An online survey

What community-based physical activities do people living with brain injury like to do?

A study conducted by the BRIDGES team



funded by an Australian government Medical Research Future Fund grant (MRF2009099)

Participant Information Statement (audio file to read out PIS)

Invitation

You are invited to participate in a survey to identify the types of physical activity people living with moderate-to-severe traumatic brain injury would like to do.

The survey is part of a research project being conducted by Associate Professor Leanne Hassett from the University of Sydney in collaboration with other researchers, clinicians, consumer representatives and brain injury organisations across Australia.

Before you decide whether you wish to complete the survey, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish.

What is the purpose of the survey?

Physical activity (e.g., playing sports, doing an exercise program, walking) can have many benefits for your physical and mental wellbeing. Unfortunately, after traumatic brain injury, many people do not do enough physical activity to get these benefits. There are many reasons why being active is difficult. This may include a lack of suitable or appealing options available.

The purpose of this survey is to understand what people living with moderate-to-severe traumatic brain injury want from community-based physical activity. The results of this survey will help us know which options we should lobby for.

Who can take part in this survey?

People living with moderate-to-severe traumatic brain injury aged 10 years and older are invited to complete this survey.

Do I have to do the survey? Can I stop once I've started?

Participation in this survey is completely voluntary. It is okay if you start the survey and decide to stop. If you decide not to finish the survey, your data will not be included.

What will happen in the survey?

You will be asked some general questions about yourself, your injury and your physical activity levels. The survey will also show you six different physical activity options and ask you to choose whether you would be willing to add that activity to your weekly program.

How much of my time will the survey take?

The survey will take approximately 15-20 minutes to complete, but this may vary from person to person.

Are there any benefits?

We will use the survey results to help us advocate for better physical activity opportunities for people living with traumatic brain injury. Completing the survey may not directly benefit you but you will be contributing to worthwhile research that we hope will improve the lives of people living with traumatic brain injury.

Are there any risks or costs?

There are no known risks or costs to you by completing this survey.

Confidentiality/Privacy: What will happen to information about me in the survey?

All responses to the survey are anonymous and cannot be linked to you. The survey will not ask you to identify yourself. The researchers do not have access to any other information about you.

What happens with the survey results?

We plan to share the results with a range of people, in different ways. This will include in academic publications, conference presentations, through brain injury consumer organisations and other forums. You will not be identifiable in papers, reports or presentations. Survey data will be retained for 7 years and then destroyed.

Will I be told the results of the study?

If you would like to know the results of the study, you can click the email link at the end of the survey and we will send you the results.

Complaints

This study has been approved by the University of Sydney. If you have any concerns about the conduct of the study, or your rights as a study participant, you may contact:

The Manager, Ethics Administration, University of Sydney:

- Telephone: +61 2 8627 8176
- Email: human.ethics@sydney.edu.au
- Fax: +61 2 8627 8177 (Facsimile).

What if I would like further information about the study?

If you would like to know more, or if you have any problems with the survey, please contact:

Associate Professor Leanne Hassett

Email leanne.hassett@sydney.edu.au

Telephone (02) 9351 9549

		uhave to be 10-ye d click 'YES' for th					, your parent o
						,	
[If < 10 years	old STOP; if 10)-17 years old, incl	lude parental cor	nsent box at botto	om of Participant (Consent Form]	

Participant Consent Form	(audio file	consent form
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I have read the participant information statement and I give my consent to participate in this survey. In giving my consent I acknowledge that:

- 1. I understand the procedures required for this study (i.e. completing a survey) and the time involved.
- 2. I understand that completing this survey is completely voluntary I am not under any obligation to consent.
- 3. I understand that my involvement is strictly confidential: the survey results may be published, but no information about me will be used in any way that is identifiable.
- 4. I understand that I can stop my participation in this survey at any time. This will not affect my treatment or my relationship with the researcher(s) or the University of Sydney now or in the future.
- 5. I understand that if I stop participating in this survey my data will not be used. However once I have submitted the survey my (anonymous) responses cannot be withdrawn.
- 6. I have been given the opportunity to discuss this information and my involvement in this study with the researcher. Any questions have been answered to my satisfaction.

