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Co-designing with adults with acquired neurological disability in the community: a scoping review and thematic synthesis

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ABSTRACT

Background. Co-design is gaining momentum in disability. However, there is limited research evidence to guide co-designing with people with acquired neurological disability. The aim of this scoping literature review was to understand when and how co-design is used with adults with acquired neurological disability, as well as the experience of participating in co-design. **Methods.** Systematic searches were conducted in CINAHL, MEDLINE, PsycINFO, Scopus and Embase databases. The search was limited to qualitative studies or studies using mixed methods in which qualitative data could be extracted for thematic analysis. **Results.** Of the 4200 articles retrieved, 45 were eligible for the review. Data extracted across the included studies showed variability in the definition and implementation of co-design, including recruitment, timing and the role of co-design contributors. Thematic analysis of the lived experience resulted in three themes: (1) a meaningful experience, (2) balancing group dynamics, and (3) an unfamiliar process. **Conclusions.** Co-design with adults with acquired neurological disability is an emerging area of practice, valued by co-design contributors with disability, health professionals and researchers. Future work is needed to better define and operationalise co-design, with investment in the facilitator role to optimise involvement of people with disability.

Keywords: acquired neurological disability, co-creation, co-design, co-production, participatory action research, patient and public involvement, research, service development, user-centred design.

Introduction

The use of co-design is increasing within healthcare practice and research (Bird *et al.* 2021). With strong roots in community development, design and technology, the origins of co-design can be traced back to participatory design techniques developed in Scandinavia in the 1970s (Dobe *et al.* 2022; Masterson *et al.* 2022). Although closely aligned with person-centred approaches to consumer engagement, co-design is a relatively new practice within healthcare, particularly with people with neurological disability and complex health needs. Although co-design often draws on qualitative research methods to understand people's experiences and perspectives, co-design differs in its core purpose and approach. Co-design actively involves end-users – such as people with disability – as active partners in shaping products, services or research (Brett *et al.* 2014; Dobe *et al.* 2022). Fundamentally, co-design values the lived experience of people with disability not merely as data, but as vital expertise that informs and directs the development process (Brett *et al.* 2014; Dobe *et al.* 2022). Integral to co-design is the collaborative partnership between people who are directly impacted by the research and healthcare service, such as people with disability and close others, and professionals, such as researchers and health professionals (Brett *et al.* 2014; Forsythe *et al.* 2019; Dobe *et al.* 2022).

Collection: Collaboration, Co-production, & Co-design: Moving Ahead in Brain Impairment

With the shared aim of creating improved outcomes that better meet the needs of people with disability, the nature of the collaborative partnership in co-design varies, ranging from brief consultations to long-term partnerships (Greenhalgh *et al.* 2016). Similarly, a range of terms (i.e. co-design, co-production, co-creation, patient and public involvement [PPI]) are used to describe the collaborative engagement process that stems from previous participatory frameworks, such as user-centred design and participatory action research (PAR; Greenhalgh *et al.* 2016; Levasseur *et al.* 2016). As the definition, terms and processes of co-design vary, there is potential for ambiguity and uncertainty on how to effectively participate in co-design. However, although there is a lack of agreement regarding the parameters of co-design, it is considered imperative to improving healthcare services and impactful research outcomes (Realpe and Wallace 2010; Greenhalgh *et al.* 2016; Bird *et al.* 2021). For example, co-designed services have been found to result in higher service user benefit and innovation compared with services created entirely by health professionals or people with lived experience independently (Trischler *et al.* 2018). With increasing expectations, and frequency of co-designing with people with neurological disability and complex health needs, co-design presents a unique opportunity for people from diverse backgrounds to contribute to research and service development that directly impacts their lives (Dobe *et al.* 2022).

Acquired neurological disability describes a group of cognitive, communicative and/or physical impairments resulting from either cerebral injury (e.g. acquired brain injury [ABI], traumatic brain injury [TBI], stroke) or neurodegenerative disease (e.g. multiple sclerosis [MS], Parkinson's disease, Huntington's disease; Ponsford *et al.* 2012). Some of the vast physical, cognitive and communicative difficulties experienced by this population include reduced memory, attention, planning and problem-solving skills, difficulties processing and expressing verbal and/or non-verbal information, as well as disturbances of muscular movements, such as control of speech (Ponsford *et al.* 2012). The compounding impact these impairments have upon self-perception and everyday participation often results in a life-long process of adjustment and community reintegration, with barriers to engaging in meaningful activities (Doig *et al.* 2008; Levack *et al.* 2010; Ownsworth and Haslam 2016). Specifically, participating in vocational, educational and community or recreational activities is critical for a person's sense of belonging within the community and overall quality of life (Hammell 2017). The lack of opportunities for community involvement can lead to increased segregation between people with acquired neurological disability and the wider community, exacerbating feelings of isolation and negatively impacting quality of life (Bergström *et al.* 2017; Bartolac and Sangster Jokić 2019; Douglas 2020). As evidenced in previous literature (D'Cruz *et al.* 2021; Carminati *et al.* 2024), co-design may create opportunities for people with acquired neurological disabilities to increase social connectedness, thereby mediating negative mental health outcomes associated with social isolation (Douglas 2020). It is important to recognise the opportunities that co-design offers for people with acquired neurological disabilities, and potential for improved community integration, self-efficacy and mental health outcomes (Bould and Callaway, 2021; Halvorsrud *et al.* 2021; Dobe *et al.* 2022).

Although it is imperative to incorporate the lived experience of people with acquired neurological disabilities within research and service development, minimal guidelines exist on how to effectively co-design with this population (Dobe *et al.* 2022). The lack of guidelines create ambiguity surrounding the roles, responsibilities and level of involvement required by both the professionals and end-users (Lindblom *et al.* 2021). Particularly in the context of people with cognitive and communicative difficulties, the lack of certainty around what level of engagement ensures best practice co-design may lead to tokenistic involvement (Slattery *et al.* 2020; Lindblom *et al.* 2021). It has previously been recognised that minimal participation in the co-design process resulted in healthcare participants feeling undervalued, underappreciated and frustrated (Slattery *et al.* 2020). However, greater commitment to shared partnership within the co-design process may not always be achievable, due to compounding issues of time constraints associated with living with a complex disability (Lindblom *et al.* 2021). Furthermore, the co-design process may perpetuate an imbalance in the power dynamics between the researchers and/or healthcare professionals and people with acquired neurological disabilities. As evidenced in recent studies by Dobe *et al.* (2022) and Lindblom *et al.* (2021), stroke survivors reflected that they often felt inferior in their knowledge when co-designing with healthcare professionals. It is essential to be aware of and to acknowledge the potential risk of further exacerbating the power inequalities when co-design is not implemented in a meaningful and accessible way for people with acquired neurological disabilities. Despite the possible benefits of co-designing with people with acquired neurological disabilities, greater knowledge regarding how to co-design effectively is needed to avoid the risk of further alienating and undermining people with disabilities.

There is yet to be a scoping review that comprehensively integrates the literature on the use of co-design within research and/or service development with people with acquired neurological disability living in the community. Moreover, as other reviews have examined the use of co-design within a hospital or rehabilitation setting (Slattery *et al.* 2020; Dobe *et al.* 2022), there is a need to further explore the use of co-design within the community context, and to understand the lived experience of co-designing with this population. This knowledge will help provide further clarification of the processes, concepts and definitions associated with current co-design practice, and in turn, help formulate recommendations to guide co-designing with people with acquired neurological disabilities living in the community.

Materials and methods

The methodology of this systematic scoping review was informed by the five-step framework proposed by Arksey and O'Malley (2005) with reporting guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis: Extension for Scoping Reviews (PRISMA-ScR; Tricco *et al.* 2018). For a detailed description of the methodology, see our scoping review protocol (D'Cruz *et al.* 2022).

Stage 1: identifying the research questions

This scoping literature review sought to address the question: When and how is co-design used with adults with acquired neurological disability living in the community, and what is the lived experience? While investigating this research question, the authors aimed to: (1) identify 'when' co-design is used, such as the context of the studies; (2) collate information about the operationalisation of co-design (for example, 'how' is co-design implemented, such as definitions of co-design, methods and roles); and (3) to better understand the lived experience of participating in co-design from the perspective of people with neurological disability and other key stakeholders.

Stage 2: identifying relevant studies

A systematic search strategy was developed by the authors in consultation with an experienced librarian (see Table 1 for full search strategy). Two broad concepts guided the search: (1) acquired neurological disability (e.g. key terms including stroke, multiple sclerosis); and (2) co-design (e.g. key terms included co-production, co-creation, participatory design and user-centred design). These two groups were combined with the 'AND' Boolean operator to conduct the search. The preliminary search was conducted in MEDLINE, which included the two key concepts and corresponding key terms. Additional Medical Subject Heading (MeSH) term structures were included after the preliminary search, and helped to refine the list of search terms and confirm the final search strategy.

The systematic search was conducted on MEDLINE, PsycINFO, CINAHL, Scopus and Embase, with search terms adapted for each bibliographic library. The searches were limited to English language peer-reviewed articles published from January 2000 to January 2025. The authors deemed the time frame of 2000 onwards appropriate given the emerging nature of co-design in this context. All references were imported into Covidence, an online platform used to conduct and manage literature reviews, which was utilised to streamline the screening process. The reference list and forward citations of the included articles were hand searched by the authors, and studies deemed eligible from this process were included in the screening. All the included references were then imported into Zotero, a reference management software.

Stage 3: study selection

Eligibility criteria

Peer reviewed articles with primary extractable data were included. The search was limited to qualitative studies or studies using mixed methods in which qualitative data could be extracted for thematic synthesis. Non-empirical studies, reviews, books/book chapters, conference proceedings and opinion pieces were excluded. Included studies reported on the use of co-design within a research or service development context, with people with acquired neurological disability (e.g. ABI, stroke, MS, TBI, Parkinson's disease and Huntington's disease) living in the community (living independently with or without support, with family and/or friends, shared accommodation, group homes or residential aged care). Studies conducted in inpatient rehabilitation settings were excluded, as the focus of this review was on community-based contexts. Community settings more closely reflect the environments in which individuals live, work and engage socially post-discharge, making this context more appropriate for exploring how co-design might support long-term outcomes. The original eligibility criteria,

Table 1. Full search strategy.

Search concepts	Search terms used in databases
Co-design	(co-design* or codesign*), (co-produc* or coproduc*), (codevise* or cocreat* or co-creat* or co-invent* or cogenerat* or co-found* or co-develop* or codevelop*), "participatory design*", "participant* led", (consumer* adj2 led), (consumer adj2 driven), "collaborative design", ("experience based" adj2 design*, ("user centered design*" or "user centred design*"), ("human centered design*" or "human centred design*"), "design led", community-based participatory research, "participatory action research", "participatory research"
Acquired neurological disability	brain injuries (MeSH), (ABI and brain*), (TBI or "traumatic brain injur*), craniocerebral trauma, intracranial hemorrhage traumatic (MeSH), (acquired adj2 neurodisabilit*), (acquired adj2 neurological adj2 disabilit*), (head or crani* or cerebr* or capitis or brain or forebrain or skull or hemisphere or intracran* or intercran*) adj3 (injur* or trauma* or damag* or lesion* or wound* or destruction* or oedema* or edema* or contusion* or fractur*), stroke (MeSH), "cerebrovascular accident", ("transient ischaemic attack" or "transient ischemic attack"), ischemic attack transient, "cerebal vascular event", multiple sclerosis (MeSH), "multiple sclerosis", huntington disease (MeSH), "huntington* disease*", parkinson disease (MeSH), "parkinson* disease*"

Note: MeSH are medical subject headings used for indexing articles for MEDLINE databases. The asterisks show where alternate endings of the words were searched. The brackets are used to define the order in which the concepts are processed. The quotation marks are used to do phrase searching. The ADJ operator is used to retrieve records that contain the terms in any order within a specified number of words of each other.

as outlined in our protocol, included adults aged 18–65 years. However, given ambiguous reporting of age limits in the retrieved studies at title/abstract screening, the criteria were updated to include adults aged ≥18 years.

