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Who decides what criteria are important to consider in exploring the outcomes of conversation approaches? A participatory health research study.

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Abstract

Background

One of the most devastating consequences of aphasia is the disruption to normal conversation. The Conversation Partner Programme emphasises communicative competence and life participation. Currently there is no recognised system for evaluating this intervention. Following policy imperatives for patient and public involvement, it is important to include service users in the development of evaluation criteria. However, people with aphasia are often excluded from such research and service development initiatives because of their communication disability. This study was designed to include people with aphasia and other key stakeholders as co-researchers in the development of evaluation criteria for a Conversation Partner Programme.

Aims

To describe the multi-perspectival co-generation of Conversation Partner Programme evaluation criteria using a participatory research approach.

Methods & Procedures

Following a pilot study, the generation and analysis of qualitative data involved a Participatory Learning and Action (PLA) approach based on the interpretive paradigm. Using purposeful sampling participants (n = 20) included: people with aphasia (n = 5); speech and language therapists (n = 5); speech and language therapy graduates and undergraduates (n = 9) and university coordinator (n = 1). Through (n = 18) individual and inter-stakeholder data generation episodes (PLA focus groups and interviews) using participatory techniques (Flexible Brainstorming, Card Sort, Direct Ranking, Seasonal Calendar), evaluation criteria were identified. The

principles of thematic analysis guided the co-analysis of data with participants. Data generated in Ireland were presented to an international inter-stakeholder group at Connect, UK, for preliminary exploration of transferability of findings.

Outcomes & Results

Conversation Partner Programme evaluation criteria agreed and prioritised by co-researchers in order of importance included: (1) shared understanding of structure, (2) clarity about the programme, (3) agreed evaluation mechanism, (4) linking with other organisations, and (5) feedback. “Shared Understanding of Structure” was ranked the most important criterion and related to the nature and number of participants, opportunities for group meetings, socialising, and stakeholder interaction. “Feedback”, the criterion ranked least important, detailed responsibilities about summarising programme experiences and sharing this information between stakeholders.

Conclusions

People with aphasia and other key stakeholders were meaningfully involved in the identification of evaluation criteria for a Conversation Partner Programme. The outcomes of this collaborative work bridge the gap between policy imperatives around involvement and actual practice and will impact the design, delivery, and evaluation of the programme for all stakeholders. Findings will be of interest to professionals in this clinical area and to those exploring innovative methodologies to include marginalised service users, especially people with communication disabilities in research.

Keywords

conversation approaches; multi-perspectival evaluation; qualitative; insider; emic; participatory health research

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Introduction

Patient and public involvement (PPI) in healthcare have increased significantly in the last decade (Neuwelt, 2012). This positive direction is recognised and supported by policy and legislation internationally (Staniszewska, 2009) with policy statements increasingly advocating PPI (Department of Health, 2001; Department of Health and Children [DoHC] Health Service Executive [HSE], 2008). Many argue that service user involvement has ethical and political underpinnings and is a citizenship right requiring no further justification (Oliver et al., 2008). Health services research and development are intrinsically linked, and PPI has the potential to (1) create more democratic research processes and (2) be a transformative experience for participants (Dewar, 2005). Service users are in a unique position to co-design services, improve quality and safety, minimise costs on inappropriate design, and highlight issues of accessibility and acceptability (Pearson et al., 2013). However, people with aphasia (PWA) are often excluded from such research and service design initiatives *because of their communication disability*. As researchers and practitioners we must address this imbalance and consider how and to what extent PWA contribute to service planning, development, and evaluation. In this article, we begin by describing conversation training approaches and available evaluation evidence and then outline key considerations for involving PWA in evaluating a conversation intervention. We report our methods and findings on behalf of the PWA who were participants and co-researchers in this process.

Conversation training approaches

In keeping with the social model of disability, conversation approaches aim to increase communicative access by training conversation partners to support and optimise communication (Kagan, 1995) and have traditionally targeted three groups (Turner & Whitworth, 2006): (1) familiar partners - family or friends (Booth & Swabey, 1999; Lock, Wilkinson, & Bryan, 2001); (2) volunteers (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; McVicker, Parr, Pound, & Duchan, 2009; Rayner & Marshall, 2003) and (3) healthcare professionals (e.g., Shale, 2004). The psychosocial consequences of aphasia are reduced as positive conversation

opportunities are increased (Byng & Duchan, 2005). Trained conversation partners reveal the competence of the person with aphasia (Kagan, 1995; Kagan et al., 2001) and social interaction is prioritised above linguistic gains (Kagan et al., 2008; McVicker et al., 2009).

Evaluating conversation approaches

To date, a broad range of methodologies including quantitative, qualitative, mixed methods, and single case study designs have been used to evaluate conversation interventions. Experimental studies have provided important information about the impacts of conversation approaches on large samples with potential aggregation across individuals and situations (Kagan et al., 2001, 2004; Rayner & Marshall, 2003). Qualitative designs, on the other hand, are flexible and non-sequential allowing participants to influence the research process across iterations. The unique contexts and characteristics of participants are considered, and individuality is often preserved during analysis and dissemination (Johansson, Carlsson, & Sonnander, 2012). Mixed method approaches have combined quantitative and qualitative measures to explore psychosocial and communication outcomes of conversation interventions (e.g., Fox, Armstrong, & Boles, 2009; Hickey, Bourgeois, & Olswang, 2004). There are also several examples of case study designs using multiple methods in this area (Barnes, Candlin, & Ferguson, 2013; Bronken, Kirkevold, Martinsen, & Kvigne, 2012; Cunningham & Ward, 2003).

From this body of work, we have learned that conversation approaches can result in enhanced well-being, increased social interaction, and improved conversation skills for PWA and conversation partners. However the existing research offers limited empirical evidence of effectiveness which is fundamental to support implementation (Turner & Whitworth, 2006). As previously noted, following PPI initiatives, PWA should be central to service evaluation and re-design. To date while many studies appear to have included PWA in some aspect(s) of evaluation, the *level of involvement* varies greatly. Therefore the possibility exists that we are missing some important elements of the emic perspective (knowledge and perspective determined by lived experience) (Creswell, 2013), which could enhance the evaluation and design process.