I give	my consent				
Yes		No 🗆			
	For the parent or legal guardian [ONLY DISPLAY FOR THOSE WHOSE AGE IS 10 TO 17] I confirm I have read and understood the above information regarding this study, and consent for my child to participate.				
Yes		No □			

Befo	ore we start, we have some questions about you to make sure you are eligible to complete the survey.
Wha	at state or territory do you live in? (this survey is only for people who are living in Australia)
	New South Wales [CONTINUE]
	Victoria [CONTINUE]
	Queensland [CONTINUE]
	Australian Capital Territory [CONTINUE]
	Tasmania [CONTINUE]
	South Australia [CONTINUE]
	Northern Territory [CONTINUE]
	Western Australia [CONTINUE]
	I do not live in Australia [STOP]
Hav	e you been diagnosed with a brain injury? (this survey is only for people who are living with a brain injury)
	Yes [CONTINUE]
	No [STOP]

Road traffic accident [CONTINUE] Fall [CONTINUE] Sport Injury [CONTINUE] Assault [CONTINUE] Blast or explosion injury [CONTINUE] Stroke [STOP] Aneurysm [STOP] Other[CONTINUE] Prefer not to say [CONTINUE] Prefer not to say [CONTINUE] Less than 12 months ago [STOP] 1 to 2 years ago [CONTINUE] 2 to 5 years ago [CONTINUE] 5 to 10 years ago [CONTINUE] More than 20 years ago [CONTINUE]		re injury (this survey is only for people who are living v	sustained more than one brain injury, please tell us about your most vith a traumatic brain injury)
Sport Injury [CONTINUE] Assault [CONTINUE] Blast or explosion injury [CONTINUE] Stroke [STOP] Aneurysm [STOP] Other[CONTINUE] Prefer not to say [CONTINUE] Prefer not to say [CONTINUE] Less than 12 months ago [STOP] 1 to 2 years ago [CONTINUE] 2 to 5 years ago [CONTINUE] 5 to 10 years ago [CONTINUE] 10 to 20 years ago [CONTINUE]		Road traffic accident [CONTINUE]	
Assault [CONTINUE] Blast or explosion injury [CONTINUE] Aneurysm [STOP] Aneurysm [STOP] Prefer not to say [CONTINUE] Prefer not to say [CONTINUE] Less than 12 months ago [STOP] 1 to 2 years ago [CONTINUE] 5 to 10 years ago [CONTINUE] 10 to 20 years ago [CONTINUE]		Fall [CONTINUE]	
Blast or explosion injury [CONTINUE] Stroke [STOP] Aneurysm [STOP] Other [CONTINUE] Prefer not to say [CONTINUE] Less than 12 months ago [STOP] 1 to 2 years ago [CONTINUE] 2 to 5 years ago [CONTINUE] 5 to 10 years ago [CONTINUE] 10 to 20 years ago [CONTINUE]		Sport Injury [CONTINUE]	
□ Stroke [STOP] □ Aneurysm [STOP] □ Other [CONTINUE] □ Prefer not to say [CONTINUE] □ Less than 12 months ago [STOP] □ 1 to 2 years ago [CONTINUE] □ 2 to 5 years ago [CONTINUE] □ 10 to 20 years ago [CONTINUE] □ 10 to 20 years ago [CONTINUE]		Assault [CONTINUE]	
□ Aneurysm [STOP] □ Other		Blast or explosion injury [CONTINUE]	
□ Other[CONTINUE] □ Prefer not to say [CONTINUE] When did your brain injury occur? (this survey is only for people who had their brain injury more than 1-year ago) □ Less than 12 months ago [STOP] □ 1 to 2 years ago [CONTINUE] □ 2 to 5 years ago [CONTINUE] □ 5 to 10 years ago [CONTINUE] □ 10 to 20 years ago [CONTINUE]		Stroke [STOP]	
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□ Less than 12 months ago [STOP] □ 1 to 2 years ago [CONTINUE] □ 2 to 5 years ago [CONTINUE] □ 5 to 10 years ago [CONTINUE] □ 10 to 20 years ago [CONTINUE]		Prefer not to say [CONTINUE]	
 □ Less than 12 months ago [STOP] □ 1 to 2 years ago [CONTINUE] □ 2 to 5 years ago [CONTINUE] □ 5 to 10 years ago [CONTINUE] □ 10 to 20 years ago [CONTINUE] 			
□ Less than 12 months ago [STOP] □ 1 to 2 years ago [CONTINUE] □ 2 to 5 years ago [CONTINUE] □ 5 to 10 years ago [CONTINUE] □ 10 to 20 years ago [CONTINUE]	Wher	n did your brain injury occur? (this survey is only for pe	eople who had their brain injury more than 1-year ago)
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□ 2 to 5 years ago [CONTINUE] □ 5 to 10 years ago [CONTINUE] □ 10 to 20 years ago [CONTINUE]			
□ 5 to 10 years ago [CONTINUE] □ 10 to 20 years ago [CONTINUE]			
□ 10 to 20 years ago [CONTINUE]			
☐ More than 20 years ago [CONTINUE]		10 to 20 years ago [CONTINUE]	
		More than 20 years ago [CONTINUE]	

