



# Limb POWER

*Living life without limbs*

## 2019

### Physical Activity and Sport Survey Results

LimbPower is a registered charity. No.1132829

This survey was analysed and written up by  
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**SPORT  
ENGLAND**

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[www.limbpower.com](http://www.limbpower.com)





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# Aim and Scope

LimbPower is a registered charity created with the aim of supporting people with limb loss / difference to engage in physical activity, sports and the arts to aid lifelong rehabilitation and well-being. To support this aim, this study sought to understand and quantify the perceptions, levels and experiences of sport and physical activity among adults and children before and after limb loss / difference. The study also sought to determine what future activities these individual participants would like to engage in and how LimbPower can best support their future goals and aspirations. Specifically, the survey considered the following three broad areas:

- **Activity levels and experiences of physical activity before limb loss / difference**
- **Activity levels and experiences of physical activity after limb loss / difference**
- **What can LimbPower do to better support engagement in physical activity?**

# Methodology

## Participants

The survey was completed by

# 289

individuals with limb loss/difference.



155 = male

134 = female

# 5 to 84

Ages ranged from under 5 to 84 years of age (see Figure 1).

# 90%

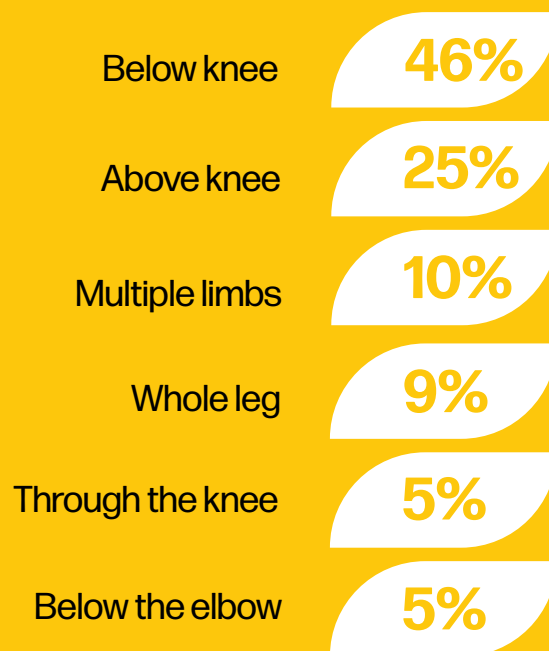
With many of the participants classifying themselves as White British.

Other ethnicities that were represented and classified by the participants as:

- White Irish
- White Welsh
- White Scottish
- Black British
- White Australian
- White American
- Asian British
- Iranian British
- Native America
- Hispanic
- Black Caribbean
- Mixed Ethnic Background



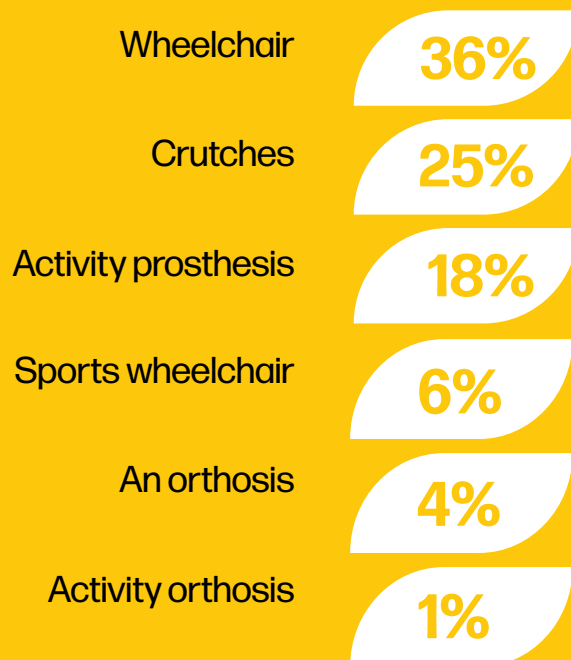
**Participants represented a range of limb loss/difference:**



**83%**

**Participants reported using a prosthesis**

**Other devices used included:**







18%

Of those that did have an activity prosthesis, recorded they were provided by the National Health Service or a private prosthetic clinics.

