Refining methods of Experience Based Co-design for application in aphasia and cognitive-communication disability

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Abstract

Purpose: Co-design of research and services alongside end users is increasingly required by funding bodies and governments. To enable meaningful inclusion of people with communication disability, planning and modification are required, as standard co-design procedures involve extensive spoken and written language. Experience Based Co-Design (EBCD) is one co-design approach that is gaining popularity; however, there are few detailed reports to date on adapting EBCD for communication disability. This paper outlines our modifications of EBCD to co-design a self-management, technology enabled platform (Communication Connect) for people living with post stroke aphasia and cognitive-communication disability from traumatic brain injury.

Method: Participants included individuals with communication disabilities (n = 8), care partners (n = 3), and health professionals (n = 20) across three Australian states. Data collection involved video-recorded interviews, focus groups, and structured prioritization workshops. This study describes the first four stages of EBCD (project setup, two experience-gathering stages, and identifying priorities).

Results: This paper presents a detailed account of the practical decisions and modifications made throughout the EBCD process. Key adaptations are outlined, including the use of text-based video editing to efficiently create touchpoint films, non-linear presentation of challenges to facilitate engagement, and visual aids to support prioritization and ranking. These modifications supported meaningful participation of co-designers including people with communication disability.

Conclusions: This method paper contributes to the growing knowledge on adapting EBCD for communication disability, which may be of use to future EBCD projects and for

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improving meaningful inclusion of people with communication disability in co-design research.

Keywords:

aphasia; cognitive-communication disorders; co-design

Introduction

Increasingly, funding bodies and governments require involvement of the public and end-users in the conception, design, evaluation and monitoring of research and service improvement, commonly called Patient and Public Involvement (PPI) (Mulvale et al., 2021; Shiggins, Coe, et al., 2022). PPI can take many forms, depending on the level of involvement or ‘power’ a consumer has and the type of project (IAP2 Australasia, n.d.). Co-design is one branch of PPI where members of the public are involved in the design (or redesign) of a service, technology or treatment (Mulvale et al., 2021). Co-design is both a method and a philosophy (Moll et al., 2020), and although terminology and specific definitions vary (Dobe et al., 2023), most applications cite similar core principles: stakeholders should be actively involved in the process of design, with an emphasis on shared input rather than passive participation, and with a goal of improving services and outcomes (Dobe et al., 2023; Moll et al., 2020). When done well, co-design elevates the voice of those with lived experience and provides important new skills to the co-designers (Moll et al., 2020).

Experience-Based Co-Design (EBCD) is one specific co-design approach with a substantial expansion of use in health services and research settings since it was first reported in 2005 (Donetto et al., 2014). EBCD emphasises the goal of understanding and improving *experiences* of a service or intervention, rather than just outcomes or processes. Understanding the key moments that influenced people’s experiences allows improvements to be made (Bate & Robert, 2006). EBCD typically involves six key stages (Donetto et al., 2015): (1) project setup, (2 and 3) gathering patient and staff experiences, respectively, (4) identifying priorities, (5) small groups working on solutions, (6) celebration event (see Table 1).

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The emphasis on understanding lived experience in co-design is particularly relevant for people with communication disability, who experience substantial disadvantage and disempowerment (Hersh, 2018). However, the inclusion of people with communication and cognitive disability in co-design can be challenging, as most co-design procedures assume unimpaired communication ability from those involved (Galliers et al., 2012) and rely heavily on written and spoken language (Shiggins, Coe, et al., 2022). Design is complex, and people with communication disability may find unmodified processes difficult due to challenges in comprehension and expression of language, dealing with abstract concepts, information recall, reasoning, and distraction. A core aspect of EBCD that may enhance accessibility for people with cognitive and communication disability is the use of video, which could overcome the challenges of reading written information experienced by many people after stroke (Singh et al., 2024). In EBCD, participant experiences are explored through interviews or focus groups, which are recorded on video and then edited to a short ‘touchpoint’ film to bring the key moments of the experience to life in subsequent stages.

There are ample publications describing how research processes can be modified to improve accessibility for those with communication disability, as participants (e.g., Brady et al., 2013; Dalemans et al., 2010; Pearl & Cruice, 2017; Shiggins, Ryan, et al., 2022), as co-producers of research (e.g., Cruice et al., 2022; Hersh et al., 2021), and specifically in co-design projects (e.g., Carminati et al., 2024; Charalambous et al., 2023; Shiggins, Coe, et al., 2022; Wilson et al., 2015; Wray et al., 2021). For example, Wilson et al. (2015) described their use of tangible—that is, non-verbal—tools such as photographs, story grids and visual prototypes to engage people with aphasia in the co-design process, thereby maximizing accessibility. People living with TBI in Carminati et al. (2024) described several helpful strategies when reflecting on their involvement in a co-design project, including the presentation of information at a slow rate, repetition, recapping of key topics and making

