



Physical Activity Preferences of People Living with Brain Injury: Formative Qualitative Research to Develop a Discrete Choice Experiment

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Abstract

Background and Objective The World Health Organization physical activity guidelines for people living with disability do not consider the needs of people living with moderate-to-severe traumatic brain injury. This paper describes the qualitative co-development of a discrete choice experiment survey to inform the adaptation of these guidelines by identifying the physical activity preferences of people living with moderate-to-severe traumatic brain injury in Australia.

Methods The research team comprised researchers, people with lived experience of traumatic brain injury and health professionals with expertise in traumatic brain injury. We followed a four-stage process: (1) identification of key constructs and initial expression of attributes, (2) critique and refinement of attributes, (3) prioritisation of attributes and refinement of levels and (4) testing and refining language, format and comprehensibility. Data collection included deliberative dialogue, focus groups and think-aloud interviews with 22 purposively sampled people living with moderate-to-severe traumatic brain injury. Strategies were used to support inclusive participation. Analysis employed qualitative description and framework methods.

Results This formative process resulted in discarding, merging, renaming and reconceptualising attributes and levels. Attributes were reduced from an initial list of 17 to six: (1) Type of activity, (2) Out-of-pocket cost, (3) Travel time, (4) Who with, (5) Facilitated by and (6) Accessibility of setting. Confusing terminology and cumbersome features of the survey instrument were also revised. Challenges included purposive recruitment, reducing diverse stakeholder views to a few attributes, finding the right language and navigating the complexity of discrete choice experiment scenarios.

Conclusions This formative co-development process significantly improved the relevance and comprehensibility of the discrete choice experiment survey tool. This process may be applicable in other discrete choice experiment studies.

1 Introduction

Physical activity has multidimensional benefits for individuals and society more broadly [1, 2], yet physical inactivity remains a global health problem causing 5.3 million deaths per year and costing healthcare systems billions worldwide [3]. Adults and children living with disability face greater barriers [4, 5] and are less likely to meet recommended physical activity levels compared with those living without disability [6, 7]. This places them at greater risk of serious health conditions [6] and compounds other forms of social disadvantage [8].

Traumatic brain injury (TBI) is a leading cause of long-term disability globally [9]. Adults and children who sustain a moderate-to-severe TBI often spend weeks or months in hospital with long periods of physical inactivity leading to reduced cardiorespiratory fitness [10]. When discharged from hospital, most people with moderate-to-severe TBI are independently mobile [11] yet continue to be less physically active in the community than their peers [12, 13]. This is likely due to barriers faced by people with TBI across multiple dimensions. Intrapersonal factors may include intense fatigue, motor impairments and depression, while anxiety about sensory overload, stigmatisation and falling can lead to a fear of leaving home [14–16]. Interpersonal factors include poor social support and community integration, often compounded by mood disorders and communication

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Key Points for Decision Makers

We undertook formative research with Australians living with moderate-to-severe traumatic brain injury to co-develop a discrete choice experiment survey about their physical activity preferences.

This process significantly enhanced the content and format of the survey, the results of which will be used to adapt World Health Organization physical activity guidelines to address the needs of people with traumatic brain injury.

Given that this formative development process is valuable yet often poorly reported, this paper describes it in sufficient detail for others to follow our process.

difficulties [17]. Institutional factors include inaccessible services and workplaces, with poor community awareness and support [18]. Lack of disability-specific physical activity information is a barrier for those living with TBI and for family members, carers and health professionals who seek to support them [19]. At the policy level, funding for appropriate programs and services is often lacking [13, 20, 21]. The COVID-19 pandemic has only exacerbated these barriers [4].

1.1 Study Overview and Aims

This study was part of a program of research conducted by the BRIDGES (BRain Injury: Developing Guidelines for physical activitiES) project. BRIDGES aims to increase physical activity by people living with TBI by adapting the 2020 WHO *physical activity and sedentary behaviour guidelines* [22] for this population's needs. These guidelines currently include recommendations for adults, children and adolescents living with disability and aim to “*facilitate ... practices that can reduce discrimination and create opportunities for inclusive physical activity participation and better health outcomes among this population*” [23]. However, no TBI-specific recommendations are included. There is a need for evidence-based clinical practice guidelines that can address the specific needs of people living with TBI, particularly for health professionals in services where managing TBI is not core business [24, 25].

