# Wear and use of prostheses in sport by adolescents with upper limb absence:
A Mixed Methods Study

*In what way can objective activity monitoring and participant interviews develop our understanding of prosthesis wear and use by adolescents with upper limb absence during sport?*

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***'You don't really believe that – that scientists don't care about the why.' 'They used to be interested in the whys,'… 'Now it seems all they're concerned with is the question of how – how does the body work, how do the planets move?'… [in response] 'Not the good scientists.'*** [1 p84]

Today has finally arrived: writing this message is the finishing touch of my thesis and marks the end of the roller-coaster that is my Masters degree. During this time I have grown as a person and a researcher.

Firstly, I would like to say a massive thank you to my primary supervisor, Dr. John Head, for all your support, patience, guidance, and particularly for having faith in me when I didn't. From you I have learnt so much, you have shaped me as a researcher and encouraged my interest in the 'whys' as well as the 'hows'. Thank you to Prof. Laurence Kenney, my co-supervisor, you are a wealth of knowledge and kept me on track even when I went off on a tangent. Together, John and Laurence challenged me to achieve more than I ever thought possible. Thanks to George Banwell, personal tutor extraordinaire, for always being there when I needed him. Also, thank you to all the other academics who have supported and guided my research over the last two years.

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To you all, thank you.

*Natalie*

# List of Abbreviations

| | |
|---|---|
| AI | Anatomically intact |
| AX3 | Axivity AX3 activity monitoring device |
| CMO | Chief Medical Officer |
| GCSE | General Certificate of Secondary Education |
| GT3X+ | ActiGraph GT3X+ activity monitoring device |
| NHS | National Health Service, UK |
| PA | Physical activity |
| PE | Physical education in school |
| TD | Terminal device |
| UK | United Kingdom |
| ULA | Upper limb absent |

# Glossary of Terms

| | | |
|---|---|---|
| Activity (relating to symmetry of upper limb use) | | The sum of the vector magnitudes of the accelerations across all three axes. |
| Adolescent | | A person aged 10 to 19 years inclusive. |
| Axivity AX3 | | An activity monitoring device that contains a triaxial accelerometer. |
| Children's Activity Prosthetic Fund | | A Department of Health England initiative which provides funding for sport-specific prosthesis provision, and research into improving prosthetic technology for children with limb absence. |
| Dominant limb | | The limb with which an anatomically intact person writes or the anatomically intact limb for an individual with limb absence. |
| Periods of activity | Everyday activity excluding sport | Period of the study not including sport. |
| | Overall | The entire duration of the study, combining "Sport" and "Everyday activity excluding sport". |
| | Sport | Periods based on self-reported times where sport was participated in. |

| | |
|---|---|
| Physical activity | Any bodily movement produced by skeletal muscles that requires energy expenditure – including activities undertaken while working, playing, carrying out household chores, travelling, and engaging in recreational pursuits. |
| Prosthesis | Devices intended to restore function and appearance for those with limb absence. |
| Prosthesis wear time (C) | Time the prosthesis was worn determined by subtracting "prosthesis non-wear", as identified by the non-wear algorithm, from the duration of the study. |
| Prosthesis wear time (SR) | Time the prosthesis was worn as identified by the self-reported wear time as indicated in the activity diary. |
| Sport | An activity involving physical exertion, with or without game or competition elements, with a minimal duration of half an hour and where skills and physical endurance are either required or to be improved. |
| Symmetry of upper limb use | The balance of upper limb use across both arms which indicates the percentage of reliance on the dominant arm and identified prosthesis use. |
| Terminal device | The aspect of an upper limb prosthesis which substitutes for the anatomical hand. |
| Upper limb absence | Partial or total absence of an upper limb, whether since birth or due to amputation. |

# Abstract

Despite clear physical and psychosocial benefits, disabled people are half as likely to participate in sport as able-bodied peers. Active adolescents typically become active adults, making early engagement in sport important. For those with upper limb absence, sport participation levels are poorly understood, with limited literature on prosthesis provision, usage or impact. Activity monitors facilitate objective data collection on arm use during sport activity, but have yet to be used to explore this.

The objectives of this feasibility study are to:

- Capture objective prosthesis wear and usage patterns from physically active upper limb absent (ULA) adolescents;
- Develop understanding of how this usage relates to sports participation; and to
- Gather sports participation data and capture participants' views on sport, prostheses and reasons for use / non-use in sport.

Three active adolescents with unilateral upper limb absence were recruited alongside four comparable anatomically intact (AI) adolescents. Bilaterally wrist-worn activity monitors and activity diaries were used for data collection over 2-weeks. The ULA participants also undertook semi-structured interviews.

Prostheses were worn between 16.2% and 56.5% of the time during sport. Reliance on the anatomical arm during prosthesis wear was 72% overall but 68% during sports. Contrastingly, AI adolescents showed similar reliance on both arms (51% reliance on dominant overall, 50% during sport). Thematically analysed interviews identified three organising themes, participants' attitudes to: sport; prosthesis use during sport and everyday prosthesis use. The global theme identified was that, "*the ability to participate in sport has a powerful influence on participants' lives. Despite minimal prosthesis wear during sport, prostheses were used when participants felt they offered specific benefits.*"

Overall data suggest minimal use of prostheses during sport, with devices used only when participants believed it functionally benefited participation. With prosthesis wear, patterns of activity were still skewed towards the anatomical side. These findings raise questions over functionality and usability of current prostheses for sports. Larger studies using similar methods are therefore warranted.

**Keywords:**

Upper limb absence, Prosthesis wear, Prosthesis use, Sport, Adolescents, Mixed methods, Activity monitoring, Semi-structured interviews

# Chapter 1: Introduction

It is well known that participating in sport provides a range of physical and psychosocial benefits, for both able bodied and disabled people. In particular, for individuals with upper limb absence, sport participation has the potential to socially re-engage the individual and reduce isolation [2].

The purpose of an upper limb prosthesis is to restore function and appearance. Additionally, wearing and using a prosthesis may reduce the risk of overuse injuries on the anatomical arm [3], although the evidence base for this is somewhat contradictory [4, 5].

At a recent international prosthetics conference a rehabilitation consultant suggested that clinical outcome measures used in prosthetics are poor due to their predominately subjective nature but that "*they're all we have*" [6]. With Chadwell and colleagues pioneering the use of activity monitoring devices to provide data on prosthesis wear times and upper limb activity patterns in adults with upper limb absence [7-9], the objective measurement of one, if not the most important outcome in the real world becomes possible.

The recently announced Government initiative to support sport-specific prosthesis provision for children recognises the importance of suitable prosthetic provision for sports activities and social inclusion [10]. Currently, there is no available evidence supporting when or how either sports-specific or other upper limb prostheses are used in sport, making it difficult to understand the impact of this provision. This thesis reports on a study using activity monitoring data and semi structured interviews to identify prosthesis wear and usage patterns in adolescents with unilateral upper limb absence during sport.

The aim of this study is to explore levels of sports participation and prosthesis wear / usage during sport in active adolescents with upper limb absence, more specifically this will be achieved by:

- Capturing objective prosthesis wear and usage patterns from physically active upper limb absent (ULA) adolescents;
- Developing an understanding of how this usage relates to sports participation; and

- Gathering sports participation data and capture participants' views on sport, prostheses and reasons for use / non-use in sport.

**Chapter 2** begins by introducing the current state and importance of sport participation in England, with reference to its impact on physical activity and inactivity. Current levels of sport participation are considered within the wider population, and amongst those with disability. Factors that influence levels of participation amongst disabled people, and particularly those with upper limb absence, are discussed, including barriers and facilitators. Prevalence and impact of upper limb absence, prosthesis options and prosthesis acceptance are also discussed alongside what is known about upper limb prosthesis use in sport.

The mixed methods study design is described in **Chapter 3**, including activity monitoring and interviews. **Chapter 4** reports the results of this study.

Finally, **Chapter 5** discusses the results, identifies limitations, and draws conclusions and recommendations for future work.

# Chapter 2: Background

Sport plays a major role in the lives of billions of people. Culturally, historically, and even politically, sport is very often used to embody the essence of nations. Sporting rivalries may even replace more serious disagreements and conflicts. The World Health Organization defines sport as ***"an activity involving physical exertion, with or without game or competition elements, with a minimal duration of half an hour and where skills and physical endurance are either required or to be improved"*** as cited by Bragaru [11 p12]. At an individual level, undertaking sport and similar activities can have many physical and psychosocial benefits, and many able-bodied people take up these opportunities. However, evidence suggests that there are fewer opportunities for individuals with limb absence to engage in sport [2], despite the rise in the levels of awareness of disability sport. Also, much of the media coverage and focus for disability sport has been directed towards elite level amputee running; there has been less focus on individuals with upper limb absence or on participation by people who are not elite level athletes.

There are many reasons why individuals do not participate in sport and activities. For most able-bodied people, these often relate to a lack of time or willingness to participate. However, according to Head and Brittles [2] for those affected by disability or limb absence, this can often be due to a lack of available resources and facilities. Not being able to access sport can compound the effects of limb loss, such as the sense of isolation and frustration; conversely, engaging in sport has the potential to help to re-energise an affected person [2] The challenge for authorities now is to understand how sport can be made more accessible to all, in real terms and at all levels of participation.

## 2.1 Physical Activity

Physical activity (PA) is defined as ***"any bodily movement produced by skeletal muscles that requires energy expenditure – including activities undertaken while working, playing, carrying out household chores, travelling, and engaging in recreational pursuits"*** [12]. Sport may be viewed as a subcategory of PA which brings with it the additional benefit of improving social well-being and reducing levels of isolation [2].

### 2.1.1 Physical Activity Recommendations

The importance of undertaking PA and the repercussions of an inactive population on healthcare and social funding are recognised nationally, with the UK Chief Medical Officers (CMOs) guidelines for PA (Table 1). These guidelines apply to able-bodied and disabled individuals alike (13). Currently, only 60.6% of the population in England meet these minimum recommendations for levels of activity (14). Furthermore, our population is approximately 20% less active than it was in the 1960s (15). If this trend continues, activity levels are set to fall by a further 35% by 2030 (15). This is of great concern since physical inactivity is in the top 10 causes of disease and disability in England (15).

*Table 1: UK guidelines for physical activity (Source: (15, 16))*

| | |
|---|---|
| Children and young people aged 5-18 years | • Minimum 60 minutes up to several hours of moderate to vigorous intensity physical activity daily.<br>• Vigorous intensity physical activity should be engaged in a minimum of 3 times per week. These activities strengthen muscle and bone.<br>• Time spent sedentary for extended periods of time should be minimised. |
| Adults aged 19-64 years | • Be active daily.<br>• 150 minutes of moderate intensity activity or 75 minutes of vigorous intensity activity per week in sessions of 10 minutes or more. Or a combination of these.<br>• Muscle strengthening activity twice per week.<br>• Time spent sedentary for extended periods of time should be minimised. |
| Adults aged 65 years and over | • Recommendations as per those for adults aged 19-64 years.<br>• Those at risk of falls should incorporate balance and coordination improving activity twice per week. |

### 2.1.2 Actual Physical Activity Levels and Trends with Time

Recent national surveys have found that PA levels decrease with age amongst adults (14, 16). Sport England (17) and Perrier et al. (18) identified the same trend and found the proportional decline is similar across both able-bodied and disabled populations. This consistent theme can be attributed to specific transition points such as increasing work commitments or becoming a parent [15]. There has generally been a decline in PA levels of adults between 2012 [16] and 2016/17 [14]. In 2012 English men were typically more physically active than English women [16]. By 2016/17, the rate of adult males meeting PA guidelines decreased from 66% to 63.2%, and adult females increased from 54% to 58.3% [14].

There was a positive trend in the proportion of children in England meeting PA recommendations by 2015 with levels increasing from 21% to 23% and 16% to 20% for boys and girls respectively [16, 19]. In 2012 English boys were typically more physically active than English girls [16]. It should be noted that in 2012 the activity levels of Scottish children far exceeded that of their respective English peers.

## 2.2 Physical Inactivity – The Cost

Physical inactivity is considered a global health crisis, placing a burden on an individual's health [20, 21] and cost the NHS £455 million in 2013-2014 [22]. This figure increased to a reported £0.9 billion per year in 2016 [15]. Physical inactivity is a key contributor to premature mortality within the UK [22].

With regard to children, in 2014 it was estimated that the inactivity of 11–25 year olds will, over their lifetimes, result in a cost of £53.3 billion [23]. However, the same report suggested that if an inactive individual changes their lifestyle to meet the recommended guidelines for PA, that savings of £18,700 can be made over the lifespan of an 11–15 year old, or £40,100 for a 16–29 year old [23]. These figures scale up to a saving of £0.8 billion if an additional 1% of the 11–25 year old population achieved the advised PA levels [23]. These savings are linked to a reduction in healthcare costs and improved life quality and longevity [23].

These projected costs, are partly why the Government has adopted policies that aim to increase PA and sport participation rates, aspiring to accomplish year-on-year growth of those achieving recommended PA levels [10, 24, 25].

## 2.3 Sport Participation Levels

In the UK 10% of the adult population regularly participate in sport. This is comparable to an average of 8% across the EU and 16% in Ireland [16]. There is a significant gender gap in sports participation in the UK, with 41% of men participating compared to 30% of women [26]. This trend was also exhibited by individuals with acquired physical disabilities [18]. On average men in England take part in sport and exercise for 2.1 hours per week and women 1.2 hours per week [16]. The participation in sport and exercise declines with age to an average of 0.5 hours/week(men) or 0.2 hours/week (women) for the over-75s [16].

Around 85% of children aged 2–15 years participate in informal sport, exercise and active play in England, whereas formal sport and exercise is engaged in by only 43% of the same demographic [16]. According to the English Health Behaviour in School-aged Children study [16], 49% of 11 year olds, 52% of 13 year olds and 57% of 15 year olds participate in sport a minimum of twice per week outside of school hours.

## 2.4 Benefits of Sport Participation in Adults and Children

### 2.4.1 General

Participation in sport and active recreation can provide physical and psychosocial benefits for able-bodied individuals, people with disability and those with limb-absence across all age groups [24, 27-33] (Figures 1 and 2). If sport participation has a positive association with happiness and well-being at a young age it is likely that this will lead to greater levels of participation in adulthood, whether the person is able-bodied or disabled [24, 34]. PA habits developed in childhood have been seen to exhibit a prolonged positive effect on bone health into adulthood [21]. Active children and adolescents typically become active adults resulting in better health at all life stages [35-37] (Figure 3). The benefits of sport have been found to improve well-being and promote a healthy lifestyle [11, 30]. Although, it is acknowledged that individuals who become excessively dependent on sport may have associated mental health problems [38] and an increased risk of injury [11].

The CMO PA guidelines and their endorsement of sport participation are as applicable to individuals with disability as to their able-bodied counterparts, taking into consideration physical capacity and specific health or risk issues [15].

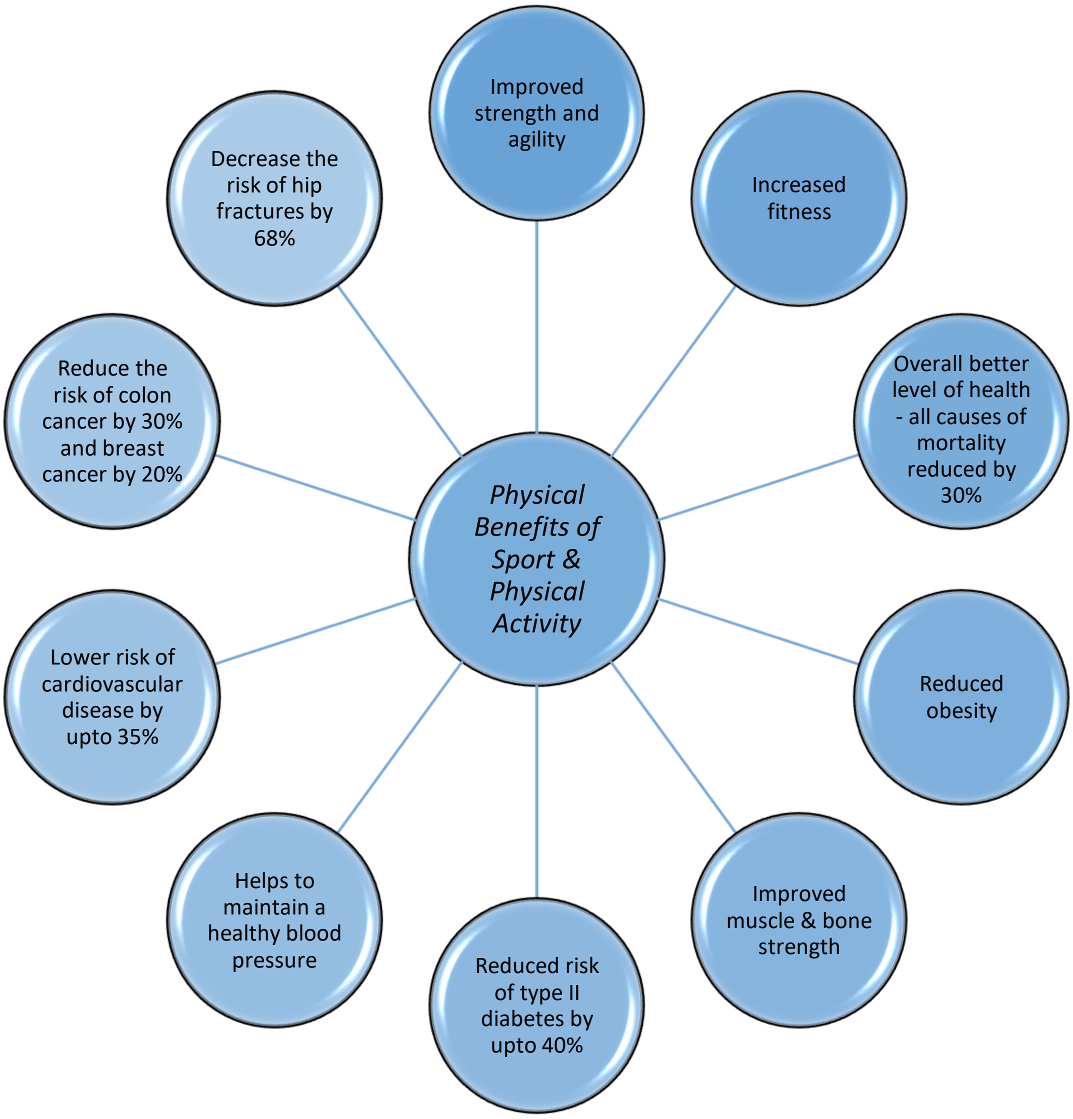


*Figure 1: Examples of physical benefits of sports and physical activity (collated by author [15, 39, 40])*


*Figure 2: Examples of psychosocial benefits of sport and physical activity (collated by author [15, 34, 39-42])*

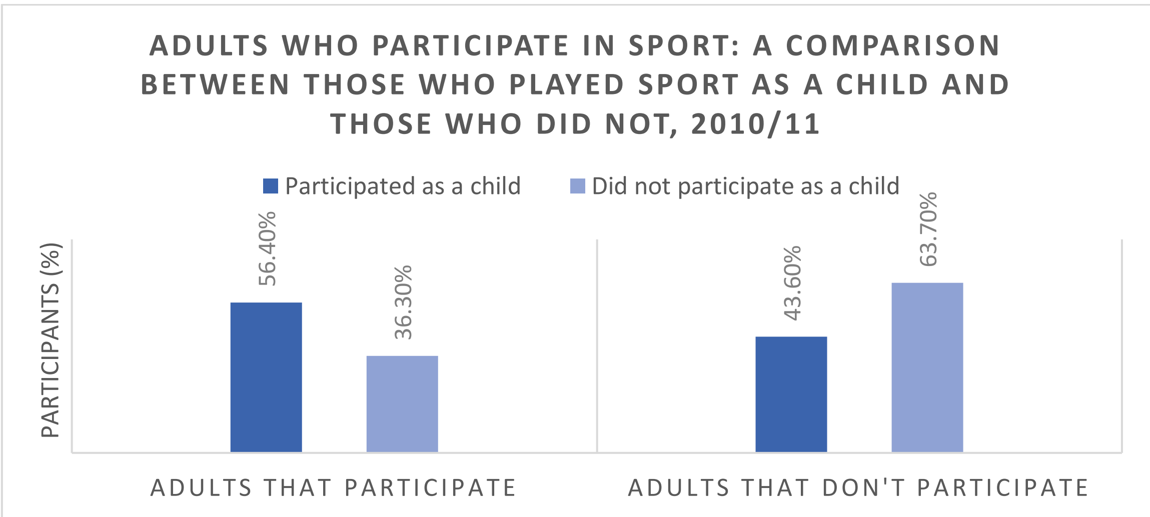


*Figure 3: Adults who participate in sport: a comparison between those who played sport as a child and those who did not, 2010/11 (Source: [37])*

### 2.4.2 Children Specific

Sport participation can be particularly beneficial for children, supporting competence development, self-determination, identity establishment and positive self-esteem whilst also improving social skills and interactions [(43-47)]. Sport participation has also been seen to improve literacy and numeracy skills in children, suggesting a link to improved academic achievement in the longer term [(48)]. Physically, skeletal development is also encouraged by weight bearing exercises allied to sport participation [(40)]. However, an inability to engage in sport has been shown to have a negative influence on a disabled child's quality of life [(31)]. Furthermore, an inability to participate can lead to segregation and psychosocial issues for the affected child, both at the time and in the future, leading potentially to depression and further isolation [(49)].

### 2.4.3 Limb Absent Specific

Bragaru et al. [(50)] proposed that the psychosocial benefits for those with limb absence were at least equal to, if not greater, than that of the general population. Indeed, some consider sport to be a comprehensive rehabilitation tool [(51)].

Studies found that participation in sport by those with limb absence improves quality of life, life satisfaction, self-esteem and body image [(52-56)]. A review by Bragaru et al. [(50)] supported these findings, reporting that participation in sport commonly improved psychological well-being including better self-esteem, body image and locus of control. Additionally, Bragaru et al. [(50)] identified that engaging in sport increased cardiopulmonary function. Sporner et al. [(52)] suggested that due to sport participation, amputees experienced improved disability acceptance and confidence. Moreover, sport active amputees also encounter fewer cogitative and physical limitations compared to non-participants, while also benefiting from socialisation with other amputees and appreciating the opportunity to be competitive [(52)]. Head and Brittles [(2)] suggested that for those with limb absence, participation in sport reduces social isolation, aids coping mechanisms and helps to maintain prosthesis socket fit. The improved prosthesis socket fit is associated with lower obesity levels and a sustained healthy weight management, thereby, improving residuum volume control [(2)]. Furthermore, Chin et al. [57] identified that higher levels of fitness can positively affect clinical outcome measures. While Yazicioglu et al. [58] found that participation in football improved balance. However, both studies only consider lower limb amputees and there is no evidence to indicate whether the same applies to upper limb amputees.

## 2.5 Disability and Sport

Long-term health issues and potential secondary disabilities are an increasing concern for people with disabilities, due to increased life expectancy [59]. Health promotion aims to reduce secondary debilitating conditions caused by inactivity, thereby facilitating healthy lives for those with disability [60]. This is evident in the NHS's *Five Year Forward View* [61] where a key strategy is illness prevention. Lack of regular sport engagement can potentially increase the risk of secondary health conditions [62]. This is particularly important for children with disability, who make up 6% of all children in the UK [63]. They have been found to have lower levels of cardiopulmonary fitness, muscle endurance and an increased tendency for obesity [32]. Furthermore, it has been reported that the greater the level of disability the lower the sport participation level [14] (Figure 4).

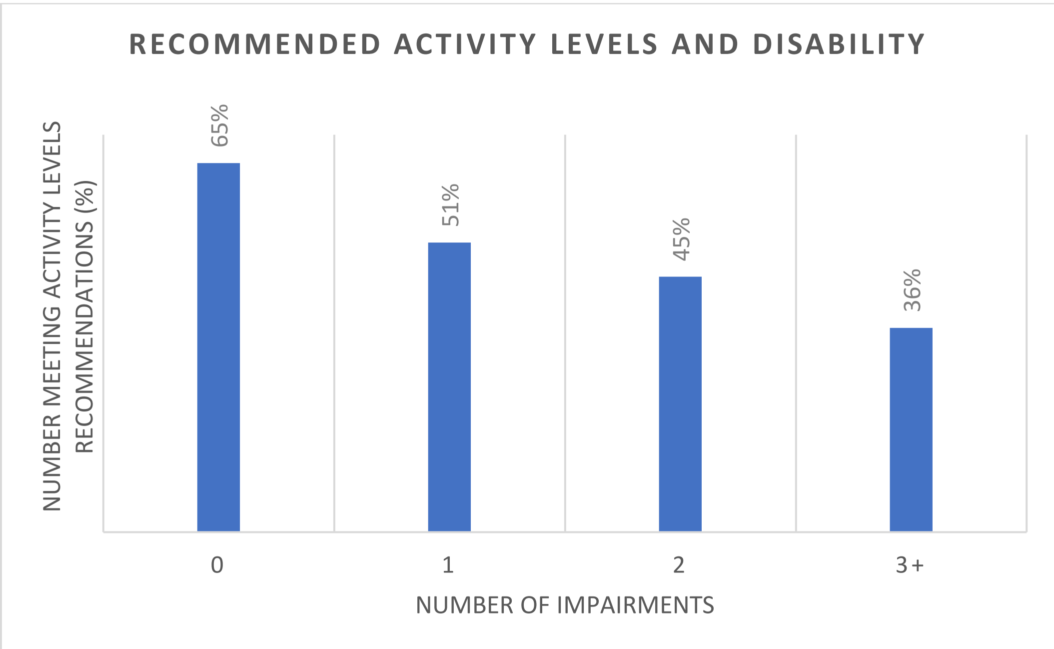


*Figure 4: Recommended activity levels and disability 2016/17 (Source: [14])*

### 2.5.1 The Rise of Elite Para-sports

Since the 1980s, opportunities for those with disability to participate in sport have increased, particularly for those people who could potentially be considered 'elite athletes' [(64)]. Events such as the Paralympics and Invictus Games, in tandem with live television coverage, has made many para-athletes household names. In London 2012, 4,237 para-athletes competed across 20 disciplines [(11)], and in Rio 2016, Team GB came second with their greatest medal haul since 1988 [(65)]. Moreover, the bold way in which the media covered the Paralympics (tackling the traditionally taboo subject of disability with insight and humour) resulted in record numbers of younger viewers [(66)].

