

1 Using the Medical Research Council Framework and public  
2 involvement for the development of a communication partner training  
3 intervention for people with primary progressive aphasia (PPA):  
4 Better Conversations with PPA

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7 **Authors:**

8 Anna Volkmer<sup>1,2</sup> (ORCID iD: 0000-0002-4149-409X), Aimee Spector<sup>1</sup>,

9 Kate Swinburn<sup>1</sup> Jason D. Warren<sup>2</sup>, Suzanne Beeke<sup>1</sup>.

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11 **Institutional Affiliations**

12 1 Division of Psychology and Language Sciences

13 2 Dementia Research Centre, Department of Neurodegenerative  
14 Disease, UCL Institute of Neurology

15 University College London, London, United Kingdom

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17 **Corresponding author:**

18 Anna Volkmer, Division of Psychology and Language Sciences, University

19 College London. [a.volkmer.15@ucl.ac.uk](mailto:a.volkmer.15@ucl.ac.uk)

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## 1 **Abstract**

2 Background: Primary progressive aphasia is a language-led dementia  
3 resulting in a gradual dissolution of language. Primary progressive aphasia  
4 has a significant psychosocial impact on both the person and their families.  
5 Speech and language therapy is one of the only available management  
6 options, and communication partner training interventions offer a practical  
7 approach to identify strategies to support conversation. The aim of this  
8 study was to define and refine a manual and an online training resource for  
9 speech and language therapists to deliver communication partner training  
10 to people with primary progressive aphasia and their communication  
11 partners called Better Conversations with primary progressive aphasia.

12 Methods: The Better Conversations with primary progressive aphasia  
13 manual and training program were developed using the Medical Research  
14 Council framework for developing complex interventions. The six-stage  
15 development process included 1. Exploratory review of existing literature  
16 including principles of applied Conversation Analysis, behaviour change  
17 theory and frameworks for chronic disease self- management, 2.  
18 Consultation and co-production over 12 meetings with the project steering  
19 group comprising representatives from key stakeholder groups, 3.  
20 Development of an initial draft, 4. Survey feedback followed by a consensus  
21 meeting using the Nominal Group Techniques with a group of speech and  
22 language therapists, 5. Two focus groups to gather opinions from people  
23 with PPA and their families were recorded, transcribed and Thematic  
24 Analysis used to examine the data, 6. Refinement.

1 Results: Co-production of the Better Conversations with primary  
2 progressive aphasia resulted in seven online training modules, and a  
3 manual describing four communication partner training intervention  
4 sessions with accompanying handouts. Eight important components of  
5 communication partner training were identified in the aggregation process  
6 of the Nominal Group Technique undertaken with 36 speech and language  
7 therapists, including use of video feedback to focus on strengths as well as  
8 areas of conversation breakdown. Analysis of the focus groups held with  
9 six people with primary progressive aphasia and seven family members  
10 identified three themes 1) Timing of intervention, 2) Speech and language  
11 therapists' understanding of types of dementia, and 3) Knowing what helps.  
12 These data informed refinements to the manual including additional  
13 practice activities and useful strategies for the future.

14 Conclusions: Using the Medical Research Council framework to develop an  
15 intervention that is underpinned by a theoretical rationale of how  
16 communication partner training causes change allows for the key  
17 intervention components to be strengthened. Co-production of the manual  
18 and training materials ensures the intervention will meet the needs of  
19 people with primary progressive aphasia and their communication partners.  
20 Gathering further data from speech and language therapists and people  
21 living with primary progressive aphasia and their families to refine the  
22 manual and the training materials enhances the feasibility of delivering this  
23 in preparation for a phase II NHS-based randomised controlled pilot-  
24 feasibility study, currently underway.

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1 **Keywords:** Primary Progressive Aphasia; Speech and Language Therapy;  
2 Intervention; conversation; co-production; consensus.

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1 **Background:**

2 The number of people living with dementia worldwide continues to rise,  
3 estimated at around 50 million at present with nearly 10 million new cases  
4 each year<sup>1</sup>. Of these, perhaps a half a million people worldwide and several  
5 thousand in the United Kingdom have primary progressive aphasia (PPA):  
6 a group of language-led dementias associated with Frontotemporal  
7 Dementia and Alzheimer's disease<sup>2</sup>. PPA presents as an insidious  
8 dissolution of language skills with relative sparing of other cognitive  
9 functions<sup>2</sup>. At present there are three internationally recognised PPA  
10 variants; people with semantic variant experience a gradual loss of word  
11 meanings affecting both comprehension and naming, people with logopenic  
12 variant PPA present with difficulties in word retrieval and processing of  
13 complex sentences, and people with non-fluent agrammatic variant PPA  
14 demonstrate effortful, distorted articulation of speech sounds (apraxia)  
15 and/or an agrammatism<sup>3</sup>. Each variant presents with a distinct  
16 neuroanatomical distribution of atrophy and underlying neuropathology<sup>2,3</sup>.  
17 Though it constitutes only a small proportion of the total dementia burden,  
18 PPA is of disproportionate clinical importance because it tends to strike  
19 people in older midlife with devastating impact on occupational and social  
20 functioning and because it presents a number of unique challenges not well  
21 met by conventional models of aphasia and dementia management.

22 People with PPA report increasing social isolation and reduced confidence  
23 as a result of their worsening communication difficulties<sup>4</sup>. More than one  
24 third of people with PPA experience depression and symptoms of anxiety  
25 are not uncommon. These likely impact directly on reports of reduced

1 quality of life amongst people with PPA<sup>5</sup>. Spouses of people with PPA  
2 report a long trajectory of change, even prior to diagnosis. This results in  
3 feelings of loss of relationship and meaningful social interaction, increasing  
4 dependency of their spouse with PPA on them for communication, and  
5 overwhelming responsibility<sup>6</sup>.

6 The research literature on speech and language treatment approaches for  
7 people with PPA is developing. The majority of research has focused on  
8 impairment-focused interventions that aim to maintain or improve the  
9 person's ability to use words<sup>7,8</sup>. Many people with PPA disengage from such  
10 naming therapies due to the frustration of practising individual words they  
11 will inevitably lose as the disease progresses<sup>9</sup>. More recently there has  
12 been a growing focus on functional communication interventions for PPA,  
13 which aim to support a person to execute an activity or participate in a life  
14 situation<sup>10</sup>. A systematic review of these diverse interventions identified two  
15 key shared components; building on existing strategies, and practising  
16 strategies with a communication partner<sup>10</sup>.

17 Despite barriers to therapy access, such as a lack of awareness of the role  
18 of the speech and language therapist in PPA, and restrictive service criteria,  
19 the number of people with this condition being referred to speech and  
20 language therapy is increasing<sup>11</sup>. In contrast to a research focus on naming  
21 therapies, in clinical practice speech and language therapists prioritise  
22 communication partner training (CPT) interventions for people with PPA  
23 and their communication partners (CPs; **who may be anyone close to the**  
24 **person such as spouses, family members or friends**)<sup>11,12</sup>.