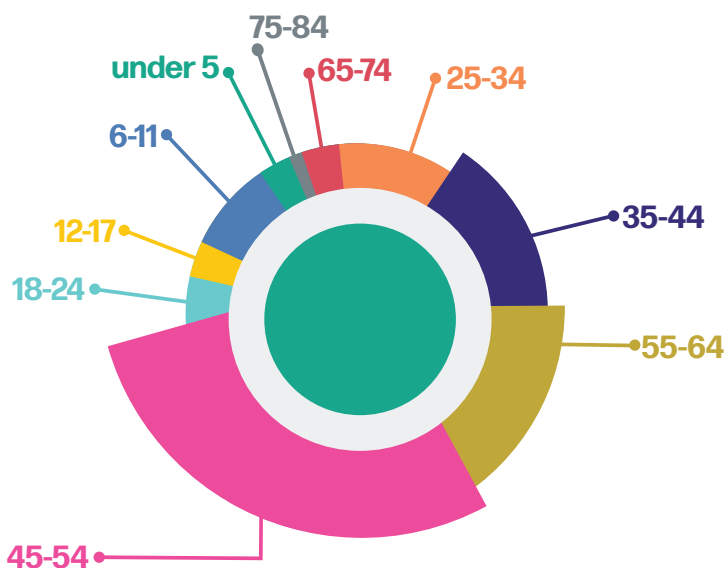
**The cause of the limb loss/difference was:**

- 40% Accident or trauma
- 24% Congenital
- 16% Infection
- 13% Cancer
- 3% Diabetes
- 4% or peripheral vascular disorder or peripheral arterial disease

It is worth noting that between **5,000** and **6,000** amputations take place every year.



**Figure 1:** Age range of participants



The **most common reason** for an amputation is a loss of blood supply to the affected area (*critical ischemia*) from either vascular disease or diabetes, which accounts for **70%** of lower limb amputations.

**Trauma** is the most common reason for upper limb amputations and accounts for **57%** (*BLESMA, Amputation Explained*).

## Method of Data collection

Aligned with the broad aim of the study, the method of data collection chosen was a **quantitative and qualitative survey** (Terry & Braun, 2017). This method was chosen because it allows for a mix of openness and standardisation, and can help to “generate rich, detailed, and varied data” (p. 17).

**The survey was constructed by LimbPower, which was underpinned by three specific questions:**


- A** Activity levels and experiences of physical activity before limb loss / difference
- B** Activity levels and experiences of physical activity after limb loss/difference
- C** What can LimbPower do to better support physical activity

### Data Analysis:

**Quantitative** data were analysed using descriptive data (e.g. percentage responses).

**Qualitative** data were analysed using thematic analysis (Braun & Clarke, 2006) via six steps:

- A** Familiarisation with the data
- B** Generating initial codes
- C** Searching for themes
- D** Reviewing themes
- E** Refining and naming themes
- F** Producing the report



The survey consisted of **35 questions** and took **~15 minutes to complete**. Survey data was collected via two modalities: **email or online**



## Activity Levels Before Limb loss / Difference

This section provides an overview of the activity levels among adults and children *'before'* limb loss / difference