To develop guidelines relevant to people living with moderate-to-severe TBI, it is crucial to understand their preferences for physical activity [21]. To this end, we will conduct a discrete choice experiment (DCE) survey to generate robust evidence about the preferences for community-based

physical activity in this population [26]. A DCE survey is a quantitative method underpinned by strong economic theory [27, 28] that is increasingly used in health research to identify and value people's preferences related to a product, service or program [29]. The preference results from DCEs can be used to modify existing clinical guidelines. For example, Janssen et al. [30] note that clinical practice guidelines on cancer screening tend to focus on both life expectancy and age; however, their DCE found that age was the most influential factor, independent of life expectancy. They conclude that guidelines should be modified to consider the value patients attach to continuing screening at younger ages, even when life expectancy is limited. Discrete choice experiment results can also support the implementation of guidelines by providing much-needed information about optimal resource allocation. Formative research to develop DCEs often generates rich data about the views and experiences that underpin patients' preferences, which can be used to inform patient/clinician consultations [31–33].

In a DCE, survey respondents choose between a series of hypothetical competing scenarios that contain several *attributes* that represent important characteristics of a product, service or program. Analyses can determine the most influential attributes and their relative value for decision making, including the extent to which participants are willing to trade-off between attributes (e.g. cost and travel time) in each scenario.

Discrete choice experiment attributes and levels must reflect values that are most important to the target population [34]. Formative work using qualitative methods is required to develop a rich understanding of people's personal ‘evaluation systems’. Tapping into expertise based on lived experience can generate insights into what attributes have most real-world importance, and why [34–36]. Qualitative methods are also most suitable for participative conceptual development and language refinement [36]. Qualitative data obtained from a purposeful sample of individuals can be used to inform the content of a DCE survey for a wider population [35].

This paper reports on a formative qualitative study of co-developing physical activity attributes for a DCE survey with people living with moderate-to-severe TBI. Attribute development is often inadequately reported, lacking detail for assessing rigour or for providing guidance for other researchers or broader methodological advancement [37]. More detailed reporting is called for [35, 36]. Here, we follow guidance by Hollin et al. [35] for reporting formative qualitative research in the development of quantitative health preference surveys. This guidance incorporates generic evaluative criteria for reporting qualitative research.

Table 1 Research stages and methods

Stages of research (goals)	Data collection methods	Data analysis methods
1. Identification of key constructs and initial expression of attributes	Review of the literature and iterative deliberative dialogue with stakeholders	Framework analysis
2. Critique and refinement of attributes	Focus groups with people living with TBI	Qualitative description
3. Prioritisation of attributes and refinement of levels	Focus groups with people living with TBI	Framework analysis
4. Testing and refining language, format and comprehensibility in the draft survey	'Think-aloud' interviews with people living with TBI	Framework analysis

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2 Methods

2.1 Theoretical Framework

In keeping with the ethos of the wider BRIDGES research program, this study adopted the pragmatic research paradigm, which is associated with producing actionable knowledge and promoting social justice [38]. It is informed by the social model of disability and its emphasis on enabling/disabling social structures and environments [39, 40]. We strove to align with the tenets of emancipatory disability research that aims to (1) include, and be accountable to, people living with disability and their organisations, and (2) produce findings that contribute to meaningful, practical and empowering outcomes for this population [41].

2.2 Research Team Characteristics and Reflexivity

The research team was a partnership involving academics with research interests in TBI and physical activity, consumer representatives (independent and from consumer organisations) with lived experience of TBI, health professionals with expertise in working with people with TBI, and an academic health economist with expertise in DCEs. The core team directly involved in data collection and analysis comprised experienced qualitative health researchers and researchers with clinical backgrounds in working with people with TBI. Focus group and interview participants were engaged as expert consultants.

Reflection on our research methods and emergent findings was facilitated via weekly meetings with the core team and periodic meetings with the wider investigator team. Frequent as-needed meetings with our DCE expert were used to explore complexities around translating participants' diverse meanings and experiences into reliable attributes and levels. In all discussions, those with lived and professional experience of TBI drew on their experiential knowledge.

2.3 Design

The research study was structured around four stages (Table 1) following guidance for DCE attribute development outlined by Janssen et al. [42, 43], Coast et al. [36] and Moor et al. [44]. Janssen and colleagues propose a five-stage model of evidence review, stakeholder engagement, qualitative attribute development, pretesting and pilot testing [42, 43]. However, we conceptualised these stages differently because stakeholder engagement was integral to the whole study. Additionally, our approach was guided by the emphasis Coast et al. place on high-quality *conceptual development* where the constructs underpinning the attributes are identified and narrowed into likely attributes, and *language refinement* where these constructs are translated into meaningful lay language and tested [36]. Moor et al. also include testing and refinement of the DCE format within the wider survey tool [44].

2.4 Recruitment

We recruited people living in Australia who had sustained a moderate-to-severe TBI. Participants had to be > 12 months post-injury with sufficient cognitive and language abilities to provide informed consent and participate in a focus group or interview either independently or with assistance from a support person. In keeping with guidance for DCE attribute development [35, 36, 45], we aimed for a purposive sample with maximum variation in age (10 years and over), geographical location (different Australian states/territories and rural/metropolitan), functional independence, time since injury and current physical activity levels.