1 CPT interventions for stroke and dementia have arisen from studies of  
2 conversation between people with communication disorders and their CPs.  
3 This research demonstrates that both people with dementia and aphasia  
4 draw on areas of retained strength, such as gesture, to maintain  
5 interactional flow<sup>13,14,15</sup>. Some CPs are seen to facilitate conversational  
6 interaction, for example through giving time, but can equally expose their  
7 partners' difficulties by using barrier behaviours, for example, test questions  
8 (to which they already know the answer, a pedagogic behaviour used with  
9 children). CPT interventions aim to change conversation behaviours, enhancing  
10 conversational skill and confidence, and reducing barriers to facilitate the flow of  
11 natural conversation<sup>16</sup>. CPT interventions result in improved quality of life and  
12 wellbeing for people with dementia, and improved competency in their  
13 CPs<sup>17</sup>.

14 Many speech and language therapists report delivering CPT to people with  
15 PPA and describe using resources developed for stroke aphasia or brain  
16 injury related communication difficulties<sup>12</sup>. CPT has a growing evidence  
17 base in stroke aphasia<sup>16,18</sup> and delivers positive changes in the  
18 conversation skills of people with aphasia as well as their CPs<sup>19,20</sup>.  
19 However, CPT approaches in stroke aphasia are not designed to meet the  
20 needs of people with progressive communication difficulties. Currently  
21 there are only case study reports of CPT for people with PPA<sup>21,22</sup>. There is  
22 some suggestion of increased communicative effectiveness as a result,  
23 however, it is difficult to attribute these gains to CPT due to the fact that  
24 individuals were concurrently participating in additional interventions. Thus,  
25 there is a clinical need to develop a CPT intervention designed to meet the

1 needs of people with PPA and their families<sup>6,23,24</sup>.

2 To our knowledge there has been no specific research undertaken asking  
3 people with PPA and their families what interventions are important or need  
4 to be developed. People with PPA have written about their general  
5 experiences of speech and language therapy and the value of developing  
6 “a wide range of personalized strategies that continually evolve as the  
7 disease progresses”<sup>25</sup>. Spouses report a need to develop practical  
8 approaches to deal with communication difficulties and maintain a close  
9 bond with their loved ones<sup>6</sup>. These issues are more likely to be met by  
10 tailored interventions, that build capacity by helping them to adjust and  
11 reframe their communication over time<sup>6</sup>. Speech and language therapists  
12 themselves have identified a need to engage family who are motivated to  
13 understand how they can best support their loved ones<sup>26</sup>. Therefore,  
14 gathering ideas and contributions of people living with PPA, often described  
15 as Public Involvement, is important to ensuring an intervention will meet  
16 their needs. Public Involvement is defined by the UK Standards for Public  
17 Involvement as research that is carried out with members of the public  
18 rather than to them<sup>27</sup>. These standards include ensuring that people are  
19 involved as early as possible and that participation is made accessible. Co-  
20 production is defined as a way of working where people (service users) and  
21 providers work together to reach a collective outcome<sup>28</sup>. The aim of this  
22 study was to work with people with PPA and their families, from the  
23 beginning, to co-produce a CPT intervention to meet their needs.

24 Ensuring strict standardisation is unlikely to be appropriate given the need  
25 to tailor CPT to an individual’s needs but understanding what causes the

1 change so this can be identified and strengthened in the development  
2 process is key. This complex intervention, with its multiple interacting  
3 components, such as working with both a person with PPA and their CP,  
4 will be difficult to evaluate. The Medical Research Council provide a  
5 framework for developing and evaluating complex interventions<sup>29</sup>. The  
6 guidance outlines the importance of preliminary development and testing of  
7 an intervention's procedures prior to piloting and evaluation. This paper  
8 therefore describes how the Medical Research Council framework was  
9 used to develop Better Conversations with PPA (BCPPA), a 4-session,  
10 manualised, CPT intervention to help people with PPA and their CPs to  
11 identify and practice strategies to reduce barriers (such as interjecting when  
12 a person may not have finished) and increase facilitators in conversations  
13 (such as giving more time). A manual and an online training resource for  
14 speech and language therapists, hosted on a life-learning platform at UCL,  
15 were developed to enable speech and language therapists to deliver the  
16 intervention. In line with stages 1 and 2 of the Medical Research Council  
17 Framework the underlying theory and proposed mechanisms of change for  
18 the BCPPA program will be described as well as primary research which  
19 informed the co-production of the manual and online training resource.

## 20 Aim

21 To use the Medical Research Council framework for developing complex  
22 interventions to define and refine a manual and an online training resource  
23 for speech and language therapists to deliver BCPPA to people with PPA  
24 and their CPs.

1 **Methods**

2 Intervention development activities were based on phases one and two in  
3 the Medical Research Council framework for development of complex  
4 interventions<sup>29</sup>. This comprised six stages including 1. examination of  
5 existing literature, 2. consultation and co-production work, 3. development  
6 of an initial draft, 4. consensus work with speech and language therapists,  
7 5. focus groups with people with PPA and their families, 6. Refinement of  
8 the BCPPA intervention and manual in preparation for the randomised  
9 controlled pilot-feasibility study. Figure 1 demonstrates how these activities  
10 map onto the Medical Research Council guidance. Intervention  
11 development also followed the GUIDED guidelines for reporting for  
12 intervention development studies<sup>30</sup>. Further patient and public involvement  
13 work undertaken to finalise outstanding training modules identified as  
14 supplementary to the RCT will not be discussed here. The first author, A.V.,  
15 an experienced speech and language therapist, led all stages. **Work was**  
16 **undertaken over two years between 2016 and 2018.**