Considerations for meaningful involvement of PWA in research

A valuable overview of PPI models and frameworks is captured by Gibson, Britten, and Lynch , (2012) with a systematic review of conceptualisation, measurement, and effectiveness detailed in Brett et al. (2010) and a critical review of involvement in primary care research and development projects by Tierney et al. (2014). From these recent contributions it is clear that problems persist in the field of PPI in terms of facilitating meaningful service user involvement. Enabling meaningful, as opposed to tokenistic, participation requires innovative methods to make the research process accessible. Specifically, according to INVOLVE (UK national advisory group), meaningful participation occurs when there is active involvement by members of the public in research and organisations. The research process becomes “with” or “by” rather than “to,” “about,” or “for” service users (INVOLVE, 2014). This definition resonates strongly with the principles and ethos of participatory research approaches (International Collaboration for Participatory Health Research (ICPHR), 2013). Examples of how participatory research has enhanced our understanding and inclusion of service user involvement are evident in the literature (Jagosh et al., 2012; MacFarlane et al., 2012).

In this study we draw upon theoretical constructs and practical tools from the field of participatory research approaches (see Chambers, 1994). Specifically, we use Participatory Learning and Action (PLA) research (O’ Reilly-de Brun & de Brún, 2010), developed from Chamber’s work (1994), aiming to move beyond tokenistic participation to meaningful service user involvement. We aim to illustrate how PLA can be used to include PWA and other key stakeholders (speech and language therapists (SLTs) and students) as research participants but also as co-researchers in a multi-perspectival evaluation of a Conversation Partner Programme (CPP).

Methods

Study setting

In 2005/2006, led by the first author, and in collaboration with the local community (Speech and Language Therapy Department Primary Community Continuing Care (PCCC) Health Services Executive (HSE) West, 2013) and Connect (the communication disability network), a

Conversation Partner Programme (CPP) was integrated into the 4-year BSc undergraduate Speech and Language Therapy curriculum at the National University of Ireland, Galway (NUI, Galway), Ireland. CPP training and participation is a mandatory requirement in the curriculum. The design of this particular programme is based on the Connect model of training, which is described in McVicker et al. (2009). The NUI, Galway CPP typically spans 14 weeks and includes 10 conversation visits and is described in McMEnamin, Tierney, and Mac Farlane (2015):

“Community Speech and Language Therapists (SLTs) refer approximately five to twenty new PWA into the programme annually. The majority of PWA choose to continue their participation across several iterations of the programme over a number of years. Third year students are trained as conversation partners, paired with a peer and matched with a person with aphasia based on interests and hobbies and geographical location. Students’ weekly conversation visits to PWAs’ homes or other locations provide unique opportunities to learn about aphasia and apply theory to practice in a relaxed environment which is different from the classroom or clinical settings. Weekly reflective logs, fortnightly tutorials and assessment involving individual and group work facilitate students’ reflective practice and learning throughout the programme.” The lived experience of aphasia and the impact of involvement in the CPP for PWA have been reported separately (McMenamin et al., 2015).

Study design

As mentioned earlier, this study is designed following the principles of PLA research (O’ Reilly-de Brun & de Brún, 2010), a form of participatory research (Chambers, 1994) based on the interpretive paradigm. This adaptive strategy aims to enable diverse stakeholder groups to learn, work, and act together in a co-operative manner, to share, enhance, and analyse knowledge, and to plan together for positive service changes (O’Reilly-de Brún & de Brún, 2011). Importantly PLA focuses on enabling stakeholders who are often marginalised or excluded to be recognised as experts of their own lived experiences and to have a “voice” in the research process. PLA aims to create a partnership between these and (usually) more powerful stakeholders and emphasises the co-construction of research between all involved. PLA techniques for data generation are interactive in nature, encouraging stakeholder involvement in reflection and thematic analysis

(Silverman, 2013) of the emergent data. The techniques often involve visual and verbal elements supporting participation for stakeholders who have communication challenges (e.g., people who do not speak the language of the community where they live) (MacFarlane et al., 2009; O'Reilly-de Brún & de Brún, 2011) or as in the current study PWA. McMenamin et al. (2015) describe how the authors' expertise contributed to making the research process communicatively accessible for co-researchers:

The multidisciplinary backgrounds and PLA experience of the three authors supported the adaption of PLA techniques and materials for use with PWA. The 1st author is a SLT with over 15 years' experience of working with PWA. The 2nd author is a Psychologist with many years' experience of working with people with intellectual disability and communication challenges. The 3rd author is a social scientist and academic and has been involved in collaborative/partnered participatory research with a broad range of stakeholder groups nationally and internationally over the last decade. All three authors are trained PLA facilitators¹ and through their combined clinical, PLA and research expertise they ensured the research process was communicatively accessible for the co-researchers with aphasia.

Research phases

This study included three research phases (see Table 1). In phase 1, the emphasis was on creating individual stakeholder groups (PWA; SLTs; students) and documenting their independent perspectives about aphasia and the CPP. Through these individual PLA data generation sessions (using PLA focus groups and PLA interviews) all stakeholders' experiences of the CPP were captured, and "current practice" was established.

In phase 2 representatives from the individual groups were invited to come together as an inter-stakeholder group to share knowledge, expertise, and ideas and listen to each other's perspectives. This inter-stakeholder group

¹ The authors were trained as PLA facilitators at the Centre for Participatory Strategies (CPS) Ross Wood Clonbur Co. Galway Ireland by Mary O'Reilly-de Brún and Tomas de Brún.

reviewed the data about the CPP generated by the three individual groups in Phase 1 and worked in partnership to identify and agree a set of evaluation criteria for the programme.

In Phase 3, to explore the transferability of findings, the evaluation criteria generated from the emic perspectives of the Irish group were reviewed by an international inter-stakeholder group at Connect (the communication disability network) to discuss findings and compare with the UK experience. Data generated in Phase 3 (see appendix H) are not included here as this article focuses on the involvement of PWA, SLTs, students and the first author as CPP co-ordinator in Phase(s) 1 and 2 with specific attention to data generated about the CPP and its evaluation.

Table 5.1: Research phases and aims

Research phases	Aim of each phase
Phase 1 (individual stakeholder groups)	To explore individual stakeholder groups emic experiences and perceptions of aphasia and the CPP
Phase 2 (inter-stakeholder groups)	To explore the inter-stakeholder groups co-analysis of the shared and different perspectives of the CPP arising from the individual stakeholder groups in Phase 1. To identify and agree CPP evaluation criteria
Phase 3 (international inter-stakeholder group)	To explore the transferability of findings generated in the Irish context

Pilot study

The research questions and PLA techniques were piloted with trained PLA experts ($n = 2$), PWA ($n = 2$), SLTs ($n = 5$), Connect CPP coordinators ($n = 2$), students/volunteers ($n = 3$), and university educators ($n = 3$). Following piloting, changes were made to improve the explanation of PLA techniques (verbal and written), timing, methods, materials, and clarity of the research questions.