We recruited via health and consumer organisations that specialise in working with people with TBI; via social media, newsletters and e-mail; and by leveraging existing networks between health professionals on the research team. A one-page flyer was used to prompt eligible people to contact the research team. People who expressed an interest in participating were asked screening questions and, if eligible,

were sent a participant information statement and invited to provide informed consent via e-mail. Consent for children aged 10–17 years to participate was given by each child and their parent/guardian. Parents/ guardians were invited to attend the focus group or interview if they and the child wished.

Consenting participants were asked to complete a short online survey that included questions about demographics, their injury, and current physical activity and functioning [46]. These data were used to inform the purposive sampling, to determine any special considerations for their research participation [47] and to inform data analysis, contributing to a better understanding of participant diversity.

Recruitment continued during initial analyses and ceased when the recruitment strategy was exhausted. At this point, we judged there were enough people overall, with a range of ages and from different geographical locations, to provide diverse viewpoints. This same pool of participants was invited to contribute to each stage of the research study.

2.5 Data Collection and Analysis

Three complementary data collection methods were used to generate triangulated data that would increase the validity of our findings and reduce the chance of missing important information [34, 48]:

1. A deliberative dialogue approach used in stage one and periodically throughout the study. This style of discussion was chosen for its emphasis on explicitly exploring assumptions and values, its accommodation of diverse views in problem solving, and its aim of guiding action [49].
2. Focus groups were selected for their ability to facilitate exploratory dialogue in which participants can build on ideas and compare views [50]. Focus groups are also effective at tapping into everyday forms of communication and thus were likely to generate (and critique) terminology for the DCE [51].
3. Think-aloud methods were used to test the survey because they facilitate expression of participants' thought processes in real time [52], and are especially useful for pretesting instruments that are complex and targeted at a group for whom survey completion may pose difficulties [53]. We adopted the collaborative approach recommended in usability research, which positions the participant as the expert and the researcher as a learner [54].

All focus groups and interviews were conducted via Zoom, allowing people to participate from diverse locations, including during COVID-19 restrictions. Previous research has shown that focus groups and interviews facilitated online

are accessible by a wide range of participants who experience minimal barriers with videoconferencing software or Internet connection [55, 56].

In focus groups and interviews, we adopted inclusionary strategies aimed at increasing meaningful participation by a wide range of people living with moderate-to-severe TBI, many of whom had communication difficulties and experienced other common characteristics of brain injury such as rapid cognitive fatigue. Strategies included small focus groups (four or fewer participants), which are less cognitively demanding and allow more time for each person to speak [47], limiting the groups to 90 min maximum with a break at 50–60 min, sending outline questions in advance and using the share screen function in Zoom to present possible attributes/levels for consideration. All participants were invited to ask a support person to attend the focus group or interview with them if they wished, so parents/carers were occasionally present in the background and offered their opinions or supplementary information if asked by the participant.

2.5.1 Stage One: Identification of Key Constructs and Initial Expression of Attributes

Using MEDLINE and papers already known to the research team, we conducted a review of the literature related to physical activity/recreation and brain injury to identify the range of issues likely to influence decision making about physical activity by people living with TBI (Supplementary file 1). Summaries of the literature were collated in a table and used to develop an initial list of 17 attributes, which was informed by ideas from the core research team and honed via deliberative dialogue with the wider investigator team. Dialogue was iterative and conducted by e-mail correspondence and Zoom meetings.

An ideal number of attributes for a DCE has not been identified as it depends on numerous factors relating to participants and context, for example, age, cognitive ability, perceived relevance of attributes, or familiarity of respondents with the choice context and attributes [57]. Systematic reviews of DCEs in primary healthcare and health economics have found the majority of studies use between four and nine attributes [58, 59], while fewer than ten are recommended to avoid respondent fatigue [44] and subsequent anomalous results [60]. This point was particularly important for our survey because of the cognitive challenges experienced by many people living with moderate-to-severe TBI. We were aiming for a final list of six attributes from the outset, while also recognising that this might not be possible if seven or more attributes were identified as essential. During stage one, some attributes were merged and others relegated, resulting in a list of nine items (eight attributes and one 'catch all' category). The results section provides

an overview of the evolution of attributes across all stages of the research.

2.5.2 Stage Two: Critique and Refinement of Attributes

Focus groups were used to critique and refine the list of attributes developed in stage one and ensure that no important concepts had been omitted [36]. A pilot focus group of consumer representatives living with TBI was held to trial the focus group questions and format. This group confirmed that most of the proposed content and our inclusion strategies were acceptable, but suggested some refinements to language and the presentation of the questions. We adopted their recommendations. The focus group for children and young adults living with TBI was developed and co-facilitated with a representative from a consumer group who works with this population, and the questions were simplified slightly for better comprehension.