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visual and memory aids readily available. Yet, despite the growing use of EBCD, to date there is minimal literature relating to the methods of modifying EBCD to include people living with stroke and traumatic brain injury. For example, two Australian government health services employed EBCD approaches to improve rehabilitation practices. Patients with brain injury were included in the research processes (Butler et al., 2020; Dimopoulos-Bick et al., 2019), but information about the cognitive-communication profiles of the co-design participants was not provided. Without this information, it is unclear whether EBCD was modified adequately to allow meaningful participation. Within stroke, Anemaat et al. (2024) have used EBCD in a large sample to design a comprehensive service for post stroke aphasia, demonstrating the feasibility of the approach for developing complex solutions with people with aphasia. However, we are unaware of any other applications of EBCD in post-stroke aphasia outside of this project.

We used EBCD for our project, Communication Connect (NHMRC, 2021), where we aimed to improve rehabilitation and self-management for individuals with communication disabilities from stroke and TBI. Through co-designing novel tools and a technology-enabled self-management platform on which to host them, Communication Connect sought to address the critical gap in post-discharge health and support services by developing innovative, accessible, and person-centered options tailored to individual recovery and support needs. Our project focused on qualitative experiences following discharge from inpatient care through to long-term challenges. We involved three key groups of people with lived experiences of aphasia and cognitive-communication disorders: those living with communication disability; care partners/family; and health professionals involved in their care.

Considering the lack of specific guidance for EBCD within the field of stroke and brain injury (Singh et al., 2024) and the limited prior work applying EBCD in communication disability, the aim of this paper is to describe our use of EBCD in detail, as one example of adapting it for this population. The prioritized challenges resulting from this work will be reported elsewhere; here we detail the process and methods used within these stages which may be applied in EBCD or other co-design.

Method

Setting

The Communication Connect EBCD process was conducted at three locations across three Australian states: Bendigo (Victoria), Brisbane (Queensland), and Sydney (New South Wales). Multiple locations were purposively selected in the hope of including a more representative sample of experiences. For example, the inclusion of Bendigo, an inland, regional city, allowed the project to gather rural perspectives of stroke and brain injury. Four health services partnered with the project: Bendigo Health, a government health service covering rural areas; Metro South Health and Metro North Hospital and Health Service - two metropolitan government health services in Brisbane; and Royal Rehab Ryde, a private non-profit rehabilitation service in Sydney. EBCD was conducted sequentially across Bendigo, Brisbane and then Sydney, which allowed us to refine procedures as required.

This project was approved by Human Research Ethics Committees at each site (Bendigo Health HREC 76866; Gold Coast University Hospital 83750; Northern Sydney Local Health District 2022/ETH02057) and at La Trobe University (HEC21199). The need for ethical approval in participatory research and co-design is debated as co-designers may be considered equal partners in some research rather than passive participants to be protected (Louise & Annette, 2019). Policies differ across countries and institutions. However, when EBCD is conducted in a research setting rather than as a local service improvement initiative, co-designers are typically considered participants (Fylan et al., 2021). Given the exploration of experiences that were possibly stressful (see interview procedures), HREC approval was considered prudent.

Co-designers

The research team included academics from a range of disciplines including speech pathology, clinical psychology and neuropsychology, Artificial Intelligence and data analytics, biostatistics, and medicine (general practice; geriatrics).

The team of co-designers included people with lived experience of communication disability, care partners and health professionals. As co-design falls within a qualitative research framework, the sample size was not calculated statistically. In addition, we sought to include the same people throughout the EBCD process where possible, rather than recruit new co-designers at the different EBCD stages. As a result, the target number of co-designers was determined based on what could be feasibly managed during these stages. Considerations for feasibility included the ability to schedule meetings at mutually convenient times, managing communication in mixed groups (researchers/health professionals/people with communication disability), and being able to sufficiently support each person with lived experience. We aimed to recruit four people with lived experience of communication disability, four care partners and four health professionals per site. Maximum variation sampling (Suri, 2011) was used to broaden the range of characteristics across our co-design participants. Characteristics considered for co-designers with lived experience included severity, aetiology (TBI/stroke), time post onset, location (rural/metropolitan), sex, and age (over or under 65). We also aimed to include carers who provided support to people across a range of these characteristics. Inclusion criteria for people with communication disability were:

- aged over 18 years
- aphasia from stroke *or* cognitive-communication impairment from a traumatic brain injury
- physical and cognitive ability to participate in an interview and workshop up to two hours.

Given the qualitative, participatory approach of EBCD, a formal assessment of communication was not undertaken as part of recruitment; rather, three speech pathologist researchers agreed on a clinical judgement of the severity of participants' communication disabilities. These judgements considered the comprehension and expression challenges with written and spoken language that were demonstrated by participants when they interacted with the research team to enquire about the project and discuss the project. People who were unable to provide informed consent with aphasia-friendly consent forms and highly supported consent procedures were excluded from the project. People with communication disability were asked whether they had a care partner interested in participating in the project, but this was not an inclusion criterion.