Were	you knocked out (lost consciousness) from
	Yes [CONTINUE]
	No [CONTINUE]
	Unsure [CONTINUE]
L	
If yes	, how long were you knocked out (lost cons
	< 30 minutes [CONTINUE]
	30 minutes to 24 hours [CONTINUE]
	> 24 hours [CONTINUE]
	Unsure [CONTINUE]
How	long did you spend as an inpatient in hospita
	I was not admitted to hospital [CONTINUE]
	Less than 1 day [CONTINUE]
	1 to 7 days [CONTINUE]
	1 to 4 weeks [CONTINUE]
	1 to 3 months [CONTINUE]
	3 to 12 months [CONTINUE]
	More than 1 year [CONTINUE]
	Unsure [CONTINUE]

About the survey:

In the survey you will see six (6) different community-based physical activity options. For each option, you will be asked if you would add this physical activity to your current weekly schedule. Some options may not currently be available to you. We want to know whether we should lobby for more options.

There are no right or wrong answers, we just want to know which features of physical activity you prefer.

The options look very similar, but each option is different. Focus on which physical activity features are most important to your decision-making.

About the survey (AUDIO FILE FOR THIS SCREEN)

Each of the physical activity options we will show you are described using six (6) features. These features are:

- 1. **Type of activity**: these include sport in a structured competition, sport with informal competition for fun, physical recreation with purpose of mental, social and/or physical satisfaction, or a structured exercise program with purpose to improve fitness, strength, flexibility and/or function.
- 2. **Out-of-pocket cost:** costs that you would have to pay per session (e.g., for travel, equipment, parking, registration fees). Out-of-pocket costs would not be covered by NDIS or other state-based insurance schemes.
- 3. **Travel time:** how much time it would take to get to the activity one way.
- 4. **Who with:** whether the other people doing the activity have a disability, the activity is open for anyone or you do the activity by yourself.
- 5. **Facilitated by:** whether the facilitator has experience of the physical activity and whether they have experience working with people who have a disability. Examples of facilitators are a support worker, a personal trainer, an exercise leader, a coach, or a health professional.
- 6. **Accessibility of setting**: whether all people with and without disabilities can access the activity without any barriers, or if there are some manageable challenges. Accessibility might involve disability parking near the entrance, accessible bathrooms, proximity to appropriate public transport, uncluttered environment, adaptive equipment to use, noise levels, lighting, and the behaviour of staff and others around you.