Screening

The study selection was informed by the PRISMA-ScR guidelines (Tricco *et al.* 2018). As shown in Fig. 1, an initial 4200 articles were identified. After the removal of duplicates, 2032 articles were double screened at title and abstract by the authors (RR, SA, SO and KD). Screening discrepancies during the title and abstract, and the full-text screening were resolved through discussion between authors. In total, 428 full-text articles were double screened, with 87 studies deemed eligible for the next stage. Three additional articles were included following forward searching the reference lists of the eligible 87 studies. Thus, a total of 90 articles were eligible for data extraction.

Stage 4: charting the data

The data extraction was an iterative process completed by the authors (RR, SA, SO and KD), with consensus discussions across the team. During this process, five articles were deemed ineligible due to the wrong inpatient hospital setting ($n = 3$), insufficient demographic information ($n = 1$) and use of qualitative interviews rather than co-design ($n = 1$). Data extraction was completed for the 85 studies in relation to study and participant characteristics, co-design definitions, reported findings of the service development and/or research, and the operationalisation of co-design. Given the aim of the scoping review to describe 'when' and 'how' co-design is used, it was decided to exclude studies that did not provide sufficient description of the operationalisation of co-design. Based on this decision, a final number of 45 articles were included in the review. A table of the original 90 studies is included as a Supplementary File S1.

Stage 5: collating, summarising and reporting the results

The PRISMA-SCR was used to collate, summarise and report the results of the review (Tricco *et al.* 2018). As per the scoping review guidelines by Arksey and O'Malley (2005), a summary of the key study and participant characteristics is reported in the results section (see Table 2). Critical appraisal of the individual studies was conducted by two authors (RR and SO), using the Critical Appraisal Skills Programme – Qualitative Studies Checklist to assess the methodological rigour of the sources (Critical Appraisal Skills Programme 2022) A table of the full appraisal of each of the 45 studies is presented as a Supplementary File S2.

A thematic synthesis of the qualitative data from the reported findings of the included studies was conducted. Included data (participant quotes and author reported findings) described the subjective experience of using co-design from the perspective of participants with disability. Additional perspectives from other key stakeholders, such as facilitators and health professionals, were also analysed if present. Thematic analysis followed the three stages of thematic synthesis proposed by Thomas and Harden (2008). The first stage involved double coding (RR and SO) of the primary data with line-by-line analysis. For example, participants described feeling 'heard' and 'valued' during the co-design process, and these quotes were line-by-line coded with initial codes, such as 'having a voice' and 'feeling included.' Stage two followed a process of comparing codes with group similarities, and developing broader descriptive themes that were reflective of the initial codes. Team discussions occurred throughout the analysis to ensure consensus on the meaning of the codes and associated descriptive themes. The analysis included the involvement of two researchers with lived experience of disability (LW and JR), who contributed to the data analysis and participated in an analytical discussion of the thematic findings. At stage three, the developed themes and sub-themes were considered in relation to the aims of the scoping review, providing lived experience insights into co-designing with people with acquired neurological disability.

A critical component of this scoping literature review and protocol (D'Cruz *et al.* 2022) was the involvement of people with disability with experience of co-design. Three people with lived experience of disability were invited to contribute across both the protocol and scoping literature review, with two contributing to the scoping literature review (LW and JR). The two people with lived experience were employed as research assistants and played a key role ensuring the relevance of the review to the experience of people with disability participating in co-design. Their involvement focused primarily on reviewing the analysis and shaping the interpretation of findings, while drawing on their disability and co-design lived experience. Throughout the project, ongoing efforts were made to ensure accessibility and inclusion, including flexible work practices to support their meaningful involvement.

Critical appraisal of studies

Critical appraisal of the included studies demonstrated generally high-quality research (see Supplementary File S2). All studies presented with clear aims and use of appropriate methodology, with the majority providing justification for their research design. The recruitment strategy across articles was mostly sufficient, with few articles needing more explanation to why a certain cohort was selected, or sampling methods used. Sufficient detail on the data collection and data analysis methodology was mostly rigorous across all studies. Only five studies (Mc Menamin *et al.* 2015; Kearns *et al.* 2020; Cruice *et al.* 2022; Quilico *et al.* 2022; El-Helou *et al.* 2023) explicitly reported and considered the relationship between the researchers and participants,

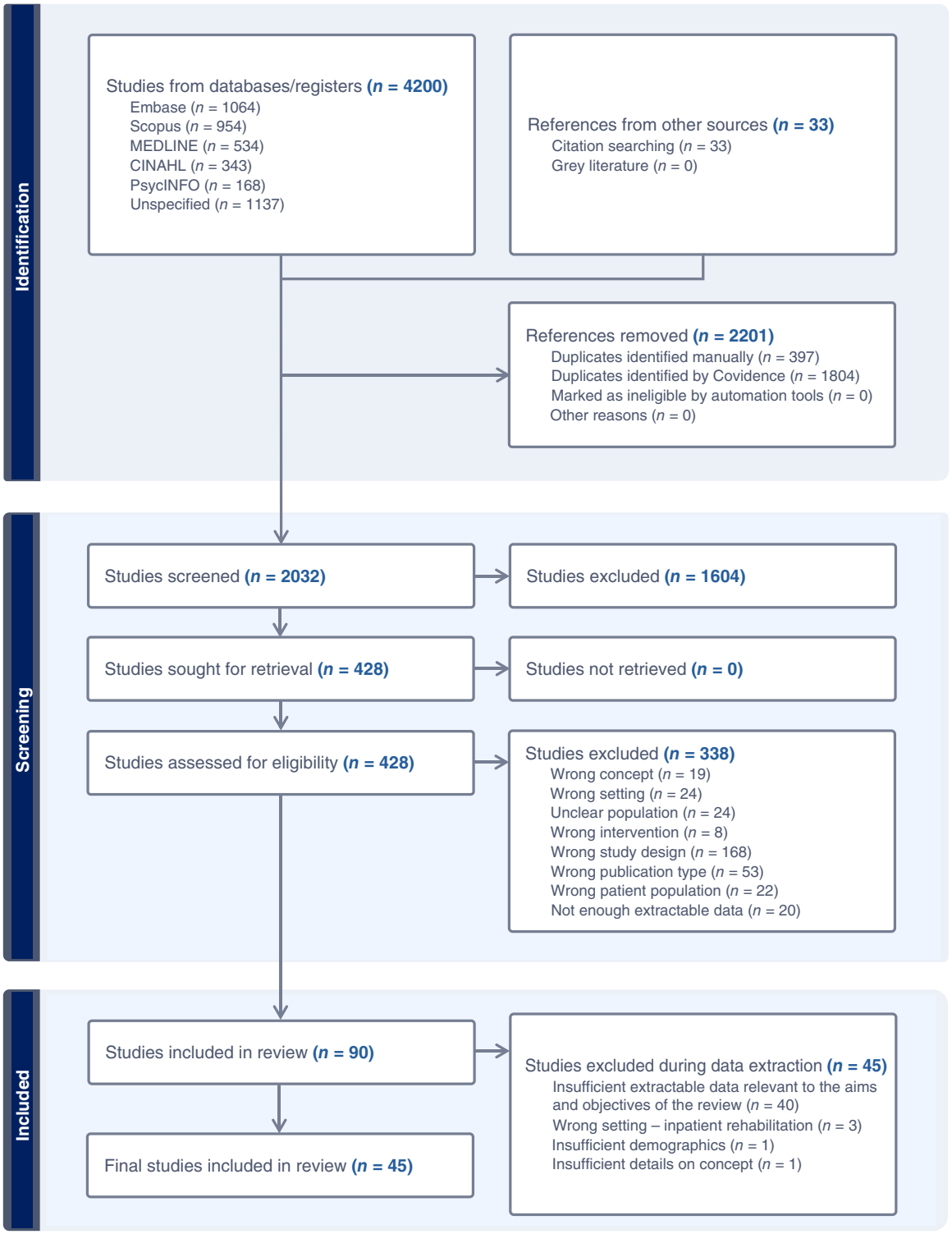

Fig. 1. PRISMA flow diagram of the included article.

which may raise concerns about the credibility of data and possible power imbalances.

Most of the studies reported to have ethics approval; however, some studies, such as Cruice *et al.* (2022), followed guidance from the governing Health Research Authority (based in the UK) responsible for PPI and, therefore, did not seek ethical approval. It was not clear across many of the studies whether consent for participation was sought for the co-design component of studies or only for the research components, such as interviews or qualitative evaluation.

All studies provided clear statements of findings and produced outcomes that contribute to the broader context by expanding on past research evidence, identifying new areas of research, and considering the transferability of findings into practice. See Supplementary File S2 for a table of the full appraisal of all studies.

Results

The term, co-design contributor, will be used to describe all stakeholders (i.e. people with an acquired neurological disability, close others and healthcare workers) who participated in the co-design of the included articles. The term, facilitator, will be used to describe the authors, researchers or external parties who helped facilitate the co-design process.

Study characteristics ('when' or the context of co-design)

The 45 articles included in the review were published between 2015 and 2024, with 33 of the articles published since 2020, highlighting the emerging nature of this area of research. The studies were from the UK (n = 10), Australia (n = 9), Canada (n = 8), Sweden (n = 4), Ireland (n = 3), Denmark (n = 2), the Netherlands (n = 2), Italy (n = 1), USA (n = 1), Austria (n = 1), Singapore (n = 1) or a mix of countries in Europe (n = 3). All articles either used qualitative methodology or a mixed methods approach, with the majority adopting an exploratory study design (n = 33). There were a range of aims reported across the studies, with most seeking to co-design an intervention (n = 20), such as exercise programs, a peer-led coaching intervention, behaviour change interventions, relaxation and self-management programs or to adapt in-person interventions to online formats. Other articles identified the aim of developing a knowledge framework (n = 9), designing a survey (n = 2) or developing resources and toolkits (n = 9). Five of the included papers (Harrison and Palmer 2015; Abma 2019; Lamontagne *et al.* 2021; Charalambous *et al.* 2022; Kuhlmann *et al.* 2024) did not produce an output or product, but aimed to develop knowledge on the use of PPI in research.

Although this scoping review focused on the use of co-design with adults with disability in the community, there was a range of contexts, including the medical or rehabilitation intervention context, community service development and research. Few articles included an evaluation of the co-design approach, with 13 studies reporting a qualitative evaluation of the experience of participating in the co-design. Despite all studies using a co-design approach, none of the studies included an evaluation of the usefulness or impact of adopting a co-design approach; however, a couple of studies reported planned pilot testing and evaluation of the effectiveness of produced resources/outputs (Carminati *et al.* 2024; Pierce *et al.* 2024). Methods of data collection included focus groups (n = 24), workshops (n = 23), semi-structured interviews (n = 19), questionnaires/surveys (n = 6), field notes (n = 2), observations (n = 2), photovoice (n = 1), reflective journals (n = 1), literature reviews (n = 1) and user testing (n = 1), and it was common to use more than one method. Some studies included data collection for the co-design component of the study, as well as for the co-design experience evaluation. See Table 2 for further information about the study characteristics.