Care partners needed to be providing care or support to someone with aphasia or cognitive-communication impairment and seeing them more than once per week.

For health professionals, we aimed to include a range of relevant disciplines, including speech pathology, occupational therapy, physiotherapy, clinical neuropsychology, clinical psychology, social work, nursing, medicine (rehabilitation, general practitioner, geriatrics), allied health management, and information technology.

The inclusion criterion for health professionals was that they needed to be working or have previously worked with people with aphasia or cognitive-communication disability, except for IT disciplines who were included to consider whether/how Communication Connect might interface with health service systems.

Reimbursement for people with lived experience and care partners was offered at an hourly rate for both direct and indirect time spent on the project, based on the casual hourly rate of the coordinating university ($48 AUD). For health professionals, reimbursement was provided to their employer.

The project was promoted through multiple channels, including the participating health services, state and national associations for stroke, aphasia and brain injury, local peer support groups, online and university research centers and participant databanks. Interested people were able to contact the researchers by telephone, email, text or Facebook messenger, and via a family member or proxy if preferred. All participants reviewed a study information statement and completed a written consent form. For people with communication disability, appointments were made for in-person, telephone or videocall meetings to jointly review the information and consent form and confirm comprehension of the study procedures.

Project setup

The project involved people with lived experience of aphasia and brain injury as consultants (IAP2 Australasia, n.d.) during the project setup – these were independent of the those involved in the EBCD. The researchers drafted communicatively accessible project materials, including written flyers, a narrated video, information and consent forms, an interview topic guide, visual aids for the interviews, and timelines. These materials were reviewed by the advisors, who provided feedback on wording, clarity, and visuals. The topic guide and visual aids for the interview were also tested in full during a mock interview with

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two members of the advisory group (a person with aphasia and their family member) who provided feedback on the process and materials. When considering how to approach research interviews with people with communication disability and their care partner who both consented to participate in the project, the research team were uncertain whether to interview them separately in case this influenced responses, or together. The project lived experience consultants recommended interviewing together to allow the care partner to support communication but to also offer a separate interview with each individual within the dyad.

The health professional focus group materials were also piloted with a group of four clinicians (PhD candidates with background in healthcare as speech pathologists) for feedback on the questions and structure and to determine whether the questions elicited desired experiences. This pilot interview and focus group data was not included in the study.

The overall process of the experience-capture and prioritization steps are outlined in Figure 1. Interviews and focus groups were held and then footage of these were used to develop touchpoint films, which were reviewed by participants and revised as needed. Next, participants viewed others' touchpoint films prior to attending the joint prioritization workshop.

[Figure 1 here]

Gathering patient and care partner experiences (EBCD stages 2-4)

Interviews were the selected method of gathering experiences from people with communication disability and care partners. The one-on-one nature of interviews allowed maximally tailored communication support. Interviews were semi-structured, based on a topic guide (Appendix A), and conducted by different researchers at each site. Each interviewer was a qualified and experienced speech pathologist. JEP, who conducted interviews at the Bendigo site, was a post-doctoral researcher with 12 years of experience in working with people with aphasia; the interviewer at Brisbane was an experienced rehabilitation clinician undertaking a PhD in aphasia; the interviewer in Sydney was a post-doctoral researcher with experience in a range of clinical and research settings including TBI. The interviewers received informal training and suggestions on supporting communication disability during the interviews from MR, a speech pathologist and researcher with substantial experience in qualitative data collection in aphasia. In-person interviews were offered to all participants, including those living in rural areas, with options offered for the interview to be conducted either at their house or an appropriate local venue; this willingness to travel to their location was important to build rapport between the researchers and the participants and minimize travel costs and fatigue. Videoconference interviews were also offered if participants preferred this mode. All interviews were recorded in full using a video camera on a tripod and standalone microphone or the recording feature on videoconference calls and ran for 1-2 hours.

When booking the interview, the researcher asked for a brief timeline of the person's stroke/brain injury and hospitalization, which could then be used as a starting point for discussion during the scheduled interview. On commencement of the interview, an overview of the goals of the Communication Connect project was given to provide context – to co-design solutions to the highest priority post-discharge challenges for communication disability. The researcher then summarized the journey through inpatient care and encouraged the participants to recall the point of discharge to the community. This structure allowed the interview to remain focused on the period of interest – from the time of discharge from inpatient care, to outpatient or community services, to the present day. Questions focused largely on experiential recall rather than directly asking about challenges or attitudes, e.g. "what was it like to leave hospital…", "tell me about that time [of receiving outpatient services]", "how did it feel as [service] ended?" The questions were also arranged in a loosely chronological order to support recall of the experience. Written copies of questions and a visual timeline were used to keep interviewees on topic (Appendix B). The interviewer indicated at the start of the interview that, in order not to use too much of their time, they would gently prompt if the conversation went off track. Other visual aids developed in the project setup stage were used including picture cards of key concepts and aphasia-friendly versions of the questions with relevant images. Markers and paper were used to write key words or phrases throughout the interviews, which supported communication and enabled people with communication disability to refer back to concepts.