Since its inauguration participant numbers have increased with each subsequent Paralympic games [(11)], with Paralympian athletes becoming high-profile, positive role models for disabled people [(51)]. The Invictus Games [(67)] also engage arguably some of the hardest-to-reach military personnel and veterans with disability. As Prince Harry, Duke of Sussex [(68)] suggested, the goal is not the medal count: sport gives purpose to competitors' lives whilst allowing the positive effect to ripple out to include participants' family and friends.

This increased awareness has led to the development of disability-centred sports organisations providing information, resources and support for most sport and leisure activities [(64, 69, 70)]. However, despite these sporting opportunities to increase PA levels, it has been found that disabled people are only half as likely to be as active as their able-bodied peers [(15)], and children with disability also display lower activity levels than their able-bodied peers [(71)].

### 2.5.2 Attitudes to Para-sport

#### *2.5.2.1 Children with Disability*

The selection of appropriate sports increases the level and extent of participation for individuals with physical disability [(62)]. Swimming, cycling and football are the most popular participation sports amongst abled-bodied and disabled children [(17, 37, 62)]. This supports

Schreuer et al. [72] and Woodmansee et al. [30] who reported that children and adolescents with disability wish to participate in the same activities as their able-bodied peers. Woodmansee et al. [30] found that children with a disability were less likely to participate in athletics, team sports, snow sports, games and non-team sports compared to their able-bodied peers. However, they were more likely to participate in dancing, horse riding and “playing on equipment” [24, 30]. Sport England [24] reported that 62% of children with disability had negative feelings about being excluded from sport due to their disability. It is important to acknowledge that some sports are better suited to, and therefore more accessible in particular environments, such as snow sports. In some areas a sport of choice may be inaccessible to all people, regardless of disability or not.

#### *2.5.2.2 People with Limb Absence*

There is limited evidence regarding sport participation and the limb absent population. However, where data is available it suggests that there are many popular sports amongst those with limb absence (Table 2) Paralympic sports with an amputee classification for competition are seen in Figure 5. LimbPower [73] found that 83% of their study population were interested in increasing their sport or activity level. Upper limb absent (ULA) participants reported that the activity participation most negatively impacted by upper limb absence, were considered to be fishing, golf, swimming and surfing [74].

LimbPower [73] found that 89% of their respondents were aged 36 years and under, with 86% having been prosthesis users for 3–10 years. Of these, 92% of individuals with specialised sports prostheses participate in sport (Figure 6). Bragaru [11] identified that people with upper limb absence demonstrate more similar sport participation characteristics to able-bodied individuals than people with lower limb absence do. This concurs with the findings of Gallagher et al. [75], where 38.5% of individuals with upper limb absence felt in some way restricted with regards to participation in sport and PA, compared to 78.6% of those with lower limb absence. A pattern has also been suggested by Head and Brittles [2], whereby those with limb absence who were active, were very active.

*Table 2: Participation in sports amongst amputees in various countries (collated by author)*

| **SPORT** | **COUNTRY** | |
|---|---|---|
| | **UK** [73] | **Netherlands *** <br> *** ULA Athletes only** [11] |
| Cycling | 29% | 44% |
| Fitness / Indoor Training | 28% | 35% |
| Golf | 10% | - |
| Racquet Sports | - | 19% |
| Running / Jogging | 10% | 21% |
| Shooting | 9% | - |
| Swimming | 35% | 21% |
| Walking | 33% | 33% |
| Weightlifting | 12% | - |
| Wheelchair Basketball | 8% | - |

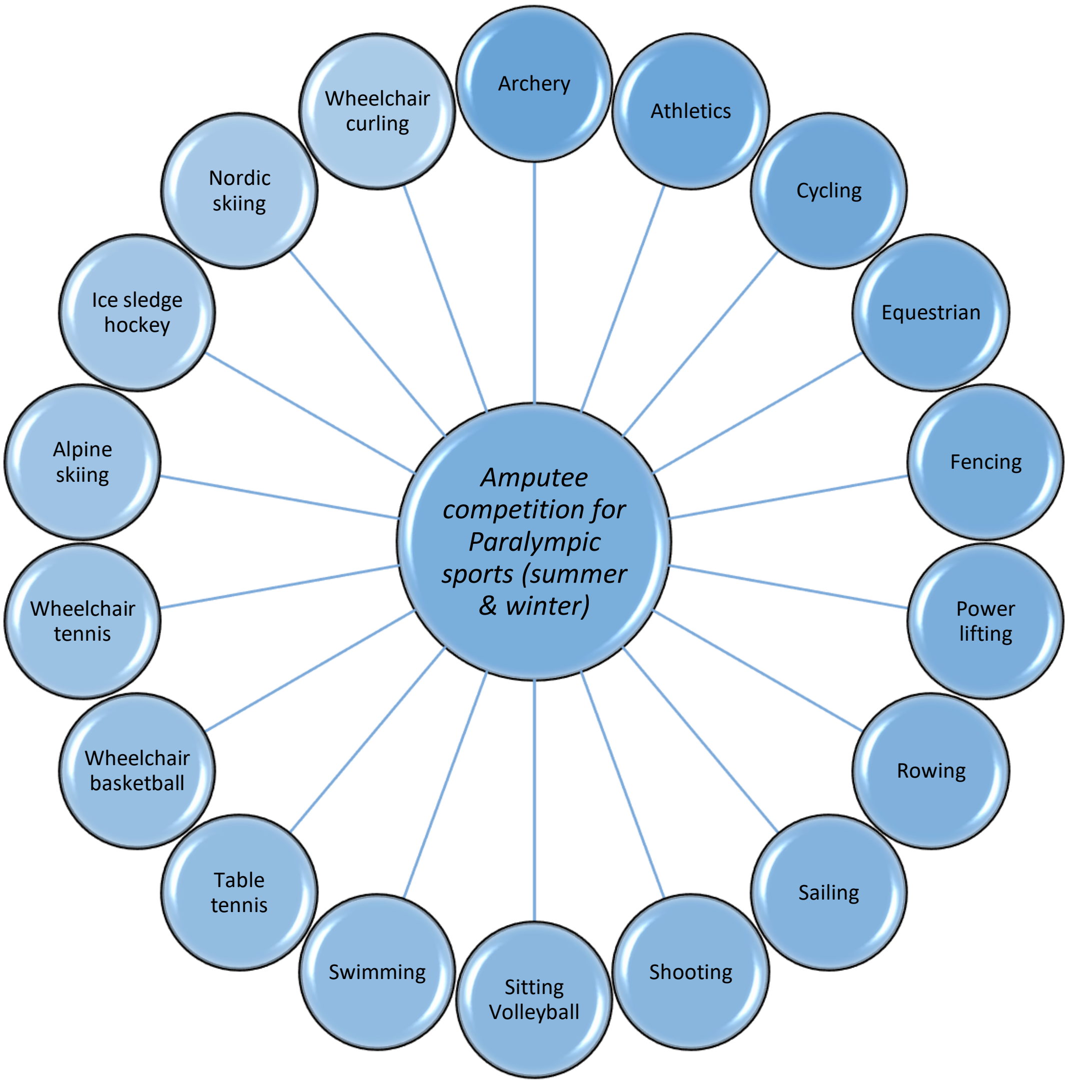


*Figure 5: Amputee competition for Paralympic sports (summer & winter) (Source: [76])*

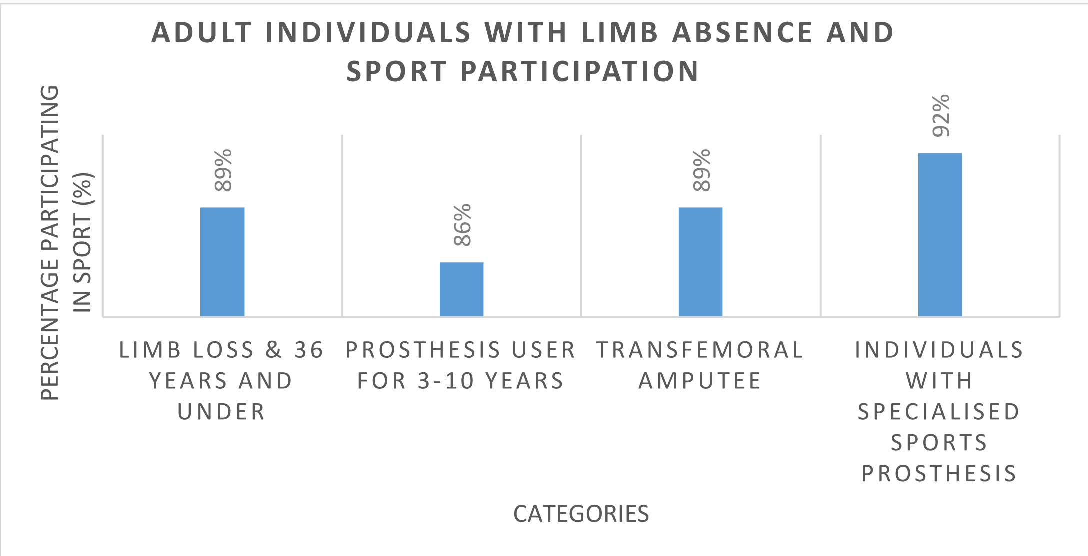


*Figure 6: Adult individuals with limb absence and sport participation (Source [73])*

## 2.5.3 Para-sport Participation Levels

### *2.5.3.1 Adults*

#### 2.5.3.1.1 Adults with Disability

In 2002 it was reported that 81% of disabled adults in England were found to have enjoyed sport whilst at school [17]. However, it should be noted that, this report does not state whether these adults had a disability when they were at school. By 2017 only 43% of adults with a disability actively participated in sport [77].

#### 2.5.3.1.2 Adults with Upper Limb Absence

In the UK 78% of adults with upper limb absence engaged in exercise, PA or sport [73]; this is a significantly higher proportion than that of the general population of people with disability. Typically, those with acquired upper limb absence participate in sport less than those with congenital upper limb absence [11]. Having been born without a partial / total upper limb those with congenital limb absence have developed their use of the residual limb in conjunction with the anatomically intact limb naturally. This demographic has an established understanding of their fundamental capacity and have grown up knowing no different. It can be said that this allows for an increased confidence in social settings compared to those with an amputation who have experienced loss of a limb and who have to adapt to a "new normal" and potentially rethink types and levels of sports participation. As such, this may in part be the cause of the difference in sport levels between those with acquired and congenital limb absence.

In the Netherlands only 19% of disabled individuals engage in sports, compared to 33% of able-bodied individuals [11]. In Europe 11%-39% of amputees participate in sport, compared to 61% in the USA [50]. However, in the Netherlands 57% of individuals with upper limb absence participate in sports regularly, in comparison to 32% of those with lower limb deficiency [11, 78]. This shows inconsistency of participation levels across the world even amongst high income countries. Levels of sports participation globally depend on several factors, these may include the perceived levels of social acceptance of disability or recreational sports participation. Furthermore, influences from conflicts may alter perceptions of and numbers of highly active amputees who may become positive role models for others with limb absence. Countries, such as the USA are known for their sports orientated culture and recent conflicts, this may account for their amputees' higher sports participation levels.

#### *2.5.3.2 Children*

##### 2.5.3.2.1 Children with Disability

In the UK in 2001, only 40% of disabled children and young people took part in some sports activities after school; 47% did so at weekends, and 59% during half-terms and holidays. By contrast, in 1999, their able-bodied peers had participation levels during the same intervals of 79%, 74% and 78% respectively [24]. Children with disabilities tend to find participation more restricted than their able-bodied peers [32, 72]. There are no figures currently available for the number of ULA children that participate in sport in the UK.

### 2.5.4 Barriers to and Facilitators of Sport Participation

Sport as a subcategory of PA is also influenced by the same barriers and facilitators, and as such, evidence for both topics has been considered. Van der Ploeg et al. [79] devised a model to identify factors that influence PA behaviour in individuals with a disability (Figure 7). Studies often divide barriers to and facilitators of sport into two categories; personal and environmental [62, 80]. Figure 8 illustrates aspects that influence sport participation for individuals with lower limb absence separated under technical, social and personal headings [11]. A review of literature concerning the perceived barriers and facilitators to PA for children with disability [81] found consistent factors amongst the studies which were categorised into personal, social, environmental, and policy or programme (Figure 9). It has been identified that the importance of an influence depends on whether the child or their parents provided the data [81]. The barriers and facilitators for children with disability have been identified as being similar to that of able-bodied peers [81].

Thirty-eight percent of individuals were found to give up a hobby following amputation, although 46% took up a new sport [82]. There is insufficient research available to compare the difference in influencing factors for those with congenital limb absence and those with amputation. In order to adjust PA behaviour, it is the modifiable factors that should primarily be addressed [80].

#### *2.5.4.1 Barriers for Children with Disability*

Barriers specific to children with disability include negative societal attitudes to disability, inadequate and inaccessible facilities, insufficient appropriate sport information and programmes, inadequately trained staff to facilitated activity, transportation, cost, fatigue, a feeling of dependency, and the severity of the disability [24, 62, 81]. However, with the increasing profile of disability in sport and on television, including children's television shows, some of these attitudes and obstacles may be becoming less apparent.

#### *2.5.4.2 Barriers for People with Limb Absence*

LimbPower [73] found key barriers for people with limb absence to be: prosthetic limitations (28%), socket fit / comfort (22%), lack of fitness (19%), lack of facility support (18%) and fear of falling (17%). Conversely, a Dutch study [50] identified insufficient facilities, lack of information, inaccessibility to suitable prosthesis, inadequate prosthesis performance, and high prosthesis cost to be key barriers. The ULA-specific study [11] found that increasing levels of disability such as additional health problems and more proximal levels of limb absence increased limitations. Typically, amputees do not take part in sport due to lack of motivation, additional medical problems, personal reasons and past experiences [11].

Sport England has a series of policies aimed at eliminating discrimination against disabled people wishing to undertake sport and improving the quality of this participation [24]. However, in many cases, where equipment and resources are needed for sports participation, the availability of these assets are restricted to the 'elite' level participants and the impact of Sport England's policies on 'ordinary' disabled people has been questioned [2]. Furthermore, evidence suggests that patients have experienced unrealistic expectations with regard to attainable targets and sport prosthesis provision, as well as having felt pressured to participate in sport with the increased profile of high-end para-sport [83].

#### 2.5.4.3 Facilitators for People with Limb Absence

Factors that increase sports participation following amputation include sporting activity prior to limb loss, and a higher level of education and sports information provided by friends / family [11]. Key motivators for participation for individuals with limb absence identified by LimbPower [73] were: enjoyment / fun (67%), fitness (61%), improving health (56%), relaxing / de-stressing (43%) and socialising (40%), whereas, Bragaru [11] found two aspects had greater motivational value: improving health (84%) and pleasure (72%). Over 50% of individuals with upper limb absence partake for physical and psychosocial benefits [11]. Bragaru et al. [50] established that the risk of injury was outweighed by the emotional benefits of participation. There is currently no available literature regarding barriers to, or facilitators of, sport for children with upper limb absence.

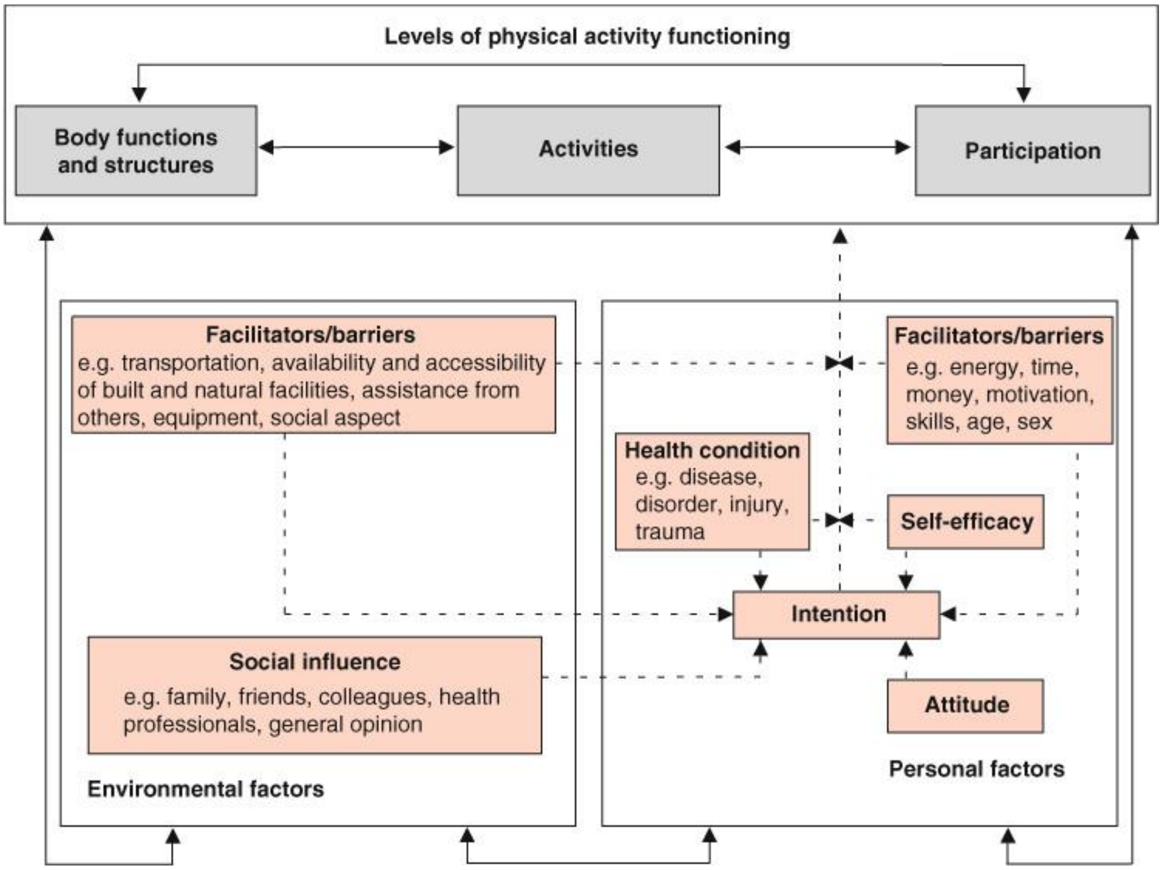


*Figure 7: Physical activity for people with a disability (PAD) model. An integrated model of physical activity behaviour and its relation with functioning and disability. The International Classification of Functioning, Disability and Health (ICF) model framework is shown by the white and grey boxes and the solid arrows. The determinants of physical activity behaviour are shown in the orange boxes. The dashed arrows represent the pathway through which these factors determine physical activity – although not all possible pathways and relations are shown. Most of the dashed arrows also work in the opposite direction and, as shown in the general framework, all components of the integrated model interact with each other. (Source: [79] Permission to reproduce this figure has been granted by Springer Nature)*

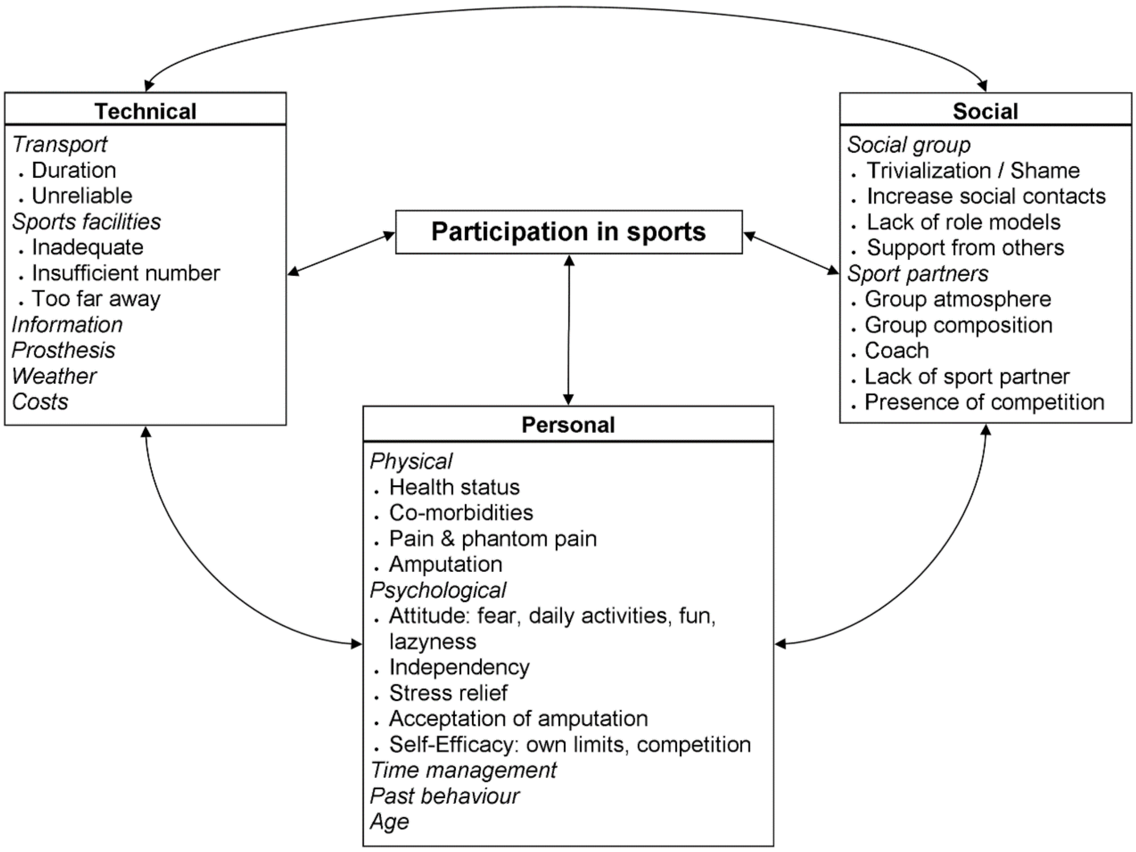


*Figure 8: Aspects that influence sport participation: lower limb absent demographic (Source [84])*

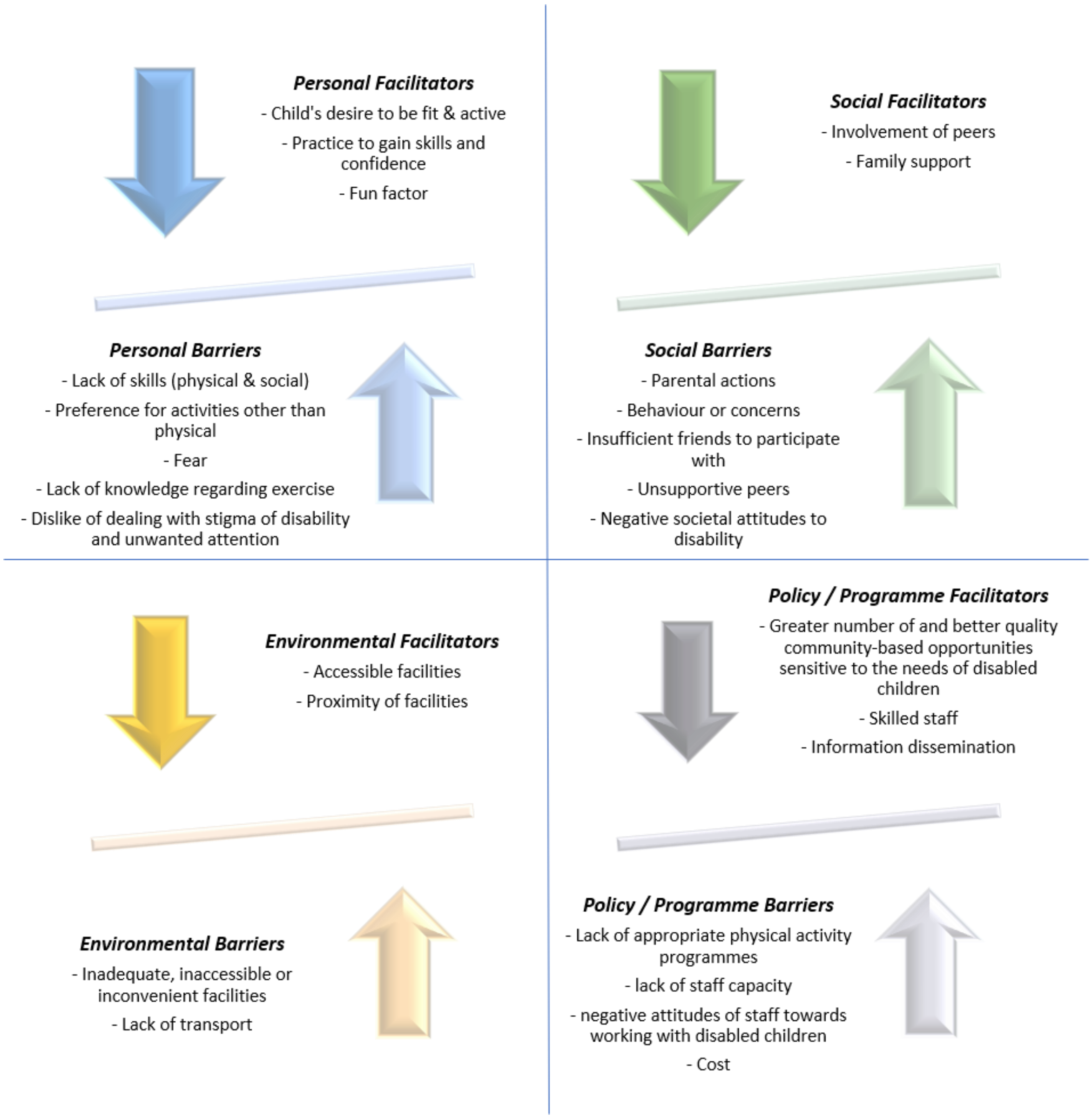


*Figure 9: Barriers to, and facilitators of, sport to children with disability (Source: adapted from Shields et al. [81])*

## 2.6 Children's Activity Prosthetic Fund

The Department of Health Children's Activity Prosthetic Fund is designed to enable engagement and increase activity levels in children with limb absence [10, 85]. This programme provides funding for sport-specific prosthesis provision, and research into improving prosthetic technology for children with limb absence [10, 85]. This initiative was first introduced in 2016 and was further extended in 2018, providing £1.5 million biennially [86]. To date, £1.75 million has been allocated for device provision and £1.25 million for research [86, 87]. Between 2016 and 2018, 220 children were supported with sport prosthesis provision [86].

