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Better conversations with Parkinson's: co-production of a novel speech and language therapy intervention with people living with Parkinson's

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Abstract

Effective engagement with stakeholders is key in health-care research and intervention development. There is currently a lack of evidence relating to the involvement of co-producers with Parkinson's-related communication difficulties. This article provides a critical reflection on co-producing a novel speech and language therapy intervention (Better Conversations with Parkinson's) with people living with Parkinson's who have an interest in, or lived experience of, communication difficulties. Evaluation is based on qualitative comments and survey responses from patient and public involvement group members, documentation and outputs from the patient and public involvement group, and reflection using the Public Involvement Impact Assessment Framework. The co-production group, research team and organisation highly valued the expertise and collaboration as equal partners gained through co-production. Key enablers included skilled facilitation and adequate time and funding. Consideration should be given to the format of participation (online or face-to-face), recruitment strategies and the role of patient and public involvement, in order to improve access to underserved groups and strengthen the voice of public and patient involvement members. Co-production with people living with Parkinson's and communication difficulties allowed the creation of a more credible, relevant intervention which responds to the needs of key stakeholders, and it was a positive experience with personal benefits for those involved. We propose offering a flexible choice of co-production methods to accommodate the differing experiences of patient and public involvement members with Parkinson's and communication difficulties.

Keywords co-production; patient and public involvement; Parkinson's; communication difficulties

Key messages

- To ensure high-quality and meaningful co-production, patient and public involvement skills such as transparent communication and skilled facilitation are particularly important when working with people with communication difficulties. This includes communication and feedback between engagement sessions, as well as facilitation within meetings.
- Co-production with people living with Parkinson's with communication difficulties can result in a more relevant intervention, and can carry personal benefits for co-production members. A balance is required between time commitments, engagement methods and the scope of co-researchers' roles, in order to maximise accessibility and the strength of their voice.
- Careful consideration and flexibility of recruitment methods and methods of engagement is required to promote accessibility and encourage diversity of experience across patient and public involvement members. Offering a choice of methods to suit participants with heterogeneous needs is particularly relevant for people living with Parkinson's who have communication difficulties.

Background

Patient and public involvement

Patient and public involvement (PPI) is an essential part of health and social care research (NIHR, 2022), defined as an active partnership in which research is carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them (NIHR, 2021a). It can empower people by providing the opportunity to influence research that is personally relevant (NIHR, 2021a), and it has potential to bring personal benefits for researchers and stakeholders, as well as to generate system changes and action (Hoekstra et al., 2020; Slattery et al., 2020).

Stakeholder engagement throughout intervention development maximises the likelihood that research addresses relevant questions, results in positive impacts on health, and leads to changes in practice and policy (Skivington et al., 2021a). Not engaging relevant stakeholders risks the intervention being considered from a narrow perspective, being unfeasible or unacceptable, or not readily implementable (Skivington et al., 2021a). Beyond contributions to the research, PPI may also develop practical skills and knowledge, feelings of confidence and empowerment, and new networks and relationships (Bird et al., 2020).

While not appropriate for every context, greater engagement can lead to better, more patient-centred outcomes (Carman et al., 2013), and can enable power and decision making to be shared more equitably with patients and the public (Ocloo and Matthews, 2016). Co-production is a form of PPI involving health and care service users, carers and communities in equal partnership, which 'engages groups of people at the earliest stages of service design, development and evaluation' (Coalition for Personalised Care, 2020: n.p.). Key principles of co-production include: sharing of power; including all perspectives and skills; respecting and valuing the knowledge of all those working together; reciprocity; and building and maintaining relationships (NIHR, 2021b). Meaningful and early engagement with patients, practitioners and policymakers is key to intervention development (O'Cathain et al., 2019; Skivington et al., 2021b).

What makes PPI work well?

There are many frameworks and evaluations concerning the process of high-quality PPI. These include offering inclusive and accessible opportunities, working together in a way that values all contributions and sustains mutually respectful relationships, and providing well-timed and relevant communications (UK Public Involvement Standards Development Partnership, 2019). Liabo et al. (2020) and Bird et al. (2020) identify principles for 'good' public involvement, including: inclusivity, partnership, purposeful involvement with clarity about roles, ensuring clear understanding and expectations, transparent communication, responsivity and valuing different kinds of knowledge. Additional case study data and reflective analysis highlight the importance of developing relationships, establishing a culture of mutual respect (Evans et al., 2014; Howe et al., 2017) and promoting openness and transparency (Cheung et al., 2016; Redman et al., 2021). It is also clear that practical components, such as the agreement of roles, appropriate funding, training and staff time are key to successful PPI (Evans et al., 2014; Liabo et al., 2020; Telford et al., 2004). Barriers include use of jargon, power imbalances between the researcher and patient partners and the impact of time pressures on the research process (Bird et al., 2020).