Physical activity option 1 of 6 (EXAMPLE- QUESTIONS WILL BE SELECTED RANDOMLY FROM 8 BLOCKS]

Type of activity:	Sport in a structured competition (some examples might include lawn bowls club competition, netball district competition, marathon, wheelchair basketball club challenge)		
Out-of-pocket cost:	\$15 per session		
Travel time:	15 minutes each way travel time		
Who with:	The activity is organised for people with any type of disability		
Facilitated by:	The activity is facilitated by a person with experience of the activity and experience working with people with disability		
Accessibility of setting:	g: Accessibility is manageable, but not ideal		
		Yes □	No 🗆

Physical activity option 2 of 6 (This option may seem similar to a previous option, but some of the features are different)

Type of activity:	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)			
Out-of-pocket cost:	\$0 per session			
Travel time:	5 minutes or less each way travel time			
Who with:	The activity is organised only for people with a disability like mine			
Facilitated by:	The activity is facilitated by person with NO experience of the activity but experience working with people with disability			
Accessibility of setting:	ity of setting: Accessibility is manageable, but not ideal			
		Yes □	No 🗆	

Physical activity option 3 of 6 (This option may seem similar to a previous option, but some of the features are different)

Type of activity:	Sport with informal competition for fun (some examples might include a running group, soccer in local park, lunchtime or school basketball game)		
Out-of-pocket cost:	\$15 per session		
Travel time:	5 minutes or less each way travel time		
Who with:	The activity is organised for people with any type of disability		
Facilitated by:	The activity has no facilitator		
Accessibility of setting:	Highly accessible – caters well for my needs		
		Yes □	No 🗆

Physical activity option 4 of 6 (This option may seem similar to a previous option, but some of the features are different)

Type of activity:	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)		
Out-of-pocket cost:	\$15 per session		
Travel time:	30 minutes each way travel time		
Who with:	I do the activity by myself		
Facilitated by:	The activity is facilitated by a person with experience of the activity and experience working with people with disability		
Accessibility of setting:	ting: Highly accessible – caters well for my needs		
		Yes □	No 🗆

Physical activity option 5 of 6 (This option may seem similar to a previous option, but some of the features are different)

Type of activity:	Physical recreation with purpose of mental, social or physical satisfaction (some examples might include Tai Chi, Yoga, dance, body surfing, bushwalking, rock climbing, aqua aerobics, walking the dog)			
Out-of-pocket cost:	\$0 per session			
Travel time:	70 minutes each way travel time			
Who with:	The activity is organised only for people with a disability like mine			
Facilitated by:	The activity is facilitated by a person with experience of the activity and experience working with people with disability			
Accessibility of setting:	g: Highly accessible – caters well for my needs			
		Yes 🗆	No 🗆	

Physical activity option 6 of 6 (This option may seem similar to a previous option, but some of the features are different)

Type of activity:	Sport in a structured competition (some examples might include lawn bowls club competition, netball district competition, marathon, wheelchair basketball club challenge)		
Out-of-pocket cost:	S15 per session		
Travel time:	30 minutes each way travel time		
Who with:	The activity is organised only for people with a disability like mine		
Facilitated by:	The activity has no facilitator		
Accessibility of setting:	Highly accessible – caters well for my needs		
		Yes □	No 🗆

•	•	•	•			t of breath som t is part of you		This may i	nclude
Pre-injury ph	ysical activity	y history:							
Think about a	typical week	just before yo	ou had your in	ury.					
On average, h breath some c		s per week did	l you engage	in physical act	ivity that incre	ased your hea	ırt rate and ma	ade you get	out of
0 days	1 day	2 d	ays	3 days	4 days	5 days	6 days	,	7 days
]						
0 mins/day	10 mins/day	20 mins/day	30 mins/day	40 mins/day	50 mins/day	60 mins/day	90 mins/day	120 mins/day	150 or greater mins/day
o minoraay	10 mmorady	20 millorday	oo miiio, aay	10 mileracy	oo minoraay	oo miino, day	oo mineraay		
									mins/day
appear if "On a	` '	many days pe		, ,		exercise or rec that increased			
		7.1							
Activity 1									
Activity 1 Activity 2									