Participant characteristics

Table 2 also summarises the study and participant characteristics of the 45 included articles. The data charted pertain to the participant characteristics of co-design contributors with disability, whereas participant characteristics for other co-designers (i.e. healthcare workers, close others) and facilitators were not charted. The participant sample size ranged from three to 95 across all studies, with a combined participant total of 632. The most common disability types reported within each study were stroke survivors (n = 22), followed by Parkinson's disease (n = 9), TBI (n = 6), ABI (n = 4) and multiple sclerosis (n = 4). The age of all participants across studies ranged from 18 to 92 years. Most studies had a greater proportion of male participants (n = 23), as opposed to females (n = 15). Six studies did not report gender or age demographics of their sample. Despite the context of co-designing with adults with acquired neurological disability, there was insufficient reporting of the severity of disability, and presence of cognitive and communication difficulties.

Operationalisation of co-design ('how' co-design is implemented)

Across the 45 retrieved articles, there was considerable variability in the operationalisation of co-design. See Table 3 for a summary. The frequency of co-design sessions fluctuated between one and 10 workshops, and the length of the sessions ranged between 30 min to half-days. Focus groups and workshops were the most utilised methods of co-design, with brainstorming sessions and group discussions also popular. There was a diverse range of co-designers engaging in co-design, including people with acquired neurological disabilities, close others of people with disability (i.e. family members, spouses, support workers) and healthcare professionals (i.e. occupational therapists, speech pathologists, nurses, neurologist, physiotherapist), as well as external facilitators and researchers. It was common to have a mix of co-designers within the one group, with some studies (n = 16) preferring to split the co-researchers into groups with similar background for the workshops (i.e. co-researchers with disability in one group, healthcare workers in one group etc).

The number of co-design contributors included in the co-design sessions ranged from up to six people per group, seven to 10 people per group and some studies involved

Table 2. Study and participant characteristics of the included articles.

Author (year); country	Study design; methodology (analysis)	Disability type (*n*)	Gender (% female); age, years (*M*)[A]	Aims	Findings
Abma (2019); the Netherlands	Exploratory; qualitative (thematic)	PD (30)	S1 (44%) S2 (33%); ≥18	Generate knowledge on how to involve patients in health and medical research settings, and redress power imbalances	Dialogue among stakeholders needs to be facilitated to enhance the personal and mutual understanding of all (end-users and professionals), which leads to relevant and useful research
Anemaat *et al.* (2024); Australia	Exploratory; qualitative (thematic)	Stroke (32)	31%; 18–70	To investigate the lived experience of post-stroke aphasia care, across the continuum of care to establish priorities for service design	Hospital-based experiences were most common for PwA and their SOs, with communication issues driving negative experiences and interpersonal connection shaping positive experiences. Improved care may be supported through training in supported communication, accessible information, psychological and peer support, and greater inclusion of SOs in rehabilitation
Bodilsen *et al.* (2023); Denmark	Exploratory; qualitative (content)	Stroke (3)	0%; 77	To develop an intervention using co-creation methods in collaboration with stroke survivors with type 2 diabetes, relatives and HcPs to increase physical activity	A co-creation framework was used to develop a tailored 12-week home-based behaviour change intervention for reducing sedentary behaviour and increasing physical activities through activities of daily living
Carminati *et al.* (2023); Australia	Exploratory; qualitative (reflexive thematic)	ABI (7)	0%; 47.7	To qualitatively evaluate the experiences of individuals with ABI and AcWs who contributed in co-designing the cybersafe training program	Co-design process extends beyond resource design for individuals with ABI, and highlights therapeutic benefits of increased insight, social opportunities and emotional awareness
Carminati *et al.* (2024); Australia	Exploratory; qualitative (reflexive thematic)	ABI (4)	50%; 54.5	To describe the process, and examine the experience of co-designing an intervention guidebook and podcast series with individuals with ABI, SOs and clinicians	Participants valued the co-design process, highlighting feelings of support, connection and increased confidence in using the PBS+PLUS resources. Co-design was found to be both therapeutically beneficial and effective for developing practical clinical tools, particularly when including individuals with ABI, their SOs and clinicians
Charalambous *et al.* (2022); Cyprus, France, Portugal & Norway	Exploratory; qualitative (thematic)	Stroke (8)	62.5%; 46.3	To compare the views of PwA and stroke survivors without aphasia on PPI, to understand factors that might hinder or promote future involvement	People living with chronic stroke and aphasia are willing to be involved as PPI partners in research, if provided with the necessary support. This support includes social, technological, communicative, contextual and ensuring their role is clearly defined
Charalambous *et al.* (2023); Cyprus, France, Portugal & Norway	Evaluation; qualitative (thematic)	Stroke (8)	62.5%; 46.3	To develop the People with Aphasia and Other Layperson Involvement (PAOLI) framework for designing and implementing PPI in aphasia research, in collaboration with PwA	The PAOLI framework is considered a practical PPI conceptual framework that motivates to empower both researchers and PwD to build interactive and 'balanced' research teams

(*Continued on next page*)

Table 2. (*Continued*)

Author (year); country	Study design; methodology (analysis)	Disability type (*n*)	Gender (% female); age, years (*M*)[A]	Aims	Findings
Cruice *et al.* (2022); UK	Exploratory; qualitative (reflexive)	Stroke (4)	NR	To report on the coproduction phase of the project, and describe the levels of partner's involvement, outcomes and the impact of coproduction	Involvement in coproduction produced positive personal outcomes. Enablers to coproduction participation were consistent session structures and conduct, good group dynamics, accessible communication, active task experimentation, and SWIM technique
Davies *et al.* (2024); UK	Complex intervention development; N/A	PD (7)	NR	To co-design the core components of a facilitated self-management toolkit to support people with Parkinson's disease living in the community	The co-design processes enabled the development of 'Live Well with Parkinson's,' an online self-management toolkit designed to provide personalised information, well-being support, goal-setting tools, and trackers for symptoms, medication and activities
Donisi *et al.* (2022); Italy	Exploratory; participatory mixed methods (inductive content)	MS (31)	71%; 32.8	To present a co-creation process of a biopsychosocial intervention for MS, including people with MS and HcPs perspectives on the intervention	The co-creation process provided valuable information on the preferences and perspectives of stakeholders on strategies to improve participation in the biopsychosocial intervention. Some preferences included helping with disease management and tangible benefits
Fasching *et al.* (2024); Austria	Exploratory; participatory mixed methods (reflexive thematic)	MS (67)	84%; 49.6	To collaboratively develop a music-supported video-based exercise program for people with MS	This co-design process engaged people with MS (pwMS), their families and specialists early in co-developing a music-supported exercise programme, guided by key PPI principles. Their input fostered trust, shaped tailored solutions and led to 148 accessible, well-received videos.
El-Helou *et al.* (2023); Australia	Exploratory; qualitative (thematic)	Stroke (12)	80%; 62	To obtain the views of stroke survivors with aphasia to inform the development of an accessible, technology-based, relaxation intervention for anxiety	Findings highlight the importance of developing an accessible self-managed relaxation intervention, to be implemented by HcPs early post-stroke
Gauthier-Beaupre *et al.* (2022); Canada	Exploratory; qualitative (thematic)	PD (10)	50%; 50–71+	To provide a greater understanding of experiences with health services, and develop an integrated care network from the perspective of people with PD and other stakeholders	The co-design process resulted in a toolkit and roadmap that understands the challenges experienced by people with PD, and that an integrated care network needs to be individualised, malleable and adaptive to their evolving needs
Grosjean *et al.* (2022); Canada	Exploratory; qualitative (thematic)	PD (15)	20%; 50–80	Develop an eHealth technology that addresses the needs and expectations of people living with PD and managing care priorities at home, using a co-design approach	The co-design process enabled collective solutions to design an interactive and socially acceptable technology which supports the management of PD self-care in the home and the capacity to generate individualised digital health communication

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Table 2. (*Continued*)

Author (year); country	Study design; methodology (analysis)	Disability type (*n*)	Gender (% female); age, years (*M*) [A]	Aims	Findings
Hall *et al.* (2020); UK	Exploratory; qualitative (thematic)	Stroke (14)	43%; 72	Develop an intervention to reduce sedentary behaviour after stroke using co-production and BCW	The combined use of co-production and the BCW to develop stroke intervention provides multiple benefits, with stroke survivors reporting that co-designing the intervention was a positive experience
Hall *et al.* (2022); UK	Exploratory; qualitative (thematic)	Stroke (6)	50%; 49.3	Develop a novel method to co-create digital stories with stroke survivors that will synthesise their experiences of interacting with HcPs.	Six lessons were developed to help increase empathy and behaviour change in HcPs working with stroke survivors. Their stories highlighted the preconceptions and behaviours embedded withing healthcare that negatively impact their recovery experience
Hammond *et al.* (2016); USA	Exploratory; qualitative (constructivist ground theory)	TBI (16)	25%; 18–66	To understand the problem of irritability in TBI survivors through utilising co-design methods, and develop a conceptual model of TBI irritability	A multi-model in which irritability has five dimensions (affective, behavioural, cognitive-perceptual, relational issues and environmental) that helps provide a framework for assessment, treatment and future research of irritability
Harrison & Palmer (2015); UK	Exploratory; qualitative (thematic)	Stroke (8)	37.5%; 68.5	To explore stroke survivors' experience of their involvement in the research process and how their symptoms impact their participation in research	Stroke survivors involved in PPI identified the personal and research benefits of PPI, what type of credibility and expertise was needed, the ideal level of involvement, and the barriers and facilitators to engaging in PPI
Harpham *et al.* (2023); UK	Evaluation; mixed methods (thematic – inductive)	PD (5)	20%; 59.8	To co-create a feasible, accessible and safe home-based high-intensity interval program for people with PD	A high-intensity interval program for people with PD was successfully co-created, and may constitute of an accessible way to incorporate this style of exercise into their daily routine and extended adherence
Haynes *et al.* (2023); Australia	Exploratory; qualitative (thematic)	TBI (22)	<50%; 18–65	To help inform current physical activity guidelines for PwD described by WHO by co-developing a discrete choice experiment survey that identifies the physical activity preferences of people with TBI	The formative co-development process improved relevance and compressibility of the discrete choice experiment survey tool, by reducing and reconceptualising six key attributes – type of activity, out-of-pocket cost, travel time, who with, facilitated by and accessibility of setting
Hebblethwaite and Curley (2015); Canada	Exploratory; qualitative (thematic – inductive)	Stroke (14)	43%; 66	To critically explore the experience of community-based recreation for stroke survivors	Involvement in therapeutic recreation helped facilitate hope, collective social support and community engagement for stroke survivors re-integrating into the community
Herbert *et al.* (2018); UK	Exploratory; qualitative (NR)	Stroke (14)	50%; 71.42	To co-design accessible information materials with people with aphasia, and to generate a set of design criteria for use in developing effective accessible material	Key criteria developed on how to create accessible information, including information consisting of one proposition expressed via everyday words, one or two images related to the keywords, sans serif font and keyword bold emphasis

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Table 2. (*Continued*)