**54%** Many reported **150 minutes** or more of moderate intensity physical activity or sport a week

**25%** Reported doing between **30-150 minutes** of physical activity or sport a week

**9%** Reported doing **30 minutes** or less of moderate intensity physical activity or sport per week

**Remaining participants** had a congenital limb loss / difference (see Figure 2).

**38%** Specifically, many reported they had participated in sport or physical activity daily

**40%** 2-3 times per week

**10%** Once a week

**4%** or they did not take part

**2%** Once a month

**2%** 2-3 times per month

**1%** Less than once a month



### The main sports they had participated in (greater than 10%) were:

**48%** Walking

**46%** Cycling

**45%** Swimming

**34%** Gym

**25%** Running or jogging

**21%** Gardening

**17%** Fitness classes

**17%** Dancing

**15%** Badminton

**14%** Athletics

**14%** Canoeing/kayaking

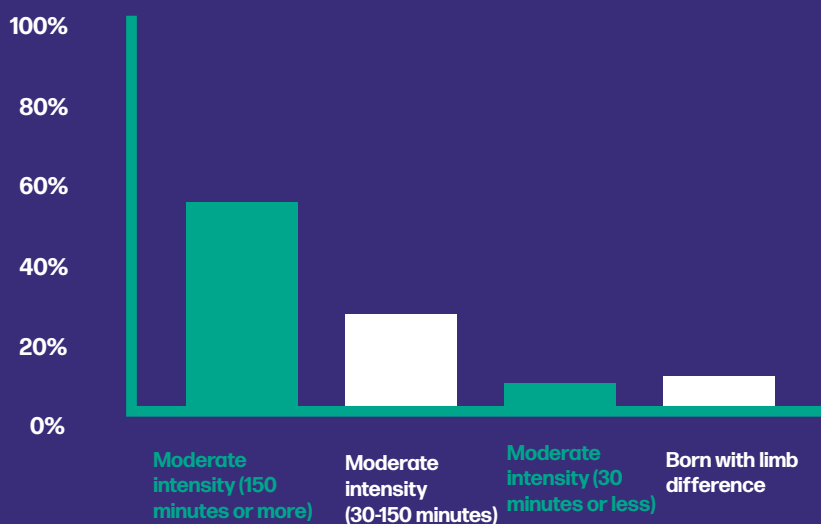
**16%** Football

**12%** Fishing

**13%** PE/school sport

**10%** Golf

**10%** Tennis



**Figure 2:** Activity levels prior to limb loss / difference

## Activity Levels Post Limb Loss / Difference

### Challenge of Becoming Active Again Post Limb Loss / Difference

This section provides an overview of the activity levels and experiences among adults and children post limb loss / difference

- 24%** Reported it was 'somewhat difficult' to get back into physical activity (see Figure 3)
- 20%** Whilst others reported it was 'very difficult'
- 19%** Regarding how long it took to become active again, participants reported it took **0-3 months**
- 19%** 4-6 months
- 18%** 7-12 months
- 16%** 2-4 years

- 14%** 1-year
- 8%** Some reported that they are still currently inactive
- 7%** In contrast, some reported it was 'very easy'
- 4%** 5-8 years
- 2%** More than 12 years





**Figure 3:** Challenge of returning to sport and physical activity

## Current Levels of Sport and Physical Activity

Of the active participants:

- 48%** 2-3 times per week
- 46%** Reported **150 minutes or more** of moderate intensity physical activity or sport a week
- 41%** Reported doing between **30-150 minutes** of physical activity or sport a week
- 32%** The participants reported doing sport or physical activity daily
- 13%** Reported doing **30 minutes or less** of moderate intensity physical activity or sport per week
- 11%** Once a week
- 3%** Less than once a month
- 3%** or they currently did not take part
- 2%** 2-3 times per month
- 2%** Once a month

The main sports participated in post limb loss/difference in the past 12 months were:

<b>53%</b>	Swimming	<b>15%</b>	Athletics
<b>50%</b>	Walking	<b>15%</b>	Archery
<b>45%</b>	Cycling	<b>15%</b>	Wheelchair basketball
<b>45%</b>	Gym	<b>13%</b>	Badminton
<b>24%</b>	Gardening	<b>13%</b>	Football
<b>17%</b>	Climbing	<b>10%</b>	Running jogging
<b>16%</b>	Fitness classes	<b>10%</b>	Fishing
<b>16%</b>	Weightlifting	<b>13%</b>	and PE/School sport



## Experiences of Sport and Physical Activity

**78%**

The majority of participants reported that they *“love being active”*

**21%**

Reported that they *“like being active”*

**1%**

Only reported that they do not *“like being active”*

No one reported that they hated physical activity. Regarding *‘who’* the participants would like to participate in sport and physical activity with (see Figure 4),

**74%**

The overriding response was participating with *‘disabled and non-disabled people participating together’*