PPI partners with communication difficulties

Despite the value to research and individuals, limitations of PPI reflect those of clinical research more broadly, in particular in relation to the inclusion of underserved groups. PPI guidance and literature predominantly focus on collaborating with those able to voice their opinions and ideas (Volkmer and Broomfield, 2022). While there is growing interest in examining the collaborative involvement of people with communication difficulties such as aphasia (Cruice et al., 2022; McMenamin et al., 2021), the evidence around inclusive co-production remains minimal (Cruice et al., 2022), in particular in relation to motor speech disorders or complex communication difficulties (Jayes et al., 2021; Moulam et al., 2020).

Barriers to meaningful involvement of those with communication difficulties can include the severity of communication difficulty, cognition and disease progression (Volkmer et al., 2022). Furthermore, the challenges of establishing PPI groups with individuals with communication difficulties can mean that the same people are involved across different projects, potentially limiting representation (Jayes et al., 2021). However, involving people with communication difficulties can lead to improvements in team communication, learning among co-researchers, improved feasibility of participant recruitment and engagement and higher quantity and quality of data accessed (Jayes et al., 2021). Co-researchers with communication difficulties describe personal benefits, such as improved communication and confidence, and an increased sense of motivation and wellbeing (McMenamin et al., 2021).

Facilitators to inclusive PPI with people with communication difficulties echo previously mentioned principles, such as building relationships and trust (Burton et al., 2019), setting clear boundaries and involving people at every stage (Swinburn, 2022; Volkmer et al., 2022). Appropriate estimations of time and funding are particularly important (Cruice and Dipper, 2022; Jayes et al., 2021), as well as careful consideration and planning of methods and materials to support engagement and meaningful inclusion (Cruice and Dipper, 2022; Shiggins et al., 2022). Practical considerations might include: use of visual and written materials or multimedia, considering how turn taking will work in a group of mixed abilities and providing content or one-to-one discussion in advance of a meeting to allow time for preparation (Ocloo and Matthews, 2016; Volkmer et al., 2022). Skills such as using communication props and ramps, regularly checking understanding and summarising and writing down key points can also support participants (Jayes et al., 2021; Ocloo and Matthews, 2016; Swinburn, 2022). Furthermore, researchers need to establish an environment supportive of additional needs, such as fatigue (Jayes et al., 2021).

PPI with people living with Parkinson's

The benefits and challenges of working in co-production with people living with Parkinson's (PLWP) reflect those in broader PPI literature. Sullivan and Poliakoff (2023) describe a long-term collaboration between someone living with Parkinson's and a researcher, with far-reaching and unexpected benefits for the research and those involved. Lithander et al. (2024) recognise the positive impacts of PPI with PLWP on designing an intervention, and recommend timely and clear communication, dedicated space for peer support and use of face-to-face approaches. However, Revenäs et al. (2018) highlight that experiences of PPI for PLWP can be paradoxical. For example, the desire for more preparation and discussions conflicted with concerns about time commitments, and the values placed on co-design contradicted beliefs about the implementation of what they were working on.

Around 90 per cent of those living with Parkinson's experience communication change, such as a quieter voice, slurred speech, difficulty joining or staying in conversations and difficulty finding words (Miller et al., 2007, 2011). While PLWP have been involved in the participatory design and as collaborators on multiple research studies, the above evaluations of co-production do not mention communication needs, and some articles cite communication impairments as an explicit barrier to participating (Monje et al., 2023). An exception is an article by Meinders et al. (2022), reflecting on the lived experiences of patient researchers. To account for difficulties with communication, cognition and organisation skills (executive functioning) caused by Parkinson's, the authors suggest giving opportunities for people to repeat themselves, offering a paired 'expert' to PPI members and providing summary handouts. The authors also raise factors beyond communication when carrying out PPI with PLWP, such as mobility issues, medication effects, difficulties with multitasking and a variety of non-motor symptoms, such as pain, apathy, depression and fatigue. There is, however, much to be learnt about successfully working in partnership with co-researchers with Parkinson's and communication difficulties. Charities advocating for PLWP heavily recommend the involvement of PLWP in PPI (Feeney et al., 2020; Parkinson's UK, 2018), but they lack specific guidance or examples of accommodating Parkinson's-related communication needs.

Aims

This article reflects upon the experience of co-producing a novel speech and language therapy intervention with PLWP with an interest in, or lived experience of, communication difficulties. It aims to respond to the need to learn together how to successfully include PLWP and communication difficulties in research.

The intervention co-produced by PLWP is called Better Conversations with Parkinson's (BCP). The BCP project, funded by Parkinson's UK, investigates the feasibility and acceptability of applying the Better Conversations approach to Parkinson's (Clay et al., 2023). Better Conversations is a broad approach to communication partner training, underpinned by conversation analytic research on communication difficulties affecting adults and children (Beeke and Bloch, 2023). It involves a speech and language therapist (SLT) working with a person with a communication difficulty and a conversation partner (for example, a family member or friend) to achieve more successful interactions in everyday life (Beeke and Bloch, 2023). BCP aims to give people resources and skills to manage communication challenges related to Parkinson's, which can affect feelings of competence and self-esteem (Johansson et al., 2020) and directly influence relationships with family members (Mach et al., 2019).

