

# BMJ Open Co-designing with adults with acquired neurological disability in the community: a scoping review protocol

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## ABSTRACT

**Introduction** Co-designing healthcare research and health services is becoming increasingly prominent. Co-design invites people with disability to leverage their lived experience knowledge to improve service provision, as well as ensuring meaningful and relevant research. Given the emerging nature of the use of co-design with adults with neurological disability, well-defined guidelines on best practice are yet to be developed. The aim of this scoping review is to synthesise available peer-reviewed literature which investigates the use of co-design in research and/or service development with adults who have an acquired neurological disability and live within the community. The findings of this review will help to guide future co-design practice, ensuring people with acquired neurological disability are best supported and engaged in the process.

**Methods and analysis** This review will follow methodology proposed by Arksey and O'Malley and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis: Extension for Scoping Reviews. Systematic electronic database searches will be conducted between the years 2000 and 2022, via MEDLINE, CINAHL, PsycINFO, Scopus and Embase. Article screening and selection will follow the five-stage framework of Arksey and O'Malley, using Covidence software to support review of each retrieved article by two independent reviewers. Final selected qualitative and/or mixed-methods studies that meet the inclusion criteria will be charted, data collated, summarised and reported. Thematic synthesis will be applied to the qualitative data extracted from these studies.

**Ethics and dissemination** Ethics approval will not be required to conduct this scoping review. It is the authors' intention for the findings of this scoping review to be made available to relevant stakeholders through open-access peer-reviewed publication and disseminated with other healthcare and research networks via translation pieces, including the development of short video summaries and practice resources.

## INTRODUCTION

In recent years, there has been a shift in healthcare research, design and service delivery to include the expertise of end-users through the process of co-design.<sup>1</sup> With roots in community development, business, design and technology,<sup>2</sup> in the healthcare context,

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Co-production and coauthorship with people with lived experience of disability is a strength of this review.
- ⇒ All studies will be double screened by two reviewers at title, abstract and full text.
- ⇒ All included studies will be critically appraised using the Critical Appraisal Skills Programme tool.
- ⇒ Thematic synthesis of qualitative data will provide insights into the lived experience of co-design participation.

co-design closely aligns with the implementation of best practice person-centred approaches to consumer engagement.<sup>3</sup> Co-design invites health service users to leverage their lived experience knowledge to improve service provision, as well as ensuring meaningful and relevant research. Central to co-design is the collaborative partnering between professionals (eg, researchers, policymakers, health professionals) and end-users (ie, people who are directly affected by such policy, research outcome or healthcare service) to create improved health outcomes for the end-user population.<sup>2 4 5</sup> While the term co-design is widely used to describe this process of collaborative engagement between professionals and end-users, other terms evident across healthcare literature include co-production, co-creation, user-centred design and participatory action research.<sup>6</sup> In addition, there is a broad spectrum of co-design engagement ranging from brief consultations to longer-term partnerships, as evidenced in a range of co-design frameworks used broadly in healthcare.<sup>7</sup> Despite a lack of consensus on the definition and parameters of co-design engagement, co-design is increasingly recognised as critical to improved health service provision and impactful research.<sup>1 7 8</sup> As evidenced by Trischler *et al*,<sup>9</sup> co-designed services result in higher service user benefit and originality compared with services

created solely by people with lived experience or health professionals independently. Importantly, co-design also creates unique opportunities for people from diverse populations to contribute to meaningful work that has a direct and positive impact on their lives. Such populations in which co-design is becoming increasingly popular include people with complex health needs, including people with acquired neurological disability.<sup>2</sup>