**55%**

There was also support for participating with friends and family

**40%**

On their own

**35%**

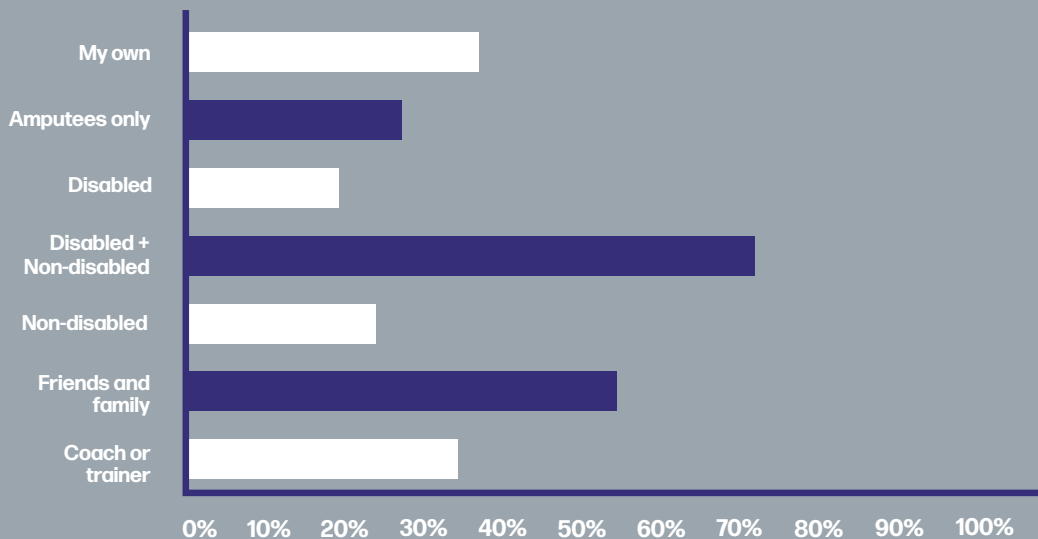
and with a coach or trainer



It is worth noting that some people want to take part with other amputees or other disabled people (**28% and 20% respectively**).

Some also reported, **“No preference, I just enjoy being active whether that is alone or with company”** and **“anyone”** or **“any of the above”**.

It is important to offer and sign-post people to different opportunities to suit their engagement preferences.



**Figure 4:** Preference who to participate with in physical activity and sport



In terms of **‘where’** they would like to participant (**see Figure 5**)

71%

The overriding response across participants was **“anywhere”**

36%

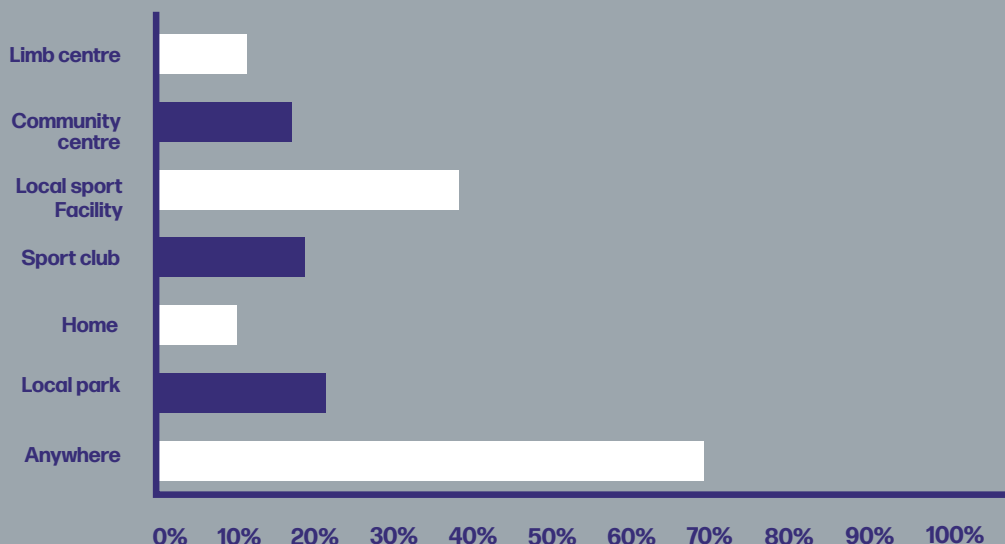
There also did appear a particular preference for local sports facility

22%

and local parks

10%

Only 10% were interested in participating in physical activity at a limb centre. This could be because the opportunity to participate at their limb centre doesn’t yet exist in many limb centres or because patients also need time to grieve for their loss prior to participating in sport.