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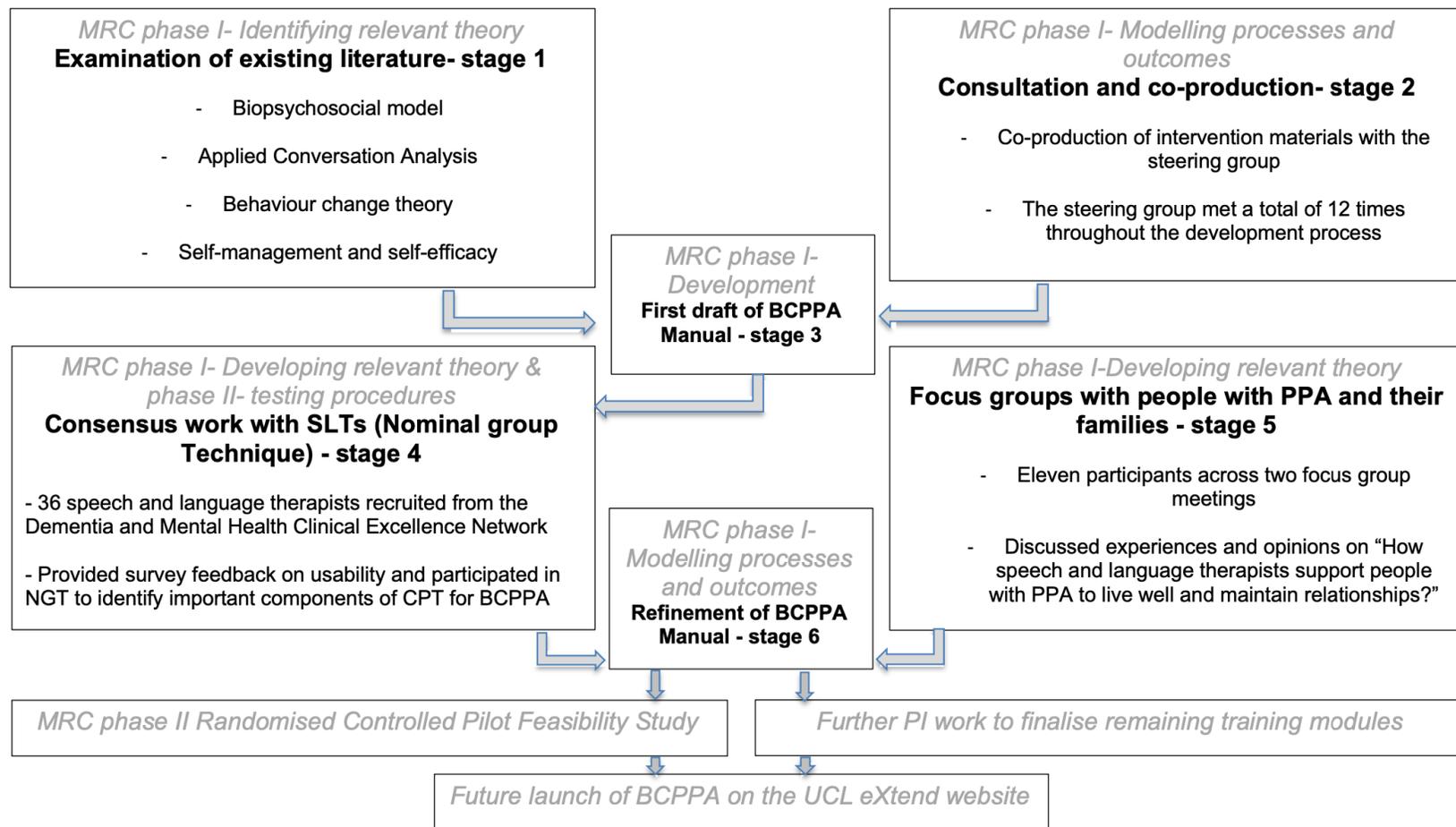
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1 Figure 1. The six stages in the development BCPPA intervention and manual drafting, mapped on to the Medical  
 2 Research Council framework for development of complex interventions.



## 1 **Recruitment**

2 *Consultation and co-production work (Stage 2):* An opportunistic sample of  
3 people with PPA and their families, specialist speech and language  
4 therapists and neuropsychologists were invited to join the project steering  
5 group. A.V. emailed people who were known to her through clinical work  
6 and asked the facilitator of the PPA branch of the Rare Dementias Support  
7 Group based at UCL (<https://www.raredementiasupport.org>) to forward an  
8 invitation email to individuals in the support group, inviting them to  
9 participate.

10 *Consensus work (Nominal Group Technique) with speech and language*  
11 *therapists (Stage 4):* speech and language therapists were recruited to  
12 participate in the Nominal Group Technique consensus study through the  
13 Royal College of Speech and Language Therapy Dementia and Mental  
14 Health Clinical Excellence Network, of which A.V. was a committee  
15 member. **An advert was placed in the Royal College of Speech and**  
16 **Language Therapy clinical practice magazine (Bulletin) and via emails**  
17 **circulated to members inviting them to attend.**

18 *Focus groups with people with PPA and their families (Stage 5):* People  
19 with PPA and their families who attend the PPA branch of the Rare  
20 Dementias Support Group at UCL were invited to participate in one of two  
21 focus group meetings held at an accessible venue on the university  
22 campus. The aim was to recruit eight people to each focus group, totaling  
23 16 participants. To optimize opportunities for individuals with  
24 communication difficulties to contribute to discussion<sup>31</sup>, group numbers

1 were capped at eight participants. Potential participants who responded to  
2 the advert were contacted by A.V. on the telephone to judge if they met the  
3 inclusion criteria of a) a diagnosis or possible diagnosis of PPA/relative with  
4 such a diagnosis, b) the ability to communicate to participate in a focus  
5 group c) see and hear well enough to participate d) English as their  
6 language of daily use. Potential participants were excluded if they had a) a  
7 history of brain lesion or major head trauma, b) major physical illness or  
8 disability which could impact on participation. criteria required.

### 9 **Examination of existing literature (Stage 1)**

10 Literature was selected following discussion with the research team to  
11 identify papers known to explore the theoretical underpinnings of  
12 interventions for dementia and CPT. The author then conducted searches  
13 of the reference lists of the articles to identify any other relevant articles.  
14 This included literature on existing models of dementia, principles of applied  
15 Conversation Analysis, behaviour change theory and frameworks for  
16 chronic disease self- management were explored. This informed the  
17 preliminary contents and focus of the intervention.

### 18 **Consultation and co-production work (Stage 2)**

19 There remains a lack of guidance on undertaking Public Involvement with  
20 people with communication difficulties<sup>32</sup> This work was therefore informed  
21 by information from the INVOLVE website<sup>28</sup> and bespoke advice from a co-  
22 author (K.S.) and expert on Public Involvement with people with stroke  
23 aphasia but modified to meet the needs of people in the group. Four people  
24 with PPA and their spouses, two expert speech and language therapists, a

1 neuropsychologist and the group facilitator (A.V.) took part in 12 formal  
2 BCPPA Public Involvement steering group meetings. Public Involvement  
3 work to co-produce the BCPPA intervention materials and training modules  
4 was informed by feedback from people with PPA who had previously  
5 received CPT<sup>32</sup>, research undertaken by A.V.<sup>10,11,12</sup> and research into the  
6 BCA program for people with stroke aphasia<sup>34</sup>. Discussion focused on  
7 identifying what distinct training modules would be required for the BCPPA  
8 training program and what the session plans and handouts would need to  
9 include for the manual. Once identified, a timeline for development was  
10 agreed and work undertaken to coproduce the content in steering group  
11 meetings. In order to support communication, steering group members  
12 were informed of the topic for discussion in advance of each meeting and  
13 invited to contribute in advance, during or after meetings using verbal,  
14 written or visual means, e.g. bringing photos, drawing pictures writing  
15 brainstorm or assembling and re-assembling draft materials.

### 16 **First draft of the manual (Stage 3)**

17 A draft of the BCPPA manual was developed using PowerPoint software.  
18 In order to upload these to the UCLeXtend website an online software  
19 package called Articulate was used to adapt the PowerPoint slides to an  
20 appropriate format. The work was undertaken with assistance from speech  
21 and language therapist researchers and four postgraduate researchers in  
22 speech and language sciences who were paid for their time.

### 23 **Consensus work (Nominal Group Technique) with speech and** 24 **language therapists (Stage 4)**

1 The Nominal Group Technique was carried out at one of the Royal College  
2 of Speech and Language Therapy, Dementia and Mental health Clinical  
3 Excellence Network meetings. Draft one of the manual was made available  
4 to attendees (speech and language therapists). In order to gain an  
5 understanding of the clinical experiences and reality of speech and  
6 language therapists a qualitative research method was identified as  
7 appropriate. Speech and language therapists were encouraged to review  
8 the resource and pilot it with their clients. To ensure the BCPPA intervention  
9 reflected a consensus view of the most important components to include in  
10 a CPT intervention for people with PPA and their families a Nominal Group  
11 Technique method was chosen. Given that many of the speech and  
12 language therapists participating in the meeting had pre-existing  
13 professional relationships that could result in certain voices being  
14 represented over others in discussions, the Nominal Group Technique  
15 method was also chosen to provide opportunities to consider ideas and  
16 experiences equally yet allowing for clarification and discussion prior to  
17 rating<sup>35</sup>.