Acquired neurological disability is an umbrella term that is used to define sequelae of physical, cognitive and communication difficulties that result from cerebral injury (eg, acquired brain injury (ABI), traumatic brain injury (TBI), stroke) or disease (eg, multiple sclerosis (MS), Huntington's disease, Parkinson's disease).<sup>10</sup> The physical, cognitive and communicative impairments experienced by this population include—but are not limited to—symptoms, such as dysphasia (difficulty expressing and understanding spoken and written language), dysarthria (disturbance of muscular control of the speech mechanism), dyspraxia (difficulty programming skilled movements) and cognitive impairment, such as difficulties processing verbal and/or non-verbal information, as well as reduced memory, attention, planning and problem-solving skills.<sup>10</sup> The complex interplay between such physical, cognitive and communication impairments impacts participation in everyday activities of people living with acquired neurological disability, including opportunities for meaningful paid and unpaid vocational engagement.<sup>11</sup> Indeed, it is recognised that the acquired nature of such impairments has a profound impact on the experience of daily life and change in sense of self, from pre/post-disability resulting in an often lifelong process of adjustment and community re-integration.<sup>12 13</sup> Involvement in occupational, educational and recreational activities is vital to maintaining overall health and quality of life and can aid in the process of community integration and increase an individual's sense of belonging.<sup>14</sup> However, the often limited community and vocational opportunities available for people with acquired neurological disability exacerbate their segregation from the wider community, leading to feelings of social isolation, and thus, reduced quality of life.<sup>15–17</sup> From a rehabilitative perspective, D'Cruz *et al*<sup>18</sup> propose that co-design may create an opportunity for people living with ABI to experience social connectedness, which has the potential to mitigate feelings associated with social isolation.<sup>17</sup> Other researchers have agreed with this notion<sup>2 19</sup> and have recognised the underused opportunities that co-design offers, such as the opportunity to engage in community and employment opportunities, as well as improve health-promoting behaviours, self-efficacy,<sup>19</sup> and physical and mental health outcomes.<sup>20</sup>

Notwithstanding the opportunities that co-design offers for people with acquired neurological disability, and the importance of incorporating the lived experience perspective into research and service development, there are few guidelines on how to best implement co-design with people with acquired neurological disability.<sup>2</sup>

This lack of guidance results in potential ambiguity regarding role definition and level of involvement, particularly in the context of people with associated cognitive and communication difficulties.<sup>21</sup> The lack of clarity surrounding the level of engagement required from people with acquired neurological disabilities can result in tokenistic involvement, as Slattery *et al*<sup>22</sup> found that minimal participation required from healthcare patients in co-design research led them to feel frustrated, unheard and unvalued. However, commitment to greater responsibility within the co-design process (eg, shared leadership) may not always be plausible, due to compounding issues of fatigue, support needs and time constraints associated with managing a complex disability.<sup>21</sup> The potential risk of co-design reinforcing inequality across health service users and providers must be acknowledged, as both Lindblom *et al*<sup>21</sup> and Dobe *et al*<sup>9</sup> demonstrate that patients who had a stroke involved in co-design stated there was hierarchical power imbalance between themselves and the researchers, which often led them to feel inferior in the decision-making process and further marginalised. Although co-design presents with a multitude of potential benefits for people with acquired neurological disabilities, it is important to understand how and when to effectively use co-design, to ensure that this population is not at risk of further alienation and decreased well-being.

Taken together, the current evidence base provides preliminary insights into the use of co-design with adults with an acquired neurological disability. However, to our knowledge, there is yet to be a review which comprehensively synthesises the literature regarding how and when co-design is used in research and/or service development with people with acquired neurological disability living in the community. While other reviews have explored the use of co-design with stroke survivors<sup>2</sup> and healthcare patients more generally,<sup>22</sup> these reviews have been conducted in hospital or rehabilitation settings. Moreover, scoping review methodology allows for the presentation of a broad overview of the literature on the use of co-design, which will provide further clarity to the ambiguous concepts, labels and definitions associated with current co-design practices. This knowledge will help formulate recommendations regarding quality practice when using co-design with people with acquired neurological disability, as well as identify social, vocational and other community-based opportunities that co-design offers.

## METHODS AND ANALYSIS

The scoping review method will be informed by methodological guidelines outlined within the literature for scoping reviews<sup>23–25</sup> with reporting guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis: Extension for Scoping Reviews (PRISMA-ScR).<sup>26</sup> In conducting this review, the authors will follow the five stages proposed by Arksey and O'Malley<sup>23</sup>: (1) identifying the research question; (2) identifying

relevant studies; (3) study selection; (4) charting the data; and (5) collating, summarising and reporting the results.

### Identifying the research question

The aim of this scoping review is to synthesise available peer-reviewed literature which investigates the use of co-design in research and/or service development with adults who have an acquired neurological disability and live within the community. The central question guiding this review is: When and how is co-design used with adults with acquired neurological disability living in the community? Through investigating this question, the authors aim to:

- ▶ Collate information about the use of co-design with this population (definitions and operationalisation of co-design, facilitation roles).
- ▶ Identify the barriers and enablers to co-designing with this population.
- ▶ Understand the lived experience of participating in co-design.