Interviewees were informed that solution generation was an important future stage in the project. Any suggestions for solutions to challenges and descriptions of positive experiences were acknowledged but not further explored in the interview or in later analysis. Throughout the interview, a list of key negative experiences or gaps was created by the interviewer with the interviewee's input (e.g. "Should I add that to this list of key challenges that you experienced?"). The list was summarized at the conclusion of the interview, with the key experiences reviewed and approved by participants.

Gathering health professional experiences

A focus group was chosen to gather experiences of health professionals as it is an efficient method of exploring and clarifying multiple perspectives (Kitzinger, 1995). The sessions were conducted in person to facilitate more natural interactions, allowing for spontaneous discussion, more multimodal communication, and dynamic exchange of ideas that may not have emerged in a virtual setting. A topic guide with open-ended questions was used to structure the focus groups, ensuring that key areas were covered while allowing flexibility for participants to bring up additional insights.

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Each focus group took place in a comfortable and private meeting room within the health services, with drinks and refreshments made available. Multiple video cameras were set up to capture footage of all participants. Seating was arranged around a table to encourage eye contact and engagement, and time was taken to build rapport before beginning the formal discussion. Participants were welcomed with introductions, including their names, roles, and experiences working communication disabilities. To create an open and relaxed atmosphere, facilitators explained the goals of the Communication Connect project and reassured participants that all contributions were valued. Co-author MR led the focus group at each site, a second researcher (NH) took detailed notes, and a third (JEP) recorded key topics and experiences on a whiteboard with live consensus from the group. Questions covered their experiences and observations of working with aphasia or cognitive-communication disorders after inpatient discharge, at conclusion of community rehabilitation and services, and over the long term. The facilitator ensured that all participants had opportunity to contribute and expand on others' experiences. As the discussion progressed, individual experiences were grouped into broader challenges, with participants collaboratively refining these categories in discussion with the researchers. The sessions lasted 1.5–2 hours, with a short break midway to allow for informal discussion. At the end of the focus group, the challenges on the whiteboard were reviewed and health professionals were asked to identify whether any other points had been missed. Experiences arising from a similar cause were themed into single challenges with the group.

General Practitioners were offered a choice of participation in the focus groups or individual interviews in case they did not have time for the former. Interviews were based on the focus group topic guide and were conducted by JEP over videoconference (Zoom) and recorded. These ran for 30 minutes and as with interviews of people with lived experience, a verbal summary of key points was taken by the interviewer and collaboratively refined at the end of the interview.

Development of touchpoint videos

Touchpoint videos in EBCD are used to capture and present firsthand narratives of participants' experiences to co-designers, enabling prioritization of challenges and co-design of solutions. Touchpoints videos were created separately for each site, without using footage or challenges from other sites, ensuring that challenges remained specific to the local context and were not influenced by previous data. While the process of analyzing footage for touchpoint videos in EBCD is not widely documented or formalized, we adopted a qualitative descriptive approach informed by Anemaat et al. (2023), situated within a constructivist–interpretivist paradigm (McChesney & Aldridge, 2019). The approach blends elements of narrative inquiry, phenomenology, and ethnography to understand and represent participants' lived experiences (Anemaat, Palmer, Copland, Binge, Druery, Druery, Mainstone, Aisthorpe, Mainstone, & Wallace, 2024). The goal was to distil the footage to a duration appropriate for co-designers to review while preserving the depth of experiences conveyed.

For each interview and focus group, a single researcher (JEP, NR or interviewer MH) familiarized themselves with the footage and corrected the transcriptions. The initial analysis was based on the agreed challenges identified within each interview and focus group (i.e., the key points confirmed by participants at the conclusion of interviews and focus groups). The researcher used the list of challenges as a guide to extract relevant content from the video data, which was placed into a new video with the heading of each challenge. In some instances, the researcher inductively identified additional challenges from the interview data that were not captured in the agreed challenges; these were incorporated into the touchpoint video.