## 2.7 Upper Limb Absence Background

Upper limb amputation is comparatively rare in contrast to lower limb amputation [88, 89]. Carter et al., as cited by Roeschlein and Domholdt [90], suggested that upper limb absence significantly restricts function, sensation and cosmesis. Children with upper limb absence are considered especially challenged in sport and physical recreation [91]. With the prevalence of upper limb absence most commonly attributed to trauma or congenital loss, this demographic is typically younger than for those with lower limb absence – which presents most frequently due to peripheral vascular disease and diabetes [11, 88, 89]. Following recent military operations there are a significant number of trauma-related military amputees [92]. In 2001-2016 there were 298 surviving UK military personnel amputees as a result of operations in Iraq and Afghanistan [93], and 21% of amputees treated in U.S. military facilities involved upper limb absence [94]. The ULA demographic appear to be particularly active and competitive; contributing factors are the youthfulness of the population, the recent increased number of military amputees, and recent growth in extreme sport popularity [11, 92].

There is little evidence regarding attitudes to sport, sport participation levels and use of prostheses during sport for those with upper limb absence [94]. There are also few studies that consider these topics against the broader amputee population [11]. There is a current focus on upper limb absence research [94], and this evidence is essential as an increase in requests for specialised upper limb sports prostheses is expected in the coming years [11, 95].

## 2.8 Current Upper Limb Devices

Upper limb prostheses are intended to restore function and appearance. They are also considered to reduce the risk of overuse injuries on the anatomical arm [3]. There are three main types of prosthetic device available to those with upper limb absence; a cosmetic prosthesis, a body-powered functional prosthesis, and a myoelectric functional prosthesis.

### 2.8.1 Cosmetic Prostheses

Cosmetic prostheses are light, passive devices intended to restore typical appearance and facilitate anatomical symmetry (96). They can often appear very life-like and can be used for simple daily tasks such as steadying objects, but have no active grasp capability (96).

### 2.8.2 Body-Powered Functional Prostheses

Body-powered functional prostheses enable the user to operate the elbow and / or terminal device using specific body movements via a harness system (96). This type of device tends to be a lighter weight than an externally-powered device, relatively quick to operate, cost effective and a durable option, particularly for active individuals (96). However, harnessing restricts movement, requires unnatural body movement to operate the functional capabilities and results in discomfort (96). These devices are typically perceived as being cosmetically poor and outdated.

### 2.8.3 Myoelectric Functional Prostheses

Myoelectric (externally-powered) functional prostheses are battery powered. They are controlled by myoelectric signals, generated by skeletal muscles within the residuum, acquired via surface differential electrodes to operate the terminal device (96). As this style of device does not require a harness, there is less movement restriction and a reduced risk of discomfort (96). They are perceived as more hi-tech, they can offer powerful grip strengths, and are considered to combine function and cosmesis (96). However, these devices are heavy, less durable, require more maintenance, are less tolerant to wet or dusty environments, require frequent battery charging, can be difficult to control, are slow to operate and are expensive (96).


*Figure 10: Upper limb prostheses - 1. cosmetic, 2. body powered functional, 3. myoelectric functional (source: collated from Inspire Health Care (97), Ottobock (98) and Saket Ortho (99))*

### 2.8.4 Terminal Devices

There is typically a trade-off between functionality, appearance and weight with upper limb prostheses, and this is particularly evident with the terminal device (TD). The TD is the aspect of the prosthesis which substitutes for the anatomical hand. For sport, the design of the TD can vary greatly, depending on the grip or action required for the activity. Despite valuable advancements in the design of lower limb running blades, there appears to be few sport-specific upper limb devices available.

One of the few companies which develop such devices is TRS Prosthetics [100]. This company offers body-powered TDs for some of the most common sports, such as ball games, swimming, cycling, skiing, climbing, gymnastics, weightlifting, martial arts and kayaking (Figure 11). However, these are expensive, and are available only to those in the UK who receive private treatment, or are under the care of prosthetists working for companies authorised to prescribe them. This means that prosthetists often have to adapt existing technology, or create new devices, on a case-by-case scenario.


*Figure 11: TRS terminal devices - 1. Cobra (throwing), 2. Barrage (volleyball), 3. The Freestyle TD (swimming), 4. Downhill Ski Racer (skiing), 5. Raptor Skyhook (climbing), 6. Shroom Tumbler (gymnastics), 7. The Dragon (martial arts), 8. Hammerhead (kayaking) (source: collated from TRS Prosthetics [100])*

## 2.9 Upper Limb Prosthesis Acceptance and the Value of Rehabilitation

Upper limb prosthetic acceptance is typically found to be lower than lower limb acceptance [101]. Wright et al. [82] found combined transhumeral and transradial usage to be 63% in the USA, and in an Australian study 56% of participants wore their prosthesis "once in a while" or "never for work and social activities" [74]. Wilson and Clayton [76] found that rejection is typically due to prostheses failing to achieve their intended purpose [101] and the device being considered no benefit in routine daily activities [91]. Current upper limb prostheses are incapable of providing sensory input and the dexterity required to simulate natural hand function [91]. The high rate of prosthesis rejection can be minimised by appropriate education, training and empowerment during rehabilitation within a specialised multidisciplinary environment [55, 94]. Furthermore, when physical training is incorporated within a rehabilitation programme, amputees progress quicker and full reintegration into the community is facilitated [50, 92].

## 2.10 Upper Limb Prosthesis Use in Sport

Bragaru [11] found that most ULA athletes chose not to use a prosthesis for sport, despite various devices being available, as they were perceived to be unnecessary. LimbPower [69], however, identified that prescription of bespoke sporting prostheses from NHS limb centres was unlikely, but agreed that they were not always required to participate in sport. It should be noted that at competition level there are sports, such as swimming, where use of a prosthesis is prohibited [64]. However, use of a prosthesis during training can facilitate muscle strengthening of the residual limb [64].

Bragaru et al. [50] suggested that high cost, insufficient knowledge regarding sports prostheses, and the deeming of specialised prostheses as unnecessary were key factors as to why individuals do not use sport specific prostheses. LimbPower [73] identified socket comfort, fit, functionality, reliability, weight and appearance as limiters to participation with a prosthetic device. It is vital that individuals, and particularly their residuum, are assessed by a doctor and prosthetist to indicate tolerance for the increased stress and demand of a chosen sport [64].

If a participant wishes to use a prosthesis to participate in sport essential considerations include: whether the prosthesis is also for daily wear or sport-specific, demand and frequency of the activity, cost, prosthesis strength, durability and tolerance to increased forces applied, suspension, socket fit, cosmesis, weight, materials and maintenance, care and device adjustment education for the user (64). Device failure during recreation or competition can have negative consequences psychologically and physically (64). Webster et al. (64) believed cosmesis is secondary to function in sport-specific prostheses; however, Head and Brittles (2) identified appearance as a factor that significantly negatively affects prosthesis acceptance. The latter study (2) also recognised that there was a clear split between individuals whose prosthesis acceptance was not overly influenced by the cosmesis and those who were, with those influenced being significantly affected.

The recent LimbPower (73) survey was the first to consider amputee sport and activity prevalence within the UK while assessing facilitators and barriers to this participation. Although not published in a journal, this data engages a related study population to this study. Due to limited relevant published papers available (11) this survey is considered a viable and current data source. With a mixed amputee demographic and considering various levels and causes for amputation or absence, the average age of the participants, at 48 years, is younger than that of the general amputee population across the UK (73, 88). LimbPower (73) found that 79% of participants used a prosthesis in everyday life and 36% had a minimum of one sport-specific prosthesis. However, anecdotal evidence suggests that these figures are higher than would be expected, partly due to the demographic of the survey being younger and more active than the typical amputee (88). It should also be considered that the majority (79%) of participants in the LimbPower study were lower limb absent with only 8% being ULA (73).

## 2.11 The Research Gap and Study Aims

As demonstrated in this chapter, sport participation has a positive impact on lives. Individually, it results in improved physical and psychosocial well-being, and at a national level it contributes to reducing the cost of inactivity. Sport participation is as beneficial to those with disability as to their able-bodied peers.

Within the ULA demographic there is a high rate of upper limb prosthesis rejection despite this being a limb absence level that is seen to significantly impact function. Despite various studies considering effects on biomechanics, kinetics, physiology and psychology for lower limb absence and sport [57, 58, 102-105], there is a lack of scientific evidence available concerning upper limb absence and sport. Sport participation levels in the ULA demographic are poorly understood, and there is limited literature on prosthesis provision, use or impact. Existing research is typically concerned with psychosocial aspects [11, 64] or individual case studies [95, 106-110].

Sport, active recreation and PA studies are typically researched using subjective, self-reported measures including, diaries, activity logs, recall surveys or questionnaires [21, 30, 62, 72, 75, 111]. These methods of collection are subject to bias, can limit study reliability and have an increased risk of error [21, 112]. However, use of activity monitors can facilitate objective data collection on arm wear and usage during sport activity, but have yet to be used to explore this.

In order to understand how to best use the Children's Activity Prosthetic Fund and facilitate sport participation for adolescents with upper limb absence, thereby improving the health of this demographic [20, 72], it is necessary to understand how and why this group use upper limb prostheses. The aim of this feasibility study is to explore levels of sports participation and prosthesis wear / usage during sport in active adolescents with upper limb absence. To achieve this the following objectives were undertaken:

- Capture objective prosthesis wear and usage patterns from physically active ULA adolescents;
- Develop understanding of how this usage relates to sports participation; and
- Gather sports participation data and capture participants' views on sport, prostheses and reasons for use / non-use in sport.

# Chapter 3: Methodology

Despite clear physical and psychosocial benefits, as presented in Chapter 2, disabled people are half as likely to participate in sport as their able-bodied peers. Active adolescents typically become active adults, thus making early engagement in sport important.

Upper limb prosthetics are prescribed to those with upper limb absence to restore, to a degree, appearance and functionality, whilst reducing the risk of overuse injuries on the anatomically intact limb. Despite this, there is a high prosthesis rejection rate by those with upper limb absence.

For those with upper limb absence, sport participation levels are very poorly understood, with virtually no information on levels of participation, reasons for (non-)participation, and whether provision of sports-specific prostheses impact on sports participation. Clinically, upper limb competencies are typically measured using in-clinic assessment tools, and in the case of stroke patients, questions have been raised as to whether these findings correlate to real-world competency (113). Primarily, research in the area uses self-reported measures only, either in the form of questionnaires or interview feedback. These methods are known to have limitations as they are dependent on reliable and unbiased responses, which can be affected both consciously and subconsciously. In addition, terminology used across studies is inconsistent rendering comparisons and contrasts between studies complex. Only Chadwell et al. (7-9) have to date published papers which discussed objective outcome measures obtained using activity monitoring devices to understand upper limb prosthesis use.

Upper limb activity monitors provide a means of gathering objective data on arm use during sports participation in the real-world, but have yet to be used to explore this, during either disabled or non-disabled sport participation.

Despite a lack of available objective data and the flaws with subjective data described above, the benefits of qualitative data should not be forgotten. They can add context to objective findings, influencing the interpretation of quantitative data. Prostheses are not just about the devices, but fundamentally about the people wearing them, and so their views and opinions are as valid and important to research as quantitative findings. This is particularly evident with the value placed on "patient experience" within the health care community.

By identifying the wear and usage patterns of prostheses during sport and adding context by investigating attitudes towards sport and the use of prostheses during participation, clinicians and researchers can target their efforts to best benefit ULA individuals.

In this chapter the methodology for a mixed methods feasibility study is outlined, with the intention to design a protocol that can also be applied to larger cohorts for statistically significant findings.

## 3.1 Methods

### 3.1.1 Ethical Approval

Ethical approval was granted for this study by the Research, Enterprise and Engagement Ethical Approval Panel, School of Health Sciences, University of Salford (REF: HSR1718-049) (Appendix 1). Informed consent was gained from all participants and parents / guardians of participants under the age of 18 years.

### 3.1.2 Ethical Considerations for Research with Adolescents

There is an increasing emphasis on the importance of listening to the voices and experiences of young people (114). It is acknowledged that adolescents should be considered capable and competent contributors to topics relating to them (115). As such, undertaking research with this demographic has its own ethical and logistical considerations. Key factors include consent, protecting the adolescent from harm, confidentiality and whether adolescents should be compensated for their time and participation (114).

Informed consent, according to Gallagher [116] requires that there is an explicit act, such as a verbal or written agreement; that participants are informed and have an understanding of the research; consent must be voluntary without coercion and that consent is renegotiable, whereby the participant can choose to withdraw at any point. It is essential that informed consent is obtained from the adolescent as well as from the parent [115].

By protecting an adolescent from harm, barriers to participation in research are raised [114], thereby restricting the right of this demographic to express their views on issues relating to them. Ultimately, there is a fine balance between benefit and risk when conducting research with adolescents [114]. However, strategies that enable this group to engage in research can only help to understand the wishes and requirements of this particular demographic.

It has been identified that adolescent-based research should be conducted in safe, private and physical locations whilst maintaining privacy through confidentiality and anonymity [114].

In relation to compensation, Hill [117] suggests that some researchers find it appropriate to provide recompense and others view it as bribery. However, considering the challenges when recruiting adolescents for specific or niche studies, such as this one, having opportunities to provide incentives can be advantageous and enable greater levels of participation.

These factors, and strategies relating to their implementation have been reflected where possible within the overall study design and the involvement of suitable participants.

### 3.1.3 Mixed Methods

A mixed methods approach provides a rich analysis of the subject area using both qualitative and quantitative methods. This approach enables a more complete picture to be obtained, by noting real-time patterns and trends whilst also facilitating more in-depth knowledge of the participants' own analysis [118], expanding and strengthening a study's conclusion [119]. It has been acknowledged that by combining qualitative and quantitative methodologies, credibility, context, illustration and utility can be improved within a study [119].

This study employs a convergent parallel design. This allows for qualitative and quantitative research to be collected independently with the point of integration at the overall interpretation [119] (Figure 12). This design permits collection of the different but complimentary data to best comprehend and develop understanding of a research problem. A QUAL + QUAN approach [119] was utilised; the quantitative and quantitative aspects were of equal status and were conducted concurrently [119].

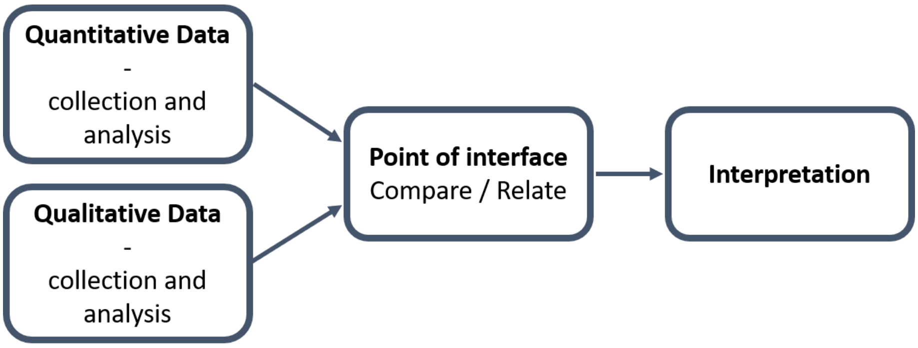


*Figure 12: Convergent parallel design (author's own image)*

### 3.1.4 Participants

Seven healthy adolescent [120] participants were recruited: three transradial level ULA participants (two males, one female, age: 10-14 years, congenital absence) and four anatomically intact (AI) participants (males, age: 10-19 years). All subjects regularly participated in sport (as defined on page 5), therefore meeting the criteria for inclusion in this study (sport participation was required a minimum of once per week). Participants had no cognitive or physical impairments which would affect sport participation during the trial. Recruitment was facilitated by charity organisations – LimbPower and REACH – and through social media.

### 3.1.5 Quantitative Protocol

#### *3.1.5.1 Equipment*

The Axivity AX3 activity monitoring device (AX3) [121] contains a tri-axial accelerometer. The AX3 is smaller, lighter and less expensive than the traditionally used ActiGraph GT3X+ (GT3X+) [122] monitors, although it does have similar electronic specifications [123]. It also has the added benefits of being reliably water resistant and having user-set sensitivity and sampling rates. Waterproof devices are important for this study as they do not have to be removed for bathing or swimming, a popular sport amongst adolescents with physical disabilities [62], then refitted – which may be awkward for those with upper limb absence. Device settings are presented in Table 3. Devices were worn as per manufacturer's mounting recommendations (Figure 13) and fitted securely to reduce the risk of vibration, slip or twisting [124]. Devices were worn within Axivity silicone wristbands and labelled with letters to indicate the limb it was to be worn on, and with an arrow indicating the correct orientation of the device (Figure 14).

*Table 3: Axivity AX3 settings for this study*

| Setting | | Reason |
|---|---|---|
| Sensitivity | 16g | • Maximum setting allows measurement of accelerations up to 16g (approximately 160m·s$^{-2}$)<br>• Setting suitable for intense activity e.g. boxing [125]<br>• Reduced risk of clipping |
| Sampling rate | 50Hz | • Allows for maximum samples per second to reliably be recorded during a 2-week data collection period. Dependent on battery longevity and storage capabilities of the device |

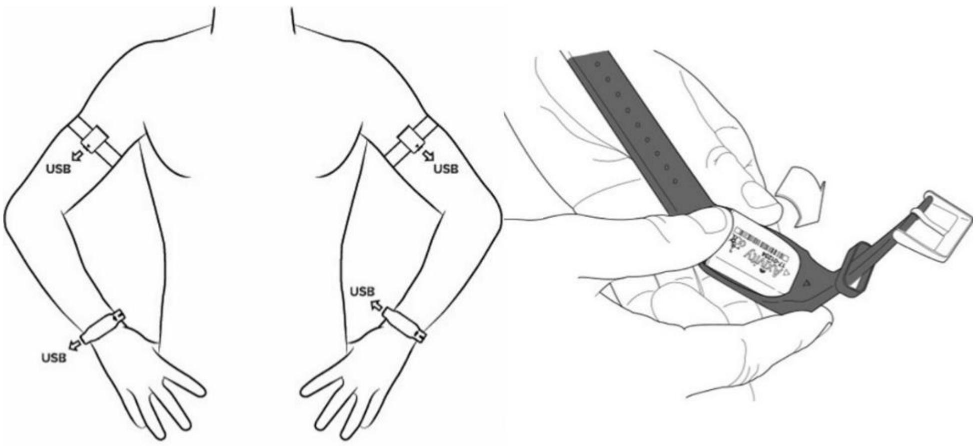


*Figure 13: Manufacturer recommended device mounting (Source: [124])*


*Figure 14: Labelled devices to indicate side to be worn on and correct orientation (author's own image)*

### *3.1.5.2 Data Collection*

A minimum of 24-hours prior to data collection participants and their parents were provided with a Participant Information Sheet (Appendix 2) Participants met with the researcher at venues facilitated by collaborating charities. All subjects completed the Consent (Appendix 3) and Demographics Forms prior to participation. As some participants were under the age of 18 years at the time of the study, legal consent was required from both the participant and the parent / guardian. For this reason, both the participant and the parent / guardian were required to sign the Consent form, ensuring that both parties were happy to proceed.

Similar to the study concerning everyday use of prostheses by adults with upper limb absence by Chadwell et al. [9], subjects in this study were asked to wear a wrist-mounted activity monitoring device on each wrist, anatomical or prosthetic (Figure 15) and maintain an activity diary for a two-week period. Participants were asked to maintain their typical behaviour during the data collection period. AX3s were set up using AX3 OMGUI Configuration and Analysis Tool software (v. 1.0.0.37) [126] to record data at 50Hz and 16g for 14 days. Recording was designated to start at 00:01 the day after the participant was fitted with the devices. The devices were worn on the wrists to continually log arm movements during normal daily routine and sports participation. Devices were only to be removed for prolonged periods of swimming or swimming at depths over 1.5m.

The activity diary was intended to aid interpretation of the activity monitoring data, identify sports participated in, and devices used. The participants used the activity diary to log dates and times sports were participated in, and the type of sport engaged in. For those with upper limb absence, they also logged whether they wore a prosthetic device for the activity and the type of prosthesis / terminal device. The two-week time frame allows for a high level of reliability (0.80 [127]) and opportunities for sport to be participated in several times.

Following the 14-day period participants returned the AX3s along with a completed activity diary in person. Those with upper limb absence subsequently completed a semi-structured interview at this meeting (Section 3.1.6).

It was intended that the participants with limb absence would be provided with up to three activity monitors; one for the anatomical side, one for their everyday limb and one for their sport-specific prostheses, if they had one. Training was provided to participants on how to transfer the activity monitor between sport-specific prostheses if they had more than one.

*Figure 15: How devices are worn on anatomically intact and limb absent participants. Left: anatomically intact Right: upper limb absent (author's own image)*

### *3.1.5.3 Anonymity*

Anonymity of each participant was achieved by replacing the participants' names with participant codes.

### *3.1.5.4 Limb Dominance Terminology*

This aspect of the study considers data from both AI and ULA adolescents, as in Chadwell et al. [7]. Within both datasets limbs are defined as either dominant or non-dominant. For the AI group the limb with which participants self-reportedly wrote with was considered dominant, and the contralateral limb non-dominant. For those with upper limb absence the anatomically intact side was labelled dominant, and the affected side non-dominant. Within the results and discussion to follow, when referring to the ULA group the terms 'anatomical arm' and 'prosthesis' are used to differentiate between respective limbs.

### *3.1.5.5 Periods of Activity Terminology*

Within the study we consider wear and use of the prosthesis during sports participation, everyday activity excluding sports participation, and overall. These are defined and labelled as follows:

**Sport** were the periods based on self-reported times where sport was participated in. **Everyday activity excluding sport** encompassed the period of the study not including sport. **Overall** were these two periods combined, encompassing the entire duration of the study.

#### *3.1.5.6 Data Processing*

Data were downloaded using the AX3 OMGUI Configuration and Analysis Tool software (v. 1.0.0.37) [126]. Data were then exported as WAV files resampled at 50Hz with auto-calibration. Resampling was necessary as sampling rates within the raw data were inconsistent (Appendix A4.3.1). Data were transferred into Matlab (v. R2018a) [128] and processed using a modified version of the code published by Chadwell et al. [8]. The modifications to the Matlab code were made by Chadwell. The modified code used an updated non-wear algorithm; the option to set the desired epoch (1 second, 10 second, 30 second and 60 second); the option to include sport participation periods, and coding by Brønd et al. [123] to convert data to be comparable to ActiGraph counts [129]. A count is "the unit of measure for activity for ActiGraph's monitors" [129] allowing processed data to be compared to existing studies that used ActiGraph devices [7] (Appendix 4).

##### 3.1.5.6.1 Removal of Prosthesis Non-Wear

Within the modified code, the non-wear algorithm [8] identified prolonged periods of inactivity in the data from the non-dominant limb for those with upper limb absence, indicating periods of prosthesis non-wear. Having applied the non-wear algorithm, the time included in calculations to determine prosthesis wear time and symmetry of upper limb activity was based on wear time only. The non-wear algorithm was applied to all of the periods analysed in this study. Although not presented in this study, the modified code also allowed for individual sports periods to be investigated. However, these are not subject to the non-wear algorithm, and therefore, the time included in these calculations are based solely on self-reporting. Table 4 shows data when the non-wear algorithm is applied. The data processed with the non-wear algorithm are not comparable to data not run through the algorithm.

*Table 4: Application and non-application of non-wear algorithm*

| | Non-wear algorithm applied | Non-wear algorithm not applied |
|---|---|---|
| Overall | ☑ | |
| Everyday Activity Excluding Sport | ☑ | |
| Sport | ☑ | |
| Individual Sports | | ☑ |

#### *3.1.5.7 Data Analysis*

From the data it was possible to identify whether a prosthesis was being worn, quantify the amount the prosthesis was used in comparison to the anatomical arm and analyse these results compared to the anatomically intact group.

Combining the activity sensor and activity diary data facilitated assessment of prosthesis wear and use during sport participation. It was also possible to identify what sports were being engaged in by participants and what prosthesis / terminal devices were worn during participation.

For prosthesis users the time spent wearing a prosthesis overall, during everyday activity excluding sport and during overall sport was calculated using the AX3 data for the 14-day period. This was calculated as "prosthesis wear time (C)". It was determined by subtracting "prosthesis non-wear", as identified by the non-wear algorithm, from the duration of the study. "Prosthesis wear time (SR)" was identified by the self-reported wear time as indicated in the activity diary. Both "prosthesis wear time (C)" and "prosthesis wear time (SR)" are as defined in Chadwell et al. (7).

The symmetry of upper limb activity were calculated for both datasets as in Chadwell et al. (7). This resulted in the percentage contribution of the dominant arm to activity for the specified epoch. The calculation used to determine the balance of use across both arms was the "Median %Reliance$_{Dom}$" [7] where all the data – when one or both arms were moving – were considered.

$$\frac{Activity_{dominant\ arm}}{Total\ Activity\ _{dominant\ arm+nondominant\ arm}}\ X\ 100$$

The symmetry measure indicated the percentage of reliance on the dominant arm. The "Activity" was the sum of the vector magnitudes of the accelerations across all three axes. This was calculated for each limb, and then this percentage reliance was subsequently calculated for each epoch. The median value was a summary measure for the study period.

All results were calculated based on 60 second epochs to allow for ease of comparison with previous studies [7, 8]. The impact of the epoch on outcomes is explored in Section 4.2.2.

#### *3.1.5.8 Statistical Analysis*

With only three participants in the limb absent group (only two of whom wore a prosthesis), and four in the anatomically intact group, the datasets in this study were too small to carry out any inferential statistics [130, 131]. Therefore, only descriptive statistics for the quantitative section of this study are presented.

#### *3.1.5.9 Data Visualisation*

As in Chadwell et al. [7] both histograms and spiral plots are presented to visualise the upper limb activity data. Histograms illustrate activity distribution between the two limbs, and spiral plots demonstrate emerging temporal patterns over the study period. Both plots are generated by the Chadwell et al. [8] modified code.