### Identifying relevant studies (developing the search)

The search strategy has been developed by the authors of the review in consultation with an expert librarian. Preliminary searches of the MEDLINE database enabled refinement of the search strategy and search terms. Two broad concepts were applied to the search: (1) acquired neurological disability (eg, terms such as traumatic brain injury, stroke, multiple sclerosis) and (2) co-design (eg, terms such as co-creation, co-production, collaborative design, participatory design). The keywords contained in the titles and abstracts of relevant articles, as well as index and search terms, were used to inform the development of suitable search terms for the concept of co-design. Consistent with the aims of a scoping literature review, a range of terms were selected to maximise the search yield. The terms within the concepts were combined with the Boolean operator 'OR', with the two broad concepts combined using the Boolean operator 'AND'. This initial search, prior knowledge of the area and already known peer-reviewed literature aided in providing additional keywords and further search terms to include (see online supplemental appendix 1 for full MEDLINE search including all terms used). Medical Subject Heading (MeSH) term structures were also used to check broader terms related to the concepts of acquired neurological disability (eg, brain injuries) and co-design (eg, co-develop). These additional search terms were added to the search strategy and iteratively tested on MEDLINE by monitoring the yield and relevancy of the search results. After reviewing the relevancy of the additional search terms, decisions were made to only include certain MeSH terms related to acquired neurological disability and co-design. Thus, the search strategy will combine the two broad concepts to identify relevant literature. Systematic and comprehensive electronic database searches will be conducted on MEDLINE, CINAHL, PsycINFO, Scopus and Embase. The search terms will be adapted for use

with each database. The reference lists of all eligible studies will be examined for relevant literature.

### Study selection

#### Eligibility criteria

To be eligible for inclusion, studies must be written in the English language, peer reviewed, have primary extractable research data and have been published since the year 2000. This time frame, consistent with other reviews of co-design in healthcare, will enable a comprehensive search of the literature, while also recognising the emerging nature of co-design in this context. The search will be limited to qualitative studies or mixed-methods studies in which qualitative data can be extracted to enable exploration of the subjective lived experience of participating in co-design. Alternative texts such as grey literature and conference proceedings will be excluded as they do not satisfy the peer-reviewed criteria. The a priori inclusion and exclusion criteria are detailed below. While the retrieved papers must include co-design engagement with people with acquired neurological disability, consistent with the above identified questions guiding this scoping literature review, the perspective captured in the data may include people with disability, close others, health professionals and researchers.

#### Inclusion criteria

- ▶ *Population*: adults (18–65 years) who have an acquired neurological disability (eg, ABI, stroke, MS, TBI, Parkinson's disease and Huntington's disease) and live in the community. For the purpose of this review, living in the community is defined as being inclusive of people living independently with or without support, with family and/or friends, in shared accommodation, group homes or residential aged care. People participating in outpatient rehabilitation or community-based rehabilitation will be considered eligible given that they reside in one of the community-based living options.
- ▶ *Concept*: studies that use any type of co-design practices (eg, ranging from brief consultations to long-term partnership) with people with acquired neurological disabilities, within a research and service development context, inclusive of terms such as co-creation, co-production, collaborative design, participatory design.
- ▶ Peer-reviewed qualitative or mixed-methods articles with extractable primary research data.
- ▶ English language studies published since 2000.

#### Exclusion criteria

Studies that involve participants who are below the age of 18 years, above the age of 65 years, who reside in hospital (ie, acute inpatient or rehabilitation settings), or who have obtained an acquired neurological disability resulting from a brain tumour or cerebral palsy will be excluded. These diagnostic groups have been excluded due to differing disability experiences and/or disease progression (ie, brain tumour: widely variable prognosis; cerebral palsy: most common

early childhood onset motor disability) from the broader acquired neurological disability population.

### Screening

Following the literature search, all identified citations will be collated and managed in Covidence, with duplicate citations removed. For the title and abstract screening, all the identified citations will be independently double screened by two reviewers (RR and SA) for assessment using the predefined inclusion criteria, with the principal reviewer evaluating all citations. Any uncertainties related to the study selection will be discussed by the reviewers during the screening process, with the search strategy to be edited if necessary.