PPI within the BCP project

PPI is key throughout the BCP feasibility study, in particular in the following stages:

Stage 1: The grant funding process involved initial feedback and guidance from PLWP who took part in a proof-of-concept study (Bloch and Beeke, 2021), and peer review of the research proposal by PLWP.

Stage 2: A steering group of PLWP, family members, expert SLTs and researchers oversaw the feasibility study for its duration, for example, supporting decisions around recruitment, participant information, outcome measures, evaluation and dissemination of research.

Stage 3: A co-production group of PLWP, family members and expert SLTs met over three months to produce the BCP intervention.

Stage 4: PLWP and expert SLTs helped us to understand the current barriers to implementing BCP and co-identified what our next research steps should be. This stage was funded by a public engagement bursary from UCL Engagement.

The first author is the research assistant and PPI facilitator for BCP. This article was written with members of the co-production group, and it provides critical reflection on the co-production process with PLWP in Stages 3 and 4.

Method

Information about PPI groups was shared via social media, by SLTs in a partner NHS Trust and through Parkinson's UK's network. Since PLWP can perceive difficulties with communication and experience conversation changes prior to manifest impairment (Miller et al., 2006), and BCP intervention can be tailored to individuals with mild and severe difficulties, there was no specified level of communication impairment to take part. In recognition of the fact that current evidence is based on a cohort of participants that does not resemble the diversity of PLWP (Siddiqi and Koemeter-Cox, 2021), a member of the research team met with all interested PPI members in an effort to achieve diversity within the groups.