Sampling and Recruitment

In Phase 1 purposive sampling (Creswell, 2013) was used to enable the selection of people with experience of a specific CPP from key stakeholder groups affiliated with NUI, Galway. As described by McMenamin et al. (2015), sampling and recruitment were supported by existing links with stakeholder groups involved in the CPP: “A letter was sent to 10 PWA (5 female and 5 male) of varying age ranges who had experience of the CPP. This letter invited PWA to participate in the research. In accordance with our ethical approval a maximum of 5 people could be recruited to this stakeholder group with up to three reminders about the study to each person. It was not ethical to contact potential younger and/or female participants a fourth time and from our recruitment drive 4 males and 1 female agreed to participate. There were no exclusion criteria and participants were not screened for cognitive, hearing, and/or visual problems.”

The seven SLTs contacted were not trained as conversation partners but all had experience of referring PWA into the CPP to be matched with the trained student group. Seven graduates (this study was conducted after graduation) and 21 undergraduates who were trained as conversation partners and had participated in the CPP during their degree programme as students at NUI, Galway were also contacted by email. This stakeholder group is similar to the “volunteer” group identified by Turner & Whitworth (2006). Participant information sheets and consent forms outlining details of the study and contact details (email and telephone number) for the first author accompanied the correspondence. SLTs and members of the student group wishing to participate were invited to respond to the first author directly.

From this recruitment drive individual stakeholder groups were formed for Phase 1. Participants from the individual stakeholder groups in Phase 1 were subsequently invited to participate in Phase 2. All views were represented around the inter-stakeholder table². Table 5.22 shows an

² *The people with aphasia had the largest representation around the inter-stakeholder table as 4/5 continued their participation in Phase 2; 4/5 SLTs participated in Phase 2 with 2 SLTs present at each inter-stakeholder session; 2/9*

overview of stakeholder groups across the research phases (i.e. Phases 1 - 3).

Table 5.2: Individual groups and inter-stakeholder groups across the research phases.

Research phase and stakeholder group	PLA sessions
Phase 1: people with aphasia ($n = 5$)	5 x 3 hr PLA focus group sessions
Phase 1: SLTs ($n = 5$)	5 x PLA interviews
Phase 1: students ($n = 9$)	2 x 3 hr PLA focus group sessions
Phase 1: CPP coordinator ($n = 1$)	1 x 2 hr PLA interview
Phase 2: inter-stakeholder Group ($n = 9$) <ul style="list-style-type: none"> • People with aphasia ($n = 4$) • Speech and language therapists ($n = 2$) • Students ($n = 2$) • CPP coordinator ($n=1$) 	3 x 3 hr PLA focus group sessions
Phase 3: international inter-stakeholder group ($n = 4$) <ul style="list-style-type: none"> • People with aphasia ($n = 2$) • Speech and language therapist and coordinator of the Connect CPP ($n = 1$) • Volunteer trained as a conversation partner ($n = 1$) 	2 x 3 hr PLA focus group sessions

Participant Characteristics

McMenamin et al. (2015) describe the characteristics of the PWA who participated in the study:

Four men and one woman with a mean age of 73 years agreed to participate in this study. Time elapsed since stroke ranged from 3 to 10 years with an average of participation in 3 iterations of the CPP i.e. 30 conversation visits, 10 visits per iteration of the programme.

graduate/undergraduate group participated in Phase 2 - both were undergraduate students.

Communication diagnoses and severity determinations were based on: 1) the objective assessment reports from the referring Speech and Language Therapists (SLTs) documented in the Speech and Language Therapy records; 2) the SLT researchers' confirmation of communication diagnoses with each referring SLT and 3) informal observations of participants throughout the study. All participants had functional comprehension in conversation with either mild or mild to moderate, comprehension difficulties. There was greater variability in expressive language ability, with a range of mild, moderate and moderate to severe disability. Similar to the Parr study (Parr, 2007), styles of communication varied as each person had adapted to communicating with aphasia in different ways, and had developed preferences for varied communication strategies. Most used gesture, intonation, facial expression, with occasional single written words or letters to supplement their speech. Nobody used drawing, word lists or portable communication devices and one person who presented with the most severe expressive disability did not spontaneously use any augmentative means to support communication. Given the older age range of participants we were aware of the possibility of co-morbid dementia however none of the participants with aphasia presented with any symptoms of dementia.

Speech and language therapists

Five SLTs agreed to participate and included various grades: manager ($n = 1$), senior ($n = 3$) and staff ($n = 1$) with clinical experience ranging from 7 to greater than 20 years. All were female and age ranges were between 28 and 47 years.

Graduates and undergraduate SLTs in training

Four graduates between 2 to 7 years post qualification were recruited. Two were in full-time employment while the other two were between posts. Three were female and one male and ages ranged from 22 to 40 years. The five undergraduates were in the third year of the 4-year BSc in Speech and Language Therapy. All graduates and undergraduates had been trained as conversation partners using the Connect model (Connect - the communication disability network) of training and had participated in the CPP at NUI, Galway, Ireland.

Consent

The process of consent was approved by the NUI, Galway, Ethics Committee. Each participant had the opportunity to read and discuss aphasia friendly project, audio recording, and photo information sheets. Signed consent forms are stored in accordance with the ethical approval requirements of the first author's institution. Data generation sessions were photographed and taped on a digital audio recorder with participants' permission. Detailed information on the consent process is provided in Mc Menamin et al. (2015).

Data co-generation and co-analysis

In *Phase 1* participants in the individual stakeholder groups used their selected PLA techniques to co-generate data in response to the following questions:

1. What are the best things about CPP?
2. What are the worst things about the CPP?
3. What would improve the CPP for me?

A variety of PLA data generation techniques were used - Flexible Brainstorming, Card Sort, Direct Ranking, and Seasonal Calendar (Chambers, 2004; O'Reilly-de Brún & de Brún, 2011), and all analyses followed the principles of thematic analysis (Silverman, 2013). The techniques were explained, discussed, and agreed with co-researchers as part of the co-design process in Phases 1 and 2. The selection of techniques for each research question varied across groups, reflecting participants' preferences and priorities (Simmons-Mackie & Lynch, 2013).