All full-text articles that meet the inclusion criteria following the title and abstract screening will be retrieved. To ensure that all full-text articles have been evaluated by two reviewers, a principal reviewer will examine all full-text articles, with two additional reviewers independently examining half of the full-text articles each. Any discrepancies that arise regarding further inclusion will be discussed, with the eligibility criteria being tightened if needed. If agreement cannot be reached, disagreements will be resolved via consultation with a fourth reviewer. If agreement still cannot be reached, the article will be included. The reference list of the included full-text studies will be searched to retrieve further relevant citations. The study selection process and number of studies at each stage will be displayed using the PRISMA flow diagram.<sup>27</sup>

### Charting the data (data extraction)

Data extraction will be performed on the included articles by two or more independent reviewers and checked by a third reviewer. A data extraction form developed by the reviewers will be used to chart the data and will be revised throughout the screening process to ensure it adequately addresses the research questions and eligibility criteria. The data extraction tool will include details related to (1) study characteristics: author, study year, study design, methodology and measures; (2) participant characteristics: population (type of acquired neurological disability), reported cognitive and/or communication difficulties, demographics (age, gender) and living status (eg, shared home, living independently with/without support, living with friends/family, residential aged care, community-based rehabilitation); (3) co-design characteristics: definition of co-design and associated terms, participation/facilitation roles of people with disability, stakeholders (eg, healthcare professionals, researchers), context of co-design use (eg, service development and/or research), and enablers and barriers to co-design engagement.

Critical appraisal of the individual sources of literature will be conducted using the Critical Appraisal Skills Programme—Qualitative Studies Checklist to assess the methodological rigour of the sources of evidence. As recommended by the PRISMA-ScR checklist of scoping reviews,<sup>26</sup> the results of this quality and relevance assessment will be reported and available as an online supplemental file to the scoping review.

### Collating, summarising and reporting the results

To guide the collating, summarising and reporting of the results, the PRISMA-ScR checklist for scoping reviews will be used.<sup>26</sup> A descriptive summary of the scoping review including the number of citations screened, and the amount of included and excluded studies at each stage, will be presented in a PRISMA flow diagram. Furthermore, in alignment with the scoping review guidelines proposed by Arksey and O'Malley,<sup>23</sup> a summary of the key characteristics (study, participants, co-design definition, facilitation, enablers and barriers) will be presented in a table format in conjunction with a high-level summary of the key characteristics in text.

Qualitative data (reported findings and participant quotes) extracted from the included qualitative studies and qualitative findings of mixed-methods studies will be analysed using thematic synthesis. Thematic synthesis will follow the three stages proposed by Thomas and Harden<sup>28</sup>—stage 1: free coding of the findings of primary studies; stage 2: the organisation of 'free codes' into related areas to construct 'descriptive themes'; and stage 3: the development of 'analytical themes'. This process of thematic synthesis will provide insights into the lived experience of participating in co-design, ensuring that the findings are grounded in the experiences of the participants in the retrieved studies. Knowledge generated about the lived experience of co-design will address evidence gaps in the use of co-design with adults with neurological disability. If there is insufficient literature for a thematic synthesis, the findings will be charted and reported in a written summary.

### Patient and public involvement

People with lived experience of an acquired neurological disability will be invited to evaluate, review and contribute to the current protocol and upcoming scoping review, to ensure that the research questions, design, content, and findings are relevant and meaningful to people with disability. People with an acquired neurological disability will be employed as a paid consultant (paid by their preferred method of gift card or monetary bank payment) via Summer Foundation's and La Trobe University's Living with Disability Research Centre's existing networks. We aim to recruit at least three paid lived experience consultants, with a range of disability and life experience to contribute to this project. The protocol and scoping review will be sent electronically to the consultant(s), enabling them to edit/contribute to the drafts at their own speed and in their location of choice. The lived experience consultants will be invited to discuss their evaluation of the drafts with the research team and are encouraged to provide feedback on all aspects of the protocol and scoping review. Overall, this review process will help to inform the interpretation and dissemination of the findings while identifying further gaps in the literature.

### ETHICS AND DISSEMINATION

Ethics approval is not required for this scoping review. The aim of this scoping review is to synthesise available peer-reviewed literature which investigates the use of co-design

in research and/or service development with adults who have an acquired neurological disability and live within the community. To the best of our knowledge, this will be the first systematic scoping review to map the use of co-design in research and/or service development within a population of people with acquired neurological disability living in the community. The findings of this review will help to guide future co-design practice, ensuring people with acquired neurological disability are best supported and engaged in the process. It is the authors' intention for the findings of this scoping review to be made available to relevant stakeholders through a peer-reviewed publication, conference presentations and short video summaries.

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