18 Six weeks prior to attending the meeting speech and language therapists  
19 were sent an email inviting them to anonymously complete a 12-item  
20 feedback survey comprising all open questions (supplementary document  
21 1), hosted online on the Google Forms platform. Survey questions were  
22 developed by A.V. in consultation with the steering group and included  
23 questions about speech and language therapists' experiences and views  
24 on the content and format of the manual.

25 The Nominal Group Technique meeting itself comprised a two-stage

1 ranking process commencing with a 90-minute group session (stage one),  
2 followed by email consultation (stage two). Meeting facilitators (AV and SB)  
3 agreed the session plan and central question for discussion in advance  
4 (see supplementary document 2), in line with guidelines for conducting  
5 Nominal Group Technique meetings<sup>14</sup>. At stage two, results of the group  
6 session were circulated via email to all participants, providing information  
7 on scores and mean rankings for each item. As per guidelines for  
8 conducting Nominal Group Technique meetings<sup>32</sup>, items describing the  
9 same ideas from the two groups were merged, following discussion and  
10 agreement between A.V. and S.B. Participants were asked to reply via  
11 email identifying and ranking their top eight items from this list (by placing  
12 a number from 1-8 to reflect which is most important - 8 and least important  
13 - 1). Following Nominal Group Technique guidelines<sup>35</sup>, scores were tallied  
14 and mean rankings calculated to identify the top eight ranked items overall.

#### 15 **Focus groups with people with PPA and their families (Stage 5)**

16 Two focus groups took place, to provide people with PPA and their families  
17 the choice of attending with or without partners. Discussion was guided by  
18 the question 'How can speech and language therapists support people with  
19 PPA to live well and maintain relationships?'. The focus groups were jointly  
20 facilitated by A.V., alongside volunteer student speech and language  
21 therapists from UCL (one per focus group). A topic guide was co-produced  
22 with the BCPPA steering group and attendees of the PPA branch of the  
23 Rare Dementia Support Group at UCL (see supplementary document 3).  
24 Focus group discussions were video recorded and transcribed by UCL

1 student speech and language therapists (using transcription guidance<sup>33</sup>).  
2 Given the researchers objectives to understand the lived experiences of  
3 people with PPA and their families, and gather opinions from them,  
4 qualitative methods employing a realist approach to reflexive thematic  
5 analysis was undertaken<sup>37,38</sup>. Initial codes were generated by  
6 systematically coding interesting features (phase 2), collating these into  
7 potential themes (phase 3) and reviewing them in relation to the coded  
8 extracts (phase 4). Potential themes were refined to generate definitions  
9 and names (phase 5), further inspected to identify and report any additional  
10 key elements (phase 6). In addition, to improve reliability of analysis, four  
11 speech and language therapist researchers with experience of thematic  
12 analysis independently extracted data from a randomly selected section of  
13 transcript, discussed and reached agreement on the coding of themes  
14 arising from the data.

#### 15 **Refinement of the BCPPA manual (Stage 6)**

16 Results of work in stages 4 and 5 of intervention development were  
17 presented to the project steering group. Refinements were jointly identified  
18 and agreed by the group members.

#### 19 **Results**

##### 20 Examination of existing literature (Stage 1)

21 Existing literature comprising the bio-psychosocial model of dementia,  
22 applied Conversation Analysis, behaviour change theory and self-  
23 management and self-efficacy theory was examined.

1

## 2 Bio-psychosocial model of dementia

3 The bio-psychosocial model<sup>39</sup> proposes that there are factors other than the  
4 organic causes of dementia that influence the nature and speed of  
5 deterioration in daily functioning. These include some factors that are fixed,  
6 such as PPA variant, that cannot be changed. The BCPPA manual  
7 therefore provides practice tasks, to maximise generalisation for people  
8 with semantic PPA, for whom this is more difficult than those with non-fluent  
9 PPA. Tractable factors, such as the way a CP interacts with a person with  
10 PPA, may be amenable to change and are directly targeted in the BCPPA  
11 intervention. Adaptive mechanisms used by the CP, such as multiple  
12 questions or test questions, may result in the person with PPA feeling  
13 incompetent<sup>40</sup>. On the other hand, the use of gesture and enactment (whole  
14 body gesture and pantomime) by a person with PPA when they are having  
15 difficulty retrieving a spoken word<sup>41</sup> could be described as an effective  
16 coping strategy. The BCPPA intervention seeks to take account of fixed  
17 factors whilst targeting tractable factors to support the dyad (person with  
18 PPA and their CP) achieve their potential function.

19

## 20 Applied Conversation Analysis

21 Conversation Analysis is an approach to the study of human social  
22 interaction through the analysis of spontaneous, naturally occurring talk<sup>42</sup>.  
23 A number of Conversation Analysis informed stroke aphasia intervention  
24 studies and clinical resources have been developed<sup>43</sup> such as Supported

1 Conversation for adults with Aphasia<sup>18</sup>, Supporting Partners of People with  
2 Aphasia in Relationships and Conversation<sup>44</sup> and BCA<sup>45</sup>. These have in  
3 common the analysis of video recordings of natural conversations  
4 between the person with aphasia and their CP, and providing these as  
5 video feedback, as a foundation for targeting therapy<sup>43</sup>. The speech and  
6 language therapist (who typically delivers such an intervention) analyses  
7 10-15 minute video-recorded interaction to identify behaviours resulting in  
8 conversational breakdown, known as barriers, and ways in which  
9 members of a dyad successfully resolve or circumvent troubles to  
10 maintain interaction, known as facilitators. The aim of video feedback is to  
11 increase awareness in one or both members of the dyad of the impact of  
12 their behaviours, and jointly agree on goals for therapy. Once the goals of  
13 therapy are agreed upon, a process of practice, through supported  
14 conversations, role play and reflection, is commonly employed<sup>43</sup>. The  
15 BCPPA intervention is informed by this well-described<sup>46</sup>, CA-underpinned  
16 approach to CPT.

17

## 18 Behaviour change theory

19 Recognising conversational barrier behaviours in video recordings of  
20 oneself and setting a goal to cease these, or adopt facilitative strategies  
21 instead, does not guarantee that a change in behaviour will occur<sup>47</sup>.  
22 Behaviour change theory, specifically the COM-B model<sup>48</sup> accounts for an  
23 individual's behaviour change as the product of three equally weighted  
24 components namely Capability, Opportunity and Motivation. Researchers  
25 examined video recordings of Conversation Analysis-underpinned CPT

1 being delivered to people with stroke aphasia and their CPs<sup>49</sup> and used the  
2 COM-B model<sup>48</sup> to identify the essential change processes and the core  
3 procedures that serve them<sup>50</sup>. The BCPPA intervention incorporates the  
4 seven core mechanisms that have been identified as essential to behaviour  
5 change in a CPT<sup>49</sup>, specifically the processes to motivate change and those  
6 that embed changes (See supplementary material 4).