A PLA Flexible Brainstorm technique was used in Phase 1 as a creative way of generating information and ideas from participants' unique experiences of the CPP³. In summary, PLA materials including a shared blank flip chart sheet, coloured markers and coloured stickies, pens, paper, key words, symbols, and pictures were centred on the table for easy access. Participants chose materials to suit their communication preferences and needs and used these materials to communicate their emic experiences of the CPP. Data generation was democratic, inclusive,

³ A full procedural account of using Flexible Brainstorm, Card Sort and PLA Interviewing techniques with PWA are described in McMenamin et al. (forthcoming)

and voluntary with no pressure on any individual to communicate verbally. There was no restriction on the number of ideas an individual could share; however, in the interest of clarity the group agreed that each stickie/symbol/picture could only represent one idea. The data generated were flexible and could be easily arranged, rearranged, clustered, and connected for other PLA techniques for example, the Card Sort categorisation technique (O'Reilly-de Brún & de Brún, 2011).

The PLA Card Sort technique was used as a categorisation method to support the organisation and sharing of complex information in an easily retrievable way. In Phase 1, participants reviewed their populated Flexible Brainstorm charts and began sorting, organising, and analysing data into meaningful groupings. Material was categorised according to participants' emic perspectives with the group often acting as good "cross-checks" on each other. The facilitators supported the categorisation process in a participatory way using supportive communication techniques. When all the individual elements were co-analysed and grouped into meaningful bundles, participants began to negotiate, debate, and co-generate overarching category headings assigning individual elements to the agreed themes. For a more detailed description of the PLA Card Sort technique with co-researchers, see Mc Menamin et al. (2015).

Phase 1 and Phase 2 data

At the end of Phase 1, the role of the first author was to synthesise the co-analysis of data generated by individual stakeholder groups during the first research phase. Quality and rigour checks were integrated into the syntheses process through reflection, debriefing, discussion, and commenting between all three authors.

In Phase 2 the inter-stakeholder group viewed the PLA charts developed by the individual groups in Phase 1. Also the first author summarised and presented her perceptions about the similarities and differences across individual stakeholder groups about the CPP. The focus in this phase was on the inter-stakeholder groups' reflections on the formal synthesis of responses to Question 3 "What would improve the CPP for me?" This was presented on a PLA chart – a synthesised Card Sort (see Table 3). The inter-stakeholder group worked collaboratively to review and validate the

synthesis. The outcome was a revised Card Sort chart which displayed the multi-perspectival picture of “best practice” for the CPP. The emerging categories and elements were the agreed CPP evaluation criteria.

Two further PLA techniques and the process of “interviewing the technique” were then used by the inter-stakeholder group on the final agreed Card Sort chart in *Phase 2*:

1. PLA Direct Ranking technique to prioritise which evaluation criteria were most important.
2. PLA Seasonal Calendar technique to progress planning for the implementation of the CPP evaluation criteria.

As there is no detailed description of using these two PLA techniques with PWA in the literature, the full procedural details are presented below.

PLA Direct Ranking Technique

Direct Ranking provided a mechanism for co-researchers to express priorities and preferences about the emergent categories of CPP evaluation criteria. The facilitators checked that (1) the final Card Sort chart was clearly visible and (2) each participant had 10 colour-coded voting tokens (10 coloured paperclips) with each token representing one vote (see Figure 5.1).

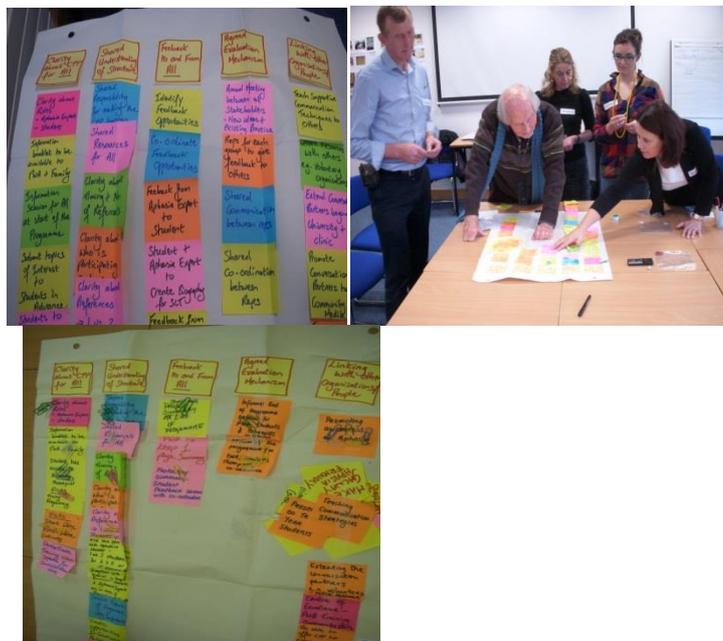


Figure 5.1: Photographs of PLA Direct Ranking Technique

The second author, as the facilitator for the Direct Ranking technique

supported the inter-stakeholder group to review the category headings and elements on the final “Card Sort” chart by reading individual stickies aloud. She then explained the Direct Ranking technique, gave an example of how to vote and highlighted that the number of paperclips placed on a category indicated the strength of the vote. Participants could place all of their paperclips on a single category if they believed that category was the most important for evaluating the CPP or they could distribute their paperclips across categories as they wished. One person with aphasia asked whether the paperclips should be placed only on the category heading during voting. Following discussion the group agreed that the paperclips could be placed anywhere on the category (heading or elements). Co-researchers were invited to cast their votes according to a single agreed criterion, for example, “most important evaluation criterion to least important evaluation criterion”. As agreed with the group, the first author participated in the voting process in her role of CPP co-ordinator.

The second part of the Direct Ranking involved reviewing and counting the votes allocated to each category. When all co-researchers were satisfied that the votes were counted and added correctly, the facilitator invited the group to reflect on the emergent prioritisations and share perspectives about the process and outcomes. This discussion enhanced knowledge around the inter-stakeholder table (See Table 5.5 in the Results section).

PLA seasonal calendar technique

Participants decided to progress the research beyond the generation of CPP evaluation criteria to planning the implementation using the PLA Seasonal Calendar technique (see Table 5.6). Following a discussion about the timeframe that would capture the progression of the CPP, the agreed timeline included three stages: “Before the Programme”, “During the Programme” and “After the Programme”. The facilitator wrote the timeline on individual stickies inviting co-researchers to place them along the top horizontal axis of the chart. On the left-hand vertical axis the CPP evaluation criteria were positioned, that is, “Clarity about the CPP for All”, “Shared Understanding of Structure,” and so on. Taking each criterion and related elements (see Table 5.3 for individual elements that made up each category) in order of priority as emerged from the Direct Ranking, the facilitator invited the group to write verbs/action words on each stickie to

facilitate the implementation of tasks, for example, the group agreed to rewrite “Clarity of Roles – PWA and Student” as “Clarify roles of PWA and student”. Colour-coding category headings and related elements (e.g., “Shared Understanding of Structure” and all the attached elements were written on pink stickies) created a clear visual link between groupings on the Seasonal Calendar chart.