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Text-based editing in Adobe Premiere Pro (Adobe Inc., 2023) was used as the video editing process, in order to allow efficient analysis of the transcript alongside the audiovisual data and production of the touchpoint films. Text-based editing refers to the process of navigating, editing and extracting video content by selecting text in the transcript alongside the footage, rather than navigating the video timeline through playback. Placing the cursor at a point in the text moves the video play head to that moment, and highlighting text isolates the dialogue for playback or extraction. The process is summarized in Figure 2. First, footage is automatically transcribed by the Adobe Premiere Pro software and synced to the video timeline. Manual corrections of the transcript are often required alongside the video which provides opportunity for additional familiarization with the dialogue and non-verbal communication. Next, relevant dialogue is identified by reading the text alongside the video, highlighting text segments to be included and inserting the matching footage onto the editing timeline for further review. This method allows the most relevant content to be highlighted based on the language used by participants, streamlining the editing process.

[Figure 2 here]

Once all relevant statements for each challenge were extracted into the timeline, the material was progressively refined by a researcher through iterative reviewing, narrowing down to the most salient touchpoints that succinctly captured the challenges and their impacts. To select the most salient touchpoints, the researcher considered clarity, emotional impact, and representativeness of each excerpt. Statements that overlapped in the same challenge were compared, with preference given to those that most succinctly illustrated the challenge and its impact, while still preserving the richness of participant expression.

For each individual interview or focus group, the footage was initially condensed from 90-120 minutes to between 30 and 45 minutes. This was then reviewed collaboratively by three team members (JEP, NJH, and MR), who further refined the list to arrive at a final touchpoint film length of approximately 15 to 20 minutes for individual co-designer interviews and around 30 minutes for the health professional co-designer focus groups. The aim of refining was to retain the authenticity of participants' voices while making the content clear for other viewers.

Before exporting these videos from Premiere Pro to a video file, captions were added to support comprehension, and titles for each challenge were displayed continuously throughout each section at the bottom of the screen. This formatting ensured that the challenge remained clear throughout the touchpoint film and helped to reduce working memory demands on the viewer. Each co-designer was sent the interview or focus group touchpoint film via a private link to view on their computer and provide feedback. People with communication disability were offered an online meeting, phone call or in-person meeting to discuss and review the content they appeared in and provide feedback. An optional, structured, aphasia-friendly form was also provided to people with communication disability to help with feedback (Appendix C). The form included the list of challenges, a priority ranking of each challenge (on a scale of 1 to 10), space for notes, and an option to request the removal of content they found too sensitive. Participants were offered phone or Zoom discussions to review their videos in more detail.

Following co-designer feedback and approval, the final synthesizing edit was carried out. Authors MR, JEP, and NJH collaboratively integrated the insights from individual interviews and focus groups, producing two comprehensive films for each site of approximately 15-20 minutes each: one representing the experiences of people with lived experience and the other capturing the perspectives of healthcare professionals. These final films encapsulated the key challenges and narratives that emerged throughout the analysis.

Identifying priorities

At each site, an in-person prioritization workshop was held with all co-designers (i.e., health professionals, people with communication disability and care partners) attending the same workshop. The participants with lived experience advised that the planned four-hour workshop should be split into two 2-hour workshops across two separate days to limit the impact of fatigue. The workshops were facilitated by three co-authors who had conducted the focus groups (MR, NH, JEP).

Several weeks prior to the prioritization workshops, participants at each site were sent touchpoint films for their own group and counterpart group; that is, in addition to their own touchpoint films, health professionals were sent the lived experience touchpoint film and people with communication disability and care partners were sent the health professional touchpoint film. This approach was intended to prompt participants to reflect on the broader issues and the complexities faced by both groups. Furthermore, it allowed those with communication disabilities to review the materials at their own pace and take notes if they wished. Reviewing firsthand challenges of living with communication disability was a potentially confronting activity for those with lived experience and this was discussed with participants prior to the workshop to ensure they felt comfortable doing this.

Prioritization workshops began with a review of the Communication Connect project goals. Principles for inclusive communication during the workshop were also established. The importance of speaking in an accessible manner was emphasized (slow rate, short statements, no professional jargon), with participants encouraged to indicate when they did not understand or when the discussion was too fast. Participants with communication disability were also asked whether there were any specific ways their communication could be supported. The challenging nature of the topics and experiences being discussed was also acknowledged. Nametags were used to facilitate communication and to reduce word-finding and recall challenges. The key challenges from both lived experiences and health professionals were reviewed, with footage from the touchpoint films of both groups combined within themes where relevant. The total duration of the footage across all challenges was approximately 30-40 minutes.

One major challenge identified prior to the workshop was that 30 minutes of film potentially posed a working memory challenge and might result in recency/primacy effects, where the first and last challenges in the film might influence participants' focus. This was particularly likely given that the workshop was split across two days. We developed a unique approach to address this. Each challenge was presented individually on a PowerPoint slide, with distinctive colors, images, and layouts to ensure clear differentiation between them. The relevant video clips were embedded into each slide, and a master "zoomable" slide provided an overview of all the challenges, allowing the facilitators to zoom into specific challenges (Figure 3). This layout allowed a non-linear viewing experience, enabled repetition of specific challenges as needed, and also created a visuospatial overview, acting as a memory aid. Participants were also provided with A5 color printouts of each challenge slide which they could rearrange and write notes on during discussions.