**Figure 5:** Preferences of where to participate in sport and physical activity

## Barriers to Sport and Physical Activity

The main barriers to sport and physical activity reported by the participants were:

- (a) Pain and discomfort (48%)
- (b) My prosthesis limits me from playing some or all sports/activities (31%)
- (c) My socket fit or comfort limits me from playing some or all sports/activities (30%)
- (d) Not having an activity prosthesis (21%)
- (e) Lack of information about what opportunities are available (19%)



- 18% Lack of support available from local sport/activity facilities for people with my impairment
- 17% Fear of injury
- 16% Other pertinent barriers that were reported included a lack of information about what sports and activities I can do with my disability
- 15% It's too expensive
- 15% I don't know how to find out about suitable sport/activity opportunities
- 15% Fear of falling
- 14% I feel self-conscious about my body-image
- 14% Lack of confidence
- 13% I can't afford to take part
- 13% Lack of energy
- 11% There are no suitable sport/activity opportunities in my area
- 10% Health conditions other than my amputation/limbloss



In contrast, **24%** of participants reported, ***“Nothing stops me from taking part in any physical activity or sport.”***



## Physical Activity Support Providers

# 35%

After limb loss / difference, many of the participants reported the main support providers to encourage sport and physical activity were partners or spouses

### Other support providers were:

- |   |   |
|---|---|
| <b>32%</b> Friends                      | <b>17%</b> Prosthetists                                   |
| <b>29%</b> Parents                      | <b>13%</b> Physiotherapists                               |
| <b>22%</b> Limb centre staff            | <b>12%</b> Personal trainers                              |
| <b>20%</b> Other amputees               | <b>11%</b> Staff at a leisure centre                      |
| <b>19%</b> Charities                    | <b>2%</b> and physical activity advisors at a limb centre |
| <b>19%</b> Sports clubs or associations |   |
| <b>17%</b> Children                     | <b>2%</b> Local authority                                 |

## Examples of specific charities and associations reported in the qualitative findings were:



- LimbPower
- Disabled Golf Association
- Arctic One
- Disability Sport Wales
- WheelPower
- BASA
- Finding Your Feet
- Help for Heroes
- Limbless Association
- Amputee Football Association
- Dan Maskell Trust
- Sports Aid

However, **18%** of participants reported that they have not received any help to support them to engage in sport or physical activity.

## Motivational Factors to Engage in Sport and Physical Activity

Regarding the participants' motivation to become physically active, the main motives were:

- 65% Improve my fitness
- 64% Improve my health
- 62% To have fun / enjoyment and
- 56% Improve my mobility





**Other motives:**

- 48%** More energy
- 48%** Increase confidence and self-esteem
- 43%** To relax and destress
- 42%** Time with family and make new friends
- 39%** Improve appearance
- 37%** Improve my skills and performance
- 35%** Improve stability
- 31%** Opportunity to compete
- 28%** and improve rehabilitation

Some of the participants reported additional motivations and considerations, *“I’d love to do stuff with my family involved, but most things are for amputees only.”* Others reported, *“balance, posture, pain management”* and *“I’ve had breast cancer recently and I do it to help reduce risk of reoccurrence.”*

## Future Levels of Sport and Physical Activity

**88%** An overwhelming majority of participants (88%) reported that over the next 12 months they would like to take part in more physical activity than they do currently.

Only **7%** did not want to take part in more physical activity or sport. Regarding the specific sports they would be interested in doing more of, **the main sports were:**

- |            |                   |            |                       |
|------------|-------------------|------------|-----------------------|
| <b>45%</b> | Swimming          | <b>21%</b> | Fitness classes       |
| <b>40%</b> | Cycling           | <b>19%</b> | Running jogging       |
| <b>37%</b> | Gym               | <b>19%</b> | Snowsports            |
| <b>33%</b> | Walking           | <b>15%</b> | Athletics             |
| <b>26%</b> | Canoeing/kayaking | <b>15%</b> | Wheelchair basketball |
| <b>26%</b> | Climbing          | <b>15%</b> | Weightlifting         |
| <b>22%</b> | Archery           | <b>13%</b> | and badminton         |
| <b>22%</b> | Dancing           |            |                       |