7

## 8 Self-management and self-efficacy

9 Central to self-management is the concept of the client as an active  
10 participant whose current status is influenced not only by diagnosis but by  
11 psychological responses and experiences. This implies interventions  
12 should address the ability to self-manage daily activities and the emotional  
13 journey, not just medical symptoms<sup>50,51</sup>. Taking action to accomplish a plan  
14 to self-manage their condition is more likely to succeed if a person has the  
15 confidence or self-efficacy to achieve it<sup>52</sup>. Self-efficacy is a mechanism that  
16 directs behaviour change, for if one feels in control of a behaviour it  
17 becomes easier to make a change to it<sup>53</sup>. Five core self-management skills  
18 and four key self-efficacy mechanisms have been highlighted for inclusion  
19 in speech and language therapist interventions with people with  
20 progressive communication difficulties<sup>52</sup> and these have been considered  
21 in the development of the BCPPA intervention (see supplementary file 4).

## 22 **Consultation and co-production work with the steering group (Stage** 23 **2)**

24 Decisions made included:

- 1 1. Identification of seven subjects to form distinct training modules within  
2 the BCPPA program. Table 1 provides an overview of the learning  
3 objectives and how these were co-produced. The three modules  
4 required for the phase II NHS based randomised controlled pilot-  
5 feasibility study (Module 3: How to make a video, Module 4: What to  
6 target in therapy and Module 5: the BCPPA therapy) were prioritised for  
7 development over the four only needed for the future general release of  
8 the online BCPPA program. Table 2 provides an overview of the content  
9 of these three modules.
- 10 2. Development of a topic list, for Module 3: How to make a video, to  
11 support participants when making video recordings of their own  
12 conversations.
- 13 3. Distillation of the components of the eight BCA sessions into four 1-  
14 hour BCPPA sessions (the duration agreed-upon by speech and  
15 language therapists as feasible<sup>11,12</sup>)
- 16

1 . Table 1. Learning objectives and timeline for development of the BCPPA training modules including the therapy  
 2 program  
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BCPPA training modules	Learning objectives for speech and language therapists accessing the module	Module components	Development timeline
Module 1: What is PPA?	To explain what PPA is according to: - People with PPA and their relatives who have worked on this module, - Speech and language therapists working in the area - The research literature in this area	Co- produced with steering group. References selected by steering group.	Prior to launch of online BCPPA program
Module 2: What is conversation training?	To explain what conversation training is to clients, based on video recorded interviews with: - Speech and language therapists working in the area - People with PPA and their relatives who have worked on this module.	Co- produced with steering group Video clips planned, filmed and selected by steering group	Prior to launch of online BCPPA program
Module 3: How to make a video	<ul style="list-style-type: none"> <li>• 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.</li> <li>• To be aware of the Mental Capacity Act (2005) and how this will impact on consent.</li> <li>• For speech and language therapists to be supported to make and store videos, in line with the data management guidance and policies of their local organisation, of conversation between a client and their conversation partner for the purpose of the BCPPA intervention.</li> <li>• To be able to set up an optimal environment for the purposes of making a video for the BCPPA intervention</li> </ul>	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.	Prior to Phase II RCT Feasibility Pilot Study
Module 4: What to target in therapy	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	Co- produced work with people with PPA included: video samples and formatting of module.	Prior to Phase II RCT Feasibility Pilot Study

Module 5: BCPPA therapy	To deliver the four <b>synchronous</b> BCPPA therapy sessions, supporting people with PPA and their communication partners (as a dyad) to: <ul style="list-style-type: none"> <li>- Understand concept of barriers and facilitators in conversation and consider thesis briefly in relation to their own conversation</li> <li>- Identify barriers and facilitators in their own conversation</li> <li>- Set goals for therapy based on this discussion</li> <li>- Practice conversation using the strategies identified during goal setting</li> <li>- Problem solve any issues that have arisen in using identified strategies in conversations outside of therapy sessions</li> <li>- Consider planning for future changes in communication</li> </ul>	Co- produced work with steering group included: Therapy handouts for sessions 1 and 4, therapy activities for session 3, video samples and formatting of module.	Prior to Phase II RCT Feasibility Pilot Study
Module 6: Measuring it	<ul style="list-style-type: none"> <li>• To consider what options are available for measuring outcomes for BCPPA;</li> <li>• To think about the pros and cons of different outcome measures;</li> <li>• To consider how to use outcome measures in clinical practice.</li> </ul>	Co-produced with speech and language therapists working with people with PPA (local collaborators who participated in the Phase II RCT Feasibility Study)	Prior to launch of online BCPPA program
Module 7: Useful Resources	<ul style="list-style-type: none"> <li>• To learn about some activities people with PPA enjoy;</li> <li>• To find out about some useful websites and resources;</li> <li>• To have thought about what has been useful in your therapy.</li> </ul>	Co-produced with steering group Online resources selected by steering group	Prior to launch of online BCPPA program

NB: The language used for module titles and learning objectives reflects vocabulary selected by the steering group during co-production and was felt appropriate and accessible for the target audience (clinical speech and language therapists). PPA: Primary Progressive Aphasia; BCPPA: Better Conversations with Primary Progressive Aphasia; RCT: Randomised Controlled Trial

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2 Table 2. Overview of content for the first draft of the BCPPA manual (Modules 3, 4 & 5).

Module	Overview of content
<p data-bbox="201 410 577 435"><b>Module 3: How to make a video</b></p> <p data-bbox="331 440 810 480"> <b>Summary: How to make a video</b></p> <p data-bbox="331 516 816 535">The following diagram summarises the key steps that have discussed in this module.</p> <div data-bbox="348 557 806 683"></div> <p data-bbox="348 727 499 833"><b>Part 1:</b> Develop a tool to gain consent for video recording clients and their conversation partners for conversation therapy.</p> <p data-bbox="520 727 659 816"><b>Part 2:</b> Make and store a video of a client and their conversation partner in your work environment</p> <p data-bbox="688 727 825 816"><b>Part 3:</b> Set up the optimal environment for the purposes of making a video for the BCPPA intervention.</p> <hr data-bbox="300 881 856 885"/> <p data-bbox="310 911 846 946"><a href="#">Module Overview</a> <a href="#">1. Learning Objectives</a> <a href="#">2. Gaining Consent</a> <a href="#">3. How to make a video</a> <a href="#">4. Make the optimal video</a> <a href="#">Module Summary</a></p>	<p data-bbox="1104 410 1984 898">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 Mental Capacity Act (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</p>

## 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 example.

5. Preparing to show a clip.

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 person with PPA 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 person with PPA 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 View the dyads and set goals together

**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 person with PPA and CP

Session 2: provision of aims, session plan, therapy handouts and home-based tasks for person with PPA and CP.

Session 3: provision of aims, session plan, therapy handouts and home-based tasks for person with PPA and CP.

Session 4: provision of aims, session plan, therapy handouts and home-based tasks for person with PPA and CP.

1 PPA: Primary Progressive Aphasia; MCA: Mental Capacity Act; CP: Communication Partner; BCPPA: Better Conversations with  
2 PPA

3

1 **First draft of BCPPA manual (Stage 3)**

2 Module 5: the BCPPA therapy, hosted the BCPPA manual comprising  
3 session plans, session handouts and home-based tasks for each of the four  
4 BCPPA intervention sessions. The session plans identified intervention  
5 components as either core or non-essential components that can be  
6 tailored to an individual's needs.