Co-researchers discussed the actions required to complete each task and plotted responsibilities across participant groups (e.g., SLTs, PWA, students, CPP coordinator). Photographs of the Seasonal Calendar technique and chart are shown in Figure 5.2.



Figure 5.2: Photographs of the PLA Seasonal Calendar technique and co-created chart.

Interviewing PLA techniques

The inter-stakeholder group “interviewed” both the Direct Ranking and Seasonal Calendar techniques meaning that the facilitator encouraged participants to review and discuss the charts before deeming the techniques complete. Participants were invited to share anything surprising or striking about the PLA techniques, process, and/or outcomes. When the group agreed that there was nothing new to add or say, the PLA technique(s) were closed.

Results

Individual stakeholder perspectives (Phase 1) - The best and worst things about the CPP

In response to Question 1 “What are the best things about the CPP?” there was resonance across individual stakeholder groups that the CPP is confidence building for both the PWA and the students. All groups commented on the relaxed nonclinical environment as a positive aspect contributing to easy conversation and a social outlet for PWA. The PWA and the students felt that the relationship between conversation partners was equal and collaborative which was different from other experiences involving intervention from SLTs and other healthcare professionals. The CPP provided an opportunity for PWA to practice conversation skills with unfamiliar people, and this was viewed by all groups as positive. The SLTs commented on the cost effectiveness of the CPP and saw the programme as a potential long-term solution for people living with aphasia.

The stakeholder groups had different ideas about their roles and contributions to the CPP. At the outset the PWA believed they were sole beneficiaries from the programme. However the other three stakeholder groups valued the unique contribution of the PWA in teaching the students about the “lived experience of aphasia.” The CPP coordinator was unique in identifying Service Learning (SL) as an appropriate pedagogy to underpin the CPP and provide students with an opportunity to apply theory to practice. The students and the SLTs appreciated the time for structured reflection as a core component of SL. One stakeholder with aphasia differed from all other stakeholders reporting that the CPP “was a waste of time” and he did not benefit from participation.

In relation to Question 2 “What are the worst things about the CPP?” stakeholders identified cost of travel, structure, organisation, and clarity of the CPP as aspects that could be improved. The lack of an agreed evaluation mechanism to improve structure, delivery, and redesign was a shared concern. Perceptions about whether the programme was a form of speech and language therapy differed across groups. The SLTs, university coordinator, students, and some PWA understood that the CPP was different from traditional speech and language therapy. One PWA was very dissatisfied with this realisation and did not value this form of intervention.

Stakeholders across individual group's generated different ways to improve the CPP (see Table 5.4).

Finally in relation to Question 3 there was a high level of agreement about "current practice" and what would create "best practice" across stakeholder groups although the dominant focus of each individual group differed for example:

1. SLTs viewed the CPP from a service delivery perspective. They were interested in how the CPP might benefit the PWA in the first instance and the students in the second with the backdrop of caseload demands and cost-effectiveness as considerations.
2. PWA viewed the CPP as an opportunity to practice talking with new people, "get out and about" and "help the students."
3. Students were interested in the "lived experience of aphasia", improving communication skills and supporting conversation partners.
4. The CPP coordinator aimed to ensure the programme ran smoothly, benefiting all participating stakeholders.

Synthesis of Phase 1 data for Phase 2 inter-stakeholder group work

The first author's synthesis of phase 1 data (described earlier) about the CPP was prepared as a combined card sort. The chart included five category headings with 25 elements across the categories. "Clarity about the CPP for All" and "Shared Understanding of Structure" had some interconnections related to the organisation and transparency of the CPP while "Feedback to and from All" and "Agreed Evaluation Mechanism" had similar ideas centred on evaluation and redesign. Table 5.3 shows the Card Sort chart presented to the inter-stakeholder group in Session 1 Phase 2.

Table 5.3: Card Sort chart presented to the inter-stakeholder group in Phase 2 by first author following synthesis from data generated with individual stakeholder groups in Phase 1.

Clarity about CPP for all	Shared understanding of structure	Feedback to and from all	Agreed evaluation mechanism	Linking with other organisations/people
Clarity of roles – PWA and student	Shared teaching, resources, responsibility for making CPP happen	Identify and coordinate feedback opportunities	Annual meeting all stakeholder reps - new ideas and existing processes	Teach supportive communication techniques to relevant others
Information booklet to be available for PWA and family	More visits	Combined feedback from PWA and student to SLT	Identify reps for each stakeholder group who would liaise with whole group	Share resources with others, e.g., voluntary organisations
Information session at the start of the programme	Clarity about referrals and participation	Feedback from PWA to student, e.g., communication rating form	Shared communication and coordination between reps	Extend conversation partners beyond university and clinic - get out into community/media
Submit conversation topics in advance	Clarity about who is participating each year (for SLT)	Biography of both PWA and student		Increase the awareness of communication partners facilitating conversations
Ask about stroke and aphasia	Clarity about PWA preferences - 1 vs. 2 students etc.	SLT – what worked well/ did not work well in conversation		
	Swapping partners during programme			
	Contact with student			
	Socialise more – opportunities for conversation partners to meet			

As described in methods, the inter-stakeholder group engaged in an active and thorough review of Table 3 moving elements between categories, creating new elements, rejecting some, and changing others. The outcome of this co-analysis and validation was 32 well-defined elements categorised to five themes that were agreed and understood by co-researchers⁴. Reviewing the Card Sort chart resulted in clarity and greater ownership of the emergent evaluation criteria and elements (see Table 4).

⁴ The card sort categories are the emergent themes/_CPP evaluation criteria and are described in detail below

Table 5.4: Completed Card Sort chart following inter-stakeholder analysis and validation (Phase 2).