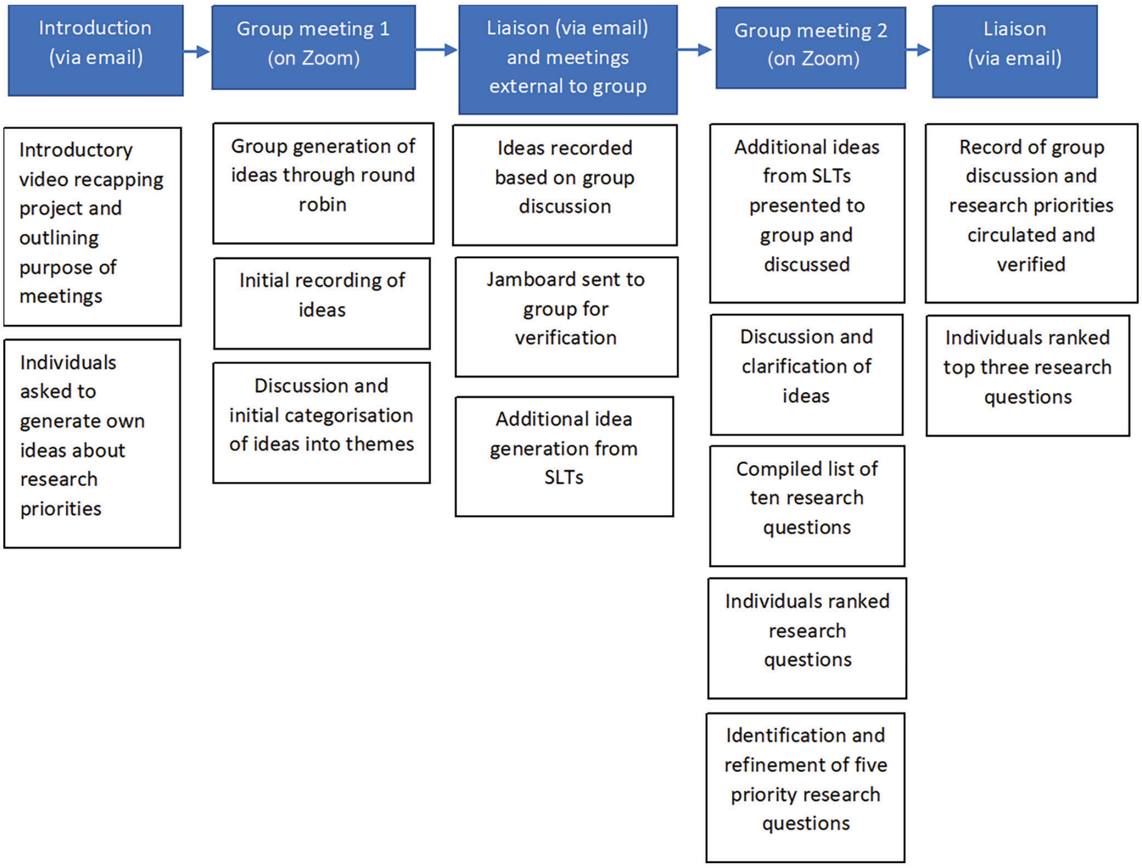
Stage 3

The BCP programme was co-produced by a group of four PLWP, one family member and three SLTs with specialist expertise in Parkinson's. The facilitator (research assistant) acted as a point of liaison between the research team and co-production group. Additional input was sought from two additional family members, with their ideas fed back to the group for discussion and decision making. The groups were held using a remote online platform (Zoom). The group met seven times fortnightly for ninety-minute meetings. The need to meet remotely, and the number of meetings, was guided by funding, and the nature of collaboration (length of meetings, contact between meetings) was decided by the group. An additional short introductory meeting was held to discuss access needs, the project aims and preferred terminology. The group was facilitated by the first author, an experienced SLT. Within group sessions, methods were used such as idea generation and open discussion. Prototypes (for example, of handouts and of a website) and voting tools were created on the basis of group discussions, and were circulated for further discussion between sessions. The platforms Mural (a collaborative online whiteboard) and Tricider (an online voting tool) were used to share ideas about the therapy activities, and to structure and decide on the number of sessions. The facilitator contacted participants between sessions for additional comments via email or video call, and provided written and video minutes for each meeting.

Stage 4

Five members of the co-production group (four PLWP and one family member) met for two online group meetings, in which the nominal group technique was used to rank priorities for the next steps of BCP

Figure 1. Outline of Stage 4 co-production process



research. Group members had a thorough knowledge of BCP and lived experience of Parkinson's. The nominal group technique was used to be accessible to participants, and to explore a diverse range of views from multiple members in a structured manner (Manera et al., 2019).

The following steps were followed (see Figure 1):

1) The subject was outlined in a video to group members.
2) Members were asked to individually generate ideas.
3) Group Meeting 1: Each group member was invited to share ideas for the next research steps. All ideas were recorded (on Google Jamboard) and discussed to clarify meanings, and to combine ideas into categories or themes.
4) The facilitator wrote up the outcome of the discussion (using Google Jamboard) and circulated it to group members for comment.
5) The facilitator conducted additional interviews (three one-to-one interviews and one meeting with a speech and language therapy team) with expert SLTs to discuss possible barriers to implementation of BCP, and to explore SLTs' perceptions about what the next stages of research should be. These ideas were recorded as written notes, and subsequently added to the group's Jamboard.
6) Group Meeting 2: The facilitator recapped ideas raised by the group, which included ideas raised by expert SLTs. The group discussed whether ideas or themes on the list should be revised, and compiled an overarching list of 10 research questions. Group members individually ranked each

research question in terms of priority from 1 to 10, with the first choice ranked the highest (10). A list of the top 5 research questions were identified by summing individual scores, and the exact meaning of these questions was refined through group discussion.

7) After Group Meeting 2, members were asked to use an online form to rank the top 3 research questions from the selected 5. These priorities will guide future BCP research.

Evaluation

Evaluation and reflection were guided by the Public Involvement Impact Assessment Framework (PiiAF) (Popay and Collins, 2014) – a framework designed to support researchers to consider how best to involve the public in research and to develop a plan to evaluate PPI (Kok, 2018). This framework was used to plan PPI and assessment of its impact within the BCP study, and to support critical reflection and evaluation of the co-production process. Critical reflection draws from: qualitative comments and survey responses from group members, meeting minutes, written documents and outputs of the co-production group, and structured individual reflections from the facilitator. Throughout Stages 3 and 4, the facilitator encouraged open communication about co-production, and forms and requests for feedback were sent via email. After Stages 3 and 4, group participants were asked to complete a survey collecting qualitative information on the experience of co-production.

Results

Table 1 provides reflection on the BCP co-production process across PiiAF domains (Popay and Collins, 2014). Co-production as an approach to PPI was highly valued by the research team, PPI members and organisations involved, with high motivation to take part, collaborate and work in equal partnership. Equal power balance and inclusion of all group members was facilitated by online working and skilled facilitation. Including alternative methods (such as face-to-face meetings, and purposive recruitment methods) might increase diversity among group members and enable contributions from PLWP with differing accessibility needs. Key practical enablers included adequate funding and time, as well as organisational support to ensure that all group members were able to meaningfully engage. Increased flexibility of funding would allow more responsivity to the needs of group members, for example providing time to explore topics in more detail. Co-production work had multiple positive impacts, allowing the research team to achieve their aims of creating a therapy programme and identifying research priorities, and to account for the perspectives of key stakeholders.

Key reflections and learning points from co-producers are presented below, considering, in particular, the experience of group members, what worked well, what could be improved in the future, and the impact of involving PLWP as co-production partners.

What was the experience of group members?

Group members described co-production as 'working together with people from different sides of the table to create a balanced approach and view', involving meetings to 'share experiences and make collective decisions'. Key values that group members associated with co-production included 'collaboration', 'partnership', 'openness and willingness', 'honesty' and 'respect'. The group described a willingness to explore options and problem solve, facilitated by an 'understanding of roles and responsibilities within the group' and by an awareness of one's own positioning and potential biases. Those with Parkinson's felt that their main contribution was first-hand experience of living with Parkinson's. Group members brought additional skills, such as one member's professional experience in developing training materials, and personal attributes, such as a 'willingness to consider others' points of view'.