The histograms present the percentage contribution of the dominant arm to overall arm activity against the number of minutes in a log scale. On the x-axis, 100% signifies all the activity was from the dominant arm, whilst 0% represents unilateral activity of the non-dominant arm. When there was equal activity bilaterally, this is indicated by 50% on the x-axis. Where the non-wear algorithm is applied (for Overall, Everyday Activity Excluding Sport and Sport states) "prosthesis non-wear" periods, and periods where both arms are at rest, are not incorporated in the plot.

The spiral plots illustrate the percentage reliance on the dominant arm for each epoch as per the allotted colour code, and sections highlighted with a black outline indicate self-reported sport participation periods (Figure 16). Each ring of the spiral denotes 24 hours revolving outwards, with midnight at the top and midday at the bottom of the ring.

| Reliance on dominant arm (%) | Category (% use) | Colour Code |
|---|---|---|
| 0% | Unilateral non-dominant | |
| 1-10% | 90-99% non-dominant | |
| 11-20% | 80-89% non-dominant | |
| 21-30% | 70-79% non-dominant | |
| 31-40% | 60-69% non-dominant | |
| 41-59% | Even contribution bilaterally | |
| 60-69% | 60-69% dominant | |
| 70-79% | 70-79% dominant | |
| 80-89% | 80-89% dominant | |
| 90-99% | 90-99% dominant | |
| 100% | Unilateral dominant | |
| Vector magnitude on both sides = 0 | Both arms at rest | |
| | Sport participation period (self-reported) | (( |

*Figure 16: Spiral plot key: vector magnitude per epoch categorised (Source: adapted from Chadwell et al. [7])*

### 3.1.6 Qualitative Protocol

This interview inquiry method was undertaken in line with a modified version of the seven stages as outlined by Brinkmann and Kvale [132]. The purpose for the investigation was established in the Background (Chapter 2) and therefore '*Thematised*'. The protocol was '*Designed'* with consideration for the knowledge that was to be captured, whilst taking account of potential ethical implications and all seven aspects of the investigation. The '*Interviewing'* process was founded on an interview guide with an element of reflective practice. '*Transcription'* took place to enable affective *'Analysis',* and the findings '*Reported'.* '*Verification',* which typically occurs following Analysis, was not undertaken due to this being a feasibility study, and the number of participants insufficient to facilitate generalisation, However, the latter would be conducted in a larger study.

#### *3.1.6.1 Data Collection*

In-depth interviews have been found to be one of the most effective means to gain insight into understanding humans and explore topics in-depth. They have also been found to enable more sensitive topics to be addressed with participants, and facilitate unforeseen meanings and connections to be made [11, 133].

Initially the interview guide was scripted to provide structure for the explorative interview. The first version of the script was based on previous studies concerned with amputation and sports participation [2, 11, 73, 84] along with issues raised in the Background (Chapter 2). This script was piloted, firstly with the research team role-playing as participants, and then with two of the University's ULA professional patients. Following each pilot session, the script was adjusted and improved as required, to achieve the most appropriate responses from the interviewees. The subsequent interview guide (Appendix 6) used brief and simple age-appropriate guiding questions to outline the topics and facilitate discussion and avoided any questions of a leading nature.

As mentioned in Quantitative Data Collection (Section 3.1.5.2), participants with upper limb absence who took park in the activity monitoring trial were asked to participate in a semi-structured interview when returning the activity monitors and activity diary to the researcher. Participants chose to have parents present during the interview, however, the parent did not contribute to the interviews. The interviewer used judgement as to how closely the guide was followed, allowing interviewees to speak freely and their answers to be followed up and new directions considered. The interviewer also took into account the age of the participant in order to ensure appropriate terminology was used and explained any words that may have been confusing for younger participants. The interviews were audio recorded for later processing.

#### *3.1.6.2 Anonymity*

Anonymity of the participant was achieved by replacing the participant's name with a code following the interview. Recordings were stored securely, with only the research team having access, and deleted once transcription of the interview was complete. Anonymised data will subsequently be archived in the University of Salford data repository.

#### *3.1.6.3 Data Processing and Analysis*

The data was thematically analysed as per the process published by Braun and Clarke [134]. This six-phase method is shown in Table 5. This form of analysis permitted pinpointing, examining and recording patterns within data [134]. This data provided narrative and context to the activity monitoring trial.

Audio recordings were transcribed verbatim, with any notes regarding the interaction annotated by the researcher within 24 hours of the interview. Interviews were transcribed using NVivo 11 software (v. 11.4.1.1064) [135]. The researcher was familiarised with the data and initially coded the information. Coding is a means to categorise the data. Coding was undertaken using NVivo 11 software (v. 11.4.1.1064) [135]. Initial coding highlighted topics of interest with a broad approach. Codes were combined as themes emerged, and these themes re-evaluated to ensure they met the combined codes. Subsequently, the themes were defined and named. As such, basic and organising themes, as well as an overall global theme were identified. A second member of the research team also conducted this analysis and both results compared. Where there was discrepancy the researchers discussed the analysis until an agreement was reached. NVivo 11 software (v. 11.4.1.1064) [135] facilitated this approach, allowing for code-and-retrieve, which permitted the researcher to easily recall coded data for further and combined inspection.

*Table 5: Phases of thematic analysis (Source: adapted from Braun and Clarke [134] Permission to reproduce this table has been granted by Taylor & Francis)*

| Phase | | Description of the process |
|---|---|---|
| 1. | *Familiarizing yourself with your data:* | Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas. |
| 2. | *Generating initial codes:* | Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code. |
| 3. | *Searching for themes:* | Collating codes into potential themes, gathering all data relevant to each potential theme. |
| 4. | *Reviewing themes:* | Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis. |
| 5. | *Defining and naming themes:* | Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme. |
| 6. | *Producing the report:* | The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis. |

#### *3.1.6.4 Data Presentation*

The findings are presented as coded extracts from the transcripts to illustrate the themes raised during the data analysis. This presentation style allows readers to experience the language used by the participants and consider their own interpretations [136]. This style should also increase the perception that the data is trustworthy [136]. A commentary for each theme is also presented, highlighting initial thoughts, and is further considered in the Discussion Chapter (Chapter 5).

# Chapter 4: Results

Upper limb prostheses are prescribed to restore appearance, improve function and reduce the risk of overuse injuries of the sound limb. Objectively measuring upper limb activity patterns outside of the clinic may help to indicate the level of functional restoration provided by a prosthesis. Incorporating participants' own feedback provides context to the rationale behind their reasoning for prosthesis (non-)wear and also highlights the value of sport and its facilitation in their lives. Presented in this chapter are the results of this study.

## 4.1 Participants

Data for seven healthy adolescents are presented in this chapter; three transradial level ULA participants (two males, one female, age: 10–14 years, congenital absence) and four AI participants (males, age: 10–19 years). Of the ULA participants, one participant wore a prosthesis for everyday activity, one wore a device only for cycling and one did not wear a prosthesis. Despite protocols being designed for users to have more than one prosthesis, none of these participants had additional devices, so these protocols were not necessary. Designated participant numbers for those with upper limb absence are 001–003 and those who are AI are 101–104. Detailed information for the participants is presented in Table 6.

*Table 6: Participant demographics*

| Participant Code | Cohort | Sex | Age | Dominant / Intact Side | Sports Participated in Regularly | Frequency of Sports Participation | Absence Level | Duration Since Limb Absence | When Prostheses Are Used |
|---|---|---|---|---|---|---|---|---|---|
| 001 | ULA | M | 14 | Right | Football | Once per week | Transradial | Congenital | Everyday and all sports bar water-based activities |
| | | | | | Taekwondo | 2-4x per week | | | |
| 002 | ULA | F | 10 | Left | Swimming | 5x + per week | Transradial | Congenital | Doesn't use a prosthesis |
| 003 | ULA | M | 13 | Right | Amputee Football | Once per week | Transradial | Congenital | Only for cycling |
| | | | | | Pan Disability Football | Once per week | | | |
| | | | | | Rugby | Once per week | | | |
| | | | | | School PE | Once per week | | | |
| | | | | | Swimming | 2-4x per week | | | |
| | | | | | Triathlon | Once per week | | | |
| 101 | AI | M | 19 | Right | Football | 2-4x per week | ----- | ----- | ----- |
| 102 | AI | M | 14 | Right | Football | Once per week | ----- | ----- | ----- |
| | | | | | Rugby | Once per week | | | |
| 103 | AI | M | 10 | Right | Football | 2-4x per week | ----- | ----- | ----- |
| | | | | | Rugby | 2-4x per week | | | |
| | | | | | Swimming | Once per week | | | |
| 104 | AI | M | 10 | Right | School PE | 2-4x per week | ----- | ----- | ----- |
| | | | | | Swimming | 2-4x per week | | | |
| | | | | | Tennis | 2-4x per week | | | |

## 4.2 Quantitative Study

### 4.2.1 Sense Checking

Prior to initiating data collection, sense checking needed to be undertaken as, although this aspect of the study was based on previous studies (7-9), a different activity monitoring device and modified data processing code was to be used.

#### *4.2.1.1 Sense Checking the Use of an AX3*

AX3 data processed using Brønd et al. (123) coding was compared to GT3X+ data to assess whether the device could be used to produce results comparable to previous studies (7-9). There was good agreement between the data, suggesting that that the device was appropriate for use (Appendix 4).

#### *4.2.1.2 Sense Checking the Use of a Modified Code*

As a modified version of Chadwell et al. (8) code was used for processing the data several processes were undertaken to sense check the process. Firstly, a visual inspection of the code was undertaken by two members of the research team to rule out any obvious errors. The results were then sense checked by examining the resultant times reported once the data had been processed using the code; this process and results are presented in Appendix 5.

### 4.2.2 Comparing Epochs

Data for Participant 001 (ULA) and Participant 103 (AI) are presented. Data were processed with a 1 second, 10 second, 30 second and 60 second epoch, to identify whether the value of the epoch affected the subsequent processed results.

As can be seen in Figure 17 the difference between the Overall "Median %Reliance$_{Dom}$" for Participant 001 was 6.68%, whereas for Participant 103 this was 0.66%. The range for Everyday Activity Excluding Sport was 7.01% and 0.83% respectively and 4.66% and 0.62% for Sport.

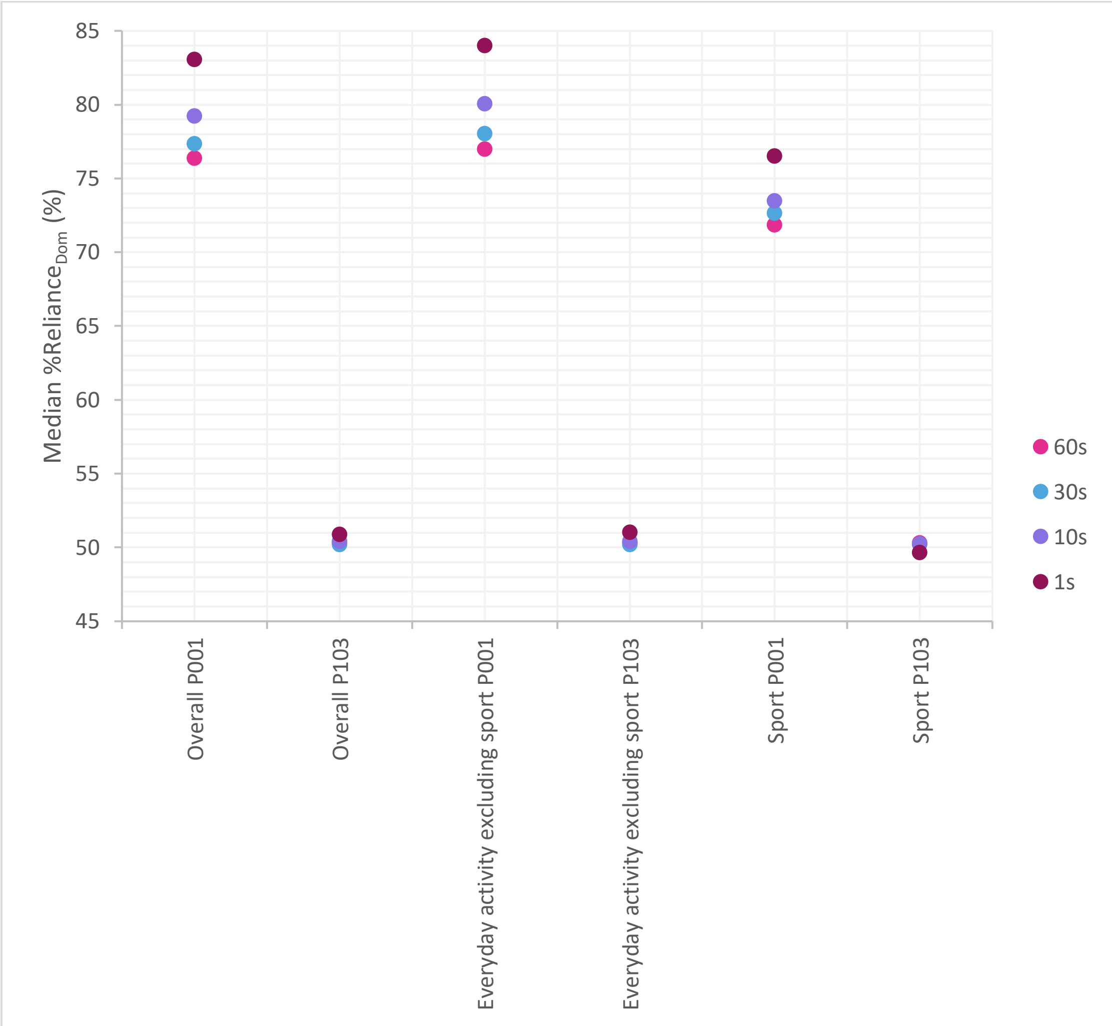


*Figure 17: Difference in data when processed with different epochs. The plot shows the "Median %Reliance$_{Dom}$" results for an upper limb absent participant (P001) and an anatomically intact participant (P103) following processing at 1s, 10s, 30s and 60s epochs.*

All of the following results were processed using 60 second epochs, enabling comparison with previous findings by Chadwell et al. [7-9].

### 4.2.3 Activity Diaries

All seven participants returned completed activity diaries, including a log of dates and times of their sport participation. ULA participants also logged when, and what type of prosthesis they wore during these periods. Some variance on the quality of self-reporting was noted: one participant used the timetable from their activity camp to indicate the times doing sport whilst at said camp, and omitted to enter the time their prosthesis was removed on two occasions; Another participant logged times to the closest minute, whereas the other subjects appeared to round to the nearest five-minute mark. When prosthesis removal times were not logged within the activity diary, this self-reported wear time was excluded from the data.

### 4.2.4 Prosthesis Wear Time

Of the three ULA participants there were two prosthesis users; one wore a prosthesis during everyday activity and for sport, the other only for sport. The self-reported "prosthesis wear time (SR)" and calculated "prosthesis wear time (C)" of these two participants are presented in the following sections.

#### *4.2.4.1 Comparison of Self-reported vs Calculated Wear Time Overall*

As presented in Table 7, during the study, Participant 001 self-reported "prosthesis wear time (SR)" to be 31.5% of the two-week period, compared to the wear algorithm calculated value of 39.0% "prosthesis wear time (C)". In addition, Participant 003 self-reported wearing a prosthesis 0.5% of the time, but the calculated wear time reported this to be 1.1% of the duration of the study. Both participants show that their self-reported prosthesis wear time that was less than the time calculated using the wear algorithm; with Participants 001 and 003 presented a 7.5% and 0.6% difference, respectively.

#### *4.2.4.2 Comparison of Self-reported vs Calculated Wear Time During Sport*

Participant 001 self-reported wearing a prosthesis 51.6% of the time that they spent participating in sport. However, their "prosthesis wear time (C)" was found to be 56.5%. Comparably, Participant 003's "prosthesis wear time (SR)" was 18.3% with the "prosthesis wear time (C)" being 16.2%. The self-reported prosthesis wear time of Participant 001 was less than the time calculated using the wear algorithm (4.9% difference). Conversely, Participant 003's self-reported time was longer than the calculated time (2.1% difference). These figures are evidenced in Table 7.

*Table 7: Self-reported and calculated prosthesis wear time by two upper limb absent adolescents over a two-week study period, during Overall and Sport. Percentage of prosthesis wear time is calculated by dividing the self-reported or calculated prosthesis wear time by the total time in that period of activity and multiplying by 100.*

| Prosthesis Wear | Self-report (SR) / Calculated (C) | Participant 001 | Participant 003 |
|---|---|---|---|
| Hours worn during 2-week study period (% worn over the 2-weeks) | SR | 105.75 hours (31.5%) | 1.75 hours (0.5%) |
| | C | 130.95 hours (39.0%) | 3.8 hours (1.1%) |
| Hours worn during Sport (% worn during Sport period) | SR | 11.75 hours (51.6%) | 1.75 hours (18.3%) |
| | C | 12.85 hours (56.5%) | 1.55 hours (16.2%) |

### 4.2.5 Prosthesis and Bilateral Arm Usage

The "Median %Reliance$_{Dom}$" calculation, as explained in Chadwell et al. [7] was used to calculate the symmetry of upper limb activity. For analysis of prosthesis users, periods of "prosthesis non-wear" were removed during data processing using the non-wear algorithm within the modified code by Chadwell et al. [8]. This meant that the results were drawn only from periods where a prosthesis was worn.

The histograms presented in Figures 18–21 plot the percentage contribution of the anatomical arm to overall arm activity against time. On the x-axis, 100% signifies that all the activity during that minute was from the anatomical / dominant limb, whilst 0% represents unilateral activity of the prosthesis or non-dominant limb. Accordingly, 50% represents an equal amount of activity is contributed by both sides during that interval. The y-axis indicates the time in minutes, and is presented using a $log_{10}$ scale to moderate the influence of large amounts of unilateral activity.

Data for the two prosthesis users and four AI participants are presented in this section below (Section 4.2.5).

### 4.2.5.1 *Overall Prosthesis Usage*

For the ULA participants, Overall, during the whole study period, the "Median $\%Reliance_{Dom}$" value for Participants 001 and 003 was 76% and 68%, respectively. These results are presented Figure 18. It is noted that reliance was skewed towards the anatomical limb (>50%) for these prosthesis users.

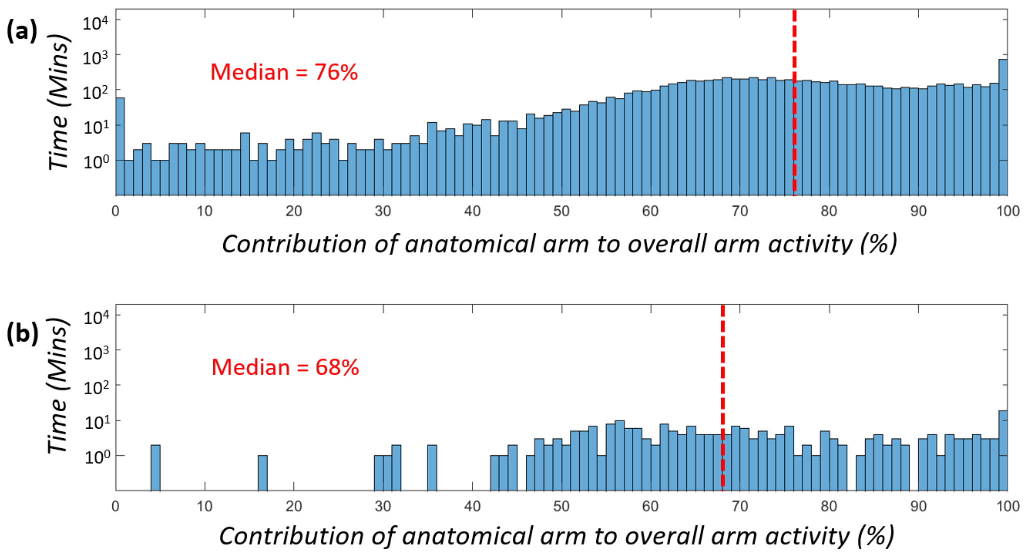


*Figure 18: Histograms illustrating upper limb prosthesis users' reliance on the anatomical limb Overall, over the 14-day study period. The data is presented for Participant 001 (a) and Participant 003 (b). The x-axis represents the contribution of the anatomical arm to overall arm activity ("Median $\%Reliance_{Dom}$). The y-axis represents the time in minutes plotted using a $log_{10}$ scale to mitigate the large quantity of unilateral activity on the anatomical arm.*

### 4.2.5.2 *Everyday Activity Excluding Sport Prosthesis Usage*

During Everyday Activity Excluding Sport, for the ULA group, Participant 001 demonstrated a "Median $\%Reliance_{Dom}$" value of 77%, whereas, Participant 003 was 71% reliant on their anatomical arm. These results are presented in Figure 19, and again demonstrated that reliance was skewed towards the anatomical limb (>50%) for these prosthesis users.

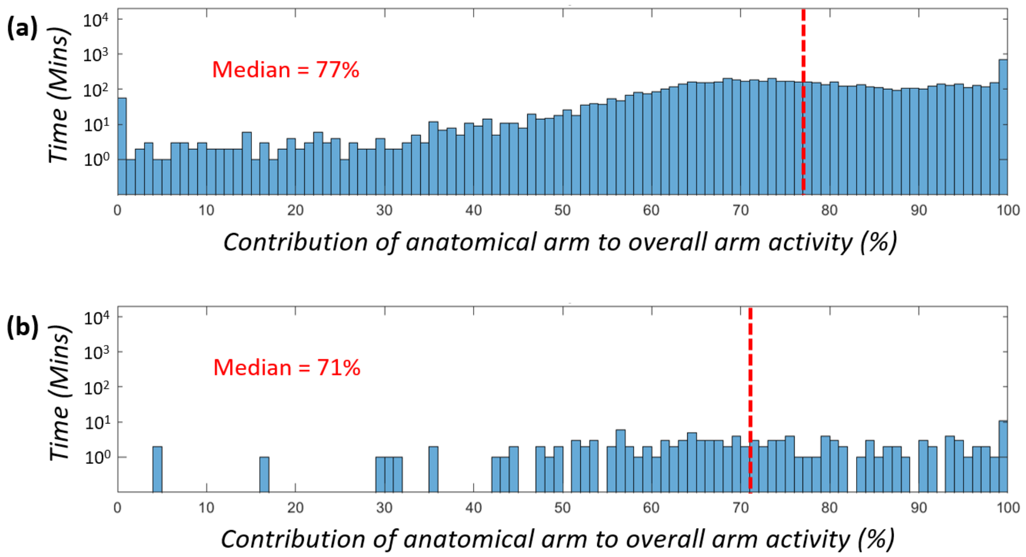


*Figure 19: Histograms illustrating upper limb prosthesis users' reliance on the anatomical limb during Everyday Activity Excluding Sport, over the 14-day study period. The data is presented for Participant 001 (a) and Participant 003 (b). The x-axis represents the contribution of the anatomical arm to overall arm activity ("Median %Reliance$_{Dom}$). The y-axis represents the time in minutes plotted using a log$_{10}$ scale to mitigate the large quantity of unilateral activity on the anatomical arm.*

### 4.2.5.3 Sport Prosthesis Usage

For the ULA cohort, Participant 001 demonstrated a "Median %Reliance$_{Dom}$" value of 72% during Sport, however, Participant 003's result showed 63% reliance on their anatomical arm. The resultant histograms (Figure 20) again show a skew towards reliance on the anatomical limb (>50%) by these prosthesis users.

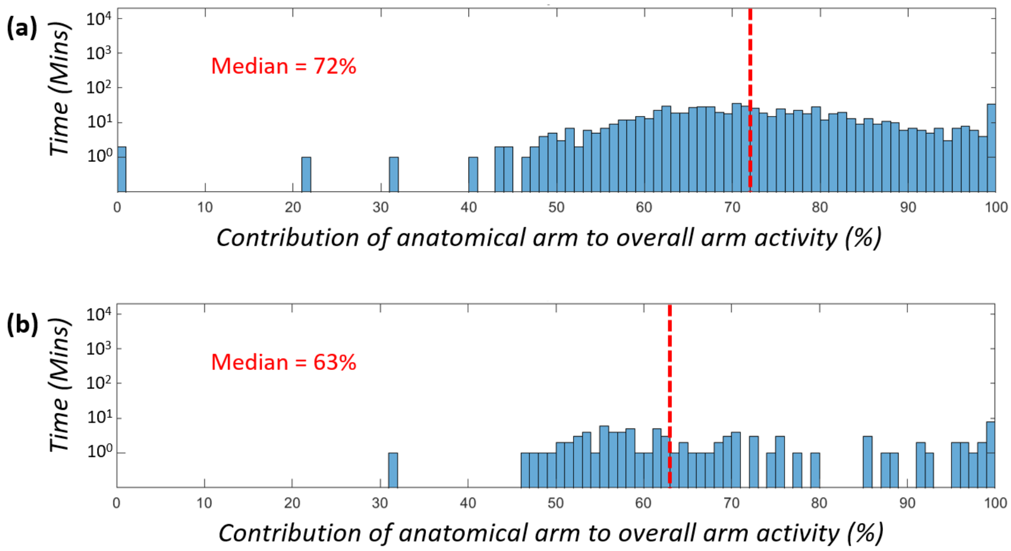


*Figure 20: Histograms illustrating upper limb prosthesis users' reliance on the anatomical limb during Sport, over the 14-day study period. The data is presented for Participant 001 (a) and Participant 003 (b). The x-axis represents the contribution of the anatomical arm to overall arm activity ("Median %Reliance$_{Dom}$). The y-axis represents the time in minutes plotted using a $log_{10}$ scale to mitigate the large quantity of unilateral activity on the anatomical arm.*

### *4.2.5.4 Bilateral Arm Usage*

The AI cohort demonstrated that Overall, the "Median %Reliance$_{Dom}$" value for Participants 101, 102, 103 and 104 were 54%, 49%, 50% and 51% respectively.

This group's "Median %Reliance$_{Dom}$" value during Everyday Activity Excluding Sport, for Participants 101, 102, 103 and 104 were 54%, 49%, 50% and 51% respectively; which corresponds with the values for Overall.

During Sport the "Median %Reliance$_{Dom}$" value was 50% for Participants 101, 102 and 103 and 51% for Participant 104.

The resultant histograms (Figure 21) illustrate an almost equal amount of activity contributed by both arms for Overall, Everyday Activity Excluding Sport, and Sport.