Clarity about CPP for all	Shared understanding of structure	Feedback to and from all	Agreed evaluation mechanism	Linking with other organisations/people
Clarity about roles: <ul style="list-style-type: none"> • Aphasia Expert • Student 	Shared responsibility for making the CPP happen	Joint (PWA & student) one-page summary at end of programme	Informal end of programme session for PWA, students, therapists, and coordinator	Promoting awareness of aphasia
Information booklet to be available for PWA and family	Shared resources for all	PWA to keep one-page summary	Review of programme for PWA, students, therapists and coordinator	Extending the conversation partners, e.g., voluntary – active retirement
Student has access to referring SLT	Clarity about the timing of referrals and the number of referrals	Photocopy summary. Student feedback session with CPP coordinator		Centre of Excellence – PWA training community/SLTs
Visits – timing and frequency	Clarity about who is participating each year (for SLT)			Be able to offer CPP to everyone who wants it – regardless of geographical location
Visits – start date/Finish date Continuity	Ask the PWA to choose 1 or 2 students for 2 x 5 or 10 sessions			Media
Develop/create training video separate from CPP visits	Clarity about who is participating each year			Teaching communication strategies to <ul style="list-style-type: none"> • Make Galway aphasia

Clarity about CPP for all	Shared understanding of structure	Feedback to and from all	Agreed evaluation mechanism	Linking with other organisations/people
				friendly <ul style="list-style-type: none"> • Government departments • Córas Iompair Éireann • Transition year students • Family members • Local shops/restaurants • Home Helps • Croí • Quest • Primary care centre
	Clear contact between student and aphasia expert, e.g., in case of cancellations			
	Social aspect of programme very important			
	Create opportunities for conversation partners to meet			
	Referral dates for therapists - ongoing			

Clarity about CPP for all	Shared understanding of structure	Feedback to and from all	Agreed evaluation mechanism	Linking with other organisations/people
	referral (during year)			
	Clarify who is responsible for administration			
	Administrator to contact key SLT prior to sending correspondence (about the CPP to PWA)			
	PWA can contact their SLT or/and CPP co-ordinator at any time with queries about the programme			
	Don't be afraid to talk about aphasia			

Later we describe each criterion highlighting inter-relationships between themes where relevant.

Theme 1: Clarity about CPP for all

The elements in this theme captured important features about the clarity of the CPP for all stakeholders. The group discussed the confusion experienced by some in relation to the purpose of the programme and agreed three separate ways to resolve this including:

- “Clarity about roles: aphasia expert and student” (all stakeholder groups to be consistent in their explanation of the CPP).
- “Information booklet to be available for PWA and family” (to be co-created by an inter-stakeholder group).
- “Create training video separate from CPP visits” (to capture conversations between trained students and PWA participating in the programme for teaching/information purposes).

Shared information about conversation visits before they begin is important for all stakeholders for example, “timing and frequency,” “start and finish dates,” “continuity of visits” (when the programme ends) to ensure transparency across groups. Finally, the group discussed dealing with student issues as they arose and agreed that students should have contact details of both the referring SLT and CPP coordinator as sources of support during the programme. Theme 1 has strong links with Theme 2 “Shared Understanding of Structure”.

Theme 2: Shared Understanding of Structure

The elements in this theme captured issues about the structure of the CPP and how to optimise organisation. Participants agreed there should be “shared responsibilities for making the CPP happen” across stakeholder groups. The person “responsible for administration” should contact the “SLT prior to sending correspondence about the CPP to PWA” as updated information may be available (e.g., PWA may no longer wish to participate, have moved). The referral issues, for example, “timing and number of referrals” resonated with the clarity issues about the timing and frequency of visits in Theme 1 “Clarity about CPP for All”. The group discussed the number of SLT referrals compared to the number of actual participants each year. Clarity about this issue is important particularly for the SLT stakeholders. There was agreement that the PWA should have:

- The opportunity to express communication preferences/needs (e.g., “PWA to choose 1 or 2 students for 5 or 10 sessions”).
- “Clear contact between student and PWA, e.g., in case of cancellations.”
- Details to “contact their SLT (even if discharged from therapy) and/or the CPP coordinator at any time with queries throughout the programme” which linked with Theme 1: Clarity about CPP for All.

The inter-stakeholder group agreed that the “social aspect of programme is very important” and we should “create opportunities for conversation partners to meet”.

Theme 3: Feedback to and from all

The elements in this theme captured issues about feedback between stakeholder groups. Participants agreed that the student conversation partner and the person with aphasia should co-create a one-page summary about their experiences of the CPP at the end of the programme –“Joint (PWA & Student) one page summary at end of programme’. Following debate and discussion about where this summary should be stored the group agreed “PWA to keep one page summary.” In this way the joint summary can be photocopied by the student for the CPP coordinator and the referring SLT. Feedback between stakeholder groups is an important criterion to assess whether the CPP is working well from a variety of perspectives and connected with Theme 4 “Agreed Evaluation Mechanism.”

Theme 4: Agreed Evaluation Mechanism

The elements in this theme captured sharing information about the CPP, for example, what is working well, not working well, and what should change for the next iteration of the programme. The inter-stakeholder group engaged in a lively debate about the best way(s) to gather this information with final agreement that an end of programme meeting for all stakeholder groups should be included as part of the CPP structure – “Informal end of programme session for PWA; students; SLTs and CPP co-ordinator.” Invitations should be sent to all participants – “Review of programme for PWA; students; Therapists and Co-ordinator” to capture multi-perspectival CPP experiences in a participatory way. The group agreed that the social

component of the programme should be maintained through a relaxed, informal gathering including refreshments that resonated with Theme 2 “Shared understanding of structure.”

Theme 5: Linking with other Organisations/People

The elements in this theme related to developing public awareness about aphasia, supportive communication strategies, and the CPP. Establishing new contacts and taking advantage of media opportunities should be pursued. The groups were very motivated to: (1) expand the CPP beyond the current structure and format – “extending the conversation partners, for example, voluntary (agencies) and active retirement (groups)” and (2) “make Galway an aphasia friendly city.” All participants pooled ideas about local amenities that would benefit from communication training provided by an inter-stakeholder team (PWA, SLTs; students; CPP coordinator), for example, public transport staff, transition year students, home helps, primary care centres, local shops, restaurants, and voluntary organisations. The group agreed that the CPP should be expanded – “be able to offer CPP to everyone who wants it – regardless of geographical location”. This is an ongoing challenge as PWA living in more remote rural areas currently cannot access the programme.