Table 1. The BCP co-production process in relation to the PiiAF

Domains of PiiAF framework	Relationship to BCP study
Values	• UCL and Parkinson's UK recognise the importance of an inclusive and dynamic engagement culture (UCL Engagement, 2021). • The Better Conversations Lab (UCL) has an established history of PPI with people with communication difficulties (Volkmer et al., 2022). • Initial meetings involved discussion around what co-production means: values of group members aligned with those of the research team. • Group members were motivated by the opportunity to contribute towards improvements for the Parkinson's community.
Approaches to public involvement	• The PPI approach was co-production, with group members as equal partners and co-creators. • Group members described working in 'collaboration and partnership', that they had influence and that contributions were recognised. • The range of engagement options (Stages 2, 3 and 4) provided flexibility of commitments and timescales. • Stage 4 aims to promote PPI from the earliest stages of future research. • Online group meetings can increase access, and one group member suggested that it facilitated an equal power balance. However, meeting online may result in limited participation from those with reduced access to, or confidence accessing, technology, or those with more significant communication impairments. • Recruitment methods (via social media and Parkinson's UK) and engagement methods (online) are likely to have generated reduced diversity within the group, despite purposive selection of group members. • Group members emphasised the key role and skills of the facilitator. Facilitation of the group by someone living with Parkinson's may have enabled a more equal power dynamic. • A mixture of one-to-one and group meetings was used to gather a wide range of perspectives. Different methods of engagement (such as face-to-face) may have enabled increased contribution from those with relevant experience, for example, those with more severe communication and cognitive impairments.
Research topic and study design	• Funding from Parkinson's UK and UCL Engagement enabled full collaboration and co-production in Stages 3 and 4. • Due to practical and funding requirements, PPI has been iterative and in separate groups. Group members indicated that being involved across more stages of the research process would strengthen their voice. • The facilitator was an SLT with skills to support the communication of PLWP. Accessibility was promoted, for example, through: use of multimedia, video and written minutes; allowing preparation in advance; and summarising and clarifying understanding of contributions. Feedback from one participant about meeting length suggests that more monitoring of fatigue was required.
Practical issues	• Group members established group expectations and support needed to take part in an initial meeting. • Parkinson's UK provided information and support for those interested in PPI. • The facilitator accessed resources and support, such as relevant guidance (NIHR INVOLVE Advisory Group, 2018), literature relating to engaging people with communication difficulties and mentorship in co-production methods and engagement. • Meeting via a remote platform (Zoom) allowed flexibility in timings and reduced issues related to travel. There were some practical issues related to being able to 'break into conversation' online. • Payment for PPI time, skills and expertise was offered as a bank transfer, voucher or donation to charity. Increased flexibility of funding would enable responsivity when members feel that more time is required.

Table 1. (continued)

Domains of PiiAF framework	Relationship to BCP study
Identifying the impacts of public involvement in research	• Achieved pre-identified aims for PPI: production of the BCP programme (including the creation of bespoke resources); identification of research priorities for next five years. • Group members felt that PPI has resulted in a more 'credible' and relevant therapy intervention. • PPI allowed the research to take account of a range of perspectives, and to respond to the needs of service users. Further work is required to widen the diversity of this perspective in future BCP research.

What worked well and what improvements can be made?

Group members described the research team as being 'open' and 'responsive' to ideas and suggestions, although they requested more communication about how co-production work fed into research. This suggests that additional communication was needed beyond the emails, and the written and video minutes after sessions. Group members described 'consideration' from all parties, being 'treated inclusively', and that their voice 'was heard'. While they indicated having influence on the research, this was limited by the group's remit, and it could have been extended through involvement in the steering group and other phases of the research process. Although separating out PPI groups can limit the scope of contribution, it allowed the steering group to oversee the co-production process, and it permitted flexibility in terms of PPI commitments.

The PiiAF framework prompted consideration of the facilitator role. Group members might feel increased power and partnership if someone with Parkinson's took on the role of facilitator, although additional funding and training would likely be required. Facilitator skills and factors which maximised the outcomes of the sessions were noted, for example: thorough preparation and organisation of sessions, making co-production aims clear, accommodating all participants' needs, using technology to support discussion and decision making, checking understanding of contributions and ensuring that everyone was comfortable and that opinions were valued. Group members highlighted the complexity of the facilitator's role. One member suggested having more than one facilitator in future research to ensure that all members are able to contribute and to encourage reflexivity and equal power balance, for example, with facilitators supporting each other to challenge biases and expectations.