7 The draft manual was evaluated by the steering group to ensure information  
8 was presented in an accessible way. This included decisions on images  
9 and formatting.

10 The first draft of the manual was uploaded to a secure area on the  
11 UCLeXtend website and made available to speech and language therapists  
12 participating in the stage 4 consensus work via a bespoke URL. It was not  
13 publicly accessible.

14

15 **Consensus work (Nominal Group Technique) with speech and**  
16 **language therapists (Stage 4)**

17 Demographics and characteristics of speech and language therapist  
18 participants

19 Thirty-six speech and language therapists took part. Of these, 17 had  
20 completed the pre- Nominal Group Technique meeting survey, 22 had  
21 viewed the first draft of the BCPPA manual and training program prior to  
22 attending, and two had been able to use the BCPPA manual with a client

1 with PPA. Table 3 presents speech and language therapist participant  
 2 demographics and their familiarity with the BCPPA manual and training  
 3 program. Following the meeting, 20 of the 36 participants completed the  
 4 final Nominal Group Technique ranking task by email.

5

6 Table 3: Demographics of speech and language therapists who participated  
 7 in the Nominal Group Technique meeting and their familiarity with the  
 8 BCPPA program

	Speech and language therapist participants (n=36)
Gender (m:f)	2:34
Years practicing as a speech and language therapist (mean and range)	12.5 (0-21)
Number of clients with PPA seen in clinical career (mean and range)	9 (0-20)
BCPPA modules viewed online prior to meeting:	
None but knows of BCA	1
None	11
Module 3 How to make a video	22
Module 4 What to target in therapy	21
Module 5 BCPPA therapy	22

1 m: male, f: female, PPA: primary progressive aphasia, BCA: Better  
2 Conversations with Aphasia program, BCPPA: Better Conversations with  
3 PPA program.

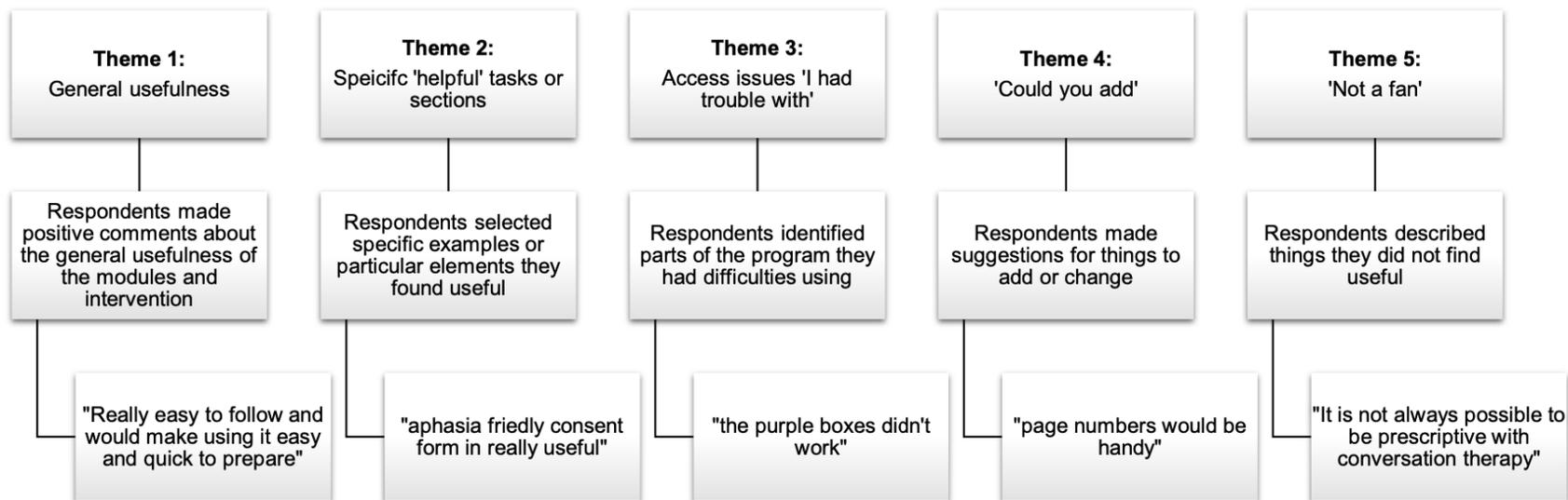
4

5 Pre- Nominal Group Technique meeting survey

6 When asked what surprised them when they first accessed the online  
7 BCPPA program five of 17 respondents (29%) commented on there being  
8 a lot of detail. Five respondents (29%) described the program as clear, easy  
9 to use and accessible; one person highlighted the comprehensive and  
10 detailed step by step guidance. A further four respondents (24%) stated  
11 that they were unsurprised by the BCPPA program, given their familiarity  
12 with the BCA program on which BCPPA is based. Respondents provided  
13 feedback on the BCPPA program including the most useful aspects (17,  
14 100%, respondents), formatting (16, 94%, respondents), additions or  
15 changes (14, 82%, respondents) and the least useful aspects of the  
16 program (10, 60%, of respondents). Five themes arose from these data: 1.  
17 General usefulness; 2. Specific 'helpful' tasks or sections; 3. Access issues,  
18 'I had trouble with'; 4. 'Could you add'; 5. 'Not a fan'. These themes are  
19 illustrated with quotes in Figure 2. Notably, access issues were generally  
20 related to glitches in the program, though some local NHS browser systems  
21 posed restrictions.

22

1 Figure 2. Themes identified from survey responses in Stage 4 consensus work.



1 Nominal Group Technique

2 After two iterations of consensus work with speech and language  
3 therapists, focused on the question “*What components of the BCPPA*  
4 *therapy sessions are important for people with PPA and their conversation*  
5 *partners?*”, eight components were identified, and ranked in order of  
6 importance, see Table 4.

7 Table 4: Final eight ranked components identified as important for the BCPPA program,  
8 from two stage Nominal Group Technique consensus work

1	Use of video feedback to identify facilitators versus barriers in conversation when focusing on people’s strengths as well as areas of potential breakdown
2	Tailored and person centred: <ul style="list-style-type: none"><li>- goals,</li><li>- conversational topics,</li><li>- strategies</li><li>- practice opportunities</li></ul>
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 speech and language therapist.
8	Providing an opportunity to discuss their communication difficulties

1 PPA: Primary Progressive Aphasia; CP: Communication Partner.

2

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

4 Demographics of participants

5 Thirteen participants, six people with PPA and seven family members,  
6 responded to the advertisement. All were eligible and agreed to participate  
7 but one couple withdrew the day before the focus group due to a conflicting  
8 commitment. The remaining 11 participants attended two focus groups (NB:  
9 these were mixed groups, whereby people with PPA and their CPs  
10 attended together, alongside some CPs and people with PPA who attended  
11 independently, group 1: seven participants; group 2: four participants).  
12 Participants with PPA represented all three variants, and atypical mixed  
13 variants. Demographic information is outlined in Table 5.