Direct Ranking: Inter-stakeholder Group (Phase 2)

Through the PLA Direct Ranking technique, the inter-stakeholder group expressed priorities and preferences and indicated categories of equal weight for the CPP evaluation criteria. Consensus was reached about the most important evaluation criterion to the least important, for example, “Shared Understanding of Structure” was allocated the most votes ($n = 16$) denoted by 16 paperclips while “Feedback to and from All” received the least number of votes ($n = 5$) denoted by five paperclips. The highest ranked categories, that is, “Theme 2: Shared Understanding of Structure” (16 votes) and “Theme 1: Clarity about CPP for All” (14 votes) have strong resonance and interconnections as previously discussed. These two themes had clear majorities receiving almost double the votes of the other three themes. The joint third- and fourth-ranked themes, that is, “Agreed Evaluation Mechanism” and “Linking with Other Organisations/People” received 7.5 votes each. The half vote reflects co-researchers’ deep consideration of category prioritisations and the voting process. One co-

researcher with aphasia asked whether he could break one of his paper clips in half to give him two half votes instead of one vote. The colour coding of voting tokens provided a visible representation of each individuals' votes on the final agreed Direct Ranking chart enabling PWA to view the voting outcomes very clearly. The emergent evaluation criteria (category headings on the stickies at the top of the chart) were rearranged and presented in order of priority. Table 5 shows the agreed prioritisation of CPP evaluation criteria in ascending order from the least important to the most important criterion. As there were five participants with 10 votes each, the total number of votes cast was 50.

Table 5.5: Results of inter-stakeholder direct ranking of CPP evaluation criteria (Phase 2).

CPP Evaluation Criteria	Number of votes
Shared understanding of structure	16
Clarity about CPP for all	14
Agreed evaluation mechanism	7.5
Linking with other organisations/people	7.5
Feedback to and from all	5

Seasonal Calendar: Inter-stakeholder Group (Phase 2)

The inter-stakeholder group in Phase 2 used the PLA Seasonal Calendar technique to map the agreed CPP evaluation criteria and arising actions from these criteria onto a timeframe in which to complete the tasks. The agreed timeline is shown across the horizontal axis of the chart, that is, "Before the Programme"; "During the Programme"; "After the Programme" with the five evaluation criteria along the vertical access, that is, "Shared Understanding of Structure" "Clarity about the CPP for All," etc. The individual elements ($n = 37$) are mapped across the timeline with the agreed stakeholder group(s) responsible for implementing the particular task, for example, "Identify key people to make the CPP happen (CPP Coordinator)". The majority of tasks ($n = 15$) are assigned to "Before the Programme" with the minority allocated to "After the Programme" ($n = 8$). Participants agreed that some elements should be included at several stages along the timeline; for example, "SLTs to develop spreadsheet of possible clients for CPP" is included "Before the Programme" and "During

the Programme” as referrals to the CPP can be made by SLTs throughout the calendar year. The elements that cross the timeline are denoted by an arrow for ease of identification ($n = 5$). Table 6 represents the Seasonal Calendar chart co-created by the inter-stakeholder group showing the planned implementation of the CPP evaluation criteria.

Table 5.6: Seasonal calendar: CPP evaluation criteria mapped onto timeline for implementation by inter-stakeholder group (Phase 2)

	Time line for CPP		
Evaluation Criteria	Before the programme	During the programme	After the programme
Shared Understanding of Structure	<ul style="list-style-type: none"> • SLTs to develop spreadsheet of possible clients for CPP • Identify key people to make the CPP happen (CPP coordinator) • SLT to let clinic know how many PWA want to take part in CPP at any time in the year • Clinic to let University know who is interested in getting involved • PWA expresses their preference about number of students and number of visits • Administrator to contact key SLT prior to sending correspondence • Clarify who is responsible for administration. 	<ul style="list-style-type: none"> • SLTs to develop spreadsheet of possible clients for CPP • PWA and students to cancel appointments with adequate time • To share resources for all • Create opportunities for Conversation Partners to meet (university and administrator) • PWA and students to share phone numbers if comfortable • Students talk about aphasia with PWA • Keep the social aspect of CPP (PWA and student) 	Social event includes the evaluation meeting
Clarity about the CPP for all	<ul style="list-style-type: none"> • Students to explain purpose of visit before and during the visits 	Students to explain purpose of visit before and during the	Develop/create training video separate from

	Time line for CPP		
Evaluation Criteria	Before the programme	During the programme	After the programme
	<ul style="list-style-type: none"> • Create information booklet to be available to PWA and family (all) • CPP coordinator to share contact details of referring SLTs with students • CPP coordinator to share information with SLTs about dates of CPP and frequency of visits in reminder e-mail 	visits	conversation partner visits (all)
Agree evaluation mechanism			<ul style="list-style-type: none"> • Informal end of programme session – PWA, SLTs, students, CPP coordinator • Social event includes the evaluation meeting
Linking with other organisations/people	<ul style="list-style-type: none"> • Centre of excellence – PWA training SLTs and community • Extending the conversation partners, e.g., volunteers, active retirement • Promote awareness of aphasia 	<ul style="list-style-type: none"> • Centre of excellence – PWA training SLTs and community • Extending the conversation partners, e.g., volunteers, active retirement • Promote awareness of 	<ul style="list-style-type: none"> • Centre of excellence – PWA training SLTs and community • Extending the conversation partners, e.g., volunteers, active

	Time line for CPP		
Evaluation Criteria	Before the programme	During the programme	After the programme
	and CPP in media • Be able to offer CPP to everyone who wants it regardless of geographical location	aphasia and CPP in media • Promoting awareness of aphasia (all)	retirement • Promote awareness of aphasia and CPP in media
Feedback to and from All		• Write joint one-page summary at the end of programme (PWA and student) • Photocopy one-page summary (student, SLT, coordinator)	PWA to keep the one-page summary

Discussion

The need to design and deliver services that respond to the on-going health and social needs of service users is fast becoming an international priority. Healthcare policy, research, and development activities worldwide show increased PPI, highlighting the importance of including the *insider* voice. Conversation approaches of all types report positive outcomes (Basso, 2010; Kagan et al., 2001; McVicker et al., 2009; Rayner & Marshall, 2003). To what extent the experiential knowledge of PWA is included in programme evaluation and redesign varies greatly. This study offers (1) a multi-perspectival evaluation of a conversation training intervention from the emic experiences of participants; (2) an innovative participatory health research approach for service design, development, and evaluation that is consistent with the living with aphasia framework (Byng & Duchan, 2005; Pound, Duchan, Penman, Hewitt, & Parr, 2007; Pound, Parr, & Duchan, 2001); and (3) an illustration of how to use PLA to include PWA and other key stakeholder groups as participants and co-researchers throughout the research process.