## How can LimbPower (and others) help?

Following 289 responses

**39%** reported that LimbPower has helped them on their journey to living a more physically active lifestyle. In response to the question how has LimbPower helped, **the main reasons were:**

- 35%** Through attending an event
- 22%** Giving advice
- 21%** Through reading a resource
- 19%** and through reading an information sheet

### Other qualitative reasons reported were:

*"A charity space for a marathon"*

*"Being inspiring and meeting others who have overcome difficulties too"*

*"Facebook group being friendly and welcoming. Helps my mental health"*

*"Always inviting me to events even if I haven't responded; I've never been left out, Thank you so much"*

*"LimbPower website"*

*"My wife and I first spoke at a LimbPower event"*





**In contrast 41%** reported that LimbPower has not helped them. A potential reason for this statistic is that **49%** of the participants have not attended a LimbPower event or workshop and **20%** have not read a LimbPower resource.

*“I am unfamiliar with LimbPower, but will be looking into them”,*

*“Look forward to getting to know LimbPower more this year”,*

*and “I’ve only just started to know about LimbPower, LimbPower is all new to me.”*

An overwhelming percentage of participants wanted to hear more from LimbPower about opportunities in physical activity and sport, and they wanted this information disseminated by

**91%** Email

**10%** Telephone

**12%** Via post

**6%** Only did not want to hear from LimbPower



## Recommended Strategies to Promote Sport and Physical Activity

Following a thematic analysis of **289** responses

Six themes were identified:

- Advocacy
- Collaboration
- Inclusivity
- Diversity
- Support
- and more of the same

Each are now reported with representative quotations from the participants.

## The First Theme

### Advocacy,

is about how LimbPower should consider advocating for the rights of individuals with an amputation and promote responsible government and organisational policies and practices.



**Specific 'calls to action' were:**

- (a)** Challenging government policies on benefit claims, how they are assessed, and how these pose a barrier to living a physically active life.

**Participants reported:**

*"I believe the problem is everyone is scared to do too much activity in case they lose their benefits"*

and

*"Act as a pressure group on decision makers"*

- (b)** Challenge the government and the National Health Service to provide activity prosthesis and insure them.

**Participants reported:**

*"Challenging government to provide more active limbs and solutions for more complex cases"*

*"Improve funding for prosthesis in the NHS"*

*"Help with funding for sports limbs"*

*"I love LimbPower sports weekends but I do get jealous of others in the same situation with better prosthesis or blades that they've managed to get on the NHS. It seems to be a postcode lottery"*

*"Advocating for insurance coverage for sport and activity prosthetic limbs. Right now, it is an out of pocket expense. Coverage of these limbs would increase the quality of life for many of us"*

- (c)** Campaign for more disabled parking at sporting arenas.

**One participant reported:**

*"Campaign for disabled parking at sports arenas or facilities."*



# The Second Theme

## Collaboration,

was defined as the need for charities and Limb Centres to work together.

*Two specific strategies were recommended by the participants:*

**(a)** Creating a central body and database.

**Two participants reported:**

*“We need a central body that ties the different charities together that cater for disabled activities”*

and

*“Creating a database of national activities and events.”*

**(b)** Collaboration between charities and Limb Centres via physical activity advisors.

**One participant reported:**

*“Having physical activity advisors based at as many limb centres as possible.”*





# The Third Theme

## Inclusivity,

is defined as being more inclusive of limb difference and regional and rural areas. Regarding inclusivity of limb difference, **one participant reported:**

*“Amputees seem to have a strong identity and support network, but for people with a limb that isn’t fully functional, yet not unable enough to come under the label of a disability it is really hard to find a place where we truly fit. I would like to feel that my limb difference counts for something – not as a limb that isn’t as “big guns” as an amputation”.*

In terms of inclusivity of regional and rural areas, **several participants reported:**

*“Help smaller areas become more inclusive. There’s more activities in bigger urban areas than rural”, “Offer more assistance in the rural areas where there is not much option for people”,*

*and*

*“Providing support for activities in local areas”.*

**One participant reported:**

*“What LimbPower currently does is amazing, but potentially having more things spread out over more of the UK would be better.”*

Specific regions mentioned were:

- East Anglia
- Lincolnshire
- Nottingham
- Portsmouth
- and London

# The Fourth Theme

## Diversity,

reflected the need for a wider range of activities.