14 Table 5: Demographic information for focus group participants

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

1 PwPPA: person with primary progressive aphasia, CP: communication

2 partner, lvPPA: logopenic variant primary progressive aphasia, svPPA:

3 semantic variant primary progressive aphasia, nfvPPA: non-fluent

4 agrammatic variant primary progressive aphasia

5

6 Themes arising from the focus groups

7 Three overarching themes emerged: 1) Timing of intervention, 2) speech

8 and language therapists' understanding of types of dementia, and 3)

9 Knowing what helps. Theme 3 encompassed five further subthemes: 'No

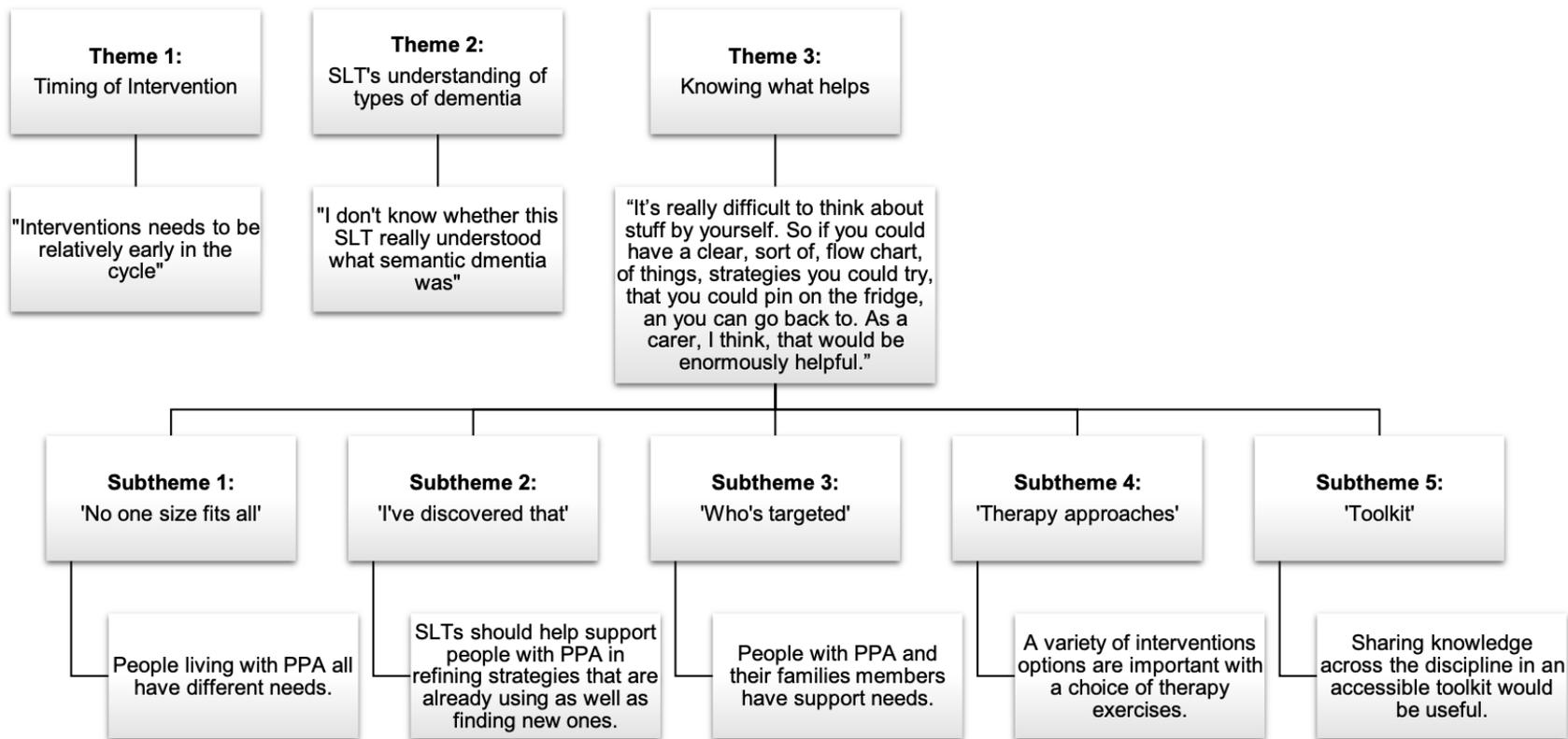
10 one size fits all', 'I've discovered that', 'who's targeted', 'therapy

11 approaches' and 'toolkit'. All themes and subthemes are presented in

12 relation to illustrative units of data in Figure 3.

13

1 Figure 3. Themes and subthemes arising from focus groups with people with PPA and their CPs



## Refinement of BCPPA manual (Stage 6)

Refinements for the BCPPA manual are presented in Table 6. The refined BCPPA program was consequently made available to participating local speech and language therapist collaborators on UCLeXtend as part of their training in preparation for delivering the intervention during the randomised controlled pilot-feasibility study. The final intervention is described in detail, using the template for Intervention Description and Replication (TiDIER), in the authors PhD thesis which this paper is based on<sup>54</sup>, and a published protocol for study which remains currently underway<sup>55</sup>. Further to this, the project steering group made plans to continue working to co-produce the remaining four modules, in anticipation of a future launch of the BCPPA program. This paper is based on work from the authors PhD thesis.

Table 6: Refinements for BCPPA manual and intervention

Decisions made	Examples of refinements made
Provide more options on strategies and practice activities in the intervention materials.	Addition of Home based 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 speech and language therapists, people with PPA and their families and a review of manuals for stroke aphasia CPT

	manuals.
Provide more information on resources and other services.	Expansion of session plan 4 to include a list of resources and other services for speech and language therapists making recommendations for the future.
Develop video examples of the intervention being delivered.	<p>Addition of video recordings of conversation breakdown and intervention being delivered inserted to Module 5: The BCPPA therapy. These included:</p> <p>Session 1:</p> <p>Video examples of Keith and Rose watching videos of themselves and the speech and language therapist facilitating them to identify barriers and facilitators.</p> <p>Session 2:</p> <p>Video examples of Keith and Rose goal setting with the speech and language therapist.</p> <p>Session 4:</p> <p>Video example of Keith and the speech and language therapist discussing a difficult subject around future planning.</p>
Include more testimonies from people with PPA in Module 1: What is PPA and Module 2: What is communication partner	Use of quotes to illustrate experience of communication facilitators and barriers in Module 4: What to target

training?	in therapy.
Provide more information on how PPA impacts on daily communication.	Refinement of Session 1. Handout 1. How does conversation work? And addition of Session 1. Handout 2. What can go wrong in conversations? in co- production with project steering group.
Provide a summary sheet including suggestions for future changes on one handout at the end of the intervention.	Addition of summary handout for session 4: Handout 6: Your strategies

BCPPA= Better Conversations with Primary Progressive Aphasia,  
PPA=primary progressive aphasia

## Discussion

The BCPPA manual and training program were developed using the framework described in the Medical Research Council guidelines for development of complex interventions<sup>29</sup>. The intervention content is underpinned by the bio-psychosocial model of dementia, applied CA, behaviour change theory, and self-management and self-efficacy literature. Consultation and co-production work with a project steering group made up of people with PPA and their family members provided the first draft of the BCPPA manual and training program. Consensus work using a Nominal Group Technique with practicing speech and language therapists and focus groups with people with PPA and their families, identified further refinements. These included additions to the manual, and modifications to improve access to and use of the materials within the modules.