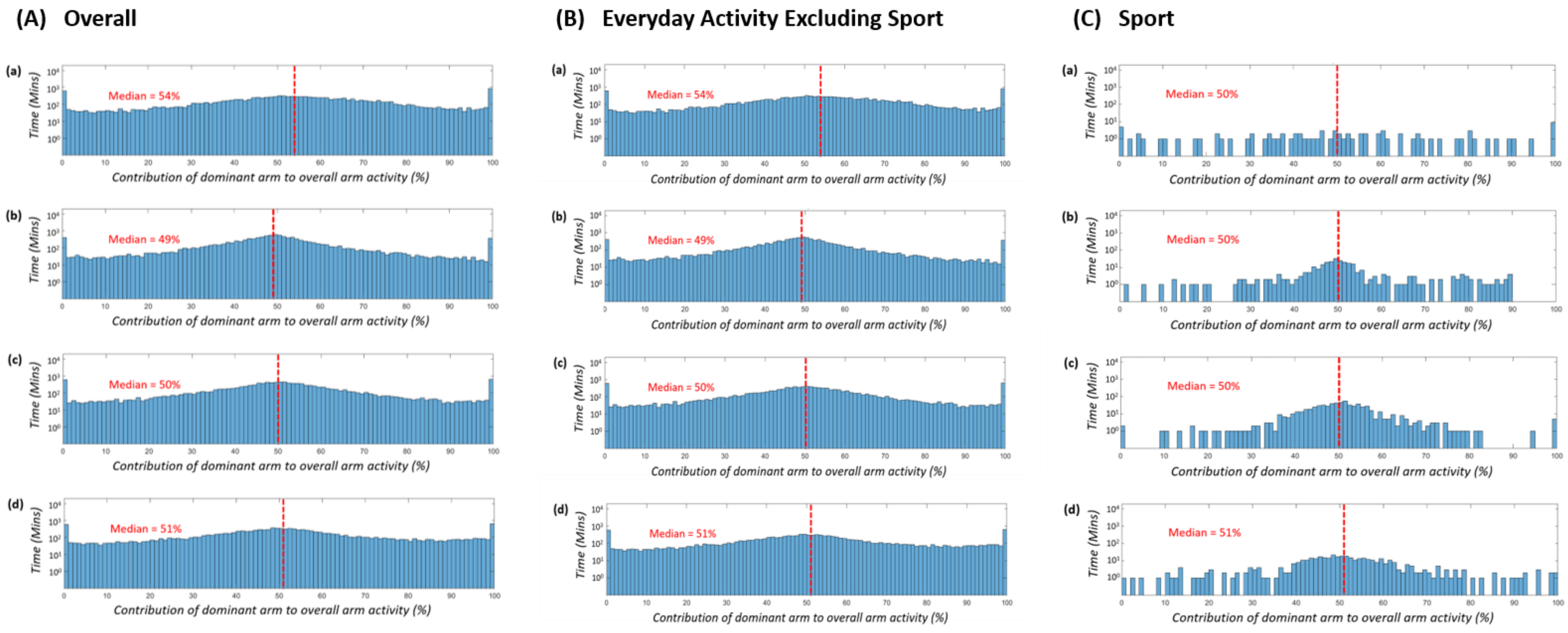


*Figure 21: Histograms illustrating anatomically intact participants' reliance on the dominant arm Overall (A), during Everyday Activity Excluding Sport (B) and during Sport (C), over the 14-day study period. The data is presented for Participant 101 (a), Participant 102 (b), Participant 103 (c) and Participant 104 (d). The x-axis represents the contribution of the anatomical arm to overall arm activity ("Median %Reliance$_{Dom}$). The y-axis represents the time in minutes plotted using a $log_{10}$ scale to enable comparison to prosthesis users.*

### 4.2.6 Prosthesis Wear Vs. Prosthesis Usage

With the data for the two prosthesis users (Participants 001 and 003), it can be seen that symmetry of upper limb usage when a prosthesis was worn was not directly influenced by "prosthesis wear time (C)". Overall, Participant 001 had a "prosthesis wear time (C)" of 130 hours 57 minutes, 12 hours 51 minutes of which was during Sport, and demonstrated "Median %$Reliance_{Dom}$" values of 76% and 72% respectively. Participant 003 Overall had a "prosthesis wear time (C)" of 3 hours 48 minutes, 1 hour 33 minutes of which was during Sport, and exhibited "Median %$Reliance_{Dom}$" values of 68% and 63% respectively. Figure 22 illustrates the spiral plots for Participants 001 (a), 002 (b), and 003 (c). Participants 001 and 003 are the two ULA participants who are prosthesis users. The "prosthesis wear time (C)" and "Median %$Reliance_{Dom}$" are reported for both Overall and Sport. Self-reported periods of sport participation are highlighted by a black edge on the plot. These spiral plots are largely magenta, suggesting periods of prosthesis removal, this was confirmed by the non-wear algorithm and self-reported activity diaries.

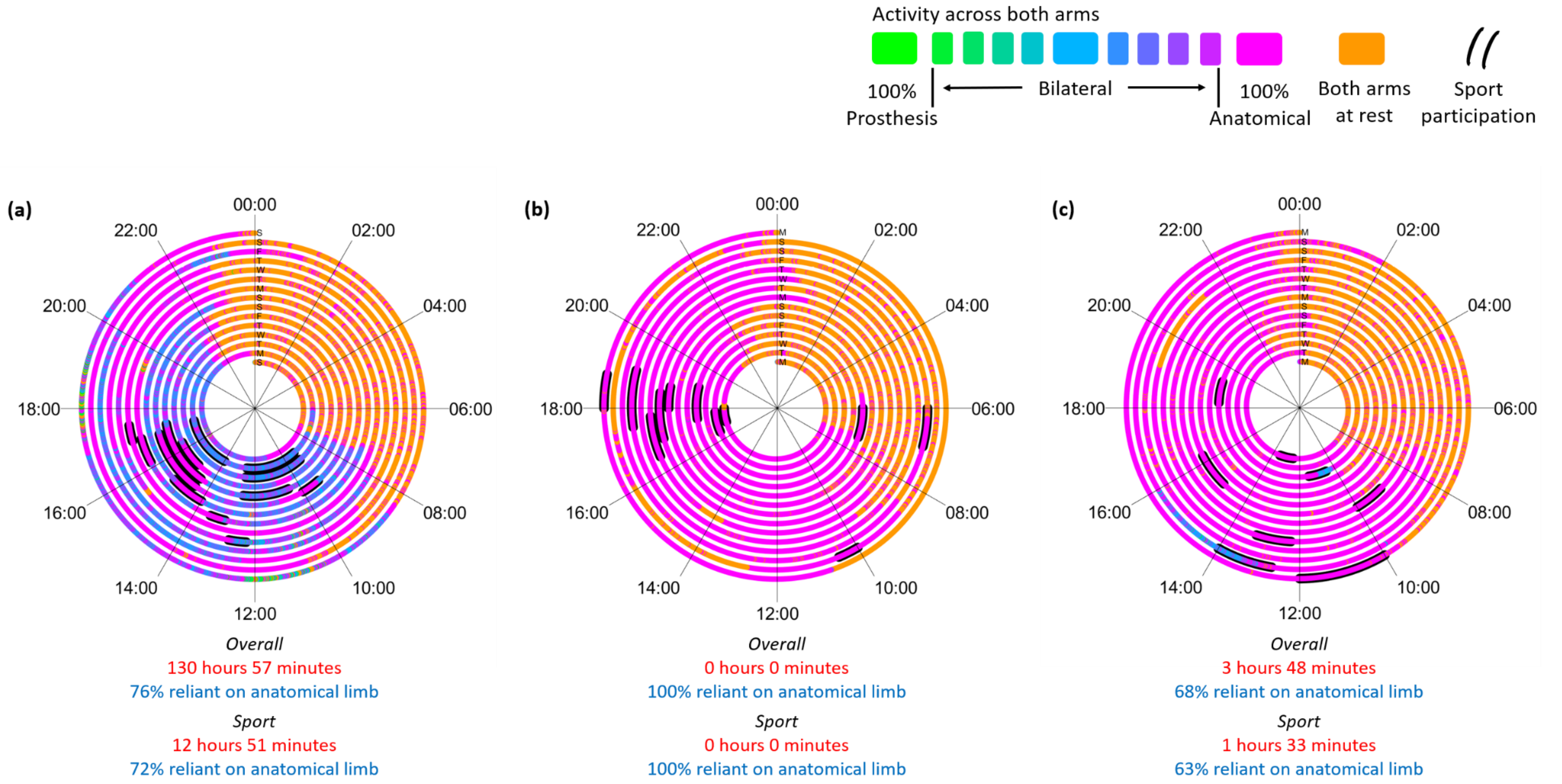


*Figure 22: Spiral plots for all three upper limb absent participants. For each participant the "prosthesis wear time (C)" is presented in red and the "Median %Reliance$_{Dom}$" presented in blue for both overall and sport. Days of the week are indicated by the letters situated at each midnight mark. The data is presented for Participant 001 (a), Participant 002 (b), and Participant 003 (c).*

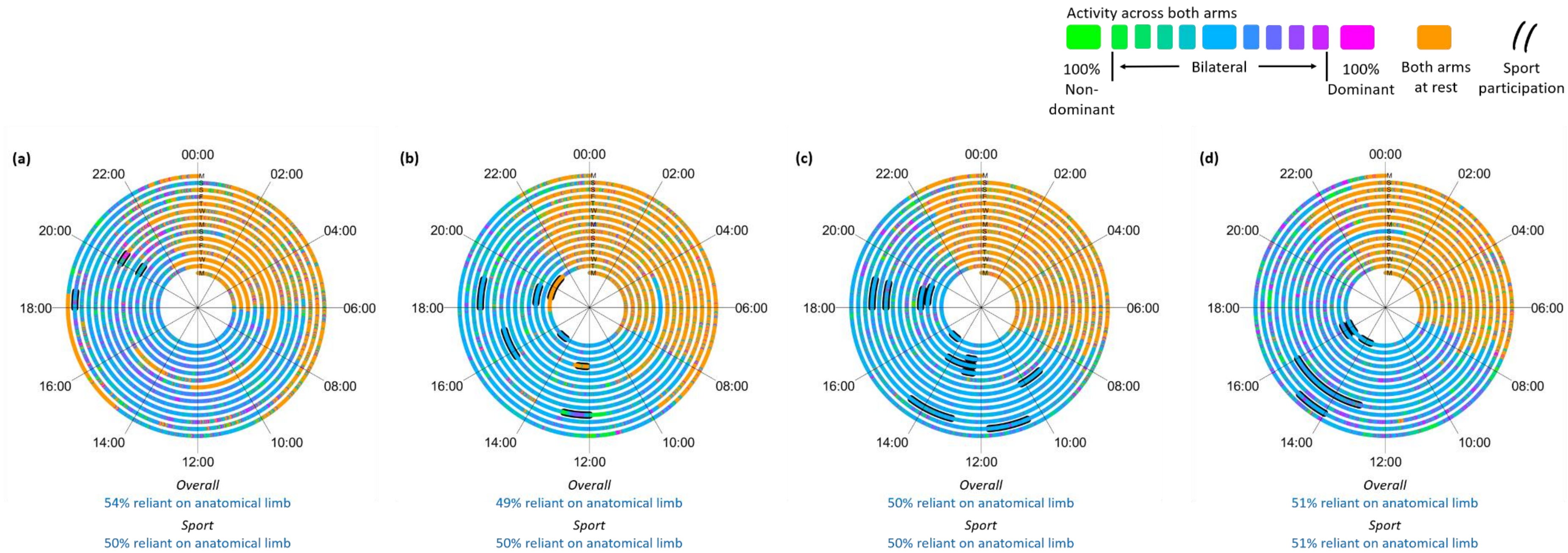


*Figure 23: Spiral plots for all four AI participants. For each participant the "Median %Reliance$_{Dom}$" presented in blue for both overall and sport. Days of the week are indicated by the letters situated at each midnight mark. The data is presented for Participant 101 (a), Participant 102 (b), Participant 103 (c), and Participant 104 (d).*

### 4.2.7 Comparison of Upper Limb Activity for Upper Limb Absent and Anatomically Intact Participants

While the data presented for the prostheses users above (Section 4.2.5) illustrates an obvious skew towards reliance on the anatomically intact arm – Overall and during both Everyday Activity Excluding Sport and Sport – the results for the AI group show a more symmetrical distribution (Section 4.2.5.4). Both groups demonstrate an increase in symmetry ("Median $\%Reliance_{Dom}$" = 50%) when participating in sport. This shift is greater for the ULA participants than by the AI group.

It should be considered that for Overall, Everyday Activity Excluding Sport and Sport, there are fewer data points used to produce the ULA participants' histograms than those of the AI group. This is because the calculations ("Median $\%Reliance_{Dom}$") for the ULA group were solely based on the periods of prosthesis wear, as identified by the non-wear algorithm.

Figure 23 presents spiral plots for the AI participants. These plots are principally blue, which signified equal contributions from both arms. However, with instances of both green and magenta, unilateral use of the dominant and non-dominant arm is shown. Comparably, the spiral plots in Figure 22 for the ULA participants are predominately more magenta (suggesting periods of prosthesis removal) and purple. In spite of this, there are also some periods where both limbs were active, illustrated by the blue sections, and a few periods of unilateral prosthesis use, indicated in green. The colour distribution on the spiral plots of the prosthesis users fit with their evident skew towards reliance on their anatomical arm. There is an obvious visual difference in the distribution of colours presented in the spiral plots of these two groups.

### 4.2.8 Prosthesis Wear for Specific Sports

Participation in specific sports was self-reported in the activity diaries by all seven participants. The ULA participants recorded which sports they wore / removed a prosthesis for, and at what times. The "prosthesis wear time (SR)" during self-reported Sport periods was supported by the data seen in the spiral plots (Figure 22). However, the periods do not always align, such as in Figure 22 (a) where the last instance of sport in the study period (2nd Tuesday) indicates that a prosthesis was initially being worn. It was specified that the participant did not wear a prosthesis for this sport (swimming) in the activity diary. The spiral plot suggests that it is likely that the self-reported start and end time of that period of Sport was misjudged slightly, starting and ending later than reported.

Data reporting the diverse sports the three ULA participants wear / do not wear a prosthesis for is illustrated in Table 8. All three participants are swimmers, with none wearing a prosthesis for the activity. Participant 001 wears a prosthesis for all sports other than water-based activities. Participant 002 does not wear a prosthesis, and Participant 003 only wears a prosthesis for cycling.

*Table 8: Sports upper limb absent participants participate in with or without a prosthesis. A tick indicates the participant wears a prosthesis for this sport, a cross indicates the participant does not wear a prosthesis for the sport. A blank box indicates the participant did not participate in this sport.*

| Sport | Participant 001 | Participant 002 | Participant 003 |
|---|---|---|---|
| Archery | ✓ | | |
| Badminton | | | ✗ |
| Climbing | ✓ | | |
| Cycling | | | ✓ |
| Kayaking | ✗ | | |
| Land training | | ✗ | |
| Rugby | | | ✗ |
| Sailing | ✗ | | |
| Shooting & Orienteering | ✓ | | |
| Skiing | ✓ | | |
| Swimming | ✗ | ✗ | ✗ |
| Walking & Pan-disability football | | | ✗ |
| Windsurfing | ✗ | | |

### 4.2.9 Summary of Quantitative Findings

In summary, the results of the activity monitoring trial found that there is a varied wear time of prostheses Overall and during Sport by the ULA participants in this study. However, when devices are worn, patterns of activity remained skewed towards the anatomical side, highlighting reliance on this limb.

## 4.3 Qualitative Study

This aspect of the study focuses on the ULA participants' experiences with and opinions on sport and the role of prostheses within this environment. The aim is to provide context to the activity monitoring facet of the study (Section 4.2), exploring commonalities and differences among the ULA participants.

Not all the data from the interviews are relevant – this is a characteristic of this style of interview technique. Silverman (1993), according to Williams [136], suggested that while approximately 30% of data mined from transcripts is not relevant to the subject area, it is however, a necessity, to encourage a participant's dialogue.

This section presents the themes identified from the interviews, illuminating how basic themes were developed and organised to subsequently formulate a global theme. Coded extracts were used to illustrate both the issues and themes discussed, to aid understanding. Presentation of excerpts also allow for readers to form their own interpretations. A commentary of each of the themes is presented, indicating initial thoughts which are further elucidated in the Discussion Chapter (Chapter 5).

### 4.3.1 The Participants

The three ULA subjects participated in semi-structured interviews. It was found that all three participants were particularly active, but differed in their attitudes towards prostheses wear, both in general and during sport. Short case studies are provided for each of the participants to provide further context to their interview responses. The participants' demographics are also presented in Table 6.

#### *4.3.1.1 Participant 001*

Participant 001 is a 14-year-old ULA male who presented with a transverse absence of the left hand and distal forearm due to amniotic band syndrome at birth. His feet are also affected bilaterally with the absence of several toes. Participant 001 wears a prosthesis daily, during everyday activity and during some sport participation. His family encouraged prosthesis wear from approximately the age of 18 months, initially with the fit of a cosmetic prosthesis, and from about the age of 4 or 5 years, with a functional split hook device. Participant 001's parents believed that they were giving him the skill set to use a device, which he could then independently choose to wear / not wear at an older age. He can operate a split hook prosthesis at a high level, reportedly being able to catch a ball with the device. Participant 001 is self-reportedly generally active, participating regularly in sport and attending sports camps during the summer holidays. Sports he regularly participates in are football and taekwondo. He is undertaking GCSE level PE and during summer he also swims frequently in his grandmother's pool.

#### *4.3.1.2 Participant 002*

A 10-year-old female, Participant 002 has congenital absence of the right hand and distal forearm and presents with a relatively long transradial residuum. She has no other conditions, nor any other limb absence. Participant 002 chooses to not wear a prosthesis, although in the past has been fitted with a functional body-powered 3D printed prosthesis and a cosmetic prosthesis. The participant also has a prosthesis for use when riding a bike, however, she rarely has the opportunity to use it as she swims competitively at a high level with most of her time dedicated to this. Her parents allowed Participant 002 autonomy to choose whether or not she wants to wear a prosthesis.

#### *4.3.1.3 Participant 003*

Participant 003 is a 13-year-old male who presents with transverse congenital absence of the left hand and distal forearm at the transradial level. This participant chooses to not wear a prosthesis for anything other than cycling, although he is engaged with ideas about the design of the device and open to trialling other designs to maximise its functionality. Participant 003's parents primarily leave the decision regarding prosthesis wear to the participant, however, in instances such as cycling they have encouraged prosthesis wear due to its positive impact on posture and reduced risk of injuries. The participant's family are particularly active and participate in several sports together. Participant 003 regularly competes in triathlon, and swimming as well as participating in amputee football, pan-disability football, rugby, and school PE – which he has chosen to continue to GCSE level.

### 4.3.2 Themes

#### *4.3.2.1 Theme 1: Attitudes to Sport*

The participants expressed their attitudes to and feelings about sport. As all the participants felt that they were particularly active there was a consensus that there was insufficient need to be more active, and all expressed contentment with their current sport participation level:

> *"… I'm **happy** with where I'm at, at the moment." Participant 001*

> *"I'm **happy** with what I'm doing now." Participant 002*

> *"I'm **happy** with the amount I'm doing at the moment but if there was anything else I'd just do it." Participant 003*

The adolescents discussed the concept of having the ability to participate in any sport removed from them, whereby, they would no longer be able to participate in any sporting activity:

> *"If I couldn't do a sport then, like, I **just go to a different one** and try and do that one if I could." Participant 001*

*"It would make me **really sad** because I'd probably, like, you know, stop doing sports and it would make me just **really sad** because I see other people doing sport and then it would make me **really annoyed**." Participant 002*

*"**Upset** but I still find a way to do sport." Participant 003*

Barriers to sport can emerge in different ways for different people. The participants revealed barriers to their sport participation:

*"We sometimes do this stroke where we've got to put a pool buoy [a leg float used in swim workouts] in between our legs and we've just got to use our arms and **I can never do that**. Because I'm always, you know, **falling behind** and it really **hurts my arm** as well." Participant 002*

*"I've got a friend in [disability] football who played for a club at a really high level and then he got **told that he can't play because of his arm**. So, I that's why **I wouldn't want to [play able bodied football],** I want to be in one [a club] that allows you to stay there forever." Participant 003*

*"I enjoy skiing but there's **not a Ski Centre nearby** if I could get the chance then yeah, I probably would [go skiing]." Participant 001*

*"I've **always wanted to** try cycling and stuff, one time I could do cycling, but then **I don't really get to go out and practice** it… it's just **time** because I'm always swimming and if I do get time it's usually we're out or it's raining." Participant 002*

*"**Money**, that's the big one." Participant 001*

*"You [can] do too much, you can get too healthy or **injuries**" Participant 001*

*"I have a kayak hook that goes on the end but no **I don't use it**, it's **too heavy**." Participant 001*

*"The disadvantages [of competitive sports participation] are that you get **very tired** and **don't get much sleep**" Participant 002*

*"I **don't like waking up really early** in the morning so that's not great." Participant 003*

Facilitators of sport participation are vital for those wanting to engage and, again, can be individual to the person. The participants expressed their ideas on what encourages and facilitates their engagement in sport:

*"The main advantages are obviously like keeping **healthy** and **fit** [and] I like **socialising** with other people." Participant 001*

*"But I really like swimming because you get to make **new friends** and it's really **fun**, because you keep yourself **active** but you're doing **fun** stuff at the same time." Participant 002*

*"You can be just out being **active** and **doing something**… it's just **fun**." Participant 003*

*"My **family are quite sporty**, so **we do a lot together**" Participant 003*

*"I've got a **prosthetic that I can hook onto my bike** and I can put my arm in, **so I can steer**" Participant 002*

*"I've got a friend in [disability] football who played for a club at a really high level and then he got told that he can't play because of his arm. So, I that's why I wouldn't want to [play able bodied football], **I want to be in one [a club] that allows you to stay there forever**." Participant 003*

*"I've **been doing it [taekwondo] for ages** since the age of 6, so I go. And football is just **fun** playing football." Participant 001*

> *"It just all started when my **mum put me into swimming lessons** to try it out and then I got told, like, I **moved up** the ways and then I **got told I was good,** and I decided to just go with it." Participant 002*

> *"In sports like that [climbing and tennis] it [a **prosthesis] gives me the extra hand**." Participant 001*

> *"They're just sports that I **enjoy**." Participant 003 on why he chose the sports he does.*

#### 4.3.2.1.1 Commentary on Theme 1: Attitudes to Sport

With a particularly active cohort who did not express a need increase their sport participation level, attitudes towards sport itself were very positive. The participants felt that sport participation was very important to their well-being. They were aware of the physical and social benefits of participation. However, no psychological benefits were specifically mentioned other than emotions that may impact psychological well-being. It would be interesting to see whether the results would be similar with less active participants.

There was resistance, and in one case out right denial, to the concept that sport participation could be reduced to non-participation. Negative emotions of sadness and annoyance were linked to this concept. However, there was a conviction and an attitude of resilience and adaptability by Participants 001 and 003 that they would find a way to participate in sport.

Barriers to sport participation included factors internal and external factors to the participants. These include lack of facilities in the local area, a lack of time or money, the increased risk of injury, fatigue (or preference to not get out of bed) and family commitments. It is interesting to note that these barriers are not linked to upper limb absence and would likely apply to AI adolescents also. However, barriers that are the result of their upper limb absence are a lack of acceptance in sporting clubs of limb difference, pain in the residuum, and prostheses not meeting a functional need.

Facilitators were diverse and although personal to each participant there were commonalities. Physical, emotional and social benefits of sport participation were mentioned repeatedly by all three subjects indicating the importance of these to the cohort. Availability of appropriate equipment and access to facilities were also identified. Participation in specific sports was often influenced by habit-formed behaviours that family had had a role in introducing the participants to. In relation specifically to upper limb absence, access to functionally appropriate prostheses is key in sports where they offer a significant positive impact for the participant.

Analysis of this theme, from the transcripts' extracted codes to organising themes, is presented in Table 9.