[Figure 3 here]

Following the viewing of each challenge, participants were asked for any further reflections. While solutions were acknowledged in this workshop, they were deliberately deferred for discussion in future workshops to maintain focus on prioritizing challenges. Halfway through each two-hour session, a bathroom and tea break were provided to allow for rest, conversation and digestion of information.

Voting on prioritization of challenges took place on the second day of the workshop, which helps focus the subsequent co-design phases on the most important challenges.

Participants were encouraged to reflect on their personal experiences as well as those of others to select the five highest priority challenges that they believed the Communication Connect project should address. Participants with communication disabilities were additionally provided with an A1 sorting mat (23.4 × 33.1 inches) divided into three columns (high, medium, and low priority), created in Microsoft Word, onto which they could physically arrange the cards representing the challenges to select their top five (Figure 4). Each co-designer was given five equally weighted votes, and these votes were tallied by the researchers. The top five group-level priorities were revealed at the end of the session and briefly discussed. This process helped foster a positive and proactive atmosphere, balancing the discussions about the challenges with a forward-looking focus on priorities that Communication Connect would address. While some participants noted that some of their individual preferences were not always reflected in the final selection, they recognized the pragmatic constraints of the project not being able to address all challenges. The meeting concluded with a discussion of next steps and encouragement for attendees to start considering potential solutions to be considered in the subsequent stages of the project.

[Figure 4 here]

Results

Across the three sites, 31 people participated in the Communication Connect project: eight people with communication disability, three care partners and 20 health professionals. Participant data are summarized in Table 2-4. The people with communication disability included a mix of severity levels and etiologies (n = 5 stroke and n = 3 TBI). Ages ranged from 47 to 81 years, with participants from both urban (n = 5) and rural (n = 3) areas. Communicative support required by participants ranged from minimal – such as providing additional time for spoken language, using written keywords and/or using agreed, structured prompts to stay on topic - through to substantial support. For example, one participant required all project information in written form due to short-term memory impairment, while another frequently relied on a collaborative communication approach in which the researcher and their spouse worked together to clarify their intended messages.

The care partners (n = 3) were all spouses of stroke survivors with aphasia. Two were rurally-based, and one was urban-based, with ages spanning 48 to 74 years. The health professionals (n = 20) represented a range of disciplines, with the largest contingents from speech pathology (n = 5), management (n = 3), and occupational therapy (n = 3), reflecting a multidisciplinary approach in supporting people with communication disability. All managers were also speech pathologists by profession.

[Tables 2-4 here]

General Practitioners (n = 2) participated in individual interviews and touchpoint film checking only due to time constraints associated with their clinical commitments preventing attendance at focus groups or prioritization workshops. All other participants completed the prioritization workshops as planned.

In total, 33 challenges were raised by participants, and five highest ranked challenges at each site were combined to leave 13 priorities for solution co-design (excluding duplicates). The findings regarding ranking and content of priorities will be presented and discussed in another paper from the Communication Connect project. Briefly, participants described a range of challenges including difficulties accessing and navigating services, unsuitable timing and delivery of care, limited support for changes in mental health, identity and family, inadequate assistance for carers, barriers to using technology, and a widespread lack of communication-supportive skills across healthcare and the community.

Discussion

This paper has contributed a detailed description of the application of EBCD when working with a range of stakeholders, including people with aphasia and cognitive-communication disorders. To date, there are limited comprehensive descriptions of how EBCD is applied and adapted when working with people with communication disabilities. Specifically, this paper described the first four of six EBCD stages: project setup, gathering patient experiences, gathering staff experiences, and identifying priorities. These stages are foundational in engaging co-designers and focusing a project on meaningful challenges. Conducting them in an inclusive way is therefore critical to understanding the key challenges experienced by people with communication disability and maximizing the impact of the project's output.

Consistent with previous reports (Donetto et al., 2014), we found that the use of touchpoint film was a strength of the EBCD method. Rather than presenting key challenges in written form, EBCD records firsthand narratives of experiences from which to identify problems. Video includes additional visual modalities compared to text, including non-verbal cues and captions, thus improving accessibility of this complex information, and may be particularly beneficial for those with reading impairments. In addition, video content can be replayed, allowing viewers to process the information at their own pace – this was advantageous for people with processing, attention, comprehension or recall impairments when reviewing videos in their own time.