Author (year); country	Study design; methodology (analysis)	Disability type (*n*)	Gender (% female); age, years (*M*)[A]	Aims	Findings
Johnson *et al.* (2024); Sweden	Complex intervention development; N/A	MS (12)	83%; NR	To describe the process used to develop a theory-based, online fall prevention self-management program for people with MS	A theory-based online fall prevention program, Fewer Falls in MS, was co-developed with people with MS and healthcare professionals through a collaborative process. Grounded in self-management principles and pedagogical models, the program uses action plans to address diverse fall risk factors and continues to be refined with user input
Kearns *et al.* (2020); Ireland	Exploratory; qualitative (thematic)	Stroke (6)	16%; 60.7	Develop a feedback questionnaire in collaboration with people with aphasia, describe the co-design process and explore the experiences of the co-designers in the design process	Co-design provided opportunities for social interaction with other people with aphasia, reflection on their own abilities, was an inclusive process, while developing a questionnaire tool relevant to people with aphasia
Kuhlmann *et al.* (2024); Canada	Exploratory; qualitative (thematic)	PD (5)	NR	To describe how components of space, process and media shaped participants' self-reported experience in the co-design process, and contributed to the successful delivery of the final product	Embodied, multimedia co-design approach helped participants move from their comfort zones and engage across disciplines, fostering curiosity, generosity and collaboration, enabling diverse perspectives to unite towards a shared creative outcome
Kwah *et al.* (2024); Singapore	Complex intervention development; N/A	Stroke (13)	NR	To develop a complex intervention targeted at improving physical activity after stroke	Using behaviour change theory and co-design with stroke survivors, caregivers and professionals, a personalised intervention was developed to address post-stroke physical inactivity. The program includes tailored support, stroke-specific resources and 21 behaviour change techniques
Lamontagne *et al.* (2021); Canada	Single blind cross-over; mixed methods (thematic content)	TBI (16)	31%; 44.9	To document the acceptability, feasibility and outcome of two methods of PPI in CPG co-design for adults with TBI	The use of focus groups and wikis allow people with TBI to participate in clinical guideline production, and demonstrate these methods are acceptable, feasible and produce positive outcomes
Lievesley *et al.* (2022); UK	Exploratory; qualitative (NR)	Stroke (7)	42.5%; 41–70	Combining a co-design approach with behaviour change theory to produce an intervention for oral health relevant to stroke survivors	The combination of experience-based co-design and behaviour change theory were effectively combined to create a patient-facing resource that helps support stroke survivors with oral care as they transition from hospital to home
Lindblom *et al.* (2021); Sweden	Exploratory; qualitative (content)	Stroke (3)	67%; 57–92	Explore how user participation manifests itself within a co-design process, including potential enablers and/or barriers	Participation in co-design processes manifests itself through the interaction between group member and their skills to handle different perspectives, roles and assignments. Individuals' participation is enabled by ever-adaptive facilitation

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Table 2. (*Continued*)

Author (year); country	Study design; methodology (analysis)	Disability type (*n*)	Gender (% female); age, years (*M*)[A]	Aims	Findings
Marier-Deschênes *et al.* (2021); Canada	Exploratory; qualitative (thematic)	TBI (5)	40%; 24–66	To report on the needs and expectations of individuals with TBI expressed through the co-creation process of an information toolkit on post-TBI sexuality	The user-centered approach discovered the sexual needs and expectations of people with TBI, which helped to develop an informative sexuality-related resources to be used in the rehabilitation process
Marwaa *et al.* (2023); Denmark	Experience-based co-design; qualitative (cross-analysis)	Stroke (5)	60%; 63–85	To examine and describe the process of using experience-based co-design to develop an app to support person-centred stroke rehabilitation	Experienced-based co-design facilitated the development of content in the app for person-centred stroke rehabilitation, including having relevant evidence-based knowledge, person-centred exercises, video guidelines and easy communicative techniques
Masterson-Algar *et al.* (2020); UK	Exploratory; mixed methods (constructivist ground theory)	Stroke (18)	44.4%; 41–83	Co-design a peer-led coaching intervention to helps stroke survivors to rebuild social and leisure activities post-stroke	Demonstrates the beneficial impact that peer-led coaching can have on stroke survivors' rehabilitation journey, and provides theoretical platform for designing and implementing peer interventions
McMenamin *et al.* (2015); Ireland	Exploratory; qualitative (thematic)	Stroke (6)	17%; 73	Describe participants experience of aphasia and a conversation partner program	The CPP program helped to acknowledge the expertise of individuals with aphasia, and provided more social and vocational opportunities. Participants reported transformative experiences regarding identity, independence and confidence
Miao *et al.* (2023); Australia	Exploratory; mixed methods (collaborative autoethnography)	ABI (10)	30%; 25–65	To support the implementation of the Social Brain Toolkit by coproducing implementation knowledge with people with ABI and other stakeholders	Stakeholders prioritised the investigation of the (1) target condition, (2) technology, (3) value proposition and (4) adopters of the Social Brain Toolkit, and developed 48 digital health implementation considerations and 52 clinician implementation strategies
O'Callaghan *et al.* (2024); Ireland	Exploratory; qualitative (collaborative discussions)	Stroke (12)	17%; 18–65+	To identify key components for a patient-centred transition-to-home support pathway, exploring feasibility within a real-world context	The co-design group identified 10 key components for a stroke transition-to-home support pathway, prioritising collaboration, streamlined processes and post-discharge continuity of care. Involvement from the stakeholder group ensured relevance, with community in-reach and improved information sharing seen as the most feasible components
Pierce *et al.* (2024); Australia	Intervention development; human-centred design framework	Stroke (3)	0%; 40–90	To adapt the evidence-based, in-person, group intervention M-MAT to an online format using co-design processes	Co-design helped identify key user needs, such as clinicians' need for broad software compatibility and PwA preference for low-cost, low-tech solutions, resulting in a telehealth tool being developed that works across major platforms with minimal technical requirements
Pinard *et al.* (2019); Canada	Exploratory; qualitative (NR)	TBI (10)	30%; 50	Collaboratively design an assisted technology device to support meal preparation for people with TBI and evaluate its usability	COOK technology is promising for clients with cognitive disabilities transitioning into community living, improving safety in the home environment and increasing independence

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Table 2. (*Continued*)

Author (year); country	Study design; methodology (analysis)	Disability type (*n*)	Gender (% female); age, years (*M*)[A]	Aims	Findings
Pogrebnoy *et al.* (2024); Australia	Design thinking framework; Integrated Knowledge Translation (iKT)	Stroke (24)	NR	To describe a systematic approach, using design thinking framework and drawing on principles of an integrated knowledge translation approach, to adapt co-designed resources to a website prototype	The research project provides a road map or exemplar for the adaptation of diet and physical activity telehealth programs to an evidence-based and co-designed website with health information to promote self-management after stroke
Quilico *et al.* (2022); Canada	Exploratory; qualitative (reflexive thematic)	TBI (17)	41.2%; 39.2	To provide a detailed account of the participation in and co-creation of a new TBI-Health Program to enhance sport participation for people with TBI	The TBI-Health Program can increase autonomy and reduce barriers to physical activity for people with TBI, which in turn, increases participation in exercise and other psychosocial benefits
Revenäs *et al.* (2018); Sweden	Exploratory; qualitative (thematic)	PD (7)	57%; 45–85	Describe different stakeholders' experience of participating in co-designing an eHealth service, focusing on the values, challenges and improvements of co-design	To generate value from co-design, methods need to adjust to the stakeholder group and context, to influence how participants experience the process. Most participants reported a positive experience of engaging in co-design
van Rooijen *et al.* (2021); Netherlands	Exploratory; qualitative (thematic – inductive & deductive)	ABI (3)	67%; 43–64	To describe a process of how to get from problem analysis to strategy selection while engaging stakeholders and providing insights into their experiences	A three-step process model and co-creation methods offer guidance in selecting implementation strategies for stakeholder engagement, which factors influence engagement, and the impact of stakeholder engagement
Russell *et al.* (2023); Australia	Multiphase sequential design	MS (6)	NR	Collaborate with people with MS and health professionals to identify the preferred content of a nutrition education program, and explore the acceptability of the online nutrition education program	Co-design and consumer feedback identified that positive messaging, credible expert advice, strong evidence and engaging online design are key to motivating healthy dietary changes in people with MS
Sylvie *et al.* (2021); Canada, Czech Republic, Germany, Spain & Ireland	Exploratory; qualitative (narrative)	PD (95 combined all countries)	36%; <50–71+	Provide better understanding of how patients trajectories could inform the design of an integrated care network for people with PD	The integration of health and social care is complex and dependent on multiple individuals, activities, and tools. Integrated care network organised around key trajectories has potential to target care priorities of people with PD
Wannheden and Revenäs, (2020); Sweden	Exploratory; qualitative (thematic – inductive & deductive)	PD (7)	57%; 45–85	Explore how co-care could be operationalised in PD care via eHealth and stakeholders' desired eHealth functionalities	Findings provide knowledge on how co-care in PD care could be operationalised, with participants reporting that they would benefit from an eHealth service
Wray *et al.* (2021); UK	Exploratory; qualitative (summary)	Stroke (5)	60%; 43–51	Report the methods and processes of a co-designed self-management intervention for stroke survivors with aphasia	Describes the processes used to develop a self-management intervention using co-production. These techniques made the intervention more feasible, acceptable in practice, help refine the intervention and develop a reasoned account as to why it is or is not effective

Note: PD, Parkinson's disease; TBI, traumatic brain injury; ABI, acquired brain injury; AcWs, attendant care workers; PwA, people with aphasia; HcPs, healthcare professionals; PPI, public patient involvement; BCW, behaviour change wheel; MS, multiple sclerosis; WHO, World Health Organization; NR, not reported.
[A]If *M* not available, then age range is reported.

Table 3. The operationalisation of co-design in the included articles.

Author	Frequency of sessions	Group size & diversity	Co-design contributors	Facilitator	Role of PwD and facilitator
Abma (2019)	1× individual interviews ranging from 1.5 to 2 h 1× 4 h focus groups	4 groups, ranging between 6 and 9 people. Groups were a mix of all co-design contributors	PwD, researchers (authors), healthcare professionals (nurses, paramedical) and funding agencies	Lived experience and researchers (authors)	PwD: Help establish teams, provide perspectives, prioritise research topics, and integrate and translate findings F: Help boost team morale and provide opportunities for PwD to make meaningful contribution to tasks
Anemaat *et al.* (2024)	23× focus groups, ranging from 1 to 3 h 13× individual interviews	Of the 23 focus groups, some were with PwD, close others, and 3 were dyadic groups (PwD and close others). Group size for PwD was capped at 3 participants	PwD, close others, researchers (authors)	Researchers (authors)	PwD: Sharing lived experience, idea generation for service improvement, ranking/prioritisation of ideas and shared decision-making F: Led the focus groups, managed group discsussion
Bodilsen *et al.* (2023)	N/A	3 groups, ranging between 3 and 10 people. One group were co-design contributors with disability, with an option to invite a close other. The other groups were only healthcare professionals	PwD, close others, healthcare professionals and researchers (authors)	Researchers (authors)	PwD: Provided their experience, perspectives, and opinions for the content of the intervention. Provided suggestions and solutions for improvement of the intervention in an iterative process F: Led the workshops and focus groups, with an additional facilitator observing the co-design contributors and taking field notes
Carminati *et al.* (2023)	1× individual interviews ranging from 20 to 56 min 3× focus groups lasting up to 3 h (7 additional focus group and/or 1:1 meetings were added due to individual needs)	3 groups, with 7 people. 1:1 focus group meetings also took place. Groups were a mix of all co-design contributors	PwD, attendant care workers, researchers (authors)	Lived experience, ambassadors from disability support organisations and researchers (authors)	PwD: Collaborated on the initial creation of the program, involved in project steering committee, broader project activities (i.e. grant writing, research question development), development of resources and project promotion F: Overviewed focus groups, led group discussions, support involvement of PwD, and provide accessible resources and stimuli for PwD
Carminati *et al.* (2024)	3× 1.5 h focus groups 1× individual interviews ranging from 25 to 75 min 1× 2 h podcast session recording	2 groups, ranging between 5 and 8 participants. One group was only co-researchers with disability and their close others, the second group was only clinicians	PwD, close others, clinicians, and researchers (authors)	Researchers (authors)	PwD: Reviewed and provided feedback on draft intervention guides, by reviewing the accessibility of language, relevance of content, layout and design elements F: Guided the co-design process, led group discussions, set clear expectations (e.g. creating a safe space) and encouraged inclusive participation