*Table 9: Organising theme 1: attitudes to sport*

| Organising Theme | Basic Themes | Issues Discussed | Codes |
|---|---|---|---|
| ***Attitudes to sport*** | *When already very active participants don't feel that they want to be more active.*<br><br>*Concept of not being able to participate in sport is met with resistance and denial. The possibility raises feelings of annoyance and sadness. However, attitudes of adaptability and resilience are employed to overcome the barrier and find a way to do sport.*<br><br>*Barriers include internal and external factors where the participant's limb absence is only a minor consideration.*<br><br>*Facilitators include the physical, emotional and social benefits of participation, availability of appropriate equipment and facilities, availability of appropriate prosthesis provision, and habit-formed behaviours.* | Attitude to current levels of sports participation | Doesn't want to do more sport |
| | | Attitude to the idea of an inability to be able to participate in sport | Adaptability |
| | | | Annoyance |
| | | | Denial |
| | | | Resilience |
| | | | Sadness |
| | | Barriers to sports participation | Disability |
| | | | Equipment |
| | | | Family |
| | | | Lack of acceptance |
| | | | Lack of facilities nearby |
| | | | Lack of time |
| | | | Money |
| | | | Pain |
| | | | Potential injury |
| | | | Prosthesis issue |
| | | | Tiredness or not wanting to get out of bed |
| | | | Unplanned cancellation of organised sports training and events |
| | | | Weather |
| | | Facilitators of sports participation:<br>- Benefits of sports participation<br>- Equipment besides prostheses that aid participation<br>- Prosthesis use<br>- Why participate in specific sports | Active |
| | | | Family time |
| | | | Fun / Enjoyment |
| | | | Health and fitness |
| | | | Social |
| | | | Success |
| | | | Gym equipment |
| | | | Style of bike handle |
| | | | Ease of activity |
| | | | Promotes better posture and or technique |
| | | | Prosthesis design |
| | | | Safety |
| | | | Sport specific prosthesis |
| | | | Acceptance |
| | | | Ambition and progression |
| | | | Family |
| | | | Habit |
| | | | Health and fitness |
| | | | Started when young |

#### *4.3.2.2 Theme 2: Attitudes to Prosthesis Use During Sport*

Participants expressed their attitudes towards prostheses and their use in sport. It was observed that acceptance of prostheses for sporting use was fundamentally based on personal preference associated with experience, habit and functional need:

> *"The best thing [about wearing a prosthesis for sport] is like **convenience**, it's easier to use because I've **used it for so long**." Participant 001*

> *"You can find **what works best for you**." Participant 003*

Participants suggested that prostheses were accepted for use in sport when the prosthesis is considered to offer a specific benefit, whether that be to improve function or for convenience:

> *"I only wear it [a prosthesis] for cycling and no other sports, I don't do any other sports that need it. **If I don't need to wear a prosthetic I won't wear one**. **I only wear a prosthetic if it's useful to me**." Participant 003*

> *"It'd be like if I was climbing it'd be **easier** with it on than climbing without. With tennis and sports like that it's **easier** with it on because you can hold the ball and pick the ball up. **In sports like that it gives me the extra hand**." Participant 001*

Participant 003 expressed how wearing a prosthesis for cycling helped him to reduce the risk of injury:

> *"Well I just feel a lot **stabler**, normally if I start riding one-handed it just feels like I'm going to **fall**, so I feel **safer** and more **balanced**. Mum also says it's better for my **posture** and all of those things so that I don't end up with a **bad back**." Participant 003*

As evident from Participant 002, there is an awareness that the need for prosthesis provision can change with both time and sports participated in, especially if there is an intention to perform at a higher level:

> *"I think as I get older I might have to use something more when I'm in the gym to help me with swimming because I've just been selected for the Team GB para-squad and **as you get older you do more** stuff in the gym and **I might need something** [a prosthesis] for the weight training." Participant 002*

Despite being the participant who wears a prosthesis the most, Participant 001 shared ideas suggesting that currently available prostheses lack functionality for sport, which can result in subsequent abandonment of the prosthesis:

> *"I **take it [the prosthesis] off** for swimming too, it's so it doesn't get wet because it **takes too long to dry**. Maybe if I had a spare arm I'd use it for swimming cos I could swap." Participant 001*

> *"I have a kayak hook that goes on the end but no **I don't use it**, it's **too heavy**." Participant 001*

Participant 003 shared that he wore a prosthesis for cycling but not for any of the other sports he participated in, which included swimming. Nor did Participant 002 wear a prosthesis for swimming – the main sport that she participates in. It emerged that there were common sports for which participants used a prosthesis, and those for which prosthesis wear was rejected:

> *"For all the watersports I took it off and wrote it on the sheet [activity diary] all the other ones I kept it on." Participant 001*

> *"I take it off for swimming too, it's so it doesn't get wet because it takes too long to dry." Participant 001*

*"I've got a prosthetic that I can hook onto my bike and I can put my arm in, so I can steer" Participant 002*

#### 4.3.2.2.1 Commentary on Theme 2: Attitudes to Prosthesis Use During Sport

The use of a prosthesis for sport appears to be based on personal preference which has its roots in previous experience, habit, and functional need. Considering the participants' level of wear of prostheses in conjunction with their parents' attitude towards prosthesis wear, it might also be inferred that parental influence also impacts the participants' personal preference.

It was suggested that a prosthesis is more likely to be accepted for wear during sport when it offered a specific benefit. These benefits involve improving stability, safety, balance, posture or function.

Participants also identified that their need for prosthesis provision for sporting activity was flexible and may change with time or the requirements of the sport that they participate in. This was particularly evident for Participant 002, who is working towards competing at a high level and acknowledges that adopting the use of a prosthesis may be necessary to improve performance.

A failure of currently available prosthetic devices to meet sport-related functional needs was raised. These illustrated the problems with using upper limb prostheses for water-based activities and the commonly referred to issues surrounding the weight of a prosthesis. These are challenges that could be raised with prosthetists and engineers for resolution.

Many of the sports chosen by these participants do not require the use of an upper limb prosthesis. Cycling was highlighted as a sport for which a prosthesis is worn, and this fundamentally appears to be due to functional need. Whereas, for swimming and water-based sports prostheses are not worn, but this seems to be in part because of a failure of prostheses to meet the needs of the user.

Analysis of this theme from the transcripts' extracted codes to organising themes is presented in Table 10.

*Table 10: Organising theme 2: attitudes to prosthesis use during sport*

<table>
<tr><th>Organising Theme</th><th>Basic Themes</th><th>Issues Discussed</th><th>Codes</th></tr>
<tr><td rowspan="18">Attitudes to prosthesis use during sport</td><td rowspan="18">Prostheses are accepted for use in sport when they offer a specific benefit, be it to improve function or due to convenience.<br><br>The acceptance of prostheses for sport use is based on personal preference associated with experience, habit and functional need.<br><br>The need for prosthesis provision can change with time depending on sports participated in and to the level at which they are engaged at.<br><br>Currently available prostheses lack functionality for example being too heavy, slow or not being able to attach to equipment.<br>The use of a prostheses in sport can assist with balance, posture, safety and stability.<br><br>Some sports such as cycling typically result in participants using a prosthesis. However, in water-based sports, in particular, swimming prostheses are not worn.</td><td rowspan="9">Attitudes to prosthesis use during sport</td><td>Adaptability</td></tr>
<tr><td>Can see possible need to change needs in the future</td></tr>
<tr><td>Convenience</td></tr>
<tr><td>Establishes what works for them</td></tr>
<tr><td>Habit</td></tr>
<tr><td>Improves function</td></tr>
<tr><td>Personal preference</td></tr>
<tr><td>Poor functionality of current devices</td></tr>
<tr><td>Prosthesis for specific benefit</td></tr>
<tr><td rowspan="4">Advantages of prosthesis use during sport</td><td>Balance</td></tr>
<tr><td>Posture</td></tr>
<tr><td>Safety</td></tr>
<tr><td>Stability</td></tr>
<tr><td rowspan="2">Sports where a prosthesis is not worn</td><td>Swimming</td></tr>
<tr><td>Watersports</td></tr>
<tr><td rowspan="3">Sports where prosthesis is worn</td><td>Climbing</td></tr>
<tr><td>Cycling</td></tr>
<tr><td>Tennis</td></tr>
</table>

#### *4.3.2.3 Theme 3: Attitudes to Everyday Prosthesis Use*

Participants discussed their attitude to prosthesis use during everyday use. It was suggested that this use was typically dependent on personal preference. This preference was informed by convenience, habit and the perceived benefit of the prosthesis:

> *"I'm having a lazy day at home I **won't put it on** but if I'm like going out I'll **probably put it on**. Yeah I wear it at School **full time**." Participant 001*

> *"Not really no, I mean I have them [prostheses], but **I don't really use them**… To be honest, **I don't feel like I need it** because I can do most things and if I can't do it I either ask somebody for a little bit of help but most things I can do. **I only wear them if they help me**." Participant 002*

> *"**I really wish that there was one that could** hold on to a skipping rope because I sometimes in the summer all my friends are doing skipping with the skipping ropes and what I have to do is sometimes try and wrap it round my arm but then it falls off." Participant 002*

> *"**Only** if I'm riding my bike." Participant 003 one whether he wears a prosthesis on a day to day basis*

##### 4.3.2.3.1 Commentary on Theme 3: Attitudes to Everyday Prosthesis Use

The attitudes raised in Theme 3 very closely mirror those raised in Theme 2. Prosthesis wear was heavily dependent on personal preference, which was informed by previous experience, habit, and functional need.

There is a failure of prostheses to meet fully the functional needs of the user, and users will only accept prosthesis wear if there is a functional benefit to themselves when using the device.

Analysis of this theme from the transcripts' extracted codes to organising themes are presented in Table 11.

*Table 11: Organising theme 3: attitudes to everyday prosthesis use*

| Organising Theme | Basic Themes | Issues Discussed | Codes |
|---|---|---|---|
| ***Attitudes to everyday prosthesis use*** | *Use of prostheses during everyday activities is due to personal preference associated with convenience, habit and perceived benefit of the device.* | When is a prosthesis worn? | At school |
| | | | For sport |
| | | | Prosthesis not worn at home |
| | | | Prosthesis generally worn when away from home |
| | | | Prosthesis not worn |
| | | Why is the prosthesis worn? | Convenience |
| | | | Ease of use |
| | | | No benefits to not wearing a prosthesis |
| | | Why isn't it worn? | Can't see a benefit in use |
| | | | No current device to meet needs |

#### *4.3.2.4 Global Theme*

The global theme emerged from the identification of the basic and organising themes. The transcripts were coded, and the codes subsequently organised into 11 basic themes (Tables 9–11). These basic themes were concentrated into three organising themes from which the global theme developed (Table 12). The global theme summarises the core meaning of the interview data. This theme was found to be that *"The ability to participate in sport has a powerful influence on participants' lives. Despite minimal prosthesis wear during sport, prostheses were used when participants felt they offered specific benefits."* Figure 24 illustrates the organisation of basic and organising themes to inform the global theme.

*Table 12: Global theme*

| Global Theme | Organising Theme |
|---|---|
| ***The ability to participate in sport has a powerful influence on participants' lives. Despite minimal prosthesis wear during sport, prostheses were used when participants felt they offered specific benefits.*** | Theme 1: Attitudes to sport |
| | Theme 2: Attitudes to prosthesis use during sport |
| | Theme 3: Attitudes to everyday prosthesis use |

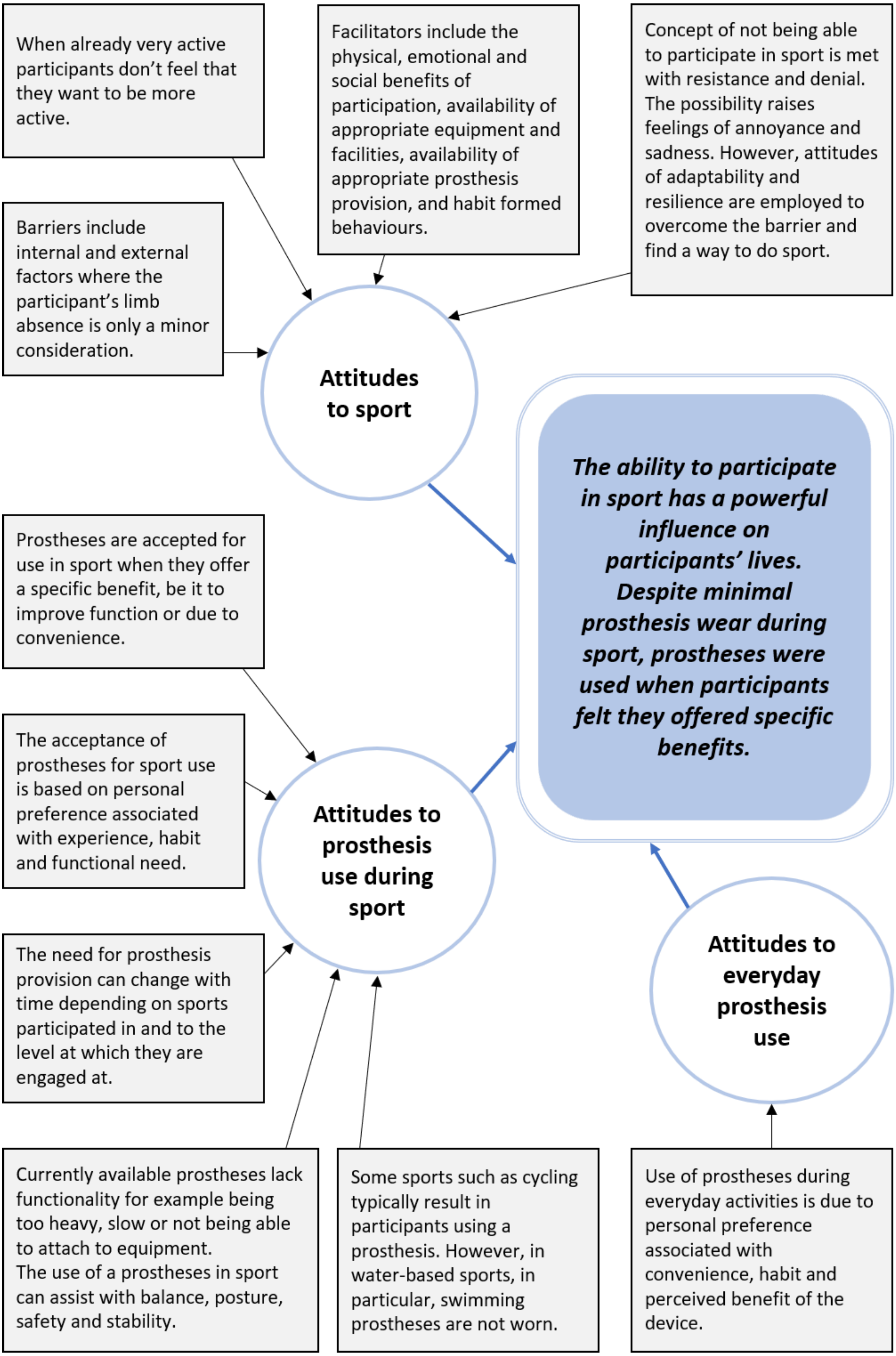


*Figure 24: Organisation of findings: basic, organising and global themes*

### 4.3.3 Summary of the Qualitative Findings

In summary the semi-structured interviews identified that participants find sport participation an integral part of their lives and value its benefits both physically and psychosocially. The concept of restricting sports participation for these individuals resulted in negative emotional feelings. Barriers to sports participation included internal and external factors, where the participant's limb absence was only a minor consideration. Facilitators included the physical, emotional and social benefits of sport participation, availability of appropriate equipment and facilities, availability of appropriate prosthesis provision, and habit-formed behaviours.

Prosthesis wear was largely influenced by personal preference and informed by experience, habit and functional need. It was identified that despite prosthesis wear, in some cases, being more minimal than others during sport participation there is an acceptance of prostheses for use when they are perceived to functionally benefit participation. Use of prostheses in some sports were seen to improve safety and reduce the risk of injury. Issues with prostheses not meeting the needs of the user for some sporting activities were identified, and the functional impact of prostheses results in sports where prostheses are generally worn, and sports where they are not.

Attitudes to everyday prosthesis wear shows a marked similarity to that of wear for sport, with emphasis on prosthesis wear being based on personal preference and dependent on perceived benefit.

# Chapter 5: Discussion, Conclusion and Future Work

This study intends to explore the objective prosthesis wear and usage patterns of ULA adolescents, in addition to gaining an insight into the participants' views on sport and prosthesis wear during sport. This chapter discusses the results, draws conclusions, identifies limitations and makes recommendations for future work.

## 5.1 The Participants

Despite there being no definitive national statistics for the number of limb absent individuals within the UK, anecdotal evidence from charities connected to this project suggests that there are between 65,000 – 100,000 limb absent people in the UK, of which an estimated 8,000 are ULA. This small number of ULA individuals nationally has meant that only a small sample size was available for use within this study which is a common issue for research within underrepresented populations (137). Small sample sizes do not negate the need for greater insight into these niche areas, but they do have an undeniable effect on statistical power and the generalisability of the findings. This difficulty recruiting sufficient participant numbers was further exacerbated by the relatively short research cycle available to complete Master's level research.

The participants in this study were primarily at the younger end of the adolescent spectrum (120); six participants were aged between 10 and 14 years, with only one AI outlier at 19 years. This can be partly be attributed to the participants' self-selection to take part in the study, and some being friends with each other.

In the UK, upper limb absence is most commonly attributed to trauma or congenital loss, however, in this study only individuals with congenital loss participated.

All three ULA participants were particularly active and sport-orientated. All participated in sport for over 9 hours across the 2-week duration (9.58 hours, 12.33 hours and 22.75 hours, respectively), as evident in Table 6. These levels of participation may have been influenced by recruitment through sport promoting charities, that none of the participants had trauma related loss, and that the study, in part, took place during the school summer holidays.

However, according to Bragaru [(11)] and Smurr et al. [(92)] the ULA population are predominately active and competitive, and Bragaru [(11)] identified that 57% of individuals with upper limb absence participated in sport for a minimum of 60 minutes per week.

Due to the restricted number of potential participants in a difficult to recruit area and the limited timeframe for study completion, the research protocol avoided adopting too many exclusion criteria. This, however, resulted in only loosely matched cohorts, whereby the groups were adolescents and active for a minimum of once per week. If the study were to be undertaken on a larger scale would be advisable to seek greater age and sex matching.

## 5.2 Epoch Choice for Data Processing

During the activity monitoring aspect of the study the impact of the choice of epoch length used for data processing was considered. As evidenced in Figure 17, the impacts of 1 second, 10 second, 30 second and 60 second epochs were investigated. It was identified that the data for the ULA participant were more affected by this choice than that of the AI participant. The *"Median %Reliance$_{Dom}$"* data showed a difference of 4.66% – 7.01% for the ULA participant across activity periods, however, this range was negligible for the AI participant (0.62% – 0.83%). For the ULA participant, in each activity period it was demonstrated that the longer the epoch the lower the resulting "Median %Reliance$_{Dom}$" value. Additionally, for this participant the impact of the epoch length was less during Sport; during this time prosthesis wearers were shown to be more symmetrical in upper limb activity. With this insight, and the evidence that the impact was negligible for the AI participant, it could be suggested that the more symmetrical the upper limb activity the less of an impact the epoch length has on the data processing.

Following this initial investigation, that an epoch of 60 seconds was selected, in line with the studies by Chadwell et al. [(7-9)], which were the first to look at upper limb activity patterns in adult prosthesis users using activity monitoring devices [(3)]. This allowed for results to be directly compared with those previous studies.

The decision to use a 60 second epoch was also influenced by Chen and Bassett [138] and Matthews et al. [139]. Chen and Bassett [138] proposed that a 60 second epoch allowed for the best balance between shorter epochs where higher resolutions of data are captured, and longer epochs where time allows for data-smoothing. Furthermore, although Matthews et al. [139] suggest that best practice is to record data at the shortest epoch possible, recommending less than 10 seconds, they subsequently endorse converting this data to 60 second epochs for processing and analysis.

## 5.3 Attitudes to Sport

To recognise the significance of prosthesis use during sport to adolescents with upper limb absence it is important to first understand the value of sport to these participants. With a particularly active cohort, participants found sport participation vital to their overall well-being and believed that they would experience negative emotions if they were prevented from engaging in their chosen activities. However, as can be seen in Table 9, they exhibited a resilient and determined attitude, proposing that they would find a way to participate in sport even if it was difficult to accomplish. This attitude was reminiscent of active adults with lower limb absence who believed that there would be negative consequences if they were to live their lives without sport participation [84]. With 49% – 57% of 11–15 years olds in England participating in sport at least twice per week [16], the proposition by Bragaru [11] that ULA individuals show similar patterns of sport participation to able-bodied individuals is supported by the data reported in this thesis, as presented in Table 6. Likewise, high levels of sport participation in adults with limb absence is reported by LimbPower [140]. A decision to participate in sport by those with upper limb absence is typically informed by personal reasons and past experiences [11], resulting in potential barriers to, and facilitators of, their chosen sport(s).

### 5.3.1 Barriers to Sport

As presented in Table 9 barriers to sport were both internal and external to the participant. These included lack of facilities in the local area, a lack of time or money, the increased risk of injury, fatigue (or preference to not get out of bed) and family commitments.

Interestingly none of these barriers related to the participants' upper limb absence and as such are likely to compare with those affecting their able-bodied peers. The idea that barriers for children with disability show a marked similarity to able-bodied children has previously been suggested by Shields et al. [81]. Likewise, other studies identified barriers for those with disability, and upper limb absence specifically, that were not directly related to disability or upper limb absence [11, 24, 73, 84]. As with this study, factors such as an increased risk of injury, a lack of local facilities, time and money were recorded as the main barriers to sport participation for young people with disability and ULA adults. Poor access to transport is also a recognised barrier for children with disability [24]. Adults with limb absence find it difficult to engage with sport when they feel insufficiently physiologically able in the first place [73].

Barriers associated with the participants' upper limb absence included a lack of acceptance in sporting clubs of limb difference, pain in the residuum and prostheses not meeting the required functional need. A common barrier related to disability experienced by children with disability and adults with limb absence, including specifically upper limb absence, is local clubs being unsuitable for purpose for the mentioned demographics [11, 24, 73, 84]. For children with disability, the disability itself was considered a barrier [24] – a feeling mirrored by adults with upper limb absence [11]. The former cohort also identified discrimination against disability by a club or general population, insufficient access to appropriate sport information and programmes, and feelings of dependency as notable barriers. An example of the result of discrimination by a club was highlighted in this study; the participant chose to participate in pan-disability football rather than join an able-bodied team. This was due to a friend's experience whereby they were rejected from their current team as they were moving up an age category. The reason given for this decision was the upper limb absence of the player. This sentiment is in opposition to the findings of Bragaru [11], which suggested that adults with upper limb absence who participate in sport for a minimum of 60 minutes per week prefer to participate in able-bodied clubs. A study of active limb absent adults found the two most influential barriers to sport were related to the prosthesis function and socket fit [73]. There was no mention of barriers related to prostheses in the study of ULA adults although it is notable that most participants chose not to wear prostheses for sport [11]. In this study the issue of a lack of appropriate prosthesis function was discussed, however, there was no mention of prosthesis socket fit as a barrier. Failure to capture issues relating to socket fit may be due to the small sample size and / or bias stemming from the minimal wear of prostheses during sport by the participants in this study.

### 5.3.2 Facilitators of Sport

Facilitators were diverse and although they were personal to each participant there were commonalities. As shown in Table 9, physical, emotional and social benefits of sport participation were repeatedly raised by all ULA participants indicating the importance of these to the group.

Participants were motivated by the benefits that sport provides and cited physiological fitness and activity as common reasons for engaging in sport whilst they also acknowledged improved socialisation with family and friends as well as having made new friends. “Fun” and enjoyment were major reasons for participation in sport. Other studies suggest that improving and maintaining physical fitness and health is a key reason that adults with limb absence, and specifically upper limb absence, participate in sport [11, 73, 84]. In line with the findings of this study, the social aspect of sport as a major motivator for engagement was also reported by Allender et al. [141], Bragaru et al. [11, 84], and LimbPower [73]. This highlights the fact that social support within existing relationships, such as family, friends and sport peers, as well as the opportunity to make new friendships, are important to able-bodied and limb absent adults and children alike. According to LimbPower [73] the most popular motivator for sport participation amongst those with limb absence is fun and enjoyment, a fact also mirrored in this study. Pleasure, fun and enjoyment have also been promoted as a sport facilitator for able-bodied adults and children, as well as limb absent, including specifically ULA adults [11, 84, 141]. Papers report that a motivator for adults with limb absence is the perceived value of sport for relaxation and de-stressing [73, 84]. However, there is also an appreciation of the enjoyment created by the competitive element that can be found in some sports [84].

Acceptance is key for the participants when choosing a sport. Participation in specific sports was often influenced by habit-formed behaviours linked to the role of the family, and how and when the participant was introduced to specific sports. When participants had engaged in a sport for “a while” it appeared that they chose to continue with it. Furthermore, a sense of achievement and participating at a relatively high level of capability keeps participants engaged. Habit-formed behaviour as a motivator to maintain sport participation has been reported in ULA adults, whereby they have always participated in sport, and so they continue to do so (11). Adults with limb absence have also been motivated to engage in sport by recommendations from health care professionals (84), thereby promoting and initiating the habit-forming behaviours.

In relation to the participants’ upper limb absence, access to functionally appropriate prosthesis provision is key when prostheses are a necessity of participation. This can be complex to achieve due to the varied and multifaceted requirements of upper limb use for different tasks associated with a diverse range of sports. Conversely, adults with lower limb absence found the prosthesis to only be an indirect motivator, that is to say, that participants found if they participated in sport that the positive physical effects meant that they could use their prosthesis more effectively (84).

### 5.3.3 Popular Sports

Having gained some understanding as to what motivates and prevents adolescents with upper limb absence from participating in sport, it is important to identify what sports they choose to engage in.

The ULA adolescents participated in a variety of sports during this study including, archery, badminton, climbing, cycling, kayaking, land training (gym), rugby, sailing, shooting, orienteering, skiing, swimming, pan-disability football and windsurfing, as set out in Table 6. Not all of these were weekly pursuits, as one participant attended an activity camp organised by Reach (an upper limb absence focused charity), although the participant did consider this to be part of their everyday life as it was a regular event for them. Other sports that participants reported participating in regularly (more than once per week) were taekwondo, football (able-bodied) and amputee football, however, during the study period these activities were not engaged in.

The popularity of swimming amongst all three ULA participants, as seen in Table 6, was in line with findings by Jaarsma et al. (62) and LimbPower (73, 140), who found swimming to be the most popular participation sport amongst children to young adults with physical disability and adults with limb absence. This activity is also the third most popular sport participated in by children in general within the UK (37).

Cycling and football are also considered to be in the top three sports participated in by able-bodied children (aged 11–15 years) and disabled adolescents (37, 62). Conversely, although cycling is reported as a popular sport amongst those with limb absence (third most popular), football is not presented in the top ten.

It is interesting to note that climbing, rugby, snow sports, football and windsurfing are activities participants of this study engaged in during the study period, as presented in Table 6. However, in a study concerned with sport participation in limb absent adults, these sports were in the top ten sports prohibited by prosthesis or limb impairment (140). Notably, climbing is considered the second most affected sport in the latter previous study (140), yet the participant in this study who climbed found that his prosthesis made participation easier and gave him an "extra hand" (P001).

Having some insight to the ULA adolescents' attitudes to sport and the sports that they choose to participate in, it is now possible to develop an understanding of prosthesis wear during sport.

## 5.4 Prosthesis Wear

### 5.4.1 Prosthesis Wear Time

The prosthesis wear time for the three upper limb absent participants varied significantly, as evidenced in Table 7. One participant wore their device daily for everyday activities and during sport. At the other extreme, another participant wore a prosthesis only for cycling, and the final participant chose not to wear a prosthesis at any time over the two-week period.

For the activity monitoring portion of the study only the data of the two prosthesis wearers were used, however, useful insights were obtained from the interview data of all three ULA participants.

#### *5.4.1.1 Self-Report Vs. Calculated Wear Time*

Self-report, when accurate can provide a reliable measure of prosthesis wear time, however, the reliability is dependent on the person supplying the data [(7)]. As this study reports, there were instances of missing data and despite guidance to use a phone or watch to record the times reported, times appeared to sometimes be estimated, rather than actual. This may be partly due to watches and / or phones not being readily available at the exact start / end of sport participation, as these are not something typically on one's person at these times.

