne Beeke, Chandler House, UCL, 2 Wakefield Street, London, WC1N 1PF. THANK YOU.