Meeting online was acceptable to group members, although it resulted in challenges, such as audio delays masking spoken contributions and difficulties breaking into conversations. One group member described meeting remotely as a 'levelling experience, with each participant viewing their co-producers tucked away in a corner of their home or office'. One group member felt that the option of face-to-face meetings would have been 'nice to have', and might have supported increased contributions from those with more significant communication difficulties. Feedback indicated that a larger group would have been acceptable, and would have increased potential for differing points of view, although this would need to be balanced against a preference for shorter meeting length (maximum 1.5 hours) and the need to ensure that everyone has opportunities to contribute. Additional challenges raised were getting to know other group members and how best to work with them online, coming to consensus on conflicting ideas and learning about some of the more technical aspects of the co-production project. These challenges were predominantly managed by the group facilitator. Two group members also highlighted that more time could have been given to allow consideration of a wider scope and in-depth exploration of more complex ideas.

Despite an effort to achieve diversity from within a pool of volunteers, the research team and co-production group all recognised the lack of involvement of members of under-represented groups within

BCP research. Factors that may have impacted this include online meetings, the limited size of the co-production group and recruitment methods. Some group members suggested alternative methods to encourage diversity and ensure that the PPI group's lived experience reflects the target group for BCP intervention. This included giving the option for PPI members to observe online meetings and then discuss views with the facilitator in a subsequent one-to-one meeting, and face-to-face meetings for increased support of those with more significant communication needs. Alternative recruitment methods, such as visiting support groups for people from diverse backgrounds or purposively seeking people with more severe communication and cognitive deficits from rehabilitation clinics, may result in increased inclusion of underserved groups.

What was the impact of involving people affected by Parkinson's in co-production in the BCP project?

Stages 3 and 4 resulted in clear PPI outcomes: the BCP therapy programme and resources, and a list of priorities for future BCP research. Outputs from Stage 3 included: clarification of the intervention aims; creation of a website (www.betterconversations-parkinsons.com); intervention handouts and videos; a structure for BCP sessions; session activities; and decisions about therapeutic processes such as goal setting, self-evaluation and monitoring of change. Documentation showed group members using their expertise to contribute to a range of decisions. Group members felt that PPI resulted in a more 'credible' therapy intervention, and added to the efficiency of research by addressing issues that otherwise may only have come to light in a later trial. Table 2 provides examples of group contributions, which demonstrate how co-production created a resource more relevant to the target population. For example, the explicit focus on building lifelong skills to manage a progressive disease, and considering how conversations might be affected in groups, are unique to the BCP programme. The number of sessions, language used and video resources also differ from other Better Conversations programmes to ensure that the intervention meets the specific needs of PLWP. Video resources and therapy content were co-designed and co-created by PLWP.

Stage 4 enabled the identification of research priorities from the perspective of key stakeholders, which aim to increase the relevance and impact of future research. PLWP and their family members generated 26 ideas for future BCP research. These were grouped into 10 overarching research questions. Concerns raised by expert SLTs in separate meetings overlapped with five of the research questions. The group agreed that two additional ideas proposed by SLTs should be incorporated within existing research

Table 2. Examples of PPI contributions and outputs

Example areas of group contributions	Example outputs
Key aims and outcomes of BCP therapy for PLWP	• A clear focus on building lifelong skills for PLWP. • An online platform and activities promoting self-management. • A session focusing on how conversation skills can be used within group settings, beyond one conversation partner.
Preferred terminology, phrasing and information content	• Information about communication in Parkinson's and speech and language therapy, to support people's understanding and expectations for therapy. • 'Parkinson's' is used in preference to 'Parkinson's disease'.
Input around delivery and achieving therapeutic change	• Self-rating scales included within therapy to encourage self-efficacy. • Schedule of practice and therapy tasks designed for maximum acceptability. • Resources supporting the generation of a personalised plan for goals and practising therapy strategies. • Videos recorded by group members (for example, about communication with Parkinson's) to maximise accessibility and relevance of resources.

questions. Ranking of the 10 research questions by PLWP and family members resulted in priorities which have formed the basis of a funding application and proposal for future BCP research.

Some impacts of PPI were not planned from the outset of the project. For example, funding from UCL Engagement to support Stage 4 grew from relationships and co-production work during Stage 3. Another unanticipated benefit is that group members asked for money reimbursing their time to be given to charitable causes, thus supporting local fundraising efforts. It is also clear that there were personal gains to both group members and the research team from co-production. The facilitator gained skills and experience through working with the co-production group, which will be valuable for future research projects. She also learnt about people's first-hand experience of the impact of Parkinson's on day-to-day life, and about PLWP's expectations for speech and language therapy. This was useful for shaping BCP research and growing understanding as a researcher. Co-production required building relationships, and, as such, it has led to meaningful connections. Group members chose to meet informally outside meetings, and one commented: 'I think it created some lovely connections which will lead to friendships'. Group members described taking part as a positive, pleasurable and 'interesting' experience in which 'new insights' were gained about Parkinson's, research, conversation therapy and communication skills. One group member described feeling more 'comfortable' when dealing with the impact of Parkinson's on communication in their day-to-day life. The personal benefits that arose from participating in research were felt to be an 'important element in dealing with Parkinson's' more generally, due to the positive reinforcement and motivation that arises from being actively engaged. This is perhaps of particular importance when living with a progressive condition which can result in apathy and reduced engagement.