Beyond the accessibility of the medium, film is often more compelling, enabling a stronger emotional connection and deeper appreciation of experiences (Donetto et al., 2014), thereby resulting in higher motivation during the co-design phase. This was considered the top strength of the approach in a survey of 57 EBCD projects (Donetto et al., 2014). Several

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of our co-designers reported that the touchpoint films enhanced their understanding of the challenges that the alternate group faced: multiple health professionals felt increased empathy for people with communication disability and their partners, while two care partners told us they better understood the system-level constraints that health professionals face. This enhanced understanding between consumers and health professionals has also been reported in other EBCD projects (Donetto et al., 2014).

A potential downside of the use of film is that, unlike text-based summaries, footage cannot be easily anonymized, potentially limiting the willingness of participants to share deeply personal experiences. In our project, three participants with lived experience (two with communication disability and one care partner) did request that specific footage not be included in the final touchpoint film as they did not feel comfortable with the personal experiences being played to a larger group. In addition, some care partners expressed prior to their interview that they did not wish to include certain challenges, such as specific aspects of carer burden and changed relationships, knowing that the person they care for would be present for the workshop. Our method had the same participants who shared their experiences also attending the prioritization workshops, thus viewing their own footage, sometimes with their family members. As an alternative, it is acceptable to include different people across the stages of EBCD and this may increase the willingness to share. Some projects have used existing patient experience videos from archives to create touchpoint films, in a process known as accelerated EBCD (Point of Care Foundation, n.d.). It is not yet known which approach is preferable in terms of engagement and representativeness of experiences, but there is some evidence that accelerated EBCD provides comparable co-design outcomes (Locock et al., 2014). Ultimately, we were still able to include the sensitive challenges through footage from other participants and use anonymized written summaries of other experiences on the slides. While film poses challenges in regard to participant willingness for disclosure, its strengths in promoting mutual understanding and enhancing accessibility make it a valuable tool for co-design in populations with communication disability.

The use of text-based editing in this project provided a substantial boost to efficiency in developing the touchpoint films. The additional time required to edit footage is a primary barrier to using touchpoint film in EBCD for many projects (Donetto et al., 2014). This issue could be compounded by the fact that many researchers may not be familiar with video editing procedures. Text-based editing allows a potentially more familiar approach where the transcript can be reviewed directly on the screen alongside the video. Traditionally, video editing involves playback of footage using the timeline, without the transcript present, and this could mean that important points are missed. Conversely, identifying key moments based only on the transcript could overlook important non-verbal aspects of participants' communication, which is particularly pertinent in interviews of people with communication disability. In transcriptions of qualitative data in this population, additional coding of non-verbal communication is often required to ensure non-verbal communication is not missed (Luck & Rose, 2007), but this is time consuming. Most importantly, text-based editing made it easy to highlight text of key quotes in the transcript and then automatically append the footage of the highlighted quotes into the draft touchpoint film, which made the process faster. We recommend this approach for future research.

As we understand it, touchpoint films in EBCD are usually a single touchpoint film. Our modification was to split the touchpoint film into different challenges and play each one embedded within a visually distinct slide. This non-linear viewing of challenges was designed to reduce the working memory load on our participants with communication disability; however, multiple other participants without communication disability reported that they found this helpful. We believe it allowed a greater number of challenges to be considered in the prioritization workshops than would otherwise have been feasible. These visual slides led directly to the use of printed cards with the same look as the slides, which were provided to support the on-line sorting and prioritization of challenges by attendees. These cards are an example of the "tangible design language" recommended by Wilson et al (2015) to enhance the accessibility of co-design.

Our procedures separated the *gathering* of experiences during interviews and focus groups from the *generation* of ideas and solutions. Where participants expressed an idea for a particular tool or resource, we acknowledged this and asked them to remember it for future idea generation meetings. This process was implemented as we were looking for a chronological recollection of experiences and organic identification of challenges, and did not want any co-designer's preferences for what solutions they wanted to influence the recollection of challenges. In contrast, in their co-design process with people with aphasia, Anemaat et al. (2024) included identification of both challenges and ideas for solutions within the interviews and focus groups. In retrospect, our separation of ideas and challenges was somewhat artificial, particularly for those participants who may have cognitive disabilities such as impaired memory. We recommend a more formal capturing of ideas throughout the phases prior to co-design so that they can be presented at the idea generation stage. It is not clear from the EBCD literature at which point idea generation is intended to occur nor whether the timing is important. The Point of Care foundation describes brainstorming processes within the small group co-design stage (Point of Care Foundation, n.d.). Although there are accepted overarching phases in the EBCD process, the details differ across sources (E.g., Dawda & Knight, 2017; Donetto et al., 2015; Point of Care Foundation, n.d.) and further variation is seen across EBCD projects (Donetto et al., 2014). EBCD is intended to be "inherently flexible" but leads to the question of what the core, non-negotiable elements are.

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While we had informal feedback from co-designers that our procedures were successful in enabling participation, we did not conduct a formal evaluation of their experiences or the effectiveness of the methods to improve accessibility. This is a limitation of this paper, as such an evaluation would have provided data on which modifications were most helpful and how successful we were in empowering people with communication disability to participate meaningfully in the project. Future work may wish to apply the Co-Design Evaluation Framework that can be used in various phases of the co-design process (Peters et al., 2024).