Prior to studies by Chadwell et al. [(7-9)] prosthesis wear time was typically measured using self-reported average daily wear times [(7)]. In line with Chadwell et al. [(7)], this study also found that there were discrepancies between the self-reported prosthesis wear time and the calculated prosthesis wear time. Furthermore, as seen in Table 7, over the two-week study period Overall, one participant self-reported prosthesis wear time to be 25.2 hours less than the calculated prosthesis wear time; a 7.5% difference. This significant difference can be attributed to failure of the participant to accurately complete the activity diary. The other participant self-reported prosthesis wear time to be 2 hours less than the calculated prosthesis wear time, a 0.6% difference. On average, Chadwell et al. [(7)] identified a difference of 4.4 hours between self-reported and calculated prosthesis wear time over seven days. Contrastingly, Chadwell et al. (7) observed that self-reported prosthesis wear times were greater than the calculated prosthesis wear time.

Interestingly, during Sport, one participant self-reported prosthesis wear time 4.9% less than the calculated prosthesis wear time, and the other self-reported prosthesis wear time 2.1% more than the calculated prosthesis wear time. As Chadwell et al. (7) did not report sport participation there was no comparable data in relation to this.

With some understanding of general upper limb prosthesis wear time it is now possible to consider how often and why upper limb prostheses are worn for sport by the ULA participants in this study.

### 5.4.2 Prosthesis Wear During Sport

#### *5.4.2.1 Prosthesis Wear Time During Sport*

The prosthesis users in this study chose to wear a prosthesis for at least one sport that they participated in. One participant took part in sport over the 2-week study period for 22.75 hours and wore a prosthesis 56.5% of the time, wearing their prosthesis for all sporting activities except watersports. Conversely, the other participant participated in sport for 9.58 hours, wore a prosthesis 16.2% of the time and only for cycling. In comparison to this, self-reported data in a study by Bragaru (11) suggested that ULA people participating in sport more than 60 minutes per week opt not to wear a prosthesis during sport.

#### *5.4.2.2 Specific Sports and Prosthesis Wear.*

The participants of this study engaged in a variety of sports during the 2-week period. There was only one common activity for all three ULA participants; swimming. For this activity no participants wore a prosthesis, as outlined in Table 6. This correlated with the findings by LimbPower (140), where 74% of adults with limb absence choose not to wear a prosthesis for swimming. This may be influenced by the fact that prostheses are not permitted for competitive swimming competitions (64), or, as suggested by a participant in this study, prostheses do not meet the functional need. Despite this there are a few sport-specific devices to facilitate training and development [(100)].

Conversely, in relation to cycling, during this study one participant chose to wear a prosthesis solely for this activity. Additionally, during the interview with the non-prosthesis-wearer, it was identified that they did have a prosthesis for cycling which they wore when participating in this sport. This again reflects the findings of LimbPower [(140)], with 90% of limb absent adults wearing a prosthesis for cycling. However, it must be noted that this study comprised of mainly lower limb amputees with only 8% upper limb, which may have heavily influenced the necessity for a prosthesis.

### 5.4.3 Reasons for Prosthesis Wear / Non-wear During Sport

Prosthesis wear was largely influenced by personal preference of the participants. This preference was typically informed by experience, habit and functional need, as seen in Table 10.

#### *5.4.3.1 Experience*

The participant's perception of the usefulness of prostheses stems from previous experience, experience of others and is influenced by their parents experience and perceptions. Bragaru [(11)] found that most ULA athletes chose not to use a prosthesis for sport despite various devices being available, as they perceived these to be unnecessary. An idea of establishing "what works best for you" with regards to prosthesis use during sport was common amongst all the participants. Furthermore, prosthesis wear was rejected when a previous device (their own or others) had been found to be of no functional value. In addition to this, LimbPower [(69)] suggested that prescription of bespoke sporting prostheses from NHS limb centres is unlikely. The reasons for prosthesis wear during sport typically mirrored that of those given for everyday wear, focusing around past experience, habit and function. For this reason, it is important to educate and encourage parents of limb absent children to support prosthesis use for sports and related activities, thereby increasing the likelihood of device use and facilitating a more diverse range of activities as the child moves into adulthood.

#### *5.4.3.2 Habit*

It can be inferred that for these participants the habit of prosthesis wear or non-wear in general and during sport participation, may have been influenced by parental attitude. The participant whose parents encouraged prosthesis wear from a young age presents with the most prosthesis wear and finds that to do so is more convenient. Conversely, the participants whose parents were less proactive in encouraging the wear of a device do not wear a prosthesis during everyday activity and only minimally, if at all, during sport participation.

Bragaru (11) suggested that people with upper limb absence, if they do wear a prosthesis for sport, typically choose to wear their "everyday" prosthesis rather than a sport-specific device. This is evident with the participant in this study who wears their prosthesis the most. The participant opts to wear their "everyday" prosthesis for all activities (except water-based sports) including, for example, climbing, rather than a specialised device.

#### *5.4.3.3 Functional Need*

It was suggested that a prosthesis is more likely to be accepted for wear during sport when it was perceived to offer the user a specific benefit. These benefits involve improved stability, safety, balance, posture or function. This is in line with findings that rejection rates for prostheses used by children and young people are strongly linked to the users' or parents' perception of how effectively the prostheses perform their function (142).

Two of the three ULA participants reported wearing a prosthesis for cycling. It was suggested that acceptance for prosthesis wear for this particular activity was due to an increased feeling of stability and balance, and a perception that their posture while riding would be improved, thereby reducing the risk of injuries. The participant that wore a prosthesis most frequently also reported that prosthesis wear during sport made participation “easier” and in some situations even “gave him an extra hand.”

Many of the sports chosen by these participants, such as swimming, do not require the use of an upper limb prosthesis. There is a failure of some currently available prosthetic devices to meet sport-related functional needs. In some cases, the sport-specific device is poorly designed; for example, in this study it was reported that a kayak terminal device was too heavy for the participant to use and thus it was rejected. Moreover, issues surrounding the wear of upper limb prostheses for water-based activities were raised. In this instance, the duration it took for a prosthesis to dry and the resultant discomfort of wearing a damp prosthesis meant that the participant chose not to wear a device for these activities.

Participants acknowledged that their need for prosthetic provision for sporting activity was flexible and may change with time or the requirements of the sports that they participate in, for example, if they progress to competing at a higher level.

A common response from all participants was that they only wear a prosthesis for sport when they feel that “it is useful” to them; they do not wear a device for the sake of wearing it. This correlated with findings by Bragaru [(11)], where people with upper limb absence chose not to wear devices for sport as they believed that they were not needed. Moreover, LimbPower [(140)] suggested that limb absent adults found functionality (78%) and usefulness (68%) of a prosthesis impacted on sport participation.

During this study it was apparent that prosthesis function during sport was a priority. The participants did not mention cosmesis as a reason for prosthesis wear during sport, however, other studies have found this to be of utmost importance [(2)].

Having considered how often and why ULA adolescents use prostheses, it is important to understand how the prosthesis wearers use their devices, and identify upper limb activity patterns to add context to the periods of prosthesis wear.

## 5.5 Prosthesis Usage

Prosthesis usage in this study has been determined by the symmetry of upper limb use across both arms as identified in the Methods Chapter (Section 3.1.5.7), and was based on the work of Chadwell et al. [7-9]. Differentiating prosthesis usage from prosthesis wear allows us to evaluate the effect of a prosthesis on the user's reliance on their anatomically intact limb. It is thought that more equal reliance across the two limbs may reduce the risk of overuse wear and tear on an ULA person's sound side. For this aspect of the study only the data of the two prosthesis users and the anatomically intact participants were used.

As can be seen in Figures 18, 20 and 22, both prosthesis users displayed a notable reliance on their anatomical limb even when wearing a prosthesis Overall and during Sport. Overall, when using a prosthesis, these two participants demonstrated 68% and 76% reliance on their anatomical limb. These results are consistent with those reported by Chadwell et al. [7], who identified that ULA adults were 66.8% – 87.3% reliant on their anatomical limb during everyday activity. During Sport where a prosthesis was used, the reliance on the anatomical limb decreased slightly to 63% and 72% respectively, showing a small improvement in upper limb activity symmetry for both participants. Despite Chadwell et al. [7] not specifically considering prosthesis use during sport, our findings during this period remain comparable to those for ULA adults, with the results from this study displaying a slightly more symmetrical presentation.

It is interesting to observe that the prosthesis user who displayed the greatest prosthesis wear time (C) (Overall = 130.95 hours, Sport = 12.85 hours) (Table 7), as seen in Figures 18 and 20, also demonstrated the greater reliance on their anatomical limb (Overall = 76%, Sport = 72%). This contrasts with the participant who only wore a prosthesis for cycling (prosthesis wear time (C): Overall = 3.8 hours, Sport = 1.55 hours) (Table 7) but who displayed greater upper limb activity symmetry (Overall = 68%, Sport = 63%), as presented in Figures 18 and 20. Chadwell et al. [7] also found that the symmetry of upper limb usage patterns is not strongly correlated to prosthesis wear time, suggesting that wear time cannot be used as a measure for potential upper limb overuse injuries of the anatomical side.

In previous studies it has been indicated that people without upper limb impairment display good symmetry of their upper limb activity during everyday activity with near equal reliance on both arms [7-9, 113]. A 51% [7, 8] to 52% [113] reliance on the dominant arm has been reported. This study found that AI participants presented with a 49% – 54% reliance on the dominant limb Overall, narrowing to 50% – 51% during Sport. These figures also fit within the 43.9% – 62.8% range identified by Chadwell et al. [7].

Having used both activity monitoring and interview data to inform the understanding of prosthesis wear during sport, and the objective data to gain insight into upper limb activity patterns during sport, it is useful to consider how the objective and subjective has been combined to enhance interpretation of the findings.

## 5.6 How Has a Mixed Methods Study Design Added Value and Understanding to this Research?

The use of a mixed methods study design allowed for insightful and in-depth findings into the area of interest, and a rich understanding of the research question [143] within what is up to now a small, but significant, niche area. In this study, the rationale of prothesis wear as described by each participant enabled a richer understanding of the quantifiable data, such as prosthesis wear time and upper limb activity pattern data. Likewise, the objectivity of the activity monitoring data bolstered the accuracy of the informative but predominantly subjective interview data.

The activity monitoring portion of this research indicated that prosthesis wear was minimal and use unbalanced. However, when paired with the interview data it is suggested that although wear is minimal, participants feel that when they do wear a prosthesis they perceived it as being valuable to them.

This combined approach allowed for knowledge to be gained concerning the sports these individuals chose to engage in and importantly why they chose them, and an insight was developed into both the how and why these adolescents wear and use prostheses during this sport participation.

## 5.7 Novelty of the Study

A mixed methods study design was used for this research with the objective data collected using activity monitoring devices. The data presented was obtained from three ULA adolescents and four AI adolescents. It is believed that this is the first study to use a mixed methods approach to data collection in the ULA demographic to assess upper limb prosthesis wear and usage patterns relating to sport. It is also thought that this is the first study in this demographic, and all demographics to use objective activity monitoring devices to collect prosthesis wear and usage patterns during sport.

## 5.8 Thesis Aims and Key Findings

The aim of this thesis was to explore levels of sports participation and prosthesis wear / usage during sport in active adolescents with upper limb absence, more specifically the objectives were to:

- Capture objective prosthesis wear and usage patterns from physically active ULA adolescents.

Data were collected using activity monitoring devices over a 2-week period. Prosthesis wear was found to be minimal, however, when worn, upper limb activity remained skewed towards the anatomical arm, indicating heavy reliance on this limb. In comparison, AI participants displayed near equal symmetry of upper limb activity.

- Develop understanding of how this usage relates to sports participation.

Prosthesis wear and upper limb activity by the three adolescents with upper limb absence who participated during sport resembles that of during everyday activity. In one case, there was no prosthesis wear recorded over the 2-week period. Prosthesis wear varied from 16.2% to 56.5% during sport participation periods. The reliance on the anatomical limb for the two ULA prosthesis wearers was high, although slightly less during sport participation than at other times. However, upper limb activity of the AI cohort was near equal across both limbs.

- Gather sports participation data and capture participants' views on sport, prostheses and reasons for use/non-use in sport.

Sports that this cohort of ULA adolescents participated in were identified. The sports were varied and individual to each participant, however the most popular sport amongst all three participants was swimming.

This group were particularly active, participating in sport for between 9.58 hours and 22.75 hours during the 2-week duration. This group of three participants showed similar levels of sport participation to able-bodied peers.

The ability to participate in sport has a powerful influence on the participants' lives. They believe that the benefits are physical and psychosocial and as such will do what they must to engage in their chosen activities.

Despite minimal prosthesis wear during sport, prostheses were worn and would be considered for wear if they were perceived to provide a specific functional benefit and were therefore perceived to be of value.

The ability to participate in sport clearly has a powerful influence on the lives of the ULA participants in this study.

In summary, the data suggests minimal use of prostheses during sport, with devices used only when participants believed it functionally benefited participation. During periods of prosthesis wear, patterns of activity were still skewed towards the anatomical side. These findings raise questions over the usability of current prostheses for sports. This feasibility study has proved to be an appropriate method by which to collect this data and thus larger studies are warranted using similar methods.

## 5.9 Limitations and Future Work Recommendations

- The number of participants recruited was small, even for a feasibility study. For any future work it is advisable to recruit from a larger pool, potentially including NHS limb centres.

- Despite recruitment being open to all ULA adolescents in the UK, as participants were self-selected with recruitment primarily through sport-promoting charities, the study only collected data for congenital and very active adolescents. It is hoped that if the previous limitation was addressed, and the number of participants increased, then this issue would be resolved allowing for more adolescents with acquired limb absence and more varied sport participation levels.

- This study only captured data within a two-week snapshot in the lives of these adolescents. The data was captured between summer and autumn, meaning that the data for some participants were captured during the summer holidays and others during term-time. This may have an impact on results and in future studies it would be beneficial to undertake a longitudinal study over a longer time span, capturing data at a series of fixed points throughout the period.

- Sport participation times were self-reported and may therefore be less reliable. With the advancement in activity monitoring devices for research there may be developments to allow for automatic recognition of sporting activities or at least a means by which to record sport start and end times on the device in real-time, such as the existing health and fitness tracker, the Fitbit Charge 3 [144].

- A significant part of sport-related prosthesis wear and usage data was not available due to the popularity of swimming (where no prosthesis was used by these participants). It would be interesting to study adolescents who do wear a prosthesis for this activity.

- We do not know how much the residuum contributes to upper limb activity patterns when a prosthesis is not worn. This could be addressed with future studies where activity monitoring devices are worn on the residuum rather than the prosthesis.

- There are two main limitations of the activity monitoring devices; firstly, they do not differentiate between whether a prosthesis is being worn or carried. Secondly, they cannot differentiate between actively or passive use, that is to say, whether the terminal device is being opened and closed, or in some other way actively operated.

# Appendix 1: Ethical Approval

On the following two pages are the letters confirming ethical approval for both the initial ethics application and the subsequent amendment.

University of Salford MANCHESTER

**Research, Enterprise and Engagement**
**Ethical Approval Panel**

Research Centres Support Team
G0.3 Joule House
University of Salford
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk/

2 March 2018

Dear Natalie,

**RE: ETHICS APPLICATION–HSR1718-049–'Real time use of prostheses in sport by adolescents with upper limb absence.'**

Based on the information that you have provided, I am pleased to inform you that ethics application HSR1718-049 has been approved.

If there are any changes to the project and/or its methodology, then please inform the Panel as soon as possible by contacting Health-ResearchEthics@salford.ac.uk

Yours sincerely,

Professor Sue McAndrew
Chair of the Research Ethics Panel

Health Research Ethical Approval Panel

## Amendment Notification Form

Please complete this form and submit it to the Health Research Ethics Panel that reviewed the original proposal: Health-ResearchEthics@Salford.ac.uk

*Title of Project:*
**Real time use of prostheses in sport by adolescents with upper limb absence.**

| | |
|---|---|
| *Name of Lead Applicant:*<br>**Natalie Chinn** | *School:*<br>**Health Sciences** |
| *Date when original approval was obtained:*<br>**$2^{nd}$ March 2018** | *Reference No:*<br>**HSR1718-049** |

*Please outline the proposed changes to the project.* ***NB.*** *If the changes require any amendments to the PIS, Consent Form(s) or recruitment material, then please submit these with this form highlighting where the changes have been made:*

**Changes modify trial period from 3 weeks to 2 weeks due to time constraints. This has resulted in changes to application form, PIS forms, Consent forms and recruitment material.**
**Prof. McAndrew's contact information has been corrected on both PIS forms**
**Activity diary (version 1.2) has been adjusted slightly for ease of use.**
**The demographics form has been amended to allow improved analysis.**
**All changes have been highlighted.**

*Please say whether the proposed changes present any new ethical issues or changes to ethical issues that were identified in the original ethics review, and provide details of how these will be addressed:*

**There is no apparent impact on ethical issues with these amendments.**

***Chair's Signature:***

***Approved:*** $6^{th}$ June 2018 ✓

Version 1.0 – 19 June 2017

# Appendix 2: Participant Information Sheets

Participant Information Sheet for those with limb absence.



University of Salford MANCHESTER

**PARTICIPANT INFORMATION SHEET**

## Real time use of prostheses in sport by adolescents with upper limb absence.

**Name of Researcher:** Natalie Chinn

I am a research student investigating the use of prostheses during sport by adolescents with upper limb absence. You are invited to participate in my research study to identify this information.

If you are interested in the research topic and before you decide to participate in this study or not, you need to know the rationale, benefits, limitations and what would be involved for you. Please take your time to read the attached information as this provides more details. If you have any questions and need more explanation please do not hesitate to contact the lead researcher (contact details at the end of this document).

If you would like to be considered for inclusion, please forward your contact information to the lead researcher and we will be in touch. If, after speaking to us you choose not to participate we will not contact you again.

**What is the purpose of the study?**

Sport plays a huge role in the lives of millions of people. Culturally, historically, and even politically, sport is very often used to capture the essence of nations. At an individual level, undertaking sports and similar activities can have many physical and psychosocial benefits. There are many reasons why people don't take part in sport but for those affected by disability or limb absence, this can often be due to a lack of available resources and facilities.

In this study the aim is to assess the relationship between adolescents with upper limb absence and the wear / use of their prostheses (limb) during sport. It is intended that findings will help to inform clinical practice improving opportunities for those with upper limb absence in sport and facilitate future research.

**Why have I been invited to take part?**

The study assesses the wear and use of upper limb prostheses during sport. Therefore, you have been invited to participate because you:

- Are between the age of 10 and 19
- Live in the United Kingdom
- Have transradial or transhumeral limb absence on one side only
- Participate in sport* at least once a week



- Have no other cognitive or physical disabilities.
- Have no injuries or conditions which would affect sport participation during the trial.

* Sport is classed as *"an activity involving physical exertion, with or without game or competition elements, with a minimal duration of half an hour and where skills and physical endurance are either required or to be improved."*

**Do I have to take part?**

Participation is voluntary, you are the only one who decides whether to take part in this study or not. Participating in this study is completely voluntary and you may withdraw at any time without providing a reason. If you decide to withdraw the information that you have given, up to the point of withdrawal, may be used in the research and you are still responsible for returning the activity monitors.

**What will happen to me if I take part?**

If you decide to take part this study will involve two meetings, both taking 30 minutes – 1 hour. Between these two meetings you will be asked to keep and activity diary and wear two watch-sized activity monitors, one on your anatomical wrist and the other on your everyday prosthesis, for 2 weeks. If you have a sport specific prosthesis you will be issued another monitor to go on this device. You are requested to bring any prostheses that you wear to the meeting. You will be required to visit either the School of Health Sciences at the University of Salford or a location arranged with a charitable organisation to undertake the meetings. This will be arranged in advance with the researcher. If you are under the age of 18 years your parent will need to be with you.

You will be asked to wear the activity monitors at all times, 24 hours per day so that they can continuously record how much your arms are moving (this does not mean that you need to wear your prosthesis at all times but please leave the activity monitor on your prosthesis even when you are not wearing it). If swimming at depths greater than 1.5m you will be asked to remove your activity monitor and log this information on the Activity Diary.

It is requested that you also keep an activity diary of the times when and which prosthesis is worn, when you sleep, when you participated in sports and which sports they were.

During this time we ask that you wear and use your prostheses as you would any other time. At the end of the 2 weeks the sensors and activity diary should be returned to the researcher at the second meeting.

During the second meeting you will be asked to participate in a short interview. The questions will be about your prosthesis wear during sport, the sports you wish to participate in and the ones you do take part in. This interview will be audio recorded so that it can be written up, the recording will then be deleted.

**Will I be paid?**

You will be offered a £10 Amazon voucher on completion of the data collection.

**What are the possible disadvantages and risks of taking part?**

As this study involves you behaving normally, albeit with monitors, there are no risks involved with participation. If for any reason a monitor becomes uncomfortable, this can be removed.

**What are the possible benefits of taking part?**

The information we get from you and other participants will help us to provide information with which a positive impact may be had on the lives of people with upper limb absence. By improving knowledge in this area we are hoping to be able to facilitate improving health within the country.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher (Natalie Chinn 0161 295 0456) who will do their best to answer your questions. If you remain unhappy and wish to complain formally you can do this by contacting the Research Supervisor (John Head 0161 295 2303). If the matter is still not resolved, please forward your concerns to Professor Susan McAndrew, Chair of the Health Research Ethical Approval Panel, Room MS1.91, Mary Seacole Building, Frederick Road Campus, University of Salford, Salford, M6 6PU. Tel: 0161 295 2778. E: s.mcandrew@salford.ac.uk'

**Will my taking part in the study be kept confidential?**

Yes. We take great care to protect the confidentiality of the information we are given. We take careful steps to ensure that data is secure at all times. The information collected is used for research purposes only and is dealt with according to the 1998 Data Protection Act. Personal details including your contact details will only be visible to the researcher named below. All personal details will be either stored securely in a locked filing cabinet accessible only by the researcher named below or on the researcher's own University networked computer; these files will be disposed of securely on completion of the study.

All information which is collected about you during the course of the research will be kept strictly confidential. Data collected during the study will be anonymised with a unique research code. Any information which leaves the Centre for Health Sciences Research, University of Salford will have your name and address removed so that you cannot be recognised from it. Anonymised data will be kept in the university repository for use by other researchers.

Participant Information Sheet – 2nd June 2018 – Version 1.3

**What if I want to leave the study early?**

You can withdraw from the study at any time. There is no danger to your leaving the study early. If you want to withdraw you may do so by notifying the researcher (contact details below). The activity monitors will need to be returned to the researcher which can be arranged upon notification.

**What will happen to the results of the research study?**

All information collected is used for research purposes and statistical analysis only and is dealt with according to the 1998 Data Protection Act. However, research councils and journals now demand that anonymised data is made publicly available for future secondary analyses. Hence, anonymised data will be archived in the University of Salford data repository. Information from this study will therefore be made available for future research studies by other researchers at the University of Salford and elsewhere. However, no information in the anonymised results can be used to identify individuals: you will be allocated a unique research code and all contact information will be removed. Disposable data will be securely disposed of according to the University of Salford guidelines (http://www.salford.ac.uk/research/research-data-management/preserve).

The findings of this study will be written up as part of the researcher's Masters thesis. Papers will be written on the findings, published in academic journals and presented at scientific conferences. The identity of all participants will remain confidential.

**Who is organising or sponsoring the research?**

This research is being undertaken as part of the researcher's Masters programme of study. The research is being organised by the Centre for Health Sciences Research, University of Salford, Salford M6 6PU. The researcher is self-funded.

**Further information and contact details:**

For further information about the study procedures, or to withdraw from the study, please contact the researcher:

**Natalie Chinn – n.m.chinn@edu.salford.ac.uk – 0161 295 0456**

**EMERGENCY CONTACTS**

**Researcher's Supervisor**
Dr John Head
0161 295 2303
j.head@salford.ac.uk

***Thank you for taking the time to read this information sheet. If you decide to take part in the study you will be given a copy of the information sheet and a signed consent form for you to keep.***

## Participant Information Sheet for anatomically intact participants



University of Salford MANCHESTER

PARTICIPANT INFORMATION SHEET

### Real time use of prostheses in sport by adolescents with upper limb absence.

**Name of Researcher:** Natalie Chinn

I am a research student investigating the use of prostheses during sport by adolescents with upper limb absence. You are invited to participate in my research study to identify this information.

If you are interested in the research topic and before you decide to participate in this study or not, you need to know the rationale, benefits, limitations and what would be involved for you. Please take your time to read the attached information as this provides more details. If you have any questions and need more explanation please do not hesitate to contact the lead researcher (contact details at the end of this document).

If you would like to be considered for inclusion, please forward your contact information to the lead researcher and we will be in touch. If, after speaking to us you choose not to participate we will not contact you again.

**What is the purpose of the study?**

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In this study the aim is to assess the relationship between adolescents with upper limb absence and the wear / use of their prostheses during sport. It is intended that findings will help to inform clinical practice improving opportunities for those with upper limb absence in sport and facilitate future research.

**Why have I been invited to take part?**

The study assesses the wear and use of upper limb prostheses during sport. Therefore, you have been invited to participate because you:

- Are between the age of 10 and 19
- Live in the United Kingdom
- Participate in sport* at least once a week
- Have no other cognitive or physical disabilities.
- Have no injuries or conditions which would affect sport participation during the trial.



* Sport is classed as *"an activity involving physical exertion, with or without game or competition elements, with a minimal duration of half an hour and where skills and physical endurance are either required or to be improved."*

**Do I have to take part?**

Participation is voluntary, you are the only one who decides whether to take part in this study or not. Participating in this study is completely voluntary and you may withdraw at any time without providing a reason. If you decide to withdraw the information that you have given, up to the point of withdrawal, may be used in the research and you are still responsible for returning the activity monitors.

**What will happen to me if I take part?**

If you decide to take part this study will involve one meeting, which will take 30 minutes – 1 hour. You will then be asked to keep and activity diary and wear two watch-sized activity monitors, one on each wrist, for 2 weeks. You will be required to visit either the School of Health Sciences at the University of Salford or a location arranged with a charitable organisation to undertake the meeting. This will be arranged in advance with the researcher. If you are under the age of 18 years your parent will need to be with you.