Current phys	ical activity p	artic	ipation:								
Think about a	typical week	for yo	ou now .								
•		s per	week do	you eng	jage ii	n physical ac	tivity that increa	ases your hear	t rate and mal	kes you ge	t out of
breath some of			0 4	-)./a) dava	4 dove	E dava	C days		7 days
0 days	1 day		2 da	•	•	3 days	4 days	5 days	6 days		7 days
				_							
On average h	now many min	utes r	per day o	n the da	VS VOI	u are active o	do you engage	in physical act	ivity at this lev	el?	
0 mins/day	10 mins/day		nins/day	30 mins		40 mins/day		60 mins/day	90 mins/day	120	150 or
										mins/day	greater mins/day
Ш								_			
How many da	ys per week d	o you	perform	muscle	streng	gthening exe	rcises, such as	bodyweight ex	ercises or res	istance tra	ining?
0 days	1 day		2 da			3 days	4 days	5 days	6 days		7 days
]							
						·			·	·	
How many day	ys per week d	o you	perform	activitie	s that	emphasise b	alance and fur	ctional strengt	h training?		
0 days	1 day		2 da	ays		3 days	4 days	5 days	6 days	'	7 days
]							
List up to three	e (3) of the mo	net co	mmon tv	nes of n	hveics	al activity you	do for sport, e	vercise or recr	eation curren	tly lonly ar	near if at
•	` '		•		•		nat increases yo				· ·
3. balance and					. , ,			- ,			
Activity 1											

Activity 2

ease rate the f	following three (3)) statements abo	ut physical acti	vity and wellbeing		
ysical activity	is important for ir	nproving my phy	sical wellbeing	?		
Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
Strongly	Disagree		Agree	Strongly agree		
disagree						
disagree	is important for ir		<u> </u>	Strongly agree		
disagree U ysical activity Strongly	is important for ir	mproving my soc	ial wellbeing?			

	I can walk by myself outdoors without using a walking	g aide or a	ssistance fo	r 1km or more			
	I can walk by myself outdoors using a walking aide o	r assistanc	e for 1km or	more			
	I can walk short distances outdoors, but usually use a	wheelchai	r for longer	distances outs	side of my hou	se	
	I usually use a manual wheelchair inside and outside	my house					
	I usually use an electric wheelchair or a carer-controll	ed wheelch	nair				
These	e questions ask about difficulties you may have becaus	se of your b	orain injury o	or other injuries	s sustained at	the same ti	me.
		No difficulty	Some difficulty	A lot of difficulty	Cannot do at all	Rather not say	Don't know
Do y	ou have difficulty seeing, even if wearing glasses?						
Do y aid(s	you have difficulty hearing, even if using a hearing s)?						
Do y	ou have difficulty walking or climbing steps?						
Do y	ou have difficulty remembering or concentrating?						
	ou have difficulty with self-care, such as washing all or dressing?						
,	ou have difficulty communicating, for example erstanding or being understood?						
	ographics (ALL) ast set of questions asks more about yourself.						

What is your gender?