Focus group participants were asked to engage in broad reflective discussion related to questions that targeted each attribute such as “*What type of physical activity would you ideally like to do?*” and “*How would the activity cater to your needs?*”, and were invited to comment on the attributes identified in stage one. This generated valuable information about the importance of each attribute and the possible range of levels, and reduced the attribute list to eight items.

Audio recordings of the focus groups were professionally transcribed and checked by the researcher leading the focus groups. Transcriptions were imported into NVivo for data management and coding, and the data were analysed using a qualitative description approach. This is a flexible, atheoretical and low inference method designed to inform health practice by providing “*a straight forward descriptive summary of the informational contents of data organized in a way that best fits the data*” [61 p.339]. Qualitative description is especially suited to studies that aim to decrease healthcare barriers for vulnerable populations [62].

Analysis focused on: (1) Immersion in the data to identify concepts and patterns in relation to our research aims, and coding these descriptively in relation to possible attributes, (2) Looking for and reflecting on the range of views expressed and commonalities and differences in the data, and reviewing codes in light of this information, (3) Gradually deciding on thematic categories that held true across the whole data set and (4) Examining the scope and salience of these categories critically in light of knowledge derived from stage one [62].

Analysis was led by one qualitative researcher, with a second qualitative researcher independently coding half the transcripts. Differences were discussed and reconciled in a final thematic overview of these data, which included a refined list of proposed attributes. This was used to inform analytic discussions with the wider research team, drawing

on their multidisciplinary and multi-experiential knowledge to critique and refine the attributes, forming a list of eight items with suggested levels [45].

2.5.3 Stage Three: Prioritisation of Attributes and Refinement of Levels

Three focus groups were conducted with the aim of refining the levels developed tentatively in stage two, exploring their content and terminology and incorporating any emergent concepts from the group discussion. This overlapped with stage two in that we continued to critique the wording and sought to reduce the number of attributes to minimise the cognitive burden for eventual survey respondents.

Participants were sent the list of eight attributes in advance of the focus group and asked to rank their top six in order of importance to physical activity decision making [32]. Their collated responses were presented to the group for discussion focusing on which levels would be most meaningful and how they should be expressed. Draft scenarios illustrating each group’s suggested attributes and levels were presented via a PowerPoint slide that was edited in real time using the share screen in Zoom. Some levels were swapped in and out to illustrate a range of options and prompt discussion about how these might affect participants’ choices.

These data were summarised in a simple matrix framework (ESM). Three researchers independently populated the framework, referring both to this data summary and the analysis conducted in stage two when proposing amended attributes and levels. These analyses were discussed with other members of the core research team, including our DCE expert. This resulted in a final agreed list of seven attributes, each with two or four levels.

2.5.4 Stage Four: Testing Language and Formatting in the Draft Survey

Using the attributes and levels identified in stages 1–3, we developed scenarios (DCE question ‘blocks’) containing different combinations that would be used randomly in the online survey [33]. These scenarios were inserted into a wider survey prototype that included the participant information statement, consent form, screening questions, questions about pre- and post-injury physical activity, current function and demographics. This was edited for readability using Hemmingway Editor [63]. The survey was developed in Microsoft Word following the proposed online format and saved as a PDF so that formatting would remain consistent when viewed on different devices (e.g. desktop computers, mobile phones, tablets).

Evolving versions of the survey were tested via ‘think-aloud’ interviews [54] with 15 participants who volunteered

for this in previous focus groups. We aimed to confirm that the participant information and instructions were clear and succinct, that questions were answerable and understood as intended, and to identify where modifications were required and what these should look like. Participants were encouraged to maintain a commentary while reading and answering the survey, but most favoured reading a short amount of text and then commenting on it (brief retrospective probing [64]). Participants were asked specific questions about clarity and cognitive demands, and about emergent issues identified in earlier interviews, for example, ‘Some people suggested we add [X category] to the list of options in this question. What do you think?’ (see the think-aloud interview guide in the ESM).

Interview data were summarised in a matrix framework comprising different parts of the survey (ESM) with additional columns for specific interview questions and miscellaneous comments. Problem areas and changes suggested by participants were marked via tracked changes in the survey document after every few interviews and were reviewed by the lead researcher who consulted with the wider research team as required to tap into specialist areas of expertise. For example, a question about levels of mobility was critiqued over several iterations of the survey, requiring input from a clinician so we could fine tune the question both for readability and clinical precision. Through this process, we tested seven iterations of the survey instrument and eight different DCE question block configurations. The final survey was also tested online for functionality by the research team and consumer representatives. The study received ethical approval from the Human Research Ethics Committee at the University of Sydney, reference 2022/088.