Specific examples from participants were:

(a) Activity weeks away

(b) More upper limb activities (e.g. *“Things like tennis are harder missing a hand”*)

(c) Family-based activities (e.g. *“Sporting events and other opportunity to meet families”*)



# The Fifth Theme

## Support,

reflected the need for more information and support for individuals with an amputation and their support networks.

**First:** Start up activities

One participant reported:

*“Need a support framework to help others initiate and set up activities or teams”.*

**Second:** More contextual and localised knowledge of clubs and activities

Participants reported:

*“Help me find clubs and activities in my area”, “Would like more information and athletics clubs in West Wales”, “Put me in touch with local organisations in my area”.*

**Third:** Support for support networks

For example: *“More support for providers of activities who have no experience of amputees ... Teachers need support. Maybe a mentee programme for those who’ve worked with amputees.”*

**Fourth:** Foster relationships.

**One participant reported:**

*“Linking me up with other amputees in my area.”*

**Fifth:** Financial support. The focus on helping to set up activities, the provision of sporting limbs, offer free activities and try and keep costs down.

**Sixth:** Advice on government policies.

**One participant reported:**

*“Support and advice that when you’re active that you’re not going to be taken off personal independence payment or reported for trying to remain active.”*

**Finally:** More online resources: buddy forums, more videos of advanced exercises and more guidance for self-directed exercises (e.g., *“yoga with pics of people with limb difference”*).

## More of the Same,

reflects LimbPower maintaining their current efforts and initiatives.

Participants reported:

*“Keep up the amazing events you are doing, help sheets, motivational posts”*

*“Continue to provide advice and opportunities for people to try different sports”*

*“Carry on what you’re doing”*

*“Keep doing what you’re doing by asking people what they want to try; the support from LimbPower has been amazing”*

## The Sixth Theme

That said, some reported wanting more of existing activities: *“More of the LimbPower junior games”*.





# Conclusion

**The aim of this study was two-fold:**

- (a)** To understand and quantify the perceptions, levels and experiences of sport and physical activity among adults and children before and after limb loss / difference, and
- (b)** To determine what future activities these individual participants would like to engage in and how LimbPower can best support their future goals and aspirations. Aligning with these aims and following an analysis of a quantitative and qualitative survey completed by **289** individuals with limb loss/difference.

**Key findings can be summarised as follows:**

**54%** of participants completed **more than** 150 minutes or more physical activity a week

**25%** between 30-150 minutes of moderate intensity physical activity or sport a week prior to their amputation. Therefore, this finding would suggest that many individuals with an amputation are likely to value physical activity in

their lives post-amputation, because it is likely to have played a significant part in their life and identity pre-amputation. The most common sports participated in were **swimming, running, walking, cycling, gym, and gardening**. However, while certain individuals might naively think it would be wise to invest more time and effort in supporting the uptake of these specific forms of physical activity moving forward, other research findings would suggest otherwise. For example, research conducted in collaboration with LimbPower has shown how it can be challenging for amputees to participate in the same sports they engaged in prior to their amputation **(Wadey & Day, 2018)**. For example, one participant from Wadey and Day's study reported,

*“For some people, going back to something they were good at before can be really disheartening. So, for me, it's good to try sports I wasn't doing before so I have nothing to compare it to. You can only ever achieve.”*

Therefore, rather than streamline the promotion of certain physical activities moving forward, there remains a need to continue to develop and/or maintain a diverse range of sports to cater for all needs across individuals and over time **(Wadey & Day, 2019)**. Put simply, a *'one-size-fits-all'* approach is unlikely to work.



Original findings from the survey have identified a broad range of responses in terms of how challenging it was for the participants to get back into physical activity post-amputation. Experiences were found to range from very easy to very difficult and took an average 7-12 months post-amputation.