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Table 3. (*Continued*)

Author	Frequency of sessions	Group size & diversity	Co-design contributors	Facilitator	Role of PwD and facilitator
Charalambous *et al.* (2022)	N/A	N/A	PwD, researchers (authors)	N/A	PwD: Involved as a researcher in the study and known as a PPI partner. Responsible for conceptualisation of research ideas, study design and data collection methods, recruitment, analysis, and dissemination of study results F: N/A
Charalambous *et al.* (2022)	N/A	N/A	PwD, researchers (authors)	N/A	PwD: Involved as a researcher in the study and known as a PPI partner. Responsible for conceptualisation of research ideas, study design and data collection methods, recruitment, analysis, and dissemination of study results F: N/A
Cruice *et al.* (2022)	5× 6-h sessions, monthly	2 groups, with 4 co-design contributors. One group was only co-design contributors with disability, the other group were only speech & language therapists	PwD, speech & language therapists, researchers (authors)	Researchers (authors)	PwD: Provided their lived experience. and their needs and preferences for the intervention, reviewed and refined key concepts, provided feedback on treatments, and made suggestions on how to design certain aspects of the intervention F: Led the workshops, facilitated group discussions, and helped support co-design contributor participation
Davies *et al.* (2024)	5× workshops	Mixed groups, ranging between 4 and 7 co-researchers	PwD, family carers, healthcare professionals, academics, researchers (authors), voluntary sector representative	Researchers (authors)	PwD: Provided lived experience and perspectives, shared decision-making, idea generation and solutions development, user-testing and prototype development F: Led the workshops, managed group discussions, designated group members sharing outputs and managed feedback responses
Donisi *et al.* (2022)	2× surveys about their perspectives of the intervention 2× focus groups	Focus group consisted of only co-design contributors with disability	PwD, healthcare professionals, researchers (authors)	NR	PwD: Provided their opinions, needs and preferences on the intervention throughout multiple time-points. Some PwD also acted as consultants on an advisory board to examine the findings and ensure it was relevant F: NR
El-Helou *et al.* (2023)	5× focus groups (3× sessions for one group, and 2× sessions for the other group)	2 groups, ranging between 3 and 5 participants. Groups were a mix of all co-design contributors	PwD, researchers (authors)	Researchers (authors)	PwD: Provided opinions, preferences and feedback on the materials created by the researchers for the intervention until consensus was reached F: Led the focus groups and group discussions, while providing tailored information sheets to each co-researcher to help facilitate involvement

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Table 3. (*Continued*)

Author	Frequency of sessions	Group size & diversity	Co-design contributors	Facilitator	Role of PwD and facilitator
Fasching *et al.* (2024)	12× focus groups ranging from 90 to 120 min, mix of online, in-person or hybrid format 1× individual intervention ranging from 90 to 120 min	Group size ranged from 3 to 5 people. One group of three, two groups of four, and nine groups of five	PwD, close others, musicians, physiotherapists, music therapists	Researchers (authors) and PwD	PwD: Shared lived experience, needs and barriers, co-developed the intervention by sharing preferences, reviewed and adapted the intervention, and evaluated and piloted the intervention F: Led the focus groups, gathered PwD preferences to inform intervention design, presented prototypes and managed participant input
Gauthier-Beaupre *et al.* (2022)	1× narrative interviews 1× pre-workshop session 1× 45 min workshop	Maximum of 6 co-design contributors per workshop group. Groups were exclusively co-design contributors with disability with an option to invite their caregiver or healthcare professionals	PwD, healthcare professionals, caregivers, researchers (authors)	NR	PwD: Provided their lived experience with access health services, identify their healthcare priorities, and brainstorming solutions and/or key resources needed for integrated care F: NR
Grosjean *et al.* (2022)	2× workshops 3× design critique sessions	Workshop and design critique groups were spilt into exclusively co-design contributors with disability or healthcare professionals. The groups ranged between 2 and 15. PwD had the option to invite an informal caregiver	PwD, healthcare professionals, caregiver, researchers (authors)	Researchers (authors)	PwD: Provided their lived experience, identify their needs and preferences for the platform, and identifying solutions to improve final prototype F: NR
Hall *et al.* (2020)	5× workshops, once per month	2 groups, ranging between 12 and 14 people. Groups were a mix of all co-design contributors	PwD, caregivers and healthcare professionals (physiotherapist, OT, nurse, support worker, exercise instructors and volunteers)	Researchers (authors)	PwD: Defined the problem, identified and developed the solutions, appraisal, and review of prototype F: Overviewed workshops, led group discussions and help support involvement of PwD in discussions
Hall *et al.* (2020)	6× workshops, over 4-months	1 group, with 6 co-design contributors with disability	PwD	NR	PwD: Provided their lived experience, identified and developed solutions via digital stories, and reviewed their digital stories F: Responsible for supporting PwD throughout each design stage
Hammond *et al.* (2016)	10× 90 min focus groups over 10 months	5 groups, ranging between 8 and 9 people. Co-researcher diversity in each group was equal and spouses were not assigned to same group	PwD, family members, spouses and healthcare professionals	External facilitators (psychiatrist, rehab scientist, psychology professor, graduate RA and spouse of individual with TBI)	PwD: Provided their lived experience and help to create solutions F: Led the workshops and guided the group discussions

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Table 3. (*Continued*)

Author	Frequency of sessions	Group size & diversity	Co-design contributors	Facilitator	Role of PwD and facilitator
Harrison & Palmer (2015)	N/A[A]	N/A[A]	N/A[A]	Researchers	PwD: Helpedto design and select research projects, helped develop information sheets, advisory groups, research analysis, interpreted and wrote results, ensured the reporting is accessible, and helpedto disseminate findings F: N/R
Harpham *et al.* (2023)	3× 45-min focus groups	2 groups ranging between 4 and 5 people. One group was exclusively PwD and their family member or caregiver. The 2nd group were exclusively clinicians	PwD, family members, caregivers, clinicians and researchers (authors)	Researchers (authors)	PwD: Helped to inform and design the practical exercise intervention, while providing feedback for each prototype F: One facilitator observed non-verbal cues and potential signs of fatigue in other co-design contributors, while another facilitator was responsible for leading the focus groups
Haynes *et al.* (2023)	3× 90-min focus groups 1× 'think aloud' interview	Each group had 4 or fewer co-design contributors with disability. There was an option for PwD to also invite a family member or caregiver to the focus group	PwD, family members, caregivers and researchers (authors)	Researcher (authors), and consumer representative of experience with TBI	PwD: Helped to inform and refine the key constructs and ideas, individually prioritise the refined concepts, then come to a consensus via group discussion on the most meaningful concepts F: Aided co-design contributors to understand and comprehend the tasks of the focus groups
Hebblethwaite and Curley (2015)	NR	NR	PwD	Researchers (authors)	PwD: Conceptualised research idea and methodology, contributed to solutions, and reviewed themes from analysis F: Led group discussions and facilitated individual interviews
Herbert *et al.* (2018)	3× 2-h meetings, 1 month apart	3 groups, ranging between 4 and 5 PwD. Each PwD had a communication partner that were paired with them support engagement	PwD	Researchers (authors)	PwD: Viewed and assessed prototypes, design revision, re-assessed updated prototypes and design finalisation F: Outlined the aims and objectives for the meetings, scheduled and ran the activities, ensured group rules were followed, and summarised key takeaways at the end of the meetings
Johnson *et al.* (2024)	5× 4 h workshops	3 groups, ranging between 6 and 7 people. One group were exclusively healthcare professionals; the other group were exclusively PwD.	PwD, social workers, OTs, nurses, physiotherapists and researchers (authors)	Inovation manager and researchers (authors)	PwD: Actively contributed personal experiences, co-created visual representations, and shared decision-making on content, format and delivery methods F: Led, planned and summarised workshops, refined materials between sessions, ensured continuity between workshops by sharing notes and setting agendas, technical support for PwD using the online meeting platforms, and facilitated group discussions

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Table 3. (*Continued*)

Author	Frequency of sessions	Group size & diversity	Co-design contributors	Facilitator	Role of PwD and facilitator
Kearns *et al.* (2020)	3× 90 min workshops per week (3 additional workshops after a 4-week break)	1 group that consisted of 7 people. All group members were PwD except for the facilitator/ author	PwD and researchers (authors)	Researcher (authors)	PwD: Brainstormed solutions, reviewed and established key content from discussions, creating accessible stimuli, trailing and refining prototype, and evaluating the co-design process F: Led the workshops, help create accessible stimuli with PwD, and facilitated exit interviews
Kuhlmann *et al.* (2024)	10× 1.5 h workshops, occuring bi-monthly	NR	PwD, graduate students, circus performers, dancers, musicians, caregiver, dance movement facilitator and researchers (authors)	Researcher (authors)	PwD: Group discussions connecting lived experience with scientific research, collaborative creation of artistic content, reviewed the metaphors and themes (data analysis), gave feedback on performance development, and helped shape the final production to reflect their lived experiences accurately F: NR
Kwah *et al.* (2024)	2× 2 h workshops	3 groups, ranging from 5 to 6 people per group. Mix of PwD and their caregivers	PwD, caregivers, neuropsychologists, physiotherapists, user experience designer and treasurer	Physiotherapist and neuropsychologist	PwD: Sharing of lived experience, solutions development and design recommendations, and reviewed solutions prototype F: Trained in implementation science and behaviour change, led workshops and small group discussions, presented summaries, and encouraged feedback and participant input during big group discussions
Lamontagne *et al.* (2021)	1× 2 h focus groups Wiki groups can access whenever and complete over 1 week	2 groups that consisted of 8 people. All group members were PwD	PwD, clinicians, mangers and policy makers	Researcher (authors)	PwD: Provided their lived experience and collaborated on design recommendations F: Led and moderated the focus groups, set the agenda for participation, help create accessible cues for PwD with cognitive difficulties
Lievesley *et al.* (2022)	3× 90 min workshops	3 groups ranging between 9 and 25 people. Groups were either only co-design contributors with disability and their carers, only healthcare professionals or a combination of both	PwD, healthcare professionals (dental/oral health practitioners, OTs, nurses, speech therapists, dietician, stroke support office and social worker)	Experienced designer-researchers	PwD: Provided their opinions and lived experience of the healthcare system, reviewed and critiqued the prototype, and evaluated final version F: Led and moderated the workshops, using a range of creative design tools to help facilitate
Lindblom *et al.* (2021)	5× half day workshops	3 groups, ranging between 4 and 5 people. One PwD to three healthcare professionals per group	PwD, significant other, and healthcare professionals (OT, nurse, speech pathologist, physiotherapist, GP)	External facilitator	PwD: Provided their lived experience, identified their needs and helped design the prototype F: Pre-trained in design thinking, moderated the workshops, led the design activities and collaborated with the researchers to help structure the workshops

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Table 3. (*Continued*)