3 Results

Twenty-two people living with moderate-to-severe TBI participated in the formative development and testing of attributes and levels for the DCE survey, many of whom were involved throughout each stage of the process (Table 2).

3.1 Reducing Attributes

The research process reduced an initial list of 17 attributes to a final list of six attributes (Table 3), each with two or four levels (Table 4), which are now being used in a national DCE survey (ESM). Major changes in this list included the following:

- **Discarding attributes**, for example, *Dose (intensity and frequency)* was not identified by participants as important in their decision making about physical activity.
- **Merging attributes**, for example, *Effect on TBI motor symptoms, physical function and fatigue + Effect on TBI cognitive function and cognitive fatigue + Effect on mood (depression, anxiety)* were merged into two more generalised concepts of *Health* and *Feeling of wellbeing* and eventually reduced to *Wellbeing* as that was considered to include health.
- **Renaming attributes**, for example, *Mode* became *Who else is doing the activity* and, eventually, *Who with*.
- **Reconceptualising attributes**, for example, we initially differentiated between travel time for regular physical activities and special or one-off events (such as a national competition or ski trip), speculating that people would be prepared to travel longer for occasional events. We later focused on regular physical activities because they were more likely to form part of a healthy and sustainable program.

The definition and scope of each attribute are described in the survey instrument (ESM).

Participants confirmed that the seven attributes tested in the think-aloud interviews (stage four) were highly relevant to their decisions about physical activity and there was no indication that any important attribute was missing. However, following this stage of the study we judged it necessary to remove a further attribute, *Wellbeing*, for two reasons. First, the concept was interpreted by participants in different ways. Each of the seven attributes were defined in the survey prior to the DCE questions, but participants did not always absorb (or even read) this. Consequently, some viewed *Wellbeing* as a holistic concept that incorporated multiple dimensions of ‘*Physical fitness, social inclusion and happiness, mental wellbeing, confidence in one’s abilities*’ (as we intended), while others perceived it as a narrower concept relating primarily to psychological contentment or balance, ‘*It’s feeling you have control, acceptance of where you’re at*’. Second, some think-aloud interviewees overruled the levels in the *Wellbeing* attribute¹, reaching their own conclusions about how the scenario described by the other six attributes would impact their wellbeing. This occurred in both directions, i.e. participants overruled a low level of improvement in wellbeing for an activity that was especially appealing, ‘*It says it wouldn’t boost wellbeing but I think it would*’, and also reduced higher levels of improvement where the activity appeared too demanding, ‘*I don’t accept it. I want improved wellbeing but ... some of these [attribute levels] would have the opposite effect*

¹ Four levels were used for the *Wellbeing* attribute: maintains current level of wellbeing/slight improvement in wellbeing/moderate improvement in wellbeing/large improvement in wellbeing.

Table 2 Participant characteristics

	Stage Two: focus groups (<i>n</i> = 17)	Stage Three: focus groups (<i>n</i> = 9)	Stage Four: think-aloud interviews (<i>n</i> = 15)
Age group (years) (<i>n</i>)			
13–17	2	0	1
18–25	1	1	0
26–35	0	0	1
36–45	5	2	5
46–55	7	6	6
56–65	2	0	2
Sex [<i>n</i> (%) male]	11 (65)	5 (56)	(8) 53
Time since injury (years) (<i>n</i>)			
1–5	5	3	6
> 5	12	6	9
State of residence			
NSW	4	2	3
QLD	3	3	2
VIC	7	2	8
WA	3	2	2
Setting			
Metropolitan	17	9	13
Rural	0	0	2
Physical activity status			
% meeting guidelines	47	22	60
Less than pre-injury (<i>n</i>)	12	8	10
Same as pre-injury (<i>n</i>)	2	0	0
More than pre-injury (<i>n</i>)	3	1	2
Not reported (<i>n</i>)	0	0	3
Washington Short Set on Functioning (<i>n</i>)			
Vision			
No difficulty	5	3	5
Some difficulty	11	5	9
A lot of difficulty	1	1	1
Hearing			
No difficulty	10	3	8
Some difficulty	6	4	6
A lot of difficulty	1	2	1
Climbing steps			
No difficulty	2	2	1
Some difficulty	9	6	10
A lot of difficulty	6	1	4
Remembering/concentrating			
No difficulty	1	0	0
Some difficulty	8	3	9
A lot of difficulty	8	6	6
Self-care			
No difficulty	5	4	6
Some difficulty	10	5	8
A lot of difficulty	2	0	1
Language			
No difficulty	6	0	4
Some difficulty	10	9	11
A lot of difficulty	1	0	0

on me'. This echoes Vass and colleagues' [60] findings that DCE respondents weighing up risk factors frequently made a determination based on personal health histories and experiences. Thus, while highly important to decision making about physical activity, we removed the *Wellbeing* attribute because it had questionable validity and reliability in the context of this DCE. Questions about the perceived impact of physical activity on physical, psychological and social wellbeing were added to the broader survey to compensate.