You will be asked to wear the activity monitors at all times, 24 hours per day unless swimming at depths greater than 1.5m, in which case you will be asked to remove your activity monitor and log this information on the Activity Diary. This is so they can continuously record how much your arms are moving.

It is requested that you also keep an activity diary of the times when you sleep, when you participated in sports and which sports they were.

During this time we ask that you go about your daily life as you would any other time. At the end of the 2 weeks the sensors and activity diary should be returned to the researcher, using the pre-paid envelope. This will be arranged in advance.

**Will I be paid?**

You will be offered a £10 Amazon voucher on completion of the data collection.

**What are the possible disadvantages and risks of taking part?**

As this study involves you behaving normally, albeit with monitors, there are no risks involved with participation. If for any reason a monitor becomes uncomfortable, this can be removed.

**What are the possible benefits of taking part?**

The information we get from you and other participants will help us to provide information with which a positive impact may be had on the lives of people with upper limb absence. By improving knowledge in this area we are hoping to be able to facilitate improving health within the country.

**What if there is a problem?**

If you have a concern about any aspect of this study, you should ask to speak to the researcher (Natalie Chinn 0161 295 0456) who will do their best to answer your questions. If you remain unhappy and wish to complain formally you can do this by contacting the Research Supervisor (John Head 0161 295 2303). If the matter is still not resolved, please forward your concerns to Professor Susan McAndrew, Chair of the Health Research Ethical Approval Panel, Room MS1.91, Mary Seacole Building, Frederick Road Campus, University of Salford, Salford, M6 6PU. Tel: 0161 295 2778. E: s.mcandrew@salford.ac.uk'

**Will my taking part in the study be kept confidential?**

Yes. We take great care to protect the confidentiality of the information we are given. We take careful steps to ensure that data is secure at all times. The information collected is used for research purposes only and is dealt with according to the 1998 Data Protection Act. Personal details including your contact details will only be visible to the researcher named below. All personal details will be either stored securely in a locked filing cabinet accessible only by the researcher named below or on the researcher's own University networked computer; these files will be disposed of securely on completion of the study.

All information which is collected about you during the course of the research will be kept strictly confidential. Data collected during the study will be anonymised with a unique research code. Any information which leaves the Centre for Health Sciences Research, University of Salford will have your name and address removed so that you cannot be recognised from it. Anonymised data will be kept in the university repository for use by other researchers.

**What if I want to leave the study early?**

You can withdraw from the study at any time. There is no danger to your leaving the study early. If you want to withdraw you may do so by notifying the researcher (contact details below). The activity monitors will need to be returned to the researcher which can be arranged upon notification.



**What will happen to the results of the research study?**

All information collected is used for research purposes and statistical analysis only and is dealt with according to the 1998 Data Protection Act. However, research councils and journals now demand that anonymised data is made publicly available for future secondary analyses. Hence, anonymised data will be archived in the University of Salford data repository. Information from this study will therefore be made available for future research studies by other researchers at the University of Salford and elsewhere. However, no information in the anonymised results can be used to identify individuals: you will be allocated a unique research code and all contact information will be removed. Disposable data will be securely disposed of according to the University of Salford guidelines (http://www.salford.ac.uk/research/research-data-management/preserve).

The findings of this study will be written up as part of the researcher's Masters thesis. Papers will be written on the findings, published in academic journals and presented at scientific conferences. The identity of all participants will remain confidential.

**Who is organising or sponsoring the research?**

This research is being undertaken as part of the researcher's Masters programme of study. The research is being organised by the Centre for Health Sciences Research, University of Salford, Salford M6 6PU. The researcher is self-funded.

**Further information and contact details:**

For further information about the study procedures, or to withdraw from the study, please contact the researcher:

**Natalie Chinn – n.m.chinn@edu.salford.ac.uk – 0161 295 0456**

**EMERGENCY CONTACTS**

**Researcher's Supervisor**
Dr John Head
0161 295 2303
j.head@salford.ac.uk

***Thank you for taking the time to read this information sheet. If you decide to take part in the study you will be given a copy of the information sheet and a signed consent form for you to keep.***

# Appendix 3: Consent Forms

Consent Form for participants with upper limb absence.

University of Salford MANCHESTER

Consent Form – 5th June 2018 – Version 1.3

**Participant ID Number:**

**CONSENT FORM**

**Title of study:** Real time use of prostheses in sport by adolescents with upper limb absence.

**Name of Researcher:** Natalie Chinn

Please complete and sign this form **after** you have read and understood the study information sheet. Read the following statements, and select 'Yes' or 'No' in the box on the right hand side.

| | | |
|---|---|---|
| 1. | I confirm that I have read and understand the **Participant Information Sheet** (version *1.3)* (dated 2/6/18*)*, for the above study. I have had the opportunity to consider the information and to ask questions Which have been answered satisfactorily. | Yes/No |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected. | Yes/No |
| 3. | If I do decide to withdraw I understand that the information I have given, up to the point of withdrawal, will be used in the research. | Yes/No |
| 4. | I agree to my participation in the tasks detailed in the information sheet | Yes/No |
| 5. | I understand that my personal details will be kept confidential and will not be revealed to people outside the research team. | Yes/No |
| 6. | I understand that my anonymised data will be used in the researcher's thesis and other academic publications and conferences presentations. | Yes/No |
| 7. | I understand that after the study, my anonymised data may be made available to other researchers at the University of Salford repository and elsewhere. However, it will not be possible to identify me from these data. | Yes/No |
| 8. | I agree to take part in the study: | Yes/No |

| | | |
|---|---|---|
| **Name of participant** | **Date** | **Signature** |
| **Name of person taking consent** | **Date** | **Signature** |

Having read the Participant Information Sheet I give consent for my child to take part in this research study

| | | |
|---|---|---|
| **Name of Parental/Guardian** | **Date** | **Signature** |

Consent Form for anatomically intact participants.

University of Salford MANCHESTER

Consent Form – 5th June 2018 – Version 2.3

| **Participant ID Number:** |
|---|

CONSENT FORM

**Title of study:** Real time use of prostheses in sport by adolescents with upper limb absence.

**Name of Researcher:** Natalie Chinn

Please complete and sign this form **after** you have read and understood the study information sheet. Read the following statements, and select 'Yes' or 'No' in the box on the right hand side.

| | | |
|---|---|---|
| 1. | I confirm that I have read and understand the **Participant Information Sheet** (version *2.3)* (dated 2/6/18*)*, for the above study. I have had the opportunity to consider the information and to ask questions Which have been answered satisfactorily. | Yes/No |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my rights being affected. | Yes/No |
| 3. | If I do decide to withdraw I understand that the information I have given, up to the point of withdrawal, will be used in the research. | Yes/No |
| 4. | I agree to my participation in the tasks detailed in the information sheet | Yes/No |
| 5. | I understand that my personal details will be kept confidential and will not be revealed to people outside the research team. | Yes/No |
| 6. | I understand that my anonymised data will be used in the researcher's thesis and other academic publications and conferences presentations. | Yes/No |
| 7. | I understand that after the study, my anonymised data may be made available to other researchers at the University of Salford repository and elsewhere. However, it will not be possible to identify me from these data. | Yes/No |
| 8. | I agree to take part in the study: | Yes/No |

| | | |
|---|---|---|
| **Name of participant** | **Date** | **Signature** |
| **Name of person taking consent** | **Date** | **Signature** |

Having read the Participant Information Sheet I give consent for my child to take part in this research study

| | | |
|---|---|---|
| **Name of Parental/Guardian** | **Date** | **Signature** |

# Appendix 4: Can Axivity AX3 and Actigraph GT3X+ Data be Comparable?

## A4.1 Choosing the Axivity AX3 Activity Monitor

Activity monitoring devices allow for real world data collection. These devices provide objective measures with which to analyse prosthesis use outside of the clinical environment. As with much current technology there is a continuous development in the devices available.

The Axivity AX3 activity monitoring devices (AX3) [(121)] contains a tri-axial accelerometer. The AX3 is smaller, lighter and less expensive than the traditionally used ActiGraph GT3X+ [(122)] monitors (GT3X+) although it does have similar electronic specifications [(123)]. Other benefits include improved water resistancy facilitating less removal of the devices during the study period, and a greater range of sensitivity of dynamic range options allowing for higher impact activities to be recorded. However, there are fewer calibration and validation studies to support the AX3 [(123)]. In deciding to use the AX3 it needed to be assessed as to whether the data from the AX3 would be comparable with that of the GT3X+, as used by Chadwell et al. [(7-9)].

Brønd et al. [(123)] developed a method by which AX3 raw data can be processed to be comparable with ActiGraph counts allowing comparability to previous studies. In the free-living validation trial Brønd et al. [(123)] mounted the monitors to the hip, whereas, in this study the monitors were wrist-worn. It was identified that an investigation should be made to check whether this code did indeed allow the data from the two monitors to be comparable.

## A4.2 Method

### A4.2.1 Equipment

An AX3 and GT3X+ were secured together using tape in the orientation as recommended by the manufacturers [(122, 124)] and mounted on an elasticated wrist band. The AX3 used settings of 50Hz and 16g, whereas the GT3X+ was set at 30Hz and 6g (device maximum).

### A4.2.2 Data Collection

The devices were initialised using their respective associated computer software programmes, for the AX3 the AX3 OMIGUI Configuration and Analysis Tool software was used and for the GT3X+ the Actilife6 software. Devices were set to record for 30 minutes at the previously mentioned settings. A member of the research team wore the devices on their dominant wrist for the duration of the 30 minutes, continuing their normal daily activities.

### A4.2.3 Data Processing

Data from both devices were downloaded using their respective computer software programmes and raw data exported to Matlab (v. R2018a) for further analysis. Following initial feedback, the AX3 data was subsequently exported as a WAV file resampled at 50Hz.

### A4.2.4 Data Analysis

Using Matlab (v. R2018a) the raw data from both devices were plotted for comparison. Following this the AX3 resampled WAV file data were plotted against the raw GT3X+. Finally the Matlab code from Brønd et al. (123) was applied to the data from both devices (AX3 WAV, GT3X+ raw) and this data was plotted on top of the GT3X+ 1-second epoch activity count exported from the Actilife6 software.

## A4.3 Results

### A4.3.1 Sampling Rate

In the early pilot work when the AX3 data was in its raw format, it was found that in the 30 minutes of data the sampling rate varied from 47Hz – 52Hz. This can be seen in Figure 25 where the plot also shows an offset due to the devices being out of time sync with each other. When the AX3 data was offset by + 7.26 seconds this lined up the data at the start, however, it was out again by the end of the data. The 7.26 seconds was added assuming a continual sampling rate at 49Hz, however, when looking at the data in Excel this showed the sampling variance.

This was resolved following advice from Brønd [145] to export the files in a resampled (50Hz) WAV format.

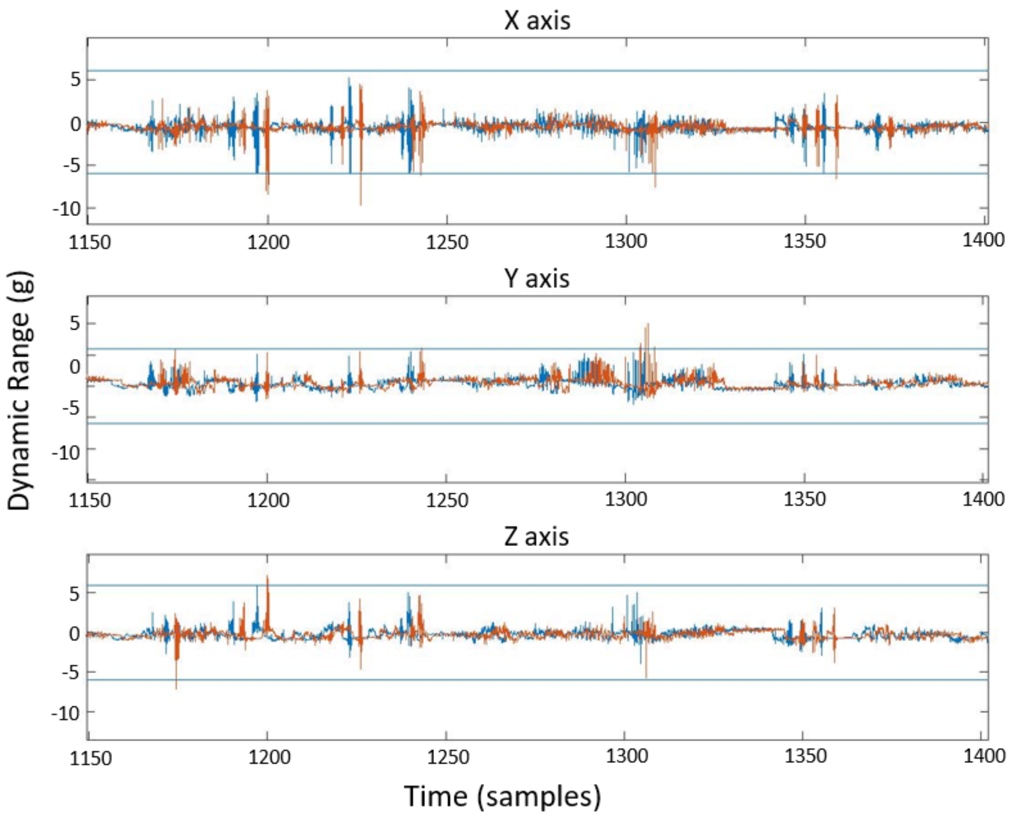


*Figure 25: XYZ axis plots of raw data from an AX3 and GT3X+. A sample from 30 minutes of data. Areas outside of the horizontal blue lines show where clipping would take place if the GT3X+ were used with its maximum sensitivity of dynamic range being 6g.*

### A4.3.2 Sensitivity of Dynamic Range

Where the GT3X+ has a maximum range of 6g, the AX3 achieves 16g. This allows for recording of higher impact activities, such as boxing, to be recorded without risk of clipping and therefore loss of data. Figure 25 shows in the highlighted areas where clipping would take place if only the GT3X+ were used with its maximum sensitivity being 6g.

### A4.3.3 Processing with Matlab Code to Convert AX3 Data to Data Comparable with ActiGraph Counts

To identify whether the code published by Brønd et al. [104] was reliable to use, firstly, a comparison was made using the same GT3X+ data, one processed with the code of Brønd et al. (104) and the other as the activity count exported from the Actilife6 software. Secondly, we processed the AX3 WAV file with the Brønd et al. (104) code and compared this to the activity count exported from the Actilife6 software.

Figure 26 shows same data from the ActiGraph GT3X+, one processed using the Brønd et al. (104) code, the other exported from the Actilife6 software with a 1 second epoch. The vector magnitude of both data are plotted and there appears to be a good agreement between the data.

Figure 27 illustrates the vector magnitude of the AX3 data processed using the Brønd et al. (104) code plotted on top of the vector magnitude of the GT3X+ data with a 1 second epoch as exported from the Actilife6 software. There is an offset seen showing that the time is not synced, this was also evident in the comparison of the two devices' raw data. Other than this there is a good agreement between the data.

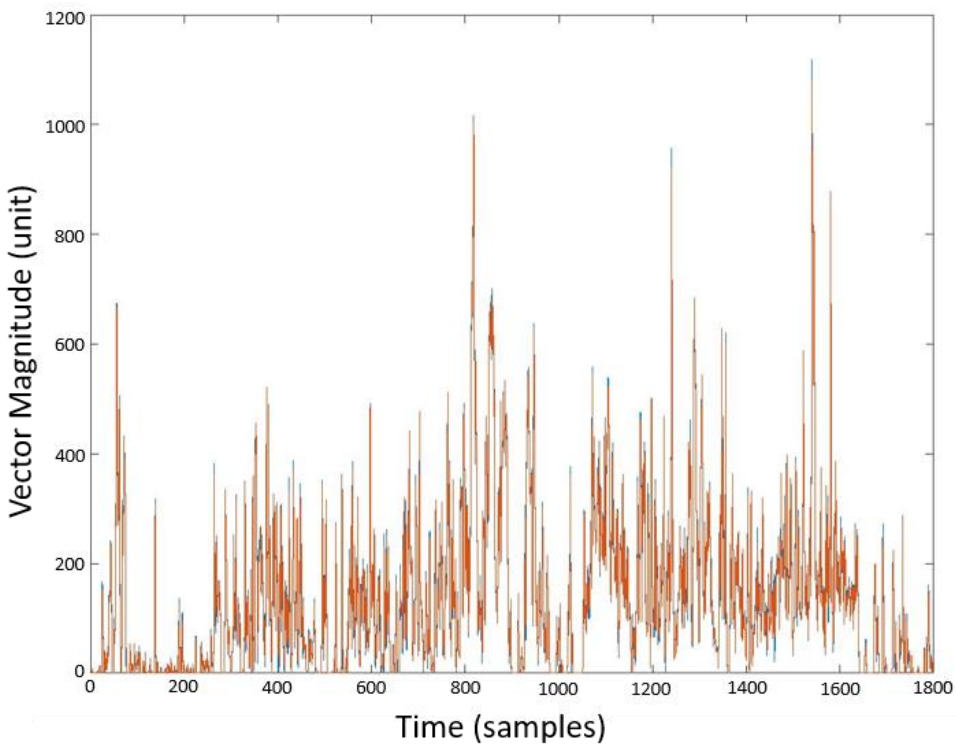


*Figure 26: Vector magnitude of GT3X+ using Brønd et al. (104) Matlab code vs. vector magnitude of GT3X+ using activity count exported from Actilife6 software.*

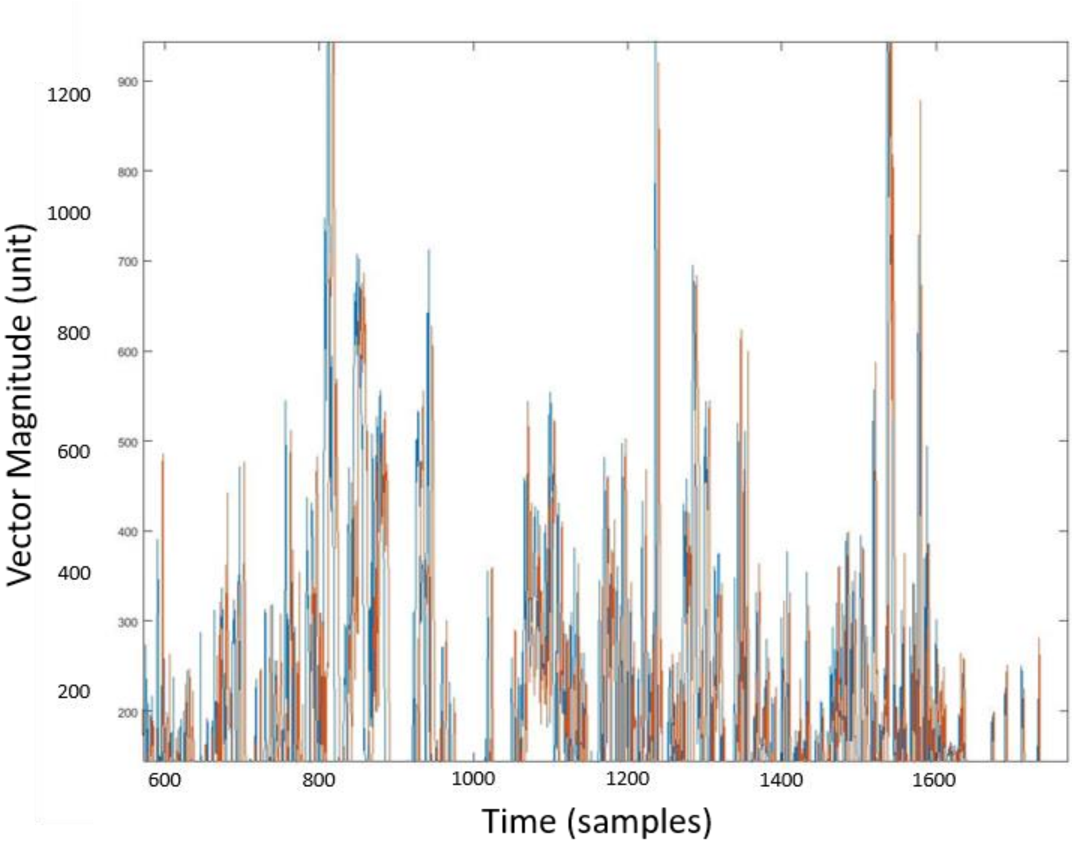


*Figure 27: Vector magnitude of AX3 using Brønd et al. [104] Matlab code vs. vector magnitude of GT3X+ using activity count exported from Actilife6 software.*

## A4.4 Conclusion

Being small, light and less expensive than other models on the market the AX3 is a promising activity monitoring device. As the study is looking at sport participation the water resistance is beneficial, in that the device can record during swimming and other water-based sports. The higher dynamic range than the GT3X+ is another bonus as it allows for higher impact activity to be recorded and result in potentially less clipping. Having resolved the inconsistent sampling rate issue by processing the AX3 data as a WAV file resampled at 50Hz the data can also be processed using code by Brønd et al. [104] allowing for comparison to the more common studies that have processed data using activity counts.

# Appendix 5: Sense Checking the Chadwell's Modified Matlab Code

For data processing of the activity monitoring study a modified version of the Chadwell et al. [(8)] Matlab code was used. The modifications were made by Chadwell to allow for the use of AX3 devices, processing of multiple weeks of data, analysis the Sport periods and user specified epoch.

As this code was modified, it was necessary to sense check the code and as such several processes were undertaken. Firstly, a visual inspection of the code was undertaken by two members of the research team to rule out any obvious errors. The results were then sense checked by checking the resultant times reported once the data had been processed using the code as seen below in Tables 13 and 14.

## A5.1 Sense Check 1: Is Overall Equal to Everyday Activity Excluding Sport and Sport?

Overall is divided into Everyday Activity Excluding Sport and Sport. Using the time included in the calculations with "prosthesis non-wear" removed it was checked whether $\text{Everyday Activity Excluding Sport} + \text{Sport} = \text{Overall}$. As can be seen in Table 13 there was no difference in these results and therefore Overall was the total of Everyday Activity Excluding Sport and Sport, indicating that the coding was processing data appropriately.

*Table 13: Time included in calculations with "prosthesis non-wear" removed.*

| | **P001** | **P002** | **P003** | **P101** | **P102** | **P103** | **P104** |
|---|---|---|---|---|---|---|---|
| **Sport** | 771 | 0 | 93 | 90 | 455 | 680 | 420 |
| **Everyday Activity Excluding Sport** | 7086 | 0 | 135 | 20070 | 19705 | 19480 | 19740 |
| **Overall** | 7857 | 0 | 228 | 20160 | 20160 | 20160 | 20160 |
| **Difference** | 0 | 0 | 0 | 0 | 0 | 0 | 0 |

## A5.2 Sense Check 2: Are Self-reported and Calculated Sport Periods Equal?

When considering Sport, the time included in calculations should be shorter or the same as the self-reported sport participation times (those given for the individual sports in the activity diary). As can be seen in Table 14 the times for the AI participants match, whereas, for those with upper limb absence the calculated time is less than the self-reported time, this is due to the non-wear algorithm removing periods of "prosthesis non-wear". This makes sense and indicated that the modified code is processing data appropriately.

*Table 14: Self-reported and calculated times for Sport.*

| | P001 | P002 | P003 | P101 | P102 | P103 | P104 |
|---|---|---|---|---|---|---|---|
| **Self-reported sport time** | 1365 | 750 | 575 | 90 | 455 | 680 | 420 |
| **Overall sport time included in calculations** | 771 | 0 | 93 | 90 | 455 | 680 | 420 |
| **Difference** | 594 | 750 | 482 | 0 | 0 | 0 | 0 |

# Appendix 6: Semi-structured Interview Guide

**Interview Guide**

**These questions will guide a conversational style interview and will be further developed in collaboration with the supervision team. Interviews will be digitally recorded using a dictaphone.**

**Researcher prompt**: Introduce self; explain aim of the project/reason for interview; duration of interview; reassurance re: anonymity/confidentiality and can withdraw at any time without giving reason. Check PIS is understood and ask if they have any questions / points that need clarification, are you still happy for me to record this interview. Confirm that participant still consents to participate.

Personal characteristics:

- Confirm demographics data still correct by going through it and that participant is happy for data to be transferred to transcription.

**Opening questions** / Trigger questions

- **Tell me about your experience with sport:**
  - What sports do you do and how often?
  - Why do you do sport?
  - Why do you choose the sport / sports you do?
  - Are there any sports you want to do but feel you can't and why?
  - Would you like to be more physically active? What activities would you like to do?
  - What stops you being more physically active?
  - What would make you stop doing sport?
  - How does sport make you feel? How would you feel if you couldn't do any sport anymore?
  - Has there been an occasion where you've been unable to participate in sport? Why? How did that make you feel?
  - What do you feel are the advantages and disadvantages of taking part in sport?
  - What motivates and demotivates you when it comes to taking part in sport?
  - What experiences have you had during sport that your limb absence has made difficult and did you / how did you overcome it?
  - Do you have any additional support / adaptations during sport you regularly take part in?

- Are there any particular types, styles, makes of sporting equipment that make participation easier?
- Has the 2 weeks you've been wearing the activity monitors been typical?
- *If the participant is an amputee:* Did you do sport before your amputation?
- *If the participant is an amputee:* Are the reasons you take part in sport different after amputation than before?

- **Tell me about your relationship with your prosthesis / prostheses during sport.**
    - Do you wear a prosthesis during sport? Elaborate - which sports? Tell me about the prostheses? Have you always worn a prosthesis for x sport? History and progression
    - How often do you wear a prosthesis day to day generally?
    - Do you have a prosthetic just for sports? Elaborate - which sports? Tell me about the prostheses
    - Why do / don't you wear a prosthesis during sport / how do you feel about your prostheses? – fit, function, cosmesis.
    - What influences you to wear your prosthesis during sport?
    - What do you feel are the advantages and disadvantages of wearing a prosthesis for sport?
    - What is the best / worst thing about your prosthesis during sport?
    - What experiences have you had during sport where your prosthesis has caused you problems and if / how you overcame them.

In-depth understanding can be developed using open ended questions such as:

- How did you feel about that?
- How important is that to you?
- How do you feel that can be improved / changed?

**Researcher prompt**: Is there anything they would like to add / do you think that I missed anything related to the topic? Ask participant how they have felt about being involved in this research. Remember to give Amazon voucher.

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