The analysis and synthesis of generated data across the research phases revealed the complex nature of emic experiences and interpretations of the CPP. Key emergent criteria relate to ensuring a shared understanding of structure, organisation, and purpose of the programme. Co-researchers were enthusiastic in their vision for the future of the CPP aiming to (1) promote public awareness of aphasia, (2) change the way the general public “talk” to PWA, and (3) increase positive communication experiences for PWA in society. Very specific ideas were generated about how to achieve these goals – for example, PWA selected local shops, restaurants and services (e.g., bus services), suggesting that these should be offered training in supportive communication techniques and Galway would become “an aphasia-friendly city.” There was a high degree of motivation to “extend the CPP” to groups not currently involved, for example, “active retirement”, “primary care centre,” and “voluntary organisations”. Involving new organisations would be a sign of success in future iterations of the programme. The desire to use the CPP to influence the way society communicates with PWA shows stakeholders’ ambitions and vision.

The numerous and varied references by co-researchers to the valued features of the CPP, for example, “easy conversation,” “social outlet for PWA,” opportunity to “practice conversation skills with unfamiliar people,” “relaxed environment” for example, own home, “confidence building,” “sense of importance,” “improved communication skills,” “cost-effectiveness” and “learning about aphasia” are consistent with previous findings reported across a range of papers in the existing literature (McVicker et al., 2009; Rayner & Marshall, 2003; Savage, Donovan, & Hoffman, 2014). However, despite the reported positive impacts

and increased popularity of conversation approaches, robust research on the effectiveness of these interventions is sparse (Turner & Whitworth, 2006). The current literature describes a global appraisal of conversation training approaches (Fox et al., 2009; Jagoe & Roseingrave, 2011; McVicker et al., 2009) with no clear set of specific evaluation criteria from the emic experiences of participants. Our findings add an original contribution to the existing literature by providing a detailed description of what criteria PWA and other key stakeholders believe to be important in evaluating a conversation training programme from their unique perspectives. The co-researchers' decision to move beyond identification of evaluation criteria to map implementation and design the future of the CPP reflects meaningful involvement in the research process.

In Phase 2 engaging representatives from all stakeholder groups in participatory dialogue using PLA techniques was a challenging task. It was difficult to negotiate and find times that suited representatives from all groups for face-to-face PLA sessions. Persistence was necessary, but worthwhile, as the data generated by the PLA inter-stakeholder group was qualitatively different from data generated by individual cohorts. For example, in the individual group (Phase 1) the PWA shared a belief that they were the primary benefactors from the CPP with little to offer the other stakeholder groups. However this view changed as the inter-stakeholder group discussed the value of learning from people with experiential knowledge of the daily challenges of aphasia. The co-researchers with aphasia listened to, and acknowledged, the ways in which the students, SLTs, and CPP coordinator benefited from and appreciated their contributions to the programme. This new understanding of reciprocal benefits changed the PWAs' original perspectives about their role in the programme which related directly to the second highest ranking evaluation criteria "Clarity about CPP for All". Another striking feature of the inter-stakeholder data was how strongly aligned the individual groups were in their views of "CPP best practice". This resonance across groups is consistent with previous studies (e.g., McVicker et al., 2009) where different perspectives of the CPP were captured. Perhaps, in a different inter-stakeholder group, more divergence of views may occur.

Methodological critique

We used an innovative participatory health research approach to identify CPP evaluation criteria from the multi-perspectival emic experiences of a small group of PWA and other key stakeholders. We acknowledge the limitations of our sample - this is a small sample size of older, predominantly male, retired participants with aphasia living at home. The participants with aphasia represented a select group of people with mixed aphasia interested in the CPP from a particular cohort. While a mixed receptive, expressive functional aphasia may reflect

the majority of PWA, we recognise that the emic experiences and data generated by people with other types of aphasia (e.g., receptive only or expressive only) and ranges of severity (e.g., severe comprehension difficulties) may differ from the data generated by our co-researchers. Recruiting people with a pure receptive or expressive aphasia and a more gender-balanced group with younger participants was beyond the scope of this study, and we acknowledge these limitations. While some older PWA may present with a co-morbid dementia, we did not experience this amongst our co-researchers; however, it is an important consideration for future studies. Despite their older age-range and data generation spanning 12 months, there was no attrition from the group nor did there appear to be any loss of connection with the data over time.

In relation to the other stakeholder groups, the majority of graduate and undergraduate participants were in their 20s and the SLT stakeholder group were all female with age ranges between 28 to 47 years which again may represent views from a particular cohort. The participants represent a select group of stakeholders affiliated with a CPP specific to a single university site. All were self-selecting and highly motivated to engage with the research process and share their emic experiences. We acknowledge that the participants included in the inter-stakeholder group are not representative of the communities from which they come, and this is a limitation of our study impacting the validity and generalisability of findings. Preliminary work on sharing the data generated in Ireland with an inter-stakeholder group in the United Kingdom in Phase 3 may contribute to the transferability of findings; however, this is a first step and further exploration of resonance across different groups and contexts is required.

Finally, it is important in qualitative research to consider issues of positionality. The first author was the coordinator of the CPP and involved in the study as a co-researcher and PLA facilitator. The movement between *insider/outsider* positions is acknowledged and may have positively biased the data although the involvement of the second author as an “outsider” facilitator was an important feature to counter such an effect. The third author also remained an “outsider” to ensure quality and rigour across the research phases. Issues of positionality will be reported in a separate methodological paper McMenamin et al. (2015).

Conclusion

In this study a small group of PWA and other key stakeholders were meaningfully involved in the identification of evaluation criteria for a conversation training intervention using PLA. The use of PLA to engage PWA as co-researchers in service design and evaluation resonates strongly with the principles of the living with aphasia framework (Byng & Duchan, 2005;

Pound et al., 2007). The outcomes of this collaborative work bridge the gap between policy imperatives around involvement and actual practice and will impact the design, evaluation, and redesign of our CPP for all stakeholders. Preliminary findings suggest some resonance between the UK and Irish contexts although this requires further exploration. This study may also be of interest to professionals in this clinical area and to those exploring new approaches to include marginalised service users, especially people with communication disabilities in research. Future studies should consider using participatory health research approaches to engage PWA of different age ranges with varying types and severity of aphasia and other key stakeholders as co-researchers in outcomes-based studies. Through partnership in the research process, we can learn from the emic experiences of PWA and other groups with communication disability, identifying and confirming important key variables in service design, development and evaluation.

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