3.2 Final Survey Modifications

It is essential that the DCE question blocks are positioned within a well-crafted survey instrument that gathers information with which to interpret the DCE responses without burdening respondents [65]. Stage four think-aloud testing (following readability revisions using Hemmingway Editor [63]) was valuable for ensuring that all parts of the instrument were readable and inclusive, and that each question could be answered meaningfully. This process resulted in substantial changes to every part of the instrument, as summarised in Table 5.

4 Discussion

We undertook a four-stage formative research process, working collaboratively with people living with TBI, to identify, critique, refine and prioritise the attributes and levels of our DCE survey. We then tested and refined the language, format and comprehensibility of the survey instrument to improve its relevance and comprehensibility to people living with moderate-to-severe TBI.

4.1 Key Challenges

4.1.1 Reducing the Breadth of Stakeholder Views and Experiences to a Few Attributes

In common with others, we found it difficult to reduce the number of attributes and describe them succinctly while incorporating diverse views and ensuring that no highly important concepts were omitted. Iterative discussion, and ranking of attributes in stage three focus groups, helped with this. As Coast et al. [36] point out, this challenge is compounded by qualitative research that foregrounds in-depth inter-related and contextualised data. However, qualitative data contribute to a deeper understanding of the factors that influence decision making for people with TBI, which can inform other aspects of our research and advocacy.

4.1.2 Participation That Reflects the TBI Spectrum

Heterogeneity of study participants added to the challenge outlined above, yet we were not able to recruit as purposefully as intended. Despite targeted efforts, we had low participation of people aged 18–35 years: a group with the highest incidence of TBI nationally [66]. We also struggled to recruit people aged 65+ years, rural community dwellers and those from culturally diverse populations, all of whom face multiple barriers to physical activity in addition to living with TBI. Although some children and young people took part in age-specific focus groups and think-aloud interviews, we cannot be certain they felt able to express their views fully in these (potentially daunting) forums.

4.1.3 Finding the Right Terminology

We struggled to find everyday language with which to describe the DCE concepts and components for stakeholders: attributes were initially called *influencers* and then *features*. However, we received invaluable guidance from participants about terminology. For example, the pilot focus group explained that we should not use the term *leisure-time physical activity* because, for people with TBI, physical activity is often integral to the hard work of rehabilitation. This echoes research by Self et al., who found that people with TBI made a distinction between recreational physical activity '*for fun*' and physical therapy/rehabilitation aimed at improving physical function [67]. Given that definitions used in this study included the breadth of these activities, we honed descriptions of physical activity types over several rounds of consultation and provided examples for each type to illustrate their scope and connection with a wide range of possible interests.

4.1.4 Navigating the Complexity of DCE Scenarios

The characteristics of a DCE survey itself presented some challenges. Think-aloud interviewees frequently scrolled back and forth between questions believing they were identical. Some participants suggested using a more traditional survey approach with individual questions that did not demand choosing between alternatives; however, when we explained the rationale behind using a DCE, they appreciated the value of this in producing a stronger evidence base.

4.2 Next Steps

The survey will be distributed Australia wide via stakeholder organisations, health providers with TBI services and social media. It will be implemented via Qualtrics [68], which provides conformance checks in relation to webpage