	Male
	Female
	Non-binary
	Other
	Prefer not to answer
	at is the postcode of where you w would you best describe the a
	Remote
	Rural
	Small regional town
	Large regional town
	Metropolitan
Wh	at are your current living arrang
	I live alone
	I live with my spouse/partner of

'	1 1:
	I live with my spouse/partner
	I live with my child/children (r
	I live with my parent(s)/guard
	I live with other relatives (not
	I live with non-relative(s)/sup
	ı
Are	you of Aboriginal or Torres St
	No
	Yes, Aboriginal
	Yes, Torres Strait Islander
	Yes, both
	Prefer not to say
Wha	at is the main language you sp
	English
	Otto (1 :£ -)
	Other (please specify):

VVII	at is your highest level of education?
	Postgraduate degree
	Graduate diploma/Graduate certificate
	Bachelor degree
	Advanced diploma/diploma
	Certificate III/IV
	Certificate I/II
	Year 12
	Year 10 or below
	Still in school
Whi	ich of the following categories best describes your o
	Employed part-time/ casual
	Not employed at the moment but looking for work
	Not employed and not looking for work
	Family caring / home duties
	Retired or on a pension
	Studying full time

Please estimate your approximate yearly household income before tax.

Up to \$35,000 (up to \$673 per week)
\$35,000- \$65,000 (\$673 - \$1250 per week)
\$65,001- \$95,000 (\$1251 - \$1826 per week)
\$95,001 - \$125,000 (\$1827 - \$2404 per week)
\$125,001 - \$150,000 (\$2404 - \$2885 per week)
>\$150,000 (more than \$2885 per week)
Prefer not to answer

Have you been accepted into a workers compensation or motor accidents scheme?

Yes
No
Currently applying
Awaiting decision on eligibility
Uncertain
Prefer not to say

⊓ave	you been accepted into the Nationa Yes	sability insurance scheme?
	No	
	Currently applying	
	Awaiting decision on eligibility	
	Uncertain	
	Prefer not to say	
Do yo	u have any other comments?	
Do yo	u have any other comments?	
		ank you for helping us with this survey!

Now we would like to ask you some questions about your pre-injury and current physical activity (Child version 10-17) [goes in same place as adult version of physical activity questions] Physical activity is any activity that increases your heart rate and makes you get out of breath some of the time. This may include sport, exercise, playing with friends, or walking to school. Some examples of physical activity are running, brisk walking or wheeling, rollerblading, biking, dancing, skateboarding, swimming, soccer, basketball, football, surfing, wheelchair rugby. Think about a **typical** week just **before** you had your injury. On average, how many days per week did you engage in physical activity that increased your heart rate and made you get out of breath some of the time? 2 days 3 days 5 days 6 days 7 days 0 days 4 days 1 day П П П П П On average, how many minutes per day of the days you were active did you engage in physical activity at this level? 0 mins/dav 10 mins/dav 20 mins/day 30 mins/dav 40 mins/day 50 mins/day 60 mins/day 90 mins/dav 150 or 120 mins/day areater mins/day List up to three (3) of the most common types of physical activity you did for sport, exercise or recreation **before your injury** [only appear if "On average how many days per week did you engage in physical activity that increased your heart rate and made you get out of breath some of the time" ≥ 1 day] Activity 1 Activity 2 Activity 3

Current physical activity participation:

0 days	1 day	2	days	,	3 days	4 days	5 days	6 days		7 days
On average. l	now manv min	utes per da	√ of the da	vs vol	ս are active do	vou engage i	n physical acti	vitv at this leve	el?	
0 mins/day	10 mins/day	20 mins/da			40 mins/day	50 mins/day	60 mins/day	90 mins/day	120 mins/day	150 or greater mins/day
□ How many da	uys per week d	o you perfo	□ m vigorou	ıs-inte	□ nsity aerobic a	□ activities as we	□ ell as those tha	t strengthen n	nuscle and	bone?
0 days	1 day		days		3 days	4 days	5 days	6 days		7 days
	many days pe						xercise or recr			
Activity 2										

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Strongly	Disagree	Neutral	Agree	Strongly agree
-	-	nproving my mer Neutral		Strongly agree
disagree				
				•
-	is important for ir Disagree	nproving my soci Neutral	al wellbeing? Agree	Strongly agree