Finally, this work provides an example of the value of co-production, and a route to understanding the difference that co-production with PLWP can make. Therefore, ongoing dissemination work, for example, through blogs and articles in professional and service user magazines, is being carried out and guided by the co-production group.

Discussion

This article provides a reflection on the process of co-producing a speech and language therapy intervention and research with PLWP, focusing, in particular, on two stages of involvement. The evaluation of the PPI process in relation to the PiiAF framework, and based on qualitative comments from group members, provides guidance for future Better Conversations work, and adds to a growing literature on the practicalities of engaging people with communication difficulties as co-production partners.

Impact

The co-production work carried out in this project aligns with the recognised need for strong and early engagement with patients when designing interventions (O'Cathain et al., 2019; Skivington et al., 2021b), and with the belief that PPI can improve the quality and relevance of research (NIHR, 2021a). Given the in-depth, integrated nature of co-production, it can be difficult to separate out the precise influence of co-researchers (Sullivan and Poliakoff, 2023). However, the design of BCP intervention by PLWP undoubtedly enabled a better understanding of relevant needs and priorities in relation to the research topic, for example, an emphasis on building lifelong skills and consideration of conversations beyond one conversation partner. This has resulted in distinct variations from existing Better Conversations programmes, and in the creation of a more relevant therapy intervention. The BCP intervention can now be evaluated within a feasibility study, and future research priorities have been identified.

An evaluation of outputs and impact shows the range of decisions that the co-production group made. This reflects the broad impact of partnership in research, from individual benefits to changes to the research process and system change (Hoekstra et al., 2020; Slattery et al., 2020). The presence of a range of unanticipated outcomes demonstrates the value of partnership rather than consultation, reflecting the potential for greater engagement to lead to better, more patient-centred outcomes (Carman et al., 2013).

As BCP research continues, qualitative evaluation of a pilot feasibility project may allow identification of how the PPI process influences outcomes for those receiving BCP intervention.

As per Bird et al.'s (2020) scoping review, personal benefits to co-production members included an increase in knowledge and skills, feelings of agency and new relationships. These benefits resulting from co-production are of particular importance to PLWP, given the high incidence of apathy among PLWP, and the need to manage a lifelong condition. PLWP who also have communication challenges experience additional barriers to everyday participation and taking part in research. It is likely that feelings of engagement and personal connections are particularly beneficial for this group of PLWP – an additional reason for researchers to proactively seek valuable partnership with this group of experts.

Facilitation and communication

Principles identified in the literature as key to PPI were noted by group members, such as partnership (Cheung et al., 2016; Liabo et al., 2020), respect (Howe et al., 2017; Liabo et al., 2020; Redman et al., 2021) and honesty (Redman et al., 2021). Group members also attributed skills to the facilitator in running the sessions, which enabled successful outcomes. As a speech and language therapist and research assistant, the facilitator brought relevant expertise, but also potential preconceptions and bias. These could be mitigated by the suggested role of a joint facilitator with Parkinson's. Skills included preparation, making the aims of co-production clear, accommodating participants' needs and ensuring that all opinions were valued. These skills reflect important ingredients of successful PPI (Howe et al., 2017), and they align with standards of inclusivity and working in a way that values all contributions (UK Public Involvement Standards Development Partnership, 2019).

Group members' comments about how 'clear' information was, the ability to voice opinions and being 'heard' reflect the importance of effective communication. While there is minimal literature about supporting the communication of PLWP with communication difficulties in PPI, strategies used by the facilitator echo recommendations for working with people with other communication difficulties. For example, there was a focus on building relationships and trust (Burton et al., 2019), practical steps were taken such as using multimedia (Ocloo and Matthews, 2016), allowing preparation prior to meetings, and offering one-to-one as well as group meetings (Volkmer et al., 2022), and the facilitator regularly checked understanding, wrote down key points and provided summaries of discussions (Jayes et al., 2021; Swinburn, 2022).

The facilitator used professional expertise to support communication during the session, as well as in interim communications (email, one-to-one conversations and video updates). Comments about requiring more regular and clear feedback to group members on the outcome of co-production work resonate with principles of transparency, being responsive and having proactive communication – principles valued by PPI members regardless of communication need (Cheung et al., 2016; Liabo et al., 2020). This evaluation emphasises the importance of exceptionally clear and responsive communication for optimum partnership with PLWP with communication difficulties. This applies not just to the use of facilitative strategies within sessions, as outlined in the literature (Jayes et al., 2021; Ocloo and Matthews, 2016; Swinburn, 2022; Volkmer et al., 2022), but also to all communications between partners, for example, when deciding how co-production will work and feeding back results of co-production.