Table 3 Evolution of attributes over stages of the research process

During Stage One: following literature review and initial ideas-generation by core research team	End of Stage One: following deliberative dialogue with wider investigator group	End of Stage Two: following 'attribute' focus groups	End of Stage Three: following 'levels' focus groups	End of Stage Four: following think-aloud interviews
<ol style="list-style-type: none"> 1. Type of activity/exercise 2. Out-of-pocket cost including travel costs 3. Type of inclusion 4. Location/type of setting 5. Who is leading or supervising or coaching the activity (and their expertise working with people with TBI) 6. Mode 7. Amount of supervision 8. Dosage (frequency and duration) 9. Travel time for general sessions 10. Travel time for special sessions 11. Activity mix 12. Effort or preparation 13. Effect on TBI motor symptoms, physical function and fatigue 14. Effect on TBI cognitive function and cognitive fatigue 15. Effect on mood (depression, anxiety) 16. Effect on your overall feeling of well-being 17. Additional reasons, e.g. social engagement, fun/enjoyment, competition/achievement, adventure/risk, structure/purpose, weight loss, respite for self/carer^a 	<ol style="list-style-type: none"> 1. Type of physical activity 2. Your out-of-pocket cost 3. Travel time 4. Who else is doing the activity 5. Skills/knowledge of the environment/setting 6. Accessibility of the environment/setting 7. Health benefits of doing the activity 8. Effect on your overall feeling of well-being 9. Additional reasons, e.g. social engagement fun/enjoyment, competition/achievement, adventure/risk, transport availability, activity intensity and frequency, options for a range of activities, equipment requirements, how easy or difficult an activity is to master, how much preparation time or effort is required, respite for self/carer 	<ol style="list-style-type: none"> 1. Type of physical activity 2. Your out-of-pocket cost 3. Travel time 4. Who else is doing the activity 5. Skills/knowledge of the activity leader/facilitator 6. Accessibility of the environment/setting 7. Benefits of doing the activity 8. Effect on your well-being 	<ol style="list-style-type: none"> 1. Type of physical activity 2. Out-of-pocket cost 3. Travel time 4. Who else is doing the activity 5. Activity facilitator's skills/knowledge 6. Accessibility of the setting 7. Effect on your well-being 	<ol style="list-style-type: none"> 1. Type of activity 2. Out-of-pocket cost 3. Travel time 4. Who with 5. Facilitated by 6. Accessibility of setting

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^a*Additional reasons* was not intended to be a stand-alone attribute but was used as a means of prompting consideration of a wide range of potentially important concepts that were not captured elsewhere. None of these emerged as crucial attributes

Table 4 Final attributes with levels

Final attributes	Attribute levels
Type of activity	<p>Sport in a structured competition (some examples might include lawn bowls club competition, netball district competition, marathon, wheelchair basketball club challenge)</p> <p>Sport with informal competition for fun (some examples might include a running group, soccer in local park, lunchtime or school basketball game)</p> <p>Physical recreation with purpose of mental, social and/or physical satisfaction (some examples might include Tai Chi, Yoga, dance, body surfing, bushwalking, rock climbing, aqua aerobics, walking the dog)</p> <p>Structured exercise program with purpose or goal to improve fitness, strength, flexibility and/or function (some examples might include a physiotherapy prescribed exercise program, gym program, treadmill or cycle ergometer, strength training)</p>
Out-of-pocket cost	<p>\$0 per session</p> <p>\$15 per session</p> <p>\$40 per session</p> <p>\$100 per session</p>
Travel time	<p>5 minutes or less each way</p> <p>15 minutes each way</p> <p>30 minutes each way</p> <p>70 minutes each way</p>
Who with	<p>The activity is organised only for people with a disability like mine</p> <p>The activity is organised for people with any type of disability</p> <p>The activity is open to everyone (mainstream)</p> <p>I do the activity by myself</p>
Facilitated by	<p>The activity is facilitated by a person with experience of the activity and experience working with people with disability</p> <p>The activity is facilitated by a person with NO experience of the activity but experience working with people with disability</p> <p>The activity is facilitated by a person with experience of the activity but NO experience working with people with disability</p> <p>The activity is facilitated by a person with experience of the activity and experience working with people with disability</p>
Accessibility of setting	<p>Accessibility is manageable, but not ideal</p> <p>Highly accessible, caters well for my needs</p>

accessibility for people with disability as outlined by the World Wide Web Consortium (W3C) Web Content Accessibility Guidelines [69]. Qualtrics enables audio files which, as requested by our testers, we will use for sections with dense text to assist people with vision and cognitive impairments. The Qualtrics platform also allows people to easily increase font size within their web browser.

4.3 Strengths and Weaknesses

Strengths of this study included the multidisciplinary and multisector research team, which was able to draw on significant lived experience of TBI and professional experience in working with people with TBI. Thus, the research findings were strongly shaped by the views of expert stakeholders,

including those who will be most affected by any policy or practice impacts arising from the research results and subsequent advocacy [36]. Triangulation of methods, including frequent discussions between research team members to critique the emergent attributes and levels, increase the trustworthiness of the findings [70]. We were aided by the generous contribution of a wide range of participants who engaged enthusiastically in focus groups and interviews, sharing their views frankly and acting as deliberative partners throughout the DCE development process. We believe this process has immeasurably improved the quality of the DCE questions and wider survey instrument. Aguiar et al. found that a similar participative approach to DCE development led to the inclusion of attributes that would likely have been excluded and to more appropriate terminology [57]. We also received positive