Author	Frequency of sessions	Group size & diversity	Co-design contributors	Facilitator	Role of PwD and facilitator
Marier-Deschênes *et al.* (2021)	2× 1 h focus groups 1× semi-structured interview	2 groups, ranging between 3 and 4 people. Groups were a mix of all co-design contributors	PwD, researchers/authors and partners	Researchers (authors)	PwD: Identified their needs and expectations for prototype, and reviewed the prototype F: Led the focus groups and actively involved in the discussions, also facilitated the individual interviews
Marwaa *et al.* (2023)	1× individual interviews 1× focus groups 2× workshops	2 groups, ranging between 9 and 11 people. Groups were a mix of all co-design contributors	PwD, OTs, physiotherapists, and researchers (authors)	Researchers (authors)	PwD: Provided their lived experience on rehabilitation, identified their unmet care needs, generated content ideas for the app, and reviewed and provided feedback for the prototype F: Developed workshop plan and led the discussions
Masterson-Algar *et al.* (2020)	6× 1 h coaching sessions 1× individual interview	Co-design activities were completed 1:1 with a peer-led facilitator and co-research with disability	PwD and carers	PwD (peer-led facilitators)	PwD: Identified factors that impacted engagement, peer-led training (for PwD who were also facilitators), shaped training content and reviewedprototype F: 2-week training workshops and led the prototype coaching intervention
McMenamin *et al.* (2015)	5× 3-h workshops across 12 months	1 group with 5 people. Group members were all PwD	PwD, speech pathologist, psychologist, social scientist, external academics and speech pathology students	Researchers (authors)	PwD: Brainstormed their perspectives and possible solutions, reviewed data collection and analysis, and evaluated the prototype F: Pre-trained in PLA, led data generation activities, helped PwD complete tasks, provide encouragement and additional 'outside' facilitator to counter effects of potential bias
Miao *et al.* (2023)	1× individual interview, ranging from 1 to 2.5 h 7× 3 h focus groups	1 group with 3–6 people. Group members were a mix of all co-design contributors	PwD, close others of PwD, clinicians and researchers (authors)	NR	PwD: Discuss at the created framework and ranked domains, while providing their lived experience of ABI. Also engaged in collaborative autoethnography to reflect on their experience of participating in co-producing research F: NR
O'Callaghan *et al.* (2024)	3× half day workshops	2 groups, ranging between 6 and and 26 people. One group HcPs and support agencies, the other group PwD and their caregivers	PwD, caregivers, HcPs and support agencies	Primary researcher (author), physiotherapist, doctoral student and person with lived experience of stroke	PwD: Provided account of their lived experience, defined the core problems, generated solutions, refined, reviewed and evaluated the final ideas and prototypes F: Led the workshops, used speciality facilitation techniques (i.e. World Cafe) and supported any communication challenges that may hinder active participation

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Author	Frequency of sessions	Group size & diversity	Co-design contributors	Facilitator	Role of PwD and facilitator
Pierce *et al.* (2024)	2 h workshops (unspecified frequency) 6× additional 30 min review meetings	2 groups, with 3 co-researcher in each group. One group were exclusively speech pathologist, the other was PwD	PwD, speech pathologists	NR	PwD: Provided their opinions and perspective of telehealth platforms, their lived experience of rehabilitation, and reviewed, tested and evaluated the final ideas and prototypes F: NR
Pinard *et al.* (2019)	9× design meetings 2× 90-min focus groups with OTs (no PwD present)	2 groups, ranging from 3 to 6 people. One group were exclusively PwD, the other were OTs	PwD, OTs, computer scientists and researchers (authors)	Researchers (authors)	PwD: Helped designed the assistive device, tested and reviewed the prototype, and provided recommendations F: Led the focus groups and collaboratively create strategies on how to best facilitate
Pogrebnoy *et al.* (2024)	Consumer advisory group (quarterly) Steering committee (unspecified frequency) Design workshops (unspecified frequency) User testing (unspecified frequency)	Stroke survivors and other key stakeholders including health professionals, researchers, medical professionals, policy makers, healthcare managers, clinical experts, experts in co-design methodology, website designers, implementation and research translation experts	2 researcher partners with lived experience of disability	Researchers (authors)	PwD: Tips to guide an authentic collaborative partnership. Provided lived experience to inform the design, development and user testing of the platform to ensure accessibility and usability F: Ensure active, accessible participation of all stakeholders
Quilico *et al.* (2022)	9× 60-min work groups (peer mentors with disability) 3× 60–90-min focus groups (peer mentors & co-design contributors with disability)	Work groups involved 3 peer mentors with disability and were considered part of the research team. Focus groups consisted of 13 co-design contributors with disability and peer mentors	PwD and researchers (authors)	Researchers (authors)	PwD: Co-design contributors were engaged in knowledge generation and providing their preferences. Peer mentors with disability had greater collaboration with the research team on designing the work group structure, content and delivery, and the responsibilities of co-design contributors F: Led the work and focus groups
Revenäs *et al.* (2018)	4× half-day co-design workshops	1 group with 16 people. 2 workshops separated PwD from health are professionals, and the other 2 workshops had all the co-design contributors	PwD and healthcare professionals (neurologists, nurses, physio)	Researchers (external to authors) and professional moderators	PwD: Identifyed key needs, helped designi the service and evaluated the usability of the prototype (same methodology as Wannheden and Revenäs 2020) F: Led group discussions, used time between breaks to facilitate more engagement and social discussions, and helped support discussions

(*Continued on next page*)

Table 3. (*Continued*)

Author	Frequency of sessions	Group size & diversity	Co-design contributors	Facilitator	Role of PwD and facilitator
van Rooijen *et al.* (2021)	6× group meetings 1× focus groups 1× semi-structured interview. All activities ranged from 32 to 58 min.	NR	PwD, researchers and professionals working at the supported living facility	Researchers (external to authors)	PwD: Identified barriers and enablers, helped categorise the data, provided lived experience, identified directions of solutions and drafted potential strategies F: Moderated focus groups
Russell *et al.* (2023)	2× 3 h workshops	1 group, with 6 people. All members of the group were PwD	PwD, researchers (authors) and nutritionist	Nutritionist	PwD: Provided lived experience, identified barriers and enablers, feedback on program topics and content, and contributed to the iterative refinement of the program F: Led workshops and discussions, ensured transparency and clear understanding among participants, collected and synthesised feedback, and implemented the iterative feedback loop
Sylvie *et al.* (2021)	1× narrative interviews 1× design workshops	NR	PwD, care partners and healthcare professionals (nurses, GP and allied health)	NR	PwD: Identifed key health needs and barriers to accessing healthcare, problem-solving solutions and helped to design the prototype F: NR
Wannheden and Revenäs, (2020)	4× half-day workshops	1 group with 16 people. 2 workshops separated PwD from healthcare professionals, and the other 2 workshops had all the co-design contributors	PwD and healthcare professionals (neurologists, nurses, physio)	Researchers (external to authors) and professional moderators	PwD: Identified key needs, helped design the service and evaluated the usability of the prototype (same methodology as Revenäs *et al.* 2018) F: Engaged in the design process with other stakeholders
Wray *et al.* (2021)	6× 2 h workshops	1 group, with 12 people. Groups were a mix of all co-design contributors, with some activities completed in separate diversity groups (i.e. only PwD	PwD, speech and language therapists, and family members	Researchers (authors)	PwD: Identified needs and challenges to aphasia, brainstormed solutions, and reviewed the prototype F: Led the workshops and discussions, helped provide design ideas, facilitated social time for PwD, helped PwD with their communication style in discussions and ensured PwD always had a 1:1 facilitator

Note: NR, not reported; PwD, people with disability; F, facilitators; OT, occupational therapists; GP, general practitioner
[A]This study utilised a sample group that had previously participated in co-design work. There were minimal details on what they were involved in.

over 11 co-design contributors per group. The group size categories (≤6, 7–10, >11) were derived inductively based on common patterns observed across the included studies, to enable meaningful synthesis of group composition and scale. Most of the co-design sessions were usually facilitated by the authors themselves (n = 26), some studies recruited external facilitators with experience facilitating focus groups (n = 8) or trained in design-thinking (n = 3), with four studies recruiting people with lived experience in disability acting as facilitators (Masterson *et al.* 2022; Carminati *et al.* 2023; Fasching *et al.* 2024; O'Callaghan *et al.* 2024). In all the studies, except one (Sylvie *et al.* 2021), facilitators led the co-design sessions, while also providing communicative support for co-design contributors with disability if needed. The roles and responsibilities of co-design contributors with disability ranged from sharing their lived experience and opinions to being involved in the design process, such as helping to create solutions to the research questions and collaboratively designing prototypes.

Most included articles referenced the term 'co-design' (n = 32), whereas others used associated terms, such as co-creation (n = 10) and co-production (n = 10). Several studies identified the use of 'co-design' based on principles from existing research design frameworks that involves end-users at the centre of the process, including participatory design (n = 10), PAR (n = 8), PPI (n = 6), user-centred design (n = 5), collaborative research (n = 3) or human-centred design thinking approaches (n = 3). Despite heterogeneity in terms across included studies, several studies (n = 27) defined their use of 'co-design', with definitions sharing common principles, such as the active engagement and collaboration with a variety of stakeholders to leverage expertise, the importance of shared and equal responsibility in the design process, and centralising people with lived experience of disability.

The lived experience of co-design

Of the included studies, 13 out of 45 studies evaluated and reported the lived experience of participating in co-design. Thematic analysis of this data produced three themes describing the experience of participating in co-design from the perspective of participants with disability, as well as other contributors, such as facilitators and health professionals. The themes are: (1) a meaningful experience, (2) balancing group dynamics, and (3) an unfamiliar process.

Theme 1: a meaningful experience

The first theme, a meaningful experience, highlights the value of participating in co-design for co-design contributors. Although co-design was identified as a challenging process that required new skills, hard work and thinking (Harrison and Palmer 2015; Abma 2019; Hall *et al.* 2020; Lindblom *et al.* 2021; Wray *et al.* 2021; Cruice *et al.* 2022; Carminati *et al.* 2023), it was also a meaningful social and learning experience (Harrison and Palmer 2015; Revenäs *et al.* 2018; Hall *et al.* 2020; Kearns *et al.* 2020; van Rooijen *et al.* 2021; Wray *et al.* 2021; Cruice *et al.* 2022; Carminati *et al.* 2023, 2024; Miao *et al.* 2023). Participating in co-design required engagement in dynamic and robust conversations (Revenäs *et al.* 2018; Abma 2019; Wray *et al.* 2021; Carminati *et al.* 2023), which often resulted in self-reflection and learning (Harrison and Palmer 2015; Revenäs *et al.* 2018; Hall *et al.* 2020; Kearns *et al.* 2020; Lindblom *et al.* 2021; van Rooijen *et al.* 2021; Wray *et al.* 2021; Cruice *et al.* 2022; Carminati *et al.* 2023; Miao *et al.* 2023). Co-design was viewed as an overwhelmingly positive experience for all co-design contributors across studies – excluding one person, who reported no personal value in participating due to being familiar with the content in the sessions (Carminati *et al.* 2023). However, this person did recognise that participating in co-design can offer meaningful social and intellectual opportunities when sessions are tailored to individual skill level (Carminati *et al.* 2023).