Accessibility and inclusion

Evaluating BCP PPI work against the PiiAF highlights key practical enablers to successful, inclusive co-production, such as adequate funding, training and support. The values and support of organisations involved were also vital to the success of the project. The importance of funding is recognised in the literature (Evans et al., 2014; Liabo et al., 2020; Telford et al., 2004), particularly with difficulties involved in costing PPI (Evans et al., 2014). This is perhaps due to the ongoing and evolving nature of PPI work:

as PPI defined the scope of the project, the need for more time to examine additional issues became apparent. Estimations of time requirements and funding may also be particularly difficult given the varied symptoms and requirements of PLWP. There are over forty symptoms of Parkinson's, and everyone's experience is different. Symptoms change from day to day, and even hour to hour. Preferences for different methods of co-production are therefore likely to vary significantly between partners, and even between meetings.

Despite purposively selecting members from volunteers to maximise diversity, and to reflect the core group of PLWP which BCP is aimed at, reduced representation of people with more severe communication difficulties or Parkinson's symptoms was raised by group members and noted in researcher reflections. This forms part of a wider issue, namely the lack of involvement of underserved groups in BCP and Parkinson's research (Siddiqi and Koemeter-Cox, 2021). This possibly results from the fact that challenges present for people with communication difficulties in PPI can result in a smaller pool of volunteers (Jayes et al., 2021), thereby limiting the representativeness of co-researchers. It is also likely that co-production methods used, such as online working, act as both enablers and barriers for PLWP. Lithander et al. (2024) recommend face-to-face working with PLWP. We would argue that online working via videoconference reduced mobility issues as a barrier, and was felt to be a 'levelling' experience. However, it may also have created barriers to PLWP with more severe communication difficulties. Given that PPI members have identified the need to adapt BCP intervention for people with more severe communication and cognitive impairments, future BCP PPI work will offer a choice of face-to-face and one-to-one, as well as online and group, working.

The PiiAF framework and qualitative feedback confirmed further varied experiences of co-production. Group members commented that a larger group size can increase the diversity of perspectives. Conversely, it could limit the ability of everyone to contribute, and could increase time commitments. One participant felt that increasing the scope of the role, for example, by merging PPI groups or through an additional group facilitator, would improve the strength of voice and power balance. Achieving power balance is of particular importance when co-production hinges so centrally on equal partnership (Carman et al., 2013; Coalition for Personalised Care, 2020; NIHR, 2021a; SCIE, 2022). However, the benefits of increased strength of voice must be weighed against the time commitments, availability of funding and potential for reduced accessibility of multiple roles. There are also advantages of PLWP overseeing the co-production process, and the issue of fatigue is particularly important to consider for PLWP (Jayes et al., 2021).

The paradoxical experiences of PLWP carrying out co-design have been raised by Revenäs et al. (2018), who note a desire to involve more stakeholders, compared with preferring to work in smaller groups, and a desire for more preparation and discussions weighed against concerns about time investment. This evaluation finds further paradoxical experiences related to online working and the scope of PPI members' roles, perhaps resulting from the additional access needs of PLWP with communication difficulties. These conflicting experiences are likely inevitable when working with a group of co-participants with heterogeneous symptoms and needs, and there is a fine balance required between the advantages and limitations of each co-production method when working with PLWP with communication difficulties. In future BCP research, we aim to include a wider range of PPI approaches and methods, to purposively recruit from underserved groups, and to implement recently published recommendations to increase diversity of participation in research (NHS Accelerated Access Collaborative, 2023). We also plan to offer a range of coexisting co-production methods (for example, one-to-one and group, face-to-face and online meetings, with options regarding time commitments). These strands of co-production will be brought together by a core co-production group whose remit encompasses the entire research process. It is only through flexibility and careful consideration of the benefits and limitations of co-production methods against the needs of co-production members that the heterogeneous needs of PLWP with communication difficulties can be accommodated to enable full, inclusive partnership.

Conclusion

This article, written with co-production group members, provides an interim evaluation of BCP co-production work. It is unique in evaluating co-production from the perspective of PLWP with communication difficulties, and it forms part of an ongoing attempt to learn from and understand the impacts and processes of PPI in research with PLWP with communication difficulties. Critical reflection has highlighted the significant impact and benefits of involving PLWP as co-producers of an intervention, and of research priorities. Principles such as honesty and respect, combined with practical enablers such as time and skilled facilitation, are key to high-quality co-production. We have also highlighted ways of improving future co-production work, such as offering a selection of co-production methods and ensuring consistently transparent communication. This is in response to the accessibility needs and heterogeneous experiences of PLWP, and to minimise barriers for PLWP who have communication difficulties. The hope is that the positive impact of group members' involvement will lead to a more successful and valuable resource for use by speech and language therapists with PLWP with communication difficulties, with benefit to those using the BCP programme in the future.

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Declarations and conflicts of interest

Research ethics statement

The authors declare that ethical approval for the research elements of the BCP study was obtained from London – Central Research Ethics Committee (Reference: 22/LO/0332).

Consent for publication statement

This article is co-authored by the PPI members whose data is here used for critical reflection. The authors declare that consent to publication of findings – including quotations and any personal or identifiable information – was secured prior to publication.

Conflicts of interest statement

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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