**The main barriers reported to sport and physical activity were:**

- (a) Pain and discomfort**
- (b) Prosthesis**
- (c) Socket fit or comfort**

However, paradoxically, research conducted in collaboration with LimbPower have also shown that participating in physical activity can result in certain benefits such as pain relief and prosthesis fit (**Wadey & Day, 2018**).



That said, physical activity can also bring about aches and pains (**Wadey & Day, 2018**), albeit temporary in nature. Therefore, it is important to recognise the dynamic and relational nature of barriers and benefits when educating amputees and their support providers about the benefits of physical activity (**Wadey & Day, 2018**). Physical activity promotional material should aim to reflect the nuanced and complex nature of physical activity experiences.





**46%** 150 minutes or more

**41%** 30-150 minutes of moderate intensity physical activity or sport a week post-amputation

An encouraging finding from the survey was that many participants reported doing:

Interestingly, there was more engagement in sport and physical activity post-amputation than pre-amputation in the category **30-150 minutes** of moderate intensity experience. However, this might be explained from **12%** of the participants having a congenital limb loss / difference, which inflated the post-amputation descriptive statistics.

An alternative interpretation might be that we need to focus less about getting people to *'move more'*, and focus more of our efforts on enhancing their experiences of the sport and physical activity that they do engage in.

To illustrate, the participants reported a desire to participate with **disabled and non-disabled people (74%) and with friends and family (55%)**, as well as maximising the provision of sport and physical activity in their local sports facilities to maintain the uptake of physical activity. That said, and rather than *'resting on our laurels'* about getting people to move more, it is important to recognise that a number of these participants are still not adhering to the World Health Organisation recommended guidelines for physical activity.



Furthermore, **88%** of the participants reported that over the next 12 months they would like to take part in more physical activity. Therefore, a clear finding from the survey is that we need to continue to maximise the uptake of sport and physical activity, as well as investing our efforts to enhance the experience for those who take part.

Based on the findings from the survey, **how can we enhance the uptake and experience of sport and physical activity?**

First, we need sustained and novel efforts to mobilise the support providers who impact amputees' participation in sport and physical activity. These providers largely include the social network (*e.g., parents, children, friends*) of individuals with an amputation. Therefore, rather than investing all or most of our efforts with amputees per se, it is likely to also be advantageous to educate and promote the uptake of physical activity of their support network.

Examples might include running workshops with support providers and constructing activities that include them rather than ‘just’ activities that focus solely on amputees.

**Second**, educational materials on physical activity should reflect the motivational factors reported by amputees, which include, amongst other things, improved fitness, improved health, fun and enjoyment, mobility, appearance, confidence and self-esteem, and time with family and friends.

The responses to this survey have given a ‘voice’ to amputees, and this voice needs to be echoed in promotional material to support the uptake of sport and physical activity.

**Lastly**, other recommended strategies to promote sport and physical activity include:

**Advocating for the rights of individuals with an amputation and promote responsible government and organizational policies and practices;**

**Fostering stronger collaborations between charities and limb centres to work together;**

**Being more inclusive of limb difference and regional and rural areas;**



**Offering a wider range of activities to cater for the needs across individuals and over time;**

**Providing more information and support for individuals with an amputation and for their support networks (e.g., start-up initiatives);**

**Sustaining the efforts of organizations (i.e., more of the same)**





Regarding these final recommendations and rather than providing generic guidelines here, it is encouraged that key stakeholders, amputees and their support networks work together and continue to discuss and debate how to maximise their uptake and the processes that will lead the achievement of these broader aims and ambitions. Generic guidelines are unlikely to work. Guidelines that are nuanced, contextual and dynamic are perhaps needed moving forward to best support the needs of individuals with an amputation for their support network.

Towards a conclusion, this survey has given voice to individuals with an amputation / people with limb difference across the United Kingdom about their perceptions, levels and experiences of sport and physical activity and how to best support their future goals and aspirations moving forward. Aside from these encouraging findings, more research is now needed to build upon this survey that goes beyond an intrapersonal perspective to account for broader social-cultural considerations. For example, an important line of research would be to consider how amputees support networks impact amputees' levels and experiences of sport and physical activity. This future line of research is not intended to detract from research on individuals with an amputation / limb difference, quite the contrary, but to reflect the wealth of social-cultural factors that can impact the uptake and experience of physical activity.