For co-design contributors with disability, co-design presented a valued work opportunity that enabled purposeful contributions and peer connection (Harrison and Palmer 2015; Abma 2019; Hall *et al.* 2020; Kearns *et al.* 2020; van Rooijen *et al.* 2021; Wray *et al.* 2021; Carminati *et al.* 2023). Co-designers with disability reported feeling understood due to connecting and sharing with people who have had similar experiences, and developing a sense of community or belonging with other contributors (Harrison and Palmer 2015; Abma 2019; Hall *et al.* 2020; Kearns *et al.* 2020; van Rooijen *et al.* 2021; Wray *et al.* 2021; Carminati *et al.* 2023; Kuhlmann *et al.* 2024). For example, one co-design contributor with Parkinson's disease (Abma 2019) shared, 'You are doing that with peers and you feel that other persons exactly know what you're talking about', with another co-design contributor with acquired brain injury (Carminati *et al.* 2023) reflecting on the 'profound change there is (in oneself) when you're amongst a group of peers.' Co-designers with disability reported gaining a deeper understanding of their own personal experiences, as well as learning about other perspectives (Harrison and Palmer 2015; Abma 2019; Kearns *et al.* 2020; Lindblom *et al.* 2021; van Rooijen *et al.* 2021; Cruice *et al.* 2022; Carminati *et al.* 2023, 2024; Miao *et al.* 2023). At times, this resulted in a change in perspective or 'positive reframing' of one's own disability or abilities (Abma 2019; Kearns *et al.* 2020; Carminati *et al.* 2023, 2024). A co-design contributor with disability reflected, 'I especially like that I am not only doing this for other care users, but also a bit for myself' – person with acquired brain injury (van Rooijen *et al.* 2021).

Co-design contributor healthcare workers also valued learning about different experiences, and reported that their learnings through co-design participation changed or improved their professional practice (Hall *et al.* 2020; van Rooijen *et al.* 2021; Wray *et al.* 2021; Cruice *et al.* 2022). Both co-design contributors with disability and healthcare

workers reported learning about research processes, interventions or the healthcare system through participating in co-design (Revenäs *et al.* 2018; Abma 2019; Hall *et al.* 2020; Kearns *et al.* 2020; van Rooijen *et al.* 2021; Wray *et al.* 2021; Cruice *et al.* 2022; Carminati *et al.* 2023). A co-designer shared, 'I have a better understanding now. The workshops have helped me to reflect on the healthcare system in a new way' – person with Parkinson's disease (Revenäs *et al.* 2018). Co-design contributor healthcare workers valued working collaboratively to create services or interventions (Revenäs *et al.* 2018; Lindblom *et al.* 2021; van Rooijen *et al.* 2021; Cruice *et al.* 2022), as shared by one healthcare worker, 'It is important to develop the co-care service together to increase the chance of future use' (Revenäs *et al.* 2018).

Theme 2: balancing group dynamics

The second theme, balancing group dynamics, emphasises the importance of managing the power dynamics between all stakeholders, including co-design contributors with disability, family members, healthcare workers and facilitators. Managing group dynamics was reported as critical to creating equal opportunities for participation (Harrison and Palmer 2015; Revenäs *et al.* 2018; Lindblom *et al.* 2021; van Rooijen *et al.* 2021; Cruice *et al.* 2022). Although having diverse stakeholders was valued by co-design contributors and facilitators, the size and composition of the group impacted participation, and at times there were challenges in reaching consensus and meeting diverse group needs (Harrison and Palmer 2015; Revenäs *et al.* 2018; Lindblom *et al.* 2021; van Rooijen *et al.* 2021; Carminati *et al.* 2023; Miao *et al.* 2023). For example, one healthcare worker shared, 'Everyone has his own way of working, and it takes a lot of effort to keep everyone on the same page' (van Rooijen *et al.* 2021).

Co-design contributors with disability reported feeling inequalities at times in the group when participating in workshops with healthcare workers (Revenäs *et al.* 2018; Lindblom *et al.* 2021). For example, a co-designer with disability shared, 'I felt inferior in that way; of course, they were experts and I wasn't' (Lindblom *et al.* 2021). Whereas some healthcare workers reported challenges working with co-design contributors with disability who did not have an in-depth knowledge of the healthcare system or experience participating in co-design workshops (Revenäs *et al.* 2018; Lindblom *et al.* 2021). A healthcare worker shared their experience working with diverse stakeholders, 'Well, patient and family members were more difficult to work with. As healthcare professionals, we think alike and know how things are done when we work, while patients/family members would like us to solve their particular problem' (Lindblom *et al.* 2021). Facilitators and co-design contributors noted that, regardless of the composition of the group, investing time to develop group rapport was essential for a healthy group dynamic (Kearns *et al.* 2020; Lindblom *et al.* 2021; van Rooijen *et al.* 2021; Cruice *et al.* 2022; Carminati *et al.* 2023; Kuhlmann *et al.* 2024). As a co-design contributor with disability shared, '… you have to know somebody before you say anything' (Kearns *et al.* 2020). Co-researchers with disability also appreciated when facilitators had prior knowledge and experience with their disability type, which helped to foster trust, mutual respect and validation (Carminati *et al.* 2023). Moreover, some co-design contributors with disabilities and their close others found it emotionally confronting and challenging to participate in co-design when having to discuss difficult topics related to their lived experience (Harrison and Palmer 2015; Cruice *et al.* 2022; Carminati 2023, 2024; Miao *et al.* 2023). Thus, the importance of empathy, being open-minded, and encouraging and supporting all co-designers was also recognised as important for a healthy group dynamic, especially in the context of the emotional nature of this work (Kearns *et al.* 2020; Lindblom *et al.* 2021; van Rooijen *et al.* 2021). A co-design contributor with disability shared, 'I think it's important to be open-minded – How should I put it? – that one is open. Everyone seemed to be very open hearted in all regards. Of course, I also opened up and they opened up as well' (Lindblom *et al.* 2021).

Theme 3: an unfamiliar process

The final theme, an unfamiliar process, describes the underpinning experience of ambiguity and uncertainty with co-design (Harrison and Palmer 2015; Revenäs *et al.* 2018; Abma 2019; Kearns *et al.* 2020; Lindblom *et al.* 2021; van Rooijen *et al.* 2021; Carminati *et al.* 2024). Co-design was a new experience for most participants across all the reviewed studies. Co-design contributors with disability, significant others and healthcare workers reported being unsure how to contribute, and a desire for increased clarity regarding roles and responsibilities. Both co-design contributors and facilitators expressed difficulties with implementing or participating in a new process (Revenäs *et al.* 2018; Abma 2019; Lindblom *et al.* 2021). For example, a significant other reflected, 'What I found hard to understand was the process itself that she had drawn up and discussed' (Lindblom *et al.* 2021) and one facilitator reported, 'There is some concern among both the project team and participants about where we are headed' (Revenäs *et al.* 2018). Co-designers stated that they felt challenged and fatigued by workshop tasks due to limited experience or training with the methods, whereas facilitators reflected on the challenges of selecting appropriate methods for participant engagement (Revenäs *et al.* 2018; Abma 2019; Lindblom *et al.* 2021). A significant other shared, 'I'm not in the swing of this and it might be difficult for us as family members who might not have the training either' (Lindblom *et al.* 2021).

Co-design contributors also experienced a 'clash of identities' regarding their role within the design process (Harrison and Palmer 2015; Revenäs *et al.* 2018; Abma 2019; Lindblom *et al.* 2021; van Rooijen *et al.* 2021). For co-design contributors

with disability and family members, this consisted of challenges understanding the purpose of workshops, and wanting to contribute beyond their lived experience, but feeling limited by their content knowledge (Kearns *et al.* 2020; Lindblom *et al.* 2021). Additionally, for significant others and healthcare workers, there was uncertainty about whether to contribute their own experience, or to focus on supporting co-design contributors with disability to participate (Lindblom *et al.* 2021; van Rooijen *et al.* 2021). As shared by one healthcare professional, 'I haven't felt like I've been on equal terms as I haven't known what you want me to do – should I help the patient as a member of staff or should I focus on my task as a participant' (Lindblom *et al.* 2021).

Optimising co-design participation

The thematic analysis and data charted from the included studies revealed important reflections, strategies and lessons learned on how to best optimise co-design participation. The four main challenges to co-design participation were identified as: (1) group dynamics, (2) role ambiguity, (3) time, and (4) accessibility. Some common strategies to overcome these challenges were to have separate, smaller focus groups for co-researchers with disability, facilitators providing an overview of the responsibilities before each session, adopting an iterative and flexible approach to the design of workshops, and providing information and activities in various multimedia forms. See Table 4 for more detail on the strategies used to optimise co-design.

Discussion

This scoping literature review sought to better understand when and how co-design is used with adults with acquired neurological disability, and the lived experience of participation. Although the search retrieved several studies using co-design with adults with acquired neurological disability, less than half of the studies included an evaluation of the experience of participating in co-design, highlighting a gap in research evidence. Consistent with literature reviews on the use of co-design with a stroke population (Dobe *et al.* 2022; Singh *et al.* 2024), data extracted across the included studies showed variability in the definition and implementation of co-design, such as use of guiding frameworks, structure of the co-design and role definition. There was also little reference to considerations for inclusive practice with people with cognitive and communication difficulties, despite the population of focus being adults with neurological disability. Although thematic analysis of the lived experience affirmed co-design as a valued and meaningful experience, co-design contributors described the experience to be unfamiliar and at times challenging, with an identified need for better role clarity. Accordingly, findings from this review contribute to an emerging body of research evidence to inform the design, delivery and evaluation of co-design with adults with acquired neurological disability.

Across the 45 included studies, there was a range of reasons identified for using co-design with adults with acquired neurological disability living in the community. Most of the studies sought to develop an intervention, such as an exercise or self-management program to support community participation, such as reducing sedentary behaviour at home (Bodilsen *et al.* 2023) or re-building social or leisure activities (Masterson-Algar *et al.* 2020). A smaller number of studies involved the co-design of surveys and practical resources, whereas fewer still sought to co-design knowledge frameworks to inform PPI in research (Harrison and Palmer 2015; Abma 2019; Lamontagne *et al.* 2021; Charalambous *et al.* 2022). Despite this variability, the included studies had a shared aim of using co-design to create outcomes that are informed by, and thus better meet the needs of, the target user. This shared aim aligns with increasing expectations for consumer participation in disability research and service development (Greenhalgh *et al.* 2016; Slattery *et al.* 2020; Dobe *et al.* 2022; Singh *et al.* 2024). However, a surprising finding from this scoping review is the lack of studies that included an evaluation of the co-design. Given the emerging nature of co-design with this population (Fusco *et al.* 2020; Dobe *et al.* 2022; Singh *et al.* 2024), and the lack of familiarity with co-design as evidenced by this review, evaluation would offer valuable insights to inform the development of best practice. In addition to evaluation of the accessibility and usefulness of co-design outcomes, such as interventions and resources (Dobe *et al.* 2022), evaluation of the lived experience of participating in co-design, particularly from the perspective of contributors with disability, is critical to tailoring co-design approaches to the needs of people with neurological disability. Without such evaluation, there is a risk of conducting 'tokenistic' co-design that is not informed by a genuine need of the target population, nor implemented in a way that is accessible and has real world impact upon the lives of people with acquired neurological disability.

Examining the operationalisation of co-design reported across the included studies demonstrated variability in approaches and, in some instances, limited description of 'how' the co-design was conducted. Although studies referenced the use of frameworks, such as the Double Diamond model of co-design (Design Council 2004), user-centred and participatory designs (Greenhalgh *et al.* 2016), there were no guidelines specific to co-designing with people with neurological disability. The lack of guidelines for using co-design with this population (Dobe *et al.* 2022; Singh *et al.* 2024) may explain the variability found across the included articles. Consistent with the findings of previous reviews exploring co-design with adults with the stroke population (Dobe *et al.* 2022; Singh *et al.* 2024), there was also variability regarding the level of involvement of co-design contributors with disability. Although the co-design projects were informed by lived experience, often gathered through

Table 4. Challenges and strategies to optimising co-design engagement.