There are speculations within the literature that co-design is sometimes misused as a label without true enactment of its principles (Moll et al., 2020); the routine inclusion of process evaluations might ensure genuine involvement and sharing of power in co-design projects, shifting emphasis toward the success of co-design rather than adherence to specific processes (Shiggins, Coe, et al., 2022). Costs of conducting EBCD were also not captured. The complexity and duration of EBCD projects are considered challenging by many and few cost analyses have been conducted (Donetto et al., 2014). Such data would allow future comparisons of different co-design methods and estimates of the funding required to co-design with people with communication disability, particularly when additional resources are required to make this process accessible for this population (Shiggins, Coe, et al., 2022).

Co-design approaches in research and service development are in an “expanding and rudimentary phase” (Dobe et al., 2023, p. 562); that is, growing rapidly but with highly variable application. There have been calls for more consistent methods and terminology for co-design within specific populations, such as stroke, to allow evaluation of its outcomes and appraisal of the quality of consumer involvement (Dobe et al., 2023). Although a standardized definition and structure for co-design might aid evaluation, it is arguably more essential to maintain flexibility to adapt processes for different contexts, populations and most importantly, individuals (Hendriks et al., 2015). This flexibility is especially crucial for co-designing with people who have unique and diverse needs, such as those with communication disability. Standard co-design methods typically rely on unstructured group interaction, the ability to comprehend and retain written information and participants being able to provide detailed suggestions and feedback throughout the process. For many with communication disability, these methods need modification to avoid becoming barriers to meaningful participation in co-design. We believe that many of the modifications we undertook within the EBCD process facilitated inclusion of people with aphasia and cognitive-communication impairments, but we recognize these are not exhaustive or the only possible approach – other methods could further enhance accessibility of EBCD. By sharing more detailed descriptions of these adapted methods, the field can gradually move toward a best practice toolkit with that supports authentic co-design in communication disability.

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Data Availability Statement

Data sharing not applicable – no new data generated.

Author Contributions

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Nelson Hernandez: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Writing – review & editing.

Damminda Alahakoon, Kelvin Hill, Miranda Rose: Conceptualization, Funding acquisition, Investigation, Methodology, Writing – review & editing.

Annie Hill, Dana Wong, Brooke Ryan, David Copland, Emma Power, Ian Kneebone, Leanne Togher, Tim Usherwood, Linda Worrall, Richard I Lindley, Tracy Sheldrick, Lucette Lanyon: Conceptualization, Funding acquisition, Methodology, Writing – review & editing.

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Table 1 - **Stages of Experience Based Co-Design (Donetto et al., 2014)**

1	**Setting up** the project
2	Gathering **staff** experiences
3	Gathering **patient and carer** experiences through observation and filmed interviews
4	Bringing staff, patients and carers together to share and **prioritise** based on a trigger film
5	Sustained **co-design** in small groups
6	Celebration and review

Table 2 - Participant data for people with communication disability

	Characteristic	**n = 8**
Severity *Based on informal clinical judgements*	Mild	2
	Mild-Moderate	2
	Moderate	1
	Moderate-Severe	3
Aetiology	Stroke	5
	TBI	3
Time post onset	Early (<2 years)	4
	Long term (>2 years)	4
Location	Rural	3
	Urban	5
Sex	Male	3
	Female	5
Age	40–49	2
	50–59	3
	60–69	2
	70–79	
	80+	1

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Table 3 - Participant data for carers

	Characteristic	**n = 3**
Location	Rural	2
	Urban	1
Sex	Male	1
	Female	2
Age	40–49	1
	50–59	
	60–69	1
	70–79	1
	80+	
Relationship	Spouse	3
	Providing care for :	
Severity *Based on informal clinical judgements*	Mild	1
	Mild-Moderate	
	Moderate	1
	Moderate-Severe	1
Aetiology	Stroke	3
	TBI	
Time post onset	Early (<2 years)	2
	Long term (>2 years)	1

Table 4 - Health professional participant data

Profession	**n**
Speech Pathology	5
Management	3
Occupational Therapy	3
Physiotherapy	2
Community Nursing	2
General Practitioner	2
IT Support	1
Neuropsychology and Clinical Psychology	1
Social Work	1
Total	**20**

Figure 1 - Overview of experience gathering and prioritization procedures

Figure 2 - Overview of text-based editing applied to EBCD

Figure 3 - Summary slide with challenges.

Figure 4 - A co-designer with aphasia sorting the challenge cards on the sorting mat.

Clicking on a slide navigates to it by zooming in. Returning to the menu zooms back out to the summary slide.

Note: Recognizable faces are hidden or blurred.