Table 5 Overview of modifications to sections of the survey

Survey components	Overview of modifications
Participant information	Removed jargon and unnecessarily formal terminology Used more specific language, e.g. referring to <i>'the survey'</i> rather than <i>'the study'</i> Reordered sections so those perceived as most important came first Reduced text overall Committed to providing an audio option in the online survey to reduce cognitive and eye fatigue
Consent form	Rearranged bullet points into a more logical sequence Minor language refinement
Screening questions	Modified language to be more specific, e.g. asking <i>'Have you been diagnosed with a brain injury?'</i> rather than <i>'Do you have a brain injury?'</i> Added explanations for personal questions, e.g. next to the question <i>'What was the main cause of your brain injury?'</i> we stated <i>'(this survey is only for people who are living with a traumatic brain injury)'</i>
Survey instructions	Changed the tense to emphasise hypothetical scenarios, e.g. travel time was defined as <i>'How much time it would take to get to the activity'</i> rather than <i>'How much time it takes to get to the activity'</i>
DCE question blocks	Removed <i>Wellbeing</i> attribute (as described above) Changed <i>'Physical activity scenario'</i> to <i>'Physical activity option'</i> Reduced the prominence of examples given for the <i>Type of activity</i> attribute Moved the main DCE question, <i>'Would you be willing to add this physical activity to your current weekly schedule?'</i> , to precede the attribute list rather than follow it Added an explanatory statement to the top of the page for questions 2–6 to reduce confusion: <i>'This option may seem similar to a previous option, but some of the features are different'</i> Replaced the option of <i>'0 minutes'</i> travel time with <i>'5 minutes or less'</i> travel time as some participants argued that 0 minutes was not possible
Physical activity questions	Refined questions for specificity, e.g. rather than asking respondents to identify three forms of physical activity they engage in, we asked for <i>'up to three'</i>
Function	Refined mobility categories
Demographics	Modified questions to be more inclusive, e.g. adding to and amending terminology in categories of mobility and employment status

feedback from people living with TBI about the process of inclusion in this research, e.g. *'When you have a brain injury you lose a lot so being able to contribute is really important'*.

Understanding the physical activity preferences of people living with TBI must take into account the high heterogeneity of this population [15]. A weakness of this study is low participation of four specific groups: people aged 18–35 years, people aged 65+ years, rural community dwellers and those from culturally diverse populations. However, Pham et al. [71] suggest that key differences in age groups relating to perceptions of physical activity by people living with TBI are less pronounced after 45 years of age, and Rydén et al. [72] found that DCE development interviews with patients across multiple countries generally produced consistent results, thus our process may not have suffered significantly from the lack of older and culturally diverse participants. Importantly, we plan to use survey implementation strategies that target people aged 18–35 years, people aged 65+ years, rural community dwellers and those from culturally diverse populations, which will ensure their views are represented in the final DCE data. The survey includes demographic questions that will provide evidence about our level of success in this endeavour. Given that the cognitive challenge of DCEs may exclude those with more severe TBI, we also plan to conduct further focus groups with consumers, carers,

clinicians, activity providers and funders from which we will gather examples of effective strategies for supporting physical activity for this group, and use this in advocacy.

5 Conclusions

This paper describes the formative co-development process of a DCE survey aimed at identifying the physical activity preferences of people living with moderate-to-severe TBI. This process included identifying, discarding, merging, renaming and reconceptualising attributes and levels, and modifying the survey instrument to reduce confusing terminology and cumbersome features. We believe this significantly improved the relevance and comprehensibility of our DCE survey. This process may be applicable in other DCE studies.

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Declarations

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Conflicts of Interest/Competing Interests Abby Haynes, Kirsten Howard, Liam Johnson, Gavin Williams, Kelly Clanchy, Sean Tweedy, Adam Scheinberg, Sakina Chaggar, Belinda Wang, Gabrielle Vassallo, Rhys Ashpole, Catherine Sherrington and Leanne Hassett have no conflicts of interest that are directly relevant to the content of this article.

Ethics Approval The study received ethical approval from the Human Research Ethics Committee at the University of Sydney, reference 2022/088.

Consent to Participate and Consent for Publication All participants gave written informed consent to participate in the research and for their de-identified data to be used in publications.

Availability of Data and Material The qualitative data supporting the findings of this methodological study are individually identifiable and cannot be made available outside the research team. All directly relevant data are included within the article in a deidentified form.

Code Availability Not applicable.

Authors' Contributions LH leads the BRIDGES program of research. AH led the writing of this manuscript. LH designed the study protocol in collaboration with AH (qualitative methods) and KH (health economist, discrete choice experiment expertise) and feedback from LJ, GW, KC, ST, AS, SC, GV, RA and CS. LH, LJ and AH conducted focus groups and interviews with a paid qualitative project officer. LH, AH, LJ, SC and BW formed the core research group who met weekly to discuss progress with additional meetings with the broader authorship team when needed for iterative deliberations about aspects of the DCE blocks and/or survey instrument. All authors critically reviewed and approved the final manuscript.

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