Challenges to co-design engagement	Description of challenge	Reflections of co-design contributors with disability	Reported strategies for co-design engagement
Group dynamics	Unbalanced group dynamics between stakeholders may lead to unequal participation and feelings of inferiority. Managing group size, diversity of stakeholders, and differences in perspectives is crucial for equal participation	• Favoured smaller focus group discussions as it allowed rapport and familiarity with each co-researcher to develop • Desire for more social breaks to help build rapport between group members	• Separating focus groups into same demographic groups (e.g. only PwD in one group, close others in one group etc.) to reduce power imbalances, and bringing all group reflections together at the end of the process • Equally balanced co-researcher in each group to ensure one type of co-researcher is not overshadowed • Small and consistent groups throughout all workshops to facilitate discussion & build rapport • 1:1 meeting with each co-researcher before meeting in a group setting to help build rapport and understanding of the role • Icebreaker activities at the start of each group sessions to facilitate group bonding between the co-researchers • Limiting focus groups sessions to 90 min maximum
Role ambiguity	Unclear roles and responsibilities for members involved in co-design results in being unsure on how to contribute, confusion regarding purpose of co-design and feeling limited by personal content knowledge.	• Wanting a skilled facilitator of co-design to help understand and guide the direction of tasks • Attending workshops consistently to understand key responsibilities	• Facilitators to explain research & design process thoroughly before starting workshops • Providing concrete plan and tasks for each session • Verbal & written summaries of each workshop • Facilitator being assigned to PwD to support during workshops • Using colour-coded notes throughout workshop process to help provide a sense of continuity through the co-design process • Skilled facilitator trained in the content topic and in co-design
Time commitment	Co-design can be a timely process and a significant commitment. A delicate balance of having enough time before and during the workshops is needed to enable equal contribution and preparation.	• Mixed preference of longer vs shorter workshops; however, it was consistently noted that having enough time in workshops was important to facilitate discussions • Prefer flexible and dynamic workshop approaches, with the session and frequency length being adaptive	• Facilitators provided extra time, patience and re-prompting when needed • Creating materials and information sheets to give to co-researchers prior to workshops to help them prepare before the focus groups • Workshops sessions were an iterative process and should be changed when necessary

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Table 4. (*Continued*)

Challenges to co-design engagement	Description of challenge	Reflections of co-design contributors with disability	Reported strategies for co-design engagement
Accessibility	Understanding the cognitive and communication needs of people with acquired neurological disorders is important for optimal engagement. It is important to tailor the content and delivery of workshops in an accessible manner	• Ensuring the physical location of the workshops were accessible (including the building itself, tables, chairs etc.) • Organised logistics of meetings (e.g. transportation options) • Providing accessible and relevant content to aid in participation • Allowing more time for breaks to combat tiredness • Having more frequent check-ins from the facilitators during the workshops	• Providing a range of multi-media (e.g. verbal, written, illustrative, videos etc.) information and content to cater to all communication & cognitive needs • Using supported conversation techniques • Using content that has been formatted to user-guidelines (e.g. stroke association or deemed 'aphasia friendly') • Allowing participants to communicate via visual-analogue scales, ranking tasks, artist illustrations and photo-diaries • Having facilitators from various background that have experience working with complex communication & cognitive needs • Facilitators monitoring for signs of fatigue or emotional distress, and encourage co-researchers to take a break when needed • Piloting focus group questions and tasks with a test group to ensure content is suitable and accessible, before undertaking the focus groups with the co-researchers • Having communication partners independent of the research paired with the co-research to support communication and engagement • Use of speciality facilitation techniques, such as 'World Cafe' or Liberating Structures • Workshop outline shared 1 week before workshop sessions and welcome video to encourage open sharing

Note: the information from the above table was extracted from the following studies (Harrison and Palmer 2015; Mc Menamin *et al.* 2015; Hammond *et al.* 2016; Revenäs *et al.* 2018; Abma 2019; Herbert *et al.* 2018; Hall *et al.* 2020; Kearns *et al.* 2020; Lamontagne *et al.* 2021; Lindblom *et al.* 2021; van Rooijen *et al.* 2021; Wray *et al.* 2021; Charalambous *et al.* 2022; Cruice *et al.* 2022; Gauthier-Beaupré *et al.* 2022; Grosjean *et al.* 2022; Quilico *et al.* 2022; Bodilsen *et al.* 2023; Carminati *et al.* 2023; El-Helou *et al.* 2023; Harpham *et al.* 2023; Haynes *et al.* 2023; Miao *et al.* 2023; Anemaat *et al.* 2024; Carminati *et al.* 2024; Fasching *et al.* 2024; Johnson *et al.* 2024; O'Callaghan *et al.* 2024; Pogrebnoy *et al.* 2024). PwD, people with disability.

literature reviews or qualitative data collection, such as research interviews or focus groups, the co-design contributors were not involved in the initial conceptualisation of the co-design projects. A notable exception in this review was a small number of studies in which people with acquired neurological disability were employed as co-researchers at the commencement of the project and were involved in shaping and implementing the co-design project (i.e. Mc Menamin *et al.* 2015; Kearns *et al.* 2020; Haynes *et al.* 2023). The choice of guiding framework also influenced the level of involvement of co-design contributors; for example, studies that were informed by user-centred design often engaged people with disability as consultants at the latter stage of projects (Hammond *et al.* 2016; Marier-Deschênes *et al.* 2021), whereas articles that referenced participatory frameworks more actively engaged co-designers earlier in the co-design process (Kearns *et al.* 2020; Wannheden and Revenäs 2020; Lindblom *et al.* 2021).

There was also a lack of reporting of the involvement of co-designers with cognitive and communication disability. Furthermore, despite cognitive and communication difficulties being a frequent sequela of neurological disability (Ponsford *et al.* 2012), only a few studies (i.e. Pogrebnoy *et al.* 2024) detailed the use of strategies, such as small groups, visual cues and supported facilitation. This is an important consideration given the frequent exclusion of people with cognitive and communication difficulties, such as those with aphasia, and concerns about this perpetuating in co-design (Hersh *et al.* 2021). Thematic analysis of the lived experience data revealed the importance of strategies for the authentic inclusion of co-designers with disability. Co-design contributors reflected upon the accessibility of their participation, noting that longer and more frequent workshops allowed them more time to meaningfully contribute; however, also increased their fatigue and feelings of exhaustion post-workshop (Kearns *et al.* 2020; Wannheden and Revenäs 2020; Lindblom *et al.* 2021). Furthermore, they expressed a desire for greater involvement in the co-design, but described a lack of skills, experience and confidence associated with contributing in this manner, necessitating practical support and training (Kearns *et al.* 2020; Wannheden and Revenäs 2020; Lindblom *et al.* 2021; Wray *et al.* 2021). Accordingly, and consistent with other studies (Dobe *et al.* 2022; Singh *et al.* 2024) the co-designers emphasised the importance of the role of the facilitator to support their meaningful participation in the co-design. They expressed a preference for facilitators trained in delivering co-design in an accessible manner and empathic to the needs of co-designers with disability (Revenäs *et al.* 2018; Kearns *et al.* 2020; Lindblom *et al.* 2021; van Rooijen *et al.* 2021). Providing sufficient structure as a facilitator without overshadowing the involvement of the co-design contributors is a difficult balancing act that runs the risk of further perpetuating power imbalances between facilitators and co-design contributors (Singh *et al.* 2017; Dobe *et al.* 2022). Reflections from facilitators revealed that facilitating co-design was 'tough' and 'tiring', and that they were often preoccupied by considering whether the tasks were appropriate and accessible for co-design contributors with disabilities (Revenäs *et al.* 2018; Kearns *et al.* 2020). In line with this finding, a recent paper by (Hersh *et al.* 2021) suggested the integration of 'element zero' as a preparation phase to support role clarification, relationship building and accessibility planning for PPI projects with adults with aphasia. Such a process could better support the involvement of people with acquired neurological disability, particularly those with cognitive and communication difficulties, in co-design.

Although many of the studies did not include an evaluation of the lived experience of participating in co-design, thematic analysis of the available data revealed valuable insights. Co-design contributors with disability shared reflections on the opportunity to build social connections and learning from peers through sharing their lived experiences in co-design (Abma 2019; Hall *et al.* 2020; Kearns *et al.* 2020; van Rooijen *et al.* 2021; Wray *et al.* 2021; Carminati *et al.* 2024). For some, this experience contributed to a developing awareness and understanding of their own disability, in addition to a stronger sense of belonging and connection with others with a shared purpose. This finding supports the proposition that co-design presents potentially underutilised opportunities for building social connectedness following acquired neurological disability, contributing to improved community integration (Bould and Callaway 2021; D'Cruz *et al.* 2021; Halvorsrud *et al.* 2021; Dobe *et al.* 2022). Although at times it may be challenging due to time constraints, researchers and health professionals are encouraged to include supported opportunities for building social connections through co-design, such as the use of familiarisation activities, social breaks and time factored into sessions for sharing lived experiences. Additional positive outcomes of co-design were observed across several studies. These benefits included positive relationship building between co-researchers with disability and health professionals or researchers, and opportunities for learning about the research and healthcare context, thus strengthening the influence of people with disability within the sector (Revenäs *et al.* 2018; Abma 2019; Hall *et al.* 2020; Kearns *et al.* 2020; van Rooijen *et al.* 2021; Wray *et al.* 2021; Carminati *et al.* 2024).

Limitations

Althogh the findings from the review provide new insights into using co-design with people with acquired neurological disabilities, some limitations are present. First, the current review's sample is skewed towards people living with acquired brain injury, including stroke, with fewer studies including the perspectives of co-designers with neurodegenerative conditions. Given the differences in disease progression and impairments between acquired brain injury and neurodegenerative disabilities, the findings may not

generalise to this cohort. Moreover, despite an inclusion in the eligibility criteria, few studies included co-design contributors with significant cognitive and/or communicative difficulties, further reducing the generalisability of the findings. It is important for future research to explore the current findings and consider how to best use co-design with cohorts such as those with neurodegenerative disabilities or severe functional impairments.

In addition, the lack of consistency in use of definitions and reporting of the operationalisation of co-design throughout the literature acts as a limitation. It is possible that some relevant studies may have been missed in the screening process, thus impacting the breadth and accuracy of the findings relating to the operationalisation of co-design. To inform the development of best practice approaches to co-designing with people with neurological disability, future authors are encouraged to better define and report on the operationalisation of co-design used in studies. Moreover, it is important to acknowledge the dominant contribution of studies included in this review from Western continents, namely Europe and North America. In addition, this review was limited to studies published in English. There is a need to broaden the cultural context in which co-design is conducted and evaluated to ensure cross-cultural sensitivity and inclusion.

Conclusions

Although co-design is becoming more common practice within disability research and service development, its operationalisation with people with acquired neurological disability is underresearched and underutilised. This review demonstrated that engaging in co-design for people with acquired neurological disabilities is an unfamiliar yet meaningful process. Involvement in co-design enabled greater community participation, social connectedness, a sense of belonging and learning. The ambiguous nature of co-design can be accredited to a lack of consistent guidelines on how to best facilitate and support participation in co-design with people with acquired neurological disabilities. Findings from this review highlight the benefits of co-design and support the continued use and evaluation of co-design to build the research evidence. The development of clear methodological guidelines and the use of consistent terminology and definitions of co-design is also required to ensure authentic engagement. To our knowledge, this is the first scoping review to synthesise the literature regarding the use of co-design with adults with an acquired neurological disability living in the community. Future research should explore the long-term outcomes, opportunities and impact that co-design can have for people with acquired neurological disabilities, as well as evaluate the usefulness of resources/outputs co-designed with, and for, people with disability.

Supplementary material

Supplementary material is available online.

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