Speech and language therapists report seeing people with PPA in their

clinics who feel incompetent in conversations, whilst their CPs feel helpless to support them in these situations<sup>56</sup>. Addressing this by exploring meaningful strategies to maintain conversation via CPT that involves both a person with PPA and their CP has been recommended by expert speech and language therapists<sup>26</sup>. Currently, speech and language therapists delivering CPT to people with PPA and their CPs report using tools designed for people with stroke aphasia because there are no PPA-specific materials<sup>11,12</sup>. The BCPPA manual and training program address this gap in the speech and language therapists' "toolkit" (described as such by participants in the focus groups) of interventions for PPA, and provides an evidence based, manualised training resource designed by and for people with PPA and their CPs.

### **Strengths and limitations**

Drawing on the best available evidence and appropriate theory to develop the BCPPA manual, in accordance with Medical Research Council guidance<sup>29</sup>, 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<sup>57</sup>. This work has involved new research with those targeted by the intervention as well as those delivering it.

There are, however, some methodological limitations. Nominal Group Technique does not allow for anonymisation in the way that other consensus methods such as Delphi do, and can thus bias the responses of participants. **Unfortunately, only 20 of the 36 participants who attended the original meeting completed the final Nominal Group**

Technique ranking task by email. These numbers may be associated with the fact that some participants did not have experience working with people with PPA. The Nominal Group Technique did nevertheless, provide a method of involving large participant numbers and incorporating mathematical voting techniques to aggregate group judgements equally<sup>35</sup>. Despite only 12 of the participants who attended the Nominal Group Technique meeting having viewed the modules beforehand, making the intervention manual available enabled scrutiny of its practicality for clinical practice in anticipation of the phase II NHS based randomised controlled pilot-feasibility study. Notably, only two males were recruited to the Nominal Group Technique, though this is generally representative of the current speech and language therapy community<sup>58</sup>. Despite being a useful method for eliciting participant's genuine and honest opinions, a focus group can be a challenging communication environment<sup>59</sup>. The role of the speech and language therapist facilitator and the student speech and language therapist co-facilitators was to mitigate this by enabling participants to contribute to discussion. The option to attend with CPs to support communication was also provided, but instead participants prioritised the convenience of meeting dates and times. Given the steering group was established a number of years prior to the recently published practice standards for Public Involvement<sup>60</sup> it is likely that the methods employed may have limited the effectiveness of the co-produced work. Some have criticised the steering group model for consulting with only a small number of individuals. There were only three couples with PPA in this group and that may have limited its value. PPA is, however, a relatively rare condition and people were approached to reflect the known diversity within the condition. Additionally, new members were sought when

others withdrew due to disease progression, and the author sought to gather perspectives of other people and their families through individual telephone contact. Despite approaching professionals from other disciplines, including medicine and social work, interested individuals were not able to attend steering group meetings. The author was able to consult with the research team, including neurology colleagues, to gather feedback and ideas.

A manualised approach enables standardised delivery of the intervention for a future trial. Given that speech and language therapists in clinical practice may have limited experience of working with people with PPA<sup>10,11</sup>, this helps to maximise ease and fidelity of delivery for future implementation. However, a manualised intervention may limit the potential to tailor an intervention to individual clients, for example by deciding not to use video recording or by delivering the intervention to a person accompanied by two CPs. Person-centred components have been identified as important for functional communication interventions for people with PPA, and have been highlighted as important for behaviour change<sup>49,50</sup>. The development of this intervention took 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 non-essential components that were amendable to tailoring. Furthermore, expecting four 1-hour therapy sessions to result in a change may seem ambitious. However, the decision on dosage was made based on the average number of sessions that speech and language therapists reported having available to deliver functional communication interventions for PPA<sup>11</sup>. Developing

an intervention that meets this requirement increases the chance of implementation.

## **Conclusions**

The six-stage process of development included a review of existing literature, and consultation and co-production with the project steering group to develop an initial draft. Consensus work undertaken with speech and language therapists and focus groups with people with PPA and their families identified further refinements. The BCPPA manual was refined in preparation for a phase II NHS based randomised controlled pilot-feasibility study which is currently underway<sup>55</sup>.

## **Abbreviations**

PPA: Primary Progressive Aphasia; CP: Communication Partner; CPT: Communication Partner Training; BCPPA: Better Conversations for Primary Progressive Aphasia; NHS: National Health Service.

## **Ethics approval and consent to participant**

All work undertaken in this study was conducted in accordance with the Declaration of Helsinki.

*Consultation and co-production work (Stage 2):* Ethical approval is not required when involving individuals in the planning or design of research, for example when they are members of a research steering or advisory group (Health Research Authority, 2019). In order to equalize participation and power issues specific strategies were used in and outside of the steering group meetings. All communication, written

and spoken, was made accessible to ensure no individuals were disadvantaged. All steering group members were required to use the same methods to contribute (raising a card to indicate they had a question or comment). People with communication difficulties were invited to contribute before others, and the author made contact with individuals with communication difficulties prior to the meeting to gather initial thoughts, to support facilitation during group discussions.

*Consensus work with speech and language therapists (Stage 4):* The UCL Research Ethics Committee confirmed the Nominal Group Technique consensus work (Stage 4) with speech and language therapist participants to be service evaluation. Participants were informed that all responses would be anonymous and at the start of the event they provided written informed consent to participate.

*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. Informed consent was obtained by A.V. following the current guidance from the Mental Capacity Act (Department of Health, 2005) and Royal College of Speech and Language Therapy, 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 were designed to be accessible to support the process of gaining informed consent. They 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. Transcriptions of focus group data were anonymised via the allocation to each participant of a unique research number, used at all times. All names, places and personal information mentioned in the discussions were pseudonymised.

The addition of video recordings demonstrating delivery of the intervention had ethical implications, requiring a minor amendment to HRA ethical approval. Having received this approval, a separate dyad were recruited through an email advert to members of the PPA branch of the UCL Rare Dementia Support Group. During the consent process it was made clear to the dyad there would be a risk that their faces and voices may be recognized from their video recordings. Information was provided regarding the course registration process and expected registrants, such as health professionals and people with PPA and their families. After consenting to participate, the dyad made four pre-intervention video recordings of their conversations, and received BCPPA therapy from the author, an experienced speech and language therapist. All four therapy sessions were video recorded. The author 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 about planning for the future. The dyad viewed these clips prior to giving final consent for their inclusion in Module 5.

### **Consent for Publication**

Not applicable

## **Availability of data and materials**

Not applicable

## **Competing Interests**

The authors declare that they have no competing interests

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[https://www.frontiersin.org/10.3389%2Fconf.fnhum.2019.01.00106/event\\_abstract](https://www.frontiersin.org/10.3389%2Fconf.fnhum.2019.01.00106/event_abstract)

## **Authors' contributions**

This paper is based on work from the first authors PhD thesis. AV conceived and designed the study, collected, analysed and interpreted

data with supervision and support from SB, AS, KS and JW. AV drafted the article with guidance from SB, AS, KS and JW, all authors critically reviewed the article and are accountable for all aspects of the work.

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